SMOKING BEHAVIOR AFTER A DIAGNOSIS OF LUNG CANCER

DISSERTATION

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By

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ABSTRACT

Tobacco use is the chief avoidable cause of lung cancer. The leading cause of cancer death for both men and women in the United States is lung cancer, responsible for approximately 160,390 deaths in 2007. Improved survival and quality of life, decreased risk of developing a second primary lung cancer and improved pulmonary symptoms and treatment outcomes are all associated with quitting smoking after a diagnosis of lung cancer. Despite the known benefits of quitting, 13-20% of lung cancer patients still do not quit after diagnosis.

It has been established that lung cancer patients are willing and ready to quit smoking and a variety of factors have been identified that are associated with continued smoking after diagnosis. However, little is known about how to successfully quit following a lung cancer diagnosis. Also, the effect of the lung cancer diagnosis on smoking behavior and cessation outcomes needs to be further examined.

Literature suggests that patient beliefs about illness influence health behavior outcomes and understanding patient's perceptions of illness can improve the day-to-day management of illness and disease. The Self-Regulation Model of Illness (SRMI) provides a useful framework for furthering an understanding of why individuals diagnosed with lung cancer continue to smoke. The SRMI theory suggests that individuals search to understand their illness or disease threat by developing an understanding of what the illness is, what it means, its causes, its consequences, how long it will last, and whether it can be cured or controlled. This understanding (or illness representation) is not necessarily scientifically or medically validated, but formulated from personal experience (physical symptoms and emotions), social influences, and/or interaction with healthcare providers. Individuals are thought to reduce their health risk or change their health behavior in ways consistent with their own illness representation. The first manuscript includes a discussion of the integration of SRMI theory with smoking behavior among lung cancer patients who are newly diagnosed.

The variables and relationships that influence smoking behavior among lung cancer patients who continue to smoke after diagnosis are poorly understood. The purpose of this dissertation study was to examine sociodemographic (age, education, income) and biobehavioral characteristics (nicotine dependence, social support), illness representation, and quality of life after a recent diagnosis of lung cancer at baseline and 6 months to further describe smoking behavior.

This study was a prospective, one-group longitudinal study that took place within the thoracic oncology outpatient clinics at an urban academic medical and comprehensive cancer center. The study included patients who were age 18 years or older, had a confirmed diagnosis of lung cancer within the past 60 days, and self-reported current smoking within the past 7 days. Participants had to be able to understand English and provide informed consent. After obtaining informed consent, patients produced a 1ml saliva sample and completed a series of questionnaires, including: sociodemographic, medical history and smoking history data forms, Fagerstrom Test for Nicotine Dependence (FTND), Illness Perception Questionnaire (Revised) (IPQ-R), Lung Cancer

Symptom Scale (LCSS), and Center for Epidemiological Studies of Depression Scale (CES-D), a depressive symptoms screening tool. The IPQ-R was repeated at a second time point, approximately 2-4 weeks after baseline data collection, to assess the stability. The entire data collection process was then repeated at 6 months. Those patients who self-reported abstinence from smoking provided a saliva cotinine concentration for biochemical verification purposes. This study was approved by and in compliance with the institution's Human Subjects Cancer Review Board. Descriptive statistics were calculated on all sociodemographic, medical history, tobacco use, illness representation, and quality of life data. Differences between mean scores for each attribute of the IPQ-R at repeated time points were calculated by Within-Subject Repeated Measures Analysis of Variances (ANOVA) and Wilcoxon Signed Rank Tests.

Fifty-three eligible patients enrolled in the study and only 27 (50.9%) reached the 6 month study endpoint. Upon entering the study, on average patients continued to smoke more than 3 weeks after diagnosis. At 6 months, seven patients self-reported quitting smoking and of these, five (18.5%) were biochemically confirmed to be abstinent by saliva cotinine. Importantly, most patients (78.1%) made at least one attempt to quit smoking in the previous 6 months. Due to the small sample size and percentage being smoke free (18.5%) at 6 months, statistical comparison between smokers and quitters was not conducted. There was a high percentage of depressive symptoms reported by the sample at baseline (60.8%) and at 6 months (40.0%). There was a significant increase in the identity and timeline (acute/chronic) attribute of the IPQ-R over the three time points and significant decreases in the person control and treatment control attributes over time.

The results of this study will be used to develop future smoking cessation interventions with lung cancer patients, and guide future research questions. The second manuscript provides a complete, detailed description of this study's design, methods, results and implications for future research.

The third manuscript discusses the comparison of two quality of life (QOL) paper and pencil instruments: Functional Assessment of Cancer Therapy-Lung Cancer (FACT-L) and Lung Cancer Symptom Scale (LCSS), specifically describing the internal consistency of both instruments and their convergence validity. This data was collected and analyzed from the previous mentioned dissertation study. A lung cancer patient's self-assessment of QOL is highly valued among clinicians as it guides treatment-related decisions and impacts clinical outcomes. To assess QOL, a reliable and valid QOL measure specific to lung cancer is required. Descriptive statistics were calculated on the FACT-L and LCSS scores, internal consistency was assessed by estimating Cronbach's alpha coefficients, and Pearson correlation coefficients were estimated between the two scales. Internal consistency coefficients demonstrated good reliability for both scales, and the two instruments demonstrated a strong correlation, suggesting good convergence validity. Either of these instruments are appropriate measures for QOL in lung cancer patients. It is important to carefully consider the research aims when selecting the appropriate QOL measurement instrument.

To my grandmother, Aileen S. Wolf, and mother, Jacqueline W. Kihm,

for inspiring me to dedicate my life to helping others

To my daughter, Kate, thank you for giving me perspective

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FIELDS OF STUDY

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CHAPTER 1

THE SELF-REGULATION MODEL OF ILLNESS APPLIED TO SMOKING BEHAVIOR IN LUNG CANCER

Introduction

Lung cancer is responsible for the most cancer deaths in the United States for both men and women (Jemal et al., 2007). For all stages of the disease, the 5 year survival rate of lung cancer is approximately 15% (Reis et al., 2006). Tobacco use is the strongest risk factor for developing lung cancer (USDHHS, 1988). It is well established that quitting smoking after a diagnosis of lung cancer improves survival, side effects of disease and treatment, and decreases the risk of developing a second smoking-related lung cancer (Johnson-Early et al., 1980; Kawahara et al., 1998; Knudsen, Schulman, Fowler, & van den Hoek, 1984; Nordquist, Simon, Cantor, Alberts, & Gepler, 2004; Richardson et al., 1993; Zhou et al., 2006). Despite known benefits of quitting, 13% to 20% of lung cancer patients continue to smoke after diagnosis (Cox et al., 2002; Dresler, Bailey, Roper, Patterson, & Cooper, 1996; Evangelista, Sarna, Brecht, Padilla, & Chen, 2003; Sridhar & Raub, 1992). The purpose of this paper is to 1) describe a theoretical model that addresses patient perceptions of illness among lung cancer patients who continue to smoke after diagnosis, and 2) further the understanding of characteristics that contribute to continued smoking behavior and guide the development of future smoking cessation interventions.

Background

Continued Smoking After Diagnosis

In patients who continue to smoke after diagnosis, tobacco may act as a carcinogenesis promoter in previously initiated cancer sites (Evangelista et al., 2003). Patients who survive lung cancer and continue to smoke risk further compromise of lung function that is diminished due to surgical resection, pulmonary toxicity from chemotherapy, and/or chest irradiation (Evangelista et al., 2003), and continued smokers report a poor quality of life (Toh et al., 2004). Findings from several studies have indicated that patients who quit smoking prior to and at the time of a lung cancer diagnosis (all stages) have a significantly better prognosis than those who continued to smoke during and subsequent to treatment (Johnson-Early et al., 1980; Kawahara et al., 1998; Nordquist et al., 2004; Richardson et al., 1993; Zhou et al., 2006). Smoking cessation after initial treatment has been shown to decrease the risk of developing a second, smoking-associated primary tumor (Erickson & Kondo, 1989; Richardson et al., 1993). In a prospective clinical treatment trial with early stage lung cancer patients (n=569), smoking status (current versus former) was a significant predictor of the development of a second, smoking-associated primary lung cancer (Rice et al., 2003).

Psychosocial and Behavioral Characteristics

Literature suggests that patient beliefs about illness influence health behavior outcomes (Hagger & Orbell, 2003). Understanding a patient’s perception of illness can improve the day-to-day management of illness and disease (Weinman & Petrie, 1997). Limited research has been conducted to explore the psychosocial and behavioral influences that contribute to continued smoking following a lung cancer diagnosis. Studies with head and neck and lung cancer patients suggest that continued smoking is associated with higher nicotine dependence, levels of perceived ‘cons’ of smoking, fatalism, and emotional distress; and lower self efficacy, perceptions of risk and perceived ‘pros’ of quitting (Schnoll et al., 2004; Schnoll et al., 2002). While these studies contribute interesting preliminary data for this population, *conceptual understanding* that exclusively examines characteristics of smoking behavior in lung cancer patients is lacking. Furthermore, insight on patient perceptions of how a lung cancer diagnosis impacts health behavior such as smoking would be useful in designing future smoking cessation interventions.

Overview of the Self-Regulation Model of Illness

The Self-Regulation Model of Illness (SRMI), initially described in 1980 as the “common sense model of illness representation” by Leventhal and colleagues, provides a framework for understanding how individual symptoms and emotions experienced during a health threat or diagnosis influence perception of illness and guide subsequent coping behavior (Diefenebach & Leventhal, 1996; Leventhal et al., 1997; Leventhal, Hudson, & Robitaille, 1997; Nerenz & Leventhal, 1983). The SRMI provides a useful framework for furthering an understanding of why individuals diagnosed with lung cancer continue to smoke. This model has been examined within multiple illnesses and health-related behaviors including coronary heart disease (Petrie, Weinman, Sharpe, & Buckley, 1996), human immunodeficiency syndrome (HIV) medication adherence (Reynolds, 2003), and diabetes self management (Lange & Piette, 2006). Components of the SRMI have been examined among oncology patients (Donovan & Ward, 2005; Johnson, Lauver, & Nail, 1989; Ward, Donovan, Owen, Grosen, & Serlin, 2000), however, there has been no examination of the SRMI among lung cancer patients who smoke at the time of diagnosis.

The SRMI theory suggests that individuals search to understand their illness or disease threat by developing an understanding of what the illness is, what it means, its causes, its consequences, how long it will last, and whether it can be cured or controlled. This understanding (or illness representation) is not necessarily scientifically or medically validated, but formulated from personal experience (physical symptoms and emotions), social influences, and/or interaction with healthcare providers. Individuals are thought to reduce their health risk or change their health behavior in ways consistent with their own illness representation. The model in Figure 1 suggests that a lung cancer patient's decision to quit or continue to smoke following diagnosis will be influenced by whether it 'makes sense' given the patient's own illness representation. The following section will discuss how the theoretical components of the SRMI can be conceptually applied to continued smoking following a lung cancer diagnosis.

SRMI and Lung Cancer

Illness Representation

Following a diagnosis of illness such as lung cancer, the individual will analyze, internalize, and interpret the meaning of the diagnosis. The individual is an active problem solver and simultaneously deals with two phenomena: the perceived reality of the illness or diagnosis and the emotional reaction. Both internal and external stimuli operate to influence the development of the *illness representation* (Diefenebach & Leventhal, 1996; Leventhal et al., 1997; Leventhal, Hudson et al., 1997; Nerenz & Leventhal, 1983). For example, a newly diagnosed lung cancer patient who is a current smoker may interpret increased coughing and worsening shortness of breath as symptoms of lung cancer. Depending on past experiences with these symptoms and influences from healthcare providers, the media, family and friends, the patient forms an illness representation with respect to his or her continued smoking after this new diagnosis (see Figure 1). Aside from recognizing the signs and symptoms (*identity*) of the disease, other components of this illness representation are cause, consequence, control, and timeline (Diefenebach & Leventhal, 1996; Leventhal, Hudson et al., 1997)**.** The patient's perception of lung cancer may or may not influence the interpretation of the *cause* of the disease. Smokers will either link past or continued smoking with the cause of the disease, or may choose not to, linking the cause with genetics, environmental exposure, or some other cause. The *consequence*s of continuing or stopping smoking will be internalized and made part of the smoker's illness representation. Perceived *control* of lung cancer symptoms and disease and whether quitting or continuing smoking will have an effect upon the symptoms and the stage of the lung cancer, become part of the illness representation. In addition, the smoker's ability to change the overall *timeline* or prognosis of the diagnosis, with respect to quitting or continuing smoking, will be an important component of the illness representation.

Illness representations are complex and dynamic. The internal and external stimuli of the individual change the illness representation over time and further guide actions of the individual in response to the health threat (Diefenebach & Leventhal, 1996;

Leventhal, Hudson et al., 1997)**.** An internal stimulus such as side effects of lung cancer treatment and external stimulus such as public opinion on causes of lung cancer and prognosis will shape the illness representation over the course of the disease. Emotions are also an integral component of the illness representation and develop simultaneously with the cognitive component. Emotional experiences such as fear, anger, depression or anxiety can motivate the individual to develop an action plan (coping procedure), or can be so overwhelming, resulting in less or no action taken (with respect to the disease) (Diefenebach & Leventhal, 1996; Leventhal et al., 1997). Receiving a cancer diagnosis can evoke a range of emotions. These emotions also contribute to the formation of the illness representation that influences the coping procedures.

Coping Procedure

The illness representation drives the individual's coping strategies. A response to the formed illness representation is instituting a behavior, or *coping procedure***.** The individual develops a response plan or procedure to cope with the illness representation, and the selection of a coping procedure is guided by the illness representation concept (Leventhal, Hudson et al., 1997; Nerenz & Leventhal, 1983). A smoker may cope with the new diagnosis of lung cancer, either by quitting or continuing to smoke. The consequences of quitting smoking may involve physical and psychological factors (both positive and negative) such as decreased shortness of breath (Knudsen et al., 1984), increased nicotine withdrawal symptomatology (Shiffman & Jarvik, 1976), increased family support (Schnoll et al., 2002), and improved survival (Johnson-Early et al., 1980; Kawahara et al., 1998; Richardson et al., 1993). Although the consequences of continued smoking may result in worsening pulmonary symptoms and possible decreased long-term survival, the patient may continue to smoke to avoid the additional stress of quitting smoking during this already stressful time.

Outcome Appraisal

The individual will engage in ongoing *outcome appraisal*, the analysis of the consequence or efficacy of the coping procedure. The outcome appraisal is the repeated evaluation of the coping procedure (continued or quitting smoking) and may be influenced by such variables as quality of life, clinical response to lung cancer treatment and lung cancer symptomatology, in addition to the consequences of quitting or continuing to smoke. Each variable influences the patient's evaluation of the coping procedure. Information gained during the coping procedure feeds back to the other constructs. If an individual perceives that a coping procedure is ineffective, an alternative coping procedure may be selected. Thus the model is fluid and dynamic, with continuous feedback between each component (Leventhal, Hudson et al., 1997; Nerenz & Leventhal, 1983). A patient may use his or her own quality of life assessment as a proxy indicator for outcome appraisal when evaluating his or her smoking behavior (coping procedure).

Quality of life.

A lung cancer patient's quality of life is important for both the physician and the patient, when making treatment-related decisions and evaluating treatment outcomes (Montazeri, Milroy, Hole, McEwen, & Gillis, 2003). Patient self assessment of quality of life has been shown to be a useful predictor of lung cancer survival (Sarna et al., 2002).

Representation of Self

The individual’s cognitive and emotional processes that form illness representations do not occur in isolation, they are influenced by the *representation of self*. A lung cancer patient’s *representation of self* is defined as their self-perception (“Who am I?” or “How do I define myself?”) and self-meaning or ‘importance of self’ (“What value do I place on myself?” or “Why do I matter?”). After a disease threat or illness (i.e. lung cancer), the *representation of self* is redefined within the context of the illness and is influenced by the individual’s social interactions (e.g. family, friends, the media, and healthcare professionals). The individual forms an illness representation as a reflection of the ‘redefined self’ (Buick, 1997; Diefenebach & Leventhal, 1996; Leventhal, Hudson et al., 1997). There are many sociodemographic and biobehavioral characteristics that are specific to an individual (self), and are known to be associated with continued smoking. Several of these characteristics will be discussed in the following section.

Characteristics associated with continued smoking (self).

Age, education, and income are several known sociodemographic characteristics that have been demonstrated to be associated with continued smoking behavior (CDC, 2006). Smoking is often initiated in adolescence, and once dependent, continues throughout adulthood (Giovino, Henningfield, Tomar, Escobedo, & Slade, 1995). The highest prevalence is among people ages 18-44 (CDC, 2006). Level of education is inversely correlated with smoking prevalence, those with a higher education are least likely to smoke and are most successful in quitting (CDC, 2006; Giovino et al., 1995; Pierce, Fiore, Novotny, Hatziandreu, & Davis, 1989). There is an inverse relationship between lower socioeconomic status (income) and smoking. Those living at or below the poverty line have a higher prevalence of smoking (CDC, 2006; Pierce et al., 1989). These sociodemographic characteristics (age, education, and income), that are specific to an individual, can further influence and guide the patient's perception of illness and coping procedure (quitting or continuing to smoke).

Biobehavioral characteristics such as higher nicotine dependence and less social support are associated with smokers who are unable to quit (Mermelstein, Lichtenstein, & McIntyre, 1983; Schnoll et al., 2002; USDHHS, 1988). Living with other smokers and having family and/or caregiver support to quit smoking can greatly influence the outcome of a patient's success at quitting smoking. A study describing psychosocial factors of tobacco use among smokers and recent quitters diagnosed with cancer (n=74) observed that having a family member at home who smokes increased the likelihood that patients will continue to smoke (Schnoll et al., 2002).

Smokers who are highly dependent on nicotine typically have a very difficult time quitting. Nicotine is the psychoactive drug in tobacco that causes acute and chronic dependence (USDHHS, 1988), and nicotine dependence often requires repeated intervention to assist individuals to successfully quit smoking (Fiore et al., 2000). Smokers who have a high dependence on nicotine often require many quit attempts and have higher relapse rates before achieving permanent abstinence (Benowitz, 1999). The level of nicotine dependence and social support can further influence the illness representation and coping procedure.

Discussion

This is the first paper to integrate smoking behavior characteristics of lung cancer patients within the contexts of the SRMI theory. The SRMI provides a framework to help guide our understanding of the complexity of illness representation formation as it applies to lung cancer patients who smoke. After a diagnosis of lung cancer, a patient forms an illness representation that consists of many cognitive and emotional processes that are drawn from many different experiences (of the patient). The 'representation of self' further influences that illness representation by presenting personal characteristics of the patient that further influences the patient's perception of lung cancer. Illness representation and 'representation of self' may be the most interesting attributes of the SRMI to examine in future research with smoking behavior among lung cancer patients. Understanding the context in which a patient perceives disease and smoking behavior may contribute to influencing behavior change. There are known characteristics that influence smoking behavior, and these characteristics must be considered or addressed before smoking behavior will change (for any patient population). Adding emotional stress and physical rigor of lung cancer treatment-related side effects, may add additional characteristics that must be considered in order for lung cancer patients to successfully stop smoking.

Implications for Future Research

A smoking cessation intervention that is designed specifically for lung cancer patients is warranted. Incorporation of nicotine dependence treatment with pharmacotherapy (as defined by the Public Health Service Clinical Practice Guideline: Treating Tobacco Use Dependence) and behavioral skills therapy that assists patients in coping with the withdrawal effects of nicotine dependence must be included (Fiore et al., 2000). Interventions to aid the lung cancer patient in coping with lung cancer treatment-related symptoms in addition to the emotional distress that living with a lung cancer diagnosis causes, all while quitting smoking, is essential.

Quitting smoking will not be a step by step approach; the lung cancer patient must undergo a conceptual change. Smoking cessation coping strategies and behavioral skills training are not likely to be successful, if they are inconsistent with or in conflict with existing illness representations or representations of self (of the patient). First addressing well-established illness representations that are driving coping strategy selection may elicit more success in getting lung cancer patients to quit smoking (Donovan & Ward, 2001). As illness representations change over the course of illness, interventions that address the change in representations over time will contribute to a higher success.

Conclusion

Quitting smoking after a diagnosis of lung cancer is an important health-related behavior change. Characteristics contributing to the continued smoking behavior among lung cancer patients are not well understood. In order for healthcare providers to deliver the most effective smoking cessation interventions to lung cancer patients, more empirical research is required. Research that tests the effectiveness of theoretically based smoking cessation interventions in a randomized, controlled trial is necessary. The proposed model in this paper attempts to illustrate the components underlying the behavior of continued smoking after a diagnosis of lung cancer, and should be utilized to guide the development of future smoking cessation interventions.

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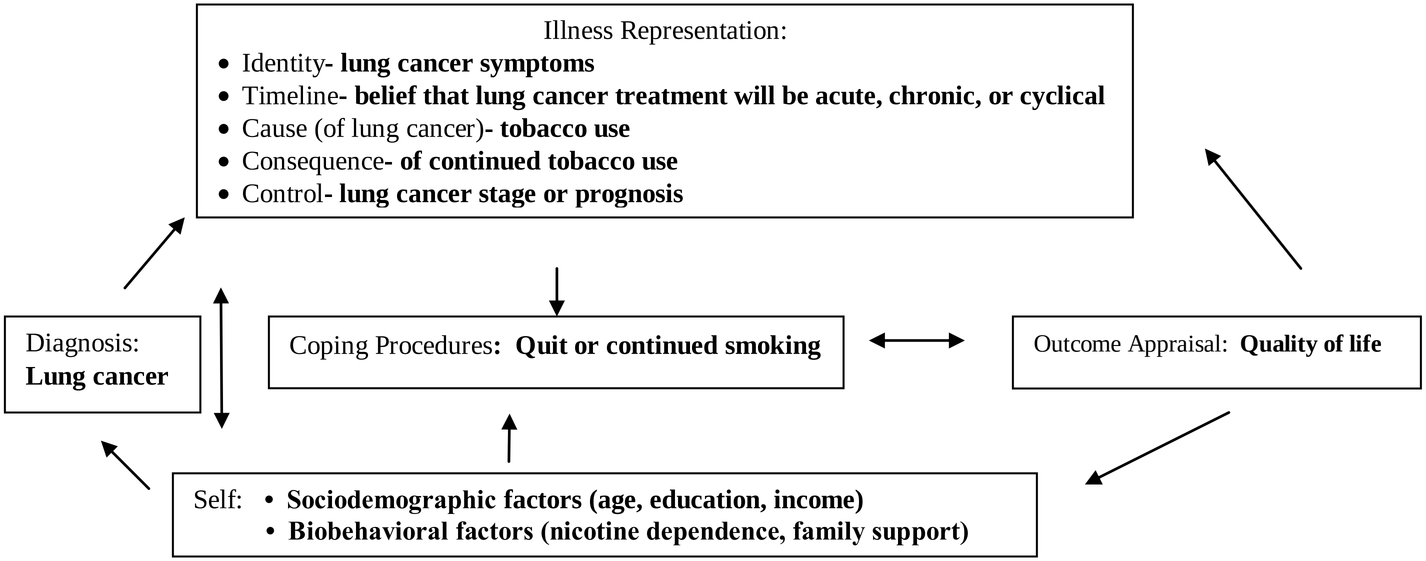

Figure 1.1
Self-regulation model applied to tobacco use in smokers recently diagnosed with lung cancer

CHAPTER 2
SMOKING BEHAVIOR AFTER A DIAGNOSIS OF LUNG CANCER

Introduction

The chief avoidable cause of lung cancer is tobacco use (Jemal et al., 2007). It is estimated that 187,050 new cases of lung cancer will be diagnosed in the year 2007, and there will be approximately 167,050 deaths (Jemal et al., 2007). Decreased risk for developing a second primary lung cancer and improved pulmonary symptoms and treatment outcomes is associated with quitting smoking after a diagnosis of lung cancer (Johnson-Early et al., 1980; Kawahara et al., 1998; Knudsen, Schulman, Fowler, & van den Hoek, 1984; Richardson et al., 1993; Videtic et al., 2003). Patients who survive lung cancer and continue to smoke, risk further compromise of lung function that is diminished due to surgical resection, pulmonary toxicity from chemotherapy, and/or chest irradiation (Evangelista, Sarna, Brecht, Padilla, & Chen, 2003). Despite the known benefits of quitting smoking after a diagnosis of lung cancer, 13-20% of lung cancer patients still do not quit (Cox, Sloan et al., 2002; Dresler, Bailey, Roper, Patterson, & Cooper, 1996; Evangelista et al., 2003; Sridhar & Raub, 1992). There is a need for research that examines factors that are associated with lung cancer patients who do not quit smoking.

Background

Benefits of Quitting After Diagnosis

Smoking cessation after a diagnosis of lung cancer is beneficial because it is associated with a higher survival rate (Johnson-Early et al., 1980; Kawahara et al., 1998; Richardson et al., 1993; Videtic et al., 2003). In studies examining survival two to five years post diagnosis, patients who discontinued smoking prior to and at the time of a lung cancer diagnosis had a significantly better prognosis than those who continue to smoke during and subsequent to treatment (Johnson-Early et al., 1980; Kawahara et al., 1998; Nordquist, Simon, Cantor, Alberts, & Gepler, 2004; Richardson et al., 1993; Videtic et al., 2003).

Smoking cessation after initial treatment has also been shown to decrease the risk of developing a second, smoking-associated primary tumor (Erickson & Kondo, 1989; Richardson et al., 1993). With continued smoking after diagnosis and surgery, patients risk the dangers of acute respiratory crisis and respiratory complications such as infections (Knudsen et al., 1984; Richardson et al., 1993).

After diagnosis, smoking cessation improves pulmonary function and reduces the risk of developing or exacerbating other serious illnesses (e.g. chronic obstructive pulmonary disease, coronary heart disease, and peripheral vascular disease) (Evangelista et al., 2003; Gritz, Nisenbaum, Elashoff, & Holmes, 1991; Gritz, 2000; Knudsen et al., 1984). Other benefits include decreased sputum production, shortness of breath, and cough, and an increased sense of taste and smell, an important factor for cancer patients experiencing ill effects of chemotherapy and radiation treatments. Psychosocial benefits, such as improved disposition, self-worth, and physical appearance have also been described (Erickson & Kondo, 1989; Gritz, 2000; Knudsen et al., 1984). Patients who quit smoking after a lung cancer diagnosis had a significantly better performance status (quality of life) at 12 months (Baser et al., 2006). Although these risks and benefits may be conveyed by a clinician to a newly diagnosed lung cancer patient, estimates suggest that one quarter to one third of lung cancer patients still continue to smoke after diagnosis (Cox et al., 2002; Cox, Sloan et al., 2002; Gritz et al., 1991; Schnoll et al., 2002; Schnoll et al., 2003).

Lung Cancer and Smoking Cessation Studies

The Public Health Service (PHS) clinical practice smoking cessation guideline provides evidence-based recommendations for successful delivery of smoking cessation treatment in clinical practice (Fiore et al., 2000). There is evidence that suggests lung cancer patients are interested in quitting smoking. For example, after receiving a scientifically-valid PHS guideline based nurse-managed smoking cessation intervention that lasted 6 months, newly diagnosed lung cancer patients (n=25) all attempted to quit smoking prior to surgery and 70% were successful (Browning, Ahijevych, Ross, & Wewers, 2000). In another pilot study among hospitalized lung cancer patients, the overwhelming majority (14 of 15) attempted smoking cessation, and 47% (n=7) were biologically confirmed to be abstinent at 6 weeks follow-up (Wewers, Jenkins, & Mignery, 1997). In a large randomized trial, cancer patients were randomly assigned (n=432) to a usual care group or an intervention group (strong advice to quit, setting a quit date, encouragement to use nicotine replacement therapy). Although there was no difference in self reported quit rates at 6 or 12 months by group, a predictive factor in quitting at both time points was a cancer site of lung or head & neck (Schnoll et al., 2003).

Although it is established that lung cancer patients are willing and ready to quit smoking. Little is known about how to successfully quit following a lung cancer diagnosis and the effect of the diagnosis on smoking behavior and cessation outcomes needs to be further examined. Lung cancer patients who smoke may represent a unique challenge, and may not be successful with the traditional smoking cessation guidelines (Schnoll et al., 2002). Patients who receive a new diagnosis of lung cancer, often with a poor prognosis, are overwhelmed and fearful of beginning cancer treatment. Quitting smoking, while important for health, may be a difficult health behavior change, requiring significant intervention.

Factors Related to Continued Smoking

Several studies have examined the relationship between various psychosocial factors and continued smoking behavior of lung cancer patients. Gritz et al. (1991) found that early stage non-small cell lung cancer patients who were successful in quitting were more likely to be female and healthier (n=840). Younger age and less education were predictive of continued smoking and shorter time to relapse after surgery for lung cancer patients (Walker, Larsen, Zona, Govindan, & Fisher, 2004). Other identified factors that are associated with continued smoking are relatives who smoke at home; completion of medical treatment; lower levels of self-efficacy, risk perceptions, and ‘pros’ of quitting; and higher levels of ‘cons’ of quitting, fatalism, emotional distress, and depressive symptoms (Schnoll et al., 2004; Schnoll et al., 2002). In women with lung cancer (n=230), younger age, depressive symptoms, and presence of smokers in the home were associated with continued smoking (Cooley et al., 2007). While these studies contribute interesting preliminary data for this population, *conceptual understanding* that exclusively examines characteristics of smoking behavior in lung cancer patients is lacking. Furthermore, insight on patient perceptions of how a lung cancer diagnosis impacts health behavior such as smoking would be useful in designing future smoking cessation interventions.

The Self-Regulation Model of Illness

Research demonstrates that patient beliefs about health and illness influence health behavior outcomes (Hagger & Orbell, 2003), and understanding patient perceptions of illness can improve the day-to-day management of disease (Weinman & Petrie, 1997). The Self-Regulation Model of Illness (SRMI) provides a framework for understanding the construction of individual illness perceptions and subsequent coping responses to health threats (Diefenebach & Leventhal, 1996). Leventhal and colleagues propose that individuals actively and emotionally analyze the meaning of health threats they experience. This process results in the construction of an illness representation, which consists of five perceptual and cognitive attributes of disease: 1) the identity or label (signs and symptoms); 2) the timeframe (acute, chronic, or cyclical); 3) the causes; 4) the consequences (physical, mental, social); and 5) the controllability (curable or manageable). The 'self' influences the perceptual and cognitive attributes of the illness representation and the diagnosis through the patient's own self-perception, self-meaning, and social interactions. The individual's illness representation guides coping procedures or behaviors to manage the health threat. The efficacy of the coping procedure, outcome appraisal, is then analyzed. Information from the outcome appraisal can feed back to the illness representation and coping procedures, making the model dynamic and continuous (Buick, 1997; Cameron & Leventhal, 2003; Diefenebach & Leventhal, 1996; Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997).

The model as applied to newly diagnosed lung cancer patients who smoke suggests that after receiving a diagnosis of lung cancer, a patient who is a current smoker, may interpret increased coughing and/or worsening shortness of breath as a symptom of lung cancer (see Figure 2.1). Depending upon past (symptom) experiences, and influences from the media, family, friends, and healthcare professionals, the patient then forms an *illness representation*. In addition to recognizing the signs and symptoms (*identity*) of the disease, the patient's perception of lung cancer will influence the interpretation of the *cause* of the disease, either linking past or continued smoking with the cause of the disease, or linking it to another cause such as genetics The *consequences* of continuing or stopping smoking, the patient's perception of *timeframe* (acute, chronic, or cyclical) will influence the illness representation as well as the *controllability,* with respect to quitting or continuing to smoke. The illness representation, along with factors of the *self* (age, education, income, nicotine dependence, and family support), influence the behavior of tobacco use; quitting or continuing to smoke (*coping procedure*). This chosen coping procedure is evaluated in the *outcome appraisal*; thus continuing the behavior or reforming the illness representation. The consequences of quitting smoking (coping procedure) may involve physical and psychological factors (both positive and negative) such as decreased dyspnea (Knudsen et al., 1984), increased nicotine withdrawal symptomatology (USDHHS, 1988), quality of life (Sarna et al., 2002), and improved survival (Johnson-Early et al., 1980; Kawahara et al., 1998; Richardson et al., 1993). Although the consequences of continued smoking may result in worsening pulmonary symptoms and decreased long-term survival, the patient may continue to smoke to avoid the additional stress of quitting smoking during this already stressful time. These consequences then become part of the cognitive process that the patient formulates as the outcome appraisal. As an example, the outcome appraisal, or repeated evaluation of the coping procedure (continued or quitting smoking), can occur in relation to variables such as lung cancer treatment effect, specific symptomatology of lung cancer, disease progression, the consequences of quitting or continuing smoking, and quality of life.

Biobehavioral characteristics of 'self'

Nicotine dependence.

Nicotine is the drug in tobacco products that acts in the brain and throughout the body to cause addiction or dependence (USDHHS, 1988). It produces pleasurable effects which motivate the user to engage in tobacco-seeking and tobacco-using behavior. This behavior leads to physical dependence and tolerance that can be characterized by withdrawal symptoms which occur following a short period of abstinence (USDHHS, 1988). Withdrawal symptomatology can be characterized by changes in mood, behavior and physical functioning such as craving for nicotine, irritability, frustration, anger, anxiety, difficulty concentrating, restlessness, decreased heart rate, and increased appetite or weight gain (USDHHS, 1988). While there is compelling evidence that nicotine is a highly addictive substance which may influence continuous smoking behavior

(USDHHS, 1988), benefits of quitting smoking after the diagnosis of lung cancer are high. Despite the knowledge of benefits, and motivation to quit, many patients continue smoking after a lung cancer diagnosis.

Family support.

Living with other smokers and having family/caregiver support to quit smoking can influence the outcome of a patient's success in quitting smoking. A study among smokers and recent quitters diagnosed with cancer reported that having a family member at home who smokes increased the likelihood that patients will continue to smoke (Schnoll et al., 2002).

Socioeconomic Characteristics of 'Self'

Lower socioeconomic status is known to be associated with increased prevalence of smoking, decreased smoking cessation, and increased lung cancer incidence and mortality (Jarvis & Wardle, 1999; Mao et al., 2001; Marmot, Wilkinson, & Wilkinson, 1999). Smoking is often initiated in adolescence and, once dependent, continues throughout adulthood (Giovino, Henningfield, Tomar, Escobedo, & Slade, 1995). Education level is inversely correlated with smoking prevalence (CDC, 2006; Giovino et al., 1995; Pierce, Fiore, Novotny, Hatziandreu, & Davis, 1989). Adults with a General Education Development (GED) diploma and/or less than a high school degree have the highest prevalence of smoking whereas those with graduate education have the lowest prevalence (CDC, 2006). Survival data from a large oncology clinical trial cooperative suggests that less educated people (grade school only) have a significantly shorter survival time than those with higher education (Cella et al., 1991). Lower income and smoking are inversely related; those living at or below the poverty level have a higher prevalence of smoking (CDC, 2006; Giovino et al., 1995). Increased risk of lung cancer was found to be associated with low income men and women, and survival data suggests that a low annual income (<$5,000) is significantly associated with shorter survival of lung cancer (Cella et al., 1991). In a case-control Canadian population-based study (cases: n=3,280, controls: n=5,073), lung cancer patients were more likely to have less education (≤8 years), lower social class, and less family income. Lower socioeconomic status was also identified to be associated with other lifestyle behaviors such as poor diet and increased occupational exposure to carcinogens (Mao et al., 2001).

Socioeconomic factors such as age, education, and income are variables that may influence 'self' (as described in the SRMI) among smokers recently diagnosed with lung cancer. Older smokers, with many past life-experiences with disease-related symptomatology, may have a different illness representation regarding a diagnosis of lung cancer than younger smokers. A lung cancer patient with low income and without health insurance may have a different illness representation with respect to 'controllability of disease' than a patient with higher income and adequate health insurance. Level of education, in addition to other contextual factors such as lifestyle and socioeconomic status, may be an influence upon a patient's illness representation of a lung cancer diagnosis. Socioeconomic characteristics such as age, level of education, and income have the potential to influence illness representation when evaluating a new diagnosis of lung cancer.

Quality of Life (Outcome Appraisal)

Quality of life is important for both physicians and lung cancer patients. Treatment-related decisions and evaluating treatment outcomes are based upon patient reported quality of life (Montazeri, Milroy, Hole, McEwen, & Gillis, 2003). Patient self assessment of quality of life has been shown to be a useful predictor of lung cancer survival (Sarna et al., 2002).

Depressive Symptoms

Sadness and psychosocial distress is an expected response that is common to cancer patients, particularly with a poor prognosis (Berard, Boermeester, & Viljoen, 1998). This distress can often progress to clinical depression. A review that included 14 clinical studies (with at least 50 participants each) indicated that 25% of lung cancer patients experienced depression during the course of the disease (Carlsen, Jensen, Jacobsen, Krasnik, & Johansen, 2005). Furthermore, in a lung cancer treatment clinical trial (n=987), of patients who had positive depressive findings at baseline, 29% were identified to have persistent depression during study follow-up (Hopwood & Stephens, 2000).

Studies have shown that there is a strong association between smoking and the diagnosis of clinical depression (Anda et al., 1990). Several studies have described a depressed mood during the nicotine withdrawal period, suggesting that tobacco use may provide psychological relief for individuals who are depressed (Covey, Glassman, & Stetner, 1997). Smokers who are depressed are at increased risk for relapse after an initial quit attempt (Anda et al., 1990). In a study with women lung cancer patients who were 6 months to 5 years post diagnosis (n=435), depression was significantly associated with continued smoking (Cooley et al., 2007).

The variables and relationships that influence smoking behavior among lung cancer patients who continue to smoke after diagnosis are poorly understood. The purpose of this study was to examine sociodemographic (age, education, income) and biobehavioral characteristics (nicotine dependence, social support), illness representation, and quality of life after a recent diagnosis of lung cancer at baseline and 6 months to further describe smoking behavior.

Methods

This was a prospective, one-group longitudinal study and included participants who were age 18 years or older, had a confirmed diagnosis of lung cancer (non-small cell or small cell) within the past 60 days, and self-reported current smoking within the past seven days. Participants had to be able to understand English and provide informed consent.

Procedure

Recruitment took place within the thoracic oncology outpatient clinics at an urban, academic medical and comprehensive cancer center. After obtaining informed consent, patients produced a 1mL saliva sample to measure nicotine dependence and completed a series of questionnaires. Informed consent was obtained during a face-to-face visit to the medical center. Patients were allowed to take unfinished baseline questionnaires home to complete and return by mail. One questionnaire (Illness Perception Questionnaire-Revised) was repeated at a second time point, approximately 2-4 weeks after baseline data collection, to assess the stability of illness representation attributes. The data were collected either during a scheduled visit to the medical center or by mail. The entire data collection process was then repeated at 6 months, either face-to-face or through the mail. Those patients who self-reported abstinence from smoking provided a saliva cotinine sample for biochemical verification purposes. Patients received $10 gift cards for participating at the 2-4 week time point and at 6 months. A smoking cessation intervention, based on the Public Health Service Clinical Practice Guideline Treating Tobacco Use and Dependence, was delivered to all participants as part of usual practice within the clinic (Fiore et al., 2000). Usual practice in the clinic included prescribing nicotine replacement and bupropion or varenicline when indicated. This study was approved by and in compliance with the institution's Human Subjects Cancer Review Board.

Measures

Medical Data and Depressive Symptoms ***(SRMI: Lung Cancer)***

Medical data that were collected from the chart included: pathology, date of pathology, stage of lung cancer, prior lung cancer treatment, and the presence of comorbid diseases such as hypertension, coronary heart disease, chronic obstructive pulmonary disease, and other cancer history and depression.

The Center for Epidemiological Studies of Depression Scale (CES-D) (Radloff, 1977), was use to screen for depressive symptoms. The instrument is a reliable and valid screening tool for depressive symptomatology and has been widely used in adults with cancer (Sarna et al., 2002). The total score ranges from 0-60, with scores greater than 15 indicating a significant level of depressive symptoms. Internal consistency (Cronbach's alpha) has been reported as 0.87 (Radloff, 1977).

Sociodemographic and Biobehavioral Data ***(SRMI: Self)***

The following sociodemographic data was collected from the patient: age, gender, insurance type, education, race/ethnicity, marital status, and household income.

Nicotine dependence data and smoking history characteristics that were collected included cigarettes per day (CPD), number of years smoked, number of serious quit attempts, the Fagerström Test for Nicotine Dependence (FTND) (Heatherton, Kozlowski, Frecker, & Fagerström, 1991), current pharmacotherapy (nicotine replacement therapy (NRT), bupropion, or varenicline), and a salivary cotinine concentration. Living with another smoker was the social support indicator that was collected.

The FTND is an accepted, reliable self-reported measure to characterize nicotine dependence among current smokers (Heatherton et al., 1991). It consists of a 6-item questionnaire, of which the internal consistency of 0.66 has been reported (Heatherton et al., 1991). Although this is a modest estimate of internal consistency, the FTND continues to be the gold standard measure utilized in all tobacco studies (Fiore et al., 2000). The FTND has been found to be highly correlated with plasma cotinine concentration ($p<0.005$), which is a biomarker for nicotine dependence as well as a measure of tobacco smoke exposure (Pomerleau, Pomerleau, Majchrzak, Kloska, & Malakuti, 1990). Cotinine, because of its long half-life, is a stable measure of nicotine intake and quantifies nicotine exposure. The association between perceived nicotine dependence as measured by the Fagerström Tolerance Questionnaire and plasma cotinine is $r=0.42$ ($p<.005$) (Pomerleau et al., 1990).

***Illness Representation** and Reasons for Smoking or Quitting*

The Illness Perception Questionnaire (Revised) (IPQ-R) (Moss-Morris et al., 2002), a quantitative measure of illness representation, contains five scales that assess each component of illness representation. It is intended to be used in a variety of diseases, inserting the specific disease or health threat where appropriate (Moss-Morris et al., 2002). The identity scale includes 14 symptoms that the patient is asked to state if present. This provides a simple measure of the number of symptoms perceived by the patient to be associated with the illness, a higher score indicating a greater number of symptoms are attributable to the disease (Moss-Morris et al., 2002). The remaining scales of the IPQ-R include acute/chronic timeline (6 items), cyclical timeline (4 items), consequences (6 items), personal control (6 items), treatment control (5 items), illness coherence (5 items), and emotional representation (6 items), and are rated by the patient on a five-point Likert-type scale ranging from *strongly disagree* to *strongly agree* (Moss-Morris et al., 2002).

Higher scores on the timeline scales, acute/chronic and cyclical, suggest a strong belief that the illness is chronic or cyclical in nature. A stronger belief that the illness has negative consequences is represented by a higher score on the consequence scale. Higher scores on the personal and treatment control scales suggest a strong belief in personal and treatment control of the disease. A greater personal understanding of the disease is represented by a higher score on the illness coherence scale and a higher score on the emotional representation scale suggests that the illness has a greater emotional meaning (Moss-Morris et al., 2002). Estimates of Cronbach alpha coefficients for the IPQ-R range from 0.79-0.89 (Moss-Morris et al., 2002).

During the baseline data collection, each patient was asked, “What is the primary reason you have not quit smoking?” At the study completion, each patient was asked: 1) “What is the primary reason you have not quit smoking?” Or, 2) “What was the primary reason you were successful in quitting smoking?”

Smoking Status ***(Coping Procedure)***

Point prevalence abstinence from smoking was defined as no self-reported use of tobacco in the past 7 days (Hughes et al., 2003) AND a saliva cotinine concentration ≤14ng/mL (M. Jarvis, Tunstall-Pedoe, Feyerabend, Vessy, & Saloohee, 1987). Cotinine is a reliable and valid measure of tobacco smoke exposure (Benowitz, 1988). Jarvis and others (1987) reported a 96% sensitivity rate and a 99% specificity rate when using 14ng/mL as a cutoff level in discriminating tobacco users from non-users. Biochemical verification of self-reported smoking status is recommended for clinic-based research trials and provides additional confirmation that self-reporting is accurate. The window for precise biochemical verification of smoking status by cotinine is within 7 days (Benowitz et al., 2002).

Quality of Life ***(Outcome Appraisal)***

The Lung Cancer Symptom Scale (LCSS) (Hollen, Gralla, Kris, & Potanovich, 1993) is another reliable, valid site-specific quality of life measure (Hollen et al., 1993). This instrument that includes nine visual analogue scales and has an overall mean score (0-100mm), with a lower score corresponding to a better quality of life. The scale focuses on physical and functional dimensions only. It includes major symptoms of lung cancer as well as a self rating of general lung cancer symptoms, how illness affects normal activities of daily living, and overall quality of life (Hollen et al., 1993). The LCSS has good reliability with reported internal consistency of 0.82 (Hollen et al., 1994).

Statistical Analyses

Descriptive statistics (means, standard deviations, percents) were calculated on all sociodemographic, medical history, tobacco use, illness representation, and quality of life data. Differences between mean scores for each attribute of the IPQ-R at repeated time points were calculated by within-subject repeated measures analysis of variance (ANOVA). Tukey-Kramer post-hoc tests were conducted to indicate pairs of data that had significantly different means. Histograms and quantile-quantile (Q-Q) plots were constructed and examined to determine if the resuiduals met the assumption of normality, and compound symmetry was assessed with Mauchly's Test of Sphericity. For data that violated the assumption of normality, Wilcoxon Signed-Rank Tests for non-parametric data were calculated (Munro, 2001; Pagano & Gauvreau, 2000). Data were analyzed using SPSS 14.0 (SPSS Inc, Chicago, IL) and SAS version 9.1 (SAS Institute Inc., Cary, NC).

Results

There were 188 patients screened from five medical oncology and thoracic surgery lung cancer clinics during the time period January 2006 through June 2007. Of the patients screened, 60 (31.9%) were eligible, seven refused to participate, and 53 (88.3%) enrolled. Of the 53 enrolled, only 27 (50.9%) reached the 6 month study endpoint. Of the remaining 26 patients, 23 (43.3%) were lost to attrition: 17 were known to be deceased, one withdrew, and five were unable to be located at 6 months. (Note: to date, three subjects have not reached the 6 month study end). Due to the small sample size at 6 months statistical comparison between smokers and quitters was not able to be conducted. As such, only a descriptive analysis was conducted for this study.

Lung Cancer Characteristics

The majority of the sample was diagnosed with non-small cell lung cancer (79.2%) and were in the late stages of disease (69.2%) (see Table 2.1). Forty-two percent of the sample had already begun cancer treatment (chemotherapy, radiation therapy, and/or surgery) at baseline. At study entry, the mean time since diagnosis (date of pathology) was 25.7 days. Almost half reported hypertension (47.2%), about one-third reported cardiac and pulmonary diseases (30.2% and 32.1%, respectively), and 11.3% had a history of a second primary cancer diagnosis. Over half of the sample, 60.8%, exhibited elevated depressive symptoms, with a mean score of 19.4 on the CES-D. Only 35.3% reported being treated for depression in the past, and 23.5% were on current anti-depressant therapy (for the indication of depression).

Sociodemographic Characteristics ***(Self)***

Sociodemographic characteristics of the sample are found in Table 2.2. The average age of this sample was 56.5 years. Fifty-one percent of the sample was female and most were married (51.9%) and were white (84.9%). Almost half of the sample reported having private insurance. Forty percent had Medicaid and 5.7% had no insurance; 42.9% reported an annual household income of <$25,000. Some college was the most reported education category (29.4%), 25.5% had a high school degree only, 11.8% had a General Education Development (GED) degree, and 7.8% had college or post graduate degrees.

Biobehavioral Characteristics ***(Self)***

The sample reported smoking 16 cigarettes per day on average and the average number of years smoked was 36.8 (see Table 2.3). The average number of quit attempts was 5.1. The sample’s mean FTND score was 5.0 and mean salivary cotinine concentration was 403.4ng/ml. A small percentage was actively using nicotine replacement therapy (15.7%), with the majority using the nicotine patch; 9.8% were currently taking bupropion or varenicline. About half of the sample reported living with a smoker (47%).

Illness Representation

The results of the IPQ-R at baseline and second time point are summarized in Table 2.4. Patients perceived, on average, 5.4 of their symptoms to be related to their lung cancer (identity) at baseline, and 6.6 at the second time point. The acute/chronic timeline attribute mean scores indicated that patients believed their disease was more chronic than acute. The cyclical timeline scores showed that patients had a stronger belief in the cyclical nature of their lung cancer. Patients held strong beliefs about the personal and treatment controllability of lung cancer. Patients had a consistently high perception of negative consequences of their lung cancer. Patients reported illness coherence (understanding of their lung cancer) scores that were in the middle of the range, 16.3 and 17.3 (baseline and second time point, respectively). The reported mean emotional representation attribute was high at both time points.

IPQ-R descriptive results for patients who provided data for all of the time points (baseline, second time point, and 6 months) and results of the within-subjects repeated measures ANOVAs and Wilcoxon Signed-Rank Tests can be found in Table 2.5. All data had a normal distribution, except for the identity attribute. The identity data (at all 3 time points) had a mixed distribution. There appeared to be a binary response, where many subjects reported having either zero or 12 symptoms, with a more normal distribution of data in between. The identity means significantly increased over the 3 time points. The second time point (p=0.026) and 6 month time point (p=0.01) had significantly higher means than at baseline. Significant differences between means of the person control attribute were detected, with the 6 month time point being significantly lower than at baseline. The acute/chronic timeline means were significantly different, the 6 month time point indicated a more chronic belief than the second time point. The treatment control attribute had different means between time points that were also significant, with the 6 month time point being lower than at baseline.

Reason for Smoking or Quitting ***(Illness Representation)***

At baseline, patients who responded to the question, “What is the primary reason you have not quit smoking?” most often identified addiction as a major reason for not quitting smoking prior to their lung cancer diagnosis (see Table 2.6). Enjoyment, lack of desire to quit, and lack of will power were also commonly reported reasons. At 6 months, smokers who responded to the question, “What is the primary reason you have not quit smoking?” stated that nervousness, anxiety, addiction, and habit were major reasons for not quitting. Successful quitters identified treatment and disease-related symptoms as motivators for their success in quitting.

Six Month Outcome Data

Lung Cancer Treatment

Twenty-five patients (92.6%) received some treatment for lung cancer (chemotherapy, radiation therapy, and/or surgery) in the previous 6 months, and the remaining two patients received radiation or had surgery prior to study entry. Twenty-one patients (77.8%) received chemotherapy as a component of their lung cancer treatment. The majority of patients (51.9%) received chemotherapy plus radiation therapy for their prescribed lung cancer treatment (data not presented in table).

Smoking Status ***(Coping Procedure)***

Twenty-seven patients completed data collection at 6 months. Seven patients self-reported quitting smoking and of these, five (18.5%) were biochemically confirmed to be abstinent by saliva cotinine. Most patients (77.8%) made at least one attempt to quit smoking in the previous 6 months, and smokers reported a high mean number of quit attempts (3.6) and their main FTND score was 4.0 (see Table 2.7). Two patients (both smokers) reported currently taking either bupropion or varenicline and three smokers reported using the nicotine patch.

Depressive Symptoms

Three quitters (1 out of 5 or 20.0%) and ten smokers (10 out of 21 or 47.6%) reported elevated depressive symptoms at 6 months (see Table 2.7). The mean CES-D score for quitters was 11.8 and the mean score for smokers was 20.1.

Illness Representation

The descriptive results of the IPQ-R at 6 months by smoking status are summarized in Table 2.8. Although not statistically compared due to small numbers, smokers reported higher mean identity, chronic and cyclical timeline, and emotional representation scores. Quitters reported higher mean person and treatment control, consequences, and illness coherence scores.

Quality of Life ***(Outcome Appraisal)***

Fifty patients provided answers for the LCSS questionnaire (0-100 scale range) and the mean score was 40.0, with a lower score indicative of a better quality of life (see

Table 2.9). At 6 months, the mean score for the LCSS (n=24) was 37.5. Although not statistically compared due to the small numbers, quitters at 6 months reported a better mean LCSS than smokers (23.8 and 39.8, respectively).

Discussion

This study was conducted to examine smoking behavior among newly diagnosed lung cancer patients at baseline and 6 months. This is the first longitudinal study to examine a comprehensive set of sociodemographic and biobehavioral characteristics, and constructs of the Self-Regulation Model of Illness exclusively in male and female lung cancer patients who smoke. The most interesting findings of this study were the high number of patients with elevated depressive symptoms and the surprising number of deaths before 6 months. Furthermore, the change in illness representation scores over time may provide a useful guide for further development of smoking cessation interventions in lung cancer patients. Unfortunately, due to the small sample size and percentage being smoke free (18.5%) at 6 months, statistical comparison between smokers and quitters was not conducted. Importantly, most patients (77.8%) made at least one attempt to quit smoking during the 6 month study period. Similar to other findings in the literature, lung cancer patients have the desire to and are motivated to quit smoking (Browning et al., 2000; Wewers et al., 1997).

At the time of study entry, patients continued to smoke on average more than 3 weeks after diagnosis, suggesting that the initial shock of having lung cancer did not motivate patients to ‘quit cold turkey’. Although patients may not have known the pathology results for a few days following biopsy, continued smoking 3 weeks after diagnosis suggests that an intensive intervention may be required to assist lung cancer patients to quit smoking.

Depressive Symptoms

It is established that patients experience depression at the time of a lung cancer diagnosis and during treatment (Carlsen et al., 2005; Hopwood & Stephens, 2000), and there is a link between depression and continued smoking (Anda et al., 1990; Berard et al., 1998; Cooley et al., 2007; Covey et al., 1997). A large number of patients in this study (61%) indicated they had depressive symptoms. Depression may have been a confounding factor contributing to the low number of successful quitters, despite having had a desire and motivation to quit smoking. In future studies with SRMI theory, depression may be best conceptualized in the model under 'representations of self'; further characterizing how a depressed individual with nicotine dependence views lung cancer.

Illness Representation

This study was the first to examine illness representation among lung cancer patients who smoke. The significant increase in the identity attribute over time was consistent with a patient experiencing increased disease and treatment-related symptomatology. Lung cancer patients were identifying their symptoms to be related to their disease. The majority of patients in this study continued to smoke, also contributing to increased symptoms. Interestingly, quitters at 6 months reported experiencing less symptoms of their lung cancer than smokers (not statistically compared).

The significantly increased belief over time that lung cancer was a chronic disease (timeline acute/chronic) suggested that at diagnosis, patients may not have understood the nature of living with a chronic disease. Over time, patients had an increased understanding of the chronicity of their disease. Although not statistically compared, smokers reported a chronic disease belief that was stronger than quitters. Continued smoking behavior may have accentuated patients' beliefs in the chronicity of their lung cancer.

The increased trend (although not significant) of the cyclical nature of lung cancer was consistent with patients who had recently completed or were receiving chemotherapy. Chemotherapy treatment for lung cancer is usually given for 1-3 days during a 21 day cycle, and the symptoms experienced by the patient also follow the same cyclical pattern. The majority of patients in this study received chemotherapy.

A strong belief in the personal and treatment controllability of lung cancer was exhibited by patients at baseline. This is appropriate for patients who were actively undergoing lung cancer treatment, which was true for all patients in this sample. Both attributes had a significantly decreased trend over time. The decrease over time could have been attributed to patients who were realizing the serious nature and poor prognosis of their disease. Unsuccessful attempts to quit smoking, as demonstrated by this sample, may also have decreased patient's beliefs in the personal and treatment controllability of their disease. Furthermore, smokers reported lower personal and treatment controllability at 6 months (not statistically compared).

The patients' consistent, strong belief that lung cancer produced negative consequences was expected, given the known toxicity of lung cancer treatment and disease. Continued smoking, despite known benefits of quitting, also may have contributed to patient's beliefs in the negative consequences of their lung cancer.

Illness coherence scores (understanding of illness) were relatively stable over time and reflected that patients were beginning to develop a comprehensive understanding of their lung cancer, but could benefit from further education. The decreased trend (although not significant) of the emotional representation attribute reflected a decreased emotional response to lung cancer, perhaps suggesting that at 6 months patients were more accepting of their diagnosis and/or treatment. Although not statistically compared, smokers reported a higher emotional representation than quitters, perhaps suggesting their emotional struggle with unsuccessful attempts to quit smoking.

Reason for Smoking or Quitting

According to the U.S. Surgeon General's report on nicotine dependence (1988), the positive effects of nicotine addiction are: pleasure, relaxation, arousal, improved attention, concentration, and reaction time, improved performance on certain activities, decreased anxiety and stress, prevention of weight gain (control hunger), and relief of withdrawal symptoms. At baseline in this study, the majority of the stated reasons for continuing to smoke were reflective of known symptoms and side effects of nicotine addiction. Furthermore, 'enjoying smoking' and 'not wanting to quit' were frequently cited as reasons for not quitting. At 6 months, however, only three smokers stated 'don't want to' as a reason for not quitting. The rest of the smokers either identified addiction-related reasons for lack of success, or stated they were trying or unable to quit. Again, these results confirm that lung cancer patients do desire to quit smoking. Successful quitters all attributed reasons for success and motivation to quit to lung cancer treatment, suggesting that beginning lung cancer treatment could be a teachable moment during smoking cessation interventions.

Six Month Outcome Data

Although statistical comparison between smokers and quitters was not able to be conducted, some descriptive characteristics of successful quitters and continued smokers in this study were congruent with findings from the literature. In this study, most patients (77.8%) had at least one quit attempt in the previous 6 months, similar to a study in women with lung cancer where 90% tried to quit in the previous year (Cooley et al., 2007), but higher than a study with head and neck and lung cancer patients where only 62% reported that they had attempted to quit for at least 24 hours in the previous 6 months (Schnoll et al., 2002).

The high percentage of depressive symptoms that was reported by this sample (at baseline and by smokers at 6 months) is similar to findings reported by Cooley et al. (2007), where women lung cancer patients with depressive symptoms were more likely to be smokers. The mean CES-D score for quitters in this study at 6 months was lower than the mean reported by the smokers (11.8 and 20.1, respectively). Only a small number of patients reported using pharmacotherapy either at study entry or at 6 months, suggesting an under utilization of known nicotine dependence treatment (Fiore et al., 2000).

Quality of Life

The quality of life scores for the LCSS were similar at baseline and 6 months, indicating that patients rated their quality of life to be relatively stable. This study's reported mean reflected a lower quality of life as compared to another study with a smoking lung cancer sample (n=75, mean=28.7, SD=5.09) (Garces et al., 2004). The current study included lung cancer patients who were within 60 days of their diagnosis as compared to the Garces et al. (2004) study that included patients who were at least 6 months to 5 years after diagnosis. Measuring quality of life in patients during the first 8 months following diagnosis may have captured a cohort that was still experiencing side effects of treatment and disease.

Limitations

A large percent of patients were deceased before reaching the study endpoint (32.1%). The sample may have been a sicker cohort of patients as compared to other lung cancer patients at another comprehensive cancer institution. Although 69% of the patients were diagnosed in late stage lung cancer, this attrition was not expected. The average length of life for a late stage lung cancer patient (non-small cell and small cell) with treatment is 10-12 months from the time of diagnosis (Mountain, 1997). In this study, smokers may have been sicker, less responsive to treatment (chemotherapy and/or radiation), and had more comorbidities. Each of these factors could have contributed to a shorter survival. The literature supports that continued smoking after diagnosis is associated with decreased survival (Johnson-Early et al., 1980; Kawahara et al., 1998; Richardson et al., 1993; Videtic et al., 2003), however, most studies have examined lung cancer survival at 2-5 years post diagnosis. Future studies should examine lung cancer survival among *smokers* in the 6 months following diagnosis.

Future Research

The results of this study will contribute to developing future smoking cessation interventions with lung cancer patients, and guide future research questions for this patient population. Research studies should examine depression and the use of anti-depressant therapy among currently smoking lung cancer patients and quitters. An unexpected large percentage of patients were deceased before reaching the 6 month study endpoint. Examining the smoking status and length of survival among lung cancer patients in a population-based sample is warranted. As demonstrated, lung cancer patients are willing to quit smoking and despite known benefits, some lung cancer patients continue to smoke. As these patients are dealing with a serious illness, likely caused by their smoking behavior, this population may require an intensive intervention to quit smoking. The next step is to use the outcome of the illness representation attributes from this study to plan a behavioral intervention as well as variables such as nicotine dependence and depression to guide an intensive smoking cessation intervention for lung cancer patients.

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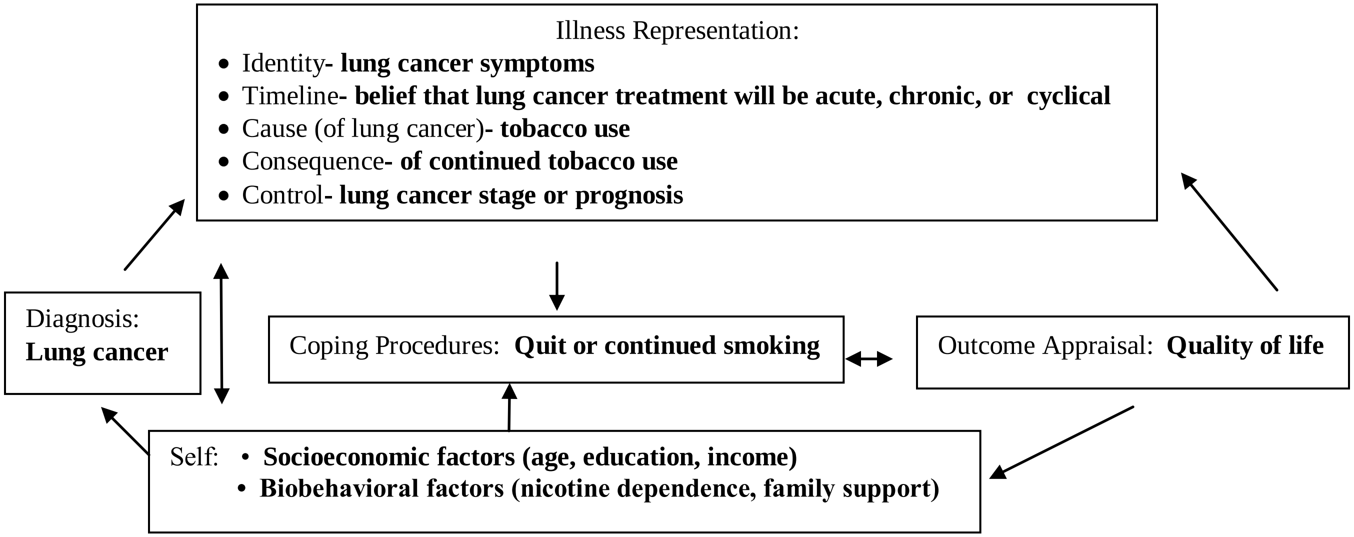

Figure 2.1
Self-regulation model applied to tobacco use in smokers recently diagnosed with lung cancer

Variables	**n**	**%**	**mean (SD)**	**range**
Pathology (n=53)				
Small cell	11	20.8		
Non-small cell	42	79.2		
Stage (n=52)				
Early (I-IIIA, limited)	16	30.8		
Late (IIIB, IV, extensive)	36	69.2		
Cancer treatment at baseline (n=53)				
No treatment	31	58.5		
Surgery	6	11.3		
Radiation (XRT)	7	13.2		
Chemotherapy	4	7.6		
Chemo + XRT	5	9.4		
Time since diagnosis (days)	53		25.7 (14.34)	3-58
Comorbidities				
Hypertension (n=53)	25	47.2		
Cardiac disease (n=53)	16	30.2		
Pulmonary disease (n=53)	17	32.1		
Other cancer (n=53)	6	11.3		
Depression data				
Depressive symptoms (n=51)	31	60.8		
CES-D total score	51		19.4 (10.61)	1-38
Previous depression treatment (n=51)	18	35.3		
Current anti-depressant medication (n=51)	12	23.5		

Table 2.1
Lung cancer characteristics at baseline

Variables	**n**	**%**	**mean (SD)**	**range**
Age	53		56.5 (10.0)	25-80
Gender (n=53)				
Male	26	49.1		
Female	27	50.9		
Insurance (n=53)				
Private	22	41.5		
Medicare	3	5.7		
Medicaid	14	26.4		
No insurance	3	5.7		
Private + Medicare	4	7.5		
Medicaid + Medicare	7	13.2		
Education (n=51)				
Some HS	11	21.6		
HS	13	25.5		
GED	6	11.8		
Trade school	1	2.0		
Associate degree	1	2.0		
Some college	15	29.4		
College	2	3.9		
Post graduate	2	3.9		
Race (n=53)				
African American	7	13.2		
White	45	84.9		
Other	1	1.9		
Marital Status (n=52)				
Married	27	51.9		
Widowed	4	7.7		
Divorced	11	21.2		
Never married	5	9.6		
Living with partner	5	9.6		
Income (n=49)				
<$25K	21	42.9		
$25K-$50K	10	20.4		
>$50K	9	18.4		
Refused	5	10.2		
Don’t know	4	8.2		

Table 2.2
Sociodemographic characteristics

Variables	**n**	**%**	**mean (SD)**	**range**
CPD	51		16.0 (11.01)	0-40
Years smoked	51		36.8 (11.24)	8-65
Previous quit attempts	50		5.1 (14.52)	0-100
FTND	46		5.0 (1.91)	1-9
Cotinine ng/mL	49		403.4 (310.84)	10-1471
Living with a smoker (n=51)	27	47.1		
Current NRT (n=51)	8	15.7		
NRT (n=8)				
gum	1	12.5		
patch	6	75.0		
combination	1	12.5		
Current bupropion/varenicline (n=51)	5	9.8		

Table 2.3
Smoking history characteristics at baseline

	Possible Range	Baseline			Second Time Point*		
IPQ-R Attributes		**n**	**mean (SD)**	**range**	**n**	**mean (SD)**	**range**
Identity	(0-14)	51	5.4 (3.86)	0-12	47	6.6 (4.34)	0-14
Timeline (acute/chronic)	(0-30)	52	17.8 (5.61)	3-29	47	18.2 (5.02)	10-30
Timeline (cyclical)	(0-20)	52	11.6 (2.28)	6-18	47	12.0 (2.59)	7-18
Personal control	(0-30)	52	22.4 (4.00)	12-30	47	21.4 (4.16)	6-30
Treatment control	(0-25)	52	18.8 (2.88)	13-25	46	18.7 (2.39)	13-24
Consequence	(0-30)	52	23.7 (3.60)	14-30	47	23.6 (4.67)	9-30
Illness coherence	(0-25)	51	16.3 (4.26)	6-24	47	17.3 (4.39)	6-25
Emotional representation	(0-30)	51	21.5 (4.58)	10-30	47	20.5 (4.44)	13-29

Table 2.4
Results of the Illness Perception Questionnaire-Revised at baseline and second time point

*2-4 weeks

IPQ-R Attributes	Possible Range	Baseline			Second Time Point*			6 Months		
		n	mean (SD)	range	n	mean (SD)	range	n	mean (SD)	range
Identity***, [d]	(0-14)	27	4.9 (3.52)	0-12	27	6.7 (4.20)	0-14	27	7.0 (3.97)	0-12
Timeline (acute/chronic)[a]	(0-30)	27	17.7 (4.55)	10-29	27	16.9 (4.43)	10-26	27	19.7 (5.35)	8-30
Timeline (cyclical)	(0-20)	26	11.6 (2.38)	6-16	26	11.8 (2.47)	8-18	26	12.4 (3.16)	7-16
Personal control[b]	(0-30)	27	23.0 (2.96)	16-28	27	21.8 (2.99)	15-28	27	21.0 (3.26)	12-26
Treatment control[c]	(0-25)	26	19.3 (2.64)	13-24	26	19.0 (2.01)	15-24	26	17.9 (3.22)	9-23
Consequence	(0-30)	26	23.9 (2.57)	19-30	26	23.2 (4.85)	9-30	26	23.4 (4.59)	10-29
Illness coherence	(0-25)	26	15.5 (4.60)	6-24	26	16.6 (4.60)	6-23	26	16.5 (3.84)	9-21
Emotional representation	(0-30)	27	21.3 (4.86)	10-30	27	19.5 (3.63)	14-26	27	19.7 (3.88)	12-29

Table 2.5
Results of the Illness Perception Questionnaire-Revised over time**

*2-4 weeks

**Differences between means calculated by within-subjects repeated measures ANOVA except for identity attribute

*** Differences between means calculated by Wilcoxon Signed-Rank Tests

[a] F=4.420, df=2, p=0.017

[b] F=4.948, df=2, p=0.011

[c] F=3.299, df=2, p=0.045

[d] Baseline vs. second time point: s=59, p=0.026; baseline vs. 6 months: s=75.5, p=0.005

Patient Responses at Baseline (n=47)	n	Smoker Responses at 6 Months (n=17)	n	Quitter Responses at 6 Months (n=5)	n
Addiction/habit	11	Nervous/anxiety	5	Surgery	2
Enjoy it	8	Addicted/habit	6	Hospitalization	1
Don’t want to quit	8	Stress	3	Acupuncture/meditation	1
No will power/can’t quit	7	Don’t want to	3	Started chemo	1
Stupid/weakness/hardheaded	4	Can’t/no will power	2	Makes cancer treatment harder	1
Calming/relaxing	3	Cutting down/trying to quit	2	Family support	1
Not ready to quit	2	Depression	1	Cancer	1
Fear/scared/overwhelmed	2	Family smokes	1		
Not sure	2	Starting medication to help quit soon	1		
Depression	1				
Weight gain	1				
Cutting down/trying to quit	1				

Table 2.6
Reasons cited as successful and not successful in quitting smoking*

*Categories are not mutually exclusive

	Quitters (n=5)			Smokers (n=22)		
Variables	**n or %**	**mean (SD)**	**range**	**n or %**	**mean (SD)**	**range**
CPD	--			19	12.2 (7.83)	1-30
FTND	--			18	4.0 (2.11)	0-8
No. of quit attempts in past 6 months	5	1.4 (0.89)	1-3	18	3.6 (3.00)	0-10
% ≥1 quit attempt in past 6 months	100%			72.7%		
% Current use of NRT [a, b]	0%			14.3%		
% Current bupropion/ varenicline use [a, b]	0%			9.5%		
% Depressive symptoms [b]	20.0%			47.6%		
CES-D total score	5	11.8 (9.39)	4-28	21	20.1 (12.14)	6-44

Table 2.7
Smoking characteristics and depressive symptoms by smoking status at 6 months

[a] missing data for quitters (n=3 for identified variables)

[b] missing data for smokers (n=21 for identified variables)

IPQ-R Attributes	Possible Range	Quitters			Smokers		
		n	**mean (SD)**	**range**	**n**	**mean (SD)**	**range**
Identity	(0-14)	5	4.8 (0.84)	4-6	22	7.3 (4.15)	0-12
Timeline (acute/chronic)	(0-30)	5	18.4 (1.67)	16-20	22	20.3 (5.73)	8-30
Timeline (cyclical)	(0-20)	5	10.2 (2.05)	8-12	21	12.4 (2.75)	7-16
Personal control	(0-30)	5	22.0 (2.83)	19-25	22	21.1 (3.39)	12-26
Treatment control	(0-25)	5	19.2 (1.92)	16-21	21	17.5 (3.42)	9-23
Consequence	(0-30)	5	26.2 (1.10)	25-27	21	22.8 (4.88)	10-29
Illness coherence	(0-25)	5	17.4 (2.97)	13-20	21	16.4 (4.12)	9-21
Emotional representation	(0-30)	5	16.4 (4.04)	12-20	22	20.4 (3.77)	14-29

Table 2.8
Results of the Illness Perception Questionnaire-Revised at 6 months by smoking status

Variables	**n**	**mean (SD)**	**range**
LCSS at baseline	50	40.0 (19.05)	9.9-86.3
LCSS at 6 months	26	37.3 (15.04)	7.0-61.0
LCSS: smokers at 6 months	21	39.8 (14.68)	14.7-61.0
LCSS: quitters at 6 months	5	23.8 (15.79)	7.0-41.3

Table 2.9
LCSS* at baseline and at 6 months by smoking status

*Lower score denotes a better (higher) quality of life, possible range of 0-100

CHAPTER 3

QUALITY OF LIFE IN LUNG CANCER PATIENTS WHO SMOKE

Lung cancer is the leading cause of cancer death for both men and women in the United States, responsible for approximately 167,050 deaths in 2007 (Jemal et al., 2007). The 5 year survival rate for all stages of lung cancer is poor, approximately 15.5% (Surveillance Epidemiology and End Result (SEER) Program & National Cancer Institute, 2007). Surgery, chemotherapy, and/or radiation therapy are the cornerstones of treatment for lung cancer, all of which directly contribute to patient quality of life (QOL) (Ettinger et al., 2006). Lung cancer patient self-assessment of QOL is highly valued among clinicians as it guides treatment-related decisions and impacts clinical outcomes (Hollen, Gralla, & Rittenberg, 2004). More than half of lung cancer patients are diagnosed in the advanced stages of the disease and chemotherapy is the primary indicated treatment (Ettinger et al., 2006; Reis et al., 2006). Patient QOL prior to cancer treatment is known to be a strong predictor of survival and toleration of treatment toxicities. For patients with advanced lung cancer with a poor prognosis, the goal of treatment is improvement in QOL and disease-related symptomotology (Cella, 2003). To assess improvement, a reliable and valid QOL measure specific to lung cancer is required.

Background

QOL is a multidimensional construct that includes physical, functional, social, psychological, and spiritual domains (Donovan, Sanson-Fisher, & Redman, 1989; Sarna et al., 2002). Research aims should guide instrument selection based on QOL components that are necessary for evaluating study outcomes (Hollen & Gralla, 1996). For example, the research aims of a chemotherapy clinical trial may require a QOL tool that measures physical and functional domains in order to assess treatment-related toxicities, while other research aims may require a broader representation of QOL, including social and psychological domains. Other factors such as length and subject burden may also be important to consider when selecting a QOL instrument.

There are several accepted disease and site specific instruments that are used to measure QOL in lung cancer patients (Hollen & Gralla, 1996). The *Functional Assessment of Cancer Therapy-Lung Cancer (FACT-L)* is a multi-dimensional QOL self-report instrument that is specific to lung cancer and includes five subscales. A core component (FACT), consisting of four subscales, is designed to measure general cancer-related QOL, including components of the physical, functional, social, and emotional domains of QOL (Cella et al., 1993; Cella et al., 1995). The addition of a lung cancer scale, which is designed to measure symptomotology related to lung cancer, comprises the FACT-L. FACT-L version 3 is the most recent psychometrically tested version of the instrument (Cella et al., 1995). The *European Organization for Research and Treatment of Cancer Quality of Life Questionnaire* (EORTC-QLQ) is another lung cancer specific QOL instrument that is similar to the FACT-L, including components of the physical, functional, social, and emotional domains (Aaronson et al., 1993). The *Lung Cancer Symptom Scale (LCSS)* is a third lung cancer specific self-report QOL instrument. This instrument is more focused as it only includes components of the physical and functional domains of QOL and lung cancer symptomotology (Hollen, Gralla, Kris, & Potanovich, 1993). These tools have all been utilized for measurement of patient reported QOL in many chemotherapy clinical trials (Hollen & Gralla, 1996; Montazeri, Gillis, & McEwen, 1998).

The relationship between QOL and smoking has been reported in the literature. Tobacco use is the strongest risk factor for developing lung cancer (USDHHS, 1988). Eighty-seven percent of lung cancer patients have a history of smoking (current or ex-smokers) and approximately 13-20% of current lung cancer patients continue to smoke after diagnosis (Cox et al., 2002; Evangelista, Sarna, Brecht, Padilla, & Chen, 2003; Schnoll et al., 2002; Schnoll et al., 2003). A population-based study of 3,010 participants reported that smokers had a significantly lower QOL than former smokers; heavier smokers had a significantly lower QOL than lighter smokers (Wilson, Parsons, & Wakefield, 1999). Tillmann et al. (1997), in a study of 1,665 individuals from nine primary care practices, found that current smokers had a lower self-rated QOL than former smokers.

To date, only one study has examined QOL in *lung cancer* patients who currently smoke. In this cross sectional study, QOL was examined at $\geq$6 months after diagnosis in 1,028 patients (Garces et al., 2004). Persistent smokers had a significantly worse QOL than never smokers as measured by the LCSS (Garces et al., 2004). Former smokers (i.e. those who quit before diagnosis) and abstinent smokers (i.e. quit between diagnosis and follow-up period) had LCSS scores similar to never smokers, which further supports an association between continued smoking and a lower QOL. The psychometric properties of the FACT-L and the LCSS QOL scales have been well studied, but have not been examined exclusively in smokers (Cella et al., 1993; Cella et al., 1995; Hollen et al., 1993; Hollen et al., 1994).

The FACT-L & EORTC-QLQ are conceptually similar in measuring QOL in lung cancer patients and both are different from the LCSS. To date, a 'gold standard' instrument for the measurement of lung cancer QOL has not been identified since there has never been a comparison study examining the correlation between these QOL instruments. The LCSS is the only QOL tool that has measured QOL in lung cancer patients who smoke but its internal consistency has not been reported. This paper will report the internal consistency and convergence validity of the FACT-L and the LCSS among newly diagnosed lung cancer patients who smoke.

Methods

Design/Sample

The data for this analysis came from a prospective, one-group longitudinal study designed to describe sociodemographic and behavioral characteristics, illness representation, and quality of life among recently diagnosed lung cancer patients who smoke. Patients were eligible if they were age 18 years or older, had a confirmed diagnosis of lung cancer (non-small cell or small cell) within the past 60 days, and self-reported current smoking within the past seven days. Patients had to be able to understand English and provide informed consent. Recruitment took place within the thoracic oncology outpatient clinics at The Ohio State University Comprehensive Cancer

Center (OSUCCC), an urban, academic, tertiary care medical center. At baseline and 6 months following enrollment, patients completed a series of questionnaires, including the QOL tools FACT-L and LCSS. Verbal and written instructions for the questionnaires were given to each patient. This study was approved by and in compliance with the institution's Human Subjects Cancer Review Board. Only the baseline QOL data is presented here.

Study Measures

Sociodemographic, lung cancer, and tobacco use history variables were collected upon study entry. Sociodemographic variables included: age, gender, insurance type, education, race/ethnicity, marital status, and household income. Histology, stage, and any prior treatment for the current diagnosis were the lung cancer variables. Tobacco use variables included cigarettes per day (CPD), number of years smoked, number of serious quit attempts, and the Fagerström Test for Nicotine Dependence (FTND), an accepted, reliable self-report measure of nicotine dependence among current smokers (Heatherton, Kozlowski, Frecker, & Fagerström, 1991).

Functional Assessment of Cancer Therapy-Lung Cancer (*FACT-L).*

The FACT-L (version 3) is a reliable and valid 44-item paper and pencil self-assessment questionnaire that measures QOL over the past week in patients with lung cancer (Cella et al., 1995). It has been widely used in clinical trials to evaluate symptoms and QOL in clinical trials with lung cancer patients (Cella et al., 2005). The FACT-L is made up of five subscales that include physical well-being (PWB), social/family well-being (SWB), emotional well-being (EWB), functional well-being (FWB), and symptoms of lung cancer scale (LCS). Each question is rated on a five-point Likert scale giving a total score for each category as well as a total overall score (0-135). A higher score corresponds to a higher (better) QOL. The Trial Outcome Index of the FACT-L (FACT-L TOI), which is the sum of the PWB, FWB and LCS scales, is a measure of the physical aspects of QOL and often utilized in chemotherapy drug clinical trials to evaluate patient QOL and symptomotology related to study medication.

If any items of the FACT-L are omitted, a score can still be estimated for the subscale as long as the majority of items within a subscale have been answered. Internal consistency (Cronbach's alpha) has been reported to be 0.68 for the LCS subscale, 0.87 for the total core scale (PWB + FWB + SWB + EWB), and 0.89 for the FACT-L TOI (PWB + FWB + LCS) (Cella et al., 1995).

Test-retest reliability for the total core scale was reported as 0.92 (Cella et al., 1993). Construct validity was demonstrated as high, reflecting good convergence and discriminant validity with appropriate scales (Cella et al., 1993; Cella et al., 1995). The sample for this psychometric testing included lung cancer patients (n=116) who either participated in the initial FACT instrument validation or were part of a psychosocial quality of life study (Cella et al., 1995).

Lung Cancer Symptom Scale (LCSS).

The LCSS is a reliable and valid disease and site-specific QOL measure which consists of nine visual analogue scales (0-100mm) assessing QOL in the past 24 hours (Hollen et al., 1993). The 9-scale mean total represents the overall score, with a lower score corresponding to a better QOL. These scales focus on physical and functional dimensions only, including six major symptoms of lung cancer: appetite, fatigue, cough, shortness of breath, hemoptysis, and pain. The remaining three items include a self rating of general lung cancer symptoms, how illness affects normal activities of daily living, and overall QOL (Hollen et al., 1993).

The LCSS has good reliability with reported internal consistency of 0.82, a high reproducibility as indicated in test-retest reliability (n=52 lung cancer patients, r>0.75), and high repeated inter-rater agreement among experts (95%-100% agreement) (Hollen et al., 1994). Validity has also been established for the LCSS. A panel of lung cancer experts, 24 medical oncologists and 28 nurses, were surveyed to confirm representation of items for content validity and 121 patients with advanced lung cancer were surveyed to validate the major symptoms of lung cancer. Results of the expert panel indicated a mean of 96% agreement for all items and lung cancer patients confirmed that symptoms matched their experiences (Hollen et al., 1993). Good convergence with a similar QOL tool and discrimination with unrelated tools demonstrated good construct validity (Hollen et al., 1993). Criterion-related validity, correlation with gold standard measures, was satisfactorily demonstrated with several significant correlations between tools (e.g. Sickness Impact Profile, Profile of Mood States, American Thoracic Society, SF-McGill Pain, and Karnofsky Performance Scale) (Hollen et al., 1993).

Statistical Analysis

Descriptive statistics (percents, means, and standard deviations) were calculated on all sociodemographic, lung cancer, and tobacco use variables and on the FACT-L and LCSS scores. Internal consistency was assessed by estimating Cronbach’s alpha coefficient on the FACT-L and LCSS scores (Nunnally & Bernstein, 1994). Pearson correlation coefficients were estimated between the total FACT-L and the LCSS, the

FACT-L TOI and the LCSS, and each FACT-L subscale and the LCSS. Scatter plots were created to visually represent the relation between each pair of scales named above. Presentation of all the scatter plots illuminates both good and poor relations between each pair of scales. A regression model was fit to each pair of scales in order to further describe the data. The regression model residuals were examined. Histograms on model residuals were examined to determine if the data met the assumption of normality. Normal probability plots were constructed to see if the residual errors were normally distributed. To further assess for model deficiency, residual plots were examined to identify variability not explained by the regression model and to identify outliers (Montgomery & Peck, 1992). All data were analyzed using SPSS 14.0 (SPSS Inc, Chicago, IL).

Results

Sample Characteristics

Fifty-one subjects completed the FACT-L and 50 subjects completed the LCSS at study entry (see Table 3.1 for sample characteristics). The average age of the sample was 57 (SD=10.2). About half of the sample was male (49%) and married (51%), and the majority were white (84%). Thirty-seven percent of subjects reported education of some college or more and 25.5% reported only having a high school education. The majority was diagnosed with late stage non-small cell lung cancer and was treatment naive. The average number of cigarettes smoked per day was 16 and the average number of years smoked was 37 years. Previous quit attempts were reported to be 5.0. The average FTND score was 5.0, indicating moderate nicotine dependence.

Scale Characteristics

The descriptive statistics of patient scores from the QOL scales are presented in Table 3.2. The mean total FACT-L score was 81.1 (range 34-123) and the FACT-L TOI (PWB + FWB + LCS) mean score was 46.3 (range 14-76). The mean score for the LCSS was 40.0 (range 9.9-86.3). In the FACT-L, a *higher* score corresponds with a higher (better) QOL, and in the LCSS, a *lowe*r score corresponds to a higher (better) QOL.

Internal consistency coefficients for the FACT-L, FACT-L subscales and LCSS are presented in Table 3.3. The PWB, SWB, FWB, and EWB scales all demonstrated good reliability with Cronbach's alpha coefficients of 0.81 or higher. The internal consistency coefficient for the LCS scales was lower, 0.61. The FACT-L TOI scale, the total FACT-L scale, and the LCSS scales indicated good reliability with coefficient alphas of 0.88, 0.87, and 0.84 respectively. One-third of participants skipped an item in the SWB subscale of the FACT-L asking about intimacy. As item analyses cannot be calculated unless all data are present, the number of participants included in the item analyses for the total FACT-L and its SWB subscale was lower.

Comparison of QOL Scales

The FACT-L subscale with the strongest correlation to the LCSS was the LCS (r= -0.78). The total FACT-L and the FACT-L TOI also were strongly correlated with the LCSS (r= -0.73 and r= -0.76, respectively). Scatter plots illustrating the relations between the FACT-L scales and the LCSS are presented in Figures 3.1 to 3.7. The correlations were negative because a higher score on the FACT-L represented a better QOL and conversely, a lower score on the LCSS represented a better QOL. The regression model residuals were examined for each pair of scales. Each plotted residual reflected normal data characteristics in the histograms and normal probability plots, and no model defects were detected in the residual plots.

Discussion

This paper was the first to report internal consistency and convergence validity for the FACT-L and the LCSS QOL instruments in a sample of lung cancer patients who smoke. Internal consistency scores were high for each FACT-L component (except for the LCS) and the LCSS, demonstrating good reliability among a sample of lung cancer patients who smoke. The internal consistency scores for the LCSS and FACT-L and its components in this study were similar to data previously reported in the literature (Cella et al., 1993; Cella et al., 1995; Cella et al., 2005; Hollen et al., 1993; Hollen et al., 1994). The FACT-L and the FACT TOI were both strongly correlated with the LCSS, supporting good convergence validity. The FACT-L TOI, which is the most conceptually-related FACT-L measure to the LCSS, demonstrated the strongest correlation. The emotional and social well-being subscales of the FACT-L demonstrated low correlation with the LCSS. Conceptually this was expected as emotional and social well-being domains are not represented components of the LCSS. This further supports the strong correlation between both instruments.

The mean scores reported in this paper for the FACT-L and its components and the LCSS corresponded with a lower (worse) QOL than reported mean scores in the literature (Cella et al., 1995; Hollen, Gralla, Kris, Eberly, & Cox, 1999; Hollen et al., 2005). Garces et al. (2004), reported adjusted mean scores for the total LCSS and individual item scores that were approximately ten points lower, representing a higher (better) QOL than the LCSS means reported in this study. The current study population included newly diagnosed (within 60 days) lung cancer patients who were smokers and the Garces et al. study included smokers who were 6 month or more following diagnosis, suggesting a population of both lung cancer survivors and patients who completed treatment. Sixty percent of the sample in this study was treatment naïve and could have been experiencing disease-related symptoms at baseline, contributing to a worse QOL. Also, 40% of this study sample were currently undergoing treatment and could have been experiencing treatment-related side effects, further affecting QOL. The Garces et al. (2004) paper did not indicate the percent of patient sample that was currently undergoing lung cancer treatment. The majority of the current study population (66%) had late stage lung cancer while only 30% of patients in the Garces et al. (2004) study were late stage. The inclusion of fewer late stage lung cancer patients could potentially contribute to the reported overall better QOL.

The LCSS measures QOL over the past 24 hours whereas the FACT-L measures QOL over the past week. This difference in time interval may limit comparisons of these two measures; however the correlations between the two scales remain high. It could be argued that accurately portraying a patient’s QOL should include subjective, open-ended questioning. Neither the FACT-L nor the LCSS allows for such patient input. However, allowing the research aims to guide the research methods and the selection of a QOL assessment instrument is important. It may be important to characterize change in QOL over a period of time, requiring use of a QOL measurement such as the FACT-L or the LCSS. The LCSS is a visual analogue scale. A criticism of this type of scale is that some patients have difficulty understanding how to mark a visual analogue scale, even with instruction. Participants tend to mark similar places along the visual analogue line, regardless of intended response (Wewers & Lowe, 1990). The short length of the LCSS (9-items) and the narrow focus on only physical and functional components of QOL is useful when evaluating specific side effects of treatment (such as chemotherapy). However, the brevity and narrow focus may not be appropriate when evaluating overall QOL (Montazeri et al., 1998).

In conclusion, QOL is an important measure that is utilized in clinical oncology practice, with several accepted QOL instruments specific to lung cancer. This paper reported good internal consistency scores for the FACT-L, FACT TOI, and the LCSS among newly diagnosed lung cancer patients who smoke. Furthermore, both the FACT-L and FACT-L TOI demonstrate a strong correlation with the LCSS, suggesting good convergence validity. Either of these instruments are appropriate measures for QOL in lung cancer patients. Given the conceptual difference between the two instruments, it is important to carefully consider the research aims when selecting the appropriate QOL measurement instrument.

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Variables	**Mean (SD)**	**n**	**%**	**Range**
Age	56.7 (10.2)	51		25-80
Gender				
Male		25	49.0	
Female		26	51.0	
Insurance				
Private		20	39.2	
Medicare		3	5.9	
Medicaid		14	27.5	
No insurance		3	5.9	
Private + Medicare		4	7.8	
Medicaid + Medicare		7	13.7	
Education				
Some HS		11	21.6	
HS		13	25.5	
GED		6	11.8	
Trade School		1	2.2	
Associate Degree		1	2.2	
Some College		15	29.4	
College		2	3.9	
Post Graduate		2	3.9	
Race				
African American		7	13.7	
White		43	84.3	
Other		1	2.0	
Marital status				
Married		26	51.0	
Widowed		4	7.8	
Divorced		11	21.6	
Never Married		5	9.8	
Living with partner		5	9.8	
Income				
<$25K		21	42.9	
$25K-$50K		10	20.4	
>$50K		9	18.4	
Refused		5	10.2	
Don’t Know		4	8.2	
Pathology				
Small Cell		11	21.6	
Non-Small Cell		40	78.4	
Stage				
Early (I-IIIA, limited)		16	32.0	
Late (IIIB, IV, extensive)		34	68.0	

Table 3.1
Sample characteristics (n=51)

Variables	**Mean (SD)**	**n**	**%**	**Range**
Treatment prior to baseline				
No treatment		30	58.8	
Surgery		6	11.8	
Radiation (XRT)		6	11.8	
Chemo		4	7.8	
Chemo + XRT		5	9.8	
CPD	16.0 (11.0)	51		0-40
Years smoked	36.8 (11.2)	51		8-65
Quit attempts	5.1 (14.5)	50		0-100
FTND	5.0 (1.9)	46		1-9

Table 3.1
Sample characteristics con’t (n=51)

Scale	n	Mean	SD	Range
FACT-L*				
PWB	51	16.5	7.3	1-27
SWB	51	20.4	5.6	4-28
FWB	51	13.8	5.9	2-27
EWB	51	14.2	4.8	3-24
LCS	51	16.2	5.2	5-28
FACT-L	51	81.1	20.1	34-123
FACT TOI	51	46.3	15.7	14-76
LCSS**				
Appetite	50	38.9	29.1	0-86
Fatigue	50	55.4	24.0	0-100
Coughing	50	42.6	28.7	0-100
SOB	50	43.3	32.0	0-100
Hemoptysis	50	11.0	21.5	0-75
Pain	50	39.0	32.2	0-100
Symptoms	50	37.7	30.5	0-100
ADL	50	49.2	29.6	0-98
QOL	50	42.9	28.3	0-100
Overall total score	50	40.0	19.1	9.9-86.3

Table 3.2
Descriptive statistics for the FACT-L and LCSS

*A higher score corresponds with a higher (better) QOL

**A lower score corresponds with a higher (better) QOL

Scale	**Number of items**	**n**	**Cronbach's alpha**
PWB	7	49	0.89
SWB	7	35*	0.81
EWB	6	51	0.83
FWB	7	51	0.83
LCS	7	50	0.61
Total FACT-L	34	34*	0.87
FACT-L TOI	21	49	0.88
Total LCSS	9	50	0.84

Table 3.3
Internal consistency of the FACT-L and the LCSS

*Data presented only for those who completed all items

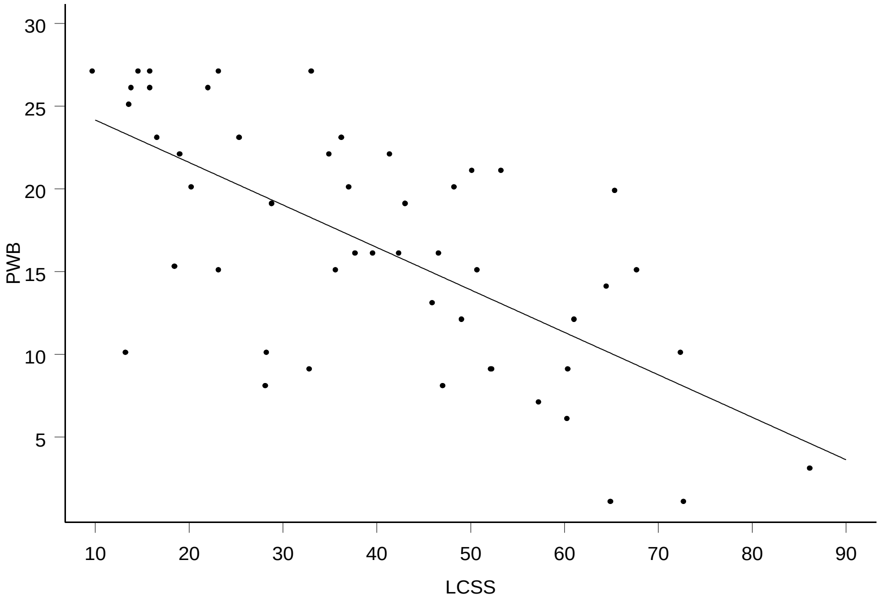

Figure 3.1
Relation between LCSS and PWB*

*r= -0.67

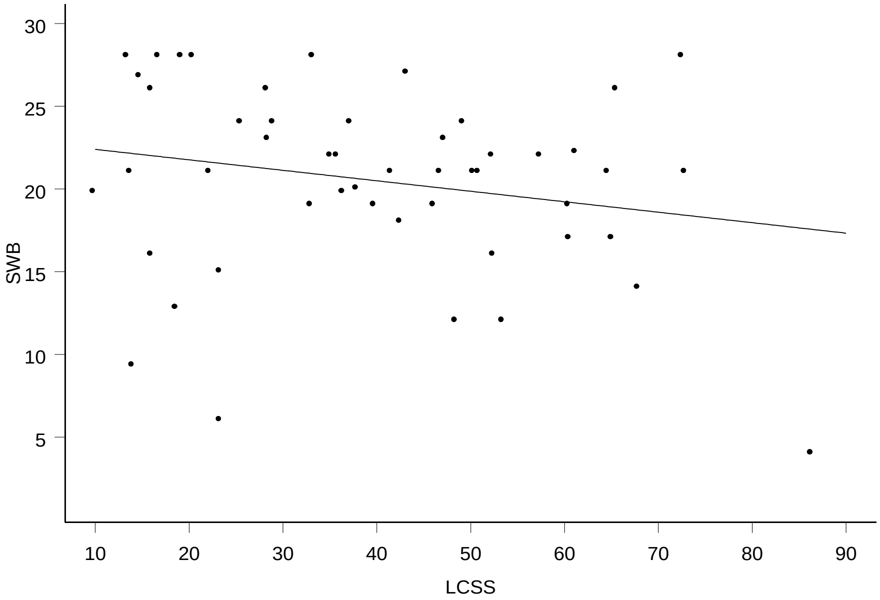

Figure 3.2
Relation between LCSS and SWB*

*r= -0.21

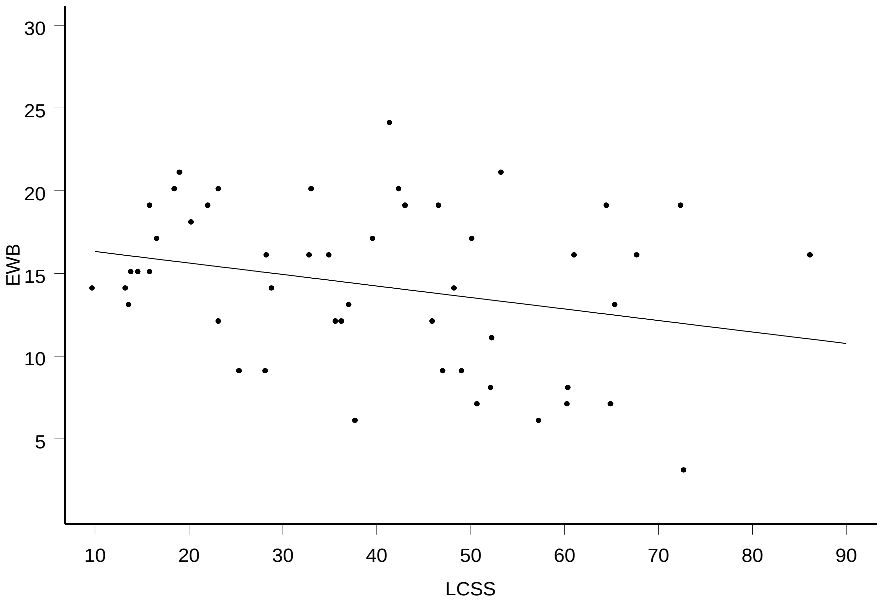

Figure 3.3
Relation between LCSS and EWB*

*r= -0.27

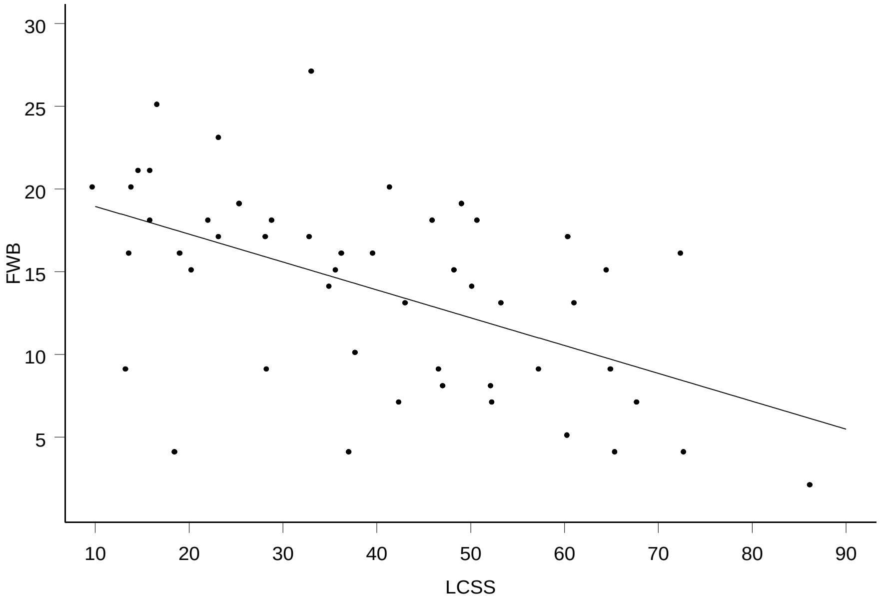

Figure 3.4
Relation between LCSS and FWB*

*r= -0.54

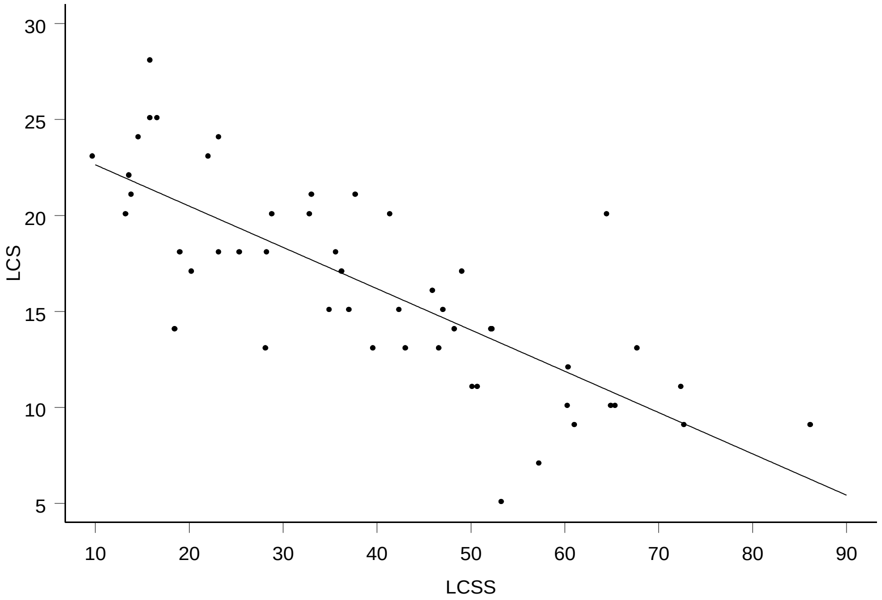

Figure 3.5
Relation between LCSS and LCS*

*r= -0.78

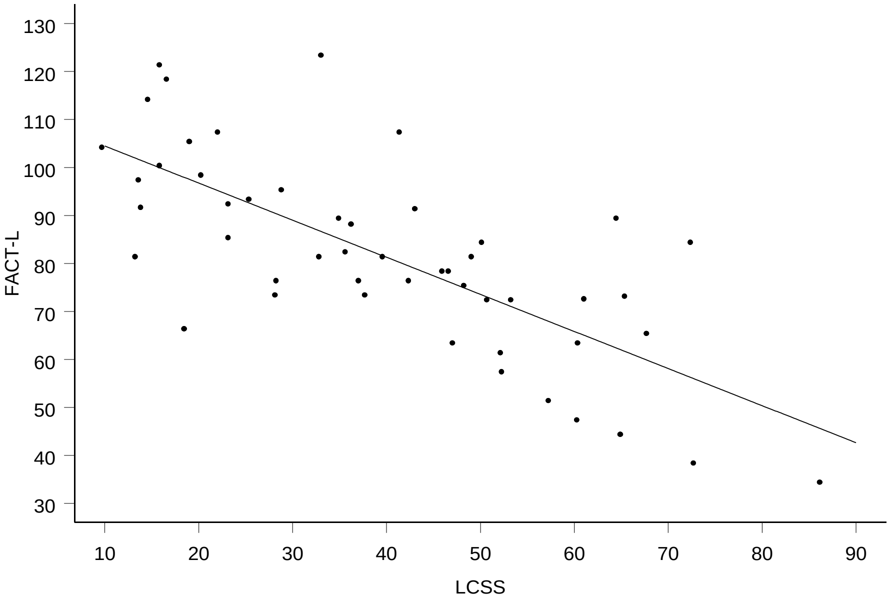

Figure 3.6
Relation between LCSS and FACT-L*

*r= -0.73

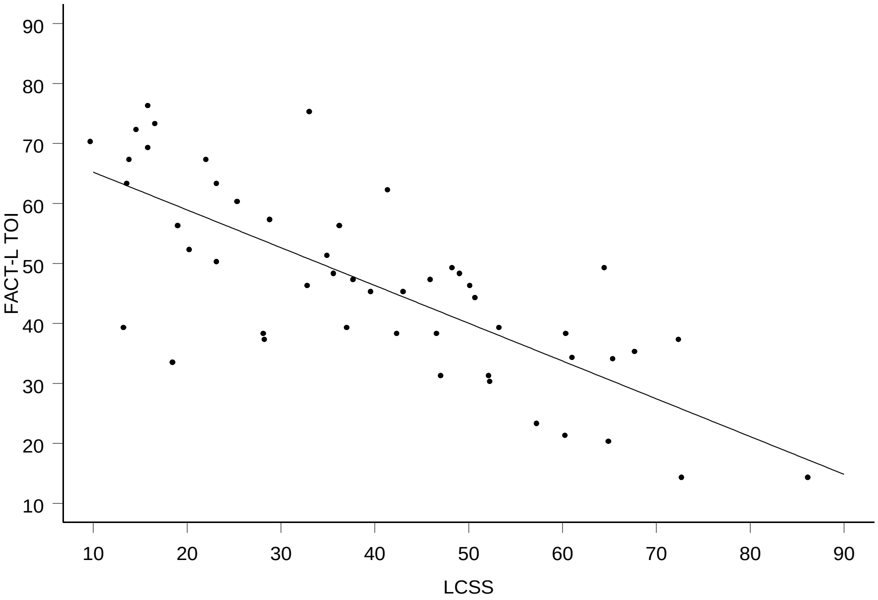

Figure 3.7
Relation between LCSS and FACT-L TOI*

*r= -0.76

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APPENDIX A

PATIENT BASELINE DATA

Name: ____

Contact Information:________________________________

Telephone Number: _________________________________

Mailing Address:___________________________________

City:____

State: ____

Zip: ____

Secondary Contact Information:

Name: ____

Relationship: ______________________________________

Telephone Number: _________________________________

Mailing Address:___________________________________

City:____

State: ____

Zip: ____

Date form completed:

__ __ / __ __ / __ __ __ __

1. Age___________ years

2. Birthdate __ __ / __ __ / __ __ __ __
MM DD YEAR

3. Sex
   1. Male
   2. Female

4. Insurance Type (circle all that apply)
   1. Private
   2. Medicare
   3. Medicaid
   4. Self-pay

5. Education
   1. Less than 9th grade
   2. Some high school
   3. High school graduate
   4. GED
   5. Trade school graduate
   6. Associate degree
   7. Some college
   8. College degree
   9. Post graduate degree

6. Ethnicity:
   1. American Indian
   2. Alaskan Native
   3. Asian or Pacific Islander
   4. Black, not of Hispanic Origin
   5. Hispanic
   6. White, not of Hispanic Origin
   7. Other ___________________

7. Are you:
    1. Married
    2. Widowed
    3. Divorced
    4. Separated
    5. Never married
    6. Living with partner
    7. Refused
    9. Don't know

8. Household income
    1. < $25,000
    2. $25,000-$50,000
    3. > $50,000
    7. Refused
    9. Don't know

9. How many adults (≥18 years old) live with you? __________

10. How many cigarettes do you smoke a day?
    ____ cigarettes

11. How many years have you smoked on a regular basis?
    ____ years

12. How many times have you made a serious attempt to stop using tobacco?
    ____ times

13. Are you currently using a nicotine replacement product such as a nicotine patch, gum, inhaler, nasal spray, or lozenge?
    1. Yes   14. If so, which one(s)?________________________
    2. No

15. Do you live with any smokers?
    1. Yes   16. If so, how many?____________________
    2. No

17. Are you currently taking the medication bupropion (Zyban or Wellbutrin)?
    1. Yes
    2. No

18. Have you ever been treated for depression in the past?
    1. Yes
    2. No

19. Are you currently taking any antidepressant medications?
    1. Yes
    2. No

20. What is the primary reason you have not quit smoking?

____

____

____

APPENDIX B

ILLNESS-REPRESENTATION QUESTIONNAIRE-REVISED

(Moss-Morris et al., 2002)

Your Views About Lung Cancer

Listed below are a number of symptoms that you may or may not have experienced since your lung cancer. Please indicate by ***circling Yes or No in each column***, whether you have experienced any of these symptoms since your lung cancer <u>and</u> whether you believe that these symptoms are related to your lung cancer.

	I have experienced this symptom since my lung cancer		**This symptom is related to my lung cancer**	
Pain	YES	NO	YES	NO
Sore Throat	YES	NO	YES	NO
Nausea	YES	NO	YES	NO
Breathlessness	YES	NO	YES	NO
Weight Loss	YES	NO	YES	NO
Fatigue	YES	NO	YES	NO
Stiff Joints	YES	NO	YES	NO
Sore Eyes	YES	NO	YES	NO
Wheeziness	YES	NO	YES	NO

	I have experienced this symptom since my lung cancer		This symptom is related to my lung cancer	
Headaches	YES	NO	YES	NO
Upset Stomach	YES	NO	YES	NO
Sleep difficulties	YES	NO	YES	NO
Dizziness	YES	NO	YES	NO
Loss of Strength	YES	NO	YES	NO

We are interested in your own personal view of how you now see your lung cancer. Please indicate how much you agree or disagree with the following statements about your lung cancer by **marking (X) the appropriate box.**

	Views About Your Lung Cancer	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
IP1	**My lung cancer will last a short time.**					
IP2	**My lung cancer is likely to be permanent rather than temporary.**					
IP3	**My lung cancer will last for a long time.**					
IP4	**This lung cancer will pass quickly.**					
IP5	**I expect to have lung cancer for the rest of my life.**					
IP6	**My lung cancer is a serious condition.**					
IP7	**My lung cancer has major consequences on my life.**					
IP8	**My lung cancer does not have much effect on my life.**					
IP9	**My lung cancer strongly affects the way others see me.**					
IP10	**My lung cancer has serious financial consequences.**					
IP11	**My lung cancer causes difficulties for those close to me.**					

	Views About Your Lung Cancer	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
IP12	**There is a lot which I can do to control my symptoms.**					
IP13	**What I do can determine whether my lung cancer gets better or worse.**					
IP14	**The course of my lung cancer depends on me.**					
IP15	**Nothing I do will affect my lung cancer.**					
IP16	**I have the power to influence my lung cancer.**					
IP17	**My actions will have no affect on the outcome of my lung cancer.**					
IP18	**My lung cancer will improve in time.**					
IP19	**There is very little that can be done to improve my lung cancer.**					
IP20	**My treatment will be effective in curing my lung cancer.**					
IP21	**The negative effects of my lung cancer can be prevented (avoided) by my treatment.**					
IP22	**My treatment can control my lung cancer.**					
IP23	**There is nothing which can help my lung cancer.**					

	Views About Your Lung Cancer	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
IP24	**The symptoms of my lung cancer are puzzling to me.**					
IP25	**My lung cancer is a mystery to me.**					
IP26	**I don't understand my lung cancer.**					
IP27	**My lung cancer doesn't make any sense to me.**					
IP28	**I have a clear picture or understanding of my lung cancer.**					
IP29	**The symptoms of my lung cancer change a great deal from day to day.**					
IP30	**My symptoms come and go in cycles.**					
IP31	**My lung cancer is very unpredictable.**					
IP32	**I go through cycles in which my lung cancer gets better and worse.**					

	Views About Your Lung Cancer	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
IP33	**I get depressed when I think about my lung cancer.**					
IP34	**When I think about my lung cancer I get upset.**					
IP35	**My lung cancer makes me feel angry.**					
IP36	**My lung cancer does not worry me.**					
IP37	**Having lung cancer makes me feel anxious.**					
IP38	**My lung cancer makes me feel afraid.**					

APPENDIX C

FAGERSTRÖM TEST FOR NICOTINE DEPENDENCE

(Heatherton, Kozlowski, Frecker, & Fagerström, 1991)

Directions: Please circle **1** response for each question

1. How soon after you wake up do you smoke your first cigarette?	Within 5 minutes 6-30 minutes 31-60 minutes After 60 minutes
2. Do you find it difficult to refrain from smoking in places where it is forbidden e.g. in church, at the library, in cinemas, etc.?	Yes No
3. Which cigarette would you hate most to give up?	The first one in the morning All others
4. How many cigarettes/day do you smoke?	10 or less 11-20 21-30 31 or more
5. Do you smoke more frequently during the first hours after waking than during the rest of the day?	Yes No
6. Do you smoke if you are so ill that you are in bed most of the day?	Yes No

APPENDIX D

CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (CES-D)

(Radloff, 1977)

Instructions: Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

During the Past Week:	Rarely or none of the time (Less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	○	○	○	○
2. I did not feel like eating: My appetite was poor.	○	○	○	○
3. I felt that I could not shake off the blues even with help from my family or friends.	○	○	○	○
4. I felt I was just as good as other people.	○	○	○	○
5. I had trouble keeping my mind on what I was doing.	○	○	○	○
6. I felt depressed.	○	○	○	○
7. I felt that everything I did was an effort.	○	○	○	○
8. I felt hopeful about the future.	○	○	○	○

During the Past Week:	Rarely or none of the time (Less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
9. I thought my life had been a failure.	○	○	○	○
10. I felt fearful.	○	○	○	○
11. My sleep was restless.	○	○	○	○
12. I was happy.	○	○	○	○
13. I talked less than usual.	○	○	○	○
14. I felt lonely.	○	○	○	○
15. People were unfriendly.	○	○	○	○
16. I enjoyed life.	○	○	○	○
17. I had crying spells.	○	○	○	○
18. I felt sad.	○	○	○	○
19. I felt that people dislike me.	○	○	○	○
20. I could not “get going”.	○	○	○	○

APPENDIX E

FACT-L

(Cella et al., 1995)

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

	<u>PHYSICAL WELL-BEING</u>	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy…………………	0	1	2	3	4
GP2	I have nausea...	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family…………………………………	0	1	2	3	4
GP4	I have pain...	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill..	0	1	2	3	4
GP7	I am forced to spend time in bed……….	0	1	2	3	4

	<u>SOCIAL/FAMILY WELL-BEING</u>	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends........................	0	1	2	3	4
GS2	I get emotional support from my family ..	0	1	2	3	4
GS3	I get support from my friends.................	0	1	2	3	4
GS4	My family has accepted my illness..........	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	***Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box ☐ and go to the next section.***					
	I am satisfied with my sex life	0	1	2	3	4

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

	ADDITIONAL CONCERNS	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
B1	I have been short of breath	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
L1	My thinking is clear	0	1	2	3	4
L2	I have been coughing	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
L3	I feel tightness in my chest	0	1	2	3	4
L4	Breathing is easy for me	0	1	2	3	4
Q3	**Have you ever smoked?** No ___ Yes ___ If yes:					
L5	I regret my smoking	0	1	2	3	4

APPENDIX F

LUNG CANCER SYMPTOM SCALE

(Hollen, Gralla, Kris, & Potanovich, 1993)

Directions: Please place a vertical mark along each line where it would best describe the symptoms of your lung cancer **DURING THE PAST DAY (within the last 24 hours)**.

Example: How good is the weather?

As good as it could be — As bad as it could be

____

1. How good is your appetite?

   As good as it could be — As bad as it could be

   ____

2. How much fatigue do you have?

   None — As much as it could be

   ____

3. How much coughing do you have?

   None — As much as it could be

   ____

4. How much shortness of breath do you have?

None As much as it could be

____

5. How much blood do you see in your sputum?

None As much as it could be

____

6. How much pain do you have?

None As much as it could be

____

7. How bad are your symptoms from lung cancer?

I have none As bad as they could be

____

8. How much has your illness affected your ability to carry out normal activities?

Not at all So much that I can do nothing for myself

____

9. How would you rate the quality of your life today?

Very high Very low

____

APPENDIX G

SIX MONTH DATA COLLECTION FORM

1. Have you been treated for depression in the past 6-months?
    1. Yes
    2. No

2. Are you currently taking antidepressant medications?
    1. Yes
    2. No

3. Have you smoked in the past 7 days?
    1. Yes…………………………..If so, how many cigarettes do you smoke a day?
    2. No _______ cigarettes

4. Are you currently using a nicotine replacement product such as a nicotine patch, gum, inhaler, nasal spray, or lozenge?
    1. Yes………………………….. If so, which one?_____________________
    2. No

5. Are you currently taking the medication bupropion (Zyban or Wellbutrin) or varenicline (Chantix)?
    1. Yes
    2. No

6. How many times have you made a serious attempt to stop using tobacco since your lung cancer diagnosis?
    _________ times

7. If you have quit smoking, when did you quit? _______ month _______ day

8. Please answer one of the following:

What is the primary reason you **have not** quit smoking?

____

____

____

What was the primary reason you **were successful** in quitting smoking?

____

____

____

9. Have you had surgery for your lung cancer?
   1. Yes Date___________, Type________________________________
   2. No

10. Have you had radiation therapy for your lung cancer?
    1. Yes Dates of 1st & last treatment:________________________________
    2. No

11. Have you had chemotherapy for your lung cancer?
    1. Yes Dates of 1st & last treatment:________________________________
    2. No

12. Have you been diagnosed with any of the following? (circle all that apply):
    1. hypertension (high blood pressure)
    2. heart disease (heart attack, angioplasty, stent, or bypass)
    3. lung disease (COPD, emphysema, or chronic bronchitis)
    4. Another cancer (specify:________________________)