Title
Behavioral correlates of lung cancer pain

Author
Wilkie, Diana J.

Publication Date
1990

Peer reviewed|Thesis/dissertation

Behavioral Correlates of Lung Cancer Pain

by

Diana Joyce Wilkie

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

Dedication

I dedicate this dissertation to my husband, Davis B. Lawrence (a.k.a. Eddie B. Barlow) for his constant support through the research process and to the patients with cancer pain to whom I provided nursing care during the past 13 years. I learned from their experiences and my passion for the study of pain was kindled.

Preface

The conduct of this dissertation research was facilitated by many individuals and organizations. Although I limit acknowledgments to several important contributions, I am grateful for the incredible support from each person and each organization.

I thank the patients who participated in this study. While experiencing pain, they found the energy to share their experiences with me. I appreciated their priceless contributions to the study and to my continued growth as a nurse scientist.

I also thank the members of the dissertation committee, Marylin Dodd, Ph.D., R.N., F.A.A.N. (Chair), Laurel Copp, Ph.D., R.N., F.A.A.N., Francis Keefe, Ph.D., and Jon Levine, Ph.D., M.D., for their guidance and encouragement throughout the research process. Each member contributed unique expertise that helped me to complete a complex study. I am grateful for the mentorship provided by each member. I also thank Steven Paul, Ph.D. for teaching me how to use the CRUNCH statistical package and for providing consultation about statistical questions. He, too, has been a wonderful mentor.

I acknowledge Jean Firenge, R.N., Lisa Bluhm, R.N., and Doretta Annis, R.N. for their assistance with subject recruitment. Although each had patient care responsibilities in busy clinical settings, they found time to help identify potential subjects and to support the conduct of the study.

I am grateful to members of the Pediatric Pain Team, Marilyn Savedra, D.N.Sc., R.N., Mary Tesler, M.S., R.N., William Holzemer, Ph.D., R.N., F.A.A.N., and Nina Barlow, for their special support throughout this research. Their interest in my work helped to sustain me. And as a member of the team, I learned much about the conduct of rigorous research.

Several sources of financial support for this research are recognized. A predoctoral fellowship award from the National Cancer Institute (1F3108256) provided four years of funding for my doctoral work. This research study would not have been possible without this fellowship.

I am grateful to the American Cancer Society, Northern California Division for granting me a dissertation award. This award allowed me to invite Dr. Copp and Dr. Keefe to be members of the committee and to benefit from their expertise.

I am also grateful for an award received from the Alpha Eta Chapter of Sigma Theta Tau. This research award helped with the expense of inter-rater reliability, a critical component for behavioral research.

The University of California, San Francisco provided generous intramural support for this research. The School of Nursing Century Club is gratefully acknowledged as well as the Graduate Division Patent Fund.

Loving acknowledgment is given to my family and friends for their encouragement throughout this research. I thank them for understanding that I could not be with them when I was involved with some piece of this dissertation.

BEHAVIORAL CORRELATES OF LUNG CANCER PAIN

Diana Joyce Wilkie, Ph.D., R.N.

University of California, San Francisco, 1990

Reflex behaviors are known protective responses to noxious stimuli, but little is known about voluntary behavioral responses to pain. Research data suggest pain behaviors are used to communicate pain to other people, to control pain, or because pain prevents usual behavior.

In a descriptive, correlational study, 45 patients with lung cancer pain were used to identify pain behaviors and examine relationships between the behaviors and selected variables. After completing the McGill-Melzack Pain Questionnaire, Visual Analogue Scale, State-Trait Anxiety Inventory, Cancer Specific Locus of Control (locus), and Coping Strategies Questionnaire, patients were asked to sit, stand, walk, and recline for ten minutes while video cameras recorded behaviors. Tapes were scored using behavioral definitions. Then, patients were interviewed to determine their intent for using the behaviors.

Patients verbally expressed pain to others (43%) or tried not to express their pain (45%). Both groups had similar pain, anxiety, and locus scores. However, patients who tried not to express their pain reported more frequent use of coping strategies.

Pain was controlled by 42 behaviors. The number of different pain reduction behaviors was significantly correlated with intensity (r=.44), quality (r=.45-.64), and some coping strategies (r=.37-.48), but was not associated with anxiety or locus scores. Multiple regression indicated that patients with complex qualities of pain and longer pain duration were likely to use greater numbers of different behaviors to reduce pain.

Most patients (84%) reported pain prevented them from completing none of the protocol activities, but that pain prevented work and recreational activities. The number of behaviors prevented by pain was significantly correlated with intensity (r=.41), quality (r=.39-.58), and anxiety (r=.55), but was not associated with locus or most coping strategies scores. Multiple regression indicated that patients with higher anxiety, complex qualities of pain, and ability to decrease pain were likely to report that pain prevented larger numbers of behavior.

This research helped to clarify the pain behavior construct. Further research is needed to examine the nature of lung cancer pain behaviors over time and to evaluate the effectiveness of specific lung cancer pain control behaviors.

Marylin J. Dodd, Ph.D., R.N., F.A.A.N
Professor, Department of Physiological Nursing

List of Tables

List of Figures

TABLE OF CONTENTS

BEHAVIORAL CORRELATES OF LUNG CANCER PAIN

Diana J. Wilkie

Department of Physiological Nursing

University of California, San Francisco

Running Head: Behavioral Correlates

CHAPTER ONE

Study Problem

Introduction

Cancer is a major health problem in the United States (US) as well as in other nations around the world. Cancer ranks second as the cause of death in the United States, accounting for approximately 22% of total deaths. Estimates indicate that nearly half of the 1,040,000 Americans diagnosed with cancer in 1990 will die from the disease (Silverberg, Boring, & Squires, 1990).

When data are considered for specific cancer sites, lung cancer is a frequent cause of death world wide, generally with under developed countries reporting lower death rates than developed countries. Of 50 selected countries monitored by the American Cancer Society, the US ranks twelfth for male and third for female in terms of the lung cancer age-adjusted death rate (Silverberg et al., 1990).

Epidemiological estimates indicate that 157,000 Americans, 102,000 men and 55,000 women, will be diagnosed with lung cancer during 1990 (Silverberg et al., 1990). A staggering number of these people are expected to die: estimates indicate that 142,000 Americans, 92,000 men and 50,000 women, will die from lung cancer in 1990 and that 15,400 of these individuals will reside in California (Silverberg et al., 1990).

During the past 50 years, lung cancer death rates have demonstrated a dramatic and steady upward incline for both men and women. Whereas a few years ago breast cancer was the leading site for cancer deaths in women, lung cancer now surpasses breast cancer with 21% of the women dying from lung cancer as compared to 18% dying from breast

cancer (Silverberg et al., 1990). For men, too, lung cancer is the leading site for cancer deaths, with 34% dying from lung cancer as compared to 11% dying from prostate cancer or colorectal cancer.

Although trends in survival from lung cancer show improvement since 1960, only 13% of white and 12% of black individuals diagnosed with lung cancer can be expected to survive five years (Silverberg et al., 1990). In part, these dismal figures reflect the prevalence of lung cancer diagnosis when distant metastases are already present (39%) as compared to the prevalence of lung cancer diagnosis when regional disease (30%) or local disease (21%) is present. Similarly, five year survival rates are greater when lung cancer is diagnosed at a localized stage (37% white; 30% black) but decrease rapidly when lung cancer is diagnosed with regional (13% white; 12% black) or distant metastases (1%) (Silverberg et al., 1990).

Frequently, lung cancer is not diagnosed until an individual presents with a complaint of pain, a sign of advanced malignancy. Sources suggest that 14% to 40% of the patients diagnosed with lung cancer have pain when the disease is diagnosed (Covelli, Zaloznik, & Shekitka, 1980; Marino, Zoppi, Morelli, Buoncristiano, & Pagni, 1986; Rahim & Sarma, 1984). Fifty-four percent of patients with superior sulcus (pancoast) syndrome were noted to have pain before or at the time of diagnosis (Watson & Evans, 1987). Hence, the data are consistent with the high prevalence of regional or metastatic disease at diagnosis.

In general, 40% to 85% of individuals with lung cancer experience pain during the course of the disease (Foley, 1979; Greenwald, Bonica, & Bergner, 1987; Marino et al., 1986; Turnbull, 1979; Ventafridda,

Tamburini, & De Conno, 1985). When advanced stage lung cancer is evaluated, incidence of pain ranges from 58% to 85% (Greenwald et al., 1987; Marino et al., 1986; Turnbull, 1979; Ventafridda, Tamburini et al., 1985). However, Greenwald and associates (1987) recently found that in a sample of 260 patients diagnosed with lung cancer, "moderate" or "very bad" pain was reported by 53% of the patients with stage one disease, 50% of the patients with stage two disease, and 56% of patients with stage three disease. These data are consistent with referral patterns to two US cancer pain management programs; approximately 25% of all referrals are patients who have pain related to primary lung cancer (Cohen, Ferrer-Brechner, Pavlov, & Reading, 1985; Krames & Wilkie, unpublished data).

Watson and Evans (1987) reported median survival time after the onset of pain in lung cancer. For patients with skeletal metastases, median survival from pain onset was nine months. This figure increased to 11 months for patients with superior sulcus (pancoast) syndrome. These data suggest that a large portion of patients with lung cancer may experience chronic pain for nearly a year, which may be an eternity for the person and family experiencing the pain.

Extrapolation of 1990 lung cancer incidence data to lung cancer pain incidence data suggests that in the US approximately 120,700 people dying from lung cancer will have pain, and that 13,090 of these people will reside in California. For nearly 60% of these people, the pain will be very severe.

Compounding the high incidence and severity of lung cancer pain is the unresponsiveness of some types of lung cancer pain to pain

management strategies (Bonica, 1982). Even properly administered analgesic medications and sophisticated pain management procedures, such as spinal opiates, are not totally effective in controlling lung cancer pain (Bonica, 1982; Kanner, Martini, & Foley, 1982; Krames, Gershow, Glassberg, Kenefick, Lyons, Taylor, & Wilkie, 1985).

Inadequate lung cancer pain management is attributed to, in part, the complex, subjective nature of lung cancer pain. As a subjective experience, lung cancer pain is not amenable to direct measurement and is poorly understood (Chapman, Casey, Dubner, Foley, Gracely, & Reading, 1985; Melzack, 1983). In order to overcome these difficulties, cancer pain experts suggest that cancer pain should be operationalized as a multidimensional experience with affective, behavioral, cognitive, and physiological-sensory components (Ahles, Blanchard, & Ruckdeschel, 1983; McGuire, 1987b). Although knowledge about each dimension is accumulating, additional research is desperately needed to fully understand and better manage lung cancer pain.

Problem Statement

Particularly lacking is research related to the behavioral dimension of lung cancer pain, a component critical to accurate assessment and increasingly important for non-pharmacological cancer pain management (Ahles, Blanchard, & Ruckdeschel, 1983; McGuire, 1987b). Existing data suggest that the behavioral dimension of pain includes behaviors used to communicate the presence of pain to others; behaviors used to control pain; and behaviors prevented by the pain (Ahles et al., 1983; Bressler, Hange, & McGuire, 1987a; Keefe, Wilkins, & Cook, 1984; McGuire, 1984; Wilkie, Lovejoy, Dodd, & Tesler, 1988). However, little

is known about these behaviors in the lung cancer population because none of the behaviors have been well delineated separately or in relationship to the other dimensions of cancer pain.

Study Purpose

The purpose of this research was to characterize behavioral correlates of lung cancer pain. Specifically, the aims were to:

1) Identify behaviors used by individuals to communicate their pain to others (pain expression behaviors);

2) Identify behaviors used by individuals to control the intensity of their perceived pain (pain control behaviors);

3) Identify behaviors prevented by pain;

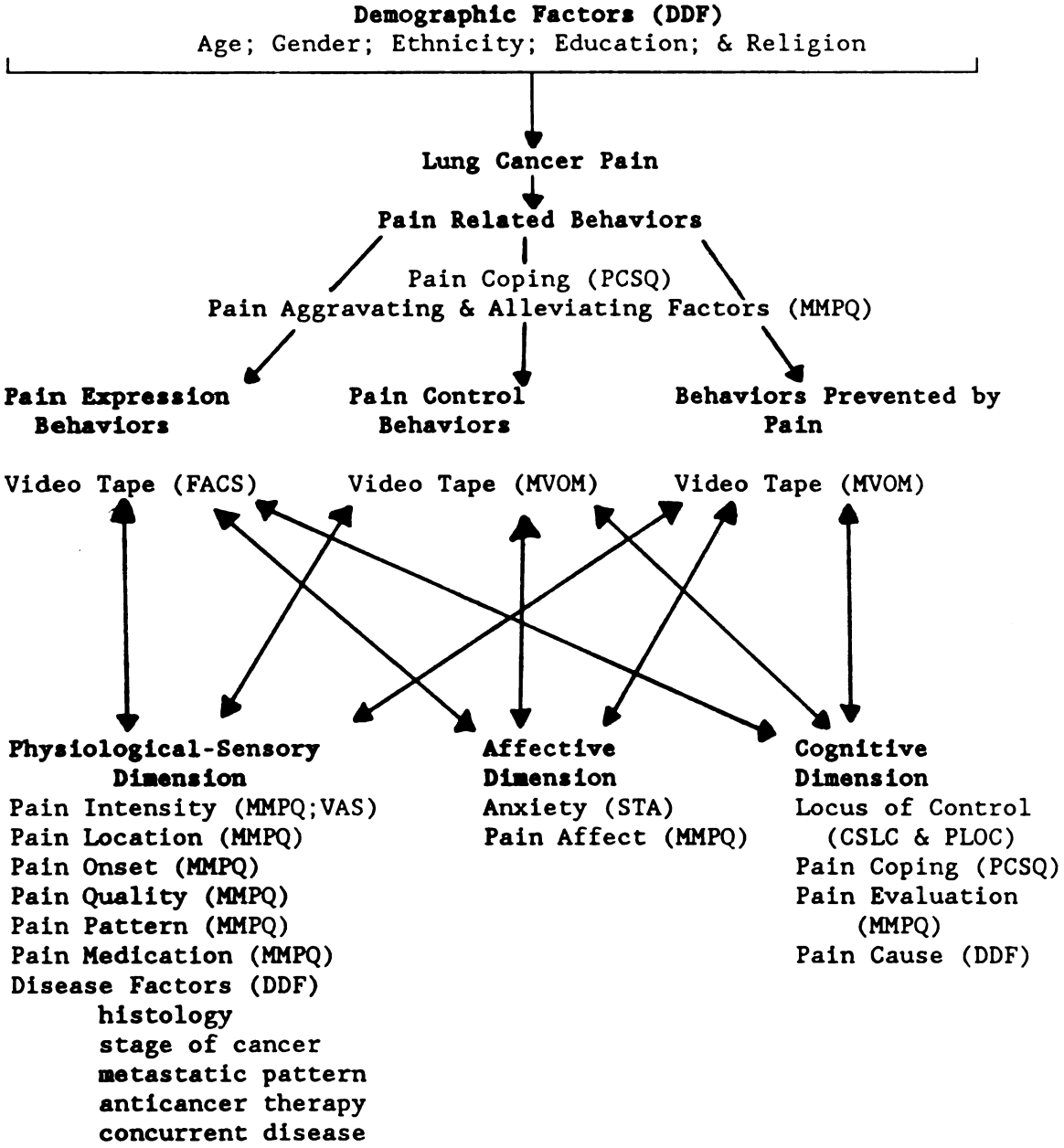
4) Characterize the relationship between pain expression behaviors, pain control behaviors, behaviors prevented by pain, and salient aspects of pain: intensity, quality, location, onset, and pattern; and

5) Describe the relationship between pain-related behaviors and selected affective, cognitive, and physiological-sensory variables (see Figure 1).

Significance

Characterization of cancer pain behaviors is important for a number of reasons. First, clinicians currently depend upon a synthesis of verbal self report and observation of the patient's behavior to draw conclusions about pain and the necessity for pain management. The relationship, however, between verbal pain report and the individual's intent for using cancer pain-related behaviors has not been adequately described (Donovan, 1987). One research group found that verbal report revealed less about pain-related behaviors than did an observation

Figure 1. Relationship Between Cancer Pain Behaviors and the Physiological-Sensory, Affective, and Cognitive Dimensions of the Lung Cancer Pain Experience as Defined by Study Variables and Instrumentation.



Key: DDF = Demographic Data Form; PCSQ = pain Coping Strategies Questionnaire; MMPQ = McGill Melzack Pain Questionnaire; FACS = Facial Action Coding System; MVOM = Manual for Video Observation Method; VAS = Visual Analogue Scale;STA = State-Trait Anxiety Inventory; CSLC = Cancer Specific Locus of Control; PLOC = Pain Locus of Control; PCSQ = pain Coping Strategies Questionnaire

method coupled with verbal report about patient-perceived pain control behaviors (Wilkie et al., 1988). Other investigators found discrepancy in verbal pain report and the nurse's assessment of pain based upon behavioral observation (Teske, Daut, & Cleeland, 1983). These findings have frequently been interpreted to mean that verbal self report of pain may not provide reliable data (Kremer, Block, & Gaylor, 1981; Teske et al., 1983). However, with so little known about the behavioral dimension of pain, the possibility cannot be excluded that nurses may not be targeting the important behaviors when assessing pain in their patients. Full characterization of the behavioral dimension of cancer pain could help clinicians to target the behaviors and more fully understand cancer pain (Wilkie et al., 1988).

Fully characterized behavioral indices of lung cancer pain also have potential to directly influence lung cancer pain management by identifying those individuals who are not utilizing effective behaviors for pain expression or pain control. If ineffective behaviors could be identified in clinical practice, patient education about more effective behaviors could improve lung cancer pain management.

Fully characterized behavioral indices of lung cancer pain could also help predict an individual most likely to respond to specific behavioral interventions, such as distraction, relaxation, or massage (Keefe, 1982; Keefe & Gil, 1986; Wilkie et al., 1988). Efficient use of behavioral strategies have the potential to reduce analgesic medication consumption (Keefe, 1982). Therefore, reductions could be seen in the financial and resource costs as well as morbidity associated with lung cancer pain management, especially costs and morbidity associated with

opiate therapy (Foley, 1985; Keefe, 1982). Overall, improved pain control in this group of unfortunate patients could dramatically improve the quality of their abbreviated life (Bonica, 1985).

Finally, information acquired about the behavioral correlates of lung cancer pain could lead to greater understanding about other types of cancer pain. The method used to explicate lung cancer pain behaviors could be applied to other populations with cancer pain to assess similarities and differences in behavioral correlates of cancer pain by primary site of cancer. Improved cancer pain control could result.

Experts contend that quality of life is severely compromised when cancer pain is not controlled (Bonica, 1985; Ventafridda et al., 1985). Feelings of helplessness, hopelessness, depression, fear, and anger ensue when pain is experienced and these feelings may interfere with the patient maximizing the time he/she has left to live. Hence not only does lung cancer represent a significant health problem, but lung cancer pain is commonly experienced, is of moderate to severe intensity, and can be a major contributor to poor quality of life.

Since alleviation of pain and promotion of comfort and quality of life are important goals in oncologic nursing, lung cancer pain is a significant problem area for cancer nursing research. Characterization of the behavioral dimension of lung cancer pain could provide significant interventions.

CHAPTER TWO

Literature Review

Overview

Although behavioral components of pain were identified as early as 1952 (Zborowski, 1952), Ahles and associates (1983) clearly operationalized the behavioral dimension of cancer pain within a multidimensional perspective. A growing body of research contributes to knowledge about this component of pain, including pain expression behaviors, pain control behaviors, and behaviors prevented by the pain.

Pain Expression Behaviors

The methods by which individuals express pain to other people in their environment has been of interest to investigators for a number of years. In a descriptive study, Zborowski (1952) utilized participant observation and informal interview to investigate the pain response pattern of 103 subjects from four cultural groups. He found that "Old Americans", third generation immigrants, had a low tolerance for pain, tended to withdraw when in pain, and avoided behavioral expression of pain. The Irish group was also found to withdraw from family and friends when in pain and responded to pain in an unemotional, calm manner. However, unlike the Old Americans, the Irish had a high tolerance for pain. The Jewish group had a low tolerance for pain and tended to give dramatic accounts of the pain experience by crying and moaning. They reportedly believed these pain manifestations would mobilize other people to offer help and sympathy because they were pessimistic about the potential of pain relief measures. Italians also had a low tolerance for pain and tended to cry and moan so that family

and friends would distract them from their pain. Zborowski attributed these difference in pain expression behaviors to reinforcement of behaviors which were consistent with culturally defined familial norms.

Zborowski's data suggested that pain expression was related to the sensitivity of the individual to painful stimuli. In a laboratory environment, Woodrow, Friedman, Siegelaub, and Collen (1975) demonstrated that tolerance to pain was related to gender, age, and ethnicity in a sample of 41,110 subjects. Pain tolerance decreased with increasing age, with those over 60 years of age tolerating two thirds to three fourths the deep pain tolerated by those under 30 years of age. Men tolerated more pain than women ($p<.001$) whereas whites tolerated more pain than blacks who tolerated more pain than oriental subjects ($p<.001$). Although these findings related to experimentally induced pain should not be generalized to the clinical pain of cancer, they do suggest that gender, age, and ethnicity may be variables which influence report of pain intensity by patients with cancer pain.

Lipton and Marbach (1984) attempted to validate Zborowski's findings using a structured interview in 200 patients with facial pain, 50 subjects per group from black, Irish, Jewish, and Puerto Rican ethnic groups. The interview included 35 questions with content validity established from literature review and review by four facial pain experts. Items were scaled on a five point lickert-type scale. In terms of the items related to behavioral expression of pain, Puerto Ricans were more likely to lose control when experiencing pain ($F=7.13$, $p<.01$). Conversely, black, Irish, Italian, and Jewish subjects were more likely to hide their pain from others ($F=2.61$, $p<.05$). Italians

were more likely to become emotional ($F=4.11$, $p<.01$). Contrary to Zborowski's findings, Irish subjects were more likely to want others around when they were experiencing pain, but no differences were found between the ethnic groups for preference for being alone when in pain.

Although Lipton and Marbach attempted to provide less subjective data than Zborowski's method provided, lickert responses were collapsed to dichotomous responses (agree or disagree) which would influence instrument sensitivity to differences between the groups. Additionally, the psychometric properties of the tool were not reported, other than content validity. Therefore, the validity and reliability of Lipton and Marbach's data must be assessed through replication of study results. Generalization of these data to cancer pain are not indicated, but again, the possible importance of ethnicity as a variable influencing behavioral responses to pain must not be neglected.

Bond and Pilowsky (1966) investigated the relationship between patients' pain intensity reports and the pain relief treatments provided by nurses. Forty-seven patients with advanced stage malignancies and multiple primary sites rated their pain intensity on a 10 cm visual analogue scale (VAS). Nurses recorded all patient requests for pain relief and all analgesic administrations. Three groups emerged from differences in the data--a group that reported no pain ($n=9$), a group (A) that reported pain but did not request or receive analgesics ($n=13$), and a group (B) that reported pain, requested and received analgesics ($n=25$). No gender differences were noted between groups. Statistically significant differences were that: group A males recorded more pain than group A females ($p<.001$); group B females recorded more pain than

group A females ($p<.001$); and group B males recorded more pain than group A females ($p<.001$). Although not analyzed for significance, the frequencies of analgesic administration demonstrated that more males requested analgesics at times which corresponded to the patient recording a 0 pain intensity (no pain) whereas more females were given analgesics on the nurse's initiative when a 0 pain intensity score was recorded by the patient. Additionally, when patients recorded pain intensity scores greater than 0, equal numbers of males and females received analgesics upon their request; however, more women received analgesics upon the initiative of the nurse.

Although the methodology of the study did not reveal possible causes for these differences, pain expression behavioral differences may account for the findings. Men certainly requested analgesics prior to onset of pain. Females, on the other hand, may have used more nonverbal pain expression behaviors to communicate their pain to the nurses who interpreted the behaviors as an indication to administer an analgesic for pain control.

In a more recent study, Ahles and associates (1983) reported that 77% of 40 patients with cancer pain believed that significant others knew when they were experiencing pain. Patients believed that facial expression (49%), mood changes (21%), going to bed (8%), and pain complaints (6%) were indicators of pain to significant others. Furthermore patients indicated that when they expressed the presence of their pain, significant others offered aid (72%) and assumed the patients' responsibilities (49%), such as doing housework. When

patients engaged in these behaviors they expected others to realize they were in pain and needed help.

Other groups targeted facial expressions as an indicator of pain. Keefe and associates (1985), studied 30 patients with squamous cell carcinoma of the head and neck (Stage II or greater) using structured interview and direct observation of motor pain behaviors: guarded movement, grimacing, rubbing, and sighing during a period where the patient was asked to sit, stand, walk, recline, rotate the head, swallow, and cough each for one minute on three occasions (at initial diagnosis, 3-6 weeks later, and 2-3 months after initial diagnosis). Behaviors were scored by trained raters who had demonstrated at least 90% inter-observer reliability in the scoring procedures. Guarded movements and grimacing were the only targeted behaviors that were noted during the observation periods. Guarding decreased over time whereas grimacing increased.

Grimacing was defined as an "obvious facial expression of pain that may include furrowed brow, narrowed eyes, tightened lips, corners of mouth pulled back, and clenched teeth" (Keefe, Brantley, Manuel, & Crisson, 1985, p.329). Grimacing occurred more frequently in patients reporting pain ($t(81)=3.24$, $p<.002$). In addition, the summed number of grimaces occurring during the three observations were correlated with the patients' pain intensity ratings ($r=.40$, $p<.001$). These data suggest that grimacing was moderately associated with pain intensity in patients with head and neck cancer. However, if grimacing serves a pain expression function or some other function remains to be determined.

Over the years, methodologies and tools to measure the expression component of the cancer pain behavioral dimension have become more sophisticated, yet surprisingly few generalizations are possible about how people express pain when different people are present or when cancer pain varies by chronicity, intensity, and etiology. Findings suggest that a number of variables may influence pain expression behaviors, including gender, age, and ethnicity. However, the impact of these variables on lung cancer pain expression behaviors has not been assessed. Although lung cancer pain expression behaviors may include gross body movements and/or facial expressions, research is required to identify behaviors patients intend as a means of communicating the presence or intensity of their pain to other individuals in their environment.

Behaviors Prevented By Pain

In the previously described study conducted by Keefe and associates (1985), responding to a structured interview at each of the three data collection points, patients recalled 1) activities that increased or relieved their pain, 2) their activity level, and 3) their pain medication intake. Over time, patients reported increased sitting and reclining time and decreased walking and standing time. Patients also reported an increased use of analgesics and the number of pain relieving methods used over time as well as an increased number of activities which increased their pain. Mean pain intensity ratings increased slightly from 2.9 to 3.4 on a 0-10 number scale. A behavioral dysfunction index (BDI) was computed as a composite measure of data obtained from the interview and observation sessions. Pain ratings were

correlated with the BDI indicating that as behavioral dysfunction increased pain intensity also increased.

Ahles and associates (1983) investigated cancer pain behaviors within a multidimensional framework that included physiological, sensory, affective, and behavioral components. They studied 40 heterogeneous patients with cancer pain and 37 pain-free patients with cancer matched on diagnosis, stage of disease, age, gender, and inpatient versus outpatient status. As with Keefe and associates' study, the behavioral dimension of pain was defined as activity level or analgesic intake. Specifically, the multidimensional measures of pain included: interview; self-observation using a daily diary in which pain intensity, analgesic use, and activity level were recorded four times a day; the pain descriptor section of the McGill Pain Questionnaire (MPQ); the Beck Depression Inventory (BDI); the State-Trait Anxiety Inventory (STAI); the Symptom Checklist-90 (SCL-90); and visual analogue scales of depression and anxiety.

The pain-free matched group completed relevant interview questions, psychological measures, and the activity level section of the diary. The pain group was found to spend significantly less time walking/standing than the pain-free group. Behavioral measures were inconsistently correlated with sensory and affective measures of pain. Medication intake was significantly correlated with sensory (intensity scale scores r=.53 and .58; MPQ sensory score r=.42), affective (MPQ affective score r=.36), and cognitive (MPQ evaluative score r=.42) variables. Activity level was negatively correlated with affective (r=-.38) and cognitive (r=-.43) scores, but not with any sensory score. No

consistent pattern was found in correlations between behavioral dimension variables and the measures of psychological state, such as anxiety or depression. Pain, not cancer, was found to be an important contributor to behavioral dysfunction since the pain group spent significantly less time walking/standing ($F(1,51)=11.69$, $p=.001$).

Daut and Cleeland (1982) investigated the relationship between perceived cause of pain and activity level by studying 407 patients with breast, cervical, uterine, ovarian, prostate, and colorectal cancer pain. When worst pain was treated as a covariate, analysis of variance indicated that the relationship between perceived cause of pain and activity interference was statistically significant ($F(2,219)=12.43$, $p<.001$). Pain perceived to be caused by the cancer was associated with greater interference with activity.

More recently, McGuire (1987a) studied 40 patients, 30% with lung and 42% with breast cancer pain. Using a descriptive design and lickert-scaled questions, most patients (58% of 40 patients) did not perceive that pain influenced their ability to concentrate or remember things. Little interference in concentration was reported by 20% of the patients, whereas 15% reported a fair amount of interference, 5% reported very much interference, and 1 patient could not respond to the question. In contrast, the majority of the patients (65%) indicated that pain partially or completely interfered with all activities, such as work, housework, and recreation. Cautious interpretation of these data are warranted given the limited assessment of the psychometric properties of the instrument used to derive these results. Content

validity was the only type of validity that had been evaluated and the reliability of the instrument had not been assessed.

Rankin (1982) conducted a longitudinal study to investigate pain patterns in 40 patients with metastatic cancer pain. The primary malignancies were predominantly breast (25%), uterine (18%), and lung (15%) cancer. Using a pain relief questionnaire with unreported validity and reliability, Rankin found that 40% of the sample denied any problems concentrating because of the pain. The remaining 60% of the sample reported that they sometimes had difficulty concentrating (28%), or often had difficulty concentrating (32%). Concentration status demonstrated no statistically significant association with pain intensity using analysis of variance procedures. Operational definitions for the responses were lacking. Although patients were using narcotics, psychotropic, and sedative drugs, concentration status was not evaluated by drug consumption.

Together these data from McGuire's and Rankin's studies suggest that caution may be warranted when administering tools to patients with metastatic cancer pain because of the possibility of compromised concentration. Pain or other factors may decrease a person's ability to concentrate which in turn could alter responses on instruments. Hence biased data could be obtained from some patients with metastatic cancer pain.

McGuire (1987a) also reported that only 35% of the 40 patients perceived that their pain did not interfere with their family relationships whereas pain was perceived as interfering with family relationships to a little extent by 15%, to a fair amount by 23%, and

very much by 13%. Social relationships were perceived as influenced in a similar manner. The majority (70%) of the patients reported that they thought that their pain upset, frightened, or worried their family and/or friends. Yet, 38% of the patients reported that their family and/or friends provided emotional support and understanding to them to help them deal with their pain. Only 15% of the patients (those without family or close friends) reported that they perceived that their family or friends did nothing to help them deal with their pain.

Sleep-related behaviors were found to be associated with cancer pain. Rankin (1982) found that patients without sedative drug orders reported significantly higher pain intensity than patients given sedatives or patients with sedative drug orders. McGuire (1987a) reported that 58% of 40 patients indicated that their pain interfered with their ability to go to sleep, and awakened 38% of the patients. Ventafridda, Tamburini, Caraceni, De Conno, and Naldi (1987) found that with systematic use of pharmacological cancer pain management strategies the number of hours patients were able to sleep improved by 50%. Hence, data suggest that cancer pain may influence behaviors related to an important protective biological mechanism, namely sleep.

McGuire (1987a) also found that patients with cancer pain reported that pain interfered with caring for their homes (65%), family (45%), and their own personal needs (55%). Family members were relied upon to help the patients meet their responsibilities.

Approaching the issue of behaviors prevented by pain from another perspective, one research group (Grobe, Ilstrup, & Ahmann, 1981) found that 27 patients with advanced stage cancer reported that they believed

their family needed to learn particular skills in order to take care of them. These skills were related to: activities of daily living (26%); ambulation (59%); bowel (33%) and bladder (22%) management; comfort care (37%); dietary control (30%); and pain management (33%). Hence, skill learning needs were consistent with the responsibilities that family members must assume when the patient is in pain and becomes more debilitated, either from the pain or the disease.

McGuire (1987a) found that pain affected patients' appetite and ability to eat. Pain reportedly was associated with complete loss of appetite for 30% of the patients, partial loss of appetite for another 30%, and no loss of appetite for 40%. Conversely, 68% reported that pain had no effect on their ability to eat. Those patients, for whom pain affected their ability to eat, reported that pain physically hindered them from consuming nutrients in their usual manner. Some (13%) of the patients, for example, had to change the hand with which they ate or had to change the consistency of the foods consumed, i.e., eat soft foods because of pain when chewing.

Stam, Goss, Rosenal, Ewens, and Urton (1985) reported that 23 patients receiving radiation therapy for unreported cancer diagnoses indicated that pain interfered with their sexual functioning. Worst pain was significantly correlated with interference of pain with sexual functioning ($r=.55$, $p<.05$); however, details of this relationship were not reported.

The impact of cancer pain upon a number of activities of daily living have been the focus of numerous investigations. Data indicate that cancer pain, including lung cancer pain, may interfere with most

activities in which a person must engage throughout the day. Although the cancer disease may also interfere with these behaviors, data suggest that the impact of pain might be differentiated from the disease impact.

Pain Control Behaviors

Although pain control behaviors were identified in the early 1970s, investigations considering these behaviors have occurred only within the past five years. Hence, this aspect of the behavioral dimension of pain is in its infancy.

In a descriptive study, Copp (1974) had nursing students interview 148 hospitalized adults to investigate the patient's perspective of suffering, or pain. Patients reported that their pain intensity was reduced by a wide range of behaviors, including: concentration exercises; food and fluid intake; pounding; pacing; rocking; biting; clenching; verbalizations, such as prayer, profanity, and nonsensical sayings; heat and cold application; position changes; massage; distraction; strenuous activity; movement restriction; breathing exercises; and use of analgesics. Many patients (exact number was not reported) were in intensive care units, yet they reported attempting to use pain control strategies known to them prior to requesting medications and again if medications were ineffective in totally relieving their pain. Sample characteristics were not reported or tested for possible relationships with pain control strategies. Hence, Copp's data provided preliminary evidence that patients in pain use behaviors to help control their pain, but did not elucidate how effective the behaviors were or the types of pain for which particular behaviors were and were not effective. Additionally, results were

limited by unreported validity and reliability of the instruments and interviews. Yet, this research initiated a unique perspective of pain, that of the patient enduring or trying to manage pain.

McGuire (1984) studied 24 inpatients with cancer pain related to a variety of primary malignancies (17% lung) using the 1970, four part version of the McGill-Melzack Pain Questionnaire (MMPQ). In response to the question, "what kinds of things relieve your pain?", 91% of the subjects reported that analgesics were helpful. Other pain relieving behaviors included: lying still or restricting movement (35%); positioning or moving an affected body part (35%); consuming food or drink (17%); and other behaviors (30%). Although pain intensity was measured with the present pain intensity scale of the MMPQ, pain intensity was not compared to pain relieving factors. Pain relieving behaviors were not analyzed by primary malignancy or stage of disease. Nor was the efficacy of the pain relieving behaviors assessed. Hence McGuire's findings from a cancer sample supported the validity of several of the behaviors Copp (1974) had identified. However, other than providing some validity and incidence data, McGuire's findings contributed little new knowledge about the construct of cancer pain behavior.

Barbour, McGuire, and Kirchhoff (1986) investigated the nonanalgesic methods of pain control used by 58 outpatients with cancer. Although the sample included a variety of primary malignancies, 29% were patients with lung cancer pain. In response to the question, "what makes your cancer pain better?", 90% of the patients gave a response, including: use of a narcotic analgesic (45%); change of position (23%);

no activity (12%); heat application (9%); physical or emotional activity (6%); and nonnarcotic drug use (5%). Of the 43 patients using nonanalgesic pain control methods, 65% used one specific behavior, 19% used two behaviors, 14% used three behaviors, and 2% used four behaviors.

Heat relieved pain "some" for 57% of 28 patients, but 32% reported heat did not help at all and one patient reported heat completely relieved the pain. Distraction was used by 9 patients, 89% of whom reported it helped "some". Position change was used by 8 patients, 86% of whom reported it helped "some" but 14% of whom reported it was not helpful. Massage (n=6), exercise (n=4), and other methods (n=5), such as, cold application, and eating specific foods were also used. Massage was somewhat helpful for 67% of the 6 patients, but not helpful for 33%. Exercise was helpful for only 25% of the 4 patients. Other behaviors were helpful to "some" degree for 60% of the five patients or "a lot" helpful for 40%.

Findings from this study are difficult to interpret because of the descriptive nature of the study and the limited assessment of instrument validity and reliability. Yet, as with McGuire's previous study, data supported Copp's findings and provided an initial assessment of the degree of pain relief obtained by using particular behaviors. However, since the data were not analyzed to consider pain variables, such as intensity, location, onset, or pattern the importance of these pain control behaviors were not clarified.

Donovan and Dillon (1987) used an interview format to study the characteristics of pain in 69 inpatients with cancer. Primary

malignancy site and stage of disease were not reported. As in the previous studies, patients reported use of a variety of behaviors in an attempt to control pain but the effect of these behaviors was highly variable between subjects. Eating increased pain for 21%, decreased pain for 3%, or had no effect on pain for 68% of the subjects. Similarly, lying down increased pain for 4%, decreased pain for 53%, or had no effect for 43% of the subjects. Mild exercise increased pain for 26%, reduced pain for 19%, had no effect for 43%, and no response was given by 13% of the subjects. For distraction, only 3% of the subjects reported pain was increased, 34% reported pain was reduced, 59% reported no effect, and 4% had no response. Similar figures were reported for use of heat (4%, 39%, 21%, and 4%); cold (19%, 4%, 29%, and 57%); and massage (1%, 26%, 26%, and 47%). For use of analgesics, no subject reported that the medication increased pain, 80% reported pain was reduced, 6% reported no effect, and 14% did not respond.

As with previous studies, data presented by Donovan and Dillon were very descriptive in nature. A variety of behaviors were used by patients to attempt to control their pain, but the effectiveness of those behaviors varied tremendously.

Wilkie and associates (1988) used interview and participant observation to record behaviors with 13 inpatients with advanced stage, solid tumor malignancies. Patients were interviewed on the first day of the study to determine what behaviors they used to help relieve their pain, what behaviors pain prevented, and to examine other pain variables, such as location, duration, onset, intensity (measured with a 10 cm, horizontal VAS, anchored with no pain and pain as bad as it could

be). Twice daily for two days, patients rated their pain intensity with the VAS, and during four 15 minute observation periods, overt behaviors were observed. At the conclusion of the final observation period, behaviors were validated by patients as behaviors they used to control their pain or behaviors unrelated to pain control.

Patients validated that pain control was provided by: three immobilizing/guarding behaviors (n=5); five distraction behaviors (n=12); five positioning behaviors (n=13); three pressure manipulation behaviors (n=8); three analgesic use behaviors (n=8); and three other types of behavior (n=7). Immobilizing/ guarding behaviors included protection of a specific body area that was painful when moved. Distraction behaviors included watching television, reading, talking with family and friends, and deep breathing exercises. Positioning behaviors included assuming special or favored positions where pain was minimized. Pressure manipulation behaviors included rubbing or massaging a body part that was painful and applying firm pressure over a painful area. Analgesic use behaviors included requesting analgesics, watching the clock to know if it was permissible to request analgesics, and talking with physicians and nurses about analgesic effectiveness. Other behaviors included sleeping, eating or drinking, and moaning. Although inter-rater reliability in behavior categorization was 93%, data were limited by lack of inter-rater reliability for the behavioral observation.

Mean pain intensity scores ranged from 28 to 45 at the four measurement periods. The summed number of pain control behaviors used during an observation period was moderately correlated with mean pain

intensity ratings at three of the four observations periods (r =.54,.64,.46; $p<.02$). When pain control behaviors were not correlated with pain intensity, patients reported lower pain intensity ratings but engaged in more activities of daily living in addition to engaging in pain control behaviors.

Interestingly, only two patients reported and were observed using the same types of pain control behaviors when the interview and the observation data were compared. This emphasizes the importance of combined interview and observational assessment because some patients were not observed using all types of behaviors they reported as useful, such as using a heating pad. Although generalizability of these findings was inappropriate, demonstration that patients could indicate their intent for using a behavior was a contribution to pain behavior methodology.

To summarize, independent research conducted by several nurse scientists corroborated many of Copp's early findings in cancer populations (Barbour et al., 1986; Bressler et al., 1986; McGuire, 1984; Donovan & Dillon, 1987; Wilkie et al., 1988). Interestingly, data collection for all of these studies occurred nearly simultaneously in two separate regions of the United States. Major findings from these studies are summarized in Table 1. Because of the descriptive nature of these studies, little can be said of the behaviors related to a specific type of cancer pain.

As Table 1 indicates, pain was reduced, increased, or not effected by the many of the behaviors. Therefore, it is difficult to predict the effect of a particular behavior for a given patient. Although

Table 1

Review of Cancer Pain Behavioral Dimension Studies.

Author Date	Sample type & Study Design	Tools	Findings	Critique
McGuire (1984) 24	Inpatient, convenience, many cancers, half metastatic disease/ Descriptive Design	MMPQ	Pain increased by: moving(57%) Eating/swallowing(13%); being cold(9%); other(9%). Pain better by: analgesics(91%); lying still/restrict movement (35%); position/move body part (35%); food/drink(17%); other(30%)	Method & reliability of category development not reported. Large % of sample included in "other". No comparison of pain variables, i.e., intensity, location, and behaviors although data collected
Barbour et al. (1986) 55	Outpatient, convenience, all stages of cancer 29% lung, 52% metastatic, 28% regional disease/ Descriptive Design	8 page interview guide-investigator developed (face validity)	Pain intensified by: walking, standing, twisting, sitting, lying flat or supine, cough, lifting, weather, medication wearing off. Pain better by: narcotic, position change inactivity, heat, exercise, distraction, nonnarcotic analgesic. Not all pts using nonpharm method found it effective, only heat provided complete relief (n=1)	Although training sessions were held to train the 11 data collectors, interrater reliability in interview was not assessed. Data reflects behaviors across multiple stages of disease. Tool validity and reliability not assessed. Nice beginning description of cancer pain behaviors. Pain variables not reported. No report on reliability of behavior categories.
Donovan et al. (1987) 69	Inpatient, random sample, cancer data not reported/ Descriptive Design	Modified MMPQ, investigator developed questions	Pain increased by: fatigue, tension; Pain increased/ decreased by: eating, lying down, exercise, noise, heat, distraction, cold, massage, analgesics.	Relationship of behavior to type of cancer or pain intensity not evaluated. Not able to draw conclusions about usefulness of a behavior for specific patient.
Wilkie et al. (1988) 13	Inpatient, convenience, Stage III-IV solid tumor cancers, 70% metastatic/ Correlational Design	PAT BVOF VAS	Pain reported decreased by: medication (85%); pressure (15%) positioning (46%); immobilizing/ guarding(15%); distraction(30%) heat/attitude (23%). Pain reduced according to validation of observed behaviors:medication (62%), pressure(62%), positioning (100%), immobilize/guard (38%), distraction (92%). Pain intensity linearly related to number of pain control behaviors used.	Lack of interrater reliability of behavior observation. High interrater reliability in categorization of behaviors (93%) Amount by which behavior reduced pain not measured. Small sample.

Key: MMPQ = McGill Pain Questionnaire; PAT = McGuire's (1981) Pain Assesment Tool; BOVF = Behavioral; Observation Validation Form; VAS = Visual Analogue Scale

specificity of behavioral effect on pain may be an unrealistic expectation, given the variable nature of cancer pain, it is possible that with improved control of relevant physiological variables that the effect of behaviors could be predicted with greater certainty. Based upon knowledge of pain and pain modulation mechanisms and the possibility that certain histological types of tumors may be associated with endogenous pain relieving substances, primary type of malignancy, tumor histology, and type of tissue involved with the nociceptive process (somatic, visceral, or neural) appear to be very relevant physiological variables. Researchers have not evaluated pain control behaviors in samples where these variables have been controlled or correlated with pain variables, such as intensity, location, quality, onset, or pattern.

Based upon the published research, the behavioral dimension of pain appears to include a variety of behavioral responses to pain, such as verbal and non-verbal expressions of pain, behaviors which control the pain, and behaviors prevented by pain. In cancer populations, the behaviors used to control pain have received preliminary description. However, little systematic research has been conducted to describe behaviors used to express cancer pain or specific behaviors with which pain interferes. Full characterization of all three types of behavior remains to be completed.

Theoretical Framework

Early research about pain behaviors was based upon theoretical assumptions related to motivational aspects of pain behaviors (Fordyce, 1976; Fordyce, Lansky, Calsyn, Shelton, Stolov & Rock, 1984). The

proposed research is based upon the neuroanatomical and neurophysiological mechanisms of pain and pain modulation (the Gate Control Theory) (Basbaum & Fields, 1984; Fields, 1987; Fields & Levine, 1984; Kelly, 1985; Melzack & Wall, 1965; Yaksh & Hammond, 1982) within the framework of the Johnson Behavioral System Model for nursing practice (Johnson, 1980). The amount of pain perceived by an individual is determined by the neurochemical events that occur within a complicated neural network. Potential exists for nociceptive signals to be modulated or altered by endogenous opiates and other neurochemicals located throughout the peripheral or central nervous system (Basbaum & Fields, 1984; Fields, 1987; Fields & Levine, 1984).

As an individual attempts to meet basic human needs, such as self protection, affiliation, gratification, dependency, waste excretion, appetitive satisfaction, and/or mastery and control, potential exists for behaviors to influence the neurochemical interaction within the nervous system and to thereby increase or reduce the pain perceived by the individual (Johnson, 1980). Theoretically, because of the physiological circuitry of pain perception, pain intensity may be modulated by behaviors that alter ascending nociceptive input to the central nervous system and/or stimulate descending pain modulating mechanisms. Individuals with cancer pain of long duration, constant pattern, and/or high intensity are most likely to develop a set of protective behaviors in order to communicate and/or to control their pain.

Yet research indicates that severe pain is associated with activity curtailment when general activities of daily living are

assessed (Ahles, Blanchard & Ruckdeschel, 1983; Cleeland, 1984; Daut & Cleeland, 1982; McGuire, 1987a). Hence, there is a critical need for the behavioral correlates of cancer pain to be characterized using discrete measures of behavior and to determine the intent of the behavior from the perspective of the individual experiencing the pain.

A lung cancer model presents an excellent opportunity to delineate the behavioral correlates of pain in a prevalent primary malignancy. In advanced stages, lung cancer pain is reported to be associated with somatic, visceral, or neural involvement and may vary by histological cell type (Greenwald et al., 1987; Marino et al., 1986; Turnbull, 1979). Hence, lung cancer pain provides a model in which the behavioral correlates of cancer pain may be investigated while considering the histology of the disease and the major etiologic factors associated with the pain (Turnbull, 1979). Additionally, because of the steep trajectory of the disease, lung cancer provides a model in which the pattern of the behavioral correlates of cancer pain may be evaluated, especially in relation to the development and modification of the behavior over the course of the disease.

Assumptions

Inherent in behavioral research is the assumption that sampled behaviors are consistent with the subject's behavioral repertoire (Scherer & Ekman, 1982; Siegman & Feldstein, 1987). Although behavior may vary by situation, when individuals perform activities associated with pain, individuals may incorporate their usual behavioral response to the sensation of pain (Keefe & Block, 1982; LeResche, 1982). Hence, observation of a sample (portion) of a person's behavior provides a

valid method of characterizing the behavioral dimension of pain. Also inherent in any pain research are the assumptions that individuals experiencing the pain are the experts about how the pain feels and that their report of the experience is the most accurate indicator of the experience (Meinhart & McCaffery, 1983). Furthermore, the conduct of this research assumed that an individual is a self-interpreting being who has "an effortless and nonreflective understanding of the self" (Benner & Wrubel, 1989, p. 41). This understanding occurs because people "are always situated in a meaningful context and because they grasp meaning directly" (Benner & Wrubel, 1989, p.49). Finally, this research was based on the assumption that individuals attempt to share their experience to the fullest extent humanly possible.

Research Questions

This research addressed the following questions:

1) What facial expressions and body movements do patients with lung cancer indicate they use to communicate their pain to other individuals?

2) What facial expressions and body movements do patients with lung cancer indicate they use to reduce the intensity of their pain?

3) What activities do patients with lung cancer indicate their pain prevents them from doing?

4) What is the relationship between pain expression behaviors (facial and body) and salient aspects of pain: intensity; quality; location; onset; and pattern?

5) What is the relationship between pain control behaviors (facial and body) and salient aspects of pain: intensity; quality; location; onset; and pattern?

6) What is the relationship between the behaviors pain prevents and salient aspects of pain: intensity; quality; location; onset; and pattern?

7) What is the relationship between pain expression behaviors and affective, cognitive, and physiological-sensory dimension variables?

8) What is the relationship between pain control behaviors and affective, cognitive, and physiological-sensory dimension variables?

9) What is the relationship between behaviors prevented by pain and affective, cognitive, and physiological-sensory dimension variables?

10) What are the best predictors of pain expression behavior from selected demographic, affective, cognitive, and physiological-sensory variables?

11) What are the best predictors of pain control behavior from selected demographic, affective, cognitive, and physiological-sensory variables?

12) What are the best predictors of behaviors with which pain interferes from selected demographic, affective, cognitive, and physiological-sensory variables?

Definition of Terms

To address the research questions, terms were defined as follows:

Age - chronological age reported by the patient

Gender - male or female designation as observed by the investigator

Ethnicity - cultural group or race to which the patient claimed membership

Education level - highest number of years of formal education

Religion - doctrine of beliefs the patient verbally reported

Tumor histology (lung) - structural categorization of malignant cells as primary squamous cell carcinoma of the lung; primary adenocarcinoma of the lung; primary oat cell carcinoma of the lung; and/or primary large cell carcinoma of the lung, as determined from the pathology report

Tumor stage - classification of a malignant lesion by size and location according to the system of the American Joint Committee on Cancer and the Union International Contre Cancer (Mountain, 1986) (see Appendix A)

Metastatic pattern - scheme of tumor spread from the primary lung lesion as documented with medical record data, such as bone scans, xrays, computerized tomography scans, etc.

Anticancer therapy - method of removing malignant tumor cells from the body: surgical procedure; radiation dose and fractionation; chemotherapy agent, dosing time span, and cumulative dose as documented from medical record review

Concurrent disease status - any active, chronic, medical diagnosis documented from medical record review or patient report

Pain - "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey, 1979).

Pain intensity - magnitude or severity of the pain as reported by the patient with a visual analogue scale and the present pain intensity scale of the McGill-Melzack Pain Questionnaire (Part 4; See Appendix B)

Pain onset - the initial point in time when the unpleasant sensory experience began, as measured by the patient's recall of the date that pain began and recorded on the Demographic Data Form (See Appendix C)

Pain pattern - the estimated duration that each episode of pain was experienced as measured by the McGill-Melzack Pain Questionnaire (Part 3)

Pain location - the area marked by the patient as representing the painful part(s) of the body using the body outline of the McGill-Melzack Pain Questionnaire (Part 1)

Pain quality - the attribute of pain described by the selection of words from the McGill-Melzack Pain Questionnaire (Part 2), including the sensory, affective, evaluative, and miscellaneous aspects of the pain

Analgesic drug consumption - all drugs consumed within 8 hours of study measures for control of pain (includes drug, dose, route, times consumed) as measured by the McGill-Melzack Pain Questionnaire

Pain aggravating factor - an endeavor associated with increases in the amount of perceived pain as measured with the McGill-Melzack Pain Questionnaire (Part 3)

Pain alleviating factor - an endeavor associated with decreases in the amount of perceived pain as measured with the McGill-Melzack Pain Questionnaire (Part 3)

Pain expression behaviors - performance aimed at communicating perceived pain to other persons as measured with the Score Sheet - Lung Cancer Pain Related Behaviors (Score Sheet) and the Manual for Video Observation Method - Lung Cancer Version (Manual) (See Appendix D)

Pain control behaviors - performance aimed at manipulating the amount of perceived pain as measured with the Score Sheet and Manual

Behaviors prevented by pain - performance prevented by the sensation of pain as measured with the Score Sheet and Manual

Behavioral pain coping strategies - action methods of managing perceived pain as measured with the pain Coping Strategies Questionnaire (See Appendix E)

Anxiety level - a sense of apprehension, uneasiness, or nervousness as measured with the State-Trait Anxiety Inventory (See Appendix F)

Pain affect - emotion related to pain as measured with the McGill-Melzack Pain Questionnaire (Part 2)

Locus of control - source of reinforcement motivating behavior as measured with the Cancer Specific Locus of Control or the Pain Locus of Control (see Appendix G and Appendix H).

Pain evaluation - appraisal of the pain as measured by the McGill-Melzack Pain Questionnaire (Part 2)

Cognitive pain coping strategies - mental methods of managing perceived pain as measured by the pain Coping Strategies Questionnaire

CHAPTER THREE

Methods

Research Design

A descriptive, correlational design was used (see Figure 1). Repeated measures were conducted for selected study variables (see Figure 2).

Research Setting

Subjects were referred by physicians from multiple institutions in the greater San Francisco Bay Area, in Fresno, CA, and in Grand Junction, CO. For the most part, an oncology nurse made the actual referral to the study. Data collection occurred in most subjects' homes.

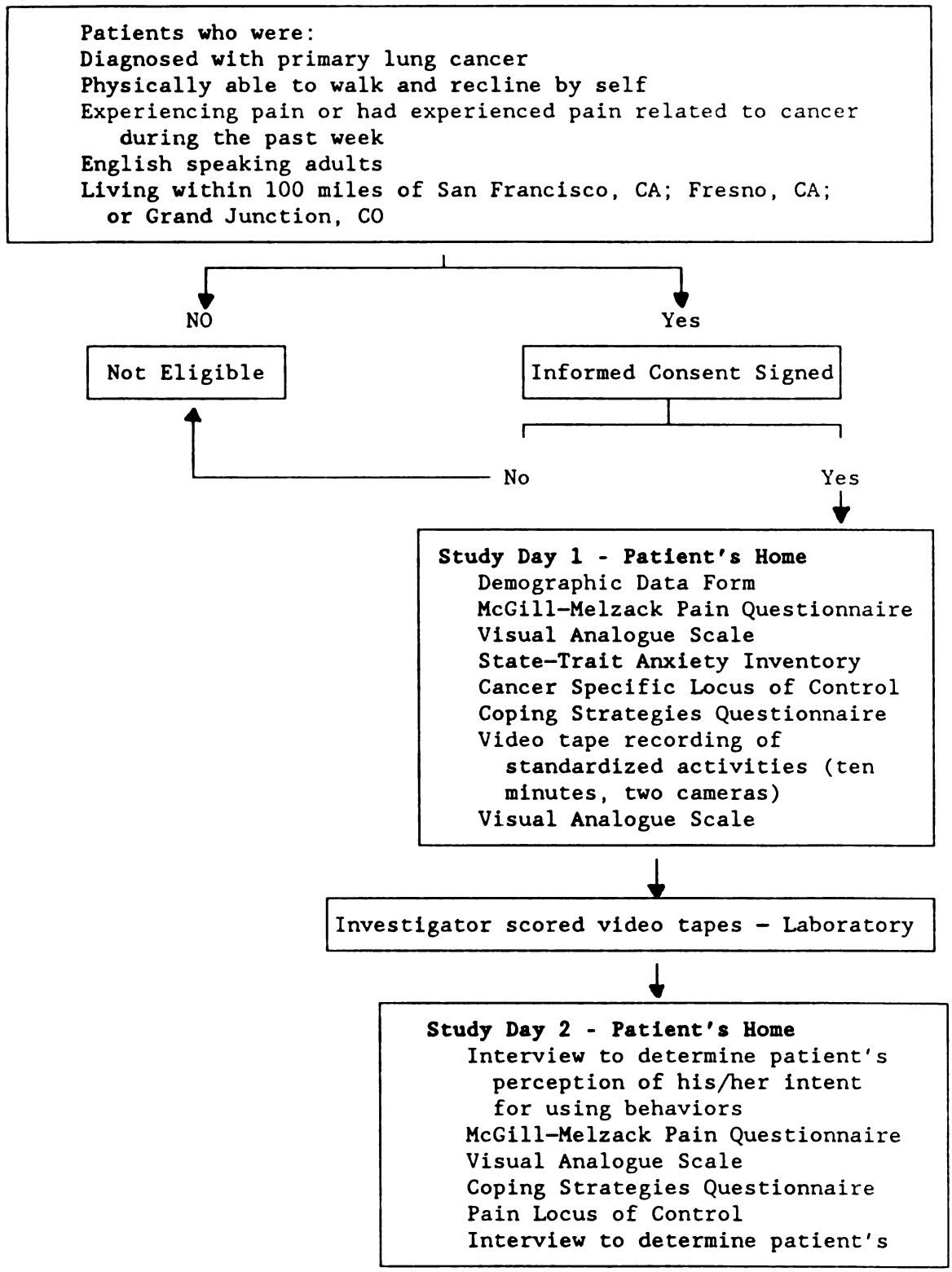
Sample

Human subjects assurance. Approval for study procedures was obtained from the University of California, San Francisco's Committee on Human Research (See Appendix I). Additionally, appropriate Institutional Review Board approval was obtained from other institutions referring subjects (See Appendix I). Written consent was obtained from each subject (See Appendix J).

Selection criteria. The following inclusion criteria were used to identify eligible subjects.

(1) Patients had a confirmed histological diagnosis of primary lung cancer - squamous cell carcinoma, oat cell carcinoma, adenocarcinoma, or large cell carcinoma;

Figure 2. **Study Design**



(2) Patients were English speaking and reading adults - at least 18 years of age; and

(3) Patients reported having experienced pain related to tumor or antitumor therapy during the week prior to data collection.

Patients were excluded if they: 1) were physically unable, without the assistance of another person, to ambulate for two minutes or to recline; or 2) lived more than 100 miles from San Francisco, CA, Fresno, CA, or Grand Junction, CO. Subject accrual required 15 months (December, 1988 through February, 1990).

Fifty patients consented to participate but 45 eligible patients completed study measures. Two patients withdrew after consenting but prior to completing any study measures, one patient died before completing any study measures, one patient became fatigued during the procedures and was then too ill to complete the study, and one patient participated but was actually ineligible because pain had not been present during the week preceding study measures. The ineligible patient had pain when he was first approached about participating and was insistent about wanting to participate even though his pain had resolved 10 days prior to the data collection.

Data Collection Methods

Data collection techniques. Interview, self-administered tools, participant observation, and medical record review methods were used. Data were collected by the investigator. The protocol was pre-tested with three patients to establish feasibility. This resulted in no substantial changes and the three patients are included in the sample.

Instrumentation. Study variables were measured using eight tools that required 90 minutes of each patient's time over two days. Tools and scoring procedures are described, and validity and reliability data for the tools are summarized.

(1) A two part **Demographic Data Form (DDF)** (Appendix C) was utilized to document demographic, disease, and selected pain variables. Part One data were obtained through patient interview regarding: 1) age; 2) gender; 3) ethnicity; 4) educational level; 5) religion; 6) cancer diagnosis date; and 7) pain onset. Part Two data were obtained through review of the patient's medical records (inpatient, outpatient, and physician office as necessary), including: 8) tumor histology; 9) tumor stage (at diagnosis and current); 10) metastatic pattern; 11) antitumor therapies (agent, cumulative dose, dosing time span); and 12) concurrent disease status. Feasibility of DDF use was determined through pre-testing in the target population. Interview time was less than three minutes unless the patient elaborated about the sequence of events since diagnosis of the lung cancer.

(2) The four part, 1970 version of the **McGill-Melzack Pain Questionnaire (MMPQ)** (Melzack, 1975) (Appendix B) was used to measure specific demographic, sensory, affective, behavioral, and cognitive dimension variables. The demographic page of the MMPQ was used to document analgesic consumption. Part One of the MMPQ measured pain location using a body outline. Pain quality (sensory, affective, evaluative, and miscellaneous) was measured with Part Two, a list of 78 word descriptors grouped into 10 sensory categories, 5 affective categories, 1 evaluative category, and 4 miscellaneous categories. One

word per category was selected, if the individual believed the word described his/her pain.

A total pain rating index (PRI-T) was obtained by summing the rank values of all words selected by the individual. A PRI-S (sensory) was calculated by summing the rank values of the sensory words selected; a PRI-A (affective) from the affective words; a PRI-E (evaluative) from the evaluative words: and a PRI-M (miscellaneous) from the miscellaneous words selected. Additionally, the total number of words chosen (NWC) provided an estimate of pain quality severity that was correlated with pain intensity (McGuire, 1984; Melzack, 1975).

Part Three of the MMPQ measured the temporal pattern of the pain, pain alleviating factors, and pain aggravating factors. Finally, Part Four measured pain intensity using a six point, word-descriptor scale. This scale was used to estimate present pain intensity (PPI), least pain intensity, and worst pain intensity as well as the intensity of the worst headache, toothache, and stomachache.

Melzack distributed a copy of the 1975 article when the investigator requested an original copy of the 1970 version. The quality of the copy was judged inadequate to produce a legible research instrument, and the investigator retyped the tool to produce a replica of Melzack's (1975) tool. Replication of the body outline was not possible so the investigator commissioned a graphic artist to redraw a body outline.

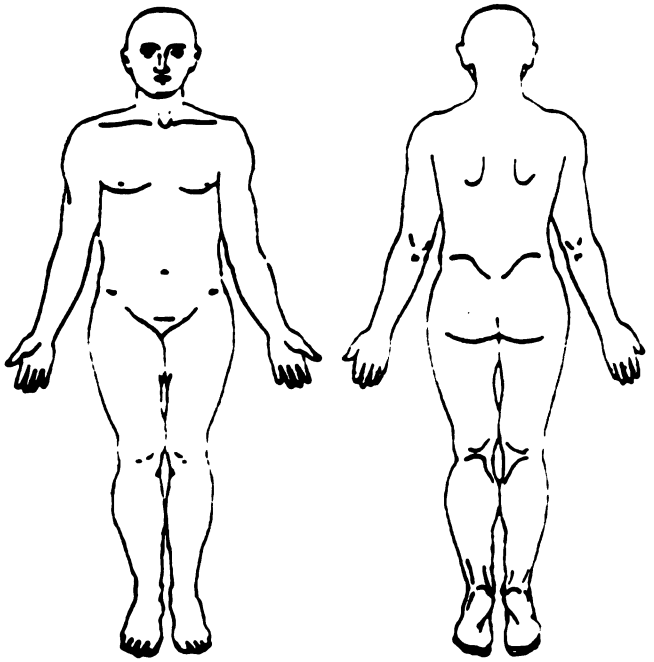
Figure 3 presents a photocopy of Melzack's body outline and the redrawn body outline figure. The minor differences were deliberate. The investigator's clinical practice indicated that patients complained

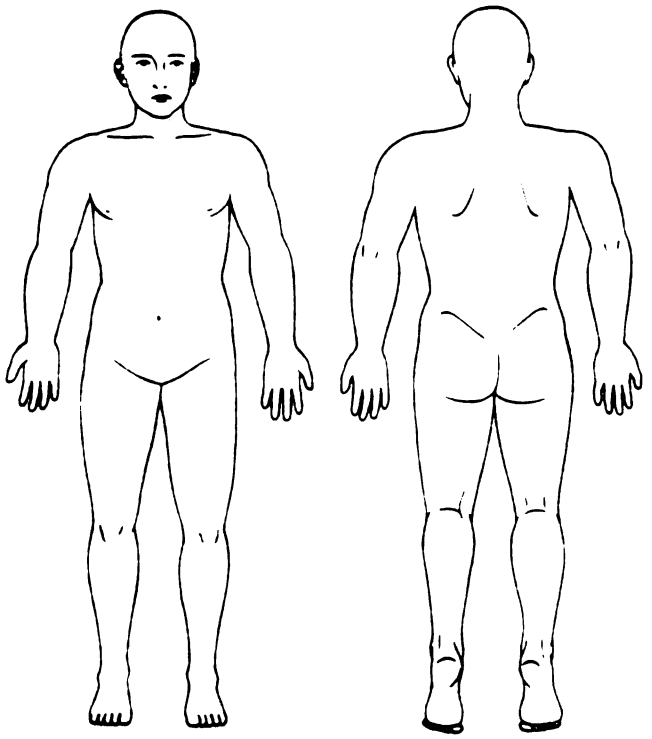
that a carbon-copy of Melzack's body outline was difficult for them to clearly mark pain located in the medial aspects of the arms and legs. Because the legs were drawn in close proximity to each other and the arms in close proximity to the torso, patients were unable to mark, for example, the medial arm without also marking the torso. To avoid this problem, the graphic artist was instructed to slightly abduct the arms and legs.

Additionally, the present pain intensity (PPI) scale of the 1970 MMPQ version was altered to include a no pain option. This was done to provide conceptual clarity for the tool and to make results comparable to data reported by current researchers who use the most popular version of the McGill Pain Questionnaire (MPQ) (Melzack, 1983). The MPQ version includes a six point PPI with a no pain option and has been used since the late 1970s (Wilkie, Savedra, Holzemer, Tesler, & Paul, 1990).

Considerable documentation is available to support the concurrent and predictive validity of the MMPQ or the MPQ as a measure of pain (Dubuisson & Melzack, 1976; Reading, Everett, & Sledmere, 1982; Sedlak, 1985; Wagstaff, Smith, & Wood, 1985; Ward et al., 1982). Construct validity is also supported (Kremer & Atkinson, 1981; Toomey, Gover, & Jones, 1983; Turk, Rudy, & Salovey, 1985), but some of the MMPQ scores are highly intercorrelated, which raises questions whether multidimensional measures are obtained (Turk et al., 1985). Alternate forms reliability (Graham, Bond, Gervovich, & Cook, 1980; Klepac, Dowling, Rokke, Dodge, & Schaefer, 1981; Reading, Hand, & Sledmere, 1983), test-retest reliability (Graham et al., 1980; Hunter, Phillips, &

Figure 3. Examples of the body outline from the McGill-Melzack Pain Questionnaire and as adapted for the current investigation.





& Rachman, 1979; Melzack, 1975), and sensitivity to standardized stimuli (Klepac, Dowling, & Hauge, 1981) have been documented. The MMPQ was completed in 10-15 minutes by outpatients with cancer (Melzack, 1975) and in 24 minutes by hospitalized patients with cancer (McGuire, 1984).

During the protocol pre-test, the investigator recognized that subjects were connecting specific pain sites with specific MMPQ words. These data were recorded. If the subject reported a specific word described a specific site, the site of pain was noted next to the word. In order to maximize this potentially useful data, subsequent subjects were asked (after they had selected all relevant descriptors) which pain site was described by each of the words. These data will be reported in a subsequent paper as they were not included in the original focus of this research.

(3) **The Speilberger State-Trait Anxiety Inventory (STA)** (Speilberger, 1983) (Appendix F) was used to measure one affective dimension variable. The self-administered tool consisted of two, 20-item tools that measured state and trait components of anxiety. Items were measured on a four-point lickert scale that ranged from one (not at all) to four (very much so). Possible scores ranged from 20-80. Whereas the A-state scale measured how the patient felt at the moment the scale was completed, the A-trait scale measured how the patient usually responded to anxiety provoking situations. The STA has been correlated with IPAT Anxiety Scale (.75 to .77); the Taylor Manifest Anxiety Scale (.79 to .83); and the Affective Checklist (.51 to .52) (Speilberger, 1983). Dodd (1984) found that 30 patients undergoing radiation therapy reported mean state/trait anxiety scores of 37/36 and

39/39, respectively at two interviews separated by 4 to 7 weeks. Ahles et al. (1983) found that a group of patients with cancer pain reported mean state/trait scores of 40/38 as compared to reports of 37/34 from a group of cancer patients without pain. Patients with cancer completed the STA scale in less than 10 minutes.

(4) The pain **Coping Strategies Questionnaire (PCSQ)** (Rosenstiel & Keefe, 1983)(Appendix E) was used to measure: 1) cognitive and behavioral strategies used by patients with pain to cope with their pain; and 2) the perceived effectiveness of these behaviors in controlling and decreasing pain. The PCSQ was a self-administered instrument with 48 items. Eight subscales were represented by six items each, including: diverting attention; reinterpreting pain sensations; coping self-statements; ignoring sensations; praying/hoping; catastrophizing; increased behavioral activity; and pain behaviors. Possible scores for all items ranged from 0-6, indicating "never do that" to "always do that"; "no control" to "complete control", or "can't decrease it at all" to "can decrease it completely."

In a sample of 61 patients with low back pain, alpha coefficients for each of seven of the eight subscales ranged from .71 to .85 (Rosenstiel & Keefe, 1983). The eighth subscale, increasing pain behavior, had an alpha coefficient of .28. Similar but slightly higher alpha coefficients were found when 40 patients with cancer pain completed the PCSQ (r=.42 to.85) (McGuire, 1987a). Therefore, the internal consistency (reliability) of the seven subscales was adequate in samples with malignant and nonmalignant pain, but internal consistency of the eighth subscale remained questionable.

Validity of the PCSQ was assessed in a low back pain sample (n=61) by determining the proportion of variance in four measures of adjustment predicted by three PCSQ factors (Rosenstiel & Keefe, 1983). The PCSQ factors were obtained through principal components analysis with the scores from the seven reliable subscales and the two effectiveness ratings (44 items). Three factors emerged with eigen values greater than or equal to one and that accounted for 68% of the variance in PCSQ scores. Hierarchial regression analysis indicated predictive validity of the PCSQ factors above and beyond that predicted by historical variables and somaticization for average pain level (22% of the variance), depression (11% of the variance), state anxiety (14% of the variance), and functional capacity (12% of the variance).

Other investigators have reported factor structure data for the PCSQ. Turner and Clancy (1986) found factors similar to Rosenstiel and Keefe (1983) when studying 74 patients with low back pain, but items loaded somewhat differently on the three factors. Again the three factors accounted for 65% of the variance in the PCSQ scores. Two factors emerged when 51 patients with osteoarthritis knee pain completed the PCSQ (Keefe, Caldwell et al., 1987); the two factors accounted for 60% of the variance in PCSQ scores. Finally, McGuire (1987a) found that three factors emerged from principal components analysis of data generated by 40 patients with cancer pain. However, item loadings differed substantially from loadings with either of the two low back pain samples (see Table 2).

Table 2

Comparison of Pain Coping Strategies Questionnaire Factors from Principal Components Analyses in Four Samples.

	Factor with Highest Loading			
Subscale	McGuire (1987a) (N=40)	Rosenstiel & Keefe (1983) (N=61)	Turner & Clancy (1986) (N=64)	Keefe et al. (1987) (N=51)
Cognitive Coping Strategies				
Diverting attention	3	3	2	1
Reinterpreting pain sensations	3	1	1	1
Coping self statements	3	1	3	1
Ignoring pain sensations	3	1	1	1
Praying or hoping	1	3	2	1
Catastrophizing	1	2	3	2
Behavioral Coping Strategies				
Increasing activity level	1	2	2	1
Increasing pain behaviors	1	-	-	-
Effectiveness Rating				
Control over pain	2	2	3	2
Ability to decrease pain	2	2	1	2

Hence, there is only modest agreement regarding the number of factors and item loadings when the various samples are considered. Perhaps the instability of factor loadings is, at least in part, related to the small samples. Since principal components analysis requires at least 10 subjects for each item entered into the analysis, none of the studies had adequate sample sizes to fully assess the factor structure of the PCSQ (Heilbron, personal communication; Marascuilo & Levin, 1983). If individual items were entered into the analysis, 500 subjects would be needed to adequately determine the factor structure of the PCSQ. If subscale scores are entered, then only 100 subjects would be needed. With the exception of the report by McGuire, it is not clear if investigators entered each item or the subscale scores. McGuire entered items at first, but found an ill-conditioned correlation matrix, so then entered subscale scores.

Although validity and reliability of the PCSQ have been estimated in various pain conditions (Keefe, Wilkins, & Cook, 1984; McGuire, 1987a; Rosenstiel & Keefe, 1983; Turner, & Clancy, 1986), the PCSQ has not been subjected to a test-retest reliability assessment. Turner and Clancy (1986) found that in a waiting list control group (n=21) the coping self-statements subscale scores decreased over an eight week period ($t=2.65$, $p<.02$). However, alpha coefficients were not reported for the subscales. Although the tool is predictive of a variety of physical and emotional adjustment levels (Keefe, Caldwell et al., 1987; Turner & Clancy, 1986), the PCSQ requires additional psychometric assessment regarding stability of factor structure across painful conditions and stability of responses over time. Given the internal

consistency of the PCSQ in McGuire's (1987a) cancer sample, its use was warranted to assess lung cancer pain. Patients completed the PCSQ in 5 to 10 minutes.

(5) The Dickson **Cancer-Specific Locus of Control (CSLC)** (Dickson, Dodd, Carrieri, Levenson, 1985) (Appendix G) measured a person's beliefs about the source of reinforcement motivating behavior. Eighteen items, measured on a six-point lickert scale from strongly disagree to strongly agree, addressed internal, chance, or powerful other as the source of expectancy for reinforcement. The three subscales were derived by summing the scores for the six items assigned to each subscale, and possible scores ranged from one to 36. Items paralleled the Multidimensional Health Locus of Control (Walston, Walston, & Devellis, 1978), but two items included cancer as the illness and instructions (adapted by Dodd, personal communication) directed that the word illness referred to the patient having had cancer. In initial testing, Cronbach alphas for the CSLC ranged from .48 to .63 for a sample of 29 patients (Dickson, Dodd, Carrieri, & Levenson, 1985). The CSLC has been used in cancer populations receiving chemotherapy and radiation therapy, but not in patients experiencing pain (Dodd, 1984). The CSLC was completed in 5 to 10 minutes.

(6) A second measure of pain intensity was used, the **Visual Analogue Scale (VAS)** (Figure 4) (Kremer, Atkinson, Ignelzi, 1981; Wilkie, Lovejoy, Dodd, & Tesler, 1990). The type of VAS was a horizontal, 10 cm line anchored on the left with "no pain" and on the right with "pain as bad as it could be". A pain score was obtained by the patient placing a mark to indicate the intensity of present pain. A

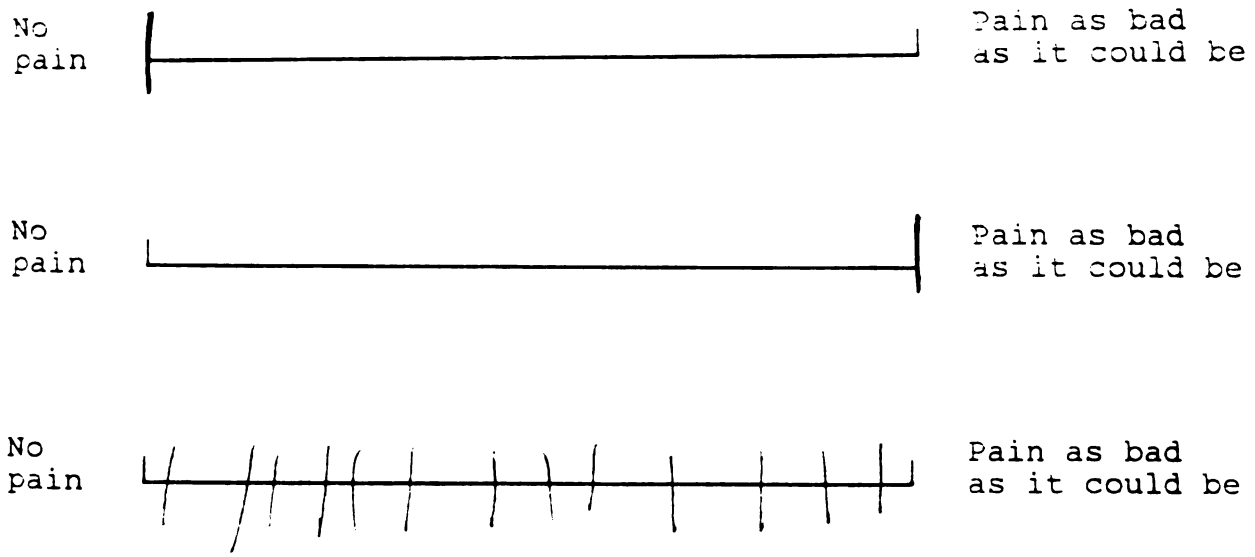
score was derived by measuring from the left side of the line to the place marked by the patient. A micrometer (Savedra, Tesler, Holzemer, Wilkie, & Ward, 1990) was used to derive scores accurate to the nearest one-tenth of a millimeter. Standardized instructions for administering the VAS were adapted from Wilkie (1984) and Tesler, Savedra, Holzemer, Holzemer, Wilkie, Ward, & Paul (1990). Using the examples listed in Figure 4, subjects were told:

> "I need to know how much pain you have. Because I can't feel your pain, I want you to use this scale to show me how much pain you have right now." (As the investigator shows the examples and points to the two markers) "This line represents <u>all</u> the pain a person could have. This side of the line means you have no pain (point to left side) and this side (trace along the line with your finger) of the line means pain as bad as it could be. If you have no pain right now, you would mark like this (point to the first example). If your pain is as bad as it could be, you would mark like this (point to the second example). Or you can mark anywhere along the line like this (show third example) to show me how much pain you have right now. (Show the blank VAS). Place a vertical mark on the line below to represent the intensity of the pain you feel now".

Validity, reliability, and sensitivity of the VAS has been estimated in numerous studies (Kremer, Atkinson, Ignelzi, 1981; Wilkie, Lovejoy, Dodd, & Tesler, 1990; Zimmerman et al., 1987). The VAS correlated significantly with the MMPQ present pain intensity scale and the total number of words selected from the list of word descriptors (Zimmerman et al., 1987). However, the VAS required much less time to complete. Research indicates patients with cancer pain take less than one minute to use the VAS, but five minutes may be needed for instruction and practice (Wilkie, Lovejoy et al., 1990).

Figure 4. Examples of the visual analogue scale marked correctly: A tool to emphasize standardized instructions.

Place a vertical mark (|) on the line below to represent the intensity of the pain you feel now.



(7) **Video tape recording** of gross body movements and facial expression were used as a measure of pain expression behaviors, pain control behaviors, and behaviors prevented by pain. Patients were asked to perform standardized behaviors using the procedures developed by Keefe and Block (1982). In random order, patients were asked to sit, stand, walk, and recline for a total of 10 minutes while one video camera was focused on the patient's body and a second video camera was focused on the patient's face. Gross body behaviors were scored using methods modified from Keefe and Block (1982) but facial expressions were scored using methods developed by Ekman and Friesen (1978). Although Keefe and Block's method included a measure of facial grimacing, the definition for grimacing was more subjective than Ekman and Friesen's method of scoring facial expression. To improve sensitivity of scoring facial expressions of pain, Ekman and Friesen's method was used.

Gross body scoring. The observational method developed by Keefe and Block (1982) allowed behavior to be recorded and scored in a highly reliable manner with one video camera. As patients performed the standardized behaviors (sit, stand, walk, recline), they were noted to employ behaviors indicative of pain. These pain behaviors were scored by using definitions from the Behavioral Observation Manual. In this manual, behaviors were well defined and relevant to specific types of pain (i.e., low back, arthritis, head and neck cancer). Observers, trained to score behavior based on the definitions, observed the video tape for 20 seconds and recorded their observations during the subsequent 10 seconds. A frequency score was obtained for each targeted behavior that occurred during the 10 minute recording session, such as:

guarding; bracing; rubbing; grimacing; sighing; rigidity; active rubbing; passive rubbing; or self stimulation.

Pain behaviors have been found to be: 1) correlated with the intensity of pain reported by the patient ($r=.71$, $p=.01$); 2) correlated with health professionals' ratings of the pain; 3) changed with pain therapy; and 4) specific to pain patients but not seen in depressed or normal controls (Keefe & Block, 1982). Hence, validity has been assessed for the behaviors. Inter-rater reliability of scoring the defined behaviors from video tapes was 90% and maintained with monthly re-training of the raters (Keefe & Block, 1982).

Keefe and Block (1982) provided an important contribution to measurement of behaviors associated with pain. The method was valid and reliable as a measure of the behavioral dimension of back pain. Several limitations, however, were inherent in the procedures. First, the targeted behaviors were identified for back pain from the interviews with patients with low back pain, health care professionals, and family members and as a result, the method targeted overt behaviors of pain, such as guarding, bracing, grimacing, rubbing, and sighing (Keefe & Block, 1982; Keefe, Crisson, & Trainor, 1987). These behaviors may not generalize to patients with other types of pain without modification of the targeted behaviors. In fact, Keefe and associates modified the targeted behaviors for arthritis patients to differentiate passive from active rubbing and to include rigidity, and self-stimulation (McDaniel, Anderson, Bradley, Young, Turner, Agudelo, & Keefe, 1986). Pilot work,

therefore, is needed to identify and assess the validity of specific behaviors to be targeted for each pain problem.

However, the patient's perspective of why a behavior was used was not considered in Keefe's methodology. Apparent assumptions, derived from the operant behavioral perspective, were that the behaviors signaled the presence of pain and continued because of reinforcement (Fordyce, 1976), but the source of reinforcement was not determined. Since the source of reinforcement for some behavior may be the freedom from or reduction of pain (Fordyce, 1976), the intent of a patient's behavior seems important for research from a nursing perspective.

Keefe's Behavioral Observation Manual, therefore, was adapted for a lung cancer population to target behaviors related to movement or position and behaviors related to pain. The number of behaviors related to pain was increased from a maximum of ten in Keefe's system to thirty-one possible behaviors (See Appendix D). The purpose of the modified system was to score all gross body movements and inquire of the patient if particular behaviors were: 1) performed to express pain; 2) performed to control pain; 3) performed because pain prevented usual behaviors; or 4) performed for no purpose or an unknown purpose (Appendix D). Such a system allowed behaviors to be recorded that were independent of particular types of pain. Additionally, the system allowed a survey approach to determine the valid behaviors to be targeted in research with patients with cancer pain.

As with Keefe's system, the behaviors related to pain included precisely defined behaviors. The behaviors were those that patients had been observed using and that patients had reported to be used to control

and/or cope with their pain. Additionally, the behaviors were discretely defined in order to begin to differentiate those behaviors with physiological potential to modulate pain, such as massaging an area proximal to the painful area or applying a counter irritant.

The Manual was tested by scoring eight video tapes of patients experiencing cancer pain. Feasibility of scoring the discrete behaviors was demonstrated by the investigator prior to initiating the study. Subsequent to collection of all data, one individual was trained by the investigator to score video tapes using the Manual. Individualized training required four to five hours using four video tapes from the data set. Using the number of agreements divided by the number of agreements plus the number of disagreements method of calculating inter-rater reliability, 90% reliabilty was established prior concluding the training period. Once training was complete, the training tapes were excluded, and 14 (30%) of the tapes were randomly selected to assess inter-rater reliability. The reliability scores ranged from 62% to 93% with an average inter-rater reliability of 82% for the 14 tapes. A third rater was trained and scored the same randomly selected tapes with an average inter-rater reliability of 87% with the investigator and 84% with the second observer. Both trained observers scored the tapes within one month of training to minimize drift effects in scoring.

Facial expression scoring. Ekman and Friesen (Ekman & Friesen, 1978), designed the **Facial Action Coding System (FACS)** to evaluate human emotions. FACS allowed facial muscle movements to be scored as

distinct, individual action units with sequence of occurrence documented. This scoring system allowed researchers to discriminate between emotions, such as fear and anger (Ekman, 1982). Inter-rater reliability of scoring the discrete action units of facial expression has been demonstrated to be maintained at 76-82% when using FACS (Ekman & Friesen, 1978).

Based upon Ekman and Friesen's facial scoring procedures, a pain expression profile has been suggested (LeResche, 1982; LeResche & Doworkin, 1988; Prkachin & Mercer, 1989). The typical pain expression included brow lowering with the skin drawn in tightly around closed eyes accompanied by a horizontally stretched, open mouth, sometimes with deepening of the nasolabial furrow (LeResche, 1982). In FACS terminology, this facial expression was scored as action units 4 + (6 or 7 or 11) + 20 + 25 or 26 or 27 + 43 (LeResche, 1982; LeResche & Doworkin, 1988).

(8) Finally, the **Pain Locus of Control (PLOC)** (Toomey, Lundeen, Mann, & Abashian, 1988) (Appendix H) was used to determine whether cancer specific locus of control or a pain specific locus of control provided more useful data when used with a cancer population. The tool consisted of 36 items, the first 18 of which paralleled the Multidimensional Health Locus of Control (Wallston et al., 1978) but included pain in the place of illness. As with the CSLC, three subscale scores were derived for the first 18 items and for the 36 items in order to compare the two scales. Reliability of the PLOC has not been assessed but construct validity of the tool was supported (Toomey, Mann, Abashian, & Lundeen, 1989; Toomey, Lundeen, Mann, & Abashian, 1988,

1989). Patients with cancer completed the 35 item tool in less than 10 minutes.

Procedures

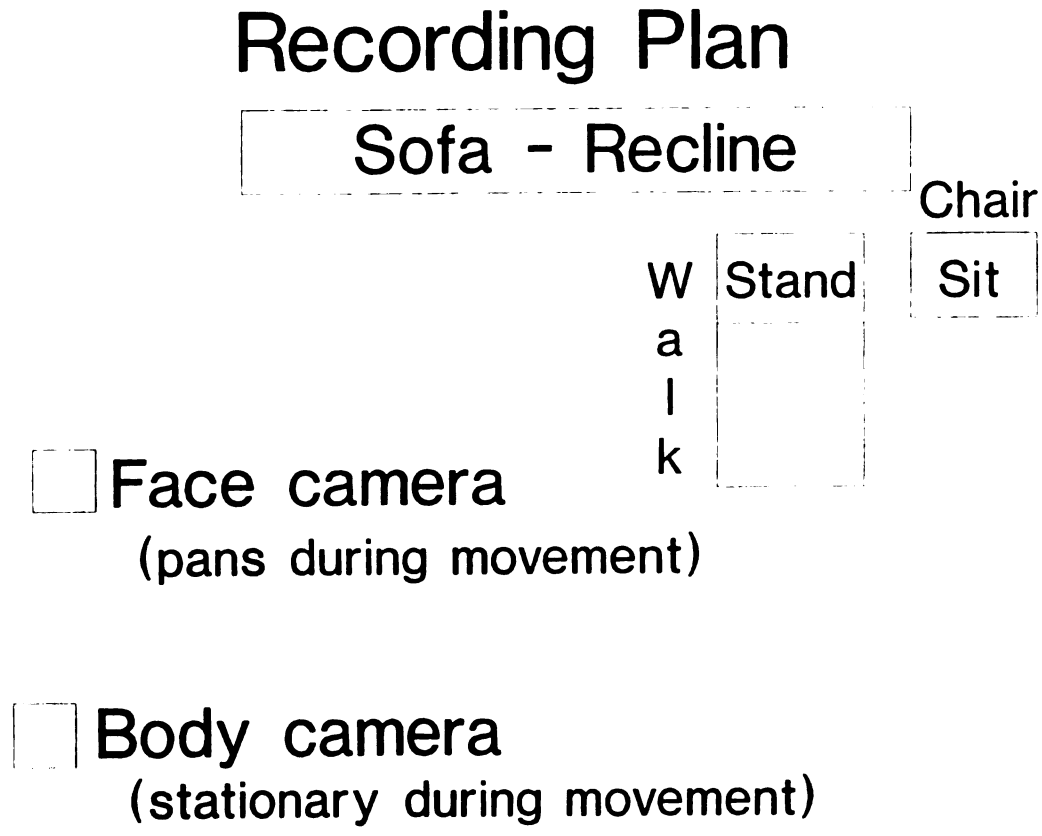
Study procedures occurred in three phases. Phase 1 (Study Day 1) and Phase 3 (Study Day 2) occurred in the patient's home and Phase 2 occurred in the investigator's laboratory.

Phase 1. The patient was interviewed to complete the DDF and MMPQ on Study Day 1. Then the patient completed the self-administered STA, PCSQ, and CSLC. Next the patient completed the VAS prior to and following a 10 minute video tape session where the patient was asked to sit, stand, recline, and ambulate while two tripod-mounted video cameras recorded gross body movements and facial expressions.

A Panasonic (PV-330) color camcorder was used to record the body movements. A RCA color video camera (WV-3240/8AF) and a Quasar (VH5975) four-head stereo recorder/player was used to record the facial expressions. A camera mounted video lamp was required to obtain adequate video records for most patients. The usual arrangement of the video cameras and investigator to the subject is diagramed in Figure 5.

Phase 2. In the laboratory, the investigator made copies of the face and body tapes. Each of the copies was audio dubbed with 20 second pause intervals. This represents a deviation from Keefe and Block's (1982) procedures because 10 seconds was not adequate time to score the possible 31 behaviors. Pausing the video tape allowed adequate time for scoring. A 30 second pause interval would have been more comparable to

Figure 5. Diagram of the video recording setting with two cameras: Documenting a place to walk, sit, stand, and recline.



comparable to Keefe and Block's (1982) procedures. This was tried for the first four subjects and proved unacceptable because most of the pauses coincided with the time the subjects shifted position. Since Keefe (personal communication, June, 1987) found the shift to be associated with increased behavior, a 20 second pause interval was tried and found feasible. This meant that the entire video tape produced data. This was in contrast to the tape producing data in 400 of the possible 600 seconds in the 10 minutes as was reported by Keefe and Block (1982).

A Sony Trinitron (KV-1393R) video monitor and the Quasar video recorder/player were used to play the dubbed tapes during the scoring procedures. The body tapes were paused every 20 seconds and each behavior meeting the scoring definitions from the Manual was identified as observed on the Score Sheet (See Appendix D). Each ten minute body tape required one to two and one-half hours to score. The face tapes were not scored until after all data had been collected for the 45 patients and the data will be reported in a subsequent document.

Phase 3. On Study Day 2, after the body video tape was scored using the Manual, the patient completed the MMPQ body outline, word list, and PPI. Then each of the scored behaviors were described to the subject and the subject was asked if the gross body behaviors were pain expression behaviors, pain control behaviors, behaviors prevented by his/her pain, or habits (not more than two days elapsed between Study Days 2 and 3). Patient's responses were recorded on the Score Sheet. The subject did not view the video tape unless he/she specifically

requested to do so, and then it was viewed only after all study procedures had been completed.

Following the video-related interview, the subject was asked to recall any other behaviors he/she used to express pain to others, behaviors used to control pain, and behaviors that were prevented by the pain. This interview was unstructured and the subject's responses were recorded by the investigator using an unstructured written format. Finally, the subject completed the self-administered VAS, PCSQ, and PLOC. A check list for these procedures was developed to assist the investigator in completing the complex protocol (See Appendix K).

Data Analyses

CRUNCH was used for data entry, preliminary data cleaning, and descriptive statistics (Crunch Software Corporation, 1987). CRUNCH also was used for appropriate statistical analyses.

Data Reduction Techniques

For the most part, data collection instruments were scored according to published instructions. Data reduction techniques utilized in data analysis are described for each data collection instrument.

(2) McGill-Melzack Pain Questionnaire (MMPQ). Analgesic medication consumed just prior to data collection was converted to an estimate of the strength of analgesia. This estimate was based on the expected onset and duration of analgesic effect for each drug. If the time since the analgesic medication had been consumed was between the onset and the duration, a strong/moderate effect was coded, but if the time since the analgesic was consumed was beyond the duration, a weak/no

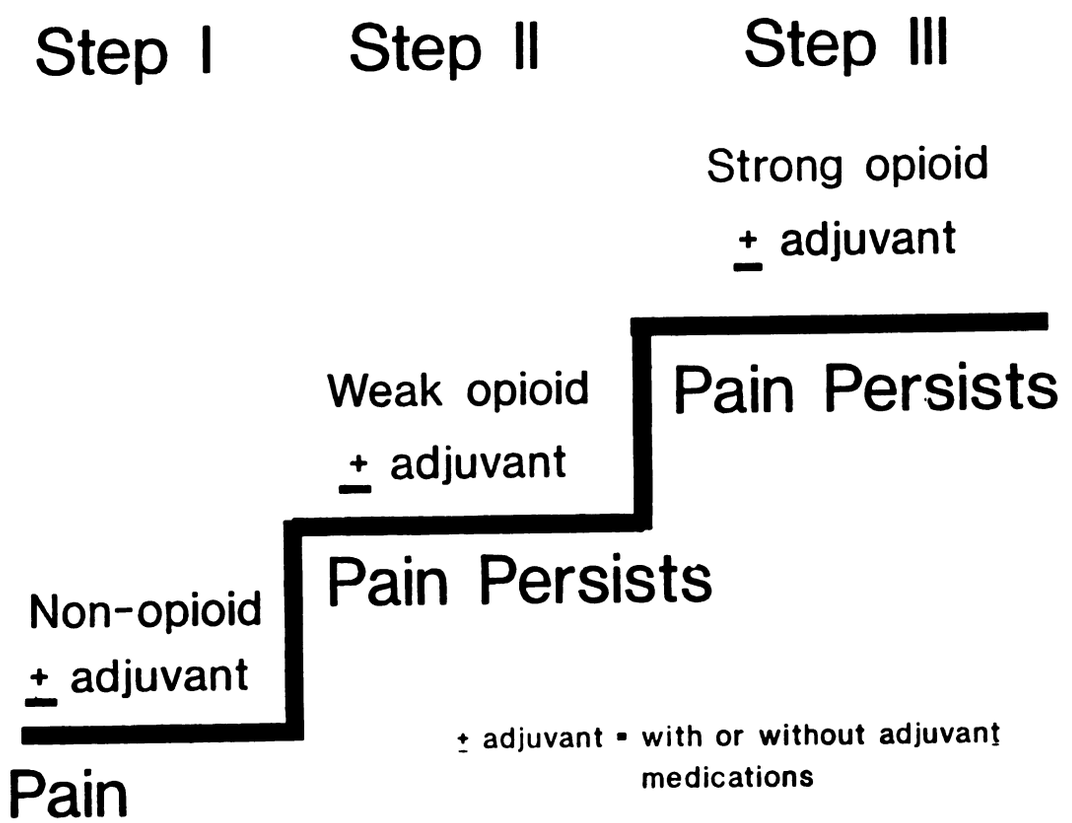
effect was coded. This dichotomous variable was used for analyses where analgesic medication intake was considered.

For descriptive purposes, analgesic medications were categorized according to the World Health Organization's (WHO) Analgesic Ladder (WHO, 1986). The WHO Analgesic Ladder is listed in Figure 6.

Pain location, measured with the body outline (MMPQ Part One), was calculated in three ways. First, a plastic template with the body outline divided into 48 segments (Figure 7) was used to count the number of segments marked by the subject. This procedure was similar to the analysis plan described by Margolis, Tait, and Krause (1986), but did not weight by amount of body surface area. The body segment count provided a continuous variable, with possible scores between 0 and 48. The second method was to count the number of pain sites. Finally, the frequently occurring body outline markings were identified and categorized by five groups. The opinion of the investigator was used to categorize the markings as: 1) restricted to the distribution of the brachial plexus; 2) restricted to the anterior and/or posterior chest; 3) including the anterior and/or posterior chest and the spine area; 4) including the anterior and/or posterior chest, the spine, and joints of the extremities; and 5) including other areas too diverse to be grouped more specifically.

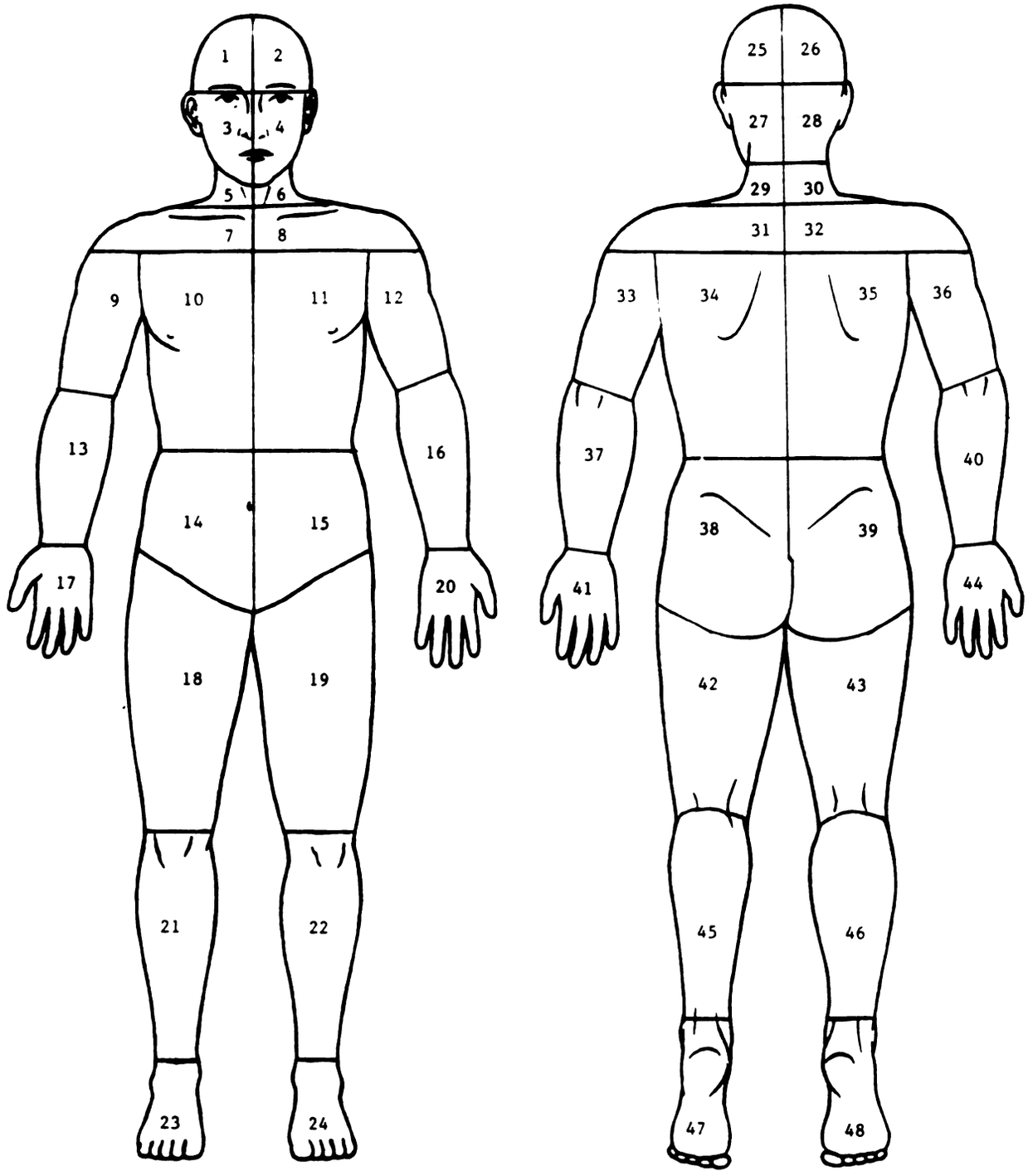
Pain pattern, as measured with the MMPQ Part 3 (question 1), was scored as a three level categorical variable. If continuous, steady, or constant were selected, pain pattern was scored as level one representing constant pain. Level two was scored if the subject selected rhythmic, periodic, or intermittent and the pain pattern

Figure 6. Example of the World Health Organization's Analgesic Ladder.



Reprinted with permission: World Health Organization, Cancer Pain Relief, 1986.

Figure 7. Example of the body outline template used to score the number of body segments.



variable represented intermittent pain pattern. Level three was scored if the subject selected brief, momentary, or transient and the pain pattern variable represented transient pain.

Responses to MMPQ Part 3 (questions 2 and 3) related to things relieving and increasing pain were treated as qualitative data. The investigator categorized these data into 11 groups, including categories reported by Wilkie and associates (1988) and three additional categories (see Table 3).

(3) State-Trait Anxiety Inventory (STA). According to Speilberger's (1983) instructions, reversed scored items were transformed in CRUNCH. Then state anxiety items were summed to create the state anxiety subscale. Trait anxiety items were summed to create the trait anxiety subscale.

(4) The pain Coping Strategies Questionnaire (PCSQ). A total coping score was created by summing responses to items one to 48. Eight subscale scores were created by summing responses to the six items included in each subscale.

(5) Dickson Cancer-Specific Locus of Control. Internal, powerful others, and chance subscale scores were calculated according to instructions provided by Dickson (A. Dickson, personal communication, 1989). Subsequent communications with other investigators (M. Dodd & S. Dibble, personal communication, May, 1990) indicated that internal and external subscales were more appropriate based on additional psychometric testing with the tool. Dodd and associates (personal communications) found that Cronbach alphas and exploratory factor

Table 3

Behavior Categories Used in Data Analyses as Adapted from Wilkie, Lovejoy, Dodd, & Tesler, 1988

Behavior Categories
Use Analgesics
Change Position
Increase Activity
Decrease Activity
Immobilize / Guard
Pressure Manipulation
Use Heat / Cold
Eat / Drink
Divert Attention / Alter Attitude
Relax
Other

analysis from approximately 100 patients with cancer indicated that reliability was improved if two items (questions 7 and 8) were deleted and only two subscales were created, an internal scale and an external scale. Therefore, the internal scale consisted of five items and the external scale consisted of 11 items. Both methods of creating subscales, Dodd and associates' and Dickson's, were used to allow comparison with findings from both researchers. The internal and external scores, however, were used in most analyses.

(7) Score Sheet. The number of different behaviors were counted to create six continuous variables. The six variables were behaviors that were: 1) reported as pain expression behaviors, 2) reported as pain control behaviors 3) reported as pain reduction behaviors, 4) reported as preventing pain onset, 5) reported as being prevented by the pain, or 6) reported as being a habit.

(8) Pain Locus of Control (PLOC). Instructions (Toomey personal communication, May 1990) were used to create internal, powerful others, and chance subscale scores for items one to 36 (Total), for items one to 18 (Form A), and for items 19 to 36 (Form B). Additionally, for Form A, items 7 and 8 were deleted and internal and external subscales were created in order to compare data obtained from the CSLC and the PLOC.

Multiple regression models. Multiple regression analyses were performed to address questions about the best predictors of the three pain-related behaviors. Simultaneous regression methods were used first to examine the significance of the proposed model with selected demographic, affective, cognitive, and physiological-sensory regressors. If full models were significant, separate hierarchial regressions were

calculated with all but one variable entered at step one and the last variable entered at step two. Regressions were calculated until all variables had rotated through entry at step two. These procedures allowed the amount of unique explained variance to be determined for each variable in the model. Then, variables accounting for a significant or a nearly significant change in the explained variance were examined with a reduced model using first simultaneous and then hierarchial regressions. The reduced model allowed examination of a model with a more appropriate subject-to-regressor ratio, and examination of the amount of unique variance accounted for by the variable that was above and beyond the variance accounted for by the other variables in the model. To do this in CRUNCH, again, separate regressions were calculated with all but one variable entered at step one and the last variable entered at step two. Regressions were calculated until all variables had rotated through entry at step two. These procedures were used because compelling evidence was not available to support a theoretical reason to control for the effects of certain variables (Cohen & Cohen, 1983; Neter, Wasserman, & Kutner, 1985).

Chapter Four

Results

The purpose of this study was to characterize the behavioral correlates of lung cancer pain. Behaviors associated with lung cancer pain were identified and examined for relationships with pain location, pain intensity, pain quality, pain onset, and pain pattern. Affective, cognitive, behavioral, and physiological-sensory variables were evaluated to determine predictors of behaviors associated with lung cancer pain.

Sample Characteristics

Demographic characteristics. The sample (N=45) consisted of 28 (62%) men and 17 (38%) women. Predominately, the subjects were white (71%), but 16% were black, 7% were Hispanic, and 7% were of other ethnic origins. Most of the patients (n=28, 62%) had between eight and 12 years of formal education whereas seven (16%) had less than an eighth-grade education. The majority of the patients were married (n=27, 60%). Demographic characteristics of the sample are listed in Table 4.

Pain characteristics. On the average, the subjects had experienced pain for an average of 15.2 months prior to the study. There was large variability, however, in the length of time the subjects had pain (SD=19.1 months; minimum=1 week, maximum=96 months, mode and median=6 months). Nine subjects (20%) reported not knowing the cause of their pain. Most of the subjects designating a cause to their pain (n=18; 40%) attributed the cause to the lung cancer. Subjects also designated surgery for the lung cancer (n=6, 13%), radiation therapy for

Table 4

Demographic, Pain, and Oncologic Characteristics of the Sample (N=45).

Variable	Frequency (%)[a]	Mean	(SD)	Median	Min-Max
Demographic					
Age In Years	— —	60.9	(8.8)	61.0	40.0-80.0
Gender					
Male	28 (62)				
Female	17 (38)				
Ethnicity					
White	32 (71)				
Black	7 (16)				
Hispanic	3 (7)				
Other	3 (7)				
Religion					
Catholic	7 (16)				
Protestant	17 (38)				
Other	21 (45)				
Education Level					
≤ 8th Grade	7 (16)				
≤ 12th Grade	28 (62)				
College	9 (20)				
Graduate School	1 (2)				
Marital Status					
Single	11 (24)				
Married	27 (60)				
Widowed	7 (16)				
Annual Family Income					
≤ $10,000	19 (42)				
$10-19,999	12 (27)				
$20-29,999	5 (11)				
$30-39,999	9 (20)				
Pain					
Perceived Cause					
Unknown	9 (20)				
Tumor	18 (40)				
Surgery	6 (13)				
Radiation	3 (7)				
Non Cancer	2 (4)				
Other	7 (16)				

Table 4 continued

Variable	Frequency (%)[a]	Mean	(SD)	Median	Min-Max
Oncologic[b]					
Months Since Diagnosis		16.4	(9.9)	8.0	1.0-96.0
Tumor Histology					
Squamous	17 (38.6)				
Adenocarcinoma	14 (31.8)				
Small cell (Oat)	4 (9.1)				
Large cell	9 (20.5)				
Primary Tumor Location					
Right Upper Lobe	15 (34.1)				
Right Lung	8 (18.2)				
Left Upper Lobe	4 (9.1)				
Left Lung	12 (27.3)				
Other	5 (11.4)				
Tumor Stage					
At Diagnosis					
Stage I	10 (23.3)				
Stage II	6 (14.0)				
Stage III	13 (30.2)				
Stage IV	14 (32.6)				
Current					
Stage I	4 (9.3)				
Stage II	5 (11.6)				
Stage III	11 (25.6)				
Stage IV	23 (53.5)				
Metastatic Disease					
None	9 (20.5)				
Local/Regional	19 (43.2)				
Distant	16 (36.4)				
Antitumor Therapies[c]					
Surgical	20 (45.5)				
Radiation	36 (81.8)				
Chemotherapy	13 (29.6)				
Other	1 (2.3)				
Smoking Status					
Non smokers	4 (10.3)				
Pack Year History		53.8	(32.7)	50.0	0-120.0
Months Since Quit		54.3	(62.2)	24.0	0-200.0
Lung Cancer Family History					
Positive	7 (23.3)				
Negative	23 (76.7)				
Concurrent Diagnoses					
Associated w/Pain	24 (53.3)				
Not Assoc. w/Pain	21 (46.7)				

[a] % rounded to nearest .1; [b] data missing for one subject
[c] subjects may have received more than one treatment

the lung cancer (n=3, 7%), and noncancer-related or other etiology (n=9, 20%) as the causes of their pain. Pain duration and perceived cause of pain are listed in Tables 4 and 5.

Few subjects (n=3, 7%) were using strong opiate analgesics or were not using any analgesics (n=2, 4%). Most of the subjects were using weak opiates (n=24, 53%) or nonopiate analgesics (n=16, 36%). All analgesics were consumed via the oral route. The analgesic effect was estimated as strong-moderate for 19 (46%) and as weak-none for 22 (54%) of the subjects. The subjects used the analgesics for pain located in the distribution of the brachial plexus (n=8, 18%); in the anterior and/or posterior chest (n=13, 29%); in the anterior and/or posterior chest, the spine, and the joints of the extremities (n=8, 18%); or in other areas (n=9, 20%).

Oncologic characteristics. All subjects had histologically confirmed primary lung cancer that had been diagnosed for an average of 16.4 months (SD=19.9). As documented from pathology reports, the histology/cytology of the malignant cells was predominately nonsmall cell lung cancer (n=41, 91%) with four subjects diagnosed with small cell lung cancer. The nonsmall cell type was diagnosed as squamous cell carcinoma for 17 (39%) subjects and adenocarcinoma for 14 (32%) subjects.

For the majority of the subjects, the primary tumor was located in the right lung (n=23, 52%). At diagnosis, nearly equal numbers of the subjects had stage three and stage four lung cancer. At the time of the study, the majority of the subjects (54%) had stage four

Table 5
Descriptive Statistics for Pain Variables.

Variable	N(%)*	Observed Min-Max	Median	Mean	SD
Pain Intensity					
VAS-Time1	45	0-98.1	17.6	25.5	28.3
VAS-Time2	44 (98)	0-94.6	19.0	29.2	29.3
VAS-Time3	44 (98)	0-96.1	19.8	26.6	26.1
PPI-Time1	45	0- 5.0	2.0	1.7	1.2
PPI-Time2	44 (98)	0- 4.0	1.5	1.5	0.9
Pain Quality	45				
PRI-S					
Time1		2-32.0	12.0	13.7	7.4
Time2		0-31.0	9.0	11.7	8.4
PRI-A					
Time1		0- 9.0	2.0	2.5	2.5
Time2		0-10.0	1.0	1.9	2.7
PRI-E					
Time1		0- 5.0	2.0	2.2	1.7
Time2		0- 5.0	2.0	1.9	1.5
PRI-M					
Time1		0-13.0	3.0	3.9	3.6
Time2		0-16.0	2.0	3.4	3.6
PRI-T					
Time1		2-52.0	19.0	22.2	12.9
Time2		0-49.0	13.0	18.9	13.9
NWC					
Time1		2-17.0	8.0	8.9	4.6
Time2		0-19.0	6.0	7.7	4.8
Pain Onset					
Months of Pain	45	0.25-96.0	6.0	15.2	19.1
Pain Pattern					
Continuous	24 (53)				
Intermittent	18 (40)				
Transient	3 (7)				
Pain Location	45				
# Sites of Pain		1- 9.0	4.0	4.0	1.9
# Body Segments		1-25.0	7.0	8.0	5.4
Pain Depth					
Internal	30 (67)				
Internal/External	15 (33)				
External	0 (0)				

* if less than 100%

lung cancer with metastatic disease documented as local or regional for 19 (43%) subjects and distant for 16 (36%) subjects.

Few subjects (n=2) had not received at least one type of antitumor therapy. Treatment included surgery for 20 (46%) subjects, radiation for 36 (82%) subjects, chemotherapy for 13 (30%) subjects, and immunotherapy for one subject. Oncologic characteristics are summarized in Table 4.

Preliminary Analyses

Before addressing study questions, descriptive statistics were calculated to determine the statistical characteristics of variables as measured with the selected instruments. Additionally, Cronbach's alpha reliability coefficients were calculated for the STA, PCSQ, CSLC, and PLOC. The preliminary analyses were important to assess the degree to which statistical assumptions were met prior to conducting analyses for the 12 study questions. Results of preliminary analyses are presented in Tables 5, 6, 7, 8, and 9.

To summarize these data, the investigator concluded that most of the variables demonstrated nearly normal distributions or distributions shifted slightly to the right which would not adversely affect robust statistical procedures (see Tables 5 and 6). All instruments demonstrated adequate internal consistency with the exception of the chance subscale (.55) of the CSLC and the internal subscale (.65) of the PLOC. Internal consistency for the CSLC and PLOC was improved when items 7 and 8 were deleted from each tool and internal and external subscales were created (see Table 6).

Table 6

Descriptive Statistics and Cronbach's Alpha Reliability Coefficients for Anxiety, Coping, and Locus of Control Instruments.

Scale/Subscale	N	Alpha	Mean	SD	Median	Min-Max
Anxiety/						
State	43	.92	37.9	12.7	33.5	20- 68
Trait	43	.93	37.8	12.0	37.0	20- 66
Pain Coping/	45					
Diverting Attention		.88	16.7	10.3	18.0	0- 36
Reinterpreting Sensation		.86	9.5	9.1	6.0	0- 36
Coping Self-Statements		.86	21.7	9.2	24.0	0- 36
Ignoring Pain		.80	15.2	8.9	17.0	0- 30
Praying / Hoping		.89	20.5	11.4	24.0	0- 36
Castastrophizing		.87	11.4	9.7	11.0	0- 36
Behavioral Activity		.79	16.1	9.0	17.0	0- 35
Pain Behavior		.53	17.1	6.8	17.0	0- 34
Total[a]		.95	135.5	56.4	137.0	0-273
Ability to Control Pain		—[b]	3.7	1.6	4.0	0- 6
Ability to Decrease Pain		—[b]	3.6	1.6	3.5	0- 6
Cancer Locus of Control/	45					
Internal - 6 items		.75	25.8	7.1	26.5	6- 36
Powerful Others - 6 items		.77	21.2	6.9	20.0	6- 34
Chance - 6 items		.55	27.8	7.0	30.0	7- 36
Internal2 - 5 items		.82	22.8	6.5	24.0	5- 30
External2 - 11 items		.77	44.3	11.6	44.0	18- 64
Pain Locus of Control	42					
Internal - 6 items		.65	25.1	6.2	26.0	2- 36
Powerful Others - 6 items		.80	26.4	7.3	26.0	6- 36
Chance - 6 items		.75	19.2	7.8	19.0	6- 35
Internal2 - 5 items		.68	22.7	5.6	24.0	4- 30
External2 - 11 items		.82	41.6	12.1	41.0	11- 65

[a] Sum of 8 subscale scores—Diverting Attention through Pain Behavior
[b] Single item

Concurrent validity of the CSLC and PLOC instruments as measures of the locus of control construct was examined by conducting a matched pair t-test for the internal, powerful others, and chance subscale scores obtained with each instrument. As indicated in Table 7, the matched pair mean scores were not statistically significant for the internal subscale but were statistically significant for the powerful others and chance subscales. Subjects reported similar scores on the internal subscale when using either the CSLC or the PLOC. Subjects, however, reported a higher score on the powerful others subscale when using the PLOC than when using the CSLC. This was reversed for the chance subscale as the subjects reported a higher score when using the CSLC than when using the PLOC. Thus, concurrent validity was supported for the internal locus of control subscale but not for the powerful others or chance subscales. These conclusions were supported when internal and external subscales were subjected to matched pair t-tests, but the magnitude of the effect was not as strong as when the three subscales were analyzed (see Table 7).

As indicated in Table 8, all of the subjects selected at least one item for each of the PCSQ subscales. Test-retest reliability was examined for the PCSQ. Spearman rank correlation coefficients for the 50 items ranged from .32 to .87. Using Fisher's Z transformation (Cohen & Cohen, 1983), the average item to item correlation was .64, but Pearson correlation coefficients for the eight PCSQ subscales ranged from .68 to .90. Only two subscales had correlation coefficients less than .70 (self statements and ignoring pain sensations). These data

Table 7

Comparison of Locus of Control Subscales as Measured with the Cancer Specific Locus of Control and the Pain Locus of Control

	Cancer		Pain		Matched			
Subscale[a]	Mean	SD	Mean	SD	t-test	p≤	r	p≤
Internal	26.2	6.6	25.2	6.3	0.9	ns	.32	.04
Powerful Others	21.5	6.9	26.0	7.2	-3.6	.01	.36	.02
Chance	28.2	6.5	19.0	7.9	7.5	.01	.40	.01
Internal2	23.1	6.1	22.7	5.6	0.4	ns	.30	.05
External2	44.8	11.2	41.6	12.1	2.4	.02	.73	.01

[a] Data were missing for 3 subjects
ns = not significant at p<.05 level

Table 8

Frequency of Pain Coping Strategies Questionnaire Subscale Scores

Reflecting Strategies were Never Used or Were Always Used

	Frequency	
Subscale	Never Used (%)	Always Used (%)
Diverting Attention	7 (16)	1 (2)
Reinterpreting Sensation	10 (22)	1 (2)
Coping Self-Statements	4 (9)	2 (4)
Ignoring Pain	5 (11)	0 (0)
Praying / Hoping	3 (7)	5 (11)
Catastrophizing	10 (22)	1 (2)
Behavioral Activity	2 (4)	1 (2)
Pain Behavior	1 (2)	1 (2)

indicate, at the subscale level, there was stability in responses separated by no more than three days and support reliability of the tool when used with patients with lung cancer. Table 9 lists the reliability data for the eight subscales and the ability to control and decrease pain items.

Research Questions

Results are presented for each of the 12 research questions with the exception of the questions related to facial expressions of pain. Although facial expression data were collected concurrently with data reported in this document, facial expression data will be reported in a subsequent document.

Question 1.

What body movements do patients with lung cancer indicate they use to communicate their pain to other individuals?

Results related to this question were provided by: 1) interview about behaviors scored from the video tape; and 2) open-ended interview. Findings indicate that all of the subjects reported that none of the behaviors scored from the video tape were used to express pain to other people. In the open-ended interview, however, nearly one-half of the subjects (n=19, 45%) reported that they tried not to express their pain to other people whereas nearly one-half of the subjects (n=18, 43%) expressed their pain directly by telling others when they were having pain. (Three subjects did not complete the open-ended interview because of fatigue.) Five subjects reported that they expressed their pain to others through their facial expressions or emotions and by crying, grunting, or sighing. The subjects reported that they used zero to

Table 9

Correlations for the Pain Coping Strategies Questionnaire Test-Retest Reliability ($p<.05$)

	Subscale Test-Retest (Pearson)	Item Test-Retest (Spearman Rank)					
Subscale Name		1	2	3	4	5	6
Diverting Attention	.78	.80	.57	.57	.56	.54	.67
Reinterpreting Sensation	.78	.55	.52	.57	.56	.57	.66
Coping Self-Statements	.60	.51	.32	.58	.58	.53	.59
Ignoring Pain	.68	.61	.69	.56	.53	.56	.68
Praying / Hoping	.90	.47	.80	.70	.87	.80	.83
Catastrophizing	.80	.54	.47	.73	.66	.74	.75
Behavioral Activity	.84	.66	.70	.83	.53	.64	.62
Pain Behavior	.71	.64	.55	.72	.53	.74	.72
Total	.83	—	—	—	—	—	—
Control Over Pain	.52[a]	.62	—	—	—	—	—
Decrease Pain	.43[a]	.45	—	—	—	—	—

[a] Single item

three different behaviors to express pain to others (mean=.83, SD=.88). When more than one pain expression behavior was used (n=7, 16%), the behaviors included emotional display, request for pain medication, or holding the painful area.

Question 2.

What body movements do patients with lung cancer indicate they use to control their pain?

Results related to this question were provided by: 1) a MMPQ question (Part 3, question 2); 2) interview about behaviors scored from the video tape; and 3) open-ended interview. Results are reported separately for each method and then as triangulated data.

MMPQ. Subjects reported that one to 11 different behaviors relieved their pain (mean=3.3, SD=2.6, mode and median=2). Subjects' responses are categorized and listed in Table 10. Nearly all (N=44, 98%) of the subjects reported that analgesic medications relieved their pain.

Video-related interview. Subjects reported that 42 different behaviors were used to control pain. As the ninth subject was being interviewed on Study Day 2, it became clear that pain control behaviors could include behaviors used to reduce the intensity of the pain or to prevent the onset of pain. Interview data from subjects 9 through 45 were collected with this insight in mind, i.e., subjects were asked to indicate if a behavior reduced pain or prevented pain onset. Thirty-two of the 42 behaviors were used to reduce pain intensity and 18 of the 42 behaviors were used to prevent the onset of pain. Eight behaviors were reported by some subjects to reduce pain and by other subjects to

Table 10

Behaviors Relieving Pain as Determined by Responses to the McGill-Melzack Pain Questionnaire (MMPQ) and to an Open-ended Interview

Type of Behavior	MMPQ Frequency[a] (%)	Interview Frequency[b] (%)
Use Analgesics	44 (98)	18 (40)
Change Position	17 (38)	26 (58)
Increase Activity	10 (22)	15 (33)
Decrease Activity	10 (22)	6 (7)
Immobilize / Guard	4 (8)	6 (7)
Pressure Manipulation	7 (16)	7 (16)
Use Heat / Cold	7 (16)	6 (13)
Eat / Drink	6 (13)	3 (7)
Divert Attention / Alter Attitude	10 (22)	12 (27)
Relax	9 (20)	4 (8)
Other	8 (18)	10 (22)

[a] N=45 but subjects reported more than one type of behavior
[b] N=42 but subjects reported more than one type of behavior

prevent the onset of pain. The 42 behaviors are described in Table 11, rank ordered in Table 12, and grouped by the categories described by Wilkie and associates (1988) in Table 13. Eighteen of the behaviors were positioning behaviors.

Subjects reported that 0 to 13 different behaviors controlled pain (mean=4.3; SD=3.3). When these pain control behaviors were examined as pain reduction or pain prevention behaviors, subjects reported that 0 to 12 behaviors reduced pain intensity (mean=3.2; SD=2.8) and that 0 to 5 behaviors prevented the onset of pain (mean=1, SD=1.2). Three subjects reported that none of the scored behaviors were related to their pain. Thirteen (29%) subjects reported that the behaviors exclusively reduced pain intensity. Many of the subjects (n=19, 42%) reported at least one behavior that reduced pain intensity and at least one behavior that prevented the onset of pain.

Open-ended interview. Again, three subjects did not complete the open-ended interview because of fatigue. Subjects reported zero to 10 behaviors (mean=3.6, SD=2.2) during the open-ended interview designed to capture behaviors not identified during the limited activities demanded during the video tape session. The types and frequency of the behaviors are listed in Table 10.

Triangulation of methods. The types of behavior reported with the three methods was examined for similarities. Twelve subjects reported that one or two behaviors were the same with both the MMPQ and the video-related interview. Most of the subjects (n=33, 73%) reported different behaviors with the two methods. No linear relationship was

Table 11

Video-Interview Generated Pain Control Behaviors

Behavior Category (Number of Behaviors)	Description of the Pain Control Behavior	N (%)	Reduce Pain[a]	Prevent[a] Pain Onset
Use Analgesics (1)	Monitored medication schedule	1 (2)	100%	---
Change Position (18	Stretched-arm, back, head & neck	5 (11)	100%	---
	Shrugged or rotated shoulder	10 (22)	90%	10%
	Repositioned specific body parts	9 (20)	67%	33%
	Crossed legs	7 (16)	71%	29%
	Reclined in specific position	4 (9)	75%	25%
	Selected arm positions:			
	Braced on arm of chair	2 (4)	100%	---
	Crossed across chest	4 (9)	100%	---
	Held / supported painful arm	1 (2)	---	100%
	Shook arm	2 (4)	100%	---
	Placed hands-to-hips	1 (2)	---	100%
	Thumbs-in-pockets	2 (4)	100%	---
	Abducted from body / barrel-like	3 (7)	100%	---
	Held perpendicular to body	2 (4)	100%	---
	Placed hands-to-knees or thighs	9 (20)	56%	44%
	Sat on foot	1 (2)	100%	---
	Shifted weight	5 (11)	100%	---
	Elevated head / shoulders with pillow	6 (13)	50%	50%
	Positioned pillow behind back when sitting	3 (7)	100%	---
Immobilize/Guard (6)	Immobilized head and neck	1 (2)	---	100%
	Braced to sit	22 (49)	84%	16%
	Braced to shift from sit / recline	19 (42)	58%	42%
	Guarded leg	2 (4)	100%	---
	Guarded arm ipsilateral to tumor	14 (31)	50%	50%
	Guarded torso or whole body	9 (20)	44%	56%
Pressure Manipulation (4)	Massaged nonpainful area	1 (2)	---	100%
	Massaged painful area	6 (13)	100%	---
	Pressure applied to painful area	13 (29)	92%	8%
	Wore no shirt	1 (2)	---	100%
Use Heat / Cold (1)	Wrapped to stay warm / heat pad use	3 (7)	100%	---
Eat / Drink (1)	Drank water	1 (2)	100%	---
Divert Attention/ Alter Attitude (6)	Engaged in conversation	1 (2)	100%	---
	Read book or magazine	2 (4)	100%	---
	Watched television	1 (2)	100%	---
	Listened to music	2 (4)	100%	---
	Breathed deeply	1 (2)	100%	---
	Gazed at object	1 (2)	100%	---
Other (5)	Rocked body	2 (4)	100%	---
	Asked God to help	1 (2)	100%	---
	Moaned	2 (4)	100%	---
	Yawned	1 (2)	100%	---
	Rested	1 (2)	100%	---

[a] = Percent of the number of subjects using the pain control behavior who reported that the pain control behavior was used to reduce or prevent pain onset.

Table 12
Pain Control Behaviors Rank-Ordered by Number of Subjects Using and Validating Behavior

Behavior	% of N = 45
Braced to sit	49%
Braced to shift from sit / recline	42%
Guarded arm ipsilateral to tumor	31%
Pressure applied to painful area	29%
Shrugged or rotated shoulder	22%
Repositioned specific body parts	20%
Placed hands-to-knees or thighs when shifting	20%
Guarded torso or whole body	20%
Crossed legs	16%
Massaged painful area	13%
Elevated head / shoulders with pillow	13%
Stretched-arm, back, head & neck	11%
Shifted weight	11%
Reclined in specific position	9%
Crossed across chest	9%
Abducted from body / barrel-like	7%
Positioned pillow behind back when sitting	7%
Wrapped to stay warm / heat pad use	7%
Braced on arm of chair	4%
Shook arm	4%
Thumbs-in-pockets	4%
Held perpendicular to body	4%
Guarded leg	4%
Wrapped to stay warm	4%
Read book or magazine	4%
Listened to music	4%
Rocked body	4%
Moaned	4%
Monitored medication schedule	2%
Held / supported painful arm	2%
Placed hands-to-hips	2%
Sat on foot	2%
Immobilized head and neck	2%
Massaged nonpainful area	2%
Wore no shirt	2%
Engaged in conversation	2%
Watched television	2%
Breathed deeply	2%
Gazed at object	2%
Asked God to help	2%
Yawned	2%
Rested	2%
Drank water	2%

Table 13

The Type and Frequency of Different Pain Control Behaviors Identified by Video-Related Interview

Type of Behavior	Number of Behaviors
Position	18
Pressure Manipulation	4
Distraction	6
Immobilize / Guard	6
Analgesic	1
Other	7

found between the number of behaviors identified with the two methods (r=.15, p>.05).

Thirteen subjects reported that one to four behaviors were the same when the video-related interview was compared with the open-ended interview. The majority of the subjects (n=29, 69%) reported different behaviors with the two methods. No linear relationship was demonstrated between the number of behaviors identified with the two methods (r=.01, p>.05)

Greater agreement was seen when the MMPQ responses were compared with the open-ended interview responses. Only 14 subjects reported different behaviors with the two methods. Most of the subjects (n=28, 67%) reported that one to five behaviors were the same with the MMPQ and the open-ended interview. The Pearson Correlation Coefficient indicated a moderate linear relationship between the number of behaviors identified by the two methods (r=.52, p<.05).

Question 3.

What activities do patients with lung cancer indicate their pain prevents them from doing?

Results related to this question were provided by: 1) a MMPQ question (Part 3, question 3); 2) interview about behaviors scored from the video tape; and 3) open-ended interview. These results are reported separately for each method, but are not triangulated because the data are not conceptually the same.

MMPQ. Subjects reported that performing zero to six behaviors increased their pain (mean=2.2, SD=1.3). For 13 subjects, at least one of the behaviors that increased pain was opposite to the MMPQ derived

behaviors that were reported to relieve pain. Rarely were specific behaviors reported. Rather, subjects indicated that stress, activity, not taking medications, and work increased pain.

Video-related interview. The majority of the subjects (n=38, 84%) reported their pain prevented them performing none of the daily living activities required by the video tape protocol. Seven (16%) of the subjects reported that at least one of the scored behaviors was performed because pain prevented usual behavior. For example, one subject reported that pain prevented him from wearing his shirt unless a skin lesion was bandaged. Another subject indicated that pain prevented shifting without using his arms to brace as he sat down or stood up.

Open-ended interview. Subjects reported zero to nine behaviors that pain prevented them from doing (mean=3, SD=2.4). Behaviors prevented by pain included housework, gardening, playing golf, shopping, working, and other usual activities.

Question 4.

> **What is the relationship between pain expression behaviors and salient aspects of pain: intensity; quality; location; onset; and pattern?**

Analyses for this question were conducted using the open-ended interview data, since none of the behaviors scored from the video were reported as pain expression behaviors. The number of behaviors reported to express pain (open-ended interview) and pain intensity, quality, location, and onset scores were examined using Pearson Correlation Coefficients. Findings indicated there were no significant linear relationships. Based on a sample of 45 subjects and alpha set at .05, correlations were statistically significant when $r>.30$.

Since nearly one-half of the subjects reported an intent not to express pain to others and one-half reported an intent to directly tell others about their pain, these two groups were used to examine pain intensity, quality, location, and onset scores using independent t-tests. Results indicate there were no statistically significant ($p<.05$) differences in pain intensity, pain quality, pain location, or pain onset scores when the two groups were compared. The two groups also had similar patterns of pain since chi square analysis was non significant.

Question 5.

What is the relationship between pain control behaviors and salient aspects of pain: intensity; quality; location; onset; and pattern?

The relationship between the number of different behaviors reported as pain control behaviors (video-related interview) and pain intensity, quality, location, and onset was examined using Pearson Correlation Coefficients. Significant linear associations were noted between the total number of different pain control behaviors and pain intensity scores and pain quality scores but not pain location or pain onset as indicated in Table 14. Similar findings were noted for the number of different behaviors used to reduce pain intensity but not for the number of different behaviors used to prevent the onset of pain (see Table 14).

Using Analysis of Variance (ANOVA) with pain pattern as the between subjects factor, a statistically significant relationship was noted for the total number of different pain control behaviors ($F(2,42)=3.4$, $p=.04$) (see Table 15). Subjects with constant pain (mean=5.5, SD=3.3) used more pain control behaviors than subjects with

Table 14

Pearson Correlation Coefficients for Pain Control Behaviors and Pain Intensity, Quality, Location, and Onset

		Pain Control Behaviors					
		Total		Reduce Pain		Prevent Pain Onset	
	N	r	p≤	r	p≤	r	p≤
Intensity							
VAS-Time1	45	.28	ns	.26	ns	.14	ns
VAS-Time2	44	.31	.04	.44	.01	-.04	ns
Quality	45						
PRI-Sensory		.51	.01	.54	.01	.19	ns
PRI-Affective		.46	.01	.47	.01	.20	ns
PRI-Evaluative		.38	.01	.45	.01	.09	ns
PRI-Miscellaneous		.53	.01	.56	.01	.21	ns
PRI-Total		.58	.01	.62	.01	.22	ns
NWC		.62	.01	.64	.01	.28	ns
Location	45						
No. of Pain Sites		.27	ns	.29	ns	.20	ns
Pain Onset							
Months of Pain	45	.01	ns	.07	ns	-.08	ns

ns = Not significant at p<.05 level

intermittent (mean=3.1, SD=2.1) or transient pain (mean=2.7, SD=3.8). Pairwise comparisons of means were not significant at the P<.05 level. ANOVAs were not significant when the number of different behaviors used to reduce or to prevent pain onset were examined by pain pattern.

Question 6.

What is the relationship between the behaviors pain prevents and salient aspects of pain: intensity; quality; location; onset; and pattern?

Since only seven subjects reported behaviors that pain prevented from the video-related interview, this question was examined using data obtained from the open-ended interview. The number of different behaviors prevented by pain and pain intensity, quality, location, and onset were evaluated with Pearson Correlation Coefficients. Findings indicate there was a weak to moderate linear relationship for most of these variables as listed in Table 16. Analysis of Variance (ANOVA) with pain pattern as the between subjects factor, demonstrated a non significant relationship for the number of different behaviors prevented by the pain.

Question 7.

What is the relationship between pain expression behaviors and affective, cognitive, and physiological-sensory dimension variables?

The number of pain expression behaviors reported with the open-ended interview was not correlated significantly with the MMPQ affective or evalualtive scores, the state or trait anxiety scores, any subscale from the PCSQ, or the internal or external locus of control scales from the CSLC and the PLOC. However, t-tests indicated that mean scores for six of the eight PCSQ subscales were significantly higher for subjects

Table 15

Analysis of Variance for the Number of Pain Control Behaviors by Pain Pattern

Pain Control Behavior	n	Mean	SD	One Way ANOVA df	F	p≤	Eta^2
Total				2,42	3.42	.04	.14
Constant Pain	24	5.5	3.6				
Intermittent Pain	18	3.1	2.1				
Transient Pain	3	2.7	3.8				
Reduce Pain				2,42	2.31	ns	.10
Constant Pain	24	4.0	3.2				
Intermittent Pain	18	2.2	1.6				
Transient Pain	3	2.7	3.8				
Prevent Pain Onset				2,42	1.96	ns	.09
Constant Pain	24	1.4	1.5				
Intermittent Pain	18	0.8	1.2				
Transient Pain	3	0.0	0.0				

ns = not significant at $p<.05$ level

Table 16

Pearson Correlation Coefficients for the Number of Behaviors Prevented by Pain per Open-ended Interview and Pain Variables

	# Behaviors Prevented by Pain	
	r	p≤
Intensity		
VAS-Time1	.18	ns
VAS-Time2[a]	.41	.01
Quality		
PRI-Sensory	.52	.01
PRI-Affective	.39	.01
PRI-Evaluative	.43	.01
PRI-Miscellaneous	.54	.01
PRI-Total	.58	.01
NWC	.54	.01
Location		
No. Sites	.35	.02
Pain Onset		
Months in Pain	.01	ns

ns = not significant at p <.05 level

[a] N=41 due to missing data; N=42 for all other correlations because of missing data.

who reported that they tried not to express their pain to others (see Table 17). Significant differences in mean scores were not found for the reinterpreting or the catastrophizing subscales.

Few differences were found in the number of pain expression behaviors reported with the open-ended interview when physiological variables were considered. The number of pain expression behaviors did not vary by metastatic disease, stage of disease, tumor histology (see Table 18), analgesics, surgical treatment, or chemotherapy, or concurrent conditions associated with pain (see Table 19). Subjects who had not received any radiation therapy reported fewer pain expression behaviors (mean=.25) than subjects who had received radiation therapy (mean=.94) (see Table 19).

Question 8.

What is the relationship between pain control behaviors and affective, cognitive, and physiological-sensory dimension variables?

When the two variables conceptually representing the affective dimension were examined, only the MPQ PRI-affective subscale score was correlated with the total number of different behaviors used to control pain (see Table 20). The MPQ PRI-affective subscale score was also correlated with the number of different behaviors used to reduce the intensity of pain but not the number of behaviors used to prevent the onset of pain. State and trait anxiety scores were not associated with with pain control behaviors at a statistically significant level (see Table 20).

Table 17

Pain Coping Strategies Questionnaire Subscales Compared for Subjects Verbalizing Pain versus Subjects Not Verbalizing Pain to Others

	Verbally Expresses Pain (n=18)		Tries Not to Express Pain (n=19)		Independent t-test	
Subscale	Mean	SD	Mean	SD	t	p ≤
Diverting Attention	12.3	9.9	20.6	8.3	-2.74	.01
Reinterpreting Sensations	7.3	7.3	11.9	8.6	-1.75	ns
Coping Self-Statements	17.9	10.2	25.6	5.6	-2.86	.01
Ignoring Pain	12.1	9.4	19.3	7.4	-2.59	.01
Praying / Hoping	16.2	12.3	24.1	9.5	-2.19	.04
Catastrophize	9.8	10.8	11.9	8.1	-0.68	ns
Behavioral Activity	11.7	7.8	20.2	6.8	-3.50	.01
Pain Behavior	14.5	4.3	19.6	7.1	-2.60	.01
Total	109.2	50.8	160.5	41.0	-3.34	.01
Ability to Control Pain	3.6	1.9	3.8	1.3	-0.34	ns
Ability to Decrease Pain	3.8	1.9	3.5	1.3	0.51	ns

ns = not significant at $p < .05$ level

Table 18

Analysis of Variance: Pain Related Behaviors by Physiological Variables

Dependent Variable	Between Subjects Factor	df	F	p	Eta^2
# of Pain Expression Behaviors					
	Metastatic Disease	2,38	1.324	ns	.07
	Lung Cancer Stage-Now	3,37	.316	ns	.03
	Histology	3,37	2.584	ns	.08
# of Pain Control Behaviors					
	Metastatic Disease	2,41	.450	ns	.02
	Lung Cancer Stage-Now	3,39	.307	ns	.02
	Histology	3,40	.527	ns	.04
# of Pain Reduction Behaviors					
	Metastatic Disease	2,41	.505	ns	.02
	Lung Cancer Stage-Now	3,39	.202	ns	.02
	Histology	3,40	.522	ns	.04
# of Behaviors Prevent Pain Onset					
	Metastatic Disease	2,41	1.02	ns	.05
	Lung Cancer Stage-Now	3,39	.704	ns	.05
	Histology	3,40	.934	ns	.07
# Behaviors Pain Prevents					
	Metastatic Disease	2,38	.446	ns	.02
	Lung Cancer Stage-Now	3,37	.599	ns	.05
	Histology	3,37	2.584	ns	.17

ns = not significant at $p<.05$ level

Table 19
Independent T-Tests: Pain-Related Behavior Examined by Physiological Variables

Dependent Variable	Group 1 Mean (SD)[a]	Group 2 Mean (SD)[a]	df	t	p<
# of Pain Expression Behaviors					
	No Surgery	Surgery	39	.37	ns
	No Radiation	Radiation	38	2.99	.01
	.25 (.46)	.94 (.91)			
	No Chemotherapy	Chemotherapy	39	1.44	ns
	No Concurrent Pain	Concurrent Pain	40	.23	ns
	Strong Analgesic	Weak Analgesic	36	.61	ns
# of Pain Control Behaviors					
	No Surgery	Surgery	42	1.03	ns
	No Radiation	Radiation	41	.63	ns
	No Chemotherapy	Chemotherapy	42	1.11	ns
	No Concurrent Pain	Concurrent Pain	43	1.99	ns
	Strong Analgesic	Weak Analgesic	39	.28	ns
# of Pain Reduction Behaviors					
	No Surgery	Surgery	42	1.32	ns
	No Radiation	Radiation	41	.48	ns
	No Chemotherapy	Chemotherapy	42	.82	ns
	No Concurrent Pain	Concurrent Pain	43	.73	ns
	Strong Analgesic	Weak Analgesic	39	.37	ns
# of Behaviors Prevent Pain Onset					
	No Surgery	Surgery	42	.31	ns
	No Radiation	Radiation	41	.07	ns
	No Chemotherapy	Chemotherapy	42	.03	ns
	No Concurrent Pain	Concurrent Pain	43	2.71	.01
	1.6 (1.6)	.54 (.88)			
	Strong Analgesic	Weak Analgesic	39	.13	ns
# Behaviors Pain Prevents					
	No Surgery	Surgery	39	.35	ns
	No Radiation	Radiation	38	.25	ns
	No Chemotherapy	Chemotherapy	39	1.81	ns
	No Concurrent Pain	Concurrent Pain	40	.71	ns
	Strong Analgesic	Weak Analgesic	36	1.10	ns

[a] if t-test significant at p<.05 level
ns = not significant at p<.05 level

Table 20
Pearson Correlation Coefficients for Pain Control Behaviors and Affective and Cognitive Dimension Variables

		Pain Control Behaviors					
		Total		Reduce Pain		Prevent Pain Onset	
	N	r	p≤	r	p≤	r	p≤
Affective							
State Anxiety	43	.20	ns	.30	ns	-.03	ns
Trait Anxiety	43	.06	ns	.16	ns	-.07	ns
MMPQ							
PRI-A	45	.46	.01	.47	.01	.20	ns
Cognitive							
Cancer Locus of Control							
Internal2	45	.17	ns	.13	ns	.07	ns
External2	45	.21	ns	.29	ns	-.03	ns
Pain Locus of Control							
Internal2	42	-.11	ns	-.10	ns	-.10	ns
External2	42	.22	ns	.29	ns	.09	ns
MMPQ							
PRI-E	45	.38	.01	.45	.01	.09	ns
Coping Strategies	45						
Diverting Attention		.34	.02	.37	.01	.16	ns
Reinterpreting Sensations		.42	.01	.39	.01	.23	ns
Coping Self-Statements		.14	ns	.17	ns	.11	ns
Ignoring Pain		.36	.01	.28	ns	.38	.01
Praying / Hoping		.18	ns	.25	ns	.00	ns
Catastrophizing		.33	.03	.48	.01	-.06	ns
Behavioral Activities		.37	.01	.40	.01	.18	ns
Pain Behavior		.20	ns	.23	ns	.12	ns
Total		.39	.01	.42	.01	.18	ns

ns = not significant at p <.05 level

Similar findings were noted for the variables conceptually representing the cognitive dimension of pain. The MMPQ PRI-evaluative subscale score was correlated with the total number of different behaviors used to control pain and to reduce pain intensity but not with the behaviors used to prevent the onset of pain (see Table 20). None of the locus of control (cancer or pain) scales were associated with pain control behaviors at a statistically significant level.

Some of the pain coping strategies subscale scores, however, were linearly associated with pain control behaviors. As indicated in Table 20, the pattern of linear association was inconsistent. For the total number of different pain control behaviors used, six subscale scores were statistically significant. Five subscale scores were statistically significant for the number of behaviors used to reduce pain intensity whereas only one subscale score was significant for the number of behaviors preventing pain onset.

Few differences were found in the total number of behaviors used to control pain, the number of behaviors used to reduce pain, or the number of behaviors that prevent pain onset when physiological variables were considered. The pain control behaviors did not vary by metastatic disease, stage of disease, tumor histology (see Table 18), analgesics, surgical treatment, radiation therapy, or chemotherapy (see Table 19). The number of behaviors that prevented pain onset differed by presence of concurrent conditions associated with pain (see Table 19). Subjects without experience with concurrent painful conditions used larger

numbers of behaviors to prevent pain onset (mean=1.6) than subjects with concurrent painful conditions (mean=.54).

Question 9.

What is the relationship between behaviors prevented by pain and affective, cognitive, and physiological-sensory dimension variables?

When the two variables conceptually representing the affective dimension were examined, the MPQ PRI-affective subscale score, state anxiety, and trait anxiety were correlated with the number of different behaviors prevented by pain (open-ended interview data) (see Table 21). Less consistent findings were noted for the variables conceptually representing the cognitive dimension of pain. The MMPQ PRI-evaluative subscale score was correlated with the number of different behaviors prevented by pain (see Table 21). Only the internal pain locus of control scale was associated with behaviors prevented by pain (see Table 21). Only one of the pain coping strategies subscale scores was linearly associated with the number of behaviors prevented by pain. The catastrophizing subscale demonstrated a moderate positive correlation with behaviors prevented by pain (see Table 21).

No differences were found in the number of behaviors prevented by pain when physiological variables were considered. The behaviors prevented by pain did not vary by metastatic disease, stage of disease, tumor histology (see Table 18), analgesics, surgical treatment, radiation therapy, chemotherapy, or concurrent painful conditions (see Table 19).

Table 21

Pearson Correlation Coefficients for the Number of Behaviors Prevented by Pain and Affective and Cognitive Dimension Variables

Variable	Behaviors Prevented by Pain (Open-ended Interview)		
	N	r	p≤
Affective			
State Anxiety	41	.55	.01
Trait Anxiety	41	.44	.01
MMPQ PRI-A	42	.52	.01
Cognitive			
Locus of Control			
Internal2 Cancer	42	-.25	ns
External2 Cancer	42	.13	ns
Internal2 Pain	40	-.35	.03
External2 Pain	40	.14	ns
MMPQ PRI-E	42	.43	.01
Pain Coping Strategies	42		
Diverting Attention		.10	ns
Reinterpreting Sensations		-.10	ns
Coping Self-Statements		-.05	ns
Ignoring Pain		-.00	ns
Praying / Hoping		.04	ns
Catastrophizing		.51	.01
Behavioral Activities		-.00	ns
Pain Behavior		-.04	ns
Total		.08	ns

ns = not significant at p <.05 level

Question 10.

What are the best predictors of pain expression behavior from selected demographic, affective, cognitive, and physiological-sensory variables?

Since few subjects (n=7, 16%) reported using no more than three behaviors to express pain to others (open-ended interview), the number of pain expression behaviors was limited by a restricted range of variance. As expected with such a distribution, simultaneous multiple regression analysis with 12 regressors resulted in non significant findings (see Table 22). A reduced model was examined because the findings in the full model may have been influenced by the high regressor-to-subject ratio. A reduced model with two regressors was also non significant (see Table 22).

Question 11.

What are the best predictors of pain control behavior from selected demographic, affective, cognitive, and physiological-sensory variables?

Pain control behaviors were represented by three variables derived from the video-related interview. The 12 regressors (see Table 23) were examined with separate regression analyses to determine the best predictors for: 1) the total number of pain control behaviors; 2) the number of behaviors used to reduce pain; and 3) the number of behaviors used to prevent pain onset.

Total number of pain control behaviors. As with the number of pain expression behaviors, simultaneous multiple regression analysis with 12 regressors resulted in non significant findings for the total number of pain control behaviors (see Table 23). A reduced model was

Table 22

Multiple Regression Analyses to Predict the Number of Behaviors Used to Express Pain (Interview) to Others from Selected Affective, Cognitive, and Physiological-Sensory Variables

Model	Source	R^2Change	sr^2	df	F change	p ≤
Full:		.2088	—	12,27	.594	.8302
	Age					
	Gender					
	No. Months of Pain					
	Pain Intensity					
	No. of MMPQ Words					
	No. of Pain Sites					
	Total Cope					
	State Anxiety					
	Internal2 Locus-Cancer					
	External2 Locus-Cancer					
	Ability to Control Pain					
	Ability to Decrease Pain					
Reduced:		.0741	—	2,37	1.481	.2387
	No. Months of Pain					
	Pain Intensity					

ns = not significant at p<.05 level

MMPQ = McGill-Melzack Pain Questionnaire

Table 23

Multiple Regression Analyses to Predict the Number of Behaviors Used to Control Pain from Selected Affective, Cognitive, and Physiological-Sensory Variables

Model	Source	R^2Change	sr^2	df	F change	p ≤
Full:		.4675	—	12,27	1.975	.0684
	Age					
	Gender					
	No. of Months Pain					
	Pain Intensity					
	No. of MMPQ Words					
	No. of Pain Sites					
	Total Cope					
	State Anxiety					
	Internal2 Locus-Cancer					
	External2 Locus-Cancer					
	Ability to Control Pain					
	Ability to Decrease Pain					
Reduced:		.4378	—	3,36	9.344	.001
	No. of MMPQ Words		.4011	1,36	25.682	.001
	No. of Months Pain		.0301	1,36	1.928	ns
	Internal2 Locus-Cancer		.0319	1,36	2.044	ns

ns = not significant at $p<.05$ level

MMPQ = McGill-Melzack Pain Questionnaire

examined because the findings in the full model may have been influenced by the high regressor-to-subject ratio. The reduced model accounted for a significant amount of variance. The number of MMPQ words, the number of months of pain, and internal locus of control-cancer together accounted for 44% of the variance in the total number of pain control behaviors. The number of MMPQ words, but no other variable alone, accounted for a significant increase in the explained variance above and beyond what was accounted for by the three variables together. The number of MMPQ words accounted for 40% of the unique variance in the total number of behaviors used to control pain.

Number of behaviors used to reduce pain intensity. In contrast, when the 12 regressors were entered simultaneously to predict the number of behaviors used to reduce pain intensity, the model was significant (see Table 24). The full model accounted for 51% of the variance in the number of behaviors used to reduce pain intensity, but the explained variance was 29% when adjusted for the regressor-to-subject ratio. The number of MMPQ words was the only variable to account for a significant increase in the explained variance above and beyond the 12 variables. The number of MMPQ words accounted for 15% of the unique variance in the number of behaviors used to reduce pain intensity.

A reduced model was tested with the four regressors that had the largest F-to-remove value; number of months of pain, the number of MMPQ words selected, the number of pain sites, and internal locus of control-cancer. The reduced model was significant and accounted for 48% of the variance in the number of behaviors used to reduce pain (see Table 24).

Table 24

Multiple Regression Analyses to Predict the Number of Behaviors Used to Reduce Pain Intensity from Selected Affective, Cognitive, and Physiological-Sensory Variables

Model	Source	R^2Change	sr^2	df	F change	p ≤
Full:		.5099	—	12,27	2.341	.03
	Age					ns
	Gender					ns
	No. of Months Pain					ns
	Pain Intensity					ns
	No. of MMPQ Words		.1549	1,27	8.532	.01
	No. of Pain Sites					ns
	Total Cope					ns
	State Anxiety					ns
	Internal2 Locus-Cancer					ns
	External2 Locus-Cancer					ns
	Ability to Control Pain					ns
	Ability to Decrease Pain					ns
Reduced:		.4753	—	4,35	6.926	.001
	No. of Months Pain		.0625	1,35	4.170	.05
	No. of Pain Sites		.0248	1,35	1.655	ns
	No. of MMPQ Words		.2341	1,35	15.612	.001
	Internal2 Locus-Cancer		.0346	1,35	2.309	ns

ns = not significant at p<.05 level

MMPQ = McGill-Melzack Pain Questionnaire

The number of MPQ words and the number of months of pain, but no other variable alone, accounted for a significant increase in the explained variance above and beyond what was accounted for by the other four variables. The number of MMPQ words accounted for 23% of the unique variance in behaviors used to reduce pain intensity. The number of months in pain accounted for 6% of the unique variance in behaviors used to reduce pain intensity.

Number of behaviors used to prevent pain onset. As with the total number of pain control behaviors, simultaneous multiple regression analysis with 12 regressors resulted in nonsignificant findings for the number of behaviors used to prevent pain onset (see Table 25). A reduced model was examined because the findings in the full model may have been influenced by the high regressor-to-subject ratio. The reduced model approached ($p=.08$) but did not reach statistical significance (see Table 25).

Question 12.

What are the best predictors of behaviors prevented by pain from selected demographic, affective, cognitive, and physiological-sensory variables?

Simultaneous regression with 12 regressors resulted in a full model that was significant and accounted for 56% of the explained variance in the number of behaviors prevented by the pain (open-ended interview) (see Table 26). Adjusted for the regressor-to-subject ratio, the explained variance was 37%. In the full model, state anxiety and the number of MMPQ words each accounted for significant increases in the explained variance above and beyond what was accounted for by the 12

Table 25

Multiple Regression Analyses to Predict the Number of Behaviors Used to Prevent the Onset of Pain from Selected Affective, Cognitive, and Physiological-Sensory Variables

Model	Source	R^2Change	sr^2	df	F change	p≤
Full:		.2741	—	12,27	.850	.6081
	Age					
	Gender					
	No. of Months Pain					
	Pain Intensity					
	No. of MMPQ Words					
	No. of Pain Sites					
	Total Cope					
	State Anxiety					
	Internal2 Locus-Cancer					
	External2 Locus-Cancer					
	Ability to Control Pain					
	Ability to Decrease Pain					
Reduced:		.0262	—	4,35	2.273	.0804
	No. of MMPQ Words					
	Ability to Decrease Pain					
	Gender					
	External2 Locus-Cancer					

ns = not significant at p<.05 level

MMPQ = McGill-Melzack Pain Questionnaire

Table 26

Multiple Regression Analyses to Predict the Number of Behaviors Prevented by Pain (Interview) from Selected Affective, Cognitive, and Physiological-Sensory Variables

Model	Source	R^2Change	sr^2	df	F change	p ≤
Full:		.5604	—	12,27	2.868	.01
	Age					ns
	Gender					ns
	No. of Months Pain					ns
	Pain Intensity		.0193	1,27	1.185	ns
	No. of MMPQ Words		.0907	1,27	5.572	.03
	No. of Pain Sites					ns
	Total Cope					ns
	State Anxiety		.0937	1,27	5.754	.02
	Internal2 Locus-Cancer		.0167	1,27	1.027	ns
	External2 Locus-Cancer					ns
	Ability to Control Pain					ns
	Ability to Decrease Pain		.0398	1,27	2.442	ns
Reduced:		.5412	—	5,34	8.023	.001
	State Anxiety		.0183	1,34	8.027	.01
	Internal2 Locus-Cancer		.0184	1,34	1.366	ns
	Ability to Decrease Pain		.0789	1,34	5.846	.02
	No. of MMPQ Words		.1096	1,34	8.119	.01
	Pain Intensity		.0224	1,34	1.657	ns

ns = not significant at $p<.05$ level

MMPQ = McGill-Melzack Pain Questionnaire

variables. The state anxiety accounted for 9% and the number of MMPQ words accounted for 9% of the unique variance in the number of behaviors prevented by the pain.

A reduced model with state anxiety, internal locus of control-cancer, ability to decrease pain, number of MMPQ words, and pain intensity was also examined. The reduced model accounted for 54% of the variance in the number of behaviors prevented by the pain (see Table 26). The unique variance accounted for by the number of MMPQ words and the state anxiety, each, was similar to the full model (see Table 26). However, in the reduced model, the ability to decrease pain also accounted for unique variance (8%) above and beyond the contribution of the other four variables.

Chapter Five

Discussion

The purpose of this study was to characterize the behavioral correlates of lung cancer pain. Using a descriptive, correlational study design and repeated measures for selected variables, behaviors associated with lung cancer pain were identified and examined for relationships with pain location, pain intensity, pain quality, pain onset, and pain pattern. Affective, cognitive, behavioral, and physiological-sensory variables were evaluated to determine predictors of behaviors associated with lung cancer pain. The discussion presented in this chapter includes: interpretation of the findings; significance of the findings; limitations of the study; implications of the findings for nursing practice; and recommendations for future research.

Interpretation of Findings

These data provide important information regarding the multidimensional nature of lung cancer pain, and the findings are interpreted within a multidimensional framework. The behavioral components are discussed in terms of pain expression behaviors, pain control behaviors, and behaviors prevented by pain. The multidimensional nature of lung cancer pain is addressed in terms of the relationships between each behavioral dimension and the physiological-sensory dimension, affective dimension, and cognitive dimension. Results also are related to the gate control theory of pain and the Johnson Behavioral System Model for nursing practice which together formed the theoretical framework for this research.

Pain expression behaviors. Findings indicate that patients with lung cancer pain did not purposefully express their pain via behavior to other people when they sat, stood, walked, reclined, and were observed by video cameras. Instead of communicating pain via behavior, nearly half of patients with lung cancer expressed their pain via verbal complaints. A small minority of patients expressed their pain via facial expressions and emotional display. A notable finding was that nearly half of the patients with lung cancer did not attempt to express their pain to other people. Methods of expressing pain to others were not associated with differences in pain intensity, quality, location, onset, or pattern; anxiety; cancer locus of control, or disease factors. Given the restricted range of variance in the number of pain expression behaviors, these correlates might demonstrate themselves in another sample.

Methods of expressing pain to others, however, were associated with pain coping strategies. Patients who did not attempt to express their pain to others reported more frequent use of six pain coping strategies and a higher total frequency of pain coping strategies. Ability to control pain or decrease pain and use of catastrophizing and reinterpreting pain sensations did not differentiate the two methods of expressing pain. It is unclear from these data whether patients perceived their method of expressing pain to be a pain coping strategy. Yet these data suggest that investigators should be cautious about interpreting PCSQ scores without considering the method the patient uses to express pain.

Cancer pain researchers previously reported that facial expression, mood, and pain complaints were recognized by patients as methods of communicating pain to others (Ahles et al., 1983). Cancer pain researchers, however, have not documented the large number of people who report that they attempt not to express pain to others. This finding was revealed by unstructured interview with the patient, and more systematic assessment of the incidence of this phenomenon is warranted before drawing conclusions. It is particularly important to address social desirability issues when examining the variables related to expressing or not expressing lung cancer pain to other people. Replication of this finding, however, would have important implications for clinical practice.

This finding supports a position recently advocated by cancer pain researchers. Cleeland (1989) contends that patients with cancer exhibit their pain in ways not recognized by clinicians and strongly suggests that patients with cancer should be taught to communicate their pain to health professionals in ways that health professionals recognize as being associated with pain. Only five patients in the present study reported using some of the behaviors that Cleeland recommended teaching patients. These were behaviors such as crying, moaning, and displaying facial expressions of suffering. Clearly most patients reported a small repertoire of such pain expression behaviors.

Pain expression results from the present study vary from findings reported by Bond and Pilowsky (1966) where gender differences were noted in pain expression and by Zborowski (1952) and by Lipton and Marbach (1984) where culture helped to discriminate how individuals expressed

their pain to others. However, in the present study, ethnicity was assessed, culture was not, and there was no attempt to determine the strength of religious affiliation. It is impossible to determine if the predominately white sample included the same cultural and religious groups studied in the previous research. The importance of these conflicting findings is unclear given the differences in classifying demographic variables.

Although the importance of expressing or not expressing pain to others is difficult to interpret, these data could provide important information from the perspective of the Johnson Behavioral System Model (Johnson, 1980). It is possible that the method of expressing pain could predict dysfunction in the dependency and achievement subsystems. Patients who attempt to conceal their pain from others might also have difficulty accepting assistance from other people, attempting instead to resolve their problems by themselves. The more frequent use of pain coping strategies by subjects who did not express their pain supports this supposition. Self-reliance may be a useful behavior to meet mastery and control needs, but as a person succumbs to lung cancer, self-reliance may less efficient than allowing others to assist with pain management.

Behaviors pain prevents. The behaviors prevented by pain were not readily discerned with the video observation and interview method. Pain did not prevent patients from engaging in the usual activities of daily living that were required by the standardized protocol. This is in contrast to a recent report with patients with cancer pain being considered for implantation of a pump to administer spinal opiates

(Ahles, Coombs, Jensen, Stukel, Maurer, & Keefe, in press). These investigators, using an adapted version of Keefe and Block's (1982) protocol, found that some (exact number was not reported) patients were unable to complete the one-to-two minutes of activity. Exclusion criteria for the present study required functional status adequate for the patient to walk for one minute and to recline without the assistance of another person. When such criteria are not used, Ahles and associates' (in press) data indicate that pain may prevent behaviors targeted by the video observation protocol.

The few behaviors identified with the video-related interview in the present study, however, were specific behaviors whereas the behaviors reported with the open-ended interview were less discrete activities. Although many patients reported that pain prevented them from walking, all were able to walk during the video tape. This suggests that patients might have perceived that the pain prevented them from walking in the manner to which they were accustomed. Although they were able to walk within a distance of four of five feet, perhaps pain prevented them from taking their daily walks or walking at the shopping center. The video observation method, as implemented, was inadequate to detect behaviors prevented by pain and other methods would be needed to explicate this component of the pain behavior construct.

Findings support previously reported results about activity interference in cancer samples (Keefe et al., 1985; Bressler et al, 1986). As with other studies, anxiety and the number of MPQ words each accounted for an unique proportion of the variance (9%) in the number of behaviors prevented by pain (open-ended interview). Ahles and

associates (1983) reported that high levels of anxiety and high affective and evaluative scores were associated with lower levels of activity. Daut and Cleeland (1982) found that higher levels of pain were associated with greater interference with activity. Together these data suggest that lower activity may be an artifact of the larger numbers of behavior that are prevented by pain which then contribute to higher levels of anxiety. Surprisingly the role of pain intensity in this cycle was not elucidated from the present data. Reasons for this are unclear since Ahles and associates (1983) also found that pain intensity was not associated with activity level.

The meaning of these data is difficult to understand. It appears that with increasing disability the patient becomes more anxious. The impact of this disability and anxiety on the physiological mechanisms of pain and on the function within the behavioral system is uncertain. Severe behavioral system dysfunction is possible, but the data are too scant for further speculation.

Pain control behaviors. This was the first attempt to use the video observation method in the home setting and to combine it with interview to examine the patient's perceived intent for performing behavior. The method was successful in helping to identify 42 different pain control behaviors that were used during pre-set, standardized activities of daily living. Thirty-two of the behaviors were used to reduce pain intensity and 18 of the behaviors were used to prevent the onset of pain as the patient sat, stood, walked, and reclined for very short periods of time. Implications of these findings for the clinical

assessment of lung cancer pain will be discussed in another section of this chapter.

Findings about the types of behaviors used to control pain support previous research (Barbour et al., 1986; Bressler et al., 1986; Wilkie et al., 1988). Ten of the 16 different types of behaviors identified as pain reduction behaviors in Copp's (1974) study were identified with the video-interview method. This convergence of findings supports the validity and generalizability of the data from the present study.

Although patients perceived that the behaviors were used to control their pain, some pain researchers would consider these behaviors as signals for the presence of pain. Fordyce (1976, p.38) proposed that "the verbal reports, the winces and grimaces, the moans, the requests for medication or for assistance, the limp or guarded motion, [and] the limiting or restricting of behavior to avoid anticipated pain" were operant behaviors. He contrasted operant and respondent behaviors by defining respondents as behaviors that "have their specific stimuli and occur automatically when the stimulus is adequate. Respondents can therefore be said to be controlled by antecedent stimuli. Operants in contrast, are responsive to the influence of the consequences that systematically follow their occurrence" (pp. 41-42). Pain behaviors are considered to be operants (voluntary, skeletal muscle responses) but they may function in respondent fashion by helping to relieve pain.

Fordyce's (1976) application of operant behavior principles was an insightful contribution to understanding chronic pain, especially chronic pain without demonstrable physical damage. However, the potential for pain behaviors to serve dual roles as operants and as

respondents suggests that the construct requires refinement. Turk and Flor (1987) advocated such clarification and careful application of the pain behavior construct.

Data generated by this study help to discern elements of the pain behavior construct from the patient's perspective. Identified were a limited repertoire of behaviors used to communicate pain to others, a large repertoire of behaviors used to reduce pain intensity, a large repertoire of behaviors used to prevent the onset of pain, and many behaviors prevented by the pain. And any of the behaviors could serve to signal the presence of pain to others. However, it is noteworthy that patients believed the behaviors were used to control pain.

Beliefs about pain and the meaning attributed to pain have long been recognized as important to pain perception (Melzack & Wall, 1965). In cancer pain, beliefs about the pain have been shown to be important predictors of pain intensity (Ahles et al., 1983). Therefore, it seems prudent to also consider the patient's belief about his/her behavior. The implications of this perspective will be detailed in a later section.

One of the assumptions of Fordyce's (1976) conceptualization of pain behavior is that anxiety can be misinterpreted as pain and responded to with pain behavior. Findings from this study do not support that supposition. Although pain intensity was strongly correlated with state anxiety levels ($r=.63$), significant associations were not found between anxiety level and the number of behaviors used to reduce pain or to prevent the onset of pain. This suggests that anxiety

was not influential in the patient's behavioral response to the pain, as Fordyce (1976) proposed.

The term cancer pain control behaviors was coined to reflect the potential of behavior to activate ascending or descending pain modulation mechanisms (Wilkie, 1984). Although the full domain of lung cancer pain behaviors has not been identified in this research, some of the 42 behaviors could conceivably alter ascending nociceptive input and others could stimulate descending pain modulation mechanisms. For example, shrugging or rotating the shoulder may serve to reduce muscle tension, improve circulation, and thereby alter ascending nociceptive input (Travell & Simon, 1983). Watching television, listening to music, or reading, for example, may serve to divert cortical attention away from the pain and thereby stimulate descending pain modulation mechanisms (Yaksh & Hammond, 1982).

Many of the behaviors appear to control pain without risk of untoward physical effects. Other behaviors, however, appear to control pain but also pose a risk for untoward physical sequela. For example, maintaining the arm ipsilateral to the neoplasm in a fixed, abducted, and externally rotated position during ambulation was reported as a pain control behavior. This behavior reduced pain for some patients and prevented the onset of pain for other patients. This behavior also has the potential, if used frequently and for extended periods of time, to contribute to a frozen shoulder syndrome and/or to myofascial pain syndromes (Travell & Simon, 1983).

Marino and associates (1986) reported that patients with lung cancer pain had muscle tenderness in muscle groups that varied with the

site of the tumor. The pectoralis major was tender to digital pressure when the neoplasm was located in the hilar region of the lung. The supinator muscle was tender when tumor was located in the upper lobes, and parascapular region tenderness was found when the neoplasm was located in the lower lobes. Reasons for the muscle tenderness were not established by Marino and associates, but they suggested the data could have diagnostic utility for pulmonary neoplasms.

Given the data from the present study, there is a possibility that patients with lung cancer pain sometimes use pain control behaviors which have the untoward sequela of muscle tenderness that corresponds with the location of the tumor. Marino and associates (1986) also found that hyperalgesia frequently occurred in the painful area. Perhaps, when a patient experiences hyperalgesia as his/her arm contacts the painful area, the patient attempts to prevent increased pain by holding the arm in a position to reduce or prevent cutaneous stimulation. Data from several patients support this hypothesis; however, data were not collected about hyperalgesia and the data are insufficient to speculate further. Muscle tenderness and hyperalgesia could be evaluated in future research in conjunction with the specific pain control behaviors used by the patient.

As reported previously (Wilkie et al., 1988), observing patients' behavior and inquiring about observed behavior was a more productive method of identifying pain control behaviors than asking open-ended questions. On the average, the video-related interview (mean 4.3) helped to identify more behaviors than was identified by open-ended questions (MMPQ mean 3.3; open-ended interview mean 3.6).

In addition to the increased number of behaviors identified by the video-related interview, the method helped to identify precise behaviors that controlled pain. Positioning behaviors were the most frequently identified pain control behavior from the video-interview method and consuming analgesic medications was the most frequently identified pain control behavior from the interview methods. Discrepancy in the behavior used and the behavior reported was also evidenced by the large number (98%) of patients who reported using medications to relieve pain but who had not consumed any medication for an extended period of time.

A previous report indicated that pain intensity was correlated with cancer pain control behaviors, but the correlation in the present study was not as strong (Wilkie et al., 1988). From these data, it is still unclear what critical level of pain is necessary to motivate patients with cancer to use behaviors to control pain. Additionally, it is obscure if the degree to which a behavior is effective in controlling pain influences the number of behaviors used. The Johnson Behavioral System Model would suggest that some patients have a very small repertoire of efficacious behaviors and other patients have a larger repertoire of less effective behaviors. The latter patient would need to use a larger number of behaviors to control pain of the same intensity as the patient who used fewer but more effective behaviors. Although such a phenomenon could explain the weak linear relationship, the present research was not designed to evaluate effectiveness ratings for each of the pain control behaviors. Therefore, the extent to which each behavior protected the patient from pain could not be determined.

The relationships between pain control behaviors and other sensory variables were less consistent. Although patients reported pain in multiple sites, the number of sites was not linearly related to the number of different pain control behaviors used by the patient. As might be expected though, patients with constant pain were more likely to use pain control behaviors. Patients with intermittent or transient pain used similar numbers of pain control behaviors but less than the number used by patients with constant pain. Contrary to what would be predicted by the Johnson Behavioral System Model (Johnson, 1980), patients who had pain for a longer period of time were not more likely to use larger numbers of pain control behaviors. The importance of this finding is uncertain without knowing how stable the pain pattern was since the pain started.

The number of behaviors used to control pain was inconsistently related to emotional and cognitive factors when examined with bivariate statistics. The lack of consistency is not readily explainable because previous researchers have not explored the relationships between pain control behaviors and emotional, cognitive, or disease factors in cancer samples.

The multivariate analyses of the number of pain control behaviors provided unexpected information. In one-half of the models tested, the quality of pain was a significant predictor, accounting for as much as 40% of the unique variance in the number of pain control behaviors. This indicates that quality or "how the pain feels" is the most important variable to consider when investigating pain control behaviors. Data were not evaluated to determine if specific qualities

of pain were associated with specific pain control behaviors, but it would be interesting to examine the data from this perspective.

Significance of Findings

This research contributed important information about applying the video observation method in the home environment using patients with cancer pain. Technical difficulties were encountered but resolved. And a protocol was developed and tested that can be used by other investigators. Thus, this research contributed methodologically to future behavioral observation research.

A major concern about behavioral observation procedures relates to the issue of behaviors observed in one setting generalizing beyond the setting. Since "most of the patient's behavior occurs at home or work, ... assessments should grasp real life behaviors in the natural environment" (Turk & Flor, 1985, p. 287). As research is conducted in various settings, assuming convergence in findings, it is possible to have greater confidence in the validity of results (Kerlinger, 1979). It is important, therefore, that data generated in the home environment were supportive of data generated about cancer pain control behaviors in a hospital setting (Wilkie et al., 1988), even though different methods were employed.

Another methodological contribution of this research is that an omnibus measure of behavior was used with adequate inter-observer reliability. The relevance of this omnibus behavioral measure to pain, however, was dependent upon validation of the patient's intent for using the behavior. Many of the scored behaviors were refuted by the patient as being related to pain, instead being reportedly performed as habit.

Such a system is less relevant than the system developed by Keefe and Block (1982) for immediate use as an assessment measure in clinical practice. The value of the omnibus measure, however, is the potential for its use to survey the domain of behavior that has relevance to pain. Given that patients report fewer behaviors when asked verbally what they do to signal pain to others, what relieves pain, and what increases pain, it seems important to conduct a grounded theory-type of study of behavior. This research has begun this and the result was that many discrete behaviors were identified. With increased sampling of the pain behavior domain to a point of saturation (Glasser & Strauss, 1967), the potential exists for a check list of behaviors to be developed. Such a check list would have the advantage of having stronger validity than check lists that have been developed by other investigators (Richards, Nepomuceno, Riles, & Suer, 1982).

The evidence provided by this research helps to clarify the pain behavior construct, as mentioned previously. Three components of the pain behavior construct were <u>a priori</u> included in the research design, based on review of the literature. Of interest was the evolution of the pain control concept as a construct. Some of the behaviors used by the patients were performed to reduce the intensity of pain whereas some of the behaviors were performed to prevent the onset of pain. Pain control behaviors may include other types of behaviors, such as behaviors performed to enable the person to tolerate higher levels of pain. The design of the present study did not permit further exploration of component behaviors for the pain control behavior construct, but it is

exciting to have begun to delineate the constructs within the behavioral dimension of pain.

Although this research has begun to clarify the pain behavior construct, it is important to note that the method of counting behaviors in this study differed from the method used by Keefe and Block (1982). and subsequent work from Keefe's laboratory (Keefe et al, 1984; 1985; Keefe & Dolan, 1986). In Keefe's procedures, a count is made of the frequency of pain behavior occurring during the 400 seconds of observed video tape. In contrast, in this study, a count was made of the 600 seconds of observed video tape. A frequency count was not made, but it is planned for secondary analysis of this data set. When that analysis is complete, it will be possible to compare results from this study with the findings from Keefe's work for each pain-related behavior.

Limitations of Findings

Several limitations are recognized in the study. They are related to sample and methodological issues.

Sample. First, subjects constituted a nonprobability sample. It is, therefore, unclear whether subjects adequately represented all individuals with lung cancer who have pain related to tumor or antitumor therapy. The sample included nearly twice as many men as women, a percentage that is representative of lung cancer epidemiology (Silverberg et al., 1990).

Certainly, individuals with small cell lung cancer were under represented since 20-25% of all lung cancer diagnoses are of the small cell variety (Comis & Martin, 1987; Jett, Cortese, & Fontana, 1983). In this study, only 9% of the subjects had small cell cancer. The

incidence of squamous cell (39%) and adenocarcinoma (32%) in this study was more representative of lung cancer diagnoses in the general population, 30% and 30-35% respectively (Jett et al., 1983; Minna, Pass, Glatstein, & Ihde, 1989; Vincent et al., 1977). The incidence of squamous cell in the current study was also congruent with Marino and associates' finding (1986) that squamous cell lung cancer was more frequently associated with pain (53% of 49 patients). A high incidence of pain with squamous cell lung cancer appears to be related to the fact that the parenchyma of the lung does not have nociceptive receptors. Malignancies arising in the peripheral segments of the lung, such as squamous cell carcinoma, are more commonly associated with pain because they are in close proximity to extend beyond the parenchyma and invade the pleura where nociceptive receptors are located (Minna et al., 1989).

It is also notable that subjects were recruited from three geographically distinct regions, including metropolitan, mid-sized, and small cities. Agencies within these cities also varied and included a tertiary, University teaching hospital; a county hospital; two Veterans Administration hospitals; three community hospitals; and two hospices. Although few subjects were recruited from each agency, the sample was more representative of the general population of patients with lung cancer in the Western United States than if the subjects were recruited from a single agency.

Forty-five subjects participated in the study and this sample size had adequate power to reach statistical significance for most of the study questions. This sample size, however, was smaller than needed to achieve stability in correlational coefficients. It is unclear if the

sample correlation coefficients obtained in this study accurately reflect the population correlation coefficients of patients with lung cancer pain. For a sample correlation coefficient of .30, which was the minimum value to reach statistical significance in this sample, the 95% confidence band indicates that the population correlation coefficient could actually range from 0 to .50 (Wonnacott & Wonnacott, 1984). Therefore, correlations obtained in this study may or may not represent the actual relationship between variables investigated.

Interpretation of study findings was limited by the type and level of pain experienced by the subjects. The pain experienced by these subjects was assumed to be related to tumor progression or antitumor therapies because at least one pain reported by the subject was not present prior to the time the lung cancer was diagnosed. Yet patients may or may not have provided information about non-cancer related pain in addition to lung cancer related pain.

Since 77% of the patients had concurrent conditions that are commonly associated with pain, it is impossible to determine if the behaviors identified were related to the lung cancer, related to lung cancer therapy, or not related to the tumor or antitumor therapy. Presence of arthritis complaints was particularly troublesome in this respect. In several situations, the patients' complaints of arthritis symptoms (swelling and pain) led to the diagnosis of the lung cancer. Since hypertrophic pulmonary osteoarthropathy has been associated with lung cancer (Bhat, Heurich, Vaquer, Dunn, Stashun, & Kamholz, 1989; Pineda, Fonseca, & Martinez-Lavin, 1990), it was impossible to determine

whether the patient's behavior was related to cancer or non cancer related arthritis.

Subjects reported a lower mean pain intensity than is usually associated with lung cancer. The mean VAS score was less than 30 on a 101 point scale at all three measurement times. Furthermore, on the MMPQ present pain intensity scale, 75% to 86% of the subjects described their pain as none, mild, or discomforting at the two measurement times. These findings are in contrast to findings from previously published studies with lung cancer samples. Greenwald and associates (1987) reported that no less than 50% of 260 subjects with lung cancer had "moderate" or "very bad" pain.

Methodology. The cross-sectional design was another limitation of the study. For most variables, data were obtained at one point in time from subjects with varied personal, disease, and family characteristics. Since pain may vary from day-to-day or even within a day, one-time measures may not adequately represent lung cancer pain. Interpretation and conclusions about study findings must reflect this limitation.

The study design also did not allow for assessment of social desirability and the possible influence this might have played on subjects' responses. It was unclear if findings, particularly related to pain expression behaviors, reflect subjects' actual beliefs or a socially acceptable response. Since three subjects denied that all scored behaviors were related to their pain, some evidence was provided to indicate that social desirability may not have been pervasive.

Another limitation was inherent in the video observation method. The presence of video equipment and observation with video cameras may

have influenced subjects' responses. The study was not designed to evaluate these testing effects on subjects' behavioral responses when monitored with two video cameras. Turk and Flor (1985) have been critical of video observation methods because of the possibility of reactive issues.

A final limitation was created by the non-standardized video recording environment. Each home represented a unique setting. Although every attempt was made to standardize the procedures, this was not always possible because of physical limitations present in the homes. It was not clear what effect, if any, this had on study findings.

Implications for Nursing

Although generalization of study findings is inappropriate because of previously noted limitations, the findings have several implications for clinical practice. Cancer pain assessment and management could be improved by consideration of study findings.

The most obvious implication is that discrete behaviors were identified that help patients with lung cancer to reduce the intensity of their pain or to prevent the onset of pain. Many of these behaviors have not been described before as behaviors associated with control of lung cancer pain. But many of these behaviors are such common behaviors that clinicians might fail to recognize their importance in the control of cancer pain. For example, shrugging or rotating the shoulders, placing thumbs in pants pockets, or placing hands on the anterior thighs are behaviors that are so commonplace that they might not be attended to by health professionals. Yet these are the very behaviors that patients

reported they used to either reduce or prevent the onset of pain.

The behaviors identified in this research could be used in clinical practice to help the clinician recognize that the patient may be experiencing pain. Targeting these, and other behaviors identified in future research, may help clinicians to more accurately predict the amount of pain being experienced by a patient with cancer. Given that nurses in repeated studies have been unable to accurately predict the amount of pain experienced by patients (Camp, 1988; Choiniere, Melzack, Girard, Rondeau, Paquin, 1990; Teske et al., 1983; Walkenstein, 1982), this could be an important contribution to the clinical management of pain. At present, text books teach nurses to target behaviors, such as "restlessness", "immobilization", "purposeless or inaccurate body movements", "voluntary flight reactions", and "rhythmic or rubbing body movements" (Meinhart & McCaffery, 1983, pp. 251-252). These behaviors are vague in definition and, therefore, subjective to interpretation. It is possible that clearly defined behaviors may decrease the subjectivity that now plagues assessment of pain behaviors in clinical nursing practice.

Fine grained analysis of pain-related behavior also has the potential to direct clinical management of lung cancer pain using the assumptions consistent with the gate control theory of pain and the Johnson Behavioral System Model. For example, interventions could be directed at reinforcing behaviors that effectively controlled pain without potential for untoward physical sequela. In contrast, those behaviors that effectively controlled pain but were accompanied by potential for untoward sequela could be targeted for extinction. For

those patients without effective pain control behaviors or with ineffective pain control behaviors (as determined by assessing the behavioral repertoire), interventions could be directed toward teaching or modeling behaviors with the potential to activate ascending pain modulation mechanisms or to stimulate descending pain modulation mechanisms. These behaviors could be taught to both the patient and the family in order to promote appropriate use of achievement and dependency behaviors when suitable to the patient's physical and mental condition. Teaching such behaviors would necessitate teaching the rationale for altering behavior in order to account for the patient's belief about using the behavior.

Future Research

Findings from this research provide direction for future studies, and two major research thrusts are discussed. First, studies are needed to assess the pain behavior construct from the perspectives of family members and health care professionals. Second, it is important to further examine the validity and to evaluate the stability of the pain behavior construct from the patient's perspective.

Although this research provided evidence about the patient's perspective on pain behaviors using triangulation methods that supported the validity of responses, to provide a comprehensive view of the pain behavior construct, it is necessary to obtain data from people other than the patient. Perhaps the clarity of the pain behavior construct would be facilitated by carefully considering the environmental context in which the pain behaviors are examined as suggested by Turk and Flor (1985). The person interpreting the behavior is an important part of

the context, yet in the research previously reported, the perspective from which the behavior is viewed has not been sorted out. This appears to result from the assumption that if a behavior signals pain to one person it must signal pain to other people. This may not be so and needs to be evaluated.

Such research could be conducted by following the model used by Keefe and Block (1982) and include the adaptation used in the present study. Family members and health professionals, separately, could review video tapes of patients with lung cancer and then be interviewed to determine which of the behaviors they believed that: 1) the patient performed to express pain to others; 2) the patient performed to reduce the intensity of the pain; 3) the patient performed to prevent the onset of pain; 4) the patient performed because pain prevented usual behavior; or 5) the patient performed out of habit. These data would provide parallel data to that generated from patients in the present study and would be a first step to describe pain behaviors from the perspective of other people. The three data sets, from patients, family members, and health professionals, could then be compared for convergent and divergent results. These studies would provide additional data to clarify the pain behavior construct and direct further research.

The second main thrust of research is needed to replicate findings from the present study in a research design with fewer limitations. A longitudinal design is needed to evaluated the stability of a patient's response about intent for performing behaviors. Lack of stability in these responses could reflect transient perceived-intent or unreliable responses. Either would pose methodological and conceptual difficulties

for the pain behavior construct. Therefore, it is essential that stability of responses be assessed longitudinally.

Longitudinal research designs would also be useful: 1) to examine how and when cancer pain behaviors are developed and modified; 2) to examine how cancer pain behaviors vary with the cancer trajectory; 3) to examine how cancer pain behaviors vary in the presence or absence of other people; 4) to examine how cancer pain behaviors vary by setting, i.e., home, inpatient, and outpatient settings; 5) to determine the critical pain intensities at which cancer pain control behaviors are initiated and terminated; 6) to evaluate the effectiveness of specific cancer pain control behaviors; 7) to examine the relationship between specific qualities of pain and specific cancer pain control behaviors; 8) to examine the relationship between cancer pain control behaviors and the presence of hyperalgesia, allodynia, or muscle tenderness; and 9) to examine the effectiveness of behavioral interventions aimed at reinforcing effective, extinguishing dangerous, and teaching or modeling new cancer pain control behaviors.

Many of the instruments used in the current study would be useful in future research. The McGill Pain Questionnaire was particularly useful, as were the State Anxiety, pain Coping Strategies Questionnaire, and the Visual Analogue Scale. The Cancer Specific Locus of Control and the Pain Locus of Control were useful in bivariate analyses, but were not significant correlates of lung cancer pain behaviors in multivariate models. The Trait Anxiety scale was not a useful correlate and could be deleted from future protocols.

Conclusions

The pain behavior construct was clarified by the findings of this study. The dimensions of lung cancer pain behaviors include, at least, behaviors used to express pain to others, behaviors used to control pain, and behaviors prevented by the pain. Furthermore, pain control behaviors is a construct represented, at least, by behaviors used to reduce pain intensity and behaviors used to prevent the onset of pain. The affective, cognitive, and physiological-sensory correlates vary for each of these types of behavior. The quality of the pain sensation is particularly important in predicting pain behavior, but additional research is needed to delineate the role between specific pain behaviors and specific qualities of pain.

Turnbull (1979, p. 375) stated, " The amorphous mass of information about pain that may be provided by patients who are afflicted with cancer of the lung needs to be clarified." This research has done much to clarify information about lung cancer pain, but much more clarity is needed.

References

Ahles, T. A., Blanchard, E. B., & Ruckdeschel, J. C. (1983). The multidimensional nature of cancer-related pain. Pain, 17, 277-288.

Ahles, T. A., Coombs, D. W., Jensen, L., Stukel, T., Maurer, L. H., & Keefe, F. J. (in press). Development of a behavioral observation technique for the assessment of pain behaviors in cancer patients. Behavior Therapy.

Barbour, L., McGuire, D., & Kirchhoff, K. (1986). Nonanalgesic methods of pain control used by cancer outpatients. Oncology Nursing Forum, 13(6), 56-60.

Basbaum, A. I, & Fields, H. L. (1984). Endogenous pain control systems: Brainstem spinal pathways and endorphin circuitry. Annual Review of Neuroscience, 7, 309-338.

Benner, P., & Wrubel, J. (1989). The primacy of caring: Stress and coping in health and illness. Menlo Park, CA: Addison-Wesley.

Bhat, S., Heurich, A. E., Vaquer, R. A., Dunn, E. K., Strashun, A. M., & Kamholz, S. L. (1989). Hypertrophic osteoarthropathy associated with pneumocystis carini pneumonia in AIDS. Chest, 96, 1208-1209.

Bond, M.R., & Pilowsky, I. (1966). Subjective assessment of pain and its relationship to the administration of analgesics in patients with advanced cancer. Journal of Psychosomatic Research, 10, 203-208.

Bonica, J. J. (1982). Management of cancer pain. Acta Anaesthesiologica Scandinavia, 74(Suppl.), 75-82.

Bonica, J. J. (1985). Treatment of cancer pain: Current status and future needs. In H. L. Fields, R. Dubner, & F. Cervero (Eds.), Advances in pain research and therapy: Vol. 9. Proceedings of the Fourth World Congress on Pain, Seattle. (pp. 589-616). New York: Raven Press.

Bressler, L. R., Hange, P. A., & McGuire, D. B. (1986). Characterization of the pain experience in a sample of cancer outpatients. Oncology Nursing Forum, 13(6), 51-55.

Camp, L. D. (1988). A comparison of nurses' recorded assessments of pain with perceptions of pain as described by cancer patients. Cancer Nursing, 11(4), 237-243.

Chapman, C. R., Casey, K. L., Dubner, R., Foley, K. M., Gracely, R. H., & Reading, A. M. (1985). Pain measurement: An overview. Pain, 22, 1-31.

Choiniere, M., Melzack, R., Girard, N., Rondeau, J., & Paquin, M. (1990). Comparisons between patients' and nurses' assessment of pain and medication in severe burn injuries. Pain, 40, 143-152.

Cleeland, C. S. (1984). The impact of pain on the patient with cancer. Cancer, 54 (Suppl.), 2635-2641.

Cleeland, C. S. (1989). Behavioral control of cancer pain: Diagnostic and treatment strategies. Paper presented at Pain and Cancer, Pittsburgh, PN, August, 1989.

Cohen, J., & Cohen, P. (1983). Applied regression/correlation analyses for the behavioral sciences (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.

Cohen, R. S., Ferrer-Brechner, T., Pavlov, A., & Reading, A. E. (1985). Prospective evaluation of treatment outcomes in patients referred to a cancer pain center. In H. L. Fields, R. Dubner, & F. Cervero (Eds.), Advances in pain research and therapy: Vol. 9 Proceedings of the Fourth World Congress on Pain, Seattle, (pp. 655-662). New York: Raven Press.

Comis, R. L., & Martin, G. (1987). Small cell carcinoma of the lung: an overview. Seminars in Oncology Nursing, 3, 174-182.

Copp, L. A. (1974). The spectrum of suffering. American Journal of Nursing, 74, 491-495.

Covelli, H. D., Zaloznik, A. J., & Shekitka, K. M. (1980). Evaluation of bone pain in carcinoma of the lung. Journal of the American Medical Association, 244(23), 2625-2627.

Crunch Software Corporation. (1987). Reference manual: Crunch statistical package. Oakland, CA: Crunch Software Corporation.

Daut, R. L. & Cleeland, C. S. (1982). The prevalence and severity of pain in cancer. Cancer, 50, 1913-1918.

Dickson, A. C., Dodd, M. J., Carrieri, V., Levenson, H. (1985). Comparison of a Cancer-Specific Locus of Control and the Multidimensional Health Locus of Control Scales in chemotherapy patients. Oncology Nursing Forum, 12(3), 49-54.

Dodd, M. J. (1984). Patterns of self care in cancer patients receiving radiation therapy. Oncology Nursing Forum, 2(3), 23-27.

Donovan, M. I. (1987). Clinical assessment of cancer pain. In D. B. McGuire & C. H. Yarbro (Eds.), Cancer pain management (pp. 105-131). Grune & Stratton: New York.

Donovan, M. I., & Dillon, P. (1987). Incidence and characteristics of pain in a sample of hospitalized cancer patients. Cancer Nursing, 10(2), 85-92.

Dubuisson, D., & Melzack, R. (1976). Classification of clinical pain descriptors by multiple group discriminant analysis. Experimental Neurology, 51, 480-487.

Ekman, P. (1982). Methods for measuring facial expression. In K. R. Scherer & P. Ekman (Eds.), Handbook of methods in nonverbal behavior research (pp. 45-90). New York: Cambridge University Press.

Ekman, P., & Friesen, W. V. (1978). Facial action coding system. Palo Alto, CA: Consulting Psychologists Press, Inc.

Fields, H. L. (1987). Pain. New York: McGraw-Hill.

Fields, H. L., & Levine, J. D. (1984). Pain-mechanisms and management. Western Journal of Medicine, 141, 347-357.

Foley, K. M. (1979). Pain syndromes in patients with cancer. In J. J. Bonica, & V. Ventafridda (Eds.), Advances in pain research and therapy: Vol. 2 International symposium on pain of advanced cancer (pp. 59-75). New York: Raven Press.

Foley, K. M. (1985). The treatment of cancer pain. New England Journal of Medicine, 313, 84-95.

Fordyce, W. E. (1976). Behavioral methods for chronic pain and illness. St. Louis: Mosby Co.

Fordyce, W. E., Lansky, D., Calsyn, D. A., Shelton, J. L., Stolov, W. C., & Rock, D. L. (1984). Pain measurement and pain behavior. Pain, 18, 53-69.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.

Graham, C., Bond, S. S., Gerkovich, M. M., & Cook, M. R. (1980). Use of the McGill Pain Questionnaire in the assessment of cancer pain: Replicability and consistency. Pain, 8, 377-387.

Greenwald, H. P., Bonica, J. J., & Bergner, M. (1987). The prevalence of pain in four cancers. Cancer, 60, 2563-2569.

Grobe, M. E., Ilstrup, D. M., & Ahmann, D. L. (1981). Skills needed by family members to maintain the care of an advanced cancer patient. Cancer Nursing, 4, 371-375.

Hunter, M., Philips, C., & Rachman, S. (1979). Memory for pain. Pain, 6, 35-46.

Jett, J. R., Cortese, D. A., & Fontana, R. S. (1983). Lung cancer: Current concepts and prospects. CA-A Journal for Clinicians, 33(2), 75-86.

Johnson, D. (1980). The behavioral system model for nursing. In J. Riehl & C. Roy (Eds.), Conceptual models for nursing practice (pp. 205-216). New York: Appleton-Century-Crofts.

Kanner, R. M., Martini, N., & Foley, K. M. (1982). Incidence of pain and other clinical manifestations of superior pulmonary sulcus (pancoast) tumors. In J. J. Bonica, V. Ventafridda, & C. A. Pagni (Eds.), Advances in pain research and therapy: Vol. 4. Management of superior pulmonary sulcus syndrome (pancoast syndrome), (pp. 27-39). New York: Raven Press.

Keefe, F. J. (1982). Behavioral assessment and treatment of chronic pain: Current status and future directions. Journal of Consulting and Clinical Psychology, 50, 896-911.

Keefe, F. J., & Block, A. R. (1982). Development of an observation method for assessing pain behavior in chronic low back pain patients. Behavior Therapy, 13, 363-375.

Keefe, F.J., Brantley, A., Manuel, G., & Crisson, J. E. (1985). Behavioral assessment of head and neck cancer pain. Pain, 23, 327-336.

Keefe, F. J., Caldwell, D. S., Queen, K. T., Gil, K. M., Martinez, S., Crisson, J. E., Ogden, W., & Nunley, J. (1987). Pain coping strategies in osteoarthritis patients. Journal of Consulting and Clinical Psychology, 55, 208-212.

Keefe, F. J., Crisson, J. E., & Trainor, M. (1987). Observational methods for assessing pain: A practical guide. In J. A. Blumenthal & D. C. McKee (Eds.), Applications in behavioral medicine and health psychology: A clinician's source book (pp. 67-93). Sarasota, FL: Professional Resource Exchange.

Keefe, F. J., & Dolan, E. (1986). Pain behavior and pain coping strategies in low back pain and myofascial pain syndrome patients, Pain, 24, 49-56.

Keefe, F. J., & Gil, K. M. (1986). Behavioral concepts in the analysis of chronic pain syndromes. Journal of Consulting and Clinical Psychology, 54, 776-783.

Keefe, F. J., Wilkins, R. H., & Cook, W. A. (1984). Direct observation of pain behavior in low back pain patients during physical examination. Pain, 20, 59-68.

Kelly, D. D. (1985). Central representations of pain and analgesia. In E. R. Kandel & J. H. Schwartz (Eds.), Principles of neural science (2nd ed.) (pp. 331-343). New York: Elsevier.

Kerlinger, F. N. (1979). Behavioral research: A conceptual approach. New York: Holt, Rinehart, & Winston.

Klepac, R. K., Dowling, J., & Hauge, G. (1981). Sensitivity of the McGill Pain Questionnaire to intensity and quality of laboratory pain. Pain, 10, 199-207.

Klepac, R. K., Dowling, J., Rokke, P., Dodge, L., & Schafer, L. (1981). Interview vs. paper-and-pencil administration of the McGill Pain Questionnaire. Pain, 11, 241-246.

Kremer, E., & Atkinson, J. H. (1981). Pain measurement: Construct validity of the affective dimension of the McGill Pain Questionnaire with chronic benign pain patients. Pain, 11, 93-100.

Kremer, E., Atkinson, J. H., Ignelzi, R. J. (1981). Measurement of pain: Patient preference does not confound pain measurement. Pain, 10, 241-248.

Kremer, E. F., Block, A., & Gaylor, M. S. (1981). Behavioral approaches to treatment of chronic pain: The inaccuracy of patient self-report measures. Archives of Physical Medicine and Rehabilitation, 62, 188-191.

Krames, E., Gershow, J., Glassberg, A., Kenefick, T., Lyons, A., Taylor, P., & Wilkie, D. (1985). Continuous infusion of spinally administered narcotics for the relief of pain due to malignant disorders. Cancer, 56, 696-702.

LeResche, L. (1982). Facial expression in pain: A study of candid photographs. Journal of Nonverbal Behavior, 7(1), 46-56.

LeResche, L., & Doworkin, S. (1988). Facial expressions of pain and emotion in chronic TMD patients. Pain, 75, 71-78.

Lipton, J. A., & Marbach, J. J., (1984). Ethnicity and the pain experience. Social Science Medicine, 19, 1279-1298.

Marascuilo, L., & Levin, J. R. (1983). Multivariate statistics in the social sciences: A researcher's guide. Monterey, CA: Brooks/Cole.

Margolis, R. B., Tait, R. C., & Krause, S. J. (1986). A rating system for use with patient pain drawings. Pain, 24, 57-65.

Marino, C., Zoppi, M., Morelli, F., Buoncristiano, U., Pagni, E. (1986). Pain in early cancer of the lungs. Pain, 27, 57-62.

McDaniel, L. K., Anderson, K. O., Bradley, L. A., Young, L. D., Turner, R. A., Agudelo, C. A., & Keefe, F. J. (1986). Development of an observation method for assessing pain behavior in rheumatoid arthritis patients. Pain, 24, 165-184.

McGuire, D. B. (1984). Assessment of pain in cancer inpatients using the McGill Pain Questionnaire. Oncology Nursing Forum, 11(6), 32-37.

McGuire, D. B. (1987a). Cancer-related pain: A multidimensional approach. Unpublished dissertation, University of Illinois at Chicago, Chicago, IL.

McGuire, D. B. (1987b). The multidimensional phenomenon of cancer pain. In D. B. McGuire & C. H. Yarbro (Eds.), Cancer Pain Management (p. 1-20). Orlando: Grune & Stratton.

Meinhart, N. T., & McCaffery, M. (1983). Pain: A nursing approach to assessment and analysis. Norwalk: Appleton-Century-Crofts.

Melzack, R. (1975). The McGill Pain Questionnaire: Major properties and scoring methods. Pain, 1, 277-299.

Melzack, R. (1983). Concepts of pain measurement. In R. Melzack (Ed.), Pain measurement and assessment (pp. 1-5). New York: Raven Press.

Melzack, R. (1983). The McGill Pain Questionnaire: An appraisal. In R. Melzack (Ed.), Pain measurement and assessment (pp. 55-61), New York: Raven Press.

Melzack, R., & Wall, P. (1965). Pain mechanisms: A new theory. Science, 150, 971-979.

Merskey, H. (Chairman: International Association for the Study of Pain, Subcommittee on Taxonomy). (1979). Pain terms: A list with definitions and notes on usage. Pain, 6, 249-252.

Minna, J. D., Pass, H., Glatstein, E. J., & Ihde, D. C. (1989). Cancer of the lung. In V.T. DeVita, S. Hellman, & S.A. Rosenberg (Eds.), Cancer principles and practice of oncology (3rd ed.) (pp. 591-705). Philadelphia: J.B. Lippincott.

Mountain, C. F. (1986). A new international staging of lung cancer. Chest, 89(Suppl.), 225S-235S.

Neter, J., Wasserman, W., & Kutner, M. H. (1985). Applied linear statistical models (2nd ed.). Homewood, Illinois: Richard D. Irwin.

Pineda, C. Fonseca, C, & Martinez-Lavin, M. (1990). The spectrum of soft tissue and skeletal abnormalities of hypertrophic osteoarthropathy. The Journal of Rheumatology, 17, 626-632.

Prkachin, K. M., & Mercer, S. R. (1989). Pain expression in patients with shoulder pathology: Validity properties and relationship to sickness impact. Pain, 39, 257-265.

Rahim, M. A., & Sarma, S. K. (1984). Pulmonary and extrapulmonary manifestations in delayed diagnosis of lung cancer in Bangladesh. Cancer Detection and Prevention, 7, 31-35.

Rankin, M. A. (1982). Use of drugs for pain with cancer patients. Cancer Nursing, 5, 181-190.

Reading, A. E., Everett, B. S., & Sledmere, C. M. (1982). The McGill Pain Questionnaire: A replication of its construction. British Journal of Clinical Psychology, 21, 339-349.

Reading, A. E., Hand, D. J,. & Sledmere, C. M. (1983). A comparison of response profiles obtained on the McGill Pain Questionnaire and an adjective checklist. Pain, 16, 375-383.

Richards, J. S., Nepomuceno, C., Riles, M., & Suer, Z. (1982). Assessing pain behavior: The UAB Pain Behavior Scale. Pain, 14, 393-398.

Rosenstiel, A. K., Keefe, F. J. (1983). The use of coping strategies in chronic low back pain patients: Relationship to patient characteristics and current adjustment. Pain, 17, 33- 44.

Savedra, M., Tesler, M., Holzemer, W. L., Wilkie, D. J., & Ward, J. A. (1990). Testing a tool to assess postoperative pediatric and adolescent pain. In D. C. Tyler, & E. J. Krane (Eds.), Advances in pain research and therapy: Vol. 15. Pediatric pain, (pp. 85-93). New York: Raven Press.

Scherer, K. R., & Ekman, P. (1982). Methodological issues in studying nonverbal behavior. In K. R. Scherer & P. Ekman (Eds.), Handbook of methods in nonverbal behavior research (pp. 1-44). New York: Cambridge University Press.

Sedlak, L. (1985). Low-back pain perception and tolerance. Spine, 10, 440-444.

Speilberger, C. D. (1983). Manual for the State-Trait Anxiety Inventory (Form Y). Palo Alto, CA: Consulting Psychologists Press.

Siegman, A. W., & Feldstein, S. (1987). Nonverbal behavior and communication (2nd ed.). New Jersey: Lawrence Erlbaum Associates.

Silverberg, E., Boring, C. C., & Squires, T. S. (1990). Cancer statistics 1990. Ca-A Journal for Clinicians, 40(1), 9-26.

Stam, H. J., Goss, C., Rosenal, L., Ewens, S., & Urton, B. (1985). Aspects of psychological distress and pain in cancer patients undergoing radiotherapy. In H. L. Fields, R. Dubner, & F. Cervero (Eds.), Advances in pain research and therapy: Vol. 9. Proceedings of the fourth world congress on pain, Seattle (pp. 569-573). New York: Raven Press.

Teske, K., Daut, R. L., & Cleeland, C. S. (1983). Relationship between nurses' observation and patient's self-report of pain. Pain, 16, 289-296.

Tesler, M. D., Savedra, M. C., Holzemer, W. L., Wilkie, D. J., Ward, J. A., & Paul, S. M. (1990). The word-graphic rating scale as a measure of children's and adolescents' pain intensity. Submitted for publication.

Toomey, T. C., Gover, V. F., & Jones, B. N. (1983). Spatial distribution of pain: A descriptive characteristic of chronic pain. Pain, 17, 289-300.

Toomey, T. C., Lundeen, T. F., Mann, J. D., & Abashian, S. (1988, November). The Pain Locus of Control Scale: A comparison of chronic pain patients and normals. Paper presented at the Joint Meeting of the Canadian Pain Society and the American Pain Society, Toronto.

Toomey, T. C., Lundeen, T. F., Mann, J. D., & Abashian, S. (1989). Pain Locus of Control: A comparison of two patient groups. Paper presented at the American Association for Dental Research, San Francisco.

Toomey, T. C., Mann, J. D., Abashian, S. & Lundeen, T. (1989, October). Relationship of locus of control to measures of pain and reported behavioral functioning. Paper presented at the meeting of the American Pain Society, Phoenix, AZ.

Travell, J. G., & Simons, D. G. (1983). Myofascial pain and dysfunction: The trigger point manual. Baltimore, MD: Williams & Wilkins.

Turnbull, F. (1979). The nature of pain that may accompany cancer of the lung. Pain, 7, 371-375.

Turk, D. C., & Flor, H. (1987). Pain > pain behaviors: The utility and limitations of the pain behavior construct. Pain, 31, 277-295.

Turk, D. C., Rudy, T. E., & Salovey, P. (1985). The McGill Pain Questionnaire reconsidered: Confirming the factor structure and examining appropriate uses. Pain, 21, 385-397.

Turner, J.A., & Clancy, S. (1986). Strategies for coping with chronic low back pain: Relationship to pain and disability. Pain, 24, 355-364.

Ventafridda, V., Tamburini, M., & De Conno, F. (1985). Comprehensive treatment in cancer pain. In H.L. Fields, R. Dubner, & F. Cervero (Eds.), Advances in pain research and therapy: Vol. 9. Proceedings of the fourth world congress on pain, Seattle (pp. 617-628). New York: Raven Press.

Ventafridda, V., Tamburini, M., Caraceni, A., De Conno, F., & Naldi, F. (1987). A validation study of the WHO method for cancer pain relief. Cancer, 59, 850-856.

Vincent, R. G., Pickren, J. W., Lane, W. W., Bross, I., Takita, H., Houten, L., Gutierrez, A. C., & Rzepka, T. (1977). The changing histopathology of lung cancer. Cancer, 39, 1647-1655.

Wagstaff, S., Smith, O. V., & Wood, P. H. N. (1985). Verbal pain descriptors used by patients with arthritis. Annals of the Rheumatic Diseases, 44, 262-265.

Wallston, K. A., Wallston, B. S., & Devellis, R. (1978). Development of the multidimensional health locus of control (MHLC) scale. Health Education Monographs, 6, 160-170.

Walkenstein, M. (1982). Comparisons of burned patients' perception of pain with nurses' perception of patients pain. Journal of Burn Care and Rehabilitation, 3, 233-236.

Ward, N. G., Bloom, V. L., Dworkin, S., Fawcett, J., Narasemhachari, N., & Friedel, R. O. (1982). Psychobiological markers in coexisting pain and depression: Toward a unified theory. Journal of Clinical Psychiatry, 43(8), 32-39.

Watson, P. N., & Evans, R. J. (1987). Intractable pain with lung cancer. Pain, 29, 163-173.

Wilkie, D. J. (1984). Pain intensity and pain control behaviors of adults diagnosed with cancer. Unpublished master's thesis. University of California, San Francisco.

Wilkie, D. J., Lovejoy, N., Dodd, M., & Tesler, M. (1988). Cancer pain control behaviors: Description and correlation with pain intensity. Oncology Nursing Forum, 15, 723-731.

Wilkie, D.J., Lovejoy, N., Dodd, M., & Tesler, M. (1990). Cancer pain intensity measurement: Concurrent validity of three instruments-finger dynamometer, pain intensity number scale, visual analogue scale. The Hospice Journal, 6(1), 1-13.

Wilkie, D.J., Savedra, M., Holzemer, W.L., Tesler, M., & Paul. (1990). Use of the McGill Pain Questionnaire to measure pain: A meta-analysis. Nursing Research, 39, 36-41.

Wonnacott, T. H., & Wonnacott, R. S. (1984). Introductory statistics for business and economics (3rd. ed.). New York: John Wiley & Sons.

Woodrow, K. M., Friedman, G. D., Siegelaub, A. B., & Collen, M. F. (1975). Pain tolerance differences according to age, sex, and race. In M. Weisenberg (Ed.), Pain: Clinical and experimental perspectives (pp. 133-140). St. Louis: C. V. Mosby.

World Health Organization. (1986). Cancer Pain Relief. Geneva: World Health Organization.

Yaksh, T. L., & Hammond, D. L. (1982). Peripheral and central substrates involved in the rostrad transmission of nociceptive information. Pain, 13(1), 1-85.

Zborowski, M. (1952). Cultural components in response to pain. Journal of Social Issues, 8, 16-30.

Zborowski, M. (1969). People in Pain. San Francisco: Jossey-Bass.

Zimmerman, L., Duncan, K., Pozehl, B., & Schmitz, R. (1987). Pain descriptors used by patients with cancer. Oncology Nursing Forum, 14(4), 67-71.

Appendix A

Classification System

TNM Definitions for Lung Cancer

From the American Joint Committee on Cancer and
the Union Internationale Contre Cancer (Mountain, 1986)

Primary Tumor (T)

TX	Tumor Proven by the presence of malignant cells in bronchopulmonary secretions but not visualized roentgenographically or bronchoscopically, or any tumor that cannot be assessed as in a retreatment staging.
T0	No evidence of primary tumor.
TIS	Carcinoma in situ
T1	A tumor that is 3.0 cm or less in greatest dimension, surrounded by lung or visceral pleura, and without evidence of invasion proximal to a lobar bronchus at bronchoscopy.*
T2	A tumor more than 3.0 cm in greatest dimension, or a tumor of any size that either invades the visceral pleura or has associated atelectasis or obstructive pneumonitis extending to the hilar region. At bronchoscopy, the proximal extent of demonstrable tumor must be within a lobar bronchus or at least 2.0 cm distal to the carina. Any associated atelectasis or obstructive pneumonitis must involve less than an entire lung.
T3	A tumor of any size with direct extension into the chest wall (including superior sulcus tumors), diaphragm, or the mediastinal pleura or pericardium without involving the heart, great vessels, trachea, esophagus or vertebral body, or a tumor in the main bronchus within 2 cm of the carina without involving the carina.
T4	A tumor of any size with invasion of the mediastinum or involving heart, great vessels, trachea, esophagus, vertebral body or carina, or presence of malignant pleural effusion.**

Nodal involvement (N)

N0	No demonstrable metastasis to regional lymph nodes.
N1	Metastasis to lymph nodes in the peribronchial or the ipsilateral hilar region, or both, including direct extension.
N2	Metastasis to ipsilateral mediastinal lymph nodes and subcarinal lymph nodes.
N3	Metastasis to contralateral mediastinal lymph nodes, contralateral hilar lymph nodes, ipsilateral or contralateral scalene or supraclavicular lymph nodes.

Distant Metastasis (M)

M0	No (known) distant metastasis
M1	Distant metastasis present - specify site(s).

---

* The uncommon superficial tumor of any size with its invasive component limited to the bronchial wall which may extend proximal to the main bronchus is classified as T1.

** Most pleural effusions associated with lung cancer are due to tumor. There are, however, some few patients in whom cytopathologic examination of pleural fluid (on more than one specimen) is negative for tumor, the fluid is non-bloody and is not an exudate. In such cases where these elements and clinical judgement dictate that the effusion is not related to the tumor, the patients should be staged T1, T2, or T3, excluding effusions as a staging element.

Appendix A
Classification System
(Cont.)

Stage Grouping of TNM Subsets

From the American Joint Committee on Cancer and
the Union International Contre Cancer (Mountain, 1986)

Occult Carcinoma	TX	NO	MO
Stage 0	TIS	Carcinoma in situ --	
Stage I	T1	NO	MO
	T2	NO	MO
Stage II	T1	N1	MO
	T2	N1	MO
Stage IIIa	T3	NO	MO
	T3	N1	MO
	T1-3	N2	MO
Stage IIIb	Any T	N3	MO
	T4	Any N	MO
Stage IV	Any T	Any N	M1

Appendix B

McGill-Melzack

PAIN QUESTIONNAIRE

Patient's name _____ Age_____

File No._____ Date_____

Clinical category (eg, cardiac, neurological, etc.)

_____

Diagnosis: _____

_____

_____

Analgesic (if already administered):

1. Type _____
2. Dosage _____
3. Time given in relation to this test _____

****

This questionnaire has been designed to tell us more about your pain. Four major questions we ask are:

1. Where is your pain?

2. What does it feel like?

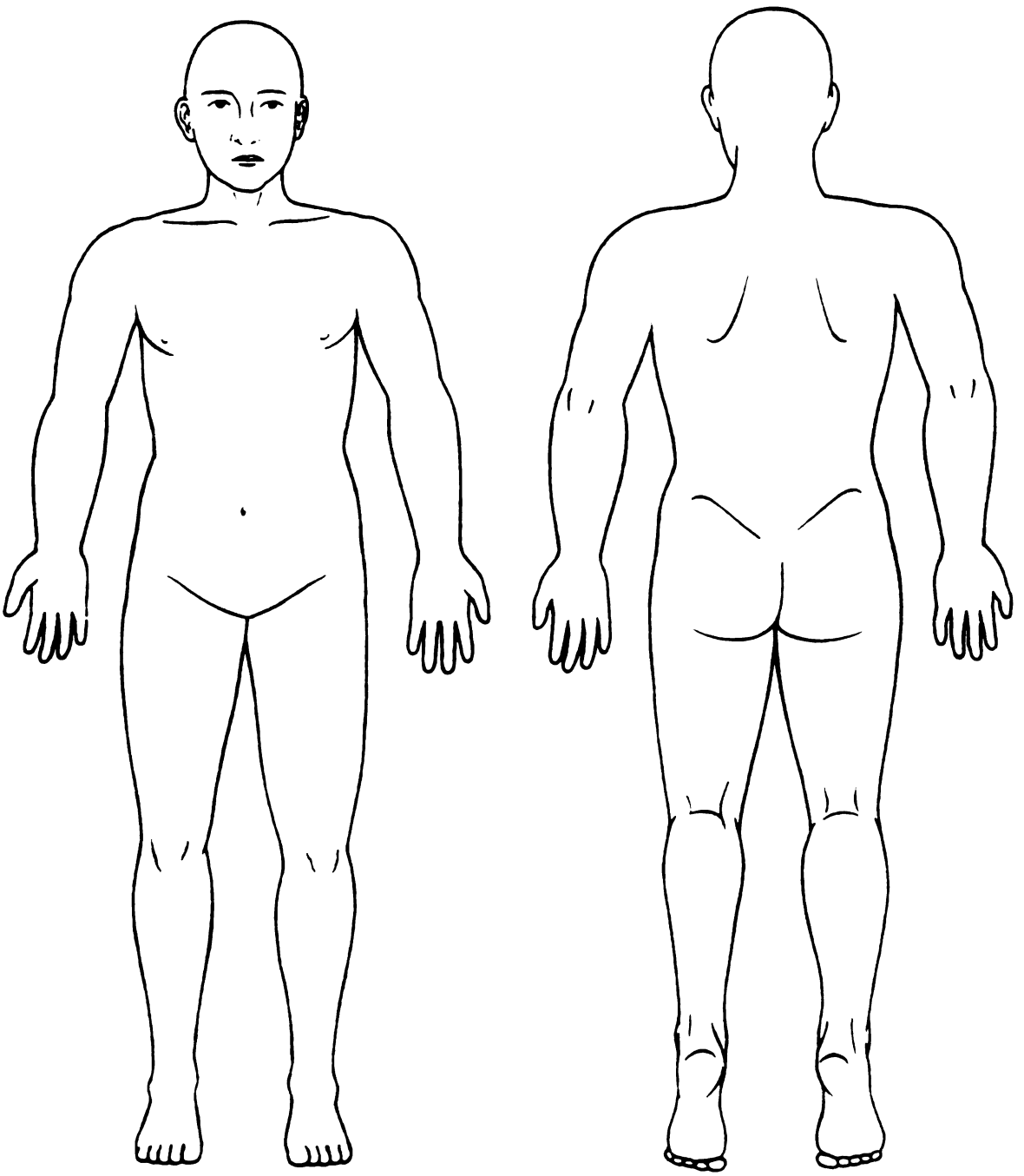
3. How does it change with time?

4. How strong is it?

It is important that you tell us how your pain feels now. Please follow the instructions at the beginning of each part.

Part 1. **Where is your Pain?**

Please mark, on the drawings below, the areas where you feel pain. Put E if external, or I if internal, near the areas which you mark. Put EI if both external and internal.



Part 2. What Does Your Pain Feel Like?

Some of the words below describe your present pain. Circle ONLY those words that best describe it. Leave out any category that is not suitable. Use only a single word on each appropriate category - the one that applies best.

1	2	3	4
Flickering	Jumping	Pricking	Sharp
Quivering	Flashing	Boring	Cutting
Pulsing	Shooting	Drilling	Lacerating
Throbbing		Stabbing	
Beating		Lancinating	
Pounding			
5	6	7	8
Pinching	Tugging	Hot	Tingling
Pressing	Pulling	Burning	Itchy
Gnawing	Wrenching	Scalding	Smarting
Cramping		Searing	Stinging
Crushing			
9	10	11	12
Dull	Tender	Tiring	Sickening
Sore	Taut	Exhausting	Suffocating
Hurting	Rasping		
Aching	Splitting		
Heavy			
13	14	15	16
Fearful	Punishing	Wretched	Annoying
Frightening	Gruelling	Blinding	Troublesome
Terrifying	Cruel		Miserable
	Vicious		Intense
	Killing		Unbearable
17	18	19	20
Spreading	Tight	Cool	Nagging
Radiating	Numb	Cold	Nauseating
Penetrating	Drawing	Freezing	Agonizing
Piercing	Squeezing		Dreadful
	Tearing		Torturing

Part 3. How Does Your Pain Change with Time?

1. Which word or words would you use to describe the pattern of your pain?

1	2	3
Continuous	Rhythmic	Brief
Steady	Periodic	Momentary
Constant	Intermittent	Transient

2. What kind of things relieve your pain?

3. What kind of things increase your pain?

Part 4. How Strong is Your Pain?

People agree that the following 5 words represent pain of increasing intensity. They are:

0	1	2	3	4	5
None	Mild	Discomforting	Distressing	Horrible	Excruciating

To answer each question below, write the number of the most appropriate word in the space beside the question.

1. Which word describes your pain right now? ____
2. Which word describes it at its worst? ____
3. Which word describes it when it is least? ____
4. Which word describes the worst toothache you ever had? ____
5. Which word describes the worst headache you ever had? ____
6. Which word describes the worst stomach-ache you ever had? ____

Appendix C

DEMOGRAPHIC DATA FORM

Code #: _____ **Date of Birth:** _____ **Age:** _____

Gender: (1) M (2) F **Occupation:** _____

Marital Status: (1) Single (2) Married (3) Widowed

Education: (1) ≤ 8th grade (2) ≤ 12th grade (3) Assoc. Degree

(4) BS (5) Masters (6) Doctoral

Annual Family Income: (1) < $10,000 (2) $10-20,000 3) $20-30,000

(4) $30-40,000 (5) > $50,000

Ethnicity: (1) White (2) Black (3) Hispanic (4) Asian (5) Other _____

Religion: (1) Catholic (2) Protestant (3) Jewish (4) Other _____

When did you first notice your pain? _____

What do you think is the cause of your pain? _____

_____

Cancer Diagnosis Date: _____

Tumor Histology: (1) Squamous (2) Adenocarcinoma

(3) Small cell (oat) (4) Large cell

Primary Tumor Location: _____

_____

_____

Tumor Stage:

(1) Diagnosis: _____

(2) Current: _____

Metastatic Tumor Diagnosis:

(1) Date: _____

(2) Location: _____

_____

_____

Antitumor Therapies:

(1) Surgical Procedure: _____

_____ Date: _____

(2) Chemo (Drug/Dose/Dates): _____

_____

_____

(3) Radiation (Dose/Dates): _____

_____

_____

Smoking Status

Smoker: (0) No (1) Yes Amount _____

Stopped: (0) No (1) Yes Date _____

Family History of Lung Cancer

(0) No (1) Yes Who _____

Concurrent Diseases

(0) None
(1) Cardiovascular _____
(2) Pulmonary _____
(3) Renal _____
(4) Diabetes _____
(5) Chronic pain _____
(6) Other _____
_____

Verbalized Drug Concerns

(1) Specifically mentioned fear/concern about addiction

_____
_____

(2) Requested information about analgesics, in such a way as to indicate fear/concern about addiction

_____
_____

(3) Other _____
_____
_____

Appendix D

Manual for Video Observation Method
Lung Cancer Version

Modified from Francis Keefe, Ph.D.

July, 1987

Movement or Position -Related Behaviors

Stand: Patient in an upright position with one or both feet on the floor for at least 3 seconds

Sit: Patient resting upon buttocks for at least 3 seconds. Includes patient sitting in chair, at the edge of the bed, in bed with head-of-the-bed raised to a 90° angle, or in a recliner with the back-of-the-recliner raised to a 90° angle. (Angle less than 90 is scored as a recline). If the patient is in the process of moving to or from a reclining position, do not score as a sit. Rather, this would be included in the shift (see below).

Recline: Patient in a horizontal or near horizontal position for at least 3 seconds while in bed or in a recliner chair, defined as the patient's buttocks or hips and torso or shoulder touching the bed of recliner chair when the head-of-the-bed or the recliner chair is positioned at less than a 90° angle.

Recline-prone = recline prone (abdomen lying) position (Scored as P)
Recline-Lside = recline left side lying position (Scored as L)
Recline-Rside = recline right side lying position (Scored as R)
Recline-supine= recline supine (back lying) position (Scored as S)

Walk: Patient moves two or more steps in any direction within the space of 3 seconds.

Shift: Patient changes position upward or downward. Patient moves from one position to another except walk-stand or stand-walk.

Pain Related Behaviors

Facial expression: Per Facial Action Coding System (Ekman & Friesen, 1978) (include grimace, clenching, biting, mood changes)

Reposition: Patient changes position other than shifting. Includes turning from side-to-side, side-to-back, back to side, raising or lowering the head-of-the-bed or the foot-of-the-bed; flexing or unflexing legs or arms; abducting or abducting legs or arms; rotating shoulders. Also includes rotating head, i.e., side to side but not from midline to side or side to midline (turning head). Does not include shifting from sit-to-another position; another position-to sit; recline-to another position; or another position-to recline because these would be scored as shifts.

L side to R side = turns from left side to right side (scored as LRSS)
R side to L side = turns from right side to left side (scored as RLSS)
Side to Back = turns from side to back (scored as LSB or RSB)
Back to side = turns from back to side (scored as BRS or BLS)
Reposition HOB| = raises HOB to less than 90° (Scored as HOB|)
Reposition HOB| = lowering HOB, except from 90° (Scored as HOB|)
Reposition FOB| = raises FOB (Scored as FOB|)
Reposition FOB| = lowering FOB (Scored as FOB|)
Reposition Arm
Reposition Leg
Reposition Shoulder
Reposition Head
Reposition Torso
Reposition Other

Limited massage: Patient moves hand over a painful body area, rubs the area for at least 3 seconds, but the area rubbed is confined to the body area marked on the body outline. Rubbing may be performed against another body part or object (i.e., a back scratcher, wall, edge of a table, or a chair). (Scored as body area #).

Full Massage: Patient moves hand over not only a painful body area but also an adjacent body surface area not recorded on the body outline, rubs a large surface area for at least 3 seconds. Rubbing may be performed against another body part of an object (i.e., back scratcher, wall, edge of a table, or a chair). If the rubbing can be inferred from motion but area not determined because of viewing problems, it is scored as a Limited Massage. (Full massage is scored as body area #) (Full Massage > Limited Massage unless separated by at least one minute).

Massage-other: Patient moves hand over a non-painful body area with another body part, rubs a non-painful body area for at least 3 seconds. The area must be clearly separate from the general body area reported painful on the body outline. (Scored as body area #).

Passive Pressure: Patient touches, rests, or holds a painful body area with another body part for at least 3 consecutive seconds. (Scored as body area#).

Passive Pressure-Other: Patient touches, rests, or holds a non-painful body area with another non-painful body part for at least 3 consecutive seconds. Does not include hand(s) folded in lap when sitting (Scored as body area #).

Active Pressure: Patient touches, rests, or holds a painful body area with some object (other than his/her body parts) for at least 3 consecutive seconds (i.e., pillow, folded blanket, table edge, another person's hand). Active pressure may also be scored if the patient appears to be applying pressure with his/her hand. In this case, firm pressure application must be apparent. Otherwise it is scored as Passive Pressure. (Scored as body area #) (Active Pressure > Passive Pressure unless separated by at least 1 interval [20 seconds]).

Guarding-whole body: Patient maintains the body in a rigid or stiff position while shifting from one position to another or while walking.

Guarding-body part: Patient maintains a body part in a stiff or rigid position while shifting from one position to another or while walking.

LA = guards left arm
RA = guards right arm
LL = guards left leg
RL = guards right leg
Tor = guards torso
Neck = guards neck-head

Bracing: Position in which an almost fully extended limb supports and maintains an abnormal distribution of weight. It cannot occur during movement (i.e., pacing and shifting) and must be held for at least 3 consecutive seconds. It most frequently is the gripping of the edge of a table, cane, or walker while sitting or standing. Bracing can occur with a leg if the patient leans against a wall using no other support, but it is not simply the shifting of weight when standing. What appears to be bracing during movement is recorded as guarding.

Immobilize-whole body: Patient maintains one body position throughout the designated activity when his/her eyes are open and the patient is positioned on the bed or recliner in a recline position. Patient appears to have complete muscle inactivity of all body parts and is restricting <u>all</u> movement.

Immobilize-body part: Patient maintains an affected body part (area reported as having pain) in one position throughout the entire designated activity when his/her eyes are open. Patient appears to have complete muscle inactivity in the painful body part and is restricting movement of the painful body part. This does not include the patient being still when reclining, sitting, or standing. Intentional restriction of movement must be seen.

LA = immobilize left arm
RA = immobilize right arm
LL = immobilize left leg
RL = immobilize right leg
Tor = immobilize torso
Neck =immobilize neck-head

Analgesic use: Patient consumes analgesic medication, requests an analgesic dose, or monitors analgesic schedule.

Analgesic talk: Patient discusses analgesic medication with another person, complains of pain to another person but does not request an analgesic dose.

Vocalization-Pain: Patient vocalizes in any of the following ways:

moans, groans, or says something like "ohh," "Oh, man" -
sigh - obvious, exaggerated exhalation of air, usually accompanied by shoulders first rising and then falling. Cheeks may be expanded.
crying -

Verbalization-Pain: Patient verbalizes in any of the following ways:
profanity - swearing, cussing
prayerful - talking to deity
nonsensical - repetition of meaningless phrases
counting - repeating numerical sequences

Conversation: Patient talking with non-health care person or persons about any subject other than pain, fatigue, or other symptoms.

Watch television: Patient has television turned on and has his/her eyes open. Includes listening to television even if not positioned to be able to see the television, but eyes must be open to score it.

Reading: Patient holding a book or a magazine when eyes are open, appears to be reading.

Music: Music playing, patient's eyes either open or closed, but patient appears to not be sleeping.

Rhythmical breathing: Patient engages in slow, rhythmical breathing through pursed or unpursed lips.

Sleeping/resting: Patient's behavior meets the definition for immobilize-whole body but eyes are closed.

Gazing/staring: Patient's eyes are fixed, rigid, looking steadily and intently at some object without verbalization or vocalization for the entire interval (20 sec).

Heat use: Patient has heating pad on bed, chair, or recliner chair where patient is located. Patient manipulates either the heating pad or the pad control mechanism.

Ice use: Patient has an ice pack on the bed, chair, or recliner chair where the patient is located. Patient manipulates the ice pack.

Pounding: Patient strikes self with hand formed into a fist or with the base of an open palm for 3 consecutive seconds.

Eating/drinking: Patient consumes food or fluid.

Rocking: Patient moves or sways back and forth or from side to side for at least 3 seconds.

Assistance/support: Patient uses cane, walker, objects of furniture, or pillow to assist with moving from one position to another, while walking, or to maintain support while in a static position. If an extended limb supports and maintains an abnormal distribution of weight, score as bracing. If weight appears equally distributed, score as assistance/support. Bracing > assistance support. Does not include resting elbows on arm of chair.

Personal assistance: Patient is assisted or supported by another person (health professional, family, or friend) when the patient engages in movement.

Other: Any behavior not described by scoring definitions in which the patient engages. All behaviors assigned to this category must be fully described on the Descriptive Notes Form.

SCORE SHEET — LBBB CHRONIC PAIN-RELATED BEHAVIORS

Code: _____ Date: _____

Interval Observed/Interval

Behaviors	1		2		3		4		5		6		7		8		9		10		11		12		13		14		15	
	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I
Stand																														
Sit																														
Recline																														
Walk																														
Shift																														
Reposition																														
Limited massage																														
Full massage																														
Massage-other																														
PPressure																														
PPressure O																														
APressure																														
WBGuarding																														
BPGuarding																														
Bracing																														
WBImmobilize																														
BPImmobilize																														
Analgesic use																														
Analgesic talk																														
Vocalization-Pain																														
Verbalization-Pain																														
Conversation																														
Watch television																														
Reading																														
Music																														
Rhythmic breathing																														
Sleeping-resting																														
Gazing/staring																														
Heat use																														
Ice use																														
Pounding																														
Eating/drinking																														
Rocking																														
Assistance/support																														
Personal assistance																														
Other																														
Specific body part:																														
Left arm																														
Right arm																														
Left leg																														
Right leg																														
Torso																														
Neck-head																														
Shoulders																														
Other																														

SCORE SHEET — LOW BACK PAIN-RELATED BEHAVIORS

Code: _____ Date: _____

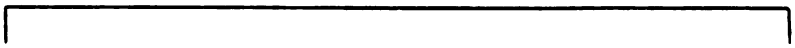
Interval
Observed/Intent

Behaviors	16		17		18		19		20		21		22		23		24		25		26		27		28		29		30	
	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I	O	I
Stand																														
Sit																														
Recline																														
Walk																														
Shift																														
Reposition																														
Limited massage																														
Full massage																														
Massage-other																														
PPressure																														
PPressure O																														
APressure																														
UPGuarding																														
BPGuarding																														
Bracing																														
UPImmobilize																														
BPImmobilize																														
Analgesic use																														
Analgesic talk																														
Vocalization-Pain																														
Verbalization-Pain																														
Conversation																														
Watch television																														
Reading																														
Music																														
Rhythmic breathing																														
Sleeping-resting																														
Gazing/staring																														
Heat use																														
Ice use																														
Pounding																														
Eating/drinking																														
Rocking																														
Assistance/support																														
Personal assistance																														
Other																														
Specific body part:																														
Left arm																														
Right arm																														
Left leg																														
Right leg																														
Torso																														
Neck-head																														
Shoulders																														
Other																														

COPING STRATEGIES

NAME _____

Individuals who experience pain have a number of ways to cope, or deal with, their pain. These include saying things to themselves when they experience pain, or engaging in different activities. Below are a list of things that patients have reported doing when they feel pain. For each activity, I want you to indicate, using the scale below, how much you engage in that activity when you feel pain, a 3 indicates you sometimes do that when you are experiencing pain. Remember, you can use any point along the scale.



0 1 2 3 4 5 6

Never do that — Sometimes that — Always do that

When I feel pain...

___ 1. I try to feel distant from the pain, almost as if the pain was in somebody else's body.

___ 2. I leave the house and do something, such as going to the movies or shopping.

___ 3. I try to think of something pleasant.

___ 4. I don't think of it as pain but rather as a dull or warm feeling.

___ 5. Its terrible and I feel its never going to get any better.

___ 6. I tell myself to be brave and carry on despite the pain.

___ 7. I read.

___ 8. I tell myself that I can overcome the pain.

___ 9. I take my medication.

___ 10. I count numbers in my head or run a song through my mind.

When I feel pain...

___ 11. I just think of it as some other sensation, such as numbness.

___ 12. Its awful and I feel that it overwhelms me.

___ 13. I play mental games with myself to keep my mind off the pain.

___ 14. I feel my life isn't worth living.

___ 15. I know someday someone will be there to help me and it will go away for awhile.

___ 16. I walk a lot.

___ 17. I pray to God it won't last long.

___ 18. I try not to think of it as my body, but rather as something separate from me.

___ 19. I relax.

___ 20. I don't think about the pain.

___ 21. I try to think years ahead, what everything will be like after I've gotten rid of the pain.

___ 22. I tell myself it doesn't hurt.

___ 23. I tell myself I can't let the pain stand in the way of what I have to do.

___ 24. I don't pay any attention to it.

___ 25. I have faith in doctors that someday there will be a cure for my pain.

___ 26. No matter how bad it gets, I know I can handle it.

___ 27. I pretend its not there.

___ 28. I worry all the time about whether it will end.

___ 29. I lie down.

___ 30. I replay in my mind pleasant experiences in the past.

___ 31. I think of people I enjoy doing things with.

___ 32. I pray for the pain to stop.

When I feel pain...

___ 33. I take a shower or a bath.

___ 34. I imagine that the pain is outside of my body.

___ 35. I just go on as if nothing happened.

___ 36. I see it as a challenge and don't let it bother me.

___ 37. Although it hurts, I just keep on going.

___ 38. I feel I can't stand it anymore.

___ 39. I try to be around other people.

___ 40. I ignore it.

___ 41. I rely on my faith in God

___ 42. I feel like I can't go on.

___ 43. I think of things I enjoy doing.

___ 44. I do anything to get my mind off the pain.

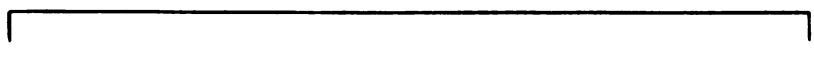
___ 45. I do something I enjoy, such as watching TV or listening to music.

___ 46. I pretend its not a part of me.

___ 47. I do something active, like household chores or projects.

___ 48. I use a heating pad.

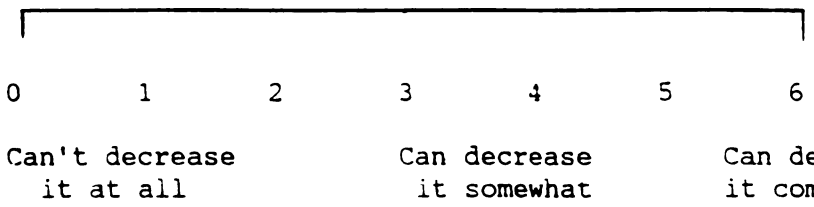
Based on all the things you do to cope, or deal with your pain, on an average day, how much control do you feel you have over it? Please circle the appropriate number. Remember, you can circle any number along the scale.



0 1 2 3 4 5 6

No control Some control Complete control

Based on all the things you do to cope, or deal with, your pain, on an average day, how much are you able to decrease it? Please circle the appropriate number. Remember, you can circle any number along the scale.



Appendix F

SELF-EVALUATION QUESTIONNAIRE

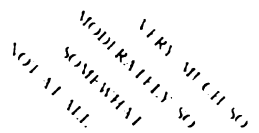
Developed by Charles D. Spielberger
in collaboration with
R. L. Gorsuch, R. Lushene, P. R. Vagg, and G. A. Jacobs

STAI Form Y-1

Name _____ Date _____ S ____

Age _____ Sex: M ____ F ____ T ____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.



1. I feel calm	①	②	③	④
2. I feel secure	①	②	③	④
3. I am tense	①	②	③	④
4. I feel strained	①	②	③	④
5. I feel at ease	①	②	③	④
6. I feel upset	①	②	③	④
7. I am presently worrying over possible misfortunes	①	②	③	④
8. I feel satisfied	①	②	③	④
9. I feel frightened	①	②	③	④
10. I feel comfortable	①	②	③	④
11. I feel self-confident	①	②	③	④
12. I feel nervous	①	②	③	④
13. I am jittery	①	②	③	④
14. I feel indecisive	①	②	③	④
15. I am relaxed	①	②	③	④
16. I feel content	①	②	③	④
17. I am worried	①	②	③	④
18. I feel confused	①	②	③	④
19. I feel steady	①	②	③	④
20. I feel pleasant	①	②	③	④

Consulting Psychologists Press
577 College Avenue, Palo Alto, California 94306

SELF-EVALUATION QUESTIONNAIRE

STAI Form Y-2

Name _____ Date _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	1	2	3	4
22. I feel nervous and restless	1	2	3	4
23. I feel satisfied with myself	1	2	3	4
24. I wish I could be as happy as others seem to be	1	2	3	4
25. I feel like a failure	1	2	3	4
26. I feel rested	1	2	3	4
27. I am "calm, cool, and collected"	1	2	3	4
28. I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
29. I worry too much over something that really doesn't matter	1	2	3	4
30. I am happy	1	2	3	4
31. I have disturbing thoughts	1	2	3	4
32. I lack self-confidence	1	2	3	4
33. I feel secure	1	2	3	4
34. I make decisions easily	1	2	3	4
35. I feel inadequate	1	2	3	4
36. I am content	1	2	3	4
37. Some unimportant thought runs through my mind and bothers me	1	2	3	4
38. I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
39. I am a steady person	1	2	3	4
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	4

Appendix G

Code # _____
Date _____
T1 _____
T4 _____
T5 _____

CHLC QUESTIONNAIRE (Modified)
Patient

Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

	IN THE FOLLOWING STATEMENTS THE WORD ILLNESS PERTAINS TO YOUR HAVING (HAD) CANCER.	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1.	It is my own behavior which determines how soon I get well again.	1	2	3	4	5	6
2.	No matter what I do, if I'm going to get worse, I'll get worse.	1	2	3	4	5	6
3.	Having regular contact with my physician is the best way for me to avoid this illness getting worse.	1	2	3	4	5	6
4.	Most things that affect my health now that I am ill, happen to me by accident.	1	2	3	4	5	6
5.	Whenever I don't feel well, I should consult a medically-trained professional.	1	2	3	4	5	6
6.	I am in control of cancer.	1	2	3	4	5	6
7.	My family has a lot to do with how well I do with this illness.	1	2	3	4	5	6

CHLC (Patient)

Code #_____
Date _____

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
8.	I am to blame for getting this illness.	1	2	3	4	5	6
9.	Luck plays a big part in determining how soon I will recover.	1	2	3	4	5	6
10.	Health professionals control cancer.	1	2	3	4	5	6
11.	Improvement of this illness is a matter of good fortune.	1	2	3	4	5	6
12.	The main thing which affects my condition is what I do myself.	1	2	3	4	5	6
13.	If I take care of myself, I can avoid progression of my illness.	1	2	3	4	5	6
14.	When I get better from this illness, it's because other people (for example: doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
15.	No matter what I do, it's likely that my illness will get worse.	1	2	3	4	5	6
16.	If it's meant to be, I will regain my health.	1	2	3	4	5	6
17.	If I take the right actions, this illness will be controlled.	1	2	3	4	5	6
18.	Regarding this illness, I can only do what my doctor tells me to.	1	2	3	4	5	6

THOM:CHLC

MHLC - PAIN

First Name_____ MI ___ Last Name _____

NCMH Unit - _____-_____-_____

Age ____ Sex ____ Race ____

Today's Date Mo ___ Day ___ Year ____

Duration of Pain Months _____ Years _____

Location of Pain _____

This is a questionnaire designed to determine the way in which different people view pain and what makes it worse or better (relieves it). Each item is a brief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every time and that you circle only one number per item. This is a measure or your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1.	If my pain gets worse, it is my own behavior which determines how soon I will get relief.	1	2	3	4	5	6
2.	No matter what I do, if my pain is going to get worse, it will get worse.	1	2	3	4	5	6

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
3.	Having regular contact with my physician is the best way for me to avoid my pain getting worse.	1	2	3	4	5	6
4.	Most things that affect my relief of pain happen to me by accident.	1	2	3	4	5	6
5.	Whenever my pain gets worse, I should consult a medically trained professional.	1	2	3	4	5	6
6.	I am in control of relieving my pain.	1	2	3	4	5	6
7.	My family has a lot to do with my pain getting worse or better.	1	2	3	4	5	6
8.	When my pain gets worse I am to blame.	1	2	3	4	5	6
9.	Luck plays a big part in determining how soon my pain is relieved.	1	2	3	4	5	6
10.	Health professionals control relief of pain.	1	2	3	4	5	6
11.	When my pain is relieved, it is largely a matter of good fortune.	1	2	3	4	5	6
12.	The main thing which affects relief of my pain is what I myself do.	1	2	3	4	5	6
13.	If I take care of myself, I can relieve my pain.	1	2	3	4	5	6
14.	When my pain is relieved; it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
15. No matter what I do, my pain is likely to get worse.	1	2	3	4	5	6
16. If its meant to be, I will have relief from pain.	1	2	3	4	5	6
17. If I take the right actions, I can relieve my pain.	1	2	3	4	5	6
18. Regarding relief of my pain, I can only do what my doctor tells me to do.	1	2	3	4	5	6
19. If my pain gets worse, I have the power to relieve it.	1	2	3	4	5	6
20. Often I feel that no matter what I do, if the pain is going to get worse, it will get worse.	1	2	3	4	5	6
21. If I see an excellent doctor regularly, my pain is less likely to get worse.	1	2	3	4	5	6
22. It seems that relief from pain is greatly influenced by accidental happenings.	1	2	3	4	5	6
23. I can only relieve my pain by consulting health professionals.	1	2	3	4	5	6
24. I am directly responsible for relief of my pain.	1	2	3	4	5	6
25. Other people play a big part in whether my pain gets better or worse.	1	2	3	4	5	6
26. Whatever makes my pain worse is my own fault.	1	2	3	4	5	6

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
27.	When my pain gets worse, I have to let nature run its course.	1	2	3	4	5	6
28.	Health professionals relieve my pain.	1	2	3	4	5	6
29.	When I have relief from pain, I'm just plain lucky.	1	2	3	4	5	6
30.	My relief from pain depends on how well I take care of myself.	1	2	3	4	5	6
31.	When my pain gets worse, I know it is because I have not been taking care of myself properly.	1	2	3	4	5	6
32.	The type of care I receive from other people is what is responsible for how much my pain is relieved.	1	2	3	4	5	6
33.	Even when I take care of myself, it's easy for my pain to get worse.	1	2	3	4	5	6
34.	When my pain gets worse, it's a matter of fate.	1	2	3	4	5	6
35.	I can pretty much relieve my pain by taking good care of myself.	1	2	3	4	5	6
36.	Following doctor's orders to the letter is the best way for me to relieve pain.	1	2	3	4	5	6

Appendix I

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH AFFAIRS, BOX 0616
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

TO: Marylin J. Dodd, R.N., Ph.D. Box 0610
Diana J. Wilkie, M.S. N-411-Y

RE: Behavioral Correlates of Lung Cancer Pain

The UCSF Committee on Human Research (an Institutional Review Board holding Department of Health and Human Services assurance #M-1169) has approved the above request to involve humans as research subjects.

APPROVAL NUMBER: H452-03836-01. This number is a UCSF CHR number which should be used on all consent forms, correspondence and patient charts.

APPROVAL DATE: November 2, 1988. Full Committee Review

EXPIRATION DATE: November 2, 1989. If the project is to continue, it must be renewed *by the expiration date.* See reverse side for details.

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within ten working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

LEGAL NOTICE: The University will defend and indemnify a principal investigator in legal actions arising from research activities involving humans only if the activities had current CHR approval.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0616.

Good luck on your project.

Sincerely,

Reese T. Jones, M.D.
Chairman
Committee on Human Research

HEPC Project # 88003836

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH AFFAIRS, Box 0616
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

TO: Marylin J. Dodd, R.N., Ph.D. Box 0610
Diana J. Wilkie, M.S. Box 0606

RE: Behavioral Correlates of Lung Cancer Pain

The UCSF Committee on Human Research (an Institutional Review Board holding Department of Health and Human Services assurance #M-1169) has approved the above request to involve humans as research subjects, with the following

COMMENT: The committee members asked for assurance that you speak with prospective subjects' physicians to make sure the patient is an appropriate prospect before actually contacting the patient. In addition, before submitting future renewal applications, please consult the CHR *Guidelines* to avoid submitting documents unnecessary for the renewal.

APPROVAL NUMBER: H452-03836-02. **This number is a UCSF CHR number which should be used on all consent forms, correspondence and patient charts.**

APPROVAL DATE: October 26, 1989. **Full Committee Review**

EXPIRATION DATE: October 15, 1990. **If the project is to continue, it must be renewed *by the expiration date.* See reverse side for details.**

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within ten working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

LEGAL NOTICE: The University will defend and indemnify a principal investigator in legal actions arising from research activities involving humans only if the activities had current CHR approval.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0616.

Good luck on your project.

Sincerely,

Reese T. Jones, M.D.
Chairman
Committee on Human Research

cc: SFGH
VAMC Research Office

HEPC Project # 88003836

October 19, 1989

Diana J. Wilkie, MS, RN
Ph.D. Candidate
1400 Tenth Avenue, No. 4
San Francisco, California 94122

Dear Diana:

The Institutional Review/Research Committee of St. Mary's Hospital & Medical Center have met and approval has been granted for your study, "Behavioral Correlates of Lung Cancer Pain".

We trust your study goes well and wish you much success.

Sincerely,

Geno Saccomanno

Geno Saccomanno, M.D.
Chairman, Institutional Review/Research Committee

GS:jc

2635 North 7th Street • P.O. Box 1628 • Grand Junction, CO 81502-1628 • (303) 244-2273

Affiliate of Sisters of Charity of Leavenworth Health Services Corporation, Inc.

Medical Center

2615 East Clinton Avenue
Fresno CA 93703

Veterans Administration

October 20, 1989

In Reply Refer To: 570/11R

Diana J. Wilkie, MS, RN
Department of Family Health Care Nursing
Room N411-Y
Box 0606
San Francisco, CA 94143-0606

Dear Ms. Wilkie:

This is in reference to your protocol entitled "Behavioral Correlates of Lung Cancer Pain".

The Research and Development Committee and Human Studies Subcommittee has unanimously approved the above protocol.

Sincerely yours,

Frederick W. Bauer, M.D.
Chairman, R&D Committee

Anita M. Xavier, M.D.
Chairman, Human Studies Subcommittee

Consent to be a Research Subject

Diana Wilkie, PhD candidate from the Department of Physiological Nursing, is conducting a study to learn about pain related to lung tumors. Because I have pain, I am being asked to participate in this study. A family member or close friend will also be asked to participate, but I may participate if he/she chooses not to participate.

If I agree to be in this study, the following will happen:

> Today, Ms. Wilkie or her associate will come to my house. I will be asked some questions and will fill out 4 questionnaires about myself and my pain. Then I will sit, stand, walk, and lay down for a total of 10 minutes while I am video taped with two cameras. This will take about 70 minutes. In a private place, Ms. Wilkie and her associate will view both video tapes to identify behaviors that may be related to my pain.
>
> Not more than two days later, Ms. Wilkie will come back to my house. I will fill out 3 questionnaires and she will ask me questions about my pain that she learned from viewing the video tape. This will take less than 20 minutes. Finally, one of my family members or a close friend will look at the video tape and answer some questions about my pain. Ms. Wilkie will review my medical records to learn about my disease and therapy.

Some of the questions may make me uncomfortable, upset, or tired, but I am free to decline to answer any questions I don't wish to, stop the interview at any time, or take questionnaires home to answer when I am less tired. Sitting, walking, standing, or laying down may increase my pain, but I am free to use my normal methods of managing my pain, including pain medications. Study records will be kept as confidential as possible. Because I will be video taped, there is greater risk of loss of confidentiality, but my name will not appear in any reports or publications resulting from the study. Study information will be kept in locked files and only study personnel will have access to the files and video tapes. As with all research data, the videotapes will be kept for least five years. If the tapes are used for teaching purposes or future studies, I will be asked to sign a standard photographic release form. If I decline to sign the form, the tapes will be used only for purposes related to the present research and will be destroyed after five years.

There will be no direct benefit to me from participating in this study. The anticipated benefit of these procedures is a better understanding of pain related to lung tumors. I am free to choose not to participate in this study. PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future care. There will be no costs to me as a result of taking part in this study. I will not be reimbursed for my participation in this study.

I have talked to Ms. Wilkie or Dr. Marylin Dodd about this study, and have had my questions answered. If I have any further questions about the study, I may call Ms. Wilkie at (415) 476-4040 or Dr. Dodd at 476-4320. I have been given a copy of this consent form and the Experimental Subject's Bill of Rights to keep. I give permission for Ms. Wilkie to look at my medical records.

_____ _____

Date Subject's Signature

H452-03836-02

_____

Person Obtaining Consent

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

1) To be told what the study is trying to find out.

2) To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice.

3) To be told about the frequent and/or important risks, side effects or discomforts of the things that will happen to me for research purposes.

4) To be told if I can expect any benefit from participating, and, if so, what the benefit might be.

5) To be told the other choices I have and how they may be better or worse than being in the study.

6) To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study.

7) To be told what sort of medical treatment is available if any complications arise.

8) To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study.

9) To receive a copy of the signed and dated consent form.

10) To be free of pressure when considering whether I wish to agree to be in the study.

If I have other questions I should ask the researcher or the research assistant. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling: (415) 476-1814 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing to the Committee on Human Research, University of California, San Francisco, CA 94143.

Call X1814 for information on translations.

12/1/78

VETERANS ADMINISTRATION MEDICAL CENTER
FRESNO, CALIFORNIA
Consent to be a Subject in a Medical Research Study

Information About: Behavioral Correlates of Lung Cancer Pain
Principal Investigator: Diana Wilkie, MS, RN, PhD Candidate

1. PURPOSE OF THE STUDY: To learn about behavior lung cancer patients show when they have pain. Because I have lung cancer and pain, I am being asked to participate in this study. A family member or close friend will also be asked to participate, but I may participate if he/she chooses not to participate.

2. PROCEDURES: If I agree to be in this study, the following will happen: Today, Ms. Wilkie or her associate will come to my house. I will be asked some questions and will fill out 4 questionnaires about myself and my pain. Then I will sit, stand, walk, and lay down for a total of 10 minutes while I am video taped with two cameras. This will take about 70 minutes. In a private place, Ms. Wilkie and her associate will view both video tapes to identify behaviors that may be related to my pain.

Not more than two days later, Ms. Wilkie will come back to my house. I will fill out 3 questionnaires and she will ask me questions about my pain after viewing the video tape. This will take less than 20 minutes. Finally, one of my family members or a close friend will look at the video tape and answer some questions about my pain. Ms. Wilkie will review my medical records to learn about my disease and therapy. I give permission for Ms. Wilkie to look at my medical records.

3. RISKS AND DISCOMFORT: Some of the questions may make me uncomfortable, upset, or tired, but I am free to decline to answer any questions I don't wish to, stop the interview at any time, or complete questionnaires later. Sitting, walking, standing, or laying down may increase my pain, but I am free to use my normal methods of managing my pain, including pain medications. If I become upset I should tell my physician.

4. POTENTIAL BENEFITS: There will be no direct benefit to me from participating in this study. The anticipated benefit of these procedures is a better understanding of pain related to lung tumors. There will be no costs to me as a result of taking part in this study. There will be no financial benefits or travel payments to me due to my participation in the study.

5. I have been informed that I can decide not to participate in this study, and that such a decision will not affect my right to receive health care or any benefit to which I am entitled. I have been informed that I can withdraw from the study at any time, for any reason, without prejudice, and that such a decision will not affect my right to receive health care or any benefit to which I am entitled.

6. My identity as a participant will not be revealed in any published or oral presentation of the results of this study. All information obtained as a result of this study will be kept confidential in accordance with the Privacy Act of 1974.

_____ _____
Date Signature
ADDENDUM TO VA FORM 10-1086
(To be retained in the patient's clinical medical record)

Information About: Behavioral Correlates of Lung Cancer Pain

7. In the unlikely event that I am injured as a result of participation in this study, the Fresno Veterans Administration Medical Center will furnish medical care as provided for by federal statutes. Compensation for such injury may be available to me under the provisions of Title 38 U.S.C. 351 and/or the Federal Tort Claims Act. For further information, contact the VA District Legal Counsel at (415) 974-0228.

8. The information on this page was explained to me by Ms. Wilkie. I understand that she will answered any questions that I may have about this study at any time. I may reach Ms. Wilkie at the University of California, San Francisco, phone (415) 476-4040, or Chairman, Research Committee, extension 5529.

MY SIGNATURE BELOW INDICATES THAT I HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT I HAVE DISCUSSED THIS STUDY WITH Ms. Wilkie. I HAVE BEEN GIVEN AN OPPORTUNITY TO ASK ANY QUESTIONS I MAY HAVE AND ALL SUCH QUESTIONS OR INQUIRIES HAVE BEEN ANSWERED TO MY SATISFACTION. I HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED. I HAVE RECEIVED A COPY OF THIS CONSENT FORM AND THE EXPERIMENTAL SUBJECT'S BILL OF RIGHTS.

SUBJECT

I, _____, certify that the above written summary was discussed and explained fully to me by Ms. Wilkie on this date.

_____ _____
Date Signature

or

SUBJECTS NEXT OF KIN OR CONSERVATOR

I, _____ the _____
Relationship/
_____ of _____
Legal Status Subject's Name

certify that the above written summary was discussed and fully explained to me by Ms. Wilkie on this date.

_____ _____
Date Signature

WITNESS

I, _____, certify that I was present during the oral presentation of the above written summary when it was given to the above subject/next of kin/conservator of the subject (circle one).

_____ _____
Date Signature

INVESTIGATOR

I have discussed the above points with the subject or his next of kin/conservator. It is my opinion that this person understands the risks, benefits, and obligations involved in participation in this study.

_____ _____
Date Signature

ADDENDUM TO VA FORM10-1086
(To be retained in the patient's clinical medical record)

Appendix K

Behavioral Correlates of Lung Cancer
Protocol Check List
Patient Procedures

Time One - Subject's Home

____ 1) Consent form signed, given copy & Experimental Bill of Rights
____ 2) Interview portions of the Demographic Data Form & MMPQ
____ 3) Instruct & have patient complete the VAS
____ 4) Instruct patient on self-administration of the STA, CSLC, & CSQ
____ 5) Record start time on Instrumentation Form
____ 6) Plan where the patient will sit, stand, walk, recline (consider lighting, room size, furniture arrangement). Chair should be positioned at 90 degree angle to couch with adequate space for the patient to ambulate 4-6 steps. Front and back lighting is preferred.
____ 7) Set-up RCA video equipment
- ____ a) RCA camera set on tripod & positioned 6-8 ft from patient (profile view angle when walking)
- ____ b) Connect RCA adapter cables to VCR
  video out to video in
  audio out-left to audio in-left
  audio out-right to audio in-right
  remote out is not connected but position so as to not cause a short
- ____ c) Plug adapter and VCR into AC outlet
- ____ d) Turn adapter power supply on
- ____ e) Insert video cassette - VCR power comes on automatically
- ____ f) Verify VCR Input Signal selector is set on line, tape speed selector is set on SP
- ____ g) Set title on camera with patient code number and date
- ____ h) Press Date/Time button twice to display stop watch
- ____ i) Focus camera on patient
- ____ j) Verify camera settings (white balance, manual focus, etc)

____ 8) Set-up Panasonic video equipment
- ____ a) Panasonic camera set on tripod & positioned 10-12 feet from patient (verify that subject will be in frame during all procedures-sit, walk, stand, recline-and that the RCA camera is not in the frame)
- ____ b) Insert video cassette
- ____ c) Check that battery pack is inserted
- ____ d) Slide selector door to camera position (all the way to the left)
- ____ e) Take lens cap off
- ____ f) Set date/time
- ____ g) Verify camera settings (white balance, auto focus, etc)
- ____ h) Focus camera

____ 9) When patient is finished with the tools, instruct about procedures (where to stand, sit, walk, recline; investigator to talk only when time to change position; how to do clap board signal with hand; patient to act as normal as possible-check if any props are needed for patient to behave normally in the positions)
____ 10) Check which position is first & second from the randomized list of numbers
____ 11) Press VCR Rec button & play button simultaneously
____ 12) Press record buttons on both cameras
____ 13) Set watch, tell patient to assume the first position, focus RCA camera on the patient's face, tell patient to do the clap board & **simultaneously** start timing watch & press RCA start/stop button to start stop-watch counting.
____ 14) Tell patient to change positions as indicated on the randomized list (every 1 to 2 minutes)
____ 15) Pan RCA camera on face when the patient is in motion, focus as necessary
____ 16) When the recording time has elapsed, state "all finished" & press stop recording buttons on both cameras
____ 17) Verify second appointment time; return equipment to carrying cases
____ 18) Record finish time on Instrumentation Form

Investigator Procedures

In Laboratory

____ 19) Copy face tape (in Panasonic set as VCR) onto "dubbed copy-face" cassette (in Quasar VCR); press appropriate play & play/record buttons; rewind each
____ 20) Copy body tape (in Panasonic set as VCR) onto "dubbed copy-body" cassette (in Quasar VCR); press appropriate play & play/record buttons; rewind each
____ 21) Place dubbing audio tape in recorder, connect cable in ear jack (out) to VCR left mic (in)
____ 23) Set signal selector to line; press play button & select left audio to monitored using the audio out select button
____ 23) Place "dubbed copy-face" in Quasar VCR; play to clap board motion made by patient; press pause/still button; press audio dub button together with play button; simultaneously press pause/still button on VCR and play button on audio recorder. Press stop button at end of patient's face tape
____ 24) Place "dubbed copy-body" in Quasar VCR; play to clap board motion made by patient; press pause/still button; press audio dub button together with play button; simultaneously press pause/still button on VCR and play button on audio recorder. Press stop button at end of patient's body tape
____ 25) Score each of the dubbed copy tapes using the appropriate score sheets and manuals

____ 26) Make face-body picture in picture tape if a family member is available to participate in the study
- ____ a) Using third VCR with cable & adapter to RCA equipment
- ____ b) Connect third VCR (set on line) video & audio in to Quasar VCR video & audio out
- ____ c) Connect Panasonic adapter (set on line) to camera & connect video & audio out to Quasar video & audio in
- ____ d) Connect Quasar (set on line) out to TV to Sony (set on video) VHF/UHF
- ____ e) Place original the face tape in Panasonic, original body tape in Quasar, & the face-body tape in the third VCR (verify that tape is set to record on blank tape at end of previous subject)
- ____ f) Play Panasonic tape to clapboard; press Panasonic pause button; play quasar tape to clapboard; press picture-in-picture button on the Quasar & position small (face) picture in appropriate corner of screen to avoid interfering with body picture; press Quasar pause/still button
- ____ g) Press record button on third VCR
- ____ h) Simultaneously press pause buttons on the Panasonic & Quasar; immediately press picture-in-picture button on Quasar and position picture in the corner determined as most appropriate in step (f)
- ____ i) While tapes are playing move small picture to appropriate corner when the patient changes positions
- ____ j) Press stop buttons on all machines when tapes complete; rewind only the face/body tape

Patient/Family Procedures

Time Two - In Patient/Family Member's Home

____ 26) Family consent form signed, given copy & Bill of Rights
____ 27) Separate patient & family member
____ 28) Interview family member to complete DDF & MMPQ; instruct on completing the VAS, CSLC-family & CSQ
____ 29) Set up equipment for family member to view face/body tape & instruct to do so when tools have been completed.
____ 30) Interview patient regarding intent of each of the scored behaviors
____ 31) Interview the patient to complete the open-ended questions about other behaviors used to express pain, control pain, or that pain prevents and to complete the MMPQ
____ 32) Patient completes the VAS, CSQ, & PLC
____ 33) Family member rates patient's pain day of video taping using the VAS
____ 34) Interview family member about behaviors observed on tape & other behaviors that the family member knows the patient uses to express pain to others, control pain, & that pain prevents
____ 35) Thank subjects for participating