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E.R.= EXIT REQUIRED.
A PHILOSOPHICAL, THEORETICAL, AND PHENOMENOLOGICAL INVESTIGATION OF CARE AT THE END-OF-LIFE IN THE EMERGENCY DEPARTMENT.

by

Garrett K. Chan

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

[redacted]

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A PHILOSOPHICAL, THEORETICAL, AND PHENOMENOLOGICAL INVESTIGATION OF CARE AT THE END-OF-LIFE IN THE EMERGENCY DEPARTMENT

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by

Garrett K. Chan

This work is dedicated to my parents, Sheila Wong and Leslie Chan;

my sister, Stephanie Chan;

and the love of my life, Russ McLaren.

ACKNOWLEDGEMENTS

> If I have seen further, it is by standing on the shoulders of giants.
> \- Sir Isaac Newton

This dissertation would not be possible without the support and guidance of many contributors in my community of faculty, friends, and family. The manuscripts in this dissertation are products of many innovative, creative, and visionary scholars who contributed generously to help me succeed.

My research advisor, Patricia Benner, is an insightful and patient mentor who gave me two pieces of sage advice and encouragement that got me through this doctoral program. In a moment of complete writer's block she said to me, "Garrett, there is no good writing; there is only good re-writing." The other piece of insightful and humbling wisdom was, "Garrett, you are no longer my student- you are my colleague. And as colleagues, we share unfinished written work to strengthen each others' writing." Patricia provided the safe ground from which I could explore. I am honored by her assessment of my scholarship, and I will continue to work hard to attain Patricia's level of expertise, wisdom and grace.

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literature and clinical practice has been invaluable. I am humbled and thankful for his kind generosity and for his skill with a red pen.

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Last year, I helped get a small group of qualitative research students together. We called ourselves the Little Fishes. We were so named because we seemed to be a small "school" of students in a large ocean of quantitative researchers. The "Fishes," Anne

Hughes, Steve Rush, and Mijung Park, have read my dissertation and have given me valuable feedback throughout my studies. Maria Gudmundsdottir is a wonderful colleague and interpretive scientist with whom I worked. Her solid understanding of the family perspective enriched my understandings about end-of-life and bereavement care. John Fazio supported me through his kind wisdom and friendship. Jack Dean has been a patient friend who has listened and helped me cope with my struggles and celebrated my successes.

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I am grateful for the organizations who have contributed to my studies and also my success: Emergency Nurses Association Foundation/ Sigma Theta Tau, International, Sigma Theta Tau- Alpha Eta Chapter, California Emergency Nurses Association, UCSF School of Nursing Century Club Funds, UCSF Graduate Division, El Camino Hospital Auxiliary Foundation and the staff at San Jose Medical Center.

I must thank all the participants in this study who so generously and honestly shared their stories, time, and experiences with me. As Ruth Malone wrote in the acknowledgment chapter of her dissertation, "it was their voices that brought this work into being, and I tried to get out of the way."

Lastly, I would like to thank my family. My mom, Sheila Wong, passed away in May, 2004. She was able to see me progress through the beginning works of this dissertation. One day, when she and I were in the Infusion Center at Kaiser Walnut Creek, she asked to read the paper I was working on during her chemotherapy. I let her read the philosophical paper of this dissertation (Chapter Three). After she finished with this difficult philosophy paper that was only half written, she said, "Garrett, I may not understand all that you have written. But, it looks like you are writing something important so keep going. People will need this paper one day." I am grateful that she was able to see me grow into the scholar I am today. My dad, Leslie Chan, has encouraged me to become the best person I can be. His quiet and constant presence has supported me. My sister, Stephanie Chan, has supported me with love and faith. She has listened patiently and compassionately to my complaints and successes. My life partner, Russ McLaren, has given me so much over the past five years. His thoughtful comments, supportive presence, intriguing debates, and love have sustained me when I needed it the most to complete this journey. I could not have done this without him.

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Chapter III is a reprint of the material as it appears in the journal *Nursing Philosophy*. I wish to thank Blackwell Publishing for granting me permission to reprint this publication in its entirety.

Chapter V will be submitted as a manuscript to the *Journal of Palliative Medicine*.

Research Advisor's Statement:

This dissertation is substantially a product of the student's period of graduate study at the University of California, San Francisco and was primarily conducted and written by the student. This published materials dissertation meets the standards of scientific and scholarly rigor and represents philosophical, theoretical, and research investigations comparable in scope and contribution to the standard dissertation it replaces.

Patricia Benner

Patricia Benner, RN, PhD, FAAN, Dissertation Chair

ABSTRACT OF THE DISSERTATION

E.R.= EXIT REQUIRED.
A PHILOSOPHICAL, THEORETICAL, AND PHENOMENOLOGICAL INVESTIGATION OF CARE AT THE END-OF-LIFE IN THE EMERGENCY DEPARTMENT

by

Garrett K. Chan

Doctor of Philosophy in Nursing

University of California, San Francisco, 2005

Emergency departments (EDs) are places of high-stress, are fast-paced, and are generally a place of transition in the hospital. Patients do not usually stay in the ED and are often transferred to an inpatient unit, transferred to another hospital for a higher level of care, or discharged home. Even though we confront transition in this rescue area, ED clinicians may not be cognizant of the types of death that they attend. The closing of a person's life is the end of a biography, and the person may not ever leave the ED.

The purpose of this interpretive study is to describe the lived experience of ED clinicians' clinical and ethical decision-making, distress, and resolution of actual or potential dying and resuscitative events in an effort to unravel the perceived personal, ethical, cultural, environmental and clinical factors that influence the care of dying ED patients. This interpretive project aims at making explicit caring practices of clinicians

and seeking common meaning in ED end-of-life care. This dissertation is a thick description of the ED culture and characteristics, a theoretical examination of end-of-life models, a philosophical investigation of how ED clinicians understand and recognize patients are dying, and how patients approach death and die in the ED. End-of-life research has not focused on end-of-life in the ED. This is a new frontier to be explored.

Chapter Two is a description of ED culture and characteristics with a review, critique, and theoretical examination of the applicability of current end-of-life models to ED care. Current end-of-life models that are based on chronic care or oncology models are difficult to apply in the ED setting. The limitations of these models are that they do not allow for the uncertainty of prognosis or for mortality in sudden illness or injury; do not take in account unpredictability of the course of treatments; and cannot accommodate the suddenness of presentation of illness or injury or the sudden change in patient condition.

Chapter Three is a philosophical examination of end-of-life care in the ED in an effort to help us understand how core medical and nursing values are embodied as care practices and ethical comportment. This chapter integrates Aristotle and other philosophers' notions of *phronesis* and *praxis* with Merleau-Ponty's ontological notions of *intentional arc* and *maximum grip* in the context of the culture and practices at the end-of-life in the emergency department setting. Chapter Four is a review of phenomenology as a research methodology.

Chapter Five is the dissertation study that describes the seven trajectories of how patients approach death and die in the ED. These seven trajectories are: 1) dead on arrival; 2) resuscitation in the field, resuscitative efforts in the ED, died in the ED; 3) resuscitation in the field, resuscitative efforts in the ED, resuscitated and admitted to the hospital; 4) terminally ill, comes to the ED; 5) frail, hovering near death; 6) arrives at the ED alive then arrests/dies suddenly in the ED; and 7) potentially preventable death by omission or commission.

Patricia Benner

Patricia Benner, RN, PhD, FAAN, Chair

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CHAPTER ONE

Introduction

Significance of the Problem

Death is not uncommon in the emergency department (ED). The Centers for Disease Control and Prevention estimated that there were approximately 379,000 deaths in United States EDs in the year 2000 (McCaig & Ly, 2002). Patients come to the ED with unexpected injuries, chronic disease exacerbations, or terminal illnesses seeking life-saving or life-prolonging treatment. At times, families and patients who have terminal illnesses activate the emergency medical system (EMS) when they panic due to the manifestation of symptoms of distress, inability to further care for the dying patient due to the difficulty controlling symptoms at home, physical and/or psychological inability to care for the patient or for cultural or spiritual reasons (Donaldson, 1998; Smeenk et al., 1998). For whatever reason they come, the American public actively solicits help and expects full assistance to treat illness and injury when they arrive at the ED (Chan, 2004; Iserson, 1996).

The ED staff is in a constant state of readiness for people who have an unexpected illness or injury or who have a sudden change in a chronic condition. Emergency clinicians see people across the lifespan with illnesses and injuries that run the gamut. A core concept of emergency medicine and nursing is to diagnose illness and injury and initiate treatment in an effort to cure (MacPhail, 1998). Emergency departments are places of high-stress, are fast-paced, and are generally a place of transition in the hospital (Chan, 2004).

Patients are triaged or sorted by the severity of their illness or injury. ED clinicians work urgently to diagnose and to stabilize the condition of a patient by performing diagnostic exams and administering therapies in an effort to determine if an emergent medical condition exists. If a serious or life-threatening illness or injury is diagnosed, the ED staff attempt to stabilize the patient and if successful, they call an admitting service and the patient is transferred to an inpatient unit or transferred to another medical facility. If no emergent medical condition exists, the patient is discharged home. Patients normally do not remain in the ED for the duration of their hospital stay. This method of triaging patients and determining a disposition, or disposing of patients, creates an environment of constant change and patient turnover (Chan, 2004).

Clinicians are called upon to make rapid decisions often with sub optimal levels of information available (ENA, 1998; Iserson, 1996; Marco, 1999; Taylor & Taylor, 1998). Relationships among the healthcare clinicians, patients, and families are limited and often hastily forged at a time when an unexpected traumatic injury or medical emergency occurs (Sanders, 1995; Walters & Tupin, 1991). Patients and families may be thrown into disequilibrium in this time of crisis (Walters & Tupin, 1991). ED clinicians may not have the benefit of knowing the patients' values and wishes to guide their clinical decisions surrounding end-of-life care (Chan, 2004). Time is measured in units of minutes to hours and not in days, weeks or months in other areas of health care (Chan, 2004). The focus of care is mainly on the patient.

Even though we confront transition in this rescue area, ED clinicians may not be cognizant of the types of death that they attend. The closing of a person's life is the end of a biography, and the person may not ever leave the ED.

End-of-life care has been identified as being substandard in the United States (National Institutes of Health, 2004). In December 2004, the NIH convened a consensus conference to review the relevant literature, examine the results of research and programmatic efforts to evaluate the current state-of-the-science, and to identify directions for future research in end-of-life care (National Institutes of Health, 2004). The State-of-the-Science panel concluded that the evidence does not yet support a definition of the interval referred to as "the end-of-life" or its "transitions." These "transitions" have not been well articulated, and there is a lack of definitional clarity to the concept of "end-of-life care," especially in the ED.

Statement of the Study Purpose

The purpose of this interpretive study is to describe the lived experience of emergency department (ED) clinicians' clinical and ethical decision-making, distress, and resolution of actual or potential dying and resuscitative events in an effort to unravel the perceived personal, ethical, cultural, environmental and clinical factors that influence the care of dying ED patients. This interpretive project aims at making explicit caring practices of clinicians and seeking common meaning in ED end-of-life care. Cases in which clinicians caring for patients dying from traumatic injuries or medical illnesses across the lifespan will be considered. From this point forward, resuscitation is defined as any intervention that will attempt to restore or maintain signs of biological life. These interventions might include, but are not limited to, cardiopulmonary resuscitation (e.g., chest compressions, advanced airway management), vital sign management (e.g., fluid resuscitation or vasopressor administration), or advanced disease or injury interventions (e.g., antibiotic administration in end-stage Alzheimer's disease). In addition, any discussion surrounding advance directives, withholding or withdrawing life-sustaining therapies, or moral distress will be considered as part of a resuscitative event and be observed and documented. There are six specific aims of this research project:

1. Describe the participants' definitions of death and dying (actual or potential) in the emergency setting in an effort to clarify conceptions of "good" and "bad" deaths and elucidate ambiguities, conflicts, and notions of competing goods surrounding death and dying.
2. Understand and interpret the lived experience of ED clinicians of caring for a dying patient or resuscitating a patient with a terminal disease or injury where they consider the care to be wise and effective, and a patient for whom the resuscitation seemed inappropriate clinically to the clinician.
3. Articulate the factors present in the ED that create ethical distress or dilemmas.
4. Systematically describe the clinical and ethical decision-making processes of clinicians during observed resuscitations and caring for dying patients including any discussions surrounding do-not-attempt-resuscitation orders, withholding or withdrawing life-sustaining measures. In addition, clinical and ethical decision making processes will be analyzed through subjects' descriptions of past resuscitations through the individual interviews.
5. Describe the ED culture and characteristics and its influence on care of the dying patient.

6. Describe self-reported caring practices of clinicians in the ED during the patient's end-of-life phase.

Content of the Dissertation

This dissertation consists of three parts. The first part (Chapters 2 and 3) is a thick description of the culture, characteristics and a philosophy of clinicians while caring for patients who are approaching death or dying in the emergency department. In addition, end-of-life models that are based on chronic illness and cancer trajectories are critiqued in light the sudden and unforeseen that is common in the ED setting.

The second part (Chapter 4) is a review of phenomenology as a methodology to understand how the caring practices of ED clinicians for dying patients can help overcome the sense of loss of self-understanding, sense of alienation, moral dilemmas, and loss of social integration for clinicians, patients, and families (see (Benner & Wrubel, 1989). This reclaiming of understanding allows us to see and understand more fully the caring and even potentially healing practices of clinicians for patients and families in crisis that constitute the foundation of nursing and medical practices. Interpretive projects can illustrate notions of good practice and the knowledge embedded in advanced levels of practice. By articulating these practices, we can confirm good practices, explore additional possibilities, and use them as a basis for new visions of practice (Benner & Wrubel, 1989).

The third part (Chapter 5) of this dissertation describes a phenomenological investigation to identify different trajectories of approaching death in an effort to describe the end-of-life experience, the transitions to the end-of-life, and care in the ED. This research addresses the new frontier of end-of-life and palliative care in the ED.

CHAPTER ONE REFERENCES

Benner, P. E., & Wrubel, J. (1989). *The primacy of caring*. Menlo Park, CA: Addison-Wesley.

Chan, G. K. (2004). End-of-life care models and emergency department care. *Academic Emergency Medicine, 11*(1), 79-86.

Donaldson, N. (1998). Terminal fears and panic. *Accid Emerg Nurs, 6*(1), 41-42.

ENA. (1998). *Resuscitative decisions* [Position Statement]. Emergency Nurses Association. Retrieved May 1, 2003, from the World Wide Web: http://www.ena.org/about/position/resuscitativedecision.asp

Iserson, K. V. (1996). Withholding and withdrawing medical treatment: an emergency medicine perspective. *Ann Emerg Med, 28*(1), 51-54.

MacPhail, E. (1998). Overview of emergency nursing. In L. Newberry (Ed.), *Sheehy's Emergency Nursing: Principles and Practice* (4th ed., pp. 3-7). St. Louis, MO: Mosby.

Marco, C. A. (1999). Ethical issues of resuscitation. *Emerg Med Clin North Am, 17*(2), 527-538, xiii-xiv.

McCaig, L. F., & Ly, N. (2002). *National Hospital Ambulatory Medical Care Survey: 2000 Emergency Department Summary* (Advance data from vital and health statistics; no. 326). Hyattsville, MD: National Center for Health Statistics.

National Institutes of Health. (2004). *National Institutes of Health state-of-the-science conference statement*. Retrieved January 21, 2005, from the World Wide Web: http://consensus.nih.gov/ta/024/024EndOfLifepostconfINTRO.htm

Sanders, A. B. (1995). Unique aspects of ethics in emergency medicine. In K. V. Iserson & A. B. Sanders & D. Mathieu (Eds.), *Ethics in Emergency Medicine* (2nd ed., pp. 7-10). Tuscon, AZ: Galen Press, Ltd.

Smeenk, F. W., de Witte, L. P., van Haastregt, J. C., Schipper, R. M., Biezemans, H. P., & Crebolder, H. F. (1998). Transmural care. A new approach in the care for terminal cancer patients: its effects on re-hospitalization and quality of life. *Patient Educ Couns, 35*(3), 189-199.

Taylor, J. P., & Taylor, J. E. (1998). Emergency nursing process and nursing diagnosis. In L. Newberry (Ed.), *Sheehy's Emergency Nursing: Principles and Practice* (4th ed., pp. 9-15). St. Louis, MO: Mosby.

Walters, D. T., & Tupin, J. P. (1991). Family grief in the emergency department. *Emergency Medical Clinics of North America, 9*, 189-207.

CHAPTER TWO

Critique of the Literature and Theories

End-of-Life Models and Emergency Department Care

Abstract

Many people die in Emergency Departments across the United States from sudden illnesses or injuries, an exacerbation of a chronic disease, or from a terminal illness. Frequently, patients and families come to the Emergency Department seeking life-saving or life-prolonging treatment. In addition, the Emergency Department is a place of transition- patients are usually transferred to an inpatient unit, transferred to another hospital, or discharged home. Rarely are patients supposed to remain in the Emergency Department. Currently, there is an increasing amount of literature related to end-of-life care. However, these end-of-life care models are based on chronic disease trajectories and have difficulty accommodating sudden death trajectories common in the Emergency Department. There is very little information about end-of-life care in the Emergency Department. This paper explores Emergency Department culture and characteristics and examines the applicability of current end-of-life care models.

Key words: emergency medicine; emergency care; end-of-life care; end-of-life models; palliative care; sudden death.

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Introduction

Death is not uncommon in the emergency department (ED). The Centers for Disease Control (CDC) estimates that there were approximately 379,000 deaths in United States EDs in the year 2000 (McCaig & Ly, 2002). Patients come to the ED with unexpected injuries, chronic disease exacerbations or perhaps terminal illnesses seeking life-saving or life-prolonging treatment. At times, families and patients who have terminal illnesses activate the emergency medical system (EMS) when they panic due to the manifestation of symptoms of distress, inability to further care for the dying patient due to the difficulty controlling symptoms at home, inadequate communication of professional caregivers with the family, and physical and/or psychological inability to care for the patient (Donaldson, 1998; Smeenk et al., 1998). For whatever reason they come, the American public actively solicits help and expects full assistance to treat illness and injury when they arrive at the ED (Iserson, 1996). Yet although death is a common ED occurrence, there is very little ED literature regarding end-of-life care (Ferrell, Grant, & Virani, 2001). Therefore, the purpose of this paper is to examine the ED specific cultural characteristics that influence end-of-life care and to consider the assumptions of existing end-of-life care models as they apply in the ED setting.

The healthcare environment has changed. There is an increase in availability of new drugs, new technology, increased responsibility to manage costs of care, increased liability, and an increase in regulatory agency surveillance. These changes exist concurrently with decreases in staff morale, a nursing and house officer shortage, an aging population with multiple chronic health problems, overcrowding of patients in hospitals, and a decrease in average length of stay which affects the ability to educate and care for patients. These conditions apply pressure on staff to “be productive” and focus primarily on outcomes, de-emphasizing process and “being with” people who need care. There is little time and space that can held open for attending to emotional and psychosocial well being. In the process, patients become “medicalized” and are transmogrified into medical terms and objectified (Rushton, Williams, & Sabatier, 2002). Malone (2003) describes three kinds of proximity that are central to relationships between nurses and patients: physical, narrative, and moral. Physical proximity aids nurses in providing direct clinical care, nurses understand the patient as a person through narrative proximity, and moral proximity assists in ethical comportment and decision-making on behalf of patients who cannot speak for themselves. These proximities are threatened or not attained in a fast-paced ED with limited relationships with patients and families.

In this healthcare environment, “ideal” patients are patients whose treatment and prognosis are unambiguous, who have easily treatable conditions, who require little time from overworked and stretched-thin staff, and who are cooperative and compliant with therapies. The ED is not designed to give end-of-life care, yet many patients die there.

One important and highly publicized study, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) funded by the Robert Wood Johnson Foundation, was a multi-site descriptive and interventional hospital study investigating death and dying in hospitals (SUPPORT Investigators, 1995). Despite an intervention aimed at improving communication among patients, families, and caregivers, the investigators found that patients were dying in hospitals in moderate to severe pain, on mechanical life support, and had prolonged stays in the intensive care unit

(SUPPORT Investigators, 1995). The SUPPORT study has played a significant role in beginning national dialogue about the state of end-of-life care.

Discussion

ED Culture and Characteristics

The ED staff is in a constant state of readiness for people who have an unexpected illness or injury or who have a sudden change in a chronic condition. Emergency clinicians see people across the lifespan with illnesses and injuries that run the gamut. A core concept of emergency medicine and nursing is to diagnose illness and injury and initiate treatment in an effort to cure (MacPhail, 1998).

In the ED, clinicians are called upon to make rapid decisions in a high stress, high anxiety and fast- paced environment, often with sub optimal levels of information available (ENA, 1998; Iserson, 1996; Marco, 1999; Taylor & Taylor, 1998). When patients and families arrive to the ED, their arrival is seen as an active solicitation for help and full assistance is expected by society (Iserson, 1996).

In the ED, relationships among the healthcare clinicians, patients, and families are limited and often hastily forged at a time when an unexpected traumatic injury or medical emergency occurs (Sanders, 1995; Walters & Tupin, 1991). Patients and families may be thrown into disequilibrium in this time of crisis (Kercher, 1991). ED clinicians do not have the benefit of knowing the patients' values and wishes to guide their clinical decisions surrounding end-of-life care.

The American culture is a rescue-oriented culture, as evidenced by the education of tens of thousands of people in cardiopulmonary resuscitation (CPR). The American Heart Association (AHA) markets early CPR and advanced care as an effective therapy that can save up to 49% of patients from death and cardiac arrest (American Heart Association, 2000). A recent study of resuscitations on the television shows *ER*, *Chicago Hope*, and *Rescue 911* demonstrated that in one television season, 65% of patients survived immediate arrest and 67% survived to discharge (Diem, Lantos, & Tulsky, 1996). These figures are inflated compared to studies that demonstrate that survival after medical cardiac arrest ranges from 5.8-8.1% for arrests that occur outside the hospital (Herlitz et al., 2000; Lindholm & Campbell, 1998) and from 11-37% for arrests that occur within a hospital (Herlitz et al., 2000; Spearpoint, McLean, & Zideman, 2000). In the United States, the standard of practice is to perform CPR in all cases of cardiopulmonary arrest in the absence of a do-not-resuscitate (DNR) order, regardless of the underlying illness. CPR is the only procedure that does not require informed consent (Blackhall, 1987; Hackler & Hiller, 1990; Iserson, 1996; Timmermans, 1999).

Death is often perceived as preventable due to the advances in technology and medicine. According to Olsen and colleagues, ED physicians may feel "a sense of impotence, guilt, incompetence, and defeat if death occurs"(Olsen, Buenefe, & Falco, 1998, p. 759). This deep seated fear of being perceived as fallible and projecting a sense of hopelessness is a result of years of medical training and conditioning (Moller, 1990).

If a patient needs intervention, it is often blatantly obvious. To do "nothing" such as withholding or withdrawing medical treatment requires enormous effort and is a traumatic decision for most clinicians (Iserson, 1996). However, heroic measures and care-and-comfort measures require special functions from the nurse (Quint, 1967). In the ED, heroic measures are the norm, while care-and-comfort care plans are not often discussed by the ED clinicians. According to Walsh and Dolan, Accident and

Emergency nurses in the United Kingdom place more emphasis and value on the technological aspects of delivering care and view interpersonal, holistic, and relational aspects of care as a low priority (Walsh & Dolan, 1999).

The ED is a unique healthcare setting that is designed as a place of transition and triage. The word triage is derived from the French verb *trier* meaning "to sort, to select, to choose"(Urwin, 1989, p. 510). In the ED, patients are triaged or sorted by the severity of their illness or injury. ED clinicians work urgently to diagnose and to stabilize the condition of a patient by performing diagnostic exams and administering therapies in an effort to determine if an emergent medical condition (EMC) exists. If a serious or life-threatening illness or injury is diagnosed, the ED staff call an admitting service and the patient is transferred to an inpatient unit or transferred to another medical facility. If no EMC exists, the patient is discharged home. Patients normally do not remain in the ED for the duration of their hospital stay. This method of triaging patients and determining a disposition (or disposing of patients) creates an environment of constant change and patient turnover. The ED was set up to provide medical care to many people and has been a catchment for people when they cannot get an appointment with their primary care provider or have no other resources (Bracken, 2003). Scientists who have studied emergency and critical care units have found that the priority of care for a single clinician or even a department rests on the severity of illness or injury of the patient (Benner, Hooper-Kyriakidis, & Stannard, 1999; Fairman & Lynaugh, 2000; Timmermans, 1999). The most acutely ill or injured person receives the most attention and care. This same person can be said to be the person who is at highest risk of unanticipated or unwanted death.

In the ED, the staff and system continually work towards getting the patient stabilized and out of the ED. The Emergency Nurses Association published benchmark data designed to assist ED nursing and medical administrators in comparing individual hospitals against national standards. Quality indicators for EDs include average and median waiting room times (in minutes), average length of stay (in hours), and hours-per-patient visit (Spaite et al., 2002; Velianoff, 2001). In the hospital, the ED takes priority over other departments with the exception of emergencies in other parts of the hospital. For example, respiratory therapy, radiology, and laboratory only receive STAT (meaning "immediate") orders from the ED and turnaround time (TAT) is commonly evaluated to ensure a rapid TAT for a decreased length of stay.

Under the current conditions of hospital downsizing and staff shortages, however, patients are staying in the ED longer. Derlet and colleagues conducted a national descriptive study investigating the overcrowding of EDs. The investigators found that increasing patient acuity and hospital bed shortage were ranked highest in perceived causes of overcrowding in the ED (Derlet, Richards, & Kravitz, 2001). Consultation delay for admission orders or for treatment was reported to be an issue that contributed to overcrowding. These findings suggest that there are an increasing number of patients who stay in the ED for inpatient care. Hospital resources need to be prioritized in this environment of scarcity. Patients who are the most acutely ill will receive the resources first. An actively dying patient who has no chance of discharge out of the hospital may be low on the priority list. These patients may stay in the ED rather than take a free inpatient bed that can be used for a patient with a reversible or treatable condition.

Organ and tissue donation is a crucial topic that influences care delivered to patients dying or who have died in the ED. While the process of approaching families about organ donation has changed from all nurses inquiring about donation to only designated requestors approaching families, combining the efforts of the bedside nurse and the designated requestor has improved consent rates of organ donation (Roark, 2000). However, in the ED, not all clinicians feel comfortable in approaching families about organ and tissue donation (Henderson, Chao, Green, Leinen, & Mallon, 1998; Kim et al., 2000; Swisher, Nieman, Nilsen, & Spivey, 1993). Organ donation requires that the patient be declared "brain dead," yet the heart continues to beat. However, critical care nurses hold open the possibility of organ donation even in the face of prognostic uncertainty (Day, 2001). These discussions of donation are difficult to initiate in light of the suddenness of illness and injury in the ED.

Victims of violence or trauma, successful suicide attempts, and people who die suddenly and unexpectedly in the ED are potential cases for the medical examiner or coroner (Lynch, 1995). The trauma or resuscitation room is then treated as a potential crime scene. The body of the deceased becomes evidence, and the crime scene must be protected until the evidence has been removed at the completion of a medico-legal investigation. Emergency clinicians are responsible for assisting, preserving and collecting evidence and documenting carefully the observations, physical assessments, and events during and post resuscitation (ENA, 2000). While this post mortem care is important to increase the possibility that the victim's perpetrator or suspect in the crime is prosecuted successfully, constituting the person who died as "evidence" distances families and complicates bereavement care.

Walters and Tupin reflected that ED clinicians' care for the patient and family seemed to end as soon as the resuscitation attempts were called to an end (Walters & Tupin, 1991). ED clinicians refocus efforts and attention to the other patients in the department who were being ignored while the resuscitation was in progress, often avoiding the grieving family and friends (Hott, 2002; Walters & Tupin, 1991). Malone (2000) described a scenario in which a person died from a traumatic injury and immediately following the pronouncement of death, all the other members of the healthcare team left the room to care for other, living patients. Meanwhile, she was left to provide postmortem care to the body of the person who died. This is another example of triaging, or prioritizing care to living patients, and is not uncommon in the ED.

Family and friends are in an unfamiliar, high-stress, and fast paced environment where access to the patient and information may be restricted (Williams, O'Brien, Laughton, & Jelinek, 2000). The family and friends who arrive to the ED wait long periods to receive news and updates of their loved one (Parrish, Holdren, Skiendzielewski, & Lumpkin, 1987). The suddenness of the fatal illness or injury combined with the delivery of the news of the death throws the survivors into a "shock-like state" (Walters & Tupin, 1991, p. 192).

Successful grief and bereavement programs include care processes that incorporate frequent and prompt attention from ED clinicians. Suggestions for improved care of dying patients and the bereaved include allowing family and friends to be present at the bedside during resuscitation, reassurance from pre-hospital and ED personnel that prompt and appropriate treatment was given, compassionate and unhurried notification of the death, assurance that the body and patient's belongings are handled appropriately, information about what to do next, and the opportunity to ask questions or follow up with the hospital and ED clinicians (LeBrocq, Charles, Chan, & Buchanan, 2003; Meyers et al., 2000; Olsen et al., 1998; Parrish et al., 1987; Walters & Tupin, 1991; Williams et al., 2000).

There are many concerns reported by emergency clinicians in providing good end-of-life care. Fear of litigation, fear of being blamed, fear of not knowing all the answers, difficulty in dealing with surviving family members' emotions, and the clinician's own personal fear of death are perceived as barriers to working with families in death preparation and bereavement care in the ED (Buckman, 1984; Olsen et al., 1998; Timmermans, 1999). In addition, limited knowledge and education surrounding end-of-life care for patients and families in the ED has been identified and reported by emergency clinicians as a barrier (Ferrell, Virani, & Grant, 1999; Rabow, Hardie, Fair, & McPhee, 2000; Schmidt & Tolle, 1990; Walters & Tupin, 1991). Schmidt and Tolle (1990) discovered that the majority of ED physicians call the family and have them come to the ED for death notification. One interpretation of this practice is that the physicians want to recognize the passage of a human life and have someone be present to support the family, even though they themselves feel inadequately prepared to help the family and do not spend much time with the family (average 15 ± 11 minutes, min-max 1-90 minutes).

There are positive ways for emergency clinicians to cope with the repeated exposure to trauma and death that exist in the ED such as using self-care techniques of self-reflection, keeping a journal, and following basic health principles of eating properly, exercising, and nurturing interests and friendships outside the workplace (Badger, 2001). Another way of coping with the daily unspeakable trauma in the ED is through the use of humor (von Wormer & Boes, 1997). However, negative coping mechanisms are also prevalent and lead to stress and burnout in ED staff (Walsh, Dolan, & Lewis, 1998). One negative self-preservation coping strategy is using dissociation, an affective and cognitive avoidance, to avoid being overwhelmed by too many intense feelings that cannot be processed at the time of the event (Kreidler, Zupancic, & Longo, 2000). Timmermans discovered that ED clinicians coped with death by distancing themselves emotionally from the dying patient during resuscitation and reviving measures (Timmermans, 1997). Cumulative stress without resolution and effective coping mechanisms may lead to affective, physical, behavioral, and/or cognitive changes in the healthcare worker (Caine & Ter-Bagdasarian, 2003).

Timmermans described resuscitation as two parts: "the highly technological life-saving attempts and [the] nontechnical family-oriented caregiving" (Timmermans, 1997, p. 154). The resuscitation is often reduced to a depersonalized event, in which, for the sake of saving a human life, the person being resuscitated is reduced to clinical parameters (Timmermans, 1997). In Timmermans' study, common traditional practice was to separate the family from the patient so that the ED clinicians can focus their attention on the patient (Timmermans, 1997, 1999). Few clinicians sought to bring in the family during the resuscitation to care for both the patient and family in a holistic manner. There are research studies that advocate for family presence at the bedside during resuscitation (Eichhorn et al., 2001; Hanson & Strawser, 1992; Meyers et al., 2000). The inclusion of families during resuscitation could renew the lost practice of staff and families bearing witness to death as a human passage.

The use and focus on technology is heavily embedded in emergency care (Iserson, Sanders, & Mathieu, 1995). Over the past century, technology has been adopted as the standard of care (Howell, 1995). However, technology taken up as central to clinical practice distances patients from clinicians and changes the role of physicians and nurses participating in intimate caring practices (Sandelowski, 2000). Hott (2002) calls upon ED physicians and other clinicians to change current practices from technical and focusing on the technologies available to a practice that incorporates healing and comforting care to patients and families.

Definitions and Models of End-of-Life Care

While defining terms may help us understand how they are utilized, definitions also can close down possibilities for seeing situations in alternative ways. However, it is important to describe the concepts of palliative care, hospice care, and end-of-life care to understand how they may apply or not apply to ED care.

Since the publication of the SUPPORT study, many national organizations have determined that end-of-life care should be the focus of research and education. The Institute of Medicine (IOM) investigated the state of end-of-life care and published their report reexamining the attitudes and care practices surrounding death and dying (Field & Cassel, 1997). End-of-life texts(Ferrell & Coyle, 2001; Field & Cassel, 1997; Matzo & Sherman, 2001), national curricula to teach end-of-life content (American Association of Colleges of Nursing and City of Hope National Medical Center, 2000; Emanuel, von Gunten, & Ferris, 1999; Ferrell & Grant, 2001), end-of-life education articles (Billings, 2000; Ferrell & Coyle, 2002), and national organization publications (National Hospice Foundation, 2003; Task Force on Palliative Care, 1997) have created campaigns to educate clinicians about ways to improve end-of-life care. These educational resources, however, are primarily based on the palliative care or hospice care models. The palliative care and hospice care models were created to care for people who had "long, progressively debilitating chronic illness" (Coyle, 2001, p. 3).

There are three widely cited definitions of palliative care in the literature. The World Health Organization has defined palliative care as "the active total care of patients whose disease is not responsive to curative treatment" (World Health Organization, 1990, p. 11). The IOM describes palliative care as care that "seeks to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure.... Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs.... It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them" (Field & Cassel, 1997, p. 31). The third definition is offered by Last Acts, a national coalition to improve care and caring near the end of life, and defines palliative care as:

> the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients, in particular those with incurable, progressive illnesses. Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family. The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms and restoration of functional capacity while remaining sensitive to personal, cultural and religious values, beliefs and practices (Task Force on Palliative Care, 1997).

Hospice care refers to a specific programmatic model for delivering palliative care. Hospice is a discrete program that assumes case management responsibilities for all care related to a person's advanced, life-limiting illness, including support for the family through the dying experience and during their bereavement (Field & Cassel, 1997; Vachon, 2001). The National Hospice Foundation provides the following definition:

> At the center of hospice is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so. The focus is on caring, not curing and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice facilities, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness (National Hospice Foundation, 2003).

Ferrell and Coyle define end-of-life care as care given in the last weeks of life when death is imminent (Ferrell & Coyle, 2002). Vachon defines end-of-life care as:

> extending the concepts of hospice and palliative care to patients with chronic, life-threatening illness who may have one to two years to live. This might involve those with chronic cardiac or respiratory diseases, or those with advanced Alzheimer's Disease.(Vachon, 2001, p. 648).

The national education curriculum called Education for Physicians on End-of-Life Care (EPEC) describes a model of the continuum of care that integrates disease-modifying therapies with palliative care (Figure 2.1)(Emanuel et al., 1999). The model illustrates how palliative care can be used in collaboration with disease-modifying therapies, hospice, and bereavement care across the patient's illness trajectory. It assumes that fewer curative or disease-modifying therapies are offered as death approaches.

The IOM offers a model for end-of-life care called the Mixed Management Model (Figure 2.2)(Field & Cassel, 1997). This model is very similar to the EPEC model in that curative therapies are concurrently administered with palliative care, advance care planning, death preparation, and family support throughout the trajectory of the illness.

Synthesis of ED Culture and Characteristics and End-of-Life Care

Upon examination of these models and the definitions of palliative care, hospice care, and end-of-life care in relation to ED care, four contradictory assumptions emerge.

The following described assumptions inherent in the end-of-life care models are difficult to apply to the ED due to the ED culture and characteristics that are embedded in ED culture and practice.

First, these end-of-life care models assume an acknowledgement and acceptance by the patient, family, and healthcare team that death is imminent. Hospice is illustrated in the EPEC model as the period of time before the person's death. In order to access hospice care, by definition, the person and family need to forgo curative therapies. In the IOM Mixed Management model, advance care planning and death preparation are integral parts that are addressed at the time of diagnosis.

In the ED, however, acutely sudden illness or injury or an acute exacerbation of illness leaves little time for discussions of advance care planning and death preparation. Due to limited information and lack of personal relationship with the patient, these discussions are often awkward and clinicians are not always sure of prognosis. For example, the clinicians may ask themselves if this particular acute episode of the chronic illness is reversible. The extent of the patient's injuries may not be completely appreciated on initial exam. The suddenness of the acute or traumatic event, and the lack of relationship with patient and family members require a compressed social construction and negotiation about an imminent death that may be nearly impossible for the family to confront and accept.

The second assumption in most of these end-of-life models is that the disease trajectory is known and pre-determined. Since these models are based on progressive chronic diseases, prognosis of mortality has been studied using statistical modeling (Field & Cassel, 1997). Investigation of disease progression and estimation to time of death provide clinicians with general notions of typical trajectories that can be used as guides to plan for care and death (Figure 2.3). However, in the ED, clinicians most commonly see patients who die as a result of sudden death (e.g., massive myocardial infarction or severe traumatic injury) or from an acute exacerbation of a chronic illness. People who die suddenly may not experience any disease trajectory and therefore are not afforded time to adjust to the idea of death. Prognoses of progressive chronic diseases are highly variable and not well understood and prediction models do not attempt to prognosticate for individuals but rather for populations. Therefore, a person who may be in moderate health may decompensate quickly and die unexpectedly. The core issues are that visits to the ED are unexpected and usually there is less than adequate information on the patient's immediate illness situation.

The third assumption of these four models is that there is time for some or all aspects of palliative care can be attended to. The x-axis on both the EPEC and IOM models is labeled as a time variable. Although neither model has attached a specific time period to death, the IOM model focuses on patients who are expected to die within days or months rather than the minutes or hours typical of ED deaths.

The last assumption in the two models is that after death, all care shifts to the family in the form of bereavement care. This implies that the focus of care shifts from the person who died to the family and survivors of the person's death. While bereavement care is crucial to end-of-life care, the person who dies is no longer the focus of attention. This is a discontinuous shift in the ED where the traditional focus is solely on the emergency needs of the person as patient rather than the family and patient as legitimate *patients.* At the point of the shift there may have been little or no contact or rapport established with the family. To create a social space for grieving requires a shift in attention and relationship. The ED personnel have born witness to both the physical and biographical end of life of the patient. An effective shift in attention to the grieving family requires a shift to bearing human witness to the end of the life of the family member. This social space and relational work usually receives inadequate attention in the ED when compared to other social contexts for dying.

In the ED, issues surrounding victims of violence and sudden death require involvement of the coroner, medical examiner, and law enforcement. If the death is suspicious, the body may be considered to be evidence of a crime. Prevention of disturbance of the body and preservation of evidence may preclude family presence after the declaration of death. Post mortem care by clinicians is crucial in these cases. Additionally, if the person is declared brain dead in the ED, discussions surrounding organ and tissue donation may be instituted quickly and decisions may need to be made hurriedly. Therefore, family and staff must confront a highly charged and difficult situation without having established a relationship with the patient or family. And in criminal cases the social space for grieving rituals such as leavetaking and bearing witness to the death as a human passage are even more constrained.

Conclusion

End-of-life care models have been developed predominantly from chronic illness models. The limitations of these models are that the models do not allow for the uncertainty of prognosis for mortality in sudden illness or injury; do not take into account unpredictability of the course of treatments; they cannot accommodate the suddenness of presentation of illness or injury or the sudden change in patient condition. The sudden and unforeseen is primary in the ED setting (Malone, 1995). Who and what controls the patient trajectory of dying and death in the ED is ambiguous and highly variable. Society and community standards assume consent for full aggressive measures for sudden death.

Inattention to end-of-life care complicates grief and bereavement of the survivors, both family and staff, and contributes to caregiver (e.g., staff) distress which can lead to burnout (Badger, 2001; Parrish et al., 1987; Sundin-Huard & Fahy, 1999; Walters & Tupin, 1991). More importantly, however, inattention to end-of-life care reduces ED care to purely technical care without attending to the caring and healing practices that are central and primary to medicine and nursing. This divide perpetuates the sense of alienation, loss of social integration, and loss of self-understanding that accompany illness (Benner & Wrubel, 1989). By distancing themselves from the patient through technology, clinicians can disengage from the suffering and pain of the patient and family (Morse, Solberg, Neander, Bottorff, & Johnson, 1990). Attending solely to the technological aspects of care does not allow clinicians to bear witness to death as a human passage.

There is little research and literature describing end-of-life care in the emergency setting. ED specific characteristics and the nature of visits by patients to the ED do not always allow for attention to the various components of the end-of-life models presented. We know relatively little about what constitutes death and dying in the ED, end-of-life care in the ED, or the types of dying trajectories of patients in the ED. Additionally, future research studies need to be conducted to describe the clinical and ethical decision-making surrounding end-of-life, resolution of dying and resuscitative events, and investigate the perceived personal, cultural, environmental and clinical factors that influence the care of terminally ill or injured ED patients.

Figure 2.1

Continuum of Care

(Emanuel et al., 1999)

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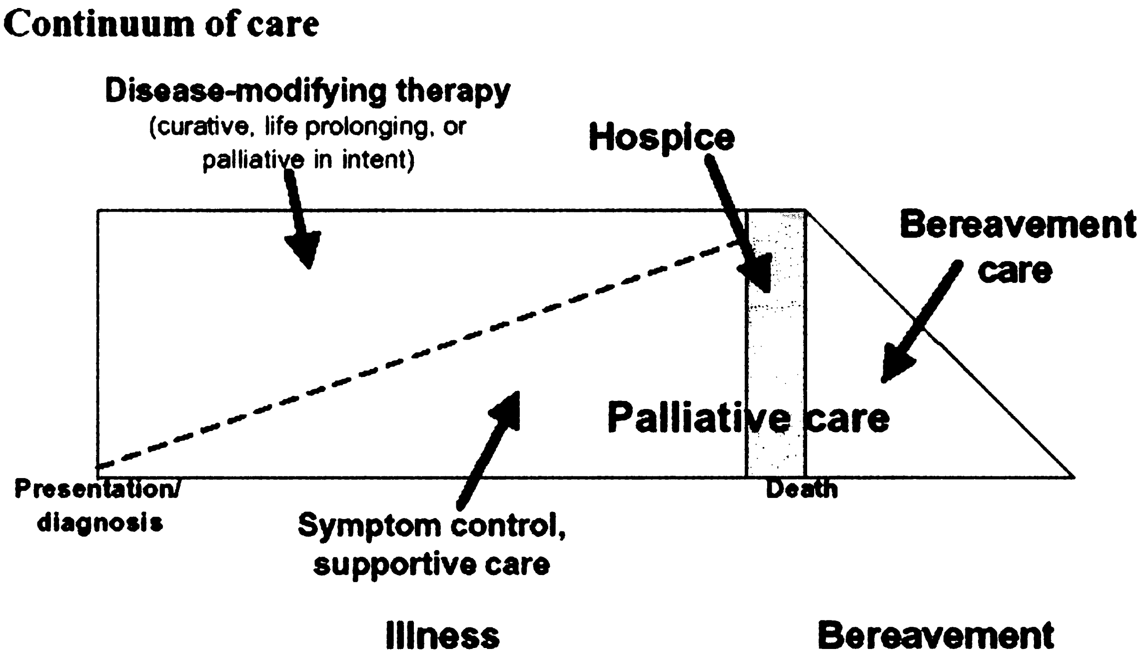

Figure 2.2

Mixed Management Model

(Field & Cassel, 1997)

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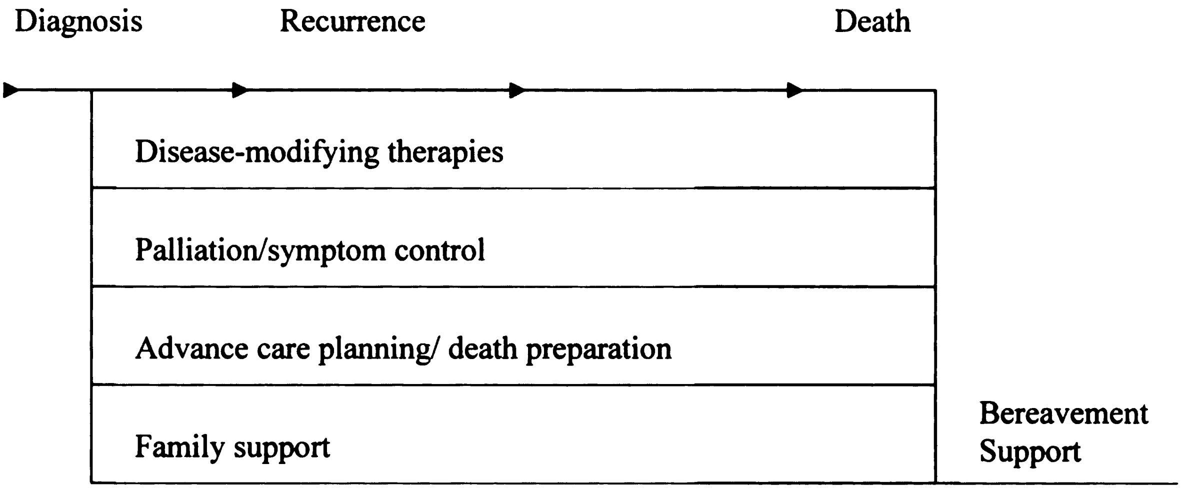

Figure 2.3

Prototypical Death Trajectories

(Field & Cassel, 1997)

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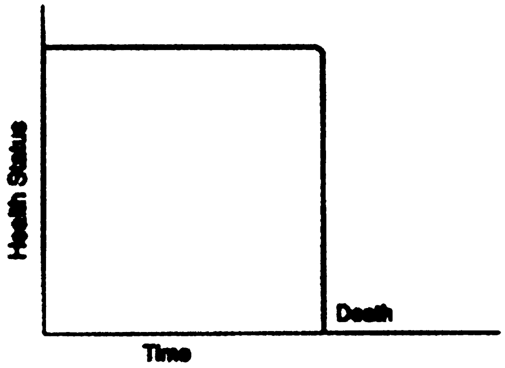
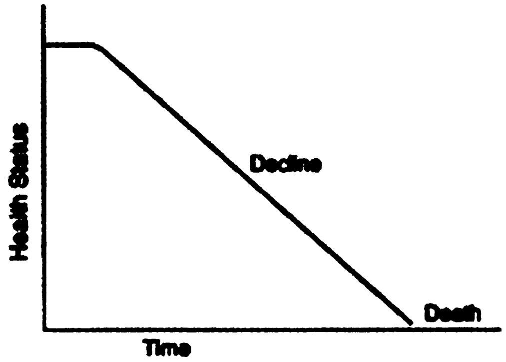
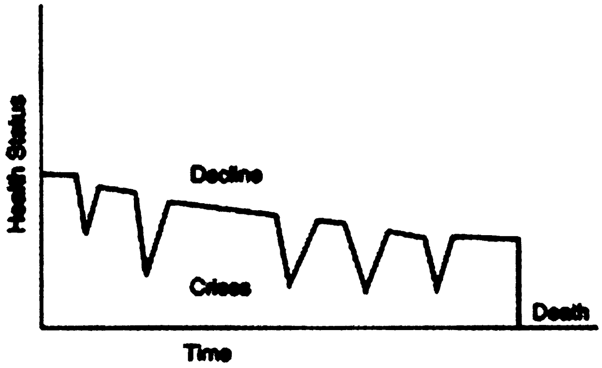
A. Sudden Death from an Unexpected Cause



B. Steady Decline from a Progressive Disease with a "Terminal" Phase



C. Advanced Illness Marked by Slow Decline with Periodic Crises and "Sudden" Death



CHAPTER TWO REFERENCES

American Association of Colleges of Nursing and City of Hope National Medical Center. (2000). The End-of-Life Nursing Education Consortium (ELNEC) Curriculum, *(Funded by the Robert Wood Johnson Foundation)*. Washington, DC: Author.

American Heart Association. (2000). *2001 Heart and Stroke Statistical Update*. Dallas, TX: American Heart Association.

Badger, J. M. (2001). Understanding secondary traumatic stress. *American Journal of Nursing, 101*(7), 26-32.

Benner, P. E., Hooper-Kyriakidis, P., & Stannard, D. (1999). *Clinical wisdom and interventions in critical care*. Philadelphia: W. B. Saunders Company.

Benner, P. E., & Wrubel, J. (1989). *The primacy of caring*. Menlo Park, CA: Addison-Wesley.

Billings, J. A. (2000). Recent advances: Palliative care. *BMJ, 321*, 555-558.

Blackhall, L. J. (1987). Must we always use CPR? *New England Journal of Medicine, 317*(20), 1281-1284.

Bracken, J. (2003). Triage. In L. Newberry (Ed.), *Sheehy's Emergency Nursing. Principles and practice.* (5th ed., pp. 75-83). St. Louis, MO: Mosby.

Buckman, R. (1984). Breaking bad news: Why is it so difficult? *BMJ, 288*, 1597-1599.

Caine, R. M., & Ter-Bagdasarian, L. (2003). Early identification and management of critical incident stress. *Critical Care Nurse, 23*(1), 59-65.

Coyle, N. (2001). Introduction to palliative nursing care. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 3-6). New York: Oxford University Press.

Day, L. (2001). How nurses shift from care of a brain-injured patient to maintenance of a brain-dead organ donor. *American Journal of Critical Care, 10*(5), 306-312.

Derlet, R. W., Richards, J. R., & Kravitz, R. L. (2001). Frequent overcrowding in U.S. emergency departments. *Academic Emergency Medicine, 8*(2), 151-155.

Diem, S. J., Lantos, J. D., & Tulsky, J. A. (1996). Cardiopulmonary resuscitation on television: Miracles and misinformation. *New England Journal of Medicine, 334*(24), 1578-1582.

Donaldson, N. (1998). Terminal fears and panic. *Accid Emerg Nurs, 6*(1), 41-42.

Eichhorn, D. J., Meyers, T. A., Guzzetta, C. E., Clark, A. P., Klein, J. D., & Taliaferro, E. (2001). Family presence during invasive procedures and resuscitation: Hearing the voice of the patient. *American Journal of Nursing, 101*(5), 48-55.

Emanuel, L., von Gunten, C., & Ferris, F. (Eds.). (1999). *The Education for Physicians on End-of-life Care (EPEC) Curriculum: © The EPEC Project*. Princeton, NJ: Robert Wood Johnson Foundation.

ENA. (1998). *Resuscitative decisions* [Position Statement]. Emergency Nurses Association. Retrieved May 1, 2003, from the World Wide Web: http://www.ena.org/about/position/resuscitativedecision.asp

ENA. (2000). *Forensic evidence collection* [Position Statement]. Emergency Nurses Association. Retrieved February 20, 2003, from the World Wide Web: http://www.ena.org/about/position/forensicevidence.asp

Fairman, J., & Lynaugh, J. (2000). *Critical care nursing: A history*. Philadelphia: University of Pennsylvania Press.

Ferrell, B., Grant, M., & Virani, R. (2001). Emergency nursing publications challenged to include end-of-life care content. *Journal of Emergency Nursing, 27*(5), 420-421.

Ferrell, B., Virani, R., & Grant, M. (1999). Analysis of end-of-life content in nursing textbooks. *Oncology Nurse Forum, 26*(5), 869-876.

Ferrell, B. R., & Coyle, N. (2002). An overview of palliative nursing care. *American Journal of Nursing, 102*(5), 26-32.

Ferrell, B. R., & Coyle, N. (Eds.). (2001). *Textbook of palliative care nursing*. New York: Oxford University Press.

Ferrell, B. R., & Grant, M. (Eds.). (2001). *End-of-Life Nursing Education Consortium (ELNEC) Curriculum. © The ELNEC Project.* Washington, DC: American Association of Colleges of Nursing.

Field, M. J., & Cassel, C. K. (1997). *Approaching death. Improving care at the end of life.* (0-309-06372-8). Washington, DC: Institute of Medicine.

Hackler, J. C., & Hiller, F. C. (1990). Family consent to orders not to resuscitate. *JAMA, 264*(10), 1281-1283.

Hanson, C., & Strawser, D. (1992). Family presence during cardiopulmonary resuscitation: Foote Hospital emergency department's nine-year perspective. *Journal of Emergency Nursing, 18*(2), 104-106.

Henderson, S. O., Chao, J. L., Green, D., Leinen, R., & Mallon, W. K. (1998). Organ procurement in an urban level I emergency department. *Annals of Emergency Medicine, 31*(4), 466-470.

Herlitz, J., Bång, A., Ekström, L., Aune, S., Lundström, G., Holmberg, S., Holmberg, M., & Lindqvist, J. (2000). A comparison between patients suffering in-hospital and out-of-hospital cardiac arrest in terms of treatment and outcome. *J Intern Med, 248*(1), 53-60.

Hott, C. (2002). Caring for the survivors. *Annals of Emergency Medicine, 39*, 570-572.

Howell, J. D. (1995). *Technology in the hospital. Transforming patient care in the early twentieth century*. Baltimore: Johns Hopkins University Press.

Iserson, K. V. (1996). Withholding and withdrawing medical treatment: an emergency medicine perspective. *Ann Emerg Med, 28*(1), 51-54.

Iserson, K. V., Sanders, A. B., & Mathieu, D. (1995). *Ethics in emergency medicine*. Tuscon, AZ: Galen Press.

Kercher, E. E. (1991). Crisis intervention in the emergency department. *Emergency Medical Clinics of North America, 9*(1), 219-232.

Kim, S. C., Kim, T. H., Jang, H. J., Ha, H. S., Hong, J. J., & Han, D. J. (2000). Potential organ donor pool for renal transplantation in the intensive care unit and emergency room. *Transplantation Proceedings, 32*, 1567-1568.

Kreidler, M. C., Zupancic, M. K., & Longo, M. B. (2000). Trauma and dissociation: Treatment perspectives. *Perspectives in Psychiatric Care, 36*(3), 77-85.

LeBrocq, P., Charles, A., Chan, T., & Buchanan, M. (2003). Establishing a bereavement program: Caring for bereaved families and staff in the emergency department. *Accident and Emergency Nursing, 11*, 85-90.

Lindholm, D. J., & Campbell, J. P. (1998). Predicting survival from out-of-hospital cardiac arrest. *Prehospital Disaster Med, 13*(2-4), 51-54.

Lynch, V. A. (1995). Clinical forensic nursing: A new perspective in the management of crime victims from trauma to trial. *Critical Care Nursing Clinics of North America, 7*(3), 489-507.

MacPhail, E. (1998). Overview of emergency nursing. In L. Newberry (Ed.), *Sheehy's Emergency Nursing: Principles and Practice* (4th ed., pp. 3-7). St. Louis, MO: Mosby.

Malone, R. E. (1995). *The almshouse revisited: Heavy users of emergency services.* Unpublished Unpublished Dissertation, University of San Francisco, San Francisco.

Malone, R. E. (2000). Dimensions of vulnerability in emergency nurses' narratives. *Advances in Nursing Science, 23*(1), 1-11.

Malone, R. E. (2003). Distal nursing. *Social Science & Medicine, 56*, 2317-2326.

Marco, C. A. (1999). Ethical issues of resuscitation. *Emerg Med Clin North Am, 17*(2), 527-538, xiii-xiv.

Matzo, M. L., & Sherman, D. W. (Eds.). (2001). *Palliative care nursing. Quality care to the end of life.* New York: Springer Publishing Company.

McCaig, L. F., & Ly, N. (2002). *National Hospital Ambulatory Medical Care Survey: 2000 Emergency Department Summary* (Advance data from vital and health statistics; no. 326). Hyattsville, MD: National Center for Health Statistics.

Meyers, T. A., Eichhorn, D. J., Guzzetta, C. E., Clark, A. P., Klein, J. D., Taliaferro, E., & Calvin, A. (2000). Family presence during invasive procedures and resuscitation. *American Journal of Nursing, 100*(2), 32-42.

Moller, D. W. (Ed.). (1990). *On death without dignity. The human impact of technological dying.* Amityville, New York: Baywood Publishing Company, Inc.

Morse, J. M., Solberg, S. M., Neander, W. L., Bottorff, J. L., & Johnson, J. L. (1990). Concepts of caring and caring as a concept. *Advances in Nursing Science, 13*(1), 1-14.

National Hospice Foundation. (2003). *What is hospice?* [Website]. National Hospice Foundation. Retrieved February 12, 2003, 2003, from the World Wide Web: http://www.hospiceinfo.org/index.cfm?webURL=/public/articles/index.cfm?cat=2

Olsen, J. C., Buenefe, M. L., & Falco, W. D. (1998). Death in the emergency department. *Annals of Emergency Medicine, 31*(6), 758-765.

Parrish, G. A., Holdren, K. S., Skiendzielewski, J. J., & Lumpkin, O. A. (1987). Emergency department experience with sudden death: a survey of survivors. *Annals of Emergency Medicine, 16*(7), 792-796.

Quint, J. C. (1967). *The nurse and the dying patient* (1st ed.). New York: The Macmillan Company.

Rabow, M. W., Hardie, G. E., Fair, J. M., & McPhee, S. J. (2000). End-of-life care content in 50 textbooks from multiple specialties. *JAMA, 283*(6), 771-778.

Roark, D. C. (2000). Overhauling the organ donation system. *American Journal of Nursing, 100*(6), 44-48.

Rushton, C. H., Williams, M. A., & Sabatier, K. H. (2002). The integration of palliative care and critical care: One vision, one voice. *Critical Care Nursing Clinics of North America, 14*, 133-140.

Sandelowski, M. (2000). *Devices & desires. Gender, technology, and American nursing.* Chapel Hill, NC: The University of North Carolina Press.

Sanders, A. B. (1995). Unique aspects of ethics in emergency medicine. In K. V. Iserson & A. B. Sanders & D. Mathieu (Eds.), *Ethics in Emergency Medicine* (2nd ed., pp. 7-10). Tuscon, AZ: Galen Press, Ltd.

Schmidt, T. A., & Tolle, S. W. (1990). Emergency physicians' responses to families following patient death. *Annals of Emergency Medicine, 19*, 125-128.

Smeenk, F. W., de Witte, L. P., van Haastregt, J. C., Schipper, R. M., Biezemans, H. P., & Crebolder, H. F. (1998). Transmural care. A new approach in the care for terminal cancer patients: its effects on re-hospitalization and quality of life. *Patient Educ Couns, 35*(3), 189-199.

Spaite, D. W., Bartholomeaux, F., Guisto, J., Lindberg, E., Hull, B., Eyherabide, A., Lanyon, S., Criss, E. A., Valenzuela, T. D., & Conroy, C. (2002). Rapid process redesign in a university-based emergency department: Decreasing wait time intervals and improving patient satisfaction. *Annals of Emergency Medicine, 39*(2), 168-177.

Spearpoint, K. G., McLean, C. P., & Zideman, D. A. (2000). Early defibrillation and the chain of survival in 'in-hospital' adult cardiac arrest; minutes count. *Resuscitation, 44*(3), 165-169.

Sundin-Huard, D., & Fahy, K. (1999). Moral distress, advocacy and burnout: Theorising the relationships. *International Journal of Nursing Practice, 5*, 8-13.

SUPPORT Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [see comments] [published erratum appears in JAMA 1996 Apr 24;275(16):1232]. *Jama, 274*(20), 1591-1598.

Swisher, L. A., Nieman, L. Z., Nilsen, G. J., & Spivey, W. H. (1993). Death notification in the emergency department: A survey of residents and attending physicians. *Annals of Emergency Medicine, 22*(8), 1319-1323.

Task Force on Palliative Care. (1997). *Precepts of Palliative Care*. Last Acts. Retrieved March 19, 2003, from the World Wide Web: http://www.lastacts.org/docs/profprecepts.pdf

Taylor, J. P., & Taylor, J. E. (1998). Emergency nursing process and nursing diagnosis. In L. Newberry (Ed.), *Sheehy's Emergency Nursing: Principles and Practice* (4th ed., pp. 9-15). St. Louis, MO: Mosby.

Timmermans, S. (1997). High touch in high tech: The presence of relatives and friends during resuscitative efforts. *Scholarly Inquiry for Nursing Practice: An International Journal, 11*(2), 153-167.

Timmermans, S. (1999). *Sudden death and the myth of CPR*. Philadelphia: Temple University Press.

Urwin, K. (1989). *Langenscheidt's compact French dictionary*. New York: Langenscheidt.

Vachon, M. L. S. (2001). The nurse's role: The world of palliative care nursing. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 647-662). New York: Oxford University Press.

Velianoff, G. (2001). Staffing standards benchmarking. *Journal of Emergency Nursing, 27*(2), 181.

von Wormer, K., & Boes, M. (1997). Humor in the emergency room: A social work perspective. *Health and Social Work, 22*(2), 87-93.

Walsh, M., & Dolan, B. (1999). Emergency nurses and their perceptions of caring. *Emergency Nurse, 7*(4), 24-31.

Walsh, M., Dolan, B., & Lewis, A. (1998). Burnout and stress among A&E nurses. *Emergency Nurse, 6*(2), 23-29.

Walters, D. T., & Tupin, J. P. (1991). Family grief in the emergency department. *Emergency Medical Clinics of North America, 9*, 189-207.

Williams, A. G., O'Brien, D. L., Laughton, K. J., & Jelinek, G. A. (2000). Improving services to bereaved relatives in the emergency department: Making healthcare more human. *Medical Journal of Australia, 173*, 480-483.

World Health Organization. (1990). *Cancer pain relief and palliative care*. Geneva, Switzerland: Author.

CHAPTER THREE

Philosophical Investigation

Understanding end-of-life caring practices in the emergency department: developing Merleau-Ponty's notions of *intentional arc* and *maximum grip* through praxis and phronesis

Abstract

The emergency department (ED) is a fast-paced, high stress environment where clinicians function with little or sub-optimal information and where time is measured in minutes and hours. In addition, death and dying are phenomena that are often experienced in the ED. Current end-of-life care models, based on chronic illness trajectories, may be difficult to apply in the ED. A philosophical approach examining end-of-life care may help us understand how core medical and nursing values are embodied as care practices and as ethical comportment. The integration of Aristotle's notions of phronesis and praxis with Merleau-Ponty's ontological notions of *intentional arc* and *maximum grip* in the context of the culture and practices of the ED offers a unique view of clinical and ethical practice at the end-of-life in the emergency setting. Caring for people at the end-of-life calls us to act virtuously based on previous experience, meanings, and local practices. The maximum grip of the ultimate particulars of the situation combined with one's experiential and theoretical knowledge opens up situated possibilities for the expert clinician.

Key words: end-of-life; emergency department care; phenomenology; ethics; phronesis; praxis; Merleau-Ponty

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Introduction

The emergency department (ED) is a fast-paced environment where patients present suddenly and unpredictably with life-threatening illnesses or injuries, and clinicians function with sub-optimal levels of information (Chan, 2004; Iserson, 1996). Despite heroic efforts, many people die in the ED (McCaig and Ly, 2002). Current end-of-life care models proposed by national educational initiatives (Emanuel et al., 1999; Ferrell and Grant, 2001) and the Institute of Medicine (IOM) (Field and Cassel, 1997) are based on chronic illness trajectories of dying that may be difficult to apply to ED end-of-life caring practices (Chan, 2004).

Care of the patient and family at the end-of-life has been identified by both the American Nurses Association (ANA) and the American Medical Association (AMA) as an important core value in their respective professions (American Nurses Association, 2001; American Medical Association's Council on Scientific Affairs, 1996; American Medical Association, 2002). In addition, attention to end-of-life issues continues to be a national priority for research and funding according to the IOM and the National Institutes of Health (NIH)(Adams and Corrigan, 2003; National Institute of Nursing Research, 2004). Poor end-of-life care is an issue for American society that must be improved (Lunney et al., 2003a).

Previous studies have focused on the epidemiology of death, provision of or lack of end-of-life care in the intensive care unit, descriptions of palliative care (e.g., symptom management, advance care planning, spiritual care), and the experience of clinicians' moral distress when caring for patients who are dying (Corley, 1995; Lunney et al., 2003b; SUPPORT Investigators, 1995; Timmermans, 1999). In critical care, national research priorities are focused on identifying and measuring processes, quality, and outcomes of end-of-life care (Clarke et al., 2003; Rubenfeld and Randall, 2001). However, reducing and testing these empirical indicators of the construct of "good end-of-life care" requires that scientists continue down an epistemological path that ignores the ontological and complex life worlds of human actions, caring, and concerns.

End-of-life scholars have spent less time talking about how philosophy could help interpret care at the end-of-life. A philosophical approach may help us understand how core medical and nursing values are embodied as care practices and as ethical comportment. The goal of this paper is to explore Merleau-Ponty's notions of the *intentional arc* and *maximum grip* as a source of influence on praxis and phronesis in embodied emergency department end-of-life care practices. First, however, an orientation to the ontological notions of what it is to be a clinician will be presented followed by a description of Merleau-Ponty's two concepts. A case exemplar will be used to illustrate different aspects and perceptions of the same phenomenon.

Philosophical Notions on What It Is to Be a Clinician

There are many philosophical notions that underlie one's understanding of what it is to be a person and a clinician that have been described by philosophers such as Martin Heidegger, Herbert Dreyfus, Charles Taylor, Patricia Benner, and Judith Wrubel. In examining these phenomenological philosophical notions, one can understand how they intertwine and support one's assumptions about being, knowing, knowledge and practice.

Praxis, Phronesis, and Embodiment

The notions of *praxis* and *phronesis* were first described by Aristotle. The Aristotelian scholar, Joseph Dunne elucidates praxis as the

> conduct in a public space with others, in which a person, without ulterior purpose and with a view to no object detachable from himself, acts in such a way as to realize excellences that he has come to appreciate in his community as constitutive of a worthwhile way of life.... [Praxis is] an activity that both involved one with other people and at the same time was a realization of one's self, praxis engaged one more intimately, or afforded one less detachment (Dunne, 1997, p. 10).

Praxis is the activity that is publicly intelligible and is held in common with other practitioners. There are singular universals and commonalities that are understood by other practitioners such as, "assess and treat Airway, Breathing, and Circulation first," and "Give the patient as much autonomous choice as possible based on one's cultural beliefs." The practitioner is engaged in the activity, is *unreflective* about the praxis (i.e., it is without rational calculation), and actualizes notions of good practice that are held by local and larger groups of professional practitioners (Benner, 2000). Praxis is not a private, idiosyncratic, or subjective habit where the only person to comprehend the practice is the practitioner him or herself.

While praxis or a practice is the public conduct, the person embodies a knowledge that is socially embedded in a practice that is gained through experience. Aristotle called this type of knowledge phronesis (Dunne, 1997). The clinician caring for a patient is involved in a practice. This practice is influenced by his or her moral agency, experiential or practical knowledge, perceptiveness to the particulars of a situation, and skillful comportment. Understanding the end-of-life experiences in the ED requires an appreciation for clinicians' actions or practices (praxis), and their embodied knowledge (phronesis).

The notion of embodiment, based on the works of philosophers such as Heidegger (1927/1962), Merleau-Ponty (1945/2001), Dreyfus (1991), Benner and Wrubel (1989) and Benner (2000) is central to a phenomenological view of what it is to be a person. These philosophers counter the Cartesian and Kantian representations of a mind-body dualism, that include mental representations and the notion that a person sits over and against a world of which he or she is not a part. In contrast, the notion of embodiment is a "social, sentient sensori-motor embodied person [who] dwells in a human world of relationships, concerns, and [common] meanings" (Benner, 2000, p. 6).

Contrary to the Cartesian notion of indubitable knowledge generated from rational calculations, Benner (2000) has described a type of certainty that clinicians develop from experiential knowledge. Development of qualitative distinctions in particular cases and the development of perceptual acuity through contrasting whole cases from past experience open possibilities and understandings of the patient for the clinician. Skillful clinicians who have experienced caring for dying patients use their senses to perceive and understand the real lifeworld of the person for whom they are caring. This understanding of the patient's real lifeworld with all of the events, consequences, and relationships by a phronetic clinician is a form of embodied realism. In other words, a sensing, embodied knower can apprehend and know the world of the patient (Benner, 2000). However, Benner also notes that phronetic knowledge is dialogical with experience and is always open to correction and improvement.

Experience, Virtue, and Ethical Comportment

Gadamer (1960/1989) has described experience as perceptions of a person that are open and dialectical with new experiences that may negate previous experiences. These experiences are not an end, or *telos*, but rather a process that is grounded in the history of the person. Experiences, or perceptions, constitute phronesis that are neither fully transparent nor fully available to the person (Dunne, 1997).

The relationship between experience and phronesis is dynamic. It is a continual refining process that shapes and influences one's lifeworld and experiences from which we draw or evolve one's knowledge and skill. Insights are gleaned from past experiences that enrich one's skilled know how and theoretical knowledge (Dreyfus et al., 1996). Over time, this continual dialogue between experience and knowledge develops expertise in the practice. This is illustrated by Dunne:

> Now when a person is experienced we might say that the virtue through which he or she exploits that experience or puts what has been learned from it to work – and in the process learns more and so further develops and refines his or her experience – is phronesis. Phronesis is what enables experience to be self-correcting and to avoid settling into mere routine or universalizing... Phronesis does not ascend to a level of abstraction or generality that leaves experience behind. It arises from experience and returns into experience. It is, we might say, the insightfulness – or using Aristotle's own metaphor, "the eye" – of a particular type of experience, and the insights it achieves are turned back into experience, which is in this way constantly reconstructed or enriched. And the more experience is reconstructed in this way, the more sensitive and insightful phronesis becomes – or, rather, the more the experiencer becomes a *phronimos* (Dunne, 1997, p. 292-293).

Virtue is central to phronesis. According to Dunne (1997), the virtue of a person is developed, often painstakingly, by experiential knowledge. Virtue is understood to be an embodied comportment that is unreflective and egoless (i.e., free of mental content) rather than as a possession (Dreyfus, Dreyfus & Benner, 1996). In other words, the world

and situation that is socially and experientially constituted solicits or calls to the person to act in a way that is meaningful and good rather than virtues being possessed by a person who will apply these good virtues to a situation and therefore the outcome is good.

The virtuous character and lifeworld are inextricably linked and reciprocal. Being a part of one's lifeworld affords us experiences that belong to one's lifeworld. Through experiencing different situations in one's lifeworld, we acquire and enrich phronesis. This knowledge-skill acquisition is an important part of phronesis. "[Phronesis] is natural…not innate but rather what is acquired by experience…" (Dunne, 1997, p. 279).

However, knowledge, virtue, and skill are iterative or circular. Background meanings, practices, skills and habits are learned by living in and moving around in a world with shared traditions and knowledge. While some skills and practices are taught through theoretical or predictive models, clinicians encounter situations that do not fit these context-free theories. A clinician who is connected and involved responds to each unique situation with experience-based intuition as a guide for ethical comportment (Dreyfus, Dreyfus & Benner, 1996). As the clinician acts in the situation, the experiential knowledge informs current and future action yet avoids routinization and universalization. Experiential knowledge changes one's interpretation and proto-interpretation of the world (Taylor, 1985). Dreyfus, Dreyfus and Benner (1996) summarize this concept in the following quote:

> When an individual becomes a master of his culture's practices or a professional practice within it, he or she no longer tries to do what one normally does, but rather responds out of a fund of experience in the culture and in the specialized practice. This requires having enough experience to give up following the rules and maxims dictating what anyone should do, and instead, acting upon the intuition that results from a life in which talent and sensibility have allowed learning from the experience of satisfaction and regret in similar situations. Authentic caring in this sense is common to … Aristotelian phronesis. (p. 274)

Aristotle advocates that "we ought to attend to the undemonstrated sayings and opinions of experienced and wise older people or of *phronimoi* not less than to demonstrations; for because experience has given them an eye they see aright" (Aristotle, as cited by Dunne, 1997, p. 280). The *phronimoi* have encountered a multitude of experiences that allows them to develop virtues and phronesis associated with practice.

Perception and 'Ultimate Particulars'

While experience and phronesis are so closely intertwined, it is important to discuss the influence that intuition or perceptiveness (*nous*) and the "ultimate particulars" (*eschaton*) have on phronesis (Dunne, 1997). It is these ultimate particulars of similar yet distinct experiences that round out the knowledge in different ways, leading to a more robust understanding of the world. As mentioned above, the relationship between experience and knowledge is dynamic. Repeated exposures to similar experiences allow for the recognition of resemblances, similarities but also the qualitative distinctions, nuanced differences, particularities, and patterns to show up for the practitioner (Benner et al., 1996; Benner et al., 1999). Expertise is cultivated. In order for phronesis to develop, one needs to be open to these insights in the particulars of the experiences and intuit (or be attentive to) the differences before they become incorporated into a habitus or sedimented pattern of experience (Dunne, 1997; Merleau-Ponty, 1945/2001).

Skillful Comportment, Style, and Situated Freedom

In practice, action is pervasive. Phronesis is constituted by experiential knowledge that influences one's embodied comportment and is pre-cognitive and nonrational. Benner, Hooper-Kyriakidis, and Stannard (1999) describe this embodied

way of knowing as "thinking-in-action" and "skilled know-how" (p. 12-13). Skilled know-how is the skillful performance of expert, embodied clinicians in clinical situations. Thinking-in-action is the practical reasoning that moves the skilled, embodied clinician to a "clearer understanding and resolves contradiction or confusion" (Benner et al., 1999, p. 10). The skilled clinical know-how combined with clinical wisdom and good judgment is more apparent in expert clinicians in crisis situations when there are life-threatening events (Benner et al., 1999).

In skill acquisition, Benner and colleagues (1999) describe two skillful comportments that are central to clinical wisdom: clinical forethought and clinical grasp. However, before one can understand clinical grasp and clinical forethought, one must examine the notion of wisdom.

According to Meacham (1990) and Weick (2001), wisdom is a delicate balance of what is known, what is not known, the realization that the knowledge is fallible, and doubt. As Meacham so eloquently writes,

> [T]he essence of wisdom...lies not in what is known but rather in the manner in which that knowledge is held and in how that knowledge is put to use. To be wise is not to know particular facts but to know without excessive confidence or excessive cautiousness.... [T]o both accumulate knowledge while remaining suspicious of it, and recognizing that much remains unknown is to be wise....The essence of wisdom is in knowing that one does not know, in the appreciation that knowledge is fallible, [and] in the balance between knowing and doubting. (1990, pp 185, 184, 210)

Meacham's definition of wisdom acknowledges that a wise person has knowledge and continually critiques and refines the knowledge all the while recognizing that the knowledge could be wrong. This understanding of wisdom allows for the practitioner to anticipate that the knowledge is a blend of what has been known, presumed and coherent in the past with the possibility that in the present, sudden discoveries of difference,

uncertainty or the unexpected might challenge the assumptive set (i.e., preconceptions) (Benner et al., 1999; Merleau-Ponty, 1945/2001).

Another aspect in understanding wisdom that is important to note is that one understands events and actions retrospectively while one lives life and act in the present and move forward (Weick, 1999). The philosopher Kierkegaard commented, "It is perfectly true, as philosophers say, that life must be understood backwards" (Kierkegaard, 1843/1967). However, Gardiner offers an insightful addition, "but they [philosophers] forget the other proposition, that it [life] must be lived forwards" (as cited by Weick, 1999, p. 134). Interpretation, justification, and meaning are attached after the action has been completed.

A skillful, embodied practitioner draws upon past experiential knowledge and the requisite theoretical knowledge and uses his or her perceptual skill to get a good grasp of the clinical situation (Benner et al., 1999). A wise, expert clinician is attuned to the clinical situation and uses perceptual skill to detect when the patient's condition is changing or not responding as expected. This expert, reflective clinician is capable of improvising and adapting interventions in the present situation based on the experiential and theoretical knowledge of the past.

Expert clinicians are able to anticipate likely clinical events based on previous experiential and theoretical knowledge. Benner and colleagues (1999) describe the combination of thinking-in-action with anticipation as clinical forethought. Clinical forethought is shaped by the clinical grasp of the phronetic practitioner and is derived from the nuanced particulars of the situation. In expert practice,

> [C]linical forethought is crucial to recognition of early changes in the patient, because it prepares the nurse to 'see' or recognize what is likely to transpire, and

> to act based on these early changes. The most effective clinical forethought is based on both scientific understanding and experiential learning of clinical trajectories (Benner et al., 1999, p. 65).

In addition, clinical forethought allows for the possibility that expectations can be confirmed or disconfirmed based on the perception of the skilled clinician.

Merleau-Ponty (1945/2001) has described the relationship between an individual's history and psychological structure having an influence on a person's "style." This style allows people to open up possibilities but it also limits the individual from seeing things in other ways that do not fit into the style or routine.

> All explanations of my conduct in terms of my past, my temperament and my environment are therefore true, provided that they be regarded not as separable contributions, but as moments of my total being, the significance of which I am entitled to make explicit in various ways, without its ever being possible to say whether I confer their meaning upon them or receive it from them. I am a psychological and historical structure, and have received, with existence, a manner of existing, a style. All my actions and thoughts stand in a relationship to this structure.... The fact remains that I am free, not in spite of, or on the hither side of, these motivations, but by means of them. (Merleau-Ponty, 1945/2001, p. 455)

In the quotation above, Merleau-Ponty also describes the notion of *situated freedom*, or the freedom to act based on one's shared and mutually accessible perceptions of the world and based on one's own culture, background, language, meanings, perspectives and sets of habits (Benner and Wrubel, 1989; Taylor, 1979). Benner and Wrubel (1989) contrast situated freedom from the notion of *radical freedom* where by people can "choose all their meanings all the time" (p. 54). From within situated freedom, situated possibilities open up for people and these situated possibilities are shaped by those meanings, perspectives, personal concerns and local practices of the profession.

Merleau-Ponty's Intentional Arc and Maximum Grip

According to Dreyfus and Dreyfus (1999), there are two concepts that are rarely discussed in Merleau-Ponty's Phenomenology of Perception (1945/2001): the *intentional arc* and the notion of *maximum grip*. These two concepts are central to perception, skill acquisition and comportment.

Intentional arc

Merleau-Ponty describes how the relationship between an involved, embodied being perceives and copes with objects and situations in the world as an *intentional arc* (1945/2001, p. 136). Dreyfus and Dreyfus (1999) describe the intentional arc as

> the tight connection between the agent and the world, viz. that, as the agent acquires skills, these skills are "stored", not as representations in the mind, but as more and more refined dispositions to respond to the solicitations of more and more refined perceptions of the current situation.

The intentional arc is the embodiment of the interconnection of skillful action and perception, and there are three ways one's embodied skills determine the way things show up for us and therefore calls us to act in certain ways: innate structures, general acquired skills for coping, and specific cultural skills (Dreyfus and Dreyfus, 1999).

The innate structures of one's body and one's own abilities help shape the possibilities for action. For example, *where* the mountains are passable or not passable is a function of one's climbing ability and not based on one's intention to pass through the mountains. One's embodied skills of going through a mountain pass are possible by the innate structures and capacities of the human body of whether one can ambulate or must use a wheelchair.

General acquired skills for coping are refined by the situations and things to which one is exposed. Situations and things show up as soliciting skillful responses as one encounters them more and more. However, situations and things cannot solicit these general acquired skills without being grounded in a cultural world that affords a context. For example, a family member who has never had an experience seeing or working with a cardiac monitor will not know what action needs to be taken if the alarms start ringing other than calling for the nurse.

The involved, embodied agent immediately sees a situation or an object from a perspective, and those situations or objects afford some action. One's skills are refined through experiential learning that can include trial and error attempts, by imitation, or through application of theoretical knowledge. The intentional arc feedback loop of the embodied agent and the perceptual world calls for responding and refining perceptions of the current situation.

Maximum grip

The concept of maximum grip is not explicitly described by Merleau-Ponty in Phenomenology of Perception but rather is an interwoven concept with distinct allusions to the notion of attaining an optimal gestalt in situations and with objects. Dreyfus and Dreyfus (1999) organized and explicated this Merleau-Pontian notion and called the concept *maximum grip*. Maximum grip is "the body's tendency to respond to these solicitations in such a way as to bring the current situation closer to the agent's sense of an optimal gestalt" (Dreyfus and Dreyfus, 1999). The following three passages from Phenomenology of Perception illustrate the concept of maximum grip.

Human beings are always tending towards getting a maximum grip on their situation or perceiving an object. Merleau-Ponty described this ability to experience the detail of an object in the following quotation where he describes how the tensions around the object fluctuate and when the tensions are minimized or solved, the details of the object comes into focus.

He offers the following example:

> For each object, as for each picture in an art gallery, there is an optimum distance from which it requires to be seen, a direction viewed from which it vouchsafes most of itself: at a shorter or greater distance we have merely a perception blurred through excess or deficiency. We therefore tend towards the maximum of visibility, and seek a better focus as with a microscope.... The living body itself appears when its microstructure is neither excessively nor insufficiently visible, and this moment equally determines its real size and shape. The distance from me to the object is not a size with increases or decreases, but a tension which fluctuates around a norm....There is one culminating point of my perception which simultaneously satisfies these...norms, and towards which the whole perceptual process tends (p. 302-303).

From this fluctuation around a norm, the embodied agent seeks to reduce the "tension" of the deviation from the norm and move towards equilibrium. This new equilibrium potentially opens up new possibilities or ways of perceiving the situation or object.

> Whether a system of motor or perceptual powers, our body is not an object for an 'I think', it is a grouping of lived-through meanings which moves towards its equilibrium. Sometimes a new cluster of meanings is formed; our former movements are integrated into a fresh motor entity, the first visual data into a fresh sensory entity, our natural powers suddenly come together in a richer meaning, which hitherto has been merely foreshadowed in our perceptual or practical field, and which has made itself felt in our experience by no more than a certain lack, and which by its coming suddenly reshuffles the elements of our equilibrium and fulfils our blind expectation (p. 153).

Maximum grip, however, is not attained through some cognitive process but rather is an embodied perception of a given object or situation at any given moment.

> The constitution of a spatial level is simply one means of constituting an integrated world: my body is geared onto the world when my perception presents me with a spectacle as varied and as clearly articulated as possible, and when my motor intentions, as they unfold, receive the responses they expect from the world. This maximum sharpness of perception and action points clearly to a perceptual *ground*, a basis of my life, a general setting in which my body can co-exist with the world. (Merleau-Ponty, 1945/2001, p. 250)

In the quotation above, Merleau-Ponty suggests that maximum grip is dependent on one's perceptual ground which forms the background of one's world. He writes that one organizes the field through one's maximum grip and it seems to be a reciprocal or co-produced process. This field is one's background from which one notices or overlook things or events and therefore can make choices, navigate and understand the world.

Maximum grip is fluid and is always being refined and influenced by new perceptions, understandings, and experiences. It is not an ultimate, static endpoint. One can sense if one is getting closer or further away from the optimum (Dreyfus and Dreyfus, 1999). Involved, skillful coping is a steady flow of skillful activity in response to one's sense of equilibrium or disequilibrium of the situation and is dependent on what skills have already been acquired through previous experiences (Dreyfus and Dreyfus, 1999).

Merleau-Ponty (1945/2001) describes several levels of one's background: A general background, cultural background, and an individual background. According to him, everything happens on a background such as making choices and co-producing one's world from the natural world. One's world both constitutes us and is constituted by the person. One is thrown into a particular life world complete with background meanings and practices that are shaped by one's concerns, relationships, culture, language, and practices. Through one's lived experiences and the history developed

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According to Dreyfus and Dreyfus (1999), the intentional arc is enriched and refined through the body's tendency towards maximum grip. To improve one's skills, one must be involved with situations and get a lot of practice.

Case Exemplar

Mrs. Gonzales (all names are pseudonyms) is a 68 year-old Hispanic, Spanish-speaking woman who came into our ED with severe shortness of breath secondary to widespread metastatic cancer. Fortunately, the physician, a respiratory therapist and I spoke Spanish almost fluently. Mrs. Gonzales had very little hair and the hair that she had was very brittle and sparse. She had a drawn, tight look about her face and body and her color was ashen. Her skin was paper-thin and hung loosely on her body. She had a smell of old urine and an unwashed body. Her oxygen saturation ranged from 82 to 90% on 15 liters per minute oxygen via non-rebreather mask. She told us that she had cancer of the ovaries, uterine, and breast for about 10 years and had undergone multiple cycles of radiation and chemotherapy. She stated that she finished her last round of chemotherapy about four months previously. Mrs. Gonzales decided that she did not want any more chemotherapy, nor did she want to continue to live. Her wishes were to die at home and she stated that her family activated the Emergency Medical Service against her wishes. We concluded based on the answers she provided to our questions and her following commands appropriately, she appeared to understand what was happening to her. We explained some of the options such as pain management and anxiolytics that would be available to her in terms that she would be able to understand. She repeated that she did not want to live and she was ready to die.

Then Mrs. Gonzales' family arrived. The large extended family consisted of her husband, eight children, and six grandchildren as well as friends who arrived to our ED in small groups. Her husband and four of her children met with our physician and told us to do everything that we could to save their loved one. The family members said that the

oncologist told them that everything would be fine, and that the oncologist never led them to believe that she was not doing well.

While the physician was meeting with the family outside of the room, Mrs. Gonzales became asystolic. Two other nurses, two respiratory therapists and I just stood there, wondering what we should do. Could we trust her judgment when she was so hypoxic? We decided to intubate and start cardiopulmonary resuscitation (CPR) while the physician came back in the room; however, everyone was moving at a slow pace. We gave her the minimal amount of epinephrine by Advanced Cardiac Life Support standards and it had no effect. I slowly gave her another round of epinephrine and her heart started beating again with a pulse. I felt terrible because I felt we were going against her wishes. The physician went out to speak with the family to explain that her heart stopped beating and what the family wanted to do if that happened again. They continued to say that they wanted "everything" done for her. She arrested again and we started chest compressions at a slow rate but gave no medications. I decided to have the family come in the room to show them what "everything" meant. Once they saw the ventilator and the ED staff perform chest compressions, what CPR really entailed, they told us to stop the code.

Once the physician announced the time of death, I asked the family if they wanted to sit and be with her. As I lowered the gurney side rails down, I encouraged those family members who wanted to touch or hold Mrs. Gonzales to do so. I brought the family members coffee, water and facial tissue. I turned down the lights to the room and brought chairs in for the family members to sit. Fortunately, there were few other patients in the ED so there was time and room to allow the family to stay as long as they wished. The family members stayed with Mrs. Gonzales for about 3 hours and then they left the ED. The husband and one of the daughters of Mrs. Gonzales thanked me for letting them have that time with their wife/mother. As they left, I told them how sorry I was for their loss. They thanked me for trying to help their wife/mother. I never saw them again.

Intentional Arc, Maximum Grip and Praxis/Phronesis in the ED

In everyday practice, ED clinicians encounter dying people and death. The skills and habits of caring for people near the end-of-life become incorporated into the clinician's body through lived-through experiences. When a dying person or a person who is dead but receiving resuscitative efforts comes to the hospital, ED clinicians perceive that the person is dying. Through multiple encounters with people dying in the ED, the ED clinicians develop an anticipation or are set to cope with the person at the end of their life often sooner than the person or person's family. According to the Centers for Disease oncologist told them that everything would be fine, and that the oncologist never led them to believe that she was not doing well.

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Control, approximately 374,000 people died in EDs throughout the United States in the year 2000 (McCaig and Ly, 2002). Through this repeated exposure to a background in which death occurs, little by little ED clinicians incorporate death and caring for dying people as being part of their background.

The emergency department is one world that clinicians join and share with each other. On a cultural level, ED clinicians share experiences and therefore develop local background meanings, practices and expectations. The ED is a micro culture that exists within clinicians' other worlds with both loose and demarcated boundaries between those worlds. ED clinicians have a sense of time, perceptions of illness and dying, and promises of technology shaped by their background experiences, habits and practices. Merleau-Ponty (1945/2001) elucidated this "link" between one's perception and the incorporation of one's skillful, sentient bodies into one's "perceptual field" or background.

While there is technical knowledge of resuscitation (e.g., chest compressions, intubation and ventilation, vasopressor administration), the skillful comportment and character of the clinicians is to apply the knowledge while being attentive to the particulars of the situation (e.g., success rates of cardiopulmonary resuscitation in terminally ill cancer patients, wishes of the patient, family wishes and desires) that allows a situation to "unconceal its own particular significance" (Dunne, 1997, p. 306).

Patients and families who come to the ED also come with their backgrounds that are shaped by their own lifeworlds and lived experiences. The patients and families may or may not be familiar with the ED micro culture; or, if they are familiar with the ED culture, they have different perceptions of illness, death and dying, and promises of

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Patients and families who come to the ED also come with their backgrounds that are shaped by their own lifeworlds and lived experiences. The patients and families may or may not be familiar with the ED micro culture; or, if they are familiar with the ED culture, they have different perceptions of illness, death and dying, and promises of biomedicine. This can also happen when patients or family members are healthcare professionals. There are local practices and knowledge that are specific to the ED culture that are not shared by other specialties in medicine and nursing. These lived experiences influence the intentional arc of the patient and family.

Chan (2004) describes the ED as a place of transition. It is a fast-paced, highly stressful environment where patients stay for a short period of time and are either discharged home or transferred to an impatient unit. ED clinicians may function with sub-optimal levels of information. These ED cultural characteristics open certain possibilities and close down others (Benner et al., 1999). For example, technological care and attempts at reviving and stabilizing patients for transfer to an inpatient unit takes priority over caring and healing practices that bear witness to death and dying as the closing of a human life (Chan, 2004).

Kaufman (2002) notes that health providers' and even the healthcare institution's perspectives on the care of a dying patient can come into conflict with a family's perspective on what is possible, or even what is hoped for a particular patient. She gives an example of a healthcare team taking care of a patient whom they understand is dying yet the family is convinced that the patient will be sustained by medical technologies. The family hopes that the organ-system failure will be reversed by these technologies. Therefore, the family refuses to withdraw any treatments. In her research, Kaufman (2002) discovered that while healthcare professionals have their own understandings about good dying practices in the hospital setting, families are "preoccupied not with good dying, but with other concerns, especially their hopes for the patient's recovery, their long-standing relationship with the patient, and their sense of overwhelming responsibility for critical decision making" (p. 36). However, in another scenario, Kaufman (1998) describes examples in the intensive care unit where healthcare professionals employ aggressive treatment techniques and focus on biological indicators of life in an attempt to stave off the inevitable death. In these cases, the human being lying in the bed is ignored, and there is no attempt to attend to the closing of a person's life.

Shared practices and meanings of the biomedical culture may be taken up differently when the dying experience is actually lived (as in the case of the patient or family with a dying member) or is imagined (as in the case of healthcare professionals). Halpern (2001) describes clinical empathy as the ability of a clinician to resonate emotionally with patients and for the clinician to be able to imagine how it feels to experience something in order to "unify the details and nuances of the patient's life into an integrated affective experience" (Halpern, 2001, p. 88). Clinical empathy allows clinicians to access the lived experience of others. An important distinction, however, is that the clinician imagines the experience in a genuine way yet does not live through the actual experience. Benner and Wrubel (1989) describe notions of expert nursing practice as a negotiation between being neither intrusively or oppressively close or involved nor being too detached and distant.

In the case exemplar, before Mrs. Gonzales' family came to the ED, there was tension around Mrs. Gonzales' condition. Mrs. Gonzales was *in extremis* (or in extreme distress) because she was very short of breath. In these times of extreme distress, as a clinician, my perception fluctuates around what is possible for this patient. Mrs. Gonzales could get better through different treatments I could provide (e.g., intubation

with mechanical ventilation on a ventilator, medications to attempt to reverse the pathophysiology present) or she could die from the advanced stage of the natural disease process. I perceived that Mrs. Gonzales was dying based on assessing her clinical condition using my senses of sight, touch, and listening to the things she said to me. From past experience, I have seen some people face their imminent death and say, "I am going to die," and they do die. So in the beginning of the case exemplar, I perceived that Mrs. Gonzales was going to die, yet the tension of whether she was going to die or live fluctuated until I could get a maximum grip on her condition and situation. Mrs. Gonzales did not want further intrusive therapies and expressed this to me.

I believe that I was able to see the detail of Mrs. Gonzales' condition because the fluctuations around the norm were minimized quickly due to my previous experience with other dying patients and my background. In a time of high stress and in a fast paced environment, my body is transparent to me. That is, body is inextricably intertwined with my individuality, background, perceptions, experience, and world. I do not have a mental representation or make a conscious decision about each individual action. My body is set to act from phronetic knowledge. Merleau-Ponty describes this embodiment an "inextricable tangle" (1945/2001, p. 454).

Refinement of phronetic knowledge can come from being perceptive in situations and of people, reflective and checking out assumptions and interpretations in order learn directly from patients and families (Benner, 2000). By being present with a person and perceiving them through one's own senses (e.g., touch, smell, sight, and hearing) and having the experiential knowledge, we are called to act in a moral way by being attuned to the situation. The embodied realism of touching a body of a person who has paper-with mechanical ventilation on a ventilator [illegible] to attempt to reverse the pathophysiology present) or she could [illegible] to the advanced stage of the natural disease process. I perceived that Mrs. Gonzales was dying based on assessing her clinical condition using my senses to [illegible] the things she said to me. From past experience, I have [illegible] sense their imminent death and say, "I am going to die," and they do die. [illegible] case exemplar, I perceived that Mrs. Gonzales was going to die. [illegible] of whether she was going to die or live fluctuated until I could get a more certain grip on her condition and situation. Mrs. Gonzales did not want further intensive therapies and expressed this to me.

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The perception that death is a part of life influences the possibilities ED clinicians perceive for a person. Many people come to the ED and are unknown to the ED clinicians. This lack of relationship shapes the background from which possibilities can be for the person. Malone (2003) describes three kinds of proximity that are central to relationships between nurses and patients: physical, narrative, and moral. Physical proximity aids nurses in providing direct clinical care, nurses understand the patient as a person through narrative proximity, and moral proximity assists in ethical comportment and decision-making on behalf of patients who cannot speak for themselves. These proximities are threatened or not attained in a fast-paced ED with limited relationships with patients and families. In the exemplar, I sought to understand the moral particulars through a hurried narrative proximity (e.g., the patient wanting to die and the family wanting to save her). Despite this truncated narrative proximity, I still held on to the narrative proximity as a way to achieve moral proximity.

Importantly, this example should not suggest that ED clinicians allow every person to die in the ED. Heroic efforts are frequently performed to attempt to stave off death. These heroic efforts are ethically and clinically defensible when the patient thin skin, smelling stale urine and an unwashed body, seeing a look of distress, discomfort and terminal disease, combined with hearing the sounds of ragged respirations revealed to those clinicians involved that death was imminent for Mrs. Gonzales. The situation called to the ED clinicians to act in a meaningful and good way. In the perception that death was imminent, the ED clinicians' care priorities and ethical comportment were on pain and symptom management and bearing witness to the human passage of a life.

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According to Jameton (1984) and Rushton (1992), moral distress occurs when clinicians are unable to turn their moral choices into moral action. In the case exemplar, I felt moral distress because I perceived that the patient was dying despite any resuscitative interventions I or anyone could have done. My background as a nurse and the patient's imploring requests to allow her to die motivated me to care for the patient in a certain way: to help her and her family pass through this stage of life in the most comfortable and peaceful way possible. Since I perceived that the only outcome for the patient was death, I could not support performing aggressive and assaulting interventions (e.g., chest compressions and defibrillation (electricity to the body) as these would not help and would go against her wishes. I felt horrible perhaps because my maximum grip on the situation was being distorted through the wishes of the family. As the family wanted to try and "fix" the problems of death, I felt that the personhood of Mrs. Gonzales recessed into the background and the process of "fixing" the illness came to the foreground and objectified Mrs. Gonzales. My habitus, or the background that is built and incorporated in one's body (Bourdieu, 1980/1992), was being thwarted making me <u>feel</u> terrible. I was actually has a chance for survival in an acceptable quality of life and gives consent to the therapies. The mandate of the professional nursing is to engage in caring practices; nurses are concerned with the human experiences and responses to birth, health, illness, and death (American Nurses Association [ANA], 2003). However, ED clinicians need to carefully balance the heroic/resuscitative care of the dying patient that includes painful and undignified procedures with the compassionate care of the family who might cling to the comforting thought that the patient died despite the healthcare team's heroic efforts. These comforting thoughts may help survivors in their bereavement.

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also conflicted about the patient's own clarity and capacity for autonomy. I believed her when she said that she wished to die. However, I was not clear about her having decision making capacity when she said this. However, her perception that she was dying matched my own perception that she was indeed dying. Benner, Hooper-Kyriakidis and Stannard (1999) note that "forcing activity against [the patient's] will is an ethical violation of [the patient's] rights and safety" (p. 27). To resolve the conflict, I had the family come into the room and witness how their abstract ideas of "everything" compared with the violent futile medical particulars of "doing everything."

In contrast to ED clinicians, patients and families often have very limited experience with dying. The family may have perceived the patient's condition differently (i.e., been given information contradictory to the clinical picture). Since the family was Hispanic, the cultural background shared not only with each other as a family but also part of the larger Hispanic culture opens certain possibilities to the family while closing down others. Families may see the person and grieve over their loss and be thrown into a crisis that shapes their perceptual field and the possibilities available to them. Therefore, intentional arc is partially shaped by these interpersonal perceptions within the situation that are a part of individual and cultural backgrounds. These influencing backgrounds allow possibilities from which people cope with the situation. The continual refinement of one's perceptions (i.e., maximum grip) combined with one's experiential knowledge and a moral agent who advocates for good are ED clinicians who strive to practice in an ethical manner. There is a risk, however, that ED clinicians are set to an optimism that allows for the clinicians to perceive themselves as always having the maximum grip yet with incomplete or perhaps misinformation, they may not have the maximum grip.

Additionally, maximum grip is threatened in situations that are infrequent or have never before been encountered; therefore, experiential knowledge is missing. There is no infallible knowledge about when one has the absolute maximum grip. This grip is perceptual, experientially gained in the situation, and is continually refined, corrected and improved through one's senses and through real events as they unfold.

In this case, the family is prevented from having a maximum grip of the patient's clinical condition by their lack of medical understanding, their desire for the patient to live, possibly religious or cultural values, and the lack of knowledge or experience to see that a person who has those signs and symptoms of a failing body (i.e., an ashen color; difficulty breathing; a drawn, tight look to her body; advanced illness) is near death. Perhaps during a crisis situation, the family may retreat into a more familiar ground. The expectation of continued survival and that familiarity and wish/dream may become so powerful that the family may not be able to go against it. The family's expectations of the medical system, their fears and hopes for their family member shape their reality and those possibilities that they perceive as possibilities for them yet the patient can still die regardless of their expectations. The family dwells in the possibilities and attachments that are set up by their connection with the patient and the situation but are also influenced by their past experiences and commitments. Most families do not have the knowledge or previous experience to imagine an alternate trajectory. The family in the exemplar was literally not able to see that the patient was dying. They relied upon the oncologist's opinion that the patient was going to be fine.

In the ED, where time is measured in minutes to hours, we see and experience a snapshot of time in the patient's illness or injury trajectory. In addition, ED clinicians are true generalists who need to possess a moderate to significant amount of knowledge in many different specialties. While an maximum grip and embodied realism can be shaped relatively quickly by illnesses and injuries that are commonly or repeatedly seen by clinicians, maximum grip of conditions or scenarios that are completely new or seen less frequently is at risk for not coming into focus and errors in judgment may ensue.

The family is situated so differently from the healthcare clinicians' perspective. Perhaps my intentional arc of being a clinically empathic nurse coping with the distress of the patient, family and healthcare team lead me to bring the family to a place of maximum grip of what "doing everything" meant in this case for their mother's body and well-being. This woman's body had become a subjugated docile body reduced to signs and symptoms of disease (Foucault, 1963/1973). Once the family saw the violent actions being applied to the docile body of a loved one, the person lying in the bed was transmogrified back from being a "patient" and returned to being their "family member." The family could also see that it was respectful and humane to stop the resuscitation. Before seeing what "everything" meant to the clinicians, the family and ED clinicians lived in two different perceptual worlds.

Conclusion

Phronesis, praxis, skillful comportment, and the local ED clinical practice set up the background from which caring practices and virtuous action can be possible. Each individual person uses perception through all senses to attempt to situate him or herself in the right context to attain a maximum grip. Maximum grip is always being refined by new perceptions, understandings and experiences.

The integration of Aristotle's notions of phronesis and praxis with Merleau-Ponty's ontological notions of intentional arc and maximum grip in the context of the culture and practices of the ED offers a unique view of clinical and ethical practice at the end-of-life in the emergency setting. The intentional arc of embodied caring for people at the end-of-life calls us to act virtuously based on previous experience, meanings, and local practices. The maximum grip of the ultimate particulars of the situation combined with one's experiential and theoretical knowledge opens up situated possibilities for the expert clinician.

CHAPTER THREE REFERENCES

Adams, K., Corrigan, J. M. (Eds.) (2003) *Priorities for national action: Transforming health care quality,* National Academies Press, Washington, DC.

American Medical Association (2002) *Code of medical ethics. Current opinions with annotations,* AMA Press, Chicago.

American Medical Association's Council on Scientific Affairs (1996) Good care of the dying patient.*JAMA,* 275, 474-478.

American Nurses Association (2001) Code of ethics for nurses with interpretive statements. In American Nurses Association, Washington, DC.

American Nurses Association (ANA) (1995) *Nursing's Social Policy Statement,* Author, Washington, DC.

Benner, P. E. (2000) The roles of embodiment, emotion and lifeworld for rationality and agency in nursing practice. *Nursing Philosophy,* 1, 5-19.

Benner, P. E., Hooper-Kyriakidis, P., Stannard, D. (1999) *Clinical wisdom and interventions in critical care,* W. B. Saunders Company, Philadelphia.

Benner, P. E., Tanner, C. A., Chesla, C. A. (1996) *Expertise in nursing practice: Caring, clinical judgment, and ethics,* Springer Publishing Co., New York.

Benner, P. E., Wrubel, J. (1989) *The primacy of caring,* Addison-Wesley, Menlo Park, CA.

Billings, J. A., Block, S. (1997) Palliative care in undergraduate medical education: Status report and future directions. *JAMA,* 278, 733-738.

Bourdieu, P. (1980/1992) *The logic of practice,* Stanford University, Stanford, CA.

Chan, G. K. (2004) End-of-life care models and emergency department care. *Academic Emergency Medicine,* 11, 79-86.

Chow, E., Harth, T., Hruby, G., Finkelstein, J., Wu, J., Danjoux, C. (2001) How accurate are physicians' clinical predictions of survival and the available prognostic tools in estimating survival times in terminally ill cancer patients? A systematic review. *Clinical Oncology,* 13, 209-218.

Clarke, E. B., Curtis, J. R., Luce, J. M., Levy, M., Danis, M., Nelson, J., Solomon, M. Z. (2003) Quality indicators for end-of-life care in the intensive care unit. *Crit Care Med,* 31, 2255-62.

Corley, M. C. (1995) Moral distress of critical care nurses. *American Journal of Critical Care,* 4, 280-285.

Dreyfus, H. L. (1991) *Being-in-the-world: A commentary on Heidegger's being and time,* MIT Press, Cambridge, MA.

Dreyfus, H. L. and Dreyfus, S. E. (1999) The challenge of Merleau-Ponty's phenomenology of embodiment for cognitive science. In *Perspective on Embodiment: The Intersections of Nature and Culture*, Vol. 2004 (Eds, Weiss, G. and Haber, H. F.) Routledge.

Dreyfus, H. L., Dreyfus, S. E., Benner, P. E. (1996) Implications of the phenomenology of expertise for teaching and learning everyday skillful ethical comportment. In *Expertise in nursing practice. Caring, clinical judgment, and ethics* (Eds, Benner, P. E., Tanner, C. A. and Chesla, C. A.) Springer, New York, pp. 258-279.

Dunne, J. (1997) *Back to the rough ground. Practical judgment and the lure of technique,* University of Notre Dame Press, Notre Dame, IN.

Emanuel, L., von Gunten, C., Ferris, F. (Eds.) (1999) *The Education for Physicians on End-of-life Care (EPEC) Curriculum: © The EPEC Project,* Robert Wood Johnson Foundation, Princeton, NJ.

Ferrell, B., Virani, R., Grant, M. (1999) Analysis of end-of-life content in nursing textbooks. *Oncology Nurse Forum,* 26, 869-876.

Ferrell, B., Virani, R., Grant, M., Coyne, P., Uman, G. (2000) End-of-life care: Nurses speak out. *Nursing2000,* 30, 54-57.

Ferrell, B. R., Grant, M. (Eds.) (2001) *End-of-Life Nursing Education Consortium (ELNEC) Curriculum. © The ELNEC Project.,* American Association of Colleges of Nursing, Washington, DC.

Field, M. J., Cassel, C. K. (1997) Approaching death. Improving care at the end of life. In Institute of Medicine, Washington, DC, pp. 437.

Foucault, M. (1963/1973) *The birth of the clinic: An archaeology of medical perception,* Vintage Books, New York.

Gadamer, H.-G. (1960/1989) *Truth and Method,* The Continuum Publishing Company, New York.

Halpern, J. (2001) *From detached concern to empathy,* Oxford University Press, New York.

Heidegger, M. (1927/1962) *Being and Time,* Harper & Row, New York.

Hill, T. P. (1995) Treating the dying patient: The challenge for medical education. *Archives of Internal Medicine,* 155, 1265-1269.

Iserson, K. V. (1996) Withholding and withdrawing medical treatment: an emergency medicine perspective. *Ann Emerg Med,* 28, 51-4.

Jameton, A. (1984) *Nursing practice: The ethical issues,* Prentice Hall, Englewood Cliffs, NJ.

Kaufman, S. R. (1998) Intensive care, old age, and the problem of death in America. *The Gerontologist,* 38, 715-725.

Kaufman, S. R. (2002) A commentary: Hospital experience and meaning at the end of life. *The Gerontologist,* 42, 34-39.

Kierkegaard, S. (1843/1967) Serial number 1030. In *Søren Kierkegaard's journals and papers*, Vol. 1, A-E (Eds, Hong, H. V. and Hong, E. H.) Indiana University Press, Bloomington, IN, pp. 450.

Lunney, J. R., Foley, K. M., Smith, T. J., Gelband, H. (Eds.) (2003a) *Describing death in America,* The National Academies Press, Washington, DC.

Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S. and Guralnik, J. M. (2003b) Patterns of functional decline at the end of life. *JAMA,* 289, 2387-2392.

Malone, R. E. (2003) Distal nursing. *Social Science & Medicine,* 56, 2317-2326.

McCaig, L. F. and Ly, N. (2002) National Hospital Ambulatory Medical Care Survey: 2000 Emergency Department Summary. In National Center for Health Statistics, Hyattsville, MD, pp. 31.

Meacham, J. A. (1990) The loss of wisdom. In *Wisdom*(Ed, Sternberg, R. J.) Cambridge, New York.

Merleau-Ponty, M. (1945/2001) *Phenomenology of Perception,* Routledge, New York.

Dunne, J. (1997) Back to the rough ground: Practical judgment and the lure of technique, University of Notre Dame Press, Notre Dame, IN.

Emanuel, L., von Gunten, C., Ferris, F. D. (1999) The Education for Physicians on End-of-life Care (EPEC) Curriculum, The EPEC Project, Robert Wood Johnson Foundation, Princeton, NJ.

Ferrell, B., Virani, R., Grant, M. (1999) Analysis of end-of-life content in nursing textbooks. Oncology Nursing Forum, 26, 869-876.

Ferrell, B., Virani, R., Grant, M., Coyne, P., Uman, G. (2000) End-of-life care: Nurses speak out. Nursing2000, 30, 54-57.

Ferrell, B. R., Grant, M. (Eds.) (2001) End-of-Life Nursing Education Consortium (ELNEC) Curriculum. Washington, DC, City of Hope and American Association of Colleges of Nursing.

Field, M. J., Cassel, C. K. (Eds.) (1997) Approaching death: Improving care at the end of life. In Institute of Medicine, National Academy Press, Washington, DC.

Foucault, M. (1963/1973) The birth of the clinic: An archaeology of medical perception. Vintage Books, New York.

Gadamer, H.-G. (1960/1989) Truth and method. The Continuum Publishing Company, New York.

Halpern, J. (2001) From detached concern to empathy: Humanizing medical practice. Oxford University Press, New York.

Heidegger, M. (1927/1962) Being and time. Harper & Row, New York.

Hill, T. P. (1995) Treating the dying patient: The challenge for medical education. Archives of Internal Medicine, 155, 1265-1269.

Iserson, K. V. (1996) Withholding and withdrawing medical treatment: an emergency medicine perspective. Ann Emerg Med, 28, 51-54.

Jameton, A. (1984) Nursing practice: The ethical issues. Prentice Hall, Englewood Cliffs, NJ.

Kaufman, S. R. (1998) Intensive care, old age, and the problem of death in America. The Gerontologist, 38, 715-725.

Kaufman, S. R. (2002) A commentary: Hospital experience and meaning at the end of life. The Gerontologist, 42, 34-39.

Kierkegaard, S. (1843/1967) Serial number 1030. In Søren Kierkegaard's journals and papers, Vol. 1, A-E (Eds. Hong, H. V. and Hong, E. H.) Indiana University Press, Bloomington, IN, pp. 450.

Lunney, J. R., Foley, K. M., Smith, T. J., Gelband, H. (Eds.) (2003a) Describing death in America. The National Academies Press, Washington, DC.

Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S. and Guralnik, J. M. (2003b) Patterns of functional decline at the end of life. JAMA, 289, 2387-2392.

Malone, R. E. (2003) Distal nursing. Social Science & Medicine, 56, 2317-2326.

McCaig, L. F. and Ly, N. (2002) National Hospital Ambulatory Medical Care Survey: 2000 Emergency Department Summary. In National Center for Health Statistics, Hyattsville, MD, pp. 31.

Meacham, J. A. (1990) The loss of wisdom. In Wisdom (Ed. Sternberg, R. J.) Cambridge, New York.

Merleau-Ponty, M. (1945/2001) Phenomenology of Perception. Routledge, New York.

National Institute of Nursing Research (NINR) (2004) 2004 areas for research opportunity. In, Vol. 2004 National Institute of Nursing Research.

Quint, J. C. (1967) *The nurse and the dying patient,* The Macmillan Company, New York.

Rabow, M. W., Hardie, G. E., Fair, J. M. and McPhee, S. J. (2000) End-of-life care content in 50 textbooks from multiple specialties. *JAMA,* 283, 771-778.

Rubenfeld, G. D. and Randall, C. J. (2001) End-of-life care in the intensive care unit: a research agenda. *Crit Care Med,* 29, 2001-6.

Rushton, C. H. (1992) Care-giver suffering in critical care nursing. *Heart & Lung,* 21, 303-306.

SUPPORT Investigators (1995) A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [see comments] [published erratum appears in JAMA 1996 Apr 24;275(16):1232]*JAMA,* 274, 1591-8.

Taylor, C. (1979) *Hegel and modern society,* Cambridge University Press, Cambridge, England.

Taylor, C. (1985) *Philosophy and the human sciences: Philosophical papers 2,* Cambridge University Press, Cambridge, United Kingdom.

Timmermans, S. (1999) *Sudden death and the myth of CPR,* Temple University Press, Philadelphia.

Weick, K. E. (1999) That's moving. Theories that matter. *Journal of Management Inquiry,* 8, 134-142.

Weick, K. E. (2001) Positive organizing and the organizational tragedy. In *Managing the unexpected. Assuring high performance in an age of complexity* (Eds, Weick, K. E. and Sutcliffe, K. M.) Jossey-Bass, San Francisco, pp. 66-80.

CHAPTER FOUR

Methodology

Interpretive Phenomenology as a Method for Studying End-of-Life Care

Introduction

Research methodologies have been divided into two broad categories: quantitative and qualitative research. Quantitative methodologies (I will call them rational-empirical methodologies) attempt to explain, predict, and generalize phenomena or experiences through the fundamental assumption that an experience or phenomenon can be reduced to context-free and abstract characteristics that can be measured or tested (Benner & Wrubel, 1989; Denzin & Lincoln, 2000; van Manen, 1990). Rational-empirical methodologies have been used for the purposes of isolating "causes and effects...operationalizing theoretical relations... [and] measuring and quantifying phenomena...allowing the generalization of findings" (Flick, 1998, p. 2-3). These methods subscribe to the positivist view of the world in that there is a single reality in the world that can be fully studied, captured and understood (Denzin & Lincoln, 2000).

Human beings are curious about ourselves and the world we live in. These curiosities about the phenomena that constitute and are constituted by our world have led scientists to ask questions to understand our world. Scientists in the qualitative research community have developed many methodologies, or, "how do we know the world or gain knowledge of it" (Denzin & Lincoln, 2000, p. 19) to understand and interpret the world. The type of research questions and lines of inquiry drive qualitative research methodology.

While qualitative research methodologies have roots in both the positivist and interpretive traditions (e.g., History, Dilthey, Law, and Hermeneutic studies of sacred texts), phenomenologists have turned away from epistemological questions of personhood because of their Cartesian interpretation of what it is to be a human being. Descartes believed that answering the epistemological question of how a person knew things, the ontological question of how a person was or existed could be answered (Benner & Wrubel, 1989). Phenomenologists have turned toward ontological questions of understanding the human embodied, lived experience and the background concerns, habits, practices and skills in actual situations that make up human being and human worlds (Benner, 1994; Dreyfus, 1991; Heidegger, 1927/1962; Merleau-Ponty, 1945/2001).

Heidegger's (1927/1962) phenomenological view on the nature of being a person proposes that humans are self-interpreting beings. When we are born into this world, we come into a pre-existing world that has meaningful contexts and practices. Over the course of living a life in a world with meaningful contexts and practices, humans are defined rather than coming into this world predefined (Benner & Wrubel, 1989). These hidden skills, practices, and meanings that are pervasive and go unnoticed make the world intelligible to us and creates possibilities and conditions for our actions (Leonard, 1994). Heidegger asserts that a person has an effortless, nonreflective understanding of self in the world because the person is always situated in a meaningful context and because the person "grasp[s] meaning directly" (Benner & Wrubel, p. 41). In contrast, when a person uses abstract or conceptual thinking, he or she stands outside of the situation. Heidegger believed that most of a person's being was in this engaged activity

and was interested in illuminating the kind of knowing that occurs when one is involved in a situation rather than standing outside of it (Benner & Wrubel, 1989).

Traditional rationalist inquiry attempts to uncover a world that is constituted by formal abstractions with an underlying structure governed by rules, axioms and principles to guide action in everyday life (Packer & Addison, 1989). The model of the person, both the researcher and the one being researched, is that of a disengaged knower standing over against an objective world. The researcher is detached and abstracts a theory from the phenomenon and shared understandings, practices, and meanings. The context is stripped away from the phenomenon as it is considered irrelevant and possibly obscuring the important underlying structures. This clearing of the context distorts the phenomenon (Taylor, 1985) and, in particular, denies access to praxis. "The practical activity is intrinsically linked to its context and has a complex temporal organization" (Packer & Addison, 1989, p. 19).

Classical empiricism holds that the world is constituted by independent entities that possess absolute, measurable, and context-free properties independent of human concerns and practices (Packer & Addison, 1989). Empiricist inquiry attempts to measure the entity's properties and discover the laws that cause interaction between entities. A de-contextualized, rational, and atomistic view of the world does not allow for a full understanding of life worlds where humans are members and participants in a historical, cultural, and familial world (Benner & Wrubel, 1989; Leonard, 1994). Rational-empirical methods remove human emotions, senses, and nuances from the research as they are deemed irrelevant and possibly over-shadowing important underlying structures or the outside, context-free reality (Packer & Addison, 1989).

Due to human concerns, actions, and the complexity of a human life, qualitative distinctions and the lived experience of the phenomenon cannot be fully captured or described by fragmented, objective, elemental empirical science (Benner & Wrubel, 1989; van Manen, 1990). Importantly, knowledge of our life world is not well articulated or understood (Fjelland & Gjengedal, 1994). Interpretive phenomenology fills gaps in understanding that are left by empirical science research approaches and offers us plausible insights that bring us in more direct contact with the lived world (Plager, 1994; van Manen, 1990). Understanding context-bound and situated life worlds and lived experiences of human beings are the goals of interpretive projects (Packer & Addison, 1989).

Rationale for using Phenomenology to study the ED

Why should we use phenomenology in studying nursing and medical emergency department (ED) practices at the end-of-life? Understanding the caring practices of ED clinicians for dying patients can help overcome the sense of loss of self-understanding, sense of alienation, moral dilemmas, and loss of social integration for clinicians, patients, and families (Benner & Wrubel, 1989). This reclaiming of understanding allows us to see and understand more fully the caring (and even potentially healing practices) of clinicians for patients and families in crisis that constitute the foundation of nursing and medical practices. Interpretive projects can illustrate notions of good practice and the knowledge embedded in advanced levels of practice. By articulating these practices, we can confirm good practices, explore additional possibilities, and use them as a basis for new visions of practice (Benner & Wrubel, 1989).

The purpose of this interpretive study is to describe the lived experience of ED clinicians' distress, clinical and ethical decision-making, and resolution of dying and resuscitative events in an effort to unravel the perceived personal, ethical, cultural, environmental and clinical factors that influence the care of terminally ill or injured ED patients. This interpretive project aims at making explicit caring practices of clinicians and seeking common meaning in end-of-life care. There are five specific aims of this research project:

7. Understand and interpret the lived experience of ED clinicians of resuscitating a patient with a terminal disease or injury where they consider the care to be wise and effective, and a patient for whom the resuscitation seemed inappropriate clinically to the clinician.
8. Describe the participants' definitions of death and dying in the emergency setting in an effort to clarify conceptions of "good" and "bad" deaths and elucidate ambiguities, conflicts, and notions of competing goods surrounding death and dying.
9. Articulate the factors present in the ED that create ethical distress or dilemmas.
10. Systematically describe the clinical and ethical decision making processes of clinicians during observed resuscitations. In addition, clinical and ethical decision making processes will be analyzed through subjects' descriptions of past resuscitations through the individual interviews.
11. Describe self-reported caring practices of clinicians in the ED during the patient's end-of-life phase.

Interpretive Assumptions

While traditional rational-empirical science seeks to explore the unknown world through analysis of brute data that are free from context, phenomenology starts from a more familiar place: a shared understanding and familiarity with the world in which human beings exist (Heidegger, 1927/1962). Phenomenologists assume humans are self-interpreting beings who are embodied and nonreflective when fully engaged in practical activity; who constitute and are constituted by the world with mutual actions and shared social meanings, backgrounds, and practices; and who cope, are involved, and are concerned in a context-bound world (Benner & Wrubel, 1989; Heidegger, 1927/1962; Plager, 1994; Taylor, 1985). In acknowledging this assumption that human beings live in a shared, social world, we need to recognize that a phenomenologist's interpretation "takes place on a background understanding of what we already know" (Gudmundsdottir, 2000, p. 75). This circular relationship between our interpretation with our background understandings is known as the hermeneutic circle. Entering the hermeneutic circle allows the researcher to understand everyday practical activity and human interactions (Packer & Addison, 1989). Before we can fully understand the hermeneutic circle, we must examine some of the underpinnings that support the interpretive circle. I will follow a similar approach to discussing these assumptions as set forth by Benner and Wrubel (1989); Benner, Tanner and Chesla (1996); Leonard (1994); and Plager (1994).

World

Humans live and are engaged in a world in which things matter that has shared meanings and practices (Heidegger, 1927/1962). Humans are thrown or situated within their world that is constituted by meaningful activities, relationships, commitments and involvements that set up possibilities and boundaries (Benner, Tanner, & Chesla, 1996).

Within the larger life world, there are many sets of local clearings that are created by social groups, skills, history, practices, and situated events (Benner, 1994; Plager, 1994). While being-in-the-world, humans are situated to have possibilities available for action and ways for being involved (Benner et al., 1996). However, the range of possibilities, the limits and the opening up of possibilities that make sense to do is shaped by the local background (Dreyfus, 1991).

Chan (2004) describes the ED as a local clearing in the larger world of healthcare. He describes the department as a place of transition where patients are expected to be transferred to an inpatient unit, transferred to another hospital, or discharged home. In addition, the ED is a fast-paced, high anxiety setting within the hospital. Minimal levels of information or even misinformation are common. Rapid and definitive diagnosis and initiation of treatment are goals of care in the ED. These characteristics set up the life world of clinicians, patients, and families who enter the ED.

Disposedness

According to Heidegger (1927/1962), disposedness is the public mood shared by people in the same local clearing. It is the way that the clinician is attuned to the situation in which certain things matter. Training, education, and past experiences shape the background practice. Disposedness cannot be chosen or completely explicit.

In the ED during a resuscitation event, the unique situation calls clinicians to behave and act based on their phronetic and theoretical knowledge. For example, clinicians' moods will be different for a baby who has died from Sudden Infant Death Syndrome (SIDS) compared to a young man who suffered a gunshot wound to the head. The mood in each situation is pre-reflective and pre-cognitive.

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Absorbed Coping

Heidegger (1927/1962) describes three modes of engagement in practical activity that exist in everyday life: ready-to-hand, unready-to-hand, and present-to-hand. Ready-to-hand is nonreflective, absorbed involvement or coping with equipment and responding to others when things are running smoothly and transparently. In a practice, ED clinicians are able to take up equipment and use it transparently or respond to others without reflection because he or she is familiar with the equipment and has developed phronetic knowledge. Hermeneutic interpretation focuses on this mode of engagement (Plager, 1994).

Unready-to-hand appears when there is a breakdown in the smooth functioning of equipment, activities, or practice. In this mode, the previously transparent and smooth coping now becomes conspicuous and noticed. This state of "problematized" breakdown is of interest to the interpretive scientist but cannot be substituted for understanding the ready-to-hand mode (Benner & Wrubel, 1989).

Present-to-hand is the mode that is most abstract and detached (and therefore less involved) from the situation. Action and context are lost due to the distance from the actual engaged activity. Two weaknesses of studying situations in the present-to-hand mode is that the smooth functioning and coping of the person cannot be captured through these static snapshots of particular states or traits and cannot give an inside-out description of the situation (Benner & Wrubel, 1989). The Cartesian tradition places the highest value on this mode and advocates that studying in this mode comes closest to the "Truth." A futher discussion of these modes of involvement will be presented in the Data Analysis section of this paper.

The World and the Possibilities

An assumption of phenomenology is that humans are engaged in their worlds and those worlds open up and close down different possibilities. Humans beings are not radically free to act but rather have situated freedom where our concerns, our shared and mutually accessible perceptions of the world, our own culture, background, language, meanings, perspectives and sets of habits set up possibilities for action (Benner et al., 1996; Benner & Wrubel, 1989; Taylor, 1979). As Benner, Tanner and Chesla so eloquently stated, "[c]oncerns, or those things that matter to the person, set up how a person enters any situation, what is seen and unseen, and how the person acts" (Benner et al., 1996, p. 352).

Embodiment

Contrary to the dualistic mind/body assumptions of Cartesian representations of human being, phenomenologists hold that being human involves a bodily intelligence that opens the possibility for us to recognize our world as a world of meaning, live in this world easily, and be skillfully involved in situations (Benner & Wrubel, 1989). Embodied intelligence allows disposedness, absorbed coping, and situated freedoms to be possible. Embodiment also allows the clinicians to be solicited by and respond to situations (Day, 1999).

Phenomenology as a Research Method

There are three parts to this research method: data collection, data analysis and writing up the findings in such a way that the reader can participate in the validation of the work.. Common methods to collect data suitable for interpretive analysis are in-depth interviews and observation of direct clinical practice with situated commentary on that action (Benner et al., 1996). Humans recount examples of caring and act "within situations according to their concerns or what matters to them" (Benner et al., 1996, p. 354). This proposed methodology of interpretive phenomenology is grounded in Heideggarian philosophy, and data collection progresses with analysis simultaneously rather than sequentially (e.g., first, data collection; second, data analysis).

Data Collection

Data will be collected through individual clinician semi-structured interviews, participant observation in one ED, and chart review of patients who died in the ED. The total number of subjects will be between 6 and 15 (at least one ED physician, one ED nurse, and one respiratory therapist) in a trauma center emergency department. The actual number of participants will be determined when enough participants have been interviewed to reach understanding (saturation) of a particular observed/described event. Any account of moral distress will be explored and the sources of distress will be clarified. Demographic data (e.g., age, sex, number of years in profession, number of years in the ED, ethnicity, and level of education) will be collected from these subjects. The clinician must be 18 years or older, speak English, and be either an ED physician, ED nurse, or a respiratory therapist. Each subject will participate in a minimum of one interview that will last between 1-2 hours.

The interpretive researcher encourages the participants to share their experiences through narratives to describe their everyday concerns and practical knowledge in order to gain access to their practical worlds (Benner, 1994). Participants are allowed to focus on what was important to them through the narratives and allow the interpretive researcher to understand what is salient to the narrator.

To gain insight to the observed caring practices of caregivers during resuscitation, participant observation will be included with the interviews at the research site. Participant observation can open other lines of inquiry as well as be a form of verification of data obtained through the interviews. Observations in the natural setting will allow the researchers to gain access to witnessing the smooth functioning of practice. According to Benner, Tanner and Chesla (1996), in direct observation of a practice,

> there is a temporal immediacy and proximity to the exigencies of a practice that is less available in the narrative presentation. The context of practice, which may be largely invisible to the practicing nurse because of its familiarity, stands out for an observer….Context includes the physical environment, the resources available on hand and the tempo and energy in the surrounding unit, as well as the events that unfold prior to a particular incident in the nurse's practice. Smooth functioning in nursing practice is more evident in observation that in narratives because the background, self-evident nature of unproblematic practice is very hard for an engaged practitioner to describe (p. 358).

Care will be taken to not influence or obstruct the natural flow of practice. There will be a review with the clinicians after the observation is made using direct questions regarding impressions, observations, and emotions. These responses will be recorded through the use of written notes and then transcribed onto a laptop computer.

Data Analysis

Fundamental issues in phenomenological data analysis are: forestructure of understanding, interpretation, the hermeneutic circle, and modes of involvement (Plager, 1994). Clinicians are situated within their local practices and life worlds that draw upon experiential knowledge, shared meanings, the nature of medical and nursing ethics, history, and skills which are not fully articulated but present nonetheless (Benner et al., 1996). Interpretive projects strive to capture engaged practical activity through the use of full narratives and observations of direct practice situated in a historical and cultural context in order to access the ready-to-hand modes of involvement.

Forestructure of understanding is the shared, public world of background meanings and practices that constitute our life worlds and makes life intelligible and understandable that allows interpretation to be possible (Benner & Wrubel, 1989; Heidegger, 1927/1962; Plager, 1994; van Manen, 1990). Plager paraphrases Heiddeger's notion of the forestructure of understanding as:

> 1. A *fore-having*: we come to a situation with a practical familiarity, that is, with background practices from our world that make an interpretation possible.
> 2. A *fore-sight*: because of our background we have a point of view from which we make an interpretation.
> 3. A *fore-conception*: because of our background we have some expectations of what we might anticipate in an interpretation. (Plager, 1994, p. 72)

An important observation is that both the investigator and the participants exist in a world with shared backgrounds and practical familiarities. Because we share understandings about the world, we must be vigilant to maintain the credibility of the interpretive project.

There are two ways to ensure the forestructure of understanding does not inappropriately affect the interpretation of the project. First, investigators must acknowledge explicitly our own biases, past experiences, and perhaps even hypotheses that may form interpretations based solely on the preconceptions of the investigators. That is, interpretive scientists should examine our own biases that might be hidden in our taken-for-granted backgrounds (Packer, 1989). Second, investigators should be attentive to not "bring forth the forestructure of understanding for the study participants" (Plager, 1994, p. 72). That is, the investigators should not lead participants in one direction that will support the researchers' hypotheses or preconceived notions about what *should* be found in the data.

We revisit and try to enter the hermeneutic circle on the background of the forestructure of understanding. As described above, humans are in the world that presupposes understanding. We live in a world that is already intelligible and meaningful, and our activities make sense and are constituted by our world (Plager, 1994). This circularity of our background understanding and allows us to interpret what we already know (Gudmundsdottir, 2000). I enter this ontological hermeneutic circle with preliminary lines of inquiry based on my fore-having of a practical familiarity with death and dying in the ED.

As an ED nurse for seven years, I have cared for many people who either were dying or were in the indistinct state between life and death. Timmermans (1999) describes four categories of death: clinical death, biological death, social death, and legal death. Clinical death occurs when signs of death are first apparent: the cessation of a life-sustaining breathing pattern and a pulse. Biological death is at the end of the clinical dying process. It occurs when all electrical and mechanical processes cease (e.g., asystole or termination of agonal breathing). Social death occurs when others (e.g., staff, family, and friends) "consider the person to be deceased and act toward the person as a deceased human being" (Timmermans, 1999, p. 130). Legal death occurs when the physician officially pronounces the person as being dead. The physician terminates resuscitative efforts and notes the time of death. My colleagues' and my care practices for people in these four categories of death were variable. At times, goals for the patient (and sometimes goals for the family) were conflicting among nurses, physicians,

respiratory therapists, and families. In these situations, clinicians experienced moral distress from the ethical dilemmas. I bring my past practical and lived experiences with me into the hermeneutic circle.

Lastly, understanding Heidegger's modes of involvement or engagement with equipment is important in determining if the researcher has accessed the phenomena of interest. Interpretive scientists try to stay close to the lived experience to articulate the actions and meanings of the participants. In order to gain insight to the lived experience, the researcher encourages the participant to narrate the story in the ready-to-hand mode of engagement of practical activity. In the ready-to-hand narrative, the participant is involved in an absorbed manner so that the activity is for the most part transparent and unnoticed (Plager, 1994).

In the unready-to-hand mode, breakdown occurs in the smooth functioning. Aspects of activities and equipment become noticed by the participant. While illiciting stories of breakdown is helpful in understanding similarities, differences, concerns, and issues, unready-to-hand accounts cannot provide an accurate interpretive account of previous ready-to-hand activity (Benner & Wrubel, 1989). Present-to-hand accounts are distant from the practical activity and "the participant stands back and observes or reflects on the situation" (Plager, 1994, p. 73). In the present-to-hand mode, participants use theoretical knowledge and experimentation in the tradition of rational-empirical science (Dreyfus, 1991). Phenomenologists attempt to avoid present-to-hand accounts in interpretive projects.

In the ED, patients, families, nurses, physicians, respiratory therapists, social workers, and others "all participate in a complex pattern of ceaseless social activity, the

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parameters of which are fluid, imprecisely articulated, and crudely delimited" (Malone, 1995, p. 60). This social, and practical, activity is grounded in practical knowledge and in the life world of the participant with the background meanings and is situated in time and place (Benner, 1994; Benner et al., 1996). Polanyi (1958/1973), states that "we cannot always theoretically account for our know-how for many common activities such as riding a bicyle or swimming...some practical knoweldge may elude scientific formulations of 'knowing that'" (p. 2). This "know-how" of expert clinical practice at the end-of-life cannot be reduced to empirical indicators that access the practical and ethical negotiation of caring for a person.

The data from the transcribed interviews and observation memos will be open coded using the qualitative data management program, ATLAS.ti®. Themes that are consistent with the research questions will be identified and analyzed following the hermeneutic phenomenology tradition as described by Benner, Tanner and Chesla (1996) and van Manen (1990). The interviews and observation memos will be read and coded by the PI, Dr. Benner, and by the research assistant. Themes will be identified and analytic memos will be written for each interview and observation memo. The group will meet to discuss the interpretations of the texts to discuss differences and agreements in interpretation. Common themes will be identified and illustrated with narrative examples (paradigm cases and exemplars) and thematic analysis (Benner, 1994).

Paradigm cases are the usual point of entering into dialogue with the text and are "strong instances of concerns or ways of being in the world, doing a practice, or taking up a project" (Benner, 1994, p. 113). The researcher arrives at a new understanding and recognizes a pattern from which he or she can understand other paradigm cases as either similar or contrasting (Gudmundsdottir, 2000). While paradigm cases allow for perceptual recognition and understanding of the text, they cannot be reduced to a set of elements to be used in prediction of behavior or practice (Benner et al., 1996; Gudmundsdottir, 2000).

Exemplars are stories or narratives of a situation as described by the participant. Exemplars illustrate aspects of a paradigm case or a thematic analysis and includes the participant's habits, actions, concerns and practices (Benner, 1994; Leonard, 1994). While the interpretive researcher, with the aid of an interpretive team, attempts to articulate and interpret the situation, the situation can never be fully articulated independent of historical and cultural context (Benner et al., 1996).

Thematic analysis is done across cases to clarify distinctions and similarities. Meaningful patterns, stances, or concerns are identified rather than elemental units such as words or phrases (Benner, 1994). This method of analysis is an attempt to gain a broad understanding from comparing and contrasting different cases, narratives, and exemplars (Benner et al., 1996). Moving back and forth between portions of the text and portions of the analysis allows the researcher to develop his or her understanding and generate new interpretive questions (Benner, 1994; Gudmundsdottir, 2000).

Writing Up Findings

Evaluation of the interpretive account is a complicated issue. In quantitative methodologies, the goal of the research project is to attempt to provide a predictive, explanatory, or prescriptive guideline (in forms of theories, conceptual and theoretical frameworks) that are context-free (Plager, 1994). In order to create these models and ensure rigor in quantitative research, the models are dependent on establishing validity, reliability, objectivity, generalizability, and repeatability (Sandelowski, 1986). In contrast to the dominant methodology of quantitative research, the goals of interpretive research studies are rather to make practices and concerns explicit and to seek universal meanings, not attempt to predict or prescribe and therefore do not seek to control validity or reliability (Benner, 1994; Benner et al., 1996; van Manen, 1990). There are, however, guidelines to evaluate methodological rigor in qualitative research (Benner et al., 1996; Denzin & Lincoln, 2000; Sandelowski, 1993).

> Benner (1994) advocates that interpretive phenomenological accounts need to be
>
> auditable and plausible, must offer increased understanding, and must articulate the practices, meanings, concerns, and practical knowledge of the world it interprets. Good interpretation is guided by an ethic of understanding and responsiveness.... [interpretive studies must have] fidelity, clarity, insightfulness, and comprehensiveness of the interpretation of the text" (p. xvii).

Integrity of the data will be ensured by allowing participants to use a natural, narrative form of interviewing to describe practice to gain insight into situated practice with context and history. Also, an informal, conversational tone will be used to get closer to the lived experience.

Central to ensuring rigor in interpretive accounts is to work in a group of interpretive scientists to discuss emerging interpretations of the data. Through this dialogue, members of the group challenge biases and blind spots in order to confirm, refute, and refine emerging interpretations to allow for a coherent and consistent interpretation. Interpretive memos will allow the research team articulate, audit, and keep track of the progress, interpretations, and any new lines of inquiry made through the research process.

There are limitations to interpretive phenomenology. Interpretive phenomenology is well-suited to investigate questions surrounding human issues, concerns, and practices in order to understand world, self, and other (Benner, 1994; Plager, 1994). Interpretive projects seek to remain close to the original text and notes while uncovering biases and blind spots. If the interpretive research begins to decontexutalize the interpretation from the original text, there is a risk of attempting to theorize away from the lived experience which is more in the tradition of natural science (quantitative research) where prediction, prescription, and explanation are the goals.

Conclusion

Caring practices of patients who are dying in the ED are poorly understood. There is a paucity of literature and research investigating death and dying in emergent situations. An interpretive project can describe the lived experience of ED clinicians' distress, clinical and ethical decision-making, and resolution of dying and resuscitative events in an effort to unravel the perceived personal, ethical, cultural, environmental and clinical factors that influence the care of terminally ill or injured ED patients. This interpretive project aims at making explicit caring practices of clinicians and seeking common meanings in end-of-life care.

CHAPTER FOUR REFERENCES

Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness.* (pp. 99-128). Thousand Oaks, CA: Sage.

Benner, P. E., Tanner, C. A., & Chesla, C. A. (1996). *Expertise in nursing practice: Caring, clinical judgment, and ethics*. New York: Springer Publishing Co.

Benner, P. E., & Wrubel, J. (1989). *The primacy of caring*. Menlo Park, CA: Addison-Wesley.

Chan, G. K. (2004). End-of-Life Care Models and Emergency Department Care. *Academic Emergency Medicine, 11*(1), 79-86.

Day, L. J. (1999). *Nursing care of potential organ donors: An articulation of ethics, etiquette and practice.* Unpublished dissertation, University of California, San Francisco, San Francisco, CA.

Denzin, N. K., & Lincoln, Y. S. (2000). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 1-28). Newbury Park: Sage.

Dreyfus, H. L. (1991). *Being-in-the-world: A commentary on Heidegger's being and time*. Cambridge, MA: MIT Press.

Fjelland, R., & Gjengedal, E. (1994). A theoretical foundation for nursing as a science. In P. E. Benner (Ed.), *Interpretive Phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 3-26). Thousand Oaks, CA: Sage.

Flick, U. (1998). *An introduction to qualitative research: Theory, method and applications*. London: Sage.

Gudmundsdottir, M. (2000). *When the world of the family is shattered: Narratives of los and healing practices after the sudden death of a child.* Unpublished dissertation, University of California, San Francisco, San Francisco, CA.

Heidegger, M. (1927/1962). *Being and Time* (J. M. E. Robinson, Trans.). New York: Harper & Row.

Leonard, V. W. (1994). A Heideggerian phenomenological perspective on the concept of Person. In P. E. Benner (Ed.), *Interpretive Phenomenology. Embodiment, caring, and ethics in health and illness* (pp. 43-63). Thousand Oaks, CA: Sage.

Malone, R. E. (1995). *The almshouse revisited: Heavy users of emergency services.* Unpublished Unpublished Dissertation, University of San Francisco, San Francisco.

Merleau-Ponty, M. (1945/2001). *Phenomenology of Perception* (C. Smith, Trans.). New York: Routledge.

Packer, M. J. (1989). Tracing the hermeneutic circle: Articulating an ontical study of moral conflicts. In R. B. Addison (Ed.), *Entering the circle: Hermeneutic investigation in psychology* (pp. 95-118). Albany, NY: State University of New York Press.

Packer, M. J., & Addison, R. B. (1989). Introduction. In R. B. Addison (Ed.), *Entering the circle: Hermeneutic investigation in psychology.* Albany, NY: State University of New York Press.

Plager, K. A. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. E. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 65-84). Thousand Oaks, CA: Sage.

Polanyi, M. (1958/1973). *Personal knowledge*. London: Routledge.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science, 16*(2), 1-8.

Taylor, C. (1979). *Hegel and modern society*. Cambridge, England: Cambridge University Press.

Taylor, C. (1985). *Philosophy and the human sciences: Philosophical papers 2*. Cambridge, United Kingdom: Cambridge University Press.

Timmermans, S. (1999). *Sudden death and the myth of CPR*. Philadelphia: Temple University Press.

van Manen, M. (1990). *Researching lived experience*. Albany, NY: The State University of New York Press.

CHAPTER FIVE

Dissertation Study

Trajectories of approaching death in the Emergency Department: Clinician narratives of the transitions to the end-of-life experience.

Abstract

Transitions to the end-of-life have not been well articulated and the end-of-life phase is not well understood in the emergency department (ED). The sudden and unforeseen is common in the ED. The purpose of this qualitative research project is to identify different trajectories of approaching death in an effort to describe the end-of-life experience in the ED. Seven trajectories of approaching death in the ED emerged from the data: 1) dead on arrival; 2) resuscitation in the field, resuscitative efforts in the ED, died in the ED; 3) resuscitation in the field, resuscitative efforts in the ED, resuscitated and admitted to the hospital; 4) terminally ill, comes to the ED; 5) frail, hovering near death; 6) arrives at the ED alive then arrests/dies suddenly in the ED; and 7) potentially preventable death by omission or commission. A descriptive articulation of the various trajectories will help clinicians be more astute in their recognition of the clinical situation and react appropriately, will help identify the transitions to the end-of-life phase, and will help to explore the possibilities open to the patient, family, and clinicians. In addition, understanding the trajectories and discussion of the clinicians' actions and communication strategies can elucidate which of the trajectories could benefit from anticipatory planning.

Key words: emergency care, end-of-life, trajectories, transitions, sudden death

Introduction

Care at the end-of-life (EOL) has been identified as being substandard in the United States (Field & Cassel, 1997; Lunney, Foley, Smith, & Gelband, 2003). In December 2004, the National Institutes of Health (NIH) convened a Consensus Conference to review the relevant literature, examine the results of research and programmatic efforts in an effort to evaluate the current state-of-the-science, and identify directions for future research in EOL care. One of the key questions the State-of-the-Science panel attempted to answer was, "what defines the transition to end of life?" (National Institutes of Health, 2004, p. 3).

The State-of-the-Science panel discovered that the evidence does not yet support a definition of the interval referred to as "the end-of-life" or its "transitions," that transitions to the EOL have not been well articulated, and there has been a lack of definitional clarity to the concept of end-of-life care (National Institutes of Health, 2004). However, the panel did discover that the evidence supports the following components as constitutive of the end-of-life phase: the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; the symptoms or impairments resulting from the underlying irreversible disease require formal or informal care and can lead to death; and older age and frailty may be surrogates for life-threatening illness and comorbidity. There appears to be little to no discussion about sudden death or death in the emergency department (ED) in the end-of-life literature.

The concept of dying described by Glaser and Strauss (1968) explicitly focuses on the notions that dying trajectories happen over time and have a shape or can be graphed. Glaser and Strauss described three general trajectories of dying: abrupt, surprise deaths;

expected deaths being either short-term or lingering; and entry-reentry deaths where people decline slowly in the hospital but return home intermittently (Glaser & Strauss, 1968; Lunney, Lynn, & Hogan, 2002). Other researchers have described the trajectories of dying in terms of functional trajectories where a person's baseline function through everyday life is affected depending on the effects of the pathology (Field & Cassel, 1997; Lunney et al., 2002). The purpose of this paper is to identify different trajectories of approaching death in an effort to describe the end-of-life experience in the ED. The description of these ED trajectories is a mix of the patient's functional trajectory and patient's health status combined with the care, decision-making, communication with the family, and recognition of death of the ED clinicians.

Defining the concept of "death" has been a topic of clinical, philosophical, ethical, legal, and public policy debate (Jones & Kessel, 2000). Although each death is unique, Timmermans (1999) described four categories of death. These four categories of death are: clinical death, biological death, social death, and legal death. Clinical death occurs when signs of death are first apparent: the cessation of a life-sustaining breathing pattern and a pulse. Clinical death is potentially reversible and therefore clinicians utilize resuscitative interventions to attempt to reverse clinical death. Biological death happens at the end of the clinical dying process. It occurs when all electrical and mechanical processes cease (e.g., asystole, termination of agonal breathing, or algor/rigor mortis). Social death occurs when others (e.g., staff, family, and friends) "consider the person to be deceased and act toward the person as a deceased human being" (Timmermans, 1999 p. 130). Legal death occurs when the physician officially pronounces and certifies the person as being dead. The physician terminates resuscitative efforts and notes the time of death. According to Timmermans, all patients who receive resuscitative efforts in the ED are presumed to be clinically dead.

There are other definitions of death that are commonly found in the literature. “Natural death” is defined as allowing the disease or injury pathologies to run their courses without any intervention from external influences (Davis & Mitoh, 1999; Seymour, 2000). “Cardiopulmonary death” is characterized by the loss of electrical and/or mechanical function of the heart with irreversible cessation of circulation and the irreversible cessation of effective respirations (American College of Critical Care Medicine and Society of Critical Care Medicine, 2001; Kerridge, Saul, Lowe, McPhee, & Williams, 2002).

Since 1968, the concept of “whole brain death” and more recently the concept of “brain stem death” have been defined as the absence of all brain function demonstrated by the presence of profound coma, apnea, and absence of all brainstem reflexes (Ad Hoc Committee of the Harvard Medical School, 1968; Kerridge et al., 2002; Lazar, Shemie, Webster, & Dickens, 2001). Additionally, there is an existential and social aspect of brain death that involves the actual or potential loss of “personhood” (Kerridge et al., 2002; Lizza, 1999; Persson, 2002). “Personhood” has been described as the capacity for intentional behavior, rationality, self awareness, sociality, and ability to conceive and carry out projects (Lizza, 1999). Although the debate over the moral and legal definitions of death still continues, cessation of a heart beat and breathing and/or brainstem or whole brain death seem to be the most widely accepted clinical definitions of death (Jones & Kessel, 2000).

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irreversible cessation of effective [illegible] Saul, Lowe, McPhee, &

Medicine and Society of Critical Care [illegible]

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The concept of dying is equally ambiguous. It is a term that is used often but is not a precise or diagnostic term (Field & Cassel, 1997; Lynn et al., 1996). A seminal study by Glaser and Strauss (1965) with further refinement by Seale and colleagues (Seale, 1998; Seale, Addington-Hall, & McCarthy, 1997) clarified that dying is a process in which an individual's capacity to understand that death is possible based on a physiological and a social context. Seale eloquently writes that "the essential condition for entry into this [dying] role is that people (who may or may not include the dying person) perceive a person to be 'dying' from a disease. This distinguishes this state from chronic illness or old age, where expectations of terminality are less pressing, or subject to greater uncertainty" (Seale, 1998, p. 47). An open awareness of the potential of death is a key component in determining if a person is in the process of dying. In order to be more inclusive, the authors of the Institute of Medicine report Approaching Death used the phrase "approaching death" to be more explicit about all trajectories that lead to death and to take advantage of the idea that death is approached not just by those who are dying but by families, friends, caregivers and communities that are involved with the dying person (Field & Cassel, 1997, p. 27).

While many people die as a result of a slow progression of chronic illness, in old age, or at the end of a period of life-limiting illness, about 10-15% of people die as a result of sudden injury or illness (Field & Cassel, 1997; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; McCaig & Ly, 2002; National Institutes of Health, 2004). According to the Centers for Disease Control and Prevention, in the year 2000, approximately 379,000 deaths occurred in United States emergency departments (EDs) (McCaig & Ly, 2002). Acutely sudden illnesses or injuries or an acute exacerbation of illness leave little time for advanced care planning and death preparation (Chan, 2004). ED clinicians must make rapid decisions in a high-stress, high-anxiety, fast-paced environment, often with suboptimal levels of information regarding medical history, mechanisms of injury, care preferences and goals (Chan, 2004; ENA, 1998; Iserson, 1996; Marco, Bessman, Schoenfeld, & Kelen, 1997; Taylor & Taylor, 1998). In addition, relationships are hastily forged among the patient, family, and healthcare providers in a time of crisis (Kercher, 1991; Sanders, 1995; Walters & Tupin, 1991).

In the medical resuscitation literature, cardiopulmonary resuscitation is considered immediately successful when the patient has a return of spontaneous circulation (ROSC) (American Heart Association, 2000). In the trauma surgery resuscitation literature, common empirical indicators of successful outcome include control of hemorrhage, ROSC, and the presence of signs of life (e.g., presence of cardiac electrical and mechanical activity, respiratory effort, and pupillary response) (Asensio et al., 2001; Rhee et al., 2000). In both the medical and trauma resuscitation literature, prediction of normal neurological outcome and survival to hospital discharge are concerns of clinicians in deciding the extent of resuscitative measures (American Heart Association, 2000; Rhee et al., 2000). ED clinicians consider resuscitation successful when there is ROSC or signs of life are restored.

Palliative care and its precepts have been central to end-of-life care. Palliative care has been described as comprehensive management to address, prevent, reduce or soothe the physical, psychological, spiritual, existential, social, and practical needs of the patient and those close to them without affecting a cure (Field & Cassel, 1997; Task Force on Palliative Care, 1997; World Health Organization, 1990). Palliative care

precepts include respecting patient goals, preferences and choices; comprehensive caring; interdisciplinary processes; acknowledging and addressing caregiver concerns; and building mechanisms of support for the patient and caregivers (Task Force on Palliative Care, 1997). It is important to incorporate palliative care and its precepts into disease-modifying medical and nursing care. However, Chan (2004) notes that while palliative care should and can be included in all caring interactions, time is an important factor in being able to employ precepts of palliative care that may not be afforded in ED.

Methodology

Interpretive phenomenology

Due to human concerns, actions, and the complexity of a human life, qualitative distinctions and the lived experience of the phenomenon cannot be fully captured or described by fragmented, objective, elemental empirical science (Benner & Wrubel, 1989; van Manen, 1990). Importantly, knowledge of our life world is not well articulated or understood (Fjelland & Gjengedal, 1994). Based on the philosophical writings of Heidegger (1927/1962), Dreyfus (1991), Merleau-Ponty (1945/2001), Benner and Wrubel (1989), interpretive phenomenology fills gaps in understanding that are left by rational-empirical research approaches and offers us plausible insights that bring us in more direct contact with the lived world (Plager, 1994; van Manen, 1990). Understanding context-bound and situated life worlds and lived experiences of human beings are the goals of interpretive projects (Packer & Addison, 1989). Seymour and Clark advocate that phenomenological methodology may elucidate the relationship

between particular styles of palliative care provision and the unique experiences of very sick people and those close to them (Seymour & Clark, 1998).

There are three parts to interpretive phenomenonology: data collection, interpretation of data and writing up the findings in such a way that the reader can participate in the validation of the work. Common methods to collect data from clinicians suitable for interpretive analysis are in-depth interviews and observation of direct clinical practice with situated commentary by the clinician on that action (Benner, Tanner, & Chesla, 1996). Humans recount their experiences "within situations according to their concerns or what matters to them" (Benner et al., 1996, p. 354). This proposed methodology of interpretive phenomenology is grounded in Heideggarian philosophy, and data collection progresses with analysis simultaneously creating an ongoing dialogue with the textual data.

Fundamental issues in phenomenological data analysis are: forestructure of understanding, interpretation, the hermeneutic circle, and modes of involvement (Dreyfus, 1991; Heidegger, 1927/1962; Plager, 1994). Clinicians are situated within their local practices and life worlds that draw upon experiential knowledge, shared meanings, the nature of medical and nursing ethics, history, and skills which are not fully articulated but present nonetheless (Benner et al., 1996). Interpretive projects strive to capture engaged practical activity through the use of full narratives and observations of direct practice situated in a historical and cultural context.

Paradigm cases are the usual point of entering into dialogue with the text and are "strong instances of concerns or ways of being in the world, doing a practice, or taking up a project" (Benner, 1994, p. 113). The researcher arrives at a new understanding and recognizes a pattern from which he or she can understand other paradigm cases as either similar or contrasting (Gudmundsdottir, 2000). While paradigm cases allow for perceptual recognition and understanding of the text, they cannot be reduced to a set of elements to be used in prediction of behavior or practice (Benner et al., 1996; Gudmundsdottir, 2000).

Exemplars are stories or narratives of a situation as described by the participant. Exemplars illustrate aspects of a paradigm case or a thematic analysis and include the participant's habits, actions, concerns and practices (Benner, 1994; Leonard, 1994). While the interpretive researcher, with the aid of an interpretive team, attempts to articulate and interpret the situation, the situation can never be fully articulated independent of historical and cultural context (Benner et al., 1996).

Thematic analysis is done across cases to clarify distinctions and similarities. Meaningful patterns, stances, or concerns are identified rather than elemental units such as words or phrases (Benner, 1994). This method of analysis is an attempt to gain a broad understanding from comparing and contrasting different cases, narratives, and exemplars (Benner et al., 1996). Moving back and forth between portions of the text and portions of the analysis allows the researcher to develop his or her understanding and generate new interpretive questions (Benner, 1994; Gudmundsdottir, 2000).

Procedures and Sample

Participant observations of clinician, patient and family interactions (n=10), brief interviews with physicians, nurses and respiratory therapists (n=8), and a convenience sample of in-depth interviews with ED physicians (n=3), ED nurses (n=5), and respiratory therapists (n=3) were conducted to understand how patients approached death in the ED and gain insight to the caring practices of caregivers during resuscitation or during a dying event. These clinicians have been intimately involved in caring for patients approaching death and dying. This study was approved by a university Institutional Review Board and procedures to protect participants were strictly followed.

The participants who agreed to the in-depth interviews included ED nurses, ED attending physicians, and respiratory therapists in one Level II trauma center emergency department in Northern California. This hospital was chosen because it is a community hospital that does not have palliative care services or hospital-based hospice services, similar to the majority of hospitals in the United States. Of these participants, there were two males and eight females. The average age was 43±8 years (range, 34-59 years) with an average of 14±8 years in emergency practice (range, 5-33 years). The clinicians self-classified as Caucasian (n=8), Black (n=1), and Asian (n=2).

The in-depth interviews were conducted in a private room either in the hospital where the clinician worked or in the participant's home and were audio recorded. Participants gave their informed consent and were assured of the confidentiality of their interviews. To further ensure confidentiality, the participants chose a pseudonym from the beginning of the interview and the audio recordings were destroyed after the interviews were transcribed verbatim by a paid transcriptionist and audited for accuracy by the researcher. In the in-depth interviews and clinical observations, "resuscitation efforts" were defined by the participants themselves or the research observer and could include any of the following: cardiopulmonary resuscitation (e.g., chest compressions, advanced airway management), vital sign support (e.g., fluid resuscitation or vasopressor administration), or advanced disease or injury interventions (e.g., antibiotic administration in end-stage Alzheimer's disease). In addition, any discussion of advance directives, any withholding or withdrawing of life-sustaining therapies, or any episodes of moral distress was considered as part of an end-of-life event and was observed and documented.

Each participant was asked to tell stories about patients who were receiving resuscitation efforts, approaching death, or dying in the ED. No stipulation was made as to how recently the experience must have occurred. The researcher encouraged the participants to recount stories in detail that were particularly meaningful to the participant in order to get as close to the lived experience and as far from theoretical description as possible (Benner, 1994). Each participant was interviewed once, and each interview lasted between 1 to 2 hours.

To gain insight to the observed caring practices of caregivers during resuscitation or during a dying event, I observed care being delivered at the research site. Participant observation can open other lines of inquiry as well as be a form of verification of data obtained through concurrent interviews. In this study, I simply observed the clinicians, and made no attempt to change the clinical practice. No identifiers of the staff were recorded. The fieldwork included observing and carefully documenting in written memos interactions among all clinicians, patients, families involved in caring for a dying patient, a dead patient, or during a resuscitative event from the moment the patient arrives to the ED (or from the moment that dying or resuscitation is a potential event) to discharge from the ED (either to an inpatient unit, to the morgue, or to the coroner's/ medical examiner's office). I assessed for appropriate timing so as not to interfere with clinical practice and then asked questions of staff after they participated in a resuscitation event in order to understand the staff's "grasp of what they were encountering, central concerns for the patient [and family] that were organizing their orientation to and work with the patient, the ways in which they reasoned or intuited the impact of their actions on the patient [and family], and how emotional cues figured into their perceptions and actions" (Benner et al., 1996, p. 359). In the exemplars, interviews, and observations, pseudonyms have been used for all participants to ensure anonymity.

Two interpretive scientists reviewed the data from the transcribed interviews and observation memos were open coded. Themes that were consistent with the research questions were identified and analyzed following the hermeneutic phenomenology tradition as described by Benner, Tanner and Chesla (1996) and van Manen (1990). Themes were identified and analytic memos were written for each interview and observation memo. The two researchers met to discuss the interpretations of the texts to discuss differences and agreements in interpretation. Common themes were identified and illustrated with narrative examples (paradigm cases and exemplars) and thematic analysis (Benner, 1994).

Findings

Seven trajectories of approaching death in the ED emerged from the data: 1) dead on arrival; 2) resuscitation in the field, resuscitative efforts in the ED, died in the ED; 3) resuscitation in the field, resuscitative efforts in the ED, resuscitated and admitted to the hospital; 4) terminally ill, comes to the ED; 5) frail, hovering near death; 6) patient arrives to the ED alive then arrests/dies suddenly in the ED; 7) potentially preventable death by omission or commission. A summary of these trajectories and the core characteristics are listed in Table 5.1. These trajectories were formulated by examining the care given to the patient, delineating the clinician's and family's communication and decision-making processes, and witnessing how the patient moved through the ED.

1. Dead on arrival

Those patients who were declared dead on arrival (DOA) were people who had sustained injuries or medical conditions that were incompatible with life. These people had received resuscitative efforts in the field (i.e., in the pre-hospital setting) and were brought into the ED. These patients were declared dead within minutes of their arrival in the ED.

> The paramedics brought in a woman in her 40's who was going through a drive-through window with her boyfriend or husband (it is unclear which it was) at a local fast-food restaurant. Per the paramedics, the boyfriend was so mad that this woman had gotten his order incorrectly that he took out his gun and shot her in the head in the drive-through. The paramedics said that there was not a lot of light [the scene was not well-illuminated] and they just scooped her up and ran her to our ED.
>
> On arrival, the patient was on a backboard with a rigid cervical collar in full spine precautions. She was intubated and her cardiac rhythm showed asystole. CPR was in progress when she came into the ED by the paramedics. The estimated downtime for this patient was about 9 minutes.
>
> When the paramedics wheeled the patient into the ED and she was transferred onto the gurney, there was a lot of blood beneath her head. The ED physician ran her hand underneath the patient's head and felt a large open area where the skull was missing. On closer examination of the blood coming from the back of her head, the ED physician and nurses noted that there were pieces of brain parenchyma mixed in with the blood. The patient was declared dead within 3 minutes of arrival.
>
> The hands of the patient were placed in paper bags and taped closed. The clothing was also placed in paper bags and taped closed. The body was left undisturbed, and all invasive lines and tubes were left untouched. The patient was placed in a room with a police officer restricting access in order to preserve the body as evidence.
>
> The patient's sister and brother-in-law came to the ED once they heard about the altercation but they were not allowed to see the patient by the police officer. The ED physician and ED charge nurse went to give the bad news to the patient's sister and brother-in-law. The family was very distraught and the physician stayed with the family for about 5 minutes. The charge nurse stayed with the family for about 10 minutes and offered to call someone or answer any questions she could. The charge nurse told the police office that she was going to

> bring the family to the closed door to see the patient. The door had a glass window. The charge nurse turned the gurney around so the head of the patient could be seen through the window. She prepared the family for the viewing by letting them know what they would see. She brought the family to the door and the family wanted to stay there until the coroner came to do the preliminary examination. The coroner came to the ED about 2 hours later to examine the body and have it taken to the Medical Examiner's office for the autopsy.
>
> The ED Charge Nurse gave the family written information about how coroner's cases are handled. The family thanked the charge nurse and ED physician for trying their hardest to help their loved one. (Observation memo)

The mechanism of injury (MOI), physical examination findings, physiological indicators, and the procedures required to maintain biological signs of life contribute to the understanding that this person is dead. There appears to be consensus among all providers as to the finality of death. There are no disputes or differing opinions from the members of the health care team. There is no involvement or participation of family in the clinical decision-making in these scenarios. Palliative care precepts are not employed before the death of the DOA patient and sometimes difficult to enact even after the death. Family concerns are acknowledged and addressed following the death.

Here, clinical and biological death precede the legal death. Social death seems to occur last in this trajectory. The family does not get to see the patient until after the physician pronounces the person dead. The clinicians recognize that the patient has died and then the charge nurse arranges the patient in the room so that the family can view the person without potentially disturbing any evidence. It appears that the charge nurse recognizes the importance of allowing the family to see the patient before the coroner takes custody of the body. This practice is supported by the literature that finds that seeing the body or being allowed to touch and hold the deceased person helps the survivors with the grieving process (Haas, 2003). The charge nurse creates an environment for leave-taking and bereavement practices while respecting the boundaries of the legal implications surrounding the death of this patient.

2. Resuscitation in the field, resuscitative efforts in the ED, dies in the ED

ED clinicians caring for these patients receive a report from paramedics in the field who initiated resuscitative efforts. The ED clinicians continue the resuscitation efforts in the ED. The clinicians use the physical examination findings and physiological indicators to help determine whether the patient is going to die imminently or not. All resources that are available and at the disposal of the clinicians are used in an effort to resuscitate the patient.

In one example, a patient had sustained serious injuries and went in and out of ventricular fibrillation (V Fib) for 3 hours. When the patient's heart responded briefly to the treatments of the lethal dysrhythmia, it gave some indication to the clinicians that there was a possibility that the patient could be admitted to the hospital for further treatment. All resources that were available to the clinicians and appropriate treatments were exhausted in the ED.

> Nurse: He was an older gentleman, probably in his early 60's, an unrestrained front seat passenger in a car that rolled down an embankment. And his son was driving and his son was wearing his seatbelt and he was fine. And this guy he came into the department and he kept on going in and out of fine V Fib kind of stuff, and the doctor that was working just kept him going even though, you know, he would code, we would get him back, and the he would code and he wouldn't give up on him.
> INT: Did the patient survive?
> Nurse: No.
> INT: How long do you think you worked on him?
> Nurse: I think he was worked on for 3 hours.
> INT: Wow. How did that make you feel, when you were in that situation?
> Nurse: I felt that we needed to stop. I felt like... you know... I... if he wanted to... if he was so bent on trying to save this guy, I was thinking we had exhausted all our resources in the Emergency Department and that he should have then taken

> him to OR where he could, you know, open him up and find out where he was bleeding from, or… yeah, I just thought he needed to stop.
> INT: Did you say anything to him [the trauma surgeon], or did anyone say anything to him?
> Nurse: Not that I can recall, no.
> INT: So, um, from what it seems like that it is like the physician in this particular case kind of ran the situation and was in complete control.
> Nurse: Yeah.
> INT: And you didn't seem comfortable perhaps or felt that it was appropriate to say anything otherwise, or did you? Did you say anything?
> Nurse: No, no I didn't. I think probably the nurses to each other said under their breaths God, when are we going to stop this, to die on his own. But I don't know that anyone said anything to the physician, I don't think. (Nurse interview)

In this example, clinical, biological and social death, according to the RN, appear to occur before legal death. The nurse recognizes that three hours of resuscitation is an ominous sign for recovery. She recognizes that the patient has died but the surgeon keeps trying different therapies in an effort to resuscitate the patient. In the ED setting, the only discipline that can pronounce a person as being legally dead is medicine. The surgeon is the last person to recognize that the person was dead. The trauma surgeon may have been uncertain whether additional therapies might be effective in returning signs of life.

This disagreement among providers and sometimes with families creates moral distress. The nurse feels unable to advocate for the patient or even for herself. She perceives that the physician is in control of the situation and that she participates in the resuscitation while not agreeing with the surgeon's plan of treatment. There are covert discussions among the other ED staff but no one will confront the surgeon.

However, in other scenarios, there appears to be no question among health care providers to continue with resuscitation efforts. For example, in a case of an infant who died from Sudden Infant Death Syndrome (SIDS), the nurses, physician, and respiratory therapists continued with CPR. In a collaborative manner, the team decided that there were no other interventions to employ and continued CPR without disagreement until ultimately the infant was pronounced dead.

The perceived neurological outcome of patients plays a significant role in whether to continue with resuscitative efforts. Despite the expertise of the clinicians, the attempts at initiating resuscitative measures are unsuccessful due to the MOI and the injuries sustained.

> RT: I was in a code where a trauma surgeon made a comment, they were having a really difficult time getting the patient intubated and he came in with a heart rate and quickly decompensated because we couldn't ventilate him. He had massive trauma to his face and his neck and so then he decompensated and went flat line [asystolic]. Yeah, we lost that gentleman. I don't even think that we ever did get him intubated. What they were thinking is that he may have had some kind of injury to actually… his nose down everything was just mooshed [severely injured beyond recognition] and they think that maybe his trachea was torn because at one time it really seemed like we should have been in the trachea. The anesthesiologist even came, a good anesthesiologist that I really have a lot of faith in, and he couldn't… you know he looked in there and he's like, "I don't know what's what!" And that person ended up dying. And you know at that point it probably was a good thing because he was without oxygen to his brain for so long that he was not going to have a good outcome. (RT interview)

This RT asserts that without oxygen, the neurological outcome of the patient would be poor. She is concerned about the ability for this patient to recover neurologically intact and fears a potentially negative outcome of neurological impairment. The RT can foresee the poor neurological outcome for this patient and is relieved that resuscitative efforts are stopped. As the pathophysiology unfolds and is diagnosed by the clinicians, the patient is recognized as physiological functions first. After the clinicians understand the extent of injury or illness, their attention is then turned to the personal and social possibilities for the injured person. This RT concludes this exemplar with a narrative of justification- reasons for the discontinuation of resuscitative efforts and explanations of why the resuscitation attempts failed. Research has also revealed that decision-making capacity is an important value of people who complete advance directives (Schonwetter, Walker, Solomon, Indurkhya, & Robinson, 1996).

3. Resuscitation in the field, resuscitation in the ED, resuscitated and admitted to the hospital (OR, ICU, Medical/Surgical unit)

From the participant observations and interviews, there seem to be two subtrajectories: a) the ED clinicians strive to save a life due to their perception that resuscitative efforts are likely to be effective or perceive the patient is likely to survive, and b) ED clinicians continue with resuscitation efforts but there is uncertainty if the resuscitation efforts will be effective or even perceive the patient is unlikely to survive. The clinicians use the various signs of mortality such as physical examination findings, physiological indicators, diagnostic findings, mechanism of injury (MOI), demographic factors, and utilization of required procedures to help them come to a complete picture of the patient's status.

a) Resuscitative efforts are likely to be effective

Some of the resuscitations described by the participants or observed by the researcher fell into a subcategory of receiving resuscitative efforts and then being resuscitated to get admitted into the hospital. One particular case involved a woman who had sustained a gunshot wound through the heart. The patient was pulseless and apneic in the field, was intubated by the paramedics, was given IV fluids in the field, and was still receiving chest compressions upon arrival to the ED. The ED clinicians employ the diagnostics and therapeutics that were appropriate interventions for this injury without hesitation or disagreement. The ED clinicians followed the standard medical and surgical algorithm for a person who needs an emergency thoracotomy.

> Nurse: That case was a gunshot wound to the chest. She got shot by her ex-husband. And we cracked open that chest [emergency thoracotomy] in 19 minutes from the time that she got into the ER to OR, she got chest cracked open, she got a unit of blood already in and another hanging, she got tubes everywhere. She got to OR and she made it [survived]. And then- I think that she was in PEA [pulseless electrical activity] when she came in. And I think that is just wonderful when everybody knows what they're doing and everybody gets pulled in to work on one case. For 19 minutes, that is impressive. And you save somebody. Because I remember that lady, there were at least five nurses jumping to that particular one. (Nurse interview)

The MOI leads the clinicians to attempt a usually unsuccessful intervention that ended up being successful in this patient. The ED team worked together and used many resources in an attempt to resuscitate this patient. The patient received a lot of care from many clinicians and was stabilized and transferred to the OR for more definitive care. The expertise of the ED clinicians also contributed to the success of the interventions.

In this exemplar, clinical death has occurred but resuscitation efforts are attempted to restore signs of life. Biological, social and legal death have not occurred nor are they even recognized as possibilities because the clinicians fully engage in the resuscitative interventions and whisk the patient to the OR.

b) Resuscitative efforts are unlikely to be effective

Here, there appears to be some uncertainty as to the ending of the patient's life from the physician, nurse, RT, or family. In one interview, a nurse caring for a child revealed that despite the physical examination findings and the type of procedures required to maintain any signs of life indicating that death was imminent. The nurse, also not entirely convinced of the patient's certain death, needed to prove to herself and to the mother that "everything" was done for the patient and urged the trauma surgeon to consider more units of blood. This patient had sustained severe injuries but the mother insisted on "everything" (i.e., more interventions). The interventions used to attempt to resuscitate the patient failed to attain the desired results. After these repeated failures to restore signs of life, the nurse realized that there was no other possibility other than death.

> Nurse: We had a 12 year-old that came in who was run over by a car. He had bilateral pneumothoraces, he was just bleeding out of his nares, his ears, his mouth. His abdomen was just swelling up because he had internal bleeding, and we put a chest tube in and he blew another pneumothorax. In less than an hour in the Emergency Room he had 4 chest tubes, he had blood [transfusion] going, I know that this outcome is not going to be good, this is not a good outcome, doesn't matter how hard we work, how hard we try, it doesn't look good. He was gray before he came in, he wasn't intubated, his vital signs tell us that this is not going to work, but I watched his mom at the door and she looked at me and she said, 'this is my ONLY child, you guys have to do EVERYTHING to save him.' I was saying to the trauma surgeon, let's order more blood, let's get more blood. And even though we were putting the blood in and it was coming out I kept going, 'let's get more blood. Let's put in another chest tube in here.' And he [the trauma surgeon] was doing it. And in the back of my mind, I know, it wasn't going to be a good outcome. But just listening to that mother and watching her, all I could hear was, 'do everything to save my child. That's my only child.' We worked on this kid and we finally transferred him out of the ER and he didn't make it. It seemed like a hopeless case, but in the back of my mind, I wanted to do everything to show her that we did everything. And as a mother, that's what I would have wanted. I'd want somebody to do EVERYTHING just to prove to me that you did everything that you could to save my child. I was sitting there thinking, ok, so I know what this child needs is more blood and more blood even though I know that it's not staying in and we're still giving more blood. You know, we try fluids, and then we were trying other stuff, we were trying ventilators. I was standing there thinking, ok, so should we stop or draw the line, because there comes a point to when you have to stop or draw the line and say, this is fruitless, you're doing it for the mom, but what is it doing to the child and is this causing the child more pain? More harm? More damage? Is this a humane thing for the child to do, like, you know, put him through all these procedures, all these tests. Isn't it more humane to kind of stop and let this child go with dignity, you know, die with dignity? So, there's a point where you say everything has to stop, this extra blood that we're going to give, 'cause deep down in my professional mind, I know that it's not going to work, but I want to give that one extra unit anyway so that when I go home tonight, I can go to bed and sleep and say, I DID do everything. Because if I didn't say to the trauma doctor, 'give that one more unit,' I'd go home and I'd think, 'would this child have lived if given that one extra unit? Would that child, you know...' So, when I go home

> I want to go, ‘ok, so I can go to sleep because I know I really did EVERYTHING. (Nurse interview)

In this exemplar, the nurse recognizes that the outcome is not going to be good. The child is teetering on the edge of clinical and social death for the nurse and trauma surgeon based on the MOI, the physical examination findings, and the interventions required to restore or maintain signs of life. There seems to be more questioning or uncertainty from the physicians, nurses, RTs or family as to the possible outcomes for the patient. The clinical actions taken by the ED staff are designed to prove or determine if the clinical decisions are sound; are in agreement with previously stated wishes in advance directives or with family wishes; are congruent with the clinicians’ moral values; and are congruent with acceptable standards of practice and patient/family expectations in order to protect the clinicians’ and hospital’s reputation and desire to avoid litigation.

4. Terminally ill person comes to the ED

In cases of the terminally ill person who comes to the ED, there is a formal recognition by the patient, family, and/or primary healthcare team that death is near. The primary physician has identified a prognosis when death might occur. In the case of patients receiving hospice care, the primary care physician certifies a prognosis for the patient is that death will occur within 6 months.

In one observation, a terminally ill patient developed severe dyspnea and an altered level of consciousness and the family activated the Emergency Medical Service (EMS) by calling 911. The patient was brought to the hospital and requested services that seemed contradictory to their wishes for the patient to die at home.

> A 62 y/o Syrian woman, Mrs. G, arrived to the ED with severe shortness of breath and altered level of consciousness with a history of extensive metastatic

> cancer to the lungs and bone with unknown primary source. Mrs. G was previously admitted to another hospital one month prior to this current admission to the ED for shortness of breath, was intubated, was able to get the symptoms controlled, and was extubated. She was in the other hospital for almost four weeks and then discharged from the other hospital one and a half days before arriving to this ED. When Mrs. G was initially diagnosed with cancer, chemotherapy and radiation therapy were initiated. Mrs. G. had received three rounds of chemotherapy and radiation treatment before she decided that she did not want to continue because the therapies and side effects made her feel worse than the cancer itself. The patient understood that if she discontinued the chemotherapy and radiation therapy, she would die within six months. The family told the ED staff that they understood that the patient had a 100% mortality rate. Upon discharge from the other hospital, the physician referred the patient to hospice and the family agreed to admit her to the hospice service. The family called 911 because Mrs. G was again experiencing severe shortness of breath, and they could not care for her at home.
>
> On arrival to the ED, Mrs. G. had severe dyspnea and had an altered level of consciousness. The husband, daughter and two sons arrived to the ED and insisted on a full code status and wanted the patient intubated. The family brought in the discharge papers from the other hospital and the ED staff became confused when they saw the referral to hospice and the discharge summary indicating that death was imminent for this patient but the family wanted Mrs. G to die at home. The family stated that the hospice team was supposed to arrive that day but the shortness of breath and altered level of consciousness got worse so they called 911. The ED physician tried to go over the discharge summary from the other hospital and give his interpretation of Mrs. G's condition that she was close to death. He explained that shortness of breath could be a symptom near the end of life and that he would order medications to help control the shortness of breath instead of putting tube down Mrs. G's throat to help her breathe. The daughter who was the spokesperson for the family said that the family understood that Mrs. G was going to die but wanted the [endotracheal] tube anyway. The nurses tried to dissuade the daughter and two sons from putting the endotracheal tube in and described that these are symptoms that could indicate that the patient is actively dying. The family insisted on the endotracheal tube. The patient was intubated in the ED and was admitted to the ICU for respiratory failure with an admission order for a full code. (Observation memo)

The family has either a misunderstanding of the role of hospice or a lack of experiential knowledge surrounding what the signs of impending death are or what death actually looks like. It seems as if they do not associate shortness of breath with one possible scenario of death. Perhaps the family believes that the patient will get through this current hospitalization just like the previous hospitalization. However, despite the discharge education from the other hospital regarding prognosis and the role of hospice, the family feels obligated to do something for the patient and activates EMS.

The nurses and support staff try to force the family to fit their conception of a “good death” by questioning why the family brought the patient to the ED to die. The pressure of the busy ED with limited space and long waiting room times limits possibilities of care for this patient. There are few physical interventions other than intubation that could reasonably be done and psychosocial interventions in the ED take a lot of adequate space, attention and time. Attempts at educating the family about the role of hospice and preparing the family for imminent death seem to be unsuccessful due to the family’s sense of panic, feelings of overwhelm, and fear of the patient’s immediate death. In addition, there is no attempt by the ED clinicians to try to get a hospice admitting team to the ED or coordinate possible admission to home hospice from the ED. Disposition of the patient is particularly difficult when hospital-based palliative care units or services are unavailable.

In this exemplar, the family does not consider the patient socially dead. However, the clinicians do consider that the patient is approaching clinical death. Neither clinical nor biological nor legal death have occurred but are imminent. The clinicians perceive that impending death is imminent and attempt to convey this to the family, but without success. This failure to have the family understand the current situation creates moral distress for the clinicians, in part because the treatment wishes of the family seem incongruent with the family’s original goal of having the patient die at home.

However, in another exemplar of a home hospice patient who arrives at the ED via ambulance, the family wanted to have the patient die outside of the home due to their cultural and spiritual beliefs that it is unlucky to have a person die in the home.

5. *Frail, hovering near death*

The frail patient population shares many aspects with the terminally ill patient population with the exception that in the frail population, the primary care physician has not done a formal prognostication and certification of "near death." While the ED clinicians institute resuscitative measures for the frail patient population, the absence of this public certification process of declaring death to be imminent creates moral questions for the ED clinicians as to the hopes and goals of the therapies that they initiate for the patient.

> At 14:20, paramedics brought in an 18 year-old boy from a state-run long-term care (LTC) facility for persons with developmental disabilities. The patient had been at this facility his whole life. He was born with severe cerebral palsy. His nurse from the facility brought in three 3-inch binders. These three binders were his medical records from this year alone. He had a past medical history of multiple rounds of aspiration pneumonia, diabetes mellitus, a latex allergy and multiple medication allergies. He was about 4 feet tall in the bed and weighed 35 kg. He had been bed bound his whole life and never gotten out of bed, even into a wheelchair. He had a percutaneous gastrostomy tube and a tracheostomy tube. He came in febrile and severely dyspneic. His mother lived about 250 miles away and came to see him infrequently, about once a year to visit him. The LTC facility nurse said that this hospitalization was his fourth time in 8 months for aspiration pneumonia.
>
> The ED nurses had a difficult time establishing an IV. The nurses insisted that the physician would need to place a central line because of the lack of usable peripheral veins. Finally, a groin line was placed. Sputum, blood and urine cultures were sent to the lab. His vital signs on arrival to the ED were heart rate 174/ minute, respirations 46/ minute, blood pressure 124/77, T 102.4°F rectally, SaO2 82% on 15 L/minute via his tracheostomy, and his urine output was about 10 mL when the ED nurse placed the Foley catheter. The chest x-ray showed diffuse bilateral infiltrates. His urine analysis came back positive for a urinary tract infection. So, diagnoses of aspiration pneumonia and UTI with possible

> urosepsis were made. The patient was started on antibiotics and transferred to the Pediatric ICU at 16:38.
>
> The ED physician and two ED nurses said that this might be the last time this patient comes to the hospital because he was so sick he might die. They were not expecting him to get discharged because of the severity of the pneumonia and urosepsis. (Observation memo)

In this exemplar, the patient was perhaps already socially dead to the mother and nearing social death for the ED clinicians before clinical, biological, and legal death occurred.

The patient is frail and critically ill and the ED clinicians, although uncertain, anticipate that the patient will die during this hospitalization due to the severe pneumonia, urinary tract infection, and possible urosepsis combined with the underlying cerebral palsy.

6. Arrives at the ED and then suddenly arrests (may die, or may be resuscitated)

In this trajectory, the clinicians are surprised by the sudden death or arrest of a patient. The clinicians try to rule out or rule in any life-threatening illnesses or injuries or are in the process of treating an identified life-threatening pathology. While the clinicians are in the process of trying to figure out the underlying pathology, the patient arrests. The clinicians use all appropriate resources in an attempt to resuscitate the patient. Deaths that fall into this trajectory are sudden and sometimes unexpected by both clinicians and family members.

The health care team relies on various factors to achieve a perception of approaching death, including such factors as chief complaint, vital signs, physical examination findings and utilization of procedures. But in this trajectory, these usual signs of approaching death are missing or inconclusive.

> At 15:40, a 56 y/o obese woman walked into the ED and was brought to the treatment area through triage. Her chief complaint was some abdominal pain located in the periumbilical area for 3 days without any trauma to the abdomen. She said that she had been having pain intermittently and it was a sharp pain without radiation to the back. The CBC, lipase and amylase were normal and the pregnancy, urine analysis, guaiac tests were negative. The physician ordered bilateral arm and leg blood pressures that were within normal limits. The vaginal examination was normal. The physician, who is an expert at ultrasound, did a bedside ultrasound to rule out a dissecting abdominal aortic aneurysm or abdominal free fluid. The physician did not see anything on ultrasound.
>
> The physician was considering sending her home when suddenly the cardiac alarm went off. The patient's blood pressure was 60's/ 30's, HR 140's and the patient was obtunded. The patient then lost her blood pressure and was in a pulseless electrical activity (PEA) rhythm and her abdomen was even more distended. CPR was started and she was intubated. A vascular surgeon was called and she came in about 20 minutes after being paged. Meanwhile, the team was still resuscitating her through chest compressions, mechanical ventilation, and hanging blood via the rapid infuser. The patient was in the OR at 17:33. The ED Charge Nurse went out to the waiting room and brought the family to the family room. The ED physician spoke to the family to let them know about the change in events. The vascular surgeon worked on the patient for about 30 minutes. The patient was pronounced dead in the OR. The vascular surgeon came back to the ED and said that her arteries to the stomach and the omentum were shredded and friable. When the vascular surgeon tried to repair the arteries, they disintegrated in her hands. The patient had exsanguinated.
>
> The ED physician, the vascular surgeon, and charge nurse went to tell the family that the patient had died. The family was shocked because the patient had walked into the hospital. They had a difficult time believing that she was dead. They were surprised, disbelieving, and angry. The physician and surgeon assured the family that everything that could have been done was done. The deceased patient's body was taken to the recovery room and the family was allowed to be with, see the patient. (Observation memo)

The ED physician attempts to rule out the pathologies that carry high risk of mortality such as the dissecting abdominal aortic aneurysm or pathologies that are associated with severe morbidity if not diagnosed such as liver, pancreatic, gallbladder disease. When all the diagnostic tests came back negative, the physician starts to think that this patient is not at high risk of death. When the vital signs change indicating impending clinical death, however, the physician and nurses are taken off guard and immediately institute resuscitation measures. Biological and legal death occur before the clinicians and family recognize the patient's social death.

However, in another scenario, a patient came into the ED with a chief complaint of chest pain and the 12-lead ECG and he had signs of myocardial ischemia and infarction. As the ED clinicians were initiating therapies to reverse the ischemia, the patient developed a lethal dysrhythmia (ventricular fibrillation) and CPR with defibrillation was initiated. The patient was transferred to the cardiac catheterization lab (CCL) while still receiving CPR and was pronounced dead in the CCL.

7. Potentially Preventable Death by Omission or Commission

There has been an increased awareness and attention to medical mistakes by the Institute of Medicine (Kohn, Corrigan, & Donaldson, 2000) and researchers (Wachter & Shojania, 2004) as a cause of death. There are many causes of medical mistakes. For example, personal misperceptions, hospital-wide processes that create confusion, and larger societal issues such as low third party reimbursement rates forcing clinicians to work more quickly to increase the volume of patients seen can contribute to errors in patient management (Wachter & Shojania, 2004).

Although perception and knowledge are important in all of the trajectories of approaching death, they are core in understanding this trajectory of the potentially preventable death. The clinicians' perceptions and what they choose to focus their attention on may lead the clinician down the wrong care and treatment pathway. According to Chan (2005), ED clinicians respond quickly and appropriately to the high acuity situations where death is perceived to be imminent based on the clinical signs of the patient and the previous experiential knowledge of the provider. However, when

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situations are unfamiliar or become routine, the index of suspicion of death or adverse event is not high and mistakes may be made (Chan, 2005).

In a brief interview with a nurse, Jim, a "frequent flier" or a person who is a heavy user of emergency services (Malone, 1995, 1998), came into the ED with an altered level of consciousness with a strong odor of alcohol on his breath similar to many nights before. However, one night, Jim did not follow his routine habits which alerted the nurse that something was wrong.

> Jim was a patient who came in about 3-5 times a week for as long as this nurse worked in this ED; at the time of his death, the nurse had worked there almost 5 years. He would come into the ED brought in by paramedics who were called by a bystander that a person was "found down." Jim would be found on the sidewalk with an altered level of consciousness and a heavy odor of alcohol on his breath. On his admissions to the ED, the nurses automatically checked a blood glucose level to make sure he was not hypoglycemic, started the patient on a "banana bag" [multivitamins, folate, thiamine, and magnesium in a liter of IV fluid], checked his pupils to evaluate his neurological status and then they let him sleep it off. He would be brought in during various times of the day but always for an overnight stay. Jim was particularly infamous in that he would frequently urinate on the staff, the wall, and on himself when he was particularly angry or was disturbed too much. They positioned him in the hallway to keep an eye on him in the event he wanted to get out of bed. He was a serious fall risk patient.
>
> Around 6:00 am when the alcohol wore off and before the Day shift nurses came, Jim would often wake up and tended to be a very nice and pleasant man. He would often joke with the staff and say that he would see them again in the morning and promise to stay off of the alcohol. The staff would get him new clothes that were donated to the ED by the hospital staff. They would very frequently give him something to eat and then send him out the door. Jim would be in the department for 6 to 10 hours before waking up and getting discharged. Once the initial assessment was performed, the staff did not disturb him until the morning. Occasionally, the ER techs would take vital signs on Jim every 4 hours, if there was little else to do in the ED. It was common that the ED physician would type up his discharge summary when he arrived to the ED.
>
> Last year, Jim came in to the ED one night at approximately 9:00 pm. He presented to the ED the same way as all the other nights before with altered level of consciousness and being "ornery." The nurse checked his blood glucose level, hung a "banana bag," and checked his pupils. They were a little sluggish but normal size. She had seen that in Jim before and she had taken care of him two nights previous. He urinated on the wall just like he did in the past. The

> department was extremely busy that night with other critically ill and injured patients.
>
> It was getting close to 6 am and Jim had not awakened and was lying on his side, snoring loudly which was not uncommon for him. The nurse went over to wake him up and had a difficult time getting a response from Jim. She spoke loudly and shook him. She even tried to elicit a response by using a sternal rub but without a response. She began to get worried and called another nurse over to help her try to arouse him. While the other nurse was coming to help, the primary nurse opened Jim's eyelids and saw that his pupils were fixed and dilated. She palpated his skull to see if could find any trauma but could not find any abnormalities. She called the ED physician over and they got him intubated and then went to get a CT of the head. The result of the CT scan was that he had a small scalp hematoma with a large subdural hematoma with a midline shift and uncal herniation. The neurosurgeon was called and came into the ED to evaluate the patient. The neurosurgeon said that the prognosis was very poor and that if they withdrew the endotracheal tube he would die shortly after extubation. Jim did not have any family to contact in an emergency. The social worker on call (they only had on call social workers for the night shift) said that she would try and look for family. However, the social worker, who had worked at the hospital for 24 years, had never been able to find any family for Jim in all the years she knew him and tried many interventions for his alcohol use.
>
> Jim was taken off the ventilator but still had the endotracheal tube in place and was put on a T piece to keep his airway open. He was admitted to the medical/surgical floor. The social worker tried to locate family for Jim and was unsuccessful. Jim was extubated two days later and died that same day. (Nurse interview)

The Guidelines for Care that set the standards of care for this particular ED state that the nurse caring for a patient should assess the patient every 1 to 4 hours based on the acuity and chief complaint of the patient. The care for Jim, however, becomes routinized and is placed low on the priority list. In addition, if a staff person tries to arouse him, that staff person is at risk of getting urinated on. In effect, had the staff adhered to the Guidelines for Care, the change in neurological condition might have been detected sooner and the subdural hematoma could have been identified much earlier and interventions initiated in an attempt to prevent Jim's death. However, the nurse and physician do not realize that the patient is approaching death. They do an initial admission physical examination that does not alert them to the fact that the patient is approaching death. The subdural hematoma comes as an unexpected finding although the physician and nurse know that subdural hematomas can occur in patients with chronic alcohol use. The nurses routinely are supposed to check the pupillary response for signs of intracranial hemorrhage.

This patient is a "frequent flier" who are commonly marginalized in the ED (see Malone, 1998 and Timmermans, 1999). But this patient in the exemplar was not recognized as being socially dead in terms of realizing the patient was a deceased human being. Once the nurse and physician suspected a subdural hematoma, they intervened appropriately according to the community standards of subdural hematoma diagnosis and treatment. Clinical, biological and legal death were not reached in the ED.

In another brief interview with a staff nurse, a 77 year-old Vietnamese man came to the ED with an altered level of consciousness after a mechanical fall. He was subsequently diagnosed with a subdural hematoma. The patient and family (including a wife) spoke Vietnamese only. The ED physician wanted to admit the patient to the hospital and called the neurosurgeon to come in to examine the patient. One of the ED nurses spoke Vietnamese fluently. The wife was very worried about the hospital bill and wanted to go to the local county hospital. The county hospital could not accept the patient due to bed unavailability but would take the patient the next day. The wife became very insistent and angry despite the encouragement and warnings from the ED physician and the Vietnamese-speaking nurse. The wife signed the patient out of the hospital against medical advice (AMA). The staff documented the encounter carefully including the signs and symptoms of a worsening subdural hematoma and the risk of

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death if help was not obtained. Despite those warnings, the patient had a respiratory arrest at home, brought back into the same ED and died that night.

This was a potentially preventable death. The ED is governed by many local, state, and federal laws and regulations. One federal statutory-regulatory complex is the Emergency Medical Treatment and Active Labor Act (EMTALA, also know as COBRA or the Anti-Dumping Law)(EMTALA.com, 2005). This statutory-regulatory complex states clearly that a patient who comes to the ED should receive an appropriate medical screening exam and appropriate and stabilizing treatments regardless of ability to pay. In addition, the referral hospital cannot transfer a patient if the receiving hospital does not have the resources available to care for the patient.

The ED physician and nurse could have gone up the chain of command, including involving the Risk Management Department. They could have called the ED Medical or Nursing Director, on call Administrator, Ethics Committee or hospital attorney to help intervene regarding care and payment issues. Clinically, the ED physician could have intubated the patient to stabilize the airway in anticipation of the needed surgery to evacuate the hematoma and to prevent the wife from taking the patient home. The ED clinicians focused too much of their attention to certain clinical and legal issues (e.g., having the patient leave AMA) while ignoring the social concerns of the family and the ethical mandates of the nursing and medical profession of providing the best care for the patient and protecting the patient from harm.

In both cases of potentially avoidable death, the clinicians either forgot the Guidelines for Care, prioritized care for patients differently, became desensitized to the care needs of the patient, or had a lack of knowledge about how to deliver the best possible care. These alternate care possibilities or interventions are not recognized by the clinicians as possibilities at the time of the initial hospitalization. It is not until after the moment when the clinicians realize that there is a negative outcome that these alternate possibilities become apparent. Although alternate interventions could have been employed to prevent the negative outcome, it is uncertain what would have happened even if they do provide the best possible care. Both patients still might die despite employing alternate interventions.

Discussion

For some people who come to the ED, the transition to EOL occurs suddenly and without warning. Sudden injury or sudden manifestations of a disease that was previously silent (i.e., without symptoms or signs) begin some transitions to the end-of-life. In the trajectory of the potentially preventable death, the patient can approach death unexpectedly, unknowingly or unrecognized by the ED clinicians or patients themselves. In the trajectories of coming to the ED alive and then arresting suddenly or in the cases of DOA, the transition to the end-of-life can be sudden. In both instances, the ED clinicians are unaware that the patient is actually approaching death. ED clinicians are constantly trying to understand whether this moment is going to be the end for this patient or not and care is given based on the clinical presentation of the patient. Entering the EOL phase may be short and may occur at the time the patient arrests and may include resuscitative efforts without other palliative care precepts. In a time-sensitive and fast-paced environment, resuscitative therapies may take precedence and palliative care principles may not be employed. Communication with families and even among clinicians can be confusing, forced and pressured in this atmosphere of high stress and crisis.

Other transitions to EOL care in the ED are more apparent. There are many factors that can lead the clinicians to recognize that death is approaching. The mechanism of injury, chief complaint, physiological indicators, physical examination findings, demographic factors, procedures required to maintain signs of life, and patient's own sense of impending doom all contribute to the clinicians' perception that death is approaching. Acknowledgement from clinicians that a person is potentially or actually dying plays a central role in the clinical and ethical decision making in the EOL phase. If clinicians perceive that the interventions might resuscitate the patient, the focus is on the clinical needs to support the vital signs. In cases where the ED clinician perceives that the resuscitative measures will not be effective, then the clinicians try to focus more on palliative care than disease-modifying therapies. ED clinicians try very quickly to identify the trajectory that will shape or influence the possibilities for each patient and family.

However, in the case of the potentially preventable death, even those factors fail to alert the clinicians that death was closer than it appears. In acute illness or injury, clinical, biological, and legal death usually precede social death. However, in chronic or terminal illness, frailty, or marginalized populations, social death may come before clinical death.

In the dead on arrival trajectory, death is sudden. Clinicians quickly arrive at an understanding that death has happened. Clinical, biological, social (from the clinicians' point of view), and legal death have occurred in the ED. The family must be told about the death of the person before familial social death can be recognized. Therefore, clinicians should focus DOA interventions on the grieving family and perhaps even ED staff who might have been affected by the death. Adamowski and colleagues (1993) suggest a protocol of how to care for the survivors after a sudden death. The protocol includes how to contact the survivors, how to approach the survivors when they arrive at the ED, how to deliver the bad news, how to cope with their grief response, helping the family view the deceased person, and how to conclude the process.

In the trajectory of resuscitation in the field, resuscitation in the ED, and dies in the ED, death comes at the end of an acute exacerbation of a chronic illness or with a sudden illness or injury. Clinical death occurs but is seen as potentially reversible. At a certain point in time, depending on the clinical response of the patient, the clinicians recognize clinical death has evolved into biological death. With pronouncement, legal death is then established and, with the sharing of the bad news with the family, social death (i.e., recognition that the patient is deceased) occurs. Interventions for this trajectory should include clear communication with the family during the period of resuscitation in the ED; family presence during resuscitation will help with the grief and bereavement and perhaps the family will arrive at the same realization of death with the clinicians; and allowing the family time with the deceased person and providing informational support and comfort measures such as facial tissue or beverages as needed.

In the trajectory of resuscitation in the field, resuscitative efforts in the ED, is resuscitated and admitted to the hospital, clinical death has already occurred. In the subtrajectory when resuscitative efforts are likely to be effective, clinical death has occurred but the clinicians perceive that the clinical death can be reversed. There seems to be little conflict among the ED clinicians and care is aggressively administered following standards without question. Neither biological, social, nor legal death are even considered in this pattern. ED clinicians focus all of their attention on attempting to restore signs of life. In this subtrajectory, two important interventions should be employed: social support should be provided to the family by social work or chaplaincy services and, if possible, the family should be present during the resuscitative efforts.

In the second subtrajectory when the resuscitative efforts are not likely to be effective, clinicians often recognize that the treatment is ineffective and so social death occurs after the brief potential for reversal of clinical death. By the MOI, physical examination, and physiological indicators, clinicians perceive that death will not occur instantly but clinical, biological or legal (as in the case of brain death) death will occur in a short period of time. Interventions appropriate for this subtrajectory are family presence during resuscitation; eliciting from the family the hopes for this patient's outcome; providing correct information as needed to the family; being honest about the benefits, risks and burdens of treatment; assuring the family that all appropriate interventions were attempted; and providing an opinion of prognosis to help create a context for the family.

Despite increasing preparation and education regarding death, the families of terminally ill patients often send them to the ED for symptom management, for cultural or spiritual reasons, or because their emotional response (e.g., panic), or because of their inability to care for the imminently dying patient. Neither clinical, biological, social nor legal death has occurred but the patient is on the precipice. In the trajectory of terminal illness, ED clinicians need more education about alternatives to dying at home such as inpatient palliative care units, aggressive symptom management at the end-of-life, and different cultural expectations and spiritual beliefs about dying at home. Armed with this information, ED clinicians can provide better symptom management and psychosocial support to the patient and family.

In the frail, hovering near death trajectory, there is a risk of social death before the clinical, biological, or legal death. Recognition that frailty is a surrogate for life-threatening illness or comorbidity will assist clinicians in providing the best care for these patients. According to the American College of Emergency Physicians (American College of Emergency Physicians (ACEP), 1998), clinicians should only offer those interventions that are appropriate and beneficial to patients and forgo nonbeneficial treatments. ACEP also recommends that clinicians maintain communication and provide comfort, support and counseling to patients, family and friends.

When patients come into the ED alive and then die suddenly, the clinicians are taken by surprise. ED clinicians attempt to identify and either rule in or rule out life-threatening diseases or injuries. Similarly, in the potentially preventable death trajectory, death also comes as a surprise to the clinicians. The ED clinicians cannot prepare the family because they themselves are unaware of the impending death. Therefore, suggested interventions appropriate for this trajectory are similar to the DOA trajectory: provide honest communication, facilitate family presence during the resuscitation, and provide intense counseling after the pronouncement of death. Additional system-wide interventions to attempt to prevent death due to medical mistakes are described elsewhere (Wachter & Shojania, 2004). Examining system processes and personal care practices and collaboration among disciplines and administration to provide and encourage systems of safety is key to reducing the opportunities for error. Unfortunately, due to human nature, errors will continue to occur. Nonetheless, active efforts to prevent these mistakes can reduce or minimize the potentially fatal outcomes of medical errors.

Examples of excellence in emergency care reveal that clinicians are present-oriented to the current situation and analyzing/perceiving all the clinical signs from the patient (Chan, 2005). Decision-making is dependent upon the perception and understanding of the clinician in a stressful situation. Examples of signs of approaching death and factors that contribute to the perception of approaching death are listed in Table 5.2. Rote behavior such as approaching care using an algorithmic approach and not checking out assumptions implied in language (e.g., “do everything for my family member”) may create ethical dilemmas or moral distress for the clinicians.

Moral distress occurs when conflict exists among ED nurses, physicians, RTs, the patient or the family. In some cases, the person experiencing moral distress attempts to advocate for the most beneficial treatment for the patient. Sometimes the advocacy results in resolution of the conflict and therefore resolves the moral problem or conflict. In other cases, the advocacy does not resolve the conflict or even worsens the relationships among the persons involved. In those cases, moral distress continues and is disturbing to the person experiencing the moral distress. In a few cases, the person who interprets the situation as ineffective, non-beneficial or torturous for the patient feels as if s/he could not say anything and fails to advocate for his or her professional judgment about the patient’s best interests. Yet professional advocacy, acting to safeguard and advance the interests of another (Rushton, Williams, & Sabatier, 2002), is central to the disciplines of nursing and medicine and can help resolve any moral conflicts or distress that a clinician experiences. Being aware of the desires, hopes and fears of patients and families will help guide ED clinicians in providing good end-of-life care and in providing care and treatment options that are congruent with patient and family wishes beneficial to the patient.

Communication with families can be stressful due to the crisis situation and the need to deliver bad news (Fallowfield & Jenkins, 2004). In the trauma setting, surviving family members of patients who died in the ICU or ED ranked the attitude of clinicians, the knowledge of the news bearer, and the clarity of the message as highly important qualities of communication (Jurkovich, Pierce, Pananen, & Rivara, 2000).

However, prognostication of death is inaccurate even when the diagnosis is known (Christakis, 1999). Lamont and Christakis (1999) have divided prognostication into two parts: foreseeing and foretelling. Foreseeing is the silent, cognitive estimate of the clinician in predicting survival. Foretelling is communicating the estimate to the patient and significant others. In the oncology setting, oncologists unwittingly foresee overly optimistic survival rates (Chow et al., 2001). In addition, they foretell even better survival rates than their foreseeing. The end effect is that the patients and significant others might be twice removed from the truth of the prognosis (Lamont & Christakis, 1999).

ED clinicians have a difficult time prognosticating mortality. ED clinicians are not afforded many opportunities to explore this issue due to the fast-paced, high stress environment. The ED clinicians often quickly transfer the patient to an inpatient unit, perhaps in part to avoid difficult end-of-life decisions. Schears (1999) describes the possibility of transferring the locus of moral decision making on final outcomes to the ICU in order to avoid the decisions in the ED. Because the ED staff choose not to address these issues, they admit the patient to the ICU in order to have the ICU staff sort out the issues. The ICU is perceived as being more equipped for deliberate end of life decision making. As palliative care unites and consultation services proliferate in US hospitals (Pantilat & Billings, 2003; von Gunten & Martinez, 1998), ED clinicians may soon have another alternative to ICU admission for this purpose.

Open communication is difficult in a high stress, fast-paced environment where decisions must be made quickly in a crisis situation. Clinicians in the ED who routinely are exposed to these sudden end-of-life situations are better equipped to work in the chaotic environment because their past experiences help them understand the situation clinically (Benner, Hooper-Kyriakidis, & Stannard, 1999; Chan, 2005). In contrast, families of patients who are dying often do not have prior experience with death and dying in this context and may have difficulty understanding the clinical, biological, social, and legal death that occurs in the ED.

In these exemplars, social death does not mean that ED clinicians abandon the patient or family. Recognition that death has occurred helps clinicians decide what interventions might be helpful to the patients and families.

These circumstances surrounding a person's death make each death unique. These unique and particular deaths cannot be fully managed using prescriptive algorithms. However, a descriptive articulation of the various trajectories can help clinicians be more astute in recognizing the clinical situation and reacting appropriately. In addition, understanding the trajectories and discussion of the clinicians' actions and communication strategies can elucidate which of the trajectories could benefit from anticipatory planning.

ED clinicians move through this world with a sense of urgency. It is difficult to foresee long-term outcomes beyond survival to discharge from the hospital. Concern about functional status is colored by the often catastrophic findings in the most acute phase of pathology. We are just beginning to understand the end-of-life experience and patient's transitions to the end-of-life in the ED. This research study examined the possible patient death and dying trajectories during ED care- it may help clinicians to understand the clinical transitions to the end-of-life phase, to explore the possibilities open to the patient, family, and clinicians, and to define what type of end-of-life care exists for patients approaching death in the ED. This is a new frontier for end-of-life and palliative care research. There is a dire need for additional research such as identifying best practices of ED-specific palliative interventions, understanding barriers to ED end-of-life care practices, and developing an educational intervention that focuses on improving end-of-life and palliative care interventions and communication skills among ED clinicians, patients, and families.

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Table 5.1
Observed E.D. Death Trajectories and Trajectory Characteristics

Trajectory	Characteristics
1. Dead on arrival	• Patient has injuries/medical conditions incompatible with life. • EMT-Ps[1] provided resuscitative efforts in the field. • Consensus among EMT-Ps and ED clinicians regarding the finality of death. • Patient declared dead within minutes of arrival to the ED.
2. Resuscitation in the field, resuscitation in the ED, dies in the ED	• Physical examination findings and physiological indicators help to determine that the patient is likely to die. • ED clinicians use all resources that are available and at the disposal are used in an effort to resuscitate the patient. • Clinicians have concerns about neurological outcome if the patient is resuscitated. • Clinicians and/or family members may have differing opinions that death is imminent. • ED clinicians may, however, continue resuscitation efforts despite obvious signs of death due to other factors (e.g., SIDS, pediatric trauma).
3. Resuscitation in the field, resuscitation in the ED, resuscitated, admitted to the hospital	• EMT-Ps and ED clinicians track and recognize various signs of mortality to achieve perceptions of approaching death.
3a) Clinicians perceive that resuscitative efforts likely to be effective	• ED clinicians strive to save a life due to their perception that the patient is likely to survive. • ED clinicians employ aggressive/invasive/ heroic efforts in attempt to resuscitate the patient. • Clinicians do not perceive that death is a probability, and they fully engage in resuscitative interventions.

3b) Clinicians perceive that resuscitative efforts unlikely to be effective	• Uncertainty as to the ending of a patient's life. • Resuscitation interventions may have a temporary effect to maintain signs of life. • Clinical actions: o are designed to prove to the family and sometimes to themselves that death is the only possible outcome o are in agreement with patient's previously stated wishes in an advance directive; o are congruent patient/family wishes or expectations in order to protect the clinician and hospital from litigation; o are congruent with the clinicians' own moral values; o are congruent with acceptable standards of practice in order to protect the clinicians' and hospital's reputation and to avoid litigation.
4. Terminally ill, comes to the ED	• Patient, family and primary provider achieve informal recognition and establish formal prognostication/certification that death is near (e.g, prognosis < 6 months enabling hospice enrollment). • Family nonetheless activates emergency medical system (e.g., calls 911) to bring patient to ED because of: o misunderstanding of the role of hospice; o lack of experiential knowledge of signs of impending death; o resistance by the family that death is imminent; o cultural/spiritual/emotional reasons.
5. Frail, hovering near death	• Patients are frail and critically ill and shares many aspects with the terminally ill patient population (e.g., poor health/functional status). • ED clinicians, although uncertain, anticipate that the patient will die during this hospitalization. • No informal recognition or formal prognostication/certification that death is near (e.g., prognosis < 6 months). • Absence of this recognition or certification process causes ED clinicians to question the hopes and goals of the therapies that they initiate for the patient.

6. Arrives at the ED alive, then arrests/dies suddenly	• Death unexpected for both the clinicians and the family. • ED clinicians are surprised by the sudden death or arrest of the patient while they are in the process of trying to rule in or rule out life-threatening pathology or are actively trying to treat life-threatening pathology. • ED clinicians use all appropriate resources in an attempt to resuscitate the patient.
7. Potentially preventable death by omission/commission	• The patient is approaching death and is dying but this is not recognized until it is potentially too late. • Can occur in both routine or unfamiliar situations. • Index of suspicion of death or adverse event is not high and mistakes may be made. • ED clinicians' perceptions and what they choose to focus their attention on may lead them down the wrong evaluation or treatment pathway. • The clinicians either forget guidelines for care, prioritize care for different patients differently, become desensitized to the care needs of the patient, or lack knowledge about how to deliver the best possible care.

[1] EMT-P- Emergency Medical Technician- Paramedic

Table 5.2
Examples of signs of mortality and factors .
that contribute to the perception of approaching death

Mechanism of Injury	• Penetrating trauma/ gunshot wound to the head • Auto vs. pedestrian at high speed • Stab wound to the heart or multiple stab wounds
Chief Complaint	• Chest pain • Dyspnea • Abdominal pain • Altered level of consciousness
Physiological Indicators and Diagnostics Findings	• Vital signs (Temp, BP, Pulse, RR, SaO2) • Cardiac rhythm (e.g., ventricular fibrillation, asystole) • Massive intracranial hemorrhage on Head CT with midline shift and uncal herniation
Physical Examination Findings	• Cranial vault disruption • Brain parenchyma outside the cranial vault • Evidence of disseminated intravascular coagulation (DIC) • Lab/radiographic findings suggestive of severe or advanced stage of pathology (e.g., urosepsis, aspiration pneumonia, high grade subdural hematoma) • Abnormal neurological findings (e.g., pupils fixed and dilated)
Demographic Factors	• Developmental indicators (e.g., age, height disproportionate to expected weight)
Patient's Sense of Impending Doom or Approaching Death	• Patient stating they are "going to die," or "don't let me die." • Clinicians listen to patients when the patient perceives that he/she is going to die (in the absence of a psychiatric problem).
Required Procedures	• Cardiopulmonary resuscitation: chest compression, intubation, cardiac pacing. • Rapid, massive transfusions • Subdural hematoma evacuation

CHAPTER FIVE REFERENCES

Ad Hoc Committee of the Harvard Medical School. (1968). A definition of irreversible coma. A report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. *Journal of the American Medical Association, 205*(6), 85-88.

Adamowski, K., Dickinson, G., Weitzman, B., Roessler, C., & Carter-Snell, C. (1993). Sudden unexpected death in the emergency department: Caring for the survivors. *Canadian Medical Association Journal, 149*(10), 1445-1451.

American College of Critical Care Medicine and Society of Critical Care Medicine. (2001). Recommendations for nonheartbeating organ donation. A position paper by the Ethics Committee, American College of Critical Care Medicine, Society of Critical Care Medicine. *Crit Care Med, 29*(9), 1826-1831.

American College of Emergency Physicians (ACEP). (1998). *Nonbeneficial ("Futile") Emergency Medical Interventions* (Policy Statement). Irving, TX: Author.

American Heart Association. (2000). Guidelines 2000 for cardiopulmonary resuscitation and emergency cardiovascular care. International consensus on science. *Circulation, 102*(8), I1-I291.

Asensio, J. A., McDuffie, L., Petrone, P., Roldan, G., Forno, W., Gambaro, E., et al. (2001). Reliable variables in the exsanguinated patient which indicate damage control and predict outcome. *Am J Surg, 182*(6), 743-751.

Benner, P. E. (Ed.). (1994). *Interpretive phenomenology. Embodiment, caring, and ethics in health and illness.* Thousand Oaks, CA: Sage.

Benner, P. E., Hooper-Kyriakidis, P., & Stannard, D. (1999). *Clinical wisdom and interventions in critical care*. Philadelphia: W. B. Saunders Company.

Benner, P. E., Tanner, C. A., & Chesla, C. A. (1996). *Expertise in nursing practice: Caring, clinical judgment, and ethics*. New York: Springer Publishing Co.

Benner, P. E., & Wrubel, J. (1989). *The primacy of caring*. Menlo Park, CA: Addison-Wesley.

Chan, G. K. (2004). End-of-life care models and emergency department care. *Academic Emergency Medicine, 11*(1), 79-86.

Chan, G. K. (2005). Understanding end-of-life caring practices in the emergency department: Developing Merleau-Ponty's notions of intentional arc and maximum grip through praxis and phronesis. *Nursing Philosophy, 6*, 19-32.

Chow, E., Harth, T., Hruby, G., Finkelstein, J., Wu, J., & Danjoux, C. (2001). How accurate are physicians' clinical predictions of survival and the available prognostic tools in estimating survival times in terminally ill cancer patients? A systematic review. *Clinical Oncology, 13*, 209-218.

Christakis, N. A. (1999). *Death foretold. Prophecy and prognosis in medical care*. Chicago: University of Chicago Press.

Davis, A., & Mitoh, T. (1999). Dying in the USA and Japan: selected legal and ethical issues. *Int Nurs Rev, 46*(5), 135-139.

Dreyfus, H. L. (1991). *Being-in-the-world: A commentary on Heidegger's being and time*. Cambridge, MA: MIT Press.

EMTALA.com. (2005). Retrieved March 10, 2005, from www.EMTALA.com

ENA. (1998). Resuscitative decisions. Retrieved May 1, 2003, from http://www.ena.org/about/position/resuscitativedecision.asp

Fallowfield, L., & Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine. *Lancet, 363*(9405), 312-319.

Field, M. J., & Cassel, C. K. (1997). *Approaching death. Improving care at the end of life.* (No. 0-309-06372-8). Washington, DC: Institute of Medicine.

Fjelland, R., & Gjengedal, E. (1994). A theoretical foundation for nursing as a science. In P. E. Benner (Ed.), *Interpretive Phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 3-26). Thousand Oaks, CA: Sage.

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying*. Chicago: Aldine Publishing Company.

Glaser, B. G., & Strauss, A. L. (1968). *Time for dying*. Chicago: Adline Publishing Company.

Gudmundsdottir, M. (2000). *When the world of the family is shattered: Narratives of loss and healing practices after the sudden death of a child.* Unpublished dissertation, University of California, San Francisco, San Francisco, CA.

Haas, F. (2003). Bereavement care: seeing the body. *Nursing Standard, 17*(28), 33-37.

Heidegger, M. (1927/1962). *Being and Time* (J. M. E. Robinson, Trans.). New York: Harper & Row.

Iserson, K. V. (1996). Withholding and withdrawing medical treatment: an emergency medicine perspective. *Ann Emerg Med, 28*(1), 51-54.

Jones, S. F., & Kessel, A. S. (2000). The 'redefinition of death' debate: Western concepts and Western bioethics. *Science and Engineering Ethics, 7*(1), 63-75.

Jurkovich, G. J., Pierce, B., Pananen, L., & Rivara, F. P. (2000). Giving bad news: the family perspective. *J Trauma, 48*(5), 865-870; discussion 870-863.

Kercher, E. E. (1991). Crisis intervention in the emergency department. *Emergency Medical Clinics of North America, 9*(1), 219-232.

Kerridge, I. H., Saul, P., Lowe, M., McPhee, J., & Williams, D. (2002). Death, dying and donation: Organ transplantation and the diagnosis of death. *Journal of Medical Ethics, 28*, 89-94.

Kohn, L. T., Corrigan, J. M., & Donaldson, M. S. (Eds.). (2000). *To err is human: Building a safer health system*. Washington, DC: National Academy Press.

Lamont, E. B., & Christakis, N. A. (1999). Some elements of prognosis in terminal cancer. *Oncology, 13*(8), 1165-1170.

Lazar, N. M., Shemie, S., Webster, G. C., & Dickens, B. M. (2001). Bioethics for clinicians: 24. brain death. *CMAJ, 164*(6), 833-836.

Leonard, V. W. (1994). A Heideggerian phenomenological perspective on the concept of Person. In P. E. Benner (Ed.), *Interpretive Phenomenology. Embodiment, caring, and ethics in health and illness* (pp. 43-63). Thousand Oaks, CA: Sage.

Lizza, J. P. (1999). Defining Death for Persons and Human Organisms. *Theoretical Medicine and Bioethics, 20*(5), 439-453.

Lunney, J. R., Foley, K. M., Smith, T. J., & Gelband, H. (Eds.). (2003). *Describing death in America: What we need to know*. Washington, DC: The National Academies Press.

Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S., & Guralnik, J. M. (2003). Patterns of functional decline at the end of life. *JAMA, 289*(18), 2387-2392.

Lunney, J. R., Lynn, J., & Hogan, C. (2002). Profiles of older Medicare decedents. *JAGS, 50*, 1108-1112.

Lynn, J., Harrell, F. E., Cohn, F., Hamel, M., Dawson, N., & Wu, A. W. (1996). Defining the "Terminally Ill": Insights from SUPPORT. *Duquesne Law Review, 35*, 311-336.

Malone, R. E. (1995). *The almshouse revisited: Heavy users of emergency services.* Unpublished Unpublished Dissertation, University of San Francisco, San Francisco.

Malone, R. E. (1998). Wither the almshouse? Overutilization and the role of the emergency department. *Journal of Health Politics, Policy and Law, 23*(5), 795-832.

Marco, C. A., Bessman, E. S., Schoenfeld, C. N., & Kelen, G. D. (1997). Ethical issues of cardiopulmonary resuscitation: current practice among emergency physicians. *Academic Emergency Medicine, 4*(9), 898-904.

McCaig, L. F., & Ly, N. (2002). *National Hospital Ambulatory Medical Care Survey: 2000 Emergency Department Summary* (No. Advance data from vital and health statistics; no. 326). Hyattsville, MD: National Center for Health Statistics.

Merleau-Ponty, M. (1945/2001). *Phenomenology of Perception* (C. Smith, Trans.). New York: Routledge.

National Institutes of Health. (2004). National Institutes of Health state-of-the-science conference statement. Retrieved January 21, 2005, from http://consensus.nih.gov/ta/024/024EndOfLifepostconfINTRO.htm

Packer, M. J., & Addison, R. B. (1989). Introduction. In M. J. Packer & R. B. Addison (Eds.), *Entering the circle: Hermeneutic investigation in psychology.* Albany, NY: State University of New York Press.

Pantilat, S. Z., & Billings, J. A. (2003). Prevalence and structure of palliative care services in California hospitals. *Arch Intern Med, 163*(9), 1084-1088.

Persson, I. (2002). Human Death - A View from the Beginning of Life. *Bioethics, 16*(1), 20-32.

Plager, K. A. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. E. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 65-84). Thousand Oaks, CA: Sage.

Rhee, P. M., Acosta, J., Bridgeman, A., Wang, D., Jordan, M., & Rich, N. (2000). Survival after emergency department thoracotomy: review of published data from the past 25 years. *J Am Coll Surg, 190*(3), 288-298.

Rushton, C. H., Williams, M. A., & Sabatier, K. H. (2002). The integration of palliative care and critical care: One vision, one voice. *Critical Care Nursing Clinics of North America, 14*, 133-140.

Sanders, A. B. (1995). Unique aspects of ethics in emergency medicine. In K. V. Iserson, A. B. Sanders & D. Mathieu (Eds.), *Ethics in Emergency Medicine* (2nd ed., pp. 7-10). Tuscon, AZ: Galen Press, Ltd.

Schears, R. M. (1999). Emergency physicians' role in end-of-life care. *Emergency Medicine Clinics of North America, 17*(2), 539-559.

Schonwetter, R. S., Walker, R. M., Solomon, M., Indurkhya, A., & Robinson, B. E. (1996). Life values, resuscitation preferences, and the applicability of living wills in an older population. *J Am Geriatr Soc, 44*(8), 954-958.

Seale, C. (1998). *Constructing death. The sociology of dying and bereavement.* Cambridge: Cambridge University Press.

Seale, C., Addington-Hall, J., & McCarthy, M. (1997). Awareness of dying: prevalence, causes and consequences. *Soc Sci Med, 45*(3), 477-484.

Seymour, J., & Clark, D. (1998). Phenomenological approaches to palliative care research. *Palliative Medicine, 12*, 127-131.

Seymour, J. E. (2000). Negotiating natural death in intensive care. *Social Science & Medicine, 51*, 1241-1252.

Task Force on Palliative Care. (1997). Precepts of Palliative Care. Retrieved March 19, 2003, from http://www.lastacts.org/docs/profprecepts.pdf

Taylor, J. P., & Taylor, J. E. (1998). Emergency nursing process and nursing diagnosis. In L. Newberry (Ed.), *Sheehy's Emergency Nursing: Principles and Practice* (4th ed., pp. 9-15). St. Louis, MO: Mosby.

Timmermans, S. (1999). *Sudden death and the myth of CPR.* Philadelphia: Temple University Press.

van Manen, M. (1990). *Researching lived experience.* Albany, NY: The State University of New York Press.

von Gunten, C. F., & Martinez, J. (1998). A program of hospice and palliative care in a private, nonprofit U.S. Teaching hospital. *J Palliat Med, 1*(3), 265-276.

Wachter, R. M., & Shojania, K. G. (2004). *Internal bleeding: The truth behind America's terrifying epidemic of medical mistakes.* New York: Rugged Land.

Walters, D. T., & Tupin, J. P. (1991). Family grief in the emergency department. *Emergency Medical Clinics of North America, 9*, 189-207.

World Health Organization. (1990). *Cancer pain relief and palliative care.* Geneva, Switzerland: Author.

CHAPTER SIX

Dissertation Summary

The ED is a place of action and transition. However, it is a major place of dying in the US. Even though we confront transition in this rescue area, clinicians are not often cognizant of the types of death they attend. Care at the end-of-life and the incorporation of palliative care precepts in the ED has been poorly understood and not well articulated. This dissertation is a thick description of end-of-life experiences in one ED with hopes of increasing consciousness of how we attend to death and dispel the myth that the ED is solely a place of transition.

Chapter Highlights

Chapter Two is a description of ED culture and characteristics with a review, critique, and theoretical examination of the applicability of current end-of-life models to ED care. Current end-of-life models that are based on chronic care or oncology models are difficult to apply in the ED setting. The limitations of these models are that they do not allow for the uncertainty of prognosis or for mortality in sudden illness or injury; do not take in account unpredictability of the course of treatments; and cannot accommodate the suddenness of presentation of illness or injury or the sudden change in patient condition.

Chapter Three is a philosophical examination of end-of-life care in the ED in an effort to help us understand how core medical and nursing values are embodied as care practices and ethical comportment. This chapter integrates Aristotle and other philosophers' notions of *phronesis* and *praxis* with Merleau-Ponty's ontological notions of *intentional arc* and *maximum grip* in the context of the culture and practices at the end-of-life in the emergency department setting.

Chapter Four is a review of phenomenology as a research methodology to understand how the caring practices of ED clinicians for dying patients can help overcome the sense of loss of self-understanding, sense of alienation, moral dilemmas, and loss of social integration for clinicians, patients, and families. As stated before, this reclaiming of understanding allows us to see and understand more fully the caring and even potentially healing practices of clinicians for patients and families in crisis that constitute the foundation of nursing and medical practices. Interpretive projects can illustrate notions of good practice and the knowledge embedded in advanced levels of practice. By articulating these practices, we can confirm good practices, explore additional possibilities, and use them as a basis for new visions of practice (Benner & Wrubel, 1989).

Chapter Five is the dissertation study that describes the seven trajectories of how patients approach death and die in the ED. These seven trajectories are: 1) dead on arrival; 2) resuscitation in the field, resuscitative efforts in the ED, died in the ED; 3) resuscitation in the field, resuscitative efforts in the ED, resuscitated and admitted to the hospital; 4) terminally ill, comes to the ED; 5) frail, hovering near death; 6) arrives at the ED alive then arrests/dies suddenly in the ED; and 7) potentially preventable death by omission or commission.

Four additional manuscripts are anticipated from this dissertation research: the social context of dying in the ED, the meaning of the term "everything" in the emergency setting, end-of-life and palliative care interventions in the ED, and spirituality in ED end-of-life care. These manuscripts will be preliminary reports to set the stage for a larger multi-site research project.

The NIH has prioritized funding for research investigating end-of-life and palliative care in rural and frontier areas (National Institutes of Health, 2005). This dissertation research is a first step to address one issue posed by the NIH Consensus Panel (National Institutes of Health, 2004) calling for an improved understanding of the "end-of-life" and its "transitions" in the frontier area of the emergency department.

However, there are many areas for additional research. A large, multi-center interpretive ethnography studying the communication patters, decision-making, and the social context of dying in the emergency department will help clinicians be more astute in their recognition of the clinical situation and incorporate appropriate end-of-life measures and bereavement interventions in their care of the patient and family in the emergency setting. In addition, a multi-center ethnographic study can help identify institutional structures and processes that influence care of the patients approaching death and dying in the ED.

A descriptive articulation of the various trajectories can add a new vision of caring to the scope of practice and duty of ED clinicians. Understanding the trajectories and discussion of the clinicians' actions and communication strategies can elucidate how each of the trajectories, if recognized earlier, could benefit from anticipatory planning and creation of guidelines for care at the end-of-life in a time of high-stress and crisis. A thick description of current "best practices" in EDs can help create guidelines for ED end-of-life, palliative, and bereavement care.

CHAPTER SIX REFERENCES

Benner, P. E., & Wrubel, J. (1989). *The primacy of caring*. Menlo Park, CA: Addison-Wesley.

National Institutes of Health. (2004). *National Institutes of Health state-of-the-science conference statement*. Retrieved January 21, 2005, from the World Wide Web: http://consensus.nih.gov/ta/024/024EndOfLifepostconfINTRO.htm

National Institutes of Health. (2005). *National Institute of Nursing Research 2006 Areas of Research Opportunity*. Retrieved May 29, 2005, from the World Wide Web: http://ninr.nih.gov/ninr/research/dea/2000AoRO.html

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