Instrument Development to Measure Critical Care Nursing Values and Behaviors when Providing End-of-Life Care

by
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A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctorate of Philosophy in the School of Nursing

Chapel Hill
2008

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ABSTRACT

Margaret G. Zomorodi: Instrument Development to Measure Critical Care Nursing
Values and Behaviors When Providing End-of-Life Care
(Under the direction of: Mary R. Lynn)

Background and Purpose: Although critical care nurses are expected to focus on life sustaining measures, many intensive care patients receive end-of-life care. The purpose of this study was to develop an instrument to measure nursing values and behaviors when providing end-of-life care.

Methods: This study consisted of three phases. Phase I consisted of item development from a content analysis of the literature and qualitative interviews. Phase II consisted of content validity assessment and pilot testing and Phase III consisted of field testing, factor analysis, and reliability estimation.

Results: Participants in all three phases were critical care nurses employed throughout the U.S. Items generated in Phase I were evaluated in Phase II by content experts (n = 8) and pilot participants (n = 12).Two instruments were the result of the first two phases. In Phase III, the *Values of Intensive Care Nurses for End-of-Life (INTEL-Values)* was subjected to an exploratory factor analysis (n = 695). A four factor model was selected --- Self-appraisal, Appraisal of Others, Emotional Strain, and Moral Distress. Individual item alphas were acceptable at .59 - .78, but the inter-item (.12 - .78) and item total correlations (.31 - .48) were often low. Reliability testing over a two week period yielded low Kappa values (.05 - .30) although the Pearson's correlations (.68 - .81) and intra-class correlation coefficients were high (.65-.79).

The *Behaviors of Intensive Care Nurses for End-of-Life (INTEL-Behaviors)* was also examined through a factor analysis (*n* = 682). A two factor model was selected --- Communication and Nursing Tasks. Individual item alphas were acceptable (.67 and .78), but the inter-item (.20 - .35) and item total correlations (.30 - .61) were also often low. Reliability testing produced low Kappa values (.02 - .40) but high Pearson and intra-class correlations (.77 - .81).

Conclusions: The *INTEL-Values* was problematic in terms of item to item correlations and test-retest reliability. This might be partially attributable to the recognized difficulty in measuring attitudes. The *INTEL-Behaviors* had higher factor loadings, possibly because behaviors are more concrete. Future work will consist of continued refinement of the instruments and construct validity testing.

ACKNOWLEDGEMENTS

It is impossible to thank all of the individuals who assisted me throughout the development of this dissertation. Special thanks to my committee, Drs. Mary Lynn, Timothy Daaleman, Barbara Jo Foley, Cheryl Jones, and Barbara Germino for their guidance and assistance. You have helped me grow in ways I never could have imagined.

I have to acknowledge my husband, Ali, who has been a constant source of support, compassion, patience, and love. I cannot thank you enough for your trust and belief in my ability to succeed.

I believe that the doctoral curriculum is a journey, and I am so fortunate to have met so many wonderful people along this travel. To my family, Joe, Chad, Cyrous, Gity, Pardis, Ed and Kathryn; I am blessed to have you in my life. To my friends, DaiWai, Joe, Jill, Stacy, Kathy, Courtney, Sala, Kristina, and Jenny; I am so thankful for your understanding, patience, and encouragement throughout this process.

I also want to express my gratitude to the faculty and staff at the School of Nursing. No matter what, you were always willing to share your guidance and support. I also must thank the critical care nurses who supported me throughout this dissertation, especially those involved in the American Association of Critical Care Nurses---your dedication to this topic and desire for change was, and will continue to be, a constant source of motivation for me.

And in loving memory, I recognize my mother, Charlotte Nelson, who was a nurse and inspiration throughout her entire life. I owe so much of who I am today, to you.

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LIST OF ABBREVIATIONS AND SYMBOLS

α	Cronbach's Coefficient Alpha
AACN	American Association of Critical Care Nurses
AHRQ	Agency for Healthcare Research and Quality
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CVI	Content Validity Index
EFA	Exploratory Factor Analysis
ELNEC	End-of-life Nursing Education Consortium
ICC	Intra-Class Correlations
ICU	Intensive Care Unit
INTEL-Behaviors	Behaviors of Intensive Care Nurses for End of Life
INTEL-Values	Values of Intensive Care Nurses for End of Life
JCAHO	Joint Commission on Accreditation for Healthcare Organization
KMO	Kaiser-Meyer-Olkin test of sphericity
NIH	National Institutes of Health
NINR	National Institute for Nursing Research
PAF	Principal Axis Factoring
PCA	Principal Components Analysis
SD	Standard Deviation
SPSS	Statistical Package for the Social Sciences
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments
VBC	Value-Behavior Congruency

INTRODUCTION

Although the ICU is typically viewed as an intensive life saving area, 20% of all hospital deaths occur in the intensive care setting (Halcomb, Daly, Jackson, & Davidson, 2004; Rocker & Curtis, 2003).The ICU is not an ideal place to die as patients are often isolated from their families in this highly technical and sterile environment (Kirchhoff et al., 2000). However, ICU deaths are increasing, and the majority of these patients are unable to make decisions about their care, often relying on their family members or significant others for decision making. There is often conflict among family members and healthcare providers in deciding whether to continue aggressive treatment or to pursue palliative interventions, even when an advance directive has been established (Gross, 2006). Many people are concerned about the quality of care at the end of life and report dissatisfaction with end-of-life care practices in the intensive care setting (Gross, 2006; Higginson, Wade, & McCarthy, 1990; "The SUPPORT Principal Investigators," 1995). Yet despite the significance of end-of-life care and growing concerns regarding the quality of care delivered, there has been minimal research on palliative care in the intensive care setting.

There has been an increased emphasis on improving the quality of dying for individuals and their families. The Joint Commission on Accreditation for Healthcare Organizations (JCAHO) has made health care professional education in end-of-life care one of the top public policy issues ("Public Policy: Health Care Education," 2006). The American Association of Critical Care Nurses (AACN) has called for ICU nurses to improve end-of-life care and the American Association of Colleges of Nursing is developing a new curriculum for end-of-life education targeting critical care nurses (American Association of Critical Care Nurses, 2000, “ELNEC Critical Care Course,” 2006). The Agency for Healthcare Research and Quality (AHRQ) has noted the need to develop instruments to evaluate the quality of palliative care as well as patient and family satisfaction with care delivery. Additionally, AHRQ has emphasized the need for testing such measures in settings other than hospice and with populations other than cancer patients to be among the top priorities (Lorenz et al., 2004). The National Institutes of Health (NIH) along with the National Institute for Nursing Research (NINR) published a State of the Science report calling for nursing to shape the future direction of end-of-life care and calling for validation or refining of instruments to address the unique issues of end-of-life research, especially for diverse groups and in diverse settings ("National Institute of Nursing Research," 2006).

Despite all of the emphasis on improving the care of dying patients and their families in the hospital, no instrument could be located that measured the quality of nursing care delivered in the ICU. Instruments examining nurses’ values and behaviors when providing end-of-life care in the ICU could help to identify variables that are important indicators of a good dying experience and ICU settings that exhibit best practice with quality care at the end of life.

Therefore the overall aim of this study was to develop an instrument that assessed nursing values and behaviors when providing end-of-life care in the intensive care unit. This study consisted of three phases of instrument development. In Phase I, a content analysis of the literature was conducted along with qualitative interviews of adult critical care nurses to identify the domains and subdomains needed to generate items for the instrument. For Phase II of the study, what became two separate instruments were assessed for content validity and pilot tested in three group sessions. Phase III consisted of field testing of the proposed instruments and the psychometric properties of the two instruments were explored.

CHAPTER 1

BACKGROUND AND SIGNIFICANCE

The Institute of Medicine defined optimum end-of-life care as an experience that is "free from avoidable distress and suffering for patients and their families, in accord with the patients' and families' wishes, and reasonably consistent with clinical, cultural, and ethical standards" (Donaldson & Field, 1998; *Institute of Medicine*, 1990). Standards for a good death include symptom management, patient and family focused-care, and spiritual well-being for both patients and families (Donaldson & Field, 1998; Finlay et al., 2002; Gazelle, Buxbaum, & Daniels, 2001; Patrick, Engelberg, & Curtis, 2001; Sahlberg-Blom, Ternestedt, & Johansson, 2001; Steinhauser et al., 2000; Thompson & McClement, 2002). The World Health Organization has defined quality end-of-life care as the "active total care of patients whose disease is not responsive to curative treatment" (*World Health Organization*, 1990, p. 11). This definition includes meeting the psychological, social, and spiritual needs for both patients and families (Donaldson & Field, 1998; Finlay et al., 2002; Gazelle et al., 2001).

The needs of patients at the end of life are heightened when they occur in the critical care setting where dying can be a noisy, complicated, and disorganized experience (Beckstrand & Kirchhoff, 2005). Most deaths in the ICU occur in a less than supportive environment. The ICU patient at the end of life is usually unresponsive, on mechanical ventilation, surrounded by invasive monitors, and isolated from their family.

Family members report concerns that their loved one is experiencing pain, and is inaccessible in the foreign, highly technical, and impersonal environment of the ICU (Kirchhoff et al., 2000).

The majority of patients with a terminal illness desire to spend their last days in comfort in their home (Brumley, 2002; Sulmasy & McIlvane, 2002). Despite this preference, only 20% of deaths occur at home (Brumley, 2002). The majority of deaths (57%) occur in the hospital setting (Brumley, 2002), and of these deaths, 20% are in an ICU (Rocker & Curtis, 2003). Although the ICU is typically viewed as an intensive life saving area, a number of patients die in the unit, and the care provided to these patients shifts from a curative focus to one of end-of-life care. Sometimes the transition from critical care to end-of-life care is instantaneous, and the urgency associated with end-of-life decisions for these patients creates challenges for the nurses providing this care. For nurses whose day-to-day practice focuses on saving lives, a sudden or even gradual change in a patient's situation to end-of-life care can cause a disconnect between what nurses routinely do in the ICU setting and what they are now expected to do. In this situation, nursing care decisions made at the end of life may no longer be critical to the patient’s survival, yet they have the potential to leave a lasting impression on the patient’s family as well as the nurse involved in providing care.

Quality Indicators from the Patient and Family

The Institute of Medicine has reported a negative perception of end-of-life care among both families and healthcare providers. Despite advanced technology, nurses and family members express great concern about the dying experience (Grady, 2005). Family members often experience stress, anxiety, and depression, and need explanations regarding their loved one’s care, decision making, treatment options, and expected disease trajectory (Lorenz et al., 2004). Greater dissatisfaction is reported with end-of-life care in the ICU among the family when the death is reported as sudden or not foreseen, often resulting in the family feeling unable to adapt to the situation and participate in care decisions (Malacrida et al., 1998). Family members report being more satisfied when they have more autonomy in end-of-life decision making, (Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003; Teno et al., 2005) and an ability to form relationships with the healthcare team (Malacrida et al., 1998). In contrast to this preference, healthcare providers and family members have been found to disagree about decision making in 48% of cases in which withdrawal of life support was considered (Breen, Abernethy, Abbott, & Tulsky, 2001). Emotional support and compassion from healthcare providers is viewed as important to the dying experience in the ICU (Bridgman & Carr, 1998; Farrell, 1989; Payne, Langley-Evans, & Hillier, 1996; Wenrich et al., 2003), and family members report greater satisfaction when communication is adequate, patients and family members have autonomy in decision making, and respect and compassion are shown to both the dying patient and the family (Heyland et al., 2003; Teno et al., 2005). Adequate symptom control, dignity, autonomy, and feeling prepared for the death were also cited as important quality indicators for family members whose loved one died in an intensive care setting (Mularski, Heine, Osborne, Ganzini, & Curtis, 2005).

Role of the Nurse

Nurses are at the bedside of the patient more than any other health care professional. While one of the main goals for nurses working with dying patients in the

ICU is to provide a peaceful death experience through compassionate care for the patient and family, they are not currently achieving this goal (Brumley, Enguidanos, & Hillary, 2003; Carson, Fitch, & Vachon, 2000; Daly, 2001; Edmonds, Stuttaford, Penny, Lynch, & Chamberlain, 1998; Fakhoury, 1998; Sulmasy & McIlvane, 2002). Analysis of interviews conducted with family members of 3,357 deceased patients revealed that 40% of family members perceived their loved ones as experiencing severe pain during most of the three days prior to death; and 25% of the decedents were perceived to experience moderate to severe anxiety or depression prior to death (Lynn et al., 1997). In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), which included 9,105 patients, their physicians, and family members, it was reported that the end-of-life hospitalization for most patients included more than a week in an undesirable state of coma, mechanical ventilation and intensive care. Family members of half of the patients enrolled in the study reported that those dying in the hospital were uncomfortable at least half the time during their final days of life, even after an intervention was developed to improve end-of-life care delivery ("The SUPPORT Principal Investigators," 1995). Efforts to improve the delivery of care at the end of life have included various interventions, with little significant benefit (Edmonds et al., 1998; Rubenfeld & Curtis, 2001; “The SUPPORT Principal Investigators,” 1995; Towlson & Rubens, 1992). One reason for the ineffectiveness of these interventions to improve care may be that the interventions were aimed at improving care from exclusively a family or exclusively a nursing perspective, but were not developed by blending the inputs of nurses and family members, and using outcomes considered important to both. In order to provide quality end-of-life care from a family and patient perspective, nurses must also be included when developing interventions to improve care delivery.

Nurses are in a pivotal position to improve care for dying patients and their families by redefining the perspective of ICU care and challenging current end-of-life care practices in their settings. By providing information, facilitating discussions, and advocating for the patient's wishes, nurses can assist patients and families in end-of-life decision making. However, critical care nurses report a lack of preparation for dealing with end-of-life care in this intensive environment (Kirchhoff, Beckstrand, & Anumandla, 2003; Kirchhoff et al., 2000; Mallory, 2003).

The Medical Model vs. The Palliative Model

In addition to inadequate education on providing end-of-life care in the intensive care unit, nurses report frustration due to their lack of knowledge, autonomy, and support for providing end-of-life care in the ICU environment (Ciccarello, 2003). Nurses' role in the ICU has been primarily focused on the curative model. The transformation of hospice to a patient centered model along with the demand for quality end-of-life care in the ICU has created challenges for critical care nurses who are not prepared to focus on a palliative, patient centered role (Finlay et al., 2002). In today's society, medicine is perceived as infallible and death is no longer an everyday thought (Kaufman, 2005). There is certainly a need to change the delivery of care in critical care settings to one that is optimum and patient-centered. More of an emphasis has been placed on providing patient centered care in the critical care setting, but this transition has been difficult to achieve. Kaufman (1998) has identified four forces that influence the delivery of care in the ICU and inhibit the ICU's transition to a blended model that focuses on patient centered and intensive care---biomedical knowledge as the dominant conceptual framework, the power of technology, ambivalence about end-of-life goals, and the incompatibility of lay and medical knowledge.

Biomedical Knowledge as the Dominant Conceptual Framework

Remarkable advances in medicine have changed how, when, and where people die (Miller, Forbes, & Boyle, 2001). Instead of being viewed as a natural event in life, death is now managed as a disease that must be treated and "cured." Today Americans develop an average of 2.2 chronic conditions and live with these conditions for an average of 17 years (Brumley, 2002). Individuals experiencing exacerbations from these chronic conditions are rescued from death by sophisticated technological interventions in critical care units (Miller et al., 2001). In the critical care unit, the biomedicalization of death has removed the patient and family from the dying experience. Patients and families are often unaware that death is approaching and thus, cannot prepare for it.

Death is no longer treated as a natural outcome of life but instead viewed as a medical failure (Farrell, 1989). Often the delivery of care in the critical care setting is so focused on saving the life of the individual, that the quality of the life saved and the pain and suffering inflicted to save the life are ignored. The focus on medical cure in the intensive care setting often involves health care providers' visualizing the patient as a disease or condition, rather than an individual with values, beliefs, and desires. This pathophysiological focus results in the values, beliefs, and desires of the patient being forgotten and the patient-centered care that is desired by patients and families is not achieved in the critical care setting. Nurses who desire to provide quality end-of-life care must include patients and families in the decision making process as well as helping them navigate through the technology of the intensive care unit.

The Power of Technology

The second force influencing patient-centered care is the power of technology. Technology guides the delivery of care in the intensive care unit to the point that there is an inability to predict accurately whether someone is surviving or dying (Miller et al., 2001). Nurses and physicians in the critical care unit often feel that they have a moral obligation to sustain life and utilize technology if it is available. Healthcare providers deliver care in the ICU under the false assumption that they will know the precise time to discontinue the medical rescue and prevent medical futility (Miller et al., 2001).

Often technology is introduced in small stages---central lines, ventilator support, dialysis, and chemical resuscitation are all technological advances that further gray the line between life and death. Technology also restricts the ability of the family and nurse to manage the patient on an individual level. The multiple IV lines, monitors, endotracheal tubes, and other devices restrict the amount of contact the patient can receive. It is difficult for healthcare providers and families to interact with the patient due to the technology in the ICU, and this barrier limits the ability of healthcare professionals to provide quality palliative and patient-centered care (Ciccarello, 2003; Curtis & Rubenfeld, 2001).

Ambivalence about end-of-life goals

The advanced technology in the ICU has resulted in the development of many specialties and extensive training for health care professionals. Patients with multiple conditions often require management by many different physician specialists which results in fragmented care (Brumley, 2002). Among the many healthcare providers and specialists there are different opinions, values, and attitudes toward treatment goals that influence decision making. Little communication exists between these specialists, and patients and families often have a different perception of the illness depending on the available medical team (Beckstrand & Kirchhoff, 2005; Carlet et al., 2004; Matzo, Sherman, Sheehan, Ferrell, & Penn, 2003). Dying patients are extremely vulnerable because it is possible for the holistic needs of the patient to be overlooked resulting in a lack of access to the healthcare system. With the lack of a consistent patient-centered system, fragmented communication exists, and the patients and their families must manage the transition through the health care system on their own.

Incompatibility of Lay and Medical Knowledge

Critical care units have developed inter-disciplinary teams to provide patient-centered care to the patient, but unfortunately the patient is a forgotten member of this team. Many institutions have implemented a team consisting of physicians, nurses, specialists, dieticians, respiratory therapists, social workers, and physical therapists who round every morning to determine the best holistic care for the patient. As the team arrives at the patient's room, the family is asked to leave the bedside or the ICU doors are shut, potentially blocking any communication between the patient's family and the healthcare team. The interdisciplinary team then makes care decisions based on the patient's organ system, psychological concern, pain, sleep, or other issue with the bedside nurse providing the only input from the patient's or family's perspective. The patient's family is reportedly removed from the inter-disciplinary rounds because of the incompatibility between lay and medical knowledge, the unwillingness of the medical community to translate, and an underlying belief that medicine knows best. Healthcare providers have allowed this removal because in their opinion, there is a vast difference between medical knowledge and lay knowledge (Miller et al., 2001).

Healthcare providers taking the time to simplify their language and assess the needs, values, and goals of the patient and family on a daily basis would improve care delivery, and make their care patient-focused, regardless of the goal for intensive or end-of-life care. With the increase of dying patients in the ICU, the critical care nurse's role must also evolve in order to provide quality care to every patient in the ICU---those requiring intensive care and those requiring care at the end of life.

Summary

The delivery of quality end-of-life care in the ICU has become a concern for patients, families, and health care providers with current focus aimed at improving care delivery in this patient population. Quality care can only be achieved by incorporating the patient and family in the plan of care, yet there are many barriers in the ICU that contribute to the inability to provide this care. The belief that medicine is infallible (biomedical knowledge), the increase of technology and the limit this places on patient-centered care (the power of technology), difficulty with decision making and fragmented care (ambivalence about end-of-life goals) and communication problems between the nurse, physician, and family (incompatibility of lay and medical knowledge) have contributed to the problem of ineffective care delivery. The role of the nurse and their response to these problems with care delivery should be addressed if effective interventions are to be developed. Identifying nurses who are able to achieve a patient-centered focus can improve the quality of dying for individuals as well as improve patient, family, and provider satisfaction.

CHAPTER 2

CONCEPTUAL FRAMEWORK

The Value-Behavior Congruency model (VBC) adapted to the ICU, suggests that end-of-life care can be improved in circumstances in which the patient, family, and nurse work together to ensure a quality death through behavioral goals. Since the focus of the current instrument development was on values and behaviors of the nurse, this conceptual framework fits well and addressed the problem of ineffective care delivery from a personal, environmental, and relational perspective.

Value-Behavior Congruency

Bowen developed a conceptual model of value behavior congruency to examine the quality of marriage and satisfaction among couples. This same model has been used to examine military and civilian families, work support, and the quality of work environments (Alpass, Long, Chamberlain, & MacDonald, 1997; Gareis & Brennan, 2003; Poster & Prasad, 2005; Secret, 2006; Secret & Sprang, 2001; Warren & Johnson, 1995). The value behavior congruency model is based on social exchange theory which connects costs and rewards to their relationships with satisfaction (Nye, 1979). After conducting qualitative interviews, Bowen expanded the exchange theory to include personal, environmental, and relational factors that can either facilitate or hinder goal-directed behavior. Bowen's value-behavior congruency model is grounded both theoretically and empirically, and Bowen has conducted several interventions based on this model and found outcomes predicted by the theory (Bowen, 1991).

A key assumption when the model was developed was derived from Harrison's (1978) person-environment-fit perspective (Bowen, 1991). This assumption is that the fit between the values of a person and the values of an environment affects a person's level of stress and satisfaction (Bowen, 1991). Bowen's model suggests that individuals must be aware of their own values and attitudes, as well as the effects of these values on personal behavior. To promote value behavior congruency and improve the quality of relationships, individuals must appraise their own knowledge, skills, and attitudes when confronting personal, environmental, or relational factors. The individual's response to these factors can influence the quality of their relationships. Value-behavior congruency leads to improved marital quality with a final outcome being an increase in marital satisfaction (Bowen, 1991).

Key Variables, Assumptions, and Relationships

Adapted to the ICU, Bowen's model suggests that the quality of end-of-life care is improved in circumstances where the patient and family are able to realize their shared goals with the ICU nurses providing the care, as well as their individual values and goals in behavior. In other words, the nurse, patient, and family must work together to ensure that their values and behaviors are congruent with each other in order for quality care to be achieved. Only when the values of the patient and family are congruent with the behaviors of the healthcare team can satisfaction and quality of care be achieved. This is especially important when transitioning the patient and family from intensive care to end-of-life care. The nurse who provides quality care is able to adjust his or her values and behaviors depending on the specific situation to meet the needs of the patient and family. In addition to the values and behaviors, the nurse's, patient's, and family's response to the healthcare system can influence the quality of end-of-life care that they are able to achieve. The nurse providing quality care selects his or her behavior as a response to the personal, environmental, and relational factors present in the healthcare system in order to facilitate the long range goals of the patient and family.

Constructs and Concepts

A key concept in Bowen's model is that of *values*. Values include "organized sets of preferences for how individuals wish to conduct their lives" (Bowen, 1991, p. 30). Values are learned through socialization and experience and this concept encapsulates terms such as goals, aims, preferences, priorities, attitudes, ambitions, wants, and aspirations (Bowen, 1991, p. 34). An assumption about values is that there is an emotional response in an individual's ability to realize their values in behavior. Emotions can be positive, negative, or neutral but must be made aware if one is to achieve value-behavior congruency (Bowen, 1991). There is certainly an emotional attachment to many values associated with end-of-life care, so this assumption fits within nursing practice. There is general agreement that values cause attitudes; with agreement that an attitude towards an object is likely to facilitate the realization of value (Mueller, 1986). *Behavior* is defined as what people do or do not do (Bowen, 1991). For those individuals who have difficulty identifying their values, behavior can be used to infer their values. For example, an ICU nurse who specifically requests to care for patients who are dying may be exhibiting an underlying value, preference, or attitude towards providing care for those dealing with death.

The ultimate outcome in Bowen's model is marital satisfaction. Marital satisfaction is defined by Bowen as an "emotional outcome of a dynamic, fluid, interactional process between spouses who are constantly working to achieve desired marital-related ends in the context of ever-changing and emerging marital-related values" (Bowen, 1991, p. 33). Marriage *quality* is achieved when the spouses' needs, values, and goals are met. The Institute of Medicine defines quality as "the degree to which health services for individuals and populations increases the likelihood of desired health outcomes and are consistent with current professional knowledge"(Donaldson & Field, 1998; Institute of Medicine, 1990). This definition can be blended with Bowen's definition of marital quality to suggest that quality is achieved when individuals are able to have access to health services that meet the patient and family's desired outcomes, values, or goals.

Another assumption of Bowen's model is that individuals pursue their values within a larger "causal context" that serves to facilitate or hinder their ability to behave in ways that are consistent with their values. This causal context is made up of personal, environmental, and relational factors, which can be conceptualized as the individual, environmental, and organizational factors faced in the intensive care setting.

Bowen's model applied to ICU nursing

To clarify this model's applicability to nursing practice, Bowen's conceptual definitions of these causal factors have been changed to reflect the roles of the nurse and the patient unit (patient and family) rather than the individual. "Individual" has been replaced by "nurse" and "patient unit" for the purpose of defining these concepts. *Personal* factors consist of the beliefs and expectations of the "nurse" and "patient." *Environmental* factors consist of the environmental factors that facilitate or inhibit the ability of the "nurse" or "patient" to perform specific behaviors. *Relational* factors are defined as the interaction of relationships between the "nurse and patient, family, or other health care providers."

Personal Factors

Personal, cultural, and professional experiences in end-of-life care may influence the value that a nurse places on the dying experience. Previous end-of-life experiences, whether from a personal, cultural, or professional perspective, have been shown to shape nurses' expectations of the current delivery of care (Beuks et al., 2006; Chen & McMurray, 2001; Dunn, Otten, & Stephens, 2005; Hall & Rocker, 2000; Heyland et al., 2003; Higginson, Wade, & McCarthy, 1990). These experiences may impact the types of behaviors provided by the nurse.

Patients in the ICU are often subjected to intense, painful, futile procedures; as a result the nurse may face individual and ethical dilemmas about suffering and death in the ICU. Nurses cite their lack of training in end-of-life care and their personal commitment to saving lives as a significant cause of stress and discomfort while providing care to dying patients and their families (Beckstrand & Kirchhoff, 2005). Despite these concerns, ICU nurses are often given the responsibility of caring for the dying patient and their family, and receive little respite from the stress of caring for these individuals.

The transition from critical care to end-of-life care is often described as a gray area due to the lack of clear prognostic indicators (Kirchhoff & Beckstrand, 2000). During this transition, nurses reported numerous challenges including fear of harming the patient; and the inability to debrief (Halcomb, Daly, Jackson, & Davidson, 2004). Nurses also identified a need to minimize pain and discomfort, promote dignity, diminish false hopes, discontinue futile treatment, and resolve communication problems with physicians. In addition, critical care nurses often have moral distress with regards to their roles and responsibilities when care transitions from critical to end-of-life care (Brown, 2003; Elpern, Covert, & Kleinpell, 2005). In one study it was reported that about half (47%) of healthcare providers in five hospital settings stated that they had acted against their own values when caring for critically ill patients (Solomon et al., 1993).

Environmental Factors

The ICU is a noisy, highly technical, complicated, and often disorganized setting, and is not an ideal environment for end-of-life care (Beckstrand & Kirchhoff, 2005; Beckstrand, Callister, & Kirchhoff, 2006; Brumley, 2002). Noise from machines, presence of multiple specialists, and the acuity of other patients are environmental factors that interfere with the nurse's ability to provide quality end-of-life care in the ICU. In addition, the ICU is a difficult place for families of patients, especially when end-of-life care is being initiated. Families are concerned that their loved ones are not approachable and they often feel unable to effectively grieve in this intense environment (Carlet et al., 2004; Farrell, 1989; Higginson et al., 1990).

Time has been cited as a key environmental factor when providing end-of-life care to intensive care patients. "Spending time with the patient and family is indispensable. Time allows the family to educate the nurse about the patient" (Ciccarello, 2003, p. 219). Unfortunately, lack of time has been cited as a factor preventing the ICU nurse from providing that care (Carlet et al., 2004; Kirchhoff & Beckstrand, 2000). Nurses need more time for self reflection and debriefing when providing end-of-life care in the ICU (Carlet et al., 2004; Cartwright, Steinberg, Williams, & Najman, 1997; Ciccarello, 2003; Halcomb et al., 2004; Kirchhoff et al., 2000). The lack of time to reflect and to teach others results in inexperienced nurses having to rely on trial and error (Kirchhoff et al., 2000). With the predicted increases in end-of-life experiences in the intensive care unit, such trial and error techniques are inadequate.

Additionally, patients and family members both define a good dying experience as having enough time to say goodbye and prepare for the death (Payne et al., 1996). Since family members report a more negative perception of the dying experience when they view the death as rushed or unanticipated (Malacrida et al., 1998), the nurse who facilitates time for the family to process the death may provide a more positive end-of-life experience (Ringdal, 2002).

Technology is another major factor in end-of-life care in the intensive care setting. The ICU is a highly technical area with invasive monitors and lines, but health care providers delivering end-of-life care to ICU patients would prefer to remove these invasive machines in order to help the family come to terms with the end of life. Nurses can remove invasive lines, turn off monitors, and lower the bedrails" (Ciccarello, 2003, p. 219) to begin the delivery of end-of-life care. Reducing technology has been identified as a skill nurses use not only to provide comfort to the family but also to make themselves feel better (Halcomb et al., 2004).

Relational Factors

The majority of patients in the ICU are unresponsive and cannot provide feedback about pain and symptom management, or express their needs and desires for care. It is estimated that less than 10% of all ICU patients are able to make treatment decisions for themselves (Carlet et al., 2004). Without living wills to direct these individuals' plans of care, many family members must serve as surrogates and substitute their judgment regarding the patient’s wishes. Often, the family is unable to vocalize their wishes during this difficult time, resulting in increasing ambiguity with treatment decisions.

The ability to help the family reduce their feelings of responsibility or guilt has been identified as key to providing quality end-of-life care in the ICU (Ciccarello, 2003). Expert nursing behaviors were identified as those that encourage families to talk about their loved ones, share what mattered most in their lives, celebrate their life, and help the family reinforce the patient’s values or wishes (Ciccarello, 2003; Halcomb et al., 2004). One component of a good death has been defined as allowing the family to obtain closure. Nurses can facilitate closure by allowing family members to participate in physical care activities, such as bathing or turning, and by suggesting that family members lie in bed with the patient, if desired (Kirchhoff & Beckstrand, 2000). Other expert nursing behaviors include communicating effectively with the patient’s family and colleagues, providing an opportunity to complete unfinished business, showing empathy, achieving pain and symptom management, and showing respect by providing a peaceful scene after death has occurred (McClement & Degner, 1995).

Communication is an important relational factor in providing end-of-life care (Carlet et al., 2004; Kirchhoff & Beckstrand, 2000; Kirchhoff et al., 2000; Matzo, Sherman, Sheehan et al., 2003; “The SUPPORT Principal Investigators,” 1995). In fact, communication at the end of life has been identified by families as the most essential skill for critical care nurses to possess (Ciccarello, 2003). Good communication skills include listening attentively, addressing concerns, dealing empathetically with emotions, and providing frequent contact and presence (Danis et al., 1999). Communication has become so important in end-of-life care that the End-of-life Nursing Education Consortium

(ELNEC) (Matzo, Sherman, Sheehan et al., 2003) has devoted a whole education session in their national certification course to teaching nurses communication skills such as listening to patients, encouraging questions, being honest and straightforward, being sensitive, and being willing to talk about dying (Curtis et al., 2001). Nurses reporting feelings of burnout identified problems with communication among patients, families, and physicians as significant contributors to their dissatisfaction, and the primary barrier identified by nurses is the tension and conflict experienced between physicians, families, and other health care providers (Halcomb et al., 2004; Kirchhoff & Beckstrand, 2000). Therefore, effective communication between nurses and other health care providers as well as between nurses and patients or family members is a skill that must be mastered.

Limitations

An obvious limitation of this model is the fact that it is a model based on marital satisfaction. This theory was derived from empirical evidence and has been used successfully to support research on marriage, but the theory's applicability to nursing practice has not been tested. However, intensive care nursing is similar to marriage in that it involves an intimate relationship between two individuals: the patient and the nurse. Another similarity to marriage is that like marriage, the nurse-patient relationship is based on trust during one of the most vulnerable points of life.

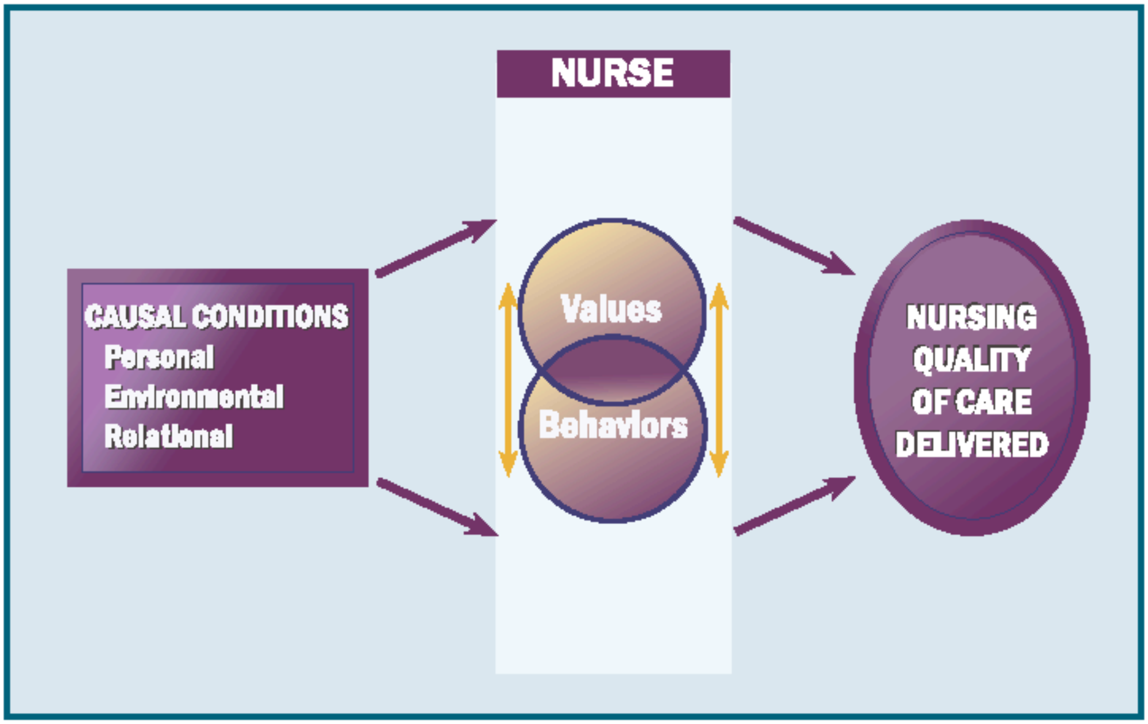
The selected theory does not fully explain nurses' ability to provide quality end of life care in the ICU, but does recognize that personal, environmental, and relational factors can influence the nurses' ability to provide this type of care. Along with the personal, environmental, and relational factors that can facilitate or hinder the nurse in this role, the nurse's values and behaviors could also be examined using this model. The values and beliefs of health care providers has been shown to highly correlate with their desire to improve their knowledge and skills, as well as their ability to provide quality care to dying individuals (Cartwright et al., 1997; Dalton et al., 1998; Danis et al., 1999; Frommelt, 1991; Mallory, 2003; Quill, 2000).

Conceptual Framework

In order to provide quality end-of-life care in the ICU, the nurse must examine the personal, environmental, and relational factors inherent in ICU nursing, in order to gain an intuitive grasp of each situation and focus on the goal of the patient and family without wasteful consideration or unsuccessful solutions. Critical care nurses have identified struggles with moral distress, ethical dilemmas, and role responsibility during the transition from critical care to end-of-life care as personal factors when caring for dying patients and their families. Within this framework, as depicted in Figure 1, the expert nurse is able to provide optimum care by examining the personal factors associated with end-of-life care and using skills such as advocacy, communication, and debriefing to reduce the impact of distress on their ability to care for these patients. In terms of environmental factors, the nurse who is able to provide optimum care will be able to provide a balance between caring for the patient and caring for the family while also allowing time for self debriefing. Skill in responding to fragmentation of care, noise, and technology in the ICU must be developed in order to reduce the effects of these environmental factors on the ability to provide end-of-life care. The expert nurse will use the technology of the ICU to benefit the patient and family without letting the technology interfere with the ability of the family to interact with the patient. In terms of relational conditions, this framework suggests that the nurse who provides optimum care will overcome the ambiguity, lack of feedback, and conflicts in decision making among the patient, family, and health care providers.

Using this conceptual framework, the nurse must respond to the personal, environmental, and relational factors inherent in the ICU system and have the values and behaviors needed to blend end of life and intensive interventions to improve the death experience from the perspectives of both the family and the nurse. Currently, there are no instruments that examine the values and behaviors of the critical care nurse when providing end-of-life care.

Figure 1: The Value-Behavior Congruency Model



Summary and Future Work

The VBC model has been useful in explaining the relationship between marital satisfaction and quality among married couples. For the current study, this conceptual model has been adapted to examine the values and behaviors critical care nurses' face when providing end-of-life care to patients and family members. The nurse who provides quality end-of-life care is one who is skilled at recognizing and addressing obstacles and developing strategies to make the transition from curative to palliative care a dignified process for patients, families, and healthcare providers (Gross, 2006).

Designing an instrument that will assess nursing values and behaviors is the first step to understanding how the values and behaviors of critical care nurses impact the delivery of care. Bowen's model indicates that in order for quality to be achieved, perspectives from the family and nurse should be examined. Although the family and patient perspective is a necessary component for Value-Behavior Congruency, the purpose of this study is to examine values and behaviors from the nursing perspective with future work concentrating on blending these identified values and behaviors in order to understand how these concepts relate to each other and the delivery of quality care.

CHAPTER 3

RESEARCH METHODOLOGY

The overall purpose of this study was to develop and test an instrument to assess nurses' values and behaviors when providing end-of-life care in the ICU. This study consisted of three phases of instrument development. In Phase I, a content analysis of the literature was conducted along with qualitative interviews of adult critical care nurses to identify the domains and subdomains needed to generate items for what became two instruments. Two instruments were created as it was evident that there was a clear distinction between nurses' values and their behaviors. For Phase II of the study, the two instruments were subjected to content validity assessment based on the domains and subdomains identified by the content analysis and pilot tested during three group sessions. Phase III consisted of field testing of the instruments and assessment of the psychometric properties of the two instruments.

Phase I

Phase I consisted of item generation based on the researcher's pilot study. The pilot study consisted of a literature synthesis and qualitative interviews with critical care nurses. According to DeVellis (2003) and Lynn (1995), identification of quality nursing behaviors with end-of-life care through literature reviews and qualitative interviews is the first step in designing two instruments to assess nurses' values and behaviors when providing end-of-life care in the ICU. The literature review was combined with results from the qualitative interviews to determine the domains for what became the two instruments.

The literature reviewed included primary peer-reviewed studies in which the role of the ICU nurse in providing end-of-life care was examined. Unpublished papers and papers published in a language other than English were excluded. Qualitative, mixed methods, and quantitative studies were reviewed to include the broadest range of research. Additionally, end-of-life textbooks, nursing textbooks, and critical care organization documents on improving end-of-life care were also examined.

Cumulative Index to Nursing and Allied Health (CINAHL), PubMed, and Dissertation Abstracts International were searched for publications between 1996-2006. Search terms included palliative care, end-of-life care, intensive care unit, nursing, competence, barriers, attitudes, behaviors, quality, and expert behavior. The concepts identified in the literature were extrapolated to identify key components of nursing quality care in the ICU setting.

After the literature review, nine nurses working in adult critical care units were interviewed and asked to describe what constitutes quality end-of-life care. Nurses were asked to define optimum end-of-life care in the ICU, identify barriers to providing this care, and offer suggestions for improving this care. The interviews were semi-structured to guide the participants to describe both positive and negative experiences with providing end-of-life care in the ICU. The transcripts were reviewed with an unbiased, receptive presence and critiqued for any personal biases, in order to suspend judgment and see the true experience of providing quality end-of-life care in the ICU (Moustakas, 1994; Patton, 1990). Field notes were reviewed to determine the emotion and context of the participants' responses, and credibility of the statements was also confirmed by examining the context to which the statement was made (Patton, 1990). The transcripts were read and independent and complete phrases underlined. The transcripts were read multiple times in order to ensure that all relevant phrases were identified (Morse & Field, 1995).

The underlined phrases were pulled from the transcripts and examined as potential items for the later instrument development. Once all of the phrases were pulled out of the transcripts, the underlined phrases were labeled as either a value or behavior and classified as either a personal, environmental, or relational factor as defined by the Value-Behavior Congruency model. The potential items were then sorted into piles of similar themes and patterns. These potential items were critiqued by a second researcher to achieve inter-researcher validity (Morse & Field, 1995; Moustakas, 1994). Dependability was determined by reviewing the transcripts and analysis with the researcher's dissertation chair (Flick, 2002; Sandelowski, 1993), whose interpretations of the data were compared to the researcher's for similarities and differences. Any discrepancies were clarified by returning to the transcripts for further analysis. After reviewing the potential items, the data were considered saturated and no additional interviews were conducted.

Due to the large number of items and apparent distinction between the two concepts of values and behaviors, it was determined that two instruments would be created. Phrases were sorted into two piles, one consisting of potential values items and one for behaviors. Similar phrases were combined and refined to create one item addressing either nursing values or nursing behaviors when providing end-of-life care in the ICU. Three critical care experts were asked to determine credibility and confirmation of the analysis by reading through the phrases in each pile and determining if the items conveyed values or behaviors when providing end-of-life care in the ICU (Halcomb et al., 2004; Sandelowski, 1993). These phrases were then selected as potential items for two nursing instruments: *Values of Intensive Care Nurses for End of Life (INTEL-Values)* and *Behaviors of Intensive Care Nurses for End of Life (INTEL-Behaviors).*

Before being subjected to content validity testing, the *INTEL-Values* consisted of 44 items designed to measure general nursing values towards providing end-of-life care in the ICU and the *INTEL-Behaviors* instrument contained 30 items assessing specific nursing behaviors performed when providing end-of-life care in the ICU.

Phase II

As part of Phase II of the instrument development process, the instruments were subjected to content validity assessment by critical care nurses actively practicing in adult intensive care units. Participants were recruited from a mix of academic institutions, university hospitals, and community hospitals in order to provide a heterogeneous sample. A total of eight critical care nurses who had cared for dying patients and their families served as content validity experts. Participants were mailed the new instruments and instructions for completing the content validity evaluations. They were asked to review the items and determine if the items were appropriate elements of nursing values and behaviors when providing end-of-life care. The content validity index (CVI) was calculated by asking participants to rate each item on a 4-point scale, as it related to the definition of nursing values or behaviors when providing end-of-life care in the ICU, with 1 = not relevant; 2 = unable to assess or in need of so much revision that it would no longer be relevant; 3 = relevant but needs minor revision; and 4 = very relevant and succinct (Lynn, 1986).

The CVI was calculated as the proportion of experts who rated each item a 3 or 4, and the CVI for the total instrument was calculated as the proportion of total items judged a 3 or 4. Items were eliminated or revised if they did not have a CVI above the recommended .80 agreement (Knapp, 1985; Lynn, 1986). In addition, items were reviewed for their clarity and conciseness, and individuals were asked if any area of quality end-of-life care in the ICU was missing. Items were deleted, revised, or added based on the recommendations of the content validity experts. After content validity testing, the *INTEL-Values* and *INTEL-Behaviors* instruments were formatted using a Likert response format. Both instruments initially used a 5-option response format which consisted of strongly disagree; disagree; sometimes disagree/agree; agree; and strongly agree.

The revised instruments were then pilot tested in three group sessions with a total of 12 critical care nurses recruited from two teaching hospitals and one community hospital. Group sessions were used for this phase of the instrument development process because this format encourages brainstorming and interaction to determine the best structure of potential items, directions, and formatting for the two instruments. Critical care nurses who had cared for dying patients and their families were eligible for participation in this phase of the instruments' development. Nurses were recruited by placing flyers in the ICU work areas as well as in each critical care nurse's mailbox. Flyers contained information about the study, purpose of the pilot groups, overall aims of the study, selected dates for the group sessions, and contact information of the researcher.

Participants contacted the researcher by email with their preferred group date, and an appointment was confirmed electronically.

Participants in the pilot test groups completed consent forms, demographic sheets, and the proposed instruments, before being asked to provide feedback regarding ease of completion and clarity of items (Damrosch, 1986). Participants also were asked to provide comments on the instruments' directions, item structure, and response options as part of an instrument review group session. This group session was audiotaped to insure clarity. Participants were instructed to maintain confidentiality of the other participants as part of the informed consent process. Participants received $25 cash after participating in the pilot test.

After completion of Phase II, the items were re-evaluated and revised based on the feedback of the pilot participants. The two nursing instruments (*INTEL-Values* and *INTEL-Behaviors)* were then formatted for online administration.

Phase III

Phase III consisted of field testing of the instruments with 857 critical care nurses in the United States. A sample of at least 510 respondents was needed because the *INTEL-Values*, the longer of the two instruments, contained 51 items, and a ratio of 10 subjects per item is recommended (DeVellis, 2003; Lynn, 1995) Participants were registered nurses who actively practiced in an ICU and had cared for at least one dying patient and his or her family. Participants were recruited from the American Association of Critical Care Nurses (AACN) national organization database. AACN is the world's largest critical care organization with over 400,000 members. AACN members are connected by an email newsletter, with the majority of members relying on email as their primary contact information. An email announcement was sent to all AACN members through the electronic newsletter which provided participants with information about the study as well as a hyperlink that connected the two instruments to the newsletter. AACN members who accessed this internet link were provided with a consent form and asked to complete the two instruments online. They were asked to provide their unique AACN membership number for identification of test-retest participants. The consent form was followed by a button that, when selected, served as their acceptance to participate in the study without obtaining any identifying information. There was no tracking or storing of email or ISP addresses. Survey Monkey was used as the platform for online administration of the instruments.

In order to assess test-retest reliability, a second email was delivered to every AACN member in the AACN database two weeks after the first completion of the instruments. In this email, the purpose of the test-retest was described and individuals were asked to complete the instruments a second time. A 2-week interval between administration times was selected because it limits the recall of responses provided on the first administration (DeVellis, 2003). Included in the email was the link to complete the instruments and a second consent form. Participants used their AACN membership number as an identification number for the second administration. The first assessments and the retest assessments were matched by the AACN membership numbers.

After the test-retest portion was completed, factor analysis and reliability testing was conducted for each instrument using Statistical Package for the Social Sciences (SPSS) 14.0. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was used to determine if the factors for each instrument were easy to identify. Bartlett's test of sphericity was used to determine whether the matrix was an identity matrix to determine if a factor model was appropriate for each instrument. The Scree plot was used to estimate the number of factors for each instrument.

The principal axis factoring method (PAF) was chosen as the extraction method in order to avoid overestimating the number of factors or the item loadings on the factors, which is common with the principal components analysis technique. Oblique and orthogonal rotations were examined to look for the most interpretable factor structure. The number of factors to be rotated was determined by the "elbow" of the Scree plot. One less and one more factor than the number of factors at the elbow were rotated to identify the most salient factor structure. The minimum factor loading was set at .35 for an item to belong to the factor, and items were not included if they contained double loadings. Double loadings were defined as having a difference of .15 between the highest and lowest loading (Tabachnick & Fidell, 2001). The factors were named by reviewing the items from the highest to the lowest factor loadings and identifying a name that best encompassed most of the items on the factor.

The data from the test-retest sample of participants were analyzed for stability across the 2-week period. Both Pearson's correlations and Kappa statistics were used to examine the stability of the factors; with stability considered sufficient with a Kappa of $>$ .5 or a Pearson correlation of $>$ .7 (DeVellis, 2003). Cronbach's alpha was calculated for each factor and alpha values >.7 were considered acceptable, as the instruments are in the first stage of development. After the factor analysis, the remaining items were considered the final instruments.

CHAPTER 4

RESULTS

The results of this study are presented using the methods presented in the three phases of instrument development previously described. In Phase I, a content analysis of the literature was conducted along with qualitative interviews to identify the domains and subdomains needed to generate items. Two instruments evolved and were used to assess ICU nursing values and behaviors when providing end-of-life care. In Phase II of the study, the two instruments were subjected to content validity assessment and pilot testing. Phase III consisted of field testing of the proposed instruments and analysis of the psychometric properties.

Phase I

Sample for qualitative component

Phase I consisted of content analysis of the literature and qualitative interviews. In order to determine nurses' perceptions of optimal values and behaviors when providing end-of-life care in the ICU, nine critical care nurses were interviewed. Participants ranged in age from 26 to 56, with an average of 10.3 years of clinical experience in adult ICU settings (*SD*= 8.57). They were employed full time at an academic medical center in the Southeastern United States in the burn center (1)[1], medical ICU (3), surgical ICU (1), coronary care unit (2), and the cardio-thoracic ICU (2). Twenty-two percent of this

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[1] The number in parentheses represents the number of nurses interviewed from the specific intensive care unit.

sample were male, and 11% were African American, which approximates the demographics of practicing critical care nurses ("AACN Member Demographics," 2004).

A total of 163 potential items were identified from the interviews with adult critical care nurses. Only items judged to be addressing the concepts of nursing values or behaviors when providing end-of-life care in the ICU were selected for inclusion in the instruments. Accordingly, the only items retained were ones that fell into these two domains. After removing duplicate items, items were eliminated based on criteria outlined in DeVellis (2003) which includes eliminating items of great length--- "*Families want to see the moment when the death occurs, so some I don't set the privacy screen, but I do minimize all of the alarms"* items containing multiple negatives---"*I am really here to help the patient, and that's what I'm supposed to be doing, not dealing with family members"* and items that elicit only a yes or no response---"*I have been accused of euthanizing the patient."* Additionally, items were eliminated if it was determined that the item would not elicit a variety of responses. For example, "*An optimum death is one free from pain"* would most likely have resulted in responses of strongly agree, and thus would not have been a good item for the purpose of this instrument development due to its small variance. Thus, the potential item pool was reduced to 74 items.

Due to the clear delineation between the two concepts of values and behaviors, it was determined that two instruments were needed. Thus, two instruments were created; one measuring nursing values, and the other examining nursing behaviors. The *Values of Intensive Care Nurses for End of Life (INTEL-Values)* instrument initially contained 44 items and the *Behaviors of Intensive Care Nurses for End of Life (INTEL-Behaviors)* contained 30 items.

Phase II

Phase II of the instrument development process involved content validity assessment and pilot testing of the instruments. Content validity assessment was performed to determine that the items were accurate indicators of values and behaviors. Content validity participants were mailed the instruments asked to rate each item on a 4-point scale as it related to the definitions of values and behaviors when providing this care in the ICU. The responses provided by the content validity experts were used to calculate content validity index scores for each item and an overall content validity index. Revisions were made to the instruments following content validity assessment and pilot testing was conducted in a group format. A group format was used to encourage brainstorming and group consensus regarding the items for both instruments. Participants completed the two instruments individually and then provided feedback regarding ease of completion and clarity of items. Participants also were asked to provide comments on the instruments' directions, item structure, and response options as part of an instrument review group session.

Sample for content validity

The content validity experts consisted of eight registered nurses at academic institutions, medical, and community hospitals throughout the United States. They were reasonably heterogeneous in their demographics as participants ranged in age from 29-54, (*mean=42.8 years; SD*=8.47) and worked an average of 15 years in the critical care setting (*SD*=7.83). All content validity experts reported comfort with providing end-of-life care to patients and their families. Additional demographic characteristics are presented in Table 1.

Table 1: Demographic Characteristics for Content Validity Experts

Variable	Frequency	Percent (%)
Gender		
Female	7	88.5
Male	1	12.5
Race		
Caucasian	7	87.5
African American	1	12.5
Highest Education Level		
Bachelor of Science in Nursing	2	29.0
Master of Science in Nursing	4	57.0
Doctorate in Nursing	1	14.0
Missing	1	---
Type of Institution		
Academic Medical Center	4	50.0
Community Hospital	2	25.0
College/University	1	12.5
Other	1	12.5
Comfort level for patients		
Strongly Agree	7	87.5
Agree	1	12.5
Comfort level for families		
Strongly Agree	7	87.5
Agree	1	12.5

The total CVI for the *INTEL-Values* instrument was 0.88. Eight items were found to have a CVI <.80, the a priori cut off for items with eight judges (Lynn, 1986). Of these 8 items, 2 were deleted and the remaining 6 were revised for clarification. The experts offered no suggestions for twenty-six items, and the remaining ten items were revised to provide clarification of the underlying concept. For example, the item "*Feel uncomfortable when families tell me 'God' will save them*" was revised for appropriateness to all religions, and was reworded to "*Feel uncomfortable when families tell me their particular spiritual belief will save them.*" The CVI for *INTEL-Values* and the item revisions are presented in Appendix 1.

For the *INTEL-Behaviors* instrument, the total CVI was 0.96 and only 1 item did not meet the recommended CVI value (>.80). The item "*Assured the family that their decisions were made carefully*" was revised based on suggestions from the experts to read "*Assured the family that they made the best decisions possible*." Twelve items did not require any changes and the remaining items had minor grammatical changes. For example, the item "*Removed myself from the room when the family had no other direct requests for me*" was revised to "*Offered privacy by leaving the room when the family had no other requests for me.*" The CVI for the *INTEL-Behaviors* instrument and the item revisions are presented in Appendix 2.

The experts made suggestions for additional items and requested more emphasis on advance care planning and decision making. For the *INTEL-Values* instrument, three questions were added: "*Find that I administer less pain medication to the patient when the family is not present during the death*," "*Feel uncomfortable staying with the family when they have no direct requests*," and "*Am comfortable asking questions to find out the patient's wishes (advance directives)*." For the *INTEL-Behaviors* instrument, two items were added: "*Inquired whether the patient had advance directives*," and "*Explained to the family what would happen to the patient throughout the dying process*." Experts also suggested adding items related to autopsy, funeral home, or organ donation but these were not added as they exceeded the scope of the newly developed instruments.

Sample for Pilot testing

Twelve adult critical care nurses from two large academic medical centers and one community hospital participated in pilot testing of the two instruments. Pilot participants were primarily female with an average age of 40.6 years (*SD*=11.4*)* and an average of 9.15 years (*SD*=8.06*)* practicing in adult intensive care units. The full demographic summary is presented in Table 2.

Table 2: Demographic Characteristics of Pilot Participants

Variable	Frequency	Percent (%)
Gender		
Female	9	75
Male	3	25
Race		
Caucasian	11	92
African American	1	8
Highest Education Level		
Diploma in Nursing	1	8
Bachelor of Science in Nursing	9	76
Master of Science in Nursing	1	8
Doctorate in Nursing	1	8
Type of Institution		
Academic Medical Center	9	75
Community Hospital	3	25
Type of ICU		
General	1	9
Medical	7	55
Surgical	2	18
Neuroscience	2	18

One group session was held for nurses from one of the academic medical centers and two group sessions were held for a mixture of academic medical center and community hospital critical care nurses. Flyers were also distributed at an additional community hospital but no nurses responded to the flyers.

After analysis of the three pilot testing group sessions, it was determined that no new information would be provided by the additional institution, and no further pilot testing feedback was needed. Thus, the decision was made that the remaining community institution was not needed.

In pilot testing the *INTEL-Values* instrument, participants reported that the items for this instrument were clear and the responses matched well with the items. They did not feel that the items elicited a yes or no response but required them to think about their true feelings regarding the items.

Additionally, they preferred a *sometimes disagree/sometimes agree* option rather than a neutral or indifferent middle. No items were deleted after pilot testing but items were revised for clarity. After feedback from the pilot participants, minor changes were made in wording and ordering of items. For example, the item "*Take a step back and try to understand the conflict the family is facing"* was revised to read "*Am able to take a step back and understand the conflict the family is facing*," as participants felt this phrasing elicited more of a valuing or attitudinal response instead of an action or behavior response. Five questions were added based on feedback from the pilot participants: "*Find that other healthcare providers I work with do not provide optimum care for a dying patient and her/his family," "Am afraid of dying,"* "*Wish I could request another assignment when assigned to a dying patient,"* "*Believe other healthcare providers* *(management/other nurses) view dying patients as an "easier" care assignment*," and "*Feel that I have no time to debrief after caring for a dying patient."*

For the *INTEL-Behaviors* instrument, no items were deleted but items were revised for clarity. One major revision based on the feedback of the pilot participants was in the response options. Originally formatted as a five response Likert scale, the majority of pilot participants indicated that this response format was problematic, especially if the behaviors occurred only once in their interaction with the patients or family. Based on their feedback, the directions were revised and participants were asked to identify how often they provided this behavior to a specific patient and/or family member. The response format was changed to the following five option rating scale: *never, rarely, sometimes, usually, or always provided care to the patient and/or family every time it was offered.* Five neuroscience critical care nurses then compared the revised format and options to the previous Likert response format. These nurses expressed unanimous support for the new response format and options.

The pilot participants also suggested minor changes in wording and ordering of questions. Items involving advance care planning and advance directives were suggested to come earlier in the *INTEL-Behaviors* instrument as they thought that this provided better structure and flow to the instrument. Four additional items were added: "*Notified the chaplain so that they could visit with the patient and family," "Informed my colleagues that this patient was dying (posted a sign, verbally informed colleagues, etc)," "Talked about my feelings after the death with a friend, manager, or colleague,"* and "*Optimized family dynamics at the bedside*."

Phase III

After pilot testing, the two instruments were formatted for online completion using Survey Monkey. The instruments were field tested using a national sample of critical care nurses obtained through an electronic newsletter distributed by the American Association of Critical Care Nurses. An email announcement was sent to all AACN members, who subscribed to the electronic newsletter, providing them with information about the study as well as a hyperlink that connected the two instruments to the newsletter. Participants read the consent form, and then completed the instruments. After field testing, the structure and psychometric properties of the instruments were examined using SPSS version 14.0.

Sample for field testing

It is impossible to determine the true response rate as some individuals may have never received the email notice due to improper mail delivery or electronic spam filters. AACN is the largest specialty critical care organization and it is estimated that 9,000 individuals subscribe to the electronic newsletter. A total of 857 critical care nurses completed some portion of the instruments with 716 completing both instruments in their entirety. Eleven people viewed the consent form but did not proceed to the instruments. Of the 716 nurses completing the two instruments, 684 participants also provided demographic information. Participants were primarily female with an average age of 44.1 years (*SD*=10.7*)* and an average of 14.71 years (*SD*=10.3*)* practicing in intensive care units. Participants came from every state in the U.S. with the exception of South Dakota and Wyoming. Additionally, nurses practicing in Canada (4)**[2]**, Belgium (1), Puerto Rico

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[2] The number in parentheses represents the number of individuals from each country.

(1), and Australia (1) completed field testing of the instruments. Demographic characteristics of these participants are presented in Tables 3 and 4.

Exploratory Factor Analysis for INTEL-Values

The data were examined and the number of missing values identified. Respondents were deleted if they had more than 10% of their responses missing. Thus, any respondent with six or more missing responses on the *INTEL-Values* instrument (51 items) were dropped from the analysis. Of the 716 individuals who completed this instrument, 21 had six or more missing responses and were deleted. A total of 695 respondents were included in this exploratory factor analysis for the *INTEL-Values* instrument. Descriptive statistics and frequency of responses for the items are included in Appendix 3.

The statistical tests preceding the Exploratory Factor Analysis (EFA) resulted in concern over the strength of the factor structures. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .75, suggesting that clear factors may not be easy to identify. The KMO should exceed .80 for ease in partialling out the variables (Pett, Lackey, & Sullivan, 2003). Bartlett's test of sphericity, which tests the hypothesis that this matrix is an identity matrix was large (5725.932) and significant ($p<.001$). This indicated that the matrix is different from the identity matrix, and therefore a relationship exists among the variables (Pett et al., 2003).

Table 3: Personal Demographics Characteristics of Field Test Participants (n=684)

Variable	Frequency	Percent
Gender		
Male	60	8.8.8
Female	621	91.2
Missing	3	---
Race		
Caucasian	628	93.5
African American	17	2.5
Native American	3	0.4
Asian	19	2.8
Other	5	0.7
Missing	12	---
Ethnicity		
Hispanic	18	3.6
Non-Hispanic	484	96.4
Missing	182	---
Personal or Family Experience with End-of-Life Care in the ICU		
Yes	243	36.2
No	429	63.8
Missing	12	---
Comfort providing end-of-life care to patients		
Strongly Disagree	16	2.3
Disagree	3	0.4
Sometimes Disagree/Agree	25	3.7
Agree	186	27.3
Strongly Agree	452	66.3
Missing	2	---
Comfort providing end-of-life care to families		
Strongly Disagree	15	2.2
Disagree	11	1.6
Sometimes Disagree/Agree	31	4.6
Agree	212	31.3
Strongly Agree	409	60.3
Missing	6	---

Table 4**:** Professional Demographics Characteristics of Field Test Participants (n=684)

Variable	Frequency	Percent
Highest Education Preparation		
Associate's Degree	104	15.2
Diploma	38	5.6
Bachelor of Science in Nursing	295	43.1
Bachelors Degree (non-nursing)	63	9.2
Master of Science in Nursing	136	19.9
Masters Degree (non-nursing)	30	4.4
Doctorate in Nursing	12	1.8
Doctorate (non-nursing)	6	0.9
Employing Institution		
Academic Medical Center	322	48.3
Federal Hospital	25	3.8
Private Hospital	67	10.1
Community Hospital	251	37.7
Other	1	0.2
Missing	18	---
Employing ICU		
Surgical	82	12.1
Coronary Care	51	7.5
Cardiothoracic	26	3.8
Neurological	51	7.5
Medical	74	10.9
General	325	48.1
Other	67	9.9
Missing	8	---
Current Position		
Registered Nurse	476	70.4
Nurse Manager	66	9.8
Nurse Practitioner	22	3.3
Staff Educator	49	7.2
Faculty	10	1.5
Clinical Specialist	46	6.8
Other	7	1.0
Missing	8	---

Principal axis factoring (PAF) was selected since it is the more conservative approach compared to principal component analysis (PCA). PAF attempts to explain the unique variances and does not attempt to explain error variance, producing lower loadings and lower explained variance (Costello & Osborne, 2005; Pett et al., 2003). The elbow of the scree plot occurred at 3 factors, which was the starting point in examining the number of factors. A thorough examination of all factors between 2 and 5 was completed, using both orthogonal and oblique rotations.

The orthogonal and oblique rotations for the two, three, and five solutions produced many double loadings, and the initial loadings of the items on the factors were not reasonably high, with only a few items loading above .35 on their respective factors. The four factor solution (oblique rotation) was the best solution because the majority of the loadings on the factors were high (>.35) and there were fewer double loadings. Thus the decision was made to select the four factor solution since the other factor solutions appeared too dispersed, possessed more double loadings, and the items on the other factors lacked a clear factor assignment. The factors on the four factor solution (oblique) were identified as follows: Self-appraisal; Appraisal of Others; Emotional Strain; and Moral Distress.

Twenty-five items were deleted due to double loadings or loadings less than 0.35 on the factor. Factor 1 (Self-appraisal) contained 13 items, Factor 2 (Appraisal of Others) contained 6 items, Factor 3 (Emotional Strain) contained 4 items, and Factor 4 (Moral Distress) contained 4 items. The total variance explained by the four factors was 25.8%. The items and respective factor loadings are presented in Appendix 4.

Reliability Analysis for INTEL-Values

Factor 1 (Self-appraisal) had an alpha of .78. No items were deleted from this factor because the alpha, if item deleted, did not indicate any increase in value. The inter-item correlations were between .12 - .41, which were lower than desirable and will be discussed in the next chapter.

Factor 2 (Appraisal of Others) had an alpha of .71. The inter-item correlations ranged from .18 - .78. The items "*Find that other healthcare providers I work with do not provide optimum care for a dying patient and her/his family*" and "*Find that other healthcare providers I work with do not know how to provide optimum care for a dying patient and her/his family*" were highly correlated (r = .78) indicating that one of the items was not needed and thus one should be deleted. However, the alpha of the factor would drop substantially (.64 and .65 respectively) so neither item was deleted.

Factor 3 (Emotional strain) had an alpha of .59. The decision was made to delete the item "*Find that some patients' deaths are more difficult because they make me think of the death of someone I cherish*." The decision to remove the item was based on the fit of the items after reading all the items in the factor. This item possessed the lowest loading on the factor (.40). The alpha increased to .62 once this item was deleted. The inter-item correlations ranged from .15 - .73. The items "*Am afraid of dying*" and "*Am afraid of death*" were highly correlated, (r=.73) suggesting these items are redundant and should be deleted. They were not deleted as the alpha would have decreased to .42 if the item was removed.

Factor 4 (Moral Distress) had an overall alpha of .60. No items were deleted from this factor. Inter-item correlations ranged from .16 - .34 which was again considered low.

Items Deleted from INTEL-Values

Two items were deleted due to loadings on more than one factor. These items addressed religious beliefs and comfort with emotions. Twenty-two items were deleted for insufficient loadings on the factor (<.35) and reflected concepts surrounding ‘Do Not Resuscitate’ orders, communication, conflict resolution, and debriefing.

Reverse Scoring of INTEL-Values

Twenty-three negatively worded items were reversed to organize the items in the same orientation and to determine if this increased the factorability of the matrix. For example, the item “*Am afraid of dying*” was reversed to be interpreted so that individuals who scored “strongly disagree” on this item would be seen in the same orientation as those who selected “strongly agree” for the item “*Believe it is undignified to prolong the dying process in the ICU*.”

Test-Retest for INTEL-Values

AACN members were sent an additional email through the electronic newsletter asking them to complete the instruments again after two weeks. Thirty individuals completed the instruments a second time. The average age of these participants was 45.37 years *(SD*=10, range 23-60 years*)* with an average of 15.9 years experience in as an ICU nurse *(SD*=10.7, range 1-35 years*)*. Pearson’s correlation and Kappa were used to assess stability of the factors over the two week time period. The intra-class correlation (ICC) was also used as another assessment of stability (Pett et al., 2003). These values are presented in Table 5.

Table 5: Test-Retest Result for INTEL-Values

Factors	Pearson's Correlation	Kappa	ICC
Self-appraisal	.68	.13	.65
Appraisal of Others	.73	.05	.70
Emotional Strain	.79	.30	.78
Moral Distress	.81	.20	.80

Sample for INTEL-Behaviors

The data were examined and respondents were deleted if they had more than 10% of missing data. Thus, any respondent with four or more missing responses on the *INTEL-Behaviors* instrument (34 items) was dropped from the analysis. Of the 687 individuals who completed this instrument, 5 had four or more missing responses and were deleted. A total of 682 respondents were included in this exploratory factor analysis for the *INTEL-Behaviors* instrument. Descriptive statistics and frequency of responses for the items are included in Appendix 5.

Exploratory Factor Analysis for INTEL-Behaviors

The statistical tests preceding the Exploratory Factor Analysis (EPA) indicated that the factors should be easier to recognize than the *INTEL-Values* instrument. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .88, with KMO values exceeding .80 exhibiting greater ease in partialling out the variables (Costello & Osborne, 2005; Pett et al., 2003). Bartlett's test of sphericity, which tests the hypothesis that this matrix is an identity matrix was large (3947.98) and significant ($p<.001$). Therefore the data were amenable to the subsequent factor analysis.

Principal axis factoring (PAF) was used for this analysis as it is the more conservative approach. The elbow of the scree plot occurred at 2 factors, which was the starting point in examining the number of factors. A thorough examination between factors two through four was completed, with both orthogonal and oblique rotations.

Orthogonal and oblique rotations for the three and four factor solutions produced many double loadings, and the initial loadings of the items on the factors were not high, with only a few items loading above .35 on their respective factors. As with the *INTEL-Values* instrument, it was determined that item loadings on the factor should be greater than .35 (Costello & Osborne, 2005). The orthogonal rotation was conducted in order to simplify the factors by maximizing the variance within each factor across the variables (Tabachnick & Fidell, 2001). The two factor solution using oblique rotation was considered to be the best solution because the three and four factor models did not have high item loadings, and only two items loaded on the last factor. Thus the decision was made to select a two factor solution since the other factor solutions appeared too dispersed, possessed more double loadings, and the items on the other factors lacked a clear factor assignment. The factors on the two factor solution (oblique) were identified as Communication and Nursing Tasks.

Fifteen items were deleted due to double loadings or loadings less than 0.35. The Communication Factor contained 12 items and the Nursing Tasks factor contained 7 items. The total variance explained by the factor analysis was 24.9%. The items and respective factor loadings are presented in Appendix 6.

Reliability Analysis for INTEL-Behaviors

Factor 1 (Communication) had an initial alpha of .78. The decision was made to delete the item "Told the family what I would do in their circumstances when they asked my opinion." The decision to remove the item was based on the fit of the items after reading all the items in the factor. This item possessed the lowest loading on the factor (.36) and the lowest inter-item loadings (.07); and the alpha increased to .79 once this item was deleted. The inter-item correlations were between .14 - .43, which were lower than desirable and will be discussed in the next chapter.

Factor 2 (Nursing Tasks) had an alpha of .67. No items were deleted in this analysis as it appeared that they correlated well with each other and the factor did not benefit from having items removed. The inter-item correlations ranged from .10 - .35.

Items Deleted from INTEL-Behaviors

There were no items in the two factor analysis that possessed double loadings. Fifteen items were deleted for insufficient loadings on the factor (<.35) and these items reflected concepts surrounding debriefing, family conflict, care after the death, pain medication, and utilizing resources.

Test-Retest for INTEL-Behaviors

The sample for the test-retest portion of the *INTEL-Behaviors* instrument was the same as the *INTEL-Values.* Pearson's and intra-class correlations (ICC), along with Kappa, were used to assess stability of the factors over the two week time period (Pett et al., 2003). These values are presented in Table 6.

Table 6: Test-Retest Results for INTEL-Behaviors

Factors	Pearson’s Correlation	Kappa	ICC
Communication & Decision Making	.77	.02	.77
Nursing Tasks Ensuring a Peaceful Death	.81	.40	.82

Summary of Results

For the *INTEL-Values* instrument, a total of 695 respondents were included in the exploratory factor analysis. A thorough examination of factor solutions 2-5 was completed after examining the scree plot, and orthogonal and oblique rotations were conducted. The four factor model (oblique rotation) was selected as the best fit with the factors identified as Self-appraisal; Appraisal of Others; Emotional Strain; and Moral Distress. Individual item alphas were acceptable at .60 - .78, but the inter-item (.12 - .78) and item total correlations (.31 - .48) were low. Reliability testing for consistency and stability over a two week period yielded low Kappa values (.05 - .30) on all four factors. Pearson’s correlations among the four factors were high (.68 - .81) and intra-correlation coefficients were high (.65 - .79).

The *INTEL-Behaviors* was administered to 682 respondents. After examining the scree plot, an exploratory factor analysis was conducted and an examination of factors 2-4 was performed. Unlike the *INTEL-Values*, this instrument possessed higher factor loadings and the items were easily interpreted across the factors. A two factor model (oblique rotation) possessed distinct domains and was selected as the best fit with the factors identified as Communication and Nursing Tasks. Individual item alphas were acceptable (.67 and .78), but the inter-item (.20 - .35) and item total correlations (.30 -

.61) were low. Reliability testing for consistency and stability over a two week period yielded low Kappa values (.02 - .40) on both factors. Correlations among the factors were high (.77 - .81). The interpretation of these findings will be discussed in the next chapter. The first page of the final *INTEL-Values* and *INTEL-Behaviors* instruments are presented as Appendix 7.

CHAPTER 5

DISCUSSION

In this chapter, the results of the study are discussed. First, the results from the instrument development process will be presented as well as their use in clinical practice and research. Projected future work on construct validity and additional psychometric testing will also be discussed. No study is without limitations and these will be identified.

INTEL-Values Factors

The *INTEL-Values* instrument was determined to have four factors. The analysis of the *INTEL-Values* instrument was difficult because the factors were not easy to identify due to the low factor loadings. This was due to the low inter-item correlations. Individual item alphas were considered low but acceptable at .60 - .78, but the inter-item (*r* =.12 - .78) and item total correlations (*r* =.31 - .48*)* were low. The lower than desired correlations and Cronbach's alpha on the factors may be due to the challenge noted when measuring values. This difficulty has been previously noted and is not exclusive to nursing (Halloran, 1976; Mueller, 1986; Wealleans, 2003). The critical care nurses in the pilot testing phase said they liked the format of the instrument but found it challenging to think about how they "truly felt" about the subject of "end-of-life care" in the ICU. This is common among critical care nurses as their culture is focused on intensive and technological procedures, and nurses have limited time to reflect on their values, attitudes, feelings, or roles when providing this care (Halcomb et al., 2004; Puntillo et al., 2001). Additionally, their patients are often unresponsive, so critical care nurses have limited opportunities to develop relationships with their patients or truly get to know them on a personal level (Carlet et al., 2004; Cartledge, 2001; Danis et al., 1999). Therefore, the difficulty that the critical care nurse respondents may have had when asked to assess, identify, and reflect on their individual attitudes, values, beliefs, or preferences may have influenced their responses which in turn affected the factorability and reliability of this instrument.

As shown in Table 7, the Pearson's correlation and ICC for the *INTEL-Values* instrument were considered relatively high, but the Kappa coefficients were low. This discrepancy is due to the sensitivity of Kappa. Pearson's correlation indicates whether the factor scores systematically covary while Kappa only indicates identical responses over time periods (Streiner & Norman, 2003). In terms of stability and consistency, the high correlations indicate that the total scores on the factors were systematically consistent across time. The Kappa results offer another interpretation. The low Kappa coefficient could be due to an instrumentation effect (Cook & Campbell, 1979). It is possible that a change in values did occur during the two week period as a result of taking the *INTEL-Values* instrument. Simply allowing the respondents to think about their own values at Time 1 could have influenced their responses at Time 2. The first administration of the *INTEL-Values* could have heightened their awareness and sensitivity about nursing values while providing end-of-life care in the ICU, thus changing their responses during the two week period. This change could have been subtle but any difference between the first and second administration would have resulted in a low Kappa value. The individual factors for the *INTEL-Values* instrument are presented below.

Factor 1 of the *INTEL-Values* instrument consisted of items related to self-appraisal when providing end-of-life care in the ICU. The items that loaded onto this factor were items describing the nurses' perception, confidence, self-evaluation, and comfort level when providing end-of-life care to patients and families. Although the items on this factor appeared to relate to each other and to the concept of self-appraisal, they possessed low inter-item correlations (.12 - .41), indicating that there was little commonality among the items. Despite the lower than desirable correlations, the alpha for the factor was high ($\alpha = .78$), implying that the items seem to 'hang' together (Pett et al., 2003). The low inter-item correlations on this factor may be due to the respondents' difficulty in appraising their own attitudes, values, or self-perceptions. In an environment where death is seen as a failure, critical care nurses report that self-appraisal of their ability to provide this care is not a major focus or concern (Dobratz, 2005; Puntillo et al., 2001). Additionally, nurses report learning from trial and error and report a lack of education on the topic of dying in the ICU (Farrell, 1989). With only 3% of educational material describing how to provide end-of-life care, nurses do not have the resources or environmental support to examine their end-of-life care values (Mallory, 2003). Additionally, nurses do not receive the necessary feedback from family members to determine if the care they provide is acceptable, making self-appraisal difficult (Beckstrand & Kirchhoff, 2005; Beckstrand et al., 2006; Kaufman, 2005; Matzo, Sherman, Lo et al., 2003). Self-appraisal is an important concept to examine as it has been shown that recognizing one's values and appraisal of these values is the first step in changing behavior, thus improving care delivery (Dalton et al., 1996; Dobratz, 2005; Frommelt, 2003; Rooda, Clements, & Jordan, 1999).

Factor 2 (Appraisal of Others) had an alpha of .71. The inter-item correlations ranged from .18 - .78. Studies asking individuals to describe a "good death," expert behaviors, or barriers noticed by others when providing care at the end of life are much more prevalent than self-appraisal or report (Beckstrand & Kirchhoff, 2005; Beckstrand et al., 2006; Kehl, 2006; Schwartz, Mazor, Rogers, Ma, & Reed, 2003). The higher correlations and alpha values indicate that these items relate to each other more strongly than those in Factor 1 and this may be due to the fact that it is easier to evaluate another individual than to self-evaluate. This factor is important since nurses, especially novices, model attitudes and behaviors of their colleagues (Benner, 1984; Puntillo et al., 2001).

Factor 3 (Emotional Strain) had an alpha value of .62. This lower than acceptable alpha value, as well as low inter-item correlations (.15 - .73), reflect the difficulty of assessing nursing values when providing end-of-life care in the ICU. Emotional strain is an important concept to examine among critical care nurses as it has been shown to correlate highly with burnout and health outcomes (AbuAlRub, 2004; Chen & McMurray, 2001; Erlen & Sereika, 1997; van der Heijden, Demerouti, & Bakker, 2008). In a recent survey of critical care nursing needs at the end of life, 49% of respondents indicated that they never had time to debrief after a death (Puntillo et al., 2001). The lack of time to process and reflect on the death can contribute to a variety of factors, including those noted in Factor 3 (Emotional Strain).

A current study examining workload demands and physical health concerns among nurses reported that the higher the nurses' job demands, including emotional strain, the higher their work-home interference which may aggravate the nurses' general health over time (van der Heijden et al., 2008). This is an important finding as it is important to identify nurses who score high on this factor, for this indicates more emotional strain, which is likely to lead to burn-out and health problems of the nurse.

Factor 4 (Moral Distress) had an overall alpha of .60, which is too low for this factor to be considered reliable. The inter-item correlations in this factor were very low, *(.16 - .34*) and item loadings on the factor were also low (.37 - .59). It is possible that the *INTEL-Values* instrument is a three factor instrument, but no previous analysis led to this conclusion. The low reliabilities, correlations, and item loadings exhibit evidence related to the struggle with identifying nursing values with end-of-life care in the ICU, which may have contributed to the low psychometric properties of this factor.

In addition to difficulty with determining nursing values, the role of the nurse in decision making is often a ‘silent’ role, and nurses are not responsible for initiating conversations regarding the decision making process. This less assertive role often produces moral distress which has been widely identified in the literature (Brown, 2003; Elpern et al., 2005). In the literature, nurses presenting with ‘moral distress’ exhibit signs of burnout, frustration, and disinterest, and may not be aware of the cause of this distress (Elpern et al., 2005), again contributing to the difficulty in measuring this concept. Previous attempts have been made to create an instrument to measure the concept of moral distress, with difficulty in capturing this concept (Corley, 1995).

Moral distress is a difficult concept to measure, with a portion of this being due to the difficulties nurses face when assisting families with decision making in the ICU. Decision making goals in the ICU vary greatly between health care providers, patients, and family members. The goals of families are often to have their loved one return to live life and engage with them, while healthcare providers are focused on sustaining life. These contrasting paradigms have resulted in a disconnect between one ideal of patient-centered care and another ideal focused solely on traditional medicine. To achieve quality at the end of life, nurses must be able to see both paradigms and assist the family through the decision making process. Holistic goals of the patient should be assessed and include the patient's treatment and dying preferences, values, definition of quality of life, the probabilities of life, death, or disability, benefits and burdens of continued treatment, and options for symptom management, but are rarely considered when delivering care in critical care settings (Miller et al., 2001). Therefore this struggle identifying moral distress is an important area for future work, and focusing on incorporating interventions to address this factor is warranted.

Communication as a Possible Factor of the INTEL-Values

Twenty-three items on the *INTEL-Values* had double loadings or did not load above .35 on any factor. Of these items, fifteen of them related to communication. These items (shown in Appendix 3) had greater variance, and many of the respondents commented on the importance of these questions. Thus, it was a concern that these items did not load on any factor. After reviewing these items, they were found to be related to the concept of communication. Communication has been cited as the primary concern among family members, physicians, and nurses (Azoulay, 2005; Beckstrand et al., 2006; Cartwright et al., 1997; Griffie, Nelson-Marten, & Muchka, 2004; Pierce, 1999; Puntillo et al., 2001; "The SUPPORT Principal Investigators," 1995) and is abundant in literature focusing on end-of-life care.

The lack of a separate communication factor may be due to the role of communication in nursing, as it is ingrained throughout the profession in every nursing task. Thus this concept may not have appeared as a separate factor because communication encompasses every aspect of end-of-life care in the ICU. However, these items did not end up loading together on any factor and the reason for this remains unknown.

Critical care nurses have identified communication problems with physicians and family members as the primary barrier to achieving a good death for the patient (Beckstrand et al., 2006). Additionally, qualitative interviews describing expert nursing during end-of-life care identified bending the rules for the family and patient, supporting the family, and effective communication as characteristics of expert (Benner, 1984; Ciccarello, 2003; Matzo, Sherman, Sheehan et al., 2003; McClement & Degner, 1995). Some aspects of communication are evident in Factor 1 (Self-appraisal) and Factor 2 (Appraisal of Others).

INTEL-Behaviors Factors

The *INTEL-Behaviors* instrument was determined to have two factors. Overall, the *INTEL-Behaviors* had higher factor loadings than in the *INTEL-Values*. The Cronbach's alpha for the *INTEL-Behaviors* factor was higher than that of the *INTEL-Values* instrument (α=.79 and .67 respectively) and the factor solutions were clearer and easier to identify. This is most likely due to the more concrete identification of behaviors compared to values. Bowen defined behavior as what people do and do not do, and thus this concept is easier to determine and measure on an instrument than values (Bowen, 1991; Mueller, 1986; Wealleans, 2003).

In general, the inter-item correlations were also low for the *INTEL-Behaviors* instrument (*r* =.10 - .43). As shown in Table 8, the Pearson's correlation (*r*= .77, .81*)* and ICC (*r*=.77, 82*)* for the *INTEL-Behaviors* instrument were relatively high, but the Kappa coefficients were low (.02, .40). For the *INTEL-Behaviors* consistency and stability of the items over time was not expected, as the use of this instrument was to measure specific behaviors when providing end-of-life care to a particular dying patient and family. The participant was asked to consider the last dying patient they had cared for when completing the instrument. It is possible that the patients considered at Time 1 and Time 2 were different, causing the scores to vary considerably over time, thereby influencing the stability. Thus, lower Kappa coefficients would be expected. Although respondents for the *INTEL-Behaviors* were relying on their memory of the patient when completing this instrument, the Kappa coefficient on Factor 2 (Nursing Tasks) was the highest value. Two explanations can be provided for this result—one that respondents actually remembered the patient they provided care for consistently over a two week period---or the fact that nurses do not vary considerably in the care they provide for patients. This second explanation is more likely, as without an intervention to change care delivery, it is unlikely that nurses would vary in behavior.

Although the items on Factor 1 (Communication) appeared to relate to each other and to the concept of communication, the items had low inter-item correlations (.14 - .43*),* indicating that there was acceptable commonality among some of the items. Despite the lower than desirable correlations, the alpha for the factor was high (α=.79), implying that the items belong together. Although the alpha for the factor indicates that the items do associate well with each other, the low inter-item correlations indicate that they do not necessarily relate when compared individually (Pett et al., 2003). As with the *INTEL-Values,* this may be due to the role of communication in nursing, as it is evident in the majority of nursing behaviors. Although communication is an important concept, it is possible that it is not easy to encapsulate.

Factor 2 (Nursing Tasks) had a lower than desired alpha of .67 as well as low inter-item correlations (r =.10 - .35*).* The low reliabilities, correlations, and item loadings exhibit evidence related to the struggle identifying what tasks nurses actually perform when providing end-of-life care in the ICU. This difficulty in assessing tasks may have contributed to the low psychometric properties of this factor.

Since previous end-of-life experiences have been shown to influence nurses' current care delivery, this factor is an important component of end-of-life care in the ICU, as these experiences may impact the types of behaviors provided by the nurse (Beuks et al., 2006; Chen & McMurray, 2001; Dunn et al., 2005; Hall & Rocker, 2000; Heyland et al., 2003; Higginson et al., 1990). Despite a lack of training in end-of-life care ICU nurses are often given the responsibility of caring for the dying patient and their family, and receive little respite from the stress of caring for these individuals (Beckstrand & Kirchhoff, 2005). The items on this factor are all supported in the literature as expert behaviors when describing a good death (Beckstrand et al., 2006; Ezzell, Anspaugh, & Oaks, 1987; Mak & Clinton, 1999; Wilkes, 1993) and thus warrant further investigation.

Instruments' relationship to Value-Behavior Congruency

The personal, environmental, and relational factors identified in Bowen's Value-Behavior Congruency model were supported throughout this instrument development. In terms of the personal factors identified in VBC, the participants' struggle identifying their individual values was noted throughout the *INTEL-Values*, especially in the self-appraisal, emotional strain, and moral distress factors. Critical care nurses report a personal commitment to saving lives, which results in moral distress as well as emotional strain when care transitions from critical to end of life care (Elpern, Covert, and Kleinpell, 2005). It would be interesting to note if nurses who have low scores on these factors report that their values do not match with the behaviors they desire to do, thus increasing their risk for moral distress. In terms of environmental factors, the curative culture of the intensive care unit, along with the expectations of conducting these "curing" behaviors, may likely impact their value of the experience as well as their ability to conduct ideal behaviors in this environment. This struggle might be evident in the Nursing Tasks factor of the *Intel-Behaviors* instrument and the Self-Appraisal and Appraisal of Others factors in the *INTEL-Values* instrument.

In terms of relational factors, the inability of the communication items to load on any factor warrant further explanation of how relational problems common to the ICU can impact care delivery. The communication factor in the *INTEL-Behaviors* instrument addresses problems related to fragmented care, multiple consult teams, and conflict among family members, nurses, and physicians. It would be interesting to explore how nursing experience and communication styles impact scores on the INTEL instruments.

Limitations

As in many studies, there were limitations. In Phase I, the qualitative interviews were limited to a convenience sample of adult critical nurses in an academic medical center. Although the data collected during the interviews was supported in the literature, it is possible that the subsequent items selected did not encompass the full domains of values and behaviors when providing end-of-life care in the ICU. The fact that the items selected were supported in the literature, and by content validity experts and pilot testing participants, suggests this limitation may have had little impact on the study.

The field testing of the instrument was designed to provide a heterogeneous sample of the population and matched closely the demographics of practicing critical care nurses. However, the instruments were only sent to individuals who are members of the American Association of Critical Care Nurses. The invitation to participate in this research was sent electronically to all members on the email list but the response rate was impossible to determine due to incorrect email addresses, or loss of the email in junk and spam mail folders. Secondly, those who chose to participate may have done so because of their desire to improve end-of-life care in the ICU or some other characteristic that separates them from the intended target population.

Future Work

The purpose of the development of these instruments was to evaluate nursing values and behaviors when providing end-of-life care in the ICU. The scope of this study did not include specific assessments of construct validity. This next step will be undertaken in future research. In terms of construct validity testing, future work could include evaluation of the death experience by family members. Ideally family members who report satisfaction with the death experience would have had care provided to them by nurses who have high scores on the *INTEL-Values* and *INTEL-Behaviors* instruments.

Criterion-related validity testing will also be used in future work to examine the relationship between these items and nurses' levels of experience and expertise. For example, the *INTEL-Values* and *INTEL-Behaviors* could be used to compare two groups of nurses---those that are considered expert in providing end-of-life care (eg. Hospice nurses) and those that are considered novice (eg. new graduate nurses or nursing students) to determine if the *INTEL-Values* and *INTEL-Behaviors* scores vary among nurses with different levels of experience and expertise. Benner describes an expert nurse as one who has an intuitive grasp of the whole situation and plans care with consideration of needed resources and limiting those that are not necessary (Benner, 1984). In the case of the dying ICU patient, the expert nurse is able to recognize the transition from critical care to end-of-life care and guide the healthcare providers, patient, and family with such activities as decision making, pain and symptom management, and achieving closure.

If the instruments have good criterion-related validity they might be used in intervention research or for educational purposes with nursing students, continuing education participants, and practicing intensive care nurses. Future work will examine if these instruments can be used as pre and post assessments to determine if an educational intervention is effective.

The *INTEL-Values* and *INTEL-Behaviors* instruments could also be used to conduct initial model testing for the Value-Behavior Congruency model. The personal, environmental, and relational factors identified in the model could be used to determine if there is a relationship to how nurses respond to these factors and their scores on the *INTEL-Values* and *INTEL-Behaviors* instruments.

Due to the large sample obtained in Phase III of the study, in the next phases of this research program, several relationships can be examined in order to determine additional areas of focus for future intervention work. Future work will consist of statistical comparisons to determine if differences exist among specialty nursing areas, institution type, experience level, gender, ethnicity, or personal experience with death. If significant differences are noted, interventions can be specifically developed to address these differences in order to improve care delivery.

Regardless, these instruments need further reliability testing and refinement as a component of future work. Reliability of the instruments should be tested with each participant group to further establish the integrity of this instrument as it is used with intervention research.

Summary of Discussion

This study developed two instruments measuring critical care nursing values and behaviors when providing end-of-life care in the ICU. During field testing of the instruments, 51 items were initially selected for the *INTEL-Values* instrument and 34 items were selected for the *INTEL-Behaviors.* After the field testing and exploratory factor analysis, 25 items were deleted from the *INTEL-Values* instrument and 16 were deleted from the *INTEL-Behaviors.* The *INTEL-Values* instrument proved to be more challenging in the analysis phase of the study. This could be because values are difficult to measure. The *INTEL-Values* was composed of four factors and individual item alphas were considered low but acceptable at .60 - .78. The inter-item (r =.12 - .78) and item total correlations (r =.31 - .48*)* were low. The Cronbach's alpha on each factor in the *INTEL-Behaviors* instrument was much higher than the *INTEL-Values* instrument (α=.79 and .67 respectively) and this instrument had a clearer factor structure, possibly due to the fact that behaviors are more concrete. Future work will consist of continued refinement of the instruments and construct validity testing. After additional work, these instruments may be used in intervention work to improve care delivery.

APPENDIX 1: CONTENT VALIDITY INDEX (CVI) OF INTEL-VALUES

Potential Item	CVI (% ranked 3 or 4)	Recommended Item Revisions
Prefer to be silent[3] and let the family lead the discussion…	1.00	Changed to “prefer to listen” as silence can be seen as abandonment or lack of interest.
Feel comfortable crying…	0.88	Added *Generally feel comfortable* as this implies every time
Believe all rules go “out the window…”	1.00	No changes made.
Am ready to transition before anyone else...	0.88	Changed ‘pursue’ to transition as end-of-life in the ICU is more of a process.
Believe the family is the most challenging aspect...	1.00	Changed to “supporting the family” as it is less harsh than dealing with the family.
Some deaths are more difficult…death of someone I cherish.	0.88	Changed to “they make me think of the death of someone I cherish” as this elicited more of an emotional response.
Feel uncomfortable when……“God will save them.”	0.88	Changed to “particular spiritual belief” as it needed to be appropriate for all religions.
Enjoy talking to others…about my experiences.	0.88	Suggested specifying who the “others” are and changed enjoy to value.

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[3] Underlined text indicates areas where changes were made from original item to revised item. Note the item is not displayed in its entirety, but has been edited to reflect the main concept.

Believe it is an expectation…for the physician to meet with the family.	0.75	Changed “privilege” to “optional”
Feel frustrated when care transitions from ICU to EOL care.	1.00	Major revision to clarify “we” and changed item to reflect the focus of care shifting from ‘intensive’ to end-of-life care.
Believe death is…a failure.	1.00	Added “healthcare providers” in order to clarify who views the death as a failure.
Adapt when unpredicted situations come up.	0.75	Deleted item as the experts felt this could be too many situations and was confusing.
Believe the family should be told everything	0.88	Added “everything they need to know” in order to clarify decision making.
Take a step back… to resolve conflict.	0.88	Major revision to clarify the conflict that family is facing.
Find that others don’t know how to provide optimum care…	0.75	Took out physicians and added “other healthcare providers I work with” to include nurses.
…handle death with humor…	0.88	No changes made.
Believe it is undignified to prolong…	0.88	Changed to “prolong the dying process” for clarification.
…honor to be present…	1.00	No changes made.
…have family weigh alternatives…	0.88	Major changes made as experts felt this statement involved two different concepts and this is not the nurses’ role.

Am emotionally drained…	1.00	No changes made.
EOL care focuses on both the patient and the family.	1.00	No changes made.
Believe it is ok to medicate more liberally...	0.63	Added “the patient.” Experts thought this was interesting so it was revised and not deleted. They also wanted a follow-up question to pain medication which was added.
Do not deal well...	1.00	No changes made.
Believe multiple care teams are a barrier…	1.00	Changed “the” to ‘having.’
Feel the patient is more of an individual…	0.75	Deleted item as experts felt this would not elicit a variety of responses.
Find it is difficult to focus on a dying patient…	0.88	No changes made, although experts felt most respondents would “strongly agree” to this.
Feel my most important role is communicator...	0.88	Took out “as” and “for” to make this a stronger statement.
Believe physicians want to tell us what to do…	0.88	Added “rather than have autonomy: at the end to clarify the item.
Think you can cry…	0.88	Changed ‘cannot’ to ‘can’ to reverse the item and decrease confusion with scoring.
Feel I am faced with many barriers…	0.88	No changes made.

Prefer the family see all of the 'extraordinary things'…	0.75	Added 'ventilators' in the parentheses.
Have religious beliefs that make me uncomfortable with EOL care…	0.88	We never withdraw "care" so this was changed to "life support"
No one should die alone.	1.00	No changes made.
Feel that the physicians abandon patients after they become EOL care.	0.88	Minor grammatical changes for clarity made.
Am sometimes angry because of decisions…	1.00	No changes made.
Believe that a 'DNR' does not mean stop care.	0.88	Reversed item as there were too many negative words in the sentence.
Prefer to limit technology…	0.88	No changes made.
Ask myself "who are we doing this for?" …	0.63	Deleted underlined text and specified care to dying patients.
Think that getting attached…is a mistake.	0.88	Added when providing end-of-life care to clarify this situation.
end-of-life care is integral…	1.00	No changes made.
Prefer to blend traditional and complimentary…	0.88	Changed "medicine" to therapies.
Am afraid of death.	1.00	No changes made.
Believe it is ultimately the patient's needs…	0.75	Added "in an end-of-life situation."
Know that some families… everything medically possible…	0.88	No changes made.

APPENDIX 2: CONTENT VALIDITY INDEX (CVI) OF INTEL-BEHAVIORS

Potential Item	CVI (% ranked 3 or 4)	Recommended Item Revisions
Avoided technical terms…	1.00	No changes made.
Encouraged the family to interact…	1.00	No changes made.
Honestly told what I would do…	0.88	No changes made.
Asked the family if they wanted to be in the room…removed.	1.00	Added "or other supportive measures" in addition to breathing tube.
Assured a quiet environment…	1.00	Changed to "tried to assure a calm and quiet environment."
Gave time to say goodbye.	1.00	Changed "an opportunity" to "the time."
Gave the family a plan...	1.00	Added "at least daily" to include a measurable time frame.
Provided a calm environment…	1.00	Took out the parentheses.
Encouraged the family to make decisions…	1.00	Added "end-of-life care."
Collaborated with the interdisciplinary team…	1.00	No changes made.
Turned the monitors off…	0.88	Changed "turned" to "silenced" as some family members like to see the monitors.
Asked about the patient prior to the hospitalization.	1.00	Added "to tell me about the patient."

Spoke with the family away from the bedside...	1.00	No changes made.
Gave pain medications…	0.88	Changed to a more objective and specific statement.
Explained the dying process…	1.00	No changes made.
Discussed the possibility of the patient dying with the family...	1.00	Added “beginning of admission” to identify transition point.
Made resources available…	1.00	No changes made.
Found it easy to speak…	0.88	No changes made.
Initiated communication…	1.00	No changes made.
Respected differing views…	1.00	Changed “patient’s” to the “family’s” as the patient is often unresponsive in the ICU.
Managed the patient’s pain…	0.88	No changes made.
Asked if they wanted the monitors off.	1.00	Added “to be silenced” as well as turned off.
Offered privacy when there were no direct requests.	1.00	Added “offered privacy by leaving the room” for clarification.
Asked questions for decision making…	1.00	No changes made.
Communicated…patient was dying.	1.00	Changed dying to “near death.”
Translated what the physician said…	1.00	No changes made.
Allowed the family to be at the bedside.	1.00	Changed “to visit” to “stay at the bedside” for clarification.

Asked for any requests…after he/she died.	1.00	Changed “cleaning” to “help care.”
Assured the family…decisions were made carefully.	0.63	Changed to “made the best decisions possible” as this was more realistic.
Assessed the patient regularly for symptoms…	1.00	Added “symptoms of pain or discomfort” for clarification.

APPENDIX 3: PERCENTAGES FOR INTEL-VALUE ITEMS

Item	SD[4] %	D %	D/A %	A %	SA %
Prefer to be silent and let the family lead the discussion…	1.0	2.0	42.0	37.3	17.1
Feel comfortable crying…	2.7	11.1	18.6	44.9	22.7
Believe all rules go "out the window…"	1.6	1.2	1.0	8.6	87.6
Am ready to transition before anyone else...	0.1	8.5	45.6	31.2	14.6
Believe the family is the most challenging aspect...	1.2	12.0	22.2	36.2	28.4
Feel uncomfortable when……"God will save them."	15.1	41.2	27.7	13.1	2.9
Enjoy talking to others…about my experiences.	0.7	4.2	17.3	52.3	25.5
Believe it is an expectation…for the physician to meet with the family.	1.4	1.2	0.9	14.6	82
Believe death is…a failure.	20.9	33.5	31.2	14.6	2.2
Believe the family should be told everything	1.0	0.1	5.3	24.9	68.6
…honor to be present…	0.3	4.2	10.5	33.2	51.8

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[4] SD indicates Strongly Disagree; D for Disagree; D/A for Sometimes Disagree/Sometimes Agree; A for Agree; and SA for Strongly Agree. F is the frequency of responses for all participants in Phase III.

Item	SD %	D %	D/A %	A %	SA %
…have family weigh alternatives…	0.3	2.7	12.4	38.9	45.7
Am emotionally drained…	2.3	12.5	44.3	27.5	13.3
EOL care focuses on both the patient and the family.	0	0	1.9	25.5	72.6
Believe it is ok to medicate more liberally…	10.6	36.1	31.0	14.8	7.5
Do not deal well…	51.4	37.5	10.1	0.3	0.6
Believe multiple care teams are a barrier…	3.6	11.2	38.8	28.8	17.5
Feel my most important role is communicator…	0.4	9.4	34.6	36.9	18.6
Believe physicians want to tell us what to do…	13.3	39.6	29.4	12.4	5.3
Think you can cry…	0.1	3.0	19.0	57.2	20.6
Feel I am faced with many barriers…	8.7	34.3	33.6	17.0	6.4
Prefer the family see all of the ‘extraordinary things’…	1.0	5.8	18.8	41.7	32.7
Want to make decisions for the family…	28	42.7	14.9	10.6	3.8
Have religious beliefs that make me uncomfortable with EOL care…	57.1	37.9	3.9	0.9	0.3
No one should die alone.	**0.7**	1.6	7.8	29.1	60.8

Item	SD %	D %	D/A %	A %	SA %
Feel that the physicians abandon patients after they become EOL care.	4.6	22.3	30.0	25.4	8.7
Am sometimes angry because of decisions…	1.4	9.4	38.3	38.9	12.0
Believe that a ‘DNR’ does not mean stop care.	68.1	28.6	2.5	0.3	0.6
Prefer to limit technology…	1.9	10.0	27.5	44.9	15.7
Ask myself “who are we doing this for?” …	2.6	8.9	43.6	30.4	14.5
Think that getting attached…is a mistake…	22.1	55.9	16.1	5.2	0.7
Prefer to blend traditional and complimentary…	0.3	0.7	7.8	52.0	39.2
end-of-life care is integral…	0.3	0.6	3.5	29.1	66.6
Am afraid of dying.	19.0	38.0	24.3	15.7	3.0
Am afraid of death.	26.4	45.8	17.4	9.1	1.3
Believe it is ultimately the patient’s needs…	0.1	5.6	0	32.3	61.9
Know that some families… everything medically possible…	0.11	0.6	4.1	53.6	41.6
Want another assignment…	41.5	45.0	12.9	0.3	0.3

Item	**SD %**	**D %**	**D/A %**	**A %**	**SA %**
Feel uncomfortable being in the room…	22.3	46.5	23.7	6.2	1.3
Believe others view EOL care as an "easier" assignment.	8.1	32.8	27.1	24.9	7.1
Find that I administer less pain when the family is not present during the death…	22.0	57.9	15.3	3.7	1.0
I have no time to debrief...	2.6	13.4	31.6	34.8	17.5
Take a step back… to resolve conflict...	0	1.2	24.3	60.6	13.9
Find that others don’t know how to provide optimum care…	5.7	27.3	41.4	19.0	6.7
…handle death with humor…	2.2	19.7	50.1	24.6	3.5

APPENDIX 4: FACTOR LOADINGS FOR INTEL-VALUES

Item	Factor 1	2	3	4
…honor to be present…	**.54**[5]			
Do not deal well...	**-.53**		.26	
Feel comfortable crying…	**.52**		.23	
Want another assignment…	**-.52**			
EOL care focuses on both the patient and the family.	**.49**			
…have family weigh alternatives…	**.48**			
Feel uncomfortable being in the room…	**-.47**			
Am comfortable asking questions about advance directives.	**.46**			
end-of-life care is integral…	**.45**			
Prefer to blend traditional and complimentary…	**.45**			
Think you can cry…	.42		.31	
Think that getting attached…is a mistake…	**-.41**			
Enjoy talking to others…about my experiences.	**.37**			
Have religious beliefs that make me uncomfortable with EOL care...	-.35			-.24

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[5] Bold text indicates primary loadings, with standard text indicating additional loadings. Loadings below .20 are not included.

Take a step back… to resolve conflict...	**.35**			
Believe the family should be told everything	.31			
Feel my most important role is communicator…	.30			
Find that I administer less pain when the family is not present during the death…	-.26			
Believe that a 'DNR' does not mean stop care.	-.26			
Believe it is ultimately the patient's needs…	.25			.24
Find it is difficult to focus my energy on a dying patient...	-.24			
No one should die alone…	.23		.22	
Want to make decisions for the family…	---			
Find that others don't provide optimum care…		**.83**		-.24
Find that others don't know how to provide optimum care…		**.82**		-.25
Feel I am faced with many barriers…		**.46**		.25
Believe others view EOL care as an "easier" assignment.		**.45**		
Feel that the physicians abandon patients after they become EOL care.		**.42**		.23
Believe physicians want to tell us what to do…		**.36**		
Feel I have no time to debrief…		.35		
Feel frustrated when the focus of care changes…	-.20	.23		
Believe death is…a failure...	---	---	---	---

Am afraid of dying.			**.66**	
Am afraid of death.	-.28		**.64**	
Am emotionally drained…			**.43**	
Find that some patient's deaths are more difficult because I think of someone I cherish.			**.40**	
Prefer to be silent and let the family lead the discussion…	---	---	**---**	---
Believe the family is the most challenging aspect...	---	---	---	---
Believe all rules go "out the window…"	---	---	---	---
Am sometimes angry because of decisions …				**.60**
Ask myself "who are we doing this for?" …				**.49**
Believe it is undignified to prolong the dying process…				**.45**
Am ready to transition before anyone else...				**.37**
Prefer to limit technology…				.30
…handle death with humor…				.29
Believe multiple care teams are a barrier…		.27		.27
Feel uncomfortable being in the room...				.27
Prefer the family see all of the 'extraordinary things'…				.25
Believe it is ok to medicate more liberally…				.23
Know that some families… everything medically possible…				.21
Believe it is an expectation…for the physician to meet with the family.				---

APPENDIX 5: PERCENTAGES FOR INTEL-BEHAVIOR ITEMS

Item	SD[6] (%)	D (%)	D/A (%)	A (%)	SA (%)
Inquired about advance directives.	2.2	2.5	5.9	30.0	59.4
Explained the dying process…	0.4	1.3	11.5	39.9	46.9
Avoided technical terms…	0.4	1.8	13.2	55.1	29.4
Encouraged the family to interact…	0.1	0	1.6	17.4	80.9
Honest told what I would do…	13.6	29.3	30.5	16.4	10.1
Asked the family if they wanted to be in the room… removed.	3.7	6.5	16.4	29.7	43.8
Gave the family a plan...	0	0.3	0.9	24.5	74.3
Provided a calm environment…	0.3	0	1.3	20.2	78.2
Encouraged the family to make decisions…	2.5	6.4	29.5	41.2	20.4
Collaborated with the interdisciplinary team…	0	2.7	7.2	40.1	50.0
<u>Turned</u> the monitors off…	1.3	1.6	8.3	33.1	55.7
Asked about the patient prior to the hospitalization.	0.9	6.3	29.9	38.8	24.1

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[6] SD indicates Strongly Disagree; D for Disagree; D/A for Sometimes Disagree/Sometimes Agree; A for Agree; and SA for Strongly Agree. F is the frequency of responses for all participants in Phase III.

Item	SD %	D %	D/A %	A %	SA %
Spoke with the family away from the bedside...	3.2	8.1	28.1	39.3	21.3
Made resources available…	0	0.7	4.1	41.3	53.8
Notified the hospital chaplain…	0.9	2.4	12.1	34.7	50.0
Found it easy to speak…	1.0	4.0	22.4	52.1	20.6
Initiated communication…	0.6	2.1	21.8	48.7	26.8
Respected differing views…	0.1	0.1	5.0	34.6	59.9
Managed the patient's pain…	0.1	0	0.4	17.2	82.2
Asked if they wanted the monitors off…	12.5	20.8	24.6	26.7	15.5
Discussed the possibility of the patient dying with the family...	0.7	2.6	21.3	49.1	26.2
Offered privacy when there were no direct requests.	0	0.3	11.3	48.3	40.1
Communicated…that the patient was dying.	0.7	1.8	12.1	37.4	48.0
Asked questions for decision making...	0.4	2.4	17.5	50.4	29.3
Translated what the physician said…	0.6	1.3	9.6	39.8	48.7
Allowed the family to be at the bedside.	0	0	0.9	20.8	78.3

Item	**SD %**	**D %**	**D/A %**	**A %**	**SA %**
Asked for any requests …after he/she died.	3.8	11.0	17.3	32.0	35.8
Assured the family …<u>decisions were made carefully.</u>	2.1	3.7	12.8	32.1	48.3
Informed my colleagues that a death was occurring…	0.7	1.8	4.9	27.7	64.9
Talked about my feelings …with a friend, manager, or colleague.	2.2	16.6	36.9	30.6	13.7
Minimized family conflict.	3.0	4.9	29.1	49.5	13.5

APPENDIX 6: FACTOR LOADINGS FOR INTEL-BEHAVIORS

Item	**Factor** 1	2
Asked questions for decision making…	**.75**[7]	-.04
Discussed the possibility of the patient dying with the family...	**.57**	-.03
Communicated…patient was dying.	**.56**	-.06
Initiated communication…	**.52**	.04
Translated what the physician said…	**.50**	.04
Asked about the patient prior to the hospitalization.	**.45**	.14
Explained the dying process…	**.45**	.11
Assured the family…decisions were made carefully.	**.42**	.20
Encouraged the family to make decisions…	**.41**	-.03
Found it easy to speak…	**.40**	.14
Asked if they wanted the monitors off.	**.38**	.01
Honestly told what I would do…	**.36**	-.17
Minimized family conflict…	.34	.21
Spoke with the family away from the bedside **…**	.27	.15
Asked…after he/she died…	.26	.22
Talked about my feelings after the death…	.26	.11

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[7] Bold text indicates primary loadings, with standard text indicating additional loadings. Loadings below .20 are not included.

Collaborated with the interdisciplinary team…	.25	.24
Inquired about advance directives…	.24	
Informed my colleagues that a death was occurring...	.22	.20
Gave increased pain medications once end-of-life care was initiated.	.18	.10
Managed the patient's pain…	-.12	**.60**
Provided a quiet environment…	-.04	**.60**
Respected differing views...	-.08	**.54**
Gave time to say goodbye.	-.08	**.50**
Assessed the patient regularly for symptoms…	.06	**.41**
Made resources available…	.21	**.39**
Encouraged the family to interact …	.14	**.38**
Turned the monitors off...	.09	.32
Gave the family a plan…	.24	.31
Avoided technical terms…	.06	.28
Allowed the family to be at the bedside…	.11	.27
Notified the chaplain…	.15	.24
Asked the family if they wanted to be in the room…removed…	.18	.20
Offered privacy when there were no direct requests.	.12	.18

APPENDIX 7: FINAL VERSION OF INSTRUMENTS

Values of Intensive Care Nurses for End of Life (INTEL-Values) FIRST PAGE ONLY

This section is composed of feelings or thoughts you might experience when providing care to dying patients and their families in the ICU.

Please indicate the extent to which these items *generally* describe you and your current work as a nurse when providing end-of-life care in the ICU.

Use the following scale when responding to the items:

If you	***Strongly Disagree***	the item is descriptive of you or your work, circle ***SD***
If you	***Disagree***	the item is descriptive of you or your work, circle ***D***
If you	***Sometimes disagree/ sometimes agree***	the item is descriptive of you or your work, circle **D/A**
If you	***Agree***	the item is descriptive of you or your work, circle ***A***
If you	***Strongly Agree***	the item is descriptive of you or your work, circle ***SA***

There are no right or wrong answers to these questions.

In my current work as a nurse I:

Generally feel comfortable crying with family members when a patient is dying.	**SD D D/A A SA**
Am ready to transition to end-of-life care long before anyone else is.	**SD D D/A A SA**
Value talking to other healthcare staff about my end-of-life care experiences.	**SD D D/A A SA**
Consider it a privilege to be present when the patient is dying.	**SD D D/A A SA**
Believe my role includes helping the family weigh alternatives.	**SD D D/A A SA**
Am emotionally drained after providing end-of-life care.	**SD D D/A A SA**
Describe end-of-life care as focusing on the needs of both the patient and the family.	**SD D D/A A SA**

Behaviors of Intensive Care Nurses for End of Life (INTEL-Behaviors)
FIRST PAGE ONLY

This section is composed of behaviors that you might or might not have been able to do for the patient identified on the cover sheet. Please indicate the extent to which these items are descriptive of the care you provided to this patient and his/her family.

Please use the following response formats:

If you **NEVER** provided this care for this patient/family, circle **N.**
If you **RARELY** provided this care for this patient/family, circle **R.**
If you **SOMETIMES** provided this care for this patient/family, circle **S.**
If you **USUALLY** provided this care for this patient/family, circle **U.**
If you **ALWAYS** provided this care for this patient/family, circle **A.**

There are no right or wrong answers to these questions

For this particular dying patient and family I:

Explained to the family what would happen to the patient throughout the dying process.	**N**	**R**	**S**	**U**	**A**
Encouraged the family to interact with the dying patient, by laying the patient's hands on top of the covers for the family to touch, placing chairs next to the patient's bed for the family to sit, etc.	**N**	**R**	**S**	**U**	**A**
Gave the family the time to say goodbye.	**N**	**R**	**S**	**U**	**A**
Provided a calm environment for the dying patient, turning down the lights, cleaning out the room, lowering the side rails, providing tissues, etc.	**N**	**R**	**S**	**U**	**A**
Encouraged the family to make decisions about discontinuing life sustaining measures a little at a time.	**N**	**R**	**S**	**U**	**A**
Asked the family to tell me about the patient and his/her life prior to the hospitalization.	**N**	**R**	**S**	**U**	**A**

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