

CRITICAL CARE NURSES' VIEWS OF OBSTACLES AND SUPPORTIVE
BEHAVIORS IN PROVIDING END-OF-LIFE CARE TO DYING PATIENTS

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Chapter I

Introduction

The Baby Boomer population in the United States (U. S.) was projected at 40.2 million in 2010, and expected to more than double by 2050 to 88.5 million (Vincent & Velkoff, 2010). According to the National Council of Aging (NCOA) (2011), 20% of the U. S. population will be over the age 65 by 2050. At least 91% of older adults cope with one chronic disease, such as diabetes, HTN, arthritis, and lung disease, and 73% cope with more than one (NCOA, 2011). Therefore, the number of older adults facing end-of-life care in the hospital will increase according to the National End of Life Care Intelligence Network, 2010 (NEoLCIN). Based on this assumption, the NEoLCIN projected that the demand for appropriate end-of-life care will continue to escalate as the aging population increases.

In addition to the demand for end-of-life care, the costs of end-of-life care will continue to rise (Harding, 2010). CBS news noted that 18-20% of Americans spend the last days of life in the Intensive Care Unit (ICU). Harding noted that the length of time spent in ICU in the last 6 months of life has also increased. Medicare paid \$55 billion in medical and hospital bills during the last 2 months of patients' lives in 2009 (CBS News, 2010). It was also noted that it costs up to \$10,000 a day to maintain a patient in the ICU.

End-of-life care in ICU involves decision making related to a number of variables. Decision making is a complex process that has ethical considerations. End-of-life decision making involves the patient, family members, and health care providers. The physician is the primary decision maker in end-of-life care. However, the most effective approach to end-of-life care is an interdisciplinary approach that involves all members of the health care team, the patient, and family members. Many cases result in ethical issues centering around discontinuation of life support for terminally ill patients. Therefore, end-of-life care must include clear communications between patients, families, and health care team members (Luce, 2010).

Family members play a key role in end-of-life decision making. Kirchhoff and Beckstrand (2000) found that the actions of family members can hinder end-of-life care of patients. Beckstrand, Callister, and Kirchhoff (2006) sought to identify barriers to providing end-of-life care in the ICU. Due to the critical nature of the situation, nurses often do not have time to address issues surrounding dying with patients and family. Beckstrand and Kirchhoff (2005) concluded that the ICU nurses' role is to decrease barriers about end-of-life issues in ICU and reduce conflicts.

Thelen (2005) sought to describe end-of-life decision making in the ICU and suggested ways to improve the end-of-life process in the ICU for patients, patients' families, and healthcare professionals. New technology and medications are being developed on a daily basis for use in ICUs to help ease or modify the effects of diseases that were previously fatal. End-of-life decision making was previously thought of as a "last resort," or to be done when death was imminent and the patient unable to participate in decision making (p. 6). Thelen concluded that relationships and communications

between patients and families, and the healthcare team are key components to enriching the end-of life decision making process. Improving the relationship and communication process will help honor patients, decrease miscommunication among the healthcare team and patients' families, and make dying in the ICU more peaceful.

Nurses working in ICU have experience with end-of-life care. Puntillo, Benner, Drought, Drew, Stotts, Stannard, Rushton, Scanlon, and White (2001) found that communications between physicians and nurses about end-of-life care was highly or somewhat effective. The authors concluded that ICU nurses agreed with withholding or withdrawing life-sustaining therapies to allow death to occur when patients, and/or the patients' families do not want further treatment, or when the treatment is not serving a purpose.

ICU nurses provide complex care to patients that are often unstable. The risk for catastrophic patient outcomes is always present in the ICU (McNutt, 2005). Statistics show that patient deaths occur in increasing proportion to age, with 73% of all ICU deaths occurring in patients over 65 years of age. McNutt concluded that ICU nursing will continue to include care of dying patients. ICU nurses will need to make care of dying patients a comfortable part of the job. Further study is needed to examine what barriers nurses encounter when dealing with end-of-life care.

Background and Significance

According to the Center to Advance Palliative Care (2011), the first palliative/end-of-life care programs began in the late 1980s in only a few hospitals. Over the past 20 years, more emphasis has been placed on end-of-life care as a directive from The Joint Commission. Currently in the US, 55% of hospitals with more than 100 beds

offer a palliative care program, and nearly one-fifth of community hospitals have palliative care programs. The number of palliative/end-of-life hospital-based programs has increased to 1,400, with 80% of the programs being in hospitals with more than 300 beds (Center to Advance Palliative Care as cited in Wikipedia, 2011).

Identifying key end-of-life care domains and quality indicators in the ICU to address deficiencies in providing end-of-life care, and proposing specific clinical and organizational behaviors to improve quality indicators, were goals addressed in a study conducted by Clarke, Curtis, Luce, Levy, Danis, Nelson, and Solomon (2003). The authors identified seven end-of-life care domains for use in the ICU, and 53 end-of-life quality indicators within the seven domains proposed. The seven end-of-life care domains in the ICU identified were the following: “(a) patient-and family-centered decision making; (b) communication; (c) continuity of care; (d) emotional and practical support; (e) symptom management and comfort care; (f) spiritual support; and (g) emotional and organizational support for intensive care unit clinicians” (pp. 2257). It was concluded that end-of-life care domains and associated quality indicators will help to provide a framework for understanding quality end-of-life care in the ICU for clinicians and researchers. The quality indicators may be used to improve end-of-life care in the ICU by acting as internal or external audits evaluating end-of-life care continuous quality improvement.

Understanding the perspectives of nurses, physicians, patients, and family members is important to providing appropriate and adequate end-of-life care. Beckstrand and Kirchhoff (2005) studied the views of critical care nurses on obstacles and supportive behaviors for end-of-life care. The authors used a questionnaire adapted to the critical

care population to evaluate nurses' views. The authors found that the two highest ranked obstacles were that physicians' opinions differed on care, and that patients' family and friends were constantly calling for updates on patients' conditions rather than the assigned family member. The authors also found the two highest ranked supportive behaviors were the agreement of physicians about the direction a patient's care should go, and the family's acceptance that a patient was dying. The authors concluded that working to decrease the obstacles and continuing to support the supportive behaviors that the study found can improve end-of-life care. Further research is needed to understand to obstacles and supportive behaviors in end-of-life care in other units such as the ICU, where end-of-life care is often needed.

Statement of Problem

Due to increased technology and medications, patients are being kept alive longer in the ICU, and require end-of-life care. Several obstacles exist in regard to providing end-of-life care in ICU. Identifying obstacles and supportive behaviors that ICU nurses encounter while providing end-of-life care will provide information to improve care and reduce conflicts (Beckstrand et al., 2009).

Purpose of the Study

The purpose of this study is to evaluate critical care nurses' perceptions of the impact of selected obstacles and supportive behaviors in providing end-of-life care. This study is a replication of Beckstrand et al.'s (2009) study.

Research Questions

1. What are the greatest obstacles to providing end-of-life care to patients in Intensive care as perceived by critical care nurses?
2. What are the most supportive behaviors surrounding end-of-life care in Intensive care as perceived by critical care nurses?

Organizing Framework

The Oncology Nursing Society (ONS) and the Association of Oncology Social Work (2007) position statements provide the framework for this study. The position statements emphasize importance of relieving physical, psychological, social, and spiritual pain and suffering whether or not cure is an option. The ONS and Association of Oncology Social Work's position statement encompasses all patients receiving timely and appropriate palliative care across the illness time-span. Palliative end-of-life care begins with the time of diagnosis and continues through end of life.

Definition of Terms

End of Life Care: Conceptual.

The Oncology Nursing Society (ONS) and the Association of Oncology Social Work (2007) defined end-of-life care as reduction of physical suffering of terminally ill patients through excellent assessment, reassessment, and management of physical symptoms and that psychosocial and spiritual care should be incorporated to support coping.

End of Life Care: Operational.

The National Survey of Critical-Care Nurses Regarding End-of-Life Care included 50-item Likert scale was developed to assess end-of-life care. The

questionnaire included obstacles and supportive behaviors in end-of-life care (Kirchhoff & Beckstrand, 2000).

Obstacles: Conceptual.

Obstacles stand in the way of providing optimal end-of-life care (Beckstrand et al., 2009).

Obstacles: Operational.

Twenty-five obstacle items on the National Survey of Critical Care Nurses Regarding End-of-Life Care were noted and were rated on a scale of 0=not an obstacle and 5= extremely large obstacle (Kirchhoff & Beckstrand, 2000).

Supportive Behaviors: Conceptual.

Supportive behaviors increase the quality of end-of-life care including nurse educators and managers being better educated and supportive of bedside ICU nurses in delivering end-of-life care (Beckstrand et al., 2009).

Supportive Behaviors: Operational.

Twenty-five supportive behavior items on the National Survey of Critical Care Nurses Regarding End-of-Life Care were noted and were rated on a scale of 0=not a support and 5= extremely large support (Kirchhoff & Beckstrand, 2000).

Limitations

The study is limited in sample size and geographic area. The study is also limited in the fact that it focuses on the perceptions of end-of-life care from experienced ICU nurses compared to less experienced ICU nurses.

Assumptions

1. Nurses face obstacles concerning end-of-life care of terminal patients in ICU.
2. Nurses can reduce conflicts by working with family and the health care team.

Summary

The study will be conducted to improve end-of-life care by identifying the greatest obstacles and most supportive behaviors involving end-of-life care as perceived by critical care nurses. This study will replicate a study by Beckstrand et al. (2009) in attempt to improve the quality of end-of-life care. The Oncology Nursing Society (ONS) and the Association of Oncology Social Work (2007) position statement will be the framework for this study. The findings will assist in identifying and understanding obstacles and supportive behaviors in end-of-life care. The results will assist healthcare providers involved in end-of-life care to give more quality end-of-life care to patients.

Chapter II

Literature Review

Introduction

End-of-life care is a responsibility of nurses to individuals dying from a progressive or chronic condition resulting in eventual death (Beckstrand & Kirchhoff, 2005). Critical care nurses encounter end of life situations on a regular basis. The purpose of this study is to evaluate critical care nurses' perceptions of the greatest obstacles, and most supportive behaviors in providing end-of-life care in Intensive care. This study is a replication of Beckstrand et al.'s (2009) study.

Research Questions

1. What are the greatest obstacles to providing end-of-life care to patients in Intensive care, as perceived by critical care nurses?
2. What are the most supportive behaviors surrounding end-of-life care in Intensive care as perceived by critical care nurses?

Organization of Literature

The literature review consists of studies which address perceptions of end-of-life care. The literature review is organized into four sections: (a) organizing framework, (b) nurses' views of end-of-life care, (c) physicians' views of end-of-life care, and (d) patients' and families' views of end-of-life care.

Organizing Framework

The Oncology Nursing Society (ONS) and the Association of Oncology Social Work (2003) position statement is the framework for this study. The position statement was developed based on the need for adequate end-of-life care for patients with terminal illnesses. The statement emphasizes importance of relieving physical, psychological, social, and spiritual pain and suffering, whether or not cure is an option. The ONS and Association of Oncology Social Work's position statement encompass all patients receiving timely and appropriate palliative care across the illness time-span. Palliative end-of-life care begins with the time of diagnosis and continues through end of life. It is provided in various settings including home, hospice, hospital, or residential facility.

According to the position statement, the family is the unit of care, and the patient is viewed as part of the family defined by the patient. Palliative and end-of-life care need to be culturally appropriate related to interactions and interventions, and includes professional interpreter services and culturally sensitive materials provided in the patient's and family's native language. The statement also includes the development of a comprehensive care plan that is implemented and adjusted according to the patient's and family's goals of care throughout the illness experience (ONS and Association of Oncology Social Work, 2003).

The position statement addresses the importance of effective communications with family, through conferences about palliative and end-of-life care. Patients and families are provided the tools and resources to make informed decisions regarding pros and cons of potential interventions and financial costs during end of life process. Palliative and end-of-life care is provided by an interdisciplinary team that includes

multiple health professionals including physicians, nurses, social workers, spiritual care professionals, allied personnel, nursing aides that are certified in essentials of palliative care according to the statement. The care is provided using evidence-based practice using quality research in palliative care (ONS and Association of Oncology Social Work, 2003).

The ONS position statement gives the ONS's views on issues of importance to members and the public it serves. The positions are developed based on trends in oncology care, and new issues that affect patient safety, nursing care, the work environment, and other areas. Position statements may be based on ONS member requests, member survey responses, and ONS Board of Directors' initiatives. The ONS position statement on end-of-life care is a statement that focuses on patients with cancer receiving the most appropriate and best palliative and end-of-life care from the time of diagnosis through the end of life (ONS and Association of Oncology Social Work, 2003).

The ONS position statement on end-of-life care is an appropriate framework for the study because it provides criteria for providing quality care to oncology patients in various settings over the span of illness. The statement incorporates providing the most coordinated and interdisciplinary end of life care to patients suffering from cancer. The organizing framework is appropriate for this study because it provides a foundation for optimal end-of-life care that can be used in the ICU setting. According to Beckstrand and Kirchhoff (2009), the organizing framework addresses end-of-life care as it pertains to the needs of patients and families.

Nurses' Views of End-of-Life Care

In 2001, Puntillo et al. conducted a descriptive study identifying the knowledge, beliefs, and ethical concerns of nurses caring for dying patients in Intensive Care Units (ICUs). The study had three specific aims: (a) to determine whether ICU nurses, when given specific clinical situations and clear definitions of clinical actions, could differentiate between specified examples provided by the authors; (b) to describe the beliefs of ICU nurses about the adequacy of pain management and the nurses' skill in providing comfort to terminally ill patients; and (c) to determine how often ICU nurses are asked by physicians, other nurses, or patients' families to assist in taking action to end the life of terminally ill patients in the ICU (pp. 217).

The population consisted of 3,000 potential subjects selected by stratified random sampling from the American Association of Critical Care Nurses (AACN) membership list. The criteria for being selected were being a staff nurse who gave direct care in adult medical-surgical ICUs (Puntillo et al., 2001).

The instrument used in the study was a questionnaire developed by the authors who are experts in critical care, pain management, ethics, and quantitative and qualitative research. Content validity was established through a review of literature, and through various phases of pilot testing. The first phase of testing was done on 75 graduate nursing students in an ethics course. After the initial phase of testing, the questionnaire was revised and validated by two nationally recognized nurse ethicists, AACN's research specialist, the chairperson of AACN's ethics committee, twelve master's and doctoral nursing students enrolled in a graduate course in healthcare ethics, and the authors of the

study. Once the questionnaire was revised, it was pilot tested again and finalized (Puntillo et al., 2001).

The final questionnaire had three sections, with a total of 61 questions. The first section included four clinical situations involving four different ICU patients. The second section involved nurses assessing participants' knowledge and opinions through various questions on pain management and end-of-life practices in the different ICUs. The third section involved demographic information about the participants. The study instrument was found to be reliable and valid. Of the 3,000 questionnaires mailed, 906 (30%) questionnaires had usable responses from eligible respondents (Puntillo et al., 2001).

The majority of the respondents were white females who worked full time providing direct patient care. Approximately 50% of the nurses had a Bachelors of Science degree. The sample consisted of 39% Protestants, and 38% Catholics, with others either somewhat or very religious. Religious beliefs were very important to actions (47%) (Puntillo et al., 2001).

Puntillo et al. (2001) found that most respondents' selections of actions were consistent with the action that was being represented in each of the scenarios in the first section of the questionnaire. For example, 91% of respondents accurately recognized assisted suicide in one scenario. The authors found that 99% to 100% of the respondents agreed with the actions of pain management, and withholding or withdrawing life support, while 17% agreed with the action of assisted suicide, and 5% agreed with the action of voluntary euthanasia in the given scenarios. It was also noted that 37% of respondents had been asked to assist in a patient's death by a patient or a family member

at least once. Forty-two percent thought that aggressive medical treatments were prolonged to a great extent, and 49% thought that treatments offered no promise of recovery. A few of the nurses expressed concerns about under-treatment during end-of-life.

The authors found that 97% were confident in the ability to provide non-pharmacological comfort measures that support end-of-life needs of dying patients and families. The majority of nurses (78%) thought that dying patients often received inadequate pain management. Fifteen percent of nurses thought that patients received more pain medication than needed. Ethics and hospice consults were available to half of the nurses. Most believed that the communication between physicians and nurses about end-of-life care was highly or somewhat effective (Puntillo et al., 2001).

Puntillo et al. (2001) concluded that nurses both support the use of analgesics to decrease suffering, and think that patients may receive an inadequate amount at times. ICU nurses agreed with withholding or withdrawing life-sustaining therapies to allow death to occur when patients and/or the patients' families do not want further treatment, or when the treatment is not serving a purpose. The authors also concluded that palliative care in the ICU should be given regardless of death being imminent or not. The authors recommended that forums to discuss end-of-life care in ICUs are needed, as well as forums to educate clinicians on optimal analgesic practice.

Critical care nurses deal with end-of-life care on a daily basis. The goal of this study by Kirchoff and Beckstrand (2000) was to identify critical care nurses' views of barriers and of assisting behaviors in providing end-of-life care for dying patients. There were two research questions: "How important are selected obstacles in restricting end-of-

life care?” and “How important are selected helps in promoting end-of-life care?” (pp. 97).

The sample consisted of 300 nurses randomly selected from the membership list of the American Association of Critical Care Nurses (AACN). The criteria for being selected included: staff nurses who provided direct patient care, employed part-time or full-time for at least 2 years in a critical care unit, and took care of dying patients. Of the 300 questionnaires mailed, 199 (66%) of the questionnaires had usable responses from eligible respondents (Kirchhoff & Beckstrand, 2000).

Of the 199 (69%) participants in the study, 197 reported gender as 13 men and 184 women. Participants ranged in age from 27 to 63 years. Participants were employed as staff nurses, charge nurses, clinical nurse specialists, and nurse educators who practiced in settings such as intensive care units, cardiovascular intensive care units, and surgical intensive care units. The participants ranged in education from diploma to master's degree (Kirchhoff & Beckstrand, 2000).

Prior to this study, the authors conducted four focus groups with ICU nurses, and used findings to develop a list of barriers and assisting behaviors mentioned by the nurses. The authors also used information from published literature to further develop the lists, which helped to strengthen the validity of the study. From previous research, the authors developed a 64-item questionnaire called the National Survey of Critical Care Nurses Regarding End-of-Life Care. The questionnaire was tested on a selected number of ICU nurses in one ICU prior to being used specifically for this study. The questionnaire ranged in responses on a scale of 0 to 5 (0=not an obstacle, 5=extremely large obstacle). The items were ranked based on mean scores. The Cronbach α was .86

for 25 of the barrier items, and .82 for the 23 assisting behavior items, which suggested that the scores were internally consistent (Kirchhoff & Beckstrand, 2000).

The results pertinent to the first research question regarding the importance of certain barriers in limiting end-of-life care were less than expected, with mean scores ranging from 1.35 to 3.76. The majority of the top ranked items related to barriers did not allow the patient to receive the best care and inappropriate aggressive care. The top barrier viewed by the participants was the family and friends continually calling the nurse, rather than calling a specific family member ($m=3.76$). The lowest barrier noted was caring for a “brain dead” patient who was to be an organ donor ($m=1.35$). The following are the potential reasons the authors found for the results being lower than expected: the sample consisted of more experienced nurses that found ways around certain barriers, the participants may have wanted to give the impression of not being controlled by outside factors, and some barriers may be so common that the barriers were useless (Kirchhoff & Beckstrand, 2000).

The mean scores of the second research question regarding certain assisting behaviors in furthering end-of-life care ranged from 2.70 to 4.57. The response choices were ranked similarly to the barrier response choices, with 0 being no assisting behavior, and 5 being a very large assisting behavior. The highest ranked assisting behavior was that all doctors agreed about the direction of care ($m=4.57$). The lowest ranked assisting behavior was nurses not having support outside of work to listen to experiences with the death of a patient ($m=2.70$). One of the top assisting behaviors that was supportive to nurses was the expression of thanks by family of dying patients. Participants also viewed

social support from co-workers and friends outside of work as an important assisting behavior (Kirchhoff & Beckstrand, 2000).

The authors concluded that no single barrier was viewed by participants as either large or very large. The highest ranked barriers were the actions of family members that hindered nurses from caring for patients, and the request of family members for more aggressive care than the patient wanted. The barriers make it difficult for the nurse to provide the dying patient with a good death. The assisting behaviors were higher than the barriers. The top and most common assisting behaviors included agreement of physicians regarding direction of care, appreciation of nurses from patients' families, and allowing nurses to provide flexibility in patients' environments (Kirchhoff & Beckstrand, 2000).

A subsequent study was conducted by Beckstrand and Kirchhoff (2005) to identify critical care nurses' views of both the intensity and frequency of obstacles and supportive behaviors in providing end-of-life care to patients and families. The authors addressed two research questions: "Which obstacles to providing end-of-life care do critical care nurses perceive as both the most intense and the most frequently occurring?"; and "Which supportive behaviors in providing end-of-life care do critical care nurses perceive as both the most intense and the most frequently occurring?" (pp. 396).

The sample consisted of 1,500 nurses randomly selected from the membership list of the American Association of Critical Care Nurses (AACN). The criteria for being selected included the following: staff nurses who worked at least part-time in a critical care setting, who lived in the United States, who were able to read English, and who

cared for at least one patient at the end-of-life. Of the 1,500 questionnaires mailed, 864 (58%) of the questionnaires had usable responses (Beckstrand & Kirchhoff, 2005).

Of the 864 participants, 856 reported gender as 57 males, and 799 females. Ages ranged from 26 to 72 years, with 3 to 50 years experience as registered nurses. The participants had 2 to 40 years of ICU experience. The educational levels of the participants ranged from diploma (14%) to doctoral (0.8%). A majority of the participants took care of over 30 dying patients during careers as nurses (Beckstrand & Kirchhoff, 2005).

The authors used a questionnaire developed during the initial study (Kirchhoff & Beckstrand, 2000) called the National Survey of Critical Care Nurses Regarding End-of-Life Care. The questionnaire was adapted by adding frequency of occurrence for both obstacles and supportive behaviors. This was done to identify if the most frequently noted items reported in the initial study were still the most frequently listed when nurses were asked to note how often each item happened. The authors also adapted the questionnaire by adding five new obstacles and one supportive behavior, which were suggested by nurses in the initial study. The additions made to the initial questionnaire for this study resulted in a total of 72 items. The questionnaire in the study was found to be reliable and valid, although no specific data were reported (Beckstrand & Kirchhoff, 2005).

Intensity scores for both obstacles and supportive behaviors were ranked from highest to lowest score. The Cronbach α was .89 for the 29 obstacle items, which suggested that the scores were internally consistent. The Cronbach α for the supportive behaviors suggested scores were internally consistent. Internal consistency figures of

reliability were done with the 29 obstacle frequency items being ($r=.89$), the 24 supportive behavior items being ($r=.86$), and the 24 supportive behavior frequency items being ($r=.81$) (Beckstrand & Kirchhoff, 2005).

Beckstrand and Kirchhoff (2005) found that the mean intensity scores for the obstacles ranged from 1.62 to 4.03. The response choices ranged from 0 to 5 (0=not an obstacle, 5=very large obstacle). The highest ranked obstacle was that physicians' opinions differed on care ($m=4.03$). The second highest ranked obstacle was patients' family and friends constantly calling a nurse for updates on patients' conditions rather than the assigned family member ($m=4.02$). The lowest obstacle noted was family visiting hours being too restrictive ($m=1.62$). Another low ranked obstacle was family visiting hours being too liberal ($m=2.06$).

The results pertinent to the first research question regarding the obstacles the participants viewed as most frequently occurring, and most intense, had two different ranges for the mean scores. The range of mean scores for the most frequently occurring obstacles was 0.98 to 3.69. The response choices ranged for 0 to 5, with 0=never occurring and 5=always occurring. The intensity scores for the most intense obstacle ranged from 2.06 to 14.83. The highest ranked most frequently occurring, and most intense obstacle, was the patients' family and friends constantly calling a nurse for an update on the patient's condition rather than calling the assigned contact person ($m=3.69$) and an intensity score ($m=14.83$). The lowest ranked most frequently occurring and most intense obstacle was the continuation of advanced treatments to dying patients because of financial benefits to the hospital ($m=.98$) and an intensity score ($m=2.06$) (Beckstrand & Kirchhoff, 2005).

Beckstrand and Kirchhoff (2005) found that the mean intensity scores for the supportive behaviors ranged from 2.61 to 4.59. The response choices ranged from 0 to 5, with 0=not supportive, to 5=very supportive. The highest ranked item was agreement of physicians about the direction a patient's care should go (m=4.59). Another highly ranked supportive behavior was family's acceptance that a patient was dying (m=4.57). The lowest ranked supportive behavior was the availability of unlicensed staff to help provide care for dying patients (m=2.61).

The authors also noted two different sets of mean scores related to the second research question regarding supportive behaviors, most intense and most frequently occurring. The range of mean scores for the most frequently occurring supportive behavior was 0.77 to 3.96. The response choices were ranked similarly to the obstacle response choices with 0=never occurs, and 5=always occurs. The intensity scores for the most intense supportive behavior ranged from 2.63 to 17.58. The highest ranked most frequently occurring, and most intense supportive behavior was allowing a patient's family unlimited time alone with the patient after death (m=3.96) with an intensity score of m=17.58. The lowest ranked most frequently occurring and most intense supportive behavior was having members of the ethics committee attend unit rounds on a routine basis (m=0.77) with an intensity score of m=2.63 (Beckstrand & Kirchhoff, 2005).

The authors concluded that the results validated the initial study conducted 5 years ago. The mean intensity scores for obstacles in this study were higher than the results from the initial study. This suggested that serious problems in end-of-life care still exist, and may be worsening. The authors noted that the ranges of mean scores for supportive behaviors were also higher than the obstacles in this study. The authors

concluded that a better understanding of the most intense and frequently occurring obstacles and supportive behaviors could lead to the improvement of end-of-life care (Beckstrand & Kirchhoff, 2005).

Wotton, Borbasi, and Redden (2005) believed end-stage heart failure (ESHF) is a growing concern among the Australian population, and that nurses were the main caregivers for patients transitioning from ESHF to death. A descriptive, exploratory study describing registered nurses' perceptions of factors influencing care for patients in the palliative phase of end-stage heart failure (ESHF) was conducted.

Purposive sampling was used to select nurses with cardiac and palliative care experiences. The sample consisted of 17 participants, including registered nurses, clinical nurse consultants, and clinical nurses or nurse managers, ranging in age from 25 to 55 years with cardiac and palliative care experience. Fixed response questions were used in the selection process for basic demographic data such as age, qualifications, and years and areas of nursing experience (Wotton et al., 2005).

A semi-structured interview guide with nondirective probes was used for interviews which lasted 1 hour. The taped interviews were later transcribed and analyzed to obtain common themes and categories. A panel of nursing experts with cardiac and palliative care backgrounds assisted in crosschecking the initial analysis and confirming emerging themes and categories (Wotton et al., 2005).

The authors identified four themes that nurses' perceived as factors influencing palliative care. The themes included the following: (a) "knowledge of the patient," (b) "health system inadequacies," (c) "knowledge of palliative care," and (d) "difficulties in the provision of palliative care." The first theme, "knowing the patient," included the

following three sub- themes: (a) “recognizing ESHF,” (b) “knowing the patient,” and (c) “patient and family knowledge of the disease process.” The second theme, “health system inadequacies,” included the following two sub-themes: (a) “difficulties with communication between the different types of physicians and nurses,” and (b) “unsatisfactory staffing levels.” The last two themes did not include any sub themes (Wotton et al., 2005, pp. 20-23).

Wotton et al. (2005, p. 23) found that “knowing the patient” was essential for nurses to provide end-of-life care to ESHF patients. The nurses expressed concern regarding lack of time and resources to provide palliative care to ESHF patients due to not knowing the knowledge level of the patient and family about ESHF disease process. The nurses expressed a need for a multidisciplinary team to coordinate palliative care in ESHF patients. The authors found that acute care nurses should have knowledge of palliative care including the physiology of heart failure (HF) and ESHF. Nurses focused on the patients’ physical and emotional comfort in providing palliative care.

The authors concluded that the nurses involved believed that the addition of plans to improve financial, social, and physical conditions for patients with ESHF should be considered as urgent and important. Palliative care for ESHF patients should have a holistic approach using a multidisciplinary cross-trained team of medical professionals. Recommendations for practice include: the need for education for patients and families regarding ESHF, and more collaboration between the members of the multidisciplinary healthcare team to assist patients with ESHF and to prepare families for the final course of the illness (Wotton et al., 2005).

Nurses working on general units care for individuals at end-of-life. Thompson, McClement, and Daeninck (2006) wanted to understand nurses' perceptions of the quality of end-of-life care being provided by nurses on an acute medical ward, and nurses' perceptions of the care. The grounded theory methodology was used to examine nurses' perceptions of quality end-of-life care.

The authors targeted the generalist nurse population's perspective on end-of-life care, in contrast to other studies that focused on one group of nurses, such as critical care nurses' perspectives. The setting was one of two adult inpatient medical units at two different university affiliated teaching hospitals in central Canada. Each unit provided active treatment for patients with acute and chronic conditions. A purposive sample consisted of 10 Registered Nurses (RNs). Eight RNs came from the first hospital, and two RNs from the second hospital. The following was the eligibility criteria for the study: 18 years of age or older, able to speak and read English, willing to participate in the study, and had worked a minimum of 3-6 months on a designated unit (Thompson et al., 2006).

Semi-structured interviews were conducted to collect data from nurses. The nurses were also observed on the units for a period of time by the authors. Interview transcripts and field notes were collected, read, and analyzed using the constant comparative method. The data analysis included multiple readings of individual transcripts and making comparisons among transcripts. Categories emerged from the coding, and then each one was coded for process, which resulted in sub-processes of the model. The sub-processes resulted in action/interaction mechanisms in which nurses carry out quality end of life care (Thompson et al., 2006).

Reliability and validity of the study was determined by the “fit, work, and grab” of the theory. This refers to how the theory applies, and whether the interpretation depicts the participants’ experiences accurately. The findings were reliable and valid according to the “fit and grab” (Thompson et al., 2006, pp. 172).

The authors identified the main themes as “creating a haven for safe passage.” The four sub-processes found under the main process were the following: “facilitating and maintaining a lane change,” “getting what’s needed,” “being there,” and “manipulating the care environment.” “Facilitating and maintaining a lane change” entails acknowledgement by physicians, nurses, the terminally ill patients, and family that death is eminent. “Getting what’s needed” relates to strategies the nurses used to make sure the needs of patients were met, and an appropriate care plan was in place. “Being there” relates to the importance of nurses being available physically and emotionally to family members of dying patients. “Manipulating the care environment” relates to changing the physical surroundings to optimize end-of-life care (Thompson et al., 2006, pp. 172-174).

Thompson et al. (2005) found that one limitation of the study was that all the participants were female. Another limitation was that there was an over representation of nurses who were minimally involved in palliative care. The final limitation was that there was no direct observations made of nurse-patient interactions during participant observation due to scheduling conflicts and time constraints. The authors concluded that nurses working on acute medical units prioritize the delivery of high quality end-of-life care, even though often pulled in multiple directions. A variety of strategies was used to deliver quality care in the hectic environment (Thompson et al., 2006).

A study conducted by Kinoshita (2007) was designed to identify reasons why intensive care (ICU) nurses experience hardships in respecting the wishes of patients in end-of-life care. The author noted that the most important part to be considered in determining a treatment plan for patients receiving end-of-life care is the wishes of the patients.

The study took place in Japan. The sample consisted of 1,210 nurse participants. The sample included 1,135 women, 47 men, and 28 unknown, with a mean age of 30 years, and a mean nursing experience of 8.6 years. The participants were ICU nurses who worked in 50 different university hospitals. The questionnaire contained items about ICU and end-of-life care. Questionnaires were mailed to the nursing unit manager of each ICU, and then distributed to ICU nurses that agreed to participate. Responses were collected by mail (Kinoshita, 2007).

Data were analyzed using content analysis and a coding schema. The author divided the data into 12 categories which were further grouped into 4 themes. The four themes were the following: "Patients' wishes unknown," "Decisions made by others," "ICU functioning unsuitable for end-of-life care," and "Characteristics of ICU end-of-life care." The themes were further cross-checked with statements made during the interviews (Kinoshita, 2007, pp. 654).

Kinoshita (2007) found that 15 participants (1.3%) thought patients' wishes were well respected, 246 participants (21.2%) thought patients' wishes were adequately respected, 623 participants (53.8%) thought patients' wishes were not adequately respected, and 274 participants (23.7%) thought patients' wishes received little respect. Of the participants, 845 indicated a reason for the above beliefs and described specific

experiences, also included in the analysis. The two categories found under “patients’ wishes unknown” were the following: circumstances prevent patients’ wishes from being determined, and lack of information about patients’ wishes. The author also noted that Japanese people avoid talking about death, and for this reason alone, many have not thought about how wish to approach dying.

The categories noted under “decisions made by others” were the following: “decision-making priority given to the family,” “decisions made mainly by doctors,” “experience of settings in which patients’ wishes were not accepted,” and “not enough information provided to patients and families about possibility of dying.” The categories noted under “characteristics of ICU end-of-life care” were the following: patients have high expectations of recovery and are not mentally ready to die; patients undergo such a change in appearance, and probably would not request treatment; and sudden death and time constraints. The other themes also noted from the data were lack of opportunity to discuss death in ICUs, and participants lacked palliative care skills (Kinoshita, 2007, pp. 655).

The author concluded that many ICU nurses in Japan believe that patients’ desires are not respected in the process of end-of-life care in ICUs. The most noted reasons ICU nurses believe the above was that acknowledging patients’ wishes was impossible, and often decision-making was performed by others regardless of whether patients’ desires are known. The author also concluded from the narrative that participants doubted whether life-saving and life-prolonging treatments should be performed or continued. The participants as a whole, expressed difficulties in respecting patients’ desires regarding end-of-life care (Kinoshita, 2007).

Oncology nurses often deal with death and dying on a regular basis, and care for patients in various stages of cancer. A descriptive study conducted by Lange, Thorn, and Kline (2008), assessed oncology nurses' attitudes about death and caring for dying cancer patients. The attitudes that oncology nurses have towards death and dying can influence the care being provided. The theoretical framework was the Nursing Role Effectiveness Model based on the Structure-Process Outcome Model of Quality Care (Doran, Sidani, Keatings, & Doidge, 2002, as cited in Lange et al., 2008).

A convenience sample consisted of 355 inpatient and outpatient oncology nurses. The setting was a 432 bed comprehensive cancer center in New York, NY. RNs throughout the hospital were invited to participate during annual RN competency review or nursing orientation. Ninety-three percent of participants were female, and 36% were between the ages of 30-39 years. Around 75% had been RNs for 5 or more years, and more than 60% worked at the cancer center for 5 or more years, and had experience working with dying patients (Lange et al., 2008).

The instruments included two different self-administered questionnaires. The Frommelt Attitude Toward Care of the Dying (FAT-COD) Scale, Form B (Frommelt, 1991) is a 30-item questionnaire to measure participants' attitudes toward caring for dying patients. It consists of an equal number of positively and negatively worded statements with response options of strongly disagree, disagree, uncertain, agree, and strongly agree. The instrument was found to be valid. The content validity index of the FATCOD was 1.00, with a computed inter-rater agreement of 0.98, which was later repeated, and found to be 1.00. The Pearson coefficient was 0.94 (Lange et al., 2008).

The second instrument was the Death Attitude Profile-Revised (DAP-R) (Wong, Reker, & Gesser, 1994). It is a 32-item questionnaire that uses a 7-point Likert scale to measure participants' attitudes toward death. It consists of the following five subscales to determine participants' feelings: fear of death, death avoidance, neutral acceptance, approach acceptance, and escape acceptance. The instrument was found to be reliable using alpha coefficients and four week test-retest coefficients (Lange et al., 2008).

Lange et al. (2008) found that viewing death from a neutral or escape perspective was directly related to a more positive attitude toward caring for dying patients and families. It was also found that variables such as education and work experience had a positive effect on communication, which contributes to improved patient outcomes. The strongest indicators of exhibiting a positive attitude toward dying patients were found to be years working as a RN, age, and years employed at cancer center. There was also a direct correlation between years of experience and viewing death as an escape from painful existence. The authors found the following limitations: participants were mainly female, with 75% having worked as RNs for 5 or more years, sample size may limit generalizability of findings, and self-report methods may result in falsely positive responses.

The authors concluded that more experienced oncology nurses view death from a more positive perspective than less experienced nurses, as well as displaying a more positive attitude in caring for dying patients. As a result, a palliative care educational component should be included in the new RN employee orientation course, as well as other hospital training programs. The results reinforced the importance of providing ongoing education on end of life care for oncology nurses (Lange et al., 2008).

A study conducted by Beckstrand et al. (2009) identified oncology nurses' views of barriers and assisting behaviors at end of life. The authors aimed to answer two research questions: "What is the magnitude of selected barriers to providing end of life care to patients with cancer as viewed by oncology nurses?"; and "What are the assisting behaviors in providing end of life care to patients with cancer as viewed by oncology nurses?" (pp. 447).

The national sample consisted of 1,000 geographically dispersed randomly selected oncology nurses obtained from the Oncology Nursing Society (ONS) membership list. The criteria for being selected included the following: ONS members that cared for inpatients with cancer, understood English, and had experience in end-of-life care (Beckstrand et al., 2009).

The authors used the Survey of Oncology Nurses' Perceptions of End-of-Life Care, which was adapted from two previous surveys with critical care nurses (Beckstrand & Kirchhoff, 2005) and emergency nurses (Beckstrand, Smith, Heaston, & Bond, 2008). The authors used information from the literature and expert opinions to further adapt and finalize the questionnaire, and to strengthen content validity. The final questionnaire had 68 items, including 50 Likert type items, 4 open ended questions, and 14 demographic questions (Beckstrand et al., 2009).

Each participant was assigned a numerical code; questionnaires were mailed. Items were ranked from highest to lowest on the basis of mean scores to determine which items were the biggest barriers and the most assistive behaviors. Reliability was reported using Cronbach alpha scores. The answers to the open-ended questions were analyzed with content analysis and categorized by like items (Beckstrand et al., 2009).

Of the 1,000 questionnaires, 375 (38%) had usable responses. Ninety- three potential participants were eliminated from the study for the following reasons: the questionnaire could not be delivered, the nurse was retired, or the participants were ineligible. Of the 375 participants, 351 were women, 18 were men, and 6 did not report gender. Participants ranged in age from 23 to 72 years old, were employed as staff or charge nurses, clinical nurse specialists, or managers or educators. The participants worked an average of 36.1 hours a week, had been RNs for a mean of 18 years, and had worked in oncology an average of 12.5 years. Participants reported practice settings to be the following: 58 % non-profit community hospitals, 11% for-profit community hospitals, 20% university medical centers, 4% county hospitals, 2% federal hospitals, 1% state hospitals, 4% county hospitals, 1% military hospitals, and 3% other. Two hundred and forty-two participants achieved certifications, such as oncology certified nurse, advanced oncology certified nurse, certified ostomy care nurse, or advanced drawing charge nurse. The majority of participants reported caring for more than 30 dying patients throughout careers. The educational levels of the participants ranged from diploma (8%) to doctoral (1%) (Beckstrand et al., 2009).

Beckstrand et al. (2009) noted mean barrier scores ranged from 1.02 to 3.56. The response choices ranged from 0 to 5, with 0=not a barrier, to 5=a very large barrier. Cronbach alpha for the 26 barrier items was high at 0.92. The highest ranked barrier to providing end of life care was nurses having to deal with angry family members (m=3.56). The second highest ranked barrier was families not accepting the patient's poor prognosis (m=3.55). The third highest ranked barrier was being called away from dying patients and families to care for other patients (m=3.53). Participants also

addressed the third barrier by stating that staffing ratios, high nurse and patient load, or lack of time to care for dying patients, were large barriers in providing end of life care. The two lowest ranked barriers were the following: no available support person for families (mean=2.03), and restrictive visiting hours (mean=1.02).

The mean scores for the 24 assistive behavior items ranged from 4.58 to 3.72. The response choices ranged from 0 to 5, with 0=not assistive, to 5=very assistive. Cronbach alpha for the 24 assistive behaviors was high at 0.9. The two highest ranked assistive behaviors were the following: allowing family members adequate time to be alone with patients after death (mean= 4.58), and having social work or palliative care staff as part of the patient care team (mean=4.55). The two lowest ranked assistive behaviors were the following: having fellow nurses care for other patients while you get away from unit for few moments after a patient's death (mean=3.78), and having families physically care for dying patients (mean=3.72) (Beckstrand et al., 2009).

The authors found the results were generalizable to the population of Oncology Nursing Society members who work in inpatient oncology settings because the sample was randomly selected, geographically dispersed, and of adequate size. Eight of the top 10 barriers to end of life care were directly related to families. The mean scores for assistive behaviors were higher for barriers because the highest scoring behaviors were behaviors under nurses' control, and were perceived as very helpful. The following were limitations noted in the study: participants were highly experienced in nursing and oncology causing views to be different from less experienced co-workers; the frequency of occurrence of the barriers and assistive behaviors was not analyzed to determine overall magnitude of each barrier and assistive behavior (Beckstrand et al., 2009).

The authors concluded that oncology nurses are dedicated, experienced, and comfortable in dealing with most issues involving end of life care. It was recommended that support for oncology nurses who provide end-of-life care to cancer patients should include strategies to correctly interact with angry, anxious, or overly optimistic family members, and to work with families to understand and accept the prognosis and dying process of loved ones. Other recommendations included involving social workers and palliative care staff on the oncology interdisciplinary team to support physicians, nurses, patients, and families in end of life care. It was also noted that the information concerning barriers and assistive behaviors in end of life care should be used by nurses, nurse managers, and advanced practice nurses to improve end of life care for cancer patients and families (Beckstrand et al., 2009).

Physicians' Views of End-of-Life Care

Oberle and Hughes (2001) expressed interest in identifying nurses' as well as physicians' perceptions of end-of-life care. Oberle and Hughes conducted a qualitative, descriptive study using a grounded theory methodology to identify and compare the perceptions of physicians and nurses regarding ethical problems in end-of-life decisions.

The sample consisted of 14 nurses and 7 physicians working on an adult medical surgical unit in a large acute care Canadian hospital. All of the nurses were female, and all but one of the physicians was male. The nurses ranged in experience from 5 to 28 years, while the physicians had been practicing for up to 20 years. Three of the nurses, and one physician, had formal ethics educational training. The nursing unit managers selected staff nurses. The physicians were recruited by being approached by a physician collaborating with the study researchers (Oberle & Hughes, 2001).

One-on-one structured interviews were conducted ranging in length from 45 to 90 minutes. The participant chose the site of the interview. Each interview began with the main question: “Please describe for me a frequently recurring ethical problem that you have experienced in practice—something that has been a common problem for you” (p. 709). Probing was used to encourage the participants to elaborate more on perceptions. Each interview was transcribed and analyzed based on the methods of Strauss and Corbin (1998). The authors began coding after each transcript was read thoroughly several times. A constant comparative analysis method was used to sort and resort individual meaning units as categories and then as patterns. Patterns were then combined into common themes. The analysis was conducted in the following three phases: (a) physicians’ and nurses’ interviews were analyzed separately and themes identified, (b) overarching of themes common to both were identified, and (c) similarities and differences within each overarching theme were identified and noted (Oberle & Hughes, 2001).

Oberle and Hughes (2001) found that the main differences between nurses’ and physicians’ ethical concerns were related to positions as caregivers. The reasoning behind the differences was that physicians make the ultimate decision on the direction of a patient’s care and write the orders. Nurses take care of the orders and live with the decisions made by physicians. The authors found that both physicians and nurses were very concerned about the decision-making process. As the authors analyzed patterns and themes from the interviews, authors found that the main problem for both physicians and nurses was witnessing suffering of patients and families, and the moral obligation to try to reduce that suffering. Oberle and Hughes also found many of the themes from the

interviews overlapped and intertwined. The common themes were “competing values,” “scarce resources,” “hierarchical processes,” and “communications” (pp. 710).

The authors also found that physicians often wrestled with making the right decision. Nurses experienced moral distress in uncertain situations when nurses believed the wrong decision was made. The physicians were stressed about how to explain to patients’ families different life- saving measures that can be provided at the end-of-life, and whether values or opinions were affecting what decision is ultimately made. In contrast, nurses were more concerned that physicians were not acting in the best interest of the patient or the family. Both physicians and nurses believed inability to exercise moral agency was a result of limits imposed by hierarchical structures. The authors also found that resource allocation was an issue among both groups. The participants found effective communication to be a key factor in end-of-life decision making (Oberle & Hughes, 2001).

Although the authors found some ethical-related differences between physicians and nurses, the majority were similar. The differences between the two groups mainly focused on the hospital’s hierarchical structure, and the assigned roles of physicians and nurses, not moral commitment or reasoning. The authors concluded that physicians make the decisions, and nurses abide by decisions. The authors recommended that cross-disciplinary discussion and mutual acknowledgement of the burden carried by the other was needed to reduce the moral distress experienced by both physicians and nurses (Oberle & Hughes, 2001).

Communication between the medical team, patients, and patients’ families is an important topic in end-of-life care. In 2003, Ahrens, Yancey, Kollef, and Kleinpell

conducted a quasi-experimental study to evaluate the effectiveness of a communication team that included a physician and a clinical nurse specialist, on length of stay and costs for patients near the end of life in the intensive care unit (ICU).

The setting of the study was a medical ICU at Barnes-Jewish Hospital (Ahrens et al., 2003). The sample consisted of 151 patients divided into two groups: 108 in the standard-practice or control group, and 43 in the intervention group. The participants selected were deemed to be at high risk of dying by the physician and clinical nurse specialist. Patients met at least two of the inclusion criteria, which included patients with the following: AIDS with a very low CD4 count, conditions associated with an unacceptable quality of life such as anoxia, imminent demise, lethal condition, treatment with mechanical ventilation for more than 3 days, and prehospitalization history of New York heart Association class IV heart failure with an ejection fraction of less than 0.20.

Two ICU clinical nurse specialists, and the medical director of the medical ICU led the study. During a 1 year period, the medical director teamed with a clinical nurse specialist who cared for 43 patients in the intervention group, and an attending physician who cared for the 108 patients in the standard-practice or control group. The physician provided daily medical updates to patients' families, offered care guidelines, and shared medical advice concerning treatment with patients and families. The role of the clinical nurse specialist was to provide daily information to the families, and to offer the opportunity to clarify any issues. The clinical nurse specialist was the primary source of information after the brief discussion with the physician (Ahrens et al., 2003).

The score on the Acute Physiology and Chronic Health Evaluation (APACHE) measured the severity of patients' illnesses. The instrument was found to be reliable and valid (Ahrens et al., 2003).

Demographic data were collected. Ahrens et al. (2003) noted that there was a slightly higher percentage of females in the study compared to males. The participants were white, African American, and Asian. The mean age of the control group participants was 61.1, and the mean age of the intervention group participants was 65.3. The participants' conditions ranged from primary cardiac to cancer. The mean APACHE scores were significantly different in the two groups (28.6 in the control group and 32.1 in the intervention group).

Ahrens et al. (2003) found that the mean ICU length of stay was reduced from 9.5 days for the standard practice group, and 6.1 days in the intervention group. The mean length of stay in the hospital was also significantly different between the two groups: 16.4 days for standard practice, and 11.3 days for the intervention group. The hospital's direct and indirect costs were lower in the intervention group than in the control group, as well as the hospital's fixed costs. Mortality during ICU admission was lower in the intervention group (74%) than in the control group (93%). With clear communication in 42 of the 43 cases in the intervention group, the patients' families decided either to withhold or withdraw care at the end of life.

In conclusion, Ahrens et al. (2003) noted that improving communications with patients and families at the end of life could help make effective decisions as well as benefit financially. Effective communication allows for a better understanding of the end of life process, and measures that can be taken during that time.

Patients' and Families' Views of End-of-Life Care

Palliative care is important in the lives of dying patients who deserve excellent care. Johnston and Smith (2005) conducted a qualitative phenomenological study to identify perceptions of palliative care nurses and patients receiving palliative care, particularly focusing on the expert palliative care nurse. The authors aimed to answer three research questions: “What is palliative nursing care from the dying patient’s perspective?”; “What is palliative nursing care from the nurse’s perspective?”; and “Are there differences between dying patients’ and nurses’ perceptions as to what constitutes expertise in palliative nursing care?” (pp. 702).

A convenience sample of 44 participants was invited. The sample consisted of 22 registered nurses, and 22 patients. The participants were gathered from two hospices, and two hospitals in the United Kingdom. The eligibility criteria for patients included the following: being cared for in one of four study sites, diagnosis of life-threatening illness, life expectancy of not greater than 2 years but not less than 2 weeks, awareness of diagnosis, and the ability to communicate in English verbally. The criteria for nurses included the following: registered nurse, post registration experience of at least 2 years, and post registration qualification in palliative care. The settings of the study were the two specified hospices and two specified hospitals in the United Kingdom (Johnston & Smith, 2005).

In-depth interviews were used to identify patients’ and nurses’ perceptions. Nurse interviews were shorter in length than patient interviews. A reflective field journal was kept during the interviews to provide an audit trail. Although the study instrument was found to be valid, reliability was difficult to assess due to an interview guide being used.

The interview tapes were transcribed and checked for accuracy. A reflective, interpretive process using Colazzi's (1978) framework and Miles and Huberman's (1994, as cited in Johnston & Smith, 2005) content analysis process were used to identify themes and categories from the interviews and journal data. The authors also used Guba and Lincoln's (1988) criteria of credibility, fittingness, auditability, and confirmability to establish rigour and reflexivity (as cited in Johnston & Smith, 2005).

The authors identified 8 themes, and 29 categories from patients' and nurses' interviews. The key theme for patients was "connecting." Connecting focused on the importance of interpersonal skills, and the value of nurse-patient relationship. The authors found that patients viewed expert palliative nursing care as effective interpersonal skills and caring skills. Patients also expressed that nurses should meet needs by helping, providing with emotional support, being someone to talk to, providing comfort, and most importantly spending time with. The perceptions of nurses indicated that effective palliative care is directly related to providing comfort, which included the ability to relieve pain and control distressing symptoms. The authors also found that the lived experience of a palliative care patient is different from the experience of a qualified nurse caring for that patient (Johnston & Smith, 2005).

The authors concluded that palliative care training should be mandatory for nurses who work in palliative care as part of a post graduate program in palliative care, or as a special course. Education about pain and symptom control should be taught, along with psychosocial aspects of palliative care, and role of effective communication and caring practices. Future research should be conducted to evaluate whether expert nurses really practice the way that palliative care should be practiced (Johnston & Smith, 2005).

A grounded theory study, conducted by Reinke, Engelberg, Shannon, Wenrich, Vig, Back, and Curtis (2008), focused on identifying perceptions of patients, families, and clinicians regarding palliative and end of life care for patients with severe chronic obstructive pulmonary disease (COPD) or advanced cancer. Both COPD and advanced metastatic cancer are diseases that can limit a person's life, and have different levels of functional decline, which in turn requires different levels of care at the end of life.

The sample consisted of physicians, nurses, patients, and patients' families. Physicians were selected first, and then patients, family members, and nurses. An expert panel of physicians from two different cities (Seattle and Tacoma), from three different specialities (oncology, pulmonary, and general medicine), was used to select physician participants. The expert panel identified physician leaders, and classified into three categories: focused on curative treatment, focused on palliative care, or "in the middle." The expert panel randomly assigned physician participants from the three categories. The following eligibility criteria was used for physician participants: $\geq 50\%$ time spent in clinical practice, and the ability to identify at least four eligible patients (Reinke et al., 2008).

Patient participants were recruited by enrolled physician participants. The eligibility criteria for patient participants included the following: diagnosis of advanced cancer (metastatic or non-operable cancer), or severe COPD, described as: "would not be surprised if the patient died from any cause in the next year." Patients that did not speak English well in an interview were excluded. Patient participants identified a family caregiver or close friend, and nurses involved in care. If patient participants were unable

to identify a nurse for the study, the patient's physician would identify a nurse involved in the patient's care (Reinke et al., 2008).

The sample consisted of 31 physician participants, 55 patient participants, 36 family member or friend participants, and 25 nurse participants. Of the patient participants, 24 had oxygen-dependent COPD, 30 had advanced cancer, and 1 had both COPD and cancer. Two patients were enrolled in hospice at the beginning of the study, and seven entered hospice during study follow-up. Twenty-one patients died within the first 6 months of the study. The average age of clinician (RNs and MDs) participants was mid 40s, and the average years of practice were 20 years. The majority of clinician participants did not have training in end of life care. The majority of family or friend participants were actual family members such as spouse, child, or sibling (Reinke et al., 2008).

Semi-structured interviews were conducted by two experienced interviewers who received training from investigators. Prior to starting the interviews, the interviewers completed 5 hours of observation. Follow-up interviews were conducted with patients at two different times: 4-6 months after study entry, and 12 months after study entry. The interviews were audiotaped and transcribed word for word (Reinke et al., 2008).

Three analytic steps were completed for the study: open coding, axial coding, and selective coding. Open coding entailed the development of a coding framework designed to identify the meaning of participants' speech. Axial coding was used to identify relationships among codes. Selective coding was used to develop theoretical constructs using open and axial codes. The investigative team developed a list of codes related to research topics of communication about hope and prognostic information.

Reliability for transitions coding was established by the following: (a) initial review of transitions coding scheme by the entire multidisciplinary team; (b) reexamination of the transition coding scheme for a quarter of the transcripts; and (c) recoding of a random sample of 30 transitions passages into the transitions coding scheme by a second investigator not affected by the initial coding results. The results represented a 90% agreement, and a k statistic of 0.85, both representing good agreement (Reinke et al., 2008).

The authors identified six themes in regards to participants experiences with transitions. Some of the themes were similar to both COPD and cancer patients, and others were particular to one of the diseases. The six themes are the following: “new or different treatments,” “no more treatment/curative to palliative care,” “activity limitations,” “initiation of oxygen therapy,” “exacerbations/hospitalizations,” and “improvement of illness.” Themes found to be common to patients with COPD and cancer as well as clinicians, were the following: “new or different treatments,” and “no more treatment/curative to palliative care.” Themes found to be unique to patients with COPD and clinicians, were the following: “activity limitations/functional decline,” and “initiation of oxygen therapy.” The theme identified as unique to clinicians for patients with COPD was the following: “illness exacerbation or hospitalization.” The theme identified as unique to patients with cancer was the following: “improvement from illness.” The authors concluded that important differences exist regarding transitions in palliative and end-of-life care between patients with COPD. Cancer, and that transition often entails more than a “one-time” transition from curative care to care focused on “comfort measures only” (Reinke et al., 2008, pp. 604-607).

One limitation was that the study was designed to identify patient, family, and clinician views, but not designed to describe the prevalence of the views identified, or the prevalence or timing of the transitions in palliative care, that the authors have described. The study was initially designed to explore how participants balance the need for prognostic information and hope and not specifically to explore transitions (Reinke et al., 2008).

Summary of Findings

Nurses' Views of End-of-Life Care.

The purpose of the study by Puntillo et al. (2001) was to identify the knowledge, beliefs, and ethical concerns of nurses caring for dying patients in Intensive Care Units (ICUs). Findings showed ICU nurses agreed with withholding or withdrawing life-sustaining therapies to allow death to occur when patients and/or the patients' families do not want further treatment, or when the treatment is not serving a purpose. The authors concluded that palliative care in the ICU should be given regardless of death being imminent or not.

The goal of the study by Kirchhoff and Beckstrand (2000) was to identify critical care nurses' views of barriers and of assisting behaviors in providing end-of-life care for dying patients. The assisting behaviors were higher than the barriers. The authors concluded that no single barrier was viewed by participants as either large or very large. The top and most common assisting behaviors included agreement of physicians regarding direction of care, appreciation of nurses from patients' families, and allowing nurses to provide flexibility in patients' environments.

The purpose of the study by Beckstrand and Kirchhoff (2005) was to identify critical care nurses' views of both the intensity and frequency of barriers and assisting behaviors in providing end-of-life care to patients and families. The greatest barriers to appropriate end-of-life care in the ICU were the actions of patients' families and the most assisting behaviors were controlled by the nurses. The results suggested that serious problems in end-of-life care still exist and may be worsening. The authors concluded that a better understanding of the most intense and frequently occurring barriers and assisting behaviors could lead to the improvement of end-of-life care.

Describing registered nurses' perceptions of factors influencing care for patients in the palliative phase of end-stage heart failure (ESHF) was the purpose of Wotton et al.'s (2005) study. The authors found that knowledge of palliative care should be given to acute care nurses. The authors also found nurses focused on the patients' physical and emotional comfort in palliative care. The authors concluded that the nurses involved believed that the addition of plans to improve financial, social, and physical conditions for patients with ESHF should be considered as urgent and important. Palliative care for ESHF patients should have a holistic approach using a multidisciplinary cross-trained team of medical professionals.

The purpose of the study by Thompson et al. (2006) was to understand nurses' perceptions of the quality of end-of-life care being provided by nurses on an acute medical ward, and nurses' perceptions of the care. The authors concluded that nurses working on acute medical units prioritize the delivery of high quality end-of-life care, even though often pulled in multiple directions.

The purpose of Kinoshita (2007) was to identify reasons why intensive care (ICU) nurses experience hardships in respecting the wishes of patients in end-of-life care. The author concluded that many ICU nurses in Japan believe that patients' desires are not respected in the process of end-of-life care in ICUs. The most noted reasons ICU nurses believe the above was that acknowledging patients' wishes was impossible, and often decision-making was performed by others regardless of whether patients' desires are known.

The purpose of Lange et al.'s (2008) study was to assess oncology nurses' attitudes about death and caring for dying cancer patients. The findings showed a direct correlation between viewing death from a neutral, or escape perspective and a more positive attitude toward caring for dying patients and families. The authors concluded that more experienced oncology nurses view death from a more positive perspective than less experienced nurses, as well as displaying a more positive attitude in caring for dying patients.

Identifying oncology nurses' views of barriers and assisting behaviors at end of life was the purpose of Beckstrand et al.'s (2009) study. The findings showed the mean scores for assistive behaviors were higher than the mean scores for barriers because the highest scoring behaviors were behaviors under nurses' control, and were perceived as very helpful. The authors concluded that oncology nurses are dedicated, experienced, and comfortable in dealing with most issues involving end of life care.

Physicians' Views of End-of-Life Care.

Identifying and comparing the perceptions of physicians and nurses regarding ethical problems in end-of-life decisions was the purpose of Oberle and Hughes (2001)

study. The findings showed the main differences between physicians' and nurses' ethical concerns were related to positions as caregivers. The authors concluded that the differences between the two groups mainly focused on the hospital's hierarchical structure, and the assigned roles of physicians and nurses, not moral commitment or reasoning.

The purpose of the study by Ahrens et al. (2003) was to evaluate the effectiveness of a communication team that included a physician and a clinical nurse specialist, on length of stay and costs for patients near the end of life in the intensive care unit (ICU). The authors concluded that improving communications with patients and families at the end of life could help make effective decisions as well as benefit financially.

Patients' and Families' Views of End-of-Life Care.

The purpose of Johnston and Smith's (2005) study was to identify perceptions of palliative care nurses and patients receiving palliative care, particularly focusing on the expert palliative care nurse. The findings showed that patients viewed expert palliative nursing care as effective interpersonal skills and caring skills. The authors concluded that palliative care training should be mandatory for nurses who work in palliative care as part of a post graduate program in palliative care, or as a special course.

Identifying perceptions of patients, families, and clinicians regarding palliative and end of life care for patients with severe chronic obstructive pulmonary disease (COPD) or advanced cancer was the purpose of Reinke et al.'s (2008) study. The authors concluded that important differences exist regarding transitions in palliative and end-of-life care between patients with COPD.

Chapter III

Methodology

Introduction

End-of-life care is a growing need for the elderly individuals who are hospitalized in ICU. End-of-life care needs to be addressed, to assist nurses dealing with end-of-life care in ICU. The purpose of this study is to evaluate critical care nurses' perceptions of the impact of selected obstacles and supportive behaviors in providing end-of-life care in ICU. This study is a replication of Beckstrand et al.'s (2009) study.

Research Questions

1. What are the greatest obstacles to providing end-of-life care to patients in Intensive care as perceived by critical care nurses?
2. What are the most supportive behaviors surrounding end-of-life care in Intensive care as perceived by critical care nurses?

Population, Sample, and Setting

The population will be critical care nurses recruited from four different hospitals in Indianapolis, IN. The hospitals include two trauma centers and two community hospitals. Each hospital has two or three ICUs. The units include: medical ICU, surgical ICU, and adult ICU. The anticipated sample will consist of 120 critical care nurses, 30 from each hospital. Inclusion criteria for nurses are: 5-7 years critical care experience,

currently employed at least part-time in critical care setting, and had cared for at least five patients at the end-of-life in the last year.

Protection of Human Rights

The study will be submitted for approval to the Institutional Review Boards of Ball State University. Approval will also be obtained from each participating hospital. A description of the study will be given to each participant describing the study.

Participation will be voluntary, with the participant being able to withdraw at any point. Confidentiality will be maintained. Each participant will be assigned a number code for data management. No risks have been identified with the study. All data will be anonymous and will not contain any names or other personal info. Benefits include providing a better understanding of nurses' views of supportive behaviors and obstacles in providing end-of-life care, and in understanding those views can help provide better end-of life care to patients.

Procedures

After receiving permission from the IRB at Ball State University and each hospital, meetings will be scheduled at each hospital with the Director of Nursing. Then meetings will be scheduled with nurse managers of the designated units, and details of the study will be discussed. A staff meeting will be scheduled with nurses at each hospital working in all ICU units to discuss the study. Participation criteria and details of the study will be discussed at the staff meeting. All staff will be invited to participate. Following the scheduled meetings, questionnaires will be placed in all staff mailboxes on the units with a cover letter. The researcher will access the staff mailboxes with the permission of the nurse managers. Questionnaires will be returned on each unit to a

secure box that will be located in the staff lounge. Completed questionnaires will then be collected by the researcher.

Instrumentation

The instrument used in the study will be a questionnaire, the National Survey of Critical Care Nurses Regarding End-of-Life Care, developed by Kirchhoff and Beckstrand (2000). Critical care nurses were asked to rate the magnitude of listed obstacles and supportive behaviors in giving end-of-life care to dying patients. The original questionnaire had 72 items: 29 obstacle items, 24 supportive behaviors, 4 open-ended items for nurses to add any items that it did not cover, and 15 demographic questions. The final questionnaire has 68 items, including 50 Likert-type items, 4 open-ended questions, and 14 demographic questions (Beckstrand & Kirchhoff, 2005). Items are scored on a scale of 0 to 5, with 0 = not an obstacle or supportive behavior, and 5 = extremely large obstacle or supportive behavior. The questionnaire was tested and adapted to fit the critical care population. The questionnaire was pilot tested by 28 nurses from three different ICUs. The participants will also be asked to list any additional obstacles and supportive behaviors encountered while caring for dying patients that had not been listed as items on the questionnaire. The study conducted by Beckstrand et al. (2009) found the National Survey of Critical-Care Nurses Regarding End of Life Care questionnaire was reliable with the Cronbach alpha for the 26 obstacle size items in the study to be 0.92 and the Cronbach alpha for the 24 supportive behavior items to be 0.9.

Design

A typical descriptive research design will be used for this study. Typical research design is a type of quantitative research used to get more information about

characteristics within a specific field of study (Burns & Grove, 2009). This design is used to identify problems with current practice, develop theory, justify current practice, make judgments, or determine what others in similar situations are doing.

Data Analysis

Responses will be entered into a data analysis file. Descriptive statistics will be used to analyze data. Measures of central tendency and dispersion and frequency will be calculated. The items will be ranked from highest to lowest based on mean scores to determine which items were the greatest obstacles and which behaviors were most supportive. Open-ended question responses will be analyzed using content analysis, and data will be categorized into categories, and frequency counts will be done (Beckstrand et al., 2009).

Summary

The study will be conducted to describe end-of-life care by identifying obstacles and supportive behaviors involving end-of-life care as perceived by critical care nurses. The questionnaire, the National Survey of Critical Care Nurses Regarding End-of-Life Care will be the instrument in the study. The design is descriptive with the sample and questionnaire. The findings will assist in identifying and understanding obstacles and supportive behaviors in end-of-life care. The results will assist healthcare providers involved in end-of-life care to give more quality end-of-life care to patients. This study will replicate a study by Beckstrand et al. (2009) in attempt to improve the quality of end-of-life care.

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