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The Relationships Among Pain, Dyspnea, Constipation and Quality of Life in Lung Cancer Patients Enrolled in a Hospice Program

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The Relationships Among Pain, Dyspnea, Constipation and Quality of Life in Lung
Cancer Patients Enrolled in a Hospice Program

by

Lisa A. Laches

A thesis submitted in partial fulfillment
of the requirements for the degree of
Masters of Science
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ABSTRACT

There is evidence of a relationship between pain and associated symptoms, specifically constipation and dyspnea, and quality of life. Literature supports that end-stage lung cancer patients suffer more symptoms than those with other types of cancers, and the course of treatment is primarily palliative, as many of these diagnosed patients cannot be cured. The purpose of this secondary analysis of data was to evaluate the relationships between pain and other common symptoms in end stage lung cancer patients in hospice care, and the relationships among pain, dyspnea, constipation and quality of life. The study sample included fifty lung cancer patients admitted to a hospice program, reporting pain. A series of Pearson's correlations were used to analyze relationships between the variables pain intensity, pain distress, dyspnea intensity, dyspnea distress, constipation intensity and the relationships of these variables with quality of life. The results showed positive significant correlations between pain intensity and pain distress ($r = .44, p = .002$), dyspnea intensity and dyspnea distress ($r = .47, p = .001$), and constipation intensity and quality of life ($r = -.57, p = .013$). Pain and the relief of pain have been studied extensively in cancer patients, yet little research has been done in the way of side effects of opioid use, specifically constipation. This study reinforces to

nursing the importance of a thorough assessment upon admission to hospice, and at each subsequent nursing visit, which includes a bowel habit history, current medications in use, potential risk for developing constipation and management of constipation once it is present.

Hospice patients with lung cancer are reporting a decrease in quality of life secondary to constipation. Prevention or rapid alleviation of this symptom will provide comfort and allow the patient to focus on important end of life tasks.

Chapter I

Introduction

Lung cancer is the leading cause of cancer death for both men and women, and is the most common malignancy worldwide (Potter & Higginson, 2003). The American Cancer Society (ACS) reports that for the year 2007 there will be about 213,380 new cases of lung cancer in the United States: 114,760 among men and 98,620 among women. About 160,390 people will die of this disease including 89,510 men and 70,380 women. About six out of ten people with lung cancer die within one year of being diagnosed. Between seven and eight out of ten will die within two years (ACS, 2007). The healthcare industry serves a large number of lung cancer patients, in either the curative or palliative phase of treatment. The ability to properly assess, treat and manage pain and disease related symptoms is a crucial component to quality of life improvement.

Medical advances such as chemotherapy, radiation therapy and surgery have provided better tumor response rates, but have demonstrated little effect in overall survival (Knop, 2005). The fact that the majority of lung cancer patients present with advanced stages of disease and receive palliative or hospice care despite curative treatment options, demonstrates the importance of symptom relief (Potter et al., 2003; Cooley, 2000).

Many patients newly diagnosed with lung cancer present with advanced disease, and have more symptoms than patients who are newly diagnosed with other types of

cancer (Gift, Jablonski, Stommel & Given, 2004). Uncontrolled pain and the multiple symptoms associated with lung cancer complicate a terminal prognosis. It is distressing for family members to conceptualize suffering and symptoms associated with pain can prevent patients from enjoying acceptable levels of quality in the remaining months of life (Lobchuk, Degner, Chateau & Hewitt, 2006; McMillan & Weitzner, 2000). Prevalence of pain in end-stage lung cancer patients ranges from forty to ninety percent, and can be caused by the cancer itself or as a result of the therapies used to treat or palliate the disease process (Knop, 2005). Pain is one of the most feared symptoms of a lung cancer diagnosis (Potter, Hami, Bryan & Quiqley, 2003). The notable predominance of palliation versus cure of lung cancer disease demonstrates the need for symptom management to be a priority (Potter et al., 2003; Tishelman, Degner, Rudman, Bertilsson, Bond, & Broberger, et al., 2005).

Problem statement

While there has been a great deal of research investigating single signs and symptoms, such as pain or dyspnea, there is little research regarding assessment and management of concurrent symptoms associated with pain in end stage lung cancer. Symptoms that occur concurrently with pain in lung cancer are often not recognized or assessed. This may be due to barriers created by both the healthcare system and the patients themselves (Paice, 2004). By identifying these symptoms, the provider can thoroughly assess general health status, and plan a course of treatment. Concurrent symptoms can have an adverse effect on patient outcomes and an overall decrease in quality of life (Dodd, Miaskowski & Paul, 2001). Therefore, it is critical for a complete assessment to incorporate all limitations and concerns. The purpose of this study was to

evaluate the relationships between pain and other common symptoms in end stage lung cancer patients in hospice care, and the relationships between pain, dyspnea and constipation on quality of life.

Research Objectives

The following objectives will guide the study:

1. To identify the incidence and intensity of pain and symptoms related to pain, specifically, constipation and dyspnea, in a sample of hospice patients with end stage lung cancer.
2. To examine the relationships between pain intensity and the following variables: pain distress, and dyspnea distress in a sample of hospice patients with end stage lung cancer.
3. To examine the relationships between pain distress and the following variables: pain intensity, dyspnea intensity and constipation intensity.
4. To examine the relationships between total quality of life scores and the following variables: pain intensity, pain distress, dyspnea intensity, dyspnea distress, and constipation intensity in a sample of hospice patients with end stage lung cancer.

Definition of Terms

For purposes of this study, the following terms are defined:

1. *Pain* is defined as nociceptive, by referring to somatic or visceral pain, or neuropathic, relating to peripheral or central nerve damage. Approximately sixty percent of lung cancer patients experience nociceptive pain, while thirty percent report neuropathic pain (Wilkie, Huang, Reilly & Cain, 2001).
2. *Dyspnea* is one of the most common subjectively perceived symptoms of advanced cancer, and is defined as an “uncomfortable sensation of breathing” (Manning &

Schwartzstein, 1995). There are multiple contributing factors to this subjective sensation such as previous life experience, cultural background, and psychological state, all which can increase or decrease the perception of dyspnea (Ripamonti & Bruera, 1997).

3. *Constipation* is defined as a decreased frequency in the passage of formed stools, and is further characterized by hard stools that are difficult to pass (McMillan, 2002).
4. *Quality of life* is defined as a multifaceted concept, comprised of various dimensions that make life worth living (McMillan & Weitzner, 1998; Gralla & Thatcher, 2004). The concept of quality of life is further defined as being both subjective (what the patient is experiencing) and multidimensional (various aspects of personal well-being) (McMillan et al., 1998).

Significance to Nursing

Much research has been done in regard to pain, resulting in the creation of a large variety of pain assessment tools and the development of evidence-based practice protocols, such as the World Health Organization (WHO) pain ladder (WHO, 2007).

Results of this study may shed light on the importance of a thorough nursing evaluation of end stage lung cancer patients upon admission to hospice, which includes not only a complete physical examination, but an assessment of pain including location, descriptors or quality, intensity, frequency, aggravating factors and alleviating factors. An important part of the pain evaluation is the identification of associated symptoms which have been shown in the literature to be prevalent in this group, such as dyspnea, fatigue, nausea and constipation.

Chapter II

Review of the Literature

It is well known that lung cancer is the leading cause of cancer-related death (ACS, 2007). This chapter presents the review of literature. First, the Theory of Unpleasant Symptoms is described. Following the introduction of the conceptual framework, qualitative and quantitative research is presented as reviews of pain, related symptoms, and quality of life in end stage lung cancer patients.

Conceptual Framework

The Theory of Unpleasant Symptoms (TOUS) (Lenz, Pugh, Milligan, Gift, & Suppe, 1997) was used as the conceptual framework for this study. The Theory of Unpleasant Symptoms proposes that similar factors may influence how a number of different symptoms are experienced. Therefore, it can be said that similar interventions may be effective for more than one symptom. The Theory of Unpleasant Symptoms also proposes that when multiple symptoms are present, the patient is likely to experience a multiplicative rather than additive effect.

The Theory of Unpleasant Symptoms is composed of three units: the symptoms that the patient is experiencing, the factors that influence the nature of the symptom experience (antecedents), and the consequences of the symptom experience. Antecedents can include physiological (unpleasant symptoms), psychological (reaction to illness) and situational variables (social situations). It is noted that these units can be related and have

a reciprocal effect. The strength of the relationships is dynamic (Lenz et al., 1997; Gift, Jablonski, Stommel & Given, 2004).

According to the Theory of Unpleasant Symptoms, each symptom the patient reports is a multidimensional experience, and can be conceptualized and measured individually or in combination with other symptoms. While the Theory of Unpleasant Symptoms recognizes that symptoms are different from each other, it establishes that there are common dimensions seen across symptoms, such as intensity, timing, level of distress and quality (Lenz et al., 1997). This study focuses on symptom intensity and its psychological effect, distress.

Literature Review

Pain

When assessing any type of pain, it is important to determine underlying etiologies and other symptoms that are likely to accompany the pain. Pain can increase the perception of severity of other symptoms (such as dyspnea, fatigue and constipation). It also communicates to the patient that there is some degree of disease progression (Griffin, Nelson, Koch, Niell, Ackerman & Thompson et al., 2006).

A 2001 study by Wilkie, Huang, Reilly and Cain evaluated whether descriptors from the McGill Pain Questionnaire (MPQ²) were congruent with lung cancer patients' descriptions of neuropathic and nociceptive pain. The final sample group consisted of one hundred twenty-three patients from three Western states who were English speaking, diagnosed with lung cancer, had at least one episode of pain within one week prior to data collection and were physically able to ambulate on their own for two minutes. Instruments used in this study included the following: the Demographic Data Form

(DDF), used to document oncologic variables and demographics; the McGill Pain Questionnaire was used to gather information from the patient regarding pain location, intensity, depth, quality and pattern; and the Lung Cancer Etiology Tool (LCET), which was developed for this study to tabulate data regarding eleven criteria defining nociceptive pain sites, and fourteen criteria defining neuropathic pain sites. To further elaborate on this tool, pain sites were considered nociceptive unless at least one neuropathic element was documented. If nociceptive and neuropathic symptoms were reported, then the site was categorized as mixed. Participants were asked to complete the Demographic Data Form and McGill Pain Questionnaire forms. The McGill Pain Questionnaire pain location and pattern was then reviewed in combination with the Demographic Data Form, tumor location and cancer treatment data. The documented pain sites (n = 457) were numbered in order of patient report and were considered in relation to other pain sites when determining the etiology category as either nociceptive (n = 343) or neuropathic (n = 114). Results of the study showed that out of the twenty-two descriptors, four words were significant for describing nociceptive pain (heavy, stinging, lacerating and suffocating), while eleven words were significant for describing neuropathic pain (aching, tender, throbbing, pricking, pulling, tugging, punishing, miserable, nagging, numb and penetrating). An interesting caveat to this population was that they did not select terms frequently associated with neuropathic pain such as burning, shooting, lancinating, tingling, itching, cold, flashing, blinding, torturing. Another significant finding of this study was that the lung cancer participants reported neuropathic pain fifty percent of the time, which is higher than neuropathic pain reported in other groups (Wilkie et al., 2001).

A 2004 phenomenological qualitative study by Coyle proposed to address perceived barriers to pain management, misconceptions regarding opioid pain medications, and fear generated by uncontrolled pain in advanced cancer patients. Seven participants consented to a series of two or more in-depth interviews lasting from thirty to sixty minutes, in the patients' own setting, scheduled anywhere from one to sixty days apart, depending on the patient's needs. Results of the interviews revealed that participants quickly learned that admitting to uncontrolled pain meant withholding of treatments (which was perceived as ultimately losing time), changes in pain medication regimen (which again lead to losing time due to side effects) and the realization that the disease was progressing. Participants also revealed that when pain was uncontrolled their level of hope and will to live was greatly diminished. Some even wished for a hastened death. The fear generated by the pain was enough to invoke anxiety attacks in one of the participants. Two of the interviewees recalled caring for family members who died in pain, and could only imagine that they would suffer the same fate. Results of the study showed that pain management was nonlinear throughout disease progression. While pain relief was essential to the participants, the side effects were considered a heavy trade-off. "What the disease was not able to destroy in their human spirit, the pain or uncontrolled side effects of the opioids were able to accomplish" (Coyle, 2004, p. 308).

Other Symptoms

Many cancer patients report multiple symptoms that occur simultaneously secondary to their disease or the treatment they are receiving (Cleeland, Mendoza, Wang, Chou, Harle, & Morrissey, et al., 2000). Determining the predominant symptoms related to pain in end stage lung cancer can establish a baseline standard of care, allowing

patients to receive adequate assessment and management of their pain, and thus maintain an acceptable level of quality of life.

Chen and Tseng (2005) proposed to examine which cancer-related symptoms cluster together, and to test the conceptual meanings of the revealed clusters. This was a cross-sectional study involving one hundred fifty-one participants with various forms of cancer in both inpatient (n = 128) and outpatient (n = 23) settings in northern Taiwan. Study results were broken down into symptom occurrence, symptom severity, and interference of symptoms with activities of living. The average number of symptoms which occurred was 8.32 (SD = 3.72), with dry mouth being the most prevalent, fatigue was next and anorexia was third. Analysis of symptom severity showed that the most severe symptom was fatigue, followed by xerostomia and distress. Symptoms interfered with work most, followed by enjoyment of life and general activity. Symptoms with the highest correlation were grouped together into three main clusters: sickness cluster, which encompassed pain, fatigue, sleep disturbance, anorexia and drowsiness; the gastrointestinal cluster, which included nausea and vomiting; and the emotional cluster, which involved distress and sadness. Validation of the symptom clusters revealed that participants with stage III and IV cancer had significantly higher sickness cluster scores than those with stage 0-II ($p < 0.001$). Participants receiving chemotherapy at the time of data collection had significantly higher scores on the gastrointestinal cluster than those not receiving chemotherapy ($p < 0.001$). Depressed participants (defined as a Hospital Anxiety Depression Scale subscale score of ≥ 8) had significantly higher scores on the emotional cluster than those who were not depressed ($p < 0.001$) (Chen et al., 2005).

Many of the symptoms in end of life care are thought to follow a trajectory,

implying that the symptoms become more severe as death approaches. There is value in understanding the trajectory as medications providing relief of symptoms may require adjustment as the disease progresses. Gift, Stommel, Jablonski and Given (2003) studied whether a symptom cluster present in lung cancer patients at diagnosis remained present three and six months later. This study was performed from a secondary analysis of one hundred twelve patients with newly diagnosed lung cancer who were assessed at baseline, three months and six months post diagnosis. The Theory of Unpleasant Symptoms served as the conceptual framework for this study. The symptom cluster was pre-established and consisted of fatigue, weakness, weight loss, appetite loss, nausea, vomiting and altered taste.

Results of this study were reported using Cronbach α scores of .66 at three months, and .75 at six months, which met reliability and showed that the symptom clusters remained relatively the same over time. The answer to the second question of changes over time in the mean number of symptoms and level of severity was shown as a decline in number of symptoms reported ($p < 0.001$) and a decrease in severity ($p < 0.002$). The third question, related to the relationship between the severity ratings for individual symptoms at each time point, was found to have only moderate correlation along each time point. The fourth question evaluated the ability to predict the number of symptom clusters reported based on factors such as age, gender, the stage of lung cancer at diagnosis, therapy received and number of co-morbid conditions. It was found that none of the between-subjects factors (surgery or not, radiation or not, gender, age, etc.) except staging of lung cancer at diagnosis showed significant correlation ($p < 0.001$). Question five evaluated whether symptom cluster severity was predictive of death. It was found

that symptom severity reported six months after diagnosis, age and stage of cancer at diagnosis were predictors of death six to nineteen months after diagnosis (Gift, et al., 2003).

Subgroups of lung cancer patients have been studied, as certain groups will present with unique needs, and will tolerate treatment differently. Knowledge of specific population needs can help health care professionals develop a plan of care that is realistic and easy to follow. Gift et al. (2004) researched symptom clusters in elderly patients with lung cancer. The purpose of their research was to identify the number, type, and cluster of symptoms this group experienced. The sample was described as two hundred twenty patients age sixty-five to eighty-nine years (mean = 72 years, SD = 5.02), newly diagnosed with both early and late stage lung cancer. This study was a secondary analysis of data collected as part of a larger study. The authors used the middle-range Theory of Unpleasant Symptoms (TOUS) as the framework to guide their research. Results of symptom occurrence showed that participants reported a mean of eleven symptoms (SD = 4.95) with fatigue, nocturia, cough, pain, and difficulty breathing as the top five. Mean symptom severity ranged from 1.31-2.33 on a 1-3 scale. Symptoms reported to be most severe were lack of sexual interest, vomiting, trouble sleeping, fatigue, pain and difficulty breathing. Symptoms perceived to cause the most limitation in daily activities were fatigue, difficulty breathing, weakness, loss of coordination, vomiting and pain. The relationship of these symptoms correlated with the ability to perform daily activities ($p < 0.01$). The seven symptoms found to form a cluster were fatigue, nausea, weakness, appetite loss, weight loss, altered taste, and vomiting (Gift et al., 2004).

Among the many distressing symptoms that end-stage lung cancer patients may experience, constipation is one of the least often evaluated (McMillan, 2002). Hospice patients are at risk of developing constipation due to the use of opioids and other medications used for symptom management, decreased food/fluid intake, decreased activity levels and comorbidities such as stroke, diabetes, electrolyte imbalances and renal failure (McMillan, 2004). Evaluation, prevention and treatment of constipation should be part of the hospice patients' daily care.

McMillan (2002) reported through secondary analysis of data collected from seventy hospice patients, that sixty-three percent reported some degree of constipation, with nineteen percent of these patients reporting severe constipation upon hospice admission. Constipation was assessed using the Constipation Assessment Scale (CAS), which is an eight-item three-point Likert-type scale that measures the presence and intensity of constipation. Each item is rated by the patient as no problem, some problem, or severe problem. Scores may range from 0 (no constipation) to 16 (worst possible constipation). Constipation was evaluated two weeks after admission, and was found to have increased to include sixty-eight percent of the patients enrolled in the study. This increase is thought to be due to the fact that it takes about two weeks to completely correct a constipation problem, and that opioids are adjusted frequently after hospice admission, usually with an increase in dosage and/or frequency. When constipation was evaluated four weeks after admission to hospice, it was found to have decreased to fifty percent (McMillan).

Symptom Distress

Symptom intensity (the extent to which the pain is bad) differs from symptom

distress (the extent to which the pain is considered mentally anguishing) and each can be approached in different fashions. Tishelman et al. (2005) discussed symptoms in patients with lung cancer and sought to specifically distinguish distress from intensity of symptoms by addressing four objectives. The first objective examined patterns of current symptom intensity in relation to patterns of distress in a population of patients newly diagnosed with inoperable lung cancer. The second objective evaluated the consistency of symptom intensity and distress patterns across various time points in the study. The third objective examined differences in patterns of intensity and distress in subgroups based on certain demographic and disease-related variables. The last objective examined the possible correlation of high symptom intensity to symptom distress. This was a longitudinal quantitative study that took place in two different university hospitals that specialize in the non-surgical treatment of lung cancer in Stockholm. Four hundred adults were recruited with the only criteria being newly diagnosed inoperable lung cancer. Self reported data was collected using an adapted version of the McCorkle and Young Symptom Distress Scale (SDS) and the Thurstone Scale of Symptom Distress – Lung Cancer (TSSD-LC) at baseline (T1), then two weeks later (T2), then one month after T1 (T3), then three months after T1 (T4), then six months after T1 (T5), then one year after T1 (T6). Nine symptoms were assessed: fatigue, breathing, outlook, cough, appetite, insomnia, pain, appearance and bowels. At T1, pain was ranked seventh in intensity, and by T6, pain was ranked third. Interestingly, there was not a significant increase in symptom distress. Fatigue and breathlessness actually caused more distress than pain. Comments made in the discussion section of this report suggest that perhaps pain is accepted as a part of cancer and to a degree may be expected, especially closer to death.

Breathlessness and fatigue were considered more distressing due to the association with progression of disease (Tishelman et al., 2005).

Broberger, Tishelman and von Essen (2005) continued the research on the original Tishelman et al. (2005) group of participants, to determine if there are discrepancies or similarities in assessment of symptom occurrence and distress among nurses and family caregivers. This portion of the study was broken up into two sections: the Patient-Nurse Study (PN Study) and the Patient-Family Caregiver Study (PFC Study). Inclusion criteria for the Patient-Nurse Study was as follows: participants should be able to communicate in Swedish, have received radiation therapy for at least five consecutive days, and data collection should coincide with one of the time points in the main project (T2-T6). Thirty-three patient-nurse dyads met eligibility. Inclusion criteria for the Patient-Family Caregiver Study was as follows: patients and family caregivers should be able to communicate in Swedish, family caregivers should be over eighteen years of age and have a close and stable relationship with the patient, and data collection should coincide with one of the time points in the main project (T2-T6). A total of fifty-four patient-family dyads were created. Data for this study was already collected from the Symptom Distress Scale and Thurstone Scale of Symptom Distress – Lung Cancer Scale from the main project. Results of the Patient-Nurse Study dyads revealed that the nurse tended to assess the patients' symptoms occurrence as greater than the patients did ($P < 0.05$). The nurses consistently rated symptom distress lower than what the patient reported ($P < 0.05$). Like the nurses, the family caregivers also rated the occurrence of symptoms greater than the patients did, although there was closer agreement than the nurses ($P < 0.01$). Family caregivers did a better job than nurses when evaluating symptom

distress ($P < 0.01$). This is thought to be due to the close nature of the relationship between the patient and the caregiver versus the relationship between the patient and the nurse (Broberger et al., 2005).

Cooley, Short and Moriarty (2003) examined symptom prevalence, distress and changes over time in adults receiving treatment for lung cancer. The purpose of this study was to describe which symptoms were most distressing, the prevalence of these symptoms, how these symptoms change over time. This study was conducted from secondary analysis of one hundred seventeen participants' responses to the Symptom Distress Scale, medical record review and interviews. Inclusion criteria involved a histologic confirmation of lung cancer, participants had received treatment for cancer (either surgery, chemotherapy, radiation, or combination of any these treatments), had no other malignancy, were diagnosed within one hundred days of entering study and completed all interviews at baseline, three months and six months.

When symptom distress was evaluated, all four treatment groups reported fatigue as being the most prevalent distressing symptom at all three time points, with frequency of pain second, insomnia third, appetite fourth and severity of pain fifth. The second aim of this study, which focused on prevalence of distressing symptoms, broke results down into the four treatment groups: surgery group ($n = 45$), radiation group ($n = 13$), chemotherapy group ($n = 8$) and combined therapy ($n = 51$). In the surgery group, pain, fatigue and insomnia were the three most distressing symptoms at baseline and again three months later. Frequency of pain, fatigue and pain severity were the most distressing symptoms six months. In the radiation group, fatigue, appetite and severity of nausea were the top three distressing symptoms at baseline, fatigue, appetite and nausea

characterized the three month mark, and by six months this group listed fatigue, frequency of pain and insomnia as the most distressing symptoms. In the chemotherapy group, fatigue, appetite and frequency of pain were most distressing at the baseline assessment and remained prevalent throughout the six months. In the combination group, fatigue, frequency of pain, and insomnia were distressing at all three time points. The third aim of this study was to evaluate how symptoms change over time. In general it was noted that the treatment groups showed a decrease in symptom severity from baseline to three months, with an increase at six months. The only consistent pattern of predictors was symptom distress reported at baseline. Symptom distress at entry was able to predict for nine of thirteen symptoms at three months, and seven of thirteen symptoms at six months (Cooley et al., 2003).

A study by Degner and Sloan (1995) study looking at symptom distress in newly diagnosed ambulatory cancer patients, and as a predictor of survival in lung cancer, examined four hundred thirty-four cancer patients, eighty-two of whom had lung cancer, in two different oncology clinics in Canada. The purpose of the study was to report levels of symptom distress and to describe factors associated with this distress over a six month period of time. Data collecting tools included participant completion of the Symptom Distress Scale, direct interview, and medical chart review. Patients eighteen years of age or older with a diagnosis of cancer within six months were approached.

Results showed that the level of symptom distress in this group was very low, with most participants rating their symptom distress as one or two on a five point scale. Fatigue, insomnia and pain were the most problematic symptoms reported. Women reported more distress than men ($p = 0.041$) and patients with advanced disease at time of

diagnosis had more distress than those with early disease ($p = 0.0001$). Level of distress was noted to depend on disease site, with lung cancer patients reporting the most distress. Survival analysis of the lung cancer patients demonstrated that symptom distress scores had a direct relation to survival. Stage of disease was seen as a covariate (Degner et al., 1995).

Oi-Ling, Man-Wah and Kam-Hung (2005) published a study evaluating symptom distress as rated by advanced cancer patients compared to the ratings of caregivers and physicians in the last week of life. This was a prospective study, which included all inpatient hospice patients admitted to a hospice ward in a Hong Kong hospital with a life expectancy of two weeks or less to live. The Symptom Distress Scale was administered to the participant upon admission to the ward, then every seven days until the patient died. The distress from each symptom was rated on a 0-5 scale, with grade 0 = not at all distressed, grade 1 = a little bit distressed, grade 2 = somewhat distressed, grade 3 = quite a bit distressed, and grade 4 = very much distressed. Only thirty patients were able to complete the two questionnaires needed to be included in the study, with nineteen of these thirty completing more than two questionnaires as they lived longer than the predicted two weeks. Only the questionnaire set completed within the last week of life was included for analysis. Caregivers and physicians also completed the same questionnaires based on their observation of the patients' symptom distress.

Results of this study reveal that the median age of the participants was sixty-nine years of age, gender ratio was equal men to women, entire sample was ethnic Chinese, and lung cancer was the most common primary tumor, with gastrointestinal cancers listed second. Of the thirteen symptoms listed on the Symptom Distress Scale,

nine symptoms (of any distress grade) were most commonly reported to cause patient distress: fatigue (100%) with a distress median score of 3, cachexia (93%) with a distress median score of 3, anorexia (93%) with a distress median score of 3, dyspnea (70%) with a distress median score of 1, dry mouth (60%) with a distress median score of 3, cough (60%) with a distress median score of 1, pain (57%) with a distress median score of 1, insomnia (47%) with a distress median score of 1, and constipation (47%) with a distress median score of 1. The four most distressing symptoms rated by participants were fatigue, cachexia, anorexia, and dry mouth, all with a distress median score of 3. Fatigue, cachexia and anorexia were shown to cause the most frequent distress and were rated the most distressing of all symptoms. Caregivers rated fatigue, cachexia and anorexia as most distressing, but didn't rate the severity of the distress as high as the patients. Statistically significant agreement between raters was only evident for the symptoms of dyspnea, cough, dry mouth, constipation and insomnia (all with P value <0.005). Physicians also rated fatigue, cachexia and anorexia as the most distressing symptoms, but again didn't rate the severity of distress as high as the patients. Symptoms that evoked statistically significant agreement between patients and physicians were dyspnea, pain, and cough (all with P value <0.005) (Oi-Ling et al., 2005).

Quality of Life

Sarna, Brown, Cooley, Williams, Chernecky, Padilla, et al. (2005) studied the quality of life (QOL) of two hundred seventeen women with non-small cell lung cancer and relationships with demographics, health status and meaning of illness (MOI). This was a descriptive, cross-sectional study. Assessment tools included the Quality of Life Scale-Patient Version (QOL-Patient) (Cronbach α of 0.71-0.91 for this study), the Short

Form-36 (Cronbach α of 0.95 for this study), and the Center for Epidemiologic Studies-Depression Scale (CES-D) (Cronbach α of 0.87 for this study). Meaning of illness was assessed using a set of eight cards, each with a statement describing illness as positive, negative or other meaning. Participants were asked to select a card with a statement most relevant to how they feel. The mean age of the participants was sixty-five years (SD = 12.00), and Caucasians had the largest representation at eighty-five percent. The majority of the participants had at least one comorbid condition (sixty-seven percent), with the most common being chronic obstructive pulmonary disease (COPD). Eighty-seven percent of the women had a history of smoking, and while ninety-nine percent attempted to quit smoking upon diagnosis, only fifty-seven percent were able to do so. Thirty-five percent indicated that they were depressed according to the results of the Center for Epidemiologic Studies-Depression Scale. Quality of life assessment found that depressed mood, meaning of illness, and a younger age were consistently related to a lower global, physical, psychological, social and spiritual quality of life (all $p < 0.0001$) (Sarna et al., 2005).

Symptom frequency and severity in patients with metastatic or locally recurrent lung cancer (LRLC) was evaluated by Lutz, Norrell, Bertucio, Kachnic, Johnson and Arthur, et al. (2001). This study was a cross-sectional analysis of sixty-nine community lung cancer patients considering radiotherapy for palliation of their advanced lung cancer. The Lung Cancer Symptom Severity (LCSS) scale, which evaluates physical and functional symptoms' impact on quality of life, was administered upon initial radiation consultation. Symptoms were reported in order of frequency as follows: fatigue (eighty percent), cough (seventy-seven percent), dyspnea (seventy-three percent), loss of appetite

(sixty-five percent), pain (fifty-seven percent), and hemoptysis (seventeen percent).

Evaluation of symptom severity revealed that fatigue, pain, dyspnea, and loss of appetite were the most frequently reported. Quality of life was reported to have diminished prior to death, with an increase of symptom frequency reported in all six categories. The major limitation to this study is that the symptoms (appetite, fatigue, cough, dyspnea, hemoptysis and pain) were predetermined by the Lung Cancer Symptom Severity Scale. If other symptoms are present, such as constipation, they are not evaluated by this tool (Lutz et al., 2001).

A 2000 quality of life descriptive study by McMillan and Weitzner reviewed previously collected data from a 1998 study to identify most and least problematic aspects of end of life care in hospice patients and the relation to quality of life. The sample consisted of two hundred thirty-one homecare hospice patients with cancer in southwest Florida. The sample mean age was seventy-one years, fifty-two percent of participants were Caucasian, and the most common cancers reported were lung (22%), colorectal (14%), breast (12%), and prostate (10%). The instrument used to collect data was the Hospice Quality of Life Index (HQLI) which is a twenty-eight item self report questionnaire broken down into three sections: functional well-being, psychophysiologic well-being and social/spiritual well-being. Results of this analysis showed that the functional well-being subscale mean score was 35.1 (SD = 14.8) (possible range of 0-70), which was the lowest of the three subscales. The symptom that participants reported as problematic most frequently was fatigue. The psychophysiologic well-being subscale mean score was 93.2 (SD = 21.8) (possible range 0-130). More than half of the patients reported feeling sad on this subscale. Items rated as the least problematic included hope,

pain relief, feeling angry and nausea. The highest item mean scores were noted in the social/spiritual well-being subscale, with almost half of participants rating satisfaction with their relationship with God (McMillan et al., 2000).

Summary

Pain in end stage lung cancer is multidimensional and should be treated in a manner that targets as many symptoms as possible. Pain can be caused by tumor involvement, diagnostic and/or therapeutic interventions and toxicities of treatment, which can cause different types of pain to occur simultaneously, requiring different types of treatment or combined therapies (McGuire, 2004). The literature review demonstrates that pain is frequently accompanied by other symptoms such as dyspnea, fatigue, constipation and loss of appetite, which can increase symptom distress and decrease quality of life.

Oncology nursing has much to gain by studying pain and accompanying symptoms in the end stage lung cancer population. This extremely symptomatic group has demonstrated that they suffer higher degrees of frequency and severity of symptoms than patients with other types of cancers, and that these symptoms increased in frequency and severity as the end of life approaches. Palliation of these symptoms will improve perceived quality of life, affording the patient more time to complete end of life tasks.

Chapter III

Methods

The literature review on end stage lung cancer patients supports the idea that there is a relationship between pain, associated symptoms and quality of life. This chapter discusses study design, sample, assessment tools used, procedures, and statistical analysis.

Sample and Setting

The sample for this present study was drawn from a previously completed study that included three hundred twenty-nine home care hospice patients from a large not-for-profit hospice agency, located in southwest Florida. Data was obtained from an original study evaluating the use of the COPE Intervention for family caregivers. This intervention was shown to improve symptom management in hospice homecare patients (McMillan & Small, 2007).

Inclusion criteria

Identification of potentially eligible participants was identified by hospice staff. Inclusion criteria for the study was as follows: participants had to be able to read, and understand English; minimum age of eighteen years or older; participants had to have a diagnosis of end stage lung cancer; participants must rate pain at a level of three or more on a 0-10 pain scale; and achieve a minimum score of eight on the Short Portable Mental Status Questionnaire (SPMSQ).

Exclusion criteria

Participants with cognitive issues who scored below eight on the Short Portable Mental Status Questionnaire were excluded. Patients who displayed a performance status of less than 40 (as determined by the Karnofsky Performance Scale) suggesting that they would not live for more than a few days, were also excluded from this study.

Instruments

Short Portable Mental Status Questionnaire

The Short Portable Mental Status Questionnaire (SPMSQ) is a simple ten item test of remote memory, knowledge of current events, and mathematical ability (Pfeiffer, 1975) (Appendix A). It is administered by the interviewer and scored on the number of errors an individual makes and measures levels of mental impairment. The SPMSQ was used to screen patients for eligibility for the study. Subjects with SPMSQ scores below eight were excluded.

Demographic Data Form

Standard demographic data was collected on patients to allow description of the sample. Data included age, gender, education, marital status, occupation, cancer diagnosis, length of time since diagnosis.

Karnofsky Performance Status Scale

The KPS is a measure of functional status developed by Karnofsky et al. (1949) that is widely used in oncology settings to assess patient functioning. The KPS is scored on a scale from 0 (dead) to 100 (normal functioning) (Appendix B). KPS scores were used to determine patient eligibility for the study. Patients with scores lower than 40 were excluded.

Pain Numeric Rating Scale

Pain intensity was assessed using an eleven point numeric rating scale (NRS) with scores ranging from 0 to 10 (Appendix C). The patient was asked to respond verbally with a number between 0 (no pain) and 10 (worst pain) to rate pain intensity at that moment (McGuire, 1984; Stewart, 1977).

Dyspnea Intensity Scale

Among patients with severe dyspnea and the resulting fatigue, an 11-point Dyspnea Graphic Rating Intensity (DGRIS) can be used to assess dyspnea intensity (Appendix D). This scale is preferred due to ease of administration and accuracy (Moody, Lowry, Yarandi, & Voss, 1997; Silvestri & Mahler, 1993). Test-retest reliability has ranged from .89-.92 and concurrent validity with other measures is .88-.94 (Moody et al., 1997).

The Constipation Assessment Scale

The Constipation Assessment Scale (CAS) (McMillan & Williams, 1989) is an eight-item three-point Likert-type scale that measures the presence and intensity of constipation. Each item is rated by the patient as no problem, some problem, or severe problem. Scores may range from 0 (no constipation) to 16 (worst possible constipation). Test-retest with brief delay provided strong evidence of reliability of this scale ($r = .98$).

Memorial Symptom Assessment Scale

The Memorial Symptom Assessment Scale (MSAS) (Portenoy et al., 1994) was used to measure distress caused by symptoms other than the three target symptoms. The Memorial Symptom Assessment Scale is a patient self-report scale that assesses a diverse group of symptoms common to persons with cancer. Subscales provide data about frequency, severity, and distress associated with these symptoms. Distress is measured on

a 5 point summated rating scale with total scale scores that may range from 0 (no distress) to 96 (very much distress). Validity was supported by high correlations with clinical status and quality of life. Alpha reliabilities were high (.83-.88).

Hospice Quality of Life Index

The Hospice Quality of Life Index (HQLI) (McMillan & Weitzner, 1998) is a twenty-eight item tool that measures overall quality of life (Appendix E). This scale is divided into three sections which measure psychophysiological well-being (physical problems and psychological problems), functional well-being (ability to complete normal activities of daily living, ability to concentrate and independence), and social/spiritual well-being (spirituality, relationship with God, relationships with family and friends). Items are reported on a zero to ten scale, with zero indicating the greatest impact on quality of life, and two hundred eighty indicating no impact on quality of life (McMillan et al., 1998). Factor analysis confirmed these subscales, and alpha coefficients ranged from 0.84-0.86.

Procedures

The original study was approved by the hospice ethics committees, and the University's Institutional Review Board. Following study approval, hospice staff members were hired and trained to perform data collection roles. Participants were identified by hospice staff, as well as medical record review, as having a diagnosis of lung cancer, and were reporting pain. Once approached, participants were educated regarding the purpose of the study, commitment required, and inclusion criteria. Upon agreement to participate, the patients were screened with the Short Portable Mental Status

Questionnaire (SPMSQ). If patients passed the SPMSQ, the symptom and quality of life scales were administered.

Data Analysis

For this current study, the existing data set from the original Caregiver Study was accessed via the Statistical Package for the Social Sciences (SPSS). Descriptive statistics were used to analyze the demographic variables, including means, standard deviations, percentages and frequencies. A series of Pearson correlations were used to analyze the relationships between pain and other identified commonly occurring symptoms, and whether these symptoms have a relationship with quality of life.

Chapter IV

Results, Discussion and Conclusions

This chapter presents the findings of the study. Included in this chapter are the study results, discussion of results, and conclusions.

Results

Demographic Data

The original study by McMillan and Small (2007) included hospice patients with thirty-nine different cancer diagnoses. Lung cancer patients made up the largest portion of this group (35%). The next largest group was colon cancer at 14%. The sample for this secondary analysis consisted of fifty end-stage lung cancer patients rating pain at a level of 3 or greater. Thirty-six were males (72%) and fourteen were females (28%). This sample was composed primarily of Caucasians (90%), African Americans (6%), and Hispanics (2%). The mean number of months since diagnosis was thirteen. The mean educational level of the sample was approximately twelve years. Thirty-four (68%) of the patients in the sample were married, ten (20%) were divorced, and five (10%) were widowed. One person was never married (Table 1).

Incidence and Intensity of Pain, Constipation and Dyspnea

The first research objective evaluated the incidence and intensity of pain, constipation and dyspnea. Data was derived from three measures, the CAS, NRS and the DGRIS. The NRS, a self-report 0-10 pain scale, was used to evaluate pain intensity. The

Table 1. Frequency and Percentage of Patients by Sex, Race, Marital Status and Education (n = 50)

Demographic	frequency	percent
Sex		
Male	36	72
Female	14	28
Race		
Caucasian	45	90
African American	3	6
Hispanic	2	4
Marital status		
Married	34	68
Divorced	10	20
Widowed	5	10
Never married	1	2
Education		
8 years or less	5	10
9 years	1	2
10 years	1	1
11 years	7	14
12 years or greater	36	72

mean pain intensity level reported was 4.7 (standard deviation = 1.5, n = 50). The CAS is a 0-16 scale which measures the presence and severity of constipation. The mean for constipation severity was 3.4 (standard deviation = 2.7, n = 50). The DGRIS is a 0-10 scale which measures dyspnea intensity. The dyspnea intensity mean for this group was 4.3 (standard deviation = 2.8, n = 50) (Table 2).

Relationships Among Variables

Each of the remaining three research objectives examined relationships among the variables, pain intensity, pain distress, dyspnea intensity, dyspnea distress, constipation intensity and quality of life. Because of missing data, some correlations were calculated with less than fifty patients.

Pain intensity and pain distress. Part one of the second research objective examined a relationship between pain intensity and pain distress. The study showed that there was a significant positive correlation ($p = .002$) between pain intensity and pain distress (Table 3).

Pain intensity and dyspnea distress. Part two of the second research objective evaluated a possible relationship between pain intensity and dyspnea distress. No significant correlation between pain intensity and dyspnea distress was found (Table 3).

Pain distress and dyspnea intensity. Part one of the third research objective evaluated a possible relationship between pain distress and dyspnea intensity. No significant correlation between pain distress and dyspnea intensity was found (Table 3).

Pain distress and constipation intensity. Part two of the third research objective examined possible correlation between pain distress and constipation intensity. No significant correlation between these two symptoms were identified (Table 3).

Table 2. Ranges, Means and Standard Deviations (SD) for the NRS, CAS, DGRIS and MSAS.

Variables	N	Possible range	Actual range	Mean	SD
Pain intensity	50	0-10	3-8	4.7	1.5
Constipation presence/ intensity	50	0-16	0-12	3.4	2.7
Dyspnea intensity	50	0-10	0-9	4.3	2.8
Pain distress	48	0-4	1-4	2.5	1.0
Dyspnea distress	44	0-4	0-4	2.3	1.3

Relationships with Quality of Life

Research objective four examined the variables pain intensity, pain distress, dyspnea intensity, dyspnea distress, constipation intensity and their relationship with quality of life.

Pain intensity and quality of life. The first part of this objective was to research a possible relationship between pain intensity and quality of life. No significant correlation was found between these two variables (Table 3).

Pain distress and quality of life. The second part of this research objective was to examine the variables pain distress and quality of life. No significant correlation was found (Table 3).

Dyspnea intensity and quality of life. The third part of the objective evaluated

Table 3. Pearson Correlations Among Pain Intensity and Pain Distress Variables from NRS, CAS, MSAS, and HQLI tools.

Variables	Dyspnea distress	Dyspnea intensity	Constipation intensity	Pain distress	Pain intensity	Quality of life
Dyspnea distress	n = r = p =		44 .21 .175			16 -.26 .332
Dyspnea intensity	n = 44 r = .47 p = .001			48 .11 .468	50 .23 .112	18 -.09 .709
Constipation intensity	n = 44 r = .18 p = .208	50 .10 .507			50 .17 .241	18 -.57 .013
Pain distress	n = 43 r = -.015 p = .925		48 .21 .152			18 -.24 .346
Pain intensity	n = 44 r = .13 p = .399			48 .44 .002		18 -.14 .578

pain intensity in relation to quality of life. The findings show that there is no significant correlation between these two variables (Table 3).

Dyspnea distress and quality of life. The fourth part of the objective addressed the two variables pain distress and quality of life. The findings show that there is not a significant correlation between pain distress and quality of life.

Constipation intensity and quality of life. The last part of this research objective evaluated the relationship between constipation intensity and quality of life, which were found to be significantly correlated ($p = .013$) (Table 3).

Discussion

This secondary analysis of previously collected data examined relationships between pain, dyspnea and constipation, and the relationships of each of these symptoms with total quality of life. Limitations of this study include the fact that it is not generalizable to the non-hospice population, the sample was primarily Caucasian, and the sample size was relatively small. Patients with lung cancer tend to present with symptoms, and because of this, palliation is started almost immediately after diagnosis. Palliation usually includes the use of opioid analgesics that are known to be constipating. Patients receiving treatment for their cancer are also at risk for constipation as they may have a decreased ability to ambulate secondary to dyspnea, and have decreased food and fluid intake due to nausea from treatment. Thorough assessment of all hospice patients upon admission and at every subsequent visit should include an evaluation of constipation, initiation of preventative measures, and follow up of intervention.

Demographic Data

The sample consisted of fifty end-stage lung cancer patients admitted to a hospice program who were reporting pain at a level of at least 3 on a 0-10 pain scale. The majority of the sample was male (72%), which is consistent with ACS statistics, that report that over half of all people diagnosed with lung cancer are male.

The overwhelming majority of study participants in this group were Caucasian. While it is not uncommon to see this type of disparity in hospice care (Greiner, Perera & Ahluwalia, 2003), it is one of the limitations of this study.

Incidence and Intensity of Pain, Constipation and Dyspnea

Pain incidence and intensity was derived from the Pain Numeric Rating Scale,

which is a self-report 0-10 pain scale used to evaluate pain intensity. A requirement of study participation was that the patient reported a pain level of at least 3. The mean pain level reported was 4.7 (SD = 1.5, n = 50). This moderate pain rating suggests that newly admitted hospice patients were experiencing some pain control, but pain was still a problem. While the mean pain level is in the moderate range, some patients reported pain intensity as great as 8. A review of research by Potter et al. (2004) reported that seventy-six percent of patients recruited from palliative care settings for a pain study reported pain. This might be a result of advanced disease including metastasis, which is usually present in end stage disease.

Constipation presence and severity was measured using the CAS, which is a 0-16 rating scale. The mean constipation severity reported for this group of newly admitted hospice patients was 3.4 (SD = 2.7, n = 50). This is a moderate rating on the CAS scale, and determines presence of a problem. Some participants reported constipation intensity as high as 12 on the scale. This finding is supported in the literature by McMillan (2002), who found that the mean score for constipation in newly admitted hospice patients was 3.3 (SD = 3.4).

Dyspnea intensity was measured using the DGRIS, which is a 0-10 rating scale. The dyspnea intensity mean for this group was 4.3 (SD = 2.8, n = 50). The highest dyspnea intensity rating reported in this group was 9. This finding is also supported in the literature by Moody and McMillan (2003) who reported that the mean dyspnea ratings reported by a group of hospice patients was 4.5 (SD = 2.2).

Relationships Among Variables

Pain intensity and pain distress. The positive significant correlation between

pain intensity and pain distress ($r = .44, p = .002$) might be expected. It has previously been reported that eighty-five percent of patients experience pain in the end of life, with fifty-six percent of these patients reporting that the pain is distressing (Edmonds, Karlsen, Kahn & Addington-Hall, 2001). A later study by Broberger et al. (2005) did not support a direct correlation between these two variables. Other symptoms were reported to be more distressing than pain, specifically fatigue and breathlessness. Broberger and colleagues (2005) concluded that lung cancer patients expect to have a certain degree of pain, especially towards death.

Pain intensity and dyspnea distress. The finding of no significant correlation between pain intensity and dyspnea distress ($r = .13, p = .399$) was unexpected. There is much literature supporting the idea that these two variables co-exist, but no literature supporting a significant relationship (Tischelman, Degner & Mueller, 2000; Higginson & McCarthy, 1989).

Pain distress and dyspnea intensity. No significant correlation was found between the two variables pain distress and dyspnea intensity ($r = .11, p = .468$). Literature supports that these two variables frequently exist together in patients with lung cancer (Higginson et al., 1989; Lutz et al., 2001), but there has been no evidence to support a direct relationship.

Pain distress and constipation intensity. There was not a significant relationship between pain distress and constipation intensity ($r = .21, p = .152$). This reasonable finding may reflect constipation as a side effect of pain management. A patient reporting a high level of distress caused by pain is probably not getting adequate treatment with pain medications, and therefore would not be as likely to be constipated. In a study by

McMillan (2002), constipation was a symptom reported most frequently by lung cancer patients.

Relationships with Quality of Life

Pain intensity and quality of life. It was unexpected that pain intensity did not have a relationship with quality of life ($r = -.14$, $p = .578$), which differs from the literature that found a direct correlation (Wang, Cleeland, Mendoza, Engstrom, Liu & Xu, et al., 1999). It is possible that the moderate mean pain level reported (4.7) was found to be less of a problem as compared to constipation. If reported pain levels were higher, a stronger correlation between pain and quality of life may have been observed. A lack of correlation between these two variables may also be secondary to a restricted range problem, as patients were excluded from this study if pain was rated less than 3 on the 0-10 pain numeric rating scale. Despite the fact that there was no correlation, it is an important finding as it demonstrates the importance of a thorough pain assessment upon admission to hospice.

Pain distress and quality of life. The finding of no significant correlation between pain distress and quality of life ($r = -.23$, $p = .346$) is understandable for the same reasons that pain intensity did not impact quality of life. Pain distress and pain intensity were significantly correlated in this study group ($r = .44$, $p = .002$).

Dyspnea intensity and quality of life. The finding of no significant correlation between dyspnea intensity and quality of life ($r = -.09$, $p = .227$) was unexpected. In this study, this finding might be explained by the moderate mean dyspnea intensity level (mean = 4.3, SD = 2.8) reported by this group. This may also be explained by early referral to hospice, before symptoms are severe. There is literature which reports a

significant increase in dyspnea at the end of life (Higginson et al., 1989), as well as an impact on the quality of life (McMillan & Weitzner, 2000).

Dyspnea distress and quality of life. It is an unexpected finding that there was no significant correlation between dyspnea distress and quality of life ($r = -.25$, $p = .332$) for the same reasons discussed in the previous section. Dyspnea distress and dyspnea intensity were significantly correlated in this study group ($r = .46$, $p = .001$).

Constipation intensity and quality of life. The two variables, constipation intensity and quality of life, were found to have a positive significant correlation ($r = -.57$, $p = .013$), and confirms results of previous studies (McMillan et al., 2000). The prevalence of constipation in the hospice population indicates the need for improved symptom assessment upon admission to hospice, teaching preventative measures, and follow up of interventions during routine nursing visits to prevent or treat the problem on a continuous basis.

Implications for Nursing

This study demonstrates the importance of addressing pain, dyspnea and constipation in the lung cancer patient receiving end of life care. The significant correlation found between constipation and quality of life warrants further investigation of the effects of pain management on constipation. Education of hospice staff on the assessment, prevention and management of constipation would greatly benefit this subpopulation of hospice patients. Implementation of a constipation assessment protocol, administered upon admission, and reevaluated upon each subsequent routine nursing visit, would be beneficial for the patient, family and hospice nursing practice.

Recommendations for Further Research

In order to improve generalizability of this research, a larger study sample could be accessed which includes a more heterogeneous mix of ethnicities representative of lung cancer statistics. The study could be replicated in other geographic regions. Distress from constipation was not assessed in this study, and future studies might include that important variable. Development of a constipation prevention protocol, which could be implemented upon admission to a hospice program, is worthy of exploring.

Conclusions

The purpose of this secondary analysis of data was to evaluate pain intensity and distress, dyspnea intensity and distress, and constipation intensity and the relationship of these variables to quality of life. The study found significant relationships between pain intensity and pain distress, and dyspnea intensity and dyspnea distress. Constipation was the only variable found to be significantly correlated with quality of life in this subpopulation. This is an important finding, as participants in this study rated pain and dyspnea at moderate levels, but constipation was the only variable shown to have a relationship with quality of life. Education of staff members regarding this important aspect of assessment will ultimately benefit the patient, and perhaps improve their overall quality of life.

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Appendices

Appendix A

SHORT, PORTABLE MENTAL STATUS QUESTIONNAIRE
Eric Pfeiffer, M.D.

Instructions: Ask questions 1-10 in this list and record all answers. Ask question 4A only if patient does not have a telephone. Record total number of errors based on ten questions.

	+	-	
1.			1. What is the date today? _____ month day year
2.			2. What day of the week is it? _____
3.			3. What is the name of this place? _____
4.			4. What is your telephone number? _____
4A.			4A. What is your street address? _____ (Ask only if patient does not have a telephone)
5.			5. How old are you? _____
6.			6. When were you born? _____
7.			7. Who is the president of the U.S. now? _____
8.			8. Who was president just before him? _____
9.			9. What was your mother's maiden name? _____
10.			10. Subtract 3 from 20 and keep subtracting 3 from each new number you get, all the way down. _____

Appendix B

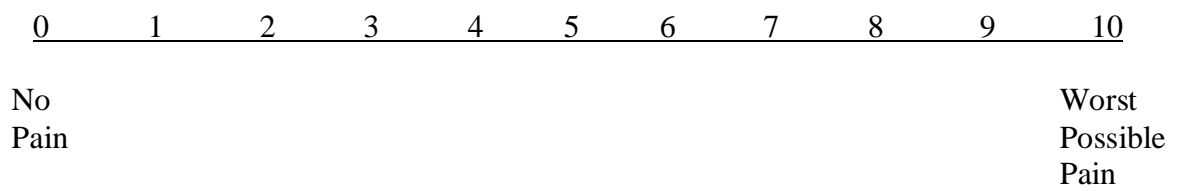
KARNOFSKY PERFORMANCE STATUS SCALE

100	Normal; no complaints; no evidence of disease.
90	Able to carry on normal activity; minor signs or symptoms of disease.
80	Normal activity with effort; some signs or symptoms of disease.
70	Cares for self; unable to carry on normal activity or to do active work.
60	Requires occasional assistance, but able to care for most needs.
50	Requires considerable assistance and frequent medical care.
40	Disabled; requires special care and assistance.
30	Severely disabled; hospitalization indicated although death not imminent.
20	Very sick; hospitalization necessary; active supportive treatment necessary.
10	Moribund; fatal processes progressing rapidly.
0	Dead

Appendix C

PAIN NUMERIC RATING SCALE

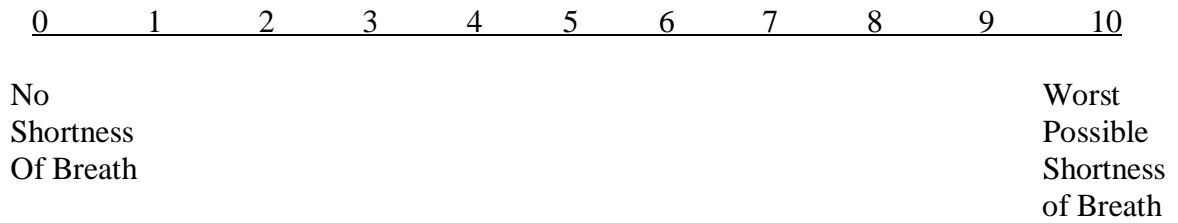
Directions: If zero is NO pain and 10 is the WORST POSSIBLE PAIN, where would you place your pain right now?



Appendix D

DYSPNOEA INTENSITY RATING SCALE

Directions: If zero is NO shortness of breath and 10 is the WORST POSSIBLE shortness of breath, where would you place your shortness of breath right now?



Appendix E

HOSPICE QUALITY OF LIFE INDEX-REVISED
1998

The questions listed below will ask about how you are feeling at the moment and how your illness has affected you. Please circle the number on the line under each of the questions that best shows what is happening to you at the present time.

1) How tired do you feel?

extremely 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

2) How well do you sleep?

not at all 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very well

3) How breathless do you feel?

extremely 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

4) How well do you eat?

poorly 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very well

5) How constipated are you?

extremely 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

6) How nauseated/sick do you feel?

extremely 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

7) **For Men:** How masculine do you feel? **For Women:** How feminine do you feel?

not at all 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 extremely

Appendix E (Continued)

8) Do you have enough physical contact with those you care about? (Touching, holding hands, hugging or other physical contact)

none 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 a great deal

9) How sad do you feel?

very sad 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

10) Do you believe that each day can still hold some good?

not at all 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 believe strongly

11) How worried do you feel about what is happening to you?

very worried 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

12) How worried do you feel about your family and friends?

very worried 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

13) How angry do you feel about what is happening to you?

very angry 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

14) How lonely do you feel?

very lonely 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

15) How satisfied do you feel with your ability to concentrate on things?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very
satisfied

Appendix E (Continued)

16) How meaningful is your life?

not at all meaningful 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very meaningful

17) How much enjoyable activity do you have?

none 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 a great deal

18) How satisfied do you feel about the amount of usual daily activities you are able to do?

(job, housework, chores, child care etc.)

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

19) How satisfied are you with your level of independence?

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

20) How satisfied are you with the support you receive from family and friends?

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

21) How satisfied are you with your social life?

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

22) How satisfied are you with the physical care that you are receiving?

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

Appendix E (Continued)

23) How satisfied are you with the emotional support you get from your health care team?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 satisfied
very

24) How satisfied are you with your relationship with God (however you define that relationship)?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 satisfied
very

25) How satisfied are you with the spiritual support you get from your health care team?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 satisfied
very

26) Do your surroundings help improve your sense of well-being?

not at all 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very much

27) How much do you worry about your living expenses/finances?

a great deal 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

28) If you experience pain, how completely is it relieved?

no relief 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 complete relief

How bad is your pain when it is at its worst?

no pain 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 worst possible