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The Experience of Cancer Pain and Barriers to Cancer Pain Management in a
Community Sample of Chinese American Cancer Patients

by

Janet Edrington, RN, MS

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

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It is great pleasure and immense gratitude that I acknowledge the help and support many people have given me in pursuing my graduate studies. Dr. Christine Miaskowski, who is my advisor, my mentor, my role model, and the chair of my defense committee, inspired me to continue on in search of possible answers to my questions about the care of vulnerable patients. Dr. Marylin Dodd first challenged me to not settle for the easy answers, but to probe more deeply into the symptoms of cancer patients. Dr. Candice Wong carefully and patiently guided me through the maze of problems associated with including minority ethnic groups in nursing research. Dr. Geraldine Padilla helped me understand many of the issues associated with the care of vulnerable patients. I would also like to acknowledge Drs. Steve Paul and Bruce Cooper for their help with statistical analyses. In addition, I am very appreciative for the dedication and commitment of my translation committee: Josephine Wong, Dr. Horning Wu, Lih Mih Chen, and Yuaner Wu. Additionally, with humility and gratitude, I would like to acknowledge the enormous support I received from the people at the Chinese Community Health Resource Center: Angela Sun, Cecilia Pang, and Kitty Wong. Without their collaboration, commitment, and knowledge this project would not have occurred. Finally, I would like to acknowledge the incredible support I received from the patients who participated in this study, who trusted me with their stories, who allowed me into their homes to record their experiences and thoughts about cancer pain, and who were committed to helping health care professionals better their understanding of the experience of cancer pain in Chinese American patients.

The Experience of Cancer Pain and Barriers to Cancer Pain Management in a
Community Sample of Chinese American Cancer Patients

Janet Edrington

Abstract

Approximately 3 million Chinese Americans live in the United States. While cancer rates are lower in the Asian population compared to the white, non-Hispanic population, certain cancer rates (i.e., liver, lung, stomach) are higher in the Chinese population. Pain is a common and persistent problem in cancer patients. However, to date no studies have evaluated the experience of cancer pain in Chinese American patients. McGuire's Multidimensional Model of cancer pain (e.g., physiologic, sensory, affective, cognitive) served as the theoretical framework for this study.

Purposes of this dissertation research, in a community sample of Chinese American patients with cancer pain, were: to describe the experience of cancer pain; to examine patient barriers to cancer pain management; and to describe the relationships between various aspects of the pain experience and patient barriers to their acculturation level.

This descriptive correlational study recruited a convenience sample of patients from three community settings in Northern California. Patients completed six self-report questionnaires on their pain severity, pain interference with function, barriers to pain management, mood disturbances, acculturation levels, and pain treatments.

Patients reported moderate to severe levels of worst pain; that pain interfered with many of their activities of daily living; as well as moderate levels of depression and anxiety. Barriers to cancer pain management reported most frequently included: concerns

about tolerance, dosage of pain medication, disease progression, and addiction. Patients with higher levels of depression, more years of education, inadequate analgesic prescription, and stronger Asian identification reported significantly higher barrier scores. A stronger Asian identification was associated with higher least and worst pain intensity scores, with higher pain interference scores, and with higher barrier subscales scores for tolerance and dosage concerns. Finally, 60% of the patients were receiving inadequate treatments for their cancer pain.

Cancer pain was found to be inadequately treated in Chinese American cancer patients. Better assessment of pain is needed for Chinese American cancer patients. Health care providers need to assess patients' concerns about pain management and the treatments they use for their pain.

(word count: 332)

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Introduction

The body of this dissertation consists of three papers. The first paper, “A Review of the Literature on the Pain Experience of Chinese Patients With Cancer”, synthesized and critiqued studies on the pain experience of Chinese patients with cancer. The literature review identified twenty-four studies that documented the experience of cancer pain in Chinese cancer patients in countries other than the United States. The multidimensional model of cancer pain (i.e., physiologic, sensory, behavioral, affective, cognitive, and sociocultural dimensions) was used as the theoretical framework for this review. This approach allowed for a more complete evaluation of the various aspects of the cancer pain experience. Only three dimensions were evaluated in the majority of the studies (i.e., physiologic, sensory, behavioral; 23 studies, 22 studies, 17 studies, respectively). The majority of the studies (n=15) reported on cancer patients with late stage disease. Most of the studies (n=19) reported that increased pain intensity levels interfered with patients’ activities of daily living and with their mood.

Across these studies, Chinese cancer patients reported moderate to severe levels of pain (i.e., pain ≥ 5 on a 0 (no pain) to 10 (worst pain imaginable) NRS scale). Nine studies reported on patient barriers to cancer pain management. The most common barriers were concerns about drug addiction, disease progression, tolerance, and dosage intervals. Seven studies reported on mood disturbances associated with cancer pain. In general, patients with higher pain intensity scores had higher anxiety and depression scores.

The second paper, “Relationships Among the Cancer Pain Experience, Acculturation, and Mood Disturbances in a Community Sample of Chinese American

Patients With Cancer” described the cancer pain experience (i.e., pain severity, pain locations, pain interference with function, pain relief adequacy of the analgesic prescription) of a community sample of Chinese American patients with cancer. In addition, relationships between two pain characteristics (i.e., intensity, interference) and demographic characteristics, performance status, analgesic prescription, and mood disturbances (i.e., depression, anxiety) were examined; and the relationship between pain characteristics and patients’ level of acculturation was examined. Findings from this study suggest that a high percentage of Chinese American cancer patients are undertreated for their pain. The mean pain intensity scores were 4.4 ± 1.9 for pain now; 2.9 ± 1.7 for least pain; 4.2 ± 1.8 for average pain; and 5.8 ± 2.3 for worst pain. Approximately 60% of these patients in our study were inadequately treated for their cancer pain based on their Pain Management Index scores.

In addition, patients with higher pain scores reported a poorer functional status and patients with higher levels of pain interference reported more anxiety and depression. Finally, less acculturated patients had significantly higher least and worst pain scores.

The third paper, “Barriers to Pain Management in a Community Sample of Chinese American Patients With Cancer” examined patients’ perceived barriers to cancer pain management. Chinese American patients reported moderately high barrier scores. The four highest scored barriers were tolerance, time intervals for dosages of pain medicine, disease progression, and addiction. These rankings are almost identical to those reported by Taiwanese cancer patients but markedly different from White Americans.

In addition, this study examined the relationships between these perceived barriers and patients’ pain characteristics (i.e., pain severity, pain interference with

function), mood disturbances, and acculturation to determine possible predictors of patients' perceived barriers to cancer pain management. Findings from this study suggest that patients with more education, with more Asian identification, with more depression, and with inadequate pain treatment reported more barriers to cancer pain management.

These studies are the first to examine the cancer pain experience of Chinese American patients, as well as their perceived barriers to cancer pain management. Findings from this study may help to identify Chinese American cancer patients who are at increased risk for undertreatment of their pain and may facilitate the development of more culturally appropriate psychoeducational interventions to improve the management of cancer pain in this vulnerable patient population.

A Review of the Literature on the Pain Experience of Chinese Patients with Cancer

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Abstract

Over 2 million new cases of cancer are diagnosed annually in China. In addition, cancer is the leading cause of death in China. Because cancer is often diagnosed in more advanced stages in China, a higher percentage of patients will experience pain related to their disease or treatment. This paper presents a review and critique of the studies that examined the experience of pain in Chinese cancer patients. Because pain is a subjective experience with multiple dimensions, this review used the multiple dimensions of cancer pain to describe the pain experience in adult Chinese patients with cancer. The results from 24 studies of cancer pain in Chinese patients are summarized. Most of these descriptive correlational studies evaluated the physiologic and sensory dimensions of the pain experience. The majority of the patients reported moderate to severe pain and that pain interfered with their normal activities and mood. In contrast, little information is available about the impact of cancer pain on the cognitive and sociocultural dimensions of the pain experience for Chinese patients.

Introduction

Unrelieved cancer pain is experienced by 30% to 70% of patients with cancer and is even more prevalent in patients with advanced stage disease.¹ Minority groups, when compared to white Americans, often receive less than optimal cancer pain management.² ³ In a study of patients with pain from metastatic cancer, minority patients were found to be at two times greater risk for inadequate pain management.⁴ However, while the study compared cancer pain treatment for African American, Hispanic, and non-Hispanic white cancer patients, it did not include Chinese cancer patients.⁴

Most of the studies that examined the prevalence of cancer pain have been done in Western countries. Only three studies³⁻⁵ have reported on differences in cancer pain and its management among African, Hispanic, and white Americans. To date, no studies have reported on cancer pain in adult Chinese American cancer patients. However, a number of studies from mainland China have provided information on the pain experience of Chinese patients with cancer. Therefore, the purposes of this paper are to provide a review and critique of the literature on the pain experience of Chinese patients with cancer. This review is structured using the multiple dimensions of the cancer pain experience (i.e., physiologic, sensory, affective, behavioral, cognitive, and sociocultural components) suggested by McGuire.⁶

Background

Cancer in Chinese Patients

Cancer is the leading cause of death in China. In 2002, 2.2 million new cases of cancer were diagnosed (1.4 million in men and 0.8 million in women).⁷ The majority of patients in China are diagnosed with late stage disease. Stomach, lung, and liver cancers

are the most common sites in Chinese men, while breast, lung, and stomach cancers are the most common sites in women.⁸

Dietary factors, bacterial/viral infections, and chemical factors often act synergistically to cause cancer in humans. The traditional Chinese diet is often high in salty, fermented foods; many areas of China have poor food storage practices; and the presence of helicobacter pylori bacteria in the drinking water are believed to contribute to the high incidence of stomach cancer in China.^{9, 10}

China has approximately 320 million smokers, which may contribute to the high incidence of lung cancer.¹¹ By 2025, it is estimated that China will have two million deaths from lung cancer and other smoking-related diseases.¹¹ Liver cancer is also common in China, perhaps due to the high incidence of hepatitis-B infection and aflatoxin consumption and the presence of a codon mutation on the p53 tumor suppressor gene in its population.^{11, 12} However, as China undergoes economic development, the incidence and mortality of more “western cancers” (e.g., colorectal, prostate, breast) are expected to increase dramatically.¹¹

Chinese American men have a higher incidence of cancer in the oral cavity, pharynx, nasopharynx, esophagus, stomach, liver, and gallbladder, compared with white, non-Hispanic men in the United States. Chinese American women have a greater incidence of cancer in the oral cavity, pharynx, nasopharynx, stomach, liver, and cervix, compared with the white, non-Hispanic women in the United States.¹³

Methods

Using the search terms cancer pain, symptoms, Chinese, pain barriers, performance status, anxiety, depression, and acculturation, PubMed®, PsychInfo, and

Google Scholar searches were conducted, for the years 1966 to 2005, for all research, published in English, that evaluated the multiple dimensions of the cancer pain experience (i.e., physiologic, sensory, affective, cognitive, behavioral, sociocultural) in adult Chinese patients, in adult Chinese American patients, and in adult Chinese immigrants. A literature search and a review of the reference lists from the studies identified the twenty-four studies that were used in this review.¹⁴⁻³⁷

This literature review and critique is organized using the six domains of the cancer pain experience (i.e., physiologic, sensory, behavioral, affective, cognitive, sociocultural) developed by McGuire⁶ (Table 1). This approach allowed for an exploration of the depth and breadth of the pain experience in Chinese patients with cancer, which is particularly important since very little is known about the experience of cancer pain in this population.

Within each of the individual dimensions of the cancer pain experience, the various studies are evaluated in terms of their designs and methods. The findings from each study are evaluated in terms of their contribution to our knowledge about cancer pain in Chinese patients. The paper concludes with a discussion of directions for future research.

Dimensions of the Cancer Pain Experience

Physiologic dimension

The physiologic dimension of the cancer pain experience is primarily concerned with the organic etiology of the pain (e.g., bone metastases), the duration of the pain (i.e., acute or chronic), and the pattern of the pain (e.g., brief, momentary, or transient; continuous, steady or constant).^{6, 38, 39, 40} In patients with cancer, the occurrence of pain

may be associated with the patient's stage of disease. Of note, Chinese patients with potentially curable diseases (e.g., cervical cancer, breast cancer, prostate cancer, colorectal cancer) are more likely to be diagnosed with progressive or advanced stage cancer than non-Hispanic white cancer patients, and, therefore, are more likely to experience cancer pain at diagnosis.^{13, 40, 41}

Nineteen of the twenty-four studies on cancer pain in Chinese patients described the stage of the patients' disease (Table 2). The two studies, that examined quality of life issues in Chinese patients newly diagnosed with gastrointestinal cancer, had metastatic cancer as an exclusion criterion for participants.^{35, 36} One study recruited only participants with localized cancer.¹⁴

In general, the studies that included stage of disease as a variable found that a large percentage of the patients (between 48% and 100%) with advanced stage disease reported moderate to severe levels of pain (worst pain levels ≥ 5 on a scale where 0 indicates no pain and 10 indicates worst pain imaginable). Patients with regional or distant metastasis were at greater risk for higher worst pain scores than patients with localized disease.¹⁷ Cancer patients with localized disease reported mild levels of pain intensity (i.e., ≤ 3 on a 0 to 10 scale).¹⁴ Three studies did not report cancer sites.^{20, 28, 37} The National Cancer Institutes' Surveillance, Epidemiology, and End Results (SEER) method was used in two studies to determine the stage of the patients' cancer.^{17, 18}

Twenty-one studies reported the site of the cancer (Table 3). The most frequently reported cancer sites were lung, breast, gastrointestinal, liver, head and neck, colorectal, gynecologic, and nasopharyngeal.

The etiology of the cancer pain was reported by Wang *et al.* who identified the primary causes of pain as bone (36%), visceral (29%), and pleuritic (24%), while 39% of patients had pain from multiple causes.³² Sze *et al.* identified the primary causes of cancer pain as nociceptive (66%), visceral (10%), or neuropathic (10%).²⁹ Patients with gastrointestinal cancer (56%), breast cancer (54%), and lung cancer (45%) reported moderate to severe levels of cancer pain (i.e., ≥ 5 on a 0 to 10 scale).²⁹ Bone pain was identified as the primary reason for pain in a study where the major metastatic sites were bone, lung, and liver (27%, 17% and 17% of the sample, respectively).³¹ In a study by Yu *et al.*, 40% of the patients had bone pain, 24% had visceral pain, and 26% had neuropathic pain, but the location of their cancer was not reported.³⁷ No study reported on the relationship between the type of pain and pain severity.

Sensory dimension

The sensory dimension of the cancer pain experience encompasses how the pain actually feels to the individual with the pain (e.g., intensity, location, pain quality).⁶ Twenty-two studies examined pain intensity levels in Chinese cancer patients. Twelve studies reported pain intensity levels using ratings of worst, average, least, and present pain intensity.^{15, 17-20, 22-26, 31, 37} Pain was categorized as mild, moderate, or severe in seven studies.^{28-30, 32-34, 37} One study reported mean pain intensity levels at two time intervals (i.e., baseline and at 6 months).¹⁶ Two studies reported an overall mean pain intensity score.^{35, 36} Two studies did not report pain intensity levels.^{16, 27}

Sixteen studies used a translated version (i.e., Chinese) of the Brief Pain Inventory (BPI).^{14, 17-20, 22-26, 28, 30-32, 37} Two studies used a Visual Analogue Scale (VAS);^{29, 34} two studies used a Numeric Rating Scale (NRS) similar to the BPI;^{15, 21} two studies

used a translated version of the Memorial Symptoms Assessment Scale (MSAS);^{35, 36} and one study used a translated version of the M.D. Anderson Symptom Inventory, Chinese version (MDASI-C), to assess pain intensity.³³

The studies that used a translated version of the BPI reported a total mean worst pain intensity score of 5.9 (SD=3.24) (where 0 indicates no pain and 10 indicates worst pain imaginable); a total mean average or “typical” pain intensity of 3.7 (SD=2.24); and a total mean present pain intensity of 2.7 (SD=2.42). Similar results were obtained when the VAS was used to assess pain intensity. Sze *et al.* found that 85% of the patients (N=70) reported moderate to severe levels of pain.²⁹ However, when Wills & Wootton used the VAS to assess pain intensity in a study with a smaller sample size (N=48), 40% of the patients rated their pain as mild to moderate, while 33% of the patients rated their pain as moderate to severe.³⁴ It should be noted that Wills & Wootton had three patients rate their pain as extremely severe (100 mm on a scale that ranged from 0 mm to 100 mm). While in the study by Sze *et al.*, a large portion of the patients (83%) had metastatic cancer, the study by Wills and Wootton did not report patients’ stage of disease, which may account for the differences between the two studies.

One study used the Chinese version of the M.D. Anderson Symptom Inventory (MDASI) to measure symptom severity in patients with cancer (N=249).³³ Using a numeric rating scale of 0 to 10 (where 0 indicates no pain and 10 indicates worst pain imaginable), patients’ overall mean pain intensity score was 3.2 (SD=2.8). Of note, more severe levels of pain were reported by patients with lung cancer, gastrointestinal cancer, and breast cancer (25%, 20%, and 17%, respectively, reported pain that ranged from 7 to 10).³³

Two studies used the Memorial Symptoms Assessment Scale (MSAS) to assess the severity and frequency of symptoms.^{35, 36} A repeated measures design was used, with a six month interval between Time 1 and Time 2, to examine the stability of symptoms across time in Chinese cancer patients (N=146). The mean pain severity score was 1.80 (SD=0.84), on a 4-point scale (where 1 indicates slight pain and 4 indicates severe pain). Pain was more prevalent at baseline than it was six months later (i.e., 45% and 27% of patients, respectively, reported pain). However, patients with metastatic cancer and with recurrent cancer were excluded from the study, which may account for the lower pain severity scores compared to other studies.

Behavioral dimension

The behavioral dimension of the cancer pain experience relates to the behaviors that an individual with pain uses (e.g., level of activity, communication) either to decrease pain (e.g., treatment interventions) or to indicate the presence of pain (e.g., limping, stiffness, body guarding).⁶ Often these behaviors will increase as pain severity increases and will decrease as pain lessens. No studies were found that reported on the pain behaviors of Chinese patients with cancer.

Cancer pain may also interfere with patients' abilities to perform daily activities and with their ability to function. Seventeen studies examined pain interference and performance status as components of the behavioral dimension of cancer pain in Chinese patients.^{14, 15, 17-20, 22- 26, 28- 30, 32, 36}

Pain interference

A Chinese version of the pain interference scale from the BPI was used to assess the effects of pain on patients' functional abilities (i.e., general activity, walk, enjoying

life, mood, sleep, work, and relations with others). Patients with more severe pain reported more interference with various activities. Patients whose pain interference ratings were different from the pain interference ratings of their family caregivers had higher pain interference scores than patients whose ratings were similar to the ratings of their family caregivers.²³

One study used the Chinese version of the Barthel ADL Index (BI), which measures 10 activities of daily living, to determine pain interference levels (N=70).²⁹ Approximately 65% of the patients (n=45) had moderate to severe interference (a score that ranged from 50 to 75) with the performance of activities of daily living, and 85% of the participants (n=59) reported moderate to severe pain. However, the correlations between pain severity and interference with activities of daily living were not reported.²⁹ One study reported that pain interference scores were significantly different ($p<0.001$) when patients (N=412) rated their pain as mild compared to moderate or severe, although the pain interference subscale scores were not reported.³⁷

Performance/functional status

Seven studies reported on the performance or functional status of Chinese patients with cancer pain.^{15, 17, 18, 23, 25, 30, 33} Two studies used the Karnofsky Performance Status (KPS) scale to measure functional status (N=203 and N=484; mean KPS=79.41 (SD=12.85) and 71.90 (SD = 18.1), respectively).^{15, 25} Pain was found to significantly impact patients' self-care ability. Patients with pain had poorer KPS scores than those without pain. Furthermore, patients with better functional status had significantly lower levels of anxiety ($r = -0.45, p<0.001$) and depressive symptoms ($r = -0.51, p<0.001$) than pain-free patients.¹⁵

Five studies used the Eastern Cooperative Oncology Group-Performance Status rating (ECOG-PSR) to measure functional status in Chinese patients with cancer pain.^{16, 17, 22, 29, 32} Higher scores on the ECOG-PSR (which indicates poorer functional status) and stage of disease were found by Ger *et al.* (N=296 and N=534) to be significant predictors of pain severity ($p<0.01$).^{17, 18} In addition, Wang *et al.* found that higher ECOG-PSR scores (≥ 2) were associated with severe pain (i.e., pain score ≥ 7).³⁰ In a more recent study, Wang *et al.* (N=249) found that higher ECOG-PSR scores were significant predictors of pain interference ($p<0.05$) and were strongly associated with symptom burden ($p<0.001$).³³

One study by Lin (N=178)²³ that compared patients' and family caregivers' reports of patient's pain and grouped dyads into those patients and family caregivers whose pain ratings were similar (congruent) and those patients and family caregivers whose pain ratings were different (non-congruent), found that patients in the non-congruent dyads experienced poorer performance status than patients in the congruent dyads. In general, patients with more severe pain had greater pain interference and poorer performance status. Higher pain severity scores were associated with poorer levels of function. However, functional status in patients with mild or well-controlled pain did not differ significantly from patients without pain.³²

Affective dimension

The affective dimension of the cancer pain experience is concerned with the effect of the pain on the individual's feelings. For example, cancer pain may have an effect on an individual's mood, outlook, sense of well-being, and other emotional states. Affective factors that are often associated with cancer pain include mood changes (e.g., depression,

anxiety, anger, fear).⁶ These affective changes can be a major source of suffering or distress for cancer patients and can pose significant pain management problems.^{42, 43} In addition, affective factors are a component of one's thought processes, which may be defined by one's culture and traditions.

In the Chinese culture and in traditional Chinese medicine, the mind, body, spirit, and nature are seen as united and interrelated.⁴⁴ Eastern philosophies of Buddhism, Taoism, and traditional Chinese medicine adopt a holistic conceptualization of an individual and his or her environment. Health is perceived as a harmonious equilibrium that exists between the interplay of 'yin' and 'yang', which are the five internal elements (i.e., metal, wood, water, fire, and earth), the six environmental conditions (i.e., dry, wet, hot, cold, wind, and flame), other external sources of harm (i.e., physical injury, insect bites, poison, overeating, and overworking), and the seven emotions (i.e., joy, sorrow, anger, worry, panic, anxiety and fear). For Chinese patients with cancer, interventions that integrate the mind, body, and spirit have resulted in significant improvements in patients' physical health, mental health, sense of control, and social support.⁴⁵

Seven studies reported on the affective dimension of the cancer pain experience in Chinese patients.^{15, 19, 25, 27, 29, 35, 36} Two studies used the Chinese version of the Hospital Anxiety and Depression Scale (HADS-C) to measure anxiety and depression in Chinese patients with cancer pain.^{15, 29} Only one study found a relationship between pain intensity and depression levels.¹⁵ When compared to Chinese patients without cancer pain, patients with pain had significantly higher anxiety ($p < 0.01$) and depression ($p < 0.01$) scores than pain-free patients. The prevalence of anxiety was significantly higher in Chinese patients with cancer pain ($p < 0.001$) compared with Chinese patients without pain. In addition, a

significant correlation was found between anxiety and functional status ($p < 0.0001$), such that patients with pain who had higher levels of anxiety reported poorer functional status.¹⁵

Although Sze *et al.* found probable depression (HADS-C scores ranged from 8 to 10) in 49% of their patients and definite depression (HADS-C score ≥ 11) in 29% of their patients with advanced cancer, they did not find statistically significant correlations between depression and pain intensity scores.²⁹

Two studies used the Chinese versions of the Spielberger State Anxiety Inventory (SSAI-C) to measure anxiety levels and the Beck Depression Inventory (BDI-C) to measure depression levels over time (six months) in Chinese patients with cancer pain.^{34,}

³⁵ One study examined symptoms (e.g., cancer pain) and psychological distress (i.e., anxiety and depression) in Chinese patients with newly diagnosed gastrointestinal cancer and found that 28% of the patients had mild to moderate depression and 2% had severe depression.³⁵ The other study examined the overall quality of life of Chinese cancer patients over a six month period and found the number of patients who reported pain decreased significantly over the six-month period ($p < 0.01$).³⁴ While anxiety scores were similar between Time 1 and Time 2, depression scores increased significantly from baseline to six months later ($t = -2.79$, $df = 106$, $p < 0.01$). This pattern suggests that patients' anxiety levels change very little over time, whereas levels of depression increase over time.³⁴

Two studies used the Chinese version of the Profile of Mood States (POMS-C) to measure mood disturbances in Chinese patients.^{25, 27} The studies found impairment in total mood disturbance (TMD) and high scores in depression, anger, and tension in

Chinese patients with cancer pain. Lin *et al.* (N=484) compared the effect of cancer pain on mood states in Taiwanese patients with and without cancer pain and found that patients with pain reported significantly higher levels of total mood disturbance ($p<0.01$) when compared with patients without pain, even after controlling for gender and stage of disease variables.²⁵ In addition, patients with pain scored significantly higher on the depression, anger, fatigue, confusion, and vigor subscales of the POMS ($p<0.01$) when compared to those without pain. In the study by Molassiotis *et al.*, depression accounted for 45% of the variance in quality of life in Chinese women with gynecological cancers (N=62).²⁷

One study used the Chinese version of the Geriatric Depression Scale, Short Form (GDS-SF) to assess depression in elderly (≥ 65 years of age) Chinese patients with cancer pain (N=70). Forty-one percent of the elderly patients with cancer pain (≥ 65 years of age) were found to be depressed (GDS-SF score ≥ 8).²⁹

One study used the Chinese version of the Mishel's Uncertainty Illness Scale (MUIS-C) to measure ambiguity and complexity in Chinese patients with and without cancer pain (N=164).¹⁹ Patients with pain had significantly higher scores ($p<0.001$) on the ambiguity and complexity subscales of the MUIS-C and had more uncertainty than pain-free participants. However, pain severity was not found to be correlated with levels of uncertainty.¹⁹ Uncertainty has been shown to be related to anxiety in a study of factors that impact parent's anxiety in families of Chinese children with cancer.⁴⁶ No studies have reported on the relationships among ambiguity, complexity, and anxiety.

Cognitive dimension

The cognitive dimension of the cancer pain experience is related to the manner in which the pain influences an individual's thought processes or the manner in which the individual views himself/herself with pain. Other cognitive factors that are often associated with cancer pain include the meaning that an individual attaches to the pain (e.g., pain may be viewed as a reminder of the disease); attitudes, knowledge, and barriers that an individual may have about pain management; and strategies that an individual uses to cope with cancer pain.⁶

Cognitive factors such as patients' attitudes and beliefs about pain and cancer pain management have been found to be important barriers to effective pain management.^{47, 48} Studies that have measured potential patient-related barriers to cancer pain in Chinese patients are summarized in Table 4.

Nine studies explored barriers to cancer pain management.^{14, 16, 21- 24, 26, 31, 34} Six studies used a translated version of the Barriers Questionnaire (BQ) to assess concerns that participants had about reporting pain and using analgesics for their cancer pain.^{14, 16, 22, 23, 24, 26} The most common barriers to cancer pain management that Chinese patients reported were concerns about drug addiction, disease progression, drug tolerance, and the dosing regimen used to administer the analgesics (around the clock versus as needed). In contrast, in a study of barriers to cancer pain management in the U.S. the most common barriers identified were concerns about drug addiction, side effects, disease progression, and the desire to be a good patient.⁴⁷

Sociocultural dimension

The sociocultural dimension of the cancer pain experience is related to the demographic and ethnic characteristics associated with pain (e.g., age, gender, ethnicity,

social support, and religious beliefs) as well as how pain affects personal, family, and social roles.^{6, 49, 50} A search of the literature, using the key words acculturation and cancer pain, found many articles that studied different cultures and the affect of acculturation on their experience of pain. However, there was a profound lack of diversity in the cultures that were studied. The overwhelming majority of the studies on pain and acculturation included only Hispanics, African Americans, and European immigrants in their samples. No studies were found that examined the impact of acculturation on the experience of pain in Asian American or Pacific Islander immigrant cancer patients.

Culture and religious beliefs

Attitudes, as well as cultural and personal meanings that are ascribed to a particular disease (e.g., cancer) or symptom (e.g., cancer pain), may influence how an illness or a symptom is embodied and lived. Culture can dictate one's personal adjustment to an illness or its symptoms.⁵¹ For example, traditional Chinese philosophies of Confucianism, Taoism, and Buddhism influence behavior and rules for social interactions. These beliefs or philosophies also provide perspectives on health issues and can influence one's attitudes toward health care.⁴⁵

Eleven studies reported on the presence or absence of patients' religious affiliations^{14, 15, 19, 21- 23, 25, 26, 33- 35}. The religions that were reported by study participants were Buddhism, Taoism, and Christianity.¹⁹ None of the studies examined the relationship between patients' religious affiliations and their experience of cancer pain (e.g., pain intensity levels, mood disturbances, cognitive dysfunctions, pain meaning).

Culturally defined roles (e.g., gender roles) are important in the perceived meaning of an illness (e.g., cancer) and its symptoms (e.g., pain). For example, the

cultural meaning of breast cancer may have a negative impact on Chinese women if it is felt that the breast cancer will interfere with their female role of mothering.⁵² Twenty-two studies reported on the patients' gender, while two studies did not provide this information.^{19, 37} None of the studies addressed the impact of cancer pain on culturally defined roles in Chinese patients with cancer.

Family caregivers and cancer pain

Social or family support was found to impact the well-being of Chinese patients with cancer pain.⁵³ A strong sense of family obligation to care for sick family members is common in traditional Chinese culture. In addition, many Chinese patients worry they may become a burden to their family.^{53, 54} Health perceptions and concerns may influence the way patients feel about their diagnosis, prognosis, and treatment, and effect their expression of cancer pain.

Often Chinese patients with cancer pain will be cared for by family members at home. In traditional Asian cultures, family members have legitimate superior medical decision-making authority, and the patient's individual needs may be subordinate to the influence of family needs and desires for the patient's care.^{55, 56} Three studies compared the pain perceptions and attitudes of patients and their family caregivers and the effect that those perceptions and attitudes had on how the cancer pain was reported and treated.^{23, 24, 28}

Lin (N=178) looked at the agreement in pain perceptions and concerns of patients and family caregivers and their relationship to reporting pain and using analgesics.²³ No significant differences were found between patients' and family caregivers' pain perceptions of patients' worst pain, average pain, and present pain intensity scores as well

as ratings of overall pain interference. However, family caregivers' perception of patients' least pain were significantly higher than patients' pain perceptions ($p < 0.05$). Overall, 70% of the dyads did not agree on the patients' present pain intensity scores. Patients who were not in agreement with their family caregivers experienced higher levels of pain and pain interference and reported a poorer performance status. Fifty-five percent of the family caregivers in the group that disagreed with the patients about their present pain (i.e., the non-congruent group) overestimated their patients' present pain, while 45% of the family caregivers in the non-congruent group underestimated the patients' present pain. In addition, patients in the non-congruent group had significantly higher concerns or barriers to cancer pain management which might suggest that they were unwilling to report pain and to use adequate doses of pain medication.²³

Lin (N=318) compared patient and family caregiver barriers to cancer pain management and found significant correlations between caregiver concerns and their hesitancy to administer analgesics ($p < 0.05$).²² Family caregivers of patients who received adequate medication for their cancer pain scored significantly lower on the BQ than those family caregivers of patients who received inadequate pain medication ($p < 0.05$). This finding suggests that barriers to cancer pain management may cause family caregivers to be less willing to administer analgesics, even when patients report high levels of pain.²²

Lin *et al.* examined the relationships between patients' pain levels and family caregivers' concerns about pain management.²⁴ Thirty-five percent of the family caregivers who stated that they were hesitant to report their patients' cancer pain had significantly higher scores on the BQ ($p < 0.05$) compared to family caregivers who were not hesitant to report their patients' pain. This finding suggests that disagreement in the

perception of the pain experience between family caregivers and patients is associated with harmful outcomes for both groups.⁵⁷

Summary and Critique

Table 1 provides a summary of the various dimensions of the cancer pain experience that have been studied in Chinese patients. Only three dimensions have been evaluated in the majority of the studies done to date (i.e., physiologic, sensory, behavioral; 23 studies, 22 studies, 17 studies, respectively). However, only minimal exploration was done of each of these dimensions. For example, within the physiologic dimension, only three studies reported on the etiology of the cancer pain.^{29, 32, 37} Cancer stage is a contributing factor to cancer pain. However, only nineteen studies reported on patients' cancer stage (Table 2). Pain intensity was the most commonly measured characteristic of the sensory dimension. In most studies, Chinese cancer patients reported moderate to severe levels of pain. No studies attempted to characterize pain using word descriptors (e.g., sharp, dull, tingling). Within the behavioral dimension, only pain indicators (e.g., pain interference behaviors, performance status affects of pain) were evaluated. Patients with more severe pain reported greater interference with various activities. None of the studies evaluated the ways in which patients attempted to control their pain (e.g., rubbing, moving) or to communicate their pain (e.g., verbal or facial expressions or posturing).

The studies that addressed the affective dimension focused mainly on emotional responses (i.e., mood states, anxiety, and depression). Patients with more severe pain had higher anxiety and depression scores than patients with mild pain or who were pain-free. None of the studies discussed the suffering and distress that can be associated with cancer

pain. The studies that examined the cognitive dimension of pain explored patient-related pain barriers and attitudes. The most common barriers to cancer pain management were concerns about drug addiction, disease progression, drug tolerance, and dosing regimen of analgesics. Cognitive dysfunction that can be associated with cancer pain was not evaluated. The studies that examined the sociocultural dimension explored cultural factors (e.g., religious affiliations, pain beliefs) and family factors (e.g., family caregiver pain beliefs and attitudes) associated with cancer pain. They did not examine other sociocultural factors such as economic factors or education that might affect patients' pain perception.

Methodological issues

Study designs

Twenty-two of the twenty-four studies in this literature review used a convenience sample, and two were retrospective studies.^{17, 28} While convenience sampling is often used to recruit participants, it does not always reflect a representative sample of the population.⁵⁸

While many of the studies examined similar aspects of the cancer pain experience, Chinese patients were asked to report their symptoms (e.g., pain intensity, pain interference, performance status, depression, anxiety, mood disturbances, and other factors related to quality of life) at different time intervals. For example, the BPI asks patients to report their levels of pain intensity and interference in the past 24 hours, to describe their worst, least, and average pain for the past two weeks, and to rate their present pain intensity. Patient recall of symptoms over an extended period of time (e.g., two weeks) has the potential to be inaccurate. One way to assure accuracy in the

assessment of symptoms over an extended period of time is to have patients use a symptom diary.⁵⁹

Two studies were randomized clinical trials that examined the impact of a pain education program on changes in pain intensity,^{14, 20} pain interference,²⁰ and pain management concerns.¹⁴ Two longitudinal studies examined the stability of pain severity as well as anxiety and depression over a six month period.^{35, 36}

Three studies compared the behavioral and affective dimensions of pain in patients with and without cancer pain.^{15, 19, 25} One study used a correlational method to evaluate the impact of pain beliefs on adherence with analgesics.²¹ Three studies used a correlational method to compare the differences between family caregivers' pain perceptions and patients' pain perceptions,²² to measure the impact of those differences, if they existed, on patients' pain interference levels and patient pain barriers,²³ and to explore the relationships between patients who were receiving life-extending therapies and the pain barriers or concerns of their family caregivers, and how those concerns affected the family caregiver's report of pain and the administration of analgesics.²⁴

The sample sizes in these studies ranged from 20 to 534. Two of the studies were pilot studies (N=37 and N=30).^{14, 20} More males participated in the studies than females (overall number of participants = 3770; males = 2056, females = 1714). One study on gynecological cancer included only female participants (N=62).²⁷ Two studies did not report participants' gender.^{19, 37} All of the studies included adult Chinese cancer patients (mean age ranged from 42 years to 62 years) with pain.

Only one study failed to describe the inclusion and exclusion criteria.¹⁶ Eight studies excluded cancer patients who had recent surgeries^{17- 22, 24, 28} to assure greater

accuracy in reporting cancer pain. Sixteen studies included patients who were currently receiving chemotherapy, radiation therapy, and/or medication therapy, which may have had an affect on their cancer-related symptoms.^{15, 17, 20-24, 26, 27, 31-33, 35-37} Twelve studies recruited participants from more than one medical site,^{18, 19, 21, 23-26, 28, 30, 32, 35, 36} which improves the generalizability of the study findings. However, all of these studies recruited patients from urban medical settings either in China or in Taiwan, which limits the generalizability of the study findings. Patients from more rural areas of China and Taiwan may have different cancer pain experiences.

Validity and reliability of the instruments

A variety of valid and reliable instruments with well demonstrated validity and reliability in these studies and other studies were used to measure the multiple dimensions of the cancer pain experience. Pain is not a symptom that exists in isolation. Often pain, especially chronic pain like cancer pain, can create additional problems for the patient (e.g., mood disturbances, fatigue, and distress) which need to be assessed.⁶⁰ Altogether, nineteen different instruments were used to measure the multiple dimensions of cancer pain. The BPI was used most often to measure the sensory and behavioral dimensions of cancer pain and has well documented validity and reliability when used in studies of cancer pain. While all of the studies in this literature review used translated instruments, only seven of the twenty-four studies described the techniques used to translate the instruments.^{18, 20, 28, 29, 32-34} Two of the twenty-four studies reported that translated instruments were used when they were available to assess the affective dimension of cancer pain.^{35, 36}

Most of the instruments used in these studies were brief and took less than fifteen minutes to complete. The time needed to complete an instrument is important because these patients are experiencing pain, which may limit their ability and desire to complete lengthy instruments.

Recommendations for Future Research

Research is beginning to identify the cultural and ethnic differences in the experience and treatment of cancer pain. However, there is a paucity of studies on cancer pain that compares the cancer pain experience of Chinese cancer patients with other cultural or ethnic groups. Studies are needed that elucidate the experience of cancer pain in this growing population.

All of the studies in this review used quantitative research methods. There is a need for qualitative research to discern various concepts of pain management that are culturally imbedded but are not currently available in existing measures. Existing instruments may not adequately capture cultural nuances of the expression of pain in Chinese cancer patients. Clinicians need to be able to help cancer patients more clearly understand their pain experience, to manage their cancer pain, and to overcome the barriers that interfere with adequate pain management. Including qualitative research studies and/or open ended questions about the meaning of cancer pain and about patients' experience of cancer pain in future research will enhance our understanding of the pain experience in this population.

Family caregivers are involved in the management of cancer pain in the Chinese population. However, there may be gaps in family dynamics and communication that may influence pain expression. Longitudinal pain education programs should target

Chinese family members and patients to help them understand cancer pain. Efforts need to be made to decrease patient-related and family caregiver-related pain barriers through culturally appropriate educational interventions aimed at patients, their family caregivers, and the general public.

Psychological distress (e.g., depression, anxiety, mood disturbances) has been shown to be related to shorter periods of survival in cancer patients.⁶⁰⁻⁶² However, little is known about the effects of psychological distress or spiritual distress on the experience of cancer pain. Additional research is needed to include these components in the study of cancer pain in diverse populations.

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Table 1 – Dimensions of the Cancer Pain Experience that Were Evaluated in Studies of Cancer Pain in Chinese Patients

Author, Year	Physiologic	Sensory	Behavior	Affective	Cognitive	Sociocultural
Chang et al. (2002)	X	X	X		X	
Chen et al. (2000)	X	X	X	X		X
Chung et al. (1999)	X				X	X
Ger et al. (1998)	X	X	X			
Ger et al. (1999)	X	X	X			
Hsu et al. (2003)	X	X	X	X		
Lai et al. (2004)	X	X	X			X
Lai et al. (2002)	X	X			X	
Lin (2000)	X	X	X		X	X
Lin (2001)	X	X	X		X	X
Lin et al. (2001)	X	X			X	
Lin et al. (2003)	X	X	X	X		X
Lin & Ward (1995)	X	X	X		X	X
Molassiotis et al. (2000)	X			X		X
Serlin et al. (1995)		X	X			
Sze et al. (2000)	X	X	X	X		
Wang et al. (1996)	X	X	X			
Wang et al. (1999)	X	X	X			
Wang et al. (2001)	X	X	X		X	
Wang et al. (2004)	X	X	X			
Wills & Wootton (1999)	X	X			X	X
Yan & Sellick (2004)(Sym)	X	X		X		X
Yan & Sellick (2004)	X	X		X		X
Yu et al. (2001)	X	X	X			

X = areas assessed; blank boxes indicate areas not assessed or detailed findings in these areas were not reported

Table 2 - Summary of the Studies That Evaluated Stage of Disease in Chinese Patients with Cancer Pain

Author / year	Sample size	Stage I or Local	Stage II or Local	Stage III or Regional	Stage IV or Distant	Metastasis
Chang et al. (2002)	N=37	---- 100%----	-----			
Chen (2000)	N= 203					56%
Ger et al. (1998)	N=296 w/pain: (n = 113)	24%		35%	41%	
% of patients reporting worst pain (where pain was ≥ 5)		14%		29%	57%	
Ger et al (1999)	N = 534	40%			60%	
Hsu et al. (2003)	N = 164			81%- w/ pain	51% - w/o pain	
Lai et al. (2002)	N = 194				70.6%	
Lai et al. (2004)	N=30		30%	20%	49%	100%
Lin (2001)	N =178	42%				58%
Lin (2000)	N = 318 (patients: n = 159)	33%				67%
Lin et al. (2001)	N=80					100%- inclusion criteria
Lin et al. (2003)	N=484	19%- w/pain 54%- w/o pain				81%- w/ pain 47% - w/o pain
Lin & Ward (1995)	N=63	36%				64%
Molassiotis et al. (2000)	N=62	33.9%	30.6%	12.9%	1.5%	
Sze et al. (2000)	N=70					83%
Wang et al. (1996)	N=147				50%	
Wang et al. (1999)	N = 216					61%
Wang et al. (2001)	N=20					40%
Wang et al (2004)	N = 249	21%	29%	29%	21%	49%
Yu et al. (2001)	N = 412					70%

Table 3 – Most Frequent Sites of Cancer in Studies of Chinese Patients with Cancer Pain

Author / year	Sample Size	Breast	Gastro-intestinal	Liver	Lung	Head & Neck	Colorectal	Naso-pharyngeal	Gyn.
Chang et al (2002)	N=37	5.4%	8.1%	5.2%	29.7%	18.9%	8.1%		
Chen (2000)	N=203	19.3%	5.9%		5.4%	22%	29%	7.9%	
Chung et al. (1999)	N=39				77%			23%	
Ger et al. (1998)	N=296 w/pain (n = 113)		20%		21%	10%	12%		
			20%		24%	10%	13%		
Ger et al. (1999)	N=534	7%	8%	9%	18%		11%		6%
Hsu et al (2003)	N=164				100%				
Lai et al (2002)	N=194	7.2%	6.2%	13.9%	31.4%		6.2%		5.6%
Lin (2000)	n=159	16%	9%	8%	16%	10%	13%	4%	4%
Lin (2001)	N = 89	19%	11%	9%	14%	9%	13%	5%	4%
Lin et al. (2001)	N=80	19%	31%		9%	8%			14%
Lin et al (2003)	N=484 w/pain (n=233)	26%	6%	11%	8%	4%	18%	10%	10%
		10%	6%	9%	16%	8%	16%	17%	8%
Lin & Ward (1995)	N=63	13%	8%		11%		5%	19%	18%
Molassiotis et al. (2000)	N=62								100%
Sze et al. (2000)	N=70	16%	4%	7%	29%		6%	15%	6%
Wang et al. (1996)	N=147	10%	27%		33%				4%
Wang et al. (1999)	N=216	16%	29%		30%				
Wang et al. (2001)	N=20		40%			15%			
Wang et al. (2004)	N=249	24%	25%		21%	6%			4%
Wills & Wootton (1999)	N = 48	15%	7%	13%	20%		8%	15%	12%
Yan & Sellick (2004) (2x)	N=146		23.3%	23.3%			36.3%	13.7%	

Table 4 – Studies that Evaluated Barriers to Cancer Pain Management Using the Taiwanese Version of the Barriers Questionnaire

Author, Year	Fatalism	Addiction	Be Good	Distract Physician	Disease Progress
Chang et al. (2002) (Pre-test) Intervention (n=18) control (n=19) (Post- test) intervention (n=18) control (n=19)	2.13 / 0.99 1.89 / 0.79 1.28 / 0.60 1.82 / 0.75	3.44 / 1.77 2.93 / 1.78 1.20 / 0.62 2.93 / 1.79	1.24 / 0.45 1.16 / 0.48 1.06 / 0.17 1.09 / 0.38	1.56 / 0.78 1.23 / 0.50 1.17 / 0.37 1.23 / 0.50	3.41 / 1.93 3.58 / 1.60 1.81 / 0.91 3.67 / 1.52
Lin (2001) c (n = 27) nc (n = 62)	2.64 / 1.02 2.59 / 0.89	3.13 / 1.46 3.35 / 1.62	1.08 / 1.23 1.43 / 1.39	2.19 / 1.53 2.64 / 1.38	2.74 / 1.71 ^a 3.90 / 1.53 ^a
Lin (2000) Patient (n = 159) Family caregiver (fc) (n = 159) Patient w/ hesitancy (n = 90) Patient w/o hesitancy (n = 69) FC hesitancy (n = 68) FC w/o hesitancy (n = 91)	1.45 / 1.05 ^b 1.53 / 0.98 ^b 1.51 / 1.09 1.30 / 1.01 1.86 / 1.11 ^c 1.32 / 0.86	3.21 / 1.67 ^c 3.01 / 1.55 ^c 3.54 / 1.50 ^a 2.65 / 1.77 3.78 / 1.34 ^c 2.60 / 1.47	0.95 / 1.21 ^b 1.06 / 1.17 ^b 1.02 / 1.17 0.77 / 1.08 1.25 / 1.15 ^b 0.85 / 1.05	2.55 / 1.34 ^b 2.24 / 1.22 ^b 2.66 / 1.35 2.34 / 1.35 2.40 / 1.10 2.09 / 1.22	3.48 / 1.73 ^b 3.56 / 1.44 ^b 3.78 / 1.72 3.27 / 1.62 3.86 / 1.40 3.41 / 1.41
Chung et al (1999) (N = 39)	2.64 / 0.74	2.46 / 0.92	2.77 / 1.13	3.44 / 0.67	3.64 / 0.82
Lin & Ward (1995) (N = 63)	2.32 / 1.33	2.98 / 1.97	1.42 / 1.47	2.82 / 1.74	3.99 / 1.61
Wills & Wooton (1999) (N = 48)	(n = 38) 2.30 / 0.66	(n = 24) 2.46 / 0.83	(n = 12) 2.80 / 0.76	(n = 10) 2.80 / 0.76	

Range for all subscale is 0 to 5 (where 0 means “do not agree at all” and 5 means “agree very much”)
exp = experimental group, con = control group; c = congruent, nc = noncongruent ; ^ap < 0.01; ^bp < 0.05, ^cp < 0.001

Table 4 – Studies that Evaluated Barriers to Cancer Pain Management Using the Taiwanese Version of the Barriers Questionnaire

Author, Year	Tolerance	Side-effects	Intervals for dosage	Religious fatalism	Total BQ-T
<i>Chang et al. (2002)</i> (Pre-test) Intervention (n=18) control (n=19) (Post- test) intervention (n=18) control (n=19)	3.15 / 1.73 3.74 / 1.55 1.20 / 0.62 3.89 / 1.40	1.80 / 0.71 1.16 / 0.20 1.80 / 0.71 1.95 / 0.60	3.06 / 1.60 3.95 / 1.30 1.35 / 0.93 4.12 / 1.17	2.11 / 1.38 1.68 / 1.02 1.41 / 0.59 1.65 / 0.98	2.30 / 0.62 2.34 / 0.68 1.27 / 0.31 2.37 / 0.65
<i>Lin (2001)</i> c (n = 27) nc (n = 62)	3.19 / 1.42 ^b 3.93 / 1.44 ^b	2.55 / 1.15 2.69 / 1.05	3.17 / 1.66 3.47 / 1.57	1.06 / 1.40 2.11 / 1.67	2.49 / 0.89 ^b 3.02 / 0.68 ^b
<i>Lin (2000)</i> Patient (n = 159) Family caregiver (fc) (n = 159) Patient w/ hesitancy (n = 90) Patient w/o hesitancy (n = 69) FC hesitancy (n = 68) FC w/o hesitancy (n = 91)	3.66 / 1.71 ^c 3.14 / 1.74 ^c 4.08 / 1.49 ^c 2.89 / 1.91 3.77 / 1.55 ^c 2.71 / 1.74	3.08/1.06 ^c 3.01/0.94 ^c 3.08 / 1.05 2.90 / 0.89 3.30 / 0.96 ^b 2.92 / 0.90	3.29 / 1.72 ^c 2.99 / 1.72 ^c 3.83 / 1.53 2.48 / 1.72 3.45 / 1.51 ^b 2.72 / 1.84	2.16 / 1.70 ^b 1.58 / 1.56 ^b 2.31 / 1.53 ^c 2.48 / 1.72 1.80 / 1.71 1.23 / 1.34	2.56 / 0.79 ^c 2.34 / 0.78 ^c 2.84 / 0.68 2.37 / 0.86 2.78 / 0.54 ^c 2.18 / 0.78
<i>Chung et al (1999)</i> (N = 39)	2.51 / 0.72	2.87 / 0.95	3.62 / 0.86	Injections 2.72 / 1.26	2.96 / 0.36
<i>Lin & Ward (1995)</i> (N = 63)	4.17 / 1.51		3.60 / 1.61	Injections 2.55 / 2.00	2.98 / 0.85
<i>Wills & Wooton (1999)</i> (N = 48)		(n = 16) 2.65 / 0.56		(n = 16) 2.81 / 0.79	

Range for all subscale is 0 to 5 (where 0 means “do not agree at all” and 5 means “agree very much”)
exp = experimental group, con = control group; c= congruent, nc = noncongruent ; ^a $p < 0.01$; ^b $p < 0.05$, ^c $p < 0.001$

Relationships Between Pain Characteristics, Mood Disturbances, and
Acculturation in a
Community Sample of Chinese American Patients With Cancer

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Running head: Cancer pain in Chinese American patients

Abstract

Advances in cancer detection and therapy are extending the life expectancy of cancer patients. However, cancer pain continues to be a persistent, disturbing, and often incapacitating cancer symptom. While cancer pain occurs in all populations, minority groups are at greater risk for unrelieved pain due to inadequate management. While African American and Hispanic American cancer patients have been evaluated, no data are available on the cancer pain experience of Chinese American patients. Therefore, the purposes of this study were: to describe the cancer pain experience (i.e., pain severity, pain locations, pain interference with function, pain relief adequacy of the analgesic prescription) of a community sample of Chinese American patients with cancer pain; to examine the relationships between two pain characteristics (i.e., intensity, interference) and demographic characteristics, performance status, analgesic prescription, and mood disturbances (i.e., depression, anxiety); and to evaluate the relationship between pain characteristics and patients' level of acculturation.

A convenience sample of 50 cancer patients recruited from three community cancer facilities in Northern California completed self-report questionnaires that evaluated their pain severity, pain interference with function, mood disturbances, acculturation levels, and cancer pain treatments. Most of the patients reported moderate to severe pain levels and that pain interfered with their activities of daily living. Mean worst pain score was 5.81 (\pm 2.3) and mean total pain interference score was 4.37 (\pm 2.2). Hospital anxiety and depression scores were moderate (i.e., anxiety, 5.96 \pm 4.6; depression, 6.57 \pm 4.5). Sixty percent of the patients were being undertreated for their cancer pain.

Patients with higher depression scores reported significantly higher pain interference scores. Patients with less acculturation reported significantly higher least and worst pain severity scores and higher pain interference scores (i.e., walk, normal work, sleep, and total BPI interference score). Our study confirms that Chinese American cancer patients have clinically significant pain that impacts their daily lives and their mood, and their pain is being undertreated.

Introduction

Advances in cancer detection and therapy are extending the life expectancy of patients. However, cancer pain continues to be a persistent, disturbing, and often incapacitating symptom (Katz, 2002; van den Beuken-van Everdingen, et al., 2007; Wang, et al., 1999). While a number of cancer pain management guidelines have been developed (Miaskowski et al., 2005; National Comprehensive Cancer Network, 2005), moderate to severe pain continues to be experienced by 30% to 70% of patients undergoing cancer treatment and by up to 90% of patients with advanced disease (Portenoy & Lesage, 1999).

Cancer pain can have deleterious effects on patients' quality of life (Katz, 2002; Lin, Lai, & Ward, 2002; Miaskowski & Dibble, 1995; Miaskowski & Lee, 1999), and is often associated with anxiety and depression (Mystakidou, et al., 2006). In addition, it is frequently underreported and undertreated in racial and ethnic minority groups (Green, et al., 2003). In fact, in a study of patients with pain from metastatic cancer (Cleeland et al., 1994), minority patients were found to have twice the risk for inadequate pain management compared to non-Hispanic white patients. However, while this study compared cancer pain treatment among African American, Hispanic, and White patients, it did not include Chinese Americans (Cleeland et al., 1994).

In a recent review of the cancer pain experience of minority patients (Edrington, et al., 2007, in press), only three studies (Anderson et al., 2000; Cleeland et al., 1994; Cleeland et al., 1997) reported on differences in cancer pain severity and its management among African American, Hispanic, and White patients. To date, no studies have evaluated the pain experience of Chinese American cancer patients. Therefore, the

purposes of this study were: to describe the cancer pain experience (i.e., pain severity, pain locations, pain interference with function, pain relief adequacy of the analgesic prescription) of a community sample of Chinese American patients with cancer pain; to examine the relationships between two pain characteristics (i.e., intensity, interference) and demographic characteristics, performance status, analgesic prescription, and mood disturbances (i.e., depression, anxiety); and to evaluate the relationship between pain characteristics and patients' level of acculturation.

Methods

Participants and Settings

A convenience sample of oncology outpatients with cancer pain was recruited from the Chinese Community Health Resource Center, the Northern California Chinese Unit of the American Cancer Society (ACS), and the Comprehensive Cancer Center at the University of California San Francisco (UCSF). Patients were included if they were: an adult over 18 years of age; had a diagnosis of cancer; had pain related to cancer in the last 24 hours (i.e., pain level of ≥ 1 on a 0 (no pain) to 10 (worst pain imaginable) numeric rating scale (NRS)); and were able to read or understand Chinese or English. Participants were excluded if they had undergone surgery in the past three months.

Instruments

The use of translated instruments is often necessary when participants do not speak, read, or understand the language of the original instrument. Furthermore, research participants may feel more comfortable reading and answering questions in their primary language. Therefore, when available, standardized pre-translated instruments were used in this study. These culturally appropriate translated instruments should be conceptually

and technically equivalent to the language of the original instrument. In addition, they should be culturally and linguistically appropriate for the target population (Marin, Sabogal, Marin et al., 1987).

A committee of bilingual Chinese-speaking health care professionals reviewed the pre-translated instruments and their English versions for clarity, equivalence, and appropriateness for Chinese persons living in Northern California. When a pre-translated instrument was not available (i.e., demographic questionnaire; consent form), the instrument was translated into Chinese by the committee method of translation and back translation recommended by Brislin (1970).

The translation committee consisted of equal numbers of expert bilingual and bicultural health care professionals who spoke Cantonese and Mandarin Chinese and English. The committee agreed to use traditional Chinese characters for the translations because these characters reflect the speaking and writing dialect of the Chinese American community in Northern California. However, translating an instrument word-for-word into another language may not adequately account for linguistic and cultural differences. Therefore, the committee members examined the wording of the items to evaluate the semantic content, the cultural relevancy, and the conceptual equivalence of the translated instruments. Revisions in the translations, if needed, were based on feedback from the bilingual committee members as recommended by Hilton and Skrutkowski (2002).

Patients were asked to complete, in their preferred language, the following instruments: demographic questionnaire; Karnofsky Performance Status (KPS) scale (Karnofsky & Burchenal, 1949); KPS-Chinese (KPS-C; Lin, Lai, & Ward, 2003); Brief Pain Inventory (BPI; Serlin et al., 1995), Brief Pain Inventory-Chinese (BPI-C; Wang et

al., 1996); Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983); HADS-Chinese (HADS-C; Chen et al., 2000); Suinn-Lew Asian Self-Identity Acculturation Scale- short form (SL-ASIA; Leong & Chou, 1998); and SL-ASIA-Chinese (SL-ASIA-C; Suinn-Lew, et al., 1995).

The demographic questionnaire obtained information on participants' age, gender, education, marital status, yearly income, religious beliefs, length of time in the United States (U.S.), and cancer diagnosis.

Patients' functional status was assessed using the KPS (Karnofsky & Burchenal, 1949) or the KPS-C (Lin, Lai, & Ward, 2003), which was designed to measure patients' ability to accomplish normal activities of daily living or their need for help or nursing care. Validity and reliability of the KPS (Buccheri et al., 1996; Mor, Laliberte, Morris, & Wiemann, 1984) and the KPS-C (Chen, Chang, & Yeh, 2000; Lin, Lai, & Ward, 2003) are well-established.

The BPI is a 9-item questionnaire that was used to assess pain intensity levels, length of time in pain, pain relief, and pain's level of interference with function (Serlin *et al.*, 1995). Ratings of present, least, average, and worst pain intensity were obtained using 0 (no pain) to 10 (worst pain imaginable) NRSs. Pain relief was rated on a 0% (no relief) to 100% (complete relief) rating scale. Pain interference with seven activities was rated on 0 (no interference at all) to 10 (complete interference) NRSs. A total interference score was calculated as the mean of the 7 interference items. In addition, patients completed a body map to indicate the location of their pain. The validity and reliability of the BPI (Serlin et al., 1995) and the BPI-C (Wang et al., 1996) are well-established.

The Pain Management Index (PMI) was used to measure the adequacy of analgesic medications used by patients. PMI categories are based on the World Health Organization's (WHO) classification of the potency of analgesics in relationship to patient's worst pain intensity score (Cleeland et al., 1994; Zelman et al., 2003). To construct the PMI, the analgesics were categorized as follows: 0 = no analgesics; 1 = non-opioid analgesics (e.g., nonsteroidal anti-inflammatory drug [NSAID] or acetaminophen); 2 = weak opioids (e.g., codeine); and 3 = strong opioids (e.g., morphine). Patient's worst BPI pain scores were grouped into the following severity cutpoints as recommended by Paul and colleagues (2005): 1 = a worst pain rating of 1 to 4; 2 = a worst pain rating of > 4 to 7; and 3 = a worst pain rating of >7 to 10. The PMI was computed by subtracting the pain level from the highest analgesic category. Negative PMI scores (i.e., -1, -2, -3) indicate inadequate medication, while positive scores (i.e., \geq 0) indicate adequate analgesia for a given level of pain severity.

The HADS is a 14-item questionnaire that was designed to assess the psychological states of patients with physical problems (Zigmond & Snaith, 1983). Anxiety and depression are each measured using 7 items that are rated using a 4-point Likert scale. Scores can range from 0 to 21 on each subscale. A subscale score of 8 to 10 indicates a doubtful case of anxiety or depression, while a subscale score of greater than 11 indicates a definite case of anxiety or depression (Zigmond & Snaith). Validity and reliability of the HADS (Beck et al., 1997; Lisspers et al., 1997; Millar et al., 1995; Savard et al., 1998) and of the HADS-C (Chen et al., 2000; Leung et al., 1993) are well-established. In this study, the Cronbach's alphas for the HADS anxiety and depression subscales were .88 and .76, respectively.

Patients' level of acculturation was assessed using the 7-item short form of the SL-ASIA. The SL-ASIA short form uses patients' preferred language to read, write, and speak; ethnic self-identity; and generation level to determine acculturation level. Each item is rated on a 5-point Likert scale. A mean acculturation score is obtained by summing the values for all of the items and dividing the sum by the total number of questions answered (Suinn, Ahuna, & Khoo, 1992). Scores can range from 1.00 (indicates low level of acculturation) to 5.00 (indicates high level of acculturation). A higher score indicates greater Western identification while a lower score indicates stronger Chinese or Asian identification. The validity and reliability of the short form of the SL-ASIA (Leong & Chou, 1998) and the SL-ASIA-C (Suinn, 2005; Suinn, Ahuna, & Khoo, 1992) are well-established. In this study, the Cronbach's alpha for the SL-ASIA was .87.

Study Procedures

To facilitate the design and content of a culturally appropriate research study, input was sought from experts within the Chinese American community to identify pertinent cancer pain management issues; to assist with the recruitment and interviews of study participants; and to assist with the analysis of the cultural meanings of the study's results. In addition, participation in community events and research activities that focused on Asian American health care problems helped to increase the cultural sensitivity, respectfulness, and flexibility of the primary investigator (J.E.). Networking with Asian American and Pacific Islander (AAPI) health care groups, attending health care meetings and conferences, and gathering information on pain beliefs and experiences directly from the Chinese American community over a period of three years facilitated the

development of trust and commitment between the primary investigator and the Chinese American community, as well as the identification of cancer pain management issues within the community.

For this study, a research partnership was developed between the Chinese Community Health Resource Center, the Northern California Chinese Unit of the ACS, and the academic research team at UCSF. The goal of this partnership was to develop a research study that would meet the cancer pain management needs of the Chinese American community.

This study was approved by the Committee of Human Research at UCSF. Flyers, distributed in the community, in the media, on community bulletin boards, and in physicians' offices, were used to recruit patients for this study. Patients who were interested called a specific telephone number. A bilingual staff member returned their call, answered their questions, and screened them for participation. Patients who met the inclusion criteria were interviewed by a bilingual research assistant and/or the investigator who described the study to them, answered their questions, and obtained written informed consent. Patients were given a choice to answer either the Chinese or English questionnaires. If a patient was unable to read or complete a questionnaire independently, the bilingual research assistant read the instructions and questionnaires to the patient in the language of their choice and recorded their responses.

Statistical Analysis

Data were analyzed using SPSS 14.0 statistical software. Descriptive statistics, summarized as frequencies and percentages for categorical variables and means and standard deviations for continuous variables, were used to describe the demographic and

clinical characteristics of the patients. Pearson's product moment correlations were used to determine the relationships between pain characteristics and demographic characteristics (i.e., age, education, KPS scores), analgesic prescription, mood disturbance (i.e., anxiety, depression), and acculturation. Independent Student's t-tests were used to evaluate for gender differences in each of the study variables. A p-value of < 0.05 was considered statistically significant.

Results

Demographic and Clinical Characteristics

A convenience sample of 50 patients participated in this study. As summarized in Table 1, the majority of the patients were born in Mainland China (78%); had resided in the U.S. between 3 and 44 years; and were female (68%). The patients were approximately 63 years of age (range 39 to 78 years), married (66%), and had 11.5 years of education. Their religious affiliations were mixed. The patients' mean (\pm SD) acculturation level was 1.79 (0.63), which indicates a strong Asian identification. The majority of the participants had breast (32%), liver (14%), and lung (14%) cancer. Over 50% of the patients had metastatic disease. Ninety-two percent of the patients completed the Chinese version of the study instruments.

Pain Characteristics and Mood Disturbance Scores

The means and standard deviations for the four pain intensity scores are illustrated in Figure 1. Based on the severity classification of Paul et al. (2005) using worst pain intensity scores, 30% of the patients had mild pain, 42% had moderate pain, and 28% had severe pain. The most common sites of pain were: back (48%); chest (32%); arms and

shoulders (30%); legs (20%); and abdomen (18%). The average number of pain locations was 3.81. The majority of patients (66%) had pain in more than one location.

Fifty-four percent of the patients had pain for seven months or longer. Thirty-four percent had pain for longer than one year (i.e., duration of pain ranged between one year and twelve years).

As shown in Figure 2, mean (\pm SD) scores for the various pain interference items ranged from 2.58 (2.3) to 5.94 (3.1). The mean (\pm SD) total interference score was 4.37 (2.2). The mean (\pm SD) pain relief score was 48.6% (30.0%). Approximately 37% of the patients reported a pain relief score \leq 20%. Mean (\pm SD) HADS anxiety and depression scores were 5.96 (4.59) and 6.57 (4.54), respectively.

Analgesic Prescription

Seventy-two percent of the patients reported receiving the following pharmacologic treatments for their cancer pain: 12 (24%) used acetaminophen; 5 (10%) used NSAIDs (e.g., ibuprofen); 13 (26%) used weak opioids (e.g., hydrocodone); 8 (16%) used strong opioids (e.g., morphine, fentanyl patch); and 6 (12%) used co-analgesics (e.g., antidepressants, anticonvulsants, steroids). Of these 36 patients, 24% used complementary or alternative medicine (CAM) (e.g., massage, acupuncture, traditional Chinese medicine (TCM)) with their prescription analgesics. Of note, 14 (28%) patients used only CAM/TCM for pain management. As shown in Figure 3, 60% of the patients had negative PMI scores.

Relationships Between Demographic Characteristics and Pain Characteristics

As shown in Table 2, significant negative correlations were found between years of education and least, average, and worst pain intensity scores, as well as between years

of education and with the majority of the BPI pain interference scores. In addition, significant negative correlations were found between KPS scores and pain now and least pain, as well as between KPS scores and the majority of the pain interference items. No relationships were found between age and gender and any of the pain intensity or pain interference scores.

Relationships Between Mood Disturbance Scores and Pain Characteristics

As shown in Table 2, none of the pain intensity scores correlated with either the HADS anxiety or HADS depression scores. However, patients with higher anxiety scores reported significantly higher pain interference scores for mood, relationships with others, enjoyment of life, as well as the total BPI interference score. In addition, higher depression scores were associated with higher BPI interference scores for general activity, mood, walking ability, normal work, relations with others, enjoyment of life, as well as the total BPI interference score.

Relationships Between Acculturation and Pain Characteristics

As shown in Table 2, significant negative correlations were found between least pain and worst pain intensity scores and levels of acculturation, such that less acculturated patients had significantly higher least and worst pain intensity scores. In addition, the less acculturated patients reported significantly higher interference scores for walking ability, ability to do normal work, sleep, as well as the total BPI interference score.

Discussion

This study is the first to evaluate the experience of cancer pain in a community sample of Chinese Americans. In addition, the relationships between a number of pain

characteristics and specific demographic characteristics, as well as depression, anxiety and level of acculturation were examined. Of note, 70% of the patients in this study reported clinically significant worst pain scores (i.e., pain intensity of ≥ 5 on a 0 to 10 NRS scale) [Cleeland & Ryan, 1994]). Most of the pain intensity scores reported by the Chinese Americans were comparable to or slightly higher than those reported in previous studies of Taiwanese cancer patients (Ger et al., 1998; Ger et al., 1999; Lin, 2000; Lin, 2001; Lin & Ward, 1995), as well as in African American and Hispanic American patients (Anderson et al., 2000; Cleeland et al., 1997). However, the majority of the pain intensity scores reported by the Chinese Americans were higher than those reported by White Americans with cancer pain (Glover et al., 1995; Ward et al., 1993).

A similar but not identical pattern was observed for the pain interference scores. The majority of the pain interference scores reported by the Chinese American patients were comparable to those reported by cancer patients in Taiwan (Ger et al., 1999; Lai et al., 2004). However, all of these BPI interference scores were higher than those reported by White Australian cancer patients (Potter et al., 2003), but lower than those reported by African Americans and Hispanic American cancer patients (Anderson et al., 2000). While the exact reasons for these differences in pain intensity and interference scores are not readily apparent, several plausible explanations could include differences in demographic characteristics, cancer diagnoses, extent of metastatic disease, and adequacy of analgesic prescriptions among the various study samples. In addition, differences in pain intensity and interference scores may be due to cultural/ethnic differences in pain perception and responses to analgesic medications as seen in studies of experimental pain (Campbell,

Edwards, & Fillingim, 2004; Rahim-Williams et al., 2007). These differences warrant additional investigation in large comparative studies of cancer pain management.

Consistent with previous reports in Taiwanese (Chen et al., 2000; Ger et al., 1998; Lin, 2001; Lin et al., 2003) and White American cancer patients (Cleeland et al., 1994; Cleeland et al., 1997; Serlin et al., 1995), increased least and present pain intensity scores were associated with decreases in functional status as measured by the KPS scale. In addition, for most of the interference items, as well as the total BPI interference score, higher scores were associated with a poorer functional status. It is not clear why average and worst pain intensity scores were not associated with KPS scores.

Cancer pain can have a deleterious effect on patients' mood (Glover et al., 1995; Spiegel et al., 1994; Strang, 1992). Using the cutpoints for HADS anxiety and depression scores recommended by Zigmond & Snaith (1983), the prevalence of clinical anxiety and depression in patients in the current study was 30% and 34%, respectively. However, a surprising finding in this study was that none of the pain intensity scores were significantly correlated with either the HADS anxiety or depression scores. While this finding is consistent with those of Sze et al. (2000) in a sample of Chinese cancer patients in a palliative care setting in Hong Kong, it is not consistent with findings from previous studies in Taiwan (Chen et al., 2000; Lin et al., 2003) that documented positive correlations between pain intensity scores and levels of anxiety and depression. One reason for these differences could be that both of the Taiwanese studies enrolled hospitalized patients. In addition, in this study, HADS anxiety and depression scores were lower than those reported by Chen and colleagues (2000). However, it should be noted that significant positive correlations were found between many of the pain

interference items and HADS anxiety and depression scores. This finding warrants additional investigation in future studies.

The PMI provides an approximation of the adequacy of analgesic medications for cancer pain management. Approximately 60% of the patients in this study had inadequate analgesic prescriptions as measured by the PMI. In addition, none of the patients had PMI scores of +2 or +3. The inadequacy of the analgesic prescription is consistent with previous reports by Cleeland et al. (1994, 1997, respectively), who found that between 59% and 65% of African American and Hispanic American patients did not receive adequate analgesic prescriptions for their cancer pain. In addition, the inadequacy of the analgesic prescription may explain the mean pain relief score of only 48.6% in this sample of Chinese Americans.

It is interesting to note that 24% of the patients in this study used CAM or TCM in addition to analgesics to manage their cancer pain. In addition, 28% of the patients in this study used only CAM or TCM treatments for their cancer pain. Additional research is warranted on the specific types of treatments that are used, as well as their effectiveness with or without traditional pharmacologic approaches to cancer pain management.

This study is the first to examine the relationship between pain characteristics and level of acculturation in Chinese American cancer patients. It is interesting to note that patients who were less acculturated or had a stronger Asian identity reported higher least and worst pain intensity scores, as well as significantly greater pain interference scores for walking ability, ability to do normal work, and sleep, as well as total pain interference.

This finding warrants replication but suggests that Chinese patients with lower levels of acculturation may be at greater risk for unrelieved cancer pain.

Several limitations of this study are worth noting. The relatively small sample size limits the generalizability of the study findings. In addition, this community sample was primarily Chinese-speaking, first generation Americans who lived in a large urban area. Therefore, the findings from this study cannot be generalized to hospitalized patients or patients in more rural areas. Although 40 of the 50 patients had lived in the U.S. for over 10 years, their acculturation score (i.e., mean = 1.8), suggested a strong Asian identification. While the recruitment of this type of sample was a major goal of this study, future research needs to include larger numbers of second and third generation Chinese American cancer patients. Finally, we relied on patients' self-reports of their analgesic regimen. Future studies need to evaluate the specifics of the medication regimen in more detail (e.g., doses of analgesic medications, adherence to the analgesic regimen, effectiveness of the analgesic regimen), as well as obtain more details on the CAM/TCM approaches that these patients use to manage cancer pain.

Future studies, with larger numbers of patients, need to extend the work reported here on the cancer pain experience of Chinese Americans. These types of studies are needed to more effectively plan intervention studies to improve cancer pain management in this vulnerable population.

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Table 1 - Demographic and clinical characteristics of the patients (n=50)

Characteristics	Frequency (%)	Mean (SD)
<i>Gender</i>		
Male	16 (32.0)	
Female	34 (68.0)	
<i>Age</i>		62.6 (11.7) years
<i>Education level</i>		11.5 (4.1) years
<i>Marital status</i>		
Married	33 (66.0)	
Widowed	8 (16.0)	
Divorced	9 (18.0)	
<i>Live alone</i>	10 (20.0)	
<i>Religious beliefs</i>		
None	18 (36.0)	
Christianity	15 (30.0)	
Buddhism	13 (26.0)	
Taoism	1 (2.0)	
Other	3 (6.0)	
<i>Country of birth</i>		
Mainland China	39 (78.0)	
Vietnam	4 (8.0)	
Hong Kong	2 (4.0)	
Taiwan	2 (4.0)	
United States	2 (4.0)	
Other	1 (2.0)	
<i>Diagnosis</i>		
Breast cancer	16 (32.0)	
Liver	7 (14.0)	
Lung	7 (14.0)	
Head and neck	5 (10.0)	
Gastrointestinal	4 (8.0)	
Prostate	1 (2.0)	
Colorectal	1 (2.0)	
Other	9 (18.0)	
<i>Disease stage</i>		
Metastatic	27 (54.0)	
Localized	18 (36.0)	
Unknown	5 (10.0)	
<i>Karnofsky Performance Status score</i>		68.0 (16.8)
<i>Acculturation level</i>		1.8 (0.6)

Table 2 – Relationships Between Pain Characteristics and Demographic Characteristics, Mood States, and Acculturation

Pain Characteristic	Age	Education	KPS	PMI	HADS Anxiety	HADS Depression	Acculturation
Pain now	.096	-.248	-.338*	-.052	.072	.238	-.152
Least pain	.279	-.413**	-.352*	-.380**	.113	.174	-.404**
Average pain	.252	-.286*	-.131	-.348*	.134	.106	-.043
Worst pain	.005	-.308*	-.060	-.487**	.130	.085	-.332
General activity	.014	-.403**	-.637**	.043	.217	.477**	-.239
Mood	-.101	-.374**	-.356*	.077	.451**	.553**	-.240
Walking	.081	-.361*	-.514**	-.006	.173	.361**	-.309*
Normal work	.054	-.284*	-.567**	.034	.258	.427**	-.400**
Relations with others	-.208	-.015	.032	.143	.512**	.371**	-.086
Sleep	-.095	-.054	-.133	-.107	.177	.198	-.323*
Enjoyment of life	-.192	-.126	-.320*	.294*	.383**	.621**	-.155
Total BPI interference score	-.084	-.309*	-.479**	.095	.416**	.577**	-.336*

*p<0.05, **p<0.01 (2-tailed)

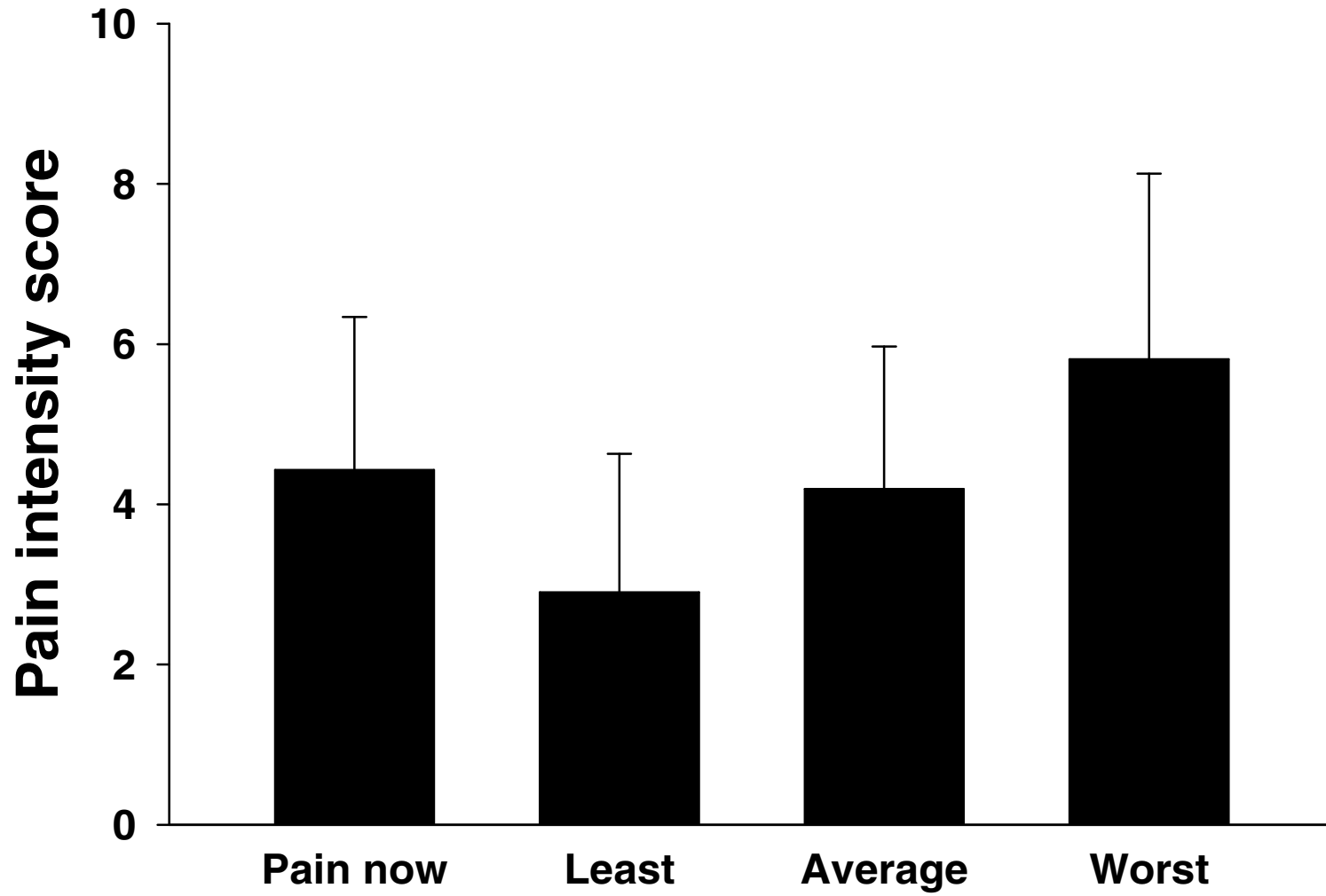
Abbreviations: HADS = BPI = Brief Pain Inventory; Hospital Anxiety and Depression Scale; KPS = Karnofsky Performance Status; PMI = Pain Management Index

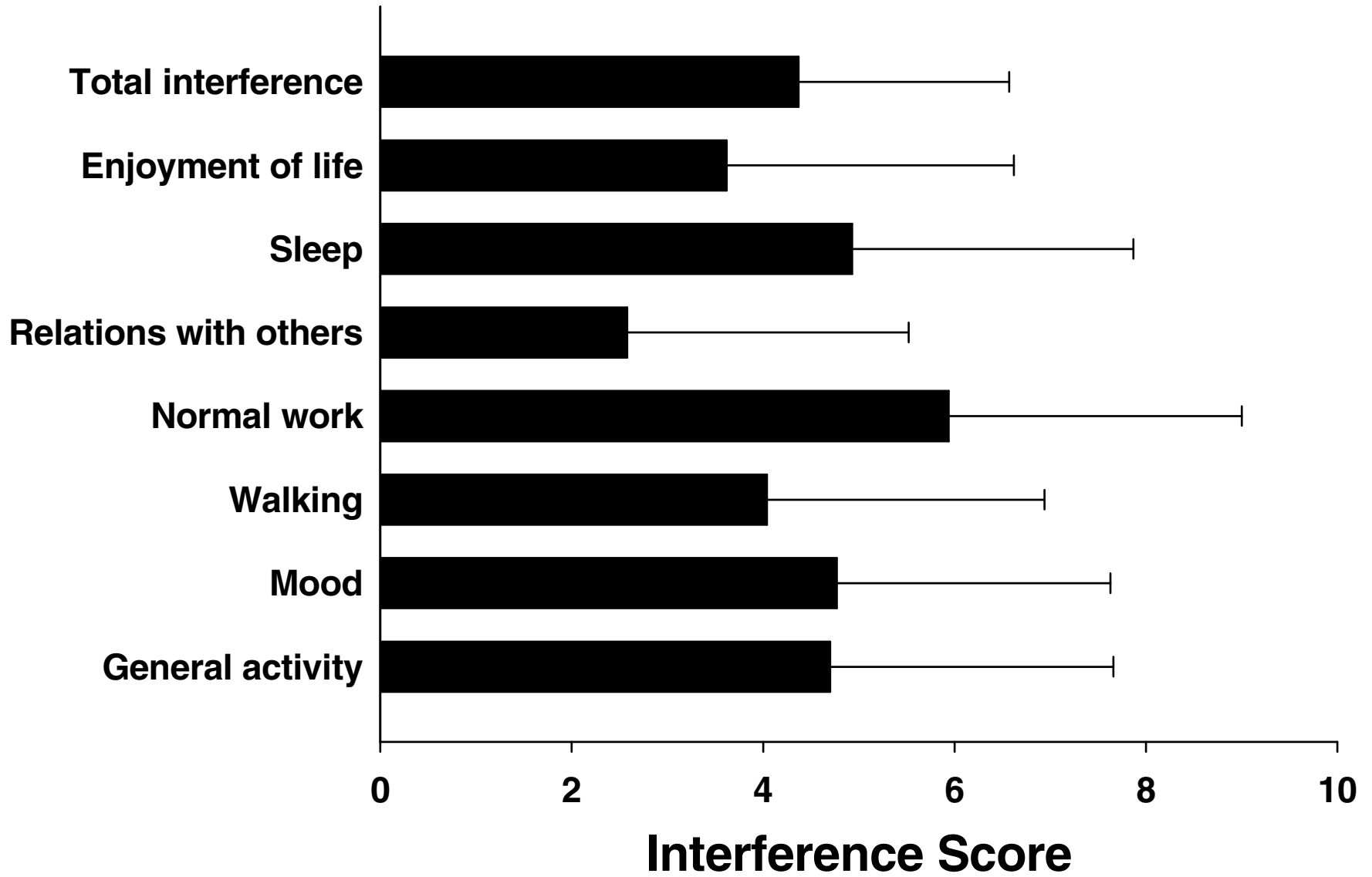
Figure legends

Figure 1 – Means and standard deviations for pain intensity scores

Figure 2 – Means and standard deviations for subscale and total pain interference scores from the Brief Pain Inventory

Figure 3 – Percentage of patients (n=50) with various Pain Management Index scores







Barriers to Pain Management in a Community Sample of
Chinese American Patients With Cancer

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Running head: Barriers to cancer pain management

Abstract

Patients' concerns or barriers to cancer pain management contribute to the undertreatment of cancer pain. Although patient barriers to cancer pain management are prevalent in the United States and other countries, including Taiwan, no studies have documented barriers to cancer pain management in Chinese Americans patients. The purposes of this study were: to describe the barriers to cancer pain management; to examine the relationships between these barriers and patients' ratings of pain intensity, pain interference with function, mood disturbances, and acculturation level; and to determine which factors predict patients' perceived barriers to cancer pain management. A convenience sample of 50 patients recruited from three community cancer facilities in Northern California completed the Brief Pain Inventory (BPI), Karnofsky Performance Status scale (KPS), Barriers Questionnaire (BQ), Hospital Anxiety and Depression Scale (HADS), Suinn-Lew Asia Self-Identity Acculturation Scale (SL-ASIA), and a demographic questionnaire.

Mean total BQ score for these patients was 2.5 (± 0.6). The highest ranked barriers were tolerance to pain medicine, time intervals for dosage of pain medicine, pain is an indication of disease progression, and addiction to pain medicine. Significant positive correlations were found between least pain and the tolerance subscale and between average pain and the religious fatalism subscale. In addition, these two subscales were positively correlated with the majority of the pain interference items. Of note, patients with higher tolerance and religious fatalism subscale scores reported higher levels of anxiety and depression. Based on the Pain Management Index, 60% of the patients were not receiving adequate treatment for their cancer pain. Patients whose

cancer pain was not adequately treated reported significantly higher subscale scores for fatalism and distracting their physician. Patients with lower levels of acculturation reported significantly higher fatalism and disease progression subscale scores. Using hierarchical regression analysis, 21.3% of the variance in the total BQ score was explained by education level, acculturation score, level of depression, and adequacy of pain treatment. Clinicians need to actively screen Chinese American cancer patients for pain and evaluate their concerns or barriers to cancer pain management in order to optimize the pain management plan.

Introduction

Cancer pain occurs in all populations, regardless of culture, ethnicity, or gender identification. However, minority groups may be at greater risk for unrelieved cancer pain due to inadequate management (Cleeland et al., 1994; Green et al., 2003). While a number of professional and system barriers may contribute to the undertreatment of cancer pain (Gordon, et al., 2005), patient barriers also contribute to inadequate management of pain (Lin, 2001; Potter et al., 2003; Ward & Gatwood, 1994). Studies have demonstrated that patient barriers to cancer pain management are prevalent in the United States (U.S.) (Ward et al., 1993) and in other countries, including Taiwan (Chang et al., 2002). However, no studies have documented barriers to cancer pain management in Chinese American patients. Therefore, the purposes of this study, in a community sample of Chinese Americans with cancer pain were: to describe the barriers to cancer pain management; to examine the relationships between these barriers and patients' ratings of pain intensity, pain interference with function, mood disturbances, and acculturation level; and to determine which factors predict patients' perceived barriers to cancer pain management.

Patient Barriers to Cancer Pain Management

In a recent study of patient barriers to pain management in Taiwanese cancer patients (Chang et al., 2002), nine common concerns that hindered patients' reports of pain or their use of analgesics included: concerns about the development of tolerance; fear of addiction; a sense of fatalism; concerns about medication side effects; a desire to be viewed as a "good patient"; concerns that pain medications are better given on an as-needed basis rather than on an around-the-clock basis; concerns about distracting one's

physician from treating the disease; concerns that cancer pain signifies the progression of the cancer; and a belief that pain is caused by or given by God or Karma and that patients have to tolerate or endure the pain to avoid carrying the pain into their next lives. Similar barriers were identified in an earlier study of Taiwanese cancer patients (Lin, 2000).

These barriers were found to contribute to patients' reluctance to report pain, as well as their use of prescribe analgesics, which, in turn, contributed to inadequate pain control.

Patient Barriers and Mood Disturbances

While studies in the U.S. (Glover et al., 1995; Spiegel et al., 1994) and Taiwan (Chen, Chang, & Yeh, 2000; Chen & Chang, 2004; Lin, Lai, & Ward, 2003; Wang et al., 2007) provide evidence of the negative effects of unrelieved pain on patients' mood, only one study has examined the relationship between patient barriers to cancer pain management and mood disturbances (Ward et al., 1998). In this study, higher barrier scores were associated with higher depression and anxiety scores. However, pain severity scores were not correlated with depression.

This review documents the need for an evaluation of the barriers to cancer pain management in Chinese American patients, as well as the relationships between these barriers and demographic characteristics, pain characteristics, and mood disturbances. In addition, since no studies were identified that examined the relationships between barriers and acculturation levels, this study will examine this relationship. Given the fact that over 3.3 million Chinese Americans of various acculturation levels are living in the U.S. today (U.S. Census Bureau), the findings from this study should provide useful information for clinicians to use in caring for these patients with cancer pain.

Methods

Participants and Settings

A convenience sample of oncology outpatients with cancer pain was recruited from the Chinese Community Health Resource Center, the Northern California Chinese Unit of the American Cancer Society (ACS), and the Comprehensive Cancer Center at the University of California San Francisco (UCSF). Patients were included if they were: an adult over 18 years of age; had a diagnosis of cancer; had pain related to cancer in the last 24 hours (i.e., pain level of ≥ 1 on a 0 (no pain) to 10 (worst pain imaginable) numeric rating scale (NRS)); and were able to read or understand Chinese or English. Participants were excluded if they had undergone surgery in the past three months.

Instruments

The use of translated instruments is often necessary when participants do not speak, read, or understand the language of the original instrument. Furthermore, research participants may feel more comfortable reading and answering questions in their primary language. Therefore, when available, standardized pre-translated instruments were used in this study. These culturally appropriate translated instruments should be conceptually and technically equivalent to the language of the original instrument. In addition they should be culturally and linguistically appropriate for the target population (Marin, Sabogal, Marin et al., 1987).

A committee of bilingual Chinese-speaking health care professionals reviewed the pre-translated instruments and their English versions for clarity, equivalence, and appropriateness for Chinese persons living in Northern California. When a pre-translated instrument was not available (i.e., demographic questionnaire; consent form), the

instrument was translated into Chinese by the committee method of translation and back translation recommended by Brislin (1970).

The translation committee consisted of equal numbers of expert bilingual and bicultural health care professionals who spoke Cantonese and Mandarin Chinese and English. The committee agreed to use traditional Chinese characters for the translations because these characters reflect the speaking and writing dialect of the Chinese American community in Northern California. However, translating an instrument word-for-word into another language may not adequately account for linguistic and cultural differences. Therefore, the committee members examined the wording of the items to evaluate the semantic content, the cultural relevancy, and the conceptual equivalence of the translated instruments. Revisions in the translations, if needed, were based on feedback from the bilingual committee members as recommended by Hilton and Skrutkowski (2002).

Patients were asked to complete, in their preferred language, the following instruments: demographic questionnaire; Karnofsky Performance Status scale (KPS; Karnofsky & Burchenal, 1949); KPS-Chinese (KPS-C; Lin, Lai, & Ward, 2003); Barriers Questionnaire (BQ; Lin & Ward, 1995); BQ-Chinese (BQ-C; Lin, 2000); Brief Pain Inventory (BPI; Serlin et al., 1995), Brief Pain Inventory-Chinese (BPI-C; Wang et al., 1996); Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983); HADS-Chinese (HADS-C; Chen et al., 2000); Suinn-Lew Asian Self-Identity Acculturation Scale- short form (SL-ASIA; Leong & Chou, 1998); and SL-ASIA-Chinese (SL-ASIA-C; Suinn-Lew et al., 1995).

The demographic questionnaire obtained information on participants' age, gender, education, marital status, yearly income, religious beliefs, length of time in the United

Stated (U.S.), and cancer diagnosis. Patients' functional status was assessed using the KPS (Karnofsky & Burchenal, 1949) or the KPS-C (Lin, Lai, & Ward, 2003), which was designed to measure patients' ability to accomplish normal activities of daily living or their need for help in nursing care. Validity and reliability of the KPS (Buccheri et al., 1996; Mor, Laliberte, Morris, & Wieman, 1984) and the KPS-C (Chen, Chang, & Yeh, 2000; Lin, Lai, & Ward, 2003) are well-established.

Patients' perceived barriers to cancer pain management were assessed using the BQ-C. Items are rated using a 0 (do not agree at all) to 5 (agree very much) Likert scale. The BQ-C consists of nine subscales (i.e., fatalism, fear of addiction, desire to be a good patient, fear of distracting physicians, fear of disease progression, tolerance, side effects, religious fatalism, and time for dosage of medications) (Lin, Lai, & Ward, 2002).

Subscale and total BQ-C scores calculated as the means of the individual items, can range from 0 to 5 with higher scores indicating higher levels of perceived barriers. Validity and reliability of the BQ-C is well-established (Lin, 2000; Lin & Ward, 1995). In this study, the Cronbach's alpha for the total BQ score was .76.

The BPI is a 9-item questionnaire that was used to assess pain intensity levels and pain's level of interference with function (Serlin et al., 1995). Ratings of present, least, average, and worst pain intensity were obtained using 0 (no pain) to 10 (worst pain imaginable) NRSs. Pain interference with seven activities was rated on 0 (no interference at all) to 10 (complete interference) NRSs. A total interference score was calculated as the mean of the 7 interference items. The validity and reliability of the BPI (Serlin et al., 1995) and the BPI-C (Wang et al., 1996) are well-established.

The Pain Management Index (PMI) was used to measure the adequacy of analgesic prescription. PMI categories are based on the World Health Organization's classification of the potency of analgesics in relationship to the patient's worst pain intensity score (Zelman et al., 1987; Cleeland et al., 1994). To construct the PMI, the analgesics were categorized as follows: 0 = no analgesics; 1 = non-opioid analgesics; 2 = weak opioids; and 3 = strong opioids. Patients' worst BPI pain scores were grouped into the following severity cutpoints as recommended by Paul and colleagues (2005): 1 = a worst pain rating of 1 to 4; 2 = a worst pain rating of > 4 to 7; and 3 = a worst pain rating of >7 to 10. The PMI was computed by subtracting the pain level from the highest analgesic category. Negative PMI scores (i.e., -1, -2, -3) indicate inadequate medication, while positive scores (i.e., ≥ 0) indicate adequate analgesia for a given level of pain severity.

The HADS is a 14-item questionnaire that was designed to assess the psychological states of patients with physical problems (Zigmond & Snaith, 1983). Anxiety and depression are each measured using 7 items that are rated using a 4-point Likert scale. Scores can range from 0 to 21 on each subscale. A subscale score of 8 to 10 indicates a doubtful case of anxiety or depression, while a subscale score of greater than 11 indicates a definite case of anxiety or depression (Zigmond & Snaith). Validity and reliability of the HADS (Beck et al., 1997; Lisspers et al., 1997; Millar et al., 1995; Savard et al., 1998) and of the HADS-C (Chen et al., 2000; Leung et al., 1993; Leung et al., 1999) are well-established. In this study, the Cronbach's alphas for the HADS anxiety and depression subscales were .88 and .76, respectively.

Patients' level of acculturation was assessed using the 7-item short form of the SL-ASIA. The SL-ASIA short form uses patients' preferred language to read, write, and speak; ethnic self-identity; and generation level to determine acculturation level. Each item is rated on a 5-point Likert scale. A mean acculturation score is obtained by summing the values for all of the items and dividing the sum by the total number of questions answered (Suinn, Ahuna, & Khoo, 1992). Scores can range from 1.00 (indicates low level of acculturation) to 5.00 (indicates high level of acculturation). A higher score indicates greater Western identification while a lower score indicates stronger Chinese or Asian identification. The validity and reliability of the short form of the SL-ASIA (Leong & Chou, 1998) and the SL-ASIA-C (Suinn, 2005; Suinn, Ahuna, & Khoo, 1992) are well-established. In this study, the Cronbach's alpha for the SL-ASIA was .87.

Study Procedures

To facilitate the design and content of a culturally appropriate research study, input was sought from experts within the Chinese American community to identify pertinent cancer pain management issues; to assist with the recruitment and interviews of study participants; and to assist with the analysis of the cultural meanings of the study's results. In addition, participation in community events and research activities that focused on Asian American health care problems helped to increase the cultural sensitivity, respectfulness, and flexibility of the primary investigator (J.E.). Networking with Asian American and Pacific Islander (AAPI) health care groups, attending health care meetings and conferences, and gathering information on pain beliefs and experiences directly from the Chinese American community over a period of three years facilitated the

development of trust and commitment between the primary investigator and the Chinese American community, as well as the identification of cancer pain management issues within the community.

For this study, a research partnership was developed between the Chinese Community Health Resource Center, the Northern California Chinese Unit of the ACS, and the academic research team at the UCSF. The goal of this partnership was to develop a research study that would meet the cancer pain management needs of the Chinese American community.

This study was approved by the Committee of Human Research at UCSF. Flyers, distributed in the community, in the media, on community bulletin boards, and in physicians' offices, were used to recruit patients for this study. Patients who were interested called a specific telephone number. A bilingual staff member returned their call, answered their questions, and screened them for participation. Patients who met the inclusion criteria were interviewed by a bilingual research assistant and/or the investigator who described the study to them, answered their questions, and obtained written informed consent. Patients were given a choice to answer either the Chinese or English questionnaires. If a patient was unable to read or complete a questionnaire independently, the bilingual research assistant read the instructions and questionnaires to the patient in the language of their choice and recorded their responses.

Statistical Analysis

Data were analyzed using SPSS 14.0 statistical software. Descriptive statistics, summarized as frequencies and percentages for categorical variables and means and standard deviations for continuous variables, were used to describe the demographic and

clinical characteristics of the patients. Pearson's product moment correlations were used to determine the relationships between patient barriers to pain management and pain severity, pain interference with function, mood disturbance (i.e., anxiety, depression), and acculturation. Independent Student's t-tests were used to evaluate for gender differences in patient barriers. Hierarchical linear regression analysis was used to determine whether demographic characteristics (i.e., age, gender, education, living arrangement), pain characteristics (i.e., worst pain, total pain interference score, PMI), mood disturbance scores (i.e., anxiety, depression), and acculturation level predicted patient barriers to cancer pain management (i.e., total BQ score). Variables that were not significant predictors were systematically removed until a parsimonious model was obtained. A p-value of <0.05 was considered statistically significant.

Results

Demographic and Clinical Characteristics

A convenience sample of 50 patients participated in this study. As summarized in Table 1, the majority of the patients were born in Mainland China (78%); had resided in the U.S. between 3 and 44 years, and were female (68%). The patients were approximately 63 years of age (range 39 to 78 years), married (66%), and had 11.5 years of education. Their religious affiliations were mixed. The patients' mean (\pm SD) acculturation level was 1.79 (0.63), which indicates a strong Asian identification. The majority of the patients had breast (32%), liver (14%), and lung (14%) cancer. Over 50% of the patients had metastatic disease. Ninety-two percent of the patients completed the Chinese version of the study instruments.

Relationships Between Patient Barriers and Demographic Characteristics

Figure 1 illustrates the mean scores (\pm standard deviation) for each of the BQ subscales as well as the total BQ score. Subscale scores ranged from 0.39 (± 0.8) for the “good patient” subscale to 4.26 (± 1.3) for the “tolerance” subscale. The mean total BQ score was 2.5 (± 0.6) which suggests a moderate level of barriers.

No significant correlations were found between any of the demographic characteristics and BQ subscale and total scores, except for gender, living arrangements, and KPS. Female patients reported higher scores on the “religious fatalism” subscale (1.37 (± 1.49) versus 0.54 (± 0.97); $p=.02$) and male patients reported higher concerns about distracting the physician (3.13 (± 0.67) versus 2.36 (± 1.25); $p=.007$). In addition, patients who lived alone reported significantly higher religious fatalism (2.0 (± 1.73) versus 0.09 (± 1.2), $p=.02$), but significantly lower time for dosage (3.30 (± 1.21) versus 4.15 (± 0.91), $p=.02$) subscale scores compared to patient who lived with someone. Finally, lower KPS scores were associated with significantly higher ($r= -.296$, $p<.05$) time for dosage subscale scores (i.e., patients with a poor functional status were more concerned about using their analgesics on an around the clock (ATC) bases).

Relationships Between Patient Barriers and Pain Severity

The majority of the pain intensity scores did not correlate with any of the subscale or total BQ scores. However, as shown in Table 2, significant positive correlations were found between least pain and the tolerance subscale ($r=.380$, $p=.007$) and between average pain and the religious fatalism subscale ($r=.282$, $p=.047$).

Relationships Between Patient Barriers and Pain Interference With Function

The tolerance subscale score was the only BQ score that was significantly correlated with the total BPI pain interference score ($r=.374$, $p=.007$). However,

significant correlations were found between the tolerance and fatalism subscale scores and a number of the pain interference items. Patients who reported higher tolerance scores reported significantly higher pain interference scores for: general activity ($r=.300$, $p=.034$), normal work ($r=.450$, $p=.001$), walking ($r=.368$, $p=.009$), and sleep ($r=.308$, $p=.029$). In addition, patients with lower fatalism scores reported more pain interference with the item “relations with other people” ($r= -.286$, $p=.044$).

Relationships Between Patient Barriers and Adequacy of Pain Treatment

Using the PMI to determine the adequacy of pain treatment, 60% of the patients were classified as being undertreated. As shown in Table 2, patients whose cancer pain was not adequately treated reported significantly higher fatalism ($r=-.426$, $p=.003$) and concerns about distracting MD ($r=-.309$, $p=.034$) BQ subscale scores.

Relationships Between Patient Barriers and Mood Disturbances

As shown in Table 2, only the tolerance and religious fatalism subscale scores of the BQ significantly correlated with the HADS anxiety and depression scores. Patients with higher tolerance ($r=.282$, $p=.047$) and higher religious fatalism ($r=.358$, $p=.011$) subscale scores reported higher HADS anxiety scores. Similar relationships were found for the HADS depression scores.

Relationships Between Patient Barriers and Acculturation Level

Three barrier subscales (i.e., tolerance, fatalism, and disease progression) were negatively correlated with SL-ASIA scores. As shown in Table 2, patients with low levels of acculturation reported significantly higher fatalism ($r= -.291$, $p=.041$), tolerance ($r= -.380$, $p=.006$), and disease progression ($r= -.377$, $p=.007$) BQ subscale scores.

Predictors of Patient Barriers to Cancer Pain Management

The results of the hierarchical regression analysis are shown in Table 3. Using the total BQ score as the dependent variable, years of education, acculturation score, PMI score, and depression score explained 21.3% of the variance in total BQ score ($p=.036$). In this study, patients with more years of education, lower levels of acculturation, an inadequate analgesic prescription, and higher depression scores reported significantly higher barrier scores.

Discussion

This study is the first to describe the barriers to cancer pain management and to determine the predictors of these barriers in a community sample of Chinese American patients. As shown in Table 4, the mean barrier score in this sample was equivalent to that reported by a Taiwanese sample of cancer patients (Lin, 2000) but higher than that reported for a sample of White American cancer patients (Ward et al., 1996). In fact, the Chinese Americans had a total BQ mean score that was 31% higher than the White American cancer patients. This difference equates with a moderate to large effect size (i.e., .72; Cohen, 1988) which suggests a clinically significant difference in barrier scores between the two groups of patients (Norman et al., 2003; Osoba, 1999).

In this study, the four barriers with the highest mean scores were: concerns about developing tolerance to the pain medication; concerns about taking the pain medication on an ATC versus an as needed basis (i.e., PRN); concerns about cancer pain being an indicator of disease progression; and concerns about the development of addiction. The ranking of these four barriers is consistent with previous studies of Taiwanese cancer patients (Lin, 2000; Lin & Ward, 1995). However, the barriers with the highest mean scores in a study of White American cancer patients are totally different (Ward et al.,

1996). It is interesting to note that for both the Chinese American and Taiwanese cancer patients concerns about the development of tolerance was the barrier with the highest mean score. However, concerns about tolerance ranked seventh in the study of White American cancer patients. This finding suggests that the Chinese Americans in this study perceived similar barriers to cancer pain management as patients in Asia and is consistent with the strong Asian identification in this sample.

Although one study found that older patients and patients with less education reported higher barriers to cancer pain management (Lin & Ward, 1995), these relationships were not supported in the current investigation. Differences between the two studies may be explained by the fact that the Chinese Americans in this study were older and better educated (mean age = 62.5 ± 11.6 years; 18% of the patients had less than high school education) than the Taiwanese cancer patients (mean age = 47 ± 15.3 years; 31% of the patients with less than high school education).

This study found that women reported higher religious fatalism scores (i.e., pain comes from God) and that men reported higher levels of concern about their pain distracting their physician from treating their disease. However, these findings are not consistent with previous reports that evaluated for gender differences in barriers to pain management (Chung et al., 1999 and Ward & Gatwood, 1994). In these two studies, male patients reported higher fatalism scores (i.e., pain is an inevitable part of cancer) than female patients. However, in both of these studies the “religious fatalism” subscale was not part of the BQ. The reasons for these gender differences among studies are not readily apparent and warrant investigation in future studies.

The barrier scores reported by the Chinese Americans in this study were relatively high and may indicate reluctance on the part of these patients to report their pain to clinicians or to adhere to their analgesic regimen. It should be noted that approximately 60% of the patients were not receiving adequate treatment for their cancer pain based on their PMI scores. In addition, patients with lower PMI scores, that indicate inadequate treatment, reported higher scores on the “fatalism” and on the “distract MD” subscales which is consistent with findings from a previous study (Lin & Ward, 1995). In addition, three of the four barriers with the highest scores were concerns related to analgesic use (i.e., tolerance, time for dosage, and addiction) (Gunnarsdottir et al., 2005) while the barriers in a study of white American cancer patients (Ward et al., 1996) were evenly divided between concerns about analgesic use and perceived barriers that hindered their communication with their health care provider about their pain (e.g., distracting the MD). Previous research (Lai et al., 2002) has shown that concerns about analgesic use contribute to poor adherence with an analgesic regimen.

This study is the first to evaluate the relationship between barriers to cancer pain management and mood disturbance in Chinese American cancer patients. In this study, higher anxiety and depression scores were associated with higher tolerance and religious fatalism subscale scores. These findings warrant further investigation in future studies.

This study is the first to evaluate for predictors of barriers to cancer pain management. Even with the relatively small sample size, 21.3% of the variance in the total BQ score was explained by four variables (i.e., education, acculturation, PMI score, and HADS depression score). While these findings warrant replication, they suggest that clinicians may be able to identify Chinese Americans who have greater concerns about

cancer pain management and may warrant additional interventions to improve the management of their cancer pain.

It should be noted that patient recruitment for this study was very difficult. Language was definitely a barrier to patients' participation in the study. However, the use of trained bilingual translators and the establishment of collaborations with the Chinese American community enabled the recruitment of a sufficient number of patients to explore that cancer pain experience of Chinese American patients.

Several limitations of this study are worth noting. The relatively small sample size limits the generalizability of the study findings. In addition, only three of the patients were able to read and write in English and only two of them were born in the U.S which restricted the examination of how level of acculturation affected patients' barriers to cancer pain management. To address this question in more detail, future studies should include second and third generation Chinese Americans. In addition, because all of the patients were from a community setting in a large urban area, these findings cannot be generalized to hospitalized patients or to patients in more rural areas.

In summary, findings from this study suggest that Chinese American patients with cancer pain have moderate levels of barriers. In addition, the barriers with the highest scores appear to be more similar to Taiwanese than to White American cancer patients. This finding has clinical implications for patient and family education. In addition, research is warranted to determine which strategies are most effective to reducing barriers to cancer pain management in Chinese American patients. This research will require cooperation with members of the Chinese community to insure its success.

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Table 1 - Demographic and clinical characteristics of the patients (n=50)

Characteristics	Frequency (%)	Mean (SD)
<i>Gender</i>		
Male	16 (32.0)	
Female	34 (68.0)	
<i>Age</i>		62.6 (11.7) years
<i>Education level</i>		11.5 (4.1) years
<i>Marital status</i>		
Married	33 (66.0)	
Widowed	8 (16.0)	
Divorced	9 (18.0)	
<i>Live alone</i>	10 (20.0)	
<i>Religious beliefs</i>		
None	18 (36.0)	
Christianity	15 (30.0)	
Buddhism	13 (26.0)	
Taoism	1 (2.0)	
Other	3 (6.0)	
<i>Country of birth</i>		
Mainland China	39 (78.0)	
Vietnam	4 (8.0)	
Hong Kong	2 (4.0)	
Taiwan	2 (4.0)	
United States	2 (4.0)	
Other	1 (2.0)	
<i>Diagnosis</i>		
Breast cancer	16 (32.0)	
Liver	7 (14.0)	
Lung	7 (14.0)	
Head and neck	5 (10.0)	
Gastrointestinal	4 (8.0)	
Prostate	1 (2.0)	
Colorectal	1 (2.0)	
Other	9 (18.0)	
<i>Disease stage</i>		
Metastatic	27 (54.0)	
Localized	18 (36.0)	
Unknown	5 (10.0)	
<i>Karnofsky Performance Status score</i>		68.0 (16.8)
<i>Acculturation level</i>		1.8 (0.6)

Table 2 Relationships between select study variables and Barriers Questionnaire subscale and total scores

<i>BQ Subscales</i>	<i>Least Pain</i>	<i>Average Pain</i>	<i>Total BPI Interference Score</i>	<i>PMI</i>	<i>HADS-A</i>	<i>HADS-D</i>	<i>SL-ASIA</i>
<i>Tolerance</i>	.380*	.138	.374*	-.217	.282*	.284*	-.380**
<i>Fatalism</i>	.101	.007	-.140	-.426**	-.037	-.105	-.291*
<i>Distract MD</i>	.199	.049	.105	-.309*	.105	.116	-.260
<i>Disease Progression</i>	.267	.075	.160	-.004	.126	.075	-.377**
<i>Religious fatalism</i>	.007	.282*	.217	.025	.358*	.353*	-.045
<i>Time for dosage</i>	.230	.045	.095	-.234	-.023	.194	-.277
<i>Total BQ score</i>	.257	.107	.218	-.189	.185	.257	-.273

*p<0.05; ** p<0.01

Abbreviations: HADS-A= Hospital Anxiety Depression Scale – Anxiety; HADS-D=Hospital Anxiety Depression Scale – Depression; PMI = Pain Management Index; SL-ASIA- Suinn-Lew Asia Self-Identity Acculturation Scale

Table 3 Hierarchical regression analysis of the predictors of barriers to cancer pain management

<i>Source</i>	<i>R²</i>	<i>Beta</i>	<i>% of explained variance</i>	<i>df</i>	<i>F</i>	<i>p</i>
<i>Overall</i>	21.3			4.42	2.84	.036
<i>Education</i>		.230	4.0			.151
<i>Acculturation</i>		-.313	8.2			.043
<i>PMI</i>		-.211	4.0			.151
<i>Depression</i>		.320	8.8			.036

Abbreviation: HADS = Hospital Anxiety and Depression Scale; PMI = Pain Management Index

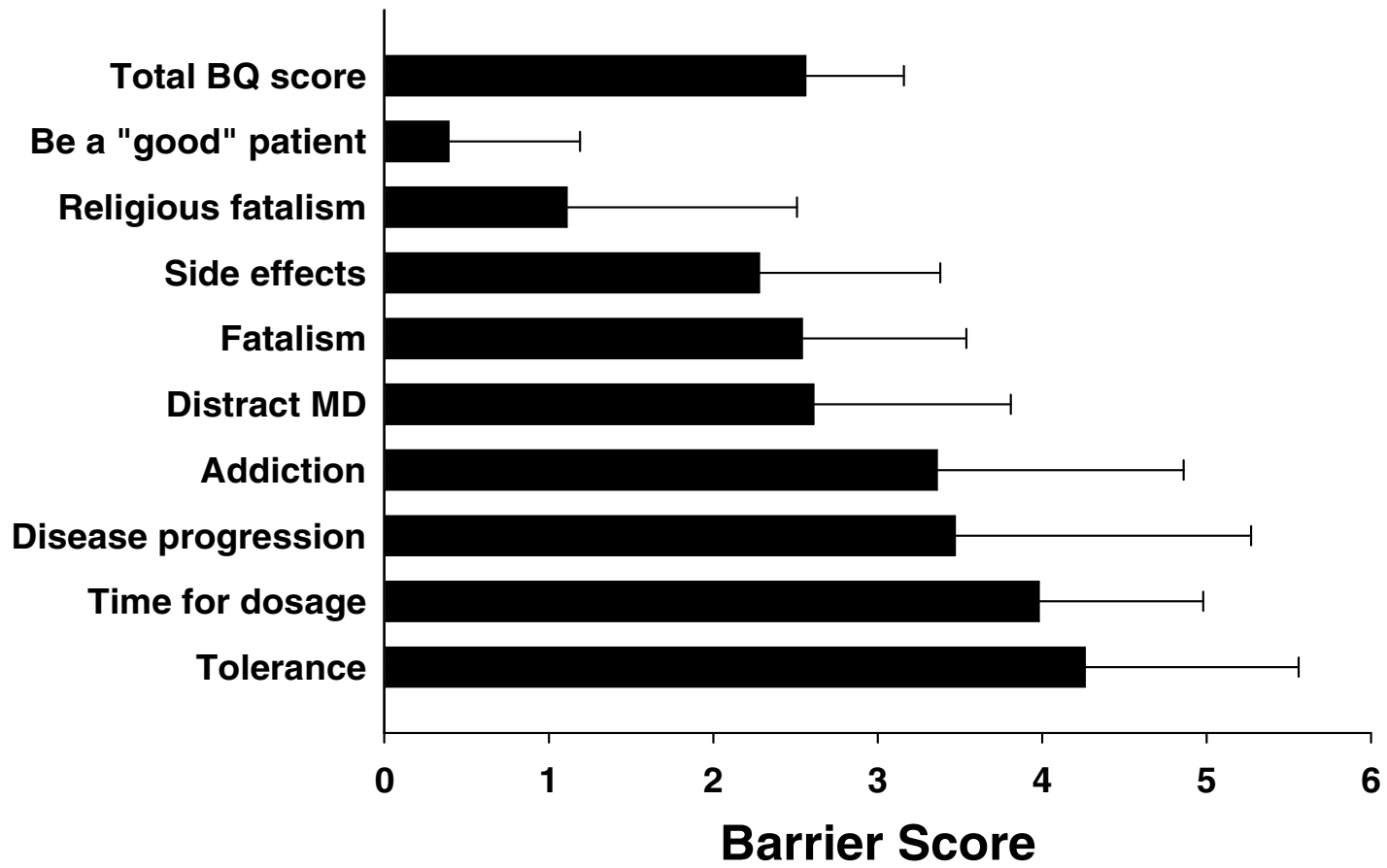
Table 4 - Comparison of the rankings (highest to lowest) of subscale and total Barriers Questionnaire (BQ) scores among three studies

Current study of Chinese American cancer patients (n=50)		Taiwanese cancer patients¹ (n=159)	White American cancer patients² (n=35)
Ranking	Subscales	Ranking	Ranking
1	Tolerance	1	7
2	Interval for dosage	3	Not evaluated
3	Disease progression	2	1
4	Addiction	4	3
5	Distract MD	6	5
6	Fatalism	8	8
7	Side effects	5	2
8	Religious fatalism	7	Not evaluated
9	Good patient	9	4
-	Not evaluated	Not evaluated	6 (Injection)
Total BQ score = 2.56 (0.64)		Total BQ score = 2.56 (0.79)	Total BQ score = 1.94 (0.85)

¹Lin (2000); ²Ward *et al.*, (1996)

Figure legend

Figure 1 – Means and standard deviations for the total and subscale scores for the Barriers Questionnaire



Summary, Conclusions, and Implications for Future Research

Despite the large number of Chinese Americans in the United States, little is known about their experience with cancer pain. A review of the literature of cancer pain in Chinese patients was conducted and found that 24 studies evaluated various dimensions of the pain experience (i.e., sensory, affective, cognitive, behavioral, and sociocultural). The physiologic dimension was the most often reported dimension of cancer pain (23 studies), followed by sensory (22 studies), behavioral (16 studies), sociocultural (11 studies), cognitive (9 studies), and affective (7 studies). However, only minimal exploration was done on each of these dimensions.

In general, the majority of the patients had late stage or metastatic cancer. These patients reported moderate to severe pain that interfered with their normal activities and with their mood. Studies that examined the sociocultural dimension evaluated cultural factors (e.g., religious affiliations, pain beliefs) of patients and family caregivers. Patients with more severe pain reported higher anxiety and depression scores than patients who were pain-free or who had mild cancer pain. The most common barriers that patients reported were concerns about drug addiction; their cancer pain being an indication of disease progression; concerns about developing tolerance; and concerns about time intervals between dosages of pain medicine. However, no studies were found that evaluated the pain experience of Chinese American patients with cancer.

Therefore, the overall aim of this dissertation research was to describe the cancer pain experience of Chinese American patients. The first study described the cancer pain experience (i.e., pain severity, pain locations, pain interference with function, pain relief

adequacy of the analgesic prescription); examined the relationships between two pain characteristics (i.e., intensity, interference) and demographic characteristics, performance status, analgesic prescription, and mood disturbances (i.e., depression, anxiety); and evaluated the relationship between pain characteristics and patients' level of acculturation in a community sample of Chinese American cancer patients. Most of the patients reported moderate to severe levels of pain that interfered with their daily activities. Thirty-four percent of the patients reported their pain had lasted for a year or longer. The relationships between a number of demographic (e.g., gender, age, education level) and pain characteristics were examined. Education level was negatively correlated with least, average, and worst pain intensity scores as well as with the majority of the pain interference items (i.e., general activity, mood, walking, normal work, and total Brief Pain Inventory (BPI) interference score).

Patients' anxiety and depression scores were in the moderate range. Surprisingly, none of the pain severity scores (i.e., pain now, least pain, average pain, worst pain) were significantly correlated with patients' anxiety scores. Patients with higher anxiety scores reported significantly higher pain interference scores (i.e., mood, relations with other people, enjoyment of life, and total BPI interference score). Higher depression scores were significantly correlated with higher pain interference scores (i.e., general activity, mood, walking ability, normal work, relations with other people, enjoyment of life, total BPI interference scores).

When the relationships between acculturation and pain characteristics were examined, significant negative correlations were found between least and worst pain

intensity levels and acculturation. Patients with lower levels of acculturation reported higher least and worst pain intensity scores.

When the patients' analgesic prescriptions were evaluated, 60% had inadequate treatment for their cancer pain. In addition, patients with Pain Management Index (PMI) scores that indicated undertreatment reported higher least, average, and worst pain intensity scores and more interference with activities of daily living.

Overall, most of the pain intensity scores reported in this study were comparable to or slightly higher than those reported in previous studies of Taiwanese cancer patients, but are higher than those reported by White American cancer patients. Similarly, the majority of pain interference scores reported by Chinese American cancer patients were consistent with scores reported by Taiwanese cancer patients, but higher than those reported by white Australian cancer patients. Findings from this study indicate that Chinese American cancer patients, like Taiwanese cancer patients and White American cancer patients, were affected by cancer pain and that their pain affected many different aspects of their lives. Taken together, these findings suggest that the negative affects of cancer pain are not culture specific.

The second study examined patients' perceived barriers to cancer pain management. The most common barriers reported by the patients were concerns about tolerance, time intervals for dosage of analgesic medications, disease progression, and addiction. An examination was made of the relationships between patient barriers and pain characteristics (i.e., pain severity, pain's level of interference with function), adequacy of pain treatment, mood disturbances, and acculturation. The tolerance subscale of the Barrier Questionnaire (BQ) was positively correlated with least pain scores, total

pain interference score, anxiety, and depression, and was negatively correlated with acculturation levels. Patients who expressed greater concern about the development of tolerance to analgesics reported higher least pain, total pain interference, anxiety, and depression scores. In addition, religious fatalism subscale scores were positively correlated with anxiety and depression scores. Patients with higher religious fatalism scores had higher anxiety and depression scores. When the relationship between barriers and level of acculturation were examined, patients with stronger Asian identification reported more concerns about the development of tolerance, fatalism, and disease progression. Even with the relatively small sample size, using a hierarchical regression analysis, 21.3% of the variance in the total BQ score was explained by years of education, acculturation, PMI scores, and depression score. The results of the regression analysis suggest that patients with more years of education, a strong Asian identification, inadequate analgesic prescription, and higher depression scores reported significantly higher BQ scores.

Findings from this study suggest that Chinese American patients with cancer pain have moderate levels of barriers. Furthermore, the barriers with the highest scores were more similar to Taiwanese cancer patients' barriers than those reported by White American cancer patients. This finding is important when developing patient and family pain education programs. Additional research is warranted to determine the most effective ways to reduce these barriers to cancer pain management in Chinese American patients.

These studies provide important information on the impact of cancer pain on the lives of Chinese American patients and demonstrate the need for a multi-dimensional

approach to cancer pain management. Many of the patients reported moderate levels of anxiety and depression. Clinicians may need to include assessments of mood disturbances along with their pain assessments. A large percentage of patients in this study reported the use of complementary or alternative medicine (CAM) or traditional Chinese medicine (TCM) to treat their cancer pain. Additional research is warranted on the specific types of treatments patients use with or without conventional analgesics to manage their pain and the effectiveness of those treatments. Future studies need to include a larger and more diverse group of Chinese American cancer patients (i.e., second or third generation Chinese American patients) which may clarify the impact of acculturation on the experience of cancer pain. In addition, more information is needed on the influence of acculturation on patients' response to their prescribed treatments. Cultural values, beliefs, and attitudes to cancer pain need to be more fully explored among a diverse group of Chinese American patients in order to provide clinicians with a better understanding of patients' cancer pain experience and to provide directions for adequate management of cancer pain.

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