An Exploratory Study of the Use of Physical and Psychosocial Techniques to Relieve Terminal Cancer Pain

By

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A Master's Research Project

Presented to
Oregon Health Sciences University
School of Nursing
in partial fulfillment of
the requirements for the degree of
Master of Science

May, 1997

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ACKNOWLEDGEMENTS

I gratefully thank my research advisor Barbara Stewart for all her dedicated hours in assisting me in this endeavor. Her encouragement and support were never ending. I also want to thank Jane Kirschling for her knowledge in hospice care and her willingness to stick with me even when she moved over 2000 miles away. I also want to express my gratitude to my academic advisor, Marie Napolitano, for encouraging me to do this study despite being in a busy family nurse practitioner program and for being a wonderful role model.

I also want to thank Kaiser Permanente Continuing Care Services in Portland, OR for their financial and administrative assistance. This study was also supported in part by a grant from Sigma Theta Tau, Beta Psi Chapter.

To my husband, Kent, thank you for all technical assistance, patience, love, and back rubs throughout this project.

ABSTRACT

TITLE:

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This exploratory study provided descriptive data on the use of 13 physical and psychosocial techniques to relieve pain in terminally ill patients with cancer. Before this study little research had been done on the use of such techniques with this population of patients. All of these techniques have been studied in relationship to other types of pain. Since terminal cancer pain remains a challenge for many hospice patients, this study used a survey design to explore the use of these techniques by hospice staff members. A total of 47 surveys were completed by hospice staff members (employees and volunteers). Employees completed 42 of the surveys for a response rate of 68% and five surveys were completed by volunteers for a response rate of 25%. Data analysis focused on data from hospice employees composed of registered nurses (56%), physical therapists (15%), home health aides (10%), occupational therapists (7%), medical social workers (5%), speech therapists (5%), and pastoral care counselors (2%).

Hospice employees most commonly used repositioning (100% of employees), relaxation exercises (87%), heat (78%), and pastoral or spiritual assistance (74%) to relieve pain in hospice patients with cancer. The least used techniques were acupuncture (28%) and therapeutic touch (20%).

The three techniques rated by hospice employees as most effective in relieving pain in hospice patients with cancer were pastoral or spiritual assistance (\underline{M} =2.82), repositioning (\underline{M} =2.64), and therapeutic touch (\underline{M} =2.50). These three mean scores fall between "somewhat effective" (2) and "quite a bit effective" (3). The techniques rated least effective were acupuncture (\underline{M} =1.55) and Transcutaneous Electrical Nerve Stimulation (TENS) (\underline{M} =1.23). These two mean scores fall between "effective a little" (1) and "somewhat effective" (2).

The mean effectiveness ratings were compared between all pairs of techniques using a 2-tailed t-test (p<.01). One-third of the techniques were significantly more effective than the other techniques. Specifically, pastoral or spiritual assistance was rated significantly more effective than 10 of the other 12 techniques. Repositioning was rated as significantly more effective than 9 of the other 12 techniques. Eleven of the 12 techniques were rated as significantly more effective than TENS. Therefore, TENS is rated as the least effective technique.

The four greatest barriers that hospice employees reported were: (1) staff member's lack of training (\underline{M} =35% of staff), (2) patient's or caregiver's lack of interest (\underline{M} =28%), (3) staff member's lack of time (\underline{M} =28%), and (4) patient's or caregiver's lack of understanding on how to use technique (\underline{M} =27%). All hospice employees had used at least one of the 13 techniques personally to relieve their own pain. The majority of

employees (71%) had also used at least one of the 13 techniques personally for other reasons besides pain.

Results of this study indicate that the two techniques most commonly used by employees personally (i.e., heat, repositioning) were also among the most frequently used techniques with hospice patients. Repositioning may have been the most used technique because it required the least amount of training and time compared to the other techniques.

Pastoral or spiritual assistance was ranked the most effective possibly because terminal cancer pain may have a greater spiritual domain than other types of pain and none of the other techniques specifically address the spiritual aspect of pain. Therapeutic touch was the least used technique, but ranked the third most effective in relieving pain by hospice employees. It may have been effective because it does not require the patient to participate. It is least used possibly because it requires specialized training and is considered a new nontraditional type of energy healing that may not be accepted very well by staff and hospice patients. Relaxation exercises were the second most effective technique and the fourth most used technique. This may be explained from the evidence that anxiety contributes to the pain experience and using relaxation exercises may give the patient some control over the emotional aspect of the pain experience.

There are many implications from these findings. First, training hospice staff in the use of these techniques will help increase the use of them. Second, further studies are needed by to demonstrate the usefulness of these technique so that their importance will be valued. If hospice programs valued these techniques more, more time could be allowed for staff to use them with hospice patients. Third, more referrals to occupational therapy

are needed because many occupational therapists are trained in these techniques as part of their job, and using occupational therapists for this function may be underutilized. Finally hospice nurses and other staff members are encouraged to use and support these techniques so that patients and caregivers may become aware of their potential effectiveness. Although this study is limited to hospice patients with terminal cancer, it is important for nurses to consider using physical, spiritual, and psychosocial techniques to address the physical, spiritual, and emotional aspects of pain when caring for anyone with pain.

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Chapter I

Introduction

Cancer is one of the leading causes of death in the United States. The American Cancer Society (1994) reports that 1 out of every 5 deaths in the United States is caused by cancer. Every year cancer is diagnosed in over 1 million Americans and it is estimated that over 8 million Americans have cancer or a history of cancer (U.S. Department of Health and Human Services, 1994). The most common symptom experienced by persons with cancer is pain. Approximately 30 to 50% of all persons with cancer experience pain and 60 to 80% of all persons with advanced cancer report pain (Spross, 1992).

Unrelieved pain leads to suffering and impacts all aspects of the person's life. It can be devastating to the person as well as the family. Overall quality of life can be diminished. Pain can disturb sleep and rest and diminish an individual's functional capacity. Pain can interfere with social interactions and impair intimacy. The individual may experience increased fear and anxiety and feel a loss of control. This can lead to feelings of hopelessness and helplessness and often depression. Spiritually, pain may cause the individual to reevaluate religious beliefs or search for the meaning of their disease.

Because cancer pain is a multidimensional experience (i.e., physical, emotional, social, spiritual), it requires a multidimensional approach to manage it. In addition to oncologists, many medical specialties may be enlisted, such as neurologists, neurosurgeons, and anesthesiologists, who may recommend pharmacologic interventions or invasive techniques. In addition, experts in physical rehabilitation, nurses, psychiatrists, and psychologists may be utilized to help with the physical and psychological aspects of pain control.

Enormous worldwide attention has been focused on improving cancer pain management. Many technologic and pharmacologic advances are made each year. Several organizations have issued guidelines on cancer pain management using a multidisciplinary approach. The Agency for Health Care Policy and Research (AHCPR) is one such agency that makes recommendations for health care based on research findings and clinical practice. The AHCPR Clinical Practice Guidelines recommend both pharmacologic and nonpharmacologic interventions to manage cancer pain (U.S. Department of Health and Human Services, 1994). The pharmacologic recommendations are based on the World Health Organization's (1990) specific step-wise analgesic plan to treat cancer pain. Drug therapy is the most common and frequently used technique because it is 90% effective in most people with cancer (Ventafridda, Caraceni, & Gamba, 1990). However, based on WHO guidelines, 20 to 25% of people with advanced cancer do not receive adequate pain relief (Ferrell, Rhiner, & Grant, 1992; Grond, Zech, Schug, Lynch, & Lehmann, 1991).

Nonpharmacologic interventions are classified as either invasive or noninvasive techniques. They should not be used instead of analgesics, but rather as an adjunct to medications (U.S. Department of Health and Human Services, 1994). Invasive techniques are interventions such as nerve blocks and radiation. Noninvasive techniques include physical interventions, such as massage and acupuncture, and psychosocial interventions, such as relaxation and imagery. Other noninvasive techniques, such as therapeutic touch, have also been found in the literature as being effective in relieving pain. These noninvasive techniques can be used to modify all the dimensions of the pain experience (Spross & Burke, 1995).

When cancer cannot be cured, there comes a time when the individual is considered terminal and is frequently given an estimated life expectancy. At this time, physicians, patients, and families have to make a decision between technological efforts that prolong life and the increasing challenge of achieving comfort and coming to terms with the end of life (Smith, 1993). If the patient and family choose to stop technologic and aggressive treatments that prolong life, they may be appropriate to receive hospice care.

Hospice is a philosophy and system of care for the terminally ill, usually in their last 6 months of life. Hospice care does not attempt to cure or prolong life, but rather emphasizes palliative treatment and emotional support for the terminally ill patient and family. It uses a multidisciplinary team approach to promote comfort through symptom control and maximizing the quality of life. Hospice care is seen within a holistic framework because the team attends to the patient's physical, psychological, social, and spiritual needs. The patient's family and/or caregiver are as important in the decision making process as the patient and play a major part in providing care for the terminally ill person. The team consists of primary health care providers, nurses, social workers, home health aides, pastoral care counselors, physical therapists, occupational therapists, speech therapists, and volunteers. Frequently there is also a consulting dietitian and pharmacist.

The National Hospice Organization (1995) reports that there are over 2,400 operating and developing hospice programs in the United States, and the Oregon Hospice Association (OHA) reports there are 51 programs in Oregon (M. Cronin, personal communication, May 22, 1996). The majority of patients on hospice have terminal cancer. In 1992, 66% of the 52,100 patients surveyed had a diagnosis of neoplasm on admission to hospice (National Home Health and Hospice Care Survey, 1994). In 1995, the OHA

(1996) reported 4,806 deaths in Oregon hospices. Of these deaths, 71% of these patients had a diagnosis of cancer.

Hospice care providers aim to achieve the highest level of pain and symptom control possible through multidisciplinary team collaboration. Hospice care providers, especially nurses, are often seen as experts in managing pain in the terminally ill. Nurses assess and evaluate patients and their caregiving situation. They are expertly skilled to assess the factors that influence pain, such as anxiety and family conflict. Social workers, home health aides, pastoral care counselors and the other disciplines also see the patient and family. As case managers, nurses collaborate with other disciplines to help the patient and family meet their physical, emotional, and spiritual needs. They educate the patient and family in ways to manage pain and other symptoms, provide emotional support, and facilitate patient and family conferences.

Although hospice team members are considered experts in pain management, complete pain relief remains a challenge in patients with terminal cancer. As stated earlier, 20 to 25% of patients with advanced cancer do not have adequate pain relief (Grond, et al., 1991). Since hospice care providers use a "low-tech and high-touch" philosophy for promoting comfort, it would be very appropriate for noninvasive techniques to be used in conjunction with pharmacological measures to maximize comfort (Smith, 1993). However, from clinical experience as a hospice nurse, I have found that health care providers primarily use a pharmacological approach to pain management.

Spross and Burke (1995) say that noninvasive techniques are underused in cancer pain management. Barriers to using noninvasive techniques exist. Donovan and Dillon (1987) found in their study that nurses rarely taught noninvasive techniques to cancer

patients because they were considered too simple to use when higher technologic treatments were available. Turk & Feldman (1992) report that some nurses who work with the terminally ill do not want to overwhelm patients and families by teaching these techniques or do not have the time to teach them. This study was designed to further explore the utilization of noninvasive techniques in hospice patients with cancer.

Chapter II

Review of the Literature

The literature review and focus of this project was on 13 nonpharmacologic noninvasive techniques to relieve terminal cancer pain. Of these 13, eight are considered physical techniques and include: (1) massage, pressure, and vibration; (2) application of cold; (3) application of heat; (4) exercise; (5) repositioning; (6) immobilization; (7) Transcutaneous Electrical Nerve Stimulation (TENS); and (8) acupuncture. Five of the 13 are psychosocial techniques and include: (9) relaxation exercises (focused-breathing, progressive muscle relaxation, and music therapy); (10) meditation and imagery; (11) distraction and reframing; (12) therapeutic touch, and (13) pastoral or spiritual assistance.

With the exception of therapeutic touch, all of the above techniques are taken from the AHCPR Clinical Practice Guidelines that recommend 16 nonpharmacologic noninvasive techniques for patients with cancer (U.S. Department of Health and Human Services, 1994). Therapeutic touch, although not part of the AHCPR recommendations, is a strategy recommended in other cancer pain management literature and is performed by some hospice nurses (Spross & Burke, 1995; U.S. Department of Health and Human Services). These 13 techniques were chosen because they can be used in the home setting where hospice patients tend to spend increasing amounts of time as their condition worsens. In addition, they have few, if any, side effects. All of these techniques, except for acupuncture, can also be taught to patients and caregivers easily and quickly. Although acupuncture has typically been used in the outpatient setting, it is becoming a more popular pain relieving technique that is easily performed by acupuncturists who make

house calls. The remaining four strategies recommended in the AHCPR guidelines include patient education, psychotherapy and structured support, hypnosis, and peer support groups (U.S. Department of Health and Human Services). Although these 4 strategies are important in cancer pain management, they are not included in this project for the following reasons: (a) the family would have to leave the home to use the strategy (e.g., peer group support), (b) experts to apply the technique are not commonly available in the area or do not make house calls (e.g., hypnosis), or (c) the strategy is too general (e.g., patient education).

Literature Search

The following search strategy was used to identify the literature on each of the 13 techniques as it relates to relieving pain in hospice patients with terminal cancer pain. Four on-line databases were searched: CINAHL (1982-1996), Health (1975-1995), Medline (1986-1996), and PsychInfo (1984-1996). The following textword and MeSH subject headings were used by themselves or in various combinations: palliative care, terminal care, hospice care, pain, alternative health care, holistic health care, oncology nursing, cancer, neoplasms, physical therapy, cryotherapy, TENS, exercise therapy, massage, breathing exercises, motion therapy, acupuncture analgesia, acupuncture therapy, heat, cold, vibration, pressure, imagery, music, behavior therapy, relaxation techniques, spirituality, pastoral counseling, and religion.

Research articles were selected if they evaluated the use of the techniques in relieving pain. The search started very specifically, then expanded. All research articles that discussed the use of each technique with terminal cancer patients receiving hospice services were included. If minimal research articles were available on the use of the

technique with terminal cancer patients, then articles on patients with any type of cancer pain were included. If research was unavailable on the technique with patients with cancer pain, then the search was expanded to include patients with any type of pain. If the technique was not studied in relationship to pain, articles relating to its use in other situations were included if pertinent. Many relevant articles and key authors were obtained by reviewing the reference lists in cancer pain management textbooks and classical studies. The literature review in this paper is not exhaustive, but rather a selection of pertinent articles from the most specific to the least specific, depending on the available research. Criteria for exclusion were foreign language journals, non-research articles, and those unavailable in universities in the Portland area.

The literature review is organized in the following manner for each of the 13 physical and psychosocial techniques (see Tables 1 to 13): (1) a definition of the intervention, (2) a description of its clinical use, (3) limitations or contraindications for use, and (4) research evidence evaluating its use.

Continued

Table 1

Massage, Vibration, and Pressure

<u>Definition</u>: These are forms of cutaneous stimulation that can promote relaxation and pain relief by touching the skin. Massage is the application of forces such as friction, vibration, or pressure to the skin and soft tissues (Haldeman, 1989). Friction is applied by stroking, kneading, or rubbing manually (Lee, Itoh, Yang, & Eason, 1990). Vibration is a variation of massage is which fine tremors are applied to the skin either manually or mechanically (Spross & Burke, 1995). Pressure, another aspect of massage, is applied evenly over muscles. When finger pressure is applied over specific tender spots that correspond to a meridian, the technique is termed acupressure.

Indications for use: Many patients may benefit from all these massage techniques, especially those who are confined to the bed or chair, have impaired communication, those who lack social interaction, have sensory deprivation, are unconscious, or those with tense muscles and/or anxiety (Spross & Burke, 1995). Vibration may be specifically helpful to relieve acute pain and inflammation and may be applied to an area of stiffness prior to movement (Spross & Burke). In addition, vibration is indicated for treatment of tension headaches, neuropathic pain, muscle spasms, itching, or phantom limb pain (McCaffery & Wolff, 1992). The advantage to these techniques is that they can be applied distal to the pain site and achieve the same or even better pain relief than if they are applied proximally (McCaffery & Wolff; Sherer, Clelland, O'Sullivan, Doleys, & Canan, 1986).

<u>Limitations and contraindications</u>: None of these techniques should be used in patients with bleeding disorders, thrombophlebitis, a hypersensitivity to touch, those who find it uncomfortable or refuse to be touched, and who might interrupt massage as a sexual advance (Spross & Burke, 1995). In addition, these techniques should not be used over broken skin or open wounds (McCaffery & Wolff, 1992). Mechanical vibration should not be used over tumor sites (U.S. Department of Health and Human Services, 1994). Pressure or acupressure should not be used over fractures or sites at risk for fractures from metastases (Spross & Burke). The technique of acupressure causes an increase in pain initially, before pain relief occurs, so many patients may not be able to tolerate it long enough to feel the benefits.

Research evidence: The following are a few studies about the effects of massage and vibration in patients without cancer. Groer et. al (1994) demonstrated that a 10-minute massage increases salivary immunoglobulin A (s-IgA) in healthy elderly adults. Fraser and Kerr (1993) demonstrated that massage can relieve anxiety as evidenced by decreased muscle activity and self-report measures in elderly institutionalized patients. Guieu, Tardy-Bervet, and Roll (1991) found that vibration used by itself or with a TENS device significantly relieved pain in patients with chronic pain compared to a control group who received no stimulus. In addition, they found that the combination of vibration and TENS together alleviated pain in more patients than used alone and had stronger and more long-

lasting analgesic effects.

The following are studies conducted on the effects on massage in patients with cancer. Ferrel-Torry and Glick (1993) demonstrated that therapeutic massage decreased pain perception and anxiety levels in male hospitalized cancer patients. Those men with moderate levels of pain and high levels of anxiety showed the most significant reduction in pain and anxiety. A study conducted on the characteristics among hospitalized cancer patients demonstrated that 26% of patients found massage to be effective in relieving pain (Donovan & Dillon, 1987). A similar study investigating the use of nonanalgesic methods of pain control used by cancer outpatients demonstrated that 75% of patients found massage to be effective in relieving pain (Barbour, McGuire, & Kirchhoff, 1986). Another study on the effects on massage in cancer patients showed that male patients experienced a significant reduction in pain immediately after a 10-minute massage, but female patients did not (Weinrich & Weinrich, 1990).

Only one study was found that investigated the effect of massage on subjects in a hospice program. Meek (1993) investigated the effects of slow stroke back massage on physiological measures of relaxation on 30 adult patients in two hospice home care programs. Subjects were in their terminal stage of illness with an estimated 6 months or less to live. Although diagnoses of the subjects were not identified, none of the subjects had known bony metastasis to the spinal column, rib cage, shoulders, or pelvic bones. Results of the study showed a significant decrease in heart rate, systolic and diastolic blood pressure, and a significant increase in skin temperature following massage. The results of this study demonstrate that slow stroke back massage administered to hospice patients may promote comfort and relaxation because the objective physiological measures of relaxation significantly changed in response to the massage intervention.

Table 2

Application of Cold

<u>Definition</u>: A cutaneous stimulation technique that can promote relaxation and pain relief through the use of ice packs, towels soaked in ice water, or commercially prepared chemical gel packs applied to the skin (U.S. Department of Health and Human Services, 1994). It causes vasoconstriction and local numbing.

Indications for use: Used to relieve inflammation after an injury or for burning perineal pain (Evans, Lloyd, & Jack, 1981; Ramler & Roberts, 1986). Indicated for muscle spasms not improved with superficial heat (Vasudevan, Hegmann, Moore, & Cerletty, 1992). Most effective in patients with musculoskeletal pain and acute or chronic myofascial syndromes (Brennan, 1993). Also used to relieve pain in fibromyalgia, ischemia, effusion, hyperesthesia, and prior to an activity that induces pain (Spross & Burke, 1995). May be used proximal, distal, or contralateral to the pain site (McCaffery & Wolff, 1992).

<u>Limitations and contraindications</u>: Cold is contraindicated in patients with peripheral vascular disease, Raynauds syndrome, connective tissue diseases or over damaged tissue caused by radiation therapy (Lehmann & de Lateur, 1990; Whitney, 1989). It should not be used on patients whose skin blanches and then reddens in response to the application of cold (Spross & Burke, 1995). Caution not to put ice directly on skin. It should not be used in patients who find it uncomfortable or those who cannot communicate.

Research evidence: The majority of research involving the use of cold therapy has been with musculoskeletal injuries and postoperative pain and swelling and show conflicting evidence (Daniel, Stone, & Arendt, 1994; Levy & Marmar, 1993). Ramler and Roberts (1986) found cold sitz baths to be significantly more effective in relieving postpartum perineal pain than warm sitz baths.

No studies were found on the use of cold in hospice patients or the terminally ill. Only two studies were found on the use of cold in patients with cancer. A study conducted on the characteristics among hospitalized cancer patients demonstrated that only 7% of patients found cold to be effective in relieving pain, 22% felt no effect, and 22% experienced an increase in pain (Donovan & Dillon, 1987). A similar study investigating the use of nonanalgesic methods of pain control used by cancer outpatients demonstrated that only 2% of patients found cold to be effective in relieving pain (Barbour, et al., 1986). None of the patients experienced an increase in pain with the use of cold.

Application of Heat

<u>Definition</u>: A cutaneous stimulation technique that can promote relaxation and pain relief through the use of hot packs, hot water bottles, hot and moist compresses, electrical heating pads, immersion in hot water, ultrasound, and menthol preparations (U.S. Department of Health and Human Services, 1994). It causes an increase in blood flow through vasodilation (Lehmann & de Lateur, 1990; Whitney, 1989) and increases muscle elasticity (Vasudevan, et al., 1992).

<u>Indications for use</u>: Used to relieve pain associated with muscle spasms, inflammation, joint stiffness, fibromyalgia, ischemia, effusion, and hyperesthesia (Spross & Burke, 1995). May be used proximal, distal, or contralateral to the pain site (McCaffery & Wolff, 1992). Patients who get the most benefit from heat are those with soft tissue pain, rheumatologic conditions that are exacerbated by their cancer, and those with back and neck discomfort caused from decreased mobility (Brennan, 1993).

<u>Limitations and contraindications</u>: Caution not to put heat directly on skin. Menthol and heat should not be used concurrently (Spross & Burke, 1995). It should not be used in patients that find it uncomfortable or those who cannot communicate (Brennan, 1993). Heat is contraindicated over damaged tissue caused by radiation therapy (U.S. Department of Health and Human Services, 1994). The use of heat directly over a tumor site is controversial. AHCPR guidelines recommend the heat may be used in patients with cancer (U.S. Department of Health and Human Services). However, ultrasound and diathermy are contraindicated over the cancer site (Lehmann & de Lateur, 1990).

Research evidence: No studies were found on the use of heat in hospice patients or the terminally ill. Only two studies were found on the use of heat in patients with cancer. A study conducted on the characteristics among hospitalized cancer patients demonstrated that 39% of patients found heat to be effective in relieving pain, 21% felt no effect, and 5% experienced an increase in pain (Donovan & Dillon, 1987). A similar study investigating the use of nonanalgesic methods of pain control used by cancer outpatients demonstrated that 74% of patients found heat to be effective in relieving pain and 38% felt no effect (Barbour, et al., 1986).

Exercise

<u>Definition</u>: Any type of activity, either active or passive movement, that helps to relieve pain by preserving or restoring the function of muscles, joints, ligaments, bones, and nerves (U.S. Department of Health and Human Services, 1994; Spross & Burke, 1995). Range-of-motion (ROM) exercises are used when mobility is limited.

<u>Indications for use</u>: Used for people with acute or chronic pain to help improve muscle strength, loosen stiff joints, improve coordination and balance, and provide cardiovascular conditioning (Vasudevan, et al., 1992). Active ROM can prevent thrombus formation and passive ROM exercise can be used in unconscious or neurologically impaired persons (Spross & Burke, 1995).

<u>Limitations and contraindications</u>: Passive ROM exercises should not be done if they increase pain (U.S. Department of Health and Human Services, 1994). Persons with acute pain should only do ROM exercises that are self-initiated (Lee, et al., 1990).

Research evidence: No studies were found on the use of exercise in hospice patients or the terminally ill. Only two studies were found on the use of exercise in patients with cancer. A study conducted on the characteristics among hospitalized cancer patients demonstrated that 14% of patients found exercise to be effective in relieving pain, 36% felt no effect, and 33% experienced an increase in pain (Donovan & Dillon, 1987). A similar study investigating the use of nonanalgesic methods of pain control used by cancer outpatients demonstrated that 34% of patients found exercise to be effective in relieving pain, 67% felt no effect, and no patients reported that exercise increased pain (Barbour, et al., 1986). ROM exercises were not specifically asked of these patients in either study.

Repositioning

<u>Definition</u>: Proper positioning and changing positions to maintain proper body alignment promotes comfort by improving circulation and relieving pressure areas (U.S. Department of Health and Human Services, 1994). Proper positioning of joints is putting the joint in an anatomical relaxed position that is comfortable to the patient (Spross & Burke, 1995).

Indications for use: Used for persons confined to the bed or chair or those who remain in the same position for extended periods of time because of pain or other symptoms (Spross & Burke, 1995). Pillows, wedge foam, or rolled towels are used to help support bones and relieve stress on joints. Repositioning should be done frequently and the skin inspected for evidence of breakdown (U.S. Department of Health and Human Services, 1994).

<u>Limitations and contraindications</u>: Caution with people who are at high risk for pathologic fractures (Spross & Burke, 1995). People with chronic illnesses and painful conditions tend to not want to change positions frequently because it increases pain (McCaffery & Wolff, 1992). If repositioning increases pain, analgesics should be given prior to repositioning.

Research Evidence: No studies were found on the use of repositioning in hospice patients or the terminally ill. Only two studies were found on the use of repositioning in patients with cancer. A study conducted on the characteristics among hospitalized cancer patients demonstrated that 56% of patients found position change or rest/lying down to be effective in relieving pain, 33% felt no effect, and 10% experienced increased pain (Donovan & Dillon, 1987). A similar study investigating the use of nonanalgesic methods of pain control used by cancer outpatients demonstrated that 85% of patients found position change or rest/lying down to be effective in relieving pain, 14% felt no effect, and 10% experienced an increase in pain (Barbour, et al., 1986).

Immobilization

<u>Definition</u>: Restricting the movement of a limb or portion of the body through the use of braces or orthotic devices to prevent pain. An example would be hugging a pillow to the chest to decrease rib movement when coughing.

<u>Indications for use</u>: Used to manage acute pain or to stabilize fractures, compromised bones and/or joints. Used in persons with bone metastasis to prevent fractures. An orthotic device such as a brace may be used to support the joint in proper alignment or relieve stress (U.S. Department of Health and Human Services, 1994; Brennan, 1993). Braces may help to maximize the function of weakened muscles and promote independence (Brennan).

<u>Limitations and contraindications</u>: Important to teach patients and families in the proper use of immobilization devices to prevent torsion with positioning (U.S. Department of Health and Human Services, 1994). "Prolonged immobilization should be avoided whenever possible to prevent joint contractures, muscle atrophy, cardiovascular deconditioning, and other untoward effects" (U.S. Department of Health and Human Services, p. 79).

Research evidence: No research evidence was found involving the use of immobilization in patients with cancer, terminal illness, or patients receiving hospice care. Most of the studies done investigate the effects of immobilization on low back pain caused from musculoskeletal problems. One such study investigated the use of different types of external immobilization in patients with lumbar burst fractures (Knight, Stornelli, Chan, Devanny, & Jackson, 1993). Results showed there was no significant difference in treatment outcomes between the non-operative and the operative group.

Table 7

Transcutaneous Electrical Nerve Stimulation (TENS)

<u>Definition</u>: A small battery-operated device that is applied to the skin to send controlled, low-voltage electrical impulses to nerve fibers in the muscle. The stimulation interrupts the way pain impulses are transmitted to the brain and may relieve pain (U.S. Department of Health and Human Services, 1994). A buzzing sensation may substitute the more uncomfortable pain (Spross & Burke, 1995).

Indications for use: Used in all kinds of musculoskeletal, arthogenic, neurogenic pains, and many kinds of cancer-related pains (Spross & Burke, 1995). Used best in patients who are alert enough to give feedback on its effectiveness and those with mild to moderate pain (Brennan, 1993). May be used proximal, distal, or contralateral to the pain site (McCaffery & Wolff, 1992). A full week trial is necessary to determine its effectiveness (Spross & Burke).

Limitations and contraindications: Absolutely contraindicated is the use of TENS with a demand-type pacemaker (Spross & Burke, 1995) and patients with arrhythmias (Brennan, 1993). Caution where electrodes are placed. They should not be placed on the eye, near the carotid sinus, or on the chest, neck, or head of patients with a history of coronary artery disease, strokes, or seizures (Spross & Burke). Electrode placement on the bony parts of the body may not be well tolerated. Therefore, cachectic patients may have limited sites (Spross & Burke). Local dermatitis from the electrodes is a possible side effect. Nonallergenic electrodes can then be used to minimize this potential side effect. TENS is usually ineffective in patients with severe pain or chemotherapy-induced peripheral neuropathy (Brennan).

Research evidence: A few studies were found on the effectiveness of TENS to provide pain relief in patients without cancer. However, no studies were found on its use with cancer pain, the terminally ill, or in hospice patients. Elliot and Foley (1989) found that TENS was no more effective than exercise in relieving chronic back pain. Librach and Rapson (1988) have used low-frequency/high intensity TENS along acupuncture meridians with positive results. Guieu, et al. (1991) found that TENS used by itself or with a vibration significantly relieved pain in patients with chronic pain compared to a control group. The control group had electrodes placed without any electrical current flowing. In addition, they found that the combination of TENS and vibration together alleviated pain in more patients than used alone and had a stronger and more long-lasting analgesic effect. Meyler, de Jongste, and Rolf (1994) found that TENS effectively relieved 53% of patients with pain caused by peripheral vascular disease, 75% of patients with anginal pain, and 69% of patients with musculoskeletal pain.

Acupuncture

<u>Definition</u>: The insertion of fine needles into specific sites along meridians in the body. The meridians are believed to be channels where life energy flows. Although not well understood, the needles help to reestablish a more balanced energy flow to promote health (Shuying, Zhiqiang, & Yu, 1995).

<u>Indications for use</u>: Used to treat all types of acute and chronic pain (Erickson, 1995), relieve secondary symptoms related to cancer, induce relaxation, and normalize immune indices in patients with myleosuppression (Boik, 1996).

<u>Limitations and contraindications</u>: Patients may initially have brief discomfort or anxiety with the insertion of needles.

Research evidence: The AHCPR guidelines recommend that when a patient seeks acupuncture treatment for palliative care that the physician should be notified (U.S. Department of Health and Human Services, 1994). They fear that the patient is seeking nontraditional treatments because of misconceptions or fears regarding current and available treatments. They make no other recommendations or state any contraindications for its use. This decision was based on inconclusive evidence on a meta-analysis of acupuncture studies with few controls (U.S. Department of Health and Human Services). However, a few studies on the use of acupuncture have been published since that time involving chronic pain and cancer pain. No studies were found on the use of acupuncture with persons receiving hospice care.

Erickson (1995) studied the effects of acupuncture in individuals with chronic pain. Results showed that 70% of the patients verbalized improvement in their pain with an average of six acupuncture treatments. There was also a reduction in the amount of pain medication needed.

Shuying, et al. (1995) studied the effects of acupuncture on cancerous abdominal pain. Data was collected over 4 years on a total of 92 patients with varying stages of hepatic, gastric, colon and abdominal cancer. All patients received the same type of acupuncture for pain and did not receive any analysesics. The average effective rate was 88%.

Table 9

Relaxation Exercises

<u>Definition</u>: Techniques such as focused-breathing, progressive muscle relaxation, and music therapy that relieve pain by promoting mental and physical relaxation. An example of a focused-breathing exercise is the use of slow rhythmic inhaling and exhaling while saying to one self, "with each exhalation, I feel more and more relaxed." Progressive muscle relaxation is done by alternating the tightening and then relaxing of each group of muscles in a systematic fashion. Music therapy may be passive (listening to music) or active (singing or playing a musical instrument) (Spross & Burke, 1995). They relieve pain through distraction and promote a sense of control over pain (U.S. Department of Health and Human Services, 1994; Passik & Breitbart, 1993).

Indications for use: These relaxation techniques are most effective when combined with meditation or pleasant imagery and when taught early in the course of illness while patients have enough energy to practice them (U.S. Department of Health and Human Services, 1994; Passik & Breitbart, 1993). These are used to relieve localized pain, anxiety, and muscle tension (Spross & Burke, 1995). They can also be effective when used prior to or during an activity or movement that causes pain (Spross & Burke). The type of music that relieves pain and anxiety is dependent on the person's background with music and personal preference. It is therefore important to let patients select their own music (Mornhinweg, 1992). Listening to music can be used in both conscious and unconscious persons to promote comfort (Shroeder-Sheker, 1994).

<u>Limitations and contraindications</u>: Breathing and muscle relaxation exercises and active music therapy require mental clarity to perform and thus have limited use in confused or unconscious persons (Passik & Breitbart, 1993). Although very rare, the physiologic responses to relaxation, such as, decreased heart rate and blood pressure, may cause hypotension or heart block in those with cardiovascular disease (Spross & Burke, 1995). Pre- and post-intervention vital sign check is recommended in those at risk (Spross & Burke). Those who are not accustomed to relaxing may get frustrated trying to relax and therefore become more aware of their pain (Spross & Burke). Persons with emphysema may have limited ability to use the breathing techniques (Spross & Burke). Some patients may not find these techniques acceptable (Breitbart, 1993).

Research evidence: Several studies investigated the use of relaxation techniques on anxiety, sleep, depression, and mood. Music therapy has shown to improve sleep in the elderly (Mornhinweg & Voignier, 1995), and improve depression, distress, self-esteem, and mood in depressed older adults (Hanser & Thompson, 1994). Although the results were not statistically significant, music therapy and music-videos showed a relaxation response and improved mood in patients who received these interventions after coronary artery bypass grafting surgery compared to a control group (Barnason, Zimmerman, & Nieveen, 1995). Progressive muscle relaxation has shown to significantly relieve state

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anxiety in cognitively intact, anxious elderly (Rankin, Gilner, Gfeller, & Katz, 1993; Scogin, Rickard, Keith, Wilson, & McElreath, 1992). A 12-week relaxation management course, which included muscle relaxation techniques and visualization, significantly decreased anxiety, improved depression, and improved overall well-being in patients with cardiac disease (Trzcieniecka-Green & Steptoe, 1994).

The following are studies conducted on the effects of relaxation techniques on pain and analgesic requirements. Relaxation techniques performed by patients prior to day surgery required significantly less time to induce anesthesia and required less anesthesia throughout the surgery compared to a control group (Markland & Hardy, 1993). Music therapy has shown to significantly decrease pain in women with rheumatoid arthritis (Schorr, 1993). Soothing music compared to stimulating music significantly raised pain thresholds in healthy volunteers (Whipple & Glynn, 1992).

No studies were found on the effects of relaxation techniques on pain in the terminally ill or hospice patients. The following are studies conducted on the effects of relaxation techniques in patients with cancer pain. Graffman and Johnson (1987) compared the effectiveness of relaxation, guided imagery, or no treatment, and found a statistically significant reduction in pain and distress between treatment and control groups. In addition, no difference in effectiveness was found between relaxation or imagery. Sloman (1995) studied 67 patients with advanced cancer who used deep breathing, muscle relaxation, or imagery compared to no treatment and found all three relaxation techniques were effective in relieving pain and decreased need for analgesics.

Table 10

Meditation and Imagery

<u>Definition:</u> Meditation is deep, focused, and reflective thought. Meditation is based on Eastern beliefs that stress is caused from the minds constant activity and that the mind can be calmed when it is rested through meditation (Boik, 1996). A calmed mind allows for self-reflection and can help a person gain a better understanding of life (Boik). Imagery is using one's imagination to visualize pleasant images or visualize a change in the pain experience while in a relaxed state (Breitbart, 1993). For example, one could visualize pain leaving the body like leaves floating down a stream. They relieve pain through distraction and promote a sense of control over pain (U.S. Department of Health and Human Services, 1994; Passik & Breitbart, 1993).

Indications for use: These relaxation techniques are most helpful when combined with breathing or muscle relaxation exercise and when taught early in the course of illness while patients have enough energy to practice them (U.S. Department of Health and Human Services; Passik & Breitbart, 1993). Used in patients with any type of cancer pain, depression, anxiety, anger, or sleep disturbances (Spross & Burke, 1995). Imagery is especially effective prior to and during an activity that is known to cause pain and/or anxiety (Spross & Burke).

<u>Limitations and contraindications</u>: These require mental clarity to perform and thus have limited use in confused or unconscious persons (Passik & Breitbart, 1993). Occasionally, patients may feel depressed after using imagery or meditation because they may have been unhappy with an event in their life or have regrets and these may surface during meditation. However, this may give them an opportunity to help work through unresolved issues and develop a better sense of well-being (Spross & Burke, 1995).

Research evidence: The following are studies conducted on the effects of imagery on anxiety or depression in patients without cancer. Thompson and Coppens (1994) studied the effects of relaxation tapes and guided imagery with patients undergoing magnetic resonance imaging (MRI). They found that clients who listened to guided imagery/relaxation tapes prior to, and during the MRI, expressed significantly less anxiety and moved less while in the MRI compared to the control group. Another study found relaxation and guided imagery effective in relieving anxiety and depression, and improving self-esteem in primiparas during the initial part of in their postpartum period (Rees, 1995).

One study investigated the effects of imagery on pain in patients without cancer. Imagery practiced preoperatively by patients undergoing abdominal surgery experienced less pain, required fewer analgesics, and coped better in the postoperative period as compared to the control group (Manyande, et al., 1995).

No studies were found on their effectiveness in the terminally ill or patients receiving

Continued

hospice care. Only two studies were found investigating the effects of imagery or meditation on pain in patients with cancer. Mears (1980) treated 73 advanced cancer patients with at least 20 sessions of meditation. Nearly all patients experienced a significant reduction in anxiety, depression, and pain. Sloman (1995) studied 67 cancer patients who used deep breathing, muscle relaxation, or imagery compared to no treatment and found all three relaxation techniques were effective in relieving pain and need for analgesics.

Table 11

Distraction and Reframing

<u>Definition</u>: Distraction is a technique that takes the attention away from the pain by focusing on something else (McCaffery & Beebe, 1989). Distraction can be either internal (e.g., counting sheep), or external (e.g., watching television or talking to others). Reframing is a way to actively control negative feelings or thoughts with positive ones (U.S. Department of Health and Human Services, 1994). For example, saying to one self, "I am strong. I have coped with this pain before, I can cope with this again". These techniques relieve pain through distraction and by promoting a sense of control over pain (U.S. Department of Health and Human Services; Passik & Breitbart, 1993).

Indications for use: Used alone for mild pain or with other psychosocial or physical techniques prior to and/or during an activity that in known to cause pain (U.S. Department of Health and Human Services, 1994). These techniques should be taught and practiced early in the course of illness while patients have enough energy (U.S. Department of Health and Human Services; Passik & Breitbart, 1993). Used in patients with any type of cancer pain, depression, anxiety, anger, or sleep disturbances (Spross & Burke, 1995).

<u>Limitations and contraindications</u>: These require mental clarity to perform and thus have limited use in confused or unconscious persons (Passik & Breitbart, 1993).

Research evidence: One study has shown the effects of distraction on anxiety in cancer patients receiving chemotherapy. It compared the effects of distraction (i.e., playing video games), progressive muscle relaxation and imagery, and no intervention (Vasterling, Jenkins, Tope, & Burish, 1993). Results showed that distraction was as effective as progressive muscle relaxation and imagery in relieving nausea and blood pressure. Both groups were significantly different from the control group. Another study showed that acceptance, positive reframing, and use of religion were the most common coping strategies used by women with newly diagnosed breast cancer (Carver, et al., 1993).

One study investigated the use of distraction in chronic pain. Eccleston (1995) demonstrated in his study with patients experiencing chronic pain that distraction is more effective in relieving mild pain than compared to patients with high levels of pain.

No studies were found on its effectiveness in terminally ill patients or those receiving hospice care. Two studies investigating the effectiveness of distraction on pain in patients with cancer. One investigated the characteristics among hospitalized cancer patients, and demonstrated that 30% of patients found distraction to be effective in relieving pain, 60% experienced no effect, and 6% experienced an increase in pain (Donovan & Dillon, 1987). A similar study investigating the use of nonanalgesic methods of pain control used by cancer outpatients demonstrated that 88% of patients found distraction to be effective in relieving pain and no patients reported that distraction had increased pain (Barbour, et al., 1986).

Therapeutic Touch

<u>Definition</u>: A method of using the hands to direct human energy to help relieve pain. The hands do not have to touch the skin. A person trained in the technique uses conscious intention to relieve pain during the treatment (Krieger, 1993).

<u>Indications for use</u>: Used to relieve any type of anxiety or pain (acute, chronic, nonmalignant, and malignant). Used to promote relaxation and accelerate normal healing processes (Krieger, 1993).

<u>Limitations and contraindications</u>: This technique requires skilled training.

Research evidence: General studies on the use of therapeutic touch in patients without cancer have been done. They have shown therapeutic touch to facilitate personal growth (Samarel, 1992), decrease anxiety in the institutionalized elderly (Simington & Laing, 1993), and decrease anxiety in psychiatric patients (Gagne & Toye, 1994).

A couple of studies have investigated the use of therapeutic touch on decreasing anxiety. One study investigated the effects of therapeutic touch on anxiety in low- and high-anxiety caregiver/student groups and controls (Olson & Sneed, 1995). Although the small sample size prevented the results from being statistically significant, the high-anxiety group had a greater reduction in anxiety compared to the control group. Kramer (1990) compared casual touch to therapeutic touch in relieving stress in hospitalized children. Stress reduction was measured through skin temperature, heart rate, and galvanic skin response on a biofeedback instrument. Results showed that therapeutic touch was significantly different than casual touch in relieving stress.

No studies on the use of therapeutic touch and hospice patients or cancer. Only two studies were found on the use of therapeutic touch and pain management. Keller and Bzdek (1986) investigated the effects of therapeutic touch on tension headache. Results demonstrated that 90% of the subjects who received therapeutic touch experienced a reduction in their headaches, and the relief lasted twice as long as the control group. Meehan (1993) compared therapeutic touch and to a placebo control in relieving postoperative pain. No significant decrease was found.

Table 13

Pastoral or Spiritual Assistance

<u>Definition</u>: Providing counseling, pastoral care, and guidance are examples of pastoral or spiritual assistance. Pastoral counseling is provided by a pastor. Spiritual counseling is counseling around a particular spiritual issue or set of issues. Pastoral care is the kind presence of someone in a caring, pastoral mode who may or may not be pastor. Spiritual guidance is helping patients and families in areas such as how to pray. All of these techniques can be used for patients and families experiencing spiritual distress or those searching for the meaning of their pain or disease (U.S. Department of Health and Human Services, 1994; Spross & Burke, 1995). Supportive care can be provided in such areas as values, relationships, or transcendence (Taylor & Ersek, 1995).

<u>Indications for use</u>: Used with any type of patient, especially those who show signs of suffering or who are at risk for suffering, such as those expressing loss of control, hopelessness, dependency, or fear of abandonment (Spross, 1993).

<u>Limitations and contraindications</u>: Some patients may feel uncomfortable discussing end of life or spiritual issues. This intervention is most effective when a therapeutic relationship has already been established.

Research evidence: A couple of studies about the importance of religion as a coping strategy were found. One study showed that 44% of newly diagnosed cancer patients found support in religion (Ginsburg, Quirt, Ginsburg, & MacKillop, 1995). Another study showed that acceptance, positive reframing, and use of religion were the most common coping strategies used by women with newly diagnosed breast cancer (Carver, et al., 1993). Kaczorowski (1989) found a consistent inverse relationship between spiritual wellbeing and state-trait anxiety in patients with cancer regardless of gender, age, marital status, group participation, and length of time since diagnosis.

Two studies investigating the connection between pain and spiritual support were found. A case report of a woman with terminal cancer and severe pain reported that her pain was relieved after discussing spiritual concerns with a pastoral care worker (MacDonald, Sandmaier, & Fainsinger, 1993). Granstrom (1987) investigated the relationship between loneliness, spiritual well-being, and Buberian religiosity among cancer patients and found an inverse relationship between religiosity and frequency of pain. In addition, she found an inverse relationship between spiritual well-being and frequency of pain.

One study looked at the spiritual component that hospice care providers provide and found that both clergy and non-clergy professionals are helpful to patients with spiritual concerns (Millison & Dudley, 1992).

Summary of the Literature

Research studies reveal that physical and psychosocial techniques are used frequently for relieving pain in individuals who do not have cancer. There is little research done on their use in the treatment of terminal cancer pain and even less research on their use with hospice patients and families. The literature contains conflicting evidence on their therapeutic value. However, many of the subjects used in the studies did not have terminal cancer. Although not abundant, studies that support the therapeutic value of these 13 modalities in patients with cancer are favorable. However, very little research has been done on the use of these techniques and their effectiveness to relieve pain in the last stages of terminal cancer.

Only two research studies were found that investigated why nurses used some techniques more often than others to help relieve pain of cancer patients (Donovan & Dillon, 1987; Turk & Feldman, 1992). They found that barriers existed to using some of these techniques, such as they were either not effective or increased pain or that the nurse did not have the time to use them. As a nurse in hospice, I have experienced these and other difficulties to using these techniques and wonder if other staff members also have difficulties. Do barriers differ for each technique? Are their other barriers that exist that I do not experience? If barriers are identified and measured, then it might be possible to modify them and support the use of the most effective techniques.

Research questions. This study provided descriptive data on the use of 13 physical and psychosocial techniques to relieve pain in terminally ill patients with cancer. The following questions were explored from the perspectives of bereaved caregivers and hospice staff: (1) To what extent are the techniques used? (2) What is their perceived

effectiveness in relieving pain? (3) What are the barriers to using them? (4) Do caregivers and hospice staff differ in their mean ratings of perceived effectiveness of these modalities in relieving pain?

In addition to the 4 research questions, other contextual factors related to staff members' use of these techniques were investigated. From personal experience, I tend to use techniques with patients that I have used myself and have found to be effective in relieving pain. I also use these techniques for other reasons, such as for relieving stress and promoting health. My personal use of these techniques certainly impacts what techniques I use with hospice patients. However, this is only one perspective. Therefore, this study investigated what techniques hospice staff used personally to relieve their own pain and if they used any of these techniques for other reasons. It also investigated if their personal experience made a difference in their using or not using these techniques with hospice patients.

Chapter III

Method

Design

This was an exploratory descriptive study using a survey design. Although the original design was to send surveys developed by the investigator to a sample of bereaved caregivers and a sample of hospice staff members, the study reported here includes only hospice staff members. The survey asked about their knowledge and opinions in using 13 techniques to relieve pain in terminally ill patients with cancer.

The pretest sample of caregivers using this survey was conducted in November and December of 1996. The response rate for the caregivers was 7% and too small to give the results any statistical power. Although other methods could have been designed to improve the response rate, due to time constraints it was decided not to investigate the perspectives of bereaved caregivers. Therefore, the original research question comparing the mean effectiveness of the techniques as perceived by caregivers and hospice staff members was deleted. Only the perspective of the hospice staff members was investigated. Setting and Sample

The setting for this study was Kaiser Permanente's Continuing Care Services in Portland, Oregon. This agency provides both home health and hospice services to Kaiser Permanente members in the Portland, Oregon and Vancouver, Washington metropolitan areas. This study focused on the responses from hospice program staff which include both employees and volunteers. Kaiser Permanente's Hospice Program has been in operation for over 12 years and has a varied enrollment of 50 to 110 hospice patients at any given point in time. Alan Bauck, Kaiser Permanente's Hospice Program Assistant, estimated that

70% of the patients receiving hospice services from Kaiser Permanente have a diagnosis of cancer (personal communication, May 6, 1996).

Kaiser Permanente's Hospice Program was chosen as the setting of this study for three reasons. First, it is the second largest hospice program in the Portland and Vancouver metropolitan area. Second, the nurse investigator has been providing hospice care for over 3 years in this agency. Furthermore, the idea for the study was suggested by the clinical manager of the program and had agency support.

Survey data were obtained from Kaiser Permanente's Hospice Program employees and volunteers. The inclusion criteria were that hospice staff must provide direct care and that they belong to one of the following disciplines: nursing, social work, home health aide, pastoral care counselor, physical therapy, occupational therapy, speech therapy, and volunteer services. In addition, they were not part of the pretest sample. There were 62 hospice employees and 70 volunteers who met this criteria. Office support staff were not included. A random sample of 20 hospice volunteers was drawn from among 70 volunteers who provide direct care to Kaiser Permanente hospice patients.

The entire accessible population of employees who met the inclusion criteria were chosen because individual practices differ between each discipline. Staff members come from different backgrounds and training. Although they collaborate and work together as a team, much of the care provided directly to the patient is done individually in their homes. In addition, staff spend different amounts of time with hospice patients and it would have been difficult to get a representative sample from the employee group. A sample of volunteers was chosen to relieve cost and because a representative sample could be obtained.

Sixty-two surveys were distributed to hospice employees and 42 were completed and returned for a response rate of 68%. Twenty surveys were mailed to volunteers and 5 were completed and returned for a response rate of 25%. Overall response rate of 47 completed surveys out of 82 distributed was 57%. Because the volunteer response rate was inadequate to give a representative sample, only the hospice staff employee data were analyzed statistically.

The 42 employees came from the following 7 disciplines: (a) registered nurses (56%), (b) physical therapists (15%), (c) home health aides (10%), (d) occupational therapists (7%), (e) medical social workers (5%), (f) speech therapists (5%), and (e) pastoral care counselors (2%). One employee did not specify what role he or she served. The majority of the subjects (62%) worked 20 to 39 hours per week and about one-third (35%) worked 40 hours per week. Because employees care for both home health and hospice patients, the percentage of hospice patients to whom they provide care for was asked. One-third (32%) of employees reported 40 to 59% of their patients were hospice patients, about one-fifth (22%) reported 20 to 39% of their patients were hospice patients, and one-third (34%) reported 0 to 19% of their patients were hospice patients. Only a small percentage (12%) of the employees reported that the majority (greater than 60%) of their patients were hospice patients.

Instruments

A 32-page survey was used to collect data on the use and effectiveness of 13 physical and psychosocial techniques to relieve cancer pain and on the barriers to using them (see Appendix A). The instrument was developed by the investigator because there was not one already in existence. Content validity with respect to the nonpharmacologic

noninvasive techniques selected was based on the AHCPR guidelines that recommend the use of these techniques in cancer pain management (U.S. Department of Health and Human Services, 1994). The exception to this was the use of therapeutic touch, which was not mentioned in these guidelines. However, the investigator knew at least one nurse in Kaiser Permanente's Hospice Program who uses therapeutic touch and teaches caregivers how to use it. The AHCPR guidelines were developed based on an expert panel's discussion and review of relevant research findings (U.S. Department of Health and Human Services). In addition, experts in the field of hospice and caregivers were consulted on the relevance of the questions. Findings from the pretest were used to revise questions before it was distributed to the actual sample.

Hospice staff member survey. The survey asked the same three questions about each of the 13 techniques. The first question asked how often they use the technique with hospice patients with cancer and were given five options to chose from. The next question asked the respondent to recall the last three hospice patients with cancer for whom the technique was used and to rate how effective it was in relieving pain on a 0-4 scale, with 0 being "not effective" and 4 being "very effective." The third question asked what barriers have made it difficult to use the technique to relieve pain in hospice patients with cancer. A list of nine potential barriers and an space to write-in a barrier was given for the respondent to chose from. Two questions asked hospice staff members if they had used any of the techniques personally to help relieve pain or if they had used them for any other reasons. On the final page, staff members were asked if their personal experience with any of these techniques made a difference in their using or not using them with the person receiving hospice care. Demographics, such as what role they serve in hospice, the amount

of time they spend in this role per week, and the percentage of hospice patients provide care for on the average was also collected. A written survey was chosen to collect data from this sample because it was the least expensive and time-consuming way to gather information from as many staff as possible.

Procedure

The proposal for this study was sent to Oregon Health Sciences University (OHSU) and Kaiser Permanente's Institutional Review Boards to obtain permission to conduct the study in relation to protecting human subjects. The proposal was determined exempt by OHSU. Permission was granted from Kaiser Permanente's Human Subjects committee. A Kaiser Permanente sponsor assisted with this procedure. Several discussions with the administrator and managers at Kaiser Permanente's Continuing Care Services were done to arrange a time to distribute the survey. Office support was utilized in printing and stapling of the surveys.

The pretest. Both surveys (the bereaved caregiver and the hospice staff member) were pretested prior to collecting data on the actual population. In November, 1996, 16 caregivers were selected from a total of 51 patients who died in May, 1996. This was 6 months after the patient had died. The 16 were selected based on the following criteria:

(a) the deceased patient had a diagnosis of cancer, (b) the patient received hospice services for at least 14 days, and (c) the patient's care was not managed by the investigator. Those that were excluded were 15 patients who did not have a diagnosis of cancer, 19 patients who received hospice care for less than 14 days, and one patient who was managed by the investigator. The administrator for Kaiser Permanente's Continuing Care Services sent 16 letters to bereaved caregivers asking them if they would like a survey to be sent to them

(see Appendix B). Of these 16 caregivers, 6 people responded and one was returned to the investigator due to an incorrect address. Of these 6 people who responded, 3 people said they would like a survey sent to them. The other 3 people did not want to participate. The surveys and pretest cover letters from the investigator were mailed and follow-up postcards were sent 10 days later (see Appendix B and C). Of the 3 surveys that were mailed to willing subjects, only 1 survey was completed and returned. As stated earlier, the response rate of 7% was inadequate and therefore this part of the study was eliminated.

The pretest was also done with a sample of 7 hospice employees and 2 volunteers in December, 1996. A representative from each of the employed disciplines received the survey and cover letters. Six were completed and returned for a response rate of 86%.

Two volunteers were selected at random and received the survey and cover letters through the mail. One survey was completed for a response rate of 50% for the volunteers. The pretest subjects were excluded from the actual project sample.

In January, 1997, after the pretest and survey revision, the investigator and clinical supervisor distributed surveys to hospice employees in a staff meeting. Two cover letters were given with the survey (see Appendix D). One was from the investigator describing the purpose of the study and their rights as participants. The other cover letter was from the agency administrator stating her support for the study and requesting their participation to help improve patient pain management. They were informed that participation was completely voluntary and by completing the survey, they were consenting to participate. There was not a separate consent form. Although they were asked not to put their name on the survey, complete anonymity could not be guaranteed.

All responses were kept confidential. Subjects placed their completed surveys in a box provided in the mailroom. Staff members who were absent from the staff meeting were known because a sign-in sheet was passed around at each meeting. Those who did not attend received a survey and cover letters in their office mailbox with instructions to return the completed survey to the established box. All disciplines who met the inclusion criteria received a survey and had three weeks to complete it. Hospice employees received two voice mail messages from the investigator during those 3 weeks requesting their participation.

Administering the survey in a semisupervised group setting was believed to be the best way to achieve the highest response rate. Surveys put into mailboxes without verbal instructions or stated purpose had produced low response rates in the past. Volunteers received the same survey and cover letters in the mail during the same week in January with instructions to mail the completed survey in the postage-paid return envelope. A follow-up postcard (see Appendix C) was sent 10 days after the initial mailing.

Data Management and Analysis

Prior to data collection, two files were set up to enter the qualitative and quantitative data. The primary investigator entered the qualitative data into a FileMaker Pro (1992) database and the quantitative data into Version 6.1 of SPSS (Norusis, M.J./SPSS Inc., 1994) database. All data were verified by a second person for accuracy. All surveys and names of volunteers and staff were kept in a locked file when not in use.

Most data were nominal and ordinal. Descriptive statistics, such as means, percentages, and standard deviations were calculated to address the research questions. Each technique's frequency of use and mean effectiveness was calculated. In addition, the

percentage of hospice staff who identified various barriers to using each technique were calculated. SPSS (Norusis, M.J./SPSS Inc.) was used to analyze the results of the quantitative data and further. Additional calculations, such as standard deviations and tests were done by the investigator. FileMaker Pro (1992) was used to organize the narrative data.

Chapter IV

Results

The findings from this study are presented in the following format. First, the employee quantitative and qualitative data are described in the order of the research questions, then, a summary of the volunteer data is given.

To What Extent are the Physical and Psychosocial Techniques Used by Hospice Employees?

Hospice employees most commonly used repositioning (100% of staff), relaxation exercises (87%), heat (78%), and pastoral or spiritual assistance (74%) to relieve pain in hospice patients with cancer (see Table 14 and Figure 1). The least used techniques were acupuncture (28%) and therapeutic touch (20%). Repositioning was the only technique that the majority (67%) of hospice staff used with all or nearly all of the hospice patients with cancer they provide care for.

How Effective are These Techniques in Relieving Pain as Perceived by Hospice Employees?

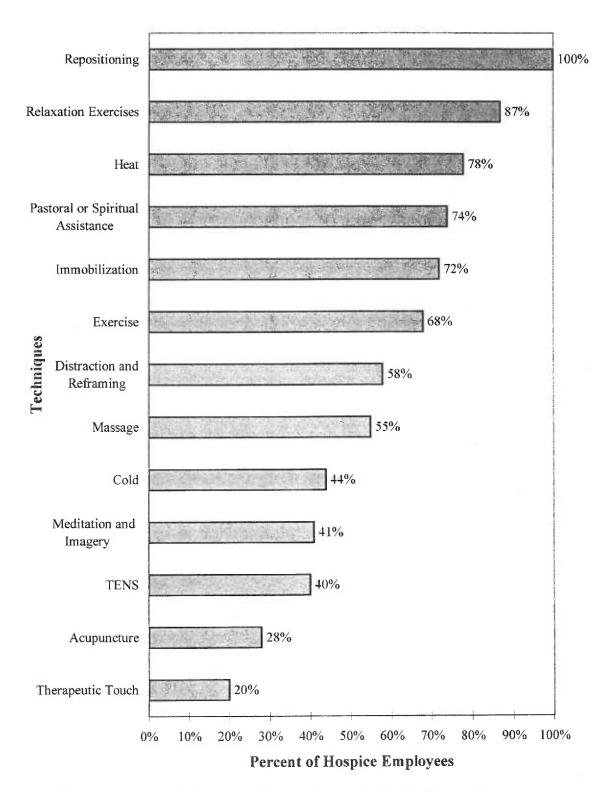
The three techniques rated by hospice employees as most effective in relieving pain in hospice patients with cancer were pastoral or spiritual assistance (\underline{M} =2.82, \underline{SD} =0.90), repositioning (\underline{M} =2.64, \underline{SD} =0.89), and therapeutic touch (\underline{M} =2.50, \underline{SD} =0.59) (see Table 15). These three mean scores fall between "somewhat effective" (2) and "quite a bit effective" (3). Of the subjects who rated these techniques, at least 92% reported that each of these three techniques was at least somewhat effective with hospice patients. The techniques rated least effective were acupuncture (\underline{M} =1.55, \underline{SD} =1.21) and TENS (\underline{M} =1.23, \underline{SD} =1.00).

Table 14

<u>Use of Techniques by Hospice Employees with Hospice Patients with Cancer</u>

	Usag Hos Emple	pice		Extent	of Use	
Тесһпіque	Never Used	Used	With only a few patients (1-24%)	With some patients (25-49%)	With many patients (50-74%)	With all or nearly all patients (75-100%)
Repositioning	0%	100%	13%	5%	15%	67%
Relaxation Exercises	13%	87%	32%	24%	21%	10%
Heat	22%	78%	44%	25%	7%	2%
Pastoral or Spiritual Assistance	26%	74%	11%	19%	26%	18%
Immobilization	28%	72%	55%	10%	5%	2%
Exercise	32%	68%	28%	20%	15%	5%
Distraction and Reframing	42%	58%	29%	20%	7%	2%
Massage	45%	55%	37%	15%	0%	3%
Cold	56%	44%	32%	7%	2%	3%
Meditation and Imagery	59%	41%	25%	8%	3%	5%
TENS	60%	40%	35%	5%	0%	0%
Acupuncture	72%	28%	23%	5%	0%	0%
Therapeutic Touch	80%	20%	13%	2%	3%	2%

Note. Techniques listed in order of usage, from most to least used.



<u>Note.</u> Acupuncture is 'suggested' rather than used. Meditation and imagery, distraction and reframing, and relaxation exercises may have been 'used or taught' to patients.

<u>Figure 1</u>. Percent of hospice employees who reported using each technique to help relieve pain in hospice patients with cancer.

Table 15
Effectiveness Ratings of Techniques Used with Hospice Patients with Cancer

				%	of Staff	Giving	Each R	ating
Тесһпіquе	Total # Patients Technique Used With	Mean Effective- ness	SD	Not Effective	Effective a Little	Somewhat Effective	Quite a Bit Effective	Very Effective
Pastoral or Spiritual Assistance	74	2.82	0.90	0	8	26	42	24
Repositioning	111	2.64	0.89	1	7	37	37	18
Therapeutic Touch	18	2.50	0.59	0	0	38	56	6
Relaxation Exercises	76	2.22	0.81	1	18	44	30	7
Heat	75	2.11	0.85	3	17	52	23	5
Distraction and Reframing	40	2.08	0.57	0	12	68	20	0
Immobilization	59	2.02	0.94	5	25	34	34	2
Exercise	64	1.97	0.94	6	23	41	27	3
Massage	55	1.91	0.91	7	22	45	24	2
Meditation and Imagery	35	1.89	0.99	6	31	37	20	6
Cold	34	1.82	0.83	3	32	47	15	3
Acupuncture	11	1.55	1.21	27	19	27	27	0
TENS	40	1.23	1.00	28	32	32	5	3

 $\underline{\text{Note.}} \ \ \text{Techniques listed in order of mean effectiveness. Possible range of effectiveness was 0 to 4.}$

The mean effectiveness ratings were compared between all pairs of techniques using a 2-tailed t-test. An alpha of .01 was chosen for the following reasons: (a) to control in part for Type I error with a large number of comparisons, but also (b) to allow for detection of differences in the first study of this kind. About one-third of the techniques were significantly more effective than the other techniques (see Table 16). Specifically, pastoral or spiritual assistance was rated as significantly more effective than 10 of the other 12 techniques (i.e., all but repositioning, therapeutic touch). Repositioning was rated as significantly more effective than 9 of the other 12 techniques (i.e., all but pastoral or spiritual counseling, therapeutic touch, acupuncture). Finally, 11 of 12 techniques were rated as significantly more effective than TENS (i.e., all but acupuncture). However, statistically significant differences may not have been identified because sample sizes were quite small for TENS, meditation and imagery, cold, therapeutic touch, and acupuncture.

In the narrative data, 6 out of 42 subjects said it was difficult to assess the effectiveness of pastoral or spiritual assistance and 2 of these 6 employees reported it was difficult to differentiate between emotional, physical, and spiritual pain. Despite this difficulty in assessing the effectiveness, pastoral or spiritual assistance was found to be the most effective technique in relieving pain in hospice patients with cancer. In addition to the 13 techniques they were asked to rate, 3 of 42 employees emphasized the importance of music and touching the patient, such as "holding hand or stroking hair," as effective techniques.

Table 16

Student's t Values and Statistical Significance for All Pair-wise Comparisons of Mean Effectiveness Between Techniques

	Pastoral or Spiritual Assistance	Repositioning	Therapeutic Touch	Relaxation Exercises	Heat	Distraction and Reframing	Immobilization	Exercise	Massage	Meditation and Imagery	Cold	Acupuncture
Repositioning	1.34											
Therapeutic Touch	1.84	98.0										
Relaxation Exercises	3.58*	3,35*	1.68									
Heat	4.95*	4.10*	2.29	0.82								
Distraction and Reframing	5.36*	4.54*	2.54	80.1	0.23							
Immobilization	4.97*	4.17*	2.59	1.30	0.57	0.40						
Exercise	5.40*	4.63*	2.91*	1.67	0.92	0.74	0:30					
Massage	\$.69*	4.84*	3.18*	2.02	1.27	1.12	0.63	0.35				
Meditation and Imagery	4.71*	4.00*	2.81	1.73	1.14	1.00	0.63	0.39	0.10			
Cold	5.66*	4.96*	3.42*	2.35	1.68	1.54	1.10	0.81	0.48	0.32		
Acupuncture	3.35*	2.91	2.44	1.78	1.48	1.41	1.22	1.01	0.94	0.85	69.0	
TENS	8.39*	7.87*	6.03*	5.40*	4.73*	4.67*	3.95*	3.75*	3.40*	2.87*	2.77*	0.81
		-	-									

 \overline{Note} . * significant values at p< .01. Techniques listed in order of mean effectiveness from most (top/left) to least (bottom/right)

What Barriers do Hospice Employees have to Using The Physical and Psychosocial Techniques?

Hospice employees indicated different barriers that made it difficult to use these techniques with hospice patients with cancer. On average, the four greatest barriers to using these techniques were: (1) staff member's lack of training (\underline{M} =35 % of staff), (2) patient's or caregiver's lack of interest (\underline{M} =28%), (3) staff member's lack of time (\underline{M} =28%), and (4) patient's or caregiver's lack of understanding on how to use technique (\underline{M} =27%) (see Table 17). On average, the three smallest barriers to using these techniques were that they were not effective (\underline{M} =12%), it was not part of the staff member's job to use them (\underline{M} =10%), and there was no order to use the techniques (\underline{M} =9%). The percent of hospice employees who indicated barriers made it difficult to use each of the techniques are represented in graphs (see Figures 2 through 14).

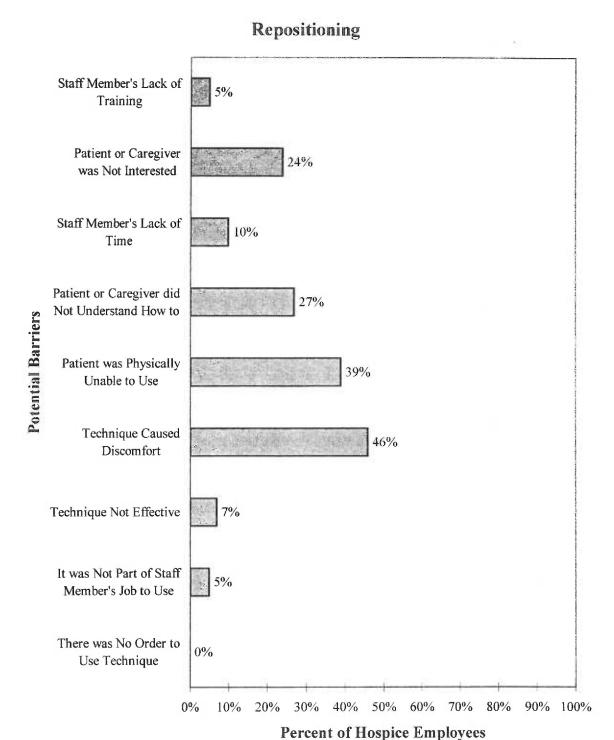
Subjects gave narrative descriptions of other barriers to using the 13 techniques. A barrier 6 out of 42 employees identified was the lack of caregiver follow through after being taught the technique. Another barrier 3 out of 42 employees identified was the patient's mental status, such as being too anxious to use some of the techniques. Three out of 42 employees reported the cost to use the technique was a barrier specific to acupuncture because the patient could not afford it and Kaiser Permanente was not willing to pay for it.

Four employees expressed that some of these techniques were not accepted or valued by the agency or hospice patients. One reported a "perceived resistance from the agency" with respect to acupuncture and another reported the time required to use massage was not valued by the agency. One employee described these techniques as not

Table 17

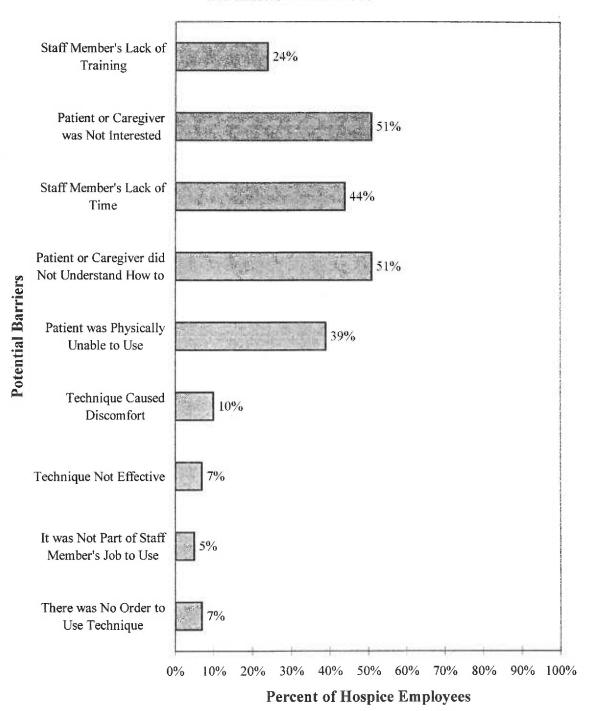
				Patient or					
Technique	Staff Member's Lack of Training	Patient or Caregiver was Not Interested	Staff Member's Lack of Time	Caregiver did Patient was Not Physically Understand Unable to U How to Use Technique Technique	Patient was Physically Unable to Use Technique	Technique Caused Discomfort	Technique Not Effective	It was Not Part of Staff Member's Job to Use Technique	There was No Order to Use Technique
Repositioning	5%	24%	10%	27%	39%	46%	%2	2%	%0
Relaxation Exercises	24%	51%	44%	51%	39%	10%	42	2%	%/
Heat	29%	17%	30%	22%	19%	15%	2%	10%	12%
Pastoral or Spiritual Assistance	29%	36%	17%	10%	%2	10%	%9	%2	2%
Immobilization	17%	20%	10%	27%	27%	15%	10%	2%	7%
Exercise	32%	37%	32%	39%	49%	54%	12%	17%	15%
Distraction and Reframing	32%	37%	24%	32%	22%	2%	19%	2%	2%
Massage	37%	20%	63%	27%	32%	22%	%2	20%	17%
Cold	37%	24%	78%	14%	20%	34%	17%	12%	15%
Meditation and Imagery	44%	32%	39%	34%	22%	2%	17%	10%	2%
TENS	\$6%	27%	19%	37%	27%	20%	34%	19%	15%
Acupuncture	26%	27%	19%	22%	12%	%2	%2	10%	17%
Therapeutic Touch	29%	19%	32%	10%	%/	10%	10%	4.2	7%
Mean	35.2%	28.5%	28.3%	27.1%	24.8%	19.5%	12.1%	10.2%	9.5%

Note. Techniques listed in order of usage, from most (top) to least (bottom) use. Barriers are listed from greatest % (left) to smallest % (right) based on the mean.

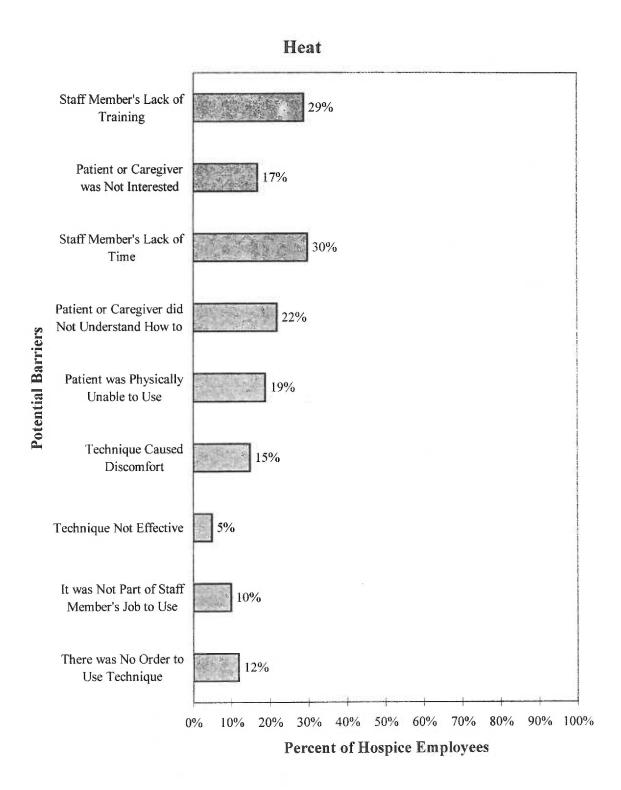


<u>Figure 2</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use repositioning to relieve pain in hospice patients with cancer.

Relaxation Exercises

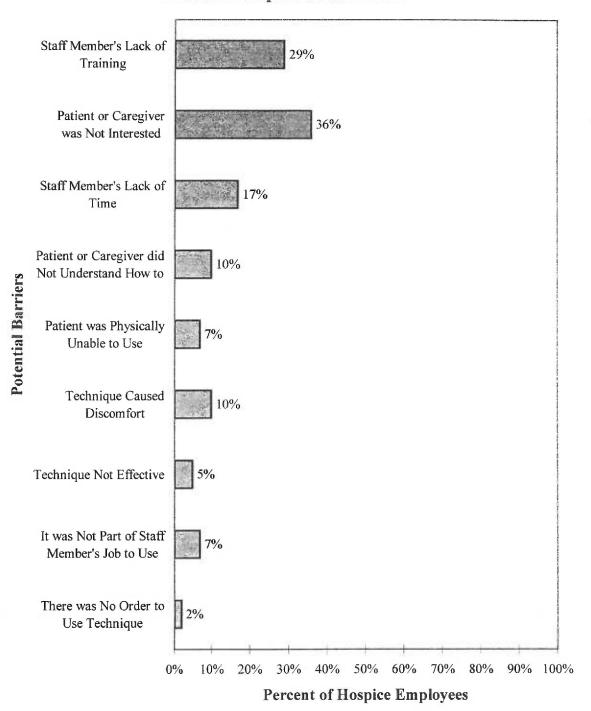


<u>Figure 3</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use or teach relaxation exercises to relieve pain in hospice patients with cancer.



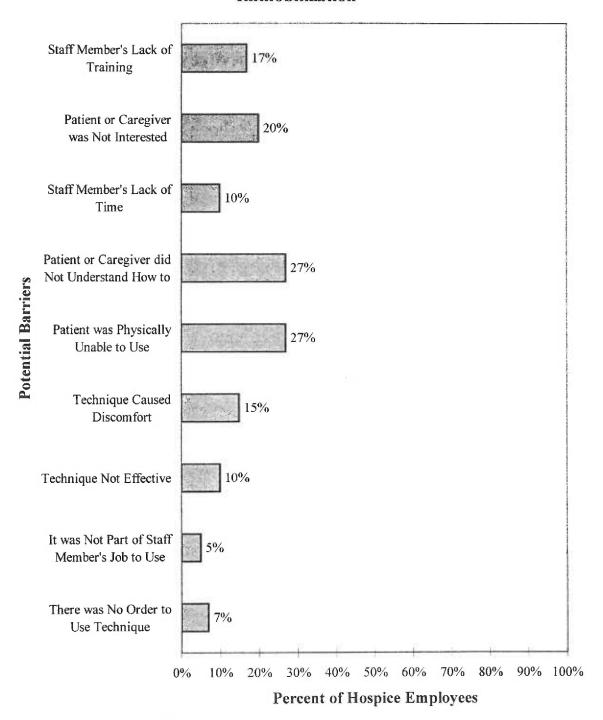
<u>Figure 4</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use heat to relieve pain in hospice patients with cancer.

Pastoral or Spiritual Assistance

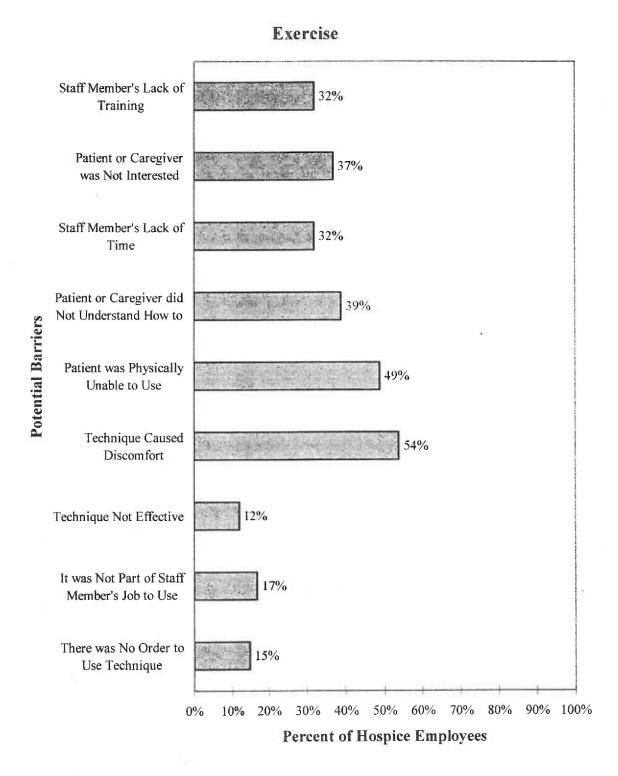


<u>Figure 5</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use pastoral or spiritual assistance to relieve pain in hospice patients with cancer.

Immobilization



<u>Figure 6</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use immobilization to relieve pain in hospice patients with cancer.

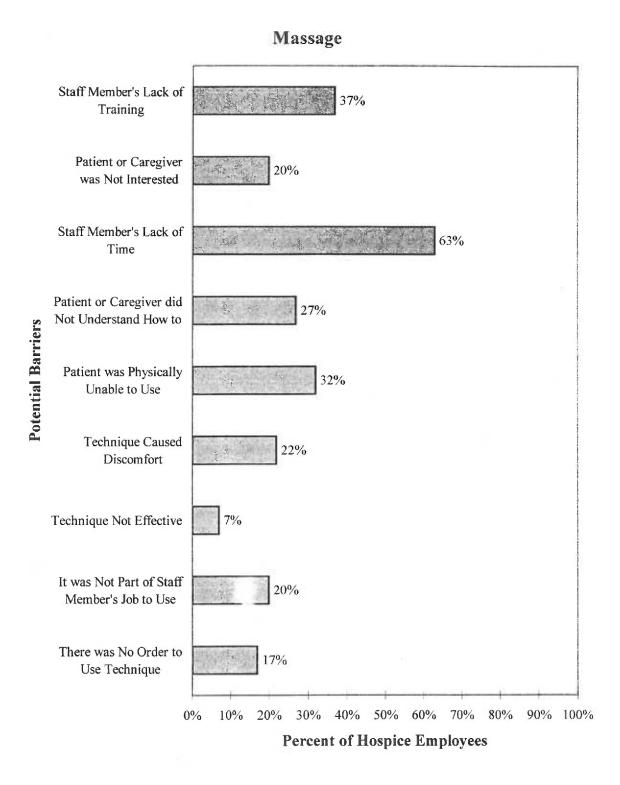


<u>Figure 7</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use exercise to relieve pain in hospice patients with cancer.

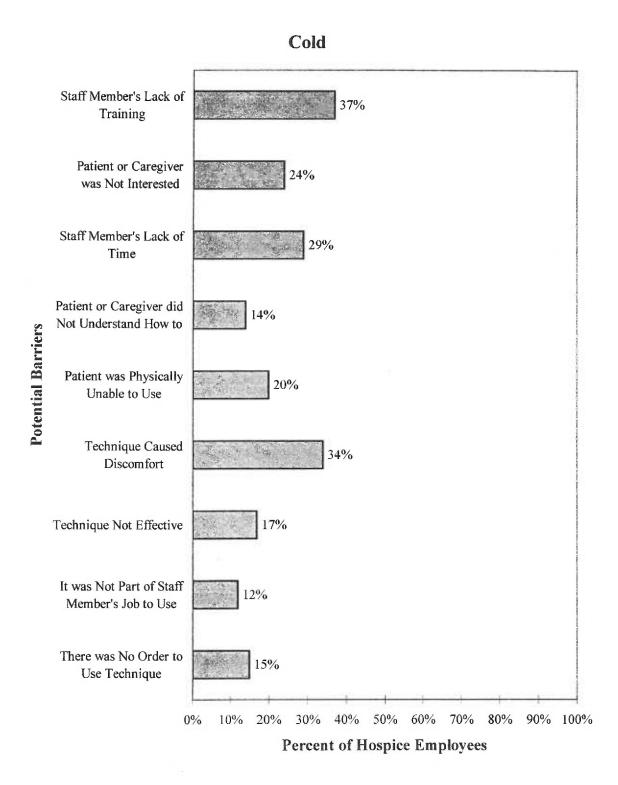
Distraction and Reframing Staff Member's Lack of Training Patient or Caregiver was Not Interested Staff Member's Lack of 24% Time Patient or Caregiver did 32% Not Understand How to Potential Barriers Patient was Physically 22% Unable to Use Technique Caused Discomfort 19% Technique Not Effective It was Not Part of Staff Member's Job to Use There was No Order to 5% Use Technique 40% 50% 60% 70% 80% 90% 100% 30% 0% 10% 20%

<u>Figure 8</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use or teach distraction and reframing to relieve pain in hospice patients with cancer.

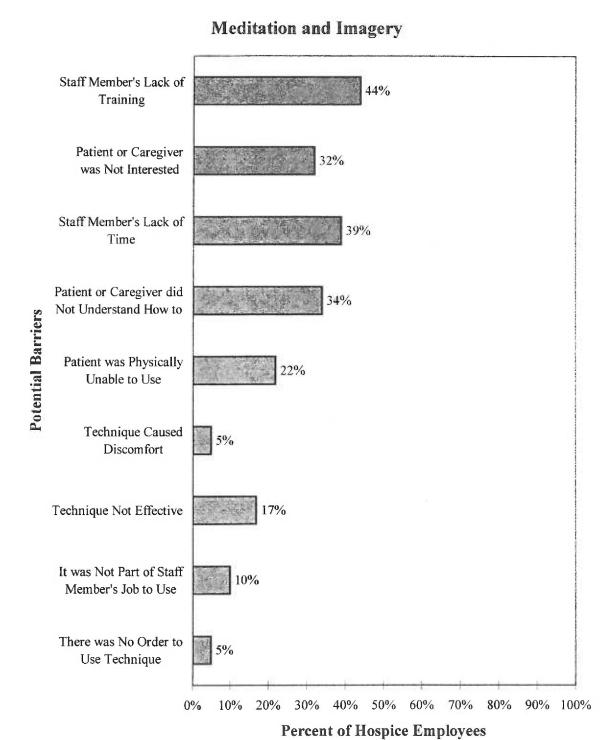
Percent of Hospice Employees



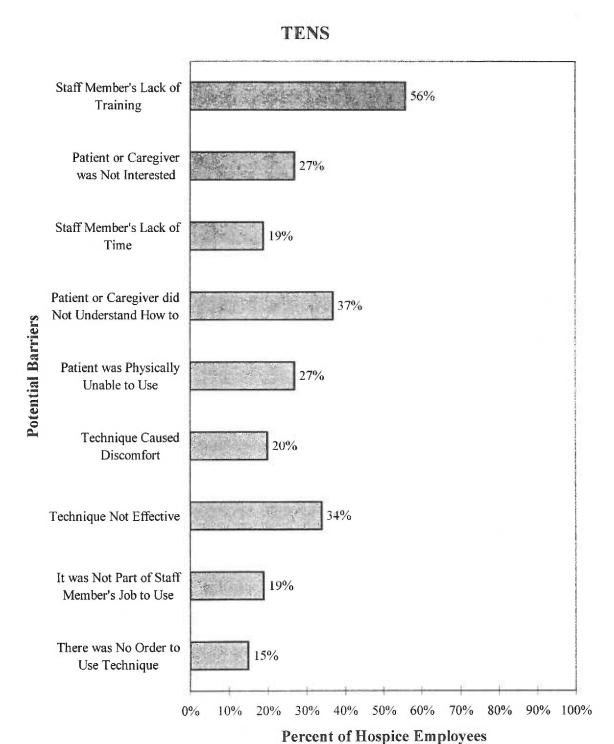
<u>Figure 9</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use massage to relieve pain in hospice patients with cancer.



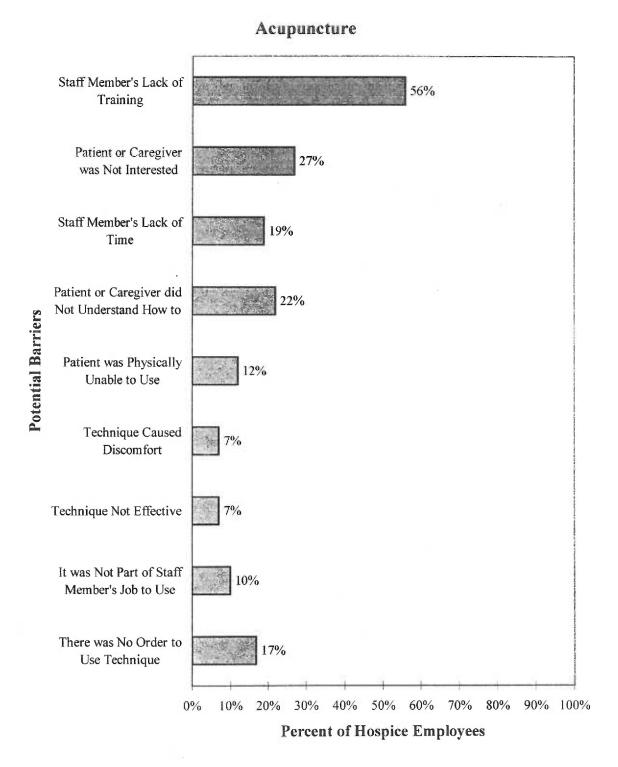
<u>Figure 10</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use cold to relieve pain in hospice patients with cancer.



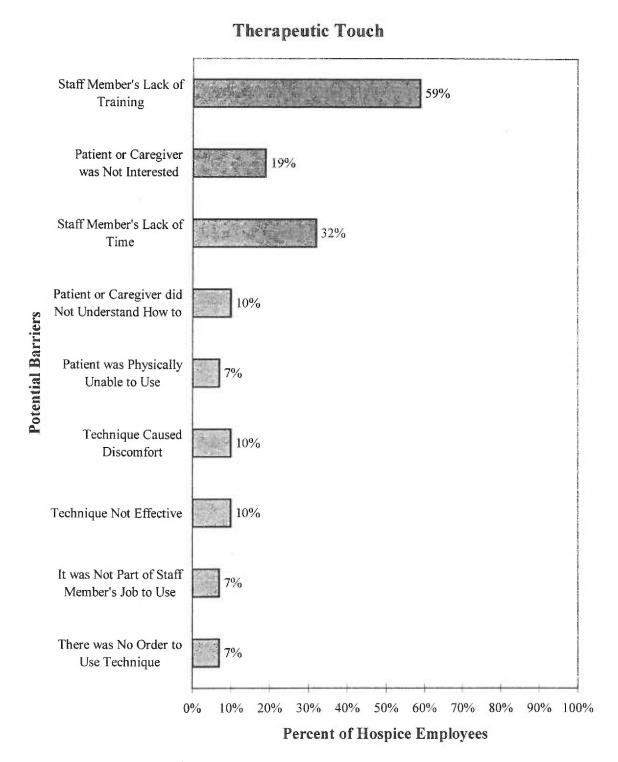
<u>Figure 11</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use or teach meditation and imagery to relieve pain in hospice patients with cancer.



<u>Figure 12</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use tens to relieve pain in hospice patients with cancer.



<u>Figure 13.</u> Percent of hospice employees who indicated these potential barriers made it difficult to suggest acupuncture to relieve pain in hospice patients with cancer.



<u>Figure 14</u>. Percent of hospice employees who indicated these potential barriers made it difficult to use therapeutic touch to relieve pain in hospice patients with cancer.

being valued by traditional medicine or nursing and another employee wished the techniques were more generally accepted by the hospice population.

What Techniques Do Hospice Employees Personally Use?

All hospice employees who participated had used at least one of the 13 physical and psychosocial techniques personally to relieve their own pain (see Table 18). Nearly all had used heat (95%), massage (93%), and repositioning (90%) to relieve their own pain.

The least used techniques were acupuncture (17%) and TENS (12%).

The majority of employees (71%) had also used at least one of the 13 techniques personally for other reasons besides pain. These most commonly were relaxation exercises (69%), distraction and reframing (65%), exercise (52%), and pastoral or spiritual assistance (52%). The two most common themes for using these techniques for other reasons included: (1) to promote relaxation, and relieve stress, tension, and anxiety (12 out of 42 employees), and (2) to promote physical, mental, and spiritual health and personal growth (9 out of 42 employees).

The majority of subjects (73%) reported that their personal experience with using these techniques made a difference in their using or not using them with hospice patients. Almost one-half of the subjects (18 out of 42 employees) reported that knowing the technique was effective made them more likely to encourage and support the use of the technique with hospice patients. Eleven out of 42 employees who responded commented on how supportive they were of the techniques, by stating things like, "wish I knew more about them," "I strongly support it. The major barrier to using these techniques is lack of training and time," "any of these techniques have much potential with further training and time permitted," and "we [occupational therapy] would like to be more involved but never

Table 18

<u>Techniques Personally Used by Hospice Employees</u>

Technique	% Who Used Technique for Pain	% Who Used Technique for Other Reasons
Heat	95%	10%
Massage	93%	45%
Repositioning	90%	10%
Exercise	83%	52%
Cold	81%	10%
Relaxation Exercises	78%	69%
Meditation and Imagery	66%	65%
Immobilization	66%	10%
Distraction and Reframing	61%	31%
Pastoral or Spiritual Assistance	56%	52%
Therapeutic Touch	42%	35%
Acupuncture	17%	14%
TENS	12%	3%

Note. Techniques used for pain listed in descending order.

[get] referred by disciplines." Another theme 3 of the 42 subjects shared was the idea that the effectiveness of the techniques is largely dependent on how accepting the patient is of the technique. The more they believe in it, the more empowered and control they feel in being able to manage their pain. For example, one subject wrote, "depends on patients acceptance of the technique. If I'm informed and give a concrete rationale, then [there is] improved success and compliance [with patients and families]."

Volunteer Surveys

A total of 5 out of 20 surveys to volunteers were returned. Only 3 of the 5 surveys were at least 25% completed. Four out of the 5 subjects volunteer less than 10 hours per week. The other subject volunteers as assigned. All except one volunteer primarily (80 to 100%) care for hospice patients.

Three volunteers had used repositioning with hospice patients and its mean effectiveness was 2.11 (somewhat effective). Distraction and reframing were used by 2 volunteers but its effectiveness was not ranked. Immobilization, exercise, cold, and massage, meditation, and pastoral or spiritual assistance were used with a few to some hospice patients (1 to 49%) by only one volunteer. Questions regarding the use of the remaining techniques--heat, TENS, acupuncture, relaxation exercises, and therapeutic touch--were either not used or not answered. Four out of 5 volunteers had used at least one technique personally to relieve their own pain. Massage, cold, heat, exercise, relaxation exercises, and mediation and imagery were used by 3 of the 4 volunteers for their own pain control. Meditation and imagery and exercise were the most commonly (3 out of 4) used techniques for other reasons. They used these techniques to relieve tension, promote relaxation, and to feel more physically and spiritually healthy. Two of the

volunteers expressed a desire to learn more about the techniques and would be willing to be trained in order to use these techniques with hospice patients.

The poor response rate from the volunteers and the lack of completeness of the surveys that were received may be a reflection of the volunteer role. As reported by Kilian Kuntz, Kaiser Permanente's Hospice Volunteer Coordinator, volunteers are not specifically trained in these techniques and are only supposed to provide care that is requested by the nurse. If they are not specifically requested to perform these interventions, they will not do them out of fear of stepping outside of their role as a volunteer (personal communication, October 16, 1996).

Chapter V

Discussion

The results of this exploratory study regarding the use of physical and psychosocial techniques by hospice staff members to relieve terminal cancer pain in hospice patients are characterized by several key findings. First, repositioning, relaxation exercises, heat, and pastoral or spiritual assistance are the most commonly used techniques by hospice employees. These 4 techniques were also among the 5 most effective techniques to relieve pain. Second, therapeutic touch was ranked the third most effective technique, but the least used technique by hospice employees. Third, the most common barriers to using the techniques were staff member's lack of training and time and the patient's or caregiver's lack of interest and understanding. Fourth, all hospice employees had used at least one of the techniques personally. The two techniques most commonly used by staff for themselves (i.e., repositioning, heat) were also used with hospice patients. The following discussion addresses the meaning of these findings and presents possible explanations.

Technique Usage in Relation to Its Effectiveness

There are a couple of reasons why repositioning was ranked the most used and the second most effective technique. First, repositioning required the least amount of training and time to use compared to any of the other techniques. In addition, it is a technique that any discipline could use. Second, most (90%) of the staff had used it personally to relieve their own pain and were therefore familiar with its effectiveness.

Pastoral or spiritual assistance was ranked the most effective technique and the fourth most commonly used technique. All pain can have a multidimensional experience. Terminal pain may have a greater spiritual domain than with other types of pain. This

might explain why it was considered the most effective since none of the other techniques specifically addresses the spiritual aspect of pain. Kaiser Permanente's Hospice Program has a full-time pastoral care counselor specifically trained to provide assistance in the spiritual domain. Hospice patients are automatically offered this assistance. If a nurse sees a patient having spiritual issues, a referral to the pastoral counselor can be easily done. Staff member's lack of time and training would not be as big of a barrier since there is someone specifically trained to provide this service. Another explanation for its effectiveness could be the physical presence of someone with the patient showing compassion and caring. This explanation is supported by Super and Plutko (1996), who express that dying patients and families want compassion and caring, not technological interventions and procedures. This might also explain why acupuncture or TENS were not utilized or found very effective.

Several possible reasons could explain why therapeutic touch was the third most effective technique but the least used technique. First, it requires specialized training.

Among all the techniques, lack of training was the greatest barrier for therapeutic touch.

Lack of staff member's time was the other significant barrier to using therapeutic touch.

Second, all the other barriers were relatively small. Therapeutic touch does not require the patient to be alert or to participate which is required with some of the other techniques. It also does not cause discomfort like some of the other techniques (repositioning, exercise, cold) since it does not require the hands touching the skin. Third, therapeutic touch is reported to have 3 major effects: reduce anxiety, relieve pain, and promote healing (Keller & Bzdek, 1986). Therapeutic touch effectiveness may be based on its influence on both pain and anxiety. Another explanation for its effectiveness could be the physical presence

of someone showing compassion and caring for the patient as was the situation with pastoral counseling. It was the third least commonly used by hospice staff personally. The less experienced staff are in using the technique themselves, the less likely they will use it with hospice patients. In addition, it is possible that some subjects rated the effectiveness of actually touching hospice patients, such as holding hands or stroking hair, and skewed the results in relation to therapeutic touch.

Therapeutic touch is an example of energy healing has been gaining more popularity. The person trained in the technique uses their intention to relieve pain. The patient does not have to believe it will work, the practitioner using therapeutic touch does (Keller & Bzdek, 1986). It is based on Roger's theory of unitary man where all persons are made up of complex energy fields that coexist with the environment. They are constantly interacting with each other. The therapist using therapeutic touch acts as a conduit to bring environmental energy to the recipient so that it can help with healing, pain relief, and anxiety (Keller & Bzdek).

Relaxation exercises were the second most used technique and the fourth most effective technique. A possible explanation for this is in the evidence that anxiety contributes to the pain experience. Relaxation exercises was the most common technique that hospice staff identified that they personally use for other reasons besides pain. The reasons given were to promote relaxation, and relieve stress, tension, and anxiety and to promote physical, mental, and spiritual health. Hospice patients also have anxiety and tension that adds to their perception of pain. The effectiveness of relaxation exercises is likely based on their ability to relieve the emotional aspect of the pain experience. The gate theory for pain can be described in terms of how anxiety opens the spinal gate and

increases sensitivity to pain, whereas relaxation closes the spinal gate and reduces the sensitivity to pain (Warner, 1992). Another explanation for its effectiveness could be that relaxation exercises gives the patient some feelings of control over the pain experience.

Barriers to Using the Techniques

The greatest barriers to using the techniques in general were staff member's lack of training and time and the patient's or caregiver's lack of interest and understanding. There is no specialized training of these techniques for any discipline in Kaiser Permanente's Hospice Program. Using these techniques with hospice patients with cancer is considered relatively new and staff are not expected to know how to use them or refer patients to them. The only special hospice training nurses receive in pain management is in the use of medications. Hospice staff have different educational experiences and background training. Although some staff may have learned how to use these techniques in the past, they were likely trained to use them in the management of other types of pain, not necessarily cancer pain. The lack of training is understandably a major barrier to using these techniques since they are not part of standardized care for hospice patients with cancer.

Hospice staff member's lack of time to use these techniques may be a reflection of the complexity of hospice care and health care restraints. Hospice patients with cancer frequently have multiple problems, such as breathing difficulties, bowel and bladder control, weakness, or confusion. Pain is just one of the problems that hospice team members try to manage. Since hospice staff primarily use pharmacological measures to control pain, they may think this problem has been at least initially addressed, and then move on to help with the other important problems. Even if hospice staff want to use the

techniques, they have a limited amount of time to see each patient. As with any business, competition demands productivity. Turk and Feldman (1992) had found similar findings regarding the limited amount of time that nurses had to teach patients how to use nonpharmacologic techniques.

The barriers of the patient or caregiver not being interested in the technique or not understanding how to use the techniques could be explained in a couple of ways. First, many of these techniques are not part of traditional medicine or nursing and have just gained recognition in the last 10 to 15 years. Many patients and caregivers may be skeptical about their effectiveness. Second, they may be too overwhelmed with learning other new things, such as medication management, to learn anything more. Turk and Feldman (1992) also found nurses did not want to overwhelm patients and families with new information. Third, many of the hospice patients with cancer are older than 65 years of age and frequently their spouse, who is likely to be at a similar age, is caring for them. Some elderly patients' and caregivers' ability to learn new things may be hampered by their cognitive skills, physical agility, and stress of the disease. This may explain the inability to understand how to use some of the techniques in some elders.

Hospice Employees Personal Use of Techniques Impacts Their Use With Hospice Patients

There is a similarity in the personal use of the techniques and the use of the techniques with hospice patients. Nearly all hospice staff used heat, massage, and repositioning personally and very few staff used therapeutic touch, acupuncture, and TENS. Except for massage, this is similar to the frequency of usage with hospice patients. Staff member's lack of time was the greatest barrier to using massage compared to any other technique. Therefore, it is likely that the use of these techniques with hospice

patients is dependent on the staff's familiarity and experiences with using the techniques personally. The lack of personal experience with therapeutic touch, TENS, and acupuncture could explain why these were the least utilized with hospice patients.

Attitudes and beliefs about these 13 techniques could also explain the effectiveness and use of these techniques by hospice staff, patients, and caregivers. Besides a pharmacological approach to pain control with hospice patients with cancer, the only other standardized care approach is to offer pastoral or spiritual assistance to every hospice patient. There is someone hired in the agency just for this purpose. It is an accepted component of hospice care. The other techniques are not part of standardized care for hospice patients with cancer. Some are considered non-traditional therapies. A few employees pointed out that they perceived a resistance from the agency or lack of support for these techniques. The amount of support that the agency gives these techniques may influence how patients and caregivers react when these techniques are offered to them.

Limitations and Suggestions for Further Research

Attitudes and Belief Systems

Several limitations existed for this study. The sample came from a program where staff care for both home health and hospice patients. If the sample had come from staff who cared only for hospice patients, the results may have been different. Hospice programs differ in their training of staff and have different productivity requirements, also influencing the results. If other programs include hired acupuncturists or massage therapists as part of their hospice staff, this could also affect the techniques' usage and effectiveness. These findings can be generalized to hospice patients with cancer only.

Another study done with patients with cancer, but who were not terminally ill may yield different results.

A larger hospice staff sample size would have increased the number of patients who used these techniques so that differences in a technique's effectiveness may have reached a statistically significant level. The usefulness of the data from the volunteers is limited because the sample size was too small to be representative. It would have also been advantageous to have the perspective of bereaved caregivers on the use of these techniques. It would be helpful to know what they think the most effective techniques are because they are with the patient 24 hours a day. Investigating their beliefs in the techniques would also be useful. Would patients and caregivers be more likely to use them if they have had prior experience with them?

It is unclear why the bereaved caregivers did not want to participate in the pretest. It is possible they wanted to put their hospice experience in the past and move on with their life. Completing a survey about how they cared for their family member or friend might have brought back painful memories that they did not want to relive. Another study with a different research design and sampling method might improve the caregiver response rate.

One idea for future research would be to assess the techniques' effectiveness with hospice patients with cancer who are not using them and use the technique as an intervention and rate the pain before and after. Using a control group would also be desirable. The concept of belief and acceptance of a technique on its use and effectiveness is also an area that needs further exploration. The placebo effect is present with medications, could it be part of these techniques too? Many more studies are needed to

assess the various techniques' effectiveness with cancer pain since very little research has been done in this area. Scientific evidence that documents the effectiveness of techniques could change people's attitudes and lead to the techniques being accepted as standard care.

Implications for Nursing

The most direct application of these findings relates to the training of hospice staff in those techniques rated as most effective. If staff were trained in noninvasive techniques, especially the ones rated most effective, they could be utilized more. If training was offered by the hospice agency it would demonstrate that the agency valued these techniques. In addition to training, expanding hospice staff job descriptions to include the use of these physical and psychosocial techniques would clarify to staff that it was appropriate to use them. Actively discussing these interventions within interdisciplinary team meetings to clarify roles to use these techniques with individual patients would also increase their use. An agency endorsement would support staff to feel more at liberty to use them. If the agency could not provide training, then staff should seek out their own training in these techniques.

The second implication is to further demonstrate the usefulness of these techniques so that their importance is valued. If they were valued more, possibly more time could be permitted to use them. Hiring someone skilled in these techniques to see patients in their home or training volunteers would also be an efficient and cost-effective way to accomplish this goal so that time would not be taken from current paid staff. Nurses when making requests of volunteer services should specifically request the use of physical and

psychosocial techniques to be performed by volunteers as their training permits and per patient preference.

More referrals to occupational therapy are needed. One occupational therapist expressed that the use of these techniques is appropriate for their discipline and their service is underutilized. Informing staff on the roles of other disciplines might improve referral rates. Finally, hospice staff, especially nurses, are encouraged to use and support these techniques with patients and families. They have very few side effects and can augment medications in pain control. If patients and caregivers see hospice staff accepting of them, they might also.

The major contribution of this study to nursing is in the support that pain is a multidimensional experience that requires a multidimensional approach. It was not until recently that the relationship between pain and other physical, psychological, and spiritual aspects of the illness had been considered in the pain management plan. Providing holistic care is a challenge in a competitive health care system. This study supports the importance of using physical, spiritual, and psychosocial techniques to address the physical, spiritual, and emotional aspects of pain. Although this study focuses on terminal cancer pain, it is important for nurses to consider the many facets of pain when caring for anyone with pain.

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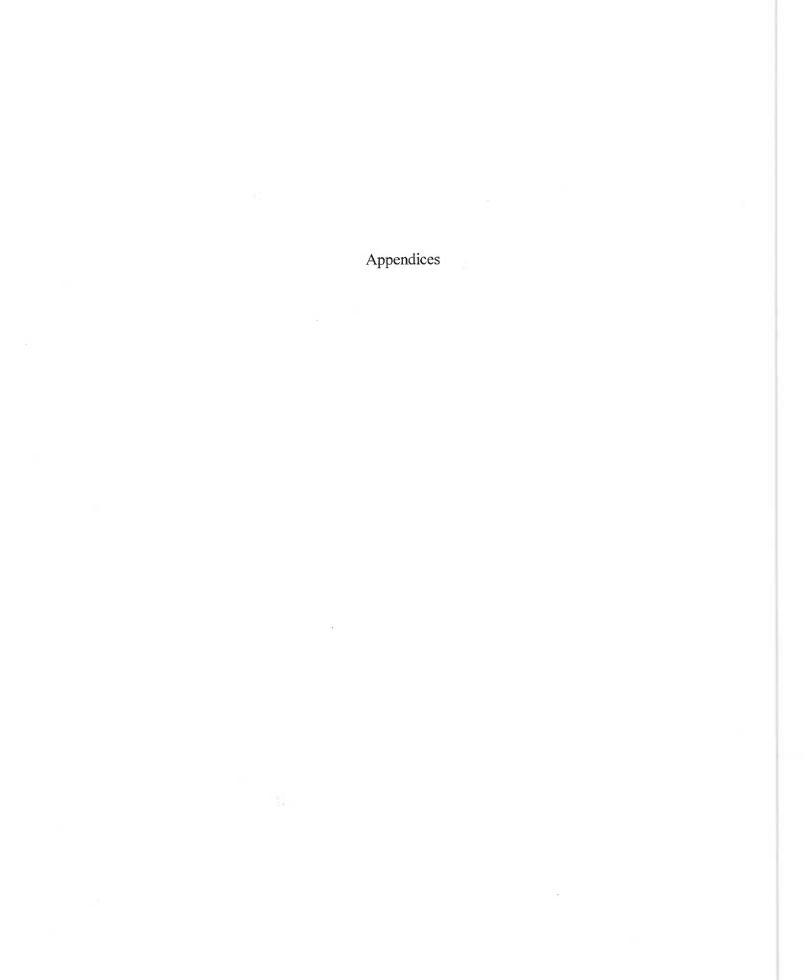
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Appendix A

Survey Instrument

The Use of Physical and Psychosocial

Techniques to Relieve Terminal Cancer Pain:

The Hospice Staff Member's Perspective

Purpose

These questions are designed for people who provide care to hospice patients and their families. Your answers will help us to learn about the use of physical and psychosocial techniques that are used along with medications to help relieve terminal cancer pain. Very little research evidence exists on the use and effectiveness of these techniques in patients with terminal cancer because they are not part of standard practice. They are more commonly used for other types of pain. However, all of you come from different backgrounds and training and have different experiences using these techniques with hospice patients with cancer. The questions ask your opinions because you are the experts in helping people control their pain.

This project is supported by Kaiser Permanente's Continuing Care Services. Findings will provide recommendations for future support of techniques that hospice staff members believe are effective in relieving pain.

Directions

Please assist us by answering the following questions. Your participation is completely voluntary and all your responses are confidential. Please do not put your name on this questionnaire.

You will be asked the same questions about 13 techniques that may have been used to relieve pain in hospice patients with cancer. Answer the questions as honestly as you can; there are no right or wrong answers. Even if you skip some sections, we would appreciate whatever information you can provide.

It should take you about 15 minutes to answer the questions.

When you are done with the questionnaire, please return it to the box in the department's mailroom. If you have received this questionnaire in the mail, please return it in the enclosed stamped envelope.

Thank you for your time and consideration.

1.	What is your role with Kaiser Permanente Continuing Care Services? Check ONE only. [] REGISTERED NURSE [] HOME HEALTH AIDE [] MEDICAL SOCIAL WORKER [] PHYSICAL THERAPIST [] OCCUPATIONAL THERAPIST [] SPEECH THERAPIST [] PASTORAL CARE COUNSELOR [] VOLUNTEER [] OTHER (specify)
2.	As an employee or volunteer with Kaiser Permanente Continuing Care Services, how much do you work or volunteer? [] 40 HOURS PER WEEK [] 20 - 39 HOURS PER WEEK [] 10 - 19 HOURS PER WEEK [] LESS THAN 10 HOURS PER WEEK [] OTHER (specify)
3.	On the average, about what percent of patients to whom you provide care are hospice patients? []

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MASSAGE

*Definition: Massage is a technique of using slow, rhythmic, stroking, kneading, and/or rubbing motions on the skin with lotion or oil to increase circulation to the skin and soft tissues. Pressure or vibration may be used with massage or by themselves. Pressure may be applied over specific sensitive spots. Vibration may be applied manually or mechanically to the skin. An example of massage is a foot or back massage.

When you provide care to hospice patients with cancer, how often do you use MASSAGE to relieve pain?

- [] WITH ALL OR NEARLY ALL PATIENTS (75-100%)
- [] WITH MANY PATIENTS (50-74%)
- [] WITH SOME PATIENTS (25-49%)
- [] WITH ONLY A FEW PATIENTS (1-24%)
- [] I NEVER USE MASSAGE

Think of your <u>last 3 hospice patients with cancer</u> for whom MASSAGE was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective MASSAGE was in relieving pain. Please **CIRCLE** ONE number for each patient.

HOW EFFECTIVE WAS MASSAGE IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	I	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	I	2	3	4

BARRIERS TO MASSAGE

What barriers have made it difficult to use MASSAGE to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Massage	Not a barrier	A barrier	Not applicable
1. MY LACK OF TRAINING	[]	1 1	[]
2. MY LACK OF TIME	[]	[1	[]
3. MASSAGE WAS NOT EFFECTIVE	[]	1 1	1.1
EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. MASSAGE CAUSED DISCOMFORT	[]	1 1	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE MASSAGE	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE MASSAGE	[]	1 1	[]
8. THERE WAS NOT AN ORDER TO USE MASSAGE	[]	[]	1 1
9. IT WAS NOT PART OF MY JOB TO USE MASSAGE	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

COLD

*Definition: Cold can be applied to the skin through the use of ice packs, towels soaked in ice water, or commercially prepared gel packs. An example of using cold is putting ice packs on the lower back.

When you provide care to hospice patients with cancer, how often do you use COLD to relieve pain?

- [] WITH ALL OR NEARLY ALL PATIENTS (75-100%)
- [] WITH MANY PATIENTS (50-74%)
- [] WITH SOME PATIENTS (25-49%)
- [] WITH ONLY A FEW PATIENTS (1-24%)
- [] I NEVER USE COLD

Think of your <u>last 3 hospice patients with cancer</u> for whom COLD was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective COLD was in relieving pain. Please <u>CIRCLE</u> ONE number for each patient.

HOW EFFECTIVE WAS COLD IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	Ĩ	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO COLD

What barriers have made it difficult to use COLD to relieve pain in patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Cold	Not a barrier	A barrier	Not applicable
MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. COLD WAS NOT EFFECTIVE	[]	[]	[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. COLD CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE COLD	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE COLD	[]	[]	[]
8. THERE WAS NOT AN ORDER TO USE COLD	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO USE COLD	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

HEAT

*Definition: Heat is applied to the skin through the use of hot water bottles, hot and moist compresses, electrical heating pads, commercially prepared chemical gel packs, menthol preparations, or immersion in hot water. An example of using heat is a warm foot soak.

When you provide care to hospice patients with cancer, how often do you use HEAT to relieve pain?

- [] WITH ALL OR NEARLY ALL PATIENTS (75-100%)
- [] WITH MANY PATIENTS (50-74%)
- [] WITH SOME PATIENTS (25-49%)
- [] WITH ONLY A FEW PATIENTS (1-24%)
- [] I NEVER USE HEAT

Think of your <u>last 3 hospice patients with cancer</u> for whom HEAT was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective HEAT was in relieving pain. Please <u>CIRCLE</u> ONE number for each patient.

HOW EFFECTIVE WAS HEAT IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	1	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO HEAT

What barriers have made it difficult to use HEAT to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Heat	Not a barrier	A barrier	Not applicable
1. MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. HEAT WAS NOT EFFECTIVE	[]		[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. HEAT CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE HEAT	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE HEAT	[]	[]	[]
8. THERE WAS NOT AN ORDER TO USE HEAT	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO USE HEAT	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

EXERCISE

*Definition: Any type of activity or movement, either done alone, or with someone else's assistance. The activity helps to preserve muscles and joints. Walking is an example of exercise or assisted range-of-motion exercises when unable to walk.

When you provide care to hospice patients with cancer, how often do you use EXERCISE to relieve pain?

WITH ALL OR NEARLY ALL PATIENTS (75-100%)
WITH MANY PATIENTS (50-74%)
WITH SOME PATIENTS (25-49%)
WITH ONLY A FEW PATIENTS (1-24%)
I NEVER USE EXERCISE

Think of your <u>last 3 hospice patients with cancer</u> for whom EXERCISE was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective EXERCISE was in relieving pain. Please CIRCLE ONE number for each patient.

HOW EFFECTIVE WAS EXERCISE IN RELIEVING PAIN?

		Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient	#1	0	1	2	3	4
Patient	#2	0	1	2	3	4
Patient	#3	0	1.	2	3	4

BARRIERS TO EXERCISE

What barriers have made it difficult to use EXERCISE to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Exercise	Not a barrier	A barrier	Not applicable
1. MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. EXERCISE WAS NOT EFFECTIVE	[]	[]	[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. EXERCISE CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE EXERCISE	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE EXERCISE	[]	[]	[]
8. THERE WAS NOT AN ORDER TO USE EXERCISE	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO USE EXERCISE	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

REPOSITIONING

*Definition: Proper positioning and changing positions to help maintain good body alignment especially for persons confined to the bed or chair. An example is using pillows against the back and between the legs when the person lies on their side in bed.

When you provide care to hospice patients with cancer, how often do you use REPOSITIONING to relieve pain?

]	WITH ALL OR NEARLY ALL PATIENTS (75-100%)
[]	WITH MANY PATIENTS (50-74%)
[]	WITH SOME PATIENTS (25-49%)
ſ	1	WITH ONLY A FEW PATIENTS (1-24%)
Ī	ī	I NEVER USE REPOSITIONING

Think of your <u>last 3 hospice patients with cancer</u> for whom REPOSITIONING was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective REPOSITIONING was in relieving pain.

Please CIRCLE ONE number for each patient.

HOW EFFECTIVE WAS REPOSITIONING IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	1	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO REPOSITIONING

What barriers have made it difficult to use REPOSITIONING to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Repositioning	Not a barrier	A barrier	Not applicable
1. MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. REPOSITIONING WAS NOT EFFECTIVE.	[]	[]	[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. REPOSITIONING CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE REPOSITIONING	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE REPOSITIONING	[]	[]	[]
8. THERE WAS NOT AN ORDER TO USE REPOSITIONING	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO USE REPOSITIONING	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

IMMOBILIZATION

*Definition: Restricting the movement of a limb or portion of the body through the use of braces or splints. An example of immobilization is squeezing a pillow against the chest when coughing to prevent the pain from getting worse.

When you provide care to hospice patients with cancer, how often do you use IMMOBILIZATION to relieve pain?

[]	WITH ALL OR NEARLY ALL PATIENTS (75-100%)
[]	WITH MANY PATIENTS (50-74%)
[]	WITH SOME PATIENTS (25-49%)
]	WITH ONLY A FEW PATIENTS (1-24%)

I NEVER USE IMMOBILIZATION

Think of your <u>last 3 hospice patients with cancer</u> for whom IMMOBILIZATION was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective IMMOBILIZATION was in relieving pain. Please **CIRCLE** ONE number for each patient.

HOW EFFECTIVE WAS IMMOBILIZATION IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	I	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO IMMOBILIZATION

What barriers have made it difficult to use IMMOBILIZATION to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Immobilization	Not a barrier	A barrier	Not applicable
MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. IMMOBILIZATION WAS NOT EFFECTIVE	[]	[]	[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	f 1
5. IMMOBILIZATION CAUSED DISCOMFORT	[]	[]	1 1
6. PATIENT WAS PHYSICALLY UNABLE TO USE IMMOBILIZATION	[]	[]	1
7. PATIENT DID NOT UNDERSTAND HOW TO USE IMMOBILIZATION	1 1	[]	1 1
8. THERE WAS NOT AN ORDER TO USE IMMOBILIZATION	[]	[]	1.1
9. IT WAS NOT PART OF MY JOB TO USE IMMOBILIZATION	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

TRANSCUTANEOUS ELECTRICAL NERVE STIMULATION (TENS)

*Definition: A small battery-operated device that is applied to the skin to send controlled, low-voltage electrical stimulation to nerve fibers in the muscles. The stimulation interrupts the way the pain impulses are sent to the brain. A buzzing or tingling sensation may substitute the more uncomfortable pain.

When you provide care to hospice patients with cancer, how often do you use TENS to relieve pain?

- [] WITH ALL OR NEARLY ALL PATIENTS (75-100%)
 [] WITH MANY PATIENTS (50-74%)
 [] WITH SOME PATIENTS (25-49%)
 [] WITH ONLY A FEW PATIENTS (1-24%)
- [] I NEVER USE TENS

Think of your <u>last 3 hospice patients with cancer</u> for whom TENS was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective TENS was in relieving pain. Please <u>CIRCLE</u> ONE number for each patient.

HOW EFFECTIVE WAS TENS IN RELIEVING PAIN?

17.	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	1	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO TENS

What barriers have made it difficult to use TENS to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using TENS	Not a barrier	A barrier	Not applicable
MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. TENS WAS NOT EFFECTIVE	[]	[]	[]
EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. TENS CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE TENS	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE TENS	[]	[]	[]
8. THERE WAS NOT AN ORDER TO USE TENS	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO USE TENS	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

ACUPUNCTURE

**Definition: An acupuncturist inserts fine needles into specific areas on the body. These areas are called meridians and are believed to be channels where life energy flows. Although not completely understood, the needles help to reestablish a more balanced energy flow to promote healing and reduce pain.

When you provide care to hospice patients with cancer, how often do you suggest the use of ACUPUNCTURE to relieve pain?

- [] WITH ALL OR NEARLY ALL PATIENTS (75-100%)
 [] WITH MANY PATIENTS (50-74%)
 [] WITH SOME PATIENTS (25-49%)
 [] WITH ONLY A FEW PATIENTS (1-24%)
 [] I NEVER SUGGEST THE USE OF ACUPUNCTURE
- Think of your <u>last 3 hospice patients with cancer</u> for whom ACUPUNCTURE was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective ACUPUNCTURE was in relieving pain. Please CIRCLE ONE number for each patient.

HOW EFFECTIVE WAS ACUPUNCTURE IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	1	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO ACUPUNCTURE

What barriers have made it difficult to suggest the use of ACUPUNCTURE to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Acupuncture	Not a barrier	A barrier	Not applicable
1. MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. ACUPUNCTURE WAS NOT EFFECTIVE	[]	[]	[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. ACUPUNCTURE CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE ACUPUNCTURE	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND THE USE OF ACUPUNCTURE	[]	[]	[]
8. THERE WAS NOT AN ORDER TO SUGGEST ACUPUNCTURE	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO SUGGEST ACUPUNCTURE	[]		[]
10. OTHER (specify)	[]	[]	[]

RELAXATION EXERCISES

*Definition: Exercises that reduce pain through relaxation and by increasing control over the pain. An example of a focused-breathing exercise is doing slow, rhythmic inhaling and exhaling while saying to oneself, "with each exhalation, I feel more relaxed." Progressive muscle relaxation is done by alternating the tightening and then relaxing of each group of muscles in a systematic fashion. Listening to music, singing, or playing a musical instrument are examples of music relaxation exercises.

When you provide care to hospice patients with cancer, how often do you use or teach RELAXATION EXERCISES to relieve pain?

[]	WITH ALL OR NEARLY ALL PATIENTS (75-100%)
]	WITH MANY PATIENTS (50-74%)
I]	WITH SOME PATIENTS (25-49%)
]	WITH ONLY A FEW PATIENTS (1-24%)
٢	1	I NEVER USE OR TEACH RELAXATION EXERCISES

Think of your <u>last 3 hospice patients with cancer</u> for whom RELAXATION EXERCISES were used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective RELAXATION EXERCISES were in relieving pain. Please <u>CIRCLE</u>ONE number for each patient.

HOW EFFECTIVE WERE RELAXATION EXERCISES IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	1	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO RELAXATION EXERCISES

What barriers have made it difficult to use RELAXATION EXERCISES to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Relaxation Exercises	Not a barrier	A barrier	Not applicable
1. MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. RELAXATION EXERCISES WERE NOT EFFECTIVE	[]	[]	[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. RELAXATION EXERCISES CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE RELAXATION EXERCISES	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE RELAXATION EXERCISES	[]	[]	[]
8. THERE WAS NOT AN ORDER TO TEACH RELAXATION EXERCISES	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO TEACH RELAXATION EXERCISES	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

MEDITATION AND IMAGERY

*Definition: Meditation is deep, focused, and reflective thought. Imagery is using one's imagination to visualize pleasant images or visualize a change in the pain experience while being relaxed. An example of imagery is visualizing that the painful leg is separate from the rest of the body and therefore the pain is not felt as much.

When you provide care to hospice patients with cancer, how often do you teach MEDITATION AND IMAGERY to relieve pain?

- WITH ALL OR NEARLY ALL PATIENTS (75-100%)
- [] WITH MANY PATIENTS (50-74%)
- [] WITH SOME PATIENTS (25-49%)
- [] WITH ONLY A FEW PATIENTS (1-24%)
- I NEVER TEACH MEDITATION AND IMAGERY

Think of your <u>last 3 hospice patients with cancer</u> for whom MEDITATION AND IMAGERY were used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective MEDITATION AND IMAGERY were in relieving pain. Please <u>CIRCLE</u> ONE number for each patient.

HOW EFFECTIVE WERE MEDITATION AND IMAGERY IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective	
Patient #1	0	ĩ	2	3	4	
Patient #2	0	1	2	3	4	
Patient #3	0	1	2	3	4	

BARRIERS TO MEDITATION AND IMAGERY

What barriers have made it difficult to use MEDITATION AND IMAGERY to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

odiner.			
Potential Barriers to Using Meditation and Imagery	Not a barrier	A barrier	Not applicable
MY LACK OF TRAINING	1 1	[]	1 1
2. MY LACK OF TIME	[]	[]	[]
MEDITATION AND IMAGERY WERE NOT EFFECTIVE	[]	[]	[]
EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
MEDITATION AND IMAGERY CAUSED DISCOMFORT	ľ I	Ĩ Ĵ	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE MEDITATION AND IMAGERY	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE MEDITATION AND IMAGERY	[]	1 1	t 1
8. THERE WAS NOT AN ORDER TO TEACH MEDITATION AND IMAGERY	1 1	1 1	1 1
9. IT WAS NOT PART OF MY JOB TO TEACH MEDITATION AND IMAGERY	[]	[]	f 1
10. OTHER (specify)	[]	[]	[]

DISTRACTION AND REFRAMING

*Definition: Distraction is taking the attention away from the pain by focusing on something else. Examples of distraction are watching television or talking to others. Reframing is a way to control feelings by replacing negative thoughts with positive ones. An example of distraction is saying to oneself, "I am strong. I have coped with this pain before, I can cope with this again."

When you provide care to hospice patients with cancer, how often do you use or teach DISTRACTION AND REFRAMING to relieve pain?

[]	WITH ALL OR NEARLY ALL PATIENTS (75-100%)
[]	WITH MANY PATIENTS (50-74%)
	WITH SOME PATIENTS (25-49%)
	WITH ONLY A FEW PATIENTS (1-24%)
	I NEVER USE OR TEACH DISTRACTION AND REFRAMING

Think of your <u>last 3 hospice patients with cancer</u> for whom DISTRACTION AND REFRAMING were used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective DISTRACTION AND REFRAMING were in relieving pain. Please <u>CIRCLE</u> ONE number for each patient.

HOW EFFECTIVE WERE DISTRACTION AND REFRAMING IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	1	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO DISTRACTION AND REFRAMING

What barriers have made it difficult to use DISTRACTION AND REFRAMING to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Distraction and Reframing	Not a barrier	A barrier	Not applicable
1. MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. DISTRACTION AND REFRAMING WERE NOT EFFECTIVE	[]	[]	[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. DISTRACTION AND REFRAMING CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE THESE TECHNIQUES	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE THESE TECHNIQUES	[]	[]	[]
8. THERE WAS NOT AN ORDER TO TEACH THESE TECHNIQUES	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO TEACH THESE TECHNIQUES	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

THERAPEUTIC TOUCH

***Definition: A method of using the hands to direct human energy to help relieve pain. The hands do not touch the skin. A person trained in this technique uses his or her hands and motivation to relieve a person's pain during the treatment. This technique can be taught to others easily.

When you provide care to hospice patients with cancer, how often do you use THERAPEUTIC TOUCH to relieve pain?

[]	WITH ALL OR NEARLY ALL PATIENTS (75-100%)
[]	WITH MANY PATIENTS (50-74%)
[]	WITH SOME PATIENTS (25-49%)
	WITH ONLY A FEW PATIENTS (1-24%)
	I NEVER USE THERAPEUTIC TOUCH

Think of your <u>last 3 hospice patients with cancer</u> for whom THERAPEUTIC TOUCH was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective THERAPEUTIC TOUCH was in relieving pain. Please **CIRCLE** ONE number for each patient.

HOW EFFECTIVE WAS THERAPEUTIC TOUCH IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	1	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO THERAPEUTIC TOUCH

What barriers have made it difficult to use THERAPEUTIC TOUCH to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

Potential Barriers to Using Therapeutic Touch	Not a barrier	A barrier	Not applicable
1. MY LACK OF TRAINING	[]	[]	[]
2. MY LACK OF TIME	[]	[]	[]
3. THERAPEUTIC TOUCH WAS NOT EFFECTIVE	[]	[]	[]
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]
5. THERAPEUTIC TOUCH CAUSED DISCOMFORT	[]	[]	[]
6. PATIENT WAS PHYSICALLY UNABLE TO USE THERAPEUTIC TOUCH	[]	[]	[]
7. PATIENT DID NOT UNDERSTAND HOW TO USE THERAPEUTIC TOUCH	[]	[]	[]
8. THERE WAS NOT AN ORDER TO USE THERAPEUTIC TOUCH	[]	[]	[]
9. IT WAS NOT PART OF MY JOB TO USE THERAPEUTIC TOUCH	[]	[]	[]
10. OTHER (specify)	[]	[]	[]

PASTORAL OR SPIRITUAL ASSISTANCE

Definition: Providing counseling, pastoral care, and guidance are examples of pastoral and spiritual assistance. Pastoral counseling is counseling provided by a pastor. Spiritual counseling is counseling around a particular spiritual issue or set of issues. Pastoral care is the kind presence of someone in a caring, pastoral mode who may or may not be a pastor. Spiritual guidance is helping patients and families in areas such as how to pray.

When you provide care to hospice patients with cancer, how often do you use PASTORAL OR SPIRITUAL ASSISTANCE to relieve pain?

	WITH ALL OR NEARLY ALL PATIENTS (75-100%)
	WITH MANY PATIENTS (50-74%)
	WITH SOME PATIENTS (25-49%)
Ϊĺ	WITH ONLY A FEW PATIENTS (1-24%)
[]	I NEVER USE PASTORAL OR SPIRITUAL ASSISTANCE

Think of your <u>last 3 hospice patients with cancer</u> for whom PASTORAL OR SPIRITUAL ASSISTANCE was used, and refer to them as Patient #1, #2, and #3. Please rate each patient separately on how effective PASTORAL OR SPIRITUAL ASSISTANCE was in relieving pain. Please CIRCLE ONE number for each patient.

HOW EFFECTIVE WAS PASTORAL OR SPIRITUAL ASSISTANCE IN RELIEVING PAIN?

	Not effective	Effective a little	Somewhat effective	Quite a bit effective	Very effective
Patient #1	0	1	2	3	4
Patient #2	0	1	2	3	4
Patient #3	0	1	2	3	4

BARRIERS TO PASTORAL OR SPIRITUAL ASSISTANCE

What barriers have made it difficult to use PASTORAL OR SPIRITUAL ASSISTANCE to relieve pain in hospice patients with cancer? Check ONE box for each potential barrier.

for each potential barrier.				
Potential Barriers to Using Pastoral or Spiritual Assistance	Not a barrier	A barrier	Not applicable	
1. MY LACK OF TRAINING	[]	[]	[]	
2. MY LACK OF TIME	[]	[]	[]	
3. PASTORAL OR SPIRITUAL ASSISTANCE WAS NOT EFFECTIVE	[]	[]	[]	
4. EITHER THE PATIENT OR THE CAREGIVER WAS NOT INTERESTED	[]	[]	[]	
5. PASTORAL OR SPIRITUAL ASSISTANCE CAUSED DISCOMFORT	[]	[]	[]	
6. PATIENT WAS PHYSICALLY UNABLE TO USE THIS TECHNIQUE	[]	[]	[]	
7. PATIENT DID NOT UNDERSTAND HOW TO USE THIS TECHNIQUE	[]	[]	[]	
8. THERE WAS NOT AN ORDER TO USE THIS TECHNIQUE		[]	[]	
9. IT WAS NOT PART OF MY JOB TO USE THIS TECHNIQUE	[]	[]	[]	
10. OTHER (specify)	[]	[]		

TELL US ABOUT YOU					
1.	Have YOU personally ever used any of these physical or psychosocial techniques to relieve your own pain?				
	[]	NO YES			
	la.	If YES, which ones? Check ALL that apply.			
		MASSAGE COLD HEAT EXERCISE REPOSITIONING IMMOBILIZATION TRANSCUTANEOUS ELECTRICAL STIMULATION (TENS) ACUPUNCTURE RELAXATION EXERCISES MEDITATION AND IMAGERY DISTRACTION AND REFRAMING THERAPEUTIC TOUCH PASTORAL OR SPIRITUAL ASSISTANCE			
2.	Have YOU personally ever used any of the above techniques for any other reasons?				
	[] []	NO YES If YES, which ones?			
	2b.	If YES, for what reasons?			

answer	answered YES to either question 1 or 2 on the previous page, please question # 3 below. If you answered NO to both questions on the us page, skip # 3.			
3.	Did YOUR personal experience with any of these techniques make a difference in your using or not using these techniques with the person receiving hospice services?			
	[] NO [] YES			
	3a. If YES, how?			
4.	Taking into consideration the potential barriers, what do you think are the 3 most effective techniques to relieve pain in hospice patients with cancer? Do not include medications, radiation, or nerve blocks. You are not limited by the list of techniques in this survey. MOST EFFECTIVE SECOND MOST EFFECTIVE THIRD MOST EFFECTIVE			
5.	Do you have any other comments about nonpharmacologic techniques to relieve pain in hospice patients with cancer?			

THANK YOU FOR YOUR TIME TO COMPLETE THIS QUESTIONNAIRE. YOUR CONTRIBUTION IS GREATLY APPRECIATED.

RESULTS OF THIS PROJECT WILL BE AVAILABLE IN APPROXIMATELY 4 MONTHS AND WILL BE GIVEN TO THE DEPARTMENT AT THAT TIME.

Source of definitions:

- * U.S. Department of Health and Human Services. (1994). <u>Management of cancer pain:</u> Clinical practice guidelines (AHCPR Publication No. 94-0592). Rockville, MD: Author.
- ** Shuying, X., Zhiqiang, L., & Yu, L. (1995). Treatment of cancerous abdominal pain by acupuncture on Zusanli (St 36): A report of 92 cases. <u>Journal of Traditional Chinese Medicine</u>, 15, 189-191.
- *** Krieger, D. (1993). Accepting your power to heal: The personal practice of therapeutic touch. Santa Fe, NM: Bear and Co.

Appendix B

Pretest Cover Letters



Date

Dear (name of caregiver):

I am sorry about your recent loss and hope that the Kaiser Permanente's Hospice Program provided the care and support you and your loved one needed.

As the administrator of the Hospice Program, I want to improve the comfort of patients and families. We are especially interested in how hospice nurses can work with families to relieve pain in their loved ones.

I would like you to consider giving us your opinions about how you managed pain—both what worked and what did not—to help us improve our care to patients. Because we know this can be a difficult time for you, we thought that obtaining your opinions on a questionnaire that you could fill out in your own home, at a time convenient for you, would be the best way to obtain your views.

Stacey Romney, RN, BSN is a nurse in the Home Health/Hospice Program and is also completing her master's degree in nursing at Oregon Health Sciences University. She has developed a questionnaire that asks caregivers like you about alternative techniques they may have used, along with medications, to help relieve pain in their loved ones who had advanced cancer.

Some techniques that can reduce pain, such as massage and relaxation exercises, are rarely used by patients with cancer and very little is known about their use. However, you or the person who received hospice services may have used some of these. You can give us an accurate picture of how helpful these techniques were in relieving pain or why they were not used.

We are inviting individuals like you, who provided care to a cancer patient who died in the last 4-6 months, to share their views with us. The questionnaire will take about 20 minutes to complete.

Because we want to be sensitive to you at this difficult time, we have enclosed a postage-paid envelope and response form for you to return indicating: (1) whether you would be able to complete the questionnaire at this time, or (2) whether you would prefer that we not send you a questionnaire. Please let us know of your interest by **December 31**, 1996. If you are willing to complete the questionnaire, Stacey will mail you a questionnaire in January.

Relieving pain is important to us and I hope that you can participate if this is a good time for you.

Thank you for your time and assisting us in this endeavor.

Sincerely,

Linda Van Buren, RN, MN Administrator Kaiser Permanente Continuing Care Services Department



3181 S.W. Sam Jackson Park Road, Portland, Oregon 97201-3098

Community Health Care Systems Cluster (503) 494-7709 (503) 494-4678 (fax)

Mail Code: SN CHC

School of Nursing

Primary Health Care Cluster (503) 494-3842 (503) 494-3878 (fax) Mail Code: SN FAM

Date

Dear (name of caregiver):

My name is Stacey Romney and I am a nurse with Kaiser Permanente's Hospice Program while also a graduate student at Oregon Health Sciences University. I am very sorry about your recent loss and appreciate your willingness to complete the enclosed questionnaire. You can help us learn about techniques that may have been used along with medications to help relieve pain in persons with advanced cancer. These techniques, such as using massage or ice, are rarely used by patients with cancer and very little is known about their use. However, you or the person who received hospice services may have used some of these. You, as a caregiver, have valuable knowledge and experience from being involved in your relative's or friend's care.

Your participation is completely voluntary. You may refuse to participate without affecting your relationship with or treatment at Kaiser Permanente or Oregon Health Sciences University. All responses are anonymous. There is no way to link your name with the information you provide in the questionnaire. Neither your name nor your identity will be used for publication or publicity purposes. If you do not want to participate, simply mail back the blank questionnaire. A postage-paid return envelope is provided for your convenience. Please return the questionnaire by **December 22**, 1996. If you would like a copy of the results of this project, please mail the enclosed postage-paid postcard separately. To assure anonymity, please do not return this cover letter or put your name on the questionnaire. If you were not a caregiver for the person who received hospice services, please give this letter and questionnaire to that person.

If you have any questions at all, please leave me a message so that I may return your call. From the Portland area, call 503/499-5141 or toll-free from Vancouver, 360/694-2210, ext. 5141. If you have any concerns regarding this project, you may contact my research advisor, Barbara Stewart, PhD, Professor at Oregon Health Sciences University at 503/494-3835. If you have questions regarding your right as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at 503/494-7887.

Please know we are sensitive to the fact that this is still a difficult time for you. Your time and assistance is greatly appreciated.

Sincerely,

Ms. Stacey Romney, RN, BSN Graduate Nursing Student



3181 S.W. Sam Jackson Park Road, Portland, Oregon 97201-3098

Community Health Care Systems Cluster (503) 494-7709

(503) 494-4678 (fax) Mail Code: SN CHC Date

School of Nursing

Primary Health Care Cluster (503) 494-3842 (503) 494-3878 (fax) Mail Code: SN FAM

Dear Hospice Staff Member:

Thank you for your willingness to give me feedback on this questionnaire. I am doing a project to learn about techniques that may have been used along with medications to help relieve pain in persons with advanced cancer. These techniques, such as using massage or ice, are rarely used by patients with cancer and very little is known about their use. Because you work with hospice patients and families, you or they may have used some of these. You can give an accurate picture of how helpful they were in relieving pain or why they were not used.

In January, all hospice staff employees and a portion of volunteers who provide direct patient care to Kaiser Permanente's Hospice patients will be invited to share their opinions about the use of the 13 physical and psychosocial techniques. Bereaved caregivers of hospice patients who died 4 to 5 months ago from cancer are receiving a similar questionnaire. Both perspectives will be used to help those who work with cancer patients and their families.

Before I send these questionnaires out in January, I am sending them to a few volunteers (like yourself) to learn what questions or instructions need clarification and revision. Since the questionnaire will be going out to all the disciplines involved with hospice care, some of the questions may need to be adapted specifically for your discipline. The questionnaire may not be appropriate to give to all disciplines because they may not be using these techniques or seeing patients/families use them. Could you provide me with any feedback about ways you would change the directions or questions to improve it? Feel free to use a red ink pen and mark up the questionnaire any way you would like. Could you also indicate how long it took you to complete the questionnaire so I can give people a rough estimate as to how long it will take to complete?

Your participation is completely voluntary. You may refuse to participate without affecting your relationship with or treatment at Kaiser Permanente or Oregon Health Sciences University. All responses are confidential. Neither your name nor your identity will be used for publication or publicity purposes. If you do not want to participate, simply put the blank questionnaire into my mailbox. Please return the questionnaire to my mailbox by December 12, 1996. Please do not return this cover letter or put your name on the questionnaire.

If you have any questions at all, please leave me a message so that I may return your call. From the Portland area, call 503/499-5141 or toll-free from Vancouver, 360/694-2210, ext. 5141. If you have any concerns regarding this project, you may contact my research advisor, Barbara Stewart, PhD, Professor at Oregon Health Sciences University at 503/494-3835. If you have questions regarding your right as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at 503/494-7887.

Your time and assistance in this project is greatly appreciated.

Sincerely,

Ms. Stacey Romney, RN, BSN Graduate Nursing Student Appendix C

Follow-up Postcard

Questionnaire Follow-up

A couple of weeks ago you received a questionnaire from me asking for your opinions about The Use of Physical and Psychosocial Techniques to Relieve Cancer Pain. I hope to obtain your opinions so that others may be helped from your experiences. If you have already responded, thank you for you help and please excuse this card. If you have not responded, could you please take a few minutes now to do so?

If you require additional information or a replacement questionnaire, please leave me a message so I may return your call. From the Portland area, call (503) 499-5141 or toll-free from Vancouver, (360) 694-2210. Again, thank you for your time and willingness to share in this project.

Stacey Romney, RN, BSN Graduate Nursing Student at Oregon Health Sciences University Appendix D

Cover Letters



Date

Dear Hospice Staff Member:

As the administrator of Kaiser Permanente's Hospice Program, I want to improve the comfort of patients and their families. One way this is accomplished is by hearing from hospice staff, like yourself, about what works and what does not work. Stacey Romney, RN, BSN is a nurse in the Home Health/Hospice Program while also a graduate student at Oregon Health Sciences University. She has developed a questionnaire to help us learn about alternative techniques that may have been used along with medications to help relieve pain in persons with advanced cancer. We are requesting your help in completing this questionnaire.

Stacey has discussed with me and received my enthusiastic approval and support. The knowledge gained from this questionnaire will improve the care we are able to provide our patients and the care of other cancer patients. This is important research and I encourage you to complete the questionnaire.

Thank you for your time and assistance in the endeavor.

Sincerely,

Linda Van Buren, RN, MN Administrator Kaiser Permanente Continuing Care Services Department



OREGON HEALTH SCIENCES UNIVERSITY

3181 S.W. Sam Jackson Park Road, Portland, Oregon 97201-3098

Community Health Care Systems Cluster (503) 494-7709 (503) 494-4678 (fax) Date

Mail Code: SN CHC

School of Nursing

Primary Health Care Cluster (503) 494-3842 (503) 494-3878 (fax) Mail Code: SN FAM

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