Title

The relationship between knowledge about cancer-related pain and selected pain characteristics

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The Relationship Between Knowledge about Cancer-Related Pain and Selected Pain Characteristics

by

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Dedication

To the memory of my mother, Ellora, who died in 1964 of metastatic breast cancer, suffering needlessly in pain.

To the increased awareness of the importance of pain control and to quality of life becoming a reality.

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Abstract

The Relationship Between Knowledge about Cancer-Related Pain and Selected Pain Characteristics

Deborah Anne Moore

Prevailing public attitude toward cancer involves a large degree of fear and anxiety. It is commonly believed that cancer is accompanied by pain. Cancer patients frequently receive insufficient pain relief, and rank pain as the most distressing symptom they experience. Numerous reasons have been cited for failure to control cancer pain; however, little research has been done to describe the knowledge and experience of the cancer patient in pain. The purposes of this study were to determine: 1) if there is a relationship between knowledge about pain and pain intensity in ambulatory oncology patients with cancer-related pain; and 2) if there is a relationship between knowledge about pain and pain duration in ambulatory oncology patients with cancer-related pain. Two hundred oncology outpatients with cancer-related pain completed several self-report questionnaires including: a Demographic Questionnaire; a Pain Experience Scale (PES) that measured the knowledge and experience of pain; and a Descriptive Numeric Rating Scale that measured pain intensity and duration. To determine if selected pain characteristics correlated with knowledge about pain, Pearson's Product Moment Correlation

Coefficients were calculated. Results indicated that patients with higher daily pain intensity ratings and higher number of days in pain had higher PES total knowledge scores but continued to suffer from uncontrolled pain. Total knowledge scores were not very high (mean=57.3) for this group of patients with cancer-related pain, suggesting that oncology outpatients who are experiencing pain have a limited knowledge about the management of cancer pain. Questions on dosing and scheduling of pain medications received the lowest scores. Mid-range responses to the questions evaluating the concepts of physical dependency and addiction may indicate uncertainty about the meaning of these concepts. The findings of this study demonstrate that pain is not being effectively controlled, and patients experiencing pain do not have the knowledge necessary to adequately control their pain. This study is among the first to examine the relationship between knowledge about pain and the experience of pain and demonstrates the need for healthcare providers to develop more effective methods to provide the patient with information and tools to relieve pain.

Christine Miaskowski RN PhD FAAN

Table of Contents

List of Tables

Chapter I: Introduction to the Problem

Prevailing public attitude toward cancer involves a large degree of fear and anxiety. It is commonly believed that cancer is inevitably accompanied by pain (Cleeland, 1985; Dent & Goulston, 1982; Levin, Cleeland, & Dar, 1985). Pain has been reported by 50% of cancer patients at all stages of the disease and by 70% to 90% of those with advanced disease (Bonica, 1985; Cleeland, 1985; Foley, 1985). The American Cancer Society estimates that in excess of 1.1 million people will be diagnosed with cancer in the United States in 1994 and that nearly 500,000 will die of the disease (American Cancer Society, 1994). Applying pain estimates to these data indicate that approximately 350,000 patients dying of cancer have pain. There is widespread recognition that patients with cancer frequently receive insufficient treatment for cancer-related pain with advanced cancer patients ranking pain as the most distressing symptom they experience (Bonica, 1985; Rimer, Kedziera, & Levy, 1992).

Inappropriate attitudes about the use of narcotics has led to inadequate pain control. In addition, myths about addiction have contributed to underdosing of narcotic analgesics by cancer patients and caregivers as well as by health professionals (Hill, 1993). Increased interest and focus on the relief of cancer pain are evidenced by the growing number of Hospice organizations, pain societies, and

State Cancer Pain Initiatives. The World Health Organization (WHO) has declared effective pain relief to be one of its top priorities (World Health Organization, 1990). Despite these national and international efforts, the undertreatment of cancer pain continues to be a significant problem (McCaffery, 1991).

Numerous reasons have been cited for failure to control cancer pain, including: the subjective nature of pain; inadequate education of patients, caregivers and health care professionals; and underprescribing of appropriate analgesics (American Pain Society, 1989; Levin et al., 1985). The patient's unfounded fears of tolerance and addiction limit opioid use. Patients may resist increasing narcotic use because it signifies disease progression and impending death (McCaffery, 1991). The "war on drugs" has the potential to negatively affect patient care with the result that the patient in pain will "just say no to pain control" (Hill, 1989; Jones, Rimer, Levy, & Kinman, 1984; McCaffery, 1991; Peteet, Tay, Cohen, & MacIntyre, 1986).

Recent work by Ward and colleagues (1993) suggests that the following concerns may prevent patients from reporting pain and taking medications: fear of addiction; concern about tolerance; concern about side effects; fatalism; desire to be a "good patient"; fear of distracting one's physician from treating the disease; concern that pain means disease progression; and fear of injections. Twycross and Lack (1983) reported unrelieved pain to be related to the patient's belief that pain in cancer is inevitable and untreatable. If more information was known about individual patient's knowledge and attitudes about cancer pain, healthcare professionals would be better able to design and test specific targeted interventions to improve the treatment and management of this important clinical problem.

The fact remains that despite advances in understanding the pathophysiology of pain, the availability of effective pain management strategies, and a wider dissemination of such knowledge, cancer pain relief is still inadequate. Changing patients' attitudes and beliefs about the dangers of therapeutic use of narcotics may aid in improving the erratic control of cancer pain. However, this may prove to be very difficult. It will be easier to correct knowledge deficits than it will be to change cultural attitudes and beliefs. Changes are called for in knowledge and attitudes along with greater public awareness and expectations about the effective treatment of pain (Hill, 1993; Jones et al., 1984; Levin et al., 1985).

To date, only five studies have evaluated parameters related to the pain experienced by oncology outpatients (Ahles, Ruckdeschel, & Blanchard, 1984; Bressler, Hange, & McGuire, 1986; Daut & Cleeland, 1982; Peteet, Tay, Cohen, & MacIntyre,1986; Portenoy et al., 1992). Knowledge about pain and its effect on the experience of pain were not addressed in these studies.

Literature review of the research on cancer-related pain reveals that little has been done to describe patients' knowledge and its effect on cancer-related pain and its treatment. A relationship between knowledge and improved pain management has numerous implications for cancer nursing practice.

Purposes of the Study

The purposes of this study are:

1. To determine if there is a relationship between knowledge about pain and pain intensity in oncology outpatients with cancer-related pain.
2. To determine if there is a relationship between knowledge about pain and the duration of pain in oncology outpatients with cancer-related pain.

Assumptions:

The underlying assumptions in this study are as follows:

1. Pain is a multidimensional phenomenon.
2. Fear of addiction and drug abuse are common.
3. Pain is one of the most feared consequences of cancer.
4. Pain can be controlled in the majority of patients.

Definition of terms

The following definition of terms will be used in this study:

1. Oncology outpatient - a patient receiving outpatient

treatment for cancer (not AIDS-related) with any single or combination of the following modalities:
(1) chemotherapy, (2) radiation therapy,
(3) hormonal therapy, and/or (4) biotherapy.

2. Cancer-related pain - pain caused by cancer or cancer treatment as determined by the medical record review and the patient's self report.

3. Pain intensity - the subjective report of cancer-related pain intensity, which includes: pain right now; average daily pain; current worst pain; and current least pain measured on a descriptive numeric rating scale ranging from 0 (no pain) to 10 (the worst pain imaginable).

4. Pain Duration - the subjective report of cancer-related pain duration, which includes: the number of days in a typical week that the subject experiences a significant amount of cancer-related pain; and the number of hours a day that the pain lasts.

5. Knowledge about pain - the knowledge subscore of the Pain Experience Scale (PES). This portion of the questionnaire obtains information on the patient's knowledge of non-drug and drug treatment for pain, addiction, drug dependence, drug dosages, drug side-effects, and drug administration schedules.

Chapter II: Literature Review

Conceptual Framework

Pain is a multidimensional phenomenon that consists of multiple components including: 1) a physiological component (i.e., the organic etiology of the pain); 2) a sensory component (i.e., attributes such as the intensity, location, and quality of the pain); 3) an affective component (i.e., depression and anxiety associated with pain); 4) a cognitive component (i.e., the manner in which the pain influences a person's thought processes or the manner in which a person views herself/himself); 5) a behavioral component (i.e., pain behaviors such as activity level or analgesic intake); and 6) a sociocultural component (i.e., demographic characteristics, ethnic background, and/or family/social support). These six components do not contribute to the pain experience in isolation or independently. They are interrelated and influence one another to make pain a multidimensional experience for the individual (Ahles, Blanchard, & Ruckdeschel, 1984; Ahles & Martin, 1992; McGuire, 1992).

The cognitive and the sensory component of the pain experience will be examined in this study. The cognitive component of cancer pain has not been well-studied. Ahles and colleagues (1984) found that 61% of patients were concerned that changes in pain were indicative of a deteriorating condition. Patients may hesitate to report pain because they believe that increases in pain signify disease progression (Arathuzik, 1991; Twycross and Lack, 1983). Ward and colleagues (1993) concluded patients who are unready to acknowledge the possibility of disease progression may be unwilling to report pain.

The patient's knowledge about pain and pain management and how the patient views the pain experience will be explored in this study. The individual's pain experience incorporates both the cognitive and the sensory components, and these two components may influence each other to alter the patient's total pain experience. Pain intensity is the most commonly measured sensory parameter. However, a major difficulty with the measurement of pain intensity is the subjective nature of pain. According to Ahles and Martin (1992), intensity readings can be influenced by any or all of the aspects of the pain experience. In order to explore the relationship between two components of the multidimensional model of pain (the cognitive and the sensory component) in a population of ambulatory oncology outpatients with cancer-related pain, one needs to compare certain pain characteristics (i.e., intensity and duration) with knowledge about pain.

Introduction

Pain has been identified as a major problem affecting millions of patients throughout the world (Bonica, 1985). The lack of information on the true impact of pain on the individual diagnosed with cancer has been described in the Oncology Nursing Society's Position Paper on Pain (Spross, McGuire, & Schmidt, 1990). Little is known about how knowledge affects the experience of pain. As the trend in oncology care moves to the outpatient setting, examination of the knowledge and experience of outpatients with cancer-related pain warrants investigation.

Healthcare professionals' knowledge about pain

It has been well-documented that physicians' and nurses' attitudes about narcotics include: 1) their over-concern of addicting patients; 2) the belief that pain cannot be relieved; 3) the acceptance of the presence of uncontrolled pain; 4) the belief that complaints of pain are related to anxiety and depression rather than pain; and 5) the willingness to write "prn" prescriptions which is tied to a lack of knowledge about pain as well as effective ways of treating it. Health care providers often fail to recognize the multidimensional nature of cancer pain (Cleeland, 1993; Cleeland, Dar, & Rinehardt, 1986; Miaskowski & Donovan, 1992; Vortherms, Ryan, & Ward, 1992). Negative attitudes, biases, prejudices, and misinformation are important deterrents to effective pain control (Cleeland, 1993).

Public knowledge and attitudes about pain

Knowledge of public opinion about cancer and cancer-related pain is very important. Levin, Cleeland, & Dar

(1985) conducted a phone survey on a representative sample of the population of Wisconsin. A total of 496 interviews were conducted by random digit dialing. Twenty-four respondents indicated that they had a cancer diagnosis, while 359 had a relative or friend with cancer. No differences in attitudes toward cancer pain were found between those individuals with a personal or familial experience with cancer and those individuals whose knowledge of cancer came from other sources. Forty-eight percent of the participants viewed cancer as a very or extremely painful disease. Sixty-nine percent of the respondents agreed that cancer pain can get so bad that a person might consider suicide. Chi-square analysis indicated that pain associated with cancer was rated significantly higher ($p<0.01$) than most other listed conditions.

The 472 respondents who had not been diagnosed with cancer were asked questions about pain as a factor in delaying treatment. Fifteen percent agreed or strongly agreed that their fear of cancer would put off their seeking medical care. Nine percent agreed or strongly agreed that their concern about the pain of cancer would lead to avoidance of medical care; and 18% indicated they would avoid seeking care because of the pain associated with cancer treatment. In addition, the majority of respondents were extremely concerned about the negative consequences of using narcotic analgesics for pain control. Fifty-eight percent reported that they would feel much concern or extreme concern about becoming mentally confused and 45% worried about the possibility of addiction (Levin et al., 1985).

The results of this study (Levin et al., 1985) confirm the strong linkage between cancer and pain in the view of the public. Fear of both disease and treatment related pain are major concerns of the public and by inference, of cancer patients as well. This was the only study of this nature found in the literature. Replication of this type of study across the country is needed. More information about the sample concerning their health history and experience with pain would have been helpful. The random sample was selected from one midwestern state so the generalizability is limited to the midwest.

Dent and Goulston (1982) evaluated community attitudes about cancer. Data were collected by questioning a random sample of 500 persons aged 18 and over in Canberra, Australia. Factor analysis showed four relatively independent attitude dimensions, namely: anxiety about cancer, denial of the threat of cancer, fatalism about prevention, and fatalism about control of cancer. Fatalism about prevention and fatalism about control showed a moderate positive correlation. This study identified dominant attitudes towards cancer among members of a community who have not themselves had cancer. One might make the assumption that if the individual is fatalistic about the control of cancer, this probably leads to the conviction that there are minimal benefits to be gained by taking action--for example by fully participating in cancer prevention or fully participating in cancer pain management.

Cleeland (1985) concluded that most members of the public think of severe and unremitting pain as a natural consequence of cancer. Public perceptions of pain may lead to a delay in diagnosis out of fear of a cancer diagnosis. The prevalent public attitude that the use of opioid analgesics is illegal is a barrier to appropriate medical use of opioids. There is an irrational fear that addiction invariably follows the use of narcotics. Hill (1989) points out that the experience with drug abuse so dominates cultural and societal thinking that even when these drugs are used legitimately for medical purposes, an illegitimate aura persists.

Pain experienced by oncology outpatients

A limited number of studies have been done on the pain experienced by ambulatory oncology patients. However, none of these studies explored the patient's knowledge of pain and its treatment. These studies (Ahles, Ruckdeschel, & Blanchard, 1984; Bressler, Hange, & McGuire, 1986; Daut & Cleeland, 1982; Peteet et al., 1986; Portenoy et al., 1992) evaluated the prevalence, characteristics, and management of pain in ambulatory oncology patients. Results indicate that the percentage of patients experiencing pain in an outpatient setting is very similar to that of hospitalized patients.

Knowledge of cancer patients about pain

Only one study was found that looked at cancer patients' knowledge regarding pain control regimens. Jones, Rimer, Levy, & Kinman (1984) studied 82 cancer patients who were prescribed pain medications. Data were gathered through a review of records and phone interviews. Patients were interviewed twice. Their knowledge of medications, compliance with prescribed pain-control regimens, level of worst pain that day, and symptoms experienced and interpreted as side effects of pain medications were evaluated.

There was a significant decrease in pain between T1 (the time they received their medication) and T2 (two weeks later; p=0.0001). At T2, 77% of the patients recalled the correct names of their pain medication and 88% had been taking them. However, an important gap in the patients' knowledge was revealed by their inability to recall any of the common side effects of pain medications. Only 4% of the patients identified nausea and vomiting, 20% identified constipation, and 8% sleepiness or difficulty concentrating as possible adverse effects. In general, the patients' concerns about possible addiction or tolerance to prescribed medications were low. There was a positive relationship between intensity of pain and concern about tolerance to drugs (p=0.003). None of the measures of pain or changes in pain from T1 to T2 was related to the patients' education, age, attending physician, prescribed medication schedule, prescribed medication strength, or measures of compliance (Jones et al., 1984).

The authors concluded that patients need more information about side effects of pain medications, need to be given a realistic assessment of the potential for addiction or tolerance, and that communications between patient and physicians regarding pain should be improved. The small sample size and patient selection based on patients currently on pain medication make generalizability of the findings limited. The levels of compliance reported in this study were higher (55%) than those found in other studies of compliance with medications for chronic diseases which may be the result of the patients' need for and relief gained from prescribed pain medications.

A second study by Rimer and colleagues (1987) revealed that only 23% of patients recalled being told to take their medications on an around the clock schedule. And only 25% recalled being told to adjust or titrate the dosage of their medications. We can infer from these data that lack of recall about how to administer pain medications may contribute to the patient experiencing inadequate pain relief.

Ley (1983) reviewed seven studies of patients attending either rheumatology or general medicine clinics and found that 37% to 61% of the information presented by the physician was forgotten. Unfortunately, very little is known about the informational needs of cancer patients who are prescribed narcotics. The available data suggest that patients may be retaining only a small amount of the information provided to them.

In an exploratory study by Ferrell & Schneider (1988), 75 cancer patients with chronic cancer pain were interviewed in the hospital and seven to ten day after discharge to determine how the experience and intensity of pain differed in the hospital and at home. Eighty-three percent of patients at home and 60% of the patients in the hospital took medications less frequently than ordered because of fear of addiction, fear of tolerance, misunderstanding of dosages, and feeling that the pain could not be treated.

Ward and colleagues (1993) explored patient-related barriers to the management of cancer pain. Two hundred and seventy patients with cancer completed a 27 item self-report questionnaire that assessed the extent to which they had concerns about reporting pain and the use of pain medications. Ages ranged from 21 to 91 years with 94% being Caucasian and 74% being married. Eighty-six percent of the patients had a high school education or higher. Concerns about addiction received the highest score. Approximately

45% of the sample agreed that "good patients" avoid talking about pain. Persons who were older, had lower levels of income, or lower levels of education had more concerns about distracting a physician from cure, were more fatalistic, and had a higher desire to be a "good patient". While sample demographics limit the generalizability of the findings, further research is needed to explore barriers to taking adequate medication for pain.

Trotter and colleagues (1981) reviewed nursing records from home visits made to 237 cancer patients. One hundred fifty-nine patients were taking analgesics. Thirty-five percent of the patients were either "not taking analgesics as prescribed" or had "misunderstood directions". The authors drew these conclusions because of self-imposed underdosing. However, specific data on patients' level of understanding were not reported in their paper.

Austin and colleagues (1986) in a retrospective study of 96 terminally ill, male cancer patients evaluated the degree of pain control as related to age, living arrangements, primary cancer site, and compliance with the analgesic regimen. Fifty-three percent of the patients were not taking their pain medication as prescribed despite complaints of severe pain. Undertreatment occurred despite education and encouragement from the Hospice staff. Generally, patients were not taking their medications because of concerns about addiction and/or the desire to maintain control. Age or living arrangements were not related to whether or not the patients followed their prescribed medication regimen. In addition, no correlation was found between a patient following their prescribed medications and level of pain control. The patients' support systems were not described in sufficient detail nor was there an evaluation of the appropriateness of the medications prescribed. Finally, the use of adjuvant medications and treatments were not evaluated.

Dar and colleagues (1992) interviewed forty married patients with metastatic cancer, who were receiving opioid medication for cancer pain. The patients were asked to assess the following: their own pain; their beliefs in regard to their own pain and cancer pain in general; beliefs about pain medications; their perception of their spouse's feelings and behavior in relation to the patient's pain; and the patient's mood. The questions for the spouse concerned the patient's pain.

Even though these patients were currently taking analgesics, patients reported an average level of worst pain of 5.45 (SD=2.92) on a 0-10 scale, with 20% reporting worst pain level of 10. When asked at what level of pain they would ask for additional analgesics, 15 patients (37.5%) answered "before the pain returns" whereas the other 25 (62.5%) answered "when the pain is moderate" or "severe". Patients in this sample tended to wait longer than they felt they should before requesting additional pain medication. It is also interesting to note that patients' level of worst pain was related to the level of pain they were willing to tolerate before requesting additional analgesics (r=0.33; p<0.05).

Patients in this study had considerable concerns about side effects, particularly addiction, mental confusion, and the development of tolerance. A majority of patients (69%) endorsed the statement "I feel I should not take narcotic medications on a regular basis but only when the pain is extreme." Waiting longer before requesting additional medication was correlated with increased concern about mental confusion (r=0.33; p<0.05), sleepiness (r=0.31; p<0.05), and addiction (r=0.38; p<0.05).

Factors related to the patient sample size may restrict the generalizability of the findings in this study. The sample represents a fairly homogeneous, rural midwestern population. The stoic attitude may be typical for this population. The small, sample size seriously constrains the power of statistical analysis. The questionnaire used in this study had never been used before. The authors did not feel this was a significant problem as these instruments measured straight forward questions (Dar, Beach, Barden, & Cleeland, 1992).

A major goal of this study by Dar and colleagues (1992) was to examine cancer pain in the context of the marital system. The results indicate the importance of considering the impact of pain on the spouse and to be aware that patients may minimize their report of pain in the presence of their spouses.

Summary:

Limited research has been done to determine the knowledge and experience of oncology outpatients who have cancer-related pain. This study will provide data on the relationship between pain intensity and duration and knowledge about cancer-related pain in a large sample of oncology outpatients. These findings may have important implications for health care providers who are developing interventions to treat cancer-related pain in the growing population of oncology outpatients.

Chapter III: Methodology

Research Design

This study is part of a larger descriptive study examining the prevalence and characteristics of cancer and noncancer-related pain in an outpatient oncology population.

Research Setting

The sample was recruited from 16 of the 35 sites that are part of the Oncology Nursing Research Network. This network was established in 1988 and is composed of over 150 oncology nurses. Nurses from 16 of the outpatient sites agreed to conduct this study at their site.

Sample Size and Criteria

A convenience sample of 435 oncology outpatients was obtained in the larger study. Inclusion criteria for the patients in the larger study included: 1) adult oncology outpatients (> 18 years); 2) who are able to read, write, and understand English; 3) who agree to participate and are able to give informed consent; 4) have a Karnofsky performance score of 50 or greater; and 5) are receiving outpatient treatment for cancer (not AIDS- related) with any single or combination of the following modalities: 1) chemotherapy, 2) radiation, 3) hormonal therapy, and/or 4) biotherapy. For this study, only patients with cancer-related pain were included.

Instruments

The instruments used in this study included a

Demographic Questionnaire, a Medical Record Review Form, the Pain Experience Scale, the Karnofsky Performance Scale, and Descriptive Numeric Rating Scales of Pain Intensity and Duration.

1. Demographic Questionnaire - (See Appendix A)

   a. Description: The Demographic Questionnaire is an eight item self-report questionnaire used to obtain information about age, gender, living arrangements, marital status, education level, ethnicity, employment status, and the patient's perception of the purpose of current cancer treatment.

   b. Scoring: Appropriate descriptive statistics and frequency distributions were generated.

   c. Reliability and validity: Content validity was established by a panel of experts in oncology nursing. This instrument has been used in previous studies by the principal investigators.

2. Medical Record Review Form - (see Appendix B)

   a. Description: The Medical Record Review Form provides detailed information on the date of initial cancer diagnosis, site of primary disease, sites and extent of metastases, previous therapy, type of surgery, current therapy, and reason for current therapy. The Medical Record Review Form was completed by either a nurse at the study site or by the Project Director based on a review of the patient's medical record and/or in consultation with the patient's nurse or physician.

b. Scoring: Appropriate descriptive statistics and frequency distributions were generated.

c. Reliability and validity: The Medical Record Review Form was developed by a panel of experts in oncology nursing. Content validity was obtained by review and revision of the instrument by the investigators. This instrument has been used in previous studies by the principal investigators.

3. Pain Experience Scale (PES) - (see Appendix C)

a. Description: The PES was developed by Ferrell and Rhiner (personal correspondence, 1991). This 13 item instrument was modeled after tools that have been used extensively to measure the knowledge and attitudes of healthcare professionals about pain and pain management. The first nine items of the PES were used in this study to measure an individual's knowledge of basic pain principles such as addiction, relief of pain, and routine analgesia. Each item on the knowledge section of the PES contains a statement about cancer pain and/or pain relief. Below each item is a 100mm linear analogue scale anchored on the left with the word "disagree" and on the right with the word "agree". Instructions ask the patient to make an "X" on the line to indicate their level of agreement or disagreement with each statement.

b. Scoring: The PES was scored using a Summa Sketch II to measure the Visual Analog Scale (VAS) responses. The PES includes nine items that measure an individual's knowledge about pain. The total knowledge score for the PES was determined by summing the scores of each individual item (the range of scores for each item is 0 to 100) and dividing by 9. Items #2, 3, 5, 8, and 9 were reversed coded so that scores reflected the degree of correctness of the response on a 0 to 100 scale.

c. Reliability and validity: The results of a series of psychometric analyses done with test-retest responses from caregivers (n=67) are as follows: content validity (CVI >.90), construct validity (ANOVA, p<.05), concurrent validity (r>.6, p<.05), and factor analysis and test-retest reliability (r>.8; Ferrell, Ferrell, Rhiner, & Grant, 1991).

4. Karnofsky Performance Scale (KPS) - (see Appendix D)

a. Description: The KPS is designed to measure the patient's ability to accomplish normal activities of daily living or their need for help and nursing care (Karnofsky & Burchenal, 1949). The KPS consists of a series of 10 items for ranking functional status from 0 (death) to 100 (adequate health status, with no complaints or evidence of disease.) For the purpose of this study, the rankings began with 30 (disability with hospitalization needed).

b. Scoring: The patient was asked to "circle the number that best describes your abilities at the present time" on a scale from 30 to 100 in increments of 10. A score of 100% indicated that the individual felt normal and had no complaints or symptoms. A score of 30% indicated that the individual was severely disabled and needed to be hospitalized.

c. Reliability and validity: Reliability and construct validity of the KPS have been established and it has been shown to be a global indicator of the functional status of patients with cancer (Schag, Heinrich, & Ganz, 1984; Yates, Chalmer, & McKegney, 1980). In one study, performance status was rated by two physicians and the patients themselves (n=100) using the KPS and the Eastern Cooperative Group (ECOG) scale to evaluate reliability and validity of the instruments (Conill, Verger, & Salamero, 1990). Correlations were significant between the two physicians scores (r=.75 for KPS, .76 for ECOG, p<.001) and between physicians' and patients' rating (.65 for KPS, and .59 for ECOG, p<.001).

To test for construct validity, the KPS has also been compared to single-item physical quality of life scales, such as the Katz ADL scale. The results of this comparison found the KPS to be unbiased and complete, with a correlation coefficient of .35 (Mor, LaLiberte, Morris, & Wiemann, 1984). Schag and colleagues (1984) studied 293 cancer patients to test the validity of the KPS and reported that the KPS had very good interrater reliability among physicians (r=.89).

5. Descriptive Numeric Rating Scales of Pain Intensity and Duration - (see Appendix E)

a. Description: The Descriptive Numeric Rating Scales of Pain Intensity each contain a horizontal row of numbers ranging from 0 to 10 with descriptors below several of the numbers (i.e., 0 = none, 2 = mild, 5 = moderate, 8 = severe, and 10 = excruciating). In addition, two questions are included about duration of pain.

b. Scoring: Patients were asked to rate the intensity of their pain using the descriptive numeric rating scale from 0 (no pain) to 10 (excruciating pain) at the time of completing the questionnaire (i.e., pain right now). In addition, patients were asked to report the following using the descriptive Numeric Rating Scale: average daily pain; current worst pain; and current pain at its least.

To obtain information on duration of pain, patients were asked to indicate: 1) how many days (0 to 7) of a typical week do you currently experience significant cancer-related pain (i.e., pain that interferes with your mood and/or your activities)?; and 2) on those days when you have signicant cancer-related pain, how many hours of the day (0 to 24) does it currently last?

c. Reliability and validity: The validity of a numeric scale is difficult to establish since there is no absolute measure of pain intensity (Wewers & Lowe, 1990). Since pain is not a static phenomenon, reliability of a pain rating scale is also difficult to establish (Huskisson, 1974). However, a number of researchers have found that numeric rating scales are reliable and valid measures of perceived pain intensity (Downie et al., 1978; Ohnhaus & Adler, 1975). In addition, a numeric rating scale is a simple, robust, and sensitive measure of pain intensity and has yielded reproducible results with many types of patients in many settings (Huskisson, 1983).

Data Collection Procedures

Human subjects approval was obtained from the Committee on Human Research at the University of California, San Francisco, California, and from the individual sites as necessary.

Nurses at all 16 sites were trained in data collection procedures by the study's co-principal investigator. After obtaining informed consent (see Appendix F), patients were asked to complete the Patient Information Questionnaire (PIQ) and return it to the nurses for review. The PIQ contains the Demographic Questionnaire, the Pain Experience Scale, and the Karnofsky Performance Scale. The final questions on the PIQ ask the patient to report whether they had experienced cancer or non-cancer related pain in the past month (see Appendix G). The nurses reviewed the PIQ for completeness and based on the patient's response to the last two questions, gave the patient the Cancer-Related Pain Questionnaire (CRPQ) if the patient had cancer-related pain. The patient was instructed to complete the questionnaire in the practice setting or take it home and bring it back at their next scheduled appointment. The CRPQ contains the Descriptive Numeric Rating Scales for pain intensity and duration. For the analysis of this study, only question 5 from the CRPQ was used (see Appendix E).

Data Analysis

Data were analyzed using the CRUNCH Statistical Software Package with a Dell Computer. Appropriate descriptive statistics including frequency distributions were generated.

In order to determine if there is a relationship between knowledge about pain and selected pain characteristics, Pearson's Product Moment Correlation coefficients were calculated. Significance was preset at

$p<.05$. Interpretation of the study’s findings was accomplished by carefully reviewing the data in light of previous research findings and clinical practice.

Chapter IV: Results

1. Patient Demographics

Participants (n=200) were primarily Caucasian (88.0%), middle-aged (mean=53.8 years, S.D.=14, range 19 to 80), with an average of two years of college education. The majority of the participants were female (58.0%), married or partnered (64.8%), and did not live alone (82.7%). Many of the patients were retired (24.5%) or disabled (27.0%), although 22.0% worked full-time. The demographic characteristics of the patients with cancer-related pain are summarized in Table 1.

These patients were diagnosed with a variety of cancers. The most common cancers included breast (23.0%), lung (12.5%), colon/rectal (12.5%), non-Hodgkin's lymphoma (6.5%), prostate (6.5%), and ovarian (6.0%). Current therapy for these patients included chemotherapy (62.9%), radiation therapy (14.7%), hormonal therapy (5.6%), and biotherapy (0.5%), with other patients receiving various combinations of these four treatment modalities. The medical record review revealed that the reason for therapy for the majority of the patients was control of the disease (45.7%), followed by cure (34.2%), and palliation (18.6%). Patients had an average Karnofsky Performance Score of 78.1. Most of the patients (70.4%) had metastatic disease.

2. Types and Causes of Cancer-Related Pain

Analysis of the medical record data and information from the patient questionnaires were used to categorize cancer-related pain as somatic, visceral, deafferentation, or a combination of somatic and deafferentation. The most frequently occurring type of cancer pain was somatic in origin (48.5%), followed by deafferentation (28.4%), visceral (19.4%), and a combination of somatic and deafferentation (3.7%). Bone metastasis (29.0%) was the most frequent cause of cancer-related pain, followed by post-surgical pain syndromes (22.6%), and pain produced by pressure on the thorax/abdomen (18.6%). The remaining causes of cancer-related pain are summarized in Table 2.

3. Intensity and Duration of Pain

The patients rated the intensity of their pain on a 0 to 10 scale. Scores were reported for pain right now (mean=2.2), average daily pain (mean=3.6), current worst pain (mean=6.4), and current pain at its least (mean=1.6). Patients reported experiencing a significant amount of pain an average of 4.2 days of the week and were in a significant amount of pain approximately 9.2 hours per day. Table 3 summarizes the patients' ratings of their pain intensity and duration.

4. Knowledge About Pain

The mean total knowledge score on the PES was 57.3 (S.D.=13.4). Each of the individual item scores on the PES are listed in Table 4.

5. Study Purpose 1: Relationship between knowledge about

pain and pain intensity ratings in oncology outpatients with cancer-related pain.

To determine if knowledge about pain in oncology outpatients with cancer-related pain was related to pain intensity, Pearson's Product Moment Coefficients were calculated for each of the items on the PES as well as the total PES score and each pain intensity measure. The results are summarized in Table 5.

a. Total PES Knowledge Score: A statistically significant positive correlation ($r=0.21$, $p<0.03$) was demonstrated between the average daily pain intensity rating and the total PES knowledge score indicating that patients with higher daily pain intensity ratings had higher PES knowledge scores. No other pain intensity measures correlated significantly with the total PES knowledge scores.

b. Question #1 of the PES: A statistically significant negative correlation was demonstrated between present pain intensity ($r=-0.25$, $p<0.004$), average daily pain intensity ($r=-0.25$, $p<0.005$), and worst pain intensity ($r=-0.21$, $p<0.02$) ratings and correct responses to the statement "cancer pain can be effectively relieved" indicating that patients with lower pain intensity scores more strongly agreed with that statement than patients with higher pain intensity scores.

c. Question #2 of the PES: None of the pain intensity measures correlated significantly with the PES knowledge score in response to the statement "pain medicines should be given only when pain is severe".

d. Question #3 of the PES: No pain intensity measures correlated significantly with the PES knowledge score in response to the statement "addiction refers to a person's desire to use drugs for their psychic effects rather than for the medical use of relieving pain. Most cancer patients on pain medicines will become psychologically addicted to the medicines over time".

e. Question #4 of the PES: No pain intensity measures correlated significantly with the PES knowledge score in response to the statement "drug dependence means that a person would go through withdrawal if a pain medicine was stopped. Most cancer patients on pain medicine will become physically dependent on the medicines over time".

f. Question #5 of the PES: No pain intensity measures correlated significantly with the PES knowledge scores in response to the statement "it is better to give the lowest amount of medicines possible early on so that larger doses will be available later if pain increases".

g. Question #6 of the PES: Statistically significant positive correlations were demonstrated between present pain intensity rating ($r=0.21$. $p<.02$), average daily pain intensity rating ($r=0.22$, $p<.02$), worst pain intensity rating ($r=0.18$, $p<.05$), and least pain intensity rating (r=0.24, p<.008) and correct responses to the statement "it is better to give pain medications around the clock (on a schedule) rather than only when needed". This indicates that patients with higher pain intensity scores agreed more strongly with that statement than those with lower pain intensity scores.

h. Question #7 of the PES: A statistically significant negative correlation (r=-0.22, p<.02) was demonstrated between least pain intensity ratings and the correct response to the statement "treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain" indicating that patients with lower least pain intensity scores more strongly agreed with that statement than patients with higher least pain intensity scores.

i. Question #8 of the PES: No pain intensity measures correlated significantly with the statement "pain medicines can often interfere with breathing".

j. Question #9 of the PES: Statistically significant positive correlations were demonstrated between the average daily pain intensity rating (r=0.23, p<.02), and worst pain intensity rating (r=0.18, p<.05) and the correct response to the statement "patients are often given too much pain medicine" indicating that patients with higher daily pain intensity ratings and higher worst pain intensity ratings more strongly disagreed with that statement than patients with lower intensity scores.

6. Study Purpose 2: Relationship between knowledge about pain and the duration ratings of pain in oncology outpatients with cancer-related pain.

To determine if knowledge about pain in oncology outpatients with cancer-related pain was related to pain duration, Pearson's Product Moment Correlation Coefficients were calculated for each of the items on the PES as well as the total PES knowledge score and each pain duration measure. The results are summarized in Table 5.

a. Total PES Knowledge Score: A statistically significant positive correlation (r=0.24, p<.01) was demonstrated between the average number of days in pain and the PES knowledge score indicating that patients with a higher number of days in pain had higher PES knowledge scores.

b. Question #1 of the PES: A statistically significant negative correlation (r=-0.19, p<.04) was demonstrated between the average number of days in pain and correct responses to the statement "cancer pain can be effectively relieved" indicating that patients with a lower average number of days in pain agreed more strongly with that statement than patients with a higher average number of days in pain.

c. Question #2 of the PES: A statistically significant positive correlation (r=0.2, p<.02) was demonstrated between the average number of days in pain and correct responses to the statement "pain medicines should be given only when pain is severe" indicating that patients with a higher average number of days in pain disagreed more strongly with that statement than patients with a lower average number of days in pain.

d. Questions #3, #4, #5, and #8 of the PES: No statistically significant correlations were found between any pain duration measures and the PES knowledge scores in response to these statements.

e. Question #6 of the PES: Statistically significant positive correlations were demonstrated between the average number of days in pain (r=0.28, p<.001) and the average number of hours per day in pain (r=0.24, p<.007) and correct responses to the statement on administering pain medications on a schedule rather than giving them only when they are needed. This indicates that patients with a higher average number of days in pain and more hours per day in pain agree more strongly with that statement than patients with pain of shorter duration.

f. Question #7 of the PES: A statistically significant negative correlation (r=-0.18, p<.05) was demonstrated between the average number of days in pain and correct responses to the statement concerning the effectiveness of treatments other than pain medications indicating that patients with lower pain duration scores agreed more strongly with that statement than patients with pain of longer duration.

g. Question #9 of the PES: Statistically significant positive correlations were demonstrated between the average number of days in pain (r=0.19, p<.04) and the average number of hours per day in pain (r=0.2, p<.03) and correct responses to the statement "patients are often given too much pain medicine". Patients with a higher number of days in pain and a greater number of hours per day in pain more strongly disagreed with that statement than patients with lower pain duration scores.

Chapter V: Discussion

This large scale study was undertaken to provide information on the amount of knowledge oncology outpatients with cancer-related pain have about cancer pain and its management, and the relationship between knowledge about cancer pain and selected pain characteristics. Limited research has been done evaluating how knowledge and the experience of pain are related. The growing population of oncology outpatients makes the findings of this study particularly pertinent. More effective pain management and educational strategies can be developed as we discover more about what patients know and understand about pain.

The relationship between knowledge about pain and pain intensity and pain duration is complex. The present pain experience, previous experience with pain, prescribing practices of the healthcare provider, and the patient's own fears about narcotics all complicate a complete understanding of the relationship between knowledge about pain and the experience of pain.

Overall, the patients who participated in this study were well-educated, relatively young, Caucasian, and did not live alone. Patients' pain intensity scores (average daily pain, mean=3.61) were fairly high, and are consistent with previously published reports (Daut & Cleeland, 1982; Peteet et al., 1986; Portenoy et al., 1992). Pain duration ratings (average number of days of the week the person experiences pain and the average number of hours per day that the pain lasts) are also consistent with those reported by Peteet and colleagues (1986).

Total knowledge scores were not very high (mean=57.3) for this group of patients with cancer-related pain. With the best possible score being 100, these data suggest that oncology outpatients who are experiencing pain have a limited amount of knowledge about the management of cancer pain. Patients scored highest on the following statements: (agreed that) cancer pain can be relieved (79.1); (disagreed that) pain medicines should be used only when pain is severe (69.6); and (agreed that) treatments other than medicines were effective in relieving pain (78.6).

Statements that evaluated knowledge about the concepts of physical dependence and psychological addiction had mid-range scores (approximately 50). These mid-range responses may indicate that patients were uncertain about the meaning of these concepts. Statements about the dosing and scheduling of pain medications had the lowest scores. This latter finding supports Cleeland's (1989) discussion of barriers to the rational management of pain in his description of patients in pain who put off taking pain medications until the pain they have is quite severe. This also supports Hode's (1989) description of patients who may not admit to continued severe pain because they worry that their physicians will prescribe a larger dose of what they fear is an addicting medication.

In analyzing the relationship between knowledge about pain and selected pain characteristics (i.e., intensity and duration), patients with higher daily pain intensity ratings and higher number of days in pain had higher PES knowledge scores. No relationships were found between knowledge scores and the ratings of pain right now, pain at its worst, or pain at its least. Additional research is warranted to determine the exact relationship between these characteristics and knowledge about pain management.

Patients with lower pain intensity scores and patients with a lower number of days in pain agreed more strongly with the statement "cancer pain can be effectively relieved." This finding suggests that these patients may be experiencing successful pain control, have experienced successful pain relief in the past, or they have not had to deal with severe and unrelieved pain. Patients who disagreed most strongly with this statement reported higher pain intensity scores and more days in pain perhaps because of their own experiences with uncontrolled pain.

Another interesting finding is that the higher the number of days in pain a patient reported, the more likely the patient would disagree with the statement "pain medication should be given only when pain is severe". These patients may have learned that it is better to take their pain medication before the pain becomes too severe.

Patients with higher mean pain intensity scores, higher average number of days in pain, and more hours per day in pain agreed more strongly with the statement pertaining to the need to schedule pain medications around the clock rather than only when needed. These patients may have experienced the benefits of anticipating the pain and taking the pain medication on a regular schedule. Additional research is warranted to determine whether patients were taught to take their medications on a regular basis or if they developed this self-care strategy over time and with experience.

Interestingly, patients with lower least pain intensity scores and lower pain duration scores were more apt to believe that treatments other than pain medications can be effective in relieving pain. Alternative therapies had either proven to be effective in relieving the symptoms of pain in this patient group or they had not experienced severe pain. Patients who disagreed and did not believe that alternative therapies were effective reported higher least pain intensity scores and a greater duration of pain, suggestive that these approaches did not work, had not been tried, or despite the combination of medication and alternative treatments, pain was still not satisfactorily controlled. Additional research is warranted to examine these relationships more carefully.

Patients with higher daily pain intensity ratings, worst pain intensity ratings, higher average number of days in pain and higher average number of hours in pain indicated a stronger level of disagreement with the statement "patients are often given too much pain medication" perhaps because they had not been given enough pain medication to relieve their pain. This suggestion is supported by the relatively high pain intensity ratings as well as the significant duration of pain these patients were experiencing.

In summary, patients experiencing higher pain intensity scores and higher number of days in pain scored higher on the total knowledge score but continued to suffer from uncontrolled pain. Inadequate knowledge about dosing and scheduling of medications, and limited understanding of the concepts of physical dependence and addiction are worth noting and suggest a need to evaluate the effectiveness of patient teaching. The findings of this study further support the multidimensional model of pain and the relationship between the patient's pain experience (sensory) and knowledge about pain (cognitive).

Limitations

Several limitations of this study need to be acknowledged. Participants in this study were selected by the nursing staff at the outpatient sites. The results are based on the patient's self-report with no objective findings to verify pain complaints. In addition, analgesics or non-pharmacological measures to control pain were not controlled for. Some patients may have reported that they were pain-free or reported a lower pain intensity rating if they were using pharmacologic or non-pharmacologic measures to control their pain. Thus, these results may not be an accurate representation of the total sample of oncology outpatients experiencing cancer-related pain. An important limitation of this study is that the findings from this well-educated sample cannot be generalized to patients with less education. An additional limitation is that the sample was predominantly Caucasian so that the results cannot be generalized to other ethnic groups.

Implications for Practice

The findings of this study demonstrate that: pain is not being effectively controlled; patients continue to experience significant pain and are not receiving adequate symptom management; patients experiencing pain do not have the knowledge necessary to adequately control their pain; and education for patients experiencing pain is necessary for improved pain management. Healthcare providers need to develop more effective methods to provide the patient with information and tools to relieve pain, and better methods to evaluate the effectiveness of these interventions.

The results of this study suggest several areas where increased effort is needed to improve cancer pain control. Capitalizing on the patient's belief that pain can be effectively relieved may be an important aspect of patient education. A high priority in educating the patient should be in the areas of dosing and scheduling of medications. Information on side effects with specific information on addiction and dependency is warranted. Education about pain and its relief should begin early in the cancer continuum since pain is a common experience. Bonica (1985) suggests that between 50 to 70 percent of all cancer patients will experience pain at some point in time during the cancer trajectory.

Implications for Future Research

Based on the results of this study, additional areas of investigation would include:

1. An intervention study to determine the most effective way to educate oncology patients about pain and pain management.

2. Additional studies with patients from different ethnic populations and varying levels of education to determine their knowledge about pain and pain management.

3. Studies that determine the extent and type of knowledge deficits, negative attitudes, and cultural biases that keep patients from successful pain management.

4. Studies that correlate the patient's description of pain with that of the healthcare provider, identifying important discrepancies.

With a better understanding of the extent to which knowledge deficits, attitudes, culture, and characteristics of the pain are responsible for inadequate treatment of pain, we may be able to reduce the suffering related to cancer pain and its lack of control.

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Table I

Demographic Data on Patients with Cancer-Related Pain

Characteristics	Pain (n=200)		
	MEAN	SD	RANGE
AGE(years)	53.8	14.0	19-80
EDUCATION(years)	14.1	2.9	7-23
KARNOFSKY PERFORMANCE SCALE	78.1	13.8	30-100

	n	(%)
GENDER		
Female	116	58.0
Male	84	42.0
LIVES ALONE		
Yes	34	17.3
No	163	82.7
MARITAL STATUS		
Married/Partnered	129	64.8
Divorced	23	11.6
Never married	23	11.6
Widowed	14	7.0
Unmarried/live together	7	3.5
Separated	3	1.5
ETHNICITY		
Caucasian	176	88.0
Hispanic	7	3.5
Black	6	3.0
Mixed Ethnic Background	5	2.5
Asian/Pacific Islander	3	1.5
American Indian	2	1.0
Other	1	0.5

Table 1 (Continued)

Patient Demographic Data

Characteristics	**Pain** (n=200) n	(%)
EMPLOYMENT STATUS		
Disability	54	27.0
Retired	49	24.5
Full-time	44	22.0
Part-time	19	9.5
Homemaker	13	6.5
Self-employed	10	5.0
Unemployed due to pain	6	3.0
Unemployed/other reasons	5	2.5
CANCER DIAGNOSIS		
Breast	46	23.0
Colon/rectal	25	12.5
Lung	25	12.5
Prostate	13	6.5
Non-Hodgkins Lymphoma	13	6.5
Ovarian	12	6.0
Hodgkin's Lymphoma	10	5.0
Multiple Myeloma	8	4.0
Other	48	24.0
METASTATIC DISEASE		
Yes	138	70.4
No	58	29.6

Table 1 (continued)

Patient Demographic Data

Characteristic	**Pain** (n=200) n	(%)
METASTATIC SITES		
None	58	29.6
2 sites or more	41	20.9
Lymph nodes	29	14.8
Bone	21	10.7
Other	18	9.2
Liver	17	8.7
Peritoneum	7	3.6
Lung	4	2.0
Brain	1	0.5
CURRENT THERAPY		
Chemotherapy(CTX)	124	62.9
Radiation(XRT)	29	14.7
XRT & CTX	12	6.1
Hormonal((HRT)	11	5.6
Other	9	4.6
XRT & HRT	5	2.5
CTX & HRT	4	2.0
Biotherapy & CTX	2	1.0
Biotherapy	1	0.5
REASON FOR CURRENT THERAPY (Medical Record Review)		
Control	91	45.7
Cure	68	34.2
Palliation	37	18.6
Other	3	1.5
SURGICAL INTERVENTION		
Yes	121	68.4
None	56	31.6

Table 2

Types and Causes of Cancer-Related Pain

TYPE OF PAIN	n	(%)
Somatic	65	48.5
Deafferentation pain	37	28.4
Visceral	26	19.4
Somatic/deafferentation	5	3.7

CAUSE OF PAIN	n	(%)
Bone Metastasis	36	29.0
Post-surgical pain syndrome	28	22.6
Other	26	21.0
Pressure of thoracic and abdominal viscera	23	18.6
Mucositis from CTX	6	4.8
Infiltration of nerve root	5	4.0

Table 3

Description of Pain

DESCRIPTION	N	MEAN	STANDARD DEVIATION
Intensity			
Pain right now	138	2.2	2.2
Average daily pain	129	3.6	2.2
Current worst pain	131	6.4	2.5
Current pain at its least	130	1.6	1.8
Duration			
Days a week experiencing pain	141	4.2	2.8
Hours of day the pain lasts	133	9.2	9.1

Table 4

Knowledge Scores of Patients with Cancer-Related Pain and Ranking of the Correct Responses

Statement	Correct Response	Cancer Pain $\bar{X}$ ± S.E.M. (n)	Rank
1. Cancer pain can be effectively relieved.	Agree	79.1 ±2.8 (185)	#1
2. Pain medicines should be given only when pain is severe.	Disagree	69.6 ±2.8 (191)	#3
3. Addiction refers to a person's desire to use drugs for their psychic effects rather than for medical use of relieving pain. Most cancer patients on pain medicines will become psychologically addicted to the medicines over time.	Disagree	62.1 ±3.0 (184)	#4
4. Drug dependence means that a person would go through withdrawal if a pain medicine was stopped. Most cancer patients on pain medicine will become physically dependent on the medicines over time.	Agree	49.9 ±3.0 (187)	#7

* Scores are reported as means ±S.E.M. of correct responses (range 0 to 100) to the knowledge statements of the PES.

Table 4 (Continued)

Knowledge Scores of Patients with Cancer-Related Pain and the Ranking of the Correct Responses

Statement	**Correct Responses**	**Cancer Pain $\bar{X}$ ± S.E.M. (n)**	**Rank**
5. It is better to give the lowest amount of medicines possible early on so that larger doses will be available later if pain increases.	Disagree	23.2 ±2.4 (193)	#9
6. It is better to give pain medications around the clock (on a schedule) rather than only when needed.	Agree	33.7 ±2.9 (190)	#8
7. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.	Agree	78.6 ±2.3 (189)	#2
8. Pain medicines can often interfere with breathing.	Disagree	54.3 ±3.2 (160)	#6
9. Patients are often given too much pain medicine.	Disagree	60.3 ±3.0 (175)	#5

* Scores are reported as means ±S.E.M. of correct responses (range 0 to 100) to the knowledge statements of the PES.

Table 5
Relationship between Knowledge about Cancer-Related Pain and Selected Pain Characteristics

KNOWLEDGE SUBSCORE	PEARSON CORRELATION COEFFICIENT	p VALUE
NOW PAIN	0.05	NS
DAILY PAIN	0.21	<.03
WORST PAIN	0.16	NS
LEAST PAIN	0.03	NS
DAYS IN PAIN	0.24	<.009
HOURS IN PAIN	0.12	NS
QUESTION #1: CANCER PAIN CAN BE EFFECTIVELY RELIEVED.		
NOW PAIN	-0.25	<.004
DAILY PAIN	-0.25	<.005
WORST PAIN	-0.21	<.02
LEAST PAIN	-0.17	NS
DAYS IN PAIN	-0.19	<.04
HOURS IN PAIN	-0.13	NS
QUESTION #2: PAIN MEDICINES SHOULD BE GIVEN ONLY WHEN PAIN IS SEVERE.		
NOW PAIN	-0.07	NS
DAILY PAIN	0.07	NS
WORST PAIN	0.10	NS
LEAST PAIN	-0.05	NS
DAYS IN PAIN	0.20	<.02
HOURS IN PAIN	0.13	NS

Table 5 (continued)
Relationship between Knowledge about Cancer-Related Pain and Selected Pain Characteristics

QUESTION #3: ADDICTION REFERS TO A PERSON'S DESIRE TO USE DRUGS FOR THEIR PSYCHIC EFFECTS RATHER THAN FOR MEDICAL USE OF RELIEVING PAIN. MOST CANCER PATIENTS ON PAIN MEDICINES WILL BECOME PSYCHOLOGICALLY ADDICTED TO THE MEDICINES OVER TIME.

	PEARSON CORRELATION COEFFICIENT	p VALUE
NOW PAIN	-0.04	NS
DAILY PAIN	0.09	NS
WORST PAIN	0.02	NS
LEAST PAIN	0.01	NS
DAYS IN PAIN	-0.01	NS
HOURS IN PAIN	0.06	NS

QUESTION #4: DRUG DEPENDENCE MEANS THAT A PERSON WOULD GO THROUGH WITHDRAWAL IF A PAIN MEDICINE WAS STOPPED. MOST CANCER PATIENTS ON PAIN MEDICINE WILL BECOME PHYSICALLY DEPENDENT ON THE MEDICINES OVER TIME.

	PEARSON CORRELATION COEFFICIENT	p VALUE
NOW PAIN	0.09	NS
DAILY PAIN	0.05	NS
WORST PAIN	0.1	NS
LEAST PAIN	0.04	NS
DAYS IN PAIN	0.09	NS
HOURS IN PAIN	0.03	NS

Table 5 (continued)
Relationship between Knowledge about Cancer-Related Pain and Selected Pain Characteristics

QUESTION #5: IT IS BETTER TO GIVE THE LOWEST AMOUNT OF MEDICINES POSSIBLE EARLY ON SO THAT LARGER DOSES WILL BE AVAILABLE LATER IF PAIN INCREASES.

	PEARSON CORRELATION COEFFICIENT	p VALUE
NOW PAIN	0.08	NS
DAILY PAIN	0.08	NS
WORST PAIN	0.0001	NS
LEAST PAIN	-0.02	NS
DAYS IN PAIN	0.10	NS
HOURS IN PAIN	-0.07	NS

QUESTION #6: IT IS BETTER TO GIVE PAIN MEDICATIONS AROUND THE CLOCK (ON A SCHEDULE) RATHER THAN ONLY WHEN NEEDED.

	PEARSON CORRELATION COEFFICIENT	p VALUE
NOW PAIN	0.21	<.02
DAILY PAIN	0.21	<.02
WORST PAIN	0.18	<.05
LEAST PAIN	0.24	<.008
DAYS IN PAIN	0.28	<.001
HOURS IN PAIN	0.24	<.007

Table 5 (continued)
Relationship between Knowledge about Cancer-Related Pain and Selected Pain Characteristics

QUESTION #7: TREATMENTS OTHER THAN MEDICATIONS (SUCH AS MASSAGE, HEAT, RELAXATION) CAN BE EFFECTIVE FOR RELIEVING PAIN.

	PEARSON CORRELATION COEFFICIENT	p VALUE
NOW PAIN	-0.12	NS
DAILY PAIN	-0.09	NS
WORST PAIN	0.04	NS
LEAST PAIN	-0.22	<.02
DAYS IN PAIN	-0.11	NS
HOURS IN PAIN	-0.18	<.05

QUESTION #8: PAIN MEDICATIONS CAN OFTEN INTERFERE WITH BREATHING.

	PEARSON CORRELATION COEFFICIENT	p VALUE
NOW PAIN	-0.02	NS
DAILY PAIN	0.14	NS
WORST PAIN	0.14	NS
LEAST PAIN	0.07	NS
DAYS IN PAIN	0.01	NS
HOURS IN PAIN	0.01	NS

Table 5 (continued)
Relationship between Knowledge about Cancer-Related Pain and Selected Pain Characteristics

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QUESTION #9: PATIENTS ARE OFTEN GIVEN TOO MUCH PAIN MEDICINE.

	PEARSON CORRELATION COEFFICIENT	p VALUE
NOW PAIN	0.15	NS
DAILY PAIN	0.23	<.02
WORST PAIN	0.18	<.05
LEAST PAIN	0.09	NS
DAYS IN PAIN	0.19	<.04
HOURS IN PAIN	0.20	<.03

Appendix A

DEMOGRAPHIC QUESTIONNAIRE

(patient information)

PATIENT INFORMATION

---

1. Your Age: ____

2. ____ Female ____ Male

3. Do you live alone? ____ Yes ____ No

4. What is your current marital status?

   ____ Married/Partnered
   ____ Widowed
   ____ Divorced
   ____ Separated
   ____ Never Married
   ____ Not married but living together

5. Circle the highest grade or year you completed in regular school, vocational school, college, or graduate professional training?

   Grade School
   1 2 3 4 5 6 7 8
   High School
   9 10 11 12
   College
   13 14 15 16
   Graduate School
   17 18 19 20 21 22 >22

6. Circle the number that best describes your ethnic group:

   1 American Indian
   2 Asian or Pacific Islander
   3 Black
   4 Caucasian/White
   5 Eurasian
   6 Hispanic
   7 Mixed Ethnic Background
   8 Other (specify)____________

7. What is your current employment status?

   ____ Full-time
   ____ Part-time
   ____ Self-employed
   ____ Homemaker
   ____ Retired
   ____ Unemployed due to pain
   ____ Unemployed for other reasons
   ____ Disability

8. What is the purpose of your present cancer treatment?

   ____ Cure my disease
   ____ Control my disease
   ____ Don't know the purpose
   ____ Treat the symptoms associated with my disease
   ____ Other (specify) ____________

ID Number__________

MEDICAL RECORD REVIEW

(Pain Survey)

Date of Diagnosis: ______/_____/19____

Please circle the number or numbers to indicate your answers to the following:

Diagnosis:

1 Breast
2 Colon
3 Head & Neck
4 Hodgkins
5 Acute Leukemia
6 Lung
7 Malignant Melanoma
8 Non-Hodgkins Lymphoma
9 Ovarian
10 Prostate
11 Other (specify) __________
____

Metastatic Sites:

1 None
2 Bone
3 Brain
4 Liver
5 Lung
6 Lymph Nodes (______/______)
7 Peritoneum
8 Other (specify)
____

Previous Therapy:

1 Surgery
2 XRT
3 Chemotherapy
4 Biotherapy
5 Hormonal Therapy

Type of Surgery:

1 None
2 Mastectomy
3 Nephrectomy
4 Radical Head/Neck
5 Thoracotomy
6 Other ____________________

Current Therapy:

1 XRT
2 Chemotherapy
3 Biotherapy
4 Hormonal Therapy

Reason for Current Therapy:

1 Cure (including adjuvant)
2 Control
3 Palliation
4 Other ______________________________

Has the patient ever received any of the following drugs as part of their chemotherapeutic protocol (do not include the decadron given to prevent nausea)?

1 Steroids (Prednisone, Decadron)
2 Vincristine
3 Vinblastine (Velban)
4 Vindesine

Appendix C

PATIENT PAIN EXPERIENCE SCALE

PAIN EXPERIENCE SCALE

Below are a number of statements about cancer pain and pain relief. Please make an X on the line to indicate your response.

Your Understanding of Pain

1. Cancer pain can be effectively relieved.

   disagree ______________________________ agree

2. Pain medicines should be given only when pain is severe.

   disagree ______________________________ agree

3. Addiction refers to a person's desire to use drugs for their psychic effects rather than for medical use of relieving pain. Most cancer patients on pain medicines will become psychologically addicted to the medicines over time.

   disagree ______________________________ agree

4. Drug dependence means that a person would go through withdrawal if a pain medicine was stopped. Most cancer patients on pain medicines will become physically dependent on the medicines over time.

   disagree ______________________________ agree

5. It is better to give the lowest amount of medicines possible early on so that larger doses will be available later if pain increases.

   disagree ______________________________ agree

6. It is better to give pain medications around the clock (on a schedule) rather than only when needed.

   disagree ______________________________ agree

7. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.

   disagree ______________________________ agree

8. Pain medicines can often interfere with breathing.

disagree ____ agree

9. Patients are often given too much pain medicine.

disagree ____ agree

10. Have you had cancer-related pain in the past month? ____ Yes ____ No

Appendix D

KARNOFSKY PERFORMANCE SCALE

KARNOFSKY PERFORMANCE STATUS

Description	Percentage (%)	
Normal, no complaints	100	Normal Activity: Fully Ambulatory
Able to carry on normal activities; minor signs or symptoms of disease	90	
Normal activity with effort	80	
Cares for self; unable to carry on normal activity or to do active work	70	Self-Care: Partially Ambulatory
Requires occasional assistance, but able to care for most of his/her needs	60	
Requires considerable assistance and frequent medical care	50	
Disabled; requires special care and assistance	40	Incapacitated: Non-Ambulatory
Severely disabled; hospitalization indicated though death not imminent	30	
Very sick; hospitalization necessary; active supportive treatment necessary	20	

Appendix E

DESCRIPTIVE NUMERIC RATING SCALES OF PAIN

5. Your current cancer-related pain intensity:

Pain Scale

0	1	2	3	4	5	6	7	8	9	10
none		mild			moderate			severe		excruciating

a. Choose the number from the scale above which best describes your degree of cancer-related pain for each of the following, and place it in the space provided:

_______ your pain right now
_______ your current average daily pain
_______ your current pain at its worst
_______ your current pain at its least

b. How many days out of a typical week do you currently experience significant cancer-related pain (pain that interferes with your mood and/or activities)?

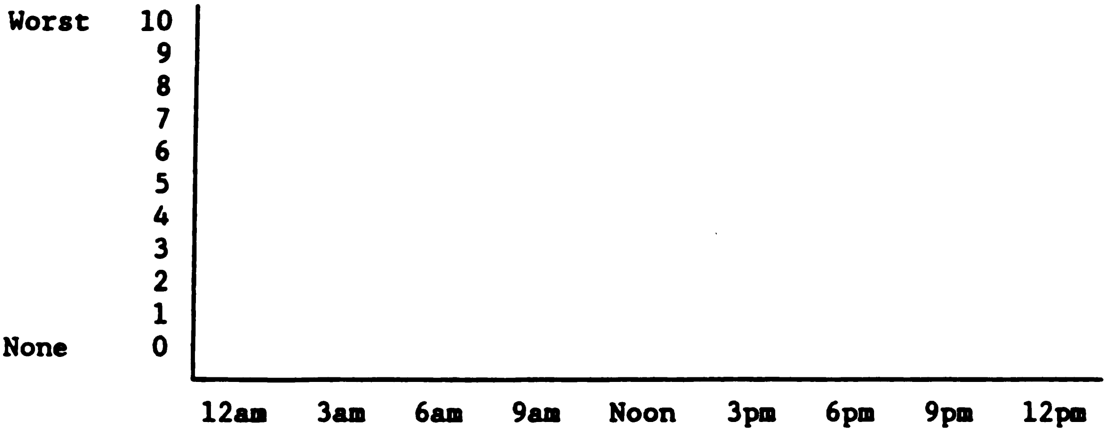
_______ (enter how many days -- 0 to 7)

c. On those days where you have significant cancer-related pain, how many hours of the day does it currently last?

_______ (enter how many hours -- 0 to 24)

6. How does your cancer-related pain change during a typical day? On the graph below, for each time of day indicate the severity of your pain (10 indicates the worst pain you have ever had).

PAIN INTENSITY



Appendix F

CONSENT TO BE A
RESEARCH SUBJECT

CHR APPROVED
JUL 12 1991
APPROVAL EXPIRES
5/15/92

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
DEPARTMENT OF PHYSIOLOGICAL NURSING
CONSENT TO BE A RESEARCH SUBJECT
(PATIENT)

A. PURPOSE AND BACKGROUND:

Christine Miaskowski, R.N., Ph.D. and Suzanne Dibble, R.N., D.N.Sc. and their associates are conducting a study to learn about cancer related and non-cancer related pain and its effects on adult ambulatory cancer patients and their caregivers. Because I am being treated for cancer, I am being asked to participate in this study.

B. PROCEDURES:

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

1. I will be asked to identify a caregiver who comes to the clinic/doctor's office with me, and this person will also be asked to participate in this study.

2. One of the investigators or their nurse associates will ask me to respond to questionnaires about my health and any pain I may have experienced. It will take approximately 60 minutes to complete these questionnaires.

3. If I have experienced any pain, the investigator or nurse associate will ask me to respond to another questionnaire packet about the pain. I can complete these questionnaires in the clinic/doctor's office, or I can take it home to complete and to bring back at my next appointment. It will take approximately 45 minutes to complete this questionnaire packet.

4. The investigators or their associates will check my medical records to gather information about my cancer and its treatment and any health problems I may have experienced.

C. RISKS/DISCOMFORTS:

1. Participation in research may result in a loss of privacy; however, study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from this study. Study information will be coded and kept in locked files at all times. Only the investigators will have access to the files.

2. Participation in this study will not interfere with my appointment, but it may add on time to the visit. To minimize this time, if I am asked to complete the second questionnire, I may take it home to complete there and return it during my next appointment.

3. Some of the questions on the questionnaires may make me uncomfortable or upset, but I am free to decline to answer any questions I don't wish to.

D. BENEFITS:

There may be no direct benefit to me from participating in this study. It is hoped that the information gained from the study will help with the identification and treatment of pain in future cancer patients.

E. ALTERNATIVES:

If I choose not to participate in this study, I will receive all my regular care, but I would not need to answer the questionnaires.

F. COSTS:

There will be no costs to me as a result of taking part in the study.

G. REIMBURSEMENT:

I will not be reimbursed for participating in this study.

H. QUESTIONS:

This study has been explained to me by Dr. Miaskowski or ________________________ and my questions were answered. If I have other questions about the study, I may call Dr. Miaskowski at (415) 476-9407, Dr. Dibble at (415) 476-5685, or

____________________________ at ____________________.

I. CONSENT:

I have been given copies of this consent form and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I have the right to decline to participate or to withdraw at any point in this study without jeopardy to my nursing or medical care.

If I wish to participate, I should sign below:

________________	________________________________	______________________
Date	Subject's Signature	Telephone Number
________________	________________________________	
Date	Witness' Signature	

PAIN/CONS
6/26/91

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 benefits 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.

Appendix G

SELF-REPORT PAIN
QUESTIONNAIRE

In the past *month*, have you experienced pain related to your cancer or cancer treatment?

____ Yes ____ No

In the past *month*, have you experienced pain from a cause other than your cancer or cancer treatment?

____ Yes ____ No

PLEASE RETURN THIS QUESTIONNAIRE TO YOUR NURSE WHEN COMPLETED.

If you answered YES to either or both of the above questions, your nurse will give you an additional questionnaire to complete. Please complete these questionnaires now or bring them back at your next scheduled appointment.