

Predictors of NICU Nurse Activism: Response to Ethical Dilemmas

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Running head: PREDICTORS OF NICU RN ACTIVISM TO ETHICAL DILEMMAS

Boston College
William F. Connell School of Nursing

PREDICTORS OF NICU NURSE ACTIVISM: RESPONSE TO ETHICAL DILEMMAS

a dissertation

by

Margaret Doyle Settle

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Predictors of NICU Nurse Activism: Response to Ethical Dilemma

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Abstract

Nurses working in newborn intensive care units (NICU) report experiencing ethical dilemmas related to treatment decisions for infants in their care. The opportunity for nurses to contribute to the formulation of treatment plans for these infants is increasing, but often nurses are required to implement treatment plans with which they may not agree. This causes conflict for the nurse and has been shown to have implications for the nurse and, ultimately, nursing and healthcare practice. Not taking action to resolve the perceived dilemma is especially problematic on several counts (Raines, 1996). Nurse Activism, the outcome variable, is defined as the range of likely actions nurses may take to resolve ethical dilemmas in practice (Penticuff & Walden, 1987). This cross-sectional study investigated the range of likely actions that nurses would take in response to a hypothetical ethical dilemma. The web-based survey was completed by 224 NICU nurses from seven Massachusetts hospitals. Subjects responded to the Nurses Ethical Involvement Survey (Penticuff & Walden, 1987) and demographic questions. Hierarchical multiple regression analysis found that NICU nurses with greater concern for the ethical aspects of clinical practice ($p = .001$) and an increased perception of their ability to influence ethical decision-making ($p = .018$) were more likely to exhibit nurse activism to resolve an ethical dilemma and these findings explained just 8.5 percent of the variance. Future research is necessary to determine other factors contributing to, and inhibiting the actions of, nurses to resolve ethical dilemmas encountered in the NICU.

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Predictors of NICU Nurse Activism: Response to Ethical Dilemmas

The Context of Nursing Care in the NICU

Chapter 1

This chapter introduces the reader to the problems that NICU nurses encounter in practice when caring for infants with an uncertain prognosis. The societal influences, including the technological advances, health care regulations and family-centered care that contribute to the complexity of care for this vulnerable patient population are explicated. A description of the study along with the definitions, research questions, and hypothesis are provided.

Statement of the Problem

All nurses, regardless of specialty, have a responsibility to be involved in the decisions concerning their patients in order to facilitate good care (American Nurses Association [ANA], 2001). This responsibility is well-supported in the nursing and nursing ethics literature and pertains to nurses working in the newborn intensive care unit (NICU) no less than other areas of practice. NICU nurses function in a unique role within the neonatal health care team. They spend the most time of any team member providing hands on care and observing the infant's response to treatments. This unique perspective enables the NICU nurse to view the infant's pain and suffering in response to his or her condition and necessary treatments, as well as the good and harms the treatments render. Studies reveal that the NICU nurse defines the good and harm a particular treatment renders by taking into account the infant's present and likely future experiences (Penticuff, 1989). If the likely outcome of the infant's overall condition is generally predicted by research to be good, the treatment is viewed as rendering more good than harm even if the particular treatment or course of treatment causes considerable suffering.

Nurses in the NICU, regardless of their level of expertise, have an obligation to act if they

observe treatments that are apparently rendering more harm than good. *Nurse Activism*, defined by Penticuff (1989) as the range of likely actions a NICU nurse would employ to resolve an ethical dilemma, includes voicing concerns to health team members regarding treatments that provide a questionable benefit to an infant in the NICU nurse's care. The nurse must voice his or her concerns because doing so may elicit explanations and rationales that permit better nursing judgments and allow nurses the opportunity to explore more fully the reasons for their discomfort. Additionally, research reveals that when nurses do not voice their concerns there can be negative consequences both for patients and nurses (Moro, Kavanaugh, Okuno-Jones, & Vankleff, 2006). A nurse's tendency to remain silent in situations perceived to be problematic can lead to sub-optimal patient care, cause distress for the nurse, and may result in the nurse leaving the profession (Moro et al., 2006). This obligation to try to make an impact exists, even if in their past experiences the nurse's voiced concerns did not alter the treatment plan (ANA, 2001).

Nurses in the NICU report experiencing ethical discomfort, which has been termed moral distress by Jameton (1984), when they are required to continue a treatment despite the belief that the pain and suffering it is causing an infant is greater than the probable benefits (Hefferman & Heilig, 1999). The experience of moral distress in nursing is characterized by the nurses knowledge of the morally right course of action, however, the nurse is constrained to act due to obstacles related to conflicts with co-workers and/or institutional structures (Jameton, 1984). Since all NICU care is ethical in nature and intended to provide a good to the infant, any obstacle to good care is an ethical issue for the nurse (Grace, 2009). Ethical issues develop from competing priorities regarding the infant's plan of care and are resolved through discussions by re-establishing priorities that enable the delivery of good care to the infant. Alternatively, ethical

dilemmas evolve from complex situations in which the choices leading to good care are unclear. The type, number, and complexity of situations that can obstruct good care are increasing due to advances in technology, pharmacology, health care regulations and family-centered decision-making (Spence, 1998). Moreover, treatment decisions in the NICU for infants with uncertain prognoses are variable from unit to unit as well as from physician to physician within the same unit (Vohr et al., 2004). This results in situations of uncertainty in which nurses provide different care to infants with the same diagnosis without a clear rationale for the difference. All of these factors add a level of ambiguity to the nurse's clinical decisions.

Nurses report that their participation in case discussions, and ability to influence clinically complex treatment decisions, is variable depending on institutional context (Monterosso et al., 2005; Raines, 1993; Roysden, 2007). Factors influencing nurses' ability to voice concerns are linked to their role in the institution, the hierarchical structure of the unit, and receptiveness of the physicians (Monterosso et al., 2005; Penticuff, 1989; Penticuff & Walden, 2000; Raines, 1993; Roysden, 2007; Spence, 1998). Specific conditions that generate concern for NICU nurses are those involving infants with uncertain prognoses including very premature infants, infants with genetically linked syndromes, and acutely ill/unstable infants (Monterosso et al., 2005; Raines, 1993; Spence, 1998). In addition to problems related to prognostic uncertainty, there are situations when NICU nurses are required to provide care to infants and families who have religious, cultural and moral values different from their own (Redman & Fry, 2000). Moreover, the values and beliefs of other members of the health care team may also differ from the nurse's and influence treatment decisions (Clarke, 2000; Peerzada, Richardson & Burns, 2004). Parents and/or other members of the health care team may consider the infant's pain and suffering to be more acceptable than death. These situations can lead to

ethical dilemmas for NICU nurses who are asked to implement a treatment plan they may not agree with because they perceive it causing unwarranted suffering for the infant in their care.

Previous research about ethical issues experienced or encountered by NICU nurses has focused on understanding the nurses' ability to identify ethical aspects of practice (Chally, 1992; Janvier, Nadeau, Deschênes, Couture, & Barrington, 2007; Miya Boardman, Harr, & Keene, 1991; Raines, 1996; Wilkinson, 1988) and participation in ethical decision-making (Davis, 1981; Elizondo, 1991; Martin, 1989; Monterosso et al., 2005; Roysden, 2007; Spence, 1998). Results from these studies indicate that nurses are able to identify ethical aspects of practice; however, the NICU nurses' participation in ethical decision-making is variable. The variability of NICU nurse participation in deliberations related to the ethical aspects of the treatment plan has been associated with elements of the practice environment (Elizondo, 1991; Martin, 1989; Monterosso et al., 2005; Roysden, 2007).

Situations that cause nurses to experience moral distress due to unresolved ethical issues while delivering care they do not agree with have also been associated with the practice environment (Dodd, Jansson, Brown-Saltzman, Shirk, & Wunch, 2004; Martin, 1989; Penticuff & Walden, 2000). Nurses report a lack of involvement in discussions related to the ethical aspects of the treatment plan. Over time, the nurses' lack of involvement in ethical discussions leads to moral distress (Corley, Minick, Elswick, & Jacobs, 2005) and a sense that the nurse has failed his or her patient (Ferrell, 2006). Alternatively, some nurses report that they are involved in ethical discussions that take place on their units and this can result in effective actions that permit resolution of an ethical dilemma. The nurses' involvement is strongly influenced by the nurses' perceptions of the receptivity of the hospital to their inclusion in ethics deliberations (Dodd, Jansson, Brown-Saltzman, Shirk, & Wunch, 2004).

Penticuff and Walden (2000) used a hypothetical case study to explore the contributions of the practice environment and nurses' personal and professional characteristics to the NICU nurses' willingness to be involved in resolving an ethical dilemma. The hypothetical case, which is utilized in this current study, involved an extremely premature infant with multiple chronic conditions that evolved from a complicated NICU course. The infant is seven months old and in critical condition and his or her parents are requesting that treatment be discontinued. Nurses were asked to select the actions they would likely employ if they disagreed with the treatment decision for this infant. The findings suggest that some NICU nurses are more likely to be involved in resolving the ethical dilemma when they perceive themselves to have higher levels of influence in their practice environment and higher levels of concern about the ethical aspects of clinical situations. Conversely, many other NICU nurses report taking no action when experiencing an ethical issue in practice. Thus, although there is some information regarding NICU nurses' experience of ethical dilemmas encountered in practice, further research is necessary to identify factors that support ethical action.

Significance

The National Association of Neonatal Nurses (NANN) (2006) and the American Academy of Pediatrics (AAP) (2007) policy and position statements acknowledge that the incidence of ethical dilemmas related to the initiation and /or withdrawal of intensive care for infants with poor prognoses is increasing. Moreover, ethical dilemmas that are not attended to in the clinical setting may lead to ambiguous emotions of "uncertainty, tension and frustration" (Cohen & Erickson, 2006, p.780) and may affect the quality of nursing care delivered (Gutierrez, 2005; Meltzer & Huckabay, 2004). The NICU nurse's ability to resolve ethical dilemmas encountered in practice influences the care delivered to the infant and family. Therefore,

improved patient care in the NICU requires an in-depth understanding of the factors that impact the NICU nurse's ability to detect and attend to ethical dilemmas encountered when caring for patients. The context of NICU care is influenced by advancing technology, individual interpretation of health care regulations, and increasing family participation in decision-making. Contemporary influences on the NICU context of care are described below.

Technological Advances. Improvements in technology and pharmacology over the past five decades enable health care providers to care for infants with previously untreatable conditions related to preterm birth. The major improvements, in the treatment of respiratory issues that are associated with preterm birth since the 1980's, include surfactant therapy, high frequency ventilation, and corticosteroid treatment of lung injury. Other improvements include such interventions as parental nutritional support, appropriately sized vascular catheters, premature infant formulas, and nutrition supplements (Pinch, 2002).

An outcome related to technological advancements includes decreased mortality rates. Many centers nationally (Lorenz, 2003; Richardson, Gray, Gortmaker, Goldman, Pursley, & McCormick, 1998) and internationally (Hosono, Shimizu, & Harada 2006; Walther, 2005) report that during the 1990s infant survival rates improved by 25 to 50 percent for infants born less than 25 weeks gestation. They attribute the declining mortality rate to aggressive application of newly developed neonatal technologies as well as improvements in obstetrical care.

Technologies have improved the likelihood of neonatal survival, but reports of decreased long-term neurologic handicaps are variable (Wilson-Costello et al., 2005; Vohr et al., 2004). Survival rates with and without neurodevelopmental impairment are increasing. However, there are few prognostic indicators to predict mild to moderate sequelae for the infant survivors with handicaps. The lack of prognostic indicators contributes to the ethical dilemmas encountered by

NICU nurses and other health team members around decision-making. It is extremely difficult to decide the most appropriate interventions for infants whose prognosis cannot be reliably predicted based on the current knowledge of treatment outcomes.

In summary, technology enables health care providers to resuscitate and treat infants with uncertain prognoses and as a result, survival rates have increased in some centers by as much as 50 percent. However, mild to profound long term neurodevelopmental morbidity rates remain unchanged and persist beyond childhood (Hack et al., 2002). For some infants, the treatment may be burdensome with no hope of recovery (Caitlin, 2008). In addition to this problem of persistent uncertainty, several politically-motivated legislative changes add to the complexity of NICU decision-making for nurses and others.

Health Care Regulations Influencing Practice. Three laws influence treatment decisions by physicians in the United States. Although the law generally recognizes the parents' right to make medical decisions for their infants by requiring health care providers to obtain consent for invasive or complex procedures, there are two exceptions. Emergency situations are one exception. When a life-saving treatment is needed but the parent(s) cannot be located or contacted for consent, providers may proceed without it. The other exception occurs when parents refuse medical treatments that are viewed by the court to be in the infant's best interests. This exception allows the court to supersede the parent's medical decision-making in order to protect the child (Hurst, 2005). Changes in health care regulations for the treatment of handicapped or ill newborns spanned two decades. These changes were adopted due to the increased reporting of end-of-life decision-making practices by physicians and parents (Anspach, 1993; Duff & Campell, 1973) regarding sick or handicapped newborns that the public found disconcerting. The legislative intent was to direct newborn and pediatric provider's decision-

making in emergency situations and with end-of-life care (Sayeed, 2005, 2006). Amendments to the Rehabilitation Act in 1984 and the Child Abuse and Protection Treatment Act in 1986, known as the 'Baby Doe' laws, forbade the withholding of fluids and medical treatment from disabled infants (Hurst, 2005).

More recently in 1997, the Emergency Medical Treatment and Labor Act (EMTLA) requires emergency services to be provided to all persons, including neonates, when the outcome is uncertain. This legislation enables parents to request that health care teams provide medical treatment even if the providers are reasonably certain that the treatment is incompatible with life (Romesberg, 2003). Although the intent of this legislation was to ensure appropriate emergency treatment for individuals regardless of their ability to pay for services, many physicians and health care providers interpreted this as a directive to institute care to ill or handicapped infants regardless of the benefits or futility of treatment.

The Born Alive Infant Protection Act (BIPA) of 2001 is the most current legislation affecting the care of neonates in the United States. This act defines certain specific signs to be considered indicative that life-preserving interventions must be initiated. Health care providers report that the threat of federal investigations compelled them to alter their treatment decisions for ill and handicapped infants (Sayeed, 2005, 2006). Moreover, there is increased concern regarding the potential inappropriate over-treatment of infants born at lower and lower gestational ages.

In summary, reports of delivery room treatment decisions, for infants with uncertain prognosis and end-of-life decision-making in the NICU, are inconsistent with the federal legislative agenda previously described (Peerzada, Richardson & Burns, 2004; Singh, Lantos, & Meadow, 2004). The federal government has left each state to interpret the application of the

laws. This creates varied treatments across state lines and within the same state for very early born infants.

Neonatologists from six New England states were surveyed regarding their decision-making for infants with varying gestational ages. The findings indicate that the neonatologists' beliefs of beneficial treatment and attitudes towards parents' requests in the context of uncertainty impacted the manner in which they discussed options with parents (Peerzada, Richardson, & Burns, 2004). In these situations, physicians are seen as impinging on family decision-making, which is increasingly viewed as important in the NICU setting. Ethical concern arises for NICU nurses when families receive limited information regarding treatment choices for their infants.

Family Centered Decision-Making. The principles of family-centered care (FCC) (Harrison, 1993) is a framework that has improved the process by which parents and professionals jointly make the most informed medical decisions for extremely early born infants. This framework evolved as a result of dialogue between parents of premature infants and physicians, with the goal of improving the NICU experience for parents and their infant. The principles undergirding this framework reflect the parent's desire to be fully informed about their infant's clinical course and educated about the required treatments as well as the known and unknown potential outcomes. Moreover, parents indicated they wanted providers to recognize their right to have access to their infant at all times, participate in their infant's care, and include family members they identified as important in the decision-making process. Although implementation of the FCC principles is variable across NICUs and health care providers have diverse experiences integrating the principles in practice, both parents and providers share a common goal: good care of the infant. The goal of the NICU nurse is to facilitate family

participation in decision-making; however, ethical challenges occur when the values and judgments of families conflict with those of the nurse. The nurse's response to the perceived ethical dilemmas that arise may negatively impact his or her relationship with the family and the infant if the nurse is unable to act to process the ethical issue.

The current practice of providing aggressive care to the majority of early born infants is due in part to a lack of good prognostic indicators (Tyson, Parikh, Langer, Green, & Higgins, 2008). Moreover, as previously described, some infants born at very early gestational ages survive without handicap (Vohr et al., 2004). Nurses' participation in discussions related to the appropriateness of care is increasing (Davis, 1981; Elizondo, 1991; Martin, 1989; Monterosso et al., 2005; Roysden, 2007; Spence, 1998). However, for the most part, nurses are still required to provide care to infants and witness their pain and suffering even if they do not agree with the treatment decisions. Catlin (2008) surveyed 422 NICU nurses and physicians regarding the experience of caring for NICU infants with long hospitalizations. The participants reported that extremely long hospital stays were often due to situations in which parents or colleagues insisted on continued treatment in the face of evidence that the interventions would not be effective for the desired outcome.

Nurses working in NICU settings bear witness (Cody, 2001) to the preterm infant's response to treatment and are responsible for educating parents regarding their infant's needs. Because of the nurse's close proximity to the patient, he or she is usually the first provider to suggest that the treatment is not achieving the intended results. The National Association of Neonatal Nurses (NANN) recognizes the NICU nurse as an important contributor to the ethical decision-making process through direct care and family education (Catlin, 2007). Of all health care team members, nurses providing care in the NICU spend the largest proportion of time

implementing treatment interventions, observing the infant's response to treatments, and providing family education and support. The experience of providing care to critically ill preterm infants for whom the NICU nurse believes that care should be redirected results in the experience of an ethical dilemma (Janvier, Nadeau, Deschênes, Couture, & Barrington, 2007). Reports of emotional exhaustion, depersonalization of the infant, and "burn out" result from the implementation of treatment plans that result in infant pain and suffering when care is perceived as purposeless (Gutierrez, 2005; Meltzer & Huckabay, 2004). For all of the above reasons, further study is necessary to identify factors in the practice environment that facilitate and inhibit the actions that NICU nurses engage in to resolve ethical dilemmas that arise when the nurse is required to implement a treatment plan with which he or she disagrees.

Purpose of Study

The purpose of this study was to identify the range of likely actions that NICU nurses working in Massachusetts employ when faced with an ethical dilemma related to a treatment decision disagreement for an infant with an uncertain prognosis. In addition, this study ascertained individual and organizational factors that enabled or inhibited the nurse's likely action to resolve the ethical dilemma. Individual nurse characteristics studied included *Concern for Ethics*, *Frequency of Ethical Conflict*, *Years of NICU Practice*, *Highest Educational Level Achieved*, *Knowledge of Organizational Ethics Resources*, *Attendance at Ethics or Legal Education Program*, and *Professional Certification*. Organizational variables included *Nursing Influence* and *Unit Characteristics*. Knowledge of these factors may lead to more supportive NICU practice environments for nurses to resolve ethical dilemmas when treatment decision disagreements arise. The variables described above have been shown in previous studies to influence the ethical practice of nurses and are addressed in greater detail in Chapter Two.

Definitions. Appendix A contains the theoretical and operational definitions of the independent and dependent variables. The outcome variable, *Nurse Activism*, was defined as the range of likely actions a NICU nurse would employ to resolve a hypothetical ethical dilemma (Penticuff & Walden, 2000). The specific range of likely actions include feeling concerned but taking no action, talking with other nurses, talking with the nurse manager, talking with a physician, requesting a team meeting to discuss concerns, talking with the family about the ethical dilemma, requesting an ethics committee meeting, discussing the case with hospital administrators outside the hospital, discussing the case with officials outside hospital, and discussing the case with media outside the hospital. These are all identified in the contemporary literature as actions nurses have taken to resolve ethical issues.

Individual nurse characteristics include *Concern for Ethics*, *Frequency of Ethical Conflict* and *Years of NICU Experience*. *Concern for Ethics* is defined as the nurses' self-reported sensitivity to the effects of nursing actions on infant well being (Penticuff & Walden, 2000). The self-reported responses are measured with a 5-point Likert scale with an item score of 1 indicating the respondent is "concerned to a very small extent" to a score of 5 signifying the respondent is "concerned to a very large extent". The *Frequency of Ethical Conflicts* is defined as the self reported rate of recurrence of ethical dilemmas in NICU. The self-reported rate of recurrence of ethical dilemmas is measured with a 5-point Likert scale. An item score of one indicates the respondent annually experiences an ethical dilemma to an item score of five indicating a monthly occurrence. *Years of NICU Experience* is defined as the length of time, measured in years of employment, the nurse has worked in a bedside care role. Professional factors include *Highest Educational Degree Achieved*, *Knowledge of Organizational Ethics Resources*, *Attendance at Legal or Ethics conference* and professional *Certification*. Nurses were

asked to select one of three choices of educational degrees achieved including Registered Nurse, baccalaureate, and masters or doctoral degree. *Knowledge of Organizational Ethics Resources* is defined as the nurse's knowledge of their organizations ethics resources. Nurses were asked to select if they were certain or uncertain regarding the availability of a specific ethics resource in their organization. Organizational ethics resources include any provision made by the institution for the resolution of ethical issues. Such resources include written hospital policies providing direction about informed consent, termination of life support, do not resuscitate, limitation of treatment, and hospice approaches (Penticuff & Walden, 2000). *Attendance at an Ethics or Legal Conference* is defined as the attendance at either an ethics or legal educational program. Nurses were asked to select whether they had attended one or both types of programs. *Certification* is defined as the nurse's desire to achieve specific knowledge and skill to care for the infant requiring nursing care in the NICU and placing nursing goals above other goals. Nurses were asked to select any of the following certifications; neonatal intensive care nursing certification (NCC), newborn-individualized developmental care program certification (NIDCAP), and/or lactation counselor (LC) certification.

Organizational characteristics include the perception of *Nursing Influence* and *Unit Characteristics*. *Nursing Influence* is defined as the nurses' perception of their ability to influence treatment decisions in their unit (Penticuff & Walden, 2000). *Unit Characteristics* is defined as the NICU nurse's perceptions of whether it is usual for nurses to be involved in ethical decision-making and receive administrative support for their involvement (Penticuff & Walden, 2000).

Research Questions and Hypothesis. The research questions this study proposed to answer were:

1. What are the likely actions a NICU nurse would employ to resolve a hypothetical ethical dilemma?
2. What factors predict NICU nurse actions when challenged with a hypothetical ethical dilemma arising from treatment decision disagreements?

The following hypothesis was tested:

More years of NICU experience, greater frequency of ethical conflicts, greater concern for ethics, higher formal education, ethics specific education, greater knowledge of ethics resources, certification, and perception of increased influence in their unit, and greater participation with administrative support to resolve ethical issues predicts nurse activism.

Assumptions

The terms moral and ethical are considered exchangeable as they are derived from the same root meaning related to right actions. In this document they are intended to refer to nursing actions that advance the goals of the profession related to the delivery of good patient care (Grace, 2009). The proposed study includes the perspective that the all nurses have a responsibility to try to resolve ethical dilemmas that arise in practice in order to promote 'good' care for their patients. Unresolved ethical dilemmas impact the care that is delivered to an infant and/or may skew the nurse's interpretation of the benefits of proposed treatments for a given infant. The response choice of inaction or action to resolve an ethical dilemma as well as the type of response selected is influenced by both the individual NICU nurse and the NICU practice environment. It is assumed that the NICU nurses completing this study have experienced this type of ethical dilemma in practice.

Summary

This chapter described the societal factors, including the technological advances, health care regulations, and family involvement in decision-making that impact the delivery of nursing care in the NICU. Previous international, national, and local studies have described the experience of all roles of NICU nurses as well as outcomes of unresolved ethical dilemmas. However, less is known specifically about the staff nurses' professional characteristics and perception of practice environments, as well as the range of likely actions they would take to resolve ethical dilemmas. Chapter 2 provides a thorough and critical review of pertinent literature and depicts a gap in the knowledge needed to enable nurse leaders to create practice environments that foster the resolution of ethical dilemmas.

Chapter 2

Theoretical Framework

Review of Literature

Nursing is recognized by society as a profession distinguished by a specialized knowledge base, a service orientation involving personal relationships between the professional nurse and the patient with the service intended to benefit the patient. The very nature of the nurse's professional involvement with patients is in behalf of planning and carrying out actions to promote patients' well being. These actions influence how patients are born, live, and die. Thus, professional nursing is a moral endeavor in which nurses hold human wellbeing in their hands (ANA, 2003; Taylor, 1998). The nursing profession has responsibilities to fulfill its obligations to patients and is accountable for both practice and knowledge development activities that facilitate practice. The theoretical framework for this study is in accordance with the foundational premise that nursing provides a 'good'. The framework and a critical review of pertinent literature are described in this chapter.

Theoretical Framework

A synthesized theoretical framework that includes aspects of *Nursing's Social Policy Statement* (ANA, 2003), The American Nurses Association's *Code of Ethics for Nurses with Interpretive Statements* (2001) and Rest's (1982, 1983) Four Component Model of Moral Action underpins this study. The ANA's Social Policy Statement outlines the professional nurse's responsibilities to individuals and society, the ANA Code of Ethics describes the manner in which care is to be delivered and Rest's four component model defines the cognitive process that underlies moral action. The discussion regarding ethical responses of NICU nurses is structured

according to the cognitive processes of the four component model. The schema of the theoretical framework is presented in Figure 1.

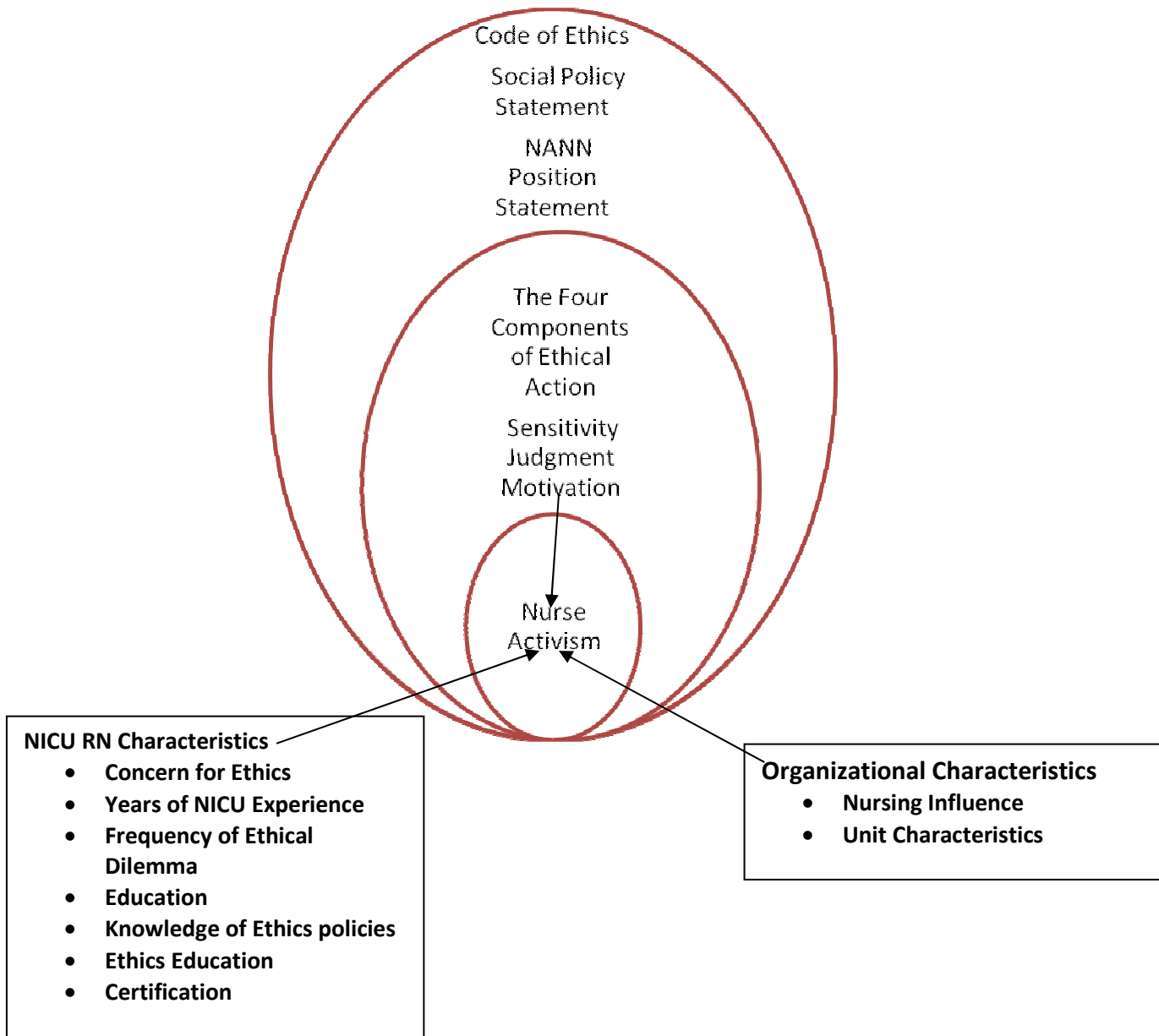


Figure 1. Theoretical Framework Schema

The two foundational documents, *Nursing's Social Policy Statement* (ANA, 2003) and the *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2001), explicate the responsibilities and obligations that professional nurses in the United States assume with each patient encounter. While these documents are specific to the United States (U.S.) context and appropriately undergird this study of a cohort of U.S. nurses, they mirror the philosophy of the nursing profession in many other developed countries. Thus, the discussion that follows may also be of interest to those working in similar settings in other countries. These documents, describing the roles and responsibilities of nurses for the health of individuals and society, are available to guide the nurse directly and indirectly in the provision of ethical practice. They provide the matrix from which the nurse's cognitive processes related to ethical decision-making should be initiated.

Nursing's Social Policy Statement. Nursing's Social Policy Statement describes professional nursing practice in the United States of America. Professional nursing is defined as "the protection, promotion and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response and advocacy in the care of individuals, families, communities, and populations" (ANA, 2003, p. 6). In addition to the above definition, there are values and assumptions that undergird nursing's social contract. Two assumptions relate specifically to the professional nurse-patient relationship. The first assumption concerns the participation of both the nurse and the patient in the process of care (ANA, 2003) such that "ethical practice becomes concrete through the personal relationship between the nurses and patient" (Gastmans, Dierckx de Casterle & Schotsmans, 1998, p. 44). The professional nurse must establish and safeguard a trusting professional relationship and maintain a patient-first orientation (Taylor, 1998). It is essential

that the nurse recognizes the ambiguity in the relationship when entering into a nurse-patient encounter. This ambiguity is related to the level of involvement the nurse may have in the caring relationship and the nurse's ability to acknowledge and appreciate the person as a self-governing individual (Gastmans, Dierckx de Casterle & Schotsmans, 1998). The establishment of the nurse-patient relationship in the NICU is unique because of the developmental level of the patients and thus is multifaceted in terms of who else is part of the nurse-patient relationship.

Nurses in the NICU consider infants in their care as members of the human community and as sons or daughters within a particular family regardless of the circumstances of their birth (Taylor, 1998). The infant's long term flourishing is largely dependent on the capabilities of his or her family. Thus, NICU nursing involves direct care for the infant and education and emotional support for the family (Penticuff, 1995). Nurses educate and coach parents regarding their infant's care with the goal of empowering them to make decisions for their child. Since the infant is as yet unable to be self-governing, in most cases the infant's parents are called upon to act in the best interest for their son or daughter. Ideally, NICU nurses, other health team members, and parents collaborate to determine optimal choices for infants in the NICU. Usually, this results in a shared vision for the infant. However, there are circumstances in which parents, nurses and health team members do not reach a unified decision regarding an optimal treatment plan. For example, in situations in which a patient or family inquires as to what course of treatment the nurse would choose, the nurse must frame his or her response to the patient or family in a manner that would not unduly influence the family in a specific direction.

The second assumption is that the interaction between the nurse and patient occurs "within the context of the values and beliefs of the patient and the nurse" (ANA, 2003, p. 3). This assumption entails understanding that care is inevitably delivered not only within the

context of the nurse's values, but also within the context of the values of the patient, the family and the hospital administration. All involved in the delivery of care should clarify their own values as well as deal with the values of others in relationship to a particular situation or types of situations. In concrete patient care situations, the moral direction is not always clear (Taylor, 1998). The nurse is required to explore and share his or her values related to situations of moral uncertainty with other health care providers in order to arrive at the best possible options for patients. However, even after each professional involved with the patient has shared their values related to the situation, the nurse has an ethical responsibility to act on behalf of the patient (Grace, 2009).

The Code of Ethics for Nurses. The *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2001) establishes the ethical standard for the profession. The Code of Ethics describes the provisions and boundaries of the nurse's duty and loyalty. It is the end result of contemporary scholarly endeavors to determine what nursing is and what it does and represents the 'promises' of the profession to society (Grace, 1998). As such, the Code of Ethics also places responsibilities on nurses to change the aspects of the health care environment that detract from the health and well being of society. There are nine provisions with interpretive statements. The first three provisions relate to the most "fundamental values and commitments of the nurse, the next three address boundaries of duty and loyalty, and the last three address aspects of duties beyond individual patient encounters" (ANA, 2001, p. 6). Provisions 2, 5, and 6 relate to the proposed study and are described in more detail below.

Provision 2 describes the nurse's primary commitment to the patient, whether "the patient is an individual, family, group or community" (ANA, 2001, p. 9). The interpretive statements of this provision describe the nurse's role in assessing the plan of care that reflects the unique needs

of the individual within the context of the family. The nurse must strive to facilitate the resolution of conflicts that arise when the patient's wishes differ from those of the family or members of the health care team. The nurse is also required to examine conflicts that arise when his or her professional and personal values are at odds. Nurses' professional responsibilities include engaging in activities to resolve their own conflicts in order to ensure optimal patient care as well as preservation of professional and personal integrity. Nurses must strive to promote a collaborative environment to ensure that all relevant parties are involved in the decision-making related to patient care (ANA, 2001).

Provision 5 describes the nurse's duty to preservation of personal integrity and safety as well as continued personal and professional growth. This provision describes the nurse's duty to engage in sound ethical decision-making through respectful and open exchange of views between and among individuals. Nurses are charged by the profession to act in a manner that preserves the values and ethics of the profession and ensures that patients and families are provided with accurate, timely and understandable information. Nurses have the responsibility to express their thoughtful and reasoned perspective, even when this may differ from the perspective of others and when it may not change the perspectives of those who differ (ANA, 2001). Although the nurse's authentic expression of his or her ethical perspective contributes to an open forum for ethical discourse, one clinician's personal opinion does not take preference over that of another. However, the nurse's participation in the discussion is crucial for unassailable ethical decision-making (ANA, 2001).

Provision 6 describes nurses' responsibilities to improve health care environments so that these are conducive to the provision of quality health care and permit good nursing practice. Environmental influences that negatively affect the ethical action of nurses should be identified

and addressed collaboratively where necessary and may require the supportive actions of nursing administrators. Appropriate environments foster ethical practice and professional fulfillment and are most likely to result in good patient care. When the nurse encounters intractable situations, then he or she has a responsibility to direct matters through appropriate channels (ANA, 2001).

In summary, professional nurses provide a 'good' for patients in terms of “preventing illness, alleviating suffering, protecting, promoting and restoring health when caring for individuals, families, groups and communities” (ANA, 2001, p. 5). The obligations of the professional nurse include the establishment and maintenance of a trusting nurse-patient relationship, knowledge of the ambiguity in the relationship, and the ability to maintain professional boundaries. In addition to the previously described documents to guide practice, many specialty organizations provide direction regarding the professional nurse’s obligations and responsibilities for a specific patient population. The National Association of Neonatal Nurses (NANN) (2006) revised position statement regarding the NICU nurses’ involvement in ethical decision-making for the treatment of critically ill newborns is discussed below.

National Association of Neonatal Nurses Position Statement, NICU Nurse Involvement in Ethical Decisions. The NANN (2006) position statement recognizes the professional neonatal nurse as an active participant in the ethical decision-making process. The NICU nurse’s constant presence and involvement in care as well as the support and education given to an infant's parents makes him or her an essential contributor to the decision-making process. The NANN supports the process of collaborative decision-making for infants with uncertain prognoses. Collaboration means that parents and all members of the health care team must work together in the interests of determining the ethical, or best possible, course of action for the neonate. The NANN recognizes that NICU nurses are for the most part the ones who are

charged with implementing care decisions, including decisions to withdraw care. Thus, they are directly and inescapably faced with ethically difficult situations. The neonatal nurse contributes to the ethical decision-making process from the perspective of being a direct care provider. In this role they observe the infant's response to treatments, as well as educate parents regarding their infant's condition. The source and boundaries of nurses' ethical responsibilities to individuals and society discussed above provides the foundation for understanding that NICU nurses also have responsibilities to ensure good care for their population. However, the nature and complexity of NICU settings, personal characteristics, and a nurse's concept of professional responsibilities have all been shown to present obstacles to good practice and interfere to varying degrees with the nurse's perceived ability to act ethically. James Rest (1982,1983), a cognitive psychologist, developed a theoretical model of the cognitive processes underlying moral action that provides a structured way to understand a nurse's ethical decision-making and resulting actions or decisions not to act.

The Four Component Model of Moral Action. The Four Component Model of Moral Action (Rest, 1982, 1983) was developed from the contemporary theory, research and literature of disparate disciplines into a framework illustrating the determinants of moral behavior including moral sensitivity, moral judgment, moral motivation, and moral character. He reasonably postulates that all four processes must occur for moral action to result. These interrelated processes do not necessarily occur in a linear fashion. Rest's (1983) early research on moral judgment involved the development of the Defining Issues Test (DIT), which measures how different people define the most important aspects of a dilemma. Research utilizing the DIT has suggested that a modest relationship exists between moral judgment and behavior. Rest concluded that the modest relationship between moral judgment and moral behavior indicated

that there are probably other processes acting together to produce a moral act. In order to more fully understand the process underlying moral action, Rest proposed that research measuring all four processes should be undertaken. His Four Component Model was derived deductively from a review and synthesis of research from the psychology of morality. According to Rest (1982, 1983), moral action is a result of the amalgamation of the four components, which leads to success in performing a moral act. He proposed that moral behavior is the result of four inner processes and the situational context in which the behavior occurs. Rest's model does not pre-define what constitutes moral action; rather it is about what has transpired in the mind of someone who wants to demonstrate the right action in a situation.

The focus on inner processes and situational contexts is fundamental to understanding, predicting and influencing moral behavior. The four inner processes include: “(1) interpreting the situation; (2) figuring out what one ought to do; (3) choosing among moral and non-moral values to decide what one actually intends to do; and (4) executing and implementing what one intends to do” (Rest, 1983, p. 26). All four processes are necessary to achieve moral action; that is, to result in an action that achieves the good that is sought. Although one process may interact and influence another process, in this model, all processes can be differentiated from each other for the purpose of describing the four distinct functions. Each process may be viewed as occurring in a logical sequence; however, they are considered interactive and not linear. Moral failure is related to a breakdown in any one of the four processes. The inner processes are related to a specific component of the model.

Component one, *moral sensitivity*, is defined by Rest (1983) as “the awareness of how our actions affect other people” (p. 23). *Moral sensitivity* includes the ability to consider the consequences of different courses of action in real world situations. *Moral judgment*, component

two, includes the person's ability to "judge which action is morally right or morally wrong" (Rest, 1983, p. 23). Once an individual is aware that different courses of action lead to different experiences for individuals involved in the situation, the individual judges which course of action is more morally right or just (Rest, 1983). Component three, *moral motivation*, is characterized by the individual's ability to "prioritize moral values relative to other values" (Rest, 1983, p. 23). *Moral motivation* is defined as "having courage, persisting, overcoming distractions and implementing skills" (Rest, 1983, p. 23). Component four results in either *moral action* or inaction and is characterized by the ability to devise a plan to execute a set of actions, overcome barriers, and persevere until the goal is achieved (Rest, 1983).

In an effort to increase application of the four component model for the ultimate purpose of improving professional practice, Rest further operationalized the components to include linkages to professional codes of ethical conduct (Rest, 1982). Although the components are described as an ensemble process, few studies measure all components concurrently, which limits our understanding of how and under what circumstances an ethical failure occurs.

The four components are described in detail below along with associated nursing research. Studies that measure two or more components may be presented with each component. In this study, the four components are intended to describe professionally required actions of nurses. Therefore, the term moral and ethical are considered to have the same meaning and the components are described below utilizing the term ethical sensitivity, ethical judgment, ethical motivation, and ethical action.

Review of the Literature

Component 1- Ethical Sensitivity. The major function of component one, ethical sensitivity, is the ability to interpret a situation by envisioning all potential options and then

considering how each action may affect the wellbeing of all involved (Rest, 1983). *Ethical sensitivity* is the ability of nurses to recognize the ethical content of a situation and is a necessary precursor for a nurse's appropriate response to the suffering and/or vulnerability cues observed while providing care (Weaver & Morse, 2006). Situational factors may influence one's ability to interpret a situation and thus impact a person's sensitivity to an issue. Specific influences include the ambiguity of a person's needs, intentions and actions, familiarity with the situation or the people in it, time allowed for interpretation, degree of personal danger and susceptibility to pressure, preoccupation with other component processes, complexity of the situation and in tracing out cause and effect chains and presuppositions, and prior expectations that blind a person to notice or think about certain aspects (Grace, 2009). Thus, *ethical sensitivity* is a crucial attribute of clinicians. It is necessary in order that the focus of care remains on the good for the infant, which necessarily includes attending both to contextual aspects of the patient situation and the environment of care in the NICU. *Ethical sensitivity* is an awareness that all patient care situations are essentially ethical in nature. They are so because they are about providing good care to individuals. That is, a health care professional's actions are subject to appraisal based on the extent to which they remain focused on providing optimal care even in the face of obstacles.

Previous quantitative and qualitative nursing research, which in view of the above definition can be categorized as related to the concept of *ethical sensitivity*, are those focused on identifying and describing characteristics of ethical conflicts experienced in multiple practice areas (Davis, 1981; Oberle & Hughes, 2001; Redman & Fry, 2000; Varcoe et al., 2004; Wilkinson, 1988). Davis (1981) surveyed a random sample of 205 nurses from multiple practice areas and nursing roles in an unspecified geographical location to elicit their definition and understanding of ethical dilemmas. Findings indicated that although approximately 75% of the

nurses could identify ethical issues in practice including withholding treatment, prolonging life with heroic measures, violations of patient autonomy, confidentiality, and allocation of resource and unethical/incompetent activity of colleagues, 25% of the nurses were unable to describe ethical aspects of their practice. Further findings of this study revealed that baccalaureate-prepared nurses provided a greater percentage of ethical dilemma definitions and were more likely to recognize the ethical aspects of situations than diploma and associate degree nurses. Age was also found to impact the nurses' ability to identify and describe the characteristics of ethical dilemmas, with nurses less than 39 years of age reporting greater frequency of ethical dilemmas than nurses 40 years and older. In addition, the type of nursing position held was significantly related to the frequency of ethical dilemmas encountered with patients and families. Staff nurses reported experiencing a greater frequency of ethical issues faced than nurses in leadership roles such as administration and education. Davis's findings suggest that younger, baccalaureate-prepared staff nurses experience a greater number of ethical dilemmas. These findings are not surprising considering the differing amount of time spent in direct patient contact for younger staff nurses versus the other groups.

Oberle and Hughes (2001) were interested in investigating whether there were similarities and differences in perceptions of the ethical issues surrounding end-of-life care for physicians and nurses in an acute care hospital. The insights from the qualitative interviews of seven nurses and seven physicians identified the same core ethical concern of witnessing suffering with the obligation to respond. The difference in their experience relates to the perceived mandates of the individual's role as either a physician who makes the decision or a nurse who must live with the decision. Contextual factors influencing the experience included the hierarchical processes in organizations and the nurse's inability to influence decisions to

relieve suffering. In their study, Redman and Fry (2000) also supported the idea that nurses experience having to live with the decision of physicians. They surveyed certified specialty nurses to identify whether there were similarities and differences in the character of ethical conflicts as experienced in the different settings. Four-hundred-seventy nurses from specialties including nephrology, pediatrics, rehabilitation, and diabetes completed the questionnaire. The predominant theme for all specialties was disagreement among providers over quality of care and the initiation and withdrawal of treatments. The respondents indicated that some conflicts evolved from institutional and health policy constraints.

In another study that focused on understanding the phenomenon of moral distress, Wilkinson (1988) interviewed a random sample of 13 in-patient nurses. Situations causing moral distress or unease for the nurses included issues of prolonging life, unnecessary tests, patients who were being lied to, and incompetent health care providers. The frequency of distress was directly related to the similarities or differences in team member values and internal and external contextual constraints. Internal constraints included the nurse's social orientation to follow orders, futility of past actions, self doubt, lack of courage, and fear of job loss. External constraints included reactions of physicians, nursing leadership, and hospital administration. Nurses reported the experience as being detrimental to their personal and professional wholeness. The reported effect of moral distress on their delivery of patient care was equally divided between better, worse, or no different. However, the respondents reported engaging in overcompensating or avoidance-type coping behaviors. Similar themes were identified by Varcoe et al. (2004) in their exploration of the meaning of ethics.

Varcoe et al. (2004) conducted focus groups with 87 nursing students, registered nurses and advanced practice nurses and asked them to describe the meaning of ethics. A predominant

theme in this study was that nurses saw ethical practice as a “way of being that leads to awareness of self as a moral agent” (Varcoe et al., p. 319). The nurses described working in a changing landscape in which they were required to hold their values in a separate space while they acted to bring about the choices of their patients based on their patients’ values. In the process of enacting care, participants acknowledged that they encountered both tension between, and conflicts among, providers and families. These studies support the idea that nurses for the most part do recognize ethical issues associated with their practice setting. Several researchers have concentrated their efforts on understanding ethical sensitivity specifically related to nurses working in newborn settings with infants who cause concerns due to their uncertain prognosis (Janvier, Nadeau, Deschênes, Couture, & Barrington, 2007; Monterosso et al., 2005; Penticuff, 1989; Raines, 1993; Zuuren & Manen, 2006).

Janvier, Nadeau, Deschênes, Couture, and Barrington (2007) surveyed the frequency with which nurses and residents were confronted with ethical dilemmas related to delivery room practices for extremely early born infants in three Canadian NICUs. Thirty-five percent of the NICU nurses and 19% of the residents experienced ethical dilemmas in practice. The only significant factor impacting the frequency of experiencing ethical dilemmas was related to nurses’ and residents’ knowledge of long term neurologic outcomes. Nurses with less knowledge of outcomes experienced more ethical dilemmas most likely due to a lack of understanding about the infant’s possible future intact survival. Residents with less knowledge of outcomes experienced fewer ethical dilemmas which the researchers suggest may be related to the resident’s length of experience with the patient population (Janvier et al., 2007).

Monterosso et al. (2005) surveyed 61 Australian nurses regarding ethical aspects of NICU nursing practice. Respondents reported that certain categories of infants are known to

cause NICU nurses concerns: these include extremely low birth weight infants with a chronic illness, low birth weight infants with good prognosis, extremely low birth weight infants with poor prognosis, term infants with a congenital anomaly and uncertain outcome, and term infants with a poor prognosis. Seventy-two percent of nurse respondents indicated concern about decisions related to ethical problems and their consequences. The key ethical issues identified by the nurses in this study included informed consent of parents, cessation of active therapy, quality-of-life issues, and potential benefits and burdens associated with active treatment.

Penticuff (1989) interviewed 20 nurses to understand factors that influence nurse advocacy in the NICU regarding an infant's discomfort and suffering in the context of providing a long term 'good' for the infant. If the nurse believed that an infant would have an intact survival, then the nurse was less conflicted about the infant's discomfort and suffering. However, when the infant's outcome was uncertain, the nurses experienced conflict regarding the best course of action for the infant. The NICU nurses in this study considered treatments ethical if there was a probability of the intact survival of the infant, regardless of the amount of suffering associated with the interventions. If treatment was either very likely or conversely not at all likely to result in intact survival, there was no conflict for the nurse to continue to provide treatments that may cause discomfort and suffering. If the outcome for a given infant was ambiguous, nurses experienced ethical anguish because they viewed the infant as suffering from the effects of continued treatment for no justifiable reason. For these nurses, their concern for the ethical aspects of a particular treatment was directly tied to the infant's prognosis.

Raines (1993) conducted an ethnographic study of five nurses from a metropolitan medical center to explore the concepts of best interest of the infant, advocacy role of NICU nurses, and decision-making for patients who are unable to speak. Participants reported that

specific types of patients including very preterm infants, infants with genetic syndromes, and acutely ill infants influenced the interactions the nurses engaged in and the kind of care plan the nurse developed for the patient. Although the sample size was small, the types of patients causing ethical concern in this study were similar to those identified by Monterosso et al. (2005) and Spence (1998).

Zuuren and Manen (2006) interviewed 13 health care providers regarding their experience of ethical dilemmas in NICUs. Findings indicated that all health care providers experience ethical dilemmas and thought them to be an inevitable part of NICU nursing practice. The participants indicated that if their infant were born at the margins of viability, they would forgo aggressive NICU interventions because they have witnessed the suffering the treatment causes to the infant.

In summary, the national and international studies described above demonstrate that there has been a substantial amount of research related to the nature and extent of nurses' sensitivity to ethical issues in the NICU. Much of the research has focused on nurses' development of their awareness of, and ability to respond to, the suffering and vulnerability cues observed in infants while providing care for them. Although the sample sizes in most studies were small, the findings consistently suggest that nurses in the NICU are specifically sensitive to the pain and suffering resulting from treatments that are prescribed for infants with uncertain or ambiguous prognosis. Sensitivity, then, was the first process involved in noticing and recognizing an ethical problem. In these studies, sensitivity was associated with the length of time nurses had practiced in a NICU, the number of treatment decision disagreements they were involved in, and their concern for ethics. For the purposes of this study, these were considered to be important

predictors of the ethically sensitive aspects of practice and served as measures of *ethical sensitivity*.

However, the NICU nurses' ability to identify the ethical aspect of a particular patient care situation does not automatically result in *ethical action*. NICU nursing studies related to *ethical sensitivity* generally have not measured other interacting components of *ethical action*, nor other factors influencing *ethical action* in NICU nurses. Prior research associated with the second of the four components of moral action, *ethical judgment* and as related to this current study is reviewed next.

Component 2-Ethical Judgment. *Ethical judgment* is related to the nurse's ability to determine which actions are the most likely to be beneficial or cause the least harm in a given situation. Underlying *ethical judgment* is the ability to recognize the ethical aspects of a situation (i.e. *ethical sensitivity*) and use prior knowledge, experience, and reasoning to determine the appropriate goal and courses of action to meet that goal. Ethical reasoning is a process that involves identifying the ethical aspects of a situation, evaluating the ethical characteristics, taking into consideration the wishes and views of the patient and/or family, and determining the likely benefits and harms of various courses of action. Finally, *ethical judgment* results in a decision about which action is likely to result in the most ethically justified plan. "Ethical reasoning also involves consideration of fundamental ethical obligations of professional caregivers, which include obligations to do good, avoid harm, respect the autonomy of competent patients and & surrogates, treat persons fairly, tell the truth, maintain privacy" (Grace, 2009, p. 11). These obligations are reflected in the Code of Ethics for Nurses (ANA, 2001). Ethical deliberation involves a process of discerning, analyzing, and articulating ethically defensible positions and then making a decision about which position is the most justifiable

(Rest, 1982; Rushton & Penticuff, 2007). Nursing research related to ethical decision-making includes studies designed to measure nurses' ethical reasoning ability (Casterlé, Izumi, Godfrey & Denhaerynck, 2008; Chally, 1992; Crisham, 1981; Girot, 2000; Grundstein-Amato, 1992; Ketefian, 1981) and studies to assess nurses' actual participation in ethical decisions affecting patients (Elizondo, 1991; Monterosso et al., 2005).

Crisham (1981) and Ketefian (1981) conducted separate studies with nurses each utilizing the cognitive theory of moral development which evolved from the work of Piaget, Kohlberg, and Rest (Rest, 1983). According to Rest (1983), Piaget based his study of moral development on the concept of justice. Justice involves ideas about fairness and protecting the rights of persons. The concept of justice originates in concerns for equality, reciprocity in human relations, and a social contract (Rest, 1983). Justice is concerned with treating each person fairly and impartially. Kohlberg expanded on the work of Piaget. He used subjects' responses to hypothetical moral dilemmas to describe the six stages of moral judgment that constitute the framework for his theory. His study was based on the proposition that having a universalized justice perspective is the highest level of moral thinking (Kohlberg, 1983). Rest (1983) was influenced by Piaget and Kohlberg. As noted earlier, he devised the Defining Issues Test (DIT) which measures how individuals discern the central issues in a dilemma. Crisham (1981) developed the Nursing Dilemmas Test (NDI) from Rest's DIT to measure nurses' responses to nursing-specific dilemmas.

Crisham (1981) compared the moral judgments of 225 nurses from differing groups, including student nurses and staff nurses with associate, baccalaureate, and master's degrees using the DIT and NDI. Findings indicated that formal education and familiarity with similar dilemmas enhanced the individual's stage of moral judgment. Ketefian (1981) investigated the

relationship between critical thinking, educational preparation, and level of moral judgment in 79 practicing nurses using the Watson Glaser Critical Thinking Test, Rest's DIT, and the nurses' educational preparation. Reliability statistics for the Critical Thinking Test were adequate with reliability coefficients ranging from .77 to .83. The reliability statistics for the DIT was .68. Education and critical thinking accounted for about one-third of the variance in moral judgment, with significant differences between associate degree nurses and baccalaureate-prepared nurses. The influence of education on ethical reasoning was also supported by a recent meta-analysis of prior studies that used the Ethical Behavior Test (EBT), a test modeled after the DIT and NDT (Casterlé, Izumi, Godfrey, & Denhaerynck, 2008).

In this study, Casterlé et al. (2008) used data from an international sample (n=1592) of registered nurses. Findings were analyzed using random-intercept regression analysis, with different samples included as random effects; the proportion of data variability was quantified by interclass correlation. Nurses in all except the expert group demonstrated a uniform pattern of conventional ethical reasoning. All nurses except the expert group gave more importance to Kohlberg's (1983) conventional stage-four reasoning described as 'authority and social-order maintaining orientation'. A nurse using conventional reasoning would allow the patient's plan of care to be determined by the physician even if the plan was not in the patient's best interest. Nurses from the expert group reasoned using universal ethical principles as described in Kohlberg's post-conventional stage 6 (Kohlberg, 1983). In this stage, a nurse may determine the right course of action based on what is just even if it is not consistent with the majority view.

Girot (2000) evaluated the development of critical thinking and decision-making skills in RNs in different stages of their academic program. Four groups of nurses with a total sample of size of 81 completed the Watson Glaser Critical Thinking Appraisal and the Jenkins Clinical

Decision-Making Scale. Reliability coefficients for the Jenkins Clinical Decision-Making Scale were adequate at .78. No psychometric data were reported for the Watson Glaser Critical Thinking Appraisal. Findings indicated that while those nurses with advanced education demonstrated improved decision-making abilities, there was no corresponding effect on critical thinking skills. The researchers concluded that nurses enrolled in advanced academic programs were more effective decision-makers than non-enrolled students.

Factors influencing decision-making include education as well as role group orientation. Grundstein-Amado (1992) investigated the ethical decision-making process of nurses and physicians in relation to a proposed ethical decision-making model. The model includes three major elements: the ethical component, the decision-making component, and the contextual component. The first component of the model is determined by the individual's value system, which is justified by ethical principles that are grounded in ethical theories. The principles of autonomy, beneficence, and justice are regularly considered in relation to ethical theories including deontology and teleology. The second component of the model includes eight decision-making steps one should proceed through in order to reach the final course of action. The contextual component of the model is the relationship between the patient and the provider and the impact of the organizational structure on the health care providers' ethical behavior. Nine nurses and nine physicians were interviewed in two phases. In phase one, informants were interviewed with unstructured questions and in phase two, the informants were probed in response to a hypothetical case. Findings from this study indicated that nurses and physicians act out of different values, motivations and expectations. Nurse informants in this study placed the highest value on the caring perspective, defined as the nurses' concern with issues of attachment

as well as attention and response to patients needs. Physicians most highly valued the patient's rights and scientific perspective.

Related to the 'caring' orientation of nursing practice, Chally (1992) explored the ethical perspective that neonatal intensive-care nurses use to make moral decisions. NICU nurses (n =26) in a large teaching hospital were interviewed. A care and justice taxonomy was developed as a result of the analysis with 65% of NICU nurses reporting that they utilized a care perspective, 23% used a care and justice perspective, and the remaining 12% used a justice perspective. Although the sample size in this study is small, the findings are consistent with those of Grundstein-Amado (1992).

Elizondo (1991) conducted a survey of 60 NANN members representing 45 states regarding their participation in ethical decision-making, conflicts that emerge from participation, and satisfaction and beliefs regarding their role in decision-making. Methods of nurse participation in ethical decision-making included informal conversations with physicians (91%), informal consultation with parents (67%), case management conferences with physicians and parents (62%), daily rounds (60%), or in five percent of cases, no participation in ethical decision-making. Seventy-six percent of the respondents reported being somewhat to very satisfied, with 24% reporting they were not satisfied with their involvement in ethical decision-making. Nurse respondents reported conflicts related to ethical decision-making with physicians (82%), with parents (59%), with their own ethical beliefs (50%), with other members of the nursing staff (39%), with laws regarding infant care in the NICU (36%), with institutional and administrative policies (32%), and with other health care providers (27%).

In summary, research related to ethical reasoning suggests that nurses reason from a caring perspective which differ from the patient's rights and scientific perspective of the

physicians. Studies investigating *ethical judgment* focused on the education level of nurses and the ethical perspective utilized in decision-making. Crisham (1981) and Ketefian (1981) found that advanced education enhanced the stage of moral development. These findings suggest that nurses with advanced educational preparation possess advanced decision-making abilities. Over two decades later, Casterlé and colleagues' (2008) work supported these findings with a large international study. The research demonstrated that education, role orientation, and familiarity with similar dilemmas impacted the nurses' ethical reasoning. The findings were consistent across practice settings and geographical areas. Education is the single measure of ethical reasoning in this study. Ethical reasoning however, does not necessarily result in action. The third process of moral reasoning as described by Rest involves motivation, which is a necessary precursor to moral action.

Component 3 -*Ethical Motivation*. Rest (1983) describes moral motivation as the desire to be moral and act morally, placing moral values above all other values. In situations where there may be competing priorities, identifying the moral course of action must be followed by the effort to create a situation in which the right action can occur. *Ethical motivation* in nursing involves the nurse's desire to consider ethical values of the discipline before all other personal and/or institutional values. It has also been associated with engaged interaction with patients. With *ethical motivation*, the nurse considers and feels compelled to act on the needs and desires of the patient and family. The ability to take action requires a clear understanding of the issue, encouragement and support from nursing and hospital administration, skillful advocacy, and a willingness to place a particular situation above other important matters. Internal and external barriers may impact the nurse's ability to take action and can undermine one's motivation to act ethically (Rushton & Penticuff, 2007).

Internal barriers influencing nurses' *ethical motivation* include a lack of experience and concern about negative personal consequences if *ethical motivation* requires actions not routinely sanctioned in their unit or hospital (Wilkinson, 1988). Moreover, nurses report moral distress due to an inability to impact patient care situations (Corley et al. 2005 & Gutierrez, 2005).

Constraints regarding *ethical motivation* include fear of backlash, hierarchical power structures, conflicting goals between nurses, family and physicians, ineffective communication between nurses and physicians, and isolation of the nurse. Factors thought to enhance the nurses' *ethical motivation* include specialty certification leading to feelings of empowerment (Cary, 2001), enhanced collaboration (Cary, 2001; Foley, 2002; Piazza, Donahue, Dykes, Griffin & Fitzpatrick, 2006), higher perceptions of formal and informal power as well as access to information (Manojilovich, 2005; Piazza et al., 2006), and knowledge of organizational ethics resources (Dodd, Jansson, Saltzman, Shirk & Wunch, 2004).

The care environment has been described as an external barrier impacting nurses' *ethical motivation*. Aiken (2008) investigated specific hospital characteristics in relationship to nurse and patient outcomes in Pennsylvania. Hospital characteristics were termed 'the care environment' and included hospital size, staffing related to patient volume, education of nurses, and nurse/physician relationships. Hospitals with better physician and nurse relationships, increased percentage of baccalaureate-prepared nurses, and nurses reported a higher perception of nursing influence regarding nurse staffing conveyed a more positive job experience and less concern with quality of care. Moreover, the patients experienced a lower risk of death. Similarly, Hamric and Blackhall (2007) investigated nurse-physician collaboration and satisfaction with the ethical climate, patient satisfaction, and nurse satisfaction with quality of care in three western American hospitals. The findings revealed that with decreased collaboration between nurses and

physicians, a negative ethical practice environment was reported, with nurses experiencing greater moral distress than physicians. Nurses experience the ethical climate of their organization in the manner in which difficult patient care situations with ethical implications are managed (Martin, 1989; Penticuff, 1989; Olson, 1998) and their participation in ethical deliberations (Corley, Minick, Elswick & Jacobs, 2005). This ultimately affects the nurses' commitment to their organization (Hart, 2005; Roysden, 2007) and the delivery of quality patient care.

The variables selected to measure the NICU nurses' motivation in this study include *Knowledge of Ethics Resources*, attendance at either an informal or formal *Ethical and/or Legal Educational Program* and neonatal *Specialty Certification*. Ideally, the cognitive processes of *ethical sensitivity, judgment, and motivation* lead to *ethical action*, Rest's fourth process.

Component Four- Ethical Action. Component four, *ethical action*, is the outcome variable in this study. *Ethical action* involves the ability to devise a set of specific actions steps to achieve the identified goal. Activities for success include the ability to work around unexpected difficulties, manage one's frustration, persevere, and not lose sight of one's purpose (Rest, 1982, 1983). Expertise necessary to carry out one's ethical decisions requires proficient collaboration and communication skills as well as strategic planning. A successful implementation requires a truthful process where expectations are clear and communication is precise (Rushton & Penticuff, 2007).

Barriers to *ethical action* were identified in many of the previously described studies selected for this review. The barriers included organizational characteristics involving nurse-physician and nurse-to-nurse relationships, the hierarchical nature of the unit, and the nurses' understanding of the ethical situation. Varcoe et al. (2004) explored the meaning of ethics and

the enactment of ethical practice in nursing through focus groups with 87 registered nurses from 19 practice settings in western Canada. Participants described encountering tension and conflicts in values between role groups, family members, patients, and themselves. The process is described as 'working in between' their values and their patient's values as well as the organization's values.

Ongoing struggles were described as being due to the traditional power structures in hierarchical relationships, which created many problems in the provision of ethical nursing care. Peter, Lunardi, and Marcfarlane (2004) conceptualized ethical practice in the form of nurses' actions of resistance to situations that compromise the moral values of patients and nurses. Categories of resistance in response to ethical concerns required nurses to speak up, confront a physician, or report a situation to a higher authority and in some instances consult an ethics committee.

Penticuff and Walden (2000) investigated the likely ethical actions of 129 NICU nurses in response to ethical dilemmas in one perinatal practice environment utilizing Rest's four components of moral action and the NEIS. Reliability coefficients for the NEIS were greater than .80, indicating psychometric adequacy. The nurses' reported concern for ethics measured the nurses' ethical sensitivity; education and ethical reasoning perspective measured ethical judgment; and participation in professional organizations and knowledge of the organization's ethics resources measured motivation to act. The NEIS also measured the nurses' perception of their ability to influence ethical decision-making as well as organizational support for their participation in ethical decision-making. Although many nurses (36%) reported they experienced ethical concern for dilemmas they encountered in practice, they took no action. The most frequently reported action taken to resolve a dilemma was identified as being able to discuss the

situation with other nurses, followed by the head nurse and physician. Only 25 percent would request an ethics meeting or go outside their unit to talk with hospital administration. The nurses concern for ethics and their perception of nursing influence accounted for the greatest amount of variance in the nurses' reported resolution actions.

Discussion of Studies. Both qualitative and quantitative studies across all practice settings were included in this review of the literature. Most quantitative studies contained small sample sizes, lacked a theoretical framework, and utilized researcher-developed instruments with no reported psychometric properties. However, the findings in most studies related to *ethical sensitivity* were consistent and focused on the types of patients that caused concern for nurses, followed by disagreements over quality of care, and initiation and withdrawal of treatment. Four studies investigated moral reasoning utilizing Kohlberg's moral stages of development and Rest's DIT. The nurses' educational level was also a consistent finding related to Kohlberg's moral stage of decision-making, with advanced education leading to higher moral levels of decision-making. However, the small sample sizes and the inclusion of nurses from all levels in the organization made the generalizability of these studies difficult.

The study samples of previous research included nurse administrators, advanced practice nurses, and educators along with staff nurses. A staff nurse's ability to impact patient care decisions may be related to his or her role in a health care organization. Moreover, the amount of time each role group spent in direct care varied and may have influenced the study findings. The nurses' sensitivity to and frequency of ethical dilemmas, their ethical reasoning ability, and their ability to take action, as well as the type of action taken to resolve an ethical dilemma may have influenced their responses. Most studies sampled nurses in one health care organization limiting the generalizability of findings. The gap in ethics research that this study was designed to address

included the fact that no overview of factors influencing *nurse activism* by direct care nurses in NICU settings had been undertaken. Thus, the findings of this study can be generalized for direct care NICU nurse providers working in Massachusetts hospitals.

Summary

Chapter One contained the significance of the societal factors that impact the delivery of nursing care in the NICU. The potential for NICU nurses to experience ethical dilemmas resulting from technological advances, health care regulations, and family involvement in decision-making was outlined. In this chapter, the theoretical framework was described and a critical review of the literature illustrated what was known and what was not known about the predictors of *nurse activism* in the NICU. In Chapter 3, the study design, methods, and sample are described.

Chapter 3

Methods

This chapter explains the study design, research questions, and hypothesis as well as the survey tool, data collection procedures and statistical analysis utilized in this study. The IRB requirements of each participating hospital are listed in Table 1. The approval documents are located in Appendix (D-I). The hospital IRB approval requisites varied with some requesting expedited IRB approval and others requiring Nurse Manager approval.

Methods

This cross-sectional study was conducted with a purposive sample of Registered Nurses working in Massachusetts newborn intensive care units (NICUs). The NICU nurses were surveyed electronically with the Demographic Data Survey, adapted from Penticuff and Martin (1987), and the Nurses Ethical Involvement Scale (NEIS) (Penticuff & Martin, 1987). The NICU nurses responded to questions that related to their ethical sensitivity, judgment, motivation, and the likelihood of action to resolve an ethical dilemma. Measures of *ethical sensitivity* included *Concern for Ethics, Frequency of Ethical Conflict and Years of NICU Nursing Experience*. *Ethical judgment* was measured by the *highest educational degree achieved* by the NICU nurse. *Ethical motivation* included variables that indicate commitment to the neonatal specialty including *Knowledge of Organizational Ethics Resources, Ethics and or Legal specific Courses, and Certification*. Measures of organizational characteristics included the subscales *Nursing Influence* and *Unit Characteristics*. The outcome variable, *Nurse Activism*, was defined as the range of likely actions taken to resolve an ethical dilemma. Descriptive statistics were computed and the findings answered research question one. Variables were then entered into a hierarchical multiple regression analysis based on the theoretical categories to answer research question two.

Research Design

The following hypothesis was tested with a cross-sectional design using survey responses obtained from nurses working in NICUs located in Massachusetts.

More years of NICU experience, greater frequency of ethical conflicts, greater concern for ethics, higher formal education, ethics specific education, greater knowledge of ethics resources, certification, perception of increased influence in their unit, and unit characteristics that foster greater participation with administrative support to resolve ethical issues predicts Nurse Activism.

The research questions this study proposed to answer were:

1. What are the likely actions a NICU nurse would employ to resolve a hypothetical ethical dilemma?
2. What factors predict NICU nurse actions when challenged with a hypothetical ethical dilemma arising from treatment decision disagreements?

Survey Monkey, a web-based survey application, was utilized to collect the responses from NICU nurses. The survey is included in Appendix C.

The e-mail contact strategy utilized to generate responses from the study population involved sending specifically timed e-mails to the study population requesting their participation (Dillman, Smyth, & Christian, 2009). Hospitals with obstetrical services and NICUs were included in the study. The hospitals that met inclusion criteria included the Brigham and Women's Hospital, Beth Israel Deaconess Medical Center, Tufts Medical Center, Caritas Saint Elizabeth Medical Center, South Shore Hospital, Boston University Medical Center, Massachusetts General Hospital, and the University of Massachusetts, Worcester, and Baystate Medical Centers. Once approval was obtained from the participating institutions, listed in Table

1, the nurse managers of the NICUs received the study invitation e-mail. The researcher requested that the Nurse Managers forward the study invitation in an e-mail to their staff.

A total of three e-mails were sent to each Nurse Manager and forwarded to NICU nurses. Samples of the recurring e-mail invitations are included in Appendix J. The study invitation e-mail included a description of the study purpose, consent information, methods, gesture of appreciation, the URL, and directions for completing the survey. The second e-mail message served as a thank-you to those who completed the study and a reminder to those who had not responded. The URL was repeated for easy access to the survey. The third and final e-mail message focused on the short time available to complete the survey, the importance of responding, and repeated the URL. Guidelines indicating the optimal frequency of e-mail recruitment have not been determined (Dillman, Smyth, & Christian, 2009). It was recommended that a specific and consistent frequency of contact be identified and adhered to by the researcher. In this study, the frequency of contact for the first two e-mails was weekly. This timeframe was determined considering the current scheduling practices of twelve-hour shifts that result in a three-to-four day work week. Moreover, part-time staff nurses may work one-to-three days per week. The final e-mail was distributed two weeks after the second and included a study end date.

A gesture of appreciation was offered to each nurse who completed the survey. The NICU nurse selected the neonatal nursing organization in which he or she wished to make a donation. Each completed survey yielded a two-dollar donation, made in the name of Massachusetts NICU nurses. Survey responses were collected anonymously through a web collector. The survey collection site was assessed daily by the researcher for completed surveys. The completed data set was down-loaded into an Excel spreadsheet and copied into the Statistical Package for the Social Sciences (SPSS) at the study end date. There was no electronic

identifying information transmitted with the completed survey. The secure sockets layer (SSL) protocol was applied to the website to ensure HIPAA compliance. Collected data were kept private and confidential in locked secure cages, requiring pass card entry and biometric recognition. The location was monitored with digital surveillance equipment, controls for temperature, humidity and smoke/fire detection, and is staffed 24hours per day, seven days per week (Survey Monkey, 2009).

Instrument

The data collection tools (Appendix C) were utilized to survey NICU nurses regarding their likely actions to a treatment decision disagreement for an infant in the NICU with an uncertain prognosis. The Demographic Data Survey adapted from Penticuff and Martin (1987) included NICU nurse specific data that measured nurses' ethical sensitivity, judgment, and motivation. The Nurses Ethical Involvement Scale (NEIS) (Penticuff & Martin, 1987) measured the nurse's perception of influence, their NICU characteristics, and the outcome variable, *Nurse Activism*.

Ethical sensitivity variables included *Concern for Ethics*, *Frequency of Ethical Conflict* and *Years of NICU Nursing Experience*. The variable, *Concern for Ethics*, was measured with a 5-point Likert scale. Item scores ranged from 1 (*concerned to a very small extent*) to 5(*concerned to a very large extent*). The *Frequency of Ethical Conflict* variable was measured with a 5-point Likert scale. Item scores ranged from 1 (*experienced ethical dilemmas annually*) to 5 (*experienced ethical dilemmas monthly*). The *Years of NICU nursing experience* variable was measured by the actual number of years the respondent worked as a NICU nurse.

Highest Level of Nursing Education Achieved was used as the single measure of *ethical judgment* for this survey. All were Registered Nurses. The categories for educational levels were

Registered Nurse, encompassing the diploma and associate degree, baccalaureate, and master's degree or higher. Since education had been shown to influence ethical reasoning in the literature, this was determined to be a credible measure. Extensive research described in chapter two regarding ethical judgment indicated that nurses' reason about ethical issues utilizing both care and justice perspectives. Moreover, studies indicate that direct care nurses utilize Kohlberg's conventional stage of reasoning when faced with a dilemma due to the rule bound nature of most health care environments (Casterlé et al., 2008).

Measures of *ethical motivation* utilized information about the nurses' *Knowledge of their Institutions Ethics Resources*, whether they had *Attended Ethics and/or Legal specific Program*, and whether the nurses had pursued *Specialty Certification*. NICU nurses' knowledge of institution specific ethics resources was summed for a total score. Responders with a higher score indicated increased knowledge of their institutions ethics resources. All of the hospitals included in this survey are accredited by the Joint Commission and as such have ethics resources as required by this regulatory body. Attendance at informal programs of legal and/or ethical content indicated the NICU nurses' commitment to understanding the ethical aspects of nursing practice. NICU nurse respondents identified active certification in neonatal intensive care nursing (NCC), newborn individualized developmental care (NIDCAP), and/or lactation consultation (LC). Achievement of one neonatal specific certification was assumed to indicate increased commitment to the provision of expert, knowledgeable neonatal nursing care.

The Nursing Ethical Involvement Scales (NEIS) (Penticuff & Martin, 1987) included three sub-scales designed to measure the variables *Nursing Influence*, *Unit Characteristics*, and the outcome variable *Nurse Activism*. The nurses were presented with a hypothetical situation that involved an extremely premature infant hospitalized for seven months in the NICU. This

ventilator-dependent infant required sedation for air hunger and was diagnosed with chronic lung disease. In addition, the infant had sustained severe brain hemorrhages. The infant's parents requested that treatment be discontinued. Nurses responded to the hypothetical situation by agreeing or disagreeing with items that provided options to a general question: "If you disagreed with the treatment decision about a similar case in your own unit, how likely would you be to..." Responses to the situation-specific case made up the nurse response scale and provided information about the range of responses nurses reported they would likely take when confronting a similar situation in their own unit (Penticuff & Martin, 1987).

The instrument included three independent scales. The Nursing Influence Scale (NIS) consists of 14 items measured on a five-point Likert scale. The NIS measured the nurses' perception of their ability to influence ethical decisions related to the comprehensive plan of care for a patient. It measured the nurses' perception of whether it is usual for nurses to be involved in ethical decision-making and whether they perceived that there was administrative support for their involvements (Penticuff & Walden, 2000). An item score of 1 indicated a respondent '*strongly disagreed*' with the particular statement to 5 indicating '*strongly agreed*' with the particular statement. The possible range was 14 (low influence) to 70 (high influence).

The Unit Characteristics Scale (UCS), a 9-item, five-point Likert scale, measured the nurses' perception of unit characteristics related to the delivery of patient care. An item score of 1 indicated a nurse '*strongly disagreed*' to a particular statement and a score of 5 indicated the nurse '*strongly agreed*' with statement. The possible score ranged from 9 (strongly disagreed) to 45 (strongly agreed). Item numbers 30 and 35 were reverse scored in the analysis.

The *Nurse Activism* Scale is a 10-item, five-point Likert scale of possible actions, including no action, that a NICU nurse would take to resolve a treatment decision disagreement

for an infant with an uncertain prognosis. An item score of 1 indicated a nurse was '*not at all likely to take action*' and a score of 5 indicated that a nurse was '*extremely likely to take action*'. The possible scores ranged from 10 (low activism) to 50 (high activism). Item number 4 was reversed scored in the analysis.

The NEIS survey was originally piloted with a national sample of 260 NICU nurses. Based on the Cronbach's Alpha coefficient range of .63 to .83, the questionnaire was modified to consist of three scales (Penticuff & Martin, 1987). Further research utilizing the modified questionnaire was conducted by Penticuff and Walden (2000). The Cronbach's Alpha coefficients in that study included .88 for nursing influence, .82 for unit characteristics, and .83 for nursing activism. For Penticuff and Walden's second study, the responses of 127 NICU nurses who completed the NEIS were analyzed using multiple regression techniques. The results suggested that nurses were more likely to be involved in dilemma resolution activities when they perceived themselves as having higher levels of influence in their practice environment (Penticuff & Walden, 2000).

The Study Sample

For this study, a purposive sample of Registered Nurses was recruited from NICUs in Massachusetts. Inclusion criteria included hospitals with a level three NICU and an obstetrical service. There are ten NICU's in the state of Massachusetts. A total of nine NICUs met inclusion criteria. Six NICUs that met inclusion criteria were located in the Boston metropolitan area, one NICU was located in the city of Worcester, one NICU in the city of Springfield, and one NICU was located in the town of Weymouth. Two hospitals declined to participate due to changes in nursing leadership at the unit level during the recruitment phase. One NICU in the Boston

metropolitan area was excluded due to lack of an obstetrical service. A total of seven NICUs participated in this study (Table 1).

Each NICU nurse working in one of the seven participating Massachusetts hospitals had the opportunity to participate. NICU nurses were recruited for this study utilizing the e-mail contact strategy described in the study design section. A sample size of 135 subjects was determined sufficient for analysis based on a moderate effect size of 0.15, a power of 0.80, and an alpha of .05.

Data Analysis

The data were exported to an Excel program, Version 2003 from the Survey Monkey web collector, reviewed for accuracy, and then imported into SPSS, Version 17.0. Descriptive statistics were calculated on demographic data and continuous variables. Independent *t* tests were computed for the variables *Ethics and or Legal Education* and *Certification*. Analysis of Variance was computed for the variable *Highest Education Level Achieved*. The categorical variables that achieved significance and all continuous variables were entered stepwise into a hierarchical multiple regression based on the components of the theoretical model. Variables that predicted NICU Nurse Activism were identified.

Research Questions

The research questions this study proposed to answer were:

1. What are the likely actions a NICU nurse would employ to resolve a hypothetical ethical dilemma?
2. What factors predict NICU nurse actions when challenged with a hypothetical ethical dilemma arising from treatment decision disagreements?

Hypothesis

The following hypothesis was tested:

More years of NICU experience, greater frequency of ethical conflicts, greater concern for ethics, higher formal education, more ethics specific education, greater knowledge of ethics resources, certification, perception of increased influence in their unit, and unit characteristics that foster greater participation with administrative support to resolve ethical issues predicts Nurse Activism.

Limitations and Threats to Validity

This cross-sectional study was designed to examine the range of likely ethical actions by Massachusetts NICU nurses in response to a hypothetical ethical dilemma. Although the NEIS has psychometric adequacy with a national sample of NICU nurses (Penticuff & Martin 1987), it is a self-reported instrument that has not been validated through correlation of response scores with observations of actual nurses' behavior. Future research will be required to investigate whether NICU nurses actually behave the way they say they would when involved in an ethical dilemma.

Regression analysis, the statistical test utilized for this study, allows for the prediction of outcomes and the explanation of the interrelationships among variables (Munro, 2005). This statistical test does not predict causation. Therefore, the findings from this study identified the relationship among variables but did not determine the cause of NICU nurse activism.

A specific threat to validity anticipated in this study is selection bias. In an effort to maintain anonymity, the researcher was unable to ensure that a representative sample of NICU nurses from each unit completed the survey. As a result, the generalizability of the study is

limited to reflect the hypothetical actions NICU nurses working in Massachusetts hospitals selected in response to the presented case.

Protection of Human Subjects

Institutional research board (IRB) approval for this study included submissions to the Boston College IRB as well as at each participating hospital. The procedures included the submission of a letter to Boston College that gave permission for the researcher to conduct the study and a signed Authorization Agreement by which the hospital would defer decision-making to the Boston College IRB. In some cases, the hospital conducted a complete review of their own in addition to BC's IRB. The individual hospital requirements and approval dates have been listed in Table 1.

The protection of human subjects in this study related specifically to the maintenance of anonymity of the responders. There were no identified risks to the participants in completing the survey. They were asked to respond to a hypothetical case, thus it was less likely that they experienced distress as they might from recounting a case where they were personally involved. The subjects' anonymity were protected by using the web-based survey system, Survey Monkey. The subjects' and hospitals' identities were de-identified when the survey was submitted to the Survey Monkey web collector (Survey Monkey User Manual, 2009).

Table 1

Institutional IRB Requirements

| Institution | Requirement | Approval Date |
|--------------------------------------|---|---------------|
| Boston College | Expedited Review | 08/24/09 |
| Massachusetts General Hospital | Partners Expedited Review | 11/12/09 |
| Brigham & Women's Hospital | Partners Expedited Review | 11/12/09 |
| Tufts Medical Center | Hospital Expedited Review | 12/10/09 |
| Beth Israel Deaconess Medical Center | Deferred review to Boston College | 12/12/09 |
| Boston Medical Center | Nurse Manager Approval | 12/15/09 |
| South Shore Hospital | Expedited Review | 12/10/09 |
| Baystate Medical Center | Human Resource & Nurse Manager Approval | 02/10/10 |

Summary

In summary, a cross-sectional study was conducted to describe selected actions NICU nurses in Massachusetts reported they would employ to resolve a hypothetical ethical dilemma. The data were collected via a web-based survey and analyzed utilizing multiple regression. The findings of this study are described in Chapter 4 and provide information about the likely actions selected by NICU nurses to resolve a hypothetical ethical dilemma.

Chapter 4

Results

This chapter documents the statistical analysis of the data. There were no reported issues for the nurses in accessing the web site or in completing the survey. Although NICU nurses had up to six weeks to respond, the sample size needed for analysis was achieved in 3 weeks. The findings will be discussed in Chapter Five.

Data Analysis Procedures

The data were exported to a Microsoft Excel program, (Version 2003), from the Survey Monkey web collector. They were reviewed for accuracy, and then imported into SPSS, Version 17.0. Descriptive statistics on all variables were computed and examined for systematic and random missing data, marked skewness, and the presence of outliers. No systematic missing data were found. Variables with random missing data that ranged from 0.4 to 8.9 percent were handled with the listwise deletion procedure. This procedure only analyzes available cases with complete data (Munro, 2005). No marked skewness was noted and no variable in the data set had significant outliers.

One variable, *Years of NICU Nursing Experience*, presented with 17.9 percent missing data. The format in the on-line survey for this question and the respondents' ability to omit an answer may have contributed to the increase in missing data for this variable. Due to the large standard deviation, the median for the variable *Years of NICU Nursing Experience* was substituted for missing data (Munro, 2005). Independent *t*tests determined no statistically significant difference in the mean of this variable when the median was substituted for missing data. Therefore, the variable, *Years of NICU Nursing Experience* was also handled with listwise

deletion (Munro, 2005). There was no marked skewness and no significant outliers were noted for this variable

Sample

The population identified for this study included all NICU nurses working in Massachusetts hospitals that offer both obstetrical services and a Level 3 NICU. Nine hospitals met the inclusion criteria and 7 hospitals participated in this study. Two hospitals did not participate due to changes in nursing leadership at the unit level during the recruitment phase. The total population of NICU nurses working in Massachusetts was estimated at 700. The estimated sample size for the seven participating hospitals was 633 NICU nurses. Of this number, 224 respondents completed the online survey resulting in a 35.4% response rate.

Categorical data (Table 2) include *Gender*, *Highest Education Level Achieved*, *Neonatal Specialty Certification* and *Attendance at an Ethics or Legal Education Program*. Ninety-eight percent of the responders reported their gender as female. Due to the high percentage of female responders to the survey, the variable gender was not included in the analysis. The variables *Attendance at Ethics or Legal Education Program* and *Neonatal Specialty Certification* were compressed into dichotomous variables. The variable attendance at *Ethics or Legal Education Program* was dichotomized into attendance at either program or no attendance. One-hundred-fifteen (51%) NICU nurses reported attending either an ethics or legal education program in the last three years. The variable *Neonatal Specialty Certification* was dichotomized to include no certification or certification in any listed neonatal specialty. Ninety-five (42%) of responders held some type of certification including certification from the National Certification Corporation (NCC) as NICU Intensive Care nurses, Newborn Individualized Developmental Care Program (NIDCAP) and/or Lactation Counselors (LC). The typical responder was female,

with a bachelor’s degree, employed in a Boston hospital, had attended an ethics or legal educational program, and was not certified in a neonatal specialty.

Table 2

Frequencies & Percents of Categorical Variables

| Variable | Frequency | Percent |
|--|-----------|---------|
| Gender | | |
| Female | 222 | 98 |
| Male | 2 | 2 |
| Highest Level of Education Achieved | | |
| Registered Nurse | 66 | 30 |
| Bachelor Degree | 128 | 57 |
| MS/PhD | 29 | 13 |
| Certification | | |
| No Certification | 129 | 57 |
| Certification | 95 | 42 |
| Certification Types | | |
| NCC | 61 | 27 |
| NIDCAP | 13 | 6 |
| LC | 21 | 9 |
| Ethics Education | | |
| Ethics/Legal | 115 | 51 |
| Neither | 109 | 49 |

-
- NCC = National Certification Corporation
 - NIDCAP = Newborn Individualized Developmental Care Program
 - LC = Lactation Counselor

Measures of Outcome Variable Nurse Activism

Frequency of Selected Likely Actions. The outcome variable, *Nurse Activism*, is defined as the range of likely actions employed to resolve an ethical dilemma. Respondents were asked to consider ten Likert-type items and select whether they were ‘*extremely*’, ‘*very*’, ‘*somewhat*’, ‘*not*’, or ‘*not at all*’ likely to take the action. The frequency of likely actions addresses research question one and is described below.

Research Question 1: What are the likely actions NICU nurses working in Massachusetts hospitals employ to resolve a hypothetical ethical dilemma?

Table 3 contains the frequency, sum, and percent of all listed actions by NICU nurses working in Massachusetts.

Table 3

Frequency and Percent (%) of All Listed Actions NICU Nurses Take in Response to Dilemma

| Item | Not at All Likely | Not Likely | Somewhat Likely | Very Likely | Extremely Likely |
|---|-------------------|------------|-----------------|-------------|------------------|
| Take No Action | 47 (21) | 79 (35) | 60 (27) | 32 (14) | 4 (2) |
| Talk with RNs | 2 (1) | 2 (1) | 15 (7) | 89 (40) | 116 (51) |
| Talk with NM | 15 (8) | 32 (14) | 49 (22) | 79 (35) | 46 (20) |
| Talk with MD | 3 (1) | 9 (4) | 39 (17) | 91 (42) | 82 (36) |
| Request Meeting | 4 (2) | 37 (16) | 51 (23) | 76 (34) | 56 (25) |
| Talk with Family | 19 (8) | 38 (17) | 66 (30) | 50 (22) | 50 (22) |
| Request Ethics Meeting | 18 (8) | 47 (21) | 71 (32) | 52 (23) | 36 (16) |
| Discuss Case with HA Outside Hospital | 172 (77) | 52 (23) | 0 | 0 | 0 |
| Discuss with Officials Outside Hospital | 179(80) | 40 (18) | 2 (1) | 0 | 0 |
| Contact Media | 211 (94) | 7 (3) | 0 | 0 | 0 |

The five Likert data points were compressed into two categories for discussion and are presented in Table 4. The ‘*somewhat*’, ‘*very*’, and ‘*extremely likely*’ data points are included in

the column labeled 'likely actions'. The '*somewhat likely*' data points were included in the '*likely*' category due to the potential for selecting action verses no action. The '*not likely*' and '*not at all likely*' data points are included in the '*not likely*' labeled column. The actions are ranked by percent of most to least likely action.

Table 4

Likely and Not Likely Actions Compressed into Two Categories

| Item | <u>Frequency/Percent (%)</u> | |
|------------------------------------|------------------------------|------------|
| | Likely | Not Likely |
| Talk with RNs | 220 (98) | 4 (2) |
| Talk with MDs | 212 (95) | 12 (5) |
| Request Team Meeting | 183 (82) | 41 (18) |
| Talk with Nurse Manager | 174 (78) | 47 (21) |
| Talk with Family | 166 (75) | 57 (25) |
| Request Ethics Meeting | 159 (71) | 65 (29) |
| Concerned but Take No Action | 96 (43) | 126 (56) |
| Discuss Officials Outside Hospital | 2 (0.9) | 219 (98) |
| Discuss with HA Outside Hospital | 0 (0) | 224 (100) |
| Contact Media | 0 (0) | 218 (97) |

Although some nurses reported they would likely feel concerned but take no action (43%), the majority of responders reported they were likely to talk with their peers (98%) and physician colleagues (95 %) followed by their Nurse Manager (78%) and infant's family (75%).

NICU nurses indicated they would likely request team (82%) and ethics (71%) meetings and discuss the case with officials outside the hospital (0.9%). No participants reported that they were likely to discuss the case with hospital administrators outside the hospital or with the media.

The NICU nurse characteristics proposed to predict *Nurse Activism* in this study include the *Nurses Concern for Ethics*, *Frequency of Ethical Dilemmas*, *Years of NICU Nursing Experience*, *Higher Formal Education*, *Knowledge of Hospital Policies*, *Ethics and or Legal Education*, and *Certification in Neonatal Specialty*. The organizational characteristics proposed to predict *Nurse Activism* include perception of *Nursing Influence* and perception of *Unit Characteristics* that foster greater participation with administrative support to resolve ethical dilemmas. Bivariate correlations and hierarchical regression analysis were calculated with variables listed above and the outcome variable *Nurse Activism* to address the second research question.

Research Question 2: What factors predict NICU nurse actions when challenged with a hypothetical ethical dilemma arising from a treatment decision disagreement?

Computation of Nurse Activism Scores. A *Nurse Activism* Score was calculated for each respondent by summing the Likert-responses to the ten items. Scores could range from 10 (*not at all likely*) to 50 (*extremely likely*). The mean *Nurse Activism* score for the 224 respondents was 27.8 (SD 4.4, range 10-40), as shown in Table 5.

Table 5

| <i>Nurse Activism Score for Full Sample (n =224)</i> | | | | |
|--|------|-----|-------|----------------|
| Variable | Mean | SD | Range | Possible Score |
| Nurse Activism | 27.8 | 4.7 | 10-40 | 10-50 |

Reliability Statistics for Nurse Activism Variable. Internal consistency reliability coefficients using Cronbach's Alpha were computed for the *Nurse Activism* subscale. The Cronbach's Alpha for the 10 item scale was .80. This reliability coefficient was consistent with previous reliability testing of .83 (Penticuff & Walden, 2000).

Analysis of Predictor Variables

To determine whether *Nurse Activism* scores varied with *Certification or Ethics Education*, independent *t* tests were computed on the *Nurse Activism* scores for the two levels of each of these variables. No significant differences were found in the *Nurse Activism* scores of respondents with or without ethics education and with or without certification. To determine whether *Nurse Activism* scores varied with highest level of education achieved, a one-way analysis of variance with post hoc analysis was computed on the *Nurse Activism* scores for the three levels of this variable. No significant differences were found in the *Nurse Activism* scores of respondents with an RN only, a BS or a MS/higher degree. Thus, these variables were not entered into the regression analysis.

The descriptive statistics for the remaining six NEIS variables hypothesized to influence *Nurse Activism* are presented in Table 6. The first four variables listed in the table are NICU nurse characteristics. The last two variables listed in the table are organizational characteristics. A *Concern for Ethics* score was identified by asking the respondents to consider one Likert-type item. Scores could range from 1 (*a very small extent*) to 5 (*a very large extent*). The mean *Concern for Ethics* score was 3.9 (SD 0.9, range 1-5). A *Frequency of Ethical Dilemma* score was identified by asking the respondents to consider one Likert-type item with scores ranging from 1 (*annually*) to 5 (*monthly*). The mean *Frequency of Ethical Dilemma* Score was 2.1 (SD 1.0, range 1-5) as shown. The *Years of NICU Experience* score asked respondents to enter the

actual years worked in a NICU. The mean *Years of NICU Nursing Experience* score was 17.9 (SD 9.8, range 2-38). The *Knowledge of Ethics Resources* score was calculated for each respondent by summing items selected as known. The mean *Knowledge of Ethics Resources* score was 3.2 (SD 1.6, range 0-5). A *Nursing Influence* score was calculated from each respondent by summing 14 Likert-type items. The mean *Nursing Influence* score was 46.3 (SD 8.7, range 2-63). A *Unit Characteristics* score was calculated from each respondent by summing 9 Likert-type items. The mean *Unit Characteristics* score was 33.7 (SD 5.7, range 16-45).

Table 6

Means, Standard Deviations (SD), Score Ranges for Predictor Variables

| Variable | Mean | SD | Range | Possible Scores |
|---------------------------------------|------|-----|-------|-----------------|
| NICU RN Characteristics | | | | |
| Concern for Ethical Issues | 3.9 | 0.9 | 1-5 | 1-5 |
| Frequency of Ethical Dilemma | 2.1 | 1.0 | 1-5 | 1-5 |
| Years of NICU Experience | 17.9 | 9.8 | 2-38 | |
| Knowledge of Ethics Resources | 3.2 | 1.6 | 0-5 | 0-5 |
| Organizational Characteristics | | | | |
| Nursing Influence | 46.3 | 8.7 | 2-63 | 14-70 |
| Unit Characteristics | 33.7 | 5.7 | 16-45 | 9-45 |

NICU nurse characteristics included the variables *Concern for Ethics*, *Frequency of Ethical Dilemmas*, and *Years of NICU Nursing Experience*. Nurses who reported a strong concern for ethical dilemmas ($M = 3.9$, $SD = 0.9$, $n = 224$), were involved in approximately two ethical dilemmas per year ($M = 2.1$, $SD = 0.1$, $n = 204$), and had an average of 18 years of NICU nursing experience ($M = 17.9$, $SD = 9.8$, $n = 185$). Although the nurses were not completely knowledgeable about their organization's ethics resources ($M = 3.2$, $SD = 1.6$, $n = 224$) and reported a moderate unit characteristic of administrative support for their involvement in ethical

decision-making ($M = 33.7$, $SD = 5.7$, $n=208$), they perceive themselves to possess higher influence related to treatment decisions ($M = 46.3$, $SD = 8.7$, $n = 213$).

Reliability Statistics for Predictor Variables. Internal consistency reliability coefficients using Cronbach's Alpha were computed for the subscales *Nursing Influence* and *Unit Characteristics*. The Cronbach's Alpha for the 14-item *Nursing Influence* subscale was .83 and the 9-item *Unit Characteristics* subscale was .88. The subscale reliabilities were consistent with previous reliability testing of .88 and .82 respectively (Penticuff & Walden, 2000).

Correlation. In order to determine if there was a relationship between *Nurse Activism* and the predictor variables, bivariate correlations were computed. Table 7 contains the outcome variable *Nurse Activism* correlated with the continuous variables *Concern for Ethics*, *Frequency of Ethical Dilemmas*, *Years of NICU Nursing Experience*, *Knowledge of Hospital Policies*, *Nursing Influence*, and *Unit Characteristics*. The variables *Concern for Ethics* ($r = .243$) and *Nursing Influence* ($r = .221$) demonstrated small correlations with the outcome variable *Nurse Activism*.

Table 7
Bivariate Correlations

| Variables | | Nurse Activism | Concern for Ethics | Dilemma Frequency | Years of NICU RN Experience | Knowledge of Hospital Policies | Nursing Influence | Unit Characte- ristics |
|---------------------------------|------------------------|-------------------|--------------------------|----------------------|-----------------------------------|--------------------------------------|----------------------|---------------------------|
| Nurse Activism | Pearson Correlation | 1 | | | | | | |
| | Sig. (2- tailed) | | | | | | | |
| | N | 224 | | | | | | |
| Concern for Ethics | Pearson Correlation | .243** | 1 | | | | | |
| | Sig. (2- tailed) | .000 | | | | | | |
| | N | 222 | | | | | | |
| Dilemma Frequency | Pearson Correlation | .053 | .106 | 1 | | | | |
| | Sig. (2- tailed) | .450 | .130 | | | | | |
| | N | 207 | 205 | | | | | |
| Years of NICU RN Experience | Pearson Correlation | .042 | .001 | .121 | 1 | | | |
| | Sig. (2- tailed) | .573 | .994 | .106 | | | | |
| | N | 185 | 185 | 185 | | | | |
| Knowledge of Hospital Policy | Pearson Correlation | .045 | .049 | .166* | .150* | 1 | | |
| | Sig. (2- tailed) | .500 | .515 | .026 | .045 | | | |
| | N | 224 | 222 | | | | | |
| Nursing Influence | Pearson Correlation | .221** | .201** | -.119 | .042 | .026 | 1 | |
| | Sig. (2- tailed) | .001 | .003 | .111 | .566 | .707 | | |
| | N | 215 | 213 | | 185 | 215 | | |
| Unit Characteristics | Pearson Correlation | .105 | .126 | -.119 | -.169* | -.33 | .533** | 1 |
| | Sig. (2- tailed) | .128 | .070 | .111 | .024 | .661 | .000 | |
| | N | 224 | 208 | 207 | 185 | 210 | 210 | |

** . Correlation is significant at the 0.01 level (2-tailed).

Regression. Regression analysis was computed with the outcome variable *Nurse Activism* and predictor variables to answer research question two. Multiple regression allows the researcher to determine whether significant predictor variables retain significance in the presence of other variables. A combination of stepwise and hierarchical regression analyses were utilized as suggested in Munro (2005). In a stepwise analysis, the independent variable(s) that demonstrates the highest correlation with the dependent variable is entered first, followed by the other variables. Hierarchical analysis requires a theoretical rationale for the order in which variables are entered. The results of the stepwise and the multiple regression analysis are presented in Table 8. The variables *Concern for Ethics* and *Nursing Influence* were entered into the regression analysis utilizing the stepwise technique. Bivariate analysis (Table 7) revealed that the variable *Concern for Ethics* ($r = .243, p = .000$) had the highest correlation with the outcome variable *Nurse Activism* and was therefore entered into the regression analysis first. The variable *Nursing Influence* ($r = .211, p = .001$) was found to have the next highest correlation with *Nurse Activism* and was entered second. Correlations for the remaining variables were not found to be statistically significant. Therefore, the variables were entered into the regression utilizing the hierarchical technique. The variables *Years of NICU experience* and *Frequency of Ethical Dilemmas* measured the nurses' ethical sensitivity and were entered into block three. *Knowledge of Hospital Policies* measured the nurses' ethical motivation and was entered into block four. The variables *Unit Characteristics* measured the nurses' perception of administrative support for their involvement in ethical decision-making and were entered into block 5. *Concern for Ethics* ($p = .001$) and *Nursing Influence* ($p = .018$) accounted for 8.5 percent of the variance. Collinearity diagnostics were computed and multicollinearity was not present.

Table 8

Results of Hierarchical Regression for Nurse Activism

| Variables | B | SE | Beta | p |
|--------------------------------|-------|------|-------|-------|
| Concern for Ethics | 1.494 | .449 | .241 | .001* |
| Nursing Influence | .129 | .054 | .172 | .018* |
| Years of NICU Experience | .262 | .377 | .051 | .171 |
| Frequency of Ethical Dilemmas | .024 | .295 | .006 | .488 |
| Knowledge of Hospital Policies | .129 | .054 | .172 | .935 |
| Unit Characteristics | -.004 | .084 | -.004 | .965 |

The hypothesis tested in this study asserted that nurse characteristics including more years of NICU experience, greater frequency of ethical dilemmas, greater concern for ethical aspects of practice, higher formal education, more ethics specific education, greater knowledge of ethics resources, and certification predict *Nurse Activism*. The organizational characteristics including the NICU nurses' perception of increased influence in their unit and unit characteristics that foster greater participation with administrative support to resolve ethical dilemmas predicted *Nurse Activism*. The variables *Concern for Ethics* and *Nursing Influence* remained significant when entered together and with other predictor variables. Those reporting a greater Concern for Ethics were more likely to take action to resolve an ethical dilemma. NICU nurses who perceived themselves to have greater influence related to ethical decision-making were more likely to take action to resolve an ethical dilemma. Therefore, the hypothesis was partially supported with the variables *Concern for Ethics* and *Nursing Influence*.

Summary

This chapter provided the statistical analysis and outcomes of the study. The results indicate that NICU nurses working in Massachusetts hospitals are concerned about ethical dilemmas encountered in their practice. The results also indicated that the majority of nurses talk with their peers, then with physician colleagues when confronted with an ethical dilemma. Nurses who feel they have higher influence in treatment decision-making report they would be more likely to take a range of actions to resolve an ethical dilemma. The following chapter provides the reader with a detailed discussion regarding the outcomes of this study along with implications for nursing practice, education, and research.

Chapter 5

Discussion

This chapter discusses the study findings and is structured according to the theoretical framework presented in Chapter 2. Study limitations are described and the implications of findings for future research endeavors, education, and practice are reviewed.

The purpose of this study was to explore which factors predict NICU nurses' enactment of their professional responsibility to address ethical dilemmas in their practice setting. A description of the types of ethical dilemmas NICU nurses encounter as discovered through the review of the literature (Chapter 2), and supported in this study, are consistent regardless of the location of the NICU (locally, nationally, internationally). The nurses' inability to fulfill their professional responsibilities has been demonstrated to result in harm for both patients and nurses. Rest's (1982, 1983) conceptual framework for moral action was used in concert with the idea that nurses have professional obligations to provide good care and participate in activities to resolve situations in which obstacles to optimal patient care exist. Rest's (1982) analysis of prior studies proposed the four processes underlying ethical action as being moral sensitivity, moral judgment, moral motivation, and moral action. For the purposes of this research study, it is necessary to take into account that nurses have preset goals related to professional practice. Therefore, the term 'ethical' was substituted for 'moral' to remain consistent with the ANA (2001) *Code of Ethics for Nurses with Interpretive Statements* .

This investigation explored NICU nurse and organizational characteristics as well as perceptions of nursing influence that affected the likely ethical actions of a cohort of 224 nurses working in NICUs in Massachusetts. There were nine independent variables and one outcome

variable. Seven variables were designed to measure three of Rest's (1982) components of moral action: *ethical sensitivity*, *ethical judgment*, and *ethical motivation*. Two variables were designed to measure perceptions of nursing influence and organizational characteristics related to participation in ethical decision-making. The outcome variable measured the range of likely actions nurses would likely take in response to a presented case pertaining to a treatment decision disagreement for a chronically acutely ill infant, now seven months old. Study findings provided some support for the relationships that were hypothesized with respect to ethical sensitivity and perceptions of nursing influence, but failed to provide support for hypothesized relationships regarding ethical judgment, ethical motivation, and perception of organizational characteristics. As noted in the literature review in Chapter 2, moral reasoning, and specifically Rest's (1982) conceptualization of the cognitive processes leading to ethical action, is an integrated process comprised of four postulated components. If any component is missing, then ethical action does not occur. However, for current purposes and for ease of understanding, the components as measured in this study are discussed individually. A discussion of the specific findings for each component of ethical action as well as nursing influence and organizational characteristics follows.

NICU Nurse Characteristics

Ethical Sensitivity. Variables measuring *ethical sensitivity* included the nurses' reported *Concern for Ethics*, utilizing Penticuff and Martin's (1987) scale that quantified the extent of the nurses' concern for the ethical issues encountered in clinical practice, *Frequency of Ethical Dilemmas and Years of NICU Nursing Experience*. The current study supported the findings of previous studies, specifically, that the extent of the nurses' *Concern for Ethics* is a predictor of *Nurse Activism*. This finding is consistent with prior research that specifically measured NICU

nurses' concern for the ethical aspects of their practice (Monterosso et al., 2005; Penticuff, 1989; Penticuff & Walden, 2000; Raines, 1993; Zuuren & Manen, 2006). In contrast to previously published studies (Janiever, et al., 2007; Zuuren & Manen, 2006; Wilkinson, 1988), years of NICU nursing practice and frequency of ethical dilemmas (Gutierrez, 2005) did not predict NICU nurse activism. The small sample size (Gutierrez, 2005; Wilkinson, 1988) and the inclusion varying roles of health team members in the sample (Zuuren & Manen, 2006) may explain the differing results.

Ethical Judgment. Highest level of education was the single measure of *ethical judgment* used in this study. The findings of this current study did not support highest level of education as a predictor of *Nurse Activism*. This is consistent with the findings of Penticuff and Walden (2000). However, other previous research has demonstrated support for a positive relationship between highest level of education and nurses' ethical judgment. Significant differences in formal education were found to impact nurses' ethical reasoning ability (Casterlé, et al., 2008; Crisham, 1981; Giro, 2000; Ketefian, 1981) with advanced practice nurses reasoning at higher levels of moral development as described by Kohlberg (1983) followed by baccalaureate degree nurses, and then associate degree and diploma nurses. Perhaps including a measurement of the nurses' ethical reasoning ability that incorporates Kohlberg's stages of moral reasoning (Kohlberg, 1983), and the type of degree held may yield a deeper understanding of factors that reflect ethical judgment in NICU nurses.

Ethical Motivation. The variables measuring the NICU nurses' *ethical motivation* included *Knowledge of Institutional Ethics Resources, Attendance at Formal or Informal Ethics or Legal Courses, and Neonatal Specialty Certification*. The variables *Knowledge of Institutional Ethics Resources* and *Attendance at Formal or Informal Ethics or Legal Courses* were not found

to be associated with *Nurse Activism*, which is inconsistent with previous research. Dodd et al. (2004) reported ethics education, as well as knowledge of institutional ethics resources as significant predictors of nurse activism. The sample from this study was recruited from three hospitals. Thus, the numbers of responders from each study site were possibly higher, leading to a more representative sample from three institutions. In the current study, maintenance of anonymity and the use of a purposive sample from the seven participating hospitals limited the researcher's ability to ensure that the responders were representative of the practice at each institution. This factor may have influenced the findings of this study. Although previous research supported an association between specialty certification and perceptions of formal and informal power leading to nurse activism, (Cary, 2001; Foley et al., 2002; Manojilovich, 2005; Piazza et al., 2006) no association was found in this study.

Ethical Action. The NICU nurse's concern for the ethical aspects of the presented case predicted *Nurse Activism* and this finding is consistent with previous research (Penticuff & Walden, 2000; Peter, Lunardi & Macfarlane, 2002; Raines, 1993; Varcoe et al., 2004). The range of actions NICU nurses reported as likely to engage in when presented with the hypothetical case have been reported in previous studies. The responses included feeling concerned but taking no action (Wilkinson, 1988), and talking with peers, physicians, nurse managers, and family (Casterlé et al., 2008; Elizondo, 1991; Hefferman & Heilig, 1999; Martin, 1989; Penticuff & Walden, 2000; Varcoe et al., 2004). The finding that 43% of NICU nurses in this study reported they were likely to be concerned but take no action is disquieting. One responder indicated that her relationship with the infant would determine the range of likely actions taken to resolve the dilemma. The nurse explained that if she was not on the primary care team, she may not feel a commitment to the patient and thus take no action. Wilkinson (1988) reported similar findings

with a small sample of NICU nurses. Although Wilkinson's research was conducted over two decades ago, the finding in this current study indicates that NICU nurses continue to remain silent regarding treatment decision disagreements and this silence may lead to ethical dilemmas.

Organizational Characteristics. Ethical action in the NICU results from the integrated processes of sensitivity, judgment, and motivation of an individual nurse. These processes are derived from an understanding of nursing goals and can be affected by the practice environment. Organizational characteristics were measured with the variables *Nursing Influence* and *Unit Characteristics*. An association was found in this study between the nurses' perception of influence in patient care situations and *Nurse Activism*, and this finding is consistent with previous research (Hamric & Blackhall, 2007; Penticuff & Walden, 2000; Spence, 1998; Varcoe et al., 2004). Nurses who reported higher perceived levels of influence in decisions related to the care of an infant assigned to them were more likely to take action to resolve an ethical dilemma.

No association was found between the variable *Unit Characteristics* and *Nurse Activism*. One possible explanation is related to the nurses' perception of a lack of resources to address ethical issues in practice. This finding is in contrast to previous results as nurse activism has been correlated with nurses' perceptions of the receptiveness of their unit leadership to inclusion in ethics deliberations (Dodd et al., 2004; Gutierrez, 2005) and the manner in which difficult patient care situations with ethical implications are managed (Hart, 2005; Olson, 1998).

The variables, *Concern for Ethics* and *Nursing Influence*, explained only 8.5 % of the variance in the regression analysis. The small amount of variance that was identified in this study resulted from the selection of variables that did not accurately measure the theoretical concepts. The NEIS was previously administered to both leadership and staff nurses in one hospital. In the current study, the NEIS was administered only to staff nurses in seven hospitals. Although the

survey included unit based questions, nurses were not asked to indicate if their hospital had achieved designation as a Magnet hospital or have a practice model that includes a shared or collaborative governance structure to involve staff in decision-making. This is an important variable because the type of professional practice environment in which the nurses work may be a predictor of nurse activism (Shirley, M.R., 2005a, 2005b).

Other possible variables that may explain *nurse activism* that were not measured in this study include unit mechanisms to resolve conflict with all members of the health care team and a measure of the nurses' knowledge of the differing obligations to the patient, other members of the health care team, and the hospital in which they are employed. The number of competing obligations nurses must consider when providing care has been shown to have an impact on ethical action (Dodd et al., 2004; Varcoe et al., 2004).

The variables measuring *ethical motivation*, including *Knowledge of Organizational Ethics Resources*, *Ethics* and/ or *Legal Education*, and *Specialty Certification* did not reflect the nurses' motivation to resolve the ethical dilemma. Future research that includes a variable measuring nursing influence may contribute to understanding the motivation necessary to resolve an ethical dilemma. Varcoe et al. (2004, p.321) reported nurses "acting (ethically) when they could". Dodd et al. (2004) reported that nurses are more inclined to participate in specific patient-level ethical resolutions rather than advocating for hospital-wide changes that would include nurses in ethical decision-making. A qualitative inquiry exploring NICU nurses' motivations, including the items listed above, may identify factors that lead to resolution of ethical dilemmas. The focus group method of inquiry may yield a rich discussion regarding the issues that impact the nurses' motivation to take action to resolve an ethical dilemma.

Relevance of Findings to NICU Nurses Working in Massachusetts Hospitals

A strength of this study is its exclusive focus on NICU staff nurses. The robust response rate of 35.4 % and the achievement of an adequate sample size in 3 weeks indicated NICU nurses' interest in the topic. Few studies measured the experience of staff nurses in the NICU who are required to remain with their patient and provide care for a shift lasting eight to twelve hours and thus, have to live with the consequences of decisions that have been made, often by others. An understanding of the NICU staff nurses' perspective and experience is critical for the development of programs that provide appropriate education and support. Supportive practice environments that encourage the identification and discussion of ethically challenging cases, in concert with the development of appropriate knowledge and skills, are important for ensuring optimal care for these extremely vulnerable infants. The findings of this study support previous research indicating that the NICU nurses' concern for the ethical aspects of a situation, as well as their perception of influence in patient care situations, predict *Nurse Activism* (Penticuff & Walden, 2000).

The current study was not able to identify the NICU nurse characteristics that aid in the practice of ethical decision-making and subsequent action. In view of prior research (Penticuff & Martin, 2000), further exploration is needed to identify factors that facilitate and/or hinder ethical action. Research investigating nursing judgment in ethically challenging situations identified the reasoning process related to educational preparation (Crisham, 1980; Davis, 1981; Girot, 2000; Ketefian, 1981). Specialty certifications have been linked to professional practice behaviors (Manojilovich, 2005; Piazza et al., 2006); however, few studies collectively explored the achievement of specialty certification in a practice setting and the subsequent effect on ethical judgment and motivation (Dodd et al., 2004; Penticuff & Walden, 2000).

Limitations

There were a number of limitations to this study. First, the study design was cross-sectional. Hence, the study identified the relationship between variables at one point in time but did not follow the participants over time to observe any differences. Moreover, the study explored the relationship between variables but did not determine causation. Nevertheless, the proposed theoretical model and relationships among variables were supported by previous research.

Second, the study data were obtained by self-report of likely and/or unlikely actions to a hypothetical dilemma. Nurses may have over-reported the actions they would have taken if engaged in an actual ethical dilemma. Hence, the data may be influenced by the hypothetical nature of the case.

The use of a purposive and non-random sample is the third limitation to this investigation. In order to maintain anonymity, it was not possible to randomize staff nurses from each institution. Therefore, the sample may reflect a higher percentage of NICU nurses with an interest in ethics rather than a unique population. It was also not possible to ensure that a representative sample of NICU nurses at each of the institutions participated in the study. The researcher is a nurse administrator in one of the participating hospitals. Although the study was anonymous, with no method to trace participants' responses, this relationship may have impacted the nurses' decision to participate as well as the survey responses. These factors limit the generalizability of the study.

The validity of the NEIS is the fourth limitation of this study. Psychometric adequacy has been established with a national sample of NICU nurses but the instrument has not been validated through the correlation of response scores with reported behaviors nurses employed

with an actual case in the clinical setting. Future research is necessary to correlate the NICU nurses' actual responses with the hypothetical responses.

The length of this online survey may be the fifth limitation of this study. The NEIS was developed and tested for psychometric adequacy as a paper and pencil instrument. It is unknown how well the NEIS survey works in an electronic format. The 43 questions may have affected the number of missing answers to questions and the response rate and thus, influenced the findings.

The use of education level as the single measure of ethical judgment is the sixth limitation of this study. The decision to narrowly define education into three categories (RN only, bachelors, and masters or doctoral degree) limited the participants' description of their educational preparation. Other measures of ethical reasoning, including a measurement of the nurses' reasoning perspective, may have strengthened the findings.

The final limitation involves three items in the *Nurse Activism* subscale. Respondents in this study reported that they were not likely to take three of the possible actions items listed in the scale. The items included the likely option of contacting hospital officials outside their hospital of employment, contacting legal officials outside their hospital of employment, and/or contacting the media regarding the presented case. These three items reflect the social-political climate regarding the treatment of infants with uncertain prognosis in NICUs during the time period of NEIS tool development (1984-1988). During this time period, nurses and other health care providers were directed to report to the government cases in which medical treatment was withheld from infants due to a medical or genetic condition. Although the number of regulations regarding the care of infants in NICUs has increased, currently, health care providers and families are encouraged to work through ethics committees to resolve their differences of opinion and involve the courts as a last resort if the issues cannot be resolved. The findings of

this study indicate the need to revise the subscale items to reflect options NICU nurses may employ in the current socio-political environment.

Implications for Future Research.

The results from this cross-sectional study provides some support for the hypothesis that more years of NICU experience, greater frequency of ethical conflicts, greater concern for ethics, higher formal education, more ethics-specific education, greater knowledge of ethics resources, certification, perception of increased influence in their unit, and greater participation with administrative support to resolve ethical issues predicts nurse activism. Most importantly, the study results provide further support for previous research findings regarding the NICU nurses' ethical sensitivity, specifically their concern for the ethical aspects of practice as a predictor of nurse activism. Moreover, the nurses' perception of their influence in their NICU also predicts nurse activism. However, the study results suggest the need to modify the tool to better capture the NICU nurses' ethical judgment, motivations, and effects of the practice environment on ethical actions.

The findings from this study identify at least six other important implications for future research. First, a representative sample of NICU nurses from each hospital with demographic variables is needed to increase the generalizability of study finding and to evaluate the study variables among geographically diverse hospitals. It is possible that nurse participants in this investigation have an increased focus on ethical situations they encounter and participated as a direct result of their involvement. Alternative recruitment methods should be utilized in future investigations in order to ensure the participation of a representative sample of NICU nurses from each hospital.

Second, further evaluation of nurse activism, such as using different patient care situations, could be used to highlight the nuances inherent in NICU nurse activism. The hypothetical patient care situation presented was just one of many possible ethically challenging patient care situations that could occur in the NICU. Future studies using a modified version of the NEIS are needed to evaluate the *ethical sensitivity*, *ethical judgment*, and *ethical motivation* that may result in activism among NICU nurses. The items in the *Nurse Activism* subscale require review and possible revision to reflect actions considered in the current health care environment.

Third, study findings support the need for further investigation of ethical judgment and nurse activism measures. Based on previous research findings, the highest level of education achieved has been used as a measure of judgment in ethical decision-making. This variable may not capture the actual reasoning process of NICU nurses in ethically challenging situations. Future investigations are needed to capture the NICU nurses' reasoning process in patient care situations.

Fourth, the findings indicate a need for continued research on the measurement of ethical motivation. The measures of ethical motivation in this study (*Knowledge of Ethics Resources*, *Ethics and/or Legal Education*, and *Specialty Certification*) did not predict *nurse activism*. Qualitative studies investigating NICU nurses' understanding of ethical motivation as it relates to nursing practice may be key to developing specific measures of *ethical motivation*.

Fifth, study findings support the need for continued ethics research on the measurement of the practice environment. Methods such as obtaining both nursing administrators' and staff nurses' perception of support for involvement in ethical decision-making may yield a more

comprehensive understanding of factors supporting or hindering NICU nurse involvement in ethical decision-making.

Six, the psychometric adequacy of the NEIS has been determined using a hypothetical patient case. Future research that investigates the experience of NICU nurses encountering an ethical dilemma when actually caring for a patient is needed to assess the psychometric adequacy of the NEIS.

Implications for Nursing Education

The findings of this study related to the NICU nurses' concern for ethics and their perception of influence in treatment decision-making have implications for the education of nurses in colleges and universities as well as academic medical centers and community hospitals that have NICUs. Ethics education is included in the curriculum of undergraduate and graduate nursing programs (Roush, 2000). Ethics education in nursing remains fragmented; some nursing programs have independent ethics courses with minimal integration of the content in the clinical setting and some try to integrate ethics throughout the curriculum with varying degrees of success (Roush, 2000). A combination of both approaches would benefit students throughout their educational experience and provide them with a basis for practice in the health care environment (Milton, 2004).

Ethical practice requires continued discussion and reflection as well as knowledge of ethical principles and theory (Crisham, 1981; Grace, 2009; Ketefian, 1981). Advanced practice nurses (APN) are in an ideal position to facilitate ongoing dialogue regarding the ethical aspects of practice. Although many hospitals have established ethics committees that provide consultation regarding a specific ethical dilemma, only a small number of hospitals have established multidisciplinary ethics meetings to review cases routinely. The goal of the ethics

meetings is to dialogue and gain appreciation for the ethical focus of different disciplines related to current patient care situation that pose ethical challenges for providers. Participation by the APN is critical to facilitate these discussions and to identify opportunities to increase nurses' understanding of their ethical responsibility in patient care situations as well as educate other members of the health care team regarding the ethical focus of nursing practice (Casterlé et al., 2008; Dodd et al., 2004; Janvier et al., 2007).

Implications for Clinical Practice

The current study provides further support for the findings of previous studies related to factors that predict the ethical actions of NICU nurses. Despite the study limitations discussed earlier, there were practice implications associated with concern for ethics, the perception of nursing influence, and the specific likely and unlikely actions NICU nurses reportedly would take in response to the presented case. Olson (1998) and Hart (2005) found that nurses' turnover intentions were related to the manner in which difficult patient care situations with ethical implications were managed. Hamric and Blackhall (2007) reported that nurses practicing in units with less physician collaboration experienced increased moral distress and held a negative perception of their practice environment. Thus, a NICU with nursing leaders that facilitate multidisciplinary dialogue regarding difficult patient care situations with ethical implications may increase collaboration, improve the nurses' perception of their practice environment and lead to a positive experience for infants and their families.

Ethical Sensitivity. Although NICU nurse responders reported experiencing at most two ethical dilemmas per year, they were concerned to a large extent about the ethical aspects of practice. In light of other work in ethics that argues for an understanding of practice issues as not necessarily dilemmas but rather everyday problems of not being able to provide the care that

judgment requires (Chamblis, 1996; Grace, 2009), this study provides further support for the need for nurses to have avenues for discussion. One strategy to facilitate this is routine ethics meetings where nurses can safely discuss with their peers and/or other disciplines the ethical issues they encounter in the delivery of patient care. In this setting, nurses will hear how other nurses approach ethical issues and become more familiar with the ethical resources available in their organization.

Nursing Influence. NICU nurses reported the perception of high influence related to treatment decisions in their NICU but they perceived an inadequate amount of administrative support for their participation in ethical decision-making. Although the variance for this variable was not overwhelming in magnitude, it provides support for insights from previous studies. This finding provides a basis to initiate a discussion between NICU nursing staff and unit leadership to explore ways in which both groups can work together to meet professional and institutional goals for good patient care by increasing nurse influence on ethical decision-making.

Nurse Activism. The majority of nurses (98%) reported they were somewhat to extremely likely to speak with their peers, followed by their physician colleagues (95%), regarding the presented case. However, only 82% were somewhat to extremely likely to request a team meeting or an ethics meeting (71%). This suggests that informal ethics discussions regarding patient care occur between NICU nurses and physicians, but formal ethics discussions with the health care team occur less often. Nurse Managers (78%) are somewhat to extremely likely to be contacted by NICU nurses and it is unclear if the consult occurs prior to requesting a team and/or an ethics meeting. Based on this assessment, NICU nursing leadership can develop a process to review with NICU nurses the presence of any ethically challenging patient care situations. Once the ethically challenging case is identified, the nurse administrator can identify

institutional resources necessary to support the NICU staff nurses involved in the case.

Moreover, the manager, director, or designated nurse leader can participate in the team and/or ethics discussion to support the involved NICU nurses.

Conclusion

This chapter provided a discussion of the statistical findings and limitations of the study, as well as potential implications for nursing research, education, and practice. The statistical analysis revealed a small amount of variance (8.5%) for the variables Concern for Ethics and Nursing Influence to explain the interactive process that leads to ethical action. The limitations of the study included the use of a hypothetical rather than an actual case, a single measure of ethical judgment, and a purposive sample. The implications for nursing research include further refinement of the variables that measure ethical judgment and motivation as well as nursing influence. Educational strategies were suggested for both academic medical centers with NICUs as well as colleges and universities. And finally, suggestions to improve the experience of direct care NICU nurses were provided.

Resolution of ethical dilemmas in clinical practice reduces 'burn out', contributes to an engaged workforce, and fosters healthy work environments as evidenced in the literature. NICU nursing leaders are obligated to create conditions that enable NICU nurses to reflect on their practice and consider aspects of their practice that require improvement in order to provide good care to infants in the NICU. Future research is necessary to identify the factors that contribute to ethical reflection and activities that result in environments in which nurses feel confident in their actions regarding the ethical care delivered to infants in the NICU.

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Appendix A

Theoretical and Operational Definitions of Predictor & Outcome Variables

Predictors of NICU Nurses’ Response to Treatment Decision Disagreements for Infants with Uncertain Prognosis

Research Questions:

1. What are the likely actions a NICU nurse would employ to resolve a hypothetical ethical dilemma?

2. What factors predict NICU nurse actions when challenged with at hypothetical ethical dilemma arising from a treatment decision disagreement?

Hypothesis:

More years of NICU experience, greater frequency of ethical conflicts, greater concern for ethics, higher formal education, more ethics specific education, greater knowledge of ethics resources, certification, perception of increased influence in their unit and greater participation administrative support to resolve ethical issues predicts nurse activism.

| Independent Variable | Theoretical Definition | Operational Definition | Survey Item # |
|---|---|---|---------------|
| NICU Nurse Characteristics | Ethical Sensitivity | Ethical Sensitivity | |
| Concern for Ethics (measured by Penticuff & Martin, 1987) | Sensitivity to the effects of nursing actions on infant well being. | 1-item 5 point Likert scale regarding nurses concern about ethical issues in clinical practice. Item score of 1 indicates respondent is concerned to a very small extent to 5 indicating concern to a very large extent. The possible score range is 1 (concerned to at very small extent) to 5 (concerned to a very large extent). | 1 |
| Frequency of ethical Conflict | Self reported rate of recurrence of ethical conflict in NICU. | 1-item 5 point Likert scale regarding frequency of ethical conflict. Item score of 1 indicates respondent experiences ethical conflict annually to 5 indicating a monthly experience of ethical conflict. The possible score range is 1 to 5. | 37 |
| Professional NICU Nursing Experience | Length of time in years working as a registered nurse. | Years of NICU nursing experience represented in whole numbers. | 41 |

| Independent Variable NICU Nurse Characteristics | Theoretical Definition Ethical Judgment | Operational Definition Ethical Judgment | Survey item # |
|---|---|---|---------------|
| Education | Formal Scholarly preparation within and outside the discipline of nursing. | Highest Education Level Achieved 1. Registered Nurse (0=no, 1= yes) 2. Bachelor Degree (0=no, 1= yes) 3. Masters Degree and PhD (0=no, 1= yes) | 3 |
| NICU Nurse Characteristics | Ethical Motivation | Ethical Motivation | |
| Knowledge of Organizational Ethics Resources | RN is knowledgeable regarding organizations policies and resources related to ethical nursing practice. | Written hospital policies providing direction about clinical situations: 1. Informed consent (0=ncertain,1=yes,) 2. Termination of life support (0=uncertain,1=yes,) 3. Do not resuscitate orders (0=uncertainno,1=yes,) 4. Limitation of Treatment (0= uncertainno,1=yes,) 5. Hospital Ethics Committee (0=uncertain 1=yes,) | 39 |
| 4-1Ethics Specific Education | Informal academic programs of ethical study | NICU RN has attended continuing education, in-services and/or workshop in the past 3 years where the major topic was: Yes/No Legal Issues in nursing Yes/ No Ethical Issues in nursing | 38 |
| Certification | Desire to achieve specific knowledge and skill to care for the infant requiring nursing care in the NICU and placing nursing goals above other goals. | Program of study concluding with neonatal specific certification of content area whereby certification is the formal method for recognizing and validating specific clinical expertise. The presence of any of the three listed certifications will indicate a yes for this item. NCC in NICU nursing (0=no, 1=yes) NIDCAP (0=no, 1 = yes) Lactation Counselor (0=no, 1=yes) | 2 |

| Independent Variable Organizational Characteristics | Theoretical Definitions | Operational Definition | Survey item # |
|---|--|--|----------------------|
| Nursing Influence Measured by Penticuff's NEIS,2000 (Reliability of .88) | NICU RN's perception of ability to influence treatment decisions in unit. | 14- item, 5 point Likert scale regarding nursing input related to ethical decision-making for infant in NICU. Item score of 1 indicates a respondent strongly disagrees to 5 indicating a respondent strongly agrees. The possible range is 14 (low influence) to 70 (high influence). | 4-13 |
| Unit Characteristics Measured by Penticuff's NEIS,2000 (Reliability of .82) | NICU RNs perceptions of whether it is usual for nurses to be involved in ethical decision-making and administrative support for their involvement. | 9-item, 5 point Likert scale regarding respondent's perception of unit characteristics related to delivery of patient care related to ethical decision-making. Item score of 1 indicates a respondent strongly disagrees to 5 indicating respondent strongly agrees with statement. The possible score range is 9 (strongly disagrees) to 45 (strongly agrees). | 14-27 |
| Outcome Variable | Theoretical Definitions | Operational Definitions | |
| Nurse Activism Measured by Penticuff's NEIS, 2000 (Reliability of .83) | NICU RNs' range of actions employed to resolve an ethical dilemma. | 10-item, 5 point Likert scale of possible responses a NICU nurse would utilize to resolve a treatment decision disagreement for an infant with an uncertain prognosis. Item score of 1 indicates a respondent is not at all likely to 5 indicating respondent is extremely likely to take action. The possible score range is 10 (low response) to 50 (high response). | 28-37 |

Appendix B

NEIS Survey Tool

Page 1 of 2

Settle, Margaret D., R.N.

From: Joy Percicuff [REDACTED]
Sent: Monday, January 12, 2009 3:59 PM
To: Settle, Margaret D., R.N.
Subject: RE: NEIS Survey Tool

Hello Peggy,

Congratulations on your academic progress! I am very pleased to give you permission to use the NEIS tool and I wish you all the best as you move forward with your proposal.

I have retired from the University of Texas at Austin School of Nursing (after 33 years!) and am now building a new BSN program at Concordia University Texas, a private Lutheran liberal arts university in Austin. I'm emerita at UT, so my email there will continue to be active and you can also email me at Concordia. All my current contact information is in the signature line below.

I know we have talked about my possibly visiting your area to talk about my research, but to tell you the truth, I am swamped these days with tight deadlines to get the nursing program proposal written and submitted by June 1st to the Texas Board of Nursing. I have gotten so involved with the Concordia project that I haven't done anything with my research for a while and I may need to forgo our plans for me to do a research presentation. I think you and I are doing similar things, because you're writing your proposal—something you bring a lot of knowledge to, but still quite different from anything you've done before—and I'm developing this nursing program. So I think we need to put my visit on indefinite hold, if that's OK with you. And the research findings are in the JPNN if people want to know about the study. If you don't have the article and want it, I can send you the pdf.

It's so good to hear from you. I hope we can stay in touch.

Every good wish,
 Joy

Joy Hinson Percicuff, AN, PhD, FAAN
 Professor
 Director, Nursing Program Development
 Concordia University Texas
 [REDACTED]

From: Settle, Margaret D., R.N. [REDACTED]
Sent: Friday, January 09, 2009 8:53 AM
To: Joy Percicuff
Subject: NEIS Survey Tool

Hi Joy,

I am excited to inform you that I am preparing my proposal and as we have discussed in the past, intend to utilize your NEIS tool. I will be surveying Massachusetts NICU nurses' actions to resolve ethical issues that arise in practice related to treatment decisions for infants with uncertain prognosis. I am required to submit your written approval regarding use of the tool. Your positive reply to this email will be sufficient to meet the documentation requirement.

Thank you in advance for your continued efforts on my behalf.

1/13/2009

Appendix C

Nursing Ethical Involvement Survey

1. Neonatal Nursing Ethical Involvement Scales

By completing this questionnaire, you are indicating your willingness to participate in a study of nurses involvement in ethical dilemmas related to treatment decision disagreements for infants with uncertain prognosis. Thank you for participating in this survey.

1. Please click the button that indicates to what extent you are concerned about ethical dilemmas you confront in clinical nursing practice.

| | 1 To a Very Small Extent | 2 Small Extent | 3 Medium Extent | 4 Large Extent | 5 To a Very Large Extent |
|--------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|--------------------------|
| Concern about ethical dilemmas | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

2. Please click on the Yes button to indicate current certifications.

| | Yes |
|---|-----------------------|
| Neonatal Certification (NCC) | <input type="radio"/> |
| Newborn Individualized Developmental Care Assessment Program (NIDCAP) | <input type="radio"/> |
| Lactation Counselor | <input type="radio"/> |
| None of the Above | <input type="radio"/> |

3. Please click the button to select your highest degree in nursing education.

| | Yes |
|------------------|-----------------------|
| Registered Nurse | <input type="radio"/> |
| Bachelor Degree | <input type="radio"/> |
| Masters/PhD | <input type="radio"/> |

The following is a vignette about a NICU patient. Please review the vignette and then select your most appropriate answer.

Bonnie is a seven month old infant admitted to the NICU shortly after birth due to extreme prematurity. Her birth weight was 482 grams and gestational age was 24 weeks. Early in her hospital course she was found to have a grade-4 ventricular hemorrhage. She has been shunted for post-hemorrhagic hydrocephalus. She now shows signs of spasticity and has been confirmed as having cerebral palsy. She receives all nutrition via gastrostomy.

Bonnie has been ventilated continuously since birth and now has advanced chronic lung disease. She continuously requires 100% oxygen and high ventilator settings, and is frequently sedated due to air hunger. During the past three days, her lungs show a worsening picture and her ventilator settings have been increased. At this time, her parents request that she be removed from the ventilator and allowed to die. The decision about whether to comply with the parents' request is being discussed in the unit.

Nursing Ethical Involvement Survey

4. If you DISAGREED with the treatment decision about a similar case in your own unit, how likely would you be to:

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Feel concerned but take no further action? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

5. How likely would you be to

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|-------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Talk with other nurses? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

6. How likely would you be to:

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|-------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Talk with your Nurse Manager? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

7. How likely would you be to:

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|--------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Talk with involved Physicians? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

8. How likely would you be to:

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Request a team meeting to discuss your concerns? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

9. How likely would you be to:

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Talk with the family about the treatment decision? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

10. How likely would you be to:

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|--------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Request an ethics committee meeting? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

11. How likely would you be to:

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Discuss the case with hospital administrators outside the hospital? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

12. How likely would you be to:

| | 1 Not at all Likely | 2 Not Likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Discuss the case with officials outside the hospital? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Nursing Ethical Involvement Survey

13. How likely would you be to;

| | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | 1 Not at all Likely | 2 Not likely | 3 Somewhat Likely | 4 Very Likely | 5 Extremely Likely |
| Discuss the case with media outside of the hospital? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

2. Nursing Ethical Involvement Scale Unit Questions

The following questions ask you about your unit. Please select the most appropriate answer from the choices provided below.

14. Staff nurses on my unit are usually involved in ethical decision-making regarding the treatment of critically ill infants.

| | | | | | |
|-----------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

15. It is considered appropriate for staff nurses to be involved in ethical decision-making in my unit.

| | | | | | |
|-----------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

16. Nursing administration often supports staff nurses involvement in resolving ethical dilemmas.

| | | | | | |
|-----------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | Agree | Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

17. Physicians often alter the plan of care for patients based on nurses' input in my unit.

| | | | | | |
|-----------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

18. Staff nurses and physicians on my unit agree on the ethical decisions which are made regarding the treatment of the patient.

| | | | | | |
|-----------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| Nursing Ethical Involvement Survey | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 19. There are established mechanisms in my unit for questioning the medical treatment plan for the patient. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. Physicians and families ususally agree on ethical decisions which are made regarding treatment on my unit. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 21. Physicians value staff nurses' judgments about patient care on my unit. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 22. Staff nurses on my unit usually agree among ourselves on the ethical decisions which are made regarding treatment of the patient. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select on response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 23. Nurses and physicians on my unit often collaborate in developing treatment plans. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 24. Staff nurses and families often agree on the ethical decisions which are made regarding treatment. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 25. Ethical dilemmas regarding treatment of patients on my unit are referred to a hospital ethics committee. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| Nursing Ethical Involvement Survey | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 26. Staff nurses on my unit are free to question the medical treatment plan. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 27. On my unit aggressive therapies are frequently withdrawn from patients who are not responding. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. Nursing Ethical Involvement Scale - Current Work Situation | | | | | |
| The following 10 items refer to your current work situation. Please indicate to what extent you agree or disagree with the following statements. | | | | | |
| 28. My unit is adequately staffed. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat agree | 4 Agree | 5 Strongly Disagree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 29. Nursing is highly valued in my unit. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 30. Staff nurses have little influence on my unit. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 31. Overall, I am satisfied with my ability to give excellent care on my unit. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32. The administration in my hospital has a real interest in the welfare and overall satisfaction of the nursing staff on my unit. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| Nursing Ethical Involvement Survey | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| 33. Nursing care on my unit is generally excellent. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 34. Medical care on my unit is generally excellent. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 35. Overall, I am dissatisfied with the working conditions on my unit. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 36. I am satisfied with my ability to influence the quality of patient care on my unit. | | | | | |
| | 1 Strongly Disagree | 2 Disagree | 3 Somewhat Agree | 4 Agree | 5 Strongly Agree |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 37. Please indicate how often your experience treatment decision disagreements for infants' with an uncertain prognosis you experience in your unit. | | | | | |
| | 1 Yearly | 2 Two Yearly | 3 Six Yearly | 4 Eight Yearly | 5 Twelve or More Yearly |
| Please select one response. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Professional Information | | | | | |
| 38. Please indicate attendance in classes listed below in the last three years. | | | | | |
| | Yes | | | | |
| Legal Issues | <input type="radio"/> | | | | |
| Ethical Issues | <input type="radio"/> | | | | |

Nursing Ethical Involvement Survey

39. Please indicate if your hospital has written policies providing directions about clinical situations.

| | Uncertain | Yes |
|-----------------------------|-----------------------|-----------------------|
| Informed Consent | <input type="radio"/> | <input type="radio"/> |
| Termination of Life Support | <input type="radio"/> | <input type="radio"/> |
| Do Not Resuscitate | <input type="radio"/> | <input type="radio"/> |
| Limitation of Treatment | <input type="radio"/> | <input type="radio"/> |
| Hospital Ethics Committee | <input type="radio"/> | <input type="radio"/> |

5. Demographic Information

The following questions include demographic information.

40. Gender

Male

Female

41. How many years have you worked in a NICU?

Years worked in NICU

42. Does your hospital have a Boston address?

| | Yes | No |
|-----------------------------|-----------------------|-----------------------|
| Please select one response. | <input type="radio"/> | <input type="radio"/> |

43. Please select the Neonatal Nursing Organization you would like to make a donation to in the name of Massachusetts NICU Nurses.

Massachusetts Association of Neonatal Nurses

Association of Women's Health Obstetric and Neonatal Nurses

Appendix D



BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 10.068.01e

DATE: August 24, 2009
TO: Margaret Settle
CC: Pamola Grace
FROM: Office of Research Protections
RE: Predictors of NICU Nurse Activism: Selected Responses to an Ethical Dilemma

Notice of Evaluation – [Exempt 45 CFR 46.101(b)] 45 CFR 46.101(2)

The Office for Research Protections (ORP) has evaluated the project named above. According to the information provided, you intend to describe selected actions NICU nurses employ when confronted with an ethical dilemma and identify predictors of NICU nurse activism. This is a minimal risk study.

This study has been granted an exemption from Boston College IRB review in accordance with 45 CFR 46.101 (b) 45 CFR 46.101(2). This designation is based on the assumption that the materials that you submitted to the ORP contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This exemption is given with the following conditions:

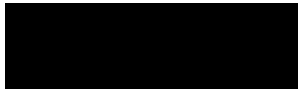
1. You will conduct the project according to the plans and protocol you submitted;
2. No further contact with the ORP is necessary unless you make changes to your project or adverse events or injuries to subjects occur;
3. If you propose to make any changes in the project, you must submit the changes to the ORP for IRB review; you will not initiate any changes until they have been reviewed and approved by the IRB;
4. If any adverse events or injuries to subjects occur, you will report these immediately to the ORP.

The University appreciates your efforts to conduct research in compliance with the federal

regulations that have been established to ensure the protection of human subjects in research.

Date of Exemption: Monday, August 24, 2009

Sincerely,



Stephen Erickson
Interim Director
Office for Research Protections
TSL

Appendix E



Partners Human Research Committee
 Partners Human Research Office
 116 Huntington Avenue, Suite 1002
 Boston, MA 02116
 Tel: (617) 424-4100
 Fax: (617) 424-4199

Application: Notification of IRB Approval/Activation

Protocol #: 2009-P-002136/1; MGH

Date: 11/03/2009

To: Margaret Settle, RN
Nursing
 Ellison 325

From: Fausta M. Figueroa
 PHS Research Management
 116 Huntington Ave Suite 1002

Title of Protocol: Predictors of NICU Nurse Activism: Selected Responses to an Ethical Dilemma
 Version/Number: None
 Version Date: 10/09/2009
 Sponsor: None
 IRB Review Type: Expedited
 Minimal Risk: 45 CFR46.110 and 21 CFR56.110
 Expedited Category/ies: (7) Research on individual or group characteristics or behavior, or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or QA methodologies.
 IRB Approval Date: 11/03/2009
 Approval Effective Date: 11/03/2009
 IRB Expiration Date: 11/03/2010

This Project has been reviewed and approved by the MGH IRB, Assurance # FWA00003136. During the review of this Project, the IRB specifically considered (i) the risks and anticipated benefits, if any, to subjects; (ii) the selection of subjects; (iii) the procedures for securing and documenting informed consent; (iv) the safety of subjects; and (v) the privacy of subjects and confidentiality of the data.

NOTES: The following documents have been reviewed and approved by the IRB:

- **Detailed Protocol & Summary Version April 2009**
- **Survey (1)**
- **Letters (3)**

As Principal Investigator you are responsible for the following:

1. Submission in writing of any and all changes to this project (e.g., protocol, recruitment materials, consent form, study completion, etc.) to the IRB for review and approval prior to initiation of the change(s), except where necessary to eliminate apparent immediate hazards to the subject(s). Changes made to eliminate apparent immediate hazards to subjects must be reported to the IRB within 24 hours.
2. Submission in writing of any and all adverse event(s) that occur during the course of this project in accordance with the IRB's policy on adverse event reporting.



Partners Human Research Committee
Partners Human Research Office
116 Huntington Avenue, Suite 1002
Boston, MA 02116
Tel: (617) 424-4100
Fax: (617) 424-4199

3. Submission in writing of any and all unanticipated problems involving risks to subjects or others.
4. Use of only IRB approved copies of the consent form(s), questionnaire(s), letter(s), advertisement(s), etc. in your research. Do not use expired consent forms.
5. Informing all physicians listed on the project of changes, adverse events, and unanticipated problems.

The IRB can and will terminate projects that are not in compliance with these requirements. Direct questions, correspondence and forms (e.g., continuing reviews, amendments, adverse events, safety reports) to Fausta M. Figueroa, (617) 424-4119.

Appendix F



February 25, 2010

Martha Griffin RN CS PhD
Director of Nursing
Education & Research
Boston Medical Center
85 East Concord St.
Boston, MA 02118

Margaret Settle RN PhD(c)
Boston College
Graduate School of Nursing
140 Commonwealth Avenue
Chestnut Hill, MA 02467-3807

RE: Research at Boston Medical Center -- NICU Participation in Survey

Dear Margaret,

I am pleased to write this letter noting support and participation from the Boston Medical Center's Neonatal Intensive Care Unit in your research survey. Please let me know if I can be of further help to your efforts. We look forward to working with you on this important study.

Sincerely,

A solid black rectangular box redacting the signature of Martha Griffin.

Martha Griffin RN CS PhD

Appendix G



**South Shore
Hospital**

South Shore Hospital
Office of Research (781) 340-4369
35 Fogg Rd., Box 26
Se. Weymouth, MA 02190-2455

MEMORANDUM

Initial Review: Notification of IRB Approval/Activation

SSH Study ID# 09-018

To: Eyad Zahr, M.D.

From: Richard D. Mirel, M.D. *RDM*
Chairman, Institutional Review Board

Date: 12/10/09

Re: Predictors of NICU Nurse Activism: Selected Responses to an Ethical Dilemma

| | |
|-------------------------------|------------------------------|
| Version/Number: | November 2009 |
| IRB Review Type: | Full Board (Convened) Review |
| IRB Approval Date: | 12/10/09 |
| IRB Approval Expiration Date: | 12/9/10 |

This research activity was reviewed and approved by the South Shore Hospital Institutional Review Board (SSH IRB), Assurance FWA#00005520.

In its review the IRB determined that this study is exempt from the twin protections of informed consent and further IRB review except where a modification to the research changes the risk associated with participation. For that reason, as Principal Investigator, you are responsible for submission in writing of any and all changes to this research activity (e.g. changes to the protocol, recruitment materials, study completion) to the IRB for review and approval prior to the activation of the change(s) except where the change is necessary to eliminate apparent immediate hazards to subjects. In the event that a change is necessary to remove an apparent immediate hazard, you must report the change to the IRB within 24 hours.

cc. Ellen Byrd, RN. **Peg Settle, RNC**

Appendix H



800 Washington Street, Box 817
Boston, MA 02111
tel 617.638.7512
fax 617.638.8394
<http://tnamecib.tufts.edu>

Health Sciences Campus Institutional Review Board

David Chelnow, MD
Chair

04 December 2009

Margaret Doyle Settle, RNC
90 Spring Street
Wrentham, MA 02093

Re: Predictors of NICU Nurse Activism: Selected Responses to an Ethical Dilemma

Ms. Settle

Thank you for your recent correspondence to the Institutional Review Board (IRB) office of Tufts Medical Center and Tufts University Health Sciences regarding the above-referenced project, which was received on 24 November 2009. On 24 November 2009, I reviewed your submitted materials. Per your submission, the role of Tufts MC staff will be limited to the NICU Nurse Manager forwarding 3 recruitment letters to NICU nurses inviting them to participate in an online research survey.

Per the 16 October 2008 guidance from the Office of Human Research Protections (OHRP) on the engagement of institutions in research, an institution is not considered to be engaged in a study when the activities of its employees or agents are limited to the following:

1. informing prospective subjects about the availability of the research;
2. providing prospective subjects with information about the research, so long as the employees do not obtain subjects' consent for the research or act as representatives of the investigators;
3. providing prospective subjects with information about contacting investigators for information or enrollment; and/or
4. seeking or obtaining the prospective subjects' permission for investigators to contact them.

The involvement of Tufts MC employees will be limited to the activities described above; as such, Tufts MC is not engaged in human subject research.

If the status of your involvement with this research changes, or if research activities related to this study will be carried out at Tufts Medical Center or Tufts University, please inform the IRB office.

Please contact me with questions pertaining to this matter.

Thank you.

Regards,

David Chelnow, MD

PLEASE RETAIN THIS LETTER WITH YOUR RESEARCH FILES.

Jointly sponsored by Tufts Medical Center and Tufts University

Appendix I

Page 1 of 1

Settle, Margaret D., R.N.

From: Perentzas, Dale [mailto:perentzas@baystatehealth.com]
Sent: Wednesday, November 25, 2009 7:58 AM
To: Settle, Margaret D., R.N.
Subject: FW: NICU Nurses' Ethical survey

From: Christanson, Karen
Sent: Thursday, September 24, 2009 2:23 PM
To: Perentzas, Dale
Subject: RE: NICU Nurses' Ethical survey

Hi Dale,

I've been going back and forth on this with our Research Integrity Officer. We are both comfortable with you proceeding without the involvement of the BWH IRB as long as you have the permission of HR and Mary Brunton to do so.

Thank!
Karen

Karen Christanson, RN, MSN, CCRP
Director
Human Resources Protection Program
Baystate Health
759 Chestnut Street
Springfield, MA 01109
Phone: (413)794-5714
Fax: (413)794-9300

From: Perentzas, Dale
Sent: Tuesday, September 08, 2009 1:49 PM
To: Christanson, Karen
Subject: NICU Nurses' Ethical survey

Hi Karen
I have been asked to participate in this project with the NICU at BWH. Pam stated that she had spoken with our IRB administrators. Would that be you?
What do I need to do/sign to have the NICU staff participate?

Dale Perentzas, MD, MPH
Surgeon in Chief
Baystate Medical Center
(413) 794-3333

CONFIDENTIALITY NOTICE: This email communication and any attachments may contain confidential and privileged information for the use of the designated recipients named above. If you are not the intended recipient, you are hereby notified that you have received this communication in error and that any review, disclosure, dissemination, distribution or copying of it or its contents is prohibited. If you have received this communication in error, please reply to the sender immediately or by telephone at (413) 794-0000 and destroy all copies of this communication and any attachments. For further information regarding Baystate Health's privacy policy, please visit our Internet website at <http://www.baystatehealth.com>.

2/2/2009

Appendix J

Initial e-mail Invitation to Staff Nurses

From: Peggy Doyle Settle, RNC

To: NICU Staff Nurses at _____

Sent: Date to be determined

Subject: NICU Nurse Ethical Involvement Survey

I am writing to ask for your participation in a research survey regarding NICU nurses involvement in ethical dilemmas. As part of my doctoral research at Boston College, I am asking Massachusetts NICU nurses like you, to reflect on your response to ethical dilemmas.

Your responses to this research survey are very important and will help create an understanding of NICU nurses' actions when faced with an ethical dilemma. As part of the research survey I am also asking about nursing influence in your unit related to ethical dilemmas.

This survey should take no more than fifteen minutes to complete. Please click on the link below and go to the survey website.

http://www.surveymonkey.com/s.aspx?sm=X4sy_2bD883gkhLmSxvvBiNg_3d_3d

Your participation is voluntary and all of your responses will be kept confidential. This study has been approved by the Boston College Institutional Review Board. Your hospital approved the distribution of this survey to you. No personal or hospital identifiable information will be associated with your responses in any reports of this data. Should you have further questions or comments, please feel free to contact me at settlelem@bc.edu.

Thank you for your time and consideration in completing this research survey. As a gesture of appreciation, once you have completed the study, you may choose a neonatal nursing organization to receive a donation in the name of Massachusetts NICU nurses. It is through the help of nurses like you that we can begin to understand NICU nurses' experience. At the conclusion of the study, each Massachusetts NICU will receive the complete study results.

Many Thanks,

Peggy Doyle Settle, RNC
Boston College Doctoral Candidate

Follow –up e-mail #1

From: Peggy Doyle Settle, RNC

To: NICU Staff Nurses at _____

Sent: Date to be determined

Subject: Please Complete the NEIS

I recently sent you an e-mail asking you to respond to a research survey about your involvement with ethical dilemmas. Your responses to this survey are important and will help create a detailed understanding of NICU nurses experience when faced with an ethical dilemma. I believe this is an important topic and designed this survey as part of my doctoral research at Boston College.

This research survey should take fifteen minutes to complete. If you have already completed the survey, I appreciate your participation. If you have not yet responded to the survey, I encourage you to take a few minutes and complete the survey.

Please click on the link below to go to the survey website.

http://www.surveymonkey.com/s.aspx?sm=X4sy_2bD883gkhLmSxvvBiNg_3d_3d

Your response is important. Getting direct feedback from NICU nurses is crucial in understanding this specific aspect of nursing practice. In addition, your response will increase the donation to your selected neonatal nursing organization. Thank you for your help in completing this study.

Sincerely,

Peggy Settle, RNC
Boston College Doctoral Student

Follow-up e-mail #2

From: Peggy Doyle Settle, RNC

To: NICU Staff Nurses at Massachusetts Hospital

Sent: Date to be determined

Subject: Last Chance to Participate in the NEIS

The NICU can be busy at times, and I understand that you are not always able to follow your shift as planned. I am hoping you may be able to give about fifteen minutes of your time before the end of your current shift to help me collect this important information for the Massachusetts NICU nurses' ethical dilemma study. I believe this is an important topic and designed this survey as part of my doctoral research at Boston College.

If you have already completed the research survey, I really appreciated your participation. If you have not responded, I would like to urge you to complete this survey. I plan to end this study next week, so I wanted to email everyone who has not responded to make sure you had a chance to participate.

Please click on the link below to go to the survey website.

http://www.surveymonkey.com/s.aspx?sm=X4sy_2bD883gkhLmSxvvBiNg_3d_3d

Thank you in advance for completing the survey. Your response is important! NICU nurses have the most current information regarding ethical dilemmas at the bedside. You will also increase the donation to your selected neonatal nursing organization.

Sincerely,

Peggy Doyle Settle, RN
Boston College Doctoral Student