ABSTRACT

PRO-SELF PAIN MANAGEMENT DIARY: AN EFFECTIVE DOCUMENTATION TOOL

Pain is among the most frequently encountered symptoms of a hospice patient at the end of life. These patients are often in the care of family or other informal caregivers who are inexperienced in ministering to pain. The ineffective communication of informal caregivers with healthcare professionals often results in less than ideal treatment for pain. This qualitative research study examined whether use of the PRO-SELF Pain Management Diary, which has been used successfully in the pain management of cancer patients, would contribute positively to the documentation and management of hospice patients’ pain. Ten informal caregivers of seven hospice patients were trained in the use of the diary. A follow-up interview was conducted after 2 weeks to determine the caregivers’ perceptions of the effectiveness of the tool. Six of the 10 caregivers reported that they found the PRO-SELF Pain Management Diary to be helpful by providing a reference that eliminated the need to rely on memory when they spoke to hospice nurses about patient pain.

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May 2015
PRO-SELF PAIN MANAGEMENT DIARY: AN EFFECTIVE DOCUMENTATION TOOL

by

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A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Nursing in the College of Health and Human Services California State University, Fresno May 2015
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Hospice care, medical and palliative care for the terminally ill, is a rapidly growing sector of healthcare in the United States. The National Hospice and Palliative Care Organization (NHPCO, 2012) has reported that the number of patients in hospice care expanded greatly over the decade from 2002 to 2012. Kelley, Demiris, Nguyen, Oliver, and Wittenberg-Lyles (2013) stated that the number of patients receiving hospice care in 2010 was three times the number who received hospice care in 1998. Approximately 1.65 million patients received hospice care in 2011 in the United States and 44.6% of all deaths in the United States occurred under the care of a hospice program (NHPCO, 2012).

Background of the Problem

In 2011, the primary diagnoses of hospice admissions were cancer (37.7%), debility unspecified (13.9%), dementia (12.5%), heart disease (11.4%), and lung disease (8.5%) (NHPCO, 2012). Most hospice patients experience various forms of discomfort, such as pain, shortness of breath, delirium, anorexia, constipation, nausea, and vomiting (Lau et al., 2009). Among these, pain is the most common and most challenging symptom patients and their families encounter in end-of-life care (Oliver et al., 2013), and pain management is one of the main objectives of the care.

Providing effective pain management is a significant challenge for clinicians. Oliver et al. (2013) found that 76% to 90% of patients who receive hospice care experience distressing symptoms such as pain. Forty percent of those at end of life have severe and unrelieved pain (Oliver et al., 2013). Poorly controlled pain contributes to cognitive failure and depression.
Cancer, which is the most common hospice admission diagnosis, has been associated with depression and poor quality of life (Mayahara, Paice, Wibur, Fogg, & Foreman, 2014). Also, cancer has been found to interfere with the activities of daily living (Prommer & Ficek, 2012). Inadequate pain relief has been found to increase psychological distress, decrease immunocompetency, complicate patients’ mobility, increase the work of breathing, and increase myocardial oxygen requirements (Sherman, Matzo, Paice, McLaughlin, & Virani, 2004).

Most hospice care is provided in patients’ homes; private residences provided the setting for 41.6% of hospice patient care in 2012 (NHPCO, 2012) and approximately 70% of hospice patients die at home (Oliver et al., 2013). In private residences, the primary caregivers for hospice patients are usually family members. They are generally referred to as informal caregivers because they lack formal medical training to take care of dying people. Kelley et al. (2013) estimated that 66.7% of hospice care in the home is provided by informal caregivers.

As hospice patients become more debilitated and the end of life draws nearer, the responsibilities of informal caregivers increase and become more urgent. The caregivers bear a great deal of responsibility for emotional support, assisting with the activities of daily living, and administering medication (McMillan & Small, 2007). Among the most challenging areas for informal caregivers is pain management (Kelley et al., 2013).

Although informal caregivers are very involved in the pain management of patients, hospices often fall short in providing the caregivers the support they needed to perform this function. The informal caregiver is often not prepared adequately for symptom management. Lau et al. (2009) reported that fewer than
60% of informal caregivers receive medication management assistance from a hospice although more than 80% of informal caregivers report that they manage medications for patients. Kelley et al. (2013) reported that although two of the central concerns of hospices are pain management and providing support to informal caregivers, empirical evidence about effective methods to meet these goals is lacking. In addition, little is known about how informal caregivers actually manage medications or what skills or training they need to manage medications at home to treat distressing symptoms at the end of life (Lau et al., 2009). Pain and other symptoms for patients who are near death have been neither adequately recognized nor sufficiently treated by clinicians or informal caregivers (Lau et al., 2009).

Oliver et al. (2013) identified several obstacles faced by informal caregivers when trying to manage pain: age, fears, beliefs, lack of assessment skills, burden, and strain. According to Mayahara et al. (2014), the most common barrier was the failure of informal caregivers to implement or maintain recommended regimens. Failure to follow pain medication regimens has been associated with higher intensity of pain. Mayahara et al., however, stated that clinicians could provide appropriate intervention, education, and support to informal caregivers once a pain medication regimen was established and the degree to which informal caregivers adhered to it estimated. Determining the degree of adherence requires effective communication between informal caregivers and healthcare professionals.

For this reason, communication among hospice providers, patients, and informal caregivers is vital to effective pain management. However, Oliver et al. (2013) also found that a major challenge of effective pain management was communication problems with providers. Family members, who usually do not have the proper training to assess the severity of a patient’s pain, have difficulty
communicating effectively about the pain in a manner that allows the clinician to choose which medication is appropriate. This communication barrier prevents establishment and maintenance of an effective pain regimen. Therefore, interventions to provide for effective pain management must address communication among patients, informal caregivers, and healthcare professionals (Johnson, Kassner, Houser, & Kutner, 2005).

Schumacher et al. (2002) explored the use of pain diaries for managing pain in cancer patients. They found that daily pain management diaries were helpful not only for pain assessment, identification of pain patterns, and evaluation of interventions, but also for facilitating communication between patients and clinicians. Making regular diary entries reduced the incidence of recall bias, provided detailed information about patients’ experience of symptoms, and provided a history that allowed clinicians to analyze symptoms over a period of time. Such diaries could provide clinicians with a valid and reliable method of assessing symptoms for hospice patients in home settings. Patients and informal caregivers could log pain patterns and interventions in pain diaries, providing a basis for feedback from healthcare professionals. Schumacher et al. found the diaries beneficial not only for patients, but also for hospice providers, such as physicians and nurses, because they provided good information about the effectiveness of pain management. This finding prompts the question of whether informal caregivers might also find a pain diary to be helpful in accurately communicating with hospice nurses about patient pain.

Statement of the Problem

Management of patient pain is a primary goal of hospice care yet the majority of people providing that care are untrained and unskilled in pain
management. Despite the fact that pain diaries have shown promise as communication tools for effective pain assessment, treatment, and evaluation, clinicians do not widely use them to help informal caregivers provide pain management for their patients (Schumacher et al., 2002). This study addressed the need hospice patients and their informal caregivers have for an effective way to document the details of pain management to use as a reference as they communicate with healthcare professionals in order to improve the treatment of patient pain.

**Purpose and Research Questions**

The purpose of this study was to establish the helpfulness of a tool that enables informal caregivers to document and communicate with healthcare professionals the pain management of end-of-life patients. The researcher interviewed informal caregivers who used a self-care nursing intervention developed by faculty at the University of California, San Francisco, called the PRO-SELF Pain Management Diary (Schumacher et al., 2002).

The effectiveness of the PRO-SELF Pain Management Diary has been established with cancer outpatients (Schumacher et al., 2002), but little research has been conducted regarding the effectiveness this or other pain diaries in the hospice setting. This study attempted to replicate the research of Schumacher and colleagues with hospice patients who were being cared for at home to find whether informal caregivers would also find the PRO-SELF Pain Management Diary to be a helpful tool. The research addressed the following questions:

1. Do informal caregivers find the PRO-SELF Pain Management Diary helpful for accurately communicating about patient pain with hospice nurses?
2. Does the PRO-SELF Pain Management Diary facilitate effective pain management for home hospice patients?

**Definition of Terms**

Some of the terms used in this study are defined below.

_Hospice_ refers to a system of family-centered care designed to assist a terminally ill person to be comfortable and maintain a satisfactory lifestyle through the phases of dying (Mosby’s, 2002).

_Hospice nurse_ is a nurse working in collaboration with hospice physicians, pharmacists, dieticians, physical therapists, social workers, certified nursing assistants, clergy, and volunteers to provide end-of-life care and support to patients and family members; a nurse educated in pain control and symptom management (Lewis, Heitkemper, & Dirksen, 2004).

_Hospice patient_ is a patient desiring hospice services and who has been certified by a physician to have 6 months or less to live (Lewis et al., 2004).

_Informal caregiver_ is a person providing care who lacks formal training to administer medications and assess the severity of pain (Lau et al., 2009).

_Pain_ refers to an unpleasant sensation caused by noxious stimulation of the sensory nerve endings; a subjective feeling provoking idiosyncratic responses in individuals (Mosby’s, 2002).

_Pain management_ denotes a nursing intervention from the Nursing Interventions Classification defined as alleviation of pain or a reduction in pain to a level of comfort that is acceptable to the patient (Mosby’s, 2002).

_PRN medication_ is medication with administration times determined by the patient’s needs (Mosby’s, 2002).
**PRO-SELF Pain Management Diary** is a daily pain management diary developed by faculty at the University of California, San Francisco (Schumacher, 2002).

**Theoretical Framework**

Three nursing theories are particularly useful in guiding nurses who are attempting to be of service to patients in a palliative care environment. These theories help the nurse remain mindful of the patient’s inner life and dignity as a human being. They are based on the hope that when patients and caregivers understand that their nurse sees them as more than collections of pathologies to be treated, a trusting relationship will develop in which discussions about pain medication as well as other delicate issues can be meaningful and successful. Pender’s (2011) health promotion model (HPM) provides a basis for behavioral counseling with the aim of establishing and strengthening health-promoting behaviors. Katherine Kolcaba’s (2001) comfort theory provides a comprehensive definition of comfort that aids nurses in assessing a patient’s level of comfort and providing comfort effectively. Jean Watson’s theory of human caring (Current Nursing, 2012) holds that remaining mindful of certain carative factors in actively caring for patients keeps the vital interpersonal component of caregiving from becoming lost in the face of interference from more impersonal factors.

The HPM is a useful framework for examining how to educate informal caregivers to become more effective collaborators in palliative care because it was designed to help nurses develop and perform health-promoting interventions that empower families (McEwen & Wills, 2011). The model identifies factors that influence health behavior. The critical points of the HPM are eight principles that
assist nurses in identifying what needs to be changed to achieve the goals of the patient (Pender, 2011).

For example, if a terminally ill patient’s caregiver misunderstands the nature of some aspect of patient care, such as pain management, the misunderstanding might be due to personal factors within the caregiver, such as religious objections, fear of addiction, or associating legal pain medication with illegal drugs. Such psychological factors provide a starting point for the HPM protocol. The behaviors that result from misunderstandings about pain management protocols may be considered in a number of ways within the framework of HPM. For example, the negative perception of pain medication could be considered a perceived barrier to action. Incorrect information about pain management, such as the belief that giving pain medication may hasten the patient’s death, affects the caregiver’s perception of self-efficacy in a negative way. When a nurse addresses such issues in a caregiver’s individual characteristics and experiences, the caregiver’s consequent behavior is more likely to be health promoting and a more knowledgeable and effective use of pain medication.

Kolcaba’s theory of comfort is another useful framework for hospice and palliative care. Nurses are responsible for providing comfort, relief from suffering, and a manner of death that is in accordance with the patient’s wishes (Kolcaba, Dowd, Steiner, & Mitzel, 2004). The theory of comfort helps nurses assess the comfort needs of terminally ill patients on the physical, psychospiritual, sociocultural, and environmental levels (Kolcaba et al., 2004). It provides a taxonomic structure in which comfort is categorized into three types: relief, ease, and transcendence. Relief is the state that results when a specific need is met or mediated. Ease is the state of calmness and contentment. Finally, transcendence
is the state that results when patients are able to rise above challenges such as pain (Kolcaba, 2001). The goal of nursing is to meet these needs for comfort in each of four contexts of experience: physical, psychospiritual, environmental, and social. When a terminally ill patient achieves transcendence in each of these contexts, the state of comfort for the patient is achieved.

This theory guides nurses in the design of holistic interventions for hospice palliative care for terminally ill patients. In this theory, the meaning of “patient” does not need to be understood solely as referring to an individual, but may also be extended to include families, communities, or institutions in need of healthcare (Kolcaba, 2001). Caregivers for terminally ill patients also need multiple and complex forms of comfort, so nurses should consider caregivers’ needs in addition to the needs of their patients (Kolcaba, 2001). In hospice care, nurses, social workers, and chaplains work very closely to support patients and families. Care team members should understand patients’ and families’ desires so they can help them accomplish their goals for the end of life. Such care can take many forms: education, encouragement, positive reinforcement, rest, socialization, and nutrition.

Families and patients often require an advocate to ensure that their wishes are understood. One of nurses’ major responsibilities is to be this advocate because they have close and frequent contact with patients and caregivers. In this capacity, nurses needed to interact with patients from various backgrounds. Some of the aspects of the patients’ lives may be outside the nurse’s experience, aspects such as family dynamics, religion, and cultural practices. Professional hospice palliative nurses have to remain focused on patient needs to achieve maximum comfort for patient and family.
Jean Watson’s theory of human caring (Current Nursing, 2012) is applicable to the care of both terminally ill patients and their caregivers. Watson warned that patients can become dehumanized when organizations undergo major administrative restructuring. Her theory helps nurses return to the caring that is at the core of nursing. It guides hospice nurses in showing acceptance and promoting a supportive and protective environment as well as providing education and intervention to patients and their caregivers.

Watson described seven assumptions and 10 primary carative factors, some of which are particularly applicable to hospice care. Watson’s caring theory was intended not primarily for medical guidance, but more for help in providing compassion to ease patients’ and caregivers’ suffering and promote their healing and dignity (Cara, n.d.). One of the assumptions of Watson’s theory is that effective caring promotes health and individual or family growth (Current Nursing, 2012). The enhancement of this growth rather than the cure of the illness is the focus of the theory (Current Nursing, 2012).

Watson’s carative factors are vital elements in hospice care. One of the factors is that humans need assistance, meaning that helping with basic needs should be done with the conscious goal of also supporting the patient’s spiritual well-being. Another carative factor is the development of a caring-trust relationship. Nurses and the patient’s caregiver must establish a relationship of mutual trust. Nurse, patient, and caregiver need to take time to make human-to-human connections. It is difficult for the nurse to know how well a patient is dealing with pain, how much difficulty family members are experiencing as they face the death of a loved one, or whether the family and patient need teaching regarding palliative care unless there is a relationship of trust between the nurse and the caregiver. Patients and families would not share their feelings and
thoughts with nurses if they did not trust them. One carative factor that goes a long way toward establishing this trust is the importance placed on showing kindness, concern, and love to patients and caregivers.

Because the type of spiritual actualization and growth that is the goal of both Kolcaba’s theory of comfort and Watson’s theory of human caring are more difficult to achieve when a patient is preoccupied by pain in the physical body, effective means of dealing with pain, not limited to but certainly including pain medication, are necessary for patient and caregivers.

Effective teaching is within the scope of nursing practice, so nurses need to consider patients’ and caregivers’ learning styles when explaining about pain management. In fact, one of Watson’s 10 carative factors is promotion of interpersonal teaching-learning (Current Nursing, 2012). Pender’s HPM provides guidance in explaining the individual characteristics and experiences that may result in resistance to taking pain medication. This information is likely to be of use when developing a plan for educating patients and caregivers. Everyone has a unique background, a unique education level, and a unique perception of a given situation. Recognizing the differences among individuals is important in developing individualized plans of education. In order to provide an effective plan, nurses and caregivers must understand their patients’ needs.

**Significance**

An effective tool that improves communication between clinicians and caregivers for the purpose of patient pain management is a necessity when providing hospice care. Ideally, this tool will be provided and explained upon commencement of hospice care, perhaps included as part of the admission packet.
If the tool is a regular component of the nursing protocol, nurses will train caregivers in its use and review it with the caregiver on every nursing visit. Its purpose should be to provide a basis for the evaluation of the medication regimen and any needed modifications in collaboration with the hospice physician.

The use of such a tool will reduce confusion when nurses assess pain management during visits or over the phone. The tool will facilitate determination of the frequency and total dosage of medication to be given to the patient.

Some hospice nurses have expressed a need for such a tool. This study investigated whether pain diaries, and specifically the PRO-SELF Pain Management Diary, could fill this need.

**Summary**

The number of hospice patients has been growing. Hospice care is often provided at home, and more than half of hospice patients at home are cared for by informal caregivers who are not adequately prepared to provide symptom management. Informal caregivers need to be able to address various forms of distress hospice patients experience at the end of life. Pain is the most common and most challenging symptom for hospice patients and informal caregivers. It is important for informal caregivers to be able to provide effective pain management for hospice patients at the end of life. Therefore, it is crucial for hospice nurses to evaluate informal caregivers’ ability to manage pain as well as any obstacles that make it difficult for them to do so and provide appropriate education and support.

Effective communication between nurses and informal caregivers is essential for evaluating informal caregivers’ pain management ability. One tool that has been demonstrated to be effective for pain management is the PRO-SELF Pain Management Diary developed by Dr. Christine Miaskowski of the faculty of
the University of California, San Francisco. The diary enhanced the communication among patients, informal caregivers, and nurses, permitting clearer understanding and therefore better management of patients’ pain and the effect of treatment. The tool has been used successfully for the pain management of cancer outpatients; this study was undertaken to determine whether it would be useful for hospice patients in the home setting.
CHAPTER 2: LITERATURE REVIEW

Many researchers have studied the effectiveness of various methods of managing end-of-life symptoms. End-of-life symptoms include physical and mental upset, anguish, and suffering (McMillan & Small, 2007). Researchers have identified possible barriers to effective symptom management and made suggestions on how to mitigate these barriers. Because the number of home hospice patients receiving care from informal caregivers with little or no medical experience has increased in recent years, the researcher reviewed the literature for research-based insights on ways to provide support to those providing care for hospice patients. A search for articles relating to hospice, palliative care, pain, and pain logs was conducted on the EBSCO system. Thirteen articles were found that were relevant to the topic. The articles identified pain as one of the most common and most difficult symptoms at the end of life. They also identified poor communication with caregivers as a significant barrier to successful pain management. The articles also discussed the effectiveness of pain diaries in contexts other than end-of-life care.

Pain Management

A number of researchers have identified pain as one of the most difficult to manage symptoms of patients in hospice care. Johnson et al. (2005) ranked pain among the most problematic symptoms, along with agitation, dyspnea, confusion, and pressure ulcers. Oliver et al. (2013) also stated that pain was one of the most prevalent and difficult symptoms to manage. McMillan and Small (2007) reported that pain was the most common symptom, requiring treatment in 82%-88% of hospice patients who suffered from cancer. Lau et al. (2009) suggested that pain
was among the most under-recognized end-of-life symptoms and therefore was insufficiently treated by nurses and informal caregivers.

The difficulty of managing pain is exacerbated when the caregiver has no medical training. Hospice patients who are cared for at home are most often in the charge of informal caregivers. These caregivers often suffer from feelings of anxiety and depression as well as physical symptoms. McMillan and Small (2007) found a high rate of medication error by informal caregivers. Older caregivers, in particular, have been reported to have difficulty managing pain for hospice patients due to the emotional stress of losing a loved one combined with the physical demands of caregiving and the physical decline caused by aging (Oliver et al., 2013).

Forty percent of nurses in one survey chose pain as one of the five “most difficult to manage” symptoms (Johnson et al., 2005, Results section, para. 1). Nevertheless, nearly all of these nurses also reported that they had been successful at treating pain. The researchers resolved this apparent contradiction by pointing out that the difficulty in treating pain lay not with a lack of knowledge about effective treatment options, but rather in poor communication among patient, family, and medical provider.

**Barriers to Pain Management**

Researchers have attempted to identify barriers to effective pain management. According to Sherman et al. (2004), successful pain management can be achieved only when the parties involved understand the obstacles to the evaluation and relief of pain. Johnson et al. (2005) analyzed survey responses from 867 hospice nurses and identified the following as the most widely noted barriers to pain management: the failure of caregivers to execute or keep up
recommended treatments (38%), objections to recommended treatments from patients or families (38%), competing demands from other symptoms (37%), and acceptance of the symptom as a consequence of other treatments (33%). Oliver et al. (2013) listed as the primary barriers to effective pain management communication problems with nurses; difficulty getting proper medications; fear of addiction; and personal attitudes, beliefs, and values. They also noted other obstacles: difficulties with the administration of medication, concern over side effects, insecurity about the accuracy of pain assessment, and frustration over poor communication with nurses. Mayahara et al. (2014) found that the most common barrier was the failure of informal caregivers to begin or follow through with recommended courses of treatment.

Communication

As seen in the previous section, several researchers numbered poor communication among the barriers to effective pain management. Part of the source of poor communication may be a difference of priorities between informal caregivers and hospice nurses. Lau et al. (2009) found a difference between what informal caregivers think they need to learn from nurses and what the nurses feel they should teach. Hospice nurses place emphasis on technical skills, such as the proper administration of medicine. In contrast, informal caregivers place more value on teamwork, daily responsibilities such as storing and keeping track of medication, and delivering care to patients who resist it. Oliver et al. (2013) also found communication problems between caregivers and nurses.

Overcoming these communication problems is an important step toward enabling nurses and informal caregivers to work together as an effective team. Improving symptom control may require interventions that draw upon the
collective knowledge and experience of patients, informal caregivers, and nurses. In this case, the ability to communicate this knowledge effectively to one another is imperative (Johnson et al., 2005). Failure to communicate results in tension between nurses and caregivers. Nurses should be aware that pain management is a source of emotional stress for caregivers (Oliver et al., 2013). One of the major issues for pain management is effective communication between nurses and informal caregivers (Kelley et al., 2013). Keeping this in mind would help nurses to be more effective communicators as they attempt to prepare caregivers for the task of pain management. Oliver et al. recommended that hospices evaluate informal caregivers’ perceptions of pain and provide clear, structured education to help caregivers understand the correct administration of medication and the side effects that may occur.

**Pain Diaries**

Providing quality care requires that nurses take a comprehensive pain history of their patients (Sherman et al., 2004). A pain diary offers one method of obtaining such a history. Schumacher et al. (2002) surveyed cancer patients and family caregivers, finding that 74% found a pain management diary to be useful. The reasons given for their usefulness fell into four categories: raising awareness of the pain experience, providing guidance for self-care behaviors, easing communication, and giving patients and informal caregivers a greater sense of self-control.

Schumacher et al. (2002) did not find that pain diaries improved communication between nurses and caregivers. Few patients in their study mentioned the pain diary as a communication tool, suggesting they did not understand its value to nurses. The researchers concluded that clear education and
coaching are needed for pain diaries to reach their full potential. They suggested that nurses should review entries in the pain management diary with patients and caregivers so they can gained a deeper understanding of how they respond to pain.

Summary

Pain is among the most difficult symptoms to manage. Hospice patients in the home setting are often cared for by informal caregivers whose lack of medical training compounds the difficulty of pain management. In contrast, experienced nurses are often successful at treating pain. In the literature that documents the difficulties informal caregivers experience when attempting to manage a patient’s pain, poor communication with nurses appears often. Overcoming communication problems is a necessary step toward nurses and caregivers working in collaboration. A pain diary provides a common focus for patient, caregiver, and nurse. Although one study did not demonstrate the ability of pain diaries to improve communication between nurses and caregivers, further attempts to refine their usage may yield different results.
CHAPTER 3: METHODOLOGY

The purpose of this study was to investigate whether the PRO-SELF Pain Management Diary, which was developed to record the pain management of cancer outpatients, would be helpful to caregivers for communicating with hospice nurses about patient pain. This chapter presents the study design, sample, data collection, purpose, instrumentation, data analysis, and human subjects review.

Informal caregivers caring for hospice patients in a home setting used the diary to maintain a record of medications and pain levels as a reference to facilitate accurate communication with hospice nurses. Data collection using the PRO-SELF Pain Management Diary was conducted over a 2-week period. At the end of this period, an end-of-study interview was conducted with the informal caregivers to elicit their opinions about the helpfulness of the diary and its influence on communication with hospice nurses about patient pain.

**Study Design**

This study had a qualitative research design; data were collected by interviewing participants. The researcher examined the effectiveness of the PRO-SELF Pain Management Diary (Appendix A), which was developed by faculty at the University of California, San Francisco (Schumacher et al., 2002), for use in the home setting. The PRO-SELF Pain Management Diary was originally developed to improve the pain management of cancer outpatients by providing a tool that patients and their informal caregivers could use to log such information as type of medication given, dosage, time of administration, side effects, and degree of pain the patient experienced.

The PRO-SELF Pain Management Diary was provided to informal caregivers of patients newly admitted to a single hospice in California who were
being cared for in a home setting. The study lasted for 2 weeks. The study period began when the researcher conducted the admission visit. After the admission process was concluded, the study was explained and consent for participation (Appendix B) was obtained.

The informal caregivers were trained in the use of the PRO-SELF Pain Management Diary. Patients who were alert and oriented were included in the training. The researcher read the document along with the informal caregivers and showed them how to fill out the PRO-SELF Pain Management Diary, which consisted of two pages on which information for a single day was to be logged. A new PRO-SELF diary was used each day of the 2-week study period.

The informal caregivers were provided with a 2-week supply of pain diaries. They were also given a contact number at which the researcher was available 24 hours a day in the event that they had any questions.

The researcher visited each participant’s house during the first week to answer questions, encourage the caregivers, and deliver individualized coaching in the use of the PRO-SELF Pain Management Diary. During the second week, the researcher made one phone contact with each informal caregiver to answer questions and provide encouragement.

At the conclusion of the 2-week period, the caregivers were asked the following two questions in an end-of-study interview to learn whether they had found the PRO-SELF Pain Management Diary to be helpful: “Tell me about the helpfulness or unhelpfulness of the pain diary” and “Do you have any suggestions about modifying the diary?” The responses to these questions were used to answer the two research questions:

1. Do informal caregivers find the PRO-SELF Pain Management Diary helpful for accurately communicating about patient pain with hospice nurses?
2. Does the PRO-SELF Pain Management Diary facilitate effective pain management for home hospice patients?

Sample
Participants who were eligible for this study were the caregivers of patients who were newly admitted to the study hospice and were receiving care at home. The original sample consisted of caregivers of 12 patients, but 5 of the patients died before the end of the 2-week study period. Therefore, they and their caregivers were removed from the study. This left seven patients and 10 caregivers who were able to participate for the duration of the study.

The average age of the patients was 84. All the caregivers were 20 years of age or older and were able to read, write, and understand English.

Data Collection
The opinions of the informal caregivers about the helpfulness of the PRO-SELF Pain Management Diary were solicited by asking the following two questions in an end-of-study interview at the home of the patient: “Tell me about the helpfulness or unhelpfulness of the pain diary” and “Do you have any suggestions about modifying the diary?”

The responses were recorded on a digital recorder, transcribed verbatim for later analysis, and used to answer the research questions. Responses were categorized according to whether they characterized the PRO-SELF Pain Management Diary as “helpful,” “not helpful,” or “not needed.” Suggestions for modifying the tool were recorded separately.
Instrument

Informal caregivers began a new PRO-SELF Pain Management Diary each day (Appendix A) and maintained it throughout the day. The PRO-SELF Pain Management Diary is a two-page document written in English. On the first page is a place for informal caregivers to record the patient’s average, least, and worst instances of pain. The directions are as follows: “Please fill out this page before going to bed, keeping in mind how your pain was during the day.” Although the PRO-SELF Pain Management Diary was designed to be maintained by either patients or informal caregivers, all patients in this study delegated that responsibility to their informal caregivers.

In order to prepare them for using the diary, informal caregivers were trained in the use of the 11-point numeric rating scale for pain, on which 0 indicated no pain and 10 indicated the worst pain they could imagine. Next, they were asked to write down how many hours of pain the patient had that day by filling in a value from 0 to 24.

Informal caregivers also recorded both routine and Pro Re Nata (PRN) medications, the dosages, and the times they were given in a table on the first page. The table was divided into two sections, one section for entering routine medications and another section, labeled “Extra,” for entering PRN medications. There was a place at the top of the page for them to record the date the information was logged.

The second page displayed a checklist of 11 possible side effects from medication, including difficulty concentrating, lack of energy, nightmares, nausea, and others. Informal caregivers and patients were prompted to make an X next to each side effect experienced. If the patient did not experience the side effect at all, the caregiver was to make an X under “Did not have.”
If the patient did experience the side effect, the caregiver was to indicate its severity by placing the X under “slight,” “moderate,” “severe,” or “very severe.” A reminder appeared at the bottom of the second page, prompting caregivers to start a new log book the following day.

**Human Subjects Review**

Prior to this research, the Department of Nursing Committee on the Protection of Human Subjects of the California State University, Fresno, reviewed the research proposal and determined that it met the criteria for Minimal Risk Institutional Review Board review (Appendix C).

The researcher obtained permission to use the PRO-SELF Pain Management Diary from its developer (Appendix D) and from the hospice (Appendix E). Consent forms (Appendix B) were signed by patients who were competent or, for patients who were not competent, by persons who had the authority to sign for them. The researcher completed the National Institute of Health (NIH) human subjects protection training (Appendix F).

All of the data collected in the course of this study and all identifying information about participants were secured in a computer with a password known only to the researcher. All of this information was deleted from the computer after the completion of this report. The recording device was kept in a locked drawer and erased after transcription was completed. All transcribed responses were also kept in a locked drawer and shredded and discarded after the completion of this report.

**Summary**

This study used a qualitative research design to examine the helpfulness of the PRO-SELF Pain Management Diary as a tool for improving the pain
management of hospice patients who received care at home from informal caregivers. The PRO-SELF Pain Management Diary was developed to improve communication with hospice nurses by providing a tool for informal caregivers to document the management of patient pain.

The informal caregivers and patients participated in the study for 2 weeks after being trained in the use of the PRO-SELF Pain Management Diary, a two-page document. Both pages of the tool were described in this chapter. At the conclusion of the study period, the researcher conducted an end-of-study interview with the informal caregivers about the helpfulness of the PRO-SELF Pain Management Diary in order to answer the research questions.
CHAPTER 4: RESULTS

The purpose of this study was to find out whether informal caregivers thought the use of the PRO-SELF Pain Management Diary resulted in better documentation of pain management for hospice patients, thereby improving communication between informal caregivers and hospice nurses. At the end of the 2-week study period, informal caregivers were interviewed about the helpfulness of the PRO-SELF Pain Management Diary and asked whether they thought the tool should be modified.

This chapter presents the demographics of the informal caregivers in the study, their relationships to the patients, and the diagnoses and medications of the patients. It also gives the results of the end-of-study interview. The majority of caregivers reported that they found the tool to be helpful in their communication with hospice nurses. Informal caregivers suggested three modifications to the tool.

Sample Demographics

The original study included 12 patients who had been admitted to a single hospice in California between January 10, 2015, and February 21, 2015, and received care from informal caregivers at home. The 12 patients were assigned to the researcher for admission to the hospice.

The informal caregivers were responsible for filling out the PRO-SELF Pain Management Diary for the patients. Five of the patients died during the period of the study. Therefore, they were removed from the study and their caregivers were not interviewed about using the PRO-SELF Pain Management Diary.
Seven patients survived until the end of the study. At the conclusion of the 2-week study period, the researcher conducted an end-of-study interview with the remaining 10 informal caregivers. The number of informal caregivers was greater than the number of patients because three of the patients had two caregivers each.

The age range of the patients who completed the study was from 75 to 91 years, with a mean of 84 (see Table 1). Two of the patients were male and five were female (see Table 1). Two of the patients were diagnosed with congestive heart failure (CHF), two with unspecified protein-calorie malnutrition, one with coronary artery disease (CAD), one with cerebral vascular accident (CVA), and one with cirrhosis of the liver (see Table 2).

All seven patients were on PRN medication, including morphine sulfate oral solution, Norco, and acetaminophen. One patient was also on routine methadone twice daily in addition to PRN medications (see Table 3).

Table 1

Demographic Characteristics of the Patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients $N = 7$</th>
<th>Informal caregivers $N = 10$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Years)</td>
<td>Mean 84.0</td>
<td>Mean 48.2</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 2

*Disease Characteristics of the Patients*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHF</td>
<td>2</td>
</tr>
<tr>
<td>Unspecified protein-calorie</td>
<td>2</td>
</tr>
<tr>
<td>Malnutrition</td>
<td></td>
</tr>
<tr>
<td>CAD</td>
<td>1</td>
</tr>
<tr>
<td>CVA</td>
<td>1</td>
</tr>
<tr>
<td>Cirrhosis of liver</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3

*Pain Medications of the Patients*

<table>
<thead>
<tr>
<th>Medication</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine solution</td>
<td>7</td>
</tr>
<tr>
<td>Norco</td>
<td>2</td>
</tr>
<tr>
<td>Acetaminophen</td>
<td>1</td>
</tr>
<tr>
<td>Methadone</td>
<td>1</td>
</tr>
</tbody>
</table>

The informal caregivers were the sample group of the study; they were the ones who filled out the PRO-SELF Pain Management Diary. None of them had any formal medical training.

The age range of the informal caregivers was 25-72 years with a mean of 48.2. The primary language of the informal caregivers was English. Six were female and four were male. By ethnicity, the informal caregivers were Caucasian \( (n = 5) \), Hispanic \( (n = 2) \), Asian \( (n = 2) \), and other \( (n = 1) \).
The majority of the informal caregivers were paid for providing the care \((n = 6)\). The other informal caregivers had personal relationships to the patients; two were spouses or significant others, one was an adult child of the patient and one was a friend.

**End-of-Study Interviews with Informal Caregivers**

After the conclusion of the 2-week study period, the researcher visited each of the 10 informal caregivers to conduct the end-of-study interview in person from January 24, 2015, to March 31, 2015. At the interview, the researcher asked two questions: “Tell me about the helpfulness or unhelpfulness of the pain diary” and “Do you have any suggestions about modifying the diary?” The researcher recorded the informal caregivers’ verbal replies with a digital recording device. The researcher also collected the pain diaries the informal caregivers had filled out during the study period.

Initially, the PRO-SELF Pain Management Diary was to be deemed “complete” if it was maintained on a daily basis for the duration of the study. The PRO-SELF Pain Management Diary is a two-page document, but only one informal caregiver maintained the second page of the diary, which contained a checklist of possible side effects. Therefore, the researcher made the determination of “complete” or “incomplete” based on whether the first page of the diary was maintained; the second page was disregarded when making this determination. Five of the pain diaries for the seven patients were complete and two were incomplete (see Table 4).

The first question in the end-of-study interview was “Tell me about the helpfulness or unhelpfulness of the pain diary.” Seven of the 10 informal
caregivers reported that they found the diary helpful. Three informal caregivers reported that it was not needed (see Table 5).

Table 4

PRO-SELF Pain Management Diary Completion

<table>
<thead>
<tr>
<th>Patient</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>No</td>
</tr>
<tr>
<td>B</td>
<td>Yes</td>
</tr>
<tr>
<td>C</td>
<td>Yes</td>
</tr>
<tr>
<td>D</td>
<td>Yes</td>
</tr>
<tr>
<td>E</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>Yes</td>
</tr>
<tr>
<td>G</td>
<td>No</td>
</tr>
</tbody>
</table>

One of the five complete pain diaries was maintained by two hired caregivers, both of whom reported that they found the PRO-SELF Pain Management Diary to be helpful. Four of the five completed pain diaries were filled out by single caregivers who were family members or friends of the patients, three of whom reported that the diary was helpful.

All of these informal caregivers said it was helpful because keeping a record of the time of administration, dosage, type of medication, and pain levels improved their communication with hospice nurses. One of the single informal caregivers said that it was not needed because the patient’s pain had been successfully managed by a single PRN medication.

The two incomplete pain diaries were provided to patients each of whom had two hired informal caregivers, accounting for four informal caregivers.
Table 5

*Helpfulness of Pain Diary as Perceived by Patients and Family Caregivers*

<table>
<thead>
<tr>
<th>Patient</th>
<th>Caregiver</th>
<th>Helpful</th>
<th>Not helpful</th>
<th>Not needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>a1</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a2</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>b1</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>C</td>
<td>c1</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>d1</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td></td>
<td>d2</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>e1</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>f1</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>G</td>
<td>g1</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>g2</td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

Despite encouragement from the researcher, use of these pain diaries was discontinued, after the first day in one case and after the third day in the other case. In each case, the informal caregivers stopped maintaining the PRO-SELF Pain Management Diary, but it was not clear to the researcher which informal caregiver stopped first.

When they were interviewed, the caregivers cited as reasons for discontinuing the PRO-SELF Pain Management Diary prior establishment of a pain management regimen that made keeping the diary unnecessary, forgetting, or being too overwhelmed with other tasks. Nevertheless, two of these four informal caregivers said they thought the PRO-SELF Pain Management Diary would have been helpful for keeping better documentation had they continued to maintain it.
The other two said it was not needed because the patients’ pain had already been successfully managed.

Participants suggested three modifications. One was to condense the pain diary to one page by including the side effects checklist on the same page as the other items. This was suggested because some informal caregivers said they forgot about the second page because it was out of sight.

Another suggested providing more spaces to enter information about medications. The third suggested modification was to remove the separation between routine and PRN medications from the table for entering information about medication because more space was needed for PRN medications.

**Changes in the Pain Management of Patients in the Study**

The detailed entries on the PRO-SELF Pain Management Diary helped informal caregivers to report accurately to nurses about their pain management activities. The more precise documentation about the timing and dosage of pain medication afforded by the diary aided nurses in tailoring the medication regimen and assisted in symptom management.

The medication regimens of four patients were modified after the informal caregiver started to use the PRO-SELF Pain Management Diary (see Table 6). One patient was prescribed bowel medication for constipation, which was a side effect of pain medication. Two patients received an increase in the amount of the lorazepam they were taking for anxiety, which may have been caused by pain. Morphine was added to the pain regimen of one patient. No changes were made in the pain regimens of the remaining three patients, but the caregivers had nursing instructions to provide pain medications “as needed” and documentation of
patients’ pain on the PRO-SELF Pain Management Diary which revealed caregivers’ compliance with these instructions.

Table 6

Medication Modification

<table>
<thead>
<tr>
<th>Care plan modification</th>
<th>Patients (N = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased Lorazepam</td>
<td>2</td>
</tr>
<tr>
<td>Added bowel medication</td>
<td>1</td>
</tr>
<tr>
<td>Added pain medication</td>
<td>1</td>
</tr>
<tr>
<td>Maintain and reinforce current medication regimen</td>
<td>3</td>
</tr>
</tbody>
</table>

Summary

In end-of-study interviews, 7 of the 10 informal caregivers in the study reported they found the PRO-SELF Pain Management Diary to be helpful by providing a common reference in their discussions with nurses, thereby mitigating the uncertainty and imprecision that occurred when reports about a patient’s pain and response to medication were based on memory. Three modifications of the instrument were suggested.
CHAPTER 5: DISCUSSION

This study was conducted to answer two research questions:

1. Do informal caregivers find the PRO-SELF Pain Management Diary helpful for accurately communicating about patient pain with hospice nurses?

2. Does the PRO-SELF Pain Management Diary facilitate effective pain management for home hospice patients?

Ten informal caregivers of seven hospice patients being cared for at home used the PRO-SELF Pain Management Diary for 2 weeks to document the timing, dosage, and frequency of medication administration as well as the pain level of the patient. They used the diaries as references when they communicated with nurses in order to ensure the accuracy of their reports. The informal caregivers were asked two questions in the end-of-study interview in order for the researcher to evaluate the helpfulness of the PRO-SELF Pain Management Diary. Seven of the 10 informal caregivers found the PRO-SELF Pain Management Diary to be helpful for improving communication with nurses. The interview also yielded three suggestions for modifying the PRO-SELF Pain Management Diary. The researcher derived answers to the research questions from the results of the end-of-study interviews. Evidence was found that the PRO-SELF Pain Management Diary was helpful to informal caregivers when reporting to nurses about patient pain. The results supported the proposition that the PRO-SELF Pain Management Diary facilitates effective pain management.

Research Questions

The first research question of the study was: Do informal caregivers find the PRO-SELF Pain Management Diary helpful for accurately communicating about patient pain with hospice nurses? The answers the 10 participating informal
caregivers gave to the first end-of-study question (“Tell me about the helpfulness or unhelpfulness of the pain diary”) provided evidence that the PRO-SELF Pain Management Diary was helpful for informal caregivers as a tool to document details of patient pain management, thereby improving communication with nurses, which has been identified as a major issue in effective pain management (Kelley et al., 2013).

Seven of the 10 informal caregivers (70%) expressed the opinion that using the PRO-SELF Pain Management Diary as a reference when reporting to nurses about the pain levels of hospice patients and the medications given to them increased their confidence in the accuracy and usefulness of their reports. The informal caregivers were provided with only enough PRO-SELF Pain Management Diary pages for the 2-week study. Two of the caregivers found enough value in the diary that they made their own additional pages so they could continue to track details of pain management beyond the time period of the study.

In contrast, Schumacher et al. (2002) found that only 31% of the participants in their study, who were caregivers of cancer outpatients, reported that they found the PRO-SELF Pain Management Diary to be useful. Three of the 10 informal caregivers in this study (30%) did not form an opinion about the helpfulness of the PRO-SELF Pain Management Diary because they had discontinued its use by the third day of the study. These findings supported the proposition that a pain diary could be used by informal caregivers to improve documentation of pain management and communication about it with hospice nurses.

The second research question of the study was: Does the PRO-SELF Pain Management Diary facilitate effective pain management for home hospice patients? Hospice nurses need detailed pain histories to provide quality care to
patients (Sherman et al., 2004). However, when hospice patients are cared for in a home setting, hospice nurses are usually not available to record details of patient pain and its treatment. The PRO-SELF Pain Management Diary is an instrument informal caregivers can use to document types, dosages, and times of administration of medications as well as patient pain levels for later reference when communicating with hospice nurses.

Use of the instrument gives a more comprehensive and accurate pain history than memory alone can provide, and thereby a better basis for making decisions about the treatment of patient pain. According to Johnson et al. (2005), the problem of treating patient pain is not a lack of knowledge about how to treat pain, but rather a lack of good communication among patients, informal caregivers, and medical professionals.

The pain regimens of 4 of the 10 patients (40%) were adjusted after their informal caregivers began using the PRO-SELF Pain Management Diary. One of these patients began receiving a laxative for the relief of constipation, which was a side effect of pain medication. Two others were prescribed an increase in the dosage of lorazepam that was being taken for pain-related anxiety. Morphine was added to the pain regimen of the fourth patient. These changes in the pain regimens of patients whose informal caregivers were documenting details of their pain management in the PRO-SELF Pain Management Diary were evidence supporting the proposition that use of this instrument facilitated effective pain management, although the small size of the study meant that this could not be considered as strong support for the proposition.
Limitations

The sample size of the study, which consisted of only seven patients and 10 informal caregivers, was too small to permit valid generalizations from the results. The study period, consisting of only 2 weeks, was too short. Two weeks may have been insufficient time for informal caregivers to decide whether the PRO-SELF Pain Management Diary was a useful tool for the documentation of pain management.

The variety of diagnoses in the study was not representative of the true distribution of diagnoses among hospice patients in the United States. The most common diagnoses among hospice patients are cancer, dementia, and lung disease (NHPCO, 2012). However, none of these conditions were represented among the patients who survived until the end of the 2-week period of this study. One of the patients who began the study had been diagnosed with cancer, but this patient died before the end of the study period and thus did not meet conditions for inclusion in the study.

Implications for Nursing

The PRO-SELF Pain Management Diary had been found to be useful for informal caregivers who were caring for patients with cancer (Schumacher et al., 2002). The results of this study suggested the helpfulness of a pain diary for informal caregivers who were caring for patients in hospice care.

More complete documentation of patients’ pain management and the greater confidence and accuracy with which informal caregivers communicated with hospice nurses led to more consistent management of symptoms, which improved patient comfort. However, the fact that 3 of the 10 informal caregivers did not maintain the PRO-SELF Pain Management Diary for the 2-week period
indicated a need to improve the rate of usage of the pain diary among informal caregivers.

Three informal caregivers in this study thought the PRO-SELF Pain Management Diary was “not needed” because a well-established pain regimen was already in place. However, informal caregivers who did not use the PRO-SELF Pain Management Diary to document patient pain might not have communicated well with nurses about changes in the patients’ responses to pain medication. If changes to their patients’ pain regimens had been needed, they might have been made after a longer period of time than necessary or not at all. Choosing interventions, tracking the effectiveness of treatment, and coordinating decisions regarding care planning across healthcare professionals and care settings requires accurate pain assessment (Herr, Bjoro, & Decker, 2006). Hospice nurses should emphasize the importance of documenting patient pain even in cases in which a settled pain regimen for the patient is in place.

The suggestions made by informal caregivers in the end-of-study interview about modifying the pain diary should be considered. The PRO-SELF Pain Management Diary was originally developed for use with cancer outpatients. Attempting to incorporate the suggestions made by informal caregivers, such as condensing the form to one page, allowing more space for entering medications, and integrating the separate sections for routine and PRN medications, might make the tool more suitable for use in hospice care.

Recommendations for Future Research

The researcher recommends that this study be replicated with a larger number of informal caregivers in the sample. The sample size of the current study was too small to obtain generalizable results.
This researcher interviewed informal caregivers to find out whether they thought that the pain diary was helpful. Another study could also interview nurses to find out whether they find the tool helpful to them and whether they would recommend any modifications to the instrument to make it more helpful.

Changes in the pain regimens of 4 of the 10 patients after the use of the PRO-SELF Pain Management Diary began supports the proposition that documentation of patient pain in a pain diary improves pain management. A quantitative study comparing a group that uses a pain dairy and a group that does not would allow researchers to obtain more definitive results.

Use of patients with a more representative collection of diagnoses would have strengthened this study. A further study should include patients with such common diagnoses in hospice as cancer, lung disease, and dementia. Inclusion of these patients would yield more generalizable results.

A future study replicating this one should be conducted for longer than 2 weeks. Ideally, it should begin at the time the caregiver begins providing services to the patient and continue until the caregiver’s services are no longer required.

Conclusion

The 2-week study was conducted to answer two research questions. The study provided evidence that informal caregivers thought the PRO-SELF Pain Management Diary was helpful for accurately communicating about patient pain with nurses. It also provided support for the statement that using the PRO-SELF Pain Management Diary facilitated effective pain management for home hospice patients.

Limitations of the study included the small sample size, the briefness of the 2-week duration of the study, and the fact that the diagnoses of the patients in the
study did not include some of the most common diagnoses among hospice patients. Although the PRO-SELF Pain Management Diary was developed for use with cancer outpatients, informal caregivers of hospice patients also thought that it was helpful for documenting the details of patient pain.

Suggestions given by study participants for modifying the pain diary should be implemented and the research repeated to find out if the modified document would be more suitable for use with hospice patients. Recommendations for future studies included using a larger sample, eliciting the opinions of nurses about the helpfulness of a pain diary, conducting a quantitative study to test whether pain diaries actually improve pain management, including patients with a more representative variety of diagnoses, and conducting the study for a longer period of time.
REFERENCES
REFERENCES


APPENDICES
APPENDIX A: PRO-SELF PAIN MANAGEMENT DIARY
Please fill out this page before going to bed, keeping in mind how your pain was during the day.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>no pain</td>
<td>mild</td>
<td>moderate</td>
<td>severe</td>
<td>worst pain</td>
<td>imaginable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Using the scale above, choose a number that best describes:
   
   A The average amount of pain you experienced today
   
   B The least amount of pain you experienced today
   
   C The worst amount of pain you experienced today

2. How many hours did you have pain today? (0-24 hours)

Directions: At the end of each day, please circle the times you took your routinely scheduled pain medicine and any extra pain medicine you needed.

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Extra</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Complete this page on:
Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday

Date: _____ / _____ / _____

SIDE-EFFECTS CHECKLIST

Below is a list of symptoms that can sometimes occur when taking pain medicine. If you have had any of these symptoms during the past week, indicate how intense or bad it usually was by marking the appropriate box with an X. If you did NOT have the symptom, mark the box marked "did not have."

<table>
<thead>
<tr>
<th>During the past week did you have any of the following symptoms from your pain medications?</th>
<th>If yes, how INTENSE was it usually?</th>
</tr>
</thead>
<tbody>
<tr>
<td>difficulty concentrating</td>
<td>slight</td>
</tr>
<tr>
<td>lack of energy</td>
<td></td>
</tr>
<tr>
<td>nightmares</td>
<td></td>
</tr>
<tr>
<td>nausea</td>
<td></td>
</tr>
<tr>
<td>vomiting</td>
<td></td>
</tr>
<tr>
<td>constipation</td>
<td></td>
</tr>
<tr>
<td>difficulty sleeping</td>
<td></td>
</tr>
<tr>
<td>feeling drowsy</td>
<td></td>
</tr>
<tr>
<td>light headedness</td>
<td></td>
</tr>
<tr>
<td>poor coordination</td>
<td></td>
</tr>
<tr>
<td>indigestion/upset stomach</td>
<td></td>
</tr>
</tbody>
</table>

START NEW LOG BOOK TOMORROW.
APPENDIX B: CONSENT FORM
PRO-SELF Pain Management Diary: An Effective Documentation Tool

You are invited to participate in a study, PRO-SELF Pain Management Diary: An Effective Documentation Tool, conducted by Ayako Bonesteel RN, a master's student in nursing at California State University, Fresno. The study is focused on learning about the effectiveness of the PRO-SELF pain management diary as a method of documenting pain management in the hospice setting. You are being approached as a possible participant in this study because you are a hospice patient.

If you decide to participate, Ayako Bonesteel RN, will instruct you in the use of the PRO-SELF pain management diary for documenting pain management. The PRO-SELF pain diary is used once a day before sleep to review the effectiveness of pain management for the day. There will be no risk or added discomforts. It will take a few minutes to complete the diary each time. The PRO-SELF pain management diary may be beneficial because it may improve communication with nurses and assist nurses in evaluating the effectiveness of your pain management. I cannot guarantee, however, that you will receive any benefits from this study.

Any information obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. If you give me your permission by signing this document, I do not plan to disclose any information that can be identified with you.

There is no compensation and no cost to you. There will no risk to you.

Your decision whether or not to participate will not prejudice your future relations with California State University, Fresno or hospice. If you decide not to participate, you are free to withdraw your consent and to discontinue participation in the study at anytime without penalty. The Committee on the Protection of Human Subjects at California State University, Fresno has reviewed and approved this study.

If you have any questions, please ask. If you have any questions later, Ayako Bonesteel RN at 559-375-0176 will be happy to answer them.

You are making a decision whether or not to participate. Your signature indicates that you have decided to participate, having read the information provided above. You will be given a copy of this form to keep.

---

Date ___________________________ Signature ___________________________

Relationship to patient
APPENDIX C: IRB APPROVAL LETTER
Date: December 19, 2014

RE: MSN-1417 Pro-Self pain management diary: An effective documentation tool.

Dear Ayako Bonesteel,

As the Chair of the Department of Nursing Research Committee, serving as the Institutional Review Board for the Department of Nursing, I have reviewed and approved your review request for the above-referenced project for a period of 12 months. I have determined your study to meet the criteria for Minimal Risk IRB review.

Under the Policy and Procedures for Research with Human Subjects at California State University, Fresno, your proposal meets minimal risk criteria according to section 3.3.7: Research in which the risks of harm anticipated are not greater, probability and magnitude, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

The Research Committee may periodically wish to assess the adequacy of research process. If, in the course of the study, you consider making any changes in the protocol or consent form, you must forward this information to the Research Committee prior to implementation unless the change is necessary to eliminate an apparent immediate hazard to the research participant(s).

This study expires: December 19, 2015

The Research Committee is authorized to periodically assess the adequacy of the consent and research process. All problems having to do with subject safety must be reported to the Research Committee. Please maintain proper data control and confidentiality.

If you have any questions, please contact me through the CSU, Fresno School of Nursing Research Committee at tereag@csufresno.edu.

Sincerely,

Terea Giannetta, DNP
School of Nursing, Research Committee, Chair
APPENDIX D: PERMISSION OF PRO-SELF PAIN MANAGEMENT DIARY
Dear Ayako:

Please forgive the delay in responding to you.
I was on vacation.

You have my permission to use the diary.
Good luck with your thesis.

Chris

Christine Miaskowski, RN, PhD, FAAN
Professor
American Cancer Society Clinical Research Professor
Sharon Lamb Endowed Chair in Symptom Management Research
Department of Physiological Nursing
University of California
2 Koret Way – N631Y
San Francisco, CA 94143-0610
415-476-9407 (phone)
415-476-8899 (fax)
chris.miaskowski@nursing.ucsf.edu
APPENDIX E: PERMISSION FROM HOSPICE
To Whom It May Concern:

We grant permission to Ayako Bonesteel to conduct her study regarding the use of the PRO-SELF pain diary for pain management at our facility.

Richard Zarandin, RN, CHM
Clinical Manager - Hospice
Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that Ayako Bonesteel successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 01/30/2013

Certification Number: 1099681
Fresno State

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**Ayako Bonesteel**

Type full name as it appears on submission

**May 7, 2015**

Date