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FEASIBILITY OF DAILY ASSESSMENT AND PREDICTORS OF DAILY QUALITY OF LIFE DURING TREATMENT FOR LUNG CANCER

by

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DISSERTATION

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

Psychology

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B.A., PSYCHOLOGY, SPANISH M.S., PSYCHOLOGY PH.D., PSYCHOLOGY

ABSTRACT

Most lung cancer patients are diagnosed with locally advanced or advance disease, which makes improving quality of life a critical component of treatment. Empirical research on daily quality of life in lung cancer is lacking, despite a growing focus on patient-reported outcomes in oncology. The goal of this study was to determine the feasibility of daily assessment of quality of life and to identify predictors of daily quality of life in lung cancer patients undergoing treatment. It was hypothesized that clinical characteristics such as treatment type would predict feasibility. It was hypothesized that patients with higher hope would report better quality of life and that daily hope would predict daily quality of life. Fifty-six of 62 patients who were approached enrolled, of which 50 (89%) completed a baseline questionnaire and sufficient daily assessments to be included in analysis. Diary patients (58% female, 78% non-small cell, 66% metastatic disease, average age = 68.66, SD = 8.78) completed an average of 20.45 (SD = 1.62, range = 15-26) days. Clinical characteristics and daily survey administration method did not predict the number of days completed. Patients with higher levels of hope reported higher social and role functioning (estimate = 3.37, SE = 0.90, 95% CI = 1.60, 5.14) and higher



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palliative wellbeing (estimate = 0.88, SE = 0.24, 95% CI = 0.40, 1.35). On days where patients reported higher hope, they reported higher social and role functioning (estimate = 2.36, SE = 0.70, 95% CI = 1.00, 3.73), better physical functioning (estimate = 2.27, SE = 0.81, 95% CI = 0.68, 3.87), and higher palliative wellbeing (estimate = 0.91, SE = 0.13, 95% CI = 0.66, 1.16). Daily hope appeared to attenuate the impact of treatment days on social and role functioning (estimate = 3.33, SE = 1.25, 95% CI = 0.88, 5.77). Daily hope did not predict quality of life in next-day models. Daily hope was not predicted by lung cancer symptoms. Results suggest that daily assessment of quality of life in lung cancer patients is feasible and that hope-based interventions may improve their quality of life. *Keywords:* Lung cancer, quality of life, daily diary, hope, stigma



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Introduction

In 2016, over 221,000 new lung cancer cases are expected in the U.S., along with 158,080 lung cancer deaths (American Cancer Society; ACS, 2016). The number of deaths caused by lung cancer is comparable to the number of deaths caused by breast, colon, pancreas, and prostate cancer combined (ACS). Overall one-year survival for lung cancer is 44%, whereas overall five-year survival for lung cancer is 17% (ACS). For patients diagnosed with localized disease, five-year survival rate is 54% compared to a rate of less than 4% for those with distant metastases. Only 15% of lung cancers are diagnosed at a localized stage; the majority of lung cancer patients will die from the disease.

In addition to a bleak future for survival, lung cancer patients can experience a host of physical symptoms from disease such as cough, fatigue, and dyspnea and neurological symptoms (Corner, Hopkinson, Fitzsimmons, Barclay, & Muers, 2005; Hamilton, Peters, Round, & Sharp, 2005; van Meerbeeck, Fennell, & De Ruysscher, 2011). There is some evidence that patients prioritize symptom management over lengthening survival time (Silvestri, Pritchard, & Welch, 1998). Treatment (chemotherapy or chemoradiotherapy) is usually the best way to manage physical symptoms and prolong life (Davidoff, Tang, Seal, & Edelman, 2010; Peters et al., 2012), but it comes with risks and side effects that can be difficult for patients to tolerate.

Maximizing patient functioning and overall quality of life is a critical component of treatment for lung cancer (Smith et al., 2012). Population studies suggest that lung cancer patients suffer higher degrees of decline in mental health, social functioning, and



overall well-being compared to other cancer patients (Reeve et al., 2009) and a larger disease burden over time (Deshields, Potter, Olsen, & Liu, 2014). Although lung cancer presents an important opportunity for quality of life research, this area of research is limited by inadequate assessment of both quality of life and disease-related variables. Studies that do assess both quality of life and disease factors often conclude that disease severity can be a risk factor for distress (Montazeri, Gillis, & McEwen, 1998), which although potentially helpful for identifying subgroups that are most likely to need services, does not provide enough direction into what should be targeted behaviorally to improve quality of life. Improving quality of life research in lung cancer patients depends on implementing study designs that will answer questions as to the relationship between disease factors, symptoms, and individual responses to the challenging nature of lung cancer. Once the relationships between disease, symptoms, behaviors, and quality of life are characterized, clinical interventions can be developed to improve quality of life.

Assessment of Quality of Life in Lung Cancer: More than Symptoms

Measures of quality of life that are included in clinical trials mostly focus on physical symptoms. Frequently, the emotional wellbeing and functional scales of quality of life measures are omitted (Zikos et al., 2014). Such a finding is not surprising given that most quality of life reports come from medical providers overseeing clinical trials in which the priority is disease response and physical symptom severity. However, physical symptoms are only one aspect of quality of life and provide little information into the patients' daily experiences, social relationships, and leisure activities that also reflect quality of life (Montazori et al., 1998).



Many symptoms are distressing to patients because of their impact on aspects of daily life—not because the symptoms themselves are inherently distressing (Ellis, 2012). Qualitative research suggests that symptoms such as cough and shortness of breath may deter socialization because of patient embarrassment about symptoms (Molassiotis, Lowe, Blackhall, & Lorigan, 2011) and interfere with daily activities (Chan, Richardson, & Richardson, 2005). Symptoms may trigger thoughts related to fear of death, lost sense of self in illness, and stigma of disease (Ellis, 2012). The impact of stigma in lung cancer on patient quality of life can be substantial and contribute to social isolation and depression (Berterö, Vanhanen, & Appelin, 2008; Cataldo, Jahan, & Pongquan, 2012; Chapple, Ziebland, & McPherson, 2004; Gonzalez & Jacobsen, 2012; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008). Assessing quality of life in lung cancer requires attention to the relationships that physical symptoms have with other aspects of patient wellbeing.

A Framework for Quality of Life in Cancer

The theme underlying research on quality of life in this area is that cancer can alter several domains including social relationships, occupation, physical ability, belief systems, and overall sense of life direction (Brennan, 2001; Folkman & Greer, 2000; Stanton, 2006). Clinical manifestations can include depression, anxiety, social isolation, withdrawal, and relationship problems. People who are able to maintain or enhance life during cancer may be less prone to clinical manifestations such as depression, but they are probably not acting with the intention of avoiding the development of depression or anxiety—they are doing something more. One possibility is that they are continuing to engage in aspects of life that are rewarding to them or identifying new ones. Planning,



setting goals, re-evaluating values, and changing priorities are all thought to be important to wellbeing by helping patients identify meaningful and feasible actions to take to improve quality of life (Schroevers, Kraaij, & Garnefski, 2011; Schroevers, Kraaij, & Garnefski, 2008).

A measure developed by Snyder and colleagues (1991) has potential to capture some aspects of this response to cancer. The measure describes a person's intentional action toward a desired and potentially achievable outcome, which Snyder called "hope." Hope is defined as agency (goal-directed energy—essentially attending to potential goals to pursue) and pathways (planning to meet goals). Hope has been associated less fatigue, depression, pain, and coughing among lung cancer patients (Berendes et al., 2010). It is also related to positive affect, which is associated with adaptive social functioning, less role restriction, and less severe bodily pain among lung cancer patients (Hirsch, Floyd, & Duberstein, 2012). Therefore, cross-sectional work suggests a correlation between hope and functioning. It remains to be seen, however, how hope and functioning influence one another longitudinally. Hope may be an adaptive response that aids quality of life or it may merely reflect lower symptom burden, which would limit its clinical utility.

An Appropriate Design for Quality of Life Research in Lung Cancer

Capturing the variability in lung cancer symptoms, their impact on daily functioning, and helpful responses to the daily challenges of the disease requires a longitudinal design. Much of the research to date on lung cancer patients has been crosssectional or has relied on assessment points every few months. In addition to recall bias, those between-person designs (i.e., designs that are cross-sectional or use statistical methods that fail to model variance occurring at the level of individual differences and



within-person behavior) are not sensitive to the day-to-day fluctuations in symptoms and functioning that are most relevant to patients' quality of life. Daily assessment methodology provides the opportunity to examine processes that are not accessible through between-person designs (Bolger, Davis, & Rafaeli, 2003; Tennen, Affleck, Armeli, & Carney, 2000) and obtains patient reports of symptoms and functioning close to the time of their occurrence, thereby minimizing retrospective bias (Laurenceau & Bolger, 2005; Tennen et al., 2000). The temporal proximity of data combined with the use of people as their own statistical control (i.e., each person's mean is considered in modeling within-person changes) strengthens the ability to make directional inference.

By modeling variance within and across individuals, daily assessment designs can determine whether symptoms such as fatigue are explained by a change in a person's behavior, are mostly accounted for by lung cancer stage or subtype, or may be impacted by certain behaviors for people with specific disease characteristics. Such questions are worth exploring given the potentially different strains that lung cancer may place on a person based on subtype, stage, and treatment. Non-small-cell lung cancer (NSCLC; 85% of all lung cancers) patients with locally advanced disease and small-cell lung cancer (SCLC; ~15% of all lung cancers) patients with limited disease undergo treatments (i.e., chemoradiotherapy or sequential treatment) with high potential for side effects. However, the possibility of a cure, although small (i.e., only occurring in 20-25% of NSCLC with locally advanced disease; Siegel, Miller, & Jemal, 2016) may help patients endure treatment. For patients with advanced NSCLC or extensive SCLC, treatment (i.e., chemotherapy) may be less grueling, but rarely cures disease. A patient with SCLC may respond quite well initially to treatment, as 80-95% of patients with limited disease and



60-80% of patients with extensive disease show an overall response (Hanna & Einhorn, 2002; Stupp, Monnerat, Turrisi III, Perry, & Leyvraz, 2004). However, SCLC tends to rapidly progress and has a shorter survival time than NSCLC. Disease characteristics and treatment factors can therefore be expected to contribute to differences in psychological response and daily functioning and can be explicitly modeled in daily assessment studies.

Despite its potential for illuminating processes underlying patient quality of life, few published studies have used daily assessment methodology with lung cancer patients; feasibility concerns have likely been prohibitive. Lung cancer tends to metastasize to the brain, especially in extensive SCLC (Beckles, Spiro, Colice, & Rudd, 2003). However, many patients have brain metastases but are cognitively asymptomatic (Seute, Leffers, ten Velde, & Twijnstra, 2008) and disease in the brain can respond to chemotherapy or chemotherapy followed by radiation (van Meerbeeck et al., 2011). Presence of brain metastases alone should not prevent lung cancer patients from participating in quality of life research. In fact, several studies suggest that lung cancer patients can engage in daily diary studies. A 12-week daily symptom diary study of 135 (103 of whom were in late stage disease) lung cancer patients receiving chemotherapy reported compliance rates of 71% at three weeks (Brown et al., 2005). A 12-week study of weekly symptom assessments among stage III and IV lung cancer patients showed an 86% adherence rate at 3 weeks (Yount et al., 2013). Although these studies have limited their scope to symptoms alone or an overall rating of quality of life (Bezjak et al., 2002), they have demonstrated daily symptom variation (e.g., pain and mood; Lasheen, Walsh, Hauser, Gutgsell, & Karafa, 2009; fatigue; Brown et al., 2005).



Whether expanding quality of life assessment beyond symptom severity decreases adherence is an empirical question. Missing data is common in quality of life research among people with advanced disease (Donaldson & Moinpour, 2005; Earle, 2004). Daily assessment may offer a way to circumvent the problems of low power for detecting effects among this population (Earle, 2004) and is aligned with the goal of identifying ways to improve patients' day-to-day lives.

Current Study

This study used daily assessment methodology to research quality of life among lung cancer patients [NSCLC stages IIIA-IV (i.e., locally advanced to metastatic); limited or extensive SCLC] undergoing treatment for lung cancer. Use of an intensive longitudinal design provided tests of the relationships between psychological factors, daily symptom severity, and functioning while controlling for concomitant medical and disease factors that could account for variance in patient quality of life.

Aims and Hypotheses

The first aim of this study was to establish the feasibility of daily quality of life assessment in patients receiving medical treatment for lung cancer and to identify potential patient characteristics that contribute to feasibility. Feasibility was quantified by: 1) the percentage of patients who consented vs. declined participation; 2) the percentage of patients consented who completed the baseline questionnaire only vs. consented with baseline data and daily diary data; 3) the average percentage of missing diary data; and 4) the number of people who required an alternative to online daily assessment (e.g., paper assessments). Those with a higher performance status (i.e., more impaired physically), lower baseline reports of quality of life, and who were undergoing



chemoradiotherapy were hypothesized to have lower daily completion rates. Those who completed the daily surveys online were hypothesized to have higher response rates than those who completed them on paper.

The second aim of this study was to provide preliminary tests of the effects of psychological risk and protective factors on patient daily quality of life when taking into account concomitant medical factors. Controlling for baseline psychosocial functioning (e.g., depression and quality of life), performance status, and patient report of the previous day's quality of life, higher daily perceived lung cancer stigma was hypothesized to predict lower daily functioning and quality of life), performance status, and patient report of the previous day's quality of lef., depression, quality of life, performance status, and patient report of the previous day's quality functioning (e.g., depression, quality of life), performance status, and patient report of the previous day's quality of life. A secondary aim of this study was to estimate effect sizes to inform future research on patient characteristics that may moderate these relationships, such as disease stage, its corresponding treatment, and performance status.

Method

Power and Sample Size Calculations

Power analysis in multilevel modeling reflects both level-1 and level-2 effect sizes, sample size (level-1 and level-2), the intraclass correlation (ICC; the amount of dependency in the data), and alpha level. Sample size requirements should be calculated based on the highest level (level-2) in the design (Hox, 2010). For studying cross-level (i.e. level-1 and level-2) interactions, Hox suggests a sample of 50 level-2 units and 20 level-1 observations. The highest level (level-2) in this project was the individual. Level-



1 variables were within-person changes day to day. The power analysis used to estimate the necessary sample size for this project was based on a similarly structured data (i.e., days nested within individuals), but involved emergency responders as participants (84 people; average number of days = 18.5, SD = 2.97 days). The analysis was conducted through MLPOWSIM (Browne, Golalizadeh, & Parker, 2009) and controlled for level-2 variables (e.g., depression and optimism) and level-1 variables (e.g., coping, pain). Based on the emergency responder sample, 48 people and 19 days of data were needed for a power of .78 for level-1 hope (hope ICC = .83; α = .05, b = .133 for predicting positive affect, 95% CI = .054 to .210). However, the effect sizes of these variables were unknown in lung cancer patients and adherence to daily survey completion among this population was expected to range from 70-80% (Brown et al. 2005, Yount et al., 2013). Given anticipated rates of missing data and dropout, enrolling 65 people and requesting 21 days of data was expected to yield a sample of 50 people with at least 15 days of data. Level-2 comparisons based on disease stage or subtype were not expected to be powered to reject the null hypothesis and were exploratory aims.

Participants

Eligibility criteria included: (a) Histologically or cytologically documented nonsmall cell lung cancer (NSCLC) stage IIIa, IIIb, or IV (7th edition staging; adenocarcinoma, large cell, squamous, or mixture of these types) or limited or extensive small cell lung cancer (SCLC); (b) 21 years of age or older; (c) Eastern Cooperative Oncology Group performance status 0-2 (0 = fully active, able to carry on all pre-disease performance without restriction; 1 = restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature; 2 = ambulatory and



capable of all self-care, but unable to carry out any work activities; up and about more than 50% of waking hours); (d) no concurrent malignancy or unstable brain metastases (defined as those with midline shift, inadequately controlled seizures or requiring escalating steroid doses); (e) undergoing treatment for lung cancer specific to stage IIIa, IIIb, or IV NSCLC or limited or extensive small cell SCLC; (f) patient could speak and read English; (g) could provide informed consent; and had (h) no active psychoses or impairment that would preclude compliance with the study.

Procedure

Recruitment Site.

UNM Cancer Center. Recruitment began in April 2014 and ended in September 2015. Participants were recruited through the University of New Mexico Cancer Center (UNMCC). A number of recruitment strategies were used within the cancer center including: recruitment cards provided to oncologists to distribute to eligible patients, fliers posted in the oncology clinic waiting area and infusion floor, and pre-screening patients for eligibility through the clinic's weekly schedule. Patients who were eligible based on the pre-screening were approached after their appointments with oncologists or at their chemotherapy appointments. A Health Insurance Portability and Accountability Act waiver was granted by the IRB for recruitment purposes with corresponding approval for the pre-screening procedure described. Patients provided written informed consent. The UNM Health Sciences Center Institutional Review Board and the New Mexico Cancer Care Alliance approved this study.

Assessment



Patients completed an initial questionnaire on a computer or on paper. Patients could choose to complete daily diaries online through Opinio, on paper, or, via telephone if needed. Patients who chose to complete surveys online were emailed a link for the daily survey each day at their preferred time of day to complete the survey. If patients had not completed the survey within 5 hours of their assessment window, an automatic reminder was sent. Patients were encouraged to report the previous day's diary before entering the current day if they missed a day. Time of completion and date were captured through the online survey system. Patients were required to enter the date their responses corresponded to, which helped assure correct sequence of dairies if a patient missed a day.

Patients who completed daily diaries on paper were given 21 daily diaries that they were to date with the time of day completed and minutes taken to complete. They were provided with a self-addressed, postage-paid return envelope. Initially, patients who completed paper diaries were given a flat-rate envelope and therefore returned all 21 diaries at once. Research staff checked in weekly with patients to assure adherence and patients had the option of receiving a reminder to do the daily survey as often as often as they felt they needed or wanted it. Halfway through the study's data collection period, patients who completed paper diaries were given envelopes to mail each week, with the intention of improving validity of daily assessment. Whether patients mailed batches of surveys and how daily surveys were administered was tracked.

Participant Remuneration

Participants were paid \$30 for completing the initial questionnaire, \$3 for each daily entry (up to \$63 possible), \$4 for each week they completed (up to \$12 possible), and \$6



for completing all 21 days. The daily portion of the study compensated up to \$81. Total remuneration could be \$111. Participants received payment in the form of gift cards to either Target or Wal-Mart.

Measures Administered

Level 2 (i.e. Baseline Individual) Variables (Appendix A).

Demographic Information. Participant sex, education, relationship status, age, ethnicity, race, income, treatment type, time since diagnosis, and smoking status and history was assessed.

Depression and Anxiety. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to assess anxiety and depression symptoms. It contains 14 items (seven specific to anxiety and seven specific to depression). Each question was answered on a four-point Likert-type scale (1 = not at all to 4 = very often). The HADS has been normed in cancer patients (Bjelland, Dahl, Haug, & Neckelmann, 2002). Internal consistency was good in this sample (depression $\alpha = .82$; anxiety $\alpha = .86$).

Neuroticism. The neuroticism items from the Big Five Personality Inventory (Benet-Martínez & John, 1998) was used to assess people's tendency to experience negative affect. Seven items assessed neuroticism with statements that were rated in terms of agreement from 1 = strongly disagree to 5 = strongly agree. Internal consistency in the sample was acceptable ($\alpha = .70$)

Optimism. The optimism items from the Life Orientation Scale-Revised (LOT-R; Scheier, Carver, & Bridges, 1994) was used to assess a person's tendency to experience positive affect. Six items assessed optimism with statements rated in terms of agreement



from 1 = *strongly disagree* to 5 = *strongly agree*. Internal consistency in this sample was good (α = .77).

Physical Symptoms and Functioning. The Functional Assessment of Cancer Therapy (FACT) version four (Cella et al., 1995) was used to assess quality of life and functioning. The FACT-L (FACT-Lung) contains four general (FACT-G; physical wellbeing, social/family well-being, emotional well-being, and functional well-being) and one lung cancer-specific subscale. The lung cancer subscale is comprised of seven items and assesses symptoms commonly reported among patients (e.g., shortness of breath). Scores on the lung cancer subscale can range from 0 to 28. Scores on the FACT-G (the four general subscales of FACT-L) can range from 0 to 108. The Trial Outcome Index (TOI) is indicated by the physical wellbeing, functional wellbeing, and lung cancer subscales. Scores can range from 0 to 84. The FACT-L total score is derived by summing five subscales. Scores can range from 0 to 136. On all scoring iterations, higher scores indicate better quality of life or fewer symptoms.

The FACT-L has been used as a secondary endpoint in large medical treatment studies to measure quality of life (e.g., ECOG Study 5592; Cella et al., 2002). A study evaluating FACT scores between two clinic visits 15 days apart showed that scores declined. Intraclass correlations between the two visits ranged from .78 (social/family well-being) to .96 (FACT-L TOI; Juliana, Jardim, Fernandes, Jamnik, & Santoro, 2010). Mean values for the FACT-G have ranged from 65.9 to 84.1 in clinical trials with cancer patients. Mean values for the lung cancer subscale have ranged from 16.2 to 20.5 in lung cancer patients (Juliana et al., 2010). Internal consistency in the current sample was good



(Physical Wellbeing $\alpha = .87$, Social Wellbeing $\alpha = .84$, Emotional Wellbeing $\alpha = .83$, Functional Wellbeing $\alpha = .85$).

The European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire in Cancer-30 (QLQ-C30) uses nine multi-item scales: five functional (physical, role, cognitive, emotional, and social functioning); three symptom scales (fatigue, pain, nausea/vomiting), and a global health status/quality of life scale. The scale was originally tested in lung cancer patients (Aaronson et al., 1993). The 30item scale norms for stage III-IV lung cancer suggest means of 54.7 (SD = 23.8) for global health status/quality of life, 65.9 (SD = 25.6) for physical functioning, 55.5 (SD = 34.5) for role functioning, 67.3 (SD = 24.1) for emotional functioning, 81.6 (SD = 22.7) for cognitive functioning, and 69.8 (SD = 30.3) for social functioning (EORTC Quality of Life Group; Scott, et al, 2001). Internal consistency in the current sample was good (Emotional functioning $\alpha = .87$, Physical functioning $\alpha = .82$, Role functioning $\alpha = .90$, Cognitive functioning $\alpha = .69$, Social functioning $\alpha = .79$).

Hope. The Dispositional Hope Scale (Snyder et al., 1991) assessed trait hope through eight items such as "I can think of many ways to get the things in life that are most important to me" on a scale of 1 = definitely false to 4 = definitely true. Internal consistency in the current sample was good ($\alpha = .77$).

Lung Cancer Stigma. Lung cancer stigma was assessed using the Cataldo Lung Cancer Stigma Scale (Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011). Thirty-one items assessed stigma and shame (11 items; e.g. "I feel guilty because I have lung cancer"), social isolation (10 items; e.g. "I have lost friends by telling them that I have lung cancer"), discrimination (5 items; "People with lung cancer are treated like



outcasts") and smoking (5 items; e.g. "Lung cancer is viewed as a self-inflicted disease") through a 4-point Likert-type scale of *strongly disagree* to *strongly agree*. Scores can range from 46-184, with higher scores indicating more stigma. In a sample of 190 lung cancer patients in all stages of disease, the average score was 120.31 (SD = 30.36; Cataldo et al., 2012). Internal consistency in the current sample was excellent ($\alpha = .94$).

Level-1 (i.e. Daily) Variables (Appendix B).

Patients were prompted to think about the past 24 hours when responding to questions in the following domains.

Level-1 (Daily) Predictor Variables

Treatment Day. Treatment day was a binary variable (0 = no) (1 = yes) indicating whether or not someone had chemotherapy or radiation that day.

Physical Symptoms. Seven items from the FACT-L (e.g. "Were you short of breath?", "Did you have pain?", "Did you lack appetite?", "How much did you cough?", "Did you feel weak?", "Did you feel nauseated?, and "Were you tired?") assessed daily physical symptoms on a scale of 1 = not at all to 4 = very much. Items were rescaled 0 to 3 and averaged. Internal consistency was good ($\alpha = 0.83$, day 1).

Daily Hope. Daily hope was assessed using four items from State Hope Scale (Snyder et al., 1996): "At the present time, I am trying to pursue my personal goals and plans" (agency), "I can think of many ways to reach my current goals" (agency), "There are ways around any problem that I am facing now" (pathways), and "I can think of many ways to reach my current goals" (pathways). Items were responded to on a scale of 1 (*definitely false*) to 8 (*definitely true*). Items were rescaled 0 to 7 and averaged. Internal consistency was good ($\alpha = 0.83$, day 1).



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Lung Cancer Stigma. Five items (e.g. "Some people act as though it is my fault that I have lung cancer", "I feel guilty because I have lung cancer", "I feel set apart, isolated from the rest of the world", "Having lung cancer makes me feel like I'm a bad person", "Some people who know have grown more distant") from the Cataldo Lung Cancer Stigma Scale (Cataldo et al., 2011) were used to assess daily experience of lung cancer stigma, shame, social isolation and discrimination. A 4-point Likert-type scale was used (1 = strongly disagree to 4 = strongly agree). Items were rescaled 0 to 3 and averaged. Internal consistency was good ($\alpha = 0.82$, day 1).

Level-1 (Daily) Dependent Variables

Social/Role Functioning. Role functioning was assessed with two items from the EORTQ-QLQ-30 ("Were you limited in pursuing your hobbies or other leisure time activities?", "Were you limited in pursuing your work or other daily activities?"). Items were responded to on a scale of 1 = not at all to 4 = very much. Following the scoring procedures from the EORTC-QLQ-30 (v.3) manual, role functioning was transformed linearly to have a range of 0-100, with higher scores reflecting higher role functioning. Internal consistency was acceptable ($\alpha = .75$, day 1). Social functioning was assessed with two items from the EORTC-QLC-30 ("Has your physical condition or medical treatment interfered with your family life today?", and "Has your physical condition or medical treatment interfered with your social life today?"). Items were responded to on a scale of 1 = not at all to 4 = very much. Following the scoring procedures from the EORTC-QLC-30 ("Has your physical condition or medical treatment interfered with your social life today?"). Items were responded to on a scale of 1 = not at all to 4 = very much. Following the scoring procedures from the EORTC-QLQ-30 (v.3) manual, interference was transformed linearly to have a range of 0-100, with higher scores reflecting better social functioning. Internal consistency was acceptable ($\alpha = .60$, day 1). Social and role functioning subscales were averaged to yield



an index of daily functioning. Following the scoring procedures from the EORTC-QLQ-30 (v.3) manual, social/role functioning was transformed linearly to have a range of 0-100, with higher scores reflecting better functioning. Internal consistency for the combined subscales was good ($\alpha = .86$, day 1).

Palliative Well-Being. Palliative well-being was assessed using 7 items from the Additional Concerns Scale of the FACIT-Palliative Care Scale ("I feel useful", "I feel independent", "I feel like a burden to my family", "I feel that my family appreciates me", "I maintain contact with my friends", "I make each day count", "I am able to openly discuss my concerns with the people closest to me") and one item from the Functional Well-Being Scale ("I am able to enjoy life"). Items were responded to on a 0 (*not at all*) to 4 (*very much*) scale. In accordance with the FACIT manual, palliative well-being was calculated if participants answered at least four FACIT questions. Items were summed, multiplied by 8, and then divided by the number of valid items. Internal consistency was adequate ($\alpha = 0.79$, day 1).

Physical Functioning. Physical functioning was assessed with the one item scale of physical functioning from the EORTC-QLQ-30 ("Did you need to stay in a bed or a chair during the day today?") responded to on a scale of 1 = not at all to 4 = very much. Following the scoring procedures from the EORTC-QLQ-30 (v.3) manual, physical functioning was transformed linearly to have a range of 0-100, with higher scores reflecting better physical functioning.

Statistical Analyses

Data were analyzed using SPSS (v. 21) and, for HLM, MPlus (v.7; Muthén & Muthén, 2012). Adherence to the daily diary was calculated as the number of completed



questionnaires divided by the expected questionnaires (i.e., number of patients x 21 days). Predictors of the number of days completed in the diary were analyzed using multiple regression in the full sample (i.e., including patients who completed 0 days of the diary). Descriptive statistics were used to summarize predictor variables. Percentages of patients reporting moderate/severe symptoms of cough, shortness of breath, pain, weakness, nausea, fatigue, staying in bed, and being bothered by side effects were also plotted across the 21 days of the diary.

The repeated (daily) data was nested within an individual. Hierarchical Linear Modeling (HLM) was used to address the nested structure (i.e., dependence) of the data and estimate both the Level-1 (daily) and Level-2 (individual) variance. HLM accommodates missing data through the use of full information maximum likelihood estimation, which maximizes the probability of the data and is recommended in quality of life research in lung cancer (Hox, 2010) (Donaldson & Moinpour, 2005). The <u>Level-1</u> <u>data</u> included daily ratings symptom severity, functioning, medical treatment events, stigma, and hope. The <u>Level-2 data</u> included demographic information (e.g. age, cancer type and stage, treatment type), baseline quality of life, personality (e.g. neuroticism, optimism), and depression and anxiety.

To separate sources of variance, Level 1 (i.e., daily) predictor variables were person-mean centered so that each person's daily predictor variable represented deviations from his or her overall average on that daily predictor variable. As such, regression slopes for Level-1 predictors represent pooled within-person relationships between the predictor and the dependent variable. A person's average on a daily predictor variable was included in the model as a Level-2 predictor. The regression slope for those



Level-2 predictors represents the between-person relationship between the average score of the predictor and the average score of the dependent variable. For Level-2 predictors assessed at baseline, if a clinically meaningful score was available for centering (e.g., a score of "8" representing a likely "case" of depression), each person's score was centered on it to make the intercept more interpretable (e.g., in the case of depression, a score of "0" would be a clinical case). Level-2 predictors without a clinically meaningful center value were grand mean centered so that each person's score represented their deviation from the overall sample mean on that predictor.

Analysis of Fixed Effect Hypotheses (Specific Aim 2)

The unconditional model was estimated first to partition variance into within and between-person variability. Next, time was included as a predictor variable to help assess for reactivity to monitoring (Barta, Tennen, & Litt, 2013). To assess for whether administration method (i.e., online vs. paper) made a difference in responses, administration method was added as a predictor. Finally, the rest of the pre-specified model was estimated. Variables that were theorized to be important disease variables to control for were maintained in all models, regardless of statistical significance; however, Level-2 control predictors such as depression, anxiety, neuroticism, and optimism were removed if they did not change the significance of predictors that were the focus of hypotheses. A reduced form equation for a final model is below. The equation below shows the "next day" model (i.e., t + 1).



 $= \gamma_{00} + \gamma_{01}Anxiety_{i} + \gamma_{02}agegc_{i} + \gamma_{03}txtype + \gamma_{04}hopepm_{i} + \gamma_{05}stigmapm_{i}$ $+ \mu_{0i} + \gamma_{06}symptomspm_{i} + \beta_{10}daysdx_{ti} + \beta_{20}txday_{ti} + \beta_{30}hopepc_{ti}$ $+ \beta_{40}stigmapc_{ti} + \beta_{50}symptomspc_{ti} + \beta_{60}socialfunct_{ti} + \beta_{70}posaffectpc_{ti}$ $+ \beta_{80}negaffectpc_{ti} + \beta_{90}hopepcXtxday_{ti} + e_{i}$

Results

Descriptive statistics are shown in Table 1. The sample (N = 56) had more females (n = 32; 57.1%) than males (n = 24; 42.9%). Average age was 68.29 years (SD = 9.47 yrs). The majority of the sample was non-Hispanic white (n = 46; 82.1%). Thirtythree people (58.9%) were married or living with their romantic partner. Average number of years of education was 13.54 (SD = 2.73 yrs). Most patients had non-small cell lung cancer (n = 42; 75.0%), advanced disease (stage IV NSC = 66.7%; extensive SC = 78.6%), and were receiving either chemotherapy (n = 30; 53.6%) or chemoradiotherapy (n = 18; 32.1%). Thirteen (23.2%) had brain metastases. Most had an ECOG performance status of 1 (n = 31; 55.4%). Demographics for the final analyzed sample (n = 50) were similar (Table 1). Descriptive statistics for clinical scales from the sample appear in Table 2. About one-third of the sample met criteria for likely clinical depression and anxiety. Lung cancer stigma was relatively low compared to previous research (Cataldo et al., 2012). Functioning and lung cancer symptom scales were similar to previous studies (Scott et al., 2001).

Feasibility

Recruitment and retention data are shown in Figure 1. Two patients responded to the recruitment fliers in waiting rooms, two were referred directly from a physician, and



the remaining patients were identified through the pre-screening procedure. Sixty-two patients were approached about the study, of which 56 (90.3%) consented. Of those who declined (n = 6; 9.7%), two said they were too busy with work, one said it sounded too tedious, one said the next 21 days were too uncertain, one was in too much pain, and one expressed concerns about a clause about limits of privacy and law enforcement in the consent form.

Of the 56 who consented, 52 (92.9%) completed at least one day of the diary. Reasons for drop out after baseline included: "busy schedule" (n = 1), death (n = 1), hospitalized for one week or more (n = 1), and "too much to handle right now" (n = 1). Fifty of the 52 people who participated in the diary were retained for daily diary analysis. Two people (3.8%) were excluded for analysis because they completed only one or four days. Reasons for drop out included being hospitalized for one week or more (n = 1) or the study being "too much to handle" (n = 1). The average number of days completed in the full sample was 18.46 (SD = 6.33; range = 0-26). The average number of days in the full sample with cap of 21 days total was 18.21 (SD = 6.23; range = 0 - 21). Of the 1,176 potential daily diaries (62 people x 21 days), 1,052 (89.5%) were completed (excluding 8 days completed beyond the 21 day window). The average number of days completed in the sample retained for daily diary analysis was 20.45 (SD = 1.62, range = 15-26). The average number of days completed in the sample retained for daily diary analysis with cap of 21 days total was 20.30 (SD = 1.34, range = 15-21). Of the 1,050 potential daily diaries (50 people x 21 days), 1,042 (99.2%) were completed (excluding 8 days completed beyond the 21 days). Forty-three (86%) of the daily diary sample completed 20 days or more.



In the full sample (N = 56), most patients (n = 34; 60.7%) completed the daily surveys on paper; 19 (33.9%) completed surveys online; 3 (5.4%) completed surveys on the telephone. Of those who completed surveys on paper, 11 (32.4%) mailed surveys to the investigator in weekly batches. For analysis concerning daily administration method, the three telephone-administered diary sets were combined with those who completed the surveys online because both groups received daily contact. In the sample retained for daily diary analysis, 56% (n = 28) completed questionnaires on paper, of which 10 (20%) mailed questionnaires in batches. In the full sample (N = 56), the average time per day to complete a diary was 10.85 minutes (SD = 7.07 minutes; range 3 – 60 minutes). In the sample retained for daily diary analysis (n = 50), the average time per day to complete a diary was 10.78 minutes (SD = 6.88; range = 3 – 45 minutes). Figure 2 shows the average number of minutes it took the sample to complete the diary per day across the diary. Missing dependent variable data for the daily diary was under 5%.

Contrary to Hypothesis 1, physician-rated performance status, baseline quality of life, treatment type (concurrent chemoradiotherapy vs. chemotherapy), and daily survey administration method did not predict number of days completed for the diary, although there was a trend for people completing the surveys on paper to complete fewer days (B = -3.19, SE = 1.84, 95% CI = -3.94, 3.40; Table 3).

Daily Quality of Life

Descriptive statistics for daily quality of life variables appear in Table 4. Most people reported relatively little restriction to the bed or chair during the day, low impairment in work and daily activities, and low interference with family and social life. Coughing, shortness of breath, fatigue, pain, and weakness were the most severe daily



physical symptoms of lung cancer. Figure 3 shows the percentages of patients who endorsed "quite a bit" or "very much" on symptoms and being bothered by symptoms across days 1-21 of the diary. Fatigue was consistently at moderate to severe levels. There were 307 days on which patients reported receiving lung cancer treatment, representing 30.8% of diary days. Cancer-related setbacks were rare, occurring only 38 times (3.6% of diary days). Correlations between study variables appear in Table 5.

Daily Social/Role Functioning. Approximately 66.8% of the variance in daily social and role functioning resided at level 2, implying that people had different average levels of functioning and that there was a lot of homogeneity on daily social and role functioning for a person. The grand mean of functioning was 68.09 (SE = 3.19). The within person variance for ratings of functioning was 247.70 and the between person variance was 497.36. There did not appear to be reactivity to the diary, as day of the diary did not predict daily functioning when added as a sole predictor (estimate = 0.12, SE = 0.08, 95% CI = -.03 to 0.28) and within and between person variance remained similar (247.51 and 498.10, respectively).

Results for predictors of daily social/role functioning appear in Table 6. Age, days since diagnosis, and treatment type did not predict daily functioning. Daily social and role functioning was predicted by differences in mean levels of hope (estimate = 5.06, SE = 1.37, 95% CI = 2.37, 7.75), baseline anxiety (estimate = -1.22, SE = 0.48, 95% CI = -2.16, -0.29), and physical symptoms of lung cancer (estimate = -21.66, SE = 3.85, 95% CI = -29.22, -14.11). On days where patients reported higher hope (estimate = 2.36, SE = 0.70; 95% CI = 1.00, 3.73) and more positive affect (estimate = 8.31, SE = 0.95, 95% CI = 6.45, 10.17), they reported better functioning, whereas on days where they reported



more stigma (estimate = -3.64, SE = 1.60, 95% CI = -6.78, -0.51) and more physical symptoms (estimate = -17.37, SE = 2.63, 95% CI = -22.52, -12.22), they reported lower functioning. Physical symptoms appeared to vary randomly across people (estimate = 138.45, SE = 58.76, 95% CI = 23.29, 253.61). Treatment day and daily hope interacted such that on days where patients experienced higher hope, they reported less of a negative effect of going to cancer treatment (estimate = 3.33, SE = 1.25, 95% CI = 0.88, 5.77; Figure 3).

Next Day Social/Role Functioning

To better understand the influence of hope and stigma on daily functioning, the same predictors were added to a model that predicted next day functioning while controlling for current day level of functioning (see equation above). A non-significant interaction between daily hope and treatment day (estimate = 2.36, SE = 1.52, p = .121) was removed from the final equation. The resulting model appears in Table 7. Age, days since diagnosis, and treatment type did not predict next day functioning. Consistent with the same day model, next day social and role functioning was predicted by differences in mean levels of physical symptoms (estimate = -13.91, SE = 2.68, 95% CI = -19.17, - 8.66), baseline anxiety (estimate = -0.72, SE = 0.30, 95% CI = -1.32, -0.13), and hope (estimate = 3.37, SE = 0.90, 95% CI = 1.60, 5.14). Unlike the same day model, daily positive affect and stigma did not predict next day social and role functioning; daily hope trended toward higher next day functioning (estimate = 1.29, SE = 0.73, 95% CI = -0.14, 2.72) and daily physical symptoms predicted lower next day functioning (estimate = -7.71, SE = 2.68, 95% CI = -12.96, -2.45).

Daily Physical Functioning



Approximately 64% of the variance in daily physical functioning occurred at level 2, implying that people had different average levels of functioning and that there was a lot of homogeneity within a person regarding how much they stayed in bed or a chair during day. The grand mean of physical functioning was 65.50 (SE = 3.86). The within person variance for ratings of physical functioning was 403.51 and the between person variance was 725.90. There did not appear to be reactivity to the diary, as day was not a significant predictor when added to the null model as a sole predictor (estimate = 0.12, SE = 0.10, 95% CI = -0.08 to 0.34) and both within and between person variance estimates remained similar with the addition of day as a predictor (400.20 and 727.05, respectively).

There was a trend for an interaction between daily hope and treatment day (estimate = 3.08, SE = 1.71, p = .072) such that higher daily hope appeared to buffer against the negative impact of treatment days on physical functioning. Results appear in Table 8. The interaction term was removed. People who were undergoing concurrent chemoradiotherapy (estimate = -10.11, SE = 4.95, 95% CI = -19.81, -0.41) and older (estimate = -0.56, SE = 0.26, 95% CI = -1.08, -0.04) and who reported more depression (estimate = -1.78, SE = 0.67, 95% CI = -3.10, -0.46) and physical symptoms (estimate = -32.06, SE = 4.83, 95% CI = -41.52, -22.60) reported lower physical functioning. On days where people experienced higher hope (estimate = 2.27, SE = 0.81; 95% CI = 0.68, 3.87) and more positive affect (estimate = 8.64, SE = 1.31; 95% CI = 6.08, 11.19), they reported better physical functioning, whereas on days where they reported more symptoms (estimate = -26.11, SE = 3.67, 95% CI = -33.30, -18.92), they reported worse



physical functioning. Lung cancer symptoms appeared to vary randomly across people (estimate = 282.59, SE = 104.57, 95% CI = 77.62, 487.55).

Next Day Physical Functioning

The same model used for predicting same day physical functioning was used to predict next day physical functioning, while controlling for current day physical functioning. Results appear in Table 9. Consistent with the same day model, people who were older, had higher levels of depression, and more physical symptoms reported lower next day functioning. Treatment type trended toward people receiving concurrent chemoradiotherapy reporting lower next day functioning (estimate = -7.39, SE = 3.88, 95% CI = -15.00, 0.21). Daily functioning was related to next day functioning (estimate = 0.27, SE = 0.05, 95% CI = 0.18, 0.36). Daily hope and positive affect were not related to next day functioning, whereas daily physical symptoms remained a significant predictor of next day functioning (estimate = -12.16, SE = 3.58, 95% CI = -19.14, -5.12).

Palliative Well-being

Approximately 75% of the variance in palliative quality of life resided at level 2, implying that people had different mean levels of palliative quality of life and there was a lot of homogeneity within a person on this measure. The grand mean of palliative quality of life was 21.20 (SE = 0.76). The within person variance for ratings of palliative quality of life was 9.61 (SE = 0.44, 95% CI = 8.79 to 10.50) and the between person variance was 28.50 (SE = 5.80, 95% CI = 19.13 to 42.46). There did not appear to be reactivity to the diary, as day was not a significant predictor when added to the null model (estimate = -0.01, SE = 0.02, 95% CI = -0.05 to 0.02) and both within and between person variance estimates remained essentially the same (9.64 and 28.51, respectively).


Results appear in Table 10. Age, treatment type, and days since diagnosis did not predict daily palliative wellbeing. Palliative wellbeing was predicted by differences in mean levels of depression (estimate = -0.38, SE = 0.15, 95% CI = -0.66, -0.09), hope (estimate = 1.54, SE = 0.37, 95% CI = 0.81, 2.26), and stigma (estimate = -3.37, SE = 1.20, 95% CI = -5.73, -1.01). On days where people reported higher levels of hope (estimate = 0.91, SE = 0.13, 95% CI = 0.66, 1.16) and positive affect (estimate = 2.05, SE = 0.20, 95% CI = 1.66, 2.45) they reported higher palliative wellbeing, whereas on days where they reported more stigma (estimate = -0.80, SE = 0.34, 95% CI = -1.46, -0.13) and had treatment (estimate = -0.45, SE = 0.22, 95% CI = -0.89, -0.02), they reported lower palliative wellbeing. Lung cancer symptoms appeared to vary randomly across people (estimate = 4.97, SE = 2.20, 95% CI = 0.66, 9.27).

Next Day Palliative Wellbeing

The same model used for predicting same day palliative wellbeing was tested for next day palliative wellbeing except that current day wellbeing was included as a control variable. Results are shown in Table 11. As in the same day model, age, days since diagnosis, treatment type, and lung cancer symptoms did not predict next day wellbeing. Palliative wellbeing was predicted by differences in mean levels of hope (estimate = 0.88, SE = 0.24, 95% CI = 0.40, 1.35), and stigma (estimate = -1.71, SE = 0.71, 95% CI = -3.10, -0.32). On days where people reported higher levels of positive affect (estimate = 0.49, SE = 0.24, 95% CI = 0.03, 0.96) they reported higher next day palliative wellbeing.

Directionality: Hope as a Predictor or Dependent Variable?

Hope was evaluated as a dependent variable of daily functioning, physical functioning, and palliative wellbeing to further clarify the relationships between study



variables. Daily functioning, physical functioning, and palliative wellbeing were first examined one at a time with the other predictor variables in same and next day models; however, they were ultimately entered into the same predictive model as results did not change when the other two predictor variables were excluded. Differences in mean social/role functioning and palliative wellbeing predicted daily hope (estimate = 0.03, SE = 0.01, 95% CI = 0.0001 to 0.05, 0.14, SE = 0.04, 95% CI = 0.06, 0.22, respectively; Table 12). On days where people reported higher social/role functioning (estimate = .01, SE = 0.002, 95% CI = 0.004, 0.01) and higher palliative wellbeing (estimate = 0.05, SE = 0.01, 95% CI = 0.04, 0.07) they reported higher daily hope.

The same model used for predicting same day hope was tested for next day hope except that current day hope was included as a control variable. Results are shown in Table 13. Differences in mean palliative wellbeing (estimate = 0.08, SE = 0.03, 95% CI = 0.03, 0.13) and higher daily palliative wellbeing (estimate = 0.03, SE = 0.01, 95% CI = 0.01, 0.04) predicted next day hope. There was a trend for differences in mean social/role functioning predicting higher next day hope (estimate = 0.01, SE = 0.01, 95% CI = 0.002, 0.03). Notably, lung cancer symptoms—neither daily nor mean levels—did not predict daily same day or next day hope.

Discussion

The goal of this study was to determine the feasibility of daily assessment of quality of life in lung cancer patients and to identify predictors of daily quality of life. This was accomplished using a 21-day intensive longitudinal design. Based on the consent rate, retention rate, adherence rate, and limited missing data, daily assessment appears to be feasible within this population. Both chemotherapy and chemoradiotherapy



patients were able to complete the daily diaries, as were patients with brain metastases or who had received whole brain radiotherapy prior to starting the study. The majority of the patients in this sample had late stage (i.e., stage IV non-small cell or extensive small cell) lung cancer, indicating that they can be included in quality of life studies of this nature. Although the daily diary questionnaire had 60 questions, average time to complete a diary each day was around 11 minutes, which suggests that daily diaries may be a quick way to assess various domains of quality of life. More patients completed the diaries on paper than online, perhaps reflecting the age of the sample and the fact that many people in the state sampled do not have internet in their homes. It did not appear that those with more physical impairment at the start of the diary completed fewer days, although small comparison groups limit this conclusion.

One of the goals of this study was to understand the within person variance of day-to-day quality of life after accounting for individual differences. Time since diagnosis did not predict daily quality of life. Lung cancer treatment type, which reflects disease stage, was also not a predictor of daily quality of life with the exception of daily physical functioning. Those who were undergoing concurrent chemoradiotherapy reported more time in bed or a chair during the day. This finding is congruent with the toxicity of chemoradiotherapy.

Daily lung cancer symptoms were clearly important to assess, as they predicted worse daily social/role functioning and physical functioning. However, daily lung cancer symptoms did not predict palliative well-being, which was surprising as some of the items on the palliative well-being scale seemed like they would fluctuate based on symptoms (e.g., "I feel independent" or "I feel like a burden to my family.") The fact that



daily lung cancer symptoms did not predict palliative wellbeing suggests that high lung cancer symptom burden does not preclude a quality of life intervention: patients are still able to stay in touch with friends, feel useful, or enjoy daily life when experiencing difficult symptoms. Those activities matter to quality of life in lung cancer patients (Montazeri et al., 1998; Schroevers et al., 2011; Schroevers et al., 2008).

Lung cancer stigma was an inconsistent predictor of daily quality of life. Higher averages of lung cancer stigma were associated with lower palliative wellbeing, even when controlling for a previous report of palliative wellbeing. Daily experiences of lung cancer stigma appeared to have a deleterious effect on social/role functioning and palliative wellbeing even when controlling for negative affect. This finding is consistent with the existing cross-sectional literature on lung cancer stigma and quality of life (Cataldo & Brodsky, 2013; Cataldo et al., 2012). Most of the patients in the sample had a history of smoking; however, all but seven reported that they were not smoking at the time of the study. The small sample size of current smokers in the study precluded meaningful comparisons of the effect of smoking status on lung cancer stigma and quality of life. However, pack years were examined in an exploratory analysis and did not predict daily quality of life or interact with the level of stigma patients reported in the daily diary (results not shown). A larger sample of current smokers would be needed to understand the effect of smoking on daily quality of life in the context of lung cancer stigma. Existing evidence suggests that lung cancer stigma is experienced regardless of smoking history (Cataldo et al., 2012).

Daily positive affect was a clear predictor of palliative wellbeing and demonstrated same-day relationships to social/role functioning and physical functioning.



This finding is not surprising, as positive affect has correlated with quality of life in other studies (Hirsch et al., 2012). For the purpose of informing intervention, it was important to determine whether or not daily hope added anything to predicting quality of life beyond positive affect. People with higher hope reported higher palliative wellbeing and social/role functioning, regardless of their previous day's report of quality of life. Results suggest that daily hope may positively impact daily quality of life, as it demonstrated same-day relationships with social/role functioning, physical functioning, and palliative well-being. Higher daily hope also appeared to be useful on days when patients had lung cancer treatments, reducing the negative impact that treatment had on social/role functioning. The interaction between daily hope and treatment day is intriguing, as treatment is a major part of life for patients and can vary from 1-6 hours of chemotherapy infusion to 15 minutes of radiation. Keeping patients active and engaged with aspects of life that they find rewarding is an important quality of life goal and supports patients through medical treatment of their disease (Arrieta et al., 2013; Greer, Pirl, Park, Lynch, & Temel, 2008; Lithoxopoulou et al., 2014; Montazeri, Milroy, Hole, McEwen, & Gillis, 2001; Lemonnier et al., 2014). Patient hope may facilitate that patient care goal.

A logical question about hope is whether or not it is should be conceptualized as a predictor of or a result of better quality of life. Longitudinal models provided some insight into directionality and seemed to suggest that daily hope was not a strong predictor once the previous day's quality of life had been taken into account. However, the relationship between daily hope and treatment days was primarily of interest for same day relationships, as the question was what helped people on days when they were receiving lung cancer treatment. Daily hope trended toward higher next day social/role



functioning. Hope was examined as a dependent variable to determine whether daily levels of hope were a byproduct of fewer symptoms or better functioning. Daily palliative wellbeing did influence daily hope, even when controlling for previous levels of daily hope, whereas daily lung cancer symptoms and physical functioning did not influence daily hope. Thus, hope does not seem to reflect higher or lower levels of lung cancer symptoms.

Results on the relationship between daily quality of life and hope are not incongruent with the construct of hope. Given that the construct of hope used was focused on personal goals, plans, and identifying ways around problems, it makes sense that better functioning and wellbeing would promote higher daily hope. When people do their work or hobbies, engage with their social life, and try to "make each day count," they are more likely to meet their personal goals, work towards fulfilling their plans, and stay focused on what matters to them. Engaging in hope behavior should promote functioning, and functioning should promote more hope behavior (Snyder, 2002). Given that higher average social/role functioning correlated with higher average hope, people who come into treatment with better functioning are likely to engage more easily in hope behavior. Patients with lower functioning at the start of treatment are likely to have lower hope—these are the patients who might benefit the most from a hope intervention.

Other researchers have suggested the potential benefit of a hope intervention for lung cancer patients (Berendes et al., 2010). Previously recommended components of a hope intervention have included: discussing patient understanding of their diagnosis, goal identification and prioritizing goals based on importance, identifying short-term and long-term goals that are realistic, identifying steps to take towards goals, and helping



patients monitor their own progress in working towards goals (Berendes et al., 2010). The behavioral targets of a hope intervention could be tailored to a person's specific situation and values as long as the clinician's organizing conceptualization is that lung cancer reduces quality of life when people disengage from activities they can still realistically carry out. The goal of a hope-based intervention, therefore, would be to promote the maintenance of realistic and valued directions in daily life while a patient faces new disease challenges and physical decline, which makes physicians an important part of hope interventions.

Communication with physicians is associated with patient outcomes (Taenzer et al., 2000). Most patients want to know about their diagnosis and have opportunities to ask questions (Hagerty et al., 2004), yet many lung cancer patients have unmet physician communication needs (Nelson et al., 2011). Providers can facilitate hope by starting conversations with patients early on about what activities are realistic and continuing to revisit patient life goals during treatment. One way to help understand patient goals may be to ask what would be important to do or what would be most important to the patient if she or he did not improve (Clayton et al., 2005). Another way would be to ask patients what they expect in the future with their illness (Roenn & Gunten, 2003). Without some sense of what might be possible from a medical standpoint, patients may have difficulty setting personal goals throughout illness, give up activities unnecessarily, or try to do too much. The ways in which patients pursue valued daily life directions should change throughout disease course (Sachs et al., 2013; Benzein, Norberg, & Saveman, 2001), which makes involving caregivers important, as caregivers are vital to cancer patients throughout disease progression. Caregivers themselves may become an appropriate focus



of intervention as disease progresses, thereby providing an indirect intervention for the patient by supporting the caregiver. Caregiver interventions are already established (Porter et al., 2011; Chih et al., 2013; Gustafson et al., 2013), although more intensive study on the relationship between caregiver intervention and patient functioning is needed in this population.

In summary, if hope is thought of as identifying available quality of life actions throughout illness, it should be useful throughout the course of disease and be influenced by direct intervention with the patient, provider behavior, and involvement with caregivers. Existing hope interventions provide starting point for designing a hope-based intervention for quality of life in lung cancer, but more work needs to be done to determine how to manipulate hope within the context of changing disease and patient abilities.

Limitations

Although to our knowledge this is the first intensive longitudinal study of quality of life among this patient population, results and conclusions are limited by a number of factors. First, the level-2 sample size made it difficult to detect between person differences based on lung cancer subtype or stage. Although some of the variability that might exist based on disease characteristics was likely reflected in treatment type, larger comparison groups might identify different needs for small cell vs. non-small cell patients or those with earlier vs. metastatic disease. Second, over half of the patients in this sample chose to complete the daily diaries on paper and less than half of those who did the diary on paper were asked to mail them in using weekly batches. Without the time stamp of online administration, it is impossible to know how precisely some of the



patients adhered to the daily diary schedule. However, investigators did check in with patients to see how they were doing completing the diaries. Similarly, because adherence was anticipated to be a problem with this population, every effort was made to make it as simple as possible, including letting patients identify their preferred time of day to complete the diary instead of forcing all patients to complete at the end of the day. Therefore, some patients were reflecting on 24 hours from a time in the morning, whereas others were reflecting on 24 hours from a time in the evening. A uniform time window would increase ability to draw conclusions about what patients were reflecting on when answering questions on the diary.

Third, assessment of reactivity to the diary was not built into the study design. It is possible that patients self-monitored (i.e., became more aware of their affect ratings or physical activity level, for example) during the diary and that this influenced their daily ratings. Response shift can occur with daily diary studies such that patients establish new levels of what anchors mean to them (e.g., "5" becomes a "3" as they reflect on previous ratings). This concern is reduced somewhat by the nature of the daily diary. Specifically, the number of items, assessment of several domains instead of one behavior, and mixed valence of behaviors/experiences measured (e.g., staying in bed vs. enjoying life) reduces the likelihood of reactivity to the diary (Barta, Tennen, & Litt, 2013). However, patients who had access to their daily diaries were at greater risk for reactivity, despite administration method not appearing to influence daily ratings. Fourth, although completion rates of the daily diary were high, it is likely that patients missed diaries on days when they were feeling the worst. This was addressed as best as possible by encouraging patients to enter a missed day prior to their current day's report; however,



that procedure introduced increased possibility of retrospective bias. Finally, patients were receiving medical oncology care from a variety of providers, which meant that there was not a uniform treatment for patients based on disease subtype or stage, making stage and subtype less useful predictors than they might be were patients receiving care from the same clinic provider.

Conclusion

Results of this study demonstrate the feasibility of assessing daily quality of life in late stage lung cancer patients, including those with disease in the brain. Given the prevalence of late stage lung cancer and the limited number of quality of life studies among the population to date, the feasibility data is encouraging. A number of predictors of daily quality of life were identified through this design, including hope and lung cancer stigma, which suggests that they may be useful intervention targets. Future studies may benefit from asking patients to identify specific activities that they did each day as a way to track what types of behaviors reflect or contribute to better quality of life. Prior to implementing a hope intervention in this population, it may be useful to try to manipulate hope by asking a subset of patients to list actionable goals for the day (e.g., call a friend, write down my questions for my oncologist, sit outside, etc.), or identify ways to increase the likelihood of it being a valued day (e.g., ask for help, remind self of reasons for doing something, etc.). Involving a caregiver in a dyadic diary study would also yield helpful information as to hope behaviors that promote quality of life. Finally, testing whether or not giving feedback to medical providers about the patients' weekly diaries prior to patient upcoming appointments might help identify whether or not diaries could improve patient care. At least one study has found a very brief assessment of quality of life to be



related to positive clinical outcomes, with minimal provider burden (Hubbard, Grothey, McWilliams, Buckner, & Sloan, 2014). Building a larger diary study from the results of this study might help to identify a set of quality of life items that are important and vary day-to-day for patients.



APPENDIX A: BASELINE QUESTIONNAIRE

Date:

Time Started:

ID: _____

REVISED 2/8/15

A. Demographic Information & Information about your cancer experience

1. Sex _____Female _____Male

2. Years of Education (including grades 1-12; HS degree = 12 years; 4 year

college degree = 16 years) _____

3. Current marital/relationship status (check one)

_____Never married _____Divorced _____Widowed

_____ Married _____ Separated _____Living with romantic partner

4. Age_____

5. Are you Hispanic or Latino/a?

____yes ___no

6. What ethnic or racial groups do you identify with (check all that apply)?

_____White _____Asian or Pacific Islander

Black American Indian or Alaskan Native

_____ Other (Specify:

7. What is your annual income (you or you and your spouse/partner)?

8. Are you currently receiving any of these treatments for you cancer?



radiation ____ surgery ____ chemotherapy combination radiation & chemo _____ combination radiation & surgery _____ combination surgery & chemo ____ combination surgery, chemo, & radiation 9. When were you diagnosed with lung cancer? date: ______ or approximate number of days ago ____ 10. Do you currently smoke? yes no a. If yes, how many cigarettes a day do you smoke? b. How many years have you smoked? c. If no, have you ever smoked? yes no d. How many cigarettes a day did you smoke? e. How many years did you smoke? 11. My expectation is that treatment will cure my lung cancer. 0 2 3 4 Not at all true slightly true somewhat true mostly true very true Please circle one number to indicate your response to each of the following questions. not at somewhat | a lot a a great all little deal

| | un | muie | | | ucui |
|--------------------------------------|----|------|---|---|------|
| To what extent do you consider | 1 | 2 | 3 | 4 | 5 |
| yourself a <u>religious person</u> ? | | | | | |
| To what extent is <u>religion</u> | 1 | 2 | 3 | 4 | 5 |
| involved in understanding or | | | | | |
| dealing with stressful situations | | | | | |
| in your life? | | | | | |
| To what extent is <u>religion</u> | 1 | 2 | 3 | 4 | 5 |
| helpful in understanding or | | | | | |
| dealing with stressful situations | | | | | |
| in your life? | | | | | |
| To what extent do you consider | 1 | 2 | 3 | 4 | 5 |
| yourself a spiritual person? | | | | | |



| To what extent is <u>spirituality</u> | 1 | 2 | 3 | 4 | 5 |
|---------------------------------------|---|---|---|---|---|
| involved in understanding or | | | | | |
| dealing with stressful situations | | | | | |
| in your life? | | | | | |
| | | | | | |
| To what extent is <u>spirituality</u> | 1 | 2 | 3 | 4 | 5 |
| helpful in understanding or | | | | | |
| dealing with stressful situations | | | | | |
| in your life? | | | | | |

EORTC. Quality of Life

| | Not at all | a little bit | quite a bit | very much |
|---|------------|--------------|-------------|--------------|
| 1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? | 1 | 2 | 3 | 4 |
| 2. Do you have any trouble taking a long walk? | 1 | 2 | 3 | 4 |
| 3. Do you have any trouble taking a short walk outside of the house? | 1 | 2 | 3 | 4 |
| 4. Do you need to stay in bed or a chair during the day? | 1 | 2 | 3 | 4 |
| 5. Do you need help with eating, dressing, washing yourself or using the toilet? | 1 | 2 | 3 | 4 |

| During the past week: | Not at all | a little bit | quite a bit | very much |
|--|------------|--------------|----------------|--------------|
| 6. Were you limited in doing either your work or other | 1 | 2 | 3 | 4 |



| daily activities? | | | | |
|---|-----------------|-------------------|----------------|--------------|
| 7. Were you limited in pursuing your hobbies or other leisure time activities? | 1 | 2 | 3 | 4 |
| 8. Were you short of breath? | 1 | 2 | 3 | 4 |
| 9. Have you had pain? | 1 | 2 | 3 | 4 |
| 10. Did you need to rest? | 1 | 2 | 3 | 4 |
| 11. Have you had trouble sleeping? | 1 | 2 | 3 | 4 |
| 12. Have you felt weak? | Not at all 1 | a little bit 2 | quite a bit | very much |
| | | | 3 | 4 |
| 13. Have you lacked appetite? | 1 | 2 | 3 | 4 |
| 14. Have you felt nauseated? | 1 | 2 | 3 | 4 |
| 15. Have you vomited? | 1 | 2 | 3 | 4 |
| 16. Have you been constipated? | 1 | 2 | 3 | 4 |
| 17. Have you had diarrhea? | 1 | 2 | 3 | 4 |
| 18. Were you tired? | 1 | 2 | 3 | 4 |
| 19. Did pain interfere with your daily activities? | 1 | 2 | 3 | 4 |
| 20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television? | 1 | 2 | 3 | 4 |
| 21. Did you feel tense? | 1 | 2 | 3 | 4 |
| 22. Did you worry? | 1 | 2 | 3 | 4 |



| 23. Did you feel irritable? | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| 24. Did you feel depressed? | 1 | 2 | 3 | 4 |
| 25. Have you had difficulty remembering things? | 1 | 2 | 3 | 4 |
| 26. Has your physical condition or medical treatment interfered with your family life? | 1 | 2 | 3 | 4 |
| 27. Has your physical condition or medical treatment interfered with your social activities? | 1 | 2 | 3 | 4 |
| 28. Has your physical condition or medical treatment caused you financial difficulties? | 1 | 2 | 3 | 4 |

For the following questions please circle the number between 1 and 7 that

best applies to you.

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7 Very poor Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7 Very poor Excellent



Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

| | PHYSICAL WELL-BEING | Not at all | A little bit | Some- what | Quite a bit | Very much |
|-----|---|---------------|--------------------|---------------|----------------|--------------|
| GP1 | I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| GP2 | I have nausea | 0 | 1 | 2 | 3 | 4 |
| GP3 | Because of my physical condition, I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| GP4 | I have pain | 0 | 1 | 2 | 3 | 4 |
| GP5 | I am bothered by side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| GP6 | I feel ill | 0 | 1 | 2 | 3 | 4 |
| GP7 | I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |
| | <u>SOCIAL/FAMILY WELL-</u> <u>BEING</u> | Not at all | A little bit | Some- what | Quite a bit | Very much |
| GS1 | I feel close to my friends | 0 | 1 | 2 | 3 | 4 |
| GS2 | I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |
| GS3 | I get support from my friends | 0 | 1 | 2 | 3 | 4 |
| GS4 | My family has accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GS5 | I am satisfied with family communication about my illness | 0 | 1 | 2 | 3 | 4 |



| GS6 | I feel close to my partner (or the person who is my main support) | 0 | 1 | 2 | 3 | 4 |
|-----|--|---|---|---|---|---|
| Q1 | Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer i lease mark this box and go to the | | | | | |
| GS7 | I am satisfied with my sex life | 0 | 1 | 2 | 3 | 4 |

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

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

| FUNCTIONAL WELL- | Not at | А | Some- | Quite | Very |
|------------------|--------|--------|-------|-------|------|
| BEING | all | little | what | a bit | much |
| | | bit | | | |



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| GF1 | I am able to work (include work at home) | 0 | 1 | 2 | 3 | 4 |
|-----|--|---|---|---|---|---|
| GF2 | My work (include work at home) is fulfilling | 0 | 1 | 2 | 3 | 4 |
| GF3 | I am able to enjoy life | 0 | 1 | 2 | 3 | 4 |
| GF4 | I have accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GF5 | I am sleeping well | 0 | 1 | 2 | 3 | 4 |
| GF6 | I am enjoying the things I usually do for fun | 0 | 1 | 2 | 3 | 4 |
| GF7 | I am content with the quality of my life right now | 0 | 1 | 2 | 3 | 4 |
| | | | | | | |

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

| | ADDITIONAL CONCERNS | Not at all | A little bit | Some- what | Quite a bit | Very much |
|----|-----------------------------|---------------|-----------------|---------------|----------------|--------------|
| | | | | | | |
| B1 | I have been short of breath | 0 | 1 | 2 | 3 | 4 |
| C2 | I am losing weight | 0 | 1 | 2 | 3 | 4 |
| L1 | My thinking is clear | 0 | 1 | 2 | 3 | 4 |
| L2 | I have been coughing | 0 | 1 | 2 | 3 | 4 |
| B5 | I am bothered by hair loss | 0 | 1 | 2 | 3 | 4 |



ľ

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| C6 | I have a good appetite | 0 | 1 | 2 | 3 | 4 |
|----|---|---|---|---|---|---|
| 0 | | 0 | | _ | | |
| L3 | I feel tightness in my chest | 0 | 1 | 2 | 3 | 4 |
| L4 | Breathing is easy for me | 0 | 1 | 2 | 3 | 4 |
| Q3 | Have you ever smoked? No Yes If yes: | | | | | |
| L5 | I regret my smoking | 0 | 1 | 2 | 3 | 4 |
| | 1 | | | | | |

| | strongly | | | strongly |
|---|----------|---|---|----------|
| | disagree | 2 | 2 | agree |
| | (1) | 2 | 3 | (4) |
| 1. I feel guilty because I have lung cancer. | 1 | 2 | 3 | 4 |
| 2. I work hard to keep my lung cancer a secret. | 1 | 2 | 3 | 4 |
| 3. Having lung cancer makes me feel like I'm a bad person. | 1 | 2 | 3 | 4 |
| 4. I'm very careful whom I tell I have lung cancer. | 1 | 2 | 3 | 4 |
| 5. I feel I'm not as good as others because I have lung cancer. | 1 | 2 | 3 | 4 |
| 6. Having lung cancer makes me feel unclean. | 1 | 2 | 3 | 4 |
| 7. I feel set apart, isolated from the rest of the world. | 1 | 2 | 3 | 4 |



| 8. My lung cancer diagnosis was delayed because I put off going to the doctor. | 1 | 2 | 3 | 4 |
|--|--|---------------------------------|-----------------------|---|
| 9. Some told me lung cancer is what I deserved for smoking. | 1 | 2 | 3 | 4 |
| 10. My lung cancer diagnosis was delayed because my healthcare provider did not take my "smoker's cough" seriously. | 1 | 2 | 3 | 4 |
| 11. Smokers could be refused treatment for lung cancer. | 1 | 2 | 3 | 4 |
| 12. I have lost friends by telling them I have lung cancer. | 1 | 2 | 3 | 4 |
| | | | | |
| 13. I stopped socializing with some because of their reactions. | strongly <u>disagree</u> (1) | 2 | 3 | strongly <u>agree</u> (4) |
| 13. I stopped socializing with some because of their reactions. 14. People have physically backed away from me. | strongly <u>disagree</u> (1) 1 | 2 | 3 | strongly <u>agree</u> (4) 4 |
| 13. I stopped socializing with some because of their reactions. 14. People have physically backed away from me. 15. People I care about stopped calling after learning that I have lung cancer. | strongly <u>disagree</u> (1) 1 1 | 2 2 2 2 2 | 3 3 3 | strongly <u>agree</u> (4) 4 4 |
| 13. I stopped socializing with some because of their reactions. 14. People have physically backed away from me. 15. People I care about stopped calling after learning that I have lung cancer. 16. People seem afraid of me because I have lung cancer. | strongly <u>disagree</u> (1) 1 1 1 | 2 2 2 2 2 | 3 3 3 3 | strongly <u>agree</u> (4) 4 4 4 |
| 13. I stopped socializing with some because of their reactions. 14. People have physically backed away from me. 15. People I care about stopped calling after learning that I have lung cancer. 16. People seem afraid of me because I have lung cancer. 17. People avoid touching me if they know I have lung cancer. | strongly disagree (1) 1 1 1 1 1 | 2 2 2 2 2 2 | 3 3 3 3 | strongly agree (4) 4 4 4 4 4 |
| 13. I stopped socializing with some because of their reactions. 14. People have physically backed away from me. 15. People I care about stopped calling after learning that I have lung cancer. 16. People seem afraid of me because I have lung cancer. 17. People avoid touching me if they know I have lung cancer. 18. People avoid you because lung cancer is associated with death. | strongly disagree (1) 1 1 1 1 1 1 1 | 2 2 2 2 2 2 2 | 3 3 3 3 3 | strongly agree (4) 4 4 4 4 4 4 4 |



| grown more distant. | | | | |
|--|-----------------------------|---|---|---------------------------------|
| 20. I was hurt how people reacted to learning I have lung cancer. | 1 | 2 | 3 | 4 |
| 21. I worry about people discriminating against me. | 1 | 2 | 3 | 4 |
| 22. People with lung cancer are treated like outcasts. | 1 | 2 | 3 | 4 |
| 23. Most people believe a person with lung cancer is dirty. | 1 | 2 | 3 | 4 |
| 24. Most are uncomfortable around someone with lung cancer. | 1 | 2 | 3 | 4 |
| 25. I worry that people may judge me when they learn I have lung cancer. | 1 | 2 | 3 | 4 |
| 26. People with lung cancer lose jobs when employers learn. | 1 | 2 | 3 | 4 |
| 27. Lung cancer is viewed as a self- inflicted disease. | strongly disagree (1) | 2 | 3 | strongly <u>agree</u> (4) |
| 28. Others assume that a patient's lung cancer was caused by smoking, even if he or she never smoked. | 1 | 2 | 3 | 4 |
| 29. Others assume that a patient's lung cancer was caused by smoking, even if he or she had stopped smoking years ago. | 1 | 2 | 3 | 4 |
| 30. Some people act as though it is my fault that I have lung cancer. | 1 | 2 | 3 | 4 |
| 31. Healthcare providers don't take | 1 | 2 | 3 | 4 |



| "smoker's cough" seriously. | | |
|-----------------------------|--|--|
| | | |



Section B: Personal Characteristics

<u>Instructions</u>: Please read each statement and decide how much you disagree or agree with it. Circle one number for each statement using the following scale.

| Do you see yourself as | strongly | disagree | neutral | agree | strongly |
|----------------------------|----------|----------|---------|-------|----------|
| someone who | disagree | | | | agree |
| 1. Is relaxed, handles | 1 | 2 | 3 | 4 | 5 |
| stress well | | | | | |
| 2. Can be moody | 1 | 2 | 3 | 4 | 5 |
| 3. Is depressed, blue | 1 | 2 | 3 | 4 | 5 |
| 4. Can be tense | 1 | 2 | 3 | 4 | 5 |
| 5. Worries a lot | 1 | 2 | 3 | 4 | 5 |
| 6. Remains calm in tense | 1 | 2 | 3 | 4 | 5 |
| situations | | | | | |
| 7. Is emotionally stable, | strongly | disagree | neutral | agree | strongly |
| not easily upset | disagree | 2 | 3 | 4 | agree |
| | 1 | | | | 5 |
| 8. Gets nervous easily | 1 | 2 | 3 | 4 | 5 |
| 9. In uncertain time, I | 1 | 2 | 3 | 4 | 5 |
| usually expect the best | | | | | |
| 10. If something can go | 1 | 2 | 3 | 4 | 5 |
| wrong for me, it will | | | | | |
| 11. I'm always optimistic | 1 | 2 | 3 | 4 | 5 |
| about my future | | | | | |
| 12. I hardly ever expect | 1 | 2 | 3 | 4 | 5 |
| things to go my way | | | | | |
| 13. I rarely count on good | 1 | 2 | 3 | 4 | 5 |



| things happening to me | | | | | |
|----------------------------|---|---|---|---|---|
| 14. Overall, I expect more | 1 | 2 | 3 | 4 | 5 |
| good things to happen to | | | | | |
| me than bad | | | | | |

Please select the number that best describes you.

| | definitely | mostly | mostly | definitely |
|--|------------|--------|--------|------------|
| | false | false | true | true |
| 1. I can think of many ways to | 1 | 2 | 3 | 4 |
| get out of a jam | | | | |
| 2. I energetically pursue my | 1 | 2 | 3 | 4 |
| goals | | | | |
| 3. There are lots of ways around any problem | 1 | 2 | 3 | 4 |
| 4. I meet the goals that I set for myself | 1 | 2 | 3 | 4 |
| | 1 | 2 | 3 | 4 |
| 5. I can think of many ways to | | | | |
| get the things in life that are most | | | | |
| important to me | | | | |
| 6. I've been pretty successful in | definitely | mostly | mostly | definitely |
| life | false | false | true | true |
| | 1 | 2 | 3 | 4 |
| 7. Even when others get | 1 | 2 | 3 | 4 |
| discouraged, I know I can find a | | | | |
| way to solve a problem | | | | |
| 8. My past experiences have | 1 | 2 | 3 | 4 |
| prepared me well for my future | | | | |
| 9. As I encounter difficulties, I | 1 | 2 | 3 | 4 |
| will not get stuck | | | | |
| 10. I see potential when I think of | | | | 4 |
| rour see potential when I think of | 1 | 2 | 3 | 4 |
| what is ahead | 1 | 2 | 3 | 4 |
| what is ahead 11. I am focused on what matters | 1 | 2 | 3 | 4 |
| what is ahead 11. I am focused on what matters to me as I go through what I am | 1 | 2 | 3 | 4 |



| 12. I am focusing on what matters to me and it shows | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| 13. I see many ways of pursuing what is most important to me now | 1 | 2 | 3 | 4 |
| 14. I am keeping in mind what matters most to me | 1 | 2 | 3 | 4 |
| 15. Even though I may not be able to meet a goal I have set for myself, I am doing what I can | 1 | 2 | 3 | 4 |
| 16. Daily life is not about the likelihood of reaching my goals, but rather about the process of working towards something | 1 | 2 | 3 | 4 |
| 17. Because it makes my life better, it is important for me to pursue what may be possible for me even if it is difficult | 1 | 2 | 3 | 4 |

Think about the past 2 weeks and check one blank for each statement.

8. I felt as if I was slowed down. 1. I felt tense or wound up. ____ Most of the time _____ Nearly all the time _____ A lot of the time ____ Very often ____ Sometimes _____ From time to time, occasionally ____ Not at all Not at all 2. I enjoyed the things I used to enjoy. 9. I got a sort of frightened feeling like butterflies in my stomach ____ Definitely as much _____ Not quite as much ____ Not at all ____ Only a little ____ Occasionally ____ Hardly at all ____ Quite often _____ Very often 3. I got a sort of frightened feeling as if 10. I have lost interest in my something awful was about to happen. appearance. _____ Very definitely and quite badly ____ Definitely I don't take so much care as I ____ Yes, but not too badly should ____ A little, but it didn't worry me ____ I may not take quite as much care ____ Not at all _____ I take just as much care as ever 11. I felt restless as if I had to be on 4. I could laugh and see the funny side of things. the move. _____ As much as I always could _____ Very much indeed ____ Not quite so much now ____ Quite a lot ____ Definitely not so much now ____ Not very much Not at all Not at all 5. Worrying thoughts went through my mind. 12. I looked forward with enjoyment to things. _____ As much as I ever did _____ A great deal of the time _____ A lot of the time _____ Rather less than I used to _____ Definitely less than I used to _____ From time to time but not too often. ____ Only occasionally _____ Hardly at all 6. I felt cheerful. 13. I got sudden feelings of panic. ____ Not at all _____ Very much indeed ____ Quite a lot ____ Not often ____ Sometimes _____ Not very much Most of the time Not at all

7. I could sit at ease and feel relaxed. program.

_ Definitely



14. I could enjoy a book/radio/TV

Often

| Usually | Sometimes |
|------------|-------------|
| Not often | Not often |
| Not at all | Very seldom |

"If I have to stop pursuing an important goal in my life..."

| | almost | | | | almost |
|--|----------|---|---|---|----------|
| | never | | | | always |
| | true (1) | - | | | true (5) |
| 1. It's easy for me to reduce my effort toward the goal. | 1 | 2 | 3 | 4 | 5 |
| 2. I find it difficult to stop trying to achieve the goal. | 1 | 2 | 3 | 4 | 5 |
| 3. I stay committed to the goal for a long time; I can't let it go. | 1 | 2 | 3 | 4 | 5 |
| 4. It's easy for me to stop thinking about the goal and let it go. | 1 | 2 | 3 | 4 | 5 |
| 5. I think about other new goals to pursue. | 1 | 2 | 3 | 4 | 5 |
| 6. I seek other meaningful goals. | 1 | 2 | 3 | 4 | 5 |
| 7. I convince myself that I have other meaningful goals to pursue. | 1 | 2 | 3 | 4 | 5 |
| 8. I tell myself that I have a number of other new goals to draw on. | 1 | 2 | 3 | 4 | 5 |
| 9. I start working on other new goals. | 1 | 2 | 3 | 4 | 5 |
| 10. I put effort toward other meaningful goals. | 1 | 2 | 3 | 4 | 5 |

Section C: Physician-Patient Relationship



Instructions: Please read each statement and decide how much you disagree or agree with it. Circle one number for each statement and answer in response to your view on your primary oncologist.

| v 0 | Strongly | | | | Strongly |
|--|----------|---|---|---|----------|
| 1. I completely trust my doctor's decisions about which treatments are best for me. | 1 | 2 | 3 | 4 | 5 |
| 2. My doctor is extremely thorough and careful. | 1 | 2 | 3 | 4 | 5 |
| 3. Sometimes my doctor cares more about what is convenient for him/her than about my medical needs. | 1 | 2 | 3 | 4 | 5 |
| 4. My doctor is totally honest with me. | 1 | 2 | 3 | 4 | 5 |
| 5. All in all, I have complete trust in this doctor. | 1 | 2 | 3 | 4 | 5 |

Primary Oncologist

Patient Perception in Communication with Physician

Think about your recent contact with your <u>primary oncologist</u>. Then answer the following questions by circling the number that best describes how you feel about your recent contact with that person.

| | very strongly disagree | strongly disagree | disagree | not sure | agree | strongly agree | very strongly agree |
|-------------------------|------------------------------|----------------------|----------|-------------|-------|-------------------|---------------------------|
| 1. I understand the | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| possible side effects | | | | | | | |
| of treatment. | | | | | | | |
| 2. If my doctor tells | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| me something that is | | | | | | | |
| different from what I | | | | | | | |
| was told before, it is | | | | | | | |
| difficult for me to ask | | | | | | | |



| about it in order to get it straightened out. | | | | | | | |
|---|------------------------------|----------------------|----------|-------------|-------|-------------------|---------------------------|
| | very strongly disagree | strongly disagree | disagree | not sure | agree | strongly agree | very strongly agree |
| 3. He/she is warm and caring toward me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. If I don't understand something my doctor says, I have difficulty asking for more information. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. My doctor told me what he/she hopes the treatment will do for me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. My doctor makes me feel comfortable about discussing personal or sensitive issues. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. It was hard for me to tell my doctor about new symptoms. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. It is hard for me to ask about how my treatment is going. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. My doctor really respects me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 10. I understand pretty well the medical plan for helping me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |



| 11. After talking to my doctor, I have a good idea of what changes to expect in my health over the next weeks and months. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|------------------------------|----------------------|----------|-------------|-------|-------------------|---------------------------|
| 12. When I talk to my doctor, I sometimes end up feeling insulted. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 13. I have difficulty asking my doctor questions. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 14. The treatment procedure was clearly explained to me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 15. My doctor <i>doesn't</i> seem interested in me as a person. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Please rate how much the physician seemed to: | very strongly disagree | strongly disagree | disagree | not sure | agree | strongly agree | very strongly agree |
| 16. Involve you in treatment decisions. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 17. Give you a sense of control of medical care. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 18. To ask you to take some responsibility for care. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Patient Perception of Primary Oncologist

| Strongly | Disagree | Neutral | Agree | Strongly |
|----------|----------|---------|-------|----------|
| disagree | | | | agree |



| 1. My doctor wants to know about my nationality. | 1 | 2 | 3 | 4 | 5 |
|---|-------------------|----------|---------|-------|----------------|
| 2. My doctor wants to know about my racial background. | 1 | 2 | 3 | 4 | 5 |
| 3. My doctor wants to know about my religious practices related to health issues. | 1 | 2 | 3 | 4 | 5 |
| 4. My doctor wants to know about my cultural background. | 1 | 2 | 3 | 4 | 5 |
| | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
| 5. My doctor asks me who makes important decisions in my family. | 1 | 2 | 3 | 4 | 5 |
| 6. My doctor asks me if I would feel discomfort if the doctor touches me during physical exam. | 1 | 2 | 3 | 4 | 5 |
| 7. My doctor wants to know if time is a concern for me with regard to health exam. | 1 | 2 | 3 | 4 | 5 |
| 8. My doctor wants to know if time is a concern for me with regard to medical treatment. | 1 | 2 | 3 | 4 | 5 |
| 9. My doctor tries to understand my feelings. | 1 | 2 | 3 | 4 | 5 |
| 10. My doctor tries to understand my emotions. | 1 | 2 | 3 | 4 | 5 |
| 11. My doctor wants to know my viewpoint on | 1 | 2 | 3 | 4 | 5 |



| illness. | | | | | |
|--|---|---|---|---|---|
| 12. My doctor wants to know my viewpoint on treatment goals. | 1 | 2 | 3 | 4 | 5 |



PITTSBURGH SLEEP QUALITY INDEX

INSTRUCTIONS:

The following questions relate to your usual sleep habits during the past month <u>only</u>. Your answers should indicate the most accurate reply for the <u>majority</u> of days and nights in the past month. Please answer all questions.

1. During the past month, what time have you usually gone to bed at night?

BED TIME _____

2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?

NUMBER OF MINUTES

3. During the past month, what time have you usually gotten up in the morning?

GETTING UP TIME

4. During the past month, how many hours of <u>actual sleep</u> did you get at night? (This may be different than the number of hours you spent in bed.)

HOURS OF SLEEP PER NIGHT _____

For each of the remaining questions, check the one best response. Please answer all questions.

- 5. During the past month, how often have you had trouble sleeping because you . . .
- a) Cannot get to sleep within 30 minutes

Not during the
past month_____Less than
once a week____Once or twice
a week____Three or more
times a week____

b) Wake up in the middle of the night or early morning

Not during the
past month____Less than
once a week____Once or twice
a week____Three or more
times a week____

c) Have to get up to use the bathroom

| Not during the | Less than | Once or twice | Three or more |
|----------------|-------------|---------------|---------------|
| past month | once a week | a week | times a week |



d) Cannot breathe comfortably

| | Not during the past month | Less than once a week | Once or twice a week | Three or more times a week |
|----|------------------------------|-----------------------|-------------------------|----------------------------|
| e) | Cough or snore lou | udly | | |
| | Not during the past month | Less than once a week | Once or twice a week | Three or more times a week |
| f) | Feel too cold | | | |
| | Not during the past month | Less than once a week | Once or twice a week | Three or more times a week |
| g) | Feel too hot | | | |
| | Not during the past month | Less than once a week | Once or twice a week | Three or more times a week |
| h) | Had bad dreams | | | |
| | Not during the past month | Less than once a week | Once or twice a week | Three or more times a week |
| i) | Have pain | | | |
| | Not during the past month | Less than once a week | Once or twice a week | Three or more times a week |

6. During the past month, how would you rate your sleep quality overall?

| Very good | |
|-------------|--|
| Fairly good | |
| Fairly bad | |
| Very bad | |
| | |

Thank you!

TIME END: _____

Please estimate how long it took you to complete this questionnaire: _____ minutes



APPENDIX B: DAILY DIARY ASSESSMENT QUESTIONS

ID: _____ DATE:_____

Daily Diary Assessment Questions rev. 2/8/2015

START TIME:

A. Mood

1. How much did you feel this way during the past day?

| | not at all | a little | moderately | quite a bit | extremely |
|------------|------------|----------|------------|-------------|-----------|
| active | 0 | 1 | 2 | 3 | 4 |
| anxious | 0 | 1 | 2 | 3 | 4 |
| quiet | 0 | 1 | 2 | 3 | 4 |
| sad | 0 | 1 | 2 | 3 | 4 |
| happy | 0 | 1 | 2 | 3 | 4 |
| relaxed | 0 | 1 | 2 | 3 | 4 |
| depressed | 0 | 1 | 2 | 3 | 4 |
| bored | 0 | 1 | 2 | 3 | 4 |
| nervous | 0 | 1 | 2 | 3 | 4 |
| рерру | 0 | 1 | 2 | 3 | 4 |
| angry | 0 | 1 | 2 | 3 | 4 |
| stimulated | 0 | 1 | 2 | 3 | 4 |
| cheerful | 0 | 1 | 2 | 3 | 4 |


| energetic | 0 | 1 | 2 | 3 | 4 |
|-----------|---|---|---|---|---|
| guilty | 0 | 1 | 2 | 3 | 4 |
| lonely | 0 | 1 | 2 | 3 | 4 |

2. How supportive were your interactions with your oncology team today?

0 1 2 3 4 not at all extremely supportive

5 = I did not have contact with my oncology team today

| 3. How diff | icult was c | hemotherapy | y today? | | |
|-----------------------|--------------|---------------|------------|------|-----|
| 0 | 1 | 2 | 3 | 4 | 5 |
| not at all applicable | a little | somewhat | moderately | very | not |
| 4. How diff | ficult was r | adiation toda | ny? | | |
| 0 | 1 | 2 | 3 | 4 | 5 |
| not at all | a little | somewhat | moderately | very | not |
| applicable | | | | | |

5. Did you have any cancer setbacks today that required you to schedule an appointment with your oncology team or healthcare provider? (e.g. bad reaction to medication, loss of feeling in a limb)

yes no

B. Stress & Relationships

| | not | а | moderately | extremely | N/A or |
|-----------------------|-----|--------|------------|-----------|---------|
| | at | little | | | no |
| | all | | | | contact |
| 1. How stressful were | 0 | 1 | 2 | 3 | 4 |
| your interpersonal | | | | | |



| interactions with people who are important to you today? | | | | | |
|--|---|---|---|---|---|
| 2. How <u>enjoyable</u> were your interpersonal interactions with people who are important to you today? | 0 | 1 | 2 | 3 | 4 |

Experiences with Lung Cancer: Remember, respond to how much you agree or disagree with these statements today.

| | strongly | | | strongly |
|--|-----------------|---|---|----------|
| | <u>disagree</u> | | | agree |
| TODAY | (1) | 2 | 3 | (4) |
| I feel set apart, isolated from the rest | 1 | 2 | 3 | 4 |
| of the world. | | | | |
| Some people act as though it is my | 1 | 2 | 3 | 4 |
| fault that I have lung cancer. | | | | |
| | | | | |
| Some people who know have grown | 1 | 2 | 3 | 4 |
| more distant. | | | | |
| I feel guilty because I have lung | 1 | 2 | 3 | 4 |
| cancer. | | | | |
| | | | | |
| Having lung cancer makes me feel like | 1 | 2 | 3 | 4 |
| I'm a bad person. | | | | |

C. Physical Symptoms

Please indicate the extent to which you experienced these symptoms or problems during the past 24 hours.

| | Not at all | a little bit | quite a bit | very much |
|------------------------------|---------------|-----------------|----------------|--------------|
| 1. How much did you cough? | 1 | 2 | 3 | 4 |
| 2. Were you short of breath? | 1 | 2 | 3 | 4 |
| 3. Did you have pain? | 1 | 2 | 3 | 4 |



| 4. Did you feel weak? | 1 | 2 | 3 | 4 |
|--|---|---|---|---|
| 5. Did you lack appetite? | 1 | 2 | 3 | 4 |
| 6. Did you feel nauseated? | 1 | 2 | 3 | 4 |
| 7. Did you have trouble sleeping? (during the night) | 1 | 2 | 3 | 4 |
| 8. Were you tired? | 1 | 2 | 3 | 4 |
| 9. How much did your symptoms interfere with your sleep? | 1 | 2 | 3 | 4 |
| 10. How satisfied are you with the quality of your sleep last night? | 1 | 2 | 3 | 4 |

D. Functioning

The following questions ask you about the potential impact that lung cancer may have had on your life today.

| | Not at all | a little | quite a bit | very much |
|---|---------------|----------|----------------|-----------|
| 1. Did you need to stay in bed or a chair during the day? | 1 | 2 | 3 | 4 |
| 2. Were you limited in doing either your work or other daily activities? | 1 | 2 | 3 | 4 |
| 3. Were you limited in pursuing your hobbies or other leisure time activities? | 1 | 2 | 3 | 4 |
| 4. Has your physical condition or medical treatment interfered with your family life today? | 1 | 2 | 3 | 4 |
| 5. Has your physical condition or medical treatment interfered with your social life today? | 1 | 2 | 3 | 4 |

Remember, respond to items for how true these statements are for you today.

| TODAY | not at all | a little bit | somewhat | quite a bit | very much |
|--|---------------|-----------------|----------|----------------|--------------|
| I am bothered by the side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| Because of my physical | 0 | 1 | 2 | 3 | 4 |



| condition, I had trouble meeting the needs of my family today. | | | | | |
|--|---|---|---|---|---|
| I feel useful. | 0 | 1 | 2 | 3 | 4 |
| I feel independent. | 0 | 1 | 2 | 3 | 4 |
| I feel like a burden to my family. | 0 | 1 | 2 | 3 | 4 |
| I feel that my family appreciates me. | 0 | 1 | 2 | 3 | 4 |
| I maintain contact with my friends. | 0 | 1 | 2 | 3 | 4 |
| I make each day count. | 0 | 1 | 2 | 3 | 4 |
| I am able to openly discuss my concerns with the people closest to me. | 0 | 1 | 2 | 3 | 4 |
| I am able to enjoy life. | 0 | 1 | 2 | 3 | 4 |

F. Use the following scale to rate these statements about today.

| | definitely FALSE | mostly false | somewhat false | slightly false | slightly true | somewhat true | mostly true | definitely TRUE |
|--|---------------------|--------------|-------------------|-------------------|---------------|------------------|-------------|--------------------|
| 1. At the present time, I am trying to pursue my personal goals and plans. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 2. There are ways around any problem that I am facing now | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 3. I can think of many ways t reach my current goals. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |



| 4. At this time, I an meeting the goals the have set for myself | n hat I | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|--|--|----|---|------------|------------------|------------------|--------|--------|-----|
| 5. I am focused on matters to me as I g through what I am t now. | what 30 facing | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 6. I see many ways pursuing what is me important to me no | of ost w | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 7. Even though I m be able to meet a go have set for myself doing what I can | ay not oal I , I am | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 8. Because it make life better, it is imp for me to pursue v may be possible fo even if it is difficul | es my portant vhat or me t | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 9. I see potential with think of what is and | hen I ead. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| | END TIM | E: | | OR, too | , estim k you | ate of today: | how lo | ong tł | nis |

Optional: please feel free to tell us anything else that is important in understanding how lung cancer affected your daily quality of life today. This is completely optional.

Please ensure that you have dated the questionnaire and provided an estimation of how many minutes it took you to complete today if you did not write down the start and end time.

Thank you! Each day you complete is a substantial contribution to this project's larger effort to establish quality of life research in lung cancer and identify potential ways to help lung cancer patients.



| Theme | Quotes from Patients |
|-------------------|---|
| Interactions with | The appointment yesterday was overwhelming with the oncologist. I |
| Medical Team | missed much of what was said, and I didn't understand what my MRI results meant. |
| | The blood transfusion nurse was very kind. It makes day-to day things and appointments easier when people are kind. |
| | Radiation doctor is great and helpful. I am glad he is back. The last radiation doctor didn't seem interested in me as a person. This |
| | I will be forever thankful for the two doctors who came my way and took me to their care and to where I am now. I owe my life to them. I could not have better care from such professional doctors. I've had nothing but excellent care from everyone. |
| | I had a difficult day at chemo. My IV had to be removed. The nurse did not put the heprarin in and they could not get the IV to work. After three tries yesterday it had to be removed. The nurse said she would call the rapid response team to have them put in a new IV. Another nurse came over and said are you ready. I told her no and to call the rapid response team. She kinda got upset but I didn't care since I didn't want unnecessary pokes at my body. The rapid response team member did an excellent job and I hope this will last til the end of the week so I don't have to go through it again this week. |
| | I had a terrible experience with chemo today. They were running late as usual. When I finally got put into a station, the nurse forgot about me and didn't even apologize. She said she was looking for me but couldn't find me. I was put in the chair awaiting my treatment, how could she not find me. She proceeded to tell me the medications were running late because the lab was training in new help. I suspect the drugs were late because she did not order them cause she couldn't find me. I was not treated with dignity and respect today. I do like the clinic but I am getting concerned with the patient care. |
| | I had lab work and my WBC shot today. The young lab tech said I did not need lab work and nothing was in the computer. I assured her to call the doctor because they always check my blood levels once I finish chemo. The other nurse or lab tech came in and took the blood work. She said this was a duplicate set of orders. I am |

APPENDIX C: Participant Qualitative Responses



| | getting tired of the poor treatment I am receiving. I have to keep going but I get angry with the staff for not knowing and doing their job. |
|----------|---|
| | the oncology people are incrediblethey're a great bunch of people |
| | Today was a very long day for me. Started with labs at 7am, then back for more doctor visit and chemo. My chemo appointment was set for 12 noon. We got started over 1 and a half hours later. Very frustrating. I am discovering that having cancer and doing what's needed is very hard work! |
| Symptoms | Tired and no appetite |
| | So tired and walking is difficult wobble |
| | SO TIRED |
| | I am in treatment I can't do much of anything asking me if I am set on goals is silly I a set on getting up and making it through the day. I throw up, can't go to the bathroom and can hardly stay awake. |
| | I am afraid I hope I get better than I am I am having trouble with walking and catching my breath hasn't gone away I am weak. I need more energy! |
| | I have a cough, can't walk a lot as I get so winded. I did not have this before, it hurts to cough and take deep breaths. |
| | Breathing seems easier. |
| | I was very anxious and nauseous today I am exhausted. |
| | Cancer symptoms came on hard. In horrible pain for the last monthsome pain management was finally approved yesterday- big difference for me not to have ups and downs |
| | Nasty flu or whatever! |
| | I just slept all day yesterday - not sure why Also have been losing weight. |
| | Feeling better after a rough week. |
| | Today was a hard day for me. Felt like I had monkeys on my back. Had to take a pain pill. Slept fairly well, but work up tired and weak |



| | for some reason. | | |
|----------------|--|--|--|
| | stressful day, feeling too tired to cope - | | |
| Treatment | Will restart chem and radiaiton hopefully after today's appointment. | | |
| Delay/Progress | Physically and mentally, not appropriate for treatment last week. This week, some improvement, but many complications and E.D. visits have happened. | | |
| | I do not feel good at all I am vomiting, have disagreed, sleep all of the time. I am certain it is because I am on treatment. | | |
| | I hope hope hope that I do well with this next round of chemotherapy. I've tried to build myself up with acupuncture and herbs | | |
| | Hope my platelet count is OK - it was very, very low. | | |
| | Today was "life interrupted". My partner was taken to hospital with an intestinal bug. I was feeling ill like I did with the high calcium in June so I called oncology to ask for a blood count. I was called back later to come in for treatment to lower the calcium level. I also have a low red cell count so I go back tomorrow for transfusion. My house is a disaster! | | |
| | Another day at Oncology for a red cell transfusion. We ran out of time to get all complete yesterday. | | |
| | Feeling pretty well. But less than a week and I start the whole process again | | |
| | First treatment went well | | |
| | Not so good today - ended up this morning in er with blood clots. Probably why have been feeling rotten the last few days/weeks. | | |
| | start radiation tomorrow | | |
| | radiation and chemotherapy tomorrow; long day ahead | | |
| | Bad day + 1 more chemo tomorrow & 3 more radiations after today. Yay! | | |
| | yesterday was radiation & chemo - so I spent the day at the cancer center, mostly in some chair/bed or another! | | |
| | yesterday was a very long day = radiation, doctor & chemo so more | | |



L

| | difficult than others. also going on the downslope to finish |
|---|---|
| | treatments & have some anxiety about that. |
| | |
| | went to hospital last night. breathing problems |
| | in hospital |
| | hospital |
| | hospital |
| | hospital |
| | still in hospital; tests and pain |
| | hospital |
| | still in hospital; dealing with meds and options |
| | discharged; out of hospital |
| | out of hospital but sore back and side weak |
| | 1 |
| | surgery tomorrow |
| | blood transfusion yesterdayreally helped me |
| | Went to my oncology Dr's assistant today. She had good news concerning improvement in my chemo treatment progresswhich was pretty much important |
| | rough day. radiation twice today. good news is son-in-law will help with afternoon radiation soon thoughtakes pressure off my spouse been a good day; radiation machine was down this morning |
| | radiation at 7 am; saw radiation doctor after that who said chemo seemed to be workingcancer appears smaller! |
| | I'm hopeful my IV lasts through the week (this round of chemo); called my surgeon about my pain and got an appt with the surgeon tomorrow morning tumor continues to shrink |
| | Radiation was quick and easy. |
| | Today was a very long day. I had radiation then51/2 hours of chemo. It was a long, tiring day buy worth it! I know I can beat this! |
| | Thanks to God and from Grace received from Jesus Christ through working of the Holy Spirit I have received a letter from my doctor saying that my condition is improving and chemo therapy is working. |
| 1 | |



| | The doctor sent me a letter and a graft showing chemo therapy is working. Today is the day I have felt the best health-wise since I started treatments |
|----------------|---|
| | I am lucky they discovered this and I'm certain I can beat it! |
| | I wake up everyday with a positive attitude and just know that I'm gonna beat this cancer! |
| | I remain positive on a daily basis! I am halfway through this treatment and have high hopes that it is working! |
| Treatment side | the side effects of my chemo were awful |
| | side effects were awful and even though it has been a couple of weeks, the effects have not gone away |
| | |
| | I experienced some side effects today, namely nose bleeds. Gotta watch that. |
| | I am tethered to oxygen 24/7, and house bound due to immune compromise. It's hard to answer some of the questions at this stage. |
| | My partner has been having issues with skin breakdown on her foot (Type II). Dr. put her 2 antibiotics to speed up the healing. I've been very careful not to share or have contact with anything she uses. Today she had bad diarrhea, which kept me in a limited area of the house. Scared me about contaminants. |
| | A lot of the cough is allergy, I'm sure. New side effect - bruising from the least little bump. Platelet infusion scheduled for tomorrow. |
| | Steroids required for chemo kept me up and somewhat anxious most of the night. This side effect is quite frustrating. |
| | Steroids make me quite anxious and make sleeping problematic. On the other hand, they provide more energy. I will be off them after tonight. |
| | Yesterday was last day of steroids. |
| | First day of the more distressing side effects of the chemo |
| | Difficult day due to chemo side effects and other external stressors |
| | |



| | Side effects of weakness and emotional fragility decreasing. I should now have about 11 pretty good days until I start the cycle over |
|--|---|
| | had to have my hair on my head shaved off. This is the second time for this. last time was about 2 years ago. It was not as traumatic as it was before. I still did cry but said to myself "hey, I can rock a bald head" lol |
| | It would be good to suggest that individuals on long-term chemo keep a journal of treatments, side effects, etc. It all starts blending together and it is hard to remember whether worrying physical symptoms could be drug side effects or new cancer symptoms. |
| | I don't like staying home because I get bored. Having to carry daytime O2 is a new burden ordered in June and it really impedes leaving the house. Coughing has improved to just a short spasm in the early morning hours. I work at deep breathing all day. |
| | Since I don't feel ill, I have a hard time not being out with my friends. Chemo has taken every ounce of energy |
| | I've been in treatment prior and know that chemotherapy was the most difficult, took at least one week just to get up and the second week to start feeling good again. It's just about the same right now, the first week is extremely rough, second is just getting there I should be much better by the end of this week. |
| | My goals were to stop vomiting, hold water down! Pretty basic. feel like I'm going to barf; 6 hour chemo and radiation today |
| | Pretty good day - still feeling steroids from Tuesday chemo so more energy, etc. |
| | More pain & side effects influenced attitude & answers |
| | diarrhea |
| | hands and feet still hurting a lotnumb, feel frozen (side effect of chemo); have a hard time picking stuff up like my pills |
| | This is my 4th week of radiation and I am starting to feel tired and a little weak. |
| | I went to the Radiology Center yesterday and had an MRI with |



| contrast that is probably why I felt nauseated today. |
|---|
| cold sweats most of the day |
| dry heaves, diarrhea, temperature, eyes wept, throat is raw, coughed all through the night; if someone was older, I don't think I'd recommend chemo and radiationit is so hard |
| Yesterday was a rough day as I was nauseated and threw up and was very tired all day. |
| radiation after effects are really tough |
| 6 episodes of diarrhea today because of radiation. very exhausted; two long days |
| radiationmy skin is dry and my throat is raw |
| second worst day I've haddiarrhea every 2 hours (7 attacks), nauseated; thank God for the pills |
| I had acid reflux last night which caused me not to feel so good, however, I feel better today! |
| I am reacting well to my treatment. No sickness or hair loss yet. |
| Doctors and physician assistants should tell their patients who wear a tube in their stomachs to wear loose clothing around their tube area to avoid pain. I learned this the hard way. I was wearing a belt which I did not realize was putting pressure on my patch area and causing pain which I thought was coming from my recent chemo treatment. |
| I am getting a pain on upper and lower back. Also from my port area where the hose is mounted for when we have to drain my lungs from excessive water. Doctor said to drain every day for 3 days- then resume prior schedule of every 3 or 4 days. First drain produce full bag. Due to empty this afternoon about 7pm. |
| Today and yesterday were not good. I had a stomach ache. It is after 2pm and now I feel better. |
| Did not feel well today. Stomach upset. |
| I am wearing a port on my right side of my body. My wife uses it to drain fluid from my lungs every 3 or 4 daysespecially if I am |



| | going to get chemo treatment the next day. The port being there has a bearing on some of the questions concerning my physical activity. | | |
|--------------|---|--|--|
| Anxiety/Fear | Anxious on my 2nd chemo treatments | | |
| | I an exhausted, My sister will be going home one week from today. I am scared. | | |
| | I guess I am a little worried, I just don't seem to bounce back as quickly this time around, I am sure four years makes a difference. I am hopeful I will get through this. | | |
| | I am so tired I know if I want to do something, I plan to do one or two things and then I'm out of energy. I worry if my treatment will work, I am worried about how I will handle anymore. It just seems like it is taking much more out of me than four years ago. I definitely feel this round of chemo. | | |
| | I worry a lot about whether or not treatment will work how much time do I have, making sure each day counts. | | |
| | Again I worry, this is a totally different experience, my symptoms are so different. I am not feeling so great and my next chemo is Monday. The first time around, by the time I had chemo I was much stronger. | | |
| | Cough is somewhat worse the past few days. I hope it is just allergies! | | |
| | As I only have 2 more weeks of treatment left I am starting to get anxious of the outcome. In my heart and mind I feel I will beat this disease and live a lot longer! That is my hope! | | |
| Activities | Finally a better day was up and around lot of diapers but manageable went outside was the best day so far | | |
| | Each day I get stronger and able to do more. | | |
| | I am getting stronger every day. | | |
| | I spent today at home cleaning house as I was physically able. Pretty sure I stirred up some dust but most rooms seem better. Now I'm tired. My partner is in hospital and may be sent to rehab for follow-up. | | |
| | My son arrives tomorrow. My last chore is to make up his bed. I've had mucho back pain from my scoliosis. | | |



| Had a pleasant active day |
|---|
| Did a lot the last few days. Very tired today. |
| yesterday I ran a lot of errands with my sister. was very tired from it, but it was a good day |
| I felt very motivated today and did chores with my family. I had a good day today! |
| Today I did a load of laundry, dishes, we went for groceries and had an early dinner with some good friends. One of my best days since being "sick". |
| Had a great weekend and I've been feeling good and I'm prepared for these next 3 weeks of treatment! My husband and I even went to a movie yesterday afternoon! |
| Today was another good day as I am feeling good! I had a visit from a co-worker today which was very nice! |
| It was a wonderful day today. A great get together with my family, especially my 5 great grandkids. I'm doing great! |
| I look at my cancer as looking at life in a different light. I seem to enjoy certain things more- like family and friends. I don't seem to focus on my cancer too much. I know it's there but I don't linger on the thought. I focus more on family- graduations- reunions, and such. |
| had a good time with daughter last nightgood food from church; in touch with my family |
| family Thanksgiving was unreallots of blessings and encouragement another wonderful day |
| This has been a good day. Had fun with my sweetie and still in a good mood. |
| Good day- Lots of laughter |
| Was able to do work my usual circle in my pasture only oncefelt weak and came in house to fill out this form |
| |



| | used to being healthy and active. walk dog, cook, clean, move freely without pain. | |
|---|---|--|
| Impact on Others husband was acting like this is my fault | | |
| | used to being healthy and active. walk dog, cook, clean, move freely without pain. not have to ask husband to help or else do it all for me today. feel like a real burden to him. thankful he is a patient loving man | |
| | husband is sick; argument (tension with husband) | |
| | My family is taking care of me. I am not taking care of them. | |



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Figure 1.

Participant Recruitment and Retention





Figure 2.

Average Number of Minutes per Day to Complete Each Diary in the Retained Sample (N = 50)





Figure 3.

Frequency of "Quite a bit" or "Very much" Symptom Severity Endorsement across 21-Day Diary





Figure 4.

Interaction between Treatment Day and Daily Hope on Daily Social/Role Functioning



Treatment Day X Daily Hope



Table 1

| | Overall Sample $(n = 5)$ | Consented 6) | Sample Re $(n = 5)$ | tained* |
|---------------------------|--------------------------|--------------|--------------------------|-----------|
| Study Variable | Mean (SD) | % (n) | Mean (SD) | % (n) |
| Age (years) | 68.29 (9.47) | | 68.66 (8.78) | |
| Sex | | | | |
| Female | | 57.1 (32) | | 58.0 (29) |
| Ethnicity | | | | |
| Hispanic | | 14.3 (8) | | 16.0 (8) |
| non-Hispanic | | 82.1 (46) | | 80.0 (40) |
| Missing (refused) | | 3.6 (2) | | 4.0 (2) |
| Race | | | | |
| Caucasian | | 82.1 (46) | | 80.0 (40) |
| African American | | 3.6 (2) | | 4.0 (2) |
| Native American | | 5.4 (3) | | 6.0 (3) |
| Asian/Pacific Islander | | 3.6 (2) | | 4.0 (2) |
| Other | | 1.98(1) | | 2.0 (1) |
| Missing (refused) | | 3.6 (2) | | 4.0 (2) |
| Highest Education (Years) | 13.54 (2.73) | | 13.48 (2.04) | |
| Annual Income (\$) | 43,671.85 (38,215.40) | | 38,662.91 (29,108.87) | |
| Lung Cancer Subtype | | | | |
| Non-small cell | | 75.0 (42) | | 78.0 (39) |
| Small-cell | | 25.0 (14) | | 22.0 (11) |
| Lung Cancer Stage | | | | |
| IIIA NSLC | | 19.6 (11) | | 22.0 (11) |
| IIIB NSCLC | | 5.4 (3) | | 6.0 (3) |
| IV NSCLC | | 50.0 (28) | | 50.0 (25) |
| Limited (SCLC) | | 5.4 (3) | | 6.0 (3) |
| (Table continues) | | | | |



| Tabl | e 1. | Continued |
|------|------|-----------|
| | | |

| Extensive (SCLC) | | 19.6 (11) | | 16.0 (8) |
|---------------------------------------|--------------------|-----------|--------------------|-----------|
| Current Treatment | | | | |
| Chemotherapy | | 53.6 (30) | | 52.0 (26) |
| Chemoradiotherapy | | 32.1 (18) | | 32.0 (16) |
| Radiation | | 8.9 (5) | | 10.0 (5) |
| Chemotherapy, radiation, and surgery | | 1.8 (1) | | 2.0 (1) |
| Surgery and radiation | | 1.8 (1) | | 2.0 (1) |
| Surgery | | 1.8 (1) | | 2.0 (1) |
| Days since diagnosis | 153.06 (202.88) | | 161.17 (209.47) | |
| ECOG Performance Status | | | | |
| 0 | | 17.9 (10) | | 20.0 (10) |
| 1 | | 55.4 (31) | | 54.0 (27) |
| 2 | | 26.8 (15) | | 26.0 (13) |
| Brain Metastases | | | | |
| Yes | | 23.2 (13) | | 20.0 (10) |
| Whole Brain Radiotherapy | | | | |
| Yes | | 19.6 (11) | | 19.6 (9) |
| Current Smoking Status | | | | |
| Currently smoking | | 14.3 (8) | | 14.0 (7) |
| Pack Years | 46.19 (39.43) | | 45.51 (40.06) | |
| Marital Status | | | | |
| Married currently/living with partner | | 58.9 (33) | | 62.0 (31) |

(Table continues)



Table 1 Continued

Note. ECOG = European Cooperative Oncology Group; Pack years = number of packs a day divided by the number of years a person has smoked. *To be retained in the sample for daily diary analysis, minimum number of days completed = 7.



Table 2

Descriptive Statistics of Predictor Variables and Clinical Characteristics

| | Overall Sample Consented $(n = 56)$ | | Sample Retained* (n = 50) | |
|--------------------------------|-------------------------------------|-----------|------------------------------|-----------|
| Study Variable | Mean (SD) | % (n) | Mean (SD) | % (n) |
| Depression | 5.48 (3.90) | | 5.34 (3.99) | |
| \geq 8 (Probable depression) | | 33.9 (19) | | 34.0 (17) |
| Anxiety | 5.57 (4.11) | | 5.22 (4.09) | |
| \geq 8 (Probable anxiety) | | 32.1 (18) | | 28.0 (14) |
| FACT-G | 74.83 (17.13) | | 75.04 (17.27) | |
| TOI | 52.05 (16.45) | | 52.20 (16.54) | |
| FACT-L | 92.11 (21.12) | | 92.45 (21.27) | |
| Lung Cancer Scale (FACT) | 17.59 (5.85) | | 17.77 (5.89) | |
| Lung Cancer Stigma | 47.21 (16.56) | | 45.22 (13.88) | |
| EORTC-QLQ-30 Symptom Scales | | | | |
| Dyspnea (EORTC) | 43.64 (36.22) | | 42.86 (36.64) | |
| Fatigue (EORTC) | 52.38 (27.36) | | 52.00 (28.26) | |
| Nausea/Vomiting | 13.69 (20.62) | | 12.33 (18.69) | |
| Pain | 34.24 (33.09) | | 33.67 (32.72) | |
| Insomnia | 35.71 (31.69) | | 34.00 (29.73) | |
| Appetite Loss | 32.74 (30.15) | | 30.67 (29.23) | |
| Constipation | 32.74 (36.23) | | 31.33 (35.89) | |
| Diarrhea | 13.10 (22.63) | | 14.00 (23.42) | |
| Financial Difficulty | 32.14 (37.04) | | 34.00 (37.79) | |
| EORTC-QLQ-30 Functional Scales | | | | |
| Physical Functioning | 59.88 (22.97) | | 59.33 (22.79) | |
| Role Functioning | 53.27 (34.59) | | 53.33 (34.83) | |
| Emotional Functioning | 71.97 (23.71) | | 74.61 (22.48) | |
| (Table Continues) | | | | |



Table 2 Continued

| Cognitive Functioning | 72.62 (24.29) | 73.00 (23.78) |
|-----------------------|---------------|---------------|
| Social Functioning | 59.52 (29.28) | 59.67 (29.37) |
| Hope (baseline) | 25.71 (3.06)_ | 25.65 (3.03) |
| Neuroticism | 16.98 (4.28) | 16.72 (4.39) |
| Optimism | 3.84 (0.72) | 45.22 (13.88) |

Note. *To be retained in the sample for daily diary analysis, minimum number of days completed = 7.


| Frediciors of the Number of Days Completed in Diary | | | | | | | |
|---|--------------|-------|---------------|--|--|--|--|
| Study Variable | B (SE) | р | 95% CI | | | | |
| Intercept | 18.07 (4.36) | <.001 | [9.32, 26.82] | | | | |
| ECOG performance status | -0.19 (1.35) | .888 | [-2.90, 2.52] | | | | |
| Baseline quality of life | 0.03 (0.05) | .514 | [-0.07, 0.14] | | | | |
| Concurrent chemoradiotherapy | -0.27 (1.83) | .882 | [-3.94, 3.40] | | | | |
| Diary administration method | -3.19 (1.84) | .089 | [-3.94, 3.40] | | | | |

Predictors of the Number of Days Completed in Diary

Note. ECOG = European Cooperative Oncology Group (0-2); Baseline quality of life measured by Functional Assessment of Cancer Therapy - General; concurrent chemoradiotherapy received = 1; not received = 0; Daily administration method of paper (1) or online/phone (0); Subtype (0 = small cell; 1 = non-small cell)



| | $\frac{M}{(SD)}$ | "Not at all" | "A little" | "Quite a Bit" | "Very Much" | Missing |
|---|------------------|-----------------|----------------|------------------|----------------|--------------|
| Scale Item | | (n, %) | | | | |
| Did you need to stay in a bed or chair? | 2.04 | 385 | 207 | 205 | 113 | 40 |
| | (1.02) | (36.6%) | (29.2%) | (19.5%) | (10.8%) | (3.8%) |
| Were you limited in either doing your work or other daily activities? | 2.14 (0.92) | 255 (24.3%) | 463 (44.1%) | 182 (17.3%) | 106 (10.1%) | 45 (4.3) |
| Were you limited in pursuing your hobbies or other leisure activities? | 2.16 (0.97) | 284 (27.0%) | 402 (38.2%) | 202 (19.2%) | 122 (11.6%) | 40 (3.8%) |
| Has your physical condition or medical treatment interfered with your family life today? | 1.68 (0.88) | 551 (52.4%) | 284 (27.0%) | 116 (11.0%) | 56 (5.3%) | 44 (4.2%) |
| Has your physical condition or medical treatment interfered with your social life today? | 1.83 (0.99) | 502 (47.8%) | 277 (26.4%) | 142 (13.5%) | 93 (8.8%) | 37 (3.5%) |
| How much did you cough? | 1.96 | 289 | 521 | 167 | 41 | 33 |
| | (0.79) | (27.5%) | (49.6%) | (15.9%) | (3.9%) | (3.1%) |
| Were you short of breath? | 1.91 | 384 | 411 | 154 | 69 | 33 |
| | (0.89) | (36.5%) | (39.1%) | (14.7%) | (6.6%) | (3.1%) |
| Did you have pain? | 1.87 | 487 | 269 | 167 | 92 | 36 |
| | (1.00) | (46.3%) | (25.6%) | (15.9%) | (8.8%) | (3.4%) |
| Did you feel weak? | 2.26 | 202 | 479 | 206 | 131 | 33 |
| | (0.92) | (19.2%) | (45.6%) | (19.6%) | (12.5%) | (3.1%) |
| Did you lack appetite? | 1.68 | 570 | 261 | 120 | 65 | 35 |
| | (0.92) | (54.2%) | (24.8%) | (11.4%) | (6.2%) | (3.3%) |
| Did you feel nauseated? | 1.38 | 757 | 161 | 44 | 47 | 42 |
| | (0.78) | (72.0%) | (15.3%) | (4.2%) | (4.5%) | (4.0%) |
| Were you tired? | 2.53 | 92 | 473 | 260 | 188 | 37 |
| | (0.90) | (8.8%) | (45.0%) | (24.7%) | (17.9%) | (3.5%) |

Average and Distribution of Functioning from Daily FACT-G Assessment and Lung Cancer Symptoms in Daily Diary Sample



Correlations between Study Variables in Diary Sample

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 |
|----------------------------|--------|--------|-------|--------|--------|--------|-------|-----|--------|--------|--------|--------|-------|-----|--------|--------|
| Level 2 | | | | | | | | | | | | | | | | |
| 1. Hope | | | | | | | | | | | | | | | | |
| 2. Stigma | 41*** | | | | | | | | | | | | | | | |
| 3. Age | 11*** | 04 | | | | | | | | | | | | | | |
| 4. Tx type | 07* | .19*** | 02 | | | | | | | | | | | | | |
| 5. Physical Symptoms | 36*** | .41*** | 19*** | .13*** | | | | | | | | | | | | |
| 6. Depression | 44*** | .40*** | .01 | .20*** | .39*** | | | | | | | | | | | |
| 7. Anxiety | 29*** | .31*** | 16*** | .06+ | .39*** | .43*** | | | | | | | | | | |
| 8. Days since diagnosis | .16*** | .13*** | 02 | 26*** | .07* | .07* | .01 | | | | | | | | | |
| 9. Hope | .00 | .00 | .00 | .00 | .00 | .00 | .00 | 01 | | | | | | | | |
| 10. Stigma | .00 | .00 | .00 | .00 | .00 | .00 | .00 | .00 | 02 | | | | | | | |
| 11. Physical Symptoms | .00 | .00 | .00 | .00 | .00 | .00 | .00 | .00 | 20*** | .23*** | | | | | | |
| 12. Positive affect | .00 | .00 | .00 | .00 | .00 | .00 | .00 | .00 | .29*** | 24*** | 52*** | | | | | |
| 13. Negative affect | .00 | .00 | .00 | .00 | .00 | .00 | .00 | .00 | 14*** | .25*** | .29*** | 38*** | | | | |
| 14.Tx day | .06+ | .07* | 05+ | .35*** | 05 | 04 | 13*** | 05 | .01 | 02 | 02 | .01 | .06+ | | | |
| 15.Social/role functioning | .51*** | 37*** | 01 | 18*** | 59*** | 42*** | 43*** | .00 | .16*** | 12*** | 30*** | .30*** | 16*** | .00 | | |
| 16. Palliative well-being | .59*** | 48*** | .03 | 16*** | 37*** | 50*** | 27*** | .02 | .17*** | 09* | 14*** | .23*** | 10** | .02 | .59*** | |
| 17. Physical functioning | .32*** | 24*** | 04 | 24*** | 60*** | 48*** | 29*** | 05 | .12*** | 08* | 29*** | .26*** | 14*** | .00 | .71*** | .40*** |
| (Table Continu | ies) | | | | | | | | | | | | | | | |



Table 5 Continued

Note. Tx type = Treatment type (0 = not concurrent chemoradiotherapy; 1 = concurrent chemoradiotherapy); Tx day = Treatment day <math>(0 = not a treatment day; 1 = treatment day).

Level-2 variables: (Age was grand mean centered; Depression and anxiety were centered on value of "8" to indicate clinical caseness; Other level-2 variables were person averages on the diary). Level-1 variables: Days since diagnosis was continuous (i.e., day +1, day +2, etc.); Predictor variables were person-mean centered (i.e., score – person mean); Dependent level-1 variables not person-mean centered.

***Significant at .001 level, **Significant at the .01 level, *Significant at the .05 level., + = p < .10



| | | | | % CI |
|-----------------------------|----------------|-------|--------|--------|
| Study Variable | Estimate (SE) | р | LL | UL |
| Fixed Effects | | | | |
| Intercept | 65.00 (8.29) | <.001 | 48.76 | 81.25 |
| Days since diagnosis | -0.01 (0.01) | .588 | -0.02 | 0.01 |
| Treatment day | -1.03 (1.04) | .322 | -3.08 | 1.01 |
| Daily hope | 2.36 (0.70) | .001 | 1.00 | 3.73 |
| Daily stigma | -3.64 (1.60) | .023 | -6.78 | -0.51 |
| Daily positive affect | 8.31 (0.95) | <.001 | 6.45 | 10.17 |
| Daily negative affect | -1.87 (1.42) | .189 | -4.65 | 0.92 |
| Daily hope X treatment day | 3.33 (1.25) | .008 | 0.88 | 5.77 |
| Daily physical symptoms | -17.37 (2.63) | <.001 | -22.52 | -12.22 |
| Average hope | 5.06 (1.37) | <.001 | 2.37 | 7.75 |
| Average stigma | -1.43 (4.57) | .755 | -13.19 | 7.52 |
| Age | -0.24 (0.22) | .293 | -0.61 | 0.18 |
| Treatment type | -4.04 (3.89) | .299 | -11.66 | 2.35 |
| Average physical symptoms | -21.66 (3.85) | <.001 | -29.22 | -14.11 |
| Baseline anxiety | -1.22 (0.48) | .010 | -2.16 | -0.29 |
| Random Effects | | | | |
| Residual (Level 2 intercept | 136.60 (6.77) | | 73.52 | 183.48 |
| Intercent variance | 128 50 (28.05) | | 18 76 | 82.25 |
| Intercept Variance | -3.58 (20.03) | | -62 70 | 55.63 |
| Slope | 138.45 (58.76) | | 23.29 | 253.61 |
| - | . , | | | |

Predictors of Daily Functioning (role and social)



| | | · | 95% CI | | | |
|-----------------------------|----------------|-------|--------|--------|--|--|
| Study Variable | Estimate (SE) | р | LL | UL | | |
| Fixed Effects | | | | | | |
| Intercept | 42.43 (13.56) | .002 | 30.14 | 53.91 | | |
| Days since diagnosis | -0.001 (0.01) | .812 | -0.01 | 0.01 | | |
| Treatment day | -0.71 (1.27) | .576 | -3.20 | 1.78 | | |
| Daily hope | 1.29 (0.73) | .078 | -0.14 | 2.72 | | |
| Daily stigma | -2.83 (1.93) | .141 | -6.61 | 0.94 | | |
| Daily positive affect | 0.71 (1.23) | .564 | -1.70 | 3.11 | | |
| Daily negative affect | 1.02 (1.73) | .554 | -2.37 | 4.41 | | |
| Daily functioning | 0.35 (0.05) | <.001 | 0.26 | 0.44 | | |
| Daily physical symptoms | -7.71 (2.68) | .004 | -12.96 | -2.45 | | |
| Average hope | 3.37 (0.90) | <.001 | 1.60 | 5.14 | | |
| Average stigma | -1.86 (3.06) | 0.543 | -7.85 | 4.43 | | |
| Age | -0.17 (0.13) | .184 | -0.42 | 0.08 | | |
| Treatment type | -2.78 (2.46) | .259 | -7.60 | 2.04 | | |
| Average physical symptoms | -13.91 (2.68) | <.001 | -19.17 | -8.66 | | |
| Baseline anxiety | -0.72 (0.30) | .017 | -1.32 | -0.13 | | |
| Random Effects | | | | | | |
| Residual (Level 2 intercept | 194.09 (10.08) | | 174.34 | 213.85 | | |
| variance) | | | | | | |
| Intercept variance | 42.43 (13.56) | | 30.14 | 53.91 | | |
| Intercept-Slope covariance | 10.18 (19.35) | | -27.75 | 48.11 | | |
| Slope | 60.51 (35.58) | | -9.23 | 130.25 | | |

Predictors of Next Day Daily Functioning (role and social)



| | | | | 959 | % CI |
|-----------------------------|--------|----------|-------|---------|--------|
| Study Variable | Estima | te (SE) | р | LL | UL |
| Fixed Effects | | | | | |
| Intercept | 85.47 | (10.33) | <.001 | 65.22 | 105.72 |
| Days since diagnosis | -0.01 | (0.01) | .280 | -0.04 | 0.01 |
| Treatment day | -0.08 | (1.44) | 0.957 | -2.90 | 2.74 |
| Daily hope | 2.27 | (0.81) | .005 | 0.68 | 3.87 |
| Daily stigma | 1.15 | (2.20) | .600 | -3.16 | 5.47 |
| Daily positive affect | 8.64 | (1.31) | <.001 | 6.08 | 11.19 |
| Daily negative affect | -1.57 | (1.96) | .422 | -5.41 | 2.26 |
| Daily physical symptoms | -26.11 | (3.67) | <.001 | -33.30 | -18.92 |
| Average hope | 1.48 | (1.81) | .323 | -1.75 | 5.32 |
| Average stigma | 8.28 | (5.79) | .152 | -3.06 | 19.63 |
| Age | -0.56 | (0.26) | .034 | -1.08 | -0.04 |
| Treatment type | -10.11 | (4.95) | .041 | -19.81 | -0.41 |
| Average physical symptoms | -32.06 | (4.83) | <.001 | -41.52 | -22.60 |
| Baseline depression | -1.78 | (0.67) | .008 | -3.10 | -0.46 |
| Random Effects | | | | | |
| Residual (Level 2 intercept | 259.42 | (12.85) | | 234.24 | 284.61 |
| variance) | | | | | |
| Intercept variance | 215.30 | (47.44) | | 122.31 | 308.28 |
| Intercept-Slope covariance | -77.48 | (58.28) | | -191.70 | 36.74 |
| Slope | 282.59 | (104.57) | | 77.62 | 487.55 |



| | | | 95% | % CI |
|-----------------------------|----------------|-------|---------|--------|
| Study Variable | Estimate (SE) | р | LL | UL |
| Fixed Effects | | | | |
| Intercept | 62.35 (8.95) | <.001 | 44.80 | 79.89 |
| Days since diagnosis | -0.01 (0.01) | .399 | -0.03 | 0.01 |
| Treatment day | 0.39 (1.75) | .822 | -3.04 | 3.83 |
| Daily hope | -0.70 (0.98) | .473 | -2.62 | 1.22 |
| Daily stigma | -2.21 (2.61) | .397 | -7.32 | 2.90 |
| Daily positive affect | 0.30 (1.63) | .852 | -2.89 | 3.49 |
| Daily negative affect | 4.01 (2.35) | .089 | -0.61 | 8.62 |
| Daily functioning | 0.27 (0.05) | <.001 | 0.18 | 0.36 |
| Daily physical symptoms | -12.16 (3.58) | <.001 | -19.14 | -5.12 |
| Average hope | 1.18 (1.40) | .398 | -1.56 | 3.92 |
| Average stigma | 5.93 (4.39) | .177 | -2.67 | 14.53 |
| Age | -0.45 (0.20) | .025 | -0.85 | -0.06 |
| Treatment type | -7.39 (3.88) | .057 | -15.00 | 0.21 |
| Average physical symptoms | -23.68 (4.10) | <.001 | -31.71 | -15.64 |
| Baseline depression | -1.49 (0.52) | .004 | -2.50 | -0.48 |
| Random Effects | | | | |
| Residual (Level 2 intercept | 362.68 (18.87) | | 325.69 | 399.67 |
| variance) | | | | |
| Intercept variance | 105.35 (30.31) | | 45.93 | 164.77 |
| Intercept-Slope covariance | -38.85 (39.84) | | -116.93 | 39.23 |
| Slope | 91.20 (61.74) | | -29.81 | 212.22 |

Predictors of Next Day Physical Functioning



| | | | 95% CI | | | |
|-----------------------------|----------------|-------|--------|-------|--|--|
| Study Variable | Estimate (SE) | р | LL | UL | | |
| Fixed Effects | | | | | | |
| Intercept | 16.19 (2.14) | <.001 | 12.00 | 20.38 | | |
| Days since diagnosis | -0.001 (0.002) | .808 | -0.01 | 0.004 | | |
| Treatment day | -0.45 (0.22) | .041 | -0.89 | -0.02 | | |
| Daily hope | 0.91 (0.13) | <.001 | 0.66 | 1.16 | | |
| Daily stigma | -0.80 (0.34) | .019 | -1.46 | -0.13 | | |
| Daily positive affect | 2.05 (0.20) | <.001 | 1.66 | 2.45 | | |
| Daily negative affect | 0.10 (0.30) | .737 | -0.49 | 0.70 | | |
| Daily physical symptoms | 0.01 (0.53) | .984 | -1.02 | 1.05 | | |
| Average hope | 1.54 (0.37) | <.001 | 0.81 | 2.26 | | |
| Average stigma | -3.37 (1.20) | .005 | -5.73 | -1.01 | | |
| Age | 0.06 (0.05) | .236 | -0.04 | 0.17 | | |
| Treatment type | -0.53 (1.02) | .606 | -2.52 | 1.47 | | |
| Average physical symptoms | -0.99 (1.07) | .355 | -3.10 | 1.11 | | |
| Baseline anxiety | 0.11 (0.13) | .390 | -0.14 | 0.35 | | |
| Baseline depression | -0.38 (0.15) | .009 | -0.66 | -0.09 | | |
| Random Effects | | | | | | |
| Residual (Level 2 intercept | 6.22 (0.31) | | 5.61 | 6.82 | | |
| variance) | | | | | | |
| Intercept variance | 9.34 (2.02) | | 5.37 | 13.30 | | |
| Intercept-Slope covariance | 2.47 (1.81) | | -1.07 | 6.01 | | |
| Slope | 4.97 (2.20) | | 0.66 | 9.27 | | |

Predictors of Palliative Wellbeing



| | | | 95% | 6 CI |
|-----------------------------|---------------|-------|--------|-------|
| Study Variable | Estimate (SE) | р | LL | UL |
| Fixed Effects | | | | |
| Intercept | 8.73 (1.45) | <.001 | 5.90 | 11.57 |
| Days since diagnosis | 0.00 (0.001) | .931 | -0.003 | 0.003 |
| Treatment day | -0.15 (0.25) | .544 | -0.63 | 0.34 |
| Daily hope | 0.13 (0.14) | .379 | -0.15 | 0.40 |
| Daily stigma | -0.34 (0.37) | .361 | -1.06 | 0.38 |
| Daily positive affect | 0.49 (0.24) | .037 | 0.03 | 0.96 |
| Daily negative affect | 0.29 (0.33) | .382 | -0.36 | 0.94 |
| Daily palliative wellbeing | 0.46 (0.04) | <.001 | 0.38 | 0.55 |
| Daily physical symptoms | 0.34 (0.48) | .485 | -0.61 | 1.28 |
| Average hope | 0.88 (0.24) | <.001 | 0.40 | 1.35 |
| Average stigma | -1.71 (0.71) | .016 | -3.10 | -0.32 |
| Age | 0.03 (0.03) | .372 | -0.03 | 0.09 |
| Treatment type | -0.46 (0.60) | .440 | -1.64 | 0.71 |
| Average physical symptoms | -0.81 (0.60) | .175 | -1.98 | 0.36 |
| Baseline anxiety | 0.06 (0.07) | .404 | -0.08 | 0.20 |
| Baseline depression | -0.16 (0.09) | .063 | -0.33 | 0.01 |
| Random Effects | | | | |
| Residual (Level 2 intercept | 7.09 (0.37) | | 6.37 | 7.81 |
| variance) | | | | |
| Intercept variance | 2.70 (0.78) | | 1.17 | 4.22 |
| Intercept-Slope covariance | 0.24 (0.83) | | -1.39 | 1.88 |
| Slope | 1.70 (1.20) | | -0.65 | 4.06 |

Predictors of Next Day Palliative Wellbeing



| | | | 959 | % CI |
|---------------------------------|---------------|-------|--------|-------|
| Study Variable | Estimate (SE) | р | LL | UL |
| Fixed Effects | | | | |
| Intercept | -0.34 (1.23) | .784 | -2.77 | 2.06 |
| Days since diagnosis | 0.001 (0.001) | .377 | -0.001 | 0.002 |
| Treatment day | 0.02 (0.06) | .684 | -0.09 | 0.14 |
| Daily positive affect | 0.10 (0.06) | .101 | -0.02 | 0.20 |
| Daily social/role functioning | 0.01 (0.002) | <.001 | 0.004 | 0.01 |
| Daily physical functioning | 0.002 (0.001) | .171 | -0.001 | 0.01 |
| Daily palliative wellbeing | 0.05 (0.01) | <.001 | 0.04 | 0.07 |
| Daily physical symptoms | 0.05 (0.17) | .779 | -0.28 | 0.38 |
| Age | -0.02 (0.02) | .375 | -0.05 | 0.02 |
| Treatment type | 0.20 (0.32) | .525 | -0.42 | 0.82 |
| Average physical symptoms | 0.17 (0.44) | .696 | -0.70 | 1.04 |
| Baseline depression | -0.03 (0.05) | .557 | -0.13 | 0.07 |
| Average social/role functioning | 0.03 (0.01) | .039 | 0.001 | 0.05 |
| Average physical functioning | -0.01 (0.01) | .642 | -0.02 | 0.02 |
| Average palliative wellbeing | 0.14 (0.04) | .001 | 0.06 | 0.22 |
| Random Effects | | | | |
| Residual (Level 2 intercept | 0.42 (0.02) | | 0.38 | 0.46 |
| variance) | | | | |
| Intercept variance | 0.89 (0.20) | | 0.51 | 1.27 |
| Intercept-Slope covariance | 0.24 (0.16) | | -0.08 | 0.55 |
| Slope | 0.67 (0.23) | | 0.22 | 1.13 |



| | | | | 95% | % CI |
|---------------------------------|--------|---------|-------|--------|-------|
| Study Variable | Estima | te (SE) | р | LL | UL |
| Fixed Effects | | | | | |
| Intercept | -0.45 | (0.74) | .537 | -1.87 | 0.99 |
| Days since diagnosis | 0.001 | (0.00) | .027 | 0.000 | 0.002 |
| Treatment day | -0.05 | (0.06) | .419 | -0.16 | 0.07 |
| Daily positive affect | 0.01 | (0.05) | .910 | -0.10 | 0.11 |
| Daily social/role functioning | 0.003 | (0.002) | .114 | -0.001 | 0.01 |
| Daily physical functioning | -0.001 | (0.001) | .601 | -0.003 | 0.002 |
| Daily palliative wellbeing | 0.03 | (0.01) | .003 | 0.01 | 0.04 |
| Daily hope | 0.43 | (0.04) | <.001 | 0.36 | 0.50 |
| Daily physical symptoms | 0.13 | (0.13) | .328 | -0.14 | 0.36 |
| Age | -0.01 | (0.01) | .264 | -0.03 | 0.01 |
| Treatment type | 0.22 | (0.19) | .232 | -0.14 | 0.59 |
| Average physical symptoms | 0.13 | (0.27) | .627 | -0.39 | 0.65 |
| Baseline depression | -0.02 | (0.03) | .459 | -0.08 | 0.04 |
| Average social/role functioning | 0.01 | (0.01) | .084 | -0.002 | 0.03 |
| Average physical functioning | 0.000 | (0.01) | .993 | -0.01 | 0.01 |
| Average palliative wellbeing | 0.08 | (0.03) | .001 | 0.03 | 0.13 |
| Random Effects | | | | | |
| Residual (Level 2 intercept | 0.38 | (0.02) | | 0.34 | 0.41 |
| variance) | | | | | |
| Intercept variance | 0.29 | (0.07) | | 0.14 | 0.43 |
| Intercept-Slope covariance | 0.04 | (0.07) | | -0.09 | 0.17 |
| Slope | 0.21 | (0.12) | | -0.02 | 0.44 |

Predictors of Next Day Hope

