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**A COMPARATIVE STUDY OF PAIN INTENSITY, INFORMATION  
SEEKING AND ADJUSTMENT TO PROSTATE CANCER IN JAPANESE  
AMERICAN AND EUROPEAN AMERICAN MEN**

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**Submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy in  
The College of Nursing  
at the College of Dentistry  
New York University  
2007**

## ABSTRACT

Mildred Kowalski, Doctor of Philosophy, 2007

Major: Nursing, at the College of Dentistry, New York University

Title of Dissertation: A Comparative Study of Pain Intensity, Information-Seeking, and Adjustment to Prostate Cancer in Japanese American Men and European American Men

Directed by: Judith Haber

## ABSTRACT

Adjustment to illness is a multi-dimensional and difficult process for many patients facing a life-threatening illness, such as prostate cancer. Adjustment encompasses changes in social interactions, physical limitations and role function (Germino et al., 1998; Hoskins et al., 1996). Information-seeking and the reporting of pain promote adjustment and are explained by the Roy Adaptation Model (Boston Based Adaptation Research in Nursing Society, 1999); which was used as a framework for this study.

As the United States becomes more ethnically diverse, nurses are challenged to care for patients from different ethnic backgrounds. The purpose of this descriptive study was to explore ethnic differences in self-reporting of pain (Brief Pain Inventory, BPI; Cleeland & Ryan, 1994), information-seeking behavior (Krantz Health Opinion Survey, KHOS; Krantz et al., 1980) and adjustment (Psychosocial Adjustment

to Illness Scale, PAIS; Derogatis & Derogatis, 1990), in Japanese American and European American men, treated for prostate cancer.

Data from 89 consenting participants, 12 Japanese American and 78 European American men, were analyzed using Wilcoxon Rank Sum. The median age was 70. Most participants were married, protestant and college graduates. The ethnic groups were well-matched for age, marital status, number of children, highest education level and income. The most common treatments for prostate cancer reported were androgen deprivation therapy (65%), surgery (55%), and radiation (53%).

Because three comparisons were performed on the same dataset, a Bonferroni adjustment for significance level was used. The significance level was set at  $p = .017$  ( $.05/3$ ), to detect an alpha of .05. Wilcoxon Rank Sum analysis was performed for each of three main comparisons: 1) information-seeking (KHOS), 2) self-reported pain (BPI), and 3) overall adjustment to illness (PAIS). A difference for information-seeking (KHOS) between the Japanese American and European American groups,  $p = .012$ , was observed. Overall, information-seeking (i.e. inquisitiveness) correlated with better adjustment ( $p = 0.006$ ). No differences were seen in overall adjustment or self-reported severity of pain.

The results of this study support ethnic differences in information-seeking patterns observed by other researchers (Kagawa-Singer, 1988; Kakai et al., 2003), and provide insight for nurses to better care for patients across ethnic groups.



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## ACKNOWLEDGMENTS

This dissertation could not have been completed had it not been for the help and encouragement of so many people. I would like to thank my dissertation committee, Drs. Judith Haber, Wendy Budin and Barbara Krainovich-Miller for their thoughtful review and suggestions. With special thanks to them for their gracious and active participation of the research process; they spent many evenings reviewing text to strengthen the presentation of the research. I would also like to acknowledge Drs. Carol N. Hoskins and Robert Malgady who provided guidance during the early aspects of this research project. I am thankful to Drs. Wendy Budin (dissertation committee), Sarah Abramowitz and Robert Norman for their statistical expertise and patience as I consulted with them.

I am indebted to many friends, colleagues, co-workers and to my family – both immediate and extended. I was blessed to be born into a large and loving family who continuously expressed interest and encouragement related to my studies. My parents wisely taught me the importance of studying, education, compassion for others, and a deep appreciation of family and friends. For these early teachings I am most grateful.

During this research I had the opportunity to work with many professionals. Their expertise and willingness to share their knowledge with me was exceptional. Dr. Marilyn Bookbinder, Dr. Nessa Coyle, Mr. Ryan Iwamoto,

Dr. Frances Cartwright-Alcarese, Dr. Marjorie Kagawa-Singer, and Dr. Rachel Jones who provided insight to my study design. Dr. Pat Nishimoto, Dr. Francisco Conde, Ms. Cheryl Wild, Ms. Christy Conroy, Ms. Jeanne Foster and Ms. Carol Lundin all helped me meet the challenge of recruitment.

Clearly, this research depended on the participation of the men who completed the surveys. Meeting under the leadership of Mr. Frank Schuerholz (Middletown), Mr. Richard Mizuta (Kuakini), and Mr. Phil Olsen (all areas of Hawaii) the men at several Us TOO Chapters provided meaningful data which led to the completion of this study. Mr. Henry Pinchot reached out to the men in California through the Prostate Cancer Research Institute. Ms. Pam Barrett and Mr. Thomas Kirk, of Us TOO International, shared information about this research with their members. These tireless leaders continue to provide support and information to men with prostate cancer, as well as to the families and healthcare providers dealing with prostate cancer. I thank the men and the leaders.

Finally, to Kathy and Anna, two remarkable women who taught me more about adjustment than any text ever could. With style and grace they each met the challenge of a cancer diagnosis while never losing their sense of humor or zest for life. I am both honored and blessed to call them my friends – and I am doubly blessed to be Anna's sister.

To all of these people – and more – I am sincerely thankful.

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## CHAPTER I

### RESEARCH OBJECTIVE

#### Introduction

Adjustment to illness is a complicated, multi-dimensional, and difficult process for many patients facing a chronic or life-threatening illness, such as prostate cancer. An ongoing process, adjustment encompasses the initial reaction to the diagnosis, treatment options, expectations, change in social interactions, physical limitations, and resultant alterations in role function (Galbraith, Ramirez, & Pedro, 2001; Germino et al., 1998). Researchers have attempted to measure various aspects of adjustment to cancer, including quality of life (Galbraith, Arechiga, Ramirez, & Pedro, 2005) physical symptoms (Galbraith et al., 2001; Scura, Budin & Garfling, 2004), role function (Galbraith et al., 2005; Germino et al., 1998), sexual function (Germino et al., 1998; Wallace, 2003), and interpersonal relationships (Budin, 1998). Researchers have also found that culture and ethnicity play an important role in information-seeking behaviors (Tsutsui, 1991), pain behaviors (Cleeland et al., 1996; Melzack & Wall, 1965/1997; Zborowski, 1952), and psychological and physical responses to illness (Uki, Mendoza, Cleeland, Nakamura, & Takeda, 1998).

Scura et al. (2004) conducted a pilot study which explored the physical (including sexual) function, interpersonal relationships, and social adaptation to

prostate cancer, using the Roy Adaptation Model (RAM) in a small ( $N = 14$ ) but diverse ethnic population. Scura et al. provided insight into the role of information seeking on adjustment.

Information-seeking is one way patients – particularly men – adjust to various illnesses, including cancer (Klemm, Hurst, Dearhott, & Trone, 1999). Kagawa-Singer (1988) found that Japanese American women with breast cancer asked fewer questions of health care providers than did their European American counterparts. Ka'opua, Gotay, Hannum, and Bunghanoy (2005) conducted a qualitative study with wives of Asian Pacific Islander men (including Japanese American men) with prostate cancer. The wives of Japanese American men ( $n = 13$ ) reported their husbands were reluctant to voice concerns related to prostate cancer. Kakai, Maskarinec, Shumay, Tatsumura, and Tasaki (2003) reported that male and female Japanese American patients were less likely to get information directly from health care providers. The extent to which different patterns of information-seeking behavior extend to both genders and to different ethnic groups is important in its potential impact on intervention by health care providers.

How cancer patients adjust to pain remains a complex and multidisciplinary area of study. Moderate to severe pain can interfere with both physical (i.e., sleep, activity) and psychosocial (i.e., interpersonal relations with family and friends) aspects of a cancer patient's life (Cleeland et al., 1996); thus, pain assessment by a health care professional, through self-report or other communication, is the first step in adequately managing pain for a cancer patient.

Like adjustment, response to pain is a highly individual phenomenon. Still, tailoring the assessment of pain to various ethnic groups may be warranted if self-reporting of pain is avoided or less frequent in any particular ethnic groups. Ethnic differences in self-reporting of pain have been documented (Cleeland et al., 1996; Melzack & Wall, 1997; Zborowski, 1952); however, although some studies have included Japanese patients with cancer (Uki et al., 1998), none have focused on the self-reporting of pain by Japanese American men with a single type of cancer (e.g., prostate cancer).

The overall adjustment to a diagnosis of and treatment for prostate cancer remains a multi-faceted process. Although large studies have aimed at identifying factors related to the quality of life of men with prostate cancer (Hu et al., 2004), as well as the role of ethnicity (Germino et al., 1998) in adjustment to prostate cancer, none of these ethnic studies of adjustment to prostate cancer have targeted Japanese American men. This study explored differences in self-reported pain intensity, information-seeking behavior, and adjustment between Japanese American and European American men with prostate cancer.

### Research Questions

1. What differences can be found in self-reports of pain intensity, information-seeking behavior, and adjustment between Japanese American and European American men treated for prostate cancer?

2. What are the relationships between pain intensity, information-seeking behavior and adjustment in Japanese American and European American men treated for prostate cancer?

#### Sub-Questions

1. What are the differences in pain intensity between Japanese American men and European American men treated for prostate cancer?

2. What are the differences in information-seeking behavior between Japanese American men and European American men treated for prostate cancer?

3. What are the differences in adjustment between Japanese American men and European American men treated for prostate cancer?

What is the relationship between pain intensity and adjustment in Japanese American men and in European American men treated for prostate cancer?

5. What is the relationship between information-seeking behaviors and adjustment in Japanese American men and European American men treated for prostate cancer?

#### Need for the Study

The United States (US) is both culturally and ethnically diverse. Currently, Asian/Pacific Islanders comprise approximately 2.9% of the US population, with a 10% increase projected by 2010 (US Bureau of the Census, 1993). Projected increases, specifically in the Japanese American population (US Department of Health and Human Services, US DHHS 1993), trigger a need to understand the



communication, behavioral, and expressive trends in people of Japanese heritage living in the US.

The importance of culture and ethnicity to health care is well documented in the literature – the influence of culture on variables of self-reported intensity of pain (Cavillo & Flaskerud, 1993; Uki, et al., 1998); information-seeking (Kagawa-Singer, Wellisch, & Durvasula, 1997; Tsutsui, 1991); and adjustment (Germino et al., 1998; Kagawa-Singer et al., 1997) has also been reported. The challenge to provide culturally sensitive health care has been ongoing (Cleeland et al., 1996; Leininger, 1994, 1996; Meleis, 1996; Napoles-Springer, Santoyo, Houston, Perez-Stable, & Stewart, 2005; Rogers, 1994). In fact, the US HDHSS (1999) has set a goal, documented in *Healthy People 2010: A Systemic Approach for Health Improvement* to eliminate health care disparities among minority groups.

One way to reduce – if not eliminate – such disparities is to understand different ethnic groups and develop interventions that address specific ethnic health needs (Brach & Fraser, 2000; Taylor & Lurie, 2004). Each time one gains an understanding of an ethnic group or culture that is different from one's own ethnicity, the door to becoming more culturally sensitive to other ethnic and cultural groups is opened. Through the understanding of ethnic diversity, best practices of nursing care can be developed and the health needs of patients from diverse ethnic groups can be appropriately addressed.

Specifically, an increased incidence of prostate cancer in both Japanese American men (Shibata et al., 1997) and European American men (American

Cancer Society, 2006), along with the prevalence of pain in cancer patients (Donnelly, Walsh, & Rybicki, 1995; Portenoy, 1989; Twycross, 2003), support the need to study psychosocial adjustment to prostate cancer. Then, too, insight into cultural and ethnic patterns of self-reported pain intensity, information-seeking behaviors, and adjustment is essential if health care professionals are to provide comprehensive and culturally sensitive care to patients with prostate cancer.

Pain intensity (Uki et al., 1998) has been documented in Japanese patients with different types of cancer, and information-seeking behaviors have been studied in both Japanese American breast cancer patients (Kagawa-Singer et al., 1997) and Japanese mothers with mildly ill children (Tsutsui, 1991). However, the impact of both pain intensity and information seeking behaviors on adjustment to cancer is not known. Thus, this study was undertaken to provide nurses and other health care providers with preliminary information about self-reported pain intensity, information-seeking behaviors, and adjustment in a single type of cancer in two ethnically diverse groups. Differences in self-reported intensity of pain, information-seeking behaviors, and adjustment between Japanese American and European American men treated for prostate cancer were explored.

### Theoretical Rationale

Roy's conceptual Adaptation Model (RAM) guided the theoretical, conceptual, and empirical framework of this study (Roy & Andrews, 1991). Roy provides a basis for understanding change or stimuli as processed by regulator

(physiologic) and/or cognator (behavioral) functions within a system. Roy (1997) clearly recognized the wholeness of the human being, but her conceptual model allows for the independent study of integrated aspects of the system. Physiologic and behavioral functions act in concert to guide effective or ineffective, adaptation of the system to changes or stimuli.

RAM classifies stimuli as focal, contextual, and residual (Roy & Andrews, 1991). A focal stimulus is one that is immediately confronting the person, such as pain related to prostate cancer or treatment. Contextual stimuli include characteristics that are integral to the person's being, such as culture and ethnicity (Fawcett & Weiss, 1993). RAM assumes that the fundamental characteristics of the individual, such as ethnicity or gender, influence the process that one employs to deal with adaptation to change (Boston-Based Adaptation Research in Nursing Society [BBARNS], 1999).

Two studies (Cavillo & Flaskerud, 1993; Fawcett & Weiss, 1993) supported the need to assess ethnicity as a contextual stimulus. Additionally, studies identified ethnicity as an important variable when adjustment and pain intensity were studied (Streltzer & Wade, 1981; Zborowski, 1969). The impact of pain intensity on role function, a component of adjustment to illness, can differ between ethnic groups (Brena, Sanders, & Motoyama, 1990; Cleeland et al., 1996; Portenoy, 1989). Thus, assessment of ethnicity is clearly indicated when assessing patients in pain (Ludwig-Beymer, 1999; McGuire & Sheidler, 1997). Cavillo and Flaskerud used self-report as a means of establishing the ethnicity of participants. Moreover, Cavillo and Flaskerud used the RAM framework to study

response to post-operative pain in Mexican American and non-Hispanic, White American women. Residual stimuli are background factors that may influence adaptation to a situation but may not be immediately apparent or readily identified as influential in a particular situation. For example, the number of children living at home might be a factor in adaptation to an adult's cancer diagnosis and treatment. In the present study, demographic traits (i.e., gender, SES, marital status, religion, education) were collected by self-report and classified as residual stimuli.

In addition to three levels of stimuli, Roy identifies four interfacing behavioral categories, or means, by which individuals achieve adaptation. The behaviors leading to adaptation support goals of survival, growth, reproduction, and/or mastery, which, in turn, promote wholeness of the individual (Roy & Andrews, 1991). To buffer stimuli and promote adaptation, the four behavioral categories -- physical, role function, interdependence, and self-concept -- can be mobilized by an individual to adjust to changes in health status (BBARNS, 1999).

Physiological behaviors aim to promote or maintain physical integrity, despite neurological disruption or symptoms related to disease (BBARNS, 1999). For this study, the empirical indicator for the physiological behavior of pain intensity was the self-report of pain via the Brief Pain Inventory (BPI) (Cleeland, 1991). Additional data about the therapies used to reduce pain were obtained by a survey created by the investigator. Although the total PAIS (Derogatis & Derogatis, 1990) was used to measure adjustment, role function was captured within the vocational, domestic, and social domains of the PAIS (see discussion

below). Interdependence behaviors are interactions with others; for example, information-seeking behavior enhances adaptation (BBARNS, 1999) through interactions with others. In this research study, the empirical indicator for information-seeking behaviors was the score from the modified Krantz Health Opinion Survey (KHOS), developed to assess preference for health care information (Krantz, Baum, & Wideman, 1980) and modified by Tsutsui (1991) to study Japanese mothers of mildly ill children. The instrument was further modified for this study, with the author's permission, to assess information needs of adult chronically ill patients, including pain related information seeking behaviors in both Japanese American and European American men (personal correspondence, Krantz, February 17, 2000, see Appendix A). A pilot study ( $N = 17$ ) was conducted with the modified KHOS to test reliability of the modified instrument. Self-concept was not measured in this study.

RAM refers to adaptation as a process of using thought and feelings to integrate human and environmental changes in a manner that supports the individual's well-being (Roy, 1997). In this study, the term *adjustment* was used to denote the process of *adaptation*. *Adaptation* is defined (BBARNS, 1999) as a complex process that uses both innate (physiological) and acquired (information processing, emotional response) means to respond to change. Adaptation is consistent with the concept of *adjustment*. *Adjustment* is defined as a multidimensional concept that includes interactions with others, as well as role function (measured in vocational, domestic, and social environment domains of the PAIS) (Derogatis & Derogatis, 1990). The term *adjustment* is consistent with

the RAM concept of *adaptation* because both incorporate the sociocultural nature of the individual and environment.

The conceptual similarities between *adaptation* and *adjustment* supported the use of the PAIS as an empirical indicator for adaptation in this study. Further support is provided by Barone (1993), who used the PAIS to measure adjustment of patients with spinal cord injury within the RAM theoretical framework. Germino et al. (1998) also used the PAIS to measure overall adjustment in a study of African American men and Caucasian men who had prostate cancer.

RAM provided a framework to link multiple variables to adjustment, incorporating self-reported intensity of pain (physical behavioral category) and information-seeking behaviors (interdependence behavioral category), and other variables that influence adjustment to illness (see Table 1). (See Appendix B for constructs with conceptual and operational definitions and key publications.)

The information-seeking behaviors of men with prostate cancer, as well as differences between the two ethnic groups, were described in the present study. Roy (BBARNS, 1999) recognizes the provision of information to patients by nurses as an interdependent behavior and a viable method to promote adjustment. Thus, information-seeking can be viewed as an example of the RAM behavior classification of interdependence. Measured information seeking behaviors, self-reported intensity of pain, and adjustment provided information about both ethnic groups and tested the proposed predictors associated with adjustment to prostate cancer. The combination of focal, contextual, and residual stimuli with patient

behaviors and resulted in a level of self-reported adaptation (BBARNS, 1999), or adjustment to illness.

RAM focal stimuli	RAM contextual stimuli	RAM Residual stimuli	RAM Behaviors* Physiological (pain) and Interdependence (information)	RAM Outcome Adaptation
			Independent variables	Dependent variable
Prostate cancer -->	Ethnicity ---->	Demographics: Age, marital status, education, SES, language ---->	Pain ( <i>BPI</i> ) ↓ ---->	Adjustment ( <i>PAIS</i> ) [includes aspects of role function*]
			Information Seeking Behavior ( <i>KHOS</i> )	

*Table 1. Variables and Theoretical Framework/Roy Adaptation Model (RAM)*

*Italics* indicate instruments used to measure the variable.

\* The four RAM Behaviors are Physiological, Role Function, Interdependence, and Self-concept. Self-concept is not measured in this study.

### Delimitations

Only consenting men diagnosed with prostate cancer and currently undergoing treatment or who had completed treatment, and who were Japanese American or European American were included. Originally, the presence of either regional or distant metastasis was required, and was to be confirmed by radiography, scan, or surgical pathology report (Rana et al., 1993) or by a health care provider. Later, to facilitate recruitment, men with self-knowledge of any

stage of disease were allowed to participate. This change was approved by the dissertation committee as well as the NYU University Committee on Activities Involving Human Subjects.

Patients who had received or who were currently receiving recognized therapies for prostate cancer at the time of participation were eligible to participate in the research study. Recognized therapies included, but were not limited to, androgen deprivation therapy (hormonal), surgical ablation of testosterone by orchiectomy, radiation (radiological ablation of testosterone by local radiation, or radioactive seed implant/brachytherapy); local radiation for metastasis; radiation for pain control; or surgical prostatectomy (Frydenberg, Stricker, & Kaye, 1997; Held-Warmkessel, 1997).

Thus, inclusion criteria for this study were men with prostate cancer who

- had any stage of prostate cancer for which they were receiving, or had received treatment (i.e. initial treatment or treatment of more advanced disease)
- had undergone a prostatectomy
- had been or were currently being treated with androgen deprivation therapy (hormonal therapy)
- had or were currently being treated with external beam radiation
- had or were currently undergoing brachytherapy (radiological seed implants)
- had or were currently being treated with chemotherapy



- had or were currently being treated with investigational pharmaceutical agents
- had any combination of the above criteria.

Patients who had undergone surgery within the six weeks preceding entry into the study and those who had documented surgical pain were excluded from participation to avoid confusing surgical pain with cancer pain (Cleeland et al., 1996).

Patients with diagnosed and untreated brain metastasis were excluded because brain metastasis can impede mental function necessary to complete self-report instruments (Pinover & Coia, 1998).

Patients not fluent in English, who would not be able to give written informed consent, comprehend directions, or complete forms (provided in English) were excluded from participation (Kagawa-Singer et al., 1997).

### Definitions

*Adjustment to Illness* – the perceived impact of living with an illness. In this study, the dependent variable was adjustment to prostate cancer. Within the RAM, the term *adaptation* is used to define the mechanism by which a human being responds to any stressor, including but not limited to cancer. For the purposes of this study, the term *adjustment* was synonymous to *adaptation*, the behavioral outcome of an event (cancer) or related events. Operationally, the adjustment to prostate cancer was measured by its impact on health care orientation, vocational environment, domestic environment, sexual relationships,

extended family relationships, social environment and psychological distress -- domains measured using the Psychosocial Adjustment to Illness Scale – Self Report (PAIS-SR) (Derogatis & Derogatis, 1990). Although a total score was used as the measure of adjustment, the individual domain scores were also reported.

*Culture* – the learned beliefs, practices, norms, mores, values, and acceptable actions of a specific, but broad, group of people (i.e., Native Americans, Asians) (Leininger, 1994).

*Ethnicity* – a more specific group than culture, ethnicity defines shared symbols, language, religion, and lifestyles, which may not be fully understood by “outsiders” (Andrews & Boyle, 1999, p. 10) of a different racial or cultural group. The term refers to specific behavior within a culture; therefore, it was used to refer to the Japanese American or European American participants in this study. The *ethnicity* of each participant (e.g. Japanese American or European American) was self-defined by the participants (Cavillo & Flaskerud, 1993).

*Ethnic Groups* – the Japanese American men and the European American men having had treatment for prostate cancer.

*European American* – participants who self-identified as non-Asian, non-Black, and non-Hispanic/Latino. For the purposes of this study, participants were to be born in North America or Hawaii, and be of European heritage. At the time of study participation, participants resided in North America or Hawaii.

*Japanese American*: participants who self-identified as non-Black, and non-Hispanic/Latino. For the purposes of this study, participants were to be born

in North America or Hawaii, and be of Japanese heritage. At the time of the study participation, participants resided in North America or Hawaii.

*Information Seeking* – a method of obtaining knowledge as a basis for decision-making or action (Tsutsui, 1991) aimed at adjustment to an event or illness. Information seeking is an independent variable in this study.

Operationally, the total score of the modified Krantz Health Opinion Survey (KHOS) was used to measure information seeking behaviors including willingness of participants to ask questions of health care providers (Krantz et al., 1980; Tsutsui, 1991). Five domains of information-seeking are measured by the modified KHOS including: Asking, Not Asking, Trust, Resignation and Explanation (Tsutsui).

*Metastatic prostate cancer* - prostate cancer that had extended outside of the prostate capsule (i.e., seminal vesicle, lymph node[s], bone liver, lung); this included men who had a rise in PSA after an initial prostatectomy.

*Prostate cancer* – pathology of cells, which are surgically removed from the prostate gland, and are histologically diagnosed as cancerous. For the purposes of this research study, data were collected on men with the following:

- local or locally advanced disease (i.e., unclear surgical margins or residual disease after surgery),
- regional (e.g., lymph node), or
- distant (e.g., visceral organ or bone) prostate cancer.

This study included men who were currently receiving treatment or who had completed treatment for prostate cancer.

*Pain* – as defined by the International Association for the Study of Pain (IASP), “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey & Bogduk, 1994, page 210).

*Self-Reported Intensity of Pain* – degree of severity of pain from the perspective of the patient. Self-reported intensity of pain – an independent variable of this study – was operationalized as the score on a numeric rating scale (NRS) from 0, equal to “no pain,” to 10, equal to “pain as bad as you can imagine.” Self-reported intensity of pain was measured for least pain, average pain and worst pain for the week preceding the completion of the scale). The worst pain score was used to measure intensity, the worst pain scale is part of the BPI Short Form (Cleeland, 1991; Cleeland & Ryan, 1994) that was completed by each participant.

*Self-Reported Interference due to Pain* – degree to which pain has interfered with seven specific activities (general activity, mood, walking ability, normal work, relations with other people, sleep and enjoyment of life). Interference due to pain – explored as an ancillary analysis – was operationalized as the sum of seven interference scores, self-reported by the participant. The level to which pain interfered with each activity was scored on a NRS from 0, equal to “does not interfere,” to 10, equal to “completely interferes.” The measurement of interference due to pain is part of the BPI Short Form (Cleeland, 1991; Cleeland & Ryan, 1994) that was completed by each participant.

## CHAPTER II

### RELATED LITERATURE

#### Prevalence of Prostate Cancer

Since 1993, prostate cancer has been the second-leading cause of death due to cancer for men in the United States (American Cancer Society, 2007). Approximately 218,890 new cases of prostate cancer are expected within the U.S.A. in 2007 (American Cancer Society); the number of deaths due to prostate cancer is estimated to reach 27,050 in 2007 (American Cancer Society). The projected 2007 death rate represents a significant decrease in deaths due to prostate cancer, as compared to 40,000 deaths in 1996 (National Comprehensive Cancer Network, [NCCN], 1996). Declining incidence and death rates from prostate cancer suggest that the widespread use of the Prostate-Specific Antigen (PSA) laboratory screening test and digital rectal exams (DRE) has increased detection (Giavannucci & Platz, 2002). More men are living with, and adjusting to, the diagnosis and treatment of prostate cancer.

Similar to breast cancer in women, the risk for developing prostate cancer in men increases with age (Sartor & Powell, 2002) for both European American men and Japanese American men (Madanay, Johnson, Miyamoto, & Gilbert, 1995). Yet, racial and ethnic differences in prostate cancer, including incidence,

mortality, and disease presentation, have been reported throughout the world (Nelson, Deweese, DeMarzo, & Brooks, 2002; Sartor & Powell, 2002).

The African American population has the highest incidence and mortality rates of prostate cancer (Shavers & Brown, 2002). Although indigenous Japanese have a lower proportion of proliferative prostate cancer (20.5%) than Whites (34.6%), Japanese Americans report a higher percent of proliferative cancer (25.6%) than native Japanese men (Karr, 1992). A similar study (Veltri et al., 2004) found differences in the amount of malignant tissues between tissues of native Japanese men ( $n = 25$ ) and Japanese Americans ( $n = 25$ ). The cancer epithelium volume was 29.9 for the native Japanese men and 24.1 for the Japanese American men,  $p = 0.03$ .

Investigators have been exploring reason(s) for differences of incidences between racial and ethnic groups, including dietary factors: fat (Marks et al., 2004); fish (Allen, et al., 2004); meat (Sonoda et al., 2004); soy (Allen et al., 2004; Marks et al., 2004); and micronutrients (Nomura, Stemmermann, Lee, & Craft, 1997). Additional research has been aimed at examining smoking and alcohol consumption (Crispo, 2004; Sonoda et al., 2004). Many potential contributing factors have been identified, but no conclusive findings have yet been reported. For example, ingestion of fish has been reported to reduce the risk of prostate cancer (Sonoda et al., 2004), but also to increase the risk for men in Japan if ingested more than four times per week (Allen et al., 2004).

### Treatment for Prostate Cancer

Standard treatment for prostate cancer includes testosterone deprivation to slow the growth of hormone dependent cancer cells (National Comprehensive Cancer Network, 2005a; Weeraratana & Issacs, 2002). Anti-androgen hormonal agents, surgical castration (orchiectomy), or radiological ablation (via external beam or brachytherapy seed implant) can result in androgen deprivation. Radical prostatectomy, an option for men with localized disease, may provide up to ten years of metastasis-free survival. Although urinary incontinence and sexual dysfunction are risks of this radical surgical procedure, new surgical techniques are being practiced to reduce these risks (Potter & Partin, 2002; Shavers & Brown, 2002), and researchers continue to study the beneficial effects and quality-of-life issues of these treatments (Talcott & Litwin, 2002). In men with a life expectancy less than 10 years due to other health issues and who have a low risk of recurrence, active surveillance (watchful waiting) may be preferred because interventions can negatively impact quality of life (Steele & Richie, 2002; Wallace, 2003).

Regardless of the initial therapy or surveillance, monitoring of the patient's prostate specific antigen (PSA) serum levels continues. A rise of PSA level and/or metastasis indicates progressive disease. After initial anti-androgen therapy, patients with a rising PSA or metastasis are considered hormone refractory patients. Treatment options for patients with hormone refractory disease include alternative anti-testosterone therapy, chemotherapy, or

experimental drugs (National Comprehensive Cancer Network, 2005b; Petrylak & Moul, 2002). Bilateral orchiectomy quickly reduces testosterone production and represents a standard option for achievement of hormonal ablation in the patient with lymph node or distant metastasis (Petrylak & Moul). This procedure does not constitute a cure but can provide symptom relief of metastatic pain (Petrylak & Moul), as well as disease-free survival in some cases (Frydenberg et al., 1997). However, the procedure is not without residual side effects, which may include hot flashes, impotence, and decreased libido (Katz, 2002; Shavers & Brown, 2002). Some patients consider the surgical procedure and/or side effects unacceptable for both physical and psychological reasons (Katz, 2002).

Despite such interventions as analgesics, radiotherapeutics (radioactive medication), radiation, or chemotherapy, control of symptoms related to metastasis remains a problem for patients, family members, and health care providers. Severe pain can impair both mobility and socialization (Cleeland et al., 1996). The impact of prostate cancer on the cancer patient's life has been well documented and reflects the behavioral classifications identified by Roy, i.e., physical (Korfage et al., 2005; Lev et al., 2004; Moyad, 2005), self-concept (Roesch et al., 2005), social roles (Kronenwetter et al., 2005; Lev et al., 2004), and interdependence domains (Germino et al., 1998; Powel & Clark, 2005).

### Adjustment to Prostate Cancer

*Psychosocial adjustment* is used to define a complex construct (Derogatis & Derogatis, 1990; Murphy, 1994), representing feelings related to interactions



and activities of daily living. In this study, adjustment to illness is operationalized as the total score on the Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis, 1983).

The importance of adjustment to cancer has been documented in the literature, with noted emphasis on breast cancer patients and their partners (Budin, 1998; Carver et al., 2005; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Hoskins, 1995; Hoskins, Baker, et al., 1996; Manne et al., 2005; Mast, 1998).

Although much investigation of adjustment has been done in patients with breast cancer some studies of adjustment in men with prostate cancer have been conducted. Roesch et al. (2005) conducted a metanalysis of 33 studies to explore adjustment in men with prostate cancer. Germino et al. (1998) conducted a large comparative study ( $N = 403$ ) which used the PAIS to study adjustment in African American men and European American men with prostate cancer and their caregivers. Scura et al. (2004) used the RAM in a pilot intervention to study adjustment to prostate cancer. Further, Barone explored adaptation in chronic illnesses using both RAM and PAIS (Barone, 1993). Patterns of adjustment in ethnically diverse groups have been explored by a few investigators.

#### Adjustment and Ethnicity

Kagawa-Singer et al. (1997) studied psychological distress and health-seeking patterns in Japanese American ( $n = 11$ ), Chinese American, ( $n = 11$ ) and Anglo American ( $n = 13$ ) women with breast cancer. Predictors of adjustment

were age, culture, and acculturation. Information-seeking patterns and requests for help were different between all three ethnic groups. Japanese American women requested help related to psychosocial issues 7 times, compared to 45 times for Anglo American women. The average number of requests for any reason (physical, medical, sexual, marital or psychosocial) per person was 9 for Chinese Americans, 7 for Japanese Americans, and 20 for Anglo Americans, with the comparison between Asian Americans and Anglo Americans showing a trend toward a statistically significant difference ( $p = .093$ ). The researchers cite different communication styles between Western and Eastern cultures as a reason for the difference in fewer requests for help by Japanese American women and also note that Japanese American women may not recognize that they need help or may not know that they can ask for help.

Ka'opua et al. (2005) examined adaptation from the perspective of the wives of men with prostate cancer living in Hawaii ( $N = 26$ : Chinese, 7; Filipino, 3; Japanese, 13; and Native Hawaiian, 2). The researchers were careful to recognize the uniqueness of, as well as the similarities between the individual ethnic groups. Shared values among the participating Asian groups included collectiveness (family value over individual), harmony of relationships, and interdependence. Values specific to the Japanese included *on*, or obligation to others (putting others first); *giri*, or reciprocity; and *amae*, or interdependence. Study findings included the importance participants placed on learning about prostate cancer and adaptation to changes. Terms used by the Japanese wives to explain adaptation included *samurai streak* to denote the

privacy of feelings, difficulty attending support groups, and stoicism; *shikata ganai*, which translates to “it cannot be helped,” to represent acceptance, the futility of worrying, and the need to “enjoy life as best you can”; and *gambate*, meaning to persevere, akin to survivorship, and doing one’s best with a situation (Ka’opua et al., 2005, p150). The study supports the need for continued research into ethnic variations of adaptation and the importance of understanding the nuances of ethnic groups to tailor information, communication, and interventions to meet the needs of cancer patients and their families.

When comparing quality-of-life measures of European American men and men with Filipino, Native Hawaiian, and Japanese heritage, Gotay et al. (2002) found differences only in areas of functioning. The analysis of men with prostate cancer ( $n = 101$ ) was part of a larger study, which also included patients with breast cancer ( $n = 126$ ). Fatigue ( $p = .01$ ), and nausea ( $p = .001$ ) were reported more frequently by Filipinos; while the number of symptoms was higher in Native Hawaiians ( $p = .001$ ) (Gotay, Holup, & Pagano, 2002).

Germino et al. (1998) studied psychosocial adjustment of patients in a quasi-experimental, randomized study of 403 African American ( $n = 69$  dyads) and European Americans ( $n = 132$  dyads) prostate cancer patients and family care providers (FCP) from a Southern region of the United States to determine the relationship of uncertainty to family coping, adjustment to illness, and spiritual factors. The patients participating had localized prostate cancer, or cancer that had spread but was contained within the prostatic capsule (which includes Stage A and Stage B classifications). Participants were randomized to one of three

intervention groups. All groups received standard medical and nursing care. The control group had no other intervention; the male patients in the second group also had weekly telephone counseling for eight weeks; and both the male patient and the FCP in the third group received weekly telephone counseling for eight weeks. The telephone counseling was conducted by a nurse interventionist who was matched to participants by gender and ethnicity.

Using Mishel's Uncertainty in Illness Scale (MUIS) (Mishel, 1984), variables of uncertainty included adult role behavior (i.e., running errands), problem-solving ability, social support, importance of God, and family coping. Psychosocial adjustment to illness was measured by using an early version of the PAIS (Morrow, Chiarello, & Derogatis, 1978), and domains of psychosocial adjustment included health care orientation, domestic environment, social environment, sexual satisfaction, extended family relationships, and psychological distress (worry). Participants completed questionnaires after their initial prostate cancer treatment and after eight weeks of telephone counseling.

African American patients and FCPs each had approximately 12 years of education as compared to European American patients and FCPs, with 15 and 14 years of education, respectively. In addition, prostatectomy was the primary treatment for European American men (77%), compared to only 55% for African American men. Conversely, more African American men (27%) had radiation than European American men (12%). Patients who had surgery were younger than those who had radiation ( $p < .005$ ), and surgical patients had more education ( $p < .05$ ). Thus the study (Germino et al., 1998) provides support to the importance of

age and education as factors related to treatment decisions, and consequently adjustment.

Although Germino et al. (1998) did not find differences in physical domains when using the PAIS to explore differences between uncertainty and adjustment in African American and European American men with prostate cancer ( $n = 403$ ), significant correlations were noted with correlations of uncertainty and adjustment in areas of domestic environment, extended family relationships and psychological distress. Higher levels of uncertainty were related to poorer adjustment,  $p < 0.05$ .

Relationships between six PAIS domains and uncertainty were analyzed. The domain of vocational environment was not measured. Although no explanation for the omission was provided by the authors, the average age of participants in the study was 65 years. It is possible that vocational environment was not applicable for many of the participants in the study Germino et al. (1988) conducted.

Statistically significant correlations were reported among four domains for the patients. Among African American patients and European American patients (respectively), the greater the uncertainty: 1) the less the ability to function in the domestic environment ( $r = -.35, r = -.21, p < 0.05$ ); 2) the less perceived support from extended family members ( $r = -.35, r = -.19, p < 0.05$ ); and 3) the more psychological distress ( $r = -.41; r = -.36, p < 0.05$ ). Among European American patients, the greater the uncertainty, the more difficulty functioning in social relationships ( $r = -0.26, p \geq 0.05$ ). The correlation between uncertainty and the

quality of sexual relationships, and the correlation between uncertainty and the patient's health care orientation were not statistically significant for either African American or European American patients (Germino et al., 1998).

Similarly, the correlation of uncertainty and health care orientation was not statistically significant for any FCP group. However, some marked ethnic differences between the correlation of uncertainty and adjustment to the remaining five measured PAIS domains were noted for the FCPs. The correlation of uncertainty with psychological distress was the only statistically significant ( $p < .05$ ) finding for the African American FCPs. The findings indicate that the higher the level of uncertainty, the more psychological distress reported by the FCPs ( $r = -.27, p < .05$ ); this finding was also noted for the European American FCPs ( $r = -.45, p < .05$ ), with a marked difference in magnitude of the correlations between ethnic groups (Germino et al., 1998). Among European American FCPs, correlations reached significance for increased uncertainty and 1) decreased function in the domestic environment ( $r = -.32, p < .05$ ); 2) decreased perceived support from extended family ( $r = -.23, p < .05$ ); 3) increased difficulty functioning in the social relationship ( $r = -.34, p < .05$ ); and 4) decreased quality of sexual function or relationships ( $r = -.19, p < .05$ ). European American FCPs were the only group to have a statistically significant correlation of uncertainty and sexual relationship, and this relationship was weak. The investigators attributed noted differences of uncertainty and adjustment between African American and European Americans to African Americans' fatalistic worldview, which is similar to Japanese philosophy (Kagawa-Singer, 1988). Unfortunately,

however, statistical comparisons between the adjustment scores of African American patients and European American patients were not reported. The reporting of *t*-test comparisons of adjustment between ethnic groups would have provided important information about disparity of patient adjustments. Germino et al. (1998) did identify education, treatment options, and ethnicity as important factors in the exploration of adjustment.

#### Psychosocial Adjustment to Illness Scale (PAIS)

Germino et al. (1998) assessed internal consistency by calculating the Cronbach coefficient alpha for six PAIS domains. Only Social Environment and Psychological Distress had alpha coefficients greater than  $r = .70$  for patients and care givers in both ethnic groups (African Americans and Whites) (Germino et al.). Alpha reliability scores for the other three domains studied (domestic environment, sexual relationships, and extended family relationship) ranged from 0.43 – 0.60. Extended family relationships had adequate internal consistency (no specific alpha reported) for care givers and for White patients, but less than adequate ( $r = .43$ ) for African American patients. In Germino's study, which included ethnic groups, the internal consistency analysis for the PAIS was lower than reported in other studies.

In addition to the research conducted by Germino et al. (1998), the PAIS was used in an exploratory quantitative study conducted by Powel and Clark (2005). In the later study, 48 men with prostate cancer completed the PAIS and the SF-36, a health status instrument. After completing both instruments, the

participants had the opportunity to comment on any other aspects of their prostate cancer that was not covered by the instruments. In this study of men having had a prostatectomy 6 – 12 months prior to entering the study, the reliability of the PAIS was 0.85.

Interestingly, Pollock studied chronic illness using the RAM in a program of study encompassing five studies, which included both interviews and completion of instruments to study adaptation, hardiness, and health promotion activities (Pollock, 1993). The five studies included 597 adults with diabetes mellitus (42%), multiple sclerosis (23%), hypertension (19%) and rheumatoid arthritis (16%) (Pollock, 1986). Pollock (1993) found that perception of illness played a larger role in adaptation than did the physiological status. Further, her studies supported the physiological mode and the psychosocial modes as distinct behaviors, as defined by RAM.

Using Pollock's work as a springboard, Barone (1993) used the RAM to frame her study of adjustment to chronic illness in patients sustaining spinal cord injury. Barone's descriptive study of 243 patients included the use of the PAIS to measure psychosocial adjustment. Additionally, hardiness, functional independence and ways of coping were studied. Barone (1993) conducted reliability testing on the PAIS domains which ranged from 0.66 (Health Care Orientation) – 0.88 (Psychological Distress). Although the participants studied by Pollock and Barone were not prostate cancer patients, their works provide support for the use of the RAM as a framework for chronic illness. Moreover, Barone identified the PAIS as a suitable means to study adaptation within the RAM.



Scura et al. (2004) utilized the RAM to study the usefulness of telephone intervention for men with prostate cancer, in a prospective randomized pilot study of 17 men. Although no statistically significant difference was noted between the control group and the intervention group, interviews conducted with the participants indicated that the telephone support and written materials may potentially provide support for men with prostate cancer (Scura et al., 2004). Importantly, Scura et al. used the RAM to study the physiological, emotional, functional and social adaptation of men to prostate cancer.

#### Prostate Cancer and Pain Intensity

Posing a significant stimulus, pain associated with prostate cancer warrants further exploration. Many men diagnosed with prostate cancer will die of causes other than cancer, due to the slow progression of the disease coupled with an advanced age at the time of disease onset. For others, the prostate cancer will advance to necessitate an increase in health care and eventually may cause death. Prostate cancer advances locally to the lymphatic system and pelvis. Pain is a significant problem caused by distant metastasis to bone (approximately 70%-80% of all metastasis), lung, liver (approximately 20% of all metastasis), or adrenal glands (Bubly, 2002; Mercadante, 1997; Olson & Pienta, 1999, Smith & Kaufman, 2002).

Like intense pain from other causes, pain related to prostate cancer or treatment results in distress (DiLorenzo et al., 2005; Portenoy et al., 1994), altered independence (Saad, Perrotte, Benard, McCormack, & Karakiewicz, 2005), and

interference with physical activity and social behavior (Cleeland & Ryan, 1994; Kylmala, Tammela, Lindholm, & Steppanen, 1994; Moore, 1997; Rondorf-Klym & Colling, 2003). The assessment and measurement of pain intensity and related factors has provided a challenge for researchers and clinicians for over 30 years (Bruera & Neumann, 2003; Gordon et al., 2005; Houde, 1982; Melzack & Wall, 1997; Owen, Klapow, & Casebeer, 2000).

### Pain Intensity and Measures

Pain intensity, like cultural differences and information-seeking behaviors, is a potential predictor of adjustment to cancer (Rustoen, Moum, Padilla, Paul, & Miaskowski, 2005). The assessment of pain intensity is paramount in the treatment of pain and influences a patient's ability to maintain routine interactions, relationships, and roles (Cleeland et al., 1996; Fitch, Johnson, Gray, & Franssen, 1999).

Assessment of pain intensity has evolved from a purely physiological perspective proposed by Descartes as early as 1644 (Melzack & Wall, 1997) to a more holistic subjective approach (Coyle, 1993; Gordon et al., 2005). Pain experts generally agree that assessment of pain intensity should be based on self-report (Jensen, 1997, 2003). A paradigm shift has occurred from physiological measurements (e.g., blood pressure, pulse) as surrogate markers for pain to self-report of pain intensity. The reliance on self-reported pain intensity emphasizes the reliance of patients to communicate with health care providers. Furthermore, the importance of self-report of the intensity of pain has resulted in the

development of assessment tools such as the Memorial Symptom Assessment Scale (Portenoy et al., 1994) and the Brief Pain Inventory (BPI), which incorporates the Numeric Rating Scale (NRS) for pain intensity (Cleeland, 1989).

The content of the BPI was based on the classic 56-item McGill Pain Questionnaire (Melzack, 1975), which includes word descriptors, pain intensity numerical scales, and numerical scales measuring interference of various activities due to pain. The BPI short form (Cleeland, 1991; US Department of Health and Human Services, 1994) includes the location of pain, pain intensity questions, interference, and pain relief questions. The difference between the long and short forms is that demographic, medical history, and word descriptors are omitted from the latter. The investigator selected the BPI short form rather than the McGill Pain Questionnaire based on ease of completion and published testing in a Japanese cancer population (Uki et al., 1998).

Construct validity of the BPI was assessed by factor analysis in a study of cancer patients from Vietnam ( $n = 36$ ) and the US ( $n = 183$ ) (Cleeland et al., 1988). A two-factor solution, consisting of pain intensity and pain interference, accounted for approximately 67% of the variance in the US group and approximately 65% in the Vietnam group. Similar domains were identified using the Japanese version (Uki et al., 1998).

In a separate study, an independent analysis of BPI results from four different countries (US, France, China, and the Philippines;  $n = 1704$ ), Cleeland et al. (1996) utilized non-metric dimensional scaling (MDS) to identify dimensions of pain interference. The dimension of interference can be further classified as

activity (walking, work, general, sleep) and “affectively related functions” (relations with others, mood, enjoyment of life) (Cleeland et al., 1996, p. 272).

Cleeland et al. (1988) tested the discriminant validity of the BPI by examining 183 patients in the US with cancer pain, either receiving opioid analgesia or a weaker, non-opioid analgesia (such as aspirin). It was postulated that the pain score obtained by the BPI would enable discrimination between patients treated with a stronger or weaker medication. Results from a discriminant function analysis supported the ability of the BPI to discriminate a difference in functional scores between the two sub-samples receiving different categories (i.e., opioid or weaker) of medications. All pain items (worst, least, average, pain now) correlated moderately with the total function score. Correlations of pain scores with interference of general activity ranged from .45 - .63.

Reliability of the BPI was assessed using the test re-test method (Daut et al., 1983). A sample of 20 inpatient cancer patients with either breast, prostate, colon-rectal, or gynecological cancer was obtained. Information about the specific number of patients with each type of cancer, ethnicity of the patients, time since diagnosis, or stage of cancer was not cited. The re-test analysis was performed for pain intensity (“worst pain,” “usual pain,” and “pain now”) and administered within 1-7 days of an initial measurement.

Analysis of repeat testing resulted in a strong correlation ( $r = .93$ ) for “worst pain.” The correlation for “usual pain” was  $r = .78$ , and for “pain now”  $r = .59$  (Daut et al., 1983). The weaker correlation obtained for “pain now” measurements could reflect an actual change in patients’ status, even over a short

span of time. In a review of self-report pain instruments, Jensen (1997) states that reliability based on test re-test assessments are relatively high for a NRS.

Additional reliability testing was conducted in cancer patients from different cultures. Cancer patients from the US ( $n = 1106$ ), France ( $n = 324$ ), Philippines ( $n = 267$ ), and China ( $n = 146$ ) completed the BPI. Coefficient alphas for pain intensity and interference due to pain were reported as  $\geq .80$  (Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995). Uki et al. (1998) administered the Japanese version of the BPI (BPI-J) to Japanese patients ( $N = 121$ ) with breast (13%), stomach (12%), lung (22%), and other types (55%) of cancer. A coefficient alpha of 0.81 was obtained for pain intensity and interference due to pain (Uki et al., 1998).

The NRS has been translated into other languages and validated and found reliable in numerous countries. Cleeland et al. (1996) evaluated validity and reliability of the BPI in a large sample ( $N = 1843$ ) accrued from China, France, Philippines, and the United States. Although differences in expressions of pain were noted between cultures, the researchers maintain that little difference exists in pain intensity and interference in physical and social activities for patients across cultures, and they encourage other researchers to look beyond pain intensity for cultural differences in pain behaviors. In a sample of 147 Chinese patients, the BPI scores were assessed as having a higher mean ( $M = 7.15$ ,  $SD = 1.81$ ) than any other group. The coefficient alpha for the pain severity of the Chinese version of the BPI (BPI-C) was assessed as .89. Although differences in functional (daily physical activities) and affective (interpersonal and social)

interference were found in the sample of Chinese patients, differences were not as clear for the other cultural groups. The overlap of functional and affective dimensions on multidimensional scaling plots indicate that physical and social activities were more closely related to each other in the Chinese sample. This pattern, coupled with the results from a study by Brena et al. (1990), which indicated less impairment of activities in Japanese patients with low back pain compared to US patients, supports the need for additional research that includes Eastern cultures and self-report of pain intensity.

#### Cultural Aspects of Pain

Culture is generally defined as learned beliefs, practices, norms, mores, values, and acceptable actions of a specific group of people (Berger, 1963; Leininger, 1994). Culture and ethnicity play an important role in pain behaviors (Bates, Edwards, & Andrews, 1993; Brena et al., 1990; Cleeland et al., 1996; Melzack & Wall, 1997; Zborowski, 1952, 1969), as illustrated in the qualitative ( $N = 103$ ) study conducted by Zborowski (1952). Although the participants were of diverse heritage, all were living in the US; thus, they represented ethnic groups, more specific groups than cultural groups, within the host North American culture. However, because Zborowski used the term *culture* at term will be retained in this review of that study.

Recognizing that neurophysiology was only a part of the pain experience, Zborowski's (1952) objective was to describe cultural attitudes and behaviors associated with pain. Participants were classified by health care providers into one

of five groups, according to culture and observed differences in pain behaviors: Jewish ( $n = 31$ ), Italian ( $n = 24$ ), Irish ( $n = 11$ ), “Old American” ( $n = 26$ ) (third-generation Americans reporting no affiliation with any other cultural group), and other ( $n = 11$ ). Because the study was conducted at a US Veterans Administration Hospital, participants were predominately males. Patients had back pain due to either a herniated disc or a spinal lesion. Interviews consisting of open-ended questions were held with the patients and healthy family members. To corroborate findings, discussions with medical personnel were conducted after the interviews.

The originally published findings (Zborowski, 1952) indicated different concerns and pain behaviors among three groups. The Italian patients were concerned with the actual sensation of pain and readily accepted pain medication. The Jewish patients were focused on the underlying cause of the pain and the projected threat to their current lifestyle. Both the Italian and Jewish patients expressed pain openly by groaning, verbalizing, and varying body language. The patients grouped as “Old Americans” were detached from their pain and described pain in a factual manner. Americans suppressed overt reactions to pain and admitted crying in severe pain, but only cried when alone; this group focused positively on the future and generally had expectations that they would be healed.

Research conducted decades later (Bates & Edwards, 1992) indicated that reasons for pain can alter a patient’s attitude toward the pain. Thus, in retrospect, the variability of the underlying reason for back pain (i.e., benign versus malignant) is an important limitation of Zborowski’s study. Nevertheless,

Zborowski (1952, 1969) identified ethnicity as an important variable associated with expression of pain.

Building on the original findings of Zborowski (1952, 1969), Bates et al. (1993) studied patients of varying cultural heritages experiencing chronic pain. Bates developed a biocultural model (Bates et al., 1993), a theoretical framework similar to the RAM (Roy & Andrews, 1999), which incorporates biological, social, cognitive and psychological aspects of pain perception and response. Data on 372 patients who attended a chronic pain center were collected over a period of nine months. Patients completed an Ethnic Pain Questionnaire (EPQ), which provides extensive data about ethnic aspects of a participant's lifestyle (Bates et al., 1993), and the McGill Pain Questionnaire (MPQ), a comprehensive questionnaire used to measure pain severity and related variables (Jensen, 1997; Melzack, 1975). Health care providers assessed each patient for location and duration of pain. Six ethnic groups were identified and included "Old American" ( $n = 100$ ), as originally identified by Zborowski (1952), Hispanic ( $n = 44$ ), Irish ( $n = 60$ ), Italian ( $n = 50$ ), French Canadian ( $n = 90$ ) and Polish ( $n = 28$ ). The findings demonstrated "stoicism" among Old Americans, thus supporting Zborowski's findings (1952, 1969). Analysis of variance indicated the Hispanic and Italian groups were more likely to communicate pain than were the Old Americans. Another important finding was an association between daily ethnic practices and the likelihood to express pain in a manner consistent with others in the cultural group.



Also recognizing that culture is associated with pain behaviors, Brena et al. (1990) studied Japanese ( $n = 10$ ) and North American ( $n = 10$ ) patients with chronic, non-malignant back pain and healthy participants from each culture (Japanese,  $n = 11$ ; North Americans,  $n = 10$ ). Patients were outpatients of pain clinics in Tokyo, Japan, and Atlanta, Georgia. The ethnicity of the North American participants was not obtained. Collection of ethnicity data would have strengthened the study because within a city may be “multiple intersecting cultures...and profound differences” (Henderson, Sampsel, Mayes, & Oakley, 1992, p. 345). The measures for all subjects consisted of a comprehensive physical examination quantified by the Medical Examination Protocol for Pain (MEPP) (developed by the investigators) and the self-administered Sickness Impact Profile (SIP) (Bergner et al., 1976), a measure of impairment of 12 broad categories of common activities that include physical, social, and emotional behavior, which, in turn, are further classified into three subscales -- psychosocial, physical, and “other.”

The PAIS domains and the Sickness Impact Profile (SIP) subscores (Bergner, Bobbitt, Carter & Gilson, 1981) overlap but are all inclusive. For example, the SIP psychosocial subscore includes social interaction, communication, alertness, and emotional behavior, while the PAIS has a specific domain for psychological distress, which focuses on emotional behavior. Similarly, the PAIS domain social environment addresses leisure interest and recreation activity, captured within the subscore of the SIP called “other.”

No differences were found in physical findings, pain assessment (MEPP), or impairment of physical activities (SIP physical subscale) between the healthy Japanese and healthy American participants (Brena et al., 1990). Similarly, no differences were noted between the Japanese and American patients with back pain ( $p \geq .05$ ). Differences in physical findings, pain assessment (MEPP), and self-reported physical impairment were found between the healthy participants and the patients. The North American patients had higher overall scores on the 136-item SIP than did the Japanese patients, indicating more impairment in activities related to the psychosocial and “other” sub-scales for the North American patients (Brena et al., 1990). An analysis of variance for main effects of culture showed a trend toward statistical significance for the overall SIP score ( $F [1, 38] = 3.5, p \leq .10$ ) for the three subgroups combined. Statistically significant ( $p \leq .05$ ) main effects for culture were identified for the psychosocial ( $F [1,38] = 4.8, p \leq .05$ ) and “other” subscale (home management, work and recreational activities) ( $F [1,38] = 4.2, p \leq .05$ ). Differences in impairment of some activities, including those classified within the psychosocial subscale (social interaction, communication, alertness, and emotional behavior) were noted between the North American patient group (more impairment) and the Japanese patient group.

Brena et al. (1990) noted that the small number ( $N = 42$ ) of participants limited the generalizability of the research findings. In addition, although physical and pain assessments were done, self-reporting of pain intensity was not used. Despite these limitations, this study suggests that psychosocial impairment

measures between Japanese patients and American patients can differ, even when physical findings and pain assessment are comparable. This finding is similar to studies conducted with Chinese patients (Cleeland et al., 1996) and Japanese patients (Uki et al., 1998), which measured self-reported pain intensity and interference with activities (BPI). While the pain intensity was similar between cultural groups, the amount of interference with specific activities was greater in American patients than in Chinese or Japanese cancer patients.

Since Zborowski's (1952) landmark study of culture and pain, culture has been recognized as an important variable in the assessment of pain intensity and impact on activity (Brena et al., 1990; Cleeland et al., 1996). A gap in the literature exists, as few comparative studies examining culture have been conducted in cancer patients. The inconclusive findings of the few studies conducted with Japanese and/or Japanese American participants underscore the need to continue research to explore differences.

#### Information-Seeking Behavior

Like self-reporting of pain, information-seeking behavior entails communication and an exchange of information between two people, or interdependence. A health care provider can give unsolicited information, or the patient can initiate an exchange of information. Similar to the exchange of information regarding intensity of pain, information-seeking behavior can be influenced by culture, specific ethnicity (Kakai et al., 2003), communication

patterns (Ishikawa et al., 2002; Ka'opua et al., 2005), and health care behaviors (Kagawa-Singer, 1988; Kakai, 2002).

Information-seeking may lead to better sense of control and more positive outcomes. A Canadian study of 101 men with prostate cancer (Wong et. al., 2000) found that men wanted detailed information about their disease, treatment, and outcome, as well as empowerment. Seventy percent of participants completing a questionnaire reported wanting detailed information about their diagnosis, treatment, survival, self-care and empowerment. Sixty percent of participants were interested in obtaining CD Rom or information via the computer. Those men interested in obtaining additional information had a higher level of optimism, as measured by the Life Orientation Test ( $p = 0.05$ ). The mean age of the participants was 70 years; however, no ethnic information about the participants was provided.

In a prostate cancer study funded by a grant from the National Institute of Nursing Research, Robinson et al. (1999) studied home care needs of patients and caregivers. In this study, 32 patients had four weeks of home care that consisted of eight home care visits and five telephone calls by advanced practice nurses. The nurses were enlisted to provide comprehensive care to the patients but were blinded to the nature of the research study. The patients, aged 60-83, were primarily White (75%) and married (90%), and had early prostate cancer without metastasis (87%). These patients were seen from the day of discharge after having surgery for prostate cancer. Thirty-one patients had had a prostatectomy and one patient had had a lymph node biopsy.

A paired *t*-test was used to compare the frequencies of types of care documented between the initial and final visit. Provision of information (first visit  $M = 6.00$ ,  $SD = 3.09$ , last visit  $M = 3.22$ ,  $SD = 2.42$ ,  $t(32) = 3.66$ ,  $p < .05$ ), assessment of baseline health status (first visit  $M = 1.31$ ,  $SD = 1.73$ , last visit  $M = 0.69$ ,  $SD = 1.00$ ,  $t(32) = 2.24$ ,  $p < .05$ ), and assessment of physiological status (first visit  $M = 1.34$ ,  $SD = 1.73$ , last visit ( $M = .63$ ,  $SD = 1.04$ ,  $t(32) = 2.86$ ,  $p < .05$ ) had statistically significant differences. Care aimed at managing the environment, general care, care focused on cognitive understanding and control, and symptom management showed no statistically significant difference in frequency between the first and last visit (Robinson et al., 1999).

Robinson et al. (1999) also held debriefing sessions with the advanced practice nurses where nurses reported that patients had residual psychosocial and informational needs that extended past the four-week duration of this clinical trial. Although the provision of information decreased from the first to the last visit, nurses did not think patients were ready to confront sexuality issues during the four weeks of the home care.

The Robinson et al. (1999) study supports the need for nursing assessment and interventions aimed at physical needs in the early weeks following prostate surgery. The need for information, symptom management, and psychological support continues past this initial period. During the initial period after surgery, the patient's main focus (focal stimuli) was, most likely, obtaining physical comfort. It is possible that, as post-operative healing evolves, the focus shifts from physical to more psychosocial issues. Physical sequelae of surgery (i.e.,

incontinence, sexual impotence), related psychosocial adjustment, and the long-term implications of prostate cancer may become more apparent to the patient after the initial post-operative period has passed. The need for information, symptom management, and psychological support to enhance adjustment continues beyond the four-week period following surgery.

Roesch et al. (2005) conducted a meta-analysis of 33 previous studies of coping and adjustment to early-stage prostate cancer (localized), which represented 3,133 participants who were predominantly White, a limitation identified by the authors (no specific demographic % reported). Studies were reviewed for coping styles reported and outcome measures of adjustment or aspects of adjustment (i.e., physical activity, socialization, normal activities, and pain). Using Cohen's Kappa and Pearson correlations, coping strategies and aspect of adjustment had high reliability (range .92 -.98). Information-seeking was classified both as a means of approaching and solving the problem, both are active forms of coping with the diagnosis of prostate cancer. Approach coping (which includes information-seeking) was noted to increase positive affect and social functioning, as well as reduce depression and general pain (mean effect size = -1.3, CI -.22 to -.04,  $p = 0.05$ ). A medium effect size was obtained for approach coping and overall adjustment (mean effect size = .23,  $p < 0.001$ ; CI = .14 to .32).

Thus, active coping, which included information-seeking, was linked to both pain control and positive adjustment. The linkage between information-seeking, pain control and adjustment reported by Roesch et al. (2005) provides support for the variables and model used in this study. Information-seeking

involves interdependence as defined by the RAM, and active communication between the patient and healthcare provider.

Communication between physicians and patients with cancer is an emerging area of study in Japan (Fujimori et al., 2005; Ishikawa et al., 2002; Kakai, 2002). Culturally driven communication patterns give insight to why Japanese Americans may seek healthcare information differently than European Americans (Kagawa-Singer, 1988; Sharts-Hopko, 1996; Ishikawa, et al., 2002).

Ishikawa et al. (2002) studied the interactions between 140 cancer patients and 12 physicians in Japan. Most participants were female (60%), with the mean age of 58.8 ( $SD= 11.0$ ). All but one physician was male; seven were internists and five were surgeons. The researchers wanted to compare physician-patient interactions to interactions reported in western countries and to explore physician-patient communication and patient satisfaction during the second office consultation with either a medical or surgical specialist for a cancer related diagnosis. Using the Roter Interaction Analysis System (RIAS) to measure physician-patient interaction (Ishikawa et al., 2002), the researchers analyzed the number of utterances and the categorization of the interactions from audiotapes and transcripts of second visits with consulting physicians.

The majority of interactions were categorized as “information giving,” supporting the role of information as important to both Japanese physicians and Japanese patients. Of physician communication, 35.2% was related to information; 34.3% of patient communication was related to information. Most of the information exchanged focused on biomedical information, rather than

psychosocial aspects of cancer. The researchers found that the Japanese patients were more satisfied when physicians asked open-ended questions and that those patients who asked more questions of the physician were less satisfied with the visit. The researchers (Ishikawa et al., 2002) note that the need to ask questions of physicians, due to inadequate explanation, may have led to less satisfaction with the physician visit.

Japanese tradition, based on Buddhism, emphasizes meditation, thinking, and understanding as ways to decrease suffering. As a result of tradition and communication patterns, “impassivity and stoicism” (Dana, 1993, p. 54) are traditional behaviors in response to pain. Therefore, Japanese American patients may not verbalize pain or seek information about it.

*Omakase* is a term for a conceptually related behavior that literally can be translated as deferring decision making to medical staff due to trust or due to resignation, and was found to account for young Japanese mothers not asking questions about their children’s minor illnesses (Tsutsui, 1991). After surveying 181 mothers in Japan, Tsutsui concluded that mothers who trusted the medical staff had fewer negative emotional outcomes ( $r = -.27, p < .01$ ), whereas, mothers who reported *Omakase* based on resignation had more negative emotional outcomes ( $r = .36, p < .01$ ). Although Tsutsui conducted her study in a sample that is different from men with prostate cancer, the concept of *Omakase* remains important to Japanese culture and may affect the information-seeking behaviors of Japanese American men with cancer.



As noted earlier, Kagawa-Singer et al. (1997) reported a similar pattern of reluctance to ask for help, in a small population ( $n = 11$ ) of Japanese American women with breast cancer. When compared to Anglo American women ( $n = 13$ ) the Japanese American women had less than half the number of requests for help and information from health care providers. Despite the extremely small sample size, and a non-significant difference in frequency of request for help between groups ( $p = .093$ ), the difference between the two groups underscores the need to further examine information-seeking behavior and adjustment in patients who have cancer and are Japanese American.

In a study of 140 cancer patients, Kakai et al. (2003) found that Caucasians preferred information obtained through medical journals, telephone services, and the Internet, whereas Japanese Americans preferred commercial sources including television, newspapers, books and magazines. Non-Japanese American Asians and Pacific Islanders used person-to-person information. Level of education did not influence these preferences.

As early as 1952, Zborowski documented qualitative findings of differences in behavior associated with pain between ethnic groups. While Zborowski's study did not include Japanese American patients, the study did establish a link between ethnicity and expression of behaviors related to pain. It remains unclear whether the perception of pain intensity is related to ethnicity or culture or whether the communication patterns such as self-reporting of intense pain, and/or information-seeking behaviors are different between ethnicities and cultures. Cultural beliefs may promote limited information-seeking behavior in an

effort to show respect for, or trust of, the health care professional. A Japanese American patient with cancer may value respect and trust of others above the perceived benefit from reporting intense pain or seeking information about an illness.

#### Krantz Health Opinion Survey (KHOS)

The KHOS (Krantz et al., 1980) was originally designed to measure overall preference for treatment approaches and includes domains of Information Seeking and Behavior Involvement. Forty original items were first developed based on face validity from a pre-existing instrument (Linn & Lewis, 1979). The 40-item instrument was completed by 200 undergraduates and an item analysis was conducted. Items which correlated less than .20 with the total score were eliminated. Twenty-six items remained.

Krantz et al. (1980) then conducted a principal components factor analysis of a 26-item survey based upon assessment of 159 undergraduates and identified the two subscales of Behavioral Involvement (active involvement in healthcare), and Information-Seeking (measuring desire to be informed). Item revision and omissions were made to the instrument, resulting in a final 16-item instrument consisting of two subscales of Behavioral Involvement (nine questions measuring active involvement), and Information Seeking (seven questions measuring desire to be informed).

Discriminant validity was also assessed in a study of three groups of students ( $N = 149$ ): students enrolled in a medical self-help course ( $n = 12$ ), and

students reporting to the medical office for routine care on weeknights ( $n = 81$ ), and freshmen dormitory students ( $n = 56$ ) not enrolled in the medical self-help course and not reporting to the medical office (Krantz et al., 1980). A trend toward a statistically significant difference between groups for the Information subscale was reported,  $t(146) = 1.76, p < .10$ . Students reporting to the medical office for minor illnesses scored lower on the Behavioral subscale than those enrolled in a self-help course,  $t(146) = 1.98, p < .05$ . However, no difference in the information subscale or overall scale was detected between the students reporting to the medical office and the students enrolled in the medical self-help course.

The reliability of the total KHOS was assessed by Krantz et al. (1980) as having a Kuder-Richardson 20 reliability score of 0.77. The alpha coefficient for Behavioral Involvement was 0.74, and for the Information Subscale, 0.76, in a sample of 200 undergraduate students (Krantz et al.). Test re-test reliability for the Behavioral, Information, and total scores were also assessed over a seven-week period, in another sample of students ( $N = 80$ ). The reliabilities for the total score, Behavioral Involvement, and Information Subscales were  $r = .74, .71, \text{ and } .59$ , respectively (Krantz et al.).

Tsutsui (1991), a nurse researcher from Japan, modified the KHOS to include concepts important to Japanese health care information-seeking behaviors: Asking, Not Asking (due to modesty, hesitancy, or psychological distance), Trust (deferring decision-making to medical staff), Resignation (reluctance to ask questions because one's fate is fixed), and Explanation (health

care provider offering information to the patient without being asked). The Information-Seeking subscale was increased from seven to 20 items. The tool was translated, back-translated, and pilot tested in Japan with Japanese mothers ( $N=18$ ). Alpha reliability for Asking, Not Asking, Trust, Resignation, and Explanation were assessed and ranged from 0.85 (Asking) to 0.56 (Explanation).

Items representing Explanation were retained, despite an alpha reliability considered lower than the minimum standard of between .60 and .70 (DeVellis, 1991; Frank-Stromborg, 1992; Nunnally, 1978). The rationale was that the overall score for the modified KHOS was being used and not just the questions dealing with explanation. In addition, the retention of the explanation items was conceptually important to the researcher's cultural study of Japanese women

Tsutsui (1991) re-assessed the Explanation subscale ( $N = 177$ ) of the modified KHOS as .65, an acceptable level. The explanation subscale had the lowest alpha reliability of all of the subscales, which ranged from .65 (Explanation) to .84 (Trust). A factor analysis revealed four factors (Asking/Not Asking, Trust, Resignation, Explanation) being retained. Each had Eigenvalues  $> 1$ , which meets standard criteria for retention (Kim & Mueller, 1978). Moreover, the sub-scales explained 56.6% of the total variance in the data ( $N = 181$ ). The KHOS was modified to include conceptual links to Japanese culture, and acceptable Eigenvalues were obtained on factor analysis of all 20 items (Tsutsui, 1991).

### Summary: Ethnicity, Pain, Information Seeking, and Adjustment

Until such time that cancer, including prostate cancer, can be cured with certainty, individuals diagnosed with cancer will need to adjust to having been diagnosed with cancer, to being treated or to having been treated for cancer. Extensive studies have focused on various aspects of prostate cancer including pain and prostate cancer (DiLorenzo et al., 2005; Rustoen et al., 2005; Saad et al., 2005), information-seeking and prostate cancer (Ka'opua et al., 2005; Robinson, et al., 1999; Wong et al., 2000), or overall adjustment to prostate cancer (Germino et al., 1998; Ka'opua et al., 2005; Roesch et al., 2005; Steele & Richie, 2002; Talcott & Litwin, 2002; Wallace, 2003). As technology and science continue to evolve, the physical adjustment for men with prostate cancer will hopefully improve. The reduction of worry and need to adjust to the physical impact of prostate cancer, including but not limited to incontinence and impotence, is only one aspect of overall adjustment. The psychosocial adjustment (altered role, interdependence with others) of being diagnosed and treated for prostate cancer remains a concern for patients, family, and healthcare providers.

The religious nature and fatalistic view of Blacks with prostate cancer (Germino et al., 1988), the timid information-seeking of Japanese women with breast cancer (Kagawa-Singer, 1988; Kagawa-Singer et al., 1997); and, the perseverance and survivorship of Japanese American men with prostate cancer, as told by their wives (Ka'opua et al., 2005) underscore the importance of understanding ethnicity and its potential impact on adjustment to cancer.

The role of ethnicity on information-seeking (Ishikawa et al., 2002; Kagawa-Singer, 1988; Kagawa-Singer et al., 1997; Tsutsui, 1991), and self-reported pain (Cleeland et al., 1996; Uki et al., 1998; Zborowski, 1969) has been documented. The role of ethnicity on adjustment to cancer is only beginning to be explored (Germino et al., 1997; Ka'opua et al., 2005).

Studies suggest that both pain and information-seeking affect overall adjustment to cancer for some individuals (Roesch et al., 2005) and that control of pain and the active seeking of information improve both physical and psychological adjustment for some men (Cleeland & Ryan, 1994; Cleeland et al., 1996; Roesch et al., 2005; Rustoen et al., 2005). Information-seeking has been noted to differ between Japanese American women and Anglo American women with breast cancer (Kagawa-Singer et al., 1997). The extent to which differences in information-seeking patterns may differ with Japanese American male cancer patients was explored in this present study.

Experts such as Cleeland (Cleeland & Ryan, 1994; Cleeland et al., 1996), Gotay (Ka'opua et al., 2005), and Miaskowski (Rustoen et al., 2005) cite the importance of considering culture and ethnicity when providing comprehensive care for men with prostate cancer. Studies performed thus far provide a platform for future research to explore specific ethnicities and impact on the adjustment of cancer for patients of diverse ethnic backgrounds. A gap in the literature exists, as no studies published thus far have examined pain intensity in Japanese or Japanese American participants with a single type of cancer. This study has attempted to bridge that gap.

## CHAPTER III

### METHOD

This chapter focuses on the methods used to conduct the current study. It begins with a brief overview of the study design, including changes made to the initially proposed study, followed by recruitment strategies, participant sample, data collection procedure, the five instruments completed by the participant in a self-administered, questionnaire packet, and data analysis procedure, including ancillary analysis. Additionally, in each of these sections, any changes resulting from a pilot study conducted by the researcher are provided. The pilot study ( $N = 17$ ) was conducted to test the reliability of the modified KHOS on participants with prostate cancer, including Japanese American men. (See Appendix C for details of the pilot study and modifications of the KHOS.)

#### Study Design

A descriptive design was used to examine the differences in self-reported pain intensity, information-seeking behaviors, and psychosocial adjustment between Japanese American and European American men treated for prostate cancer. The relationship between pain intensity, information-seeking behavior, and adjustment between these two ethnic groups was also investigated.

Based on a cross-cultural study (Brena et al., 1990) which showed differences ( $p < .05$ ) in physical and psychosocial adjustment to illness between Japanese men and American men with back pain, a moderate effect ( $r = .30$ ), power of .80, and alpha of 0.05 were used to obtain the sample size estimate (Cohen, 1988) for the current study. Based on these parameters the sample size was estimated at  $N = 84$ .

### Recruitment

The original plan for this study was to compare two ethnic groups – second-generation Japanese American men and third-generation European American men – with metastatic prostate cancer. Recruiting participants for such a limited, defined sample (particularly Japanese Americans) was challenging. Initially, recruitment of participants included, but was not limited to, 126 Letters of Introduction (Appendix D) sent to oncology nurses and physicians, organizations, and support groups.

The initial contact to the health care provider (physician or nurse from either one of two New Jersey medical centers) was by a Letter of Introduction describing the study, including its limitations, instruments to be completed, estimated participation time, and confirmation of protection of human subjects. The researcher then provided additional information to personnel at centers who expressed interest, or support group leaders. Information was provided either at a face-to-face meeting, or by telephone.



Healthcare providers who expressed interest in participating in the study collaborated with the investigator and submitted formal applications to the Institutional Review Boards (IRB), of their respective institutions (Saint Barnabas Medical Center in Livingston, NJ; Valley Hospital in Ridgewood, NJ). IRB approval letters were obtained for these two institutions (Appendix E, F).

Potential participants in the hospital, clinic or office setting were informed about the research study by the physician or nurse. The UCAIHS-approved Description of the Research (Appendix G) was given to office personnel or support group personnel for distribution to potential participants. Potential participants were screened for the criterion of prostate cancer with treatment by the health care provider either during regular office visit or were self-identified at support group meetings. Potential participants indicated willingness to participate by informing the physician or nurse in the office, or in the support group setting. An IRB approved consent form (Appendix H) was provided to the potential participant for review.

Potential participants were provided contact information for the investigator, including phone number, e-mail address, and land mail on the consent form, fliers and advertisements. The use of pre-stamped response cards or e-mail was an option to contact the investigator so potential participants did not incur any cost by contacting the investigator. Potential participants could use the contact information to express interest in participating in the research, or to ask the investigator questions about the research study.

The researcher traveled to Hawaii to invite members of the local Us TOO, International support group held at Kuakini Medical Center, to participate in the research study. Other recruitment efforts included the researcher attending the National Conference on Prostate Cancer 2005: Exploring New Pathways: Sharing the Journey. Sponsors of the conference were the Foundation for Cancer Research and Education and Us Too, International. The conference was held June 16 – 19<sup>th</sup> 2005, in Washington, DC. The audience of the conference was men with prostate cancer and their care givers.

However, between January 2002 and August 2005, only six Japanese American men had been recruited for the study. An exploration of the reason for the slow enrollment led to conversations with a physician and a support group leader. After communicating with Andrew Zablow, MD, a physician practicing at Saint Barnabas Medical Center in New Jersey (August 4, 2005); and, communication with Philip Olsen, a leader of the Hawaiian branches of Us TOO, International as well as the Hawaii State Representative for the National Prostate Cancer Coalition (June 18, 2005) each agreed that requiring participants be men with metastatic cancer, of either second-generation or third-generation in North America or Hawaii was most probably inhibiting recruitment because many of the men they encountered were not second or third-generation, or did not have metastatic prostate cancer.

Thus, as of September 2005, the sample criteria was broadened to include Japanese American or European American men of Japanese or European heritage or ancestry, with approval of the Dissertation Committee and the University

Committee on Activities Involving Human Subjects (UCAIHS) at New York University. In other words, to be included in the study, participants only had to have been born in North America or Hawaii, be of Japanese or European heritage, and inclusion was allowed regardless of the number of generations their families had lived in North America or Hawaii. In addition, to facilitate recruitment, it was agreed that the sample could include men with and without metastasis, and men with any stage of prostate cancer, who had or were currently receiving treatment. Treatment included surgery, radiation, chemotherapy, hormonal deprivation (i.e., anti-androgen therapy), vaccines, investigational therapy, or any combination of these treatments. Consistent with previous research (Cleeland et al., 1996), men who had had surgery less than six weeks previously or who had residual surgical pain were excluded from the study to prevent confusing surgical pain with cancer pain.

Admittedly, the stage of prostate cancer (e.g., metastatic versus non-metastatic) affects adjustment (Blank & Bellizi, 2006), as does time since diagnosis (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003; Perczek, Burke, Carver, Krongrad, & Terris, 2002). Research has shown that adjustment to cancer changes over time (Bowman et al., 2003; Hoskins, 1997; Perczek et al., 2002; Roesch et al., 2005) and that men with early-stage prostate cancer versus those with metastatic or advanced prostate cancer face different psychological challenges (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2004). To address concerns of stage of prostate cancer and time since diagnosis, the latter

was identified as a co-variate and an exploratory analysis excluding men with metastatic disease was to be performed.

As a result of these changes in inclusion criteria, efforts to enroll Japanese American and European American participants included but were not limited to:

- Letters of introduction were mailed to 15 support group leaders.
- Letters of introduction were sent to health care providers (three physicians, three oncology nurses, and one PhD manager of research), all in Hawaii.
- Letters of introduction were sent out to five agencies dealing with healthcare provisions for Japanese American, or diverse populations (i.e. FDA Office of Special Health Issues, Asian American Network for Cancer Awareness, Administration for Aging in San Francisco, Intercultural Cancer Council, 100<sup>th</sup> Battalion in Honolulu, HI).
- Nationally known support groups were contacted (e.g. Us TOO, International, Man-to-Man) to obtain permission to explain the study and offer voluntary participation to support group members. A notice (Appendix I) was also placed in an Us Too on-line newsletter. Specifically the January 9, 2006 issue of Us TOO, International *Hot Sheet*, which reaches approximately 50,000 members each month.
- Contact with the leadership of the Kuakini Us TOO Support group and a second visit was made to Hawaii to personally recruit participants at the support group meeting in Honolulu.

- A second support group was visited in Kaiser Permanente in Maui, Hawaii and participants were informed about the research study.
- While in Hawaii, the investigator met with the IRB manager, nurse, and a radiation oncologist at Kuakini Medical Center. Paperwork was submitted to have the research approved and participants recruited through the radiology department at Kuakini Medical Center (approval letter Appendix J).
- Two UCAIHS-approved advertisements were placed in the *Asian Reporter*; a newspaper printed in a West Coast newspaper (circulation 20,000) (Appendix K).

### Sample

A convenience sample for this research was 89. Men expressed interest in the research study, signed an informed consent, and obtained a questionnaire packet from the investigator or designee between February 2002 and June 2006. Each of 91 men who signed an informed consent returned a completed five-part questionnaire. Two men, recruited through support groups, were excluded from the sample and all analyses because they had not received treatment for their prostate cancer, as defined in the study inclusion criteria. One had never been treated for prostate cancer, only surveillance of prostate cancer only (sometimes known as watchful waiting); the other managed his prostate cancer with exercise, diet and supplements (not further described).

Consistent with examples in the literature (Cavillo & Flaskerud, 1993; Kakai et al., 2003; Kagawa-Singer, 1997; Kagawa-Singer et al., 1998), ethnic background was determined by asking potential participants to self-identify their cultural/ethnic background prior to enrollment and/or by reviewing the written inclusion criteria provided in the Description of the Research.

The final sample was comprised of 89 men who had received or were currently receiving treatment for prostate cancer: Japanese American men ( $n = 12$ ) born in North America or Hawaii and of Japanese heritage, and European American men ( $n = 77$ ) born in North America or Hawaii and of European heritage. All were currently living in either Hawaii or North America. Participants were currently undergoing or had completed treatment for prostate cancer including surgery, radiation (external beam or seed implants), androgen deprivation therapy (hormonal therapy), chemotherapy, vaccines, or investigational therapy.

#### Data Collection

If the man agreed to participate, the investigator provided (by mail or in person) an envelope which included:

1. Two copies of the same consent form (Appendix H), one for the researcher and the other retained by the participant,
2. A questionnaire packet including the Instructions (L), the Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis & Derogatis, 1990) (Appendix M provides sample questions), the Brief Pain Inventory (BPI) (Cleeland, 1991; Daut,

Cleeland, & Flanery, 1983) (Appendix N), and the modified Krantz Health Opinion Survey (KHOS) (Krantz et al., 1980) (Appendix O), a Demographic Information Sheet (Appendix P), a Medical Information Form (Appendix Q),

3. Two pre-addressed stamped return envelopes (one labeled *Consent* and the other labeled *Questionnaire*).

If the health care provider (physician or nurse) agreed, the consent forms and questionnaire packet were handed to potential participants who verbally expressing interest, while in the hospital, clinic or office setting.

The description of the research and the consent form emphasized the voluntary nature of study participation and confidentiality of information. Participants were directed to place the consent form in the white pre-addressed stamped envelope labeled *Consent* and then seal the envelope. The contents of the questionnaire packets were arranged in the same order for each participant. The order of the forms making up the questionnaire packet was: Instructions, PAIS, BPI, KHOS, Demographic Information Sheet, and Medical Information Form. Participants were told to return the completed questionnaire packet to the investigator in a separate pre-addressed stamped envelope labeled *Questionnaire*.

Participating individuals were assigned a code number that was used on all data forms in lieu of names to ensure confidentiality. Only the investigator had access to the names matching the code numbers. A Microsoft® Excel spreadsheet was kept with the initiation date and code numbers. The consent forms are currently stored in a locked file cabinet separate from the completed questionnaire packets; the spreadsheet is stored on a password protected computer. The

questionnaire packets will be retained until two years after submission of the final report and any publication, after which time the completed questionnaire packets will be destroyed in a confidential fashion (e.g., by shredding).

### Instruments

#### Psychosocial Adjustment to Illness Scale (PAIS)

The Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis & Derogatis, 1990) is a 46-item pencil and paper instrument used in both the pilot and the core study without modification. The tool was developed to assess an individual's adjustment to illness in each of seven primary domains. The domains are Health Care Orientation (attitudes toward care, information, and expectations), Vocational Environment (impairment, time lost on job, goals, conflicts), Domestic Environment (quality of relationships, communication, dependency, financial resources), Sexual Relationships (quality of sexual relationships, sexual interest, sexual satisfaction, interpersonal conflict related to sexual issues), Extended Family Relationships (interest in interacting, physical and social dependency, quality of relationship), Social Environment (leisure and social interest and activity), and Psychological Distress (anxiety, depression, hostility, guilt worry, self-devaluation, body image) (Derogatis & Derogatis, 1990).

Convergent validity was tested with the PAIS and Global Adjustment to Illness Scale (Derogatis & Derogatis, 1990). Derogatis, Abeloff, and Melisaratos (1979) administered the PAIS and Global Adjustment to Illness Scale (GAIS) to 27 breast cancer patients. The GAIS was developed by Morrow and Feldstein



(1981). A high correlation ( $r = .81$ ) of total scores between the PAIS and GAIS exceeded the correlation between domains (Derogatis & Derogatis, 1990). The high correlation with the GAIS supports the value of the PAIS in measuring adjustment.

Derogatis and Derogatis (1990) documented the ability of the PAIS to discriminate between patients with lung cancer ( $n = 120$ ) and those patients screened negative for lung cancer ( $n = 86$ ), in a repeated measures study. Comparing measurements from baseline and repeated measurements (one to three months from baseline), those patients with confirmed lung cancer had higher overall scores (indicating poorer adjustment) than controls,  $t(204) = 2.09$ ,  $p < .005$ . Moreover, differences were observed in five of the seven domains identified by the developers.

The total score of the PAIS was used in this research because it provides a valid and reliable measure of adjustment (Budin, 1998; Derogatis & Derogatis, 1990; Germino et al., 1998, Hoskins, 1995). Items were rated from 0 – 3 (four point scale). The total PAIS score was obtained by summing the scores of each item (after reversing negatively worded items). Higher ratings indicated poorer adjustment on the PAIS (Derogatis & Derogatis, 1990). The possible range for the total score, on the 46-item tool was 0 to 138, where 138 represented the poorest adjustment.

Although the sample size for the pilot study was small ( $N = 17$ ), an exploratory analysis was performed. The mean overall adjustment score of the PAIS (Derogatis & Derogatis, 1983), did not differ significantly between

Japanese American and European American men. However, further exploration of the seven domains measured by the PAIS (vocational, domestic, extended family, social, sexual, health care, and anxiety or worry), showed the mean adjustment score for the extended family was lower (better adjustment) for Japanese American men ( $M = .83, SD = .41$ ) compared to the mean for the European American men ( $M = 2.36, SD = 2.25$ ),  $t(15) = -2.192, p = .050$ , using an independent  $t$ -test.

Although not statistically significant, the mean score for domestic environment domain showed a trend toward statistical significance between the two ethnic groups. The Japanese American participants had a lower mean ( $M = 2.33, SD = 2.88$ ) compared to the mean for European American participants ( $M = 5.45, SD = 3.64, t(15) = 1.805, p = 0.91$ ). As previously stated, lower scores for the PAIS indicate better adjustment. Therefore, the pilot study showed intriguing differences in adjustment scores between Japanese American men and European American men. Exploratory findings from the pilot study hinted at more positive adjustment scores for Japanese American men compared to European men, with regard to extended family and domestic environment. The patterns noted in the PAIS for the pilot study supported further research conducted in the larger core study ( $N = 89$ ), reported here.

#### Brief Pain Inventory (BPI)

The BPI (Cleeland et al., 1983) is a 23-item self-report questionnaire used in the current study without modification. A numeric rating scale (NRS) from 0 -

10 was used to indicate the intensity of pain, or the interference with a given activity due to pain.

Participants indicated the pain intensity by circling a whole integer between “0,” indicating no pain, and “10,” indicating pain as bad as you can imagine on a NRS. Three pain intensity measurements (least, worst, and average) were self-reported by each participant. In this study, the worst pain score was used for the analysis of pain intensity because the literature indicates (Jensen, 1997) that differences are most likely to be seen between groups using the worst pain score.

Seven interference items were also measured. Participants indicated the number that described how, during the past 24 hours, pain interfered with general activity, mood, walking ability, normal work, relations with other people, sleep, and enjoyment of life. Participants indicated interference by circling a whole integer between “0” (does not interfere) and “10” (completely interferes) on a NRS. The interference score was the sum of all seven interference items (possible range 0 – 70).

#### Modified Krantz Health Opinion Survey (KHOS)

An instrument modified from the self-administered paper-and-pencil Krantz Health Opinion Survey (KHOS) (Krantz et al., 1980) was used to measure information-seeking behavior in this study. The KHOS was further modified by the investigator, with permission from the author (personal correspondence,

February 17, 2000). The modification was an addition of one pain question to each of five sub-scales, which were developed by Tsutsui (1991).

Twenty-five items of the modified KHOS were used in this research (Appendix O). These 25 items included the 20 items that comprise Tsutsui's (1991) modified version and five additional items pertaining to pain added by the investigator. The instrument used a three-point Likert scale ranging from "disagree" (scored as 1) to "agree" (scored as 3). The ratings from each item were added, yielding a final score for the information-seeking behavior. This modified KHOS has five subscales (Asking, Not Asking, Trust, Resignation, and Explanation) consisting of five items each. Thus, each subscale has a score range of 5 – 15, and the total score of all five subscale scores is 25-75. Higher scores indicate participants were informed of treatment, had greater inquisitiveness about health care, had a desire or ability to ask questions of the health care provider, and were informed and involved with decision making. An English version of the 25-question modified KHOS was used for the pilot test, as well as for the core study.

Prior to the pilot study, three nurses, all with advanced nursing degrees, expertise in Japanese culture, and experience caring for cancer patients reviewed the modified questions for relevance to the appropriate five subcategories, as identified by Tsutsui (1991). Content validity was also established prior to using the modified KHOS in the pilot test. An index of content validity (CVI) of 0.996 was obtained by noting the proportion of items rated as relevant with minor revision or very relevant (King, 1988; Waltz & Bausell, 1986). No items were judged as needing revision or not relevant.

This modified instrument was then pilot tested on a sample of Japanese American patients ( $n = 6$ ) and European American ( $n = 11$ ) patients with prostate cancer to assess the reliability of this further modification of the KHOS to include culturally sensitive questions and pain-related questions. Secondary objectives included assessing the practical aspects of the test administration for all instruments, including ease of completion, readability, and understanding (Guillemin, Bombardier, & Beaton, 1993; Henderson et al., 1992; Jones & Kay, 1992). All participants were able to complete the questionnaire packets and no language barriers were identified. No changes to the KHOS were made. However, the pilot study resulted in three changes to the Demographic Information Sheet. The changes to the Demographic Information Sheet were: 1) the inclusion of marriage as an option for marital status which was omitted in error on the pilot study forms, 2) the inclusion of information about religious preference, because researchers (Feher & Maly, 1999; Germino et al., 1998) have shown that religion can impact adjustment to cancer, and 3) the inclusion of information about the birthplace of maternal and paternal grandparents, to provide information about the number of generations the participant's family lived in North America or Hawaii. The number of generations living in a host country has been linked to acculturation (Spector, 1996). These changes were approved by the NYU UCAIHS.

The Chronbach alpha reliability of the KHOS used in the pilot study was assessed as 0.81, with subscores ranging from 0.472 – 0.80. Alpha reliability for the subscores of Not Asking (.473) and Asking (0.527) were lower than the

established levels of acceptability (DeVellis, 1991; Frank-Stromborg, 1992; Nunnally, 1978). Similar to the strategy used by Tsutsui (1991), the questions were retained for use in this current larger study ( $N = 89$ ) because the overall KHOS score had an acceptable alpha reliability. Reliability for the overall score and all sub-scores in the current core study increased to  $> 0.70$  and are reported in Chapter IV.

#### Demographic Information Sheet

The investigator compiled questions to obtain demographic information of the participants, including age, marital status, number of children, ethnic characteristics, religion, educational level, employment status, and income (Appendix P). Like previous studies comparing cultures, information about the heritage of the participant, his parents, and his grandparents was obtained and compared as part of the demographics, including length of residence in North America or Hawaii, language preference; and association with friends from similar, or with friends from different ethnic backgrounds (Gotay, Holup, & Pagano, 2002; Kagawa-Singer et. al., 1997; Kodama & Canetto, 1995; Spector, 1996; White, Biddlecom, & Guo, 1993).

#### Medical Information Form

The Medical Information Form (see Appendix Q), completed by each participant, included date of initial diagnosis, treatment(s), dates of diagnosis of metastases, type of metastases (visceral and/or bone), types of pain (somatic,

visceral or neuropathic), use of bisphosphonates, treatments for pain, co-morbidity and performance status (amount of activity patient is able to perform). Although permission to review the participant's medical chart was included in the consent form, with the advent of Health Insurance Portability and Accountability Act (HIPAA) of 1996 (US Department of Health and Human Services, 2003, 2006), the chart review became optional for participants. Kuakini Medical Center required a separate signature providing consent for the chart review; however, no participants were enrolled at Kuakini Medical Center. Thus, no chart reviews were conducted and the investigator did not review any personal information.

#### Data Analysis

Data analysis was conducted using the Statistical Package for the Social Sciences (SPSS for Windows, Version 10.0) (1999), after data entry and 100% review for quality assurance. Descriptive statistics were computed for all variables identified in the study and included percentage for nominal and ordinal variables, means, medians, ranges, and standard deviations for continuous variables.

Missing data appeared to be random and evenly distributed across variables. For participants with one random-missing item, the mean of the subscale score for each missing value was used to replace the missing data. When data for a participant had more than one missing variable, the group mean for the variable was used (McCleary, 2002).

Box plots, histograms, and statistical tables were generated for data-screening purposes. Data were checked for outliers and evidence of normal distribution; data transformations were performed, as necessary.

In examining whether any differences could be found in self-reports of pain intensity, information-seeking behavior, and adjustment between Japanese American and European American men treated for prostate cancer, the mean, standard deviation, and frequency distribution of scores for “worst pain” on the BPI (pain intensity), overall KHOS (information-seeking behavior), and overall PAIS (adjustment) were calculated and examined. To determine differences, “worst pain” BPI (Sub-question A, pain intensity), KHOS (Sub-question B, information-seeking) and PAIS (Sub-question C, adjustment) were each analyzed using non-parametric method. A Wilcoxin Rank Sum, comparing the sum of the ranks between Japanese American and European American men, was used for the analysis. An analysis of covariance was conducted to explore the role of some variables, identified as predictors, which were not well-matched between Japanese American and European American participants.

To determine whether any differences occurred in the relationship between pain intensity and information-seeking behavior and adjustment between these ethnic groups, relationships between the variables “worst pain” on BPI and overall PAIS (for Sub-question D) and between variables overall KHOS and overall PAIS (for Sub-question E) were explored using Pearson’s correlation for both Japanese American men and European American men who received treatment for prostate cancer.



Ancillary analyses included a description and comparison of “least pain” and “average pain” to adjustment for those participants who reported having pain. In addition, seven interference items measuring self-report of interference with physical activities (four items) and interpersonal relations (three items) were included in the BPI. A 10-cm linear numeric rating scale (NRS) was provided for each of the seven items. Numbers on the NRS range from 0, indicating pain does not interfere with this activity, to “10,” indicating pain completely interferes with this activity. The sum of all interference items was used as the pain interference score. A correlation of interference with overall adjustment was performed for both Japanese American and European American men treated for prostate cancer.

## CHAPTER IV

## RESULTS

The focus of this study was on self-reported pain intensity, information-seeking behavior, and overall adjustment to prostate cancer in Japanese American ( $n = 12$ ) and European American ( $n = 77$ ) men treated for prostate cancer. All eligible participants ( $N = 89$ ) completed a five-part questionnaire packet comprised of a demographic information form; a medical information form; the PAIS (Derogatis & Derogatis, 1990), measuring adjustment; the modified KHOS (modified from Krantz et al., 1980), measuring information-seeking behaviors; and the BPI (Cleeland & Ryan, 1994), measuring self-reported pain (worst, least, average) and interference with activities, mood, and interpersonal relationships due to pain. The results of the analyses of these data provide the framework for this chapter.

Prescreening of Data

Prior to the analysis, KHOS (Krantz et al., 1980) total and sub-scales; worst pain, least pain, average pain, and interference score on BPI; Psychosocial Adjustment to Illness Scale (total score and domains), demographics, and acculturation variables were carefully reviewed for accuracy of data entry,

missing values, outliers and normal distribution. These variables were examined separately for Japanese American and European American participants.

Missing values were imputed as discussed in Chapter III. Several variables (KHOS, PAIS) and subscores (asking, not asking, resignation) did not demonstrate normal distribution. Significant skew ( $> 2$ ) was noted, and although transformation improved the normality of most of the variables, in some cases (e.g., resignation) transformation improved the normal distribution of the variable for one ethnic group (in this case, European American) but worsened the skew for the Japanese American group.

Although equal variances were observed between ethnic groups for the key variables, the larger European American participant group showed the smaller variance for the overall KHOS score and subscores. Further, worst pain, information-seeking, and adjustment all showed severe skew,  $> 3$  (Tabachnick & Fidell, 1996). The unequal sizes of the ethnic groups, the small variance of the larger European American group, and the difficulty transforming all variables to a normal distribution for both ethnic groups potentially threatened the robustness of the independent *t*-test (Zar, 1999). Therefore, a Wilcoxon rank sum nonparametric statistical method was used in lieu of the independent *t*-test. Nonparametric tests do not make the assumption that the sample be normally distributed, although nonparametric tests assume the sample populations have the same shape (Zar, 1999). Similarities in the shape of the distributions were noted for each of the variables.

### Demographics

Table 2 provides a summary of demographics, including frequency and percent by ethnic group. The age of participants ranged from 55 – 84 years. The median age was 70 years; the mean age for the group was  $M = 70$ ,  $SD = 6.6$ . The mean age for participants who were Japanese American and European American was  $M = 69$ ,  $SD = 1.62$ ; and  $M = 71$ ,  $SD = .77$ , respectively.

Table 2.

#### *Demographic Frequencies by Ethnic Group (N = 89)*

Variable	Japanese American	European American	Total	Sig. (two-tailed)
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
	12 (100)	77 (100)	89 (100)	
<b>Age</b>				
Mean ± SD	69 ± 1.62	71 ± 0.77	70 ± 6.6	0.349
50-55	0 (0)	1 (1)	1 (1)	
56-65	3 (25)	21 (27)	24 (27)	
66-75	7 (58)	36 (47)	43 (48)	
76-85	2 (17)	19 (25)	21 (24)	
Did not respond	0 (0)	1 (1)	1 (1)	
<b>Marital Status</b>				
Married	11 (92)	56 (73)	67 (75)	0.362†
Single	1 (8)	8 (10)	9 (10)	
Divorced	0 (0)	8 (10)	8 (9)	
Widower	0 (0)	3 (4)	3 (3)	
Other	0 (0)	1 (1)	1 (1)	
Did not respond	0 (0)	1 (1)	1 (1)	
<b>Children</b>				
No Children	2 (17)	15 (19)	17 (19)	0.574
One or Two	3 (25)	24 (31)	27 (30)	
Three or Four	7 (58)	31 (40)	38 (43)	
5 or more	0 (0)	5 (6)	5 (6)	
Did not respond	0 (0)	2 (3)	2 (2)	

Table 2 (continued).

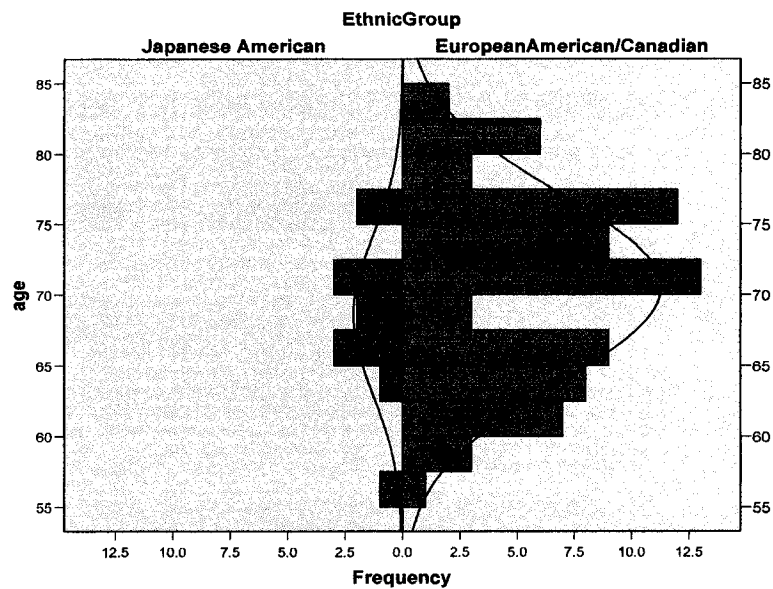
*Demographic Frequencies by Ethnic Group**(N = 89)*

Variable	Japanese American		European American		Total	Sig. (two-tailed)
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i> (%)	
	12	(100)	77	(100)	89 (100)	
<b>Education</b>						
Doctorate	1	(8)	11	(14)	12 (13)	0.141
Masters degree	0	(0)	18	(23)	18 (20)	
Baccalaureate degree	3	(25)	22	(29)	25 (28)	
Some college	5	(42)	16	(21)	21 (24)	
High school graduate	2	(17)	7	(9)	9 (10)	
Grade school	0	(0)	1	(1)	1 (1)	
Other (technical)	1	(8)	2	(3)	3 (3)	
Did not respond	0	(0)	1	(1)	1 (1)	
<b>Religion</b>						
Protestant	2	(17)	26	(34)	28 (31)	<0.001***†
No Religious Preference	0	(0)	17	(22)	17 (19)	
Catholic	0	(0)	11	(14)	11 (12)	
Buddhist	3	(25)	0	(0)	3 (3)	
Jewish	0	(0)	8	(10)	8 (9)	
Other	0	(0)	3	(4)	3 (3)	
Did not respond	7	(58)	12	(16)	19 (21)	
<b>Employment</b>						
Retired	8	(67)	49	(64)	57 (64)	0.623†
Full-time (≥ 30 hours)	3	(25)	11	(14)	14 (16)	
Part-time	1	(8)	10	(13)	11 (12)	
Medical disability	0	(0)	3	(4)	3 (3)	
Unemployed	0	(0)	1	(1)	1 (1)	
Other not specified	0	(0)	2	(3)	2 (2)	
Did not respond	0	(0)	1	(1)	1 (1)	
<b>Income</b>						
\$ > 50,001	4	(33)	44	(57)	48 (54)	0.212†
\$ 30,001 - 50,000	6	(50)	18	(23)	24 (27)	
\$20,001 - 30,000	1	(8)	6	(8)	7 (8)	
\$ < 10,000 - 20,000	0	(0)	4	(5)	4 (4)	
Did not respond	1	(8)	5	(6)	6 (7)	

\*\* Statistically significant  $p < .001$ Significance test is independence  $\chi^2$ -test unless otherwise noted;

† Chi Square test

As Figure 1 illustrates, because most Japanese American men ( $n = 7$ , 55%) were between ages 66–75, the frequency distribution was skewed to the left. Fewer European American men were between ages 66–75 ( $n = 36$ , 48%), with only three men age 68 or 69, resulting in a dip in an otherwise normally distributed curve. Despite these differences, the ethnic groups were similar in mean age,  $t(86) = -.942, p = .349$ . Boxplots of the mean age by ethnic group are provided in Figure 2.



*Figure 1* Population plot: age by ethnic group ( $n = 88$ )

Married participants made up the majority of both ethnic groups ( $n = 67$ , 75%) and only 9 participants were single. Eight self-identified themselves as divorced, three as widowed, and 1 as “other” (not-specified) – all only found within the European American group. A chi-square test of independence

determined no statistically significant difference in marital status by ethnicity:

$\chi^2(1, n = 88) = .833, p = .362$ . (see Fig. 3)

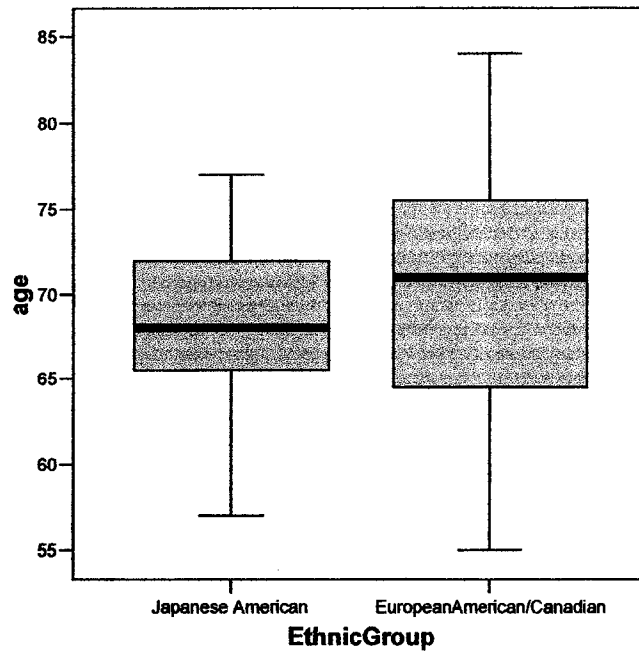


Figure 2. Box plots, mean age by ethnic group ( $n = 88$ )

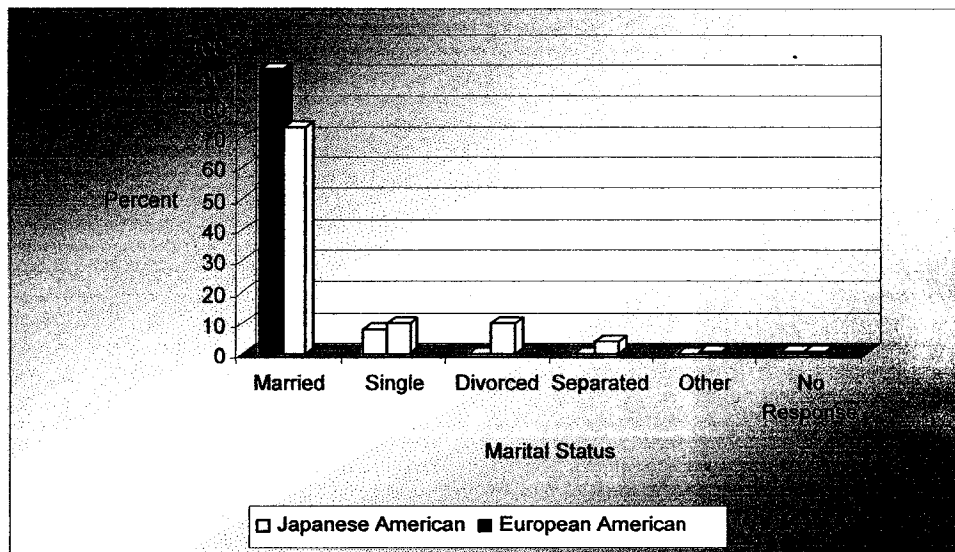


Figure 3. Marital status by ethnicity ( $N = 89$ )

Most participants had at least one child ( $n = 71$ , 79%). The number of children ranged from 1 – 5, with only European Americans having more than four children. For both ethnic groups, the most frequent number of children was three or four ( $n = 38$ , 42%). An independent  $t$ -test comparing the number of children in each ethnic group was not statistically significant,  $t(85)$ , .565,  $p = .574$ . (See Fig. 4.)

Twenty-nine (32%) participants reported earning a masters or doctorate degree; 11 (12%) participants had doctorates (1 Japanese American 8%, and 10 European American, 13%). Twenty-five participants reported that their highest level of education was four years of college (28%). One European American participant reported having no high school education, and two listed “other” education (not further specified); data were missing for one patient. A chi-square test of independence determined no statistically significant difference in education by ethnicity:  $\chi^2(1, n = 88) = 2.162$ ,  $p = 0.141$ . (see Fig. 5)

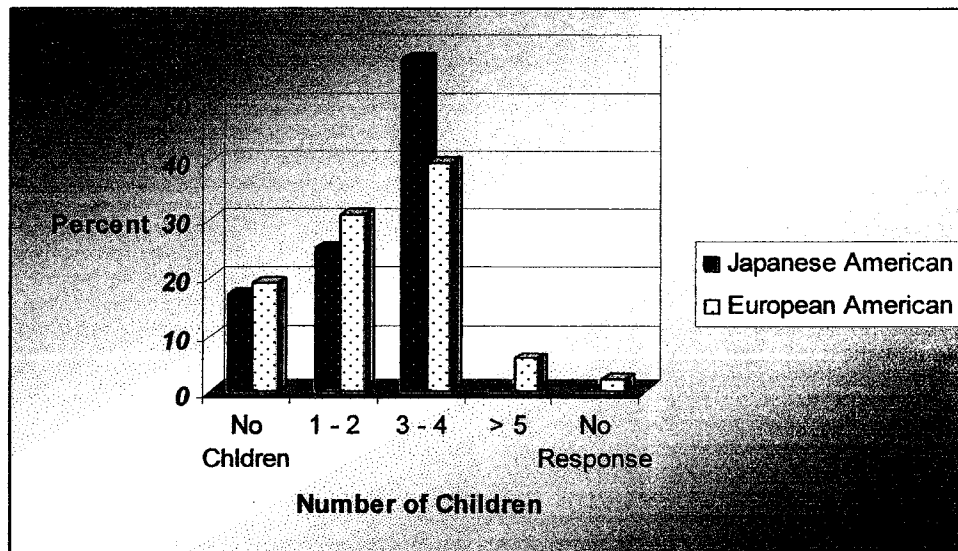
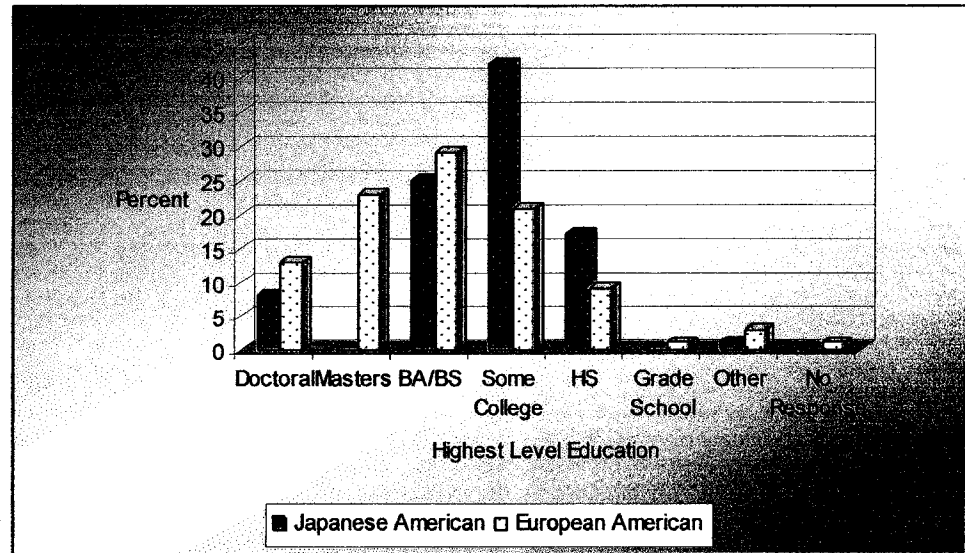


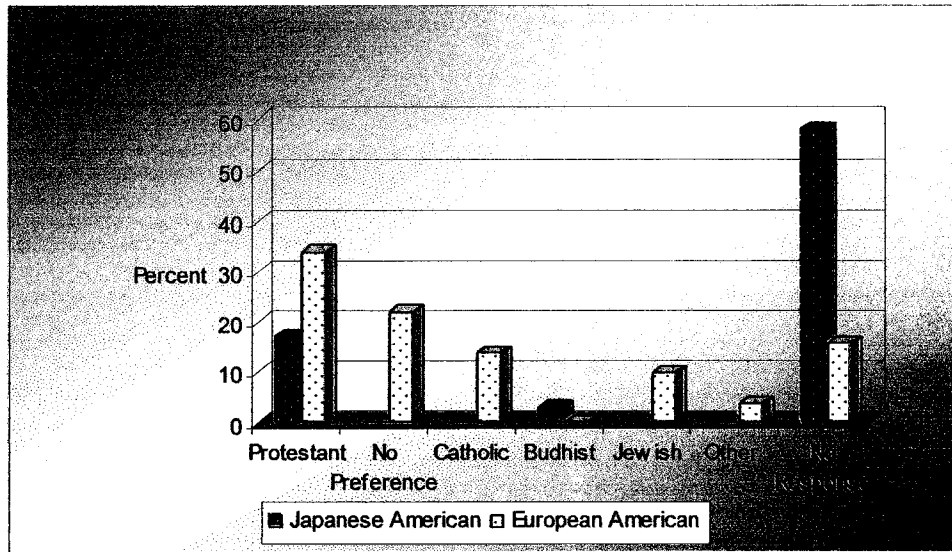
Figure 4. Number of children by ethnic group ( $N = 89$ )





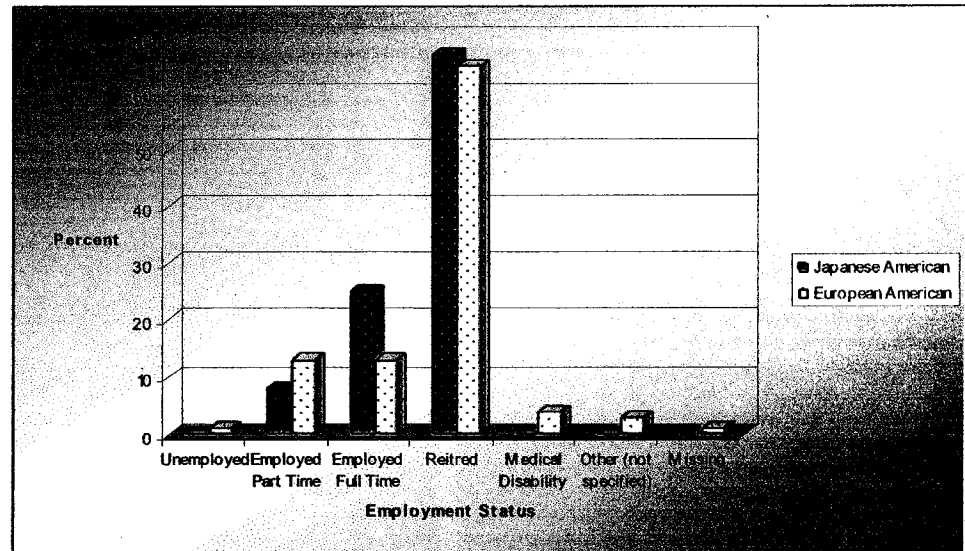
*Figure 5.* Education by ethnic group ( $N = 89$ )

As a whole, most participants were Protestant ( $n = 28, 31\%$ ). This was the most common religious preference for the European American group ( $n = 26, 29\%$ ), compared with only 2 (17%) of the Japanese Americans. One-quarter of the Japanese Americans ( $n = 3$ ) were Buddhist. Many participants (21%) chose not to respond to the religious preference question – over half (58%,  $n = 7$ ) of the Japanese Americans. For the entire group, after Protestant, the most frequent response categories, respectively, were “no religious preference” ( $n = 17, 19\%$ ), Catholic ( $n = 11, 12\%$ ), Jewish ( $n = 8, 9\%$ ) Buddhist ( $n = 3, 3\%$ ), or “other” ( $n = 2, 2\%$ ) indicating a religion other than noted on the questionnaire, but participants did not specify. A chi-square test of independence was conducted on completed data about religion, which determined a statistically significant difference in religion by ethnic groups  $\chi^2(1, n = 70) = 35.257, p < .001$ . (see Fig. 6)



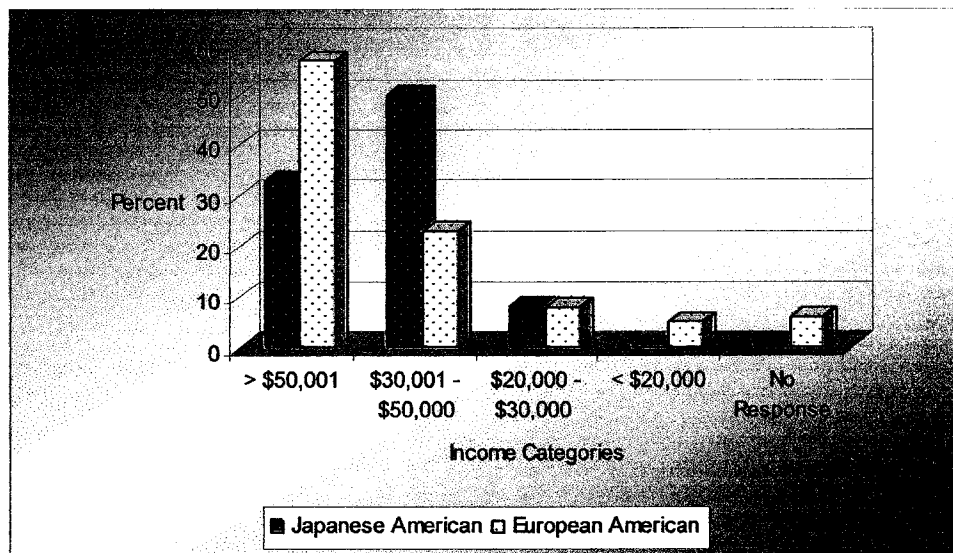
*Figure 6. Religion by ethnic group (N = 89)*

As Table 2 also reflects, most participants ( $n = 57, 64\%$ ) were retired, over one-fourth ( $n = 25, 28\%$ ) were employed either full time ( $n = 14, 16\%$ ) or part-time ( $n = 11, 12\%$ ) (For purposes of this study, part-time was defined as less than 30 hours/week). Three (4%) European American participants were on medical disability, and one (1%) was unemployed; none of the Japanese American participants reported medical disability or unemployment. A chi-square test of independence determined no statistically significant difference in employment status by ethnic group:  $\chi^2(1, n = 88) = .241, p = .623$ . (see Fig. 7)



*Figure 7.* Employment by ethnicity ( $N = 89$ )

The annual income ranged from less than \$20,000 to over \$50,001. Over half ( $n = 48$ , 54%) of the participants reported an annual income over \$50,001, which reflected the most frequent income category for the European American group ( $n = 44$ , 57%) but only one-third ( $n = 4$ ) for the Japanese American group, whose most frequent income bracket was \$30,000 - \$50,000 ( $n = 6$ , 50%), compared to 18 (23%) for European Americans. Over three-fourths ( $n = 72$ , 81%) of all participants had incomes above \$30,001. A chi-square test of independence determined no statistically significant difference in income status by ethnic group:  $\chi^2(1, n = 84) = 1.557, p = .212$ . (see Fig. 8)



*Figure 8. Income by ethnic group (N = 89)*

Thus, the two ethnic groups were well matched for age in years, marital status, number of children, highest level of education, and annual household income.

### Acculturation

To help determine the level of acculturation to the host culture of North America or the US, several variables were measured:

- Number of years the participant lived in the US
- Country in which the participant, parents, and grandparents were born, to determine the generation of the participant (first, second, third) living in the US or North America
- Language spoken at home
- Ethnicity of friends (whether same as or different than that of

participant. (Results are found in Table 3.)

The number of years participants lived in the US ranged from 0 to 84. Although participants of European heritage living in North America were included in the study, the questionnaire specifically asked about living in the US, but not North America. Two European Americans had been born and lived in Canada, so they responded with “0” for numbers of years living in the US. Two additional participants had been born in Europe – one in Sweden and the other in England – but had lived in the US for 20 and 25 years, respectively. Two additional patients had been born in the US. One was age 67 and had only lived in the US for 27 years; the rest of the time was spent outside the US because he had been in the military. The other was age 70 and had lived in the US for 40 years; the other years he had spent outside of the US because he was doing missionary work). Excluding the four men not born in the US and the two men who had not lived in the US for a lengthy period of time, the number of years participants lived in the US ranged from 55- 84. (see Fig. 9)

Many participants ( $n = 38$ , 43%) were second-generation Americans (living in the US or North America); 26 (29%) were third-generation; 22 (25%) were first-generation, and 2 (2%) were immigrants from Europe and living in North America or Hawaii for 20 and 24 years. Some participants were from Canada and wrote in information on the questionnaire, which asked only about US residence. All third-generation participants were European American. Half ( $n = 16$ , 50%) of the Japanese Americans were first generation, compared to 21% ( $n$

= 16) of the European Americans. The mean for generations living in the US or North America were statistically significantly different,  $t(86) = -2.385, p = .019$  (see Figure 10).

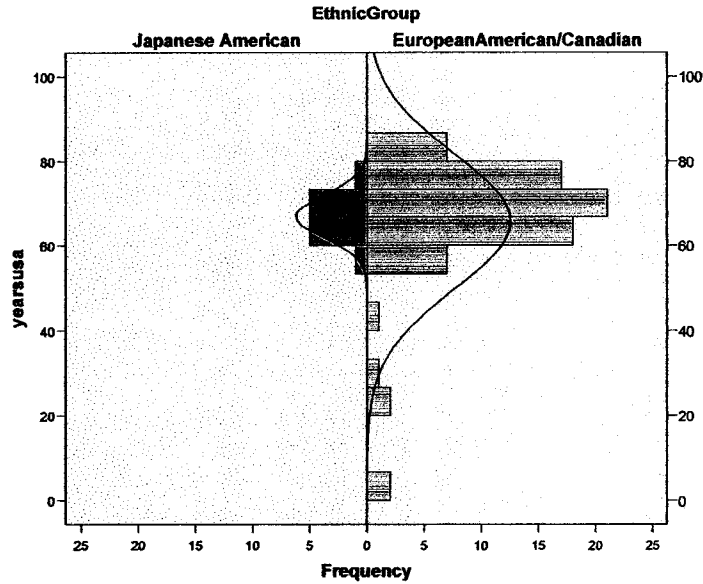


Figure 9. Population pyramid for years living in the North America or Hawaii (N = 89)

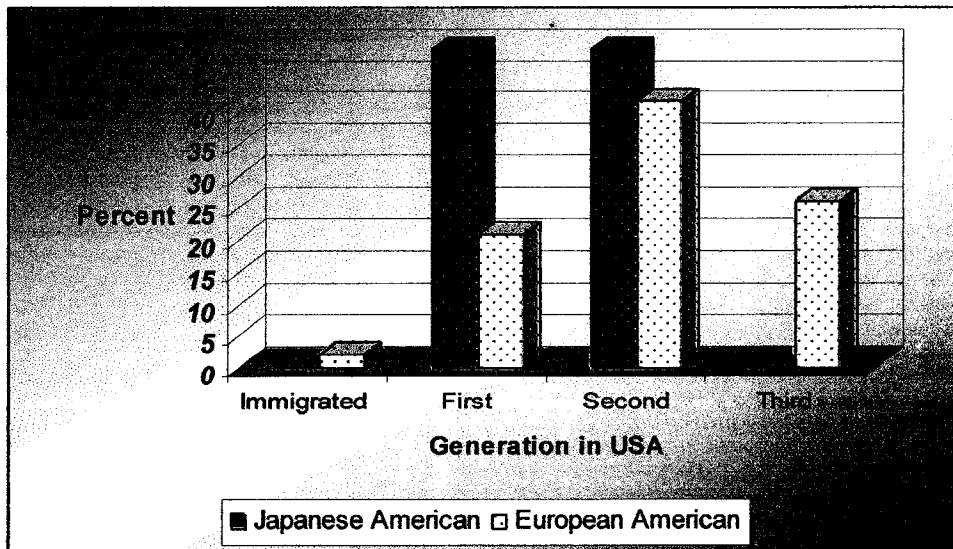


Figure 10. Generation in North America or Hawaii by ethnic group (n = 88)

Table 3

Demographic Frequencies Related to Acculturation by Ethnic Group ( $N = 89$ )

Variable	Japanese American		European American		Total	Sig. (two-tailed)
	<i>n</i>	(%)	<i>n</i>	(%)		
	12	(100)	77	(100)	89	100)
<b>Years Living in US</b>						
< 45	0	( 0)	4	( 5)	4	( 4) 0.799
45-55	0	( 0)	3	( 4)	3	( 3)
56-65	5	(42)	19	(24)	24	(27)
66-75	6	(50)	30	(38)	36	(40)
76-85	1	( 8)	18	(23)	19	(21)
n/a (Canadian)	0	( 0)	2	( 3)	2	( 2)
Did not respond	0	( 0)	1	( 1)	1	( 1)
<b>Generation living in US<sup>†</sup></b>						
Third +	0	( 0)	26	(33)	26	(29) 0.019
Second	6	(50)	33	(42)	39	(32)
First	6	(50)	16	(21)	22	(24)
Immigrated	0	( 0)	2	( 3)	2	( 2)
[yrs in US]				[25, 20]		
<b>Language Spoken at Home</b>						
English <sup>‡</sup>	12	(100)	76	(97)	88	(98) 0.317
Another Language	0	( 0)	1	( 1)	1	( 1)
Did not respond	0	( 0)	1	( 1)	1	( 1)
<b>Ethnicity of Friends</b>						
Some same, some diff	8	(67)	41	(53)	49	(54) 0.001**
Most same, few diff	3	(33)	15	(19)	18	(20)
Few same, most diff	0	( 0)	17	(22)	17	(19)
Do not know	0	( 0)	4	(5)	4	( 4)
Did not respond	0	( 0)	1	( 1)	1	( 1)

Note. \*\* statistically significant,  $p < .01$

<sup>†</sup>Third+ generation – grandparents born in US; second-generation – parents born in US; first-generation – participant born in US

<sup>‡</sup> includes one bilingual participant in each ethnic group

Most participants ( $n = 86, 97\%$ ) spoke only English in the home. Two participants were bilingual. One Japanese American indicated that he spoke both Japanese and English at home, and one European American noted he spoke French and English at home. One European American stated he spoke Danish at home. Only one participant, a 63-year-old European American stated he had difficulty reading and understanding English. He was a third-generation North American who had worked with police and fire rescue efforts prior to retirement. The average time for completing the questionnaire among European American participants was 37.33 minutes ( $SD = 1.86$ ), yet this participant took only 35 minutes. The mean number of minutes for Japanese Americans to complete the questionnaire packet was longer,  $M = 48.75$  minutes,  $SD = 5.04$ .

To help determine acculturation level, the questionnaire included a question on the ethnic background of the participant's friends (Kadama & Canetto, 1995). Most participants ( $n = 49, 55\%$ ) reported that "some friends are the same; some are different"; 19 (21%) said that "most are the same; few are different"; 16 (18%) reported that "few are the same; most are different," and 4 (4%) did not know the ethnicity of their friends. For this variable, differences were seen between ethnic groups; homogeneity of variance was not assumed (Levene's test,  $p = .004$ ). A chi-square test of independence showed a statistically significant difference in categories of friends (similar or different) by ethnic group:  $\chi^2(1, n = 88) = 49.91, p < .001$ . (see Fig. 11)



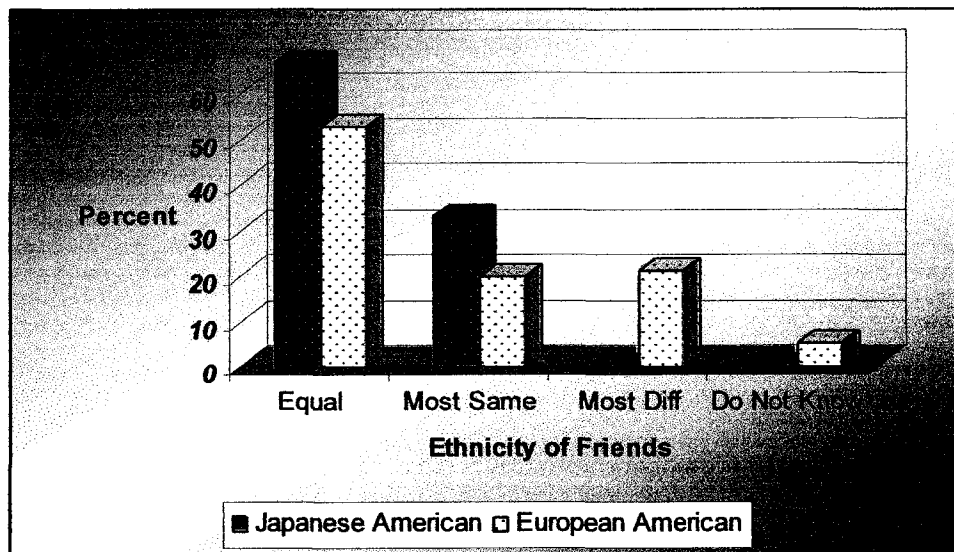


Figure 11. Category of friends, by ethnic group ( $n = 88$ )

#### Medical Information Sheet

The Medical Information Sheet (Appendix Q) was developed by the investigator based on variables identified in the literature to be predictors of pain management and adjustment to cancer (Germino et al., 1998; Hoskins et al., 1996), as well as variables important to the medical and nursing management of prostate cancer (Litwin et al., 1995; Mason, Glaholm, & Dearnaley, 1994).

The time since diagnosis was calculated, in months, from the date of diagnosis and recorded date for completion of questionnaire packet. The median time from diagnosis to study participation was 52 months. The European American men had a median time of 57 months, whereas the Japanese American men had a median time of 40 months. Differences were seen between ethnic groups, and homogeneity of variance was not assumed (Levene's test  $p = .020$ ). Further, an independent  $t$ -test showed a trend toward statistically significant

differences of means between ethnic groups:  $t(21.933) = -2.012, p = .057$ . An analysis of covariance (ANCOVA) was performed to control for any potential impact of differences noted between ethnic groups, with relation to the variable “time since diagnosis,” as well as variables related to acculturation (generation in the US, ethnicity of friends).

All participants had had surgery or had received standard androgen deprivation/hormonal, radiation therapy, or a combination of therapies for their prostate cancer. Descriptive statistics for the type of medical treatment are reported in Table 3 and depicted in Figure 12. Over half ( $n = 49, 55\%$ ) of the participants had had surgery as treatment for the underlying prostate cancer – 7 (58%) of the Japanese Americans and 42 (55%) of the European Americans. The most frequent treatment for both ethnic groups was androgen deprivation therapy. Of all participants, 58 (65%) had received androgen deprivation therapy, including 5 (42%) Japanese American participants and 53 (69%) European American participants. Forty-seven (53%) of all participants had received radiation therapy for their prostate cancer, 6 (50%) of the Japanese Americans and 41 (53%) of the European Americans. Sixty-four (72%) of the total participants had more than one medical intervention (radiation, androgen deprivation, surgery, or other treatment: 5 (42%) of Japanese Americans and 59 (77%) of European Americans. Twenty (22%) participants had more than two treatment modalities: 2 (17%) Japanese American and 18 (23%) European American participants. Chi square test for independence showed statistically significant differences between

ethnic groups for androgen deprivation therapy, chemotherapy, other therapies, and combined therapy, as noted in Table 4.

Twenty-two (25%) of the participants reported having metastasis (spread or growth of the cancer outside of the prostate gland); all were European American (Figure 13). For the men with metastasis, the time since diagnosis averaged 8 years (97.14 months). The areas of metastasis included bone ( $n = 6$ ), lymph ( $n = 10$ ), other, not specified ( $n = 2$ ), and more than one area ( $n = 4$ ). Metastasis to bone, or to more than one location, is indicative of advanced metastatic disease or D2 staging (Wefer & Hricak, 2002). Therefore, advanced metastatic disease was reported in 10 (11%) of all participants; local disease was also reported in 10 (11%). Two patients with metastasis did not define the extent of their metastasis. (See Figure 14 for a histogram of time since diagnosis for men who reported metastasis.)

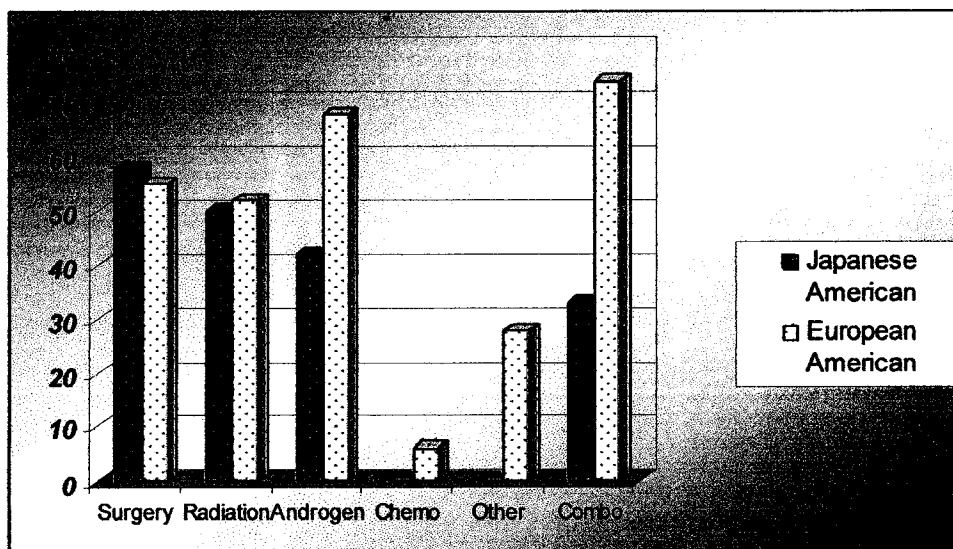


Figure 12. Medical treatment by ethnic group ( $N = 89$ )

Table 4  
 Descriptive Summary Statistics for Medical Information (N = 89)

	Japanese American n = 12 (100%)	European American n = 77 (100%)	Total n = 89 (100%)	x <sup>2</sup> Significance
Median Months Since Diagnosis	40.50	57.00	51.50	
Mean Months Since Diagnosis	46.33	68.01	64.89	
Metastasis				0.003*
No	10 (83)	37 (48)	47 (53)	
Yes	0 ( 0)	22 (29)	22 (25)	
Unknown	2 (17)	18 (23)	20 (22)	
Areas of Metastasis				
Bone	0 ( 0)	6 ( 8)	6 ( 7)	
Lymph	0 ( 0)	10 (13)	10 (11)	
Other	0 ( 0)	2 ( 3)	2 ( 2)	
Combination	0 ( 0)	4 ( 5)	4 ( 4)	
Treatment				
Surgery	7 (58)	42 (55)	49 (55)	0.286
Radiation	6 (50)	41 (53)	47 (53)	0.522
Androgen Deprivation Rx	5 (42)	53 (69)	58 (65)	0.003*
Chemo	0 ( 0)	5 ( 6)	5 ( 6)	<0.001**
Other (i.e. vaccine)	0 ( 0)	13 (17)	13 (15)	<0.001**
Combination	5 (42)	59 (77)	64 (72)	<0.001**
Bisphosphonate Therapy*				0.001**
Yes	1 ( 8)	26 (34)	27 (30)	
No	10 (84)	51 (66)	61 (69)	
Unknown	1 ( 8)	1 ( 1)	2 ( 2)	
Performance Status*				<0.001**
0 - No symptoms	9 (75)	44 (57)	53 (60)	
1 - Sx normal activities	3 (25)	27 (35)	30 (34)	
2 - Sx, rest < 50%	0 ( 0)	2 ( 3)	2 ( 2)	
3 - Sx, rest bed > 50 %	0 ( 0)	2 ( 3)	2 ( 2)	
Did not respond	0 ( 0)	2 ( 3)	2 ( 2)	

% not equal to 100% due to rounding error

\* statistically significant  $\leq .05$  ; \*\* statistically significant  $\leq .001$

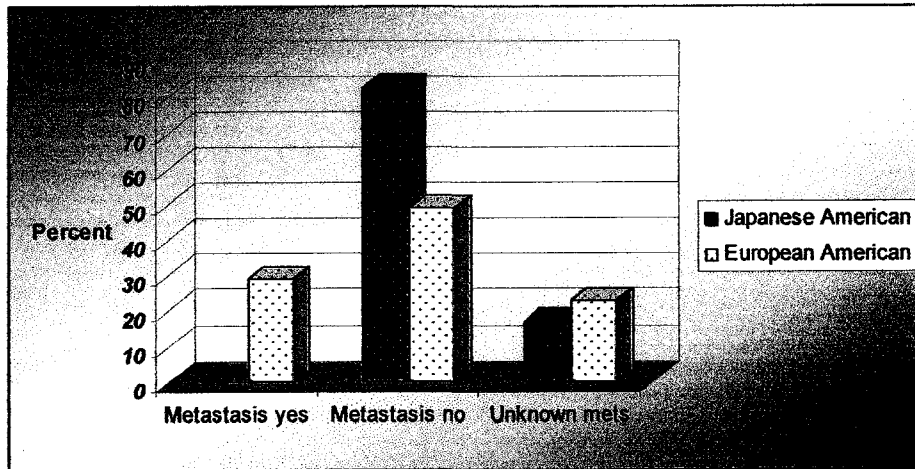


Figure 13. Presence of metastasis by ethnic group (N = 89)

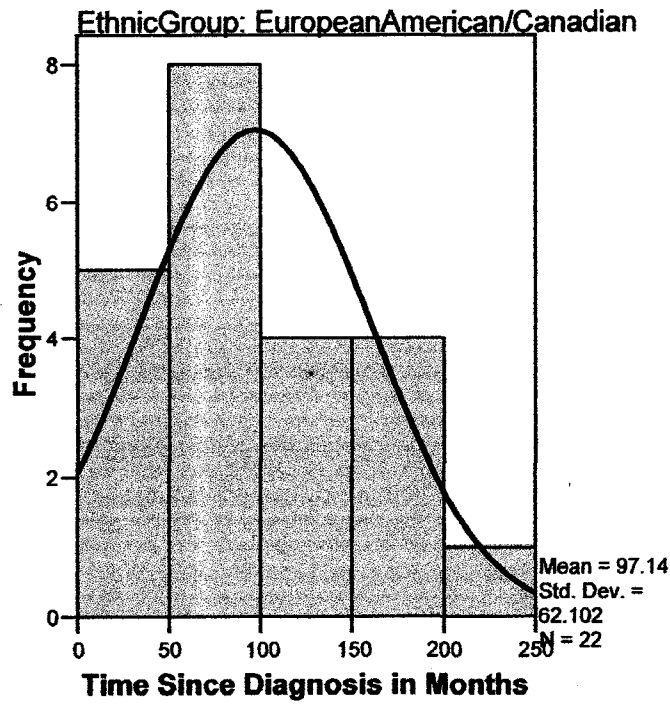


Figure 14. Histogram of time since diagnosis in months: participants with metastasis (n = 22)

Although 22 participants (25%) reported metastasis, most ( $n = 53$ , 60%) participants denied symptoms. Thirty participants (34%) had some symptoms but carried out all daily activities. The remainder of participants reported symptoms and resting in bed less than half the day ( $n = 2$ , 2%), symptoms and resting in bed more than half the day (2%) or no response (2%).

### Bonferroni Adjustment

Three comparisons were being performed on the same dataset, therefore the rate of a Type 1 error was increased (Weinberg & Abramowitz, 2002). To avoid a Type 1 error due to multiple comparisons on the same dataset, a Bonferroni adjustment for significance level was performed (Weinberg & Abramowitz, 2002). The significance level was set at 0.017 ( $.05/3$ ), adjusting for each of three main comparisons: 1) information-seeking (KHOS), 2) self-reported pain (BPI), and 3) overall adjustment to illness (PAIS). A confidence interval of 98.3% was used. Each of these three datasets is discussed below.

### Modified Krantz Health Opinion Survey (KHOS)

The modified KHOS is a 25-item Likert scale instrument, with values of 1-3 possible for each question; therefore, the overall range for the total KHOS score is 25 - 75. High scores indicate more informed treatment on the part of patients (Krantz et al., 1980).

The reliability of the KHOS (Krantz et al., 1980) was assessed, from scores obtained in this study, using the SPSS (1999). Chronbach alpha reliability,

a model for internal consistency based on the average inter-item correlation (SPSS), yielded an alpha reliability of 0.781 for the total modified KHOS score. Alpha reliability for sub-scores of asking (0.717), not asking (0.777), trust (0.802), resignation (0.801), and explanation (0.744) were all at acceptable levels between 0.60 - 0.70 (DeVellis, 1991; Frank-Stromborg, 1992; Nunnally, 1978). Generally, the reliability scores in the core study improved over those reported in the pilot study. With the exception of resignation (core 0.801, pilot 0.90) all sub-scores increased over reliability obtained in the pilot study.

#### Differences in Information-Seeking Behavior

To determine differences in information-seeking behavior between Japanese American and European American men treated for prostate cancer, a Wilcoxon rank sum test was conducted on the overall total score for the KHOS between ethnic groups (Japanese American and European American participants). The Wilcoxon Rank Sum test for the overall KHOS yielded a significant difference in the information-seeking behavior between the Japanese American and European American groups,  $p = .012$  (See Table 4). To further explore specific differences in information-seeking, the five domains of the KHOS were analyzed: Asking, Not Asking, Trust, Resignation, and Explanation by analyzing each domain using a Wilcoxon Rank Sum test. A Bonferroni adjustment of the alpha level,  $p$  value of .01 (.05/5) for acceptance of significance was applied for the conduction of multiple analyses, reported in Table 5.

Differences for the sum of the ranks between Japanese American and European American ethnic groups for Resignation, or reluctance to ask due to resignation, was found to be significant,  $p < .002$ . Lower scores indicated less inquisitiveness about treatment, a lesser desire or ability to ask questions, less involvement in decision making (either due to trust or resignation) and being less informed about treatment decisions. Higher scores indicated more self direction of care and involvement in treatment decisions. Comparing the sum of ranks for other domains of the KHOS indicated no statistically significant difference for any other KHOS domain (see Figure 15 and Table 5).

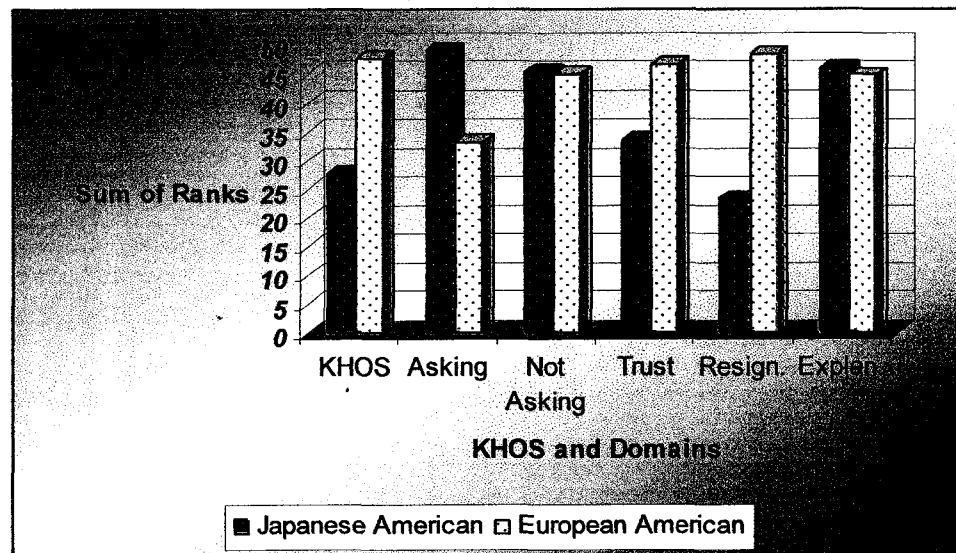


Figure 15. KHOS and domains, by ethnic group Wilcoxon Rank Sum ( $N = 89$ )



Table 5

*Wilcoxon Rank Sum for KHOS and Domains, by Ethnic Group**(N = 89; Japanese American = 12; European American = 77)*

Domain	Ethnic Group	Mean Rank	Sum of Ranks	Significance (2-tailed)
Overall KHOS	Japanese American	27.67	332.00	
	European American	47.70	3673.00	.012*
Asking	Japanese American	49.13	589.50	
	European American	44.36	3415.50	.464
Not Asking	Japanese American	45.29	543.50	
	European American	44.95	3461.50	.964
Trust	Japanese American	33.67	404.00	
	European American	46.77	3601.00	.100
Resignation	Japanese American	23.42	281.00	
	European American	48.36	3724.00	.002**
Explanation	Japanese American	46.04	552.50	
	European American	44.84	3452.50	.879

\* Significance &lt; .017

\*\* Significance &lt; .01

Brief Pain Inventory (BPI)

The BPI (Cleeland & Ryan, 1994) is a self-reported inventory of severity using a numeric rating scale (NRS) from 0 (no pain) to 10 (pain as bad as you can imagine) for worst pain, average pain, least pain, and pain now. Similarly, interference of activities or relationships (i.e., sleeping, working, walking, relationships with others, mood) is rated as a 0 to 10 NRS from 0 (does not

interfere) to 10 (completely interferes). A description of the findings related to the BPI is noted in Table 6.

The reliability of the BPI in this study was assessed using the SPSS (1999). Chronbach alpha reliability was based on the correlation of one question about presence of pain on the BPI and one question about pain on the Medical Information Form. From the BPI, Question 1 asks about pain other than everyday kind of pain, and Question 4 on the Medical Information Form asks, "Do you currently have pain?" The correlation yielded an alpha reliability of 0.663, indicating a strong correlation (Cohen, 1997; Weinberg & Abramowitz, 2002), or consistency, between answers to the two questions.

Chronbach alpha reliability based on the inter-item correlation of interference items (discussed in pre-planned analysis) to overall interference (sum of all interference items) was 0.793. The alpha reliability for each interference item related to overall interference was  $> 0.60$  and deemed acceptable (DeVellis, 1991; Frank-Stromborg, 1992; Nunnally, 1978). Alpha reliability scores were activity (0.91), mood (0.850), walking ability (0.75), normal work (0.939), relations (0.807), sleep (0.659), and enjoyment of life (0.914).

#### Differences in Pain Intensity

To determine differences in pain intensity between Japanese American men and European American men treated for prostate cancer the presence of metastasis, or spread of the prostate cancer, as well as the self-reported worst pain score on the BPI were explored.

Although 22 (25%) of the participants reported prostate cancer metastasis and 22 (25%) reported having pain on the medical information form, not all patients with pain had metastasis. Further, 32 (36%) reported “pain other than minor pain today” (e.g., minor pain would include sprain or toothache) on the BPI (Question 1). Four (33%) Japanese Americans reported pain today on the BPI; no Japanese Americans had metastasis. Twenty-eight (32%) European Americans reported pain on the BPI but only 22 European Americans reported metastasis. Some participants did clarify that their pain was not related to prostate cancer.

Prior to conducting the analysis for worst pain between ethnic groups, a comparison of the shape of the distribution of the variable, by ethnic group was conducted. For European American participants with pain ( $n = 43$ ), the distribution was skewed to the right (skew = 4.09). Fewer Japanese Americans reported pain ( $n = 6$ ), and the shape of the distribution appeared bimodal (skew = .497) but similar to part of the curve observed for the European American group (see Figures 16 and 17).

The mean rank of the worst pain score was higher for Japanese Americans (Mean Rank = 28.42) than for European Americans (Mean Rank = 24.52), but the difference was not significant,  $p = .541$  (see Table 7). Of the 49 (55%) participants with scores for worst pain greater than “0” (Japanese American,  $n = 6$ ; European American  $n = 43$ ), the most frequent type of pain reported was bone pain ( $n = 7$ ), followed by nerve pain ( $n = 5$ ), visceral pain ( $n = 5$ ), and other

Table 6

*Descriptive Summary of BPI*  
(N = 89)

	Japanese American n = 12 (100%)		European American n = 77 (100%)		Comment
Pain today -- yes	4 (33)		32 (42)		Pain as reported on Question 1 on the BPI
Severity of Pain	(n = 6) (50)		(n = 43) (56)		
	Range	Mean (SD)	Range (SD)	Mean	
Worst Pain	1 - 7	4.33 (3.01)	1 - 10	3.31 (2.31)	Includes only participants with worst pain > 0.
Average Pain	1 - 7	3.67 (2.66)	0 - 6	2.29 (1.55)	
Least Pain	1 - 5	2.83 (1.84)	0 - 9	1.30 (1.73)	
Pain Now	0 - 7	2.25 (2.25)	0 - 7	1.25 (1.76)	
Treatment for pain	2 (17)		23 (30)		Treatment (Rx) other than medication (meds): Physical Therapy = 2 Chiropractor = 1 Shiatsu message = 1 Radiation for pain = 1. *Sometimes provided with medication.
Treatment with medication	2 (17)		21 (27)		
Rx other than med*	0 ( 0)		4 ( 5)		
No treatment	10 (83)		54 (70)		
Relief **					
90 – 100%	1 (50)		7 (30)		
70 – 80%	0 ( 0)		5 (22)		
≤ 50%**	1 (50)		8 (35)		
Missing	0 ( 0)		3 (13)		

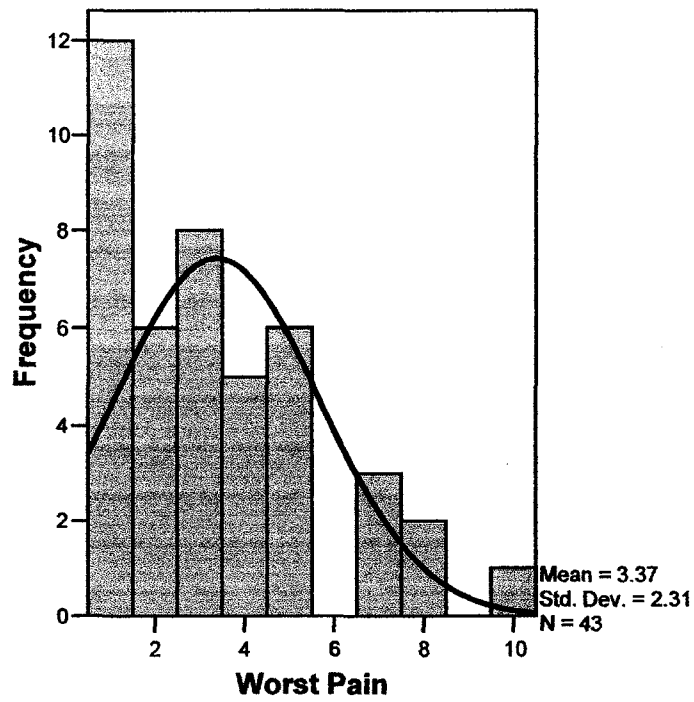


Figure 16. Distribution of worst pain for European American men ( $n = 43$ )

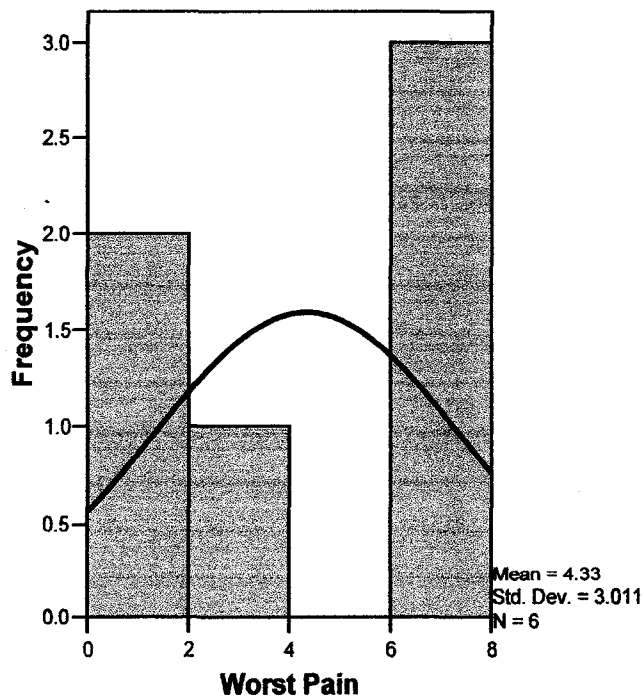


Figure 17. Distribution of worst pain for Japanese American men ( $n = 6$ )

No additional information for the response of “other” was provided. Type of pain was provided by the 43 European American participants with pain (greater than 0). Two Japanese American participants reported type of pain unknown.

The most frequent anatomical areas of pain included the lower back, flank, pubic area, shoulders, upper back, and hips. Other areas of pain reported included: neck, hip, glut, knee, head, hands, arm legs, chest, all joints, feet, and abdomen (See Table 7 for details).

Table 7

*Wilcoxon Rank Sum – Worst Pain by Ethnic Group*  
( $n = 49$ ; Japanese American  $n = 6$ ; European Americans  $n = 43$ )

Domain	Ethnic Group	Mean Rank	Sum of Ranks	Significance (2-tailed)
Worst Pain	Japanese American	28.42	170.5	.541
	European American	24.52	1054.5	

#### Treatment for Pain

Twenty-five (28%) participants had some treatment for pain. Medication was the most common treatment. Two (17%) Japanese Americans and 19 (24%) European Americans took medication for pain. An additional two European Americans (17%) had physical therapy for pain, one (1%) had radiation for pain, and another one (1%) had Shiatsu message for pain.

Medication varied from mild analgesics (i.e. acetaminophen) to narcotics (e.g. OxyContin). Thirteen of the 23 (57%) participants who were treated with

Table 8

*Descriptive Summary: Areas of Pain*  
(n = 49)

Area of Pain	Japanese American n = 6 (%)	European American n = 43 (%)	Comment
Lower back	3 (50)	11 (26)	For participants with scores for worst pain > 0 (n = 49)
Flank	2 (33)	2 (5)	
Pubic area	1 (17)	7 (16)	
Shoulders	1 (17)	5 (12)	
Lower back	1 (17)	2 (5)	
Hips	4 (9)	4 (9)	
Other	0 (0)	16 (37)	

Other included: glut (2), knee (3), head (1), arm (1), neck (3), legs (1), chest (1), joints (1), feet (1) and abdomen (1)

medication received pain relief more than 70% of the time. Eight patients (35%, who were treated with medication for pain relief, received relief about 50% of the time or less from similarly classified medications. One Japanese American patient receiving naproxen did not provide information about the amount of relief he had from the medication. Table 9 provides a summary of medication and relief by ethnic group.

Table 9

*Summary of Self-Reported Pain Medication and Percent Relief based on BPI by Ethnic Group*  
(n = 20)

	Percent Relief	Number	Medication(s)
Japanese American	90%	1	Naproxen
	no response	1	Naproxen
European American	100%	3	oxycodone and oxybutynin; acetaminophen; Neurontin
	90%	4	Elmiron and pyridium; aspirin and ibuprofen; glucosamine sulfate; Celebrex
	80%	4	aspirin; Neurontin; OxyContin and oxycodone; acetaminophen
	70%	1	ibuprofen
	≤ 50%	6	ibuprofen; Vicodin; Celebrex; acetaminophen, Celebrex and aspirin; aspirin; Percocet

#### Psychosocial Adjustment to Illness Scale (PAIS)

The PAIS is a 46-item instrument with multiple-choice questions that measures adjustment to illness in seven domains: healthcare orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress. Each domain has sub-scores, with an overall adjustment score being the sum of all items. The



overall adjustment score had a possible range of 0 - 138. A lower score indicated positive psychosocial adjustment to illness.

Cronbach alpha reliability for internal consistency based on the scale correlation (SPSS, 1999) yielded an alpha reliability of  $\alpha = 0.771$  for the total PAIS score. Alpha reliability for sub-scores of vocational environment, or leisure activities if retired ( $\alpha = 0.686$ ); domestic environment ( $\alpha = 0.835$ ); sexual relationships ( $\alpha = 0.625$ ); extended family relationships ( $\alpha = 0.614$ ); social environment ( $\alpha = 0.761$ ); and psychological distress ( $\alpha = 0.813$ ) were all at acceptable levels between 0.60 - 0.70 (DeVillis, 1991; Frank-Stromborg, 1992; Nunnally, 1978). Healthcare orientation ( $\alpha = 0.538$ ) was slightly lower than the recommended alpha reliability.

#### Differences in Adjustment

To determine differences in adjustment between Japanese American men and European American men treated for prostate cancer a Wilcoxon Rank Sum test was performed for overall PAIS (sum of all domain scores). The rank sums for the overall PAIS were not significantly different for the two ethnic groups,  $p = .188$ . This finding was similar to the findings obtained with an independent  $t$ -test in the pilot study. A Wilcoxon Rank Sum test comparison of PAIS for participants with worst pain score  $> 0$ , by ethnic group, was also performed; no statistical significance was observed,  $p = 0.315$ .

For all domains the general pattern of adjustment was similar between ethnic groups (see Figure 18). Japanese Americans had lower scores (more

positive adjustment) in most domains; Japanese Americans had a higher scores (poorer adjustment) only in healthcare orientation (Median = 6.5,  $M = 6.17$ ,  $SD = 3.88$ ) compared to European Americans (Median = 6.0,  $M = 5.40$ ,  $SD = 3.12$ ). A higher, but not significant, mean score for healthcare orientation was also noted in results of the pilot study, as noted in Appendix C.

No variation of scores within the Japanese American group was noted for the extended family relationship domain,  $M = 0$ ;  $SD = 0$ , indicating no problems in any areas of this domain. The European American group had a slight variation in the extended family relationship scores,  $M = .792$ ,  $SD = 1.71$ . The median for both Japanese American and European American participants was 0 for this domain.

Figure 18 reflects that the greatest differences between ethnic groups were noted for the social environment and psychological distress domains, noting a higher score indicates poorer adjustment. Median scores for the domains of health care orientation, vocational environment, and sexual relationship were most similar between ethnic groups. Although the Wilcoxon rank sum for the overall psychosocial adjustment score was not significantly different, statistical comparisons of domain scores are reported for the purpose of comparison (see Table 10).

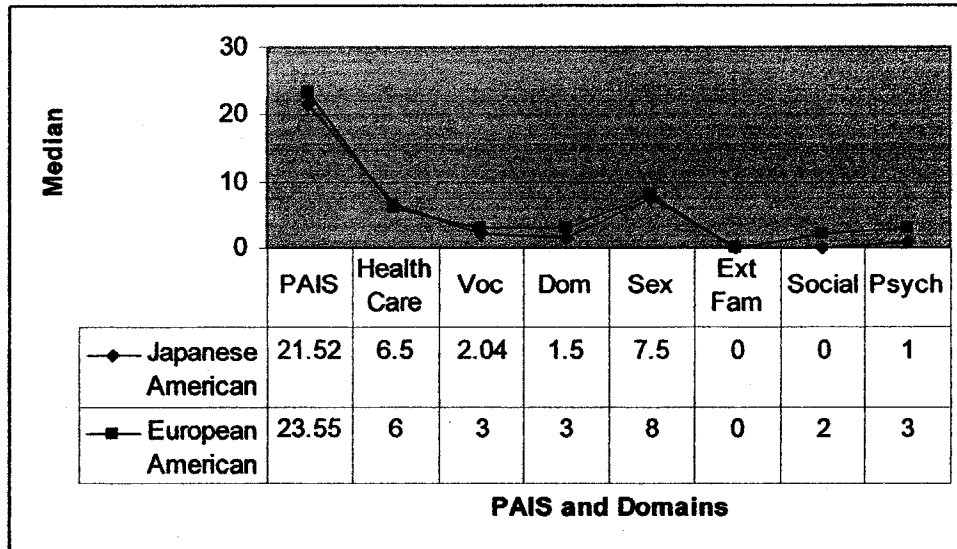


Figure 18. Median PAIS and domain scores, by ethnic group ( $N = 89$ )

### Pre-planned Ancillary Analyses

#### Least and Average Pain Scores from BPI

Ancillary analyses were planned and included a comparison of “least pain” BPI scores of the ethnic groups. The distribution curves for “least pain” and “average pain” were compared between Japanese American and European American participants. Although fewer Japanese American participants reported pain ( $n = 6$ ) than did European Americans ( $n = 43$ ), the appearance of distribution curve observed for the Japanese American participants is similar to a portion of the curve observed for the European Americans.

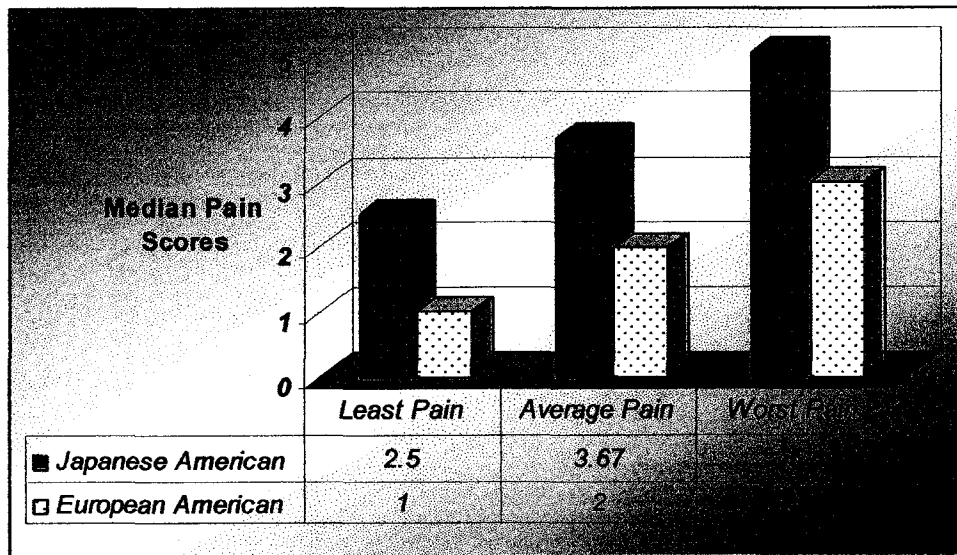
Self-reported pain scores by Japanese American participants were higher, indicating more pain, than scores reported by European American men (see Figure 19). A Wilcoxon Rank Sum analysis showed a statistically significant

Table 10

*Wilcoxon Rank Sum for PAIS and Domains, by Ethnic Group*  
 (N = 89; Japanese American n = 12; European American n = 77)

Domain	Ethnic Group	Mean Rank	Sum of Ranks	Significance (2-tailed)
Overall PAIS	Japanese American	35.88	430.50	
	European American	46.42	3574.50	.188
Health Care Orientation	Japanese American	49.38	592.50	
	European American	44.32	3412.50	.526
Vocation Environment	Japanese American	35.17	422.00	
	European American	46.53	3583.00	.154
Domestic Environment	Japanese American	27.33	328.00	
	European American	47.75	3677.00	.010
Sexual Relationships	Japanese American	42.96	515.50	
	European American	45.32	3489.50	.768
Extended Family Relationships	Japanese American	34.50	414.00	
	European American	46.64	3591.00	.042
Social Environment	Japanese American	31.50	378.00	
	European American	47.10	3627.00	.043
Psychological Distress	Japanese American	31.29	375.50	
	European American	47.14	3629.50	.046

difference,  $p = .029$ ) in least pain scores between ethnic groups, Japanese American and European American participants. Japanese American men reported least pain at a median intensity of 2.5, compared to European American men who reported pain at a median intensity of 1, which may reflect a greater tolerance to pain by the Japanese American men. No significant difference was found for average pain scores,  $p = .273$ . Table 11 presents the Wilcoxon rank sum analysis.



*Figure 19.* Median least, average and worst pain scores, by ethnic group ( $n = 49$ )

### Correlations

Relationships between variables (pain intensity; information-seeking behavior and adjustment) were explored using Pearson's correlation.

Table 11

*Wilcoxon Rank Sum – Least and Average Pain by Ethnic Group*  
 ( $n = 49$ ; Japanese Americans,  $n = 6$ ; European Americans,  $n = 43$ )

Domain	Ethnic Group	Mean Rank	Sum of Ranks	Significance (2-tailed)
Least Pain	Japanese American	36.75	220.50	
	European American	23.36	1004.50	.029
Average Pain	Japanese American	31.08	186.50	
	European American	24.15	1038.50	.273

#### Information-Seeking Behavior and Pain Intensity

Pearson's correlation between KHOS overall score and worst pain score was obtained for a sub-sample ( $n = 49$ ) of participants with scores for worst pain  $> 0$ . There is weak and non-significant, negative correlation,  $r (n = 49) = - 0.233$ ,  $p = 0.107$  (two-tailed), for all participants. Correlations for each ethnic group were also explored. For the Japanese American group a strong, statistically significant, positive correlation was obtained between information-seeking behavior and worst pain,  $r (n = 6) = 0.817$ ,  $p = 0.047$  (two-tailed). For the European American group, a modest, statistically significant, negative correlation was obtained,  $r (n = 43) = - 0.450$ ,  $p = 0.002$  (two-tailed).

Japanese American participants with worst pain scores  $> 0$  ( $n = 6$ ) had higher median worst pain scores than their European American counterparts. Japanese American patients with high worst pain scores tended to have high

information-seeking scores, indicating more involvement in healthcare and questions. However, European Americans with high information-seeking scores, i.e., more involvement in healthcare and more questions, tended to have lower pain scores (less pain). Figure 20 presents a scatterplot depicting the relationship between information-seeking and worst pain for the two ethnic groups.

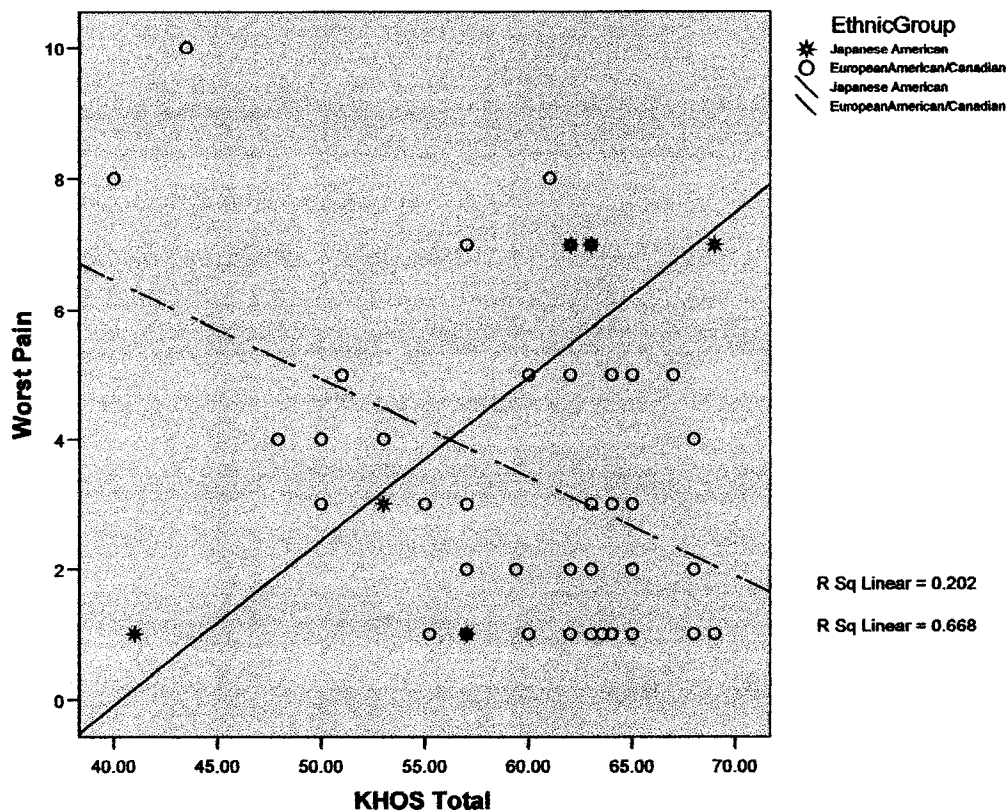


Figure 20. Scatterplot of worst pain and information-seeking, by ethnic group (n = 49)

### Pain Intensity and Adjustment

Pearson's correlation between worst pain and overall adjustment (PAIS Total Score) for participants with worst pain > 0 reported ( $n = 49$ ) was not significant for the total group or for either ethnic group. The findings indicate a moderate positive but non-significant correlation,  $r (n = 49) = 0.209, p = 0.150$  (two-tailed). Neither the correlation for the Japanese American group was significant ( $r [n = 6] = -0.376, p = 0.463$  [two-tailed]) nor was the correlation for the European American group ( $r [n = 43] = 0.283, p = 0.066$  [two-tailed]).

Figure 21 shows that although worst pain scores are noted for the Japanese American participants, the overall adjustment remains better (lower PAIS scores). A different pattern is seen for European American men, who have a change in adjustment scores. As pain scores increase (more pain), PAIS scores also increase, indicating poorer adjustment.

### Information-Seeking and Adjustment

The Pearson correlation between information-seeking and adjustment indicated a weak but significant, negative correlation for all participants ( $r [n = 89] = -0.287, p = 0.006$  [two-tailed]) for all participants. That is, when information scores were high (more inquisitiveness, more involvement in healthcare decisions), adjustment scores were low (better adjustment). This pattern is depicted by noting the patterns for the both groups on the scatterplot in Figure 22.



For the European American participants a modest, statistically significant, negative correlation was obtained ( $r [n = 77] = -0.308, p = .001$ ), compared to a small, non-significant, negative correlation ( $r [n = 12] = -.0212, p = .508$ ) for the Japanese American participants.

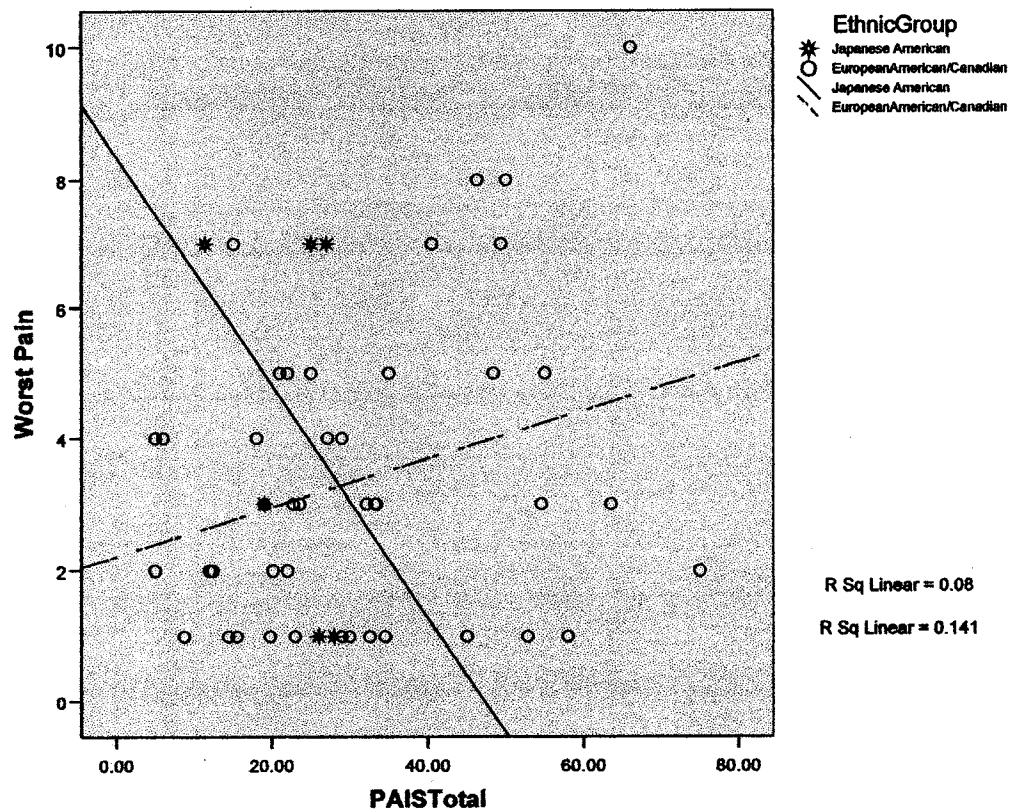


Figure 21. Scatterplot of worst pain and overall adjustment, by ethnic group ( $n = 49$ )

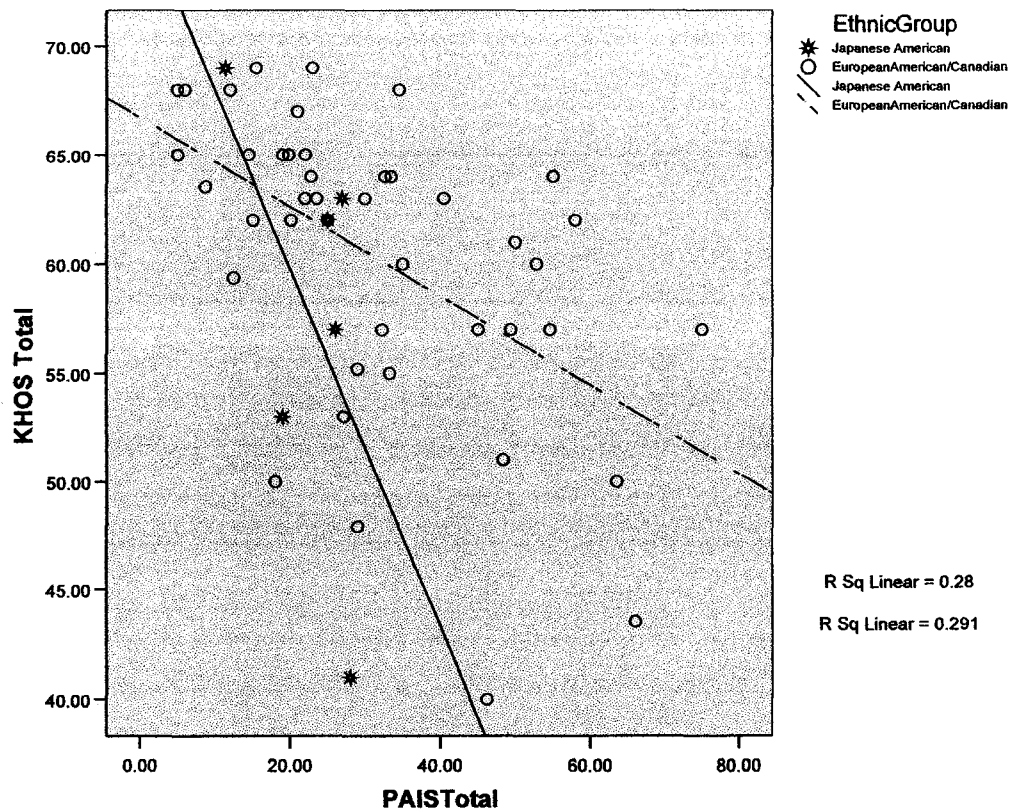


Figure 22. Scatterplot of information-seeking behavior and overall adjustment, by ethnic group ( $N = 89$ )

### Interference Due to Pain

Seven interference items measuring self-report of interference with physical activities (four items) and interpersonal relations (three items) are included in the BPI. A 10-cm linear NRS is provided for each of the seven items. Numbers on the NRS range from “0” indicating pain does not interfere with this activity to “10” indicating pain completely interferes with this activity. The sum of the interference items was used as the pain interference score. To include only patients with interference of activities related to pain, analyses with interference

score were conducted only for participants reporting a worst pain score  $> 0$ ,  $n = 49$ .

Forty-nine (55%) participants reported interference from pain. The Japanese American participants reported slightly more interference, ( $n = 6$ ), median 10.5,  $M = 16.50$ ,  $SD = 14.79$ , than the European patients, ( $n = 43$ ), median 9.50,  $M = 15.58$ ,  $SD = 14.94$ . A Wilcoxon rank sum analysis showed no significant mean difference for interference, between ethnic groups;  $p = .787$ . See Table 12 for mean ranks.

Table 12

Wilcoxon Rank Sum – Interference due to Pain by Ethnic Group  
( $n = 49$ ; Japanese Americans  $n = 6$ ; European Americans  $n = 43$ )

	Ethnic Group	Mean Rank	Sum of Ranks	Significance (2-tailed)
Interference	Japanese American	24.93	149.50	
	European American	23.29	931.50	.787

A Pearson correlation ( $n = 46$ ) between interference due to pain and overall adjustment showed a significant moderate positive correlation,  $r (n = 46) = .575$ ,  $p < .001$ . That is, when interference of activities due to pain increased (high interference score), the participant reported poorer overall adjustment (adjustment score higher) as depicted in Figure 23. This finding was also seen in the larger European American group,  $r (n = 46) = 0.659$ ,  $p < .001$ .

Interestingly, a different trend was noted in the smaller Japanese American group of participants with interference due to pain ( $n = 6$ ). Overall adjustment

scores remained low (better overall adjustment), even when the pain caused interference (the interference score is high). This moderate negative correlation was not significant,  $r(n = 6) = -0.588, p = .220$ , in this small subset of patients.

#### Analysis of Covariance (ANCOVA)

Several variables did not meet the assumption of equal variances between Japanese American and European American participants. An analysis of covariance (ANCOVA) was conducted to analyze adjustment, while removing the effect of covariates (Tabachnick & Fidell, 1996). A second ANCOVA was performed with information-seeking (KHOS) as the dependent variable. Each ANCOVA was performed on the two ethnic groups, while controlling for variables that were not well-matched between the groups. Prior to the ANCOVA, transformation of variables was conducted, as necessary to reduce skew (Tabachnick & Fidell).

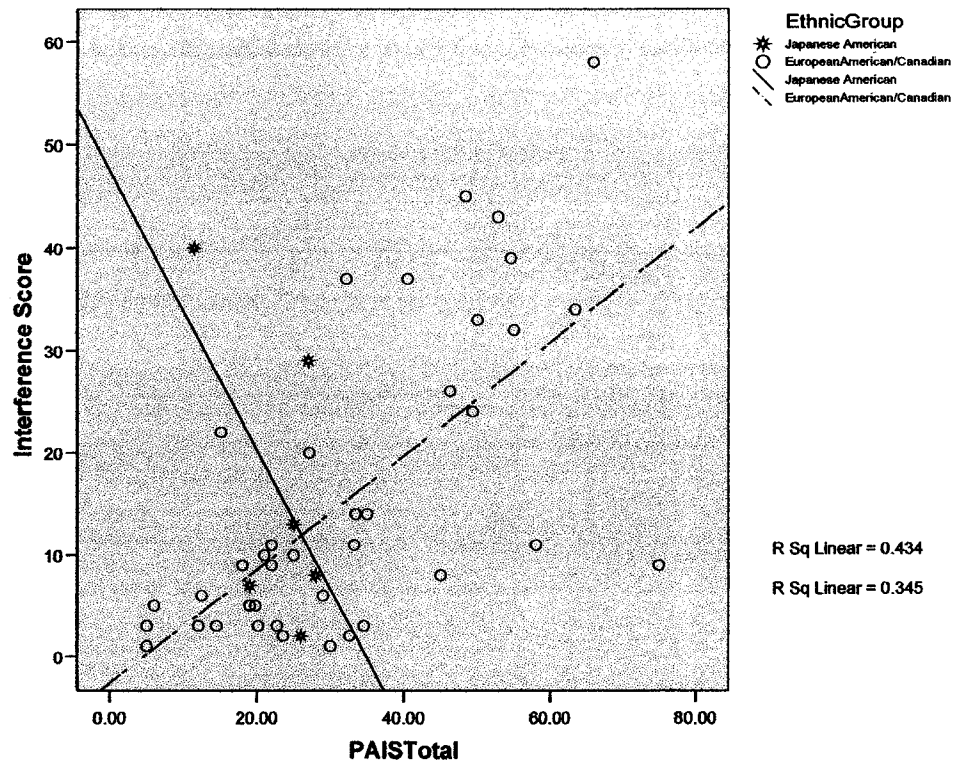


Figure 23. Scatterplot of interference due to pain and adjustment by ethnic group ( $n = 49$ )

The variables found to be significant ( $p \leq .05$ ) by chi square analyses between ethnic groups (SPSS 10.0, 1999) and potential predictors for adjustment were:

1. Ethnicity of friends same or different (related to acculturation)
2. Generation of participant living in the US (related to acculturation)
3. Time since diagnosis (months) (medical information related to adjustment)
4. Type of treatment (surgery, androgen deprivation, radiation, and combination therapies)

5. Metastasis (medical information related to adjustment).

The ANCOVA analysis was conducted to explore the influence of the above mentioned variables on the previously conducted Wilcoxon Rank Sum, which showed differences of KHOS scores for ethnic groups. Prior to the analysis, variables were transformed to more closely approximate a normal distribution.

The variable friends (same or different ethnicity) and type of treatment, both classified as nominal variables, were included as a between-subjects factor. Additionally, adjustment to illness can change over time (Jakobsson, Hallberg, & Lovin, 1997; Northouse & Peters-Golden, 1993); therefore, the influence of the variable “time since diagnosis” was explored. To eliminate the influence of metastasis on adjustment (Cleary, Morrissey, & Oster, 1995), patients with known metastasis were not included in this analysis. Twenty-three European American men with known metastasis were excluded from the analysis.

To summarize:

1. ANCOVA was performed using PAIS as the dependent variable. A second analysis was performed using KHOS as the dependent variable.
2. Fixed variables were ethnic groups and friends (same or different ethnicity).
3. Covariates were generation living in the US and time since diagnosis.

4. Participants with known metastasis were excluded from the ANCOVA analysis. Therefore, the ANOCVA sample size was  $n = 67$ ; Japanese Americans  $n = 12$ ; European Americans,  $n = 55$ .

Prior to conducting the ANCOVA, correlations between selected covariates were performed. The variables “presence of metastasis” and “friends” (same or different ethnicity) correlated,  $r = 0.242$ ,  $p = .023$ . No other significant correlations were obtained. Because participants with metastasis (which included only European American participants) were excluded, the correlation between presence of metastasis and friends (same or different ethnicity) did not impact the ANCOVA.

ANCOVA between ethnic groups showed statistically significant mean differences in information-seeking,  $F(19, 46) = 2.369 = p < .009$  when identifying ethnicity of friends and treatment as fixed variables, controlling for generation, time since diagnosis, and treatment, for participants without metastases (see Tables 13 and 14).

Using ANCOVA to correct for ethnicity of friends, generation in the US, treatment, and time since diagnosis, a difference in pattern was noted for information-seeking behaviors (KHOS) between ethnic groups, which was similar to findings obtained with the Wilcoxon Rank Sum analysis. Japanese Americans participants were less inquisitive than European American participants.

Further, ANCOVA correcting for ethnicity of friends, generation in the US, treatment, and time since diagnosis did not show a difference in overall adjustment (PAIS) between ethnic groups, similar to the findings obtained with Wilcoxon Rank Sum analysis.



Table 13

*Analysis of Covariance of KHOS, Adjusting for Friends, Time Since Diagnosis, Treatment, and Generation, Excluding Participants with Metastasis (n = 67)*

Source	Df	F	D	D <sup>2</sup>	P
Between Subjects					
KHOS, Ethnicity, Friends, Time since dx, Treatment, Generation	19	2.369	.704	.495	< .009*
Ethnicity	1	3.169	.253	.064	.082
Friends	3	2.207	.355	.126	.100
Time since dx	1	3.162	.205	.064	.082
Treatment	3	1.419	.292	.085	.249
Generation	1	1.478	.176	.031	.031
Ethnicity x Friends	1	1.315	.167	.028	.257
Friends x Treatment	5	1.846	.409	.167	.123
Treatment x Ethnicity	3	2.028	.342	.117	.123
Friends x Treatment x Ethnicity	1	.963	.145	.021	.332
Error	46				

Note. \* Statistically significant,  $p < .017$

\*\* Statistically significant,  $p < .001$

Table 14

*Analysis of Covariance of PAIS, Adjusting for Friends, Time since Diagnosis, Treatment, and Generation, Excluding Participants with Metastasis (n = 67)*

Source	Df	F	$\eta^2$	$\eta^2$	P
Between Subjects					
PAIS, Ethnicity, Friends, Time since dx, Treatment, Generation	19	1.025	.546	.298	.453
Ethnicity	1	.017	.000	.000	.895
Friends	3	2.474	.371	.139	.073
Time since dx	1	3.780	.276	.076	.058
Treatment	3	.112	.084	.007	.953
Generation	1	.003	.000	.000	.957
Ethnicity x Friends	1	.092	.045	.002	.762
Friends x Treatment	5	2.193	.439	.193	.071
Treatment x Ethnicity	3	.315	.141	.020	.814
Friends x Treatment x Ethnicity	1	.154	.055	.003	.697
Error	46				

Note. \* Statistically significant,  $p < .017$

\*\* Statistically significant,  $p < .001$

## CHAPTER V

## DISCUSSION

This study comprises an important step in understanding the health care needs of two ethnically diverse groups, Japanese American and European American men treated for prostate cancer. It explored differences and similarities of self-reported pain intensity, information-seeking behaviors, and overall adjustment related to prostate cancer between these two groups. Its conceptual framework was the Roy Adaptation Model (RAM), which recognizes the impact of physical, social, psychological, and spiritual aspects of individuals as they adapt to stressful life situations, such as cancer.

No differences in pain intensity were found between Japanese American and European American men, and their overall adjustment to prostate cancer was similar; however, statistically significant differences were found in information-seeking behaviors. This chapter focuses on a discussion of these findings.

#### Self-Reported Pain Intensity and Ethnicity

Sub-question 1 focused on the differences in pain intensity between Japanese American men and European American men treated for prostate cancer. No differences in pain intensity were found between Japanese American and

European American men,  $p = .451$ . This similarity of self-reported pain intensity between ethnic groups is an important finding.

On a scale of 0 – 10, where 10 represents “pain as bad as you can imagine”), 64% of the participants reported worst pain  $> 0$ . This included six – half of the Japanese Americans, and 59% of the European Americans. A Wilcoxon Rank Sum analysis showed that the mean rank of the worst pain score was higher for the Japanese American participants (28.42) than for the European American men (24.52); the difference was not significant ( $p = .541$ ).

The high number of participants with pain in this study, of Japanese American and European American men, is consistent with reports by other investigators (Cleeland, 2006; Pargen & Hailey, 1999; Twycross, 2003) reporting on the incidence of pain in the overall cancer population. Clearly, despite the efforts of various professional organizations to prioritize assessing and managing pain (Joint Commission on the Accreditation of Healthcare Organizations, 2004; Oncology Nursing Society, 2004; US DHHS, 1994), many cancer patients still experience pain. Yet not all ethnic groups may actively report pain intensity or distress in a clinical setting (Cleeland, 2006; Fawcett & Weiss, 1993; Im, 2006; Kagawa-Singer, 1988; Zborowski, 1952). Thus, the under-reporting of pain is an ongoing challenge to adequately manage pain (Cleeland, 2006). As Pargen and Hailey concluded that under-reporting of pain may be due to a) low expectations of patients and professionals regarding pain relief, b) patient and professional ethnic and cultural influences; or c) deficits in overall knowledge (e.g., fear of addiction because of misconceptions regarding

therapies). Other researchers (Kagawa-Singer, 1988; Ogasawara, Kume, & Andou, 2003) cite beliefs that pain should be tolerated without complaint by those of Japanese heritage, which provides a potential explanation of under-reporting of pain.

In this study, 22 (29%) of the European American men and none of the Japanese American men ( $n = 12$ ) had known metastasis. The European Americans had a lower mean score for worst pain, of all participants, and no statistical difference was noted in pain scores for worst pain between Japanese American and European American men. This finding was consistent even when excluding participants with metastasis: the Japanese Americans maintained a higher mean rank (19.50) than European Americans (17.06) but with no significant difference ( $p = .612$ ).

Only one-third of the Japanese Americans with pain provided any response to the type of pain experienced (e.g., bone, nerve, visceral), and that response was “unknown.” Only the European Americans with pain specified the type of pain: Overall, the most frequent type reported was bone pain (14%), followed by nerve and visceral pain (each 10%). Both ethnic groups listed medication as the most common pain treatment, but unlike the Japanese Americans, 4% of European Americans noted having physical therapy, and 2% reported having Shiatsu massage, an additional 2% reported having radiation for pain.

The similarity of pain findings, most notably self-reported pain intensity between ethnic groups, is an important finding. Pain needs to be assessed and

monitoring self-reported pain intensity needs to be actively sought for each patient, regardless of ethnicity. Pain plays an important role in the ability and desire of a person to participate in activities and interpersonal relationships, thus impacting overall psychosocial adjustment to illness. Severe pain, defined as pain reported  $\geq 6$  on the BPI, interferes with sleep, socialization and relationships (Cleeland & Ryan, 1994). Similarly, pain is a component behavior within the physiological mode, impacting adjustment (Roy & Andrews, 1999). Patients not reporting pain without prompting (i.e., completion of the BPI or other clinical assessment) could impact adjustment.

Over half (52%) of the participants reported interference due to pain, and a significant positive relationship between interference and overall adjustment was observed  $r(n = 46) = .444, p < .001$ . For the European Americans, an increase in interference from pain correlated with poorer adjustment (higher adjustment scores); for the Japanese Americans, adjustment remained better (lower adjustment scores), even in the face of interference with activities and social interactions due to pain,  $r(n = 6) = -0.616, p = .193, ns$ .

The Japanese Americans reported slightly more interference ( $n = 6$ ), median 10.5,  $M = 16.50, SD = 14.79$ , than the European patients, ( $n = 43$ ), median 9.50,  $M = 15.58, SD = 14.94$ . A Wilcoxon rank sum analysis showed no significant difference for interference, between ethnic groups ( $p = .787$ ). Thus, worst pain scores and interference scores were higher but not significantly different for Japanese American men having had treatment for prostate cancer. Yet, despite higher scores related to pain and interference, the adjustment scores were lower,

indicating more positive adjustment to prostate cancer, even with pain. This finding suggests that Japanese American men are able to positively adjust to illness, despite pain and interference of activities due to pain. The trend of Japanese Americans to adjust to illness is consistent with that described by Kagawa-Singer (1988) in her study of Japanese American women with breast cancer.

#### Information-Seeking Behaviors

The second sub-question asked: what are the differences in information-seeking behavior between Japanese American men and European American men treated for prostate cancer.

Attributes of information-seeking behavior have been consistently demonstrated including physician-patient communication, willingness to talk about the cancer, asking of questions, and initiation of discussion about topics related to cancer (Bilodeau & Debner, 1996; Borgers et al., 1993; Degner et al., 1997, Lovey & Klaich, 1991). These attributes differ from the lack of communication between physicians and patients, as observed in Japanese or Japanese American patients (Kagawa-Singer 1988; Kai et al., 1993; Wellisch et al., 1999).

The findings indicate a significantly different pattern of information-seeking behavior between Japanese American and European American men, with the former less open. That is, Japanese American men (mean rank = 27.67) reported a likelihood of seeking information less frequently than European

American men (mean rank = 47.70,  $p = .012$ ) when presented with the same hypothetical questions. Further analysis indicated less information-seeking (lower score) due to resignation for Japanese Americans (mean rank = 23.42) compared to European Americans (mean rank 48.36),  $p = .002$ . No other subscores were significant for information-seeking behaviors.

Japanese Americans reported more reluctance to ask questions of their healthcare providers and were more resigned to and accepting of their illness, consistent with the literature that supports a trusting nature and reluctance to ask questions in Japanese American cancer patients (Kagawa-Singer, 1988; Kakai et al., 2003; Tsutsui, 1991; Wellisch et al., 1999). Additionally, a fatalistic attitude (Kakai et al., 2003; Yamazaki, 1996) has been reportedly observed in Japanese patients. Trust of professionals (e.g., physician, nurse) who are perceived as superior to patients is consistent with the Japanese concept of *enryo*, or trust due to respect, which is consistent with less assertive behavior, such as asking questions (Tsutsui, 1991). However, this study did not identify reluctance to ask questions due to trust.

The sample size met the planned number of participants ( $N = 84$ ), based on a power analysis (see page 51) to measure differences in adjustment between groups. The sample size was not estimated to detect differences in subscores between ethnic groups. The small number of Japanese American participants may have led to decreased power in the overall sample to detect differences in trust or other subscores (Pedhazur & Schmelkin, 1991). Among the European American men, information-seeking behavior showed trends toward open communication



and freedom to ask questions, consistent with the findings of Wong et al. (2000) and Roesch et al. (2005).

### Overall Psychosocial Adjustment

The third sub-question asked: what are the differences in adjustment between Japanese American men and European American men treated for prostate cancer. The results reflect similarity in overall adjustment to prostate cancer between the two ethnic groups ( $p = .188$ ).

Despite higher scores related to pain and interference with activities due to pain, the Japanese American men had lower adjustment scores, indicating more positive adjustment. In addition, in all domains other than health care orientation, Japanese American participants had lower mean rank scores, suggesting that they are able to positively adjust to illness, despite pain and interference of activities due to pain. This trend to adjust to illness is consistent with that noted by Gotay et al. (2002) and Kagawa-Singer (1988), who theorized that adjustment and acceptance is part of Japanese culture.

Items included in the health care orientation domain of the PAIS (Derogatis & Derogatis, 1990) are patient information about treatment, general attitude toward medicine and doctors, and patient expectancies about the disorder. As previously noted, the information-seeking patterns of the Japanese Americans in this study differed from those of the European Americans. Further, the literature reflects Japanese as being generally more accepting of medicine and doctors (Kagawa-Singer, 1988; Kakai et al., 2003). Therefore, it is not surprising

that the results for the health care orientation domain of the PAIS, which measures typical posture or attitude toward health care, had a higher mean rank for Japanese Americans than European Americans. Those domains showing the most difference between ethnic groups were domestic environment ( $p = .010$ ), extended family relationships ( $p = .042$ ), and social environment ( $p = .043$ ). However, because the overall PAIS showed no statistical difference between ethnic groups, differences observed between domain scores are not considered significantly different (Weinberg & Abramowitz, 2002).

This study did not replicate the statistical significance observed by Brena et al. (1990), of adjustment between Japanese and European men with back pain. The current study did find better adjustment among the Japanese patients, as well as differences noted in areas of recreation, socialization, and worry. It is important to note that Brena et al. conducted their study in Japan and in the U.S.A., so the population was not defined as Japanese American and European American. Further, their participants did not have cancer.

#### Relationship between Pain Intensity and Adjustment

The fourth sub-question asked: what is the relationship between pain intensity and adjustment in Japanese American and European American men treated for prostate cancer. Although the Japanese American men reported worst pain (higher pain scores), they had better adjustment (lower overall adjustment scores). A comparison using Wilcoxon Rank Sum of overall adjustment of participants with pain ( $n = 49$ ), by ethnic group (Japanese American or European

American), showed no statistical difference,  $p = .315$ . Further, a Pearson's correlation between worst pain and overall adjustment (PAIS Total Score) for participants with worst pain  $> 0$  reported was not significant for either the total group or for either ethnic group (Japanese American or European American). The findings indicate a moderate but not significant positive correlation ( $r = 0.209$ ,  $p = 0.150$  [two-tailed]) between reported worst pain and adjustment scores. As pain worsened (increased score), adjustment was poorer (increased score), but not statistically significant.

Interestingly, the pattern of increased pain and poorer adjustment was also observed for the European American men but differed from that noted for the smaller group of Japanese American men. For the European American men, the positive correlation between pain and adjustment showed a trend toward significance,  $r = 0.283$ ,  $p = 0.066$  (two-tailed). This finding is consistent with that found by Roesch et al. (2005). In contrast, the correlation of pain and adjustment in Japanese American men was negative ( $r = -0.376$ ,  $p = 0.463$  [two-tailed]). That is, even when pain scores were high (increased pain), adjustment scores remained low (better adjustment). Admittedly, these analyses must be interpreted with caution, due to the small number of patients with pain, as well as the small number of patients in the Japanese American group. Nevertheless, the pattern of adjustment with pain in Japanese American men supports the underlying ethnic values of perseverance, endurance through adversity, and acceptance (Kagawa-Singer, 1988; Kakai et al., 2003; Ka'opua et al., 2005).

### Relationship of Information-Seeking and Adjustment

The fifth sub-question asked: what is the relationship between information-seeking behaviors and adjustment in Japanese American men and European American men treated for prostate cancer.

Adjusting to physical, psychological, social, and/or spiritual challenges, or stress, is a complex and multifaceted dynamic process. The positive impact of information on adaptation has been supported by research (Roesch et al., 2005; Tsutsui, 1991), and has been described by others (Budin, 1998; Hoskins, Baker, et al., 1996; Ka'opua et al., 2005; Roy & Andrews, 1999; Scura et al., 2004).

The role of ethnicity on information-seeking, and overall psychosocial adjustment is both clinically relevant and theoretically intriguing.

Non-statistically significant differences in pain and adjustment were noted between Japanese American and European American participants. As discussed previously in this chapter, despite reporting higher pain scores and more interference with activities due to pain, Japanese American participants had better adjustment (lower scores). Within the RAM, pain and interference with function due to pain represent stressors to normal physiological, psychological and social function (Roy & Andrews, 1999). This finding suggests that Japanese American men are able to positively adjust to illness, despite pain and interference of activities due to pain. The trend of Japanese Americans to adjust to illness is consistent with characteristics of the Japanese culture, of acceptance, as described by Kagawa-Singer (1988). Admittedly, taking medication, as noted by 47% of the participants in this study reporting pain, may help with adjustment to pain.

Seeking information is another mechanism of adjustment (Hoskins, Baker, et al., 1996; Roy & Andrews, 1999; Scura et al., 2004).

The information-seeking exchange between patient and health care provider represent interdependence, defined by the RAM and explored by other researchers versed in Japanese American ethnicity (Kagawa-Singer, 1988; Kai et al., 1993; Ka'opua et al., 2005). In this study, information-seeking patterns were significantly different between Japanese American and European American participants,  $p = .012$ . The pattern of information-seeking reported by Japanese American men was less open than that of the European American men. That is, when presented with hypothetical questions, the Japanese American men reported a likelihood of seeking information less frequently than did the European American participants. It remains unclear if pain and treatment for cancer causes the same level of stress for Japanese American participants as for European American participants or if avoiding information-seeking promotes adjustment for Japanese American men.

Ogasawara et al. (2003) reported that satisfaction with information from health care providers to Japanese patients and family members were better when patients were receiving medical treatment for curative purposes. As medical treatment options dwindled due to advanced disease, adjustment to illness became harder and information was communicated less (Ogasawara et al.). Although the Ogasawara et al findings do not measure active information-seeking by patients, the study does link information-seeking and adjustment.

It is therefore not surprising that although the correlation of information-seeking and adjustment was weak, it was still significant for all participants;  $r (N = 89) = -0.287, p = 0.006$  (two-tailed). When information-seeking was exhibited (higher score) adjustment was better (lower score). Statistical significance was also noted for the European American men ( $p = .001$ ), but not for the Japanese American participants, who reported different information-seeking behaviors.

Zabalegui (1999) reported lower levels of psychological distress were associated with low levels of escape-avoidance and high levels of distancing among patients with advanced cancer. Thus, Japanese American patients may be engaged in treatment as their physician dictates and then resume work and other activities to distance themselves from their cancer, regardless of the stage of disease.

Japanese American participants with pain (worst pain score  $> 0$ ) tended to have high information-seeking scores, consistent with RAM, theorizing information-seeking as a means to promote adjustment (Roy & Andrews, 1999). In contrast, European American participants tended to have high information-seeking scores even when pain scores were low. Furthermore, it should be noted that the enrollment in this study was limited to those men who were aware of their cancer diagnosis.

## Demographic Variables and Adjustment

### Age

Age is considered an important factor in understanding adjustment (Germino et al., 1998; Hu et al., 2004), with older men more accepting of illness (Germino et al.; Roesch et al., 2005) and younger men recovering more completely from physical aspects of illness and surgery (Hu et al., 2004). Roy (1999) would interpret the ability of younger men (< 65 years of age) to return to baseline physical health a result of physiological, anatomical, and motivational dynamics.

The mean age of participants was 70 years ( $M = 70$ ,  $SD = 6.6$ ), with Japanese American men  $M = 69$ ,  $SD = 1.6$  and European American men  $M = 71$ ,  $SD = .77$ . The age of this sample was representative of men with prostate cancer: as of 2002, the highest rates of prostate cancer were identified in men from 65 to 74 years of age (Albersten, 2002).

Roesch et al. (2005) failed to support age as a predictor of type of coping used (i.e., approach, avoidance or problem solving) for adjustment of prostate cancer. In the current study, no significant relationship was found between age and information-seeking ( $p = .541$ ), self-report of pain ( $p = .298$ ), or adjustment ( $p = .454$ ).

### Education

Most participants were educated beyond high school; in fact, 84% had attended college. Only one participant (a European American) reported grade

school as the highest formal education completed; another European American had attended trade school, and a third did not respond to the question about education. Most participants attended college, 75(84%). There were fewer doctorate and masters prepared Japanese American participants (8%) than European American participants (36%).

Interestingly, Gotay et al. (2002) studied prostate cancer patients from different ethnic groups; a multivariate analysis controlling for education revealed robust differences in ability to cope with symptoms, with Filipino and Native Hawaiian men reporting less favorable coping. Kakai et al. (2003) showed that Caucasian patients preferred objective, scientific, and published materials, while Japanese American patients turned to television, radio, and lay press for information. The preferred mode of information did not change when the analysis was controlled for education level (Kakai et al., 2003).

In this study, no statistically relevant relationship was found between education and adjustment ( $p = .414$ ), consistent with studies by Rees and Bath (2001) and Derdarian (1987). However, a positive relationship was observed between education and information-seeking ( $r = .418, p < .001$ ), indicating that the desire for information is stronger in more educated participants and consistent with the findings of Kakai et al. (2003). The European American participants comprised the larger, more educated group. Therefore, the role of education, rather than ethnicity, cannot be determined with certainty in this study.



### Employment and Income

Employment status was similar between the Japanese Americans and European Americans, with most men retired (64%). Over one-fourth (28%) of the men worked at a full-time (16%) or part-time (12%) position; some men reported working after retirement. Four percent of the European American men were on medical disability, and another 4% did not provide complete information about their employment or unemployment.

Similarly, no statistical difference was noticed in income between ethnic groups ( $p = .785$ ). Most participants (81%) had income greater than or equal to \$30,001; 12% had income less than or equal to \$30,000, and 7% did not provide information about income. Although not significant, the current study showed a pattern of relationship similar to those reported by other researchers (Krupski, Fink et al., 2005; Krupski, Sonn et al., 2005) participants with lower income had poorer adjustment ( $r = -.095, p = .392$ ) and did not seek information ( $r = .031, p = .783$ ).

### Marital Status

Most men were married ( $n = 67, 75\%$ ); more Japanese American men ( $n = 11, 92\%$ ) were married than European American men ( $n = 56, 73\%$ ). Marriage or relationships with significant others is viewed within the interdependence mode, or means of adjustment, of the RAM. Interdependence encompasses willingness to accept, knowledge sharing, communication, commitment, and affiliation (dependence) (Roy & Andrews, 1999). The role of

the spouse or caregiver related to the ability of a patient with prostate cancer to positively adjust to the treatment of prostate cancer is an area of interest but one with inconclusive findings.

Banthia et al. (2003) found that the strength of the couples' relationships was linked to less distress of both physical symptoms and mood. In contrast, Knight et al. (2004) reported no difference in quality of life findings when controlling for marital status, in a study of 95 African American men and White men with prostate cancer. In the current study, no difference was found between adjustment of married versus non-married men (single, divorced, or widowed),  $p = .484$ . Information-seeking behaviors ( $p = .573$ ) and self-reported pain ( $p = .660$ ) did not differ by marital status.

### Children

Most of the participants (79%) had at least one child, and no difference was found in the number of children by ethnic group ( $p = .574$ ). The most frequent number of children for participants, regardless of ethnic group, was three or four.

While the presence of social support (Hoskins, Baker et al., 1996; Tsutsui, 1991) has been linked to positive adjustment, the role of parenthood in adjustment has not been widely studied in men with prostate cancer, possibly because prostate cancer is usually diagnosed when men are in their fifth decade or beyond. If men delayed fatherhood to later years, the impact of prostate cancer on their parenting role may take on more significance. Although prostate cancer is most

often diagnosed in men older than 75 (Albertsen, 2002), it can be diagnosed in younger men. In addition, men can be fathers of young children while age 60 or older. Therefore, it may be important to consider the role of parenthood when studying adjustment to cancer.

RAM recognizes the multiple roles in an individual's life (e.g., patient, spouse or significant other, parent, employee). When adjusting to stressors -- in this case, treatment for prostate cancer -- one considers the roles in the decision-making process. A parent and breadwinner may consider a treatment choice that limits disability more than would a retired man without work and child care responsibilities.

#### Acculturation

To describe the level of acculturation of participants, several variables were included: years living in the USA (Kagawa-Singer, 1988; White et al., 1993); generation living in the US (Spector, 1996), language spoken at home (Kagawa-Singer et al., 1997; White et al.), and friends same or different ethnicity (Kodama & Canetto, 1995).

#### Years Lived in North America or Hawaii

The number of years having lived in the host country is an index of acculturation; the number of years living in the host country equates with exposure to new values and integration (Kagawa-Singer, 1988; White et al., 1993).

All participants lived in North America or Hawaii. The majority (89%) lived in North America or Hawaii for more than 55 years. Only 2% of participants had lived in North America or Hawaii less than 45 years. No difference was found between Japanese Americans and European Americans when comparing years living in the North America or Hawaii ( $p = .799$ ).

#### Generations in North America or Hawaii

The number of generations having lived in the host country (in this study North America or Hawaii) is another index of acculturation (Spector, 1996). To assess this in the current study, the birth of grandparents and parents was surveyed. This study was amended to allow participants to enroll without regard to number of years living in North America or Hawaii, and most participants (73%) were second- or third-generation Americans.

ANCOVA was performed, adjusting for generation in North America or Hawaii and factoring in ethnicity of friends (same or different). Findings were consistent with those observed with the Wilcoxon Rank Sum analysis. That is, 1) a significant difference ( $p = .009$ ) between ethnic groups was observed in information seeking, and 2) no difference ( $p = .440$ ) was observed for adjustment between ethnic groups. The ANCOVA is discussed in more detail in the ancillary findings section of this chapter.

### Language Spoken at Home

Almost all participants (98%) spoke English at home as their preferred language; additionally, two men (one Japanese American and one European American) considered themselves bilingual. One European American stated that he spoke Danish at home; another reported difficulty reading English, yet he completed the survey within the number of minutes as other participants. He was a third-generation North American and had worked as a rescue worker prior to retirement. It is possible that his perceived difficulty reading may have been due to his reading skill level rather than a reflection of acculturation.

### Ethnicity of Friends

A significant difference was found in the ethnicity of friends when comparing the two ethnic groups ( $p < .001$ ). To determine whether the differences observed in the friends variable, a measure of acculturation, had an impact on information-seeking or adjustment, an ANCOVA was performed, controlling for the variable "friends (ethnicity same or different)" and other variables (generation, time since diagnosis, metastasis). As noted previously, the ANCOVA confirmed differences between the two ethnic groups in information-seeking,  $p = .009$ , as observed with Wilcoxin Rank Sum analysis. Similar to the Wilcoxin Rank Sum analysis, no differences were observed for adjustment between ethnic groups with the ANCOVA.

### Religion

The role of religion and spirituality to adjustment is not clear. Germino et al. (1998) stress the role of religion on adjustment, indicating that men with strong religious beliefs may be resigned to the prognosis of prostate cancer. Krupski et al. (2005) found that spirituality in men with early-stage prostate cancer was related to better adjustment. However, Roesch et al. (2005) identified religion as a potential avoidance coping mechanism, with less favorable adjustment patterns to prostate cancer, than men who actively engage in positive behaviors (e.g., diet, exercise).

The majority (60%) of participants in this study self-identified as having a religious preference, but no statistically significant difference was found between the two ethnic groups ( $p = .906$ ). Types of religion self-identified included Protestant (31%), Catholic (12%), Jewish (9%), Buddhist (3%), and other (not specified, 3%). It is of interest to note that 40% of the participants either had no religious preference (19%) or did not respond (21%). All participants stating no religious preference were European American, while a higher proportion of those who did not respond (58%) were Japanese American, compared to 16% of European American participants. It seems that the European Americans felt comfortable replying that they had no religious preference, but Japanese Americans did not respond. No conclusion about the lack of response can be made.

## Medical Variables and Adjustment

### Treatment for Prostate Cancer

The RAM recognizes the impact of treatment and side effects as both physical and psychosocial stimuli affecting adjustment (Roy & Andrews, 1999). Incontinence and sexual dysfunction can be side effects for men who have undergone surgery and/or radiation (Lev et al., 2004; Litwin et al., 1995, Scura et al., 2004), influencing physical and psychological (self-concept, role function, interdependence) modes.

In the current study, treatments received by participants included androgen deprivation (i.e., hormonal therapy to reduce testosterone production), surgery, radiation, chemotherapy, other treatments (such as vaccines), or a combination of these treatments. Most ( $n = 64$ , 72%) participants had more than one type of therapy. All participants who had chemotherapy had at least one additional therapy.

The current study found no differences in adjustment to prostate cancer related to the ethnicity of participants by Wilcoxon rank sum,  $p = .188$ . Moreover, this finding was consistent when data were further explored with ANCOVA controlling for friends, treatment, time since diagnosis, and generation living in the US.

### Metastasis

The spread of cancer outside of the prostate gland was reported for 25% ( $n = 22$ ) of participants – all European American men; no Japanese American men had known metastasis. However, 22% ( $n = 20$ ) of the total participants, including two (17%) of the Japanese American men, did not know whether they had metastasis. For those with known metastasis, metastasis significantly correlated with time from diagnosis ( $r = .364, p = .002$ ).

Adjustment to cancer for which there is currently no cure, such as prostate cancer with metastasis (Laufer & Eisenberger, 2002), is different than adjustment to early stage cancer (Cleary et al., 1995). Men with a known diagnosis of metastasis face the reality of their mortality, which can influence adjustment (Maxwell, Givant, & Kowalski, 2001). Therefore, in this study, men with metastasis were excluded from the ANCOVA analysis. No differences in adjustment related to ethnicity (Japanese American and European American) were identified in independent analyses including patients with metastasis (Wilcoxon Rank Sum,  $p = .188$ ) or in the analyses excluding participants with known metastasis (ANCOVA,  $n = 67, p = .453$ ).

Not surprisingly, a small but positive and significant relationship was found between metastasis and adjustment ( $r = .244, p = .043$ ). Participants with known metastasis had poorer adjustment (higher scores) than participants without metastasis. As noted above, poorer adjustment related to metastasis is expected because metastasis can represent an insult to existing physical, psychosocial, and spiritual status. But it is important to note that modification in physical (use of



walker or wheelchair to facilitate mobility), psychosocial (increased social support), and spiritual modes (reliance on religion) can be employed to facilitate adjustment to cancer (Germino et al., 1998; Maxwell et al., 2001), including metastatic cancer.

### Bisphosphonate Use

Bisphosphonates refer to a classification of drugs that have shown to be effective in slowing bone loss and in preventing skeletal related complications, such as fractures, spinal cord compression, and pain associated with bone metastasis, which can be observed in men with prostate cancer (Fulfaro, Casuccio, Ticozzi, & Ripamonti, 1998; Maxwell et al., 2001; Maxwell & Viale, 2005; Nelson & Smith, 2004).

Healthy bone is constantly undergoing remodeling, a breakdown of bone by specialized osteoclast cells, and a rebuilding of bone by specialized osteoblast cells. To maintain a healthy skeleton and stable bone mass, the rate of bone breakdown and building must be balanced. The stress of cancer and treatments such as hormonal androgen deprivation for prostate cancer or hormonal estrogen deprivation for breast cancer speed bone loss (Nelson & Smith, 2004).

Thirty percent of the men in the current study ( $n = 27$ ) received bisphosphonate therapy in addition to their underlying cancer treatment, the majority of whom (74%) had known cancer spread to an area in the body other than the prostate). Of those receiving bisphosphonates, 41% had intravenous bisphosphonate therapy, 37% had zoledronic acid, 4% received pamidronate, 11%

reported treatment with an oral bisphosphonate (alendronate or risidronate), and the remaining 7% did know the name of the bisphosphonate they received.

RAM clearly identifies physical activity and interdependence as one way to positively adjust to illness (Roy & Andrews, 1991). Bone metastasis can impede physical wellness, independence, and adjustment (Maxwell et al., 2001). Further, metastasis can cause pain, which has been linked to independence and adjustment in this and other studies (Cleary et al., 1995; Cleeland & Ryan, 1994; Coyle, Adelhardt, Foley, & Portenoy, 1990; Fulfaro et al., 1998). Nurses can play an important role in sustaining physical function and interdependence in men with prostate cancer by administering bisphosphonates as adjuvant therapy in men with metastasis to the bone (intravenous agents) or bone loss (oral agents).

### Performance Status

Most participants ( $n = 53$ , 60%) had no symptoms; an additional 34% ( $n = 30$ ) had symptoms but were able to function normally; 4% ( $n = 4$ ) of participants -- all European Americans -- had symptoms which resulted in rest. The ability of Japanese Americans to perform normally supports research reported by Brena et al. (1990), but is inconclusive in this study.

As performance status decreased (higher score) adjustment became poorer (higher score),  $r = .405$ ,  $p < .001$ . This finding is consistent with Litwin's (1994) reference to performance status as the "earliest predecessor to modern quality of life studies" (p.1883).

### Other Medical Problems

Five (5%) patients reported concomitant medical problems which could be considered serious. These were diabetes, arterial stent, pneumonia, kidney stone and monitoring for lung complications. Eleven (12%) other participants reported muscle and bone ailments, such as arthritis. These medical problems were noted in both Japanese American ( $n = 2$ , 17%) and European American ( $n = 9$ , 12%) participants.

### Ancillary Findings

#### Relationship of Self-Reported Pain and Information-Seeking Behavior

The findings in the study are consistent with RAM, theorizing information-seeking as a means to aid adjustment. For all participants, a weak and non-significant negative correlation between worst pain and information-seeking behavior was found ( $r = -0.233$ ,  $p = 0.107$  [two-tailed]). Japanese American participants with worst pain scores  $> 0$  ( $n = 6$ ) tended to have high information-seeking scores,  $r = 0.817$ ,  $p = 0.047$ . This pattern was not observed in the European American group.

Kakai et al. (2003) found that Japanese American men participants were less likely to seek information from physicians, and the researchers posited that although the participants valued the physician's knowledge, they did not want to offend the physician by asking questions or they may have felt unworthy of

asking questions of the expert professional physician. The Japanese American participants in this study with pain reported they would ask questions, ask for information, and report pain more than Japanese American participants without pain.

In contrast, the European American participants tended to have high information-seeking scores, even when pain scores were low. This may mean that they used or needed information-seeking as a means to adjust earlier than the Japanese Americans. It may also reflect more assertive behaviors or more open communication frequently attributed to European American patients than seen in either Japanese or Japanese American patients (Brena et al., 1990; Kagawa-Singer, 1988; Kagawa-Singer et al., 1997; Kai et al., 1993; Tsutsui, 1991).

#### Effect of Time Since Diagnosis on Information-Seeking Behavior

Researchers believe that information needs change over time (Davison, Degner, & Morgan, 1995; Hoskins, Baker, et al., 1996; Roesch et al., 2005). The current study entry criteria did not delineate specific time since diagnosis. Men entered the study any time after having been treated for prostate cancer. The median time since diagnosis was 51.5 months, the mean time since diagnosis was  $M = 64.80$ ,  $SD = 50.014$  (Japanese American  $M = 46.33$ ,  $SD = 31.198$ ; European American  $M = 68.01$ ,  $SD = 58.877$ ). An independent  $t$ -test for time since diagnosis by ethnic group (Japanese American and European American) showed a trend toward significance,  $p = .057$ .

Thus, because time since diagnosis was not delineated at entry to the study, an ancillary analysis was performed (ANCOVA). To provide some control for stage of cancer, patients with known metastasis were excluded. The variables identified for control were known predictors of adjustment (including time since diagnosis and stage of cancer) or variables associated to adjustment (types of friends of same or different ethnicity, generation in US) were related to ethnicity and acculturation, which has been shown to be associated with adjustment (Brena, et al., 1990; Cavillo & Flaskerud, 1993; Kagawa-Singer, 1988). Further, since the variables were not equally distributed between ethnic groups, the ANCOVA was performed to identify the impact, if any, of the variables to the significant findings in information-seeking between ethnic groups.

Controlling for the above-mentioned variables resulted in an analysis of 66 participants (12 Japanese American; 54 European American). ANCOVA yielded a statistical difference between ethnic groups for information-seeking,  $p < .009$ . The ANCOVA provided support of the robust finding of ethnic differences in information-seeking previously obtained in the Wilcoxon Rank Sum analysis.

#### Effect of Time since Diagnosis on Adjustment

To determine if time since diagnosis affected adjustment, ANCOVA was conducted controlling for time since diagnosis, plus the other variables noted in the previous section. Jakobsson et al. (1997) and Northouse and Peters-Golden (1993) noted changes in adjustment over time. Similar to information needs,

Hoskins, Baker, et al. (1996) and Roesch et al. (2005) also reported changes in adjustment as people with cancer become acclimated to their diagnosis.

The Wilcoxon Rank Sum analysis for overall adjustment (PAIS) did not show a significance difference between ethnic groups (Japanese American and European American). Further, the ANCOVA controlling for time since diagnosis and other variables confirmed non-significant results,  $p = .453$  (see Table 13).

### Methodological Issues and Limitations

#### Modified Krantz Health Opinion Survey (KHOS)

Krantz et al. (1980) reported a reliability score of 0.77 for the KHOS to measure self-reported information seeking and interactions with toward healthcare providers. The KHOS was revised to include pain questions and wording to address ethnic differences were made. An alpha reliability of 0.781 for the total modified KHOS score was obtained, and the alpha reliability for each of five subscores was at least 0.717, thus acceptable based on criteria established by DeVillis (1991), Frank-Stromborg (1992), and Nunnaly (1978).

Yet, further modifications would be required if the instrument were used as a definitive measure in a study with ethnically diverse groups, other than Japanese American and European American participants. To establish reliability, exploration of use of the modified KHOS in cancer populations and diverse ethnic groups should continue.

### Brief Pain Inventory (BPI)

Most participants (97%) completed the BPI (Cleeland, 1991); those who did not reported no pain on the Medical Information Form.

The first question of the BPI, regarding “pain today,” could be misleading. Participants who experience pain might not yet have experienced pain on the day that they had completed the packet, and some participants did not have pain, so the responses to pain and interference items were “0.” To include only participants with pain in the analyses related to pain, participants without pain, that is participants reporting worst pain response “0”, were excluded from analyses related to pain scores.

Similarly, a question about pain was also included on the medical information form asking, “Do you currently have pain?” The results from that question differed from those on the BPI asking about pain “today.” Therefore, to avoid confusion, it seemed reasonable to recommend that for future studies, only one source of information be obtained for a single variable.

In the future, a slight modification to the directions prior to completing the BPI might be considered. Participants could be asked if they ever have pain (other than minor headaches, sprains, and toothaches) on a daily basis. For those participants denying pain, instruction not to complete the BPI could be provided.

### Psychosocial Adjustment to Illness Scale (PAIS)

In the current study, the overall reliability of the PAIS was 0.771. The alpha reliability for healthcare orientation was  $\alpha = 0.538$ . The alpha reliability for

the extended family domain was  $\alpha = 0.614$ . The alpha reliability of the other domains exceeded 0.614.

The use of PAIS with Japanese American participants has not been documented. It is possible that the use of the PAIS in diverse ethnic studies threatens the reliability. It is possible that the view of healthcare professionals by Japanese American participants, one of respect and deference (Kagawa-Singer, 1988; Kakai et al., 2003), is responsible for the lower than expected alpha reliability obtained in the current study. Further exploration of the PAIS in diverse populations would provide insight as to the reason for variability of reliability in different ethnic groups, as observed by Germino et al. (1998), as well as the current study.

#### Unequal Sample Sizes

The unequal sample sizes for the two ethnic groups (Japanese American and European American) presented both a challenge and a limitation. Despite extensive recruitment efforts, only 12 Japanese American men participated in the study.

Prior to the analysis, distributions of each variable were examined for each ethnic group. For information-seeking (total KHOS score), self-reported pain (worst pain score on BPI), and adjustment (overall PAIS score), the basic assumption of normal distribution was violated due to skewness  $> 2.25$  (Norris, 2003).



A *t*-test can be performed on unequal sample sizes if the distributions are normal and variances are equal; however, the robustness of the test is increased with a large sample size (Zar, 1999). With transformation of variables, skew was reduced for the European American group with the abnormal distribution. However, for the Japanese American group, transformation increased the skew of the distribution. Although not normally distributed, the distributions displayed symmetry around the median, thus meeting the assumption for the Wilcoxon rank sum test (Zar, 1999).

Therefore, the non-parametric Wilcoxon rank sum test was used. A significant difference in information seeking was supported by both Wilcoxon rank sum ( $p = .012$ ) and ANCOVA ( $p = .009$ ). The results obtained for both analyses were consistent with research previously reported information-seeking patterns of Japanese Americans with cancer (Kagawa-Singer, 1988; Kagawa-Singer et al., 1997; Kakai et al., 2003), that is, less information-seeking patterns noted in Japanese Americans than in European Americans. Non-significant findings were observed for both the Wilcoxon rank sum and ANCOVA for differences in adjustment between ethnic groups.

It is important to note that transformation of the variables was performed prior to ANCOVA. KHOS was negatively skewed. The KHOS was reflected prior to transforming with square root (Tabachnick & Fidell, 1996). Therefore, the higher KHOS score for the reflected variable represented decreased inquisitiveness in the Japanese American group.

The unequal sample size between the two ethnic groups and the small sample of Japanese American participants warrants the study be repeated with a larger sample size. Confirmation of differences noted in information-seeking between Japanese American and European American men could occur with replication of the study. Moreover, the lack of significant differences in self-reported pain and adjustment found in the current study might be a product of this limitation. Replication of the study with a larger sample size for the Japanese American group might support (or contradict) this study's findings of similarities between self-reported pain and adjustment.

#### Recruitment Challenges

Researchers have been challenged when conducting studies among ethnically diverse groups (Amador, Travis, McAuley, Bernard, & McCutcheon, 2006; Bailey, Bieniasz, Kmak, Brenner, & Ruffin, 2004; Coward, 2005; Fowler, Rodney, Roberts, & Broadus, 2005; Hussain-Gambles et al., 2004; Keyzer et al., 2005; Lai et al., 2006; Oakley, Wiggins, Turner, Rajan, & Barker, 2003; Swanson & Ward, 1995), as well as among the elderly (Ehrenberger & Breeden, 2003; Lai et al.; Swanson & Ward).

Multiple strategies were used to enhance recruitment in the current study. Recruitment was accomplished largely through six face-to-face meetings with support group attendees ( $n = 39$ , 44%), outreach through the National Prostate Cancer Coalition, an advocacy organization ( $n = 25$ , 28%), attendance at a patient conference ( $n = 15$ , 16%), and through nurse recruitment at a medical center

( $n = 10$ , 11%). Only one of the institutions, a hospital in a large metropolitan area, actively recruited patients. The researcher had close communications with the nurses at Valley Hospital, who were actively involved with the recruitment of patients. The active role of nurses in recruiting patients for clinical trials has been highlighted as a key strategy for success by multiple researchers, including Barrett (2002), Coward (2005), Connolly, Schneider, and Hill (2004); Ehrenberger and Breeden (2003); and Fowler et al. (2005). The Oncology Nursing Society (2004) also believes that nurses are paramount in the clinical trial recruitment and management process.

The number of men participating in support groups is low as compared to the number with prostate cancer; further, male support group participants are typically White, retired, and highly educated (Weber & Sherwill-Navarro, 2005). Interestingly, Swanson and Ward (1995) identify participants in clinical trials as White married males. Both of these overlapping profiles describe the European American men who participated in this study. Hussain-Gambles et al. (2004) offer additional insight into low enrollment of South Asian participants in research studies, citing failure to identify with or feel a belonging to the group extending the invitation to participate. Although South Asian participants were not the target population of the current study, lack of affiliation may have been a factor for the low enrollment.

Further, multiple researchers identify lack of trust as a barrier to clinical trial enrollment (Connolly et al., 2004; Coward, 2005; Ehrenberger & Breeden, 2003). Not surprisingly, awareness and education is also cited as a strategy to

bolster the limited enrollment of adults in clinical trials (Barrett, 2002); Connolly et al., 2004; Ehrenberger & Breeden; Husasain-Gambles et al., 2004; Oncology Nursing Society, 2004).

Culturally sensitive advertisements were placed in an Asian newsletter, advertising was posted on the Us TOO patient advocacy website, phone calls were made, recruitment letters and e-mails were written, and, most importantly, community support groups and a patient conference were personally attended by the researcher. Despite these efforts, although the European American participants were recruited successfully, the Japanese American recruitment numbers were not met. Similarly, Wallace (2003) reported difficulty recruiting patients with prostate cancer for a study in watchful waiting. Despite advertising in *The New York Times*, writing letters to 4,500 physicians, and announcing the study on a website, Wallace only recruited 19 men with prostate cancer.

The success of face-to-face community outreach, realized in this study, is consistent with effective recruitment efforts reported by Keyzer et al. (2005), who recruited 80% of 255 participants through direct community outreach or direct mail. Other strategies recommended by researchers and used in the current study include community outreach through face-to-face meetings (Amador et al., 2006; Connolly et al., 2004; Coward, 2005; Ehrenberger & Breeden, 2004, Fowler et al., 2005; Oakley et al., 2003; Swanson & Ward, 1995) and involvement of organizations (such as Us TOO, International, and the National Prostate Cancer Coalition) (Amador et al., 2006; Connolly et al., 2004; Coward, 2005; Ehrenberger & Breeden, 2004; Im et al., 2006). Specific recruitment efforts

included changing the inclusion criteria. Men with any stage of prostate cancer who had received treatment for prostate cancer were included. Additionally, men born in and residing in North America or Hawaii who were of Japanese or European heritage were included, regardless of the number of generations their families had lived in North America or Hawaii.

#### Stage of Disease Limitations

Not controlling for stage of disease or time from diagnosis at entry into this study was a weakness. As discussed in the recruitment challenges section, the inclusion of men with any stage of disease was approved by amendment to the research in an effort to enhance recruitment. Although the inclusion of men without metastasis was a necessary change, it nevertheless weakened the study design. Future studies should delineate a parameter for time since diagnosis and stage of disease.

## CHAPTER VI

## SUMMARY, CONCLUSIONS, IMPLICATIONS, RECOMMENDATIONS

Summary

This descriptive study was conducted to explore similarities and differences of self-reported pain, information-seeking behaviors, and psychosocial adjustment to illness between Japanese American and European American men being treated for prostate cancer. It also explored the relationship between self-reported pain, information-seeking behaviors, and psychosocial adjustment to illness.

The conceptual framework for this study was the Roy Adaptation Model (RAM) (Roy & Andrews, 1999). Within the RAM, physical response (e.g., to pain) and psychosocial interdependence (e.g., information-seeking) are behaviors used to adjust to changes or stressors, in this case a participant's treatment for prostate cancer.

For prostate cancer patients, managing pain can begin with the self-reporting of pain; similarly, the provision of information by the healthcare professional can be triggered by questions from the patient. Relieving the physical pain of patients and providing information to patients is thought to aid their adjustment to illness (Budin, 1998; Hoskins, Baker, et al., 1996; Robinson et al., 1999; Roesch et al., 2005; Roy & Andrews, 1999). The challenges of

understanding self-reported pain, information-seeking behaviors, and adjustment are further complicated by ethnic differences noted in Japanese American and European American men.

This study was conducted among a convenience sample ( $N = 89$ ) of English-speaking men, each with a history of prostate cancer for which they received medical treatment. The volunteer participants were recruited through support groups, advocacy organizations, a hospital clinic, and attendees of a patient conference that had a support group component. Each participant completed a questionnaire packet, which included the BPI (Cleeland, 1991), KHOS (Krantz et al., 1980), PAIS (Derogatis & Derogatis, 1990), a medical information form, and demographic information sheet. The group was well-matched for age (*Mean age = 70, SD = 6.6*), marital status, education, and income.

Treatment modalities for prostate cancer included surgery, radiation, hormonal deprivation, chemotherapy, vaccine, or a combination of these modalities. The most common treatments were surgery (55%), radiation (53%) and androgen deprivation (65%), consistent with the National Comprehensive Cancer Network [NCCN] guidelines (2005). Almost one-third (30%) received adjuvant bisphosphonate therapy for either bone metastasis or bone loss, which is also included in the NCCN guidelines. Differences between ethnic groups were observed for: treatment with androgen deprivation therapies, chemotherapy, other (e.g., vaccine), combination therapy, and use of bisphosphonates.

The data were analyzed using Wilcoxon rank sum because the key variables -- worst pain scores, information-seeking KHOS scores, and adjustment PAIS score -- as well as several subscale variables, showed severe skew ( $> 2$ ) (Weinberg & Abramowitz, 2002). It was found that Japanese American men currently being treated or having had treatment for prostate cancer were less inquisitive than European American men ( $p = .012$ ) because of their reluctance to ask questions or for information from health care providers. While no differences of self-reported pain intensity or psychosocial adjustment were noted between Japanese American and European American participants, some interesting relationships were observed between variables.

Differences in information-seeking behavior were confirmed by ANCOVA ( $p = .009$ ), adjusting for friends same or different ethnicity, generation living in North America or Hawaii (measures of acculturation) (Andrews & Boyle, 1999; Spector, 1996; White et al., 1993), time since diagnosis, and treatment method (predictors of adjustment) (Jakobsson et al., 1997; Northouse & Peters-Golden, 1993).

#### Research Questions and Sub-Questions

Five sub-questions were developed to address specific aspects of two research questions previously discussed. The first sub-question asked, "What are the differences in pain intensity between Japanese American men and European American men with prostate cancer?" No difference in pain intensity was observed between the two groups. The similarity of pain intensity between ethnic



groups, including Japanese and other Eastern cultures, has been reported by Cleeland & Ryan (1994), Serlin et al. (1995), and Uki et al. (1998).

However, despite a trend toward higher pain scores reported on the BPI by Japanese American participants, adjustment remained better (lower scores) for Japanese Americans. Observing better adjustment in the presence of high pain scores might either indicate the expectation of pain (Im, 2006; Pargson & Hailey, 1999) or reflect the ability to internalize and not show pain (*gaman* -- Kagawa-Singer, 1988, p. 287). Researchers (Ogasawara et al., 2003; Kagawa-Singer, 1988) report the tolerance without complaint exhibited by people of Japanese heritage. The need to assess and manage pain in every patient, regardless of the patient's ethnicity, is an ongoing professional responsibility

The second sub-question asked, "What are the differences in information-seeking behavior between Japanese American men and European American men with prostate cancer?" – differences were observed ( $p = .012$ ). Japanese American participants were resigned to their illness and reluctant to ask about pain or other information (resignation subscore  $p = .002$ ), which has also been documented by other researchers (Kagawa-Singer, 1988; Kagawa-Singer et al., 1997; Kakai, et al., 2003; Ka'opua et al., 2005; Tsustui, 1991). This is an important finding because information, when shared, provides an avenue for adjustment to stressors, such as prostate cancer (Hoskins, 1995; Hoskins, Baker, et al., 1996; Kagawa-Singer et al., 1997; Ka'opua et al., 2005; Robinson et al., 1999; Roesch et al., 2005; Roy & Andrews, 1991). In the absence of information-seeking behavior,

healthcare professionals must anticipate the need for information and provide information proactively.

The third sub-question asked, "What are the differences in adjustment between Japanese American men and European American men with prostate cancer?" No differences were observed in psychosocial adjustment (PAIS scores) between the two ethnic groups. Further, the difference noted in information-seeking behavior did not affect the overall adjustment to illness (PAIS) between the two ethnic groups. Although the differences were not significant, in general, the adjustment scores for the Japanese American participants reflected better adjustment.

The fourth sub-question asked, "What is the relationship between pain intensity and adjustment in Japanese American men and in European American men with prostate cancer?" Although no significant difference was noted, the Japanese American group showed a trend toward better adjustment, even when pain scores were higher. This can be explained by researchers who have noted that Japanese American patients may expect hardship (i.e., pain) and do not complain (Kagawa-Singer, 1988; Ka'opua et al., 2005; Ohnuki-Tierney, 1984).

The fifth sub-question asked, "What is the relationship between information-seeking behaviors and adjustment in Japanese American men and European American men with prostate cancer?" A weak but significant negative correlation ( $r = -0.285, p = 0.006$ ) was noted; as more information-seeking behaviors were reported, better adjustment was observed. A similar pattern was

noted for each of the two ethnic groups; however, only findings for the total group ( $p = .006$ ) and the European American group ( $p = .001$ ) reached significance.

### Ancillary Findings

#### Relationship of Self-Reported Pain and Information-Seeking Behavior

The Japanese American participants reported information-seeking behavior when their pain scores were high ( $p = 0.047$ ), in contrast to European American participants who reported information-seeking behavior even when their pain scores were low ( $p = 0.002$ ). This finding is consistent with the literature (Kagawa-Singer, 1988; Kagawa-Singer et al., 1997, Kai et al., 1993; Ka'opua et al., 2005; Tsutsui, 1991) reporting reserved nature and reluctance to ask questions by Japanese and Japanese Americans. Further, the information-seeking behavior observed in this study by the European American participants supports a more assertive nature, open-communication, and a comfort level allowing questions to be asked of healthcare providers (Kagawa-Singer et al., 1997).

### Interference

Seven interference items measuring self-report of interference with physical and interpersonal relations are included on the BPI (Cleeland, 1991). The arithmetic mean of all interference items was used as the pain interference score. In order to include only patients with interference of activities related to pain, the

analysis with interference scores included only those participants with worst score  $> 0$  ( $n = 49$ ).

The Japanese American participants reported slightly more interference, ( $n = 6$ ), median 1.5,  $M = 2.36$ ,  $SD = 2.11$ , than the European American participants ( $n = 43$ ), median 1.36,  $M = 2.22$ ,  $SD = 2.13$ . No significant difference was found between interference scores ( $p = .769$ ). Overall adjustment scores remained low (better adjustment) for the Japanese American participants, even with the reported interference due to pain. Results must be interpreted with caution, given the small number of subjects included in this analysis.

#### Effect of Time since Diagnosis on Information-seeking and Adjustment

ANCOVA between the two ethnic groups showed significant mean differences of KHOS,  $F(19, 46) = 2.369 = p = .009$  when controlling for ethnicity of friends (same or different), generation living in North America or Hawaii, time since diagnosis, and type of treatment: Participants reporting known metastasis were excluded from ANCOVA. ANCOVA did not show significant difference in adjustment between ethnic groups (Japanese American and European American). These findings were consistent with the results of the Wilcoxon rank sum analyses.

#### Conclusions

The study provided important findings related to differences observed between ethnic groups. The findings have limited generalizability to other

populations, such as Japanese Americans residing outside of Hawaii or other ethnic groups that may share Eastern worldviews. Limited generalizability is due to the use of a convenience sample, the small sample size, and in particular the number of Japanese American participants ( $n = 12$ ). Nevertheless, some important findings were obtained.

This study found that Japanese American men, when compared to European American men, were reluctant to ask questions or seek information due to resignation of their health status. This is supported by the statistically significant overall difference of mean rank and the subscore analysis indicating less information-seeking due to resignation observed for Japanese American men (*mean rank* = 23.42), compared to European American men (*mean rank* = 48.36),  $p = .002$ . When caring for Japanese American patients, healthcare providers must be mindful that not all patients will report discomfort, a finding that has clinical implications.

The analysis revealed no significant differences in self-reported pain or adjustment when comparing Japanese American and European American men treated for prostate cancer. The findings also revealed a higher self-report of pain intensity and interference with activities due to pain for the Japanese American men. Yet, the overall adjustment for the Japanese American group was better than the adjustment for the European American men. Again, the theme of tolerating pain and discomfort without complaint and expecting pain provide an explanation for this important finding (Im, 2006; Kagawa-Singer, 1988; Kagawa-Singer et al.,

1997, Kakai et al., 2003; Ogasawara et al., 2003; Pargson & Hailey, 1999), a finding which also has implications in the clinical setting.

For the entire group, an increase in interference from pain correlated with poorer adjustment (higher adjustment scores),  $r = .444, p < .001$ . Not all participants in the study reported having pain. Nevertheless, of the participants with pain, less than half (47%) reported receiving medication for pain. Fewer Japanese American men (17%) with pain received some type of treatment (including medication, physical therapy, massage, chiropractor visits, and radiation) when compared to European American men (30%) with pain. This finding may be related to the Japanese American men's lack of reporting of pain to healthcare providers, but it truly cannot be determined fully from this study.

Despite the inconclusive nature of the ability of Japanese American men to show better adjustment while in pain, the study serves an important reminder for nurse educators and clinicians to carefully assess, treat, or obtain treatment for pain in all patients. The assessment and treatment of pain will maximize independence, activities of daily living and social interaction for patients. Further the finding underscores the need sharpen communication skills to accurately assess pain in patients who may not readily self-report pain due to ethnic beliefs.

#### Study Implications

Understanding the reported reluctance of Japanese Americans to ask questions (including questions about pain) and to actively seek-information reiterates the importance for oncology nurses to be proactive in the care of

Japanese American men by providing information about prostate cancer, treatment, and psychosocial adjustment.

Further, pain assessment and interference remain paramount in the care of patients with cancer, including prostate cancer patients. Regardless of ethnicity, nurses and physicians should always assess and treat pain (Cleeland, 2006; JCAHO, 2004). To assess pain, a healthcare provider should ask questions about pain rather than expect a Japanese American patient to offer information or complain about pain. The absence of complaint by a patient does not equate with lack of pain.

Kakai et al. (2003) supported complementary alternatives to traditional therapies for pain and other symptoms. Only one participant in the current study reported using Shiatsu massage as a way of dealing with pain – and that participant, paradoxically, was European American. This may be due to the small number of Japanese American men participating and that all were from support groups. Participating in a support group might represent an activity exercised by men who are more acculturated (Ka'opua et al., 2005) and those less likely to use complementary therapies. Nurses should inform patients about the use of complementary therapies for pain, as appropriate.

Another consideration for action would be if a man being treated for prostate cancer asks about pain or states he has pain; such questions or comments invite exploration. Because Japanese American men were found to be reluctant to ask questions, report pain, or engage in open communication, healthcare providers must not dismiss a patient with Japanese heritage, even if the patient appears

comfortable and well-adjusted. It is important for nurses to be aware that communication patterns for Japanese American men may be different, less open, and less focused on the specific individuals than European American men (Kagawa-Singer, 1988; Kai et al., 1993; Ka'opua et al., 2005; Ogasawara et al., 2003). Nevertheless, using patient-initiated conversation about pain to obtain more information about the presence of pain is a good communication skill for healthcare providers to use for all patients. Additionally, it is recommended that nurses maintain open communication with all patients and specifically ask if patients are experiencing pain now, or have experienced pain recently.

To provide quality care, understanding general characteristics of ethnic groups while maintaining a patient's individuality is essential for healthcare professionals. Nurses can ask questions that may provide insight into personal preferences or behaviors that support reported ethnic preferences. For example, it should not be assumed that a Japanese American man would not want to share his experience by participating in a support group for prostate cancer survivors. The invitation should be extended, and the survivor can decide if he chooses to participate, regardless of his ethnicity. At this time, nurses could also provide patients with known local and national (Us TOO, International; National Prostate Cancer Coalition) resources. Further, the development and provision of culturally sensitive educational materials for patients with cancer would be ideal.

It is noteworthy that overall information-seeking behaviors were associated with better adjustment. Therefore, providing men with sources of



information about prostate cancer, treatment, and impact is an important nursing function.

## Recommendations

### Practice Setting

Implications for practice in the clinical setting can be drawn from this study which showed that many of the men with prostate cancer are not being treated for pain. Compliance with standards established for the assessment and treatment of pain by JCAHO (2004) and Oncology Nursing Society (2004) must be carefully monitored and should be included in both practice as well as future research studies.

The BPI, a reliable and valid instrument, could be used in the clinical setting to assess and monitor pain for patients. Further the BPI has demonstrated usefulness in many different ethnic groups.

### Education

In addition to educating nurses about the need to assess, treat and monitor pain, educating nurses about ethnic preferences (e.g. resignation of Japanese Americans about cancer) is appropriate in academic, clinical, and research settings. Nurses may teach other healthcare professionals what they know about the ethnic group(s). Input from staff nurses who have insight about the ethnic group, either through experience or affiliation, should be encouraged and suggestions considered. Specific culturally and ethnically sensitive approaches

could be shared with all involved, for example respectful generation of open-ended questions. This education could avoid inadvertently offending patients from diverse ethnic groups. Nurses must expand their knowledge of different ethnic groups, to share this knowledge, and to recognize that behaviors observed in patients may be due to ethnic affiliations.

### Research

Future studies would be strengthened if stricter standards for entry based on stage of disease or time since diagnosis were established. The current study included mostly men with early-stage disease; only 25% had known metastatic disease. Stage of disease influences treatment modalities and may influence adjustment. Thus, this study would have been strengthened if all participants had had a single stage of prostate cancer and if there had been a clear delineation of inclusion criteria with respect to time since diagnosis and stage of disease.

In the setting of advanced prostate cancer (metastatic disease), pain and interference of activities due to pain usually increase (Cleary et al., 1995; Cleeland et al., 1994; Coyle et al., 1990). Exploration of the relationship of ethnicity, pain, and adjustment could be conducted in a study of patients with advanced prostate cancer. Further, the inclusion of other ethnic groups would provide valuable information regarding trends in reporting pain and the influence on adjustment. Implementing interventions (i.e. open communication, respectful dialogue, provision of ethnically appropriate information) to enhance ethnically sensitive nurse care could be studied in a randomized study to support usefulness.

*Recruitment of participants* to a study of diverse populations presents a methodological challenge (Amador et al., 2006; Bailey et al. 2004; Coward, 2005; Fowler et al., 2005; Hussain-Gambles et al., 2004; Keyzer et al., 2005; Lai et al., 2006; Oakley et al., 2003; Swanson & Ward, 1995). Specific steps recommended prior to embarking on replication of the current study or conducting any study aimed at capturing a diverse population include the following:

1. Establishing a physical (face-to-face) community presence (Coward, 2005; Keyzer et al., 2005; MacEntee et al., 2002; Oakley et al., 2003) within the community in which one is aiming to recruit. Affiliate with a professional from the ethnic group(s) if possible. One must remember that trust is an issue (Barrett, 2002; Connolly et al., 2004; Coward, 2005; Im et al., 2006), so involvement must be long-term and the researcher must give back to this community in the form of shared information or services.

2. Developing culturally and ethnically sensitive recruitment materials (Fowler et al., 2005).

3. Proactively outreaching to national advocacy groups (e.g., Us TOO, International, National Prostate Cancer Coalition, Prostate Cancer Coalition), which may have a local chapter (Amador et al., 2006; Ehrenberger & Breeden, 2003; Im et al., 2006).

4. Affiliating with a physician (Barrett, 2002) who treats individuals meeting the established criteria; the physician must be open to collaboration, prior to and during the recruitment of participants.

5. Placing the study at an institution or setting with a person dedicated to screening and enrollment for the specific research study (Connolly et al., 2004).

6. Planning and having in place recruitment strategies prior to the initiation of the research study. The strategies should be monitored, reviewed, and evaluated for potential revision throughout the course of the study (Barrett, 2002; Im et al., 2006).

Nurses currently engaged in clinical trials should not underestimate the importance of their role. Approachable and friendly nurses, physicians, and allied health professionals influence the experience of research participants and their willingness to participate in research studies in the future or to recommend others to participate. If culturally and ethnically sensitive care is rendered, the experience may be more positive for participants.

If possible, potential research participants should be asked about research questions that are of interest to them. Patient concerns should be incorporated into the study design when possible. Importantly, it is recommended that information derived from research must be shared with the participants in an ethnically appropriate manner. Participants must be thanked and understand that their participation helps further knowledge for the general good of patients, and for their community. In addition to sharing the research outcomes with participants, the findings from studies, including the current study, should be disseminated through publication so both professionals and patients can benefit.

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## APPENDIX A

## PERSONAL CORRESPONDANCE FROM KRANTZ

14 Newman Place  
East Hanover, NJ 07936  
February 14, 2000

David S. Krantz, M.D., PhD.  
Department of Medical Psychology  
Uniformed Services University of the Health Sciences  
4301 Jones Bridge Road  
Bethesda, MD 20014

Dear Dr. Krantz,

As a doctoral candidate at New York University, your article entitled, "Assessment of Preferences for Self-Treatment and Information in Health Care" is of great interest to me. My doctoral research will include information-seeking behaviors of Japanese American cancer patients.

While at NYU, I have also had the opportunity to review work done by Dr. M. Tsutsui, PhD. She obtained permission and used a modified version of your Krantz Health Opinion Survey (KHOS) in her 1991 NYU dissertation, on mothers with mildly ill children.

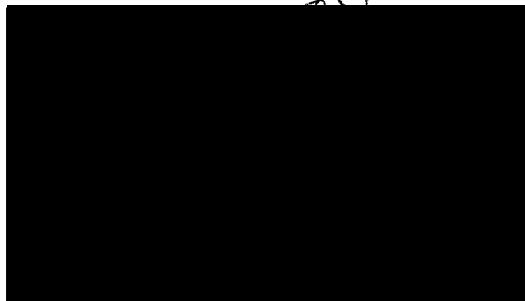
This letter is written to request permission to use a modified version of the KHOS in a study that I would like to conduct, in men with prostate cancer. The modifications made by Tsutsui, which expanded the information seeking questions, have been further modified. The slight modifications were made to obtain information needs of prostate cancer population, rather than young mothers with mildly ill children.

A copy of the proposed Modified Version is included in this letter. This version would be used only after obtaining your written and signed authorization. This documentation is necessary to meet New York University requirements. I have included a stamped return envelope. Dr. Krantz, would you also consider granting permission for me to obtain a professional translation of the instrument to Japanese? A translation might help me obtain information from Japanese Americans who do not read English. If you grant permission for the use, and a Japanese version is obtained to enhance enrollment, I would provide you with a copy of the translated version.

Thank you for any help you can offer. I hope to hear from you soon. Please feel free to contact me via telephone at [REDACTED], if you need additional information. I appreciate you taking the time to consider my requests.

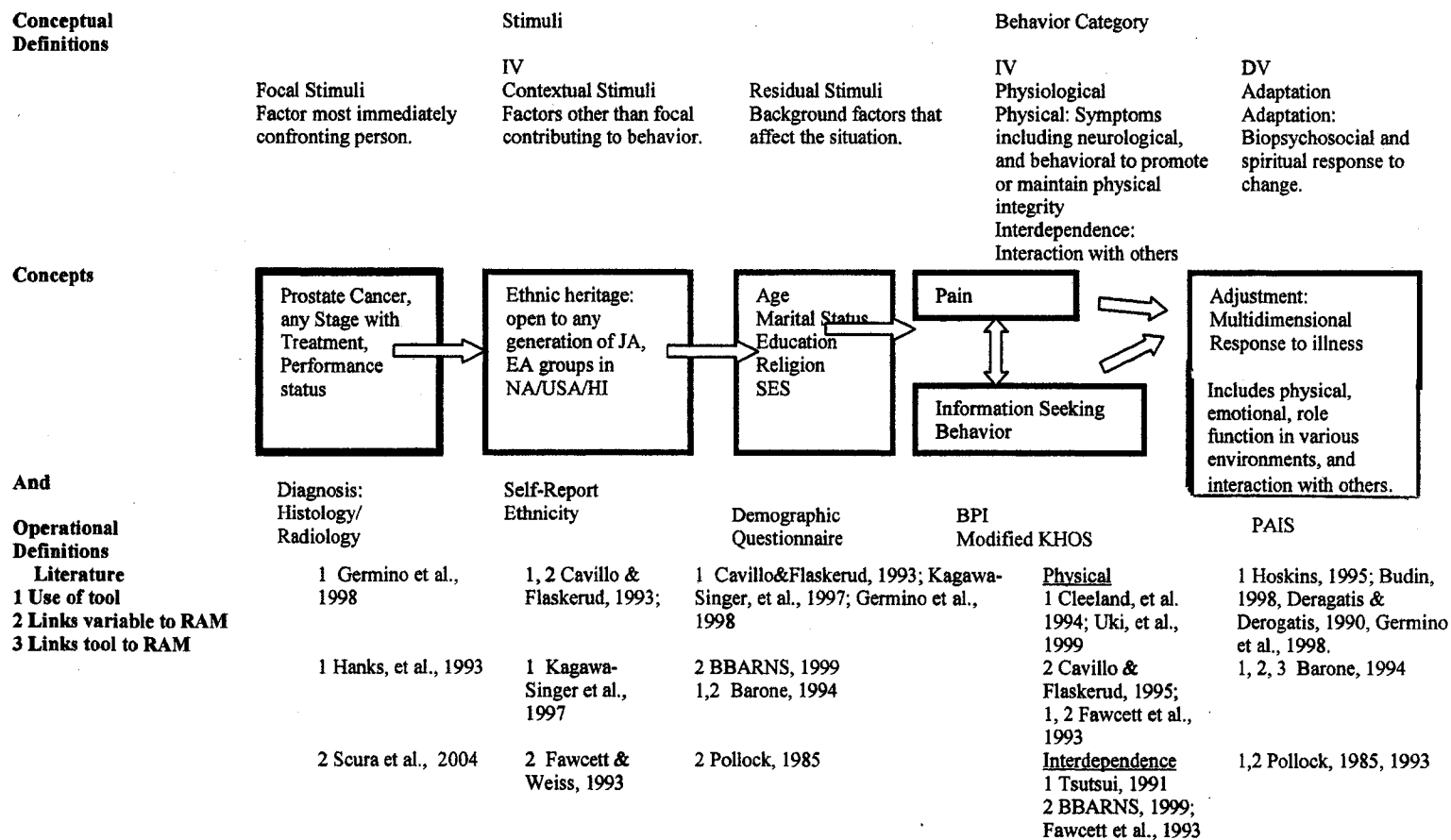
Sincerely,

[REDACTED]  
Mildred Ortu Kowalski, RN, PhD Candidate  
New York University  
Division of Nursing



## APPENDIX B

### ROY ADAPTATION MODEL: THEORETICAL, CONCEPTUAL AND EMPIRICAL



APPENDIX C  
PILOT STUDY TO TEST THE MODIFIED KRANTZ HEALTH OPINION  
SURVEY (KHOS)

Objectives

A pilot test was conducted in advance of the proposed core research study. The KHOS (Krantz et al., 1980) was modified for cultural sensitivity (please see section on Modified KHOS), in a population of chronically ill participants. The primary purpose of the pilot study was to assess practical aspects of the test administration for all tests, related to ease of completion, readability, and understanding (Guillemin, Bombardier, & Beaton, 1993; Henderson et al., 1992; Jones & Kay, 1992). Secondary objectives included identifying necessary changes in any instruments or research procedures, as well as conducting a preliminary analysis to explore differences between two ethnic groups, although the sample size was not established with the objective of assessing statistical significance.

Sample

The sample consisted of seventeen prostate cancer patients with metastasis (six second generation Japanese American patients, and 11 third generation European American patients) consenting to participate in a pilot study. The NYU UCAIHS approved consent form for the pilot was slightly different from the consent form planned for the core study. Important differences in the

consent forms between the pilot and the core were the purpose of the research study, the planned number of participants, and the inclusion of newly implemented HIPPA regulations in the core consent form.

Attendees of the Kuakini Us Too prostate cancer support group located in Honolulu, Hawaii were invited to participate in the pilot study. 17 participants enrolled in the pilot study between January 2002 and October 2002. Participants, self-identified as Japanese American or European American, requested questionnaires from the investigator or designee. Although the original plan was to enroll an equal number of participants ( $N = 20$ ) to each ethnic group, the pilot study enrolled 17 participants (Japanese Americans,  $n = 6$ ; European Americans,  $n = 11$ ) due to difficulty identifying Japanese American participants at this support group.

None of the participants in the pilot reported having metastatic prostate cancer, which was a criterion for inclusion into the study. Nevertheless, the pilot study allowed for the assessment of the methodological procedures and assessment of the modified KHOS instrument.

### Method

The 25-question modified KHOS version (Appendix O) was administered with the other instruments to be used in the main study. The other instruments included the Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis & Derogatis, 1990), the Brief Pain Inventory (BPI) (Cleeland, 1991), a Demographic Information Sheet and a Medical Information Form both developed by the

investigator. The instruments were supplied to the participants as a five-part questionnaire in a spiral bound booklet for ease of completion and return. The order of the instruments was the same in each questionnaire; the order was PAIS, BPI, KHOS, Demographics Information Sheet, and Medical Information Form. A consent form and the five-part questionnaire were provided to potential participants upon request after the study was explained and a written description was made available to each potential participant. The consent form and questionnaire were written in English.

The investigator supplied pre-paid, pre-addressed envelopes to each participant to return the completed questionnaire to the investigator. Signed consent forms were mailed back to the investigator in a separate pre-stamped, pre-addressed envelope. As stated in the consent form, each participant received \$10.00 for the return of a completed questionnaire.

The investigator stored the returned consent form and the completed questionnaires in different locations from each other. The data were entered into SPSS (Version 10.0) using single data entry, with uniform coding, and a quality review of all data points was conducted by a second individual.

#### Modified Krantz Health Opinion Survey (KHOS)

The version of the Information Scale of the KHOS (Krantz et al., 1980) was modified by Tsutsui (1991), to include five Japanese concepts (Asking, Not Asking, *Omakase* or leaving decision making to health care professionals based on Trust, *Omakase* based on Resignation, and Explanation). With permission

from the author (Appendix A), the KHOS was further modified to include five pain questions (pain items are: f, l, o, r, v). After a review of the literature, five questions related to cultural aspects of pain behaviors and communication were developed by the investigator. One pain question was added to each of the five sub-scales previously identified by Tsutsui. In addition, a question was added to the instrument to allow participants the opportunity to indicate any aspects of care about which they would like more information.

### Content Validity

Prior to conducting the pilot test on the modified KHOS, content validity was assessed, as described by Waltz and Bausell (1986). Three nurses with advanced nursing degrees and expertise in Japanese culture and cancer care quantitatively assessed the relevancy of each of 25 items to the construct definition and content addressed by the five sub-scales. The items were rated for relevance to the construct sub-categories using a four-point rating scale (1 – not relevant, 2 – unable to assess relevance without revision of the item, 3 – relevant but needs minor revision, and 4 – very relevant). The sub-categories and brief descriptions are:

- Asking: Comfort with asking health care professionals questions.
- Not Asking: A desire to ask questions, but not asking freely due to modesty, hesitancy, or psychological discomfort.
- Trust: Entrusting health care providers with making care decisions.
- Resignation: Relinquishing care decisions to health care providers.
- Explanation: Health care professionals provide desired information to patient.

The index of content validity (CVI) was 0.996 (Waltz & Bausell, 1986); all questions were retained. No item received a score lower than 3. The review of the items did result in minor changes of wording of four questions (b, f, o, and v) to make the questions more applicable to the concepts as well as culturally sensitive to both Japanese Americans and European Americans. Additionally, the phrase “doctor or nurse” was changed to health care professional in several questions.

Table 15

## Modified KHOS Items after Content Validity Review by Expert Nurses

Item	Suggested Item Modified Krantz Health Opinion Survey-Chronic Illness	Changed version
General change in all questions where applicable.	Change of the phrase “doctor or nurse.”	Change to “healthcare professional”
b.	Occasionally, I did not feel free to ask the doctor or nurse about my illness.	Occasionally, I did not feel able to ask a health care professional about my illness
f	I trust the doctor or nurse to treat my pain without information from me.	I trust the healthcare professional to treat my pain without my asking for information.
o.	My doctor or nurse asks about my pain, so I do not need to ask them questions about my pain.	Either the doctor or the nurse asked about my pain, so I did not need to ask them questions about my pain.
v.	I would hesitate to ask the doctor or the nurse for information about pain.	I would hesitate to ask a healthcare professional questions about my pain even if I found the pain distressful.

Responses

All patients who submitted a signed consent form completed the five-part questionnaire. Not all questions were completed by all patients, with some questions marked not applicable and some questions left blank without

explanation. One participant left several pages blank, suggesting that entire pages may have been missed; or, the participant may have been interrupted during completion of the booklet.

The participants may have considered some questions too sensitive or too personal to answer. The possibility that not all participants would want to answer all questions was anticipated prior to the initiation of the study. The instructions provided with the pilot questionnaires requested participants to identify those questions for which they did not care to respond (“Do not care to respond”). However, no items with missing data were identified as purposely omitted.

For the purpose of the preliminary analysis of the data for the pilot, the mean value for the average domain score of each subject was substituted for missing values in the PAIS (Derogatis & Derogatis, 1990), when at least partial responses were available. For other measurement tools, missing values were substituted with the individual’s average (Tabachnick & Fidell, 1996). No substitute for income was made.

The five-part questionnaire took on average 41 minutes for completion, with a range of between 15 and 90 minutes. Only four participants took more than 45 minutes to complete the questionnaire, including one participant that took 90 minutes. None of the participants indicated that they had difficulty reading English (Demographic Information Sheet, item #9), which was supported by a non-statistically significant difference when comparing mean time for completion of the two ethnic groups.



### Pilot Analysis

A comparison of ethnic groups was conducted to determine homogeneity of variance with regards to demographic variables. A Levene's Test for Equality of Variance was used to compare the differences between the observed distributions, of variables, for both samples. No statistically significant difference was noted for age in years, marital status, years living in North America/Hawaii, highest level of education, or annual household income (see Table 16). One participant did not provide information about annual income; there were no other missing demographic data.

### Medical Information Sheet

The Medical Information Sheet was developed by the investigator based on variables identified in the literature to be predictors of adjustment to cancer (Hoskins et al., 1996; Germino et al., 1998).

None of the patients reported having known metastasis of prostate cancer, a criterion for study inclusion. The Medical Information Sheet revealed participants receiving standard androgen deprivation/hormonal, radiation, and surveillance (watchful waiting) therapies. Descriptive statistics are reported in Table 17. A Levene's Test for Homogeneity of Variance showed no statistically significant differences in the Medical Information variables between the groups.

Table 16

Levene's Test for Equality of Variances  
Demographic Variables  
(age in years, highest level education, annual household income, marital  
status, number of years living NA/Hawaii)

Variable	<i>N</i>	<i>Mean</i>	<i>Std. Deviation</i>	<i>F</i>	<i>Sig. (2-tailed)</i>
Age in years	17	70.12	5.73	.535	.476
Japanese American	6	68.00	6.81		
European American	11	71.27	5.02		
Marital Status	17	-		2.672	.123
Japanese American	6	-	2.041		
European American	11	-	2.412		
Years in NA/H	17	66.46	5.92	1.101	.311
Japanese American	6	64.67	4.93		
European American	11	67.45	6.39		
Education	17	5.18	1.19	.519	.482
Japanese American	6	4.50	1.38		
European American	11	5.55	.93		
Annual income	15	5.13	1.02	.099	.758
Japanese American*	5	4.60	.89		
European American	10	5.36	1.03		

Education codes; 4 = some college, 5 = 4 years college, 6 = Masters Degree

Annual income codes; 4 = \$30,001 - \$40,000, 5 = \$40,001 - \$50,000, 6 = > \$50,001

\*Note one case is missing

Table 17

## Descriptive Summary Statistics for Medical Information

	Japanese American 6 (100%)	European American 11 (100%)	Total 17 (100%)
Median Years from Diagnosis	2 years	3 years	2.5 years
Treatment			
Surgery	4 (66.7%)	6 (54.4%)	10 (58.8%)
Radiation	1 (16.7%)	1 (9.0%)	2 (11.8%)
Androgen Deprivation Therapy	4 (66.7%)	5 (45.5%)	9 (52.9%)
Metastasis			
No	5 (83.3%)	8 (72.7%)	13 (76.5%)
Unknown	1 (16.7%)	3 (27.3%)	4 (23.5%)
Performance Status			
0 - No symptoms	4 (66.7%)	7 (63.6%)	11 (64.7%)
1 - Sx normal activities	2 (33.3%)	3 (27.3%)	5 (29.4%)
2 - Sx, rest < 50%	0 (0%)	1 (9.0%)	1 (5.9%)
Pain (yes on BPI)	1 (16.7%)	5(45.5%)	6(35.3%)

Psychosocial Adjustment to Illness Scale (PAIS)

The PAIS (Derogatis & Derogatis, 1990) is a 46-item instrument, with multiple choice answers, measures adjustment to illness in seven domains (Appendix M). The seven domains are healthcare, vocational, domestic, sexual relationships, extended family relationships, social situations and psychological adjustment. Each domain has a sub-score, with an overall adjustment score being

the sum of all items. A lower score (total possible range of 46 - 184) indicates a higher level of psychosocial adjustment.

An independent t-test for equality of means was performed for overall PAIS (sum of all scores, after transformation of negatively scored questions). The overall PAIS score was not significantly different between ethnic groups.

Japanese American participants had a lower mean PAIS ( $M = 25.83$ ,  $SD = 6.49$ ) compared to European Americans ( $M = 28.09$ ,  $SD = 17.35$ ),  $t(15) = -.304$ ,  $p = .766$ ).

The mean values for the extended family domain are statistically significantly different; mean extended family domain for Japanese Americans ( $M = .83$ ,  $SD = .41$ ) compared to the mean for the European Americans ( $M = 2.36$ ,  $SD = 2.25$ ),  $t(15) = -2.192$ ,  $p = .050$ . Although not statistically significant the mean for domestic environment domain showed a trend toward statistical significance between ethnic groups; Japanese American participants had a lower mean ( $M = 2.33$ ,  $SD = 2.88$ ) compared to the mean for European American participants ( $M = 5.45$ ,  $SD = 3.64$ ,  $t(15) = -1.805$ ,  $p = .091$ ). For all other domains the general pattern of adjustment is similar between ethnic groups (see Table 18, and Figure 24). Japanese Americans had lower scores (more adjustment) in most domains. Japanese Americans had higher scores (less adjustment) in healthcare orientation and sexual relationship domains, although the differences were not statistically significant.

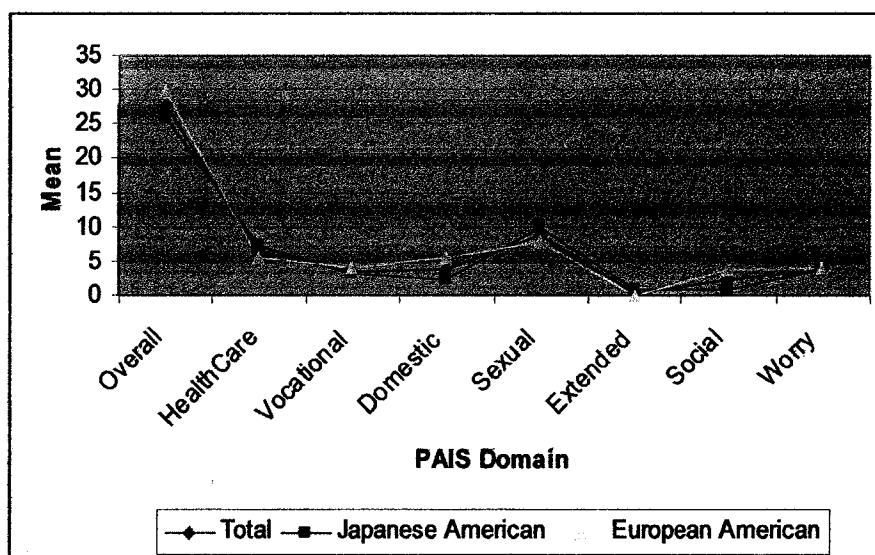
Table 18

PAIS and Domains: Independent t-Test for Equality of Means  
Mean (*M*), Standard Deviation (*SD*) and Statistical Significance (2-tailed)

	Japanese American <i>n</i> = 6	European American <i>n</i> = 11	<i>t</i>	Significance (2-tailed)
Overall Adjustment	<i>M</i> = 25.83, <i>SD</i> = 6.49	<i>M</i> = 29.70, <i>SD</i> = 17.35	-.304	.766
Healthcare	<i>M</i> = 7.17, <i>SD</i> = 1.94	<i>M</i> = 5.45, <i>SD</i> = 2.46	1.465	.164
Vocation (hobby)	<i>M</i> = 3.20, <i>SD</i> = 3.96	<i>M</i> = 4.09, <i>SD</i> = 2.95	-.505	.621
Domestic Environment	<i>M</i> = 2.33, <i>SD</i> = 2.88	<i>M</i> = 5.45, <i>SD</i> = 3.64	-1.805	.091
Sexual Adjustment	<i>M</i> = 9.83, <i>SD</i> = 2.14	<i>M</i> = 7.73, <i>SD</i> = 3.90	1.215	.243
Extended Family Relationships	<i>M</i> = .83, <i>SD</i> = .41	<i>M</i> = 2.36, <i>SD</i> = 2.25	-2.192	.050
Social Interactions	<i>M</i> = .83, <i>SD</i> = 1.60	<i>M</i> = 3.09, <i>SD</i> = 3.67	-1.755	.100
Worry/Psychological Adjustment	<i>M</i> = 3.83, <i>SD</i> = 3.55	<i>M</i> = 4.00, <i>SD</i> = 3.13	-0.98	.923

Figure 24

*Pilot Study – Adjustment by Ethnic Group (N = 17)*



### Brief Pain Inventory (BPI)

The BPI (Cleeland, 1991) (Appendix N) is a self-reported inventory of severity using a numeric rating scale (NRS) from 0 (no pain) to 10 (pain as bad as you can imagine) for worst pain, average pain, least pain and pain now. Similarly interference of activities or relationships (i.e. sleeping, working, walking, relationships with others, mood) is rated as a 0-10 NRS from 0 (does not interfere) to 10 (completely interferes).

Although none of the participants in the pilot reported prostate cancer metastasis, many ( $n = 6$ , 35.3%) did have pain. Four patients with pain took

medication ( $n = 4$ , 44.4 %), and one patient (11%) had physical therapy for pain. Of the participants who reported pain on any question on the BPI or Medical Information Form ( $n = 6$ ), two had pain but took no medicinal treatment (33.3%). The one Japanese American patient with pain took no pain medication; of the five European American patients with pain only one (20%) did not take pain medication, but did have physical therapy.

A description of the findings related to the BPI is noted in Table 19. Given the small number of patients with pain, no further analysis of the BPI was conducted for the pilot study.

Table 19  
Descriptive Summary of Pilot BPI

	Japanese American $n = 6$	European American $n = 11$	Comment
Pain yes	1 (16.7%)	5 (45.5%)	Pain as reported any answer to BPI or on Medical Information Form
no	5 (83.3%)	6 (54.5%)	
Severity of Pain	Range	Range	Pain severity based on 0 – 10 numeric rating scale.
Worst Pain	0 - 7	0 - 8	
Average Pain	0 - 6	0 - 5	
Least Pain	0 - 5	0 - 5	
Pain Now	0 - 5	0 - 7	
Interference > 4 areas	2 (30%)	5 (45.5%)	
Treatment for pain			Of five patients with pain who had treatment: one patient received Physical Therapy for pain, the remaining 4 received medication.
No med. treatment	1 (16.7%)	1 (9%)	
Med Rx for pain	0	4 (36%)	
Rx other than med	0 (0%)	1 (9%)	
Relief < 50%*	-	3 (60%)	*Percent based on those patients with pain, JA 1 of 1, EA 3 of 5
Missing	1 (100%)	-	

Modified Krantz Health Opinion Survey (KHOS)

After transforming negatively worded items, a two-tailed Independent Samples t-test for equality of means was conducted on the overall KHOS and all five sub-scores. The sub-scores include asking, not asking, trust, resignation and explanation. Higher scores indicate participants were informed of treatment, had greater inquisitiveness about health care, had a desire or ability to ask questions of the health care provider, and were informed and involved with decision making.

The participants who were Japanese American had a statistically significantly lower mean total score ( $M = 53.50, SD = 7.49$ ) than the participants who were European American ( $M = 64.55, SD = 3.62$ ),  $t(15) = -4.03, p = .001$ . Lower scores indicate less inquisitiveness about treatment, a lesser desire or ability to ask questions, less involvement in decision making (either due to trust or resignation) and being less informed about treatment decisions. Higher scores indicate more self direction of care and involvement in treatment decisions.

The difference in the mean overall information seeking KHOS score between ethnic groups was further explored. An independent t-test for equality of means showed statistically significant differences of mean values for trust ( $p < .002$ ) and resignation ( $p = .002$ ) (see Table 14). Scores in this preliminary and small study indicate that the Japanese American group was both more trusting of healthcare providers, as well as more resigned to their healthcare. These preliminary findings are consistent with the literature which reports trust of physicians and resignation typical of Japanese patients and family members (Tsutsui, 1991). The results of this pilot study should be viewed with caution, and



generalizability may be limited because of the small number of participants in this study ( $N = 17$ ).

#### Chronbach Alpha Reliability

The reliability of the modified KHOS in a chronically ill population was assessed in this pilot study ( $N=17$ ) using Statistical Package for the Social Sciences (Version 10.0). Chronbach alpha reliability, a model for internal consistency based on the average inter-item correlation (SPSS), yielded an alpha reliability of 0.81 for the total modified KHOS score. Alpha reliability for sub-scores of asking (0.527), trust (0.712), resignation (0.80), and explanation (.652) were all at acceptable levels between 0.60 - 0.70 (DeVillis, 1991; Frank-Stromborg, 1992; Nunnally, 1978). The sub-score for not asking (.473) and asking (0.527) were lower than the established level of acceptability. A lack of variance in the response to two questions, e and q, could be responsible for the low alpha reliability.

These items will be retained and the modified KHOS will be used for the core study because the alpha reliability of the overall score was acceptable. Additional validity and reliability assessment will be conducted on a larger data set ( $N = 84$ ) planned for collection in the core study.

Table 20

Independent Samples *t*-Test for Equality of Means in KHOS by Ethnic Group  
Mean (*M*), Standard Deviation (*SD*)

	Japanese American <i>n</i> = 6	European American <i>n</i> = 11	<i>t</i>	Statistical Significance (2- tailed)
Overall	<i>M</i> = 53.83, <i>SD</i> = 7.49	<i>M</i> = 64.55, <i>SD</i> = 3.62	-4.030	.001
Asking	<i>M</i> = 14.17, <i>SD</i> = 2.04	<i>M</i> = 14.55, <i>SD</i> = .82	-.551	.590
Not asking	<i>M</i> = 12.67, <i>SD</i> = 2.34	<i>M</i> = 13.18, <i>SD</i> = 1.40	-.574	.575
Trust	<i>M</i> = 8.83, <i>SD</i> = 1.47	<i>M</i> = 12.82, <i>SD</i> = 1.66	-4.902	<.002
Resignation	<i>M</i> = 8.17, <i>SD</i> = 2.86	<i>M</i> = 12.82, <i>SD</i> = 2.18	-3.774	.002
Explanation	<i>M</i> = 10.00, <i>SD</i> = 2.53	<i>M</i> = 11.88, <i>SD</i> = 1.89	-1.097	.290

### Summary of Pilot Study

The methodology used in the pilot study resulted in completion of 17 of 20 planned questionnaires. Methodological challenges included the enrollment of participants who did not have metastasis as stated in the inclusion criteria for the study. Nevertheless, the participants were able to complete the questionnaires and provided a sample adequate to test the methodology and instruments. Another challenge was the omission of some questionnaire items. The percent of missing items was 6.5% or less for all instruments. For the modified KHOS, no items were missed by any participant, supporting the adequate readability and understanding of the instrument.

Preliminary findings of the pilot study were obtained and indicated the ethnic groups were similar in age, marital status, education, and income. The Medical Information Sheet revealed participants receiving standard hormonal, chemotherapy, radiation and surveillance (watchful waiting) therapies. No further analysis or comparison, of demographic data, was performed for this pilot study.

The overall adjustment to illness PAIS scores were similar with a statistical difference of means, between ethnic groups, noted in the area of extended family relationships. A trend toward statistical significance ( $p = .091$ ) of mean differences between the ethnic groups, for the domestic environment domain. The KHOS indicated statistically significant mean differences in overall information seeking behaviors between ethnic groups ( $p = .001$ ). Areas of trust and resignation were subscales for which the means between the two ethnic groups were statistically significantly different. Although none of the participants in the pilot reported metastasis of their prostate cancer, many reported pain ( $n = 6$ , 35.3%).

#### Implications for the Core Study

The modified KHOS was completed by all participants. The alpha reliability of the overall test was acceptable at 0.81; therefore, the instrument will be used in the core study without modification.

As a result of conducting the pilot study, several minor changes will be made in the procedures for the core study, as well to the Demographic Information Sheet. Listed below are some changes which were made.

**Changes to the Demographic Information Sheet:**

- An option for married will be added to the marital status question (question #2) on the demographic information sheet, which was omitted in error on the pilot questionnaire.
- Information about the birth place of grandparents will be added to the demographic information sheet, to cross-check the ancestry and second or third generational status of the participant.
- The religion of the participant will be obtained because religion has been shown to be related to psychosocial adjustment to illness (Germino et al., 1998).

**Changes to the Methodology:**

- Modification of the core consent form to include HIPAA language and an updated contact phone number for the investigator.
- The assistance of a nurse will be used to identify potential participants with metastasis.
- Whenever possible, the investigator or designee will remind each participant to review the five-part questionnaire for completeness before the participant mails the questionnaire to the investigator. This may prevent unintentionally missed questions.

## APPENDIX D

## LETTER OF INTRODUCTION

As a doctoral candidate at the Division of Nursing at New York University, I am conducting a study on how men from different cultures adjust to the events associated with prostate cancer and pain secondary to metastasis. This knowledge will help nurses and other health care professionals better understand factors related to adjustment in the Japanese American and European American population. I am requesting your help in obtaining volunteers to participate in a research study (N = 84).

To be eligible to participate, the men must meet the following inclusion/exclusion criteria:

**Inclusion criteria:**

- Indicate interest in participation
- Self-identify as a second generation Japanese American man: a man born in North America/Hawaii, currently residing in North America/Hawaii, with at least one parent born in Japan or,
- Self-identify as a third generation European American: a man born in North American/Hawaii (grandparents or greater were immigrants from Europe), currently living in North America/Hawaii.
- Able to read and understand English
- Have prostate cancer and metastasis (local – distant)

**Exclusion criteria:**

- Had surgery within the last six weeks, or have residual surgical pain.
- Diagnosed with brain metastasis.

With permission from your IRB or support group administrator, a written description of the study along with the requirements for participation will be made available to potential participants. No use of the word cancer appears in the study description for patients. The voluntary nature of the study and confidentiality of information are stressed in the description. Each participant who indicates willingness to participate, by contacting the researcher, or returning a reply card, will be asked to sign a consent form and complete five-part questionnaire, obtained by mail. Participation is voluntary. The procedure may be modified to allow a nurse or physician to supply the questionnaire and consent form in an office or support group setting.

The questionnaire will take approximately 40 minutes to complete. A small (\$10.00) remuneration for this time will be mailed to each participant, when the investigator receives the five-part questionnaire. The consent form and questionnaire are returned separately in self-addressed stamped envelopes to

protect the participant's confidentiality. The information provided will be kept strictly confidential and all data will be analyzed by using code numbers only.

Participation is voluntary. The decision to participate or not to participate in this study will in no way affect the care received from physicians, nurses, or any other healthcare personnel. If participants have any questions they may ask the Investigator when they call to indicate interest in participation. They may also contact the Kuakini Research and Institutional Review Committee at [REDACTED]

I will be pleased to provide additional information pertaining to the study. If you need any other information, please feel free to contact me. I will be happy to discuss any additional aspects of this study. Thank you for your consideration.

Sincerely,

Mildred Ortu Kowalski, RN, MPA  
Doctoral Candidate, NYU Division of Nursing

APPENDIX E

SAINT BARNABAS IRB APPROVAL

JAN-25-2005 12:55

RADIATION ONCOLOGY SB/C

973 322 5648 P. 02



RONALD J. DEL MAURO  
Chairman  
Board of Trustees

Monday, December 20, 2004

Andrew Zablow, M.D.  
Saint Barnabas Medical Center  
Department of Radiation Oncology  
34 Old Short Hills Road  
Livingston, NJ 07039

RE: IRB Study # 04-70 At: Saint Barnabas Med Ct

Dear Dr. Zablow:

**Protocol Title:**  
EXPEDITED REVIEW - A RESEARCH STUDY ABOUT ADJUSTMENT TO ILLNESS IN BOTH  
JAPANESE-AMERICAN AND EUROPEAN-AMERICAN MEN

This letter is to acknowledge the receipt of the information identified below.

Expiration Date: 11/2/2005  
Our Internal #: 1126  
Type of Change: Consent Modification Approved  
Expedited?:   
Date of Change: 12/20/2004  
Date Received: 12/20/2004  
On Meeting Date: ~~12/21/2004~~ *11/16/04*  
Description: Revised informed consent form - change in contact information

Respectfully yours,

[Redacted Signature]

N. Peter Zauber, M.D.  
Co-Chairman, IRB



APPENDIX F

VALLEY HOSPITAL IRB APPROVAL

20.2005 2:57PM

NO. 483 P. 3



December 15, 2005

Christy Conroy, RN  
 Radiation Oncology  
 The Valley Hospital Radiation Oncology Department  
 One Valley Health Plaza  
 Paramus, NJ. 07652

223 North Van Dien Avenue  
 Ridgewood, NJ 07450-2736

RE: IRB Study # 04.0025

Dear Ms. Conroy:

Meeting Date: 1/12/06 At: The Valley Hospital

Protocol Title:

A Comparative Study of Pain Intensity, Information Seeking, and Adjustment to Prostate Cancer and Metastasis in Japanese American Men and European American Men - A Questionnaire.

This is to advise you that the above referenced Study has been presented to the Institutional Review Board, and the following action taken:

The following advertisement was approved via the mechanism of Expedited Review and will be ratified at the next IRB meeting scheduled for January 12, 2006.

Internal #: 1106  
 Expiration Date: 9/7/06  
 On Agenda For: Expedited  
 Reason 1: Procedure Reason 2: Advertisement  
 Description: Advertisement created to recruit men into QOL protocol.  
 IRB ACTION: Approved  
 Action: VIA EXPEDITED REVIEW  
 Explanation:

Sincerely yours,

Institutional Review Board

DM/lo



## APPENDIX G

### Written Description of the Research

You are invited to consider participation in a research study. If you meet certain requirements you may be eligible to participate in this study.

To participate you must:

- Self-identify as a Japanese American man: a man born in North America/Hawaii, currently residing in North America/Hawaii, who is of Japanese ancestry or,
- Self-identify as a European American man: a man born in North America/Hawaii, currently residing in North America/Hawaii, who is of European ancestry.
- Be able to read and understand English
- Indicate interest in participation

You will not be able to participate if you have had:

- Surgery within the last six weeks, or still have surgical pain, regardless of the date of your surgery.

This study will explore how men from specific ethnic groups adjust to prostate illness. If you meet the requirements above, but you have questions about the study, please contact the research investigator, Mildred Ortu Kowalski at [REDACTED]

The research study involves the completion of an English written survey take approximately 30 – 60 minutes to complete. If you decide to participate, please contact the research investigator at the telephone number listed below.

Participation means you will be asked to sign a consent form and complete a five-part questionnaire. The questionnaire includes:

- 1) a measure of adjustment to illness,
- 2) a self-report of pain intensity;
- 3) a health opinion survey,
- 4) a demographic information sheet, which asks general information about your background, and
- 5) a medical information form, which asks for information about your illness.

The information that you provide will be kept strictly confidential and all data will be analyzed by using a code number rather than by your name.

Your participation is completely voluntary. Your decision to participate or not to participate in this study will in no way affect the care you receive from your physicians, nurses or any other health care personnel.

For additional information about the study please call Mildred Ortu Kowalski at



Thank you.

APPENDIX H  
CONSENT FORM

I have been invited to take part in a research study to learn more about how men from different cultures adjust to prostate related illness. Approximately 84 men will participate in this research project. This study will be conducted by Mildred Ortu Kowalski, a registered nurse and a doctoral candidate at New York University. Her faculty sponsor is Professor Judith Haber, who can be contacted at NYU School of Education, Division of Nursing (by phone [REDACTED] or e-mail [REDACTED]@nyu.edu). Although the research may help doctors and nurses understand how to better care for patients, there may be no direct benefit to me.

I understand that as a participant I will be asked to complete the enclosed five-part questionnaire. The questionnaire will take approximately 60 minutes to complete. I will complete the questionnaire and return it to the Investigator in a self-addressed, stamped envelope provided. I will be paid \$10.00 for completing and returning the five-part questionnaire. This research may help doctors and nurses understand how to better care for patients.

I am aware that some of the information is of a sensitive or personal nature. In that event, I may get a referral to a counselor through my physician or by contacting the investigator. All of the questions asked are important to the investigator. However, I am not required to complete any questions that I do not feel comfortable answering.

I am aware that the investigator may review my medical chart for information about my illness (such as dates and current treatment). No photocopies of my chart will be made, no personal information will be copied from my chart, to ensure confidentiality. Only a code number will be used.

The investigator has provided a written explanation about this study to me. I am aware that the Investigator will be available to answer any questions I may have concerning the procedures used in this study. If I have any additional questions or wish to report a research-related problem, I may contact the investigator, Mildred Ortu Kowalski, at ([REDACTED] [REDACTED]), e-mail [REDACTED]@usa.net, or Professor Judith Haber at NYU Division of Nursing ([REDACTED] [REDACTED]). For questions about your rights as a research participant, I may contact the University Committee on Activities Involving Human Subjects, New York University, [REDACTED] or [REDACTED]@nyu.edu.

I understand that my participation is voluntary. I may refuse to participate or withdraw from participation at any time. My decision to participate, or not to participate in this research study will in no way affect the care I receive from my physicians, nurses, or any other health care personnel.

Confidentiality of my research records will be strictly maintained. All the information will be analyzed using a code number, rather than by using my name.

I have received a copy of this consent document to keep.

**Agreement to Participate**

---

Signature of Participant

Date

---

Signature of Witness

Date

Page 2 of 3

I do not wish to receive the results of the study.

I do wish to receive the results of the study.

---

Name

---

Address

---

3 or 3

## APPENDIX I

## US TOO NEWSLETTER NOTICE

Ongoing Survey Research  
Participants Needed

A doctoral research study is ongoing to explore how men from specific ethnic groups adjust to prostate cancer, report pain and seek healthcare information. The purpose of this study is to help nurses and doctors learn how to better care for patients with diverse ethnic backgrounds. This research study will include Japanese American and European American men with prostate cancer, who meet additional requirements.

The study requires the participant to sign a written informed consent, complete a five part written survey (usually taking between 30 – 60 minutes), and return the survey via mail (pre-addressed envelope and postage provided).

Approval for this research study has been obtained through New York University Committee on Activities Involving Human Subjects. If you are interested in learning more about this research study, please contact the investigator (doctoral nursing student) by e-mail or phone:

Mildred Ortu Kowalski, RN, MPA

██████████  
██████████@usa.net

Thank you!

## APPENDIX J

## KUAKINI MEDICAL CENTER IRB APPROVAL

Document No.: 12050502



**KUAKINI MEDICAL CENTER  
OFFICE OF RESEARCH**

**NOTIFICATION: PROPOSED RESEARCH PROJECT**

Research Project Title: 05-02: A Comparative Study of Pain Intensity, Information Seeking, and Adjustment to Prostate Cancer and Metastasis in Japanese-American Men and European-American Men

Principal Investigator: Mildred Ortu Kowalski, RN

Research Project application received: May 3, 2005

Research Project application determined complete: May 5, 2005

Recommended clarifications/revisions received: September 16, October 5, and November 29, 2005

Kuakini Medical Center, Kuakini Geriatric Care, Inc. Administration review dates: October 17 and December 16, 2005

IRB review date: October 13, 2005

IRB Chair expedited review (recommended clarifications/revisions) date: December 2, 2005

The decision making on the proposed research project is as follows:

Administration Approval.

IRB Approval of project's human subject protections. Expiration date: December 2, 2006

[Redacted Signature]  
Gary K. Kajiwara  
President and Chief Executive Officer  
Kuakini Medical Center, Kuakini Geriatric Care, Inc.

December 20, 2005  
Date

[Redacted Signature]  
Rob(in) Miyamoto, PhD  
Chair, Kuakini Institutional Review Board

December 20, 2005  
Date

An appeal to the decision rendered may be requested in writing, with supportive documents and addressed to the following:

Kuakini Medical Center  
Attention: Office of Research  
347 N. Kuakini Street  
Honolulu, Hawaii 96817


If you have any questions, please contact the Office of Research at [Redacted] Thank you.

## APPENDIX K

## ASIAN REPORTER NEWSPAPER ADVERTISEMENT

Scholarship & Award Program

### Ongoing Survey Research Participants Needed



Are you a Japanese-American  
or European-American man who has  
been treated for prostate cancer  
(currently or in the past)?

If YES, your participation is  
requested in a research study that  
will assist nurses and physicians:

- Determine how men ask for information; what information would be helpful for patients with prostate cancer
- Assess how men report pain to their doctor or nurse
- Understand what changes result from the diagnosis and/or treatment of prostate cancer

Participants will receive \$10 in appreciation for taking the time to complete a paper and pencil survey.

For more information,  
please contact the nurse investigator:

**Mildred Ortu Kowalski, RN, MPA**

e-mail: [REDACTED]

Thank you!



## APPENDIX L

## INSTRUCTIONS FOR PARTICIPANTS

Thank you for considering participating in this research study. Before you begin answering any questions, please carefully read the following instructions.

Included in this packet are a description of the study, a consent form, a five-part questionnaire and two return envelopes. After reading the description of the study and the consent form, please decide if you wish to participate. If you wish to participate, please sign and date the consent form and return it in the white envelope that is labeled with the word "CONSENT."

You are asked to complete the five-part questionnaire as an essential part of learning about your responses to your prostate illness. Please complete the questionnaire without the help of anyone else. Please complete the questionnaires in the following order:

1. The Psychosocial Adjustment to Illness Scale, Self-Report (PAIS-SR) contains a set of questions concerning the effects that your illness has had on your daily life. Please place a check mark, "✓", in the box next to the answer that best describes your experience.

If none of the answers to a question match your experience exactly, please choose the answer that comes closest to the experience you have had. For example, if questions ask about your job, and you are retired, please answer based on your daily activity or main hobby.

If a specific question is not applicable to your situation (such as children living at home), please indicate by putting "NA" next to the question.

2. The Brief Pain Inventory (BPI) asks about pain you may be having. You are asked to rate the intensity of your pain on a numerical scale. Additional questions about your pain and any interference your pain may have on activities are also asked.
3. The Health Opinion Survey, which asks about your health beliefs, ways that you maintain your health, and how you obtain health information.
4. Demographic Information, which provides general information about you (such as age, marital status, number of children, and ethnic/cultural background).
5. Medical Information Form, which asks for information about your illness.

Please answer all items on all parts of the questionnaire even though they may seem long and some questions may seem similar. All of the information is valuable for this research,

but your comfort is also very important. If you are uncomfortable answering any of the questions, please indicate by writing, "Do not care to respond" next to the question.

All responses will be held in confidence and will not be linked to your name, because code numbers will be used on the questionnaire. Please do not place your name anywhere on the forms that you complete.

Please place the completed questionnaire in the self-addressed, stamped brown envelope labeled with the word, "QUESTIONNAIRE". You may contact me at (██████████), if you have any questions. Thank you very much for your participation, it is greatly appreciated.

Mildred Ortu Kowalski, RN, PhD Candidate  
14 Newman Place  
East Hanover, New Jersey 07936

Telephone ██████████

## APPENDIX M

PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE, SELF-REPORT  
(PAIS-SR)

Copyright and trademark laws do not permit the reproduction of the complete Psychosocial Adjustment to Illness Scale.

The following sample items are provided.

(1) When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.

- a) I am sure that I am going to overcome the illness and its problems quickly and get back to being my old self.
- b) My illness has caused some problems for me, but I feel I will overcome them fairly soon and get back to the way I was before.
- c) My illness has really put a great strain on me, both physically and mentally, but I am trying very hard to overcome it, and feel sure that I will be back to my old self one of these days.
- d) I feel worn out and very weak from my illness, and there are times when I don't if I am really ever going to be able to overcome it.

(2) Has your illness interfered with your ability to do your job (schoolwork)?

- a) No problems with my job
- b) Some problems, but only minor ones
- c) Some serious problems
- d) Illness has totally prevented me from doing my job

(3) How much has your illness interfered with your work and duties around the house?

- a) Not at all
- b) Slight problems, easily overcome
- c) Moderate problems, not all of which can be overcome
- d) Severe difficulties with household duties

(4) Sometimes when people are ill they report a loss of interest in sexual activities. Have you experienced less sexual interest since your illness?

- a) Absolutely no sexual interest since illness
- b) A marked loss of sexual interest
- c) A slight loss of sexual interest
- d) No loss of sexual interest

(5) Are you still as interested in your leisure time activities and hobbies as you were prior to your illness?

- a) Same level of interest as previously
- b) Slightly less interest than before
- c) Significantly less interest than before
- d) Little or no interest remaining

(6) Recently, have you felt afraid, tense, nervous, or anxious?

- a) Not at all
- b) A little bit
- c) Quite a bit
- d) Extremely

## APPENDIX N

## BRIEF PAIN INVENTORY (SHORT FORM)

STUDY ID: \_\_\_\_\_ HOSPITAL # \_\_\_\_\_

DO NOT WRITE ABOVE THIS LINE

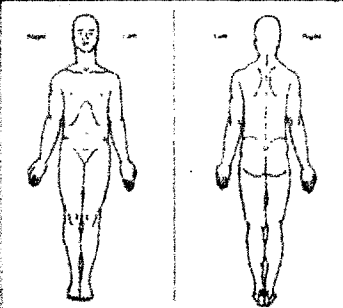
**Brief Pain Inventory (Short Form)**

Date: \_\_\_\_\_ Time: \_\_\_\_\_

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

1. Yes                      2. No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by circling the one number that best describes your pain at its **worst** in the last 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No										Pain as bad as
Pain										you can imagine

4. Please rate your pain by circling the one number that best describes your pain at its **least** in the last 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No										Pain as bad as
Pain										you can imagine

5. Please rate your pain by circling the one number that best describes your pain on **the average**.

0	1	2	3	4	5	6	7	8	9	10
No										Pain as bad as
Pain										you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have **right now**.

0	1	2	3	4	5	6	7	8	9	10
No										Pain as bad as
Pain										you can imagine

7 What treatments or medications are you receiving for your pain?

8 In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%  
 No Relief Complete Relief

9 Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

**A General Activity**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Interfere Completely Interferes

**B Mood**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Interfere Completely Interferes

**C Walking Ability**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Interfere Completely Interferes

**D Normal Work (includes both work outside the home and housework)**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Interfere Completely Interferes

**E Relations with other people**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Interfere Completely Interferes

**F Sleep**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Interfere Completely Interferes

**G Enjoyment of life**

0 1 2 3 4 5 6 7 8 9 10  
 Does not Interfere Completely Interferes

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 Pain Research Group  
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## APPENDIX O

**MODIFIED KRANTZ HEALTH OPINION SURVEY (KHOS)  
Information Scale**

**Please recall your last visit to the doctor for your illness.**

The items in this questionnaire are intended to determine how you obtained the information you felt you needed from a health care professional (either a doctor or a nurse) at your last visit for your illness. Please try to remember exactly what happened during the last visit as you respond to the items.

Please read first all items and circle the appropriate number to indicate the extent to which the action was true for you. It is important that you answer all items. Please be sure to think through each item carefully in order to determine your true feeling. There are no right or wrong answers. Circle only one response for each item according to the following scale:

	1	2	3
	DISAGREE	NEUTRAL	AGREE
a. I was able to ask a health care professional about my illness.....	1	2	3
b. Occasionally, I did not feel able to ask a health care professional about my illness.....	1	2	3
c. A health care professional explained my illness and how to take care of myself.....	1	2	3
d. I left the decision making to the health care professional because my own knowledge was limited.....	1	2	3
e. I could not ask the health care professional many questions, which I wanted to ask about my illness, because I felt that asking too many questions was impolite. ....	1	2	3
f. I trust the health care professional to treat my pain without my asking for information .....	1	2	3
g. I trusted the health care professional because I felt they would make the best decision for my care. ....	1	2	3
h. The health care professional made it clear as to how I could care for myself. ....	1	2	3

i. I obeyed the health care professional because I believed they knew what treatment was best for my illness.....	1	2	3
j. I left the decision making to the health care professional because I trusted them.....	1	2	3
k. Because I knew very little about my illness, I felt I should leave things to the health care professionals .....	1	2	3
l. I would feel comfortable asking the health care professional for information about my pain.....	1	2	3
m. The purpose of my visit to the doctor was to consult about my illness and I was able to do that. ....	1	2	3
n. I wanted to ask questions but sometimes I hesitated to do so.....	1	2	3
o. Either the doctor or the nurse asked about my pain, so I did not need to ask them questions about my pain.....	1	2	3
p. I resigned myself to leaving the decision on what was best to the health care professional .....	1	2	3
q. I felt free to ask the health care professional questions about my illness.....	1	2	3
r. I would leave decisions about my pain to the health care professionals, because they know best.....	1	2	3
s. At times, I could not ask the health care professional about my illness because they seemed so busy....	1	2	3
t. Because a health care professional explained about my symptoms so well, I did not have to ask many questions.....	1	2	3
u. I thought I should know about my illness so I was comfortable asking for information. ....	1	2	3
v. I would hesitate to ask a health care professional questions about my pain even if I found the pain distressful .....	1	2	3
w. I trusted the health care professional's thoughts and behaviors about my illness.....	1	2	3
x. I followed the doctor's order because I did not know what else I could do.....	1	2	3
y. A health care professional answered my questions about my illness without my having to ask.....	1	2	3

Please note any aspects of your health care that you would like more information about?

---



## APPENDIX P

## DEMOGRAPHIC INFORMATION SHEET

Your answers to these questions are an important part of this research study. Please answer all questions as completely as possible. Please do not write your name on this form.

Please provide your answers by placing a CIRCLE around the best response, or by writing your response in the space provided.

1. Your present age (in years) \_\_\_\_\_
2. Marital status
  - a. Single-never-married
  - b. Married
  - c. Divorced
  - d. Separated
  - e. Widowed
  - f. Other (Single, living with a partner) Please specify \_\_\_\_\_
3. Do you have children?
  - a. No
  - b. Yes, if yes, how many \_\_\_\_\_
4. How would you describe your ethnic background
  - a. Japanese American
  - b. European American
  - c. Other, Please specify \_\_\_\_\_
5. In what country were you born? \_\_\_\_\_
6. In what country was your mother born? \_\_\_\_\_
  - a. In what country was your mother's mother born? \_\_\_\_\_
  - b. In what country was your mother's father born? \_\_\_\_\_
7. In what country was your father born? \_\_\_\_\_
  - a. In what country was your father's mother born? \_\_\_\_\_
  - b. In what country was your father's father born? \_\_\_\_\_

8. What is your religious preference?
- a. Protestant, please specify \_\_\_\_\_
  - b. Catholic
  - c. Buddhist
  - d. Jewish
  - e. Islam
  - f. Other \_\_\_\_\_
  - g. No religious preference
9. Do you have any difficulty reading and understanding English?
- a. No
  - b. Yes
10. What is the language that you speak at home?
- a. English
  - b. Japanese
  - c. Other, Please specify \_\_\_\_\_
11. What is the language that you prefer to read? \_\_\_\_\_
12. How many years have you lived in the United States? \_\_\_\_\_
13. Are your friends of a similar ethnic background as you are? (Some examples of specific ethnic backgrounds are: Japanese, French, Italian, Polish, British, or others.)
- a. Some are the same, some are different
  - b. Most are the same, few are different
  - c. Few are the same, most are different
  - d. Do not know
14. Highest level of education completed:
- a. Grade School (9 years or less)
  - b. Some High School (less than 12 years schooling)
  - c. High School Graduate
  - d. Some College
  - e. Baccalaureate Degree (4 years of college)
  - f. Masters Degree
  - g. Doctorate
  - h. Other, Please specify \_\_\_\_\_

15. Your employment status at present:

- a. Unemployed
- b. Employed Part Time (less than 30 hours)
- c. Employed Full Time (30 hours or more)
- d. Retired
- e. Medical Disability
- f. Other, Please specify \_\_\_\_\_

16. If employed, what is your occupation? \_\_\_\_\_

17. If retired, what was your occupation? \_\_\_\_\_

18. Approximate annual household income:

- a. Less than \$10,000
- b. Between \$10,001 and \$20,000
- c. Between \$20,001 and \$30,000
- d. Between \$30,001 and \$40,000
- e. Between \$40,001 and \$50,000
- f. More than \$50,001

18. In the past two months, have you experienced any serious medical or surgical conditions, other than your prostate illness?

- a. No
- b. Yes, Please specify \_\_\_\_\_

## APPENDIX Q

## MEDICAL INFORMATION FORM

Please complete the following information by checking the box next to the response that best describes your medical treatment, or by writing in the information. When dates are requested, please provide an exact date, or estimate the date if the exact date is not known.

---

1. When were you first diagnosed with your prostate illness?

Month \_\_\_\_\_ Year \_\_\_\_\_

2. Did you have prostate surgery?  yes  
 no

If yes, on what date? Month \_\_\_\_\_ Year \_\_\_\_\_

3. What type of treatment or treatments did you have/are you having for your illness?  
Check all that apply.

- Hormonal deprivation
- Chemotherapy agents
- Radiation or x-ray therapy
- Other \_\_\_\_\_(please specify)
- Not known

4. Do you currently have pain?  Yes  No

If yes, what kind of pain do you have? (please check all that apply)

- Stomach or intestinal or lung pain
- Bone pain
- Nerve pain
- Type of pain not known

5. *What type of pain medication do you currently use? Please list all that apply.*

Name of pain medication \_\_\_\_\_

Dose of medication if known \_\_\_\_\_

- About how often do you take this medication
- Five times a day or more
  - Three or four times a day
  - Two times a day
  - Once a day
  - Less than once a day
  - Three times a week
  - Once or twice a week
  - Less than once a week
  - Patch put on 3 times per week
- Other \_\_\_\_\_

6. *Have you ever been given a medication known as a bisphosphonate?*

Some medications which are bisphosphonates are Aredia, pamidronate, Zometa, zoledronate, zoledronic acid, Fosamax, alendronate, and risidronate.

- Yes       No

If yes, please provide information about the medication, dose, start and end date:

- Alendronate or Fosamax    Dose if known \_\_\_\_\_  
**Start date**    **Month** \_\_\_\_\_    **Year** \_\_\_\_\_  
**End Date**    **Month** \_\_\_\_\_    **Year** \_\_\_\_\_
- Aredia or pamidronate    Dose if known \_\_\_\_\_  
**Start date**    **Month** \_\_\_\_\_    **Year** \_\_\_\_\_  
**End Date**    **Month** \_\_\_\_\_    **Year** \_\_\_\_\_
- Zometa or zoledronate or zoledronic acid    Dose if known \_\_\_\_\_  
**Start date**    **Month** \_\_\_\_\_    **Year** \_\_\_\_\_  
**End Date**    **Month** \_\_\_\_\_    **Year** \_\_\_\_\_
- Risidronate    Dose if known \_\_\_\_\_  
**Start date**    **Month** \_\_\_\_\_    **Year** \_\_\_\_\_  
**End Date**    **Month** \_\_\_\_\_    **Year** \_\_\_\_\_

7. Have you ever had radiation for pain (including radiotherapeutic agents such as Strontium or Samarium)?  Yes  No

8. Did you have surgery to determine if your illness has spread to another area of your body?  
 Yes  No  Not known

9. Did you have radiation (x-rays or scans) to determine if your illness has spread to another area of your body?  
 Yes  No  Not known

10. Has your prostate illness spread to another area of your body?  
 Yes  No  Not known

If yes, check area if known:  Bone  
 Lymph nodes  
 Pelvis/abdomen  
 Other \_\_\_\_\_

If bone involvement, check number of bone lesions (if known):  
 1 bone lesion  
 2-5 lesions  
 6 or more lesions  
 Not known

11. Please check the response that best describes how you feel and your activity level, most of the time.  
 I have no symptoms  
 I have some symptoms, but carry out all daily activities.  
 I have symptoms and I rest in bed; I rest in less than half of the day.  
 I have symptoms and rest in bed or than half of the day.  
 I rest in bed most of the day.

Approximately how many minutes did it take you to complete the five-part questionnaire? \_\_\_\_\_