Perceptual and Attitudinal Bases Influencing Cancer Patient/Care Giver Dyads' Use of Pain Medications In Home Care Settings

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Introduction

Cancer patients in the home care setting frequently experience inadequate pain control (Rimer, Levy, Keintz, Fox, Engstrom and MacElwee, 1987). Many clinical practice experiences corroborate the above experts' contention that the lack of adequate cancer pain control is indeed a significant problem. Adequate pain control does not mean that there is eradication of pain. Rather, patients with controlled pain are able to maximize their functionality while having limited side effects from the pain medications.

Clinical experiences, and interviews with hospital and home care nurses, have shown that inadequate pain control is a noteworthy problem in both the acute and home care settings. In addition, the dramatic increase in the home care of cancer patients has transformed the issue of pain control into a significant health care issue for patients, families, and health care professionals. In 1983, the federal government implemented a cost-control system of prospective payment to care providers called diagnosis-related groupings (DRGs). This system has encouraged a pattern of earlier discharge of patients from the hospital who are able to perform only partial self care. It has also meant a stronger emphasis on early home care for chronically ill patients, such as terminal cancer patients, who experience pain (Wingate and Lackey, 1989). These changes have created a need for greater involvement in the home care

of cancer patients by the family, or designated care givers.

At two local home health care agencies, for instance, there has been a doubling of patient visits by each agency within the last 12 months. Based on interviews with the director of each agency, there is reason to believe that this trend will continue.

It has been noted that cancer patients in the home care setting experience varying degrees of pain. For instance, there are cases in which the care givers perceived the cancer patients to be in relatively pain-free states and withheld pain medication. Follow-up interviews with these same patients revealed that the patients indeed had pain and their discomfort was exacerbated because of missed doses of medications. Thus, home setting care givers encounter similar assessment dilemmas as professional nurses in acute settings, but have less skills to deal with them.

In this study, pain is defined as what the patient says it is. Ferrell and Schneider (1988) described cancer pain as "...an overwhelming and all-consuming experience for the patients and their care providers" (P. 84). Jones, Rimer, Levy and Kinman (1987) stated, "Despite the fact that most pain can be controlled by narcotic analgesics, many patients receive inadequate treatment for pain" (p. 159). Twycross and Lack (1983) reported that after a prolonged period of pain (weeks or months), many cancer patients become overwhelmed by pain which envelops their whole outlook

towards life.

Problem Statement

This study focused on describing some of the factors related to the management of cancer pain in patients in home care settings. One of the principle barriers to effective pain control is the inconsistent use of prescribed pain medications by cancer patients. The causes for this inconsistency are multifactorial. This study was conducted to: 1) identify those attitudes which affect cancer patients' use of pain medications in home care settings; 2) describe the patients' and care givers' perceptions regarding the intensity of the cancer patients' pain; and, 3) describe the relationship between those perceptions, and attitudes and the patterns of use of pain medications.

Due to inadequate pain control, patients with cancer experience needless suffering, feel a loss of control over their pain and are unable to maximize their functionality. Optimal functionality is defined as the patient being able to perform all of those tasks which the disease process permits; thus, the rationale for seeking effective pain control was to promote the patient's optimal functionality.

Review of the Literature

Many cancer patients living at home experience needless suffering because they take or receive their pain medications inappropriately or at sub-therapeutic doses. Inadequate cancer pain control in the home care setting is a

significant, but unnecessary problem. "Leaders in the field of palliative care have demonstrated that pain can be effectively controlled and that dignified death can indeed be a reality" (Ferrell and Schneider, 1988, p. 85). These experts also suggest there are occasions when "...pain is not effectively managed by cancer patients at home and that pain management is critical to functional ability." Twycross and Lack (1983) reported that the implications of unrelieved pain vary according to its cause: "In cancer, the pain is usually continuous and tends to get worse. This produces mental and physical exhaustion" (p. 9). They further described this chronic and acute pain as leading to patients becoming demoralized, depressed, fearful, increasingly incapacitated by pain, and prematurely housebound or bedfast. Ferrell and Schneider (1988) cited cancer pain "... as an overwhelming and all-consuming experience for the patients and their care providers. It, therefore, becomes an immobilizing force for the family and professional care providers in their frustration of managing this complex symptom" (p. 84). Thus, a primary component of home care nursing is assisting patients and their care givers to develop effective pain management strategies.

Wingate and Lackey (1989) defined a primary care giver as "...that individual that the cancer patient identifies as the significant individual who helps meet the patient's self-care deficits but who does not receive remuneration

from a health care agency for these services" (p. 218). Certainly patients' families or care givers play key roles in home care settings. According to Ferrell and Schneider (1988), "The problem of pain management is of particular importance in outpatient and home health care where complex symptom management is often provided by family members of patients themselves" (p. 84). In other words, care givers are often the decision makers about if and when patients will receive pain medications. Pain management at home is a problem because patients and care givers may perceive the characteristics of the pain differently.

This disparity in perception may contribute to an inadequate use of pain medications, and have a direct, negative impact on the cancer patients' pain control. Unfortunately, there remains a dearth of reported data regarding the pain perceptions of cancer patients and their care givers.

There are numerous variables which may influence the perceptions of pain intensity and the attitudes towards pain medications. Some of these are past experiences, age, ethnicity, gender and concomitant illness. With regard to age, McMillan (1989) reported that actual pain may not be less but that older people may just perceive it as less. There are also cultural and gender factors affecting people's perceptions of pain. McCaffrey and Beebe (1989) reported, "In many cultures a value judgement is placed on

pain tolerance. High pain tolerance may be admired. Men are usually expected to tolerate more pain than women and adults to tolerate more pain than children" (p. 16). Concomitant illnesses may influence perceptions of pain because signs and symptoms of secondary illnesses such as nausea, vomiting and constipation (Ferrer-Brechner, 1986), may mimic or enhance cancer pain.

Medication utilization is influenced by the patients' and care givers' attitudes and concerns towards pain medications. The term "use of" is employed throughout this paper. This concept indicates the patients' consumption of prescribed and over-the-counter pain medications to control cancer pain. This term does not necessarily indicate adherence to a physician's or health care practitioner's prescribed medication regimen.

A review of the literature pertinent to the effects that attitudes about pain medications have on the use of pain medications revealed several essential concepts. One of these concepts is the "general" attitude that patients and physicians have toward the use of pain medications; there seems to be a societal stigma against drug use. Hill (1990) made the point that "drug abuse so dominates cultural and societal thinking that even when these drugs are used legitimately for medical purposes, an illegitimate aura persists." Hill (1990), Hill et al. (1988), and Twycross and Lack (1983) cited the following as factors influencing

the use of pain medications:

- irrational or exaggerated fears of addiction;
- the belief by patients and care givers that pain in cancer is inevitable and untreatable;
- the belief that one should take analgesics only "if absolutely necessary";
- the belief that medication "won't work when you really need it" because analgesic tolerance may develop; Jaffe (1985) defines analgesic tolerance as the need for increasing doses of narcotics to achieve a constant level of pain relief;
- the unsavory image that narcotics have among the general public, and
- cultural beliefs that pain is something to be endured and a virtue that demonstrates strong character.

Despite the above references, the literature was limited concerning the factors which influence the use of pain medications. The above authors (Twycross and Lack, and Hill et al.) did not cite the sources for the factors that they reported as impacting the use of pain medications. As other sources were reviewed, even less information specific to these concepts was found. Dalton, Toomey and Workman (1988) stated that "factors such as patient beliefs about pain management, expectations of pain relief and treatment outcomes have not been studied" (p. 322).

Clinical experiences suggested that there was another variable which affected patients' pain control. This variable was the tendency of some physicians' to underprescribe appropriate medications, or adequate doses of pain medications for individual patients.

Conceptual Framework

Cancer patients and their care givers have different sets of life experiences which affect their individual and collective attitudes toward the use of pain medications. It is the investigators' belief that patients' and care givers' perceptions of pain intensity, and their attitudes toward the use of pain medications, are influenced by the universal factors of ethnicity, age and gender as depicted in Figure 1: The Conceptual Model for pain management in cancer patients in home care settings. In addition, the patients' and care givers' perceptions of pain intensity, and their attitudes toward the use of pain medications, may be influenced by the cancer diagnosis, the time since diagnosis and any concomitant illnesses experienced by the patients or care givers. These influencing factors, perceptions and attitudes have a positive, negative or neutral effect on the use of pain medications by patients. Any discrepancies between the patients' and care givers' attitudes towards the use of pain medications will have an impact on the use of pain medications.

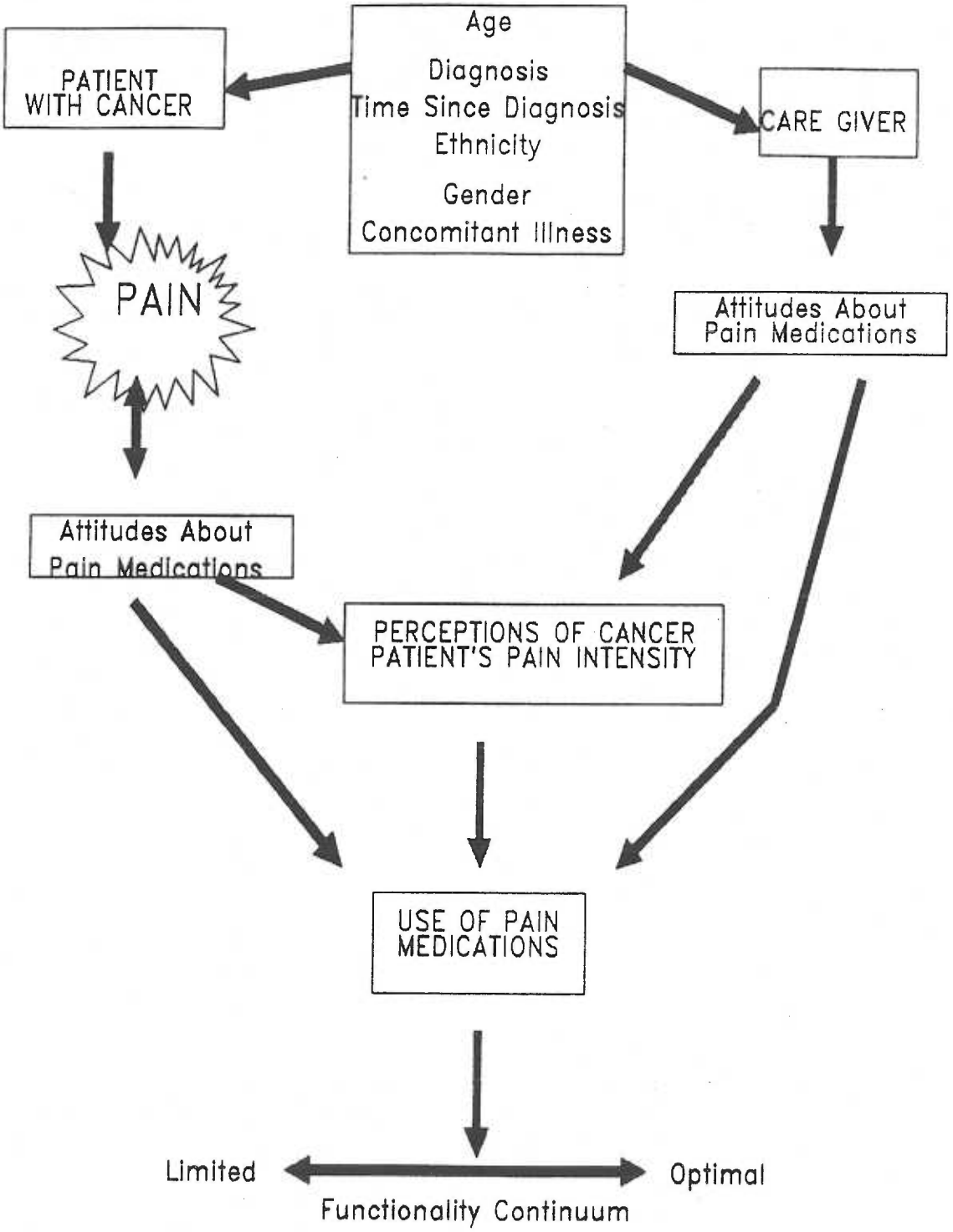

FIGURE 1: Conceptual Model For Pain Management in Cancer Patients in Home Care Settings

Patients' and care givers' perceptions of the patients' pain intensity will also influence the manner in which pain medications are used. If there are shared perceptions of the patients' pain intensity, there will be a greater probability of using pain medications. Dissimilar perceptions of the patients' pain intensity, will likely result in under-utilization of pain medications. A recent clinical experience illustrated this point. A patient stated to the home health nurse, "I need a pain pill!" The wife/care giver replied, "No, he doesn't have pain." Obviously the discrepancy was going to affect the use of pain medications.

It is believed that the use of pain medications will enhance patient functionality. Appropriate use of pain medications is more likely to facilitate the patients' movement towards the optimal end of the functionality continuum. Conversely, inappropriate use of pain medications is more likely to permit only limited functionality on the continuum. Appropriate use was defined as using pain medications as prescribed by the primary health care provider, or in accordance with the product's specifications. Optimal functionality was the goal of pain medication use. It, however, was not the focus of this specific study.

Research Questions

This study focused on three issues regarding pain

control in cancer patients in the home care setting. The research questions were:

1. Do patients and care givers possess significantly different attitudes towards the use of pain medications?
2. Do patients and care givers have significantly different perceptions of the intensity of pain that cancer patients experience?
3. Is there a positive correlation between patients' and care givers' attitudes towards the use of pain medications and the actual use of pain medications?

Methods

Design and Sample

A descriptive correlational design was utilized for this exploratory investigation. The sample size originally selected was 60 dyads. However, it became clear that such numbers could not be accessible within the designated time frame of this study. Thus, the sample size of 23 dyads was accepted based on two factors. First, 23 dyads provided sufficient data to explore a multiple set of variables. Second, there was a limited number of patient-care giver dyads available due to the size of the community, the eligibility criteria and the timing of the investigation.

A dyad consisted of one cancer patient and a primary care giver. Potential patients were drawn from the

practices of medical and radiation oncologists in the local area, and patients enrolled in a home health service, or as part of a hospice program. Thus, the subjects comprised a convenience sample.

There was a list of eligibility criteria for cancer patients and a separate list for the care givers. All criteria were met for inclusion in the study. If one part of the dyad did not meet the criteria then the entire dyad was determined to be ineligible. Patients who were enrolled in the study met the following criteria:

- were identified by nurses and physicians as cancer patients who experienced cancer pain as a result of their cancer diagnoses;
- had signed the research consent form;
- had no diagnosed or suspected brain metastases;
- demonstrated adequate mental acuity as evidenced by appropriate speech patterns and the ability to independently and appropriately respond to the measurement tools;
- had a primary care giver, and
- had a prescribed pain medication regimen for pain control.

Care givers who were enrolled in the study met the following set of criteria:

- signed the consent form;
- provided the care for a cancer patient who was

receiving medications for pain control; and

- could independently complete the measurement tools.

The first 23 patient-care giver dyads who met the eligibility criteria comprised the sample. By obtaining a non-random sample, it was acknowledged that selection bias could influence the results of the study.

Instruments

The study employed three measurement tools, all of which were completed by both the patients and the primary care givers. The visual analogue scale, designated as the Baumgart Pain Intensity Tool (BPIT), was the first tool to be administered (see Appendix A). This instrument was given before the other tools in order to avoid influencing the respondents' attitudes. The BPIT was a linear scale designed to represent bi-polar views of pain intensity. The second tool, a study-specific Likert Scale, named the Harvey Attitude Likert Scale (HALS), was used to measure the varying attitudes and concerns that affect the use of pain medications (see Appendix B). This tool was given second in order to facilitate the accuracy of responses before the respondents became fatigued. Finally, a study specific demographic and self-report tool, titled the Kerns Self Report Tool (KSRT), was used to collect background demographic data about the dyad and the patient's use of pain medications (see Appendix C). This tool was given last

because the care givers and patients were working together to give responses and were less affected by fatigue than if they responded individually. Approximately 30-45 minutes was needed for completion of all of the tools. Approximately five minutes were required to complete the BPIT assessment, which included the researchers' explanations about the BPIT to the subjects. Respondents needed approximately 10 to 15 minutes to complete the HALS, which included the time the researchers need to explain the tool to the subjects. The KSRT required approximately 20 minutes for the researchers to complete, based on input from the subjects.

Baumgart Pain Intensity Tool (BPIT)

Description and administration. The BPIT was used to measure patients' pain intensity from three different time periods within the 24 hours preceding the interview: upon awakening (6-8 A.M.), mid-afternoon (2-4 P.M.) and late-evening (8-10 P.M.). These time periods were chosen because of the varying intensities of pain that can occur throughout the day. Frequently, people wake up with pain, develop pain as their activity increases, and may have exacerbated pain in the late evening because of fatigue. This tool collected data for Research Question Two. The BPIT was a horizontal line of an exact divisible length (ten centimeters), which was drawn with endpoint descriptors at either end describing feelings regarding pain. The terms "no pain" and "worst

pain imaginable" reflected levels of pain intensity as described in the clinical setting. The subjects were asked to individually note their perceptions of the patients' pain intensity on the continuum line, by making a mark. The BPIT presented three separate lines, each one depicting a different time period. The expectation was that this tool would reveal whether patients and care givers perceive the patients' pain intensity similarly.

Reliability. A study of cancer patients by Ahles, Ruckdeschel, and Blanchard (1984) using the Visual Analogue Scale found a test-retest reliability correlation of 0.78 when it was used to assess cancer related pain.

Scoring. A primary goal of this research project was to identify the percentage of individual dyads which were "concordant" or "discordant" in their perceptions of the patients' pain intensity. For purposes of this study, concordant perceptions between patients' and care givers' were demonstrated when there was a maximum mean difference of two centimeters or less in their BPIT scores. Discordant perceptions were demonstrated when there was a difference of greater than 2.0 centimeters between the patients' and care givers' BPIT scores.

Logistical Complications.

* Several subjects found that the time frames of BPIT coincided with their sleep schedules and this confused some subjects about what were appropriate responses.

For example, they were uncertain how to respond if they were asleep from 2-4 P.M., because they felt uncertain about how to evaluate their pain levels during episodes of sleep. To promote valid responses, the researchers consistently reinforced to the respondents, the guidelines as originally outlined.

* The BPIT presented unforseen difficulties in the interpretation of the responses when the data were scored. For example, some subjects responded by marking with "Xs" or check marks, instead of drawing a crisp vertical line through the VAS as instructed. In those cases, the researchers determined the mid-point of the mark and used that as the score.

* Subjects frequently sought guidance from the investigators regarding an appropriate response. For example, when completing the BPIT, numerous patients would state "My pain is pretty bad," and seek guidance from the investigator as to where the mark should be made. In other words, the concept of transferring perceived pain to a mark on the BPIT was found to be difficult by various subjects. Again, the investigators repeated the instructions as originally given to the respondents.

Harvey Attitude Likert Scale (HALS)

Description and administration. The HALS was used to measure the varying attitudes and concerns of the subjects

that affected the use of pain medications. This tool collected data for testing Research Question One. The HALS was based on attitudes and concerns obtained from interviews with patients and care givers. These attitudes and concerns were then compared with those referenced in journal articles and texts on pain and the most frequently occurring attitudes and concerns were used as the basis for the HALS items.

The HALS focused on four significant concepts: fear of addiction (items 5, 7, 11, 17 and 19), tolerance to pain medication (items 2, 4, 13, 16 and 23), the side effects of pain medications (items 8, 14, 15, 18 and 21) and locus of control (items 1, 3, 6, 9, 10, 12, 20, and 22). These four concepts seemed to be the primary forces which shape patients' and care givers' attitudes toward, and the use of, prescribed pain medications for controlling pain. In formulating the HALS, an equal number of items was assigned to three concepts because it was judged that each of the three was of equal importance. The fourth concept, locus of control, contained more items due to the complex nature of this concept. Locus of control was defined as patients and care givers feeling in control of the patients' pain.

Validity. The content validity of this tool was established and verified by a panel of cancer specialists. The panel was composed of two medical oncologists, two Masters-prepared oncology clinical nurse specialists and

three home health/hospice nurses. The two medical oncologists were chosen because one is the medical director of the hospice program and the other has expressed an interest in home care cancer pain management. The clinical nurse specialists were chosen due to their expertise in academic research and cancer pain management. The hospice/home health nurses were selected because of their current clinical experiences with home cancer patients. Only those questions that received 80% agreement by the panel as having content validity were included in the final tool.

An "expert panel packet" was distributed to each panel member. Included in this packet was a cover letter outlining the research project, a copy of the HALS and an evaluation form for each of the items which comprise the HALS. The evaluation form asked each HALS rater to respond "yes" or "no" as to whether each item measures the intended concept. This meant that at least six out of the seven panel members would have to agree that the item measures the concept in question for that item to be considered valid. (See Appendix D for the "Expert Panel Packet".)

The expert panel dismissed seven items from the originally-proposed HALS because the members felt the items were not valid for the concept in question. In order to establish concept validity, seven new items were developed and approved by the expert panel evaluation, but only five

were included in the final HALS. Not all approved items were included in the HALS because investigators weighted the number of items per concept for the reasons previously described. (See Appendix E for the scoring per item of each panel member for the original HALS statements and the replacement statements.)

Scoring. The data collected regarding the four concepts were scored separately. For example, each member of a given dyad received a score for each concept. A total score for all four concepts was not calculated, however, so as to maintain the validity of each concept.

One key goal of this research project was to identify the percentage of individual dyads which were "concordant" or "discordant" in their attitudes regarding the use of pain medications. For purposes of this study, concordant attitudes between patients' and care givers' were demonstrated when there was a difference of less than 20% in their scores. This value was chosen because 80% agreement is a generally-accepted appropriate value for clinical significance in studies of this nature. In the three concepts of fear of addiction, fear of tolerance to pain medications and fear of side effects to pain medication, which had five items each, concordance was demonstrated by scores within five points of each other. In the fourth concept, locus of control, involving eight items, concordance was demonstrated by scores within eight points

of each other. Discordant attitudes were demonstrated when there was a difference of greater than five points between the patients' and care givers' HALS scores for fear of addiction, fear of tolerance to pain medications and fear of side effects to pain medication. Discordant attitudes were demonstrated when there was a difference of greater than eight points between patients' and care givers' HALS scores for the concept of locus of control.

Logistical complications. Numerous subjects expressed difficulty answering some of the statements on the HALS because they may not have experienced or considered that concept before. If respondents were uncertain of a concept in question, they were reminded there was no "right" or "wrong" answers and were encouraged to consider "Uncertain" as a potential response.

Kerns Self-Report Tool (KSRT)

Description and administration. The KSRT documented the use of pain medications. It was completed by the investigators based on the responses of patients and care givers, and by the investigators examining the patients' medication list. The KSRT attempted to document patients' medication use in relationship to their pain. It was believed that such factors as age, gender, ethnicity, level of education and concomitant treatment (i.e., chemotherapy and radiation therapy) had an influence on the patients' and care givers' perception of pain intensity, and the use of

pain medications to control pain. To describe the characteristics of the sample, the diagnosis and time since diagnosis were collected. It was felt that for secondary analysis it would be helpful to know the relationship (married, friends, etc.) of the patients and the care givers, as well as who was the primary dispenser of pain medications. It was believed, for example, that a long-term spouse, who was a care giver, would be better equipped to anticipate and meet a patient's needs than a neighbor, who was the care giver. This tool collected data relative to testing Research Question Three. The KSRT sought the following information:

- the current prescribed pain medication regimen: this information was used to define the current pain medication regimens;
- how and when patients used all pain medications -- prescribed and over-the-counter -- within the last 24 hours: this information was used to determine the relationship between the pain intensity and medication use; and
- why the patients took the medications at the time they did; this was to evaluate whether patients used their pain medications based on prescribed schedules primarily in response to pain, or in anticipation of pain.

Reliability. In order to ensure accurate scoring of

pain medication usage the three researchers scored the responses as a group based on the guidelines outlined above.

Scoring. One purpose of the KSRT was to determine if the patients used the medications (for pain, nausea and anxiety) within guidelines outlined by either the patients' physicians, or as recommended by the labels on the adjunctive medication packages. The procedure for calculating patients' use of medications was done in the following manner: patients' medication intake was recorded at the time of the interview. This was to determine if a scheduled medicine was taken as prescribed; it was done also to ascertain if as-needed ("p.r.n.") medications were used as recommended.

The medications were divided into two categories, prescribed pain medications and adjunctive medications. For purposes of this study, the term "primary pain medications" was used to describe all narcotic analgesics that patients were taking, whether on a scheduled or as-needed basis. This category referred to such medications as morphine sulfate, codeine and meperidine. Any other medications that the patients took to reduce pain were considered "adjunct pain medications." These included such medications as ASA and acetaminophen products, benzodiazapines, tricyclic anti-depressants, corticosteroids, non-steroidal anti-inflammatory agents, and muscle relaxants. It was decided to develop these two categories because it was felt that

some patients would be more inclined to take non-narcotic pain medications rather than narcotic pain medications on a regular basis if fear of addiction to the narcotic medication was a concern.

Each category's total allowable minimum amount of milligrams for 24 hours was compared to the total number of milligrams of each medication taken in that time period. In the prescribed pain medication category, the positive or negative sums of milligrams taken versus allowable milligrams (mg) prescribed are represented as a percentage. For example, if a physician orders 60 mg. of sustained-release morphine sulfate in a 24 hour period and a given patient reports using 30 mg., this would be described as "50% usage." The following example will illustrate this concept: If a pain medication order read "one-to-two tabs every four to six hours," the minimum dose was four tabs. If four tabs were taken in the 24-hour study period, "100%" was scored for that medication.

In evaluating non-prescribed medication usage, the investigators originally planned to record maximum potential doses as written on the product's label. During data collection, however, it became clear that to follow this format would lead to distorted values since patients routinely attempted to utilize the minimum recommended doses when possible instead of the maximum recommended doses. For example, when a recommended dose was "one-to-two tabs every

four to six hours," patients often took one every six hours instead of the allowable two tabs every four hours. The following situation illustrates how these guidelines were utilized to obtain a percentage of usage: patients who used acetaminophen as an adjunctive pain medication, had an allowable minimum dose of 1000 mg. in a 24-hour period, based on the manufacturer's label. A percentage was determined by dividing the number of mgs. taken by the allowable 1000 mg. If a patient took one tab, his or her score was evaluated as "25% usage." This formula was followed for each category.

When evaluating the data, the two medication categories---prescribed pain medications and adjunct medications--were analyzed separately. In addition, the medication usages in both categories was added together then averaged. The investigators chose to group and sum the pain medications because this study did not aim to evaluate specific pain medications, specific types of cancer pain, or how they correlated with each other. For instance, if a specific patient took 80% of prescribed sustained release morphine sulfate, and 60% of p.r.n. prescribed morphine elixir, the percentages were averaged; in this scenario the average of pain medication usage in this category was 70%. This same formula was followed for all pain medications.

Logistical complications. Upon further evaluation of the medication percentages, the researchers concluded that

the original plan for scoring the medication by percent usage did not portray an accurate picture of medication usage if a patient was on p.r.n. medications only. For instance, a patient used only one p.r.n. dose of morphine sulfate elixir for pain control when the order was written as "one-to-two teaspoons every four-to-six hours as needed." In the previously-described scoring method this patient was scored as "25% medication usage" because he took only one of four possible doses in the 24-hour period. A reader might perceive this as inadequate use of p.r.n. pain medications even though this patient used the medications within prescribed guidelines. To further clarify pain medication usage by the patients, the researchers developed an alternative scoring method. Whereas the first method was more accurate in portraying the use of scheduled medications, this new method more accurately indicated whether or not the medication usage was within prescribed/recommended guidelines for p.r.n. medications.

The investigators created three categories for scoring the usage of pain medications in order to more accurately reflect whether pain medications were taken as recommended by a physician. The first category denoted patients who used medications less than the prescribed/recommended range as outlined by either the physicians or manufacturers' labels. Example: the physician prescribed MS Contin 30 milligram (mg.) three times a day. The patient, however,

took the medication only twice a day. Thus, this is below the prescribed dose and is less than the recommended range for this individual. A middle category referred to patients who used the medications within the prescribed/recommended range. Citing the above example, the patient took all three prescribed doses and, therefore, was within the prescribed/recommended range. A third category indicated patient usage which exceeded the prescribed/recommended range. This was seen when the patient took a fourth pill within the 24-hour study period.

Logistical Complications Of The Study

The researchers had originally planned to do a study based on a descriptive correlational design, using 60 patient/care giver dyads. At the outset of data collection, the researchers felt confident they would acquire the 60 dyads. During four months of data collection the investigators found 23 of 48 potential dyad referrals were eligible for the study.

The following are some of the problems accounting for the discrepancy between the projected and actual dyad interviews:

* Several patients who were potential subjects were experiencing excessive pain which rendered them unwilling or unable to participate;
* Several referred patients were in a terminal state that did not allow them to participate;

* Since the researchers experienced a lack of direct contact with the home health case managers in one of the referring Home Health Agencies, referrals were notably less than anticipated;
* Referrals from oncology physicians were less than anticipated despite their stated interest in the study. Two oncology physicians, for example, mentioned difficulty remembering to screen their patients for this study;
* The investigators perceived a lack of enthusiasm on the part of some staff nurses for providing referrals. Some nurses expressed discomfort approaching potential subjects who were in varying states of grief. Other nurses stated feelings that the study would be an invasion of patients' privacy;
* Both nurses and investigators expressed reticence in approaching some patients and care givers about participating in this study because of sensitive home situations;
* Several potential patients were deemed ineligible because they reported no pain and used no pain medicines;
* In several cases, one part of the dyad was willing to participate in the study while the other refused to even discuss cancer openly; and
* Upon arriving at a subjects' home, it was determined by

the investigator that the patient was incapable of providing reliable answers because of medication-induced confusion.

At the end of four months, the investigators petitioned their advisory committee for permission to discontinue data collection efforts. The researchers felt that 23 dyads were sufficient for testing the concepts in question. Furthermore, the pre-determined time frame for data collection had elapsed.

During the interview phase of the data collection process, the investigators encountered assorted unexpected problems. Several were mentioned in the discussion of specific tools, however, one problem was frequently evident: Patients and care givers needed frequent reminders from the researchers to not discuss the answers until both parties had finished completing the first two tools.

Procedure

To identify potential subjects, the investigators contacted medical and radiation oncology physicians, oncology office nurses and home health nurses in the mid-Willamette Valley area. The purpose of the study, eligibility criteria and possible patient benefits were explained. The above cancer specialists identified potential subjects for the researchers. Those identified patients were contacted, via telephone, by one of the researchers to outline the study and request an in-home

visit to administer the research tools. The study proceeded as follows:

1. Referrals were obtained from various health care providers.
2. The investigators contacted the cancer patient/care giver dyads by phone, and explained the purposes of the investigation and sought permission for a home follow-up visit.
3. During the home visit, the researchers explained the purposes, potential risks and benefits of the study to the patients and care givers. These concepts were delineated in the Subject Consent Form that was signed prior to initiating the study (see Appendix F). The researchers informed both the patient and care giver that individual responses would be kept confidential. However, both parties were encouraged to discuss their individual responses with each other after completing the tools. If they wished additional information, they were encouraged to discuss their concerns with their primary health care provider.
4. Demographic information was obtained from the patients' medical records. These data included such details as age, culture, gender, primary cancer sites, any known metastases, current oncologic treatment, etc. The rationale for

seeking such data was to explore incidental correlations, such as the relationships between patients' pain and specific tumor sites.

5. The researchers provided the instrument packets containing the tools, to both the patients and care givers, reminding them to complete the items independently. The standardized, prepared explanation for each tool was given before the subjects completed that tool (see Appendix G). The researchers did not deviate from the prepared explanation. The researchers remained with the subjects during completion of the tools and collected the completed tools, after ensuring that all data were collected. In cases where incomplete data were collected, the dyad was disqualified from the study.
6. The relationship was then terminated.

Results

Research Question Number One

The data were analyzed using the Statistical Package for Social Sciences (SPSS). For Research Question Number One, a paired t-test revealed no statistically different attitudes about the use of pain medications between the patient and care giver at α=.05 level. A paired t-test was utilized as part of this study because of the intimate nature between patients and care givers. In other words,

patients and care givers had relatively similar attitudes regarding fear of addiction (t= -.987) tolerance (t= -1.83), fear of side effects (t= -.56) and locus of control (t= -.91) in the use of pain medications. Patients consistently scored lower on these concepts than the care givers, however, those differences were not statistically significant, as previously stated. A larger sample might have demonstrated a statistically significant difference in these scores.

Research Question Number Two

The data revealed no significant differences between the patients and care givers scores on the BPIT (t= .49), which addressed Research Question Number Two. In this study there were ten concordant and 13 discordant dyads (see Appendix H); concordance between patients and care givers within a dyad was defined as a difference no greater than 2.0 cm. on a 10 cm. scale. Patients consistently scored their pain higher on the VAS than the care givers rated the patients' pain, but not enough to be statistically significant. As depicted in Figure 1. the mean value for the patients' BPIT was 4.4 centimeter (cm.) on the 10 cm. Visual Analogue Scale. The mean value for the care givers' BPIT was 4.0 cm. A larger sample might have revealed this difference to be of significance.

No Pain	4.4 BPIT - Patient Mean	Worst Pain Imaginable
No Pain	4.0 BPIT - Care Giver Mean	Worst Pain Imaginable

Figure 2. BPIT Values

Research Question Number Three

Regarding Research Question Number Three, there was no statistical significance when comparing the patients' and care givers' scores on the HALS to the use of pain medication by either percentage of total allowable doses or the second scoring method of medication use by the three prescribed/recommended categories. The correlation coefficients are demonstrated in Table 1.

Table 1

Correlation Coefficients of Medication Use

	Med. %	Med.Cat.
Patients	P value	P value
fear of addiction	-.2564	.0745
fear of tolerance	-.2047	.0361
fear of side effects	-.0172	.0687
locus of control	-.0226	.1956
Care Givers		
fear of addiction	-.0775	.2878
fear of tolerance	.1019	.3224
fear of side effects	-.0258	.0405
locus of control	-.0887	.0776

Notes: 1) No correlations were significant at the .05 level; 2) Med. cat. refers to the three pain medication use categories.

Sample Description

The study sample was composed of 23 patient/care giver dyads (see Tables 2 and 3). There were 11 female and 12 male patients, yet there were 16 female and seven male care givers. The mean age of the patients was 67 while the mean age of the care giver was 57. The primary diagnoses were of the lung (35%) and

Table 2

Patient Demographics

Age: Range = 31-95		Gender:	Female	11	(48%)
Mean = 66.6			Males	12	(52%)

Diagnosis:

Lung =	8	(35%)
Genito-urinary =	8	(35%)
Gastro-intestinal =	3	(13%)
Other =	4	(17%)

Time Since Diagnosis in Months:
Range = 1-312
Median = 8 months

Education:	Up To High School	14	(61%)
	Some College	8	(35%)
	College Degree Plus	1	(4%)

Current Treatment:

No Treatment =	15	(65%)
Radiation Therapy =	2	(9%)
Chemotherapy =	3	(13%)
Both treatments =	3	(13%)

Who Decides When Pain Medications Are Given?

Patient =	11	(48%)
Care Giver =	2	(8%)
Both =	10	(44%)

Table 3

Care Giver Demographics

Age: Range = 31-80	Gender:	Female	16 (70%)
Mean = 57		Male	7 (30%)

Education:	Up To High School	17	(74%)
	Some College	3	(13%)
	College Degree Plus	3	(13%)

Relationship To Patient:		
Spouse =	14	(61%)
Offspring =	5	(22%)
Other Relative =	4	(17%)

genito-urinary (35%), while gastro-intestinal (13%) and other (17%) comprised the cancer sites. The genito-urinary category consisted of gynecologic and prostate cancers. In addition, the gastro-intestinal category consisted mostly of oropharyngeal, esophageal, colon and stomach cancers. The fourth ("other") category was comprised of breast, multiple myeloma and jaw cancers.

A cross-tabulation of diagnosis and gender is revealed in Table 4.

Table 4

Cross-tabulation of Diagnosis and Gender

Diagnosis	Female	Male
Lung	1	7
G.U.	6	2
G.I.	0	3
Other	4	0

The range of time since diagnosis was one month to 312 months (27 years), however the median was approximately 8 months. Levels of education included patients who had attended up to high school (61%), some college (35%) and some graduate school (4%). Care givers, on the other hand, included those who had attended up to high school (74%), some college (13%) and some graduate school (13%).

Most patients were not receiving chemotherapy or radiation therapy (65%), yet 9% were receiving radiation therapy, 13% were receiving chemotherapy and 13% were receiving both modalities. In 48% of the dyads, the patients decided when to use pain medications; in 9% of the dyads the care givers made

this decision, and in 44% of the dyads this decision was made jointly. The 24-hour study period was characterized by 61% of the participants as a typical day versus 39% who described it as an atypical day of activity.

The investigators sought to measure the use of pain medications in percentages and medication-use categories. Percentages were based on the frequency of medications taken using the prescribed/recommended dosage ranges of narcotic and adjunctive pain medications. The percent of medication usage ranged from 15%-125% based on the investigators' scoring method. The mode of percentage was 100%; the mean was 84.3%.

Medication-use categories provided the following results:

Table 5

Medication Use by Category

1: Med. use < prescribed/recommended range:	3 (13%)
2: Med. use = prescribed/recommended range:	19 (83%)
3: Med. use > prescribed/recommended range:	1 (4%)

As part of the HALS, the concept of fear of

addiction to pain medications was evaluated. The range of possible scores was 5-25; a lower score indicated more fear of addiction while a higher score indicated less fear of addiction to pain medications. The range of actual scores of this concept for patients was 8-25; for care givers, the range was 13-25. The mean score of the patients was 16.8; the mean score of the care givers was 17.7. This difference was not statistically significant at the .05 alpha level. The data suggested that three dyads were discordant while the remaining 20 dyads were concordant for this concept of fear of addiction; concordance was defined as a difference of no greater than five points on HALS.

This study evaluated the concept of fear of tolerance to pain medications as a deterrent to pain medication use. The possible range of scores was 5-25; a lower score indicated more fear of tolerance to pain medications while a higher score indicated less fear of tolerance to pain medications. The actual range of scores for patients was 11-20; the actual range of scores for care givers was 13-23. The mean score of the patients was 16.7; the mean score of the care givers was 17.8. This difference was not

statistically significant at the .05 alpha level. The data showed that one dyad was discordant while the remaining 22 dyads were concordant for this concept of fear of tolerance to pain medications; concordance was defined as a difference of no greater than five points on the HALS.

The concept of fear of side effects of pain medications was also investigated using the HALS. The possible range of scores was 5-25; a lower score indicated more fear of side effects to pain medications while a higher score indicated less fear of side effects to pain medications. The actual range of scores for the patients was 10-23; the actual range of scores for the care givers was 12-20. The mean score was 16.0 for the patients; the mean score for care givers was 16.4. This difference was not statistically significant at the .05 alpha level. The data showed that one dyad was discordant while the remaining 22 dyads were concordant for this concept of fear of side effects to pain medications; concordance was defined as a difference of no greater than five points on the HALS.

The concept of locus of control (whether

respondents feel cancer pain can be controlled) was evaluated using the HALS. The range of possible scores was 8-40; a lower score indicated lesser confidence that cancer pain can be controlled, whereas a higher score indicated greater confidence that cancer pain can be controlled. The patients' actual range of scores for this concept was 14-32; the care givers' actual range of scores was 14-29. The patients' mean score was 21.2; the care givers mean score was 22.4. This difference was not statistically significant at the .05 alpha level. The data showed that one dyad was discordant while the remaining 22 dyads were concordant for locus of control; concordance was defined as a difference of no greater than eight points on the HALS.

The investigators developed a system by which to rank the dyads' responses to the four HALS' concepts. This system provided a better understanding of the study sample. An average score of each patient and care giver's response, within each dyad, was obtained. For the three concepts of fear of addiction, fear of tolerance and fear of side effects, the following scale was used: 5-11 indicated greater fear; 12-19 indicated moderate fear; and 20-25 indicated lesser

fear.

The concept of locus of control required a different scale with which to rank the dyads' responses to this concept. This was because locus of control had eight items compared to five items for each of the other three concepts. Again, the average scores were obtained as previously described. A score of 8-18 indicated a lesser feeling of control; 19-29 indicated a moderate feeling of control; and 30-40 indicated a greater feeling of control. Table 6 illustrates that, for each of the four concepts, the majority of dyads scored in the moderate range.

Table 6

Ranges of Dyad Attitudes

	Greater	Moderate	Lesser
Fear of addiction	0	20	3
Fear of tolerance	0	20	3
Fear of side effects	0	21	2
Locus of Control	1	19	3

At the .01 a level of significance, the following noteworthy correlations were evident:

* the fear of addiction care givers reported correlated positively with their reported fear of tolerance to pain medications;
* the fear of addiction care givers reported correlated positively with their reported fear of side effects to pain medications;
* if the patients report less fear of side effects then the care givers report greater locus of control.

Discussion

The sample for this study (23 dyads) was insufficient to validate Hill (1990), Hill et al. (1988) and Twycross and Lack's (1983) belief that attitudes about pain medications influenced the use of these medications. The literature is sparse regarding these attitudinal issues in control of cancer pain. Statistical analysis of data from this study did not show statistical significance with regard to the three Research Questions.

Research Question Number One

There were, however, several secondary and potentially clinically significant inferences to be drawn:

* forty-five of forty-six subjects were Caucasian, English speaking, and literate. A study done in a larger urban setting would presumably yield a more diverse population mix. In addition, a study done in a larger urban area would yield the 60 patient/care giver dyads. This larger sample would present researchers with more statistically significant data because the population would have more diverse cultural and personal experiences which would influence attitudes about pain control, and
* patients and care givers shared similar views with regard to their attitudes about the use of pain medications. A possible explanation for this outcome is the fact that most care givers were spouses (61%) and likely shared similar views and information about pain control.

Research Question Number Two

* patients and care givers had relatively similar perceptions of the patients' pain intensity. This is probably related to the

same factors described above;

* the data suggest that, while dyads may share similar perceptions of pain intensity, there was still a population (five of twenty three patients) who scored their pain intensity greater than 5 cm. on the BPIT. While this was not a primary focus of this investigation, the data implied to the investigators that these patients had unsatisfactory pain control, since a reasonable goal for pain control is "no pain";

Research Question Number Three

* 74% of the referrals were from local home health agencies; the investigators speculated that this population had received similar education about the use of pain medications from home health staff. Patients with this background presumably used the pain medications within the prescribed/recommended guidelines;
* the data do not support the idea that the attitudes of the patients and their care

givers interfere with the patients' use of pain medications. In other words, patients took pain medications as prescribed/recommended despite any concerns they may have had as expressed on the HALS.

* in 52% of the dyads, the care giver or both patient and care giver decided when the pain medications were to be taken. Patients frequently experience drowsy and forgetful periods. Having a care giver share responsibility for pain medication usage presumably helps ensure accurate dosing, and
* at the .05 level of significance, men were more likely to take their pain medication than women. The investigators are uncertain why this occurred.

Summary

Clinical experiences and an extensive review of the literature support the notion that cancer patients in home-care settings experience unnecessary pain. The researchers' conceptual framework suggested that patients and care givers bring different sets of life experiences to their encounters with cancer pain. It

was believed these experiences would influence the attitudes about the use of pain medications and the perceptions of the patients' pain intensity. Furthermore, it was felt that these attitudes and perceptions would influence the actual use of pain medications, which was the central focus of this study. In addition, it was postulated that the use of pain medications would influence the patients' functionality. The data were inconclusive to fully answer the research questions.

Using a descriptive correlational design of 23 patient/care giver dyads, this study was conducted to: 1) attempt to quantify those attitudes which affect cancer patients' use of pain medications in home care settings; 2) describe the patients' and care givers' perceptions regarding the intensity of the cancer patients' pain; and, 3) describe the relationship between those perceptions, and attitudes and the actual use of pain medications. The data suggested that patients and care givers shared relatively similar attitudes towards the use of pain medications and the perceptions of the patients' pain intensity. Additionally, patient and care giver attitudes did not

significantly influence the use of pain medications by patients for cancer pain control.

Implications For Nursing

Current economic trends suggest that cancer patients and their symptoms will be cared for increasingly in home care settings (Ferrell and Schneider, 1988). While successful home care involves managing multiple problems, such as nutrition, elimination, and mobility, one of the immediate areas continues to be pain control in order to maximize functionality.

The data demonstrated that over 50% of the care givers were involved in the decision making about the patients' use of pain medications. A reasonable inference can be made from this study that nurses should provide care givers with information and support regarding therapeutic care of cancer patients with pain. No significant differences or correlations within dyads regarding the three research questions actually were demonstrated, yet two other pertinent deductions seem reasonable based on the data:

* Nurses should not enter into home care settings with preconceived notions about the patients' and

care givers' attitudes with regard to the use of pain medications;

* Nurses should not assume that differences in attitudes or perceptions of the patients' pain intensity will influence the actual use of pain medications by the patients.

Pain control and optimal functionality were identified in this Conceptual Model as the ultimate goals for patients with cancer pain. It is incumbent upon nurses providing care to these patients to include assessment of the dyads' attitudes and perceptions about the use of pain medications at the start of care. This is an integral part of in-home cancer care and will do much to facilitate optimum functionality among patients.

Suggestions For Future Studies

Two primary limitations of the study included a small sample population and a lack of ethnic and demographic diversity. The researchers suggest the following ideas for future studies which will strengthen the understanding of cancer pain control in the home care setting. These include:

* What is the effect of non-family member care givers and other family members on patients'

and care givers' perceptions about patients' pain intensity and pain medication usage?

* What impact does the patient's willingness to be medicated have on the use of pain medications? More specifically, attempt to measure the degree of patients' willingness to be medicated for pain regardless of their attitudes or perceptions about the use of pain medications?
* To what degree do the care givers impede the use of the pain medications by the patients because of the care givers' attitudes about pain medications?
* How effective are pain medications in controlling cancer pain despite the influence attitudes about pain medication have on the actual use of pain medications?

Other investigators wanting to use these tools may want to consider these modifications to the study:

* conduct a pilot study of five dyads to refine the data collection methods and to ensure inter-rater reliability;
* include a composite score of all three "fear"

concepts in order to provide a wider spectrum for evaluating patients' and care givers' fear toward the pain medications;

* change times on the BPIT to "morning," "afternoon" and "evening" to allow for differences in schedules from one patient to another;
* physically separate the patients and care givers into different rooms during the data collection procedure to prevent respondent bias;
* add word descriptors along the 10 cm. line of the BPIT to capture data from subjects who have difficulty conceptualizing their pain on a 10 cm. line; and,
* use only three categories of pain medication use during the scoring process.

Patients and care givers hold varying attitudes towards the use of pain medications to control cancer pain. It behooves nursing to investigate these attitudes in working with cancer patients and care givers to promote optimal functionality.

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Appendix A

Baumgart Pain Intensity Tool

The Baumgart Pain Intensity Tool (BPIT)
For Measuring Pain Intensity
Patient Version

No Pain _____ Worst Pain Imaginable

6 to 8 A.M.

No Pain _____ Worst Pain Imaginable

2 to 4 P.M.

No Pain _____ Worst Pain Imaginable

8 to 10 P.M.

The Baumgart Pain Intensity Tool (BPIT)
For Measuring Pain Intensity
Care Giver Version

No Pain _____ Worst Pain Imaginable

6 to 8 A.M.

No Pain _____ Worst Pain Imaginable

2 to 4 P.M.

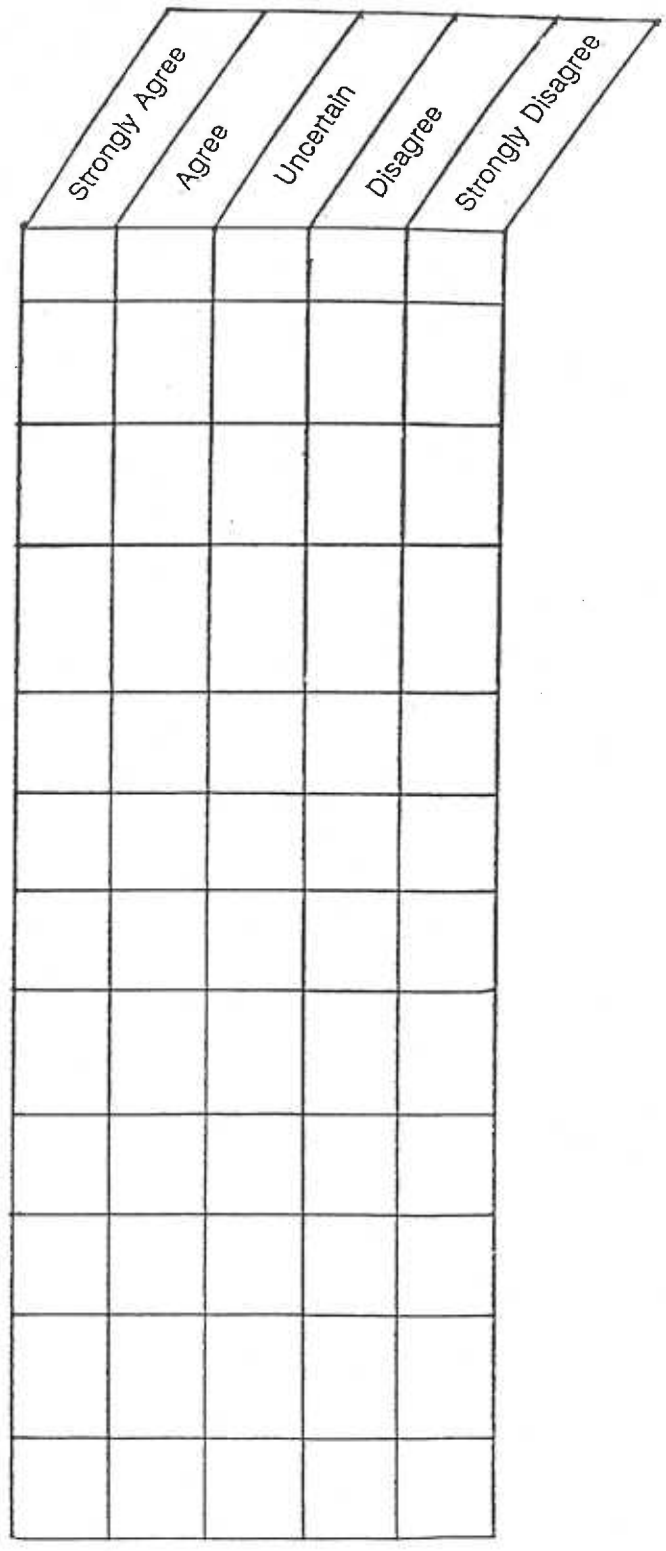
No Pain _____ Worst Pain Imaginable

8 to 10 P.M.

Appendix B

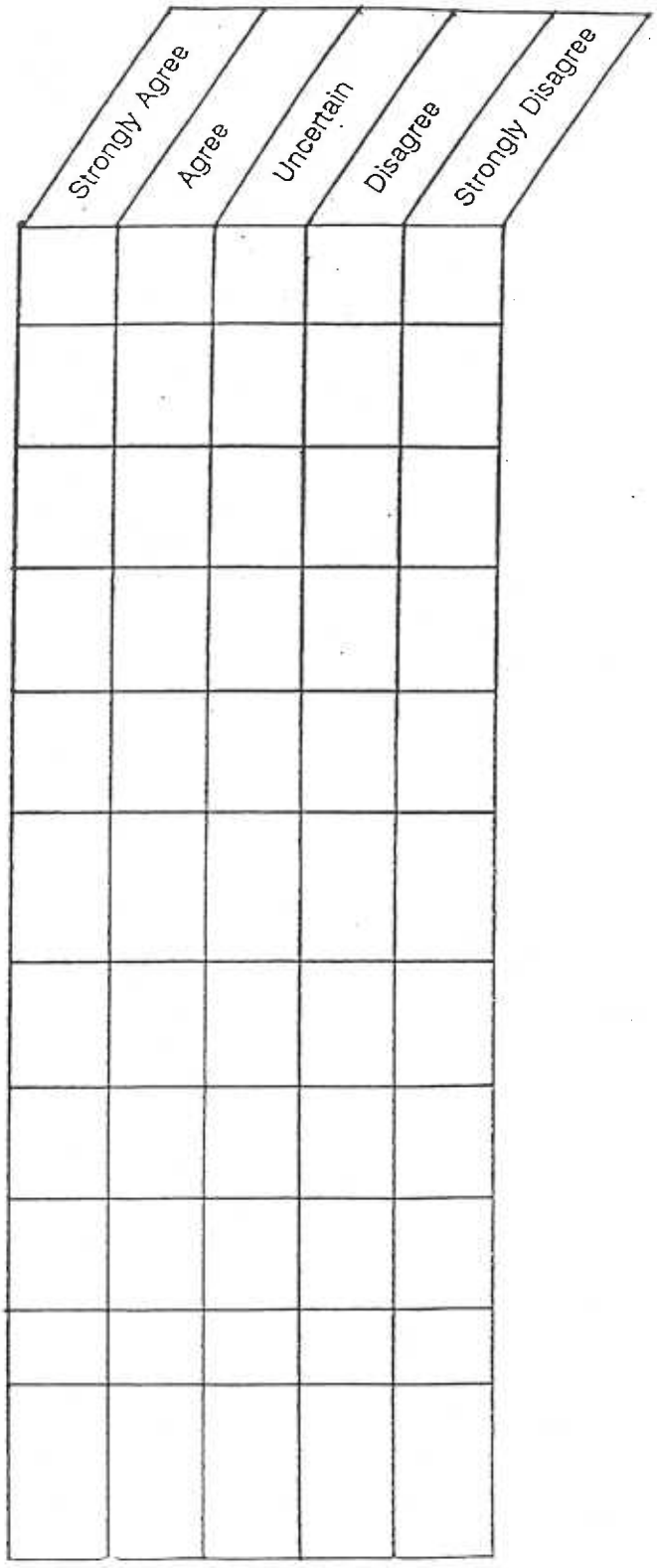
Harvey Attitude Likert Scale (HALS)

HARVEY ATTITUDE LIKERT SCALE (HALS)
Patient Version



1. Cancer pain is beyond my control.
2. I expect to need stronger doses of pain medicine if my pain stays the same or gets worse.
3. Cancer pain is something that can never be fully relieved.
4. Using the pain medications now, means that they won't work for me when I really need them.
5. Pain medication is addicting.
6. Modern medicines have made cancer pain avoidable.
7. I am not afraid to ask for stronger pain medicine.
8. I don't use as much pain medication as the doctor ordered because it makes me too sleepy.
9. Pain medication does not completely control cancer pain.
10. Cancer pain can be easily controlled.
11. I'm not worried about becoming addicted to the pain medication.
12. Cancer pain makes me feel like I'm not in control of my life.

Participant #_____



13. I will build up a resistance to the pain medication.

14. Pain medications interfere with my thinking clearly.

15. The side effects are worth the pain relief I get when I take the pain medicines.

16. If the pain gets worse, I can always adjust my doses to control the pain.

17. I am confident I won't become addicted to the pain medications.

18. I don't want to use pain medicine because it makes me constipated.

19. If I take pain medication on a regular basis I will become addicted.

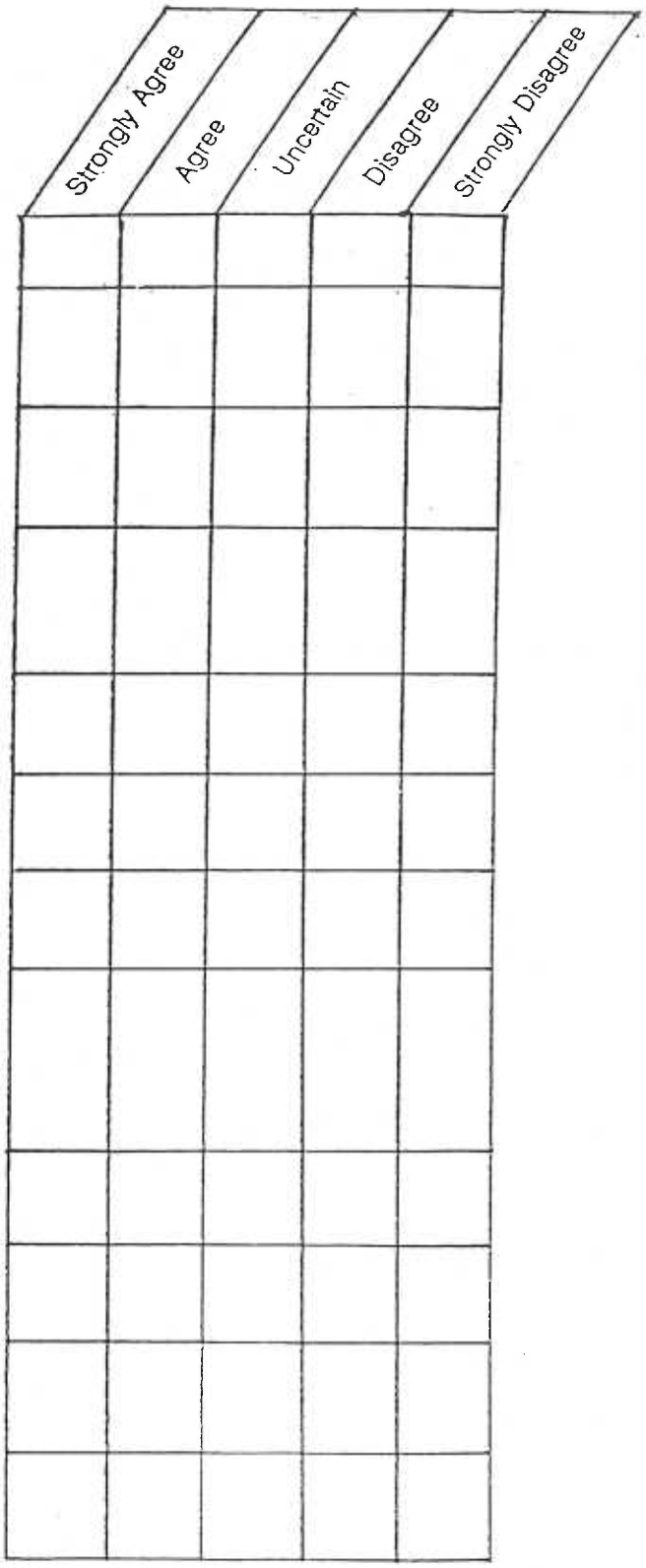
20. Pain is inevitable with cancer.

21. The pain medicine upsets my stomach.

22. I can control my pain.

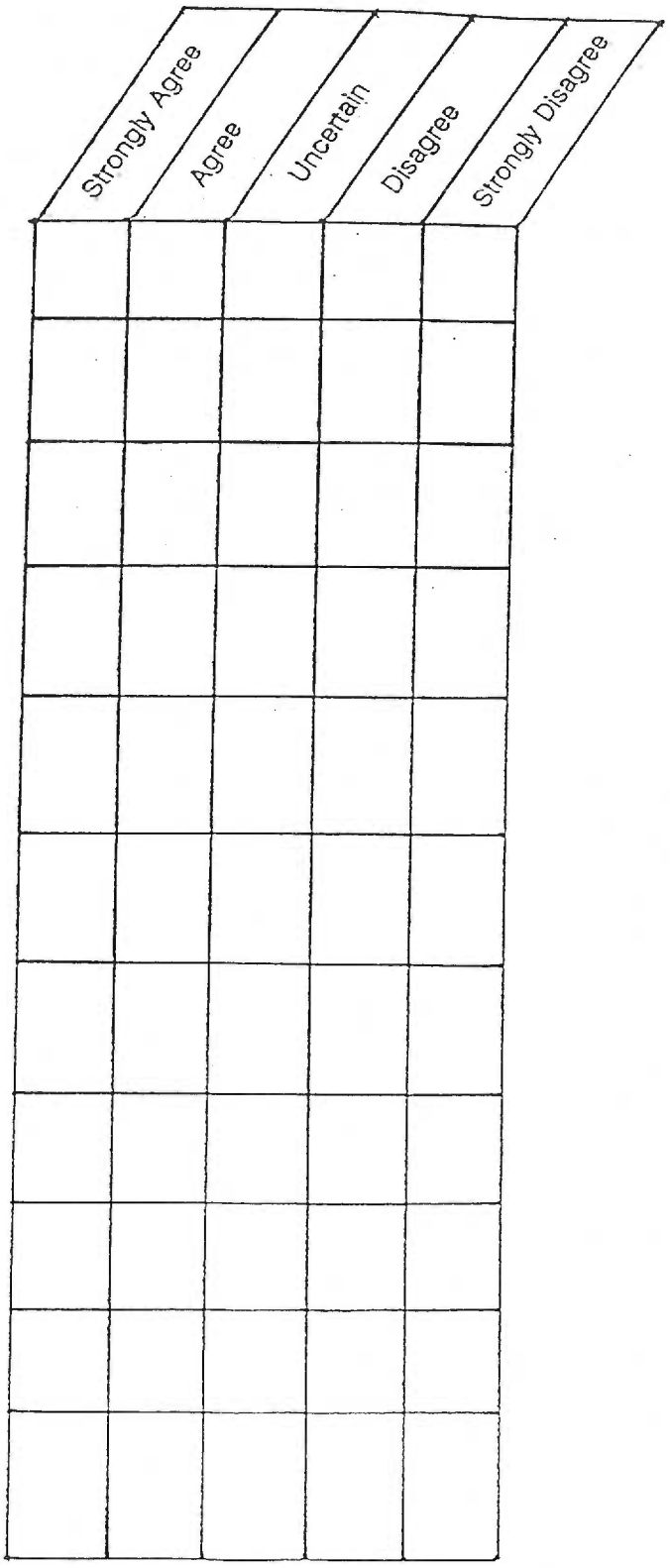
23. I am confident I can take my prescribed pain medication now, and still get pain relief later.

HARVEY ATTITUDE LIKERT SCALE (HALS)
Care Giver Version



1. Cancer pain is beyond a person's control.
2. Cancer pain requires stronger doses of pain medicine if the pain stays the same or gets worse.
3. Cancer pain is something that can never be fully relieved.
4. Using the pain medications early, means that they won't work when they are really needed.
5. Pain medication is addicting.
6. Modern medicines have made cancer pain avoidable.
7. Cancer patients should not be afraid to ask for stronger pain medicine.
8. It is preferable to use less pain medication than the doctor orders because it makes cancer patients too sleepy.
9. Pain medication does not completely control cancer pain.
10. Cancer pain can be easily controlled.
11. Cancer patients should not be worried about becoming addicted to the pain medication.
12. Cancer pain makes a caner patient feel as if "I'm not in control of my life."

Participant #_____



13. Cancer patients will build up a resistance to the pain medication.

14. Pain medications interfere with clear thinking.

15. The side effects are worth the pain relief provided by pain medications.

16. If the pain gets worse, pain medication doses can always be adjusted to control the pain.

17. Cancer patients can be confident they won't become addicted to the pain medications.

18. Pain medicines should be avoided because they cause constipation.

19. Pain medications taken on a regular basis leads to addiction.

20. Pain is inevitable with cancer.

21. Pain medicine commonly causes an upset stomach.

22. Cancer pain can be controlled.

23. Patients can feel confident they can take prescribed pain medications now and still get pain relief later.

Appendix C

Kerns Self-Report Tool

Kerns Self-Report Tool (KSRT)

DEMOGRAPHIC INFORMATION:

Date and Time of Data Collection:_____
Researcher:_____
Dyad Number:_____
Diagnosis:_____
Time Since Diagnosis:_____
Patient: Age:_____ Gender: male female
Highest Level of Education Completed:_____
Ethnicity: Hispanic Native American
Black White Other
Care Giver's Age:____Gender: male female
Highest Level of Education Completed:_____
Ethnicity: Hispanic Native American
Black White Other
Presently Undergoing Radiation Treatment: yes no
Presently Undergoing Chemotherapy Treatment: yes no
Concomitant Illnesses:_____
Relationship of Care Giver to Patient:_____
Who decides when the patient will be given pain medicine to take? pt. c.g. both
Would you characterize the last 24 hours as a typical day of activity? yes no If no, why not?_____
_____
_____

PAIN MEDICATION USE:

Prescribed & Unprescribed Pain Meds:	When Taken:	How Much Was Taken:	Why Was It Taken:

PAIN MEDICATION USE:

Prescribed & Unprescribed Pain Meds:	When Taken:	How Much Was Taken:	Why Was It Taken:

Appendix D

Expert Panel Response Form

Expert Panel Response Form

Dear Expert Panel Member,

Thank you for agreeing to participate in our Master's Research Project on cancer pain in the home care setting. This project has three areas of investigation. Our research questions are:

- Patients and care givers possess significantly different attitudes towards the use of pain medications;
- Patients and care givers have significantly different perceptions of the intensity of pain that cancer patients experience; and
- There is a positive correlation between patients' and care givers' attitudes towards the use of pain medications and the actual use of pain medications.

The four main attitudinal concepts we have identified are fear of addiction, tolerance to pain medications, side effects to pain medications and locus of control. We have developed a tool, called the Harvey Attitude Likert Scale (HALS), which is designed to measure the attitudes of cancer patients and care givers about the use of pain medications. Please evaluate the following statements for content validity. You will recall that content validity is concerned with the sampling adequacy of the content being measured. In other words, these statements are designed to measure knowledge and attitudes in a specific content area.

To the right of each statement you will find the words "Yes" and "No". Please circle "Yes" if each statement adequately reflects the concept of that statement section. Please circle "No" if the statement does not adequately reflect the concept of that statement section. The HALS incorporates positive and negative statements to reduce the possibility of socially desirable responses by the subjects.

It would greatly appreciated if you would complete this form within one week and return to us in the enclosed self-addressed stamped envelope.

Thank you for your assistance!
Sincerely,

Jeff Baumgart Michele Harvey Will Kerns

Please return to:
Will Kerns
860 Pioneer Ct.
Eugene, OR 97401

FEAR OF ADDICTION:

5. Pain medication is addicting.
Yes No

7. I am not afraid to ask for stronger pain medicine.
Yes No

11. I'm not worried about becoming addicted to the pain medication.
Yes No

18. I am confident I won't become addicted to the pain medications.
Yes No

21. I need pain medication on a regular basis to stay comfortable.
Yes No

TOLERANCE TO PAIN MEDICATIONS:

2. I expect to need stronger doses of pain medicine if my pain stays the same or gets worse.
Yes No

4. Using the pain medications now, means that they won't work for me when I really need them.
Yes No

13. I will build up a resistance to the pain medication.
Yes No

17. If the pain gets worse, I can always adjust the doses to control the pain.
Yes No

25. I will use only the non-prescribed medications now, so the prescribed ones will work later when the pain gets worse.
Yes No

SIDE EFFECTS OF PAIN MEDICATIONS:

8. I don't use as much pain medication as the doctor ordered because it makes me too sleepy.
Yes No

14. Pain medications interfere with my thinking clearly.
Yes No

16. The side effects are worth the pain relief I get when I take the pain medicines.
Yes No

20. I don't want to use pain medicine because it makes me constipated.
Yes No

23. The pain medicine upsets my stomach.
Yes No

LOCUS OF CONTROL:

1. Cancer pain is something to be endured.
Yes No

3. Cancer pain is something that can never be fully relieved.
Yes No

6. Modern medicines have made cancer pain avoidable.
Yes No

9. Cancer pain is almost unbearable.
Yes No

10. Cancer pain can easily be controlled.
Yes No

12. Constant pain is not necessary.
Yes No

15. I shouldn't burden others by talking about my pain.
Yes No

19. Other people have it worse than I do, so I shouldn't complain.
Yes No

22. Pain is inevitable with cancer.
Yes No

24. I can control my pain.
Yes No

Discarded HALS items from Appendix D

FEAR OF ADDICTION TO PAIN MEDICATIONS: Number 21.

FEAR OF TOLERANCE TO PAIN MEDICATIONS: Number 25.

FEAR OF SIDE EFFECTS TO PAIN MEDICATIONS: All approved.

LOCUS OF CONTROL: Numbers 1, 9, 12, 15 and 19.

Expert panel members rejected the above items because they felt the original HALS statements did not accurately measure the validity of the concept in question for that item.

New HALS items from Appendix B

FEAR OF ADDICTION TO PAIN MEDICATIONS: 19. If I take pain medications on a regular basis I will become addicted.

FEAR OF TOLERANCE TO PAIN MEDICATIONS: 23. I am confident I can take my prescribed pain medication now, and still get pain relief later.

LOCUS OF CONTROL: 1. Cancer pain is beyond my control.
9. Pain medication does not completely control cancer pain.
12. Cancer pain makes me feel like I'm not in control of my life.

All above approved items are written here for the HALS Patient Version. These items were also reworded to be appropriate for the HALS Care Giver Version.

Appendix E

Expert Panel Responses

Expert Panel Responses

Item #	MD	MD	OCNS	OCNS	RN	RN	RN	% AGREE
1			No			No		71.4
2	No							85.7
3								100
4						No		85.7
5						No		85.7
6								100
7						No		85.7
8								100
9	No		No			No		57.1
10			No					85.7
11								100
12	No		No					71.4
13								100
14								100
15	No		No	No		No		42.5
16								100
17			No					85.7
18						No		85.7
19	No		No	No				57.1

Item #	MD	MD	OCNS	OCNS	RN	RN	RN	% AGREE
20				No				85.7
21			No	No				71.4
22	No							85.7
23								100
24						No		85.7
25	No		No			No		57.1

Note: Empty boxes indicate agreement with the statements.

Expert Panel Responses To Replacement Statements

Item #	MD	MD	OCNS	OCNS	RN	RN	RN	% AGREE
1								100
9								100
12	No							85.7
21								100
25								100

Note: Empty boxes indicate agreement with the statements. Items #15 and 19 from the original HALS were deleted from the final version. Subsequently, the order of items were renumbered with the inclusion of the replacement statements.

Appendix F

Subject Consent Form

Subject Consent Form

Dear Participant:

Thank you for agreeing to participate in this research study. The nurse researchers are studying attitudes about pain control in persons with cancer. The risks to both of you by participating are that you may discover differences in your attitudes toward cancer pain control. These differences may create tension in your relationship with each other. If there are differences you wish to explore further, you will be referred to your primary health care provider. The possible benefits are that you may develop a better understanding of your own pain and therefore become more skilled at managing it. Other cancer patients may benefit from your participation because the factors which influence cancer pain control may be identified. Your participation is voluntary and you have the right to withdraw from this research study at any time. There will be no penalty or withholding of medical, nursing or support services if you decide to withdraw. Any information obtained from you will be kept strictly confidential and you will not be identified in any way when the results of this research study are released.

If you have any questions about this study or the people conducting it, you may call_____, who is one of the nurse researchers, or Charold L. Baer, R.N., Ph.D., FCCM, CCRN, who is the research advisor for these students. This study has been approved by the Investigational Review Boards at McKenzie-Willamette Hospital, Sacred Heart General Hospital and The Oregon Health Sciences University.

We,_____(patient's printed name),

_____(care giver's printed name) have read and understood all of the information given above. All of our questions have been answered to our satisfaction and we voluntarily agree to participate in this research study.

_____ _____
Signature of Patient Date

_____
Signature of Care Giver

I, the undersigned, have fully explained the purpose of this research study to the above patients/care givers.

_____ _____
Signature of Investigator Date

Appendix G

Explanation Of Study to Patients/Care Givers

Explanation Of Study to Patients/Care Givers

You are being handed one form to fill out which relates to the patient's cancer pain. **(RESEARCHER: HAND OUT THE BPIT SCALES TO THE SUBJECTS.)** When answering this set of questions only, it is important that you answer from the perspective of the cancer patient. Care givers: please respond by marking on the lines how intense you think the patient's pain is.

This first question has three parts to it and is asking you to rate the intensity of the patient's pain. Please make a slash mark of approximately one-half inch length through each of the three different lines. These marks indicate the intensity of the patient's pain (or how much it hurts) for the different times of day. The top line is for when the patient awakens in the morning, approximately 6-8 A.M.; the middle line is for mid-afternoon, approximately 2-4 P.M., and the third line is for late-evening, approximately 8-10 P.M. The scale is set up so that "no pain" is on the left side of the line, and "the worst pain" is on the right. Both the patients and care givers are responding to this question because we want to find out both parties' ratings of the patient's pain intensity.

(RESEARCHER: UPON COMPLETION OF THE BPIT, BEGIN EXPLANATION OF THE HALS AND HAND OUT HALS.)

The next form is used to evaluate your attitudes about the use of pain medications. You will find 25 statements with columns to the right. The first column will read "Strongly Agree" , the second "Agree", the third "Uncertain", the fourth "Disagree", and fifth "Strongly Disagree". For each statement, please put a mark in the appropriate column which most closely reflects your own attitude about that statement. Care givers: please answer these statements from your own viewpoint and not that of the patient.

(RESEARCHER: UPON COMPLETION OF THE HALS, BEGIN EXPLANATION OF THE KSRT.)

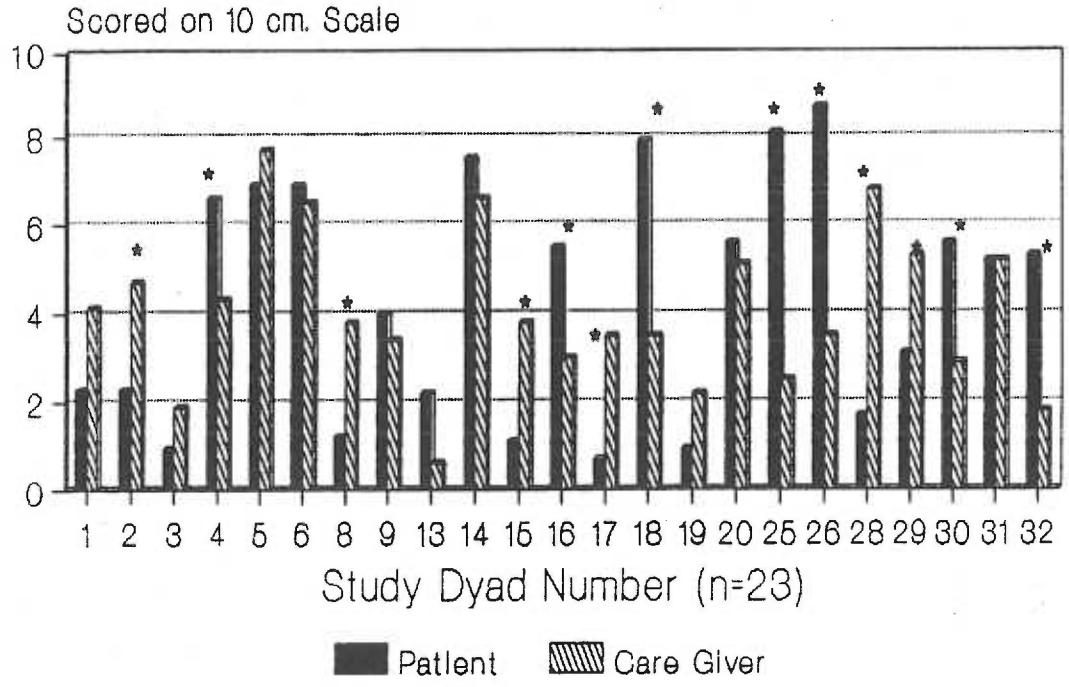
This last tool is to find out when and why the patient takes his or her pain medications. In other words, what factors influence the patient's pain medication schedule. For example, do you take the pain medicine before an expected activity, such

as getting out of bed or going for a walk? Or do you take the pain medicine because the pain is constant? We are especially interested in pain medications your doctor has prescribed. These would include pain medicines such as Morphine, Tylox, Percodan, Tylenol #3, or Demerol. We are also interested in any other pain medications you may use to control pain, which the doctor may or may not have prescribed. These could include over-the-counter medicines such as aspirin, Tylenol, Advil or Bufferin.
(RESEARCHER: COMPLETE THE REST OF THE TOOL, ANSWERING ALL OF THE QUESTIONS. MAKE SURE ALL ITEMS ON ALL OF THE TOOLS ARE COMPLETED.)

Appendix H

Average Pain Intensity Scores

Average Pain Intensity Scores
For Cancer Patient/Care Giver Dyads



Data collected by Baumgart Pain Intensity Tool (BPIT)
*=Discordant Dyads (difference >2.0 cm.)

Abstract

The researchers identified that cancer pain control in the home care setting is a significant problem. Clinical experiences and the literature reinforce this idea. The reasons for inadequate pain control are multifactorial. The researchers sought to identify cancer patients' and care givers' attitudes and perceptions about pain and pain medications which may impede pain medication usage. In addition, the study investigated the influences these attitudes and perceptions had on the actual use of pain medications. This descriptive correlational study analyzed data from 23 cancer patient/care giver dyads. At the .05 level of significance the data suggested: there was no significant correlation between the patients' and care givers' attitudes towards the use of pain medications; there was no significant difference in the perceptions of the patients' pain, and there was no correlation between the attitudes towards the use of pain medications and the actual use of pain medications.
It is incumbent upon nurses providing care to patients in the home care setting to include ongoing assessment of the dyads' attitudes and perceptions about the use of pain medications as part the nursing care plan.

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