Nurses' Attitudes Toward Assisting Patients/Families with End-of-Life Decision-Making

by

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Dedication

I have always been the luckiest person in the world for I have been surrounded by people who have loved me and helped me grow in so many ways. I dedicate this work to my parents, Jay and Lindy Wise, who instilled in me the belief that I could do anything I wanted; to my brothers Jim and Bob, who have given frequent encouragement; and to my husband, Stuart, whose admiration and support mean more to me than he will ever know. It is his belief in me that made this possible.

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ABSTRACT

Nurses often feel unable to help with decision-making near the end of life. The purpose of this study was to develop an instrument to measure medical-surgical nurses' attitudes toward assisting patients and families with end-of-life decision-making and to evaluate its psychometric properties.

The Nurses' Attitudes Toward End-of-Life Decision-Making (NATED), a 37-item instrument with a Likert-scale format was developed based on analysis of interviews with medical-surgical nurses and their experiences with patients and families making end-of-life decisions. The interviews were analyzed and common themes with corresponding instrument items identified. After Content Validity was estimated by a panel of expert consultants (CVI = .78), the resulting instrument was administered to acute care medical-surgical nurses (n=100). The responses of participants to this instrument were subjected to principal components analysis (PCA) with varimax rotation.

The final PCA model consisted of 29 variables in five factors accounting for 44% of the total variance. These factors were Advocate Role – influenced by ethical and legal guidelines; Preparation – influenced by education and experience; Physician Behavior; Helplessness; and No Time. Internal consistency reliability, using

Cronbach's alpha, for the final 29-item instrument was .85.

The NATED can be a useful instrument for measuring acute-care medical-surgical nurses' attitudes toward assisting patients and families with end-of-life decision-making and designing educational programs and patient care interventions. Future research with groups of nurses in different acute care settings in various geographic areas would expand our understanding of nurses' attitudes.

Chapter I

Introduction

There have been many advances in the past four decades in life-prolonging technology. However, extending the length of life does not always extend the quality of that life. Today, technology has made it possible to prolong the dying process, often in spite of severe disability and poor quality of life (Eisemann, Eriksson, Molloy, Nordenstam & Richter, 1999). Not all people who are candidates for invasive technological interventions wish to use them. The withholding or withdrawing of the technology does not cause death; it allows a natural death to occur (Devettere, 2000).

Medical-surgical nurses working in acute care hospitals are often the ones to whom patients and families turn when confronted with over-whelming and emotion-charged end of life decisions. This research project explored medical-surgical nurses' attitudes concerning this important aspect of patient care. This exploration led to the development of an instrument to measure nurses' attitudes toward assisting patients and families with end-of-life decision-making. A better understanding of nurses' attitudes in these situations can lead to better patient care.

Codes of Ethics

Codes of ethics guide the behavior of persons and groups of people. Many professional organizations have developed codes of professional ethics. The American

Bar Associations' Model Rules of Professional Conduct guides the professional conduct of attorneys. The American Psychological Association's Ethical Principles of Psychologists guides the behavior of psychologists. Several disciplines have published codes of ethics regarding health care choices and end-of-life/quality-of-life decisions.

One of the first codes of ethics is the Oath of Hippocrates. It was conceived during the period of Greek greatness, probably in the fifth century B.C. and has come down through history as a statement of ideals to be followed by physicians. It protected the rights of the patient and appealed to the inner and finer aspects of the physician. Subsequent to Hippocrates, Thomas Percival, an English physician and philosopher, made the most significant contribution to modern bioethics. In 1803, he published his Code of Medical Ethics (American Medical Association, 2002).

The misuse of human subjects for medical experimentation by the Germans and Japanese during World War II; and medical experiments in the United States such as the Tuskegee Syphilis Study, the Willowbrook School, and the Jewish Hospital in New York created widespread moral outrage. This outrage led to the development of biomedical ethics standards in the United States and around the world.

During World War II, prisoners were forced into dangerous and painful medical experiments. In Nazi Germany, people were infected with diseases to test the efficacy of vaccines and treatments, placed in altitude chambers to gather data affecting air crews at high altitudes, exposed to cold so the revival of extremely chilled bodies could be studied, shot so treatment of gunshot wounds could be improved, given electric shocks to see how much electricity people could survive, and exposed to radiation in experiments designed to sterilize them. Japanese physicians injected Chinese prisoners with syphilis, cholera, plague, and other diseases in order to observe how the illnesses progressed. Some people died, others suffered terribly, and most were killed when they were no longer useful to the experiments (Devettere, 2000).

In the United States, in the 1930s and 1940s, the medical scientists of the United States Public Health Service (USPHS) wanted to find out how lethal syphilis would be if not treated and designed a study that compared the health and longevity of people infected with the disease with those not infected. The USPHS selected a group of people in Macon County, Alabama, where about 40 percent of the men were infected with syphilis. It selected 600 adult males for the research. About 400 had syphilis, and the remaining 200 served as a control group. The infected group was not treated. The research was centered in Tuskegee, and hence the project became known as the Tuskegee Syphilis Study (Bandman & Bandman, 2002).

The men in the Tuskegee Syphilis Study were not informed about the nature of the research. They did not receive any treatment for their syphilis, although researchers sometimes told them that spinal taps were a treatment when they wanted specimens for analysis, and local physicians were prohibited from administering antibiotics to them for any reason. The study continued long after it became known that penicillin was successful in treating syphilis. The research continued until 1972, when public outrage arose after the *New York Times* ran the story on the front page and Senator Edward Kennedy of Massachusetts chaired a congressional hearing on the research (Devettere, 2000).

The Willowbrook State School on Staten Island was an institution for retarded children. A large number of the children were infected with hepatitis, mainly due to poor toilet training and infection control measures. In an effort to develop an immunization for hepatitis during the 1950s and 1960s, two researchers from the New York University School of Medicine, over a fourteen-year period, injected newly admitted children with gamma globulin and divided them into two groups. The children in one group were deliberately infected with hepatitis to learn how effective the inoculations were. Although parental consent was sought, children were only accepted to the school if the parents consented to having their child take part in the study (Munson, 1992).

In 1963, a physician at the Sloan-Kettering Institute for Cancer Research in New York organized a study at the Jewish Chronic Disease Hospital that involved injecting live cancer cells into debilitated patients to research the ability of the body's immune system to fight cancer. The research was funded in part by Sloan-Kettering, the U. S. Public Health Service, and the American Cancer Society. The patients were not told that they would be injected with live cancer cells and no documentation of consent was kept (Devettere, 2000).

In the 1950s, the Institute of Religion at Texas Medical Center in Houston began working on ethical issues and formed The Society for Health and Human Values. In the 1960s, the first Department of Medical Humanities was started at Pennsylvania State University Medical Center in Hershey, Pennsylvania. The late 1960s and early 1970s witnessed the appearance of the Hastings Center in Hastings, New York, and the

Kennedy Institute of Ethics at Georgetown University. Both of these initiatives attempted to bring depth and rigor to the new discipline referred to now as bioethics (Drane, 1994). Informed consent by an educated adult was one of the most important requirements of these new bio-medical ethics (Drane, 1994).

Modern bioethics is based on a common set of normative principles and rules that we are obliged to follow in practice, taking care of people impartially and equally (Devettere, 2000). Healthcare providers are expected to apply the principles of autonomy, beneficence, and nonmaleficence; and the rules of veracity, confidentiality, fidelity, and justice to particular situations to determine what they are morally obliged to do.

Use of increasingly sophisticated medical technologies that enable health care professionals to extend biological life, but not necessarily to return patients to a prior level of comfort and function, has made physicians into warriors battling disease, sometimes at the expense of the patient's quality of life (Post, Blustein & Dubler, 1999). Physicians sometimes see giving up on the battle and allowing patients to die a natural death as a defeat of their abilities and skills. They are often reluctant to refer patients to hospice organizations early enough in the battle to allow the patients to gain the full benefit of palliative care (Finns & Nilson, 2000; Barnard, et. al., 1999).

Codes of Ethics/Bioethics in Nursing

The history of nursing is one in which people, usually women, have attempted to care for others and relieve suffering (Burkhardt & Nathaniel, 2002). "Every woman … has, at one time or another of her life, charge of the personal health of somebody, whether child or invalid – in other words, every woman is a nurse" (Nightingale, 1859, preface). Dealing with ethics in nursing requires skill in the processes of values clarification, ethical decision-making, self-awareness, and empowerment. The Nightingale Pledge continues to influence generations of nurses (Gretter, 2001).

The American Nurses Association (ANA) has proposed ethical guidelines for addressing a host of difficult questions about the use of life-sustaining technologies (ANA, 1992). In 1993, the ANA published position statements on dealing with Nursing and the Patient Self-Determination Act, Promotion of Comfort and Relief of Pain in Dying Patients, Forgoing Artificial Nutrition and Hydration, and Nursing Care and Do-Not-Resuscitate Decisions (Murphy, 1994).

Ethics is discussed in the nursing literature from the early 1880s. The journal *The Trained Nurse*, the first true journal of nursing, began in 1888 and published a six-part series of articles on ethics in nursing in 1889 (Davis, Liaschenko, Aroskar, & Drought, 1997). Between 1900 and 1980, the *American Journal of Nursing (AJN)* has published over 400 articles devoted to ethics (Fowler, 1984).

In 1973, the International Council of Nurses developed *Ethical Concepts Applied to Nursing*. It states that the fundamental responsibility of the nurse is fourfold: to promote health, to prevent illness, to restore health, and to alleviate suffering. The ANA (2001) stated that to demonstrate respect for persons, autonomy, beneficence, nonmaleficence, veracity, confidentiality, fidelity, and justice are values that nurses must embrace. Nurses must value the uniqueness of persons with genuine regard and respect. Each client (person, family, and/or community) is considered unique and valuable.

Historically nurses and physicians approach ethical matters from different angles. Part of this may be due to the separation that exists between the different ways physicians and nurses are educated. Also, no matter what nurses are taught in schools, if the employment setting is not supportive of nursing advocacy and nurses are not encouraged to behave in assertive ways as members of the health care team with input that is valued, nurses will continue to struggle to be a part of the decision-making team.

Court Decisions

There have been many court decisions that have had an impact on the end-of-life decision-making process. In 1976, three landmark precedents occurred that had a profound impact on medical intervention at the end of life: the 1976 California Natural Death Act, the Massachusetts General Hospital Critical Care Committee guidelines on Do Not Resuscitate orders, and the Karen Ann Quinlan case.

The 1976 California Natural Death Act was the first state legislation that clarified the rights of persons to write specific instructions about the end-of-life care that they desired (Burnell, 1993). It also established the Substitute Judgment Standard in the instance of allowing a mother to decide to terminate a ventilator from her daughter against the advice of the physician (Basta, 1996). Also in 1976, the Massachusetts General Hospital Critical Care Committee developed guidelines for the treatment of hopelessly ill patients and for Do Not Resuscitate (DNR) orders (Rabkin, Dillerman, & Rice, 1976).

In re Quinlan (1976), the court decision concerning Karen Ann Quinlan, is one of the most famous cases in health care ethics and made the public aware of the everwidening debate about stopping life-sustaining therapies and of court interventions in health care decision-making (Hoefler, 1994). The case was significant in establishing that a right of privacy permits a patient to decide to refuse medical treatment and that this right can be exercised by a parent or guardian when the patient is unable to do so (Munson, 1992).

Patient self-determination involves the right of individuals to decide what will or will not happen to their bodies. Informed consent and advance directives are two elements of patient self-determination. Competent adults are now recognized as having the rights to consent to or refuse medical treatment. These rights have evolved as medical technology has evolved and the courts have been asked to decide when physicians/ hospitals and patients/families disagree on their use. *Bartling v. Superior Court* (1984) was the first time an appellate court had directly addressed a case in which a clearly competent patient refused necessary life-sustaining treatment (Guido, 2001). The second case of a competent patient refusing life-sustaining technology was *Bouvia v. Superior Court* (1986).

There are three elements of decision-making capacity: the ability to understand and communicate relevant information; the ability to make value judgments; and the ability to reason about different outcomes, risks and chances of success. Removing life-sustaining technology when the patient is incompetent, and/or, their wishes are not clearly written, can be an entirely different matter. The patient is not able to make decisions and a proxy must make decisions for them. In the case of substituted judgment, the proxy merely reports the patient's wishes. When the patient's wishes are not known, the best interests standard may be used by the proxy. The best interests standard is what will be in the best interest of the patient, all things considered. A third standard that may be used by a proxy decision maker when the patient's wishes are not known and the patient has no best interest (as when the patient is in a persistent vegetative state), is the reasonable treatment standard (Devettere, 2000).

Several court cases have addressed the issue of proxies making decisions for incompetent patients with no prior written directives: *Superintendent of Belchertown State School v. Saikewicz* (1977), *Eichner v. Dillon* (1980), *Brophy v. New England Sinai Hospital* (1986), and *Cruzan v. Director, Missouri Department of Health* (1990) are only a few of the many recent cases.

Advance Directives

After the Cruzan decision, Congress expressed support for the use of advance directives and the patient's right to refuse medical treatment with the passage of the Patient Self-Determination Act (PSDA) of 1990 (enacted in 1991). The PSDA requires all hospitals, skilled nursing facilities, home health agencies and hospice programs that receive federal funds to inform patients of their right to refuse medical treatment under the state's laws and to execute advance directives (Omnibus Budget Reconciliation Act of 1990). If individuals entering a health care system participating in the Medicare or Medicaid program have neither a living will nor a legally designated individual who would act for them, the health care provider is required to educate them about these documents (Storch & Dossetor, 1998).

In Florida, an advance directive is a witnessed statement (oral or written) made by a competent adult, giving instructions with regard to the individual's future medical care in the event the individual becomes unable to speak for him or herself due to illness or mental incapacity. An advance directive may be in the form of a living will, a values history, the designation of a health care surrogate, or a durable power of attorney for health care (Thomison, 2001). Nurses have an important role in empowering patients to articulate their end-of-life preferences in writing. Malin (1994) found that hospitals often meet the letter of the law but not the intent, missing attention to the human dimension of the policy.

Nursing Role Stress

The role of the nurse in the end-of-life decision-making process is not well-delineated (Jezewski & Finnell, 1998; Henneman, Baird, Bellamy, Faber & Oye, 1994). Bishop and Scudder (1996) stated that nurses often work in an in-between stance. The nurse fosters the patient's well-being by bringing together the physician's plan, the institution's policies and resources, and the patient's values (Bishop & Scudder, 1990). Patients, families and nurses frequently feel they are being held hostage in situations to continue seemingly futile medical treatment (Storch & Dossetor, 1998).

Often medical-surgical nurses are the persons to whom patients and families turn for information during a time of great emotional distress for all persons involved. Patient treatment decisions do not always coincide with the personal and professional values of the nurse (Drew & Fleming, 1995). Nurses may feel uncertain about the legal, moral and ethical obligations surrounding their participation in this enormously significant aspect of patient care (Jarr, Henderson & Henley, 1998).

Nurses may feel conflict with their multiple roles as health team member, patient/family advocate-educator, ethical decision-maker, and institutional employee during this extremely important time in the life of a patient/family. Multiple and often conflicting demands have been identified as sources of stress for nurses (Huber, 1994). Several studies have been done concerning stress felt by nurses assisting patients and families with end-of-life decision-making.

As part of the Study to Understand Prognosis and Preferences of Outcomes and Risks of Treatment (SUPPORT), Hiltunen, et al., (1995) concluded that "Nurses at the bedside are in a unique position to communicate patients' preferences and … nursing participation on the multi-disciplinary team is essential to clarify patient preferences and individualize the treatment plan to meet patient wishes" (p. 75). Nurses' participation should not only be allowed, but expected by physicians and patients.

Medical-surgical nurses also are involved in many of the processes that lead patients and families to make (or not make) end-of-life decisions. Many families look to their physicians to make decisions without fully understanding their options or the consequences of each option. Even though the law requires that patients be educated about their rights, patients are not fully aware of their ability to refuse treatment options or to seek other opinions.

Medical-surgical nurses may feel unable to adequately assist patients and families with end-of-life decision-making and unable to fulfill the spirit of the laws on advance directives and the ethical guidelines of the American Nurses Association. There is a conflict between the role that nurses are required to implement by legal and ethical standards and the reality of modern healthcare.

This role conflict leads to high levels of stress for nurses (Huber, 1994). Nurses' attitudes toward these stressors make a difference in the nurses' ability to assist patients and families. Studies have shown that as stress levels rise for nurses, job satisfaction falls (McGowan, 2001; Healy & McKay, 2000; Larrabee, et al., 2003).

Problem to be Studied

Attitude includes all aspects of affect, feelings, values and beliefs. Role attitudes are subjective phenomena learned from social and cultural experiences (Hardy & Conway, 1988). When we measure attitudes, we must rely on inference, because it is impossible to measure attitudes directly. Attitude measurement generally calls for assessment of the attitudes of a group of people (Henerson, Morris, & Fitz-Gibbon, 1987).

An understanding of nurses' attitudes toward the stress their multiple roles engender while caring for patients at the end of life is important to be able to assist nurses with personal growth and management of these stresses. High levels of work-related stress are thought to affect nurses' health, job satisfaction, absenteeism and turnover, and patient welfare (Hardy and Conway, 1988). As nursing care is not likely to get easier or less stressful, it is important for nurses to learn from their experiences and gain confidence in this extremely complex interplay between patients, families, nurses, physicians, hospital administration, advances in technology, and legal and ethical demands. However, no measurement tool is currently available to assess nurses' attitudes about assisting patients and families with end-of-life decision-making.

Purpose

The purpose of this project was to develop a valid and reliable instrument to measure nurses' attitudes toward their role in assisting families with end-of-life decision-making. A better understanding of nurses' attitudes will lead to insight into this demanding aspect of nurses' work and can be used to design interventions to assist nurses with their conflicting roles. This project consisted of three phases. The purpose of each phase is described here.

Phase I: The purpose of Phase I was to explore hospital-based medical-surgical nurses' experiences with patients and families who were involved in end-of-life decision-making. Using these nurses' descriptions, common themes were extracted concerning opinions, attitudes and beliefs about nurses' experiences. The themes identified during Phase I were used to develop the proposed instrument items used in Phase II.

Phase II: The purpose of Phase II was to develop a norm-referenced, objective, written multiple-choice instrument to measure nurses' attitudes toward their role assisting patients and families with end-of-life decision-making. Content validity of the Nurses' Attitudes Toward End-of-Life Decision-Making Instrument was estimated by a panel of published experts in the field.

Phase III: The purpose of Phase III was to assess the validity and reliability of the revised Nurses' Attitudes Toward End-of-Life Decision-Making Instrument.

Research Questions

Phase I:

1. What are medical-surgical nurses' experiences with families who are involved in end-of-life decision-making?

2. What role do nurses have in end-of-life decision-making?

3. How do nurses feel about their role in the decision-making process?

Phase II:

What is the content validity index (CVI) for the Nurses' Attitudes Toward End-of-Life Decision-Making Instrument (NATED)?

Phase III:

1. Is the NATED valid for measuring medical-surgical nurses' attitudes toward their experiences with families who are involved with end-of-life decision-making?

2. Is the NATED reliable in measuring medical-surgical nurses' attitudes toward their experiences with families who are involved with end-of-life decision-making?

Definitions of Terms

End-of-life care: the total active, palliative care of patients whose disease is not responsive to curative treatment. The goal is to relieve physical, emotional, social, and spiritual pain and suffering and promote the best possible quality of life for patients and their families (World Health Organization, 1990).

Decision-making: a process of gathering data, comparing options, using some criteria for weighing the merit of each option, and making a choice (Burkhardt & Nathaniel, 2002).

Life-sustaining technology: mechanical devices or procedures designed to prolong the patient's life rather than to cure the problem. Examples include ventilators, renal dialysis, enteric tube feeding, cardiopulmonary resuscitation (CPR), and intravenous hydration (Devettere, 2000).

Role stress: social structure creating very difficult, conflicting, or impossible demands for occupants of positions within it. The role stress for one individual also results in ambiguous and discordant conditions for occupants of interdependent positions (Hardy & Conway, 1988).

Significance of the Study

Patients and families involved in end-of-life decision-making experience one of the most distressing times in their lives. Medical-surgical nurses today do more than merely provide comfort care to dying patients. They also assist patients and families in making difficult decisions regarding care and choices regarding death (Haisfield-Wolfe, 1996). An instrument to study medical-surgical nurses' attitudes toward assisting patients and families with end-of-life decisions will be very valuable in understanding the expanding nursing role that is end-of-life care. This role must continue to be recognized, developed and evaluated in order to provide quality outcomes for patients and families.

Chapter II

Review of Literature

This purpose of this discussion is to focus on literature related to end-of-life decision-making and the nurses' role in that process. The chapter is divided into two sections. In the first section, advance directives are discussed. The second section focuses on research concerning the nurse's role in end-of-life decision-making.

Advance Directives

Several studies have shown that after many years since implementation of the Patient Self-Determination Act (PSDA), many people have not written their end-of-life wishes. Of hospital admissions, only 15%-20% of persons have executed advance directives (Haynor, 1998). Dupree (2000) found that although the rate of completion of advance directives in the general population is low, it is even lower in the African American population.

Other studies have found that culture (Hallenbeck & Goldstein, 1999), race (Caralis, Davis, Wright, & Marcial, 1993), and ethnicity (Blackhall, et al., 1999) influence their wishes concerning life-sustaining technologies. Other factors such as health beliefs (Bradley, Walker, Wetle, & Horwitz, 1998); discussions with physicians (Johnson, 1996); education (Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000); age (Frank, Smyer, Grisso, & Applebaum, 1999); advance directive education (Havens, 1995); and perceptions of their health, physical state, mental state, presence of pain (Coppola, et al., 1999); and the ability to function and/or prognosis (Weeks, et al., 1998) influence their choices.

Baer (1992), using a researcher-developed Life-sustaining Technologies Scale and the Miller Hope Scale found gender, age, marital status, and having an advance directive correlated significantly with persons' preferences for life-sustaining technologies. In 1998, Weeks, et al., found that patients' estimates of survival probabilities influence their preferences about medical therapies.

Through chart review, patient interview, and surrogate interview using scripted interviews, Coppola, et al., (1999), found an inverse relationship between preferences for technology and cognitive impairment, poor chance for recovery, and pain. Fears of over-treatment and concerns about health care related to desire for control over decisions were identified by Eiseman and Richter (1999) via a mailed questionnaire. Singer, Martin and Kelner (1999) found that patients were concerned with pain control, symptom control, inappropriate prolongation of dying, a sense of control, relieving burden on their families and strengthening relationships with loved ones.

Level of education was found to be the most important factor differentiating between patients who did and did not execute an advance directive in a study by Mezey, Leitman, Mitty, Bottrell and Ramsey (2000). Many people believe that the physician should make treatment decisions for the patient (Schlenk, 1997; Perry, Nicholas, Molzahn & Dossetor, 1995; Storch & Dossetor, 1998). Murphy (1994) found that often DNRs are written too infrequently and too late. Physicians and nurses often wait for the family to initiate conversation.

Studies concerning nurse's role in end-of-life decision-making

Many studies have been conducted concerning the nurse's role in end-of-life decision-making and care, but few have focused on the medical-surgical nurse's role. Studies have been published concerning end-of-life decisions and advance practice nurses. In 2000, Schlegal and Shannon, using a descriptive study, found that nurse practitioners are knowledgeable about legal guidelines related to end-of-life decision-making and are comfortable counseling patients regarding end-of-life decisions. Blatt (1999) found that the advance practice nurse played multiple roles including allowing the family to verbalize their fears and anxieties and feelings regarding CPR.

Jezewski and Finnell (1998), using grounded theory method, found that oncology nurses used strategies such as communicating, caring, educating, collaborating, and advocating to prevent or resolve conflict between patients, families and health care providers when making decisions about DNR orders. Briggs and Colvin (2002) found that although oncology nurses play a pivotal role in helping individuals understand, explore and communicate their preferences regarding medical decisions and end-of-life care, they are unclear and confused when confronted with situations that demand advocacy. Some of the barriers to nursing advocacy identified in the study included minimal training and lack of role models and organizational support.

Nurses in intensive care units (ICU) often are involved in end-of-life decision-making and care. In a qualitative study of ICU nurses, Jezuit (2000) found that nurses experience emotions described as suffering when caring for patients at end of life. Reckling (1997) found that in the ICU under study, a physician always initiated end-of-life decisions with patients' families and then nurses discussed related issues. Situational constraints on the roles adopted by nurses in the end-of-life decision-making process were observed. Nurses did not support unpopular positions even when they thought it was the morally right thing to do and adopted a passive role.

Miller, Forbes and Boyle (2001) suggested that ICU nurses have a limited role in end-of-life decision-making. In a study of the implementation of advance directives, Kirmse (1998) stated that critical care nurses have a key role in educating nurses, their patients, and physicians about advance directives. Using data collected in the SUPPORT study, Hiltunen, Medich, Chase, Peterson, and Farrow (1999) found that nurses facilitated the process of discussion between families and physicians, the nurse shared in the families' experience of grief, and that nurses help the families actually hear what is being said to them. They likened the role to that of a mid-wife, one who understands the process and can be present with the family.

Blatt (1999) identified nurse behaviors that families judged as being supportive. Behaviors that were helpful included receiving consistent information in understandable terms, knowing what to expect, assisting with decisions and with the grieving process. Jezuit (2000) found that ICU nurses become emotionally involved with patients and families and experience an emotion described as suffering. In another study of ICU nurses, Miller, Forbes, and Boyle (2001), found that nurses have a limited role in end-of-life decision-making discussions with families. Kirchhoff et al., (2002) found that families of patients in ICU relied on nurses to keep them informed about the patient's condition.

Using data collected during the SUPPORT study, Kennard, et al., (1996) found that 67% of nurses had little or no knowledge of their patients' preferences, 53% did not advocate these preferences, and 77% felt they had little or no influence on the plan of care. The nurse's education and clinical experience were found to be significantly associated with confidence and ability to assist patients and families. In a study of advance directives, Johns (1996) found that patient education is a key element in initiating advance directives and that patient education is an important role of nurses.

In a study of 107 hospital-employed registered nurses, Jarr, Henderson, and Henley (1998) reported that a majority of nurses report they do not have enough information to discuss advance directives with their patients and most nurses do not follow their institutional policy about how to get help for patients who want more information about advance directives. Those who feel that they do have enough information, did not uniformly agree that it is primarily a nurse's responsibility to discuss advance directives with patients and families. In an editorial, Fetter (2000) stated "the nursing role at the end of life has not been described and researched adequately" (p. 231).

Barriers to assisting patients and families with implementing advance directives were identified as the nurses' lack of knowledge, legal concerns, a perception of a lack of concern for ethical issues by the institution, and limited time (Ryan, et al., 2001). Other research has shown nurses may be educationally unprepared, experience moral conflicts with personal beliefs, or are resistant to the responsibility of discussing end-of-life decision-making with patients and families (Goodwin, Kiehl, & Peterson, 2002).

Chapter Summary

This chapter reviewed the literature concerning advance directives and studies that have been done of the nurse's role. Through this literature review emerged a partial understanding of the complexity of the responsibility that nurses face when dealing with patients and families at the end of life.

The ethical and legal responsibilities of nurses are clearly delineated in state and federal law and in nursing ethics guidelines, but the workplace environment is not always supportive of the nurse's role as a patient advocate and educator. Nurses often feel conflict with their responsibilities and their own individual beliefs. Empowerment of nurses by institutional administration and physicians is lacking in many settings and nurses often feel overwhelmed by being in the middle of this emotional and extremely important time in their patients' lives. This study is important because a better understanding of nurses' roles and their attitudes toward their roles can be used to assist nurses, and therefore patients and families, to make better-informed decisions at end of life.

Chapter III

Methods

This chapter includes a discussion of the setting, sample, instruments, procedures and data analyses that guided this study. In the first section of this chapter, the research questions are reintroduced. Section two of this chapter provides background information about the research setting. The third section discusses the sample, instrument, procedures, and analysis used in each of the three phases of this study.

Research Questions

Research questions pertaining to each research phase are:

Phase I:

1. What are medical-surgical nurses' experiences with families who are involved in end-of-life decision-making?

2. What role do nurses have in end-of-life decision-making?

3. How do nurses feel about their role in the decision-making process?

Phase II:

What is the content validity index (CVI) for the Nurses' Attitudes Toward End-of-Life Decision-Making Instrument (NATED)?

Phase III:

1. Is the NATED valid for measuring medical-surgical nurses' attitudes toward their experiences with families who are involved with end-of-life decision-making?

2. Is the NATED reliable in measuring medical-surgical nurses' attitudes toward their experiences with families who are involved with end-of-life decision-making?

Setting

The setting for this research study was several acute-care hospitals on the East Coast of Florida. Volunteers who participated in this study were registered nurses working at these hospitals. The hospitals were: a) a 101-bed, acute-care, for-profit hospital providing a full range of medical-surgical services, both in-patient and out-patient, in a small, rural town; b) a 194-bed, acute-care, for-profit facility offering cardiac catheterization, comprehensive cancer services including a peripheral stem cell transplantation program, Orthopedic Center of Excellence and a wound care center; and c) a 293-bed, acute care, community-owned, not-for-profit hospital with a Regional Cancer Center, Center for Emotional and Behavioral Health, Joint Implant Center, and Partners in Women's Health.

Phase I

Sample

The purpose of Phase I was to determine nurses' attitudes toward their role in assisting patients and families with end-of-life decision-making. The nurses used in this study were chosen based on the schedules, availability, and willingness. Volunteer registered nurses (RNs) working in medical-surgical hospitals were approached during staff meetings. Inclusion criteria were being a registered nurse, working in an acute-care setting, and able to read and understand English. Licensed Practical Nurses and other health care workers were excluded.

Instruments

The *Nurse Participant Interview Schedule* (Appendix A) was used to guide interviews in Phase I. The interview schedule was designed to ask twelve open-ended questions. Open-ended questions encouraged the respondents to talk about whatever they wish that was relevant to the topic of their experiences and attitudes toward assisting patients and families with end-of-life decision-making.

The *Demographic Information Sheet* (Appendix B) was used to gather demographic information about the participants in Phases I and III of the study. The demographic form asked for information such as age, gender, race/ethnicity, length of time working as a nurse, and level of education.

Procedures

Institutional review approvals from the hospitals (Appendix C) and the University of South Florida Institutional Review Board (Appendix D) were obtained. A convenience sample of RN participants was recruited from medical-surgical institutions in cities on the Southeast coast of Florida.

The purpose of the project was explained to potential participants during staff meetings and they were asked to volunteer. They were told that there are no adverse consequences of their not participating. Appointments were made with volunteers on their own time away from the medical-surgical facility. Meetings took place in private meeting rooms at local libraries. Volunteers were given a chance to ask questions, and then they signed an informed consent form (Appendix E).

After consenting, the nurses completed a demographic information sheet (Appendix B). In Phase I, audio-taped interviews were conducted privately with each participant. Using a schedule of guiding questions, each interview lasted approximately one hour.

Data Analysis

The qualitative method of content analysis was used to focus on eliciting and describing medical-surgical nurses' experiences with patients and families who were involved in end-of-life decision-making. Content analysis was used for getting a sense of what is in the data (Norwood, 2000). Categories were created and data coded into these categories (Nieswiadomy, 1998). The goal of content analysis is to reduce the data into defined categories (Flick, 1999).

Analysis was assisted by the use of a computer software program, Ethnograph v5.0. Ethnograph assisted with noticing, collecting and then thinking about ideas that came from the interviews. The process is not linear but spiral, in that each of the three steps leads back and forth to the other steps. The interviews were transcribed into Ethnograph and then read and reread. As ideas emerged from the interviews, they were given code names. The common codes were then collected to become themes, or categories of ideas. The pieces of data were then reconstructed into usable patterns. In thinking about the patterns that emerged from the interviews, relationships were identified and given names. A memo for each code clarified the definition of the code.

Phase II

The purpose of Phase II was to determine the Content Validity Index (CVI) of proposed instrument items and develop an objective, written, instrument from themes identified in Phase I. A panel of experts in the field of nurses' roles in end-of-life decision-making was consulted to determine the CVI of the instrument items.

Consultant Panel

Consultant experts were nurses who have published research findings in the area of advance directives, end of life care and/or the nurse's role in end of life treatment decisions. A panel of seven nurse experts in the field of end-of-life care was identified based on their published journal articles. Each was contacted by e-mail and invited to participate. They were asked to evaluate proposed instrument items. As each agreed to participate, they were sent proposed instrument items arranged by themes identified in Phase I.

Instrument

The Content Validity Index Tool was used by the experts (Appendix F). The consultants were asked to evaluate each proposed instrument item. The form required them to indicate yes, no, or uncertain to whether or not each item measures some aspect of the nurse's attitude toward one of the themes identified in the qualitative interviews of Phase I. Members of the expert panel were instructed to assess the relevance of each item to the concept under study using the following scale: 1 = relevant, -1 = not relevant, 0 = uncertain. The CVI was determined for each item and the instrument as a whole.

Procedures

The consultants were e-mailed and asked independently to link each objective with its respective item, assess the relevancy of the items and to judge if they believe the items on the tool adequately represent the objectives of the study. The experts assessed the relevancy of each item to determine if the items adequately represent the content or behaviors in the domain. Instruments were then e-mailed back to the researcher.

Analysis

The CVI for each item was calculated by adding the number of item ratings and dividing that total by the total number of ratings. If the item CVI was .70 or higher, it was accepted as an instrument item. If the agreement was less than .70, the item was deleted. The CVI for the entire instrument was estimated by dividing the number of items with a rating of 1 by the total number of items. A CVI of .75 or higher is acceptable (Waltz, Strickland, & Lenz, 1991; Norwood, 2000).

Phase III

Sample

The purpose of Phase III was to estimate the validity and reliability of the instrument. The groups used in Phase III of this study were chosen based on their availability. Registered nurses working in the medical-surgical hospitals were approached during staff meetings. The project was explained to them and volunteers were solicited. Inclusion criteria were being a registered nurse, working in an acute-care setting, and able to read and understand English. Registered nurses who have been in practice fewer than six months were excluded as were Licensed Practical Nurses and other health care workers.

Instruments

Nurses' Attitudes Toward End-of-Life Decision-Making Instrument (NATED) (Appendix G), a 37-item, four-response summated rating scale ranging from 4 (always), 3 (usually), 2 (sometimes) to 1 (never) was developed from statements identified in the qualitative interviews. Responses to the items were in the same metric with some items reverse scored (Green, Salkind, Akey, 2000). Possible scores range from 37 to 148 with a high score indicating that the nurse is more comfortable (experiencing less stress) in the role of assisting patients/families with end-of-life decision-making and a low score indicating that the nurse is less comfortable (experiencing more stress).

The *Demographic Information Sheet* (Appendix B) was used to gather demographic information about the participants in Phases I and III of the study. The demographic form asked for information such as age, gender, race/ethnicity, length of time working as a nurse, and level of education.

Procedures

Institutional review approvals from the hospitals (Appendix C) and the University of South Florida Institutional Review Board (Appendix H) were obtained. A convenience sample of RN participants was recruited from three medical-surgical institutions in cities on the Southeast coast of Florida.

The purpose of the project was explained to potential participants during staff meetings and they were asked to volunteer. They were told that there are no adverse consequences of their not participating. Volunteers were given a chance to ask questions, and then they signed an informed consent form (Appendix I).

After consenting, the nurses completed a demographic information form (Appendix B). The Nurses' Attitudes Toward Assisting Patients/Families With End-of-Life Decision-Making (NATED) was administered to the volunteers and reactions to the instrument were solicited in written and verbal form.

Data Analysis

The instrument was evaluated for validity and reliability. Validity refers to the extent to which a study's findings accurately depict the phenomenon studied (Norwood, 2000). Validity focuses on whether the NATED accurately measures nurses' attitudes toward end-of-life decision-making. Reliability refers to the degree of dependability or consistency with which an instrument measures what it was designed to measure (Polit, 1996). An instrument can be reliable without being valid, but an unreliable instrument cannot be valid (Fox, 1982).

Sample size. There are diverse and often contradictory recommendations in the literature regarding the adequacy of sample size to maximize statistical power of factor analysis (MacCallum, Widaman, Zhang, & Hong, 1999). Hatcher (1994) stated that the number of subjects should be the larger of 5 times the number of variables, or 100. Some experts suggest that for optimal statistical power, the number of participants is ten for each instrument item (Norman & Streiner, 1994). Hutcheson and Sofroniou (1999) recommend at least 150 to 300, more toward the 150 end when there are a few highly correlated variables. The sample size should be at least 200 (Gorsuch, 1983).

Validity. Statistics software by SPSS was used to confirm relationships between the latent variable (attitude) and the observable variable (score on test items). Construct validity was estimated using factor analysis. Factor analysis is a statistical technique applied to a single set of variables (the variables are the instrument items) to discover which variables in the set form coherent subsets (the subsets are the attitudes of nurses) that are relatively independent of one another (Waltz, Strickland, & Lenz, 1991). Those items that did not demonstrate value to the instrument were revised or deleted.

Reliability. Internal consistency reliability is the statistical determination of how well each item on an instrument relates to all other items and provides an indication of how consistently individuals respond to all items on an instrument (Wilson, 1989). The most widely used measure of reliability is the Cronbach's coefficient alpha (Frank-Stromborg & Olsen, 1997). Cronbach's alpha measures the extent to which performance on any one item in the instrument indicates performance on other items in the instrument (Waltz, Strickland, & Lenz, 1991). This was calculated on any subscales and for the total scale score at the time factor analysis was conducted.

Chapter Summary

This chapter included a discussion of the setting, sample, instruments, procedures, and data analyses that guided this study. Research questions were reintroduced and background information about the research setting was presented.

Chapter IV

Results

As this study was conducted in three phases, the results are reported for each phase. The purpose of Phase I was to explore with hospital-based medical-surgical nurses their experiences with patients and families who were involved in end-of-life decision-making using a qualitative approach and individual audio-taped interviews.

The purpose of Phase II was to develop an objective multiple-choice instrument to measure nurses' attitudes toward their role assisting patients and families with end-of-life decision-making. Content validity of the Nurses' Attitudes Toward End-of-Life Decision-Making (NATED) was estimated. The purpose of Phase III was to assess the validity and reliability of the revised Nurses' Attitudes Toward End-of-Life Decision-Making.

Phase I

In Phase I, data were collected through individual, one-on-one audio tape-recorded interviews with each participant (n = 6). The interviews were transcribed and, using the software program Ethnograph v5, analyzed for common statements, concepts or phenomena using content analysis to express data in the form of concepts.

Sample

All of the volunteers were female. Their ages were between 49 and 60 years old. Four had been nurses for 21to 30 years with one 11 to 15 years and one a nurse for 40 years. One volunteer was a diploma graduate, two graduated from ADN programs, and three were BSN graduates. All were working in acute care but had had ICU and/or oncology experience. The demographics of the participants are reported in Table 1.

Table 1

Demographics of Phase I Interviewees

Nurse	Level of Education	Years of Experience	Years at Current Institution	Age
A	ADN	11-15	0-5	49
B	BSN	21-30	16-20	47
C	BSN	21-30	11-15	48
D	BSN	40	0-5	60
E	ADN	21-30	11-15	47
F	Diploma	21-30	0-5	58

Themes

Eleven themes emerged and were identified from the interviews with nurse participants. Six of the identified themes were concerns of the patients/families and were discussed with or expressed to the nurse. The following common themes were identified as being expressions of the patients/families as difficulties and areas where the nurses were expected to understand and offer assistance: (a) abandon, (b) denial, (c) ethics, (d) family guilt, (e) family rescinds, and (f) knowledge.

Five main themes were identified related to the nurses' feelings and attitudes about their role in assisting families with end-of-life decisions. The five themes are identified as (a) Advocate Role, (b) Preparation, (c) Helplessness, (d) No Time, and (e) MD Behavior.

Patients' and Families' Concerns

Abandon. Often patients/families expressed to the nurses an unwillingness to agree to a Do-Not-Resuscitate order (DNR) because they feared that the patient would be abandoned by nurses. They often felt that the patient's symptoms would not be addressed and that perhaps the patient would be left to die alone. Participants indicated that family members often ask if the care will be different. The families sometimes feel that if they agree to a DNR order that the nursing staff will just let the patient lie in the room and ignore them.

> Excerpt: "If we go with a DNR, will they be treated? We don't want it if … we want him to be treated."
>
> Excerpt: "Does this mean that you will stop … the care will be different?"

Denial. Nurses expressed that the patients/families often do not see the need for end-of-life decisions. Sometimes the feeling is that the patient has been through so much and has always successfully come out of trouble so that they are invincible. Many times the physicians reinforced the idea that any disease process can be treated and defeated. It appears to the participants that the families want to fight and not give up.

The diagnosis can sometimes influence the way people think about prognoses. When a patient has cancer, people are more ready to discuss end-of-life issues because people readily equate cancer with death. They may not equate end-stage chronic obstructive pulmonary disease (COPD) or end-stage renal failure or Alzheimer's disease with death. Because people often live for many years with chronic illnesses, many patients and physicians do not recognize them as terminal illnesses.

> Excerpt: "Most of the other nurses feel similar to what I do and we feel frustrated because there seems to be in this country the one thing we don't accept is the fact that we're all going to die."

Ethics. The ethics committee of an institution can be called when a situation arises that is difficult to resolve. The interviewed nurses were aware of their institution's ethics committee and had called on its help in a few situations. Most of the time, ethical issues were settled with discussion between nurses, physicians and families but sometimes the nurses felt that they had to go to the ethics committee to resolve tough issues.

One nurse had contacted the ethics committee because the nurses and the family wanted a patient deemed as brain-dead removed from the ventilator over the objections of the physician. The ethics committee was called to serve in the role as the peer of the doctor who was unable to discuss end-of-life issues and treatment decisions with a family. The peer discussion was valuable to allow the physician to explore issues without feeling threatened or confronted.

One situation involved a woman who was very, very ill and her companion. They were not married but had lived together for many years. Her companion told the nurses that he wanted everything done for her to keep her alive as long as possible because he needed her Social Security check to keep the house. The ethics committee was consulted on this case and the inappropriate prolonging of life was made clear to the companion.

Family guilt. The participants indicated that family guilt can influence the decisions the family is making. Nurses expressed that some families appear to have some kind of guilt or disturbed family dynamics; usually they just do not want to say. At the other extreme, some just do not want to let go and they refuse to honor a patient's wishes. Crises such as a family member facing death can bring out the best, or worst, in a family.

> Excerpt: "Sometimes family members have unresolved issues or unsaid things with that person, and they feel guilty about the decisions they make."

One nurse recounted that a daughter of an elderly woman had brought her mother to the emergency room because of difficulty breathing. Following administration of diuretics, steroids, and inhalation therapy, the patient improved and her daughter said "What are you doing bringing her back? She was supposed to die."

> Excerpt: "The mother was in her 80s and the woman in her 60s and said she was tired of taking care of her mother."

Another source of conflict reported by an interviewee was when there is a second spouse and the children of the first spouse are in conflict with the other family.

> Excerpt: "You know, you get caught in the middle, especially in the hospital when you have one family member telling you not to answer questions when so-and-so calls. Who has the right to the information?"

Some nurses reported that families express concern that the person who is dying cannot die until all family members arrive at the bedside. They may reside in another section of the country and it is difficult for the nurses when they are asked to continue futile life-sustaining treatments so that family members can travel to the bedside.

> Excerpt: "It's hard to keep somebody alive so that everybody can be there. I know it is not ethical but that is what's happening. We see it a lot."

Family rescinds. There are times when the family changes the decisions that the patient has made. Even though it is the intent of the law that the patient's wishes be followed at all times, some families do not want to let go. The nurses recognize feeling that it is wrong but without a strong surrogate who will speak the patient's wishes, changes can be made if the patient is unable to communicate.

> Excerpt: "And they refuse to honor a patient's DNR, because they can rescind it, you know, once the patient is not able to talk, they can rescind the DNR. I've seen them do it. I've also seen them rescind those orders when the patient is unable to speak. That happens sometimes."
>
> Excerpt: "I'm not sure if it is legal or not. But this is what happens. And it is very disturbing."

One nurse reported that a daughter was able to influence decisions that were being made even though the mother was conscious and saying "I want this" (a morphine drip) she (the daughter) was still a dissenting family member. It was difficult for the mother who could not deal with the daughter directly. It was difficult for the physicians and for the nurses who wanted to do as the patient requested. But the daughter was disruptive and the mother relented and changed her request under the pressure of the daughter and did not receive the morphine drip.

Knowledge. Evidence indicated that the participants perceived patients and families do not always understand advance directives.

> Excerpt: "There is also a lot of ignorance about the differences between living wills, DNRs, and healthcare surrogates and what will be done, or what can be done."

> Excerpt: "Some people equate the phrase "living will" with a financial will and we nurses have to explain it to them."

Nurses' Attitudes

Five main themes were identified related to the nurses' feelings about their role in assisting families with end-of-life decisions. The five themes are identified as (a) Advocate Role, (b) Preparation, (c) Helplessness, (d) No Time, and (e) MD Behavior.

Advocate role. Nurses see their role as advocates for the patients. This theme was repeated many, many times in the interviews.

> Excerpt: "… so I would prefer to talk to families myself a lot of time because many times doctors don't know how to approach families."

> Excerpt "I've had to intervene and tell the doctor that that is not really the patient's choice …"

> Excerpt: "Usually I approach families … after having a number of experiences with death and dying in home health."

> Excerpt: "Sometimes, though, situations change and we would have to start talking to the family, sort of gently tell them that the patient is not going to make it, that they were probably going to die …"

Many nurses stated that the physicians did not feel comfortable with discussing end-of-life decisions with families.

Excerpt: "I think our training prepares for dealing with families, in a way. I mean, we have a more holistic approach than physicians do. They don't seem to have any training or background in dealing with the families as social structure, as an extension of the patient. The nurses have a more holistic approach than the doctors."

Excerpt: "They (the doctors) expect you (the nurse) to take care of it. They don't discuss it with the patient. They just simply ask you "What's the status?" And so, generally, I like to bring it up with the families."

Excerpt: "I would prefer to talk to families myself a lot of time because many times doctors don't know how to approach families."

Excerpt: "The nurses start the conversation. The physicians usually don't initiate."

Excerpt: "Without a doubt it is the nurses who start the talk about end of life and what to expect."

Nurses often feel like they are in-between the patient, family, physician, and the system. "When the patient hasn't written their wishes down or hasn't made a formal advance directive, the family's not really aware of the person's wishes. Or for some reason they are unable or unwilling to carry them out and the nurse gets involved in the process and learns the patient's wishes. It can be difficult to stand up for the patient, for what you (the nurse) knows as the patent's rights or their wishes."

Other nurses felt strong and confident in their role as patient advocate.

Excerpt: "My role has been to continuously represent the patient's wishes and to try to convince the family to go with what the patient wishes and how that is so much more important. It's a matter of just repeating what he wanted, what he has written."

Excerpt: "I think you'd just have to be the patient advocate … You just keep repeating and repeating what the patient either said or wrote."

Excerpt: "You sometimes have to stand up to physicians and family members who might be a little belligerent. That's what we are supposed to do. Somebody has to talk for that person who can't talk."

Excerpt: "Hopefully, you know enough about them (the patient's wishes) before you get into that situation and I think that's one of the reasons you have to start the family out when you meet them for the first time. Someway you have to have some rapport with them."

Excerpt: "I think that those are the good things. When you can help someone and you can help their family go through what they need to go through so that they can say goodbye, so that they are leaving this world."

Excerpt: "Where I work the nurses feel assertive and confident enough to intervene with doctors and families. And there are some that are better at it than others."

One nurse was able to speak to patients/families by using a gentle approach. "You try to parcel it down. – "Well, if the breathing gets real bad, do you want him put on a respirator?" and explain what a respirator is and also go into, co-morbid things that could determine whether or not you think that Mom or Dad will ever get off that respirator. Or if they do, how long it would take. And then what they might go back to (quality of life)."

Preparation. How a nurse learns to assist patients/families was seen as a concern for many of the interviewees. According to one interviewee "Nurses are definitely not adequately prepared in school for this."

> Excerpt: "I learned basically through experiences and talking with other nurses and kind of putting two and two together. A lot of it has to do with experience."
>
> Excerpt: "I was 19 when I got out of nursing school so I was just a child really. I didn't understand the ANA ethics, end-of-life ethics."
>
> Excerpt: "I don't think that nursing school prepared me. I think that my basic values were things that I acquired and used and then it was based on experience."
>
> Excerpt: "It's not the training you receive in nursing school, it's experience."

One nurse felt that her nursing training had prepared her. She stated that, "When I went to school, we were definitely put in an advocacy role and taught to be independent. I am a bachelor's prepared nurse ... and I think that prepared me a lot more than the other programs might have." One nurse said that training beyond her basic nursing education was what prepared her for end-of-life decision-making. She stated, "I went back to get my BSN years later where we formally talked about end-of-life issues. I also attended some seminars to prepare me for those kinds of things about end-of-life issues. We talked to people in hospice who had really dealt with these issues and it helped me have a voice to talk about end-of-life ... what did the law say ... what we were permitted to do."

Helplessness. Nurses expressed feeling helpless to intervene or to change a situation. Nurses can be caught in a situation where they interpret their role as patient's advocates but are blocked by physician or institutional policy.

> Excerpt: “Nurses were not allowed to mention hospice to a patient until the doctor initiated the conversation.”

One nurse expressed “There needs to be a time when we say “enough. We have done what we can but this is futile.” And that is rare. It doesn’t happen. Or we see it happen after weeks to months of terribly invasive treatments.”

> Excerpt: “We often feel helpless and frustrated with not being able to help patients and family members.”

Occasionally, an institution or the structure of the nursing administration does not support the nurse’s role as advocate. One nurse related speaking with a family member about her mother’s condition being terminal. The daughter’s reaction was to go to the nursing supervisor and complain about the nurse. “How dare you speak to me about this when the doctor didn’t say my mother was that sick.” The nursing supervisor did not support the nurse and she was reprimanded for speaking to the family without the prior knowledge of the physician.

Participants reported that working with other nurses who are not able to assist families adds to their frustration. One stated, “You know I work with a lot of nurses but those who are not oncology have a lot more difficult time and don’t know how to speak to the families. They don’t even know what to do. They just don’t do well in these situations.”

Some participants reported that many times nurses will ask an experienced nurse to speak to patients or families because they are not comfortable talking about end-of-life decisions, seeking advice from the more confident nurse.

Excerpt: “Some nurses have problems advocating for the patient’s wishes when it is in conflict with what the physician wants to do.”

Excerpt: “I think most of the floor nurses would run from answering specific questions that the family might have about advance directives, DNRs, comfort care. They are not prepared and don’t want to deal with it.”

Excerpt: “It depends on their age group. The older nurse probably has seen more and is more comfortable with it. The younger nurses are just skirting around it.”

Many nurses expressed the feeling that they are prolonging suffering by prolonging the death of the patients. This causes a great deal of distress for many nurses.

Excerpt: “They are just prolonging the inevitable and making the patient suffer.”

Excerpt: “He was on a vent and he was just anasarca. He was a mess. He would beg us. He would just sit there and plead with us, you know, folding his hands and begging us – please, please, please, pull his tube. We had to restrain him.”

Excerpt: “When in fact what you are doing is torturing them.”

Excerpt: “Well, when I do cry it’s more like I couldn’t get a DNR and they and did this to this person and they died anyway or they put them on the vent and nothing is going to happen and they are suffering. That bothers me a lot more.”

Excerpt: “If you keep giving fluids all you do is cause more pain and more edema and that causes a lot more suffering.”

Excerpt: “And they’re (the physicians) are not with the patient on a daily basis. I don’t think they recognize the amount of pain and discomfort that the patient’s actually go through.”

Excerpt: “She was in ICU for 3 months with no hope of recovery. That’s torture.”

Many nurses felt strongly that stopping the life-sustaining treatments allows a natural process to evolve.

Excerpt: “And many times I have to explain that if she, and say, she is not going to get better, do you want this or do you want her to go naturally?”

Excerpt: “That you are not killing that patient, the natural disease process is causing them to die. You are just taking away the intervention that prolongs their life, or prolongs their death.”

Excerpt: “What we are currently doing with our technology is interfering with a natural process. Once we know that what we are doing is futile and we are prolonging the death process, then it is reasonable to withdraw that and let the natural process to occur.”

No time. Adding to the nurses’ feelings of helplessness is that they feel they have no time to spend with the patient and family to build a caring, trusting relationship.

Excerpt: “And back then, I’ve been a nurse 40 years, you could stay with the patient when they were dying. You could sit there and hold their hand, you could talk to them, you could do all those things you just don’t have time for anymore.”

Excerpt: “I think that the fact that we work 2 days on and 2 days off and float from floor to floor the family might see twelve different nurses and they are not getting the consistent person they can rely on and ask questions.”

Excerpt: “You know, they are really under stress. I wish we could do more than we do. I wish we had the time to spend with them.”

Physician Behavior. Many nurses perceived that physicians resist discontinuing medical treatments or surgical interventions and allowing a patient to die a natural death. Participants perceived that futile interventions often continued even when they did not improve patients' prognoses or quality of life. The participants perceived this as "torture". Adding to the role stress that nurses experience when dealing with dying patients and stressed-out families, they also feel that they are often in opposition to the physicians caring for the patient.

> Excerpt: "Um, the doctor didn't like to give up on patients. He would agree to some things but other things he would fight. He just did not accept giving up on his patients."
>
> Excerpt: "Many doctors like to treat aggressively even when, because of the patient's quality of life, aggression is not the thing to do."
>
> Excerpt: "I think our training prepares for dealing with families, in a way. I mean, we have a more holistic approach than physicians do. They don't seem to have any training or background in dealing with the families as social structure, as an extension of the patient."

One nurse reported that she was involved with a patient that was diagnosed as brain dead. The primary doctor kept the patient in ICU and told the nurses to keep him in life-sustaining equipment because that is what his wife wanted. When the nurses discussed the situation with the wife, she had not been told that it was a grave situation and she didn't want everything done. The doctor was not telling the truth to her. She said that the doctor said her husband would recover and return home.

One family-member, the daughter of an elderly, severely demented patient was told by the physician that if she did not give consent for the insertion of a gastrostomy tube the daughter would be responsible for starving her mother to death. "The doctor told me that it will be my fault if I don't sign these papers and she dies."

Several of the participants reported that physicians are perceived not to be comfortable discussing the topic of end-of-life care and do not bring it up to the patient or family.

> Excerpt: "Many physicians, except perhaps oncologists, are not comfortable and they just simply leave it up to the nurses to take care of it. They do not discuss it with the patient. They just simply ask the nurse "What's the status?"

Nurses are often caught in between physicians and patients/families as each looks to the nurse for help with difficult discussions. One nurse stated that the majority of physicians do not talk to the patients/families about these difficult issues and the nurse is expected to talk to the family.

> Excerpt: "We live in a very litigious society. Some physicians are more concerned with legalities and liabilities rather than the patient's quality of life."

Many nurses expressed concern with a patient's quality of life – as defined by the patient him or herself.

> Excerpt: "I don't know what the cut-off point is, you know, but I always thought it was quality of life. If you don't have quality of life, what are we doing?"
>
> Excerpt: "It is really heart-breaking that physicians don't have a better knowledge than that of what end-of-life issues are and what we're really doing."

Excerpt: "I think it's a combination of factors. I think that they are looking at things from a physician's point of view and they are looking at the physical part of the person. They are not looking at the whole person – their spiritual nature, too. And they're not with the patient on a day-in-day-out basis and don't recognize the amount of pain and discomfort that patients actually go through.

Comments Written on the Surveys

Several participants wrote comments on the surveys. They also included comments on the advocate role, nurse preparation, helplessness, no time, and MD behavior.

Advocate role. Comment: "Nurses are not educated well enough to be assertive with MDs concerning DNRs and discontinuing aggressive treatments."

Preparation. Comment: "I feel that training beyond basis nursing education would have a more favorable impact on "younger" nurses when dealing with end-of-life issues."

Helplessness. Comment: "It is heart breaking to participate with someone being resuscitated when this was not their wish."

No time. Comment: "I'm too busy to assist patients/families with end-of-life decisions, but I make the time."

Comment: "Even though terminally ill patient's or family's needs are more time consuming, I usually give them my focus, and condense care/attention elsewhere."

Comment: "My assignments keep me too busy to sit with patients/families making end-of-life decisions, but you just make the time."

Comment: "I feel because of the pace of our daily routine, the patient/family care will most always be less than what is truly needed."

Physician behavior. Comment: "With DNR patients or terminally ill patients I see a lot of tests and procedures being performed that put the patient in a lot of stress and financial strain. I'm not sure it is in the best interest of the patient."

Comment: "A lot of doctors treat the family instead of the patient. A patient's wishes should always be respected and that is not always the case."

Comment: "I find physicians do not want to give in. Families of terminally ill patients are not told by physicians that they should quit aggressive treatments."

The above quotes answer the three research questions which were proposed at the beginning of this study: a) What are medical-surgical nurses' experiences with patients and families who are involved in end-of-life decision-making? b) What role do nurses have in end-of-life decision-making? and c) How do nurses feel about their role in the decision-making process?

From the above excerpts and comments were extracted the five main themes of Advocate Role, which is influenced by legal and ethical guidelines; Preparation, which is influenced by the education and experience of the nurse; Helplessness, which is influenced by the suffering of the patients and the nurses' inability to alleviate that suffering; No Time or not enough time to assist patients and families; and MD Behavior. Each of these themes contributes to the role stress experienced by acute care nurses. Figure 1 illustrates the conceptual model derived from the five identified themes.

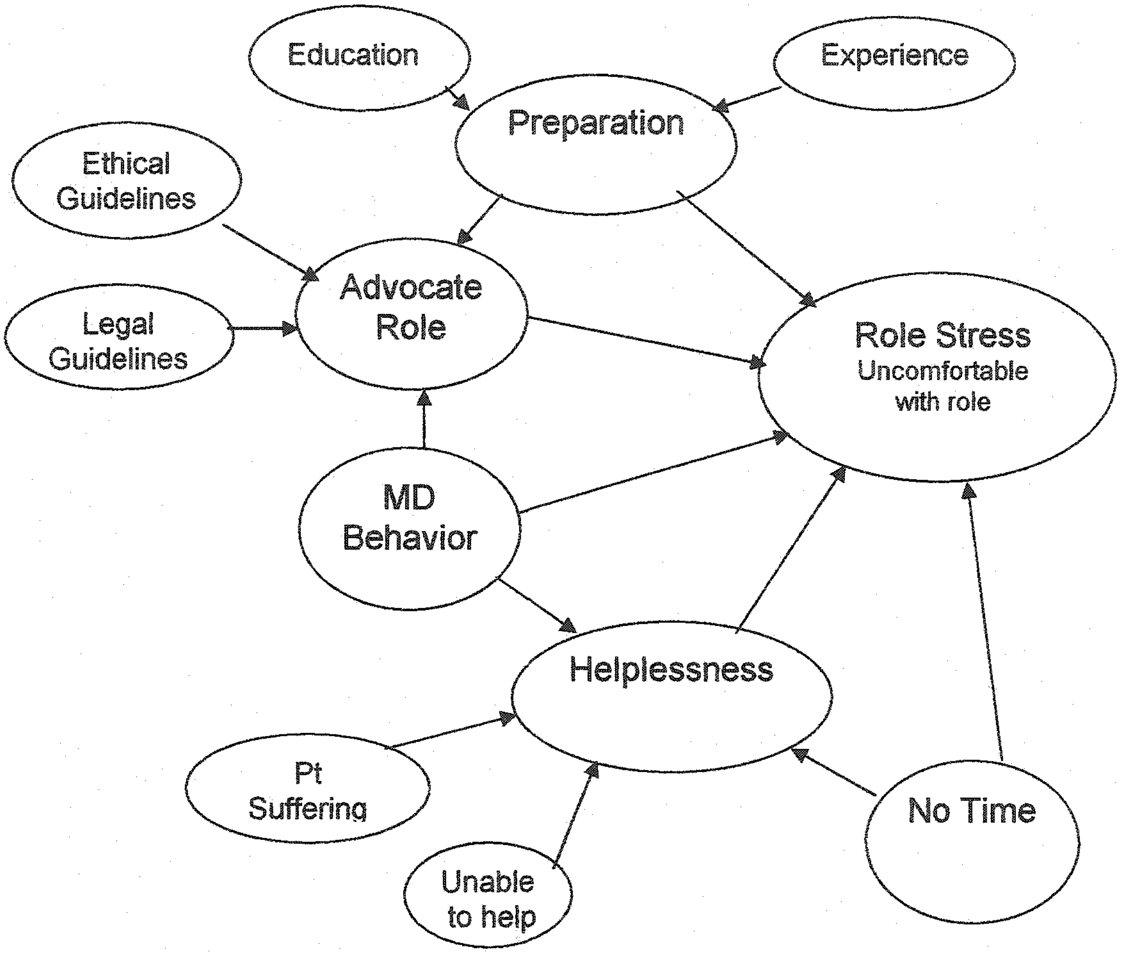

Figure 1. Conceptual model of the five themes identified from interviews with nurses.

Phase II

The purpose of Phase II was to develop an objective, written instrument from themes identified in Phase I and to determine the Content Validity Index (CVI) of proposed instrument items. The five main themes identified in Phase I related to the nurses' attitudes about their role in assisting families with end-of-life decisions. They were: Preparation, related to education and experience; Advocate Role, related to ethical and legal guidelines; MD Behavior; Helplessness, related to patient suffering and being unable to help; and No Time.

Eight to ten instrument items were proposed for each theme. The items were taken from the statements made by the nurses in Phase I. A panel of experts in the field of nurses' roles in end-of-life decision- making was consulted to determine the CVI of the instrument items. The experts were chosen from a literature search of published journal articles in areas related to end-of-life care and the nurses' role. Each expert was contacted by e-mail. The study was described to the expert and assistance was solicited to assist with determining Content Validity.

Each member of the panel of experts was asked to determine if each of the statements measures some aspect of the identified theme. The Content Validity Index Tool is attached as Appendix F. The CVI for each proposed item is reported in Table 2.

Based on the CVI estimated by the expert panel, eleven potential instrument items were excluded because of their low numerical score. The remaining 37 items were randomized. Eleven of the items were reverse scored so that the total score of all items would indicate the nurse's level of comfort with assisting patients and families with end-of-life decision-making. The possible total score for the 37 items is 37 to 148, with a lower score indicating less comfort with assisting patients/families with end-of-life decision-making and a higher score indicating more comfort in that role. The resulting instrument, the Nurses Attitudes Toward Assisting Patients/Families with End-of-Life Decision-making (NATED) is attached (Appendix G).

Table 2

Content Validity Index of proposed instrument items

	Theme				
Item #	Advocate Role	Preparation	Helplessness	No Time	MD Behavior
1	1.0	1.0	1.0	1.0	.71
2	1.0	.86	1.0	1.0	.43
3	1.0	1.0	.86	1.0	1.0
4	.86	.86	1.0	1.0	.57
5	1.0	.86	1.0	1.0	.43
6	1.0	1.0	.43	1.0	.71
7	1.0	1.0	.71	1.0	-.14
8	1.0	.86	.42	1.0	.57
9	1.0	1.0	.57		.86
10	.43	1.0	.57		.57

Phase III

The purpose of Phase III was to assess the validity and reliability of the Nurses' Attitudes Toward End-of-Life Decision-Making instrument. Demographic information was analyzed for trends. Psychometric evaluation of the NATED included: (a) item analysis, (b) principle components analysis (PCA), and (c) internal consistency reliability using Cronbach's alpha.

Demographic information

The convenience sample included 100 medical-surgical nurses working in an acute care setting. Fifty-one percent of the nurses who completed the NATED were educated at the Associate Degree in Nursing (ADN) level, a two-year training program. Nine percent graduated from a Diploma program, a three-year training program. Forty percent were educated at the baccalaureate level with thirty-five earning a Bachelors of Science in Nursing degree and five percent with their Master's of Science in Nursing degree.

Thirty-two percent had been working as nurses for fewer than five years with twenty-five percent working for six to ten years. Twelve percent had worked for 11 to 15 years and eleven percent had worked for 16 to 20 years. Twenty percent of the participants had been nurses for more than 21 years. Participants ranged in age from 21 to 65 with a median age of 41.5 years old. Only eleven percent of the nurses who participated were male.

Item analysis

Participants expressed their attitudes toward the statements on the NATED. The responses were quantified using a four-point Likert-type scale as follows: 1 – Never; 2 – Sometimes, 3 – Usually, or 4 – Always. Possible scores on the items ranged from 1 to 4. Mean scores of the 37 items ranged from 1.98 (item 18 – Work assignments are made based on the patients' acuities) to 3.56 (item 28 – I delegate many of the tasks associated with caring for a dying patient to others so that I can finish my other work. This item was reverse scored with a resulting score of 3.56. Item means and ranges are depicted in Table 3. Total scores ranged from 68 to 129 in a possible range of 37 to 148. Higher scores

Table 3 – Item Means and Ranges

Item	Mean	Range
25	2.85	2
28	3.56	2
30	2.79	2
31	3.26	2
1	2.78	3
2	2.53	3
3	2.90	3
4	2.91	3
5	2.63	3
6	2.00	3
7	2.91	3
8	3.44	3
9	2.84	3
10	2.58	3
11	2.90	3
12	2.68	3
13	3.51	3
14	2.30	3
15	2.92	3
16	2.63	3
17	2.21	3
18	1.98	3
19	3.14	3
20	2.27	3
21	3.03	3
22	2.47	3
23	2.78	3
24	2.47	3
26	2.81	3
27	3.13	3
29	2.97	3
32	2.05	3
33	2.31	3
34	2.72	3
35	3.14	3
36	2.67	3
37	2.70	3

indicate that the nurse experiences more comfort with their role in assisting patients and families with end-of-life decision-making.

The relationships between age, years of nursing experience, and/or level of education and total score on the NATED were explored. No significant correlations were found.

Principal Components Analysis

A principal components factor analysis (PCA) was used to examine the construct validity and factor structure and to assess if the five factors identified in Phase I would be replicated. The 37 items were then subjected to PCA with varimax rotation. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.68, which represents a satisfactory level (Norman & Schriener, 1994).

Application of Kaiser's criterion of using all unrotated factors with Eigenvalues >1.0 resulted in twelve components accounting for 68% of variance. However, the scree plot with graphing of the eigenvalues was more parsimonious, indicating a five-component solution (Cattell, 1967).

Because five factors had emerged from the qualitative data, a second PCA was performed specifying five components. Thirty-one items loaded >.40 on one of the five components. Six items loaded weakly with .33 to .39 values. Factors with loadings less than .40 were excluded (Nunnally, 1978). Two items were eliminated as they did not fit the conceptual model, leaving a modified twenty-nine item instrument which are listed in Table 4.

Table 4. Factor Analysis Table

	Factor Loadings				
Variable	Advocate	Preparation	Helplessness	No Time	MD Behavior
I am able to apply ethical guidelines	.68				
I am comfortable intervening with MDs	.64				
I make suggestions to MDs	.60				
I have had good experiences with MDs	.55				
I initiate planning with patients/families	.52				
I develop strong relationships with patients	.59				
I have support from administration	.50				
MDs know patients wishes	.50				
Written directives reduce stress	.42				
I have opportunities to develop skills		.75			
Staff training helps me		.71			
I can answer questions from patients		.63			
Assignments are made on patient acuity		.55			
Explaining options is a nursing responsibility		.51			
I have autonomy to assist patients/families		.48			
I want to take a more active role		.46			
I feel comfortable assisting patients/families		.45			
I feel unprepared to assist patients/families			.67		
I turn to other nurses to help			.59		
I would rather send a patient to ICU than deal with death			.48		
I feel unprepared to assist patients/families			.48		
My assignments keep me too busy				.74	
I am too busy to assist patients/families				.60	
I am not able to spend adequate time				.53	
I don't spend adequate time with patients and families				.53	
I don't think I spend enough time with patients and families				.49	
Physicians resist writing DNRs until too late					.61
Physicians view DNR orders as "giving up"					.57
I feel caught in the middle between patient's wishes, family demands and MD orders					.57

Table 4 lists the 29 retained items with their respective factor loadings.

The five components accounted for a total of 44.048% of initially extracted common variance. Components 1 through 5 had eigenvalues of 6.87, 3.16, 2.40, 2.07, and 1.80, respectively. Factors 1 through 5 accounted for 18.57%, 8.55%, 6.48%, 5.59%, and 4.86% of the variance, respectively. Variance explained by each factor was calculated using principal component analysis with varimax rotation and Kaiser Normalization. The five identified components were labeled respectively advocate role (9 items), preparation (8 items), helplessness (4 items), time (5 items), and MD behavior (3 items). The investigator concluded that the five PCA-derived components were very similar to the original conceptually-derived NATED subscales.

Internal Consistency Reliability Using Cronbach's Alpha

As a measure of internal consistency, Cronbach's alphas were calculated for each of the derived subscales of the NATED. Acceptable levels of reliability have been defined as follows: Cronbach's alpha coefficients below .50 indicate poor reliability, coefficients from .50 to .75 suggest moderate reliability, and values above .75 indicate good reliability (Portney & Watkins, 1993).

Reliability coefficients for the NATED were .77, .78, .60, .70, and .77 for factors 1 through 5, respectively (Table 5). Internal consistency reliability, using Cronbach's alpha, for the final 29-item instrument was .84.

Table 5 Reliability Coefficients for the NATED

Theme	Reliability Coefficient
Advocate Role	.77
Preparation	.78
Helplessness	.60
No Time	.70
MD Behavior	.77
29-item NATED	.84

Chapter V

Discussion

Research has been conducted with advance practice nurses, oncology nurses and nurses working in intensive care, little research has been done with medical-surgical acute-care nurses regarding their attitudes toward assisting patients and families with end-of-life decision-making. Attitudes are difficult to measure as they are multi-dimensional and complex. The purpose of this study was to develop and evaluate the psychometric properties of the Nurses' Attitudes Toward Assisting Patients and Families with End-of-Life Decision-Making (NATED) instrument. The study was conducted in three phases, and discussion of results for each of the three phases of this study is presented here.

Phase I

The purpose of Phase I was to explore with hospital-based medical-surgical nurses their experiences with patients and families who were involved in end-of-life decision-making using a qualitative approach and individual audio-taped interviews. The sample and the identified common themes are discussed here.

Sample

In Phase I all interviewees were female, none were new graduates, and all were over the age of 47. The group was self-selected as only those nurses who were comfortable talking about death and dying with families volunteered to be interviewed.

Those who are not comfortable talking about these issues were the ones who did not volunteer. It is possible that important information was missed because those nurses who are not comfortable with this subject could not be accrued to the study. Those who did volunteer had had experience working with oncology, intensive care unit, or hospice patients.

More mature nurses are often more ready to take a possibly uncomfortable position between a physician, institutional practices, and family members. These nurses also reported anecdotally that they had personally experienced these types of conversations and decisions with members of their own or their spouse's family. Nurses with less personal or professional experience may have different attitudes and may report different approaches to communication with families and physicians than the volunteers in this study.

Phase I volunteers were from two institutions on the East Coast of South Florida. Results may have been different or additional information may have been obtained if the number of interviewees was larger or if they came from other types of settings, or other geographic areas.

Themes

Eleven themes emerged from the data and were classified in two areas. Six of the themes reported by the nurses were concerns expressed to them by families and patients. In each of these areas the nurses were expected to assist the families with their decision-making. These themes are abandon, denial, ethics, family guilt, family rescinds, and knowledge. Five of the themes were attitudes expressed by the nurses toward their role in this process. These themes are advocate role, preparation, helplessness, no time, and MD behavior. The focus of this study was on nurses' attitudes. The patients' and families' concerns are appropriate areas for future research.

Patients' and Families' Concerns

Patients and families expressed many concerns to the nurses and expected the nurses to explain their options or to intervene with other family members, physicians, or the institution. They were afraid that by agreeing to a DNR order, the patient would be abandoned and not receive adequate care. Many families continue to deny that their family member is as ill as he/she is, even after the nursing staff understands that recovery is slim or impossible. Occasionally, families situations or conflicts just cannot be resolved and one possible arbitrator is an ethics committee. However, the members of an ethics committee are often led by the risk manager of the institution. One must wonder if this does not influence some of their recommendations.

Families who have unresolved conflicts or a history of discord may find that these emotions and feelings are heightened when in a situation of crisis and decision-making. Such families are often unable to resolve past problems and work through feelings to make clear decisions in the best interest of the patient. This family guilt over past occurrences can color their ability to make decisions in the present. There are also times when families feel that the patient has made a wrong decision and when the patient is unable to speak or make decisions, the family rescinds the patient's wishes, sometimes even when the wishes are written and witnessed. This rescission is against ethical and legal guidelines, but it was reported by each of the six interviewees.

Perhaps the most common concerns that patients and families express are related to lack of knowledge about their ability to make decisions, to accept or refuse treatments, what their options are, and the consequences of the options. Not all people are aware that they can place their wishes in writing, that they are entitled to full information concerning their health care and that they are entitled to opinions other than that of their primary physician. Although the Patient Self-Determination Act has placed the responsibility for such education on health care institutions, patients and families are too stressed and nurses are too busy to provide full information and answers at the time of an inpatient admission of a person in a health crisis.

Nurses' Attitudes

Five themes were identified as relating to nurses' attitudes toward assisting patients and families with end-of-life decision-making – advocate role, preparation, helplessness, no time, and MD behavior. These themes were identified by all of the interviewees and they spoke adamantly about their feelings in these areas.

Nurses felt strongly that they have a responsibility to act as advocates for the patients who cannot speak for themselves. The nurses often expressed that the acute care system can be cruel and some patients are victimized by futile treatments and technology. They most often stated that the treatments should be geared more toward the quality of life that the patients would resume, and not whether the tumor could be removed or the heart restarted. The interviewees stated that it is the nurse's responsibility to know the wishes of the patient and to stand up to all that would go against those wishes whether that is the family, the physician, or the institution. The strength and the absolute conviction of these nurses about patient advocacy were obvious. Perhaps younger or less strong nurses would not feel so confident or would be more overwhelmed by the numerous tasks of an acute care nurse.

Two of the interviewed nurses felt that their nursing education had prepared them to act in the best interests of their patients and had educated them as to appropriate legal and ethical guidelines of end-of-life decision-making. The other interviewees felt that they had developed the appropriate skills through life and work experiences. Each of the participants had worked through some of these decisions personally and all had worked with numerous patients and families. They also expressed some comfort in collaborating with physicians and with institutional administration. These life skills were augmented by their understanding of ethical and legal guidelines and their expectations for estimating patients' quality of life.

There are times, however, when the nurses expressed helplessness with being unable to intervene or advocate for a patient. They stated that at times they felt they are prolonging the suffering of the patient if they assist with or carry out orders or policies that they are helpless to change or refuse. They expressed that stopping futile treatments or discontinuing some technologies allows a natural death to occur. The patients can be kept comfortable, pain free, clean and dry and in the company of their family. Some patients and families choose to go home with hospice and spend their last days with family members and not in an institution, surrounded by strangers, hooked up to machinery.

A common theme expressed by the nurses was that their time with each patient is limited by the sheer amount of work that there is to do in an acute care setting. Numbers of patients per nurse can vary, but most acute care nurses reported caring for six to ten patients per shift and reported that they had little time to spend with each terminal patient and their very emotionally needy families.

A commonly stated concern of the nurses was the behavior of physicians. The nurses felt that physicians do not like to give up on a patient and continue to fight a disease process when the patient has become just a battlefield with little or no chance for recovering an acceptable quality of life. They stated that physicians tend to promote their own values and do not listen to what the patient is asking or wishing. Physicians sometimes ignore or override patient's wishes, but more often just do not ask what the patient wants at end of life. There are other times when the physician responds to the family's wishes and not the patient's because the family is more vocal and will live longer.

Phase II

The purpose of Phase II was to develop an objective, written multiple-choice instrument to measure nurses' attitudes toward their role in assisting patients and families with end-of-life decision-making. Content validity of the Nurses' Attitudes Toward End-of-Life Decision-Making (NATED) was estimated by a panel of seven expert consultants.

Potential consultants were chosen based on their published research. The published research varied in the areas of end-of-life care, the nurses' role in end-of-life decision-making, advance directives, ethics in practice at patients' end of life, and nurses' perceptions of and preparation for caring for patients at end of life. The members of the panel indicated yes, no, or uncertainty about each of the proposed instrument items and how they relate to the five identified themes. Items that were scored less than .70 were rejected. In each case, the experts gave a rationale for rejecting the item. Rejected items and rationales are shown in Table 6.

Table 6 Rejected instrument item and expert's rationale

Rejected instrument item	Expert's comment(s)
Theme: Preparation	
I am aware of the ANA ethical guidelines on end-of-life care.	Does not measure attitude
I am aware of federal and state guidelines and regulations concerning end-of-life decisions.	Does not measure attitude
I know where patients can get information about advance directives.	Does not measure attitude
Theme: Advocate Role	
Patients/families question me when they do not understand the physician's explanations, prognoses or treatments.	Does not measure attitude Not under nurse's control Relates to family behavior
Theme: MD Behavior	
Physicians ask nurses for input into end-of-life decision-making.	Does not measure attitude Unclear statement
A competent patient cannot refuse life-sustaining therapies that his/her physician orders.	Does not measure attitude Some or all MDs? Ambiguously worded
I believe that many patient's deaths are prolonged unnecessarily.	Does not include MD Not related to MD
Theme: Helplessness	
Families are adequately involved in the patient's end-of-life decisions.	Not related to helplessness Related to family, not nurse
Families are often ill-prepared for end of life, typically bringing to the situation their own family dynamics and conflicts.	Not related to helplessness Related to family, not nurse
Patients/families do not want to talk about end-of-life decisions.	Not related to helplessness
When a patient is near death, they should be taken out of ICU, put in a private room, and kept comfortable.	Not related to helplessness

As a result of rejecting proposed instrument items and refining the tool, a more clearly focused instrument emerged. In addition, many useful comments, words of encouragement, and advice on this research were offered. A panel of medical-surgical nurses may have weighted the proposed instrument items differently. Such a panel of nurses actively working in an acute care setting may have a different perspective because their experiences are personal and experiential, not hypothetical.

Phase III

The purpose of Phase III was to assess the validity and reliability of the revised Nurses' Attitudes Toward End-of-Life Decision-Making. The sample size for Phase III was somewhat small, composed of a convenience sample of 100 acute care medical-surgical nurses.

Demographic Information

Over 300 nurses were contacted in staff meetings at three hospitals over four months. One hundred of these nurses agreed to and completed the NATED instrument. Many nurses refused to fill out the questionnaire, citing reasons such as no time, too tired and/or too busy. But, many nurses stated that they did not see the value of research and felt that research studies are a complete waste of everyone's time. This is a nursing attitude that should be further explored. The fact that RNs do not value the role that nursing research plays in nursing education and practice opens up an area for attitude assessment. Perhaps the fact that 60% of the participants were educated at less than a bachelor's degree in nursing may have some impact on their valuing of research. It would be interesting to know the level of education of those who refused to fill out the NATED.

Because only 11% of the participants were male, it would also be interesting to study whether there are differences between groups of equal numbers of male and female nurses. Male nurses make up approximately 6% of the nursing population (*Male Nurse Magazine*, 2004) and it would be interesting to study any differences in their attitudes toward the five themes of advocate role, preparation, helplessness, no time, and MD behavior.

Item Analysis

Several items had low mean scores: Work assignments are made based on the patients' acuities (1.98); Physicians view DNR orders as "giving up" on the patient (2.0); I am offered learning opportunities where I work to develop my skills assisting patients/families with end-of-life decision-making (2.05); I am able to spend adequate time with patients/families to meet their end of life needs (2.21); and I feel that staff training has helped me learn to deal with patients/families and end-of-life decisions (2.27). Low scores indicate a lower level of comfort and a higher feeling of stress for the nurses.

These instrument items correlate well with each other and lead to ways in which institutions can have an influence on nurses' abilities to assist patients and families. Work assignments based on patient acuity would allow nurses the time to spend with patients and families who are more emotionally needy and require information and support. Institutional atmosphere has a great deal to do with physician attitudes. When building interdisciplinary collegiality is a focus of an institution, everyone involved gains and patient care is improved. Nurses also seek educational opportunities from employers, another way institutions could have a positive impact on nurses' feelings of role stress.

Several items had high mean scores. I have a responsibility to explain accepting or rejecting treatment options (3.14); I feel prepared to assist patients/families with end-of-life decisions (3.26); I would rather not send a patient to ICU than deal with death on the floor (3.44); I feel that I have an ethical obligation to relieve the suffering associated with the dying process (3.51); and I do not delegate many of the tasks associated with caring for a dying patient to others so that I can finish my other work (3.56). High scores indicate a higher level of comfort and a lower feeling of stress for the nurses.

These instrument items correlate very well with the interview results from Phase I. Confident, capable, prepared nurses feel strongly positive about their role in assisting patients at end of life. This sense of patient advocacy and responsibility indicates a high level of comfort with their role and an ability to work around everyday stressors.

Principal Components Analysis

Using Principal Components Analysis, all but eight of the proposed instrument items loaded on one of the five themes originally identified in the interviews conducted in Phase I. The advocate role factor (11%) and the preparation factor (10%) accounted for most of the variance in nurses' attitudes. This finding confirms the importance placed on the advocate role and the reported feeling of being prepared by education and experience by the interviewees in Phase I.

The other factors accounted for an additional 22% and were fairly equally weighted with helplessness, no time and MD behavior 8%, 7% and 7% respectively. This suggests that these are significant concerns of medical-surgical nurses working in acute care settings. These areas are opportunities for improvement both in nurses' education and policy revision in institutions. Nurses need to be supported by each other, collegial relationships with physicians, and support of institutional policy and administration.

Internal Consistency Using Cronbach's Alpha

The identified themes of Advocate Role, Preparation, and MD Behavior were estimated to be reliable at the .77, .78, and .77 levels respectively. This indicates that these three themes are important to nurses and may have an impact on how they conduct themselves when assisting patients and families with end-of-life decisions. As nurses are better prepared to assume the role of the patients' advocate and educated about ethical and legal responsibilities, there may develop in each nurse a confidence and an ability to form more congenial relationships with physicians and administration. These more capable and confident nurses would be better able to approach difficult end of life decisions and speak up for those who do not have a voice.

The Helplessness subscale had a somewhat weak reliability coefficient (.60) and should be further explored. Perhaps Helplessness is better identified as Frustration. In either case, nurses who are more educated, confident, and capable (Preparation and Advocate Role) would be able to better manage in difficult situations where they felt helpless or frustrated to assist a patient. These more capable and confident nurses may be able to better interact with physicians and influence some of the discussions that occur (or do not occur) between physicians and patients and families.

With a Cronbach's alpha of .84, the revised 29-item instrument is considered to have good reliability. However, the small sample size affected the external validity of the results and generalization of the results cannot be made to persons working in other institutions or in other geographic areas. Future research should build upon the results of this pilot study to further evaluate the reliability and validity of the NATED. Further research is needed in other settings and geographic areas about the attitudes of nurses when involved in assisting patients and families with end-of-life decision-making.

Conclusions

An instrument such as the NATED, used to measure acute-care nurses' attitudes toward assisting patients and families with end-of-life decision-making, has potential usefulness in educational, practice, and research settings. This study is the first step toward the development of an understanding of the important role that nurses must assume in their practice settings. Future research should combine studies of attitudes with measures of role stress, feelings of burnout, and turnover with employers.

Assessment of nurses' attitudes is most useful when developing educational programs in basic nursing education, continuing education, and in staff development programs. An understanding of how nurses perceive their role and the barriers to attaining desired goals can be used as a framework for educating and bolstering nurses' information, understanding of their ethical obligations, and confidence. Several of the interviewees in Phase I stated that they had not felt prepared for this role by their basic nursing education. Such educational programs must include discussions of the nurses' role and end of life care perhaps through discussion, case studies, and/or role-playing.

The practice setting will benefit by nurses' gaining a greater understanding of their role in end-of-life care. Greater insight into information and ethical obligations will lead to higher levels of confidence, will enable nurses to better assist patients and families, and will lower nurses' feelings of stress and frustration. Based on research into nurses' attitudes and experiences, institutions have an opportunity to develop an environment of congeniality and teamwork. Strong role models, preceptors, and mentors can have a positive impact on nurses' abilities to model their behavior after capable leaders. As the population of aging Americans continues to grow and adjust to chronic illness, they will demand and deserve improved satisfaction with end-of-life care.

Research opportunities abound. It is important to note that attitudes toward end-of-life decision-making are complex constructs that may be inadequately measured with any single instrument. It is evident that continuing work is needed to determine the usefulness, reliability, and validity of this instrument. Studies involving larger groups of nurses in varied practice settings and geographical areas would add to the knowledge base and establish validity and reliability more accurately.

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Appendices

Appendix A: Nurse Participant Interview Schedule

Nurses' Experiences
With Patients/Families and End-of-life Decision-Making

Tell me about a time when you were involved with a patient/family who was/were making end-of-life decisions.

Subquestions:

1. When did you become aware that decisions were being made?
2. Who seemed to be the primary decision-maker?
3. To whom did he/she/they speak to assist in making a decision?
4. What kinds of information did he/she/they already have?
5. What kinds of information did he/she/they seek?
6. Was the patient able to participate in this process? If yes, tell me how he/she contributed.
7. Were you asked to be involved? If yes, by whom and how?
8. How were you able to assist them in the decision-making process?
9. Tell me how you felt about your preparation to assist patients and/or families making end-of-life decisions?
10. How did you feel about being involved with this time in a patient's life?
11. How did you feel about the decision that was made?
12. How did you feel about your part in the decision-making process?

Appendix B: Demographic Information

Nurses' Experiences with Families and End-of-Life Decision-making

Please answer the following questions. If appropriate, you may circle more than one time in each category and/or you may write in comments.

1) Employment status
    - a) Full-time RN
    - b) Part-time RN
    - c) Traveling/agency RN
    - d) Other ____________________________
2) Education level
    - a) ADN
    - b) Diploma program
    - c) BSN
    - d) MSN
    - e) Other ____________________________
3) Number of years as a nurse
    - a) 0 - 5
    - b) 6 – 10
    - c) 11 – 15
    - d) 16 – 20
    - e) 21 – 30
    - f) Other ____________________________
4) Number of years working at current institution
    - a) 0 - 5
    - b) 6 – 10
    - c) 11 – 15
    - d) 16 – 20
    - e) 21 – 30
    - f) Other ____________________________
5) Gender
    - a) female
    - b) male
6) Age _______ years

Comments____
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Raulerson Hospital
1796 Highway 441 North
P. O. Box 1307
Okeechobee, Florida 34973-1307
Phone (863) 763-2151
www.raulersonhospital.com

August 12, 2002

Susan Wise
[redacted]

Dear Ms. Wise,

I am the recorder and leader of the Bioethics/Institutional Review Board of Raulerson Hospital. I have reviewed your letter and proposal for a qualitative, exploratory study using nurse volunteers from our facility with Lorene Perona, our Ethics and Compliance Officer. Finding no objection to your proposal, we grant permission for your study.

As your study progresses, we will need to review your consent forms, data collection plan, tools used for your research, and the data.

Please feel free to contact me at [redacted] extension [redacted], for any further questions.

Sincerely,

[redacted]

Clarissa Hall, RN, BSN, LHRM
Director of Administrative Services

Customers
Employees
Quality
SLMC
St. Lucie Medical Center

January 14, 2003

To Whom It May Concern:

I, Nancy Hilton, Chief Nursing Officer – St. Lucie Medical Center grant permission for Susan Wise, R.N.C., B.S.N., to conduct her study of experiences hospital nurses have with patients and families during end of life decision making. I understand that Ms. Wise's study is a three-part project that will take place over the next two (2) years.

Should you have any questions, please feel free to contact me at [redacted].

Sincerely,

[redacted]
Chief Nursing Officer

c: P. Gonzalez, ECO
M. Sanker, QM Coordinator

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IRMH Indian River Memorial Hospital
We're Here for Life

Lee M. Klinetobe
Chairman, Board of Directors

Jeffrey L. Susi
President, Chief Executive Officer

January 22, 2003

University of South Florida

To Whom It May Concern:

Susan Wise has submitted her research proposal "Nurses' experiences with families who are involved in end-of-life decision-making". She has received approval to interview our nurses in accordance with her proposal.

Please give me a call [redacted], should you have any questions.

Sincerely,

[redacted]

Karen Marple, RN
Director Patient Care Services

1000 36th Street • Vero Beach, Florida 32960 • 772.567.4311 • Fax 772.562.5628 • www.irmh.com
Vision: *Indian River Memorial Hospital strives to be the finest community-based health care organization anywhere.*

Appendix D - USF IRB Approval Letter – Phase I

**University of
South Florida**
USF

March 14, 2003

Susan M. Wise, RNC, BSN, MSM-MBA
[redacted]

Dear Ms. Wise:

Your new protocol (**IRB #101229**) entitled, **"Nurses' Experiences with Families and End-of-Life Decision-Making"** including your Adult Informed Consent Form has been reviewed under Expedited review categories numbers six and seven (6,7). Having made any required revisions, the approval period for your protocol and the Adult Informed Consent Form is from 03/06/03 through the date stamped below. This information shall be presented to the Institutional Review Board-02 at its next convened meeting on April 18, 2003. You should take special note of the following:

- Approval is for up to a twelve-month period, after date of initial review. A Research Progress Report to request renewed approval must be submitted to this office ***by the submission deadline in the eleventh month of this approval period.*** A final report must be submitted if the study was never initiated, or you or the sponsor closed the study.
- Any changes in the above referenced study may not be initiated without IRB approval except in the event of a life-threatening situation where there has not been sufficient time to obtain IRB approval.
- All changes in the protocol must be reported to the IRB.
- If there are any adverse events, the Chairperson of the IRB must be notified immediately in writing.

If you have any questions regarding this matter please do not hesitate to call me [redacted]

Sincerely,

[redacted]

Louis A. Penner, Ph.D.
Chairperson, IRB-02

LP: amr

cc: Mary Lou VanCott, RN, PhD
Tricia Holtje

APPROVED THRU

MAR 0 4 2004

USF-02 INSTITUTIONAL
REVIEW BOARD FWA00001669

Submit your Research Progress Report by the submission deadline ***one month prior to the above date.*** Failure to meet this deadline will result in closure of this study.

Office of Research, Division of Research Compliance
Institutional Review Boards, FWA No. 00001669
University of South Florida • 12901 Bruce B. Downs Blvd., MDC035 • Tampa, Florida 33612-4799
(813) 974-5638 • FAX (813) 974-5618

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Appendix E – Informed Consent Form – Phase I

Social Sciences/Behavioral
Adult Informed Consent

University of South Florida

Information for People Who Take Part in Research Studies

The following information is being presented to help you decide whether or not you want to be a part of a minimal risk research study. Please read carefully. If you do not understand anything, ask the Person in Charge of the Study.

Title of Study: Nurses experiences with families and end-of-life decision-making
Principal Investigator: Susan Wise, RNC, BSN, MSN-MBA
Study Location(s): Raulerson Hospital, Okeechobee, FL; Lawnwood Regional Medical Center, Ft. Pierce, FL

You are being asked to participate because as a nurse in an acute care institution, you have had experiences with families who were involved in end-of-life decision-making.

General Information about the Research Study

The purpose of this research study is to explore and describe nurses' experiences with families who are involved in end-of-life decision-making.

Plan of Study

- The Principal Investigator, Susan Wise, will meet with you at your convenience and interview you for approximately 45 minutes. The interview will be audiotape recorded. During this interview you will be asked questions regarding your experiences with families involved in end-of-life decision-making.
- **Payment for Participation**
  You will not be paid for your participation in this study.

Benefits of Being a Part of this Research Study

- You will not directly benefit from participating in this study. However, by taking part in this research study, you may provide valuable information to increase our overall knowledge of factors regarding the nurses' role in end-of-life decision-making.

Risks of Being a Part of this Research Study

- There are no known risks to you if you participate in this research study. However, discussing end-of-life decision-making may be upsetting to you. If this is true, you may stop the interview at any time.

Confidentiality of Your Records

- Your privacy and research records will be kept confidential to the extent of the law. Records and data pertaining to you will be assigned a code number for identification purposes. Only the researcher will have access to the file. The data will be kept in the researcher's office in a secured file. Authorized research personnel, employees of the Department of Health and Human Services and the USF Institutional Review Board may inspect the records from this research project.

  The results of this study may be published. However, the data obtained from you will be combined with data from other people in the publication. The published results will not include your name or any other information that would in any way personally identify you.

IRB# 101229

APPROVED THRU
MAR 0 4 2004
USF-02 INSTITUTIONAL
REVIEW BOARD FWA00001669

Volunteering to Be Part of this Research Study

- Your decision to participate in this research study is completely voluntary. You are free to participate in this research study or to withdraw at any time. If you choose not to participate, or if you withdraw, there will be no penalty or loss of benefits that you are entitled to receive. Your decision about participation will in no way affect your job status.

Questions and Contacts

- If you have any questions about this research study, contact Susan Wise at [redacted].

- If you have questions about your rights as a person who is taking part in a research study, you may contact a member of the Division of Research Compliance of the University of South Florida at [redacted]

Your Consent—By signing this form I agree that:

- I have fully read or have had read and explained to me this informed consent form describing a research project. I have had the opportunity to question one of the persons in charge of this research and have received satisfactory answers.
- I understand that I am being asked to participate in research. I understand the risks and benefits, and I freely give my consent to participate in the research project outlined in this form, under the conditions indicated in it.
- I understand that I will keep confidential the names and protect the identities of the patients/families referred to in this research.
- I have been given a signed copy of this informed consent form, which is mine to keep.

Signature of Participant	Printed Name of Participant	Date

Investigator Statement

I have carefully explained to the subject the nature of the above protocol. I hereby certify that to the best of my knowledge the subject signing this consent form understands the nature, demands, risks and benefits involved in participating in this study.

	Susan M. Wise, RNC	
Signature of Investigator Or Authorized research investigators designated by the Principal Investigator	Printed Name of Investigator	Date

Institutional Approval of Study and Informed Consent

This research project/study and informed consent form were reviewed and approved by the University of South Florida Institutional Review Board for the protection of human subjects. This approval is valid until the date provided below. The board may be contacted at [redacted]

Approval Consent Form Expiration Date:

Revision Date:________________

APPROVED THRU
MAR 0 4 2004
USF-02 INSTITUTIONAL
REVIEW BOARD FWA00001669

IRB# 101229

Appendix F – Content Validity Index Tool

Susan Wise, RNC, BSN, MSN-MBA, PhD Candidate
[redacted]

Dear Dr. __________ :

Thank you for agreeing to participate on my panel of expert consultants to determine the Content Validity Index of instrument items.

The following five concepts emerged from the content analysis done on the transcribed interviews with nurses working in an medical-surgical setting. If you wish to return this by e-mail, please delete the answers (yes, no, uncertain) you do not choose, leaving only one response for each item, and e-mail it back to [redacted] If you wish to print and mail it back, send to Susan Wise, [redacted]

Concept 1: Preparation – How the nurse learns to assist patients/families with end-of-life decision-making. This concept included the themes of education and experience.

Question: Does each item measure some aspect of the nurses' attitudes toward their preparation for dealing with patients/families making end-of-life decisions?

1. I feel unprepared to assist patients/families with end-of-life decisions.	yes no uncertain
2. My nursing education prepared me for assisting patients/families with end-of-life decision-making.	yes no uncertain
3. The longer I am a nurse the more comfortable I am talking with patients/families about end-of-life decision-making.	yes no uncertain
4. I am aware of the American Nurses Association ethical guidelines on end-of-life care.	yes no uncertain
5. I am aware of federal and state guidelines and regulations concerning end-of-life decisions.	yes no uncertain
6. I understand advance directives and can answer patients/families' questions.	yes no uncertain
7. I know where patients can get information about advance directives.	yes no uncertain
8. Staff training has helped me learn to deal with patients/families and end-of-life decision-making.	yes no uncertain
9. I am offered learning opportunities where I work to develop my skills assisting patients/families with end-of-life decision-making.	yes no uncertain
10. I feel that a mentor would help me learn the role of assisting patients/families with end-of-life decision-making.	yes no uncertain

Comments____

Concept 2: Advocate Role – Nurses see their role as advocates for patients. This concept included the themes of ethical guidelines and legal guidelines.

Question: Does each item measure some aspect of the nurses' attitude toward their role as advocate with patients/families making end-of-life decisions?

1. I want to take a more active role in assisting patients/families with end-of-life decision-making.	yes no uncertain
2. Explaining advance directives is a nursing responsibility.	yes no uncertain
3. Having a written advance directive can reduce stress for families and nurses.	yes no uncertain
4. I have support from nursing administration to deal with patients/families and end-of-life decision-making.	yes no uncertain
5. I have an ethical obligation to relieve the suffering associated with the dying process.	yes no uncertain
6. I have a responsibility to explain advance directives.	yes no uncertain
7. I have a responsibility to explain accepting or rejecting treatment options.	yes no uncertain
8. I initiate advance care planning with my patients rather than wait for them to begin the discussion.	yes no uncertain
9. I intervene with physicians when I feel that patients are experiencing debilitating side effects of futile treatments.	yes no uncertain
10. Patients/families question me when they do not understand the physician's explanations, prognoses or treatments.	yes no uncertain

Comments

Concept 3: MD Behavior – Physicians do not want to give up and continue with medically futile treatments.

Question: Does each item measure some aspect of the nurses' attitudes toward MD behavior?

1. Physicians know the patients/families end-of-life wishes.	yes no uncertain
2. Physicians ask nurses for input into end-of-life decision-making.	yes no uncertain
3. I am able to make suggestions to physicians about a patient's or family's end-of-life wishes.	yes no uncertain

4. I've had good experience with physicians when assisting patients/families with end-of-life decision-making.	yes no uncertain
5. Physicians are willing to discuss end-of-life decision-making with patients/families.	yes no uncertain
6. Continued medical treatment of dying patients can sometimes be worse than a peaceful death.	yes no uncertain
7. A competent patient cannot refuse life-sustaining therapies that his/her physician orders.	yes no uncertain
8. I believe that many patients' deaths are prolonged unnecessarily.	yes no uncertain
9. Physicians view DNR orders as "giving up" on the patient.	yes no uncertain
10. Physicians resist writing DNR orders until very late in the patient's illness.	yes no uncertain

Comments

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Concept 4: Helplessness – Nurses expressed feelings of helplessness in dealing with patients/families making end-of-life decisions. This concept included the themes of patient suffering and feeling unable to assist.

Question: Does each item measure some aspect of the nurses' attitude toward feeling helpless?

1. I feel comfortable when patients/families ask me about end-of-life issues.	yes no uncertain
2. I am able to develop strong relationships with my patients/families.	yes no uncertain
3. I turn to other nurses on the unit who are better able to deal with patient/family end-of-life decision-making.	yes no uncertain
4. Where I work, I have the autonomy I need to assist patients/families with end-of-life decisions.	yes no uncertain
5. Sometimes I feel caught in the middle between the patient's wishes, the family's demands, and the physician's orders.	yes no uncertain
6. Families are adequately involved in the patient's end-of-life decisions.	yes no uncertain
7. I would rather send a patient to ICU than deal with death on the floor.	yes no uncertain
8. When a patient is near death they should be taken out of ICU, put in a private room, and kept comfortable.	yes no uncertain
9. Families often are ill-prepared for end of life, typically bringing to the situation their own family dynamics and conflicts.	yes no uncertain

10. Patients/families do not want to talk about end-of-life decision-making.	yes no uncertain

Comments

Concept 5: No Time – Nurses said that short staffing, patient acuity, and not having enough time to explain and answer questions contributed toward their attitudes in dealing with patients/families making end-of-life decisions.

Question: Does each item measure some aspect of nurses' attitudes toward having limited time?

1. I am able to spend adequate time with patients/families to meet their end-of-life decision-making needs.	yes no uncertain
2. Patients/families need more time that I have to give when making end-of-life decisions.	yes no uncertain
3. I am usually not too busy to assist patients/families with end-of-life decisions.	yes no uncertain
4. Nurse/patient ratios allow me to spend time with patients/families making end-of-life decisions.	yes no uncertain
5. My assignment usually keeps me too busy to sit with patients/families making end-of-life decisions.	yes no uncertain
6. Assignments are made based on the patients' acuity, so I have enough time to spend with those near death.	yes no uncertain
7. I delegate many of the tasks associated with caring for a dying patient to others so that I can finish my other work.	yes no uncertain
8. I think I spend too much time with paperwork and not enough time with patients and families.	yes no uncertain

Comments

Appendix G

Nurses' Attitudes Toward Assisting Patients/Families with End-of-Life Decision-Making

Circle the number that most closely indicates your opinion (or your feelings).

1. I am able to apply the American Nurses Association ethical guidelines and state and federal regulations to end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

2. I feel that my nursing education prepared me for assisting patients/families with end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

3. I have support from nursing administration to deal with patients/families and end-of-life decision-making.

1	2	3	4
Never	Sometimes	Usually	Always

4. I feel comfortable intervening with physicians when I feel that patients are experiencing debilitating side effects of futile treatments.

1	2	3	4
Never	Sometimes	Usually	Always

5. I've had good experience with physicians when assisting patients/families with end-of-life decision-making.

1	2	3	4
Never	Sometimes	Usually	Always

6. Physicians view DNR orders as "giving up" on the patient.

1	2	3	4
Never	Sometimes	Usually	Always

7. I turn to other nurses on the unit who are better able to deal with patient/family end-of-life decision-making.

1	2	3	4
Never	Sometimes	Usually	Always

8. I would rather send a patient to ICU than deal with death on the floor.

1	2	3	4
Never	Sometimes	Usually	Always

9. My assignments keep me too busy to sit with patients/families making end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

10. I think I don't spend enough time with patients/families.

1	2	3	4
Never	Sometimes	Usually	Always

11. I can answer patients/families' questions about advance directives.

1	2	3	4
Never	Sometimes	Usually	Always

12. Explaining advance directives is a nursing responsibility.

1	2	3	4
Never	Sometimes	Usually	Always

13. I feel that I have an ethical obligation to relieve the suffering associated with the dying process.

1	2	3	4
Never	Sometimes	Usually	Always

14. Physicians know the patients/families end-of-life wishes.

1	2	3	4
Never	Sometimes	Usually	Always

15. I feel comfortable when patients/families ask me about end-of-life issues.

1	2	3	4
Never	Sometimes	Usually	Always

16. Where I work, I have autonomy to assist patients/families with end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

17. I am able to spend adequate time with patients/families to meet their end-of-life needs.

1	2	3	4
Never	Sometimes	Usually	Always

18. Work assignments are made based on the patients' acuity.

1	2	3	4
Never	Sometimes	Usually	Always

19. I feel unprepared to assist patients/families with end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

20. I feel that staff training has helped me learn to deal with patients/families and end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

21. Having a written advance directive can reduce stress for families and nurses.

1	2	3	4
Never	Sometimes	Usually	Always

22. I initiate advance care planning with my patients rather than wait for them to begin the discussion.

1	2	3	4
Never	Sometimes	Usually	Always

23. I am able to make suggestions to physicians about a patient's or family's end-of-life wishes.

1	2	3	4
Never	Sometimes	Usually	Always

24. Physicians are willing to discuss end-of-life decision-making with patients/families.

1	2	3	4
Never	Sometimes	Usually	Always

25. I am able to develop strong relationships with my patients/families.

1	2	3	4
Never	Sometimes	Usually	Always

26. I feel caught in the middle between the patient's wishes, the family's demands, and the physician's orders.

1	2	3	4
Never	Sometimes	Usually	Always

27. I am not too busy to assist patients/families with end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

28. I delegate many of the tasks associated with caring for a dying patient to others so that I can finish my other work.

1	2	3	4
Never	Sometimes	Usually	Always

29. I feel that the longer I am a nurse the more comfortable I am talking with patients/families about end-of-life decision-making.

1	2	3	4
Never	Sometimes	Usually	Always

30. Continued medical treatment of dying patients can be worse than a peaceful death.

1	2	3	4
Never	Sometimes	Usually	Always

31. I feel unprepared to assist patients/families with end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

32. I am offered learning opportunities where I work to develop my skills assisting patients/families with end-of-life decision-making.

1	2	3	4
Never	Sometimes	Usually	Always

33. I feel that a mentor would help me learn the role of assisting patients/families with end-of-life decision-making.

1	2	3	4
Never	Sometimes	Usually	Always

34. I want to take a more active role in assisting patients/families with end-of-life decision-making.

1	2	3	4
Never	Sometimes	Usually	Always

35. I have a responsibility to explain accepting or rejecting treatment options.

1	2	3	4
Never	Sometimes	Usually	Always

36. Physicians resist writing DNR orders until very late in the patient's illness.

1	2	3	4
Never	Sometimes	Usually	Always

37. Patients/families need more time than I have to give when making end-of-life decisions.

1	2	3	4
Never	Sometimes	Usually	Always

Comments____

Appendix H – University of South Florida IRB Approval Letter – Phase III

USF
UNIVERSITY OF
SOUTH FLORIDA

February 17, 2004

Susan M. Wise, RNC, BSN, MSN-MBA
[redacted]

Dear Ms. Wise:

Your new protocol **(IRB #102231)** entitled, "Nurses attitudes toward assisting patients/families with end-of-life decision-making / Phase III" including the informed consent form, has been reviewed under expedited review category number seven (7). Having made any required revisions, the approval period for your protocol is shown on the stamp below. This information shall be presented to the Institutional Review Board-02 at its next convened meeting on March 19, 2004.

You should take special note of the following:

- Unless the requirement has been waived by the IRB, documentation of informed consent/assent must be obtained on copies of the attached stamped informed consent/assent document. Please note the form is valid only during the period stamped on the informed consent/assent document.
- Approval is for up to a twelve-month period, after date of initial review. A Research Progress Report to request renewed approval must be submitted to this office ***by the submission deadline in the eleventh month of this approval period.*** A final report must be submitted if the study was never initiated, or you or the sponsor closed the study.
- Any changes in the above referenced study may not be initiated without IRB approval except in the event of a life-threatening situation where there has not been sufficient time to obtain IRB approval.
- All changes in the protocol must be reported to the IRB.
- If there are any adverse events, the Chairperson of the IRB must be notified immediately in writing.

Based on the new HIPAA Privacy Rule, if you are generating, collecting, using, or disclosing private health information about subjects, they cannot be enrolled into your research study without signing an appropriately approved Authorization Form. Please forward a copy of the approved authorization form from the site's privacy officer for the file.

If you have any questions regarding this matter, please do not hesitate to call Christy Stephens at ([redacted] [redacted] or myself at [redacted].

Sincerely,

[redacted]

Paul G. Stiles, J.D., Ph.D.
Chairperson, IRB-02

PGS: cas

pc: Dr. McMillan

IRB Approval
FWA 00001669
IRB Number: 102231
From 2·17·04
Thru 2·15·05

OFFICE OF RESEARCH • DIVISION OF RESEARCH COMPLIANCE
INSTITUTIONAL REVIEW BOARDS, FWA NO. 00001669
University of South Florida • 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-5618

Appendix I – Informed Consent Form – Phase III

IRB Approval
FWA 00001669
IRB Number: 102231
From 2-17-04
Thru 2-15-05

Informed Consent

Social and Behavioral Sciences
University of South Florida

Information for People Who Take Part in Research Studies

The following information is being presented to help you decide whether or not you want to take part in a minimal risk research study. Please read this carefully. If you do not understand anything, ask the person in charge of the study.

Title of Study: Nurses' attitudes toward assisting with patients/families and end-of-life decision-making

Principal Investigator: Susan Wise, RNC, BSN, MSN-MBA

Study Location(s): Raulerson Hospital, Okeechobee, FL; Indian River Memorial Hospital, Vero Beach, FL; and St. Lucie Medical Center, Port St. Lucie, FL

You are being asked to participate because you are a medical-surgical nurse who works with patients/families who are involved in end-of-life decision-making.

General Information about the Research Study

The purpose of this research study is to determine the validity and reliability of a newly designed instrument to assess medical-surgical nurses' attitudes toward assisting patients and families with end-of-life decision-making.

Plan of Study

You will be asked to spend one session lasting about 15 minutes filling out a 37-item instrument and a short demographic information sheet asking simple information such as how long you have been a nurse, what kind of education you experienced, your gender and age. You and the researcher will meet at a mutually agreed upon time at a mutually agreed upon place. A quiet place will be chosen where you will be able to fill out the instrument. You will be asked to strongly agree, agree, disagree, or strongly disagree with statements about your experiences with patients and families who were involved in end-of-life decision-making. We ask that you not mention any names of any patients or families.

Payment for Participation

We will not pay you for the time you volunteer in this study.

Benefits of Being a Part of this Research Study

You will not directly benefit from participating in this study. However, by taking part in this study, we may gain a better understanding of the nurse's role in assisting patients and families with end-of-life decision-making.

Risks of Being a Part of this Research Study

There are no known risks to those who take part in this study.

Confidentiality of Your Records

Your privacy and research records will be kept confidential to the extent of the law. Authorized research personnel, employees of the Department of Health and Human Services, and the USF Institutional Review Board and its staff, and other individuals acting on behalf of USF may inspect the records from this research project.

IRB #: 102231
Approved From 2·17·04
Approved Thru 2·15·05

The results of this study may be published. However, the data obtained from you will be combined with data from others in the publication. The published results will not include your name or any other information that would personally identify you in any way.

All instruments, records and data pertaining to you will be assigned a code number for identification purposes. The documentation will be kept locked in the researchers' office.

Volunteering to Be Part of this Research Study

Your decision to participate in this research study is completely voluntary. You are free to participate in this research study or to withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive, if you stop taking part in the study. Your participation or lack of participation in no way affects your job status.

Questions and Contacts

- If you have any questions about this research study, contact Susan Wise at [redacted]
- If you have questions about your rights as a person who is taking part in a research study, you may contact the Division of Research Compliance of the University of South Florida at [redacted]

Consent to Take Part in This Research Study

By signing this form I agree that:

- I have fully read or have had read and explained to me this informed consent form describing this research project.
- I have had the opportunity to question one of the persons in charge of this research and have received satisfactory answers.
- I understand that I am being asked to participate in research. I understand the risks and benefits, and I freely give my consent to participate in the research project outlined in this form, under the conditions indicated in it.
- I have been given a signed copy of this informed consent form, which is mine to keep.

Signature of Participant	Printed Name of Participant	Date

Investigator Statement

I have carefully explained to the subject the nature of the above research study. I hereby certify that to the best of my knowledge the subject signing this consent form understands the nature, demands, risks, and benefits involved in participating in this study.

[redacted]	[redacted]	
Signature of Person Obtaining Informed Consent	Printed Name of Person Obtaining Informed Consent	Date

About the Author

Susan Wise received an Associate Degree in Nursing from Indian River Community College in Ft. Pierce, Florida in 1982. She has worked as a medical-surgical nurse in acute care settings and home health since that time. She completed her Bachelor's of Science in Nursing and a dual Master's of Science of Nursing - Master's of Business Administration at Barry University in 1992, 1994, and 1996 respectively. She entered the Nursing PhD program at the University of South Florida in 2000.

She started teaching in the Associate Degree in Nursing program at Indian River Community College in 1998 and continues both teaching and acute care nursing.