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I am submitting herewith a dissertation written by Phyllis Ann King entitled “Promises to Keep: A Phenomenological Study of ICU Nurses’ Experiences Caring for Dying Patients.” I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

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PROMISES TO KEEP: A PHENOMENOLOGICAL STUDY OF ICU NURSES'
EXPERIENCES CARING FOR DYING PATIENTS

A Dissertation

Presented for the

Doctor of Philosophy Degree

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Phyllis Ann King

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Dedication

This dissertation is dedicated to my family, my husband, Bruce King, my sons, William and John, who gave me patient and loving support in this long process; and to the memory of my parents, Frances Barnes Kirkland and William Roy Kirkland who inspired me to go beyond my dreams.

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I want to thank the participants of my study who shared their stories with me. They allowed me into the world they work in every day and I am honored to be trusted to describe the essences of their experiences.

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Abstract

The purpose of this study was to describe the experience of nurses caring for dying patients in the critical care unit. Using a phenomenological approach based on the works of Merleau-Ponty, the researcher completed 14 interviews in which ICU nurses were asked to describe experiences of caring for patients who died while in their care. The interviews were transcribed verbatim and analyzed using a hermeneutical approach developed by Pollio and applied to nursing research by Thomas. Each interview was examined within the context of all the interviews to identify themes found throughout. The world of the ICU was grounded in the contexts of death, time, and others. The purpose of the ICU, and the nurses there, was to prevent death or to delay it for another day. When those efforts failed, nurses experienced loss and grief similar to the patients and families they cared for. When death had, or was going to occur, care changed from *“a paradigm of curing to a paradigm of caring.”* Marked as a transition point in time, roles of nurses changed from curing with technology to caring with compassion. An encompassing theme of *promises to keep* wove throughout the interviews as nurses described the implicit and explicit promises made to patients and families in their care with the moral obligations those promises entailed. Five sub-themes manifested within the encompassing theme including: (1) *“it wasn’t time for someone to die”—“we see it coming a long way down the road;”* (2) *“just one more day”—“they had enough time;”* (3) *“a promise I couldn’t keep”—“I honor what I say;”* (4) *“nurses are in the game of reality”—“doctors can’t say that;”* and (5) *“it doesn’t end at the time of death”—“you feel very good, because you did your job.”* Each sub-theme revealed unique promises,

involving different responsibilities and eliciting different responses from the nurse.

Study findings suggests that nurses assume moral obligations to provide compassionate care to dying patients and their families in environments that foster a “paradigm of curing” rather than a “paradigm of caring.”

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Chapter 1

Introduction

When all medical treatment has been offered and has proved to no avail, the last and most important role the nurse performs is attending the patient in the final stages of life, providing comfort, dignity, and freedom from suffering. No less than a peaceful death, with multidisciplinary and holistic measures provided to meet the patient's every need, is acceptable. This is the understood standard of care and yet we struggle with many obstacles in meeting this standard and more than a few of these obstacles are caused by the medical milieu of health care today. The medical treatment meant to cure or ease diseases many times may inflict burdensome hardships and pain at a time when the patient would otherwise be seeking symptom palliation and rest from suffering. The medical model of cure is personified by critical care units of acute care facilities. Within these units, life-sustaining technology not only can appropriately support the acutely ill patient until curative therapy is successful, it can also prolong the dying patient's suffering. The critical care nurse is caught in a struggle to provide both cure and palliation. The purpose of this study is to explore the lived experience and meanings emerging from the experience of critical care nurses providing care to the dying patient within this medical context. This chapter will describe the philosophical and social context of the study as available from the extant literature, provide research questions and concepts to be explored in the study, and introduce a framework for the study.

Philosophical Lens of the Study

In my dissertation research, I have chosen to explore the experience of the nurse caring for the dying patient in critical care units using a phenomenological approach. This approach is appropriate when studying the perception and experience of the person within the environment. The philosophical basis of my strategy is existential phenomenology as developed by Merleau-Ponty. Based on these philosophical tenets, experience is composed of essences that are identifiable through perception or through *being-in-the-world* (Pollio, Henley, & Thompson, 1997; Thomas & Pollio, 2002, p. 14). The perceptions of the individual, what stands out to the person in his or her experiences, reveal a connection and interaction between the individual and the world. Understanding of another person's experience can be realized only through a holistic understanding of the meaning (or perception) of that experience by and for the person. Perception is derived within the interaction of the person with the environment and is expressed in the awareness of the person to specific aspects of the environment over others, termed *intentionality* by Husserl and Merleau-Ponty (Merleau-Ponty, 1948/2003). Behavior or *functional intentionality* is always understood within the context of the person's interaction with the environment, what is called *being-in-the-world*.

Social Context of the Phenomenon

There are several reasons for studying this topic in nursing research. The emphasis in acute care is focusing more on a curative approach utilizing high technological approaches to disease and de-emphasizing basic caring strategies

(Bookbinder, Rutledge, Donaldson, & Pravikoff, 2002). These changes in healthcare emphasis and focus introduce nurses to multidimensional dilemmas including ethical, moral and legal issues. Nurses receive requests from patients and family members for assistance in suicide; provide care for patients suffering unrelieved symptoms of dying including pain; and advocate for patient rights amidst conflicts between patient families and physicians (Doutrich, Wros, & Izumi, 2001; Hall, J., 1996; Kirchoff & Beckstrand, 2000). The issues resulting from the changing environment of the acute care facility impact the least to the most vulnerable patients.

Research Problem

Among the most vulnerable patients are those critically ill with life-threatening disorders. Patients are dying in higher numbers in critical care units. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) and the Hospitalized Elderly Longitudinal Project (HELP) studied over 9000 subjects to determine trends and issues in healthcare for the elderly and to determine needs for future research (Rutledge, Bookbinder, Donaldson, & Pravikoff, 2001). This study revealed that the dying are often treated in intensive care units (ICU) with aggressive curative treatments instead of with the emotional and physical support needed for peaceful death. The results also showed that symptoms are not adequately treated while disease processes are overly treated. The researchers proposed that caring for dying patients in intensive care units is a new and important area for future research (Rutledge, et al., 2001). They report that the majority of research on caring for the dying patient has focused on the care relationship between the hospice nurse and the dying

patient. Few studies have been conducted on the relationship between the critical care nurse and the dying patient, although the numbers of patients dying in critical care units outweighs the number in hospice and the need for improved end-of-life care is well documented.

Summary of the Research

Research on care of the dying patient has historically been focused on hospice care and outcomes of hospice care. Studies on care of the critically ill dying patient have been on spiritual care for the patient (Clark & Heidenreich, 1995; Hermann, 2001; Michley & Cowels, 2001; Moser, Sowell, & Phillips, 2001), spirituality of hospice nurses (Carroll, 2001; Messenger & Roberts, 1994), interventions to improve symptom control (Halstead & Roscoe, 2002), and research in policy issues affecting dying patients and families (Jacobs, Boruch, & Burton, 2002; Li, Chan, & Lee, 2002). Research into the needs of dying patients within acute care facilities has resulted in standards for palliative care, but has provided only preliminary explorations in providing the care to meet those standards (Rutledge, et al., 2001).

Researchers have identified through numerous studies the complex needs of the dying patient and the necessary holistic approach to those needs (Burton, 1998; Hall, B. A., 1997; Phillips & Morrow, 1998). Physical, emotional, and spiritual needs are just three facets of the overall experience of the dying patient and are inextricably joined (Bailey, 1997; Phillips & Morrow, 1998). Our knowledge of the complexities of and interventions for these needs is incomplete and inadequate (Fulton & Moore, 1995; Hall, B. A., 1997; Rutledge, et al., 2001). The impact on the nurse caring for patients with

complex care needs with limited potential for recovery has been the focus of fewer studies and the results of those studies are disturbing. Most of these studies to date have been qualitative studies revealing that caring for dying patients arouses emotions of fear (Shattell, Moody, Hawkins, & Creasia, 2001; Tyra & Crocker, 1999), “guilt, sadness, anger” (Brysiewicz & Bhengu, 2000, p. 18), and helplessness (Tyra & Crocker, 1999; Yam, Rossiter, Cheung, 2001). Studies in the late 1990’s demonstrated a growing concern by intensive care nurses for the suffering of dying patients. According to survey reports, these concerns resulted in nurses participating in or supporting physician and nurse active euthanasia and assisted suicide (Asch, 1996; Kowalski, 2000; Hall, J, 1997; Kirchoff, Spunhler, Walker, Hutton, Cole, & Clemmer, 2000; Leiser, Mitchell, Hahn, Slome, & Abrams, 1998). The alarming incidence of nurses faced with patient requests for assistance in suicide reported in these and other studies (Matzo & Schwartz, 2001; Puntillo, et al., 2001) and elevates the need for research and development of supportive interventions for both the patient and nurse at this critical time of care.

The nurse caring for a suffering patient in the intensive care unit or trauma unit, especially when the patient is dying, has been shown to affect the nurse in various emotional, physical and spiritual ways. Nurses in studies often reported moral distress and grief responses when caring for dying patients (Fry, Hawey, Hurley, & Foley, 2002; Georges & Grypdonck, 2002; Papadatou & Bellale, 2002; Yam, Rossiter, & Cheung, 2001). In several studies nurses reported that the decision making process in discontinuing life support or changing code status to “do not resuscitate” becomes a complicated process requiring the nurse to communicate and advocate in the patient’s

best interest under stressful circumstances (Burger, Botes, & Nel, 1999; Hopkinson, 2002; Johnson, 2002; Storch, Rodney, Pauly, Brown, & Strazomske, 2002; Yang, 2001). Other studies have also addressed how caring for dying patients has increased nurses' stress and emotional responses. Stress levels in critical care and hospice nurses have been shown to be significantly higher than nurses in other areas of care (Cooper & Mitchell, 1990). Stressors identified in critical care units included communication with physicians and family members (Davies, 2004; Hibbert, 1995), feelings of grief and sadness (Papadatou & Bellali, 2002), and the perception of overtreatment of dying patients (Simmonds, 1997).

Less research has been conducted on the physiological and behavioral impact on the nurse of caring for critically ill dying patients. Tyra and Crocker (1999) studied the experiences of trauma care nurses caring for dying patients using a qualitative methodology. Findings of this study suggested to the researchers that trauma nurses exhibit symptoms of vicarious traumatization (VT). Similar results were identified in other studies by Stauton-Bandiero (1998), Brysiewicz and Bhengu (2000), and Dickerson, Jezewski, Nelson, Tuttle, Shipkey, Wilk, and Crandall (2002). In these studies, researchers discovered emotional and physical symptoms of posttraumatic stress disorder (PTSD). Several of the studies found symptoms of intrusive thoughts, alcohol abuse, and physical and emotional avoidance resulting from vicarious traumatization. Stebnichi (2002) described the response as empathy fatigue or "emotional secondary stress and grief reactions that occur during helping interactions" (p. 23).

Qualitative studies of nurses caring for dying patients provide a richer and more

complete understanding of the complexities of the phenomenon. Many of these studies have been conducted in other countries (Nordgren & Olsson, 2004; Papadatou & Bellali, 2002; Yam, Rossiter, & Cheung, 2001). The results of these studies suggest that some facets of the phenomenon are universal, such as grieving with the patient and family, while others may be culturally specific such as cultural taboos and inhibitions (Yam, Rossiter, & Cheung, 2001).

Qualitative studies of this phenomenon conducted in the United States are fewer than in other countries. One reason for this discrepancy may be that qualitative research has more support in the international research community; another may be a tendency toward quantitative measures in the critical care healthcare community, including research in the field. In existing studies, participants responded that there were many sources of stress and concern in caring for dying patients in the critical care unit including conflicts between curative and caring goals, difficulties in maintaining hope, and navigating disagreements between families and physicians (Kirchoff, et al., 2000). Qualitative results indicate that nurses are also suffering emotional and spiritual distress as the respondents report disappointment in their nursing role and threats to their personal and professional integrity (Jezuit, 2000).

While there have been several qualitative research studies conducted in this area of research, most have been outside the United States and/or directed at one aspect or facet of the phenomenon such as communication with family and physicians (Davies, 2004; Simmonds, 1997), differences in grieving for patients between nurses and physicians (Papadatou & Bellali, 2002), determining the difference between caring for

patients who have or have not been designated as *do-not-resuscitate* (Jezuit, 2000), and determining the degree of agreement nurses had with assisting patient suicide (Schwarz, 2004). Only Jezuit (2000), using grounded theory, and Schwarz (2004) have conducted studies in the United States and both have focused on one aspect of the phenomenon rather than in a more holistic approach. However, the richness of the data from Jezuit's study and the level of increased understanding of the experience of the nurses and physicians involved suggest that we have much to learn from critical care nurses concerning the phenomenon of caring for dying patients in the critical care unit, and a qualitative approach is appropriate to discover these emerging themes.

Purpose Statement

The purpose of this study is to describe the lived experience of nurses caring for patients who die in the critical care unit. Using an existential phenomenological approach, the focus will be on a description of nurses' perceptions of this situation.

Assumptions

Assumptions for this study are found in both the philosophy of existential phenomenology and in the experiential basis of my nursing career. The first three assumptions are based in my experience as a nurse caring for dying patients in various roles and settings:

These assumptions are:

- the level and quality of the nurse-client interaction affects the quality of care given to the client and to client outcomes,
- contact with dying patients is inherent in critical care areas and constitutes a

challenging aspect of the nurse's practice, and

- caring for the dying patient has the potential to affect the nurse's practice and life to varying degrees and to elicit a multi-dimensional response from the nurse.

The second set of assumptions emerge from the existential phenomenology approach of this study and are taken from the qualitative approach developed by Pollio as presented in Pollio, Henley, and Thompson (1997) and Thomas and Pollio (2002). These assumptions are:

- through perception we are provided "a direct experience of ...phenomena of the world" (Thomas & Pollio, 2002, p. 14);
- behavior is "always located in some context or situation" (Thomas & Pollio, 2002, p. 16); and
- to understand the meaning of an experience, we must "describe the situated perspective of the event from the point of view of the experiencing person" (Pollio, Henley, & Thompson, 1997, p. 8).

Definitions of Terms

Dying patient: In this study, a dying patient is an adult patient who has died while the nurse was in attendance and responsible for the care of that patient at that time.

Critical care nurse: a registered nurse who works predominantly on a unit that is designated as acute, critical or intensive care either as a cardiac, medical, surgical, neurological or trauma unit. This nurse would have predominantly adult patients.

Critical care unit: a designated unit with a population of patients who require life-

sustaining therapies due to cardiac, trauma, medical, surgical or neurological processes which are life-threatening.

Delimitations

Delimitations of this study will include a sample of nurses recruited from professional associations and graduate programs of nursing in at least two different regions with Level I trauma hospitals and education opportunities to both nursing and medical students from area universities. The criteria for inclusion were limited only by the participant's interest in being interviewed about the topic of caring for dying patients and that the participant has cared for at least one patient who has died while he or she had primary responsibility for the patient's care.

Summary

Meeting the needs of dying patients presents a complex and often difficult challenge to the nurse in any setting. Loss, grief, and impending death are only some of the conflicting and emotionally charged facets of the dying patient's concerns. Disease processes leading to death cause symptoms that are often difficult to control or relieve. Patients too often die experiencing pain, depression, and fear. These challenges are worsened in critical care settings if aggressive life-sustaining therapies are used at the expense of a peaceful, dignified death. Studies of nurses in this climate of medical *overtreatment* provide a limited and preliminary understanding of the implications to nurse stress and patient care decisions arising from the demands in this environment; although overtreatment is only one aspect of the intensive care milieu. Our knowledge in this area is incomplete and we must continue to study this phenomenon to learn the

meaning of this experience for nurses and to provide an understanding from listening to their stories.

Chapter 2

Review of the Literature

In this chapter I will present a review of the literature describing research in end-of-life care with emphasis on the experience of the nurse caring for dying patients in critical care units. To prepare this review I used several sources and searches to explore the concepts of death and dying, including books and journals on philosophy, religion, psychology, and thanatology. Using the keywords *death, terminal care, medical futility, bereavement, spirituality, passive euthanasia, assisted suicide, grief, guilt, coping, post-traumatic stress disorders, critical care nursing and psychosocial factors*, I did a systematic search of CINAHL, the dissertation database and MEDLINE. This search provided more than 100 research studies and dissertations on this topic.

I will begin with a brief review of the existential bases for our understanding of the phenomena of death and dying through philosophical, religious, and scientific disciplines, continue with an overview of the research in end-of-life (EOL) care, and end with a comprehensive review of the research into the experience of the critical care nurse caring for dying patients. My review of the concepts of *death and dying* is intended to be foundational, not comprehensive, as a description of the context for end-of-life (EOL) care. Death and dying are concepts found in writings of ancient times and continue as concepts of interest into our contemporary society demonstrating that we are both haunted and captured by these topics. I have attempted a comprehensive review of the research into the experience of the critical care nurse and the literature most germane to the present study.

Death and Dying as Existential Issues

The ultimate question of this study may be “How do we experience death?” This question has certainly been the topic of many writings and studies, ranging from philosophical and religious writings to scientific papers and texts. Merleau-Ponty (1948/2003) wrote briefly of death as an example of an argument against a mechanistic understanding of body as object. In that argument, he proposed that we become aware of death through the absence of someone where or when we expect their presence. He argues that we “at first” avoid awareness of that absence but the act of avoidance is evidence that we “intuit” or are aware of the absence (p. 93). Kierkegaard (1959) wrote about the imposition of death on life as, “So it is with all joy; life’s supreme and richest moment of pleasure is coupled with death” (p. 20). He suggests that the reality of death’s imminence makes the experience of life richer and more meaningful and intensifies the emotions of both everyday and extraordinary experiences. Viktor Frankl (1962) described life and death in a Nazi concentration camp in his writings and his efforts there to prevent suicide attempts. Frankl’s actions under conditions of such suffering demonstrated the value he placed on the sanctity of life. He wrote that people can find purpose and meaning to life under difficult circumstances such as suffering which can sustain them when nothing else can (Frankl, 1962; King & Jordan-Welch, 2003).

We of the human species have been fascinated by death and its mysterious impact on our lives. We have studied, pondered, explored, and challenged that impact, but it remains mysterious. Our understanding of the phenomenon *death*, and the human experience of it, continues to be just out of reach of scientific study and analysis. The

experience of death can only be known by proxy through the study of *dying* as we face our own dying or share the experience of another person's death. According to Heidegger (1962), we experience *dying* or *Being-towards-death* (p. 301) but not *death*. We study the experience of dying to better understand death, realizing that we may actually be learning nothing about *death* because at that point "we reach theoretical domains of knowledge" (p. 301).

Death and Dying in Religious Contexts

The earliest experiences and writings of death and dying are found within religious contexts and faiths. Religious views of death are found throughout historical and contemporary writings. According to Ross (1997), "Eastern thought...assumes an endless series of births and deaths that the human being must suffer through until proper knowledge is obtained to break the cycle and reach enlightenment" (p. 299). In both Buddhism and Hinduism, death is believed to be "recurrent" and a step in the process of "transmigration" in the "course of the soul in its various incarnations" (Amore, p. 125). In these incarnations, the person accumulates good and bad Karma until the soul evolves, bad Karma is "cleared off," and no additional good Karma is accumulated so that rebirth is unnecessary (p. 126). At this stage of freedom from rebirth, the person is also free from death and reaches Nirvana. Hinduism and Buddhism differ in beliefs of the importance and power of the gods to control the cyclic incarnations as Hinduism attributes this power to the gods and Buddhism attributes helping powers to spiritual beings or *Bodhisattvas* (Amore, p. 123).

Early Hebrew religion described death in contrasting terms to life or *unit of vital*

power (Silberman, p. 15). Death was the absence or weakening of life power. The dead still existed in a place called *She'ol* and were thought by some to enjoy reward or suffer torment there depending on their actions in life (Silberman, 1969). According to Silberman, later Jewish belief included those who held an apocalyptic belief that death is related to judgment and resurrection. Teachings in the New Testament depicted death as a combination of Jewish *apocalyptic* belief and the Greek or Hellenistic belief of resurrection in a spiritual rather than a physical form (Keck, 1969). In the apocalyptic belief it is vital to repent before death to prevent punishment. Death is to be dreaded and feared but conquered through faith and repentance. In Hellenistic belief the person is a spirit within a physical body that is released at death to its original state, also known as Gnostic belief. The common theme is victory over death and suffering through faith and resurrection.

Death and Dying Within the Discipline of Psychology

Several writers in psychology and psychoanalysis share viewpoints of death and the emotional concerns generated by thoughts of death termed by many as *death anxiety*. Freud wrote on many anxieties and proposed antecedents and causes of common anxieties and neuroses. In his writings, Freud (1959) attributes death anxiety to a learned fear of “loss, a separation” (p. 130), developing from the original separation at human birth. Becker (1971) wrote that humans are unique in the fear of death because we are the only species with awareness of time and loss of time through death. Becker expresses a belief that fear of death is paramount for humans as he writes, “...death is man’s peculiar and greatest anxiety” (p. 70). Becker describes human death and burial rituals as

a form of defiance to this fear of death. The human fear of death and the concept of death anxiety have been topics of many research studies, often referred to as *death studies*.

Early Studies on Death and Dying: Concept and Tool Development

Early studies on death and dying began in the 20th century, especially after World War II with the “pervasive death anxiety coming in aftermath of Hiroshima” (Benoliel, 1983, p. 102). Early seminal work in death studies is often attributed to a physician of the mid-to late-20th century, Elisabeth Kubler-Ross. Kubler-Ross (1978) describes the beginning of her work in post-WWII Poland with concentration camp survivors, where she found evidence of the human struggle with death and dying leading to her interest in research and foundational to her work on stages of grief. She describes the camps and that experience as she writes, “In those camps I saw dying in its most horrible form, but also living and surviving in its most gracious form” (p. 18). From that experience, Kubler-Ross went on to a lifetime work that provided the health and social sciences with an understanding of the grief responses to death known as *denial, anger, bargaining, depression, and acceptance*. Originally referred to as stages of death, these are not stages that a person moves systematically through in a chronological order, but responses to death that may be permanent, temporary, or imperceptible. Kubler-Ross’ work influenced death studies by providing a foundation of research of those suffering from grief, loss, and dying with compassion for their suffering, respect for their expertise in the experience, and appreciation for their contribution to our understanding. Her work is also foundational to the development of end-of-life care concepts in health care today that I

will discuss later in this chapter.

Death studies in psychology and sociology began slowly in the 1950's, increasing in the 60's and 70's with Kalish and Katenbaum's newsletter in 1966, which later became the journal *Omega: The Journal on Death and Dying* in 1970 (Benoliel, 1983). Glaser and Strauss' research in the late 50's to early 60's studied the experience of hospital staff and patients during the end of life (Glaser & Strauss, 1968; Quint, 1967). The study, funded by a Public Health Service Research Grant, revealed, among other things, that societal changes placed dying patients in acute care facilities more frequently than the traditional home site for death. This change in location meant that the nurse was positioned to have many interactions with dying patients and nurses became the healthcare professional with predominant responsibility for the care of dying patients. Nurses, however, were uncomfortable with interacting with dying patients and often avoided opportunities for interaction due to that discomfort. Other studies in medicine and nursing disciplines began at roughly the same time with early work on care modalities by Saunders in England in the 1960's ultimately leading to the development of hospice care, a holistic model of care for dying patients providing interventions for dying patients.

Nursing research in death and dying began as early as the 1950's by Norris, Peplau, and Quint who later became Benoliel (1983). Before this time, death and dying were not often addressed as nursing issues as evidenced by only 18 articles on the topics in the *American Journal of Nursing* between 1900 and 1960 (Quint, 1967). This lack of attention to care modalities and psychological needs of dying patients began to change

with Glaser and Strauss' study. As a part of that study, Benoliel used a qualitative methodology to explore the preparation of nursing students for care of dying patients after graduation in five schools in the San Francisco Bay area. Her results suggested that students were not adequately prepared to care for dying patients. The rare graduate who was comfortable caring for dying patients had exceptional experiences in nursing school, fostered by faculty to provide unique educational opportunities (Quint, 1967). This early work was foundational for studies of nurses caring for dying patients and established Benoliel as an early leader in nursing research in this area.

In the 1970's, according to Benoliel (1983), nursing research in death and dying focused on nurses' attitudes about death and responses of patients to impending death and families to bereavement. Sociology and psychology played an important role in providing the theoretical framework and methodology for nursing research studies. Benoliel reports that early research was hampered by design problems such as quantitative studies without control groups or adequate control of researcher bias. Researchers in the 1970's were also developing conceptual and operational definitions for factors related to death and dying such as death attitudes and death anxiety scales. Kurlychek (1978) has provided a discussion and critique of these early methods, which I have summarized in Table 1. Examples of researchers using these tools can be found in the nursing and related health sciences literature including research that relates to the study of the experience of critical care nurses caring for dying patients (Sherman, 1996; Taylor, 1983).

Table 1

Early Quantitative Tools Used in Death Studies

Measurement Tool	Developers or Users	Comments
Death Attitude Frequency of Thoughts	Hall and Scott	Limited by questionable reliability
Death Anxiety Scales	Means, Middleton, and Bakshis Gottschalk, Winget, and Glaser	Problems with “standardization and interpretation” (p. 38)
Projective methods Thematic Apperception Test (TAT)	Klopfer, Rhudick, Dibner, Shrut	Not used recently because of low reliability and validity scores
Physiological measures Galvanic Skin Response (GSR)	Alexander, Adlerstien, Meissner, and Templer	Adequate reliability; concerns with interpretation of specific emotions aroused.

Table 1

Continued

Measurement Tool	Developers or Users	Comments
Death attitude scales	Sarnoff and Corwin	Reliability score of .79 and
Fear of death	Boyer	variable validity scores
	Lester	Lester's tool had test-retest
		score of .58 but higher
		scores for construct validity
		testing with established
		tools
Templar Death Anxiety	Used widely	15 items with true-false
Scale (DAS)		format—test-retest score
		.83, no correlation with
		Marlow-Crowne scale for
		'social desirability
		influence', construct
		validity and criterion
		validity testing were applied
		with acceptable scores

Table 1

Continued

Measurement Tool	Developers or Users	Comments
Death Concern	Dickson	Split-half reliability testing .85, acceptable validity testing but correlates with Marlowe-Crowne scale for social desirability influence
Death Acceptance Scale	Kurlychek	Uses semantic differentials

In the 1980's and 90's, nursing and related health researchers responded to the changing health care environment identified by Glaser and Strauss by studying the care needs of dying patients and the outcomes of current care modalities. In 1992, Benoliel wrote, "the medicalization of major human transition experiences—such as birth, childhood, adolescence, marriage, old age, and death—has contributed to a growing dependence on *experts* for advice...It is important for the future of humankind that we in thanatology foster and encourage the creation of caregiving environments in which: (a) the model of delivery is by a *community of colleagues*; (b) the mode of action is through partnerships with patients, families, and other providers; and (c) the mode of relationship is equal and reciprocal" (p. 22).

In the last decades of the 20th century, researchers in various fields sought to

understand the phenomenon of dying so that end-of-life care would meet the needs of patients and their families. In 1987, Ross explored the existential meanings of death in a phenomenological study. In that study, he asked 26 adults to describe their experiences with death and dying using both open-ended interview questions and a list of commonly used metaphors related to death and dying developed by Knapp. In a hermeneutical analysis of interview transcripts, Ross found that participants described death in terms of the “immediacy” and the “consequences” of the experience (p. 357). Existential themes of the study included “death perceived as meaningless” when described as a “barrier” or “disruption;” death perceived as meaningful,” when described as a “relief;” and “death perceived as absence of meaning” when described as foreign or “denied” (p. 262).

In this first decade of the 21st century, nursing research is focused on various aspects of death and dying, including care interventions and modalities, outcomes focused research, and the emotional and inter-relational aspects of end-of-life care. End-of-life care has become a field of practice and research that has the resources of international governments and healthcare organizations dedicated to understanding all facets of the concept and to improving care for those experiencing the realities of its impact on life.

The Concept of End-of-Life Care: What is Known

Through the efforts of researchers and providers, end-of life care has become a specialty within healthcare designed to meet the unique needs of the dying patient. Another term, *palliative care* is also used to describe care emphasizing measures to provide comfort and dignity to the terminally ill patient whether they are imminently

dying or functionally well but living with a potentially terminal illness. The goals of such care modalities include those common to all patients, such as symptom management, communication, education, and psychosocial support, while addressing the unique needs of the dying patient.

Based on studies of the last four decades, researchers identified changes in health care that precipitated a crisis in end-of-life care. In 1998, Benoliel wrote that implementation of hospice and palliative care was “slow” because “they did not fit well with the organizing framework of disease and treatment” although the needs from multi-national and multi-cultural care “challenges” in death and bereavement would only increase in the 21st century (p. 267). According to Kyba (2002), legal and ethical issues in end-of-life care present “challenges for a ‘death with dignity’ in America” (p. 141). Direct threats to providing a peaceful death in the critical care unit include: the sociocultural context of curative instead of caring treatment, a technologic imperative to do everything possible for the patient, barriers to palliative care (ranging from cultural and ethnic differences in acceptance of hospice care and financial payor issues), legal perspectives of advance directives and surrogate decision making, and multiple ethical perspectives on topics such as nutrition, refusal of treatment, medical futility, and pain management. Research in these areas is exploratory, with few answers for the critical care nurse.

There have been challenges to implementing hospice and palliative care for a large number of dying patients. Barriers to palliative care introduce the nurse to many challenges in caring for the dying patient. One of these challenges is ameliorating pain

and suffering. Suffering and the nurse's perspective was the topic of a study in the late 1980's by Steeves, Kahn, and Benoliel (1990) using semi-structured interviews in a qualitative descriptive study of "nurses' interpretation of the suffering of their patients" (p. 715). In that study, 26 graduate nursing students (20 female, 6 male) described *exemplars* of patient suffering and provided researchers with words they would use interchangeably with *suffering*. From the interviews, the researchers were able to identify three themes of nurse interpretation of suffering and two transitions between the themes. The themes were: "suffering as a patient condition"; "suffering as an experience"; and "suffering personalized by nurses" (p. 719). Transitions represented changing perceptions that brought participants from the concept of suffering as a medical condition to suffering as a human experience; one that they engaged in with the patient or necessarily inflicted on the patient. This well-designed study provides insight in the dynamic interaction between the nurse and the dying patient who is suffering, often as a result of the treatment protocol implemented by the nurse. This is characteristic of many nurse-patient interactions in the intensive care unit where medical treatment modalities may result in increased suffering by the patient.

Many end-of-life patient needs have been identified through well designed studies such as the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) and the Hospitalized Elderly Longitudinal Project (HELP) in the mid 1990's to 2000. In these studies, in a two phase approach, the researchers first used an observational methodology and then a blind control group intervention with a total of over 9000 subjects to determine the trends and issues in healthcare for the elderly and

needs for future research (Rutledge, Donaldson, & Pravikoff, 2001; Rutledge, Bookbinder, Donaldson, & Pravikoff, 2001). Results of phase I revealed alarming results: dying patients often were treated in intensive care units with aggressive curative treatments instead of with emotional and physical support needed for peaceful death and symptoms were not adequately treated while disease processes were overly treated. In a well designed phase II, the intervention phase of the study, patients were randomly assigned to control and treatment groups and interventions planned to improve communication and decision making in caring for patients were implemented. This phase resulted in a non-significant difference in outcomes of several measures of patient care (i.e., days in intensive care or reports of pain). The study researchers proposed that research into caring for dying patients in intensive care units is a new and important area for future research (Rutledge, et al., 2001).

End-of-life Care and Spirituality

The spiritual needs of dying patients have various components including, but not exclusively, those which are religious (Burton, 1998; Hall, B. A., 1997). Whatever the cause and whatever the timeframe of preparation, the nurse is responsible to assess for, and provide holistic care, that includes not only physiological and psychosocial, but spiritual issues as well. The complicated spiritual needs of the dying patient are eloquently described as Bailey (1997) writes, “Cancer can force a person to confront the reality of death and challenge their way of life, world-view, way of making sense, regrets, desire for forgiveness, urge to make amends, immortal yearning, and longing for God” (p. 242). A dying patient who is suffering spiritual distress is at greater risk for hastened

death and unrelieved physical and emotional suffering. Patients who have “a sense of spiritual well-being” (Phillips & Morrow, 1998, p. 387) may benefit from improved physiological and emotional well being.

Although spiritual distress is acknowledged as a nursing care need and patients benefit from spiritual well being, nursing knowledge of assessing for and providing spiritual care is incomplete (Hall, B. A., 1997). Smucker (1993) interviewed 10 participants in a phenomenological study about their experiences with spiritual distress, “being concerned about the meaning of life/death and/or belief” (p. 13). In that study, two phases of spiritual distress emerged. The first phase, titled “breaking the web” included an “intense” questioning with a sense of instability and searching. The second phase, titled “rebuilding the web” included a renewed wonder in life with a new excitement and engagement (pp. 105-106). An evolution of the conceptual definition of spiritual care from religion and faith based ideology to a concept including religious, culture, and existential concepts has affected the role of nursing care in spirituality. Nursing researchers contributed to the evolvement of the conceptual definition by identifying concepts to be included in a new definition and studying how these concepts relate to care of the dying patient (Grey, 1994; Mahoney & Graci, 1999). Within the context of this “cultural movement” (Daaleman & VandCreek, 2000, p. 2517), nursing scholars have broadened the definition of spirituality to include concepts of meaning, transcendence, connecting or connectedness, seeking, and becoming (Goldberg, 1998; Martsoff, 1997). Researchers studied the spiritual experience of the dying patient to identify factors and indicators for spiritual health or distress (Leetan, 1996; McCanse,

1995) and found that factors such as connectedness, meaning, purpose, support, and belief systems influenced the spiritual wellbeing of the dying patient. Thus far, few research studies on nursing interventions and fewer still on outcomes of interventions have been conducted. Most research studies have been descriptive or exploratory quantitative or qualitative studies on HIV or cancer patients.

Surprisingly few studies of spirituality took place in intensive care units, though nurses in that setting presumably encounter the spiritual care needs of dying patients every day. One research study conducted in this setting studied patients recovering from life threatening illnesses. In a qualitative study, Clark and Heidenreich (1995) used open ended question interviews and content analysis of 63 critical care patients after discharge from the intensive care units. The researchers sought to discover the contributing factors of care that promoted or inhibited perceived spiritual wellbeing for patients. Themes identified included trust relationships, connection to support systems of family, friends, clergy, and maintenance of hope. Interventions from nursing staff that enhanced or provided for spiritual well being were identified. Included in the interventions were “providing hope and meaning” (p. 79), providing for family support and providing a trusting relationship. Limitations of this report were little discussion of rigor and inadequate description of procedure used in content analysis. The study did illustrate one method for studying the difficult question of the spiritual needs of the critically ill patient, although findings may not represent all dying patients even in the same setting.

Health care providers in hospice settings and acute non-critical care areas were the subject of several nursing research studies on spirituality. Messenger and Roberts

(1994) reported a descriptive survey study of hospice nurses on “serenity nursing interventions” (p. 17) using a convenience sample of 59 hospice nurses. Serenity was defined as “a spiritual experience of inner peace, trust, and connectedness that exists independently of external events” (p. 17). Nurses in the study were asked to rate various serenity interventions for effectiveness. The researchers developed a tool for the study with a high Cronbach's alpha (0.97) and all interventions were rated above three on a scale of one to five. The highest rated interventions were pain control, building a trusting relationship, and therapeutic touch. In the survey tool, however, therapeutic touch could have meant comforting touch or a protocol from Krieger's work (Krieger, 1990). A convenience sample and the vagueness of survey items limited utility and generalizability of the study.

In another study of 220 nurses of varying cultural, racial, education, and practice settings, Sherman (1996) explored the relationships between nurses' attitudes toward caring for terminally ill patients with HIV and spirituality, perceived social support, and death anxiety as assessed by the Templer Death Anxiety Scale (DAS). Of the convenience sample of nurses from eight hospitals in New York City area, 40% (n=88) worked on AIDS-dedicated units and the remaining 60% worked on medical-surgical units (p. 207). Sherman used Rogers' science of unitary human beings as a framework for studying nurses' attitudes toward caring for HIV patients. Spirituality is not an explicit component of Rogers' theory but Sherman felt the concepts were congruent with the science of unitary human beings (p. 206). A new tool was developed for the study to measure willingness to care for AIDS patients while the Templer Death Anxiety Scale

(DAS) was used to measure death anxiety in this study. In a pilot study the internal consistency for this new tool was reasonable with a coefficient of .76 although the coefficient dropped to .63 in the study itself. Criterion and construct validity testing has been reported with testing on a highly anxious group of psychiatric patients. A correlation of .74 with the Boyar's Fear of Death Scale was found. Test-retest is adequate with a .83 result. The tool would need to be pilot tested again before use due to the inconsistent reliability scores in this study.

Sherman (1996) found the spirituality indicators of connectedness, transcendence, and awareness had positive relationships to a willingness to care for AIDS patients. Death anxiety was inversely related to perceived spirituality and willingness to care for AIDS patients. The correlation was very small ($r = -.14$) though statistically significant ($p < .001$). Social support was another statistically significant, though very small factor ($r = .10$, $p < .001$) in the willingness of nurses to care for AIDS patients. Only 17% of the variance of willingness to care for AIDS patients was accounted for by the factors in the study while 22% was explained by whether the nurses worked on an AIDS dedicated unit or not. Sherman addressed the weakness of the correlations and suggested that the study was actually inconclusive and results need to be tested in other settings and with larger, more heterogeneous samples. This study, although limited by a convenience sample and a new instrument, poses questions concerning the relationships between death anxiety, unit identity, social support, spirituality and willingness to care for dying patients in intensive care unit nurses.

End-of-life Care and Stress/Coping

Both quantitative and qualitative research methodologies have been used to study the relationship between stress levels of critical care nurses and caring for dying patients. Quantitative methodology has presented design challenges to researchers in intensive care units. One study by Cooper and Mitchell (1990) attempted to use a quantitative research approach to identifying factors related to stress for nurses working in critical care units of seven hospitals and four hospices in northern England. Survey questionnaires were sent to 300 nurses with an adequate return of 117 completed surveys for a response rate of 47% including 37 hospice nurses and 80 hospital nurses. Three established tools to measure variables of nurse stress (Nurse Stress Index), job satisfaction (Job Satisfaction Scale), anxiety and depression (Crown-Crisp Experiential Index) were used. No pilot study was conducted but internal consistency reliability (Cronbach's alpha) was computed on the scales with all but one scoring greater than 0.6. Appropriate statistical analysis included: Factor analysis and Mann Whitney U to determine relationships between the variables and to compare relationships between groups; Pearson correlations to determine co-variability of scales; and multiple regressions to determine predictors of nurse stress and job satisfaction. Results of the study indicated statistically significant differences between hospital nurses and hospice nurses on both job satisfaction and job dissatisfaction scales with less job satisfaction in hospital nurses than in hospice nurses. There was no significant difference in nurse stress levels between hospital and hospice nurses.

The researchers then compared stress levels between hospital and hospice nurses

with another group of nurse managers and demonstrated a significant difference with more stress in both the hospital group and the hospice group than in the nurse manager group. Other study results suggested that predictors for anxiety in both the hospital and hospice nurses included relationships between nurses and patients/relatives and “involvement in decision making” (p. 305.) Work/home concerns and *staff support* predicted anxiety levels for hospital nurses, while *workload* and time between admission of the patient to hospice and death predicted anxiety levels for hospice nurses. Limitations of the study that were not identified included the self-selection in return of a mailed questionnaire, the disproportionate size of the comparison groups, the failure to address reasons for non-participation and the lack of a report of the representation of the sample to the population. This research suggests interesting results that need to be studied further to identify sources of stress and job dissatisfaction/satisfaction in these nurse populations. This study provides further rationale for the need of qualitative studies in this area.

Qualitative studies have been used to identify concerns with patient care and nurse stress in the critical care unit. One study by Tucker (1992) explored the relationships between caring for dying patients, critical care nurse stress, and coping strategies in a study that employed semi-structured interviews with predetermined questions to address. The topics centered on the concept of “do not resuscitate” (DNR) and the role of the nurse on the critical care unit. Content analysis was used including coding and developing interview themes through categories and domains. Working alone in the interpretive phase of the study, Tucker relied on the texts of the interviews for

verification of patterns of themes and domains. Although this methodology can be used in qualitative studies effectively, the researcher must be vigilant that personal bias does not influence the analysis inappropriately. Tucker addressed these concerns by keeping a journal of personal thoughts and reactions to identify potential biases in interpretation and verifying themes and domains with selected participants.

In contrast to the study by Tittle, et al. (1992) where DNR designated patients received more care time, the findings of Tucker's study (1992) presented an unsympathetic representation of critical care nurses who neglected their DNR designated patients for other patients and competed with other units to have the best "groomed" patients (p. 40). The researcher reported the nurses' emotions "ranged widely from relief and acceptance to dissatisfaction, frustration, and anger with the DNR decision" (p. 38) depending on their agreement with the decision. Another finding of the study included the nurses' diverting care and attention from the patient to the families of the patient when the DNR decision was made. Tucker was conservative in generalizing the results and encouraged more research with critical care nurses in other sites to discover if similar results would be found.

Another qualitative study using open ended questions and content analysis to determine the stressors that nurses experience when caring for organ donor patients and their families was conducted by Hibbert (1995). The researchers used Lazarus and Folkman's theory of stress and coping as a framework for content analysis of interviews with 17 nurses in a neurological intensive care unit. The questions were provided in the article and the researcher provided evidence of rigor in interviewing and analysis. The

analysis was based on Wilson's method of categorizing coded units. Hibbert applied Cohen's Kappa statistical analysis for reliability testing on the categories with appropriately high results ($\geq .90$). Results demonstrated that nurses identified areas of stress in communicating with family members during the care of the donor, specifically finding time to support the family in their grief while meeting the demanding schedule of caring for and preparing the donor for retrieval of organs. The nurses also described stressors when physicians did not institute appropriate orders necessary for organ retrieval or did not act in the appropriate time period to make the donation of organs possible. The researcher identified the sample size, the instrument and the nature of self-report data as weaknesses of the study but these are really not weaknesses of a qualitative design as they are in quantitative studies. They are simply a part of the nature of qualitative research rather than quantitative research. Based on her findings, Hibbert suggested the need for education for nurses in similar roles and debriefing sessions for nurses within specific time frames.

One mixed methodology exploratory study by Papadatou and Bellali (2002) explored the stress and grief responses of physicians and nurses to deaths of patients in 2 pediatric oncology units in Athens, Greece. The participants included 14 physicians (9 female and 5 male) and 16 nurses (15 female and one male). In the qualitative part of the study, the researchers used semi-structured interviews with a grounded theory analysis approach to explore concepts related to caring for dying pediatric patients. In the quantitative part of the study, the researchers used a rating scale to explore relationships between the level of stress and elements of care of dying patients. No reliability or

validity testing was reported on the quantitative tool developed by the researchers for this study. Questions used in the interviews were not listed but were reported to direct the participant to discuss “difficulties,” “stressors,” and “rewards” and the provider’s “response” to experiences (p. 348). “Difficulties” included the death occurrence itself, communication with families, and feelings of “helplessness and powerlessness” (p. 348).

The results of both methods in Papadatou and Bellali’s (2002) study were enlightening and informative. Nurses and physicians reported the highest stress from painful death and unrelieved pain. The groups differed as nurses rated long term relationships more stressful and physicians rated the same as less stressful. Physicians reported that symptom control and peaceful death was a greater reward and nurses reported that “contribution to care,” close relationship, and recognition from the family were greatest sources of reward (p. 349). In rating their response to the meaning and importance of presence at death, physicians felt it was something above and beyond their duty to support the patient/family and to bring closure. Nurses felt being present at the death was a part of their role and responsibility in care. Bathing and dressing the body after death was an important part of care for the nurses. Nurses were more distressed if the death occurred while they were alone on shift without someone with whom to debrief. Both groups described patterns of “experiencing and avoiding grief” (p. 350) which differed as physicians described their grief as a “private affair” (p. 350). Nurses grieved similarly to physicians with sadness, feelings of loss and reviewing the occurrence, but sought out other staff for emotional support. Physicians were “more systematic and structured” in their attempts to control the cycle of “experiencing and avoiding grief” (p.

350). Physicians grieved over the failure of the therapy while nurses grieved over loss of relationships. In attributing “meaning” to the deaths, physicians determined meaning within the context of their role in curing the disease and whether they had tried everything possible and were able to control the symptoms for a peaceful death. Nurses attributed meaning in the context of relationships and their role in physical and psychological care of the child.

In their discussion, Papadatou and Bellali (2002) suggested that a healthy response to grief depended on whether the nurse or physician had a healthy “fluctuation” between “experiencing and avoiding” grief (p. 351). Little fluctuation led to pathological response and greater burnout. When asked if they would prefer to stay in their present position or leave if given the choice, a majority of the nurses responded that they would rather stay and a majority of physicians reported they would rather leave. Nurses attributed their positive response to “contribution” of their work and to relationships with their patients (p. 351). Physicians attributed their negative response to their lack of positive relationships with other medical colleagues. Results of this study support the findings of other studies that physicians and nurses differ in their response to the dying patient and their roles in patient care (Simmonds, 1997). The sample comprised of more females than males in both groups does not support speculation on, and the researchers do not report, gender differences in responses.

Critical Care Nurses and Empathy

The relationship between empathy and other variables such as age, gender, etc., has been studied in critical care nurses. In a study by Bailey (1996) in Australia using the

Empathy Construct Rating Scale (ECRS) developed by La Monica, non-significant correlations were found between empathy scores and demographic variables such as gender, level of education, and years experience. Using a scale ranging “from -252 (lack of empathy) to +252 (well-developed empathy)” the mean of empathy scores for the participants was 186, interpreted by the researcher as “moderately well-developed empathy” (p. 124). The study was weakened by a non-randomized convenience sample with self-selection of respondents. There is no way of determining the representativeness of this group or of comparing these results with non-critical care nurses to determine if this is true of all nurses in that population. The validity and reliability testing of the tool was reported to have been established before use, but the actual results were not adequately described. Internal consistency was established with a coefficient of 0.97. The study presented interesting results, but the limitations of the study and the inadequate discussion of instrument validity suggest the need for further studies using randomized sampling and testing instrument reliability and validity.

Watt-Watson (1997) and Watt-Watson, Stevens, Garfinkel, Streiner, and Gallop (2001) studied critical care nurse characteristics and pain management. Among the characteristics studied were empathy levels and pain management knowledge. These factors were then compared to the pain management outcomes for post-cardiac surgery patients in the care of nurses. The studies were well designed with adequate numbers of participants (94 nurses and over 200 patients for each study) and IRB approval was obtained. Results of the studies were troubling because no correlation was found between empathy levels and pain management outcomes, or between pain management

knowledge and outcomes. In the pain knowledge study, patients reported moderate to severe pain levels while they had received less than half the prescribed pain medication. In the conclusions of these studies, the researchers report that they could not correlate either high empathy levels or pain knowledge to pain management outcomes, suggesting other factors influenced pain outcomes.

The relationship of empathy to care outcomes and moral judgments has been addressed in nursing research with implications for nursing practice. In a study in the United Kingdom, Reynolds, Scott, and Austin (2000) found that empathy education was effective for nursing staff but that barriers to use of the new skills occurred when workload was too high, privacy and uninterrupted patient encounters were not possible, and that staff colleagues were not supportive of the nurse. Other areas that need to be addressed to encourage empathy are the time constraints presented by short length of stays and need for supportive supervisors. Fostering of empathic care of patients and its relationship to patient outcomes and nurse stress and burnout is an important topic for future nursing research.

End-of-life Care and Communication

In another qualitative research study using semi-structured interviews with 10 nurses in ICU setting in Brazil, Trovo de Araujo and Paes da Silva (2004) use Bardin's method of content analysis to explore the ways and importance of communicating with dying patients in ICU. The researchers provided only a brief description of a "semantic or thematic" approach to thematic structuring (p. 145). Findings suggested that although all nurses felt communication with patients, especially dying ones, was important, they

varied on how often they communicated with dying patients and their families in the ICU. Some nurses communicated readily about aspects of care with patients despite the patient's inability to respond. Other nurses did not attempt to communicate with patients. Some of the reasons nurses gave for not attempting communication with patients stemmed from the incapacity of patients to respond, the level of sedation the patient was experiencing, and the nurses' perceived inability to communicate appropriately with the patient due to sedation or technological obstacles such as ventilator dependency. Nurses also expressed a reluctance to address the issues of dying with the patient due to feeling ill-prepared to deal with the patient's issues of dying. Reasons given by the nurses for not attempting to communicate with patients' families stemmed from an inability to empathize with the needs of the patient, as one nurse expressed, "We seldom stop to think about the stress a person undergoes in visiting a relative at ICU. For us it is so much routine to come here, to be here, to work here, that we overlook this issue" (p. 147). The findings of this study are validated in other research, but the study is limited to a focus on one aspect of care, the importance of communicating with the ICU patient. Nurses caring for dying patients present complex challenges of which communication is only one. A more holistic approach to the multidimensional aspects of this complicated interaction is appropriate for future research.

End-of-life Care and Assisted Suicide

The need for urgency in research involving critical care nurses caring for dying patients is supported by the results of several research studies on assisted suicide and passive euthanasia in the 1990's. The American Nurses Association (1994) has taken a

position against assisted suicide and voluntary active euthanasia although research findings suggested that some nurses disagreed with the position (King & Jordan-Welch, 2003). A survey in South Carolina by Shuman, Fournet, Zelhart, Roland, and Estes (1992) suggested that nurses with liberal political views and stronger feelings about individual freedom of choice in health care decisions were likely supporters of euthanasia. Also, the frequency with which nurses cared for dying patients positively correlated with support of euthanasia. The research suggested a need for more study of the factors contributing to nurses' attitudes about euthanasia. In 1994, the ANA reiterated its position on nurses' duty to relieve suffering while causing no harm, and clarified the nurse's role in care of a dying patient. While assisted suicide is considered unethical, patients may benefit when nurses therapeutically discuss patients' thoughts about suicide and other concerns without disapproval or judgment.

Asch (1996) conducted a survey study to determine the frequency of nurses working in intensive care units participation in or initiation of assisted suicide or euthanasia. In that study, of the nurses responding, 19% reported having participated in or performed assisted suicide or euthanasia. Reasons the nurses gave for their actions related to their frustration that medical practice use of technology maintains life when patients do not wish it or suffer because of it. The study results were criticized because of absence of control and instrument reliability and validity concerns (Dunn, 1996; Scanlon, 1996; Szaflorski & Closhey, 1996). Study findings, however, were supported by other research (King & Jordan-Welch), such as a survey study of Nevada nurses (Kowalski, 1997), providing further evidence of concern. In Kowalski's study, 539

nurses responded with results supporting that the majority agreed with physician passive euthanasia (92%), double-effect euthanasia (85%), and physician assisted suicide (53%), but not with active euthanasia (44%). The majority felt, however, that they would not participate, whether or not it was legal to do so. Most opinions supported that physicians should be the accountable and participating provider, not the nurse. Leiser, Mitchell, Hahn, Slome, and Abrams (1998) surveyed 215 nurses with results demonstrating that over 50% responding that assisted suicide was appropriate for patients who suffered intractable pain and that they supported nurse participation in assisted suicide with or without a physician's involvement.

In a similar study by Matzo and Schwartz (2001), who surveyed oncology nurses in New England, more than 30% of the nurses surveyed reported being asked to assist in suicide at least once and some were asked up to 20 times in just the year before the survey. A small number of those responding had performed euthanasia (almost 5%) or had assisted suicide (1%). When content analysis was performed on participant comments, data indicated that nurses need to talk about patients' suffering and dying and these areas need to be researched more in the future. Nurses also reported a need for more education about care and ethical issues of patient dying. Generalization of the findings in each of these studies is limited by the mailed survey design and lack of reported instrument validity, but findings do lend support to the impression that nurses are being asked to assist patients in dying and some are choosing to honor that request.

Studies in other countries also provide findings supporting Asch's study (King & Jordan-Welch). Kitchener (1998) surveyed 2000 randomly selected nurses from the list of

registered nurses in the Australian Capital Territory. Survey questions compared attitudes towards active voluntary euthanasia (AVE) with regard to nurses' age, religion, gender, percentage of patients they care for who are terminally ill, area of specialty, and interest in issue. An adequate response rate of 61% of surveyed nurses strengthened the study. Co-linearity of variables was statistically controlled using a logistic regression analysis. All factors studied were significantly correlated with support of AVE except gender. Palliative care specialty nurses were the only group not supporting AVE (33%). Most nurses supported AVE and most reported that they would participate in AVE. In these findings, results mirrored surveys of the general public in this area, only less so. Younger nurses were more in favor and more willing to assist in AVE. The researchers postulated that this could show a changing trend in society's attitude since it mirrored trends in the general population as well. This is a possibility, but I would propose that it could be a developmental difference in attitude between older and younger generations' members. Researchers identified that they asked only about religious preference and did not address level of religiosity in their survey. Palliative care nurses differed in a less than majority (33.3%) agreement with AVE compared to 65% of oncology nurses. An inverse relationship emerged between time spent caring for terminally ill patients and agreement with AVE. Researchers addressed limitations of study and were conservative in generalizing the findings.

A more recent large quantitative study in the United States by several leaders in nursing research explored nurses' attitudes and knowledge of specific issues in end-of-life care in critical care units. Puntillo, Benner, Drought, Drew, Stotts, Stannard, Rushton,

Scanlon, Stotts, and White (2001) used a survey in a randomized sample to study perceptions and knowledge of end-of-life issues including voluntary and non-voluntary euthanasia, assisted suicide, double-effect principle, withdrawing treatment, and pain management. The survey was sent to 3000 members of the American Association of Critical-Care Nurses with a return of 906 respondents (30% rate) differing significantly from the nursing population in level of education (more diploma graduates) and race (more White Caucasian). Responses from these participants lend support to other studies in this area. Most responded that dying patients' pain was sometimes or often unrelieved; some felt that inappropriately high amounts of pain medication were administered.

The nurses also responded that support services such as end-of-life (EOL) consults in ethics or hospice or "grief counseling and debriefing for the staff...rarely...or never...occurred" (p. 223). In scenarios provided on the questionnaire, most respondents accurately recognized withholding treatment, assisted suicide, and double-effect principle. Respondents had some difficulty distinguishing between voluntary or non-voluntary euthanasia and assisted suicide or double-effect principle. When asked whether they agreed with the actions in the scenarios, most disagreed with assisted suicide although 17% responded in agreement to the action. A surprising 37% reported that they had been asked in the last 3 years by a patient or family member "to assist in hastening a patient's death" and 34% "thought that they sometimes acted against their conscience," with 6% reporting "to a great extent" (p. 222). The study seemed well conducted but was limited by mailed survey design with a newly developed instrument. The researchers did generalize to the larger population, perhaps inappropriately

considering the demographics of the respondents.

Qualitative study results provide a more complete understanding of the factors involved in the decision to assist or not assist in the dying patient's suicide. In a phenomenological study conducted by Schwarz (2004), 10 nurses, who had received and responded to patients' requests for assistance in dying, were studied using Van Manen's methodological approach to analyze the interview transcripts with collegial review for confirmation of the researcher's thematic interpretations. Themes identified included: "being open to hear and hearing"; "interpreting and responding to the meaning"; "responding to persistent requests for assistance in dying"; and "reflections" (p. 228). The nurses heard the plea of the patient for assistance in dying, explored and found the patient's meaning in and for the request, responded to the request, sometimes assisting with death, and then reflected on the experience and its implications for future practice. The resulting analysis disclosed that nurses may or may not have participated in active or passive euthanasia and nurse-assisted suicide based on a solitary decision making process and felt varying degrees of moral and ethical distress due to the sensitive legal and professional issues related to the circumstances. The study was well planned and revealed insights into a difficult set of circumstances affecting the nursing profession. More research in this sensitive and challenging area of end-of-life care is urgently needed.

End-of-life Care and the Critical Care Nurse

Most research on end-of-life care takes place in settings providing hospice care modalities (Rutledge, et al., 2001). Studies of patients with cancer and HIV have provided both a better understanding of the multidimensional needs of the dying patient

and some understanding of the needs of the nurse caring for the dying patient.

However, more patients die in acute care settings and critical care units than at home or in inpatient hospice settings (Rutledge, et al., 2001). Fewer studies have utilized the critical care unit as a site and fewer still have studied the critical care nurse's experience of caring for dying patients. Most of these largely questionnaire studies have been performed outside the United States in Australia, New Zealand, Canada, England, Greece, and Hong Kong. Nurse researchers have found qualitative research useful in exploring the perceptions of nurses caring for dying patients. In one grounded theory study using Strauss and Corbin's framework, Simmonds (1997) studied the experience of 21 nurses and physicians who worked in intensive care units in Canada and found differences in the experiences described by nurses to those of physicians. Interviews began with the question of "what they liked and what they found difficult about working in intensive care" (p. 12). The researcher reported IRB approval but did not discuss the method of informed consent. The researchers reported no demographic information other than their intent to maximize variability.

Results of Simmonds' study (1997) indicated that both nurses and physicians felt that patients were *overtreated* in intensive care units, although themes demonstrated a different perspective between groups. Physicians expressed satisfaction in "saving life" whereas nurses expressed satisfaction in providing comfort and restoring health (p. 13). Nurses expressed failure as patients suffered, but physicians expressed a reluctance to make the decision or initiate the family's decision to stop doing everything possible for the patient. According to physician interviews, it was easier to continue the technology

until the patient died and avoid the discussion allowing the physician to effectively “ignore” or “deny” what was actually happening to the patient. In response to *overtreatment*, participants expressed feelings of “powerlessness” (p. 14), and each felt it was most prominent when he or she had no power to change decisions about care. Simmonds comments that “[t]he most significant finding of this study was that physicians find it easier to continue treating until someone else, either the patient’s body or the family calls a halt. Continuing treatment allows one to avoid difficult conversations and ethical decisions. Nurses did not identify continuing treatment as the easier choice as they are the ones who have to work with the results of non-decision by providing hands-on care to a patient, 12 hours at a time” (p. 14).

In a phenomenological study by Andrews (1998) in New Zealand, interviews by critical care nurses were analyzed using Heideggerian hermeneutics and Van Manen’s methodology. In this study Andrews describes appropriate rigor including journaling, verification of transcripts and feedback on themes from participants, and validation of themes from two ICU nurse non-participants. Themes included: *being there*, “a sense of presence with the family”; *sharing*, “shared humanity extends to exist between the nurse and family”; *supporting*, “active help and assistance”; *involving*, “including family in aspects of the care and decision making”; *interpreting*, “provider and interpreter of information”; *advocating*, “ensure the rights of the family are upheld”; and *strategies*, representing “direct interactions between the nurse and the family” (pp. 62-63). The nurse shares in the “suffering and loss” and utilizes “strategies for coping” although the report did not elaborate on what those strategies were or the response of the nurse to the

shared suffering (p. 64).

In a similar study in Norway, Bunch (2001) used grounded theory to explore ethical dilemmas in critical care units. Through purposeful observation and multiple participant interviews over several months on a trauma unit, six ethical dilemmas were identified through open coding, selective coding, and theoretical coding and analysis. The ethical dilemmas included: “end-of-life issues”; “whether there should be an age limit for coronary surgery”; “disturbing limited resources”; “resource allocation in terms of better staffing”; “situations in which it is more harmful than beneficial to continue treatment”; and “transferring patients to other facilities” (p. 57). Bunch identified one core theme of “hidden and emerging drama in the context of ambiguity” and one sub process of “the emulation of composure while routinizing the handling of complex technology” (p. 60). The researcher found that “drama was hidden behind quiet voices and a situation in which the staff never ran...” (p. 60). The composure of the staff and the façade of calm and equanimity on the unit contradicted what was actually happening. The casual observer could not appreciate the “hidden drama” as Bunch wrote that only after time and experience observing on the unit was he able to identify when patients were in crises and “fighting for survival” (p. 60).

Researchers are using mixed methodology to study complex topics in healthcare issues such as end-of-life care. Kirchoff and Beckstrand (2000) found mixed methodology helpful in a series of studies of intensive care nurses caring for dying patients. In this mailed survey design study of 288 critical care nurses randomly chosen from American Association of Critical-Care Nurses, 199 critical care nurses responded

for a 69% response rate. The researchers used new but well developed Likert scale instruments, deriving both from a focus group study of critical care nurses and from a review of the literature. Items in the questionnaire were grouped into two sections of “obstacles to providing end-of-life care to dying patients and their families” (p. 99) and “possible helps to providing end-of-life care to dying patients and their families” (p. 100). Respondents were also given the opportunity to list additional obstacles and helps at the end of each section. Demographic information on age, gender, years of experience, and numbers of dying patients cared for, etc., was included. Results indicated that interactions with the families and physicians were rated *most helpful* if positive and *most obstacle* if negative. Communication interactions between nurse and patient, nurse and family, and physician and family were perceived by the nurse as obstacles or helps based on the quality of the interactions, such as the agreement between physicians to the treatment plan and to the level of understanding of poor prognosis by the family. Nurses rated a family’s expression of gratitude for care as a help.

Limitations of Kirchoff and Beckstrand’s (2000) study included the mailed survey design and newly developed instrument. Researchers were cautious in generalizing beyond the sampled population (members of AACN) but felt that the sample was representative of the population and findings could be generalized to that group. Researchers briefly addressed limitations of the instruments by stating that the phrasing of the items as “obstacles” and “helps” did not address frequency of the items in the day to day care of patients, only the “size” of the obstacle when it occurred. This leaves the reader with unanswered questions about whether these obstacles are everyday

occurrences or only occasional ones.

Focus group design has been useful for study of end-of-life care perceptions in intensive care units. Kirchoff, Spuhler, Walker, Hutton, Cole, and Clemmer (2000) used a focus group design in two hospitals involving four different focus groups of volunteer nurse participants. A cross-sectional design with review of transcriptions before the next interviews provided a dynamic semi-structured interview format. The initial interview was developed from pretesting and revision in a faculty focus group. Well documented rigor in establishment of guidelines for interviews and data analysis was included in the report. Themes identified in the analysis included “transition from curative to end-of-life care” to be “often a ‘gray area’” (p. 40). Nurses relied on “intuition” and found “dissonance” between care that would provide a peaceful, good end at death and “curative care” having the goal of “preserving life at all costs” (p. 40). Nurses described curative care as “flogging” and expressed concern and discomfort with the uncertainty about whether the curative care was the right choice. Curative care often caused suffering, but to stop the curative care would mean certain death.

Other areas of dissonance (Kirchoff, et al., 2000) occurred when physician communication with family and/or patients was optimistic and gave what nurses feared was false hope. Nurses expressed difficulty with the role of providing more accurate information about the patient’s status and were concerned that they would actually be “taking hope away” (p. 40). The milieu of the intensive care unit formed obstacles to end-of-life care because of “lack of space and privacy” (p. 40), and family members were seen as most affected by this state of affairs. Nurses expressed a lack of emotional

support from their colleagues to deal with the impact of their work. A theme of “separation” was expressed by nurses, especially when there was disagreement between healthcare providers and/or family members (p. 41). Good end-of-life care was provided by collaboration, cooperation, and consensus among the providers and family members. Researchers were appropriately conservative in generalizing their findings beyond this group but did note that they supported other studies in generating new directions for future research with healthcare providers such as physicians or social workers.

Other researchers have started using qualitative methods to explore and understand the complex issues of caring for dying patients in the intensive care unit. In one dissertation study, Jezuit (2001) used grounded theory analysis of data from semi-structured interviews of ten nurses in critical care units in several Midwestern medical centers. Using methodology developed by Strauss and Corbin, Jezuit explored the nurses’ experiences of suffering as they interpreted it. Nurses were asked their definitions of suffering and whether they were personally experienced suffering as a result of their work in the ICU. Categories identified in the analysis included the following phases of the suffering process: the mute phase in which the nurse is unable to express suffering for various reasons; the expressive phase in which the nurse seeks a peer to express the suffering; and the new idea phase in which the nurse attached “meaning to the suffering to establish a new identity, absent of the suffering feelings” (p. 237). Surprisingly, nurses were able to define suffering and identify suffering in their patients but when asked if they experienced *suffering*, they did not identify themselves as suffering although they did describe experiencing the same emotions. Jezuit also identified the nurses’ partial

successes in progressing through to the *new idea phase* of suffering. She attributed this to an inability to attach a meaning to their suffering when establishing a new identity, that of a more competent nurse. Nurses also described end-of-life decision making, conflicts in values and roles, ethical issues, and emotional responses to patient suffering as areas causing nurse suffering. Some nurses in the study expressed a desire to leave nursing roles due to their level of suffering. Jezuit recommends further research, especially addressing areas of disappointments in roles and threats to personal and professional integrity.

In a larger study using content analysis for coding and thematic interpretation of open-ended structured interviews, Yam, Rossiter, and Cheung (2001) interviewed 10 nurses in one Hong Kong facility to explore the experience of caring for dying infants in a neonatal intensive care unit. Nurses expressed themes of disbelief, shock, anger, hopelessness, and a perceived incompetence in comforting the grieving family. Nurses also identified that an emphasis on aggressive life-sustaining treatment often hindered them from providing adequate palliative care to both patients and families. The researchers attributed a portion of the difficulty in communication and treatment planning to the Chinese culture with specific reference to the taboo against speaking of death in front of the patient. Conclusions from the study were conservative because of the small sample with limited diversity. Interpretation of the data into codes and themes was complicated by the translation from Cantonese (the native language of the nurses) into English and then reversal of that process for coding. Questions used for the interviews were not included and, therefore, the reader is unable to judge validity, although face

validity was reported through expert nurse review. The need for further research was recommended with more qualitative research to capture the complexities of the experiences. Also, the researchers recommended more education of nurses in caring for dying patients and palliative care.

In a qualitative study of nine healthcare providers in a Coronary Care Unit in Sweden, Nordgren and Olsson (2004) used a content analysis procedure. The focus of the study was the nurses' (7) and physicians' (2) perceptions of the nature, benefits, and obstacles to providing palliative care in the coronary care unit (CCU) setting. Using a "constant comparative approach," these researchers found similarities in perception of good palliative care among caregivers, although problems in communication between types of caregivers presented barriers to providing effective palliative care. Participants noted that experience with palliative care increased their competence but that there is a need for improved education in palliative care in nursing schools. Another obstacle to palliative care was the need for standardized guidelines in the CCU where palliative care is a relatively new concept. Nurses expressed concern about unnecessary patient suffering and ineffective therapies and the impact of these on dignity in death.

Summary

Death and dying are mysterious aspects of the human experience that have invaded our thoughts and writings since the earliest of times. Studies of death and dying began in the early 20th century and increased after WWII with most disciplines examining some aspect of this topic. Early death studies demonstrated progress in conceptual and operational definitions with the development of several tools to measure death anxiety

and death attitudes (Benoliel, 1983; Kurlychek, 1978). After Glaser and Strauss' study in the late 1950's, researchers developed procedures to examine interventions and measure outcomes of care modalities for dying patients, although most studies were done in hospice settings or on oncology units (Rutledge, et al., 2001). Increased medicalization of care, especially in critical care units, resulted in a crisis in healthcare as dying patients were overtreated with life-saving technology and under treated for symptoms of dying (Rutledge, et al., 2002; Kyba, 2002).

Nurses caring for the suffering patient in the intensive care unit or trauma unit, especially when the patient is dying, have been shown to exhibit various emotional, physical, and spiritual experiences. Nurses often reported moral distress and grief responses when caring for dying patients (Jezuit, 2001; Kirchoff, Spuhler, Walker, Hutton, Cole, & Clemmer, 2000; Papadatou & Bellale, 2002; Yam, Rossiter, & Cheung, 2001). Large surveys of critical care nurses suggested that they were supportive of, engaged in, or initiated assisted suicide or active euthanasia (Shuman, et al., 1992; Asch, 1996; Kowalski, 1997). An urgent need for studying the critical care nurse's experience of caring for dying patients in the ICU became apparent, and government and other healthcare agencies made resources available for relevant research.

In spite of these resources, few studies in the United States have utilized the critical care unit as a site, and fewer still have studied the experience of the critical care nurse. Most relevant studies have been conducted outside the United States. We do know that dying patients in ICU's have complex needs including physical, emotional, and spiritual needs which are inextricably joined (Burton, 1998; Hall, B. A., 1997; Phillips &

Morrow, 1998). Critical care nurses direct their care for the patient to include the needs of the patient's family with whom they share a sense of grief and loss (Andrews, 1998; Bunch, 2001; Papadatou & Bellale, 2002). Results suggest that nurses have coping strategies for dealing with feelings of moral distress, shared grief and suffering, and overwhelming emotions, although such strategies are not clearly defined in the literature and few interventions are suggested for these feelings. To date, no researchers have implemented studies of coping strategies for caregiver stress and grief in critical care units (Bunch, 2001; Jezuit, 2001). An inductive qualitative approach is needed to understand the experience of the critical care nurse and to expand that understanding into an approach capable of providing a basis of interventions for *caring for the caregiver*.

Chapter 3

Methodology

In this study I will explore the experience of the nurse caring for a dying patient in the critical care unit using a qualitative approach that derives from an existential phenomenology perspective. In Chapter One, I introduced the philosophical perspective of Merleau-Ponty and presented the assumptions of an approach based on his work. In this chapter I will present three important components of the study including my basis for choosing this perspective, the historical background of existential phenomenology, and the steps in using phenomenological methodology. The steps of methodology I will describe are recruiting appropriate participants, collecting data through interviews, interpreting interviews hermeneutically, maintaining rigor, and ensuring validity. I will begin with an argument for using a qualitative phenomenological approach.

Characteristics of Qualitative Method

Researchers use qualitative methodology to “study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin, 1998, p. 3). Nurse researchers now use qualitative methodology more frequently now than in the past because it can be used in dealing with “phenomena of key interest to nurses” such as “health, illness, and life transitions,” especially in providing information when phenomena contain “subtleties and complexities of human responses” (Sandelowski & Barroso, 2003, p. 782). The phenomenon of interest in this study is the experience of the nurse caring for a dying patient in the critical care unit. This experience has many facets and meanings for the nurse. It would seem to engender

multiple perspectives that cannot be adequately evaluated by surveys, questionnaires, or other instruments developed to reveal the nature of this experience for the nurse. This experience is much too complex and the emotional dimensions too diverse to be captured by even the most well-developed tool. For example, Sherman (1996) studied nurses caring for patients with terminal diseases and found statistically significant correlations between factors measured in the study such as death anxiety and the nurses' willingness to care for dying patients. Surprisingly, she could only account for 16% of the variance with these factors, leaving 84% of the variance unaccounted for. How do we begin to know and understand the unexplained and unaccounted portion of this experience of a relationship with a dying patient?

If we are to understand the relationships between nurses and patients, we must seek to understand the phenomenon with all of its *subtleties and complexities*. We must discover the emotional subtleties of the relationships and somehow begin to understand the *Gestalt* of the relationship instead of a Cartesian sum of parts (Pollio, Henley, & Thompson, 1997). As Thomas (2005) argues, phenomenology provides a methodology to understand "relational commitments" and to allow participants "to describe their experience in an unfettered manner" without fruitlessly trying to force the experience to be "operationalized and factor-analyzed" (p. 64). I have chosen existential phenomenology, based on Merleau-Ponty's work, to provide the method to explore and describe this phenomenon of the complex relationship between the critical care nurse and the patient at the most emotionally complex time of death.

Phenomenological Philosophy Linked to Method

The philosophical works of Merleau-Ponty provide an appropriate basis for studying the human perception of experience. Much of his writings speak specifically of the relationships between *experience, perception, and truth*. In *Phenomenology of Perception* (1945/2003) he wrote, “We must not, therefore, wonder whether we really perceive a world, we must instead say: the world is what we perceive....To seek the essence of perception is to declare that perception is, not presumed true, but defined as access to truth” (p. xviii). If we would gain knowledge and understanding of our world and ourselves, we seek to know and understand our perceptions of the world. Lawrence and O’Conner (1967) write, “Modern phenomenology offers a new approach to comprehending these crucial aspects of human existence. It aims to cover the whole range of types of human experience, neglecting none and preferring none” (p. 6). Nursing research based on understanding of human experience through the perceptions of those who have lived the experience provides a deeper and richer understanding of human phenomenon than is possible through quantitative methods. The existential phenomenological perspective of Merleau-Ponty provides a strong philosophical basis for this study.

History of existential phenomenology.

Philosophical existential phenomenology foundations began with Soren Kierkegaard in the first half of the 19th century. Kierkegaard was Danish by birth and wrote throughout his relatively short life against the teachings of Catholicism, arguing that man is individualistic with freedom of choice (Dupree, 2003) and cannot be

predicted through rationalism (MacIntyre, 2006). In his writings, Kierkegaard began a philosophical exploration of the human experience and sought to reveal “the fundamental themes with which human beings invariably struggle” (Valle, 1989, p. 6). Considered by many to be the “father of modern existentialism” (Dupre, 2003, p. 166), Kierkegaard (1859/1998) argued that subjectivity is superior to objectivity and only through the experiences of the person can we understand existence.

After Kierkegaard’s death, in the second half of the 19th century and in the early 20th century, a German philosopher, Edmund Husserl became an advocate of phenomenology in the academic setting as a means of studying the meaning and essences of human experience and is considered to be “the founding figure of the philosophical movement known as phenomenology” (Drummond, 2006, p. 521). Educated as a mathematician and receiving his PhD in that discipline, Husserl chose to study philosophy under Brentano in Vienna in the late 1880’s (Drummond, 2006). Husserl sought a rigorous scientific approach to understanding “pure consciousness” through subjectivity and to exploring “universal essences” (Spiegelberg, 1982, p. 81, 95). His pursuit of a new approach to the study of the philosophical foundations of mathematics and science led to the development of foundational arguments for phenomenology (Schmitt, 2006).

Heidegger, a student of Husserl’s, was one of the first to merge existential and phenomenological thought in the study of human experience (Valle, 1989). Heidegger sought to describe human *Being* (Blitz, 2006). This was a fundamental difference from Husserl because Husserl studied *consciousness* and Heidegger studied *Being*

(Speigelberg, 1982). According to Speigelberg, Heidegger wanted to return to a study of the meaning of existence, to *Being*, and not to a study of *the beings*, the objects of existence. This took phenomenology in a different direction, soon to be followed by others of that time.

Husserl and Heidegger, in Germany, were near contemporaries of Sartre and Merleau-Ponty in France. Sartre, like Heidegger, differed from Husserl on a fundamental point, that phenomenology is a methodology of science (Schmitt, 2006). However, Sartre is criticized for developing “philosophical theories” based on identified *essences* rather than preserving the descriptive emphasis of his phenomenological approach (Schmitt, 2006, p. 297). Better known as an existentialist than a phenomenologist (Flynn, 2006; Spiegelberg, 1982), Sartre did not describe his phenomenological methodology as other writers did, including his contemporary, Merleau-Ponty.

Like Sartre, Merleau-Ponty was influenced by his contemporaries as well as by the societal events of the war in Europe and his experiences as a soldier and prisoner in that war (Thomas, 2005). With his death in 1961, Merleau-Ponty’s work remained unfinished; however, his contribution to philosophical thinking continues to influence modern day thought (Dillon, 2006). Merleau-Ponty is credited with the significant argument against Cartesian dualism that conveys the role of the *lived body* in perception and understanding of experience (Dillon, 2006). This assertion is illustrated as he writes, “I am the absolute source, my existence does not stem from my antecedents, from my physical and social environment; instead it moves out towards them and sustains them, for I alone bring into being for myself (and therefore into being in the only sense that the

word can have for me) the tradition which I elect to carry on, or the horizon whose distance from me would be abolished—since that distance is not one of its properties—if I were not there to scan it with my gaze” (Merleau-Ponty, 1948/2003, p. ix). In Merleau-Ponty’s writings, he agrees with Husserl that phenomenology is to be descriptive only and not analytical or for the purpose of explaining causal relationships.

Definition of existential phenomenology.

The philosophical basis of my strategy is existential phenomenology as developed by Merleau-Ponty. Based on these philosophical tenets, experience is composed of essences that are identifiable through perception, and always take place *in-the-world* (Merleau-Ponty, 1948/2003; Pollio, Henley, & Thompson, 1997). Understanding of another person’s experience can be realized only through a holistic understanding of the meaning of some experience of the person. Meaning is derived within the interaction of the person with the environment and is expressed in the awareness of the person to specific aspects of the environment over others (Dillon, 2006; Pollio, et al., 1997; Thomas & Pollio, 2002). Behavior, or *functional intentionality*, is an expression of perception by the person and is always understood within the context of the person’s interaction with, and perception of, the environment (Thomas & Pollio, 2002).

Application of existential phenomenology.

Existential phenomenology has been the philosophical and methodological basis for increasing numbers of nursing studies in the last decades of the 20th century and now in the 21st century. Thomas and Pollio (2002) describe an evolutionary process as American phenomenological researchers began to investigate human experience within a

cultural context rather than seeking *universal essences* (p. 11). This evolution would seem congruent with Merleau-Ponty's (1942/2003) work as he wrote, "...man is in the world, and only in the world does he know himself" (p. xii) and "... it is clear that the essence is here not the end, but a means, that our effective involvement in the world is precisely what has to be understood and made amenable to conceptualization, for it is what polarizes all our conceptual particularizations" (p. xvi). The possible applications of phenomenological methodology appear countless as the number of phenomena in human relationships and responses to disease processes continue to grow. Ihde (1986) answered the question of what topics or phenomena could be considered appropriate for phenomenological research when he wrote, "...all phenomena as 'present to a subject' may be regarded as worthy of investigation. Images, percepts, moods, arithmetical phenomena or whatever, may be a valid region for inquiry" (p. 23). Lawrence and O'Conner (1967) write, "Modern phenomenology offers a new approach to comprehending these crucial aspects of human existence. It aims to cover the whole range of types of human experience neglecting none and preferring none" (p. 6).

The usefulness to nursing research, as we seek to understand the experiences of patients, nurses, families, and others as we care for, appears to be large as well. Several nursing researchers began using a phenomenological approach to the study of human experience. Studies were conducted in the 1970's by Paterson and Zelarad; in the 1980's by Parse, Oiler, Omery, and Benner; and in the 1990's and this decade by Thomas, Munhall, and Porter (Thomas & Pollio, 2002). Differing in some aspects of methodology such as number of interviews, sources of texts, or methods of analysis, the

forms of phenomenology being employed by nurse researchers derive from the same philosophical tenets of exploring phenomena of healthcare today for the purpose of better understanding our patients and ourselves (Thomas & Pollio, 2002; Thomas, 2005).

Ethical issues.

Though the risks to participants in phenomenological research studies are few, we must always be aware of and minimize those risks to the individuals that honor us by sharing their stories. I received approval for the study from the University of Tennessee Institutional Review Board before beginning the interviews. (See Appendix). To protect the rights and minimize risks to the participants of this study, I maintained strict confidentiality of all interviews and transcripts. Pseudonyms were used for any identifying information in the transcripts and no identifying information was kept with the interviews, recordings, or transcripts. All transcripts, informed consent forms, and recordings were kept in a locked filing cabinet when not in use. Confidentiality statements were signed by the participants in the Phenomenology Research Group and the transcriber for the interviews. (See Appendix).

Discussing issues such as death and dying may prove emotionally distressing, especially when the participant found the experience emotionally painful and the suffering of the patient overwhelming. Reliving or reviewing those experiences may engender strong and uncomfortable emotions. Researchers in other studies, however, have reported the participants found the opportunity to discuss the experiences beneficial and helpful in dealing with the emotional sequelae of the experience (Thomas & Pollio, 2002). To minimize any risk to the participant, I remained supportive and open to the

participant's descriptions of the experience. No follow-up needs were identified by the participants or the researcher and participants reported that the interviews had a beneficial effect as the participant was able to express emotions and feelings openly and freely with an interested researcher.

Sampling Strategies

The participants for this study were recruited from several different sources including professional associations of critical care nurses, recruitment announcements in professional newsletters, and flyers at hospital critical care units and nursing schools with graduate programs. A snowball networking approach with other nurses, faculty, and hospital staff were the most helpful recruiting measures for this study. I used these sources at several different regional locations in different states to increase the availability of participants from varied cultural backgrounds and varied patient populations. My intent was to have participants who had cared for patients dying from various types of disease processes such as cardiovascular, neurological, traumatic and respiratory processes.

Recruitment of participants.

A purposeful networking approach was used to recruit participants. A participant could be any nurse presently working in a critical care unit who had been present and responsible for care of a patient who died while he or she was caring for the patient. Diversity in age, experience level, education level and cultural background was sought. Participants were recruited until the data reached saturation as described by Denzin (1998), "adequacy is attained when sufficient data has been collected that saturation

occurs and variation is both accounted for and understood” (p. 76). The total number of nurses recruited and interviewed was fourteen. Recruitment was unexpectedly easy and exciting as nurses began agreeing to be interviewed as soon as IRB approval was granted. I completed eight interviews within two months and continued interviewing for four more months, doing interviews in as many areas of the east coast as possible. In the final number, fourteen nurses were interviewed from five different states in the Southeastern and Northeastern regions of the United States.

Participants were male (2) and female (12), Caucasian (13) and African-American (1), BSN, AD, and MSN graduates with a range of two years to over thirty years of ICU experience. When several nurses in one hospital wanted to participate, the staff scheduled two days of interviews and allowed interested nurses on the units to have unlimited time to talk to me in a private office, providing extra staffing those days so that patient care was covered. It became quickly apparent that critical care nurses wanted to talk about this topic and they wanted to tell about their experiences with dying patients.

Participants

Trish is a nurse in the surgical trauma intensive care unit of a large teaching hospital. She has a baccalaureate degree and has spent all of her six years of practice in intensive care. Nursing is her second career and although she has had fewer years of experience than several of the other participants, she considers herself as an experienced nurse, making it easier to communicate with patients and families, especially when the patient is dying. Most of the nurses considered themselves as very experienced and told of various experiences with intensely emotional and physical facets in caring for critically

ill and dying patients. As Trish spoke of her patients and families, she told of “bonding” emotionally with many and how ICU nurses must control their emotional involvement with the patient and family. She spoke eloquently as she said, “you allow yourself to get involved emotionally to some degree because you want to be empathetic and be able to empathize with the family and support them. But at the same time you can’t allow yourself to become over the top involved.” As she spoke of her patients and families, however, she showed her emotional caring as she held back tears and told of how “rewarding but sad” her job often was.

Betty is a nurse in the medical intensive care unit of a smaller hospital in a large metropolitan area. She also has a baccalaureate degree and is in graduate school. She has been a critical care nurse for six of her fifteen years of nursing experience and nursing is also a second career for her. For Betty, death is an almost everyday occurrence in her work as she tells that “one out of every four patients” on the unit will probably die. She spoke of the spiritual impact that her work has had on her and described her experiences as either being “good” or “bad.” Good experiences included enough time for the family to come to acceptance and provided opportunities for demonstrating mutual respect and closeness with the family; bad experiences involved horrific images of patients suffering and of families in complete chaos from trauma and grief. Betty expressed a sense of satisfaction with being able to talk about her experiences because she rarely got to do that and was surprised that she had “not cried more.”

Joyce is a nurse in the surgical-trauma intensive care unit of a large university hospital with all of her five years experience in the critical care area. Joyce has an

associate degree in nursing. Joyce spoke of the emotional impact of caring for a dying patient as “hard” and of the emotional ties that form between her and her patients and families. She said that nurses “push [the emotions] to the back” and do not think about the impact and grief they experience with dying patients. She found the words difficult sometimes because of the emotion as she spoke of how “hard” caring for young dying patients is and how it makes the nurse realize “how...in an instant [your life] can be changed forever.”

Ruth is a critical care nurse in a medical intensive care unit with a baccalaureate degree in nursing and thirteen years in the critical care area. Ruth finds it difficult to be unemotional with the patient and family, sometimes finding release in tears as she realizes that “this patient is not going to make it, short of a miracle.” She puts her “emotions aside” as she helps the family prepare for the patient’s coming death.

Ellen is a critical care nurse in the medical intensive care unit of a large metropolitan hospital with all or her eight years in nursing as a critical care nurse. She has an associate degree in nursing and chose nursing as her second career. She remembered patients who were unusual and based her evaluation of whether it was a good experience or a bad experience on whether she did her job well or whether the patient suffered unnecessarily. She said that she still gets emotionally involved with her patients and does not ever want to get to the point where she can be totally objective and not care. She says, “If you have gotten to that point where you can do that...I don’t want to be a nurse that way.”

Judy is a critical care nurse in a community hospital. She has a baccalaureate

degree in nursing and has practiced all of her career in the critical care unit. She spoke of patients and families as her neighbors and knew several from outside the hospital. She became very involved in the family dynamics of her patients and expressed deep concern for their well-being. Judy remembered aspects of the patients' appearance with striking detail as she told poignant stories of caring for patients above and beyond the invasive therapies and treatments by curling an older patient's hair and painting her nails, or braiding the long hair of a teenage girl mortally injured in a traffic accident.

Denise is a Masters prepared nurse who has been a critical care unit more than 25 years in several hospitals as both staff and management roles. She spoke of the changes that have occurred in the practice of critical care over the years but how her values of never allowing a patient to die alone and of allowing families more time with the dying patient have never changed and are just now becoming a practice in most hospitals. She describes caring for the dying patient as an active role for the nurse in which the nurse intervenes with the family to mend rifts in the patient/family relationships.

Gayle is a critical care nurse in a medical intensive care unit and has been a medical-surgical nurse longer than she has been a critical care nurse. She has a baccalaureate degree in nursing and works in a large metropolitan hospital. The patients she described as standing out to her were ones that "weighed heavy on [her] heart" or were exceptional in some other way. She described one experience as "devastating" in which the nurses had given "110%" in caring with an expectation that the patient would recover, but the patient died suddenly. She expressed concern that nurses do not have resources to help them cope with emotionally difficult circumstances and were left to

“dealing with it.”

Ben is a baccalaureate degree prepared nurse who has spent the last few years in the neurological unit of a large teaching hospital. Most of his patients are trauma victims and he deals with the sensitive issues of declaring patients brain dead and requesting organ donation. Ben expressed a conviction that nurses have an enormous responsibility for the patient achieving a “good death.” He believes that participating in a “good death” can be very rewarding which brings the nurse back to work each day rather than the unrewarding death experiences which “moves the nurse further from the ICU.”

Hannah has an associate degree in nursing and has been a critical care nurse for most of her career. She practices in the trauma surgical unit of a large teaching hospital. She describes the difficulties of caring for dying patients when she disagrees with the medical treatment but finds that physicians can make a difference in how a nurse copes with a difficult death in the unit by reassuring them that they did everything they could for the patient.

Bob is nurse with a baccalaureate in nursing, practicing in the cardiac and trauma care units of a large hospital. He expressed that communication is a key element of caring for dying patients and the nurse starts with information, which is easy, and progresses to decision making, which is difficult. For Bob, the cultural diversity of patients in his units is a challenging part of his job and can be frightening to nurses who are not prepared for family responses to death.

Jenny is an associate degree prepared nurse working in the medical intensive care unit of a large metropolitan hospital. She has been a critical care nurse for less than half

of her more than 20 years of nursing experience. Her personal experiences with death have given her insight to use when caring for dying patients and their families. Her goals for her dying patients include death with dignity and she strives to give her patients “any kind of dignity that I can give them.” Her concern for dignity continues to respect for the body after death. She is “haunted” by the death of a young patient for whom she was unable to care for as she would have due to the circumstances of the accident. She tries to help families know what to anticipate about the death, and afterwards, in their grief.

Chelsea is a baccalaureate degree prepared nurse in the cardiac unit of a large community and teaching hospital. She feels that “the family becomes part of the patient” for the nurse because the nurse is “trying to help them heal too.” She described patient deaths that were difficult because the family did not agree on the decisions about what to do or she felt were making a decision based on incomplete information. Chelsea could remember and describe in detail the first patient who died in her care. She expressed surprise that recalling that experience brought tears and sadness after more than 10 years.

Sarah is a Masters prepared nurse in the cardiac critical care unit of a community hospital. She has more than 20 years of experience in both nursing and in the critical care unit. She commented on the importance of communication between all healthcare providers, especially physicians and nurses, in caring for dying patients and their families. She described good communication as a collaborative relationship. She also identified the chaplain as a strong member of the healthcare team and one who benefits the patients and families when making care decisions.

Data Collection

Method of collection.

This study employed dialogical interviews with critical care nurses about their experiences of caring for a patient as he or she died in the critical care unit. An initial interview, called a bracketing interview, is one in which the researcher's describes her experiences with the phenomenon. Ihde (1986) describes this process as "an *epoche*", which means to suspend or step back from our ordinary ways of looking, to set aside our usual assumptions regarding things" (p. 32). The researcher cannot completely disregard all prior assumptions but must be aware of and continuously attempt to prevent presuppositions from interfering with her receptivity and unbiased interpretation of the participant's description of his or her experience (Thomas & Pollio, 2002). According to Lawrence and O'Conner (1967), "The great aim is to preserve the manifold appearance in its richness and its untampered-with innocence" (p. 7).

In the bracketing interview, the research group and I explored my experiences caring for dying patients, especially in the critical care unit. I discovered that I would need to bracket my assumptions that nurses grieve with dying patients and their families, and may be traumatized by deaths of patients. Another assumption that I had and must bracket was that all deaths are unique and teach us something that nurses need to learn. I assumed that nurses feel capable of "dealing with" unique situations, but subsequently relive past events. I had experienced that doctors may "add to the burden" of nurses when caring for dying patients, and something can be done to prevent the burden or trauma nurses experience.

Other interviews took place as participants were recruited and each participant was interviewed once after informed consent was obtained. The interviews lasted about one hour as I asked the participant to tell me about an experience when he or she took care of a patient in the critical care unit who died while in his or her care. The participant decided what experience to describe and what to tell the researcher about the experience. Further questions followed the first and were directed toward encouraging the participant to describe what it was like for him or her to have that experience. The interviews continued as long as the participant had more to say about the experience and ended when the participant decided he or she had nothing more to say. All interviews were recorded verbatim with the participant's knowledge.

Data Analysis

Typed transcripts of the bracketing and participant interviews were analyzed through a hermeneutical approach based on Gadamer's writings on interpreting texts within the *language, culture, and histories* of the participants and the researcher (Thomas & Pollio, 2002, p. 22). As Thomas and Pollio (2002) write, "Existential-phenomenological interpretation is rooted in a continuous process of relating a part of some text to the whole of the text, and any and all passages are always understood in terms of their relationship to the larger whole" (p. 35). Interpretation of one transcript is within the context of all the transcripts and interpretation of all the transcripts with respect to each of the transcripts. The researcher seeks a thematic interpretation of the phenomenon through a process of thematization and synthesis.

Thematization and Synthesis

The analysis of participant interviews began with an interdisciplinary group reading a transcript aloud and allowing pauses from any member of the group to discuss possible interpretations of the text. The researcher(s) read(s) the transcripts, looking for emerging patterns of experience, meanings, and themes in all the transcripts. Word, phrases, and metaphors used by the participant were used as the basis for “meaning units,” evolving into interpreted patterns of meanings or themes for each transcript. I used the first reading as an organization tool to read the remaining transcripts. I brought other transcripts to the group to further develop interpretations of meanings, patterns, and themes of individual transcripts within the context of all of the transcripts. As the researcher in this study, I used the interpreted themes of the transcripts emerging from my individual and the group’s readings to develop a general thematic structure describing the experiences of all the participants. The outcome of this approach provided a descriptive *structure* to common *patterns* of experience and themes in all the transcripts (Thomas & Pollio, 2002, p. 37).

Reading the transcripts was a combination of individual reading by the researcher and group readings of the first and several other transcripts by the phenomenology research group. For my research, the group was an established phenomenology research group that has been meeting on Tuesday afternoons for 12 years in Knoxville at the University of Tennessee College of Nursing. I have participated in this research group process several semesters and have studied under the two leaders of this group, Dr. Sandra Thomas and Dr. Howard Pollio. When I had developed preliminary themes and a

theme structure, I returned to the group with those themes for refinement based on the group interpretative process. Validation of the themes was sought in the transcripts and themes were phrased in the participants' own words. The thematic structure was then presented to five of the sample participants for verification; two participants responded with confirmation of the thematic structure.

Rigor of the Study

According to Pollio, Henley, and Thompson (1997), validity of an interpretation is based on both methodological (*rigor and appropriateness*) and experiential (*plausible and illuminating*) grounds (p. 55). Rigor was maintained in the following ways: the researcher tried to bracket preconceived concepts or understanding of the phenomenon, the interviewer gave control to the interviewee while maintaining a focus on the perceived experience, and the interdisciplinary group interpreted the themes of the transcript within the context of the whole transcript. An experiential basis for validity will be established through the insights and understanding of the phenomenon the interpretations provide to the researcher and the reader. In this instance, it is hoped that these themes will provide insights for understanding patterns of experience of critical care nurses caring for dying patients.

Summary

Rigor and feasibility are two important criteria suggested by Morse (2003) for the evaluation of research proposals. Rigor addresses issues of *adequacy and appropriateness* of the methodology and design (p. 837). A phenomenological research design is both appropriate and adequate to study the phenomenon of caring for dying

patients in the critical care unit. Based in the philosophical ground of existential phenomenology as developed by Merleau-Ponty and using the methodology design developed by Pollio and Thomas (2002), the participants in this study provided rich descriptions of their experiences. From these descriptions, common themes emerged to allow us to understand the lived experiences of the participants. Feasibility addresses ethical, logistical, and researcher qualification issues. Ethical issues have been addressed and were considered throughout this study. The researcher had appropriate training for this study and access to potential participants at various sites. Adequate time was available to the researcher due to a successful grant for an extended sabbatical for this study. This project appears to meet these important criteria and I look forward to sharing the study findings with my colleagues. The following chapter is devoted to the findings.

Chapter 4

Findings

As I get off the elevator on my way to do an interview in an ICU, I confront two doors with a tiny window in each to look through. I try to open the doors and find that they are locked. I look through the window, but no one appears to notice me or knows that I am there. I look for some lever or button to push on the wall and find a key pad with a telephone placed above it on the wall. Not knowing the code to the keypad, I pick up the receiver to talk to whoever will answer. Someone immediately answers, and after I tell her who I am to meet, she comes to the door to give me access to the unit. As I walk down the corridor of the intensive care unit to my participant's location, I note the hallway of rooms where nurses stand by the bedsides of patients connected to tubes and monitors, some with arms and legs restrained and often with ventilators echoing breaths as if to reassure everyone that life is still present when consciousness is not.

The unit I see is not a frenzied scene as one might expect when life and death scenarios are played out daily. It is a place of unusual noises as though what is happening there is too real or too important to allow frivolous or normal noise. Somewhere an alarm goes off, and someone moves to respond to it. Everywhere the monitors mark the passage of time by measuring some aspect of life and some aspect of threatening death. Everywhere nurses move through this intense reflection of death on life with a quiet confidence that belies the seriousness of their actions. I am reminded of descriptions of ICU's in the research by Bunch (2001) that describes an ICU to a novice in much the same way, as an "emergent drama" (p. 61) that only reveals the true seriousness of what

is happening to the experienced eye.

The world of the ICU is the contextual ground within which the experiences of nurses caring for dying patients take place. The participants described their work in the ICU in the first contextual theme of the study, the world of the ICU, which is grounded in the contexts of *death*, *time*, and *others*. *Death* is an ever present threat in the ICU and nurses there view their role as that of protecting the patient from death. *Time* becomes an important ground as nurses act to delay death or to provide time for the patient and family to make necessary care decisions, especially decisions to discontinue medically futile care and to remove barriers to healing. All the experiences of the participants are grounded in the experiences of *others* as they describe caring for patients and then expanding that care to a patient/family dyad as the patient approaches death. Two contextual themes emerged from these grounds expressed by participants as “*you lose your heart about once a day*” and “*from a paradigm of curing to a paradigm of caring.*” Participants’ expressions of meanings of their experiences emerge from the descriptions of what happens to the patients and families there, the *others* in their world.

An encompassing theme of *promises to keep* emerges from the descriptions of the ICU nurses’ experiences and weaves throughout the interviews as nurses described the implicit and explicit promises made to patients and families in their care with the moral obligations those promises entailed. Five sub-themes manifested within the encompassing theme including: (1) “*it wasn’t time for someone to die*”—“*we see it coming a long way down the road;*” (2) “*just one more day*”—“*they had enough time;*” (3) “*a promise I couldn’t keep*”—“*I honor what I say;*” (4) “*nurses are in the game of reality*”—“*doctors*

can't say that;" and (5) *"it doesn't end at the time of death"*—*"you feel very good, because you did your job."* Each sub-theme revealed unique promises, involving different responsibilities and eliciting different responses from the nurse.

Contextual Ground of the Experiences

Participants described life in the ICU within the context of an ever present threat of death. The purpose of ICU nurses was to prevent death or to delay it for another day. When those efforts failed, nurses experienced loss and grief similar to the patients and families they cared for. When death had, or was going to occur, care changed from *"a paradigm of curing to a paradigm of caring."* In the descriptions of those events, everyone marked this change as a transition point in time, often noting specific dates, hours of the day, or passages of time as families and nurses kept a "death vigil" with the patient. Participants described a change in roles for nurses at that time from curing with technology to caring with compassion.

"You lose your heart about once a day"

In the interviews, as the nurses talked about working in the ICU, they reveal the passion they have for their work. All participants had worked in critical care for years, and all planned to continue there indefinitely. They spoke with seriousness and passion of their dedication to critical care nursing and their acceptance of the responsibility to care for patients who have critical needs, showing an emotional investment in the outcomes of their care. This is exemplified by the first theme of the contextual ground.

I don't think I'd ever want to work anyplace else. It just, you know...it changes...I said ICU is one of those places where you'll always be

challenged, you'll never be bored, and you lose your heart about once a day (Judy).

In their interviews, ICU nurses described their world, not through descriptions of monitors and pumps, or ventilators and tubes, but through descriptions of patients' lives in that world and what happened to them there. The participants told of life and death through the experiences of patients and their families, the *others* of their lives, and in doing that, described the meaning of that experience for them.

Death in the hospital is described by the nurses as the regrettable end to the life of an individual, and they describe the effect of that death on the family members. In the ICU, death is real and always close. The focus of their job is to prevent death, to delay death for another day. For some they cannot prevent or delay death despite the best efforts of medical care. When death comes for these patients, the nurses describe the experience in its complexity and its troubling effect on everyone, especially when they are unprepared.

But for me to be able to appropriately emote, then I wouldn't be able to take care of my families because you get attached to them...you get attached to them because you want them to have what they want... what they think they need. They want their family member healthy and whole. Nobody wants to be up on the unit experiencing death; nobody expects to. Everybody expects that their going to die in their sleep. It is going to be an immediate... not dragged out... you have to make this decision thing and they don't want to be put in that position. Is a stressful thing even without the death part. You are going to have to make this

emotional thing. They don't want to have to be in that position. It is a stressful job, even without the death part (Betty).

I mean, I feel bad for anyone who dies in a hospital. I think that it's most important to die at home where you're surrounded by your family and people who love you, than it is to die in an ICU with an ICU nurse, and, you know, hopefully your family, but maybe not. I mean, you don't know. A lot of families don't want to be in for the end of...you know, for the resuscitation process, and it's very hard to watch. Obviously, if they want to, then we would encourage that, but, you know, it's just sad when they die with us without their family being there (Trish).

Most times when you have...you're trying...you're doing so much to try to prevent death, that when it comes, you're just so reactive, you know, your adrenaline is going, and ...and I think it's not until it's all done that it finally "okay, oh my goodness," you know, hits you that for those ...that...for those certain patients that die suddenly are the ones that you...or very very sick and you're just constantly trying to do so many different things to keep them alive (Joyce).

When they come in, the hardest time is when you have somebody that they coded you didn't expect to die right away or whatever, and these deaths that happen out

of the blue...or something happened that they went into v-tach [ventricular tachycardia], and we shocked them and did all that, and they died. And then you call them, they rush up in here. And you hate to tell them, you know, "Well, they're dead." You don't tell them that they've passed. "You need to get up here, they've had a real turn for the worst, heart rate's really bad." You give them a little bit of information, ask them not to drive too fast, you know, "We'll be here, we'll let you come on in." But, when they find out that they're dead, that is...that's pretty rough on them, and pretty rough on everybody, because it's just all to pieces. We didn't anticipate it, so we weren't ready mentally...uh...mentally prepared ourselves, so that's a little bit harder (Jenny).

I don't drink or anything like that. That might help. I mean there has been times when you just, you sit back and, you know, like I said, coming out of that room when they were singing *Amazing Grace*, and the kids were holding their mom, and "Just don't go, Mama"...that takes your breath away, you know, you're sitting...and, you know, you go in the bathroom, you close the door, and you start crying, and, you know, you have to get all that out, and then you can go back and you can face the rest of your day. But it does, I mean, it does change you inside (Gayle).

“From a Paradigm of Curing to a Paradigm of Caring”

In contrast to sudden unexpected deaths, nurses described an ability to anticipate the impending deaths of many of their patients and the subsequent opportunity to prepare the patient and/or family for the inevitable. For the dying patient, the care changed from a focus on a medical course of curing to a nursing course of caring. This point in time was marked carefully by everyone involved as decisions were made and plans were formed for how the care would change. Several nurses described the setting for this change and the interaction between nurse, patient, and family. When physicians were included in the descriptions, their interactions were brief or preliminary to the change.

And now we're going to transfer care from a paradigm of curing to a paradigm of caring for the dying patient. And so we sit down with the family, and we actually have one room we use all the time in our ICU...it's a little conference room...and the doctor goes in, and we go in with them, and we talk to them. And the family says, "Yeah, you know, okay, let's extubate," or "let's stop moving forward," or whatever it happens to be. And then the physician kind of leaves and the nurse hangs behind (Ben).

And it was decided to do what we considered a terminal wean from the ventilator. So she was extubated yesterday, placed on...we have a protocol in the hospital called "comfort care." It's a level of care, it's not acute care, it is palliative, just to keep the patient comfortable. We use medications, analgesics, sedation, and we were in the process of...we kept her in the

intensive care unit, with the understanding that if she was maintained, we would then move her to a med surg floor, so that it would not be tying up an ICU bed (Bob).

Whether the death was expected or unexpected, the participants in this study described facets of the interaction with the patient and the family, some from time of admission to the unit to death, and some from the time following death and into the grieving of the family. For most participants, the emotions of the patient and family mirrored their own emotions as the nurse described experiencing peace and satisfaction with the experience only when the patient and family were at peace or satisfied. These facets of interaction coalesced into themes running through all of the interviews, weaving an intricate and textured tapestry of emotion and courage as nurses accepted the role of caring for dying patients.

Themes: “Promises to Keep”

All the themes emerged from a central theme of keeping promises. The nurses described the promises they made when assuming care for patients and the responsibilities from those promises to the patient and to the family that extended to the time of death and beyond. The implicit promise of care in the ICU is that death will be prevented, as care in a medical curing paradigm provides every technology possible to help patients recover. Within this paradigm, nurses promised patients that they would provide every option possible to achieve as full a recovery as possible. Sometimes recovery was not possible and the nurse knew the patient would die. When nurses knew

this, their promises changed to providing every intervention available to make the death as peaceful as possible without unnecessary suffering, whether from the disease or from the restrictive environment of the ICU setting. They ultimately promised the patient and the family to make the experience of death in the ICU as peaceful and non-traumatic as possible. In all their experiences with patients, nurses promised patients and families to be honest and truthful in preparing for what was to come. They made promises to the patient to keep them comfortable and symptom free and to the family to let them know what decisions would have to be made. Five sub-themes emerged from *promises to keep* as participants described different facets of caring for dying patients and promises involved in those facets.

Theme One. “It wasn’t time for someone to die” – “We can see it coming a long way down the road”

The first subtheme of *promises to keep* involved the differences between experiences of nurses when death was unexpected as opposed to an expected death and was described by the participants as “*it wasn’t time for someone to die*” versus “*we can see it coming a long way down the road.*” When death was unexpected, care for the patient continued in the curing paradigm and the nurses shared in the patient’s goal of recovery. Nurses and physicians made promises to do everything medically possible to keep the patient alive and prevent death. This focus contrasted with the promises made when death was expected and care shifted to a paradigm of caring, as promises changed to providing a peaceful death with dignity.

“It wasn’t time for someone to die.”

Participants described their experience of caring for the patient who died unexpectedly and the emotional impact they and the family experienced from unexpected deaths for which they could not prepare. When nurses could not anticipate the death of the patient and no one, not even the nurse was prepared for what happened, participants described feeling devastated and sharing in the shock, disbelief and grief of the family. These patients may have been trauma victims, young people, or a patient that they had cared for who started to recover and then died suddenly.

But it was sad, ‘cause he had just gotten back to where he was going back to school, you know, he’d caught up on his school work and was going back to school... So that was a situation where it wasn’t time for someone to die, and he died. It was someone who meant a lot to all of us, and it was hard (Hannah).

One in particular ...was a thirty six year old patient we had... who came in severely septic, and her husband was [in healthcare]. And she ended up dying. We became very close to the family. ...she was in the ICU for probably about five weeks ...was on four or five pressers [cardiac medications to sustain blood pressure] and full life support for weeks. And she got better, and went to the step down unit, and then went to the [another facility] ... and had a massive aneurysm, and came back and died here. And it was very difficult when we found out...(Gayle).

So sometimes those cases are difficult, too, when, you know, the patient comes in, and it looks like the patient's not going to make it, you do everything, get them on the proper medication, as far as the doctor's treatment and everything, follow up on the labs, you're doing everything for the patient, and then the patient turns around and starts getting better. And then suddenly just dies from something else (Ruth).

I actually got report, went into the room...I went into the room and he was not breathing. And, I got emotional after the code. I was really upset because he died. And it was a...just a shock, because I had him the day before and ...he was doing okay... And then to come in, get report, and go in the room, say good morning, and find him not breathing...that was a...a definite shock, and I became emotional after that (Chelsea).

When death was unexpected and curing care had failed, participants described reflecting on that care and being comforted by the thought that they did everything possible to protect the patient from death. The realization that they had kept their promise of doing everything medically possible alleviated some of the emotional impact of the death, especially if this was confirmed by others such as the attending physician.

It happened right at shift change, and I was told that all of the nurses that were working on him were just sobbing. And I've never, ever seen that much

involvement and emotion with the nursing team, and, I mean, even the doctors...well, right after it happened...and we all came in right at shift change, it had just...they had just finished the code and called it, and the attending brought every single one of us out to the nurse's station, and he told us that we had done everything we could to keep that boy alive. He reassured us that we had nothing to be ashamed of, and that...it just sort of gave us a sense of closure. It gave us a sense of serenity about all of us doing everything we could. (Hannah)

"We can see it coming a long way down the road."

When death was anticipated, participants described the responsibility that comes from the knowledge that the patient is dying, a knowledge that sometimes comes early in the care of the patient and sometimes later. When the nurse knew that the patient was dying, he or she assumed a responsibility to the patient and family to prepare them for what was to come next and the decisions that would have to be made in the care. Promises changed from doing everything to prevent death to doing everything to relieve suffering and prepare for a peaceful death with dignity.

There's a point in every case, in many cases, where all of the aggressive treatment is not producing the desired effects. We're not seeing the improvement, you know, there's a difference between a long slow wean off the ventilator, and someone who is just not improving, and actually deteriorating (Bob).

Actually, when I think about the patients that have died, especially...really in the

past ten years, because I'm in neuro, we can usually see it coming. And we can see it coming a long way down the road...sometimes the family's ready, but not ready. If they're not ready at all, and the patient's progressing to brain death, well, there's the puzzle. And you've got to figure out the key to solving that puzzle, because whether the family wants it or not, grandma is going to die. And you're going to have to be taking care of grandma while she's dying, and that family's going to be involved or uninvolved, or concerned or unconcerned, or with you or not with you, but, I mean, this is progressing in a direction that you have no control over. "Can't, can't keep grandma alive. We're trying, trying hard, but I can see it coming" (Ben).

And we sort of contract with the family on what's their involvement, what are the things they want. And that's been a huge range, I mean, I've had families that... I had one son who insisted not only on being there when the tube was taken out, but he put his hands on the respiratory therapist's hands, as the tube was removed, and... it was something he needed to do. He had promised his dad, "Dad, I'm not...you know, I'm going to make sure on it." And that was sort of his connectivity to it....Other families, you know, their... contract with their dying family member...you just have to figure out *what is it* that that family needs, and everyone's different (Ben).

And here she was, six months pregnant, out in the waiting room with just she and

the little three-year-old boy, and she would bring him back to the nurse's station, and we'd kind of play with him and watch him while she went in to visit him, because she didn't have anybody to leave him out there with. And he was staying at the hospital with her all the time, and she was, of course, real reluctant to leave because, you know, he was doing so badly.... and they made the decision to terminally wean him off the vent, and turn the balloon pump off. And, when we did that, she brought the little boy in, and sat him up in the bed, and he laid there on his daddy's chest while his daddy passed away. And it was one of the sweetest things that I can ever remember happening, because, you know, he kept wanting to talk to his daddy, and see his daddy, and he'd lay there on him, and he'd say, "Daddy, you'll be okay, you'll be okay," and he was just so sweet (Judy).

Theme Two. "Just one more day"—"They had enough time"

In the second sub-theme of *promises to keep*, participants described the promises they made to patients and families to inform them of necessary decisions about care and to provide time for difficult decision making. Nurses described taking an active role in approaching families about the decision to remove futile treatments. When patients and families were not ready to make those decisions, nurses advocated for "just one more day." This active role has not been addressed in the literature before as the critical care nurse described interventions directed toward assisting the patient and family toward preparation for the patient's death, including discussions about initiating or delaying withdrawal of futile measures of life-support. The role includes an active involvement in

family dynamics and decision making.

Sometimes the family's not ready at all. And, again, that's part of that puzzle, you know. And if they're not ready at all, sometimes in the neuro ICU, you've got time. You can buy some readiness, "Okay, well, we'll talk again tomorrow" (Ben).

I had one patient that was really really sick, and it was kind of a touch-and-go situation whether he wanted to be kept alive by mechanical means. And at that point in time, his family was making the decision. And we had to have the Ethics Committee come in on it...and I can't remember the exact position I was taking, I know I was wanting to just give the patient one more day, give the patient one more day...They gave the patient one more day, and I think the very next day they did decide that it was his choice to be removed from mechanical means. (Chelsea).

"They had enough time"

Participants described personal and professional satisfaction they experienced when advocating for patients and families provided enough time to make difficult decisions about discontinuing futile care and to prepare for the patient's death.

We actually kept him on his vasopressors. I asked the physician if I could leave it on and maintain his blood pressure while this process took place, and once everything was resolved and they'd had their conversations and loved and hugged

one another and were sitting there talking about, you know, trips they took as kids and what were their favorite times together as a family, I began to decrease the infusions. And he died that evening about four hours later, but it was personally satisfying to me (Denise).

So that was actually a really good experience, you know, with somebody dying and I think they had enough time, because they had enough time to come to grips with it. One person said, “Mom, I wanted to tell you last week but you weren’t ready to listen.” And that’s the truth, you know, she wasn’t ready to listen (Betty).

Theme Three. “A promise I couldn’t keep”—“I honor what I say”

Emerging from the theme of *promises to keep*, participants described the moral distress they experienced when they were unable to keep a promise made to a patient and the personal satisfaction when they were able to “keep their word.” It did not seem to matter whether the promise was explicitly or implicitly made, both obligated the nurse to follow through or to assure that the patient’s expectation was met.

“A promise I couldn’t keep.”

In many interviews nurse participants spoke of promises made to the patients they were unable to keep. Nurses remembered the promises they were unable to keep years before with clarity of detail and a level of emotion that revealed how vivid the memories were to them.

But I feel like I let them down because I didn’t know the whole story when he got

there. And I thought he was going to get better from what they were telling me. I went by...they seemed very knowledgeable and I went by what they were telling me. And I thought he was going to get better (Betty).

I was taking care of him the day that he was intubated, and I knew that he needed to be intubated, because he was getting more and more confused, and more and more combative. So, when I spoke to the wife about it, she was very hesitant to want to do that. But I assured her that it was just a temporary thing, that we just needed to get him through that particular bad time. Of course, he never came off. Things progressively got worse, so I felt some ownership of that, you know, almost like I had made a promise I couldn't keep (Trish).

"I honor what I say."

Throughout the interviews, the nurses spoke of going to unexpected measures to keep a promise to a patient or family even though that promise may have been unspoken and only assumed on the part of the nurse as a part of his or her duty to a dying patient. Nurses spoke of breaking rules in the ICU so that they would not have to break promises and how there was no real struggle with whether that was the right thing to do but only a struggle with how well that met the needs of the patient and the family.

I have been for a very long time a believer in patients should not die alone, and years ago when I was a fairly young staff nurse, if a patient was made a "do not resuscitate" and the patient was pretty much comatose, the nurses would close the

blinds and close the door, and would sit at the nurses station and watch, you know, take all the drips off and watch the rhythm on the monitor outside of the room. And I used to quietly slip in and stay at the bedside for as long as I could, and for most of these patients it was a short period of time, and I would stay with the patient 'til the patient died, and I didn't say anything to anybody (Denise).

And I think that the most important thing for me...there's two most important things for me up there on the unit when I have a patient who is dying is to be a good death...be a comfortable death. They maintain their dignity that they are not sitting up and screaming in pain and agony or in fear. And that the family is comfortable as comfortable as we can possibly make them and if it's really close family and everybody wants to have a hand on them I can take the side rails down, I'll take the foot board off, I'll take the bed out in the middle of the room so they can put their hands on them. That's my job at that point. It's not to be legalistic about things and "Oh their side rails have to be up" ohhh you know...Let them crawl in bed with them if they want to...It's not my job to prevent the family or the patient from getting what they need (Betty).

[The family says] "No, we've seen him at our best, and we don't want to see him go like this" or her, you know, "we want to remember him the good way." And I say, "Fine, then, I'll just tell you, I'll make him comfortable, and I'll be with him. He won't be alone, and I'll be talking to him, you know, when he passes. If he

passes with me, I'll be with him." And I usually try, really really try to do that....Yeah, I honor what I say because I don't want anybody to be alone, to die alone, that would be awful (Jenny).

Theme Four. "Nurses are in the game of reality"—"Doctors can't say that;"

A fourth theme of *promises to keep* was the obligation to honesty and truthfulness in interactions with patients and families when discussing the possibility of death and the expected outcome of interventions.

But we do have patients' families who are given the reality and the gravity of the situation and been asked to make a decision, and...and they know it's the right thing to do, but maybe they're not completely comfortable, and I think where the approach from the nurse gets a little different is we support both families, but maybe the nurse is going to spend a little bit more time giving some clinical information that helps to validate that their decision was a good decision (Bob).

"Nurses are in the game of reality."

Within this theme, the participants described the ethical considerations to revealing enough information about the patient's prognosis to make an informed decision, but being very careful not to influence the decision inappropriately.

I don't know when it's going to happen. And everybody wants to know when, "Well, how long do you think?" "I have no idea." You know, got a strong heart, you know, pretty good lungs. Who knows? That's not my decision; he's in

God's hands. (Jenny).

I try very hard to present things very factually based without opinions...It is a very fine line, the facial expression. Or the ...you look at them... That you have to make sure you don't do when you are talking about their family members' life and death because I don't ever want to be the reason somebody made an inappropriate decision. I want to be the person who helped them make the right decision for their family member (Betty).

And you...and you feel that you're asking them to make a (pause) a loving decision, you know, you...you know, if you could just say that, you know, "I'm asking you to make a loving decision to end your mother's suffering which I don't think God would want."

Denise was able to initiate conversations that addressed the impending death of the patient and the interactions that took place facilitating communication and decision making.

There've been occasions that I've sat down with the wife or with the husband and said, "You know, I think on some level he knows that there is no...he's not going to get better. Do you feel that?" Now, you take a chance when you do that. And I've had people say, "No, he doesn't know it, and I don't want him to know, and don't you dare tell him," and I say, "I would not, I wouldn't, I wouldn't do that.

That's, you know, that's up to you. I would not do that unless he specifically asked me." And then others who have said, "Do you think, because I wanted to bring it up, but I'm afraid that if he doesn't know, this will frighten him." So then we kind of talk about, you know, was he hinting, is he sending messages that he thinks this is the end (Denise).

Ellen expressed her concern that she might have unduly influenced the decision of discontinuing futile treatments and the risk that she might have made that decision for the patient and family rather than their making the right decision for themselves.

But you can't do that, you know, you have to be very careful. You can't do that...I can't have that kind of a conversation with somebody. That's just not...that's not my role. That is not my role. I can't do that. That's not my role (Ellen).

"But doctors can't say that."

Participants described the nurse's role as both patient advocate and informer, which sometimes conflicted with the medical model to do everything possible to prolong life. Participants expressed concern, and sometimes frustration, when communication with physicians did not adequately prepare the patient and family for what would eventually happen and prevented them from making appropriate decisions about care. To prevent that from happening, nurses assumed an active role in communication for the purpose of preparing patients and families for what was to happen and what to expect.

I find that most doctors ...tend ...they tend to skirt the issue a little bit. They give them a little bit of...some doctors will give them a little bit of the information and be a little bit pessimistic, and give them the...I mean, give them the truth, but give them it sort of smooth. And some...some of the doctors will be a little more blunt...And nurses [are] in the game of reality. But I understand the doctor's view, too, they want to give you clinical, what they know, and that's what they usually stick with. But we go there and beyond that...And I warn them ahead of time that this is what's going to happen (Jenny).

I said, "I don't [have] a problem telling my families. That is a part of what I do. The doctor will say that he has a grim outlook.' And I'm going to tell you that that this is what is truly going on..." Doctors can't say that...(Betty).

And...and I try to be very careful about the terms that I use, because it makes me crazy to hear these doctors come in and say, "Well, if her heart was to stop, would you want us to do everything to save her life?" And I think, "How could anybody not say 'yes'?"... I mean how could you not say yes to that question? But that's not really the real...that's not a true...that's not a real question....I feel like I at least have to let them know the reality of it without...and it's...you know, without making it sound as if I'm telling them what they should do...(Ellen).

Theme Five. “It doesn’t end at the time of death”—“You feel very good, because you did your job”

The last theme emerging from *promises to keep* expressed connections between nurses to patients and families that continued after death and sometimes lasted for years, if not a lifetime. Participants described caring for the patient’s body and family after the patient’s death with a sustained commitment to respect and dignity promised before death. This lingering commitment brought complex and sometimes troubling emotional responses for the nurse.

“It doesn’t end at the time of death.”

In this theme, the participants described responsibilities to the patient and family immediately after death and extending into the days and weeks following, including an emotional connection that lingered, sometimes for years, for the nurse.

It sort of seems like people think of caring for the dying patient as ending at the time the patient dies. And it doesn’t really end until the patient and the family have...or the patient’s body...all ties with you, with your ICU, have been severed. It doesn’t end until that family has gone to the elevator, and is never going to contact you again. Or until you’ve gotten that letter back from them, you know, “Thanks for your help with mom,” you know, it doesn’t end until the patient’s body is out of the ICU. And back in the day when we used to transport them to the morgue, before they had other people to do that, it didn’t end until you left the morgue. And then you’re giving that care to someone else, you know, a funeral director, or whatever. But it doesn’t end at the time of death (Ben).

Sometimes nurses did not have the assurance from the family that they intervened appropriately. When this happened, the nurse was left to reflect on the experience and question his or her actions alone.

That's how I felt. Just emotionally...I didn't want to go to work the next day thought I would never... You don't want to go back to work ...you're just so overwhelmed with ... should I really have helped them reach this decision, was that really the right thing for me to do? You wonder if you said something just the right way to make them make an inappropriate decision....sometimes...you know. And that...that can...make you question because we are all human and we all do that ...make you question what are you doing (Betty).

"You feel very good, because you did your job."

When interactions with the family occurred following the death, and were positive, they brought a sense of satisfaction to the nurse, as Chelsea and Gayle described their experiences.

And the family came back to me and thanked me for giving them one more day with him so they could talk, and talk to him, because he was awake enough, you know, but kind of in and out of consciousness... They were like, "We needed that one extra day." (Chelsea).

And it wasn't until months later that they came back, a special trip to the hospital

just to talk to me. And she said she appreciated how direct I was in telling her...she said because she couldn't get a direct answer from anybody else (Gayle).

Several participants described participating in activities with the families after the death such as going to funerals, checking on families through mutual acquaintances, or seeing family members in the community. When they connected with the family after the patient's death, they described a significant and satisfying experience.

We had a police officer in the unit ... we had police officers in and out of there all the time, and we got really close with them, and the family, and one of the things that helped us that... if we got close with the family, we were invited to the funeral, and a lot of the nurses went to the funeral ...and it helped, kind of helped with the grieving (Joyce).

They [the family] were so nice after they had the funeral. They even sent me a basket up, and thanked me, and wrote me a note, and just said that they appreciated everything I'd done for them, and that without me they didn't know how easily the transition could have been, and it just...it makes you feel good to...like I went home that day, and I was sad, but at the same time I felt very good, because I felt like what I did was a very good thing for that family, and that maybe made it a little bit easier, not that it's ever easy, but to maybe just be the advocate or be, you know, help them in their transition. I just felt like that was a

great thing, so it's sad, but at the same time you feel good, 'cause you did your job (Trish).

And I have had patients that... we have attended their funeral. And so the family's very appreciative that you remember them outside of the hospital setting, and that you cared enough to even go to the funeral when you can. It's a nice nice feeling to see the family, you know, trying to go through that, everybody's together, supporting one another, and, you know, just realizing this is, you know, pretty much the best thing for the patient, considering how the patient was in the hospital, and that we still care, you know, even though he didn't make it, we still care about the family. When you go, outside of the hospital, you want something extra. That's the extra, 'cause that's really not part of your job. You know, once they leave the hospital, then, you know, really that could be it. But if you care enough, and you follow up, you know, with to, "Okay, well, I saw the obituary in the paper, and I thought about you." And for them to see you, it sent...to me, it seems like it gives them a little joy to see, "Okay, well, she took the time to stop by, to come to the funeral" (Ruth).

Some connections with families continued and extended long into the future as Judy described in one example.

You would see him [the husband] out...he would come to [city] and get his groceries, and you'd see him out occasionally, and he would still know exactly

who you were, ask you how you were doing, ask you about your kids, what they were doing now, I mean, he never forgot one of us, ever...(Judy).

Summary

Several themes emerged from the participant interviews revealing strong emotional and professional ties between the nurses and their patients and families. The five sub-themes manifested within the encompassing theme of *keeping promises*. In this theme the nurses described commitments to keeping promises to care for the patient and family, while providing as peaceful and dignified death as possible with an opportunity for the patient and family to prepare for the death in whatever way they needed. The nurses described the emotional trauma to the family and nurse when the deaths were unexpected, especially if the patients were young or the nurses had expected the patient to survive. If a nurse was unable to keep a promise, especially if the patient or family had an unrealized hope of recovery, the nurse vividly remembered caring for the patient, sometimes years afterward with expressed feelings of regret.

A paramount commitment for the nurses involved truth telling in all communication with the patient and/or family to provide enough information to make decisions about care without influencing decisions inappropriately, especially decisions to terminate futile care. This commitment sometimes contradicted or conflicted with communication from medical staff, placing nurses in an ethical dilemma of not telling the truth versus undermining the patient's confidence in his or her physician. Nurses described the commitments and/or emotional connections with patients and their families

continuing after the death of the patient and extending in some cases for years as nurses remembered a complex array of emotions, troubling and rewarding, associated with caring for dying patients.

Chapter 5

Discussion

The purpose of this study was to describe the experience of nurses caring for dying patients in the critical care unit. Using a phenomenological approach based on the works of Merleau-Ponty, the researcher conducted 14 interviews with participant nurses after a bracketing interview to identify personal preconceived impressions or suppositions. All nurses were asked to describe experiences of caring for patients who died in the critical care unit. The audio-recordings of the interviews were transcribed verbatim and analyzed using a hermeneutical approach developed by Pollio (Pollio, Henley, & Thompson, 1997) and applied to nursing research by Thomas (Thomas & Pollio, 2002). Each interview was examined within the context of all the interviews to identify themes found throughout.

The nurse participants described experiences ranging from years in the past to ones as recent as two days before the interview. Some participants described the first death they encountered in the critical care unit while others spoke of the most recent. Some spoke of both. The clarity of recall for details in both distant and recent remembrances suggested that the memories held significant meaning to the participants and perhaps significant emotional connection. Almost all found it easy to choose which patient to discuss and described the experiences as “good,” “bad,” “devastating,” “peaceful,” or “horrific.” The words they used reflected what the experience was like for the patient and family as well as for themselves. They described the world of the ICU through the experiences of the patients and their families. A thematic structure developed

from the shared themes of the interviews which provided new insights into the experience of dying in the ICU and in some cases supported or refuted findings in prior research and theory on end-of-life care. In this chapter, these findings and relevant research will be discussed.

Thematic Structure

“Promises to Keep”

The encompassing theme of the study, *promises to keep*, represents the duty and responsibilities of the nurse to care for the patient and family during and following the patient’s death. According to the *Merriam-Webster Dictionary* (2003), the word *promise* derives from the French word *promis* and the Latin word *promissum*, which are translated as “to send forth” (p. 933). *Promise* may be used as a noun or a verb and can mean either a statement or assurance that one will do something, can expect something, or supply something. There is a sense of a positive outcome of an endeavor or an improvement in something. In philosophy, the *promise* provides a “normative power” for behavior that is lacking in cultures that have no such convention and represents a “device for obligating oneself” (Wallace, 2006, p. 53). In that context, a promise becomes a “moral obligation” when actions of the promise affect something valued by the person to whom the promise is made (p. 53). Promises may represent a legal obligation if stated in the form of a contractual agreement.

Western culture uses the word *promise* frequently as shown by a metasearch of the University of Tennessee’s library search engines for items with the word *promise* in the title (5637) or anywhere in the document (over 20,000 items). Included in these items

were works of literature including books and poetry describing promises. Other items were listings for articles and books about the latest technology and research for medicine such as gene therapy and stem cell research.

In searching the nursing literature, the word *promise* is used in the title of over 900 articles in the *Cumulative Index of Nursing and Allied Health Literature* (CINAHL). However, few items discuss the promises made by nurses to patients or the moral obligation implied by such an act. One article by Marck (2000) addresses the nurse within the environment of the ICU specifically and develops the theme of promises within a technological milieu. According to Marck, technology has been both “promise and problem” exposing the nurse to “everyday moral choices” (p. 7). To make these decisions appropriately and compassionately, Marck recommends that the nurse take the emphasis off *technics* and put it back on *ethics* (p. 7). Ethical decision making is a vital element in nursing practice and has become more complex as technology has gained in emphasis and use. Marck writes that “the habits, practices, and orientations that pattern daily practice assume moral significance in a technological world” (p. 7). To make morally and ethically sound decisions, nurses seek guidance in ethical practice from the standards provided by the profession.

The theme of promises and moral obligation is found in the *American Nurses Association (ANA) Code of Ethics for Nurses* (2001) including several interpretive statements about the nurse’s obligation to the patient for compassionate care, ensuring dignity and protection of the rights of patients. If promising obligates the person morally and legally when made about something of value to the recipient or if the promise

represents a contractual agreement, promises within the healthcare milieu would have significant meaning and importance, especially in a critical care setting. Participants in the study described various aspects of the nurse's obligation to provide compassionate care in their experiences in the ICU. This promise of compassionate care exposed the nurse to the physical, psychological, and spiritual suffering of both the patient and family. At times the suffering of the patient and family became the nurse's shared suffering, especially when the death was unexpected.

"It wasn't time for someone to die"—"We see it coming a long way down the road"

"It wasn't time for someone to die."

As they described experiences when patients died unexpectedly, participants expressed surprise, disbelief, and a shared emotional response with the family. Chelsea describes this emotion as shock as she recalls, "I got emotional after the code. I was really upset because he died. And it was a...just a shock, because I had him the day before and ...he was doing okay..." Shock and disbelief were also expressed by nurses in descriptions of the reaction of nurses to dying patients in research by Yam, Rossiter, and Cheung (2001) as nurses in Hong Kong responded to the death of pediatric patients. This finding supports Andrews (1998) research as nurses described a *shared humanity* with the patient and family, leading to subsequent suffering and loss (pp. 62-64).

Participants described shared suffering with the family when they had cared for the patient for an extended time and the patient had died unexpectedly. As Gayle described, "...she was in the ICU for probably about five weeks ... And she got better, then went to the [another facility] and had a massive aneurysm, and came back and died

here. And it was very difficult when we found out.” This theme supports the findings of Glaser and Strauss (1968) that the temporal differences in expected and unexpected deaths generate different and more complex responses to death, especially when the patient who was expected to die improves and seems to be recovering before death. The study findings differ, however, as participants in the Glaser and Strauss study were strongly discouraged from expressing emotions which were deemed unprofessional and problematic for hospital staff.

These findings also support Papadatou and Bellali (2002) that the nurses form relationships with patients and families over time in the ICU and these relationships increase feelings of sadness and loss when patients die. Nurses in that study also expressed grief at the loss of the relationship comparable to the loss described by Judy when she said: “Why couldn’t I have known him before the accident instead of knowing him when he’s not there? Especially when they have families like that and you know they must have just been this awesome person.”

“We can see it coming a long way down the road.”

Participants in the study described experiences where they anticipated the death of the patient, sometimes far in advance of the actual death. The knowledge brought increased obligations and responsibilities to both the patient and the family. The nurses reveal an empathic and intuitive understanding of the complex emotional responses and psychological needs of the patient and family as they begin to realize that the patient will not recover. Participants described the care they take to make appropriate promises and to follow through on those promises. This care is shown as Jenny explains how she

reassures a family that decides they cannot stay with the patient as he or she dies, that their loved one will not die alone, “I’ll be with him. He won’t be alone, and I’ll be talking to him, you know, when he passes. If he passes with me, I’ll be with him.’ And I usually try, really really try to do that....Yeah, I honor what I say because I don’t want anybody to be alone, to die alone, that would be awful”. This finding supports those of Clark and Heidenreich (1995) that the nurse forms a trust relationship with the patient and fosters connections to support the patient and family.

“Just one more day”—“They had enough time”

As advocates for patients and families, participants described actively participating in care decisions to begin or delay removing medically futile care based on an assessment of the patient’s or family’s readiness and needs. This role supports the research of Glaser and Strauss (1968) as nurses in that study expressed a “moral obligation” to wait until a patient’s family was ready to change care from a curing focus to a caring focus (p. 91). Nurses in that study did not take an active role in decision making, however, as participants described in this study. In Glaser and Strauss’ study, nurses were responsive to the direction of the medical care and made no autonomous actions to inform or advocate for patients or families. Another difference between findings from this study and that of Glaser and Strauss is found in the approach to family care. In the Glaser study, families were to be “controlled” and not allowed to interfere in the hospital care and routine (p. 158-159) to the point of discouraging the family from coming to the hospital or viewing the patient after death. In this study, nurses described a commitment to the patient’s family that developed from the commitment to the patient

and lasted beyond the death of the patient, including care for the families that facilitated healthy grieving and healing.

“A promise I couldn’t keep”—“I honor what I say”

The importance of a promise made to a dying patient and his or her family was demonstrated in the themes of this study. In the interviews, participants referred to promises made to patients and families that were kept or not kept and the results of those promises to the patient, the family, and the nurse. When promises were not kept, whether explicitly or implicitly made, the nurse described the emotional suffering that he or she experienced in not keeping the promise. Betty described this as she said, “... but I feel like I let them down because I didn’t know the whole story when he got there.” The feeling of remorse is personal, as described by Trish: “But I assured her that it was just a temporary thing, that we just needed to get him through that particular bad time. Of course, he never came off. Things progressively got worse, so I felt some ownership of that, you know, almost like I had made a promise I couldn’t keep.”

This theme supports the findings of Clark and Heidenreich (1995) and Messinger and Roberts (1994) that an important strategy of nursing care involves forming trust relationships with patients. The inability to keep a promise challenges that trust. Jezuit (2000) reported that nurses found satisfaction in the trust relationships formed with patients and families and suffered professionally and personally when that trust was broken.

“Nurses are in the game of reality”—“Doctors can’t say that”

In this theme the nurses expressed a willingness to discuss the impending death with both the patient and the family. They characterized their communication with the family as being more direct and sometimes more honest than the physician’s. When the nurses felt that the physicians were too clinically oriented and did not address the implications of the clinical trajectory of the patient’s condition or the futility of the medical treatment, the nurse would become an interpreter for the patient and family so they could make an informed decision about care. The difference in communication between nurses and physicians supports the findings of Simmonds (1997) that physicians are sometimes reluctant to stop treatments and nurses express the concern that continuing treatment is not the best choice for the patient. In that study, nurse satisfaction came from providing comfort for the patient, and patient suffering reflected the failure of the nurse.

Findings from this study also support the findings of Rutledge, Bookbinder, Donaldson, and Prafikoff (2001) suggesting that curative medical treatments lead to burdensome over-treatment and suffering for dying patients. In this study, assuming the role of informer and advocate in decisions concerning discontinuing life support or refusing futile aggressive treatments presented the nurses with ethical dilemmas and introduced moral distress as nurses grappled with the concern of whether they had inappropriately influenced patients and families to make a wrong decision. This finding supports the conclusions of several researchers that nurses communicated with and advocated for patients under difficult circumstances when faced with a decision to

discontinue life support (Burger, Bates, & Nel, 1999; Hopkinson, 2002; Johnson, 2002; Storch, et al., 2002; Yang, 2001). Lutzen, Cronqvist, Magnusson, and Andersson (2003) refer to this concept as “moral sensitivity,” where the nurse is “morally sensitive to the patient’s vulnerability and lack of autonomy” (p. 319). Nurses experience “moral distress” when they “experience that external factors prevent them from doing what they think is best for the patients” (p. 319).

This study also supported the findings of Kirchoff, et al. (2000) that ethical and moral dilemmas resulted when patients and/or families sought relief from suffering and asked nurses to hasten death or assist in suicide. Hannah described this dilemma as she described her concern with the “double effect” of treating pain and suffering, but perhaps hastening death as a result.

Well, it’s...as a nurse, you know, as a clinician, I recognize when people are suffering. I also believe that I have the ability to sort of...have the intuition of, you know, enough’s enough. So, I guess what I’m saying is, I’m very much for stopping when it’s time to stop. You know what I’m saying? I do not...we...we call it “flogging.” I don’t believe in flogging someone. Especially when their outcome is going to be very poor. So on that part of it, if I can go ahead and come to terms with the fact that it’s time for them to die, and then give them that medicine to help make it easier, I think it’s a good thing. But at the same time, you can’t help but wonder, “Am I participating in the actual death process, in a way that...where I’m facilitating this death?” You know what I’m saying? I don’t think I’ve ever truly believed that I’ve done that, but you can’t help but

wonder.

When nurses are unable to relieve suffering for the dying patient and were unable to keep promises to make death peaceful, they described experiencing elements of moral distress, sometimes with lingering emotions and troubling memories for years afterward.

“It doesn’t end at the time of death”—“You feel very good, because you did your job”

As nurses cared for patients and their families in difficult end-of-life circumstances, connections were formed between the nurse and the patient or family that did not end with death. Care for the patient extended to caring for the body and transferring it for interment. Care for the family extended to psychological and emotional support after the death and was sometimes expressed by attendance at a wake or funeral. Connections between the nurse and patient or family continued into the days and weeks, and sometimes years following the death. The nurses reflected on their contributions to and the role they played in care of the patient. When families acknowledged the nurses’ role in the care of the patient by reconnecting after the death and recognizing or thanking the nurse for his or her contribution to the care, the nurse described a sense of satisfaction and a reassurance of professional integrity in the performance of the nursing role.

When there was no acknowledgement of the contribution from the family, the nurse sought affirmation through self-reflection or from colleagues. Confirmations from other nurses or physicians, or from their own evaluation that they did “everything they could” for the patient or family supported their professional and personal sense of integrity. This theme supports the findings of Papadatou and Bellali (2002) that nurses

find reward for the difficult role of caring for dying patients in their contributions to the care of the patient, their close relationship with patients and families, and from the recognition of their contributions from the family.

Implications for Theory

Stress Theory

The findings of the study support the conceptual definitions and relationships of several theoretical models. I have chosen three frameworks to discuss in this chapter that appear to be useful to further research and study of death in critical care units based on the findings of this study. The first framework is Lazarus and Folkman's Stress Theory (1984). Lazarus and Folkman's theory has been used in studies of the relationship of empathy and stress in both formal and informal caregivers (Lee, Brennan, & Daly, 2001; Omdahl & O'Donnell, 1999). As stated in Chapter 2, several researchers have also used Lazarus and Folkman's Stress Theory as a framework for studies of critical care nurses.

Lazarus and colleagues (1984) developed the widely used theory of stress response as an interaction between the person and the environment (Zakowski, Hall, Klein, & Baum, 2001). Lazarus's Stress Model (1999) began with his early work in post-WWII with soldiers suffering posttraumatic stress disorder. Emphasis at that time was on the event causing the stress rather than on characteristics of the person experiencing the stress. Lazarus began studying individual differences between persons as he writes, "...what makes the stimulus stressful depends to some extent on the characteristics of the person exposed to it..." (p. 53). In his stress model, Lazarus describes stress as a

response to the interaction between environment and the person. This dynamic interaction involves a reciprocal relationship between the person and the perceived threat in the environment. Nurses in this study described responses to their environment in the ICU, including stress and difficult emotions associated with caring for dying patients. Nurses described feeling overwhelmed and inadequate to meet the complex needs of the dying patient and or family, and traumatic experiences of caring for suffering patients associated with feelings of guilt, sadness, and devastation. In cases when nurses felt adequate to meet the needs of the patient and or family, the nurse expressed feelings of satisfaction and reward.

A second concept in this study related to Lazarus' theory was *empathy*. Empathy is defined by Lazarus (1999) as an understanding of another's emotional response to suffering. The ability to be empathic varies with the individual from a level of no empathy in the sociopath to higher levels, which, according to Lazarus, serve as the basis for compassion. Compassion in nursing is necessary for a caring and therapeutic relationship. Lazarus proposes that we can be too compassionate and may hinder our emotional health or be too distant and dispassionate and hinder our therapeutic relationship. Nurses' interviews revealed support of this concept as they described navigating the difficult course between empathizing with the patient and family as a basis for compassionate care and experiencing shared suffering and loss as the patient died. Trish described this tenuous balance when she said, "you allow yourself to get involved emotionally to some degree because you want to be empathetic and be able to empathize

with the family and support them. But at the same time you can't allow yourself to become over the top involved."

The third concept that is applicable to this study is *death anxiety*. Lazarus (1999) defines anxiety as the "existential threat of death and nonbeing" (p. 160). Nurses caring for patients in the ICU are exposed to death or the threat of death daily. The nurses described feeling either satisfaction in their experiences as they were able to give compassionate care to the patients, relieve suffering, and meet the needs of patients and families; or dissatisfaction and discomfort if they were unable to meet those needs. Lazarus (1999) observed that the person may appraise the environment as primarily stressful and secondarily as a threat or a challenge. Ben articulated this concept as he said, "So much of it can be rewarding. And, if it's not rewarding, then every death experience moves the nurse further from the ICU. Right? Well, shish. If it's not rewarding, you're going to go, 'I don't want to experience that again.' But, if it is rewarding, 'Wow, I want to go back to work again tomorrow.'"

Caring in Nursing

The second theoretical framework that relates to the findings of this study is Habermas' Theory of Moral Consciousness and Communicative Action as applied by Sumner (2001) to caring in nursing. In this framework, Sumner uses concepts of Habermas to describe the interaction levels of nurses with patients as the moral development of the nurse matures. In the interactions of the nurse and patient/family relationships form as a "moral ideal" (p. 931). In that relationship both the patient/family

and nurse demonstrate a moral development level. These levels may be the *preconventional*, *conventional*, and *post conventional* (p. 930).

The preconventional level is the inexperienced nurse or patient/family that is “obedient to the rules” and unable to empathize with the other. In the conventional level, the nurse is “beginning to see the patient behind the illness” but the interaction is for the purpose of strategically reaching a goal and goals are not mutually set. The patient/family at the conventional level is able to be a voice in the interaction, but does not have an equal voice. In the post conventional level, the experienced nurse “functions autonomously” (p. 930). The patient/family at the post conventional level has an equal voice in the decision making. Goals at this level are mutually set giving each a fulfilling and satisfying experience. Interaction at the post conventional level is characterized by both truth and truthfulness, characterizing a “normative claim to right where there is mutual acceptance of the norms and values imbedded in the interaction” (p. 930).

Nurses in this study described interactions at all three levels of moral development. Sumner (2001) acknowledges that patients in many circumstances will be inexperienced in their illness and remain at the preconventional level of maturity. Patients in the ICU may be unable to display any developmental level, but may still communicate a need for interaction with the nurse. This would seem most possible in the ICU as few patients have experienced that serious an illness before or are unable to articulate their needs. This level would be characterized by reliance on the nurse to provide for the needs of this patient and a level of consideration in the relationship. Nurses in the study described

interactions with dying patients and their families from a conventional or post conventional level of moral maturity. They were able to empathize with the patient and family and either mutually set goals for the care or include the patient and family in setting goals. This difference in levels of interaction was described by Denise as she said,

If a patient was made a ‘do not resuscitate’ and the patient was pretty much comatose, the nurses would close the blinds and close the door, and would sit at the nurses station and watch, you know, take all the drips off and watch the rhythm on the monitor outside of the room. And I used to quietly slip in and stay at the bedside for as long as I could, and for most of these patients it was a short period of time, and I would stay with the patient ‘til the patient died, and I didn’t say anything to anybody.

Nurses described a sense of satisfaction in interactions if goals were mutually set, when patients and or family were involved in goal setting, and when the patients and/or families identified that their needs had been met.

Transformative Leadership

The third framework that relates to the concepts emerging from the interviews is Watson’s writings on transformative leadership based on her development of the concepts of caring-healing and postmodern nursing, and her application of chaos theory to 21st century nursing administration (Watson, 1999, 2000). In her writings, Watson describes a “fourfold path” of transformative leadership. This path or *via* is composed of the *Via Negativa*, the *Via Positiva*, the *Via Creativa*, and the *Via Tranformativa* (p. 1).

In the *Via Negativa*, the nurse responds to his or her calling to care in areas where

caring is not rewarded and not recognized because this is where caring is most needed (pp. 1-2). The nurses in this study demonstrated such leadership throughout the interviews as they described going to extraordinary measures to show caring in an environment where *curing* rather than *caring* is the norm. As Betty described, “That’s my job at that point. It’s not to be legalistic about things and “Oh their side rails have to be up” ohhh you know...Let them crawl in bed with them if they want to...It’s not my job to prevent the family or the patient from getting what they need.”

In the *Via Positiva*, through a sense of “gratitude” and acknowledgement of the “privilege” of being a nurse, we bring healing energy to our practice (pp. 2-3). Judy describes this acknowledgement about being a nurse in the ICU as she says, “I don’t think I’d ever want to work anyplace else. It just, you know...it changes...I said ICU is one of those places where you’ll always be challenged, you’ll never be bored, and you lose your heart about once a day.” Participants spoke frequently of relationships they formed with patients and families during the unusual and vulnerable time in their lives. They found the relationships rewarding and satisfying professionally and personally. Denise acknowledges the satisfaction of caring when she describes a time when she intervened to allow a family more time with their dying loved one. “We actually kept him on his vasopressors. I asked the physician if I could leave it on and maintain his blood pressure while this process took place, and once everything was resolved and they’d had their conversations and loved and hugged one another and were sitting there talking about, you know, trips they took as kids and what were their favorite times together as a family, I began to decrease the infusions. And he died that evening about four hours

later, but it was personally satisfying to me.”

The third pathway, the *Via Creativa*, emerges as nurses find previously unmanifested gifts and talents to offer their profession (p. 3). Participants demonstrated this style as they described developing an intuitive practice of identifying and meeting the needs of their patients. They were able, within a technological environment of a critical care unit to show compassionate and sensitive care. This is demonstrated by Ben as he describes solving the puzzle of a son’s needs as his father dies and assisting him in achieving what he needed. “I had one son who insisted not only on being there when the tube was taken out, but he put his hands on the respiratory therapist’s hands, as the tube was removed, and... it was something he needed to do. He had promised his dad, ‘Dad, I’m not...you know, I’m going to make sure on it.’ And that was sort of his connectivity to it.”

In the fourth pathway direction, the *Via Transformativa*, “visionaries, teachers, and healers for systems emerge, leading from the ‘inside out’” (p. 4). This pathway is exemplified by all the nurses in the study who cared daily for patients dying in the ICU. Though they do not acknowledge themselves as leaders and visionaries, their continued practice and efforts to provide peaceful deaths, ones that are free from suffering, filled with dignity, and marked by hope in a world of technological tunnel vision distinguishes them as just that and provides exemplars for Watson’s concept of caring-healing.

Implications for Nursing

In the *ANA Code of Ethics* (2001), nurses are provided a standard of practice that includes assurances of the patient’s moral and legal rights to self-determination, including

accurate information that is complete and sufficient enough to make decisions about care. Nurses are encouraged to assist patients in weighing alternatives in care when they are competent to do so. The nurses in this study described how promises of compassionate care at the end of life morally obligated them to advocate for and assist patients and families in making difficult decisions when curative care was futile and burdensome to the patient. Bailey (2006) recommends that critical care practitioners use the best interest principle to make ethical decisions in the ICU. Three components she would include in that process are “absence of absorbing and intractable pain, bodily integrity and relatively normal body function, and capacity to be autonomous” (p. 286). Each of these areas were identified by the participants as important factors when used in the context of compassionate care for the dignity of another person, whatever that person’s medical or psychological status may be. Maintaining a focus on the integrity of personhood regardless of functional ability integrated all aspects of the nurse’s care, and it should be a vital concern within all areas of nursing practice. However, the emphasis of curing versus caring found in ICU’s threatens this focus and makes moral decision making a necessity for critical care nurses.

Practice and Policy

Technological advances in ICU’s across the nation have complicated ethical decision making for all critical care nurses. Administrative policy in ICU’s must reflect the importance of ethical and moral responses to suffering when decisions are made on care. Nurses must be assured a voice in the decisions concerning patient care and empowered to use that voice in advocating for the patient. Day (2006) describes the

concepts of *advocacy* and *agency*, as defined by Benner, in the context of critical care nursing. *Agency* is the nurse's ability to perceive the impact of their care and develop as a contributing member to the overall care of the patient. *Advocacy* and *agency* are related concepts because patient advocacy is one way of contributing to patient care and facilitates the nurse's development of *agency*. All of the nurses described varying ways and levels of advocating for their patients and families. When participants described advocating for patients and recognized their contribution to a peaceful death, they experienced satisfaction and reward. When nursing policy and practice facilitates nurses actively participating in patient care decisions and fosters ethical care decisions, patient care in ICU's improves and nurses respond with increased job satisfaction and decreased stress.

Advocacy and agency both emerge in an atmosphere of open, positive and complete communication. Boyle, Miller, and Forbes-Thompson (2005) reported that communication fosters good patient care in the critical care unit. Nurses and physicians who collaborate in patient care decisions and include the patient and family in an informed decision making approach to care experience greater satisfaction with their decisions and note that patients and families are more satisfied as well. Participants in the study expressed concerns as well as hope when describing communication in patient care. Jenny and Ellen describe difficulties with the way physicians inform patients. Bob and Sarah describe good communication in a collaborative team approach that benefits the patient, the family, and the staff. Policy and practice based that facilitates complete and adequate communication between all involved provides a basis for improved care

and assurance of individual rights to self-determination.

Education

Education in appropriate end-of-life care is imperative to assuring compassionate and appropriate care within a technologically focused environment. It is evident that education of students and staff in the ICU must provide for a competency level sufficient to function at a high technological level. However, the multidimensional needs of vulnerable patients found in that environment necessitate various other educational needs as well. Participants in this study expressed a need for experiential learning as they spoke of how their responses to patient needs and suffering had changed with time and experience. They spoke of physicians who were able to communicate with families and patients better because they understood and communicated better. Denise expressed a concern that students were not receiving enough education on the ingredients of compassionate care and encouraged more on meeting the needs of patients beyond the physical and medical care. Day (2005) recommends that education for students in critical care include “ethical comportment,” a concept that she describes as promoting “civic professionalism” (p. 435). It seems apparent from this study that ICU nurses are presented with ethical and legal decision making every day and will face ethical dilemmas more often or make good practice decisions less frequently if they are not prepared to apply ethical and legal principles to nursing practice. Participants described conflicted feelings and concerns about the double effect of medications, patients receiving futile care, and difficulties in providing for self-determination when the patient’s wishes cannot be known.

Several suggestions about education in end-of-life care are supported by the findings of this study. Skillful communication and an interdisciplinary approach to care of the dying patient would be facilitated by an interdisciplinary approach in education where nurses, physicians, social workers, clergy, and allied healthcare providers are brought together to develop skills and acquire knowledge necessary to provide competent and compassionate care. Participants described ethical and moral dilemmas arising when there was dissonance between the nursing and medical approaches. Moral distress was alleviated or avoided when an interdisciplinary approach to care decisions was applied and all members of the healthcare team communicated appropriately with the patient and family members. This education also must include an understanding of family care and dynamics, as participants described a refocus of care to include the family of the dying patient. Family care in the ICU is a necessary aspect of nursing care, but is not always identified as a critical care competency.

Research

Ethics has not historically been an area deemed appropriate for nursing research. However, experience of ethical decision making and if the response to incidental or continuous ethical and moral distress have become areas of research in several disciplines, including nursing. Ferrell (2006) interviewed 108 nurses from various specialties, including critical care, using a qualitative approach asking about experiences with medically futile care and moral distress. Findings from this study supported her findings that nurses became involved in the conflict. Her findings also revealed feelings consistent with the concept of moral distress as did the findings from this study. There is

a need for further research in this area. A finding from this study that was not discussed in Ferrell's report nor found elsewhere in the literature is the experience of nurses as they describe actively initiating discussions with patients and families to discontinue futile treatments. This is an area that needs further exploration and study as nurses are demonstrating the skills and autonomous practice level, advocating for the patient, as described and recommended in the *ANA Code of Ethics* for a competent and experienced nurse. It will be interesting and exciting to see whether this is an emerging new area of leadership for nurses in the healthcare environment.

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APPENDIX

**INFORMED CONSENT STATEMENT
DYING IN THE ICU: A PHENOMENOLOGICAL STUDY OF THE
NURSE'S PERSPECTIVE**

INTRODUCTION

You are invited by Mrs. Phyllis King, MSN, RN,C to participate in a research study to describe the experience of nurses caring for patients who die in the critical care unit. Mrs. King is conducting this study as her dissertation research for her PhD in Nursing at the University of Tennessee. She is working with Dr. Sandra Thomas and a research group at the University who have an interest and experience with this and other topics of patient care. The results of this study may be presented in at professional conferences and published in journals and books. Results will be presented as aggregate or collective data and no identifying information will be given for any individual data presented.

INFORMATION

You will be interviewed by Mrs. King at a private location of your choice. There will be one interview and it will take approximately one hour. The interview will be audio taped to make sure your experience is recorded exactly as you described it. The transcriptions will be read by an interdisciplinary research group at the University of Tennessee to identify themes. The themes will be used by the researcher to describe the experience of nurses caring for dying patients in critical care units. If you agree, Mrs. King may contact you later to discuss the study results and findings. There will be 10 to 20 nurses interviewed in this study. The study is due for completion in December, 2006.

CONFIDENTIALITY

Interview tapes, transcripts, and data will be stored securely in a locked file and kept confidential with no identifying references included in the transcripts or in the results of the study. The researchers, transcriptionists, and members of the research group will sign a pledge of confidentiality. Mrs. King will be the only person who knows your name, address and any other identifying information about you. The tapes will be destroyed after transcription. If you would like, you may have a copy of the results of the study.

RISKS

There are minimal risks to you as a participant in this study but a potential risk is the emotional discomfort of describing your experience. If you feel distressed and wish to, you may end the interview at any time. Should you want to seek counseling for any emotional distress from the description of your experience, Mrs. King will provide you with information about accessing counseling in your area. You will be responsible for any fees associated with counseling.

BENEFITS

You may find that discussing your experience with an interested nurse researcher is a benefit of this study. Participants in other studies like this one have found discussing experiences to be helpful and satisfying. This study may provide a greater understanding

of your experience as a nurse for the nursing discipline as a basis for promoting the wellbeing and health of nurses and other health care providers in the critical care unit. This research may also contribute knowledge for improving education in end-of-life care and as a basis for policy development in acute care facilities to improve patient care and support the bedside nurse caring for the acutely ill, dying patient.

CONTACT INFORMATION

For further information, questions about the study at any time, or to report any adverse effects from the experience, you may contact Mrs. Phyllis King, MSN, RN,C, c/o Dr. Sandra Thomas at 1200 Volunteer Boulevard, University of Tennessee, Knoxville, Tennessee, 37996, or by telephone at (865) 974-7581. For questions about your rights as a participant in a research study at the University of Tennessee, Knoxville, you may contact the Compliance Services Officer at the Office of Research at (865) 974-3466.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at anytime. If you withdraw from the study before data collection is completed, your data will be returned to you or destroyed.

CONSENT

I have read the above information. I have received a copy of this form. I agree to participate in this study.

Participant's name (please print) _____

Participant's signature _____

Date _____

Researcher's Name Phyllis King, MSN, RN,C

Researcher's Signature _____

Date _____

Dying in the ICU: A Phenomenological Study of the Nurse's Perspective

CONFIDENTIALITY PLEDGE OF GROUP MEMBER

I, _____, a member of the Phenomenology Research Group at the College of Nursing, University of Tennessee, pledge to maintain confidentiality of this audio taped research interview following discussions of the transcripts in the research group. I will not discuss the contents of the transcripts outside the research group.

Dying in the ICU: A Phenomenological Study of the Nurse's Perspective

CONFIDENTIALITY PLEDGE OF TRANSCRIPTIONIST

I, _____, as a transcriptionist for this study,
pledge to maintain confidentiality of this audio-taped research interview during and
following transcription. I will not discuss the transcript with anyone other than the
Principle Investigator.

Date: _____

VITA

Phyllis Ann King was born in Knoxville, Tennessee on September 23, 1953. She graduated from Doyle High School in Knox County, Tennessee. She received a BSN, magna cum laude, from East Tennessee State University in 1975 and a MSN from The University of Tennessee, Knoxville in 1995. While a student at UT, Knoxville, she was named Who's Who Among Students in American Universities and Colleges. She has over 30 years of experience in nursing, including experience in critical care nursing and staff development. She has taught adult medical surgical nursing and nursing leadership for 12 years at Milligan College in Northeast Tennessee.

While a doctoral student in the College of Nursing at UT, Knoxville, she has received the Sylvia Hart Scholarship Award, been named to Who's Who Among Students in American Universities and Colleges, been inducted to Phi Kappa Phi, and received the Appalachian Colleges Association Wilma Dykeman Fellowship. She is a member of Sigma Theta Tau, International, American Nurses Association, Tennessee Nurses Association, and Southern Nursing Research Society. She received her Doctorate of Philosophy in Nursing from the University of Tennessee, Knoxville in December, 2006.