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The purpose of this study was to convey the experiences of nurses who care for or have cared for patients with lung cancer in different settings and to discover how these experiences relate to the stigma associated with lung cancer. The study was conducted using a narrative approach. Two stigma theories were used to guide this study; Goffman's theory, which describes stigma at the micro level, and Link and Phelan's theory, which describes stigma process at the macro level. The main theoretical concepts used to guide this study are the stigma process as a downward trajectory for the disease and the people who have the disease, which begins with labeling, associating labels with negative stereotypes, separation, status loss, and structural discrimination. "Normals" contribute to this process and the "wise", or nurses, counteract this process.

Thematic analysis of nurses' experiences caring for patients with lung cancer yielded four themes: addiction in action, cancer of a functioning organ, jumping through hoops, and securing the journey. The subthemes of addiction in action were stigma-related thoughts, struggle, and frustration; for cancer of a functioning organ the subthemes were dyspnea, sick, and secretions, for jumping through hoops the subthemes were push back, attitude barriers, and system level barriers; and for securing the journey the subthemes were progressing, following, connecting, and challenges to the journey.

At the micro level of the stigma process, nurses are considered to be "wise" persons who have knowledge of the difficulties of people who have a stigmatized illness and are positioned to help the stigmatized counteract stigma, but the "wise" are also

“normals”. Nurses’ experiences, communicated through narratives, further informed the characteristics of “wise” persons so that these qualities can be known and taught in nursing. This study added a more nuanced understanding of the experiences of nurses as the “wise” and nurses as “normals”, and the actions they take to help deal with struggles they have when caring for patients with smoking addiction, and lung cancer. Maintaining integrity of the nursing profession requires in depth knowledge of how nurses embody the expectations of their profession and the care they provide, and when they struggle to do so, or when they see the struggles of other health care professionals.

Conditions that are commonly stigmatized, like smoking addiction, were at times transformed by the “wise” as something that can protect the person who has addiction from further judgement, which adds complexity to the identity of nurses and other health care professionals as “normals” and “wise”, and the process of labeling. However, nurses had a fragmented understanding of smoking addiction that contributed to their difficulties in witnessing smoking behaviors, and frustration with effectively addressing smoking cessation. This fragmented understanding allows for the continuation of extant negative stereotypes and labels in the health care setting. The “wise” thoughts and “wise” actions that nurses had and did can be used to build a framework for approaching patients with a stigmatized disease, and it also provides guidance for what additional research needs to be done.

THE EXPERIENCES OF NURSES WHO CARE FOR  
PATIENTS WITH LUNG CANCER

by

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To my wonderful husband Charles, you have been my champion through all my endeavors.

To my five older siblings and my parents, you helped  
to keep me laughing through this journey.

Mom and dad, you are my first mentors and my heroes.

APPROVAL PAGE

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## CHAPTER I

### INTRODUCTION

In *The Scarlet Letter*, Nathaniel Hawthorne wrote of the character Hester Prynne after her release from jail “On the breast of her gown, in fine red cloth surrounded with an elaborate embroidery and fantastic flourishes of gold thread, appeared the letter ‘A’” (Hawthorne, 1983, p. 49). The letter on her chest represented her crime of adultery. Some members of the town thought this an unfitting punishment and suggested branding the letter on her skin (Hawthorne, 1983). The “A” on her clothing was part of her stigma, a way to distinguish Hester from everyone else in the town, to cast her out socially, and to ensure her crime would be known wherever she went.

Stigma is one consequence of humanity’s struggle to discover, define, and describe what is normal, and what to do about what is not normal. Examples of this struggle can be found in history, literature, religion, science, and health care, from the Greeks who branded their criminals, to Nathaniel Hawthorne’s tale of a marked woman who was openly stigmatized while her co-adulterer concealed his deviance, but suffered inwardly from shame and self-stigma (Hawthorne, 1983). In the Old Testament, some illnesses were considered to be a “curse from God” (Chitando & Gunda, 2007, p. 192) as punishment for immoral behavior; and punishments extended beyond the original deviant

like the mark put upon Cain by God for murdering his brother Abel; hence all descendants of Cain were doomed from the depravity of their progenitor.

While science might appear to be separate from religion, medicine at times struggled to find the cause for diseases that religious and moral views were quick to supply (Herek, 1990). Before it was known that cholera was caused by bacteria in water, outbreaks of the disease in the United States incited fear and blame directed at the poor, prostitutes, blacks, and immigrants because it was thought that these groups had certain innate characteristics like laziness, drunkenness, and sexual promiscuity, that predisposed them to cholera (Rosenberg, 1962). Ironically, those who drank alcohol likely had an advantage due to the sterilization processes in alcohol production. When the cause was finally linked to poor sanitation, it was determined that the aforementioned groups were the most vulnerable to the disease and the stigma attached to it (Rosenberg, 1962).

Certain diseases, even today, still carry a stigma due to their link to behaviors that are deemed immoral or deviant by society. The HIV/AIDS epidemic is a near repeat of the cholera outbreaks because, again, moral judgments were more expedient than science. Morality, extant in most aspects of culture including government, religion, and social interactions, already guided how people should judge a new disease and those who have it – particularly when said people are outside the parameters of normal. When at first it seemed as though the disease was restricted to gay men, not only did those who fell within the normal parameters of a heterosexual group feel safe, but the existence of the disease seemed to indicate that judgment had finally fallen upon the morally corrupt (Herek, 1990).

Unfortunately, this inaccurate, premature view of the disease greatly contributed to the spread of it and the many stigmas involved linger today (Balaji, Bowles, Hess, Smith, & Paz-Bailey, 2016), further delaying access to treatment (Golub & Gamarel, 2013).

While the stigma of HIV/AIDS was most prevalent among already stigmatized and marginalized groups, some behaviors related to diseases undergo a transformation from normal and accepted to deviant and socially unacceptable. Smoking is one such behavior, and the disease it is most strongly linked to, lung cancer, has also undergone a transformation among the people who have it. When cigarette consumption was increasing in the early twentieth century, early attempts to counteract consumption were led by religious and secular organizations who focused less on health as a reason to stop smoking and more on moral degradation (Brandt, 1990; U.S. Department of Health and Human Services, 2014). These efforts could not stop the tide of mass production and advertising of cigarettes, but the moral argument would be used again to decrease smoking behavior. Some of the results of this transformation of smoking behavior from popular to aberrant, are the social construction of smoking behavior and lung cancer into a behavior and disease, respectively, that are burdened with issues of stereotyping, status loss, and discrimination. These issues place an additional social and psychological burden on patients with lung cancer and the people who care for them.

### **Problem Statement**

Nurses are key people among health care professionals that care for people with lung cancer. Nursing is one of the most rapidly expanding healthcare professions in the United States; with a projected increase of 16% over the next eight years (U.S.

Department of Labor, 2014). Most patients have multiple and sometimes prolonged care encounters with nurses, making them the most critical and pivotal members of the healthcare team, and the most likely, other than close family and friends, to detect social and psychological burdens among their patients (Abrahamson, 2010).

At the center of most care related decisions made for and with patients are nurses, and they must coordinate with multiple other health care professionals in order to provide safe, effective care. Nurses who work with patients that have conditions which carry a stigma can undo the nurse patient relationship when they exhibit a negative attitude (Dickinson & Hurley, 2012). One study provided a glimpse of such attitudes when nurses from China were surveyed and the results indicated that some diseases, like lung cancer, are worthy of more blame than other cancers (Wang, Zhan, Zhang, & Xia, 2015).

The attitudes, perspectives, and beliefs of nurses toward stigmatizing conditions have been studied. Only one study examined their attitudes toward lung cancer with a cross-sectional survey design (Wang et al., 2015). Other studies interviewed nurses about their perspectives on obesity and stigma using a qualitative design, but the perspective was from nurses who had the stigmatized condition (Aranda & McGreevy, 2014; I. Brown & Thompson, 2007). The obesity studies revealed that nurses are aware of extant stereotypes about stigmatized diseases and the damage that they do, yet they still expressed negative emotions about their patients who had weight problems (Aranda & McGreevy, 2014).

In addition, it has been theorized that nurses may act as a buffer against the negative impact of stigma (Goffman, 1963; Hamann et al., 2014). However, few studies

have examined what actions nurses take to counteract stigma. Studying the experience of the nurse, in detail, using qualitative methodology with a narrative approach, would contribute to completing the knowledge of the impact of stigma on patient care and hence ways to improve the care of patients with lung cancer.

There are key national goals related to lung cancer, namely reducing the death rate, increasing the number of cancer survivors living five years or longer to 72.8%, and improving overall well-being of all cancer survivors (U.S. Department of Health and Human Services, 2014). Learning more about how nurses perceive the care of patients with lung cancer will provide the information on how to improve their care and treatment outcomes. Considering that patients with lung cancer can have poor five-year survival rates (National Cancer Institute, 2016), their psychosocial issues must be detected and addressed early in order to provide the best and most holistic care.

### **Purpose of the Study**

The purpose of this study is to explore the experiences of nurses who care for patients with lung cancer in a variety of settings to better understand their perspective of issues related to care of the patient with lung cancer and stigma. The perspectives of nurses are underrepresented in the literature on lung cancer and stigma, however the perspectives of patients, physicians, clinical social workers, and lay caregivers have been represented. Studying nurses is also key to the conceptual development of stigma because theoretically they are considered a counteracting force against stigma (Goffman, 1963), yet they can also perpetuate it. Nurses are integral to improving the quality of care for patients with lung cancer. A qualitative study will provide the needed contextual

information to design interventions that help patients have the best outcomes. Without supportive context, any interventions to mitigate stigma and improve the psychosocial issues surrounding it will have little meaning for the patients and nurses engaged in these interventions (Munhall, 2007).

### **Background and Significance**

Lung cancer has the highest mortality rate of all the major, most prevalent cancers (National Cancer Institute, 2016), yet it has low public support and low funding. When comparing 2016 funding for three major cancers: congressional appropriations for breast \$120 million (a total of 3.6 billion from 1992-2015), prostate \$80 million (1.45 billion from 1997-2015), and lung \$12 million (89.5 million from 2009-2015); lung cancer continues to be underfunded in spite of the high prevalence and mortality (Department of Defense, 2014). Furthermore, in 2013 the National Cancer institute spent \$559.1 million on breast cancer and only \$285.9 million on lung cancer (National Cancer Institute, 2014). Funding is a proxy for public support because it increases awareness and education about diseases which are necessary precursors for support.

### **National Statistics**

Cancer is the second leading cause of death in the United States (Heron, 2016), with an estimated 1,685,210 deaths for 2016 (National Cancer Institute, 2016). Medical costs for cancer in 2013 were \$74.8 billion (National Cancer Institute, 2016). Lung cancer is the leading cause of cancer death for men and women (American Cancer Society, 2017), and the fifth leading cause of death worldwide at 1.7 million deaths in 2015 (World Health Organization, 2017). Lung cancer prevalence in 2013 was over

415,500, which was less than prostate, breast, or colon cancers but the death rate was higher (National Cancer Institute, 2016).

### **Lung Cancer**

Of the four cancers that have new cases over 100,000 per person in 2016, lung and bronchus (224,390), breast (246,660), prostate (180,890), and colon (134,490); lung and bronchus cancers have the highest number of deaths at 158,080 people, and the lowest five-year survival rate at 17.7% (National Cancer Institute, 2016). The five-year survival rate is based on the Surveillance, Epidemiology, and End Results Program (SEER) data from 2006-2012. Over half of the people who are diagnosed with lung cancer will die from the disease before one year has passed (American Lung Association, 2017). While the survival rates of lung cancer have increased slightly for men and women from 1977 to 2010; the incidence and mortality decreased for men while these rates increased for women, indicating momentum in fighting cancer for the former but not the latter (Cho, Mariotto, Schwartz, Luo, & Woloshin, 2014).

Like the aforementioned cancers, lung cancer is most frequently diagnosed late in life with 32.4% of new cases in the 65-74 age group, 27.4% in the 75-84 age group, and 21.5% in the 55-64 age group. Incidence rates of lung cancer are higher in men than women, 67.9% versus 49.4%; and the highest incidence and mortality is seen in black men at 90.9% and 73.1% respectively; although not uniformly for gender in the black race/ethnicity category because white women have higher mortality rates than black women, per 100,000 persons (National Cancer Institute, 2016). However, lung cancer is also typically diagnosed at a late stage (American Cancer Society, 2016) which in

addition to diagnosis late in life, contributes to the poor five-year survival rate. The type of lung cancer, the stage, how quickly it spreads, treatment options that are partly based on co-morbidities, and health behaviors before, during, and after treatment also impact survival and treatment outcomes (American Cancer Society, 2016). The health behavior that has been most closely linked with lung cancer is cigarette smoking.

### **Cigarette Smoking**

Cigarette smoking overshadows all causes of preventable death because it is linked to many leading causes of death such as heart disease and cancer (Jamal et al., 2015); it is also the primary cause of lung cancer (U.S. Department of Health and Human Services, 2014). Smoking prevalence data tends to be congruent with lung cancer incidence data; for example, men have a higher prevalence of smoking and smoke more cigarettes than women, and people between the ages of 45 and 74 smoke on average more cigarettes per day than any other adult age group (Schoenborn, Adams, & Peregoy, 2013). However, over 30% of current smokers in their early 20s started smoking before age 16 (Schoenborn et al., 2013), and most smoking initiation occurs before age 18 (U.S. Department of Health and Human Services, 2014); early initiation adds to the risk of young people becoming lifelong smokers (National Center for Chronic Disease Prevention and Health Promotion (US) Office on Smoking and Health, 2012). This information also indicates that people who have smoking related diseases likely started smoking at a time in their lives when they were susceptible to peer pressure, advertising, and the desire to belong, and therefore vulnerable to initiating risky behaviors, and when they are addictive, maintaining them (Shadel & Cervone, 2011).

The trend of smoking initiation in early adolescence diverges when examining data on smoking incidence in Blacks, who smoke fewer cigarettes than whites and start smoking later in life (Schoenborn et al., 2013); yet they have the highest rate of lung cancer incidence (31.8) in the 40-49 age group when compared to: Whites (21.7), American Indians/Alaska Natives (AIs/ANs) (13.4), Asian/Pacific Islander (As/Pis) (10.8), and Hispanics (8.5) (Underwood et al., 2012). These numbers are also regionally dependent in that Whites have higher incidence of lung cancer in the South (75.6), Blacks in the Midwest (88.9), and AIs/Pis in the West (40.0) (Underwood et al., 2012). Differences in mortality of lung cancer are also noted among certain groups examined with county-level data (Rubin, Clouston, & Link, 2014). There is support that mortality rates of lung cancer are higher among people in areas that have higher rates of low education attainment, lower number of people in white collar jobs, and fewer people above the federally-defined poverty level (Rubin et al., 2014).

Smoking prevalence has similar socioeconomic ties. Although there has been a marked decline in smoking prevalence over the past five decades, from 42.4% in 1965 (Lavinghouze et al., 2015) to 16.8% in 2014 (Jamal et al., 2015); the rates are still high for people who have low education attainment and low income (Jamal et al., 2015). Specifically, for people with a general education development certificate the rate was 43.0% compared to people with a graduate degree, 5.4%, and those living below the federal poverty level, 26.3%, compared to those living above, 15.2%, in 2014 (Jamal et al., 2015).

The metrics on lung cancer and smoking indicate that there are differences in death, survival, incidence, and prevalence rates among different cancers, and specifically for lung cancer, by gender, by race, and by socioeconomic status (SES). Differences in prevalence rates for smoking by SES are also present. Theorists and researchers have hypothesized that the decrease in smoking prevalence among higher educated and higher income individuals and hence the lower levels of lung cancer incidence in these groups, is due to their potential greater ability to understand health information and respond to it (Rubin et al., 2014). In general, this thesis indicates that both disease development and health risk behaviors are not just biological, they are imbued with larger social implications.

Lung cancer has a strong association to smoking not only with regard to disease causality, but also with social perception (Rohan, Boehm, Allen, & Poehlman, 2016). Smoking was socially acceptable and widely prevalent in the early to mid-twentieth century (Brandt, 2007). Over the past five decades, science and policy have not only provided overwhelming support that smoking is unhealthy, it has also been deemed deviant (Bayer, 2008; Markle & Troyer, 1979). Patients with lung cancer who never smoked feel that they must explain their non-smoking status when they reveal their diagnosis (Conlon, Gilbert, Jones, & Aldredge, 2010). There is also support that stigma for patients with lung cancer is related to psychosocial issues such as a decrease in quality of life (Brown Johnson, Brodsky, & Cataldo, 2014; Cataldo, Jahan, & Pongquan, 2012), increase in depression (Gonzalez & Jacobsen, 2012), increase in self-blame and decrease in self-esteem (Else-Quest, LoConte, Schiller, & Hyde, 2009) and delays in

seeking care (Carter-Harris, 2015; Carter-Harris, Hermann, Schreiber, Weaver, & Rawl, 2014; Tod & Joanne, 2010).

The perspectives of health care professionals have revealed that patients with lung cancer delay seeking care because of vague symptoms (Dunn et al., 2016), shame related to smoking (Dunn et al., 2016; Tran et al., 2015), and stigma (Dunn et al., 2016). Further, health care professionals note that people with lung cancer think they are at fault regardless of smoking status (Conlon et al., 2010; Dunn et al., 2016); there is nihilism and pessimism among professionals and people who smoke (Dunn et al., 2016; Scott, Crane, Lafontaine, Seale, & Currow, 2015; Tran et al., 2015) which also contributes to delays in care and negative attitudes.

Nurses are considered to be, professionally, the epitome of impartiality and acceptance; however, their therapeutic relationships with the myriad of patients they encounter can involve a mosaic of complicated thoughts and feelings (Peternelj-Taylor, 1989). Ignoring this complexity, and failing to acknowledge that “nurses are people first and nurses second” (Peternelj-Taylor, 1989, p. 745) creates an environment that increases the challenges of fully understanding and adhering to professional practice standards. Examples of current practice standards for nurses from specialties like oncology, home health, and the overall standards from the American Nurses Association (ANA), that are pertinent to stigma, indicate that nurses are expected to self-examine, reflect, and inventory their beliefs, values, and culture that could impact patient care (American Nurses Association, 2015; Brant & Wickham, 2013), that the home health nurse “advocates for equitable care” (American Nurses Association, 2014, p. 61), and that all

nurses examine the influence of discrimination on the care of those who are vulnerable (American Nurses Association, 2015).

Nurses have been studied exclusively in only one study in China, which examined their different attitudes toward diseases that carry stigma such as lung cancer, obesity, liver cancer, colon, and breast cancers; more nurses assigned blame to lung cancer than any other cancer presented. However, attitudes toward a disease are influenced by cultural norms, which may be different in China than the United States. Nurses have also been included in mixed samples of clinicians in qualitative studies, but their perspective is seldom distinguishable from other clinicians. When their perspective is presented, nurses express awareness of patients' potential self-blame and perceived stigma related to smoking (Tod & Joanne, 2010). Lastly, qualitative studies of nurses' attitudes toward obesity elicited complex beliefs and feelings about their own body size and education for overweight and obese patients (Aranda & McGreevy, 2014; Brown & Thompson, 2007). These complex attitudes included: awareness of stereotypes such as 'fat', 'lazy', and unhealthy, counteracting stereotypes by asserting that thin people have health problems too and body size is not about health but social norms and acceptance, and their negative attitudes sometimes overruled empathy when educating patients about weight reduction (Aranda & McGreevy).

In order to counteract pessimism and avoid emotions, nurses hid behind their professional role or noted the hypocrisy of educating about risk factors they themselves had (Aranda & McGreevy, 2014). In another study nurses were uncomfortable talking about obesity, avoided the word obesity with their patients because it was deemed a

disagreeable label, and used rapport and a neutral attitude to offset stigma (Brown & Thompson, 2007). Other nurses asserted that personal responsibility was key to behavior change and judgement is a constant (Brown & Thompson). Nurses also expressed frustration with patient requests for quick fixes and noncompliance (Brown & Thompson). All of these studies were in other countries, China and England respectively, so the perspectives presented reflect, to some degree, the culture of that country and the health care system.

Since so little is known about nurses' perspectives about lung cancer and stigma, a qualitative approach is warranted. Moreover, prior research into nurses' perceptions of stigmatized conditions reveals complex attitudes toward both the condition and their patients. Narrative inquiry allows for the exploration and analysis of complex, layered experiences (Frost, 2011). Narratives are drawn from cultural and social experiences which can also reveal aspects of the teller's identity and personality (Lieblich, Tuval-Mashiach, & Zilber, 1998), making it an ideal approach to study nurses' experiences of caring for people with lung cancer and how these experiences relate to stigma.

### **Theoretical Framework**

The purpose of this study is to explore the experiences of nurses who care for patients with lung cancer, using stigma theory as a guide. Two stigma conceptual frameworks will guide the study. The first framework is Erving Goffman's theoretical analysis of the micro-level interactions among individuals where stigmatization occurs (Goffman, 1963). Stigma is defined as a label that is linked to a stereotype that discredits the person who has it (Goffman). The individual interactions surrounding stigma involve

those who have a stigmatized condition, or “the stigmatized”, those who do not, “normals”, those who understand the stigmatized and work to advocate for them, the “wise” who are also “normals”, and those who share the experience of having the stigmatized condition, the “own”. (Goffman).

Examples of “wise” people provided by Goffman are nurses, physical therapists, relatives, and friends, however, there is little description in his theory or in studies about how “wise” people, specifically health care professionals, counteract stigma and advocate for those who have a stigmatized disease. Learning more about nurses as “wise” people through research is important because they are part of a profession for which there are expectations of caring, empathy, knowledge, understanding, advocacy for equitable care, and examination of the impact of discrimination on vulnerable people. Maintaining integrity of the profession requires in depth knowledge of how nurses embody these expectations and when they struggle to do so, or when they see the struggle of other health care professionals.

Other concepts in Goffman’s theory are social and psychological consequences of stigma such as social exclusion, avoidance, stereotyping, and decreased empathy from “normals” (Goffman, 1963). Additional consequences experienced by the stigmatized are self-blame, shame, self-isolation, and concealment from internalizing, perceiving, or actually experiencing negative attitudes, social exclusion, and stereotyping from “normals” (Goffman). Actions to counteract stigma are also described as self-advocacy, collective advocacy, rejecting the stigma, and rejecting other stigmatized individuals.

Goffman (1963) defined stigma as an “attribute that is deeply discrediting” (p. 3); the attribute can be visible, like weight or height, or invisible, like some diseases. Attributes are objectively constructed as a way to identify objects and people and communicate about them. Attributes are also socially constructed in which the label takes on connotations, subtext (Volinn, 1983), and stereotypes (Goffman; Link & Phelan, 2001). For example, lung cancer is an objective diagnosis and can also be associated with a behavior, smoking, or label, smoker. People who smoke have been described by people who do not smoke as lacking intelligence (McCool, Hoek, Edwards, Thomson, & Gifford, 2013), selfish and ignorant (Wigginton & Lee, 2013), having a weak character and personal failings (Stuber, Galea, & Link, 2008), and being dirty (Greaves, Oliffe, Ponic, Kelly, & Bottorff, 2010).

There are psychological, behavioral, and social consequences of stigma. Affective responses to stigma include shame, depression, and anxiety. Psychological and behavioral responses include internalization of negative attitudes and stereotypes or internalized stigma, self-blame, anticipation of stigma, and rejection of the stigma and others who have it. Social consequences include concealment of the stigmatized condition, self-induced isolation, avoidance, and advocacy.

The second conceptual framework presents stigma as a macro-level process of a downward social trajectory (Link & Phelan, 2001). In addition to Goffman’s description of stigma that is a label-stereotype link that discredits a person, Link and Phelan further describe stigma as a process that leads to separation, status loss, and limited access to resources in the context of power. There are five main concepts in the Link and Phelan

theory that describe a downward social trajectory: labeling, stereotyping, separation, status loss, discrimination, and power. Power is the driving force behind the stigma process that helps create and perpetuate negative stereotypes that are linked to labels, and power differences exacerbate separation, status loss, and discrimination (Link & Phelan). Indeed, this theory is distinguished from other stigma theories and even Goffman's because the creators assert that "[s]tigma is entirely dependent on social, economic, and political power – it takes power to stigmatize" (Link & Phelan, p. 375).

For the purposes of this study, stigma is a process whereby labels of individuals or groups are linked to negative stereotypes that can be used to separate that individual or group from the rest of society or from comparable groups, diminish their social status, and withhold, divert, or decrease their access to resources (Link & Phelan, 2001). Stigma is also described as a characteristic used to identify an individual that can disgrace and dehumanize them in certain situations, and is temporally dependent (Goffman, 1963; Link & Phelan). Social, cultural, and political components of society determine which labels and characteristics fall within normal parameters and which do not (Link & Phelan); those that do not, acquire negative focus and stereotypes (Goffman).

### **Assumptions**

The following assumptions were retained for the planning and conduct of the research study:

- Nurses are attuned to and willing to talk about the psychological and social issues surrounding the diagnosis of lung cancer.

- Nurses are able to recognize and willing to talk about the psychosocial issues of their patients with lung cancer.
- Nurses recognize and are willing to talk about their own experiences with stereotyping, status loss, and discrimination.

### **Research Questions**

This study answers the following broad, qualitative research question: what are the experiences of nurses who care for patients with lung cancer? The other question is, how are these experiences related to the stigma associated with lung cancer? The two stigma theories mentioned and a narrative inquiry approach will provide guidance toward answering this question. Using a narrative inquiry approach to study nurses' experiences of caring for patients with lung cancer will provide rich experiences that are oriented to the narrator's identity and personality, are drawn from culture, and are socially contextual.

### **Definition of Terms**

This study employed the following terms and definitions:

1. Label: Diseases and diagnoses are labels. For this study, the label of interest is lung cancer.
2. Stereotype: Negative characteristics linked to a label (Link & Phelan, 2001) that are cognitively expedient but have low accuracy (Volinn, 1983).
3. Separation: The mental, physical, political, and social processes of placing individuals or groups into separate categories based on labels and stereotypes, or excluding them socially.

4. Status Loss: The social sequelae of labeling, stereotyping, and separation (Link & Phelan, 2001). A diminished position of a group, disease, or individual in a hierarchical structure.
5. Discrimination: The social sequelae of labeling, stereotyping, separation, and status loss which leads to a reduction in access and opportunities.
6. “Normals”: Health care professionals, lay caregivers, and members of the general public who create a “virtual identity” of the person with lung cancer (Goffman, 1963, p.2).
7. “Stigmatized”: People with lung cancer and people who smoke and who know their “actual social identity” or the array of characteristics they know they possess (Goffman, 1963, p. 2).
8. The “Wise”: “Normals” who have knowledge of the plight of the stigmatized and have empathy for them.
9. The “Own”: Other people with lung cancer who have empathy for the shared experience of having a stigmatized form of cancer.
10. Shame: A psychological consequence of internalizing stereotypes, separation, and status loss.
11. Psychological Consequences of Stigma – experiences of the stigmatized that include anticipation of or actual instances of stereotyping, negative attitudes, status loss, separation, and discrimination that includes feelings of shame, self-blame, anxiety, depression, and decreased self-esteem.

12. Social Consequences of Stigma – alterations in social contacts that include avoidance, exclusion, concealment, and decreased empathy from “normals”.
13. Counteracting Stigma- Actions taken by the “stigmatized”, “normals”, and/or the “wise” that decrease the negative perception of the stigmatized condition and support those who have it.

## **CHAPTER II**

### **REVIEW OF LITERATURE**

The following chapter is both an explanation of two theoretical frameworks that are used to organize the review of literature and underpin the study, and a review of the literature on stigma and lung cancer. First there will be an overview of the concepts in each theory. Second there will be a review of the literature organized by some of the major concepts in each theory. Finally, sections of the literature review will be concluded by tying them back to the concepts in the theories.

#### **Stigma Theories**

The two stigma frameworks that will be used to guide this study are Erving Goffman's (1963) micro-level theory of stigmatization that occurs during interactions of individuals, and the second theory, by Link and Phelan (2001), describes stigma as a macro-level process involving labeling, stereotyping, separation, status loss, and discrimination; with power as the driving force behind the process. The first stigma theory, Goffman's (1963), was chosen because it is the most frequently used theory in studies of stigma and lung cancer, the concepts and processes within are supported by the literature, it is useful for understanding social and psychological aspects of stigma at the individual level, and includes the concept of the "wise" as knowledgeable advocates for the stigmatized

The second theory, by Link and Phelan (2001), was chosen because it has conceptual overlap and basis with Goffman's theory, and is useful in understanding the driving force behind stigmatization which is not explained in Goffman's theory. For those who have a disease that carries stigma, both of these conceptualizations are pertinent. Patients experience stereotyping and status loss with one on one interactions with people and they are also aware of and susceptible to larger processes that negatively impact society's perception of the disease (Bell, 2014; Chapple, Ziebland, & McPherson, 2004; Hamann et al., 2014; Rohan et al., 2016; Tod, Craven, & Allmark, 2008). The literature also supports that health care professionals are aware of and retain negative attitudes and stereotypes, and they note the structural discrimination of low funding and support for lung cancer given the high mortality and low five-year survival rates.

The review of literature will be organized under the following concepts from Link and Phelan's (2001) theory: discrimination, separation, and status loss. Concepts from Goffman's theory will be grouped under psychological and social consequences of stigma. There will be subheadings under concepts that refer to the main theme of the studies starting with delays in care, comparisons of lung cancer to other cancers and stigmatized conditions, comparing smoking behaviors of patients with lung cancer, then narratives and measurements of psychological and social aspects of stigma.

## **Stigma**

Stigma is a process whereby labels of individuals or a group are linked to negative stereotypes (Goffman, 1963) that can be used to separate that individual or group from the rest of society or from comparable groups, diminish their social status, and withhold

or divert resources from them (Link & Phelan, 2001). Stigma is also described as a characteristic used to identify an individual that can disgrace and dehumanize them in certain situations, and is contextually and temporally dependent (Goffman; Link & Phelan). Social, cultural, and political components of society determine which labels and characteristics fall within normal parameters and which do not (Link & Phelan); those that do not, acquire negative focus and stereotypes (Goffman). Members of society who determine what is normal are referred to as “normals”, and those who are not are the “stigmatized” (Goffman). For the purposes of this study, the label is a diagnosis, lung cancer, and the stereotypes are smoker, self-inflicted disease, personally responsible, pessimism, and nihilism. The negative qualifiers for these stereotypes are deviant, stupid, unclean, lazy, dirty, and ‘leper’. While the discipline of medicine created the label of lung cancer, society attaches additional meanings to this label so that the disease becomes not only biologically defined, but socially defined.

**Goffman.** The concept of stigma also contains the various people who interact to create it, realize it, counteract it, perpetuate it, receive it, and endure the consequences of it. People who determine what is normal and what is different, or outside normal parameters, are called “normals” (Goffman, 1963, p. 5), and they also fall within said parameters. “Normals” hold expectations of social situations regarding what should and should not be, and with these expectations create a “virtual identity” of the stigmatized. “Normals” retain judgements, attitudes, beliefs, biases, and stereotypes about people with lung cancer which may or may not be damaging. The “Own” and the “Wise”, are those

who share the stigma and are empathetic and knowledgeable about the plight of the stigmatized respectively (Goffman).

The “stigmatized” are the recipients of these judgements, attitudes, beliefs, biases, and stereotypes because they have a label that not only places them outside the parameters of normal, but can become an all-encompassing identifier when examined by “normals”. Labels that are judged range from visible abnormalities, to ethnicity, to “blemishes of individual character” such as “addiction” (Goffman, 1963, p. 4). The “stigmatized”, at times, endure several social and psychological continuums (a) their status may move from “discreditable” to “discredited” (Goffman, p. 4) in which their stigma is not known and becomes known; (b) accepted to rejected when they interact with others who are stigmatized and then with normals; (c) self-blame, self-stigma, and shame to defiance when they absorb society’s perceptions of their condition or reject it.

What is normal and what is different is determined by personal values, beliefs, and knowledge which stem from larger social values and the culture in which a group or individual is situated (Link & Phelan, 2001). Determination of what is normal and what is not helps a society and individuals within to organize their social world (Jones et al., 1984) such that labels become background, are seldom questioned, and are “...taken for granted as being just the way things are” (Link & Phelan, p. 367). Labels and stereotypes are also permeated with moral meanings that validate them and have the potential to elicit strong reactions from individuals and groups (Jones et al.). The process of labeling and stereotyping begins as a way to organize and categorize information to simplify cognitive

processes (Volinn, 1983), yet the consequences of this process are detrimental socially and psychologically for individuals and groups.

Stigma has also been distinguished as a "...language of relationships, not attributes..." (Goffman, 1963, p.4), meaning that stigma is lessened or amplified depending on the social context and what comparisons are being made. For diseases that carry a stigma, there is also a language of associations. The disease acquires stereotypes and status loss before the person develops it, then the person inherits the stigma associated with the disease as well as having to cope with physical symptoms. Consequently, disease-related stigma creates a disparity among diseases where some are burdened with social, psychological, and political problems more than others. In the context of lung cancer stigma, this can mean that certain diseases that also carry a stigma seem normal in comparison or that those who have had diseases that are more stigmatized may not notice the stigma associated with lung cancer. For example, a patient with lung cancer who also has HIV notices the stigma associated with HIV but not with lung cancer (Rohan et al., 2016). Likewise, when lung cancer is compared to a disease that carries minimal negative stereotypes, the stigma is amplified.

### **Psychological and Social Consequences of Stigma**

The psychological consequences of stigma include anticipation of or actual instances of stereotyping, negative attitudes, status loss, separation, and discrimination that yields experiences of shame, self-blame, anxiety, depression, and decreased self-esteem. Shame is an awareness of being a lesser person based on knowledge of societal norms (Goffman, 1963). In this sense, shame is linked to status loss, because the

experience of it is associated with diminution of a person's own status in addition to the negative perceptions from society.

### **Social Consequences of Stigma**

The social consequences of stigma are alterations in social contacts that include avoidance, exclusion, concealment, and decreased empathy from "normals" (Goffman, 1963). Avoidance behaviors may be initiated by either "normals" or the "stigmatized" in order to decrease the chances of an awkward interaction (Goffman). For the "stigmatized", avoidance to a certain degree may lead to self-isolation, not only to decrease awkwardness, but to avoid stigmatizing attitudes from others (Goffman). Exclusion can be actual or anticipated, for example, a patient with lung cancer may anticipate feeling out of place at a breast cancer support group or may have actually experienced such a feeling.

### **Counteracting Stigma**

The "stigmatized" may reject stereotypes linked to their label, and may even reject other people with the same stigmatized label (Goffman, 1963). For example, when people who have never smoked reveal their diagnosis of lung cancer they quickly reinforce that they have never smoked (Conlon et al., 2010) and that "...normal people who weren't smokers...do get lung cancer" (Brown & Cataldo, 2013, p. 358). People with a stigmatized status may also react with antagonism in order to place "normals" in the defensive position (Goffman). In contrast, self and group advocacy occur as another mechanism to offset stigmatization, emphasize normal characteristics and labels, and provide support to those who have similar characteristics or the "own" (Goffman, p.33).

There are members of society who already know the struggles of those who have conditions that carry stigma. These are the people who work closely with those who are stigmatized, yet do not place emphasis on the undesirable labels and stereotypes. Goffman referred to these individuals as the “wise” who provide support, help, sympathy, and advocacy; he provided examples of health care professionals; yet health care professionals may also perpetuate the stigma consciously or unconsciously. A “wise” person can also be someone who is related or a friend to the person with a disease that carries stigma.

A person or group can also have other labels in addition to their disease that carry stigmas, or multiple stigmas. For example, people with lung cancer may also have the stigmatized label of smoker, low income or poor, and low education attainment, which in turn are linked to multiple negative stereotypes. Stigma researchers have given this problem different names such as “stacked stigma” (Conlon et al., 2010, p. 99), “multiple disadvantaged statuses” (Stuber, Meyer, & Link, 2008, p. 353), and “compound[ded]” or “layered” stigma (Jain & Nyblade, 2012, p. 3). Whatever the nomenclature, a person who has multiple labels that are linked to stereotypes has an increased chance of subsequent social problems, such as social exclusion, diminished social status, and discrimination.

### **Stereotyping and Status Loss**

For stigma, stereotypes are a set of “undesirable characteristics” (Link & Phelan, 2001, p. 369) that are linked to labels as a cognitively expedient process that may happen without full awareness. The negative nature of the stereotypes contributes to the process of separation, and the process of separation is not necessarily physical or spatial but

social demarcations of “us” versus “them” (Link & Phelan, p. 370). The group with the greater negative valence from stereotypes loses the most in social standing and acceptance. Separation is also initiated with diagnostic labels when people are referred to as their disease or behavior, for example: ‘diabetic’, ‘epileptic’, and ‘smoker’ (Link & Phelan).

### **Discrimination**

Discrimination, according to Link and Phelan (2001) is not confined to one person limiting the chances of another. There are broader forces that contribute to structural discrimination, or practices, policies, and barriers that work toward creating a disadvantaged status (Link and Phelan). They provide funding disparities for certain diseases, like schizophrenia, noting that it creates a disadvantage for the people who work with patients who have a stigmatized disease and the patients themselves (Link & Phelan). The authors assert that stigma “...affect[s] the structure around the person, leading the person to be exposed to a host of untoward circumstances” (p. 373). A downward social status trajectory from a label-stereotype link is another form of discrimination because the new lower status further limits opportunities and access to resources (Link & Phelan).

**Funding.** Lung cancer is a diagnosis and label that simultaneously links those who have it to other patients with cancer yet differentiates them as having a unique form of cancer. The ‘why’ of this uniqueness is not just cellular or biological. Lung cancer has a strong link to social and psychological issues such as high mortality, socially and morally reprehensible behaviors, and disparate funding. The differences in funding have

been noted by several prominent scholars in nursing, public health, and psychology.

These scholars assert that the stigmatization of smoking and lung cancer are responsible for low funding and that:

A number of factors have contributed to this inequity. First, a large and vocal group of breast, prostate, and colon cancer survivors have raised the public profile of these cancers and successfully lobbied for increased funding. This pressure has translated into important budget earmarks and research emphases. Unfortunately, survivors of lung cancer are relatively few and thus underrepresented in the voices clamoring for more research support (Gritz, Sarna, Dresler, & Heaton, 2007, p. 860).

Other scholars offer a similar perspective, noting that many famous women have talked openly about their experiences with breast cancer, creating a powerful force in support for breast cancer, while lung cancer has not benefitted from such support (Gulyn & Youssef, 2010). A journalist, and friend of Peter Jennings who died of lung cancer, recounted that he quit smoking when he heard of Jennings' death and that the "...relatively paltry funding for lung cancer research suffers from the impact of smoker's guilt — the "we bring it on ourselves" lament that even Peter referenced in his very last broadcast, saying he'd "been weak" and had gone back to smoking after 9/11." (Taibbi, 2007, para. 13).

### **Power**

Power is the driving force behind stigma that allows it to be created, perpetuated, and maintained (Link & Phelan, 2001). Sources of power are social, political, and economic, but they may not be obvious since observations of differences tend to focus on characteristics, not the myriad of forces contributing to a lack of equity (Link & Phelan).

Stigma can involve links to many stereotypes, which can in turn consume the person's identity (Goffman, 1963; Link & Phelan; Volinn, 1983) leading others to see them as a lesser person and threaten their social status. Part of the power of stigma is that it may not be detected until the consequences have damaged a person's identity, for example a person who never smoked can get lung cancer and subsequently be included in the stereotype of a 'self-inflicted' disease (Conlon et al., 2010).

Health care professionals and other "normals" have power first and foremost because they typically do not have lung cancer, and because of their status as trusted professionals that the public has become reliant on for knowledge about health (Starr, 1982). This status allows them to create labels in the form of diagnoses, form judgements about causes and behaviors past or present, plan care based on those judgements (at the individual level or population level), and they are aware of and can carry forward extant stereotypes, negative attitudes, and beliefs about diseases that are stigmatized because they occur in the culture in which they practice (Volinn, 1983).

All health care professionals have power in relation to the people they care for because patients interact with the health care system when they are at their most vulnerable or progressing toward that state, and at times, their naiveté of the health care system contributes to powerlessness in being active agents in their care. More importantly, patients, due to their more vulnerable position as an ill person in a large and complicated health care system, are less able to offset negative stereotypes. Because there is a power difference between patients and health care professionals, if patients were to

stereotype health care professionals this would not result in stigma because it does not originate from the same status or knowledge level.

This vulnerable position is compounded, in part, by labeling processes that are in the control of health care practitioners (Volinn, 1983). Health care professionals, nurses specifically, also control the patterns and routines of care, which stem from facility policies, and impacts communication and interactions with patients (Hewison, 1995). While retaining the intention to help and promote health, health care professionals are also positioned to set the goals and interventions for health promotion, requiring little input from patients; yet when the interventions are not successful there are negative physical, social, and psychological consequences for patients (Tengland, 2016).

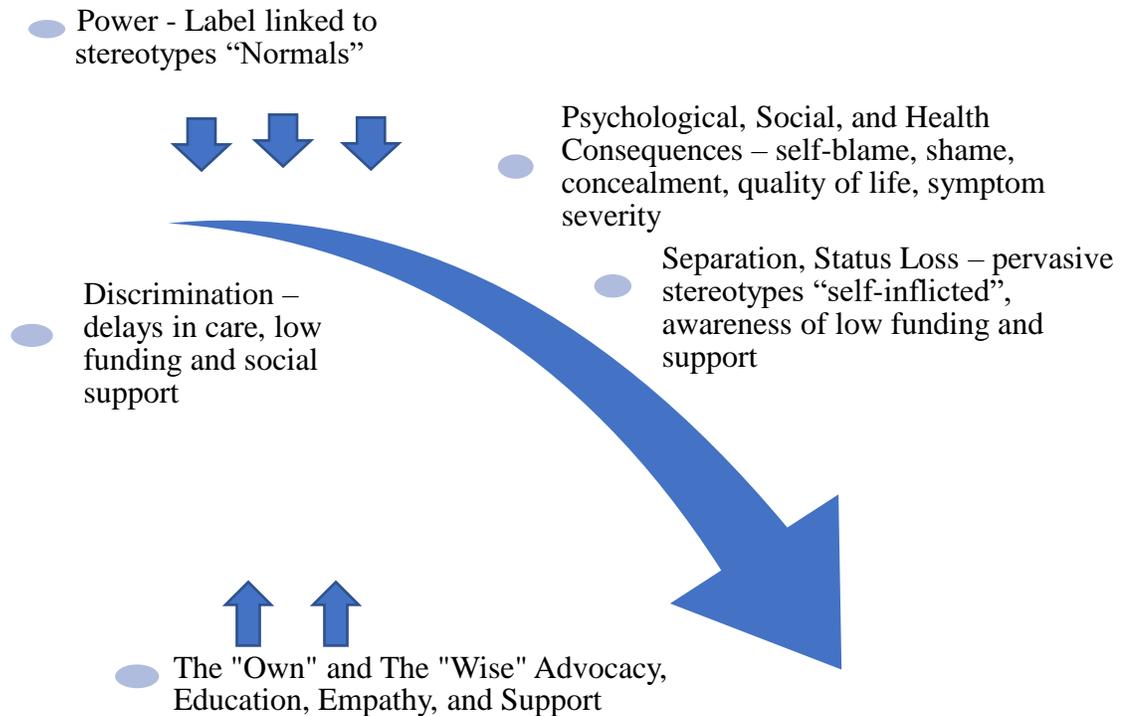
While health care professionals may or may not be able to transmit stereotypes and negative attitudes to the broader public, they can do so within their professions because they are responsible for teaching and mentoring students in their respective disciplines. They also transmit their attitudes to other health care workers during day to day interactions with patients in the form of slang, games, and derogatory humor (Wear, Aultman, Varley, & Zarconi, 2006). Third and fourth-year medical students, n =58, who participated in focus groups where they were asked to describe cynical or derogatory humor about patients, students described the people who were the object of humor who were mostly obese patients, and anyone who is at fault for their disease including people who smoke, drink, use drugs, have unsafe sex, practice illegal behaviors, and those who are noncompliant (Wear et al.). The status of an experienced professional which includes their advanced knowledge, stable status in the profession, and expertise, means they may

not be questioned about the way they choose to express their beliefs, attitudes, or stereotypes, particularly from their students, mentees, or supposed subordinates (Wear et al.).

The stigmatized alternate between two identities, one that contains their actual characteristics, and the other which consists of imputed characteristics from society and “normals” (Goffman, 1963). Hence, actual characteristics that carry a stigma and are known make the stigmatized a “discredited” person; when they are not known, a “discreditable” one (Goffman, p. 41). Extant stereotypes, labels, and characteristics are also an expedient method of organizing and simplifying information in order to mitigate uncertainty in encounters; health care encounters are no exception (Puhl & Suh, 2015; Sriram et al., 2015; Volinn, 1983); however, such methods potentially have low accuracy and a high degree of adverse psychosocial outcomes (Goffman; Volinn).

Psychological and social processes occur for “normals” and “stigmatized” alike with regard to stigma. Social construction of diseases means, in part, that people form “lay theor[ies]” about the illness and how it fits within the social hierarchy; are people with the disease welcomed, empathized with, or judged harshly and excluded (Link & Phelan, 2001, p. 373). Psychological processes of stigma for the stigmatized can include incorporating the negative attitudes of “normals” in the form of self-blame, shame, and essentially stigmatizing oneself (Goffman, 1963). Figure one is a diagram of the major concepts in both Link and Phelan’s theory and Goffman’s Theory.

Figure 1. Diagram of Concepts in Stigma Theories.



This study focuses specifically on stigma as it relates to lung cancer and the nurses who care for patients with lung cancer. Society, health care professionals, and lay caregivers of people with lung cancer have been studied as the perspective of “normals” and potential stigmatizers. Stigma frameworks have also been used to study patients with lung cancer. Nurses as a distinct profession within health care have not been studied qualitatively except in studies of obesity-related stigma (Aranda & McGreevy, 2014; Brown & Thompson, 2007), and HIV/AIDS and stigma (Greeff & Phetlhu, 2007). There is one quantitative study that examines the perspectives of nurses in relation to lung cancer stigma (Wang et al., 2015).

The following review of the literature is organized by concepts from Goffman's theory of stigma (1963) and those from the Link & Phelan (2001) conceptualization. Other concepts that emerged from the literature will also be discussed with regard to studies that tested or explored them. The process of stigma begins with links that are made between labels and stereotypes, then progresses to separation of the stigmatized from other groups in society that are considered normal, and finally discrimination; with power as the social, political, and economic force behind the stigmatization process (Link & Phelan).

### **Stereotypes, Bias, Negative Attitudes, and Therapeutic Nihilism**

The social construction of disease that includes connecting stereotypes to labels can contribute to biased perceptions that are in favor of or against an illness (Dovidio & Fiske, 2012). For example, some diseases may be favored by health care professionals because they have a clearer treatment course, and some patients may be favored because they are viewed as curable or treatable (Ford, Liske, & Ort, 1962; Wear et al., 2006). Diseases that are difficult to treat typically have sequelae or outcomes that do not return to normal parameters. For example, most of the cancers with high incidence rates also now have high five-year survival rates, except lung cancer (American Lung Association, 2017).

Knowing that a patient with lung cancer has a higher likelihood of dying than surviving may not only foster an anti-lung cancer bias (Sriram et al., 2015), but create room for therapeutic nihilism, or the belief that because the disease has poor treatment outcomes it is not treatable (Schroen, Detterbeck, Crawford, Rivera, & Socinski, 2000),

and only natural, or nonmedical, forces could lead to good outcomes (Starr, 1982).

Encounters with patients who have a disease such as lung cancer that has a high mortality rate may imbue people with a fear of dying; a powerful existential crisis that pushes against the boundaries of normal parameters (Jones, 1984).

## **Smoking and Stigma**

### **History of Lung Cancer and Smoking Stigma**

Lung cancer has been linked to smoking since the mid twentieth century when scientists, statisticians, and physicians suspected the link, but could not study the problem until there was appropriate funding for such research (Mukherjee, 2011), and the extreme doubt and ridicule of other scientists and physicians of the proposed link was overcome (Brandt, 2007). This effort and the overwhelming scientific evidentiary support that followed the initial link were so controversial that other causes of lung cancer did not have the same strong connection in the public's mind (Mukherjee). Moreover, an existing struggle at the time, to find the cure and cause of cancer, made lung cancer both famous and infamous because finally there was a known cause for a type of cancer and it could be prevented (Mukherjee).

The 1964 Surgeon General's report on the dangers of smoking solidified the science – yet politically the report was downplayed so as not to offend tobacco companies and politicians who supported them (Mukherjee, 2011). However, the report led to important policies to limit the impact of tobacco advertising on the public which to that point was mostly unfettered and unregulated (U.S. Department of Health and Human Services, 2014). Meanwhile, people who smoked were having a difficult time quitting,

because the scientific focus was on epidemiology not physiology, or addiction (U.S. Department of Health and Human Services). When scientific focus moved toward smoking and addiction, again propaganda thwarted efforts to address the problem of smoking realistically. Smoking was advertised to be not only a personal choice, but a matter of freedom (Brandt, 2007). There was additional reluctance to proclaim that smoking was addictive because the association to ‘addict’ was considered to be too much of a negative connotation.

Other stereotypes and judgements that were propagated at this time were that smoking was a choice (Mukherjee, 2011), smokers were selfish, immoral with character flaws (Brandt, 2007), and that lung cancer was self-inflicted (Mukherjee). In addition, since non-smokers were “innocent victims” of second-hand smoke, it was their health concerns, not those of people who smoked, that garnered widespread attention and cigarette smoke was soon on par with industrial level air pollution (Brandt, p. 281). Smoking, at the time, was also linked to heart and vascular disease and heart disease was termed “tobacco heart” (Brandt, p. 146); yet this stereotype (for there are now many hypotheses about the cause of heart disease) did not have the same lasting link as smoking to lung cancer. Although there is almost no comparable link to smoking and other cancers, the behavior is by no means uncommon to other cancers. For example, a recent study of people diagnosed with breast cancer revealed that of the 975 breast cancer patients who participated, 20% were current smokers and 29% were former smokers. (Izano, Satariano, Hiatt, & Braithwaite, 2015).

**Social.** Smoking underwent a dramatic change from socially acceptable to deviant over the past century to the present (Brandt, 2007). Social forces that discourage smoking are often the same entities that link the behavior to disparaging stereotypes such as all people who smoke are lazy, stupid, careless, and selfish. These stereotypes are based on taken for granted ideas that extant knowledge of the dangers of smoking should be an automatic stimulus for immediate behavior change (Brandt, 1990) – therefore those who have not responded have inherent character flaws. This belief, that widely disseminated health information is synonymous with lasting behavior change, has largely been debunked (Rollnick, Mason, & Butler, 1999), and does not apply only to smoking cessation – behavior change and adherence to that change is difficult and complex, and does not occur only with advice (Rollnick et al.).

**Political.** The social influences on stigma and smoking, and hence stigma and lung cancer stem in part from policy and politics. Political power allowed tobacco companies to advertise, campaign, and lie about cigarettes for many decades (Brandt, 2007). Policies that counteracted the negative influence of tobacco companies led to broad sweeping public health initiatives such as tobacco denormalization. These initiatives were a direct counter measure to the powerful propaganda and advertising from the tobacco companies, but did little to address the complex issues of dependence. Furthermore, there was delayed recognition of the negative consequences of denormalization campaigns such as marginalization of vulnerable groups of people who smoke like those with low education attainment, mental illness, low income, and minority ethnic groups (Brandt, 1990).

Throughout the enactments of policies and positions, and counter policies and positions about smoking and lung cancer, there are descriptions of the process that allude to a battle or war (Mukherjee, 2011). Since one side of the battle, the tobacco companies, had enormous economic, political, and social influence – not to mention consumers who were addicted to their product – they had to be met from opposing sides with an equal force which was directed both at tobacco companies and the behavior of smoking in the public realm. Two main goals of this battle were to decrease the influence of tobacco companies and their ability to retain customers and lure new ones, and the other was to change public perception about smoking.

These negative stereotypes linked to smoking, make people who smoke and smoking related diseases a politically weak, negatively constructed deviant group that is more likely to be punished than given advantage politically and with public policy (Schneider & Ingram, 1993). The attorneys general of 46 states sued the largest four tobacco companies in the Master Settlement Agreement (MSA) for billions of dollars to be paid to the states over several decades, ideally for smoking related illnesses and tobacco use prevention; this may seem like a politically powerful and strong advocacy effort on behalf of those who smoke and have smoking-related illnesses. However, use of the money for tobacco use prevention and tobacco-related illnesses was never specified in the settlement, consequently, over the years the money has been used to fund various budgets that were not even health related (U.S. Department of Health and Human Services, 2014).

Smoking now is not only a risky health behavior, but a deviant behavior since it is banned in most public places. These policies to restrict smoking have interacted with individuals' struggles with nicotine dependence, leading to social situations fraught with conflict (Greaves et al., 2010; Ritchie, Amos, & Martin, 2010). Deviance has also been attached to smoking via clean air policies that were initiated in response to anti-smoking advocacy groups asserting that people who smoke are endangering the lives of others intentionally (Markle & Troyer, 1979). Markle and Troyer presaged the stigmatization of smoking when they noted that “[c]igarette smokers, who in increasing numbers see themselves as deviant actors, have been labeled as drug addicts and neurotics as well as air polluters and fire hazards” (p. 622).

Political and social power have worked both for and against lung cancer due to their influential attachment of the disease to smoking. The link to smoking stimulated policies to reduce smoking and counteract the tobacco companies, but it also dehumanized people who smoke by portraying them with grotesque images and as engaging in horrific acts (Thompson, Barnett, & Pearce, 2009; *The Real Cost*, 2016). While there are arguments both for and against fear-based smoking denormalization campaigns, the target groups for these messages are already vulnerable and marginalized groups where smoking prevalence is high such as low income, low education attainment (Garrett, Dube, Winder, & Caraballo, 2013), people with mental illness (Centers for Disease Control and Prevention, 2013), lesbians, gays, and bisexuals, and ethnic minority groups such as American Indians/Alaska Natives (Martell, Garrett, & Caraballo, 2016). The disgusting images portrayed in these campaigns gives tacit permission to further

stigmatize these groups who are already struggling with multiple stigmas. The denormalization campaign was effective with high income, high education attainment smokers and less so with people on the other end of the sociodemographic spectrum. In addition, vulnerable and marginalized groups, today, have high smoking prevalence and more difficulty with quitting.

The U.S. Department of Health and Human Services 2014 report on smoking and health consequences notes that when smoking was first linked to lung cancer and other diseases, there was little knowledge on how addictive it was. While this information was eventually gathered and disseminated in a 1988 report, there is still a significant lag in bringing this information and the clinical practice guidelines for tobacco cessation to the patient who smokes to provide the best opportunity for tobacco cessation. There were powerful efforts to convince people to stop smoking, and minimal support for people who smoke to achieve smoking cessation and maintain the behavior change (Leventhal & Cleary, 1980). The denormalization of smoking, the lag in wide dissemination of cessation support, the political ties of the tobacco companies to the U.S. Government, and ambiguous advocacy efforts in the form of the Master Settlement Agreement have all contributed to a general pall over smoking behavior and expressions of distrust by some people who smoke toward screening for lung cancer (Carter-Harris, Ceppa, Hanna, & Rawl, 2015).

The stigmatization of smoking has been studied and examined since the 1970s. Even then, scholars were concerned that the battle to decrease smoking prevalence among the public would change into a fight between smokers and non-smokers (Markle

& Troyer, 1979). Further investigations in the late 90s indicated that smoking was no longer only viewed as a health concern, 16.8% of a sample of 715 students, their parents and grandparents agreed that smoking was immoral, and the feelings of disgust expressed by non-smokers is more closely correlated with morality ( $r = 0.40$ ) than health ( $r = 0.14$ ) and this difference remained significant across six subsamples ( $p < 0.02$ ) (Rozin & Singh, 1999).

While there is some support that the anti-smoking attitudes push people toward behavior change when they feel shame ( $p = 0.043$ ), stereotypes of smokers having a weak character was not a predictor of behavior change (Kim & Shanahan, 2003). In addition, most studies that examine the impact of stigma on behavior change are cross sectional, so there is no way to determine the direction of this relationship: does a failed attempt at behavior change lead to shame and thoughts about trying again, or the reverse? Even less apparent is how long shame is useful as a stimulus for behavior change. The most telling outcome of years of shaming citizens through public health campaigns is that none of the clinical practice guidelines or behavior change techniques endorse shaming or stigma as a way to interact with a patient; as a matter of fact, this is considered to be counterproductive and damaging (Kim & Shanahan). Unfortunately, public health initiatives regarding denormalization of cigarette smoking set the stage for how smoking cessation should be viewed, that it is the individual's responsibility (Brandt, 1990). These initiatives conflict with current cessation guidelines that are underpinned with motivational interviewing techniques that use a partnership model for behavior change assistance (Miller & Rollnick, 2013).

While judgements of intelligence by the public toward smokers might seem justified, since the harms of smoking have been widely disseminated for many decades, it also demonstrates a stereotype that if something is known to be harmful and is done anyway, the person must lack intelligence. The stereotype negates the complex dimensions of cigarette dependence, and the person, not the behavior, is criticized.

### **Delays in Care**

Delays in seeking care for symptoms of lung cancer represent the concepts of stereotyping, status loss, and discrimination. Patients delay seeking care for symptoms related to lung cancer because of extant stereotypes about the causes of lung cancer, their symptoms are vague, they have fear, and there are nihilistic attitudes retained by patients and physicians. There is also a desire to improve their status by quitting smoking before they go to their doctor, something Goffman (1963) referred to as attempting to mitigate faults in order to obtain "...fully normal status..." (p.9), but only achieving partial acceptance as someone with a history of stigma.

### **Delays in Care, Studies of "Normals"**

Delays in care emerged as an issue in the care of patients with lung cancer in four qualitative studies with mixed samples of health care professionals and one quantitative study of physicians. One qualitative study design was specific to creating a health advertisement for people at risk for lung cancer so they would not delay getting care (Tod & Joanne, 2010), the other studies explored outcomes and support (Dunn et al., 2016), how practitioners perceive symptoms and referrals (Scott et al., 2015), and barriers to care, for patients with lung cancer (Tran et al., 2015). The perceptions of physicians, and

the potential impact on referral and knowledge of patients with breast cancer versus lung was represented in one quantitative study (Wassenaar et al., 2007).

In a qualitative study with a purpose of creating a health advertisement to prevent delay in care seeking for people at risk for lung cancer, Tod and Joanne (2010) interviewed 14 health care professionals (nurses and pharmacists). The participants reported that delays in care-seeking behavior occurred because the patients were afraid of being blamed, shamed, judged, and not being treated well because of continued smoking. Additionally, health care professionals noted that people at risk for lung cancer fear a potential diagnosis of cancer, have fatalistic beliefs that are exacerbated by negative advertisement campaigns against smoking, try to manage the symptoms themselves, or wait until they are severe.

Similarly, in another study of physicians, nurses, therapists, and health workers in Australia, n = 31, delays in receiving care occurred when a patient's symptoms were immediately linked to smoking by the practitioner, without further investigation or screening for lung cancer, patients attribute their own symptoms to other causes, they feel like they do not deserve care, they have shame related to smoking, and they do not want to be blamed by health care professionals (Dunn et al., 2016). Health care professionals also noted that smokers and nonsmokers experience the stigma associated with lung cancer, and engage in self-blame. Fear, again, spurred by negative public health advertisements was noted to be a deterrent to timely care (Dunn et al.).

Two other qualitative studies had themes related to barriers or delays in care for patients with lung cancer from the perspective of general practitioners in Australia, n =

10 (Scott et al., 2015), and another sampled health care professionals and non-healthcare professionals, n = 74, who work for lung cancer nonprofit organizations in Canada (Tran et al., 2015). General practitioners noted that there is more compassion for patients who get lung cancer and never smoked, and those who never smoked have a delayed path to diagnosis because lung cancer is not factored into the differential diagnosis (Scott et al.).

One general practitioner remarked:

Because it presents so late, there's not much you can really do except to tell people "If you get it because you were smoking, well we told you, you shouldn't have smoked. If you didn't smoke at all and you still got it, you're just really unlucky" (Scott et al., p. 620).

Patients at risk for lung cancer who sense or experience these attitudes from their physicians may not only delay returning for worsening or repeating symptoms, they lose trust in health care professionals.

Of the 74 participants in the Tran et al. (2015) study, 28% endorsed that there is a general unfavorable view toward lung cancer. A radiologist indicated that the shame and self-blame that patients experience diminishes their self-agency, and they do not take action related to their symptoms. A thoracic surgeon and oncology social worker asserted that nihilism related to lung cancer is still a problematic attitude among health care professionals and impacts care decisions and referrals to cancer centers. A physician recalled discussions with other physicians about lung cancer screening and arguments against it for people who smoke (Tran et al.). Fifty-eight of the 74 participants in this study did not see stigma as a problem related to barriers in lung cancer care, however, the

authors only provide two examples of this response, one from a health administrator and the other participant had no title attached to their quote.

Delays in care may also occur after a diagnosis of lung cancer. A cross-sectional, experimental, factorial study of 672 internal medicine and family physicians who were randomly assigned to one of four vignettes of patients with lung cancer or breast cancer in which the smoking status and tumor stage were manipulated, revealed that perceptions of lung cancer differ from those of breast cancer in the context of referral decisions, therapy benefit, and follow up (Wassenar et al., 2007). Patients with lung cancer and metastatic disease were significantly less likely to be referred to an oncologist than breast cancer patients ( $p < 0.001$ ), less likely than breast cancer patients to receive follow up every one to two weeks ( $p < 0.0256$ ), and knowledge about adjuvant therapy and the survival benefits were less for lung cancer than breast cancer ( $p = 0.001$ ). Although these findings might be attributable to lack of knowledge there was no statistical difference between physicians who saw fewer cancer patients than those who saw more (Wassenar et al.).

### **Critique**

The studies discussed above have limitations. First, the qualitative studies all have mixed samples of health care professionals and do not always identify the profession of the person quoted. Second, some of them did not adequately describe their analytic rigor (Tod & Joanne, 2010, Scott, 2015). None of the studies addressed saturation of the sample.

While all of the studies provided diverse viewpoints among the different health care professions, all of the studies were also conducted in places with socialized medicine, which is different from the United States; however certain psychosocial issues related to lung cancer likely span health care cultures. Most of the studies did not ask about stigma directly, but used broad open ended questions about practices, barriers, and support for lung cancer. One study asked the main interview questions first, then asked about stigma and nihilism with prompts (Dunn et al., 2016).

The instrument used in the Wassenar et al., 2007 study was not an established instrument, although it was partially validated with feedback from the research group and medical oncologists, and was piloted. Despite this limitation, some of the findings in the study are congruent with comments from participants in more recent qualitative studies.

### **Summary**

Overall, the perceptions of health care professionals are that patients with lung cancer experience stigma. While one study found that the majority of people interviewed did not see lung cancer as a stigmatized disease (Tran et al., 2015), the other studies found that this was the minority perception. Since these different perceptions will likely occur in future studies, it would be useful to obtain a richer description of how people view lung cancer if they do not see any stigma attached to it; perhaps not only the label of lung cancer, but the stereotypes, status loss, and discrimination have become "...taken for granted as being just the way things are" (Link & Phelan, 2001, p. 367).

## **Delays in Care, Studies of Patients**

Delays in care can also be examined from the perspective of people at risk for lung cancer and people who have been recently diagnosed. Three qualitative studies explored delays in seeking care for symptoms related to lung cancer (Tod et al., 2008), trajectories of being diagnosed with lung cancer (Carter-Harris, Hermann, & Draucker, 2015), and perceptions of screening for lung cancer (Carter-Harris, Ceppa, et al., 2015). These studies represent patients with lung cancer and patients at risk for lung cancer.

A qualitative study of 18 patients who had been diagnosed with lung cancer in the past six months (n=16), and two who were 18 month survivors in the United Kingdom, revealed congruency with statements made by health care professionals about potential delays in seeking care (Tod et al., 2008). When recounting their symptoms prior to diagnosis, participants noted that they would attribute new symptoms to changes in their environment or their age, but not a serious illness. Participants also stated that there was more information about breast cancer than lung cancer noting "You're more likely to think of yourself getting breast cancer than lung cancer, even as a smoker" (Tod et al., p.340), and that advertisements that use scare tactics were deterrents to wanting to find out about health problems.

Negative advertisements that link lung cancer to smoking also portray the idea that smoking is the only cause of lung cancer. Participants who quit smoking believed they were no longer at risk for lung cancer, and those who smoked and did not quit anticipated blame related to their behavior and were questioned repeatedly about their smoking behavior (Tod et al., 2008). Beliefs about when to see a doctor, when the

problem is severe, and how much it would cost (prior to universal health care) also contributed to delays (Tod et al.).

Another qualitative study of patients with lung cancer who smoked,  $n = 11$ , in the United States, sought to discover how patients with lung cancer become diagnosed (Carter-Harris, Hermann, et al., 2015). All of the participants in this study sought care when they noticed their symptoms persisted or were accompanied by other symptoms such as weight loss, exhaustion, and chest pain. However, their stories of finally getting diagnosed with lung cancer reveal experiences of frustration and duress because the prescribed treatments for the supposed problems of pneumonia, high blood pressure, and sinusitis never worked; one woman was told by her physician that it was “all in her head” and this delayed her seeking care again when her symptoms became more severe (Carter-Harris, Hermann, et al., p. 579). She was finally diagnosed when she went to the emergency room and a chest x-ray was done. Another participant spoke of her many visits to a health care provider because the antibiotics were not working, she started crying in frustration during an office visit where she had a CT scan and was diagnosed with stage IV non-small lung cancer. Other participants, who had more drastic symptoms such as hemoptysis, a better rapport with their physician, or had tests related to another problem, had a quicker pathway to diagnosis.

The patients in this study were all at high risk for lung cancer, yet the screening process for some of them was not triggered despite having a smoking history and indicative symptoms. Moreover, patients had further delays due to the attitudes of their providers who did not believe the problem was serious or who did not take their patients’

concerns seriously. Delays in diagnosis are further complicated by the perceptions of people at risk for lung cancer.

In a mixed method study, 163 people from communities of low socioeconomic status in England who currently smoked or had a history of smoking revealed their own sense of pessimism regarding lung cancer screening (Quaife, Marlow, McEwen, Janes, & Wardle, 2016). Among participants who smoked, 20% believed that there was no benefit to screening for a prolonged history of smoking or current smoking, and 30% thought a negative screening result meant they could continue smoking without further risk of lung cancer. Lung cancer was thought to be a “death sentence” by 48%, and 20% thought that people who perform the screening would be rude to people who smoke (Quaife et al., p. 5). These results further amplify the belief among smokers that they have to quit before they seek treatment or screening, instead of viewing health care professionals as people who can help with quitting. Comments from participants also revealed anticipated stigma and blame from health care professionals and feelings of guilt and regret.

Similar results emerged in another mixed methods study in Australia (Crane et al., 2016). Data from 16 focus groups were compared to survey information from 1,000 randomly sampled people who answered a telephone survey. From the survey results, participants who had higher SES, were older and female had better knowledge of the symptoms of lung cancer. Some of the participants who were current smokers offset the link of smoking to lung cancer by attributing the risk to air pollution (28.1%) and aerosolized chemicals (30.8%). A participant who was a current smoker noted “We know the facts, yet we still smoke. So we’re obviously in denial about a lot of things. We can

accept one point of view and another, because we're playing mind games with ourselves" (Crane et al., p. 6). Other participants noted barriers to going to the doctor such as delaying for as long as possible because the problem is "self-inflicted" and another noted "Possibly a feeling that the doctor is going to focus on your smoking "don't bother coming back until you've fixed your smoking" (Crane et al., p. 5).

The last qualitative study included 26 long-term smokers who were recruited for four different focus groups; two focus groups included people who had been screened for lung cancer and two groups were comprised of those who had not been screened (Carter-Harris, Ceppa et al., 2015). During the focus groups, participants discussed potential obstacles to screening and ways it can help people at risk for lung cancer. Consistent with comments from health care professionals, people at risk for lung cancer, and current and former smokers, pictured having lung cancer as a fearful, horrible experience that inevitably results in death, and that health care professionals blame them for smoking and treat them as if they are "stupid" for doing so (Carter-Harris, Ceppa, et al., p. 7). While participants thought that current and former smokers should be screened, they also expressed poor knowledge of the existence of lung cancer screening and how it is done, even those who had been screened, and there was mistrust of both tobacco companies and the government for supporting and profiting from them. These suspicions carried over to screening which was seen as a way to make money – a way to get people in for one test then order more tests. One participant noted that the historical timing of lung cancer screening seemed suspicious:

I hate to be kind of skeptical of modern technology...all of a sudden now we're hearing about lung screening. All of these years, how long have cigarettes been

around, and how many people have died from lung cancer or whatever, now we have the screen (Carter- Harris, Ceppa et al., 2015, p. 6).

### **Critique**

All of the studies above provided explanations of analytic rigor as far as using an analytic plan, multiple coders, and discussion of codes, but again did not address saturation or an audit trail. Samples for these studies were mostly White, so they underrepresent minority views on these issues, and it is not clear from the quotes which people expressed what opinions. It cannot be ruled out that while breast cancer appears to dominate the cancer discourse, White participants, so far, dominate the discourse on perceptions of lung cancer in the literature. One study, Tod et al. (2008), did not report the ethnicity of their participants or the education level, and another study, Carter-Harris, Ceppa, et al. (2015), reported the mean education level but did not include this category in their demographic table. However, one study, Carter-Harris, Hermann, et al. (2015) had a near even split between low and high education attainment participants. Low education attainment is one of the key demographics for high smoking prevalence.

### **Summary**

Many of the comments made by patients in these qualitative studies are consistent with what health care professionals have said about problems with perceptions of lung cancer. Patients note the fear surrounding smoking and lung cancer from public health advertisements, that breast cancer and other cancers are more prominent in the media and have more support, symptoms of lung cancer can be vague or not taken seriously due to

smoking, and that people who smoke anticipate, or are actually blamed and made to feel small.

### **Comparing Lung Cancer to Other Cancers**

The comparison of lung cancer to other cancers is a form of separation and discrimination. While this comparison is sometimes prompted by the research design, there is support that lung cancer is not treated like any cancer and not just because of biological processes, but because it is linked to a behavioral cause which is not as perceptually prevalent for other cancers.

### **Perspective of “Normals”**

Lung cancer is compared to breast cancer by both patients with lung cancer, the public, health care professionals, and as part of study designs as a non-stigmatized disease referent. Breast cancer is used as a referent because there is no widely known behavioral cause of the disease. Patients with lung cancer note that a lump in the breast is treated more seriously by health care professionals than a persistent cough (Chapple et al., 2004). In other qualitative studies breast cancer is perceived to have more support and funding (Conlon et al., 2010; Scott et al., 2015), more overall public awareness (Conlon et al.; Tod & Joanne, 2010), and this is fueled in part by longer five-year survival which contributes to self-advocacy among breast cancer survivors (Conlon et al.).

Oncology social workers, n = 18, from 17 different hospitals in 13 different states were interviewed for their perspectives on differences between lung cancer and other cancers and differences among patients with lung cancer (Conlon et al., 2010). Among other themes such as smoking status and poor outcomes, participants noted the difference

between advocacy for breast cancer and for lung cancer stating “there seems to be so much awareness and advocacy at a national level and in the media that really helps women to understand this cancer” and “...the resources are just not there for people diagnosed with lung cancer. Susan G. Komen has this nice \$1,000 grant that they are giving to people with breast cancer but there is nothing like that for lung” (Conlon et al., p. 106). Other participants note the differences in support and funding saying:

[w]ith the more common cancers, such as prostate and breast cancer, there is more information, support, and money for patients—especially for breast cancer. There’s more grant funding. I meet breast patients in outpatient radiation. There seems to be so many resources for them. It’s a shame because with brain and lung, especially lung, there seems to be so much less available (Conlon et al., p. 107).

Another participant notes the impact on patients, saying:

And, there’s the frustration that there are not as many resources for lung cancer. There’s not as many walks and talks and volunteering. My patients would get things about this breast cancer run and that leukemia and lymphoma event. There was just nothing for them. There wasn’t that same kind of outpouring for lung cancer. Patients would be frustrated with that, with the lack of resources. That played into that feeling of this disease being stigmatized. They struggled with that (Conlon et al., 2010, p. 107).

The comments are supported by a quantitative experimental, factorial design study that examined the funding choices of 462 and 299 college students in two separate studies (Knapp-Oliver & Moyer, 2012). In the first study, participants were randomly assigned to a scenario that was high or no risk and either lung cancer (caused by secondhand smoke or smoking) or breast cancer. In the first study, participants preferred less risky programs to fund and the cause of the cancer did not change the direction or

strength of the relationship between how the disease was presented and provision of funding (Knapp-Oliver & Moyer, 2012). In the second study, lung cancer and breast cancer were presented as being in competition for funding. Findings for this study indicate that even among college students, who are theoretically not involved in real funding decisions, the behavioral cause of the cancer led them to choose funding breast cancer over lung cancer when the two cancers were in competition for funding. When participants were exposed to scenarios where the cause of lung cancer was not the patient's fault, lung cancer funding was preferred. When students were asked to explain their funding choice, the majority of responses (27.6%) involved noting the behavioral cause of lung cancer, and one participant noted specifically that lung cancer is caused by "lifestyle choices" while breast cancer "occurs naturally" (Knapp-Oliver & Moyer, p. 2378). While other participants (11.2%) noted that lung cancer patients have a lower survival rate and should therefore receive more funding – however these views were in the minority.

Similarly, in a cross-sectional study of 1,071 participants who were randomly sampled from the general public, 18% reported being involved in a breast cancer support organization and only 8% reported this for lung cancer, and future monetary support was 29% and 18% respectively (Weiss, Stephenson, Edwards, Rigney, & Copeland, 2014). The results of this study also indicate that people have mixed views about the cause of lung cancer, while 94% believed that a person can get lung cancer even if they do not smoke, most participants also indicated that the cause of lung cancer is due to "lifestyle choices"- echoing the participants in the Knapp-Oliver and Moyer (2012) study. While

only 23% of participants believed that all lung cancer is caused by smoking, 43% thought that prevention of lung cancer could be achieved by prohibiting smoking, and 59% noted that people with lung cancer can be blamed in part for their disease. People who attributed the cause of lung cancer to genetics and thought that it could be cured when detected early were more likely to monetarily support the disease. The dominant reason for supporting one cancer over another was knowing someone who had the cancer and thinking that one might get the cancer (Weiss et al.).

Lung cancer also has implicit negative associations among cancer patients (N = 243), caregivers (N = 677), health care providers (N = 142), and members of general public (N = 716) (Sriram et al., 2015). The majority of participants, 75%, associated lung cancer with despair, and 66% with shame versus 9% and 17% respectively for breast cancer ( $p < 0.001$ ) (Sriram et al., 2015). The association of shame to lung cancer is, psychosocially, a potentially powerful link; shame is not part of the epidemiological data of lung cancer (mortality, incidence, prevalence, and survival), indicating that people are associating aspects of their moral judgements with the disease. The shame association could also stem from the lack of public awareness campaigns for lung cancer; indicating that a disease that carries shame should stay silent.

When lung cancer is compared to several other cancers such as cervical, breast, skin, and colorectal, a convenience sample of 1,205 people from an online survey panel in England responded with similar negative perceptions (Marlow, Waller, & Wardle, 2015). Participants were randomly assigned to one of five cancers to rate on awkwardness, severity, avoidance, policy opposition, personal responsibility, and

financial discrimination; lung cancer was rated higher than breast and cervical cancers in all six dimensions, but skin cancer scored higher on financial discrimination (Marlow et al.). In a similar experimental study design, a sample of women,  $n = 1,620$ , who were randomly selected from a pool of potential participants, 15% attributed blame to people with breast cancer, while 70% assigned blame to lung cancer which was less than blame assigned to chlamydia (87%), and obesity (96%) (Marlow et al., 2010). When participants knew the behavioral causes related to a disease, like chlamydia, they were more likely to endorse blame ( $p < 0.001$ ) (Marlow et al.). However, only one item was used to assess blame, the variable was dichotomized to no blame and some blame, and higher cutoffs for the blame score yielded smaller differences among cancer groups.

Oncology nurses in China responded slightly differently to the same survey used in the Marlow et al. (2010) study. Among 317 oncology nurses in a hospital in Beijing, 82% attributed some blame to lung cancer patients for their condition versus 67.5% to patients with breast cancer (Wang et al., 2015). This was the only study that sampled nurses exclusively. While the percentage who blamed patients with breast cancer is higher than other studies, the results in this study are still consistent with other studies where blame was highest for diseases linked to behaviors that are considered to be controllable. In this study, the most blame went to patients with obesity at 88.6%. Participants were mostly female, young, and educated. Additionally, causes of illness in China are likely viewed differently. An ethnographic study of 15 Chinese-Australians with different degrees of acculturation, revealed that participants retained biomedical and traditional beliefs about cancer (Yeo et al., 2005). Karma and retribution, in particular,

are belief systems that link illness to bad behaviors by ancestors or in a previous life (Yeo et al.).

A cross-sectional analysis of existing data from a prospective study was done to compare clinicians (physicians, advanced practice nurses, and physician assistants) ratings of 3,106 lung, breast, prostate and colon cancer patients on quality of life (QOL), care challenges, and symptoms (Hamann, Lee et al., 2013). Responses by clinicians, most of which were from the patients' attending physicians, indicated that the odds of reporting care challenges were five times higher for lung cancer patients than for other cancer patients ( $p < 0.001$ ), yet statistical significance did not remain when covariates were included in the model. However, poor QOL and challenges with weight changes ratings were 3.6 and 3.2 times greater for patients with lung cancer than other cancers after adjusting for covariates ( $p < 0.0001$ ,  $p = 0.0002$ ). For QOL and weight changes, the model was adjusted for patients' own ratings of these issues; 47% and 33% of patients with lung cancer rated their QOL as good or fair.

### **Critique**

The Conlon et al. (2010) study had the limitation of no explanation of analytic rigor, however the origins of their sample were diverse, and like the Weiss et al. (2015) study, participants contributed actual experiences versus responding to a hypothetical stimulus. Participants in the quantitative studies are often presented with minimal or acontextual stimuli about a disease they are prompted to judge therefore, attitudes could be different in a less controlled settings. The Knapp-Oliver et al. (2012) study sampled from university students, which while more diverse than most of the samples discussed so

far, are still limited by less life experience and a narrow age range; however, validity of the design was enhanced by participants providing an explanation for their funding choice. The two Marlow et al. (2010; 2015) studies used instruments that are well supported by theory but the 2010 study did not report reliability, and the 2015 study found low reliability for the policy opposition subscale but high reliability for the other subscales (Marlow et al., 2015). While the Hamann, Lee et al. (2013) study had a large sample size, it was mostly female, and mostly White.

### **Summary**

These studies had sampling, design, and measurement limitations, yet there is support across the studies that lung cancer and the people who have it attract blame from the general public and from health care professionals, more so than other cancers. Clinicians may view lung cancer with more pessimism, poorer quality of life, and more care challenges than other prominent cancers, and with more pessimism than their patients do (Hamann, Lee et al., 2013), and associate it with shame (Siriam et al., 2015). Other diseases, like obesity and chlamydia, that also have behavior-related causes, can attract more blame than lung cancer because the former is more visible (Jones, 1984) and the latter is linked to sexual behavior.

### **Perspectives of Patients with Lung Cancer**

Stigma is not exclusive to one type of cancer. Studies that compare the level of stigma among patients with different cancers helps to distinguish the degree to which lung cancer patients experience stigma more than other patients with other cancers such

as breast, prostate, head, and neck cancers. Breast and prostate cancers have high incidence rates compared to other cancers but are rarely linked to behavioral causes.

In a longitudinal study, 172 patients with stage IV lung, breast, or prostate cancer answered survey questions at three time points, baseline, two and six months (LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008). Perceived cancer-related stigma was significantly greater among patients with lung cancer than the comparison groups ( $p < .01$ ). Shame, embarrassment, perceived family shame, and behavioral self-blame were endorsed more by patients with lung cancer than comparison groups ( $p < .001$ ,  $p < .05$ ,  $p < .05$ ,  $p < .001$ ); these comparisons did not remain significant at the two and six-month time points. Patients with lung cancer did not endorse the statement that they deserved their type of cancer or ‘people judge me for my type of cancer’ more than the comparison groups. While other patients with cancer may experience stigma, patients with lung cancer have a unique experience in that they may suffer shaming from others as well as directing it at themselves; though these perceptions and experiences may change over time.

Patients with lung,  $n = 107$ , and head and neck cancers,  $n = 99$ , who were survivors less than three years were compared on positive health changes, stigma, and self-blame (Lebel, Feldstain et al., 2013). Overall, there was no significant difference between groups on stigma scores; however, self-blame was significantly more prevalent in patients with lung cancer than in patients with head or neck cancers ( $p < .001$ ). While self-blame was a predictor of positive health changes,  $p = 0.02$ , stigma was not,  $p = .12$ . Most of the patients in this study endorsed engaging in positive health changes, which

may explain why average stigma scores were low. Positive health changes may indicate that participants were already coping with any perceived stigma and this mitigated the perception. In addition, the stigma instrument was adapted for this study, maintaining good reliability, but limitations in validity must be considered. This sample was also mostly middle to high income, post-secondary and higher education, and former and never smokers.

In a similar study of the same participants the authors examined the impact of stigma on depression and well-being, and found significant positive and negative correlations respectively (Lebel, Castonguay, et al., 2013). Again, these participants reported low levels of stigma, however, even at low levels there is still significant relationships in the expected directions for variables such as depression and well-being which has been supported in other studies of patients with lung cancer (Cataldo & Brodsky, 2013; Cataldo et al., 2012).

In a sample of 96 lung, 30 breast, and 46 prostate cancer patients, lung cancer patients were significantly more likely to endorse that their behavior caused their cancer, or self-blame (Else-Quest et al., 2009). Among all the groups there was a significant negative relationship between perceived stigma and self-esteem and a positive significant relationship to self-blame, depression, anger, and anxiety. Regression models revealed a significant, negative relationship between perceived stigma and self-esteem that was mediated by self-blame, a model that explained 40.1% of the variance among patients with lung cancer versus 24.1% in a combined group of breast and prostate cancer patients. These findings support the presence of perceived stigma among different

patients with different cancers, but more so in patients with lung cancer. However, for this study, stigma was measured with one item derived from patients in support groups. The rest of the instruments were established with good reliability and validity.

In a qualitative study described earlier (Tod et al., 2008), the participants with lung cancer noted that the prominence of breast, testicular, and prostate cancers meant that knowledge of the risks of lung cancer were not known, and thought to be nonexistent if a person does not smoke (Tod et al.). In another qualitative study of 21 patients with lung cancer in the United States, a participant asserted “If it’s not pink and on an M&M, well God help you because there’s just not a lot of sympathy or money out there for you... [with lung cancer] we have people dying. You know, where should our attention be? ...and that frustrates me. So, if I could become a poster child, I certainly would...I want to write a book that says, “Don’t judge me.” (Rohan et al., 2016, p. 177). This participant represents the difficulty in not feeling judged when compared to a disease, breast cancer, which has widespread commercial and public support. Many other participants talked about the lack of support locally and nationally.

These feelings are not restricted to people with lung cancer. ‘Pink envy’ is a descriptor used by people with other cancers to describe an inferior identity in relation to breast cancer (Chelsea, 2011). Barbara Ehrenreich, a survivor of breast cancer, critically noted that it overshadows other prominent diseases that kill women, like heart disease and lung cancer, and that the positive attitude portrayed by women with breast cancer overpowers other viewpoints (Ehrenreich, 2001). Responses she received from other women with breast cancer after posting a comment to an online support group about the

challenges she was facing during her illness and eschewing the pink ribbons were that she had a “bad attitude” and from another person that she needed “counseling” (Ehrenreich, p. 50).

### **Perspectives of “Normals” on Smoking Behavior and Lung Cancer**

Patients with lung cancer who never smoked, are former smokers, or current smokers are viewed differently by society and at times by health care professionals and their caregivers. Lung cancer and people with the disease are also portrayed differently in the media, magazines and television news, based on behaviors related to the disease. The following section of the literature review represents the concepts of separation and discrimination.

Several studies examined the difference in attitudes toward patients with lung cancer by using an experimental, factorial design and presenting participants with a vignette of a patient with lung cancer where the smoking status was manipulated (Bresnahan, Silk, & Zhuang, 2013; Hamann, Howell, & McDonald, 2013; Stump, LaPergola, Cross, & Else-Quest, 2016). Participants in the first study, 224 undergraduate students, responded to a vignette of a person with lung cancer who was a heavy, moderate, occasional, or non-smoker (Bresnahan et al., 2013). The participants also had different smoking behaviors: 113 nonsmokers, 111 occasional smokers, 22 heavy smokers, and 38% knew someone who died of lung cancer. Participants assigned significantly less blame to the condition where the person with lung cancer was a non-smoker ( $p < 0.001$ ), moreover when non-smoking and smoking participants were compared, non-smoking participants assigned significantly more negative stereotypes to

people with lung cancer such as “selfish” and lack “willpower” ( $p < .001$ ), and assigned more blame to tobacco companies and cigarette advertisements than to a person with lung cancer ( $p < .01$ ,  $p < .001$ ) (Bresnahan et al., 2013, p. E135). Participants who did not smoke and did not know someone with lung cancer assigned significantly more blame than non-smokers who did know someone ( $p < .001$ ). Those that perceived smoking to be a highly controllable behavior and had confidence in their ability to quit assigned more negative stereotypes to people with lung cancer.

The second study had a similar sample of 147 undergraduate students where they responded to a vignette of a person with lung cancer who smoked, had a genetic predisposition, and had both (Hamann, Howell, et al., 2013). There were significant differences in perception between the smoking and genetic condition. Participants who responded to the smoking condition perceived that the person had more control over, could have “easily avoided” getting their cancer, was at fault, more responsible, deserved less pity and more anger, than those in the genetic condition. Participants who reported a family history of lung cancer assigned greater responsibility and control to the person in the vignette. There was also a significant negative relationship between wanting to help the person in the vignette and assignment of responsibility and a positive relationship with feelings of pity.

Another study used a similar design and sample, 242 psychology students, but the manipulation of the vignettes included a smoking, nonsmoking, and unknown condition (Stump et al., 2016). Participants who responded to the smoking vignette assigned more blame and anger, and less sympathy than to the nonsmoking condition; sympathy

mediated the relationship between blame, assignment of responsibility and desire to help the person at an individual or institutional level ( $p = .01$ ).

Another study used a similar experimental design with a random sample of 486 general practitioners (GPs) and pulmonologists in France, where participants responded to a vignette of a person with lung cancer who worked in a shipyard and the smoking status was manipulated (Verger et al., 2008). Participants were asked if they would make a recommendation for filing a worker's compensation claim, which was significantly higher among GPs who were presented with vignette of a nonsmoker. Pulmonologists did not differ by smoking condition.

Similar outcomes have been measured among lay caregivers of patients with lung cancer (Lobchuk, McClement, McPherson, & Cheang, 2008, 2012; Lobchuk, McPherson, et al., 2012); analyses used were exploratory factor analysis (EFA) and structural equation modeling (SEM). All the studies surveyed patients with lung cancer and the people who cared for them as a unit. In the first study  $n = 100$  dyads (50 caregivers and 50 patients), significantly higher levels of anger, fault, blame, aggravation and annoyance were reported among caregivers who cared for someone with lung cancer who was a current smoker versus those who cared for someone who had quit ( $p < .05$ ) (Lobchuk et al., 2008). There was no statistical difference among caregivers in their reported helping behaviors toward current versus former smokers; yet their feelings of anger and annoyance were significantly, negatively correlated with empathic communication ( $p = .029$ ,  $p = .004$ ). However, overall, the average scores for positive feelings such as pride, satisfaction, and hope were higher than average scores for negative feelings.

In a later study with 304 dyads, a SEM analysis revealed that anger was significantly, negatively correlated with the caregiver knowing the patient's thoughts and feelings ( $p < .05$ ) and aggravation and annoyance were significantly ( $p = .01, p = .02$ ), negatively correlated with open communication toward the patient with lung cancer, but, mean scores for blame, fault, responsibility, anger, annoyance, and aggravation were very low (Lobchuk, McClement, et al., 2012). In the last study, the authors studied the same 304 dyads, but wanted to determine how family caregivers and patients view control over disease (Lobchuk, McPherson, et al., 2012). Linking the control of lung cancer to external factors such as fate was associated with caregivers directing anger and blame at themselves. Linking control to a team effort was associated with more self-blame (caregivers blamed themselves), open communication, and more coping assistance for the patient. Conversely, when patients attributed control to fate, this was associated with more attempts at stopping smoking and feelings of satisfaction in their own disease management.

Qualitative ethnographic studies that have analyzed online comments (Luberto, Hyland, Streck, Temel, & Park, 2016), news stories in magazines (Clarke & Everest, 2006) and on television (MacKenzie, Chapman, & Holding, 2011) regarding beliefs about lung cancer and smoking behavior provide support for pessimistic and nihilistic beliefs about smoking and lung cancer, and blame directed at tobacco companies. Media frames endorse medical and lifestyle descriptions of cancer and emphasize fear and battle metaphors (Clarke & Everest), and emphasize the smoking status of people who die of lung cancer (MacKenzie et al.).

Document analysis of 139 online comments in response to an article about smoking prevalence for lung and colorectal cancers revealed stigmatizing attitudes, fatalistic, nihilistic, and pessimistic beliefs about quitting smoking, from people with and without lung cancer. The authors developed a conceptual framework from the comments that indicated a relationship between smoking beliefs such as “smokers should be able to quit”, those that do not are stupid and this is what keeps them from quitting, tax money should not go to smoking-related illnesses, and stigmatizing attitudes (Luberto et al., 2016). One participant expressed nihilism by saying “So what? I mean if you’ve already got cancer, why quit?” (Luberto et al., p. 2196). Pessimistically, another commenter noted “[y]ou smoke, you get cancer, your fault, no treatment, you die. Simple as that” (Luberto et al., p. 2196). Some participants noted the fault of tobacco companies and the Food and Drug Administration “...they all know they are selling a product that is addictive and has the potential to kill. Only an immoral, unethical person would do such a thing,” and “[t]hat the FDA has not classified it as a narcotic or a controlled substance is bewildering ... smoking kills—just ban it” and this was associated with sympathetic attitudes in the framework (Luberto et al., p. 2197).

Analysis of 23 magazines and a total of 131 articles about cancer revealed that breast cancer dominated cancer news, medical followed by lifestyle description frames were most prominent, and fear was a common theme among articles (Clarke & Everest, 2006). The theme of fear, represented by 70 references, reflected the aforementioned nihilistic beliefs that cancer is “inevitable” “growing silently and secretly” (Clarke & Everest, p. 2595) and the related statistics impart a grim picture. Analysis of 2,042

television reports about cancer in Australia revealed that only 45 were about lung cancer, and 68% of the relevant content of the reports relayed the smoking behavior of the people who had lung cancer (MacKenzie et al., 2011). Of the 33 news reports on celebrities with lung cancer, mostly Dana Reeves, 24 highlighted her non-smoking behavior. Articles on treatment frequently emphasized high mortality and invasiveness of lung cancer, and articles on causes were dominated by smoking. Lastly news reports pitted non-smokers or “tragic victims” (p. 68) and those with mesothelioma against people with lung cancer who smoked.

The lifestyle frame of cancer news provides some reassurances to the public that cancer is preventable and controllable, yet confusion can also occur when people who have quit many years ago receive a diagnosis of lung cancer. Portraying lung cancer as a controllable disease related mostly to lifestyle has the potential to reinforce the notion that smoking is and was a choice for current and former smokers. However, as Dackis and O’Brien (2005) assert, addictive drugs alter the brain by “activating and dysregulating endogenous reward centers, addictive drugs essentially hijack brain circuits that exert considerable dominance over rational thought, leading to progressive loss of control over drug intake in the face of medical, interpersonal, occupational and legal hazards.” (p. 1431).

While experimental studies provide an idea of how people perceive a vignette of a person with lung cancer, they do not provide empirical data about actual behavior and their controlled nature limits external validity and real world applicability. Perhaps one of the most compelling studies is one that consists of recorded conversations between

physicians, oncologists and thoracic surgeons, and their encounters with patients with lung cancer (Morse, Edwardsen, & Gordon, 2008). When patients with lung cancer make statements, or ask questions that require the use of empathy, 384 instances from 20 conversations, physicians rely heavily on medical explanations and empathy is used only 10% of the time, but more empathy occurred with oncologists than with surgeons ( $p = .02$ ). Moreover, physicians make blaming statements directly linking the patient's smoking behavior to their lung disease (Morse et al.).

### **Critique**

Most of the studies had convenience samples of university students in the United States who were mostly White, young, and believe they have low risk for developing a smoking related disease, yet the experimental designs of these studies enhanced internal validity. Internal validity is also supported by the instruments and scales which had good reliability,  $\alpha > .70$ , and validity was supported by theory (Bresnahan et al., 2013), or theory and replication of findings (Hamann, Howell, et al., 2013; Stump et al., 2016). External and internal validity were threatened by convenience sampling, and external validity is limited by the controlled, experimental conditions of the studies. The ethnographic studies of television news and magazine articles had analytic rigor, yet they were short on thick descriptions of their findings such as descriptions of image content as well as text and verbal content. Description of the tone surrounding the online comments in the Luberto et al. (2016) study would have provided thicker description and better context.

## **Summary**

A combination of experimental and qualitative design research studies have provided support that people with lung cancer who smoke are viewed differently than those that do not smoke, incurring more blame and negative stereotypes, particularly from people who do not smoke or see it as a controllable behavior. These beliefs and attitudes are, at times, related to emotions such as annoyance and aggravation that can interfere with open, interpersonal communication. Some attitudes and beliefs about lung cancer come from how it is portrayed in the media; highly fatal, related to lifestyle (a controllable cause), and that smokers and nonsmokers are unfairly competing for resources.

### **Patients with Lung Cancer Who Have Different Smoking Behaviors**

People with lung cancer also provide perspectives on smoking, lung cancer, and stigma. Researchers to date have done psychometric testing on a lung cancer stigma scale, the Cataldo Lung Cancer Stigma Scale (Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011), an instrument that has been used in other studies (Brown Johnson et al., 2014; Cataldo & Brodsky, 2013; Cataldo et al., 2012), all of which compared perceived stigma among patients with lung cancer and different smoking histories. Different perspectives based on smoking behaviors have also been reported in qualitative studies (Brown, & Cataldo, 2013). Other researchers used different psychometrically tested instruments such as the Cancer Responsibility and Regret Scale (CRRS) (Criswell, Owen, Thornton, & Stanton, 2016), an adapted version of the Shame and Stigma Scale previously tested in head and neck cancer patients (Shen et al., 2015). People at risk for

lung cancer and who have different smoking histories have been surveyed on beliefs about screening and risk for lung cancer (Crane et al., 2016; Quaife et al., 2016).

The psychometric testing of the Cataldo Lung Cancer Stigma Scale (CLSS) included administering the instrument online to a convenience sample of 186 people with lung cancer, factor analysis of the data, and correlation analyses with related concepts such as depression, measured by the Center for Epidemiological Studies–Depression Scale (CES-D); anxiety, measured by the Rosenberg Self-Esteem Scale (RSES); self-esteem measure by the Rosenberg Self-Esteem Scale (RSES), social support and social conflict, measured by the Social Support Indices; and quality of life, measured by the Quality of Life Inventory (Cataldo et al., 2011). Factor analysis yielded 31 items divided among four subscales (stigma and shame, social isolation, discrimination, and smoking) with a reliability alpha coefficient of .96. Lung cancer stigma was significantly and negatively correlated with QOL, self-esteem, social support, and being involved in one's own social network ( $p = .01$ ). Positive and significant correlations of lung cancer stigma, depression, and social conflict ( $p = .01$ ) were found.

In a similar study, a convenience sample of 190 patients with lung cancer recruited from online support networks revealed an overall average CLCSS score of 102.6 with a range of 46 – 184, which was slightly lower among never smokers, 99.5, and slightly higher among ever smokers, 103.7 (Cataldo et al., 2012). Again, lung cancer stigma (LCS) was significantly and negatively correlated with QOL, and significantly and positively correlated with depression. A regression model with five covariates including smoking status, age, gender, and depression explained 62.5% of the variance in

QOL ( $p < .001$ ), with LCS and depression contributing to 2.1% and 22.5% of the explained variance respectively ( $p < .001$ ).

A third study of 144 people with lung cancer revealed a mean CLCSS score of 75.7 with a possible range of 31 – 124 (Cataldo & Brodsky, 2013). This study also examined the relationship between LCS and symptom severity (fatigue, dyspnea, pain, cough, appetite loss, and hemoptysis) where the average score for symptom severity was 17.8, range of 9 – 45. Correlation analyses supported a strong positive relationship between LCS and anxiety, depression, and each aspect of symptom severity ( $p < .001$ ). Regression modeling of the impact of LCS on symptom severity, controlling for age, anxiety, and depression, explained 53% of the total variance ( $p < .001$ ) with LCS accounting for 1.3% ( $p < .05$ ) of the variance. While the authors collected information on smoking history, comparisons were not made for this variable.

Similarly, 149 people with lung cancer had a mean QOL score of 5.6, with a possible range of 1 – 10 (Brown Johnson et al., 2014). Lung cancer stigma was included in a model controlling for age, gender, anxiety, and depression which explained 71.0% of the variance in QOL with LCS explaining 1.2% ( $p = .015$ ). None of these variables differed by smoking behavior when comparing current and former smokers as one group to never smokers.

A recent study examined 141 patients with lung cancer with different categories of smoking history: never smokers, quit before diagnosis or after diagnosis, and current smokers (Shen et al., 2015). A higher number of participants achieved less than a college degree than in the previous studies and education level had a significant inverse

relationship and stigma had a significant positive relationship with psychological distress, measured by the Hospital Anxiety and Depression Scale (HADS). Positive self-appraisals from having a cancer diagnosis or post-traumatic growth (PTG), moderated the relationship between stigma and psychological distress only among people who had quit smoking after their diagnosis, but there was no statistical difference between pre and post diagnosis cessation and levels of stigma.

A study of 213 patients with lung cancer revealed that current and former smokers report significantly higher levels of personal responsibility, self-blame, and regret when compared to never smokers, but being older was associated with lower levels (Criswell et al., 2016). However, the strongest relationships between personal responsibility and other outcomes such as depression ( $r = .49$ ), care satisfaction ( $r = -.57$ ), and avoidance coping ( $r = .37$ ) were significant only among never smokers (Criswell et al.). Regret and the same outcomes, except care satisfaction, were significant among current and former smokers (Criswell et al.).

Among 174 people with lung cancer, current smokers, compared to former and never smokers, were significantly more likely to report that health care providers and society treat patients with lung cancer differently than patients with other cancers, and overall 25% thought that they were treated differently by insurance companies (Weiss et al., 2016). Current smokers also had significantly higher stigma scores than former or never smokers, but never smokers perceived less satisfaction with care compared to former and current smokers combined (Weiss et al.).

Lastly, a qualitative study of eight women with lung cancer with different smoking histories elicited themes of people's attitudes toward lung cancer, encounters with health care professionals, diagnosis, alterations in social connections, experiences with stigma, and coping with stigma (Brown & Cataldo, 2013). Former smokers noted how strong smoking addiction is, growing up with the Marlboro Man and no knowledge of smoking dangers, that general practitioners have a pessimistic view of lung cancer, oncology staff were generally more hopeful and supportive and do not focus on smoking. Nonmedical encounters, however, always included the question 'did you smoke?' when finding out about lung cancer (Brown & Cataldo, p. 357). Also, advocacy efforts from supportive organizations have focused on young nonsmoking people with lung cancer leading one woman to remark "But, frankly, the rest of us survivors who were at the run/walk last year, felt a little belittled, because we are, too. That's the fact. You know, as a sixty-year-old ex-smoker, I, too, am the face of lung cancer." (p. 357). A nonsmoking woman remarked that she likes to share her diagnosis with people because "I think sharing is important to make people aware that normal people who weren't smokers...do get lung cancer" (Brown & Cataldo, p. 357).

### **Critique**

Again, convenience sampling is a limitation for internal and external validity, particularly since the samples tended to be White, female, educated with some or more college, and former smokers for the first four studies. Internal validity was supported with valid and reliable instruments used in the studies. Lung cancer stigma scores tended to be at the midpoint of the possible range of values which is higher than stigma scores in

other studies that had a higher mean age for their participants and used different stigma instruments (Lebel, Feldstain, et al., 2013; LoConte et al., 2008). One study examined response shift regarding fatigue among 23 people with non-small cell lung cancer as part of a quality of life instrument (Westerman et al., 2007). Participants reported their fatigue as minimal, in an effort to appear positive and not sick when surveyed, but the same participants, when interviewed, indicated more severe fatigue on a regular basis. While this study only examined fatigue, there are implications that patients with lung cancer may want to present themselves in research as feeling or coping better than they are in order to control their cancer narrative and maintain a positive outlook which can result in response bias due to social desirability. Reporting actual severity of symptoms or feelings may also be perceived as complaining (Westerman et al.).

### **Summary**

People with lung cancer have different experiences which, in part, stem from the stereotype of a self-inflicted disease. Nonsmokers want to distinguish themselves as “normal” lung cancer patients, and at times are less satisfied with their care because they may endure a “courtesy stigma” (Goffman, 1963, p. 30) in that they are assumed to be people who smoke and have a difficult time with self-advocacy due to their illness, the perceived reputation of their disease, and low social support and funding. For current smokers, studies provide less clear data about from where their perceptions of blame and stigma originate. If they first direct stigma and blame at themselves, it may be easier for them to perceive that others think poorly of them. Studies that provide examples of enacted stigma (Morse et al., 2008), stigmatizing behaviors from others toward patients

with lung cancer, do not close the communication loop by asking the patient about what the experience meant to them. Some of these experiences will be represented in the following section about the psychological, social, and health consequences of stigma. There is also support that different medical specialties have different attitudes toward lung cancer. However, what is not known is how active these clinicians are in public advocacy for lung cancer considering that they are aware of the disparities.

### **Psychological and Social Consequences of Stigma**

The psychological and social consequences of stigma are represented in the literature mostly from the patient perspective in both qualitative and quantitative studies. The perspectives of “normals” on this issue were addressed in previous sections of this review of the literature. Thus far, there is support in the literature that lay people and health care professionals associate negative stereotypes and shame to lung cancer, and assign blame to those who have it. In studies of patients with lung cancer, psychological consequences of stigma are depression, anxiety, fear, shame, and self-blame. Social consequences are restricted social networks due to diagnosis concealment, avoiding awkward or potentially judgmental interactions, and not wanting people to express worry or pity.

Among 95 patients with non-small cell lung cancer there was a significant positive correlation between perceived stigma, measured with the Social Impact Scale (SIS), and depressive symptoms, measured using the CES-D ( $p < .001$ ) (Gonzalez & Jacobsen, 2012). However, two dimensions of the SIS, social rejection and internalized shame, did not have significant correlations with the CES-D. A regression model that

controlled for history of depression, time since diagnosis, avoidant coping, social support, and dysfunctional attitudes, revealed that perceived stigma accounted for 3% ( $p = .043$ ) of the variance in depressive symptoms. The regression model was conducted using the separate dimensions of the SIS scale, financial insecurity and social isolation accounted for 3% ( $p < .036$ ) and 7% ( $p < .001$ ) of the variance in depressive symptoms respectively.

Shame in this study was measured as a dimension of stigma and included statements related to blame from others, self-blame, and hiding an illness. Framing an illness positively included statements about what one says to oneself about one's illness to make things better. Possibly, patients feel shame and self-blame related to their lung cancer but also want to control the narrative of their disease and avoid negative comments from others. This supposition is echoed in the comments of people who care for patients, one nurse remarked "Some of them don't want to go to their GP to be told that it's because of their smoking" and another said "Well, I think smokers especially...they'll not present themselves with problems because they think it's self-inflicted, and they think medical professionals look down on them for that" (Tod & Joanne, 2010, p. 41).

Concealment is a way of coping with a stigmatized disease that places a cognitive and social burden on the person with lung cancer. They must decide to whom they will reveal their diagnosis which potentially restricts their social interactions and relationships (Hamann et al., 2014). In the qualitative studies discussed earlier, participants have said that they have bone cancer instead of lung cancer to make social interactions easier (Rohan et al., 2016), not tell their family or only tell certain people to avoid judgment,

and avoid telling their oncologist they have started smoking again so they don't "let them down" (Hamann et al., p. 85).

A quantitative study of 117 patients with non-small cell or small cell lung cancer, participants were asked to report if they had concealed their diagnosis in the past month from either family, friends, or coworkers (Gonzalez et al., 2015). Overall, 26% of participants reported concealing their diagnosis mostly from informal friends, 67%, and close friends, 40%, and less frequently from relatives who were not close, 27%. Concealment from more than one person occurred for 33% of participants who reported it, and the most frequently reported reasons were they did not want the person to worry about or pity them. Compared to those who did not conceal, those who did, reported higher levels of internalized shame ( $p < .01$ ). The reasons for concealment are congruent with the reported higher levels of shame because people who feel shame do not think they deserve to have others worry about or pity them.

Among newly diagnosed patients with lung cancer,  $n = 151$ , 49% and 41% had moderate levels of anxiety and depression respectively, measured by the Hospital Anxiety and Depression Scale (HADS), however older participants,  $> 60$  years, had lower levels of anxiety and depression (Chambers et al., 2015). Age, gender, and stigma, measured with the CLCSS, were entered into a regression model which accounted for 28% ( $p < .001$ ) of the variance in anxiety; age and gender alone accounted for 10% of the variance. Stigma and age explained 30% of the variance in total psychological distress (anxiety and depression).

Similar responses are found in qualitative studies. Among 45 patients with lung cancer in England, emergent themes were fear, stigma, and opposing blame and stigma. Participants experienced restricted social networks because of increased awkwardness of interactions, fear of stigma because of prior experience with it from a different disease (epilepsy), and family members telling them they felt “dirtied” being near cancer (Chapple et al., 2004, p. 1471). Fear was also experienced in relation to distressing public health announcements related to smoking and lung cancer, and for people who smoke, not being taken seriously by health care professionals.

Research on the social aspects of stigma has also focused on measures of social support such as the Social Support Indices (O’Brien, Wortman, Kessler, & Joseph, 1993), two components of which were used in the Cataldo et al. (2011) study; perceived availability of support,  $\alpha = 0.87$ , and social conflict,  $\alpha = 0.82$  (O’Brien et al.). Additionally, the same study examined the construct validity of the Cataldo Lung Cancer Stigma Scale with factor analysis and one of the subscales measures social isolation, with an alpha coefficient of 0.98 (Cataldo et al.). There were significant positive correlations between lung cancer stigma (LCS) and social conflict (0.619), and significant negative correlations between LCS and perceived availability of social support (-0.547), social support validation (-0.512), and subjective integration (-0.627). Lastly, there was a strong, significant negative correlation between social isolation and self-esteem (-0.738) (Cataldo et al., 2011).

## **Critique**

While there is support that patients with lung cancer experience depression and stigma, due to the cross-sectional nature of the studies it is difficult to know which comes first; depression may make someone more susceptible to self-blame and isolation or possibly the reverse. Patients with lung cancer also must decide to whom they will reveal their disease, but these people may not be prominent in their social network, nonetheless social encounters are more awkward when one person feels the need to hide something. Although sampling in the Chapple et al. (2004) study was designed to represent people with different social backgrounds, the people represented in quotes are all from a support group, though it is not clear what kind. The authors used methods to increase analytic rigor, and performed member checks.

## **Summary**

While concealment of a lung cancer diagnosis or smoking behavior is a form of coping with stigma, the negative impact on social interactions and participation in care means it can be a dysfunctional form of coping. There are also health-related sequelae for the psycho-social problems of stigma. People with lung cancer are at risk for smoking relapse from the stress of their diagnosis and treatment (Simmons et al., 2013), however if they have too much shame to tell their health care provider they cannot receive comprehensive help with quitting. Smoking can interfere with treatment, exacerbate symptoms, and increase risk for cancer recurrence. While the studies mentioned so far do not examine stigma and therapy adherence, an inference can be made that additional

psychological and social problems such as fear, self-blame, shame, and concealment have the potential to disrupt the illness trajectory.

### **Nurses and Stigma**

The perspective of nurses in the literature on lung cancer and stigma is represented in one study (Wang et al., 2015) which was discussed earlier in this chapter. Nurses' perspectives regarding stigma have also been studied with obesity and stigma (Aranda & McGreevy, 2014; Brown & Thompson, 2007; Peternelj-Taylor, 1989) and HIV/AIDS and stigma (Greeff & Phetlhu, 2007). Qualitative studies of nurses' attitudes toward obesity have highlighted complex beliefs and feelings about their own body size and education that they provide for overweight and obese patients (Aranda & McGreevy; Brown & Thompson). These complex attitudes included: awareness of stereotypes such as 'fat', 'lazy', and unhealthy, counteracting stereotypes by asserting that thin people have health problems too, and body size is not about health but social norms and acceptance. Their negative attitudes sometimes overruled empathy when educating patients about weight reduction (Aranda & McGreevy).

In order to counteract pessimism and avoid emotions, nurses hid behind their professional role or noted the hypocrisy of educating about risk factors they themselves had (Aranda & McGreevy, 2014). In a similar qualitative study, nurses were uncomfortable talking about obesity, avoided the word obesity with their patients because it was deemed a disagreeable label, and used rapport and a neutral attitude to offset stigma (Brown & Thompson, 2007). Other nurses asserted that personal responsibility was key to behavior change and judgement is a constant (Brown & Thompson). Nurses

also expressed frustration with patient requests for quick fixes and noncompliance (Brown & Thompson). Yet these studies also represent nurses who work in countries that have socialized medicine, so the perspectives are representative of the medical and general culture of those nations.

HIV/AIDS is mentioned as another disease that is stigmatized, but it carries a negative valence of a different origin within social and cultural values. Since it is a primarily sexually transmitted disease, originally thought to only occur among gay men, there is a strong association with high risk sex behaviors and sexual deviance (Herek, 1990). A qualitative study that analyzed focus group discussions of patients living with AIDS (PLWA) (n = 18), nurses who care for them (n = 16), and volunteers who care for them (n = 6) in South Africa revealed themes of received stigma, internal stigma, associated stigma, results of stigma, and disclosure (Greeff & Phetlhu, 2007). Nurses reported that PLWA experienced social and physical separation from their family, other health care professionals would not hire PLWA to work in their home, and people in the community did not understand why nurses cared for these patients. Other problems that were reported were: a counseling room for PLWA was dubbed the “AIDS room”, AIDS was largely considered a self-inflicted disease, there was pessimism surrounding the care of PLWA, and the patients enacted self-imposed isolation.

Although the authors of these studies report analytic rigor, the Greeff and Phetlhu (2007) study did not always provide rich context for their quotes and the same quote was used in multiple themes. The authors also reported that they asked the participants to describe their own understanding of discrimination and stigma, but they do not provide

the results for this question in a way that helps the reader to distinguish it from other questions. If the authors had provided descriptions of how their participants perceived concepts related to stigma, there would be a better understanding of how their personal descriptions of the concepts matched or did not match what they experienced while caring for PLWA.

Thus far, both qualitative and quantitative studies have retained the assumption that participants share the researchers' understanding of concepts used in instruments and interviews. While psychometric analysis provides support for confidence in such assumptions, there are discrepancies among what patients with lung cancer report to be their level of stigma in various quantitative studies and their reported perceptions in qualitative studies. If nurses were to be surveyed about concepts related to stigma, the survey would perform better if nurses' descriptions were used to construct it. Also, from qualitative studies of nurses concerning obesity, there is little professional biographical background context for their perceptions of issues related to their own body size and that of their patients, which would provide context for not only who the participant is, but how their perspective as a nurse has changed over time, given that stigma is a temporal construct.

We still do not know how any of the "normals" in the studies examined thus far, define or describe major concepts related to stigma such as self-blame, shame, discrimination, stereotyping, status loss, separation, being judged, and personal responsibility; particularly as they relate to lung cancer. There is also minimal information on what nurses know or perceive about the stigma related to lung cancer and

the patients who have it. Furthermore, there is only a small glimpse of what impact these issues have on patient outcomes and nursing care.

### **Feasibility Study**

A qualitative feasibility study conducted in preparation for this study (Abrams, 2015) revealed that nurses who care for patients with lung cancer in the oncology setting, n = 3, noted the difference in support and funding for breast cancer versus lung cancer. For one nurse this difference was noted when recounting conflicts expressed by the lung cancer nurse navigator; that stigma reduces the funding for lung cancer, and breast cancer *“gets all the money because there’s a negative stigma against lung cancer patients that they do it to themselves because they smoke.”* However, this nurse also noted that stigma related to lung cancer is *“it’s just a general public stigma and donation wise and money wise.”* Poor survival was also noted and a form of joking was developed to cope with this:

I mean there’s kind of this joke um... about the we’ve shared with the nurse who works at the desk with the lung cancer doctor about how she doesn’t get close to her patients because they’re not around long enough. I mean it’s just it’s kind of one of those things you just come to accept like in the doctor’s constantly taking on new patients and the joke is he’s always got room for new patients because his patients are always dying. I mean it’s just something that’s known that the lung cancer patients definitely have a shorter survival period from diagnosis like where you’ve got breast cancer patients who have like been patients for 20 years versus you know your lung cancer patient who will probably be around a year or two.

The nurses who were interviewed all worked in oncology settings, both inpatient and outpatient, and might be insulated from understanding how stigma impacts patients since they tended to refer to it in vague or general terms, but not as something that

impacts the illness trajectory. One nurse noted something another nurse said about unequal funding but did not validate this comment and said it was a “*general public stigma*” not something that impacts the health care system, yet funding supports research and research supports care. Potentially, nurse navigators are exposed to aspects of stigma related to lung cancer because they have a broader perspective of the patient’s trajectory. Another nurse noted the support for breast cancer versus lung cancer when she said:

all these wonderful runs and support groups and things for breast cancer patients you know and everybody wears pink and you know life is support breast cancer and you don’t see as much of that for the lung cancer and I don’t know if it’s just that general thought that they did this to themselves.

This nurse expresses ambivalence by saying a common stigmatizing belief, “*they did this to themselves*”, but not knowing if this is the reason for differences in support. Yet another nurse noted that patients with lung cancer believed “*that they had it coming to them anyway ‘cause they smoked.*” The joking about survival may indicate a way to cope with caring for people with lung cancer who have poor survival and the oncology staff either do not feel empowered to advocate to change this or they do not see the need to do anything, a ‘this is just the way things are’ type of mentality. Two of the nurses noted the stark contrast between lung and breast cancer patients, similar to qualitative studies discussed earlier.

### **Summary**

Within the broader narratives in the literature on stigma and stigma and lung cancer, are the stories of people who have lung cancer and the people who care for them as well as quantitative studies that have provided psychometric, correlational, and

modeling of stigma and related concepts. The two stigma theories presented posit that stigma occurs at the macro and micro levels and that the people involved in the stigma process have overlapping identities with extant and emerging statuses that promote or prevent a downward social trajectory related to a stigmatized condition. People who are “normals” or “wise” may also have a stigmatized condition, however their status in society can determine how easily they can conceal their stigmatized condition and what they can do to counteract the stigma (Goffman, 1963). For health care professionals, their status as a professional engenders assumptions that they are empathic, impartial, social justice activists and advocates, which may cloak their personal judgements and attitudes about what is normal while simultaneously informing their more “wise” approach to care.

A major gap among the perspectives presented in the literature is that of nurses who are not only considered to be “wise” persons; they are positioned at the center of care with the patient who has lung cancer. Their experience, communicated through narratives, further informs the identity of “wise” persons so that these qualities can be known and taught in nursing. Maintaining integrity of the nursing profession requires in depth knowledge of how nurses embody these expectations and when they struggle to do so, or when they see the struggle of other health care professionals.

A feasibility study of nurses’ experiences with caring for patients with lung cancer (Abrams, 2015) also revealed broader conflicts about the disease such as unequal funding, and a milieu of pessimism that is at times offset with humor as a possible form of coping with these issues. Responses in the feasibility study also indicate that oncology nurses are aware of the stigma associated with lung cancer but believe it is external to the

health care setting and the care that is provided. The participants were not asked further about their ambivalence regarding the knowledge of differences in support and general stigmatizing attitudes and not knowing if this is related, and what impact this has on people with lung cancer. There is also no sense of who these nurses are and how their perspective of lung cancer has changed over time, which would add to the knowledge of who 'wise' persons are, particularly in health care.

### **CHAPTER III**

### **METHODOLOGY**

The history of stigma reveals humanity's past struggles to discover, define, and describe what is normal, and what to do about what is not normal. Throughout this history people have grappled with the coexistence and intermingling of scientific and social explanations of health-related phenomena. These struggles, at times, yield social constructions of diseases that result in stigmatization of the disease and those who have it. Socially, stigma is often portrayed as a grand conflict, a narrative with key characters, a setting (time and place), and pivotal events. A disease is discovered and people in different settings, scientific and social, take action to discover the cause.

The narrative of the discovery of lung cancer has a similar story arc; it begins with an increase in the number of lung cancer cases and several conflicts in the scientific community about how to address it, and ends with a disease that is powerfully and inextricably linked to a stigmatized behavior, smoking. The story arc of smoking involves the transformation from a socially desirable, therapeutic, commercially successful, politically protected behavior and product to a deviant, unhealthy, polluting "habit". When these two narratives collided, it yielded a behavior that went from ubiquitous and socially desirable to tainted and dwindling, and a disease that is set apart from most cancers because it has a strong link to a discredited behavior, smoking. Researchers are

still studying the consequences of this collision, while simultaneously working to denormalize smoking behavior in order to decrease prevalence.

Stigma is a psycho-social, cultural phenomenon that, in the literature, is linked to delays in diagnosis (Carter-Harris, 2015; Carter-Harris, Hermann, et al., 2015) and care (Dunn et al., 2016; Scott et al., 2015; Tod & Joanne, 2010; Tran et al., 2015; Wassenaar et al., 2007). The delays, in turn, are related to psychological and social sequelae of stigma like perceived blame and shame by people at risk for lung cancer (Chapple et al., 2004; Crane et al., 2016; Tod et al., 2008), nihilistic and pessimistic attitudes (Carter-Harris et al., 2015a; Quaife et al., 2016; Siriam et al., 2016), and blame (Wang et al., 2015) and shame from health care professionals (Siriam et al., 2016; Wang et al.).

Currently, there is no clear understanding of the experiences of nurses who care for patients with lung cancer and how these experiences relate to the phenomenon of stigma; a qualitative study is not only most appropriate when there is little known about a perspective, but also provides a rich, in-depth description of this perspective.

### **Research Design**

Qualitative research is a subjective, inductive form of inquiry that is conducted to answer broad questions about a phenomenon that is not well known (Streubert & Carpenter, 2011). Specifically, a narrative, qualitative approach allows for the exploration and understanding of the “experienced reality” through the natural communication style of personal narrative (Lieblich, Tuval-Mashiach, & Zilber, 1998, p.7). Telling of experiences using narration reveals the speaker’s identity, personality, and the cultural and social meaning of the telling (Lieblich et al., 1998, p. 7). As Lieblich

et al. (1998) note “[p]eople are meaning-generating organisms; they construct their identities and self-narratives from building blocks available in their common culture, above and beyond their individual experience” (p. 8).

### **Research Question**

The broad research question for this study is: what are the experiences of nurses who care for patients with lung cancer? The secondary question is how are these experiences related to the stigma associated with lung cancer? The two stigma theories described in Chapter Two and a narrative inquiry approach provided guidance toward answering these questions. Using a narrative inquiry approach to study nurses’ experiences of caring for patients with lung cancer provided rich experiences that were oriented to the narrator’s identity and personality, drawn from culture, and socially contextual.

### **Sample**

Registered nurses who have practiced for at least two years, have cared for patients with lung cancer at least six months of their career, and are currently practicing in the Southeastern United States, were recruited for this study. A minimum of six months caring for patients with lung cancer was needed as an inclusion criterion to ensure that participants had enough experience to be good informants. Narrative studies that have used experience in a clinical area as an inclusion criterion used six months for nurses in any setting (Chan, Jones, & Wong, 2013), two years for cardiovascular nursing (Lapum et al., 2016), and four months for nurse practitioners (Hernandez & Anderson, 2012). The focus of this study was not on a specific specialty, but nurses in different

settings who have cared for, or are caring for patients with lung cancer. A pilot study revealed that while oncology nursing is an obvious specialty from which to recruit, home health and hospice nurses also care for patients with lung cancer (Abrams, 2015).

Exclusion criteria were nurses who are not registered nurses, who have cared for patients with lung cancer less than six months of their career, and who have not cared for patients who have been diagnosed with lung cancer.

A combination of purposive and snowball sampling was used. Purposive sampling includes directing recruitment at groups or people who have “had experience with or are part of the culture of the phenomenon of interest” (Streubert & Carpenter, 2011, p. 29) and snowball sampling is “using one informant to find another” (Streubert & Carpenter, p. 29). Nurses who care for patients with lung cancer include, but are not limited to, nurses who work in inpatient and outpatient oncology, acute care, lung cancer nurse navigators, home health nurses, hospice nurses, and palliative care nurses.

**Incentive.** Participants signed for and were provided a \$15.00 Target gift card at the end of the first interview and a \$10.00 Target gift card for the follow-up interview. The gift cards were provided in an unsealed envelope that contained a ‘thank you’ card for their participation with three of the researcher’s information cards. The information card was a business-type card that has the University logo, the researcher’s name, e-mail, a contact number, current student status, and the title of the study. Participants were also given three recruitment flyers to give to people they knew who were eligible for the study as part of snowball sampling. Participant were instructed not to post the flyer anywhere without permission; this statement was also in the recruitment flyer.

## **Data Collection Procedures**

### **Interviews**

The main data collection method employed was the semi-structured interview with the researcher as the instrument of analysis. All participants who consented were interviewed at least once. Those who agreed to be contacted again for a second interview, on the consent form, were contacted via e-mail to schedule an interview. Participants who did not respond to the first request to schedule a follow-up interview were contacted one more time then considered as lost to follow-up. All participants were interviewed in-person in an agreed upon location that was relatively private, quiet, with few interruptions. This type of setting was necessary to ensure confidentiality, quality of the data, and sound quality for the recording of the interviews. The researcher recommended places that were away from the participant's place of work to ensure privacy and confidentiality. After the consent was signed, the PI began data collection by asking participants a series of demographic questions which included age, gender, ethnicity, where they grew up, state of prelicensure education, number of years as a registered nurse, highest education level obtained, current clinical setting and setting, shift and how long they cared for patients with lung cancer, tobacco use, and if a family or friend had ever been diagnosed, and or died of lung cancer.

**Follow-up Interviews.** Follow-up questions were developed to further probe issues that were unfolding during the analysis. Questions specifically about stigma were reserved until the very end of the interview unless the participant mentioned stigma first; this was done to mitigate bias during the interview so the participant's experience could

be freely described. The questions on the interview guide were derived from the two stigma theories, and the review of the literature.

**Interview Questions.** The free association questions at the beginning of the interview were asked to elicit initial impressions and potential extant stereotypes about people and objects (patients who smoke and cigarettes, respectively, as an example). Questions about lung cancer were derived from other qualitative studies about health care professionals who care for patients with lung cancer (Conlon et al., 2010; Tran et al., 2015). These studies addressed differences between lung cancer and other cancers, people who smoke and those who do not smoke, and support for patients with lung cancer. The background biographical questions were designed to provide contextual background of the narrator related to nursing, the profession in which they care for patients with lung cancer, lung cancer and smoking behavior, and prior exposure to smoking behavior and lung cancer, before becoming a nurse. Of the few qualitative studies that investigated nurses' views on diseases that carry stigma such as obesity (Aranda & McGreevy, 2014; Brown & Thompson, 2007), participants provided background information about their own struggles with weight gain which provided context for the care they provided for their patients who were obese (Aranda & McGreevy, 2014).

Interviews were audio recorded with a digital audio recorder, and uploaded to a secure cloud space. Interview recordings were then transcribed verbatim by either the PI or a transcriptionist. Field notes were completed after the interview in which the PI made notes about date, time, and setting of the interview and the length of data collection. Field

notes also included overall impressions, non-verbal behavior, and interruptions during the interview. For interviews transcribed by a transcriptionist, the PI listened to the entire interview recording to verify the transcript and make notes of audible non-verbal occurrences such as laughter and pauses, and verbal occurrences such as self-interruptions, interruptions by the PI, and when the participant spoke as if they were another person (such as a patient).

After the initial interview, participants were sent a copy of the transcript with a member check form so they could indicate whether or not they agreed with the transcript and any questions or comments they had. The copy of the transcript had continuously numbered lines that the participant could refer to when making a comment. Three participants participated in verification of their initial transcript, and three participants participated in verification of their follow-up interview transcript.

### **Data Management**

Data were transcribed into a word processing document by the PI, de-identified, and saved on a secure hard drive and backed up in secure cloud space, using UNCG BOX, both of which are password protected. All raw data were assigned a number that corresponded with a participant. Near the conclusion of analysis, pseudonyms were created that corresponded with the numbers. Recordings that were transcribed by a transcriptionist or needed to be verified by the PI's committee chair were shared using functions in the secure cloud space. Any words that could potentially identify the participant such as locations and names were removed from the transcript and in brackets the PI put [name of place] or [name of person]. Forms, such as consent forms, with

participant signatures were kept in a locked box throughout the study. Other forms with no personal identifiers, such as demographic forms, were kept in a separate locked box.

### **Protection of Human Subjects**

Institutional review board (IRB) approval was obtained from the University of North Carolina at Greensboro IRB before recruitment and data collection. Potential participants who expressed an interest in participating contacted the PI by e-mail or phone. The PI set up a time and place to meet with the interested person, then presented and discussed informed consent before beginning data collection. The participant was provided with a copy of their consent and the PI kept the signed copy.

**Participant Rights.** The PI explained to the potential participant, from the consent form, that they had the right to refuse to participate or to withdraw at any time, without penalty. If they did withdraw, it would not affect them in any way. If they chose to withdraw, they may request that any of their data which had been collected be destroyed unless it was in a de-identifiable state. The investigator had the right to stop their participation at any time. This could occur because they have had an unexpected reaction, or have failed to follow instructions, or because the entire study had been stopped.

**Participant Risks.** The risks to the potential participant were explained in the consent form and read to the participant. These risks that were explained were: because their voice will be potentially identifiable by persons who hear the recording, their anonymity cannot be guaranteed. The PI will limit access to the audio recording to the following persons: the PI, who will need to listen to and verify each interview and may

need to transcribe some of the interviews, one committee member who will need to verify the interview, and a transcriptionist unless the participant wishes to have the access to the recording limited to the PI only. In the event that the interview becomes emotionally distressing, the researcher would pause the interview so that the participant can take a break, get some water, and/or walk around the room. The researcher would ask them if they want to take a longer break or resume the interview at a later time, or not participate in the study. If the emotional distress persists then the researcher would offer the participant the option of withdrawing from the study. If withdrawing from the study, the participant would be provided with the incentive at that time and a list of counseling services if needed. None of the participants experienced emotional distress or withdrew from the study.

### **Number of Participants and Rationale**

The final sample size of six was determined by the principles of saturation, or when no new themes were interpreted in the data (Streubert & Carpenter, 2011). An estimated sample size of 10 was based on other studies that used a similar sample, nurses, and methodology, narrative. A narrative study that recruited a heterogeneous sample of nurses from eight different specialties achieved saturation at 11 participants (Jackson et al., 2010). In a study of acute care nurses' experiences caring for patients with COPD, the sample size was 10, but the authors did not discuss saturation (Bailey, Colella, & Mossey, 2004). Another study interviewed seven nurses about the discharge process for patients who had heart surgery and noted that their sample size was supported by their methodology [Lieblich et al., (1998)] (Lapum et al., 2016). Nurses' experiences with

humor was studied with a sample size of four, which the authors noted was adequate to address their research question (Haydon & van der Riet, 2014). Qualitative studies that have the following design characteristics require smaller sample sizes: studies that are informed by theory, studies with “good interview dialogue” versus “weak interview dialogue”, studies that recruit a specific type of participant, and studies that have more narrow aims (Varpio, Ajjawi, Monrouxe, O’Brien, & Rees, 2017).

### **Rigor for Narrative Inquiry**

Several techniques can be employed by the qualitative researcher to enhance the rigor of their findings regardless of the methodological approach. Rigor is enhanced with the use of member checks, maintaining an audit trail, and reflexive analysis. Member checking allows participant involvement in analysis of the data to the extent that they can respond to the accuracy of the transcript or analytic summary (Birt, Scott, Cavers, Campbell, & Walter, 2016). In this study, participants were sent a copy of their transcript, with numbered lines, along with a form for them to indicate whether they agreed or disagreed with the transcript and a space to make comments.

An audit trail provides a detailed description of the analytic process that could be used to audit the research process (Streubert & Carpenter, 2011). The audit trail provides a ‘road map’ of “evidence and thought processes that led to the conclusions” (Streubert & Carpenter, p. 49) reached by the qualitative researcher. In narrative inquiry, Lieblich et al. (1998) refers to the audit trail as “width”, or the quality of both the data collection and analytic methods, which includes multiple quotes and different explanations to allow for others to evaluate this criterion (p. 10). Lastly, unlike quantitative research, generating

qualitative research data is a combined effort between the researcher, the participant, and their interactions (Finlay, 2002). Through a structured process of reflexive analysis, the researcher seeks to determine ways in which their “position, perspective, and presence” affects the research (Finlay, 2002, p.532). While it is assumed in narrative inquiry that the researcher does influence the research, reflexive journals assist with documenting how this influence evolved. In addition, narrative inquiry also requires coherence, insightfulness, and parsimony (Lieblich, 1998). Coherence is the way the analytic components come together to form a “picture” (Lieblich, p. 10) and is evaluated either during the process or by comparing the analysis to extant research and theories which was done as part of the discussion of this dissertation, Chapter Five. Insightfulness refers to the ability of the researcher and others to glean new understandings from the analyses of the narratives. Parsimony is achieving an analytic outcome with as few concepts or themes as are necessary.

### **Audit Trail**

An audit trail was maintained in several ways. The interviews were recorded with a digital recorder and transcribed, and the transcriptions were checked for accuracy, errors, and personal information that is a threat to confidentiality and anonymity. Field notes were written after the interview to record impressions about the overall interview, reactions to questions and the tone of responses, and interruptions during the interview and why they occurred. The demographic form was filled out by the researcher before the interview. The recorded interview, transcription, and field notes are considered the “raw data” for the audit trail (Lincoln & Guba, 1985, p. 382). The process of data analysis and

reduction, and related processes such as reflexive notes, were likewise documented throughout the steps of coding, analytic thoughts, memos, comparisons, themes, relationships, and questions asked of the data. These aspects of analysis and reduction were kept with the transcript, or in a separate document in a folder with the transcript.

### **Reflexivity**

Reflexive thinking and analysis, a form of thorough self-evaluation, occurs before the research study begins, and during data collection and analysis (Finlay, 2002). Before the research begins a reflexive journal was kept, and has already been started, where the researcher wrote about her relationship to lung cancer, stigma, smoking, and nursing. During this process of reflection, the researcher considered her motivations, assumptions, and interests because this is what potentially “skew[s] the research in particular directions” (Finlay, 2002, p. 536). Lastly, during data analysis the researcher examined her assumptions and feelings about participants’ narratives and responses, which was also included in the reflexive journal (Finlay, 2002).

## **CHAPTER IV**

### **FINDINGS**

The purpose of this study was to explore the experiences of nurses who had at least six months of cumulative experience caring for patients with lung cancer, had been registered nurses for at least two years, and who were practicing nursing in the Southeastern United States. A secondary aim of this study was to explore how these experiences are related to the stigma associated with lung cancer.

#### **Recruitment**

Participants were recruited using a gradual rollout method of recruitment materials including an electronic flyer and brief recruitment message. First, potential participants were recruited through the Oncology Nursing Society Piedmont Chapter electronic newsletter and Facebook page by posting a recruitment flyer to both venues. After a week, the PI used two social media platforms, LinkedIn and Facebook, to share a recruitment flyer among her personal network with instructions to share among other networks. The original exposure to the flyer was limited to the network of the PI, with a request by the PI to the people in the network to use the “share” and “like” functions in Facebook and the “re-share” function in LinkedIn to disseminate the flyer beyond the PI’s network. The flyer was posted using the “create an event” function in Facebook and the “Share an article, update, or photo” function in LinkedIn. In the recruitment flyer was a statement that asked participants to consider other people they know who may be

eligible for the study. The PI's e-mail and phone number were on the flyer with instructions for those who were interested in participating to contact the PI through the provided e-mail address or phone number. For those who expressed interest in participating, the researcher contacted them by e-mail or phone, per their preference, to ensure they understood the eligibility requirements for the study. This was done to ensure the potential participants understood the flyer before an interview is scheduled.

After a week passed, the PI began the next phase of recruitment. A brief recruitment message, which was an abbreviated version of the recruitment flyer, was posted on the Sigma Theta Tau International Global Member Forum in "The Circle." Messages posted to this forum are accessed by members' e-mail or by logging onto the forum. The PI also recruited in-person through an Oncology Nursing Society local Chapter meeting which had approximately 20 attendees. The PI continued the next phase of recruitment after several weeks to provide time for coding and analysis. Next, the PI purchased and posted a brief recruitment message in the North Carolina Nurses Association electronic publication which has an estimated distribution of 5200 members.

For recruitment flyers and messages that had a wide and variable distribution like social media, the PI used a separate phone number from her personal phone number and a secure UNCG e-mail address. This was done to ensure that research correspondence was kept separate from other correspondence, and that the researcher's personal phone number was not widely advertised.

## **Analysis**

The narrative analysis was informed by a constructivist approach. A constructivist approach is suited for analysis in which the researcher will focus on aspects that contribute to the construction of narratives such as, but not limited to, themes, hidden meanings, and the social and power relations that bring about these meanings (Frost, 2011). Analysis of the data was based on the four stages of thematic analysis proposed by Frost (2011), and derived from Riessman (2008) which focuses more on ‘what’ participants say versus ‘how’ they say it. This model includes the following steps: selection of segments of the data; in this case codes were used to represent sections of the transcript, grouping the material into categories; defining thematic categories with words and sentence; and drawing conclusions. Structural analysis of the data was based on the components of a narrative proposed by Labov (1972). These components are (a) abstract, (b) orientation, (c) complicating action, (d) evaluation (e) result, (f) coda. The abstract is at the beginning of the narrative and provides a summary of the point of the narrative, the orientation provides the time, place, and people involved, the complicating action is the crisis, the evaluation is why the narrative was told, the result or resolution is the outcome of the story, and the coda is a clause that signals the conclusion of the narrative and may include information the narrator gained from the experience.

Analysis of data began with the first interview and continued as interviews were completed so that initial analyses informed subsequent interviews. For example, in the first interview, addiction was a code that was used several times; therefore, in subsequent interviews and follow-up interviews, this issue was explored further. A key component of

data analysis is data immersion which involved the writing of field notes, listening and transcribing interviews, listening to and verifying transcripts, and writing initial codes and notes while reading and re-reading the transcripts. The transcripts were put in a table format with four columns: the first column was the transcript, the second column contained codes, the third column contained analytic thoughts related to the transcripts and the codes, and the fourth column was a summary of categories and themes. Codes from each interview analytic table were transferred to a code book that contained three columns: categories with codes, supporting quotes, and summary explanations of categories to assist with theme development. A reflexive journal was maintained throughout the research process in which the PI wrote about biases, thoughts, questions to be asked of the data, and to track analysis as a way to form an analytic audit trail to enhance rigor of the findings. The analytic process was reviewed by a member of the dissertation committee who is a qualitative researcher. All participants were assigned a pseudonym to maintain their confidentiality.

### **Sample**

Six nurses were interviewed for this study. Saturation was assumed after four interviews, however, to ensure that saturation was reached, two additional interviews were conducted which supported repetition of categories. Participants were asked during consent if they would agree to be contacted for a second interview. Five of the six participants agreed to be contacted; three participants participated in a follow-up interview, one participant did not respond to two attempts to schedule a follow-up, and one participant was not scheduled for follow-up because their initial interview occurred

after saturation had been reached. Participants were also provided with an electronic copy of their transcript with a member check form, sent through email, to verify and comment on the transcript. Three participants verified their transcripts, one participant did so by returning the completed member check form at the beginning of the follow-up interview and the other two participants agreed with the transcript through e-mail correspondence but did not return the form. Of the six participants, four were recruited via purposive means and two through snowball sampling.

Data were collected from July, 2017 to January, 2018. A pause in data collection occurred from August to September to allow for coding and analysis. The average length of an interview, including the two follow-up interviews, was 68 minutes. The initial interviews ranged from 51 to 94 minutes, and the follow-up interviews ranged from 36 to 60 minutes. Recruitment was conducted over a five-month period.

### **Sample Description**

All participants were female, with an average age of 50.5 (30, 70), average years of being a nurse 24.7 (6, 50), and an average of 13.5 (6, 22) years caring for patients with lung cancer. Regarding education level, four (66.7%) achieved a Bachelor of Science degree in Nursing (BSN) or higher at the time of the interview, one had an associate degree (ADN) and one a diploma. All participants received their pre-licensure education in the Southeastern United States. Most participants, 83%, also grew up in the southeast, and had a family member who had lung cancer and died from the disease. One participant reported smoking cigarettes.

The following is a description of the participants. Each participant was given a pseudonym. Pseudonyms were based on names of the PI's family members and childhood friends.

**Sylvia.** Sylvia is an older nurse with over 30 years of experience; she has cared for patients with lung cancer for 13 years. She currently works in hospice and home health, and cares for patients with lung cancer in both settings. Like many of the nurses interviewed, she spent most of her time growing up in and received her prelicensure education in the Southeastern U.S. She also grew up in a household where both parents smoked. She had a friend that was diagnosed with and died of lung cancer.

**Rebecca.** Rebecca has been a nurse for over 20 years and has cared for patients with lung cancer for most of that time in both the acute care setting and as a case manager. She grew up and received her prelicensure education in the Southeastern U.S. Her paternal grandmother was a strong role model, and was a driving influence for her to go to nursing school. She describes her as “...*she was just the matriarch of the family she was just such a strong woman and that you know I wanted to be like her*”. Her grandmother died of lung cancer and continued to smoke after her diagnosis. Rebecca recalls her grandmother's response to smoking cessation after her diagnosis “*she wasn't very old, maybe 60s, but she's like “I enjoy it, it relaxes me...I'm not putting 'em down.”*”

**Jenny.** Jenny has the least experience of the six participants; she has been a nurse for six years and has been caring for patients with lung cancer for the same amount of time in the acute care setting. She grew up in and received her prelicensure education in the Southeastern U.S. Both her parents smoked and her sister, she recalls, snuck

cigarettes from their mom to try and fit in with her friends. She was recruited into nursing by a hospice nurse, while she cared for her grandmothers who were dying of lung cancer.

**Tracy.** Tracy has been a nurse for 22 years and has cared for patients with lung cancer for the same amount of time in acute care and oncology. She grew up in and received her prelicensure education in the Southeastern U.S. Both of her parents smoked, but while her mom smoked cigarettes, her dad smoked a pipe; she relays pleasant memories of both her parents' tobacco use. She experienced an entrée to nursing that is linked to tobacco. Her dad, a physician, took her on his rounds while he smoked a pipe and, she notes, this was also when nurses could smoke in the hospital. This early experience of nursing she describes as: *“seeing the nurses and their pretty white outfits you know and their stockings and just looking you know so great...they seemed really smart...”*.

**Anne.** Anne has been a nurse for 50 years and has cared for patients with lung cancer for 20 years. She grew up in and received her prelicensure education in the Southeastern U.S. An uncle died of lung cancer, and she grew up in a smoking environment that she describes as *“...like you're swimming in a haze...”* and *“really foggy”* then continues by quipping *“Lucky I was short. You know, the smoke, it kind of went up high at least”* [laughs]. She now reflects that this smoke-filled environment made sense since her dad ran a tobacco farm, which helped pay for her nursing education. She describes wanting to be a nurse since a young age: *“I never wanted to do anything else. As far as I can remember, I wanted to be a nurse. My mother even made me a nurses' outfit...when I was six years old for Christmas.”*

**Julie.** Julie has been a nurse for 10 years and has cared for patients with lung cancer for five years. She grew up in the Northeastern U.S. but received her prelicensure education in the Southeastern U.S. No one in her household smoked when she was growing up and no one in her family or her friends has or had lung cancer. Her earliest memory of cigarette smoking was from television: “...*everybody on TV smoked. The young women, the pretty women. You hardly ever saw an ugly woman smoke. It was people who looked always put together. It was always young pretty people who smoked and they just looked cool.*”

### **Analytic Findings**

A qualitative narrative approach was used to explore the aims of this research. Thematic analysis of the transcripts yielded four themes. Some of the themes are derived from InVivo codes, which came from powerful narrative segments within participants’ experiences. The four themes are: (1) addiction in action, (2) cancer of a functioning organ, (3) jumping through hoops, and (4) securing the journey.

### **Themes**

The following is a description of the themes and subthemes derived from the analytic steps mentioned earlier in the chapter, with supporting quotes. After the first theme is a table, Table 2, that represents part of the analytic audit trail: a section of the transcript, codes, categories, and subthemes. Each theme will also have a description of how it is linked to one or both of the stigma theories explained in Chapter Two. Table 1 shows the structural analysis of a narrative segment in the theme addiction in action.

Table 3, at the end of the explanation of themes, will also provide a summary of the concepts of the two stigma theories and how they relate to sections of the transcript.

**Addiction in action.** The first theme, addiction in action, is derived from an InVivo code and represents the struggles participants had surrounding the discordance between what they expected of patients and what patients did or said. Fundamentally, this discordance, at times, highlighted a mismatch in values, knowledge, and perceptions between nurses and the patients they cared for. Nurses used the label of “addiction” to offset the potential conflict surrounding this mismatch and to help explain the irrational and, at times, unsafe behaviors they witnessed. Subthemes for addiction in action are stigma-related thoughts, struggle, and frustration. Table 2 provides an example of a section of the audit trail associated with the theme addiction in action which includes a narrative segment from the transcript and associated codes, categories, and subtheme.

*Stigma-related thoughts.* While most participants expressed sympathy for patients who have smoking addiction they also had responses that were more representative of negative stereotypes of smoking and people who smoke such as “*dumb*”, “*filth*”, “*stupid*”, “*smoker*”, and “*addict*”. At times, reactions to smoking addiction and talking about the causes of lung cancer elicited stigma related responses such as when Jenny shared her reaction to lung cancer “*...I mean...I guess maybe it's...sometimes you think...I mean you don't want to say you did this to yourself but...you know because there's different circumstances but...I mean you think that.*”

While Jenny remarks on stigmatizing and unspoken thoughts, this form of judgment and blame, for Rebecca, had a logical connection to smoking and getting lung

cancer “...you know I think at that point they’re just really mad [people who never smoked] you know and I would be too... at least if you smoke and you get cancer you’re like...I did it to myself.” Sylvia had a similar reaction to the uniqueness of lung cancer as a disease linked to an unhealthy behavior, yet is simultaneously able to recognize the strong feelings patients have related to a disease that is linked to an unhealthy behavior

Hmm...I would say for the most part is the... component of realizing that you did have a hand in it... you know some remorsefulness... there are not many other cancers that are that cause and effect...really...I’m trying to think of any...maybe some GYN cancers...so I think that would be part of it.

The topic of smoking also elicited associations to other stigmatized statuses, and strong reactions as Sylvia and Julie describe. Sylvia:

...I guess I have to say I think of it as sort of a, and I know this isn’t true, in my head, but I think of it as sort of...a blue collar, uneducated habit you know that if you really knew better you wouldn’t do it, again I know it’s an addiction.

Julie recalled encounters with people who smoke and assigns intent to their behavior while proposing more stringent rules about where people can smoke.

It’s just the people around me. That feel like they have to share their smoke with me. And I don’t like it, and I think there should be a designated spot, like a mile away from any building that I have to enter, or my children have to enter. So, they can go there and smoke. We shouldn’t have to be subjected to that. We don’t want to be and if they want the convenience...of having the next fix, then they need to walk a mile to do that. So, standing outside the door is not enough, because I have to go through that door.

According to Link and Phelan (2001), linking a labeled group, in this case people who smoke, to negative attributes like other stigmatized statuses “*uneducated habit*” and

intent to provoke “*feel like they have to share their smoke with me*” facilitates the act of separation and an “us”, people who “*know better*” such as Julie and her children, versus “them”, the uneducated and people who smoke around buildings, approach which is illustrated in Julie’s suggestion that they have a “*designated spot, like a mile away*”. Labels, negative attributes, and separation (us versus them) are what then contribute to a further disadvantaged status for the group that is stigmatized.

Sylvia and Tracy both indicated that current policies that keep people who smoke away from buildings and warning labels on cigarettes, do not address the issue of addiction. Sylvia says about this issue “*I just feel like as a society, I wish we would treat it more as an addiction and not just ‘you can’t smoke here, you can’t smoke here’ um... because people still will go find places to smoke.*” Tracy says the following about overall neglect of the issue of addiction, and the ineffectiveness of warning labels on cigarettes:

I mean I don’t condemn or condone either way. It’s kind of a choice. But...in this field and what I’ve experienced personally and professionally... it’s an addiction. I mean these patients are addicted to this nicotine... and...just kind of makes me sad that...we don’t recognize that as a society... and there is a piece missing that should...be looked at in the fact that...how easy accessible it is. Yes, there’s labels and this kinda stuff, who’s gonna read a label?

**Struggle.** The subtheme of struggle represents the problems that participants faced when they tried to reconcile their emotions and beliefs about addiction with their professional behavior. Smoking addiction was defined and described as involuntary, yet participants also used words that implied a voluntary behavior like “*choice*” “*nothing better to do*” “*just something they do*”. Several of the participants offered a definition of addiction that was medical and rational, and spoke about knowing that smoking is an

addiction, yet they were still “*blown away*”, shocked, surprised, or disappointed when smoking behavior continued with their patients. Sylvia offers a powerful description of this struggle when talking about addiction in her family:

Because my father did quit smoking when he got heart disease but he then started drinking so all my life with him there was addiction behavior and so that’s a struggle where I know in my head what addiction does but it’s still emotionally like why can’t you just stop doing this... Um...It’s kind of a duality you always have to fight.

The “duality” that Sylvia describes represents the internal struggle of the two identities of the “wise”, knowing the difficulties of smoking addiction from interactions with their patients and their families, and wanting a someone to be “normal” and not smoke. For Tracy, the struggle and fight became an almost literal struggle between her efforts to fight lung cancer with treatment and support and her patient feeding the cancer with smoking:

... I try to tell them not to blame themselves and... it is what it is, let’s just deal with it. Let’s just go forward from here...let’s not... let’s not even think about it. But yet it’s very difficult to know that they’re still smoking and yet...and I tell them, I was like you’re feeding the cancer and I’m trying to kill the cancer...you’re feeding the cancer...I’m trying to kill... it’s not gonna to work.

In this interaction, we also see Tracy exhibiting “wise” behaviors by helping the patient counteract their self-blame. Tracy also describes the difficulties of engaging her patients in smoking cessation when their response is “*I love it.*” She explains: “*That’s pretty strong... I love it! How do I...as a nurse speak to you about... quitting when you love something? I find those words – I’m just like...wow, okay!*”.

Julie presents issues related to acute care where smoking addiction is treated with nicotine patches that are refused by patients:

We have had several patients who have refused the patch. And opted to take their IV pole with them out to the sidewalk to smoke. We have had patients on oxygen, whose family members will bring cigarettes in and the assumption is that they understand that you tell them that they could blow everybody to smithereens, if they have any kind of fire or flame next to that oxygen tank. Or you know, you assume that they understand because they appear to be intelligent people, but the craving, I believe, far supersedes what common sense will say.

Like Sylvia, Julie includes the safety issues of smoking around oxygen, and brings up an assumption that patients and families understand these safety issues. This description of smoking addiction among patients in acute care highlights that these are not safe assumptions, particularly in light of the more rational definition that participants provide for addiction “*they cannot voluntarily stop*” from Julie, and as Tracy notes, there is an element of deception

...the lies and the deception [of smoking addiction] is the same you know. “Are you smoking?” [speaking as a nurse to a patient] “Psst, no.” [speaking as the patient] “What are those in your pocket?” Ah! Or you can smell it on ‘em. I mean, it’s not like you can’t smell it and they’re like “no, I’m not smoking”. OK...[laughs] you know so...um the lies and the manipulation and that kind of stuff is exactly the same with a regular addict.

However, Julie arrives at this conclusion of unsafe assumptions by the end of her explanation “*the craving, I believe, supersedes what common sense will say.*” Sylvia provides a similar conclusion when talking about a patient’s husband smoking in the same room as the patient who has a tracheostomy and feeding tube:

this just struck me... her husband and his friend came in and they were both smoking... and I just sat there thinking I'm sitting here, your wife's got a trach and a G-tube seriously! You know I didn't say anything but I just... I mean it just it is a conundrum to me how people can look at somebody sit'n there with a trach and a G-tube and continue to smoke so there just has to be a component that transcends... judgment...

***Relationship to theory.*** Goffman (1963) wrote that “normals” have “normative expectations” of others that can change into “righteously presented demands” when they encounter the stigmatized (p. 2). The theme of addiction in action reveals the overlapping identities of the “wise”, the “wise” as “normals” who expect their patients to behave rationally, and the “wise” as “wise” who have sympathy for their patients because they know cigarette smoking is addictive, and help them counteract self-blame. Goffman (1963) explained that addiction is a type of stigma that is in the category of “...blemishes of individual character...” (p. 4). However, when nurses struggled with empathy for addiction, their patients at times became their oppositional voice. Tracy talks about a patient who got lung cancer because her husband smoked:

Or... second-hand smoke, like the husband smoked for 50 years and the wife gets lung cancer... and she's like... “you gave me lung cancer” [speaking as the wife in a serious voice]. I'm thinking, “yep, he sure did!” I'm just like “Ohhh that's bad! ooh, I couldn't live with myself on that one” But yeah...they're mad...

While participants engaged in “wise” behaviors, there were limits to helping people who smoke not blame themselves as Tracy explained in her follow-up interview about the same patient “*Not for the second hand one, I was like... “let em' have it!” I just let her go off on him, it was awesome, I was like, “you totally deserve that and more”.*

Addiction was partially transformed by participants from an identity with negative valence “weak character” to one that offered protection and engendered sympathy for those who suffered from it. The stigmatized label of addiction or addict, for these participants, was also used as a way to avoid passing judgement on irrational behavior such as smoking while on oxygen, smoking while receiving cancer treatment, and trading alcohol addiction for cigarette addiction. Participants mentioned other stigmatized statuses and behaviors that were associated with smoking, but the label of addiction was a way to discuss a health issue without delving into problems that were associated with greater negativity like self-harm. However, Tracy hints at this issue in her first interview “*what I feel when my patients talk to me about it...they will say words like ‘I love it’ ...I love it’ ...*” She continues by comparing nicotine addiction to other addictions then concludes with “*Because it’s... “I love it?” ...and it’s killing you.*”

***Frustration.*** Frustration was an emotional response, expressed explicitly and implicitly, to dealing with the irrational behaviors of addiction among their family members and patients. These emotions were often expressed when participants were struggling to reconcile their scientific rational explanation of addiction and the irrational behaviors they witnessed. They were also expressed when smoking cessation was perceived to be an urgent intervention but was unsuccessful. Sylvia talks about caring for a patient on oxygen who smokes:

...it was my first patient that I was sitting in the home with...she had oxygen and she lit up a cigarette and I just...just the thought that you would put us all at such a risk... you know so I think, I think that I see people still smoking...having these diseases, and again I think in their minds it didn’t matter at that point, but I think just the...the frustration that came of seeing...addiction in action.

Tracy also offers a frustrating experience. This description stems from a free association question about cigarettes “*When you hear or read the word cigarettes what comes to mind?*” In the first interview she said “*a packet of cigarettes.*” In the follow-up interview I revisited this response and she said:

...I guess with my role it's just...kinda that... I almost find them to be a nuisance [emphasizes this word] ... with the cigarette...when I think of smoking and cigarettes I mean that just pops into my head. And it's almost, for me, a frustrating image. You know? I'm just so tired of that...and I'm tired of the...the bigger picture of not seeing the addiction to nicotine...and...yeah it just, it's a frustrating image...yeah. Because you know I'm sitting here talking to... a forty-four-year-old with stage four lung cancer...they've got a pack of cigarettes in their pocket [pats chest to demonstrate where the pack of cigarettes are]. I had a patient who actually had a CT chest scan... and in his shirt pocket, I'm not kidding, the image – I'm not kidding – the image came back... and I was like, what is that? [says this in a loud whisper]. So, I showed it to my doctor and he's like, “what do you think that is?” [speaking as the physician, flatly]. And I was like... “I really, I don't know”. “That's a pack of cigarettes.” [speaking as the physician again]. I was like “he wore that in his CT chest scan...for staging for lung cancer?” He said, “yep”! I was like...just yeah...yeah.

**Tables.** Table 1 represents the structural analysis of a narrative segment of addiction in action. An explanation of the structural analysis will follow. Table 2 represents a section of the audit trail for the theme addiction in action.

Table 1

Structural Analysis of Narrative Segments According to Labov (1972)

Narrative Segment	Components of the narrative
1. <i>“but I do remember a home health patient...</i>	Orientation
2. <i>she may have had COPD</i>	1. Person
3. <i>but it was my first patient that I was sitting in the home with</i>	2. Situation
4. <i>she had oxygen and</i>	3. Time
5. <i>she lit up a cigarette and</i>	Complicating Action
6. <i>I just...the thought that you would put us all at such a risk...</i>	4. she had oxygen
7. <i>so I think, I think that I see people still smoking...having these diseases and again I think in their minds it didn't matter at that point but</i>	5. she lit up a cigarette
8. <i>I think just the, the frustration</i>	Evaluation
9. <i>that came of seeing um...addiction in action.”</i>	6. Safety risk
	7. Irreverent patient
	Result
	8. Frustration
	Coda
	9. addiction in action

**Structural analysis.** Table 1 represents the structural analysis for a narrative segment within the theme addiction in action. The structural analysis was conducted according to the components of narrative described by Labov (1972). These components are (a) abstract, (b) orientation, (c) complicating action, (d) evaluation (e) result, (f) coda. For this narrative segment, there is no abstract. Sylvia first orients us to the people involved, herself and a home health patient. The situation, the patient had chronic obstructive pulmonary disease (COPD), helps us understand the rest of the narrative or why the patient was on oxygen. She provides an idea of when this happened, her first patient she was sitting in the home with then transitions into the complicating action, that the patient was on oxygen and lit up a cigarette. While she does not explicitly say that this was a safety risk, her point of telling this story is to illustrate a safety issue that home

health nurses can encounter during their care of patients with smoking addiction, and that these actions may not pose much significance to the patient. The result is her response to this situation, frustration, although she does not provide any actions that she took. Lastly, she provides a clause that signals the end of the narrative, or the coda which is also her observation of the significance of the narrative.

Participants described encounters that represent addiction in action and the associated irrational smoking behavior in different ways. Sylvia and Tracy provide examples of two different ways that the narrator (participant) draws in the listener in order to express the importance of what is happening. Sylvia does this by presenting an organized account of what happened; she sets the scene (time, place, people) before proceeding to the complicating action. By focusing on action and not dialogue, she quickly brings to the foreground the issue at stake, safety, a repeated theme in her narratives. Through the evaluation component of the narrative, she also presents a situational irony that represents oppositional expectations of the patient and the nurse in the context of a safety threat, smoking while on oxygen therapy. The patient expects to be able to smoke in her home and the nurse expects the patient to not smoke in front of her, especially while on oxygen therapy. Sylvia is shocked by the risk that the patient's behavior presents "... *just the thought that you would put us all at such a risk...*" and assigns an irreverent attitude to people who smoke "...*in their minds it didn't matter at that point...*". Sylvia also offers the listener more of her feelings about the encounter, "*frustration*" and summarizes the event with a label "*addiction in action.*"

Tracy describes a similar situational irony. She expects her patients to forego smoking while receiving cancer treatment, but sees a packet of cigarettes in their pocket. While she describes the scenario of a patient getting a CT scan, she presents her own dialogue along with the physician's to help illustrate her disbelief. In another similar situation in which she speaks with a patient who is smoking outside the treatment center, she presents her patient's side of the encounter by relaying what he says and changing her voice to match that of a sheepish male patient:

...Even with their diagnosis of lung cancer. I mean, there's some of them who are still smoking outside the [hospital] ...I mean that's addiction...It's crazy. And I'm like "what are you doing, Mr. so and so"? And they're like, "oh, [draws out "oh"] you shouldn't have caught me" [speaking in a deep voice] I'm like, "yeah! you're right, I shouldn't have caught you!" So that, that's how I just...I try to take it from an addiction kinda standpoint.

Her account is not as organized as Sylvia's, she changes quickly from describing addiction to the patient encounter. Yet when she does begin describing the encounter, she draws the listener in quickly with presenting both people present through dialogue and acting out each part. Table two represents the analytic audit trail for the theme addiction in action.

Table 2

Analytic Audit Trail for the Theme Addiction in Action.

Narrative Segment	Codes	Categories	Subtheme
<p><i>...she had oxygen and she lit up a cigarette and I...just the thought that you would put us all at such a risk...so I think that I see people still smoking...having these diseases...I think just the...the frustration that came of seeing...addiction in action. Because my father did quit smoking when he got heart disease but he then started drinking, all my life with him there was addiction behavior and so ...that's a struggle where I know in my head what addiction does but it's still emotionally like why can't you just stop doing this.</i></p>	Safety	Addiction	Struggle
	Safety risk	Smoking	Frustration
	Addiction	Smoking	
	Addiction in action	Addiction	
	Irrational	Patients with lung cancer	
	Frustration	who smoke	
	Emotional		
	Struggle		
	Duality		
	Family		
Situational			
Irony			
<p><i>...it's almost, for me, a frustrating image. I'm just so tired of that...and I'm tired of the ...the bigger picture of not seeing the addiction to nicotine...and..., it's a frustrating image...yeah. Because you know I'm sitting here talking to... you know a forty-four-year-old with stage four lung cancer. You know they've got a pack of cigarettes in their pocket I had a patient who actually had a CT chest scan... and in his shirt pocket, I'm not kidding, the image – I'm not kidding – the image came back... and I was like, what is that? [says this in a loud whisper]. So, I showed it to my doctor and he's like, "what do you think that is?" [speaking as the physician, flatly]. And I was like... "I really, I don't know". "That's a pack of cigarettes." [speaking as the physician again]. I was like "he wore that in his CT chest scan...for staging for lung cancer?" He said, "yep"! I was like...just yeah...yeah.</i></p>	Addiction	Addiction	Struggle
	Frustration	Smoking	Frustration
	Irrational	Smoking	
	Addiction in Action	addiction	
	Situational	Patients with lung cancer	
	Irony	who smoke	

Participants spoke about society's lack of recognition of smoking addiction and remarked that people who smoke are "left to their own devices" with regard to smoking cessation. They also compared smoking addiction with other drug addictions and with other addiction treatments. The explanations of the overall neglect by society of addressing smoking addiction, of how cigarettes are readily available, and the lack of transfer of treatment options, such as mentoring, from alcohol and overweight treatment, point to a disadvantaged status for smoking addiction.

**Cancer of a functioning organ.** The second theme, cancer of a functioning organ, is also derived from an InVivo code. This theme represents nurses' impressions and descriptions of lung cancer and how it impacted the people who had it, in their personal and professional lives. Because lung cancer invades an organ where dysfunction in that organ can be immediately sensed and is frightening (difficulty breathing), participants spoke frequently about what was needed to support this organ; they identified with how patients and their own family members felt when there were alterations in its functions. Subthemes for cancer of a functioning organ are: dyspnea, sick, intimidating, secretions.

Dyspnea (difficult breathing) was described as being worse than pain, a significant, negative impact on quality of life, and as a ubiquitous symptom for patients with lung cancer. Participants frequently used the adjective "*sick*" to describe patients with lung cancer which overlaps with descriptions of how scary and intimidating it was to encounter the complexity of care they needed. Secretions were described as thick,

harrowing, loud, and having a memorable smell. While Tracy describes the smell of “*drainage*”, this experience is grouped under secretions.

**Dyspnea.** Sylvia best illustrates this theme when she prioritizes lung cancer and the related symptoms based on the organ that it disrupts and the distress that patients experience:

I mean just... the breathing and the fact that breathing becomes your focus of activity... I think because...fatigue and breathing begin to... be so tied up that they're...because you have breathe constantly say if you had another cancer it wouldn't be a cancer of a functioning organ.

Jenny describes a similar focus with her grandmothers who both died of lung cancer and how it diminished their quality of life “*It was debilitating, I mean they couldn't live their lives the way they wanted to they... couldn't breathe.*” Tracy’s account of her grandfather’s struggle with lung cancer, again, focuses on pulmonary problems:

...I remember his dressings, and he would keep a dressing on that area on his chest and...you know the, the difficulty when he started to have trouble breathing and the wheezing and how - I mean, he was loud [draws out this word]. You know...you'd sit beside him and he was just real loud. And so obviously he was struggling.

Dyspnea, according to Sylvia, was worse than pain, and caused a great deal of fear and suffering near the end of life requiring aggressive symptom management, “*breathlessness and dyspnea is probably worse than pain most people would say and so we're doing a lot of modalities to... maximize their physical positioning...*”. Yet she also notes that there is little evidence to support the therapies that are done for dyspnea calling the research “*anecdotal*” she goes on to say:

... just trying to keep people calm and supported as much as possible with these few modalities then as I mentioned there's some secretions when people are terminal they can develop secretions... apparently there is a higher propensity for people with lung disease... but it's distressing to families so we're doing a lot of family care...and there's often a lot of anger if the person smoked and they know that this is the way it ended...there might be resentment in family members so... we're trying to support them as well.

Here, Sylvia describes how the distress of dyspnea extends beyond the patient to the family and can elicit feelings of anger at the original cause of the symptom.

***Sick and intimidating.*** Lung cancer patients were described as sick and complex due to the impact that the disease and treatments had on their pulmonary and sometimes cardiac systems, existing comorbidities, and the struggles the patients had in adhering to these treatments. Because of these issues, caring for patients with lung cancer was initially intimidating for several nurses:

Lung cancer patients were described as sick as Tracy succinctly states “...*truly my lung cancer patients are sick. They can't breathe, they're on oxygen. I mean they are so sick...*” Rebecca echoes this description “...*and those patients were just sick... you know they just had a lot going on...*”

***Intimidating.*** Jenny describes how patients with lung cancer first seemed to her and how difficult it was to do interventions due to fear of accidents and complications.

...it was very intimidating. Because you could have one patient that was stable as far as their vital signs and their pain and they were fine and comfortable and OK and then you had others who still had the chest tubes, the chest tubes were horrifying when I first started... I, I didn't want to touch it, I didn't want to move it, I was afraid of it...and then you have those other patients that due to the surgery and their illness plus their comorbidities...something would go wrong they would go into a-fib they would develop respiratory distress God forbid pull out their chest tube...so lung patients were scary at first... you start off and you

don't even want to ambulate your patient with their chest tube because you're terrified it's gonna come out...

The complexity of the patients she cared for also made empathy a challenge initially:

... I was so overwhelmed at first by all of their things that I had a harder time seeing the person. And as I've gained experience...and I'm more comfortable with... their tubes, lines, and all of that I can focus more on the person who's going through that and who...eight times out of ten has just been diagnosed with this and...that's a lot, that's a heavy load for some people to carry.

**Secretions.** Similarly, Tracy talks about caring for patients with lung cancer in the ICU. She also recalls chest tubes, but offers a more visceral description of her experience. Her account ends with a repeating issue in her narratives, the negative impact of smoking as a force that nurses have to work against to deliver their care and help patients heal. Her last statement returns to ambulating her patients with the chest tubes.

I... remember the tubes...the large chest tubes that these patients had to deal with...all the lines and wires and... the enormous scar that they would have and the dressing for those scars...those were there, I remember that. I can even remember like the touch and the feel of it and the smell of all that serous drainage from those... poor incisions and all those poor patients because you know they're not healing appropriately with their smoking history and... that's what I remember. Yeah, walking around with those chest tubes, getting them up...

**Secretions and intimidating.** Julie also describes caring for a patient with lung cancer in the acute care setting. While she starts by describing the patient's phlegm, she ends by relaying how unprepared she felt to care for a patient who was so sick "*on paper*":

He also had a lot of phlegm that he liked to spit on the floor. It was thick and yellow. And I did step in it. But I also think that he did know what he was doing. That was, it was, it was sad.

Later she talks about the same patient, but relays more of her feelings about the gravity of the experience:

And it was a scary moment. It was a scary shift. Because when I read the progress notes, I realized that this guy had one and a half lungs. And I didn't expect him to be, for such a sick man on paper. He was really, really sick on paper. He didn't seem to be so sick in person. Ambulating all over the place. Filthy mouth. Uh, cursed at you because he couldn't get a cigarette. Wanting to eat when he couldn't eat. Refused for you, you know, to feed him. It was scary for me, because the labs, everything on paper, did not match the person in the bed. Or the person strolling through the halls. And as a new nurse, I was thinking this is probably somebody who is going to die on my shift. Because this doesn't match that. And I felt like I wasn't prepared to take care of him.

She talks about the patient removing his oxygen:

But he did not get an oxygen tank on the unit, he had to stay in his room, hooked up to the wall. But he would take it off, he would take it off. So, these things you learn in nursing school that this shouldn't happen and this can't happen, it happened!

**Structural analysis.** Three participants recall a past experience in caring for patients with lung cancer, two of these experiences coincided with being a new nurse, Jenny and Julie. Jenny and Tracy include descriptions of tubes, drainage, and complications in their descriptions. Julie's narrative focuses on alternating contrasts between the patient's illness "*on paper*"; "*one and half lungs*", "*labs*", with how he behaved in the acute care setting; "*strolling through the halls*", "*cursing*". She further contrasts this experience with what she was taught in nursing school, that patients should

not take off their oxygen. There is also a glimpse of other aspects of the patient that are not necessarily included in the paper charting and progress notes, their mood “*filthy mouth*” and the way they view their illness and treatments prescribed by the plan of care “*Wanting to eat when he couldn’t eat.*” The narrator gives very little of the patient perspective other than attempting to exercise his autonomy in opposition to his treatment.

***Relationship to theory.*** The contrasts in Julie’s narrative illustrate the differences between the rational expectations and plan of care in the chart with the patient’s irrational behavior. Information about the patient is gathered from the chart and from report, but it is the person, in real time, with whom the nurse engages. The normative expectations are that the patient behave like the sick person on paper and that they are obedient with regard to routines and treatments. These normative expectations, with regard to the theme of cancer of a functioning organ, are best seen by contrasting Julie’s narrative with Rebecca’s. Rebecca describes a patient with lung cancer who had severe dyspnea and was dependent on oxygen:

...she came in, she couldn’t breathe I mean...we had her on a non-rebreather, she couldn’t compensate...- you took the breather off for a second she’d go into the 60’s. I mean she couldn’t move in bed she couldn’t talk...she was in a bad way and she was up there for a long time and I took care of her...

She continues by describing restrictions placed on the patient because of her severe dyspnea, and a label the patient acquired, “*needy*”. Rebecca offers a solution to this conflict that she considers to be the duty of the health care professional, “*meeting people where they are*” instead of telling them how to behave and what they cannot do:

Yeah needy you know but... I never found her to be needy...she liked things the way she liked them but I didn't find her to be needy ...you know, you gotta meet them where they are, you gotta anticipate what they want. You know if she... likes to curse don't stop her. "Don't talk that way to me!" [says this as an indignant whisper – speaking as a co-worker] you know you can't do that to them...

She continues by recalling the conflict the staff had with this patient because she had a strong, no nonsense personality and was dyspneic with minimal activity

...she's no nonsense, you go in and try to bullshit her she's gonna cut ya down she's gonna see... right through you. She's not gonna put up with it. You talk down to her she's gonna cut ya down, you act like she's stupid she's gonna cut ya down and that's what people were doing...they'd go in and condescend to her, or tell her she can't do something or... "you can't do that!" ... if she wants to get up and go to the bathroom by God take her into the bathroom, she knows she can't breathe...she's not stupid she knows she can't breathe. Bring her oxygen and go in there. I think it's just funny 'cause so many people just... think they know best...and a lot of health care professionals think they know best. We don't know, we don't...

**Jumping through hoops.** The third theme, jumping through hoops, is derived from an InVivo code. This theme represents the collaborative actions that nurses took to ensure that their patients with lung cancer received fundamental and key aspects of their care, and the complicated, and at times, unnecessary, barriers they faced when doing so. Fundamental standards that nurses worked to execute included calling the doctor for pain medication, obtaining a portable oxygen compressor for patients who were physically unable to manage a regular sized oxygen tank, and getting an order for adequate amounts of morphine for end of life care. The last scenario is what Sylvia describes as a "gold standard" of care, yet she still encountered barriers. Subthemes for jumping through hoops are: push back, attitude barriers, and system level barriers.

Push back is a subtheme that is similar to attitude barriers but can be distinguished as an active process of negative displacement when nurses are engaging in advocacy. The negative displacement is psychological in the sense that the nurse perceives they are in a less effective position after the push back than before; they then must expend additional time and effort to make the advocacy effective. Negative attitudes are described by nurses not as an active thing but as a type of passive barrier they have to work around or deal with. System level barriers were obstacles in the system, such as insurance requirements and scheduling logistics, that were between the nurse's assessment of what was needed for the patient and providing the care to the patient.

***Push back and attitude barriers.*** Jenny describes caring for a postoperative patient who had low blood pressure:

... probably a couple of years ago... I had this super sweet patient that had come in earlier on day shift, I came in at seven was about to start my shift, blood pressure was a little low you know he's fresh post op so all this stuff is going on...so I call early in the night and I'm like hey this is the situation, I get orders for the blood pressure, he's OK pain-wise... has his PCA doing that every now and then once the blood pressure comes back up... get him up to the chair like I'm supposed to at six in the morning...he's hurting still he doesn't want to use the pain medication because now he's afraid it's gonna make his blood pressure drop. I try to explain you know 'If you're hurting it's, it's OK we can do something about your blood pressure it's OK I don't want you to be in pain and I've got these other things I can give you if you want, I think I had Tylenol it was like a standard order... patient says to me well I don't usually take Tylenol because I've had liver issues or whatever it was I usually take Ibuprofen and it works, that's what works for me and that's all I would need right now. So, I paged the physician, on call physician, and I'm like all I need is an order for what - how much ever ibuprofen you wanna give me. And I just, I mean I just get it, I mean he's yelling, he's asking me why don't you wanna give your patient pain medicine like didn't even remember this is the same patient I'm calling about earlier in the shift his blood pressure was in the 60s...I don't think - maybe the narcotics aren't a good idea which is what I said you know maybe the IV narcotics aren't such a good idea because the blood pressure was low at the

beginning of the shift I don't really want to do that to day shift and all he wants is an ibuprofen and I have to get that order from you unfortunately I have to call you at 6:30 in the morning I do apologize. It's just situations like that, you know, um...where you get push back when you try to do the right thing...

Jenny offers another explanation that shows that negative attitudes from physicians is not an uncommon barrier:

Ah...surgeons, the attitudes...the attitudes the um...'why are you calling me' you know kind of thing especially working night shift oh my goodness um...and you know...sometimes it makes you not want to call or not want to reach out or not want to say anything...because nobody likes to be yelled at or made to feel incompetent that's not what we're there for but it still happens.

*Structural analysis.* Jenny uses the words 'push back' after describing a situation where she is advocating for her patient and doing patient centered care, and the physician shifts the focus away from the patient, towards Jenny and insubordination. She has to take additional time to try to shift the focus back to the patient and re-emphasize urgent issues like blood pressure and poor pain control. Jenny also talks about the attitudes of physicians and sees this as a deterrent to intervening on behalf of the patient, yet with this knowledge, she continues to "*do the right thing*" as her first account illustrates. Her emphasis, at the beginning of the narrative and throughout, of her relationship with the patient "*super sweet patient*" and early efforts to ensure good post-operative care, provide a sharp contrast to the way the physician reacts "*I mean I just get it, I mean he's yelling*". With this contrast and build-up in the narrative, push back almost becomes too bland of a description for the verbal abuse that occurred.

Sylvia also describes stigma-related, negative attitudes that are damaging and interfere with caring for patients at the end of life:

I think there's still um...I think there still is...thought about 'you've done this to yourself'...I do still hear residents or physicians or people higher up the process, with comments like well you know 'what do you expect they smoked' you know they're not gonna do any different...so I do think that is still a mindset at a different point on the healthcare continuum...where people are young and healthy and don't have these habits are very easy to dismiss the struggles that people might have.

I asked her if these attitudes impacted her ability to deliver care to her patients and she said:

I mean sure 'cause if you gotta go back to the doctor for orders...it does still exist where... they would never say it, but I think there is some kind of a punitive mindset...there's this big divide between hospice and non-hospice when it comes to so many things including pain management...because people who don't do hospice pain management, they're going 'oh they just want drugs' or 'oh they're just addicts'... and in hospice... it's completely a neutral tool...with lung disease and lung cancer morphine is the gold standard for dyspnea so trying to get someone who doesn't understand that, doesn't have that liberality of thought that a hospice nurse would have to treat dyspnea with free amounts of morphine... I mean if you're at a certain point in your disease, that's what you need...trying to get that across to a physician that's a huge block...

Rebecca describes a slightly different attitude barrier, that nurses are not taken seriously by physicians which leads to problems communicating important assessment findings and delays in treatment. She describes caring for a patient with a significant leak from his postoperative wound. The patient had soaking wet linens every four hours and skin break down. This pattern had been occurring for several days with repeated calls to

the physician. Rebecca was finally able to apply an ostomy bag hooked to a Foley catheter to measure the drainage. She evaluates the situation this way:

I felt horrible for him because it didn't make any sense why he'd been laying like this for days...but they eventually took him back to surgery. It took days...but you know it was one of those things too I think...but for him [this particular patient] it took being able to measure, quantify the amount before the surgeon would do anything. I think you had to quantify the amount of drainage he had - say "look, he's had four liters out in the last 24 hours." Do something! Because we were saying 'change dressing, pads wet.' I don't think it clicked in the surgeon's mind how much this man was actually draining. Until you could quantify it into a number and then they were like "Oh crap!" you know "That's crazy!" and then they did something when they could quantify it and see it because I don't think they take nurses seriously a lot of the times...

*System level barriers.* While Rebecca does not describe push back or negative attitudes, she notes the multiple, complex, and seemingly unnecessary steps to obtain portable oxygen, a common and critical therapy for patients with lung cancer:

... making sure they're getting their oxygen...fight'n for oxygen which is crazy but...most of my patients were Medicare patients so...they're carrying around that huge oxygen tank...to go to the store, or go to the doctor's office and trying to get them the portable tanks the... little...concentrator so that they could go to the store without carrying that heavy tank...'cause a lot of em are in a walker and carrying a tank and they can't do it...they cannot do it and...it's heart breaking...and you would not believe the hoops you have to jump through to get them a concentrator. She goes on to describe the hoops: ...you would have to get the doctor, the doctor has to fill out all this paperwork they have to have pulmonary function tests, they have to have... go through PT to get evaluated to be able to get a portable concentrator.

Then she describes the reason for the hoops:

...the insurance won't pay for the... small regulator, the small concentrator. The home ones they'll do but not the portable...It's awful I've, I've spent a lot of time trying to get those things taken care of trying to get the pulmonary function tests and the PT evaluation and stuff 'cause they... I mean truly they cannot walk with

a walker and manage an oxygen tank, you can't do it. I mean it's hard for us to do it while we're walking patients can you imagine trying to do it by yourself. She goes on to describe the process but it's getting there 'cause it's not like the doctor signing orders for a concentrator they have to write pretty much a dissertation why this patient needs it...so much work for them that you can see why they're hesitant to do it for everybody...because it's a whole lot more work... they have to write up why, and that's why they need the pulmonary function and they need physical therapy to say they can't carry around that oxygen tank and so everybody has to sign off on it. But they're agreeable they just - it's a pain in the butt...they make it hard.

Rebecca describes a situation where the patient, with the advocacy efforts of the nurse, has to prove a certain level of diminished physical and pulmonary capacity in order to obtain a critical therapy that will also allow them to participate in their care, travel to doctor's appointments, and perform activities of daily living, such as going to the store.

Tracy recalls a long-term struggle with system level barriers when trying to coordinate a multidisciplinary clinic for patients with lung cancer. In order to have a successful clinic, everyone needs to be present, however:

...my surgeons sometimes will... not come to clinic when they have patients because they either have an emergency or whatever...and there's no backup plan. And I have begged for a backup plan for...five years? So...and...I'm just kind over them not having a plan so I went to my manger and I was like...we need to kind of have higher up management talk to these guys and...we all need to come together and have a plan.

She continues by explaining the impact on the patient when physicians do not attend:

And when they [the surgeons] don't come it...does kind of mess up and kinda spoil the plan...the patients are already stressed out enough, they don't need to be

called to rearrange an appointment they're like 'Ahhhh! I wanted to come and talk to a doctor and see what this is in my chest!' [speaking as a patient under stress]

In her follow-up interview she says that when the surgeon attends the clinic they can provide input about whether a surgical intervention can be done. When the patient only sees the oncologist and not the surgeon: "*if we had not had the multi-disciplinary clinic, if he had just gone to see the oncologist, or just seen Radoc...he would've been delayed in his care. And that would have been horrible for him.*" She ultimately attributes the difficulty in organizing this clinic to "*...the mechanics and logistics don't work as well as they do at these other places.*".

***Relationship to theory, structural discrimination.*** When nurses spoke of jumping through hoops to care for their patients they frequently mentioned that they did so from a disadvantaged status. In Link and Phelan's (2001) framework for stigma, structural discrimination is posited to have negative consequences for those who have a disease that carries stigma, yet the people who advocate for them often work in the same system that has the discriminatory practices. Tracy offers a direct account of this issue:

... I think the adequacy of staffing is poor...um...obviously they're trying to get away with... throwing as much... on a nurse as possible...when in...in reality, I mean nursing is not medicine. We work together because we understand the same language, but we have our own science, we have our own... protocols and guidelines...and they have theirs. I think that the miscommunication with the physicians and nurses, it's a hierarchy and if you're not okay with being down here, when you're getting orders... then you're gonna buck the doc or buck the physician's assistant...that's not gonna go well, well it's not gonna go well for the patient, that's really at the bottom line...I think an emphasis on... nursing is important...our things that we provide for our patients...I don't think that that's really utilized and...I'm sad about that...I don't like the fact that we are kind of...dismissed...

This miscommunication echoes Jenny's account of a physician shifting the focus of care away from the patient to the nurse when she called for pain medication. Tracy also describes the issue of the lack of emphasis on nursing as a current problem that has not been resolved, however, she also does not propose a solution to this issue. Rebecca provides a similar description of nurses intervening on behalf of patients from a disadvantaged status:

...and nurses do get the short end of the stick because you can tell a doctor umpteen times what's going on and they don't see it. Unless they walk in and actually see it you know they don't understand. So, nurses kind of get the short end of that a lot of times but that's the way of the world.

Nurses, in this description, have acquired a stereotyped label as a group that should not be taken seriously. The consequences of this stereotype are that nurses repeat themselves and are not heard until they translate what they are saying into something the physician can understand. Rebecca indicates that this stereotype and the subsequent disadvantaged status has become "taken for granted as being just the way things are" (Link & Phelan, 2001, p. 367) or "*the way of the world*".

**Securing the journey.** The fourth theme is securing the journey. One participant referred to lung cancer as a journey directly, however, other words and descriptions were used that alluded to this concept such as "*leading down a path*", "*next steps*" and "*where they are in the process*". There were also descriptions of how nurses tried to ensure the best trajectory for their patients by providing education, empowerment, and support beyond their prescribed roles, and they were always looking beyond their own care encounters to what the patient would need next or long term.

Participants cared for patients with lung cancer in different settings and at different times along their cancer journey. While the setting that they worked in and the roles they performed within these settings informed the ways they approached providing quality care and helping patients achieve quality of life, they often desired connections beyond what was prescribed by their practice setting and worried about patients being lost in the health care system. All of the nurses interviewed saw patients with lung cancer as a particularly vulnerable group that needed a unique kind of connection, care, and empathy. Patients occupied their thoughts outside of their care settings when they problem-solved ways to improve difficult patient care situations, and when they worked to maintain connections with patients. The narrative segments that describe additional ways in which they formed deeper connections with patients draw in the recipients of these narratives in a way that magnifies the importance of what they did, what they thought, and how they felt about it. Subthemes for securing the journey are progressing, following, connecting, challenges to connecting, and challenges in the journey.

***Progressing.*** In the acute care setting, Jenny and Rebecca repeatedly mention the importance of progressing patients so that when they return home they can “...*start living the way or as close to the way they could before they came in the hospital that’s, that’s the best scenario.*” Rebecca frequently commented on aspects of acute care, including progression, that were “hands on” which was more gratifying than educating patients over the phone:

...when you’re working in acute setting... you can do the dressing change, you can do the incentive spirometer, you can walk ‘em, you can talk to ‘em, but in case management you’re just educating... and you hang up the phone.

**Following.** Sylvia and Rebecca both reflected on why following patients with lung cancer is so important, however Sylvia indicated that patients can be lost to follow-up from inability of the health care system to keep track of patients because of the potential for self-blame among patients who smoke. She explains these two issues:

I do remember another home care patient...just this really salty lady and we hit it off...she came on the service with lung cancer and when I read her files she had been lost to follow up and this was in the probably gosh 80s or 90s and maybe it's not as easy to get lost any more...in some ways I see it as even more likely... it's like with the more information we have the less...people actually do follow up, but I remember just being broken hearted because by the time they did catch up with her again she had metastatic disease and she had been diagnosed as just a spot...I don't know how much that is still an issue but...following people or maybe more aggressive [screening]...and then if they do have an earlier stage identified... that they do have a way to keep tabs on people...because...I don't think it's a stretch to say...if someone has such an unhealthy behavior it may be easier without a follow up to say well I deserve this and I did this to myself...

Rebecca also talked about the importance of following patients to make sure they have the right resources when they leave the acute care setting, however her perspective comes from working in acute care and case management and realizing that some patients struggle with basic disease self-management like taking medications, which can lead to them acquiring the label 'noncompliant'.

I think it [case management] gives me an appreciation for what these people are coming from... 'cause they come into the hospital and...we say noncompliance and yeah it's noncompliance but it's not really because they don't want to it's because they can't and I think it gives a whole new perception of let's find out what they need for when they go home. And again...yes that falls on nurses but I think hospital case managers, they need to be right there following these people and finding out what happened that they came into the hospital, what can we do to keep you from coming back.

**Relationship to theory.** Rebecca mentions that patients can acquire the label “*noncompliant*”. She also talks about the implied negative stereotype associated with it “*they don’t want to.*” While she does not explicitly say that patients are not followed because of this label, she hints at the risk that the label implies for being able, as a health care professional, to understand and continue to anticipate the needs of the patient.

**Connecting.** Connecting means being involved with the patient’s care beyond and at a deeper level than the initial professional encounter. Re-connecting with patients after acute care encounters allowed nurses to witness patients as people in a different part of their cancer journey, that of healing and improving. Equally important was hearing from patients again which allowed nurses to feel like they had made an impact and to know that the patient and family were doing well. When patients returned to the acute care setting to see the nursing staff this was a positive experience as Jenny describes “*Seeing patients that come back and say “Oh OK I just celebrated my six-month anniversary...had my follow up chest CT and I’m good and...I’ve gained weight!” and it’s yeah, it’s amazing.*”

Rebecca offers a description that is at the core of the connecting subtheme:

... the most positive thing for me is hearing from them again. Seeing them... making sure they’re OK or being able to connect with them after they leave me in some form or fashion... ‘cause I think it...for nurses, it lets nurses know you impacted somebody’s life you didn’t just do your shift and keep ‘em alive until 7:05...you did more than that...you’ve made a difference and I think for nurses that goes a long way...especially... in the hospital when you just...do so much and you feel so much and you’re just trying to get it all done.

This is particularly important for Rebecca because in her description of how nursing has changed she recalls that she went from believing she was going to “*change the world*” to “...*putt’n a Band-Aid on a lot of people and...you give ‘em education and pat ‘em on their back and send ‘em out...*” For Rebecca, connecting also meant being physically close to patients with lung cancer in order to make an impact because the beginning of their trajectory, diagnosis, is a very emotional time for them:

They just wanna know if they’re gonna live. You know so I think it’s...different I think you just need to listen to them and hold their hand and you know sit down, I mean, and I think that’s a lost art, you know... sit on the bed with ‘em listen to them talk and I do that, I still do that... I’ll sit down...sit in the chair, sit in the bed and listen to them and I think that’s more important than anything else you can do. I just listen to them and let them talk and let them cry, and you know ask them what they’re thinking about doing because that way it empowers them to know what they wanna do, to have a plan and kinda start going that way.

Tracy echoes the emphasis on physical connection and listening:

I’m probably... more sympathetic than empathetic – I mean... I did have somebody who had lung cancer in my family but...I truly feel like they need...an ear, they need to vent, they need just to know somebody’s there... I can give them my card and they can call me directly. And that is a connection and they latch onto that...and I’m the one that gives the hugs. I had a patient bring in her mom and her sister, I hadn’t met them yet. And I saw her, and I just adore this woman, she’s been through a lot. I came up and gave her a hug, she goes “oh my hug” and she introduced me she’s like ‘mom the lady that gives me the hug every time I come!’ I’m like that’s me, totally that’s me. Um...You know, I try to encourage them, I’m their cheerleader...but yet I try to be as honest as I can and...you know say yeah... that’s probably gonna happen next.

However, as Rebecca and Tracy both assert, there is a wrong way to connect with patients and that is by sharing a story of someone you know who survived lung cancer and by saying you know how the patient feels:

I do know people who tell stories... 'well my grandmama had...' and I just think that is so the wrong way to go 'cause they don't care...they only care about what's happening right now to them, and they don't wanna hear that your grandmama lived.

Tracy says about this issue:

...I don't think they want to hear that, I think they just want the support... saying to somebody I know what you're going through... um...I don't think they wanna hear that. I know I don't think I would wanna hear somebody say that to me. No, you don't know what I'm going through. I just wanna support you and encourage you to make the best decision for you. And it may not be chemo, it may be palliative. Let's make you comfortable. You know, what are your goals? What do you want to do with your... six months?

*Challenges to connecting.* For Sylvia and Tracy, securing the patient's journey included palliative and end of life care and planning. This made connecting a psycho-emotional challenge because they were aware of a poor prognosis while engaging with a hopeful patient, an emotionally stressful experience as Sylvia describes:

I do have a homecare patient right now and...she was sharing how she had just stopped smoking she has got a head and neck and...lung cancer diagnosis...but she had told me that she had smoked and drank heavily and she had quit and she was going to church and... but because of smoking and the drinking she had gotten head and neck...she had an ostomy, a trach that was capped, and a G-tube because she can't eat enough... but she's doing immunotherapy and she's very upbeat about her chances, however it is metastatic and... I read her chart...and the immunotherapy that she's taking isn't making a difference, she thinks it is but it's not, she feels better and... a lot of it is probably placebo which is fine... but she's getting out and is more upbeat, but I know it's not gonna end well and it's just really hard to sit there and... just try to be where she is right now and encourage her and say that's great and what do you wanna do she just went to the beach with her friends you know and how was that but I know when I see her again... it's gonna be not in a great place and that's just you know sadly so many that you're gonna see at these stages and I think my [family member] the [profession] that smokes you know she'll say she has the same experience with her patients that

come in at different points and you know so I think that's a hard thing to know you're gonna see that.

Tracy offers a sharp juxtaposition of the challenges of caring for patients with a serious and terminal illness by saying that it is *"nice but it's also very hard."*

... the oncology part it's, it's nice but...it's also very hard because lung cancer patients die. I mean... they do... and you get a bond with them, you get a bond with their family and then when they start to... not do well the family is panicking...the patient is panicking, you're panicking...and there's just not a lot of hope that you can give and you've gotta transition 'em to... palliative and hospice care and... I mean that's so stressful for everybody and then you're getting calls from Uncle Bob who lives in New York and you know, Aunt Sally in Texas and trying to educate and you know and talk about next steps and... they're like 'you're giving up' [speaking as the patient] some of 'em are like, you're giving up or some of 'em are like pfft it's my time, it's, I can't do this anymore kinda thing so it, this part is you get a little, a little bit more of attachment with these patients and...it's you know it's just hard to see them not do well...

Coping mechanisms were used that helped nurses maintain connections when they witnessed psychological and emotional stress among their patients as Anne explains: *"...I don't want to say later you get cold to it, but you have to... you have to kinda buck up and... be strong for them."*

***Challenges in the journey.*** Lung cancer is a disease that presented significant challenges to the resources of patients and their families. The main tangible resources included money, transportation, and physical energy. The less tangible resources included abilities to cope with psychological, social, and emotional stressors. Participants describe patients experiencing: *"financial devastation"* related to treatment costs and being *"scared they can't afford everything...transportation that sort of thing"*.

At times these costs lead to interruptions in care as Tracy explains “*I’ve had one to stop treatment, with immunotherapy, it still works... for a while after you stop so one patient stopped actually for a while...got scans...I think for about six months stopped, just financially couldn’t do it anymore.*”

Patients also had difficulties overcoming the shock of their diagnosis, and emotional turmoil during treatment related to uncertainty about their trajectory and about their caregivers. Anne describes talking with patients and their caregivers:

their primary care giver... it’s really amazing the husbands and/or wives that come in with...the patient and they’re trying to be all positive and... say how he felt today, or how he didn’t feel so good today and... their prognosis is really kind of bad but they’re trying to be so upbeat, and they look so worn out...and...you just gotta feel for ‘em. Yeah, you gotta feel for ‘em...physically, you can look at ‘em...tearful sometimes... like I said, just their physical, emotional appearance...even the patient will comment, he or she is just working themselves to death, she needs help, I know I’m being a burden...

Patients experienced different emotional challenges based on their smoking status and their age. Jenny recalls a frequent saying among her patients who smoke “*I wish I would have never started*” yet she also expresses a juxtaposition regarding smoking behavior and a lung cancer diagnosis: “*I think a lot of people...tend to think ‘oh well this just happened all of a sudden’ you know, when how many ever years they’ve put themselves at risk...*” she continues by contrasting people who never smoked with people who do:

...people who never smoked I think have a little bit harder time with it, with answering the why because then you have other people who have seen all the ads and know they’ve smoked however long in their lifetime and well here we are you know it kinda it almost seems like it’s in the back of their minds but they still have this thing that they’re doing that they don’t need to be doing...um... it’s a –

I hate to say almost expected but...more than expected than someone that never smoked.

Tracy recalls a female patient who spent a long time trying to find the cause of her cancer, but she starts with a common perception among her patients: *Oh! I mean you... you only get lung cancer if you smoke, right? Right, that's what they're thinking.*

She goes on to talk about the reaction of her patients who have never smoked:

...but they are completely shocked. And... it takes a while for them to digest it. And the questions that they have – I mean they're very angry...a lot of mine that are diagnosed with lung cancer are like “well I did it to myself” I'm like “well...let's not blame ourselves but...you gotta quit smoking. This is why you got lung cancer. And the...ones that never smoked are like, “what did I do wrong?”

She continues by talking about the struggles of a specific patient who did not smoke:

You know, one of them actually said that to me, ‘what did I do wrong?’ And she tested her house for radon...and she did all these things and...she's like - it took her, it took her like a year to really be like... “OK”. She's like – she just kept on blaming herself – ‘what did I do wrong, what did I do wrong?’ And I was like, you didn't do anything wrong. It's just a bad, nasty cancer.

This, Tracy explains, is a frustrating experience for both her and the patient.

**Structural analysis.** Tracy alternates between the perceptions of people who smoke and have lung cancer “*well I did it to myself*” and those who never smoked “*what did I do wrong?*”, “*shocked*”, and “*angry*”. These two types of patient are in a virtual side by side position as she explains the different reactions to a lung cancer diagnosis, yet she provides a story about a woman who never smoked and her search for the cause of her diagnosis, while the brief description of the person who smoked indicates that this

person already has their answer to the question “*what did I do wrong?*” Tracy’s response to this question involves personifying lung cancer “*it’s just a bad, nasty cancer*”.

***Relationship to theory.*** Tracy talks about psychological consequences of her patients with lung cancer who smoke and who never smoked. While she does not mention the ongoing consequences of self-blame for patients who smoke, her efforts to counteract their self-blame and refocus the issue to smoking cessation indicates that she does not think self-blame is a productive line of thinking. Her narrative of the patient who was diagnosed with lung cancer and who never smoked illustrates the negative effects that a label and associated negative stereotypes: “*I mean you... you only get lung cancer if you smoke, right? Right, that’s what they’re thinking*” and “*...but they are completely shocked. And... it takes a while for them to digest it. And the questions that they have – I mean they’re very angry...*” have on people with a disease, lung cancer, that carries a stigma self-inflicted, and a “*bad, nasty cancer*”.

Older patients seemed to take their diagnosis “*in their stride*” and were on more of an “*even keel*”. Younger patients had unique struggles according to all participants because they had kids, and were “*not ready*”. Anne talks about the emotions of her younger patients:

They’re just stressed...it’s so much their life now...it’s every day...insurance, what they’re not paying... you know, “I’m worried I can’t get this medicine, they’re not paying this, I’ve gotta work with them - the doctors are working with me to get it, but if I don’t get it...I’m wondering how long will I last?” It is so much, they’re just...they’re thinking about it all the time, they’re asking questions about it all the time... it’s question after question after question - not that they don’t still do this over with the navigators, with the oncologist the radiologist... their radiology/oncologist. But it’s forever on their mind. Worrying about their families...

Various forms of support were mentioned as important during the patient's journey such as family support, financial support, and support groups. Family support could be beneficial and problematic when they dominated or contrasted with the goals of the patient. Nurses worked to fill the gaps in support as Anne, Tracy, and Jenny describe. Anne notes that even when patients block support initially, it is important to check on them later: *And that happens sometimes... they don't want to hear it, they've heard it before...they know it's not gonna get 'em anywhere, they know the ending is gonna still be the same...* She goes on to explain how she responds: *"...sometimes I even say I'm gonna – and I do, that I'm gonna give you a call later, in a couple - few days, check on you...and I do."* Tracy says: *"I help them fill out SCAT applications to get here, Medicaid, transportation I'm always on the phone calling to get help for these patients."* Jenny describes how her unit pitched in to help a patient and her family:

I guess she was like in her 70s, 60s, 70s and had complicated lung cancer she was keeping her two grandchildren her husband was out of work so they were the sole responsibility of their grandkids, he was out of work so like the unit got together, we fund raised we got them a thanksgiving dinner, Christmas dinner, toys I mean...and that's all from...our hearts to them so we do a very good job at that... going above and beyond.

Similar to Anne's observations about patients being emotionally distressed enough to shut down and block support, Tracy notes the struggles she has had organizing a support group for patients with lung cancer, something she notes is key to their journey:

...there's support groups that are out there but my patient population just doesn't go. We have worded it differently, we have...reached out... and we are just so unsuccessful in getting a support group for those patients 'cause they don't want it.

While she believes that this is because their various invasive therapies leave them exhausted, solutions to poor attendance focused on offering support through smoking cessation or one on one support. Other cancer diagnoses do not have this same issue:

Like prostate... they've got a great group. GI...they have a great group. Breast cancer, has like five groups... the young... the old... the you know, I mean they have...you know a ton. Which is great but...we even have like we call like 'living with cancer', which would be basically my patient population. And not interested in that. We have...worded kind of funny to try to get our patients in. I can't even remember what that group is called, but... they're absolutely not interested. There's flyers everywhere, we send them out... when it's lung cancer awareness month, which is November, you know we are just trying to push this information. And I think that they don't understand that. This is a journey. And really, we're here to support you and your family.

Other support that participants thought patients with lung cancer needed was similar support and public recognition as breast cancer, represented in Table 3, more integrated cancer care early in their diagnosis, and more timely education about their diagnosis.

Table 3

## Relationship of Sections of Transcript to Stigma Theory

Sections of Transcripts	Theoretical Concept
<i>“smoker”, and “addict” “noncompliant” “cause and effect” disease [lung cancer]</i>	Labels/Labeling (Link & Phelan, 2001)
<i>“dumb” [person who smokes] “filth” [cigarettes] “stupid” [people who smoke in front of patients]</i>	Stereotyping (Link & Phelan, 2001)
<i>“I would say for the most part is...the component of realizing that you did have a hand in it some remorsefulness there aren’t many other cancers that are that cause and effect...”</i>	Separation “us” versus “them” (Link & Phelan, 2001)
<i>“...I mean...I guess maybe it’s...sometimes you think...I mean you don’t want to say you did this to yourself but... because there’s different circumstances but...I mean you think that.” “... I mean it’s always this thing about breast cancer, breast cancer, breast cancer. And that’s fine ...but it’s never that much about lung cancer.”</i>	Status Loss (Link & Phelan, 2001)
<i>“there is a piece missing that should...be looked at in the fact that...how easy accessible it is. Yes, there’s labels and this kinda stuff, whose gonna read a label?”</i>	Structural Discrimination (Link & Phelan, 2001)
<i>“...you can’t blame people, people can’t blame themselves. We all make poor decisions. We all make decisions that are gonna affect our health later on um...and I think as a nurse taking care of those patients you just have to...look beyond that and meet their patient wherever they are...”</i>	“Wise” Thoughts
<i>“...they would give anybody anything, especially my dad’s mom...she would give the shirt off her back to a stranger...and she smoked all her life, from the time she was like eleven... and just the path that it led her down... it didn’t mean she was a bad person, it just meant she made some bad choices”</i>	“Wise” Experience and “Wise” Logic
<i>“...I’ll say things like you know I’ve never smoked but I understand it’s very hard to give up...”</i>	“Wise” Actions (Goffman, 1963)

Table 3 summarizes the relationship of what participants said to the different concepts in one of the two stigma theories discussed in Chapter Two. The concepts presented in the table are labeling, stereotyping, separation, structural discrimination, and the “Wise”. The first row shows examples of labels that are associated with people who smoke, people who have an addiction, and people with lung cancer or the disease lung cancer. These labels overlap with the concept of stereotyping because “addict” is both a label that matters socially and is a cognitively expedient way to describe a person who has an addiction, yet it also summarizes their identity in a negative way. The second row provides examples from the transcripts of participants responses to the free association questions at the beginning of the interview and other stereotypes that were mentioned throughout the interview. The word “dumb” for example, is a negative stereotype that is imputed from knowing that people still smoke in the presence of widely known health risks. The third row provides an example of how patients with lung cancer are separated and distinguished from other cancers as the “cause and effect” cancer. This separation also contributes to status loss or a “*you did this to yourself*” type of cancer, and less comparative public support than breast cancer. Structural discrimination is represented by the neglect that participants noted with regard to adequately addressing and treating smoking addiction or nicotine addiction either among people who smoke in general or people with lung cancer who smoke. The last three rows of the table represent the thoughts, experience, logic, and actions of participants considered to be components of “Wise” persons who have intimate knowledge of persons with a stigmatized disease and show empathy and help to counteract stigma.

## **Summary**

The purpose of this study was to understand the experiences of nurses who care for patients with lung cancer and how these experiences relate to the stigma associated with lung cancer. The four themes were: addiction in action, cancer of a functioning organ, jumping through hoops, and securing the journey. Smoking addiction was an issue among patients with lung cancer that nurses struggled with and was both a stigmatized label and used to understand the irrational behaviors that nurses witnessed among their patients. Other struggles included attitude and system level barriers that became “hoops” that nurses had to jump through, from a disadvantaged status. The pulmonary issues associated with having lung cancer was a repeated concern and differentiated lung cancer from other types of cancer. Lung cancer was referred to as a journey in which patients experienced financial and psychological stress. Nurses helped patients during their journey by mobilizing support and resources, and initiating and maintaining strong connections, which at times was challenging.

## **CHAPTER V**

### **DISCUSSION**

The purpose of this study was to explore the experiences of nurses who had at least six months of cumulative experience caring for patients with lung cancer, had been registered nurses for at least two years, and who were practicing in the Southeastern United States. A secondary aim of this study was to explore how these experiences are related to the stigma associated with lung cancer. This chapter is organized by the themes in Chapter Four: addiction in action, cancer of a functioning organ, jumping through hoops, and securing the journey. Within the discussion of each theme will be recommendations for nursing practice or future research.

#### **Addiction in Action**

Smoking, in this study, was described both as an addiction and as an implied behavioral choice. Addiction was described as involuntary and something that yielded deceit, such as when patients denied smoking when there were signs that they were smoking. Smoking cessation was perceived to have very low success rates and be a challenge when patients said things about smoking like "*I love it*". This study provides additional context surrounding the empathy toward people who smoke that stems from knowing that it is an addiction; yet the nurses did not fully understand addiction. Nurses in this study have dealt with smoking addiction multiple times in their careers and in their families. So, while they have empathy, they still struggle with their patients' smoking

addictions, particularly because as nurses they are strongly invested in the health and well-being of their patients. Other than frustration and shock at the smoking behaviors of their patients, it is unknown what the long-term effects are for the nurse regarding this repeated cycle of frustration and shock for caring for patients with smoking addiction; potentially, this can wear away at empathy and lead to burnout. Burnout might be exacerbated if the nurse is not educated in effective evidence-based smoking cessation or if there is no evidenced-based framework within the work setting that can be applied to the care of the patient with lung cancer who has smoking addiction.

Additionally, nurses' descriptions of smoking and smoking addiction revealed a lack of full understanding of addiction as a chronic disease that requires multiple interventions and follow-up by health care professionals. Nurses spoke of smoking as a habit that could be voluntarily stopped, and often did not acknowledge the likelihood of multiple relapses before a lasting quit attempt. This can lead to frustration for nurses in trying to help patients quit and may result in perceiving the problem to be unsolvable. Nurses had a fragmented understanding of smoking addiction that contributed to their difficulties in witnessing smoking behaviors, and frustration with effectively addressing smoking cessation. This fragmented understanding allows for the continuation of extant negative stereotypes and labels in the health care setting. For example, the stereotypes that a person who smokes or the act of smoking is "dumb," and that smoking is a "choice," highlights a gap in understanding that addiction is a chronic disease where addictive substances "...hijack brain circuits that exert considerable dominance over rational thought, leading to progressive loss of control over drug intake in the face of

medical, interpersonal, occupational and legal hazards” (Dackis & O’Brien, 2005, p. 1431).

Research on the neurobiology and pathology of addiction indicates that the person has very little control or “choice” regarding the behaviors surrounding the addiction. Labeling certain health behaviors to be a “choice” might be a way of coping for nurses because it indicates a certain level of control over oneself, and places the majority of responsibility for health maintenance on patients. This is not to say that patients have no responsibility for their health, but that too much responsibility may be placed on them too early in their disease trajectory. There was no mention, by participants, of what they did to address ambivalence about quitting or patients in the precontemplation stage of change; although they described interacting with patients in these stages of change. Nurses should also have simulation practice and training in not only the five As of smoking cessation (ask, advise, assess, assist, arrange follow-up) but the five Rs (relevance, risks rewards, roadblocks, repetition) which are used when a patient is not interested in quitting (Fiore et al., 2008). The five Rs are based on the principles of motivational interviewing (MI) which can help health care professionals who are performing smoking cessation to “roll with resistance” (Fiore et al., 2008, p. 57).

Education about addiction would help nurses to not frame smoking behaviors as a choice but as an addiction, and addiction as a chronic disease. The chronicity of addiction means that the judgment of people who have it, with regard to safety and their own health, can be overridden repeatedly by the pathways in the brain that support continued and regular use of the substance. Therefore, nurses should expect to have to

reemphasize safety issues with patients frequently and firmly. They will also need the full support of their practice areas in maintaining a culture of safety for their patients, themselves, and the patient's family. Participants expressed dissatisfaction with current policies to deter smoking such as smoke-free areas around buildings and warning labels on packages, indicating that they see a need for change. Having comprehensive knowledge of smoking addiction in addition to a desire for better deterrents from obtaining cigarettes and better treatment for addiction would also allow nurses to be more effective advocates for increased support for smoking cessation for patients both in their practice areas and with regard to local, state, and national policies.

Participants described the care they gave as episodic because it occurred during a shift or during a home or office visit. Care that is designed around brief encounters can generate frustration when addressing a chronic and intractable health issue like smoking addiction. During these brief encounters, where there is limited time to make an impact or do an intervention, nurses and other health care professionals may be disappointed when they do not see immediate results such as they might when they perform other more specific tasks like changing a dressing or ambulating a patient. Participants also described the acts of being able to "fix" and have resolutions to patient problems as important to them. If patients express ambivalence or lack of readiness regarding smoking cessation, part of their care can appear to be an open-ended issue with no foreseeable resolution, and a potentially disappointing experience for nurses, particularly if they have no evidenced-based framework to apply to these issues.

This study revealed that it is possible to know stereotypes of people who smoke and smoking-related illnesses and also have empathy, and that stereotypes or judgements do not necessarily translate into action. However, “wise” people who are also “normals”, or people who do not smoke and do not have cancer, had expectations of their patients that included not smoking in their presence or while receiving treatment. However, nurses’ encounters with patients who smoke while receiving treatment or lying about smoking reveals that it is not the people they are frustrated with, but the more troubling behaviors that are associated with smoking addiction.

Nurses, although sympathetic, encountered difficulty with not viewing lung cancer as a self-inflicted “*you did this to yourself*” disease and smoking as a “*habit*” that if a person “*knew better*” they would not do it, a “*choice*”, and a “*dumb*” behavior. This finding is somewhat similar to a cross-sectional study of nurses in China which revealed that nurses assigned more blame to lung cancer than any other cancer, but less blame than they assigned to obesity (Wang et al., 2015). One nurse in this study remarked that HIV/AIDS is more stigmatized than lung cancer; something she witnessed while working because people, family and staff, were afraid to touch people with this disease. Several nurses in this study compared different addiction behaviors like food addiction, alcohol addiction, and illegal substance addiction with smoking addiction but they generally did not offer comparisons on stigmatized diseases. However, knowing that smoking is an addiction is supported in another study to be associated with more empathy toward people who smoke (McCool et al., 2013).

Although nurses in this study had stigma-related thoughts but did not describe stigma-related actions, education surrounding stigmatized diseases and the impacts they have on the patients who have them would help nurses re-frame their thinking toward what the patient is saying and experiencing, and away from common negative stereotypes and labels. Although it is not explicitly hypothesized in either Goffman's or Link and Phelan's stigma theory, in order to advocate for people with stigmatized diseases the "wise" or any advocate would need to have comprehensive knowledge of the processes of stigma. More research is needed on an organizing framework to help nurses assess and intervene with patients who have lung cancer who experience self-stigma or perceived stigma.

In addition, all health care professionals would benefit from in-person dialogue with patients, in a small group educational setting, that would allow the patient to describe their struggles, what it is like to be a patient, and the negative and positive impact that health care professionals have on patient experiences. This experience could also include a reflection exercise and discussion about ways to improve care for patients. Stigma researchers have proposed using a continuum model to approach reduction of stigma related attitudes (Schomerus et al., 2014) by thinking of oneself as a person somewhere on a wellness-illness continuum, that everyone will be closer to the illness end of the continuum at some point and that everyone has unhealthy habits.

A smoking related illness may be considered by health care professionals to be a "wake-up" call that can provide most of the motivation for smoking cessation for all patients who smoke. A cancer diagnosis, however, is not maximized as a "teachable

moment” by health care professionals, often because they do not know how to use effective smoking cessation interventions (Gritz et al., 2006). Health care professionals, according to this study, may believe that the diagnosis of lung cancer is enough of a wake-up call and continued motivational stimulus for the patient and their family, and does not necessitate additional or advanced interventions. Moreover, a perceived lack of interest from the patient may deter the practitioner or nurse from further engagement with the patient on smoking cessation.

At times, the perspectives of clinicians regarding smoking cessation interventions for patients were described by nurses as being in conflict with current evidence-based guidelines. This conflict stemmed from the belief that nicotine withdrawal and cravings are short term and that nicotine replacement therapy (NRT) only prolonged the problems with withdrawal. These discrepancies can confuse the patient, since they may receive conflicting education from different clinicians which undermines smoking cessation interventions, leading patients to conclude, as one participant observed, that they are “*left to their own devices*” for quitting smoking. Chart audits are a potentially useful way to evaluate adherence to clinical procedures and protocols. Low adherence can be addressed through online educational modules or one-on- one coaching.

Participants acknowledged negative stereotypes linked to smoking such as “*filth*”, and to smokers such as “*blue collar*” and “*uneducated*”; the negativity of these stereotypes were attenuated by saying “*I know it’s an addiction*”. Nurses may care for patients with smoking addiction who have low SES and low education attainment, but may not realize that smoking is potentially higher in this group because efforts to

denormalize and reduce smoking did not reach all demographics to the same degree (Garrett, Dube, Babb, & McAfee, 2015; Graham, 2012). Key aspects of decreased smoking prevalence such as public, workplace, and household smoking bans and absence of tobacco company advertising may be less readily adopted and enforced in low SES communities (Garret et al., 2015). People in these communities can experience more financial stress and have less access to adequate smoking cessation services, making quitting more difficult (Centers for Disease Control and Prevention, 2015; Garret et al., 2015). Indoor smoking bans may not be as prevalent in low SES households as they are in higher SES ones (King, Hyland, Borland, McNeill, & Cummings, 2011) or in places where individuals with low SES work like casinos (Centers for Disease Control and Prevention, 2015).

Although smoking prevalence has declined overall, there are still high smoking rates among people who have low income and low education attainment, mental illness, and among certain ethnic minorities like American Indians and Alaska Natives (AI/AN) (Jamal et al., 2015). These demographics are also potential stigmatized statuses described by Conlon et al. (2010) as “stacked stigmas” or “co-occurring stigmas that can be linked to the primary stigma event” (p. 100). Education about stacked stigmas and the impact of smoking denormalization on different demographic groups would help nurses and all health care professionals counteract negative stereotypes within themselves and those that are expressed in the workplace and in their communities. All health care professionals should learn about the social determinants of health that contribute to smoking initiation

and addiction, to better understand the diverse needs and circumstances of the communities they serve.

Smoking cessation for these groups may also be a unique challenge because they may come from micro communities where smoking is considered normal. One participant recalled that different generations in the same family were observed to have smoking addiction and develop lung cancer. Nurses who work in home health may go to these communities to care for people and encounter dangerous situations, such as a patient smoking while on oxygen or other people in the household smoking near oxygen, whereas nurses in acute care may have less exposure to smoking near oxygen due to a highly regulated environment. Smoking was viewed not only as detrimental to health but as capable of threatening the safety of the patient, the patient's family, and health care professionals. Thus far in the literature, smoking addiction and people who smoke have not been labeled and stereotyped as dangerous, like people with mental illness (Link & Phelan, 2001). Extant theories of stigma and attribution support that danger or "peril" (Jones, 1998, p.65) are stereotypes associated with some stigmatized conditions, and the threat of harm they contain contributes to negative identities, isolation, and negative emotions and actions on the part of "normals" (Jones, 1988, Weiner, 2006). Smoking behavior presented uncertainty for nurses with regard to safety. People who smoked were expected to have smoking addiction, but not to let that addiction threaten the safety of others.

Participants remarked on how ineffectual the current policies of banning smoking in certain areas and warning labels on cigarettes are at deterring smoking in the absence

of recognition and proper treatment of smoking addiction. These policies stem largely from influential groups of nonsmokers who saw second-hand smoke as a threat to the general public and assigned people who smoke the label of dangerous. While this strategy has decreased smoking prevalence, it has been at the cost of further marginalizing already vulnerable groups.

Part of the evidence-based guidelines for tobacco cessation includes follow-up with patients who are planning to quit and supporting them through the cessation process. This may be somewhat unrealistic for clinicians, however, one participant observed that patients who have a partner have a better success rate in quitting smoking than those who do not. Conceivably, a partner can provide the support and follow-up that bridges the gap in the smoking cessation trajectory, something that is not emphasized in the guidelines. Health care professionals should include the family in smoking cessation, particularly if the patient lives with someone who smokes even if the patient does not smoke, or the reverse.

Although participants spoke about lung cancer in a way that negatively distinguishes it from other cancers, a “you did this to yourself” type of disease, there were no descriptions of actions or intentions toward speaking out against the stigma associated with lung cancer. Very little has been studied about how the wise advocate for the stigmatized, however a recent study using latent class analysis found that the “wise” fall into two categories: active “wise” who endorse challenging stigmatization, and passive “wise”, who do not (Smith, 2012). As “wise” persons, nurses helped to counteract patients’ expressions of self-blame, an active process. However, the literature

and theory still lack clarity as to who initiates challenges to stigma and under what circumstances. Lung cancer patients would likely have difficulty challenging stigmatization if they are (a) too sick to do so and (b) engaging in their own self-blame or self-stigmatization, so they may rely more on the “wise” and other advocates to help enact positive changes to their care.

### **Public Support and Status Loss**

Table 3 in Chapter Four summarizes the relationship of what participants said to the different concepts in one of the two stigma theories discussed in Chapter Two. One participant indicated that there is greater support for breast cancer than lung cancer. Poor awareness and public support for lung cancer is frequently mentioned in studies of patients and clinicians who care for this population (Chapple, 2004; Conlon et al., 2010; Rohan et al., 2016; Tod & Joanne, 2010). Other scholars have attributed this to better survival rates for breast cancer, and other solid tumor cancers, which have allowed patients to engage in their own successful lobbying and advocacy for more funding (Gritz et al., 2007; Gulyin & Youssef, 2010) which “...translated into important budget earmarks and research emphases” (Gritz et al., p. 860).

This has occurred over the last two decades because advocacy groups that lobby for specific diseases to the U.S. Congress have been able to shift the focus from the general public and science being the recipients of the benefits of funding to specific people with the disease, which allowed members of Congress to make judgements and decide the moral worthiness of diseases and the people who have them; stigma became a deciding factor in how money should be spent (Best, 2012). In addition, according to

Best, who studied medical research funding of 53 diseases over 18 years, diseases that had high mortality rates and were associated with deviant behaviors such as liver and lung cancer, received less funding over this time instead of more or the same amount.

Results of the Best (2012) study indicate that poor public support and funding are, in part, due to the stigma associated with lung cancer as a self-inflicted disease. While nurses may think that increasing public support for lung cancer is out of their reach, they can use a stepwise approach to bridging the perceptual barrier between patients with lung cancer and clinicians and the public by starting with the areas in which they practice and their local communities. Patients with lung cancer or families of patients can be invited to various educational meetings of health care professionals to tell their story of what it is like to be a patient and a person with lung cancer. Nurses can be politically active by contacting their local or state representative and telling them about this patient population in a way that is more nuanced and personal than statistical information.

### **Cancer of a Functioning Organ**

Patients with lung cancer have a myriad of distressing symptoms that have been reported in other studies such as pain, cough, dyspnea, and weight loss (Conlon et al., 2010; Hamann et al., 2013). Dyspnea was described as a prominent symptom that interfered with quality of life, and the complexity of multiple symptoms and comorbidities was summarized with the description “*sick*”. The negative impact of symptoms like dyspnea on quality of life has been reported by clinicians in another study (Conlon et al., 2010). When compared to patients with other cancers, patients with lung cancer have been rated by clinicians as having the poorest quality of life and more

distressing symptoms such as weight loss (Hamann et al., 2013). However, when 97 patients with stage IIIb or IV lung cancer in a longitudinal study reported and ranked their own symptoms, moderate or severe dyspnea and fatigue were two of the most frequently reported symptoms which persisted throughout the time they were followed, whereas cough and appetite problems were reported closer to the end of life (LeBlanc et al., 2015). Clinicians may potentially be focused on symptoms or signs that they deem serious, such as weight loss, while the patient and family have different concerns such as dyspnea and fatigue. According to participants who also had the perspective of a family member of someone with lung cancer, family members are also negatively impacted by distressing symptoms such as loud breathing, secretions, and seeing their loved one struggle to breathe. Symptoms were given hierarchical importance, for example, dyspnea was ranked higher than pain.

Lung cancer was observed to be often diagnosed at a late stage, which may mean that more symptoms are present and the disease is more advanced, leading to more aggressive treatments. Cancer care to date has mostly been focused on stopping the progression of the disease, and less on physical symptoms and psychosocial components (Greer, Jackson, Meier, & Temel, 2013). Palliative care is one way to ensure that both physical symptoms and psychosocial problems are addressed while improving quality of life (Greer et al., 2013; Smith et al., 2012). Assessments done by health care professionals should be combined with patient and caregiver or family concerns to drive the plan of care. Palliative care, by a palliative care clinician or a team trained in

palliative care, should be combined with standard oncology treatment early in the patient's trajectory (Greer et al., 2013).

Complexity of care and the sickness of patients was reported to be a stressful aspect of caring for patients with lung cancer. Due to the complexity of care of patients with lung cancer, novice nurses need to be mentored in care of the physical aspects of their care such as tubes, drains, and lines, and in seeing the patient as a person. This can be done in a simulation setting where the patient has a complex plan of care and also sociocultural background information that helps the student or novice nurse to keep the care person-centered instead of task-centered. Post clinical discussion can include how student nurses distinguish the patient "in the chart" from the patient in the room, from the person, who happens to be a patient.

### **Jumping Through Hoops**

Nurses spoke of "hoops" they had to jump through to secure basic therapies for their patients with lung cancer. One such therapy was a portable oxygen compressor that allows the patient to perform activities of daily living such as going to the store or to doctor's appointments. Being able to perform activities of daily living, maintaining independence, sleep, and decreasing fatigue were rated very important or important to maintaining quality of life by 90% of participants in a cross-sectional study of 660 patients with lung cancer (Gralla, Hollen, Msaouel, Davis, & Petersen, 2014). Some of the tests required to obtain a portable oxygen compressor, such as a pulmonary function test, can be difficult or exacerbate fatigue for patients with lung cancer. Not having portable oxygen could further tether them to their home and potentially interfere with

traveling to medical appointments. Removing some of the barriers to accessing important therapies could facilitate the ability of patients to engage in activities of daily living and help maintain their quality of life. However, more research should be done on patients with lung cancer and their caregivers to determine the impact of system level barriers on their quality of life.

Actions that nurses took to care for their patients came from what they perceived to be a disadvantaged status of being “*dismissed*” as nurses and not being taken seriously. The status of nurses in the hierarchy of health care professionals has not been mentioned in the literature on stigma and lung cancer. Further research needs to be done that explores the mechanisms, conflicts, and perceptions that contribute to nurses not being taken seriously, being dismissed, and having to spend additional time and energy refocusing care interventions so that care is delivered to the patient in a timely and safe manner. If nurses perceive themselves to have a disadvantaged status in the healthcare team, or when they experience repeated push back or negative attitudes when they carry out interventions during patient care, they are at risk for burnout and leaving their workplace or even the profession. Moreover, the patient is at risk for poor outcomes if the nurse hesitates or is reluctant to call the physician when orders are needed, or if nurses think they need to design care around the needs of the physician instead of the patient. Case studies of situations similar to what participants described can be developed and reviewed in multidisciplinary educational meetings, conferences, or through online modules that can help clinicians see the potential detrimental impact of negative attitudes and unproductive communication that shifts the focus of care away from the patient.

Leadership training in conflict resolution and listening to understand can provide guidance in these situations. Also, the nurse can reorient any conflict situation back to the goal of care and the patient at the center of the care, particularly when communication starts to become unfocused or unprofessional.

### **Securing the Journey**

The theme of securing the journey revealed the importance of and challenges to connecting with patients with lung cancer and the witnessed challenges that patients faced. Labeling of patients as “noncompliant” was thought to misrepresent patients’ abilities versus their intentions, “*they can’t*” versus “*they don’t want to*”; one being the patients’ actual identity and the other a stereotype of their virtual identity. Saying that patients are noncompliant, according to Huffman (2010), is “...labeling [that] fosters a belief that the individual has refused to cooperate with instructions or guidance” (p. 246). While it was not said explicitly that patients did not receive follow-up from healthcare professionals because of this label, there is an implied risk that the health care professional will be less able to understand and continue to anticipate the needs of the patient because of the stereotype associated with the “noncompliant” label. In a study of student physicians, patients that had addictions that contributed to their illness or who were noncompliant elicited cynical reactions and disrespectful humor (Wear et al., 2006). Labels like “noncompliant” and “needy” require discussion and reflection among health care professionals regarding the potential damage that they do to patient care, because the former label places the entire responsibility of behavior change on the patient, and the

latter requires the patient to behave in a way, “not needy”, that suits the health care environment.

Self-blame was mentioned hypothetically as a psychological barrier to follow-up; this is supported by responses of patients with lung cancer in qualitative studies (Hamann et al., 2014) and as a barrier to diagnosis of lung cancer (Scott et al., 2015). Self-blame and self-stigma has also been reported by clinicians who care for patients with lung cancer (Tran et al., 2015). However, studies to date of lung cancer have not investigated the long-term effects of self-stigma on disease trajectory. A recent longitudinal randomized controlled trial of people with mental illness supported that people who had more self-blame at baseline had greater difficulty coping after one year than people who reported less self-blame (Oxele et al., 2017). Similar longitudinal studies should be done with patients who have lung cancer. Since palliative care is an essential aspect of cancer care, therapies to counteract the negative effects of self-blame and self-stigma as well as feelings of regret, remorse, and shame can be incorporated into the palliative care model.

Nurses reported that patients who do not smoke had a difficult time answering the question of why they have lung cancer, which is consistent with the literature (Conlon et al., 2010; Hamann et al., 2014; Tod & Joanne, 2010). Difficulty with answering the “why” question, in this study, was also attributed to a stereotype that a participant explained as “*you only get lung cancer if you smoked*”. The literature however has not provided long term consequences of this initial difficulty, which a participant in this study described as a protracted process. A person who spends a year trying to find the cause of their cancer may be distracted from engaging in disease self-management and

may have delayed coping with the diagnosis. More research should be done on how patients with lung cancer initially cope with their diagnosis, how their coping changes over time, and what impact it has on their trajectory. This can also be assessed during care encounters by the nurse or the palliative care team.

“Meeting patients where they are” was an important empathic approach as a part of “connecting” mentioned by two participants that involved understanding the patient’s perspective in order to provide patient centered care. This approach helped nurses to keep their care centered on what was important to the patient, versus the perceived rationality or irrationality of the patient’s behaviors. This approach can be modeled to new nurses and other staff who are struggling to provide care to the patient because of perceived inappropriateness of the patient’s behavior.

While participants talked about lung cancer being a particularly emotional and difficult diagnosis for younger patients because they have children, this assumption may be problematic in situations where older patients are the sole caregivers of their grandchildren. Moreover, families were frequently noted to be an important part of the patient’s cancer journey and were at risk for becoming overwhelmed or exhausted from providing care and support for the patient. Healthcare professionals should assess not only the patient’s financial resources but their supportive roles in their families or social lives; they should not assume that older patients do not have similar familial caregiver roles as younger patients, just because they are older.

In this study, there was a lack of knowledge about why participants did not attend support groups, although potential reasons such as fatigue were offered. Problems with

support groups for patients with lung cancer have been found in one other qualitative study (Conlon et al., 2010). These problems included the introduction of smoking stigma during the groups by patients with lung cancer who did not smoke when they indicated they did not deserve lung cancer and, passively, that people who smoked did deserve it. Also, people who smoked avoided the support groups because they felt like they would have to lie about their smoking status in order to be accepted in the group.

This issue needs to be studied from the patient perspective to determine how support can be provided to patients with lung cancer and what prevents them from using certain support services. Nurses should assess the social and emotional support their patients currently have, and help the patient determine additional support needed, if any, and what will work best for the patient. Some patients may prefer less formal settings, or one on one interactions, to give and receive emotional support. It could potentially be beneficial to invite patients who have attended support groups or who have advice on giving and receiving emotional support to multidisciplinary clinics as a way to help patients understand the benefits of this form of support from someone who has used it.

### **Limitations**

All of the participants were women, which is consistent with other qualitative studies of nurse's perceptions of diseases that carry stigma (Aranda et al., 2014; Brown & Thompson, 2007). Most of the participants were also Non-Hispanic White, had over 15 years of experience as nurses, and were older, which, along with gender, limits the diversity of perspectives presented in this study. Some of the follow-up interviews occurred months after the initial interview, meaning participants may have had trouble

recapturing their original thoughts. However, participants were mostly consistent from one interview to the next. Participants were, at times, talking about events that occurred several or many years ago, so this recall represents their reflection of events and their memory of how they felt at the time. They were also telling their perspectives to another nurse, this could have impacted the way they expressed themselves and what they chose to say.

Purposive sampling was done through social media and through nursing organizations, therefore the sample is limited to people who access social media on a regular basis and are in the network of the principal investigator, to people who are members of and read organization newsletters and publications, and the extent to which the recruitment message is disseminated.

Transferability of the findings is limited because of the setting of the study, the Southeastern United States. Both the region of the U.S. where the nurse is from and where she practiced during the time she cared for patients with lung cancer can be a factor in their perspectives of both the disease and the associated behavior. For example, North Carolina is historically a tobacco state, meaning that the commerce surrounding tobacco production and sales was important to local economies (Fallin & Glantz, 2015). The way people perceive tobacco related diseases in North Carolina may be different than in a region or country where the historical ties to tobacco are less strong. In addition, there may be other cultural aspects that are revealed that may or may not be useful to people who read the study. However, in these cases, it is important for the researcher to try and give context to the culture of the people being studied when appropriate.

## **Conclusion**

Nurses' experiences, communicated through narratives, further informs the identity of "wise" persons so that these qualities can be known and taught in nursing. Maintaining integrity of the nursing profession requires in-depth knowledge of how nurses embody these expectations and when they struggle to do so, or when they see the struggle of other health care professionals.

A narrative approach provided a richer understanding of how nurses as "wise" persons think and what actions they take to counteract stigma in their patient encounters, which has been missing from the lung cancer and stigma literature to date. Their stories of smoking addiction and lung cancer in their families provides some understanding of the roots of their empathy and advocacy; yet negative stereotypes were still present in their experiences with people who smoke and people with lung cancer. Nurses enter the profession with experiences of health and illness from their sociocultural background and can reflect on and draw from these experiences. While the exact frequency of encountering smoking addiction among lung cancer patients, especially when they smoke in clinical setting, is not clear, for these nurses, these encounters were significant.

The two stigma theories presented in Chapter Two posit that stigma occurs at the macro and micro levels and that the people involved in the stigma process have overlapping identities with extant and emerging statuses that promote or prevent a downward social trajectory related to a stigmatized condition. People who are "normals" or "wise" may also have a stigmatized condition, however their status in society can determine how easily they can conceal their stigmatized condition and what they can do

to counteract the stigma (Goffman, 1963). For health care professionals, their status as a professional engenders assumptions that they are empathic, impartial, social justice activists and advocates, which may cloak their personal judgements and attitudes about what is normal while simultaneously informing their more “wise” approach to care.

At the micro level, in Goffman’s theory, nurses are considered to be “wise” persons who have knowledge of the difficulties of people who have a stigmatized illness and are positioned to help the stigmatized counteract stigma, but the “wise” are also “normals”. This study added a more nuanced understanding of the experiences of nurses as the “wise” and nurses as “normals”, and the actions they take to help deal with struggles they have when caring for patients with smoking addiction, and lung cancer.

Addiction, as a stigmatized condition, was partially transformed by the “wise” to a label that could protect the patient from further judgement. How the “wise” behave and think as such is not clearly described by Goffman’s theory. This study potentially adds another way in which nurses as “wise” persons counteract stigma by reducing the negative valence around labels and stereotypes. However, nurses demonstrated a fragmented understanding of smoking addiction that contributed to their difficulties in witnessing smoking behaviors, and frustration with effectively addressing smoking cessation. This fragmented understanding allows for the continuation of extant negative stereotypes and labels in the health care setting. The “wise thoughts” and “wise actions” they had and did can be used to build a framework for approaching patients with a stigmatized disease, and it also provides guidance for what additional research needs to

be done. For example, the need to study those who engage in “wise” actions on a larger scale beyond patient care encounters to understand their stories of advocacy.

At the macro level, Link and Phelan’s (2001) theory was a helpful framework for seeing and interpreting labels and stereotypes and how they are used to provide quick solutions to patient problems such as the labels “noncompliant” and “needy”, and how they have become part of the background in health care. Separation, status loss, and structural discrimination are still components of smoking stigma and lung cancer stigma. Nurses reported a diminished status among health care professionals; the “wise” may, at times, advocate for people with a stigmatized disease while dealing with their own stigmas that they cannot hide because they emerge in their care of patients. These problems can be addressed by continually working to professionally resolve conflicts and keep the focus of care on the patient and not on interprofessional and intraprofessional conflicts. However, space and time should be set aside to address these conflicts so that they are not emerging during patient care.

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**APPENDIX A**  
**DEMOGRAPHICS FORM**

**1. What year were you born?**

\_\_\_\_\_

**2. What is your gender?**

\_\_\_\_\_ male    \_\_\_\_\_ female    \_\_\_\_\_ Prefer to self-describe (please specify)

\_\_\_\_\_ Prefer not to say

**3. Where did you grow up?**

\_\_\_\_\_

**4. In what state did you receive your pre-licensure nursing education?**

\_\_\_\_\_

**5. How many years have you been a registered nurse?**

\_\_\_\_\_

**6. What is the highest education level you have obtained?**

\_\_\_\_\_ Associate Degree

\_\_\_\_\_ Diploma

\_\_\_\_\_ Bachelor's degree

\_\_\_\_\_ Master's degree.

\_\_\_\_\_ DNP

\_\_\_\_\_ PhD

**7. What type of clinical setting do you currently work in?**

\_\_\_\_\_ Oncology Inpatient

\_\_\_\_\_ Oncology Outpatient

\_\_\_\_\_ Home Health

\_\_\_\_\_ Hospice

- Palliative Care
- Telemetry
- Medical Surgical
- Step-down
- ICU

\_\_\_\_\_ Other – please write in

**8. What type of setting did you care for patients with lung cancer?**

\_\_\_\_\_

**9. How many years have you cared for patients with lung cancer?**

\_\_\_\_\_

**10. When caring for patients with lung cancer what is a typical shift that you have worked?**

\_\_\_\_\_

**11. Do you currently use tobacco products?**

Yes

No

**12. If “yes” what type of tobacco product do you use?**

\_\_\_\_\_

**13. Have you ever smoked or used tobacco products?**

Yes

No

**14. What type of tobacco product did you use?**

\_\_\_\_\_

**15. Has a family member or close friend ever been diagnosed with lung cancer?**

\_\_\_\_\_Yes                      \_\_\_\_\_No

**16. Has a family member or close friend ever died of lung cancer?**

\_\_\_\_\_Yes                      \_\_\_\_\_No

**17. Have you ever been diagnosed with cancer?**

\_\_\_\_\_Yes                      \_\_\_\_\_No

**18. If so, what type of cancer?**

\_\_\_\_\_

**19. Which race/ethnicity most closely describes how you identify yourself?**

\_\_\_\_\_ Caucasian or White

\_\_\_\_\_ Black/African American

\_\_\_\_\_ Hispanic/Latino

\_\_\_\_\_ American Indian/Alaska Native

\_\_\_\_\_ Asian/Pacific Islander

\_\_\_\_\_ Other

## **APPENDIX B**

### **INTERVIEW GUIDE**

#### **Free Association**

- When you hear the word healthy what comes to mind?
- When you hear or read the word smoker what comes to mind?
- When you hear or read the word cigarettes what comes to mind?
- When you care for a patient who smokes the first thing you think is...?
- What are your thoughts on why people start smoking and why they continue to smoke?
- What has been your experience with people who smoke? How has this impacted the way you care for people who smoke or used to smoke?
- When I am assigned a new patient with lung cancer the first thing I think is...? How are these thoughts different from other patients to which you are assigned?

#### **Biographical Narrative Questions**

- What is your first memory of or what was your first experience with lung cancer?
- What is your first memory of or what was your first experience with smoking?
- Tell me about how you got into nursing?
- How has your perspective of nursing changed since you first started as a nurse?
- Tell me about when you started to care for patients with lung cancer (what was it like for you)?
- Describe how your perspective may have changed about lung cancer since you first started to care for patients with lung cancer?

#### **Semi-structured Interview**

- Describe your work environment and some of the things you do to care for/help patients with lung cancer.
  - How are you supported in your role of caring for patients with lung cancer?
  - What support is needed for care of patients with lung cancer?
- What have you noticed about how people talk about lung cancer?
- What are some common words, phrases, or progress notes used to describe patients with lung cancer when you are working?
- How do you use empathy in your communication with patients with lung cancer?
- When is it a challenge to use empathy?
- What are some common things that patients and family members say about lung cancer?
  - How do you respond and/or feel about what is said?

- How do you advocate for your patients with lung cancer?
  - What facilitates this advocacy?
  - What barriers to advocacy do you encounter?
- Describe any differences you have noticed between
  - Your patients with lung cancer and your patients with other cancer diagnoses.
  - Your patients with lung cancer who are older and those who are younger.
  - Who currently smoke and those who do not.
- What are some of the challenges that arise when caring for patients with lung cancer?
- What are some of the positive experiences you have noted when caring for patients with lung cancer?
- Recall a time when caring for a patient with lung cancer when the care or treatment went well...
  - Describe what happened during this time.
  - What was the outcome and why do you think it was good?
  - What was the reaction of the patient, family, and professionals who provided care for this person.
  - What feelings did you have regarding this event?
- Recall a time when caring for a patient with lung cancer when the care or treatment did not go well...
  - Describe what happened during this time.
  - What was the outcome and why do you think it was not good?
  - What was the reaction of the patient, family, and professionals who provided care for this person?
  - What feelings did you have regarding this event?
- What are your thoughts on the stigma associated with lung cancer?

## APPENDIX C

### MEMBER CHECK FORM

This form is designed for the participant (you) to comment on the accuracy of the transcript. This is only your data that you are seeing. Please answer the following questions about this transcript.

Please indicate, by **circling** AGREE OR DISAGREE, whether you agree or do not agree with the transcript.

I AGREE with the transcript.

I DO NOT AGREE with the transcript.

Please indicate WHY you AGREE or DO NOT AGREE with the transcript AND/OR offer any comments you have about the transcript.

## APPENDIX D

### RECRUITMENT FLYER

#### RESEARCH PARTICIPANTS NEEDED

My name is Sarah Abrams and I am a Registered Nurse and a graduate student pursuing my PhD at the University of North Carolina at Greensboro School of Nursing. **My dissertation research is on the experiences of nurses who care for patients with lung cancer. Much of the research on people with lung cancer has been done from the perspective of the patient, so not much is known about the perspective of nurses.**

- PURPOSE:** A qualitative study to describe the care of patients with lung cancer from the perspective of Registered Nurses who care for them.
- PROCEDURE:** Participants will be interviewed no more than twice by the principal investigator (Sarah Abrams). The first Interview will take approximately 90 minutes and will be **audio-recorded**. If a second interview is needed it will be no more than 30 minutes and will be audio-recorded.
- ELIGIBILITY:**
- Must be a **registered nurse** caring for or have cared for patients with lung cancer and are practicing in the Southeastern United States.
  - Must have **at least two years of nursing experience.**
  - Must be **caring for or have cared for patients with lung cancer for at least 6 months of your career.**

**\*\*\* If you know someone who meets these criteria, please SHARE on social media or direct them to/show them/send them this flyer \*\*\***

**If you need a copy of the flyer please send a request to [siabrams@uncg.edu](mailto:siabrams@uncg.edu)**

**\*\*\*\*\*Please DO NOT POST THIS FLYER ANYWHERE WITHOUT PERMISSION i.e. the place where you work**

**\*\*\*\*\***

**COMPENSATION:** Participants will receive a gift card compensation for their time.

**CONTACT:** For more information please contact the principal investigator

**Sarah Abrams RN, MSN, PhD**  
**student at the University of North**  
**Carolina at Greensboro**

[siabrams@uncg.edu](mailto:siabrams@uncg.edu)