BEHIND THE CURTAIN:

NURSING CARE OF DYING PATIENTS IN CRITICAL CARE

By

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Humanizing the High Tech Environment: Nursing Care of Dying Patients in Critical Care

> "The awful terrible act of his dying was, he could see, reduced by those about him to the level of a casual, unpleasant, and almost indecorous incident..."
>
> Tolstoy, The Death of Ivan Ilych

CHAPTER I. INTRODUCTION

In the not-so-distant past, people died at home among family and friends. Dying was more likely to be simple and predictable. Death occurred in familiar surroundings with loved ones gathered at the bedside. But with the development of biomedical technology, dying has become more complex. Approximately 80% of deaths in the United States occur in hospitals and long-term care institutions (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). Approximately 70% of these deaths are managed, or the result of deciding to do or not do something to prolong dying (Caplan, 1992). The outcome of illness often is dependent on medications, machines, and the health care professionals who control them. With this dependence on technology, determination of the moment of death is sometimes questionable, prompting ethical questions concerning even basic who, when and how issues of dying. Families may remain in the background of the institutional environment,

and patients as people often are not the center of their personal dying experience. Rather they are the biological focus of a maze of treatment options and ethical/legal dilemmas. The President's Commission has taken a stand that dying is not a disease calling for remedies, but is the extinguishing of a human life. Those who provide medical care while patients are dying are admonished that they cannot treat symptoms effectively without caring for the patient as a person.

Critical care units (ICU's) have evolved to maximize the use of technologies in saving lives; however, death is an everyday occurrence there (Woods, 1984). According to bioethicist John J. Paris, "walk into any intensive care unit in America and you'll find at least two beds occupied by patients with no prospects for recovery" (Briggs, 1992, p. A3) The American Association of Critical Care Nurses (1988) projected 74,680 ICU admissions for 1990 and 82,380 for 1995. Researchers estimate that 15-25% of ICU patients die and that at any one time 10-20% of critically ill patients receive extraordinary life support for days, weeks, or months (Raffin, 1989). Some of these patients actually die after transfer, however the end-of-life questions are addressed in the critical care unit. Although life-sustaining treatment is withheld or withdrawn from patients in critical care with relative infrequency, such decisions

precipitate about half of all deaths in ICUs (Smedira et al., 1990)

The dense technological space of the ICU surrounding patients includes monitoring and therapeutic equipment, much of which is invasive. Although technology can facilitate cure, it often impedes communication, touch, and other human processes. It has also created another dimension of ethical dilemmas surrounding end-of-life issues. ICU nurses are concerned with maintaining the balance between sustaining life through technology and avoiding senseless suffering. As agents of caring, nurses are in the best position to humanize the technological space.

Nursing care of patients dying in ICU may be different from that in other settings because of the interplay among the characteristics of the environment, the work, and the patients. The nurse-patient ratio is high, often approaching 1:1 to facilitate the priority of the unit, which is saving lives. Significant ethical concerns underlie everyday decisions in ICU's, including end-of-life and resource allocation issues. The technological focus on rapid diagnosis and treatment sets a fast pace. Patients are acutely ill and often unstable, suffering from severe illness or exacerbation. ICU patients either die or are transferred to another unit. However, patients and families (Caswell & Omery, 1990) as well as health professionals maintain the expectation that life-saving miracles can

happen in the ICU.

When a patient is identified as dying, ICU care shifts from a cure focus to a comfort orientation in which psychological and emotional support of patient and family, symptom control, and comfort take precedence over medical treatments (Caswell & Omery, 1990). The responsibility for care tends to shift from medicine to nursing when it becomes apparent that the patient is dying (Muller & Koenig, 1988). Although medical care becomes futile at some point in the dying trajectory, caring does not (Gadow, 1989). Benner and Tanner's work (research in progress) has revealed that there are critical care nurses who have developed specialized expertise in caring for dying patients and their families. However, very little research has focused on nursing care of dying patients in critical care settings.

Statement of the Problem

Many patients die in critical care units, and nurses provide care to dying patients and their families in that setting. However, there is little published about expert nursing care for dying patients in ICU's. The ICU has unique characteristics including the interplay among the work organization and priorities of the unit, ongoing ethical concerns, technological focus on rapid diagnosis and treatment, patterns of care in the unit, illness trajectories, and, often, a failure to recognize or acknowledge impending death. It is premature to assume that

nursing practice in caring for dying patients in critical care is the same as nursing care for dying patients in other settings.

Research Questions

The purpose of this study was to explicate and understand the caring practices of nurses caring for dying patients in the ICU. The specific questions were:

1. What are specific caring practices of expert nurses caring for dying patients and their family members in critical care?

2. What are the interpersonal concerns and background meanings that shape expert nurses' caring for dying patients in critical care, including moral beliefs and issues?

3. What are the interpersonal concerns and background meanings of bereaved family members related to nursing care during the time the patient is dying in critical care?

Significance of the Problem

The concern for nursing care of dying patients in critical care is significant in consideration of two developments: the current debate over resource allocation and bed utilization in the ICU and the gradual eclipsing of caring practices by the emphasis on cure in the current health care environment. Although nurses have been providing care to dying patients in this setting for many years, these practices have not been explicated. The time that nurses spend at the bedside of individual patients is

being compressed, and procedural practices which can be quantified have become primary. Given an economic climate in which health care professionals compete for resources, dollars which are now paying for caring practices will be redistributed without understanding what has been lost.

Policies regarding admission or continued care of dying patients in critical care historically have been controversial. The issue in the literature revolves around whether or not patients for whom sustaining life is no longer a goal belong in critical care. Two concerns regarding cost and continuity of care are relevant. First, should high level technological support be made available for dying patients? Although a high level of care can be given on other units and in different settings, a dying patient may need the technological support and intense nursing resources offered in the ICU, including patient and family support and comfort care. Second is the question of whether critical care patients identified as dying should remain in the ICU or be transferred to less acute units. Although nursing care of patients was not observed after transfer from critical care in this study, the nursing care needs of patients dying in the ICU were considered, and the kind of expert care possible in that setting was described. Information regarding patient needs and care possibilities are often overlooked in policy decisions; such information could indirectly inform the policy question. To date, data

related to this important aspect of death care have not been published for consideration in the debate.

Terminally ill patients generally are not looked upon favorably as candidates for ICU admission. Some hospitals do not allow do-not-resuscitate (DNR) patients, such as those with cancer and the elderly, into critical care units (Bellamy & Oye, 1987; Rubins, 1989; Shedd & Whedon, 1991; Youngner, Allen, Montenegro, Hreha, & Lazarus, 1988). Hospital policy may also mandate transfer of patients labeled DNR during their critical care stay to other units to die. The negative consequence of this inflexibility can be a situation in which the DNR label cannot be ordered for a patient who needs the high nurse:patient ratio of care, potentially resulting in unwanted and inappropriate resuscitation measures. Not allowing DNR patients in ICU can make it difficult for practitioners to treat reversible problems within the context of irreversible disease (Youngner et al.) or to use technology for reasons other than as a means of saving lives. Use of sophisticated technology and high level of care in ICU's has been justified for DNR patients (Capron, 1986; President's Commission, 1983); however, the practice of keeping DNR patients in the ICU is not evident in many institutions, perhaps stymied by the issue of scarce resources. If the philosophy is that ICU care can only be curative, then perhaps these policies are justified. However, if ICU care

means intensive nursing care for all patients who need it regardless of outcome, then there is little justification for denying care in ICU's to dying patients (Caswell & Omery, 1990).

Critical care is very expensive in relation to general hospital care. As health care dollars become more scarce, administrators are looking at ways to conserve critical care resources. The most common way to do this is to base the decision to provide or continue critical care services on likelihood, quality, and length of survival (Engelhardt & Rie, 1986). Many studies have been done to document variables predicting the best outcomes (Weir, 1989). The choice of survival as an outcome (rather than "good death") reflects the underlying values guiding the policy question. The response in the nursing literature to the question of whether or not dying patients belong in the ICU reflects the tension between these values. Omery (1991) believes that nurses have a moral obligation to assure that the lives of dying critical care patients end with comfort and dignity. Practices to assure this may include withdrawal of life support and transfer of patients out of critical care but may also mean continued investment of time, technology, resources, and self. Campbell and Field (1991) have developed a cost-saving program for transferring DNR patients out of the ICU environment, given that the outcomes for those patients have been shown to be extremely poor

despite high levels of nursing care (Lewandowski, Daly, McClish, Juknialis, & Youngner, 1985).

The second reason that this study is so important is that many of the caring practices of nurses are being obscured or considered less important in health care environments where non-professionals take over direct care, technological and organizational competencies are rewarded, time and resource scarcity mandates prioritizing of task over touch, and outcomes are measured in terms of survival or cost-effectiveness rather than comfort, quality of life, or satisfaction. There has been a recent resurgence of interest and value in caring as the fundamental concern of nursing. Although the rituals and caring practices of nurses surrounding death in hospitals have been described (Wolf, 1988), these have been largely ignored in the critical care setting. If caring practices are not explicated, they may be lost.

Benner and Wrubel (1989) view caring as the human capacity for connection and involvement. For nurses, caring is based on their ability to understand the meanings of illness, or in this case dying, for patients. Caring, even in the midst of high technology, is primary in that it sets up what matters, enables connection and concern, and creates the possibility for giving and receiving help (Benner & Wrubel). Technological success in many ways is dependent on caring attention to human aspects of the situation. Concern

enables patients to better tolerate the personal demands, such as pain, inflicted by the technology.

Nursing practice evolves from the human trait of caring, and various levels of practice can be expected to exist. Although the ability to care is enhanced by learning, it is also influenced by who the nurse is as a person (personhood), including values. Differences in nursing practice reflect levels of expertise in understanding the meaning of the patient's experience (Benner & Wrubel, 1989). Benner (1984) has explicated a model of development of expertise in nursing practice based on Dreyfus' model of skill acquisition (Dreyfus, 1979; Dreyfus, Dreyfus, & Athanasiou, 1986). In this model, as nurses progress from novice to expert they rely less on theoretical direction and more on practical experience and intuition, they see situations as a whole with salient rather than equally relevant parts, and they become involved in the clinical reality (Benner, Tanner, & Chesla, 1992). Experience, defined by Benner (1984) as the refinement of preconceived notions and theory through encounters with practical situations, creates the possibility for personal enrichment, clinical maturity, and reflection. Expertise in care of dying patients can be developed through a rich history of patient care experiences and is reflected in everyday caring practices.

Description and understanding of caring practices can

serve as a stimulus for critical care nurses to reflect on the possibilities and responsibilities for providing intensive care to dying patients. Findings may influence consideration of ethical issues such as resource allocation in ICU and the role of the nurse in end-of-life decisions. This study also contributes to the general body of knowledge concerning nursing care of dying patients and their families in critical care.

CHAPTER II. REVIEW OF LITERATURE

Little has been published concerning nursing care of dying patients in the ICU; however, relevant literature contributes to understanding of the organizational, technological, and ethical context of dying in the ICU. The review of these contextual areas is followed by an analysis of current literature related to nursing care of dying patients and their families. In addition, preliminary research on clinical judgment in critical care nursing (Benner & Tanner, research in progress) that has uncovered several themes which reflect the importance and involvement of nurses caring for dying patients in the ICU will be discussed.

Organizational Context

In the early sixties, Glaser and Strauss (1965, 1968) conducted a comprehensive study of dying in hospitals using grounded theory as a methodology. Many of the examples and specifics in the study are incongruent with today's hospital setting, but current research suggests that the theories which they advanced continue to have relevance.

Awareness

Glaser and Strauss (1965) proposed that interactions between health care providers, dying patients and their families are based on awareness of dying (Quint, 1966). Comatose dying patients were considered more desirable to care for since the nurse did not need to become emotionally

involved, provided the family could be avoided. Changes in care following the realization that a patient was dying involved a reordering of priorities and routines accompanied by physical and emotional withdrawal of the physician. The nurse was allowed to take over care when there was nothing left to do.

Current studies show that nurses are less reluctant than physicians to identify patients as dying and to limit aggressive management (Anspach, 1987; Frampton & Mayewski, 1987; Muller & Koenig, 1988). Differing perspectives of the two disciplines apparently arise from differences in orientation to cure or care (Muller & Koenig) and the primacy of scientific knowing in the culture and social structure of ICU settings (Anspach). These perspectives often result in interprofessional conflict surrounding end-of-life issues.

Hospital Work and Dying Trajectories

Glaser and Strauss (1968) also asserted that the work and organization of various units in hospitals are oriented to different dying trajectories, and that deviations from these usual patterns disrupt the social order of the unit. The ICU was held up as a special case in that not all kinds of dying patients were even allowed admittance or permitted to stay once it was determined that they were dying. Hopelessness was viewed as incompatible with the mission and motivation to save lives. When patients died there, the

usual dying trajectory was identified as quick, with little family involvement.

In synchrony with the cure focus of ICU, patients and families often unrealistically expect discharge to pre-illness condition (Caswell & Omery, 1990). Since the acknowledged workload of the unit is directed toward survival, patients who are dying may be transferred out of ICU. The moral and economical implications of this practice are currently being debated in the literature (Campbell & Field, 1991; Omery, 1991).

Technological Context

Heidegger (1977) defined technology as both a human activity and a means to an end, including: (a) the manufacture and utilization of equipment, tools, and machines, (b) the manufactured and used things themselves, and (c) the needs and ends that they serve. In this and other definitions, 'high technology' refers not only to machines but to the human knowledge and skills involved in their development and use (Ashworth, 1990). Direct patient application of critical care technology includes arrhythmia monitors, physiologic monitors, and special purpose systems such as ventilators, intra-aortic balloon pumps, pacemakers, and intracranial pressure monitors. Although the technological sophistication improves assessment and treatment capacities in nursing care, it has contributed directly to problems such as iatrogenic injury,

overdependence, increased liability, and increased stress (Sinclair, 1988).

Heidegger (1977) viewed the most dangerous threat of technology as the distraction from elemental human concerns and subsequent flattening of perception and understanding. Of primary concern to nurses is dehumanization of care which can occur when patients are viewed as extensions of the equipment (Ashworth, 1990; Marsden, 1991; Sinclair, 1988). Gadow (1985) sees technology as a violation of dignity, removing persons from the center of their experience. This can more easily occur in ICU where patients are often comatose, sedated, or confused (Marsden, 1991). Adams (1986) suggests that although technology supports the scientific aspects of nursing, it threatens the art of nursing, including the interpersonal, social, and nurturing aspects. When the nursing care focus is on machines instead of caring, caregivers as well as patients can become dehumanized, contributing to high stress and 'burnout' (Marsden, 1991; Sinclair, 1988). Ray (1987) described ways that nurses show caring, identified as 'technological caring', in the ICU. In this phenomenological study, nurses explained what caring meant to them, although specific practices were not explicated. Caring was identified as a process of growth, marked by achieving technical competence, developing compassionate relationships with patients and families, and making moral and ethical judgments.

The cure emphasis associated with the high technology environment is inconsistent with dying despite the frequency of death in the ICU (Woods, 1984). Very little research has focused on dying in the high technology environment of the critical care unit.

Ethical Context

The majority of literature related to dying in the ICU is concerned with ethical issues. In addition to the dehumanizing effect of technology, the primary issues identified are related to inappropriate use of technology for prolongation of life, including DNR decisions and withholding/withdrawing nutrition and life support, and allocation of resources.

The Ethics of Everyday Practice

Critical care nurses are constantly faced with multifaceted ethical responsibilities when confronted with human needs and wants in the complex critical care environment (Pierce, 1989). Both patients and practicing health professionals too frequently find themselves caught in moral dilemmas, in which there are conflicting opinions of right and wrong. Nurses are often in the "in-between position" of synthesizing the perspectives of the physicians, the institution, and the patient (Engelhardt, 1985). Although viewed by Yarling and McElmurray (1986) as an untenable lack of autonomy, the in-between position is seen by Bishop and Scudder (1990) as powerful and

privileged, often strategically placing the nurse to promote good patient care. This positive view is based on the assumption that nurses follow the moral sense of nursing and are primarily concerned with the well-being of their patients. The in-between position does not free the nurse from the responsibility for making moral decisions, but it sets up the context in which those decisions must be made (Bishop & Scudder, 1990).

Advocates of the rational approach indicate that ethical situations should be approached using formal ethical reasoning in an attempt to arrive at the ideal solution. Decisions are based on identified ethical principles such as autonomy, beneficence, nonmaleficence, and justice (Krekeler, 1987). Regarding the dilemma of withholding or withdrawing life support, the "correct" solution could vary according to the principle cited. Weir (1989) describes a continuum of positions from extreme "pro-life" options, where abatement of life-sustaining treatment is never justified, to extreme "pro-choice" options, which allows intentional killing as a moral and legal alternative. This continuum incorporates religious traditions as well as numerous ethical positions. Critical care nurses have been encouraged to become more educated regarding formal, theory-based resolution of ethical issues in order to participate in informed, logical and consistent decisions in the clinical setting (Catalano, 1991). Although it can be

argued that people's behaviors are based on some underlying ethical stance, an alternate perspective seems more compatible with the phenomenological tradition. In this view, nursing is a practice with an inherent moral sense (Bishop & Scudder, 1990). Consequently, much of nursing ethics is integrated into everyday practice and comportment and not labeled as moral decision-making.

More central to this study than ethical positions is the moral notion of the good captured by MacIntyre (1984). In his critique of the salient characteristics of contemporary moral disagreement, rival arguments are conceptually incommensurable, (the arguments cannot be weighed against each other; all arguments are logically valid), paradoxically value rational decision-making, and are based on decontextualized concepts which have changed in meaning over time.

MacIntyre (1984) makes two additional relevant contentions about morality. First, he asserts that "the narrative in which human life is embodied has a form in which the subject... is set a task in the completion of which lies their peculiar appropriation of the human good" (p. 175). Morality is revealed through narrative describing human action embedded in culture rather than rational examination. Secondly, MacIntyre views morality in practice as follows:

> "what is distinctive in a practice is in part the way in which conception of the relevant goods and end which

> the technical skills serve...are transformed and enriched by these extensions of human powers and by that regard for its own internal goods which are partially definitive of each particular practice or type of practice" (p.193).

An individual's search for good is conducted within a professional and personal tradition. In this interpretation, the notion of the good inherent in a profession is embodied in excellent practice (MacIntyre, 1984).

Bishop and Scudder (1990) have applied these concepts to nursing practice. They believe that sound nursing practice has an integral moral sense that fosters the good of the patient by excellent nursing care. Nursing is primarily concerned with bringing about its inherent good in the world, not by applying science and technology, but by the practice of caring. Since a practice is founded on the good it is designed to achieve and makes no sense apart from it, nurses "become aware of the moral sense of their practice only when it is replaced or challenged by goals other than the good that health care is designed to achieve" (Bishop & Scudder, 1990, p.33). The current study searched to uncover the notions of good that underlie the caring practices seen in excellent nursing practices. These moral aspects, while difficult to articulate, were revealed in the skilled behavior of everyday nursing practice. The nursing care described and observed reflected the notion of good inherent in the personal and professional being of the nurse and embedded in the culture of critical care nursing.

Inappropriate Use of Technology for Prolongation of Life

Issues of withdrawing or withholding therapy, including DNR decisions, revolve around the actual and perceived moral distinction between the two and related to the technological imperative (Childress, 1986; President's Commission, 1983; Weir, 1989). Withholding and withdrawing treatment are processes by which medical interventions and technology are either never initiated or subsequently discontinued with the expectation that the patient will die as a result (Luce & Raffin, 1988). Common issues in critical care involve withholding or withdrawal of experimental therapy, resuscitation procedures, mechanical ventilation, vasoactive agents which artificially maintain blood pressure and cardiac output, and intravenous and gastric feedings (Fry, 1988; Lynn, 1986; NIH Workshop Summary, 1986; Schneiderman & Spragg, 1988; Weir; Wurzbach, 1990). Although there have been extensive studies and commentaries concerning the decision to withhold or withdraw care, little attention has focused on the care of dying patients once the decisions have been made. Two recent studies described withdrawal of life support in clinical practice. Faber-Langendoen and Bartels (1992) described the range and sequence of medical interventions withdrawn from patients who are hopelessly ill. Wilson, Smedira, Fink, McDowell, and Luce (1992) described administration of analgesics after withdrawal of mechanical ventilation. The process of terminal weaning has

been described anecdotally as a method for discontinuing mechanical ventilation from patients who are hopelessly ill. In this procedure, mechanical ventilation is gradually decreased and sedation is titrated according to symptoms of distress or discomfort (Campbell & Carlson, 1992; Grevnik, 1983). However, this method is not universally practiced or supported (Faber-Langendoen & Bartels, 1992; Schneiderman & Spragg, 1988). Other issues related to administration of sedation during withdrawal of life support include the use of high doses of narcotics and paralytic agents after extubation (Schneiderman & Spragg).

The DNR literature deals both with issues surrounding advance directives and the decision either not to resuscitate in the event of cardiopulmonary arrest or not to continue maximal therapeutic efforts. Topics regarding DNR decisions include characteristics of DNR patients (Keatinge, 1989; Schwartz & Reilly, 1986; Tittle, Moody, & Becker, 1992; Witte, 1984), types of DNR designations and their implications (Anderson, 1988; Paris, 1982), and the meaning and impact of the DNR decision (Lewandowski et al., 1985; Luce, 1990; Shelley, Zahorchak, & Gambrill, 1987).

The issue most relevant for this study is the process of making the DNR decision. The President's Commission (1983) has made recommendations regarding appropriate implementation of DNR orders in health care institutions. Although the literature, including the report cited above,

promotes collaborative decision-making between patient, physician, and family, studies show surprisingly little involvement of family and even less of patients in the process (Blackhall, Cobb, & Moskowitz, 1989; Jonsson, McNamee, & Campion, 1988). Communication often involves misunderstanding of meanings resulting in uninformed decision-making and lack of cohesive and consistent treatment plans (Nolan, 1987). The situation becomes even more complex in ICU where patients often are unable to participate in any decision-making and families act as surrogates (Brennan, 1988; Marsden, 1990; Moskowitz & Moskowitz, 1986). The role of the nurse regarding DNR decisions remains unclear. There is controversy whether nurses should focus on advocacy, that is, assisting patients and families with values clarification and then supporting the resulting decisions, rather than expressing an independent position based on moral beliefs, ethical positions, and clinical knowledge (Anderson, 1988; Bishop & Scudder, 1987; Gadow, 1980, 1989; Luce, 1990; Pierce, 1989).

Allocation of Resources

Allocation of critical care resources is currently a highly debated issue driven by ethical arguments concerning economic rationality. In this controversy, respect for individuals is at odds with the moral obligation to discontinue care that harms others, including wasting resources (Callahan, 1987; Childress, 1986). Research has

focused on development of criteria and classification systems for predicting critical care outcomes and making bed-utilization decisions (Bellamy & Oye, 1987; Engelhardt & Rie, 1986; Ewer, Ali, Atta, Morice, & Balakrishnan, 1986; Lemeshow, Teres, Avrunin, & Pastides, 1987; Luce, 1990; Raffin, 1989; Shedd & Whedon, 1991). The most common scoring systems for determining who is most likely to benefit from critical care are the Therapeutic Intervention Scoring System (TISS) and Acute Physiological and Chronic Health Evaluation (APACHE) scales (Keene & Cullen, 1983; Knaus, Draper, Wagner, & Zimmerman, 1985). Some nurses argue that dying patients who need intensive nursing care should remain in the ICU despite projected outcomes if death with comfort and dignity requires the resources available there (Caswell & Omery, 1990; Omery, 1991); others have developed cost-effective, alternative care systems to facilitate transfer of dying patients to a more "respectful, dignified, private" environment (Campbell & Field, 1991, p.345).

Nursing Care of Dying Patients and Their Families in ICU

Very little research has been published related to nursing care of dying patients and their families in critical care. Studies related to the nursing care of dying patients in other settings may not be applicable for nursing care in ICU's. A few anecdotal articles have been written describing nursing care of dying patients in critical care.

These have been primarily case studies focused on moral concerns or decontextualized discussions prescribing care for dying patients. Only three studies have been published on the topic of nursing care of dying patients in critical care. Beyond those studies, understanding of the demands of the care must be extrapolated from research describing nurse stress and family needs in critical care.

Direct Care of Dying Patients

Tittle et al. (1992) examined the differences in demographic characteristics and nursing care requirements of 62 DNR patients and 62 randomly selected non-DNR patients in the critical care units of three community hospitals. The research design was an ex-post facto, prospective study. All patients designated DNR during the data collection period were included in the study. When a DNR patient was admitted into the study, a random non-DNR patient was also admitted. Nursing care requirements for patients were measured daily using the Medicus Nursing Productivity and Quality System (NPAQ) to classify patient acuity for nursing staffing. Severity of illness was also determined daily using the Acute Physiology and Chronic Health Evaluation (APACHE II) scale. Data were analyzed using the chi-square test and scatterplots. Results showed that subjects with DNR orders required more nursing care than the non-DNR subjects, even at comparable levels of severity of illness. DNR patients received significantly more nursing care after

the DNR order was written than before, and the length of their ICU stay was significantly longer. The study also identified descriptive characteristics of DNR patients and described DNR orders.

This study quantified and compared the nursing care of DNR and non-DNR patients in critical care. The NPAQ and APACHE II scales used to analyze the nursing care requirements and severity of illness are proven instruments and validity was reported. However, there are limitations in using this methodology to describe nursing care. There was no attempt to explicate the specifics of the care given by the nurses. Because of the lack of contextual detail, the researcher was unable to elaborate on the nature of the differences in care or explain why patients with DNR orders received more nursing care. Although this study quantified specific factors, it failed to describe actual care given to DNR patients.

Caswell and Omery (1990) reported results of a retrospective chart audit of an unspecified number of DNR patients who died in the ICU over a two year period. The purpose of the study was to develop a plan of care for dying patients in ICU, so patients with sudden death were excluded from the sample. Defining characteristics of patients who died included: septic, comatose, coagulopathy, renal failure, and unresponsive. These characteristics along with ongoing medical treatments were used to determine the tasks

that nurses were responsible for in caring for these dying patients. Nursing documentation, including flow sheets and the nursing care plan, was used to determine the nursing goals for the patients. The most commonly identified goal was "maintenance of comfort and dignity throughout the dying process." Two additional goals, "maintenance of fluid and electrolyte homeostasis" and "maintenance of respiratory function" were subsumed under the broader first goal (Caswell & Omery, p. 183). General categories of nursing intervention identified included pain control, hygiene, family care and post-mortem care. As a result of this study, a new nursing diagnosis, Terminal Syndrome, was proposed.

Although Caswell and Omery (1991) attempted to describe nursing care of dying patients as a model for practice, the methodology used, retrospective chart audit, has some limitations. The use of medical records to describe practice assumes nurses document everything they do. Quite to the contrary, it could be argued that much of clinical practice could not be reflected objectively on a flow sheet or care plan. Rather, the particulars of how nurses individualize care for a patient in a particular context, which may be the essence of nursing practice, cannot be found on the chart. In addition, the retrospective audit does not take into consideration the importance of the awareness of dying. In this study, the DNR order need only

have been written 24 hours prior to the patient's death, and the link between the time the order was written and the time period the data represents was not clear. The fact that nurses become aware of the patient's dying prior to physicians has been well documented. Much of the nurse's role in caring for dying patients may be advocating for the DNR or withdrawal of medical therapy (Benner & Tanner, research in progress). In any case, nursing care may change with awareness of impending death, whether or not a DNR order has been written. In order to apply the study results, the context of the care needed to be more clearly explicated.

Lewandowski et al. (1985) studied 506 patients admitted to a medical ICU over a one year period of time to determine the levels of resource consumption of DNR patients, the impact of the DNR order on withdrawal or initiation of life-sustaining and nursing interventions, and survival of DNR patients. Patient care categorization (PCC) scores were used to quantify nursing care requirements of DNR patients in categories of physical dependency, observation required, social/emotional, and rehabilitation/teaching. Analysis of grouped data compared the mean PCC scores for 3 days prior to and after the DNR designation using a signed-rank test. Results showed that DNR patients required more nursing care than all the non-DNR patients. Designating a patient DNR did not alter the amount of nursing care required. The only

category of care that decreased after the DNR designation was observations required, and the reduced level was still in the high to intense range.

This study quantified nursing care of dying patients as a way of measuring resource consumption, but did not attempt to describe the care or the context in any detail. Although the instrument (PCC) had been extensively used in the institution for approximately 7 years, no reliability and validity data were reported. In using data of this type as a basis for policy making and ethical decisions, the researchers concede that it is not possible to comment on the appropriateness of aggressive treatment or care of DNR patients. Although conclusions were drawn regarding the amount of nursing care given, the particulars of that care were not included.

Nurse Stress

Caring for the dying patient has been identified as a cause of job stress and dissatisfaction in studies of critical care nurses. In one of the original studies describing stress in critical care nurses, Huckabay and Jagla (1979) surveyed 46 critical care nurses from six hospitals to identify work related stressors. Out of 16 factors ranked, death of a patient ranked second (to workload and amount of physical work). The investigators thought this finding was related to lack of knowledge, since many schools of nursing did not include concepts related to

death and dying in their curriculum. Subsequent studies have continued to show that death and dying situations are very stressful for critical care nurses (Anderson & Basteyns, 1981; Chiriboga & Bailey, 1986; Cooper & Mitchell, 1990; Foxall, Zimmerman, Standley, & Captain, 1990; Gentry & Parkes, 1982; Kelly & Cross, 1985; Spoth & Konewko, 1987; Stehle, 1981; Vincent & Coleman, 1986).

Other studies have focused specifically on describing the experiences and feelings of critical care nurses caring for dying patients. Field (1989a, 1989b) observed and interviewed 18 nurses on a coronary care unit over a 3-month period. Although the method of analysis was not specified, conclusions were supported with excerpts from the text. Both "quick deaths" and "slow deaths" were reported on this unit. Although the organization of the nursing work facilitated involvement and open communication among nurses, patients, and families, and the emotional cost of involvement was high, dying experiences tended to be most often positive because of the supportive nursing organization. Death was not seen as a failure, but it was important for the nurses to believe that everything possible had been done for the patient. Working with relatives was identified as emotionally more difficult then giving support to the dying patient.

Cooper and Mitchell (1990) studied 117 nurses to describe and quantify the stressors faced by nurses involved

with care of critically and terminally ill patients. The researchers also attempted to identify job stressors and demographic characteristics predictive of job satisfaction and mental ill health. Both hospice and hospital nurses, including critical care nurses, were included in the sample. Management/organization factors related to caring for critically ill or dying patients were less stressful to nurses than emotional factors of coping with patients and their families and the impact of the job on their own home environment. Multivariate analysis showed that hospital based nurses dealing with death and dying were significantly more dissatisfied with their job than hospice nurses. Depression in the hospital sample was related to staff support and involvement in decision-making, the nature of the final relationship between the nurse and patient, greater age, lower status, and home problems.

Two phenomenological studies described the moral dissonance and emotional struggles of nurses caring for dying patients in the ICU. Rodney (1988) studied nurses' ethical perspectives on caring for dying patients in the critical care setting. The major theme identified was senselessness, which was related to the conflicts and ethical dilemmas of decision-making, the experience of patients and families, and the nurse's own activities. She found that nurses dealt with these issues by shifting the focus of their care to making the patient comfortable,

supporting family members, and using the experience to develop their personal moral philosophy by finding or creating new meanings in the situation.

In another study, Borozny (1990) attempted to understand, from the perspective of the ICU nurse, the experience of providing care to the brain dead patient awaiting organ donation. Dissonance was the major theme. Personal dissonance occurred regarding reconciliation with what their philosophy of nursing was in giving care to brain dead patients, conflicts concerning what type of care was appropriate, lack of acceptance of the diagnosis/prognosis, lack of internal harmony concerning the procedure of organ retrieval and transplantation, and conflicting responsibilities for supporting the family taking care of their own emotional needs. Interpersonal dissonance occurred when the nurse's beliefs, values, opinion, knowledge or behaviors opposed those of the family, physicians, or colleagues. Initially, nurses often continued to have a relationship with the brain dead patient, wanting to humanize care and facilitate a dignified death. However, their dissonance often resulted in personal distress, which caused them subsequently to distance themselves from the patient and focus care on the family.

Family Needs

Although many studies have been reported describing family needs in ICU from the perspective of both nurses and

family members (Bouman, 1984; Daley, 1984; Leske, 1986; Molter, 1979; Norris & Grove, 1986; O'Malley et al., 1991; Rodgers, 1983), none have focused on special needs when the patient is dying in ICU. Most of the studies are based on an instrument developed by Molter or a modification of that instrument (Leske, 1986; Norris & Grove; Spatt, Ganas, Hying, Kirsch, & Koch, 1986). Needs identified using these instruments can be classified according to the following conceptual categories which represent ways that nurses serve as a resource for family members: information, emotional support, empathy, family visit, family-staff relations, and support resources (Simpson, 1989). In all studies, information needs were most frequently identified as one of the most important needs (Hickey, 1990). Molter's instrument has been shown to have acceptable internal consistency (Leske, 1991a; Mathis, 1984; Norris & Grove; Rodgers), content validity, and test-retest reliability (Macey & Bouman, 1991). The only needs assessments of special populations in critical care units have been with families of comatose patients with acute brain injury (Mathis) and families of patients receiving respiratory support (Riggio, Singer, & Hartman, 1982).

Since there is a high level of agreement among studies concerning general family needs in the ICU, the challenge currently is to design intervention studies focused on identified needs. Existing intervention studies have

described and evaluated crisis intervention plans (Hodovanic, Reardon, Reese, & Hedges, 1984), support groups (Halm, 1990; Sobo et al., 1989), and educational/orientation programs (Chavez & Faber, 1987). However, it has been difficult for researchers to specify interventions and evaluate the outcomes since family needs are complex, multidimensional phenomena (Leske, 1991b) and contextually embedded. To date, studies have not demonstrated the effectiveness of specific interventions to meet selected needs (Simpson, 1989). No studies have been reported describing bedside care of individual families. In summarizing the interpreted results of the study by Benner and Tanner (research in progress), Chesla (1990) reported that expertise in family care was the exception in adult ICUs, but was most common in narratives in which the patient's death was imminent. Anecdotal articles describe working with families of dying patients, but no additional studies have been reported.

In summary, only three studies have specifically addressed the nursing care of dying patients and their families in critical care. Two of these quantified nursing care of DNR patients. The other study was a retrospective chart audit used to develop a nursing care plan. Research related to nurse stress in caring for dying patients and family needs in critical care provide some understanding of the demands involved in nursing care of dying patients.

Preliminary Study

This research project has evolved from a broader study of the development of expert clinical judgment in critical care nursing practice (Benner, Tanner, & Chesla, 1992). The researcher was a research assistant in all phases of this preliminary study on clinical judgment. This researcher's own interpretation of the data related to nursing care of dying patients and their families, which is reported below, helped to focus the current study.

The purposes of the parent study were: (a) to describe characteristics of beginning, intermediate and expert clinical judgment in nursing, (b) to document areas of advanced clinical knowledge used as the basis for clinical judgment, (c) to document the degree of accuracy of expert recognitional abilities, and (d) to develop instructional materials which could be used to enhance expertise in clinical judgment. For this phenomenological study, 130 nurses in the intensive care units of eight hospitals in three metropolitan areas were interviewed to obtain narrative accounts of their experience. Forty-eight of the nurses were observed in their practices. The data revealed nursing practices during death and dying as a dominant data category. Preliminary interpretation of these data resulted in explication of themes related to the dimensions of care, background that particular nurses bring to the situation, and issues in practice.

Dimensions of Care

Nursing care of dying patients included assessment of comfort and appropriate intervention, emotional support, orchestrating the details of the death, including communicating with physicians, and family care.

Expertise in Care of Dying Patients

Despite the extensive collection of stories related to death and dying in critical care, examples of direct nursing care of dying patients were rare. The following narrative is an excerpt from a paradigm case that embodies the research team's beliefs regarding expertise in critical care nursing of dying patients. This story is told by a nurse recognized as an expert in caring for dying patients by her peers. The patient was a young man with liver failure admitted for a transplant. It turned out that he was too septic for the procedure, and he deteriorated quickly. His wife fought hard for the transplant, but finally realized that it wasn't going to happen for them.

> And when I got there I didn't do too much for her. You just put your arm around her and ask her if there's anything she needs. And right away she started telling me what she needed was to be able to get in bed with him. First she went and talked to the doctor and called her family and had them bring her nine year old son in. And then she came back in and I had already moved him over. I didn't do very much. I talked to the ICU doctors to make sure that this wasn't going to get prolonged. We got orders for medications and they said extubate him if she wanted that. I asked her if she would like to have the tubes taken out of him and she said yes. So we disconnected all the IV's except one and took almost everything apart, moved him over, put a blanket there for her to lie on. They came in and extubated him while she was there and she got in

> bed with him and held him for about an hour until he died. It's funny how he looked so calm. His heart rate stayed the same and his blood pressure was pretty OK until his nine year old son came in. His brother and his mother and everybody had been coming in and out. Then the son came in and started crying and hugged his dad and he took his last breath and he just died, just like that, with his son there.

Characteristics of this nurse and her care that stand out as expert include her sensitivity to and awareness of the meaning and nuances of the situation to the patient and family. This is evidenced by the way in which the nurse understood the wife's need for physical closeness with her dying husband, allowed the family relative freedom to be in the room, and timed getting orders and withdrawing medications and equipment with the wife's readiness. In another segment of this narrative, the nurse discussed assessment of comfort, even in this unconscious patient, and skillful use of medication; "He didn't need much. He was ready anyway." (239) She created a space for the death by physically making a place for the wife, removing tubes and equipment, and by orchestrating the time sequence. She maintained appropriate involvement by staying in the background yet maintained supportive communication with the patient's wife weeks after the death event until the relationship was no longer necessary.

Emotional Support of Patients

Most patients dying in the ICU are unconscious, yet some nurses engage in a variety of activities such as touching, praying, holding, and singing (in the case of a

child), talking to them, and encouraging or giving them permission to die. In one group interview, a nurse described how she routinely would go into the room of unconscious patients who were struggling with dying, close the door, and "get right down in their face" and tell them that it was alright to die. Other nurses around the table were amazed, admitting that they did the same thing, but didn't know that anyone else did.

Family Care

Although some nurses focused primarily on the patient and kept family at a distance, even seeing them as an intrusion, others facilitated the presence and involvement of the family during the dying process. In some circumstances, the family became the focus of the care: "And the primary concern, really, was her. Because we couldn't do anything more to help him".

Within the context of the ICU, nurses enabled family's physical and emotional access to the ill family member; they provided perspective for families by helping them to understand the patient's condition and implications; and they supported family coping and integrity (Chesla, 1990). The following is an example of a nurse's efforts to teach a woman about her husband's condition after he suffered a subarachnoid hemorrhage. Although it focuses on helping the wife to understand the patient's status as a basis for decision-making, the episode also reflects how the nurse

facilitated the wife's position at the bedside and supported their integrity as a couple.

> I tried to be honest. She was looking at less than 50/50 odds. Maybe 20-30% survival. And, she asked me how will she decide what to? And she really asked a lot of questions over and over about different things we were doing....And I let her spend lots of time with her husband, answered every question, talked about all different things. She practically interviewed me about all different things and what I felt about... I tried to tell her about every piece of equipment that was on him, everything I was giving him so she would know exactly what was required, what I can do for him, what's necessary, what is actually keeping him alive. I tried to make her feel free to have as much time with him as she needed and have contact with him. And she was able to make the decision. She would leave things as they were as far as intervention that we were doing.

In addition, the nursing care of the patient was enriched as the nurses learned about the patient as a person through the family, were motivated by the family's concerns, and included family members in the care as a source of support and comfort for the patient (Chesla, 1990).

Background of Nurses

Nurses came to each death as individuals with unique yet common understandings and feelings regarding ethical and moral issues surrounding death in the ICU and an opinion about what makes a "good death".

Moral Dilemma/Notion of the Good

Most of the data on death and dying focused on ethical issues. Nurses expressed much frustration and despair related to situations where they perceived senseless suffering. Most commonly, issues in which there was

conflict with physicians concerned continuation of treatment. An example involved the treatment of a baby following cardiac surgery who didn't do well from the start. It was decided that the baby would be placed on an extracorporeal membrane oxygenator (ECMO) as a last effort to save her life:

> "...immediately she starts pouring blood out of everywhere, just a mess. We did this for two days. We ECMOized this kid and the nurses all knew that this was ridiculous what we're doing. And we must have replaced her blood volume 40 times in the first, in those two days, and her kidneys shut down and they put her on hemofiltration...And we're saying 'Why? Why are we doing this?'...This kid's not going to make it and they just won't accept that."

Concept of a Good Death

The narrative cited earlier about the patient with liver failure also reflects the interpretation of good death in critical care. Good deaths were described as those with dignity. These occurred when the patient was allowed to stay in the ICU to die under the care of familiar nurses, as opposed to being transferred to another unit, when the medical staff did not 'flog' the patient (a term commonly used to describe senseless continuation of care), where equipment was discontinued, facilitating comfort, and physical contact with the family. A good death was described as peaceful and comfortable, with the family in attendance.

Issues in Practice

Clinical situations were identified in which a

particular understanding of the clinical reality affected nurses' attitudes and their care of dying patients. The two described below are related to the nurse's interpretation of the patient's clinical status and aspects of intuition and embodied knowing.

Early-warning/Awareness of Dying

Nurses reported early recognition of downward trajectories that would result in death. They were not always able to communicate the urgency of these situations to physicians and then often blamed themselves when the patient did not get timely intervention. In the following excerpt (Benner & Tanner, research in progress), an elderly woman who was first day post-op for an abdominal aortic aneurysm repair began a downward trajectory:

> I had a sense of what was going on and I looked at the patient and there were two things that I noticed right off. One that her abdomen was very large and very firm, and the other thing was that her knees were mottled, and I said, "She has a dead bowel."

The nurse tried to convince the staff that the woman needed to return to surgery, but the attending physician could not be reached and the house staff did not understand the urgency of the situation. The patient quickly decompensated and died:

> I said, "This woman is going to die." And as I'm saying this, the family needs to know. Someone better go talk to the family now...I was very sad, very angry because I felt that I was giving them every clue that they could have to make a decision about this woman...I really think at times they see with different eyes than we do. And the

> attending had come in and said...they were thinking that it was just part of the patient's recovery and they were having a rocky recovery course.

When the Patient is "Already Gone"

Critical care nurses sometimes reported an intuitive sense of unconscious patients being "in" or "out" of their bodies. When a patients were "out" of their bodies, it was understood that they were already dead. This impression of the presence of the patient as a person influenced how the nurses interacted with the patient and their opinions regarding discontinuing treatment and allowing the patient to die.

In summary, preliminary interpretation of these data pointed out that there is practical knowledge embedded in expert nursing care of dying patients. Although dying was identified as an emergent theme within the broad perspective of the clinical judgment study, a focused study was needed to further describe and understand nursing care of dying patients and their families in critical care. The design of the parent study was incorporated into the current study, including particular phenomenological methods and interpretive strategies. Data from the parent study conceptually influenced and supported interpretation of data from this study.

Summary

The literature specifically describing the nursing care of dying patients in critical care is sparse. Literature

related to the organizational, technological, and ethical context of death in critical care was reviewed. Early studies of dying in hospitals suggested that interactions between health professionals and dying patients in hospitals was related to awareness that the patient was dying and contingent on the work and organization of the particular hospital unit. In critical care, the focus was identified as cure and the dying trajectory as quick. Literature related to technology viewed it as dehumanizing and a threat to caring. The majority of literature related to dying in ICU was related to ethical issues, specifically use of technology to prolong life and allocation of health care resources. The moral tradition of nursing and the role of the nurse in decision-making were also discussed.

There were three studies in the literature specifically related to nursing care of dying patients in critical care. Two studies quantified nursing care of DNR patients for the purpose of informing the question of resource allocation. The other study was a retrospective chart audit describing nursing care of dying patients to develop a plan of care. Research on nurse stress identified death of patients as a source of job stress, dissatisfaction, and moral distress for critical care nurses. Although there was no research specifically describing needs of family members of dying patients, several studies reported lists of family needs, which were subsequently used as the basis for intervention

studies.

A preliminary study on clinical judgment in critical care nursing which focused the current study was described. In this preliminary study, nursing care of dying patients was identified as an area of expertise in critical care nursing practice. Specific caring practices were described, and the family identified as a focus of care. Notions of a good death as well as ethical concerns were cited. Clinical situations were identified in which the effect of the nurses' interpretation of the patient's clinical status influenced their attitudes and care.

CHAPTER III. METHODS

The method chosen for this study was interpretive or hermeneutical. This method best facilitated understanding of the practices and meanings of caring for dying patients in critical care in the context of the clinical world and our larger cultural tradition.

Philosophic Assumptions of the Research Approach

The interpretive method used in this study is based on Heideggarian phenomenology as applied to nursing and explicated by Benner and Wrubel (1989). Hermeneutics is based on a unique view of humans which is wholistic, that is, it goes beyond the representative Cartesian view of the mind-body split (subjective-objective dialogue) to recognize and actualize a view of humans as integrated beings who are part of their world. Although the technological view is appropriate for study of nonhuman objects such as diseases, the phenomenological model reveals the meaning and embeddedness required for understanding of human phenomena. In this section, aspects of the phenomenological view of humans is described and then discussed in relation to a situational model of expertise that is incorporated into the study.

View of Humans

Selection of hermeneutics as the method for studying nursing care of dying patients required certain assumptions regarding what it means to be human. These ideas were drawn

from Heideggerian phenomenology and the interpretation of Heidegger's early works by Dreyfus (1991). In this view, ontology precedes epistemology. The answer to the question of being is primary and leads to knowing and understanding (Benner & Wrubel, 1989). This view redefines the role and methods of inquiry in human science. Understanding of humans can be best achieved by becoming involved in the pre-reflective and context embedded situation. However, even in these best of circumstances, the lived world can never be made completely explicit (Leonard, 1989). Aspects of the phenomenological view of humans discussed includes background meaning, practical knowing, concern and involvement, and context.

Background Meaning

Background meaning is a personally held but culturally derived sense of reality which is taken for granted and transparent (Wrubel, 1985). People are born into a culture made up of a meaningful set of relationships, practices, and language (Leonard, 1989) and are situated in the world. Humans are part of a culture, a subculture, and a family (Benner & Wrubel, 1989). For example, an ICU nurse comes to the bedside with a unique personality and style, culturally and genetically determined by growing up in a family and community. The nurse also understands and operates within the societal view of dying, that is that death is to be avoided, and the approach and attitudes towards death and

caring for dying patients and their families in the particular ICU. These meanings are often so much a part of the practice that nurses are oblivious to their content, yet they shape perceptions and as such are an integral part of the skill and comfort with which nurses function in their everyday world; they are in the background. As such, people live through their background meanings (Chesla, 1988).

Human beings constitute and are constituted by their world (Benner & Wrubel, 1989). Although unable to be made explicit, these meanings set up individual possibilities and limitations. They are a powerful force in shaping personal identity and daily interactions in the world. While every person may constitute the world in their own particular way, there are aspects of the world that people have in common, shared meanings by virtue of communal participation in the collective culture and world (Leonard, 1989). One example involves conversational distance. In the shared American culture there is an appropriate distance to stand from a conversational partner. If the principle is violated, the interchange has new meaning. For example, it may be interpreted as intimate or secretive, or the interchange may become intrusive and uncomfortable. The knower understands and responds to this immediately and without thinking. Distance is not an issue unless violated; it remains in the background until challenged.

Based on this view, problems defined in science

concerning the relationship of the knower to the known, subject to object dissolve. Within the hermeneutic circle of interpretation, subjects and researchers are both already in the world (Leonard, 1989). Subjects may not be able to explicate meanings but will be unable to escape them. Human action can then be interpreted by researchers who seek understanding and who share common cultural aspects. The concept of shared background meaning redefines the relationship of the researcher and subject. Meanings can be inferred based on a shared culture between the researcher and the subject. Objectivity is neither an issue nor is it possible in this paradigm.

Practical versus Theoretical Knowing

Heidegger (1962) describes three modes of involvement in a situation: ready-to-hand, unready-to-hand, and present-to-hand. In the ready-to-hand mode, equipment and actions are unnoticed and automatic; functioning is smooth and unconscious. For example, a critical care nurse titrating vasoactive drugs may observe the physiological monitors and perform discrete adjustments of medications without much thought. In the unready-to-hand situation, in which something goes wrong and is noticed, a blood pressure or heart rate may exceed high or low limitations, and an alarm sounds, bringing the situation to the attention of the nurse. In the present-to-hand mode a person assumes an outside-in, analytical stance; the nurse examines the alarm

to verify the presence of a problem, then decides how to adjust the drugs based on theoretical knowledge of their actions. The titration of the medications remains in the background until a problem arises. Practical knowing, or ready-to-hand functioning, is the primary way of being in the world and is acquired over time through a culturally skilled body (Benner & Wrubel, 1989).

A basic understanding in phenomenology is that people's bodies as well as their minds are knowers; humans are truly beings with mind-body unity having the capacity to be in a situation in meaningful ways. Embodiment makes it possible to live in the world non-reflectively (Benner & Wrubel, 1989). This conception clarifies the distinction between wholism, where the mind and body function in unity, and multidimensionality, in which the person is divided into physical, psychological, social, and spiritual components. The whole is truly greater than the sum of it's parts (Benner, 1984).

Although skilled (practical) knowing has commonly been regarded as less than theoretical knowing, it is in fact fundamental, and precedes "higher" forms of human intelligence and cognitive functioning (Benner & Wrubel, 1989). For example, a person can't study theory until they can read. Reading, once learned, is a pre-reflective skill. It remains automatic and unconscious unless difficulty arises, such as encountering new words or a foreign

language. However, people rely on and "live through" that skill many times daily without thinking about it or talking about the rules of reading. In the same way, critical care nurses report knowing when patients are going to deteriorate precipitously. They act on these judgments, yet are often unable to give objective data to support this "gut feeling" (Benner, 1984; Smith, 1988).

Embodied intelligence can be described as a back and forth interplay between knowing and doing. As practical knowing it is invisible and implicit (Benner & Wrubel, 1989; Dreyfus, 1991) as well as ineffable (Polanyi, 1964). In this mode, people perform tasks and skills without awareness of the details of the performance. For example, in driving a car an experienced driver sometimes daydreams, unable to recall the mechanics of driving and the surroundings for a short period of time. Yet smooth functioning continues; the car safely maneuvers down the road. It allows one to meet the contingencies of a technical or social situation and continue to function (Chesla, 1988). It underlies smooth functioning and automatic living. Embodied intelligence is used when a nurse inserts an intravenous (IV) catheter into a vein. The nurse uses sensations/knowledge from her hand as well as that which is in her head to implement the procedure. Explaining the nuances of the skill is difficult since, by definition, the quality is lost in reflection.

Theoretical knowing occurs when a situation is

considered in an abstract way, with aspects of it separated out for examination (Dreyfus, 1991). However, situations don't come to an individual's attention as problems for analysis unless there is breakdown in the smooth functioning involved in practical knowing. In fact, if a person tries to think about something they usually do practically, the overall performance falters, as in the example of starting an IV. Reflection causes breakdown and disruption of the activity (Polanyi, 1964). For example, in explaining or teaching a skill, the process may not go as well as usual, or the nuances that would really allow another to achieve the right feeling for the skill seem inexpressible. Heidegger even questions the desirability and possibility of making everyday assumptions explicit (Dreyfus, 1991).

Concerns and Involvement

The meanings of dying are embedded in our culture: the critical care culture, personal/family culture, and the overall cultural tradition. Background meanings set up what matters. The concerns that arise for nurses caring for dying persons are influenced by their background meanings and shape care practices.

A person is a being for whom things matter. And because things matter, people become involved in their world. Heidegger (1962) calls this way of being involved "concern". People have qualitatively different concerns based in culture, language, and individual situations

(Leonard, 1989). A person cannot plan their involvement or concern, but rather it is solicited by the meaning of the situation for the self. This meaning is directly apprehended, because people inhabit their worlds in an involved rather than subject-object way: people are constituted by their worlds and are solicited by them (Benner & Wrubel, 1989).

Concerns set up what is salient about a situation, what stands out as needing attention (Benner & Wrubel, 1989). This involvement guides practice. In a particular situation, one nurse may notice the need for the family to be at the bedside and readily involve them in a meaningful way; another nurse may never recognize their needs, or may choose to enforce visiting hours and send them to the waiting room.

Context: The Role of the Situation

Context describes all the ways a person is connected to the world, including temporality. Background meaning and concern are also embedded in context in such a way that the person and the situation define each other (Benner & Wrubel, 1989). Within this interpretation, events, behaviors, meanings, or concerns cannot be decontextualized. To understand a person's behavior or expressions, the person must be studied in context, for it is only there that what a person values and finds significant is visible (Leonard, 1989).

Real world contexts change over time, affected by events, maturation, and relationships. Within new contexts, previous background meanings, habitual body, and concerns no longer allow for smooth functioning. Breakdown occurs, stimulating awareness and reflection on the situation (Benner & Wrubel, 1989). New contexts of technology create shifts in everyday functioning in critical care and nurses must re-orient to deal with them. Respirators, intra-aortic balloon pumps, and pacemakers have all created new contexts and questions surrounding even the definition of dying. New technology mandates new formulations of reality. Conflicts that nurses have regarding care of dying patients are of interest in that these point out areas in which there is lack of situatedness and where new understandings are evolving.

Situational Model of Expertise

Within traditional rationalistic conceptions, expertise is understood as the accumulation of theory and the ability of an individual to put that theory into practice. Consistent with the Heideggarian view of a person as culturally embedded and the primacy of practical knowing, the phenomenological perspective is that theory must ultimately rely on intuition when it touches reality (Dreyfus, 1987). In this sense, expertise is derived from experience with enough related situations to provide a basis for the level of qualitative distinction required to support

immediate, intuitive responses. The nurse who is an expert in caring enters into the situation of the patient and is guided by involvement rather than detachment (Dreyfus, 1987). The particulars of participation in the clinical reality are based on and exemplify practical knowledge.

Practical knowledge is developed over time as the result of many clinical experiences. Practical knowledge cannot always be explained by science, but it is embedded in the everyday caring activities of practicing nurses. As such, it can be best understood by studying caring practices of expert nurses in the clinical context. The experiences that comprise clinical learning and practical knowledge in nursing practice are actual clinical situations, and these are the narrative focus of hermeneutic interpretation (Benner, Tanner & Chesla, 1992).

Overview of the Research Approach

A qualitative design using interpretive phenomenological methods was used to study the caring practices of nurses caring for dying patients in ICU. Hermeneutic methods study lived experience as way of understanding practical knowing (VanManen, 1990). Clinical practices are not easy to access because often people live through them and don't or are unable to explicate them. Asking nurses to discuss or evaluate their care of dying patients would give an incomplete picture. Analytic discussion bypasses practical knowing and eliminates the

possibility for understanding (Benner, 1984). Studying the lived experience involves dense description of situations and observations as a basis for interpretations of background meaning and interpersonal concerns driving action (Benner & Wrubel, 1989; Packer & Addison, 1989). Interpretive analysis, or hermeneutics, based on Heideggerian phenomenology, is a systematic approach to making sense or deriving meaning from the text or text-analogues generated (Taylor, 1985).

Data were collected in four phases: (a) group interviews of critical care nurses, (b) clinical observation of dying events, (c) intensive interviewing of key nurse informants, and (d) interviewing bereaved family members. Interviews and observations were tape recorded and compiled in transcripts. Background meanings and interpersonal concerns were derived from interpretation of lived experiences of nurses caring for dying patients and bereaved family members to develop understanding of this area of practice.

Sample

Critical care nurses experienced in care of dying patients were key informants, functioning both as models of good practice as well as facilitating entree into the clinical setting for bedside observation and for introduction to families. Fifteen registered nurses participated as key informants in the study. Thirteen were

women, two men. All were of caucasian descent. Ages ranged from 27 to 44 years of age. Nine held bachelors degrees in nursing and the remaining six graduated from a diploma or associate degree program. Experience in nursing ranged from 4 to 22 years, and in critical care from 2 to 22 years. See Table 1 for a description of the sample for each phase of the study.

Table 1

Sample for Each Phase of the Study

	N of Sample			
Study Phase	Key Informants	Secondary Nurses	Dying Patients	Family Members
Phase I Group Interviews	15	6	65	NA
Phase II Observations	7	6	8	7
Phase III Intensive Interviews	7	NA	8	NA
Phase IV Identified from group interviews	NA	NA	4	5
Identified from observations	NA	NA	3	3

Group Interviews of Critical Care Nurses

In phase I, nurses were nominated for participation in the study by nurse managers and participated in group interviews. The criteria for nomination included a minimum of five years experience in the ICU, a criterion for expertise consistent with Benner's model of development of expertise in nursing (Benner, 1984) and the preliminary study design (Benner, Tanner, & Chesla, 1992), and demonstrated expertise in caring for dying patients. Indicators of expertise included interest and comfort in caring for dying patients, the ability to get involved and work well with both patients and families, and demonstrated technical proficiency.

Five nurses nominated had less than five years experience in critical care nursing. However, in all cases the nurse had close to five years experience in nursing and showed particular expertise in care of dying patients, so the criterion for five years experience in the ICU was waived and the nurse was invited to participate in the study. This was based on the understanding that nurses gained experience in care of dying patients prior to critical care. In addition, the researcher gave the nurse managers three clinical exemplars from the preliminary study which together exemplified the identified dimensions of expertise in care of the dying patient and asked for nomination of nurses whose practices seemed similar. This

nomination strategy worked best if the nurse managers approached the nurses they wanted to nominate and received their permission to submit their names to the researcher. On one unit, the nurse manager felt uncomfortable recruiting the participants since she perceived that nursing care of dying patients was a difficult topic for the nurses to discuss. Nurses were recruited on that unit through inservices given by the researcher in which nurses nominated themselves or their peers. Nominees were contacted initially by letter, then by phone. Three nurses who were nominated declined to participate in the study.

Clinical Observation of Nurses Caring for Dying Patients

Phase II involved observations of the nursing care given to eight dying patients over a period of six months. Although the original study design designated that six expert nurses would be chosen for observation based on their expertise and reliability, the plan was changed when it became apparent that this approach would extend the observation period by several months. The availability of observations was sporatic, based on nurses' work hours and assignments. Although many patients died in the critical care units during the observation period, the key informants often were not on duty or not assigned to the patients who were dying. For these reasons, all nurses in the study were asked to participate in the observation phase. Only one nurse was observed more than once. The nurses identified

adult patients who, in their best judgment, were likely to die within hours or days and for whom decision making about DNR orders had been initiated.

Additional nurses caring for the dying patient involved in the dying event were asked to participate as secondary informants based on their involvement in significant events during the time that the patient was dying. Six secondary informants were included in the study. All were women of caucasian descent. Their ages ranged in age from 27 to 46 years of age. These nurses had from 7 to 13 years of experience in nursing, and from 4 to 10 years of experience in critical care.

During phase II, preparation was made for phase IV (interviewing bereaved family members) by informing family members about the study. The investigator told them that there was a study involving nursing care of critically ill patients taking place and that they might be contacted at a later date to determine if they would be interested in being interviewed about their perception of this time period and the nursing care provided. Of the five family members approached verbally, all consented to be contacted later.

Early in the observation period, it became apparent that all patients did not have family members present at the bedside during the time that they were dying, so that a family perspective would not be possible in all situations. An alternate strategy was implemented to supplement the

family data. The transcripts of the nurse group interviews were reviewed for descriptions of deaths within the past year which provided significant detail about nurse and family involvement in the patient's dying. Key informants who had been involved with the families contacted them to ascertain their interest in learning more about the study. Six family members were contacted by five nurse informants. All indicated that they were interested and were subsequently approached by the researcher and asked to participate.

Intensive Interviewing of Key Nurse Informants

During Phase III the key nurse informants who participated in the observation phase were interviewed individually regarding their practices in caring for the particular patient and family as well as personal beliefs and values related to nursing care of dying patients. This interview took place within one week after the observations had been completed. The one nurse who was observed twice was interviewed after both deaths.

Interviewing Bereaved Family Members

In Phase IV bereaved family members were interviewed. Altogether, seven families and eight individuals were interviewed (one brother and sister wanted to participate together). This included three family members recruited during observations and five who were identified from group interviews and were recruited by the key informants. Family

members interviewed included three women and five men: two wives, two husbands, one daughter, two sons, and one partner. Data from an eighth family interview used to pilot the interview guide was included as supportive evidence only.

For families recruited during observations, key informants identified one family member per dying episode who was the primary significant other and would be a reliable informant (i.e. had participated in the death and would provide thoughtful and accurate information). The researcher approached that family member and obtained permission to contact them at a future date. The family member informant was subsequently recruited for the study by mail 8 to 12 weeks following the death. The researcher contacted them by phone within one week of the letter to determine their willingness to participate. This time period allowed the family privacy for initial grieving and time to deal with the logistics of the death, yet was early enough for the memory and feelings concerning the death to be clear. One family member who was recruited in this manner, the wife of a man who died following an observation, declined to participate. Another family member, the brother of a woman who died during an observation, was not contacted for interview because of his lack of involvement and presence during the time that she was dying.

Family members identified through the group interview

were initially contacted by key informants, as described above. The researcher subsequently recruited these family members by letter, then contacted them by phone to determine if they were interested in participating in the study. One family member recruited in this manner, also the wife of a patient who died in critical care, declined to participate.

Setting

Nurses were recruited from five critical care units at two different hospitals, one a private institution with one adult multipurpose critical care unit and the other a university hospital with four specialty units. Both were medical center teaching hospitals. Multiple sites were chosen to provide variation in the philosophies and procedures regarding care of dying patients, the type of nursing care required, and the disease processes of the patients.

Data Collection Procedures

A pilot study was planned on one unit for the purpose of testing the procedures and the interview guides. However, the nurse chosen for the pilot did not have an opportunity to care for a dying patient during the two month pilot period. Instead, the first interviews and observations in each phase of the study were reviewed and evaluated as pilot data.

Group interviews, observations, and individual nurse interviews took place in each critical care area over a

period of several weeks. This prolonged engagement increased exposure to the contexts and meanings for each nurse at each site and helped to establish trust between the nurses and the researcher.

In phase I, four groups of three or four critical care nurses were interviewed to collect descriptive narrative accounts of caring for dying patients in ICU. One group included only nurses from the same unit, the others included nurses from two or three units. Two interviews were conducted for each group. The first focused on recollection of episodes caring for dying patients in ICU that stood out for the participants. The second was used to clarify information and validate impressions from the first, ask for additional episodes, and discuss the particularities of caring for dying patients in each unit (see Appendix A for interview guide). Each interview lasted approximately one and one-half hours. Interviews were tape recorded and transcribed verbatim.

Phase II included clinical observation and intensive interviews for the purpose of collecting thick description surrounding the dying of a specific patient. Key informants notified the researcher when they became aware that a patient they were caring for was dying. Precipitous deaths with the focus on resuscitation were not included. Observations of the expert nurse and secondary informants were done by the researcher for 2 to 10 hours over one to

four days. Observations concluded when the patient died or was transferred from the critical care unit. Of eight completed observations, four patients died in the critical care unit and four were transferred from the unit. The four patients who were transferred died within hours or days after transfer. A variety of nursing activities were included in the observations, including physical care, assessments and monitoring activities, comfort measures, and interpersonal interactions with patient and family, physicians, and other health care workers. The researcher attended three patient care conferences and was present at the time of death in all cases when the patient died in the ICU. Written sources of information used as supportive data included the medical record, unit policies and procedures, nurses' personal written accounts of their experiences, and written communications from families to nurses.

The observation method used was close observation (VanManen, 1990), described as participating in the lifeworld of the relevant persons as closely as possible while retaining a hermeneutic alertness to situations and their meaning. The researcher, in this approach, gathers anecdotes while the story unfolds. Persistant observations are done to follow up perceptions of salience or nontypical factors (Lincoln & Guba, 1985). Field notes were kept during the observation, including observational, methodological, and theoretical entries and were

subsequently transcribed. The field notes were supplemented by commentary tape-recorded immediately following the observation and a personal journal kept by the researcher.

In phase III, key informants observed were interviewed using a semi-structured interview guide to elicit additional understanding of concerns and background meanings surrounding death and dying as well as perspectives on the death observed (see Appendix B for interview guide). Each interview lasted approximately one to one and one-half hours. Interviews were tape recorded and transcribed.

In phase IV, one bereaved family member for each deceased patient was interviewed for the purpose of obtaining the perspective of the bereaved family member experiencing the dying event as a recipient of nursing care in the particular situation, and also as an agent of the patient. (One exception to this was a brother and sister who wanted to be interviewed together.) Family members observed during the last month of data collection were not interviewed due to time constraints. Additional family members were recruited by key informants based on group interviews as described. Although families initially consented to two interviews, all interviews were completed in one session. Reasons for the one session included the emotional difficulty of the interviews for some family members and their preference to complete the interviews in one longer session if possible. In addition, family members

were able to complete the discussion of their experiences related to nursing care within one session. All family members consented to be contacted at a later time if the researcher had additional questions.

The interviews lasted approximately one to two hours (see Appendix C for interview guide). During the interviews, family members were initially asked to describe their experience of having a family member die in ICU. The researcher subsequently asked questions to explore their personal concerns and meanings regarding death and dying, their involvement in care of their family member, and how their needs were met during the dying time. If the nursing care was not specifically discussed to that point, the family member was asked to describe nursing practices and any continued contact with nurses since the hospital event. Interviews were tape recorded and transcribed.

Data collection proceeded over a period of six months, with phases overlapping. Group interviews were completed over approximately six weeks. As soon as both interviews were finished for each group, nurse participants were given instructions to begin identifying dying patients for the observation phase. Observations progressed slowly for the next four months. Individual interviews of nurses followed each observation within one week. After 8 to 12 weeks, the patients' families were contacted and interviewed. Families contacted by the nurses based on group interview data were

interviewed concurrently with the final three phases of the study.

Analysis

In all phases of data analysis, clinical episodes were treated as text and interpretive or hermeneutical strategies were applied. Interpretive analysis, or hermeneutics, is a systematic approach to making sense or deriving meaning from text or text-analogues, in this case transcriptions and field notes. In establishing a certain reading or understanding, the hermeneutic circle is entered, in which the whole and the parts of the text are in constant interplay. Parts (situations) are used to explicate (in language) an understanding of the whole text and the broader understanding of the whole text extends insight into the parts (Taylor, 1985).

The interpretive process involved systematic analysis of the whole text, the parts of the text, and a comparison of the two. Three strategies were employed by the interpreter: thematic analysis, exemplars, and paradigm cases (Benner, 1985). Thematic analysis is the process which facilitates emergence of the lived meanings from the text, serving as a means to give expression and describe the content of notions about that experience (VanManen, 1990). An exemplar is an instance or example that captures the meaning of the situation for the interpreter (Benner, 1985). All relevant aspects of the exemplar are coded together in

order to retain the coherence and context that contributed to the interpretive process. Exemplars are included in the study report to illustrate important aspects of the interpretation and appeal to the reader by virtue of the common understanding provided by the lived experience. The paradigm case is a strong instance of a particular pattern of meanings (Benner, 1985) which stands out for the participant or the researcher. Paradigm cases stand out vividly as a whole to stimulate a shift or particular grasp of understanding (relationship or meaning) which may or may not be ineffable. These are included in the study report where possible as the basis for interpretive analyses.

Data analysis incorporated five strategies that were overlapping and did not occur sequentially:

1. Group interview data were read through and summarized to get a sense of the concerns represented by the clinical episodes reported by the nurse informants. Data from observations were read and summarized as a whole, together with related individual nurse and family interview data. Where families were identified in group interviews and recruited by nurse participants, the original narrative as told by the nurse and the family interview were considered together.

2. Themes and issues were identified through reflective thinking, subsequent readings of the data, and interpretive sessions. Additional lines of inquiry were added as they

emerged and incorporated into subsequent phases of the study. For example, an early interpretation related to the asynchronous recognition that the patient was dying between nurses and physicians influenced inquiry about contrasting cases in subsequent groups and individual interviews.

3. An interpretive plan was developed. Recurring themes and issues were synthesized, and a set of codes was generated (see Appendix D for codes). Strategies for retrieving information using these codes were planned.

4. Each text was coded and segments retrieved according to the interpretive plan using the interactive computer program Ethnograph 3.0 (Seidel, 1988).

5. Coded segments were read and synthesized for identification of exemplars and paradigm cases which explicated the concerns and issues embedded in the recurring themes. These were used as the basis for reflective writing.

The most prominent themes were compiled into the research report (VanManen, 1990) and substantiated by narrative. During the writing process, individual cases were repeatedly consulted to validate the data. As data collection progressed, study participants were asked to supplement or clarify data, or to validate interpretations.

During the data collection and analysis periods, debriefing was used as a strategy for assisting the researcher to identify and deal with personal biases or

blocks and to stimulate aspects of inquiry or interpretation which may have been overlooked. Weekly meetings were held with the committee chair, who is skilled in interpretive processes, and two doctoral students in nursing who are familiar with hermeneutic methods. One member of the committee who has a background in mental health and family nursing and is a bereavement specialist also participated in some interpretive sessions. This group assisted with debriefing as well as exploration of emerging themes and methodological issues.

Rigor in Interpretive Methods

Given that the philosophic assumptions and view of humans and science in phenomenology differ from those originating from a positivistic framework, the reliability and validity criteria used as a standard for empirical studies do not apply to interpretive methods. The only commonly used criteria for qualitative studies, those developed by Lincoln and Guba (1985), are not specific to hermeneutic inquiry, but can be applied broadly to all types of naturalistic inquiry.

Qualitative Validity

Lincoln and Guba (1985) suggest four criteria for determining trustworthiness of naturalistic research: credibility, transferability, dependability, and confirmability. These criteria parallel empirical criteria for reliability and validity. Techniques for assuring these

criteria were incorporated into the study.

Credibility

Naturalistic research embraces the assumption of multiple constructed realities. By incorporating strategies which focus on adequate representation of those multiple constructions, the researcher increases the credibility of the findings (Lincoln & Guba, 1985). Prolonged engagement over several months and persistent observation of particular situations provided the researcher the opportunity to explore the scope and depth of nursing practices caring for dying patients in critical care. Triangulation of sources and methods provided additional credibility. Data were collected from nurses and family members using group and individual interviews as well as observation methods. In addition, the data underwent several levels of analysis by multiple nurse researchers as part of an interpretive team. Regular interpretive sessions also provided an opportunity for peer debriefing, an exploration of feelings and processes of the researcher as well as methodology. Contrast cases were explored through hermeneutic analysis and are represented in the study report. In the process of data collection, the researcher shared initial interpretations with both nurse and family participants, providing them with the opportunity to respond to the interpretations. Two nurses informants, each from a different hospital, reviewed the study results presented in

chapters IV and V.

Transferability

Qualitative researchers are not responsible for establishing the applicability or generalizability of the research findings. Rather they are responsible for providing thick description of findings, which will allow the readers to make their own judgments about tranferability of the results to another situation (Lincoln & Guba, 1985). In this study, nurses who were seen as experts in nursing care of dying patients were chosen to participate. Most (13 of 15) of the nurses studied were women, and all were caucasian. Data were not collected to systematically sample diverse populations of nurses and bereaved family members. However, the researcher concluded through observation and conversation that bereaved family members came from diverse living conditions, and various religious, educational, and employment backgrounds. Families were represented by participation of spouses, adult children, and partners of patients who died in critical care. Detailed accounts of situations from multiple perspectives provided context for the interpretive analysis of the nursing practices studied.

Dependability

Dependability refers to the consistency of research findings, that is, whether or not they could be repeated (Lincoln & Guba, 1985). The techniques described in relation to credibility contribute to the dependability of

the findings. An audit trail was kept by maintaining detailed notes (and occasionally audiotapes) of interpretive sessions and coding strategies. In addition, a journal was kept which included methodological concerns and solutions tracked as the study progressed. These notes will be saved for future reference and reflection.

Confirmability

Confirmability techniques seek to establish neutrality of the findings and minimize the bias of the researcher. This is primarily done by maintaining an adequate distance between the researcher and participants. The focus of this criteria in naturalistic research is on the data, rather than the investigator (Lincoln & Guba, 1985).
Confirmability of the data in this study was addressed by maintaining an audit trail and participating in regular peer debriefing.

Risks and Human Subject Protection

This study was reviewed and approved with revisions by the Institutional Review Board at the Oregon Health Sciences University. An addendum was submitted and approved with revisions at the beginning of the observation period (see Appendixes E, F and G for consent forms). In addition, procedures for review, approval and implementation were followed at the respective participating hospitals.

There were minimal risks involved in participating in the study. Informed consent was obtained from all

participants. Although some of the nurses experienced mild psychological discomfort during interviews concerning specific episodes, they expressed appreciation for the opportunity to discuss and reflect on their experiences. Interviews of family members precipitated more emotional responses. Discussing the death of their loved one was difficult for some family members who participated in the study. Although a mental health professional with experience in bereavement therapy was available as a consultant to the researcher, her services were not required during the study.

Some of the nurses and family members nominated for the study chose not to participate. All informants were free not to answer specific questions. Data were coded and identifying information was removed. A complete set of transcripts and written data were kept in a locked file and accessed only by the researcher and the dissertation chairperson. Selected transcripts were reviewed by the dissertation committee and two doctoral students who participated in interpretive analysis. Audiotapes and participant code lists will be destroyed as soon as the study is completed and abstracts are distributed to informants. Identifying information, including names of participants, hospitals, and detailed descriptions of situations, will be deleted in any presentation of findings.

Chapter IV. RESULTS AND DISCUSSION: DESCRIPTION OF NURSING CARE

Introduction

What follows is an interpretive analysis of data from group and individual interviews of nurses identified as expert in caring for dying patients and bereaved family members whose significant other has died in critical care. Data from the observations of the care of dying patients in critical care are also integrated.

The analysis is written in three chapters, one for each of the three research questions. This chapter describes nursing care of dying patients in critical care. Chapter V describes the interpersonal concerns and background meanings that shape expert nurses' caring for dying patients, including a discussion of the moral agency of nurses. Chapter VI describes the interpersonal concerns and background meanings of families of patients dying in critical care as they are related to the nursing care.

In the interpretation of these findings, it is important to understand that even though the nurse participants were designated as expert practitioners in nursing care of dying patients, the practice (as opposed to the nurses) is expert. Many of the practices considered to be excellent and described in this study are dependent on an accurate clinical grasp of the situation described and practical understanding on the part of the nurse regarding

appropriate follow-through.

Major themes that are discussed related to these findings are those supported by data across nurses, settings, and situations and affirmed by clinical observation. Throughout the discussion of findings, the data are presented using paradigm cases when they exist. These are strong cases which capture many of the issues and concerns related to particular themes (Benner, 1985). The interpretive analysis of each paradigm case is supplemented by additional exemplars to support and illustrate explanations and to expand understanding.

Several strategies are employed in the writing of this report to protect the confidentiality and anonymity of study participants. Although two of the nurse participants in the study were men, gender references are all feminine in order to protect anonymity. Names of patients, family members and nurses included in data excerpts are fictitious to protect their identities. Finally, only enough detail of each situation will be included in paradigm cases and exemplars to provide a basic understanding of the situation.

Description of Nursing Care

The description of the nursing care of dying patients and their families in critical care embedded in the study narratives created a rich understanding of bedside nursing practices. Since care is predicated on the nurse's understanding of the clinical situation, this section begins

with a discussion of clinical grasp and how it influences nursing care. The nurse's role in facilitating end-of-life decision-making and strategies for managing a death are discussed. Specific caring practices are reported, including humanizing strategies and changes in routine nursing care as the patient approaches death. Finally, the nurse's work with families after the patient dies is described.

Grasp of the Clinical Situation

Many narratives describing excellent nursing care of dying patients and their families were elicited during the interviews and observations. In each situation where the nurse intervened effectively, the care was predicated on an understanding that the patient was dying. This clinical grasp of the illness trajectory was thought to be more often possible with some groups of patients than others. For example, "with neurological deaths you can usually see it coming", as opposed to cardiac patients who just suddenly roll their eyes back and code (cardio-pulmonary arrest). Having a good clinical grasp meant having a "feel for" or a "gestalt" about a situation and related demands, and was necessary for the nurse to give care which was involved and meaningful for the patient and bereaved family members. A paradigm case is presented in order to capture the salient aspects of clinical grasp as it relates to care of dying patients and their families. This case is followed by an

interpretive analysis. Other exemplars supplement and support this narrative in the subsequent discussion. Discussion focuses on defining clinical grasp and describing how nurses reach and act on clinical grasp.

Paradigm Case: "I Didn't Want to Rain on her Parade"

The patient, Don, was a recently retired and active man who had suffered a massive myocardial infarction (MI) following surgery. He had been resuscitated, and was in the intensive care unit supported by a ventilator and an intra-aortic balloon pump. It soon became apparent to the nurse, Kris, that the patient was not going to survive. Although the patient's heart function was improving, his neurological recovery was not promising. The nurse also realized that Mary, his wife had not yet given up hope that he would live.

> That day cardiac-wise he was stabilizing. But his blood pressure was kind of bad, and neuro-wise his wife felt that he had responded, squeezed her hand for her, that kind of thing. But he wasn't squeezing for me. But granted, he could do it for a family member. But we did talk about that some things were reflex reactions and you know, and that he squeezed was good, but you know how a baby does that. The better indicator is if he lets go when you ask. Cause that shows that he thought about it, was able to hear what you said, and respond to it. So we talked about that a little bit. But I didn't want to rain on her parade. I spent a lot of time with the family.

Kris encouraged family and friends to come in and out of the room at will all day. During the night, the patient had a hypotensive episode and subsequently wasn't responding to any stimuli. The nurse dissuaded the physician from sending the patient to CT scan (which would entail a transfer by

cart and would be quite a task with the balloon pump and a ventilator), and instead to order an electroencephalogram (EEG). When Mary came in, she asked if he was waking up.

> The day before his pupils were reacting, but after the incident during the night, his pupils were dilated and not particularly reactive. So we talked about that when they started doing the little neuro thing. Well you remember yesterday his pupils were kind of smaller and now they're bigger. This isn't a good sign. And I was pretty blunt about that. And we know he isn't really responding. It's like his heart was better. Now, we got him so the balloon pump was doing great. But his neuro was really bad. No response to anything. This doesn't look good. And it was interesting, because the day before I told the doctors, "you know, he looks to me like he's posturing." And they're all pooh poohing me. Well they weren't pooh poohing the next day. It was so subtle. It wasn't like it was a dramatic thing. But it seemed to me that when we got any kind of response it was posturing. I'm not a neuro nurse, so I wasn't really going to stand my ground real strong. But I wanted to see something more than bring them in (decerebrate response to stimulation; inappropriate neurological response), you know. Anyway, so things weren't good at all the next day. So we had that whole day talking about things not working out. And then we arranged a family conference for that day.

Kris cried during the day with the family as they reminisced, and she learned about their history and relationships. They continued to talk throughout the day about how things weren't looking good. The EEG report was "flat", although the nurse did not share the findings with the family.

At the conference the physicians reviewed all the signs that were bad, and Kris noted that "I don't think she heard anything in the initial spiel that the physicians said that she hadn't already heard [from me]." The family was told

about the EEG, and made the decision to withdraw life support. Because of the flat EEG, the nurse anticipated that he would be apneic off the ventilator. However, she wanted the family to be prepared for whatever happened when the ET tube was taken out.

> I thought I want to give them some idea of what is going to happen. Because I know I'd feel like pins and needles, on the edge of my chair. And so I said, "Well, there's a couple of things that could happen here". And I said, "I'm going to pull this out and I have a little suction thing here and it's going to sound like the dentist when they suction you out. There could be a lot of secretions there so something might run out of his mouth and I want to make sure I get that. So don't be surprised if you see that. And he might groan or make a noise." I kind of ran through some things, you know, how they sounded. I was trying to think, what are they likely to see?

The patient was disconnected from the ventilator and died without ever taking a breath.

From the beginning, this nurse understood that the patient was not going to live, and her care for both the patient and family incorporated this knowledge. This paradigm case focuses the following discussion on defining, reaching, and acting on clinical grasp.

Defining Clinical Grasp

Having an expert grasp of the clinical situation involved more than predicting that the patient would die. Rather it involved apprehending the particular demands of the clinical situation. In the patient situation described above, the nurse, Kris, understood that the patient had poor neurological function despite improving cardiac status. She

also knew that this lack of neurological recovery after resuscitation was ominous. She did not expect him to survive very long without respiratory support. Although she anticipated that he would not breathe when the ventilator was disconnected, she would not specifically predict his course off the ventilator (e.g., how long he would live or what particular symptoms would accompany his dying). Rather she explained the possible symptoms to his wife. In this situation, having a clinical grasp involved a general understanding of whether or not the patient would die, when he would die, and what he might experience at the time of death. Specific aspects of the course of dying were more difficult to predict as described in several other situations where patients who were not expected to survive extubation continued to breathe for hours or days after life support was withdrawn.

During the two days she worked with the patient, Kris also worked closely with the patient's wife. Her grasp of the clinical situation included an understanding of how Mary was coping with the situation and her readiness to assimilate information about her husband's condition and to accept the inevitability of his death. Having a clinical grasp extended to understanding about the family, including an awareness of family dynamics, how individuals were perceiving and responding to the situation, and how they were coping with the potential loss of their loved one. In

some situations it also included an understanding of patient and family wishes and readiness to discuss end-of-life issues.

The personhood of Don was not manifest in the paradigm case, and the nurse described him as "already gone". Other nurses also talked about patients being gone from their bodies, expressing a perception that a particular patient was already dead and that the body was being kept alive by life support. One nurse tried to describe the feeling:

> I left that night and he was very sick and I was sure he was going to code that night. But he didn't. Except when I came in the morning, it was clear he wasn't in there. I don't assume they're not in there, but there's this sense that the spirit is gone, that it's only a body. His pupils were still reactive, he wasn't brain dead. But there was a sense that this person was no longer an intact person. There wasn't a spirit there, or whatever you want to call it. I don't even know the words to use.

This understanding made continuation of life support and treatment seem ludicrous to the nurse.

In contrast, nurses describing other deaths expressed an understanding of patients' struggles to survive and their awareness of and feelings about their impending death. This occurred even when patients were intubated, medicated, and unconscious. One nurse related a story of a critically ill patient who was very obese and unable to undergo emergency surgery because of her weight. The patient's family was unable to be present for several days. When a sister finally came in, the physician began to talk to her at the bedside about discontinuing the ventilator. The patient's

heart rate and blood pressure increased dramatically, and the nurse was certain the patient could hear even though she was unresponsive.

> The doctor walked into the room and said, "I need to talk to you about taking the ventilator off your sister." And the patient's heart rate zipped up to 160 and the alarms went off. This lady knew what was going on. And they do. And to this day I do not believe this lady wanted to die. And I had a very difficult time with them taking her off the ventilator... Her boyfriend called me and said, "I'm in a wheelchair and I can't come to see her, but just tell her I love her and I want to marry her." So I went in and I told her that and immediately her heart rate went up, her blood pressure, and I tried to relay all this information to the physicians and they laughed at me. They thought I was very foolish because obviously this lady, from a medical standpoint, was not going to make it.

The nurse, acting on her feeling that the patient was "in there" and wanted to live, tried to convince the physicians to reconsider their treatment plan.

The nurse participants demonstrated an ability to apprehend patients' dying trajectories in a general way and understand the particular responses of individual patients and their family members to the impending death. This understanding was the result of a grasp of many facets of the situation.

Reaching a Clinical Grasp

An accurate clinical grasp was based on the integration of influencing factors from the realms of formal, practical, and personal knowledge. Kris, the nurse caring for Don, reached a practical understanding of the patient's impending death and the family's response by integrating salient

clinical information with experience and personal values. In this situation and others, objective formal information sources included patient history, response to treatment, assessment data, diagnostic data, and the medical prognosis. The nurses' knowledge of the particular patient's pattern of responses helped in picking up subtle cues which indicated a downward trajectory. The nurses' practical knowledge and experience helped them to focus on the salient information and understand the implications of data for the patient's clinical course. Personal values related to the meaning of death, the nature of the nurse-patient relationship, and the role of the family affected the nurses' responses to the dying patient and their ability to direct attention to the needs of family members.

Formal data sources. In the paradigm case, the nurse understood from the first day that the patient would most likely die. This judgment was based on her understanding of the patient's course post-resuscitation and his lack of response to medical intervention. Even though his heart was better, she understood that the neurological assessment, including hand grasps, pupillary responses, and declining blood pressure, meant that he could not regain function. The physicians suspected that the patient was "brain dead", and the EEG confirmed their diagnosis. This kind of physiological data and diagnostic reports provided a

concrete basis for understanding the patient's clinical status.

The nurses described other objective data that assisted them in understanding the patient's dying trajectory. The vital signs often gave a clue regarding the timing of death. When patients were "bradying down" (heart rate slowing), they would die shortly.

> I checked his room and his blood pressure was extremely low. I don't remember exactly what it was. And I noticed that he was bradying down and obviously dying.

Beyond a certain point, the signs and symptoms of unabated brain swelling indicated that patients would not reverse their course and gave cues regarding the timing of their demise.

> She's at this point unresponsive. And that's kind of hard to tell whether it's due to the swelling that the CT scan has shown or whether indeed it's due to the medication. The swelling versus the medication. And they're around the bedside praying for this big miracle and meanwhile inside of me I know that her brain is swelling. I'm watching things that aren't painting a picture. The heart rate's slowing. Blood pressure's okay right now. It's a little bit higher than before, but no big changes.

Probably the strongest evidence that neurological death had occurred and that biological death was inevitable was when the pupils were "blown" (fixed and dilated).

> They were going to try and keep her alive. Well, she remained in our unit for about an hour, and I was kind of wandering around and finally I looked at her pupils and they were blown. So I found a staff physician, looked him in the eyes, and I said, "Do you know that this lady's pupils are blown?" And he said, "Oh." And so he went and he looked at them and he said, "Let's stop". And we just stopped and then she died.

Nurses integrated an enormous amount of assessment and diagnostic data into their determination of the patient's dying trajectory. This ability to focus on the salient information is a skill that develops with time and experience (Benner, 1984).

Practical knowledge. Practical knowledge, gained from experience, was the basis for understanding and interpreting information about the patient's course. Knowing individual patients and their particular attributes and responses was important in getting the right clinical grasp. In the paradigm case, the nurse, Kris, had spent many hours at the bedside. She recognized the subtle changes as Don Anderson began to posture in response to stimuli, and interpreted this as further evidence that he was continuing his downward spiral. Just as the nurse in the paradigm case was able to incorporate the subtle changes in assessment into the overall understanding of the patient's course, another nurse who was not situated expressed her inability to get a grasp on the patient's course. In the following situation, the patient's daughter asked about the DNR status.

> At the time I didn't know whether we were talking because this person was going to die or just wasn't looking good. And I had such a lack of information. I hadn't taken care of her before. I really didn't know her. It was like flying by the seat of your pants.

Making the qualitative distinctions necessary to understand a patient's particular situation was also contingent on knowing the patient within the context of the nurse's

previous clinical experiences.

Having worked with post-resuscitation MI patients previously, the nurse caring for Don knew that his neurological responses were not adequate. As nurses worked with a group of patients for a period of time they learned which indicators predicted that a patient wouldn't survive. Recognition of the outcome of particular illnesses was based on particular complications and parameters, seen over the course of the same disease across many patient experiences. Indicators also occurred across illnesses and included the number of times that they return to the ICU, the length of time in the unit, and the number of complications. The following nurse described her clinical understanding regarding a patient who died after repeated admissions to critical care for surgical complications.

> You know, about the third time he came back down I knew he would never get out of there again. It's like when you get that many strikes you don't come back out of the unit.

In contrast, nurses were able to look back to when they began practice and did not have the experience to put their experiences in context. This nurse talked about her inexperienced response to a patient who had a huge myocardial infarction:

> I remember talking to him about his children and saying, "Oh come on, you're going to make it through this." And I honestly thought he would. Because I didn't understand the extent of the infarct or injury that he had.

Experience was essential for putting information into

perspective and having a good clinical grasp of the situation.

Personal knowledge. Personal knowledge opened the nurse to the possibilities for meaningful human understanding. The nurse in the paradigm case was comfortable with the fact that the patient was going to die. Rather than avoiding or denying that the patient was dying, that understanding oriented and shaped the care that she gave to the patient and family. She understood the patient as a part of a family, and expanded her focus to include an assessment of the family. She valued the patient's relationship with his family, which made possible her understanding of the meaning of the death for family members. Overall, the nurses' values and maturity shaped their ability to see and react to the clinical reality.

> At this point I'm resigned to the fact that the patient won't live, and that's usually alright with me... At this point I'm very comfortable with people dying. I have no real problem with letting go of patients once I see there's not much else we can do.

Comfort with dying allowed the nurses to be open to providing a different kind of care for dying patients and their families.

The nurses also described, on a feeling level, a clinical grasp of the patient's struggle and suffering. Suffering in this context is understood as meaning more than pain, but rather "distress brought about by the actual or perceived impending threat to the integrity or continued

existence of the whole person" (Cassell, 1991, p.24). This includes patients being maintained on life support against their will. In the paradigm case, Kris felt that Don was "already gone". A sense of his personhood was missing from the narrative. Because it was difficult to translate this embodied knowing into objective language, nurses didn't usually talk about their understanding of the patient's presence; however the understanding of a silent patient's presence or suffering influenced care and shaped nurses' efforts regarding continuing or discontinuing life support.

Acting on the Clinical Grasp

The understanding of the clinical reality that the patient was dying patient affected nursing care and intervention in many different ways. It was essential for giving appropriate and meaningful care to patients and their families, and helped the nurses in setting goals and priorities for their shift. Clinical grasp helped make administrative decisions about bed utilization and staffing. It stimulated discussion about end-of-life issues between family and health care providers, and affected decisions about withdrawing treatment. And finally, having an understanding that death was a possibility helped make the death easier for the nurse.

In the paradigm case, understanding that Don would not survive guided Kris in helping the family towards acceptance. Over two days, she worked with Mary to explain

the meaning of the signs and symptoms of his neurological demise. She encouraged reminiscence to help her begin to let go. And when the decision-making conference was finally held, the patient's wife was ready to withdraw support. The nurse's grasp that the patient was already gone allowed her to make predictions to the family about the patient's response when he was extubated. Her acceptance of the patient's demise and values concerning undue cost and hardship for herself and the patient motivated her to convince the physician to use an EEG instead of a CT scan to diagnose the patient's brain function. This not only prevented the costly x-ray procedure, but averted a cumbersome trip for the patient and all of his technology to the radiology department. After the patient died, the nurse felt a sense of accomplishment and closure instead of guilt that the patient had died under her care.

Understanding that a patient would die allowed the nurses to prepare both the family and themselves before the death event. A period of adjustment during which everyone had time to acknowledge the impending death was important.

> If you have a chance to say "hi" to the family, "this is a serious situation that we have here", and you're able to acknowledge that this is a sick situation that the patient is going through, then it's easier to deal with finality if it happens. Whereas if you, the critical care nurse, if we're not able to be in control of that awful thing maybe that's going to happen, then it catches us by surprise as if we were on the street.

This grasp that the patient was dying guided the shift in focus from cure to care.

Understanding the signs of impending death was necessary in order to gather the appropriate family and friends and prepare for the death event. In many situations the nurse called family and friends from their homes, the waiting area, or the cafeteria so that they could be at the bedside during the final minutes of life. If the family was not available or did not wish to be at the bedside, the nurses reprioritized their workloads so that they could remain with patients as they died. Without that warning, many patients would die alone.

Nurses, physicians, and family members often arrived asynchronously at the realization that the patient was dying. When the clinical grasp was different between providers, there was potential for conflict. The conflict was most likely to occur between the nurse, whose priority was to end senseless suffering, and the physician, whose priority was to exhaust medical therapy in an attempt to save the patient's life. However, nurses also disagreed among themselves based on different clinical grasps of the same situation. One nurse, identified as having expertise in care of dying patients, described a situation in which she and another nurse acted on divergent understandings. The patient was unresponsive following a massive internal bleed. She was DNR and dying, but the decision had not been made to withdraw life support. The nurse telling the story wasn't sure if the patient would make it through the night,

so she called the patient's husband to come in just in case.

> The nurse that was working with me thought I should have told him that she was dying and that he ought to know that. But I didn't think tonight was that night. And this nurse thought that I should just be in there at her bedside and hold her hand the whole time. I was in charge, we were busy and understaffed and I didn't have time to do that and I didn't feel at that point that it was really necessary. And this nurse took it upon herself to go in there and tell my patient that she was dying. "You're going to die." is what she told her. And sat in there and held her hand. And I went in there and said, "What are you doing? " And she said, "I'm just holding her hand." And she goes, "Yeah, I told her that she was going to die." And I said, "Get out of my patient's room."

The patient didn't die that night, and the nurse spent a great deal of time "back pedaling", assuring the patient that she was loved and that she could quit fighting "if she was ready". This excerpt demonstrates how different clinical grasps prescribe different priorities and approaches to nursing care. Secondarily, it points out the contrast regarding ways that nurses with different skill levels approach dying patients.

Although nurses told many stories where they were the ones who first understood that a patient was dying, occasional situations were cited where the physician and/or family believed the patient was dying and the nurse did not. In one contrasting situation, a nurse told a story about a patient where she had a different clinical grasp of the patient's illness trajectory. The patient had many complications following surgery and fell outside of the usual rapid recovery course for patients within that

clinical specialty. As a result, he was "written off" as "unsalvageable". A nurse floating to that critical care unit from another unit where they cared for longer term patients recognized that he was not terminal, and intervened by asking to have him transferred to her unit. The physicians agreed and stood back from the patient's care, only participating by ordering changes in ventilator settings. As a "nursing patient", he was slowly weaned off drugs and the ventilator while activity was increased. After six months of patience and slow progress, the man was discharged and is writing a book about his experiences. The nurse's correct clinical grasp that he was not "unsalvageable" was an essential element that turned this man's care around and eventually resulted in his recovery.

Clinical grasp involved apprehension of the particular demands of the clinical situation. This apprehension that the patient was dying and understanding of the particular patient and family responses and needs was based on the integration of the salient aspects of formal, practical, and personal knowledge. A correct clinical grasp of the situation was the basis for effective and meaningful nursing care of dying patients and their families.

Facilitating Decision-making

According to these data, nurses consistently recognized that the patient was dying before the family and the physician. When this occurred, they worked deliberately to

bring the others to that realization. Although the nurses typically did not make decisions regarding DNR or withholding or withdrawing life support, they influenced the process and content of the decisions in several ways. In this discussion, a paradigm case from observation data is presented which captures the central concerns and issues regarding the nursing role in decision-making, followed by an interpretive analysis. The analysis is supported by additional exemplars.

Paradigm Case: "I Feel Like I Could Fly"

An elderly woman, Emma, was on a ventilator because of progression of an undiagnosed neurological disease. She had an advance directive which made it clear that she did not want her life prolonged on a ventilator. Her son Peter held the power of attorney for health care. However, at the time of her intubation, the physicians were unsure if her respiratory failure was a temporary or a permanent condition. Emma was in a great deal of pain and distress, pounding her fists on the bed and silently screaming to be taken off the ventilator. (The endotracheal [ET] tube obstructed the vocal cords and prevented her from talking.) Her hands were restrained so that she wouldn't dislodge the ET tube. Peter did not want her kept on life support, however she was maintained in this manner for five days while the physicians hoped for improvement and tried to decide how to manage the situation.

As the physicians kept extending the "wait and see" window, two nurses, Kate and Annie, became more assertive about getting the patient extubated. Annie contacted a member of the ethics committee, who supported her contention that this situation was ethically problematic and complicated by the lack of a specific medical diagnosis. These two nurses, motivated by their perception of the patient's suffering and her wish to be taken off the ventilator, insisted that the physicians address this issue. Amid increasing conflict, they arranged a care conference.

The conference was attended by several physicians, both nurses, an ethics committee member, a chaplain who was involved with the family, the respiratory therapist who had intubated the patient, and the patient's son, Peter. The nurses participated in the conference by describing their assessments of Emma's competence and suffering, and their understanding that she did not wish to remain intubated. When the conversation turned to the mechanics of extubation, some of the physicians acknowledged how emotionally difficult it is to discontinue the life support. However, the nurses quickly disagreed with them. Annie explained that for her, it is much easier to make people comfortable off the ventilator than to see them continue to suffer with interventions they don't want. Emma was eventually extubated, and when the tube was taken out and her hands were released from the restraints, she happily whispered, "I

feel like I could fly!" She died less than two weeks later after returning to the skilled care facility where she had been living because of her progressive neurological disorder.

Four particular ways that nurses influenced decision-making stand out in this situation. The nurses influenced decision-making by preparing families for decision-making, working out asynchronous clinical perceptions with physicians, orchestrating care conferences, and advocating for the patient's wishes. Each of these aspects of nursing practice is discussed and supported with exemplars.

Preparing Families for Decision-making

Nurses focused on the family by initiating or supporting discussion between patient and family or among family members about patient wishes concerning life support. Although Emma's son, Peter, had discussed end-of-life issues with his mother and held the power of attorney, he did not initially understand that the ventilator was a violation of his mother's wishes not to be maintained on life support. As the days passed and she was not able to meet the criteria to be weaned from the respirator, Kate and Annie tried to clarify the patient's wishes with her. Emma continually asked that the endotracheal tube be removed. The nurses talked to Peter, explaining how frantic his mother was to have the tube removed. But they also told him that they weren't sure about her orientation, and whether she

understood that she would not survive without respiratory support. In discussing the particulars of the situation, they tried to clarify what Peter wished for his mother, given that he knew her and had talked with her about the advance directive. He understood the hopelessness of her illness and the implications of removing the life support, and wanted to abide by his mother's wishes.

Other family members studied were not ready to accept that the patient was dying. In these situations, nurses began to disclose the grave reality of the situation to family members, balancing reality with hope as families understood and accepted the course of dying. This gradual disclosure served the purpose of laying the foundation for later inevitable end-of-life decisions that the family would need to make. One nurse explained:

> While they're still alert enough to make a decision, I will say, if I've built up a rapport with the family, what has your doctor said about your disease? Have they given you a length of time that they think you're going to survive? Have they talked to you about what we can do for you to maintain? Most of the time they say, "No, we haven't discussed it." And I say, "Well, have you and your husband or your wife sat down and said to each other, 'What do you want if it comes to the point of life support?'" And most people are really savvy about what we can do. They've seen it on TV. And I say, "Do you want breathing tubes? Do you want me to push on your chest if your heart should stop?" And no one's ever asked them that before. And I don't think I need a physician's permission to ask that because it's not like you're saying "You are going to die." You're just trying to gain some input, and I don't do it to everybody. Just the people that I get a feel that they are not going to do well.

The reason for this kind of approach was to facilitate

discussion among family members concerning what patients would want for themselves before a crisis situation occurred. In many situations, the patient and family had never discussed end-of-life issues.

> It's a hard question to approach. I think at one point in my nursing career I wouldn't have been the initiator. But I think having seen the awful position that you're doing CPR and you're ambu bagging somebody. Then everybody starts saying, "Well, what do you think maybe we should do? Did anybody ever ask?" And then everybody goes, "Oh no, I never asked." And then now, when you're doing this, then you go to the family and say, "Well, you have five minutes to make up your mind." And we're in there pressing on their chest and we're making them breathe, but if we stop she's going to die. "What do you think we should do?" that's a tough decision.

As an example, this same nurse described a situation where a woman with alcoholism was bleeding from esophageal varices. She had survived the first bleed, but was obtunded and on a ventilator. Her prognosis was poor, and it was likely that she would bleed again. She had a large family who was beginning to ask if she was going to make it.

> It seemed like we needed to make a statement on where we were going and what would she want? And so we started in, and I started asking her sister, "Did she ever say what she wanted? Did she ever say that she had the motivation to stop drinking?"... And they said, "Well, we don't know." And I said, "Well, you guys need to sit down and talk to each other about what you think she would want."

This nurse worked with the family to begin to address issues that would affect the decisions that they would ultimately have to make. She encouraged them to talk about how aggressively the patient would have wanted them to pursue saving her life, about her own will to live given her

depression and alcoholism. She tried to help them to consider aspects of the patient's person and life story that could help them understand what she would have wanted them to decide.

Although the nurses in the study did not believe that it was their role to directly disclose the patient's prognosis to the patient or family, they regularly assumed the role of interpreting the trajectory of the clinical situation for them. In the paradigm case, Kate and Annie kept Peter up to date concerning Emma's progress. They answered his questions at the bedside regarding her condition, and interpreted assessment data in terms of her illness trajectory. For example, when her lung volumes were not improving, Annie told him that her lungs were worse and that she would not be able to breath adequately on her own off the ventilator. Nurses in the study frequently translated and interpreted the meaning of clinical parameters, including physical assessment findings and test results, and helped family members to understand what was relevant. Unless death was imminent, the directness and pace of the nurses' approaches were determined by the family's readiness to deal with the implications of the information.

In the following observation, the nurse was working with the wife of a patient in his forties with cerebral anoxia (brain damage) following extensive resuscitation

efforts. He had suffered a massive myocardial infarction, and was unresponsive on a ventilator.

> The wife was in "big time denial". The physician had told her the day before that her husband had brain damage. In helping the wife to interpret that information, but not wanting to alienate her, (the wife didn't want anyone taking care of her husband who thought he was going to die) the nurse's deliberate approach was to talk in generalities about different types of brain death, for example, not able to walk or talk like Karen Quinlan, not able to breathe without a ventilator. She told the wife she wasn't sure which one (kind of brain death) he was yet. She was careful not to dash her hopes.

Early the next morning, the physicians stepped-up the patient's cardiac intervention because the electrocardiogram (EKG) showed that he was sustaining additional heart damage. The nurse spoke with the patient's brother, who saw the outlook as grim and was interested in having a conference to discuss the details of the patient's condition and to help the patient's wife.

> The wife called, and the nurse took the call at the bedside. She explained the details of the bradycardia, how slow, how long, that the EKG showed ischemia and why (additional coronary artery blockage). She explained that the balloon pump had been turned back up to 1:1, and that he had been started on a drug to relax the coronaries and a diuretic and why. She explained that he had an increase in ectopy (irregular heartbeat), and that wasn't a good sign. The blood pressure had been good, but sometimes that's one of the last things to have problems with. The heart was not as stable as yesterday. He was not any more responsive, and she reviewed the assessments: he was pointing his feet more, and the color in his feet was not as good. He had spiked a fever during the night. This could have been due to the heart, but also the brain. She explained how the fever could have occurred as a result of damaged temperature control in the brain. The wife asked why, if he was having more heart problems, they were not taking him back to the cath lab. The nurse said he was too unstable. The wife

> asked why they couldn't do surgery. She said that he wouldn't tolerate surgery, and because he was worse neurologically. They couldn't take him to surgery if his head wasn't stable. She told the wife that he had not tolerated tube feeding yesterday, but that she would try again today. Overall, she told her that things were not positive."

This nurse presented salient information to the wife, with explanations in understandable language about his condition, and some interpretation that he was continuing on a downhill course. She took as much time as the wife needed on the phone. The wife spent the day at the bedside, periodically breaking down then pulling herself together and telling her husband he had to fight. By the end of the conference later that afternoon, she was ready to withdraw life support.

Nurses prepared family members for decision-making by easing them towards the realization that the patient was dying and by encouraging them to talk about the patient's end-of-life wishes. As they worked with family members, the nurses also began to approach the physicians, encouraging them to talk with the family and to begin to consider the decisions that would need to be made.

Working Out Asynchronous Clinical Perceptions with Physicians

In the paradigm case, the nurses pressured the physicians almost from the beginning to reconsider treatment decisions. Being at the bedside constantly, they understood Emma's agony and her urgency to have the ventilator discontinued. They also understood the Peter's concern that

his mother's wishes were not being respected and his feeling of responsibility as the power of attorney. The nurses continued to confront the physicians with the patient's suffering, her frantic requests for extubation, and the advance directive. They encouraged communication with the son. They were concerned not only that life support was discontinued according to the patient's wishes, but that DNR and contingency orders not to re-intubate Emma once the ventilator was disconnected be written. These aspects of approaching physicians with concerns of the family and anticipating the "what-if" contingencies of the situation were evident in other situations described in the data.

Whether or not physicians themselves had come to the realization that the patient was dying, nurses often approached them and prompted them to talk to family members and to begin to make decisions about continuation of treatment.

> I think the nurse is in a position to kind of see. Because you see the family and you see the physicians... The staff is saying, "Let's transfer him out of the unit fast before they die" type of deal. And then you hear that and then the family says, "My aunt looks better today, don't you think? And don't you think that if I bring her nightgown in it's going to make her feel better? And do her good?" And you go, "Well, you know it doesn't hurt to bring her nightgown in." And then you kind of make some excuse to go out and you catch the physicians and go, "Wait, come back. I think somebody needs to make a statement because I hear you guys saying this person is going to die and I think this person is probably going to die. But the family is worrying about the nightgown."

In other situations they initiated discussions with

physicians by communicating the wishes of the patient and the family regarding continuation of treatment and life support.

Because of the complexities of treatment and technology in critical care, a simple DNR order didn't usually deal with all the eventualities of a situation in which a patient is dying. Nurses asked several "what-if" questions to clarify how they should respond to problems, given the patient's inevitable death. For example, nurses questioned whether patients would be re-intubated once they were extubated. One nurse discussed the decision-making surrounding the withdrawal of life support on a young woman with cancer.

> They [the family] were so focused on this ventilator and that the goal was to extubate her. But they couldn't see what happens if we do extubate her. We all knew that if we extubated her she would die, and we did not want to get put in a position of having to resuscitate and get her back, you know, that kind of thing. So I personally have gotten better about that forethought of "Okay, well, if we take them off the machine, or take them off of something, it's going to very likely mean that we have to put them back on. Let's, before we get to that place, and it's an emergency crunch situation, let's find out as much as we can about what, how we're going to handle that." What if, what if, what if? So it's not just disaster.

This forward thinking to allay potential problems surrounding the dying event was a common practice among nurses in this study.

The decision-making situations which informants perceived to be the best happened when the nurse, physician, and patient/family worked together openly and in synchrony

from the start. One nurse described what she considered to be "an incredible experience" because of the cohesive approach to the situation by all involved. A woman developed end-stage liver failure after eating a poisonous plant. But she was obtunded and there were no treatment possibilities left for her.

> She had this great family. They weren't highly educated or anything, but they had this real strength and ability to face things head on and to ask the hard questions and to talk among themselves and to reach decisions. And the attending that was on was willing to ask all the hard questions and to sit down with the family every day and see where they were at with things. And just take that 20 minutes every day just to say, "This is where we're at and this is where we're going, and doing and what we're thinking about this." And for me it was a privilege to be with all of the family...Sometimes there'd be 20 people together and with the nurse that was on that day and the doctors that you work with. And if that's the way it could be every time. Because what I think the original game plan was we'd give her 72 hours to see if she would turn around. And she didn't. And so then the decision was made to let her go, but yet we still had her on some pressure support medications and she was still ventilated. And then, you know, you just reach a point where you just know the family's ready. They've said their goodbyes and they're ready for it to be over. I just kind of sensed that in them and I said, "You know we don't have to continue with this if you don't want to." And they were fine with that and so we called the doctors again and that was like the second or third conference that day. And we all sat down again and decided to take her off support...By that point I felt like were all of one mind. That we had given this woman every chance and she was not going to get better. And she didn't end up dying until sometime during that night.

This nurse described this situation as "just all the gods coming together at once". This is an example of the possibilities for excellent care that exist when health care professionals and families are realistic and open about

impending death and collaborate in decision-making in the ICU. One mechanism for coordinating the plan of care for dying patients was the care conference.

Orchestrating Care Conferences

The nurses frequently arranged care conferences for purposes of communication among health care team members making decisions related to end-of-life issues. In the paradigm case, Kate and Annie suggested and arranged a care conference to discuss the end-of-life issues causing conflict among health professionals and between health professionals and the family. Both nurses participated in the conference, Kate coming in on her day off to support the patient and family. The nurses explained their understanding of the woman's wish to be taken off the ventilator and her suffering. One physician led the conference and other physicians participated willingly, while still others refused to attend. Although physicians sometimes asked for the conferences, nurses felt that in general they were resistant:

> For the most part I really feel there is a resistance from the physicians. I mean, they're not real gung ho about it. And I think a lot of it is that they just think that the only reason we want this is because this patient isn't going to make it and that's what we want to address and make them a DNR. Or there's troubles and they feel threatened somehow. In reality, it doesn't have anything to do with whether we or anyone wants to change the code status. We can't seem to get it through to them that it's a matter of what direction are we taking?

Standard practice regarding the particulars of conferences

were different in different units and hospitals and varied for the situation. Sometimes family members were invited to the conference, but other times the conference was an arena for the health care professionals to talk frankly about prognosis and vent frustrations. In that case, families were not included.

Nurses arranged the conferences, making numerous phone calls to coordinate schedules of family members and physicians and other involved health care professionals. However, because of the shift scheduling, the nurse arranging the conference or those most involved with the patient did not always attend. On occasion, nurses came in on their off-shifts if they were very involved with a patient or family. Nurses described sometimes taking a leadership role, but in all conferences observed in the study, which were held for decision-making purposes, a physician led the conference. The physicians gave information about the patient condition and prognosis, fielded questions, and directed decision-making. Nurses were sometimes asked to express an opinion, but most often played a supportive role. Sometimes they reported acting like the hostess, arranging the room, making coffee, and introducing family and physicians. During conferences they sometimes translated and clarified technical information for family members and made sure they understood. Nurses also talked about their responsibility to represent the concerns

of the patients, who were not able to be at the conference. In the following narrative, one nurse described how she represents patients:

> The patient knows this care conference is going on. But what do I have to say here? So I always write down a list. I ask them. I let them know what's going on and tell them to think about it, like a day or two in advance. I tell them and then we write down what points she wants to make or what points they want to make. And I take that, not showing it to the family or anything. I bring it up after everyone there has had their time to ask their questions and vent their feelings. And then I say, "Well, this is what so and so's concerns were." And then afterwards I make the physicians report back to the patient what was said. Because they know it's happening. They see all their family showing up and they know all this is going on and then, you know, what about me? It is about me.

The nurse acted as the voice of the patient, keeping her and her wishes at the center of the discussion. This was particularly important in this situation, where there was conflict between the patient and family.

In the following exemplar, a nurse described how she used the care conference as a tool for restoring coordination to a treatment plan. The patient was a man who never recovered after a routine surgery and experienced multiple complications. He was suffering greatly, and his wife was always in attendance at the bedside. He had many physicians, but no one seemed to be in charge. The nurse thought the patient was dying, and pulled the wife aside in the waiting room to find out what she thought about the situation. The woman burst into tears, saying that she had no idea what was going on.

> I have no idea who is the doctor in charge. I haven't even met some of the doctors. I don't know what's going on, and I'm scared to death he's going to die. So I said okay. We made a little list that we need to figure out who's in charge. She said no one has talked to her in days. So I said, "Well, we need to find out who's in charge and we need to set up regular times to talk." And so we needed to connect there and I said, "We need to talk about some of your concerns." And one was that she thought he was going to die and she thought he was in pain and she was really worried. And so we had these little goals and I went back and talked to the residents and we had a care conference. ...Well as it turned out, it was just a real lack of communication and I said, "Who's in charge here?" And somebody volunteering that they would take over. They would be in charge and they would talk to the wife and they would talk to the surgeons and we set out some goals and she was real pleased. She was part of the team. They went on to make him a DNR after a few more days of trying things. But finally it was clear and she said he wouldn't want to live like this, and they went through with the dying.

In this situation, as in many others, the care conference worked to coordinate the health care team and create positive outcomes for patients and families, including a peaceful death.

Advocating for the Patient's Wishes

The nurses studied did not see themselves as primary decision-makers in the case of dying patients, but rather as patient advocates. In the paradigm case, Kate and Annie acted as strong advocates throughout the situation. Emma's wish not to be maintained on the ventilator motivated them to confront physicians, arrange the conference, and speak up on her behalf. Although conflict with physicians was stressful for nurse informants, the inherent good in removing the unwanted technology and helping patients to die

peacefully was their reward.

Many of the previous exemplars reflect elements of advocacy. These elements included finding out and acting on patients' wishes, speaking for patients at conferences, relaying patient and family issues to physicians, interpreting suffering to physicians, and helping patients and families to negotiate the system. In many situations the nurses defended a patient's end-of-life choices during the decision-making process, then later discussed their own conflicting beliefs about what they would have done in that situation.

One nurse described advocating for a patient who had metastatic cancer complicated by several other medical problems. The patient was totally oriented, but maintained on a ventilator. "At ten minutes to two in the morning, when everybody thought everything was fine and cool and all was well with the night shift, she extubated herself." The nurse called the doctor to come and re-intubate the woman, then went back to the bedside.

> And then I went back into the room and she grabs my hand. She says, "Don't let them put that tube back down me. I don't want it. I want to die." And so we started talking and she said she was going to die anyway, and it was miserable living like this. They didn't give her a very good chance of coming off the ventilator. I mean, she just had all her reasons. When the docs came, we were still giving her oxygen and stuff and making sure everything was okay. And I went out and told him, "She doesn't want to be re-intubated." Well the resident said, "We have to do it".

The doctor talked briefly to the patient and asserted that

the patient was disoriented and needed to be re-intubated emergently. The nurse was furious, and said, "You've got to listen to the patient!" Embroiled in conflict with the physician, the nurse called the patient's husband to come in and help with the decision. Ultimately, the patient was not reintubated, and died. In reflecting on the situation later, the nurse admitted that even though she supported the patient's decision, she would not have made the same decision herself.

> People were supportive of what I did, but there's a real conflict within me. Because it's not that I believe that she should have died. I think she would have been viable for a year maybe down the road. But it wasn't my decision. It was my patient's and ultimately it was up to the patient. And that's what she wanted.

Nurses in the study consistently repressed their own beliefs and values in order to support patients' and families' end-of-life decisions. However, in many situations they were able to acknowledge that there was a conflict. Some nurses were disturbed by the cognitive dissonance, while others were clear that their own choices were irrelevant. In either case, the acknowledgement of differences is important so that nurses do not unknowingly inflict their own feelings on patients or families and unwittingly influence decisions. In the spirit of existential advocacy, the role of the nurse is to assist patients and families to examine and clarify their own values in the context of the situation in order to make decisions (Gadow, 1980).

In summary, nurses played a powerful yet often background role in the decision-making process. They facilitated decisions by initiating discussion with families about eventual life support issues and helping them to understand the declining trajectory. They asked physicians to make difficult and detailed decisions, addressing potential problems and contingencies. They arranged and participated in care conferences. The nurses primarily saw their role as one of advocacy, sometimes putting aside what they would choose to do in a particular situation to support patients and families.

Managing the Death

Critical care nurses had considerable expertise in withdrawing life support and providing comfort measures to patients and their families at the end of life. When the patient was dying and the focus of patient care shifted from cure to care, the nurses assumed a different pace and level of responsibility for care. This discussion begins with a summary of various clinical trajectories of dying that nurses dealt with in the ICU. What follows is a description of how nurses managed space, time, and comfort as the patient died. This is explicated by interpretive analysis of one paradigm case that captures many of the issues and concerns nurses described related to managing dying. Supportive exemplars will be used to illustrate and expand concepts relevant to the discussion.

DNR Designations

Nurses facilitated decision-making and managed patients' deaths in a wide variety of situations. These situations can be broadly categorized, dispelling an implicit assumption in previous nursing studies that DNR patients are a homogeneous population (Caswell & Omery, 1990; Lewandowski et al., 1985; Tittle et al., 1992). Although the specifics of the care varied with the DNR designation and aggressiveness of medical therapy, nursing practice was not limited by these decontextualized categorizations. Rather it was shaped by the nurses' clinical grasp of particular situations. Four possible clinical situations describing withholding or discontinuing life support were identified within the study data:

1. Do-not-resuscitate (DNR) with continuation of aggressive therapy. Patients continued to receive high tech diagnostic and treatment interventions but would not be resuscitated in the event of a cardiopulmonary arrest. The nurses continued to take frequent vital signs and titrate medications. This designation was identified as common with patients who had terminal diseases (e.g., cancer) but were being treated for a potentially reversible problem (e.g., cardiac dysrhytmias).

2. DNR with status quo intervention. Technology and current interventions (such as the ventilator and vasoactive drugs) were continued, but the focus of care switched from

cure to care. Additional technology or aggressive diagnostic interventions were limited, and patients were not to be resuscitated. Patients died with technology in place. The nurses continued to care for the technology with less vigilant monitoring and more focus on comfort and family care.

3. DNR with complete or partial withdrawal of life support. Any or all technology could be withdrawn, including the ventilator, monitoring equipment, drugs, or intra-aortic balloon pumps. Sometimes everything was withdrawn at once; sometimes technology was withdrawn in a sequential manner until the patient died. Patients were either extubated, the endotracheal (ET) tube left in with the ventilator removed, or the ET tube was left connected to a ventilator with the oxygen setting turned to room air. Terminal weaning as defined in the literature (Campbell & Carlson, 1992; Grevnik, 1983) was neither seen in observations nor discussed in nurse interviews. Patients were expected to die, and the care was focused on comfort and family care. The particulars of care depended on how quickly patients died. Sometimes they died immediately after withdrawal of support, sometimes they deteriorated steadily over a period of minutes or hours, and sometimes they lingered beyond hours for days (or more if vegetative). If patients did not die within a few hours, they were commonly transferred out of the critical care unit to a less

acute part of the hospital.

4. No DNR, no resuscitation. In this situation, patients were allowed to die without a formal decision-making process based on obvious futility. A DNR order was not written, but nurses and physicians understood that patients were neither to be resuscitated nor treated aggressively. These patients were either connected to technology, or it may have been withdrawn. Since cure was not possible, the focus was on care.

Although many patient situations described in this study did not involve withdrawal of life support, the topic surfaced regularly in group interviews. Life support, primarily ventilator support, was withdrawn in five of seven family accounts and seven of eight observations (some overlap between family interviews and observations). The data showed little evidence of communication about the technicalities of withdrawing life support between health care professionals beyond directions on what to leave in place and what to remove. There was nothing in organizational policy and very little in the nursing literature to guide them. Often physicians and/or nurses seemed unclear about the best way to accomplish the task, and nurses reported that they learned by experience.

In the most common scenario related to withdrawal of support, once the decision-making process was completed the physician wrote an order for extubation and sedation, then

left the unit. The nurse dealt with the technical aspects of discontinuing the life-sustaining technology, providing comfort, and supporting the patient and/or family as the patient died.

Paradigm Case: "It Was Quiet"

The following is a narrative in which a nurse, Joan, described how she orchestrated the patient's death. David was a young man who had received a cardiac transplant and was now unresponsive and supported by a respirator and a ventricular assist device. The medical team had tried everything, but the nurse realized that the patient was going to die. The physicians also came to that conclusion, and the family said, "No more". The family requested that he be comfortable, and his wife, Beverly, wanted to be with him when he died, although she didn't think any other family members needed to be there.

> I let her in and while she was talking to him, the patient's blood pressure began to dip further and I said, "The blood pressure's starting to go now. He may begin to feel some anxiety, you know, he may be able to feel something at this point. And if you are ready, I'll give him this medication so that he will be totally pain free." And she says, "Okay." She said her last piece and I gave him the medication. And he began to sink a little further and coincidentally the epinephrine infusion ran out. And he began to fade a little faster and I just came through the curtain and asked the cardio-perfusionist that ran the assist device to come and clamp off the device. I thought there was no benefit to keeping this guy's blood pressure at 30. He clamped off the device and the instant it was closed, the patient went asystolic. I turned off the monitors and everything. It was quiet.

This is an example of managing death in critical care. The

nurse, Joan, entered and facilitated the dying trajectory to bring about a peaceful death for the patient. She created a space for Beverly at the bedside and assured her privacy by pulling the curtain. Rather than controlling David's dying, the patient's deterioration guided her interventions. She stayed focused on the natural rhythm and pace of the dying by allowing the drug to run out and asking the perfusionist to discontinue the ventricular assist device when the systolic blood pressure dropped to 30. Joan kept the patient comfortable by giving the sedation. Her final action of turning off the monitors in the room and the quiet that ensued created the space the wife needed to begin her grieving. After David died, Joan waited outside the room until Beverly was ready for other family members to join her.

Space

The nurse caring for the dying transplant patient in the paradigm case created a private, almost existential space for the patient's dying. She pulled the curtain, and entered that dying space with the patient's wife. Some nurses expressed a feeling of privilege at being a part of the dying space. One nurse described her feelings:

> It makes me feel so special that I can be that intimately involved with somebody's life at that particular moment in time which is not going to be any other moment in their life. It's not like next week she's going to be going through this again and I wonder what somebody else is going to say to her. You only have that one little window of time to hopefully say what you think. To be the last one to help that

person.

She went on to describe how sometimes when she is caring for a dying patient she looks out the window and sees the everyday activity of people walking down the street and feels overwhelmed at being present and involved in someone's death, understanding how profound this work is.

Given this sense of privilege, these nurses worked hard to create an appropriate space for a peaceful death. The environment was modified by dimming room lights, silencing alarms and removing excess equipment or residue reminders (like overflowing trash) of failed resuscitation attempts. Often the monitors were dimmed or blacked out all together to facilitate the family's focus on the patient instead of the numbers and waveforms which marked the patient's decline.

Families were invited into the space and the nurses tried to make them feel as comfortable as possible in the unfamiliar environment. Families were encouraged to be in the room as much or as little as they wanted; visiting restrictions were suspended and often even the youngest family members were welcomed. The nurses tried to create a sense of privacy even where there was none by pulling curtains and closing doors. Other strategies included making sure that there were enough chairs for family members to sit in, and providing tissues, coffee, and other miscellaneous conveniences. If family members seemed unsure

of how to interact with the patient, the nurse showed them how to touch and talk to a dying patient. They also explained unfamiliar equipment and told them what to expect when the patient died to help them to feel more at ease. This dying space was a vigil, a space and time where families said good-byes and resolved issues. The nurses recognized the importance of the dying space for patients and families.

The following is the description of how a nurse created a space and facilitated a good death experience for a woman despite obstacles.

> She was out in the middle of an open [room], but heck, I don't care, pulled the curtain. And they came in afraid to [approach her]... And I said, "Talk to her and tell her what you want her to know. Tell her all the things that you need to say to her." "Well can she hear me?" "I don't know. We have to assume that she does." They took turns being over nearest to her and her face and they talked right down near her and her face and kissed her and loved and held her hand and talked. An I'm standing there bawling. But it was great because they were amazed that they were allowed to do that. They were a real tight knit family. A big family. And there were kids too and everybody was in at one time. None of this two at a time stuff. Cause she was going to go, I mean, in a minute here folks.

Nurses entered the dying space with the patient and family, often with a feelings of reverence and respect. They tried to modify the environment to minimize the technology and addressed the comfort and needs of the family as the patient died.

Time

The nurses understood and sometimes exercised

techniques and technology to predict and assist the timing of death. In the paradigm case, as David died, Joan observed the monitors to gauge her actions as she administered sedation, allowed the vasoactive drugs that were maintaining his blood pressure to run out, and asked the technician to clamp off the balloon pump. Related to this manipulation of technology, this practice of regulating dying was identified as unique to critical care. As one nurse explained,

> Coming from the floor where a lot of patients died; you didn't have the control over their death and the timing of it, I guess. And in the ICU, you know certain meds, if you stop those meds they're going to go much quicker or you know because of the ventilator settings that they're doing worse or the O2 sat (oxygen saturation) monitor. All these things that on the floor you don't have. You just walk in one day and your patient's not breathing any longer and they're DNR and you say a prayer of whatever. You don't have as much control over the timing. Where in ICU, you do. And therefore, you have all this equipment, more medication. You have more ability to control the time and everything.

Although the nurses often referred to this process as "control", they were in fact easing the patient and family through the dying transition. As the patient waned, the monitors showed the falling heart rate, blood pressure, and oxygen saturation. Alarms highlighted changing rhythms and respiratory effort. Vigilant nurses had the opportunity to gather family, friends, ministers, and other supports to be with the patient and to participate in the end of the patient's life. Nurses affected the timing by manipulating

the technology, using sedation, positioning, and talking to patients.

When physicians wrote an order to extubate a patient, the actual act of discontinuing the life support, which often resulted in the patient's immediate death, was left up to the nurse. In the following excerpt, a nurse talked about a patient dying of complications of AIDS. The decision was made to extubate the patient, who was awake but not alert.

> The doctors, of course, washed their hands of it and left it up to me to decide when this guy would die. Because it was clear that, once we extubated him, he would die. And I kept trying to say, "When are we going to do this?" And finally I really sat down and talked to myself about what this meant for me and what was going to happen to this guy and finally decided that I could do it. So the respiratory therapist came in and we extubated him and the guy talked for a little while and wanted a chocolate chip cookie, and then just sort of faded.

It was difficult for this nurse to extubate the patient, knowing that her actions would result in his death. The temporal relationship of her actions and the patient's death were inextricably linked, and resulted in moral dissonance. Since technology sustains life, the act of withdrawing the life support systems was sometimes construed as imminently causing the death, even though it was certainly the disease that truly caused the patient's demise. How the nurses dealt with the moral consequences of the responsibility of being the "agent of death" is discussed in chapter V.

The order to withdraw a respirator or other life

support measures was usually accompanied by an order to sedate the patient. Sometimes sedatives were given before, and sometimes after the respirator was removed. In one case, the patient was placed on a morphine drip before extubation which the nurse continued to titrate afterwards. Physicians commonly wrote orders giving the nurses lattitude to titrate the medication to the patient's symptoms. Morphine or tranquilizing agents such as Valium or Versed were used to allay the symptoms of suffering accompanying death, such as pain, anxiety, and air hunger. These drugs also suppressed respirations and in some cases expedited the death. Nurses understood that even though a patient was unresponsive, any signs of suffering were particularly distressing to family members. This nurse described a death within her own family, in which a close relative died from complications of cancer treatment.

> The most rewarding thing was when he finally died, it's like relief. And he had a major seizure. His mother goes flying out of the room and she's like, "He's shaking and I can't watch this. Do something!" And all I remember is some blessed nurse came in with a 30 cc syringe and I have no idea what was in it and I do not care to this day, shot it in and he was finally at peace. And he finally died.

Even though the family knew that the nurse administered the medication that immediately resulted in the patient's death, they did not blame the nurse. Instead, they were grateful that his suffering was over.

In contrast, holding sedation prolonged the dying in some situations. In the following narrative, the nurse gave

sedation sparingly, hoping to forestall the patient's death until all family members had arrived.

> I had given her some morphine and they were concerned about, there was one other family member that they were trying to have get there. And she actually finally did make it, but they weren't wanting me to give her too much morphine or anything for fear that she would go faster. She lingered a couple of hours from the time we put her on the airway. Just enough time for all the family to be there.

This nurse administered drugs cautiously and conservatively, balancing the patient's comfort with the family's need to assemble at the bedside before she died.

In knowing the particular patient and having experience in titrating particular drugs with many dying patients, the nurses were often skilled in balancing the right amount of sedation. Subtle assessments which were sometimes ineffable guided them in giving just the right amount of a drug. In one observation the nurse gauged morphine administration initially on the patient's restlessness, then later on the assessment of the patient's "agonal breathing". The agonal breathing, deep gasping respirations typically seen at death, was difficult to see since the patient was ventilated, but as soon as her breathing eased, the difference was obvious.

Since sedative drugs, particularly morphine, often do have the physiological effect of suppressing respiratory effort, they could potentially hasten death. The nurses needed to understand how much sedation was enough to prevent suffering and not enough to "kill" the patient. Although

the nurses sometimes referred to administration of sedatives as "killing" the patient, this did not denote any purposeful action to hasten death on the part of the nurses, but rather a sometimes unavoidable consequence of making the patient comfortable. The moral responsibility for "walking this line" is discussed chapter V.

It was interesting to note that some patients did not receive sedation. Those included, but were not limited to, patients who were not perceived as being able to experience suffering, such as those with no/minimum brain stem functioning. One nurse expressed an opinion that sedation, in fact, prolonged the dying and therefore the suffering.

Nurses also talked about how other care procedures could influence how slowly or quickly a patient died. In one example, a patient's blood pressure began falling while a family member was in route to the hospital from the airport. The nurse placed the patient in Trendelenburg position to maintain the blood pressure until all the family arrived. She also did not turn or suction the patient, for fear of causing hypoxia that would "rock the boat".

Nurses commonly talked to patients at the end of life, encouraging them to "let go", that it's okay to die. Giving them permission to die and to leave their loved ones behind was another practice perceived to affect the timing of death. This practice is not unique to critical care nursing, and is discussed in hospice literature (Callanan &

Kelley, 1992). These kinds of practices, including talking to patients and bringing family members to the bedside, are based on the understanding that patients sometimes do not let go of life until they are ready or certain conditions have been met.

Comfort

With no exception, patient comfort was a care priority for the nurses in this study. The nurse caring for the transplant patient in the paradigm case sedated David so that he would not feel discomfort as he died. According to one nurse,

> I don't want people to be in pain. I personally believe that death, you know, I believe in heaven. So I hope that everybody that dies is going to be peaceful. And when they're sick and sitting there fighting for air, I don't feel bad that they're going to die. I just want to make sure that it's not rough getting there.

Comfort was understood as physical sensation that included but was not limited to pain caused by disease or technology. Other sources of discomfort described were air hunger, nursing or medical procedures, and positioning.

The nurses used several parameters for assessing a patient's pain. If patients were able to respond, nurses frequently asked them if they were in pain. Since most of the patients in this study were unresponsive and on ventilators, the nurses relied on other ways to assess pain. Nurses relied on family members to assist. In more than one observation the nurse asked a family member if and where the

patient usually had pain. Further, they gained perspective from the family member regarding how the patient usually responded to pain, what measures worked to control the pain, and incorporated that information into their assessment.

Other indicators of pain included facial grimacing, restlessness, changes in blood pressure and heart rate, and level of sedation. In one observation, an elderly patient with a chronic neurological disorder had been having severe back pain prior to being admitted to critical care for respiratory failure. The patient was intubated, but awake. She was lying on her side in bed, restrained and struggling. She was breathing rapidly, triggering the ventilator with quick, rapid breaths. Her neck was hyperextended and her position looked very uncomfortable. She was grimacing, extremely agitated, and silently screaming around the ET tube. The nurse's first priority was to get an order from the physician to increase the morphine order and administer it. When, over the course of the day, the patient still was not able to rest, the nurse asked the physician to add a tranquilizer, and the patient was finally able to rest comfortably.

In their commitment to control patients' pain as they died, the nurses dealt with issues related to over or undersedation and iatrogenic pain. The possibility of oversedation was an underlying concern. If patients remained ventilated, the fear of immediately suppressing

respirations was not as pressing, and nurses felt freer to give larger doses of sedatives. If support had been withdrawn, they sometimes struggled with decisions about how much medication was too much. However, one nurse expressed that "a morphine death looks a lot prettier than a non-morphine death from our perspective".

In one situation, a family member of a long-term patient expressed concern about the sedative effects of analgesics and tranquilizers and possible addiction. Although the nurses understood his desire to have his wife be present (and alert), their perception of her suffering without pharmacological support moved them to continue to medicate her. Addiction with dying patients was not a concern addressed by any of the nurses in the study, although they did raise the issue of drug tolerance and the need to increase dosages on long-term dying patients.

Nurses were concerned with doing procedures which they believed to be painful and unnecessary with patients who were approaching the end of their life. In one situation, the nurses were very attached to a young woman dying from complications of cancer treatment who they had cared for over several weeks.

> I would try to weigh high tech with just tender loving care and I would, when I came on I'd think okay now, do I really need to be taking this blood pressure every hour. I mean, this woman needs her sleep. She's been up all night... She hated the non-invasive blood pressure cuff, hated it. And they hurt. Okay, why don't we relax a little bit on this blood pressure thing, you know. (Another nurse agreed, making fun of

their "anal attentive" need to take a blood pressure every hour.)

In other situations, the nurses would question the need for (or just not do) procedures that were invasive or would cause the patient to be placed in uncomfortable positions, for example blood draws from the lab, finger sticks for glucose checks, x-ray procedures or enemas. They frequently did not turn and reposition a patient on the customary every two hour ICU schedule if the patient looked comfortable or if they would have to interrupt the family to accomplish the task. This change in focus represented the shift from a cure to a care modality.

In summary, nurses managed the death of patients by attending to space, timing, and comfort. They created a peaceful and respectful space in which the family could be comfortable as the patient died. They sometimes manipulated technology to facilitate death, or in other situations where family members were not yet gathered, used a variety of practices to slow the dying process. They carefully attended to assessment of dying patients' discomfort and pain, administered analgesics, protected them from uncomfortable application of technology, and employed other practices to make patients comfortable as they died.

Specific Caring Practices

Beyond managing the death, nurses incorporated specific practices that had particular relevance for the care of dying patients. They humanized nursing practices through

use of touch and talk. Timing and priority of routine care was modified when the focus of care changed from cure to care. In the absence of one narrative that captures all caring practices, exemplars are used to explicate the caring practices embedded in the data.

Humanizing Care

Nurses admitted that it was easy in the critical care unit to forget that the patient was a human being. They were aware that even the language surrounding death can be dehumanizing, for example "harvesting" organs after death. In order to regain that human focus, they incorporated strategies into their care to "try to provide some respect" to patients and their bodies. Nurses gained perspective on patients as people primarily through the family.

> The family did make their mother very real to me. I asked a few questions about what she liked, but they were grieving already and like you would do at a wake or whatever. They were talking about what kind of a woman she was and things and they let me be a part of that. That was nice. They were kind of talking among themselves. I didn't feel like I was hindering the discussion, and was able to, you know, which made the woman more real to me. That's one of the hardest...part of the problem is people aren't real. I mean, it's a body lying there with a lot of machinery and you know, I always ask them to bring in pictures or something so I know, I just have a vision of what this person was like. It makes them a human being. I mean, no matter how banged up their heads are or how many dressings they have or how many extra liters of fluid they have on board now, that gives me an idea of who they were. ...That they were a real person in a real active family that did things. They were a vital part of the family, and we don't get that. It is a story we don't have. If I see a picture on the wall of this person with one of their family members it's like, "that is a person". Instead of that is my job.

This patient became human through pictures and learning about the patient as a person before her hospitalization. Other personal belongings brought into the room by family members also helped the nurse to know the patient. Although sometimes families initiated these kinds of insights, it often took effort on the part of the nurses to find out about the patient. In some cases there was no family involved, and the nurses could only relate to the patient in the present. It was important to the nurses that patients looked clean and neat, and they commonly touched and talked to patients in a respectful, caring way.

Touch. Nurses touched patients who were dying in the process of completing procedures and basic care, but more importantly to comfort them. They commonly stroked their faces or arms as they were talking to them. If the patient became agitated they tended to touch them less. In contrast, they touched patients more if they were involved with the patient. In the following excerpt, the nurse had cared for this patient for several weeks, and recognized the importance of touch.

> At first she wasn't a real touchy feely person, but towards the end she was much more. Wanted to hold your hand. Sometimes she was just scared and she wanted, I'd say, "Are you scared?" Just wanted to held your hand, wanted to hug you, wanted to touch you. She was constantly reaching up for your hair and she'd hold it up to your face and she didn't want to be alone. She needed somebody to touch."

Touch was an important part of the relationship between the nurse and the patient in this situation, and reflected their

mutual involvement.

Families were often afraid to interact with patients dying in the midst of critical care technology. The nurses frequently coached families to touch patients. The following narrative is an account of a nurse responding to the needs of a mother to touch her dying child. This adolescent had tried to commit suicide, and was brain dead and maintained on a ventilator.

> The mother was so distraught that she couldn't touch her daughter. And she just kept telling me, "If I can hold her, if I can just hold her one more time." So I put the side rail down and she went up and laid her head on her daughter's chest and just kind of held her and so then I just scooted her to the side of the bed so her mother could get up and crawl in bed with her and just kind of hold her daughter. And I felt really good about that. Letting the family come in and be with her and her brother was able to come in as well and just kind of hold her and get close to her, you know, while she was still warm.

Although understanding that this was not appropriate for every situation, this nurse went on to describe how she routinely helps families to touch the patient when the patient is dying.

> My typical scenario when a family member is in the active process of dying, you know, we've withdrawn support is I let the family come up and hold them. A lot of times they're not in as good condition to be held as she was. Usually they've got central lines , IVs and are on vasopressors and I try to get as much equipment out of the room as I can. And a lot of the time what I usually do is just encourage them to hold hands and they'll stroke their arms. Which is a safe, safe place, you know.

This nurse and others advocated removing any possible technology to make it easier for the family to be close to

the patient. They observed physical responses to touch, such as increased blood pressure and heart rate on the monitor, as an indicator of a patient's level of consciousness and emotional state of arousal.

Talk. Even if patients were unresponsive, nurses related to them through the embodied skills of touch and talk. The importance of talking to patients as they died originated in the pervasive belief among the nurses that hearing is the last sense to be lost; even though unresponsive patients can't respond, they can hear. Nurses talked to all patients almost every time they approached the bedside, telling them what they were doing and explaining any sensations they might feel. They became uncomfortable when anyone talked over the patient or within earshot of the patient about the patient's condition, and often asked physicians or others to continue their conversations elsewhere. This understanding that unresponsive patients can hear was conveyed to family members, who were encouraged to talk to their loved ones as they died.

The nurses sometimes talked with patients about their impending deaths, which was seen as more difficult than talking with families. They explained the process of discontinuing life support to patients, and what they might feel. Although most patients were unresponsive as they died, the following nurse described her interaction with a patient whom she had cared for over several weeks and who

had requested to be taken off the ventilator and allowed to die.

> She knew she was dying, and we talked about how it would feel to die. Because she would become oxygen starved, I talked about the fact that we'd make her comfortable by giving her drugs so that she wouldn't feel pain. That she would start getting, she would lose her thoughts and start being confused. People might talk to her and she might not understand, and not be able to converse back. And she seemed to, and then she would nod yes and mouth words like she really understood and she was ready for this and she knew that she couldn't go on like this anymore.

In this way, the nurse coached her about what to expect in preparation for taking her off the ventilator. She described what the process of dying might feel like in order to alleviate the patient's anxiety.

The nurses felt that it was important that someone be with the patient as they were dying, and would remain at the bedside if the there was no family or if the family chose not to stay. The nurses talked with patients as they died, repeating a similar message in all settings.

> One of the memorable but extremely brief experiences that I had with the death of a patient who was an elderly gentleman who had been there for probably a couple of weeks and I really don't recall what the diagnosis was because I was on the periphery. I maybe had taken care of him a couple of times. But this particular day he wasn't my patient. He had been made a DNR. I knew he didn't have family, and I was just generally aware of what he had been through...His nurse had gone to lunch and asked me to watch him. And unbeknownst to me, I checked his room and he had extremely low blood pressure. And I noticed that he was bradying down and obviously dying. And I didn't really know much about his mental status at that time, whether he had been alert and conversant or anything. He didn't appear to be responsive much at all. But I never did feel comfortable just letting a patient die by themselves. And so I just went in the room and I

> talked with him and I just comforted him. I rubbed his head and I used his name. His eyes were kind of half open. I didn't know if he could hear me or not. I just talked to him and told him it was okay. It was okay to let go. That he had been through a lot. That he deserved some peace finally. That he had tried really hard. What a good job he had done, but that it was okay now to let go. And I just kept saying things like that to him and touching him and kind of rubbing his head like I would my child. In the whole time, not knowing if I was talking for my benefit or his. But knowing that it was something I needed to do. And I could see him gradually, you know, his heart rate as he was monitored, he was just gradually, almost asystoling (heart stopping), his eyes were closing, his respirations were slowing. And he was finally asystolic and his respirations stopped and as his eyes closed, a tear rolled down his face. And it was so significant to me and something I will never forget. Making me realize that yes, indeed, he heard me. And we never know if our patients are aware. And a lot of times we assume they're not aware or they can't hear us or they're not responsive. But I really feel he heard me. And it mattered and what I did mattered. And it was a really wonderful experience.

The nurses described a similar script repeated with many dying patients. This ritualistic talk included validation of their struggle to survive, reassuring them that their families loved them and would be okay, and that it was okay to die when they were ready to.

The nurses were concerned with humanizing their care for dying patients. This was sometimes difficult, particularly if the patient was unresponsive and had no family. The two most common strategies that the nurses used to humanize their care were touch and talk. They also encouraged or taught family members to interact with the patient at the bedside.

Routine Nursing Care

During the time that patients were dying, nurses continued to deliver basic nursing care, including monitoring and treatment activities related to specific technologies. The frequency of these activities varied related to the nurses' understanding of when the patient would die. The pace of care was slower, and less focused on the clock. Nurses administered basic hygiene, and turned and repositioned the patient. But if family members were at the bedside or if the patient looked comfortable, the care often waited. The patients continued to be monitored, but vital signs and other parameters were assessed and documented less frequently (usually every hour or two) and less regularly. Monitors were no longer used to guide treatment, but more as a tool to assess the patient's physical responses to family or nursing care or to observe the progress of a patient's dying. Nurses were less compulsive in attending to medically ordered treatments, such as IV rates, tube feedings, and blood glucose sticks. They also made suggestions for discontinuing diagnostic therapies such as lab draws and x-ray procedures. Care was organized around comfort as a priority rather than treatment.

Specific caring practices changed when the nurses recognized that the patient was dying. They tried to show respect for the dying patient by incorporating strategies to

humanize the particular patient's care, such as touch and talk. When the family was present, the nurses often attempted to find out more about the patient as a person, which gave them further understanding of the meaning of the death and impacted subsequent care of the patient and family.

Family Care After the Patient's Death

After patients died, the nurses encouraged family members to stay in the room until they were ready to leave. Usually nurses remained within calling distance, but outside the room, checking in periodically to see if family members needed anything. The nurses removed any remaining tubes or technology possible, and often washed the patient so that the family could be close to them after death. The following narrative describes one nurse's care of a family who lost their newborn after surgery for cardiac anomalies. The parents were allowed in the room during the final resuscitation effort, and made the decision to let the baby die.

> ...And I said, "Are we going to leave this ET (endotracheal) tube in?" And they took out the tube. They clamped off the lines on the CVP (central intravenous line) and he was put in their arms... The parents held him and took turns and the grandparents and they were in there a long time... I was hugging them and reminding them what good parents they were. They had advocated for this baby the whole time. Lots of kleenex was in there and I told them I was going to give them space. Told them that I would hear my name if they called. And I just kind of kept tabs but the curtains remained closed and the door. And they stayed in a long time. And they wanted their toddler to come in, and the grandmother brought him in. But I think

> initially that most important thing was, "I was holding my baby. We were a family for that few minutes. Even though he was black (cyanotic)."

These practices occurred consistently after the death of adult patients also, as evidenced in both interviews and observations. The nurses created a space for family members in the room for as long as they needed to stay, and affirmed and supported the difficult decisions they had made. They removed the technological barriers between patients and their families, such as endotracheal tubes.

In some situations, the nurses helped the family to see symbolic meaning in the dying that they could take away with them. The nurse telling the following account knew the family well, although she wasn't taking care of the patient the day she died. The patient was an elderly woman with end stage respiratory failure, and the nurse talked with her son after she died.

> So I went out and talked with him. He was by himself and the nurse was kind of cleaning the patient up and he was going to be coming back in the room again to see her one more time. So I went out in the waiting room and the chaplain was with him. And I just wanted to tell him how sorry I was and that he'd been through a lot and I felt bad about it and that I knew she was comfortable and I told him how I'd gone in and seen her that morning and he was crying. I said something about you had just gotten here and he said, "I wasn't in there five minutes." And I said, "Well, that was really special, you know, that you were able to be there before she died." And he said, "Yeah, it's almost like she knew." And I just, you know, you agree and it's like you never know.

The nurses worked to help family members find meaning in the dying, and were concerned that they begin to find some

resolution before they left the hospital.

Nurses sometimes attended funerals of patients with whom they had been especially involved. Even weeks after the death event, some nurses had contact with family members. For example, in the above narrative where the newborn died, the mother maintained contact with the nurses in the unit.

> They kept contact for a couple of years. [The mother] wanted to know if she could come up and feed babies and we put her in touch with that area. I don't know if she ever did. But she did come and at the time we had a baby who didn't have a mom that was involved and she came into that room and talked to that child and we haven't seen her back in our unit since. She said then, "I feel like I've helped someone else."

The nurses were available until the mother apparently resolved her issues and no longer needed to maintain that contact. In another situation, the daughters of a patient who died of Guillian-Barre asked a nurse out to lunch in order to get more detail from her about their father on the night he died. "We all cried together at lunch. And they sent me a real nice card and everything. They were real thankful."

Some of the critical care units participated in a bereavement program, in which nurses called family members at scheduled intervals after the patient died. Although some nurses regularly contacted families, others did not believe that it was always appropriate or helpful. After the particularly tragic death of a young man from

complications of cancer treatment, one nurse talked about her feelings:

> I think that was one of the cases that made me feel that the bereavement program was not something that I felt was a particularly good thing. And that was that every time I would call the family member it would just bring back the event of the death. Back fresh again and just tear everything open and people were getting on with their lives and trying to heal those things up. They'll have time to remember when they're ready to remember rather than getting a phone call.

Other nurses expressed similar feelings, for example, about not being sure how to act when seeing family members after the death, not wanting to bring painful memories back to the family.

Nurses continued their work with families after the patient's death by creating a space for them to begin grieving. If the family needed to maintain contact, they were open to being available as the family dealt with unresolved issues. In some situations, they attended funerals or made bereavement calls. However, these contacts outside of the hospital were not universally supported by all nurses.

Summary

Expert nursing care of dying patients was contingent on an accurate grasp of each patient's clinical course and the particular responses and concerns of the patient and family. This clinical grasp was the result of the integration of salient clinical information, understanding of the patient's particular symptoms in the context of many experiences, and

personal values related to dying and what it means to be part of a family. Acting on these perceptions, the nurses provided meaningful and effective care to dying patients and their families in a variety of situations. The nursing care was based on the demands of each situation, as well as the DNR status and related treatment plan. The potential for conflict existed when different members of the health care team had different clinical grasps, and therefore different care priorities.

The nurses often understood that patients were dying before families or physicians, and worked to bring the others to that realization to create a positive, synchronous situation. The nurses sensitively disclosed and interpreted information about the patient's condition to family members and encouraged them to discuss the patient's wishes. They facilitated communication between families and physicians, and organized care conferences. The nurses further supported decision-making by advocating for patients and families, sometimes at risk of conflict with physicians.

Although nurses cared for dying patients in a variety of situations, in the most common scenario physicians wrote orders for nurses to discontinue life support and sedate patients as they died. Nurses managed the dying process by withdrawing technology, providing comfort, and supporting the patient and family as the patient died. They created space for the death which was private and encouraged contact

between the family and the patient. They facilitated the dying transition by manipulating technology, titrating sedation, encouraging patients to "let go", and using other nursing strategies which affected hemodynamic stability. They incorporated humanizing strategies into care of dying patients, commonly touching and talking to them during care.

Although nurses continued routine care practices such as hygiene, assessment, and nursing procedures, the shift in priority from cure to care was accompanied by less concern for these practices. Instead, they focused on coordinating and orchestrating the dying and the death. After a patient died, some nurses continued their support of family members until they left the hospital, and occasionally interacted with them later through bereavement calls or contact initiated by the family.

CHAPTER V. RESULTS AND DISCUSSION: INTERPERSONAL CONCERNS AND BACKGROUND MEANINGS OF CRITICAL CARE NURSES

Critical care nurses work within a technological culture that, by it's very nature, values cure and instantaneous therapies. Yet each critical care unit has it's own unique characteristics that constitute and are constituted by the nurses who work there. In addition, nurses bring to the bedside and work environment their own personalities and values, culturally and genetically determined by growing up in a family, community, and society. As such, the background meanings of each nurse, which make up their perspective and sense of reality, set up what matters to them as they care for patients. This involved concern influences what is important in patient care situations, and guides practice.

One way to understand these concerns and meanings is through interpretations of everyday narratives and experiences such as those depicted in the interviews and observations of this study. In order to understand the expert nursing care of dying patients described in the study, it is important to explicate the background meanings and concerns of nurses that shaped and influenced those practices. Recurring themes that provide insight into the nursing practices described in the previous chapter include the meaning of death, ethical and moral meaning, the health

care organization, physicians, and family care.

Meaning of Death

The meaning of a patient's death varied across nurses and situations. This discussion will describe critical care nurses' shared understanding of death and dying in the ICU and their common emotional responses to patient deaths. The description of the meaning of death incorporates reflective thoughts about caring for dying patients that is based on nurses' experience with many deaths. Next follows a description of aspects of a good death, described in contrast to a bad or empty death. Cases which capture the central issues, concerns, and recurring themes are presented followed by interpretive analysis. Finally, an interpretive discussion of the emotional responses of critical care nurses incorporates supportive exemplars from nurse interviews.

The meanings and concerns represented by the nurses in this study are somewhat homogeneous given their expertise and experience in working with dying patients. However, individual variations certainly existed. Most of the nurses interviewed described past personal experiences involving an actual or threatened death to themselves, family members, or friends that stimulated reflective thinking about death and interest in care for dying patients.

Some nurses expressed their understanding of "death as a normal part of life". Several others commented that part

of their work as a critical care nurse was caring for dying patients.

> A lot of what we do is geared towards saving people. That is the ultimate and that is what we try to do. But a lot of what we do is we help people die. At least that's what I do. I just had a friend in from out of town that I hadn't talked to in a long time and he hasn't been around when I've been doing a lot of this. And trying to explain to him that, you know, I've watched a lot of people die. But that sounds to the average person like such a negative thing. And he said, "How can you do that?" And I said, "Well, it's a really positive thing. It really can be."

Acknowledging the avoidance of death that exists in our society and in critical care units, one nurse pondered, "I think death is a reality and it's hard to understand and it's hard to grasp and it's hard to live with." They admitted that many of the issues surrounding death in critical care are not openly discussed, and that excellent practice in this realm is not often recognized or rewarded. Rewards come primarily through family gratitude, personal feelings of having done a good job, and sometimes supportive colleagues.

Most nurses did not talk about dying in spiritual or religious terms, but some talked about death as transcending the event.

> It's a real honor to be with someone when they die. And I really, truly consider it an honor. It's as important to me to be with someone when they die as it is when they're born... That's where I come from and that's why I do it. That's such a special time. It's a passage on to whatever belief, whatever life, whatever space. And how special that I can be there for that.

References to religious interventions with dying patients

and their families were carefully couched within the context of the patient's or family's beliefs. For example, one nurse, knowing that the patient and his family had been extremely involved in the Methodist church all his life, talked to the patient about his dying as an "Easter promise".

Practice experience with death caused changes in perspectives. They learned that death was universal and sometimes "for the better".

> When I think back to when I first started nursing, to be successful your patients don't die. And you take it almost as a personal insult if your patients die. And as you get further along in nursing, whether it's a degree of comfort or whether it's because you now realize that not everybody makes it. And it's good that not everybody makes it.

Dying seemed more emotionally draining if the nurse had developed a relationship with the patient or family, if the patient was suffering, or if the death was unexpected or violent.

Good Death

Despite the intrusions and implications of technology and the environment, the nurses felt that it was possible for a patient to experience a good death in critical care. The following situation was described by a nurse who recognized the family of a church member as she passed the waiting room of another critical care unit on her way to lunch. The patient, Joel, who had been hospitalized with pulmonary complications of AIDS, was dying. She

subsequently spent her break involved in the bedside vigil.

The patient's partner was interviewed at a later date. Since the nurse entered the situation late, the family interview data is used to fill out the background details. However, the story is told from the perspective of the nurse.

Both the family and nurse considered this to be a good, even extraordinary death. The nurse described Joel's death as "by far the most beautiful death I have ever witnessed". The reason for this was that the patient was "the boss". The patient had been experiencing progressively more pain, and had become debilitated and dependent over the preceding weeks. He was admitted to critical care in respiratory failure, and placed on a ventilator. He was awake, but sedated. When his partner came in to visit that morning, Joel was restrained. The nurse told him that he had been trying to pull out the endotracheal tube during the night, and that she thought that the patient didn't want to be maintained any longer on the ventilator. His partner spent some time with him and felt that indeed, he didn't want to prolong his dying any longer. He approached the physicians requesting that life support be withdrawn. The patient's family, including his parents and many friends, gathered at the hospital. They visited freely, verified for themselves that the patient did not want to continue, and attended a care conference. At the conference, the physicians asked

that Joel's sedatives be discontinued for several hours so that they could ask him directly about his wishes. During the waiting time, the nurse was available to assist the patient and family as needed.

> The whole staff worked as a team so that the nurse was there when she was needed to be there. She did for him what he needed. He looked very clean and comfortable when I went in. Cared for. Groomed. Dignified.

After a waiting period, Joel was asked what he thought, and he verified that he did not want to continue. His family and friends, including the nurse telling the story, gathered at his bedside as the nurses prepared to extubate him.

> His partner asked him if he had everybody there now that he wanted. Was now the time? Was he ready? The nurses asked him if it was time to take out the tube. They talked about pulling the tape off, and it's going to hurt a little bit but we're using this stuff to make the tape less sticky. You let me know when you're ready. Raise your thumb. And he gave some kind of a signal that it was okay. He'd had the secretions removed. He'd come back to a spot of not being out of breath, now the tube could be pulled. So it was a very easy extubation. There were no secretions there to make it awful. And they asked how long is it going to be? And the nurse said, "We don't know how long it's going to be. It will be as long as God and Joel need it to be."

The patient was not sedated, and did not live long after the extubation. The family remained at the bedside until after he died.

> Everyone just held everybody, circling the bed, holding hands, touching some part of him or the sheets or the covers and each other. It was the most intense worship or encounter that I've been in. There was cheyne stoking type respirations for a moment, then one final breath. And afterwards there was no big sobbing at all. There was everyone hugging everybody that was there. I think they were extremely appreciative, the whole family, of so many significant people allowed in

> the ICU. The curtains were drawn. You didn't feel like you were being observed.

The nurse caring for the patient remained outside of the curtain but within easy calling distance. She re-entered the room to turn off the monitor and verify that he was dead, then everyone prayed. The family stayed in the room for awhile, his partner staying last to say his good-byes.

This narrative exemplifies many aspects of a good death in critical care. The patient was physically well cared for. He was comfortable and clean. His dying was acknowledged by the health care team and the family, and his choice for discontinuing life support was respected without controversy. There seemed to be good communication between members of the health care team and between the health care team and family. The family was not divided by disagreement or animosity. His death was not so fast that the family did not have time to prepare themselves, and not so slow as to prolong suffering. Space was made to accommodate his dying, and family and friends had ready access to him. He was not alone, but had loved ones at his side who talked to him and touched him as he died. Once the decision was made and the endotracheal tube removed, he did not linger, and death was allowed to take it's course without additional biomedical intervention. His death was not violent, and he did not struggle. The patient remained the center of the experience throughout. His family was able to find peace and leave the hospital feeling that his death was beautiful and

meaningful. These were aspects of good death also expressed by nurses in other interviews and observations in the study.

Breakdown

In contrast to good death, nurses described situations where patients experienced a bad or empty death. Three types of situations were identified that particularly bothered them. The first occurred when there was no hope for survival, yet treatment, including resuscitation, was continued beyond what they considered reasonable (sometimes called "flogging" the patient). In the second, the death was unexpected and out of control. This meant that the patient died without warning, sometimes of an unknown cause, and resuscitation was frantic. In the third, nurses described "empty death" as a kind of breakdown where there was no connection or emotional involvement between the nurses and the patient or family.

One nurse described a situation in which a woman with a chest tumor was admitted into the ICU with superior vena cave syndrome, a complication of the malignant growth. She was treated there for several weeks before she died. As a result of the venous obstruction, her head became terribly enlarged, and she was in severe pain. She didn't want a lot of heroic measures, but her family agreed to the physicians' request to intubate her and complete a course of radiation therapy. The tumor did not shrink as hoped with the radiation.

> During this situation she extubated herself twice. She wanted to die and her husband said that she'd already talked to him about this, but there was some hope that the radiation would shrink the tumor back enough that the swelling would go down. They had actually gone in and declotted her vena cava and put in a stent, and it cleared it briefly. But it was only a palliative measure. She was a strong enough person that she could look death in the face and knew that this was inevitable, and did not want to go through a horrible end. They put her on a Vecuronium (paralytic agent) and fentanyl (analgesic) drip. They sedated her over the last week or two.

The medical plan was to get her extubated. However, it became apparent that was not going to happen.

> She had been aware up until right at the end. She was awake and was actually trying to mouth words through the Vecuronium. We could see her trying to say things and really the Vecuronium isolated her and it was one of those catch 22's, where you knew you were doing the right thing clinically, but it was awful what you were putting this woman through. The very thing that she did not want.

After attempting to extubate herself repeatedly, she was restrained. After several days, she was taken off the Vecuronium, but remained comatose without sedation. A conference was held, and the family and physicians finally agreed that the situation was futile. A decision was made to take her off the ventilator, and the family chose not to stay with her while the tube was taken out. The ventilator was turned off and she died immediately.

This situation represents several concerns that frustrated and in some situations enraged nurses. The primary concern was that the woman's treatment continued beyond the point where she chose to quit. Her wishes were not addressed in a timely manner by either the health care

team or the family. She struggled against technology even sedated and restrained. Her dying was not directly acknowledged, and her family chose not to be with her when she died. Although nurses consistently supported families who did not want to remain at the bedside as the patient died, involved family members were an important aspect of a good death. This situation is a stark contrast to the previous story of a good death.

In other discussions of breakdown, nurses described situations in which patients, treated beyond futility, died without ever being released from the technology and life support. In many of these situations, patients were resuscitated again and again when there was no hope of long-term survival. This was described as a "real traumatic end to someone's life." The concern was magnified when the nurse understood that patients were already dead and gone from their bodies. Often these kinds of situations occurred when patients had not previously expressed their wishes and now were unresponsive, and sometimes when a physician "just [couldn't] stop". These conflicts regarding prolonged suffering and treatment seemed the essence of what nurses considered to be negative death experiences. Sometimes the concern was exacerbated by poor communication between the health care team and the family. In situations where the nurses were able to intervene effectively and advocate for the patient, they expressed satisfaction that the patient

was allowed to die comfortably in a (more) timely manner, but if the process involved extensive conflict with physicians or family members, they sometimes asked themselves, "Is it worth it?"

Empty death was described as one that was really neither good nor bad, but which seemed to be lacking in caring and involvement with the patient or family. During one observation, the nurse was caring for a patient who was dying from complications of a stroke. The biomedical struggle to save his life had occurred earlier in the day, and at change of shifts he was designated DNR and the ventilator removed. The family had said their good-byes and gone home, leaving a phone number where they could be reached. The nurse was assigned to the unresponsive and dying patient. She expected him to die on her shift, and her priority was to make him comfortable. She talked about her lack of situatedness, not knowing either the patient or family.

> I'd never met or dealt with the patient. And I didn't know how to deal with the family. You don't know what you should say to them, and how you can say it to them. You know, there's no feel. You don't know how to approach it... I felt like I was kind of like an alien. And I felt more like I was in a service mode that night instead of a care-giving mode. And my service was to make him comfortable and if the family called, to say no, he's not dead. And then I don't know if I should say he's dying, he's passing on. You don't know those words to use and those words that to me are real key to help people accept it and how they react.

In the absence of particular knowledge, she felt no involvement with patient or family. She medicated him

regularly, and did occasional assessments and vital signs. She talked to him when she provided nursing care, but it seemed perfunctory to her. She was busy helping out with another critical patient, and was not able to spend much time in the room. The nurses were alerted to his death, which occurred towards the end of the shift, when the monitor alarmed. Basic care was given, but the connection was missing, and she felt uncomfortable and inadequate.

Emotional Responses to Death

Nurses experienced a variety of responses to patients' deaths depending on the situation and their involvement. Feelings included sadness, relief, satisfaction, and exhaustion. Some expressed an awed feeling, based on their understanding of death as a great event. In many narratives, nurses described crying with families during the dying time or at the patient's death. In two situations in particular, where nurses had been very involved with patients during a long struggle, the nurses described their grief and loss when the patient died.

In order to protect themselves from emotional pain, some nurses described distancing themselves or keeping safe involvement with dying patients. Although this was thought to be easier to do in critical care with unconscious patients, the nurses described situations where they were "caught off guard" and solicited, or drawn into the situation, by dying patients or families. Other nurses

described that they regularly became very involved with patients and families in dying situations.

Nurses sometimes felt guilt and responsibility surrounding the death of a patient. After caring for a woman dying of complications of cancer therapy for several weeks, one nurse lamented, "I had two nights where I couldn't sleep and I cried and I thought, 'What have I done to this woman? Why did she have to suffer?" This kind of attitude was reflected in other stories, where the nurses felt responsible for making the patient's dying as good as it could be. The strength of these feelings seemed dependent on involvement and caring. They expressed guilt over inflicting pain and suffering, not fighting hard enough to get physicians to give the right treatment (or stop treatment), or not predicting a death (and therefore not preparing the patient and family).

Feeling guilt over contributing to the patient's death was most common in narratives describing sudden and unexpected deaths. This nurse described a colleague's recent experience:

> What's the first thing we think about if someone unexpectedly codes? The first thing we think of is what did I do? And then if they die, you beat yourself up for years, going I know the reason they died is because I gave them 10 of morphine, or missed their impending congestive heart failure. I should have noticed that change. We had a patient unexpectedly code and he had said all his good-byes that day. He said to the doctor, "Thank you for everything you've done for me." Told his wife that he loved her, good-bye, and tied up a lot of loose ends that day. That night about 4:00 he coded and died. And the nurse just

> beat herself up one side and down the other. "What did I do? I sat him up to shave him. I shouldn't have sat him up. I missed something." Very distraught over what she could have missed. And the attending came back, and said he'd blown his left ventricle. "There's nothing you could have done." But a lot of times we don't hear that end. Because of who we are and what we do, I think we end up taking a lot of responsibility for these people's deaths. And I don't think necessarily we need to. But it's still something I do.

These feelings of responsibility and guilt varied between units, and may have been related to the support available within different unit/hospital cultures. Several of the stories described experiences that had occurred earlier in the nurses' critical care careers, yet had not seemingly been resolved. Strategies that seemed to help alleviate the feelings included getting a copy of the post-mortem exam (or some other feedback about the cause of death) and support from colleagues. Formal debriefing after deaths was not done in any of the units studied.

To summarize, the meaning of death for the nurse varied depending on their nurses' previous personal and professional experience, their involvement with the patient and family, circumstances surrounding the death (including suffering and the course of the illness), and the nurses' understanding of the spiritual dimension of death. Nurses agreed on characteristics of good and bad deaths. Emotional responses were dependent on the context of the situation, and sometimes included guilt and excessive responsibility for the death itself or for not creating the best possible death for the patient and family.

Ethical/Moral Meanings and Concerns

Although an ethical tradition focused on abstract moral principles has been the dominant model in biomedical ethics, nursing has been searching for a moral tradition that more closely reflects the values and the work of the profession. Nursing theorists Watson (1979), Leininger (1981), Benner (Benner & Wrubel, 1989) and others have proposed the concept of caring as fundamental to the work of nursing. This view has stimulated the development of an ethic of care that has received support among nursing scholars as the moral foundation of nursing. In this discussion, the words "moral" and "ethical" will be used interchangeably, as they are in the literature.

Gilligan (1982), a femininist ethicist, has proposed a theoretical framework for moral deliberation in which the relational bias and contextually relevant posture which women bring to moral decision making, coupled with an awareness of the interdependent nature of relationships, reflect a pattern of moral decision making that is grounded in a perspective of care (Cooper, 1989). This approach emphasizes relationality, responsibility, caring, and connectedness over values inherent in traditional principle-oriented ethics such as rationality, objectivity, duty, and detachment (Cooper, 1991; Davis, 1986; Gilligan, 1982). Gilligan's paradigm has been suggested as an appropriate foundation upon which to base a practice-derived formulation

of nursing ethics (Cooper, 1991; Davis, 1986).

Many of the narratives describe practices and concerns socially embedded in the moral culture of nursing and specifically related to caring for the dying patient. In an effort to capture the complexity of the moral stories shared by nurses, a paradigm case which summarizes many of the meanings, concerns, and issues is presented and followed by an interpretive analysis. Supportive exemplars are added to further illustrate and expand the reader's understanding beyond the paradigm case cited.

Paradigm Case: "Do No Harm"

This account describes the group practice of several nurses caring for Sharon, a young woman dying of complications of cancer treatment. After many months in and out of hospitals, the patient was hospitalized in the critical care unit for several weeks. She was on a ventilator, receiving kidney dialysis, and desperately ill. The patient's husband, Mark, who was a health care professional, was very involved in her care. This was not usually allowed and initially caused controversy among staff. However, as the hospitalization stretched on, a core group of nurses assumed the care of the Sharon and her husband. Several of them were involved in the story-telling.

N1: After about two weeks, I was drawn into their stream of things.
N2: And I found it really rewarding and interesting and a major challenge to take care of her.

N1: And him.

N3: Well, you get so invested. It seemed for me I got so invested in it that I, even on my days off, I mean it was all I thought about. And part of it was because there were particulars about it that once you got involved with it and knew, it was easier to do because you knew him, you knew her, you knew the situation.

The nurses described the kind of care that was required as they came to know and understand the particulars of the patient and the family.

N3: I took care of her from the time she was first admitted. And before she was intubated, we did talk. She had this very soft sweet voice and she would say my name. And she was a real people person. She knew your name, knew who you were, wanted to know about you and she connected with you right away. And so every time I'd see her before she was intubated, she remembered who I was and when I'd come into the room she'd say my name. She'd say, Shelley, I'm so tired, I'm just so tired. I've been through so much, you know. She'd talk but it would tire her to talk. She didn't talk a whole lot. And then after she was intubated, she would write notes up to a point and she liked just little comfort things. At first she wasn't a real touchy feely person but towards the end she was much more. Wanted to hold your hand. Sometimes she was just scared and I'd say, "Are you scared?" Just wanted to hold you hand, wanted to hug you, wanted to touch you.

N1: She was constantly reaching up for your hair and holding it up to your face and she didn't want to be alone. She needed somebody to touch.

N3: And in that way I almost thought of her as a child in certain ways. Because she was very small and petite anyway. And then that need, you just knew that she needed that comfort and reassurance. [She and her husband] weren't very demonstrative at all. At the end they were more so. But at first they weren't, and you'd kind of want to fill in the gaps, so to speak. And so that's how I got connected with her right from the beginning in speaking with her and knowing that every time I came in the room she always said my name... And sometimes you could not comfort her. She would be almost psychotic. She'd be desperate, frantic and fighting for every breath and wasting so much

energy that she'd make herself worse. And I could never turn my back on her. I could never just walk out of the room and turn my back on her and leave.

N2: I always tried to figure out how to tell her that I really cared. Like little things like she couldn't stand certain TV shows. And she couldn't stand rock and roll... And every morning I'd come in and there'd be this rock and roll station on. So finally I put up this little sign that said, "Classical only". And little things like that. Just trying to help make it as pleasant as we could.

N3: We spent one afternoon, I swear, an hour. She loved cooking shows. Trying to get her so she could see that dang TV. Well it wasn't just quite right and her glasses weren't quite right and then her position today wasn't quite right, and I thought, you know, for who else would I spend this much time trying to get the dang cooking show. You just wouldn't spend that much time doing it but those little things were so important to her to be able to have that piece of her day. And when we got her all situated, it was probably at least three quarters through the show and she could really see it. Well, then she fell asleep. But she was happy. She got to get in the right position. Thank God she's asleep.

N1: I'm going to take her Valium!

The nurses also described how they learned about Mark, and integrated his needs and concerns into their care while still tending to the patient. For example, the nurses were very concerned for the patient's comfort, and wanted to use drugs for pain management. Her husband, however, was concerned about the use and over-use of analgesics and sedatives. (In interviewing the patient's husband, he believed that medications may have been overused, and preferred that they use other strategies like holding her hand or distracting her with television or radio.)

N3: Well like little things like he didn't want her to have Inapsine, didn't want her to have any

allopurinol or any of that stuff because she had reactions to it. And other doctors would say, "Oh, she didn't have that bad a reaction. Oh she really didn't have that." Well, but you know it got to the point of why fight with him about it. There's other things that we could use, that we could try. He'd even find stuff. He wanted her on Serentil, not on Haldol. He wanted her to be, and really when it came right down to it, it's that tug-of-war, that control issue but it really shouldn't be that. What it came right down to, it was just as fine for her to get the other drug. And he wasn't wrong, you know. And once she did get inapsine that did have a strange lasting effect.

N2: I had a hard time because I would, I perceived that she was in a lot of pain at times. And one day I'll never forget, her husband just said, "Pain isn't an issue."

N3: He was always afraid of her being addicted to anything

N1: And he did not want her to be knocked out by it. He didn't like that. Because then she couldn't be her. I mean she was sick but then she'd go in and she'd become very agitated and doing this and...

N2: She appeared to be suffering at times.

N1: Yeah, she appeared to be in pain and when you asked her if she was in pain, she would nod yes.

N3: She wanted the morphine...

N1: Do you want pain medication, she'd say yes. So we'd take that as...

N3: She wrote me a note, she wrote me a note once. I asked her if she wanted some morphine and she said, "Yes, but he doesn't want me to have it."

IN: So, did she get it?

N3: Yes, she'd still get it. At one time [during her illness] she did get addicted to morphine. And so he didn't want that to happen again. Well, she did get addicted while she was intubated. And towards the end we gave it to her anyway.

The nurses used a variety of other pain management strategies, but when necessary also relied on drugs.

As the nurses became more certain that Sharon was going to die, they also became more fearful of what the death event could be. They described their approach to decision-making.

N3: We made the physicians have care conferences every couple of weeks because they didn't want to talk about it. They didn't want to deal with it. Anyway, her oncologist is kind of an optimistic kind of guy. He kept saying that there is this one percent chance that she could survive. But her husband would hear that one percent and he couldn't withdraw. He couldn't stop things. So in care conferences we would spend a lot of time dealing with the what-ifs. And the biggest what-if that scared everybody was what-if she coded and what-if her husband was there. She was so tiny and frail.

N1: Are we going to break her ribs, are we going to pounce on her like we normally would do?

N2: It's the ethical dilemma that I had. I kept thinking, I don't want to hurt her and if her heart stops I don't want to push on her chest and crack a rib. And I cannot ethically do this. And I couldn't sleep for a couple of nights until we finally had a care conference and made her "no chest compression", because I didn't feel I could do it.

One nurse further explained the process involved in making this decision, which occurred about a month before the patient died.

N2: I finally contacted the ethics committee and talked [to one particular member] about this particular case. He really helped me get things more systematic. He helped me figure out what was causing my distress. And I was able to focus on what was causing my stress and it was fear of harm. And this is an ethical principle and I hadn't really had the time or the knowledge to figure this all out. In that I didn't know what was bothering me but something was bothering me really bad and I didn't know what to do about it. And he helped me get it down to fear of harm and what is it that we can do about that. There was a conference like the next day or two and I brought up the ethical situation of the fear of harm and how I arrived at it and that's when we made the first, "Do not do chest compressions." And I felt this major relief, albeit temporary, that I wasn't going to have to pounce on her. And then after a few days of that and she's still lingering, then the stress kind of built up again because I was fearing, I didn't want to shock her even and then

the fact that we kept having these little talks every week. Then I would have something to focus on.

As the patient continued to decline, it became emotionally more difficult for the nurses to continue to care for her.

N2: And you know, one thing that sort of kept me going with her too, since I didn't know her [before she was ill] and I heard what a feisty gal she was. I had a hard time with my own feelings because I would think, "Well now, if I was her I would want people to just let me go." but then I'd think, "Well now wait a second." She was her own person. She's been married for so many years and it's not my choice or my decision on what's going to be done. So I'm going to take the role of what can I do to make the situation as good as it can be. Because I'm not in charge of the decisions other than it's important for me to communicate what's happening and what I've seen. But that kept me going too...

IN: So she wanted to keep going too?

N3: We had to believe that of her husband and also her attending that everybody communicated that was always her wish. Cause when it got to the point where she really couldn't communicate with us anymore, you didn't know how much she could understand, and I had to keep remembering that too. Because it came to a point where if this were me...and I thought that every day. If this were me I would not want this, for me to live like this.

In the end, the nurses believed that the patient had died with dignity and that her care was the best they had ever given.

N2: When she finally died she did surprise me. I mean I knew for weeks that she was going to die, but it was like when they finally die you can't believe it's really happened. She went asystolic. Her husband and I were shooting the breeze about something. And he said, "Oh no." And it was quiet. It was so quiet. The doctors they came in. We just all came in and we just...it was not violent. We did drugs, atropine, but she had just died. And he was just standing there and he didn't raise his voice. He just said, is this

everything? Is there anything else that we can do?

N1: He stood back in the anteroom and just took his glasses down on his nose and he just looked.

N2: And the doctor just said, "No." And that was it. It was very peaceful.

The nurses went to the patient's funeral, and described their grief after she died.

This paradigm case was similar to many other situations described by the nurses in that Sharon was desperately ill and unconscious for much of her stay in critical care. She was connected to a multitude of technological supports. Mark's vigilance in supervising her medical care was an extreme case of "standing guard", which occurred with other families. His protectiveness was the result of her vulnerability, their experiences with medical care prior to this hospitalization, the nature of their relationship, and his background as a health care professional. The situation was different from some of the other cases because of the length of time Sharon was a patient in critical care and the degree of involvement of the core group of nurses. The situation was very powerful for these nurses, perhaps in part because the patient was herself a young health care professional.

This situation incorporated recurring themes found in many of the stories told by the nurses. The interpretive analysis of this paradigm case includes a description of characteristics of an ethic of care, the role of judicial ethics in decision-making, and specific moral concerns

expressed by nurses.

Ethic of Care

The values embedded in this paradigm case focus on caring and relationship. The discourse was characterized by it's subjectivity, flexibility, and contextuality. Words describing the care include "invested", "involved", "connected", "cared", "needs", and "particulars". The focus of the story was relief of suffering and maintaining dignity.

The relationship described between Sharon and the nurses was one of interdependence and reciprocity, in which the patient, when able, was involved in sharing of personal experiences. Sharon knew at least one nurse by name and wanted to know about her as a person. That kind of relationship was extended also to the patient's husband, Mark, as an individual for whom they developed understanding and compassion. Respect for relationship was shown by valuing and preserving the history and essence of the marital relationship, for example by facilitating his involvement in her care and respecting their ways of interacting. The nurses were able to describe particular characteristics and needs of Sharon and Mark on which the moral context of caring turned, for example her need for touch. The empathy that the nurses felt for the patient generated the moral distress they felt for the patient's suffering, which they worked to minimize through careful

attention to detail and continuity. However, even in their involvement, the nurses maintained an understanding that this was not their struggle. Gadow (1980) describes this relationship as "fellow feeling", in which nurses participate in the patient's suffering, but don't suffer themselves. This distinction in focus between fellow feeling and emotional identification is important in preventing the nurses' emotional depletion.

The theme of relationship was further played out in the ongoing discussion of issues between physicians and nurses. The nurses insisted on regular conferences. The process of maintaining a dialogue and sharing perspectives was seen as vitally important in the quest towards a positive outcome. However, much of the communication seemed one-way, and the nurses did not always feel supported by physicians. The nurses acknowledged that their role was not as decision-maker, but as communicator, and they struggled to maintain open communication. During the last three months of the patient's illness, working relationships between nurses and physicians, family and physicians, nurses and family were maintained as they approached concerns each from their own perspectives.

The moral agency of the nurses was heard in defining moral choices surrounding end-of-life issues. Although they did not see themselves as responsible for decisions, their issues and communications were the focus of regular team

conferences, at which decisions were made. This role is in part a manifestation of the "in-between" position, in which nurses skillfully facilitate communal decisions (Bishop & Scudder, 1987; Bishop & Scudder, 1990). However, the nurses' role went beyond adjudicate between the physician, the patient, and the hospital. Their actions were shaped by their own moral conscience and notions of suffering and a good death. In this situation as in others, the moral agency of the nurse influenced important aspects of the patient's death.

The nurses' involvement and relationship with Sharon and Mark informed the nurses' moral struggle surrounding continuation of life support. Understanding Mark's inability to let go and trusting his interpretation of his wife's will to live, the concerns did not focus on whether or not to withdraw life support, but on to how to create a peaceful death within the circumstances by anticipating the what-ifs. The decision was made by the patient's husband and physician that support would not be withdrawn, but neither would there be aggressive measures administered at her death. Issues of control were subjugated to concerns related to relationship and suffering, for example regarding pain management. Although the nurses had conflicting views with Mark concerning the patient's pain, they were able to understand his concerns for his wife's mental and physiological responses to sedation. They worked with him

towards a compromise, using drugs that he suggested and incorporating strategies besides sedation to control her discomfort; however they persisted in medicating her to control her air hunger.

The primary moral concern in this narrative was the patient as herself, as opposed to ethical principle. The driving force behind her care was not patient rights and autonomy, common in some of the narratives and seen by Gadow (1980) as the basis for advocacy. Sharon's personal wishes regarding continuation of treatment were really unknown. Her husband and primary physician said that although typically she would initially refuse some procedures, she would eventually consent with encouragement. In the absence of specific knowledge about the patient's view, the nurses' understanding of the patient's notion of the boundary between harm and benefit was assumed through embodied knowing grounded in relationship (Gadow, 1989). Her suffering was understood through her bodily responses, particularly later in her illness when she was unresponsive. They struggled with a concern that they may have gone too far in treatment, but despite this, the patient was not abandoned. One nurse talked about not being able to turn her back on the patient when she was in need of comfort. The concern was with her ongoing suffering and her dignity. Morale was dependent on the ability of the nurses to provide this care. Even in the context of unresponsiveness and high

technology, the patient was not dehumanized. Instead, the effort at playing her favorite music and tuning in her favorite television show reflected the particularities of the patient's life. These practices support the notion that care is needed to temper the technology (Cooper, 1991). Gadow (1990) goes even further in her assertion that efforts at cure without care are immoral.

The care was contextual not only in its responsiveness to the particular needs of the patient and husband, but in that the rules and norms of the unit were, in some sense, irrelevant and cast aside. In the most obvious example, Mark was permitted and even supported in supervising medical treatment for his wife. The demands of the situation drove the action, rather than rigid and external expectations.

In the final analysis, the nurses were satisfied with the care they had given. Beyond giving good physical care, they were responsive to the particular demands of the situation. Relationships were maintained, and the patient died without having to undergo additional suffering which would have resulted from resuscitation attempts. This expression of satisfaction supports conclusions drawn in a study by Condon (1988) that when nurses felt that they had been caring, they felt fulfilled and self-actualized, having achieved the moral ideal.

Role of Principle-oriented Ethics

As in the larger data set, this narrative focused

primarily on the ethic of care, but also incorporated some reference to abstract moral principles. This tradition, as understood in contemporary philosophy, "is built on a model in which reliance upon rules and principles is primary in moral action and justification. Moral choice involves a consideration of competing principles" (Cooper, 1991, p.23). Contrary to values arising from an ethic of care which describe involvement and relationship, values arising from the principle-oriented model arise from detached principles, rules, and rights.

In one section of the narrative, a nurse described her fear of hurting the patient, who was frail and depleted, by using aggressive resuscitation measures. She contacted a member of the ethics committee, who helped her to translate her emotional turmoil into the language of principled ethics. She invoked the principle of non-maleficence, or "do no harm". Using this language, she was able to approach physicians at a care conference, and use the principle to get an order not to do chest massage if the patient should have a cardio-pulmonary arrest. At a later date she used the same strategy to prevent defibrillation. It is notable that even the language in the nurse's description of the situation changed as she switched perspectives from a feeling to a cognitive approach to her concern. In discussing her actions after the ethics consultation, the words that the nurse used to describe the situation changed

from caring/relational language to rational language. Words like "dilemma", "systematic", "principle", and "knowledge" showed up in the narrative. Gilligan (1982) contends that it is impossible to see both moral perspectives at one time, "instead, a shift in orientation denotes a restructuring of moral perception, changing the meaning of moral language and thus the definition of moral conflict and moral action". (Cooper, 1989, p. 12)

This interplay of contrasting approaches to ethics is interesting in that although both played a role in the final outcome, formal ethics language was deliberately used to communicate to physicians in this situation where the stakes were high. Although the physicians may have, in fact, responded to the naive expression of the nurse's fear of causing additional pain and suffering to this woman who had already gone through so much, the use of cognitive language may have been a more powerful tool when confronting the issue within the medical paradigm.

The appearance of both kinds of ethics in this narrative can be interpreted in different ways. Davis (1986) contends that medicine and nursing arise from different ethical/philosophical convictions. Medicine, along with other health care professions, is concerned with specific and circumscribed needs of patients. On the other hand, nurses view patients in their wholeness, in their integrity as persons (Davis). As such, they should adopt

different forms of ethical thinking: relational ethics for nurses, rights-based ethics for physicians. Davis, however, does not discuss whether these approaches are mutually exclusive.

Cooper (1990; 1991) asserts that nurses use both kinds of ethics, primarily relying on ethical rules and principles initially. As the nurse becomes more involved with the patient and the particularities of the patient's experience, the moral perspective broadens and tension develops between the abstractions and the caring response to the situation.

Callahan (1988) describes the need for both emotion and cognition, as human traits selected through evolution, in comprehensive ethical decision-making. In fact, often the emotional experience is primary, in that it brings the issue forward for consideration, energizes the quest, and motivates perseverance in finding the right answer. In this narrative, the nurse's feelings stimulated discussion of the non-maleficence issue; her continued discomfort assured subsequent discussion until all the "what-if" questions were answered. As such, the ethic of caring represented by nurses, and the principle-oriented ethic, represented by medicine, are equally important in clinical ethics.

Another explanation for the application of both ethical approaches by nurses has been developed based on Heideggerian phenomenology and is described below. In this conception, ethical <u>being</u> precedes ethical <u>thinking</u>

(ontology precedes epistemology).

Skilled Ethical Comportment

Dreyfus, Dreyfus and Benner (1990) offer an alternative explanation for the interface between caring and principle-oriented ethics that is based on models of development of expertise (Benner, 1984; Dreyfus, Dreyfus, & Athanasiou, 1986). Their understanding is shaped by a phenomenological perception of ethics which is concerned with what is good, as opposed to what is right. In this conception, ethical theories and judgments are dependent on expertise in everyday skillful ethical comportment, which is defined as "embodied, skilled know-how of relating to others in ways that are respectful and support their concerns" (Benner, 1991, p. 2). The novice nurse comes into a situation with some ethical and relational skills as a result of growing up in a shared culture. Skills of involvement and connection are modified and extended through clinical practice and ethical theory to meet the demands of nursing. In the novice stage the nurse relies primarily on rule-governed behavior, for example following guidelines offered by theories on therapeutic relationships. As nurses gain experience, they gradually compile a background of clinical situations in which the rules for interacting as a nurse with patients are grounded in experience. Some situations may particularly stand out because the nurse feels better or worse (Benner, 1991). The practitioner experiences directly

what "the good" feels like and looks like over the course of many situations. One nurse described a situation early in her career where she learned about involvement:

> N1: I remember once when a 15 year old was dying of leukemia that I was really uncomfortable taking care of her. And I avoided it, took care of all her physical things, kept her, I kept everything taken care of but there was more lacking. You know, she confronted me. I was blown out of the water. I didn't know what to respond. And finally I realized what was going on was that she was younger than me and dealing with the ultimate.
>
> IN: So you were holding yourself away. What happened after she confronted you with that?
>
> N1: I broke down, as I am right now (crying). She was able to understand and she allowed me the space that I needed. But by the same token I was more able to be there for her later because of it.

This nurse learned about the moral value and obligation of connectedness through the challenge given to her by her young patient. Through her own feelings of shame/discomfort at not being present with her patient, she learned to respond to the moral demands of each situation. This patient needed her, and she was later able to respond based on her new understanding.

The skilled ethical comportment of the expert nurse incorporates many of these background situations, and the nurse develops an ability to respond immediately to the demands of the particular situation. Acting ethically in a situation is automatic and non-reflective. The following narrative is the account of a nurse responding to the needs of a mother to touch her dying child. This teen-aged girl had tried to commit suicide, and was brain dead and

maintained on a ventilator.

> The mother was so distraught that she couldn't touch her daughter. And she just kept telling me, "If I can hold her, if I can just hold her one more time." So I put the side rail down and she went up and laid her head on her daughter's chest and just kind of held her and so then I just scooted her to the side of the bed so her mother could get up and crawl in bed with her and just kind of hold her daughter. And I felt really good about that. Letting the family come in and be with her and her brother was able to come in as well and just kind of hold her and get close to her, you know, while she was still warm.

Some nurses might not have heard the plea of the mother, or understood her need. Others would have dismissed her request as impossible given the technological environment or the rules of the unit. The nurse could easily and truthfully have responded that "we don't do this", believing it not to be possible. But this nurse both heard and responded from a framework that values caring and connection, and she responded immediately, sensitively and morally by making room for the mother next to her daughter. Understanding that this kind of care would not seem proper to all families, she nonetheless responded in this situation to the mother's particular needs. She felt very good about what she did and remains open to this kind of "risky practice" in the future. This is an example of skilled ethical comportment.

Consistent with this novice to expert model, rational deliberation is only necessary in the case of ethical breakdown or in the case of conflicting or competing values. Principles are unable to produce expert ethical behavior,

and falling back on them may produce inferior responses (Dreyfus, Dreyfus, & Benner, 1990). In a situation where intuition does not produce automatic responses, an experienced practitioner can make a good decision through involved deliberation on the intuitive aspects if the situation is familiar. "In familiar but problematic situations, therefore, rather than standing back and applying abstract principles, the expert deliberates about the appropriateness of his intuitions" (Dreyfus et al., 1990, p. 28). In contrast, the detached deliberation of an expert in a novel situation produces inferior responses. Principles are unable to produce expert ethical behavior. In this conception, intuition is primary both in moral comportment and problem-solving.

For example, in the paradigm case, the nurses were confronted with the collision of two competing but key values, those of preventing needless suffering and upholding the patient's right to make her own decisions about medical treatment. Each value would direct the nurses' responses to the situation in a different way. To prevent suffering they would be compelled to push for withdrawal of life support; to protect the patient's right to decide would direct them to fight for the patient's life tenaciously until the end. In most situations, these values didn't compete because patients or families requested that their suffering be ended by termination of life support. Although they understood

that this patient was both dying and suffering, they continued to care for her, based on their understanding that the patient wanted to continue on. This situation did not feel right to some of them, who began to ask the "what if" questions that finally resulted in the patient's peaceful death. One nurse in the paradigm case deliberated about the appropriateness of her fear that she would harm the patient, not on the competing principles at stake. The nurses' involvement and intimate knowledge of the patient and family, their experience with similar cases, and their understanding of the possible interventions and outcomes guided questions they asked which were specific to the situation. In the end they were able to sustain both values by preventing further suffering inflicted by useless resuscitation procedures, but not removing life support.

Exploration and explication of the relationship between ethics of caring and judicial ethics in nursing is continuing. Further understanding of the moral values of nurses can be drawn from concerns expressed in the narrative.

Moral Concerns

Moral concerns, understood as what the nurses believed to be good or right in the particular context, showed up in how they focused their practice as well as in situations of breakdown, when the smooth functioning of practice was disrupted. Several concerns were expressed by the nurses

which were based on the caring values of involvement and connection, including comfort, and respect for others. Those expressed in this narrative include (a) relief of suffering, (b) patient involvement in choice/wishes respected, (c) priority of family needs, and (d) maintaining dignity. Other concerns expressed in the study data but not included in the paradigm case are: (e) non-discriminating treatment of patients, and (f) acting as the agent of death. Exemplars will support the addition of these concerns to the list.

Relief of suffering

Relief of suffering was a concern throughout the paradigm case. Nursing care focused on pain management and control of air hunger but also, in a broader sense, on providing some distraction from the technological space in which the patient was imprisoned, for example by finding a comfortable position to watch a cooking show. The nurses tried to make the situation "as good as it [could] be", finding less painful ways to perform procedures such as catheter irrigations and being with her when she was afraid or lonely. The nurses were concerned about their own role in not wanting to inflict pain or prolonged torture by providing aggressive resuscitation measures. They were concerned and struggled with their role in prolonging her suffering and their morale was, in part, dependent on their

ability to act in ways that would minimize her pain and suffering.

Patient choice

The nurses were consistently concerned, in this and other narratives, that the patient should be involved in decisions regarding their care. They did not agree with assumptions that being severely ill and medicated, or even unconscious, in critical care precluded participation in care or decision-making, and were enraged when patients were overlooked or overridden. Sometimes nurses solicited patients' concerns, others responded to verbal or non-verbal cues at the bedside. These understandings of the patients' wants/choices formed the basis for the strong advocacy role assumed by the nurses. In the paradigm case, Sharon was directly consulted regarding pain management, and treatment was negotiated with her husband. The nurses were uncomfortable that they had not directly spoken with the patient about how far she wanted to continue with therapy, but respected Mark's interpretation instead and did not push the issue of withdrawal of life support (as they did in other situations when the patient/family did not want to continue).

Family needs

The nurses were concerned with maintaining the integrity of the family as much as possible given the technological space and the demands of the situation. They

were also concerned with the primacy of family needs over the demands of the institution or even the physician. In the paradigm case, the nurses extended their view of the patient to include her husband, and modified their approaches in consideration of his needs. They incorporated his suggestions in giving care. In this situation as in others, families of dying patients were allowed, even encouraged, to visit whenever and as long as they wished. This kind of flexibility was sometimes seen as risky practice, which might not have the approval of other nurses in the unit. Mitchell (1981) discusses the moral distress nurses regularly experience when their loyalties to patient/family and physician/organization are in conflict. Because they cannot be consistently trustworthy to either, they are unable to maintain their integrity and become dissatisfied.

Maintaining dignity

The nurses were concerned with maintaining the patients' dignity. This was in part related to prevention of suffering and supporting their right to direct their care, but also involved the importance of privacy and respectful care of the body and the personhood of the patient. For example, playing rock-and-roll was interpreted as disrespectful of the patient's personhood and violated her dignity. Several nurses remarked about the indignity of being restrained during dying. One nurse described a

situation early in her career in which an elderly man had experienced a heart attack became confused and combative.

> This man we had tied down in four-point restraints and he was fighting with us and he was a heart attack person and a real old person. My thoughts were that must be just the most awful way to die. To have your body tied down, fighting and we're tying you down for your safety as well as so you don't beat us up. And I felt real guilty over his death because of what he must have experienced within himself, with being tied and then dying. And being captive.

Dignity was also maintained by the attitudes of others toward the dying patient. For example, staff talking over the patient as if they weren't there or uninvolved staff making derogatory comments about patients were seen as violations of dignity. One nurse discussed her outrage when others would react to a patient she was caring for:

> I would get so involved in it and I would get really mad sometimes. IV nurses, for instance, would come up. "Oh I just hate working on her." "Oh I just hate sticking her." "Oh she was so deadly when she was on the floor." And "I hope she dies." "This is so sad." Or the old, "This is so cruel."

Gadow (1985) describes commitment to the protection and enhancement of human dignity as the ultimate goal of caring. Dignity was embedded in the meaning of the experience for the individual patient, and is diminished by reducing the person to the status of objects. External interpretations, such as those above, negate the patient's integrity, and violate dignity. This is unconscionable within an ethic of caring.

Differential treatment

Two additional concerns expressed by nurses in the

study were not represented in the paradigm case. In several different stories, nurses expressed their concern with differential treatment of patients. One nurse described a morbidly obese patient with an acute abdomen who the physicians could not take to surgery because of her weight. The nurse believed that the patient did not want to be taken off the ventilator, based on her physiological responses to bedside talk about discontinuing life support. The woman's family was of lower socioeconomic status and was not able to travel to the hospital to be with her. The nurse believed that there was the possibility that eventually the diverticulum could have walled itself off, but the woman could not survive without ventilator support. Because of her perception that the patient wanted to keep trying, the nurse wanted the physicians to keep trying. The woman was disconnected from the respirator and died, and the nurse commented:

> I don't know what to think. Are we at a point where if you don't listen or take care of a patient as well when the family members are not there looking out for them? Or, and in addition to that, when we have simple people come into our high tech environment are they also not treated as well? Those are my two unresolved questions.

Other patients that were identified as at risk for less than optimum treatment (versus "going to the wall" or" full court press") or for not being involved in their own decision-making included unconscious or incompetent patients without families, persons with AIDS, and drug abusers.

Agent of death

In the most common scenario related to the withdrawal of life support, the physician wrote an order to extubate patients and keep them comfortable as they died. The medication order was usually a liberal sedation order for morphine or Valium, giving the nurses the latitude to titrate drugs intravenously if the patient seemed to be suffering or struggling. The physician then most often left the unit, and the nurse proceeded to withdraw the life support.

Although the nurses all understood that it was the patient's illness or condition that caused death, there were feelings expressed by some nurses about being the agent of death. In general, they viewed their role with dying patients as positive, and themselves as facilitating the end to the patient's suffering or a peaceful death. The nurses were most often the health care professional to disconnect the breathing apparatus and to give the sedation. It is important to note that many of the sedatives routinely ordered for comfort also caused respiratory depression, and the difference in dosage for either purpose varied between patients. Although patients usually received small doses titrated to symptoms frequently, many times the patient's death occurred shortly after a sedative dose. The nurses were all aware that the medication most likely precipitated the death. Although most nurses denied that this was a

problem for them, others struggled with the notion. The subject came up frequently in interview and observation data, where they sometimes referred to "killing their patients".

N1: I'm thinking of specific situations that I know of. We're extubating, but can they do it on their own and, you know, try to progress from there. So are you keeping them comfortable or are you suppressing their respiratory drive?
IN: It's a fine line.
N1: I think 23 (dosage of morphine) is over [more than] fine.
IN: An act of commission as opposed to an act of omission?
N2: Yeah, it's really on the line between active and passive euthanasia when you're turning that drip up.
N1: You know, chances are that person would have died anyway. But which caused it?
IN: So that's a routine thing?
N1: Not a routine thing, but it's something that happens. It's not necessarily that bad.
N3: A morphine death looks a lot prettier than a non-morphine death. From our perspective.
IN: And do you feel comfortable doing it?
N2: It depends.

Although individually nurses acknowledged that their sedative injections most likely contributed to death, that was not universally acknowledged or discussed within a moral context among involved health professionals. It would be erroneous to assume that nurses carry a moral burden because of their role in the timing of the patient's death, however the data point out that some nurses struggle with the concern. In a study by Wilson et al. (1992), both physicians and nurses verified that they ordered and administered sedatives and analgesics when life support was withdrawn to hasten death, although that was never the only

reason. This was deemed ethical if the intention to relieve the suffering was primary rather than an intent to hasten death.

A concern related to assuming the responsibility for the death revolved around the perceived lack of concern and participation of the physician during the dying time. One nurse expressed her feelings:

> I get so sick of those "extubate patient and keep comfortable" [orders]...And a lot of times it's not even, they're not even in the unit writing it. It's over the phone, or whatever. And then they leave. They're either not there or they write it and they leave. And it's not even, it's not even thought that they would be in the room or participating in the death. And so that's where you struggle sometimes with that. You know, look what I've done and whatever."

Although the nurses seemed to relate the absence of the physician to devaluing of the dying patient, there are other explanations including fear, feelings of guilt or failure, and unfamiliarity or discomfort with the dying vigil. It is important to point out that although several nurses struggled with the absence of the physician, others were comfortable being in the situation alone. Among those who were concerned, they did not want the physician to take over the withdrawal and subsequent vigil, but to be available and validate the significance of the event.

One nurse described in painstaking detail how she felt her way through the process of extubating a patient for the first time after she realized that the physicians weren't going to be there or tell her how to proceed. Although she

was experienced in the technical aspects of taking the tubes out, she was unclear about how to make the whole process go smoothly. While waiting for the respiratory therapist to come in and turn off the machine, she took out the nasogastric tube, took the tape off the patient's face, and tried to think ahead.

> And finally the respiratory therapist came in and turned the thing off. And then I thought I wanted to give them some idea of what is going to happen. Because I know I'd feel like pins and needles, on the edge of my chair. So I said, "Well now, there's a couple of things that could happen here. I'm going to pull this out and I have a little suction thing here and it's going to sound like the dentist, you know, where they suction. There could be a lot of secretions there so something might run out of his mouth or something. So don't be surprised if you see that." And I said that he might groan or make a noise. I was trying to think, well, what are they likely to see. And then I just extubated him, deflated the thing and I'm thinking, "Where are these doctors? Why am I doing this? Is there some protocol for doing this and I just don't know what it is? But I can't tell this family one moment please while I go out and find out what it is." ... And (his wife) sat right in the chair and held his hand and I extubated him and not a sound or anything."

The nurse worked through the experience, and the struggle was invisible to the family who later said only, "They just turned everything off."

As nurses became more experienced with the process of discontinuing life support, the details became less of an issue and didn't show up in their narratives. But the nurses expressed continued frustration that when the patient was dying, the physician left the bedside. One nurse told a contrasting story, in which a physician coached the family through withdrawal decision-making, then helped the nurse

extubate the patient.

N1: Usually the physician will come in and write the order and leave, which I'm used to. And I've had to go in the patient's room, extubate them by myself and then proceed with whatever orders to keep them comfortable and the family and everything else. But no, this doctor, what he said was, he looked at me in this conference room and he said, "Will you help me?" And I tried not to look too shocked in front of the family. Only I thought, "You bet I will." And I'd get him out in the hall and like go "whoa". So he went in there with me and he actually, literally, hands on, untaped the endotracheal tube while I got morphine and suction and we together extubated this patient.
N2: I've never seen that happen!
N3: Never, never seen that happen.
N2: Banner over his office. DR. EXTRAORDINAIRE.

Nurses considered the care for dying patients as an area of practice that has belonged to them and which they don't want to give up. However, what they seemed to be asking for was some recognition that this is, in fact, an important area of practice which is valued by both nurses and physicians.

Values and concerns describing the moral foundations of nursing are embedded in nursing practice. These need to be incorporated into an ethical theory specific to nursing and encompassing both everyday notions of good practice and decision-making.

Organizational Concerns

As the nurses described their experiences with dying patients, they revealed supports and impediments to care of the dying patient and their family that existed within the structure and function of the critical units, hospital, and health care system. Although several themes emerged across

the data, they were not captured in a single story. Examples will be given to illustrate the interpretation of the data.

Supports to Good Death Care

Nurses acknowledged the importance of the support of their colleagues in caring for dying patients. Since no formal mechanism existed for dealing with the guilt, sadness or other feelings that accompanied this kind of care, nurses developed informal alliances with whom they could safely share their thoughts. One nurse shared her gratitude with a colleague:

> You know, I always feel good when people come and say, "Oh, you are doing such a good job. You did that one night when a patient of mine died. This patient had been dialyzed and she'd had renal failure and she was in such pain and I was just really torn up about her dying. And some people, it bothers them when you cry at work and I was kind of holding it together and everything there and then you walked up and put your arms around me and said, "You did a really good job." Well, that was it. Then I was bawling (laughing).

Acknowledging the experience was important for the nurses to resolve their own feelings and remain open to this kind of practice. Another nurse described a ritual on her shift where each nurse would go to the cafeteria and buy their favorite junk food after a difficult code. They would eat, not together (because they were usually too busy with patient care), but just engaging in this group behavior provided support. Other nurses talked to spouses or friends when they were involved in a particularly difficult situation. In the absence of formal acknowledgement and

discussion about care of dying patients and families, each nurse sought out their own support systems, often peers who understood the demands involved in care of dying patients.

Nurses described several programs or procedures that were in place in their hospitals that assisted them as they provided care to dying patients and their families. Some of the most frequently mentioned supports were non-nurse support staff who were available to assist grieving families while patients were dying. This included chaplains, patient advocates, and social workers. The nurses were often busy with the physical aspects of providing care to the patient, particularly if there was a lot of technology involved, and didn't have as much time as needed to work with family members. During two observations at one particular hospital, a chaplain maintained a vigil with the family for many hours during decision-making and the last hours of life. One nurse commented on her previous experience with that kind of support.

N1: I had a situation at another hospital where a lady was dying and there was a pastor or priest, I don't know what they called them, but they have like an intermediary between the nurse and the family. They spend a tremendous amount of training for that. And they come to you and they really work with you. Boy, did I really like that. It was readily supportive and a life-giving type of relationship. And that is absolutely gone where I work. It doesn't exist.

IN: So you don't really have anyone you can call to be with the family if they are really having a difficult time?

N1: Not in that capacity. This person deals with the spiritual aspect, a kind of more global aspect than a social worker or just a religious person, a

> pastor or a nursing supervisor. Those are our three choices. Social worker, pastor that's on-call, or a nursing supervisor. All of these people are spread very, very thin. That's not their primary focus. Where at this other hospital that was their focus. They were there with the family no matter what.

At another hospital, a patient advocate was frequently mentioned as a person who could help with problem-solving, but was not able to remain with families or help them with their grief.

Ethics committees were in place at both hospitals in the study, and were generally seen as positive supports in working through end-of-life issues. One nurse, however, expressed her concern that decisions made under the supervision of the ethics committee "[aren't] based on people", perhaps expressing the tension between principle-based and relational ethics.

In some units, nurses were able to approach ethics committee members with concerns, and received direction and support in problem-solving. In one observation, an elderly woman with a progressive neurologic disorder had an advanced directive asking that she not be maintained on a ventilator. She had been intubated and placed on a respirator because the physicians did not have a definitive diagnosis and were not sure if her respiratory failure was treatable or permanent. Her son, who had the power of attorney for health care, was struggling with his responsibility in advocating for his mother, and the woman was agitated and

apparently suffering. The nurse contacted a member of the ethics committee, who validated her concern regarding the conflict between the wishes of the patient and those of the physician. The committee member reviewed the chart and brought up the case at an ethics meeting, then participated in the care conference the next morning by bringing up concerns regarding competence. The participation of this committee member was seen as very supportive by the nurse.

This observation also highlighted issues related to advance directives. Currently, patients entering acute care facilities are offered information concerning advance directives. Nurses thought that, in general, advance directives were helpful, but that they were still new and not yet well integrated into the system and decision-making processes. One nurse expressed her frustration about patient's wishes being overlooked despite "living wills".

> Maybe things will change now that we're asking people about their DNR status prior to entering the ICU. Or on admission to the hospital. But how easily they are overridden by family members is so incredibly frustrating. I mean you have to have it stapled to your chest. Doctors can override it. Everyone can override those things."

One particular issue that came up at a care conference during an observation regarded whether or not <u>patients</u> (as opposed to physicians or family members) should be allowed to change their minds regarding end-of-life issues (as written in the advance directive) when they were in the ICU with a terminal illness/condition. Issues such as these

must be worked out as the advance directives are integrated into the health care system.

Impediments to Good Death Care

Nurses identified several organizational impediments that prevented them from giving optimal care. Some were seen as changeable, most not. Within the critical care unit, staffing patterns sometimes interfered with continuity of care and being able to be with the patient at the time of death. Both were highly held values among the nurses in the study. In the following situation, the nurse talked about her frustration when she was caring for an elderly man with pulmonary complications post surgery. He was ventilated and septic and his condition was seen as futile. A decision was made to extubate him and keep him comfortable.

> We expected very much for him to not make it more than another two hours or at least through the shift. They gave me him and another patient who was also intubated and wild. It kind of made me mad because they thought, "Well, he's a DNR and so he won't need much time." And that really made me angry because I said to the charge nurse, "I don't feel comfortable just giving him morphine, taking that ventilator away, and then leaving him alone." That's not fair. With both though, it was a bad day...I was promised I would get help, but it was a bad night, real bad.

Nurses felt strongly that they should stay at the bedside of a patient who would imminently die, which was not possible if they were also assigned to another patient. This was often the case, especially if staffing was "tight".

The organization of shift work also interfered with the work of caring for dying patients. Several nurses mentioned

the frustration they felt when the patient was close to death, but their shift was over and they could not continue to care for the patient and family. They expressed a sense of lack of closure. Sometimes telephone follow-up kept them in touch with the situation as it continued to evolve and the patient died. In other situations, nurses spent a great deal of time arranging care conferences which they were not able to attend. Conferences were arranged around the schedules of the physicians and family members, and off-duty nurses usually did not attend unless they were very involved with the patient and family or invested in the outcome of the conference.

The environment of the critical care unit was sometimes seen by the nurses as problematic in providing a respectful dying space for patient and family. "I've seen some units where you don't have any privacy and so we have to pull a curtain and there's still all the loud noises and the nursing laughter." The physical structure of some units, including the proximity of beds and curtains for walls, was seen as preventing visual and auditory privacy. Equipment, including side rails on the beds and other more invasive technology, was seen as creating physical barriers between the patient and their family. Visiting restrictions, while seen as potentially problematic if enforced, were not enforced during any of the observations in the study.

Some procedures within the hospital were seen as

problematic in providing optimal care for dying patients. Although they understood the economic rationale, nurses were sometimes disturbed about the implications of bed utilization. In some situations, this meant transfer of patients who had life support withdrawn and were dying to another unit. In most cases, if the patients died quickly, they remained in critical care. But if they survived beyond a few hours, they were transferred to a less acute area of the hospital. In other situations, bed utilization meant quickly transporting a patient's body to the morgue so that another patient could be admitted.

> Pull that curtain and give them that space. But you know, then it's like, "You've got to get her out of here. We've got another person coming in." You know? It's so ugly sometimes. I mean sometimes you're allowed lots of time for the family to be able to let go. And other times you've got to whisk that body out of there and replace it with another one. "

This clash of economic accountability and the desire for caring closure was sometimes difficult for the nurses to resolve.

The most pervasive complaints that the nurses expressed regarding impediments to caring for dying patients were related to lack of coordination of medical care and reluctance to declare DNR status. Two nurses discussed a young woman with cancer who died of respiratory failure and sepsis in their unit. The nurses became very attached to the patient, and were disturbed by the lack of coordinated care that she received during the months of her

hospitalization. She described her concern with the DNR issue:

> We knew after time with those ventilator settings that she was never going to be able to go home. And several cases like this have come through our unit where there is frustration amongst the nurses because we feel the doctors, the house physicians, change every week. And the DNR status. How much she wanted to fight never got discussed. Over this three month period the nurses would bring it up and talk to the staff physician and he would never discuss it with her.

Initially, no one would approach the subject with the patient. But eventually, the doctors began to talk with the patient about end-of-life issues.

> And then when they would switch off one week at a time, they would fail to report to the physician that maybe it was approached about the DNR, maybe it wasn't. But they would fail to report that off. So each week this poor lady went through, "Well, what do you think about being a DNR? Do you want CPR?" I mean constantly being asked that question.

This nurse was frustrated with the frequent changing of physicians, which resulted in lack of continuity for the patient and an uncoordinated, and seemingly unfeeling, approach to decision-making. Even on the night of the patient's death, there was a lack of a consistent approach to her treatment.

> And then it was new interns and residents on the night she died. And that's enough to make you angry because they were so nonchalant about it. It was like, "Look, I've been here with her for two months, you haven't. Don't sit there and tell me there's nothing more you can do. Get in here and look at the chart and do something instead of just saying, "Oh well, she's going to die". It didn't mean anything. It was just like they had written her off.

Differences in commitment to a particular patient, specific

knowledge gained by caring for the patient over time, practical knowledge differences between experienced nurses and inexperienced physicians, and the status inequity between physicians and nurses laid the groundwork for conflicts.

However, not all problems identified by the nurses were related to inexperience and rapid turnover. The lack of coordination of care with resulting breakdowns in communication among physicians, between physicians and families, and between physicians and nurses seems to be a consequence of the current specialized medical system in which one patient is often seen by many consultants. This problem is sometimes accentuated in the ICU where the primary physician often stands aside for specialists, and there is no physician coordinating the care. One nurse described a situation in which an elderly patient was admitted to critical care multiple times over several weeks because of various complications. The nurse was disturbed by the lack of coordinated medical care. "He had so many doctors that there was no clear leader. It seemed like he had been sort of abandoned by the physicians, but he had all these hands in the pot." She arranged a care conference, and the physicians pulled together to resolve the nurse's concerns. Although the issue of lack of coordination of care is not specific to care of dying patients, the lack of coordination may become more of a problem when end-of-life

decisions need to be made.

Another issue discussed by nurses revolved around the hesitancy of physicians to intervene in decision-making for another physician, even when they were "covering" for another physician who was off. In one situation, the nurse was caring for a young patient who was "found down, doing drugs". She discovered that he had "blown a pupil", and felt that he was dead despite being supported on a ventilator. This occurred on a weekend, and she worked with the resident to get someone to discontinue life support.

> So the resident called the chief of medicine because he wanted to withdraw. I mean we're keeping a dead person alive, and the chief said, "No, I wouldn't do it. I wouldn't." You know, cover your butt and wait until the attendings get back. This was Saturday, and they weren't coming in until Monday. So I said, "Well okay then, you'd better give me a pretty good sedation order."

The concern of the nurse was that the patient's suffering was prolonged out of convenience for the physician and their professional agreements not to disturb each other when not on call. In another similar story, a family expressed their dismay that their father could not be taken off the ventilator until the attending physician came back from a weekend off. In both situations, no one attempted to contact the primary physician to ask for his consent to discontinue the life support in a timely manner. These practices among physicians were very unsettling for both nurses and families, who understood that the patient continued to suffer until the physician returned.

Critical care units were not conceived to provide care to dying patients and their families. Although programs have been developed to assist with family support, such as pastoral services, and decision-making, such as ethics committees and advance directives, these are not well developed or accessible in all institutions. Rather the staffing patterns, environment, bed utilization policies, and systems for physician training and practice interfere with providing the kind of care required.

Other Comments on Meanings and Concerns Related to Physicians

Discourse related to physicians was pervasive in these data. From the beginning to the end of the dying process, negotiation with physicians was frequently an issue. Although discussion about physicians has been incorporated into other sections of this paper, a summary of related concerns is given here.

The conflictual narratives underscore the cultural differences between the professions of medicine and nursing, and often lack of understanding between the cultures. In general, physicians were not seen to acknowledge the contributions or struggles of nurses related to care of dying patients in critical care. This is consistent with the literature, in which nurses are not recognized (disenfranchised clinical and moral agents) by physicians as participants in clinical situations (Prescott & Bowen, 1985,

Wros, 1993) or in ethical conflicts (Gramelspacher, Howell, & Young, 1986). Primary areas of conflict included asynchronous recognition of dying, different priorities, values, and processes in decision-making, and lack of participation in the patient's death.

However, the nurses in the study enthusiastically recited narratives describing what they considered to be good medical practice. These were situations in which the physician communicated openly with nurses and family, faced the "hard questions" in a timely manner, and worked with the nurse at the bedside or supported/acknowledged their work with the dying patient and family. Throughout the observation period of the study, the care conferences stood out as an arena in which physicians who attended appeared compassionate and competent as they moved families towards decision-making.

Although nurses expressed a desire for collegial relationships with physicians, equal collaboration and mutual understanding between nurses and physicians did not occur in most of the narratives. Rather the nurses bore the responsibility for convincing the physicians of their positions and maintaining the working relationship. However, the physician perspective is not represented in this study and cannot be assumed.

Meanings and Concerns Related to Family Care

As described, nurses in the study provided care to

families as well as patients during the dying time and in some cases afterwards. According to unpublished data from a study on clinical judgment in critical care nursing (Chesla, 1990), as nurses develop expertise in practice, the view of family shifts from being an obstacle to seeing the patient/family as a unit of care. There is evidence in data from the current study that a view of the patient encompassing family members is socially embedded in expert practice. The nurses considered family to include those related by blood, marriage, or meaningful emotional bonds. This definition, derived from the data, will be assumed during the following discussion.

Paradigm Case: I've Never Felt So Comfortable Touching My Mother

Discussion of meaning and concerns related to family care will center around the interpretive analysis of the following narrative. This nurse preceded the story with an admission that she routinely gets close to family members. In her story an older woman, Jean, who was the matriarch of the family, was dying following complications of surgery.

> She had four family members, her husband, her two sons, and her daughter. And when she came to us she had some abdominal surgery. I remember the whole family there, which was just incredible and a great learning experience for me. And what happened was she came in with this family having tremendous expectations that she would come and be out of the hospital in three weeks. Well, she had complications such that she developed sepsis and then she developed liver failure and the whole scenario. On the ventilator, on the dopamine, on Pavulon, and the whole nine yards.

She described the way each family member responded to the situation.

> I can specifically remember all these family members coming in. I had the husband at the bedside, who would just sit there and look at every single movement. I can remember his face just looking to see "this is a change, she's going to get better". I remember seeing that in his eyes and talking to him about that. And then I remember the son coming to me and I happened to put her on a flexicare bed and they just thought that was wonderful. And so he pulled me aside and he says, "I want to hire you to work with her every night." And he was a high tech person, had a good job, he thought, "Okay, this person did this. I want them to be there all the time." He had certain nurses he wanted to hire to be with his mother so that she would receive the best possible care. The other son would sit in the room and read and we'd talk about what she was like. And that's how I got to know the patient, through him. Because he was able to relay to me what his mom was like, how she felt, what she was like as a mother. How she was a matriarch, how she was the very strong individual who held this family together. And to see her dying was just literally breaking them apart. And then there was the daughter, and the daughter is the one person who I really learned from. She came into the room and it was apparent that we were going to get along because we just started talking and we'd joke and we'd laugh and we had a good time. And not to say the patient isn't there, but still, in some ways you forget that this person is dying.

She intuitively responded to the needs of the daughter, Cathy, and together they created a ritual that helped the daughter begin to accept the reality of her mother's death and begin grieving.

> And so she came in and I was, I like to give my patients baths. I don't do it because I want them clean. I do it because I find out so much more about them. I find out what their skin care is like, what's going on with them. I have to turn them so that way it forces me to do things that I maybe normally wouldn't do. So I said, "Well, I'm going to give your mother a bath. Would you like to help me?" And she just looked at me. And she said, "Is it okay?" Sure, it's just fine. So she, I'll never forget, she took and she just

> stroked her mother's hair really gently and she just talked to me about all the things her mother used to do for her. She gave her a manicure, she rubbed her back and every day there was this little routine she would go through after that. And a week later her mother died and I got a little note from her probably two weeks later, and she said, "You know, I don't think that I've ever felt so comfortable touching my mother as the time I had when I could just rub her and care for her as she cared for me." And what it did is it facilitated the grieving process for her. And maybe there were other issues going on within the family, but at least she could be one to say, you know, it's time to move on. The guy who wanted to hire someone, to have his sister there to facilitate that. And then the guy who was sitting there reading, was already okay. The father was very angry. But he had his daughter who was able to facilitate.

The nurse reflected that she had learned a great deal about family care during death from this situation.

> I've never, ever realized how important it was for a family to be able to touch their loved ones and to just caress them and kind of give back what they had given. Or just to give. And they don't have that opportunity and it just kills me because when I see nurses who say, "No, you can't come in for just five minutes every hour." Because I view that as being real detrimental when the patient is dying and they need their loved ones around. And it happens all the time. It really does. and I guess that's why you see my tears because I, not so much from the interaction I had with that family because it was very, very positive. But for all the families that really missed out on that.

This narrative points out several aspects related to family care that were supported by other nursing practice cited in the data.

According to Chesla (1990), nursing practice with families in critical care can be divided into two domains of practice. In the first, nurses directly provide care to families by teaching, coaching, and helping. In the second, nursing practice is informed and transformed by families.

Both domains were evident in these data. The understanding that the patient's identity as a patient who is dying in the ICU is ancillary to their identity as a person who is a member of a family and community focused the nurses' concerns and shaped their ability to provide meaningful family care. Families also created meanings and concerns for nurses by soliciting or blocking caring and involvement of the nurse in the patient situation, by making the patient a person for the nurse, and by giving the nurse perspective on good/bad care. These aspects of the nurses' concerns and background meanings related to families are described based on the above narrative and supportive data.

Families as Patients

There was a point in the dying process, when the patient was unresponsive and death was inevitable, when the primary focus of care shifted to the family. Although a discussion of the specifics of family care was integrated into Chapter IV, the concerns and meanings of the nurses are explicated here. In the paradigm case, the technology and other direct patient care was absent from the story. The focus was, instead, on helping family members to move towards healing their relationships, accepting the impending death, making difficult decisions, and saying good-bye. The nurse's work with the daughter, Cathy, was significant in helping her to work through unresolved conflicts with her mother and allow her to begin to grieve the loss. In this,

as in other situations described in the study, the nurse did not know, or need to know, the details of the family conflict in order to be able to support the family in a meaningful and effective way. She intuitively created a situation which allowed the healing to occur between mother and daughter. This work with the daughter also supported the rest of the family, given that Cathy acted as the connection and catalyst for the rest of the family as the situation unfolded.

The nurse in this exemplar also understood that different family members reacted to the dying situation in their own unique ways. One son tried to control his mother's care by hiring "the best" nurses. Another sat quietly reading and reminiscing at the bedside. The father hung onto every movement, looking for hope. And the daughter helped to care for her mother. This understanding of individual differences in expectations, coping skills, behaviors, and acceptance was apparent throughout the interviews and observations. The nurses understood that families were experiencing severe anxiety, often complicated by sleep deprivation and a host of emotional responses. Most of the nurses viewed these differences very nonjudgmentally, trying to understand family members' needs and relationships as a basis for meaningful intervention. One nurse explained her approach to the wife of a dying patient who had difficulty in getting along with some nurses

in the unit.

> People are different, and I don't know her. I don't know what her life is like. I don't know how she functions in a crisis. I don't know what her home life is. I don't know what that situation is between her and her husband. I don't know those things, so I'm not really in a position to say, that's irritating or that's hard to deal with. But, all that aside, you just don't know. You don't know what those family dynamics are. You can look at them and say, "Woo, there's family dynamics going on." And there's certainly a little here. And you can see that as much as you do, it's going to be there. So you know, you do the best you can.

The nurses understood that they couldn't change family dynamics during this crisis time when someone was dying, so they tried to accept the family members as they were and create the best situation possible. In most situations, the nurses did not try to project how families should behave. Rather, family members were allowed to do what they needed to do to get through the death.

One contrast case was discussed, in which the struggle of the family was never really understood or resolved. In this situation, a young woman was dying of respiratory failure secondary to complications of cancer.

> There were a lot of frustrations in this case because she was there for three months. She had a very strong, angry mother who was mad at the world that her daughter never got to have a child, never got to do the things most women get to do. And so she was constantly striking out at the nurses and very hostile to the physicians. She would play one nurse against the other nurse, one physician against the other physician, which broke away the teamwork in our unit. Because the nurses would burn out or not want to deal with the mother. We lost the focus of the whole patient, who was alert, oriented, and had a strong will.

Although some nurses developed a close relationship with the

patient, the mother played out her anger by trying to control the situation. She excluded her daughter from decision-making, specified caregivers, and limited visitors. A patient advocate was brought in to mediate, but the situation did not radically improve. The continuous conflict between health professionals and the mother alienated many of the nurses, who tried to focus on the patient's well-being, but were sometimes drawn into the power struggle.

> She had two sisters who loved to take care of her, bathe her and help in her AM care and stuff like that. And they were willing to participate but the nurses got so burnt out with the family, especially the mother being so controlling, that they would tell her no, you can't have visitors right now. So they would cut back her time for having family there.

In the end the patient died peacefully with her friends around her, but her mother stood alone at the end of the bed. The nurse looked back at the situation with regret, wishing the dying could have been different. This example of breakdown highlights the importance of connection with the family of dying patients.

Shaping Caring and Involvement

Specific characteristics of family members and relationships solicited or impeded the nurse's interest and involvement in caring for the dying patient and their family. The nurse in this story was herself very involved and committed in a family, and admitted that she gets very involved with families. She was interested in each member

of the family and their different responses to the situation, and particularly related to the daughter, with whom she developed a special relationship.

Nurses in the study expressed different degrees of ability and willingness to be involved with patients and families. Dreyfus et al. (1990) describe involvement as a skill that nurses develop with experience. Nurses themselves are parents, children, partners, and friends. As human beings in their own personal relationships, they may identify with specific family members or relationships which have characteristics of their own. Knowing what it means to be part of a family, nurses can understand and relate to feelings families might experience as their loved one is dying, for example understanding the kind of connection that is possible after being married for many years. They understood the potential impact of death on the lives of family members, and that the pain and suffering of the family would extend beyond the short time in the ICU.

These understandings of the patient as part of a family created the perception of the family needs as primary. They understood that the patient's environment represented the family's time and space to say good-bye and begin the rest of their lives. They also understood that hospital policies and technologies were secondary and, in fact, often inappropriate and superfluous to the true meaning of the situation. Several nurses were able to relate specifically

how personal experiences with death helped them to understand the concerns of families, for example making DNR decisions for an elderly parent or experiencing the untimely loss of a sibling. In one exemplar, a nurse related her experiences with the death of her brother-in-law. He died from complications of treatment for leukemia. She described his decline, in which she alone, as an experienced critical care nurse, understood that he was dying. As the days passed, he was taken out of protective isolation, ventilated, and unresponsive. She vainly implored the physicians to acknowledge his impending death, but only the night nurses answered her honestly, encouraging her to continue asking questions. The other family members remained in denial until the end. She reflected back on what she had learned and how it affected her practice.

> I have learned that my schedule and others can be different. And so I try to keep, and remember that when patients are dying. To give the family a chance even if I think, "Oh, this is really cruel."

Other nurses understood family concerns based on their practical experience in similar clinical situations. Understanding and relating to family members was a strong incentive to become involved.

Characteristics of family members that solicited some nurses alienated others. Certain family problems or behaviors which caused some nurses to choose other assignments were perceived by others as a challenge, for example family members who were angry or having trouble

coping. Families who needed help in negotiating the system also engaged some nurses, for example those with language barriers, who were frustrated in their attempts at communicating with physicians, or who displayed behaviors that pointed out their need for assistance. In one situation, the nurse was solicited by her curiosity about a patient's wife. The patient had complications of routine surgery and was progressing poorly.

> He had this wife who was just always in attendance. And I couldn't figure out how this woman slept. Because every time I came in, she was always there. And every time I left, she was always there. It was the weirdest thing. And I had this feeling of "I really would like to sit down and talk to her."

The nurse's clinical grasp that something was amiss was correct. The wife was very distressed and didn't know where to take her concerns. The nurse helped the wife to resolve her concerns, and the patient died peacefully several days later with the wife feeling more informed and involved.

Understanding the Patient as a Person

Family members helped the nurse to understand the personhood of the patient. In the paradigm case, the son who read at the bedside talked with the nurse about what his mother was like and about her role in holding the family together. This knowledge contributed to the nurse's understanding that the family was falling apart without the mother, and gave her perspective as she continued to help them understand that their mother was dying. Other nurses discussed using information about the patient to personalize

the patient's care, for example knowing how to comb someone's hair, or what to say to them. Knowing the patient's feelings and wishes regarding end-of-life issues directed the nurses as advocates. In one observation, an elderly woman with a progressive neurological disorder had an advanced directive stating that she did not want to be maintained on a ventilator. She was intubated as a temporary measure to prolong a diagnostic window, but the window kept lengthening. The woman was in a great deal of pain, agitated, and trying to pull her tube out. She was subsequently restrained. The nurses understood the woman's wish from a number of sources, including her son and friends at the care center where she had been staying. Two nurses supported each other in building a case for extubation and arranging a care conference. She was extubated and died several days later after returning to the care facility. Other nurses talked about how learning about the patient helped them to see beyond the technology to understand unresponsive patients lying passively in the bed as people and to humanize their approaches.

Perspectives on Good Care

Relationships and contact with family members after the patient's death were important in helping the nurses to understand what constituted good care of the dying patient and their family. The feedback that the nurse in the paradigm case received from the daughter validated her good

feelings about her work with helping Cathy to bathe her mother, and she has continued to incorporate that strategy in her care when appropriate. Nurses talked about cards, notes, gifts, and phone calls helping them to understand what parts of their care were appreciated and meaningful. They learned that their sense of humor, their cheerfulness, or their willingness to listen helped the family to make it through the most difficult of times. They learned that singing to patients or giving them a shave was much appreciated. This feedback was extremely validating and set up the possibility for future practice.

Summary

The nurse informants understood that death was a part of critical care nursing. Deaths were easier if they had some warning, otherwise they sometimes struggled with feelings of responsibility for the patient's demise. It was also more emotionally difficult to work with dying patients with whom they had been involved long-term. The nurses felt strongly that it was possible to have a good death in critical care. Elements of a good death focused on the patient as a person, and included patient choice, family involvement, and comfort. In contrast, a bad death was unexpected and out of control, or involved persistent medical treatment beyond what they considered reasonable. An empty death was one in which neither family nor nurses were involved with the patient.

Most of the narratives and observations involved moral discourse. A strong sense of caring, involvement, and relationship was evident in the discourse, representing the moral goods inherent in the practice of nursing. There was little reference to decontextualized ethical principles, except as a way of communicating with physicians. Recurring ethical concerns included the importance of patient choice, relief of unnecessary suffering, maintenance of dignity, the primacy of family needs, and non-discriminating treatment of patients. Some nurses were also concerned with their role as the "agent of death", in which they assumed the responsibility for discontinuing life support and sedating patients as they died.

The general organization of critical care and the health care system did not support nursing care of dying patients. Although some supports were in place in the hospital setting, including chaplains (or others who supported families), ethics committees, and advance directives, these were not consistently available. Nurses received their primary support from other colleagues who were interested in care of dying patients. Nursing workload, assignment, and staffing patterns in general did not facilitate continuity of care or adequate attention to dying patients and families. In some situations, lack of coordination of medical care was seen as a concern, as well as the uninvolved stance of physicians as patients died.

At some point in the dying trajectory, particularly if the patient was unconscious, the focus of nursing care changed from patient to family. Often family members solicited involvement of the nurse in the situation. The nurses understood that family members coped differently and had different needs as the patient died. This understanding helped them to remain non-judgmental of individual behaviors and responses to the situation. Although they supported family members who did not want to be at the bedside as the patient died, family involvement was considered to be an aspect of a good death. Families helped nurses to know the patient as a person, and subsequently deliver more individualized and meaningful care to both patients and families. Feedback from family members provided perspective for nurse about their care, serving as an important stimulus for reflection and personal and professional growth.

CHAPTER VI. RESULTS AND DISCUSSION: INTERPERSONAL CONCERNS AND BACKGROUND MEANINGS OF BEREAVED FAMILY MEMBERS

Eight families members participated in the family interview portion of the study. These family members were chosen in two ways. Some were recruited by the researcher during observations of nursing care of dying patients. Others were selected from group interview data as families who were very involved in the death of their family member.

During the dying vigil and at the time of death, some family members remained at the bedside. Others said good-bye to the patient and went home. Some patients had no family at all. The family interview data were contextual, in that each situation and those involved was very different. Most families had little or no previous experience with critical care and were in crisis at the time of the death. The perspective they presented was often very focused and emotional. During interpretive analysis, the family meanings and concerns showed up best against a background of the observation data (if available) and nurse interview data (group or individual). Given the clarity of that interpretive lens, one data triad, consisting of observation, personal history, and family interview is summarized. This triad was chosen as the paradigm case because it represents and highlights family meanings and concerns that were central and recurrent across the data.

Specific issues describing breakdown in nursing practice are also seen and discussed within the context of both this situation and other family narratives. These data are organized to present the following aspects of the situation from the viewpoint of the observer, nurse, and family member: (a) the patient's medical condition, (b) family involvement in decision-making and at the time of death, (c) major aspects of nursing care, and (d) the role of each key participant in the situation. The triad of data is followed by an interpretive analysis. This analysis is supplemented by other exemplars and excerpts which support and expand the interpretive summary.

Paradigm Case: "Turning Him Off"

Introduction to the Patient Situation

The situation presented describes the dying and death of a middle aged man named Allen following a sudden cardiac event. At the time of his collapse, he was at work and his wife Laura was present. Allen was taken to the emergency room by paramedics and resuscitated for hours. By the time his cardiac rhythm was restored, he had suffered anoxic brain damage. He was unresponsive when he was admitted to critical care. Allen was extremely unstable during his five day stay in critical care. He experienced several cardiac arrests, and emergency angioplasty with insertion of an intra-aortic balloon pump. Four days later an EEG was done and interpreted as "silent". The following day a conference

was held with the family, and life support was discontinued. Allen was transferred from critical care to a general hospital unit on the sixth day, and died the seventh, one week after his admission.

Allen's family included his wife of three years, his elderly father, and a brother and sister who lived out-of-state and had flown in to be at their brother's bedside. One of Laura's friends and her husband and son, as well as Laura's teen-aged son were at the bedside in critical care and involved in the situation. Laura later admitted that she constantly referred to her friend as her sister, in order to ensure visiting privileges for her major support person.

Joyce, a nurse participant in the study, had first been in contact with Laura when she answered a phone call asking about Allen's condition. The nurse caring for Allen at the time was busy in the room, where Allen was coding almost continuously. Joyce encouraged Laura to tell her story about her husband's collapse, keeping an eye on the room as she talked. She was solicited to the situation by her concern for Laura and challenged by Laura's reputation among the staff as demanding and controlling.

Observation

The observation began on Allen's fifth hospital day as decision-making regarding discontinuation of life support was beginning. Allen was a big man, lying on his back in

bed, unresponsive, with his eyes patched and taped shut. He was supported by a variety of technology, including a ventilator, an intra-aortic balloon pump, many intravenous medications including antibiotics and vasoactive drugs, and tube feedings. He also was connected to a plethora of monitoring equipment: cardiac monitor, pulmonary arterial catheter, arterial line, foley catheter, and venous saturation monitor.

Nurse Interview

It was obvious to the nurse from the beginning that Allen "had big time damage and he probably wasn't going to make it".

> He's got a balloon pump and a lot of busy work kind of things. But it isn't like this balloon pump is saving his life. And it's going to be on for a couple of days but it's not really doing anything because he's got such big-time damage and probably neurological damage too. And even though the EEG hadn't been done yet when I first took care of him, it was pretty obvious that things were not looking up. He didn't have a huge down time, but you know how it is. If they start to wake up twelve hours out, you feel a little more optimistic. But when it's twenty-four hours out and they're not any better than when they first came in, and they've coded and coded, it's just not in their favor.

The nurse's view contrasted with Laura's, which was based on her own understanding of her husband's medical condition and her need to maintain hope.

Family Interview

Laura, who had previous experience as a nursing assistant, understood that her husband had a major heart attack and suffered brain damage as a result of the

prolonged resuscitation effort. She explained his condition and treatment as she understood it based on the explanation given by the cardiologist after returning from the catheterization lab:

> And the doctor came out and he said, "Oh, I'm glad you're here. Your husband's main valve to his heart collapsed." A section of the cholesterol had broken off when his valve collapsed and had gone to the end of the valve. And had almost dropped into the main chamber of his heart. He says this is where the problem was. He says we've got the valve cleaned out and we have him on a heart pump machine. He says now it's one-to-one ratio. His heart beats once and the machine beats once. He says we'll see how that goes.

Laura also understood that the EEG would provide information about the degree of Allen's brain damage, but remained hopeful until the results were presented to her at the care conference.

Family Involvement in Decision-making and at the Time of Death

Decision-making

Observation. Joyce cared for Allen on the morning of the observation. She answered phone calls first from the patient's brother, then later from Laura. Allen's brother, who understood the gravity of Allen's condition, expressed his concern over Laura's denial. At the suggestion of the nurse, his brother agreed to attend a care conference later that day. When Laura called and heard about the conference, she was concerned with who's idea it was and what the purpose was. Although she agreed to attend, she wanted to be sure that this would not be the last opportunity for

decision-making. She also made it clear that she, not other family members, needed primary access to information about Allen's condition and would make any decisions about his care.

When Laura arrived in the ICU later that morning, she sat at the bedside, touching and talking to Allen and encouraging him to keep fighting. She alternated between sobbing and a maintaining a stone-faced facade. A care conference was held later that morning. The conference concluded with Laura's decision not to resuscitate Allen if he should have a cardiac arrest, but she said that she wanted to wait until her son arrived to decide about withdrawing life support. Laura would not talk to the rest of the family, and left Allen's room when they came in. She spent the afternoon wandering between the waiting room, the smoking lounge, and Allen's bedside. Late in the afternoon, Laura asked to talk with the physician. She announced to the resident that she was ready to discontinue the life support.

Nurse interview. Up to the day of decision-making, Joyce felt that Laura was "in big time denial". She believed that she really knew that he was dying, but was fighting to suppress the notion. She believed that control issues were important with Laura, who didn't even want anyone caring for Allen who believed that he would die. Joyce purposefully talked about Allen's condition in

generalities, not forcing the conclusion that he was dying and letting her process information at her own speed.

After the conference, Joyce believed that Laura would withdraw life support later that day. She believed that Laura wanted to make the decision herself based on information that she received from the physicians. She understood that there was some conflict between family members concerning Allen's prognosis and making decisions, but didn't get involved with the detail. She remained nonjudgmental about Laura's behavior throughout, explaining that she did not know Laura or the family history. She understood that Laura was " bombarded and overloaded", and "My God, her husband was dying! She had only been married three years, and she was grappling with that". Joyce understood that Laura was struggling to cope while she made this most difficult decision.

Family interview. Laura said that "shutting him down" was the most stressful part the whole experience for her. Allen and Laura had never talked together about their end-of-life wishes because they were young and didn't anticipate death so soon. Before the conference, she had not been willing to hear other family members talk about "shutting him off". Even after being presented with hopeless EEG results, she was disappointed that Allen wasn't given a second chance with another EEG.

> I guess I was looking for a miracle. I knew it wasn't there, but I was looking for it. I was looking for

> something that would say there was a spark. They said they were going to give it a couple of days and run [the EEG] again. They never did.

Disappointed that the EEG would not be repeated, Laura made her decision, believing that Allen would not have wanted to live with brain damage. However, she wished that she would have had more support from hospital staff as she struggled to make her decision.

> When they tell you that in all aspects your husband is considered brain dead, and you're having to make a humongous effort to tell them to shut it off, it would have helped if they had somebody there to counsel you. To let you know that you are making the right decisions or no, you shouldn't make that decision now. Give it a little bit longer.

Laura felt alone in her decision-making.

Family Involvement at the Time of Death

Observation. As the nurse prepared to discontinue the ventilator, Allen's father and brother went to his bedside to say good-bye, then left the hospital. The nurse asked Laura if she wanted time alone with him before she extubated him, but she declined. However, she wanted to be at the bedside, saying, "He would do it for me." Laura held Allen's hand as the nurse extubated him.

Laura, her friend, and Allen's sister came in and out of the room over the next few hours, keeping a vigil. Laura seemed more relaxed and peaceful than she had all day. She sat at the bedside, stroking his arms and talking to him.

Nurse interview. The night nurse talked about Laura's involvement during the night and problems with the nurse the

next morning. During the night, Laura and others remained at Allen's bedside. As the family realized that he was not going to die right then, they relaxed and began to reminisce. Laura called the nurse when he needed to be suctioned, and assisted by removing and replacing the oxygen mask. She expressed concern about his fever, and whether or not that was making him uncomfortable.

The next day the nurses reported that they had a difficult time with Laura. She argued with Allen's brother and the assigned nurse, who she dismissed after a loud argument about the proper way to suction him. Allen was transferred out of critical care early that afternoon after the intra-aortic balloon pump was discontinued.

Family interview. Laura described how she stayed at the bedside during the time that Allen was dying. Based on information that she gleaned from the nurses, she exercised his legs so that he wouldn't draw them into a fetal position, massaged his hands so that the venous saturation monitor worked better, and kept a cool cloth on his head to keep his fever down. After Allen was transferred from critical care, she slept at the bedside. Laura called the nurses when he needed to be suctioned, and explained what size suction tubing to use. She continued to put cool cloths on his brow. Allen died the morning after transfer while she was at breakfast.

Major Aspects of Nursing Care

Major aspects of nursing care that appeared in this paradigm case described the direct provision of care, the care conference, and withdrawing the life support. These will again be presented from the viewpoint of observer, nurse and family.

Provision of Care

Observation. During the observation, Joyce worked with a new graduate nurse to provide technical care to Allen. This care included monitoring vital signs and urine output, suctioning, tube feeding, administering medications and treatments, and tuning the balloon pump. Although Joyce was sometimes serious, she was also cheerful and smiling, talking to Allen as she cared for him.

Over the phone, Joyce showed concern for Laura, responding to her questions and concerns, but also asking her how she was doing. And when Laura arrived at the bedside, she comforted her as she cried. The nurse spoke with her at length, explaining every detail of the patient's assessment to his wife and interpreting what was "not a good sign" and what would be more encouraging.

After the care conference, the nurse went back into the room and bathed Allen. As various family members came in and out of the room, she talked with them and comforted them. She made sure that Laura had time alone with her husband. The nurse was offered the opportunity to go home

early because of staffing, but she refused, wanting to see this situation through.

Nurse interview. Since the nurse knew that Allen was not going to make it, her biggest concern from the start was the family, particularly Laura. She supervised the graduate nurse who performed the technical care, and she focused on the balloon pump (which is complicated) and the family. The nurse's deliberate approach was to give Laura credit for the knowledge she had gained as a nursing assistant, and not to put her on the defensive. She gave her information in generalities so she could decide "what she likes and what she doesn't".

Family interview. When Allen was first taken to critical care, the nurses were very busy working on him, and kept telling the family that it would be 15 minutes to one-half hour until they could come in. But no one ever came to get them or communicated otherwise. They had to keep asking. After several hours, Laura finally insisted that Allen's elderly father be allowed to see him, so that he could go home for the night. She was allowed into the room several hours later.

> They finally came out and said, "You can go in and see him." And I understand that they have certain things they have to do to get this patient stabilized. But don't get the family's hopes built up by saying "15 minutes, half an hour". We're stabilizing him and we'll let you know as soon as possible. It may be an hour, it may be two hours, but please bear with us. But don't cut us off, you know, we're human beings too, and we happen to be concerned.

When she finally saw Allen hours later, she kidded him and thought he smiled.

Laura talked about the importance of skill, and observed the nurses closely. It was particularly important to her that the nurses talked to her husband.

> They were firm, but gentle. They would talk to him, tell him what they were doing. I'm going to be suctioning you out now. I'm going to turn you and I'm sticking some pillows under you. You need to have a shot or this or we're hooking up some more medicine into you. [They] would always talk to my husband, which is something I did appreciate.

In contrast, she explained her difficulty with unexpected or unexplained events.

> Friday night, I had gone to supper and I had come back and they had the bed, everything disconnected from my husband. They had him on portable oxygen. And I'm standing there, what in the blazes is going on?...the doctor says, "We're going to take him in and find out what is wrong with his heart. Otherwise he's not going to last the night. And I need you to sign this paper." and he explained what he was going to do and I signed the paper and off they went.

Laura was told that if they were gone longer than two hours, they had probably run into complications. After two hours, she assumed that they had run into a problem, but no one had told her that he was on his way back. On Allen's return, with a balloon pump in place, he was moved to a larger room. After he had been back for over an hour without anyone calling her in, she went looking for him, and found an empty bed. This caused her to panic, thinking that he had died and they had not bothered to tell her. She ruefully referred to other situations where nurses did not respect time

projections, such as not calling her when an EEG had been rescheduled so that she could change her visiting plans.

Laura was also upset that every day, every shift, Allen had a different nurse. It seemed to her like no one wanted to take care of her husband. This made her feel like she needed to tell each one how to care for Allen and protect him from unfamiliar care-givers. After he was extubated, suctioning with the right sized catheter became an issue with Laura, and she became angry at one nurse who wouldn't suction as she requested. She felt that suctioning with a large catheter hurt her husband, and explained how he clenched his teeth. She talked about assessing the skill of that same new caregiver, comparing her with other nurses and having her come up short.

> The nurses had taken a black marking pen and had marked the pulses on the top and the side of his foot so they would be easier to find. This is where you could feel the pulse best so that we will know that the heart was getting blood down there to his feet. This nurse was feeling all over the place, and I said, "What are you doing?" And she said, "I'm trying to find his pulse on his foot." And I said, "Do you see those black marks there on his foot?" And she said, "Yes." And I said, "Why don't you try there. You might find that is where the pulse is."

This perception of incompetence, coupled with the suctioning incident, resulted in Laura telling the nurse she no longer would allow her to care for her husband. Laura appreciated nurses talking to her about procedures, so she understood and could follow through explaining to others.

Laura expected that Allen would have one-to-one care in

ICU, which he had when he was unstable and on the balloon pump. She was later confused when the nurses weren't as available. [When he was made DNR and life support was withdrawn, he no longer had his own nurse.] Laura watched Allen's responsiveness decrease, assisted by the interpretation of clinical signs by the nurses.

> They would do like this (nailbed pressure). They did that to see how much of a reaction there was. And she said, "this is one thing that he doesn't like". And he did like this to where it really hurt, and he was trying to yank away. But it seemed like as the days went by, it was less and less.

Laura was very upset when Allen was transferred out of the critical care unit. She interpreted the move as a shock to his system, rushing him towards death. He was put in another environment where it was hot and the nursing care was "indifferent". The nurses on the new floor didn't talk to her husband, and it took her a long time to find someone to suction him. When they did come the suction machine was old.

Laura did appreciate one nurse in particular on the medical unit who was "concerned". This nurse talked to her husband and asked her if there was anything she needed. "For a change somebody was concerned about the family." She brought her a recliner, and a bucket of ice to keep his fever down. Laura said that she would have liked to stay in the room with her husband toward the end of his stay in ICU, but that option was not offered. The nurse was also the first person who asked her advice about Allen's comfort and

gave him pain medication. The nurse positioned and shaved him - all of which she appreciated. She encouraged Laura to go eat, then turned down the other bed in the room so she could lie down when she returned from breakfast. As Laura was paying for her food, the nurse appeared, picked up her tray and took it to a table for her, then gently told her that Allen had died as soon as she left the room.

Laura felt that in general Allen had excellent care. "They checked the machinery and kept him suctioned." They also did things to keep him comfortable like raising his bed up so he could breathe easier, propping a pillow to keep him on his side so he wouldn't end up with bed sores, and massaging him. Laura was delighted by a card sent by the critical care staff about a week after his death. However, she also commented that the pamphlet about where to go for help sent by the hospital a month and a half later was too late.

Care Conference

Observation. Joyce arranged the conference by calling all involved physicians and coordinating their schedules. At the appointed time, she called everyone again. Residents conducted the conference; neither the staff neurologist nor the cardiologist attended. All the family attended, with the exception of Laura's son, and Joyce was also present. The residents interpreted the EEG and explained that Allen had no higher brain function and no hope of recovery. Family

members asked questions about whether or not he was suffering, and what their options were. Laura wanted to know if the EEG could change. The residents said that it would not, and recommended that he not be maintained by the technology. Laura tearfully agreed that Allen should not be resuscitated, but wanted to wait until her son arrived to decide on withdrawing support.

During the conference Joyce gave examples and interpretations of some of the residents' explanations. She also recommended that the balloon pump be discontinued fairly quickly, since it was not functioning properly. Finally, the nurse clearly told the family that even though the patient was not responding, he was most likely aware of their presence at the bedside. The residents left. As the nurse walked past the family, they literally grabbed her pantleg and detained her in the conference room, asking questions for another 10 or 15 minutes.

Nurse interview. The nurse felt good about the conference, because she had already explained much of the terminology the day before that the residents had used to explain the situation, and she felt that the family understood what they were told. She also thought that the residents did a good job in the conference, and was glad that the family was given sufficient time to make their decision.

Family interview. At the conference, the doctors told

Laura the results of the EEG.

> And they told us then that the main brain, all the lines were flat. And the doctor said, "You know, you have two brains. The upper brain and the lower brain, the brain stem. That main part of your brain, there's no response there whatsoever.

Laura understood this to mean that Allen was a "vegetable". She really didn't admit to herself that he was going to die until then.

Withdrawal of Life Support

Observation. Aware that Laura's son had arrived and that a decision would be made soon, family members began to gather at the nurses' station in the critical care unit. Laura asked to speak to the resident and requested that Allen's life support be discontinued. A staff physician asked the nurse and respiratory therapist to do a trial off the ventilator. The results of the trial indicated that Allen could survive hours after extubation. Joyce asked the doctors to clarify the details and sequence of withdrawing support, feeling that Laura needed to know the particulars of what was going to happen. The nurse went into the room and quickly removed the nasogastric tube and stopped the intravenous medications. Laura then joined her at the bedside. The physicians talked about the best way to discontinue the ventilator, told the nurse to extubate Allen, then left the room. Allen's father and brother said good-bye, but Laura remained at the bedside, holding Allen's hand while the nurse extubated him.

After extubation, Allen had rapid, shallow respirations and moaned periodically. He clenched his teeth, making suctioning difficult. The nurse gave him intravenous Valium until he relaxed enough to insert an airway, and then suctioned him. A resident returned saying that the balloon pump would not be removed until the next day because the resident that would do that had already gone home for the day.

Nurse interview. Joyce was concerned because she could not pin the physicians down to a plan of action for withdrawing various technologies when the life support was discontinued. She was concerned that last-minute changes related to the ventilator trial and withdrawing the balloon pump would be problematic for Laura, who liked to know exactly what was going on and didn't deal well with changes in the plan. However, it worked out okay. The nurse's concern was, "How can I make this better?"

Family interview. Laura explained that when the old airway (endotracheal tube) was taken out, the nurse tried to put a new one (oral airway) in place. She chuckled when she described how Allen clenched his teeth so tightly that she could not get it in place. Laura teased Allen, encouraging him to relax his jaw. Finally they gave him enough muscle relaxant to get the airway in, and Joyce was able to suction him.

> And she told me the large suction tubing is not good because his teeth in the back are still clenched enough

> that if we use the larger one all it's going to do is damage his teeth or create worse problems. And I said, "No, I don't want to cause anymore problems. The guy has had enough as it is."

This understanding of a particular way of suctioning was reassuring to Laura, but became a point of contention with other nurses during the next day and one-half of Allen's life.

Role of Each Participant

In summary, the role of the nurse, physicians, and family will be discussed from the perspectives of the observer, the nurse, and the patient's wife. It is important to note that, although physicians were observed in their interactions with nurses in the study, the physician perspective is not represented in the data.

Role of the Nurse

One nurse was observed during this patient situation. During the observation Joyce directed the technical care and monitoring of the patient, communicated with physicians about the plan of care, and cared for the family. She kept the family updated on the patient's condition, interpreted information for them, and comforted them. Joyce coordinated the care conference, and participated primarily by interpreting for the family. She bathed the patient, and provided other basic nursing care. After the decision was made to withdraw life support, the nurse withdrew the technology (with the exception of the balloon pump, which needed to be taken out by a resident), and supported the

family at the bedside vigil until her shift was over.

Joyce described her own focus of care as the family. She did not want Laura to have a bad experience. She worked hard to understand Laura's concerns, and approach her in a way that would meet her needs. She gave her information which would help her to move towards understanding her husband's condition as she was ready. Although she also described her technical, coordinating, and teaching (of the new graduate nurse) functions, these were background for her work with Laura.

In contrast, the technical work of the nurse was definitely in the foreground for the family. Laura described the role of the nurses as giving physical care to Allen, such as suctioning, repositioning, and massaging. She also saw them managing the equipment and giving medications. It was important to Laura that the nurses be caring and technically skilled. She also described how the nurses communicated with her about Allen's current condition and explained how to take care of him, for example how to suction.

Role of the Physician

Since physicians were not a primary focus of the study, they were seen during the observation only in contact with the nurses, for example making rounds and discussing specific orders with the nurse. Physicians led the care conference, explained Allen's diagnosis and prognosis and

recommended that he not be maintained on life support but that some or all of the equipment be withdrawn. When Laura told them that they were ready to withdraw life support, the physicians talked with her briefly, wrote the order, waited at the desk until the ventilator had been disconnected, then left the unit.

Joyce perceived the physicians as responsible for decision-making. In this situation they contributed to a good death by not letting the situation drag on too long, yet giving the wife time to deal with the inevitability of the death. She also commended them for doing a good job explaining the situation to the family in the conference. Joyce expected the physicians to discuss the withdrawal procedures with her, and said that she preferred that they would disconnect the life support themselves out of respect for the situation (although experience told her that they would not).

Laura looked to the doctors as the final authority regarding management of her husband's case. She described how the physicians explained Allen's medical diagnosis and prognosis, for example the results of the EEG. The physician was clearly the authority and the person she talked to regarding the decision to withdraw life support.

Role of the Family

During the observation, Laura, as the primary family member, tried to understand and control her husband's

situation as best as she could. She spent much time at the bedside, grieving, caring for Allen, and observing or supervising nursing care. When she wasn't there, she phoned in regularly. She attended the conference, and clarified her concerns. Laura made the final decision to withdraw his life support.

Joyce understood that it was Laura's role to make the decision about life support, and to get through the situation however she could. She did not hold many expectations for the wife's behavior.

Laura saw herself as the decision-maker, but also described standing guard over her husband, making sure that he received good care. She provided loving physical care, for example putting a cold cloth on his head, and kept a vigil until he died.

Summary

These three perspectives regarding this man's dying in critical care highlight family meanings and concerns regarding nursing care of dying patients in critical care. They also provide additional understanding of situations in which there is breakdown of nursing care. Although the stories are consistent, each has a different focus. The researcher described events as they unfolded from a detached perspective. The nurse focused on the details of her process with the family and her focus on orchestrating the best possible death. The patient's wife described the

struggle and suffering of coping and making the most difficult of decisions in the most stressful of situations. The interpretation of this triad of narratives highlights some general themes that are central to the family data. Four aspects will be explicated. First, much of the nursing care was invisible to families during the time that the patient was dying. Second, critical care was a difficult system for families to negotiate. Third, families assumed a role of standing guard for the patient. And fourth, it was very important to families that the nurses cared about the patient as a person. Discussion of these general meanings will be followed by a summary of nursing practices that families appreciated and suggestions for improving care. It is important to keep in mind that many different nurses cared for the patients during the dying time, and the comments of family members are not limited to the care given by those identified as expert at nursing care of dying patients.

Interpretive Analysis

Meanings related to Nursing Care, Critical Care, and Family Role

The Invisibility of Expert Nursing Practice

There was very little focus on nurses or nursing care in the accounts family members told of the dying time. In comparing the family accounts of situations with those of the nurses and the observation data, it was apparent that

much of the care that nurses provided was background for the family and invisible to them. For example, Joyce discussed Laura as the primary focus of her care. She talked about a deliberate approach to validate her suffering and her experience, and to move her towards understanding the futility of her husband's condition. She hugged and comforted her and participated in reminiscence about the patient. She asked her about how she was getting along, and tried to avoid conflict by encouraging physicians to explicate and follow a plan of care. She arranged a care conference, then participated by translating and interpreting medical information during and after the conference. She remained nonjudgmental and did not take sides in the family quarrel, but considered the needs of all family members. Between visitors, she quickly worked to wash the patient, complete nursing procedures, and begin to remove life support equipment. She brought chairs into the room, and gave family time alone with the patient. Typical of other family accounts, these practices were not described by the patient's wife.

Although bereaved family members recognized the nurses who provided the most caring and skilled care, they did not notice many of the supportive, organizing, and coordinating (including decision-making) practices involved in the care. Even when directly questioned, it was apparent that much of the nursing care was background to the stressful situation

confronting them, and showed up primarily in the case of breakdown. Another family member reflected about his lack of recollection about the details of nursing care.

> It seemed like since everything was going so smoothly, the nurses were doing whatever they were supposed to do. It seemed like there was nothing that he really needed, because they were there to be sure that he was comfortable or whatever. That was never really a concern of ours, because he looked like everything was okay. Nothing was out of place. Whatever they did was just so transparent.

While good nursing practices were transparent, those that fell short caused anger and conflict. For example, in Laura's account, when the new nurse did not focus on the family and did not incorporate suctioning suggestions into nursing care, the wife became irate.

Most of the deaths described by family members occurred quickly, over a period of hours or days. As such, it was not surprising that the particulars of the nursing care went unnoticed. Family members were often under a great deal of stress and focused on the events as they unfolded. In contrast, the husband of a woman hospitalized for several weeks in critical care before her death gained appreciation for the centrality of nursing work. He realized the importance of nurses to the patient and family: "doctors come and go, but the patient is left with the nurse." He understood how the nurses were involved, and appreciated how the daily management of the patient was dependent on the skill of individual nurses.

Negotiating Critical Care

Admission of the patient to critical care was a shock to most families, because it indicated the seriousness of the patient's illness. The critical care unit was often a difficult place for family members to negotiate. In the paradigm case, Laura saw the unit as uninviting and difficult to access. The work to save her husband that was going on in the unit had great meaning for her, yet she felt that she was kept out of touch with the what was happening and relegated to the waiting area. Most aspects of his care were out of her control, including who cared for him. She felt like an outsider with the biggest investment to lose.

One man explained his first impression of ICU when his mother was admitted following intubation for a respiratory emergency.

> Now I go into critical care the first night, and I walk in there and it was a different environment. I don't know what I was expecting, but it was different. My first impression, you walk down there and I'm looking for the desk to talk to someone from critical care and I can't find it. And finally I look on the wall and see a sign that's down here and my eyes are about a foot above it saying, "Ring bell". And I think, what type of place is this?

Once entering the critical care unit, most understood that this was a different kind of place. Although families were encouraged by the technical expertise and the high level of organization in the care, they were also very aware that they didn't understand what was going on much of the time. Explanations of technology and pathology given by family

members in interviews often missed the mark, showing only fuzzy understanding. For example, Laura understood that Allen's heart attack was caused by cholesterol in the heart valve rather than a coronary artery. Situations that they didn't fully understand in the first place changed quickly, creating a stream of events they could never quite catch up with. For example, Laura did not completely grasp her husband's deteriorating condition. Yet on returning from supper, she was surprised to find him on a cart ready to move to the cardiac catheterization lab, and was expected to quickly sign a consent for a procedure urgently explained. Another family member asked the researcher at an interview to explain a Swan Gans catheter, a procedure that he had signed for on behalf of his dying wife weeks before, but never understood. Some family members dealt with the technological maze by gathering information, and focused on that information as a way of coping. Some said that they did not even know what questions to ask. Still others did not ask for details, assuming (or hoping) that everything was being taken care of. For some family members the critical care experience was a blur; others remembered everything in graphic detail.

Family members also understood that they were dependent on the critical care nurses to give the kind of care and make the kind of decisions that their loved one needed to either survive or die peacefully according to their wishes.

One husband described his concern this way:

> It's hard to tell a nurse sometimes, "I don't like what you're doing" because the family is convinced that the patient is dependent on the care that the nurses give and the doctors give over to the nurses now. How do you get family members to maybe speak up more and to have nurses be able to handle that? And that it's okay that somebody objects to what you are doing. It's hard because, being put in that position, you don't want that nurse to then dislike you or dislike that patient and not give optimal care. And I think that can happen. So you need mature enough people handling patients that are in that kind of situation.

Family members were aware that critical care was a complex and sometimes unfriendly environment in which they often needed to maintain relationships with the caregivers and at the same time stand back and not interfere with the high technology care. On the other hand, the family knew the patient, and much of the meaningful care that nurses provided rested on the intimate kind of understanding that the family could contribute about the particular situation.

Standing Guard

Many family members described a sense of responsibility for monitoring the care of the dying patient. This occurred in large part because of the multiple nurses caring for critically ill patients, which created a context in which the family didn't know the nurses and the approach to care was constantly changing. Families also tried to protect the patient from judgments that were inconsistent with the goals for cure or care. This included scrutiny of bedside nursing procedures as well as medical intervention.

In the family interview described above, Laura

carefully evaluated the technical expertise of nurses assigned to care for her husband, and intervened when she thought they were hurting him or doing a procedure incorrectly. She was particularly concerned with oral suctioning, understanding the rationale behind using a small suction catheter because of Allen's habit of clenching his teeth.

Because of the staffing and organization of the units, patients usually had many different nurses caring for them. Trust was not an issue for some families, who felt comfortable that the patient would receive good care. One family member described his feeling of trust in the critical care staff.

> What we normally did was just go home because we knew that he was in good care and that if they ever needed us, that they would call us.

In contrast, others stood guard, feeling more comfortable leaving the bedside once they knew and trusted the nurse. Family members described their need to protect their unresponsive and vulnerable loved one. One husband described his feelings about nurses who were new to the situation.

> Sometimes a new nurse would come in and start to develop this whole new treatment plan. And sometimes that's good, you know, to get a whole fresh new look. And also it's like I would sometimes just back off and say to myself, "Okay, as long as you're not going to hurt her, then I'll let you go through what you have to go through until you learn some of the things I already know."

In more than one interview, family members recalled stepping

in to stop a procedure that was unnecessary or inappropriate considering the patient's condition. In the following situation, the patient was getting routine finger sticks to check the patient's blood glucose because she was on total parenteral nutrition. Her husband reacted:

> I think sometimes maybe some nurses could have realized that certain tests should be questioned because they would maybe contribute to discomfort. Such as when somebody's on the parenteral nutrition. They could see what was happening to her fingers and all the pokes she was getting for blood sugars. And they were even becoming infected like. And sometimes you have to kind of think, you know, maybe you don't do stuff like that. And I'd have to be the one that would just say no. You know, sometimes I felt that I had to say that too much. I would have liked a little more, in some of the nurses, common sense used for that kind of patient care. Not for all the nurses. Some were very aware. Some were very aware of comfort and what mattered.

In another situation, a son stepped in to stop a chest x-ray from being taken of his dying father. Family members often relied on the caregiver's judgment to protect the patient from unnecessary practices or procedures. In some cases they weren't able to be at the bedside constantly; in others they simply weren't able to distinguish what was not important or consistent with the care plan. In still other situations they were hesitant to intervene.

In another aspect of standing guard, family members protected the patient from unwanted medical treatment. In half of the family interviews, they discussed struggling with health care professionals to discontinue medical treatment and resuscitation orders in accord with the patient's wishes. In all of those situations, the nurse was

seen as supportive of the family members and instrumental in helping them to negotiate the system to prevent resuscitation efforts or get the life support discontinued. From the family's perspective, this was done primarily by listening and validating their concerns and facilitating communications with physicians. In one particularly conflictive situation, a son tried to get the life support withdrawn from his mother who had been intubated for a progressive neurological disorder. She had been clear previously that she did not want to be maintained on a ventilator, and the son was concerned that her wishes be respected. Amid disagreement and uncertainty among physicians, he saw the nurses as being his major support. In discussing their aggressive support of his (and his mother's) wishes and the resulting conflict between nurse and physicians, he said:

> But when it comes to a nurse and doctor, whether it's a male/female thing or a professional level thing, it's sort of a big difference. But to me, I walk into there and I'm looking for the person that does a job for me. I go to the one that gives me what I want.

This son understood the line of authority between physicians and nurses, and appreciated that the nurses had gone to the line for him in his struggle to follow his mothers wishes to be removed from the ventilator.

The Importance of Caring

In almost every family interview, it was very meaningful for bereaved family members that the nurses

showed expressions of caring and involvement with the dying patient as a person, rather than treating them as if they were non-people or already dead. Laura described how important it was to her that the nurses talked to Allen about what they were going to do, and treated him as if he cared and was able to understand. She appreciated when the nurses shaved and massaged him. These practices respected his personhood and his need to be clean and comfortable. Indications that they liked Allen, such as caring for him more than one day, were also important to Laura. Understanding and accepting (even joking about) personal aspects of the patient were appreciated by families of several patients. Examples included Allen clenching his teeth and another patient's ornery disposition.

Other families identified gestures that signified to them that the nurses cared for and valued their family member. In one situation, it was important for a wife that her husband was kept covered with a blanket, to keep him warm and preserve his dignity. In another, a husband was touched that a nurse talked to his wife as she died, even after she probably was beyond awareness.

In all interviews, family members were most appreciative of caring and personalized approaches to the patient demonstrated by nurses. Although caring had different meanings for different families, all family members reiterated many times how important it was to them

that nurses would talk to and touch the dying patient.

In summary, four general themes were central to understanding the family perspective. First, much of expert nursing care was background to families who were struggling with the crisis of a dying loved one. Second, critical care was a foreign environment where they often felt that they were "in the way". Third, some families felt that they needed to "stand guard" and protect the critically ill patient who could not speak for themselves. Finally, in the context of this threatening and complex environment, family members appreciated caring nursing practices that recognized the personhood of the patient. These concerns emphasize the stressful nature of the situation and families' struggles to cope and find some good in the worst of circumstances.

What Families Appreciated

Bereaved family members appreciated and acknowledged many aspects of the nursing care during the time that their family member was dying. Many of the nursing practices described were individualized and contextual, although some general themes are discussed. It was clear that different families held different expectations regarding nursing care, and that the nurses' clinical grasp of these expectations affected the comfort and involvement of family members.

Personal and Professional Traits of Nurses

Family members valued nurses' technical competence, skillful ability to handle patients, knowledge of medicine,

and experience with people. They appreciated knowing something about the nurses as people, and valued personal characteristics such as a positive attitude, honesty, and a sense of humor. One wife talked about how a nurse's attitude helped her through her husband's death.

> She just always seemed so up. She was so cheerful and it helped. And she seemed to care. I mean, here's somebody that you don't know and you won't see again, but she seemed to care.

Another man described qualities of a particular nurse that were important to him as he struggled to make end-of-life decisions for his elderly mother.

> I walked in and all of a sudden she just came over and started talking to me. And she was casual, very professional. She looked me in the eye when she was talking. I didn't feel like she was trying to hide anything or lead me on. I felt she understood what I was trying to communicate with her... But she looked me right in the eye, and I can still remember she was sitting on part of the counter top and she had her legs up like that and her hands across the knee and a little knee bent, and she was looking at me and nodding. And then she would volunteer some information.

This family member appreciated the honesty, seriousness, and involvement of this nurse. Various family members identified aspects about nurses that were important to them in their situation which helped to create trust and establish a bond between family and nurse.

Bedside Teaching

Although not recognized by some family members, others understood and valued the bedside teaching that nurses did. Laura appreciated that nurses took the time to explain procedures and their rationale, so she could follow through

and explain it to others. In another situation a son recognized how the nurse helped him to put information into perspective.

> She talked about my mom. I would say, "You know, she looks kind of pale." And she'd put that into perspective of really what that meant. Was it really serious or not? Some people would say, "Yeah, she's running a fever." What does that mean? A hundred and one. In her condition, is that good, bad or ugly? "

Although family members were able to talk about specific information that they had received from the nurse, they did not always perceive the significance of that information in decision-making. For example, in one situation a son and daughter were making decisions to discontinue life support on their elderly father who had suffered a stroke. They talked about how the nurse told them that, given his other symptoms, their father was probably aphasic. Another nurse explained how the ventilator controls showed that the father was not breathing on his own. They later talked about how both these details helped to stimulate and support their decision to discontinue life support. Yet when asked if the nurses had any input into decision-making, they said no. Family members seemed to identify decision-making as a specific interaction between family and physicians resulting in a particular outcome, such as a decision to discontinue life support, rather than a process which had occurred over hours or days.

Participating in Care

Some families appreciated being able to participate in

the physical care of the patient. Laura valued being involved in Allen's care, for example helping with suctioning and exercising his legs. Other family members preferred to watch from the sidelines or leave the room altogether during care.

Preparing the Family for Death

Families appreciated the nurses' insights regarding what extubation and the dying process might be like. This knowledge helped to prepare them for what to expect and to decide whether they wanted to stay with the patient or leave the bedside. In other situations where families were not at the bedside constantly, they appreciated being called to the bedside as death approached.

Attending to the Family's Own Needs

Family members valued seemingly insignificant personal courtesies during the dying time. Even a cup of coffee or a kind word from the unit clerk was important. Families appreciated the nurses' concern over their own well-being, and sometimes acknowledged that they needed encouragement to leave the unit to get something to eat or nap in the waiting room. One wife even mentioned that her family was so appreciative that there was a jigsaw puzzle in the waiting room to keep them occupied while they waited as her husband was resuscitated (even if three pieces were missing).

Families interviewed did not sustain much contact with nurses after their hospital experience. Although in some

situations nurses contacted family members regarding participation in the study, no specific bereavement calls were made. Laura was touched by the sympathy card signed and sent by the nursing staff, but other families did not seem to expect or desire any contact. In one case, the family was not sure that they could emotionally handle that intimate reminder of the death. In two other situations, family members later contacted physicians to ask questions about the patient's illness and treatment.

Beyond their central concerns, families appreciated many aspects of nurses and nursing care that supported them through the dying of their family member. These included gaining respect for the knowledge and skill required of a critical care nurse as well as involvement and connection with particular nurses as people. They valued the everyday teaching that nurses did at the bedside, but most often did not see that information within the broader perspective of goals set by the nurse, such as helping them to accept the inevitability of the death or preparing them for decision-making. Some families liked being involved in care of the patient. In many situations they relied on the nurses to prepare them for the death event. Many families mentioned how good personal courtesies felt to them during the time the patient was dying.

What Families Want

Although all family members interviewed expressed

gratitude for the nursing care their family member received, they identified some areas of concern. Family need for information, consistency, access, and consideration stand out in the narrative describing Allen and Laura's story, and are consistent with other family discourse.

Information

It was clear from the data that families wanted information about the patient. Even when Allen first entered ICU, Laura wanted progress reports concerning her husband's condition in a timely fashion, and struggled to understand explanations about pathophysiology and procedures. Whenever Laura entered the room, she asked for an update on his condition. If she was away from the hospital, she called in periodically. She asked for test results, such as the EEG. She wanted to know the particulars of the plan of care so that she knew what to expect. Too much information was confusing or stressful for some family members; however for others information offered a sense of control and focus, and was a way of coping with an otherwise untenable situation. Some family members relied on detailed information to make informed decisions. In one observation/interview, a husband described how he regularly searched the literature and read journal articles for information about his wife's illness and treatment.

Consistency

For families involved in the death of a loved one,

change was a major concern. Family members appreciated consistent caregivers and approaches to care. Laura was disturbed by constantly changing nurses with different skill levels who used different suction techniques. She panicked when she was not approached or forewarned about an emergency trip to the cardiac catheterization lab, and then when Allen's room was changed without notifying her. The transfer from the critical care unit to a medical unit in his last hours of life were also extremely stressful. She had difficulty adjusting to new caregivers, environment, equipment, and routines. In situations where dying patients were transferred out of critical care, families understood the economic reasons for transfer, but wished it wasn't necessary. Transfer seemed to be a greater concern if death was expected imminently.

Access

Most families were concerned with access to their family member. Although they realized that they needed to leave the bedside during critical times when the patient was unstable, they otherwise appreciated the freedom to come and go. In all observations and interviews, visiting hours were not enforced with families of dying patients, but some families reported that this was inconsistent between different nurses and different shifts. However, a distinction must be made between getting in and feeling welcome\comfortable in the bedside space. Family members

consistently lied about relationships to assure entry of friends. Laura wished that she could have been offered a recliner or a cot and invited to spend the night in critical care as she was on the medical floor. Although she had access, she did not feel comfortable asking for that privilege. Another family member talked about the lack of privacy as difficult for him.

> There's really no privacy. My wife happened to have one of the private rooms there and that was so much better. But yet your life is sort of an open book. I mean, I lived in the hospital with her in a sense. It's hard to get people to respect that. I can't think of any instances where people invaded my privacy. It's just that it's somehow a fact of life and I guess that people are aware of it and work with it and maybe that helps too. That they are aware that these are human beings, their lives are their own too.

Although families usually could get in, they did not consistently feel welcomed and comfortable.

Consideration

Families also asked for consideration. This was most strongly stated in the paradigm case where Laura described quite emphatically her need to be considered as someone who loved the patient and was concerned. She described over and over how she was put off or forgotten while the staff tended to the patient. While she was watching the clock, the staff was not. Although it is understandable how time flies in an emergency, the wife was demoralized and angered by what she considered to be inconsideration of her personhood and relationship with the patient.

Bereaved family members pointed out some aspects of

nursing practice that they believed could be improved. These related to their concerns and needs during the time that the patient was dying in critical care. Families asked for information, consistency, access, and consideration.

The literature does not speak directly to the needs of families of dying patients in critical care. However, there have been several studies that have focused on needs and concerns of families of critically ill patients. These studies have primarily used a structured interview format to create decontextualized lists of family needs from the perspective of relatives and nurses. This study has approached the topic differently in two ways. First, a narrative format was used to solicit the needs and concerns of family members non-reflectively and to understand the underlying family meanings. Secondly, the comparison of three data sources, specifically observation, nurse interview, and family interview, highlights the context and perceptions that the family are unable to see because of their lack of situatedness and lack of understanding of the possibilities for nursing practice.

Many of the needs and concerns identified in this study and on the lists generated through previous research are similar. Review articles (Hickey, 1990; Simpson, 1989) summarized results of several studies. Needs and concerns were identified in the following categories: informational, empathy, emotional, family visit, family-staff

relationships, and support resources. However, the current study pointed out that these needs and concerns are very contextual, depending on the situation and the people involved. For example, every family does not want information or involvement in physical care of their family member. Different families have different backgrounds and expectations; the meaning of the critical care experience is very different depending on the reason for the admission and the family relationships. Although the lists are helpful in laying out possible areas of concern, expert nursing practice relies on a clinical grasp of the particular demands of each situation. These lists also do not offer any insight into processes that work to meet the needs of individual family members, for example how to talk to families about the possibility of death.

Family concern for the patients' comfort and regarding technology is interesting in it's absence. Although specifically asked, families did not believe that their family member was in pain or experiencing undue suffering. In two particular situations, they indicated that the patient was expected to tolerate some discomfort. No family member mentioned any concern with technology blocking their access to the patient. Equipment (particularly respirators) became a problem for families in two kinds of situations: one in which life support wasn't removed when the family requested, and the other when it prolonged the dying process

beyond their expectations. In those situations the concern was an ethical consideration with maintaining life support not wanted by the patient or prolonging death.

Summary

Family members of patients who died in the critical care unit were interviewed following the death. In the context of the narratives, nursing care was background to the crisis in which they were involved. Families remembered caring practices and technological skill, or a particular nurse's intervention to assist with a particular concern or need. However, the involvement, managing, and coordinating aspects of nursing practice showed up primarily when they weren't satisfactory.

Family concerns related to nursing were contextual. Although some basic themes consistently appeared in the accounts, many of the needs and concerns described by family members were particular to the family and the nurse in the situation. Recurring themes included the discomfort that families experienced in negotiating critical care, their feelings of responsibility for protecting the patient from health care professionals, and their gratitude for caring gestures and practices extended by nurses toward the dying patient. It was most important to family members that the nurses talked to and touched the patients as they died.

Family members valued various personal qualities of nurses, for example honesty or a sense of humor, depending

on their need. Interactions which facilitated their comfort at the bedside were important, for example assisting a family member to participate in the patient's physical care or describing what the dying process would be like after extubation. Expressions of caring and concern about the family themselves were appreciated.

Physicians were viewed by family members as responsible for decision-making with critically ill and dying patients. They were disappointed with physicians primarily under two circumstances: first when physicians did not support them in their decisions to discontinue life support, particularly if the patient's wishes were known, and second when staff physicians did not attend care conferences where end-of-life decisions were being made. There was no expectation stated that the physician should be at the bedside when life support was discontinued and as the patient died.

In all aspects of care, families wanted information about the patient's condition and prognosis, consistency of caregivers and procedures, access to the bedside, and consideration as the persons who care most about the patient. Family members have a unique perspective on the nursing care of dying patients in critical care that expands the understanding of this area of practice.

CHAPTER VII. SUMMARY, CONCLUSIONS, AND IMPLICATIONS

Summary of the Study

The purpose of this phenomenological study was to describe and understand nursing care of dying patients and their families in critical care units. The specific study questions were:

1. What are specific caring practices of expert nurses caring for dying patients and their families in critical care?

2. What are the interpersonal concerns and background meanings that shape expert nurses' caring for dying patients in critical care, including moral beliefs and issues?

3. What are the interpersonal concerns and background meanings of bereaved family members related to nursing care during the time the patient was dying in critical care?

Procedures and Analysis

The key study informants were 15 critical care nurses from five critical care units in two hospitals with experience and expertise in nursing care of dying patients and their families. These key informants were nominated by nurse managers for participation in the study. The study was carried out in four phases. In Phase I, key informants were interviewed in groups about their experiences in caring for dying patients and their families in critical care. In Phase II, key informants were observed in clinical practice as they cared for dying patients and their families. Eight

observations were completed. An additional six nurses were included as secondary informants and observed during this phase. In Phase III, the nurses who were observed in Phase II were interviewed about the particular episode observed as well as about their personal beliefs and values related to nursing care of dying patients in critical care. In Phase IV, bereaved family members of patients who died in critical care were interviewed. The family members were recruited during observations and from Phase I group interview data. Eight bereaved family members were interviewed.

All interviews were tape-recorded and transcribed verbatim. Field notes were kept during observations and supplemented by tape-recorded commentary and a personal journal kept by the researcher. Data were analyzed using interpretive analysis, or hermeneutics. This analytic process incorporated the following overlapping strategies: reflective interpretation of data, identification of major themes, coding and retrieval of data according to an interpretive plan, and reflective writing based on paradigm cases and exemplars explicating the major themes and issues.

Description of Nursing Care

Expert nursing care of dying patients and their families was based on a clinical grasp that the patient was dying and an understanding of the particular demands of the situation. The nurses in the study described many situations in which they understood before the family and

physicians that the patient was dying. In those cases, they worked to bring the others to that realization. Rather than asserting an independent position in end-of-life decisions, the nurses facilitated those decisions by preparing families for decision-making, working out asynchronous clinical perceptions with physicians, facilitating care conferences, and advocating for the patient's or family's wishes.

Managing the death was a recurring theme in nurses' narratives and prominent in observation data. This involved making sure that the family had a good experience and that the patient's death was peaceful. The nurses created a space for the death that encompassed the family, and often helped family members to touch and talk to patients as they died. They facilitated the dying transition according to patient's own dying trajectory and the demands of the situation, and kept patients comfortable as they died. The nurses humanized and individualized the patients' deaths by learning about each patient as a person and incorporating that knowledge into their care, touching the patients, and talking to them as they died. Routine nursing and medical care were still administered, but less frequently or regularly. Rather, the nurses were most concerned with the patient's comfort and the family's need to be close. After the patient died, the nurses continued to work with family members until they left the hospital or sometimes afterwards, typically in response to family need.

Background Meanings and Concerns of Nurses

The nurses in the study understood that caring for dying patients was a part of their work as a critical care nurse. Their early grasp that a patient was dying gave them time to prepare themselves for the death, so that they didn't feel guilty or responsible. Deaths were more emotionally difficult for the nurses if they were involved with the patients or family, particularly with long-term patients. The nurse participants believed that the key aspects of a good death in critical care included respect for the patient's choices (and involvement of the patient in decision-making when possible), family involvement, and patient comfort as they died. They also described bad deaths, where patients were "flogged" when there was no hope of survival, and empty deaths, where neither family nor nurses were involved with the patient.

Involvement, caring, and relationship were strong moral themes throughout the narratives. Major ethical concerns focused on relief of suffering, patient choice, priority of family needs, maintaining dignity, and non-discriminating treatment of patients. Since the nurses were most commonly responsible for the actual discontinuation of life support and sedation of patients as they died, issues and feelings about the nurse as the agent of death also stood out as a major concern.

Organizational supports and impediments to expert

nursing care of dying patients were identified in the data. Although no formal education or recognition was given for this kind of work, selected peers offered the most consistent support. Chaplains and ethics committees were supportive to the nurses in working with families and decision-making. Advance directives, when available, provided clarity about patients' wishes, and helped the nurses in their advocacy role related to end-of-life decisions. Nursing staffing patterns, workload, the critical care environment, and bed utilization practices sometimes prevented the continuity and quality of care the nurses felt was important with dying patients. Concerns about communication with physicians, the lack of coordination of medical care, and lack of involvement of physicians with dying patients and their families were pervasive throughout the narratives. These concerns emphasized the cultural differences and tensions between nursing and medicine.

A view of the patient which encompassed family members was embedded both in the narratives and in the expert nursing practice observed. If the patient was unconscious and dying, the focus of nursing care often shifted from the patient to the family. Work with family members was based on an understanding that different family members reacted to the dying situation in different ways, and that each had unique needs. The nurses' primary focus was to help family

members heal their relationships, accept the impending death, make difficult decisions, and say good-bye. Family members helped the nurses to understand the patient as a person, and gave them perspective on what constituted good nursing care for dying patients and their families.

Background Meanings and Concerns of Families

Much of nursing care was invisible to families of dying patients in critical care. Family members valued the caring aspects of nursing practice. However, the involvement of nurses and the managing and coordinating aspects of care identified as most important by nurses were not recognized by bereaved family members. It was very important to family members that the nurses touched and talked to dying patients, and treated them as though they were responsive and cared about. Although bedside exchanges of information and pleasantries were appreciated, these were not understood as deliberate or as part of the larger context of preparing and supporting them through the death. Physicians were seen as responsible for decisions and imparting important information concerning the patient's prognosis.

The critical care unit was viewed by the families as a complex environment which was sometimes difficult to negotiate. Particular information about the patients' illnesses, conditions, and treatments were sometimes difficult to understand. Family members often felt like they needed to "stand guard" and protect the unresponsive or

desperately ill patient from judgments of caregivers that were inconsistent with the goals for cure or care, including scrutiny of the need for nursing procedures or medical treatments. However, this feeling was not universal and in some cases trust depended on the development of relationships with individual caregivers.

Family members identified particular needs related to their critical care experience. Families wanted information about the patient from physicians and nurses, and they asked for consistent caregivers and approaches to care. Change of any kind was most difficult for them. They wanted access to the patient, and a welcome place at the bedside. Families asked to be treated with consideration and respect, as those who cared most about the outcome of the illness.

Conclusions

Nursing care of dying patients and their families in critical care is a particular area of expertise in nursing practice. The work of the nurses described in this study is profound and captures the moral integrity of the profession of nursing. Many of the narratives described interactions, practices, and issues that are not generally discussed or acknowledged among critical care nurses or with other health care professionals.

The nursing practices described were shaped by the nurses' understanding of particular patient and family concerns, and cannot be considered routine or standard for

all dying patients. In order to facilitate meaningful experiences, expert care sometimes included risky practices carried out behind the curtain. These risky practices were not openly discussed, and included coaching the patient regarding what to expect during dying, giving the patient permission to die, disregarding visiting restrictions, encouraging family members to hold or touch their dying loved ones as they died, crying with families, and titrating sedatives.

Expert nursing care of dying patients and their families required a wide range of human and technical skills. The nurses relied on skills of assessment and data interpretation as well as technical abilities to work with complex medical equipment and provide basic nursing care. They had to be able to provide good family care, and negotiate with physicians. They needed to be caring, sensitive, willing to become involved, open to the possibilities in each situation, and willing to take risks. The nurses developed their expertise in caring for dying patients through experience, and were supported most often by a small group of colleagues with similar values and concerns related to care of dying patients.

The moral goods inherent in the profession of nursing were embedded in the nursing care of dying patients described and observed in critical care. The concerns in these data were primarily focused on what is <u>good</u> in the

particular situation as opposed to what is right according to any specific moral principle. Values of relationship, caring, and involvement focused the concerns and practices of nurses. However, the ability to do what was good (or best) in a particular situation was not always possible within the health care system, given the focus on cure and financial accountability.

The expert practices described in the study were contextual, that is, responsive to the demands of the situation. Much of the nursing care of dying patients in critical care was invisible to bereaved family members. This may have been due to the stress that the family experienced during the time the patient was dying, and the focus on the events as they unfolded rather than on the background or supporting roles of health care professionals. However, the invisibility of care may also have been affected by role expectations related to nursing practice as viewed from outside the profession.

Implications

This study was intended to contribute to nursing science in several ways. It was hoped that the description of expert nursing care of dying patients in critical care would be a stimulus for nurses to reflect on the possibilities and responsibilities for providing intensive care for dying patients. It was also believed that the findings could inform and influence ethical issues

surrounding dying in critical care. Finally, it was expected that this study would contribute to the general body of knowledge concerning nursing care of dying patients and their families. Consideration of these potential contributions is incorporated into the discussion of the implications of this study for nursing theory, practice, and research.

Implications for Nursing Theory

The findings of this study are an initial attempt to describe the role of nurses in caring for dying patients in critical care units. Although nurses have been working with dying patients in this setting for many years, the practices have been eclipsed by the emphasis on life-saving technologies and cure. It is important to describe these practices so they are not lost, but rather to open dialogue as a basis for developing this area of expertise. It is also important that these caring practices be acknowledged and discussed regarding how they fit into the overall plan for distribution of scarce health care resources.

This study explored nursing care of dying patients and their families as a complex and meaningful experience which is based on the lived experiences of nurses and bereaved family members. The results provide a rich description of expert nursing practices within the context of specific clinical situations. The findings of this study contribute to theory development related to nursing care of dying

patients and their families in critical care and the moral foundation of nursing. Each of these is discussed in relation to existing theory and the data from the current study, and additional questions are posed.

Nursing Care of Dying Patients in Critical Care

Very little previous research has been done describing nursing care of dying patients and their families in ICU. Results of two studies that have quantified nursing care of DNR patients showed that these patients require more care than other critically ill patients (Lewandowski et al., 1985, Tittle et al, 1992). Another study described general categories of nursing intervention for the purpose of developing a standardized model of practice. These categories included pain control, hygiene, family care, and post-mortem care (Caswell & Omery, 1990). Studies on stress in critical care nurses have typically identified caring for the dying patient as a cause of job stress and dissatisfaction. Studies describing family needs in critical care have not focused specifically on families of dying patients, but have provided decontextualized lists of family concerns and needs.

This study did not assume similarities between nursing care of patients dying in critical care and other settings. Nursing care of dying patients and families in critical care may be different because of the organization and cure focus of the unit, the high tech environment, high nurse-patient

ratios, patient acuity, and ethical concerns related to technology and prolonging death.

This study described the contextuality of caring for dying patients and their families. An expert clinical grasp oriented nurses to the particular demand of each death and created the possibility for meaningful nursing care. DNR patients required varied levels of nursing care depending on these situational demands as well as the medical and technological interventions ordered. Clinical narratives and situations observed characterized the dimensions of the role of the nurse regarding decision-making and managing the death, as well as specific practices.

This study contributed to the understanding of the role of the nurse related to end-of-life decisions. The data captured an understanding of the nurse not as the person who makes the decision, but as the one who stimulates, mediates, and supports decision-making between the family and the physician. To some extent, this supports the contention that nurses assume a powerful in-between position, setting-up the context for decision-making (Bishop & Scudder, 1987). However, beyond mediating, the independent moral agency of the nurse was apparent throughout the decision-making process. The insights and issues that were seen as salient and communicated between patients, families, and physicians were influenced by the nurse's experience and system of values. When breakdown occurred, the usual response of the

nurse was to advocate for the patient and family. For these nurses, acting as an independent moral agent didn't mean inflicting their personal choices about withholding or withdrawing life support onto the patient or family, but following their notion of what was good (and required) in a particular situation. Their actions were guided by their concerns for suffering, dignity, and patient choice.

The results of this study demonstrate that nurses are able to assert their moral agency even under difficult and conflictual moral circumstances. Tripp-Reimer (1984) asserts that it is within nursing's domain to mediate between the biomedical (disease) and patient (illness) models to understand, interpret, and intervene based on an understanding of both perceptions. This is a legitimate position for nurses that must be acknowledged.

The description of managing a patient's death in critical care begins to fill out existing theory that has provided a skeletal outline of nursing care. These findings extend the theory beyond <u>how much</u> nurses do in what categories of the domain to <u>what</u> nurses do. The details of managing the death of a patient in critical care are the foundation of the description of nursing care of dying patients and their families in critical care. These details are remarkable in themselves, but also in that the nurses were expected to learn how to manage a variety of dying situations without benefit of written or verbal guidelines.

Most nurses learned for themselves, from experience, and didn't typically share the details of their most profound and compelling experiences.

Nurses created a space and a time for dying behind the privacy of a curtain. There they provided comfort to patients, and talked to them and touched them as they died. They also worked with families within the dying space, creating possibilities for a meaningful passing instead of a perfunctory end. An important understanding about family care was that when patients were unconscious and dying, the focus of the nurse changed from the patient to the family, helping them to understand that the patient was dying and preparing them for decision-making and withdrawal of life support.

The nurses providing this end-of-life care felt a range of emotions, depending on the demands and outcome of the situation, from exhaustion to guilt to gratification. Although these results confirm that nurses experience moral dissonance in some situations as reported by Rodney (1988) and Borozny (1990), the data conflict with previous findings alluding to universal feelings of stress and dissatisfaction among critical care nurses caring for dying patients. Some deaths were seen as positive, consistent with findings reported by Field (1989a, 1989b). This again emphasizes the contextual nature of nurse-patient interactions.

Through interviews and observations of families, the

data offered a glimpse into the family perspective of dying in critical care. For nursing, the most remarkable finding was that much of expert nursing care was invisible to families who were involved in the crisis of the death of a loved one. Although the family needs and concerns expressed by bereaved family members approximate previous research, this study points out the contextual nature of these needs and concerns and the importance of the nurses' clinical grasp to understand and modify care according to the particulars of each situation to create a meaningful death for the patient and family.

The findings of this research add dimension to and support the findings of previous studies. The contextual detail of the narratives and observations begin to explain the high level of nursing care required for DNR patients, and extend the possibilities for nursing interventions prescribed in a care plan.

Two particular questions remain regarding the nursing care of dying patients and their families. The first refers to the particulars of withdrawing life support, that is, what is the best procedure for taking patients off ventilators and what are the best drugs in what dosages to sedate patients? In the second, what are the particulars of nursing care of families after the patient dies? Both of these questions should be considered in future research.

Moral Foundation of Nursing

Current theory describing the ethical context of nursing care of dying patients and their families in critical care focuses on two areas. The first is the understanding and explication of the moral foundation of nursing. The second is related to application of ethical principles to end-of-life decision-making. Specific concerns that affect this domain of nursing practice include prolongation of life with technology and allocation of health care resources.

Much of the data in this study was moral discourse. That is, it reflected the notion of the good inherent in the practice of nursing. The values of the nurses embedded in the narrative included those related to caring and relationship, supporting current theory regarding the developing moral tradition of nursing. Specific concerns pertained to suffering, dignity, patient choice, family involvement, and differential treatment of patients. The concern of the nurses as agents of death in critical care was identified.

These accounts support the conception of nursing as a moral art engaged in an ethic of care, and provide evidence regarding the relationship between the ethic of care and principle-based ethics in nursing practice. These data provide evidence that nurses incorporate both kinds of ethics into their practices. Cooper (1990, 1991) states

that initially nurses focus more on patient rights and other decontextualized principles. However, as nurses become more involved with particular patients, the caring ethic predominates, and tension develops between the two moral cultures. From another perspective, Dreyfus et al. (1990) explains that skilled ethical comportment develops with experience and rational deliberation is necessary only with ethical breakdown or conflicting values. This study also showed how the language of principle-based ethics can be used as a way of communicating involved concerns effectively with physicians. Additional exploration is needed to fill out the moral theory of nursing by explicating the values and concerns imbedded in expert practice and describing the relationship to traditional ethics.

This study was not designed as an evaluation of ethical issues, and does not directly address theoretical questions regarding prolongation of life and allocation of resources. However, the moral, contextual concerns of nurses regarding suffering, dignity, family, and patients as the center of their dying experience give dimension to ethical questions from the perspective of the involved moral stance of nurses. This understanding of an alternative perspective hopefully will invoke theorists considering ethical principle as well as clinical ethicists making decisions on individual cases to include this perspective. This melding of involved and detached perspectives is supported by Callahan (1988).

Two additional questions emerged during the course of the study which hinge on the relationship between practical clinical ethics and a more detached philosophical stance. In the first, nurses expressed concerns over the clinical implementation of advance directives, which are being used as a way of protecting individual choice. One particular question seemed especially disconcerting regarding whether or not patients are "allowed" to change their minds about their previous choices when they are actually experiencing technology and possible death. In the second, nurses sometimes struggled with the moral implications of withdrawing life support. Although there is theoretically no moral distinction between withholding and withdrawing life support (Childress, 1986; Weir, 1989), the emotional responses of nurses, as evidenced in this study, and physicians (Edwards & Tolle, 1992) may indicate that there is a practical difference in the clinical world. Theoretical consideration of both these concerns would contribute to necessary dialogue between ethical theory and clinical practice.

Implications for Nursing Practice

This interpretive account of expert nursing practice extends the possibilities for nursing care of dying patients and their families in critical care. Explicating and understanding what practices are possible and what skills are necessary to give this kind of care provides an

important basis for teaching nurses, further developing the practice, and supporting the care. This is an area of practice where some nurses have functioned and excelled unpretentiously for many years. The wholistic approach and focus on care that is essential in caring for dying patients are consistent with the goals and work of nursing practice.

Nurses providing care for dying patients and their families required mastery of a wide range of skills and qualities, including technical competence, assessment skills, personal communication and mediation skills, understanding of family care, personal sensitivity, and the ability to be open to the unique demands of each situation. Because of the priority of technology and cure in critical care, these skills have not been equally taught or rewarded. Although these narratives do not provide a template that nurses can use to administer care, they can sensitize nurses to the concerns and issues, and the suffering and reward in caring for dying patients and their families. Hopefully the interpretive account will open up understanding and possibilities for practice that were not possible before.

Specific Nursing Practices

Although most of the care was contextual and based on the demands of the particular situation, specific nursing practices can be suggested based on these findings. These recommendations are primarily based on family interview data.

Nurses should continue to talk to patients who are unresponsive and dying, and make the effort to provide humanistic and individualized care to unconscious patients. This can be done by touching patients and keeping them clean and comfortable. These caring practices were very important and reassuring to families studied. In addition, families can provide insights describing the patient as a person which can orient meaningful bedside care.

Nurses should legitimize open visiting for families and friends of dying patients, including children. Even though visiting hours were suspended for most families, access to the patient varied between shifts and units. Family members admitted to "lying" in order to assure that good friends were allowed at the bedside. Nurses admitted risking disapproval by allowing family members of all ages at the bedside of dying patients. Friends and children have been described as populations whose grief and loss associated with death is not acknowledged in our society (Deck & Folta, 1989; Ellis, 1989). Perhaps the changes in visiting hours for families of dying patients should be clearly stated, and friends and children re-enfranchised as legitimate grievers as well as support to family members.

Nurses should make the environment more comfortable, welcome, and accessible for family members. This again would involve suspending previous taboos about legitimate uses (or ownership) of critical care space and the primacy

of cure and technology. Since the patient is a part of a family who is grieving and saying good-bye, their needs for involvement and privacy should be considered as primary. For example, a family member might be offered the opportunity to spend the night in a cot at the bedside or be present during care and treatments.

Nurses should be aware of the anxiety and grief of family members, and find a way to keep them informed and involved. Although it is understandable that nurses get involved in the details of complex care of the patient (or multiple patients), family members described the torment of waiting. Family members studied were attentive to the meaning of every word and gesture, looking for signs of hope, information about the patient's condition, or an invitation to the bedside. In some units, chaplains, were available to sit with families in crisis. If nurses are unable to provide family care and support, other resources should be made available to assist family members who are grieving and making end-of-life decisions.

Staffing and patient assignments should focus on continuity of care. Different nurses with different approaches to care on every shift were disconcerting to families, and hindered the development of trust and involvement with the nursing staff. Change of routine, environment, or personnel was very difficult for family members in crisis, including unexpected procedures or

transfer from critical care.

Nurses caring for dying patients in critical care should be given an assignment that allows adequate time to attend to the needs of the dying patient and family. Often the dying patient was seen as requiring less care, and the assigned nurse was also caring for another complex, unstable patient. When possible, other nurses temporarily assumed part of the workload as the patient neared death, allowing the nurse to remain at the bedside. At other times the nurse was not available when the patient died because of the primacy of the demands of another patient who was unstable or struggling to survive. If patients who are dying remain in critical care, acuity scales should be expanded to accommodate their care demands.

Finally, nurses should remain open to the needs of family members after death. Both nurses and family members studied expressed mixed feelings about contact after the hospital. Some nurses regularly made bereavement calls according to a protocol, but others felt that unrequested contact was intrusive, in some cases causing untimely and painful reminders of the death. Cards from nursing staff were regularly sent to family members in some units. At times, family members initiated contact with nurses as they worked through their grief. In these circumstances, nurses were willing to sustain whatever supportive contact was required. Families who received cards appreciated the

gesture. Some indicated that they were not sure they could emotionally tolerate contact with the nurses, and others didn't seem to need or want any contact. Some family members sought additional information from physicians as a way of resolving issues. The contextual nature of families' needs calls into question policies that require nurses to make bereavement calls to surviving family members. Although sympathy cards may be a gesture universally appreciated by family members, perhaps the decision about whether or not to make the call would be best left up to the judgment of the nurse most involved, who understands the particulars of the situation.

Development of the Clinical Domain

Even though the critical care unit may not be the optimal place to die, and even if DNR patients are routinely transferred to other units, deaths will continue to occur in critical care. If the nursing care of dying patients and their families is explicated, legitimized, and supported in critical care, clinical practice can develop further. The nurses in the study learned a great deal from each other as they listened to the experiences of the other participants. Practicing nurses should feel free to discuss their situations and their feelings related to care of dying patients, and learn more about effective care for dying patients from each other. As nurses in critical care embrace the care of dying patients as part of their domain,

investigation of the applicability of practices from other specialty areas such as hospice and cancer care could further expand their repertoire of practices. For example, the use of rituals at the time of death as practiced in hospice care could have application for patients and families in the critical care setting (Schneider & Bernard, 1991). As the body of knowledge regarding nursing care of dying patients and their families develops, theory should be taught in critical care education regarding how to manage a death, support decision-making, and work effectively with grieving families.

Implications for Critical Care Systems

Findings of this study also suggested organizational supports needed to facilitate nursing care of dying patients in critical care. First, the moral concerns of nurses involved in care of dying patients, particularly where life support is withdrawn, need to be explicitly addressed. Issues related to euthanasia, such as discontinuing ventilators and sedating dying patients, need to be discussed openly among nurses and between health care professionals. Nurses do have concerns about the legality and morality of some of their practices, and shouldn't be expected to struggle with these issues alone. Nurses also need to be included in discussions related to end-of-life decisions for particular patients, since they can offer an involved and practical perspective not represented by

physicians or ethics committee members. Callahan (1988) believes that the perspectives of reason and care tutor each other, and together create sound moral decisions.

Second, nurses need emotional support, debriefing and follow-up regarding their involvement and moral struggles with specific deaths. Situations which were particularly difficult for nurses in this study included long-term patients with whom they had been involved, sudden deaths, and catastrophic. Nurses need to have regular feedback regarding the cause of death in their patients. They need to be able to explore their concerns about how they could have anticipated catastrophic situations openly and reflectively. They need to discuss their moral conflicts and concerns about decisions and treatment. They need to be able to legitimately grieve for a patient with whom they are involved.

Third, nurses need to be informally and formally recognized for providing good care to dying patients. This might include acknowledgement from peers and managers, as well as performance reviews or nursing rounds. Expert care of dying patients and their families as explicated in this research required much skill and energy, and sometimes emotionally depleted individual nurses. Although many of the nurses in the study were rewarded by the knowledge of a job well done, or by peers, they wished for additional acknowledgement for their efforts.

Fourth, there needs to be a commitment of resources that balances the cure as the economic priority with care and respect for death as a part of life. The demands of each situation should be considered. Nurses caring for patients who are imminently dying should be relieved of other responsibilities to attend to the needs of the dying patient and family. Some patients may be transferred to units where nurses are skilled at dealing with dying patients, or the environment is more conducive to a peaceful and dignified death. Others may need to remain in critical care because of comfort needs or the need for continued use of technology. Each situation should be considered regarding how to create the best possible death which respects and honors the patient's passing.

While this study did not directly address bed utilization or resource allocation questions, the data raised concerns about differential treatment of patients and transferring DNR or dying patients out of critical care. Nurses understood the economic drive behind transferring patients, but often felt a lack of resolution in not being able to continue to care for the patient and family until the patient died. This was particularly a concern if the nurses were very involved with the patient or family, or if the patient was expected to live only a few hours after withdrawal of life support. Families had a more difficult time with transfers, needing to adjust to new surroundings,

procedures, and relationships during a time of grief and crisis. Changes in staffing ratios or transfer to other units seemed to support the feeling of some families that dying patients were abandoned to a lesser level of care and expertise, both in critical care and on general units. These factors need to be considered and accounted for in hospital policies and practices. Institutions should be challenged to consider the moral implications which balance fiscal concerns related to DNR and transfer policies and be held accountable for considering alternative ways to deliver excellent care to dying patients. As an example, one hospital developed a program for transferring DNR patients out of critical care to a unit where the staff was specially trained in the technical and psychosocial skills needed to care for dying patients supported by technology and their families (Campbell & Field, 1991).

Implications for Nursing Research

Since this study represents one of few attempts to describe nursing care of dying patients and their families in critical care, the possibilities and implications for nursing research are numerous. Suggestions for future research and limitations of the current study, including ethical and methodological issues, are discussed.

Future Research

This is a beginning phenomenological exploration of nursing care of dying patients in critical care. While many

important practices and experiences were explicated and explored in this study, the entire domain of nursing care of dying patients has not been captured. Further phenomenological study of nurses and families is warranted.

Phenomenology was the appropriate research design for describing and understanding nursing practices surrounding nursing care of dying patients in critical care. This method facilitated insights, detail, and background understandings that would not have been possible with other methods. It was particularly useful in explicating moral values and issues which are embedded in practice and often difficult to articulate. Based on the findings of this study, several suggestions can be made regarding future research.

First, because physicians were so involved in the situations described by patients and families, a subsequent study should be designed to include the physician as well as the family perspective. This approach would provide a basis for integrating and comparing moral approaches, role perceptions, priorities, and moral concerns surrounding dying in critical care.

A second suggestion relates to the difficulty in obtaining observations in this study. In the current study, key informants initiated the observations by calling the researcher when they were caring for a patient who was dying. This placed the burden of participation on the

informant, who tried to negotiate assignment to patients who seemed to be approaching death and then remember to initiate the call, sometimes in the midst of demanding patient-care situations. Many patients died in the units during the data collection period who were involved with other nurses or when the key informants were not working. A more effective method for subsequent studies is suggested. In an alternate approach, the researcher would study all the deaths in one unit in depth for a period of time, then focus on additional units sequentially. If multiple researchers were collecting data, each could work with one critical care unit. The researcher could assume the responsibility for regularly contacting the units for possible observation situations, instead of the participants remembering to call in the midst of a crisis. It would also alleviate the problem of specific nurses not being involved in dying situations. This approach would encourage a relationship between the researcher and many health care professionals during the data collection period, increase the number of observations, and the depth of cultural understanding. In addition, focusing in-depth on particular units would provide data across levels of nursing expertise, facilitating contrasts and understanding concerning the development of expertise in care of dying patients.

Another suggestion regards the scope of the study. This study focused primarily on nursing care during the

decision-making period and the time that the patient was dying. Observations ended at the time the patient died or was transferred from the unit. As a result, there was very little opportunity for observation of work that nurses did with families after the death. The group interviews suggested that meaningful interactions take place in the hospital after the patient dies. A subsequent study should extend the focus of observations into that time period.

The strategy of comparing observation and nurse interview data with family interview data was helpful in filling out situations, but also provided insights about nursing practices that are invisible to families. This proved to be a valuable technique, and is recommended for future study on this topic and in other studies where the methodology calls for interpretation of a phenomena from a variety of perspectives. However, an ethical concern regarding confidentiality must be addressed. The researcher must be cognizant of inadvertently sharing confidences when interviewing nurses and families about the same situation. Since the nurses and family members know each other's identities and are discussing different perspectives of the same situation, the researcher's line of questioning during interviews must pursue, yet at the same time guard, information and perspectives shared by the other informant. This consideration is necessary to protect the confidentiality of all participants.

This study raised additional questions regarding the withdrawal of life support to be addressed by nurse researchers. Although these data described various concerns and methods of discontinuing life support and providing comfort, including sedation, to dying patients in critical care, more detail is needed to facilitate nursing practice. Future research is needed to describe causes and kinds of discomfort during dying, symptoms which indicate discomfort or suffering, and specific information regarding how to treat these symptoms, including types and doses of drugs which are effective in different circumstances.

These data hinted at the use of rituals with dying patients in critical care, for example ritualistic talk at the time of death, and the existence of a subculture focused on the spiritual aspects of illness and dying. These data are not sufficient to determine whether or not these practices are in fact infrequent, or whether they are deeply hidden behind the curtains. Additional study focusing more on the culture of a single unit might provide more insight into these kinds of practices.

This study focused primarily on deaths that were predictable, where nurses recognized that the patient would die and incorporated that understanding into the care. However, some nurses talked about their feelings and concerns with sudden or catastrophic deaths. Issues that surfaced included family attendance at codes, nurse guilt,

and caring practices with patients who repeatedly code or are awake during codes or other emergency procedures. This is another area of nursing practice that needs to be studied.

Concerns about advance directives and their implementation into practice were expressed in this study. As a new phenomena in health care, additional research needs to be done regarding problems and issues encountered by bedside health care practitioners, including nurses, related to the implementation and application of advance directives.

Finally, although this study assumed differences in nursing care of dying patients and their families in critical care in contrast to other settings, this research described nursing care only in the critical care setting. Additional research should be done comparing and contrasting the demands of nursing care and practices employed in critical care with those in other areas, such as hospice or cancer care. This comparison and integration is important in order to expand and create cohesive nursing theory related to nursing care of dying patients.

Limitations

Although the methodology for this study was appropriate and resulted in rich description and understanding of this area of practice, there were some limitations. Methodological concerns and issues are discussed.

The responsibility of the naturalistic researcher is to

give as much detail as possible in order to provide thick description for interested persons wanting to apply results. However, because of the limited number of participants in the study, the danger exists that nurses or family members would be recognized in the data. For this reason, the researcher made a judgment regarding the depth of descriptive information needed for the reader to understand the situation. This could possibly affect the reader's ability to judge applicability of data to other situations.

The addition of interviews of bereaved family members to provide an alternative perspective regarding nursing care was implemented in this study. This first attempt at incorporating family data with a phenomenological study of nursing care extended the methodology of the parent study on clinical judgment (Benner et al., 1991). Although the data base provided ample description of nursing care through multiple group and individual interviews of nurses and observations, the family data provided the least comprehensive perspective in comparison. Eight family members were interviewed in a single one to two hour interview. These interviews were emotionally difficult for some family members, but seemed to be adequate in each case for each person to tell their story. However, there was so much variability between families and their particular situations and responses that this study does not claim to have described all the issues. More work is needed in

subsequent studies to fill out the family perspective. Future studies related to families should continue to explore these family needs and concerns related to nursing care in particular contexts or situations.

As previously stated, phenomenology proved to be an excellent method for this study aimed at describing and understanding the phenomena of nursing care of dying patients in critical care. However, the inexperience of the researcher must be mentioned as a final limitation to the study. Although the researcher had participated in all phases of a major phenomenological investigation prior to this project, this was the first study in which this researcher was principal investigator, primary data collector, and central interpretive analyst. In this kind of research, the researcher serves as the instrument to collect and interpret data. The task of getting involvement right with the participants and the data as well as mastering the details of the methodology were a learning experience. However, the assistance of the interpretive analysis group as well as the dissertation committee served to monitor, direct, and supplement the inexperienced work of the researcher.

Summary

This study described and created understanding surrounding the caring practices of nurses caring for dying patients in critical care. As rewarding as this experience

has been, the researcher is left with a grave concern that caring practices of nurses are being jeopardized by the focus of our health care system on cure, technology, and distribution of resources. This study has shown that expert caring practices exist, but that they are often covered over in practice. Nurses hide some of the most profound human experiences behind the curtain, fearful of being misunderstood or ridiculed by fellow nurses or other health care professionals. Dimensions of this expertise are all but unnoticed by family members and possibly by physicians, unless problems arise in it's absence. Caring practices, such as those described in this study, play a major role in the survival and satisfaction of patients and families experiencing health care crises as well as influencing their trust and good feelings about the health care system. Gordon (1992) has described nurses as the "missing voices" in health care today. As the representatives of the caring perspective in health care, nurses need to participate in discussions concerning health care policy and reorganization. If not, the caring tradition that serves as the moral balance to fiscal responsibility and cure may be unknowingly eliminated from our health care system.

Referring back to the quotation from Tolstoy at the beginning of this dissertation:

> The awful terrible act of his dying was, he could see, reduced by those about him to the level of a casual, unpleasant, and almost indecorous incident...
>
> Tolstoy, The Death of Ivan Ilych

The caring practices of nurses clearly represent the moral values in our health care system that can prevent the reduction of death to a casual, unpleasant, and almost indecorous incident. For the sake of all those who will die in critical care units in the future, these practices need to be preserved.

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TABLE OF APPENDIXES

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APPENDIX A

INTERVIEW SCHEDULES

Appendix A: Group Interview Guide

Purpose: To solicit narratives depicting nursing care practices and concerns in caring for dying patients in critical care.

1. Describe patient situations that stand out for you in which you were involved with caring for a dying patient in critical care. These may include episodes which describe any of the following:
    a. you gave excellent care to the patient or family
    b. an instance of a very good or a very bad death
    c. that was very stressful for you
    d. where you learned something that changed your practice or your way of looking at things
    e. that was a very good or very bad personal or professional experience.
    f. where you were very involved with the patient or family
    g. that made you very uncomfortable
    h. the most recent episode of caring for a dying patient
    i. a typical death in your unit

2. Additional probes:
    a. How are dying patients viewed in your unit? Are dying patients ever admitted to the unit? If it becomes apparent that the patient is going to die, do they stay in the unit?
    b. How does care change for patients identified as dying?
    c. What are your concerns about caring for dying patients in this setting?
    d. In general, what are your priorities in caring for dying patients in the ICU?
    e. How do you feel about caring for dying patients in the ICU? How do you perceive that other nurses feel?
    f. What are the organizational difficulties that arise when a patient is dying in the unit? Other problems?
    g. What are the ethical issues common to caring for dying patients in your unit?
    h. What is a good death in ICU like?
    f. How are families involved with the dying process in your unit?
    g. What is the usual course for patients who die in your unit?

3. Does anyone have anything else to share concerning nursing care of dying patients in the ICU?

APPENDIX B

Appendix B: Intensive Interview Guide

Purpose: To gain additional perspective from key informants on the dying episode observed. To understand the nurse's concerns and background meanings related to the dying episode.

1. Describe this patient's dying.
    a. Describe your involvement with the patient's dying
    b. What stands out for you as being important/different about this patient's dying? What is unique about this death and dying?
    c. What were your priorities in caring for the patient?
    d. How was the family involved in the dying? Will you have any continued contact with them?
    e. Did this patient have a good death? What would you change?
    f. What specific concerns did you have during the dying time?
    g. When did you first become aware that the patient was dying?
    h. Did things go as you expected?
    i. Were there ethical concerns? Organizational problems?
    j.How did you feel while you were caring for the patient as he/she was dying? How do you feel, in retrospect, about this patient's death and dying?

2. Now I'd like to broaden the questions beyond the care of this particular patient.
    a.Have you had other experiences with patients that were similar/helped you to care for this patient/family? Describe.
    b.Have you had any personal experiences (with relatives, friends) that influenced your attitudes or practices in caring for dying patients in the ICU?
    c.Do you have any values that guide you in caring for dying patients? Any personal rules or principles?
    d.What qualities does a nurse need to give good nursing care to patients dying in ICU?

3. Do you have anything else you'd like to share about caring for dying patients in the ICU?

APPENDIX C

Appendix C: Family Member Interview Guide

Purpose: To explicate the bereaved family member's perspective on the dying episode, specifically in relation to the nursing care. To understand the concerns and background meanings of the family members as care receivers as well as agents of the patient in order to interpret their expectations and evaluation of the nursing care.

1. Introductory discussion: Tell me about your relationship with your family member (fm).
    a. What is your relationship to (fm)?
    b. How many years did you and (fm) know each other?
    c. What was your relationship with (fm) like? Give me an example.
    d. Tell me about (fm)'s illness.

2. What was it like to have (fm) in the ICU. Please talk about what that experience was like for you.
    a. When was he/she admitted to the ICU? Describe the series of events.
    b. Were you worried about the seriousness of the illness?
    c. Did you think that (fm) was going to die?
    d. When did you first realize that (fm) might die? How did you know? Did anyone discuss this with you?

3. Now focus on the time period when (fm) was dying. What happened?
    a. Describe the process of your (fm)'s dying
        1) Who was there? Who talked to you?
        2) Describe the sequence of events.
        3) Often times people will think about whether their (fm)'s deaths are preventable. Do you think his/her death was preventable?
        4) Do you think that (fm) knew that he/she was dying?
        5) Do you think that (fm) was uncomfortable or in pain while he/she was dying?
        6) Did his/her dying take too long? Did it take a shorter or longer time than you expected?
        7) What would you have changed about the way that (fm) died?
        8) Were there things that made you angry about the way that (fm) died?
        9) Did he/she have any strong personal feelings or beliefs concerning death and dying? Was this how he/she would have liked their death to be?
    b. Describe your thoughts, feelings, concerns, and needs during this time.
        1) How did you react when you first realized that

(fm) was dying? Did anyone help you with these feelings?
2) What were your personal thoughts and fears during the time (fm) was dying? How did you cope with what was happening?
3) Were you involved in the his/her care while they were dying? Were there any decisions to be made? Describe these.
4) What were your needs during that time? How were they met? What would have been more helpful to you?
5) Do you have any strong personal feelings or beliefs concerning death or dying? How were these respected or not during the time he/she was dying in ICU?
6) What was the most stressful part of the experience?
7) Were there any parts of the dying process that were satisfying to you or that you feel good about?
8) Did you have any unfinished business in your relationship with your (fm)?

c. Now I'd like you to think about the nursing care that you and your (family member) received while he/she was dying

1) Describe the nursing care. Were there any particular nurses that gave especially good care? Describe/give an example.
2) How did you interact with the nurses? Were there any particular nurses that helped you during that time? Describe/give an example.
3) Did (fm's) nursing care change when he/she was dying?
4) Did you feel like (fm) was well cared for? Give an example.
5) What concerns did/do you have about (fm's) care? Give an example.
6) Some family members like to be involved in different ways in the care of their (fm) in the ICU. Were you able to get involved or give suggestions? Would you have liked to?
7) Have you had other experiences with relatives or friends who have died in critical care? How was their nursing care the same/different?
8) Have you had any contact with any of the nurses since he/she died? Describe.
9) Does (expert nurse) stand out in your memory? Do you remember anything in particular about the care she gave to your (fm)?

4. Is there anything else you'd like to share about your experiences with your (fm) dying in the ICU?

APPENDIX D

CODING SYSTEM FOR ETHNOGRAPH

Clinical Episode

CE	Clinical Episode
CONCERN	Concern
PCASE	Paradigm Case

Dimensions of Practice (specific practices)

MANAGE	Managing death
COMFORT	comfort measures
WITHDRAW	withdrawal of life support
SPACE	creating space/environment for dying
TIME	affecting the time/timing of death
WHATIF	anticipating "what-ifs" or possible clinical problems/concerns
Communication with patient	
TOUCH	touch
TALK	talk
RITUAL	Care rituals
HUMANIZE	Humanizing strategies
DX	Monitoring (includes pt. assessment/pt. response)
RX	Therapies
BNC	Basic Nursing Care
ONP	Other Practices

Background (sets up possibility for doing)

KNOWPT	Knowing the particulars of the patient and how their illness affects their life story
KNOWFAM	Knowing the particulars of the family and how the patient's illness/death affects their life story
PRACKNOW	Practical knowledge; understanding developed as a result of clinical experience
PERSKNOW	Personal knowledge; understanding because of personal experience
CLINGRASP	Clinical grasp; understanding the trajectory of the clinical situation
MORIDEAL	Moral ideal; notion of the good; sense of how patient care should be
INVOLVE	Emotional involvement; includes guilt, responsibility, caring
GRIEF	Grieving by the nurse
LEARN	Instances where nurses note their understanding has changed
UNITCULT	Unit culture; practices, beliefs or knowledge that is part of the common understanding in the unit
MEANDTH	Meaning of death; includes personal confrontation or more abstract ideas about the meaning of death

NSGBURDEN Nursing Burden; aspects of practice with which the nurse must cope; care demands
SOLICIT What solicits the nurse about a situation or patient; when things begin to matter

Focus of Practice
FAM Family care
MD Physician involvement in situations, including MD\RN relations

Trajectory of Events
CURECARE Cure-care transition
DNR Includes all discussion concerning end of life decision-making
DISCLOSE Disclosing information to families; includes balancing hope with reality
Death event
GOODDTH Good death
BREAKDOWN Includes bad death and empty death; situation which is not a good death
CODE Death in which resuscitation is attempted
POSTDTH After death; includes donor status

Miscellaneous
CONFLICT Between health care providers, family, patient; can include moral and legal conflict; includes control issues
MORAGCY Moral agency; acting as a moral being; showing awareness of the moral issues
ADVOCAT Acting in the role of advocating for patient or family
INBET In-between position; acting as go-between/translator between MD and family
N3 Expert nursing practice
ORG Organization; refers to problems, concerns or supports to care at the level of the unit, institution or health care system
INVIS Invisible aspects of nursing practice

Coding strategies:
1. Double code the major theme of each story with concern.
2. Double code MD/Advocate for positive situations involving physicians (to retrieve nurse advocate data, use advocate-MD).
3. Double code N3/moragcy for paradigm cases of moral agency.
4. Double code talk/fam for situations where nurse is coaching families how to talk to patients.

APPENDIX E

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form for Nurse Informants

TITLE Humanizing the High Tech Environment: Nursing Care of Dying Patients in Critical Care

PRINCIPAL INVESTIGATOR Peggy L. Wros (503) 638-9063

PURPOSE The purpose of this study is to describe and understand the caring practices of nurses caring for dying patients and their family members in critical care units. To learn about these practices, it is necessary to collect descriptions from and observe the practices of nurses who are experienced in that care. It is also necessary to talk to family members who have had the experience of having someone die in the critical care unit. The time of participation will span approximately two to three months.

PROCEDURES If I agree to participate in the study, I will attend two group interview sessions which will be tape recorded. Each interview will last approximately one to one and one-half hours and involve questions about my experience caring for dying patients in the critical care unit. I may also be asked to participate in the observation part of the study. If so requested, I agree to notify the researcher when I am caring for a dying patient so that my practice can be observed. This observation time is not anticipated to exceed 2-4 hours each shift for 3 days. I will also then participate in a personal interview related to the dying episode observed which will last from one to one and one-half hours. The interviews will be arranged at a time convenient for me. I may be called upon after the group or personal interviews for additional information or to provide clarification.

RISKS AND DISCOMFORTS Psychological discomfort could potentially occur as a result of talking about caring for dying patients. I am free to decline to discuss any topics or answer any questions that may be uncomfortable for me.

BENEFITS Possible personal benefits of participation may include personal and professional growth from the opportunity to reflect on my practice and share experiences with other critical care nurses. Health science benefits may include informing other nurses about care of dying patients in critical care and influencing related ethical issues which may benefit patients in the future.

CONFIDENTIALITY Neither my name nor my identity will be used for publication or publicity purposes. The researcher will keep my name separate from the recorded interview, all transcripts, and observation notes. My name will be coded by

number and kept in a locked file so that my confidentiality will be protected. Tape recordings will be erased after transcription. Study records may be reviewed by funding or regulating federal agencies.

COSTS There will be no cost to me for participating in this study.

LIABILITY The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Funds. If I suffer any injury from the research project, compensation would be available to me only if I establish that the injury occurred through the fault of the University, its officers or employees. If I have any further questions, I may call Dr. Michael Baird at (503) 494-8014.

QUESTIONS Peggy Wros has offered to answer any questions that I might have. She can be reached at (503) 638-9063.

VOLUNTARY PARTICIPATION Participation in this study is voluntary. I may refuse to participate or may withdraw from this study at any time without affecting my relationship with or treatment at the Oregon Health Sciences University.

COPY OF CONSENT GIVEN TO PARTICIPANTS I will receive a copy of this consent form to keep.

My signature below indicates that I have read the foregoing and agree to participate in this study.

_____ _____

Signature of co-participant/Date

Signature of witness/Date

APPENDIX F

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form for Bereaved Family Members

TITLE Humanizing the High Tech Environment: Nursing Care of Dying Patients in Critical Care

PRINCIPAL INVESTIGATOR Peggy L. Wros (503) 638-9063

PURPOSE The purpose of this study is to describe and understand the caring practices of nurses caring for dying patients and their family members in critical care units. To learn about these practices, it is necessary to collect descriptions from and observe the practices of nurses who are experienced in that care. It is also necessary to talk to family members who have had the experience of having someone die in the critical care unit. The time of participation will span approximately two weeks.

PROCEDURES If I agree to participate in the study, my participation will include two tape recorded interviews. Each interview will last approximately one hour and involve questions about the dying of my family member in critical care, my feelings during that time, and the nursing care my family member received. The interviews will be held in my home or another location convenient to me. I may be called upon after the interviews for additional information or to provide clarification.

RISKS AND DISCOMFORTS Psychological discomfort could potentially occur as a result of talking about the dying of my family member. I am free to decline to discuss any topics or answer any questions that may be uncomfortable for me. If needed, a referral to a bereavement specialist will be made available to me to help me with my feelings.

BENEFITS Possible personal benefits of participation may include the opportunity to talk about the dying of my family member in the critical care unit and increased understanding which may come as a result of sharing thoughts, concerns, insights, and feelings. Health science benefits of this study may include education of nurses about caring for dying patients and their families and influencing related ethical issues which may benefit patients in the future.

CONFIDENTIALITY Neither my name nor my identity will be used for publication or publicity purposes. The researcher will keep my name separate from the recorded interview, all transcripts, and observation notes. My name will be coded by number and kept in a locked file so that my confidentiality will be protected. Tape recordings will be erased after transcription. Study records may be reviewed by funding or regulating federal agencies.

COSTS There will be no cost to me for participating in this study.

LIABILITY The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Funds. If I suffer any injury from the research project, compensation would be available to me only if I establish that the injury occurred through the fault of the University, its officers or employees. If I have any further questions, I may call Dr. Michael Baird at (503) 494-8014.

QUESTIONS Peggy Wros has offered to answer any questions that I might have. She can be reached at (503) 638-9063.

VOLUNTARY PARTICIPATION Participation in this study is voluntary. I may refuse to participate or may withdraw from this study at any time without affecting my relationship with or treatment at the Oregon Health Sciences University.

COPY OF CONSENT GIVEN TO PARTICIPANTS I will receive a copy of this consent form to keep.

My signature below indicates that I have read the foregoing and agree to participate in this study.

_____ _____

Signature of co-participant/Date

Signature of witness/Date

APPENDIX G

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form for Secondary Nurse Informants
and Other Health Professionals

TITLE Humanizing the High Tech Environment: Nursing Care of Dying Patients in Critical Care

PRINCIPAL INVESTIGATOR Peggy L. Wros (503) 638-9063

PURPOSE The purpose of this study is to describe and understand the caring practices of nurses caring for dying patients and their family members in critical care units. To learn about these practices, it is necessary to collect stories from and observe the practices of nurses who are experienced in that care. It is also necessary to talk to family members who have had the experience of having someone die in the critical care unit. In addition, it may be important to observe or talk to other nurses or health care professionals involved in the patient's dying. The time of participation will be one to three days.

PROCEDURES If I agree to participate in the study, my participation will include allowing the researcher to observe my practice in caring for the identified dying patient and to ask me related questions. Conversations between myself and the interviewer may be tape recorded. One to two observations are anticipated. Each observation may last two to four hours. I may be called upon after the observation for additional information or to provide clarification.

RISKS AND DISCOMFORTS Psychological discomfort could potentially occur as a result of having someone observe my practice and ask questions about my care. I am free to decline to discuss any topics or answer any questions that may be uncomfortable for me.

BENEFITS Possible benefits of participation may include personal and professional growth from the opportunity to reflect on my practice. Health science benefits of this study may include education of nurses about caring for dying patients and their families and influencing related ethical issues which may benefit patients in the future.

CONFIDENTIALITY Neither my name nor my identity will be used for publication or publicity purposes. The researcher will keep my name separate from the recorded interview, all transcripts, and observation notes. My name will be coded by number and kept in a locked file so that my confidentiality will be protected. Any tape recordings will be erased after transcription. Study records may be reviewed by funding or

regulating federal agencies.

COSTS There will be no cost to me for participating in this study.

LIABILITY The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Funds. If I suffer any injury from the research project, compensation would be available to me only if I establish that the injury occurred through the fault of the University, its officers or employees. If I have any further questions, I may call Dr. Michael Baird at (503) 494-8014.

QUESTIONS Peggy Wros has offered to answer any questions that I might have. She can be reached at (503) 638-9063.

VOLUNTARY PARTICIPATION Participation in this study is voluntary. I may refuse to participate or may withdraw from this study at any time without affecting my relationship with or treatment at the Oregon Health Sciences University.

COPY OF CONSENT GIVEN TO PARTICIPANTS I will receive a copy of this consent form to keep.

My signature below indicates that I have read the foregoing and agree to participate in this study.

_____ _____

Signature of co-participant/Date

Signature of witness/Date

ABSTRACT

TITLE: Behind the Curtain: Nursing Care of Dying Patients in Critical Care

AUTHOR: Peggy L. Wros

APPROVED: Christine A Tanner
Christine A. Tanner, RN, PhD

The purpose of this phenomenological study was to describe and understand the nursing care of patients dying in critical care and their families. Interpersonal concerns and background meanings of nurses and bereaved family members were explicated. The key study informants were fifteen critical care nurses from five critical care units in two hospitals with experience and expertise in nursing care of dying patients and their families.

The study was carried out in four phases. In Phase I, key informants were interviewed in groups about their experiences in caring for dying patients and their families in critical care. In Phase II, selected key informants were observed in clinical practice as they cared for dying patients and their families. Eight observations were completed. In Phase III, the nurses observed in phase II were interviewed about the particular episode observed as well as about their personal beliefs and values related to nursing care of dying patients in critical care. In Phase IV, bereaved family members of patients who died in critical care were interviewed. The family members were recruited during observations and from phase I group interview data.

Eight bereaved family members were interviewed.

Expert nursing care was based on a clinical grasp that the patient was dying and an understanding of the particular demands of the situation. The nurses played a significant role in end-of-life decision-making. Rather than taking an independent position, they facilitated decisions by preparing families, working with physicians, arranging care conferences, and advocating for the patient and family. The nurses managed dying situations by creating a space for the death, facilitating the life to death transition, and making patients comfortable. They humanized care by touching and talking to patients, and helped the family to approach the bedside as the patient died. Routine nursing and medical care became secondary. If family members were involved, the focus of nursing care changed from patient to family as unconscious patients neared death. Family members helped nurses to know the patient, and understand what constituted good nursing care.

Nurses expressed many responses to the death of patients, including grief and guilt. Nurses described good deaths as those which included patient choice, family involvement, and patient comfort. Involvement, caring, and relationship were strong moral themes throughout the narratives. Major ethical concerns were relief of suffering, patient choice, priority of family needs, maintaining dignity, non-discriminating patient treatment,

and acting as the agent of death. Organizational supports for nursing care of dying patients included chaplain services, ethics committees, and advance directives. Organizational impediments included staffing patterns, workload, the critical care environment, and bed utilization policies. Additional concerns included communication with physicians, coordination of medical care with nursing care, and involvement of physicians with dying patients and their families.

Family members valued both the caring and technical skill of critical care nurses. However, the involvement, managing, and coordinating aspects of nursing practice were not generally recognized by bereaved family members. Family members felt that the critical care unit was difficult to negotiate, and sometimes assumed the role of standing guard for the dying patient. Family members identified particular needs related to their critical care experience. They wanted information about the patient, consistent caregivers and approaches to care, welcome access to the bedside, and consideration for family's overwhelming involvement and concern.

Explicating and understanding what kinds of practice are possible provides an important basis for teaching nurses and students, developing the clinical domain, and supporting the nursing care of dying patients and their families in critical care. The results also have implications for the

development of moral theory for nursing.