DEVELOPMENT OF AN END-OF-LIFE CARE/DECISION

PAMPHLET IN THE ICU

A Project

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Jennifer Murrish

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ABSTRACT

DEVELOPMENT OF AN END-OF-LIFE CARE/DECISION PAMPHLET IN THE ICU

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Nurses were surveyed about information desired in an end-of-life pamphlet specific to the needs of ICU patients. Nurses determined information about physical changes, pain control, definition of terms, and resources were key components in a pamphlet. Fifty percent of nurse participants did not feel comfortable discussing end-of-life care with patients. Current literature on the topic, The Peaceful End-of-Life Theory, and nurse surveys were used to develop an end-of-life pamphlet.
CHAPTER I

INTRODUCTION

Background

End-of-life care is a frequent occurrence in many intensive care units (Ciccarello, 2003). Between 15% and 55% of all Medicare beneficiaries who are dying are admitted to an intensive care unit at least once within six months of their death and at least one-fifth die there (Maxwell & Pope, 2006). Patients undergoing life sustaining therapies, and unable to live or maintain life without these therapies or when death is inevitable must make end-of-life decisions. End-of-life decisions for patients and their families are often difficult decisions to make. There are times that exist when patients are unable to make medical decisions on their own. This is when medical staff turn to families to make medical decisions. However, family members often do not want to be the ultimate decision maker when death is inevitable. Often, end-of-life decision making is left to the family at the most inopportune times or at times of extreme emotional circumstances. Patients may not have discussed end-of-life decisions and wishes with their families while they were healthy and competent to make their own decisions; creating an environment where making end-of-life decisions is difficult and stressful for the family. “End-of-life decision making is the process that healthcare providers, patients, and patients’ families go through when considering what treatments will or will not be used to treat a life threatening illness” (Thelen, 2005, p. 29)
At times, intensive care unit nurses may have difficulty supporting patients and families during this sensitive and difficult time due to lack of information available to them, and to patients and their families. Throughout a patient’s hospital stay, education and informational pamphlets are available for many common diseases and therapies. Although end-of-life care is often not thought of as therapy; at the time these types of decisions need to be made, informational pamphlets can be helpful for patients, families, and nurses because they provide supportive information. An informational booklet/pamphlet, also known as a decision aid, will allow patients and families to understand end-of-life care/decisions as well as to offer guidance for nursing staff. Informational pamphlets provide patients and family members with a tangible item, which they can refer to at any time, and can augment any verbal information received (Paul, Hendry, & Cabrelli, 2004).

Admission to an ICU often brings forth conversations of life sustaining therapies and guidance when a cardiac or respiratory arrest occurs. This scenario usually aids in clarifying a person’s wishes regarding resuscitation; also known as a person’s ‘code status’. Code status offers some choices; full code, partial code, or do not resuscitate (DNR). Full code status means that when a person’s heart or breathing stops, causing respiratory or cardiac arrest, all life saving therapies are to be attempted and initiated (Wiegand, 2006). Therapies can include but are not limited to mechanical ventilation with intubation, dialysis, defibrillation, and administration of emergency medicines to increase heart rate and/or blood pressure. A partial code, offers some of these therapies, but not all, a choice made by the patients and/or the family (Wiegand, 2006). Do not resuscitate is defined as “a patient’s wishes regarding resuscitation, more
specifically, the patient’s desire to avoid cardiopulmonary resuscitation” (Payne & Thornlow, 2008, p. 11)

For patients who have been given all life-sustaining therapies but have a poor prognosis with death inevitable, the multidisciplinary team will usually need to meet and discuss end-of-life care. A multidisciplinary care team is a supportive team of individual care providers from different disciplines who coordinate the care of patients (Doyle, 2008). The multidisciplinary team can often include but is not limited to family members, physicians, nurses, social worker, chaplain, and interpreter (if indicated). Once the decision for end-of-life care has been made, the patient is placed on what is commonly called ‘comfort care’ or palliative care. Comfort care is defined as discontinuing any diagnostic or therapeutic procedures that do not contribute to the patient’s comfort, as well as ensuring there is adequate analgesic or sedative therapies to control pain or shortness of breath, or any other uncomfortable symptoms (Thelen, 2005).

Families and patients often rely on nursing staff to provide all necessary information about end-of-life care, but because nurses are indoctrinated to the medical environment, they become immune to clarifying medical jargon (Limerick, 2007). Families or patients may be intimidated or feel uncomfortable to ask the nurse for lay terms or for an explanation of terms. Use of technical terms can lead to miscommunication and confusion for families or patients, especially when discussing end-of-life care (Limerick, 2007). Providing written end-of-life educational material may provide consistency and clarity to end-of-life care/decisions by eliminating the medical jargon that confuses patients or families. Limerick concluded that families felt
communication with nursing staff providing consistent information, without the use of medical jargon, assisted in end-of-life decision making.

Nurses working in the ICU often teach patients and families about care and therapies. For patients and families the end-of-life decision can be a time when they are experiencing calamity. Kolcaba, Tilton, and Drouin (2006) demonstrated that once the process of comfort care was initiated, patients and families valued timely responses from hospital staff about their emotional needs, concerns, and complaints. In order to be sensitive to grieving families, the author has chosen to develop an end-of-life care/decision pamphlet that provides supportive information while maintaining consistent and clear messages for nurses to teach/support families and patients.

Problem Statement

End-of-life decisions are difficult for any family member to make. When families are left to make the decision to go from aggressive life saving therapy to end-of-life care, they look to each other and to the healthcare team for support. Having this support is an important component to make the decision toward end-of-life care. While the healthcare team members cannot be the ultimate decision makers for families, the healthcare team can offer support and understanding during this difficult time. Thelan (2005) suggested that during a time when patients cannot make end-of-life decisions, physicians and hospital staff look to the surviving family members to make these decisions. In the United States, family members are involved in end-of-life decisions 60-80% of the time (Thelan, 2005). Hospital nursing staff are usually available to offer their support, opinion, and professional guidance. However, there is often no written
information that families can take away with them to read that would help them to make decisions about end-of-life care for their loved one.

Currently in an urban intensive care unit there is no end-of-life care/decision pamphlet or information kit that provides information to patients and families. Often, family concerns regarding end-of-life care are directed towards pain control, nutrition, expectations about the process of comfort care, and how long it will take for their loved one to die (Weissman, 2000). It is often difficult for family members to recognize that the concept of end-of-life care is to provide the treatment of comfort. Research has shown when patients and families have been educated on treatment modalities and options, and provided written material, anxiety levels during the dying process decreased (Kolcaba et al., 2006).

Written materials are effective in providing education about diseases and therapies to families and patients (Mahat, Scoloveno, & Donnelly, 2007). An end-of-life care/decision informational pamphlet providing consistency and clarity for patients and families is important during the time when life sustaining therapy is no longer an option. Limerick (2007) stated that consistent language among healthcare professionals can eliminate conflicting information and establish goals. The current nursing practice in the ICU is to speak with patients and families about end-of-life care; however, there is no written material available to offer information for patients and families. An end-of-life care/decision pamphlet will provide patients and families with necessary information about the dying process.
Relevance and Importance to Nursing

This project is relevant to nursing because the author has been unable to identify educational tools that could assist nurses to help patients and families to make end-of-life decisions. In some instances, patients and family members cannot retain information being given to them by the physician or nurse because of shock, anger, or denial. They may get information about their loved one’s condition from one nurse and get different information from another nurse, causing confusion and inconsistency at a stressful and difficult time. This project will be helpful to the nurses because it will provide them with detailed information and a clear message of what is important when providing information to families and patients about end-of-life care and decision making. Providing this educational pamphlet will give guidance to nurses and a tangible item to those recipients of the pamphlet.

Wiegand (2006) found that communication between health care providers and patients families was clearest when consistency among health care providers was maintained. Written end-of-life care educational material can provide consistency from nurse to nurse while providing a clear message to family members and patients. The primary goal of the end-of-life care/decision pamphlet is to provide information to patients and families and increase communication by providing a consistent message from the nursing staff. The project director will design and develop an educational pamphlet about end-of-life care for patients and families in the ICU setting.
Theoretical Framework

The theoretical framework that was used for this project was the Peaceful End of Life Theory developed by Cornelia Ruland and Shirley Moore (1998). This theory was derived from standards of care written by expert nurses. It is a middle range theory that was developed by a student (Shirley Moore) and a faculty member (Cornelia Ruland) during a doctoral theory course (Tomey & Alligood, 2006). Although the Peaceful End of Life Theory was developed for the terminally ill, the concept of this theory encompasses the true therapy at end-of-life. The Peaceful End of Life Theory has a family structured system (Ruland & Moore, 1998). Ruland and Moore stated, “the main focus for standard development is not on the final instance of dying itself, but on contributing to peaceful and meaningful living in the time that remained for the patients and their significant others” (p. 171).

Five outcome indicators were derived from the Peace end of life Theory: “not being in pain, experience of comfort, experience of dignity/respect, being at peace, and closeness to significant others/persons who care” (Ruland & Moore, 1998, p. 172). These five indicators are key components to the end-of-life care. Pain in this model is simply having the patients not experience any pain (Ruland & Moore, 1998).

Ruland and Moore (1998) determined the definitions of the five outcome indicators:

The experience of comfort is standardized as the patient not experiencing nausea, thirst, experience a pleasant environment and experiences optimal comfort. Experience of dignity/respect is that the patient and family members participate in decision making, and be treated with dignity and respect by hospital personnel. Being at peace is a standard where the patient and significant others maintain hope and meaningfulness, the patient does not die alone, and the patient is at peace. Lastly, closeness of patients to their significant other or family and friends who care
are participating in care of the dying patient, can say farewell in compliance with their religious or cultural beliefs, and informed about funeral procedures and possibilities. (p. 173)

The Peaceful End of Life Theory is a good fit for the problem identified in one urban Northern California ICU because the five outcome indicators are the focus for nurses who are providing end-of-life care. Families shift their concern from cure to comfort and peace (Thelan, 2005). Family members do not want their loved ones to suffer or experience pain at end-of-life. Including family members in the assessment of pain and inquiring about their opinion can provide comfort. Allowing families or loved ones to be active participants in the end-of-life process can put them at peace with the end-of-life decision because they will be helping keep their loved one comfortable and peaceful, maintain their dignity and respect, and provide support.

Ruland and Moore (1998) stated:

A person’s approach to end of life is a highly personal experience, that nursing care plays a major role in making this a peaceful experience, and that nurses are able to observe and interpret cues that reflect the patient’s experience of being or not being in a peaceful state and appropriately intervene. (p. 172)

ICU nurses are able to make observations and interpret cues of comfort or discomfort, allowing nurses to promote a peaceful death in an environment that is often fast paced and directed towards life sustaining therapies.

The author used this theory when developing the end-of-life care/decision pamphlet because the five major concepts of this theory are the essence of end-of-life therapy. The pamphlet will emphasize the five major concepts of the Peaceful End of Life Theory. In one urban northern California ICU, family centered care is encouraged and supported by the healthcare team. For all patients whose therapy has been guided
toward end-of-life care the components of the Peaceful End of Life Theory will be the standard of care. Utilizing this theory, in combination with other literature and the input from nurses, the author developed a pamphlet that is easy to understand for nurses, patients, and families.

Purpose

The purpose of this project is to design and develop an end-of-life care pamphlet that ICU nurses can use to aid in end-of-life care/decisions for patients and families. This pamphlet will provide general information about the process of end-of-life care in order to assist patients and families in the decision making process. The material that has been found on end-of-life care/decisions is cumbersome and included with other aging, disease processes, and end-of-life home care material, which does not provide clear, simple and direct guidelines for teaching or information sharing by nurses in the inpatient setting. There is a gap in end-of-life inpatient care/decision educational guidelines for the nursing staff when teaching patients and families about end-of-life care/decisions, leaving questions as to what the previous nurse talked about to the patient or family. A lack of educational material may often lead to inconsistency from nurse to nurse, resulting in confusion for patients and families.

An intended accomplishment of this project is to provide the nursing staff with end-of-life care/decision educational material that has a consistent and clear message. The nursing staff may utilize this educational material for their patients and families when life sustaining therapy is no longer the focus of treatment. The availability of educational material for nurses to provide patients and families who are making end-
of-life care decisions should be readily available, accessible, and easy to understand. Educational materials about end-of-life care/decisions that nurses can utilize will provide nurses, patients and families consistency and clarity at a time of emotional distress and shock. It will also provide families and patients comfort and help with the grieving process by knowing they made an informed decision for their loved one.

Definitions of Terms

- An advanced directive is a living will and/or Durable Power of Attorney for Health Care (DPAHC). Gupta, Goyal, Chauhan, Mishra, and Bhatnagar (2008) define the living will as a document in which the patient, in the event that he or she becomes terminally ill, directs the physicians to withhold or withdraw life-sustaining treatment. A DPAHC is the form used when the patient has previously appointed an agent; either a family member or close friend, and allows that person to make health care decisions in the event that he/she cannot speak for him or herself.

- Comfort care is defined as care given to improve the quality of life of patients who have a serious or life threatening disease or illness (“Comfort Care,” n.d.)

- Do Not Resuscitate (DNR) means resuscitation should not be attempted or initiated if a person suffers cardiac or respiratory arrest (Wikipedia, 2010).

- End-of-life care is defined as care during the last stage of life. End-of-life care forgoes life sustaining treatment (Campbell & Guzman, 2003). The focus of end-of-life care is to provide comfort to patients (Wiegand, 2006).
Life saving therapy is therapy offered to continue one’s life (Bailey, 2006).

Life saving therapy is therapy that will continue or maintain one’s life, possibly to cure or sustain at the current state.

Standardized is defined as bringing to conformity, with a standard, to compare with a standard (“Standardized,” n.d.).

Qualification of the Project Director

The researcher received her registered nursing license in May 2001 from College of Marin’s nursing school. Upon graduating, she began working on the medical-surgical floor. After nine months, she transferred to the ICU. The ICU has provided an environment where she broadened her nursing skills and increased her knowledge of critically ill patients. This environment also offered many opportunities for working with terminally ill patients and their families. These experiences have provided the researcher with a greater understanding of the issues surrounding the end-of-life discussions that occur between the health care team and patients.

This project director has been working as an ICU nurse for eight years. In 2003, she obtained a position as a travel nurse working in a large teaching hospital in New York City, New York. After a short time, she returned to California where she again briefly worked at a large teaching hospital and focused on patients in the neurological intensive care unit. In 2005, she received her Bachelor of Science degree in Nursing from California State University, Chico. She is currently a Master’s student at California State University, Chico and has completed coursework that includes nursing research and theory courses.
Transitional Statements

The goal of this project is to provide teaching material with a clear and consistent message from nurses in order to properly inform patients and families about end-of-life care/decisions in an ICU setting. The end-of-life care pamphlet will benefit the nursing staff involved in teaching patients and families because it will streamline basic information about end-of-life care/decisions.

It has been identified that having written educational material for the nursing staff is an effective form of communication and end-of-life care material is necessary to provide a consistent and clear message for families and patients. A literature review will follow in the next chapter and illuminate the need for end-of-life care/decision pamphlet in an urban ICU setting.
CHAPTER II

LITERATURE REVIEW

Introduction

In Chapter I, it was established that the purpose of this project was to design and develop an end-of-life care pamphlet that ICU nurses can use to aid in end-of-life care and decisions for patients and their families. This pamphlet will provide general information about the process of end-of-life care in order to assist patients and families in the decision making process. The material that has been published about end-of-life care/decisions is cumbersome. It is often included with other aging concerns, disease processes, and end-of-life home care. There is not a large amount of literature or information about end-of-life care in the ICU environment.

PubMed and CINAHL were utilized to obtain information for this literature review. Articles and studies from 2005-2009 were utilized for this literature review. Search terms used for this literature review were: end-of-life, EOL in the ICU setting, end-of-life care in the ICU, end-of-life and ICU, palliative care, palliative care and ICU, end-of-life education, end-of-life and families, surrogate decision makers, surrogate decision making, end-of-life care, end-of-life transition, good death and ICU, good death and end-of-life, withdraw of life sustaining therapy, nurses’ perception and end of life care, end-of-life nursing care, quality of life, quality of life and decision making, and end-of-life and decision making.
This literature review provides current information about end-of-life care/decision making for families and patients. The themes identified in the literature that relate to end-of-life care for the ICU setting are: 1) nurses’ perceptions and/or views of gaps in end-of-life care, 2) the decision maker’s process at end-of-life, and 3) the impact of a proactive approach to end-of-life care.

Nurses’ Views and Perceptions of Gaps in End-of-Life Care

One of the most stressful times in the ICU environment for staff members and families has revolved around end-of-life issues. In order to appropriately care for patients who have to make end-of-life decisions, it is critical for nurses to acknowledge their personal views about comfort during the dying process. Nurses would benefit from exploring their own feelings about death, dying, and comfort in order to view dying as a natural process. Having nurses go through this process can help them better to understand the care necessary for a dying patient (American Association of Colleges of Nursing [AACN], 2004).

Badger (2005) studied nurses’ experiences with end-of-life care. This study used a descriptive qualitative research design using observation and focus group interviews. The sample size consisted of 19 female nurses and five male nurses in an 18 bed medical ICU in a 719-bed Rhode Island hospital (Badger). Badger determined nurses had the most distress during end-of-life decisions when families had conflict, when patients were younger with an acute life threatening disease, or when physicians would recommend therapies that would not affect the end result-death. Badger identified that a limitation of this study was that the staff who work in the ICU where the study took place
have worked together for many years and have done extensive research on end-of-life care, which could have affected the results and reactions of the staff members involved in this study.

A grounded theory study completed by Thompson, McClement, and Daeninck (2006) studied nurses (n = 10) in an acute care setting who were attempting to provide high quality end-of-life care to patients while continually multitasking. This study is important to nursing because it accounts for what actually goes on in the acute care setting. Many nurses have more than one patient, taking them away from the dying patient and their families at a time when emotional support is of greatest importance. The participating nurses in this study determined that nurses must be comfortable with themselves about issues of death and dying if they were going to be authentically present to the patients and families going through the end-of-life process (Thompson et al.).

A study done by Beckstrand, Callister, and Kirchhoff (2006) collected suggestions from critical care nurses (n = 861) to improve end-of-life care in the ICU setting. Obtaining information from bedside critical care nurses about their views and suggestions of what barriers currently exist with end-of-life care is relevant to nursing because it provides actual information from the bedside nurse who is caring for end-of-life patients. Barriers consisted of short staffing, time constraints, lack of communication from physicians to family members, and treatment based on physicians’ needs rather than patients’ needs (Beckstrand et al.). The researchers sent out 1,409 questionnaires to members of the American Association of Critical Care Nurses. Over 500 suggestions were offered on how to provide a “good death.” Findings included, “study participants’ emphasis on dying with dignity and not dying alone is a reflection of nurses’ personal
attitudes, fears, experiences, or regrets possibly related to specific care experiences that created moral distress” (Beckstrand et al., p. 43). Specific findings from the Beckstrand et al. study provided the researcher information about nurses’ views and perceptions of what barriers around end-of-life care currently exist. The identified barriers were lack of communication and inadequate communication.

This type of literature provides information that will be helpful in development of an end-of-life pamphlet. Identifying nurses’ views of gaps that currently exist is an important consideration when developing the end-of-life pamphlet. Gaps that currently exist are inadequate communication, lack of communication, nurses being comfortable with themselves about death and dying especially when patients are young, and physician ordered therapies that will not significantly improve the patient’s outcome. The goal is to provide families and patients with a better understanding of the treatment available at end-of-life. Because communication is an important factor in the hospital setting, providing a communication device such as the end-of-life care pamphlet for patients, families, and nurses to utilize can help to close these gaps.

Decision Makers’ Thought Process

A grounded theory study by Limerick (2007) examined the process of those persons who make decisions for people who can no longer speak for themselves; called surrogate decision making. The researcher defined a surrogate decision maker as legally designated or legislatively directed to act for a person incapable of participating in his or her decisions (Limerick, 2007).
Limerick’s (2007) study consisted of a sample size of 17 surrogates, whose loved one had a variety of diagnoses, including cancer. The age of these surrogate participants ranged from 23-82 years. This study is noteworthy to nursing because it determined that there were specific processes surrogates go through when making the decision to turn towards end-of-life care. Findings include rallying family support, evaluating the patient’s condition with the person’s own understanding of the situation, realizing the patient’s past and current quality of life, developing a relationship with hospital/nursing staff members, seeking to obtain information from nurses, and lastly coming to the final decision of end-of-life (Limerick, 2007).

The study revealed that “nurses can and do assist surrogates in making decisions to withhold and withdraw life-sustaining measures” (Limerick, 2007, p. 338). Surrogates told the researcher that they were confused by physicians’ opinions and felt that nurses should make sure they clearly understand the care and the continued treatment versus discontinuation of treatment (Limerick, 2007). These findings highlight that nurses are in a unique position as they are present at the bedside more than physicians. This is an educational opportunity for nurses to make sure families understand exactly what is going on and can be available to answer any questions that may arise.

A phenomenological study by Wiegand (2006) researched families who made the decision to go from life sustaining care to comfort care. This study used interviews and observations of families as they participated in withdrawal of life support of their loved one. The total sample size for this study was 19 families including 56 family members. Specific findings that are relevant to the project of an end-of-life care pamphlet
were that families in this situation most needed information, support, and guidance (Wiegand, 2006).

Vig, Taylor, Starks, Hopley, and Fryer-Edwards (2006) conducted a study to characterize how surrogates plan to make medical decisions for others. This was a descriptive study that employed semi-structured qualitative interviews. The participants were 55 surrogate decision makers of older chronically ill veterans. These participants had previously participated in a randomized controlled trial to promote advanced planning (Vig et al.). Significant findings of this study were that surrogates described five different ways they planned to or made decisions at end-of-life. These five ways were 1) conversations; making decisions based on their knowledge of their loved ones preferences; 2) relying on documents such as an advanced directive; 3) shared experience, making decisions based on a sense of shared values and lived experience with their loved one; 4) surrogates own values and preferences about life; and 5) surrogates network; enlisting the help of others (Vig et al.).

Shalowitz, Garrett-Mayer, and Wendler (2006) completed a systematic literature review to look at the accuracy of surrogate decision makers. The researchers conducted their search using PubMed, the Cochrane Library, and manuscript references. Sixteen studies were found to be eligible. Twelve of the 16 studies assessed the type of error surrogates make when they misjudge patients treatment preferences; of these three were found to have surrogates err by allowing interventions to be performed that the patient would have otherwise not wanted. One of the 12 found that the surrogate withheld interventions the patient would have wanted, and eight had mixed results (Shalowitz et al.). These studies were hypothetical scenarios that were used to determine if patients and
their surrogates would make the same decisions if the patients were incapacitated.

Patients were in one room and the surrogate decision makers were independently asked to predict what choices their loved one would desire. The interventions brought forth were those interventions that were necessary to sustain the patient’s life.

Significant findings by Shalowitz et al. (2006) were:

In an attempt to extend patient autonomy, current practice is to rely on surrogates and to instruct them to attempt to make the decision that the patient would have made if he or she were capacitated. Despite widespread acceptance of this practice, next of kin surrogates failed to predict patient’s end-of-life treatment preferences accurately in one third of all cases. (p. 496)

Vig et al. (2006) also investigated the challenges of decision making from the surrogate’s perspective. Semi structured telephone interviews were analyzed to investigate surrogates’ decision making. Fifty surrogates participated in this study. Significant findings included four factors that hampered the surrogate’s decision making at end-of-life. The four factors were: 1) life circumstances and characteristics, 2) surrogates social network, 3) surrogate-patient relationships and communication, and 4) surrogate-clinician communication and relationships. Vig et al. determined that the burden of decision making is lessened if surrogates are aware of a patient’s preferences either from conversations or advance care directives, and when they receive honest and truthful medical information from healthcare providers. (p. 1278).

Surrogate decision makers are going through a difficult time emotionally during loved ones’ end-of-life process. Providing an end-of-life pamphlet that offers communication will provide for increased support from the healthcare team. Utilizing open communication, patients’ advance care directive, and the offering of information and guidance can help family members at this difficult time. The end-of-life care
pamphlet will address communication from the healthcare side and allow the opportunity for families to ask more questions and to better understand the process of end-of-life care.

Support for End-of-Life Care

A study conducted by Campbell and Guzman (2003) explored the impact of a proactive approach for end-of-life care in patients with multi system organ failure (MOSF) and global cerebral ischemia (GCI). The sample size for this study consisted of 38 patients with GCI and 43 patients with MSOF. This study consisted of two cohorts: a retrospective cohort and a prospective cohort (Campbell & Guzman, 2003). The retrospective cohort was carried out by chart review of patients with GCI after cardiac arrest or the admitting diagnosis of MSOF. The prospective cohort was the same patient population as the retrospective cohort, but patients were also subjected to a proactive palliative care approach (Campbell & Guzman, 2003). A proactive palliative care approach in this study meant the palliative care team searched the medical ICU census daily for patients meeting the study criteria. The palliative care team looked at five inclusion criteria: 1) early involvement of the palliative care team communicating prognostic news to families, 2) assisting in identifying patient’s advance directive or preferences for end-of-life, 3) assisting with discussion of prognosis and treatment options with patients or their surrogates, 4) implementing palliative care strategies when the goal shifted to comfort measures only, and 5) consultation and education to the primary team regarding palliative care strategies (Campbell & Guzman, 2003).

The results of this study determined that a proactive palliative care approach in this ICU decreased the time hopelessly ill patients spent in the ICU before a change in
treatment goals to focus on comfort, compared to the retrospective group (Campbell & Guzman, 2003). In this study, the significant finding of utilizing the palliative care team proactively shifted the goals of life sustaining therapy to comfort earlier in the disease process (Campbell & Guzman, 2003).

An investigation conducted by Hansen, Goodell, DeHaven, and Smith (2009) determined that nurses lacked knowledge, skills, and support to provide patients and families end-of-life care. The purpose of this study was to discover ICU nurses’ perceptions of knowledge and ability, work environment, support for staff, and stress related to specific work situations regarding end-of-life care (Hansen et al.). “The researchers suspected that caring for dying patients without sufficient education, adequate practice environment, or emotional and instrumental support could influence critical care nurses’ experiences in providing end-of-life care” (Hansen et al., p. 265).

The Hansen et al. (2009) study took place in four ICUs at a university medical center using an investigator-designed tool with a Likert scale. The study was conducted in two phases, therefore there were two separate sample sizes used for this study. Phase One consisted of 91 participants and Phase Two had 127 participants. Findings included that ongoing education and support for nurses was necessary to improve nurses’ perceptions and increase the quality of end-of-life care. Nurses with greater ICU experience and increased communication provided exceptional end-of-life care in the ICU environment.

Nurses being patient advocates ensure patients have appropriate treatments and medications. Advocating for safe and appropriate treatment and medications can lead to patient safety and comfort. Nurses are trained to observe the patient’s environment and
assess for comfort needs. This observation is especially true during end-of-life care.

“Nursing professionals are in key positions to support end-of-life decisions and to advocate for patients and families across all healthcare settings” (Thacker, 2008, p. 174).

Thacker (2008) studied nurse advocacy and support for end-of-life patients. Death and dying is part of core curricula in many nursing programs, however, according to Thacker (2008), end-of-life teachings are only often touched upon. This study researched nurses’ advocacy techniques and support of end-of-life decisions for nursing.

The Thacker (2008) study identified that support systems for nurses throughout end-of-life care consisted of nurse educators, nurse managers, and coworkers. A critical finding was that advocacy was paramount in end-of-life care. Identification of support systems can help support nurses’ advocacy skills during this stressful time. Often in an ICU setting once a patient has transitioned to end-of-life care, their priority level for the physician may become lower. Thacker (2008) identified that having nurses as an advocate can improve end-of-life care.

A study by Mosenthal et al. (2008) researched changing the culture around end-of-life care in a trauma ICU. The researchers hypothesized that early, structured communication in the trauma ICU would improve end-of-life care practice (Mosenthal et al., 2008). This study was a prospective, observational study on trauma patients admitted to the ICU. Data for this study were collected for two years. There were 286 admissions in the first year (baseline year) and 367 admissions in the intervention year (second year). Of these patients admitted 306 patients (83%) had complete intervention, the other 61 (17%) patients either died before completion, had late intervention due to visitor restriction or paperwork submitted late, or patients were discharged home. Mosenthal et
al. (2008) findings determined that early communication with healthcare team members, psychological support and family participation increased the discussion about goals, which sequentially leads to timely end-of-life decisions and decreased pre-terminal ICU days for dying patients.

The literature suggests that providing the healthcare team with a supportive end-of-life environment can increase communication from nurses to patients and families. The increased communication and supportive environment can help to decrease the patient’s ICU stay and decrease unnecessary procedures or tests for patients who will not benefit from aggressive life saving therapies.

Transitional Statements

The research articles reviewed provide a foundation for the need of an end-of-life care/decision pamphlet. This pamphlet will provide family and patients with information regarding end-of-life care. The gaps found in the literature review included inadequate communication, a need for sensitivity toward surrogate decision makers, a lack (from nurses) of recognizing own beliefs about death and dying, and the need for providing a supportive environment for nursing staff at end-of-life. No pamphlet was found in the literature that provided patients and families with communication and information about the end-of-life care/decision gaps.

Evidence-based research on palliative care and the information family desire during end-of-life care brought this pamphlet to fruition. Time is often a necessary factor when families are making the decision to go from aggressive life saving therapy to end-of-life care. Time allows families to begin to come to terms that recovery is not possible
for their loved one. Providing families with the knowledge that the healthcare team is available and will support their decision is comforting to many families. The proposed end-of-life care pamphlet will offer information to support families during this difficult time. The following chapter will address the steps to be taken in order to complete this project and include an analysis of this project.
CHAPTER III

METHODOLOGY

Introduction

The purpose of this project was to design and develop an end-of-life care pamphlet that ICU nurses could use to aid in end-of-life care/decisions for patients and families. This pamphlet provides information about end-of-life care in order to assist nurses when teaching patients and families about the decision making process. Nurses can utilize this pamphlet to streamline end-of-life care education.

Having a pamphlet allows families and patients to take away tangible educational material from the bedside for future reference. Providing an end-of-life pamphlet to the nursing staff allows the subject of end-of-life care and decisions to be approached slowly and with ease. A benefit of developing the end-of-life pamphlet is that it will bring evidence-based educational material from nurses to patients and families during their stressful time in ICU.

Project Design

Patient education is a key component for any given treatment or therapy in a hospital setting. End-of-life situations are no different when it comes to informing and educating patients and family members. As with any event, having a team of people
approach families or patients regarding end-of-life care without prior discussion from the primary bedside nurse or physician, can be intimidating and perceived as bombarding.

The purpose of this project was to develop an end-of-life care/decision pamphlet with input from the literature and nurses working in an ICU. After the pamphlet was developed nurse feedback was sought and revisions were made as necessary. The final version of the pamphlet was given back to the nurses for final feedback prior to concluding pamphlet development.

Theoretical/Philosophical Underpinning
Informing the Methodology

The theoretical underpinning of the pamphlet was the framework of Cornelia Ruland and Shirley Moore’s The Peaceful End of Life Theory (Ruland & Moore, 1998). This theory is a family structured system. Ruland and Moore stated “the main focus for standard development was not on the final instance of dying itself, but on contributing to peaceful and meaningful living in the time that remained for the patients and their significant others” (p. 171). Five outcome indicators were derived from The Peace End of Life Theory “not being in pain, experience of comfort, experience of dignity/respect, being at peace, and closeness to significant others/persons who care” (Ruland & Moore, p. 172). These five indicators were used (along with input from nurses and the literature) to develop the end-of-life pamphlet for the ICU.

Population/Sampling

Sampling is defined as “involving a selected group of people, events, behaviors, or other elements with which to conduct a study” (Burns & Grove, 2005, p.
The project director recruited ICU nurses as the sample that provided actual data. Inclusion criterion to be a subject in this project was nurses who were currently employed at the facility in which the project took place. The demographic data form for nurses included age, gender, years of service in nursing, years in ICU, experience with end-of-life care, and level of education (Appendix A). Demographics were used to describe sample characteristics. The sampling technique used was nonprobability. This type of sampling method requires that not every person has the opportunity to be included in the study (Burns & Grove, 2005). This project applied a convenience (accidental) sampling method. Convenience (accidental) sampling is defined by Burns and Grove (2005) as “subjects included in the study because they happened to be in the right place at the right time” (p. 350). The rationale for using convenience (accidental) sampling was that it was inexpensive, accessible, and that it supported the purpose of this project. The population of a study includes all the elements that meet a certain criteria (Burns & Grove, 2005). The population of this project was nurses who worked in a small northern California ICU.

The project director sought input from nurses in order to obtain the information about end-of-life needs of patients in the ICU setting. The director then used this information plus the Peaceful End of Life Theory and the literature to develop the pamphlet. Once a draft pamphlet was developed, the project director went back to the ICU nurses and asked nurses for their feedback on the developed pamphlet. The end-of-life care pamphlet was created based on current evidence-based research and utilized information gained from the sample of nurses so the pamphlet is both relevant and reflects an ICU environment.
Demographic Data

From the demographic data obtained, all participants \((n=5)\) were between the ages of 36-65. All participants were female. One participant had less than one year of nursing experience, two participants had 6-10 years nursing experience, and two participants had 20 or more years of nursing experience. All participants with the exception of one nurse had experience with end-of-life care. One participant had between 7 months and 1 year ICU experience, two had between 6-10 years experience, one had 11-15 years, and one had more than 20 years experience. Ten percent of the participants had a master’s degree; ninety percent had an Associate Degree in Nursing.

Ethical Considerations-Human Subjects’ Protection

According to the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, “on July 12, 1974, the National Research Act (Pub. L. 93-348) was signed into law thereby establishing a National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research” (1979, Summary, para. 1). This institution identified three basic ethical principles in regards to human subjects involved in research studies. These ethical principles are respect for persons, beneficence, and justice.

- Respect for persons incorporates at least two ethical convictions: first, individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, B. Basic Ethical Principles, para. 2)

- The Belmont Report states two rules of beneficent actions: “do not harm and maximize possible benefits and minimize possible harms” (National Commission for the
Protection of Human Subjects of Biomedical and Behavioral Research, 1979, B. Basic Ethical Principles, para. 7). Do no harm is just as it states, do not allow harm or injury to participants. Minimize possible harm is accomplished by recognizing what is harmful (National Institutes of Health, 1979).

☐ Justice is defined as treating each study subject equally regardless of ethnicity, age, or financial status (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

Burns and Grove (2005) stated, human rights that require protection in research are (1) the right to self-determination, (2) the right to privacy, (3) the right to anonymity and confidentiality, (4) the right to fair treatment, and (5) the right to protection from discomfort and harm. (p. 181)

All the above stated human rights were protected in the development and evaluation of the pamphlet.

The project director maintained the privacy, anonymity, and confidentiality of all participants by not revealing their identity and not sharing any specific information obtained by the participants. All participant identification was coded and is kept in a locked file cabinet. The project director was the only person that had access to this information. Each participant was treated fairly and equally. All participants were asked the same questions for consistency. The plan to protect against discomfort and harm was revealed to each participant at the presentation of the project. The potential for discomfort during this project was the potential of psychological discomfort when discussing end-of-life care. The process that was set up if participant’s experienced this, was to have
participants immediately stop filling out the questionnaire, however this was not needed for this project.

Human rights are defined as claims and demands that have been justified in the eyes of an individual or by the consensus of a group of individuals (Burns & Grove, 2005). First and foremost the most important aspect to human rights is protection from discomfort and harm. This project did not place any participant at risk for injury or harm. All participants volunteered for this project and had the ability to withdraw at any given time without any ramifications.

Privacy is defined as the right an individual has to determine the time, extent, and general circumstances under which personal information will be shared with or withheld from others (Burns & Grove, 2005). Privacy of the participants was maintained throughout this project by storing all information in a locked cabinet, where the key was kept only by the project developer. No information was shared from nurse to nurse. All comments and information provided by the participants has been kept confidential. Researchers have the responsibility to protect the anonymity of subjects and to maintain the confidentiality of data collected during a study (Burns & Grove, 2005).

Specific Method for Data Collection

The plan for data collection was to develop an end-of-life care pamphlet for the ICU environment once a consent form was given to nurses who volunteered to participate in this project (Appendix B). Once a nurse participant agreed to participate in the project a standardized questionnaire (Appendix C) was used and included the following questions: 1) what type of information would you like to see in an end-of-life
pamphlet that is not currently available to nurses? 2) What important end-of-life care information is lacking for patients and families in the ICU? Please describe this information in detail. 3) Do you feel comfortable discussing end-of-life care with patients and families in the ICU setting? If yes, please describe the type of information you provide/discuss. If no, please describe the type of information you think should be discussed. 4) Describe how would a pamphlet about this topic help you to educate patients/families about end-of-life care in the ICU? How would it be useful to you in your nursing role as a patient and family educator?

Each questionnaire contained ample room for responses. Writing utensils were provided by the project director, to encourage it to be done at the time of presentation to participants. The participants placed their completed questionnaires in a box at the nurse’s station. The researcher continued to visit the facility until the minimum sample size was obtained.

Once information from the sample group was collected and reviewed, it was analyzed with information from the literature and theory and a draft pamphlet was developed. After the pamphlet was developed, it was returned to the nurses for member checking to determine if their ideas and information were contained within the pamphlet.

Data Collection Procedure

Initial information was obtained from nurses before development of the pamphlet. The pamphlet was then developed utilizing this information, current evidence-based and theoretical information. Nurses had the opportunity to participate in this project once a small presentation about the project was given at a staff meeting at the
facility. A script was used for the project director when speaking to nurses about this project (Appendix D). Nurses from each shift were given the opportunity to participate. Participation in this project included answering specific questions about end-of-life care. During the presentation the project director reviewed the consent, the questions and instructions for how to complete the questionnaire. There was a question about the purpose of this project from one of the nurses via email. The project director responded via email and provided the purpose of this project; however, that particular nurse chose to not participate in the project.

Once the pamphlet was developed it was returned to nurses and they were instructed to write on the pamphlet if they believed there was some information that was important and was not included. This was done for accuracy and final comments. After the member checking phase with nurses was concluded, the pamphlet was finalized (Appendix E).

Data Analysis

Data from participants were collected and common thematic areas were determined. These themes were used along with the evidence obtained from the literature to design and develop the pamphlet. The data analysis plan for this project was to look at each of the questions asked to the nurses. Significant words and/or statements were extracted and grouping of similar ideas were identified (Burns & Grove, 2005). These grouping were labeled as abstract themes. The themes were used with the previously identified themes of the literature and theoretical framework of The Peaceful End-of-Life theory to develop the pamphlet.
Face and Content Validity

This project addressed face and content validity. Face validity is defined as “a type of validity that basically verifies if the instrument gives the appearance of measuring the concept” (LoBiondo-Wood & Haber, 2002, p. 315). Content validity is defined as “the degree to which the content of the measure represents the universe of content or the domain of a given behavior” (LoBiondo-Woods & Haber, 2002, p. 490). “Validity addresses the appropriateness, meaningfulness, and usefulness of the specific inferences made from instrument scores” (Burns & Grove, 2005, p. 376). Member checking in this project was completed by taking the pamphlet back to the participants to see if what they said was represented. This member checking provided content and face validity.

Due to the small size of the ICU (number of beds), five nurses compromised the sample group for this project. The ICU nursing staff were the expert panel of this project. The expert panel provided feedback on the developed pamphlet for content, readability, and usability.

Transitional Statements

The pamphlet utilized the Peaceful End of Life Theory by Ruland and Moore (1998) and information from nurses and the literature. The pamphlet was then developed and given to nurses in one small northern California ICU. The pamphlet was checked by these nurses and revisions were made as needed. Once revisions took place, the pamphlet was in its complete form. The finality of the analysis process was to seek relevance to the importance of this tool for utilization in the educational process for nurses when educating patients and families with end-of-life issues. The pamphlet may become part of
the facility’s end-of-life education booklet, which is readily available to ICU nurses.

Chapter IV will provide the findings from the survey.
CHAPTER IV

RESULTS

Introduction

A questionnaire was developed containing four questions and a demographic data section. Five (5) registered nurses, working in an Intensive Care unit answered these questions. Input was sought from participating nurses in order to obtain information about end-of-life needs of patients in the ICU setting. The purpose of this project was to develop an end-of-life pamphlet to be utilized for nurses to educate patients about end-of-life care/decisions. The results of the questionnaire will be discussed in this chapter. The idea behind development of an end-of-life pamphlet was to discover common themes and ideas between patient education and nurse teachings. A combination of the data from the questionnaires, the previous literature search, and the five key points of the Peaceful End-of-Life Theory were used to develop the final pamphlet. The final themes that emerged from the data are presented here.

Not Being in Pain

All nurses in this study placed pain as a priority during end-of-life care. Teaching families about what the patient may or may not experience during the dying process and helping provide comfort and a pain free experience were also important. Nurses felt it was important to provide information about physical changes that may
occur, information about which pain medications may be utilized, and that it may require a large amount of pain medication to make their loved one comfortable. Nurse survey data includes; “it would be nice to have information about which drugs may be utilized for pain during the dying process and notify the families that the patient may need a large amount of pain meds to be comfortable.” One nurse stated “to keep the patients comfortable and pain free” and another nurse stated “types of pain control.” The data suggests that nurses determine pain control as a key factor during the dying process.

Experience of Comfort

The experience of comfort was also identified as a key component during the dying process, suggesting that a calm environment is necessary during the dying process. This calming experience is for both patients and family members. Nurses wrote about making sure that families were aware that it is okay to touch and talk to their loved one during the dying process. “Providing a calm environment during the dying process for the family and the patient, provide information that it is okay to touch and talk to their loved one” was a common response by nurses. Nurses in this study had a variety of suggestions about what comfort may mean to each patient and family member such as bringing in a family pet or the patient’s favorite music. Another nurse suggested “ways to provide ambiance in ICU” to provide comfort. The data supports that nurses feel strongly about the need for maintaining patient comfort during the dying process.

Providing Written Information

The data suggested that having written information for families to take with them would greatly benefit end-of-life education for their patient population because this
currently does not exist. A nurse stated “A booklet or teaching tool for the families would be helpful,” while another nurse suggested “information to take away from the ICU & read at home or somewhere at a later time, the hospital is a stressful place and at times take home material is helpful so they can read when they are ready.” Also mentioned was “something for patients/families to take home about end-of-life.” Currently in this facility there is no standard education about the dying process or end-of-life care. Providing this type of information will be beneficial to both the nurses and the patients. Another nurse stated “it would help to bring up questions from families and patients and foster conversation about some hard to discuss topics. Would make them feel normal for their questions and feelings.” These nurses highlight the importance of written information for patients and their families.

Closeness to Significant Other/Persons Who Care

Providing family members with the knowledge that they can be present and close to their family member during the dying process was suggested by nurses throughout the data collection. Nurses suggest that unlimited visiting hours be utilized. A nurse stated “allowing visitors at anytime and allowing families to be present throughout the dying process is important.” Another nurse also mentioned “it is OK to touch your family and let them know you are nearby during this time and it is OK that they die.” Data showed that offering physical comforts such as touch was an important component to end-of-life care and the dying process.
Advance Directives and Making Dying Wishes Known

Data from the nurses showed having clear written documentation about what therapies they would want if they were dying would help healthcare team members, family members, and decision makers during end-of-life care. Nurses suggested “wishes or expectations” by patients would be beneficial. Another nurse stated “end-of-life planning and making their wishes known after their death” is critical to sensitive end-of-life care. Data suggests providing this information would greatly help to ease family members or loved ones during the dying process.

Definition of Terms

Data showed that providing the definition of terms such as DNR and comfort care would give families and patient’s guidance and standardized definitions. A nurse stated “they hear very little after the doctor talks to them, maybe a handout of options and definitions of words the doctors used and definitions of Advance life support techniques.” Another nurse stated “definitions of “common” terms in the ICU & the definition of DNR, not to mean do nothing.” Nurses suggest that with this consistency patient’s and family members will be well informed, potentially making it easier for decisions to be made. Nurses felt strongly that identifying terms used during the dying process would be beneficial.

Community Resources

Data showed that providing community resources would be beneficial to the patients and family members. Nurses stated “[specific county stated] resources (e.g.,
mortuaries, bereavement support, and hospice) and utilization of hospice.” Another nurse stated “utilizing hospital resources such as a Chaplin or social worker.” Nurses suggest strongly that the use of these types of resources would greatly benefit patients and families in preparation of death.

Additional Findings

Other statements emerged from the survey but were not included in the thematic discussion of this chapter because there was not consistency or enough information to validate that they represented an important or critical topic. Examples included; “directions on how to fill out their wishes before death,” “a bilingual pamphlet in Chinese or Spanish.” Additionally one nurse suggested “an in-service on how to use the pamphlet once it has be developed and approved for use in the ICU.” All three of these finding did not have enough substance to constitute a thematic area.

Transitional Statements

There were several key thematic areas from the data about end-of-life care for the ICU patients. They include not being in pain, experience of comfort, providing written information, closeness to significant others or persons who care, advance directives and making wishes known, definition of terms, and community resources. Chapter V will discuss the findings in general and how information was or was not determined for placement into the pamphlet.
CHAPTER V

DISCUSSION

Introduction

Nurses in a small rural hospital were surveyed about suggestions for an end-of-life pamphlet. Data were reviewed, a pamphlet was developed, it was then returned to the nurse participants for evaluation and corrections were made as suggested. The end-of-life pamphlet was developed based on data obtained by nurses, the Peaceful End of Life Theory, and current literature. The purpose of the pamphlet is that it be used as an educational and teaching aid for end-of-life discussion with patients and families. The intended accomplishment of this project is to provide the nursing staff with end-of-life care/decision educational material that has a consistent and clear message. The final themes that emerged from the data were; not being in pain, experience of comfort, providing written information, closeness to significant others/persons who care, advance directives and making dying wishes known, definition of terms, and community resources. The five key components of the Peaceful End-of-Life Theory by Ruland and Moore (1998) were used for pamphlet development. These five components are not being in pain, experience of comfort, dignity/respect, being at peace and closeness to significant others/persons who care.
Discussion and Reflection on the Findings

The information that emerged from the nurse survey was a key component in the development of the pamphlet. Not being in pain was a main concept of all the nurses participating in this survey, which also parallels Ruland and Moore’s Peaceful End of Life Theory. Pain is defined by Ruland and Moore (1998) as simply not experiencing any pain. This information was included in the pamphlet because it is an important component of the dying process. Patients do not want to experience pain and family members do not want to watch their loved one in pain. Information on what types of medication are used and the possibility that the patient may require a large amount of this medication is a key aspect of not being in pain.

Providing information about possible physical changes that may occur during the dying process opens communication with the healthcare team. Types of medication and physical changes were utilized in the pamphlet because these changes are visual and families who have not seen another person die need to know that these changes are normal during the dying process.

Experience of comfort is a component of the Peaceful End of Life Theory. The experience of comfort is identified as the patient not experiencing nausea, thirst, and as experiencing a pleasant environment and optimal comfort (Ruland & Moore, 1998). Allowing families to touch their loved one can create a comfortable and peaceful experience for the family and patient. This information was included in the pamphlet because it is important for the patient to feel their family presence and it is important for families to realize they can offer the comfort of touch during the dying process. The category of closeness to significant others/persons who care was incorporated with the
experience of comfort because upon evaluation of the data it intertwined the two concepts. “Closeness of patients to their significant other or family and friends who care are participating in care of the dying patient, can say farewell in compliance with their religious or cultural beliefs” (Ruland & Moore, 1998, p. 173). Providing ambiance in the ICU emerged from the data suggesting the use of candles, visitation at any time, and music. This was not used in the pamphlet because this may not be in compliance with the hospital’s policy and procedures. The project developer decided if the hospital wanted to make this part of their end-of-life practice; it can be done without the use of this pamphlet.

Providing written information was evident in all nurse surveys. Currently this facility does not offer any end-of-life pamphlet for their patients or family members. It was determined from the data that all nurses felt any information about end-of-life would be beneficial. Informational pamphlets provide patients and family members with a tangible item, which they can refer to at any time, and can augment any verbal information received (Paul et al., 2004). This was critical to pamphlet development, which is why the design of the pamphlet includes a frequently asked question section.

Advance directives and making wishes known emerged from the survey results. An advanced directive is a living will and/or Durable Power of Attorney for Health Care (DPAHC). Gupta et al. (2005) defined the living will as a document in which the patient, in the event that he or she becomes terminally ill, directs the physicians to withhold or withdraw life-sustaining treatment. The advance directive has a previously appointed agent. This was not utilized in the pamphlet because once a patient has been placed on comfort care or the family had made the decision to withdraw life support, it is
often not a time the patient can fill out his or her advance directive. Providing an advance
directive or a written statement about dying wishes is something that often needs to be
done before coming to the hospital. Some hospitals can facilitate an advance directive
being completed during their hospital stay, however this takes planning. The subject of
advance directive was not included a part of the pamphlet because this is something that
should be done before admission or before a person becomes so sick they are not
coherent enough to fill out paperwork or appoint a spokesperson. Some facilities offer
classes to the community and this is a suggestion for future classes but is not pertinent for
this pamphlet.

Definition of terms was utilized for the pamphlet. Beckstrand et al. (2006)
determined that barriers that exist around end-of-life care are lack of communication and
inadequate communication. It was determined that having definition of terms would be
beneficial to patients and family members because this will open the lines of
communication between the healthcare team and family members. The data received
from nurses emphasized the importance and need for defining terms surrounding end-of-
life care. It was decided that defining the terms comfort care, palliative care, and end-of-
life care were key terms used as medical jargon throughout the dying process. Including
these three terms was important because there are significant differences among all three.
Depending on the situation and time one may be chosen over the other.

Resource availability was suggested by the nurses, therefore it was included in
the pamphlet. The resources chosen for the pamphlet were internet resources. These were
chosen because they are accessible through the facility’s library via the internet or any
other internet connection. Often families or patients look towards the internet for more
information about the diseases or therapies. Having a list of websites the patients or families can look at for other support or guidance is helpful because they will not have to search for resources, they can go to these sites and obtain information or ask questions and get some answers and the sites given are reputable. Patients and families can use key terms such as comfort care as a search term in order to look information up on the internet.

The experience of dignity/respect means that the patient and family members participate in decision making, and are treated with dignity and respect by hospital personnel (Ruland & Moore, 1998). A study by Limerick (2007) looked at the process of decision makers during the end-of-life decisions and deemed that family support, patient’s past and current quality of life, and relationships developed with staff members and information obtained from nurses were key factors in end-of-life decision making. Respecting all patients and their loved ones throughout the hospital stay is a key component during the dying process because this allows for family members to gain trust in the healthcare team.

Being at peace is a standard where the patient and significant others maintain hope and meaningfulness, the patient does not die alone, and the patient is at peace (Ruland & Moore, 1998). Providing information about the patient’s illness, options, and therapies that have been completed or previously attempted with failure are important for families to be aware of during the decision making process of end-of-life care. If able, having patients understand their disease and the imminent outcome of death is best but when this is not possible, it is important to have the family at peace with their decision. Utilization of music, candles (if permitted), pictures, pets, and family presence are some
ways nurses in the survey suggested that might create a peaceful environment for the patient. These were not used for pamphlet development because of restrictions of electronic devices and open flames in most hospital environments.

Limerick (2007) examined the process of persons who make decisions for people who can no longer speak for themselves, and found that rallying family support aids in the decision making process. “Closeness of patients to their significant other or family and friends who care are participating in care of the dying patient, can say farewell in compliance with their religious or cultural beliefs” (Ruland & Moore, 1998, p. 173). This was used in the pamphlet by commenting on family closeness, expressions of touch being okay, and talking to the patient during the dying process.

Limitations of the Study

The limitations of this study were the sample size was small, patient and/or family members were not used for this study, and the facility size was small. After multiple attempts and months trying to obtain participants for this study only five (5) nurses volunteered to participate. One nurse had questions that were answered via email but this nurse did not participate. After multiple attempts to advocate for patient and family participants in two separate facilities, the project director was denied the ability to utilize patients and family members for this study. Approval was given by the thesis team for only staff nurses employed and currently working in the ICU to be included as the only participants in the development of the pamphlet.
Implications for Practice

Implications for practice include giving the pamphlet to the facility where the study took place. The facility is responsible for approval of the pamphlet and any changes they wish to make to contour the pamphlet to their specific policies. It is suggested that an in-service about the pamphlet as well as end-of-life education be offered to the nurses before implementation of the pamphlet. The usefulness of this pamphlet in any ICU would greatly benefit patients because it will give patients some information to review and begin conversations about end-of-life care/decisions. This pamphlet will also benefit the nurses because it will give them some guidance and standardization on specific common issues or concerns that come up during the dying process.

Implications for Research

Suggestions for future research include involvement of actual patients and family members who are currently admitted to the intensive care unit. Patient and family contact was not approved at this facility for the project developer. Obtaining actual information from current and past patients and families would greatly benefit this type of pamphlet because as time goes by hospital staff and personnel become immune to the intimidating environment of the hospital. Involving patients and families in the future for the refinement of a pamphlet could help to make a better pamphlet because it will give nurses a realistic perspective in the eyes of the patient/family. Including patients and families in the information gathering will provide a strong backbone for the pamphlet and will allow more specificity in relation to the ICU.
Implications for Education

As mentioned above, an in-service about the pamphlet would benefit the nurses and allow for more dialogue about end-of-life care. It was recommended by a nurse that an in-service about the pamphlet be given to the nurses. A class on end-of-life care and the ICU setting would be of interest to this group of nurses who volunteered to participate in this study. Having this pamphlet available for all patients and family members may create conversations earlier in the hospital stay between patients and their families, which can in turn promote advance directives or a conversation about dying wishes so that patients can spend less time receiving treatments or therapies they did not want or that were futile. It is recommended that end-of-life education be broadened in nursing schools to give both undergraduate students and new nurses a better understanding about the concepts around end-of-life care and the dying process.

Summary, Conclusions, and Recommendations

Findings included the need for an informational pamphlet about end-of-life care/decisions for patients admitted to the ICU. Specific findings included; not being in pain, experience of comfort, advance directives and making dying wishes known, definition of terms, and community resources. A conclusion that was derived from this project is that patients currently are not given any written information about end-of-life care/decisions. Half of the nurses who participated felt uncomfortable talking with patients and families about end-of-life care/decisions leading to the recommendation that end-of-life care education be further introduced and education to nurses about end-of-life be offered. This will allow for nurses to become more comfortable educating patients and
their families about this subject. Another recommendation is to educate the patients and families in the community of the hospital about advance directives and the benefit to having this done before any admission to the hospital. It is also recommended that persons make their dying wishes, treatment, and therapies known to their loved ones or someone designated to make decisions when they can no longer make them. It is recommended that this pamphlet be used to create education for patients and families to communicate dying wishes.
REFERENCES
REFERENCES


Name: ______________________________

☐ Age: ___ 18-25 years of age
     ___ 26-35 years of age
     ___ 36-50 years of age
     ___ 51-65 years of age
     ___ 66+ years of age
     ___ Decline to state

☐ Gender: ___ Male   ___ Female

☐ Years of Service in the nursing field:
     ___ Less than 1 year
     ___ 1-5 years
     ___ 6-10 years
     ___ 11-15 years
     ___ 15-20 years
     ___ 20+ years

☐ Do you have experience with end-of-life care? ___ Yes   ___ No

     If yes, how many years? ____________
☐ How many years have you worked in an ICU setting?
   ___ Less than 6 months
   ___ 7 months-1 year
   ___ 1-5 years
   ___ 6-10 years
   ___ 11-15 years
   ___ 15-20 years
   ___ 20+ years

☐ What is your level of nursing education?
   ___ RN Diploma Program
   ___ Associate Degree in Nursing
   ___ Bachelor’s Degree in Nursing
   ___ Bachelor’s Degree in other field
   ___ Master’s Degree in Nursing
   ___ Master’s Degree in other field
   ___ Doctoral Degree in Nursing
APPENDIX B
CONSENT TO SERVE AS A NURSE
PARTICIPANT IN A RESEARCH
PROJECT

Project title: End-of-life care/decision pamphlet for the Intensive Care Unit

Project Director: Jennifer Murrish, RN, BSN

Dear Nurse,

Jennifer Murrish is a registered nurse who is performing a research project as a component of a Master’s degree in Nursing at California State University, Chico. She is interested in improving end-of-life education for nurses and patients and/or families in the Intensive Care Unit (ICU). The purpose of this project is to design and develop an end-of-life care pamphlet that ICU nurses can use to aid in end-of-life care/discussions and decisions for patients and families. This pamphlet would provide general information about the process of end-of-life care in order to assist patients and families in the decision making process. You are being asked to participate in this project conducted at Palm Drive Hospital in Sebastopol, CA, because you work in the ICU where the project is taking place.

The project director believes there are minimal discomforts and/or risks of this project. Some nurses may experience psychological discomfort when discussing end-of-life, if this occurs, the project director will ask you to stop filling out the questionnaire. The project director will not place any participant at risk for injury or harm. Participating in this project may be of no direct benefit to you. It is believed however, that the developed pamphlet will be useful when nurses educate patients and families about end-of-life issues. Your participation in this research project is entirely voluntary. Not participating will not result in any penalty or affect your employment. You have the right to withdraw at any time and any data collected will be destroyed. There is no cost to participate in this project. There is no monetary value or reward for participation.

Your name will not be included or appear on any of the documents included in this project. This consent form will not be kept with any other data that pertains to the project. All comments and information provided by the participants will be kept confidential. The project has been approved by CSU, Chico’s Human Subject in Research Committee (HSRC) and Palm Drive Hospital. The project director will have access to this data. All data will be collected by Jennifer Murrish, stored in a secured locked file in her office. All data records will be destroyed five (5) years after the completion of this project. If you have questions about your rights as a participant you can contact the HSRC at CSU, Chico at (530) 898-4677.
The procedures include: answering a short questionnaire about end-of-life care in the ICU environment and completing a demographic data record. Once the pamphlet is completed and revisions have been made as needed, the pamphlet will be redistributed to the participating nursing staff for accuracy and final comments. Initial participation in this study will take approximately 15 minutes to complete the questionnaire. You will be asked to look at the developed pamphlet twice to determine if you feel it reflects your comments/ideas. The timeframe for this extra participation should be less than an hour. For further information about the nature of this project, questions or concerns, please feel free to contact Jennifer Murrish at (707) 481-4746.

By signing this consent form you agree to participate in this project.

Participant’s signature

Date

I have explained to you in detail the purpose, procedures used, potential discomforts, risks and benefits of your participation.

Project Director’s Signature

Date
QUESTIONNAIRE FOR NURSES
PARTICIPATING IN THE END-OF-LIFE PAMPHLET DEVELOPMENT

1. What type of information would you like to see in an end-of-life pamphlet that is not currently available to nurses?

2. What important end-of-life care information is lacking for patients and families in the ICU? Please describe this information in detail.

3. How comfortable do you feel discussing end-of-life care with patients and families in the ICU setting? Please describe the type of information you think should be discussed.

4. Describe how would a pamphlet about this topic help you to educate patients/families about end-of-life care in the ICU? How would it be useful to you in your nursing role as a patient and family educator?
APPENDIX D
Hello, my name is Jennifer Murrish. I am a registered nurse working in a local ICU. I have nine years of experience as a bedside nurse; the past eight have been in ICU. I am enrolled in CSU, Chico’s Master’s in nursing program. As part of my master’s project I am developing an end-of-life care/decision pamphlet that nurses can use for patient education in the ICU. I will be obtaining patient/family information about end-of-life care/decision as well as nurse information. This pamphlet is going to be specific to the ICU. I will use both patient/family comments and nurse’s comments and current evidence-based literature to develop the pamphlet. I would appreciate your participation in this project. There is a required consent form to sign and in order to participate I will have you complete first. I also have a short questionnaire about end-of-life issues that I would like you to complete. After I design and develop a draft pamphlet I will bring it back to participating nurses for feedback. Following those revisions I will ask for one final viewing of the pamphlet after it is completed to see if you think it reflects your comments and current issues in end-of-life education. Thank you for considering participation in my project.
END-OF-LIFE CARE AND THE ICU

An Informational Booklet

By Jennifer Murrish, RN
MSN student, CSU, Chico
Master’s Project

GENERAL INFORMATION

This is a very difficult time whether your loved one has been sick for many years or if the current hospitalization was brought on suddenly. During this challenging emotional time for you and your loved ones, the nurses would like you to know that we are here to help you and provide comfort to you, your loved one, family and friends.

This information pamphlet provides answers to some frequently asked questions and general information about End-of-Life care associated with patients in the Intensive Care Unit. This pamphlet serves as an informational guide and is not intended to provide a medical treatment plan or determine care for your loved one. Each patient is different, therefore, some therapies may or may not be used during the End-of-Life process. The purpose of this pamphlet is to help patients and family members better understand the End-of-Life process while in the intensive care unit setting.

There are several key points that nurses believe are important for peaceful End-of-Life care. These are:

1. Not being in pain
2. Experience of comfort
3. Dignity/respect
4. Being at peace
5. Closeness to significant others/persons who care

If you have any concerns about your loved one and these key points, please talk to the nurse about your concerns. Remember that each member of your loved one’s healthcare team is available to answer any questions or concerns you may have. It is OK to ask questions.
Frequently Asked Questions (FAQ)

What is comfort care/palliative care/End-of-life Care?
Comfort care is care that is given to improve the quality of life for persons who have a serious or life threatening illness. Palliative care is the medical specialty focused on relief of the pain, stress and other debilitating symptoms of serious illness. End-of-Life care means forgoing life sustaining treatments and/or therapies. The focus of End-of-Life care is to provide comfort to patients and control pain in an environment that represents dignity and respect.

What can I expect for my loved one during end-of-life care while in the ICU? If your loved one has a breathing tube this is often taken out by the respiratory therapist or nurse. This can cause some discomforting noises and is usually done without family or friends present. Turning every 2 hours or more frequently may be done to promote comfort. Suctioning inside the mouth may be done for comfort. Fluids can be administered by an IV fluid bag, but nutrition is not usually administered. Urinary catheters are often left in the patient’s bladder as a comfort measure. IV lines may or may not be taken out.

What types of medications can be used? Medications may be ordered depending on your loved one’s illness. A few commonly used medications are Morphine for pain & comfort and Ativan for anxiety or restlessness, and Scopolamine patch or drops for secretion control. Oxygen may or may not be used. If you think your loved one is in pain or uncomfortable, be sure to ask the nurse for additional medication.

How long will it take for my loved one to die once end-of-life or comfort care has begun? This question is difficult to answer. We cannot determine when a patient is going to die. It can be minutes, hours, or in some cases days. The most important thing to remember is that comfort and pain management are the priority. We want to keep your loved one comfortable and pain free during their last few minutes, hours, or days.
FAQ CONTINUED & RESOURCES

Is it OK for me to touch or hold my loved one's hand? Can I talk to them? Yes, having you close to your loved one while dying can help with your grieving and give comfort knowing you are there. It is OK to talk to them, they may not answer or show signs of understanding your words but letting them know you are near can be comforting. It is important to promote a peaceful and calm environment during end-of-life care. Providing a peaceful & calm environment is encouraged.

On line information resources:
www.caringinfo.org
www.getpalliativecare.org
www.growthhouse.org

REFERENCES


I would like to thank the nurses who gave their time to complete surveys that were used to help write this pamphlet.