

ENGAGEMENT IN CARE AMONG PATIENTS WITH LUNG CANCER

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DEDICATION

To the Muntzes, Johnsons, and Thomases
for their unwavering support,
and to my patients for daily inspiration.

ENGAGEMENT IN CARE AMONG PATIENTS WITH LUNG CANCER

by

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DISSERTATION / THESIS

Presented to the Faculty of the Graduate School of Biomedical Sciences

The University of Texas Southwestern Medical Center at Dallas

In Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF PHILOSOPHY

The University of Texas Southwestern Medical Center at Dallas

Dallas, Texas

August, 2016

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Background: Engagement in care broadly refers to patients' knowledge, skills, ability and willingness to play an active role in their health. Patient activation is a core component of engagement and has been associated with better care outcomes in several chronic health populations. Despite these findings, patient activation has been understudied in oncology populations broadly, with little focus on lung cancer patients specifically. *Objective:* The primary aim of this study was to describe patient activation among surveyed lung cancer patients. A second aim was to explore specific demographic, smoking-related, and psychosocial correlates of patient activation. *Method:* The sample included 231 lung patients who participated in a cross-sectional, multisite study. Patients completed a patient activation

self-report instrument, along with demographic, clinical, and psychosocial measures.

Analysis: Data related to study aims were analyzed using univariate and multivariable analysis. *Results:* Among lung cancer patients, overall patient activation scores were significantly lower for current smokers compared to former and never smokers ($F(2, 218) = 4.50, p = 0.01$), for men when compared with women ($F(1, 220) = 8.75, p < 0.01$), and for those who reported clinically significant depressive symptoms when compared with those who did not ($F(1, 219) = 13.95, p < 0.001$). In multivariable analysis, these significant main effects of smoking status, gender, and depressive symptoms remained. *Discussion:* Among lung cancer patients, those who were current smokers, were male, and those who endorsed high depressive symptomatology were likely to have the lowest activation scores in the sample. Practical recommendations include clinically identifying these high-risk patients through assessment and addressing activation via evidence based intervention.

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PRIOR PUBLICATIONS

Shen, M. J., Hamann, H., Thomas, A.J., & Ostroff, J. (2015) Association between patient-provider communication and lung cancer stigma. *Supportive Care in Cancer*. Advance online publication. doi: 10.1007/s00520-015-3014-0

Naar-King, S., Parsons, J.T., & Johnson, A.M. (2012) Motivational interviewing targeting risk reduction for people with HIV: A systematic review. *Current HIV/AIDS Reports*. 9(4), 335-343. doi:10.1007/s11904-012-0132-x

Johnson, A.M. (2012) A review of “Hooking Up: Sex, Dating and Relationships on Campus.” *Journal of Sex and Marital Therapy*. 38(1), 112-113.
doi:10.1080/0092623x.2012.633787

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LIST OF ABBREVIATIONS

ACA – Affordable Care Act

ACS - American Cancer Society

BMI – Body Mass Index

COPD - Chronic Obstructive Pulmonary Disease

EMR – Electronic Medical Record

HIV – Human Immunodeficiency Virus

HSC – Center for Studying Health Change

IOM – Institute of Medicine

MS – Multiple Sclerosis

MSKCC – Memorial Sloan Kettering Cancer Center

NHW – Non-Hispanic Whites

NSCLC – Non-Small Cell Lung Cancer

PAM – Patient Activation Measure

PANAS – Positive Affect Negative Affect Scale

PPACA— Patient Protection and Affordable Care Act

SCLC – Small-Cell Lung Cancer

UTSW – UT Southwestern Medical Center

CHAPTER ONE

Introduction

The importance of health care quality has received increased policy focus with the recent passage of the Patient Protection and Affordable Care Act (PPACA; 2010). Among its many aims, this law incorporates movement toward establishing “patient-centeredness” to increase quality in health care delivery. This goal was first designated in a report by the Institute of Medicine (IOM) as one of six aspirations for a 21st century health care system. Health care focused on the patient highlights a respect and responsiveness to “individual patient preferences, needs and values,” with regard to clinical decision-making (IOM, 2001).

Advocates for patient-centered care emphasize the importance of engaging patients through education and facilitation of active decision-making. The field of research focused on these aims is known broadly as *patient engagement* (James, Hibbard, Agres, Lott, & Dentzer, 2013), and involves a core component of *patient activation*. The definition of patient activation broadly refers to a patient’s knowledge, skills, ability, and willingness to play an active role in their health and care (Hibbard, Stockard, Mahoney, & Tusler, 2004). Numerous studies have reported better health outcomes associated with increased patient activation, a subset of which suggest activation is amenable to intervention (Alegría et al., 2008; Hibbard, Greene, & Tusler, 2009; Parchman, Zeber, & Palmer, 2010). The importance of patient activation has been shown in a range of patient populations, including primary and tertiary care settings, and among racially and ethnically diverse patients.

Despite compelling evidence that patient engagement may be a core strategy to improve health care quality, there is limited study within oncology settings. Further, there are few systematic investigations of patient engagement in lung cancer populations. Lung cancer is a deadly and devastating disease, and remains the leading cancer-related cause of death for Americans annually, more than colon, breast and prostate cancers combined (American Cancer Society [ACS], 2016). There are a myriad of reasons why lung cancer remains a significant health challenge, including delayed detection, treatment toxicity, complicated symptom burdens and multiple comorbidities (Spiro & Sylvestri, 2005; Youlden et al., 2008). Further, due to the well-established behavioral risk factors for lung cancer (most notably, smoking), many patients (both smokers and non-smokers) report experiencing lung cancer stigma, which can lead to negative psychosocial outcomes (Chambers et al., 2012; Chapple, Ziebland & McPherson, 2004; Else-Quest et al., 2009; Holland et al., 2010; LoConte et al., 2008; Weiss et al., 2012). Associations have been made between perceived stigma and diagnostic delay (Tod, Craven & Allmark, 2008), as well as underreporting of symptoms and smoking behaviors (Koller et al., 1996; Westerman et al., 2007). Anecdotal evidence suggests that “therapeutic nihilism” among lung cancer patients may impact both their help-seeking behavior, as well as the treatments or quality of care medical providers might offer (for review, see Chambers et al., 2012). These complex psychosocial and medical challenges highlight the difficulties facing both lung cancer patients and care providers.

Lung cancer disproportionately affects populations that traditionally demonstrate lower engagement in care, including racial/ethnic minorities, those with lower educational attainment, and tobacco users. The prevalence of distress (e.g., depression & anxiety) in lung

cancer patients has also been well documented, and is found at higher rates than in other cancer populations (Zabora et al., 2001). This relationship to depression is important in this context, as there is evidence of a relationship between depressive symptoms and low patient activation in patients with chronic health conditions (Hibbard & Cunningham, 2008). It has been suggested that depression may prevent patients from becoming activated (Hibbard et al., 2007). Finally, prevalent behavioral risk factors in this population (i.e., smoking behaviors) present potential opportunity for intervention. These unique factors highlight need for a thorough understanding of patient engagement in this population.

To address these issues, the present study aimed to fully understand patient activation among individuals diagnosed with lung cancer, as well as to identify specific demographic, smoking-related and psychosocial correlates of patient activation in this population. Results from the analyses allow greater understanding of patient-centered factors impacting engagement, and provide information on how intervention might best be developed to serve these individuals.

CHAPTER TWO

Review of the Literature

OVERVIEW OF PATIENT ACTIVATION

The Patient Protection and Affordable Care Act (PPACA; 2010) emphasizes the measurement of patients' care experiences and utilization of this information to improve health care quality. The legislation has also brought to light the importance of patients' active engagement in their health care decisions and interactions with their health care providers as a way to increase patient-centered care. Of particular note is the concept of *patient activation*, defined as a patient's skills, knowledge, and confidence for participation in their own clinical care (Hibbard et al., 2004). Evidence suggests patients who are more activated have better health outcomes and overall care experiences. These findings have sparked significant interest in considering patient activation as a possible strategy for reducing health care costs, increasing health outcomes and improving patient satisfaction with their health care encounters.

The relevance of patient activation has been increasingly recognized over the past decade, largely due to the work of Hibbard and colleagues, particularly their development and validation of a 13-item quantitative assessment, the Patient Activation Measure (PAM-13 or PAM; Hibbard et al., 2005). Scores on this scale reflect what Hibbard considers the latent construct underlying patient activation – “an individual's overall self-concept as a manager

of his or her healthcare”. The scale focuses on one’s perceived role in health care interactions and how competent they feel in this role (Hibbard, 2015).

Patient scores on the PAM can range from 0-100, and these scores can segment patient responses into one of four stages of patient activation along a continuum. Hibbard et al. (2007) define the four levels an individual moves through in order to become a competent manager of their health as follows:

- “At Stage 1: People do not yet grasp that they must play an active role in their own health, they may still believe they can just be a passive recipient of care....
- At Stage 2: People may lack the basic facts or have not connected the facts into a larger understanding about their health or recommended health regimens....
- At Stage 3: People have the key facts and are beginning to take action but may lack confidence and skill to support new behaviors....
- At Stage 4: People have adopted new behaviors but may not be able to maintain them in the face of life stress or health crises. (p. 1445)”

There have been promising findings of how patient activation may factor into health quality improvement, specifically with regard to health outcomes, patient satisfaction, and cost reduction. For example, a large cross-sectional study indicated that patients with higher patient activation scores were more likely to have received preventive care, less likely to smoke or be obese (measured by body mass index or BMI), and less likely to use the emergency department than patients with lower activation scores. Patients with higher patient activation scores were also more likely to have better clinical indicators, such as blood pressure and cholesterol biomarkers, compared with those with lower activation scores

(Greene & Hubbard, 2012). Other cross-sectional studies conducted across patient populations and in diverse health settings indicated that activation scores correlate positively with several protective health behaviors, including prevention (e.g., health screenings, immunizations), healthy lifestyle behaviors (e.g., maintaining a healthy diet and exercising; avoiding smoking and illegal drug use), self-management (e.g., medication adherence and self-monitoring) and health-information seeking (Fowles et al., 2009; Greene & Hibbard, 2012; Hibbard et al., 2007; Mosen et al., 2007; Rask et al., 2009; Salyers et al., 2009).

Prospective studies of patient activation have also documented linkages between activation and health outcomes. For example, in a retrospective longitudinal analysis of patients with diabetes, those with higher activation scores were more likely to experience better outcomes than those with lower activation scores (as measured by hemoglobin A1c testing; Remmers et al., 2009). Another study focused on the association between preoperative patient activation and functional recovery after spine surgery and found that patients with highest activation levels (e.g., Stage 4) experienced a greater decrease in pain and disability than those with the lowest activation scores (Skolasky, Mackenzie, Wegener, & Riley, 2011).

Based on the positive effects of increased patient activation (demonstrated by both prospective and cross-sectional studies), recent focus has turned to interventions designed to increase activation among at-risk populations (Alegría et al., 2008; Deen et al., 2011; Druss et al., 2010; Frosch et al., 2010; Hibbard et al., 2009; Parchman et al., 2010; Solomon, Wagner, & Goes, 2012). These interventions have been conducted in a variety of settings including the workplace, community clinics, hospitals, primary care settings and the Internet,

and have utilized a variety of population-specific approaches in order to bolster patient activation.

For example, two interventions have focused on increasing self-management through health education (Frosch et al., 2010; Solomon, Wagner & Goes, 2012), while another aimed to improve patient-provider communication through bolstering a patient's ability to obtain information from providers (Alegría et al., 2008). Importantly, all of these studies have documented improvement in activation scores associated with the activation interventions. However, despite these promising pilot studies, there is much to be known about which interventions work best within each patient population, how to engage or recruit low activated patients for interventions, and the longer-term effects of these interventions (Hibbard & Greene, 2013).

SOCIODEMOGRAPHIC AND PSYCHOSOCIAL PREDICTORS OF PATIENT ACTIVATION

In an effort to identify and target interventions to the most at-risk populations, several studies have focused on important predictors of patient activation. Of particular interest has been the association of sociodemographic characteristics, such as education and income. Data from the Center for Studying Health System Change's (HSC) 2007 Health Tracking Household Survey, a large, nationally representative sample ($N = 17,800$), indicated that patient activation varies by education and income. Specifically, activation levels were highest in individuals with more education and higher incomes (Hibbard & Cunningham, 2008);

follow-up analyses indicated that educational difference predominantly drove these differences. Another study focused on underserved populations ($N = 527$), and found that patients who were more educated were significantly more activated than their less educated counterparts (Lubetkin, Lu, & Gold, 2010).

Racial and ethnic differences in activation have also been found, with African Americans and Hispanics reporting lower activation relative to Non-Hispanic Whites (NHW). In the HSC survey mentioned above, for example, 45.3% of NHWs reported the highest level of patient activation, compared to a rate of 39.5% of African Americans and 24.8% of Hispanics (Cunningham, Hibbard, & Gibbons, 2011). These data are consistent with other known racial/ethnic differences in patient engagement, such as patient-provider relationships and health-care related knowledge (Cooper-Patrick et al., 1999; Schaafsma, Raynorr, & de Jong van den Berg, 2003).

To address psychosocial factors, a subset of studies have investigated the relationship between depression and patient activation. For example, Skolasky et al. (2008) reported findings of a longitudinal prospective study where the severity of depressive symptoms decreased as activation scores increased. Stepelman et al. (2010) also reported an inverse relationship between activation scores and depressive symptoms in a population of patients with multiple sclerosis (MS). Further, Hibbard & Mahoney (2010) have focused specifically on the relationship between emotions (measured via the Positive Affect Negative Affect Scale, or PANAS) and activation scores. Their data suggest that respondents who reported highest patient activation level reported far fewer negative emotions and a greater number of positive emotions, relative to those who reported the lowest level of patient activation.

IMPORTANCE OF UNDERSTANDING PATIENT ACTIVATION IN LUNG CANCER

Despite the increased recognition of patient activation and its benefits, there has been little work focused on oncology broadly, and lung cancer specifically. This lack of focus is surprising given the impact and challenges associated with lung cancer. Despite recent advances in screening and treatment, lung cancer remains the leading cancer killer of Americans, and is more lethal than breast, prostate, and colon cancers combined (ACS, 2016). Treatment regimens for lung cancer are often complex in that they can involve surgery, chemotherapy, radiation, and immunotherapy, and require patients to communicate and coordinate care with multiple specialists (ACS, 2016).

Although empirical data are limited, anecdotal evidence suggests that lung cancer patients are less involved in their care decisions compared to, for example, breast cancer patients (Raleigh, 2010); this reduced involvement may have serious consequences for patient-provider communication (Hillen, de Haes, & Smets, 2011; Holwerda et al., 2013; Wassenaar et al., 2007), clinical trial uptake (Curran, Schiller, Wolkin, & Comis, 2008), and disease prognosis (Tod, Craven, & Allmark, 2008). Such characteristics underscore the need to understand, and potentially intervene with, patient activation among lung cancer patients.

Specific sociodemographic and psychosocial characteristics of lung cancer patients also underscore the need to examine patient activation in this population. Individuals with lower socioeconomic status are disproportionately burdened by lung cancer; contributors include higher smoking prevalence, greater use of nonfilter, high-tar cigarettes and lower quit

rates among low SES populations (Alberg & Nonemaker, 2008). Racial minorities (especially African Americans) are also disproportionately diagnosed with lung cancer, largely due to a higher rate of smoking than any other racial/ethnic group in the United States (Alberg & Nonemaker, 2008). Specifically, for invasive lung cancer, African-American men have an incidence rate of 91/100,000, compared to 75/100,000 for NHW men (Howlader et al., 2015). As noted previously, those with lower socioeconomic status (defined by lower education and income) and racial/ethnic minorities are less likely to report high activation, when compared with more resourced patients. Further, smokers demonstrate significantly lower activation scores as compared with non-smokers (Greene & Hibbard, 2012). In addition, numerous studies show that lung cancer patients report high rates of distress, especially depressive symptoms, a known risk factor for lowered patient activation. Of note is a large-scale study in which 43.4% of lung cancer patients reported significant distress (as assessed via the Brief Symptom Inventory) compared to an average of 35.1% among patients with other cancers (Zabora et al., 2001).

A final reason to focus on patient activation in lung cancer relates to the poor health behavior profile of many patients. Previous work has identified patient activation as a predictor of health behavior change, with interventions suggesting that an increase in activation can help initiate and sustain such changes. For lung cancer patients specifically, the well-established connection between health behaviors (e.g., smoking) and lung cancer incidence points to the need to reduce smoking and address other behavioral targets. Recent data suggest that a significant minority of lung cancer patients who smoked before diagnosis continued to smoke immediately after diagnosis (Park et al., 2012). Several observational

studies have demonstrated that people who continue to smoke post-diagnosis have an increased risk of recurrence, higher incidence of a second primary tumor, and higher mortality rates (Parsons, Daley, Begh, & Aveyard, 2010). In contrast, smoking cessation among lung cancer patients is associated with better response to treatment (especially surgery and radiation), and lower mortality (Dresler, 2003; Gritz et al., 2006; Parsons et al., 2010; Richardson et al., 1993).

Another potential area for health behavior intervention is in the area of physical activity. Promising work by Jones et al. (2012) suggests that increases in exercise, even among the sickest of lung cancer patients, can have significant benefits for prognosis. As such, intervention efforts to address these health behaviors via improvements in patient activation may have beneficial consequences for quality of life and survival.

SUMMARY

Evidence to date strongly supports the unique potential for activated patients to improve several outcomes within the health care system. While studies of activation and associated correlates and outcomes have focused on a variety of patient populations, including disadvantaged populations, few have looked specifically within the oncology setting or specific cancer populations. Lung cancer poses a unique challenge within public health. It is a disease that disproportionately affects racial/ethnic minority individuals and those with lower education levels. Patients report high rates of distress (particularly depression), are generally less engaged in their care as compared to other cancer populations, and some continue to engage in unhealthy behaviors (e.g. smoking) after diagnosis. These

complex factors underscore the need to understand, and potentially intervene on, patient activation among lung cancer patients.

Exploring patient activation and related correlates provides evidence as to whether intervention aimed at activation may be a viable and beneficial option, and what that intervention might specifically look like. Thus this study had two primary aims: (1) to describe patient activation among surveyed lung cancer patients; and (2) examine specific demographic, smoking-related and psychosocial correlates of patient activation in the surveyed population.

CHAPTER THREE

Aims & Hypotheses

Overall Aim

The aim of this study was to investigate patient activation and associated correlates (e.g., demographic, smoking-related and psychosocial factors) in a lung cancer population.

Aims and Hypotheses

Aim 1: Describe patient activation among surveyed lung cancer patients.

Aim 2: Examine specific demographic, smoking-related, and psychosocial correlates of patient activation in the surveyed population.

Hypothesis I: Patients with lower education levels will report significantly lower patient activation in comparison to those with higher education levels.

Hypothesis II: Patients who are current smokers will report significantly lower patient activation when compared to those who are former or never smokers.

Hypothesis III: Patients who endorse higher rates of depression will report significantly lower patient activation than those who do not.

CHAPTER FOUR

Method

The proposed analysis utilized data from 231 lung cancer patients collected as part of a multi-site cross-sectional study of psychosocial concerns and behavioral outcomes. Participants were recruited from three separate sites: two outpatient oncology settings associated with the UTSW Simmons Cancer Center (Parkland Hospital & University Hospital) in Dallas, TX, and Memorial Sloan Kettering Cancer Center (MSKCC) in New York, NY. This study was approved by the UT Southwestern Institutional Review Board (STU 042013-047) and the Memorial Sloan Kettering Cancer Center Institutional Review Board.

PATIENT RECRUITMENT

Patients who were scheduled for an appointment with an oncologist at one of the three study location sites were evaluated for potential eligibility via electronic medical record review. Potentially eligible individuals included those with a confirmed lung cancer diagnosis (both non-small cell lung cancer [NSCLC] and small cell lung cancer [SCLC], any stage). Eligible participants were adults (18 years and older) with either a lung cancer diagnosis or lung cancer treatment in the last 12 months, able to read and comprehend English, and the capacity to comprehend study information. At the time of study enrollment, participants were also either: a) undergoing anti-cancer treatment (chemotherapy, radiation

therapy) or, b) had undergone surgical resection, radiation treatment or chemotherapy within the previous 12 months.

STUDY MATERIALS AND PROCEDURES

Once participants were identified as potentially eligible, they were approached in-person by a member of study staff during scheduled clinic appointments. Once eligibility was confirmed, patients were informed about the study and asked about their interest. As indicated in Figure 1, 272 (76.4%) of 356 eligible patients consented to study procedures; the other 84 participants either actively or passively declined. The most commonly cited reasons for refusal included time constraints and the patient not feeling well. Among the 272 consented patients, 231 returned surveys.

Consented study participants were asked to complete a 30-40 minute survey. Questionnaire scales were carefully chosen to reflect potentially important concepts related to lung cancer stigma. Participants either a) completed the questionnaire on a tablet computer provided by the trained research team member, b) completed the questionnaire through a secure electronic (web-based) portal from their own computer, or c) completed a paper-based version of the survey.

Web-based study materials utilized REDCap (Research Electronic Data Capture), a data management software system supported by UT Southwestern Medical Center (UTSW). REDCap is a tool for the creation and collection of customized, secure data management systems including web-based data entry forms, reporting tools, and a full array of security

features including user- and group-based privileges and an audit trail of data manipulation and export procedures. Data from participants who completed paper surveys were entered into REDCap by study staff in order to maintain all survey data in one repository. Paper surveys were kept in a secure, locked file cabinet accessible only to study staff.

MEASURES

Dependent Variable

Patient activation. Patient activation was measured by patient reports on the *Patient Activation Measure* (PAM; Hibbard et al., 2005; Hibbard et al., 2004), a well-established and psychometrically sound measure that has been used in many clinical populations. The PAM was originally developed as a 22-item measure and has shown both high reliability and validity (Rasch person reliability for the preliminary measure was 0.85 [real] and 0.87 [model]; Cronbach's alpha was 0.87). The short form has been found to have similar reliability (Rasch person reliability of 0.81 [real] and 0.85 [model]; Hibbard et al., 2005). In a study of patient activation in underserved individuals, the short-form measure produced a Cronbach's alpha of 0.87 (Lubetkin, Lu & Gold, 2010). Further, because of the shorter length, it is more feasible to use in patient populations (Hibbard et al., 2005). Study investigators received permission from Insignia Health to use this measure in this research capacity.

This study used the short-form of the PAM, which is the 13-item version. A score is determined by responses to statements about health care beliefs, confidence in managing

health-related tasks, and knowledge. Lower scores indicate less activated patients and higher scores indicate more activated patients. All items are measured using a Likert-type scale ranging from 1 (“Strongly Disagree”) to 4 (“Strongly Agree”). Patient responses were scored according to scoring guidelines established by Hibbard et al. (2004) and provided by Insignia Health. The raw score total was calculated by taking a total sum of the items completed (if all 13 items were completed). If there were items with “not applicable” or a question was left blank, these items were scored as “missing”. In this case, the point total was divided by the number of items completed with a 1-4 response (excluding the “missing” responses) and then multiplied by 13 to get the raw score. Patient raw scores were transformed onto a continuous scale of 0-100 using an empirically derived calibration table. This score is considered an “Activation Score”, which was used to categorize patients into four levels of activation. Regarding activation level cut points, Level 1 was indicated by scores of 47.0 or lower; Level 2 was scores of 47.1 to 55.1; Level 3 was scores of 55.2 to 72.4; and Level 4 was scores of 72.5 or above. These were the established cut-off scores as stated in the Insignia Health scoring manual (dated 2013),

Independent and Control Variables

Demographic and background information. The majority of the demographic and clinical information was assessed via patient self-report (e.g., age, gender, race, ethnicity, education level, marital status, smoking status). Smoking status was evaluated with the following two questions regarding smoking history and status: a) “Have you smoked at least 100 cigarettes in your lifetime?” and b) “Do you smoke cigarettes every day, some days, or

not at all?” Those participants who reported smoking at least 100 cigarettes and that they were currently smoking at time of survey (e.g., “Every day” or “Some days”) were categorized as “current” smokers; those who endorsed past smoking but reported they were not currently smoking (e.g., “Not at all”) were categorized as “former” smokers. Finally, those who reported smoking less than 100 cigarettes in their lifetime were considered “never” smokers.

Clinical information. The following clinical information was assessed by self-report: time since diagnosis and treatment history. Disease type (NSCLC vs. SCLC) and lung cancer stage at diagnosis (e.g., Stage I, II, III & IV) were determined both through self-report and the electronic medical record (EMR).

Depressive symptoms. Depressive symptoms were evaluated by the 10-item short form of the *Center for Epidemiologic Studies - Depression Scale* (CES-D; Radloff, 1977). Responses are measured on a Likert-type scale ranging from 0 (“Rarely or None of the Time”) to 3 (“All of the Time”). The possible range of scores is 0 – 30, with the higher scores indicating the presence of more symptomatology. The CES-D is a well-validated measure of depressive symptoms that has been used in a number of studies of medical patients, as it is brief and focuses on affective and cognitive symptoms of depression, rather than somatic features. The CES-D has been shown to be a valid measure of depressive symptomatology with high internal consistency (Cronbach’s alpha coefficients > 0.85 for both groups tested) in a sample of cancer patients (Hann, Winter, & Jacobsen, 1999). The established short-form cut-off score for clinically significant depressive symptomatology is the total of raw score equal to or greater than 10 (Andresen et al., 1994).

ANALYSES

General data preparation. Data relevant to the proposed study were imported into the Statistical Package for Social Sciences (SPSS) version 22.0 (IBM Corp, Armonk, NY). Data from the current sample was downloaded from REDCap and maintained in a central database. Prior to conducting the analyses, data were screened for outliers that may have impacted analyses.

Aim 1. To address the study aims, descriptive results were produced for all variables of interest, including frequencies and percentages for categorical variables, and means and standard deviations for continuous variables. A thorough description of the study sample was generated.

Aim 2. Both univariate comparisons and multivariable analyses were used to evaluate the relationship between demographic, clinical, and psychosocial factors, and patient activation in the lung cancer sample. Patient activation was operationalized by patient activation scores on the PAM (the raw score converted to the activation score). Statistical assumptions for all data were examined prior to analysis to ensure the appropriateness of the analytical approach. Patient activation scores were not normally distributed with a skewness of 0.89 ($SE = 0.163$) and kurtosis of 0.48 ($SE = 0.325$), indicating strongly positively skewed data. Based on analysis of normality, a logarithmic transformation was applied. After the data was transformed, it was normally distributed with a skewness of 0.35 ($SE = 0.16$) and kurtosis of -0.07 ($SE = 0.33$). Statistical significance was set at $p < 0.05$.

CHAPTER FIVE

Results

Sample Characteristics

Participants included 231 lung cancer patients recruited from Parkland Hospital (n=32; 13.9%), Simmons Cancer Center (n=39; 16.9%), and MSKCC (n=160; 69.3%). The mean age of participants was 62.8 years old ($SD= 11.0$). In terms of other demographics, the majority of participants identified as White (78.8%), married (62.8%), and female (63.6%). There was a fairly even split on patients' educational level, with approximately half (49.0%) reporting having a college degree or higher (i.e., masters or professional degree). Educational achievement was reported as follows: less than a high school degree (8.7%), high school degree or GED (20.3%), some college (18.6%), college graduate (29.0%) and Master's or professional degree (19.0%) with 4.3% of patient data not reported or missing. Patients were represented across all four disease stages: 11.7% Stage I, 8.2% Stage II, 18.6% Stage III and 55.4% Stage IV (with 6.1% of patient staging information not reported or missing). The majority of participants were former smokers (65.1%), while 26.0% were never smokers and 8.7% were current smokers. For more detailed demographic and clinical characteristics, see Table 1.

Aim 1 Results

Patient activation scores. The goal of Aim 1 was to describe patient activation among surveyed lung cancer patients. To address this aim, total overall PAM scores for our surveyed lung cancer patients were examined (those patients who completed at least 70% of

the survey, prorated as appropriate; $N = 222$). Overall, activation scores on the PAM ranged from 35.50 –100 ($M = 63.21$, $SD = 13.86$). For descriptive purposes, PAM activation scores were categorized into four levels or stages per cut-off scores stated in the PAM scoring manual. Patients in the current sample were represented across all four activation levels: 20.8% of the total sample was categorized as highly activated (Level 4; $N=48$), 51.1% as Level 3 ($N=118$), 15.6% as Level 2 ($N=36$) and 8.7% as Level 1 (least activated; $N=20$).

Aim 2 Results

The goals of Aim 2 were to examine specific demographic, smoking-related, and psychosocial correlates of patient activation in the surveyed population. Hypotheses indicated that lower education, current smoking, and higher depression scores would be associated with lower overall levels of patient activation. To address this aim, we first conducted univariate analyses with the variables of interest and transformed PAM activation scores (transformed using logarithmic transformation as described in methods section); variables that were found to be significant in the univariate analysis were then included in a multivariable analysis. See Table 2 for further detailed data involving univariate analyses.

Univariate Analyses

Smoking status. A one-way ANOVA was conducted with three levels of smoking status (current, former, never) as the independent variable and PAM activation score as the dependent variables. The omnibus F indicated a significant difference in activation scores based on smoking status, $F(2, 218) = 4.50$, $p < .05$. Tukey post-hoc test was used in order to

assess statistical significance for each pairwise comparison. Tukey's post-hoc test defines a value known as the Honest Significant Difference (HSD) and this value is used to determine which groups in a sample have significant differences. Results from Tukey's post hoc tests support this aim's hypothesis by revealing that overall patient activation scores were significantly lower for current smokers ($M = 53.13$; $SD = 6.57$) compared to both former ($M = 63.90$; $SD = 13.80$, $p < .05$) and never ($M = 64.23$; $SD = 14.34$, $p < .05$) smokers. There were no statistically significant differences between former and never smokers ($p = 0.99$). These results confirmed this aim's hypothesis regarding smoking status, and post-hoc analysis offered additional information about the relationship between these variables.

Education level. A one-way ANOVA was used to assess differences between education level (operationalized as an ordinal variable; five categories) and activation scores. There were no statistically significant differences in activation scores based on education categories, $F(4, 216) = 0.41$, $p = 0.80$. Education was also explored as a dichotomous variable between those who with a high school degree or less vs. those with "some college" or greater. There were no statistically significant differences in activation scores found between these groups, $F(1, 219) = 0.64$, $p = 0.42$. Further, these data were also explored as a dichotomous variable between those with less than a high school degree and those with a high school degree or higher; no statistically significant differences were found. $F(1, 219) = 0.85$, $p = 0.36$. Therefore, the aim's hypothesis focused on education was not supported in these data.

Depressive symptoms. This was explored as a dichotomous variable using established short-form cut-off (Andresen et al., 1994) for clinically significant depressive

symptomatology (the total of raw score equal to or greater than 10 on the CES-D). A one-way ANOVA was used to assess differences in PAM scores among those who reported clinically significant depressive symptoms vs. those who did not. Results were consistent with the hypothesis, showing lower activation scores among those who reported clinically significant depressive symptoms ($N=82$; $M=59.03$; $SD=12.77$) compared with those who did not report clinically significant depressive symptoms ($N=139$; $M=65.66$; $SD=13.98$); $F(1, 219) = 13.95, p < 0.001$.

Other variables of interest. Although no other variables were included in the hypotheses, we ran univariate analyses on other demographic and clinical variables (including age, recruitment site, race/ethnicity and lung cancer stage). Results indicated that only gender was associated with PAM score differences; females ($N = 140$; $M=65.29$; $SD=14.61$) reported higher activation levels than males ($N = 82$; $M=59.65$; $SD=11.73$; $F(1, 220) = 8.75, p < .01$). Other variables of interest, including age (as a continuous variable), recruitment site (three groups), race/ethnicity (Non-Hispanic White vs. other), and lung cancer stage (early (Stage I & II) vs. late (III & IV)), were found to be non-significant with regard to their relationship to activation scores on the PAM (see Table 2 for full statistical results).

Multivariable Analyses

To further understand the relevant predictors of PAM scores, we entered all variables found to be significant in the univariate analyses into a factorial ANOVA: smoking status (current smoker vs. former/never), gender (male vs. female), and depressive symptoms

(using cut-off scores of the short form CES-D). These were the only variables included in the analysis because they were the only demographic and clinical characteristics with an association with patient activation of $p \leq .05$. A custom model evaluated whether there was a main effect of the variables; interactions were not included, as there were no apriori hypotheses that focused on interactions. The smoking variable was collapsed from three categories (current vs. former vs. never) into two categories (current smoker vs. former/never) based on results from univariate analyses. Overall, 220 patients were included in the analysis.

There was homogeneity of variances for patient activation for all group combinations of smoking status, depressive symptoms and gender, as assessed by Levene's test for equality of variances, $p = 0.145$. Results indicate there was a significant main effect of smoking status ($F(1, 220) = 5.637, p = 0.018$), gender ($F(1, 220) = 5.120, p = 0.025$) and depressive symptoms ($F(1, 220) = 11.606, p = 0.001$) on patient activation. All results were consistent with the univariate analyses (current smoking, male sex, and clinically significant depressive symptoms were associated with lower activation scores).

CHAPTER SIX

Discussion

The overall aims of this study were to examine an important element of patient engagement (patient activation) in a lung cancer population. Goals of the first analysis were to describe patient activation. Patients in this sample reported activation levels across all four levels, or stages, of activation. More than half of these patients reported activation scores that fell in the third “stage” of the four-stage progression towards activation. According to the definition by Hibbard et al. (2009), patients at this stage are taking action regarding health, but may not have the confidence nor skills to support self-management of health behaviors. Additionally, about a quarter of this sample’s scores fell in the first and second stages of activation, indicating a low perception of action with regard to health behavior self-management.

A 2008 report from the Center for Studying Health Change (HSC)’s 2007 Health Tracking Household Survey reported patient activation scores from a large, nationally representative sample (approximately 17,797 people), including patients with chronic health conditions (Hibbard & Cunningham, 2008). The HSC survey may provide the best available resource to better understand how the activation scores in our sample compared to a broader oncology population. The HSC survey was administered via phone between April 2007 and January 2008 to non-institutionalized US households, and assessed whether participants had one or more of ten common chronic conditions (including diabetes, arthritis, asthma, COPD, heart disease, hypertension, cancer, skin cancer, depression or uterine bleeding). Those who

reported any chronic illness received the original 13-item PAM measure utilized in the current study; activation scores and levels were reported for selected conditions, including cancer. Cancer history was assessed as follows: “Has a doctor or health professional ever told you that you had skin cancer?” and “Has a doctor or health professional told you that you had cancer other than skin cancer?”

The overall activation scores of patients in our lung cancer sample (63.2) were slightly lower to this national sample of patients who reported cancer histories (65.8; from the HSC 2007 survey; analysis reported in Hibbard & Cunningham, 2008). With regard to activation level, the percentage of lung cancer patients in the highest level of activation (level 4; 20.8%) was lower than the national cancer sample (45.5%). There were also more participants in our lung cancer sample scoring in the lower levels of activation compared to the national sample of those with a history of cancer (15.6% vs. 12.2% at level 2; 8.7% vs. 7.8% at level 1). Although these comparisons were not statistically analyzed, the differences indicate that lung cancer patients may be less activated than other cancer patients. There may be concerns about stigma and self-advocacy among lung cancer patients that are reflected in these slightly lower scores. However, caution is recommended in overstating these potential differences. Generally, these data reinforce the relevance and applicability of previous activation research.

Our second aim focused on exploring demographic, smoking-related and psychosocial correlates of patient activation in an effort to understand who may be at higher risk of reduced activation levels. We hypothesized a relationship between lower education level and activation, current smoking status and activation, and an inverse relationship

between depressive symptomatology and activation levels. Both in univariate and multivariable analyses, the hypothesis related to smoking status and activation was supported by our data. Patients who identified as current smokers were significantly less activated than those who identified as never smokers and former smokers. This finding supports previous research in patient activation, wherein patients with lower activation scores are less likely to engage in general preventative behaviors such as smoking cessation, exercising regularly, and following a low-fat diet (Hibbard et al., 2004). The relationship between smoking status and reduced activation is also suggested by broader health research demonstrating that smokers are less likely to engage in self-management behaviors, such as cancer screening (e.g., Carlos et al., 2005).

Our study findings suggest a unique vulnerability in lung cancer patients who continue to smoke after diagnosis. Research has indicated several reasons why cancer patients and survivors continue to smoke after diagnosis, including lack of knowledge or denial about both the impact of tobacco on cancer etiology and/or the adverse affect of smoking on treatment and survival. Patients may have strong nicotine dependence and find it difficult to fight this addiction. Smoking behavior in cancer patients is also impacted by negative psychosocial factors, such as perceived stigma and/or affective symptoms (Carmack, Basen-Engquist, & Gritz, 2011). Those who are actively smoking at time of diagnosis are encouraged to quit smoking at the same time they are coping with the added stress of a new chronic illness and treatment. Those who are not able to quit or do not have the desire to quit may feel guilt or self-deprecation (Lehto, 2014). Previous qualitative work by Hamann et al. (2014) found that current smokers and those who quit at diagnosis

described experiences of internalized stigma in higher frequency than those long-term quitters or never smokers. These individuals expressed self-blame, guilt and shame related to smoking behaviors that limited their medical self-advocacy. If patients feel that they may disappoint their medical providers (and family, friends, themselves), they may feel limited in their ability to change and lack confidence in their health change behaviors. There is significant literature that highlights the adverse impact of continuing smoking during lung cancer treatment, including increased tumor progression, exacerbation of side effects, and resistance to cancer therapy (CDC, 2000; Moller et al., 2003). Finding ways to effectively measure and reduce feelings of stigma, guilt and self-blame in this population could be a possible route to address low activation, impact cessation behavior and improve overall health outcomes. Although the current analyses did not find significant differences among former smokers, this sample was relatively heterogeneous and it is possible that former smokers who have recently quit may also have issues with activation. Future studies could focus on former smokers (specifically evaluating for timeline, duration and success of cessation efforts) in order to further understand the relationship between smoking status and activation.

We also predicted that patients who endorsed higher rates of depression (measured as depressive symptomatology) would report significantly lower patient activation than those who do not. Results found this relationship to be significant in our study sample in both univariate and multivariable analyses. An inverse association between depressive symptoms and activation has been noted in other chronic illness populations, including multiple sclerosis (Stepleman et al., 2010) and HIV (Marshall et al., 2013). Depressed patients in the

broader population have also demonstrated lower activation, and have also been shown to be less responsive to activation interventions (Hibbard et al., 2007). Due to the cross-sectional nature of this study, the mechanism of the association between mood and activation is not fully understood. Despite this, the relationship highlights a growing understanding of the need to effectively assess and treat depression among lung cancer patients, who have the highest rates of clinically significant symptoms among all cancer patients (Gonzalez & Jacobson, 2012). In addition to other benefits, effective treatment of depression may increase engagement generally, and activation specifically, among patients. One possible treatment approach focuses on improving both depressive symptoms and activation simultaneously. Previous work by Magnezi et al. (2014) in the primary care setting, describes a “self-perpetuating cycle” between mood symptoms (feelings of hopelessness, associated decreased QOL), and activation. They suggest that the relationship between mood and activation has significant potential as a point of intervention to “break the cycle”. For example, providing patients with information, clear instructions or specific tasks for self-management may help them feel empowered. These small successes may bolster their confidence and self-efficacy, and encourage them to take on additional actions to increase health behaviors (Hibbard & Tussler, 2007).

Although we hypothesized that patients with lower education levels would report significantly lower patient activation in comparison with those with higher education levels, our analysis found no significant difference between education levels. Previous studies have demonstrated a significant impact of educational attainment on greater activation, although the strength of association has been mixed (Greene et al., 2005). Although the current sample

did reflect a wide range in education, the preponderance of individuals at the higher levels may have limited the ability to detect meaningful differences. Future studies that include a more robust set of SES predictors (e.g., income and insurance status, health literacy) could provide more information on these associations (Smith et al., 2013).

Our last significant finding was in regard to gender; women were more activated than men in our analyses. This pattern is similar to findings from Hibbard and colleagues (2008) and generally supports literature noting higher levels of engagement in health care among women (Berkatis et al., 2000). Other investigators have found that women tend to report greater interest in participating in health care decision-making (Flynn, Smith & Vanness, 2006). Reasons for such findings are complex, with hypotheses focused on greater numbers of health care contacts for women's preventive and maternal health (Mustard et al., 1998; Van Wijk et al., 1997), illness perceptions, health beliefs, symptom management behaviors that facilitate health care engagement (Hibbard & Pope, 1983), and greater acceptability of health care involvement associated with the feminine gender role (Cleary, Mechanic & Greenley, 1982; Waldron, 1983; Verbugge, 1985). With regard to patient activation specifically, more information is needed in order to further understand the relationship with gender and associated mechanisms.

Limitations

The current study incorporated a cross-sectional design, limiting conclusions about causality. In addition, there were a disproportionate number of never smokers in our study.

Given the relationship between current smoking and activation, our sample may have been generally more activated than lung cancer patients in general. We also do not know the activation levels of patients who declined the study; it is possible that these were less activated individuals.

Clinical Relevance and Practical Recommendations

Results from this study are relevant for efforts to consider patient engagement in a clinical setting and generally “scale up” these efforts. Based on our experience, an assessment of patient activation could be implemented in oncology clinics by medical and support staff, and be utilized to increase knowledge of activation levels of oncology patients more broadly. Data from various specialties within oncology may serve to identify differences in self-management related to cancer type.

Correlational analysis identified characteristics that may indicate someone is low in activation – current smokers, those with depressive symptomatology and male gender. These patients may be classified as particularly vulnerable, due to the demonstrated impact of negative psychosocial factors on treatment engagement. Though this study did not explore the specific mechanisms at work with regard to activation in this population, understanding the characteristics that indicate a patient may be vulnerable or high risk could help medical providers and/or support staff in their ability to identify, screen and intervene in these individuals. If medical providers (or oncology clinics more broadly) have a better

understanding of where these patients fall in regards to their activation scores, these can be used as a guideline for action.

Next steps for study include considering the most effective ways to increase activation and improve outcomes for lung cancer patients. Typically, studies focusing on improving activation have focused on both individual-level intervention and organization-level improvements as pathways for change (Hibbard & Gilbert, 2014). Those interventions focused on an individual level typically focus on one or more of these three strategies: skill development, problem-solving, and peer support; changing the social environment and/or tailoring support to the patient's activation level (Hibbard & Greene, 2013). Tailored support, or tailored coaching, models of intervention consider the context of the patient and attempt to meet and understand the patient based on where they are in regards to their activation level. When a patient is told to make significant lifestyle changes (as they often are at cancer diagnosis), they may feel overwhelmed by the recommendations and feel unable to achieve the changes. This can be particularly difficult for patients who may already have a negative self-concept or be experiencing feelings of internalized stigma, guilt or shame. There may also be cultural factors that drive beliefs about physicians as "experts" and discourage active participation and questions by patients (Alegria et al., 2009). In Latino culture, for example, normative cultural values include the concept of *respeto*, or "respect", wherein health providers would be shown deferential behavior based on their position of authority (Flores, 2000). These culture values may be an explanation for the increased preference to delegate decisions about treatment demonstrated in Hispanic patients when compared with Non-Hispanic White patients (Levinson et al., 2005). Latino individuals also uphold the concept

of *simpatía*, which values an emphasis on politeness and pleasantness even in times of stress. Perceptions of a physician as lacking *simpatía* may foster resentment in a patient and result in non-adherence and information withholding behaviors (Flores, 2000).

Brief Negotiation (Kaiser Permanente, Regional Health Education, 2005) and Motivational Interviewing (MI; Miller & Rollnick, 2002) are both methods that utilize a tailored approach. Tailored coaching education interventions have been successfully utilized in oncology settings to target pain management (specifically, reducing pain misconceptions and enhancing self-efficacy for communicating with providers; Kravitz et al., 2011; Street et al., 2010). Results have shown that while pain outcomes did not improve, patients did report improvement in both of its goals (Kravitz et al., 2011). Although the target for improvement for these studies was not activation specifically, it suggests that this type of intervention is feasible in a large, metropolitan oncology population. Providers could use tailored approaches to address many health behaviors in lung cancer patients, including smoking cessation, increased adherence to medications and treatment recommendations, as well as to address pain management and bolster coping skills in times of stress.

When considering which individuals to target with intervention, it is useful to note that individuals at all activation levels can improve with regard to their activation behaviors. Deen et al. (2011) found that patients with the lowest level of activation (levels 1 and 2) gained the most from intervention, although patients in levels 3 and 4 also had improvement in their activation scores. However, Harvey et al. (2012) found changes in activation improved across stages, but especially in individuals in level 4. These disparate findings bolster the idea that patients can make significant gains in activation across all stages,

although focus of intervention may be different. Those more passive patients may need intervention focused on building a foundation of knowledge, skills and self-efficacy, while more active patients may benefit from broader goal-setting, health behavior change and stress management.

While it may not be feasible to intervene with every patient in improving activation, both providers and patients could benefit from knowing their activation scores. For example, an assessment of activation during an office visit or nursing assessment could quickly identify those at highest risk and augment their treatment with referrals to supportive services or support groups who can provide appropriately tailored treatment approaches. Further, providers could engage less activated patients using brief motivational interviewing techniques that help patients explore and resolve ambivalence to behavior change. Those more highly activated patients could benefit from a conversation with providers to ensure they are continuing to do well with regard to self-management behaviors (e.g., adherence to treatment recommendations, smoking cessation), especially in times of stress. With the increased focus on patient-centered care and patient engagement, further study and application of such interventions will be crucial for improving health care outcomes.

APPENDIX A

Tables

Table 1. *Demographic and Clinical Characteristics of the Sample (N=231). *Not all percentages = 100% due to missing data.*

Characteristic	Number	Percentage
Age (in years)	<i>M</i> =62.80	<i>SD</i> =10.96
Recruitment Site		
Parkland Hospital	32	13.9
UTSW/Simmons Cancer Center	39	16.9
Memorial Sloan Kettering Cancer Center	160	69.3
Gender		
Female	147	63.6
Male	84	36.4
Race*		
White	182	78.8
Black/African-American	33	14.3
Asian/Pacific-Islander	8	3.5
Other	6	2.6
Ethnicity*		
Hispanic	7	3.0
Non-Hispanic	220	95.2
Education		
Less than college degree	118	51.0
College degree or higher	113	49.0
Marital Status*		
Married/Partnered	145	62.8
Divorced	27	11.3
Widowed	21	11.7
Single, Never Married	26	9.1
Type of Lung Cancer		
Non-small cell lung cancer (NSCLC)	183	79.2
Small cell lung cancer (SCLC)	22	9.5
Information not available	26	11.3
Disease Stage		
Stage I	27	11.7
Stage II	19	8.2
Stage III	43	18.6
Stage IV	128	55.4
Information not available	14	6.1
Smoking Status*		
Never smoker (<100 cigarettes in lifetime)	58	25.1
Former smoker (>100 cigarettes in lifetime: not smoking at time of study)	156	67.5
Current smoker (>100 cigarettes in lifetime; smoking at time of study)	14	6.1

Table 2. Means, Standard Deviations and Comparisons of Patient Activation Scores by Demographic and Clinical Characteristics.

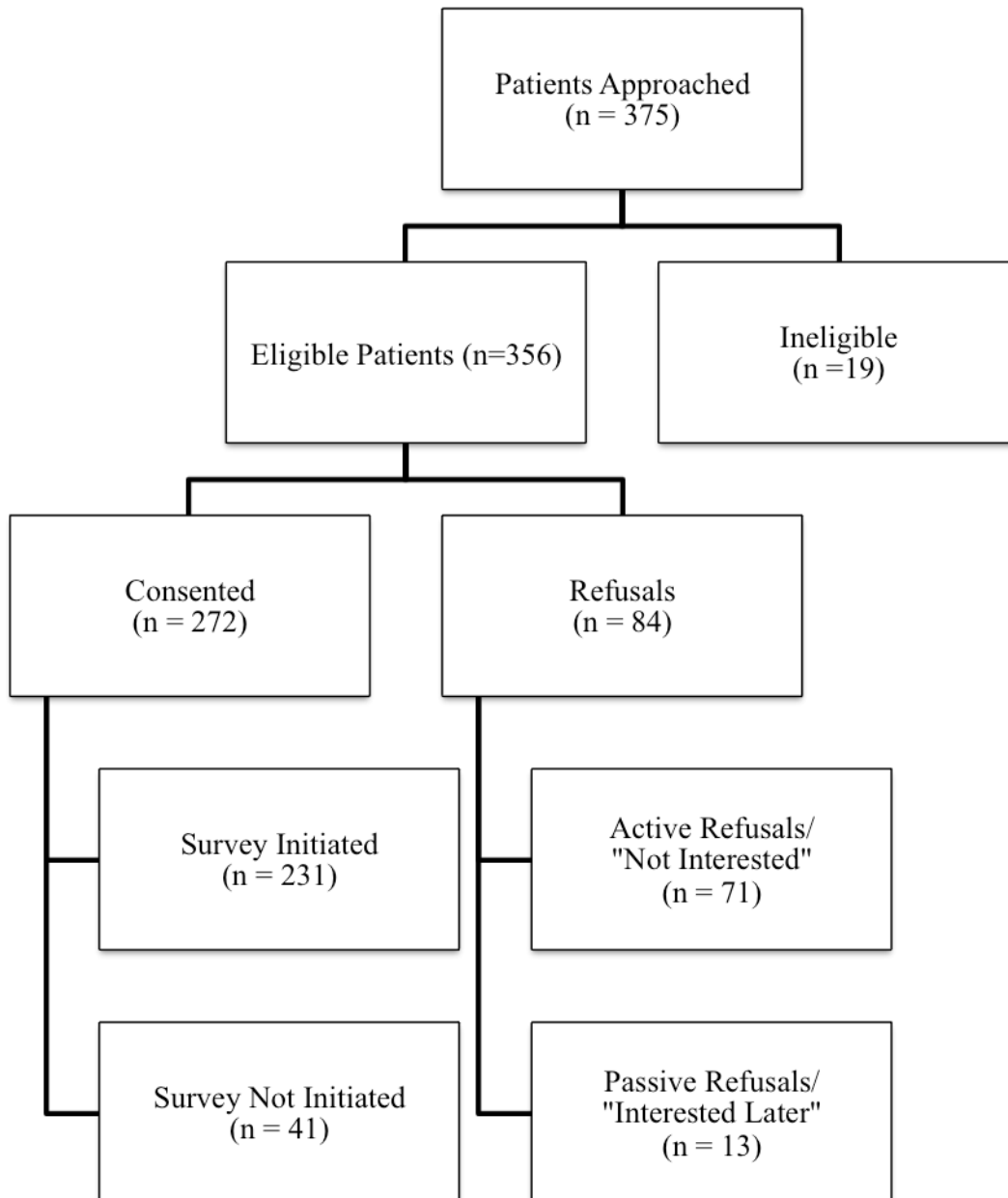
Characteristic	N	PAM Activation Score (Range 0-100)				
		Mean	SD	Df	r	F
Age	222	--	--	--	-0.04	--
Site	--	--	--	2,219	--	1.63
Parkland	28	64.17	17.30	--	--	--
UTSW	35	59.32	11.52	--	--	--
MSKCC	159	63.90	13.60	--	--	--
Gender	--	--	--	1, 220	--	8.75**
Female	140	65.29	14.61	--	--	--
Male	82	59.65	11.73	--	--	--
Educational attainment	--	--	--	4, 216	--	0.41
Less than high school	20	60.46	16.30	--	--	--
High school graduate or GED	47	63.25	15.19	--	--	--
Some college	43	62.58	12.48	--	--	--
College graduate	67	63.99	14.52	--	--	--
Masters or professional degree	44	63.80	11.90	--	--	--
Race/Ethnicity	--	--	--	1, 220	--	0.17
Non-Hispanic, White	171	63.42	13.69	--	--	--
Other	51	62.50	14.82	--	--	--
Lung Cancer Stage	--	--	--	1, 208	--	0.22
Early (Stage I-II)	45	64.31	15.06	--	--	--
Late (Stage III-IV)	165	63.09	13.58	--	--	--
Smoking Status	--	--	--	2, 218	--	4.50*
Current Smoker	14	53.15	6.57	--	--	--
Former Smoker	150	63.90	13.80	--	--	--
Never Smoker	57	64.23	14.34	--	--	--

Note: * p < 0.05, **p < 0.01, *** p < 0.001

APPENDIX B

Figures

Figure 1. *CONSORT Diagram of Study Participants*



BIBLIOGRAPHY

- Alberg, A.J., & Nonemaker, J. (2008). Who is at high risk for lung cancer? Population-level and individual-level perspectives. *Seminars in Respiratory and Critical Care Medicine*, 29(3), 223-232. doi: 10.1055/s-2008-1076742
- Alegria, M., Polo, A., Gao, S., Santana, L., Rothstein, D., Jimenez, A., Hunter, M., Mendieta, F., Oddo, V., & Normand, S. (2008). Evaluation of a patient activation and empowerment intervention in mental health care. *Medical Care*, 46(3), 247-256. doi: 10.1097/MLR.0b013e318158af52
- Alegria, M., Sribney, W., Perez, D., Laderman, M., & Keefe, K. (2009). The role of patient activation on patient-provider communication and quality of care for US and foreign born Latino patients. *Journal of General Internal Medicine*, 24(3), 534-541.
- American Cancer Society. Cancer Facts & Figures 2016. American Cancer Society; Atlanta: 2016.
- Andresen E. M., Malmgren J.A., Carter W.B., & Patrick D.L. Screening for depression in well older adults: Evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *American Journal of Preventative Medicine*.10: 77-84.

- Berkatis, K.D., Azari, R., Helms, L. J., Callahan, E. J., & Robbins, J. A. (2000). Gender differences in the utilization of health care services. *Journal of Family Practice*, 49(2), 147-152.
- Carlos, R. C., Fendrick, A. M., Patterson, S. K., & Bernstein, S. J. (2005). Associations in breast and colon cancer screening behavior in women. *Academic Radiology*, 12(4), 451-458.
- Carmack, C. L., Basen-Engquist, K., & Gritz, E. R. (2011). Survivors at higher risk for adverse late outcomes due to psychosocial and behavioral risk factors. *Cancer Epidemiology Biomarkers & Prevention*, 20(10), 2068-2077.
- CDC. Cigarette smoking-attributable morbidity—United States, 2000. *Morbidity & Mortality Weekly Report* 2003;5:842–844.
- Chambers, S., et al. (2012) A systematic review of the impact of stigma and nihilism on lung cancer outcomes. *BMC Cancer*. 12(1):184. doi: 10.1186/1471-2407-12-184.
- Chapple, A., Ziebland, S., & McPherson, A. (2004) Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *BMJ*. 328(7454):1470. doi: 10.1136/bmj.38111.639734.7C.
- Cleary, P. D., Mechanic, D., & Greenley, J. R. (1982). Sex differences in medical care utilization: an empirical investigation. *Journal of Health and Social Behavior*, 106-119.

- Committee on Quality of Health Care in America. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.
- Cooper-Patrick, L., Gallo, J.L., Gonzales, J.J., Vu, H.T., Powe, N.R., Nelson, C., & Ford, D.E. (1999). Race, gender, and partnership in the patient-physician relationship. *JAMA*, 282(6), 583-589. doi: doi:10.1001/jama.282.6.583
- Cunningham, P.J., Hibbard, J., & Gibbons, C.B. (2011). Raising low ‘patient activation’ rates among hispanic immigrants may equal expanded coverage in reducing access disparities. *Health Affairs*, 30(10), 1888-1894. doi: 10.1377/hlthaff.2009.0805
- Curran, W.J., Schiller, J.H., Wolkin, A.C., & Comis, R.L. (2008). Addressing the current challenges of non–small-cell lung cancer clinical trial accrual. *Clinical Lung Cancer*, 9(4), 222-226. doi: 10.3816/CLC.2008.n.033
- Deen, D., Lu, W.-H., Rothstein, D., Santana, L., & Gold, M.R. (2011). Asking questions: The effect of a brief intervention in community health centers on patient activation. *Patient Education and Counseling*, 84(2), 257-260.
- Dresler, C.M. (2003). Is it more important to quit smoking than which chemotherapy is used? *Lung Cancer*, 39(2), 119-124.
- Druss, B.G., Zhao, L., Silke, A., Bona, J.R., Fricks, L., Jenkins-Tucker, S., Sterling, E., DiClemente, R., Lorig, K. (2010). The health and recovery peer (HARP)

- program: A peer-led intervention to improve medical self-management for persons with serious mental illness. *Schizophrenia Research*, 118(1), 264-270. doi: 10.1016/j.schres.2010.01.026
- Else-Quest, N.M., et al. (2009) Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychology & Health*. 24(8):949–964. doi: 10.1080/08870440802074664.
- Flores, G. (2000). Culture and the patient-physician relationship: achieving cultural competency in health care. *The Journal of Pediatrics*, 136(1), 14-23.
- Flynn, K.E., Smith, M.A., & Vanness, D. (2006). A typology of preferences for participation in healthcare decision making. *Social Science & Medicine*, 63(5) 1158-1169.
- Fowles, J.B., Terry, P., Xi, M., Hibbard, J., Bloom, C.T., & Harvey, L. (2009). Measuring self-management of patients' and employees' health: Further validation of the patient activation measure (PAM) based on its relation to employee characteristics. *Patient Education and Counseling*, 77(1), 116-122. doi: 10.1016/j.pec.2009.02.018
- Franks, P., & Clancy, C. M. (1997). Referrals of adult patients from primary care: demographic disparities and their relationship to HMO insurance. *Journal of Family Practice*, 45(1), 47-54.

- Frosch, D.L., Rincon, D., Ochoa, S., & Mangione, C.M. (2010). Activating seniors to improve chronic disease care: Results from a pilot intervention study. *Journal of the American Geriatrics Society*, 58(8), 1496-1503. doi: 10.1111/j.1532-5415.2010.02980.x.
- Gonzalez, B. D., & Jacobsen, P. B. (2012). Depression in lung cancer patients: the role of perceived stigma. *Psycho-Oncology*, 21(3), 239-246.
- Greene J, Hibbard JH, Tusler M (2005) How much do health literacy and patient activation contribute to older adults' ability to manage their health? Washington DC: AARP. Available at:
https://assets.aarp.org/rgcenter/health/2005_05_literacy.pdf
- Greene, J., & Hibbard, J.H. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), 520-526. doi: 10.1007/s11606-011-1931-2
- Gritz, E.R., Fingeret, M.C., Vidrine, D.J., Lazev, A.B., Mehta, N.V., & Reece, G.P. (2006). Successes and failures of the teachable moment. *Cancer*, 106(1), 17-27.
- Hamann, H. A., Ostroff, J. S., Marks, E. G., Gerber, D. E., Schiller, J. H., & Lee, S. J. C. (2014). Stigma among patients with lung cancer: a patient-reported measurement model. *Psycho-Oncology*, 23(1), 81-92.

- Hann, D., Winter, K., & Jacobsen, P. (1999). Measurement of depressive symptoms in cancer patients: Evaluation of the center for epidemiological studies depression scale (ces-d). *Journal of Psychosomatic Research*, 46(5), 437-443.
- Harvey, L., Fowles, J. B., Xi, M., & Terry, P. (2012). When activation changes, what else changes? The relationship between change in patient activation measure (PAM) and employees' health status and health behaviors. *Patient education and counseling*, 88(2), 338-343.
- Hibbard, J. H., & Pope, C. R. (1983). Gender roles, illness orientation and use of medical services. *Social Science & Medicine*, 17(3), 129-137.
- Hibbard, J., & Gilburt, H. (2014). *Supporting People To Manage Their Health: An Introduction To Patient Activation*. London: The King's Fund. Retrieved from <http://www.mylifeplus.org.uk/wp-content/uploads/2014/09/supporting-people-manage-health-patient-activation-may14.pdf>.
- Hibbard, J.H., & Cunningham, P.J. (2008). How engaged are consumers in their health and health care, and why does it matter *Accessed from* <http://www.hschange.com/CONTENT/1019/> (Vol. 8, pp. 1-9). Washington, D.C.: Center for Studying Health System Change.
- Hibbard, J.H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*, 32(2), 207-214. doi: 10.1377/hlthaff.2012.1061

- Hibbard, J.H., & Mahoney, E. (2010). Toward a theory of patient and consumer activation. *Patient Education and Counseling*, 78(3), 377-381. doi: 0.1016/j.pec.2009.12.015
- Hibbard, J.H., Greene, J., & Tusler, M. (2009). Improving the outcomes of disease management by tailoring care to the patient's level of activation. *The American Journal of Managed Care*, 15(6), 353-360.
- Hibbard, J.H., Mahoney, E.R., Stock, R., & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research*, 42(4), 1443-1463.
- Hibbard, J.H., Mahoney, E.R., Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the patient activation measure. *Health Services Research*, 40(6p1), 1918-1930.
- Hibbard, J.H., Stockard, J., Mahoney, E.R., & Tusler, M. (2004). Development of the patient activation measure (pam): Conceptualizing and measuring activation in patients and consumers. *Health Services Research*, 39(4p1), 1005-1026.
- Hillen, M.A., de Haes, H., & Smets, E. (2011). Cancer patients' trust in their physician—a review. *Psycho-Oncology*, 20(3), 227-241.
- Holland, J.C., Kelly, B.J., & Weinberger, M.I. (2010) Why psychosocial care is difficult to integrate into routine cancer care: stigma is the elephant in the room. *Journal of the National Comprehensive Cancer Network*. 8(4):362–6.

- Holwerda, N., Sanderman, R., Pool, G., Hinnen, C., Langendijk, J.A., Bemelman, W.A., Hagedoorn, M., & Sprangers, M.A. (2013). Do patients trust their physician? The role of attachment style in the patient-physician relationship within one year after a cancer diagnosis. *Acta Oncologica*, 52(1), 110-117.
- Howlader, N., Noone, A. M., & Krapcho, M. (2015). SEER Cancer Statistics Review, 1975-2012. April 2015. Bethesda, MD: National Cancer Institute. From http://seer.cancer.gov/csr/1975_2012/
- James, J., Hibbard, J., Agres, T., Lott, R., & Dentzer, S. (2013). Health policy brief: Patient engagement. *Health Affairs*, 33(6).
- Jones, L.W., Hornsby, W.E., Goetzinger, A., Forbes, L.M., Sherrard, E.L., Quist, M., Lane, A.T., West, M., Eves, N.D., Gradison, M., & Coan, A. (2012). Prognostic significance of functional capacity and exercise behavior in patients with metastatic non-small cell lung cancer. *Lung Cancer*, 76(2), 248-252. doi: 10.1016/j.lungcan.2011.10.009
- Kaiser Permanente (2005) *Behavior change counseling using the brief negotiation method*. Oakland, CA: Regional Health Education, Northern California Region.
- Koller, M., Kussman, J., Lorenz, W., Jenkins, M., Voss, M., Arens, E., Richter, E. & Rothmund, M. (1996). Symptom reporting in cancer patients: the role of negative affect and experienced social stigma. *Cancer*, 77(5), 983-995.

- Kravitz, R. L., Tancredi, D. J., Grennan, T., Kalauokalani, D., Street, R. L., Slee, C. K.,
Wun, T., Oliver, J.W., Lorig, K. & Franks, P. (2011). Cancer Health
Empowerment for Living without Pain (Ca-HELP): effects of a tailored education
and coaching intervention on pain and impairment. *PAIN*, 152(7), 1572-1582.
- Lehto, R. H. (2014). Patient views on smoking, lung cancer, and stigma: A focus group
perspective. *European Journal of Oncology Nursing*, 18(3), 316-322.
- Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005). Not all patients want to
participate in decision making. *Journal of General Internal Medicine*, 20(6), 531-
535.
- LoConte, N.K., et al. (2008) Assessment of guilt and shame in patients with non-small-
cell lung cancer compared with patients with breast and prostate cancer.
Clinical Lung Cancer. 9(3):171–178. doi: 10.3816/CLC.2008.n.026.
- Lubetkin, E. I., Lu, W. H., & Gold, M. R. (2010). Levels and correlates of patient
activation in health center settings: Building strategies for improving health
outcomes. *Journal of Health Care for the Poor and Underserved*, 21(3), 796-808.
- Magnezi, R., Glasser, S., Shalev, H., Sheiber, A., & Reuveni, H. (2014). Patient
activation, depression and quality of life. *Patient education and counseling*, 94(3),
432-437.
- Marshall, R., Beach, M. C., Saha, S., Mori, T., Loveless, M. O., Hibbard, J. H., Cohn,
J.A., Sharp, V.L. & Korthuis, P. T. (2013). Patient activation and improved

- outcomes in HIV-infected patients. *Journal of general internal medicine*, 28(5), 668-674.
- Miller, W. R., & Rollnick, S. (2002). *Motivational interviewing: Preparing people for change* (1st edition) Guilford. New York.
- Møller, A. M., Pedersen, T., Villebro, N., Schnaberich, A., Haas, M., & Tønnesen, R. (2003). A study of the impact of long-term tobacco smoking on postoperative intensive care admission. *Anaesthesia*, 58(1), 55-59.
- Mosen, D.M., Schmittiel, J., Hibbard, J., Sobel, D., Remmers, C., & Bellows, J. (2007). Is patient activation associated with outcomes of care for adults with chronic conditions? *The Journal of Ambulatory Care Management*, 30(1), 21-29.
- Mustard, C. A., Kaufert, P., Kozyrskyj, A., & Mayer, T. (1998). Sex differences in the use of health care services. *New England Journal of Medicine*, 338(23), 1678-1683.
- Parchman, M.L., Zeber, J.E., & Palmer, R.F. (2010). Participatory decision making, patient activation, medication adherence, and intermediate clinical outcomes in type 2 diabetes: A starnet study. *The Annals of Family Medicine*, 8(5), 410-417. doi: 10.1370/afm.1161
- Park, E.R., Japuntich, S.J., Rigotti, N.A., Traeger, L., He, Y., Wallace, R.B., Malin, J.L., Zallen, J.P., & Keating, N.L. (2012). A snapshot of smokers after lung and

colorectal cancer diagnosis. *Cancer*, 118(12), 3153-3164. doi:
10.1002/cncr.26545

Parsons, A., Daley, A., Begh, R., & Aveyard, P. (2010). Influence of smoking cessation after diagnosis of early stage lung cancer on prognosis: Systematic review of observational studies with meta-analysis. *BMJ*, 340. doi: 10.1136/bmj.b5569

Patient Protection and Affordable Care Act, 42 U.S.C. § 18001 et seq. (2010).

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385-401.

Raleigh, Z.T. (2010). A biopsychosocial perspective on the experience of lung cancer. *Journal of Psychosocial Oncology*, 28(1), 116-125. doi:
10.1080/07347330903438990

Rask, K.J., Ziemer, D.C., Kohler, S.A., Hawley, J.N., Arinde, F.J., & Barnes, C.S. (2009). Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population. *The Diabetes Educator*, 35(4), 622-630. doi: 10.1177/0145721709335004

Remmers, C., Hibbard, J., Mosen, D.M., Wagenfield, M., Hoyer, R.E., & Jones, C. (2009). Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? *The Journal of Ambulatory Care Management*, 32(4), 320-327. doi: 10.1097/JAC.0b013e3181ba6e77

- Richardson, G.E., Tucker, M.A., Venzon, D.J., Linnoila, R.I., Phelps, R., Phares, J.C., Edison, M., Ihde, D.C., & Johnson, B.E. (1993). Smoking cessation after successful treatment of small-cell lung cancer is associated with fewer smoking-related second primary cancers. *Annals of Internal Medicine*, 119(5), 383-390.
- Salyers, M.P., Matthias, M.S., Spann, C.L., Lydick, J.M., Rollins, A.L., & Frankel, R.M. (2009). The role of patient activation in psychiatric visits. *Psychiatric Services*, 60(11), 1535-1539.
- Schaafsma, E.S., Raynorr, D., & de Jong-van den Berg, L.T. (2003). Accessing medication information by ethnic minorities: Barriers and possible solutions. *Pharmacy World and Science*, 25(5), 185-190.
- Skolasky, R.L., Mackenzie, E.J., Wegener, S.T., & Riley III, L.H. (2008). Patient activation and adherence to physical therapy in persons undergoing spine surgery. *Spine*, 33(21), E784-E791. doi: 10.1097/BRS.0b013e31818027f1
- Skolasky, R.L., Mackenzie, E.J., Wegener, S.T., & Riley, L.H. (2011). Patient activation and functional recovery in persons undergoing spine surgery. *The Journal of Bone & Joint Surgery*, 93(18), 1665-1671. doi: 10.2106/JBJS.J.00855
- Smith, S. G., Curtis, L. M., Wardle, J., von Wagner, C., & Wolf, M. S. (2013). Skill set or mind set? Associations between health literacy, patient activation and health. *PloS one*, 8(9), e74373.

- Solomon, M., Wagner, S.L., & Goes, J. (2012). Effects of a web-based intervention for adults with chronic conditions on patient activation: Online randomized controlled trial. *Journal of Medical Internet Research*, 14(1), e32. doi: 10.2196/jmir.1924
- Spiro, S. G., & Silvestri, G. A. (2005). One hundred years of lung cancer. *American Journal of Respiratory and Critical Care Medicine*, 172(5), 523-529.
- Stepleman, L., Rutter, M.-C., Hibbard, J., Johns, L., Wright, D., & Hughes, M. (2010). Validation of the patient activation measure in a multiple sclerosis clinic sample and implications for care. *Disability and Rehabilitation*, 32(19), 1558-1567. doi: 10.3109/09638280903567885
- Street, R. L., Slee, C., Kalauokalani, D. K., Dean, D. E., Tancredi, D. J., & Kravitz, R. L. (2010). Improving physician–patient communication about cancer pain with a tailored education-coaching intervention. *Patient education and counseling*, 80(1), 42-47.
- Tod, A.M., Craven, J., & Allmark, P. (2008). Diagnostic delay in lung cancer: A qualitative study. *Journal of Advanced Nursing*, 61(3), 336-343.
- van Wijk, C. M. G., Kolk, A. M., van Den Bosch, W. J., & Van Den Hoogen, H. J. (1992). Male and female morbidity in general practice: the nature of sex differences. *Social Science & Medicine*, 35(5), 665-678.

- Verbrugge, L. M. (1985). Gender and health: an update on hypotheses and evidence. *Journal of Health and Social Behavior*, 156-182.
- Waldron, I. (1983). Sex differences in illness incidence, prognosis and mortality: issues and evidence. *Social Science & Medicine*, 17(16), 1107-1123.
- Wassenaar, T.R., Eickhoff, J.C., Jarzemsky, D.R., Smith, S.S., Larson, M.L., & Schiller, J.H. (2007). Differences in primary care clinicians' approach to non-small cell lung cancer patients compared with breast cancer. *Journal of Thoracic Oncology*, 2(8), 722-728.
- Weiss, T., et al. (2012) A 30-year perspective on psychosocial issues in lung cancer: how lung cancer “came out of the closet.” *Thoracic Surgery Clinics*. 22(4):449–56. doi: 10.1016/j.thorsurg.2012.07.008.
- Westerman, M. J., Sprangers, M. A., Groen, H. J., van der Wal, G., & Hak, T. (2007). Small-cell lung cancer patients are just ‘a little bit’ tired: response shift and self-presentation in the measurement of fatigue. *Quality of Life Research*, 16(5), 853-861.
- Youlden, D. R., Cramb, S. M., & Baade, P. D. (2008). The international epidemiology of lung cancer: geographical distribution and secular trends. *Journal of Thoracic Oncology*, 3(8), 819-831.

Zabora, J., Brintzenhofesoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10(1), 19-28.

VITAE

Anna Johnson Thomas was born in Houston, Texas, the daughter of Julie Muntz and Peter Johnson. After completing an I.B. diploma at Lamar High School in 2003, she entered the Plan II Honors Program at the University of Texas at Austin and graduated in 2007 with dual degrees in Plan II and English Literature. After graduation, she pursued a career in book publishing in New York City. Her developing interests in Social and Clinical Psychology led her to pursue graduate study at Hunter College of the City University of New York, where she completed a Master of Arts degree in General Psychology in 2011. She worked at the Center for HIV Educational Studies and Training (CHEST) before moving to Texas to pursue doctoral-level training in Clinical Health Psychology. She will complete her post-doctoral fellowship in Women's Health Psychology at Baylor University Medical Center in Dallas, TX. Anna hopes to continue working with underserved populations throughout her career.