

KNOWLEDGE, BACKGROUND, AND PERCEPTIONS:
PAIN AND PALLIATIVE CARE GIVING

RESEARCH PROPOSAL
SUBMITTED TO THE GRADUATE SCHOOL
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE

MASTERS OF SCIENCE

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MUNCIE, INDIANA

MAY 2010

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Chapter I

Introduction

The Merck Institute of Aging and Health (MIAH) reports by the year 2030, a sudden surge of individuals over the age of 65 will account for nearly 20% of the American population (MIAH, 2009). The delivery of health care will be significantly impacted due to this aging population. It is postulated that 71 million elderly American will suffer from at least one chronic illness (MIAH, 2009). Elderly Americans suffer from an average of three chronic conditions and use five different prescription drugs (MIAH, 2009). Medical technology has afforded American longer and more productive lives, but has not protected them from progressive illnesses and how we care during end-of-life (EOL) (Rao, Anderson, & Smith, 2002).

Approximately 2 million Americans died in 2007 (United States Department of Health and Human Services, 2008). With increasing longevity of Americans, more people have chronic diseases. These diseases all have a development that is specific for an individual, in which the chronic phase can gradually turn into the palliative phase (Davies & Higginson, 2005). The Center for Medicare and Medicaid (2008) estimate that Medicare expenditures in the last month of life is twenty times higher than average monthly expenditures which they attribute to a significant increase in the use of intensive

inpatient hospital services. These progressive chronic illnesses result in prolonged death, wrought with significant emotional expense (Rao et al., 2002).

According to the World Health Organization (WHO) (2009) palliative care is the active total care of a patient whose disease is not responsive to curative treatment. The WHO (2009) states that palliative care:

1. Aims to achieve the best possible quality of life for patients and their families.
2. Affirms life and regards dying as a normal process.
3. Neither hastens nor postpones death.
4. Provides relief from pain and other distressing symptoms.
5. Integrates the psychological and spiritual aspects of patient care.
6. Offers a support system to help the family cope during the patient's illness and in subsequent bereavement.

Health providers have an ethical and moral obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care.

Specific end-of-life curriculums have been developed, but are being used inconsistently to train health care professionals and lacking evaluation of the outcomes (National Institutes of Health, 2004). Evidence suggests persistent shortcomings of health professionals and educators to meet the needs of the dying (Mallory, 2003). Few EOL

education initiatives have been systematically evaluated (Degner & Gow, 1998) and the need for additional outcomes persists (Kurz & Hayes, 2006).

Millions of Americans die each year, and the majority of deaths occur in hospitals, medical centers, and or skilled facilities where nurses provide the majority of care (Kwekkeboom, Vahl, & Eland, 2005). As the population ages, nurses will be required to provide palliative care for an increasing number of patients. A anticipated increase in the number of people diagnosed with cancer will result in cancer death rates doubling from 1.3 million in 2000 to 2.6 million in 2050 (MIAH, 2009). Nurses are central figures in advocating for interventions that minimize burden and distress and enhance quality of life for their patients who are terminally ill (Fox, 2007). Given these extremely important responsibilities, novice to expert nurses must be adequately prepared to provide sensitive quality care for patient at the end of life. Implementation of educational opportunities within curricula as well as other strategies to prepare nurses for death, dying, and bereavement have been long in coming. Educators must focus on improving nurses' knowledge and attitudes to lessen their concerns about caring for dying patients in order to deliver quality care.

Background and Significance

Palliative care is a healthcare approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual (WHO, 2009). Nurses spend more time with patients at the end-of-life than

any other health discipline (Foley & Gelband, 2003). Lack of professional education has been identified as a major barrier to providing quality palliative care to patients (Marra, 2000). End-of-life education in undergraduate nursing programs is minimal and does not adequately prepare new nurses to provide high quality palliative care (White, Coyne, & Patel, 2001).

Death education and experiences was given very little attention in the 1960s and 1970's for nursing students and existing nurses (Thrush, Paulus, & Thrush, 1979). Integration of death and dying units became prevalent in 80% of baccalaureate nursing programs, by integrating end-of-life information into other courses and lectures, with 12% of the programs offering a full semester in death and dying (Dickinson, 2006). Offerings in end-of-life care have increased in nursing schools in recent years, yet in 1997 the National Academy of Sciences identified large gaps in health care professionals' knowledge of strategies in dealing with patients end-of-life-care issues (Aulino & Foley, 2001). Nurses do not feel competent or confident in implementing end-of-life care (Meraviglia, McQuire, & Chelsey, 2003). Curriculum and professional training needs to be continually upgraded despite recent improvements on end-of life care.

Benner (1984) have demonstrated that knowledge, embedded in actual nursing practice or practical knowledge is a requisite for the development of expertise. Clinical knowledge grows over time, requiring nurses to formulate strategies to refine and extend knowledge and expertise (Schlairet, 2009). Nurses working in different situations with common issues, such as end-of-life care and dying, develop universal meanings about perceptions, options, knowledge, and coping (Fox, 2007).

Knowledge and competence of optimal pain management at the end-of life enhances the patient-health care provider relationship (Saunders, 1976). The vision of delivering quality end-of-life care demands for nurses to be knowledgeable in the concept of perception of pain management in palliative care within nursing education and practice (Fox, 2007).

Fox (2007) conducted a study and found that nurses and health care professionals in Kansas believe they are ill prepared to provide palliative care and want professional education to improve skill in this area. The study reports that nurses and health professionals learn about end-of-life not through formal education, but through on the job training. In developing consistent palliative care curricula, it is important to gain knowledge of effective end-of-life practices, and awareness of one's perceptions to deliver quality palliative care to patients (Fox).

Statement of Problem

All patients deserve to be cared for in a humane nature when approaching death. Persistent deficiencies and variables exist in end-of-life nursing care practice and education to support that care (Fox, 2007). When the end of life makes its inevitable appearance, patients should be able to expect reliable, humane, and effective care giving. Yet too many dying patients suffer unnecessarily. Determination of nurses' knowledge, background, and perceptions of pain management may impact delivery of palliative care; therefore, it is important to identify variables that influence and improve knowledge and improving practice in this area.

Purpose of the Study

The purpose of this study is to examine health care providers' knowledge, background, perceptions and opinions about pain management in palliative care. This is a replication of Fox's (2007) study.

Research Question

What are the relationships among health care professionals' knowledge, background, perceptions, and opinions about pain management in palliative care?

Conceptual Framework

The Total Pain Model (Saunders, 1976) is the framework for this study. The concept of total pain is becoming increasingly important as a means of providing knowledge to care givers into the perception of physical and nonphysical components of discomfort in palliative care (Saunders). McCaffrey, Frock, & Garguilo (2003) defined pain as whatever the experiencing person says it is, existing whenever he/she says it does. Pain Management is identifying the components affecting patients' perception of pain, and providing the care to alleviate or to reduce pain (Saunders). This framework is appropriate for the study because it identifies components that may affect patients' perception of total pain individually or in combination of the components as follows: (a) physical noxious stimuli, (b) anxiety, (c) interpersonal conflicts, and (d) non-acceptance of one's own dying. The need for nurses to be knowledgeable and competent in the concept of perception of pain management in palliative care is repeatedly emphasized (Saunders). It is important to investigate health care providers' knowledge and background, perceptions, and opinions about pain management in palliative care.

Definition of Terms

Conceptual: Pain Management: Pain is defined by McCaffrey et al. (2003), is whatever the experiencing person says it is, existing whenever he/she says it does. Pain Management is identifying the components (knowledge, background perceptions) affecting patients' perception of pain, and providing the care to alleviate or to reduce (Saunders, 1976). Variables used in this replication is health professionals' clinical discipline, type and level of training, and perception or perceived support, concern, and knowledge.

Operational: Pain Management related to nurses and healthcare professionals' assessing demographics, practice pattern, education in pain management, confidence in pain management system, and visions for pain management will be measured by Fox's (2007) Living Initiatives for End-of-Life Care Project Pain Management Survey.

Limitations

One limitation is that the study will occur in one location. Another limitation of this study is the relatively small sample size. Both limitations will limit the generalization of the study findings.

Assumptions

Health care education has been widely criticized for not providing professional education within end-of-life care, resulting in anxiety, interpersonal conflict and ineffective pain management in palliative care (Fox, 2007). Improved pain management is a necessity for end-of-care patients. End-of-care pain management is influenced by health care professionals' knowledge, background, perceptions, and opinions.

Summary

Nurses do not feel competent or confident in implementing end-of-life care (Meraviglia et al., 2003). Curriculum and professional training needs to be continually upgraded despite recent improvements on palliative care. The purpose of this study is to examine health care providers' knowledge, background, perceptions and opinions about pain management in palliative care. Saunderson's (1976) Total Pain Model addresses health professionals' knowledge, background and perceptions of pain management, impacting delivery of palliative care; therefore, it is important to identify variables that influence and improve knowledge and improving practice in this area. Findings will provide information to determine the effectiveness of pain management in palliative care nursing. The ability for nurses deliver reliable and effective pain management in palliative care will enable end-of-life patients the assistance to die well.

Chapter II

Review of Literature

Introduction

Palliative care is an approach for nurses to improve the quality of life of patients and their families who are facing a life-threatening illness. All patients deserve to be cared for in a humane manner when one is approaching death. There are persistent deficiencies and variables in the end-of-life nursing care practice and the education to support that care (Fox, 2007). Specific end-of-life curricula have been developed, but are being used inconsistently to educate nurses within undergraduate studies and practicing nurses. Therefore, it is a social and ethical obligation of practitioners to gain knowledge of effective end-of-life practices, and awareness of one's perceptions to deliver quality palliative care to patients.

Purpose

The purpose of this study is to examine health care providers' knowledge, background, perceptions, and opinions about pain management in palliative care. This is a replication of Fox's (2007) study.

Organization of Literature

The literature review to support this study is divided into four sections: (a) conceptual model; (b) nurses' knowledge of pain management in palliative care; (c)

perceptions of pain management by patients; and (d) palliative care and patients' satisfaction.

Conceptual Model

The Total Pain Model (Saunders, 1976) is the framework for this study. The concept of total pain is becoming increasingly important as a means of providing knowledge to care givers into the perception of physical and nonphysical components of discomfort in palliative care (Saunders). McCaffrey et al. (2003) defined pain as whatever the experiencing person says it is, existing whenever he/she says it does. Total Pain is defined as the sum of four components: physical noxious stimuli, anxiety, interpersonal conflicts, and non-acceptance of one's own dying (Saunders). The four components defined by Saunders may affect patients' perception of total pain individually or in combination of the components as follows: (a) total pain-physical noxious pain is categorized in terms of its temporal nature and delineated into somatic, visceral, and neuropathic pain; (b) total pain-anxiety associated with affect or emotional discomfort from organic causes or caused by altered metabolic states; (c) total pain-interpersonal interactions with families and individuals, experiencing marital, financial, isolation and other familial strains; and (d) total pain-non-acceptance of the threat of death coupled with personal values of self and life's experiences, which are not specific religious tenets. Knowledge and competence of the components encourages optimal pain management at the end-of-life, enhancing the patient-health care provider relationship.

The need for nurses to be knowledgeable and competent in the concept of perception of pain management in palliative care has been repeatedly emphasized

(Saunders, 1976). It is therefore important to investigate health care providers' knowledge and background, perceptions, and opinions about pain management in palliative care. The Total Pain Model was used to assist the Kansas Living Initiatives for End-of-Life Care (LIFE) Project Partners to develop a survey for healthcare providers' measuring knowledge and background, opinions, and perceptions of pain management in palliative care (Fox, 2007).

Nurses' Knowledge of Pain Management in Palliative Care

Nurses spend the most time in direct care activities with dying patients and their family members managing physical, psychological, emotional, and spiritual symptoms, yet many nurses feel anxious and unprepared to care for palliative patients. The purpose of Kwekkeboom et al. (2005) study was to determine if participation in a Palliative Care Companion (PCC) program would enhance nursing student's knowledge, attitudes and concerns about caring for palliative patients. The conceptual framework fostered within the companion program was experimental learning theory, emphasizing learning through action and reflection (Kolb, Boyatzis, & Mainemelis, 2000). Principles of experimental learning theory include: (a) learning occurs when the subject matter is relevant to personal interests; (b) learning is facilitated when external threats are at a minimum; and (c) self-initiated learning is the most lasting and pervasive (Kolb et al., 2000).

The PCC program was developed through a collaborative effort between the nursing school faculty and the palliative consult service consisting of an advanced practice nurse. Recruitment consisted of undergraduate nurses being informed of the opportunity to volunteer for the PCC program upon the start of each semester. Faculty selected 10 students in each semester with a total of 20 students (first and second

semester) based on seniority. One student was unable to participate due to lack of response. Components of the PCC were completed in a 2 hour orientation program. The three components were as follows: (a) orientation group sessions discussing palliative care philosophy, the dying process, societal attitudes towards death and dying, psychological and spiritual need of patient and family, signs of dying; being present with the dying patient, the bereavement process, and bedside tasks; (b) companion services consisted of nurse/patient visits and bereavement phone calls; and (c) optional education hospice support groups, hospital based oncology courses, viewing video series of dying *On Our Own Terms*, and participation in palliative care electronic newsletter. Kwekkeboom et al. (2005) implementation of the program was in accordance to the experimental learning theory of self-initiated learning. Patient selection and visitation was student driven without direct care to the patient.

The sample consisted of 19 nursing student companions during first two semesters and 15 undergraduate peers as controls in this qualitative study. The control group did not participate in the PCC program. Faculty members obtained written consent from the students. Demographics information including year within the nursing program, and amount of didactic content they had received related to palliative care. Knowledge/attitude questionnaires were obtained from each participant examining personal experiences of death, and care of the dying.

A 20-item survey given to the participants (Ross, McDonald & McGuinness, 1996) assessed the knowledge of the palliative care philosophy, symptom management, and psychosocial care. Higher scores of the coded responses indicated a more accurate knowledge. Reliability and validity was demonstrated in previous uses (Ross et al.,

1996). A 12-item questionnaire, designed for the literature review, assessed attitudes related to palliative care (Kwekkeboom et al., 2005). Three constructs were evaluated as follows: (a) views about roles and responsibilities of health professionals in caring for patients that cannot be cured; (b) the degree to which one believes palliative care provides additional benefits not offered in conventional medical care; and (c) one's view about the role and importance of clinician-patient communication.

Attitudinal statements were rated on agreement. Negative items were reversed coded. Higher scores reflected a more a positive attitude. Acceptable reliability and Cronbach's alpha (0.86) validity was reported. Six items related to areas of concern to nursing students included: (a) providing emotional support to grieving families; (b) providing emotional support to dying patients; (c) being able to provide post-mortem care; (d) psychological effects on oneself; (e) being able to maintain composure when working with dying patients; and (f) being able to provide physical care for dying patients. Higher the rating scale indicated more concern/worry about caring for dying patients (Kwekkeboom et al., 2005).

Results of the descriptive data reported significance amongst knowledge scores over time amongst the companion students ($F = 4.69, p < 0.05$) and control group (mean = 12.29, standard error of measurement = .53). The PCC group showed significance in student's attitude toward palliative care and reduction in concerns of nurses of dying patients by spending increasing time with the palliative patient ($F = 5.93, p < 0.05$) (Kwekkeboom et al., 2005). Experimental theory was useful within the PCC program to help student learn in a flexible way, based on their individual needs and abilities. Limitations of the study include small sample size and limited time frame.

In conclusion of Kwekkeboom et al. (2005) study, the PCC program experience has relevance by providing educational experiences to undergraduate nursing students within palliative care. Lack of the incorporation of end-of-life content tends to be pervasive in undergraduate schools thus inadequately preparing nurses to provide high quality palliative care in the work force.

In communicating with patients receiving palliative care, empathy impacts how care is perceived. Palliative patients are usually cared for by nurses who have only basic nursing education and verbal communication skills; therefore it is important to begin addressing themes that concern palliative care early within undergraduate programs. The purpose of the study is to gain insight into the validity and reliability of an instrument, the Staff-Patient Interaction Response Scale for Palliative Nursing (SPIRS-PN), to measure empathetic capacity of various nursing students within vocational and bachelor programs. Adriaansen, Van Achterberg, & Borm (2008) was used as the theoretical framework for concept of perceived empathy.

Adriaansen et al. (2008) conceptual study, empathy is defined as a process composed of multiple phases that are effected by a number of contextual factors and is considered an essential component in nursing behaviors. The phases are as follows: (a) the inner process of empathetic listening and understanding of another individual; (b) the communication with the patient during which empathetic understanding is expressed; and (c) the perception of patient concerning what the other is expressing; the patient continues or discontinues the communication based on this perception.

Adriaansen et al. (2008) convenience sample consisted of 372 nursing students from associate and bachelor nursing programs. Participant inclusion consisted of: (a)

associate degree nursing students in their first year with 5 months of experience and completed a basic communications course; (b) associate degree nursing students midway into two year, completed a communication course and a ten week nursing home experience; (c) secular bachelor program of nursing students in their first year with five months of experience and completed a basic communication course; (d) a bachelor program with a religious orientation (Dutch reformed denomination) of nursing students in the end of their first year with four weeks of practical experience; and (e) registered nurses in a postgraduate training program in palliative care with years of experience.

The SPIS-PCN test was given to the participants after written approval was obtained. Written responses to 20 written statements made by hypothetical patients were completed. Coded answers were ranked into nine categories in accordance with the instrument with a possible score of 1-9. Open answers scored higher than closed answers with ratings below (Adriaansen et al., 2008): (a) 1- very probably causes a defensive attitude; (b) 2-4 - avoids interaction; (c) 5-7 - engages in interaction; and (d) 8-9 - keeps the conversation going.

Adriaansen et al. (2008) findings of the correlational study was significant within empathy testing and the amount of experience and religious orientation ($p < 0.001$). The level of degree (associate or bachelor) program did not have significance of students' empathetic capacity and could be attributed to measurements being taken at the beginning of their studies; a period which both students had similar characteristics regarding age and experience. Secular students scored lower than religious student ($p < 0.001$). Students with palliative experience scored higher than students with no experience ($p < 0.05$). Thus,

the SPIRS-PCN is a reliable instrument to measure expressed empathy of nursing students by gaining insight into the strengths and weaknesses one's empathetic capacity.

Hypotheses not confirmed in Adriaansen et al. (2008) study confirmed that educational level and gender is not positively correlated with SPIRS-PCN. Results of the qualitative study reveal that the SPIRS-PCN could be used in measuring the effect of training during various phases of the study program but further research is needed for validation.

In conclusion of Adriaansen et al. (2008) study, the validity of the SPIRS-PCN was partially supported, whereas reliability was demonstrated. Empathy is a crucial concept in palliative care communication with patients, for this reason, the development of the empathetic capacity of nursing student is important to this process.

Despite the need for good palliative care nursing education, many nurses are not provided with quality education within this area. In the United States, a barrier to dying in one's home is access to home care and knowledge needed to assist patients to die well. The purpose of Wallace et al. (2009) study is to evaluate nursing student's knowledge, experience assessment of end-of-life care (EOL), and curriculum integration to increase care competencies of the palliative patient. The theoretical framework of concept of knowledge and perceptions of end-of-life care was used to guide this comparative study.

Wallace et al. (2009) study sample of 111 undergraduate nursing students who completed their sophomore (61) and senior (50) year within a baccalaureate program. Inclusion criteria consist of successful completion of communication, introduction to palliative care modules as well as health care delivery and hours of death module during

the sophomore year. Successful completion of more in-depth palliative care module, pain assessment and management module, loss, grief and bereavement and symptom management modules for senior nursing students.

A 50- item multiple choice test was designed from a 109-item test, based on the literature, representing the modules of the End of Life Nursing Education Consortium (ELNEC). Permission was obtained for the use of the modules test. The five to six items in each domain with the highest item-to-total scale correlation narrowed the inclusion ($r=0.26-0.48$). A self-administered questionnaire was given to identify age, race, gender, religious background, and EOL experiences (Wallace et al., 2009). Lastly a 16-item open ended questionnaire was distributed by faculty to the same sophomores and seniors to elicit student's beliefs regarding palliative care. Questions were asked about definitions and essential elements of palliative care, role of nurses in providing palliative care, personal and professional experiences in palliative care, student educational needs regarding palliative care, and perceptions of good and bad deaths. Reliability was not reported.

Wallace et al. (2009) findings revealed that 84.6% of the sophomores and 62.5% of the seniors felt they were lacking experience in EOL care. Ninety-six percent of sophomores and 95.1% of seniors felt EOL education was lacking in their curriculum. Sophomore ELNEC pretest scores ranged from 20% to 86% with a mean of 60.98 ($SD = 11.83$). Senior pretest range for 70% to 96% with a mean of 83.26 ($SD = 6.6$) reflecting an average grade of a "D" for both populations in reference to current knowledge of palliative care nursing. An independent t test was conducted to determine if there was a difference in group mean knowledge between sophomore and senior

students. Levine's t test was significant ($F = 4.22$, $p < 0.05$), revealing t test with equal variance is significant between sophomore and senior group mean ($t = -10.44$, $p < 0.001$). The research suggests added components of education and clinical experiences are warranted.

Content analysis was ascertained on the qualitative open-ended questions data. Sophomore and senior students were analyzed separately. Dominant themes and subthemes were identified. Four themes emerged as essential elements of palliative for the seniors: comfort care (68%), pain management (30%), emotional support (28%), and support of the family (28%). Fifty-three percent of the seniors described palliative care as EOL care, with 63% linking this care with comfort of the patient. Sophomore data was not reported within this section. The sophomores' students' primary perception of the role of the nurse is to provide comfort. Significance was noted at 34% of the sophomores' perception of relieving pain and suffering. Forty-two percent of the sophomores cited basic knowledge of palliative care, and 35% of the seniors felt the need for specific education and clinical days within palliative care. Sixty-eight percent of both groups described a good death as pain free, while 83% described a bad death was dying in pain. The results clearly identify a need for EOL care throughout nursing curricula, which may be best accomplished through program integration (Wallace et al. 2009).

Wallace et al. (2009) concluded that many nurses are not provided with quality education within the area of palliative care. Integrating the ELNEC within undergraduate education is in place and need to be documented with evidence-based studies. The study shows relevance for knowledgeable clinicians and leaders in EOL nursing care. Nurse

educators have the responsibility to prepare graduating nurses to be prepared and provide compassionate and effective EOL care to patients across care settings.

Deficiencies in end-of-life nursing care practice, and the education to support that care continues to persist. Nurses are working in hospitals, clinics, and community setting without knowledge of how best to assist patients and families facing end-of-life care. The purpose of Schlairet (2009) study was to gain insight of nurses' persistent education needs in relation to prior participation in formalized end-of life-care versus end-of-life continuing education. The theoretical framework of Benner's novice-to-expert theory guided this descriptive study.

A survey was published and mailed to an approximate population of 51,000 registered nurses within the southeastern state of Georgia (Schlairet, 2009). Study sample consisted of 567 valid returned surveys were returned for a response rate of 1.1%. Most respondents were white (93%) and non-Hispanic (84%) with a mean age of 46.5 years of age, and had completed their initial nursing education 20 years earlier. Hospice nurses accounted for 5% of the sample with indicating that approximately 18% of the patients they care for were in the end-of-life phase. Thirty-nine percent of the nurses had participated in end-of-life continuing education and 33% had formal end-of-life instruction during in initial nursing education.

A descriptive cross-sectional survey was developed, from the literature review, by Schlairet (2009) addressing nurses' attitude/belief, knowledge/skill, competence, prior education desire, and workplace appropriateness for essential competencies or core content for end-of-life care. Utilizing Benner's Theory, a 5-point Likert item was used for attitude/belief, and knowledge/skill, with responses from strongly disagreeing to strongly

agreeing. Educational experiences and competencies were listed as yes and no answers. Inclusion criteria were registered nurses currently working within the southeastern portion of Georgia. Reliability was not reported.

Schlairet's (2009) findings of the qualitative data suggest positive relationships between nurses wanting to deliver quality end-of-life care (90%) and those wanting to improve knowledge through education ($r = 0.615$, $p < 0.01$). Nurses willing to participate in continuing education for end-of-life care were ($r = 0.570$, $p < 0.01$). Descriptive and ANOVA were performed on the dependent variables. Significant findings were reported on nurses who received formal end-of-life care during initial nursing education scored lower on knowledge/skill questions versus nurses with continuing education in end-of-life care scored significantly higher. Findings suggest that content, process and outcomes of existing undergraduate end-of-life should be evaluated, and shortfalls, if identified, to be addressed.

Nurse's views on end-of-life workplace appropriateness and desire for education were not significant (Schlairet, 2009). The findings refute the claim that continuing education does not adequately prepare clinicians for the delivery of end-of-life care. Reliability was assessed and supported the finding of internal consistency for nurses' attitudes towards end-of-life and the knowledge/skill constructs. According to the criteria, reliability was more than adequate for all constructs.

Schlairet (2009) concluded that the data suggest undergraduate and graduate education may not prepare students with appropriate attitudes, knowledge, and skill for the delivery of competent end-of-life care. To identify and respond to shortfalls in the

end-of-life care nursing practice and education needs, nurse educators continue to investigate and evaluate outcomes associated with end-of-life initiatives.

Perceptions of Pain Management by Patients

Pain is one of the most frequent symptoms among cancer patients with metastatic disease. Despite widespread use and recognition of recommendations from the World Health Organization (WHO, 2009) for the treatment of cancer pain, results from retrospective and prospective surveys consistently show that pain is still prevalent in patients with malignant disease (Klepstad, Kaasa, Cherny, Hanks, & de Conno, 2005). The purpose of the study was to examine the incidence and intensity of pain utilizing analgesic medicine within palliative care units in Europe. The theoretical framework of Comfort Theory guided this descriptive study.

A convenience sample of healthcare professional answered questionnaires regarding 3030 cancer patients, obtained from 143 palliative care centers in Europe (Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, United Kingdom, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Netherlands, Norway, Portugal, Romania, Spain, Sweden and Switzerland). Inclusion criteria included a cross sectional survey performed in palliative care programs of all, inpatients and outpatients, during week 23 of the year 2000 (Klepstad et al., 2005). Current opioid and non-opioid medications used for pain control was listed at the time of inclusion. The descriptive data was analyzed using SPSS for Windows.

Questionnaires that consisted of questions about demographics such as age, gender, cancer diagnosis and presence of metastasis were completed by physicians or other healthcare professional for each current patient within the palliative care service. A

4-point verbal rating score that assessed patient symptom severity, with descriptors of none, mild, moderate or severe was performed by Klepstad et al. (2005) over a 24 hour period. The symptoms rates were pain, fatigue, generalized weakness, focal weakness, anxiety, anorexia, depression, confusion, constipation, diarrhea, nausea, vomiting, sleep disturbance, dyspnea, itching, hallucination and hiccups. Statistical analysis of SPSS was used and applied to the descriptive data. Reliability was not reported.

In Klepstad et al. (2005) study, patients mean age was 66 years old with 39% of the population treated in hospices or treated as outpatients (26%). The majority of the patients suffered from a malignant disease (94%). Other diseases were neurological (3%), respiratory (0.5%), cardiac (0.5%), renal (0.3%) or Acquired Immune Deficiency Syndrome (AIDS) (0.3%). Among those patients with cancer, breast was the predominate diagnosis, with lung and colorectal cancer as second and third most prevalent cancer respectively. Thirty percent of the patients had bone metastases. Lung and liver metastases were observed in more than one-tenth of the patients.

A total of 32% of the patients reported having pain intensity of moderate or severe. According to Klepstad et al. (2005) no significant difference between the countries and the pain intensities were identified using the WHO pain ladder. A prevalence of symptoms other than pain was significant within this population. Symptoms of moderate or greater severity was generalized weakness (53%), fatigue (51%), anxiety (30%), anorexia (27%), constipation (20%), mood disorder (19%), lack of sleep (17%), dyspnea (16%) and nausea (10%).

Non-opioid analgesics most frequently used were non-steroidal anti-inflammatory drugs (NSAIDS) and paracetamol in tandem with adjuvant analgesics. Thirty-nine

percent of patients used dexamethasone, with tricyclics (11%) was less frequently used. Use of non-opioid analgesics and adjuvant analgesic varied amongst the countries. Significance amongst the countries was not noted. Opioid analgesics administered for mild to moderate pain were codeine (8%), dextropropoxyphene (5%), and dihydrocodeine (2%). Morphine was the most frequently used for moderate to severe pain: oral normal release morphine (21%), oral sustained released morphine (19%), and intravenous morphine (10%). Three-quarters of the patients receiving morphine were treated with doses of <150 mg/24 hours, and only a very small minority used a dose >1000 mg. Klepstad et al. (2005) found considerable variability between use of non-opioids, and a similar large variability between countries in the selection of opioids. One-third of the patients had clinically significant pain. A p value was not stated for Klepstad et al. (2005) study.

Klepstad et al. (2005) concluded that most patients are treated with moderate doses of morphine with considerable variability between countries in the use of non-opioids and the selection of opioids. Potential causes are lack of knowledge of adequate pain treatment, fear of prescribing opioids and or related barriers towards the use of opioids. The researchers encourage further research in order for healthcare professionals to gain insight and knowledge on treating palliative care patients with pain.

The incidence of cancer is one of the major causes of death around the world. Patients with terminal cancer suffer from diverse physical and psychological symptoms that can undermine their quality of life. The purpose of Szeto & Cheng (2006) study was to determine the levels of quality of life of the terminally ill cancer patients receiving home-based palliative care, and to examine the correlations between patient

characteristics, intensity of pain and quality of life. The theoretical framework of Comfort Theory with the concept underpinnings of coping, anxiety and stress, guided this descriptive correlational study.

Study sample of 85 terminal cancer patients recently discharged from a regional hospital in Hong Kong was recruited. Inclusion criteria consisted of patients older than 18 years, mentally alert, able to speak Cantonese, and with a predicted life expectancy of less than 12 months entering into palliative home care. Exclusion criteria included patients participating in a curative treatment regime (Szeto & Cheng, 2006). The study was conducted over 4 months.

Szeto & Cheng (2006) used a Hong Kong Chinese version of the McGill Quality of Life Questionnaire (MQOL-HK) that was modified into five subscales: physical well-being, psychological well-being, existential well-being, support, and sexual function. An additional item to measure overall quality of life was added. Overall validation of the MQOL-HK was considered good by the researchers. Test-retest reliability conducted 48 hours after data collection was significant (0.75). Responses were recorded by the authors of the study. Descriptive statistics was used to summarize the variables studied.

Szeto & Cheng (2006) quantitative data measured a moderately high mean value for the overall quality of life of 6.36 (SD=1.32) out of 10. Among the various domains, physical and existential domains scored relatively low and most compromised with a mean value of 4.9 (SD=1.28) and 6.12 (SD=1.6) out of 10 respectively. Conversely, subscales of sexual functioning and support yielded the highest scores with mean values of 7.45 (SD=4.0) and 6.8 (SD=1.9) respectively. Findings support the literature indicating pain, which is prevalent in cancer patients, has a major effect on many aspects of quality

of life. Data supports the correlation between pain intensity, moderate to severe, and physical, as well as psychological spheres ($r=0.57$, $p<0.01$). A significant moderate correlation between age and the mean total quality of life scores ($r=0.53$, $p<0.01$).

Szeto & Cheng (2006) concluded that patients with terminal cancer receiving palliative home care experienced a moderately high level of quality of life, especially in the area of support. The researcher encourages further investigation in a longitudinal and comparative study, for the current study describes quality of life at one point in time. Collaborative efforts to provide increased biopsychosocial and spiritual life are relevant to ensure acceptable quality of life for patients until the very end.

Most people in Western countries live long and generally healthy lives. As a consequence of longer life, most people today die of a chronic and or progressive disease. Therefore, care for patients who are in the last phase of life is an important aspect of health care. The purpose of de Vogel-Voogt et al. (2007) study was to gain insight by examining and analyzing terminal cancer patients' satisfaction of end-of-life care driven by primary care in a Dutch healthcare system. The theoretical framework of Glaser's Grounded Theory/Qualitative Data Analysis (QDA) guided this comparative study.

Study sample was recruited through primary care physician referrals from 128 outpatients with incurable cancers. Inclusion criteria were patients within 2 months of being informed cancer was incurable with a projected survival rate of less than 2 years. de Vogel-Voogt et al. (2007) conducted the study with evaluation of care questionnaires every 6 months until end-of-life. Out of the 128 outpatients, 87 patients, consisting of 47 males and 41 females, lived to complete three sets of questionnaires.

Participating patients filled out a written questionnaire based upon the Problem and Needs in Palliative Care (PNPC) listing eight problems concerning practical and organizational aspects of end-of-life care. de Vogel-Voogt et al. (2007) instructed patients to indicate whether problems had occurred never, sometimes or often during the 3 months prior to the initial assessment. Focused interviews were also conducted, consisting of self-constructed questions about contacts and satisfaction with general practitioner, clinical specialists, hospital nurse, oncology nurse, district nurse, home-helper, allied health professionals, religious or spiritual caregivers and complementary or alternative caregivers. Satisfaction was measured by means of a 10-point evaluation scale ranging from very poor to excellent. Follow-up questionnaires were completed every 6 months with an inclusion of three open-ended questions about the quality of end-of-life care. Frequency tables were used with comparative patient characteristics and problems with end-of-life-care. Reliability was not reported.

Bivariate comparisons were made amongst the frequency tables. Chi-square and Student's t-test were implemented to assess significance of relationships of characteristics of end-of-life care with patients' and disease characteristics. de Vogel-Voogt et al. (2007) findings on the qualitative data care related to contact with health care professionals table indicates that 81% of the patients had contact with their general practitioner, and 95% had contact with one or more clinical specialists in the 3 months prior to the assessment. More than half (52%) had seen an oncology nurse, as well as 45% had contact with a hospital nurse. Patient who made contact with a district nurse (17%) were living without a partner. Eighteen percent contacted allied health professional, and 15% had personal contact with a spiritual or religious caregiver. Characteristics of patients table revealed a

mean age of 65.2 (SD 10.6) with a disease duration of 25.5 months (SD 33.3) and time to death of 2.6 months (SD 1.7). A breakdown of 53% males and 47% females had living arrangement of having a partner at home (74%) and not having a partner at home (26%). Educational status revealed 31% had higher education, consisting of intermediate/higher vocational education or university training, and 69% had lower education, consisting lower vocational or primary school. Disease characteristics consisted of 55% with lung cancer, 18% with breast cancer, 13% with colorectal cancer, 10% with ovarian cancer and 7% with prostate cancer. Satisfaction with care and problem in end-of-life health care professionals was rated from 1 to 10: 1 represented very poor satisfaction and 10 represented excellent satisfaction. The table reveals a mean satisfaction score ranged from 7.3 to 7.8 on the 10 point scale representing the majority were satisfied with their health care professionals. Patients with higher education were the least satisfied with their caregivers. Communication difficulties and accessibility of end-of-life care to acute problems were the most mentioned on the questionnaires, and was higher when death was nearing ($-0.26, p = 0.02$).

de Vogel-Voogt et al. (2007) concluded that most cancer patients receive multidisciplinary end-of-life care, but not all disciplines were equally involved and the care was not always easily accessible. Communication between patient and healthcare givers is crucial for a positive end-of-life experience. The researchers further encourage coordination of interdisciplinary care and easy access to end-of-life care in efforts to improve the quality of care at the end of life.

Patient's self-perception about becoming a burden to others impacts one's illness and care needs, resulting in guilt, pain, and feelings of responsibility and diminished

sense of self (McPhearson, Wilson, Lobchuk, & Brajtman, 2007). The purpose of the study was to examine the prevalence and correlation of the sense of self-perceived burden (SPB) among palliative care patients in association with caregiver's report of burden. The framework for this study is the concept of self-perception

Permission to conduct McPhearson et al. (2007) qualitative study was obtained by Elisabeth Bruyere Research Institute by the University of Ottawa. Inclusion criteria for selection were individuals with advanced cancer (Stage III of IV) through Ottawa Community Care Access Centre (OC-CAC) that provides home care nursing support. Each patient identified a family caregiver who provided the largest component of their care. Purposive sampling of 65 patients and their caregivers were interviewed simultaneously in their homes by experienced palliative care personnel. Conversations were based on measures of functional performance status, physical and psychological symptoms and measures of SPB.

Patients were assessed by the interviewer using the Palliative Performance Scale (PPS), based on ambulation, activity limitation, self-care, nutritional intake, and level of consciousness. Scores on the PPS ranged from 0% (death) to 100% (full ambulation and no evidence of disease) in increments of 10%. The Memorial Symptom Assessment Schedule (MSAS) assessed 12 physical and six psychological symptoms commonly experienced by the advanced cancer patient. Frequency, intensity, and distress dimension associated with each symptom were scored independently on a 4-5 point Likert scale. Higher scores on the MSAS indicated an increase in frequency, intensity, or distressing symptoms. Validity and reliability of the instrument is documented and widely used in palliative research (McPhearson et al., 2007).

Interview questions were taken from the Structured Interview of Symptoms and Concerns (SISC) to assess patients SPB. The single-item interview is based on a seven-point rating scale: (a) 0 to 1=no problem; (b) 2=mild; (c) 3=moderate; (d) 4=strong; (e) 5=severe; and (f) 6=extreme common problems arising from palliative care. Reported validity and reliability ($r=0.92$ when both rater and observer are present at the interview) and a strong correlation with a visual analog assessment of the same construct ($r=0.85$). Various aspects of the SPB construct were evaluated by a 10-item questionnaire, the Self-Perceived Burden Scale (SPBS). The SPBS instrument evaluated frequency in which respondents experience ranges of concerns. Ratings were made on a five-point scale ranging from 1= none of the time to 5=all of the time. Caregiver burden was assessed with the Caregiver reaction Assessment (CRA) instrument. The CRA evaluates effects of care giving on four negative dimensions: disrupted schedule, financial problems, lack of family support, and health problems. One positive dimension of caregiver self-esteem was measured. A 5 point Likert scale that ranged from strongly disagrees, to strongly agrees, with higher scores reflecting greater caregiver reaction. The CRA was found to be a valid and reliable instrument within McPherson et al. (2007) study.

The quantitative data was analyzed by using Pearson r correlations to examine the relationship between two measures of self-burden in McPherson et al. (2007) study. Multiple regression was utilized to examine various factors to the sense of burden, using SISC and SPBS scores as criterion variables.

The findings of McPherson et al. (2007) study reported SPB was experienced at minimal to mild levels by 35% of the patients, while 28% experience SBP at a moderate to extreme levels. Correlations between structured interview ratings and individual items

on the self-perceived burden scales was statistically significant in all categories ($p < 0.01$). Correlations between the SPB measures and MSAS items were significant where vomiting was correlated with both measures ($p < 0.05$). Correlations of psychological symptoms were significant ; feeling sad, worrying, feeling nervous, and difficulty concentrating were correlated significantly with both the SPBS and the SISC scores ($p < 0.05$). Family members of patients who reported that the SPB was a significant problem had higher scores on the caregiver burden scale than family members of other patients ($p = 0.048$).

McPherson et al. (2007) concluded that Self-perceived Burden is a common and distressing concern for many patients receiving palliative care, thus increasing pain. The study is relevant for nurses dealing in palliative care to help facilitate various expressions of different perspectives within the nurse, patient, and caregiver relationship to elevate pain. Mutual appreciation of these roles can assist in alleviating a patients' sense of becoming a burden to others and lacking significance as a human being.

Palliative Care and Patients' Satisfaction

Patients with terminal cancer present enormous challenges for healthcare professional. As the disease progresses, these patients have to contend with worsening symptoms, deteriorating physical health and adverse psychological and social effects that require ongoing medical and nursing care and support. According to Peters & Sellick (2006) location of palliative care may influence healthy outcomes and quality of end-of-life. The purpose of this study is to determine which care setting, home versus institutional, provides optimal satisfaction of pain management, social support, and quality of life within the terminal cancer patient. The theoretical framework of Comfort

Theory, threaded through concepts of anxiety, stress and needs guided this comparative study.

Peters & Sellick (2006) study sample was two independent samples of terminally ill cancer patients receiving palliative care were selected. One sample consisted of patients receiving palliative care from three inpatient care centers, and the other patients received home-based palliative care within Melbourne, Australia. Out of 93 patients who met the selection criteria, 58 consented to participate: 32 from the inpatient centers and 26 from the home setting. Inclusion criteria were that patients had a primary diagnosis of cancer, a prognosis of at least 2 months, were aged 18 years and over, and were able to speak and understand English. Questionnaires were administered by personal interview at bedside for inpatients and in homes lasting for approximately 30 minutes. Medical information was obtained from patient's medical files and of assigned nurse.

Self-reported questionnaire and a medical checklist, developed on the basis of a detailed literature review, was used to obtain demographic and medical details, and specific measures of health status, symptom experience, personal control and quality of life. Questionnaires responses and medical details were coded and checked for accuracy of entry, missing values and internal consistency. Participants sample characteristics and questionnaires answers were used for descriptive and inferential statistics. For all inferential testing, the type I error rate was set at 0.5 for two-tailed hypothesis. Multiple regression was used to identify factors predicting scores on the quality of life measure (Peters & Sellick, 2006).

Symptom experience was assessed using a self-report instrument, Memorial Symptom Assessment Scale (MSAS) that includes four key measures in relation to 32

symptoms (physical and psychological) commonly reported by cancer patients. Participants specified what symptom they have experienced, rating the frequency, severity and distress on a 4-5 point Likert scale. The Palliative Performance Scale (PPS) assessed physical health and the physical status developed for terminally ill patients receiving palliative care and global physical condition scales of the EORTC QLQ-C30. Performance rating of the PPS is based on five criteria: ambulation, activity, self-care, food and fluid intake, and state of consciousness. The PPS, according to the literature, is reported to be a valid and reliable tool. The EORTC QLQ-C30, cancer specific 30 item questionnaire, incorporates 5 multi-item functional scales (physical, role, cognitive, emotional and social), symptom scales (fatigue, pain, nausea and vomiting), additional single item symptom measures and two rating scales of global and health life (Peters & Sellick, 2006).

Peters & Selleck (2006) used the Hospital Anxiety and Depression Scale (HADS), a self-reporting scale consisting of two subscales, each with seven items to assess psychological health indicators of anxiety and stress. According to the literature review, HADS has been reported as valid and reliable measure of depression and anxiety of cancer patients within home and palliative care settings. A three single-item scale assessed the degree to which patients perceived they had personal control over daily symptoms, medical care and treatment, and the course of illness. Peters & Sellick (2006) used a 7-point Likert scale to rate their personal control on each item. Four measures were used from the EORTC QLQ-C30 assessing quality of life to avoid overlapping results from the MSAS, PPS, and HADS scales. Specific measures were pain, family, social and financial quality of life and global quality of life.

Peters & Sellick's (2006) findings on the comparative data front were generated over 8 months. Inpatient and home-based groups revealed similar demographic characteristics, with the exception of marital status, country of birth and private health insurance. Chi-square analysis found a significantly higher population of inpatients who were not married ($p < 0.01$), of non-Australian descent ($p < 0.05$), and without private health insurance ($p < 0.05$). Data suggest that patients living alone or who without a support person are more likely to require admission to the hospital. Comparison of inpatient and homed based group identified a higher prevalence of diarrhea ($p < 0.01$), lack of appetite ($p < 0.05$) and belching ($p < 0.05$) in the inpatient group, possibly due to lack of meal individuality. Physical and psychological health status showed home-based patients had significantly higher physical health scores for physical status ($p < 0.001$) and global physical condition ($p < 0.01$) with lower depression scores ($p < 0.05$) than inpatients. Data suggests that home-based care may be the preferred option for patients in better health.

The home-based group scored significantly higher on all measures for personal control over daily symptoms ($p < 0.05$), course of illness ($p < 0.001$), medical care and treatment ($p < 0.01$), and total control score ($p < 0.001$). Data suggest having more control over the situation improved patients' quality of care. Analysis of quality of life and global quality of life scales shows the impact disease has on quality of life was less for patients at home than those receiving inpatient care on all measures (Peters & Sellick, 2006).

Peters & Sellick (2006) concluded the main implications for the role of nurses and healthcare professionals is early detection and management of both physical and psychological symptoms, and to use strategies that will empower patients to have a greater sense of control over illness and treatment, whether it be home-based or inpatient.

The researchers suggest further investigation to confirm results, and to identify other factors that may impact quality of life as an inpatient and within the home.

Palliative care services and facilities are not yet sufficiently available throughout Europe, and within some areas of the United States. Both the cost of care in medical institutions and the patients' wish to die at home necessitates new care arrangements. The purpose of Dumitrescu & van den Heuvel (2007) study was to examine relationships of four palliative home care teams in Eastern Europe and the level of perceived satisfaction of the bereaved families with a new palliative care service in Romania. The theoretical framework of Perceptions and Quality of Care Concept guided this quantitative study.

Dumitrescu & van den Heuvel (2007) population of 106 patients was derived from 4\four home palliative care teams over a 2 year time frame. Inclusion of the study consisted of patients' families whose relative or significant other received palliative care at home and had expired. Eighty-nine patients died during that time frame with 73 families willing to participate in the study.

A questionnaire consisting of 17 closed questions was developed for this correlational study to measure the quality of palliative care information and communication, the families' expectations, accessibility of the palliative care service at home, conflicts caused by the palliative care, and overall satisfaction with the delivered care. Questions were pre-coded with two to four answer categories, followed by an open ended question offering the interviewee and the interviewer the opportunity to expand, explain or comment on the answer. Dumitrescu & van den Heuval (2007) data was analyzed using Solar Power Satellite System (SPSS) software. Chi square and phi testing was utilized for categorical variables, and Pearson correlations was used for continuous

variables. Statistical significance level of the data was set at $p < 0.05$ and reported as reliable.

Dumitrescu & van den Heuvel (2007) findings on the quantitative data reveals satisfaction from 69% of the family members was met with information and communication from the health care professionals. Family members who did not have a central role with informal care giving indicated that they had not received all the information they required from the palliative care team. Eighty percent of the family members stated that their expectations had been fully met by the physician and nurse. Family members who did not play a central role as care giver indicated that their expectations had not been fully met ($\phi = 0.415$; $p < 0.001$). Accessibility of professionals to patients and family when needed was hallmark. Eighty-one percent of family members stated they could reach the professionals immediately, and no family reported that the team could not be reached. Many (50%) family members reported that the care provided the team actually prevented conflicts in the family. Prevention of conflicts was prevalent in those cases where children and the spouse were the central care givers ($\chi^2 = 7.256$; $p < 0.03$).

Overall satisfaction ratings from family members of care being delivered was 46% very satisfied, 38% satisfied, and 16% not satisfied. Satisfied families did not realize so much could be done to help the patient in relieving discomfort, anxiety, pain and uncertainty. Overall satisfaction was related to the type of relationship the family member had with the patient ($\chi^2 = 18.572$; $p < 0.001$). The greater the familial involvement reflected more satisfaction (Dumitrescu & van den Heuvel, 2007). The validity of the findings is revealed through strong correlations between the aspects used to evaluate the

palliative care at home from the families' perspective indicating a strong coherence in the concept measures and in the answering patterns.

Dumitrescu & van den Heuvel (2007) concluded that the services of palliative care at home were appreciated by most families of the patients who received this care. Patients and family satisfaction correlates highly with open communication among healthcare professionals and the palliative care team, enabling the patient to remain at home.

Gaining insight into the perceptions of terminal patients at the end-of-life is an extremely sensitive issue. There is some evidence of the positive effect of continuity of care in general practice on patient's satisfaction with care and trust in healthcare providers (Michiels, Deschepper, Van Der Kelen, Berheim, Mortier, & Vander Stichele, 2007). The purpose of the study is to develop a guideline for general practitioner's (GP) on communication with terminal patients to identify barriers to the delivery of continuous primary end-of-life care. The theoretical framework of Grounded Theory with the underlying concept of end-of-life communication guided this descriptive study.

Study sample was 17 metastatic cancer patients were approached by Flemish physicians associated with their palliative care center in Belgium. Inclusion criteria were advanced illness with an estimated life expectancy of 3 months, being informed of diagnosis and prognosis, wishing to die at home and aged over 18 years (Michiels et al., 2007). Oral information about the studies' objectives and consent was obtained from all participants. Reliability was not reported.

A semi-structured interview guide, developed on the basis of a detailed literature review, was used to collect data during face-to-face interviews with the patient and health

scientist. Focus of the interviews was on the patient's point of view, supported by next of kin, partner, or significant other throughout the interview process. Two consecutive interviews were audio taped, transcribed and coded into categories for constant comparisons. In eight cases the next of kin was present and participated in the interview. Eleven follow-up interviews took place: four with the patient, five with the next of kin and two with both (Michiels et al., 2007). The concept specifically addressed was end-of-life communication for continuous continuity of care.

Seventeen patients interviewed 10 men and seven women, valued aspects of continuity of care as an important task along with the attitude of their GP. Michiels, et al. (2007) identified two types of continuity that emerged from the qualitative interviews. The two types of continuity were as follows: (a) relational continuity by having an ongoing relationship with the same GP that existed for years, covering life cycle changes, life crisis and chronic/acute illness episodes; and (b) informational continuity of valued information flow between specialists, the GP and themselves. Discussion of their disease, even if diagnosed by a specialist, prognosis, and possible treatment was expected to be managed by their GP. Lack of time formed an important barrier to informational and relational continuity: time to listen to the patient, and time to call the specialist to obtain information or visit. GP's lack of initiative was seen as a barrier to some patients who wanted their GP's to start discussions about palliative care facilities, medications or to call spontaneously. One patient identified GP's holidays as a barrier to continuity.

Michiels et al. (2007) findings confirm the importance of continuity of care at the end-of-life and explored the concepts of informational and relational continuity, identified in the detailed literature review, as important types of continuity. The study

also supports that continuity of care is especially important between the GP and the end-of-life patient in coordination of communication between various caregivers and specialists, allowing for better supportive care at home.

Michiels et al. (2007) concluded that gaining insight into the perceptions of the terminally ill patients contributes to the clarification of the concepts of relational and informational continuity in the context of primary end-of-life care and identifies barriers to this continuity. Results of the study has relevance because it contributes a better understanding of consequences for terminally ill patients of present developments in general practice and provides insights for physicians on improving end-of-life care.

Perceptions of palliative care patients are important in order to enhance nursing care for patients receiving palliative care. The purpose of Gourdji, McVey, & Purden (2009) study is to explore meaning and quality of life (QOL) from the perspective of terminally ill patients on a palliative care unit, and to identify factors that bring quality to their lives. The theoretical framework of McGill's Model of Nursing and Kring's concept of "good death" guided this qualitative study.

Study sample was recruited from a palliative care unit for this descriptive study. Patients are admitted to this unit for symptom management, respite care for the family, or end-of-life. Five women and five men with a mean age of 57.9 were included in the study. Inclusion criteria were receiving end-of-life care, 18 years or greater, English-speaking, cognitive ability to provide consent, and well enough to participate in an interview (Gourdji et al., 2009). All patients were diagnosed with metastatic carcinoma.

McGill's Model of Nursing views health and illness as a coexisting disease with health encompassing the dimensions of coping and development (Gottlieb & Rowat,

1997). Additionally, Kring's concept of good death (Kring, 2006) has four main determinants that guided this conceptual study as follows: (a) pain control and symptom relief; (b) presence of others; (c) having spiritual needs met; and (d) making preparations. McGill's Model of Nursing and Kring's concept of a good death work in unison for one to possibly achieve healthy living even in the face of tragic circumstances.

Semi-structured, audio-taped interviews with open-ended questions took place within a week of admission. Over the course of Gourджи et al. (2009) study, four patients died, one transferred to hospice, three were discharged home, and two remained on the unit. Two patients had follow-up interviews. Individual interviews were obtained by an experience oncology nurse, lasting 16-20 minutes in length, dependent on patient fatigue. Three distinct aspects were discussed when questioned about their QOL: (a) the meaning of a quality life at this stage in their illness trajectory; (b) the experience of living with the illness; and (c) factors that contributed to their QOL. Non-verbal behaviors, events at the bedside, and the atmosphere in the room were documented. The patient's hospital chart was reviewed by the investigator for documentation pertaining to QOL. Investigator triangulation occurred at the time of data analysis, reducing the possibility of a biased interpretation and validating the reliability. Thematic analysis was used to uncover meaning embedded in patients' stories.

Gourджи et al. (2009) findings of the qualitative data identified three themes from the palliative care patients: (a) maintaining a sense of normalcy; (b) contributing to the well-being of others; and (c) experiencing appropriate care and support. Themes were supported by patient responses consisting of three factors shaping the patient's EOL experience: (a) approach to life having a positive outlook through humor, hope, and

spirituality; (b) illness life detractors from QOL were physical symptoms, limitations, emotions, and concern of self and family; (c) ideal quality of life consisted of being independent, happy, without pain, and healthy; and (d) quality end-of-life consisting of doing the things ones usually would do, being helpful to others, and living in a caring environment.

Findings of Gourджи et al. (2009) descriptive study highlight the importance of understanding influences taking place with the patient during palliative care. The results have practical significance for nurses when planning interventions to help patients live out their lives in ways that are meaningful to them. Focusing on patient strengths rather than their deficits is an empowering influence. Modifications of routines and providing opportunities to make choices and respect the choices they make are also significant. Further research is needed to explore characteristics in which patient and their families view health care provider's impact their quality end-of-life.

Gourджи et al. (2009) concluded from this study from a palliative care patient perspective, it is pertinent important for the patients to do the things they usually do, to be helpful to others, and to live in a caring environment. This is relevant within this patient population to transcend any negative lived experiences and focus on living life to the fullest despite physical limitations.

Summary

Knowledge deficiencies and lack of formal education in pain management and palliative care settings significantly inhibits quality end-of-life-care. The literature review provided considerable evidence of nurse and patient misperceptions leading to sub-optimal care giving and patient dissatisfaction. The findings support that extensive end-

of-life curricula have been developed, but are being used inconsistently to educate nurses to effectively support patients in palliative care. The literature revealed pivotal components for nurses to deliver quality palliative care by increasing their knowledge and perceptions of pain management during end-of-life. Persistent lack of knowledge and professional educational efforts within palliative were identified in the studies by Kwekkeboom et al. (2005), Wallace et al. (2009), and Schlairet (2009). The authors found significant care incompetency's within professional nurses and nursing students from lack of didactic and educational experiences of caring for palliative patients. The study by Adriaansen et al. (2008) found high knowledge scores among student nurses seeking out palliative care experiences and a significant relationship between perceptions of empathy via communication skills coupled with prior religious background. Finding point to a need for increased educational programs within undergraduate curricula and nursing professionals aimed at knowledge and background of palliative care.

The literature review supported how perceptions of pain management affect the quality of end-of-life care. Klepstad et al. (2009) study found patients with perceptions of high stress and anxiety found significance of ineffective pain relief with moderate amounts of opioids. Szeto & Cheng (2006) recognized a moderate correlation between pain intensity and the perception of professional and family support. Home based palliative care increased patients perception of appropriate care and support given with moderate pain intensity. The studies by de Vogel-Voogt, van der Heide, Visser, van Leeuwen, van der Rijt, & van der Maas (2007) and McPhearson et al. (2007) identified higher incidences of pain and distressing symptoms during end-of-life when deficits in communication with patients and caregivers are present. McPhearson et al. (2007) study

utilized framework of Self-Perception of Burden correlating significance of a higher level of self-perception of burden, implicating a higher level of inadequate pain control. The studies provided valuable information about patient and caregiver perceptions of pain management within palliative care.

The literature review also supported patients wanting to receive palliative care within the home setting and communicating their beliefs for increased satisfaction. Satisfaction within home-based palliative care was supported by Peters & Sellick (2006) and Dumitrescu & van den Heuvel (2007). Michiels et al. (2007) gained insights into patients' beliefs and increased satisfaction of receiving continuous primary end-of-life care. Gourdgji et al. (2009) found significant satisfaction of quality of life throughout palliative care by nurses empowering patients to focus on their strengths. Findings point to a need for nurses to gain insight into patients' beliefs to support a satisfactory palliative care experience.

Patients, family members, nurses, health care providers and palliative care groups were incorporated in the literature review. Data were obtained through interviews, focused interviews, surveys, and self-reported questionnaires. Variables were examined by numerous tools to collect the data of pain management in palliative care. Study frameworks included Experimental Learning Theory, Comfort Theory, Benner's Novice to Expert Theory, Self-Perception of Burden, Grounded Theory, and McGill's Model of Nursing. Concepts of perceptions, anxiety, stress within palliative care. This diverse collection of evidence points increasing knowledge for effective end-of-life practices, and awareness of one's perceptions to deliver quality palliative care to patients.

Chapter III

Methodology

Introduction

Specific end-of-life curricula have been developed but are being used inconsistently to educate nurses. Health care education has been widely criticized for providing minimal training in end-of-life care, for most education in palliative is on the job training. Nurses believe that they are ill-prepared to provide palliative care and want professional education to improve knowledge and skills in this area. The purpose of this descriptive, correlational study is to examine registered nurses and healthcare professional's background, perceptions, and opinions about pain management. This is a replication of Fox's (2007) study. This chapter presents the population, sample, methodology, and procedures that will be utilized for this study.

Research Question

What are the relationships among health care professionals' knowledge, background, perceptions, and opinions about pain management in palliative care?

Population, Sample, and Setting

The population for this study is nurses and healthcare professionals working in the Spectrum Health-Palliative Care Center in Michigan, attending a one-day, on site workshop entitled "Person-Centered Pain Management". Criteria for inclusion are: all

full-time and part-time registered nurses, licensed practical nurses, physician assistants, physical therapists, occupational therapists, social workers, certified nursing assistants, certified medical assistants, and administrators who work within Spectrum Health-Palliative Care Center and are present at the one-day workshop. A convenience, self – selected sample of 175 healthcare professionals is anticipated with half of the population consisting of nurses.

Protection of Human Rights

The study will be submitted to the Ball State Institutional Board and the participating care center for approval. In order to protect human rights of the participating healthcare professionals, this study will be voluntary. The workshop is free of charge, providing free continuing education credits. Upon conclusion of the workshop, participants will be requested to complete the survey. Consent of the participation is indicated with the completion of the survey. No risks have been identified with this study. The benefit of this study will include the opportunity for nurses and other healthcare professionals to contribute to the acquisition of information which may contribute to the care of palliative care patients by determining healthcare professional's knowledge, background, perceptions and opinions about pain management and end-of-life care.

Procedures

After Institutional Review Board approvals, a letter will be sent to the Vice President of Nursing, Vice President of Medicine, and the Director of Ancillary Care requesting a meeting. The meeting will discuss the purpose of the study, criteria for inclusion, anticipated sample and review of the instrument to be used after the palliative

care workshop. The workshop is free of charge and will provide continuing education credits. At the end of the workshop, participants will be requested to complete the survey.

Design

This study will use a descriptive, correlational design. This type of design describes the variables and examines the relationships that exist in a study situation (Burns & Grove, 2005). The design will allow the researcher to identify personal and professional demographic variables and examine the relationships among variables and the health professionals need for knowledge and skill within palliative care.

Instrumentation

The Living Initiatives for End-of-Life Care Project Pain Management Survey (Fox, 2007) was developed to examine health care providers' background, perceptions, and opinions about pain management. The closed-ended survey consisted of data in the areas of: (a) demographics (personal and professional), (b) practice patterns in reference to pain management, (c) education in pain management, (d) confidence in own and others' pain management systems, and (e) visions for good pain management systems. Demographics to be measured were age, gender, profession, and relationship to caring for someone with pain. Practice patterns in reference to pain management scale ratings from 1 to 5, with 1 associated with almost always true, to 5 almost never true. Education in pain management to be rated by specifying type of training through lecture in professional training, formal training in clinical training, part of clinical training in direct patient care, continuing education, and hours. Confidence in own and others' pain management systems to be measured on a scale from 0 to 10, with 0 associated with not

confident at all, and 10 associated with completely confident. Visions for good pain management systems on a rating scale from 1 to 5, with 1 associated with action is critical for real change to improve pain management, to 5 associated with action is not helpful and would not impact improved pain management. One open-ended question will be asked at the end of the survey regarding opinions of the current pain management system. The survey has face validity, but no further tests of validity and reliability were developed or reported.

Summary

Nurses and other health care providers believe they are ill-prepared to provide palliative care and want professional education to improve knowledge and skills within this area. The purpose of this descriptive, correlational study is to examine registered nurses and healthcare professional's background, perceptions, and opinions about pain management. Further studies in this area would reiterate that contemporary health professions education has inverted an ancient charge to healers such that we now train health care providers to comfort rarely, and the need for knowledge within this area is vast.

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Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
Kwekkeboom, K., Vahl, C., & Eland, J. (2005)	Lack of knowledge and professional education efforts remains a barrier to ensure quality palliative care to dying patients.	To determine if participation in Palliative Care Companion (PCC) program enhances nursing student's knowledge, attitudes while caring for palliative patients.	Experimental Learning Theory -anxiety -attitudes	19 under graduate nursing students. 15 under graduate nursing student peers	Descriptive/ Comparative	Demographic Questionnaire includes age, gender, race, year in nursing program, and didactic content related to palliative care. 20-item survey to assess knowledge related to palliative care. 12-item questionnaire to assess nurses' attitudes relating to palliative care.	Significance among companion nurses knowledge and attitude scores when spending more time with dying patients ($p < 0.05$). A reduction in concerns of companion nurses caring for dying patients when spending increased time with palliative patients ($p < 0.05$).
Adriaansen, M., Van Achterberg,	Nursing students developing	To determine the validity and	Perception of Empathy	357 nursing students	Correlational	20 written hypothetical coded questions with	Validity of the SPIRS-PCN was partially

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T., & Borm, G. (2008)	empathetic verbal communication skills to impact the process of quality palliative care.	reliability of the Staff-Patient Interaction Reaction Response Scale for Palliative Care Nursing (SPIRS-PCN) measuring perceived knowledge of empathy in nursing students.	-attitudes	140 associate program students 168 baccalaureate Program students 40 post graduate students		open answers.	supporter. Reliability was demonstrated. Insights were gained by experiencing increased educational experiences and religious knowledge ($p < 0.001$). No significance was noted in level of education or gender.

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
Wallace, M., Grossman, S., Campbell, S., Robert, T., Lange, J., & Shea, J. (2009)	Lack of end-of- life (EOL) education within nursing undergraduate curricula is prevalent resulting in decreased care competencies of palliative patients.	To examine nursing students knowledge, experience, and interrogation of curriculum to increase palliative care competencies.	Framework of Knowledge and perception of end-of-life care -beliefs	111 under graduate nursing students. 61 sophomores 50 seniors	Descriptive/ Comparative	50-item multiple choice test representing the modules from the End of Life Nursing Consortium to determine baseline knowledge of end-of- life (EOL) care. Self-administered questionnaire identifying gender, race, religious background, and EOL experiences. 16-item open ended questionnaire designed to elicit student beliefs of palliative care.	Sophomore scores ranged 20%-86% with a mean of 60.98 of baseline knowledge. Seniors scores ranged from 76%-96% with a mean score of 83.26 of baseline knowledge. Difference in group mean knowledge between sophomores and seniors was significant (t=-10.44, P<0.001).

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
Schlairet, M. (2009)	Persistent knowledge deficiencies in end-of-life nursing care practice and the education to support that care within the state of Georgia	To examine end-of-life care knowledge/skill, attitude/belief, and desire for education differ based on formal or continuing education on end-of-life.	Benner's Novice to Expert Theory	567 nurses in Georgia	Comparative Descriptive	<p>Cross-sectional self-administered survey to explore attitude/knowledge/skill, and learner characteristics, and views on workplace appropriateness.</p> <p>Survey A: 5-point Likert described relationship between professional knowledge and skills as a continuum of knowledge.</p> <p>Survey B: Respondent description of personal goals, type of instruction desired, support and barriers to end-of-life education.</p> <p>Survey C: 5-point self-rated continuum of competencies with end-of-life clinical</p>	<p>Significant relationships between nurses wanting to deliver quality end-of-life care and those wanting to improve knowledge through education ($r=0.614$, $p<0.01$) and between improving knowledge through education and those willing to participate in continuing education ($r=0.570$, $p<0.01$). Nurse with formal education score significantly less than nurses with continuing education.</p>

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
						<p>assessment and decision making.</p> <p>Survey D: 2-single response for overall self-rating of knowledge and delivery of end-of-life care.</p> <p>Survey E: 12-single response demographic items.</p> <p>Survey F: Open-ended format specific to items wanting to be learned within end-of-life topics.</p>	

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
Klepstad, P., Kaasa, S., Cherny, N., Hanks, G., & de Conno, F. (2005)	Incidence of inadequate pain management, utilizing non-opioids, opioids, and adjuvant analgesics, remains prevalent within European palliative care units.	To examine the incidence and intensity of pain utilizing analgesic medicine within palliative/cancer care units in Europe.	Comfort Theory -anxiety -stress	3030 cancer patients in palliative care	Descriptive	Questionnaires completed by physicians/health care professionals. Data was analyzed using SPSS for Windows.	Majority of patients are treated with moderate doses of morphine. Considerable variability is noted between use of non-opioids, and a similar large variability between countries in the selection of opioids. 1/3 of the patients had clinically significant pain. Intensities of pain were evenly distributed across the participating country utilizing a large variation of analgesics for controlled pain

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
							relief. No p value.
Szeto, Y. & Cheng, K. (2006)	Lack of multidisciplinary collaborative efforts to ensure acceptable quality of life with the terminally ill cancer patients receiving home based palliative care in Hong Kong.	To determine the levels of quality of life of the terminally ill cancer patients receiving home based palliative care, and to examine the correlations between patients' characteristics, intensity of pain, and quality of life.	Comfort Theory -coping -anxiety -stress	85 patients 37 males 48 females	Descriptive/ Correlational	Sociodemographic and clinical data sheets designed for this study. Hong Kong Chinese version of the McGill Quality of Life Questionnaire (MQOL-HK). Data sheets and questionnaire was translated and validated by the interviewer. Data was analyzed using SPSS for Windows.	Significant moderate correlation between age and the mean total quality of life ($r=0.53$, $p<0.01$). A moderate negative correlation between pain intensity and physical sub-scale ($r=0.57$, $p<0.01$). Patients with terminal cancer receiving palliative home care experienced a moderately high level of quality of life, especially in the area of support.

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de Vogel-Voogt, E., van der Heide, A., Visser, A., van Leeuwen, A. F., CD van der Rijt, C., & van der Maas, P.J. (2007)	Response to caregivers' communication and care needs fulfillment on an acute basis with end-of-life care.	Gain insight by examining and analyzing terminal cancer patients' satisfaction of end-of-life care driven by primary care in a Dutch healthcare system.	Grounded Theory (Glaser) Qualitative Data Analysis (QDA) -satisfaction -needs -problems -attitudes	87 patients Lived to complete questionnaire 47 males 41 females 128 patients with incurable cancer, 100 died during the research	Comparative	Focused Interviews Problems & Needs in Palliative Care 10-pt. evaluation scale Questionnaire which patients filled out every 6 months until end-of-life. 3 open ended ?s were added at the end. Tables were used with comparative patient characteristics & problems with care.	Satisfaction with caregivers was the majority rule, except those patients with higher education. Significant pain management control. There were communication difficulties in timely coordination and accessibility of end-of-life care on acute level

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McPhearson, C, Wilson, K., Lobchuk, M., & Brajtman, S. (2007)	Self-Perceptual Burden (SPB) is implicated in physical and psychological symptoms and end-of life decisions that are distressing to patients and family members.	To examine prevalence and correlation of patients self-perceived burden and the association with caregiver reports of burden within the palliative care population.	Framework of Self-Perception of Burden -empathy	65 advanced cancer patients and their caregivers.	Correlational	Palliative Performance Scale (PPS) is clinician assessed based on patient's ambulation, activity, self-care, nutritional intake, and consciousness in 10% increments. Memorial Symptom Assessment Schedule (MSAS) assessed 12	Family members of patients reporting SPB revealed high significance on the care burden scale than family members of other patients (p=0.048). Overall correlation was modest. Distressing concerns correlated with distressing

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
						<p>physical and 6 psychological symptoms scored on a 4 and 5 point Likert scales.</p> <p>Burden to Others Single Item Interview was formatted in single item screening assessing common problems arising in palliative care.</p> <p>Self-Perceived Burden Scale (SPBS) 10-item questionnaire evaluated the frequency of respondents concerns associated with SPS.</p>	symptoms.
Peters, L. & Sellick, K. (2006)	Various levels of satisfaction amongst Australian terminal cancer patients in the home vs. institutional setting.	To determine which care setting, home vs. institutional, provides optimal satisfaction of pain management, social support, and quality of life	Comfort Theory -anxiety -stress -needs	58 patients 22 males 36 females	Comparative	Cross-sectional survey. Self-report questionnaires: Memorial Symptom Assessment Scale (MSAS), Palliative Performance Scale (PPS), EORTC QLQ-C30-physical status and	Inpatient and home-based groups revealed similar demographic characteristics, with the exception of marital status, country of birth, and private insurance. Chi-square analysis found a

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
		within the terminal cancer patient.				global condition, EORTC QLC-C30 cancer specific quality of life, Anxiety and Depression Scale (HADS), and a seven point Likert scale. Coded and analyzed using Statistical Package for the Social Science (SPSS) for Windows.	statistically significant higher population of inpatients were not married ($p < 0.01$), of non-Australian descent ($p < 0.05$), and without private insurance ($p < 0/05$). Neither location of care nor the symptom distress was significant in determinants of quality of care.
Dumitrescu, L. & van den Heuvel, W. (2007)	E. European countries lack health care resources and have a strong tradition of patients wishing to	To examine relationships of 4 palliative home care teams and the level of perceived satisfaction of the	Framework of Perceptions Quality of Care Concept	74 out of 89 families of deceased mainly cancer patients in the terminal phase	Correlational Quantitative	Focused, mainly phone interviews with a 17 closed questionnaire with pre-coded (2-4 answer) categories followed by an open	Satisfaction from 69% of the family members was met with information and communication with the new palliative care

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	die at home. E. Europe offers few hospices and/or SNFs.	bereaved families with a new palliative care service in Romania.	Information Communication	with < 2 years of life		question to the interviewee. No validity/reliability reported	service in Romania. SPSS software analyzed the categorical variables (chi sq./phi testing); for continuous variables, Pearson correlations were calculated with a significance level set a $p < 0.05$. The validity of the findings is revealed through strong correlations between the aspects used to evaluate the palliative care at home from the families' perspective indicate a strong coherence in the concept measures and in the answering patterns.
Michiels, E., Deschepper, R., Van Der Kelen,	Barriers are within the General Practitioner's role	To develop a guideline for GPs on communication	Grounded Theory	17 patients 10 males	Qualitative Consecutive Interview	Focused interviews taped & transcribed Coding comparisons.	Insights were gained into terminal patients' perceptions of

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
G., Berheim, J. L., Mortier, F. J., & Vander Stichele, R. (2007)	in delivering continuous end-of-life care to terminal patients in Belgium	with terminal patients to determine the continuity of care.		7 females			continuous primary end-of-life care. Continuity is valued in Belgium wherein the physicians are looking into group practices to provide same and maintain a quality of life themselves.

Source	Problem	Purpose Research Questions	Framework or Concepts	Sample	Design	Instruments	Results
Gourdji, I., McVey, L., & Purden, M. (2009)	Lack of understanding and knowledge of patients' approach to life, and illness with life within effects quality of life within the palliative care setting.	To explore the meaning and quality of life from the perspective of terminally ill patients on a palliative care unit, identification of factors bringing quality to their lives.	McGill Model of Nursing. Kring's Concept of a "good death".	10 palliative care patients 5 males 5 females Diagnosed with metastatic carcinoma with < 4-9 months to live.	Qualitative Descriptive	Semi-structured audio taped interviews with open ended questions. Thematic analysis used to uncover embedded meanings.	Nurses who empowered patients by focusing on their strengths, assisted patients to focus on living life to the fullest during the palliative care stages.