PHYSICIAN'S EXPERIENCES WITH DEATH AND DYING: A PHENOMENOLOGICAL STUDY

Deborah Jo Corker

Follow this and additional works at: http://opensiuc.lib.siu.edu/dissertations

Recommended Citation

PHYSICIAN’S EXPERIENCES WITH DEATH AND DYING:
A PHENOMENOLOGICAL STUDY

by

Deborah Jo Corker

M. Div., Fuller Theological Seminary, 1983
M.S.C.P., Alaska Pacific University, 1995

A Dissertation
Submitted in Partial Fulfillment of the Requirements for the
Doctorate of Philosophy Degree

Interdisciplinary Program
Health Education, Educational Psychology,
and Curriculum & Instruction
in the Graduate School
Southern Illinois University Carbondale
August 2010
DISSERTATION APPROVAL

PHYSICIAN’S EXPERIENCES WITH DEATH AND DYING:
A PHENOMENOLOGICAL STUDY

By
Deborah Jo Corker

A Dissertation Submitted in Partial
Fulfillment of the Requirements
for the Degree of
Doctorate of Philosophy
in the field of Education
An Interdisciplinary Program in
Health Education, Educational Psychology,
and Curriculum & Instruction

Approved by:
Dr. Judy C Drolet, Chair
Dr. Joyce Fetro
Dr. Sharon Gilbert
Dr. Jacqueline Scolari
Dr. Kim Asner-Self

Graduate School
Southern Illinois University Carbondale
May 4th, 2010
AN ABSTRACT OF THE DISSERTATION OF
Deborah Jo Corker, for the Doctor of Philosophy degree in Education, an interdisciplinary degree in Health Education, Educational Psychology and Curriculum and Instruction, presented on May 4th, 2010, at Southern Illinois University Carbondale.

TITLE: PHYSICIAN’S EXPERIENCES WITH DEATH AND DYING:
A PHENOMENOLOGICAL STUDY

MAJOR PROFESSOR: Dr. Judy C. Drolet

End-of-Life, the topic of the decade of 1990-2000, brought the focus on how we die in America. Death encompasses cultural, ethnic, spiritual, social and physical elements, which are often played out under the guidance of a medical provider or in medical setting. As society redefines how we wish to handle our dying process and end-of-life care, medical society must also redefine how it trains its physicians and prepares them to handle our death and dying. Medical school curriculum has added some end-of-life training, but there are limitations in time and scope of training available.

This qualitative phenomenological study attempts to gain the physician’s essences, meanings and understanding surrounding death and dying. Starting with themes revealed in literature, in-depth interviews were used to ask selected physicians providing care: How does death affect them? Are physicians receiving adequate training in end-of-life care? Does the medical culture still see death as failure? How do they find meaning in end-of-life care? Using three different groups of physicians: early in career, mid-career, and retired, this research attempted to examine the phenomena of death and dying over apparent time and developmental experiences of physicians.

Results: Physicians have not been adequately trained to handle end-of-life care. Communications skills, specific end-of-life care training and support for physicians dealing with death and dying are needed.
ACKNOWLEDGEMENTS

Thank you to everyone who continued to believe in me, especially my parents Susan and John Corker who never gave up supporting, prodding, and not letting me give up. To all the faculty and staff at graduate school who encouraged and helped me, thank you it was more help than words can express. This study is for every patient and family member who suffered just a little more than they needed to at the end of their life or the life of a loved one, because their physician didn’t have end-of-life care skills.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>CHAPTER</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>i</td>
</tr>
<tr>
<td>ACKNOWLEDGMENTS</td>
<td>ii</td>
</tr>
<tr>
<td>CHAPTERS</td>
<td>iii-viii</td>
</tr>
<tr>
<td>TABLES</td>
<td>ix</td>
</tr>
<tr>
<td>CHAPTER 1 – Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Background of Problem</td>
<td>3</td>
</tr>
<tr>
<td>Statement of Problem</td>
<td>7</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>15</td>
</tr>
<tr>
<td>Need for the Study</td>
<td>16</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>24</td>
</tr>
<tr>
<td>Research Questions</td>
<td>26</td>
</tr>
<tr>
<td>Research Design</td>
<td>26</td>
</tr>
<tr>
<td>Study Participants</td>
<td>26</td>
</tr>
<tr>
<td>Data Collection</td>
<td>29</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>30</td>
</tr>
<tr>
<td>Limitations</td>
<td>30</td>
</tr>
<tr>
<td>Delimitation</td>
<td>33</td>
</tr>
<tr>
<td>Assumptions</td>
<td>33</td>
</tr>
<tr>
<td>Definitions</td>
<td>34</td>
</tr>
<tr>
<td>Summary</td>
<td>35</td>
</tr>
</tbody>
</table>
CHAPTER 2 – Literature Review

Hospice

Palliative Care

Communication Skills

Advanced Directives

Caregivers

Cultural Issues

Ethics

Spirituality

Psychological Issues

Health Literacy

Medical End-of-Life Curriculum

Hidden Curriculum and Medical Culture

Good Death

Physician Healer-Humanizing medicine

Physician Attitudes on Death and Dying

Research Foundation Information

Summary

CHAPTER 3 – Methods

Purpose of study

Phenomena under study

Research Questions
Theme One - Personality and gender differences play a role in how a Physician deals with patients, the practice of medicine, and with end-of-life issues.

Theme Two – The role of death in medical practice has mixed or conflicting function and importance.

Memorable patient deaths

Death is failure

Death pronouncements

Medical culture’s hidden curriculum about death
Theme Three – Physicians believe experience is the best teacher in dealing with death.......................................................142

Theme Four – Physicians believe communication skills are more important than end-of-life skills .............................................144

Mentoring and modeling.....................................................147

Advance directives...........................................................148

Theme Five - Physicians’ moving from cure to care, focusing on quality of life instead of continuation of life, and trusting patient make decisions about end-of-life care.......... ....151

Hospice and palliative care .................................................151

Patients role in care ..........................................................153

Quality vs quantity of life ...................................................153

Impact of patient’s death....................................................157

Theme Six – Little time for death exists in medical practice professionally or personally.......................................................159

Lack of physical time........................................................159

Lack of time is institutional ...............................................160

Take just a little time/Mentoring .........................................161

Lack of emotional time and energy ..................................161

Interdisciplinary teams extend time ....................................162

Theme Seven - Coping mechanism for physicians dealing with end-of-life issues include spirituality, turning inward and family support.................................................................163

Physician & Patient spirituality ..........................................163

Physician support for emotional issues .........................165
Appendix F – ACGHE requirements for end-of-life training, National Consensus Conference on Education for Care Near the End-of-Life, New End-of-Life Guidelines

Appendix G – Death Pronouncement Protocol

Appendix H – Interview Questions and Expert Panel

Appendix I – Themes with Expanded Components

Appendix J – Outline Guide of Procedures for Analysis of Data

Appendix K – Concept of Good Death Measure Characteristics

Appendix L - Hippocratic Oath, Two Versions

Appendix M – Spiritual History

Appendix N – Demographic Information Data Sheet

Appendix O – Informed Consent Form & Consent to A/V Taping

Appendix P – Human Subjects and Committee Approval Paperwork

Appendix Q - Additional Resources

Curriculum Vita
LIST OF TABLES

Table 1 - Participants by research group…………………………………………123
Table 2 - End-of-life Training received by participant physicians………………126
CHAPTER I
INTRODUCTION

A famous story about the Buddha (Siddhartha Gautama, 563-483 BCE) tells of his encounter with a teenage mother who has lost her infant to death. She is frantic with grief and outrage and has traveled from village to village, carrying her child on her hip, looking for a miracle that could bring the child back to life. Someone tells her that only the Buddha, who is preaching in a nearby town, would be capable of such a miracle. When she arrives at the town and finds the crowds around the Buddha, she pushes her way through and stands before him. “If you would perform a miracle and bring my child back to life, I would do anything in return,” she says with touching sincerity. The Buddha sees the depth of her grief and says, “If you bring me a mustard seed from a home in which there has been no death, then I will perform the miracle.” This sounds like a small task and she readily agrees, setting off with the deepest gratitude in her heart.

She travels from door to door in this and other villages, carrying her dead child and asking at each house if there has ever been a death. She hears about many difficult deaths and much disease and her heart is opened to other people’s pain. Eventually, she realizes that all families have been touched by death and she returns to the Buddha. “I know now what you were trying to teach me,” she says. “I am not alone in my misery.”
All people must endure death, not only their own, but others around them.” (Young, 1996, p.188-89).

Death, dying, and bereavement are fundamental and pervasive aspects of the human experience. Individuals and societies can only achieve fullness of living by understanding and appreciating these realities. The absence of such understanding and appreciation may result in unnecessary suffering, loss of dignity, alienation, and diminished quality of living. Therefore, education about death, dying, and bereavement is an essential component of the educational process at all levels, both formal and informal (International Work Group on Death, Dying and Bereavement, 1994, p. ii).

The above two statements encompass 2,500 years of human history to address the one phenomenon of life that humanity cannot overcome: death. The phenomenon of death has been embraced, avoided, and approached from every possible avenue. In the 21st century, Americans turn to medicine to defeat, or at least keep at bay, the adversary: death. In truth, we will be no more successful than our ancestors in defeating death. Today, the control we have over death resides in how we have developed ways to handle the causes of death; controlling physical body functions, slowing down the dying process, or prolonging the natural progression of a disease, disability, or physical defect. Death remains a reality. Even physicians who are expertly trained in curing disease, handling disabilities, and prolonging life, must still face death. Death is part of the cycle of life. Death and dying are phenomena that are unavoidable.
When asked about my goal for my work, or more specifically, the work contained within this study, I reply succinctly: “I’m working on designing curriculum to teach doctors how to deal with death and dying.” The almost unanimous response is “They sure need it!” There are some qualifying disclaimers. Some doctors deliver bad news well. Some physicians take time to explain the disease and dying process. Some doctors “show up” for the family as the patient died. Unfortunately, however, an overall pervasive sense of disappointment exists in the medical profession’s methods of dealing with death and dying.

**Background of the Problem**

Dying in America today has changed significantly in the last 100 years when people lived and died at home. Not so long ago, doctors provided care in the home, as did the undertaker (DeSpelder & Strickland, 2005).

Only a century ago, death was common at every age and dying usually quickly followed the onset of disease or injury. Now, public health measures and health care prevent or cure many previously fatal illnesses or injuries, allowing most Americans to live into old age. Medications and treatments now often allow prolonged survival with serious chronic conditions…Rather than a brief, well-defined period, the “end of life” today refers to a prolonged, uncertain period of difficulty because many Americans today live their last years with an advanced, chronic illness (The Agency for Healthcare Research and Quality (AHRQ), 2004, Chap 1, p.1).
Currently, the natural course of death and dying, most often, has been replaced by technological, professional, and institutional treatment (Mesler, 1995). Caregivers frequently provide clinically inappropriate or unwanted (by patients) treatments, or under use effective treatments to relieve pain or reduce other physical and psychological symptoms. These practices cause unnecessary suffering and distress in efforts to prolong life (SUPPORT (The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), 1995; Institutes of Medicine (IOM), 1997 & 2003; Bomba, 2005).

“Improvements in medical science and health care have gradually changed the nature of dying” (National Institute of Health (NIH), 2004, Introduction section, ¶1). When Rene Laennec serendipitously invented the stethoscope in 1816, it was considered to be the first technological medical diagnostic breakthrough. The microscope, ophthalmoscope, laryngoscope, and x-ray, soon followed allowing physicians to see and hear parts of the human body previously inaccessible. In 1957, Frank Pantridge and John Geddes introduced cardiopulmonary resuscitation (CPR) changing radically the possibility of saving a life and holding off death. From 1964 to 1978, vaccines for measles, mumps, rubella, chicken pox, pneumonia, and meningitis were developed. Diseases that once decimated human populations became no more than childhood diseases where death became the exception, rather than the rule (World Health Organization, Child and Adolescent Health and Development (CAH) overview of world child epidemiology statistics, 2000). “Historically the definition of death has been closely related to the extent of medical knowledge and the availability of technology. For the centuries prior to
artificial respirators, death was defined as the absence of breathing” (DeMiranda, Doggett, & Evans, 2005, p. 12). With advances in knowledge of human physiology the definition of death moved from just a person’s breathing to included the beating heart, blood and oxygen components. Development of technological advances in supportive therapy, resuscitation, cardiovascular assistive devices, and organ transplantation further complicated the decision about when death occurs and how to define death. With development of the EEG, brain function became a component of life and death. Today, clinical death requires termination of activity in three areas: the lungs, heart, and brain (Dickerson, 2002, Humber, 1991, Ott, 1995). Because of advancements in medical technology, we have been forced to reexamine the once simple definition of death.

Medical technology has created new ethical dilemmas for medical professionals. Medical technology has forced the re-evaluation of the traditional definitions of life and death…. The concept of death is also being revisited as patients can now be resuscitated after prolonged heart, lung, or even brain failure (DeMiranda, et al, 2005, p. 13).

Life and death are being redefined based on the technology available, not the natural course of a person’s life. Humanity is replaced with technology. Traditionally, American culture embraces the new and seeks to vanquish that which threatens prosperity or advancements. Technology is seen as a tool in this quest. This belief includes the idea that technology should be the foundation of the medical profession and part of overcoming death and dying (Sanders, 2004). Technological advances have brought medicine the ability to do, to see, to
perform, to cure diseases and dysfunctions of the human body that stretch our imagination and possibilities. Technology also allows the medical profession to prolong life, often at great cost, both financially and emotionally, to the dying and the living (Bomba, 2005).

There is nothing neutral about technology. For every intended benefit, there can be identified an unintended harm. Postman argues that technology creates its own imperatives and subsequently, a social system to reinforce these imperatives. When it comes to medical technology, technology changes medicine by redefining physicians, redirecting their focus, and reconceptualizing how they view their patients and illness. In essence, physicians don’t use technology to do what they do. Rather, they are ‘used’ by technology (Sanders, 2004, p.7, Postman, 1992).

The use of technology is a two-sided coin. Just as technology directs physicians, so too, patients are motivated by technology. A patient may want the best, the latest, the most technological treatments, even when existing, long-standing, and non-technical procedures are effective (Sanders, 2004).

As medical technology progresses, it raises as yet unresolved medical, ethical, and legal questions such as: What are physicians’ obligations regarding patient treatment, or when is enough, enough? “Until society decides, it will not be clear what is beneficial or undesirable in regard to the intersection of human values, morals, and ethics with respect to innovative medical technologies” (DeMiranda et al, 2005, p. 13).
Clearly, expressing the attitudes of an American culture that places high credence on technology and science, and demonstrates an avoidance of death, the National Institutes of Health, December, 2004, conference published this statement on improving end-of-life care.

End-of-life care has emerged as a field of scientific inquiry in the past two decades. It is a vitally important area to public health in terms of resource considerations and to individuals. All people will die. Most deaths are not sudden. Most persons will experience death also as caregivers or family (NIH, 2004, Introduction).

Whether one is a grieving mother or a physician with all of modern technology at one’s disposal, death can not be avoided. Whether or not we believe in the miracle of reincarnation, or postponement of the inevitable by technology, death still rises victorious. If we equip our medical caregivers with technology to postpone death, then we must equip these same caregivers with the skills and expertise to deal with death and dying when it comes (Sanders, 2004; Bomba, 2005; DeMiranda et al, 2005).

**Statement of the Problem**

Death and end-of-life concerns are not simple, straightforward issues. They can be approached from numerous aspects, for example: medical, ethical, spiritual, cultural, social, and psychological. Although death is inevitable, Americans have forced it to be shadowed, removed from our daily existence, something to be feared instead of acknowledged. According to Phillipe Aries, “the more man tames the earth, the more savage death becomes. This is so for three
reasons. First, death becomes more foreign as it holds a less prominent place in everyday life. Second, man steadily discards the symbols and rituals that once held death in check. Third, he is increasingly terrified by the death that takes the self and the earth which he, the modern person, cherishes above all else” (Aries, 1974, p.23).

According to Canine (1996), Americans expend great energies toward fending off death. He lists three reasons for this:

a) The secularization of American society - without a religious perspective death’s meaning is uncertain.

b) Americans’ diluted intimacy with death – traditions and rituals surrounding death are disappearing. We have de-ritualized grief (Rando, 1984) leaving griever and their supporters without guidelines.

c) The growth of impersonal technology. Hospitals, nursing homes, and institutions house the dying person who has become, literally and figuratively, “detached” from loved ones long before death (p. 5).

Traditional society externalized the dead and was thereby able to bury the dead, mourn the dead, pray for the dead – in effect control the dead – whereas modern society increasingly internalized the dead, and thus they escape the bonds of our rituals and the space which we have allotted them. The dead are now alive as they never were before (Amato, 1985, p. 68).
American’s discussion of death is, at least, uncomfortable, and generally avoided. The belief that death is a natural part of life has become foreign (Amato, 1985, Canine, 1996, Hamilton & Reid, 1980, Kubler-Ross, 1969).

In the 1960’s, Dame Cicely Saunders and Elizabeth Kübler-Ross brought death and dying back into the vocabulary of both our medical culture and society at large. Almost everyone can cite Kübler-Ross’s five stages of dying: denial, anger, bargaining, depression, and acceptance, which have become the benchmarks in all areas of dying, grief, and mourning (Kübler-Ross, 1969).

Kübler-Ross gave us a vocabulary and way to define dying; Dr. Saunders gave us the method to deal with dying. Most people in the United States are familiar with hospice, even if they don’t know its origins, nor can explain the concept.

Dame Dr. Cicely Saunders, in 1967, opened St Christopher’s Hospice in London. She recognized that dying patients and their families were receiving inadequate care in hospitals and at home. She created the Hospice for the Dying movement (Hamilton & Reid, 1980). “At St. Christopher’s, therefore, death is not seen as an academic subject—a phenomenon of interest to the pathologist, theologian, psychologist, anthropologist, or nurse. Instead, it is seen as a very human event, a legitimate and normal process” (Hamilton & Reid, 1980, p.48). Death became part of the medical process and medical culture in that setting. The four-fold concept of hospice care includes the physical (medical), and non-medical: care of the spiritual, psychological and social aspects of individuals and families who are dying and facing death. The spiritual, psychological, and social
aspects had been alienated from traditional Western medicine, in general, but now are included in the medical hospice process (Hamilton & Reid, 1980).

In 1959, Herman Feifel published “The Meaning of Death” and was subsequently dubbed the father of the thanatology movement (Andrus, 1997, p. ix). In 1965, Robert Fulton published a sociological perspective on death (Ellis, 1992). Psychology, the study of human behavior and the mind of man, however, remains amazingly reticent about death. Death’s influence, impact, and effect on human behavior and emotional well-being is surprisingly under-researched, rarely clinically examined, and selectively taught (DeSpelder & Strickland, 2005, Corr, 1998). Today, thanatologists know the names of Wass, Rando, Worden, Corr, Doka (Appendix A) as educational bellwethers who reintegrated death, dying, grief, and loss, back into daily life. But their numbers are few. Most exist within the confines of other disciplines, such as gerontology, psychology, health education, or social work. The American Psychological Association (APA) lists end of life issues as one of its program areas. Grief and bereavement appear in the DSM IV (V62.82 Bereavement), not as pathology, but a legitimate area for treatment. Unfortunately, it is the exception to find a psychology or counseling program that includes curriculum that covers grief and loss (Duggan, 2000; Ratner & Song, 2002; Werth, 2002).

In 1990, a new era of death awareness began in American society. George Soros created the “Death in America” project. The Robert Wood Johnson Foundation focused on end-of-life care, creating the Last Act initiative, based in part on the information gathered by SUPPORT Study (The Study to Understand
Prognosis and Preferences of Outcomes and Risk of Treatments, Hasting Center Report, 1995). Over four billion dollars from private funders were expended on end-of-life issues between 1990 and 2000. The vast majority of this money was spent on identifying what Americans think constitutes a good death, how Americans should care for the dying, and what appropriate medical care at the end-of-life entails (Appendices A, C, E, F, K, Q).

To better understand current American public values about end-of-life issues, public discussions, focus group research, professional society experts, and the community at large came together to identify a framework for end-of-life issues (Steinhauser et al., 2000a & b; Teno et al., 2001; IOM, 2003). As expected different groups used different terminology, and had different frameworks for discussing end-of-life care, but surprisingly agreed on the important components. Basically they all include:

1) “management of symptoms
2) spiritual and personal growth
3) a familiar setting, surrounded by love ones
4) understandable information to guide decision making and planning
5) confidence that one will not be a financial, emotional, or physical burden to family members
6) the right of self-determination and control of treatment choices” (IOM, 2003, p. 5).

The AHRQ publication, End-of-Life Care and Outcomes (2004) lists the major domains for evaluating the end-of-life experience as:
1) pain and other symptom prevention and treatment
2) adequate support for families and caregivers, including bereavement
3) continuity of health care
4) treatment consistent with patient and family preferences and medical knowledge
5) effective, empathic communication about diagnoses, prognosis, and care plans
6) well-being, including addressing existential and spiritual concerns
7) function and self-determination
8) length of survival (Chap 1, p.2).

In response to this decade of research and public attention on end-of-life issues, the medical community began talking about death and dying as a component of medical care. The medical community heard voices from beyond their professional circle expressing concerns about end-of-life care. Due to life sustaining and extending medical advancements, end-of-life issues became more and more complex. The American public spoke loudly and clearly regarding concerns, needs, and desires regarding end-of-life issues. The medical community responded by considering how end-of-life issues should be incorporated into education and formal practice of medicine.

The Association of American Medical Colleges (AAMC) reviewed its criteria for medical schools, focusing on physician relationships to patients, institutional policies, medical ethics, societal ethics and ideas, cultural and spiritual issues, providing end-of-life care, palliative care, hospice care, family
dynamics, advocacy, and communication skills as some of the central concentrations that need to be addressed within their medical training and integrated into medical perspectives. The outcome was the AAMC Medical School Objectives Project (See Appendix F) that resulted in medical schools across the country investigated the scope, strengths, and weaknesses of medical training being provided in the above listed areas. The subject area of medical humanities curriculum emerged to incorporate these areas.

Death education, although clearly integrated into the undergraduate educational component, still maintains only a small toehold in the medical school curriculum (Dickenson, 2002). In 2006-2007, physicians emerged from medical schools with some end-of-life care training. Graduate programs offer elective rotations in palliative care or hospice. These electives are chosen by a minority of students and are not a guarantee that every physician will have some hands-on practical exposure to death and dying. Unfortunately, physicians currently in the field, working every day, may not have the skills or training to deal with death and dying, professionally or personally.

At the 2006 annual Association of Death Educators and Counselors (ADEC) conference, in one of the breakout sessions a medical social worker, whose job is a hospice worker in a large hospital, shared her personal experience when her family members were in a fatal accident. Her son was killed, and her mother died shortly thereafter in the hospital. The social worker knew the hospital rules for access to patients in critical care situations that involved a death. She had assisted others in situations similar to her own now.
Yet, on this night, she was not a hospital staff person, but a family member. She was denied access to her own dying family members. She was not provided with the support she provided others. Her knowledge of the hospital, its policies, and procedures, could not overcome the decisions made by the attending physician to deny her access to her family on that night.

When her time came to talk with the doctors, the social worker stated that she seethed at the rehearsed forced pause that was scripted for the doctor after giving minimal information and a pronouncement of a death. She watched the doctor’s every choreographed movement, knowing what came next, she shared how she felt helpless and dehumanized. In her job, she has sat many times with other family members trying to assist others in similar situations. Her skills in helping patients cope with the associated emotions of a death, the subsequent decisions, and medical interactions that occurred, on this night were rendered useless.

After the event, she voiced her frustrations, concerns, experiences, and complaints to the hospital. Hospital administration responded to the issues raised. Acknowledgements of poor decisions made were attributed to being short staffed on that fateful evening. Changes in procedures at the hospital subsequently occurred. To this day, however, the doctor who denied her access and sat in the family room delivering the death script, has not acknowledged responsibility for mishandling the patients and the family that night. He failed to realize the additional trauma caused to the family because of his decisions and his handling of two people’s death. The doctor says he followed medical
procedures. The truth is, this doctor did not engage in the phenomena of death or deal with the experiential reality of death and dying with this family or himself. His medical procedures, sans human engagement, have had consequences long past that actual event. (Jill Englар seminar presented at the annual ADEC Conference, 2006, April).

It should be noted that some hospitals have trained doctors how to deliver bad news with their own guided script. From this story, a script, which is a tool often used without additional training, may be insufficient to adequately handle a real life end-of-life situation. There are programs available for those who do not have hospital scripts or training in end-of-life issues: Educating Physicians on the End-of-life Care (EPEC), End of Life Physician Education Resource Center (EPERC), Program in Palliative Care Education and Practice (PCEP), Harvard Medical School faculty development, Stanford Faculty Development Center, End-of-life care curriculum for medical teachers. All are designed to assist the physician to deliver bad news, engage in end-of-life issues, and do it in a manner that is productive for patient, family, and physician.

**Purpose of the Study**

The purpose of this study was to describe how physicians construct meaning of the phenomena of death and dying within their medical profession. A secondary purpose was to examine how physicians integrate the reality of death and dying within their professional practice.
Need for the Study

Extensive time, effort and money have gone into studying end-of-life issues in the past decade and half, as suggested by reports that are published in professional organizations, such as The National Hospice and Palliative Care Organization (NHPCO). Key outcomes were created for end-of-life care (See Appendix C). Foundational areas include: focus on the patient, quality of life, and a good death. A concerted effort has been made to identify needs of the patients (Last Acts, 2002, PDIA, 2003, SUPPORT, 1999). In contrast the needs of physicians, both professional and personal, have not been adequately addressed. Death is common to all – physician and patient – and both go through it together. The medical community must address the needs of physicians regarding end-of-life issues in their personal spiritual, psychological, social, cultural, and individual beliefs, just as is being done for patients and families.

One wonders why doctors, who make life and death decisions on a daily basis, have such a difficult time with the actual processes of dying and acknowledgment of death. “This century’s scientific and medical advances have made living easier and dying harder,” says Dr. Kirsti A. Dyer in her 2001 article, Caring for the person, not just the patient in end-of-life care.

…doctors are taught in medical school to view death as a failure…

Medical education places a high priority on teaching how to diagnose, treat and cure-the concerns of the living. Teaching how to help patients to live until they die has been ignored [italics added]…Why can’t a doctor
take the time to hold the patient’s hand and just be there? The answer is simple. In taking someone’s hand, a doctor risks losing the objectivity and the distancing we are so carefully taught in training and possibly connecting with someone who is dying (Dyer, 2001, p.2).

In the medical culture, death is failure. That statement alone may contain all the information necessary to understand why doctors have such difficulty dealing with death and dying. “These attitudes coalesce into practice patterns that tend to devalue the provision of palliative care even though the public increasingly asserts the importance of humane medical care at the end of life” (Fins & Nilson, 2000, p. 662). If every aspect of a physician’s training and medical culture, excluding those who specialize in palliative and/or hospice care, focuses on defeating or delaying death, how then can we, as patients, expect doctors to deal with our death and dying effectively? Physicians need training to assist them in addressing their own attitudes, beliefs, and values surrounding death and dying and their role in medical culture.

Dr. Boris Veysman, in an editorial in Academic Medicine (2005), talks about walking a new medical student through her first death of a patient: “That day was unlike any other since I began in this profession. I did what I wish was done for me when I was ‘growing up’ as doctor. See one, do one, teach one” (p. 290). If we expect healthcare professionals to assist those in the process of death, dying, grief, and loss, we must equip them with necessary skills and personal awareness of death, dying, grief, loss, and perceive death, as a natural process of life.
These skills, including a personal awareness and understand of death as a natural process, should be integrated in the medical school’s required curriculum. Until the late 1990’s, the basic format in medical education changed little since publication of the Flexner report in 1910 (Hafferty, 1998; Schindler, 1995; Wear, 2002; AAMC Project on the Clinical Education of Medical Students, 2005). In 1999, The Association of American Medical Colleges Medical School Objectives Project addressed some issues related to death and dying; including end-of-life care, communication skills, physician-patient relations, and professionalism. Medical schools across the country investigated the scope and weaknesses of medical training surrounding end-of-life issues. Changes are being implemented (See Appendix F, Dickenson, 2002).

In the past decade, medical curriculums have grown to include specific topic areas. One topic is patient care, which includes interpersonal skills encompassing basic communication skills, attentive listening skills, interview techniques, and assisting patients to become health literate. Because of available technology, doctors also must be aware, and willing, to confront ethical and end-of-life issues today. Additionally, the area of “professional development” has grown to include staying abreast of current medical knowledge, identifying personal strengths and weaknesses, developing coping strategies, taking and responding to constructive criticism appropriately, and learning how to seek help or rely on a medical team (AAMA & AAMC Reports, 1999, 2001).

More and more medical curriculums are incorporating either problem-based learning, or performance-based assessments, which provides the student
physician the opportunity to experience “real-life” situations and respond in situ. This type of learning serves not only to give hands-on experience and assess existing knowledge, but also to develop on-the-ground problem solving and responsive action, by taking a medical student out of the textbook and into day-to-day medical practice (Schindler, 1995; Walters 1995; Dickinson, 2002; Braddock Eckstrom, 2004).

The online catalog description for the medical school curriculum at University of California San Francisco School of Medicine, which debuted in 2001, states under its Innovation section: “The curriculum challenges old assumptions about the way students learn and encourage their active participation in the process of study and investigation. Medical education must inspire…” (University of California, San Francisco, School of Medicine, Competencies and Outcome Learning Objectives for the Doctor of Medicine Program, http://medschool.ucsf.edu/).

The University of Massachusetts (UMASS) Medical School at Worcester online curriculum overview tells the reader that “the practice of medicine is undergoing a monumental transformation. Society expects the physician to be both a skilled practitioner and a gifted communicator, intellectually driven and compassionate, sensitive to the needs of individuals and responsive to the need of populations” (University of Massachusetts Medical School, School of Medicine Curriculum at a Glance, http://www.umassmed.edu/som/curriculum/index.aspx).

The University of North Carolina School of Medicine mission states, “the curriculum cannot expect to incorporate all of those skills that a competent
practicing physician acquires during a lifetime of practice and learning…”

(University of North Carolina School of Medicine, The MD Curriculum
http://www.med.unc.edu/cme/ mission.htm). These three curriculum statements
realistically acknowledge both the expectations for physicians and all that a
physician’s knowledge must attempt to encompass, as well as an unspoken
acknowledgement of the informal or hidden curriculum that also drives physicians
in training.

This development and expansion of the medical educational curriculum
focuses on patient relations and patient care. Teaching methods have changed
from purely didactic to include small groups, mentoring, and other interpersonal
educational opportunities. Still, little consideration has been given to the
individual medical student and his or her need for personal introspection
regarding death, ethics, and personal values and attitudes

“In analyzing the informal curriculum, Hundert and colleagues concluded
that many students suppress humanistic values simply to get on with their work.
These authors also believe that the culture of the medical wards is antithetical to
the reflection and self-discovery needed for professional development” (Branch,
1998, p. 740). “As Turner and Kelly observed, ‘Doctors may be well-equipped for
the biomedical aspects of illness but not for the challenges of understanding the
psychological, social and cultural dimensions of illness and health” (Kirsner,
2002, p.1909). The acknowledgment has arrived: doctors need more than just
biomedical training, they also need psycho-social training. The expectation is
physicians will engage with patients and with death, but if they cross that line
from objectivity to engagement are the physicians prepared? “If medical culture imposes physical or psychological constraints on practitioners then it is our very conception of medicine, reflected in the training process, and its potential to spoil the human beings it turns into doctors that should be the subject of our concern” (Kirklin, 2001, p. 89).

When physicians are dealing with end-of-life issues, O’Gorman (1998) stated that "once a death label has been attached, the individual is perceived as an illness rather than a human being…The effect is to distance the professionals from the patients and their relatives…” (p. 1132). When confronted with incurable illness the physician disengages, often failing to realize the importance of their role during end-of-life. “It is unusual for physicians to identify end-of-life care as an area of competency that can be improved or updated,…What complicates this further is our inability, as a medical culture, to clearly define a “gold standard” for end-of-life care” (Levy, 2001, p. N56-N57).

Dr. Carolyn Muller, (2004) a gynecologic oncologist gives an aperçu of the life cycle.

From the first day of internship…we are taught to expend all of our energy maximizing the joyful experience of bringing a human life into the world…But what about the other end of this spectrum of life? Is the experience of leaving the world any less important than the experience of entering it? Although the specific technical skills needed to manage birth and death are distinct, the importance of the process and the impact it has on our patients, their families and ourselves cannot be underscored. Yet
the dying experience is never mentioned as a positive aspect of medical student, residency, or fellowship training. In fact, the absence of a focus on death and dying issues in medical schools perpetuates this subconscious omission of its important place in medicine and neglects the potential for personal fulfillment in the practice of medicine, leading new physicians to early experiences filled with fear, uncertainty, and helplessness” (p. 1315).

The subconscious omission of the importance of end-of-life allows medicine as a science to create a disconnection between treatment and human interaction. Karon Schindler in her article titled Humanizing Medical Education writes that “medical schools strive to make their education more humane and less dependent on rote memorization of a litany of facts divorced from their clinical application” (Emory Medicine, Spring 1995). For the past 10 years or more, medical schools have been reevaluating their curriculums and humanizing them. Kirsner (2002) tells us that “the patient-physician relationship is, in fact, a powerful therapeutic force, synergistic with medication” (p.1909).

Yet in 2007, when I say I want to educate doctors on how to deal with death and dying, the overwhelming response has been: “They sure need it!” Attention to communication skills and physician-patient interactions are still lacking something. I posit that ‘something’ is a doctor’s personal sense of awareness about their own beliefs, attitudes, and experiences with death and dying and how that translates to day-to-day interactions with patients and
professional practice. In phenomenological terms: allowing the phenomena of death and dying to rise to conscious awareness and influence personal practice.

A report in *Families, Systems, and Health* (2004) stated that “watching films that inspire compassion may make medical students more sympathetic to patients, more altruistic, and more understanding. This “Don Quixote effect” – in which imagination overcomes reality - could be introduced into the medical curriculum to help medical students develop more compassion, kindness, and caring…” (p. 447). In cinema, there is no responsibility. Medical students have the luxury of experiencing emotions for which they bear no accountability in the real world.

Three key words appear above: responsibility, emotion, accountability. These words raise specific questions. Does a physician have to remove emotion to be a responsible doctor? Do demands of the medical profession – the accountability for medical decisions - relieve the physician of the interpersonal responsibility of the physician-patient relationship? Medical curriculum changes seems to be addressing these questions, but one remains unanswered: If death is failure, does the medical culture prevent physicians from making meaning of death and dying, thereby preventing them from integrating their own understanding of death and dying into the reality of their professional practice?

Hafferty (1998) offers us insight into physician learning. “Not all of what is taught during medical training is captured in course catalogs, class syllabi, lecture notes…Indeed, a great deal of what is taught – and most of what is
learned – in medical school takes place not within formal course offerings but within medicine’s ‘hidden curriculum’ “(p. 403). Malterud and Hollnagel’s (2005) qualitative study offers this thought:

We never forget the dominant lesson from medical school: doctors are omnipotent, detached, and impersonal…Mutual trust in the relationship between doctor and patient is grounded on the presumption that relevant information and emotions should be shared…. Our study illuminates how vulnerability is a human quality, and the doctor does not always have the option of balancing the pros and cons of expressing emotion…(p. 348)

Whereas an illness may be approached clinically and dealt with scientifically, death is a human event, an emotional activity that may involve moral or ethical decisions. Even if a doctor can remain detached emotionally, the patient, family, caregivers are driven by the emotions that surround end of life. “Hunter reminds us that moral knowing is not separable from clinical judgment. Translated to the clinical context, the doctor’s perception and exposure of emotions are essential to understand patients and their problems and to recognize the distinctive relations character of general practice (Malterud and Hollnagel, 2005, p. 352).

**Significance of the Study**

The significance of this study is that it goes directly to the source - physicians. Instead of asking for family or patient needs, or others' beliefs about how physicians should do their job, the physicians are being asked directly. Studies have been conducted regarding curriculum taught and medical student reactions and responses. Studies have been done on what the patient, family,
and society think should be done at the end-of-life or in death and dying situations. Few studies have queried physicians directly about their actual practices, beliefs, and the impact death and dying of patients has on them personally. Only four studies, from the USA or UK, which deal directly with physicians’ emotions and attitudes surrounding the issues of death and dying, were known to this author when the interviews for this study were completed.

Another EBSCO search involving Medline, ERIC and Academic Search Premier was performed in March 2010. Fourteen articles were found that discussed medical students attitudes and emotions surrounding death and dying based on classes they received in communication skills, death and dying curriculum courses, hospice/palliative care training opportunities, and the hidden curriculum surrounding death and dying in medical culture. Two articles were found that discussed physician-patient discussions about end-of-life care and advance directives and why physicians avoid these topics. Only two additional articles were found that targeted physicians’ emotions and attitudes surrounding end-of-life care. A new audience for end-of-life care issues was noted in the journal articles. Several international hospitals and countries are addressing end-of-life care and included physician attitudes and emotional reactions in their studies. Many used comparative studies with other countries, included the USA.

An additional significance of this research is that is had been formulated and grounded with an interdisciplinary approach using health education, curriculum and instruction, and educational psychology. Physicians were addressed directly regarding the phenomenon and once the essence was
uncovered it was placed in the broader context of educational training, psychological components, curriculum design to see how death and dying can be addressed throughout the educational process.

**Research Questions**

To reveal the phenomenon under study, the following two research questions were developed:

How do selected physicians describe the essence and meaning of death and dying?

How do selected physicians interpret their understanding of death and dying and then integrate the reality of death and dying into their personal medical culture and practice?

**Research Design**

This qualitative study was built on a phenomenological research approach and designed to be descriptive. The phenomenon, for this study, is not the physiological processes of dying or physical death, but the psycho-social aspects – specifically how physicians construct meaning of death and dying, and then how they integrate the reality of death into professional practice. The physicians’ understanding of death evolves from the doctors’ personal worldview, experiences, and medical training/culture, which in turn affects and directs their interaction with patients and families.

This researcher holds the epistemological position that part of the training of physicians involves Social Constructionism. The practice of medicine is constructed within a group (physicians) and a context (medical culture) and then
perceived as the social reality. As a researcher examining the phenomenon of physicians/death or dying/patient interaction, the following questions come to mind:

1) How does the physician make meaning of death and dying within a social reality that defines death as failure?
2) If death is avoided, then what kind of care do patients receive?
3) When a patient dies, how does the physician cope with ‘failure’?
4) How does a physician become a healer people and not just a curer of disease?

While not specifically the research questions for this study, the essence of each is being explored via the interview process.

“The phenomenological research design is the study of essences; it seeks to uncover the meanings in our everyday existence” (van Manen, 1990, p 12). The phenomenological interview approach attempted to uncover and describe how these selected participant physicians perceive and understand attitudes and meaning surrounding death and dying within the medical cultural context, and their own personal cultural context. Additionally, interviews hoped to reveal how these participating physicians integrate the meaning messages and attitudes that have evolved from their experiences with death and dying into their professional practice, their interaction with patients, and with the other medical professionals with whom they construct their social reality.

Phenomenological interviewing involves conducting in-depth interviews with each participant. Semi-structured interviews, according to Best and Kahn
(1993) “are used to gather information regarding an individual’s experiences and knowledge; his or her opinions, beliefs, and feelings; and demographic data” (p. 202). Seidman (1998) states that “at the root of in-depth interviewing is an interest in understanding the experience of other people and the meaning they make of that experience” (p.3). “The very process of putting experience into language is a meaning-making process (Vygotsky, 1987)” (Siedman, 1998, p. 12).

A physician’s context, professionally, is the medical culture, which may or may not overlap, blend, or conflict with other contexts of a physician’s life. “People’s behavior becomes meaningful and understandable when placed in the context of their lives and the lives of those around them, without context there is little possibility of exploring the meaning of an experience” (Patton, 1989, Seidman, 1998).

(See Appendix H– interview questions). All interviews were coded (see Chapter 3 – interview coding instrument). Once all data were collected and coded; comparison of themes, descriptive analyses, and phenomenological research guidelines were used to answer the primary research questions.

**Study Participants**

The interviewee selection targeted physicians not currently practicing in an end-of-life specialty, such as palliative care, gerontology, or oncology. Family medicine practitioners were the specialty of choice for interviewees, but other specialists consented to be interviewed when an insufficient number of family practitioners failed to agree to participate in this study. Six males and five
females were interviewed. Four interviews in each group were planned to be conducted using a cross section of physicians. The three groups were defined as: those who are recently graduated – 1 to 5 years out, those who have been in practice 10-20 years, and retired physicians. Each interview consisted of a 60 +/- minute audio tape recorded session.

A purposeful sampling of convenience identified physicians in the local area of Southern Illinois, as reported on the American Medical Association’s (AMA) website in 2007. There were 61 licensed family medicine physicians in the Jackson county area. Twelve interviews represents 19.6% of the family practice physician population. Physicians were identified from referrals by individuals (key informants) known to the researcher and from Southern Illinois Healthcare (SIH). Southern Illinois Healthcare is a not-for-profit health care system, dedicated to promoting health and well being in Anna, Carbondale, Herrin, Marion, Murphysboro, and West Frankfort, Illinois.

Data Collection

After approval from SIUC’s Human Subjects Committee, semi-structured tape recorded interviews were conducted at the time and location of convenience to the interviewees. Phenomenological interviewing techniques were used to explore the physician’s personal experiences with a patient’s death, dying and surrounding events; personal reflection on the physician’s own attitudes and beliefs around death and dying; the physician’s medical training in end-of-life areas; the physician’s perception and understanding of the medical culture; and how physicians integrate their own meaning, experiences, and training into reality of
death and dying in their medical culture (Fins & Nilson, 2000). Interview questions were designed to assist participants to be introspective, recall memories, and give a detailed description of the phenomenon of the participant’s confrontation with death and dying personally and professionally.

Participants were offered the opportunity to read their transcripts and offer any corrections or clarification. Member checking provides validation of accuracy of interview content. Participants were encouraged to clarify, expand, and provide further information, if desired. As both an incentive to participate and thank you for participating, participants were offered an executive summary of the final study, the opportunity to have a follow-up discussion and a resource list of training opportunities that are available concerning end-of-life issues.

**Data Analysis**

Data analysis began as soon as the initial interview was completed. Interviews were transcribed and then coded. Data were analyzed using coding-recoding techniques. A coding instrument was created from the interview transcripts. Member checking was used as well as peer review. Medical reviewers were used as insider analysts to assist with validation of themes identified. Responses and themes were used to answer the research question(s).

**Limitations**

“Limitations are the boundaries of the problem established by factors or people other than the researcher” (Neutens & Rubinson, 2002, p. 20). For the scope of this research limitations were:
1) Due to resource and time constraints, all interviewees were located within a 150 mile radius of the Southern Illinois University Carbondale campus.

2) Interviewees were primarily family physicians. A family physician who also had worked with a hospice, a hematologist/family physician who throughout the course of his practice became an oncologist, and a gynecology surgeon were among those interviewed. The intent was to uncover the medical training received by medical students, in general over, a period of 30+ years of medical school education in the USA. Originally, it was assumed by the researcher that end-of-life specialties have had specific training in death and dying issues and would bias this research. But interviews revealed that was not necessarily the case. For most interviewees, it was both personal and professional experience, not medical school, which shaped their views, attitudes, and actions concerning death and dying with their patients.

3) Due to the time constraints on physicians, instead of using the traditional three sessions equaling three to five hours for each participant, interviews were limited to one 60-90 minute session.

4) Interviews relied on memory, recall, or projection into the future. They were confined and controlled by the subjective world of the interviewee.

5) The limited study sample and qualitative design impacts transferability to the wider medical profession. Medicine has numerous different specialties which can not be individually investigated in this study. Use of different participant types and interviews conducted until saturation of data occurs
should supply credibility and dependability for the broader context within family practitioner specialties, targeted in this study.

6) I am not a physician and, therefore, will be an outsider (An outsider or detached observer is someone looking into the context, not coming from or participating in the context of phenomena (Moustakas, 1994; Hycner, 1985). This limits my understanding of medical culture, but allows me to query without preconceived or learned medical culture expectations of a physician.

7) Both researcher and interviewee beliefs and biases influenced collection and interpretation of data. The researcher had personal experiences with end-of-life both personally and professionally as a hospice worker, grief counselor, and teacher. Researcher experiences created the perceived need to examine physician training in end-of-life care. Bracketing by any individual has inherent limitations, because a person can never wholly separate themselves from their experiences. Every attempt was made to do so in the coding and review of interviews, so that past experiences did not color current information and interactions.

8) For the scope of this research, end-of-life referred to natural deaths, chronic illness, dying and death over a period of time. All interviewees experienced a traumatic or sudden death caused by an accident or intent of another. Trauma and traumatic deaths have a different educational component and emotional and experiential identity that is not addressed within this study.
Delimitations

“Delimitations are precise limits of the problem as set by the researcher” (Neutens & Rubinson, 2002, p. 20). In the scope of this research the delimitations are:

1) Interview participants were identified by referrals from individual residents of southern Illinois and Southern Illinois Healthcare (SIH)
2) This study is qualitative. Validity and reliability measures, as defined by quantitative studies, do not apply. Trustworthiness strategies, such as code-recode and research reflexivity, and member checking, were used to assist with qualitative rigor and confirmability in analyzing the data.
3) The author is the researcher who conducted all interviews and analyzed all data.

Assumptions

“Assumptions are conditions taken for granted, without which the research effort would be impossible” (Neutens & Rubinson, 2002, p. 20). In designing and executing this study the assumptions are:

1) Death and dying are highly personal issues for physicians as well as issues with which they are confronted professionally.
2) Death is seen as failure in the medical culture.
3) A gap in medical training exists regarding death and dying.
4) Those interviewed are able to verbalize their understanding of death, dying, end-of-life care, and feel free to express themselves honestly.
5) Physicians should be able, and trained, to handle both the physical and emotional aspects of death and dying.

6) The phenomenological aspect of dying is unique and different from other medical conditions, treatments, diseases and medical practice, therefore, requires specialized training.

Definitions

“Research studies employ terms that may have special meaning to the study itself…[a] term must be defined as it relates to the project at hand” (Neutens & Rubinson, 2002, p. 21). For the purposes of this study, the following definitions are included:

*End-of-Life:* “includes the period of time during which an individual copes with declining health from an ultimately terminal illness, from a serious, though perhaps chronic, illness or from the frailties associated with advanced age even if death is not clearly imminent.

1) the presence of a chronic disease or symptoms or functional impairments that persist but may also fluctuate and

2) the symptoms, or impairments resulting from the underlying irreversible disease, require formal (paid, professional) or informal (unpaid) care and can lead to death. Older age or frailty may be surrogates for life-threatening illness and co-morbidity; however, there is insufficient evidence for understanding these variables as components of end of life” (IOM 2004, p. 22).
Prognosticate: from prognosis which ‘the act, or art of foretelling the course of disease,… make a prognosis about the probable outcome of a disease’ (http://www.merriam-webster.com/medical/).

Advance Directives: “a legal document (as a living will) signed by a living competent person in order to provide guidance for medical and health-care decisions (as the termination of life support or organ donation) in the event that the person becomes incompetent to make such decisions” (http://www.merriam-webster.com/medical/).

Good Death: is contained within three domains: 1) Closure – which reflects the psychosocial or spiritual aspects of good death, 2) Personal Control – focus on physical aspects of dying, 3) Clinical – biomedical aspects (Schwartz, Mazor, Rogers, Yunshen, M & Reed, 2003).

Medical Education – Undergraduate and Graduate: Undergraduate medical education represents the four years of medical school and usually an internship. Graduate medical education is residency, in the field training.

Summary

People die in their own way, with highly individual courses near death and with no one’s last chapter being quite the same as another person’s. Yet, the courses do tend to be rather similar for people with similar medical conditions and co-morbidities, similar symptoms and disabilities, and ordinary living circumstances. At least as an initial organizing principle, looking to those patterns and highlighting a small number of very common

The above statement is a description from the medical culture’s approach to death and dying: designing systems, organizing information, and catalyzing reforms, all of which are analytical, technical, objective, and institutionally obtainable. For the physician, the human being, the practice of medicine and personal experiences are both involved in the phenomenon of death and dying. How physicians reconcile their medical culture with their own psychological, cultural, spiritual attitudes, and beliefs about death and dying is an ongoing phenomenological process.

Chapter one introduced the research topic, gave the background of the problem, statement of the problem, purpose of the study, and need for the study. Research questions, research design, participants, data collection and analysis, limitations, delimitations, assumptions and definitions were provided. Chapter two will include a review of the literature relevant to this study. Chapter three will describe methods used for this study including underlying theories, phenomenological techniques, research questions, research design, sampling, interview techniques and questions, data collection and analysis. Chapter four describes the demographics of participants, and findings based on interviews and field notes. Chapter five includes a summary of the study, discussion of conclusions, findings, implications, and recommendations.
CHAPTER II
LITERATURE REVIEW

Physicians have not been taught to deal with death, says Dr. Larry Librach,…We’ve been cure-focused….People have spiritual, emotional, psychological needs. We need to help people address their issues of suffering and …to help people and their families understand that dying is part of life. The soul needs more than morphine (Sornberger, 2004, p. 1161).

Whether it is the soul of a patient or the soul of a doctor, the necessary attention, skills, and competency in dealing with death and dying are integral to the health and life of all of us. Even though everyone will face death, some professions, such as physicians, will become more intimate with death and dying. Individuals will turn to these professionals for guidance, support, assistance, with the expectation that they have been trained and are skilled in end-of-life matters. Most of us, whether by intent or need, rely on physicians to be resources during death and dying. If death and dying is an essential component of the medical profession, then medical training should include how to deal with end-of-life care of others and the physician’s personal preparation to deal with death of patients.

The purpose of this study was to describe how physicians construct meaning of the phenomena of death and dying within their medical profession. A secondary purpose was to examine how physicians integrate the reality of death and dying within their professional practice. The phenomenon of death and dying was examined from the perspectives of participants via interviews.
When searching related literature to find materials about how doctors deal with death and dying personally, and within the medical culture, a paucity of direct information from the phenomenological perspective exists. Yet the phenomena of physicians/death and dying/patient interaction appears as a notation, secondary finding, an outcome of interviews, and an integral part of the research understudy, but not directly addressed.

As Sornberger pointed out, medicine has been cure-focused. Only in the past two decades, have end-of-life issues been compartmentalized into a specialized area of medicine. The importance of all physicians having specific skills in areas of end-of-life care has taken hold only in the last decade. In the mid-1990’s through the early 2000’s, millions of dollars from private foundations (Open Society Institute, the Robert Wood Johnson Foundation, and others) were given to explore issues of how to provide for end-of-life care, medically, psychologically, spiritually, and culturally. With this support, a number of studies, investigations, research projects, and program reviews were done and several resources were created, among them are: Americans for Better Care of the Dying; Education in Palliative and End-of-life care; Institute of Medicine – Describing death in America: What we need to know; Last Acts; the end-of-life care PEACE Series Brochures; Project of Death in America; Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT); and UNIPAC Book Series: Hospice/Palliative Care Training for Physicians, A Self Study Program.
While much attention was focused on the physician’s role to assist others in the end-of-life process, little attention was given to the physician’s personal psychological, cultural, and spiritual well-being when dealing with death and dying. Therefore, this literature search was expanded to encompass the following list of end-of-life issues.

End-of-life issues and areas include (but are not limited to) hospice, palliative care, communication skills, advance directives, caregivers, cultural issues, ethics, spirituality, psychological issues, health literacy, end-of-life curriculum and death education, physician attitudes and beliefs, and research information. This literature review begins with specific end-of-life programs, moves on to topics that are encompassed in end-of-life issues, then touches on medical training, and finally addresses physicians’ attitudes and beliefs. This review also includes research tools and methods that explain phenomenological interviewing and research.

**Hospice**

Originally, hospices were places of shelter for weary and sick travelers on pilgrimages and run by religious societies. The Latin root: *hospes*, means ‘guest’. When hospitals began as formal institutions in 12th century “there was no practical difference between the meaning of *hospital* and *hospice*” (von Gunten & Ryndes, 2005, p. 655). In 1967, Dr. Cicely Saunders established the first modern hospice in St. Christopher’s Hospital in London, England. The first hospice in the United States was established in New Haven, Connecticut in 1974 (Hamilton & Reid, 1980). “The legitimization of hospice as a national policy
occurred when hospice care became covered under Medicare as part of the Tax Equity and Fiscal Responsibility Act (TEFRA) in August 1982” (Miller, & Mike, 1995, p.535). In the United States in 2007, there were nearly 1.4 million people who utilized hospice (Hospice Foundation of America, http://www.hospicefoundation.org).

The keystone of hospice is that it is “not a place, but a concept of care” (Hospice Foundation of America). Some of the fundamental underpinnings of Hospice are:

1) Hospice care neither prolongs life nor hastens death.

2) Hospice’s goal is to improve the quality of a patient’s last days.

3) Hospice care is provided by an interdisciplinary team, addressing all symptoms of a disease, and deals with the emotional, social, spiritual and medical needs of the patient.

4) Continuity of care includes the family and bereavement follow-up (Hospice Foundation of America, http://www.hospicefoundation.org/hospiceInfo/)


referral from a physician, making doctors the *gatekeepers* to end of life care offered by hospice. According to Elizabeth Bergman’s (2006) study on *Breaking Down Barriers to the Hospice Care Option*, she found physicians resistant to making hospice referrals due to misconceptions, lack of information, prognostication, and the drive to cure. A hospice referral means failure for the physician (Hynman & Bulkin, 1991; McGorty & Bornstein, 2003). Miller, Miller, and Single’s (1997) findings showed that lack of access to hospice care, lack of insurance coverage, or guidelines for coverage (Medicare), prognostication, inadequate physician training in terminal care, pain management, hospice care, and the family practice physician’s loss of control of patient’s care, contributed to low hospice referrals.

Medicine has adopted informed consent as a core medical principle. Informed consent states that patients must have the information needed to make an informed choice about their medical care. Informed consent as a medical precedent has occurred because legal cases involving end-of-life care: Nancy Cruzan case lead to the 1990 *Patient Self-Determination Act*. During any illness large amounts of complex medical information must be processed by patients and families to determine their course of care, during end-of-life patients may not receive an review of their condition or be given time to understand treatments, medications, and services available, before the patient must decide for or against them.

During end-of-life situations this complex medical process is further complicated by the emotional component inherent in dying. Hospice care is
designed to allow for education of the patient and caregivers especially since care has transitioned to quality of life and palliative care versus curative treatments. Additionally, hospice care addresses a patient’s characteristics and cultural issues which influence the dynamic of decision making (Casarett, 2005). Often the decision involves facing substantial financial burdens (insurance coverage, payment, requirements), and caregiving burdens if a patient goes home, another component include in hospice care. Priorities change because it is the end of life.

Studies found that the majority of patients and families had no knowledge of hospice at the time of the initial hospice visit. This result is surprising because the physician or another healthcare provider and patient should have discussed hospice and the referral before the hospice visit (Hynman & Bulkin, 1991). Unfortunately, this isn’t unusual because according to McGorty and Bornstein’s (2003) research, physicians rarely have a complete understanding of hospice and are uncomfortable with end-of-life discussions.

In an attempt to overcome physician discomfort with death and dying, several medical schools offer an elective hospice experience. Participating hospices provide training without remuneration and at great expense to their staffs’ time and financial resources, “based on feelings of obligation and the opportunity to promote the hospice philosophy” (Fischer, et al 2005, p. 39). Surveys show that the hospice experience has a profound effect on physician participants. While participating in hospice training, doctors are encouraged to reflect on patients, families and their own beliefs and fears about dying, gaining

Most hospice care occurs in the patient’s home. The in-home hospice experience provides a different perspective to those practicing institutional medicine and allows the physician to witness the “roles of the psychological, social, financial, and spiritual issues that may contribute to the suffering of a dying patient, and how they need to be explored fully in order to provide adequate palliative care” (Plymale, et al, 2001, p. 48).

**Palliative Care**

Palliative care has its roots in hospice care. Until the foundation of hospice in the late 1960’s and Kübler-Ross’s seminal work with dying patients (Kübler-Ross, 1969), terminal care was the term used for care of the incurable patient. Until 1980, palliative care was known as terminal care and was firmly associated with cancer services and the period of imminent death. Palliative care was recognized as a distinct field of medicine in 1987. Then palliative care became “active” as opposed to “terminal” care (Ditillo, 2002, Billings, 1998, NHPCO).

Palliative care has evolved under the umbrella of hospice and “embraces the hospice philosophy of care and seeks to bring this approach into clinical practice” (Billings, 1998, p. 75). It has been incorporated into Hospice organizations and organizational names: National Hospice and Palliative Care Organization (NHPCO), American Academy of Hospice and Palliative Medicine (AAHPM), American Board
of Hospice and Palliative Medicine (ABHPM), Hospice and Palliative Nurses Association (HPNA). As of September 19, 2006 the Assembly of the American Board of Medical Specialties recognized the subspecialty of Hospice and Palliative Medicine (http://www.aahpm.org/about/recognition).

According to the American Academy of Hospice and Palliative Medicine, palliative care is defined as:

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care (AAHPM website, Definition of Palliative Care, http://www.aahpm.org/ positions/definition.html). (Other versions of a definition of palliative care can be found in Appendix D– Palliative Care Definitions.)

Palliation means literally ‘to cloak or to cover.’ In medical terms, palliation originally referred to primary relief of pain and symptoms, relieving suffering, or simply means the patient feels better. The use of the term has been expanded, however, to alleviating the disease process without curing it, and to maximizing
dignity, and quality of life (Karlawish, et al, 1999; Ditillo, 2002; Appleton and Corboy, 2005; Bomba, 2005).

“Although it is palliative care that is pursued in hospice programs, the principles are robust enough to be incorporated into care in other aspects of the healthcare system” (Muir, Krammer, von Gunten, 1999, p. 91). The Institute of Medicine (1997) recommended that palliative medicine should be incorporated into the training and clinical practice of all physicians because it is being viewed as being “a vital and integral part of all clinical practice, whatever the illness or its stage” (Ditillo, 2002, p. 128; Carmondy, 2005). Whereas hospice utilizes a team of practitioners across various fields, a comfort team, as suggested by Bascom (1997), would allow “the principles of palliative care to be extended to a great variety of patients, not just those who are terminally ill” (Alaeddini et al 2000, p. 69).

Hanson and Ersek (2006) talk about palliative care being a way “to help them live until they die”. The reality is that physicians are gatekeepers to palliative care (Alaeddini et al 2000) just as they are for hospice care.

“One of the most difficult transitions for non-hospice physicians learning to work with terminally ill patients is accepting the inevitability of death, learning to reject useless and potentially harmful treatments, learning to accept and share their own sense of helplessness, and learning to focus on caring without cure” (Appleton & Corboy, 2005, p. 169).

Clinicians who care for dying patients and their families are faced with a complex set of clinical tasks. In addition to managing pain and multiple physical sources of
distress, excellence in palliative care requires competencies in recognizing and treating psychological and spiritual distress, responding appropriately to intense emotions of patients and their families, understanding patients’ and families’ perspectives on care, appreciating cultural differences, recognizing and communicating the imminence of death, facilitating difficult decision making, supporting colleagues, and managing one’s own sense of discomfort, uncertainty, or loss. It is common practice to transfer patients to specialists when confronted with terminal illness. Unfortunately “transfer can result in loss of continuity of care, increasing patient suffering and family distress” (Sullivan et al, 2005, p.684).

Koffman (2001) identified one of the many strengths of hospice in the team approach. The team enables the caregivers to more fully assess needs, have a broader base of professional advice, integrate patient and family perceptions and involve them more directly in care decisions. With the team a greater ability to supervise treatments, monitor progress and anticipate and support the end-of-life process is shared and provided to the patient and family. This eclectic approach can be utilized in palliative care as well (p.87 & 88). The team approach can be useful in most areas of medical care, but “given the complexity of issues related to quality of life, quantity of life, and the trade-off between them in a system that is in large part designed to treat acute illness, a multidisciplinary team approach to the conceptualization, implementation and interpretation of end-of-life research is vital” (Rocker & Heyland, 2003, p. 1).
Only since the year 2000, have medical students graduated with education in specific end-of-life issues. Palliative care, as part of medical school curriculums is still developing and transitioning and has not yet become an integral part of basic medical education. In the void, several resources have been developed to assist in this process. Two such resources are:

1) The Center to Advance Palliative Care (CAPC) with Palliative Care Leadership Centers (PCLC)

2) Building Academic Palliative Care and Program in Palliative Care Education and Practice (PCEP), Harvard Medical School, Faculty development

(See Appendix E- end-of-life education resources, a sample palliative care curriculum, and the domains of end-of-life care.)

Surveys of the palliative care and end-of-life education programs currently in place, show there is still a long way to go to provided adequate training (Wood et al, 2002; Porter-Williamson et al, 2004; Mast et al, 2004; Carmody et al, 2005; Ross et al, 2005; Sullivan et al, 2005). Sullivan et al (2005) point out that one of the factors for inadequate education, according to the data, is “that faculty feel unprepared to teach many of these competencies” (p.657).

As mentioned above, palliative care encompasses many skills, which require training specifically in end-of-life areas as well as in general medicine. All skills are not purely scientific or medical. “Effective communication styles and skills are of particular importance to medical educators in general and are critical in hospice and palliative medicine” (Muir, et al, 1999, p.91).
Communication Skills

"The quality of communication with patients, family, and team members was indeed found by medical specialists to be fundamental to the quality of care for the dying. Ineffective communication was found to be one of the major barriers to optimal end-of-life care at the health care provider level" (de Haes & Teunissen, 2005, p.345).

Virtually, every resource explored on communications skills begins with a phrase such as: Good communication skills are key to…(Hockley, 2000; Banja, 2005; Cherlin 2005; Fineberg, 2005; Han et al, 2005; Alexander et al, 2006). Karlawish et al (1999) goes further by acknowledging the growing recognition that "end-of-life communication is a specialized type of therapeutic communication that requires specialized education" (p.835).

Another common theme found in related literature is that of the medical student’s perception and attitude about the importance of communication skills (Banja, 2005; Davies, 2006; Fallowfield, 2006; Wright et al, 2006). Communication skills are seen as being subjective and a soft science approach, not as important in medicine, a hard science. Since attitudes are often important predictors of behaviors, medical training that includes the importance of, and adequate communication skill training from year one is crucial (Wright, et al, 2006). As Tulsky explains, just because you go to medical school doesn’t mean you have the communication skills to tell a person that they are going to die. “Frankly, most physicians are not born with these skills. But they can be learned” (Duke University study, 1996).
Several research articles discussed a review of communication skills curriculums, or programs in place, before proposing their own option (Field & Copp, 1999; Buss et al, 2005; Curtis et al, 2005; de Haes & Teunissen, 2005; Fineberg, 2005; Han et al, 2005; Alexander et al, 2006; Fallowfield, 2006; Wright et al, 2006). These studies acknowledge that attention and importance have been placed on communication skill both in medical schools and in the medical field, but that communication skill training is still insufficient.

In 2004, the National Board of Medical Examiners started testing all U.S. medical school graduates on their clinical skills, assessing how they performed a physical exam, took a patient history and talked to the patient (Basler, 2006; Weissman & Block, 2002). Communication skills are an important component included in what is being tested. Communication skills are being evaluated on the student level and being taught, through continuing education to physicians. Recognition has come that end-of-life communications skills are unique skills that need to be learned and involve different elements than day-to-day medical interactions (Hales & Hawryluck, 2008; Runkle, Wu, Wang, Gordon, & Frankel, 2008).

Communication is not just asking diagnostic questions, or delivering pronouncements of prognosis. It is an interpersonal conversation that often includes emotional content for the physician and patient. Difficult medical information that must be explained and understood, it takes time and effort by the physician to insure the patient’s understanding. Both physician and patient need to be willing to confront the emotional content of dying. Lack of communication
skills can lead to a perceived *therapeutic failure* and avoidance by physicians. (Fallowfield, 2006; Banja, 2005; Hockley, 2000). According to Segal's (2005) rhetorical principle: “Two people are not fully engaged in a rhetorical process if only one of them really knows what they are talking about” (p. 114). In addition to acknowledging the need to effectively communicate, the physician’s beliefs influence their communication skills.

How the physician communicates hinges upon the physician’s personal beliefs about patients’ right to know. In Field and Copp’s (1999) study of four San Francisco hospitals, they identified four categories of physicians’ communication beliefs about a patient’s death awareness needs:

1) Closed awareness where staff kept patients ignorant of their impending death.

2) Suspicion awareness where patients suspected that they were dying and tried to get staff and relatives to confirm their suspicion.

3) Mutual pretence, where all parties knew that the patient was dying but did not acknowledge this, pretending that ‘everything was normal’.

4) Open awareness, where all parties knew about and acknowledged that the patient was dying and were able to talk about dying (p.461).

This list parallels patterns found in other studies (Banja, 2005; Cherlin 2005; Segal, 2005; Fallowfield, 2006). de Haes and Teunissen (2005) identified five aspects involved with physician-patient communication around end-of-life issues: 1) Relationship building: trust is key, and being respectful, competent, reliable, and frank, were the most important values of a physician; 2) Information
exchange: gathering and giving, conveying hope while being straight forward;
3) Decision making: requires a complex integration of relevant conceptual knowledge of ethical implication, the principles of surrogate decision making, legal consideration, and communication skills that address the highly charged emotional issues under discussion; 4) Giving advice: implies taking into account the patient’s condition, preferences, and possibilities; 5) Handling emotions: “One of the goals of palliative care is the promotion of quality of life with practical, functional, emotional, and spiritual support and minimization of distress (p.347-8) Hockley (2000) states that physicians need to gain an “intuitive antennae alert to picking up clues and being proactive in our search for unspoken fear” (p. 906).

End-of-life conversations do not happen in isolation. Often they occur on ICU wards, as family conferences, with caregivers, or with an interdisciplinary team. They require consensus building, coordination and collaboration of participants, and dealing with highly emotionally charged situations (Cherlin, et al, 2005; Curtis, et al 2005; Fineberg, 2005; Segal, 2005). Medical school educators are looking for creative ways to assist in communication skill building. Shapiro (2006) used the movie Wit that allows medical students to react emotionally to a patient, not their own. The students were empathic and compassionate toward the Wit patient. Translating that empathy to their own patients is the skill to be acquired. In attempts to improve communication skills, two-thirds of all medical schools employ actors to help young doctors perfect their bedside manner – stressing respect and empathy for patients as well as medical knowledge (Basler, 2006).
For the most part medical residents are supposed to develop communication competence without formal training. Residents are put in situations where they must discuss end-of-life issues, e.g. giving bad news, or patient wishes. Any skills residents develop are done informally (Han, et al, 2005). Informal learning does not guarantee competence and has too many unknown factors. Weiner and Cole (2004) designed a program to overcome emotional, cognitive, and skill barriers of physicians and develop communication skill competence (See Appendix R).

Communication exists in cultural contexts. Medical culture has its own language and method of communicating. Medical language is technical, low context. “Low context communication has the advantage of being very precise. Low context interactions tend to be task oriented” (Hallenbeck, 2006, p. 114). Medical language has precise terminology, brevity, has clear direction, and is concrete task oriented. Medical vocabulary is meant to identify or define, not evoke or emote. The world of illness and dying, however, exists in a world of evocative high context communication.

“In high context communication, a large amount of meaning is embedded in the situation (or context) within which communication is occurring” (Hallenbeck, 2006, p. 113). The very nature of these phenomena, the medical culture and dying, put each at odds with the communication style of the other’s context. “Within language, context acts rather like a compression program for computer code-more information can be shared per unit of transmitted data…However, if the receiver does not understand the code, then
communication fails miserably” (p.114). While a physician may think they are being precise and technically clear, their communication may be no more than gibberish, a foreign language, within the context of an end-of-life situation. Here is a simplified example of low context communication the physician says “You have a terminal prognosis.” To a non-medical person both terminal and prognosis may be unclear terms. The same information in high context communication might be expressed this way “We have explored all possible options for your illness. There is nothing else medically we can do to cure you. It’s time to focus on creating the highest quality of life with the time you have remaining.” Not only the specifics of the illness but attention to the emotional context of end-of-life are included.

Communications have many unseen constrains. Hallenbock (2006) explains that people from different cultures relate to time in very different ways. In addition to cultural time, research has demonstrated that as we age we generally experience time as passing more quickly. “The social implications of differing perceptions of time in healthcare are profound. To more elderly patients, young clinicians may move so fast as to be almost invisible. To young clinicians, some elderly may move so slowly as to be almost statues” (Hallenbock, 2006, p. 115).

Advance Directives

“Proper end-of-life communication is time-intensive but it results in a care plan which staff can follow and thus reduces stress related to decision making in emergencies” (Volicer, Hurley, Blasi, 2001, p. 195).
The Nancy Cruzan case that began in 1983 (SUPREME COURT OF THE UNITED STATES 497 U.S. 261 June 25, 1990, Decided) lead to the 1990 Patient Self-Determination Act, that requires patients be informed about their right to accept or refuse medical or surgical treatment and the right to formulate advance directives.

Advance directives include simply:

a) A Living Will: which states what treatments you do or do not want if you are incapable of making medical decisions,

b) Appointing a Durable Power of Attorney for Health Care: designating a health care representative to act to insure that the patient’s wishes for care are honored/executed (Solomon et al, 1993; Tolle & Tilden, 2002; Clayton et al 2005; Dunn, 2005). (See Appendix A for three different versions of advance directives.)

Treatment options usually addressed in a Living Will include but are not limited to: cardiopulmonary resuscitation (CPR), use of artificial hydration and nutrition, hospitalization at the end of life, whether to consider certain treatments such as mechanical ventilators, antibiotics, pain control, dialysis, and comfort care such as hospice. Physician discussion of these options seems a straightforward practice in the discussion of treatment and care with patients. Unfortunately, many physicians are not comfortable initiating this kind of discussion. Clayton, et al (2005) gives the four most commonly used conversation methods used for discussing advance directives. 1) Wait for the patient or caregiver to raise the topic. 2) Offer all palliative care patients and their
cogenerated the opportunity to discuss the future. 3) Initiate the discussion when
the patients and/or their family need to know. 4) Initiate the discussion when the
patients and/or their family seem ready.

Additionally, many physicians still have moral or ethical issues with
withholding and withdrawing life support measures, and distinguishing between
‘extraordinary and ‘ordinary’ treatments, despite recommendations that these
distinctions should not be considered ethically or legally relevant in clinical
decision making (Solomon, et al, 1993, p. 17)

“Assuring that patient wishes are followed requires organizational systems
that translate patients’ preferences into physicians’ orders. Medical orders that
are standardized and formatted increase the likelihood that they will be respected
when transferred across care settings” (Tolle & Tilden, 2002, p. 313). In 1991,
Oregon physicians created the POLST (Physician Orders for Life-Sustaining
Treatment) Task Force. The document provided a standardized format for end-
of-life physician orders, but continued to face implementation challenges ten
years later when reviewed by Tolle & Tilden (2002),

The Institute of Medicine estimated that an average of 17 years is required
for new knowledge to be incorporated into practice (IOM, 2001). Changes are
underway toward improving advance planning for end-of-life (EOL). Progress,
however, takes time (Tolle & Tilden, 2002, p.315). Changes include improved
end-of-life care education, which includes hospice and palliative care training.
“Having a doctor who is willing to talk about dying and who is sensitive to when
patients are ready to discuss this issue [advance directive] has been identified by
patients and their families as one of the most important needs at the EOL” (Clayton, et al, 2005, p. 132). At the end-of-life families and caregivers rely on physician communication as pivotal in their own understanding of the patient’s condition (Cherlin, 2005). Like physicians, most caregivers lack the skills or knowledge to deal with the end-of-life of a loved one, and turn to the physician for assistance assuming physicians have the necessary knowledge.

**Caregivers**

Effective caregiving was linked to effective communication skills. Patients and family members expressed the need to obtain information from health professionals, and reported difficulties being told information in an abrupt manner and communicating with family members when information given to one family member was different from information given to another member (Lev, 1991, p. 91).

Rarely, do physicians treat a patient at the end-of-life in isolation. Family and caregivers, both personal and professional, create the unit of care. The role and support of caregivers plays an integral part in the quality of care for a patient at the end-of-life. “Even for patients receiving complex, intensive medical care for serious and life-threatening illness, family caregiving is typically at the core of what sustains patients at the end of life” (Rabow, Hauser, & Adams, 2004, p. 483).

Physicians have a key linkage role between providing care for the patient, assessing the caregiver’s abilities, and providing support for both. “Many family caregivers are insufficiently prepared for the demanding and complex role of
providing physical and psychosocial care for advanced patients at home” (Pickett, Barg, & Lynch, 2001, p. 20). The impact of family caregiving, or caregiver burden with terminal patients is far reaching. “The physical and emotional demands of caregiving can overwhelm the caregiver” (Redinbaugh, Baum, Tarbell, & Arnold, 2003, p. 901).

Caregivers dealing with a dying loved one face several challenges in three areas: interpersonal, extrapersonal, and intrapersonal. Interpersonal stressors include: lack of both non-medical and medical support, lack of information about physiological processes at end-of-life and about how to provide care giving, and insufficient or poor coordination of service. Extrapersonal stressors involve financial, and legal issues. Intrapersonal stressors encompass the caregiver’s health, role fatigue, and coping with impending death (Decker & Young, 1991). A stressor that occurs in all three areas is loss. “Loss is inherent in the care giving experience: loss of hopes, dreams, plans, body image, or security (Doka, 2001, p. 217).

Men and women have different models for care. Men set more limits and ask for more assistance. Women often take on more and become socially isolated. “Social support is, therefore, a theoretically proposed antecedent to caregiving burden” (Robinson, 1990, p. 192).

End-of-life care also may be complicated by denial. “Denial refers to a lack of awareness of, or ability to recognize or discuss the patient’s illness, diagnosis, or terminality, despite being informed of it” (Levine et al, 1987). Reese’s (2000) study on primary caregiver denial showed that caregiver denial may influence
treatment decisions on behalf of the patient that are in opposition to the patient’s wishes (p. 16).

As noted above, caregivers are usually not prepared for the intense level of care needed at the end-of-life (Leis, Kristianson, Koop & Laizner, 1997). The cure for a caregiver’s lack of skills can be found in education and training programs for caregivers. Two such programs are the 1992 Commonwealth of Pennsylvania Department of Health’s, Cancer Control Program: Family Caregiver Cancer Education Program (FCCEP), a six hour educational program designed to address a broad spectrum of cancer topics, and Hospice/Home Care Family Caregiver Cancer Education Program Topics for Home-Based Instruction, from the Pennsylvania Department of Health Cancer Control Program 1998-1999 (See Appendix O).

In addition to training the caregiver, Pickett, et al (2001) said “it is interesting to note that health care professionals often view family caregivers as ‘health care resources’ for advanced cancer patients rather than as ‘potential recipients’ of services” (p. 20). Rabow, et al (2004) and Lev (1991) describe how physicians have opportunities to serve families and caregivers at the end-of-life:

1) Excellent communication with family: Careful listening is paramount for physicians - “The definition of patient and family concerns is based on communication with patients and families rather than the pathology” (Lev, 1991, p 91).
2) Advance care planning and clear decision making: “Encouraging the patients to be as much a part of the decision-making process as possible is appropriate” (Lev, 1991, p. 92).

3) Support for Home Care: “Interventions with family members that foster their strengths, provide information, and advocate choice are helpful” (Lev, 1991, p. 92).

4) Empathy for family emotions and relationships: “Interventions are based on the premise that care of the patient and family is always possible, even when cure is no longer possible” (Lev, 1991, p. 91).

5) Attention to grief and bereavement (Rabow, et al, 2004, p. 489): “Providing anticipatory guidance enables family members to feel that they were expecting the outcome, and are prepared to deal with it. The well-being of survivors is a primary concern” (Lev, 1991, p. 92).

Researchers studying caregiving remind us not to forget the professional caregivers, including the physician. Papadatou (2000) emphasized that professional caregivers also experience loss. “Sensitively negotiating family issues can be difficult for physicians, but it is intensified when families challenge the physician’s authority, are plagued by their own disagreements, raise the specter of litigation, or are culturally or religiously diverse from the physician” (Levine & Zuckerman, 1999, Crawley, Marshall, Lo & Koenig, 1999). Expanded end-of-life training will assist patient, physician, family and caregivers.
Cultural Issues

Death and dying, probably more so than most medical events, are seated in socio-cultural norms, belief systems, values, and death and dying cultural meaning specific to patient, family, caregivers, and physicians that supersede medical protocols.

Death is infused with socio-cultural norms and meaning. Medical care at end-of-life must be especially culturally sensitive, with the acknowledgment that medical providers and patients may not share similar understandings about the end-of-life and death. “Differences in beliefs, values, and traditional health care practices are of particular relevance at the end of life. Health care providers and patients may not have shared understandings of the meaning of illness or death and may not agree on the best strategies to plan for the end of life or to alleviate pain and suffering” (Crawley et al, 2002, abstract). Schreiner, et al stated that good communication skills have the best potential for bridging cultural differences. Providing culturally appropriate services, while always important, when it involves, surrounding death and dying which are so grounded in cultural meaning (Diver, Molassiotis, & Weeks, 2003; Koenig, Gates-Williams, 1995).

Culture is the internal and external manifestation of a person’s values, norms, and beliefs that he or she learns or develops throughout a lifetime. “Culture is the essence of existence and helps direct and move everyday decisions and interactions with others” (Warren, 2005 p.44). “Cultural awareness has been defined as the consciousness of cultural similarities and differences” (Delaware statewide Multicultural Education Committee, 1990). “Cultural sensitivity implies knowledge that cultural
differences (as well as similarities) exist, along with a refusal to assign to cultural differences such values as better or worse, more or less intelligent, right or wrong; they are simply differences” (Anderson & Fenichel, 1989, p. 8).

*Cultural competence* refers to knowledge and skills rather than attitudes. Competence is the interpersonal, circular process whereby a health care provider, group, or organization acquires knowledge and understanding, and learns to value different world view. With this knowledge a medical individual or system then acculturates this information into their health care management of clients and other providers (Crawley, 2003; Orlandi, 1992; Warren, 2005). Cultural competence has become a buzz word, or given certain cachet, in health care and educational settings (Mazanec, 2004). The cultural aspects in end-of-life situations often are overlooked or ignored, and physician competence, or lack thereof, is even more evident than normal medical situations,

“Medicine itself is a cultural system with its own specific language, values, and practices that must be translated, interpreted, and negotiated with patients and their families” (Crawley, 2003, p. 676). Medical ethnocentrism may foster unconscious stereotyping and patient perceptions by health care providers that create problems in the provision of care for cultural minorities (Crawley, 2003; Diver, et al, 2003; Dovidio, Kawkami & Johnson, 1997; Mazanec, 2004; van Ryn & Burke, 2000). When society in general, is perceived to devalue a particular group’s culture, the “cultural mistrust is a response that is unfortunate but real” (Cort, 2004, p. 70). Cultural mistrust can be especially powerful when translated into a medical setting or during the decisions made for end-of-life care.
“A patient’s cultural background is a fundamental dimension to consider when providing health care. Health and illness are culturally constructed concepts that frame people’s responses to diagnosis and treatment. Culture can be viewed as a tool with which people create their reality and define their purpose in life with that reality. Cultures significantly define the proper way to behave in a given situation to maintain integrity and self-respect” (Kagawa-Singer, 1996. p.1685).

It is important that practitioners explore the multi-layers of culture surrounding the patient. Doorenbos, Briller, and Chapleski (2003) identified five layers:

a) Culture that patients/family bring with them into a care setting

b) Culture that dying patients create for themselves

c) Culture of the care staff

d) Culture of the organizational setting

e) Culture of biomedicine (pp. 406- 407).

Dowd, Poole, Davidhizar and Giger (1998) stated that “effective interactions with persons from diverse cultures, races, and ethnic backgrounds require an ability to assess differences in order to develop appropriate responses” (p. 34). Physicians and healthcare providers should collect information in specific topic areas, such as space and time, that tend to differ between and within cultural groups and can provide data by which to formulate an effective and culturally competent educational plan for the client and family.
Topic areas include communication, space, social organization, time, environmental control, and biological variations (Dowd, et al, 1998).

Cort (2004) describes a curriculum for training health care workers in cultural competence that includes:

1) Understanding one’s own cultural and social location to reduce ethnocentrism.

2) Gaining knowledge of other cultures that includes awareness of history, tradition and values of other groups.

3) Recognizing cultural competence as a dynamic experience rather than a state of accomplished expertise (p. 68-69).

Culture is an important consideration in end-of-life situations. Culture shapes our rituals, practices, values, and morals surrounding death and dying. Physicians have a medical culture and personal culture that need to be acknowledged, especially when they consider discontinuing treatment a moral decision. Morality focuses on what people believe to be right and good within a specific cultural context, which affects ethical analysis (Field & Kassell, 1997, APA …End-of-Life Decisions, 2000).

Ethics

“Ethics is the generic term for various ways of understanding and examining the moral life” (Dablin, 2004, p.2). “Ethics deals with systematic approaches to questions of morality. Ethics provide a philosophical framework for analyzing and making decisions with regard to moral
choices [concerning end-of-life issues] within specific cultural settings” (Field, & Kassel, 1997, p. 410).

Currently, medical ethics are products of western cultural influences (Field & Kassel, 1997; World Health Organization (WHO)). Ethical dilemmas pervade modern medicine, especially at the end of life (Clarfield, Gordon, Markwell, & Alibhai, 2003). The primary healthcare principles of nonmaleficence, confidentiality, beneficence, autonomy, truth-telling, informed consent, and justice guide ethical medical practice. When graduating, physicians take the Hippocratic Oath (See Appendix M) to affirm their belief and willingness to follow these principles. Their education should include preparation to face ethical dilemmas. Studies indicate, however, that ethics education is presently ineffectual in fostering ethical conduct (Feudtner, Christakis, & Christakis, 1994). Attig (1995) explained that “ethics involves discerning what can and should be done to respect persons, especially in full appreciation of the fragility of life and human vulnerability… In general, ethical theory shares the limits of generalization.” He cautioned that “generalizations often fit poorly when they are applied to particular cases” (p. 9).

Medical ethical ‘principles’ today are derived more for use by courts and review committees. End-of-life ethics in the United States have been shaped by legal cases (Karen Ann Quinlan, 1976; Claire Conroy, 1985; Elizabeth Bouvia, 1986; Terry Schiavo, 2003-2005). Nancy Cruzan v. Director, Missouri Department of Health (1990) resulted in the 1990 Patient Self-Determination Act that guides patient information and shaped the use of advance directives in all 50
states. Vacco v. Quill and Washington v. Glucksberg (1997) have clarified that patients have a right to palliative care that provides comfort even if it may hasten death (Attig, 1995; Clarfield, et al, 2003; Dablin, 2004; Field & Kassel, 1997).

Ethical behavior integrates moral sensitivity (ability to recognize ethical issues), moral commitment (determination to do what is right), and moral behavior (skills at implementation), with moral reasoning (being able to weigh the rights of others and principles at stake) (Branch, 2001). Ethical decisions are not made in isolation but include all parties involved: physicians, patients, family, caregivers, institutional policy and the public (Chiswick, 2001).

Ethical behavior includes ethical communication. Latimer (1998) identified four components of ethical communication: 1) ethical communication must be timely and desired by the patient, 2) it must be accurate, 3) it must be provided in words that are understandable to patient and family, 4) it must be conveyed in a gentle, respectful and compassionate manner (p. 1743).

Latimer (1998) believed that “the medical profession has a strong moral imperative to do all that can be done to prevent and treat physical symptoms, such as pain, and to work toward the alleviation of suffering” (p. 1744). When facing ethical issues in death and dying “the dialogue requires an honest acknowledgment of human fragility, confronting the mysteries of life and death and suffering shared by humanity” (Attig, 1995, p.8). End-of-life care cannot be merely a diagnostic evaluation of a disease. Death is not merely a physical event. Death involves moral and ethical behavior, transcends the mere physical, and is also a spiritual events.
Spirituality

“Victor Frankl wrote that ‘man is not destroyed by suffering; he is destroyed by suffering without meaning’ (Frankl, 1984, p. 135). ‘Spirituality helps give meaning to people’s suffering…Spirituality helps people find hope in the midst of despair.’ We, as care givers, need to engage with our patients on the same spiritual level” (Puchalski, 2002, p. 290).

Within the World Health Organization’s definition of palliative care, control of spiritual problems is one of the key components (Wright, 2002). The Institute of Medicine lists spirituality as one of the six domains of end-of-life care. The Association of American Medical Colleges Medical School Objectives Project 1999 report stated “spirituality is recognized as a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies” (p.25). The Joint Commission on Accreditation of Healthcare Organization policy explains that “pastoral counseling and other spiritual services are often an integral part of the patient’s daily life” (p. RI-15).

Driscoll (2001) found that 70.6% of patients indicated spirituality as the primary resource of hope in dealing with their illness. Cohen, Wheeler, and Scott’s (2001) survey of physicians found that 58-96% thought spirituality was an important health component. In a survey taken by TIME magazine, 65-95% of respondents said they wanted their physicians to address their spiritual issues with them, yet only about 10% of their physicians actually do (Ehman, Ott, Short, et al, 1999).
Spirituality is an important component in end-of-life care. Yet the difficulty of delivering spiritual care is highlighted in a literature review where Cohen, Wheeler, and Scott (2001) found 92 definitions of spirituality with seven different themes. Driscoll (2001), in a call to make medicine a healing profession, again asked the questions “Is the call to be a healer predominantly a spiritual one? And if so, how does one separate out personal belief and professional practice?” (p. 333). Often physicians and patients have different concepts of spirituality. Physicians may feel uncomfortable broaching spiritual issues with patients.

Thomson (2000) defined spirituality as “that quality of curiosity in a person that seeks to find meaning” (p.14). Breitbart, Gibson, Poppito and Berg (2004) found that “spiritual well-being and a sense of meaning and peace appear to substantially benefit persons suffering psychological distress at the end of life” (p. 368). They go further expressing the importance of integrating spiritual care by saying: “Palliative care practitioners have the privilege of promoting, witnessing, and validating patients’ existential explorations within this unfolding dialogue” (p. 370).

Without a care team, or access to spiritual professionals, physicians who recognize and acknowledge the importance of spirituality in the care of patients need additional skills or resources to address these issues. Bruce Ambuel (2003) explained how to take a spiritual inventory using the anagram S.P.I.R.I.T. (See Appendix N). “The physician should not take on the role of spiritual advisor or teacher, but can play a valuable role by encouraging the patient and family to keep sacred space open for exploration” (p.932).
Psychological Issues

The role of the physician-healer is to establish connexional relationships with his or her patients and guide them in reworking their life narratives to create meaning in and transcend their suffering … Unfortunately, medicine does little to prepare physicians to guide sufferers. Physicians are not trained to hear patients’ stories, often fail to solicit the patient’s agenda or pick up on a patient’s clues, and often limit storytelling to maintain diagnostic clarity, support efficiency, and avoid confusion and unpleasant feelings (Egnew, 2005, p. 259).

According to Block (2006) “Psychological suffering is a virtually universal experience for patients at the end of life and their families” (p.751). Physicians caring for the dying must be experts in assessing and differentiating the major types of psychological distress (End-of-Life Care APM Ad hoc committee, 1998; McKenry, 2005; Rando, 1993). Psychiatric issues at the end-of-life include: anxiety, depression, cognitive disorders, suicidal ideation, perceived lack of support, and spiritual issues. Both psychological suffering and psychiatric complications at the end of life are treatable, but often go unrecognized and untreated, despite the fact that studies show 30-85% of terminal patients suffer from at least one of the conditions listed (Rando, 1993; Stiefel & Razai, 1994; Shuster, Breitbart, & Chochinove, 1998; Lawrie, Lloyd-Williams, &Taylor, 2004).

McKenry (2005) reminds end-of-life professionals that “dealing with death is a process, not an event” (p. 94). Block says “the expert palliative care physician will understand the personal impact of caring for the dying, as well as
the impact of this work on clinical staff, and will be expert in addressing self-care and staff support” (p. 751). The psychological component of death and dying is as relevant as the physical and as worthy of care as any medical condition for both caregiver and patient. Shared care by a team which includes chaplains, social workers, grief counselors, psychologist, and more, provides the ability to identify and address psychological issue have them more integrated into end-of-life care.

Physicians who see their end-of-life care encompassing both biomedical and psychosocial issues, have better communication with patients, see end-of-life care as a process and have greater coping skills personally for dealing with the death of patients (Jackson, Mack, Matsuyama, Lakoma, Sullivan, Arnold, Weeks, & Block, 2008). Care of the terminally ill also takes its toll on the caregiver/physician. Psychological components of burnout and compassion fatigue are not uncommon and must be addressed by the physician (Kearney, Weininger, Vachon, Harrison, & Mount, 2009).

A psychological component that has been ignored, or overlooked by the medical profession when dealing with dying patients and their grieving families, is the very real activity of transference and counter-transference. Counter-transference is defined as when the caregiver-therapist or doctor, and so on, transfers their own repressed feelings to the patient. Counter-transference is further defined as the entire body of feelings that the caregiver – physician has toward the patient, and also includes cases where the caregiver – physician literally takes on the suffering of her patient (Jung, 1957, p. 8).
Literature found on counter-transference focuses on ethical issues-requests for assisted-suicide (Kelly, Varghese, & Pelusi, 2003), or communication skills where a physician’s own motivations, needs, and desires, must not overshadow the patients’ suffering, needs, and requests (Berger, Rosner, Potash, Kark, & Bennett, 2000; Hughes & Kerr, 2000), or specifically on end-of-life psychotherapy (Cohen & Block, 2004). Only recently has acknowledgement of physicians’ own grief and loss begun to be addressed, and how that can manifest itself in counter-transference with patients (Katz & Johnson, 2006; Williams, Wilson & Olsen, 2005). Physicians do not have to become inured with end-of-life care, rather awareness of the journey and the role that is theirs to play, can become part of professional practice. Hughes and Kerr (2000) sum it up best. “Awareness of the transference-counter-transference relationship allows reflection and thoughtful response rather than unthinking reaction from the doctor” (p.62).

Physicians’ awareness of their own and their patients’ psychological issues will allow both to have a higher quality of care at end-of-life. Another tool to help improve care at end-of-life is health literacy, patients need to attend to the complexity of care and decisions required at end-of-life, and physicians need to recognize the complexity of care both biomedically and psychosocially.

**Health Literacy**

The state of American health literacy has been called a silent epidemic, which is not easy to detect (Smith, 2006). A 2004 report from the Institute of Medicine (Nielson-Bohlman, 2004) suggests that health literacy is limited to approximately half of American adults. That represents nearly 90 million people.
*Healthy People 2010* defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (¶ 1 [http://nnlm.gov/outreach/consumer/hlthlit.html](http://nnlm.gov/outreach/consumer/hlthlit.html)). As mentioned in the communication section, physicians must speak to patients and families in a language and context they understand, especially regarding end-of-life issues. Communication should be a two-way dialogue of equals, not a one up power monologue from physician to patient (Segal, 2005) and must facilitate health literacy for patients. Parker, et al. (1995) stated that “we know that patients with limited health literacy skills face enormous obstacles navigating the health care system and struggle with tasks that many of us take for granted” (p.538). Henry (1999) offers hope that “patient education, if it is well constructed, can serve as a bridge over the turbulent waters of the ever-changing healthcare environment for both the provider and the patient” (p.244).

Simple direct methods of addressing health literacy are readily available to all providers. *The Ask Me 3* program was developed by the Partnership for Clear Health Communication. The patient asks three simple, yet direct questions:

1) What is my main problem? 2) What do I need to do? 3) Why is it important for me to do this? The goal is to increase clear communication between health care providers and patients and increase health literacy (Pfizer – www.chcs.org).

Mika, et al (2005) offered these simple strategies for improving health literacy:

1) Teach step-by-step processes, starting with most important first.
2) Ask patients to restate their understanding and instructions just received.

3) Use a variety of visual aids and clearly identify items of importance.

4) Use simple language, avoid jargon, especially medical jargon.

5) Make communication interactive, a loop between provider and patient.

6) Encourage patient questions, inquiries and sharing (p. 355).

The federal government’s website on health literacy and plain language outlines further means for increasing health literacy:

1) Organizing information so most important points come first.

2) Break up complex information into understandable chunks or pieces.

3) Use simple language (6th to 8th grade level) and define technical terms in simple language.

4) Use the active voice.

Fast fact and concept #153 on health literacy in palliative medicine suggests:

1) Ask patients to read, repeat, and explain information and materials given.

2) Use of larger print materials written in simple language (5th grade level), and pictograms.

3) Plan to spend extra time discussing information.

4) Slow down rate of speech. Use simple or common words and shorter sentences.

5) Limit information to three (3) key items in any given conversation.

6) Tape conversations, eliciting questions, and have follow-up conversations.

7) Include caregivers and other providers in conversations.
The Joint Committee on National Health Education Standards (1995) describes health education as a continuum of learning which enables students, as individuals and as members of social structures, to voluntarily make decisions, modify behavior, and change social conditions in ways that are health enhancing, and requires health literacy. Physicians are no different than their patients when they lack adequate skills or knowledge to assimilate and process information. The guilt and shame associated with health illiteracy is universal. The key is to create a shame free environment (Mika, et al. 2005). Konner in Medicine at the Crossroads said that “today patients can be brought in both as students of the illness and equals in the process of treatment or cure. The doctor’s role becomes one of teacher as well as healer” (Henry, 1999, p. 250).

Within the confines of this study the concept of health literacy has two specific applications. The first is in the presentation and educational materials given to medical students in their education experience regarding death and dying, and end-of-life issues. It is a false assumption that because a person is a physician s/he has adequate end-of-life knowledge or skills. The other application is for the patient. Physicians, caregivers, and institutions need to educate patients traveling the end-of-life path, to help patients negotiate, understand, and make informed decisions about their end-of-life care. The ability of physicians to help patients be health literate is especially important at the end-of-life and is another skill which could be taught in end-of-life curriculum in medical school.
Medical End-of-Life Curriculum

Despite these advances in knowledge and consensus about the importance of education and training in care for patients near the end of life, evidence suggests that these efforts have not yet translated into measurable and meaningful improvements in undergraduate medical education. Medical schools are ‘notoriously’ resistant to change (Sullivan, Warren, Lakoma, Liaw, Hwang, & Block, 2004, p.761).

The importance of medical care including end-of-life care was acknowledged with the work of Dr. Cicely Saunders and Elizabeth Kübler-Ross in the 1960’s. In the 1990’s, the attention by private foundations (Open Society, Robert Wood Johnson Foundation, the Commonwealth Fund, the Greenwall Foundation, and the Culpepper Foundation) generated the professional recommendations and policy statements issued by the Institute of Medicine and the American Medical Association; followed by learning objectives and training requirements from the Association of American Medical Colleges Medical School Objectives Projects, the American Board of Internal Medicine, and the Liaison Committee on Medical Education. Consensus exists that specific training in care for patients near the end-of-life is still needed. “These efforts [promotion of end-of-life training] have not yet translated into measurable and meaningful improvements” (Sullivan, et al, 2004, p. 761).

Sullivan, et al’s (2004) national survey of medical education deans found that 84% saw end-of-life care education (EOL) as ‘very important’, while 66% said there was insufficient time given in the curriculum to it. Opposition to
required EOL courses came from 59% of deans, while 70% opposed required EOL clerkships. Sullivan, et al’s (2004) study of medical school deans and Weissman, et al’s (2002) study of internal medicine residency programs found similar barriers: insufficient time was allotted in the curriculum; lack of faculty knowledge in pain and non-pain symptom management, communication skills, little comfort with end-of-life issues; barriers reflected in the attitudes of physician’s personal mortality and emotions; lack of faculty leadership to develop new curriculum in end-of-life care; and resources - financial and institutional. These studies parallel findings of medical student studies.

Undergraduate medical students stated they felt unprepared to deal with patients and end-of-life care regardless of the medical school training they received. Graduate medical students felt there was a lack of training provided by residents and attendings. Little was done to provide guidance, such as role-modeling, during the end-of-life process. Graduate medical students/residents felt that after death they could have provided a debriefing, or simply had a moment to talk about the emotional issues a death can evoke; or to promote self-care and self-reflection (Billings & Block, 1997; Buss et al, 2005; Donohoe, 2002; Kvale, et al, 1999; Meier, et al, 2001; Reilly & Ring, 2004; Rhodes-Kropf, et al, 2005; Sullivan et al, 2003; Williams, Wilson, & Olsen, 2005).

In 2002, Weissman and Block reported on the status of selected undergraduate medical programs, using the Accreditation Council for Graduate Medical Education (ACGME) requirements for end-of-life training as their
guideline. There are nine domains that encompass ACGME’s end-of-life care training:

- Pain assessment and management.
- Non-pain symptoms assessment and management – depression, anxiety, existential, spiritual issues
- Ethics
- Physician-patient communication
- End-of-Life (EOL) communication skills - discussing do-not-resuscitate orders, treatment goals, advance care planning, hospice and/or palliative care, and giving bad news.
- Psychosocial care – attention to death as a life-cycle event, patient and family coping and support.
- Death and dying – bereavement and miscellaneous EOL content
- Personal awareness – physicians' self-care or personal reflection
- EOL clinical experiences, including hospice or palliative care rotations.

Results showed a lack of comprehensive end-of-life training exists in undergraduate medical schools. Medical ethics was the most commonly required and provided end-of-life domain, followed by psychosocial care. Non-pain symptoms assessment and management, end-of-life communication, personal awareness and end-of-life clinical experiences were the least common domains of required end-of-life training available.

Some end-of-life care trainings were required for specific specialty fields. Pain assessment and management was required in internal medicine (IM)

specialties only. End-of-life clinical experiences in hospice or palliative care were required for geriatrics only. Personal awareness, psychosocial care, death and dying topics were required in some internal medicine specialties. If physicians choose to learn more about end-of-life their most direct option are continuing medical education (CME) courses

On March 3, 2010 an EBSCO search, using MEDLINE, ERIC and Academic Search Premier, was made to see the progress of how EOL topics were being integrated into medical schools. Not one article was found that stated end-of-life care is being adequately provided in medical schools. Articles did discuss that more attention is being paid to communication skills and end-of-life training experience, which are demonstrating elevated levels of confidence and competence (Billings, Engelberg, Curtis, Block & Sullivan, 2010; Ellman, Rosenbaum, Cherlin & Bia, 2008; Runkle et al, 2008; Singer & Carmel, 2009; Schroder, Heyland, Xuran, Rocker, & Dodek, 2009).

A survey of the top 35 medical schools, based on the 2006 U.S. News and World report of the best medical schools in the USA, found that all had some form of medical humanities programs incorporated into their curriculums. End-of-life content comprised a very small part of those curriculum. Most end-of-life topics were identified by titles similar to: physician-patient interactions, professionalism, or medical humanism. The curriculum topics taught are not necessarily end-of-life care specific. They also include: physician-patient relationships, communication skills, advance directives, ethics, professionalism, policy issues, institutional and legal concerns and other ‘soft’ science areas.
Few third and fourth year clinical internships offered hospice or palliative rotations. When they were offered, they were electives. Despite advances overall, end-of-life training does not meet the level required to adequately equip physicians to deal with care at the end-of-life either professionally or personally (Appendix F – Core Principles for end-of-life care). The 2010 *U.S. News and World* review of 146 medical schools and a distinct shift in curriculum design was seen. Six competencies were addressed at most schools: professionalism, physician as scientist, communication skills, clinical problem solver, physician as patient and community advocate. These focuses combined with a learner-centered integrated curriculum demonstrate a shift in medical training. Another note of interest was that several of the top 20 schools had received, within the last five years grants or awards for end-of-life programs. Unfortunately three specific factors, or curriculum types, continue to contribute to the slow integration in end-of-life training.

**Hidden Curriculum & Medical Culture**

In curriculum theory, three types of curriculum exist: (Gofton & Regher, 2006; Hafferty, 1998; Tanner & Tanner, 1995):

1) **Endorsed curriculum** – what is stated, intended, formally offered.

2) **Informal curriculum** – the unscripted, ad hoc, highly interpersonal teaching and learning between faculty and students. “The informal curriculum is the process by which a learner’s knowledge and skills becomes situated in the context of daily work” (Gofton & Regher, 2006, p. 20).
3) Hidden curriculum – the set of influences that function at the level of organizational structure and culture. “To quote Albert Schweitzer, ‘Example is not the main thing in influencing others; it is the only thing;’ it is as true in medical education as anywhere else” (Gofton & Regher, 2006, p. 21).

Braddock (2004) explained that the hidden curriculum consists of common understandings, customs, rituals, and taken-for-granted aspects of what goes on in clinical components of medical education. Branch (1998) and Wear (2000) in articles on ‘deconstructing the white coat’, explained that the white coat overtly affirms the humanistic values of medicine while covertly symbolizing medical power and authority that is part of the hidden curriculum. Gofton and Regher (2006) reminded medical educators that the “concept and importance of the hidden curriculum is not well understood by the medical community at large” (p. 22). Rhodes-Kropf, Carmody, Seltzer, Redinbaugh, Gadmer, Block, and Arnold (2005) stated that “the values, attitudes, beliefs, and behaviors that students learn through their daily interaction with health care providers, and how they learn what the medical community thinks is important to being a doctor, are conveyed through the hidden curriculum” (p.634).

The hidden curriculum in medical education is not confined to the student. According to Hafferty (1998), the hidden curriculum affects policy development, evaluation, resource allocation, and institutional nomenclature. Only by identifying the hidden curriculum and strengthening humanism, values and attitudes consistent with a compassionate professional, will the medical culture

The impact of the medical culture, both hidden and overt, is pervasive and shapes medical students and physicians.

"New physicians enter the medical profession with certain attitudes and feelings toward patients that will be shaped until they more or less comply with those of the medical profession as a whole" (Dickinson, Tournier, & Still, 1999, p.1743). The only way to make end-of-life care a part of medicine is to change "the culture of our learning environment" (Gofton & Regher, 2006, p. 24) and by identifying the commonly held "understandings, customs, rituals, taken-for-granted aspects of what goes on in the life space we call medical education" (Hafferty, 1998, p. 404). Sullivan’s et al (2003) report on the status of medical education in end-of-life care, and the lack thereof, illustrates the concepts of a culture of end-of-life care versus the hidden curriculum with the following points: a paucity of teaching about end-of-life care; lack of exposure to care of dying patients at home; and to models of care for the dying such as hospice; perceived communications by teachers that end-of-life care is less important than other aspects of clinical care; tolerance of lack of preparation for clinically ubiquitous psychosocial and communication tasks related to end-of-life care; and perceived mixed message about end-of-life care… “Our data suggest that current educational practices in the United States are not adequate to ensure excellent physician education and patient care at the end of life” (p. 692-693).
Good Death

“Dying is part of living. Dying well is a part of living well. We need to reshape our idea of what a good death is according to what we learn from dying persons and their families” (Duke Univ. Program).

Steinhauser, Clipp, McNeilly, Christakis, McIntyre, and Tulsky (2000), through a series of focus groups and interviews, identified six components of a good death: pain and symptom management, clear decision making, preparation for death, completion of life, contributing to others, and the affirmation of the whole person (p.827). (Appendix L) Not surprisingly, what Lo and Synder (1999) found as end-of-life skills lacking in physicians shadow the six components: pain management, knowing patient preferences, missed opportunities to address patient concerns and fears, communication skills and care for the dying. “To avoid these problems, physicians should take a ‘both/and’ approach to palliative and disease-oriented care instead of an ‘either/or’ approach” (p. 773)

There is agreement that definition of a good death includes quality of life and preparation for death at the end of life. “Physicians sometimes find themselves prolonging the process of dying without providing the patient with either an improved quality of life or time to prepare for death” (Dickinson, Tournier & Still, 1999, p. 1741). A 2004 University of Pittsburgh study found that 75% of people surveyed said “they would trade some amount of healthy life to improve the quality of end-of-life care… On average, interviewees were willing to trade seven months of healthy life just to ensure better quality of care in the final
month of life.” Harvard’s 1999 study found that 70% of Americans prefer to die at home as part of their conception of quality of life at the end of life.

*Approaching Death* (1997) introduced the concept of *quality of dying*. This concept focuses on a person’s experience of living while terminally ill or imminently dying (Wallston et al, 1988). The focus turns to the special world of the dying patient. Some outcomes are less realistic, while other aspects such as spirituality and well-being, become more meaningful. Unfortunately, despite the growth in hospice and palliative care, access to medical technology continues to grow and medical culture still sees death as failure. This makes it difficult for the physician to be *healer* when providing care at the end of life.

**Physician Healer – Humanizing Medicine**

“Throughout the ages, when most remedies were worthless or harmful, and most theories of disease were wrong, many patients still recovered, in part because of the healing power, the ‘humanistic medicine’, in doctor-patient relationships” (Novack, Epstein, & Paulsen, 1999, p.516).

Emory University Medical School has been striving to humanize medicine for years. Their physician-patient interaction course, according to Dr. Jonas Shulman, Associate Dean for Medical Education and Student Affairs at Emory, “is a humbling experience, but it’s good for them. If you don’t learn how to connect with patients, nothing else really matters” (Schindler, 1995, p.1).

Crawley, et al (2002) in the context of cultural competency, explained that “a respectful inquiry, followed by a willingness to listen to the patient’s story and acknowledge his experience, helped restore a trusting relationship” (p. 675). The
American Medical Association’s online journal, *The Virtual Mentor* (2006), stated that compassionate care at the end of life is an essential tenet of humanism and medicine.

Wear (2002) and Novack, et al (1999) explained that students are taught diagnosis, investigation, and cure, which leaves little room or respect for a focus on relief of symptoms and suffering. Chiswick (2001) talks about perceived ethical issues that result in a failure to alleviate suffering. Latimer (1998) declared that “the medical profession has a strong moral imperative … to work toward the alleviation of suffering” (p. 1744). Carmody, et al (2005) says succinctly, “The goal of good palliative care is to relieve suffering and to improve the quality of life” (p. 1005).

Egnew (2005) exhort the physician to become ‘healer of the sick’ rather than ‘curer of disease’. He admits the difficulty for physicians because “medicine promotes no operational definition of healing, nor does it provide any explanation of its mechanisms, saving those describing narrow physiological processes associated with curing disease” (p. 256). Feudtner (2005) offered a definition of healing: “*Healing* has been defined as those physical, mental, social, and spiritual processes of recovery, repair, renewal, and transformation that increase wholeness and often (though not invariably) order and coherence” (p. S30). Healing at the end of life is not an unrealistic expectation, just a different way of medically viewing what healing is: “While cure may not always be possible, healing – restoration of wholeness- may be possible to the very end of life” (Puchalski, 2002, p.290).

To the typical physician, my illness is a routine incident in his rounds, while for me it’s the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity… I see no reason or need for my doctor to love me—nor would I expect him to suffer with me. I wouldn’t demand a lot of my doctor’s time: I just wish he would *brood* on my situation for perhaps five minutes, that he would give me his whole mind just once, be *bonded* with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way (pp. 43-44).

**Physician Attitudes and Beliefs**

“After 20 years of practicing medicine, the physicians we surveyed seem to have become more accustomed to dealing with death and/or were forced to come to grips with their attitudes toward death” (Dickinson, Tournier, & Still, 1999, p.1743).

Medical students’ and physicians’ attitudes have come a long way in the last three decades. Previously students viewed attention to the ‘soft’ sciences that required learning communication skills and physician-patient interpersonal dynamics, as low priority; and end-of-life care as an unwelcome event (Dickinson et al, 1997; Novak et al, 1999). In 2001 Wayne State Medical School created a hospice experience for their students, though not a required part of the curriculum. “We want our doctors to understand how caring for dying patients fits
in part of medicine,’ said Dr. Schwartz… “Doctors must play a role, and they must be prepared for it” (Dicresce, 2001, p.ii). Mogi et al (2003) found that it was the physician’s personal death experiences that served to shape their views of death and treatment of patients.

In specialties that deal with death more frequently there has been acknowledgement of the emotional and physical toll end-of-life care creates. Wolpin, Chabner, Lynch, and Penson (2005) explain that “patients’ deaths can lead to feelings of failure on the part of the oncologist and a desire to distance oneself from patients to avoid personal harm” (p. 454). Given the high rate of burnout, it is important that the skills in end-of-life care necessary to strike a balance between availability for the patient and emotional protection for the physician are adequately taught (Wolpin, Chabner, Lynch, Penson, 2005).

Malterud and Hollnagel (2005) caution that “we never forget the dominant lesson from medical school: doctors are omnipotent, detached, and impersonal” (p. 348). This position of the detached caregiver has had far-reaching effects on physicians. It may cause physicians to assume their decisions about care outweigh the patients. Or if they cross the emotional line and become personally invested, a patient’s death also touches the physician. “The personal emotions of physicians are often ignored, repressed, and under examined, but they may surface at less-than-opportune times” (Serwint, et al, 2002, p.283). Much is written and great attention has been given to the grieving process of patients and families, yet little is known about caregiver grief, or specifically physician grief and loss. “Unfortunately, although physicians often successfully execute their
duty of support to patients and families, they commonly have little time to process their own sorrow about their patients’ death and suffering” (Shanafelt, Adjei & Meyskens, 2003, p. 2616-2617).

In a 2005 article, Jackson, Sullivan, Gadmer, Seltzer, Mitchell, Lakoma, Arnold, and Block state: “To our knowledge, this is the first study of physicians’ emotional reactions to their patients’ deaths using a random sample of patients to identify participants” (p.655). They found expressions of guilt and anxiety in physicians. There was little influence of medical training on the management of dying patients. The researchers found burnout, medical errors, and post-traumatic stress disorder among trainees who did not adequately deal with their emotions and attitudes about death and dying.

Four other studies were found, not directly linked to a curriculum or assessment for death anxiety, about physician attitudes and beliefs in end-of-life issues. In Saunderson and Ridsdale’s (1999) study of general practitioners’ beliefs and attitudes about how to respond to death and bereavement, the following concerns emerged for bereaved patients:

1) General practitioners’ fear of making mistakes; feelings of guilt and self-blame when expectations differed from reality, the need to take responsibility and confess error when death occurs.

2) Different approaches in hospital and in general practice – urgency vs. fuzziness

3) Effect of medical training vs. personal experience of life – how poor or no training and/or experience shaped responses
4) Doctors’ different approaches toward contacting the bereaved

5) Doctors’ own sense of loss

Williams, Wilson and Olsen (2005) found these results from medical students regarding dying, death and medical education:

1) Guilt, fear, blame, impotence

2) Personal experience with death – how it shaped attitudes

3) Survivorship and professionalism - trying to find the balance between too much emotion/caring and detachment. Identifying coping strategies.

4) The meaning of death – different in different situations: unexpected, of a child, generalized fear of death, after a long illness, etc.

5) The effects of religion or spirituality on their attitudes

The similarity between these two studies after six years of end-of-life education being integrated into medical school education asks the question of how effective or useful is current end-of-life curriculum.

Kasket’s 2006 phenomenological investigation of doctors and death, began with four presuppositions (only two cited here from his article):

1) Professionalism - emotions do not get in the way of the work

2) Physicians do have emotional responses to death, but training and societal expectations make it difficult to know what to do with them.

With end-of-life curriculum being expanded, communication skills and cultural awareness increased, Kasket’s study indicated that the hidden curriculum of medical culture is still firmly entrenched: Physician’s should be effective and
proficient at the end-of-life with patient care, but should not be affected by their patient’s death.

Research Foundation Information

The very nature of this research challenges the medical worldview of hard science. The researcher’s fundamental understanding is founded on an existential position.

“Existentialism is based on the fundamental premise that human beings have the unique capacity to question and reflect upon their own existence, that is, ‘to be or not to be’…Palliative care practitioners have the privilege of promoting, witnessing, and validating patients’ existential explorations within this unfolding dialogue (Breitbart, Gibson, Poppito & Berg, 2004, p. 370).

As presented under spirituality, end-of-life is an existential process. The search for meaning takes place on many levels. “Husserl (1970b) employed the word act rather than presentation to refer to experiences of meaning, emphasizing that the meaning of a phenomenon is in the act of experience and not in the object” (Moustakas, 1994, p. 51). The experience of (the act of) working with a dying patient or being presented with the death of another is the phenomena under study. This experience occurs in the context of the medical culture. “The prevailing medical culture continues to view death as a medical failure” (Fins & Nilson, 2000, p. 662). This belief has translated into a medical practice of cure at any cost, or quantity of life over quality of life, use any means to hold off death, cure not care (Dyer, 2001; IOM, 1997; IOM, 2002; Veysman,
2005). Uncovering the phenomenon of death and dying requires identifying the physician’s personal beliefs and experiences as well as those they’ve been expected to acculturate from medical culture.

Dr. Buckman, a medical oncologist who has written and taught extensively on doctor-patient communication and breaking bad news, reminds both patients and doctors that “the job of a physician often asks an ordinary being to transcend human feelings to carry out a duty for people in need” (http://www.ethics.emory.edu/news/archives/000149.html). The search for meaning, the raising of awareness, the uncovering of essences and understanding, are the underpinnings of a phenomenological approach.

The identification of the researcher’s theoretical and epistemological views identifies biases and motivations. The interview process will engage researcher and participant in a joint discovery of the phenomenon that is the interaction and experience between a doctor/death and dying/and a patient.

**Summary**

As this literature review shows, end-of-life care involves many components. While strides have been made in integrating end-of-life care training in medical school education, there is a long way to go. Medical culture and hidden curriculum still predominantly influence physician attitudes that death as failure, or as Segal (2005) explains “a biomedical rhetoric of death as ‘medical failure’ now competes with an emerging public rhetoric of death-as-part-of-life” (p. 93).
Insufficient time and energy are being invested in preparation of medical students; both for care of patients, and self-care and support for physicians, surrounding death and dying. The phenomenon of death and dying will continue to be a reality in medicine. Whether physicians are prepared through curriculum, psychological support or other forms of the health education spectrum, skills and education are needed for both physician and patient to effectively and humanely handle the end-of-life care and journey.

This literature review has given an overview of hospice, palliative care, communication skills, advance directives, caregivers, cultural issues, ethics, spirituality, psychological issues, health literacy, end-of-life curriculum, hidden curriculum, medical culture, good death, physician healer, humanizing medicine, physician attitudes and beliefs, and research information not included in chapter three.

Chapter three describes the purpose of the study, the phenomena under study, research questions, research design, researcher bias and impact, participant selection, interview sites, study participants, interview techniques, interview questions and expert panel, data collection, and data analysis.
CHAPTER III

METHODS

Chapter three describes the purpose of the study, the phenomena under study, research questions, research design, researcher bias and impact. Participant selection, study participants, interviews and interview logistics, interview questions and expert panel, data collection, and data analysis are included.

Purpose of Study

The purpose of this study was to describe how physicians construct meaning of the phenomena of death and dying within their medical profession. A secondary purpose was to examine how physicians integrate the reality of death and dying within their professional practice. The phenomenon of death and dying was examined from the perspectives of the participants via semi-structured in-depth interviews.

Phenomena under Study

This study was based on the theory of phenomenology. “Phenomenology is, on the one hand, description of the lived-through quality of lived experience, and on the other hand, description of the meaning of the expressions of lived experience” (van Manen, 1990, p. 25). The lived experience and expression of lived experience being explored in this study were how physicians made meaning of death and dying personally and professionally.

The phenomena, for this study, is not dying or death physiologically as a medical condition, but how the physician interacts with his or her own personal
worldview and beliefs, the medical culture, and a patient and/or family members. Restated: the phenomena is the observable event: the lived experience, of the interaction among a doctor/death or dying/and a patient. The interview process was used as a means to uncover the meaning and understanding attributed to the phenomena by the participants. Interviews attempted to discern how the physician perceives and understands this interaction, what factors influence the way the interaction occurs, and how meaning of this interaction is made by these physicians. By eliciting these factors, identification of possible gaps in medical training, medical culture, or personal needs were illuminated.

In investigating these phenomena, to understand how participants perceive and make meaning of the phenomena, it is important to identify language and communication styles of the participants. Implications of communication styles apply to the interview process, future use of this study for curriculum design for medical training, implementing effective communication styles in health education, and end-of-life areas.

**Research Questions**

For the purposes of this study the following research questions were used:

How do selected physicians describe the essence and meaning of death and dying?

How do selected physicians interpret their understanding of death and dying and then integrate the reality of death and dying into their personal medical culture and practice?
Research Design

Upon approval of the Human Subjects Committee at Southern Illinois University Carbondale, (Appendix Q) this qualitative study was conducted in the Southern Illinois area. Qualitative research is descriptive and heuristic. According to Moustakas (1994), heuristic research is “aimed at discovery, a way of self-inquiry and dialogue with others aimed at finding the underlying meanings of important human experiences” (p. 18). This study was built on a phenomenological research approach.

“Phenomenological questions are meaning questions. They ask for the meaning and significance of certain phenomena. Meaning questions cannot be solved and thus done away with (Marcel, 1949)” (van Manen, 1990, p. 23). For the researcher, this search for meaning leads to “development of methods and procedures for further investigation and analysis” (Moustakas, 1990, p. 9). For participants, an internal searching of memories and experiences occurs, where they may discover the nature and meaning of those experiences. The verstehen, according to Max Weber, is the interpretive understanding of this human interaction (Neutens & Rubinson, 2002, p. 163-167).

In qualitative research, the researcher is the primary instrument. The researcher is attempting to gain a deeper understanding and comprehensive picture of the phenomenon being studied. The method and procedure used for this study was in-depth interviews conducted with physicians. The method and task for phenomenological interviews is to engage in a two-way conversation, in an informal, interactive process utilizing open-ended questions that assist the
participant in reconstructing experiences and obtaining information relevant to purpose of this study (Moustakas, 1990; Gordon, 1992; Seidman, 1998). Using a phenomenologically based in-depth interview served to allow the researcher to facilitate reconstruction of experiences of participants.

As the researcher, I contacted key informants who identified potential study participants who were family practitioners. Key informants were long time residents of Southern Illinois known to the researcher, SIUC faculty members, and professional contacts within the health care community previous established by the researcher in the Southern Illinois area. Key informants were asked to contact potential interviewees to see if they would be willing to participate. Those doctors who agreed to be interviewed were contacted first by phone, a follow-up letter (if no phone contact was made), a second phone call was made if no contact was achieved, but no further attempts were made.

Interviews were arranged at the time, location, and convenience of the interviewee. Due to the nature of medical practice, and the great demands placed on the time and energy of physicians, instead of asking selected physicians for 3-5 hours of their time over three sessions, one 60-90 minute session was held. Three groups of physicians were interviewed. Physician groups were defined as: recently graduated (1-5 years out), in mid-career (10-20 years of practice), and retired physicians. Interviews were audio taped, transcribed, each into an electronic file, a hard copy was printed and then sent to each participant for their review, additional input, or comments. Transcribed
interviews were read and analyzed. Content analysis was the primary data analysis tool. Analysis included a four step coding process.

Four different coding steps were used. First, I as researcher, bracketed my preconceived ideas, experiences, and expectations. This was a three part process, after the interviews I made notes, comments and reflections on the interview, interviewee and my reactions and response to what was said and occurred. Before the actual reading began, I mentally put my mind in a neutral space trying, as much as humanly possible, to be a clean slate while I read the interview as a narrative. Finally as notes were made in the margin of ideas and concepts that came forth during the reading of the transcripts, again d my perceptions and reactions were noted and literally bracketed with { }, to set them off from interview discoveries. All margin notes were collected and combined from all interviews, margin notes made where of ideas and concepts that came forth during the reading of the transcripts. From margin notes identification of common concepts and meanings were grouped. These groupings would evolve into themes.

Secondly, transcriptions were read and coded by individuals outside the study to assist in verifiability and trustworthiness. Readers were asked to give their impressions about what concepts, ideas, meaning, or common themes, they found in the interviews. They were also asked to make margin notes of their impressions as they read the interviews. One reader, a physician, repeatedly asked for specific instructions and was finally told: “Be spontaneous, don’t over think. Write your impressions of what you read - as you read. Anything you see,
feel, or react too, is correct. I (for the research) am not ‘looking’ for anything.”

Outside readers were not asked to bracket (First, because the phenomenological research process was not explained in depth to readers and secondly, because their honest, unguarded response were also part of the phenomenological process in this study.), but only respond honestly to what they read. The reader margin notes and comments were then combined with researcher margin notes. These two different source readings were triangulated with field notes, observations, demographic information, and thick, rich descriptions to identify the themes. Thirdly, after themes had been defined, a clean copy of each interview was read with a list of the identified themes on hand. Each theme was assigned a number for ease of collection after completion of readings. Although I had identified themes to guide the second reading, it was important to continue to keep new eyes, allow the dialogue to continue, and be open to the possibility for other themes and meaning to surface. Each interview’s quotes were highlighted and identified by theme. After all interviews had been re-read and quotes highlighted, all quotes - by theme, were copied onto a theme reference page, each quote was identified by participant and interview page number. A few highlighted quotes that did not fall clearly under one of the identified themes, were listed on an uncategorized reference page.

Finally, a few weeks after completion of quote/theme identification, clean copies of interviews were read again to see if any other concepts, meaning or themes emerged. The break in time between readings was done to assist me, as researcher, to read the interviews with new eyes and see the interviews as
new information, since I was also the interviewer (van Manen, 1990, Moustakas, 1990, Neutens & Rubinson, 2003). Margin notes were made again identifying ideas and concepts and quotes highlighted. Any new margin notes or quotes highlighted were added to the theme reference pages.

The theme reference quote pages were re-read to verify that quotes were identified under the appropriate theme and were salient. Some quotes were moved to different themes, and an additional theme emerged in this re-reading. With the identified themes and quotes the narrative of this phenomenological research could be told.

From the initial contact, data collection, and analysis begins. Data collection encompasses observational data as well as the recorded interview. “The collection of observational data may have three purposes: (1) to provide descriptions of behavior; (2) to record situational behavior; and (3) to study a topic that lends itself to this method” (Neutens & Rubinson, 2002, p. 169). The setting, participants’ non-verbal cues and behaviors, interviewer’s observations and reactions during initial contact and follow-up are all observational data. The actual recorded interview, transcription, coding, and field notes, make up the interview component. Demographic data information, which included gender, age, ethnicity, medical school, specialty, years in practice, contact information and specifics about end-of-life training received (Appendix N), informed consent forms (Appendix O), letters sent or received, and a research journal, comprise the documents component. The audio-visual component included audio tapes
and emails that complete the data set collected for this research (Creswell, 1998).

**Researcher Bias and Impact**

Part of the phenomenological process is the knowledge and assumptions, the researcher, interviewer, and reviewer, bring to this exercise and how they partition personal reality. As such, they must be identified, noted as potential researcher bias, how the possibly influence the interview itself, be part of both interviewer and researcher bracketing (See data analysis) when analyzing data (Merriam, 2002), and reintegrated when making conclusions and interpretations.

Regarding researcher bias, I the researcher, am not a physician, nor currently part of the medical culture, thus, an outsider. Knowledge of the medical culture comes from the literature review (See Introduction and Chapter Two: Medical Culture) and personal experiences working in hospice, grief counseling, and as a spiritual care worker in hospitals. Use of interviews serves to bring me, briefly and in a limited manner, into the context and experience of a physician, gaining an temporary insider’s perspective, through the experiences and narratives of the physician participants.

My connection to the medical culture and training surrounding end-of-life issues began as a hospice volunteer. My research assumptions, at the beginning of this research, were grounded in my belief that humans must engage, interact, and participate in death and dying, not promote nor postpone death, nor deny or sacrifice the quality of life to technology. Hospice is still a relatively new concept in modern medicine (See Introduction and Chapter Two:
Hospice). Dr. Balfour Mount in a 1995 keynote described how “hospice, and palliative care…, was beginning to be integrated into the modern health care system…” (Schonwetter, p.236). (See Chapter Two—palliative care). It took 11 years. In 2006 palliative care become an approved sub-specialty of medicine (http://www.aahpm.org/about/recognition). I, as the researcher, only knew end-of-life care from a hospice and palliative care perspective, so in essence, the physician participants and I were speaking different languages and my hospice bias could interfere with the participants’ perspectives. Each interview had to be approached with an intentional setting aside of my experiences, bracketing of my expectations, and the willingness and readiness to hear what the participants were really saying and sharing about their experiences.

Another of my fundamental research assumptions is that death is a natural process. A death causes loss and grief to the living. Confronting and embracing grief and loss is a process that requires healing and growth (Corr, 1994; Doka, 2004; Rando, 1993; Worden, 2002; See Appendix A). Doctors may be able to cure illness, temporarily avoiding death, or refer dying patients away, but the issues of loss, grief, and one’s own mortality, are personal and real for doctors. This research hoped to uncover whether the support (or lack thereof), training (or lack thereof), and personal confrontation (or lack thereof) with death, had a profound effect on how doctors dealt with end-of-life issues, and how they treated patients confronting death and dying.
Participant Selection

“The aim of a sampling process is to yield participants who are representative of the phenomena of interest” (Krippendorff, 1980, p. 69). A true random sample was not made for this research because it was impossible for this researcher, due to time and resources, to obtain a random sample of all licensed family practitioners in the United States of America. Additionally there was an a priori knowledge about the phenomena under study. Everyone dies; everyone experiences death and dying personally and vicariously through the media, personal associates, and so on. Yet each individual physician is unique in how he or she integrates education, experience, and practice, when facing end-of-life issues. Finally, as a researcher I had no authority to compel all family practitioners in Southern Illinois to participate and be randomly sampled in this study.

Participant selection targeted physicians not currently practicing in an end-of-life specialty (such as palliative care, gerontology, or hospice). Family medicine practitioner was the preferred specialty for participants. A male and female physician in each group was sought. Interviews with four physicians in each group were sought. The groups as initially defined were: 1) recently graduated (1 to 5 years out of medical school), 2) those in the midst of practice (10 to 20 years experience), and 3) retired physicians. The artificial creation of longitudinal experiences and apparent time was attempted by using three different groups of participants at three different stages of life and medical practice (Dickinson, Tournier, & Still, 1999).
A sample of convenience, in sufficient number to achieve salience of themes, using physicians in the local area of Southern Illinois was sought. This random selective sample in no way attempted to reflect all physicians, or be a representative sample of all physicians. According to the AMA’s website in February, 2007, 61 licensed family medicine physicians were in the Jackson county area of Southern Illinois. Twelve interviews represent 19.6% of the family medicine physician population for this area.

Residents of Southern Illinois (key informants) who were knowledgeable about physicians in the medical community gave potential participants’ names to me. Key informants were known to me personally. They were faculty, friends, family, business associates, and physicians who agreed to be interviewed. The individual names received from key informants were contacted directly by me and requested to be interviewed. No more than two referrals came from any key informant to reduce referential bias, and to get a diverse potential participant list. Referrals from participant physicians were solicited for more potential participants, again referential bias was a consideration.

Despite the fact that there are several healthcare institutions and physicians in the area, it was difficult to secure participants. Southern Illinois Healthcare (SIH), a not-for-profit health care system in Carbondale, Herrin, Marion, Illinois and surrounding areas, was contacted. I asked to make a presentation requesting participants at a monthly doctor’s meeting, or in any other institutionally acceptable manner. SIH shared contact names and numbers of three hospitals in their system. Each agency was contacted two or three
times. Messages were left letting them know from whom the contact information was received, and the research topic. No direct contact was achieved with any contact person. No return calls were received from these individuals or institutions. During a follow-up call with the original SIH contact, he shared that time was limited for physicians. He also stated that the research topic area wasn’t one most people wanted to discuss.

Southern Illinois University Carbondale’s (SIUC) student health service was contacted. I spoke with both the director, and physician who oversees SIUC health services physicians. I requested to speak with physicians explaining the research study, and to request participants. Both said they would present the request at the next staff meeting. Again, no return calls from any physician in the SIUC health care system were received however, one retired SIUC health services physician did agree to participant. Initial contact was made through a key informant, not the SIUC health services. During the interview she explained that, in general, university health care providers do not have much exposure to end-of-life issues or fatal medical events.

**Study Participants**

Of the 19 physician names given by key informants, six did not respond to any of my attempts to contact them. All key informants had been asked to contact the physician first so the researchers’ contact with the physician would not be a ‘cold call’, and the physician would have some knowledge about the research and upcoming call. Based on information given by participants during initial contact, all but two had received these calls. It is unknown whether those
physicians who did not return contact calls received the initial contact from the key informants. Physicians who did participate either responded to the first phone call, or personal interaction, in a timely fashion. Three physicians responded after a week’s delay, explaining that they had been on vacation, or out of the office, and apologized for the late response.

The intent of this research was to talk to physicians without end-of-life training. Eleven physicians agreed to be participants from the 13 contacts made from names received from key informants. During interviews it was discovered that initially key informants only referred family physicians whom they thought did end-of-life issues well.

After interviews began, and because of participant comments that: “it should be the physicians who don’t do this well, being interviewed”, key informants were approached again and asked for names of physicians who may not handle end-of-life issues well. Six more names were received. None of the non end-of-life skilled physicians responded to requests for an interview. Referrals for non-skilled end-of-life care physicians were requested from participants. One physician hesitated, then declined, explaining that she did not think those particular physicians would be interviewed, for exactly the same reasons they should be agreeing to the interview.

Three of the physicians who had been referred, and interviewed, were mentioned by all other interviewees: the hematologist/oncologist, and two family practitioners; one of whom had been the hospice medical director, and the other who also teaches at the SIUC medical school. Everyone considered them the
“people to talk to” regarding end-of-life issues and how doctors should practice end-of-life care. Something that was also noted in research data collection.

By using retired physicians, those physicians in the midst of their practice, and physicians just beginning practice, the context and details of the phenomena under study were artificially spread over time, called apparent time in sociolinguistic studies, and developmental experiences, among these participants. It was anticipated that meaning making and understanding would be reflected differently in different developmental and professional stages of a physician’s practice, and his or her experiences with death and dying. Studies showed, however, similar responses may be found despite years in practice (Dickinson, Tournier, & Still, 1999; Meier, Back, Morrison, 2001; Sunderson & Ridsdale, 1999; Williams, Wilson & Olsen, 2005). Similar studies supported my initial assumptions that lack of training and personal self-awareness affects how physicians deal with death and dying.

When determining how many interviews were enough in purposeful sampling, Seidman (1998) gives two criteria: a) sufficiency to accurately reflect population and, b) saturation of information, hearing the same information reported (Douglas, 1976; Glaser & Strauss, 1967; Lincoln & Guba, 1985; Rubin & Rubin, 1995, Seidman, 1998). For the purpose of this study, these three to four interviews in each group were expected to sufficiently reflect the phenomena under study (Bryman & Burgess (eds.), 1999; Kvale, 1996) The participants represented 19% of the family physician population and in interviews saturation of information and common themes did occur.
Interviews

Best and Kahn (1993) say that ‘interviews are used to gather information regarding an individual’s experiences and knowledge; his or her opinions, beliefs, and feelings; and demographic data” (p. 202). Seidman (1998) states that “at the root of in-depth interviewing is an interest in understanding the experience of other people and the meaning they make of that experience” (p.3). By using in-depth interviews, this study sought to portray a deeper understanding of the physician’s elements perceived as important in the phenomenological understanding, meaning, and essences surrounding death and dying, and how they translate to a physician’s personal identity and patient interactions.

Phenomenology lends itself well to interviewing as a research tool (Moustakas, 1994) as well as being an appropriate qualitative research tool (Mason, 1996).

“A significant factor here is what the researcher brings to the situation” (Holliday, 2002, p.11). Patton (2001) quoting Guba and Lincoln said “the credibility of qualitative methods, therefore, hinges to a great extent on the skill, competence, and rigor of the person doing fieldwork-as well as things going on in a person’s life that might prove a distraction (Guba & Lincoln 1981)” (p. 20).

According to Mason (1996), “Good qualitative interviewing is hard, creative work… a formidable task for which a high degree of intellectual and social skill is required” (p. 42 & 45). He further explained that good interviewing skills require being able to think on your feet, effectively, quickly, coherently and to remain consistent with the research questions. Decisions about content and sequence of interview, the substance, style, and scope, generate the quality of
data for the research under study. It is vital for interviewers and researchers to develop the skills needed for interview interactions (p. 42-46). Listening – really listening - to what people are saying includes:

1) Remembering what people have said to you and what you’ve already asked them.

2) Achieving a good balance between talking and listening.

3) Observing – picking up verbal and non-verbal cues

4) Becoming accomplished in the practicalities of interviewing – note taking, using equipment.

Using the above skills, one 60 minute in-depth interviews were conducted with each participant. Interviews were conducted at the participant’s choice of time and location.

All interviews were audio taped. A portable tape recorder with plug-in cord and batteries was used. Before each interview, the tape recorder was checked for sound clarity and volume. A list of interview questions and probes were available for reference and use by the interviewer during the interviews. Interviews were expected to take between 60 to 90 minutes. Interview notes were be kept by the researcher. Transcribing of interviews began soon after each interview was completed.

Detailed field notes and observations were made after each interview by the interviewer. Observed behaviors of participants and personal reflections of participants, manner, presentation, and so on, were made upon completion of each interview. Following Mason’s (1996) admonition: “You need to remember
that, however ‘objective’ you try to be in your records, you are continually making
judgments about what to write down or record, what you have observed, heard
and experienced, what you think it means. Your records need to provide the
fullest possible justification for your own decisions” (p. 52).

Qualitative research acknowledges that no researcher can be completely
non-biased. Both interviewee and interviewer are set in a social reality in which
they construct meaning using their views, understandings, interpretations, and
experiences, principles and methods, based in their epistemological position.
The researcher must both elicit and explore, via open-ended questions and
probes, the interviewees’ points of view, understandings, and meanings, while
recognizing her own construction of meaning and point of view. (Mason, 1996;
Patton, 2002)

Using guidance from Straus and Corbin (1998), that “one’s research is
tempered with the realization that phenomena are complex and their meanings
are not easily fathomed or just taken for granted…therefore flexibility and
openness are linked with having learned to sustain a fair amount of ambiguity…”
(p. 5-6). Each interview process was reviewed. Adjustments were made in
interview style to facilitate flexibility and openness, as described in interview
logistics, or with specific question formats. Such as, more or less medical
terminology was used in a question, to elicit a more emotive, or low
communication response. Or a personal question was phrased in high
communication, so it could be responded to within a participant’s professional
reference. As interviews progressed questions were modified slightly to facilitate
responses, and assist in eliciting participant descriptions, meanings, essences, and understandings reflecting the phenomena under study.

**Interview Logistics**

Interviews were conducted at the time and location of convenience for participants. One interview was held in a participants' home, two interviews were held in public spaces, and eight of the interviews were at work place or participants’ offices. Each setting appeared to afford the same amount of privacy, but were not exclusively private. Interviewers must be prepared for unanticipated interruptions or events (Seidman, 1998). During these interviews, every interview was interrupted by either a person entering the room, a phone call (some for the participant, some not), or noise and activity created by others. One participant received two beeper pages and had to take a brief break in the interview to handle medical issues. These events became part of the observational notes, adding another dimension to participant interaction with their environment.

It is also important to accommodate the comfort of the interviewee. While it was my intent to sit across from the participants with no barriers between us, providing an open, unblocked interview space (Gordon, 1992, Seidman, 1998) three of the participants placed a desk between us, and one participant sat beside, but faced away from me during the interview. The participants’ choice seating arrangement and the placement of physical barriers between us during the interview became part of the observational data for this research.
The interviewer and interviewer skills are critical components of this research. The perception of the interviewee of the interviewer can be affected by race, gender, age, physical appearance, speech, and mannerisms which can affect whether a participant agrees to be interviewed and if interviewed, the kind and quality of information that is shared (Burns & Grove, 1993; Berg 2001; Neutens & Rubinson, 2002, p.110). Gordon (1992) stresses that “interviewing skills are not simple motor skills… rather; they involve a high-order combination of observation, empathic sensitivity, and intellectual judgment” (p.7).

Advantages of interviews are personalization of the study to a participant, flexibility for further probing, observing verbal and nonverbal behavior, spontaneity, as well as the ability to record. The advantages can be outweighed by such disadvantages as interviewer bias and personality clashes between interviewee and interviewer (Neutens & Rubinson, 2002). A large component of this research study dealt with the personal interaction between doctor and patient, and the perceptions therein, during end-of-life. Physician bias and physician-patient personality clashes are a very real component of end-of-life care. The personal interaction between physician participant and interviewer was carefully observed, documented in field notes, and became part of data collection notes, giving the interviewer, me, an additional insight into interpersonal dynamics of participants, which in turn helped shape the narrative of the research.

As researcher, I was the sole interviewer. Bearing in mind the influence the interviewer may have on interviewees, I consciously tried to present the
same, neutral, professional, and open presence to each participant. Participants’ dress and demeanor were part of the phenomenological research notes. For example only two participants, who met during work hours; were in white coats which represents their profession. Field notes were kept prior to the start of each interview and immediately following. Some field notes were hand written then typed into electronic files; most were created on the audio tape used for the interview and later transcribed to computer files.

Interviews require participants to make commitments of time, it was important to be mindful of their time. Two interviews began late because of miscommunication, which could have affected the interview. Both participants agreed to a delayed interview and fully participated stating that they thought this was important research, and they could wait a few minutes to participate in the interview. All such information became part of the observations data and phenomenological research.

After the first two interviews, which were with retired physicians, it became evident that a 90 minute interview was not a comfortable or reasonable time frame to which participants would be willing to commit. When the interview time was reduced to 60 minutes maximum more physicians were more receptive and willing to become participants. My willingness to keep the interview within the confines of a workday and 60 minute time frame, assisted in securing some of the interviews. Of the original 13 referrals and appointments set, only two declined stating time conflicts resulting in 11 interviews. Four in the early in career and mid-career groups and three in the retired group.
Interview Questions and Expert Panel

The following represents questions I used as a guide to assist in exploration of the phenomena under study. These questions were designed, with the help of the expert panel, to follow Dolbeare and Schuman's (Schuman, 1982) three interview phenomenological format condensed into one interview (Seidman, 1998).

Interviews began with a question designed to provide a history of the participant in time and relation to the phenomena under study.

1. How did you decide to become a doctor?

The second step in the interview concentrated on concrete details of participants’ experiences related to the phenomena.

2. Would you be willing to share your memories of the first death you remember?

3. Do you remember your first patient death, or a medical death that affected you as a physician?

   PROMPT: Ask for details - What was going on in the medical setting, the family setting, and other details that are remembered.

The third step in the interview focused upon meaning. Asking the participant to reflect back on what she or he was thinking and feeling, and addressed the intellectual and emotional connection between their profession as a physician and their experiences with death and dying.

4. What do you remember thinking and feeling during that first (shared) experience of a death/dying patient?
PROMPT: Did you feel prepared, or trained, to deal with the death and surrounding aspects? Please elaborate.

5. What have you learned from dealing with patients and families who are dying or who have died?

6. What do you wish you had been taught or would have learned in medical school to help you deal with death and dying?

PROMPT: Have you taken any training in end-of-life issues specifically? Describe the content or lack thereof.

7. How would you describe what medicine and the medical culture’s view of death and dying?

As a follow up to discover how training, or lack thereof, affected the phenomena of physicians/death or dying/patient interactions, and to allow participants further reflection and input, a form the following questions were utilized.

8. Would you share with me how a physician balances emotions and the responsibilities of being a doctor, particularly in regards to a dying patient or a death?

9. What are your perspectives or views on medical school end-of-life training/curriculum?

PROMPT: How did it prepare you to deal with a patient’s death?

What training did you received that helped you deal effectively and/or compassionately with patients and families? What sort of resources
for end-of-life cultural, spiritual, and psychosocial issues do you use?

What do you wish someone had done for you?

10. Reflecting back on the things we’ve talked about, is there anything you’d like to share?

Using Dolbeare and Schuman’s guidelines for qualitative research questions, these questions were submitted to an expert panel for review. The expert panel consisted of: Dr. Elaine Blinde, a qualitative interview expert, Dr. Julia Colyar, a qualitative research specialist, Dr. Sandra Bertman, an end-of-life specialty professional and academic (Appendix H).

Data Collection

Upon approval from SIUC Human Subjects Committee, data collection began in the form of in-depth interviews with physicians. Basic demographic information was obtained (Appendix N) before each interview began. The purpose of interviewing was to understand the essences, meaning, and values, the physicians’ attributed to the phenomena under study (Seidman, 1998). Interviewing does pose a problem in that the researcher is in the presence of the participant for only a brief period of time, and must draw inferences about the rest of the participant’s life based on that brief period (Maxwell, 1992). Using a strategy called member checking (described in detail under Data Analysis) was intended to reduce researcher inference misunderstandings.

Informed consent was obtained from all participants (Appendix N). Informed consent included an explanation of the handling of all interview materials, confidentiality issues and anonymity procedures for participants, and
the option to withdraw at any time. Once informed consent was obtained, all interviews were recorded by audiotape to provide an unobtrusive and accurate record of the participant’s comments (Blinde & McClund, 1997). Interviews were originally scheduled for 90 minutes, then reduced to 60 minutes. If no common themes emerged in the initial set of scheduled interviews, additional interviews would have been conducted until saturation of key themes occurred (Kvale, 1996; Seidman, 1998). During the first readings of the original 11 interviews similar information and common themes emerged. Themes appeared saturated within these interviews, so no additional interviews were arranged. Transcribed audiotapes and written notes will be destroyed after completion of research and approval of dissertation committee. As noted before, the interview was only one component of the data set. Data including researcher notes will also be destroyed.

**Data Analysis**

Because this qualitative phenomenological study was designed to collect data that described the essences, understandings, and meanings of a phenomenon, data analysis began from the moment data collection started (Moustakas, 1994). I, as researcher, immediately after an interview, added personal observations, reflections, and insights at the end of the tape recorded interview, or made handwritten notes, to insure my own phenomenological essences, understandings and meanings as interviewer were captured.

The tools of content analysis and coding, were used for analyzing this research. In content analysis, the basic task is inference. “Inferences are made
from data to certain aspects of their context and to justify these inferences in terms of the knowledge about the stable factors in the system of interest” (Krippendorff, 1980, p. 27). When analyzing phenomena, it is crucial for the content analysis to utilize all knowledge about the system of interest. The complexity of end-of-life care, death and dying, physician’s personal and professional experience, is why exploration of such a diverse number of topics related to physicians, medicine, and medical culture, was conducted for the literature review and then utilized to analyze and code the interviews.

According to Krippendorff (1990) content analysis research is data making, requires data reduction, inference, and analysis. Interviewing generates a large quantity of materials so “reducing the data must be done inductively rather than deductively” (Seidman, p. 100). According to van Manen “the insight into the essence of a phenomenon involves a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of lived experiences” (p.77). Hycner (1985) cautions that ‘analysis’ has dangerous connotations for phenomenology. “The term analysis usually means a ‘breaking into parts’ and, therefore, often means a loss of the whole phenomenon … whereas explicitation implies an investigation of the constituents of a phenomenon while keeping the context of the whole” (p. 161).

The Explicitation process involves: 1) bracketing and phenomenological reduction, 2) delineating units of meaning, 3) clustering of units of meanings to form themes, 4) summarizing each interview, validating it, where necessary
modifying it, 5) extracting general and unique themes from all the interview and making a composite summary (Hycner, 1985).

Moustakas’ (1994) steps of Phenomenological Reduction include:

1) **Bracketing**, the intentional setting aside of the researcher’s preconceived ideas, experiences and expectations, in an attempt to observe the research with clear eyes or a blank slate.

2) **Horizontalizing**, every statement initially is treated as having equal value. Later, statements irrelevant to the topic and questions as well as those that are repetitive or overlapping are deleted, leaving only the **Horizons** (the textural meanings and invariant constituents of the phenomenon).

3) **Clustering and Organizing the Horizons**, into themes and organizing the Horizons and themes into a coherent textural description of the phenomenon (p. 97).

Data analysis involves what Seidman (1998), quoting Rowan (1981), calls a dialectical process. The researcher must “make the familiar strange” (Holliday 2002, p. 13) and allow the participants, via the interview, to tell their own story. Participants share what has happened, how they understood and retold the happening, and where the researcher responds, synthesizes, interprets, and retells their story (Seideman, 1998, Holliday, 2002).

Strauss and Corbin (1998) outlined the data analysis procedures as conceptualizing, reducing data, elaborating categories, relating through prepositional statements, i.e., coding. Seidman (1998) described reading and
marking transcripts, organizing excerpts into categories, then finding connecting threads and patterns, i.e. Themes. “The process of noting what is interesting, labeling it, and placing it into appropriate files is called…'coding' data” (p. 107).

According to Strauss and Corbin (1998) “coding is the analytic processes through which data are fractured, conceptualized, and integrated to form theory” (p.3). Coding “serves to organize and assemble” (Neutens & Rubinson, 2002, p. 187) collected data. While this process sounds straightforward, virtually all phenomenological research sources cautioned the researcher about the danger of having something in mind and finding or forcing excerpts to fit the researcher's idea (Seidman, 1998, Moustakas, 1994, Creswell, 1998, van Manen, 1990).

Moustakas explained that the “Epoche (process) is a way of looking and being, an unfettered stance, to look and see, as if for the first time” (p. 85). To accomplish an unfettered stance researcher bracketing must occur. Holliday (2002) described bracketing as the researcher “setting aside one’s taken-for-granted orientation (Holsten and Gubrium 1994: 263)” (p.17). Creswell (1998) called bracketing “setting aside all prejudgments” (p.52). “It [bracketing] means …entering into the world of the unique individual who was interviewed. It means using the matrices of that person’s world-view to understand the meaning of what that person is saying, rather than what the researcher expects the person to say” (Hycner, 1985, p. 144). The researcher sets aside preconceived ideas, codes the interviews, identified themes and has them reviewed.

Interviews for this research were transcribed soon after the completion of each interview. At the time of transcription, additional interviewer observations
were transcribed. Transcriptions of interviews were sent to participants and shared with reviewers. After the participants made any corrections or comments on the transcripts, they were sent back to me. I set the data, corrected transcripts, original interview transcripts and notes aside for no less than three weeks. This period of time was selected as sufficient for me, as researcher, to be able to step away from my role as interviewer and transcriber, and begin the *Epochen* of reading the interviews as narratives.

Once interviews were identified in units of meaning (quotes) and clustered (themes), all interview materials were set aside again. After reviewed interviews returned I bracketed my own conceptualizations from my first ready, took reviewer notes, and clustered their responses with my own notes and highlighted quotes. Virtually all themes identified were similar between researcher and reviewers. A seventh theme emerged because of a slightly different focus of importance regarding time and support, as perceived by the two reviewers who were physicians. Again all materials were set aside for approximately one month to allow my thoughts to clear and prepare for a final “new” and “strangely familiar” final reading.

A phenomenological study must be verifiable, credible and trustworthy. Mason (1996) outlines four steps of analysis to insure qualitative verifiability of data. First, the researcher reads the transcript for its literal, actual dialogue, form, sequence, and substance of phenomena under study. Secondly, the transcripts are read for the literal and interpretive or reflexive reading of the phenomena. Thirdly, the researcher performs an interpretive reading, reading
what I think it means, inferring about something outside of the interview itself.

Finally, the interview is handled reflexively. I, as researcher, identify something about my role and my interface with the study (p.54). This is called a code–recode process, which assists to insure credibility (Gordon, 1992).

Trustworthiness is a term describing how qualitative research should be conducted. A trustworthy study gives the reader confidence in the findings. Four criteria are used to assess trustworthiness: credibility, dependability, transferability, and confirmability (Lincoln and Guba, 1985; Peecworks – online resource, 2006). Moustakas (1990) gave an eight step process which parallels Mason and Gordon’s processes that are all designed to make a qualitative study verifiable and credible. Creswell (1998) outlined eight procedures to insure trustworthiness and suggests that at least two are performed by a researcher:

1) Prolonged engagement and persistent observation, 2) triangulation, 3) peer review or debriefing, 4) negative case analysis, 5) clarifying researcher bias, 6) member checks, 7) rich, thick description, and 8) external audits (p. 201-203). As the researcher, I selected to use:

1) Clarifying researcher bias (done in Chapter 1 and 3, Researcher Impact and Bias),

2) Peer review - “Peer reviewers play devil’s advocate, keeping the researcher honest by asking hard questions about methods, meanings and interpretations” (Lincoln & Guba, 1987, p. 413; Creswell, 2000, p. 202). My peer reviewers came from family practitioners (not interviewed), a thanatologist, and fellow PhD students. They initially reviewed transcripts and provided notes and
themes. After my three readings were complete the identified themes were shared with reviewers for their feedback, challenges of interpretations, or clarification of themes that had been made.

3) Member checks - Participants were encouraged to read their marked transcripts to “see if what the researcher marked as being of interest and important seems that way to the participant” (Seidman, 1998, p. 100). Member checking reinforces verifiability and credibility (Krefting, 1999, Creswell, 1998).

4) A combination of triangulation and thick rich description. Triangulation uses different sources to provide corroborating evidence: interview transcript, interview notes, and field notes. Thick, rich descriptions provide enough detailed description that ‘enables the reader to transfer information to other settings and to determine whether the findings can be transferred ‘because of shared characteristics’ (Erlandson et al, 1993, p. 32; Creswell, 1998, p. 203). “It is not the [researcher’s] task to provide an index of transferability; but…to provide the data base that makes transferability judgments possible on the part of potential appliers” (Lincoln & Guba, 1985, p. 420).

When it came time to document my results all quotes were read with as much Epoche as possible. I, as researcher, tried to continue to look with “new” eyes at the materials, allowing the themes to continue to evolve. Slight modifications were made to existing themes. Content of each theme was clarified with quotes. Some quotes found different themes and an additional theme emerged. Sub-headings within each theme were identified.
When conducting a qualitative study the rigor of methodology is paramount. Trustworthiness, credibility, dependability and transferability serve as the foundations for the research process. The researcher’s perceptions are constantly being challenged, set aside, reflected upon, and added to. “The whole process of reducing toward what is texturally meaningful and essential is… dependant on competent and clear reflectiveness, on an ability to attend, recognize, and describe with clarity…Things become clearer as they are considered again and again” (Moustakas, 1994, p. 93).

**Summary**

The purpose of this study was to describe in narrative how physicians construct meaning of the phenomena of death and dying within their medical profession. A secondary purpose was to examine how physicians integrate the reality of death and dying within their professional practice. The phenomenon of death and dying was examined from the perspectives of the participants via interviews.

Chapter three described the purpose of the study, the phenomena under study, research questions, research design, researcher bias and impact. Participant selection, study participants, interviews and interview logistics, interview questions and expert panel, data collection, and data analysis are included.

Chapter four describes the demographics of participants, and findings based on interviews and field notes. Chapter five includes a summary of the study, discussion of conclusions, findings, implications, and recommendations.
CHAPTER IV

FINDINGS

Chapter four describes the purpose of the study, demographics of participants, and findings based on interviews and field notes.

Purpose of the Study

The purpose of this study was to describe how physicians construct meaning of the phenomena of death and dying within their medical profession. A secondary purpose was to examine how physicians integrate the reality of death and dying within their professional practice. The phenomenon of death and dying was examined from the perspectives of the participants via semi-structured in-depth interviews.

Participant Demographics

All participants completed a demographic information sheet after completion of the interview. There were six males, five females, nine Caucasians, one African-American and one Hispanic. Seven participants were family practitioners, one in internal medicine, one in obstetrics-gynecology, one in hematology, and one trained in pediatric/neonatal who is currently medical school faculty only. The attempt to find physicians in three distinct groups: early in practice (1-5 years), middle of career (10-20 years) and retired was partially successful. Very few retired physicians were found and even fewer women than in other groups.
Table 1 – Participants by research group

<table>
<thead>
<tr>
<th>Gender</th>
<th>Early in Practice</th>
<th>Middle of Career</th>
<th>Retired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>5 yrs &amp; 11 yrs</td>
<td>20 yrs &amp; 20 yrs</td>
<td>24 yrs</td>
</tr>
<tr>
<td>Male</td>
<td>2 yrs &amp; 5 yrs</td>
<td>26 yrs &amp; 36 yrs*</td>
<td>36 yrs &amp; 44 yrs</td>
</tr>
</tbody>
</table>

*Retired from medical practice after 25 years, currently medical school faculty.

These physicians attended medical school and residency in various places; the country of Peru, in the states of New York, Missouri, Ohio and Illinois. Two were military medical personnel before starting private practice.

Participants Biographies

For use in this research, and to maintain anonymity of participants, all participants have been given a pseudonym, along with a brief generalized profile.

Early in Practice:

Anna, female Caucasian, was a family practitioner born and raised in the Midwest. She attended medical school and is practicing in Southern Illinois.

Beth, female African American, was a family practitioner in a large metropolitan area hospital. Born, raised, and attended medical school in the Midwest, she recently returned to Southern Illinois to work in a small group practice.

Curt, male Caucasian, was a resident in the SIH group. Born and raised, in New England, he attended medical school in the east and selected a residency in Southern Illinois.
Doug, male Caucasian, was an internist at Carbondale hospital. Born, raised, and attended medical school in the Midwest, he had a teaching role in the hospital as well as his practice.

*Middle of Career:*

Ellen, female Caucasian, was a family practitioner in Southern Illinois. Born and raised in the Midwest, she attended medical school in the Midwest. She currently works on the medical school faculty, in addition to her group practice.

Fran, female Latina, was a family practitioner in Southern Illinois. Born and raised in South America, her initial medical training was in her homeland before coming to the United States. Since completing her medical school she has practiced in the Midwest.

Greg, male Caucasian, was a family practitioner in Southern Illinois. Born and raised in New England, he attended medical school in the East. He has served as a consultant to, and an attending, hospice physician.

Harry, male Caucasian, was a pediatric/neonatal specialist. Born, raised and attended medical school in the Midwest, he also was a military doctor before returning to private practice. Retired from practice, he is on the medical school faculty.

*Retired:*

Iris, female Caucasian, was a family practitioner at Southern Illinois University. Born and raised in the Midwest, she attended medical school later in
life. She taught and worked with hospice after retiring from working as a University physician.

Jack, male Caucasian, was a hematologist who evolved into an Oncologist. Born, raised, and attended medical school in the Midwest, he went into military service right out of medical school. After his term he came to Southern Illinois serving in various capacities before retiring.

Ken, male Caucasian, was a pediatric/neonatal specialist. Born, raised and attended medical school in the Midwest, he also was a military doctor before returning to private practice. Retired from practice, he is on the medical school faculty.

Participants were asked to identify what end-of-life related training they received and under which area of their training. The items listed on Table 2 were gleaned from the literature review, review of current medical school curriculum, and items identified as pivotal to end-of-life care by assorted agencies that focus on end-of-life issues. Table 2 displays the various training received or taken voluntarily on end-of-life issues.
Table 2 - End-of-life Training received by participant physicians

<table>
<thead>
<tr>
<th>End-of-Life Areas</th>
<th>Medical School Curriculum</th>
<th>Residency</th>
<th>Continuing Ed.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Directives</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication Skills</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cultural Issues</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death Pronouncements</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delivering Bad News</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grief &amp; Bereavement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospice</td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Palliative Care</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Physician/ Patient Relations</td>
<td></td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Geriatrics</td>
</tr>
</tbody>
</table>

While not all participants were originally local to the region of the study, with the exception of one, all had long standing ties to the community, either residing here over 20 years, or returning here after completing medical school and residency. This research study hoped to find diversity in participants: ethnically, culturally, spiritually and educationally. Those who were willing to participate were predominately Caucasian, Christian and trained in the Midwestern United States.

According to the AMA’s website as of June 2007, 39 licensed family medicine physicians were in the Jackson county area of Southern Illinois. Roughly 36% were female. Ethnicity, from the AMA website, was
Demographic information for Jackson County in Southern Illinois, dated 2003, showed a population that was 51% female, 81% Caucasian, and 13% African-American. This research study’s participants were fairly representative of both physicians and residents of Jackson County with 45% female, 82% Caucasian and 9% African-American.

**Emerging Themes**

In this phenomenological study, major themes found in the literature such as: communication skills, advance directives, medical culture, spirituality, end-of-life training and curriculum, medical culture’s notion of death is failure, professionalism, and physician’s personal meaning of death, were incorporated into interview questions. The goal was uncovering themes and meaning as yet unidentified in previous studies, or further validating existing themes. During the course of interviews participants demonstrated behaviors and attitudes that were found in the literature review.

In response to questions participants clearly separated and identified personal and professional behavior, and attitudes, around death and dying. All participants appeared to be candid and forthcoming. All questions were answered succinctly with minimal elaboration or description unless prompted. This style corroborated use of high communication and technical language in medical communication, versus low communication and emotive language use in end-of-life communications discussed in Chapter Two.

As interviewer, I was responsible to elicit both objective and subjective responses from participants, high and low communication, allowing space for
responses that provided both participants’ professional and personal reflections on the death and dying. Based on the responses received I think question design and interviewer skills were accomplished this goal. Some themes identified in the related literature review were clearly demonstrated during the course of each interview: 1) personality and gender differences, 2) physician preparation regarding end-of-life issues, and 3) professional versus personal demeanor and interaction.

Adhering to the principles of phenomenology I, attempted to set aside my preconceived expectations and experiences, to see and hear, the interviews with “new eyes”. Allowing participants to tell their stories and identify the themes salient to their life and experiences without researcher bias or influence. To clearly illuminate the themes, participant interview quotes have been used. Criteria for use of selected quotes were: 1) quotations were part of transcribed interview with participant, 2) quotations were representative of themes identified, and 3) quotations reflected clear and coherent thoughts of participants.

Themes

Theme One: Personality and gender differences play a role in how a physician deals with patients, the practice of medicine, and end-of-life issues

Observing the participants as they were interviewed revealed and demonstrated this theme, even if participants had not enunciated it themselves. In general female physicians were more open, personable, emotional, and
altruistic. Male physicians voiced and demonstrated detached concern, pragmatic, intellectual approaches to patients at end-of-life.

The first question to all participants was: "Why did you become a doctor?" Most participants paused and commented reflectively on the question by saying "that’s a good question". Common responses were: “Because I liked science.” “I had family members, or people I respected in the medical field”. Some participants stated more altruistic reasons: “Working with people one-on-one”, “helping others”, “helping people and making a difference”, “a good way to serve”. Others referred to economic gains. All five female participants expressed altruistic reasons for becoming physicians. Five of the six male participants stated economic or academic reasons as the primary motivation for becoming physicians, with altruistic reasons emerging over time.

Beth said: “I wanted to be a doctor in high school because there weren’t a lot of lady doctors around.” Ellen and Fran shared that life changing events led them into medicine:

“I think it started off with my mother, when I was young, my mother had cancer and I got involved in the medical system (she begins to choke up, tears coming to her eyes).” Ellen

“When I was young my brother had asthma and was very sick. I promised him I would be a doctor when I grew up…(a long pause) so I did… (pausing to reflect silently).” Fran

Participants clearly self-identified the role of personality as an important factor in medical practice. All participants noted that some physicians are more
suited to non-patient care work, even if the individuals themselves may not have identified their own strengths and weaknesses regarding physician-patient interactions. The response, or one similar about how personality plays a role in a physician’s practice, was heard from every participant.

“Some people pick fields of medicine so they don’t have to deal with it (death and dying), or at least not very often…” Ken

“We all have different personalities. Some people are prepared, just by virtue of that, which means other people aren’t. My personality is such that I am in tune with people.” Beth

“We all have a different bedside manner. I think you have to do what’s true to your own personality and your relationship with your patient.” Fran

“It’s hard, you can’t really teach it…how to read people and pick up on their personalities… It’s more of an art form… Either you have it or you don’t.” Ellen

“You wonder why some people go into medicine. Those people are just aren’t fit for direct patient care.” Jack

An unasked, but witnessed aspect of personality, or an individual characteristic, was gender. In the course of these interviews, definite gender differences occurred in the approach and discussion of end-of-life care. Female physicians offered a more emotionally open and personal interaction with their patients.
“I have a good relationship with my patients... A lot of them appreciate that I care about them (tear forming in her eye)...It can sometimes be hard, because it does feel like an extension of my family.”  Ellen

“I’m not good at hiding my emotions with my patients...I was examining a patient and when I looked up, he could see it on my face and I didn’t even realize it. He said: ‘I waited too long didn’t I?’ (she chokes up and pauses to collect herself before continuing)“  Anna

"My patients are like family, they are close to me... It's a little selfish because the family tells you: you’re so wonderful, but that is not my intention, just the end result ... (of the close relationship).”  Fran

Four of the five female participants had at least one moment, if not more, when they became choked up, or tearful when remembering, or discussing a patient who died, a difficult death, or a patient’s family situation surrounding a death.

“Some physicians feel you should be strong. I turn to the family, just like the patient does... Then I go home to my husband and cry. You grieve it, just like you grieve the loss of a friend or family member.”  Anna

“I think women physicians are more likely to (cry with a patient); even studies have shown the difference between men and women...”  Iris

Another example of how gender differences affect physician-patient dynamics was seen in what a physician does after the death of a patient. All female doctors stated that they had attended a patient’s funeral. The reasons given included; support for family, and emotional closure for themselves. Three
of the male physicians either contemplated attending a funeral or said they had attended once, but it was an exception and not their common practice.

“I’ve never attended the funeral of one of my patients…hmmm, that is something to think about.” Curt

“I often go to the funeral home. I think that it helps me (tearing up), because I get to say goodbye.” Ellen

“There was one woman who died of breast cancer who was just phenomenal. She really impressed me. I usually didn’t go to a patient’s visitation, but I went to that one. I went to see her family because she was just a marvelous person.” Jack

“I try to go to the funeral. I can’t always go, but I always try… Two patients died this weekend. I can’t go to one (funeral) but I will get to the other.” Fran

All participants acknowledged the reality of death and death in medical practice:

“Everyone dies.” Ken

“We all have to go sometime.” Jack

“If you don’t accept the fact that patients will die you need to find a different profession.” Iris

“I’ve never seen anyone stop death…pretty arrogant of a doctor to think he has power over death.” Greg

“Death is the natural outcome, the fact of life.” Fran
“There is nothing wrong with dying. It’s part of life. We’re all gonna die. We’re not going to be here forever.” Curt

“I tell the resident, this is the first of many that will occur. You have to decide how you will deal with this personally. It’s okay to be sad; it’s a natural emotion when somebody dies…” Doug

“People die every day. You have to accept it.” Harry

“I knew if you take care of older people they’re gonna die.” Anna

How this acknowledgement of death translated to medical practice was another issue, stated very elegantly by one of the retired physicians:

“There is a difference between knowing it intellectually and knowing it emotionally.” Jack

Those interviewed appeared to be very cognizant of other physicians’ personalities, how individual personality affects physician-patient relations, and chosen fields of medicine. During the interview, the female physicians all became choked up, or even shed a tear when sharing stories about dying patients. The male physicians intellectually discussed the emotional aspect of dying, acknowledging their conscious choice to work with patients who are dying had an emotional aspect.

**Theme Two: The role of death in medical practice has mixed or conflicting function and importance**

As discussed in the literature review, death in medicine can be marginalized. A common practice is for death pronouncements to be passed from Senior Residents to new residents with little training. The reality is that a
death pronouncement is a legal task doctors have to accomplish, separated from their medical tasks. The hidden curriculum holds death as failure. There is little training or experience with end-of-life in medical school, and new physicians are either fortunate to have attendings who are good mentors who model how to deal with death and dying, or are further reinforced to avoid death by poor mentors you do so themselves.

All participants were asked to share the first death they remembered. For seven participants, it was a grandparent when they were young, under the age of 12. Some remember going to funerals, some of the rituals, but not really understanding about death, or what it meant that a person was dead. Four participants’ first death experience was an animal, beloved pet, or farm animal. These four also shared another first death of either a grandparent or patient. Four participants’ first death experience was a patient. In general, descriptions of these first death experiences were brief. To get a richer, thicker description of participants’ experiences with death as physicians, they also were asked to relate a memorable patient’s death experiences specifically, or to expand on the information given.

“There was this really pleasant, spry 85 year old woman, who was doing really well but with many chronic problems, we were managing… There was an ongoing relationship because she was in more and more, and then she wasn’t there anymore…It wasn’t something I went home and cried about. It was just one of those acknowledgments about the mortal coil.”

Curt
“I remember my first patient death clearly. I had been here but a couple of days. I took a history from a man. I turned around and was writing at my desk and he hit the floor. I called for help and we worked on him for a while but we couldn’t bring him back…He had a bad heart. The family wasn’t surprised, upset of course…” Jack

“As a third year medical student, I kept going in day after day; to this woman who was almost comatose, she never said a word… I was just keeping numbers on her. We didn’t have any interaction… It was my routine, and one day she wasn’t there…(she stops, a far away look on her face, after a few moments shakes her head and looks at interviewer waiting for the next question).” Beth

“In the first month of my residency seven patients died. The first was a psychiatric patient who was emotionally traumatic just to interact with, I medicated him and about an hour later the nurse came and said he was dead, and he was (stated emphatically)! He was blue and cold, and there was nothing I could do. The next death was a man with lung cancer who I worked on and stayed with for 14 hours. I did everything I knew how to do, called in specialists, never left his side…. And he died...(a heavy sigh, eyes averted for a moment) those are the ones that stay with you.” Doug

Participants differentiated between one’s own patient, someone else’s patient, and the interpersonal relationship between physician and patient.

“It’s always harder when it’s your own patient…” Ellen

“Until it’s your patient it isn’t real, you know what I mean?” Curt
“Even though, it wasn’t my patient, we had a relationship and it was a loss.” Beth

Participants were asked questions about what they had been taught about death and dying, and the medical culture’s view of death. Specifically had they been taught: “death was failure” in medical school or their residency? Half of participants said yes immediately to the question. Half said no, or I don’t believe that personally, but eventually admitted that this message did exist in medical culture. Only one physician denied being told, taught, or witnessing that death was failure in medical culture.

“There was a lot of that (death is failure) when I was in medical school and residency. But it became fairly obvious to me fairly soon that it wasn’t true.” Ken

(Responding to the question before it was even finished) “Yes, yes I do, that’s what I got in medical school. We’re trying to teach differently now…The old guard, my teachers are moving on, the philosophy of: Do everything is …dying.” Greg

“ABSOLUTELY, I completely agree with that…Definitely the medical community has the attitude of life at all costs. Patients and doctors struggle with that because of their fear of the unknown.” Ellen

“Hmm, I think that, (death is failure) isn’t true for me and how I operate, but yes, I do think that was a message that was given to us. I do know that some of my classmates and physicians I work with definitely see death as failure.” Curt
“Yup, yes… when I was in school everything was: keep the patient alive, keep the patient alive as long as you can, as long as you can.” Jack

“When I was in school the emphasis was on keeping people alive. So you order more tests, keep doing what you’re doing, keep the patient alive.” Beth

“ Aside from whether the patient really had any quality of life or should have lived or anything else, our goal initially is to keep people alive.” Harry

“I think so. It kinda of irritates me. From my perspective it’s more in particular specialties than others. Those in family practice are probably a little bit better about that, realizing that (death is part of life).” Ken

“It probably is, …you have done everything possible, but there is no more… I don’t know… I don’t find it (death) to be failure. Death is part of life. I used to be afraid of dying myself. In truth I still am.” Anna

“Yes, and that was definitely true with the situation with my father… They were working their buns off trying to keep my dad alive regardless of what anybody (patient or family) wanted. To allow him to die was failure.” Iris

“I don’t think so… there are deaths we accept, especially in the elderly, or cancers that have spread. We accept those…its acute events where you are trying to reverse a trauma, or something like that, … there is a sense of failure.” Doug

Physicians’ first personal confrontation with death in their medical practice often comes when they have to do a death pronouncement.
pronouncements were mentioned by all participants regardless of age, or years in practice, as a task often given to the newest resident or intern. All had similar unpleasant experiences that had left a lasting impression and enduring phenomenological experiences surrounding death.

Training and mentoring, or lack thereof, greatly influenced the impact and self-perceived emotional preparedness and skill for performing death pronouncements. The activity of performing a death pronouncement is basic: Check pulse, respiration, heart, pupil, and response to stimuli.

“Actually we were given a checklist of what we needed to do and had to check before we could pronounce. I can rattle off the paragraph I memorized to do this, but no, no real training.” Curt

“Your resident says on the first day. ‘Write these five things down and that’s it. That’s you being taught it (how to do a death pronouncement).’” Doug

The dis-ease with doing death pronouncements was evident in all participants by their tone of voice or body posture; such as a negative shaking of the head while relating the incident, or leaning away from the interviewer. Most participants said their first pronouncement was done without assistance or guidance. Also, the death pronouncement was done cold, meaning they did not know the family or patient prior to having to do the death pronouncement. It was the exception to witness a pronouncement by a more experienced doctor prior to having to do their first, or to have any support or discussion after the event.

“The first time you have to do it (pronounce), it’s real tough. Hopefully someone else is there with them to give them support.” Greg
“What was expected was your senior resident would walk you through the first one. That see one, do one, teach one philosophy…but that didn’t happen.” Harry

“A lot of times we would pronounce a person dead… You really don’t know the patient… so it is kinda an awkward feeling.” Beth

“Pronouncing can be really different if the family is present or not. If not you go in, do the things you have to do, then fill out the chart, and you’re done in maybe 2-3 minutes.” Anna

“Residents on call get the call, ‘Doctor So and So, you need to come and pronounce this patient.’ They don’t know this person and the family is walking in and the resident is thinking: ‘I’m gonna get out of here before they start asking me questions, because I don’t know anything!’” Iris

The last quote is an example of the hidden curriculum, where the interviewees where being taught the medical culture’s attitude toward death by other physicians indirectly. The avoidance demonstrated during death pronouncements by senior residents or their compassionate handling of patient and family speaks volumes to younger physicians.

“On my neurology elective I was following the doctor… He walks in the room and probably ten words came out of his mouth. He turned around and just walked out. As he got to the door … he looked at me and said: ‘Well come on!’ So I did my student thing and followed him out. We got to the bottom of the stairs and he said: "When you tell people things like that, never hang around.” Beth
“A code was called, and here is this 2nd year medical student who’s never seen a code run before, just trying to keep out of the way…the patient died…I was fortunate enough to be following the doctor. I saw this very compassionate doctor while he talked to the family. Well I just started bawling, crying and later apologized to him… he said to me “I would be concerned if you weren’t emotional.” Iris

“XX was faculty when I went through medical school. I was actually with her when this gentleman went into the hospital… I remember her being there and comforting the family, but also that it bothered her. … That was something I really remembered, how much it really touched her.” Anna

The medical culture’s hidden curriculum surrounding death and dying, as discussed in the literature review, and related by participants above, could be categorized in three different ways.

1) Unimportance of death: the lack of training and attention to how to do end-of-life events well, minimizes its importance. A death pronouncement is another duty as assigned, something to get done and move on.

2) Avoidance of death: Don’t spend a lot of time on it. Physicians have more important things to do. Once a patient is dead our job was over, so don’t waste your time with the dead or family.

“When you are on-call at night you cover 60, 100 patients. You don’t know the patients…pronouncing was just one of the jobs you had.” Doug
"You didn’t take time… generally they had a primary care physician who was taking care of them, but they (primary care physician) didn’t get the call at 2 am…” Greg

3) Discomfort of senior physicians with death, is passed on.

“My first day a patient died, the attending looked at me and asked if I knew how to pronounce. I nodded. He said go do it and walked away.” Curt

“I was (a resident) on call and a man asked me to look at his wife. She was dead…He looked at me and said: ‘How am I going to tell my kids?’ I can see that man like he’s sitting right there. (pointing to an empty chair) I remember thinking: ‘You don’t understand. I’m only 23 years old…You’re asking me that?’ I asked him if he’d like to talk to someone else (the attending, the primary care physician), but I knew they weren’t around and I was it.” Beth

This confused status of death and end-of-life issues within the medical profession can be seen reflected in training received, or lack thereof. As indicated in Chapter Two, in the last 5 to 10 years, changes in medical curriculum to include end-of-life training have occurred. Millions of research dollars and specifically designed end-of-life programs have been created. The pervasive attitude of participants was that there was still a lack of adequate end-of-life training in medical school. None stated that they felt adequately prepared or trained to deal with death and dying in their medical practice. Those teaching said that curriculum and training for end-of-life care is improving. Overall, the
predominate attitude of participants was that you can’t really educate about handling end-of-life. Death can only be truly be learned by experience.

**Theme Three: Physicians believe experience is the best teacher in dealing with death**

Despite millions of dollars in research on how to prepare physicians for end-of-life care, additional courses for end-of-life care added to undergraduate medical school curriculum, participants felt a class couldn’t prepare you for the reality of death and dying in their own practice. Most acknowledged some end-of-life didactic training, but placed a higher value on experiences in residency and graduate medical training, or modeling they witnessed by senior physicians.

“We had classes in it (end-of-life issues)...but you’re never prepared until you get out there and do it. You have to learn by doing. Although their (medical school) intentions were good, I don’t feel I was adequately prepared.” Curt

“We had it pounded into us in some sort of didactic fashion (in medical school)...but it’s how you treat patients on a day to day basis, not how you deal with death and loss.” Ken

“Unfortunately I do not think you can teach doctors about death, they have to experience it. I hope I have gotten better at handling my dying patients as I have gotten more experience.” Doug

“I think XXX does a very good job in their behavioral science sections and even more so now,… But there is nothing that can substitute for having to deal with it personally.” Anna
“As far as how to deal with it (death), it’s a life experience. You can read about it in books, someone can tell you and talk about it, … I think until you’ve experienced it, been there in the last moments, it’s a frightening thing.” Beth

“Oh absolutely! (Medical school should) at least prepare people to deal with it (death)...I just think the way people deal with patient’s dying varies widely based on the individual and their experiences.” Ellen

“Today medical schools has it (death and dying) as part of the curriculum. You have a choice, they will teach you about death and dying, wherever you go, it’s a course, …But did we get anything (1974-78) – NO,…what I learned was through experience.” Greg

“In medical school we had a behavioral science class that went through your standard stages of grief and whatever…Our residency program was lead by people who were very progressive and forward thinking. You did home health and hospice, it was a requirement. You had to do it whether you wanted to or not. So we all got exposure there… It was a little bit much for me too, but you needed to see that… So that was interesting and I remember thinking; ‘I can see a little bit of this, but I DON’T want to do this all the time, it’s too much!’.” Iris

“We had 2 ½ days of hospice experience…You know it’s all about evidence-based practice and the volume of quantifiable research on this or that, but in truth a lot of what we learn is modeled for us by physicians around us.” Beth
When asked, ‘You seem very comfortable with end-of life issues’:

“I feel like I’ve had a lot of experiences, in a lot of different settings. In residency from hospice to hospital patients, to pronouncing patients you’ve never seen, experiencing caring for a patient and accepting that (death) was going to happen.” Fran

“We had some excellent talks about death and dying through my medical school and residency experience. But there is nothing that can substitute for having to deal with it personally.” Anna

“As a doctor you should learn, before you have to experience. But I don’t know if you could have a course that teaches how to deal with death…” Jack

Medical education is highly didactic. Participants felt death was a phenomena that one can only master through personal experience. Interviewees had highly emotive responses to patient deaths, and having to do death pronouncements with minimal training or experience, but still stated that end-of-life activities could only be learned from experience.

**Theme Four: Physicians believe communication skills are more important than end-of-life skills**

These participants stated that end-of-life training was needed, but in lieu of end-of-life curriculum, experience was a greater teacher. Participants felt that communication skills filled the end-of-life skill set and training needed, and were the more important skills. As the literature review showed, just because you get a medical degree it doesn’t mean you know how to talk to people. The
importance of good communications skills are reiterated again and again by end-of-life agencies and noted in the literature review. More recently medical school curriculums have moved to problem-based learning with communication between physician and patient a priority. End-of-life communication skills are different than general communications skills. Physicians need to be able to discuss advance directives, and assist patients with personal end-of-life choices.

Topics participants included in communication skills were learning compassion and empathy, being able to discuss advance directive and hospice care. As noted before, while identifying the importance of being taught communications skills, they felt that communication skills were also learned by experience.

“Physicians need to learn how to communicate. I can’t stress how important that is for all areas, not just death.” Harry

“I don’t know if you could have a course on how to deal with death. You can teach them how to understand where the patient is coming from, or what they believe, or how they want to end their life.” Jack

“I don’t think you can teach pity, empathy, appropriateness, …I think all this needs to be taught. You need to be able to communicate (with patient and family)... just do it as humanely and compassionately as you are able.” Ellen

“We need to teach ways to approach the patient and family... How to talk about when enough is enough... Teach them how to talk to people about
issues of grief and our emotions, (teach students) that you are dealing with other human beings.” Harry

“We had classes in it, we saw videos about how to talk to patients, we were taught how to take histories and talk to patients, and give bad news…. But you’re never prepared until you get out there and do it.” Curt

“You have to put yourself in their shoes, imagine you’re talking to one of your own family members… You have to know who you’re talking to or have a sense of who you are talking to and talk to them that way. That’s what I try to teach my students. It’s hard, you can’t really teach it, you just have to learn it as you do it.” Greg

“I think it is more important to teach a doctor how to talk to family and to get them together. Communication skills….Teach doctors to understand that people will scream at them sometimes, not because of anything they have done but because they are scared, suffering, frustrated, grieving…” Fran

“I think the biggest thing they (doctors) can to is to be a good communicator…Get that communication education….I remember that we were working on communication skills from day one.” Anna

“What doctors have to learn in end-of-life scenarios is to LISTEN!...If you can teach doctors that and teach them to say okay, instead of oh no you’ve got to do this, then I think you’ve really accomplished something.” Iris
Participants continually repeated the importance of experience in learning both for end-of-life issues and communication skills. Mentoring and modeling by senior physicians is another part of the hidden curriculum and medical culture that is experiential. Most participants mentioned mentoring experiences.

“…but in truth a lot of what we learn is modeled for us by physicians around us…” Doug

“I wish I had the opportunity to see how to deal with dying, and terminally ill patients by an experienced physician who do it well.” Jack

“I remember her (another physician) being there and comforting the family, that made such an impression on me.” Anna

“The only way to do it is by showing them (students/residents) how to do it, one on one, relating to patients on a personal basis.” Ellen

“You learn to communicate…by following examples. I had superb mentors.” Beth

“You know every once in a while I work with a physician who’s really good at end-of-life stuff. Then I found out they are a hospice director also. I’d say about 1/3 of physicians do it (end-of-life stuff) well but 2/3 don’t…” Greg

“Every new doctor should have the opportunity to see how to deal with dying, terminally ill patients, by experienced physicians who do it well.” (After a death the interviewee comments on the attending physician), “I learned a lot about compassion. I learned a lot about how to talk to a family, about a very unexpected death.” Iris
“While we don’t deal a lot with death in teaching first year medical students, we are teaching how to interview patients and how to do physical exams. I HOPE, I’m giving them some insight into compassion… (Received teaching evaluations) ‘Dr. X is compassionate. Dr. X shares with us her professional experiences which are all very helpful’ … I want to show them the human side (of medicine).” Harry

Another application of communication skills in end-of-life issues, is the ability to have discussions with family and patients about advance directives, treatment options, and hospice. The Karen Ann Quinlan (1976), Nancy Cruzan (1990) and more recently Terry Schiavo (2005) cases have forced medical institutions to clearly define who can make life and death decisions for patients. These legal requirements have created an environment where many hospitals require advance directives for all admitted patients, regardless of their condition.

“In my hospital … if you didn’t have your advance directives a social worker was sent in to talk to you about them. That paperwork was on the chart.” Beth

Most participants were in private practice outside an institution. The need to know the patient’s wishes meant the conversation must be initiated by the physician. When asked if they discussed advanced directives with their patients, the most common response was: “Not as often as I should”.

“It’s hard because you want to follow what’s legally correct, but you also want to try and make sure when talking with the family that we know what the person’s wishes were…” Fran
Good health care directives are common from physicians: get enough sleep, eat right, take your medications, contact us immediately if there was a change in your condition. These guidelines are heard every day. Good death care directives often are avoided until absolutely necessary. Having discussions about what you want to happen medically if a traumatic event occurs, or in the case of a terminal illness, or at the end-of-life, is not an easy conversation for physician or patient. Usually participants did not discuss advance directives unless a terminal prognosis has been given, or someone was elderly.

“I try to have that conversation with every older patient… (thoughtful pause) I probably should have that conversation with everyone… I make a judgment call… Perhaps I should (have the conversation with everyone).” Fran

“Sometimes with the elderly we’ll talk about general stuff about advance directives, but mostly it comes up when a diagnosis has been made… You try to talk about it before things get too far advanced. We don’t want to wait until you’re at death’s door…” Anna

“I probably don’t do that as well as I should with new patients and healthy patients, which is a good time to do it, before you are facing a crisis…” Curt

“When the time is right, but that is difficult to say. We discuss advance directives all the time on a regular basis… People need a Power of Attorney in Illinois; a living will is meaningless…” Greg
“Most people don’t realize the heavy burden it is to be the Power of Attorney and make decisions for a loved one. The doctor has to be the support for them.” Harry

“I get advance directives ahead of time. Most of my patients are long term… I usually know my patients, but I feel very sad if I have to make decisions for a stranger and don’t know what they want.” Ellen

“I actively discuss what a patient wants, especially the elderly, with a certain disease, before anything happens so that I know what the patient wants. I try to do it with a family member present so they know and we can make decisions together. Fran

When asked if participants themselves had advance directives, 80% said yes. They were also emphatic that they did not want extraordinary means used to extend their life. Participants also had concerns about placing the burden of those decisions on someone else.

“I have a living will and a durable power of attorney already assigned. I don’t want any heroic measures.” Jack

“My wife is my POA. She knows if I get into a scenario that I am barely alive, she is supposed to sign those papers that say LEAVE HIM ALONE!” Ken

“Now that I’m retired, I finally got my own, I’m embarrassed to say. I had a living will but that was before the whole laws about advance directives. I figured if I was going to talk about them I should have them in order myself.” Iris
The dying process affects physician and patient emotionally, but it is the physician who needs the communication skills to open the conversation, communicate the medical information, help facilitate discussion, and guide decisions. Death is not a single event, but involves many components that need to be discussed and addressed. Physicians are usually the ones to initiate these conversations and also must being able to step aside so that the patient and family make their own decisions.

**Theme Five: Physicians’ moving from cure to care, focusing on quality of life instead of continuation of life, and trusting patients to make decisions about end-of-life care**

At end-of-life medical care takes on a different focus. Physicians have to learn and accept that their role may change from curing to caring. Referral to hospice care, use of palliative care, discussing quality of life, and allowing patients to at least share control of their treatment options is not the normal practice for physicians. Physicians are also faced with the mortality of those they care for and how the age and illness of a patient may impact them personally.

Hospice is another component in end-of-life care. Despite physicians having minimal training in hospice or palliative care, a hospice referral must be made by a physician. Patients can’t have access to hospice care without a physician’s referral. Several factors may complicate the referral process: type of terminal diagnosis, length of life expectancy, place for hospice care, availability of hospice care, and so on. Two major issues for these physicians were their communication skills and personal death issues.
The concept of palliative care is not familiar to most physicians. Curt said, “I’ve always associated palliative care with hospice.” As discussed in Chapter Two, palliative care principles can be applied to any chronic, long-term illness. As defined by AAHPM website: “The goal of palliative care was to prevent and relieve suffering and to support the best possible quality of life for patients and their families, *regardless of the stage of the disease or the need for other therapies* (italics added).” It is a shift in thinking from trying to cure something to providing comfort through the course of an illness.

“Those in family practice are probably a little bit better about that, realizing we are not God. We’re not going to save people. We are helping people through their life and death.” Greg

“I tried to get rid of my ego that I might have in some areas because it gets in the way of taking care of people and people being kept comfortable. I couldn’t see any point in it.” Ellen

“You have to learn yourself what you think is reasonable. You’ve got to be talking with the family and telling them what can and can’t be done. They’ve got to know what can be done. Basically, they’ve got to make the decision and live with their decision…” Fran

“Once you’ve told the patient and family what can be done, and what the options are, then you have to kick it back to the patients and say: Hey, what do you want to do? Doctor’s don’t do that very often. Doctors feel like we are the ones who say – you do this, you do that, because I know better than you.” Beth
“It is important that patients have some control in their own care…” Jack

Participants shared that physicians need to have both the belief in the patient’s ability to make reasonable decisions about the course of treatment at end-of-life, and also have the willingness to transition from a cure model to a care model.

“It’s very common to go in with a game plan and you think everyone’s on board and we all know what we are going to do... and they have that ‘what if’, and ‘how about one more day’. We try and work with them and talk to them about what is reasonable... and usually the family comes around. If you give them time to come to terms with it. It may not be that day or in a time you think, but they come back and say...I think we’re all okay with it now.” Greg

“First and foremost you’ve got to get to know the patient. You’ve got to try and be as honest as you can and give them options. Even if it’s completely against what you believe. You have to respect that.” Ellen

Even for those comfortable with end-of-life medicine, conflict begins when the questions becomes quality of life rather than quantity of life.

“I think a lot of what we do medically is just to help people with fear and keeping them alive as long as possible even if their quality of life isn’t very good, because they’re afraid. But I’m not going to force that belief on other person. If people are afraid and want to live, my Hippocratic Oath says keep people alive, so I do that. That’s about it, I’ll do that, ethically it’s not a problem to keep people alive for longer than I may think is
necessary, if that's what they want, for their benefit, I'll help them do it.”

Curt

“You do what you can do for people. Cure ‘em if you can. Keep ‘em comfortable if you can. You can always do something to keep them more comfortable. When the inevitable happens, it happens. Help the family deal with it the best you can within whatever limits you have.” Ken

“You don’t become a doctor to save people. You become a doctor because you want to help people….but I can't make the decisions for you.” Doug

“Quality of life is a tough one. Either you know your patient well enough, or the family does, and is able to say enough. A lot of family members are not ready to let go. You do your best to guide the family to do what they think the patient wants. Anna

“Sometimes I think we can just prolong the torture of the body, but that’s not my decision… I don’t know their minds. I have to go with their decisions.” Ken

“There is always something you can do. You tell them what you can do and the consequences of doing that and let them decide.” Jack

“I definitely believe in the quality of life and that there is a point where all the technology should stop… we should be teaching them (medical students) that death is not a failure in medicine. We’re not here to cure everybody. We’re here to care for them.” Harry
Once the conversation has occurred, the actual referral to hospice is another matter all together.

“I’m very frustrated by how people in this country don’t utilize hospice.”

Greg

“I’m cheating because I am a hospice fan. In the old days it was all about keeping people alive, now it’s about how to extend the quality of life and making their life something to their liking.” Ellen

“I agree with hospice philosophy and the importance of quality of life. But many doctors don’t, and that’s fine. Many families don’t but I try to help them make the right decision for the patient.” Beth

“I believe hospice is viewed by different people in many different ways. Some people think – oh we’re sending you hospice because we’ve given up on you. Others view it as a wonderful resource to help to extend the care I give as a physician, in a greater way than I can. I’m hoping that more us will feel that way.” Fran

“It’s never done early enough. We never get them (Hospice) involved soon enough. There are always a lot of things that can be done while people are still around, but we wait to call hospice, and three days later they are dead… We doctor’s don’t think about hospice because, by golly, we think we can get them healthy again.” Harry

“There is a process… it takes time to accept that it’s terminal and I’m not going to find anything to make it better… Usually the family says enough of being poked and prodded and asks to take them home.” Greg
“I know this family that had finally come to terms with their mother’s death. They took her home and got hospice. We all thought she was going to die in a couple days. She lived another three weeks. It was really tough on the family because they had accepted her death and she was still alive. But they had the hospice support and got through it.” Anna

(Discussing a late hospice referral) “You shouldn’t be spending your last few days in a tizzy. It’s supposed to be spent doing what you need to do with your family, or saying the things that need to be said, or lying next to them. (Softly and compassionately) Those precious moments are wasted…I think it’s because people refuse to acknowledge that death is inevitable.” Ellen

“I don’t know how often we cure anything. Care is what we provide to anyone with a medical problem… My goal is to control that disease to the best of my abilities. Slow the progression as best I can, so that person has a good quality of life. But curing it, that’s not something I have the ability to do.” Beth

Even when the conversation had happened, all the pieces were in place, the transition to hospice is not definite.

“I had discharged this man to hospice and his wife took him home. She was the Durable Power of Medical Care, he had a DNR (do not resuscitate order) and had taken her husband home with hospice. That night they showed up at the ER. He died in the ambulance but she demanded everything be done. I reminded her that he had a DNR. She
was emphatic. We did compressions for several minutes and she eventually relented.” Doug

Virtually every participant acknowledged that there was at least one patient who died for whom he or she asked the question: “Could I have done something more?” Most often that question was asked in relation to a sudden or traumatic death, not a long term illness, or patient who had received a terminal prognosis and subsequent treatment.

Medical school teaches physicians to assess, diagnosis, and treat. While end-of-life issues are only minimally addressed medically in school, the personal dynamic of a death on a physician does not appear to be taught or addressed in any area of teaching. The type of death, the age of the patient, the physician-patient relationship, all are factors on the phenomena death may affect a physician personally.

“Some people you’ve just met and they die; you don’t feel the same as someone you’ve known or taken care of for 20 years. You don’t feel the same way about an adult and a child.” Fran

“Anybody you’ve had any relationship with that you lose, I think you lose a little bit of something (yourself). That’s not the reason I retired, but I’m sure it was part of it.” Jack

“If it’s been someone who’s been sick a long time, like an Alzheimer’s patient, somehow it’s easier to handle that a cancer patient. Cancer is always hard because of my family history, or a younger person, or an unexpected death.” Ellen
“The death that affected me most was the death of my first grandchild… She was induced of a stillborn... She and my son-in-law got off the plane. They were preceded off the plane by a new mother with her newborn, taking her to see her grandparents. I thought, ‘Gee I wish I was them,’ instead of meeting my weeping daughter and her husband.” Ken

“The biggest problem was in the emergency room. People would be brought in who were badly hurt and weren’t going to make it. It was sudden… and it was difficult for both family and physician.” Beth

(Difficult deaths) “…there are acute events where you are trying to reverse a trauma, or something like that… On the other hand there are deaths we accept, especially in the elderly, or cancers that have spread.” Doug

“When you’re talking about end-of-life and terminal illness, its (death) is not a failure, but with babies it is…” Ken

“It was the exact opposite of the other person I evaluated, put on medication and left. I never saw him again until after he died. But this guy I was at his bedside. Fourteen - 15 hours straight I was doing everything I could, getting all the best specialists in to help. I worked on him as hard as I could, and he didn’t make it (pausing)... It was humbling to realize that despite the best care you know how to give, people still die.” Doug

(After experiencing a family death) “I wished I had some idea of what it would be like, have an idea of how unsettling it can be (death). …Because of my own experience, I try to explain as much about the process (to patient and family).” Anna
“An infant came into the ER and ended up dying. The attending could see I was upset, so he drew me aside and said: ‘People die, sometimes those people are children. And it’s the worst thing to have to watch.’. It took just a few moments of his time, but it showed his caring…I don't have so much trouble with infants now, but kids, kids my kid’s age…(she shutters)... I’ll never forget her (the child who died) or him (the doctor). Doctors like that shape you.” Beth

Theme Six: There is little time for death in medical practice professionally or personally

In Chapter Two the perception of time was briefly discussed. The reality in the medical profession is that there is rarely enough time to get everything done medically and spend time with patients. Again, good modeling and mentoring is key, early and appropriate hospice referrals important and being able to make wise decisions about where to invest emotional energy: walking that fine line between professional energy and personal time. Here is what participants said about the lack of physical time:

“If you’re on-call you’ve got 60 people who depend on you. You can’t spend two hours with a dying patient or family member.” Beth

“…there is a lot of conflicting responsibilities. I've got to be here, I've got to be there, I don't have time for this (death)... Perhaps it is an attempt to protect ourselves from an emotional experience.” Greg

“It gets really tough when I have to make the decision to spend time with a patient and miss my son’s baseball game…” Fran
“I’ve taken a cut in pay and prestige in this job, but I made the conscious decision that I wanted to be home with my family at night.” Doug

“Even when I get home there is no time for me to decompress. My family wants me to do this or that, they’re just not enough time in the day, something has to be sacrificed and it’s usually me…” Ellen

“During my residency a nurse was telling me Dr. X had sat down and cried because she was so exhausted. She was just having a bad day, normally that didn’t happen. But it shows that doctors are people too. What we do takes a lot of our time and mental energy. You go through periods where you just can’t give anymore today…but tomorrow I can.” Iris

In addition to the reality of practicing medicine, most physicians either belong to a larger group, or practice in an institution, such as a hospital or clinic, which has its own requirements and demands on the physicians time. It could be said that lack of time has been institutionalized.

“It’s all about the numbers. Until the institution makes space for the dying, doctors don’t have time for them.” Doug

Mentoring can have a profound effect on physicians who are learning how to manage their time. Realizing, that it actually takes just a little time to make a profound effect, was a lesson well learned by several participants.

“I was really upset by that death. My attending took maybe five minutes to talk to me. Let me get composed. He said people die; you have to deal to deal with it and keep going. It wasn’t profound, … it was, he just took time for me.” Beth
“After a pronouncement the resident asked if he could do anything. The wife asked for a drink of water. He poured it for her, waited. After a few minutes, he said ‘I’ll get the nurse’. She looked up and was truly grateful when she said: Thank you doctor. It took all of five minutes…” Anna

In addition to the physical time required for medical care and institutional requirements, the emotional component of medicine consumes a physician, both at work and off the job. Participants identified it as lack of emotional time and energy.

“My mom died in the middle of the afternoon. I had three patients waiting. I went out and told them I was leaving and would reschedule people. One person was very put off that I was going to leave and not see him and he demanded to be seen. So I did and then I left and attended to my mother’s death.” Greg

“Especially if the patient has become family it’s a loss and you grieve it.” Fran

“You lose a little bit of yourself with every patient that dies.” Jack

“You try to compartmentalize your life so things don’t spill over. But it’s difficult and sometimes you lose sleep at night.” Doug

“It’s difficult after you have immersed yourself in a family, not letting it emotionally affect you for too long after.” Ellen

“If you do spend time with patients, what about your life? You can only have so much emotional investment in each patient. Some can invest more because that’s their makeup.” Beth
“It doesn’t stop. Just because a patient died, your 15 patients waiting
don’t go away. The way you cope is to re-engage with the next patient. It
can be good and bad. You keep moving forward. Hopefully you have a
moment to cry, or be sad, but your job never stops, so neither can you.”

Greg

An extender of time, and under used or unavailable resource in end-of life
care, is utilizing a team, such as found in hospice. An end-of-life team may be
comprised of; psycho-social providers such as social workers, psychologist or
counselors; spiritual providers such as clergy and spiritual care laypeople;
specialists in end-of-life care such as a palliative care specialist, a hospice
doctor, nurse, or agency; legal support and personal management supplied by
the hospital staff or a case manager. Participants did utilize and refer some of
the components of end-of-life teams.

“No, no team. I do refer to hospice.” Doug

“I may be too quick to refer to hospice, but I know they provide such good
support.” Ellen

“I offer ministers, counselors, or the hospital social worker.” Jack

“I made use of counselors all the time and hospice, hospital social
workers, clergy, whatever seemed most appropriate for that family. I was
perfectly willing to get all the help I could get.” Curt

“I made a lot of referrals to ILAC: I Lost a Child…” Ken

Having identified that death personally affected participants and that there
was a severe lack of time, in all aspects, to adequately deal with deaths,
participants were asked how they cope, what skills had they developed to deal with these issues. Spirituality was sited as the most useful resource for dealing with death and dying.

**Theme Seven:** Coping mechanism for physicians dealing with end-of-life issues include spirituality, turning inward and family support

Coping mechanism, common discussion in psychological circles seem to be a rarity in medical practice. Spirituality was often expressed as a personal choice and coping tool. Mostly a pragmatic stance was adopted: people die, you have more patients, occasionally family provided support, but rarely other physicians. A physician’s personal grief found small purchase.

“I was a lot more comfortable than my classmates… I think this comes from my very strong Christian background, personally. My parents talked about things, we dealt with them directly, and of course the farm… A lot of my classmates seemed to have issues with death who didn’t have the spiritual base to refer or rely on like I did…” Curt

“You see I’m a Christian. I know where I’m going. I know it’s important…It helped me get through the challenging times, when shifts were too long, or I just needed a lift. It was what I could fall back on.” Beth

“It does come up, but I am cautious because I don’t want to offend anyone with different beliefs than mine. As a Christian I will share my beliefs but don’t want to push it on them. It’s what guides me.” Doug
“Spirituality – yes, it enters into that. (coping)… I did relate it (a very difficult death/suicide) to some spiritual mentors of mine… and they showed me compassion, but a lot was within myself.” Iris

“I think there are certain patients, that are just a lot harder than others … it’s very emotionally draining. I think for me, having my own faith, turning to God (crying) helps get me through.” Ellen

“Personally, I think a lot of what we do medically, is unhelpful. A lot of what we do to extend life is based on fear of the unknown. I’m comfortable that when I leave here I am going to a better place.” Jack

When asked if they ask patients about spirituality, especially in end-of-life situations, participants replied:

“No, not as often as I would like and think I should. We do the intake and it’s one of the questions, but I don’t usually bring it up.” Doug

“I probably should ask everybody about their spiritual beliefs but I don’t. If I know them and know their faith is important I will talk about it.” Beth

“That’s a difficult one. I don’t bring it up. I wait for pastoral care.” Jack

“Not as much as there could be…, I’d be too embarrassed. It’s not part of my personality.” Fran

“I wish it played more of a role.” Anna

“A patient once asked me for a Bible. I had the Daily Word in my pocket. I pulled it out and asked: Will this do? He smiled and thanked me. We didn’t get a chance to talk again, but I knew he appreciated it, and it was important to him, and me.” Beth
Spirituality is considered a highly personal matter within many circles, not just medical culture. Participants appeared to hold the view that death and their emotional reactions also were personal, and not to be shared with other physicians. This perspective limits their support circle to family, spiritual guides or themselves for dealing with end-of-life issues.

“All my colleagues I talked to about a situation have been somewhat dismissive and didn’t elaborate their own stories. They knew it was difficult but didn’t necessarily care because it didn’t affect them.” Doug

“Resident’s don’t know how to give support.” Curt

“I don’t know any organization that deals with physicians who need a boost against the common enemy. I don’t know what it would be … death is bad, life is good – I think we knew that… (laughter)” Ken

“You have to be a little detached or you won’t be able to practice correct medicine.” Harry

“It’s important to remember who you are. You are there to care for the patient and guide them to make good decisions but it’s not about you.” Beth

“I remember when one doctor, who founded the clinic, died. He was a patient of another doctor and asked me to consult. I think it was because I was new and he wanted moral support and it was safe to talk to me…”

“I talk to my dad on the phone…since he hasn’t been in the same situation it’s basically someone for me to vent to, and he isn’t really listening, he’s just always encouraging and letting me get it off my chest.” Jack
“I go home at the end of the day, and cry to my husband, (laughter) or sometimes he cries with me because of such things. You grieve it, just like you would grieve the loss of a friend or family member.” Anna

“I don’t need personal support for that (a death of an in utero fetus). No, it’s the patient who needs the support not the doctor…” Ken

“I try to have time to myself afterwards…some time to kinda decompress.” (A faculty participant speaks to helping students deal with death.) “First, I’d find out circumstances and have them talk it out. I think that’s the thing we need the most, to be able to talk about it. I’d give them a chance to do that.” Ellen

“I’ve generally been able to get the job done, regardless of how I’ve felt. There’s a term for practicing so you don’t get sued. You always want to ‘first do not harm’.” Jack

“You need to look at yourself. What is your view, your culture, your faith, what do you feel. You need to clearly examine that, but you also need to remember that you’ve chosen something that requires you to be objective… Keep a balance in your life… You’ve got to survive and thrive, and they (patients) do to.” Fran

“My coping mechanism is: you acknowledge the death, you might be sad, may even cry a little bit, with family or by yourself. But if it happens at two in the afternoon, you still have 15 patients waiting for you. So our coping mechanism as family practice physicians is to go back to work. Which is terrible! But we don’t have any choice! You can’t sit there and carry that to
the next five patients… We have the same emotions as everybody else
does, but we’re taught, what you do to get over that sadness – you see
the next patient.” Greg

Findings that Answered the Research Questions

1) How do selected physicians describe the essence and meaning of death
and dying?

Participants readily acknowledged the reality of death in medical practice.
The meaning of death was divided into professional and personal essences.
Personal meaning was influenced by individual personality type, gender, and
spirituality. Professionally, medicine and death is objective with tasks to
accomplish such as discussions about advance directives and treatment plans. To
change the focus of care at end-of-life from quantity of life and additional
treatments to quality of life and care not cure was more than purely medical
decisions. Physicians had to be able to make the cure to care transition
professionally and personally. Additionally, physicians must have confidence in
patients and family to assist in the direction, directives and course at end-of-life
and be willing to follow those directives, even if they vary from the physicians’
choices.

Participants described their professional medical attitude as: doing
everything that can be done, medically, the best you can do it. At the end-of-life
more than just medical treatments are involved, the relationship between physician
and patient adds a personal component to professional medical decisions. When
all medical activity was done, personally there was family to console, funerals to
attend, personal loss and grief to grapple with, the reality of having to take care of the next patient – even when all you wanted to do was take a break and cry.

Professionally, the meaning of death for participants was defined by medical culture and reinforced by the training, or lack there of, they received. Mentors and attending physicians greatly influenced participants understanding of what it meant to be a doctor when dealing with a patient’s death or dying. For some, the example was poor and they strove to become more compassionate and humane. For some, the mentoring examples were stellar and they used them as guides for their own practice. Death as failure was rejected, acknowledging end-of-life medicine gave death meaning, and dying was embraced within their medical practices.

Participants differentiated between sudden and traumatic death, long-term illnesses, the age of a patient, unknown patient deaths, and their own patient deaths. The first two were considered out of their control, and not much an issue of emotional concern or a reflection on their professional practice, although the phenomena of the death remained with them. The death and dying of patients known to the physician created the need for practicing detached concern and reserving their emotional energy based on what they were taught. The quality of the physician-patient relationship and the quality of care at end-of-life, remained with the physician and gave a patient’s death meaning. Physicians’ are confronted with deaths by trauma, where a great amount of energy is spent to save a life, strangers whom they pronounce, and patients known to them and whose life and death leave their emotional mark.
For female physicians interviewed, patients often become like family members. They made an effort to be present while a patient was dying. They interacted with family members and often attended the patient’s funeral. This emotional attachment to their patients did not appear to diminish their professional status in the eyes of patient or peer. This kind of emotional engagement with the patient made these physicians *the ones to talk to* regarding end-of-life care and medical care in general. The way they handled their patients dying and death gave meaning and validated their day-to-day dealings with patients.

2) How do selected physicians interpret their understanding of death and dying and then integrate the reality of death and dying into their personal medical culture and practice?

Participants of this study were self-selected. In their own professional practice they already had developed a more patient-centered approach to care at the end-of-life. These physicians considered themselves part of a minority. They expressed the belief that end-of-life care was something one learned through experience and then made conscious choices about how to provide care to the dying. These participants chose to invest more emotional energy in their patients, and were willing to risk the emotional consequences when patient, now friend, died. Three of these physicians were revered by other physicians for the kind of compassionate quality end-of-life care they provided to patients.

Participants clearly identified the role of advance directives, hospice care, utilizing a team: counselors, ministers, social workers, and others, at the end-of-life in their practices, while acknowledging they did not always utilize them. They
expressed the belief, and practice, that patients and family should be part of medical decisions and treatments at the end-of-life, if at all possible, and that involved good communication between physician and patient.

Several of the participants had taken the role of teacher and mentor in addition to being physicians. They bring to medical students their own experiences, understandings, meanings, and humanity, to help teach the students their profession. These participants wanted to influence a medical culture that still perpetuates the concept that death is failure to acknowledge end-of-life care and that physicians are here assist patients through their life and death.

**Summary**

In this chapter I analyzed the information collected from phenomenological interviews, field notes and observations with selected physicians to identify themes the evolved from this study. Triangulation and inter-raters were used to confirm identified themes. All physicians were currently employed or retired and living in the Carbondale, Illinois area. Sixty-four percent were family practitioners. Participants were asked to schedule 60 minute interview times. The interviews averaged approximately 50 minutes. Participants responded to a set of questions specifically, shared their experiences, feelings, and believes, around the topic area of death and dying and the medical profession.

The overall theme gleaned from interviews was that despite advances in end-of-life care and curriculums, the family practitioner was not equipped with skills to effectively deal with death and dying in their professional practice. The
skills acquired were learned through personal experiences. Professionally there is a lack of time available for all patients but especially when dealing with death and dying. Personally the death of patient has a personal impact. Little time exists, however, to address the emotional toll on physicians and find support. Knowledge about and use of available resources, such as palliative care, hospice, a care team with ministers, social workers, counselors, and end-of-life specialists, were not fully integrated into physicians’ medical toolkits.

A summary of the study, discussion, conclusions, implications and recommendations regarding these findings will be presented in Chapter Five.
CHAPTER V

OVERVIEW – WHY THIS STUDY?

While death is a very personal event for an individual, death rarely happens in isolation. Death, as a phenomenon, encompasses cultural, ethnic, spiritual, social and physical elements, which are often played out under the guidance of a medical provider or in medical setting. (Chapter 2: Cultural issues, Spirituality, Psychological issues, Good death). As society redefines how we wish to handle our dying process, medical society must also redefine how it trains its physicians and prepares them to handle our death and dying (Chapter 2: Hidden Curriculum & Medical Culture, Good Death, Physician Healer-Humanizing medicine).

Since the 1990’s Americans, as a society, have begun to focus on dying as a medical process, as well as acknowledging death is a natural part of life. Over four billion dollars in private foundation money spent on investigating and making changes in the way Americans die (See Chapter 1 and Appendice A, E, F, L, R) between 1994-2004. Medical curriculums have made changes to teaching methods and curriculum content designed to facilitate students’ personal growth and incorporate end-of-life issues (Chapter 2: Medical End-of-Life Curriculum).

To date, most discussion surrounding death and dying has begun outside the medical community (George Soros’ “Death in America” project and the Robert Wood Johnson Foundation Last Act initiative). Two extraordinary medical exceptions are: Dame Dr. Cicely Saunders’ development of hospice and Dr.
Elizabeth Kübler-Ross’ definition and clarification of the psychological process individuals’ experience during dying. A keystone in the medical community came with the 1995 publication of the SUPPORT study. More recently, Harvard Medical School and Stanford’s Medical School have developed programs that designed to train and equip physicians with end-of-life skills (Appendices: A, B, R). Medically end-of-life care is still considered a specialization that is focused in hospice and palliative care professions. Very little actual training or preparation is done with physicians who, on a daily basis, are supposed to care for our health in the course of being our family physicians and execute our wishes as they help us live and die.

This study is one of six known, at this writing, that involved a researcher speaking directly with physicians about how they viewed and handled death and dying both emotionally and professionally. Most end-of-life research focuses on the patient and family, and how the patient perceives a good death. The essence of end-of-life experiences is unique to everyone who shares the phenomenon. Despite advances in palliative care medicine, and the resources available to end-of-life professionals, the average family physician is neither trained, nor adequately prepared for, the eventual patient death. A physician may have specific medical training, but not emotional preparation, or they may have had personal experiences that help shaped their professional practice.

Medical school curriculums have added end-of-life care, but there are limitations in time and scope of training available. End-of-life care encompasses advance directives, palliative care, hospice, and a team of non-medical
providers: clergy, counselors, social workers, and others, (Chapter 2: Hospice, Palliative care, Communication skills, Advance directives). While family practitioners often do not feel they have had training in these areas, they feel that adequate communication skills are sufficient to deal with all end-of-life issues (Chapter 4: Theme four). Additionally, end-of-life care involves a shift from cure to care. For many transitions quality of care means curing/healing, when quality of life means helping people die well it can be a difficult role for a physician.

The identification of communication and caring at end-of-life may be part of what can be called the essence of death and dying. Without both, regardless of the medicine being practiced, death remains a failure. For the participants in this study the integration of different communication, advance directives or patient guided treatment, and the willingness to cease the medical directive to cure and shift to utilizing medicine to care and help give meaning to patients death.

Some physicians, by personal choice, elect to work with populations where they are more likely to experience death more frequently such as geriatric populations, oncology, palliative care, or hospice. The practice of family practitioners focuses on the lifespan of individuals. Those who stay in one area and age with their patients are likely to experience the death of long-time patients, some who have become friends, and may even be considered family. While death may have a very specific medical definition, the reality and impact of death and dying on the physician is not adequately addressed in generalized physician training (Chapter 4: Theme three). Death, via a pronouncement,
becomes a legal act, medical skill is no longer necessary, but the phenomenon of
depth does not end. Physicians experience grief and loss when they lose
patients, but often don’t have the physical or emotional time or support to deal
with these losses. The meaning moves from activity to reflection.

The world views the physician as a medical professional whose job it is to
take care of our medical needs from birth through death. Expectations we hold
for physicians, as the patient, are very high. As patients we are unaware of the
emotional tolls of stressful work settings, unrealistic expectations, demands for
more and more with less and less, lack of time for patients or for self, trying to
have a life that is balanced professionally and personally by doctors. A physician
experiences loss both personal and professional and are being dealt with by the
human beings we call doctors (Chapter 4: Theme five). If we want to re-
humanize the dying process within medical culture, we must re-humanize the
expectations we have of our physicians and prepare them with the skills to
perform medicine in a more humanistic way (Chapter 2: Hidden curriculum &
medical culture, Physician attitudes on death & dying, Chapter 4: Theme six).

Review of Study

This qualitative phenomenological study attempted to gain the physician’s
essences, meanings and understanding surrounding death and dying. Starting
with themes revealed in literature, research questions were clarified and
interview questions created. Three different groups of physicians: early in
practice, mid-career, and retired; were selected in an attempt, using apparent
time, to see how length of time in practice and experience affects the physician’s
view on death and dying. In-depth interviews were used to gain information from the personal experiences and recollections of the physicians.

Member checking, peer review, and explicitation, were used to uncover the essences, meanings, understanding, and perceived needs, physicians identified both professionally and personally surrounding end-of-life. As is necessary in phenomenological studies, the researcher’s own assumptions, perceptions, and experiences, continually had to be bracketed to read the interviews with fresh eyes, as if seeing them for the first time, each time, allowing participants’ words to reveal the story. Coding materials and reviewers’ input identified themes that serve to direct the conclusions reached in this study.

**Conclusions**

The following conclusions were based on the themes identified in this study and discussed in chapter four, information gathered in the related literature review, and through use of the phenomenological method.

1. Participants do not believe there are specific skills directly related to end-of-life care that can be taught in undergraduate medical school curriculums. Dealing with death and dying is a phenomenological experience; and experience, in their mind, is the best teacher. This belief by physicians, those with little professional experience and those with many years, reinforced that undergraduate medical school curriculums still are not providing adequate end-of-life training and graduate medical school and residences also do not provide end-of-life skills opportunities to gain this experience prior to having to deal with death professionally.
2. Communication skills are key in all aspects of medical practice. Specific end-of-life communication skills are needed. Communication skills are only one component of dealing with death and dying in medical practice more comprehensive end-of-life care training is needed.

3. Physicians, in this study, find meaning in death and life, in the relationships they develop with patients.

4. Death takes an emotional toll on everyone who deals with it, even physicians who approach it clinically, or transfer dying patients, or make the shift from cure to caring at end-of-life. Physicians need to have support networks in place, not only to assist in providing care, but also for the physician’s own emotional support. Physicians need to be taught to seek personal assistance and emotional support from one another, specifically when patients die.

5. Spirituality provides a resource for coping with death and dying for participants in this study.

6. A physician’s personality places a key role in providing care at end-of-life, regardless of training or experience and defines how death has meaning and the essence of dealing with patients who are dying.

Discussion

Despite changes in medical curriculums (Chapter 2: End-of-life curriculum, Appendices B, E, F) the subject matter of death and dying and end-of-life care is still evolving. In general, end-of-life care is viewed as the purview of a palliative care or hospice specialist s (Chapter 2: Hospice, Palliative care, Good death). Good communication skills that benefit all medical personnel regardless of their
particular specialty (Chapter 2: Communication skill, Chapter 4: Theme 4, Appendix R) are seen as sufficient end-of-life care skills.

The importance of good communications skills are reiterated again and again for end-of-life care (Karlawish et al, 1999; Hockley, 2000; Banja, 2005; Cherlin 2005; Fineberg, 2005; Han et al, 2005; Alexander et al, 2006), and more recently medical school training programs have moved to problem-based learning with communication between physician and patient a priority. Communication skills alone, however, do not necessarily include specific end-of-life skills: delivering bad news, discussing advance directives, end-of-life care options, an understanding and comprehension of the appropriate use of palliative care, and how to make a timely referral to hospice. The need for these specific skills have not yet pervaded the medical consciousness, medical culture, or the medical institutions, in which care is most often provided (Chapter 2: Hidden curriculum & medical culture, Physician attitudes on death and dying, Theme Five).

The physician must be able, emotionally and professionally, to have the conversation about end-of-life care with patient and family. Legal requirements require institutions to have advance directives for patients. Physicians may not have started the conversation, but they are the one’s explaining the ramifications of advance directives to patients and caregivers. Often the physician must let go of being the primary care physician, and release the need to do one more thing. Counter to training and perhaps desire, the physician must be willing move from a cure to care, or let the patient go elsewhere. A shift needs to occur to accept
death as inevitable, the releasing of cure and movement into care and comfort, is not often a comfortable shift for physicians. Stepping away from the medical culture's death is failure is not easy. A good death is still not an acceptable prognosis.

Physicians who have been in practice for many years still model behaviors and attitudes to new colleagues that perpetuate the notion that death in medicine is failure. Dying patients are avoided. Death is minimized to a legal checklist called a death pronouncement. One participant, when an intern, was told by the neurologist she was shadowing after a death pronouncement: Get in and get out don’t hang around. The legal activity of pronouncing could lead to the emotional activity of interacting with family members. The unspoken but very clear message, don’t waste your time with the dead; there are more important things to do, and for some physicians, avoidance of the living who have lost a loved one, because there is nothing they can do for them medically.

Medical training, once purely didactic, has developed into problem-based learning and includes small groups, interactive classrooms and mentors (Basu & Heuser, 2003; Anderson et al, 2008; Fernandes et al, 2008; Kitzes et al, 2008; Ellman et al, 2009). Yet new physicians in this study still felt less than fully prepared to deal with death and end-of-life issues. Only providing elective options that address end-of-life care, such as a two day hospice experience or one day on a palliative care rotation, are not adequate teaching or learning opportunities to assist physicians with end-of-life care. Educational changes have begun to create opportunities for physicians to take time to explore their
own personal beliefs and attitudes surrounding their death and dying in the medical profession. But the personal and emotional component of death for the physician is still not adequately addressed in medical school training (Wear, 2002; Ratanawongsa et al, 2005; William, Wilson & Olsen, 2005; Luthy et al, 2009, Rousseau, 2009).

The coping mechanisms taught new physicians, by example and in curriculum: no emotional investment, limit time spent, transfer patients to an end-of-life specialist, go on to the next patient; may get a physician through their busy day but do not adequately assist the physician in dealing with end-of-life issues. Loss and its associated grief, is reality for all who experience death. The thanatological community knows that grief is cumulative, and will manifest itself despite our best intentions to ignore it. If one does not have a community to share loss, individual resources must be found. Spirituality served most of the participants as the touchstone for support and coping with their losses (Chapter 4: Theme 6). Most kept the emotional components of their death experiences in their medical practice – private, especially from other physicians. Physicians shared with family or spiritual mentors, because they had not found, or did not believe that other physicians would provide that opportunity for debriefing, venting, and shared experiences. According to this study’s participants the pervasive medical culture is still denying death.

I realized that those who agreed to be interviewed for this study have chosen a more patient-centered, rather than medically-focused approach, when confronted with death and dying patients (Chapter 1: Limitation #2). But even
these compassionate individuals expressed shortcomings in their training, their skills, and their understanding of end-of-life care. What was revealing in this research was how even individuals who have made conscious choices about how to care for people at end-of-life believed that they could not have been taught these skills or more fully prepared. Death, the phenomenon, can not be defined and dealt with as simply as the legal act of pronouncing. Participants view end-of-life skills as something that can't be learned, only experienced, and developed through personal experience (Chapter 4: Theme Four).

Unfortunately, in professional practice, physicians are isolated and their time fully consumed with patient care. For a physician with limited end-of-life care training or experience, few opportunities to discuss or debrief the end of a patient's life and the events of their care, occur. Even rarer, is the opportunity to interact on a personal level, with colleagues concerning the death of a patient, family dynamics surrounding a dying patient, or personal issues that may have been triggered or evoked in the course of their professional practice doing end-of-life care.

The networks and support systems, nurses, social workers, end-of-life care specialists considered vital to effective hospice and end-of-life practice, need to become acceptable and integrated components of physicians' practice on a day-to-day basis. In a world where medicine is, in part, guided by the numbers produced or patients seen, attempting to include time spent with the dying is a difficult job to accomplish (Chapter 2: Psychological issues, Good death, Physician healer-humanizing medicine, Chapter 4: Theme Four and Five,
Appendices C, D, E, F). The psychological components of patient care are still viewed as less than the physiological (Chapter 2: Good death, Appendix L), as one participant said: if the patient starts getting emotional I'll call in the chaplain or social worker. Acknowledgment of the benefits of psychological care in healing is secondary. The importance of acknowledging there is a time to stop trying to cure a physiological illness and focus on caring for psycho-social aspects of a patient is fundamental to hospice care, but not integrated into the family practitioners' day-to-day medical practice. Emotional support and psychological treatments don’t necessarily generate any medical statistics to be counted institutionally, only as referrals. In reality they do generate peace of mind and improved quality of care for everyone involved, but acknowledging these treatments as integral components and getting “credit” for them, is still a work in process.

There was almost a cavalier attitude by participants that some doctors were lousy communicators and had little social skills, because lack thereof wasn’t viewed as medically necessary. Personality differences were noted, because some physicians just do not have the personality for patient care (Chapter 4: Theme One) and elect specialties that have minimum interpersonal interactions with patients. When the first participant made a comment about personality differences between doctors, my bracketing failed and this mental response occurred: “You’re just making excuses for those physicians who don’t do end-of-life issues well, or don’t have good communication skills”. But as the literature review showed, just because you get a medical degree it doesn’t mean you know
how to talk to people. When I was able to step back, and see that every participant expressed a similar idea. I set aside my expectations and experiences and realized that personality and gender does play a role in how physicians deal with patients, in general and specifically at end-of-life, regardless of their training.

Acknowledging that the topic of this research: death and dying and end-of-life care, was not an easy topic to discuss, it was my speculation that the physicians felt more comfortable in their professional setting, especially discussing emotive and non-medical topics, like death and dying. Most interviews, by participants’ request, were held at their workplace. Later, realizing how valuable time was, this made sense, but it also gave them an “out” if they felt the need to terminate the interview.

I also observed that I appeared to be much more distracted by the interruptions of a medical setting than the participants. The participants demonstrated the ability to appear to focus single-mindedly on the interview, to the exclusion of everything else. I, as interviewer, was not aware if they were distracted or giving heed to the extemporaneous interruptions. This single-minded focus may be a product of medical training, the result of time limitations that require accomplishing tasks quickly and precisely, or a preservation tool honed in a chaotic world of medicine.

This raised the question in my mind; if a physician is single-minded on the task of curing, medicating, or monitoring a patient’s condition, how attentive is the physician to the other salient issues surrounding the patient? Particularly at the end-of-life, when the physiological issues and tasks are often not the considered
medically important. The emotional component of end-of-life is a difficult area for physicians to address because it was outside their medical model. Addressing the psychological issues provides better care at end-of-life (Appendix L), but is again outside the training most physicians receive and not something that there is time for, whether because of medical crisis’ or unwillingness.

Since I was an outsider to the medical community (Chapter 1: Limitation #5), I was struck by the dilemma physicians’ face daily on where to spend their time. Lack of time to spend time with all patients, much less with dying patients, and having to make a choice between a patient/family relationship and personal/family relationships, because of limited time, is an ongoing battle. Being willing to invest emotional energy in patients, whom they know will die, and create a loss that should be grieved, means sacrifice somewhere else in physicians’ time or emotional resources (Theme Five). Along with addressing care at end-of-life institutionally, an institutional change of physicians’ time is needed. For this study, the essence of death and dying, in several cases, came down to a decision about how to spend the one’s resources, not how to care for a dying patient and meaning was found in the choices made.

One of the focuses of this phenomenological study was to uncover the meaning physicians make surrounding death and dying. The phenomenon of death is not contained in a clinical setting or medical prognosis. Death moved beyond the termination of bodily function and included emotional components. For these participants, death’s understanding was set in a context, such as: age, condition, and treatments given. Death and dying’s meaning medically was
embedded within the quality care of patients and families received, during the
dying process and after death with the families.

These selected physicians found meaning in the relationships they built
with patients. The personal interactions that supported patient and families also
supported the physician during the dying process. Meaning came from quality of
life, of caring, of medical care, of relationships (Chapter 4: Theme Four, Five).
The sacrifices of their personal time and emotional resources were outweighed
by the time spent with dying patients. As one participant shared, “today I’ll go to
the funeral, tomorrow my son’s ballgame”.

These physicians had to find their own emotional reserves outside their
medical community, often via their spirituality, to move through the emotional
aspects of the death of a patient. When the shift occurred, time spent, and
emotional energy given, a patient’s death had meaning. Sharing with their own
family, or patient family members often did not include spiritual communications,
but served as their silent guide. The participants had an understanding of the
spiritual aspect of death as a phenomenon but did not integrate it as part of the
current common medical procedures at end-of-life.

The standard of care for end-of-life care is not universal in medical culture.
The hidden curriculum that death is to be avoided and unimportant because the
physician’s medical job was over, still existed even within these physicians who
had consciously chosen to make end-of-life care as important as the rest of their
practice. However, moving from the hard science of medicine, into soft science
of psychological and spiritual issues, may be one of the most difficult skills
physicians need to acquire. These skills may not even be acknowledged as important in a doctor’s medical skill set. They are not one being taught directly in medical schools but are becoming more integrated into personal process skills for the physician.

The interviews for this research ended Spring 2007. A journal search of articles published between 2007 and 2010 showed 14 articles about communication skills training for end-of-life care, and numerous articles on end-of-life ethical issues were found. Since the original journal search in 2006-2007 the additional articles give a little more attention to the emotional component of death and dying and how that is being addressed in medical schools, but medical institutions and physicians currently practicing, like the physicians interview herein, still appear to believe and act as if, experience is the only true training ground for end-of-life care. Six articles were found which addressed the physician’s emotional component in dealing with death and dying. The lack of research and attention is a fact that leaves both physician and patient still wanting at the end-of-life.

Death needs to become part of life. With adequate communication skills physicians or caregivers should not be hesitant to discuss advance directives in the course of regular check-ups. Decisions about end-of-life care, spiritual, cultural, and personal preference should be discussed before a terminal diagnosis is given or a medical crisis occurs. If physicians normalized the cycle of life including its conclusion in death, quality of care would improve throughout
the life cycle. Palliation and quality of life could be come routine rather than the alternative to medical care.

**Limitations of this Study**

This study was conducted in Southern Illinois, which is primarily a rural area and may not be representative of large, metropolitan area physicians. The majority of physicians who participated in this study were Caucasian and Christian, that was demographically representative of Southern Illinois physicians and it's general population, but not of United States physicians or population as a whole. This study did not intentionally seek out cultural or spiritual diversity, because the focus was on locating family practitioners in Southern Illinois. Despite trying to speak with physicians who represented the general family practitioner, physicians who agreed to participate represented the minority who felt comfortable with end-of-life issues. Their views may not adequately reflect all family practitioner attitudes for end-of-life issues, or those not comfortable with the topic, and, therefore, chose not to be interviewed.

Since only six other studies, known to this researcher, studied physicians’ emotional responses to death and dealing with dying patients professionally, the additional physicians interviewed in this study, still represent only a small proportion of physicians currently in practice. The findings of this study were similar with the other six studies that indicated physicians are still not adequately prepared for end-of-life care and that the phenomena of death is still an enigma.

While this study may reinforce that medical education and training in end-of-life care has a way to go, the fact that participants felt experience was the best
teacher, failed to identify specific educational deficiencies or highlights that could shape further studies or changes in medical school curriculum.

As with any research relying on interviews the researcher’s, my own, biases have guided how I interpreted the findings. My best intentions and attempts to bracket personal experience and expectation have limitations. Likewise, a phenomenological study attempts to make meaning of an evolving and changing phenomenon. Death may be a single event set in time, but the events surrounding them, how physicians handled each situation; people involved and how they made meaning of it all, can’t be limited to the written word, just as the experience can not be pinpointed in a point in time.

As is true in so many aspects of life, those who need to learn about an issue are often the ones who avoid it. Participants noted that this was true for this research also; physicians, whom they knew, who had the fewest skills in end-of-life should have been the ones discussing this issue, but choose not to participate.

**Recommendations based on this Study**

As a result of this study the following recommendations were made in the areas of health education, curriculum and instruction, and education psychology:
1) Undergraduate medical school curriculums should continue to grow and include skills specifically related to end-of-life care, ideally all nine domains of ACGME end-of-life care training: pain assessment and management, non-pain symptoms assessment and management, ethics, physician-patient communication, end-of-life (EOL) communication: skills in giving bad news,
discussing do-not-resuscitate orders, discussing treatment goals, discussing advance care planning, discussing hospice care, psychosocial care – attention to death as a life-cycle event, patient and family coping and support, etc., death and dying – bereavement and miscellaneous EOL content, personal awareness – physicians’ self-care or personal reflection, EOL clinical experiences, including hospice or palliative care rotations.

2) The training currently in place in undergraduate medical school curriculums appears incomplete, or ineffective, in preparing physicians for end-of-life issues. EOL skills need to be taught in a psycho-social model that creates personal reflection by the physicians and validates the emotional social component medical care. End-of-life treatments that include: social, psychological, and spiritual care should be viable and valued parts of medical care and this needs to be included in undergraduate medical training. Likewise graduate medical school training and residences should continue teaching both the clinical skills and psycho-social skills need for end-of-life care. EOL skills should not be isolated to hospice, palliative, or gerontological rotations.

3) If end-of-life skill training becomes integrated into medical school curriculum then faculty need to be trained and qualified to teach in the methods mentioned above and on end-of-life topics. Health educators, educational psychologists, hospice specialists, etc., could partner with physician faculty to teach end-of-life skills. Likewise graduate medical school and residences should also include end-of-life skills training, taking theory into practice, again utilizing learning opportunities and educators skilled in end-of-life care.
4) Thanatological training, including grief and loss, should be a required component of all psychology training. More counselors, psychologists, psychiatrists should have in depth death and dying skills that can be used as part of an end-of-life care team. If physicians do not receive specific end-of-life training in grief and loss they should be familiar with the appropriate resources and refer appropriately. They should also feel comfortable utilizing end-of-life specialist personally. Physicians, no matter how skilled at their medical craft, are human beings who have their own fears and issues with death. Medicine as a profession needs to create a support net of physicians, which is given institutional time and to which physicians are encouraged to participate. Just as there are widows’ grief groups, and support groups for those whose children have died, physicians should have a physicians group to share their grief and get support for the patients that have died. Hospital counselors equipped with end-of-life skills should set up debriefing opportunities and support groups specifically for physicians. This means addressing a fundamental principle taught in medical school that doctors’ need to have detached concern and stand alone in medical decision-making. Teach that consulting, reaching out to another physician, isn’t purely medical, but also can be supportive and a sign of strength and wisdom in practice.

5) A shift must occur in societal expectations of physicians and patients. End-of-life care involves individual responsibility in decision making for both the kind of medical care provided and choices made at end-of-life. This is a shift for both physician and patient. This shift means educating everyone about end-of-life
starting in elementary school forward part of required health education curriculum
and college and medical school curriculum. Both physician and patient need to
be taught about their shared role at end-of-life. Death should be normalized and
reintegrated into the activities and discussion of day-to-day life. Instead of only
addressing grief and loss topics after a death has occurred, discussion of end-of-
life issues, beliefs and practices surrounding death and dying, the spiritual,
social, cultural components of death and dying can be components of curriculum
in virtually any area: history, sociology, mathematics, psychology, and others, in
addition to health education. Pre-med and undergraduate medical school
curriculums should include death education courses. This would validate the
importance of end-of-life issues and provide physicians to be, experiences,
opportunities to reflect, and help them address life and death decisions prior to
becoming a physician, facing a medical crisis, or confronting death personally as
a physician.

6) Health educators need to be trained in, and have a comfort level with death
and dying issues, so that they can begin the process of integrating death
education curriculum in K-12 as well as college and graduate level training. This
may require thanatology training as part of health education masters’ and PhD
level training. Health educators could be the death education educators in
medical schools. One of the shortcomings, as revealed in the literature search,
about teaching end-of-life courses by medical school faculty, primarily MD’s, was
that they did not feel adequately prepared or equipped to teach end-of-life
classes. If health educators were trained they could fill in this gap.
A new field of interpersonal, end-of-life case management is developing as American society ages. Medical institutions and physicians should develop professional relationships with end-of-life case management agencies and individuals, to enlarge the circle of care provided, enhance end-of-life care, and relieve some of the burden of end-of-life care from physicians. As end-of-life care occurs both in and out of medical settings and requires more legal decisions and preparation by individuals for their own final decisions; medical providers, health educators, counselors, social workers, can play a pivotal role in preparing individuals for these decisions and educating them about the resources available as end-of-life care managers.

The continued move toward a more holistic approach is needed in preparing physicians in medical school and residency to deal with death and dying. Didactics, mentoring, internships in end-of-life can all contribute. Over and over again modeling and mentoring was mentioned by the participants as the most valuable learning tool and resource. The concept of a team approach to end-of-life care has been common from the creation of hospice and was a viable resource that should be part of a practicing physician’s resources, but are not available or known to all physicians. Physicians should to be able to move from the primary care role to part of team both for patient care and personal support during end-of-life care, but for many physicians’ end-of-life care means handing over of the patient’s care to another, rather than a transition to an end-of-life care team.
Recommendations for Future Research

Based on this research, and my personal experiences and revelations about end-of-life medical practice, physicians, and death and dying, the following recommendations for future research were made:

1) More studies directly talking to physicians about their needs, should to be conducted. Research about the emotional and psychological components of physicians both personally and professionally surrounding end-of-life, and their support systems, would aid in identifying ways to address these issues successfully, create effective curriculum, help prepare future physicians better, and hopefully provide a support network for physicians.

2) Study into the effectiveness of current end-of-life training in medical curriculum should be continued and expanded. Based on the physicians who have come out of the new curriculum, which includes end-of-life training, little of the training they received prepared them to deal with death and dying. A study of different teaching methods that may enhance learning and integration of end-of-life care more effectively for all physicians is needed. More research has been focused on communication skills, but specific identification of end-of-life skills and learning opportunities, such as hospice rotations or palliative care training is needed.

3) Continue to evaluate current communication skills taught and their application in end-of-life areas. This could include clarifying high and low communication and its appropriate use, especially at the end-of-life. Clarifying
how effective continuing education for physicians on communication skills is in end-of-life care.

4) Mentoring, whether intentional or unintentional, is a fundamental aspect of medical learning and training, studies on the impact of mentoring in medical culture can identify and provide intentional opportunities where new physicians can be mentored by physicians whom have comprehensive and inclusive end-of-life skills integrated their daily practice. Studying mentoring includes identifying the hidden curriculum surrounding death and dying and working to change it so new physician’s are not acculturated without opportunities for positive end-of-life experiences.

5) Continued research into death and dying curriculums and its use and effectiveness in health education and psychology curriculums.

5) Ideally, a survey of every physician currently in practice should be asked about his or her professional beliefs and practices concerning end-of-life issues. This would assist in creating institutional and medical cultural changes regarding end-of-life care. Changes in end-of-life care primarily have been instituted outside the medical community, or by a very small group of physicians who deal with end-of-life care as a primary part of their professional practice. Neither group truly reflects the general practitioner and his professional experience. Input from this group may significantly alter what is being taught, the skills required and the most effective method of putting death back into the ordinary course of life.
Epilogue

Despite the hope that this study would discover that physicians have begun to put ‘the life back into death’ and that medical curriculum was adequately addressing end-of-life issues: death and dying are still feared, ignored, and minimized. End-of-life care still exists more in a state of crisis, rather than part of an integrated program of care. Those who told me that "doctors sure need help" providing care at end-of-life weren’t just referring to older physicians, or oncologist, but to most physicians.

If I, as a dying patient expect to get the best end-of-life care from my physician, my physician needs to be getting better training and personal exploration of the meaning of life and death in medical school and residency, before they are confronted with it in private practice. Hard and soft science are not necessarily at opposite ends of the medical spectrum when it comes to treating patients, physicians need to be validated and supported in their humanity, just as they are driven to excel in their medical knowledge.

The concept of care, not cure, allows for death to be a prognosis, not a diagnosis to be cured. Western medicine with its technology and continuing push to alleviate disease and prolong death, has been given great authority in our American society, so that we have bowed to its quantitative directives and lost sight of the importance of quality over quantity, and alternative treatments more common is eastern medicine, or just humane relationships with others. Technology is a tool that should be used to promote the best possible outcome for any individual, even if that outcome is death. Until medicine accepts the
inevitable and teaches physicians acceptance of the dying process and the importance of specialized care at the end-of-life for patient, family, staff and physician will continue to deny death.

The meaning of the phenomenon of death, which is experiential, is found in the practice of medicine in the relationship between physician and patient. Some of the essence of death and dying is within the interpersonal and emotional investment between physician and patient, which in part, creates or helps facilitates a good death. Phenomenological understanding comes when physicians are able to make the shift in their medical treatments that insure the patient’s quality, not quantity of life or curative treatments regardless of outcome.

Dealing with death and dying, doing end-of life care is being done by human beings. Being a physician doesn’t magically exempt you from the emotional and psychological components of being human. Society needs to support, encourage, train, and nourish the physician so they have the ability technically, physically, spiritually, and emotionally to help both themselves and their patients walk through life and death.

The essence of the phenomenon of death is that it can’t be avoided. Is it hubris or ignorance that continues to push humanity to deny it? A physician is the person that is often looked to, to guide us through the end of life’s journey. If we expect them to be our guides, then let’s be sure they are trained and equipped to lead us.
REFERENCES


Brody, J. (2006, November). More patients with incurable illnesses are placing importance on having 'a good death'. *St.Louis Post-Dispatch*, p. 6.


International Work Group on Death, Dying and Bereavement (1994)


Steinhauser, K.E., Clipp, E.C., McNeilly, M., Christakis, N.A., McIntyre, L.M. & Tulsky, J.A. (2000). In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine, Vol. 132*, pp. 825-832.


*University of California San Francisco School of Medicine, online catalog.* Retrieved on April 23, 2006 from http://medschool.ucsf.edu/


APPENDIX A

Thanatologist Reference & Resource List
APPENDIX A

Thanatologist Reference & Resource List

Advance Directives Materials

POLST – Physician Orders For Life-Sustaining Treatment Form
http://www.ohsu.edu/polst/

Five Wishes – Advance Directives Booklet from Aging with Dignity
http://www.agingwithdignity.org/five-wishes-resources.php


Caregiver resources


Hospice/Home Care Family Caregiver Cancer Education Program Topics for Home-Based Instruction, contact Mary.pickett@villanova.edu


USA.gov, caregiver resources:

Educational textbooks, resources


**Journals**


**Medical and Foundation Sources**


Describing Death in America (2004)

Project on Death in America in the mid 1990’s was originally funded by OSI – Open Society Institute, [www.soros.org](http://www.soros.org). It had grant programs in seven priority areas: 1) Epidemiology/ethnography/history of dying and bereavement in US, 2) physical/emotional/spiritual/existential components, 3) contribution to the arts and humanities, 4) public education, 5) professional education, 6) new service delivery models, 7) government and institutional policy. Significant new educational and policy changes evolved from this project.

Robert Wood Jonson Foundation Studies, [www.rwjf.org](http://www.rwjf.org), in the 1990’s funding research focusing on improving end of life care, this evolved from the late 1980’s SUPPORT project - The Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatment. This phase of grant funding targeted: professional education, institutional change and public engagement.


Organizations with end-of-life resources

AARP, www.aarp.org/families/end_life/

Americans for Better Care for the Dying, www.abcd-caring.org

American Psychological Association, end-of-life resources, www.apa.org/pi/eol/


Compassion and Choices, www.compassionandchoices.org

Griefnet, www.griefnet.org


Hospice Foundation of America, www.hospicefoundation.org

Hospice International, www.hospiceinternational.com/orgsusa.htm#usa resource list only.

National Hospice and Palliative Care Organization, www.nhpco.org

APPENDIX B

Spirituality, Cultural Issues, End-of-Life care included in
Communication in Medicine
“Health is not just absence of disease, but a state of well-being that includes a sense that life has purpose and meaning.” AAMC, Report III, p22

REPORT III Communication in Medicine

Learning Objectives

“With regard to end-of-life care issues, before graduation, students will have demonstrated to the satisfaction of the faculty:

- An understanding that death is a natural part of life, that suffering and loss are an integral part of the human life cycle, and that the physician’s role encompasses the comprehensive care of the patient and their family during the entire transition between life and death. (p26)

- The ability to deliver difficult news about end-of-life issues to patients and their families in a caring and compassionate manner; to elicit patients’ values, beliefs, and preferences for treatment at the end of life; to obtain advance directives and knowledge of surrogate issues.

- Recognize that when death becomes a likely possibility, treatment options may change depending on the risks and benefits of a particular treatment, the consequences of that treatment for the patient and patient preference for type of care.

- An understanding that the concept of palliative care refers to all of the dimensions of care (physical, emotional, social, and spiritual) that should be provided at the end of life.

- The ability to recognize the spectrum of the physical, emotional, sociocultural, and spiritual symptoms of distress patients may exhibit at the end of life, and the appropriate ways to respond to them.

- The ability to work with, and value, a multi-disciplinary team delivering end-of-life care, and to communicate effectively both orally and in writing with colleagues and other health care providers in order to deliver appropriate care to patients at the end of life.

- The ability to access data on end-of-life issues and utilize these data in the case formulations and management plans of patients at the end of life.
APPENDIX C

NHPCO Key Outcomes for End-of-life care

National Hospice and Palliative Care Organization
Recommended Outcomes
APPENDIX C

NHPCO Key Outcomes for End-of-life care

National Hospice and Palliative Care Organization
Recommended Outcomes

Self-determined life closure
- Staff will prevent problems associated with coping, grieving, and existential results related to imminence of death.
- Staff will support the patient in achieving the optimal level of consciousness.
- Staff will promote adaptive behaviors that are personally effective for patient and family caregiver.

Safe and comfortable dying
- Staff appropriately treat and prevent extension of disease and/or comorbidity.
- Staff treat and prevent treatment side effects.
- Staff treat and prevent distressing symptoms in concert with patient’s wishes.
- Staff tailor treatments to patient’s and family’s functional capacity.
- Staff prevent crises from arising due to resource deficits.
- Staff respond appropriately to financial, legal, and environment problems that compromise care.

Effective grieving
- Staff treat and prevent coping problems.
- Staff coach the patient and family through normal grieving.
- Staff assess and respond to anticipatory grief.
- Staff prevent unnecessary premature death.
- Staff identify opportunities for family members’ grief work.
- Staff assess the potential for complicated grief and respond appropriately.
- Staff assist the family in integrating the memory of their loved one into their lives.

Summary from IOM, Describing Death in America, 20004, pg 23
APPENDIX D

Definitions of Palliative Care
Definitions of Palliative Care

World Health Organization 1990  “Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti-cancer treatment. Palliative care:

- Affirms life and regards dying as a natural process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement.

IOM 1997  “Palliative care 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 dying or those enrolled in a hospice program. It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.”

Center for the advancement of Palliative Care 2002  “Palliative care is interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families. It is offered simultaneous with all other appropriate medical treatment.”

J. Andrews Billing. M.D 1998  “Palliative care is characterized as follows

1) Limiting itself to a particular clinical condition: terminal illness or care at the end of life. Unlike hospice, as currently regulated in this country, we do not need to specify a prognosis. In describing ourselves as caring for the dying, we want to avoid euphemisms, but also not be so blunt as to frighten patients and their families (e.g. speaking about ‘incurable’ or ‘terminal’ diseases), nor be so kindly as to become hopelessly vague (e.g. describing patients as ‘advanced’). With our health-care colleagues, ‘terminal illness’ is a relatively clear notion and allows us the flexibility to participate in the earlier phases of ‘active, progressive’ fatal conditions that eventually become ‘far-advanced’. For patients and families, ‘life-threatening illness’ may be the most appropriate descriptive terms, though it includes conditions, such as acute trauma, that are not typically within our domain.”
2) Employing a distinct method of evaluation and management, a special expertise: a) comprehensive and b) interdisciplinary (or collaborative) care.

3) Directing care to the patient and the family and, by implication, extending care into the period of bereavement.

4) Focusing on a specific management goal: promoting quality of life (of living as well as possible). This goal includes alleviating suffering, providing support, and making the best of remaining time, but need not exclude other goals, including cure or remission. Alternative terms that may be more acceptable to patients and families are “comfort care or supportive care”, although I find that the form tends to imply passivity and withhold, as suggested by ‘comfort measures only,’ whereas the latter also can mean treatments clearly aimed at prolonging or sustaining life.”

Hence, palliative care is comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a terminal illness and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include assuring physical comfort, psychosocial and spiritual support, and provision of coordinated services across various sites of care. This explication, which still is a mouthful, does not mention anything about supporting the service providers, an essential feature of any palliative care program, yet one that does not seem to deserve inclusion in a brief definition statement. The definition also does not specifically address the components of an interdisciplinary team and, like other definitions above, does not specifically mention volunteers or bereavement services. (pp. 79-80)

American Academy of Hospice and Palliative Medicine

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and cultures(s). Evaluation and treatment should be comprehensive and patient-centered, with a focus on the central role of the family unit in decision-making. Palliative care affirms life by supporting the patient and family’s goals for the future, including their hopes for
cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death. Palliative care aims to guide
and assist the patient and family in making decisions that enable them to work toward their goals during whatever time they have remaining. Comprehensive palliative care services often require the expertise of various providers in order to adequately assess and treat the complex needs of seriously ill patients and their families. Members of a palliative care team may include professionals from medicine, nursing, social work, chaplaincy, nutrition, rehabilitation, pharmacy and other professional disciplines. Leadership, collaboration, coordination and communication are key elements for effective integration of these disciplines and services.
APPENDIX E

End-of-Life - Hospice – Palliative Care Resources
Appendix E

End-of-Life - Hospice - Palliative Care Resources

AAHPM – American Academy of Hospice and Palliative Medicine –
http://www.aahpm.org

UNIPAC Book Series: Hospice/Palliative Care Training for Physicians, A Self Study Program

Accreditation Council for Graduate Medical Education (ACGME)


American Academy of Hospice and Palliative Medicine (RWJF)
http://www.aahpm.org

American Board of Hospice and Palliative Medicine (ABHPM)
http://www.abhpm.org

American for Better Care of the Dying (ABCD) dedicated to ensuring that all Americans receive good end-of-life care by seeking to achieve health care reform through improved policy, professional practice, and reimbursement: www.abcd-caring.org

Center to Advance Palliative Care (CAPC): national resource for hospital and health systems interested in developing palliative care programs: www.capc.org

PCLC – Palliative Care Leadership Centers – Building Academic Palliative Care


Educating Physicians on the End-of-Life Care (EPEC) program for physicians, consisting of interactive video modules, that provides a core curriculum of basic knowledge and skills needed for appropriate end-of-life care: www.epec.net

End of Life Physician Education Resource Center (EPERC) internet educational resource center for end-of-life issues: www.eperc.mcw.edu
Epidemiology of Dying and End of Life Experience (EDELE)  
http://www.edeledata.org

Growth House, Inc. end-of-life internet resource center including links and a search engine: www.growthhouse.org


Hospice and Palliative Nurses Association (HPNA)  http://www.hpna.org

Hospice Foundation of America  http://www.hospicefoundation.org/hospiceInfo/  

Improving Care at the End of Life: A sourcebook for healthcare managers and clinicians

Innovations in End-of-Life Care: online journal: www.edc.org/lastacts

International Association for Hospice & Palliative Care, www.hospicecare.com

Kuhl, D. “What dying People want."

Liaison Committee on Medical Education (LCME)


National Hospice and Palliative Care Organization  
http://www.nhpco.org/templates/1/homepage.cfm

National Citizens’ Coalition for Nursing Home Reform (NCCNHR)  
http://www.nccnhr.org


NIH (National Institutes of Health) PPCS (Pain and Palliative Care Service)

National Internal Medicine Residency Curriculum Project a project to integrate end-of–life care into internal medicine, in cooperation with the American Board of Internal Medicine: www.eperc.mcw.edu

National Palliative Care Research and Training Center (Kornfeld Foundation)
National Residency Education in End-of-Life Care Project. Directors: David Weissman & Pat Mullan

*Oxford Textbook of Palliative Medicine*


Palliative Care Education Resource Team for Nursing Homes (PERT) [http://www.swedishmedical.org/pert](http://www.swedishmedical.org/pert)

PCLC - Palliative Care Leadership Centers, [http://www.capc.org/palliative](http://www.capc.org/palliative). Building Academic Palliative Care

PEAT – Palliative Education Assessment Tool (funded by RWJF in NY) *used on all 4 years of medical school curriculum to uncover where palliative care is taught.*

Palliative Medicine Residency Review Committee

Program in Palliative Care Education and Practice (PCEP), Harvard Medical School. Faculty development

Physician Orders for Life-Sustaining Treatment (POLST) [http://www.ohsu.edu/ethics/polst/index.shtml](http://www.ohsu.edu/ethics/polst/index.shtml)


World Health Organization [http://www/who.int](http://www/who.int)
End-of-Life surveys

Physicians Cancer Pain Control Survey – symptom-control checklist

Nurses 34 item multiple choice questionnaire – Kristjanson, Hanson & Barkwell, Krisjanson, L.J., Hanson, E., Barkwell, D. (1994). Palliative care nursing knowledge scale (unpublished manuscript)

Social workers - 25 item questionnaire – Nelson
Nelson, F. (1994). Palliative care social worker knowledge scale (unpublished manuscript)

Winget Questionnaire for Understanding Dying Person and Family

American Association of Hospice and Palliative Medicine, Hospice and Palliative Nurses Association, National Association for Home Care & Hospice, National Hospice and Palliative Care Organization, National Hospice Work Group, and Visiting Nurses Association of America.

Spiritual History

APPENDIX F

(Accreditation Council for Graduate Medical Education)
ACGME Requirements for End-of-life Training

National Consensus Conference on Medical Education for Care
Near the End of Life

&

New End-of-Life Guidelines
APPENDIX F

ACGME Requirements for End-of-life Training

National Consensus Conference on Medical Education for Care Near the End of Life

Nine Domains:

- Pain assessment and management.
- Non-pain symptoms assessment and management
- Ethics
- Physician-patient communication
- EOL Communication: skills in giving bad news, discussing do-not-resuscitate orders, discussing treatment goals, discussing advance care planning, discussing hospice care.
- Psychosocial care – attention to death as a life-cycle event, patient and family coping and support, etc.
- Death and dying – bereavement and miscellaneous EOL content
- Personal awareness – physicians’ self-care or personal reflection
- EOL clinical experiences, including hospice or palliative care rotations.

Overview:
Ethics was the most commonly required EOL domain, followed by psychosocial care
Non-pain symptoms assessment and management, EOL communication, personal awareness and EOL clinical experiences were the least common domains of required EOL training.

Pain assessment and management required in internal medicine (IM) only, EOL clinical experiences-hospice or palliative care required in geriatrics only, personal awareness, psychosocial care, death and dying topics were required in some IM specialties.

Clinical policy of care at the end of life and the professional practice it guides should:
1. Respect the dignity of both patient and caregivers;
2. Be sensitive to and respectful of the patient’s and family’s wishes;
3. Use the most appropriate measures that are consistent with patient choices;
4. Encompass alleviation of pain and other physical symptoms;
5. Access and manage psychological, social, and spiritual/religious problems;
6. Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers);
7. Provide access to any therapy which may realistically be expected to improve the patient’s quality of life, including alternative or nontraditional treatments;
8. Provide access to palliative care and hospice care;
9. Respect the right to refuse treatment;
10. Respect the physician’s professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;
11. Promote clinical and evidence-based research on providing care at the end of life.

The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) adopted the Core Principles. The following organizations have formally adopted the Core Principles as written: the American Medical Association, Academy of Psychosomatic Medicine, American Academy of Hospice and Palliative Medicine, American College of Chest Physicians, American Pain Society, and the National Kidney Foundation. Four societies adopted with some modifications: the American Academy of Pediatrics, the American College of Surgeons, the American College of Physicians-American Society of Internal Medicine, and the American Geriatrics Society. The American Society of Bioethics and Humanities supports these principles. The American Academy of Neurology and the American Society of Clinical Oncology drafted their own statements which embody all the Core Principles.


Milbank Memorial Fund, [www.milbank.org/endoflife/index.html](http://www.milbank.org/endoflife/index.html) or 212-355-8400
APPENDIX G

Death Pronouncement Protocol
Listed below is an example of how to do a death pronouncement as carried in a pocket card by physicians.

Carefully follow the clinical protocol for death pronouncement.

Document death in chart with date, time, brief statement of cause of death, and other pertinent information

- **Check ID** bracelet and **pulse**.
- **Check pupils** for position and response to light.
- Note **response to tactile stimuli** in a respectful way.
  
  (NO sternal rubs or nipple pinches.)
- **Look and listen for spontaneous respirations.**
- **Listen for heart sounds** and fell for **pulses.**
APPENDIX H

Interview Questions

1) How did you decide to become a doctor?

2) Would you be willing to share your memories of your first patient death?

3) Are there other patient deaths, or a significant death, you remember and would be willing to share?

4) What have you learned from dealing with patients and families who are dying or who have died?

5) What do you wish you had been taught or would have learned in medical school to help you deal with death and dying?

6) How would you describe what medicine and the medical culture’s view of death and dying?

7) Would you share with me how a physician balances emotions and the responsibilities of being a doctor, particularly in regards to a dying patient or a death?

8) What are your perspectives or views on medical school end-of-life training or curriculum?

9) Reflecting back on the things we’ve talked about, is there anything you’d like to share?
Expert Panel Reviewing Interview Questions

Dr. Sandra Bertman, Director of Medical Humanities at University of Massachusetts., affiliated with Graduate School of Social Work at Boston College as a research professor in palliative care. FT – Distinguished professor of Thanatology and Arts at the National Center for Death Education, Mount Ida College. Adjunct faculty at Dartmouth Medical School and Nova University. End-of-life specialist.

Dr. Elaine M Blinde, Department Chair Kinesiology, College of Education at Southern Illinois University, Carbondale, (SIUC) and faculty in the Department of Sociology at SIUC. Qualitative research methods specialist.

Dr. Julia Colyar, Assistant professor of Educational Administration and Higher Education at SIUC (at time of research). As of 2008 – University of Buffalo, NY, Assistant professor of Educational Leadership and Policy. Qualitative research specialist.
APPENDIX I

THEMES

Expanded with components
APPENDIX I

THEMES
Expanded with components identified

Theme One: Personality and gender differences play a role in how a physician deals with patients, the practice of medicine, and with end-of-life issues

Why one is a doctor

Physician-patient relationships

Attending funerals and grieving with patient families

Death is a reality

– difference between intellectual knowledge and emotional knowledge

Theme Two: The role of death in medical practice has mixed or conflicting function and importance.

Type of death / Clinical deaths

Relationship with patient

Death is failure in medical culture

Death Pronouncements

Hidden curriculum

Lack of training for - unimportance of death

Modeled by residents and attendings – avoidance of death
Theme Three: Physicians believe experience is the best teacher in dealing with death.

Inadequate medical school curriculum for preparing physicians to handle end-of-life issues

Theme Four: Physicians believe communication skills are more important than end-of-life skills.

Need to be taught in medical school – experience is also teacher

Includes having compassion and empathy

Role of mentors/models

Ability to discuss and utilize end-of-life topics such as advance directives and hospice

Belief in patient’s ability to make end-of-life choices

Burden on physicians if unstated by patient.

Relinquishing primary care, referring to hospice care

Personal affect of patient’s deaths on physicians

Theme Five: Physicians’ moving from cure to care, focusing on quality of life instead of continuation of life, and trusting patient make decisions about end-of-life care

Hospice and palliative care

Patients’ role in care

Quality vs quantity of life

Impact of patient’s death
Theme Six: There is little time for death in medical practice professionally or personally.

- Lack of physical time
- Lack of time is institutional
- Taking a little time can make a profound effect
- Lack of emotional time and energy
- Using an end-of-life team extends time

Theme Seven: Coping mechanism for physicians dealing with end-of-life issues include spirituality, turning inward and family support.

- Personal role of spirituality
- Medical role of spirituality
- Keeping the affect of death to oneself, not sharing with other physicians
- Family support
APPENDIX J

Outline Guide of Procedures for Analysis of Data
Outline Guide of Procedures for Analysis of Data


1) In the first step in organization, handling, and synthesizing, the researcher gathers all of the data from one participant (recording, transcript, notes, journal, personal documents, poems, artwork, etc.).

2) The researcher enters into the material in timeless immersion until it is understood. Knowledge of the individual participant's experience as a whole and in its detail is comprehensively apprehended by the researcher.

3) The data is set aside for awhile, encouraging an interval of rest and return to the data, procedures which facilitate the awakening of fresh energy and perspective. Then, after reviewing again all of the materials derived from the individual, the researcher takes notes, identifying the qualities and themes manifested in the data. Further study and review of the data and notes enables the heuristic researcher to construct an individual depiction of the experience. The individual depiction retains the language and includes examples drawn from the individual co-researcher’s experience of the phenomenon. It includes qualities and themes that encompass the research participant’s experience.

4) The next step requires a return to the original data of the individual co-researcher. Does the individual depiction of the experience fit the data from which it was developed? Does it contain the qualities and themes essential to the experience? If it does, the researcher is ready to move on to the next co-researcher. If not, the individual depiction must be revised to include what has been omitted or deleted, and what are or are not essential dimensions of the experience. The individual depiction may also be shared with the research participant for affirmation of its comprehensiveness and accuracy and for suggested deletions and additions.

5) When the above steps have been completed for one research participant, the investigator undertakes the same course of organization and analysis of the data for each of the other research participants until individual depiction of each co-researcher’s experience of the phenomenon has been constructed.

6) The individual depictions as a group, representing each co-researcher’s experience, are gathered together. The researcher again enters into an immersion process with intervals of rest until the universal qualities and themes of the experience are thoroughly internalized and understood. At a timely point in knowledge and readiness, the researcher develops a composite depiction that represents the common qualities and themes that
7) embrace the experience of the co-researchers. The composite depiction (a group depiction reflecting the experience of individual participants) includes exemplary narratives, descriptive accounts, conversations, illustrations, and verbatim excerpts that accentuate the flow, spirit, and life inherent in the experience. It should be vivid, accurate, alive, and clear, and encompass the core qualities and themes inherent in the experience. The composite depiction includes all the core meanings of the phenomenon as experienced by the individual participants and by the group as a whole.

8) The heuristic researcher returns again to the raw material derived from each co-researcher’s experience, and the individual depictions derived from the raw material. From these data, the researcher selects two or three participants whose clearly exemplify the group as a whole. The researcher then develops individual portraits of these persons, utilizing the raw data, individual depictions and autobiographical material that was gathered during preliminary contacts and meetings, contained in personal documents, or shared during the interview. The individual portraits should be presented in such a way that both the phenomenon investigates and the individual persons emerge in a vital and unified manner.

9) The final step in heuristic presentation and handling of data is the development of a creative synthesis of the experience. The creative synthesis encourages a wide range of freedom in characterizing the phenomenon. It invites a recognition of tacit-intuitive awarenesses of the researcher, knowledge that has been incubating over months through processes of immersion, illumination, and explication of the phenomenon investigated. The researcher as scientist-artist develops an aesthetic rendition of the themes and essential meanings of the phenomenon. The researcher taps into imaginative and contemplative sources of knowledge and insight in synthesizing the experience, in presenting the discovery of essences – peaks and valleys, highlights and horizons. In the creative synthesis, there is a free reign of though and feeling that supports the researcher’s knowledge, passion, and presence; this infuses the work with a personal, professional, and literary value that can be expressed through a narrative, story, poem, work of art, metaphor, analogy, or tale.
APPENDIX K

Concept of Good Death Measure Characteristics
Concept of Good Death Measure Characteristics

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Item Content</th>
<th>% Rated as “essential”</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLOSURE</td>
<td>That family and doctors follow the person’s wishes</td>
<td>79</td>
</tr>
<tr>
<td></td>
<td>That it be peaceful</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>That loved ones be present</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>That the person’s spiritual needs be met</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td>That the person be able to accept death</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>That the person had a chance to complete important tasks</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>That the person had an opportunity to say good-bye</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>That the person was able to remain at home</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>That the person lived until a key event</td>
<td>2</td>
</tr>
<tr>
<td>PERSONAL CONTROL</td>
<td>That there be mental alertness until the end</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>That there be control of bodily functions until death</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>That the ability to communicate be present until death</td>
<td>10</td>
</tr>
<tr>
<td>CLINICAL</td>
<td>That it be painless or largely pain-free</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>That the dying period be short</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>That it be sudden and unexpected</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>That it occur naturally, without technical equipment</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>That death occurs during sleep</td>
<td>2</td>
</tr>
</tbody>
</table>

Original scale: 1- Not necessary, 2 - Desirable, 3 – Important, 4 - Essential

APPENDIX L

The Hippocratic Oath

Two Versions
APPENDIX L

The Hippocratic Oath
(Older Version)

I swear by Apollo the physician and Aesculapius, and Health, and All-heal, and all the gods and goddesses, that, according to my ability and judgement, I will keep this Oath and this stipulation.

To reckon him who taught me this Art equally dear to me as my parents, to share my substance with him, and relieve his necessities if required; to look upon his offspring in the same footing as my own brothers, and to teach them this art, if they shall wish to learn it, without fee or stipulation; and that by precept, lecture, and every other mode of instruction, I will impart a knowledge of the Art to my own sons, and those of my teachers, and to disciples bound by a stipulation and oath according to the law of medicine, but to none others.

I will follow that system of regimen which, according to my ability and judgement, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous. I will give no deadly medicine to any one if asked, nor suggest any such counsel; and in like manner I will not give to a woman a pessary to produce abortion.

With purity and with holiness I will pass my life and practice my Art. I will not cut persons labouring under the stone, but will leave this to be done by men who are practitioners of this work. Into whatever houses I enter, I will go into them for the benefit of the sick, and will abstain from every voluntary act of mischief and corruption; and, further, from the seduction of females or males, of freemen and slaves.

Whatever, in connection with my professional service, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret. While I continue to keep this Oath unviolated, may it be granted to me to enjoy life and the practice of the art, respected by all men, in all times. But should I trespass and violate this Oath, may the reverse be my lot.
Hippocratic Oath
(Modern Version)

I swear to fulfill, to the best of my ability and judgment this covenant:

I will respect the hard won scientific gains of those physicians in whose steps I walk, and gladly share such knowledge as is mine with those who are to follow.

I will apply, for the benefit of the sick, all measures [that] are required, avoiding those won traps of over treatment and therapeutic nihilism.

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon’s knife or the chemist’s drug.

I will not be ashamed to say “I know not,” nor will I fail to call in my colleagues when the skills of another are needed for a patient’s recovery.

I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God.

I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person’s family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.

I will prevent disease whenever I can, for prevention is preferable to cure.

I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm.

If I do not violate this oath, may I enjoy life and art, respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help.

(Written in 1964 by Louis Lasagna, Academic Dean of the School of Medicine at Tufts University, and used in many medical schools today.)
APPENDIX M

Spiritual History
APPENDIX M

Spiritual History


“In addition some patients have specific preferences or needs regarding medical care, death, and dying that are based on their spiritual and religious beliefs...Taking a spiritual history is one way to support the patient in their exploration.” p.932

Ambuel uses the anachronism S.P.I.R.I.T. to highlight the important areas covered in a spiritual history.

S – Spiritual belief system

P – Personal spirituality

I – Integration with spiritual community

R – Ritualized practices and restrictions

I – Implications medical care

T – Terminal events planning.
APPENDIX N

Demographic Information Data Sheet
APPENDIX N

Demographic Information

__ Male    __ Female   Age _____   Ethnicity______________________________

Specialty_______________________________ Years in Practice ___________

Medical School ___________________________________________________

1) What year did you graduate from medical school? __________

2) Did your medical school curriculum include: (check all that apply)
   ___ Communication skills
   ___ Physician patient interaction training
   ___ Cultural issues
   ___ Advance directives
   ___ Delivering bad news
   ___ Death pronouncements

3) Did your curriculum require a course or training in: (check all that apply)
   ___ A palliative care
   ___ A hospice rotation
   ___ Either offered as a elective
   ___ Not available

4) What was your reaction to your first death? (check or fill-in)
   ___ It was a good death
   ___ It was an unexpected
   ___ It was a shocking

   ________________________________________________________________

5) Did you feel prepared for your first death by your classes?

6) Did you receive support from your attending (or others) after the death?
7) Since you’ve been in practice have you taken end-of-life classes such as:

___ End of life palliative care
___ Hospice care
___ End-of-life communication skills
___ Delivering bad news skills
___ Death pronouncements
___ Grief or Bereavement seminars

8) Do you feel that medical school taught you the message that death is failure?

___ Yes
___ No

9) How did the message: death is failure, affect the way you treated patients?

10) What kind of training to deal with dying patients do you wish you had?

11) What kind of training or experiences would you recommend for medical students?

12) Is there anything else you would like to share about end-of life issues, death, dying, etc?

For contact information only. This tab will be removed and destroyed. All personal data will be removed from interviews and materials published in dissertation.

NAME:_________________________________________________________

PHONE #:_______________________________________________________

BEST TIME TO CONTACT:__________________________________________
APPENDIX O

Informed Consent Form

&

Consent to A/V Taping
APPENDIX O
Informed Consent Form

CONSENT FORM FOR
PARTICIPATION IN RESEARCH

My name is Deborah Jo Corker. I am a graduate student at Southern Illinois University Carbondale.

I am asking you to participate in my research study. The purpose of this study is to describe how physicians construct meaning of the phenomena of death and dying within their medical profession.

Participation is voluntary. If you choose to participate in the study, it will take approximately 60-90 minutes of your time. You will be asked to have a face to face semi-structured interview with the researcher. There are approximately 10 questions you will be asked. The interview will be audio taped and later transcribed. You will be given a copy of your interview transcribed for review and comment.

All your responses will be kept confidential within reasonable limits. Only those directly involved with this project will have access to the data.

If you have any questions about the study, please contact me or Dr. Judy C. Drolet.
Deborah J. Corker, phone: 618-303-7002 or Dr. Judy C. Drolet, phone: 618-453-2777.

Thank you for taking the time to assist me in this research.

Participant ___________________________ Date ___________________________

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Research Development and Administration, SIUC, Carbondale, IL 62901-4709. Phone (618) 453-4533. Email: siuhs@siu.edu
Consent to A/V Taping

I, ________________________________, agree to participate in this research project conducted by Deborah Jo Corker, MDiv, MSCP, CT, ABD at Southern Illinois University Carbondale, College of Education and Human Services.

I understand the purpose of this study is to describe how physicians construct meaning of the phenomena of death and dying within their medical profession.

I understand my participation is strictly voluntary and may refuse to answer any questions without penalty. I am also informed that my participation will last 60 – 90 minutes, with the opportunity to see the written transcript of my interview.

I understand that my responses to the questions will be audio taped, and that these tapes will be transcribed/stored and kept for 180 days in a locked file cabinet. Afterward, these tapes will be destroyed.

I understand questions or concerns about this study are to be directed to Deborah Jo Corker, at 618-303-7002 or AKCorker@siu.edu, or her advisor Dr. Judy C. Drolet, Health Education, 618-453-2777 at jdrolet@siu.edu.

I have read the information above and any questions I asked have been answered to my satisfaction. I agree to participate in this activity and know my responses will be tape recorded. I understand a copy of this form will be made available to me for the relevant information and phone numbers.

“I agree _____ I disagree _____ to have my responses recorded on audio tape.”

“I agree _____ I disagree _____ that Deborah Jo Corker may quote me in her dissertation.”

__________________________________  ______________________________
Participant Signature                              Date

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Research Development and Administration, SIUC, Carbondale, IL 62901-4709. Phone (618) 453-4533. Email: siuhs@siu.edu
APPENDIX P

Human Subjects Paperwork
APPENDIX Q

ADDITIONAL RESOURCES
APPENDIX Q

ADDITIONAL RESOURCES

PHYSICIANS AND END-OF-LIFE

American Academy on Physician and Patient (AAPP).
    Goals and Objective for promoting Medical Students’ Self-Awareness, Personal Growth, and Well-Being


Guidelines for Physician Communication


Table 6: Common Spiritual Themes,

American Academy on Physician and Patient (AAPP).
Goals and Objective for promoting Medical Students’ Self-Awareness,
Personal Growth, and Well-Being

**Overall Goals:**
1) to ensure that students understand how their personal histories and current personal lives, as well as their values, attitudes, and biases, affect their care of patients, so that they can use their emotional responses in patient care to their patients’ benefit: and
2) to ensure that students care for themselves physically and emotionally, and welcome and seek opportunities for enhancing their self-awareness and personal growth.

**Objectives:**

**Self-Knowledge:** Students should
1) understand their own psychological strengths and emotional triggers
2) understand how their own personality characteristics (such as gregariousness, need for approval, tendency to be judgmental, needs for perfection and control, etc.) affect their relationships with patients and colleagues
3) be able to particulate their core beliefs, ideals, and personal philosophies of life, relating these to their own goals in medicine
4) know how family-of-origin, race, class, religion, and gender issues have shaped their attitudes and abilities to discuss these issues with patients
5) understand the difference between feelings of sympathy and feelings of empathy for specific patients and be able to describe factors within themselves and within patients that enhance or interfere with their abilities to experience and convey empathy
6) understand their own attitudes toward uncertainty and risk taking and their needs for reassurance
7) be able to describe how their relationships with certain patients reflect their attitudes toward paternalism, autonomy, benevolence, nonmaleficence, and justice; and
8) recognize their own feelings (love, anger, frustration, vulnerability, intimacy, etc.) in ‘easy’ and difficult patient-doctor interactions.

**Abilities:** Student should
1) be able to create boundaries with patients that allow for therapeutic emotional connections.
2) Challenge authority appropriately from a firm sense of their own values and integrity, and respond appropriately to situation that involve abuse, unethical behavior, and coercion;
3) Recognize their own limits and seek appropriate support and consultation
4) Work collaboratively and effectively with colleagues and other members of health care teams
5) Manage effectively their commitments to work and their personal lives, taking the time to nurture important relationships, and themselves; and
6) Recognize the warning signs of emotional ill health and be able to ask for appropriate help.

**Attitudes:** Students should
1) commit to the life long process of developing and fostering self-awareness, personal growth, and well-being; and
2) be open to receiving feedback from others as to how their attitudes and behaviors are affecting their care of patients and their interactions with others.
Assessing Cultural Variations in End-of-Life Decision Making

From “Understanding Cultural Differences in Caring for Dying Patients, by BA Koenig & J. Gates-Williams, 1995, Western Journal of Medicine, Vol. 163, pp. 244-249 – Copyright 1985 by British Medical Group, - Permission needed.

- Assess the language that the patient and family use in discussing the illness and the disease, including the extent of openness with regard to the diagnosis, prognosis, and death.
- Determine the locus of decision making. Is it the individual patient, the family or another social unit?
- Solicit the patient’s and family’s views about the appropriate location and timing of death, including the preferred role of family members and healthcare providers.
- Assess the degree of fatalism or activism within the patient and family, is there acceptance regarding future events or a desire to control aspects of these events?
- Consider gender issues and power relationships within the decision-making unit.
- Assess religious beliefs of the patient and family, focusing on the meaning of death, the existence of an afterlife, and belief in miracles. Also establish beliefs about the body after death (e.g. Who owns the body and how is it to be treated?).
- Assess how hope is maintained within the family. How is hope negotiated with healthcare providers? What are the cultural meanings associated with maintaining hope?
- Consider sociopolitical and historical factors that influence beliefs about illness, healthcare, and death, such as poverty, refugee status, past discrimination, and issues related to access to health care.
- Solicit information from all possible sources within the community, including religious leaders and language interpreters. p. 1687

Guidelines for Physician Communication

Does your doctor:
  a) knock before entering the exam room?
  b) make eye contact?
  c) put you at ease?
  d) summarize your compliant and condition?
  e) avoid medical jargon unless immediately defined?
  f) encourage your questions?
  g) show respect and empathy?
  h) wash his/her hands before the physical exam?
  i) place the stethoscope directly on the skin, not on clothing? (Basler, 2006, p. 23)

Physician how to:
  a) communicator to sit down,
  b) speak gently and slowly,
  c) offer brief relies,
  d) resist interrupting and dominating the conversation,
  e) always go where the conversation goes,
  f) extraordinarily important to tolerate silence during such conversations,
  g) resist anticipating how the listener will react  (Banja, 2005, p. 38)

How physician’s can avoid a missed opportunity
  1) to listen and respond to family members
  2) acknowledge and address emotions
  3) explain key tenets of medical ethics and palliative care, including
      exploration of patient treatment preferences, explanation of surrogate
Potential Impact of Unexamined Physician Feelings of Patient Care and Physician Well-being

Impact on Patient Care

Poor-quality patient care
Failure to identify patient-specific and family-specific values influencing decisions
Incoherent care goals
Increased health care use and inappropriate use of life-sustaining medical technologies because of failure to engage in time-consuming decision processes, lack of clarity about care goals
Patient and family mistrust of health care system and medical profession
Avoidance leading to increased medical complications and length of hospital stay

Impact on Physicians

Professional loneliness
Loss of professional sense of meaning and mission
Loss of clarity about the ends of medicine
Cynicism, helplessness, hopelessness, frustration
Physician anger about the health system and the practice of medicine
Loss of sense of patient as a fellow human being
Increase risk of professional burnout, depression

Lessons for Medical Educators Supervising Physicians-In-Training
who care for Dying Patients.
(Formulated during a Study conducted at
two Medical Centers in Boston, Ma & Pittsburgh, PA, 1999-2001)

- Patient deaths that occur early in medical training are particularly emotionally powerful.
- Trainees differ from more senior physicians in how they experience patient deaths.
- Physicians-in-training may be more likely than experienced physicians to attribute a patient death to a lack of personal competence.
- Physicians-in-training may find patient deaths shocking or unexpected even when the death is the result of a common causes such as stroke of pneumonia.
- Physicians-in-training may experience feelings of guilt, trauma, and helplessness when caring for dying patients but not approach senior physicians for guidance.
- Caring for dying patients provides an opportunity for educators to promote self-reflection among trainees.

Strategies for compassionate end-of-life care in the intensive care unit.

1. Developing a personal relationship with death
   a. Making a personal relationship with the dying process
   b. Contemplate death and loss
   c. Develop comfort with the uncertainty of illness and death

2. Communication skills: being genuine and present
   a. Be genuine
   b. Manifest a compassionate presence
   c. Listen without distraction

3. Creating the proper environment
   a. Take the family to a separate room
   b. Do not abandon conversations to house staff
   c. Include nursing and house staff

4. Willingness to give up control
   a. Be willing to show discomfort
   b. Be willing to say, “I don’t Know”
   c. Allow the family to set the tone of communication
   d. Discover what patients and family members need
   e. Know when to gather the family together

5. Facilitating end-of-life decisions
   a. Evoke the patient’s wishes/encourage families to remember conversations with the patient
   b. Put yourself in the place of a family member
   c. Don’t abandon decisions-making to the patient and family
   d. Don’t be afraid to help the family make a decision
   e. Present what you would do

The essence of spiritual care, Table 6 Clusters of common themes

**Spirituality**
a) Personhood – values, beliefs, achievements  
b) Relationships – self, others, universe, a life force or God  
c) Search for meaning – the ‘big questions’, mortality  
d) Transcendence – something both beyond and within  
e) Religion – worship

**Prompts**
a) Personal experience – of life and its losses  
b) Dissatisfaction – with materialism  
c) Role of to others – their example and influence  
d) Spiritual awareness – ‘something other ‘ or God  
e) Vocation – the call/commitment to God  
f) Religious decline – in its organized forms  
g) Illness – its nature and meaning

**Spiritual care**
a) Personnel = a wide range of a caregivers  
b) Focus – on religious and non-religious spiritual needs  
c) Culture – acknowledgement of the cultural aspects of life  
d) The individual – affirmation of uniqueness and value  
e) Relationships – with family and others  
f) Being there – empathizing, valuing, listening and loving  
g) Respect – of the person to the point of death

**Difficulties**
a) Definition – varied understandings  
b) Service provision – patient throughout, cultural inappropriateness  
c) Delivery – focus on physical care, loss of human touch, spiritual care industry  
d) Personal challenges – to spiritual caregivers  
e) Lack of confidence – amongst health professionals

**Hopes**
a) Improvement – to do better, bring back the human touch  
b) Assessment – a more consistent approach  
c) Research – more concrete, national research  
d) Resources – increased provision,  
e) Training – recognition of spiritual issues, needs of religious groups  
f) Chaplaincy – more accessible, co-ordinating role, regional office (p.130)

Deborah Jo Corker  

7145 Jill Place, Anchorage, AK 99502  

phdcorker@aim.com  

Southern Illinois University Carbondale  
Bachelor of Science, Anthropology & Religious Studies, May 1979  

Fuller Theological Seminary, Pasadena, CA.  
Master of Divinity, May 1983  

Alaska Pacific University, Anchorage, AK  
Masters of Science, Counseling Psychology, Dec. 1996  

Dissertation Title:  

PHYSICIAN’S EXPERIENCES WITH DEATH AND DYING:  
A PHENOMENOLOGICAL STUDY  

Major Professor: Dr. Judy C. Drolet