2007

Building Blocks for the Development of a Chronic Care Lung Cancer Model

Leeanne Berlinsky
Medical University of South Carolina

Recommended Citation

Berlinsky, Leeanne, "Building Blocks for the Development of a Chronic Care Lung Cancer Model" (2007). *MUSC Theses and Dissertations*. 108.
https://medica-musc.researchcommons.org/theses/108

BUILDING BLOCKS FOR THE DEVELOPMENT OF A CHRONIC CARE LUNG CANCER MODEL

BY

LEEANNE BERLINSKY

A doctoral project submitted to the faculty of the Medical University of South Carolina in partial fulfillment of the requirement for the degree of Doctor of Health Administration in the College of Health Professions

BUILDING BLOCKS FOR THE DEVELOPMENT OF A CHRONIC CARE LUNG CANCER MODEL

BY

LeeAnne Berlinsky

Approved by:

Kit Simpson 8/15/07

Chair, Project Committee Kit Simpson, Dr. P.H. Date

Andrea W. White 8/15/07

Member, Project Committee Andrea W. White, Ph.D. Date

Anil Potti 08-12-07

Member, Project Committee Anil Potti, M.D. Date

7/05/07

Dean and Professor,
College of Health Professions Mark S. Sothmann, Ph.D. Date

Acknowledgements

I want to thank my committee for their support during this phase of my doctoral work. Kit Simpson gave me countless hours of advice and encouragement that helped me continue to see that what I was doing was worthwhile and that I was on the right track, especially during times when I felt that I should start over. Andy White challenged me to think about how I could ask better research questions to get to better answers that ultimately would help us understand more about patients. She was instrumental in helping me think through potential new research ideas to explore later. Anil Potti became a friend and a mentor during this process, and I can't thank him enough for taking time away from working towards developing new cancer treatments and seeing patients in an effort to help me finalize this project.

I want to thank my family: my children, Zac and Nic, for continuing to tell me for the last three years that I was going to get an "A", my parents for continuing to tell me how proud they were of what I was trying to accomplish, and my husband, Philip, for giving me the daily encouragement, support and love that I needed while trying to balance work, school and family.

TABLE OF CONTENTS

List of Figures

List of Tables

Abstract of Doctoral Project Report Presented to the Executive Doctoral Program
in Health Administration & Leadership
Medical University of South Carolina
In Partial Fulfillment of the Requirements for the
Degree of Doctor of Health Administration

Building Blocks for the Development of a Chronic Care Lung Cancer Model

By

LeeAnne Berlinsky

Chairperson :	Kit Simpson, Dr.P.H.
Committee:	Andrea W. White, Ph.D.
	Anil Potti, M.D.

Lung cancer, is the leading cause of cancer death in the United States for both men and women, and as such, represents a tremendous burden on the healthcare system. Survival rates have remained relatively unchanged over the past forty years, yet we seem to be on the verge of a paradigm shift as a result of advances in early screening, diagnosis and better treatment modalities. Lung cancer is different from all other cancers in that 90% of lung cancer cases can be attributed to the conscious behavioral risk factor of smoking, either currently or previously engaged in by the patient. Funding and research has been limited in terms of identifying the unique characteristics and needs of these patients, their physicians and their caregivers. If survival rates improve dramatically, these patients will be managed chronically rather than acutely in the near future. When this occurs, a lung cancer treatment model for the future must be developed in order to more successfully

prepare the market place for adapting to these unique patients and their providers who will be operating in a chronic rather than acute care environment. Prior to the development of such a model, the need exists to first develop a comprehensive information map identifying knowledge and knowledge gaps with regards to these patients and providers and their healthcare interactions and individualized needs. Productive patient provider interactions are critical for successful chronic disease management, and therefore several questions must be answered as they relate to treating lung cancer in a more chronic versus acute environment.

INTRODUCTION

Lung cancer represents only 13% of all new cancer diagnoses, yet it is the leading cause of cancer death in the US for both men and women, accounting for almost 30% of all cancer deaths (Lung Cancer Alliance, p1). Five year survival rates for lung cancer are extraordinarily low, at less than fifteen percent, due to the fact that very few cases are diagnosed at an early stage, local disease, with no lymph node involvement. Almost 70% of all new lung cancers are diagnosed at very late stages of the disease, stage IIIb or stage IV, and survival rates today are not dramatically different than they were in the early 1970's despite increases in survival rates for most other major cancers (Lung Cancer Alliance, p1). The number of deaths each year from breast cancer, prostate cancer, colon cancer, liver cancer, kidney cancer and melanoma combined will not surpass the number of deaths each year from lung cancer (Lung Cancer Alliance, p1).

The medical costs alone for lung cancer are almost $5 billion annually (Lungusa, p2). The American Cancer Society (2006) estimated that there would be 174,470 new cases of lung cancer diagnosed and that there would be 162,460 lung cancer related deaths last year. As with most cancers, there is a tremendous disparity with regards to lung cancer diagnoses, with a disproportionate impact on minorities and those with a lower socioeconomic status. African American men are 50% more likely than white men to develop lung cancer. The incidence rate of lung cancer is equal for African American women and white women, although the rates of smoking are much lower in the former group (American Cancer Society, 2006). African Americans have both increased incidence rates as well as lower survival rates regardless of the stage in which diagnosis is made, making the disparity for this group even more pronounced (NCI, 2004).

Prevention and early detection are key to reducing costs and the burden of illness. Twice as many women will die from lung cancer compared to breast cancer, and three times as many men will die from lung cancer compared to prostate cancer, and yet there are currently no screening guidelines from the American Cancer Society related to early detection of lung cancer in asymptomatic individuals (Lung Cancer Alliance, p1). The fact that five year survival rates increase to almost 50% when a diagnosis is made early, gives a strong push towards developing new screening tests, molecular markers, and genetic breakthroughs to improve early detection as well as surgical or treatment expectations for these patients. These advances, if successful, are likely to make early diagnosis and more effective treatments a reality in the near future.

Molecular and cellular epidemiological research has focused on improving our ability to understand the histologic changes that take place over the course of time, leading from a normal healthy bronchial pathway to a malignant lung cancer cell. These efforts are aimed at predicting not only which agents will cause cancer and the sequence of events that will take place morphologically, but at identifying which patients are genetically more predisposed to developing lung cancer in the presence or absence of those identified agents and causal factors (Alberg, 2005). Fifteen years ago, the Early Lung Cancer Action Project assessed the impact of an early diagnosis in smokers who underwent annual spiral computed tomography – CT screening (Henschke, CI et al, 1999). They found that 80% of patients diagnosed with lung cancer following annual CT screening had early stage I cancer (Henschke, CI., et al, 2004). Later follow up studies with these patients (Henschke, CI., et al 2006) found that those who were diagnosed with stage I cancer, had improved ten year survival rates that were as high as 88%; and that all patients diagnosed with lung cancer, regardless of tumor stage, had a ten year survival rate of approximately 80%. Based on the screening specificity seen in this trial with high risk yet asymptomatic individuals, which was equal to or better than the specificity for breast cancer screening via mammography (Henschke, CI., et al 2006), it still remains controversial as to why CT screening at less than $200 per person is not part of a routine guideline. This remains a possibility in the near future that could have profound implications for patients, physicians and third party payers.

New chemotherapy agents, along with the addition of targeted agents, have already significantly improved median survival time and both one and two year survival times (Molina, 2006). Further efforts that are successful in preventing lung cancer, detecting lung cancer earlier or providing treatments that offer better outcomes, could help change the way we view and treat lung cancer, which today is as an aggressive, acute disease with a high mortality rate, shifting it towards a more chronically managed condition that patients may live with for decades.

Due to the overwhelming mortality rates from lung cancer and possibly due to the stigma associated with the disease, there has not been a tremendous amount of information, research, and support developed for this particular group of cancer patients, their caregivers or their physicians. Over 75% of physicians felt that if the stigma of lung cancer being a self inflicted disease was not present, more patients would seek medical information and treatment (LungCancer.org, p 2). A simple internet search revealed twenty times more information readily available for breast cancer patients compared to lung cancer patients. If patients are to play a more prominent role in the management of their disease, then we have to know more about what types of information they are asking for and what types of information they need in order to improve the patient / provider interaction in a chronic treatment setting. If gaps can be readily identified then a research agenda can be developed outlining areas most in need of funding.

From 1999 to 2004, Congressional funding at the Department of Defense for breast cancer was almost $1.7 billion compared to $33 million for lung cancer over that same time frame. Over $200 million was allocated to the Center for Disease control in support of breast cancer research in 2005, while there was zero funding allocated to this group for lung cancer research that same year (Lung Cancer Alliance, p1). In 2004, $13,953 was spent on research for every breast cancer death versus $1,723 for every lung cancer death (LungCancer.org, p 3). Despite the fact that lung cancer remains the leading cause of cancer death, the amount of funding spent on research broken out per patient death provides further evidence that there has been very little attention devoted to learning about this particular group of cancer patients.

Mapping what we do know and identifying gaps with regards to these patients is important for several reasons. Of the new lung cancer patients diagnosed each year, 35%-40% are current smokers, 50% are former smokers and only 10% -15% are never smokers (Lung Cancer Alliance, p1). Understanding more about the treatment interactions and information needs of these patients is important due to the fact that lung cancer patients may be inherently different from other cancer patients in that the majority of lung patients engaged in smoking behavior, which is strongly associated with the development of the disease. This could have a profound impact with regards to the potential long term interactions they may need to have with their oncologists and their treatment teams.

Retrospective and prospective studies throughout the 1950's began to report on the association between cigarette smoking and lung cancer. The 1964 Surgeon General's Report definitively concluded that smoking caused lung cancer (US Dept of Health Education and Welfare, 1964). And yet despite all the awareness of smoking related health risks, an estimated 45 million Americans are current smokers (American Cancer Society, p 36). The fact that the majority of lung cancer patients engage in behavior known to cause cancer, and that they subsequently face the stigma society attributes to smokers, may indicate a marked difference in their health literacy as well as their health beliefs, compared to other cancer patients, which will in turn impact their resource needs as they move through the medical system. Additionally, the treating physicians as well as caregivers may respond differently to these cancer patients and their disease management needs.

Currently most lung cancer patients can be characterized as having an acute illness due to the severity and mortality associated with most lung cancer diagnoses. There may not be enough time in the treatment plan for patients to become very knowledgeable, aware and involved in their particular treatment plan. Conversely, patients with any chronic condition are generally encouraged to become more involved and more informed with regards their health care, their disease, their treatment options and their disease management.

In response to a quality report from the Institute of Medicine, Wagner et al, (2001) developed a chronic care illness model that served as a framework for understanding system changes necessary to provide quality chronic care. While their model focuses on chronic care in the primary health care setting, the physical, mental and social challenges they identify for patients and caregivers are arguably applicable in any setting. Ultimately Wagner et al, (2001) identify six "essential elements" overlapping the community, the healthcare system and the provider organization that must work together in order for quality chronic care to be delivered effectively. They identified the need for 1) linkages to community based resources, 2) appropriate culture within an organization that supports and rewards good chronic care, 3) self management support with the patient as an active participant, 4) adequate delivery systems and practice teams, 5) evidence based decision support, and 6) clinical information systems to support and evaluate decision making (p 69). As supported by Wagner et al, (2001) and outlined in the Institute of Medicine's Quality report, quality is likely to improve if the interaction between the patient and the treatment team can become more productive.

Bodenheimer, Wagner and Grumbach (2002) assess that medical professionals must work to help patients and caregivers develop the skills as well as the motivation and confidence to self manage, set goals and follow up appropriately. Oncologists who treat lung cancer patients must have a clear understanding of their potentially unique patient characteristics if they are to work in a collaborative and productive treatment environment. Based on Wagner's (2001) chronic care model, four components are critical for the thoracic treatment team to optimize during provider patient interactions: garnering patient perspective regarding the course and management of the illness, assisting the patient in goal setting and problem solving, applying clinical and behavioral interventions aimed at reducing complications and improving well being and finally to ensure continuous follow up. It is unclear at this point as to how prepared oncologists are to organize and coordinate these types of interactions specifically for their patients diagnosed and treated for lung cancer.

An essential question then becomes, what do we know and what do we need to know in order to successfully anticipate and meet lung cancer patients' needs in the chronic care setting? In order to better anticipate and meet the needs of these patients in the future, we must be able to determine what information patients need now and what questions they are asking now, as well as how they view their disease and make treatment decisions. We also need to understand what is known about how physicians treating these patients are able to anticipate and meet their needs and what challenges they must overcome in the future in order to do so in the chronic care setting. To do so we need a comprehensive model of the lung cancer of the future which incorporates what is known about cancer management from other more treatable cancers as well as what is known about the management of chronic diseases developed from the primary care setting.

With both breast and prostate cancer, there has been a tremendous increase in patient awareness regarding screening guidelines, symptom development and treatment considerations, as well as an increase in the patients' self management of those disease states. In order for this to occur with lung cancer, we must better understand what commonalities and differences they may have with other patients who manage serious, chronic conditions for five to ten years following diagnosis as well as identify a research agenda to fill in gaps in our informational market analysis.

We are on the verge of a paradigm shift with regards to the treatment model for lung cancer. The final step is to develop a comprehensive model that integrates what is known from other cancers and adapt it specifically to lung cancer and the unique needs of those patients and their treating physicians.

This project will encompass two main objectives. The first objective will be to complete an integrative mapping of the literature and information available regarding lung cancer patient characteristics as they relate to: 1) current lung cancer diagnosis and treatment considerations, obstacles and barriers, 2) lung cancer patients' health beliefs, therapy goals, treatment needs, and preferences as they relate to quality of life and well being, 3) availability and operability of lung cancer patients' support networks and caregiver needs, 4) current barriers and obstacles faced by these patients, including the stigma associated with being a smoker, and 5) identification of a future research agenda necessary to fill in all the knowledge gaps that would currently prevent the successful disease state management of lung cancer as a chronic condition as outlined in the chronic care model of disease management specifically as it relates to the physician-patient interaction. The integrative mapping of the relevant literature will in fact be a case study or market analysis of this patient population. In mapping what we know about the characteristics of lung cancer patients, their decision making, and their information needs, as well as their perceptions of their physicians and caregivers, I will develop several hypotheses regarding how we can better anticipate and meet the needs of this patient group as they relate to the chronic care model of illness. Additionally, this integrative knowledge mapping should elucidate several gaps in the literature regarding the specific health drivers related to this particular group of patients.

The second objective will be to develop a theoretical model from the patient perspective that addresses both internal and external factors related to lung cancer patients becoming active, motivated and engaged participants in their chronic health care management. This model will incorporate what is known about successful chronic care patient interactions and incorporate specific influences that may face those patients diagnosed with lung cancer.

METHODS

The first objective was to identify literature on the evidence and gaps with regards to our knowledge surrounding 1) the decision making process and health beliefs relating to lung cancer patients, their information needs and factors relating to their ultimate treatment decisions, 2) barriers relating to diagnosis, treatment and subsequent behavior interventions for lung cancer patients who are primarily smokers, 3) interventions and goals of therapy that improve patient care and / or outcomes for lung cancer patients diagnosed at both early and late stages of lung cancer, 4) tools and support services available to help patients become more informed, active participants in their care choices, and 5) information needed by clinicians to better coordinate and anticipate the care needs of lung cancer patients for longer periods of time.

This research also identified where there was congruence with regards to physician perception of patient related goals and preferences versus actual patient goals and preferences, as well as the barriers faced in following through with recommended treatment protocols. Following this review, a knowledge map was developed that will later be useful in the knowledge transfer chain to providers, patients and health systems via the Chronic Care Model as well as in the development of a future research agenda.

Knowledge mapping has been supported and developed over the last ten years by numerous health agencies, including the World Health Organization, and has been useful at the institutional level, the community level and the policy level (Ebener, et al, 2006). Prostate cancer researchers at Dana Farber Cancer Institute in Boston, Massachussets, were successful in developing a knowledge map identifying the multiple domains of inequality as well as their interactions and relative contributions (Gilligan, 2005). Through their development of a knowledge map, they were able to identify where there was inequality, the overall relevance of that inequality, as well as the subsequent identification of a targeted research agenda. Alborz, McNally and Glendinning (2005) were successful in mapping the issues faced by people with learning disabilities as they related to healthcare access. The result of their mapping process was a modified access to care model that was patient specific for those with learning disabilities. Again, the mapping exercise allowed them to identify research gaps at both the macro and the micro level resulting in the identification of several strategies to overcome specific barriers.

For this project, several data sources were identified and included bibliographic databases, organizational websites and library catalogues. Literature reviews were conducted using the following databases: Medline, CINHAL, PsychInfo, PubMed, and Cancer Lit. Only articles published in English were included in the review. Thesaurus terms were initially identified and searched in an integrative approach to identify the literature that pertains to the following research questions: "what do we know about lung cancer patients, what do we know about how they make decisions, what do we know about their health beliefs, what do we know about their support systems, what do we know about their information needs as well as those of their caregiver networks, what do we know about their decision making and preferences regarding different therapy options, what questions are they asking now and what questions might they be asking in the future, and what do we know about how they communicate with their physicians or how they would like to communicate with their physicians in the future?"

The development of a search strategy was an iterative process that involved the following initial search and mapping of key terms followed by sequential searching based on the findings or lack thereof. The following search terms were systematically reviewed both individually and combined: lung cancer, epidemiology, statistics, descriptive statistics, decision making, quality of life, health screening, cancer screening, health beliefs, smokers, non-smokers, smoking cessation, patient attitudes, patient navigators, patient expectations, health behavior, health promotion, health services accessibility, preventive health care, risk factors, diagnosis, symptoms, decision aids, decision support techniques, caregiver networks, barriers to care, barriers to access, chemotherapy, palliative care, patient education, attitude towards health, oncologists perceptions, adapting to cancer diagnosis, stigma, unrealistic optimism, information needs, information seeking, doctor-patient communication, therapy goals, follow up, and goal setting.

Abstracts were then retrieved and reviewed for relevance. Original articles were then retrieved and grouped according to topic. References in each article were then hand searched to determine whether they should be included or to determine whether they led to new search terms to be used in the process. Free text searching also took place to identify any gaps in the search process. Research papers identified were then cross referenced for similar papers and papers citing the work in question.

Quantitative and qualitative studies were included in the research review. Studies that involved lung cancer patients and patients at risk for lung cancer were the primary target during this review. However there was a need to include studies that involved cancer patients in general or patients facing end of life decisions since they provided additional insight into the development of the model. The goal was to identify the population at risk, those diagnosed with lung cancer or those at risk for being diagnosed with lung cancer, and then to find out what information was available about those patients that may or may not differentiate them from other cancer patients based on the fact that this is the singular cancer that arises primarily as a result of patient behavior deemed to be risky and self imposed. Additionally the goal was to assess the gaps in the literature regarding the care and needs specifically of lung cancer patients that need to be addressed in order for the model of care to move successfully from one of acute care to chronic care.

Issues and concepts were identified that related to health beliefs, decision support, access to care, support networks, stigma, physician bias, and patient preferences, fears and misperceptions regarding the quality or outcome of various care options. Articles were included on smokers' attitudes towards health and risky behaviors, even though many of those articles did not include patients diagnosed with lung cancer. The rationale for this was that this patient population might have an unrealistic perception regarding the risk of smoking and therefore may have an unrealistic perception regarding the benefit of early diagnosis and various treatment options once they are potentially diagnosed with lung cancer.

The literature searching was both an integrative and an iterative process that built upon itself based on what was discovered. A knowledge mapping framework was then developed that encompassed directional arrows representing hypothesized relationships based on our knowledge from other cancer patients and incorporating what was actually found regarding lung cancer patients specifically.

Rather than using a reference manager database, the entire search file was saved on the MUSC library search engine so that it could be continually evaluated for continuity, directional growth and additions to the literature over time.

There are several limitations with this method of mapping. A limited number of studies specific to patients with lung cancer were identified in the literature review and there may be data that was not included or identified during the search process. Numerous studies were identified that provided information on cancer patients' beliefs and needs, and while those studies included lung cancer patients, their specific information was not usually stratified based on tumor type, tumor stage, prognosis or smoking status. The majority of studies that were reviewed had a small sample size of lung cancer patients, and usually included patients with advanced disease and poor prognosis. There were very few studies addressing lung cancer patients diagnosed early, presenting with a much better prognosis, who may have somewhat different attitudes towards future health decisions. Another limitation of this type of research is that based on the stigma related to lung cancer, a number of patients have not been identified as smokers, or have failed to acknowledge the role their behavior had in the development of their disease and often have failed to be forthcoming regarding their true behaviors or their expectations regarding their treatment methods, needs or outcomes. Given the fact that lung cancer survival rates are so low, many patients may not have been told of their true prognosis, many have not accepted their true prognosis and or many may not have actually had the time to make health behavior changes prior to their final mortality related outcome. However, the decision making process in this group of patients, regardless of whether it is based on a realistic expectation of the outcome, is very relevant given that they are in fact making health care decisions in some cases without appropriate knowledge or true informed consent.

Studies were not given a quality rating, as has been the case in other research using literature reviews, but were used to develop the mapping concepts and assess whether there is enough information to make a determination regarding a knowledge base versus a gap. Any data available was deemed relevant in developing the knowledge map, even if that ultimately represented a portion of the map that was more representative of a knowledge gap or an area deserving of further research and exploration. This created the opportunity to develop hypotheses for further testing. The quantity of the data for any given subject heading was ultimately helpful in determining whether there was in fact a knowledge base or a knowledge gap that should be further examined.

RESULTS

The mapping process took place in two stages, the first of which occurred simultaneously with the information review. The first stage of knowledge mapping involved the development of the mapping domains along with a visual representation of their interrelationships. Initially several domains were identified and mapped on a white board. The starting point began with lung cancer patient characteristics and health beliefs specific to people who were current or former smokers. During the search for information, as new domains began to emerge they were added to the map.

Upon checking the references in each article identified, new domains were often identified if they represented a knowledge base in another cancer type or another disease type even if there was not data representative of what was known in lung cancer. The identification of these domains then in turn led to the development of additional search criteria and subsequently additional mapping domains.

Often the references in an article that pertained to another type of cancer were helpful in developing a mapping domain even if that domain ultimately represented a knowledge gap with regards to lung cancer patients. Reference checking was also helpful in identifying articles that did not initially appear under a specific lung cancer patient search but that included lung patient perspectives on topics such as communicating prognosis or decision making. This data was often embedded in a study dealing with numerous types of cancer patients.

The second part of the mapping involved synthesizing the information for each given domain and developing an overall summary for each portion of the map. Initially articles were read for content and a summary paragraph of key learning was written for each article. Article summaries were grouped and an overall summary was developed for each map domain. Map domains were ultimately characterized based on whether there was clear evidence, conflicting evidence or no evidence with regards to each topic. After information was synthesized, articles were numbered and counted based on whether or not they contributed to the overall information in one or more map domains. This information is depicted in table 1. Numerous articles contributed information to more than one map domain, which accounts for the fact that articles are referenced more than once in the table.

Many papers represented information derived from a very small sample size, and while the papers themselves may not have been relevant, they were helpful in developing many of the mapping concepts that are still open for future research and development. Ultimately 141 studies were included based on the value of the data provided to enhance the development of a knowledge map and subsequent model development. Additionally, studies were included that provided insight into patient decision making based on their health status or their health behaviors leading up to a lung cancer diagnosis, which primarily included those dealing with smokers and risk, optimism or cessation interventions. Studies were also included that were literature reviews themselves, and in those cases, all of the articles were not reviewed separately if the overall conclusions could be ascertained from the primary review.

The only texts that were excluded involved studies relating to factors regarding patient care or treatment outcomes that were outside the realm of individual patient decision making, beliefs or quality of life, such as those relating to improvements in genomics research, tumor staging, and treatment with investigational drug therapy. It was assumed that these factors were more relevant to changes in actual treatment innovations, and they represented therapy related outcomes rather than patient choices, decision making, self management, QOL interventions, or information and communication needs. Additionally specific pharmaceutical studies related to drug efficacy were excluded because they provided little information regarding patient motivation or choice with the exception of studies that specifically addressed patient related choices based on quality of life measures when deciding between therapy options.

The following summaries are representative of the information reviewed for each mapping domain that ultimately guided in understanding what we know about the specific characteristics of lung cancer patients with regards to how they make decisions regarding the management of their disease:

Health Beliefs / Smokers

In developing a clear understanding of how to manage lung cancer patients in a chronic care setting, it is important to understand their health beliefs may be different than those of other cancer patients, and as such, they may need to be managed with different considerations. For years the detrimental effects of smoking have been well documented and publicized. Since the majority of patients with lung cancer have engaged in a behavior known to cause such cancer, their perception of risk and optimism may be different regarding health care, risks and benefits and medical decision making.

Optimism and Risk

Numerous studies show that smokers tend to be overly optimistic regarding their chance of developing a smoking related illness such as lung cancer as well as the possibility of cure in the event they do develop cancer. Smokers tend to attribute lung cancer to a number of other factors outside of cigarette smoking and greatly underestimate their actual risk of developing lung cancer (Brownson, 1992; Dias, 2006; Dillard, 2006; Donovan, 2006; Dowding, 2006; Hay, 2005; Ma, 2002; Oncken, 2005; Salander, 2006; Silvestri, 2006; and Weinstein, 2005). Additionally smokers tend to overestimate the survivability of lung cancer and have false optimism about the cure rates (Dillard, 2006).

This false optimism seen by smokers is also demonstrated at times by patients with lung cancer. Like smokers without cancer, lung cancer patients also overestimate the survivability (Weeks, 1998) and may also fail to recognize the benefits of quitting smoking even after being diagnosed with lung cancer. Studies have shown that the majority of lung cancer patients believed that lung cancer was curable when they were diagnosed, and less than 10% of those patients knew that their life expectancy was less than one year (Malin, 2006). This is a very different thought process than what is seen with other at risk cancer patients, such as with those at risk for breast cancer, who are often overly pessimistic and think their prognosis is much worse than expected (Lipkus, 2001).

This misperception or denial of risk and false optimism seen in smokers and also in lung cancer patients may be particularly important for physicians to understand as they are trying to communicate accurate risks and expected outcomes of various therapy choices so they can work jointly with patients to play an active role in deciding how to manage disease (Cykert, 2004; and The, 2000). It is also important in thinking forward regarding future health behavior interventions that if patients in fact end up surviving lung cancer for longer periods of time, then their false optimism may seem justified in their mind. This might make it difficult for physicians to convince them of the importance of preventing future health complications or modify health behavior.

Stigma

Several studies and surveys have reported on and hypothesized about the role that stigma as it relates to smoking and its cause and effect relationship with lung cancer may play with regards to low funding levels for lung cancer research. Additionally, the stigma that many lung cancer patients feel from community, friends, family and health care providers may also play a role in their decision to seek medical help, which in turn can delay diagnosis and treatment (Chapple, 2004). Studies have found that smokers often feel unworthy of care (Street, 2004 and Corner 2005) and are ashamed and embarrassed to tell people of their smoking related illness. This in turn could lead to a decreased use of community based resources aimed at support, behavioral interventions, and outreach. Additionally, the stigma faced by some may in fact prevent them from recognizing or accepting the role smoking played in the development of their lung cancer (Chapple, 2004). This inability to look at cause and effect may impact patients' future decisions or attempts to try to quit smoking as many lung cancer patients never accept the fact that smoking behavior was related to their lung cancer diagnosis.

Access

Several studies indicate that socioeconomic status, insurance status and geography play a role in decreasing patients' access to care, resulting in poorer outcomes (Campbell, 2001; Earle, 2002; Hall, 2004; and Silverstein, 2002). This may account for some of the disparities in survival seen with African American patients (Ferguson, 2003; Holzman, 1995; and McDavid, 2003). However, other data suggests that when access was universal, there were no differences in outcomes (Mulligan, 2006). One factor that has not been studied that must be addressed is service capacity as it relates to access. If lung cancer patients have increased survival rates, there will be a tremendous increase in the number of patients being managed in the system. It is unclear what impact this will have on physicians, nursing staff and the multidisciplinary treatment team. If lung cancer survival increased by twelve months, over 150,000 patients would remain in the system in the first year alone. These patients would need three or four follow up visits during that year. Access might be limited based on the number of providers and support staff, and lengthy delays in follow up care or in new patient visits could occur. Economic and feasibility studies need to be done to see what changes must be made in the system in order to meet access needs if there is an increase in demand.

Diagnosis and Treatment Delay

Lung cancer patients as a group have a much higher likelihood of individuals delaying diagnosis or treatment versus those with other cancers. While there is limited data on both patient as well as physician delay, preliminary evidence suggests that the majority of patients delay seeking help by more than three months (Salomaa, 2005). As discussed above, several studies have reported on the role that stigma and feelings of guilt that led to patients' feeling unworthy of care resulted in delays in seeking medical attention, thus delaying diagnosis and treatment. Additionally, numerous studies report a general lack of understanding and awareness regarding the early warning symptoms of lung cancer that should in fact prompt patients' to seek help (Corner, 2005 and Levealahti, 2006). While there is almost universal awareness regarding breast self exams and the need to get suspicious changes or lumps checked by a physician, it has been estimated that more than half of smokers fail to identify symptoms of lung cancer (O'Conaill, 2005). Patients in several studies reported having symptoms for months or years prior to the diagnosis of lung cancer, but often felt the symptoms weren't serious enough to warrant medical care, were related to their other health comorbidities rather than a new, more serious condition, or were simply part of getting older (Corner, 2005; Corner, 2005; and Levealahti, 2006).

This represents a serious need for awareness campaigns that educate smokers about the early signs and symptoms of lung cancer.

Disease Management / Treatment Decision Making

In order for any patient to be actively involved in the decisions regarding treatment, they have to be well informed and have a clear understanding of the treatment, the expectations or goals, the risks, side effects and alternatives. Studies have documented wide variability in treatment choice among lung cancer patients based on cure, response, toxicity, prognosis, and symptom relief (Hirose, 2005; Markman, 2006; Matsuyama, 2006; Silverstri, 1998; and Skinn, 1994). Data suggests that most lung cancer patients want a collaborative role in making treatment decisions (Davidson, 1999). They also need specific information regarding details of the therapy, anticipated early and later side effects, survival estimates, and symptom relief to make choices consistent with their beliefs (Feldman-Stewart, 2004; Sorensen, 2004; and Weeks, 1998). However, studies have shown that fewer than half of lung cancer patients being treated ever had a discussion with their physician about therapy choices or about selecting therapy based on side effect profiles (Dubey, 2005). Physician goals of therapy agreed with patient goals of therapy only 50% of the time in one study (Chu, 2007), and other data suggests that fewer than 25% of patients would choose their same treatment again, indicating a lack of clear communication and understanding between physician and patient (Krishnasamy, 2001; Quirt, 1997; and Silvestri, 1998).

Understanding how lung cancer patients make decisions is critical given their health beliefs, risk assessments and often unrealistic optimism. A number of factors including race, ethnicity, age, spirituality, coping skills, and familial support have been identified as having an impact on lung cancer patients' treatment decision making process (Lathan, 2006; Markman, 2006; Margolis, 2003; Sharf, 2005; Silvestri, 2003; Siminoff, 2006; and True, 2005). While their specific impact or role in decision making is not fully known, physicians often failed to recognize them as being important factors to consider when talking with patients about therapy options, and data suggests that treatment teams failed to improve the quality of decision making versus that of individual physicians (Kee, 2004).

Numerous studies have shown that decision aids are effective in helping lung cancer patients increase their knowledge as well as make therapy choices that reflect their true values and desires (Brundage, 1998, 2000, 2001; Fiset, 2000; and Leighl, 2004). However, there is no clear standard as to the content that should be included and patients' needs and comprehension skills vary widely. It has also proven difficult to include risk assessments in an accurate manner given smokers' beliefs regarding risk versus non smokers' beliefs regarding risks (Feldman-Stewart, 2004). There is data that suggests that lung cancer patients are in fact willing to accept small benefits with big risks more so than other patients (Cykert, 2004; Hirose, 2005; and Matsuyama, 2006). Physicians should be aware of the differences in risk perception among smokers, and thus most of their lung cancer patients.

Communication

Since risk decisions can only be made with accurate information, physicians are often at a loss as to how to communicate risk to lung cancer patients who, as a group made up primarily of smokers, tend to make unrealistic risk assessments. There is little information regarding communication needs and preferences with lung cancer patients specifically, yet limited data suggests that patients who receive diagnosis and information from a specialist are more likely to be clear on the disease specifics (Krishnasamy, 2001). The fact that several studies showed wide disagreement with regards to patient and physician stated therapy goals, actual therapy choices or expected prognosis shows that this is an area for future research (Chu, 2007; Quirt, 1997; Sharf, 2005; Weeks, 1998; and Yardley, 2001). Numerous studies exist with breast cancer patients regarding the communication preferences regarding prognosis and therapy and data suggests this may vary by tumor type (Hagerty, 2005). Studies need to be done with lung cancer patients specifically.

Physicians must recognize that patients have attachment needs and that in order to include them in the decision making process, they must establish a relationship and trust (Cykert, 2004) and in some cases starting that communication prior to the first patient visit was viewed as positive (Quinn, 2007). This may be particularly true when dealing with African American patients who reported lower levels of trust based on their perception of poor physician communication (Gordon, 2006). Patients' desires for increased communication or information may in fact be an increased need for relationship building and further communication on the part of the physician (Salandar, 2005 and Sharf, 2005). Physician communication style was seen as one of the strongest predictors of patient participation during the consultation (Street, 2005). Physicians who used more supportive and partnership building communication styles had patients with increased levels of participation (Street, 2006). Whether this type of communication style is widely used by oncologists is currently unknown.

Information

Lung cancer patients get their information from a variety of sources both formal and informal, however the quality and completeness of that information is often low (Matsuyama, 2006). However, patients often overrate the quality of the information they receive from sources other than their physician (Peterson, 2003). There is a lack of information available that addresses survivability or treatment success (Donovan, 2006 and Matsuyama, 2006), and this is often the type of information patients ask for and need in order to make informed choices. Additionally data suggests that much of the information available needs to be written at lower reading level in order to be useful to the majority of lung cancer patients (Powers, 2006). Most data showed that lung cancer patients wanted and needed detailed, specific information in order for them to participate with a high level of involvement (Davidson, 1999 and Sorensen, 2004).

There was evidence that race may also play a role in the amount of information lung cancer patients receive from their physician. Sometimes black patients received less information from their physicians. It is unclear as to why this is the case, however it could be related to the fact that black patients often participated less frequently and were less likely to bring a companion with them during their consultation versus white lung cancer patients (Gordon, 2006). Limited data exists regarding the role race and ethnicity play on the preferred information venue with cancer patients in general, with data from one study suggestive of white patients preferring medical journals, telephone and internet sources, Japanese patients preferring media and commercial sources of information, and other Asian patients preferring personal communication with physicians, peers and social groups (Kakai, 2003).

The internet was the most common source of information for lung cancer patients outside their physician (Peterson, 2003), however there are no studies measuring the effectiveness of internet education in lung cancer. Lung cancer patients who used the internet expressed strong interest in participating in clinical trials (Markman, 2005), and smokers who used the internet expressed greater interest in quitting smoking (Stoddard, 2006).

It is important to recognize that lung cancer patients' information needs may change over the course of their illness and their preferred method of communication may change as well (Moore, 2006). Patients seemed to express interest and satisfaction using e-mail and telephone calls for advice, information and follow up (Moore, 2004). Further investigation into the information and resource needs of lung cancer patients is warranted and should also try to illuminate further information regarding the specific needs of different ethnic and minority groups.

Problem Solving

Patients managed in the chronic care setting must partner with their provider so that can be actively involved in problem solving. There was no data available to determine lung cancer patients' preferences or abilities to problem solve in an acute or chronic care environment.

Goal Setting

No data exists on how lung cancer patients and physicians work together to set realistic goals related to patients' treatment, behavioral interventions and follow up plans. Lung cancer patient advocacy groups were limited with their information on patient expectations. Data showed that when breast cancer patients used a combination of physical and psychological interventions, including goal setting, they were better able to manage chronic pain (Robb, 2006). Patients in a general cancer population were most likely to set rehabilitation goals to improve self care, leisure activities and productivity (Watterson, 2004). These goals were rated as equally important to the patient. There is also data suggesting that in the general cancer population, misdirected goal setting was associated with increases in depression (Street, 2003).

There is clear need for further research involving lung cancer patients and their ability to set and meet both short term and long term treatment, interventional and follow up goals. Additionally, studies to outline appropriate goals are necessary so that patients can have a clear understanding of which goals might be realistic and appropriate for their given care plan. Although hospice patients are in a terminal phase, it is possible that we could learn from the body of evidence regarding how those patients, including lung cancer patients, set goals with regards to physical, emotional or spiritual needs at the end of life and apply this information in a more chronic phase (Pizzi, 2004).

Self Management

There was limited information regarding how to help lung cancer patients take a more active role in self managing their disease, their symptoms and their quality of life. Numerous studies did show that patients who were directly involved in managing their care had improved quality of life scores, and that those patients also exhibited a strong awareness of resources, had strong self efficacy beliefs and lower anxiety or depression versus other lung cancer patients (Boehmer, 2007; Downe-Wamboldt, 2006; and Maliski, 2003). Additionally, several studies found that patients using complementary or alternative medicine were more likely to be involved in self management and considered their use of those therapies as a positive step towards fighting cancer (Fouladbakhsh, 2005 and Molassiotis, 2006). There was conflicting evidence regarding how well caregivers were able to assess a patient's ability to self manage, with some studies showing that caregivers over rated patients' abilities while others showed that they underestimated patients' abilities (Madison, 1995 and Porter, 2002).

This indicates a need for treatment teams to help patients understand all the resources available, and to assess and treat depression and anxiety as quickly as possible in order for the patient to optimize self management skills. Furthermore, the studies represented here indicate a need for further research aimed at helping the physician assess patients' abilities more accurately rather than using surrogate assessments from caregivers. Further work needs to be done to determine which types of interventions are most helpful in increasing lung cancer patients self efficacy beliefs and coping skills.

Follow Up

There is a lack of general consensus on how to follow up with lung cancer patients using evidence based guidelines that ensure quality care that is cost effective

(Saunders, 2003). Studies indicate there is a need for patients to have access to the well informed, multidisciplinary treatment teams, but no clear measure of how to do this effectively. The follow-up expectations that are in place focus solely on follow up for acute lung cancer, and there are not any specific recommendations for chronic care management or coordination (Smith, 2003).

Several studies showed that patients were willing to follow up with the help of nursing led clinics or interventions and that up to 20% of all follow up might be appropriately led by nurses, particularly if the follow up involved physical or psychological needs (Cox, 2006). Training and support needs have been preliminarily outlined for these demanding roles and further implementation guidelines are necessary. Lung cancer patients expressed satisfaction with nursing follow up services in person and via telephone as they transitioned from active care to follow up care (Moore, 2006).

There is a clear need for more information regarding cost effective follow up care that takes into account the comorbidities and health behavior interventions necessary for lung cancer patients to lead longer, more productive lives. There is no clear cut method for providing, developing or coordinating follow up care plans.

Quality of life / Well being

Maintaining a good quality of life is important for all cancer patients, and health related quality of life domains of importance differ by tumor type (Osoba, 2006) and may prove to have inherent prognostic value (Maione, 2005). It is important to identify the many needs of lung cancer patients and their support groups or caregivers, prior to the start of therapy, as these patients present with greater psychological and physical burden compared to most other cancers (Bozcuk, 2006 and Ko, 2003), and persistent smoking often decreases quality of life even further among this group of patients (Garces, 2006). A review of the literature revealed that there is no clear cut evidence regarding who is best qualified to lead, manage or coordinate behavioral interventions aimed at improving well being and quality of life for lung cancer patients (Thompson, 2005). This illuminates a need for research into whether patient navigators, thoracic nurse specialists or another member of the multidisciplinary team should take on this responsibility.

Psychosocial

Lung cancer survivors may have more physical and psychosocial needs than other cancer survivors (Schag, 1994), and yet they often feel that their psychosocial issues are not being addressed by their provider, and this often leads to distress. These needs are expressed by caregivers as well (Li, 2006). Social constraints among spouses including denial, conflict, and criticism can lead to increased distress (Badr, 2006). Less than half of lung cancer patients felt that their concerns had been discussed with their healthcare team, and psychosocial issues were the ones most often overlooked (Hill, 2003). Improving physicians' understanding of specific patient concerns as well as the addition of psychosocial interventions may improve quality of life scores (Montazeri, 1998)

Emotional/Psychological

From a quality of life perspective, lung cancer patients exhibit some of the highest levels of emotional and psychological distress of any cancer patient group (Li, 2006; Lidstone, 2003; Walker, 2006; and Zabora, 2001). Feelings of anger may be more prevalent among this group of cancer patients versus others. Interestingly, some studies showed that this level of psychological distress was not correlated with a lack of family support or religion as might be expected (Kuo, 2002). Younger patients seemed to experience greater levels of distress than older patients (Graves, 2007), and those patients who used adaptive coping skills along with problem focused coping skills tended to improve more so than those who used emotion focused coping strategies (Kuo, 2002 and Walker, 2006). There was also a positive correlation between increased symptom distress and increased emotional distress, underscoring the need to address all aspects of lung cancer patients' physical and psychological concerns jointly (Montazeri, 2003). Additionally, the fact that some types of coping skills work better than others, indicates a need for physicians and support team members to be aware of which types of coping skills patients might typically use versus those they may need to be taught.

Spiritual

Several studies have shown that for lung cancer patients, spirituality plays an important role in both decision making as well as in quality of life, and in one study it ranked second only behind oncologists' recommendations in helping patients make critical decisions (Silvestri, 2003). However, the spiritual needs of patients and their caregivers are often not taken into account by physicians (Murray, 2004). Spirituality had a positive effect on physical and psychological quality of life for lung cancer patients (Meraviglia, 2004) and led to less depression in spouses who used moderate religious coping skills with patients (Abernethy, 2002). Physicians need to be aware that spirituality and coping skills often differ by ethnicity and race and that this may lead patients to make different choices than recommended or expected (True, 2005). One study compared lung cancer patients with heart failure patients and found spiritual needs to be different based on the different disease trajectories (Murray, 2002). This could raise future questions regarding the spiritual needs of lung cancer patients if it becomes a more chronic condition with a disease trajectory more similar to cardiac failure.

Depression/Anxiety

Studies estimate that as many as one third to half of all lung cancer patients experience depression during the course of their illness and this rate may be higher than for most other cancer patients (Carlsen, 2005; Krishnasamy, 2001; Sarna, 2005; and Walker, 2006). Often this depression goes undiagnosed by the treating oncologist. Studies show there are also discrepancies in physician and patient reported levels of anxiety (Krishnasamy, 2001). Recognizing and treating depression early in this group of patients has been successful (Carlsen, 2005), and it is critical for chronic care management due to the relationship between depression and quality of life, symptom management and the patients' ability to participate successfully in health behavior interventions (Fox, 2006). Lung cancer patients who are depressed have decreased quality of life scores, report increased levels of fatigue as well as increased likelihood of smoking relapse (Walker, 2004). While depression itself was not related to decreased survival rates, those patients who used depressive coping skills did have decreased survival (Faller, 2004). Additionally, studies of patients with chronic diseases have shown that in patients with chronic disease the addition of depression resulted in a doubling of the use of acute services (Himelhoch, 2004). Oncologists need to screen, identify and treat depression early in all their lung cancer patients.

Support Networks / Caregivers

The support networks available to cancer patients play a vital role in helping those patients cope with and manage their disease. There is very little information regarding the specific supportive care needs of lung cancer patients or how their support networks help meet those needs. There is data to suggest that lung cancer patients compared with other cancer patients have a greater number of unmet psychological, physical and daily needs, many of which are not recognized by the caregivers (Broberger, 2005; Lidstone, 2003; and Madison, 1995). This may be related to the fact that they present with more comorbidities, a greater likelihood of depression and possibly fail to seek support due to the stigma they feel as a result of their disease. Limited information suggests that fewer than half of lung cancer patients were able to get the help they needed from community based services, while physicians often underestimate the available support for patients (Krishnasamy, 2001 and Sharpe, 2005).

Caregivers of lung cancer patients often take on a great burden in caring for these patients, and they are also at risk for decreased quality of life and depression (Downe-Wamboldt, 2006; Sarna, 2006; and Pinquart, 2005). Studies have shown that family members often feel the impact of the patient's fatigue even more so than the patient (Hamilton, 2001). Reducing caregiver burden was shown to be more important than increasing social services in at least one study (Kim, 2005). Interventions that aided the caregiver in learning about the disease, treatments, and problem solving or coping skills reduced their burden (Abernethy, 2002). Further information needs to be gained regarding the coping skills that could be useful in reducing caregiver depression and quality of life so that they can be better positioned to help the lung cancer patient.

Health Behavior Interventions

Numerous health behavior interventions have been identified that enable cancer survivors to live healthy lives with improved quality of life scores (Hately, 2003; Ryan, 1996; andThompson, 2005). However, most cancer patients don't receive this guidance from their oncologist. One review found that fewer than 20% of oncologists give their patients guidance on health behavior interventions aimed at improving health and decreasing risk of other progressive diseases (Denmark-Wahnefried, 2005). These types of interventions will apply more frequently to lung cancer patients in the future should their life expectancy increase and they become managed like patients with other chronic conditions. This is particularly true for lung cancer patients because they tend to have decreased quality of life scores versus other cancer patients along with a heavier burden of illness (Sugimura, 2006). The impact of comorbid conditions on lung cancer survivability is currently unknown. This represents a change in the types of health concerns oncologists will need to manage with their lung cancer survivors in the future. In patients with lung cancer, there is no clear data on who is most qualified to coordinate or lead these interventions from the multidisciplinary team, although there are several studies indicating that many health behavior interventions can be and should be led by qualified nurses.

Smoking Cessation

There is a wealth of published information on smoking cessation, behavioral interventions, and relapse in the general population, which won't be discussed in detail here. Given the fact that 90% of lung cancer patients are current or former smokers, smoking cessation in this specific group of patients is particularly important. Many oncologists agree that given the short prognosis, smoking cessation is often not a primary concern even though smoking cessation improved performance status in at least one group of lung cancer patients (Baser, 2006). One study showed that only 25% of lung cancer patients were told by their physician that they needed to quit smoking following a diagnosis of lung cancer (Evangelista, 2003). Various studies show that a number of lung cancer patients who are smoking at the time of diagnosis continue smoking during or after treatment (Cox, 2002; and Schnoll, 2003).

Relapse rates among quitters was also high, with as many as 40% of patients relapsing after one year and 60% relapsing after two years (Walker, 2004). Relapse seems to occur most frequently after only two months (Walker, 2004, 2006), and most often by those who failed to admit the role tobacco played in the development of their illness (Schnoll, 2002, 2004). Relapse was also high among patients who waited until surgery to quit smoking (Walker, 2004, 2006) as well as among patients whose family members continued to smoke.

There is little data regarding which types of programs are most effective for lung cancer patients, but data points towards a combination of behavioral conditioning and reinforcement strategies (Schnoll, 2002). There is information that indicates that patients who are most likely to decline smoking cessation interventions altogether include those with fewer physical symptoms and those who are light smokers (Schnoll, 2004). Regardless of the type of program, many physician led smoking interventions were not effective, indicating a need for identifying effective smoking cessation programs led by others (Gritz, 1993; Schnoll, 2003).

Given the totality of the health risks and the comorbidity associated with smoking, in the chronic care setting smoking cessation will become more important for those patients expecting to survive lung cancer for several years. As many smokers cling to myths regarding the impact of smoking on health (Dillard, 2006), physicians must focus their efforts on getting patients to understand the benefits of smoking cessation as it relates to lung cancer as well as other health conditions.

Physical Interventions

There is very limited data on the successful implementation of behavioral interventions to increase physical activity with cancer patients in general and none were found relating to lung cancer patients. Yet this is an important variable given the limited evidence suggesting that lung cancer patients may have a higher number of physical symptoms and concerns versus other cancer patients. Studies show women with lung cancer may present with worse physical functioning than women with other cancers (Doorenbos, 2006), and that lung cancer patients' physical mobility generally declines after treatment. Data from the American Cancer Society is very limited and only includes a recommendation that lung cancer survivors increase physical activity (Ashley, 2005). Limited information shows that interventions improving physical functioning in other cancer patients improved quality of life (Smith, 1996) as well as patients' ability to manage pain (Robb, 2006). This information needs to be determined in the lung cancer population.

Alcohol / Nutrition

There is very limited data regarding behavioral interventions designed to improve dietary habits and alcohol intake among cancer patients in general and even less information specific to lung cancer patients. Given the short prognosis for lung cancer, this has not been a concern for most oncologists. However, data suggests a correlation between alcohol use and smoking, therefore information on patients' alcohol use is most likely going to be an important factor during the management of lung cancer patients in the chronic care setting. Data from one study suggests that almost 60% of long term lung cancer survivors continued their use of alcohol and that 50 % of long term lung cancer survivors were overweight five years post treatment (Evangelista, 2003). Data from the American Cancer Society if very limited at best, recommending only that it is probably beneficial for lung cancer survivors to maintain a healthy weight and to increase fruit and vegetable intake (Ashley, 2005). There are no recommendations regarding how patients should accomplish this, and yet there is data that nutritional status is often already compromised when patients present with lung cancer diagnosis (Beach, 2001) and that status worsens during treatment.

There is a need for understanding which behavioral interventions work as well as a need to determine how to present these interventions and gain agreement from patients regarding their impact and importance. Additionally, as family members often continue to drink, there may be a need to target them along with the patient (Sarna, 2006).

Comorbidities

Numerous studies have reported on and identified the comorbidities associated with lung cancer that are often attributed to smoking. Lung cancer patients have an extremely high incidence of comorbidity, with almost 90% of patients presenting with at least one and 50% of patients presenting with three or more comorbid conditions (Tammemagi, 2004). The presence of comorbid conditions in lung cancer patients has been shown to be predictive of lower health utility scores (Ko, 2003; Sugimura, 2006). While some studies have failed to show an association between comorbidity and survival, others have shown that survival is adversely effected independent of treatment, thus leaving it unclear as to the true impact comorbid conditions may have on long term survival (Sugimura, 2006; Tammemagi, 2004). There is no data regarding the management or follow up of these comorbid conditions in lung cancer patients and there are no current recommendations.

Symptom Management

Symptom management and therapy side effect management is critical for all cancer patients, however given the heavy burden of illness seen with lung cancer patients, it is vital for physicians to understand the distress felt by their patients, along with an understanding of their primary concerns (Dubey, 2005; Hsu, 2003; Lidstone, 2003). Fatigue, pain and depression and breathlessness are the most common symptoms experienced by lung cancer patients (Kiteley, 2006; Kuo, 2002; Lidstone, 2003), and while there is often agreement between the patient and physician regarding symptoms experienced (Basch, 2006), several studies showed that both physicians and caregivers or family members often overrated or underrated lung cancer patients' symptoms (Broberger, 2005; Lobchuk, 2006; Madison, 1995). Lung cancer patients often used complementary or alternative medicine to control or alleviate symptoms and this varied widely based on gender, age and geography (Fouladbakhsh, 2005; Wells, 2007). Patients often learned of these methods through family, friends and other lung cancer patients. The lack of data regarding symptom management once the patient is out of the acute phase underscores the need for interventions for both patients and caregivers.

DISCUSSION

A visual model representing the factors that could influence or could represent what is necessary for a more active and informed lung cancer patient was developed (Fig 2). This model is adapted from and incorporates elements of Wagner's (2001) chronic care model that specifically relate to the patient side of the physician – patient interaction. Four key components detailed in Wagner's model that are necessary for an active, informed patient participant in the chronic care setting serve as the core, central theme in this model, and are critical in order for lung cancer patients to play a role in managing their own chronic health care needs. These four themes can be thought of as internal in the context that they relate to individual patients and their knowledge, how they process that knowledge to make decisions, how they internally take responsibility for self management, how they internalize quality of life measures as well as apply QOL interventions, and how they accept responsibility for follow up care. The model itself should be viewed as cyclical rather than static, in that during each stage of chronic care management, or during new acute stages, the patient should be expected to go through the same circle or thought process.

The outer portion of the circle represents the various external factors that may influence or place strain on the patients in their attempt to play an active, informed role. The factors include community communication and information transfer examples of which are literacy levels of information, technology available to deliver and receive information, venue of communication, and lack of prepared patient information. Examples of community based barriers include geography, finances, physical limitations, and service capacity. Examples of community support networks that need to be considered are the availability of caregivers, community support groups, outreach and advocacy groups. Finally the community health beliefs that may exert influence on the patient include stigma, anti-smoking legislation, and media influence.

Future research should focus not on the internal or the external components individually, but should reflect the impact they may have with one another. For example, it is difficult to assess appropriate follow up care plans without also assessing how lung cancer patients want to communicate regarding follow up, how their support network can assist them with follow up, and what barriers might exist that prevent them from actively participating in their follow up plan on a routine basis.

This model represents the fact that in order to prepare the market place for a more chronic version of lung cancer, numerous research questions must be addressed and explored in order to develop an appropriate strategy that aids lung cancer patients in becoming both informed and motivated to a level where they can actively participate in their health care decisions over a prolonged period of time.

In this mapping exercise I have tried to address the following questions:

1) what do we know about lung cancer patients' health beliefs and how does that influence their decision making regarding treatment decisions and quality of life
2) what do we know about lung cancer patients' and their communication and information preferences including both physician communication and preferred information seeking methods and tools
3) what do we know about lung cancer patient support systems both internally and externally driven

4) what do we know about specific barriers faced by patients with lung cancer with regards to managing their health needs

The interrelationship of these themes with the chronic care model has been incorporated into the new model representing the dynamics that should be considered when assessing lung cancer patients' readiness to participate in a productive chronic care relationship with their oncologist. This patient oriented model represents the first step towards developing a more extensive assessment of chronic care lung cancer treatment.

CONCLUSION

This integrative research study has identified 23 individual factors that are known to encompass the individual building blocks needed to move the management of lung cancer from the current acute, terminal care mode towards a chronic care model. This review indicates that much research needs to be done before we can begin to successfully manage lung cancer as a chronic disease. In only three of the 23 areas do we have good information related to lung cancer, and in no case is information at the level of excellence. In three areas, there is good evidence in general cancer, but not specifically for lung cancer, and in the remaining 17 areas there is inadequate or no evidence.

Given the current level of funding for lung cancer research, it is unlikely that we will be able to gain evidence in the near future. Thus, the promises for long term survival that are emerging from screening and treatment advances are unlikely to come to fruition for patients under real practice conditions unless a major change in research funding for lung cancer occurs soon. This study provides information on the building blocks needed to move lung cancer care into the future. It is imperative that research on these building blocks for future lung cancer care is recognized by leaders in the field and receive attention and funding. Without this evidence we can not move forward in caring for lung cancer patients.

In assessing the knowledge gaps or discrepancies identified in this knowledge mapping exercise, two important areas to address that would have an immediate impact on patients now and in the future are identified. There is clearly a need for better tools to help improve communication regarding treatment options and goals so that there is improved understanding at the patient level and improved agreement between patients and physicians regarding the actual expectations from therapy. Secondly the gap in identifying and treating depression in this group of patients must be addressed to improve quality of life in both the short term and the long term for acute and chronically treated lung cancer patients.

In addition to the research gaps identified in the knowledge mapping exercise, the next research need to be addressed in the future should involve a focus how physicians treating lung cancer can prepare for more productive physician-patient interactions and relationships . We must understand physician perceptions regarding their readiness to participate in and manage lung cancer patients through a much more prolonged series of productive physician patient interactions, as well as identifying their perceived barriers to this type of interaction at the individual, institutional and system levels of care.

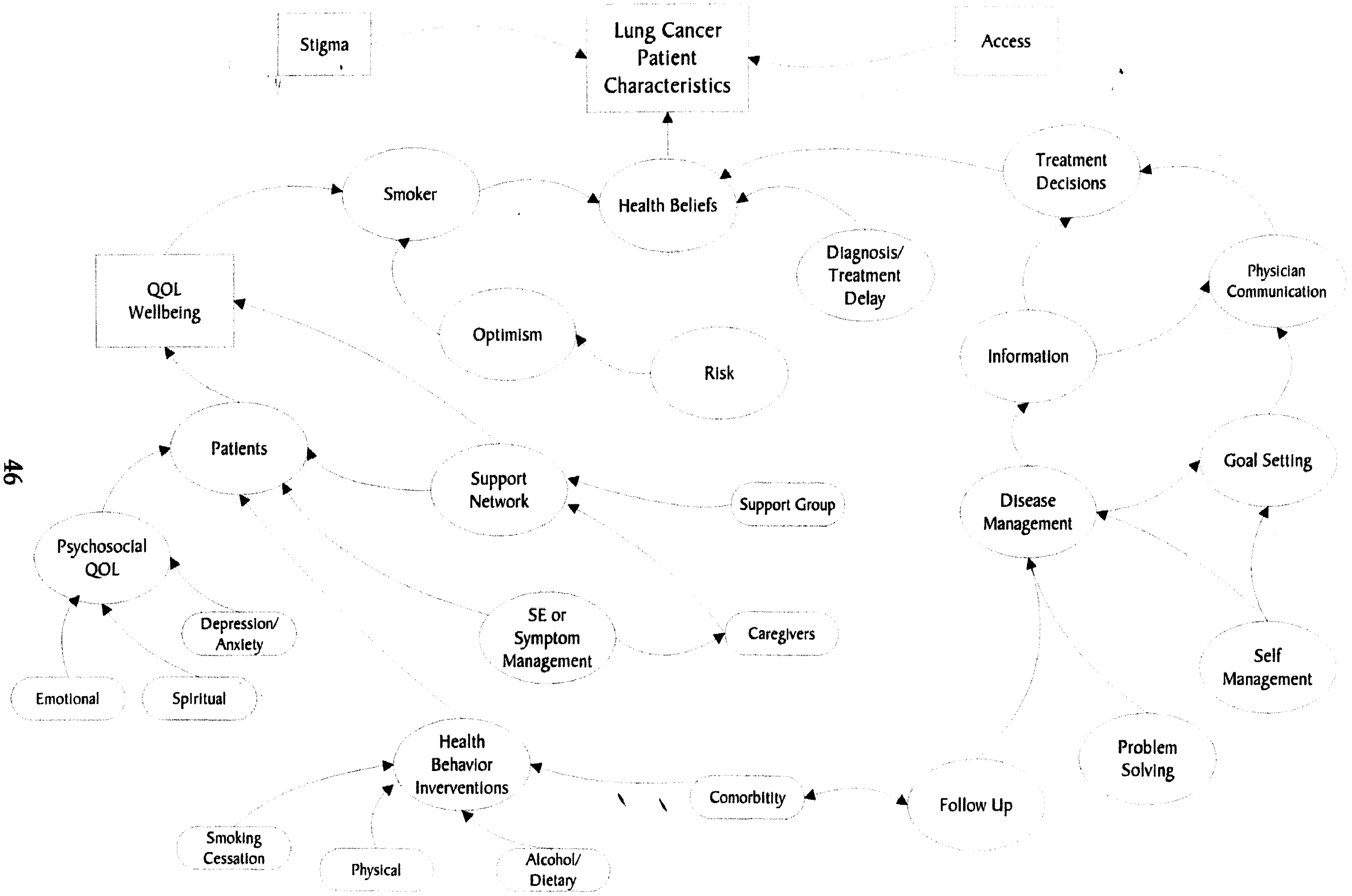
Table 1

Mapping Domains	References Included	Domain Rating
Stigma	Chapple, Corner, Corner, Street (2004)	2
Access	Campbell, Earle, Ferguson, Hall, Holzman McDavid, Mulligan, Silverstein, Street (2005)	0
Health Beliefs/ Smokers		
Optimism	Dillard, Donovan, Hay, Malin, The, Weeks	2
Risk	Brownson, Cykert(2004), Dias, Dillard, Dowding, Hay, Ma, Lipkus, Malin, Oncken, Salander (2006), Silvestri (2006) Weinstein	2
Diagnosis / Treatment Delay	Corner, Corner, Levealahti, , O'Conaill, Salomaa, Sharf	0
Treatment Decisions / Disease Management	Brundage 1998,2000, 2001, Chu, Cykert 2003, 2004, Davidson, Dubey, Earle, Feldman, Fiset, Hirose, Kee, Krishnasamy, Lathan, Leighl, Margolis, Markman 2005, 2006 Matsuyama, Molassiotis, Quirt, Sharf, Silvestri 1998, 2003, Siminoff, Skinn, True, Weeks	0
Information	Davidson, Donovan, Feldman, Gordon, Hagerty, Kakai, Malin, Markman 2005, Matsuyama, Molassiotis, Moore (2004, 2006, 2006), Peterson, Powers, Sorensen, Stoddard,	0
Physician Communication	Chu, Cykert, 2004, Gordon, Hagerty, Krishnasamy, Leighl, Quinn, Quirt, Salander 2005, Sharf, Street 2005, 2006, Yardley, Weeks	1
Goal Setting	Pizzi, Robb, Smith (1996), Street (2003), Watterson	0
Self Management	Boehmer, Downe – Wamboldt, Lobchuk, Fouladbakhsh, Madison, Maliski, Molassiotis Porter,	0
Problem Solving		0
Follow Up	Cox (2006), Moore (2006), Saunders, Smith 2003	0
Comorbidity	Ko, Sugimura, Tammemagi,	0
QOL – Well Being	Bozcuk, Downe – Wamboldt, Garces, Ko, Maione, Maliski, Osoba, Ryan, Thompson	0
Support Networks	Broberger, Chapple, Downe – Wamboldt, Hamilton, Kim, Krishnasamy Li, Lidstone, Lobchuk, Madison, Sharpe	
Caregivers	Abernethy, Moore, Pinquart, Sarna 2006	0

Side Effects / Symptom Management	Basch, Broberger, Downe – Wamboldt, Dubey, Fox, Hsu, Kitely, Kuo, Lidstone, Lobchuk, Madison, Molassiotis, Wells	0
Psychosocial QOL	Badr, Graves, Hill, Li, Montazeri (1998, 2003), Schag	0
Emotional	Kuo, Lidstone, Sarna 2006, Walker 2006, Zabora	0
Spiritual	Abernethy, Meraviglia, Murray, True, Silvestri 2003	0
Depression / Anxiety	Carlsen, Faller, Fox, Himelhoch, Krishnasamy Kuo, Sarna 2005, Walker 2004, 2006,	1
Health Behavior Interventions	Denmark- Wahnefried, Hately, Ryan, Sugimura, Thompson,	
Smoking Cessation	Baser, Cox 2002, Dillard, Evangelista, Gritz, Sarna 2006, Schnoll 2002, 2003, 2004, Walker 2004, 2006	1
Physical	Ashley, Doorenbos, Lidstone, Smith 1996, Robb	0
Alcohol / Dietary	Ashley, Beach, Evangelista, Sarna 2006,	0

Scale –	0	no evidence or inadequate evidence
	1	good evidence; not in lung cancer
	2	good evidence; lung cancer patients
	3	excellent evidence; lung cancer patients

Figure 1

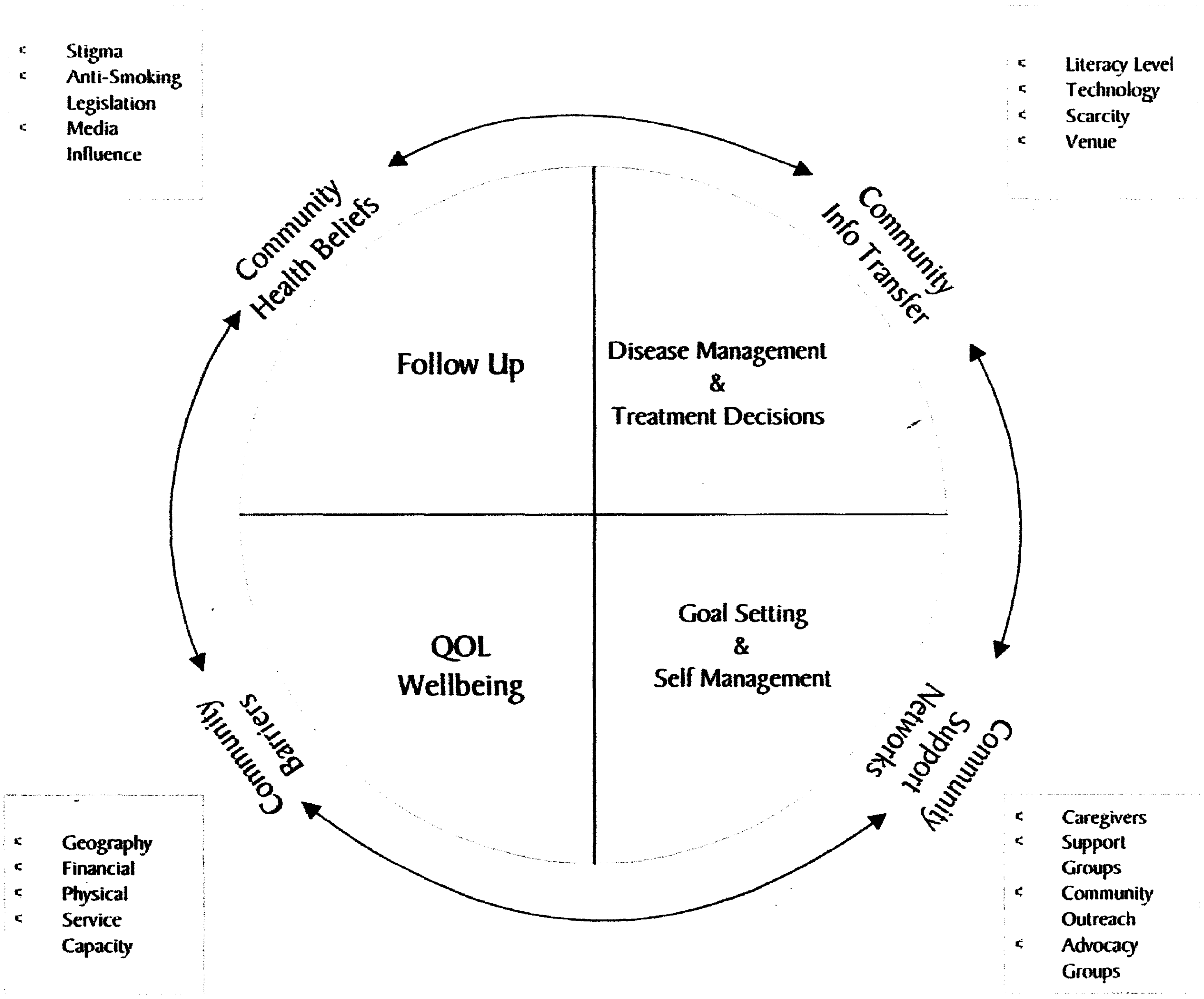


KNOWLEDGE MAP

LUNG CANCER PATIENT CHARACTERISTICS

Figure 2

MODEL FOR ACTIVE, INFORMED LUNG CANCER PATIENTS
Internal And External Influences In Chronic Care Settings



References

Abernethy, Alexis, et al. (2002). Religious coping and depression among spouses of people with lung cancer. Psychosomatics, vol 43, p 456 – 463.

Alberg, AJ, Maclolm Brock, and Johnathan Samet. (2005). Epidemiology of Lung Cancer: Looking to the Future. Journal of Clinical Oncology, vol 23, no 14, p 3175 – 3185.

Alborz, Alison, Rosalind McNally, and Caroline Glendinning. (2005). Access to healthcare for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. Journal Health Services Research Policy, Vol 10, no 3, p 173-182.

American Cancer Society, 2006 – Cancer Facts and Figures 2006. Surveillance, Epidemiology, and End Results Program, 1975-2001, Division of Cancer Control and Population Sciences, National Cancer Center.

Ashley, Judith. (2005). Diet recommendations for cancer survivors. Nurtrition and the MD, vol 31, no 7, p 1 – 8.

Badr, Hoda, and Cindy Taylor. (2006). Social constraints and spousal communication in lung cancer. Psycho-oncology, vol 15, p 673 – 683.

Basch, Ethan, et al. (2006). Patient versus clinican symptom reporting using the National Cancer Institute common terminology criteria for adverse events: results of a questionnaire based study. Lancet, vol 7, p 903 – 909.

Baser, Sevin, et al. (2006). Smoking cessation after diagnosis of lung cancer is associated with a beneficial effect on performance status. Chest, vol 130, no 6, p 1784 – 1790.

Beach, Patricia, et al. (2001). Relationship between fatigue and nutritional status in patients receiving radiation therapy to treat lung cancer. Oncology Nursing Forum, vol 28, no 6, p 1027 – 1031.

Bodenheimer, T., E. Wagner, and K. Grumbach. (2002). Improving primary care for patients with chronic illness. JAMA, vol 288, no 14, p 1775 – 1779.

Bodenheimer, T., E. Wagner, and K. Grumbach. (2002). Improving primary care for patients with chronic illness – the chronic care model: part 2. JAMA, vol 288, no 15, p 1909 – 1914.

Boehmer, Sonja, A. Luszczynska, and R. Schwarzer. (2007). Coping and quality of life after tumor surgery: personal and social resources promote different domains of quality of life. Anxiety, Street and Coping: An International Journal, vol 20, no 1, p 61 – 75.

Bozcuk, Hakan, et al. (2006). Quality of life in patients with non-small cell lung cancer. Cancer Nursing, vol 29, no 2, p 104 – 110.

Broberger, Eva, Carol Tishelman, and Louise van Essen. (2005). Discrepancies and similarities in how patients with lung cancer and their professional and family caregivers assess symptom occurrence and symptom distress. Journal of Pain and Symptom Management, vol 29, no 6, p 572 – 583.

Brownson, R.C., et al. (1992). Demographic and socioeconomic differences in beliefs about the health effects of smoking. American Journal of Public Health, vol 82, no 1, p 99 – 103.

Brundage, M.D., et al. (2000). A treatment trade off based decision aid for patients with locally advanced non small cell lung cancer. Health Expectations, vol 3, p 55 – 68.

Brundage, M.D., et al. (1999). Using a treatment tradeoff method to elicit preferences for the treatment of locally advanced non small cell lung cancer. Medical Decision Making, vol 18, no 3, p 256 – 267.

Brundage, M.D. et al. (2001). Cancer patients' attitudes toward treatment options for advanced non-small cell lung cancer: implications for patient education and decision support. Patient Education and Counseling, vol 45, p 149 – 157.

Campbell, N.C., et al. (2001). Rural and urban differences in stage at diagnosis of colorectal and lung cancers. British Journal of Cancer, vol 84, p 910 – 914.

Carlsen, Katherine, et al. (2005). Psychosocial aspects of lung cancer. Lung Cancer, vol 47, no 3, p 293 – 300.

Chapple, A., S. Ziebland and A. McPherson. (2004). Stigma, shame and blame experienced by patients with lung cancer: qualitative study. British Medical Journal, vol 328, p 1470 – 1475.

Chu, Da-Tong, et al. (2007). Patient attitudes towards chemotherapy as assessed by patient versus physician: a prospective observational study in advanced non small cell lung cancer. Lung Cancer, vol 56, no 3, p 433 - 443.

Coughlan, Roy. (2004). Stigma, shame and blame experienced by patients with lung cancer: health promotion and support groups have a role. British Medical Journal, vol 329, p 402 - 403.

Corner, Jessica, et al. (2005). Is late diagnosis of lung cancer inevitable? Interview study of patients' recollections of symptoms before diagnosis. Thorax, vol 60, no 4, p 314 - 319.

Corner, Jessica, Jane Hopkinson, and Liz Roffe. (2005). Experience of health changes and reasons for delay in seeking care: A UK study of the months prior to the diagnosis of lung cancer. Social Science and Medicine, vol 62, p 1381 - 1391.

Cox, Karen, et al. (2006). Preferences for follow up after treatment for lung cancer. Cancer Nursing, vol 29, no 3, p 176 - 187.

Cox, Lisa, et al. (2002). Smoking behavior of 226 patients with diagnosis of stage IIIA/IIIB non small cell lung cancer. Psycho-oncology, vol 11, no 6, p 472 - 478.

Cykert, S. (2004). Risk acceptance and risk aversion: patients' perspectives on lung surgery. Thoracic Surgery Clinic, vol 14, no 3, p 287 - 293.

Cykert, S., and Nancy Phifer. (2003). Surgical decisions for early stage, non small cell lung cancer: which racially sensitive perceptions of cancer are likely to explain racial variation in surgery? Medical Decision Making, vol 23, no 2, p 167 - 176.

Davidson, J.R., M. Brundage, and D. Stewart-Feldman. (1999). Lung cancer treatment decisions: patients' desires for participation and information. Psycho-oncology, vol 8, no 6, p 511 - 520.

Demark-Wahnefried, W., et al. (2005). Riding the crest of the teachable moment: promoting long term health after the diagnosis of cancer. Journal of Clinical Oncology, vol 23, no 24, p 5814 - 5830.

Dias, Olivia Meira, and Egberto Turato. (2006). Cigarette smokers views on their habit and the causes of their illness following lung cancer diagnosis: a clinical-qualitative study. Sao Paulo Medical Journal, vol 124, no 3. p 1 - 13.

Dillard, Amanda, et al. (2006). Unrealistic optimism in smokers: implications for smoking myth endorsement and self protective motivation. Journal of Health Communication, vol 11, supplement 1, p 93 - 102.

Donovan, Robert, Owen Carter and Michael Byrne. (2006). People's perceptions of cancer survivability: implications for oncologists. Lancet, vol, 7, p 668 - 675.

Doorenbos, Ardith, et al. (2006). Physical functioning: effect of behavioral intervention for symptoms among individuals with cancer. Nursing Research, vol 55, no 3, p 161 - 171.

Dowding, D. (2006). Personal beliefs, experiences and emotions influenced smokers' perceptions of their cancer risk. Evidence Based Nursing, vol 9, no 3, p 92.

Downe-Wamboldt, Barbara, Lorna Butler, and Lynn Coulter. (2006). The relationship between meaning of illness, social support, coping strategies and quality of life for lung cancer patients and their family members. Cancer Nursing, vol 29, no 2, p 111 - 119.

Dubey, S., et al. (2005). Patient preferences in choosing chemotherapy regimens for advanced non small cell lung cancer. Journal of Supportive Oncology, vol 3, no 2, p 149 - 154.

Earle, Craig., et al. (2002). Impact of referral patterns on the use of chemotherapy for lung cancer. Journal of Clinical Oncology, vol 20, no 7, p 1786 - 1792.

Ebener, S., et al. (2006). Knowledge mapping as a technique to support Knowledge translation. Bulletin of the World Health Organization, Aug, vol 84, p 636 642.

Evangelista, Lorraine, et al. (2003). Health perceptions and risk behaviors of lung cancer survivors. Heart and Lung, vol 32, no 2, p 131 - 139.

Faller, H. and Michael Schmidt. (2004). Prognostic value of depressive coping and depression in survival of lung cancer patients. Psycho-oncology, vol 13, no 5, p 359 - 363.

Feldman – Stewart, Deb and Michael Brundage. (2004). Challenges for designing and implementing decision aids. Patient Education and Counseling, vol 54, p 265 – 273.

Ferguson, R.J., et al. (2003). Lung cancer: the importance of seeing a respiratory physician. European Respiratory Journal, vol 21, p 606 – 610.

Fiset, Valerie, et al. (2000). Development and evaluation of a decision aid for patients with stage IV non small cell lung cancer. Health Expectations, vol 3, p 125 – 136.

Fouladbakhsh, Judith, et al. (2005). Predictors of use of complementary and alternative therapies among patients with cancer. Oncology Nursing Forum, vol 32, no 6, p 1115 – 1122.

Fox, S.W. and D.E. Lyon. (2006). Symptom clusters and quality of life in survivors of lung cancer. Oncology Nursing Forum, vol 33, no 5, p 931 – 936.

Garces, Y. I., et al. (2004). The relationship between cigarette smoking and quality of life after lung cancer diagnosis. Chest, vol 126, no 6, p 1733 – 1741.

Gilligan, Timothy. (2005). Social Disparities and prostate cancer: mapping the gaps in our knowledge. Cancer Causes and Control, Vol 16; 45 – 53.

Gordon, Howard, et al. (2006). Racial differences in trust and lung cancer patients' perceptions of physician communication. Journal of Clinical Oncology, vol 24, no 6, p 904 – 909.

Graves, Kristi, et al. (2007). Distress screening in a multidisciplinary lung cancer clinic: prevalence and predictors of clinically significant distress. Lung Cancer, vol 55, no 2, p 215 – 224.

Gritz, E.R., C. Carr, and D. Rapkin. (1993). Predictors of long term smoking cessation in head and neck cancer patients. Cancer Epidemiology Bio Prevention, vol 2, p 261 – 270.

Hagerty, R. G., et al. (2005). Communicating prognosis in cancer care: a systematic review of the literature. Annals of Oncology, vol 16, p 1005 – 1053.

Hall, S., et al. (2004). The influence of socioeconomic and locational disadvantage on survival after a diagnosis of lung or breat cancer in Western Australia. Journal Health Services Research and Policy, vol 9, suppl 2, p 10 – 16.

Hamilton, J., et al. (2001). The impact and management of cancer related fatigue on patients and families. Canadian Oncology Nursing Journal, vol 11, no 4, p 192-198.

Hately, Juliet, et al. (2003). Breathlessness clinics within specialist palliative care settings can improve the quality of life and functional capacity of patients with lung cancer. Palliative Medicine, vol 17, no 5, p 410 – 417.

Hay, Jennifer. (2005). Thinking through cancer risk: characterizing smokers process of risk determination. Qualitative Health Research, vol 15, no 8, p 1074 – 1085.

Henschke, CI., et al. (1999). Early Lung Cancer Action Project: overall design and findings from baseline screening. Lancet, 354: 99-105.

Henschke, CI., et al. (2004). CT Screening for lung cancer: assessing a regimen's diagnostic performance. Clin Imaging, 28: 317-321.

Henschke, CI., et al. (2006). Survival of Patients with stage 1 lung cancer detected on CT screening. New England Journal of Medicine, vol 355, no 17, p 1763-1771.

Hill, K.M. et al. (2003). Do newly diagnosed lung cancer patients feel their concerns are being met? European Journal of Cancer Care, vol 12, no 1, p 35 – 45.

Himelhoch, Seth, et al. (2004). Chronic medical illness, depression, and use of acute medical services among Medicare beneficiaries. Medical Care, vol 42, no 6, p 512 – 521.

Hirose, T., et al. (2005). Patients preferences in chemotherapy for advanced non small cell lung cancer. Internal Medicine, vol 44, no 2, p 107 – 113.

Holzman, D. (1995). Better access for the poor may improve lung cancer survival. Journal National Cancer Institute, vol 87, p 1212.

Hsu, Tsui-Hsia, et al. (2003). The relationship of pain, uncertainty and hope in Taiwanese lung cancer patients. Journal of Pain and Symptom Management, vol 26, no 3, p 835 – 842.

http://cancer.gov

http://lungcanceralliance.org

http://www.lungcancer.org/patients/1c_101/1c_101_lack.htm http://www.lungusa.org

Kaki, Hisaki, et al. (2003). Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: an exploratory study with correspondence analysis. Social Science and Medicine, vol 56, no 4, p 851 – 862.

Kee, Frank, Tracy Owen, and Ruth Leathem. (2004). Decision making in a multidisciplinary cancer team: does team discussion result in better quality decisions? Medical Decision Making, vol 24, no 6, p 602 – 613.

Kim, Youngmee, et al. (2005). Levels of depressive symptoms in spouses of people with lung cancer: Effects of personality, social support and caregiver burden. Psychosomatics, vol 46, no 2, p 123 – 130.

Kiteley, C.A., and M.I. Fitch. (2006). Understanding the symptoms experienced by individuals with lung cancer. Canadian Oncology Nursing Journal, vol 16, no 1, p 25 – 30.

Ko, Clifford, Melinda Maggard, and Edward Livingston. (2003). Evaluating health utility in patients with melanoma, breast cancer, colon cancer and lung cancer: a nationwide, population based assessment. Journal of Surgical Research, vol 114, no 1, p 1 – 5.

Krishnasamy, Meinir, Erna Wilkie, and Jo Haviland. (2001). Lung cancer health care needs assessment: patients' and informal careers' responses to a national mail questionnaire survey. Palliative Medicine, vol 15, p 213 – 227.

Kuo, Ting Ting and Fung Chi Ma. (2002). Symptom distress and coping strategies in patients with non small cell lung cancer. Cancer Nursing, vol 25, no 4, p 309 - 317.

Lathan, Christopher, Bridget Neville, and Craig Earle. (2006). The effect of race on invasive staging and surgery in non small cell lung cancer. Journal of Clinical Oncology, vol 24, no 3, p 413 - 418.

Leighl, Natasha, et al. (2004). Treatment decision aids in advanced cancer: When the goal is not cure and the answer is not clear. Journal of Clinical Oncology, vol 22, no 9, p 1759 - 1762.

Levealahti, H., C Tishelman, C., and J. Ohlen. (2006). Framing the onset of lung cancer biographically: narratives of continuity and disruption. Psychooncology, Aug 16 EPUB ahead of print.

Li, Jiong, and Afaf Girgis. (2006). Supportive care needs: are patients with lung cancer a neglected population? Psycho-oncology, vol 15, p 509 - 516.

Lidstone, V., et al. (2003). Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. Palliative Medicine, vol 17, p 588 - 595.

Lipkus, I.M., Klein, W.M., and B.K. Rimmer. (2001). Communicating breast cancer risks to women using different formats. Cancer Epidemiology Biomarkers and Prevention, vol 10, no 8, p 895 - 898.

Lobchuk, Michelle, et al. (2006). Promoting enhanced patient and family caregiver congruence on lung cancer symptom experiences. Oncology Nursing Forum, vol 33, no 2, p 273 - 282.

Ma, G. X., et al. (2002). Perceived risks of certain types of cancer and heart disease among Asian American smokers and non-smokers. Journal of Community Health, vol 27, no 4, p 233 - 246.

Madison, J.L., and D.J. Wilkie. (1995). Family members' perceptions of cancer pain: comparisons with patient sensory report and by patient psychologic status. Nursing Clinics of North America, vol 30, No 4, p 625-645.

Maliski, S., L. Sarna, and L. Evangelista. (2003). The aftermath of lung cancer – balancing the good and the bad. Cancer Nursing, vol 26, p 237 - 243.

Maione, Paolo, et al. (2005). Pretreatment quality of life and functional status assessment significantly predict survival of elderly patients with advanced non small cell lung cancer receiving chemotherapy: a prognostic analysis of the multicenter Italian lung cancer in the elderly study. Journal of Clinical Oncology, vol 23, no 28, p 6865 - 6872.

Malin, Jennifer, et al. (2006). Understanding cancer patients' experience and outcomes: development and pilot study of the cancer care outcomes research and surveillance patient survey. Support Care Cancer, vol 14, p 837 - 848.

Margolis, Mitchell et al. (2003). Racial differences pertaining to a belief about lung cancer surgery. Annals of Internal Medicine, vol 139, no 7, p 558 - 564.

Markman, Maurie, Judith Petersen, and Robert Montgomery. (2005). An examination of characteristics of lung and colon cancer patients participating in a web based decision support program. Oncology, vol 69, p 311 – 316.

Markman, Maurie, Judith Petersen, and Robert Montgomery. (2006). Influence of tumor type, disease status and patient age on self reported interest regarding participation in cancer clinical trials. Cancer, vol 107, no 4, p 849 – 853.

Matsuyama, Robin, Sashidhar Reddy, and Thomas Smith. (2006). Why do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer. Journal of Clinical Oncology, vol 24, no 21, p 3490 – 3496.

McDavid, K., et al. (2003). Cancer survival in Kentucky and health insurance coverage. Archives of Internal Medicine, vol 163, p 2135 – 2144.

Meraviglia, Martha. (2004). The effects of spirituality on well being of people with lung cancer. Oncology Nursing Forum, vol 31, no 1, p 89 – 94.

Molassiotis, A., et al. (2006). Complementary and alternative medicine use in lung cancer patients in eight European countries. Complementary Therapies in Clinical Practice, vol 12, no 1, p 34 – 39.

Molina, JR, Alex Adjei, and James Jett. (2006). Advances in chemotherapy Non small Cell Lung Cancer. Chest, vol 130, p 1211-1219.

Montazeri, A., C.R. Gillis, and J. McEwen. (1998). Quality of life in patients with lung cancer: a review of the literature from 1970 - 1995. Chest, vol 113, no 2, p 467 - 481.

Montazeri, A., et al. (2003). How quality of life data contribute to our understanding of cancer patients' experiences? A study of patients with lung cancer. Quality of Life Research, vol 12, no 2, p 157 - 166.

Moore, Sally, and Amanda Sherwin. (2004). Improving patient access to healthcare professionals: a prospective audit evaluating the role of e-mail communication for patients with lung cancer. European Journal of Oncology Nursing, vol 8, p 350 - 354.

Moore, Sally, et al. (2006). Caring for carers: A prospective audit of nurse specialists contact with families and carers of patients with lung cancer. European Journal of Oncology Nursing, vol 10, p 207 - 211.

Moore, Sally, et al. (2006). Nurse specialist led follow up in lung cancer: the experience of developing and delivering a new model of care. European Journal of Oncology Nursing, vol 10, no 5, p 364 - 377.

Mulligan, Charles, et al. (2006). Unlimited access to care: effect of racial disparity and prognostic factors in lung cancer. Cancer Epidemiology Biomarkers Prevention, vol 15, no 1, p 25 - 31.

Murray, Scott, et al. (2002). Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. British Medical Journal, vol 325, p 1 - 5.

Murray, Scott, et al. (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. Palliative Medicine, vol 18, p 39-45.

O'Conaill, Mita. (2005). Ignoring early symptoms of lung cancer. Cancer Nursin Practice, vol 4, no 4, p 6.

Oncken, C., et al. (2005). Knowledge and perceived risk of smoking related conditions: a survey of cigarette smokers. Preventive Medicine, vol 40, no 6, p 779 - 784.

Osoba, David, et al. (2006) Stated preferences of patients with cancer for health related quality of life (HRQOL) domains during treatment. Quality of Life Research, vol 15, no 2, p 273-283.

Peterson, Michael and Peter Fretz. (2003). Patient use of the internet for information in a lung cancer clinic. Chest, vol 123, p 452 - 457.

Pinquart, M., and P. Duberstein. (2005). Optimism, pessimism and depressive symptoms in spouses of lung cancer patients. Psychology and Health, vol 20, no 5, p 565 - 578.

Pizzi, Michael, and Richard Briggs. (2004). Occupational and physical therapy in hospice. Topics in Geriatric Rehabilitation, vol 20, no 2, p 120 - 130.

Porter, Laura, et al. (2002). Perceptions of patients' self-efficacy for managing pain and lung cancer symptoms: correspondence between patients and family caregivers. Pain, vol 98, p 169-178.

Powers, B. (2006). Reading level of lung cancer patient education materials: a ten year follow up study. Journal of Hospital Libr, vol 6, no 4, p 69 - 74.

Quinn, G.P., et al. (2007). The guinea pig syndrome: improving clinical trial participation among thoracic patients. Journal of Thoracic Oncology, vol 2, no 3, p 191 - 196.

Quirt, C. F., et al. (1997). Do doctors know when their patients don't? A survey of doctor-patient communication in lung cancer. Lung Cancer, vol 18, p 1 - 20.

Robb, Karen A., et al. (2006). A pain management program for chronic cancer – treatment related pain: a preliminary study. The Journal of Pain, vol 7, no 2, p 82 - 90.

Ryan, L.S. (1996). Psychosocial issues and lung cancer: a behavioral approach. Seminars in Oncology Nursing, vol 12, no 4, p 318 - 323.

Salander, Par. (2006). Attributions of lung cancer: my own illness is hardly caused by smoking. Psycho-oncology, vol 6, p 27.

Salander, Par, and Roger Henriksson. (2005). Severely diseased lung cancer patients narrate the importance of being included in a helping relationship. Lung Cancer, vol 50, p 155 - 162.

Salomaa, Eija., et al (2005). Delays in the diagnosis and treatment of lung cancer. Chest, vol 128, p 2282 - 2288.

Sarna, L., et al. (2005). Quality of life and meaning of illness of women with lung cancer. Oncology Nursing Forum, vol 32, no 1, p E9-19.

Sarna, L., et al. (2006). Quality of life and health status of dyads of women with lung cancer and family members. Oncology Nursing Forum, vol 33, no 6, p 1109 - 1116.

Saunders, M., et al. (2003). Consensus: the follow up of the treated patient. Lung Cancer, vol 42, supplement 1, p S17 – 19.

Schag, C., et al. (1994). Quality of life in adult survivors of lung, colon and prostate cancer. Quality of Life Research, vol 3, p 127 – 141.

Schnoll, Robert A., et al. (2003). Brief physician initiated quit smoking strategies for clinical oncology settings: a trial of coordinated by the eastern cooperative oncology group. Journal of Clinical Oncology, vol 21, no 2, p 355 – 365.

Schnoll, Robert A., et al. (2004). Comparing cancer patients who enroll in a smoking cessation program at a comprehensive cancer center with those who decline enrollment. Head and Neck, vol 26, no 3, p 278 – 286.

Scnholl, Robert, et al. (2002). Process of change related to smoking behavior among cancer patients. Cancer Practice: A Multidisciplinary Journal of Cancer Care, vol 10, no 1, p 11 – 19.

Sharf, Barbara, Linda Stelljes and Howard Gordon. (2005). ' A little bitty spot and I'm a big man': patients' perspectives on refusing diagnosis or treatment for lung cancer. Psycho-oncology, vol 14, p 636 – 646.

Sharpe, L., et al. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. Psycho-oncology, vol 14, no 2, p 102 – 114.

Silverstein, M.D., et al. (2002). Access to care and stage at diagnosis for patients with lung and esophageal cancer: analysis of the Savannah River Region

Information System cancer registry data. Southern Medical Journal, vol 95, p 900 – 908.

Silvestri, G.A., et al. (2006). Attitudes towards screening for lung cancer among smokers and their non smoking counterparts. Thorax, online edition, Nov, 13, doi:10.1136/thx.2005.056036.

Silvestri, G. A., et al. (2003). Importance of faith on medical decisions regarding cancer care. Journal of Clinical Oncology, vol 21, no 7, p 1379 – 1382.

Silverstri, G. A., Robert Pritchard, and H. G. Welch. (1998). Preferences for chemotherapy in patients with advanced non small cell lung cancer: descriptive study based on scripted interviews. British Medical Journal, vol 317, p 771 – 775.

Siminoff, Laura, et al. (2006). Measuring discord in treatment decision making; progress toward development of a cancer communication and decision making assessment tool. Psycho-Oncology, vol 15, no 6, p 528 – 540.

Skinn, B. (1994). The relationship of belief in control and purpose in life to adult lung cancer patients' inclination to use unproven cancer therapies. Canadian Oncology Nursing Journal, vol 4, no 2, p 66 – 71.

Smith, S.L. (1996). Physical exercise as an oncology nursing intervention to enhance quality of life. Oncology Nursing Forum, vol 23, no 5, p 771 – 778.

Smith, Thomas J. (2003). Evidence based follow up of lung cancer patients. Seminars in Oncology, vol 30, no 3, p 361 – 368.

Sorensen, J.B., P. Rossel, and S. Holm. (2004). Patient-physician communication concerning participation in cancer chemotherapy trials. British Journal of Cancer, vol 90, no 2, p 328 - 332.

Street, A. (2004). Ask your doctor: The construction of smoking in advertising posters produced in 1946 and 2004. Nursing Inquiry, vol 11, no 4, p 226 - 237.

Street, Helen. (2003). The psychosocial of cancer: exploring relationships between conditional goal setting and depression. Psycho-Oncology, vol 12, no 6, p 580-589.

Street, Richard, et al. (2005). Patient participation in medical consultations - why some patients are more involved than others. Medical Care, vol 43, no 10, p 960 - 969.

Street, Richard, and Howard Gordon. (2006). The clinical context and patient participation in post diagnostic consultations. Patient Education and Counseling, vol 64, p 217 - 224.

Stoddard, J., and E. Augustson. (2006). Smokers who use Internet and smokers who don't: data from the Health Information and National Trends Survey. Nicotine and Tobacco Research, vol 8, S p 77 - 85.

Sugimura, Hiroshi, and Ping Yang. (2006). Long term survivorship in lung cancer. Chest, vol 129, no 4, p 1088 - 1097.

Tammemagi, C.M., et al. (2004). In lung cancer patients, age, race-ethnicity, gender and smoking predict adverse comorbidity, which in turn predicts treatment and survival. Journal of Clinical Epidemiology, vol 57, p 597 - 609.

The, A., T. Hak, and G. Koeter. (2001). Collusion in doctor patient communication about imminent death: An ethnographic study. Western Journal of Medicine, vol 174, p 247 - 253.

Thompson, Elinor, Ivan Sola and Mireia Subirana. (2005). Non invasive interventions for improving well being and quality of life in patients with lung cancer - A systematic review of the evidence. Lung Cancer, vol 50, p 163 - 176.

True, Gala., et al. (2005). Treatment preferences and advance care planning at end of life: the role of ethnicity and spiritual coping in cancer patients. Annals of Behavioural Medicine, vol 30, no 2, p 174 - 179.

Wagner, E. H. , et al. (2001). Improving Chronic Illness Care: Translating Evidence Into Action. Health Affairs, Vol 20, no 6, p 64-78.

Walker, Mark S., et al. (2004). Smoking urges and relapse among lung cancer patients: findings from a preliminary retrospective study. Preventive Medicine, vol 39, p 449 - 457.

Walker, Mark S., et al. (2006). Depressive symptoms after lung cancer surgery: their relation to coping style and social support. Psycho-oncology, vol 15, p 684 - 693.

Walker, Mark S., et al. (2006). Smoking relapse during the first year after treatment for early stage non small cell lung cancer. Cancer

Epidemiology, Biomarkers and Prevention: A Publication Of The American Association For Cancer Research, vol 15, no 12, p 2370 - 2377.

Watterson, J., et al. (2004). Rehabilitation goals identified by inpatients with cancer using the COPM. International Journal of Therapy and Rehabilitation, vo 11, no 5, p 219 - 225.

Weeks, Jane., et al. (1998). Relationship between cancer patients' predictions of prognosis and their treatment preferences. JAMA, vol 279, no 21, p 1709 - 1714.

Weinstein, N.D., S. E. Marcus, and R. P. Moser. (2005). Smokers' unrealistic optimism about their risk. Tobacco Control, vol 14, p 55 - 59.

Wells, M., et al. (2007). Use of complementary and alternative medicine therapies to control symptoms in women living with lung cancer. Cancer Nursing, vol 30, no 1, p 45 - 57.

US Department of Health Education and Welfare: Smoking and health. Report of the Advisory Committee to the Surgeon General. DHEW Publication No. (PHS) 1103. Washington, DC, US Government Printing Office, 1964.

Yardley, S.J., C Davis, and F. Sheldon. (2001). Receiving a diagnosis of lung cancer: patients' interpretations, perceptions and perspectives. Palliative Medicine, vol 15, p 379 - 386.

Zabora, James, et al. (2001). The prevalence of psychological distress by cancer site. Psycho-oncology, vol 10, no 1, p 19 - 28.