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Critical Care Nurses’ Perspectives on End-Of-Life Decision-Making with Patients in Intensive Care Units

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CRITICAL CARE NURSES' PERSPECTIVES ON END-OF-LIFE DECISION-MAKING WITH PATIENTS IN INTENSIVE CARE UNITS

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ABSTRACT

Critical care nurses, who work in intensive care units, assess and provide interventions to seriously ill patients daily. Due to the uncertainty of outcome during critical illness, patients and their families are involuntarily placed in situations that require end-of-life decision-making. Often critical care nurses are asked by patients and their families to assist in the decision-making process. At present, the literature is scarce concerning how nurses' beliefs, attitudes and values may impact on patients and their families' processes in making end-of-life decisions. The purpose of this exploratory study will be to describe critical care nurses' perspectives on how they assist patients and their families in making end-of-life decisions in intensive care units. Utilizing exploratory/descriptive theory as the framework, nurses will be interviewed in a hospital in a suburban area of the Midwestern United States. Open-ended questions will explore their beliefs, attitudes and values concerning assisting patients and their families in making end-of-life decisions. Exploratory analysis will be used to identify themes of attitudes and behaviors nurses describe in aiding patients and their families in the decision-making process. The findings of this study may provide a beginning understanding of the nurse's role in assisting patients and their families with end-of-life decision-making.

DEDICATION

I am dedicating this dissertation to three wonderful girls, my daughters Rebecca, Melissa, and Denise, who have been extraordinarily supportive to their mother, the perpetual student. They have been my cheerleaders, showing unending support for me and confidence in my ability to finish my terminal degree. I love you very much and could not have done it without you.

Special mention goes to my invaluable friends and colleagues: Georgine, Jay, Jeanette, Kurt, Vickie, and a number of others who on an almost daily basis kept asking me how I was progressing on this project. Your unending support was wonderfully annoying, yet touching and invaluable.

Of course, last but definitely not least, I thank my final dissertation committee, Dr. Linda Perkel, a most understanding and supportive Dissertation Chair; Dr. Marcia Hacker; and Dr. Jesse Colin; who bridged the 1400 mile gap by facilitating my matriculation in every way possible.

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CHAPTER I

AIM OF THE STUDY

Death is an inevitable and inescapable event in everyone's life. A person cannot always plan the way that life will end, or prevent the use of life-supporting measures that would unduly prolong and extend suffering. Planning for the end of life can provide peace of mind to patients and their families. Consider the following scenarios:

Three patients in the Intensive Care Unit (ICU) of a moderately large community hospital are facing the possibility of imminent death. As the already grieving family leaves the room of Mr. M., the nurse enters his room. She sits at the bedside, holds his hand, and quietly tells him that it is acceptable to let go now and die. His family will be saddened but can cope with his death. He nods gravely. The nurse asks him how he would like to experience the last few hours or days of his life. Mr. M. tells her that he would like to have his family around him so that they could say their final good-byes to each other. He wishes that no extraordinary measures be used to prolong his life. She leaves the room and starts making arrangements to fulfill his requests.

In another ICU room, Ms. R. is calling for her nurse. She is visibly upset and crying. The nurse is at the desk, wondering what she is going to tell Mrs. R. The patient has been vacillating about her decision to forgo all potential life support efforts if her heart should return to a lethal arrhythmia as has happened in the past. As the nurse enters the room, Mrs. R. asks the nurse how much longer she has to live; should she call her family to help her make some important decisions. The nurse hesitates and then tells the patient that it is her decision to make about life support and that no one can predict when life will end. There is always hope. Concluding the conversation with, "Call me when you make up your mind and we can decide if your family should be notified," the nurse leaves the room.

Lastly, Mr. K is in ICU, Room 3. He is comatose, having signed the Do Not Resuscitate (DNR) order last week. His family is crowded in the room, unsure of what to do. Some are crying and distraught, wanting to rescind the DNR order. Others are holding his hands and reminiscing. Mr. K.'s nurse enters the room and states that there is no sense in the family staying with the patient. They all need to go to the waiting room; the decisions have been made. She will call them when it appears that he is going to "pass away." At that time they can return.

What are the final outcomes? Mr. M.'s bed is facing the picture window of his room, where the sun is setting. His family is sitting around him in a semi-circle saying good-bye, sharing anecdotes of the past. Several hours after they have kissed him and left, he passes away peacefully. The family is at peace.

Mrs. R.'s condition deteriorates. She has requested that the Chaplain be notified to help her with her end-of-life decisions. Unfortunately, he does not arrive in time. Mrs. R. expires after multiple attempts to revive her that night. Her family is notified and rushes to the hospital, but arrives too late to see her prior to her death.

Mr. K. dies alone. His nurse is busy with another patient when his heart slows to a stop. The family is distraught that they were not called to be with him during his last few moments of life. They file a complaint with the Director of Nursing.

These true personal stories have three very different nurses and three very different outcomes. Scenarios such as these are not uncommon in health care settings today. It prompts speculation about what processes nurses use to deal with end-of-life decision-making and from what personal and/or educational foundations these processes are drawn.

Observed scenarios, like the ones noted above on almost a weekly basis for many years, prompted this researcher to question the processes that critical care nurses utilize in assisting patients and families in end-of-life decision-making in ICU settings. Informal conversations with many nurses and a review of the literature has established that there is a paucity of studies that focus on how and why nurses assist patients and their families with end-of-life decision-making. In addition, there are numerous factors involved with end-of-life decision-making, such as patient rights, decision-making strategies, and barriers to making decisions.

The problem remains that there are significant differences in the approaches that critical care nurses use when assisting patients and their significant others in end-of-life decision-making. Many times these differences disrupt the continuity of patient care and have the potential of creating confusion for the patient. In addition, confusion can also result when there is a conflict between the patients' and nurses' values and beliefs.

This exploratory study describes the perspectives of critical care nurses when assisting patients and their families on end-of-life decision-making. Nurses' perspectives on end-of-life decision-making are a key issue that has implications for nurse educators in both clinical and academic settings. Education regarding the nurses' role in end-of-life decision-making emphasizes the importance of nurses as patient advocates in helping to ensure that decisions patients make will be honored.

Justification for the Study

Implications for Nursing Administration and for Public Policy

Many people have no idea who they can turn to for help in end-of-life decision-making. People frequently have questions and need clarification of the relevant issues. Many times nurses, physicians, and other healthcare workers feel ill at ease introducing the topic of death. After all, the goal of health care professionals is to cure and save lives, not to acknowledge possible failures where the outcome is death.

It is the nurse who spends the most time with patients. By virtue of that fact, it follows that it is the nurse who has the most opportunity to advocate for patients. Patients have the opportunity to divulge their wishes, questions and fears to the nurses, who can relay their thoughts and feelings to other healthcare professionals to better meet the patients' needs. Traditionally, nurses have advocated for patients' rights. Scanlon (1997) states that:

> There has been a long-standing allegiance by the nursing profession and individual practitioners to the centrality of the patients' role in decision-making, particularly at the end-of-life. It is the nurse who often discusses the benefits and limitations of interventions and helps the patient understand the clinical situation. Nurses often have an in-depth knowledge of their patients' concerns and preferences and they can do much to protect and advocate for them (p. 59).

Currently, there is a great deal of controversy regarding advance directives, withdrawal of life support, patients' rights, and physician-assisted suicide. Critical care nurses in ICUs address these topics daily. We are experiencing a new trend in healthcare, when patient autonomy and patient rights at the end-of-life have become an issue for public scrutiny and debate. Critical care nurses, because of their one-to-one relationship with patients, have a unique perspective as well as involvement in patients' decision-making processes at the end-of-life. Yet we know little about the nurses' involvement, as this process has not been empirically examined.

The American Nurses Association states that nurses have a responsibility to educate patients and families about all forms of life-sustaining treatments as well as to provide information about advance directives (American Nurses Association, 2000, p. 22). The American Association of Critical Care Nurses has similar guidelines, recommending that "critical care nurses act as patient advocates, initiate and promote the decision-making process and assure that nursing goals are consistent with patient preferences or best interests" (p. 23).

In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) (1995), it was found that families were not encouraged by physicians to share decision-making discussions with other healthcare professionals. Clearly, the nursing profession needs to address this problem to better understand how to meet its responsibility to patients and families. "Our obligation to the patient and the patient's family during the dying process is not to look away, but to attend to the changes we see happening" (Chapple, 1999, p. 30).

Because few investigators have addressed the role of nurses in end-of-life decision-making, Baggs and Schmitt (2000) find "a need for continued research about ICU end-of-life decision-making in a qualitative paradigm, observing behavior, and eliciting different perceptions and values" (p. 161). They also believe that "studying multiple participants in the same decision-making would support the identification of barriers to decision-making and these studies should be both ethically and empirically based" (p. 162). Documenting nurses' perspectives is the first step in understanding what processes nurses' utilize when participating in end-of-life decision-making.

Critical care nurses are sometimes very frustrated about their role in assisting patients in decision-making. Often this frustration stems from an expressed need for more education on end-of-life issues and bioethical decision-making (Baggs & Schmitt, 2000; Beland & Froman, 1995; Hausfeld & Wolfe, 1996; Kennard et al., 1996; Kirchoff et al., 2000; Oddi et al., 1995; Tilden, 1999).

While nurses are able to refer to their education to provide a foundation for adequate technological and palliative nursing care for patients, the question becomes, "To what frame of reference does the critical care nurse refer for guidance regarding the ethical, moral and legal issues surrounding end-of-life decision-making?" Complicating this issue even further for nurses are the findings of the SUPPORT (1995) study, which suggest that providing information and guidance to patients and their families regarding end-of-life issues is the responsibility of physicians alone.

As ambiguous as the issue is regarding whose role it is to inform and advise patients and their families about end-of-life issues, there is even greater ambiguity regarding the underlying belief system and methods that nurses should use as their framework while addressing these issues. There are many variables that can influence nurses' views on death and dying, such as: education, culture, religion, and life experiences. Tuttas (2002) suggests that:

> Although nurses might not be taught or encouraged to assume this responsibility, nurses are in a position to initiate discussions about values and beliefs that could play a distinctive role in determining patients’ preferences for care. Why then are nurses not more involved? Nurses might not seek the opportunity to participate in discussions about do not resuscitate (DNR) decision-making because of their own role perception, education, experience or emotional comfort in discussing end-of-life issues (p. 14).

The findings of this study should help to illuminate the wide variations that routinely occur in ICUs regarding critical care nurses’ methods of presenting end-of-life options to patients. Being aware of the beliefs, values, and attitudes upon which nursing approaches are based should help provide nurse educators with evidence-based practice regarding end-of-life decision-making. Through education, based upon continuing research, nurses and nursing students may gain knowledge to better understand and standardize approaches that influence their efforts to assist patients in end-of-life decision-making. Administration may use the findings to assist with clinical policies.

Nurses need to be involved in public policy issues related to level of life. For example, this study may provide a basis and impetus for nurses to lobby lawmakers to consider more aggressive and binding guidelines for the general population in regard to documentation of their wishes regarding end-of-life decisions. In addition, guidelines for potential laws could be suggested by nurses that encompass the responsibility of nurses, as well as other healthcare workers, concerning end-of-life decision-making and patient care.

Evidence-based practice is not only confined to the technological aspects of nursing, but also applies to the psychosocial, ethical, cultural and religious needs of patients. Understanding current practice is the first step in developing appropriate strategies in the end-of-life decision-making process.

Aims of the Study

The proposed study provides insight into nurses’ perspectives concerning experiences with patients and families who are engaged in the process of end-of-life decision-making. Examining the foundations which influence these perspectives could clarify the diversity of methods nurses employ when helping patients cope with end-of-life issues in ICUs. Therefore, the specific aims of the study are:

1. To explore critical care nurses’ perspectives (attitudes, values, and beliefs) in end-of-life decision-making.
2. To describe critical care nurses’ perspectives (attitudes, values, and beliefs) in end-of-life decision-making.
3. To describe the role of critical care nurses in end-of-life decision-making with patients and their families.

The research questions addressed that explore and describe the aims of this study are:

1. What are the perspectives (attitudes, values, and beliefs) of critical care nurses in end-of-life decision-making with patients in Intensive Care Units?
2. What are critical care nurses’ perspectives (attitudes, values, and beliefs) regarding their role in end-of-life decision-making with patients in Intensive Care Units?

3. How do critical care nurses facilitate end-of-life decision-making for patients and families in the Intensive Care Unit setting?

Philosophical Underpinnings and Methodology

The Constructivist Paradigm and Qualitative Inquiry

The aim of this qualitative study was to explore and describe critical care nurses' perspectives on end-of-life decision-making in ICUs. This study was grounded by the philosophical underpinnings of social constructivism. In studies (Baggs & Schmitt, 2000; Beland & Froman, 1995; Chapple, 1999; Hausfeld & Wolfe, 1996; Kennard et al., 1996: Kirchoff et al., 2000; Oddi et al., 1995; Tilden, 1999) that have addressed the relationship between critical care nurses and end-of-life decision-making, the investigators indicate that critical care nurses have expressed dissatisfaction, lack of understanding, and ineptitude in dealing with end-of-life decision-making in Intensive Care Units. These results suggest the need for further study and provide the impetus to explore and describe the perspectives of critical care nurses about this aspect of their professional responsibilities.

According to Schwandt (2003), "The qualitative inquiry movement is built on a profound concern with understanding what other human beings are doing or saying" (p. 311). The operative words in this context are "doing" and "saying." The researcher's identification of themes and the pursuant respondents' verification of those themes, which is inherent in analyzing results of exploratory methodology, requires continuous social interaction and use of language to convey perspectives.

Additionally, interaction and communication are a crucial part of the nursing process which Engelbretson & Littleton (2001) state is "an interaction between the nurse and client/family, which occurs within the culture of the health care system. This entire relationship is embedded in the social context of the culture in which it occurs" (p. 224).

Lincoln and Guba (2003) describe social constructivism as the nature of the philosophy of individual reconstructions coalescing around consensus. The knowledge gathered is from more informed and sophisticated reconstruction of vicarious experiences. Researchers and participants share information, experiences, and content. Participants become facilitators of multi-voice reconstruction of perceptions of "truth" and "knowing." The exploratory process is one of collaboration to discover "truths" and develop knowledge. The ontology and epistemology of this social constructivism provide a basis for exploratory qualitative research.

Biases and Assumptions

Researcher bias is an important aspect to consider when conducting research. Ely, Vinz, Downing, and Anzul (1999) state that "Distortions, blind spots, and limitations that contribute to our various stances are what people usually mean by bias. Some dictionary meanings of bias are a) bent, a tendency; b) an inclination of temperament or outlook, especially a personal and sometimes unreasoned judgment" (pp. 346-347).

In general, Ely et al. (1999) understand "bias to encompass our preconceptions, assumptions, passionate inclinations, aversions and all the experience and learning we bring to the scene. Some go unrecognized and prevent us from doing justice to our material. Others act as energizers, facilitators in shaping our material" (p. 347).

Assumptions, on the other hand, are generally recognized as something presumed to be true without absolute evidence. Biases can be said to form assumptions, both of which the researcher needs to acknowledge when collecting and analyzing data.

One identifiable assumption is that variations in assistance that nurses demonstrate during end-of-life decision-making can be harmful to patients and their families by not meeting their needs at this difficult time. Second, there are a number of personal factors, or variables, such as culture, religion, educational level, experience, and gender, that form the foundation for the processes that critical care nurses employ in assisting end-of-life decision-making.

Another significant assumption is to believe that there is need for change based on outcomes that are deemed undesirable. Nurses' involvement with end-of-life decision-making is a significantly complex ethical and moral issue. Lastly, nurses will be truthful in sharing their true feelings. Otherwise this may impede interpretation.

The researcher bracketed some personal biases, which included:

1. Believing there is a definite need to educate nurses about how to deal with end-of-life decisions of their patients and families.
2. Assuming from personal experience that there is not a standard method that nurses use to facilitate end-of-life decision-making of patients and their families.
3. Acknowledging the possibility that the nurses with the most education have a more holistic view of the care of ICU patients.

Summary

Patients, families, and critical care nurses all share frustration with making end-of-life decisions. While the patients and families carry the onus of making end-of-life decisions, nurses are in a quandary regarding the role they are to play in assisting patients and families with these decisions. Because there is no concrete basis or job description for nurses regarding the end-of-life decision-making issue, they may have to draw from their personal attitudes, values, and beliefs to provide information and support to patients for end-of-life decision-making. The problem is that there are significant differences and approaches that critical care nurses use when assisting patients and their significant others with these issues.

Through nurses articulating their attitudes, values, and beliefs to a researcher, information can be gathered to determine what critical care nurses believe their role to be in end-of-life decision-making and how they determine their scope of participation in this role. Qualitative inquiry in the form of an exploratory study was chosen to investigate the critical care nurses' perspectives of their attitudes, values, and beliefs about end-of-life decision-making. These perspectives guide the nurses' involvement. By the use of language, communication, and trust, as gleaned from the social constructivist philosophy, an exploratory study may contribute valuable insights to the problem. These insights may be able to provide significant implications for public policy and administration regarding how nurses can most effectively participate in end-of-life decision-making of their patients and significant others.

CHAPTER II

EVOLUTION OF THE STUDY

Historical Context

To elucidate the meaning of end-of-life decision-making in terms of this research, it is necessary to discriminate between end-of-life care and end-of-life decision-making. There have been a multitude of studies conducted about end-of-life care (Davidson, Intiona, Daly, Parell et al., 2003; Kirchoff et al., 2000; Kirchoff & Beckstrand, 2000; Meltzer & Huckabay, 2004; Puntillo et al., 2001; Resnick & Andrews, 2002; among many others). These researchers view end-of-life care as issues encompassing actual withdrawal of life-support, administration of fluids, food, palliative drugs, or simple maintenance of comfort care. End-of-life decision-making becomes the preamble to or first step in end-of-life care. Tuttas (2002) explains:

> The presence of and support offered by nurses prepared to address end-of-life care topics (including but not limited to discussion about advance directives) can greatly enhance the coping and decision-making capability of patients and families facing such circumstances. In the acute care setting, patients and families tend to develop an optimal trust and comfort level with nurses. Nurses are the around-the-clock health care providers who perform assessments and administer health care interventions while providing support and personal care at an intimate level to patients in these environments.

One of the top three most important end-of-life care competencies identified (by 2/3 of the nurses in a study by White et al. in 1997-1999) was “how to talk to patients and families about dying followed by techniques to relieve pain, and finally comfort interventions” (p. 11).

While end-of-life decision-making is an integral component of end-of-life care, its importance lies in the fact that it determines the nature and extent of the rest of end-of-life care. It is the discussion of end-of-life decision-making that lays the foundation for what treatments, procedures, and care a patient wishes to have at the end-of-life.

For the purpose of this research study, end-of-life decision-making was defined as: The determination regarding care of the patient when there is a possibility of cessation of life or cessation of what the patient considers to be quality of life. Components of care at that time include:

a. The type of care desired

b. Documentation of who the designated decision-maker(s) will be

c. What treatments are acceptable and not acceptable to the patient or designated proxy

d. At what point, if any, all treatments will be discontinued

e. The adoption of a living will or Durable Power of Attorney of Healthcare.

There are a number of reasons that patients do not make, or are not encouraged to make, end-of-life decisions. Although the Patient Self-Determination Act of 1990 mandates that hospitals inform patients about advance directives, only about 20% of the patients have executed advance directives. The majority of all patients need further direction on end-of-life decision-making (Ahrens, Yancey, Kollef, & Kleinpell, 2003;

Blatt, 1998; Chapple, 1999; Drought & Koenig, 2002; Kirmse, 1998; Mezey, Leitman, Mitty, Bothill, & Ramsey, 2000; Tilden, 1999).

As early as 1967, Quint discovered that nurses have a limited involvement with dying patients and actually withdraw from them, due to the lack of educational preparation on death and dying. Later in 1995, McClement and Degner expanded Quint's model and suggested that nurses had anxiety and negative attitudes toward end-of-life decision making because there was a lack of data on which to base their actions.

Although there has been a plethora of material (Ahrens, Yancy, Kollef, & Kleinpell, 2003; Baggs & Schmitt, 2000; Blatt, 1998; Cook, 1997; Drought & Koeney, 2002; Erlen & Sereika, 1997; Hausfeld-Wolfe, 1996; Kennard et al., 1996; Kirchoff et al., 2000; McLaughlen, Miller, & Wooten, 1999; Scanlon, 1997; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999; Tuttas, 2002) written about opinions concerning end-of-life decision-making from the perspectives of families, patients, and physicians, there is a scarcity of information addressing nurses' perspectives on the end-of-life decision-making process.

As Kirmse (1998) noted:

> End-of-life decisions have become a topic of great interest due to rapidly escalating health care costs, aging populations, new life-sustaining technology, increasing patient awareness and demands for autonomy, and increasing litigation associated with heath care. Some nurses have not been involved in discussing advance directives with patients and their families because of the traditional model of physician responsibility (p. 83).

Also in 1998, Crego conducted a study to determine nurses (n=295) knowledge of advance directives. It was found that nurses require more education regarding the legal and psychosocial ramifications of advance directives. This is quite important, as the general public, as well as the patient population needs, to be educated about advance directives so that they can effectively address this topic and make informed decisions.

Following Crego's study (1998), Tuttas (2002) conducted a study, involving 728 nurses that examined if they had adequate knowledge to facilitate end-of-life decision-making. The results of the study suggest that "delaying discussion of patient preferences for end-of-life care until the medical condition has deteriorated beyond the feasibility of such is not an uncommon occurrence. The role of the RN as it pertains to the education and counseling of patients and families is pivotal in creating an environment where patients can feel more at ease in addressing end-of-life issues in a timely manner" (p. 14).

In a grounded theory study by Tilden et al. (1999), it was found that nurses (n=30) had a wide range of opinions regarding their role in the decision-making process. Nurses are unsure of how, and if, their personal opinions and morality should be articulated to the patients and their families.

Baggs and Schmitt (2000) found that there were very few studies of nurse involvement in the process of end-of-life decision-making. The SUPPORT (the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) study was conducted in 1995 to determine if seriously ill patients (n=9,105) understood their prognoses, treatments, risks, and preferences of the outcomes of treatment. In this study (1995), the ICU nurses were found to be not very involved in the level of treatment decision-making for their patients. The absence of much data about nurses in end-of-life decision-making may reflect what one physician has identified as hierarchic authority in decision-making (p. 160).

Several researchers (Bowman, 2000; Hohenleitner, 2002; Tuttas, 2002) have found that while nurses are ideal healthcare workers to assist patients and their families with end-of-life decisions, they are ill-prepared to do so, by their own admission. And in a study by Husted (2000), she investigated the experience of nurses (n=15) and patients/families (n=5/n=15) related to their reflections regarding end-of-life decision-making. The findings suggest that nurses could alleviate the fear and anxiety associated with end-of-life decision-making, and indeed may be the persons responsible for that. However, there is little empirical literature to discover why this is not happening.

Mezey, Leitman, Mitty, Bottrell, and Ramsey (2000) conducted a quantitative study of 1016 randomly drawn patients in New York City in an attempt to understand why hospital patients do and do not execute an advance directive. The findings indicated that "level of education was the most important factor, in a study in which race, education, language spoken, and income are associated with reason for executing or not executing a directive" (p. 165).

Beckstrand and Kirchoff (2005) randomly sampled 864 critical care nurses, using an experimental post-test only survey, to find out the perceived obstacles to end-of-life care. Results indicated that the interference of family members in care and physician's disagreement about the plan of care were major factors in presenting road blocks to end-of-life decisions.

In a quantitative study by Thibault-Provost, Jensen, and Hodgins (2000), 405 critical care nurses were surveyed to discover their perceptions of what a DNR status means. Awareness of the rationale for DNR designation and documentation of a complete treatment plan were strategies that were suggested, based on the results of this research.

Philosophical Underpinnings

Definition of Social Constructivism

Social constructivism defines the exploratory methodological process, namely focusing on language and collaboration, which was utilized in conducting this study. Denzin and Lincoln (1998) stated that constructivism is the “understanding and reconstruction of the constructions that people initially hold, aiming toward consensus but still open to new interpretations as information and sophistication improve” (p. 211). Slife and Williams (1995) elaborated on the definition stating that:

> Social constructivism is a unique way of knowing. It does not simply occur through sensory experiences, or other logical reasoning. It occurs in the relations among individuals as they converse and negotiate and share their world with one another. Just as the whole is greater than the sum of parts, the social whole as a social construction can be greater than the sum of individual members. What we “know” is how we understand and how we understand is a product of historical and social discourse (p. 82).

Collaboration is inherent in social constructivism. According to Garrison (1995):

> A thoroughgoing social constructivist must acknowledge that all meanings, as well as the minds that manipulate them, emerge from making something common out of at least two centers of action. Therefore, cognitive meanings (or truth

> claims) must also involve two or more persons as intending some object. Objectivity is then intersubjectivity" (p.723).

Other experts (Dewey, 1981; Garrison, 1995; Schwandt, 2003; Slife & Williams, 1995) agree that individuals, through their experiences communicated by gestures and language, are describing their situational relationships in which they are enmeshed. These individuals are representative of larger relationships with people who share common objectives. Schwandt (2003) suggests that this communication allows the researcher to, "invent concepts, models, and schemes to make sense of experience and we continually test and modify these constructions in light of new experiences. We do not contrast our interpretations in isolation, but against a backdrop of shared understandings, practices, language and so forth" (p. 305). These principles of language, collaboration, and understanding through interaction and discourse are the essence of qualitative exploratory research.

Therefore, Denzin and Lincoln (1998) postulate that, ontologically, realities are based on multiple experiences, ideas, and beliefs of individual persons or groups of persons. They are both experientially and socially based—a collaborative effort. There is no "truth," but rather ideas and opinions that are more or less sophisticated and/or informed. These perceptions are ever changing, as more information is accumulated and assimilated. Processing promotes sophistication of the perceptions.

Likewise, epistemologically, the researcher and participants are equally involved. There is mutual dialogue through language. The findings are created and discovered together. This methodology requires that the participants and researcher interact and refine the data together. Once again, collaboration is essential. Denzin and Lincoln

(1998) believe that results should provide “a consensus construction that is more informed and sophisticated than any of the predecessor constructions” (p. 207).

Philosophy of Social Constructivism

There are a number of authorities on social constructivism (Beten, 1997; Dewey,1984; Garrison, 1995; Ginter et al., 1996; Gergen, 1991; Goodman, 1978; Lincoln & Guba, 2003; Longeno, 1993; Maturana, 1981; Schwandt, 2003) who agree on the principles that knowledge and truth are a matter of perspective. They are an accumulation of experiences, viewpoints, and theories that are articulated through language. “Truths” are ever changing as interaction and intersubjective experiences cause the “truth” and “knowledge” to be re-defined and re-interpreted.

Denzin and Lincoln (1998) believe that the “philosopher most responsible for defining the contours of a constructivist theory of reality and cognition is Nelson Goodman. He characterizes his view as ‘irrealism,’ a kind of rigorously constrained radical relativism that does not hold that everything or even anything is real, but sees the world melting into versions and versions making worlds…” (p.238).

Goodman suggests that we disclaim the notion of certainty and embrace the notion of adoption. He believes that there is no ready-made world, but rather a world in the making. It is constantly being revised by our continuous experiences and learning. There become different versions of the world and it is continuously subject to interpretation and re-interpretation. It is through interpretation and re-interpretation of nurses’ dialogue that nursing can gain understanding of the factors that influence techniques that nurses use when dealing with decision-making of patients and their families.

Because the world is constantly changing and being revised, it suggests that the concept of “truth” will also be changing. Therefore, this leads to the concept of relativism. Everything is relative to the time and experience. Morality and its relationship to ethical beliefs then change as the dual concept of right/wrong changes, as it relates to new experiences and information. This presents a problem for some critics of postmodernism and the constructivist theory.

Longeno (1993) also ascribes to the theme of intersubjectivity as it relates to qualitative research. He states that:

> Methods employed to generate, analyze, and organize data and to link evidence to hypotheses are not under the control of an autonomous, disengaged, disembodied subject, knower, or ideal epistemic agent. Rather, such matters are “contextual” in that they are constituted by a context of intersubjectively determined background assumptions that are the vehicles by which social values and ideology are expressed in inquiry and become subtly inscribed in theories, hypotheses, and models defining research programs (p. 263).

Several social constructivists (Dewey, 1984; Wittgenstein, 1953) emphasized the importance of language in discerning “truths,” “knowledge,” and “meaning.” Garrison (1995) explains that, “Dialogicality and multiple authorship are implied in Dewey’s cooperative social behaviorist theory of meaning. He saw language as a social construction, one in which co-designation and co-reference are crucial” (p. 727). Dewey (1984) explained that, “The final actuality is accomplished in face-to-face relationships by means of direct give and take. Logic in its fulfillment recurs to the primitive sense of the word: dialogue. Ideas which are not communicated, shared, and reborn in expression are but soliloquy, and soliloquy is but broken and imperfect thought" (p. 371).

Language and intersubjectivity, being embedded in the social constructivist philosophy, provide the basis for qualitative exploratory methodology, which relies on language, intersubjectivity, and collaboration to describe and evaluate life experiences. Therefore, social constructivism provides the philosophical underpinnings for exploratory methodology.

Because of the importance of language and intersubjectivity in communicating with critical care nurses regarding their perspectives on end-of-life decision-making, qualitative research is the preferred methodology. Exploratory research of this nature will provide information about the impact of real world life experiences have had for ICU critical care nurses as well as how, and if, these experiences have shaped nurses' approaches to patients and their families having to make decisions about end-of-life options.

Experiential Context

The topic of this research study, critical care nurses' perspectives on end-of-life decision-making with patients in Intensive Care Units, was developed as a result of the desire to understand what frameworks, if any, nurses use when discussing end-of-life decision-making with patients and their families. Having been a critical care nurse for 20 years, I have observed three basic conflicts in Intensive Care Units that I believe are a result of critical care nurses not having an underlying philosophy or framework on which to base their end-of-life dialogue with patients and families.

The first is conflict between staff members themselves, between nurse and nurse, nurse and doctor, nurse and administration, nurse and ancillary department members, or some combination of these professionals. Each combination of professionals has a possible, if not probable, difference in level of education, culture, age, religion, and life experience. All of these individual variables account for varying viewpoints on end-of-life issues.

Even within nursing education I have found there are very few courses that address how nurses should approach, explain, and assist in end-of-life decision-making with families and patients. One consequence is significant differences in the interventions nurses employ. Families and patients are therefore forced to discern between mixed messages received from staff members. At a time that is fraught with emotions of uncertainty and fear, such confusion is certainly not helpful and may possibly be harmful.

The second conflict is between nurses and the patients and their families. Many times families and patients have erroneous or pre-conceived ideas about what options they have at end-of-life. A discussion about possible death is a sensitive issue that requires the nurse to engage in compassionate dialogue, respecting the viewpoints of family members involved, while at the same time dispassionately explaining the decisions that lie ahead.

Culture, education, religion, and life experiences are significant components in the perspectives of those involved. If the patient or family perceives differences in attitudes and beliefs held by nurses, they often retreat and may refuse to discuss pertinent issues regarding care and decision-making. Likewise, if the nurse’s perception of the "right thing to do" is the antithesis of what the family believes or wishes, many times the nurse will retreat and not attempt to explain the situation and options available to the patient and the family. Neither scenario results in optimum outcomes.

The third conflict is the uncertainty of the nurse. In the beginning of my nursing career, I vividly remember my first experiences with attempting to discuss end-of-life decisions with patients and their families:

(a) How would I approach the topics of advance directives, organ donation, and end-of-life care, without upsetting the patient and family

(b) Was it my responsibility to introduce these topics

(c) How should I approach the topic of death

(d) What were the beliefs of the patient and family

(e) Could I ask questions without constructing a barrier between us, and

(f) How could I keep from influencing my patients with my personal feelings?

There were so many questions and nothing from which to draw in designing an intervention.

In the ICU these conflicts manifest themselves daily. Discussions between nurses that denigrate the attitudes, beliefs, and techniques of fellow employees concerning end-of-life decisions result in the development of non-collegial adversarial relationships. To avoid offending or upsetting families, nurses sometimes avoid dialogue about end-of-life issues by completing technical aspects of patient care, thereby avoiding communication. Negative evaluations from patients' families regarding ICU care at the end-of-life leave some nurses with feelings of guilt that they have not met their patients' needs. Patients and families can suffer needlessly because of a lack of open and honest communication.

Summary

None of the above outcomes are necessary. It is of utmost importance that nurses dialogue about ideologies that motivate their interaction with ICU patients and their families when end-of-life becomes an issue. By understanding the motivations and foundations upon which critical care nurses act, perhaps institutions and academic facilities could design interventions that will facilitate how nurses address end-of-life decision-making in Intensive Care Units.

CHAPTER III

METHODOLOGY—GENERAL

Exploratory Methodology

Introduction

As Poole and Jones (1996) state, “To study methodology is not simply to examine the exercise of method, it is to study a way of knowing; in other words methodology and epistemology are linked. The phenomenon under investigation should determine the research methodology utilized” (p. 109). In general, qualitative data collection methods are based on unstructured interviewing, unstructured observations, unstructured available data, small samples, and a variety of forms of content analysis. Exploratory methodology was utilized in this study. The reasons for implementing an exploratory method will be addressed after a brief explanation of its goals.

Several researchers (Brink, 1994; Huttlinger, 1999; Poole & Jones, 1996) propose that exploratory studies are the first step in initiating a researchable project or developing a research program. This is basically because exploratory methodology investigates a process or topic about which little is known. It is a flexible methodology because it enables the researcher to examine a phenomenon holistically, exploring new insights by following the diverse opinions and human behaviors of the participants. Huttlinger (1999) and Brink (1994) also suggest that exploratory data is insightful because the researcher has the flexibility to change directions and develop new ideas and concepts as the data are collected and analyzed.

Exploratory research is descriptive of the phenomenon being studied. There is no hypothesis nor does it generate theory. It is theory-neutral. The data collected and analyzed may lead to a phenomenon to be researched. Poole and Jones (1996) explain that:

> The premise of theory-neutral observations depends upon the artificial distinction between sensory experience and the cognitive process of perception. Perception is a function of prior knowledge and experience, which also influences how sensory experience is conceptually organized by both the researcher and the participants" (p. 108).

Huttlinger (1999) believes that, "These kind of studies have been very useful in nursing research in finding out more about nursing-related problems that occur in all areas of clinical practice, administration and academe" (p. 29).

Characteristics of Exploratory Research

Rudiments of exploratory methodology, according to Brink (1994) are:

1. Personal involvement of the investigator with a small number of people (usually fewer than 25)
2. Small geographical or circumscribed setting (such as a hospital ward, a village, or a small interest group)
3. Repeated unstructured or semi-structured interviews (usually accompanied by observations of the same participants over time)

4. Data recorded in the form of field notes, ongoing content analysis yielding categories of mutually exclusive contact
5. Negative cases to explore further with the sample
6. Insights and hunches to pursue the following day (p.315).

There is a general consensus (Brink, 1994; Poole & Jones, 1999; Streubert & Carpenter, 1999) that exploratory designs have two major goals. The first goal is problem discovery. The problem that is to be identified and described has never been previously studied or known. The second goal is that the concepts need to be explored in a flexible, free-ranging way that provides in-depth insight into their meanings. Assumptions that follow these goals are that those participants in the sample have personal experience and knowledge about the topic and that the topic has not been previously studied from the perspectives of the participants.

Rationale for Methodology

There are several reasons for choosing exploratory methodology to conduct this study. The specific aims of the study which address critical care nurses' perceptions of their roles, their perspectives, and their participation in end-of-life decision-making of ICU patients are definitive of the hallmark of exploratory study. According to Brink (1994), the hallmark of exploratory studies ais "observing or asking about previously unexamined, everyday occurrences, trying to 'tease out' the essence of what is going on. The result is an examination and subsequent explanation of the processes and procedures or rules underlying human behavior and interaction" (p. 310).

Critical care nurses are confronted with issues related to end-of-life decision-making on a daily basis. While there have been many studies that explore end-of-life care and end-of-life decision-making of critical care patients, there is a dearth of studies that explore the attitudes, values, and beliefs (perspectives) critical care nurses have regarding their role and participation in the decision-making process.

Implementing an exploratory methodology allowed the researcher to use a small sample of critical care nurses to focus on the specific area of interest (end-of-life decision-making) and on two other concepts (nurses' roles and participation) in this process. "By using semi-structured, open-ended questions, it is possible to focus on aspects of human behavior that are difficult to measure in numeric terms" (Huttlinger, 1999). Thereby, this provides a rich description of the phenomenon of interest.

The resultant findings gleaned from exploring behaviors and perceptions of critical care nurses about end-of-life decision-making in ICUs may be of benefit to nurses who have had similar experiences. The findings may provide effective alternative interventions which conform to their perspectives and particular work situations.

While the interviews guide the researcher's direction, a relationship develops between the researcher and participants as together they explore and validate the evolving themes of the interviews. Applicability of qualitative techniques to explain the processes under study, use of collaborative research techniques between the researcher and the participants, flexibility, and lack of previous information about the topic of study, are the reasons exploratory methodology was chosen.

Definition of Terms and Concepts

For the purposes of this study the following operational definitions were used:

1. *Critical care nurses:* Registered nurses whose responsibility is to care for patients treated in Medical Intensive Care Units, Surgical Intensive Care Units, Cardiovascular Care Units and/or Cardiac Care Units.
2. *Perspectives:* The attitudes, values, and beliefs of an ICU nurse, regarding a particular situation or components of a situation, such as end-of-life decision-making.
3. *End-of-life decision-making:* The determination regarding care of the patient when there is a possibility of cessation of life or cessation of what the patient considers to be quality of life. Components of care at that time include:
    a. The type of care desired
    b. Documentation of who the designated decision-maker(s) will be
    c. What treatments are acceptable and not acceptable to the patient or designated proxy
    d. At what point, if any, all treatments will be discontinued
    e. The adoption of a living will or Durable Power of Attorney of Healthcare.
4. *Intensive Care Unit:* Hospital unit that cares for critically ill adult patients, such as medical intensive care, cardiac intensive care, surgical intensive care, or cardiovascular intensive care.
5. *Role:* Expectation or pattern of behavior determined by an individual’s status in a particular setting or society.
6. *Participation:* The action or state of taking part in something in association with others, usually with specific rights and obligations.

General Steps of the Exploratory Methodology

Specific details regarding the implementation of the study will be addressed in the following section. However, the general steps of exploratory methodology include:

1. Obtaining IRB approval from Barry University, as well as the hospitals involved in the studies
2. Obtaining informed consent from a relatively small sample population (less than 25)
3. Conducting semi-structured interviews with open-ended questions
4. Performing content analysis by coding and prolonged engagement with the data
5. Assuring rigor with member checking
6. Keeping meticulous memos and journals
7. Bracketing the researcher’s feelings and opinions
8. Maintaining an audit trail
9. Performing a literature search to determine if the themes are consistent with current studies.

Summary

Qualitative inquiry, as evidenced in exploratory research, is rich in insight because of the free-flowing language between the researcher and the participants who have had experiences specific to end-of-life decision-making in the ICUs. Exploratory research becomes very descriptive of the phenomenon being studied. The flexibility of exploratory research and collaboration between the researcher and the participants are excellent and effective methods to discover the attitudes, values, and beliefs of critical care nurses in regard to end-of-life decision-making.

CHAPTER IV

METHOD OF INQUIRY—APPLIED

Exploratory Methodology

Aim

The aim of exploratory methodology is to investigate a process about which little is known, through a flexible, insightful interviewing process. The investigation explored the research questions:

1. What are critical care nurses' perspectives (attitudes, values, and beliefs regarding their role in end-of-life decision-making with patients in Intensive Care Units?
2. What are the perspectives (attitudes, values, and beliefs) of critical care nurses in end-of-life decision-making with patients in Intensive Care Units?
3. How do critical care nurses participate with patients and their families in Intensive Care Units making end-of-life decisions?

Sample

Purposive sampling was implemented in this exploratory descriptive study. According to Miles & Huberman (1994), qualitative samples tend to be purposive rather than random. That tendency is partly because the initial definition of the universe is more limited and partly because social processes have a logic and a coherence that random sampling can reduce to uninterpretable sawdust (p. 48).

Seidman (1998) states that:

> The purpose of an in-depth study is to understand the experience of those who are interviewed, not to predict or control that experience. Because hypotheses are not being tested, the issue is not whether the researcher can generalize the findings of an interview study to a broader population. Instead, the researcher's task is to present the experience of the people he or she interviews in compelling enough detail and in sufficient depth that those who read the study can connect to that experience, learn how it is constituted, and deepen their understanding of the issues it reflects (p. 44).

The concept of target population is not uncommon in exploratory studies. According to Brink (1999), the purpose of the research dictates the rationale for selecting participants. The researcher should interview those who have experienced the phenomenon being studied. Samples are usually small and should reflect the desired perspective. This is, then, purposive selection. According to Speziale and Carpenter (2003), "Individuals are selected to participate in qualitative research based on their first-hand experience with a culture, social process or phenomenon of interest. Participants are selected for the purpose of describing an experience that they have been a party of (sic)" (p. 24). Generally, exploratory design involves a small number of participants (usually less than 25), from small settings (Brink, 1999; Cone & Foster, 2001; Speziale & Carpenter, 2003).

Researchers (Lincoln & Guba, 1985; Miles & Huberman, 1994; Patton, 1990; Speziale & Carpenter, 2003) believe that purposive sampling provides information-rich cases for in-depth study. It represents commitment to interviewing and observing people who had had experience with or are a part of the area of interest. The result of the interviews should be a rich description of the phenomenon. Purposive sampling is theoretically driven allowing for choice of informants with episodes and interactions that are being driven by research or conceptual questions, not by concern for representativeness.

Seidman (1998) agrees, stating that, “The job of an in-depth interviewer is to go to such depth in the interviews that surface considerations of representativeness and generalizability are replaced by a compelling evocation of an individual’s experience” (p. 44). Thus, quality and depth of interview override the concept of quantity in selecting a sample for a qualitative study such as this one.

Because the purpose was to explore the perspectives of critical care nurses in ICUs, the target population was critical care nurses who work in ICUs from two mid-sized (100-200 bed) suburban hospitals. Exploration and description of critical care nurses’ perspectives are related to a number of variables including education, culture, age, gender, and religion; therefore, there are limited exclusion criteria. Exclusion criteria will include nurses with less than one year of critical care experience and nurses whose area of expertise is with the pediatric population. The criteria will be determined from the demographic questionnaire (Appendix A).

Volunteers were solicited by posting requests (Appendix D) for study participants in the ICUs of the two hospitals. Nurses who met the criteria for the study and expressed willingness to participate were sent further information detailing the purpose of the study, how the study will be conducted, where the study will take place, and an informed consent (see Appendix C).

Sample Size

Sample size was determined by data generated and the data analysis. The sample was complete when saturation was achieved at 11 participants. According to Hutchinson (1986):

> Saturation refers to the completeness of all levels of codes when no new conceptual information is available to indicate new codes or the expansion of existing ones. The researcher, by repeatedly checking and asking questions of the data, ultimately achieves a sense of closure (p. 125).

Seidman (1998), on the other hand, believes that there are two criteria that need to be satisfied to determine saturation:

1. *Sufficiency:* Sufficient enough numbers to reflect the range of participants and sites that make up the population so that others outside the sample might have a chance to connect to the experiences of those in it
2. *Information:* A point in the study at which the interviewer begins to hear the same information reported. He or she is no longer learning anything new. It s an interactive reflection of every stop of the interview process and different for each study and each researcher (p. 47).

For purposes of this study the initial sample size consisted of 10 interviews. The data was analyzed as it was collected so that the investigator was able to determine if saturation had been achieved or if collecting further data was necessary. In this study, saturation was reached when information from the participants became repetitive, yet the sample was large enough to provide diverse information about experiences with which the population of ICU nurses can relate.

Setting

The settings of mid-sized suburban hospitals was chosen because of the inclusion criteria of having several ICUs with 10 or more beds, and the exclusion criteria of a teaching hospital where the addition of interns and residents could affect the nurse's role. The approval of the study by hospital's IRB committee was necessary prior to the acquisition of respondents, and it was obtained.

Human Subject Considerations

The researcher obtained approval from the Institutional Review Boards (IRBs) of both Barry University, Miami Shores, Florida (Appendix E), Edward Hospital, Naperville, Illinois, and St. Joseph Hospital in Elgin, Illinois. prior to conducting any of the data collection..

The areas of voluntary participation, confidentiality, informed consent, and reporting of research information were stressed in the IRB reviews. The consent includes information about voluntary participation; study risks and benefits; the right to withdraw from the study without penalty; storage of research materials including audiotapes, transcriptions of the tapes, consent forms, journals, memos; and research and ethical guidelines required by the Barry University IRB and all of the federally required information (see Appendix C).

Each participant chose an alias that identified his or her demographic data and interviews. Confidentiality was maintained in this manner. All interviews, transcripts, and communication were identified using the code of the participant. There was no other identifying information. The transcriptionist did not have access to the participants' identities.

The interviews were audio taped and transcribed. They will be stored in a locked file cabinet in the researcher's office for at least 5 years and then destroyed. The alphanumeric codes and corresponding identifying information will be stored for 5 years, separately from the consents and transcribed materials, and then destroyed.

Risks to participants are minimal and may include stress related to dialogue regarding potentially upsetting memories about interactions with patients and their families at the end-of-life. Another potential risk would be the loss of personal time for the commitment of interview and time needed to review their transcripts as a member-check. The researcher endeavored to create a trusting, relaxed atmosphere during the interview to promote honest, casual conversation, designed to decrease the participant's tension if memories were upsetting. Possible positive outcomes of the study were emphasized and articulated to the participants in order to provide rationale that justifies the amount of time that they are expending in the interviews.

Benefits could include the possible relief following the type of debriefing that the interviews would provide. Another benefit might be the possibility of a system changing the current healthcare system by clarifying the role and participation of nurses in end-of-life decision-making.

When conducting qualitative research, Seidman (1998) explains that in-depth interviews ask participants to reconstruct their life history as it relates to the subject of inquiry. In the process, a measure of intimacy can develop between interviewers and participants that leads the participants to share aspects of their lives that, if misused, could leave them extremely vulnerable (p. 49).

Because of this vulnerability, the process of informed consent becomes essential.

Steubert and Carpenter (1999) explain that informed consent must ensure that "participants have adequate information related to research; are capable of comprehending the information; have power of free choice, enabling them to consent voluntarily to participate in the research or decline participation" (p. 34). Cones and Foster (2001) list the components of informed consent in ethically conducted research to be:

1. A description of the study and its purpose
2. The information the respondent will be asked to provide, if any
3. A description of what the respondent will be asked to do
4. A description of potential risks and benefits to individual respondents
5. A statement that participation is voluntary and that the subject can withdraw at any time without penalty
6. Reassurance that all data will be kept confidential
7. The name and phone number of a person the respondent may call to get further information about the research
8. The name and phone number of a person, other than the researcher, the respondent may call if he or she has any complaints as a result of participating in the study
9. Signatures of the respondent and the researcher (p. 138).

Speciale and Carpenter (2003) suggest that:

> The very nature of data collection in a qualitative investigation makes anonymity impossible. The personal one-to-one interaction during the interview process allows researchers to know the participants in ways that are impossible and

> unnecessary in quantitative designs. Small sample size and thick descriptions provided in the presentation of the findings can present problems in maintaining confidentiality (p. 315).

Suggested methods (Miles & Huberman, 1994; Seidman, 1998; Yow, 1994) to alleviate concerns about the possible lack of anonymity in qualitative studies include:

1. Providing the participants ahead of time with as much information as possible about the interviewing process, member checking, and dissemination of the results
2. Obtaining a release from the participant to use the interview material as the researcher plans to use it
3. Developing and sustaining a positive relationship with the participant throughout the interviewing and member-checking process
4. Explaining and discussing the informed consent prior to the participant signing it
5. Using member-checking to verify and/or extend interpretations
6. Enhancing trust by explaining in detail where the audio tapes and transcriptions will be stored, who will have access to them.

Informed consent becomes a *process* because the nature of qualitative research precludes the guarantee of participant anonymity. Therefore, not only does the participant need to read, understand, agree to, and sign the informed consent, but ideally he/she must have a sense of trust that the researcher will maintain an ethical study. The researcher should spend the amount of time necessary to earn this trust by verbally explaining the consent, answering any and all participant questions, explaining and obtaining a release to use the results in the research study, and discussing the member-checking procedure to be implemented. The participant should be comfortable with the concept that he/she may withdraw from the study at any time and have access to the results of the study when completed.

Procedure

Following IRB approval, fliers (Appendix D) were posted in the various ICUs at Edward Hospital in Naperville, Illinois and St. Joseph Hospital in Elgin, Illinois. Fliers were also distributed in the mailboxes of nurses in these units. Each flier had a phone number and e-mail address at which respondents who were interested in participating in the study could contact the researcher.

After being contacted, the researcher arranged to speak directly and individually with each respondent. At that time the nature of the study and the consent were explained in detail. If the respondent was interested in becoming a participant and met the criteria, the consent was signed and arrangements were made for the interview at the participant's convenience.

The participant was given a demographic questionnaire to complete and return to the researcher following the interview. The questionnaire included general demographic data, information about: age, gender, geographic location, religion, ethnicity, education level, years of ICU experience, years of nursing experience, and areas of past nursing experience (Appendix A). This information was useful in describing the participants, as well as in correlating coding trends during data analysis. In addition to the questionnaire, the participant chose a pseudonym by which the questionnaire, interviews, and any other communication will be identified.

The interviews were held at the facility at which the nurse works. They occurred in a separate room during non-working hours. To insure privacy, the room was in an area apart from the nursing unit. They had a door that prevented the conversation from being heard by anyone other than the participant and the researcher. The interviews were audio taped with the consent of the participant. There were two audio-recorders to assure accuracy in the event that one of the recorders did not work. Each interview lasted one to two hours.

Semi-structured interviews were scheduled with each individual participant. According to Hutchinson and Wilson (1999), the interview is a major data strategy that aims to obtain textual, qualitative data, reflecting the personal perspective of the interviewed individuals. The interview creates an interactional situation in a face-to-face encounter between researcher and participant" (p. 100). Fitzpatrick (1999) explains that semi structured interviews:

> Obtain information about a certain subject from all participants, but phrasing and sequence of questions may be varied to reflect the characteristics of the participants in the context. Time is permitted to encourage participants to introduce other subjects they believe are relevant or to elaborate often with the interviewee's process. The interviewer acts as the instrument and through carefully designed questions, attempts to elicit the other person's opinions, attributing knowledge about a given topic (p. 100).

Hutchinson and Wilson (1999) propose that there are three phases to the interview. During the introduction phase, the participant is informed about the anticipated length of time of the interview. Initial comments are made to relax the participant and to assist with the transition from social to research context. The second phase is the working phase. Themes of the research are introduced. The researcher and participant work toward generating a shared understanding. The final phase closes the interview. A summarization is articulated and the interview concludes with a brief social conversation.

Questions progressed from general to specific and became focused as patterns emerged. The questions were unambiguous, meaningful, and successful in involving the participant. The open-ended questions promoted free-flowing conversation and followed the thinking of the participant. Topics arose naturally from the conversation. However, the researcher was prepared to develop topics from the information given by the participant. Polit and Denise (1999) state:

> When self-report data are gathered in an unstructured way, the researcher typically does not have a specific set of questions that must be asked in a specific order or worded in a general way. Instead, the researcher starts with general questions and allows respondents to tell their stories in a natural conversational format (p. 67-68).

Questions and possible probes that were implemented to stimulate conversation with the participants included those in Appendix B.

After the data was analyzed the participants were asked to participate in a second interview. During this session the participant had access to the transcription of the first interview as well as the researcher’s analysis of the data gleaned from the interview. The participant was asked if the data accurately reflected what he/she was saying. The participants also agreed on a composite definition of end-of-life decision-making, based on their interviews.

The researcher took notes during the interview in addition to the audio taping. The notes will serve as incidental observational data. Immediately following the interview the researcher wrote detailed memos about the session. Miles and Huberman (2001) explain that :

> Memos are primarily conceptual in intent. They don’t just report data; they tie together different pieces of data into a recognizable cluster, often to show that those data are instances of a general concept. Memos can...be personal, methodological, and substantive. They are one of the most useful and powerful sense-making tools at hand (p. 72).

It is important that memos be written down intelligibly and without ambiguity to ensure accurate exploratory analysis. Memos can be stored in filing boxes or in computer files to be saved for this study or future studies. A journal was also kept by the researcher detailing general ideas about the study as they presented themselves. Journaling can also provide an audit trail to monitor each step as it is taken and clarify how and when the steps of the data collection procedure were completed.

An independent transcriptionist transcribed all interviews. Within 24-48 hours, the researcher crosschecked the transcription with the tapes to assure accuracy. Each transcription was identified by alphanumeric code, ensuring confidentiality. The transcripts were then put in the locked file until coding took place. They remained in the locked file when not being directly used.

An essential aspect to exploratory research is the concept of *bracketing.* Brink (1998) explains that:

> *Bracketing* is for the researcher to first write out, fully, everything she or he has ever experienced or thought about the particular topic to date. This constitutes a full and complete exploratory interview of the researcher by the researcher. This 'bracket' is then set aside as apart of the data and is used to refer to later as a possible bias or direction that has influenced the 'intuitive' process (p. 313).

By examining the memos and bracketing, the researcher and participants involved in member checking can develop insights to avoid skewing the results related to personal biases in the questions and coding.

Data Analysis

Interviewing is the foundation for data analysis. Data analysis begins as data collection starts. The researcher must maintain records in the form of journals, memos, interviews, and audit trails and constantly review them. The researcher must become immersed in the data. Audio taping of all interviews precludes recall bias and allows the interviewer to focus solely on the contents of the interview. The constant comparative method (Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990) will be used to generate an explanation of nurses' experiences and perspectives. Data is examined, phrase-by-phrase. Each phrase is classified or *coded* under a specific topic or theme. These clusters of coded data are constantly reviewed and possibly re-coded, as their relationship to the context of the entire bank of data is determined. Categories and sub-categories of themes are developed.

This type of data analysis is known as content analysis. Hettlinger (1999) states that:

> Content analysis begins with reading the text or written transcription of an interview, notes for an observation, or some other mode of data collection….The investigator reads that completed text and determines the main ideas or topics, then re-reads and assigns a code. It is re-read again and assigned a code to each segment of groups of lines—*labeling.* The codes reflect some commonality, such as action, behavior or context (p. 64).

Speziale and Carpenter (2003) categorize coding into three levels. Level I coding often uses words verbatim from the participants. Level II compares the codes and the data from one category to another, and one participant to another. The data are clustered according to code and each category is compared with the others to assure category exclusivity. Level III describes what is going on with the data and identifies central themes and processes.

Level two contains several types of coding. Creswell (1998) categorizes them as follows:

1. *Open coding:* The researcher forms initial categories of information about the phenomenon being studied by segmenting information. Within the categories, the researcher finds several properties and looks for data to dimensionalize the properties.
2. *Axial coding:* The researcher assembles the data in new ways after open coding. The researcher identifies a central phenomenon, explores causal

> conditions, specified strategies, identifies the context, and delineates the consequences for the phenomenon (p. 57).

Level 3 contains what Creswell (1998) calls the "*Conditional Matrix,* where the researcher develops and visually portrays a conditional matrix that elucidates the social, historical and economic conditions influencing the central phenomenon" (p. 57).

Following the leveling procedures, the remaining categories are combined into a category of a broad scope that explains the phenomena being explored. The categories are descriptions of what is happening with the phenomenon. This process is similar to that of grounded theory except that exploratory methodology is theory neutral, providing a background or springboard for further studies that will lead to an understanding, or theory, of specific behaviors and results.

During the data analysis participants participated in member checking. If topics are based on a concept, framework or focus, they must be justified, described, and explained in terms of being representative of that focus (Kitt, 1999). According to Speziale and Carpenter (2003), member checking allows participants to check and verify the accuracy of the information recorded. Member checking assures the rigor of the study and is a part of what Lincoln and Guba (1985) define as trustworthiness criteria. Member checking occurred after the data from each interview had been coded and themes emerged. Participants were asked to review their comments and agree or disagree with the themes that the researcher applied to their interviews. None of the participants disagreed with the emerging themes or data.

Following the explanation of the phenomenon under study, a literature search was completed to learn what has been published in relationship to what had been discovered through the exploratory study. It provided explanations or contradictions to the perceptions and perspectives discovered in the initial analysis.

Strengths and Limitations

Major reliability and validity issues of context analysis involve the subjective nature of researcher-determined topics or category labels. Reliability can be assured by having two or more participants agree that the topics are appropriate for a particular study and that data can be easily organized into each topic. A limitation to the study was that, due to the subjectivity of the research and sample size, the results are not easily replicated. Another limitation is that the settings of the study were two mid-size suburban hospitals and did not necessarily reflect the perspectives of nurses employed in other types of facilities, such as teaching hospitals, small community hospitals, and medical centers.

A major strength lies in the researcher's extensive critical care experience which enhances the ability to focus on pertinent current issues relating to the aims of the research. The researcher possesses a working knowledge of critical care protocols which are rudimentary to nursing practice.

Conclusion

This exploratory study described the perspectives (attitudes, values, and beliefs) critical care nurses have regarding end-of-life decision-making with patients in ICUs. Essential to this study was the determination of what the foundations are for the attitudes, values, and beliefs of the ICU nurses. The purpose of constructing explanations for the perspectives was to ensure that patients and families receive care and guidance that will facilitate end-of-life decision-making. Patients and families who are given information and are encouraged by ICU nurses to make end-of-life decisions will hopefully be satisfied that they received the information and care needed to make informed decisions that reflect how they wish life to end. An additional benefit is that the findings of this study may provide nurses, in clinical and academic settings, a foundation to develop processes for patient and family advocacy on the issue of end-of-life decision-making.

CHAPTER V

FINDINGS OF THE STUDY

Introduction

The findings of this study were compiled following taped interviews, written transcriptions, coding, and grouping of the interview data into pertinent themes. Themes were organized according to the research question to which they applied. The research questions are:

1. What are critical care nurses’ perspectives regarding their role in end-of-life decision-making with patients in Intensive Care Units?
2. What are the perspectives of critical care nurses in end-of-life decision-making with patients in Intensive Care Units?
3. How do critical care nurse participate with patients and their families in Intensive Care Units making end-of-life decisions?

Substantiation of the findings was confirmed through member checking and is best illustrated in specific examples or scenarios related by the participants during the interviews. The examples used are representative of the findings gathered from the majority of the participants.

The participants were found using purposeful sampling. All of the participants volunteered after reading fliers that were distributed to the adult Intensive Care Units of Edward Hospital in Naperville, Illinois, and Provena St. Joseph Hospital in Elgin, Illinois.

Saturation was achieved after in-depth interviews with 11 participants. There was no new material presented and the majority of participants were in agreement about key themes that will be discussed in the following specific sections.

Demographic Results

Ninety-one percent (n=10) of the nurses interviewed were female. Eighteen percent of the nurses (n=4) were between 31 and 35 years of age, all of whom worked full-time in adult Intensive Care Units. Sixty-four percent (n=7) of the nurses have earned certification in their specialty area. The average number of years of working experience was in the category of between 11 and 15, with the most experienced nurse having 30 years of experience and the least experienced nurse having worked in the Intensive Care Unit for one year. Sixty-four percent (n=7) of the nurses are Caucasian, nine percent (n=1) are Hispanic, 9 % (n=1) are African-American and 18% (n=2) are Asian American. Forty-five percent (n=5) of those interviewed are Protestant, 37% (n=4) are Catholic, 9% (n=1) are “other” and 9% (n=1) are atheist. (Appendix G)

Perspectives of Critical Care Nurses in End-of-Life Decision-Making with Patients in ICUs

There were six major themes identified by the participants after dialoging about their attitudes, values, and beliefs regarding end-of-life decision-making with patients in ICUs. The themes were: quality of life; religion, spirituality and culture; decision-makers; advance directives; barriers to decision-making; and attitudes about death. Each theme was based on a definition of “end-of-life decision-making” that was a conglomerate of the definitions given by each participant. The definition was formed by synthesizing the concepts about end-of-life decision –making from all of the participants. During member checking, all of the participants validated that the definition derived from the interviews reflected their beliefs.

For the purpose of this study, the participants' definition of end-of-life decision-making is: End-of life decisions are those decisions made by patients and/or families, after considering the possible options of treatment. These decisions are based on quality of life, comfort, and/or ability to maintain self-care, resulting in the establishment of a do not resuscitate order, living will, and/or Durable Power of Attorney of Healthcare.

Quality of life. Quality of life was expressed by the participants as being the basis on which patients and families make end-of-life decisions. Participants indicated that patients' perceptions of quality of life, in fact, instigates the process of end-of-life decision-making. Two viewpoints of quality of life were addressed by the participants. The first was what critical care nurses themselves perceive as quality of life. As one participant expressed:

> Well, I think quality of life is very important to me. I think approaching a person by saying that if they come out of this, what's going to be their life if they get past this one portion? For instance, are they going to be on a trach [tracheostomy] and a ventilator the rest of their life, stuck in bed, and they are 80 years old? Are they going to be strong enough to get off of it? I think approaching the family with those quality of life issues is important.

Yet another participant illustrated a viewpoint of quality of life in this manner:

> Yes, I think I used to think, when I first came out of nursing school, 'Da da da da da da! Charge! Save lives!' And now it is more like, 'Okay. Discuss this person's quality of life. If we continue to sustain them on a trach [tracheostomy] or a vent [ventilator], with a tube feed, or they are not really responding, is that really a good quality of life for this person and for the family members who have to witness this, and so on and so forth?' I don't know, I think as I've gone through my nursing career, it just depends on what they have. Because if you have cancer, then obviously, it is kind of a terminal thing. Then yes, it's going to be a natural death. Let go. But I think more and more, you know, I think for me personally it is more acceptable now that it was before to help my patients die with dignity, versus at all costs by saying, 'Let's save them.'

Quality of life was expressed by one participant to be different for everyone: nurse, patient, and family. It was explained like this:

> I think quality of life is a huge issue for me. I see what we do to some of these patients. We leave them sitting in a bed for three weeks if there's no expectation of them getting their life back, and not necessarily just having life, but gaining what life is to them. If I don't see that as a reality for them, I take it upon myself to just kind of feel them out. If they are having the same thoughts, you don't have to say much to get all those emotions and conversations going…I think there's a difference in quality of life; and that's a definition that we each have for ourselves. There's no universal definition of what quality of life is. And that's a discussion that I frequently have with patients' families. They (patients) may survive this, but you're not going to get your mom or dad back. For some reason they have an easier concept of grasping that. What is the goal? Is the goal to get then home to pass at home, if they're in critical care? Is the goal just to get them off the vent so that you can talk to them one more time? Is the goal to get them well enough to walk out of this hospital? Because there are a lot of issues, a lot of times walking out of the hospital is probably not going to be an option. So I think that's a discussion that is also, what do you want out of this? And then it goes back to, what is your definition of quality of life?

Participants also expressed that patients themselves may have their own opinions about what quality of life is, which greatly impacts their decision-making process. One nurse explained:

> I have a gentleman that we are taking care of; he has a whole list of things wrong with him, and he knows that he's not going to be around maybe two more years. But right now he's hanging on and I think he's hanging on for his family because he's tired of fighting and it's hard. I think a lot of it (decision-making) has to do with, 'Am I going to be able to do what I've always done?' And for the most part, the answer is usually 'no.' But I think that a lot of the patients feel that at least they can enjoy their family. They can have quality time with their family, even if they're not up walking and doing everything they used to do. If they are at least neurologically functioning, they can talk and interact with family members.

And as one participant succinctly put it, "I think it comes down to quality of life versus quantity."

Religious, spiritual, and cultural beliefs. Eight of the twelve participants expressed that religious or spiritual beliefs have a major impact on end-of-life decision-making for the nurses, personally, and the patients and/or their families. When asked how a person should deal with death and decision-making on a personal level, one participant stated that:

> I think you have to consider what you think your purpose in life is and what you think, if there's eternal life or there's not or what your perception of that is, so that would be evaluating your faith and what that means to you. I think regardless of religious background or lack thereof, that's the biggest question about death, is about what happens afterwards. So people who assume that there is no afterlife---or people who think that, you know, the physical death is it. There is no emotional, sorry, spiritual afterlife. That's a choice in religion automatically for them. I think your perception of death is a direct reflection of what religious or lack thereof you have…Physically, it's the death of the body. There's no discussion about that. It's a finite concept. It's the spiritual aspect that's the hardest part to deal with.

Another commented that, "It seems like the religious role does play a factor, either positive or negative. Some religious beliefs are so strong that it's interpreted that you must do everything to preserve life, and then some feel that the quality of life is so much more important than the quantity."

One participant who indicated that religion plays a large role in end-of-life decision-making mentioned religious clergy:

> Especially like religious priests and rabbis who really, you don't see them visit a lot, like some of these people, but they do at the end-of-life time. They feel more close to having to talk to them and get ideas of what family members and patients do. They will sit at the other end of the phone, talking most of the time, and say that's not the right thing to do. They feel guilty. I think those people play a very big role in the decision-making, too.

Several participants commented about how religion influences families about what end-of-life decisions to make. One commented that:

> I think, growing up, my parents always said, you know, 'Don't ever keep us alive unnecessarily.' Your wishes were always known, and I know when we recently made the decision—my dad actually made it for my mother to do the terminal wean. There were several members of our family who aren't in the healthcare field who were very upset, but went along with my dad's decision to do it because knowing she would never come off the ventilator, that it was so sudden with my mom. With my dad we had time to assimilate it, too. I think their view on, a lot of times, their faith, their religious faith. We are Catholic, so we know you will be in everlasting life with God. And my dad's looking forward to being together

> with my mom, and all the people he hasn't seen in so long. Just knowing that it really isn't the end of life, being the end of life on earth, so to say.

Contrary to the previous anecdote, another participant told a story about how religion can prevent end-of-life decision-making:

> We had one case one time that the daughter was mad at the nurse because he kept saying, 'Well, she's turning for the worst, and I don't think we can do anything. I think we've done everything, and I think this is it, or something, and we need to decide what you want to do with him, blah, blah, blah.' And the family was just quiet. And every time this nurse walked in the room, he'd just say the same thing. I think they did it three times, and the daughter was supposed to be a lawyer. And she said, 'He made us think like we're so stupid, and we don't' know what it is about.' And they didn't have a Durable Power Of Attorney (DPOA) because the parents didn't want to sign, even though she was a lawyer. They came from a very religious family, Catholic. And they call it 'mercy-killing.' We coded him three times before he finally died. My religion? They do not accept. I'm Catholic and they do not accept, what do you call this? Like the DPOA thing, I don't know if they accept that at this point, because this is like mercy killing or something.

Two participants expressed that their understanding of religious beliefs and their importance in end-of-life decision-making were instrumental in understanding how and why decisions were made. When asked by the interviewer, "What aspects of your life do you think influence how you feel about death and dying?" the first participant stated:

> I think a lot of it is my strong belief in my Christianity. You know, personally if it's my time to go, it's my time to go. I've got three little kids. I don't want to go, and if I even say I've thought about it I would just cry, knowing that I couldn't enjoy my kids' lives. But luckily for us, we're not dealing with 34-year-olds. Most of the time we are dealing with patients who have lived their lives and they need to be able to enjoy it. And so when it comes to that I just try to encourage the family to celebrate their lives, and I do that a lot of time sat the bedside when we're doing a terminal wean. 'I understand you're hurting and you're going to miss them, but tell them how much you love them, and tell them how much they've meant to you. Celebrate everything they've ever –you know, all the good times you've had.' And a lot of times they do. We have a patient right now who's been here for, gosh, I think she's going on three or four weeks. The family has made it quite clear: we're going to take her home. And they've make it clear, whether they are Christian or not, they're believers in God and so I try to use that to my advantage, because I am very much Christian. I very much believe that God has His time for us. And if I know they're comfortable in hearing that, because I know not everybody is when it comes to religion, I'll say, 'You know, if you honestly feel that it's in God's hands, then you're not stopping

> Him from doing what He's ready to do. Because He's ready for your mom, but you're not letting Him take her.' And actually, I've had quite a few patients be very receptive to that and they come back in, whether it's a few days or a few hours or a day, and say, 'You're right. My mom wouldn't want this, and you know, she's a strong Christian, and this is what she wants.' Sometimes it works. I won't use it unless I know that I've heard them speak openly about God or not wanting them to suffer.

The second participant, approached it from a slightly different aspect, relating:

> There are some religious groups where it's very difficult, like Holiness Pentecostals, because they do believe in miraculous healing, perhaps more than other groups. They even have some rituals like laying on of hands and they might feel more comfortable. I am lucky that I have a whole county full of relatives in Indiana who are Holy Pentecostal, so I might have more understanding of it. And I've used that understanding, I think pretty well, because to the chagrin of my coworkers, I've sometimes said, " Why doesn't everybody come in at once and lay on hands?" Well, that makes everybody kind of wince in the unit, but sometimes if you do that then you just encourage them that they've turned it over to God and they can go home. And they do!

Culture was also addressed as a pertinent issue in end-of-life decision-making by many of the participants. As one explained:

> I definitely think there's a cultural component, and forgive me if I'm stereotyping, but it definitely seems like the African American population has difficulty with end-of-life decisions, or making decisions about that. Definitely Asian culture as well. They value life so much that they have a tendency to overlook the quality of life. So I think culturally it plays a huge role. And then the spiritual role as well. It seems like the religious role does play a factor, either positive or negative. Some religious beliefs are so strong that it's interpreted that you must do everything to preserve life, and then some feel that the quality of life is so much more important than the quantity.

One of the Asian participants described the cultural component like this:

> Most people from Asia -- I'm from Asia too-- have different opinions about end-of-life, but you have to have an open mind and kind of like see what's going on. Asians, they don't believe in like the—they don't really do like the DNR thing, kind of like life is built in, at least exhaust your options. In fact, my best friend back home, her mother is eight-five and she has lymphoma and she's just going in and out of the hospital. Back home, you know, we don't talk of dying. Like personally my brother was diagnosed with cancer in 1989. He was in the Philippines and had to go home there three times, and we cannot tell him he has cancer. Because when they find out that they have a terminal illness, they lose hope, and the faster they die. It's like they will not eat; they get depressed.

> Whereas here you tell them so they could prepare. It's really a different culture, and even my uncle, who lived with him at that time, I couldn't tell him. The only reason he found out was that I was writing the US Consulate to expedite his interview, because he has an approved permission to come here. Then when they finally sent me a letter, he was gone. He was diagnosed at the end of September, had surgery the first of October, and died December 5th. And you know, we kept asking him, 'Is there anything you want to know?' like leading him on to ask questions, but he would only ask if there is any certain restrictions and what he could eat, since it's gastric, he wanted to make sure that anything he would eat would be okay. But he never asked what he had or why did they do the surgery. And I even asked the surgeon, when he told me it's cancer, 'So when do we tell him?' He said, 'You don't.' And that's the practice back home.

Decision-makers. All 11 participants agreed that the responsibility for making end-of-life decisions lies with the patients themselves. The decision should be autonomous. The most powerful example, when asked whose wishes should be followed at the end-of-life, was given by a participant regarding patient autonomy at the end-of-life:

> The patient's wishes. I wasn't even an RN; I was a graduate nurse working in an ICU with two corpsmen in a military hospital, and it was a Vietnam return center, and we had a guy who'd come back and his wife had given that sigh of relief, that she no longer had to bear all the family responsibility. The stations assist at Fort Riley. He was running fevers, and they worked him up, and it turned out the man had Hodgkin's, was end-stage, and they put him in ICU because our wards were full of Vietnam returnees who didn't even see another day. He was in our unit almost a month, and every time I would see his wife, she would say, 'Promise me you'll call.' And I would promise her that I would call. And the night he died, he went into fulminating pulmonary edema, and I'm raising the head of his bed up and I'm yelling at the corpsman to get the doctor on the phone, and he grabbed my arm and said, 'Don't call.' And that really wasn't fair, because I was really only a graduate nurse. And I didn't call her. And when it was over, I called the chaplain who'd been working with her who went to the home and got her and brought her in. And that was a hard lesson. I thought about it for a long time. Did I do the right thing? I now know I did the right thing, but at the time I wasn't sure that I did. But he had the right, and it was not a pretty death, and I can understand why he didn't want her to see it and have that memory.

Believing that end-of-life decision-making should be autonomous was not exclusive of family involvement according to several of the participants. When asked what end-of-life decision-making involved, one participant explained:

> It is ultimately the quality of care, and this is an ICU setting, their quality of care, their wishes, what the family's perceptions of their wishes are, who the DPOA is, or the decision-maker, if they're on a ventilator and can't communicate. If they are able to communicate, are alert and oriented, ultimately, it's what their wishes are. And if they choose to, I guess, withdraw treatment, actually, it is ultimately their choice. If there is a spouse, it should be between that person and the spouse or the significant other, first and foremost, and then the family.

Another explanation was that:

> I think it should be family-oriented type thing, but ultimately it is the patient. If the patient is competent enough, he has the final decision. He or she has the final decision whether, you know, he just wants comfort measures or end-of-life terminal weaning from a ventilator. I think it should be a family process, but keeping in mind that it is the patient's decision. But on the other hand, if a patient's not fully aware of his surroundings or not in a state where he can make his own decisions, then I think it should be the family.

Advance directives. The presence or absence of advance directives was addressed by all of the participants as being crucial to the issue of end-of-life decision-making. For the most part, the participating critical care nurses believe that not only are advance directives an integral part of end-of-life decision-making, but are in essence the definition of end-of-life decision-making. For example, when one participant was asked, "When do you think that you should start discussing end-of-life decision-making", the response was, " I think if somebody has a family and they're still healthy, they should try to get some sort of discussion going. I guess for me I feel like it's kind of like the same thing as advance directives. You know what I mean? It kind of encompasses everything."

Yet another participant explained:

> I think if people have already explored that (living wills and durable power of attorney) before they come into the hospital, it makes it so much easier. When that is defined clearly as to, you know, where you're going in your treatment modality. It defines their wishes as to if they were ever in a position where something weren't reversible or transient, and if they had a terminal illness, that type of thing, that their wishes be known that they did not want to be kept alive for naught.

Other nurses stated that advance directives are the “link” that facilitates discussion of treatment and decision-making with both patients and families. When asked how she participated in end-of-life decision-making, the participant stated:

> Discussion of end-of-life issues should begin upon admission. Upon admission we should give them the option. Ask them whether they have a power of attorney or offer them services that are like a living will or definitely begin it upon admission. Then I would probably participate to a certain extent to the point where, if the patient has s living will or an advance directive, I would probably just comment that, you know, this is what your mother has stated in her living will. I would just bring that up, but I wouldn’t be overbearing to the fact that where I would basically be telling them. I would just kind of restate, reinforce, that the patient has a living will, durable power of healthcare, and I would just kind of end it like that…just kind of bring it up.

Another perception was summarized by what the majority of the participants related:

> I think power of attorneys and living wills should be done, ideally, when death is not imminent. But at that point then, whenever you’re appointing your agent as your power of attorney, at that point you should have family discussions. When people are healthy, the time when you’re healthy and you’re not sick, that’s the time you’re going to have the clearest perception of what you may want in those situations. Oftentimes—and not that it can’t change—you make a conscious decision at that point. When you’re already lying in a critical care bed and multiple drips are infusing, I think we’re dealing with more issues of fear and anxiety than what they would really want, because you know, it’s not that their perceptions can’t change, but I think that those discussions should happen when death is not imminent or death is not a threat to them at all. That’s when you’re going to have a healthier discussion about what they want.

Only one participant discussed advance directives in a negative light. It was stated that:

> I think that the whole Living Will thing is kind of a joke. I’ve seen it on the chart where it’s disregarded by family members, either because they can’t make a decision, or they don’t know the family well enough to honor it, which is really sad. Or I’ve seen the opposite where it’s the family needs more time and the medical staff, you know, definitely goes with the wishes of the patient and kind of disregards the whole family issue. It seems like, if you’ve got that DNR by your name, then the care that’s provided to you might be less, and sometimes it’s interpreted by the family as well. And I don’t interpret it that sway, because actually the care of an end-of-life patient can actually be more challenging than

> treatment itself, because you're dealing with care of the family, you know, oral care, skin care, and turning comfort care. But I find that to be a huge difference between critical care nurses, and some of it's interpreted as, 'I don't have to do anything now.' Or so they're--it's funny, you find out with the DNR, it really isn't related to what they're here for now. Like, they're a DNR, but the patient came in with a ruptured appendix and surgically post-op is doing well. It has nothing to do with his treatment now. So there's that confusion. Well, I think that we loosely use this DNR paper. I think legislation just stuck it out there and like no one knows what to do with it. I think it—we have all these different rules about it, like, 'It doesn't really apply because they had surgery. So now it applies for 24-hours after.' Well if the guy bleeds out 26 hours after a surgery, does that mean that you're not going to do anything, but if he would have bled out 23 hours after surgery, you would have done something? It just seems like we try to look at it from a paper perspective rather than from a brain perspective. Looking at the patient as a human being and why they wrote the DNR order in the first place has everything to do about how you treat the patient, and the only way you're going to know that is if you know the patient and if you talk with the patient and if you've established a rapport with this human being, because that's what we're working on, is human beings.

Barriers to end-of-life decision-making. Another perspective that was addressed by all of the participants was that there are definite barriers to patients and families making end-of-life decisions. These barriers are manifested in several different manners. The most prevalent barriers, according to the participants, are those involving physician resistance, family denial, and unreasonable expectations of the patients and families involved. When asked, "Who deters end-of-life decision-making," one participant replied:

> There are some doctors…you know a lot of our patients are older, eighties, nineties, a hundred. Families come to term with the fact that they're going to be passing here soon, one way or the other. The patient will point blank say, 'I've had a great life. I'm ready.' And sometimes the doctors, I don't know, they are not ready or what holds them back, but sometimes the process of withdrawing treatment and end-of-life is longer than it should be. It takes several days to a week longer because the doctor doesn't want to give us—because the order will come from the doctor, and they talk to the family and will wait another 24-48 hours. Wait. There's another thing. Well, let's wait this long. And the family starts getting frustrated. It's a tricky business. I have to call in Pastoral Care. Not to say legality is a primary concern, but you have to make sure everybody's on the same page, and I can't pull off the vent without a doctor's order legally. So I need help. (laughter) Lot's of help.

A second participant concurred, stating that, “I certainly think that whether or not physicians believe it or not, they truly have a lot more of a role (in decision-making). I’ve had things (end-of-life decisions) established and then they’ve shot it down because of their own personal comfortableness with the situation, especially surgeons.”

Yet another participant was even more vocal about this issue. When asked, “What is your biggest obstacle right now to end-of-life decision-making,” the response was:

> Doctors. Doctors don’t want to write DNRs. I don’t know if it’s…I don’t know why they don’t. I think more ICU patients should have DNRs, because we’re doing everything already. You know, cracking somebody’s ribs doesn’t necessarily bring them back, you know? Once you’re doing all these interventions, I think most of them should be DNRs. Or there should be some set point: We’ll go to here. And maybe we need to redefine the levels of DNR. Maybe it needs to go beyond, you know, if somebody defibrillates, we’ll shock him. You know, that’s easy to do, but to intubate them? I don’t know. So we still have the problem of the physician having the final say about what is terminal. I think everyone should have Advanced Directives, but there are still times when we have to fight with the physician to get that order not to resuscitate or they’re doing things that are just…you know, I think that when it’s obvious that someone is terminal, they need to stop doing even some of the diagnostics. At what point are we just wasting everybody’s time and giving false hope?

Another barrier identified by the participants was that of unrealistic expectations. Generally, it is unrealistic expectations of the patient’s family. As one participant verbalized it, “ I think families have, they obviously don’t have the knowledge base, but I think they have unreasonable expectations at times when we’re at end-stage disease processes. I think they have just unrealistic expectations.” One example that was given was:

> I know that we had a lady that had expressed to her daughter that she did not—or everyone knew that she did not want to really live any longer, but she knew her daughter could not live without her, so she said, ‘I’m doing this for my daughter. I’m staying alive for my daughter.’ She said the daughter was just so unrealistic that she, as I said, was willing for her mother to go on needlessly when she didn’t want to just for the sake of her. I think a lot of times by the time that there might

> be a conflict, a lot of time the patient has lost consciousness here, so basically it's the conflict resides within the family and whoever is the Durable Power of Attorney, and their own internal conflict, because a lot of times we don't see a lot of conflict. It's basically the family trying to make the best decision that they can live with once their loved one is gone, because I tell everyone, you know, 'We just want you to feel right with making a decision you can live with, because that is not our desire to have you make something that you don't feel comfortable with about your loved one and have to live with that and not feel right about it, because once that patient is dead, you're the one who's going to have to live with that for the rest of your life, and we don't want to put that guilt or whatever on you. That's not our intention.'

When denial is an issue, it can lead to further barriers, as indicated by another participant:

> Really it's some of the family members that just are in denial of what's going on sometimes. It's a little harder to approach them about end-of-life decisions or to get them to realize what exactly is going on with the patient if they're not getting better or they're going downhill or something. I just continue to explain to them what exactly is going on with the patient; asking the doctors to sit down and talk with the family member about the prognosis; I think that's really important. Sometimes the doctor, they just, they all kind of just, well, from the standpoint he's okay, and 'Well, we're going to keep watching,' Sometimes they don't actually tell the family member, 'Look, this is what's going on. This doesn't look good.' I think that the doctors sometimes need to sit down with the family members more and actually talk about the prognosis of the patient.

Critical care nurses' attitudes toward death. The majority of participants agreed that death is a natural, inevitable event. This was not only articulated by the participants, but the participants were also very stoic and pragmatic when discussing death and dying, relating scenarios from experiences, and discussing the concept of death and death in their personal lives. Very little emotion was evident into their voices or mannerisms.

Only one nurse showed emotion when being interviewed. She cried throughout the entire interview because she stated that she was relating the death experience to her aunt who had recently passed away. This nurse was the participant with the least experience in ICU. She had been in critical care for only one year and had recently switched from the night shift to day shift. She explained that she had not had much experience in dealing with families and patients who were dying and was learning from the more experienced nurses on the day shift how to handle these situations.

In response to the nurse's distress, she was encouraged to vent her feelings regarding the death of her aunt. The interviewer shared experiences of dealing with death early in her career and how there are different methods of dealing with personal feelings while providing support to the families. The participant was reassured that crying is perfectly normal. When asked if she felt that she needed any personal assistance with dealing with issues of death and dying, the participant stated that it was not necessary, the other nurses in Intensive Care were very supportive and were mentoring her quite well.

The majority of those interviewed felt that death is a fact of life that we all have to deal with, especially nurses. Some of the comments included: "My feelings about death and dying are natural. We should let patients die with respect and dignity." " I think it (death) is natural. I don't think people should go out of this world in pain or very agitated."

Others explained how the concept of death being natural has affected their nursing practice:

> I don't know, I think as I've gone through my nursing career, it just depends on what they have, because if you have cancer, then obviously, and it's kind of a terminal thing, then, yes, it's going to be a natural death. Let go. But I think more and more, you know, I think for me personally like it's more acceptable now than it was before to help my patients die with dignity versus at all costs, let's save them. So death is definitely obviously a part of life and everyone's going to die and obviously you don't want that to happen, but I think, for me, it's definitely more acceptable than it would have been even five years ago. In the United States, when you grow up and you're like, "I'm going to live forever!" Like nothing can stop me, type thing, and then there ARE things that can stop you, obviously, and I think it's just, in our culture, especially, I don't think death is as acceptable as in another country, like Peru, where death is almost a grace, like you are lucky.

Yet another participant stated that:

> I think it’s part of life. I don’t think death is always a bad result. It’s the end result of every single living creature, and I don’t think it’s something we should be avoiding. I guess you see – in critical care you see so many people pass away—and you realize that that is the end result for every single one of us. And I guess, as a nurse, you start to reconsider what the goal of nursing is. And it’s not always to prolong life. I think when we get in those situations the goal is to make what’s left of life the most comfortable or the most meaningful for that patient and that family. And I think that the goal then is to make the passing more peaceful and painless and the best experience, unfortunately, that’s going to happen. Physically it’s the death of the body. There is no discussion about that. It’s a finite concept. It’s the spiritual aspect that’s the hardest part to deal with. I think you have to consider what you think your purpose in life is and what you think, if there’s eternal life or there’s not or what your perception of that is, so that would be evaluating your faith and what that means to you. I think regardless of religious background or lack thereof, that’s the biggest question about death, is about what happens afterwards. So people who assume that there is no—or people who think that, you know, the physical death is it, and there is no emotional, sorry, spiritual afterlife, that’s a choice in religious automatically for them. I think so your perception of death is a direct reflection of what religious or lack thereof you have.

What Are Critical Care Nurses’ Perspectives Regarding Their Role in End-of-Life Decision-Making?

There are three distinct characteristics that describe the role of the critical care nurse’s role in end-of-life decision-making according to the participants. There were no deviations from these characteristics and every participant mentioned all three characteristics. The role of the nurse was explained as being three-fold. The critical care nurse is felt to be an advocate, an educator, and a communicator to the patient and the family.

Nurse as advocate. When asked what the role of the nurse was in end-of-life decision-making, some of the comments regarding nurses’ role as patient advocate included:

> I think my role is supporter of the family members, advocate between them, and communication with the doctor. If they have second thoughts about whatever decision they’re trying to make, relaying that to the doctor. I think that should be clarified. Also trying to mediate communication between the patient and the

> family, not just fighting, if it comes down to that. We actually had a patient here who was a Jehovah's Witness and he didn't want any blood products. And his family said, 'What do you mean you don't want this blood. Are you crazy?' They weren't part of that religion's beliefs. And I think it's just mediator between the patient and the family, trying to explain to them why the patient wants this decision made.

Another participant explained:

> Well first and foremost it's being a patient advocate. It's like it's horrible, especially when you're in the Intensive Care and you can't—you don't—you aren't—you're basically just a shell half the time, you know what I mean? You're sedated or you know on all sorts of stuff that where you're just not able to fully speak for yourself. I don't know, mostly like just the basic goals: following patients' wishes, and being a patient advocate. Being a patient advocate in critical care is adjusting the knowledge deficit that comes along with all the morbidity and the disease and processes and treatments and everything else, but it's making—a lot of the patients make informed decisions, and I think that 's the key word, "informed." If they choose something that I would not choose, but they're appropriately informed about it, I respect that. I get concerned when patients or families make decisions not based on not having all the facts. I think nursing, that's the job, to make sure that our patients have informed decisions about what's involved, about what treatments they want and how far they go.

Another participant agreed that:

> We are basically the spokesperson for the patient and the family member. Sometimes we can talk for the family to a physician in helping them make the decision, or sometimes a certain culture of people do want to come to that decision to help their family member not suffer a lot, but they feel guilty, so I think as a nurse I can be their voice to help them understand how other family members understand, and religious people understand, as well as to bring the doctor in terms with the family members so that they can sit down and have a conversation, I think. They do recognize that. I've been a part of some of them.

Other participants likened being an advocate to "being a cheerleader for the patient, regardless of what the family issues might be. I think it ultimately falls to what the patient desires," and "being the patient advocate and going with the paperwork kind of thing and helping make it a little more black and white versus gray." All in all, what did the participants believe patient advocacy to be? As one defined it:

> Patient advocacy, well, when there's something going on, first and foremost, we're taking care of our patients, We're stepping up for our patients. If we're looking at patients who've been intubated for day nineteen, day twenty, around

> day nineteen, day twenty we should be talking trach or you know, let's say this family really wants to withdraw treatment, this is what the patient wants, and we're looking at intubating, and there is a Living Will. Calling the doctors. Before we get to that point where' it's an emergency, saying, "Hey. This is what the patient wants. This is what the family wants. I heard it from them. If you need to hear it from the patient, you need to get in here." So that procedures don't get done to the patient that they don't want, or a procedures do get done that they do want. And everybody…you know, patients will change their minds as they're informed, so it's our job to inform the patients to certain things and then evaluate whether or not that's what they want.

Thus, according to the participants, advocacy involves being a liaison between doctors and patients, families, and patients; being a voice for the incapacitated; being a patient support person; and providing information for informed decisions.

Nurse As Educator. The second most common characteristic identified by the participants as a role of the nurse was that of educator. The participants stated that intensive care nurses have the role of educating patients, families and physicians about various aspects of care, patient rights and disease processes, in the hopes that this knowledge can facilitate them in making informed decisions. It was suggested by several participants that the nurse should fully explain what the patient's prognosis is, what the options are, and then let the family member or the patient make their own decision. Basically, just teaching and making the family member aware of the disease process is the responsibility of the nurse.

One participant stated that:

> They [family and patient] just don't know when to ask questions. They don't know what the progress is of the plan of care. So you really have to guide them into that saying, 'This is what we can do. These are the directions that we can take.' I'll go in different avenues with them and then I'll ask them, 'Do you want more information on any of these subjects?'

Another participant plainly stated that, "I think that part of the whole death and dying, there needs to be a whole lot more education, to the family, if they are going home, and to the family if they are staying in the hospital. There needs to be more education to the doctors and to the nursing staff taking care of them."

In general the critical care nurses stated that the patient wants to be educated about what is happening to them, what to expect and why. And the family needs to understand those same issues. In addition, the family needs to recognize what resources are available to them at the hospital, as well as in the community, to facilitate dealing with the possible outcomes.

Nurse as communicator. Of course, in order to educate, one must communicate. However, participants did identify other reasons to communicate and why simple communication with the patients and/or their families is quite valuable. For example, when asked the question, " If you were a patient and there would be a possibility that things could go from bad to worse, what would you want the ICU nurse to do for you and your family," one participant answered, "Oh, I guess just to keep the communication lines open. To let her know what my wishes would be and have it documented in the chart."

In another scenario, when asked, "How do you deal with family members who start to pull back from a dying family member because they cannot handle it and it is affecting the patient," the participant answered:

> A lot of times this happens. It's not really uncommon. You'll ask them how they're doing. You talk to them. You tell them what's going on. Encourage them to talk about their feelings, and if there are any stories. If a patient told me personally about them, because if they share with it, it usually makes them laugh. I don't say that I take the focus quite off the death and dying, but I ask them to tell me a little bit about their family member. You know, 'Can you tell me about him? I only got to see him like this. Can you tell me what a great person this person was basically?' And yet, especially if they're emotionally let down, it kind of starts to help stop that, I guess, to loosen out that whole freaking out stage, because they're focusing on how now 'MY mother or MY father used to point

> their finger at me and I knew I was in trouble,' or, you know, 'My mother spoiled my kids. I came down one day and they were eating cookies and whatever.' Usually they're laughing about it and crying about it, and I think they need that emotional release. Whenever I'm doing something and they're in the back corner freaking out, I explain why I'm doing and why I'm doing it. I'll say, 'I'm turning him because I don't want him to be sore. He may not be able to talk to us, but he knows that he suffers, because he's been lying on it.' Or, you know, 'I don't want him to have that fuzzy mouth, so I'm cleaning his mouth out because it will make him more comfortable. But even if he's not able to communicate, he's still there and he can still feel that.' I try to encourage that they can still hear you and they can, even though they can't participate with you, they still hear you, and so sometimes it works and sometimes it doesn't. Sometimes they need emotional support from the rest of the family. Sometimes that's just what they do. They don't want to deal with it.

Several of the participants related incidents illustrating how simple communication, initiated by the nurse, clarified end-of-life situations and resulted in positive outcomes for the patients as well as the critical care nurses. In one case a participant related that:

> Most recently I had a patient that was what I would consider, you know, DNR, Do Not Resuscitate, do not actually withdraw treatments for—and I think the family just needed another human being to say that that was all right, that that was okay; but because the primary care physician did not even approach that, we continued care, and I came in the first time I provided care for this patient, and I called the daughter right away, and I said, 'I'm sorry. Please explain to me what the plan of care is for this patient today. How—what are your expectations?' And when I chatted with her, it didn't take very long. It was a ten-minute chat. When I chatted with her, the woman had had a Living Will that she had never brought in. And she was just given the impression from the emergency room physician as well as the primary care provider that these—that what she had—was reversible, or whatever, and they were, but it didn't change the fact that the lady was demented and wasn't following commands prior to the event and was in a care facility. So if she was going to die, she would die of a complication other than her Alzheimer's and her dementia. She should die because of her pneumonia, her respiratory status, or something else, which is what she came in for. So I guess once I explored how did she expect her mother to die someday, ever, down the road, when I kind of explained it to her that way, she was like, why wouldn't you treat those things? And I felt great about it. I did, because she was given hospice. I actually made contact with the family member later; and she died 48 hours later very peacefully in her hospice setting with her family around her. So it was a positive outcome. But I was able to follow up as well, which was unusual.

How Do Critical Care Nurses Facilitate End-of-Life Decision-Making for Patients and Their Families?

The vast majority of the participants mentioned three specific nursing interventions that facilitate end-of-life decision-making for ICU patients and their families. They are: communication, involving multidisciplinary departments, and nurses initiating conversations about end-of-life decision-making. However, regardless of the implementation of these methods, over 60% (n=7) of the participants did not feel that their personal attitudes, values, and beliefs were used to influence the patients or their families.

Communication. Inherent to communication, in addition to basic communication with the patients, families, and physicians, were the concepts of veracity and emotional support. All of the participants mentioned communication as being essential to facilitate end-of-life decision-making. As one participant explained about veracity at end-of-life:

> I think you need to be—I think we need to be honest with the patient and the family about what it's taking to maintain life in the unit. You know, they may look good, but it's because we've got three drips and the ventilator going, and that doesn't mean that they're really better, it just means that we're hanging by a thread. I think that we need to tell them if we've had to go up and down on the treatments. If we're able to wean, I think that's great. If we're having to add treatments, we need to keep them informed with what we're doing. I'm very much for open visiting. I think that we should let them see what we're doing so they know that their loved one is getting care and they're getting everything possible. Honesty is most important, because I've seen a patient with a pressure of 60, and you talk to the family, they're having trouble accepting that this is really bad, and the doctor blows through and says, "Yeah, he might be a bit better," and of course the family then ignores everything you've said for the last hour and they're back into dreamland. The patient still dies. The family isn't ready.

Veracity coupled with emotional support was addressed like this by one of the participants:

> Sometimes we give patients and families unrealistic expectations. That could be in the beginning when the patient gets admitted and everybody knows that the

> prognosis is poor. I just feel very sad when we are in the nurse's station or away from the patient's room. The patient can remember what was said, then have a different attitude towards a situation. There is a family member; they offer all these hopes; and you…having family members myself…hang on to every word that comes out of the doctor's mouth. Even one word that encourages them; that's all they need. And if it's not realistic, we should not offer it, if we're not able to. And I think a lot of times it becomes very hard for the family, for the nurses taking care of them, for the families and patients to come up to a decision which could be more comfortable if they could have had support.

Other issues regarding communication being essential to both the role of the ICU nurse and the perspectives of the ICU nurse were addressed in previous sections. The concept of adequate and continuous communication with patients, families, physicians, and other departments was a theme that was threaded throughout the interviews of all of the participants, accentuating its importance.

Involving multidisciplinary departments. One hundred percent of the participants in the study targeted procuring the involvement of multidisciplinary departments as a major way that ICU nurses can facilitate end-of-life decision-making. The department mentioned most was Pastoral Care, followed by Social Work. Participants frequently mentioned family conferences that include physicians, nurses, pastors, case managers, social workers, and members of the bioethics committee, as well as family members. Sometimes the patient outcomes are good, sometimes they are not, according to the participants. For example, family conferences can be a useful tool. According to one participant:

> Oh, I think sometimes we've got patients who aren't doing well. You know, we'll ask them, 'Do you want the chaplain to come?' and a lot of times our chaplain (our chaplain's wonderful, and it's good to have them as a support). Sometimes Social Work helps, whether we're trying to get a patient home where they can be in hospice care. I think we use our resources well, and we've got really good relationships with our physicians here, and I think a lot of times that, you know, we feel like we're not getting anywhere. We call family conferences, and physicians—you know, with physicians—and I think we all just try to work together as much as we can to help with each situation.

Yet another offered both positive and negative outcomes:

> We’ve had patients that have had multiple family conferences with legal, the doctors, nurses, whatever, but the family is like, ‘No. We still want to do this intervention.’ I don’t know. I’m not real good with all that like legal stuff, but for some reason, whatever happens in those conferences, they can still push through and say we want this, this, and this done. You just kind of grin and bear it. It sucks for the patient, but…. Yes, the conferences are good. You know, we’re pretty good about initiating a care conference, especially when there’s like a couple of, you know, too many hands in the pot type thing, as far as family members. They are not necessarily being on the same page, especially if the patient isn’t able to advocate for themselves. I think the nurses are pretty good. We’ve gotten that all going. Another thing they have is like discharge rounds here during the week so that can kind of keep tabs on, ‘Why is the patient still here?’ ‘Is it going anywhere?’ ‘Do we need to get him shipped out to an extended care facility?’

Initiating end-of-life decision-making by the critical care nurse. Participants agreed unanimously that critical care nurses should initiate the discussion of end-of-life options to ICU patients and/or their families. There were several opinions, however, on what should precipitate initiation of the conversations and how the nurse feels about what she is doing before and after the conversation. Generally speaking, the nurses interviewed believed in initiating the decision-making conversation with either the family or the patient for a number of reasons. As one participant described it:

> Usually if I see that the patient has a chance of dying or the quality of life is greatly decreased I can either bring it up with the patient. You know, it’s just kind of a sense. You go in there and you see that the family’s got questions. I really don’t go in seeking to ask that, but you can kind of go in and ask about their plans, what do they want? What does the family want or the patient? If that subject comes up, then I will talk about it. I really won’t go into it, into a conversation saying, ‘I’m going to talk about this.’ If the family’s ready, then I’ll bring it up. If I see that the patient’s really going downhill or something, or I think there’s an impending death, then I guess I will bring it up.
>
> Initiating end-of-life issues can be done with ease according to one participant:
> I, in my own practice, I would say that I am kind of initiator in some of those discussions. I think quality of life is a huge issue for me, and I see what we do to some of these patients, and we leave them sitting in a bed for three weeks if there’s no expectation of them getting their life back, and not necessarily just having life, but gaining what life is to them. If I don’t see that as a reality for

> them, you know, I take it upon myself to just kind of feel them out, if that's…if they're having the same thoughts, you don't have to say much to get all those emotions and conversations going.

Discussing the issues affected the participants in a number of different ways. Typical of their responses were the comments of two ICU nurses. The first nurse describes feelings of frustration and inadequacy:

> If the illness was—you know, I talk about end-of-life decisions with patients that may not have end-of-life decision making for a little while, but if their diagnosis is terminal, or if they have a pulmonary element that I know that in the next two years I'm going to see them a lot, and they have not established or even talked about that with their family members, I'll encourage that, because, again, I'm not into suffering. I'm more than happy. That's what I do for a living. There are times when I feel like I'm not sure about my nursing. So if I know or understand the illness enough to know that I will see this patient again, that these things will come up, and they haven't talked about it, I will say to them, 'You know, you really need to sit down and talk with your family.' Or I'll say to the family, 'You really need to sit down and talk with dad or mom, because this will come up, and you don't want to be put….' You know, it's kind of like people who pay for their funeral ahead of time. If you don't want to put your children in this situation or, you know, that you will have to think about that. Is my job, is my role here to continue to see him suffering, or is my role here to—you know, I've had patients where I've went home and I thought, this wasn't nursing today. I was inflicting pain and suffering today.

Another participant expresses feeling ethically torn:

> I think if it's with patients who just come in, unless it's just like, you know, a brain injury and we just know that we can't do anything, we give it time, depending on with each patient if it's—whether it's a couple days or a week or so, we just say, 'Listen: We've done everything we can. We have him on maximum ventilation support. We have him on maximum human dynamic support. There's really nothing more that we're going to be able to do.' You know, then we can bring it up. Or if it's somebody, you know, who's just been suffering so much, and we got a patient just the other day. The patient might die who needed surgery, but the family didn't want to put her through that. So then we talked about it. I said, 'You know, you've got your two options: You put her through the surgery and hope that she gets better, when there was actually a strong possibility she wasn't going to, because the doctors really didn't know what they were going to find when they opened her up. You know she could have had massive bleeding which would have killed her anyway.' Or 'Do you want to make her comfortable? You know, we can give her the medication, we can make sure she's not suffering, we can make sure she's not feeling like she's suffocating with her breathing, and we'll let her go peacefully.' So each patient is different; and so is when you

> approach them and how you approach them. Some of the families are very difficult to approach, because they've made it quite clear that they're going to be difficult to approach. Or they've made it quite clear: you're doing everything you can for my mother. And that's hard. That's really hard, because you're feeling ethically that you really need to have that talk with them, because you feel like you've been putting that patient through something they shouldn't be going through for weeks.

Participants explained that there are several techniques that can be employed in initiating discussion about end-of-life issues. Techniques can vary from nurse to nurse, depending on their expertise in dealing with patients, families, or physicians. Some believe that timing is essential; others believe the manner of approaching the family is important; and others felt that being assertive is the best technique. For example one participant related:

> I think–the nurses usually do because they're here twelve hours of the day, as opposed to the doctor who's in and out. You know, they form a bond with the family members and they think that the nurses tend to do it more often, and that, if you can tell that the family members, in talking with the doctors, are getting to that point where decisions are needed to be made, I think the nurses can approach the family, at least just starting to think about what to do. You have to go in there with a caring attitude. You can't go in there and just, 'Your father's not getting better. Deal with it.' I mean, starting slow with bring up some things is better than just being blunt about it.

Another participant explained:

> I think it is just a matter of finding the right time and maybe that person's favorite nurse or whatever, and just sitting down and saying, 'Hey listen. I know you probably don't want to talk about this, but let's talk about it while you can still make decisions for yourself. Let's get it written down and stamped and sighed before other people have to make decisions for you that you may not necessarily want.' You know. Kind of an easing and a gentle probably process you know, and then unfortunately probably ganging up on him, like bringing in family members and doctors and, you know, to kind of reiterate the same thing until it kind of sinks in. Which is kind of horrible because if you're in denial you don't want to hear it, but if you were terminal and didn't want to hear about it at all. I'd have to respect that but no matter what, I'd want you to be, as my patient, an informed patient. So I would do everything in my power to make sure that that was the case, and even if it's got to be more like, 'No, I don't want to hear about it,' then I would say, 'Okay, we'll talk another time.'

Therefore, technique, feelings of personal or professional obligation, and definition of the nursing role, are all addressed by the participants when discussing the initiation of conversation regarding decision-making in ICU. Even though the participants relate initiating conversations of this nature, they state that they do not believe that their personal attitudes, feelings, and beliefs influence the decisions of the patients and/or their families.

Influencing end-of-life decision-making with the personal perceptions of ICU nurses. One of the nurses interviewed believed that personal attitudes, values, and/or beliefs were used in influencing the decision-making ICU patients and/or their families. The remainder of the participants stated that their personal perceptions were bracketed and they merely initiated discussion without attempting to sway the patients and/or families to adopt the nurse's beliefs. One participant stated unequivocally that, "Once I explored how did she expect her mother to die someday, ever, down the road. When I kind of explained it to her that way, she was like, why wouldn't you treat those things? So I did influence her with my personal views."

In response to the topic of if ICU nurses influence patients with their personal beliefs, one participant's response reflected the opinions of all of the others interviewed:

> I do have a lot of personal feelings on the subject, but I don't let that influence me when I talk to a patient about it. No matter what their religion is, and a lot of times I don't understand the religion. It's not a religion. Buddhism, you know, I'll bring in a priest or a spiritual advisor, if it's important to them, and have a conversation with the three of them, saying, 'These are your options. I'm not sure what you believe in. Let me know.' I can learn from it also. But no. Absolutely not. I give them all the options.

Several participants explained that it is not always what one believes in that dictates interaction with the patients making end-of-life decisions. Religion, or lack thereof, is the issue:

> If I had a brain trauma or if I had to have my normal function in bed and bedridden, I have asked my family, "Do not do that to me." That's just from my living. The person, not as a nurse alone but as a person. But if I'm functional and take care of my kids and do everything, and all of a sudden I can't do anything. I just lay there and do nothing. That's just my personal opinion. I do not judge other people with that, and if they have more different opinions, I totally respect them, but just for myself I feel like we should respect everybody as I respect myself. Nothing to do with nursing, because experience includes my job. Nothing to do with that. Because as I said, I have taken care of people who are older who are active and functional and very useful in society, and I've taken care of younger people who just want to be taken care of and they still want everything done because they just want to be taken care of. You see the kinds of people in your lifetime, but to help them make the decisions, my personal--nothing to do with religion, because I think my religion will always say, 'Do it to the max.'

The next participant expresses bracketing feelings and impartiality in discussion of end-of-life options that lead to intense personal satisfaction:

> For myself, I don't want to die in an ICU after spending two months here. If I can't leave the house, can't go outside and enjoy the fall leaves and the beach, then I probably wouldn't want to live. It's easy for me to say right now because I'm not in that position. I'm only speaking from what I've seen. As far as spiritually, I'm an atheist. I don't believe in God. I believe in a higher power, but I'm the first person to bring in a minister and talk to him about that. My father's a minister, which is kind of interesting. So I'm very open to that. I'm not closed to anything. I respect their beliefs. I'll do whatever I can to facilitate their beliefs, but personally, no. I think once I die, that's all. Why I like this job so much is that I might die, but my actions and my life will be remembered, and if I can help a thousand people, ten thousand people, then you really don't die in that respect. So that's why I do this job. That's why I love this job.

Participants' Perceptions Concerning What Characteristics Influence Their Personal Decision-Making. The participants stated that only two different characteristics influenced their personal decision-making. Those characteristics were religion/spirituality and professional experience. Some of the statements given when asked, "What do use as a basis for decision-making in your personal life?" were:

"I think my faith plays a huge issue. I think my perception on what would I want or what would I want for my parents is a big issue in the experiences that I've had in the past in nursing and in life in general."

"It is my strong belief in Christianity."

"Experience at work."

"I think part of it has to do with my religion, but mostly it has to do with me becoming a nurse and being in the medical field."

"Definitely my spiritual life is extremely important to make that decision. My experience was probably my best preparation."

"My trip to Peru, seeing the medical conditions there…and my experience working on an oncology unit."

The participants articulated that spirituality and personal/professional experiences were the basis for their personal decision-making. However, when speaking about the basis for the patients' and families' decision-making, the spiritual aspect was mentioned, but the personal experiences of the patients' and their families' was not considered to be a factor in their decision-making process. One wonders if the patients and their families simply did not share this information with the critical care nurses or if the nurses discounted the past experiences of the patients and families.

Many of the participants state that their involvement with end-of-life decision-making has evolved through their work experience. They indicated that it would be helpful to have continuing education regarding the process of dying and how to communicate effectively with patients, families, as well as other healthcare workers when dealing with end-of-life issues. The most experienced nurses stated that having more formal education about dealing with all aspects of death and dying would be especially helpful.

> One participant who has been a critical care nurse for over 20 years stated: Education would be helpful because some nurses, they're not prepared to see death and dying. I was telling them I was just lucky when I was a student, nobody died. Then I graduated. They always died the next shift when my reliever came. Then I was okay. I don't get scared if I don't know them.

Another participant who has only five years of experience stated a need for education on coping with death and dying, too:

> Education on death and dying is what they (students) need. I think the scenarios are probably the closest things that you can get to teaching them. You can teach everybody about different cultures and everything, but when you're in the real situation, it doesn't—it's more based on interactions with people. It's your people skills, and your ability to talk in layman's terms about technical aspects of care. I know that, this just came up this morning, that we were going to pull some of our newer nurses off the floor and give them some scenarios. 'What are you going to say to a patient when they say this?'

When asked, "What do you think nursing can do to promote the profession in helping people make these end-of-life decisions," another nurse with more than 20 years of experience stated, "Probably more in the way of education, because I think some people don't even know where to begin, or they feel afraid to begin.

An apt analogy regarding nursing education was provided by another participant who stated:

> I think the education ministry is really important, and I think for—that it should be—I mean, we all bring a lot of skills, but that's not a skill, is it? It's kind of like how you never ever get a class on how to be a parent unless you go out and pay for one. It's not required. You all get to be parents if you have ovaries. You get to have kids, but there's no stamp that says that you've been approved to do it, and it's kind of (I can't believe I said that on the tape) you don't—I'm approved to do it even though I don't have a stamp of approval that my approach is appropriate or okay. I don't think that's necessarily right. You get a stamp of approval for other things and other skills, but this is so serious now. We are approaching the Baby Boomers and, you know, healthcare is at high market cost, and we have the ability to keep people alive longer than we've ever had before, but yet you can't standardize it, but you can educate it.

Researcher Journaling

During and immediately after the interviews, the researcher wrote notes in the fashion of a journal. These notes commented on the expressions, attitudes, and body language of the participants, as they related incidents and provided information about their perspectives about end-of-life decision-making in ICUs. With the exception of one participant, all of those interviewed were excited, adamant, and opinionated about the subject of end-of-life decision-making. By virtue of eye contact, certainty of voice, and animation, they exuded confidence in their abilities. All of them seemed very pleased with their positions and ability to help patients and their families at such difficult times of their lives.

There was very little hesitation by the participants in providing examples or scenarios to substantiate what their main points were. Most of the scenarios were fraught with emotional situations. However, with rare exception, the participants relayed the scenarios with constraint and a definite matter-of-fact tone. Yet their facial expressions revealed a self-pleasure with the outcomes that were positive (smiling, bright eyes) and a level of disgust (rolling eyes, taut lips and frowns) for those that were, in their opinions, disasters.

Without fail, however, the participants conveyed lack of tolerance for those who were lacking in appropriate skills, brushing them off (with brushing hand motions) and suggesting the need for further education or mentoring in the ICU.

The one exception was the young nurse who had only been in the ICU setting for one year and had very little day shift experience. She cried throughout the entire interview and acknowledged her need for further mentoring and skill development. This participant apologized repeatedly, as if showing emotion to this extent was not acceptable in this setting.

Summary

In conclusion, the findings indicate that the participants are in agreement about their roles as advocates, communicators, and educators. In essence, they also agree that their job requires them to bracket their personal attitudes, values, and beliefs in order to advocate for the patients and their families. The participants' perspectives on their attitudes, values, and beliefs about decision-making at the end of life are diverse yet common in theme, attaining acceptable patient and family outcomes. However, there is a need for education regarding advance directives, dealing with death and dying, and learning and perfecting communication skills.

As end-of-life is becoming a popular research topic, critical care nurses are becoming more sensitive and responsive to the needs of the patients and their families. It is not only end-of-life care that is an issue in Intensive Care Units, but also end-of-life decision-making that should precede that care.

CHAPTER VI

ANALYSIS AND IMPLICATIONS

Analysis

As discussed in earlier chapters, it has been frequently found in research studies that because of technological advances and healthcare’s ability to maintain life for indefinite periods of time, end-of-life decision-making has become a pertinent, and sometimes volatile, issue in healthcare today. The institution of the Patient Self-Determination Act (PSDA) in 1990 has not been effective in assuring the establishment of personal advance directives upon admission to the hospital, not to mention prior to admission. Responsibility for initiating dialogue about designating a Durable Power of Attorney Of Healthcare (DPOA) or adopting a living will to patients and families in Intensive Care Units (ICUs) has filtered down to the critical care nurse, almost by default.

The resulting question becomes: “How prepared are critical care nurses to embrace this responsibility?” Possible answers to the preceding question can be found by asking the following research questions of this study: “What are critical care nurses’ attitudes, values, and beliefs about end-of-life decision-making;” “What do critical care nurses believe their roles are in this process;” and “ How do critical care nurses participate in end-of-life decision-making with patients and their families in ICUs?”

The data analysis process was completed in the following steps:

1. Fliers were distributed in Adult Intensive Care Units requesting participants for the study.
2. The study was explained to the volunteers and an informed consent was signed.
3. Data was collected in a 1-2 hour interview with the participants in a quiet room, secured for privacy.
4. The data was transcribed.
5. Data was analyzed line by line and words that indicated the feelings and experiences of the interviewee were identified.
6. These words were then separated into ideas that were similar
7. The ideas were grouped into major themes.

What Are the Perspectives of Critical Care Nurses in End-of-Life Decision-Making with Patients in ICUs?

When analyzing the results of the first research question, the information can be discussed in an interdependent format, much like a staircase, with one step leading to the next, the end-of-life decision being the top landing (see Figure 1). While initially there appeared to be chaos and confusion in end-of-life decision-making in ICUs, the participants in this study expressed a clarity of the process which is revealed in the model. The conceptual model indicates the process of decision-making that the participants have identified as those that patients and families use, consciously, or unconsciously.

Indecision. The landing of “indecision” is the point at which the patient and/or the family find that some kind of end-of-life decision must be made. It is the beginning the of the end-of-life decision-making process. The concept of “indecision” can continually weave throughout the following steps, but should diminish in importance as the individual and /or family nears the top landing.

Religion, spirituality and culture. The first step is concepts, values, beliefs that form and affect the patient’s life. This step, according to the participants, is religion, spirituality, and culture. In the participants’ viewpoints and also those of a number of researchers, the patient is aware of these core beliefs, either consciously or subconsciously.

A number of studies (Blatt, 1999; Marrone, 1999; Matzo, 2002; Thomas, 2001) agree with that viewpoint. Research has shown that nurses have much to learn about all aspects of culture in order to develop an open and trusting relationship with the patient and understand their wishes. For example, according to the findings of Matzo et al. (2002):

> An individual’s cultural background person and to how he or she views life, living dying and death. Given that nurses have a responsibility to care for all people everywhere, there is also an inherent responsibility to be open to learning about others and to appreciate diversity as it relates to all domains of culture (p. 277).

Marrone (1999) postulates that, for some, death is anticipated as a release from pain and suffering, while for others it is a terrifying prospect. Whatever the reason may be, “Resolving spiritual issues and existential concerns will probably be integral, if not central, to the process of dying” (p. 435). As a result of spiritual centrality, he states that,

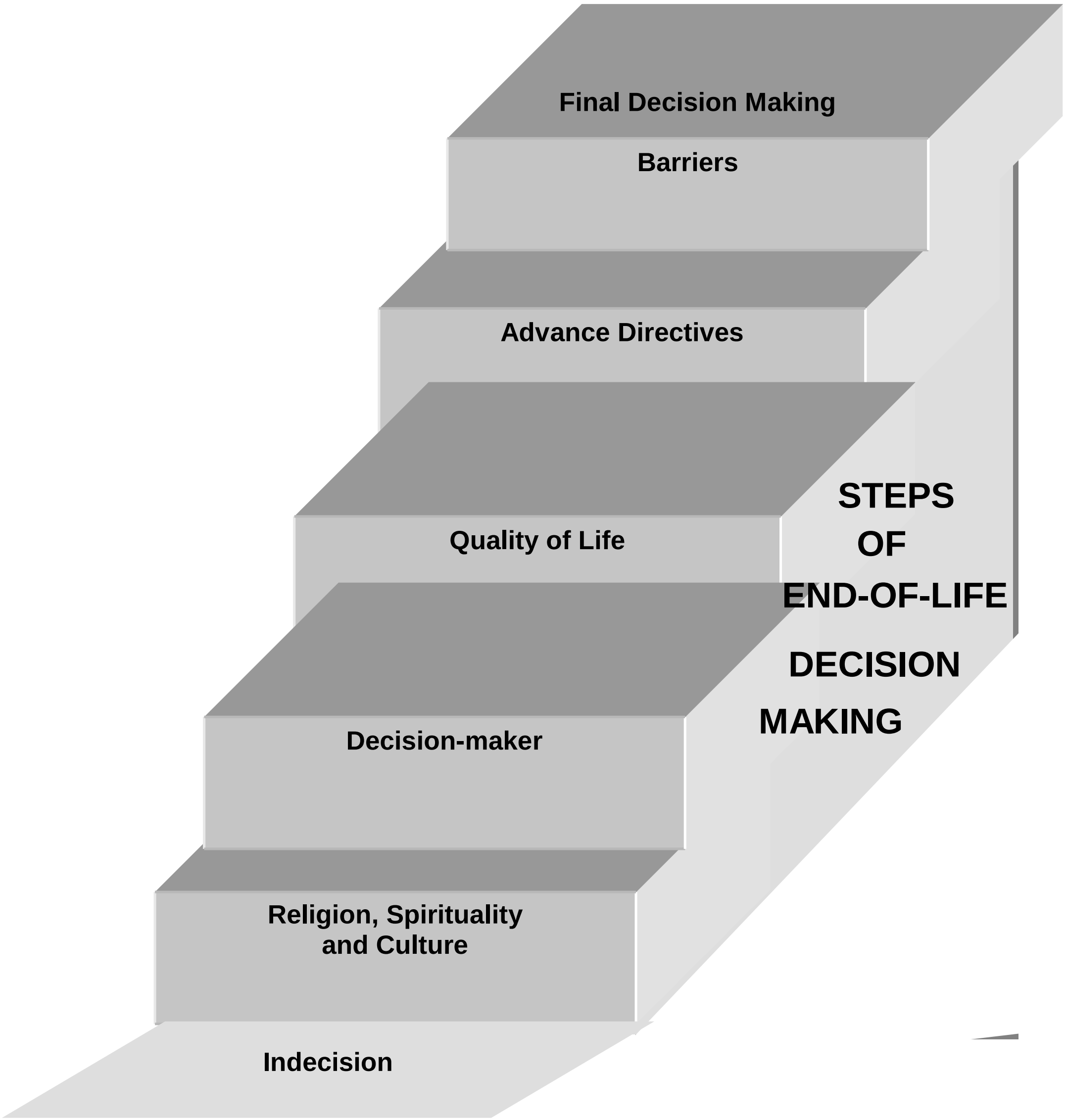

Figure 1. Elder’s Nursing Steps in End-of-Life Decision-Making (2006)

"We have much to learn about the spiritual experience, cognitive upheaval, and psychospiritual transformation in the face of death. We know that personal philosophies, religious belief systems, and spiritual explorations are especially important to individuals facing death…" (p. 435).

It is these beliefs that determine what the patient and/or the family considers to be the basis for quality of life, or if quality of life is even an issue for making end-of-life decisions. The participants targeted several religious/spiritual aspects that affected end-of-life decision-making in their experience and opinion.

The belief of existence or non-existence of an after-life is an issue for many individuals. Many times those believing in an after-life are anxious to see their departed loved ones and either welcome or do not fear death. In these cases, the patient either makes an autonomous decision or asks their surrogates to forgo treatment if the quality of life is not what the patient desires it to be. According to the participants, what the religious and spiritual beliefs are, in and of themselves, is not that important. What is essential is that the critical care nurse respects those beliefs, however contrary to the nurse's own beliefs they might be.

The patients' beliefs are an integral part of their life and will most definitely impact the decision-making process. The critical care nurse must acknowledge that fact, consider that fact, and accept the patient's right to act according to those beliefs. In addition, the nurse must take the initiative and offer to contact the religious leader or member of the patient's choice who can provide support and advice.

Although culture is a much broader term, culture and ethnicity were generally discussed together. The participants explained that culture, ethnicity, and religion were very influential components for patients when considering end-of-life decision-making. They stated that issues involved with those components were taken into consideration when caring for those populations at the end-of-life.

The participants who were African-American and Asian described the different attitudes and beliefs of their cultures. Even though the participants stated the understanding of cultural differences, it was unclear as to how effectively the differences were approached and integrated into care. They verbalized knowledge of cultural values, as exemplified most often by their family members or friends. While their understanding is acknowledged, research findings question if the knowledge is taken into consideration in real-life situations.

Thomas (2001) has explained that although cultural differences are acknowledged, there is very little done by healthcare workers, including critical care nurses, to ascertain specific religious/cultural rituals, dietary requirements/requests, and beliefs that would decrease the death anxiety for both minority and non-minority patients. Communication is an essential issue in integrating issues into care. He states that:

> Communication about end-of-life issues is the key to understanding and making rational decisions. However, effective communication between health care practitioners and patients regarding their wishes at the end-of-life is often missing. African American and Hispanic persons were less likely to communicate their end-of-life issues than non-Hispanic white respondents (p. 44).

The findings of this study are consistent with a number of experts (Blatt, 1999; Candib et al., 2002; Corr et al., 1994; Kastenbaum, 2001; Miller et al, 2001, Thomas, 2001), who found that, in many instances, ethnicity and religion play a pivotal role in end-of-life decision-making. Hispanics and Asian Americans may view discussion about end-of-life issues as a poor prognosis and possible lack of effort of healthcare workers to prolong their lives. They prefer to leave their fate to God or another spiritual power, as do many African-Americans. Those of the Jewish faith value life and prolong it as long as possible. Catholics tend to be more accepting of DNR orders. (Corr, 1994)

Decision-maker. The next step is the decision-maker. It is the primary decision-maker who determines what type of advance directive will be implemented, if one is to be implemented at all. While all of the participants articulated the belief that end-of-life decisions should be made in advance of a critical illness and reflect the autonomy of the cognizant patient, they expressed that this is not always the case.

Western Anglo-Saxon cultures generally believe in autonomy. The patient either makes his own decision or appoints someone trusted to act on his behalf. By virtue of the American Nurses Association (2000), patient autonomy is the most basic of bioethical principles.

However, statistics substantiate the lack of autonomy in advanced decision-making. According to one study conducted by Mezey, Leitman, Mitty, Bothill and Ramsey (2000), only 21% of elderly patients had advanced directives. Of the 79% who did, 47% thought they needed more information to decide, 38% thought that their family would make the decision, and 33% believed that they were too sick to think about it. Way (2002) also found that:

> Clinicians and families make most of the decisions about life support in intensive care as less than 5% of patients are able to communicate with clinicians at the time. When facing potential mental incapacitation, 90% of patients prefer family members to act as the decision-makers and request that decisions are made in conjunction with their physicians. Unfortunately, few patients have ever discussed their resuscitation preferences with a family member and decision by surrogate may not accurately reflect patients' preferences (p. 1,342).

Quality of life. Researchers (Bowman, 2000; Thomas, 2001) agree with the study's findings by maintaining that after considering culture and identifying the decision-maker, the quality of life can be determined. That is another essential perspective on end-of-life decision-making, according to what the participants have identified patients and families do. Just as there are a number of differing opinions on when life begins, there are also varying opinions about what "life" is. At what point does a person consider the quality of life to not be worth living?

The participants suggested that the definition of quality of life could be disparate for all of those involved in the process of decision-making. However, that does not lessen the importance of its concept. Quality of life was found by several researchers (Baggs & Schmitt, 1999; Thibault-Provost, Jensen & Hodgins, 2000) to be a major factor in determining aggressiveness of care by 93% of nurses and 88% of physicians. Tilden (1999) found that "quality of life was a major consideration for spouses when reasoning about the DNR decisions. They (spouses) described not wanting their partner to suffer" (p. 430).

Participants described quality of life as patients being able to perform the tasks of daily living and interacting with their significant others in their home environment. For others, such as patients and families, quality of life can mean anything from merely existing in a bed for the peace of mind of their loved ones, to being awake, alert, oriented, and cognizant of what is happening around them.

One cannot lose sight of the fact that it is generally the interpretation of quality of life that instigates formulation of the end-of-life decision. When is the quality of life so poor that further treatment is rejected? As Haas (1999) suggested in his model of quality of life, there are four dimensions: physical, psychological, social, and spiritual, and three key indicators: well-being, satisfaction with life, and functional status. Other experts (Campbell, Converse, & Roberts, 1976; Lewis, 1982) suggest that quality of life lies in the experience of life, the essence of which is the person's own evaluation and the extent to which one has self-esteem, a purpose in life, and minimal anxiety. All of these definitions are subjective evaluations of Haas' four dimensions. Therefore, the essence of quality of life is as diverse as people themselves are.

Religion, spirituality, culture, the designated decision-makers, and barriers can all dictate the perception of quality of life. Those variables all contribute to the answer of the questions of when, how, by whom, and if end-of-life decisions are made.

Advance directives. Obvious to all of the participants was that it is essential for the patient to adopt some type of advance directive in order to express and assure that end-of-life decisions are recorded and upheld. Generally the document is either a Living Will or Durable Power of Attorney of Healthcare. Interviews with the participants incited several pertinent questions regarding advance directives. First of all, when is the best time for a person to discuss and decide upon his/her wishes and initiate an advance directive? Secondly, why do people not do this? Finally, are advance directives effective?

The majority of the participants averred that people should have the discussion regarding health care wishes while they are healthy and able to realistically determine their decisions based on concrete values and beliefs. Many experts (Baggs & Schmitt, 2000; Crego, 1999; Husted, 2001; Mezey et al., 2000; Oddi et al., 1995), also maintain that this is the best approach to assure compliance with end-of-life decisions. However, if patients fail to do this, as 77% do, the participants believe that the issue should be addressed on admission.

Since 1990, the Patient Self-Determination Act (PSDA) has been in effect. All hospitals are required to address the issue of advance directives upon admission. The majority of participants either expressed that this procedure was inadequate or failed to mention their knowledge about it. Advance directives were mentioned to patients on admission, but there was no follow-up in the nursing units. As a result, when confronted with end-of-life decisions, the vast majority of patients are unprepared.

One interesting insight is suggested by Drought and Koenig (2002). They postulate that even though a person might want to discuss and prepare an advance directive, one is not qualified or prepared to determine the feelings encountered at the end-of-life. There is no frame of reference from which to pull this speculative information. They suggest that:

> Although the autonomy paradigm was initially resisted because of its inherent challenge to professional authority, its procedural approach has been easily adopted as the quick ethical fix to the challengers presented by the clinical demands of end-of-life care, symbolized most clearly by the availability of new technologies (p. 117).

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They continue to suggest that there is an imbalance of power that naturalistically prohibits the option of autonomy:

> At the most extreme, dying patients seem to be required to make a choice between life and death. On the basis of our ethnographic research on end-of-life care, the patient translates a choice about assumption of risk for the possibility of statistical benefit into the choice of doing something to live versus the option of giving up and dying. The irony of the choice paradigm is that it seems to present a choice that does not exist—the choice not to die of a terminal illness. Patient choice is presented in situations in which the possibility of choice is wholly dependent on the interpretation and presentation of that choice by the clinician (p. 118).

Therefore when the time occurs to follow through with the decisions made, the person, now in a totally new, unfathomable, position, no longer feels as he/she did when the document was prepared and discussions were conducted. It follows then, that critical care nurses should be prepared for a patient to change his/her mind. And this change of heart should be seriously regarded.

A myriad of reasons have been suggested by researchers (Beckstrand & Kirchoff, 2005; Blatt, 1999; Bowman, 2000; Crego, 1999; Fedorka & Husted, 2004; Kirchoff, 2000; Mewzey et al., 2000; Miller et al., 2001; Rushton et al., 2004) as to why people do not discuss end-of-life issues and prepare advance directives. The main reasons include denial of condition, reliance on families to make the proper decision, postponing decision-making until becoming ill, waiting for healthcare workers to address the issue with them, and conflict with religious and/or cultural issues.

The participants rarely addressed why their patients did not address end-of-life issues prior to admission. As a result of the PSDA, the issue of advance directives is mandated to be addressed upon admission to health care institutions (PSDA, 1990). The participants, in many cases seemed to ignore or be unaware of this fact. Their comments included that they thought that advance directives should be dealt with upon admission to the hospital. And, in fact, they are. Not only do the admission representatives inquire about advance directives, but it is also a question on every nursing unit's admission form.

In a study by Thiebault-Prevost, Jensen, and Hodgins (2000), it was found that only 48.6% of the critical care nurses surveyed (n=405) correctly defined DNR by its legal intent. Failure to distinguish DNR form other end-of-life decisions was shown by 52.6% of the respondents. In fact, 62.6% of the respondents identified themselves as being a part of end-of-life decision-making. The majority of critical care nurses surveyed had a generalized lack of knowledge about advance directives.

Barriers to decision-making. The majority of participants in this study expressed that one important element that precluded the establishment of advance directives includes the barriers to decision-making. These barriers occur primarily when in the hospital setting and include physician reluctance, family denial, and unreasonable expectations of the family. Barriers are the last step prior to the final end-of-life decision-making "landing."

Participants stated that physicians are reluctant to write DNR orders. They hesitate to "give up" on the patient's recovery and feel uncomfortable about removing life support because they view it as a failure. Several participants equated this reluctance by physicians as giving false hope to the families, depriving the patient of the ability to die with dignity, and wasting resources.

These are not new concepts. Tammelleo (2000) found that "Twenty-five percent of nurses have seen other healthcare providers deliberately disregard a patient's advance directive, such as a living will, a durable power or attorney, or a healthcare proxy document. The same study shows that among ICU nurses, more than half claim to have witnessed such an occurrence" (p. 75). A study by Thiebault-Provost, Jensen and Hodgins (2000) found that 70% of the critical care nurses surveyed stated that they observed physicians were hesitant in writing DNR orders.

Another barrier identified by the participants was the unrealistic expectations of both the patients and their families. Generally, participants indicated, this is because of lack of knowledge or denial to believe the knowledge that patients and/or families are given. As a result, critical care nurses are obligated, according to those interviewed, to continually communicate with and educate the patient and the family about the disease process, the treatments, and the prognosis. One of the questions in a research study by Kirchoff and Beckstrand (2000) dealt with obstacles to end-of-life decision-making:

Five of the nine themes of obstacles involved nurses' difficulty with physicians' behaviors. These behaviors included disregarding a patient's wishes for care, giving false hope, avoiding members of the patient's family, not allowing the patient to die of the patient's disease, disagreeing with other physicians about the course of treatment, and not providing nurses with adequate orders for pain relief (p. 104).

A follow-up study done by Beckstrand and Kirchoff (2005) found that the physician/nurse barrier was becoming even more problematic as a barrier. Physicians were found to be evasive with families and not allowing patients to die from their disease processes. In addition, it was discovered that not only were nurses' opinions disregarded, but also they were not valued or considered (p. 100).

Denial is a typical, yet difficult, emotion with which critical care nurses must deal. Participants stated that family members are generally resistant to information that they do not understand or wish to believe. Denial can be augmented by the physician's reluctance to be forthright regarding the patient's prognosis, according to those interviewed. This concept is further justified by the research of Kirchoff and Beckstrand (2000) who found that the highest ranked obstacles to nurses in appropriating or discussing advance directives is family denial of the patient's prognosis and the family not understanding the care being suggested for the patient.

The participants' solutions to both denial and unrealistic explanations revolve around repetitive teaching, continuous communication, and the involvement of multidisciplinary teams. These options are more fully discussed in addressing the final research question.

Finally, the plateau of final decision-making is attained. The questions remaining unanswered are, "Does healthcare honor the final decision?" "How can critical care nurses ensure that the stairs are climbed to reach the plateau?"

What Are Critical Care Nurses' Perspectives Regarding Their Role in End-of-Life Decision-Making?

In the results of the interviews, the participants indicated that the final two questions must be answered through implementation of their perceived role in end-of-life decision-making. Participants unanimously identified three distinct roles of the critical care nurse in the process of end-of-life decision-making: the roles of advocate, educator, and communicator.

Nurses' role as communicator. The participants identified communication and the role of communicator as being the basis of both their role and for facilitating patients' end-of-life decision-making. Education and advocacy cannot be attained without adequate communication skills. The participants explained how end-of-life decisions could evolve by beginning with simple communication with the patients and/or their families. Engagement, active listening and veracity instituted toward the patient and/or family, by the nurse, can develop a trusting relationship that is vital to the ability to develop an atmosphere that is conducive to the acceptance of education and advocacy.

Way, Back and Curtis (2002) found that communication, negotiation, and consensus building are the most important tools. Seventy-one percent of respondents in the study stated that the most common approach was directly educating and negotiating with patients. Mezey et al. (2002) agree, stating that:

> It is in the area of information and education that a nurse can be a highly effective advocate for autonomous patient decision-making. The nurse's responsibility to the patient lies, essentially in ensuring that the patient made the decision to execute or not execute a directive with sufficient information to understand the consequences of treatment choices (or refusals) and of appointing (or not appointing) someone else to make treatment decisions for them should they lose the capacity to do so (p. 169).

And Kennard et al. (1996) reported in a follow-up to the SUPPORT study, "Fifty percent of the patients and surrogates reported that conversations with nurses were 'very much' or 'quite a bit' helpful in making health care decisions" (p. 206). Drought and Koenig (2002) also report that if clear communication could be achieved, it "might diminish the apparent contradiction between wanting everything that can be done and, at the same time, wanting an idealized good death" (p. 123).

However, there are other research studies (Baggs & Schmitt, 2000; Tuttas, 2002), which have found that at least 25% of the families involved in end-of-life decision-making could not recall communication with the nurses regarding end-of-life decision-making. And the major recommendation was to improve communication between healthcare workers and families.

Nurses' role as patient advocate. The nurse as patient advocate has been addressed in innumerable research studies and books (Ahrens et al., 2003; Baggs and Schmitt, 2000; Bowman, 2000; Davidson et al., 2003; Drought & Koenig, 2002; Husted, 2001; Meltzer & Huckabay, 2004; Miller et al., 2001; Pattison, 2004, etc.). Indeed, it is a part of the ANA Code of Ethics (2001) that the nurse's role is that of a patient advocate.

All of the participants emphasized the importance of advocating for the patients' right to autonomy, justice, beneficence, and veracity. Encompassing these traits, bioethics was indirectly identified as a primary role of the critical care nurse. Advocacy is not only a role, but also a duty.

In a historical study by Mallik and Rafferty (2000), the authors state that a function of nursing that has evolved over the past 25 years has been that of advocate. They trace the history of nursing advocacy from the antecedents of advocacy in 1976 to the exploration of advocacy options in 1981, to the claiming of advocacy as a nursing role in 1986, to the consolidation of the role in 1991-1995. The duty of being a patient advocate is documented to be an essential part of the nurse's role.

Nurses' role as educator. The participants described strong feelings that the critical care nurse's role is to educate the patient about the meaning of treatments, disease processes, and prognoses associated with them. Education should also take the form of explaining about the importance of discussing decision options before the making of the decisions becomes emergent.

According to the participants, lack of understanding by the patient and/or his/her family is one of the main reasons that end-of-life decisions are not addressed or followed. Lack of understanding includes, but is not necessarily limited to, understanding about disease processes and prognosis, the meaning of advance directives, and possible alternatives or risks.

Therefore, by communicating frequently and honestly with the patients and their families, the critical care nurse is able to develop a trusting relationship and simultaneously educate and advocate in the best interests of the patient. Research has substantially upheld these roles and responsibilities of the nurse. Crego (1999) explains that:

> Decisions about self-determination and advance directives should be addressed by the patient and family before serious illness and critical cardiovascular disease occur. Critical care nurses are involved in providing patients with varied and diverse facts regarding their disease and related care. It is proposed that patient information regarding self-determination and end-of-life choices be considered a vital part of the patient education process (p. 92).

How Do Critical Care Nurses Facilitate End-of-Life Decision-Making?

Involving interdisciplinary teams. Involving multidisciplinary teams is another method that participants identified as being crucial to facilitating end-of-life decision-making. Consulting healthcare workers from multidisciplinary areas is not limited to only physical aspects of care. Social workers, pastoral care, case managers, and bioethics committees all have valuable contributions to make regarding issues of end-of-life decision-making.

While several textbooks (Corr, Nabe, & Corr, 1994; DeSpelder & Strickland, 2003; Kastenbaum, 2001) and interdisciplinary literature (Bowman, 2000; Clements, Vigil, Manno, & Henry, 2003) emphasize the inclusion of interdisciplinary teams in end-of-life decision-making, there is no appreciable mention of this concept in nursing literature. However, 100% of the participants identified involving interdisciplinary team members as an asset to dealing with end-of-life decision-making.

Critical care nurses instigating decision-making conversations. The final method of facilitating end-of-life decision-making was identified by the participants in this study to be critical nurses instigating conversations about the need for decision-making. Research has shown that many times patients desire and expect the physician to be the person who institutes communication regarding end-of-life decisions (Drought & Koenig, 2002; Kennard et al., 1996; SUPPORT, 1995; Way et al., 2002).

It was postulated by the research participants that since the nurse is the individual who is with the patient and family the most, communicates the most with the patient, and provides most of the education, the critical care nurse is the most logical person to discuss decision-making. Tuttas (2002) stated that:

> The presence of and support offered by nurses prepared to address end-of-life care topics can greatly enhance the coping and decision-making capability of patients and families facing such circumstances. In the acute care setting, patients and families tend to develop an optimal trust and comfort level with nurses (p. 11).

Once again, however, research (Baggs & Schmitt, 2000; Kennard et al., 1996) has shown that not only are many patients and/or families resistant to this conversation, but many critical nurses are reluctant to indulge in decision-making conversations. There have been a variety of reasons suggested for this behavior (Crego, 1999; Husted, 2001; Kennard et al., 1996; Schwartz, 2002; Tuttas, 2002), including lack of education about end-of-life issues, advance directives, and communication skills; lack of time; physician barriers; and lack of self-confidence.

As end-of-life is becoming a popular research topic, studies have shown that critical care nurses are becoming more sensitive and responsive to the needs of the patients and their families. It is not only end-of-life care that is an issue in Intensive Care Units, but also end-of-life decision-making that should precede that care.

Personal Viewpoints Regarding the Analysis of the Data Collected

What I found from the data collected was quite different from the opinions and pre-conceived viewpoints that I had bracketed prior to the interviews. The participants were in total agreement on their roles as advocates, communicators, and educators. All of the participants, except for one, agreed that although they may have definite spiritual/religious, cultural, or experiential opinions regarding death, dying, and end-of-life issues, they put them aside when dealing with patients and their families.

When dealing with patients and families, the participants stated that they defer to the wishes and beliefs of those experiencing the possibility of impending death. In considering those wishes, the participants educate the patients and families, involve multidisciplinary members, and make every attempt to adhere to their wishes and spiritual/cultural protocols.

This is in direct opposition to what I have experienced in clinical practice and anticipated would be the results of the study. Much of the time, in my experience, the critical care nurses treated families and patients based on the nurses' own personal belief system. Ignoring the patients' wishes, the nurses would attempt to sway the patient to either stop all treatment or continue treatment when the condition was futile, depending on the nurses' personal beliefs.

The interviews of these participants were a reaffirming experience for me, personally. These critical care nurses express concern for the patients' welfare and respect for the patients' wishes and beliefs. While critical care nurses might have diverse personal beliefs and opinions regarding end-of-life decision-making, they all stipulated that those beliefs and opinions were withheld from the patient. All of the participants stated that by respecting the values, attitudes, and beliefs of the patients and/or their families, they worked together as a team for favorable patient and family outcomes.

The results also indicated a basic misunderstanding about the legal and ethical importance of advance directives. While all of the participants agreed that advance directives were a necessity, it was obvious that many of them were unaware that the issue of obtaining and educating the patients about advance directives are a responsibility of the healthcare system in general. However, the burden usually becomes that of the nurse, whether it is the floor nurse or the critical care nurse. This has been a law since 1990, as stipulated by the PSDA.

As indicated by the lack of knowledge about the PSDA in the demographic survey, as well as the through the interviews, there is a need for nursing education. Many of the participants indicated that they had been educated about death and dying in their nursing programs. However, upon further questioning, the education was basically about the stages of grieving and the legalities of malpractice, active euthanasia, and other acts that result in litigation.

Therefore, formal education is needed to prepare students for dealing with death and dying. And continuing education is also necessary to perfect communication skills in order for critical care nurses to deal effectively with patients, families, and colleagues when end-of-life issues are involved.

After a literature review was conducted, it was found that although there is a plethora of studies done about end-of-life care, there were very few conducted about how critical care nurses handled the issue of end-of-life decision-making with patients and their families. Results of several studies, (Baggs & Schmitt, 2000; SUPPORT Investigators, 1995; Tuttas, 2002) suggested that nurses had very little impact on end-of-life decision-making. What was not found, however, were the reasons why nurses have such little impact and what the nurses’ perspectives were on end-of-life decision-making and their role in the process.

As a result, it was proposed for this research that an exploratory study be conducted to discover what answers critical care nurses would provide to these questions. Exploratory methodology was chosen because there is very little known about the issue of critical care nurses' and their perspectives on end-of-life decision-making. In addition, the results could suggest avenues of further exploration and provide suggestions to alleviate any problems that might be identified.

Conclusions

Critical care nurse participants were found to be self-assured, confident, and vocal about their perceived responsibilities to their patients and their families regarding end-of-life decision-making. There was no variation in what they perceived their roles to be. Participants viewed themselves and their peers to be advocates, communicators, and educators to their patients regarding, but not limited to, end-of-life decision-making.

The participants described their perceptions a bout patients' decision-making in such a way that it was possible to construct "steps of end-of-life decision-making" from their input. Issues that they perceived were most important to patients/families were: quality of life; religious, spiritual and cultural issues for both themselves and the patients/families involved; who the decision-makers are; the importance of advance directives; attitudes toward death and dying; and the barriers to end-of-life decision-making in ICUs. All of the above categories have one common goal for the participants, and that is outcomes that are acceptable to the patients and their families.

The participants all believed that they bracketed whatever personal attitudes, values, and beliefs they possess, in order to address the patients' and families' belief systems instead. In addition, participants felt that they attempt to effectively communicate with patients and their families and involve interdisciplinary teams to assist in meeting their needs as far as end-of-life decisions are concerned.

Inclusion of the traits that the participants believed they embodied comprises what this researcher chooses to call the “ICU mentality.” “ICU mentality” is characterized as a compassionate pragmatism. This is the ability to realistically, yet compassionately, communicate, educate, and support the patient and family during the stressful process of dealing with end-of-life issues. Included in this process is the bracketing of personal attitudes, values, and beliefs that might conflict with those of the patient and/or family. The critical care nurse with the “ICU mentality” is realistic, knowledgeable, secure, confidant, and passionate about his/her work, yet aware of his/her limitations. He/she considers the healthcare team to be collegial, without hierarchy. This nurse is not hesitant to request assistance from other disciplines to ensure holistic attention to the needs of the patients and their families. Education is considered a life-long journey, staying abreast with the latest treatments, and perfecting the art of communication and psychosocial interventions.

Therefore, it follows that the participants also believe that there is a definite need for nursing education to include instruction about death and dying in the curriculum. Novice nurses are unprepared, many times, to deal with the issues of death and dying in ICUs. Prior knowledge about the rudiments of death and dying would help prepare them for further mentoring upon initiation of a career in Intensive Care Units. Additionally, continuing education should emphasize dealing with patients and families at the end-of-life by providing instruction on effective communication, religious/spiritual/cultural beliefs, barriers to decision-making, and legal issues surrounding advance directives.

Individual institutions have various protocols regarding end-of-life decision-making. However, common to all of them are the legalities of the PSDA and encouragement of patients to establish advance directives. This issue is all too often discounted after admission until forced as an issue by the deteriorating condition of the patient. Many times, at this point, the patient has lost consciousness or is mentally unable to be autonomous in the decision-making process. This situation adds to the complexity of the role of the critical care nurse and stress of the family, all of which could be avoided with adequate education for critical care nurses to employ in the education and preparation of both the patient and their families. Drought and Koenig (2002) agree, as they state that, "Survivors of patients who have died express the need for more preparation around the details of dying…Relationships with the health care team are often problematic, and many cite the need for staff training in communication and more development of compassion" (p. 122).

Limitations

Exploratory research, by definition, is designed to discover the issues of a previously unexplored question and leads to a phenomenon to be researched. In this case, the research is qualitative in nature, which limits the size of a sample to be studied. The sample is small at 11 participants. These participants are also from mid-sized suburban hospitals. Therefore, the perspectives might be rather consistent due to sampling in similar environments, decreasing the possibility of generalizability.

However, the perceptions of end-of-life decision-making, the roles of the critical care nurses and how they facilitate decision-making can be easily generalized to adult critical care units. This is because literature supports "Elder's Nursing Steps of End-of-

Life Decision-Making" that was developed upon the information gleaned from the interviews. The literature also substantiates the various roles of the critical care nurse as it relates to decision-making in ICUs.

The findings are certainly also valid and applicable for critical care nurses. This is obvious because dealing with end-of-life decision-making is a daily issue for the majority of critical care nurses. The significance and implications regarding the perspectives that critical care nurses give about decision-making, roles, and facilitating decisions that can provide solutions that will enhance the satisfaction of families and a possible "good death" for patients.

Age is another limitation of this study. Seventy-three percent (n=8) of the participants are under the age of 40. According to the American Association of Colleges of Nursing (2004) and Dracup & Bryan-Brown (2005), the average age of nurses in general and critical care nurses is 45. The dichotomy of young versus old nurse is an interesting one. Dracup and Bryan-Brown (2005) explain that while older nurses have the most experience, resulting in a more realistic view of life and death, the stress of working in Intensive Care Units leads to burnout. Many times, nurses move to areas of less stress to finish their careers.

On the other hand, young nurses crave the excitement and action found in an Intensive Care Unit. However, it takes a number of years of career and life experience to understand the meaning and implications of end-of-life issues. The viewpoint of a "young" nurse could possibly reflect a much different attitude toward death than an older nurse who has experienced more end-of-life situations and is considering personal options of the same nature. There could be a number of reasons why the majority of the participants are “young” by nursing standards. This is a phenomenon that requires more research.

Implications for Education

This study has revealed that there are two significant gaps in nursing knowledge that need to be addressed through education. The most significant gap is that involving nursing curriculum that deals with death and dying. Not only are the aspects of death and dying addressed in a mere cursory fashion, according to the participants, but also many times the various aspects of death and dying are not addressed at all. The participants suggest that if critical care nurses enter the workforce with a basic knowledge of the physical, emotional, and spiritual aspects of death, they will be much better prepared to handle the more subtle aspects such as effective communication and support of patients and their families.

The second issue that requires educational attention is that of the ethics and legalities of advance directives. Although the PSDA requires advance directives to be addressed upon admission, the lack of advance directives is infrequently pursued again until a crisis situation is reached. Participants indicated that the topic of advance directives is not always a comfortable one to present to gravely ill patients and their families. So, not only do the particulars of advance directives need to be explicated, but also the method of effective communication of advance directives must be explored. Tuttas (2002) states that:

> On the basis of both the literature finding and professional experience, it would seem beneficial at all levels of nursing education to include more comprehensive content regarding end-of-life issues, including a focus on when and how to initiate and conduct these discussions with patients (p.14).

An option for end-of-life education for nurses could be the alternative of having end-of-life continuing education as part of the required CEU's for re-licensure. The evidence gleaned from this study illustrates the need for well-planned, easily accessible educational programs that would develop and enhance end-of-life decision-making skills for critical care nurses.

In addition to educating nurses in academia and providing continuing education to nurses on the job, another implication for education would be to implement an educational program for the general public to make them more aware of the legalities, ethics, and psychosocial implications of advance directives. Having an informed patient population could result in patients being prepared for possible end-of-life issues prior to hospitalization. The critical care nurse's focus could then be directed to more salient issues such as patient care, support, and comfort. The added stress of making end-of-life decisions would no longer be a moot point.

Implications for Nursing Practice

This research study suggests that by exploring methods to educate nurses regarding effective communication, ethics, and legalities of advance directives, and aspects of death and dying, end-of-life decision-making in ICUs might become more easily understood and accomplished. With increased self-confidence and empowerment, critical care nurses might develop a more sophisticated and natural approach to the feelings and problems of the seriously ill and their families.

There are a number of tactics that are suggested and upheld in research studies (Beckstrand & Kirchoff, 2005; Bowman, 2000; Mezey et al., 2000; Miller et al., 2001; Thibault-Prevost et al., 2000) that illustrate how nursing practice in Intensive Care Units can address the implications of ineffective end-of-life decision-making, also exemplified by results of this study:

1. Explore new ways of disseminating information about patients to the patients' family members on a regular basis.
2. Clarify with patients and their family members their understanding of terms and lifesaving measures so that they understand how the options may affect the patients.
3. Clearly defined goals of treatment, including CPR, should be considered from the perspectives of both patients and critical care nurses.
4. Assess the extent to which decisions made by patients are congruent with what nurses have observed to be patients' specific wishes, concerns, or fears and what patients understand as the consequences of their decisions.
5. Create written policies and protocols regarding interdisciplinary accountability and roles around informing/educating patients and proxies, and ensure theses polices are enforced.
6. Periodically review the protocols for end-of-life decision-making by the ethics committee.
7. Re-evaluate the admissions procedures to ICU and ensure that discussion about end-of-life decision-making and advance directives is consistently addressed.
8. Evaluate the critical care nurses' preparation for death, including interaction with families, goals, their own values and beliefs, and the language (lay versus medical) used in communication with patients and their families.

Implications for Public Policy

In 1990, the Patient Self-Determination Act was enacted to ensure that individuals retain control over what treatment they receive or do not receive when hospitalized. Shortly thereafter, hospitals became mandated to determine, upon admission, if patients have advance directives. If they do not, the institution must give them information regarding advance directives. This public policy was designed to ensure autonomy and prevent the problems that one incurs regarding end-of-life decision-making in the hospital setting.

However, as this study has demonstrated, the majority of patients do not have advance directives. And many times, when they do, the physicians and/or families choose not to honor them. This is so frequently the case that critical care nurses often find that patients are unaware of the necessity to have a living will or a DPOA, or they refuse to consider it based on religious, cultural, or experiential reasons.

In this researcher’s opinion, because of the basic tenet of freedom of choice, it would be difficult to enact a public policy that is any stronger than the PSDA. Individuals have the freedom to choose how they deal with end-of-life issues, even if that means to ignore the issues themselves. The most that healthcare can do is to remind the patients of this choice and offer information to them in an effort to emphasize its importance.

However to decrease the prevalence of this problem, critical care nurses must be educated to introduce the topic of end-of-life decision-making to the patients and their families at the first possible opportunity. It is in the critical care setting that the issues of death and dying are most pronounced. By offering this information, the hope would be that the topic would be at least considered, if not discussed, by the families and the patients. If this were standard procedure, perhaps many of delays and misunderstandings could be avoided and public policy would be more effective.

This study also implies that the public policy of the PSDA is oftentimes ignored or overridden by healthcare providers. It is the responsibility of critical care nurses, as well as nurses in general, to ensure that the PSDA is communicated to patients and the public, followed by the healthcare system, and respected by families and physicians.

Implications for Research

This exploratory study has unearthed several possible areas of study to elucidate how critical care nurses can be more effective in improving patient outcomes and family satisfaction with their participation in end-of-life decision-making. In accordance with suggestions by Drought and Koenig (2002), future directions of research might include a descriptive research on the experience of patients through the disease and dying trajectory, which could help fashion an ethics of end-of-life decision-making that "reflects the values and concerns of patients and their families" (p. 131).

As mentioned in the previous section, a study that explores how the young nurses care for the older population and the their beliefs about aging would provide some insight into why intensive care nurses are many times a younger population than that of generic nurses. It could also provide some insight on the younger nurses' perspectives on growing old in the 21st century and how it affects nursing care.

Communication was one of the most important characteristics identified as being crucial to end-of-life decision-making. Therefore, another area of research on nurse-patient communication could explore how a nurse might help the patient understand and interpret the physical changes and symptoms that he/she is experiencing in relation to the prognosis or medical trajectory.

To substantiate or refute the findings of the qualitative studies, a large-scale quantitative survey study could be done to objectively assess the qualities of critical care nurses and the methods they employ in facilitating or assisting families in end-of-life decision-making. A longitudinal quantitative study could be undertaken to assess the development of the “ICU mentality” in nurses as they matriculate through nursing school to the ICU setting as graduate nurses.

Baggs and Schmitt (2000) state that there is “ a need for continued research about ICU end-of-life decision-making in a qualitative paradigm, observing behavior and eliciting differing perceptions and values” (p. 161). In addition, “No studies were found in which researchers assessed the influence of differing ICU cultures on limitation of treatment discussions” (p. 161). Furthermore, no studies were found to include the participation of both providers and families in the decision-making process.

Another option is for a quantitative study that would assess the benefits of death and dying education on nurses’ beliefs and resulting participation in educating patients and their families on end-of-life decision-making. The options are virtually endless, as there has been a paucity of studies that address the perceptions, qualities and competence of nurses in this capacity, other than a few studies that compare nurses to physicians in decision-making situations.

Finally, when considering the possibility of an “ICU mentality,” there are ample areas of that concept to investigate. A qualitative or quantitative study of personality and career characteristics of critical care nurses in adult ICUs would shed light on whether there are actually traits that would comprise an “ICU mentality.”

Emerging Framework Evolving from the Study

There is one major framework that has evolved from this study. The synthesis of observations and experiences from the participants reveal that there are a series of steps that they believe individuals take prior to making end-of-life decisions. These steps are comprised of the components that influence end-of-life decision-making. There is a specific order to this staircase of decision-making at the end-of-life. Each step leads to the next in a logical order. (See figure 1).

The significance of this conceptual framework is that if critical care nurses are cognizant of how end-of-life decisions are made, they can first determine where their patient is on the “staircase”, and then how to facilitate their journey to the “landing”. It can be difficult for the patient and/or the family to skip steps yet be comfortable making a decision. For example, if the decision-maker has been identified and is asked immediately to develop an advance directive, it might be a confusing decision to make if the concept of quality of life has not been addressed. So in addition to assisting the nurse in identifying the progress of a patient in the decision-making process, the conceptual model could also assist the patient and/or family in identifying and determining what the next step should be.

The validity of this conceptual framework needs to be examined more thoroughly through research. However, the participant interviews and member checking in this study confirmed the basic premise.

Summary

End-of-life decision-making is a difficult, yet unavoidable, task for those who are facing end-of-life issues in the healthcare setting. Even not making a decision becomes a conscious resolution. As Drought and Koenig (2002) propose, patients are:

> Distracted from the reality of death by their preoccupation with the choices presented by the discourse. They focus attention on the choices, rather than on the situation creating the need for the choices, and the reality of death becomes lost. Patients and providers resist the choices surrounding death, but the resistance is to the admission of death itself. It is only when death's proximity can no longer be denied, and choice has given way to fate, that the end-of-life practices are readily accepted and employed. At that point there is no more choice in the matter (p. 130).

It is at that point, the times of personal sorrow and stress, that families and patients may need communication and education from critical care nurses, based on their expertise. This study found that there are many components to consider when dealing with end-of-life decisions. Critical care nurses must be cognizant and knowledgeable about all of them in order to help the patients in their time of need.

The participants in this study identified the most pertinent concepts to be considered in end-of-life decision-making, their roles in the process, and how they felt they facilitated the decision-making methods of patients and their families. These concepts provide questions that prompt further research and education to determine if, in fact, there is an "ICU mentality" that facilitates the ladder of end-of-life decision-making.

The findings of this research study will hopefully illuminate the importance of critical care nurses' roles in end-of-life decision-making with patients in ICU units. The synergy of the critical care nurses' perspectives on end-of-life issues with their roles is of utmost value to patients, their families, and the Intensive Care Unit environment. Further study is recommended to validate the ideas and issues that were elucidated in this qualitative exploratory study.

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APPENDIX A

Demographic Instrument

Directions: Please read the following questions and check the most appropriate answers for each question. Reports of the demographic data will only be recorded as group information.

1. Gender:

    ___ Male
    ___ Female

2. Age: _____

3. Employment Status:

    ___Full-time (Working 36 hours/week or more)
    ___Part-time (Working 1-15 hours/week or more)
    ___PRN (Variable working hours as requested)

4. Total years as a registered nurse: _____

5. What is your specialty and number of months/years of experience?

___Adult Intensive Care _______years _______months
___Adult Cardiac Care _______years ________months
___Adult Trauma Intensive Care _____years _______months
___Adult Surgical Intensive Care _____years _____months
___General Adult Intensive Care _____years _____months
___Adult Cardio-Vascular Surgical Intensive Care
___Other: Please Specify: ___________________

6. Ethnicity:

    ___Caucasian
    ___Hispanic
    ___Asian
    ___African-American
    ___Other (please specify) _______________

7. Religion:

    ___Protestant
    ___Catholic
    ___Jewish

___Hindu
___Buddhist
___Islam
___No Religious Affiliation
___Other (please specify) _________________

8. Have you ever received formal instruction on end-of-life decision-making?

___Yes
___Within your formal education
___As an in-service
___No

9. Have you ever received formal instruction on dealing with death and dying?

___Yes
___Within your formal education
___As an in-service
___No

APPENDIX B

Interview Questions and Possible Probes

1. What do you think your role is in end-of-life decision-making with your patients and their families?

   Probes:

   a. How does your healthcare facility/unit define your nursing role regarding end-of-life issues?

   b. What does patient advocacy mean to you?

   c. What are the boundaries, if any, for the nurse regarding patient advocacy?

2. How do you participate in the end-of-life decision-making with your patients and their families?

   Probes:

   a. Can you tell me how you introduce the subject of end-of-life decision-making with your patients and their families?

   b. What situation prompts you to participate in conversations about end-of-life decision-making with your patients and/or their families?

   c. What specific issues about end-of-life do you address with your patients?

   d. Can you tell me what other health care professionals are involved in the decision-making process with you and the patient?

   e. Describe the techniques and unique approaches you use in discussing/participating in end-of-life issues?

3. What do you think may influence your interaction with patients and families who are making, or need to make, end-of-life decisions?

   Probes:

   a. What aspects of your life determine your personal daily decision-making?
   b. How would you describe your personal attitude toward death and dying?

4. How do your personal ideas regarding end-of-life decision-making influence how you interact with patients making end-of-life decisions?

   Probes:

   a. How did your family deal with death?
   b. How does your religion deal with death?
   c. Can you tell me about personal experiences that you have had with someone who died?
   d. How did your education address the issues of death and dying?
   e. Can you tell me about how your family members or friends have provided for the possibility of critical illness or death?
   f. What do you think would be helpful to ICU nurses who deal with end-of-life situations?

APPENDIX C

Critical Care Nurses' Perspectives on End-of-Life Decision Making with Patients in Intensive Care Units

Your participation in a research study is requested. The research is being conducted by Stacie J. Elder, M.S., R.N., a doctoral student in the School of Nursing at Barry University, and is seeking information that will be useful in the field of nursing. The aims of the research are: 1) To explore and describe critical care nurses' attitudes, values and beliefs of their role in end-of-life decision making; 2) To explore and describe critical care nurses' perspectives (attitudes, values and beliefs) in end-of-life decision making; and 3) To explore and describe how critical care nurses participate in end-of-life decision making with patients and families. In accordance with these aims, the following procedures will be used: Critical care nurses will be interviewed and qualitative methods will be used to interpret the data. We anticipate the number of participants to be ten.

You will be asked to participate in two interviews which will take approximately two hours of your time. The first interview will consist of questions which deal with end-of-life decision-making in the ICU. The questions will explore your attitudes, values and beliefs about your role, your perspectives and your participation in these decisions. In the second interview (approximately one hour in length) the researcher will share with you a transcript of the first interview including how your answers were analyzed. The researcher will ask you if this accurately reflects what you said, and what you were trying to convey with your answers. Each interview will be audio taped. It will then be transcribed by a transcriptionist who will not have access to your identity, other than the alphanumeric code that you selected.

Your consent to be a research participant is strictly voluntary and should you decline to participate or should you choose to drop out at any time during the study, there will be no adverse effects on your employment. The maximum number of participants in this study will be twenty.

The risks of involvement in this study are minimal. There may be some possible discomfort when relating experiences. Although you may not benefit directly from participating, your contributions may clarify the role and participation of nurses in end-of-life decision-making. This may result in the altering of the current health care system by facilitating the end-of-life decision-making process. A summary of the final research results will be made available to you at the completion of the study, if you so desire. The researcher will maintain strict confidentiality regarding your interview and provide a professional psychiatric referral for debriefing if relating the experiences should cause any emotional or psychological discomfort.

As a research participant, information you provide will be held in confidence to the extent permitted by law. Any published results of the research will refer to group averages only and no names will be used in the study. Data will be kept in a locked file in the researcher's office. Audiotapes of the interviews will be transcribed and stored in a separate locked file in the researcher’s office. After 5 years, the tapes will be erased and destroyed. Your signed consent form will be kept separate from the data. All data will be destroyed after five years.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Stacie Elder, at (815)766-1375, or my dissertation committee chairperson, Dr. Linda Perkel, at (305)899-4857, or via e-mail at: lperkel@mail.barry.edu or the point of contact for the IRB, Nildy Planco, (305) 899-3020. If you are satisfied with the information provided and are willing to participate in this research, please signify your consent by signing this.

I acknowledge that I have been informed of the nature and purposes of this study by Stacie Elder, M.S., R.N. and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in this experiment.

Researcher	*Date*	*Signature of Participant*	*Date*

APPENDIX D

PARTICIPANTS NEEDED FOR RESEARCH STUDY

Critical Care Nurses' Perspectives on End-of-Life Decision-Making with Patients in Intensive Care Units.

My name is Stacie Elder. I am a registered nurse completing my doctoral degree in nursing. I am searching for critical care nurses who would agree to participate in my research study.

If you are a critical care nurse with more than one year experience in adult critical care, you are eligible to participate in the research study. The study is entitled:

Critical Care Nurses' Perspectives on End-of-Life Decision-Making with Patients in Intensive Care Units.

The purpose of the study is to describe critical care nurses' perspectives on how they assist patients and their families in making end-of-life decisions in intensive care units. There will be an approximately one-hour interview of each participant, followed by a review of the interview several weeks later for approximately 15- 30 minutes.

If you are interested in participating in this interesting and important study, please contact me by phone: 815-766-1375 or by e-mail: sjern48@comcast.net and I will provide you with more detailed information regarding this project and answer any questions that you might have.

APPENDIX E

Barry University
Research with Human Participants
Protocol Form

PROJECT INFORMATION

1. **Title of Project:** Critical Care Nurses' Perspectives on End-of-Life Decision Making with Patients in Intensive Care Units

2. **Principal Investigator:** Stacie Elder, M.S., R.N.; 1527 Pebblewood Drive;
Sycamore, IL 60178; 815-766-1375; **sjern48@comcast.net**; Barry University

3. **Faculty Sponsor**: Dr. Linda Perkel; Barry University; School of Nursing; 11300 NE 2nd Avenue; Miami Shores, FL 33161; 355-899-3800; **Lperkel@mail.barry.edu**

Faculty Sponsor Signature:______________________________
Date: ______________

4. **Dean/Administrator of school targeted for research** (If Applicable)
(Name, title, school, department, mailing address, telephone number, email address)

Approval Signature:______________________________
Date: ____________

5. **Funding Agency or Research Sponsor**
(Name, Address)

6. **Proposed Project Dates**
Start: September 1, 2005
End: September 1, 2006

Note: It is appropriate to begin your research project (i.e., the data collection process) only *after* you have been granted approval by this board. Proposals that list starting dates occurring before the date of submission will be returned without review.

Please Provide the Information Requested Below

A. Project activity STATUS is: (Check one of the following three as appropriate.)

_X__ NEW PROJECT
___ PERIODIC REVIEW ON CONTINUING PROJECT
___ PROCEDURAL REVISION TO PREVIOUSLY APPROVED PROJECT
(Please indicate in the **PROTOCOL** section the way in which the project has been revised.

B. This project involves the use of an **INVESTIGATIONAL NEW DRUG (IND) OR AN APPROVED DRUG FOR AN UNAPPROVED USE** in or on human participants.
___YES _X__ NO
Drug name, IND number and company:
____

C. This project involves the use of an **INVESTIGATIONAL MEDICAL DEVICE (IMD)** or an **APPROVED MEDICAL DEVICE FOR AN UNAPPROVED USE.**
___YES _X__ NO

D. This project involves the use of **RADIATION** or **RADIOISOTOPES** in or on human participants.
___YES _X__ NO

E. This project involves the use of Barry University students as participants. (If any students are minors, please indicate this as well.)
___YES Barry Students will be participants
(Will minors be included? ___ YES ___ NO)
_X__ NO Barry Students will participate

F. **HUMAN PARTICIPANTS** from the following population(s) would be involved in this study:

___Minors (under age 18)
___Abortuses
___Prisoners
___Mentally Disabled
___Other institutionalized persons (specify)
_X__ Other (specify) Nurses who are employed in critical care units
____

___ Fetuses
___ Pregnant Women
___ Mentally Retarded

G. Total Number of Participants to be Studied: ___10__

Description of Project

1. Abstract (200 words or less)

Critical care nurses, who work in intensive care units, assess and provide interventions to seriously ill patients daily. Due to the uncertainty of outcome during critical illness, patients and their families are involuntarily placed in situations that require end-of-life decision-making. Often critical care nurses are asked by patients and their families to assist in the decision-making process. At present, the literature is scarce concerning how nurses' beliefs, attitudes and values may impact on patients and their families' processes in making end-of-life decisions. The purpose of this exploratory study will be to describe critical care nurses' perspectives on how they assist patients and their families in making end-of-life decisions in intensive care units. Utilizing exploratory/descriptive theory as the framework, nurses will be interviewed in a hospital in a suburban area of the Midwestern United States. Open-ended questions will explore their beliefs, attitudes and values concerning assisting patients and their families in making end- of-life decisions. Exploratory analysis will be used to identify themes of attitudes and behaviors nurses describe in aiding patients and their families in the decision-making process. It is hoped that the findings of this study will provide a beginning understanding of the nurse's role in assisting patients and their families with end-of-life decision-making.

2. Recruitment Procedures

Describe the selection of participants and methods of recruitment, including recruitment letter if applicable. (**NOTE**: If the investigator has access to participants by virtue of his or her position within the study setting, please provide a brief description of such access.)

Inclusion criteria for the selection of participants are that: the participants are registered nurses who have worked in an intensive care unit (ICU) for at least a year; the nurses work with adult (age >18 years) populations; the hospital is a mid-sized hospital <120 beds; the hospital is not a teaching hospital. The sample will be purposive. There will be notices posted in the ICUs of Edward Hospital in Naperville, IL and Provena-St. Joseph Hospital in Elgin, IL, requesting nurses who fulfill the criteria to volunteer for the study. Please see recruitment flier and recruitment letter. ICU nurses who qualify will phone or e-mail the researcher indicating their desire to participate in this study will be contacted by the researcher who will explain the research procedure and informed consent. A minimum of ten participants and maximum of 20 participants will be interviewed.

3. Methods

Taking part in this study will involve two audio taped interviews that will take approximately one hour each. The first interview will primarily consist of the participants’ reflections and discussion of their experiences, both personal and professional, with end-of-life decision-making. The interview will be audio taped so I can better remember and accurately record the discussions. Following the first interview I will ask the participants to complete a demographic information form, which will aid in compiling data regarding how nurses of varying age, education, ethnicity, religion, and experience deal with end-of-life decision-making in the ICU. During the second audio taped interview, the participant will review the transcription and analyzed data of the first interview to assess it for accuracy.

4. Alternative Procedures

Involvement in this study is entirely the decision of the participant as participation is voluntary, if the participant fulfills the criteria of having at least one year of ICU/CCU/CVCU experience with an adult patient population. The possible participant has the option of signing the consent to participate or declining to participate in the study. Following consent to participate in this study, the participants have the right to stop the interview, refuse to answer the questions, or refuse to talk about issues that might make them uncomfortable. Participants have the right to withdraw from the study at any time without any affect on employment status at the hospital.

5. Benefits

Although there may not be any direct benefits from participating in the study, contributions of participants may clarify the role and participation of nurses in end-of-life decision-making. This may result in altering the current health care system by facilitating the end-of-life decision-making process.

6. Risks

The risks of involvement in this study are minimal and include loss of personal time during the interviews and the reviewing the transcripts. There may also be some possible discomfort when relating experiences. If a participant experiences psychological discomfort as a result of relating experiences, a psychology nurse practitioner, Georgine Berent (815) 753-6561, will be available for counseling at no charge to the participant.

7. Anonymity/Confidentiality

Confidentiality in this study will be maintained regarding any personal identifying information. Those who consent to participate will be asked to choose a pseudonym during the first interview. I will verify that there are not duplicate codes used by other participants. Once a participant has chosen a code, I will use this alias in all interviews, transcripts, and any other communication. No names, places, or other identifying information will appear in the research reports. Although direct quotes may be reported in some cases, any data that may identify participants will be removed or fictionalized. Comments will not be shared with anyone outside my research committee or my transcriptionist, including nursing supervisors, administrators, peers, mentors or preceptors. The transcriptionist will sign a confidentiality statement prior to receiving any of the materials to be transcribed.

All research materials, including the interview audiotapes, will be stored in the researcher’s office in locked files for at least five years and then destroyed. The consents will be stored separately from the data. The list of pseudonyms, interview tapes, transcripts, and other materials will be stored separately from consent forms containing participants’ true identities.

8. Consent

Attach a copy of the consent form(s) to be signed by the participant and/or any statements to be read to the participant or informational letter to be directed to the participant. **(A copy of the consent form should be offered to each participant.)** If this is an anonymous study, attach a cover letter in place of a consent form.

9. Certification

I certify that the protocol and method of obtaining informed consent as approved by the Institutional Review Board (IRB) will be followed during the period covered by this research project. Any future changes will be submitted to IRB review and approval prior to implementation. I will prepare a summary of the project results annually, to include identification of adverse effects occurring to human participants in this study. I have consulted with the department or program faculty/administrators and the Dean of the school which is to be the subject of research and have received prior approval to conduct the research and/or to disseminate the results of the study. A copy of that approval has been included with this protocol.

______________________________ ______________________

Principal Investigator *Date*

***Reminder*: Be sure to submit fifteen (15) individually collated and bound (i.e. stapled or paper clipped) copies of this form with your application.**

APPENDIX F

Curriculum Vitae

STACIE J. ELDER, M.S., R.N., C.C.R.N.
1527 Pebblewood Drive
Sycamore, Il 60178
Home: 815-766-1375
E-mail: selder@niu.edu

CURRICULUM VITAE

Illinois Licensure Number—RN041-234011
Critical Care Nursing Certification—CCRN Number 0078246

EDUCATION BACKGROUND

Year	**Institution**	**Specialization**
2002	Barry University	In Progress; Ph.D. in Nursing
1995	Northern Illinois	MS in Nursing; Univ. Adult Medicine
1990	Aurora University	BSN; Nursing
1985	Elgin Comm. Coll.	ADN/AS; Nursing-Highest Honor
1976-78	Northern Illinois	English/Speech

PROFESSIONAL EMPLOYMENT

1/05-present	ASSISTANT PROFESSOR OF NURSING AT NORTHERN ILLINOIS UNIVERSITY, DEKALB, IL
9/01-12/04	GRADUATE ACADEMIC ADVISOR AT NIU SCHOOL OF NURSING, DEKALB, IL
1/04-8/05	CLINICAL NURSE AT EDWARD HOSPITAL—NAPERVILLE, IL
9/02-6/04	MEMBER OF ABC STAFFING
6/00-9/01	STAFF NURSE—Health Park Medical Center, Fort Myers, Fl.
09/98-8/99	VISITING INSTRUCTOR—FLORIDA GULF COAST UNIVERSITY, FORT MYERS, FL.
8/96-6/00	NAPLES COMMUNITY HOSPITAL EMPLOYEE

5/93-8/96	STAFF NURSE LOYOLA UNIVERSITY MEDICAL CENTER
1/94-6/95	GRADUATE RESEARCH ASSISTANT NIU SCHOOL OF NURSING
5/85-6/93	STAFF NURSE AT ST. JOSEPH HOSPITAL—ELGIN, IL.

APPENDIX G

Reported Characteristics of Registered Nurse Respondents in Adult Critical Care Units

N=11		Number	Percent of Respondents
Sex:	Male	1	9.1
	Female	10	90.9
Age:	20-25	0	0
	26-30	2	18.2
	31-35	4	36.3
	36-40	2	18.2
	40-45	0	0
	46-50	1	9.1
	51-55	2	18.2
	56-60	0	0
Employment:	Full Time	10	90.9
	Part Time	0	0
	PRN	1	9.1
Highest Level of Education:	Associate Degree	2	18.2
	Baccalaureate Degree	9	81.8
	Masters Degree	0	0
Certification in Specialty:	ACLS	5	45.5
	PALS	2	18.2
	CCRN	3	27.3
	TNS	2	18.2
	CLNC	1	9.1
	Oncology	1	9.1
Total Years Working in ICU:	1-5	1	9.1
	6-10	3	27.3
	11-15	4	36.4
	16-20	0	0
	21-25	2	18.2
	26-30	0	0
	30 +	1	9.1

Specialty ICU Unit:	Adult ICU	11	100
Ethnicity:	Caucasian	7	63.6
	Hispanic	1	9.1
	Asian-American	2	18.2
	African-American	1	9.1

Table continued on next page.

Table (continued).

N=11		Number	Percent of Respondents
Religion:	Protestant	4	36.4
	Catholic	4	36.4
	Jewish	0	0
	Hindu	0	0
	Buddhist	0	0
	Islam	0	0
	No Religious Beliefs	1	9.1
	Other	1	9.1
Formal Instruction on End-of-Life:	Yes	8	73
	As an in-service	3	27.3
	In formal education	3	27.3
	No answer	2	18.2
	No	3	27.3
Formal Instruction on Death/Dying:	Yes	8	73
	As an in-service	3	27.3
	In formal education	1	9.1
	No	3	27.3