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The relationship between sleep-wake disturbance and pain in cancer patients admitted to hospice home care

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The Relationship Between Sleep-Wake Disturbance and Pain in Cancer Patients

Admitted to Hospice Home Care

by

Marjorie Acierno

A thesis submitted in partial fulfillment
of the requirements for the degree of
Masters of Science
College of Nursing
University of South Florida

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ABSTRACT

There is evidence of a relationship between sleep-wake disturbances and pain variables in cancer patients. It is hypothesized that pain affects all aspects of sleep patterns. Pain has been known to affect sleep disturbances; however there are different facets of sleep-disturbances and pain that can be evaluated. These variables include pain distress, pain intensity, pain at its worst, relief from pain, sleep distress, how well the patient sleeps, how tired one feels, and drowsiness distress. Several studies identify relationships between sleep-disturbances and pain. This study using secondary analysis was designed to correlate variables related to sleep-wake disturbance and pain in cancer patients admitted to hospice home care. The study sample included 209 cancer patients from a previously completed clinical trial with various cancer diagnoses. Results of sleep and pain variables were re-analyzed using Pearson correlations. The results showed significant positive relationships between pain distress and sleep distress ($p = .000$), difficulty sleeping and pain intensity ($p = .008$), and sleep distress and pain at its worst ($p = .008$). There were no significant relationships found between sleep distress and relief from pain, pain distress and how well the patient sleeps, pain distress and how tired one feels, and pain distress and drowsiness distress.

Sleep-wake disturbances and pain have been studied in cancer patients, but there is little known concerning pain and its correlation to sleep disturbances of cancer patients admitted to hospice home care. This study provided important information on the relationship between sleep-wake disturbance and pain variables in this group of cancer patients. This study provides data to support the necessity to provide complete and accurate assessments of sleep and pain symptoms on admission to hospice home care and throughout the patient's care to aid in improved quality of life.

Chapter I

Introduction

The American Cancer Society (2007) estimates 1,444,920 new cancer cases for both sexes and all tumor sites in 2007. Also, an estimated 559,650 people will die of cancer in 2007. From the onset of diagnosis, the cancer patient is faced with many psychological and physiological changes, usually as a combination of factors increasing morbidity by causing symptom distress. Pain distress and sleep distress are addressed within the concept of symptom distress. Symptom distress has been defined as “the mental anguish or suffering caused by the symptom and it is the emotional component of the symptom experience” (De Geest & Moons, 2000, p. 458).

Sleep disturbances and pain are common problems for the cancer patient. It has been documented that between 30% and 88% of newly diagnosed and treated cancer patients will report difficulty sleeping (Clark, Cunningham, McMillan, Vena, & Parker, 2004). Also, evidence shows cancer patients experience sleep-wake disturbances with approximately 60% reporting drowsiness and 40% as feeling excessively sleepy (Clark, et. al., 2004). One study by Savard, Simard, Hervouet, Ivers, Lacombe, and Fradet (2005) reported 51% with insomnia and 19% of those meeting the Diagnostic and Statistical Manual of Mental Disorder (DSM-IV) diagnostic criteria. It is important to note that all reported sleep disturbances or insomnia do not meet the DSM-IV criteria for the diagnosis of insomnia. This lack of criteria would not justify disregarding sleep

disturbances as a major concern for cancer patients in hospice home care.

There are many factors affecting sleep patterns in cancer patients including demographics such as age and female sex, psychological issues, life style factors, radiation treatments, surgical intervention, local invasion of the tumor, byproducts of tumor activity, chemotherapy, hormonal therapy, and corticosteroids. It also has been documented that insomnia is present more frequently in cancer patients than patients in good health. There are several disease-related factors influencing sleep patterns in cancer patients. Pain is a primary cause of sleep disturbance with pain known to be affecting 80% of cancer patients (Vena, Parker, Cunningham, Clark, & McMillan, 2004) and according to the National Comprehensive Cancer Network (NCCN) practice guidelines (2007) is documented as the most common symptom associated with cancer .

Pain, according to NCCN guidelines, affects the quality of life of cancer patients through many debilitating outcomes including decreased comfort, isolation from friends and family, and lack of motivation (NCCN, 2007). In a study on veterans with cancer, it was found that pain caused the most significant hindrance to sleep and ambulation (McMillan, Tittle, Hagan, & Laughlin, 2000). This present research study will address the variables of pain and the relationship of pain to sleep-wake disturbances as a secondary data analysis from a previous clinical trial.

Problem Statement

Sleep-wake disturbances and pain have been studied in cancer patients, but there is little known concerning pain and its correlation to sleep disturbances of cancer patients admitted to hospice home care. The NCCN (2007) reports 75% of cancer patients with advanced disease experience pain and over 50% of cancer patients report sleep

disturbances related to their pain (Theobald, 2004). Since the correlation of pain and sleep-wake disturbances has been established in cancer patients, it is imperative for health care providers to obtain accurate assessment of pain and sleep-wake patterns and to understand the relationship between them in the subgroup of cancer patients in hospice home care. This information will assist health care providers to implement appropriate and effective treatment. The purpose of this study is to evaluate the relationships between sleep-wake disturbance and pain variables in hospice home care patients with cancer.

Research Questions

The following questions are the focus of this study:

1. Is there a significant correlation between sleep distress and each of the following variables: pain distress, pain intensity, pain relief, and pain at its worst in cancer patients admitted to hospice home care?
2. Is there a significant correlation between pain distress and each of the following variables: how well the person sleeps, how tired the person feels, and distress from drowsiness in cancer patients admitted to hospice home care?

Definition of Terms

1. *Sleep-wake disturbances* refer to issues with daytime drowsiness and night-time sleep problems (Clark et al., 2004).
2. *Insomnia* is a sleep disturbance (O'Donnell, 2004). According to the DSM-IV and The International Classification of Sleep Disorder it is defined based on criteria and is labeled as insomnia syndrome. It is characterized by either or both of the following: difficulty initiating sleep, difficulty maintaining sleep with corresponding sleep efficiency less than 85%, and occurs at least three nights per week causing significant

impairment of daytime functioning including fatigue or marked distress. The duration is also a factor as transient or situational insomnia is defined as insomnia lasting one month or less, subacute insomnia is defined as insomnia lasting more than one month and less than six months, and chronic insomnia lasting six months or more (Savard et al., 2005).

3. *Pain* is defined in NCCN guidelines as “an independent and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (NCCN, 2005, p. 23).
4. *Pain distress* is defined as the mental anguish or suffering caused by pain.
5. *Sleep distress* is defined as the mental anguish or sufferings caused by sleep disruptions.

Significance to Nursing

Cancer patients live with many distressing issues related to their disease process. As health care providers, registered nurses and advanced practice nurses need to understand pain and sleep disturbances in cancer patients enrolled in hospice home care. An adequate evaluation of the patient’s pain and sleep disturbances in addition to an understanding of the relationship between pain and sleep will assist in providing guidance for appropriate intervention. Results of this study are intended to reveal clinical information on the relationship between pain variables and sleep-wake disturbance variables which may improve the quality of life for cancer patients receiving hospice home care.

Chapter II

Review of the Literature

The research articles summarized provide current knowledge regarding pain and sleep-wake disturbances in cancer patients. The information is quantitative and qualitative presenting evidenced-based results linking pain and sleep-wake disturbances in the cancer patient and non-cancer patient populations. The current published research highlights the significance of understanding patterns of sleep-wake disturbances and the relationship to pain in cancer patients admitted to hospice home care.

Conceptual Framework

Model for a Peaceful Death

There is evidence demonstrating the correlation between pain and sleep-wake disturbances in cancer patients. The degree of feeling drowsy, lack of energy, difficulty sleeping, how tired one feels, and how well one sleeps are influenced by pain. Notions of distress from pain and perceived level of pain in cancer patients admitted to hospice are critical in the conceptual framework illustrating the components of the sleep-wake disturbance construct. The Model for a Peaceful Death (Emanuel & Emanuel, 1998) is specific to end of life concerns (Figure 1) and includes fixed variables and modifiable variables. In this model, fixed variables are defined as age, gender, and diagnosis. Modifiable variables are considered to be physical, psychological, social, and spiritual needs of patients. The present study includes only patient pain and sleep, which are

considered in the model to be modifiable characteristics.

This theoretical framework proposes that the implementation of evidenced-based interventions, psychological and physical, will improve patient quality of life at the end of life. The components of the framework in the diagram that follows (figure 1) were used in the original study. This present study involves selected variables from the previously completed study, specifically, pain and sleep related variables that are located in the physical and psychological symptoms boxes. This is a secondary analysis correlation study that will not have outcomes so the latter aspect of the model is not tested. Demographic variables described in the sample are represented in the fixed characteristics.

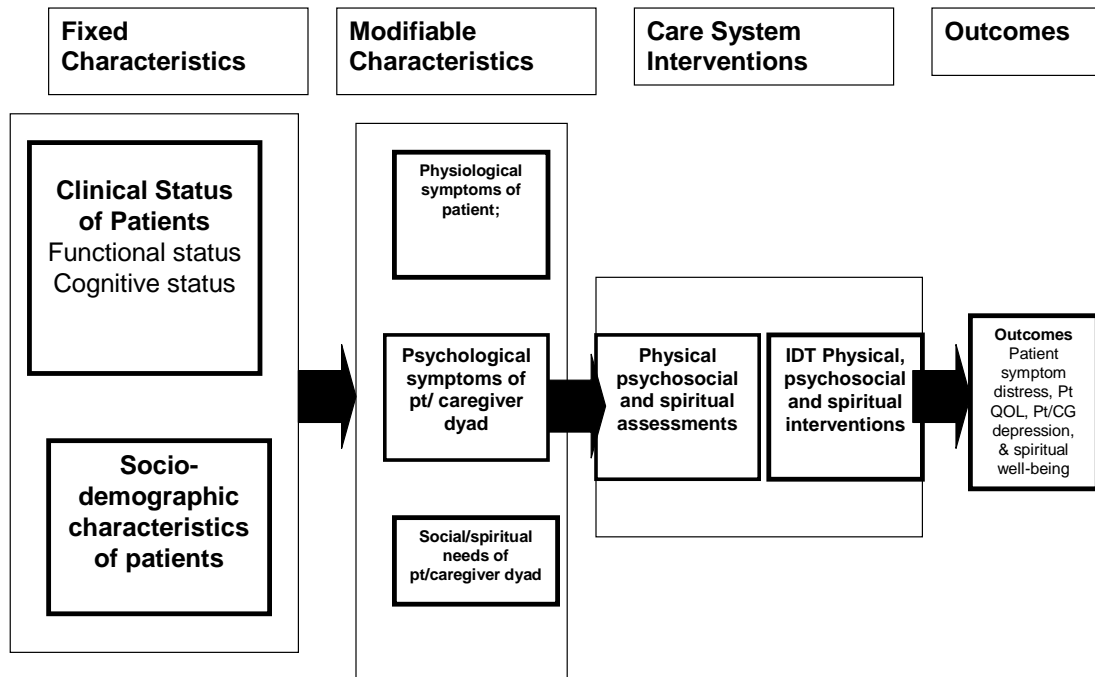


Figure 1. Modified Emanuel & Emanuel (1998) Model for a Peaceful Death

Empirical Literature

Pain and Insomnia

Insomnia has been studied in populations not specific to hospice patients; however the data are germane to understanding sleep-wake disturbances in relation to pain in cancer patients under the care of hospice. A non-experimental, cross-sectional study by Wilson, Eriksson, D'Eon, Mikail, and Emery (2002) was conducted to assess insomnia and depression, which was determined to be common with chronic pain. The combined effect of major depression and insomnia on individuals with non-malignant chronic pain was assessed. Data were collected from 150 patients, who reported having chronic pain. Multiple regression analyses were made to determine whether the sleep disturbance contributed exclusively to the prediction of pain severity and depression. It was found that there was a direct correlation between severity of insomnia, major depression, and chronic pain.

A non-experimental, cross-sectional quantitative study by Ohayon (2004) was conducted to investigate pain and insomnia in the general population. The sample for the study were non-institutionalized residents aged 15 or over living in the United Kingdom, German, Italy, Portugal and Spain. Inclusion criteria included an insomnia symptom at least three times per week for at least one month and minimal consequences on daytime functioning. No other inclusion criteria were stated in the research article. Pain and insomnia symptoms were analyzed and correlated with the use of post-stratification of N-values, standard errors chi-square test bi-variant analysis with SUDAAN software.

Results of the study by Ohayon (2004) showed several associations between sleep disturbance variables, pain variables, and demographics of the participants. There was a

positive relationship between pain and number of insomnia symptoms compared to participants with insomnia and no complaints of pain. There was a positive relationship between middle aged individuals with a chronic painful physical condition (CPPC) and insomnia symptoms. It was interesting that the study results showed that anxiety is not significant in insomnia symptoms because it has been reported as causing insomnia symptoms in other studies. The participants with CPPC experienced insomnia symptoms longer and increased daytime disturbances as well.

Sub-groups of cancer patients suffering from sleep disturbances have been studied concerning the effects of cancer diagnosis and treatment on sleep disturbances. A cross-sectional nonexperimental study by Savard et al. (2005) assessed the prevalence, clinical characteristics, and risk factors for insomnia in patients with a history of prostate cancer. The participants of the study were 327 French-Canadian men with a mean age of 66 years.

The data were gathered with questionnaires completed at home and mailed into the clinic. There also was a review of the participant's medical chart. The questionnaires included a sociodemographic questionnaire, the insomnia severity index (ISI) using the summated rating scale with the addition of two questions specific to the persons' sleep difficulties and use of sleep medications. Also, three questions were added to determine the diagnosis of insomnia syndrome. The questions were based on the international classification of sleep disorders, DSM-IV.

According to results of the Savard et al. (2005) study, approximately 30% of this prostate cancer patient group reported non-specific sleep difficulties and 20% reported having taken a sleep type substance in the past month. In addition, approximately 30%

reported scores indicative of insomnia symptoms, and 18% were DSM IV diagnosed with insomnia syndrome. The study also included specific characteristics of sleep disturbances. Of the 327 men in the sample, 4% had difficulty initiating sleep, 34% reported difficulties maintaining sleep, and 52% reported both initiating and maintaining sleep issues three nights a week. Sixty-eight percent of the participants with documented insomnia prior to their diagnosis of prostate cancer reported cancer-related factors aggravated it. The variables with a positive relationship associated with non-specific sleep difficulties included intestinal and urinary symptoms, anxiety issues, androgen blockade-related symptoms, and pain (Savard et al., 2005).

This study by Savard et al. (2005) showed insomnia is highly prevalent in men after a radical prostatectomy for prostate cancer. Pain, as well as other stated variables, are associated with sleep disturbances in this patient population. A significant proportion of the men with pre-existing insomnia reported cancer or its treatment as a catalyst for their already disturbing insomnia dilemma. Prostate cancer patients demonstrate insomnia symptoms three times as frequent as in the general population.

Pain and Sleep Disturbances

A study by Mercadante, Girelli, and Casuccio (2004) was completed on 123 cancer patients in a supportive care facility. The study evaluated the frequency of sleep disturbance in terms of quantity and quality as well as possible associated factors. A positive relationship of sleep disturbance and fatigue severity caused by inadequate pain control was found in this sample of oncology patients. To be included, participants reported to have at least five hours of sleep a night. Fifty-eight percent of the patients in the study stated pain as the main reason for admission to the supportive care center. In the

sample, there was a significant amount of awakenings at night, early morning awakenings, difficulty returning to sleep, and disturbing nightmares. All of these variables promoted a decrease in sleep, lack of restorative sleep, increase in fatigue, and drowsiness during the day.

In addition, this study showed that depression was closely related to restorative sleep, fatigue, and ability to return to sleep. Also, nightmares were related to anxiety and depression. This study determined no significant positive relationship between the age of the person, the type of primary tumor, the level of information provided to the patient, the documented Karnofsky status, and history of depression or confusion. The stated possible cause of awakenings and increased drowsiness was related to the use of opioids for pain management and the use of hypnotics for sleep. The awakenings were also associated with the patient's history of co-morbidities, and the use of alcohol or coffee (Mercadante, et al., 2004).

A cross-sectional study by Koopman, Nouriani, Irckson, Anupindi, Butler, and Bachmann, et al. (2002) found a positive relationship between sleep disturbance, pain, and depression in patients with the diagnosis of metastatic breast cancer. Variables of depression, social support, and salivary cortisol levels were also evaluated. The sample consisted of 97 predominantly Caucasian women with the mean age of 53 years who were included in a larger previous study. The instrumentation used included a chart review, a nine item pain questionnaire, a ten point visual analog scale, and a 27 item sleep questionnaire from the Stanford University Medical School assessing quantity and quality of sleep. In addition, depression symptoms were evaluated with an epidemiological studies depression scale, and social support was evaluated with a single

item called the single-item measure of social support (SIMSS).

The results of this study by Koopman et al. (2002) demonstrated that 63% of patients reported one or more types of sleep disturbance, and 37% of the participants reported using sleeping pills within the past 30 days. There was a positive relationship between greater pain, depressive symptoms, and problems falling asleep. The more pain a patient reported, the more medication was taken to assist with sleeping. There was a significant positive relationship between getting to sleep and with problems waking during the night ($p = 0.001$), waking or getting up in the morning ($p < 0.05$), and with the number of hours slept ($p < 0.001$). If the participant woke up at night and the amount of episodes awakened at night were both positively related to the ability to get up in the morning ($p < 0.05$). This significant positive relationship between getting to sleep and problems waking during the night was also seen with the typical number of hours slept ($p < 0.001$) and drowsiness during the day ($p < 0.001$). Also, difficulty falling to sleep in the evening had a positive relationship to higher pain and women who reported fewer typical hours of sleep were more likely to be those with bone metastases.

A study by Smith, Perlis, Smith, Giles, and Carmondy (2000) included a sample of 51 people of 84 screened for the study who responded to public advertising. Seventy-two percent of the sample was Euro-American, 45% completed at least four years of college, 25% were on disability, and 43% were taking narcotics at that time. The study was designed to characterize the degree and character of sleep disturbances of chronic pain patients and to examine the factors that predict sleep quality. The participants completed self-reporting instruments including the Pittsburgh Sleep Quality Index, the Pre-Sleep Arousal Scale, the Multidimensional Pain Inventory, and the Beck Depression

Inventory. The results found that 88% of the participants complained of some degree of sleep disturbances. The correlation of sleep variables to pain showed a positive relationship between pain severity and poorer sleep quality ($p = .05$), but pain severity did not predict severity of sleep disturbance.

A study by Bradley, Davis, and Chow (2005) involved a sample of 1296 cancer patients with metastatic disease receiving treatment at an outpatient palliative radiotherapy clinic. The study focused on determining and rating of distressing symptoms patients have who are receiving palliative radiotherapy. In the study the sample included 677 men and 619 females with a median age on 69 years. Age and sex was not a significant factor related to the symptoms focused on in this study except for nausea and anxiety. All symptoms studied included pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, sense of well-being, and shortness of breath. The primary cancer sites documented included lung at 32%, breast at 20%, and prostate at 15%, unknown at 2%, and other at 31%.

The results showed that pain ($n = 1137$) and drowsiness ($n = 1096$) were among symptoms seen most often while fatigue was the most distressing symptom. Patients coming from the hospital or from hospice had significantly worse scores on several symptoms mentioned which included distress from drowsiness ($p > 0.001$). In addition, patients on opioids had significantly higher symptom distress scores for distress from pain ($p > 0.001$) and distress from drowsiness ($p > 0.001$) (Bradley, et al., 2005) .

A cross-sectional study in Taiwan by Wang, Wang, Chang, and Lin (2007) explored the difference between cancer pain and non-cancer pain in terms of the patient's pain, mood, and sleep disturbance profiles. Chronic daily headache was used as the

comparison for the sample with non-cancer pain. The study was conducted at headache and cancer outpatient centers. There were a total of 94 patients being treated for mild to moderate pain. There was a female to male ratio of approximately 2:1 from each group, respectively. Forty-seven were being treated for chronic daily headaches and 47 were being treated for chronic cancer pain. The patients completed several questionnaires including the Brief Pain Inventory, Profile of Mood States, and the Pittsburgh Sleep Quality Index.

The results reported by Wang et al., (2007) showed both groups equally with 83% reporting poor sleep quality. The study also showed patients with chronic daily headaches reported more sleep disturbance and use of more sleep medications. The patients with cancer pain showed more daytime dysfunction ($p = 0.001$) and lower sleep efficiency ($p = 0.03$). Overall, there were similar experiences between the two groups concerning pain intensity, mood disturbance, and sleep quality. This study showed no difference between the means of cancer pain and non-cancer pain concerning the presence of sleep disturbances.

Pain

A cross sectional descriptive study was conducted by McMillan, Tittle, Hagan, and Laughlin (2000) to evaluate pain management outcomes in a group of veterans with cancer receiving inpatient care. The final sample included 90 veteran cancer patients mostly male (93.3%) and also white (82.8%). The information was collected from two geographically close veterans' facilities over a two month period. Their ages ranged from 36 to 87 with a mean of 64.5. The most common cancers were lung, head and neck, and colorectal malignancies.

The instruments used for the study were included in part of a larger ongoing project. The Visual Analog Scale (VAS) for pain was used, the Brief Pain Inventory (BPI) and Constipation Assessment Scale (CAS). A chart audit by data collectors was performed using Chart Audit for Pain (CAP). The patients were excluded if disoriented, comatose, or unable to give consent. Constipation was evaluated on non-surgical patients only. The patient could be taking any method of pain management (McMillan, et al., 2000).

Among the results, it was revealed that pain interference with activity had a high positive relationship to pain intensity. Interference items from the BPI were documented on 87 participants of the sample to determine how much pain interfered with quality of life issues. Sleep was included in this information and 50% of patients reported that pain interfered with sleep. Pain showed the greatest interference with sleep (McMillan, et al, 2000).

A prospective study by Zeppetella, O'Doherty, and Collins (2000) was conducted to determine the prevalence and characteristics of breakthrough pain in cancer patients admitted to hospice. It was shown that breakthrough pain is common (and often poorly controlled) among terminally ill cancer patients admitted to a hospice facility. The information gathered was collected between February and August of 1998 and the participants were documented to have a prognosis of less than six months. There were a total 432 admissions with 414 having a cancer diagnosis.

The instrument used was a survey on hospice admissions adapted from Portenoy and Hagen. The instrument provided information on pain and its location, duration, and severity. It also provided information from a 24 hour period of time on the patient's

characteristics and temporal aspects of pain including breakthrough pain and its location, duration, and severity as well as its relationship to scheduled analgesic dose, aggravating factors, and palliative causes. Information was also extrapolated on medications documented and the participant's satisfaction with management of their pain (Zeppetella, et al, 2000).

The results of this study by Zeppetella et al., (2000) suggested that 38% of the patients had severe pain. There were at least seven episodes of breakthrough pain over the 24 hours studied, with 40% sudden pain, 59% unpredictable pain, and 72% with pain lasting more than 30 minutes. Seventy-five percent of the participants were unhappy with the management of their pain. The results showed most chronic, breakthrough pain was related to the patient's bulky cancer tumor, and the amounts of breakthrough pain episodes were not related to reported chronic pain. It was also significant that 17% of the patients had failure of scheduled pain medications with the need for additional medication prior to the next available dose. The pain was unpredictable in over 50% of the patients and lasted more than 30 minutes in approximately two thirds of the patients. Analgesics relieved breakthrough pain over 50% of the time while just lying still alleviated the pain 32% of the time. Overall, when answering the questionnaire, only 25% of the 281 patients with documented breakthrough pain were satisfied with their pain medications. Overall, the patients who were dissatisfied had significantly more occurrences of breakthrough pains.

Summary

The literature shows sleep disturbances are of profound concern in at least 30% of the advanced cancer patient population which is presently 48% of the hospice patient

population. In addition, pain and sleep disturbances occur in both sexes although the studies suggest that there is a slight increase in women. The research also suggests that pain and sleep disturbances are a significant factor in the general population as well as with cancer patients. There were no studies found on the relationship between pain variables and sleep variables in cancer patients admitted to hospice home care. There was a positive relationship between the combination of major depression, insomnia, and increased levels of pain prominent throughout the literature concerning cancer and non-cancer research. It has been demonstrated that chronic non-cancer pain has similar symptoms to chronic cancer pain and that chronic pain is often found in cancer patients. In addition, a positive relationship was found between sleep disturbances and pain in cancer and non- cancer patients. Cancer pain is also associated with an increasing number of insomnia symptoms, longer periods of insomnia, and daytime consequences of insomnia.

The literature also showed sleep disturbances commonly parallel pain as well as other symptomatology. It is essential for nurses to remember other variables known to cause sleep disturbances in the cancer patients including demographic, psychological, physical factors, radiotherapy, hormonal therapy, anxiety, and pain. Sleep disturbances for any reason will affect activities and can perpetuate pain intensity causing a vicious circle of uncomfortable symptoms affecting the patient's quality of life.

In addition, the study on breakthrough pain medication and difficulty managing this type of pain showed its contribution to sleep disturbances in the terminally ill patient. This study can be associated with hospice home care patients because most are terminally ill. It is also important for nurses to understand barriers in pain management that may

affect sleep for cancer patients in hospice home care. These barriers include past personal experience, fears of addiction, attitudes related to addiction, and the religious beliefs that sometimes acknowledge pain as a part of necessary life suffering. The nurse needs to understand these behaviors to assist with providing effective evidence-based treatment for pain and sleep-wake disturbances.

It is important that nurses caring for this subgroup of patients do a thorough assessment for sleep disturbances and pain on a routine basis while these patients are in hospice home care. This is essential for optimal quality of life in cancer patients on hospice home care and will provide valid documentation offering a better understanding of this patient population's pain and sleep disturbances. The studies reviewed suggest there is a need to continue the evaluation of pain and its correlation with sleep disturbances in subgroups of cancer patients including cancer patients admitted to hospice home care.

CHAPTER III

Methods

This chapter presents study methods. The sample selection, inclusion and exclusion criteria, instruments and procedures are illustrated specific to this secondary data analysis. The data analysis also is discussed in this section.

Sample

The sample was derived from an original study designed to determine whether hospice plus a coping skill training intervention improved family caregivers' quality of life as compared to the usual hospice support (McMillan, Small, Weitzner, Schonwetter, Tittle, Moody, et al., 2006). The information was collected from 354 participants between March 1999 and May 2003. The sample for this secondary data analysis was selected from the 354 original participants.

Inclusion Criteria.

The original study sample included adult patients with a diagnosis of cancer and an identified family caregiver who was a spouse or adult child, and both had to consent to participate. Both had at least a sixth grade education and were able to read and understand English, and achieve a minimum score of eight on the Short Portable Mini-mental Status Exam. In this study, data were extrapolated from only the patients that had a documented pain level from one to ten on the patient's screening assessment of pain scale.

Exclusion Criteria.

In the original study, patients were excluded if they had Karnofsky Performance Status scores less than 40, ADL Index scores of less than “C” (independent in all but bathing and one additional function) or mental status scores less than eight. Because the study focuses primarily on management of three common problems, pain, dyspnea, and constipation, patients were excluded if they did not have two of these three problems as documented by baseline data collection. Caregivers were excluded if they were in active treatment for cancer themselves or had mental status scores < 8. In the present study, patients were excluded if they had a pain level of 0 on the patient’s screening assessment of pain scale.

Instruments

Palliative Performance Scale.

The Palliative Performance Scale (PPS) is a measure of the functional status of the patient and is a rating based on a scale from 0 to 100 with 0 being death and 100 being self ambulatory with normal activity and no evidence of disease. This was used to screen the patient into the original study.

The PPS score validity was studied previously as noted in one study where the prognostic value of the PPS was studied as a predictor of mortality in a heterogeneous hospice population. It was also used to determine whether it performs equally well across diagnoses and sites of care. The study showed a strong independent predictor of mortality with the Kaplan Meier survival curves at $p < 0.001$. The PPS scale was proven to be useful in guiding plans for hospice care (Harrold et al., 2005).

Memorial Symptom Assessment Scale.

The Memorial Symptom Assessment Scale (*MSAS*) was used to measure distress caused by symptoms. The MSAS consists of a patient self-report scale that assesses a diverse group of symptoms common to cancer patients. Subscales provide data about frequency, severity, and distress associated with these symptoms. Total symptom distress was measured on a five point summated rating scale with scores that may range from 0 (no distress) to 96 (very much distress). Validity was supported by high correlations with clinical status and quality of life. Alpha reliabilities were high (.83 to .88) (Lobchuk, Degner, Chateau, & Hewitt, 2006). The symptoms included in this analysis were distress from lack of energy, feeling drowsy, and difficulty sleeping.

Hospice Quality of Life Index.

The Hospice Quality of Life Index (HQLI) is a 28-item self-report tool that includes three aspects of overall quality of life: Psychophysiological Well-being; Functional well-being; and Social/spiritual Well-being. Total scores may range from a low of zero to a high of 280. Evidence of validity and reliability of the HQLI was generated by a previously completed study (McMillan & Weitzner, 1998). Evidence of validity was provided by the ability of the HQLI to differentiate between hospice patients and apparently healthy controls using both discriminate analysis ($p=.00$) and comparison of means ($p=.00$). Previously, the HQLI has been validated for use with hospice patients with cancer; the inability of the HQLI to discriminate between hospice patients with cancer and AIDS ($p=.27$) supports the use of the HQLI with AIDS patients. Results of these two comparisons seem to suggest that while the HQLI scores will not vary by diagnostic category, they are sensitive to actual differences in quality of life that are

present. The finding that HQLI scores correlated at the expected level ($r=.26$; $p=.00$) with functional status scores provides further evidence of validity. Finally, factor analysis confirmed the factor structure of the HQLI. Reliability of the HQLI was provided by generation of coefficient alphas for both total scale scores and subscale scores. Subscale alphas all were .84 and the total scale alpha was high for both cancer ($r=.88$) and AIDS ($r=.93$) patients.

Pain Intensity Scale.

Pain intensity was assessed using an eleven point numeric rating scale (NRS) with scores ranging from 0 to 10. This tool was used as part of the intervention to assist the caregivers in the original study to be more systematic in assessing the patient's pain intensity. The patient was asked to respond verbally with a number between 0 (no pain) and 10 (worst pain) to rate pain intensity at that moment. One advantage of the NRS is its ease of use by debilitated patients. Investigators have found that patients prefer the 0 to 10 NRS over other pain rating scales. It was simple to administer and score, and the scaling was understandable to the patients. This is a brief simple tool that provided a relatively sensitive measure of pain intensity. Previous research indicates that the NRS is valid and reliable. The NRS correlates well ($r=.59-.86$) with other measures of pain intensity. A comparison among the NRS, a visual analog scale, a Box Scale, a behavioral rating scale, a 4-point verbal rating scale, and a 5-point verbal rating scale resulted in similar results in the number of subjects who responded correctly and the predictive value of each measure. The NRS was found to be more sensitive than the other scales (McMillan & Weitzner, 1998).

Demographic Data Form.

Standard demographic data was collected on patients to allow description of the sample. Data included age, gender, education level, marital status, religion, occupation, cancer diagnosis, length of time since diagnosis, and Functional Performance Status as measured by the Karnofsky Performance Status Scale (KPS). The KPS is recorded on every patient on admission by the hospice.

Procedures

The original proposal was submitted to the Bioethics Committee of the LifePath Hospice and then to the institutional review board of the University of South Florida. Following the approval, the data were collected.

Data Collection

Data for all subjects were collected on admission to the study, one week post-intervention (day 16 of hospice admission) and two weeks post-intervention (day 30). Baseline data were collected within 48 hours of admission to hospice.

The Home Health Aide (HHA) data collector collected patient data and stayed with the patient to assist as needed and to reassure the caregiver that the patient was not alone while the Registered Nurse (RN) data collector was collecting data from the caregiver. The HHAs interviewed the patients independently to obtain demographic information, the HQLI was administered, present pain intensity was assessed (0-10), present dyspnea intensity was assessed (0-10), and the Constipation Assessment Scale (CAS) was administered. These three symptom assessments determined which problems the patient was experiencing so the intervention for Group III was tailored to each patient's situation. Also, patients completed the Memorial Symptom Assessment Scale (MSAS) to

assess for symptom distress caused by symptoms other than pain, dyspnea or constipation. Only the baseline data from the HQLI, PPI, MSAS, Pain Intensity Scale, and Demographic Data Form completed on admission were included in this descriptive analysis.

Data Analysis.

The data analysis was performed using the Statistical Package for the Social Sciences (SPSS). The product moment correlation coefficient was used to determine the relationship between the variables of pain and sleep disturbances. The mean and standard deviations was used to describe the sample. Descriptive statistics including the mean, standard deviation, minimum and maximum were calculated. Demographic data was analyzed using descriptive statistics. These included frequencies, percentages, means, and standard deviations.

Research question 1: Is there a significant correlation between sleep distress and each of the following variables: pain distress, pain intensity, pain relief, and pain at its worst in cancer patients admitted to hospice care? This question was analyzed with a series of Pearson correlations. Research question 2: Is there a significant correlation between pain distress and each of the following variables: how well the person sleeps, how tired the person feels, distress from drowsiness, and difficulty sleeping in cancer patients admitted to hospice care? This question also was analyzed using a series of Pearson Correlation coefficients.

Chapter IV

Results, Discussion, and Conclusions

This chapter presents the findings of the study. Included in this chapter are the results, discussion, and conclusions.

Results

The sample consists of 209 cancer patients admitted to hospice home care including 131 males and 78 females. The sample was mostly Caucasian (85.6%), African American (6.2%), and Hispanic (4.8%). The other participants were of a diverse ethnic background. One hundred thirty-one of the patients were married with the remainder divorced, widowed, or never married (Table 1). Most participants were living with a spouse (61.2%). The mean educational level of was approximately 12 years of education (Table 2), and the most prevalent cancer diagnosis was lung cancer (32.5%). The next three most prevalent cancers were colon (31%), prostate (17%), and pancreas (15%) (Table 3).

Means of Scores

Scores of relevant items taken from three measures, the HQLI, MSAS, PIS were used to answer the research questions. The variables pain distress, drowsiness distress, and sleep distress, were taken from the MSAS. These variables asked how much the symptom distressed or bothered the participant. The scale was from 0 (not at all) to 4 (very much). Of 195 of the patients who answered these questions, the mean for pain

Table 1. Frequency and Percentage of Patients by Sex, Race, Marital Status and Diagnosis

Demographic	frequency	percentage
Sex	209	
Male	131	62.7
Female	78	37.3
Race	206	
Caucasian	178	86.9
African American	13	6.3
Hispanic	10	4.9
Asian/pacific Islander	1	.5
Eskimo/Native American Indian	1	.5
Mixed	1	.5
Other	1	.5
Marital Status	205	
Currently married	145	70.7
Divorced	27	13.2
Widowed	26	12.7
Never Married	7	3.4

Table 2. Frequency and Percentage of Patients by Living Arrangement and Education

Demographic	frequency	percentage
Living Arrangement	209	
Lives alone	7	3.3
Lives with spouse/partner	128	61.2
Lives with spouse/partner; children	25	12.0
Lives with children no spouse	25	12.0
Lives with roommate	3	1.4
Lives with parents	9	4.3
Other	12	5.7
Educational Level	206	
8 years	12	5.8
11 years	19	9.2
12 years	73	35.4
14 years	28	13.6
16 years	21	10.2
1 to 25 years (Remaining 20)	each <10	25.7
Missing	3	.5

distress was 2.45 (standard deviation = 1.089; n = 195). The mean for drowsiness distress was .92 (standard deviation = 1.197; n = 158). Finally, the mean for sleep distress was 2.24 (standard deviation = 1.197; n = 158) (Table 4).

Table 3. Frequency and Percentage of the Five Most Frequently Occurring Cancer Diagnoses (n = 209)

	frequency	percentage
Diagnoses		
Lung	68	32.5
Colon	31	14.8
Prostate	17	8.1
Pancreas	15	7.2
Breast	10	4.8
Other*	78	33.6

*Others (total 30 different types of cancer)

The HQLI variables included how tired do you feel, how well do you sleep, and relief from pain. These variables were determined on a scale from 0 (very dissatisfied) to 10 (very satisfied). The variable of pain at its worst was evaluated with 0 (no pain) to 10 (worst possible pain) scale. All participants with no pain were excluded from the study.

The mean for the item asking how tired you feel was 5.35 (standard deviation = 2.527; n = 205). The mean for how well do you sleep was 6.79 (standard deviation = 2.871; n = 205). The mean for relief from pain was 8.14 (standard deviation = 1.796; n = 204). The mean for pain at its worst was 7.70 (standard deviation = 2.335; n = 204).

The PIS variable was the assessment of present pain intensity. This present intensity of pain variable was measured by a numeric scale from 0 (no pain) to 10 (worst possible pain). It is important to note that patients having no pain were excluded from the

Table 4. Study Variables, Possible Ranges, and Standard Deviations for Individual Study Variables (n = 209)

Variables	N	Mean	Std. Deviation
Pain intensity	209	4.12	2.303
Pain Distress	195	2.45	1.089
Pain relief	204	8.14	1.796
Pain at its worst	204	7.70	2.335
How well you sleep	205	6.79	2.871
How tired you feel	205	5.35	2.527
Drowsiness distress	158	.92	1.197
Sleep distress	82	2.24	1.320

the study. The mean from participants within 1 to 10 range was 4.12 (standard deviation = 2.303; n = 209) (Table 4).

Sleep Distress and Pain Distress. Research question 1a addressed the two variables of sleep distress and pain distress to examine if there was a significant relationship between them. The results showed a significant positive correlation ($p=.000$) between sleep distress and pain distress (Table 5).

Sleep Distress and Pain Intensity. Research question 1b addressed the two variables of sleep distress and pain intensity. This question examined if there was a significant relationship between sleep distress and present pain intensity. The study showed that there is a significant positive relationship between sleep distress and pain intensity ($p = .008$) (Table 5).

Sleep Distress and Pain Relief. Research question 1c addressed the two variables of sleep distress and relief from pain. Although the correlation was negative, as might be expected, it was not statistically significant (Table 5).

Sleep Distress and Pain at its Worst. Research question 1d addressed the two variables of sleep distress and pain at its worst. The findings show there is a significant positive correlation ($p = .008$) between distress from difficulty sleeping and pain at its worst (Table 5).

Pain Distress and How Well the Person Sleeps. Research question 2a addressed the two variables of pain distress and how well the person sleeps. The finding showed there is no significant correlation between pain distress and how well the patient sleeps (Table 5).

Pain Distress and Fatigue. Research question 2b addressed the two variables of pain distress and how tired the person feels. The findings showed no significant correlation between pain distress and how tired you feel (Table 5).

Pain Distress and Distress from Drowsiness. Research question 2c addressed the two variables of pain distress and feelings of drowsiness. The findings showed there is no significant correlation between pain distress and distress from drowsiness (Table 5).

Discussion

This study evaluated the relationship between sleep-wake disturbance and pain variables in hospice patients with cancer. Sleep-wake disturbances and pain are significant concerns among non-cancer and cancer patients as previously stated in the literature review.

Table 5. Pearson Correlations Among Pain and Sleep-wake Disturbance Variables from MSAS, HQLI, and PPI Scale self evaluation tools

Variables	Sleep Distress	Pain Distress
Difficulty sleeping (Sleep distress)		n = 80 r = .385 p = .000
Pain intensity (How bad is the pain) (Assessment of pain)	n = 82 r = .292 p = .008	
Pain relief	n = 82 r = -.152 p = .172	
Pain at its worst	n = 82 r = .292 p = .008	
How well you sleep		n = 193 r = -.121 p = .093
How tired you feel		n = 193 r = -.115 p = .111
Distress from drowsiness		n = 151 r = .024 p = .772

Sample

The sample was predominantly males and the most common cancer was cancer of lungs. It is interesting to note the American Cancer Society (ACS) (2007) identifies lung and bronchus cancer as leading in mortality for both sexes. One limitation of this study was that mostly men participated in the study although women are affected equally by the

most prominent cancer diagnosis in the study. In addition, lung and bronchus cancer is second in new cases for both men (114,760) and women (98,620) (ACS, 2007). Overall, the ACS (2007) reports the mortality rate of all cancers as higher in men than women. The number of deaths from lung and bronchus cancer in men is 31% of all cancers and totals 89,510. This is slightly higher than women at 26% totaling 70,880 (ACS, 2007). The mortality rate annually for all cancer sites for men is 289,550 (ACS, 2007) and for women is 270,100 (ACS, 2007). Overall, there is approximately a 20,000 difference between males and females.

In the study, there were 131 males to 78 females. It is likely that the preponderance of male patients is related to how the original sample was collected. The study included only patients in homecare who had caregivers available. This might have eliminated some female patients who had outlived their spouses, making them ineligible for the study.

In addition, concerning racial limitations, this study presents mainly with white subjects when in the statistics from the ACS (2007) mortality was higher in the African American race from 1999 to 2003. Apparently, the African American cancer patients do not seek hospice home care at the same rate that white patients do.

Also, the educational level of this patient sample showed 73 participants (35.4 %) received at least 12 years of education, 18.4 % fell below the 12 years mark with only 7.3% at less than 8 years of education. Another 36.9% had more than 12 years of formal education. In this study, education was not a significant limiting factor especially with trained research assistants administering the questionnaires.

Sleep Distress and Pain Distress

The positive relationship between sleep distress and pain distress confirms results of previous studies. In addition, this result compares with a previous study by McMillan, et al, 2000 that evaluated pain management in a population of veterans diagnosed with cancer. The researchers found that pain interfered with sleep in 50% of the patients. Nurses should consider pain as a major cause of sleep problems and pain control must be maintained even in hours of sleep to increase quality of life in cancer patients on hospice home care. Providing the patient with pain medication as ordered, documenting effective relief or lack of relief, and notifying the prescribing authority for necessary alteration in medication is vital.

However, it must be noted that the relationship between sleep distress and pain distress was not strong ($r = .39, p = .000$). Thus, it must be inferred that there are other factors related to sleep distress as well. Among these might be anxiety about the future, depression because of impending death, or other symptoms such as dyspnea. Further research is needed.

Sleep Distress and Pain Intensity

The positive significant correlation between sleep distress and pain intensity ($r = .29, p = .008$) provides additional validity to previous study conclusions. Pain was documented as causing interference with QOL issues and sleep disturbances do affect QOL. Increase in pain intensity is a direct hindrance to sleep in the cancer patient population (McMillan, et al, 2000). Also, in a study by Wang et al., (2007) evidence showed cancer pain has been documented as causing similar symptoms to non-cancer pain. A study by Smith, Perlis, and Haythornthwaite (2004) explored sleep onset,

insomnia, and pain intensity. The results showed that chronic pain patients with high pain intensity and daytime dysfunction, a form of sleep distress, were also more likely to have increased depressive symptoms. This may suggest implementation and proper management of pain could possibly assist in elevating sleep distress and ultimately decrease depressive symptoms.

However, it should be noted that the relationship between sleep distress and pain intensity was weak. Thus there are other factors that should be explored.

Sleep Distress and Pain Relief

It might be expected that there would be a negative relationship between sleep distress and pain relief ($r = -.152, p = .172$). However, no relationship was found. This is at variance with a previous study by Ohayon (2004) on pain and insomnia in the general population. That study showed chronic pain is directly related to insomnia and having no relief from pain can be compared to a form of chronic pain. It is unclear why no relationship was found. Perhaps a more sophisticated measure of sleep would have yielded different results.

Sleep Distress and Pain at its Worst

The results of this study presented a significant relationship between sleep distress and pain at its worst ($r = .29, p = .008$) supporting results of a study by Koopman, et al (2002) of patients with breast cancer showing a direct positive relationship between greater pain, depressive symptoms, and problems falling asleep. In the same study, higher pain was directly related to distresses from sleep disturbance including difficulty waking in the morning and drowsiness during the day. Although this correlation was weak, it was significant. Future studies should include other variables such as depression.

Pain Distress and How Well the Person Sleeps

The finding of no significant correlation between pain distress and how well the person sleeps ($r = -.121$, $p = .093$) deviates from findings of previous research (Theobald, 2004). Specifically, a previous study by Theobald 2004 looked at insomnia in comparison to other symptoms common to cancer patients including pain and distress. This previous study showed pain as one of the most common factors related to insomnia in the cancer patient population. Subsequently, one could infer, since pain causes distress and insomnia is a distressing symptom for cancer patients, the two would have a positive relationship. The sleep item in this case was a single satisfaction item taken from a quality of life scale. Future studies should include a validated sleep questionnaire.

Pain Distress and Fatigue

There was not a significant relationship between pain distress and how tired one feels ($r = -.115$, $p = .111$). Although there is literature on fatigue and pain, no specific studies were found on the relationship between pain distress and how tired one feels. It is documented that tiredness is synonymous with fatigue, as well as exhaustion, lethargy, and weariness. One study on breast cancer patients showed better pain coping strategies, as well as other symptom relief, with decreased fatigue (Reddick, Nanda, Campbell, Ryman, & Gaston-Johansson, 2005). This would be beneficial for cancer patients in the hospice home care as well.

Pain Distress and Drowsiness Distress

The finding of no correlation between pain distress and distress from drowsiness ($r = .024$, $p = .772$) is understandable in that pain would not cause one to be drowsy, but its management has been documented to cause drowsiness. In a study by Mercadante,

Villari, Ferrera, and Casuccio (2006), where opioids were used for the treatment of pain on a palliative care unit, the opioids caused side effects which included significant drowsiness. It is also noted in a study by Bradley et al. (2005) patients with advanced cancer, although within an outpatient setting similar to the population of this study of cancer patients on hospice, are often multisymptomatic including fatigue and pain in the highest score range, but drowsiness was common as well. In this study by Bradley et al. (2005), drowsiness again showed a positive relationship with opioids use ($p = <0.0001$). However, in this present study drowsiness was not positively correlated with pain. It is unclear why this occurred. It is possible the patients were experiencing some drowsiness, but were not distressed by it. The item does not ask about intensity of drowsiness, but how distressing it is.

Implications for Nursing

This study supports the importance of addressing sleep distress and pain distress. The fact that there were significant relationships identified among three of the variables and no significant relationship in four of the variables indicates there is need to further investigate pain and sleep relationships which are highly important to quality of life in the cancer patient in hospice home care. Further studies are needed in a larger population using multiple geographical locations and by using a more diverse cancer population in the hospice home care setting. These further studies might assist with supporting the results of this study. With the known documentation of sleep disturbances and pain affecting quality of life, continuing studies on variables related to these two significant issues could assist with evidence to support continued research on developing effective interventions to assist with alleviating these stressors at the end of life for this

subpopulation of cancer patients. This is critical to optimal quality of life at end of life.

Recommendations for Further Research

Limitations of this study lead to suggestions for further research. Since this sample was mostly White and non-Hispanic with the diagnosis of lung cancer, in future research a more diverse population needs to be studied. Furthermore, although the sample was adequate, it would be beneficial to repeat this research with a larger sample, at multiple sites. Also, Since the information for this study was obtained at the time of admission, in the future, it may also benefit to evaluate these variables several times if possible noting the changes in demographics, because the results could vary with provided care, treatment, and comfort measures.

Because this study was funded by NIH the possibility of unreliable data collection is minimal. The original investigators had built in quality assurances for this study. For example, ten percent of all interviews were tape recorded by the investigators for review of data collection accuracy. In addition, the investigator had evidence that the hospice standard of care did not deviate throughout the study. Also, throughout the study the RN data collector and the HHA swapped forms and patients during the admission process to validate the information provided by two different trained individuals. Throughout the process of the study on a monthly basis, the investigator randomly selected ten percent of the patients and reviewed their records with the inclusion and exclusion criteria. All patients selected for the study were deemed eligible according to the determined guidelines. These, as well as additional documented mandatory quality assurances, leave little doubt concerning reliability of the data collection.

In summary, investigation of sleep disturbance and pain variables help provide

insight into relationships between these variable to assist with possible alterations in intervention and treatment plan. Future research could include whether the subjects find certain interventions most effective to assist with relief of these symptoms. A reproduction of this study with the inclusion of other variables such as depression, anxiety, and other physiological symptoms in a larger number of participants would improve the reliability of this study. In addition, the study could address other symptom relationships along with sleep disturbance and pain variable.

Conclusions

The results of this study show there is a positive relationship between sleep distress and pain distress, pain intensity, and pain at its worst. Sleep distress was found to have no relationship to pain relief. In addition, pain distress was not found to have a positive relationship to how well one sleeps, how tired one feels, and distress from drowsiness in the cancer patient admitted to hospice home care.

Clearly, sleep disturbances and pain are of great concern not only in the general population of cancer patients, but should be of even greater concern with cancer patients admitted to hospice home care. It is important for nurses to provide the best possible care at the end of life. Based on the findings from this study, it is imperative to conduct a thorough nursing assessment that includes a sleep and pain. This will assist with implementation of appropriate evidenced-based nursing interventions to promote optimum quality of life. It is necessary as nurses to educate the patient and healthcare provider on evidence-based pharmaceutical and non-pharmaceutical treatment of both pain and sleep disturbance. These interventions will ultimately improve the quality of life of the cancer patient on hospice home care.

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