12-2004

An Analysis of the End-of-Life Choices of Elderly Patients and their Healthcare Providers at a Community Hospital in Tennessee

Elizabeth Harder Dobbins
University of Tennessee - Knoxville

Recommended Citation

Dobbins, Elizabeth Harder, "An Analysis of the End-of-Life Choices of Elderly Patients and their Healthcare Providers at a Community Hospital in Tennessee. " PhD diss., University of Tennessee, 2004.
https://trace.tennessee.edu/utk_graddiss/2162

To the Graduate Council:

I am submitting herewith a dissertation written by Elizabeth Harder Dobbins entitled "An Analysis of the End-of-Life Choices of Elderly Patients and their Healthcare Providers at a Community Hospital in Tennessee." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Human Ecology.

James J. Neutens, Major Professor

We have read this dissertation and recommend its acceptance:

June Gorski, Diane A. Klein, Ralph G. Brockett

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

To the Graduate Council:

I am submitting herewith a dissertation written by Elizabeth Harder Dobbins entitled "An Analysis of the End-of-Life Choices of Elderly Patients and their Healthcare Providers at a Community Hospital in Tennessee." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Human Ecology.

James J. Neutens
Major Professor

We have read this dissertation
and recommend its acceptance:

June Gorski

Diane A. Klein

Ralph G. Brockett

Accepted for the Council:

Anne Mayhew

Vice Chancellor and Dean of
Graduate Studies

(Original signatures are on file with official student records.)

AN ANALYSIS OF THE END-OF-LIFE CHOICES OF ELDERLY PATIENTS AND THEIR HEALTHCARE PROVIDERS AT A COMMUNITY HOSPITAL IN TENNESSEE

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Elizabeth Harder Dobbins

December 2004

DEDICATION

This dissertation is dedicated to my family. To my husband, Darrell, who has tolerated (and survived) my latest adventure into higher education: Thank you for your patience and encouragement as I have rearranged our lives during the past years. To my children, Emily and John: You are truly my pride and joy and I am proud to be your mother. May you, too, realize your seemingly impossible dreams! I love you three dearly.

In loving memory of my parents.

ACKNOWLEDGEMENTS

The journey leading to this graduate degree was not a solitary one. I wish to thank those who excited and encouraged me to continue until I reached my goal. To the many professors teaching in the Department of Health and Safety Sciences who have crossed my path, especially Drs. Kirk and Pursley: Thank you for your encouragement and inspiration as I reentered the world of the university student. To my Committee Chair, Dr. Neutens: Thank you for taking on an unknown student and guiding her through the dissertation process. I have appreciated and will be forever grateful for your guidance and support. To Drs. Gorski and Klein: Thank you for your wise contributions to my study. I have learned much from both of you. To Dr. Brockett: Thank you for a most enjoyable trip into the world of Educational Psychology. I use the gifts you have given me every day.

I wish to express my sincere gratitude to the administration of Morristown-Hamblen Healthcare System for the opportunity to complete this project at the facility. I also wish to thank my wonderfully supportive colleagues at the hospital, especially Mrs. Jennie Morris, my mentor and inspiration, who practices nursing as it should be, both a science and an art.

ABSTRACT

The Patient Self-Determination Act of 1990 was expected to popularize the use of advance directives (living wills and durable powers of attorney for healthcare (DPOA-HC)). Since the law was passed, researchers have found that the use of the documents has not increased as expected and that the documents, when present, were not always respected by healthcare providers.

The purpose of this study was to analyze the end-of-life choices of elderly patients and their healthcare providers in a community hospital setting. The subjects of this study were 160 patients, aged 65 years and older, who died in a community hospital in Tennessee in 2002. Medical record data were abstracted using a modified form of the Chart Abstraction Instrument developed by Fins, Miller, Acres, Bacchetta, Huzzard, & Rapkin (1999). Chi square tests and binary logistic regression were used to analyze the data.

The findings of this study confirmed that the use of advance directives has not changed much over the past decade. Nearly 27% of the patients had living wills, 20.6% of the patients had a formal DPOA-HC, and an informal DPOA-HC was recognized by staff for 76.3% patients.

Healthcare providers were not influenced by the presence of any advance directive in their decisions involving the unit of treatment, use of life-sustaining treatments, or initiation of comfort care plans. Over half of the patients (56.3%) experienced pain during their last two days of life. More than one-quarter of the patients with pain were not treated with medications accepted as standard-of-care. Healthcare providers did appear to be influenced by the presence of a living will in their decisions to write do-not-resuscitate orders more often ($p < 0.05$) and use cardiopulmonary resuscitation less often ($p < 0.05$) for patients possessing the document.

Recommendations for future research included study replication using samples drawn from facilities in other regions of the country and the evaluation of educational initiatives for both healthcare consumers and healthcare providers. The continued development and implementation of evidence-based protocols was also recommended.

TABLE OF CONTENTS

LIST OF TABLES

TABLE PAGE

Chapter I

Introduction to the Study

The purpose of this chapter is to establish the need for and parameters of a study addressing how elderly people are dying in the United States today. A review of the literature has shown that a growing number of people are asking ethical and economic questions regarding the use of available high technology services at the end of their lives. The now middle-aged Baby Boomers are watching their parents die. They are witnessing that, although recent technological advances have made longer living possible, the quality of this longer life is often unacceptable. There is a growing demand to respect a person's autonomy regarding use or nonuse of sophisticated technology to extend life (Chambers, Diamond, Perkel, & Lasch, 1994).

The Patient Self-Determination Act (PSDA) of 1990 was enacted by Congress as an amendment to Title XVIII of the Social Security Act (Medicare). This amendment was addressed by the Omnibus Budget Reform Act and became effective on December 1, 1991. It is directed at health care facilities that receive Medicare or Medicaid funding and requires that those facilities (hospitals, skilled nursing facilities, home health agencies, or hospices) (Title 42, 1990):

1. Develop written policies respecting advance directives;
2. Document whether or not an individual has executed an advance directive in the patient's medical record;
3. Educate staff and the community about advance directives; and

4. Give patients written information about agency policies and the patient's right to prepare advance directives in accordance with the laws of the state in which the facility is located.

By 1992, all 50 states and the District of Colombia had passed legislation to legalize some form of advance directive (Hecht, 1996-2003).

The PSDA was passed by Congress in response to a national debate that began as a reaction to the unfortunate situations of two young women. Karen Ann Quinlan was 21 years old when she fell into a persistent vegetative state after she stopped breathing in 1975. Her family took their battle to remove the ventilator from Karen to the New Jersey Supreme Court. Although her father won the case on her behalf and the Court ruled that the mechanical ventilation could be stopped, she was able to breathe on her own for another ten years. She died in 1985 (Karen Ann Quinlan, n.d.).

The second situation involved a 25-year-old Missouri woman, Nancy Beth Cruzan, who, as a result of an automobile accident in 1983, also fell into a persistent vegetative state. After several years of watching her lie in a nursing home nourished only by a feeding tube, her family fought a battle through the court system to discontinue her feedings. Nancy's friends spoke on her behalf, reporting conversations they had had with her before her accident in which she had stated she would never want to live in a vegetative state. The United States Supreme Court ruled that mentally competent people have the right to make treatment decisions even when death is an outcome. Recognizing Nancy's conversations with her friends, the Justices wrote that individual states could respect clear and convincing evidence of a person's wishes. At that point, the State of Missouri dropped its opposition to the removal of her feeding tube. Nancy Beth Cruzan died a short time later (Tilden, 2000).

The PSDA has given all residents of the United States the power to make their end-of-life care wishes known to their families and healthcare providers. In response to the PSDA and public interest in end-of-life issues, a growing body of literature has emerged addressing how to provide a *good death* for terminally ill patients. Healthcare providers have long been interested in promoting quality of life for their patients. Recognizing that every person will die in time, physicians and nurses have realized that they have a tremendous opportunity to add quality not only to life, but, more specifically, to the end of life by addressing pain and symptom management and the use of unwanted technology.

This chapter begins with a discussion of the way hospitalized elderly are dying in our country today. The individual end-of-life situations that arise do so in direct response to the choices made by dying individuals and their healthcare providers. The following sections are included in this chapter: statement of the problem, need for the study, theoretical framework, basic assumptions, delimitations and limitations of the study, and definition of terms. A summary concludes the chapter.

Statement of the Problem

The purpose of this study was to analyze the end-of-life choices of elderly patients and their healthcare providers in a community hospital setting. In order to address the purpose of the study, the following research questions were formulated:

1. What is the likelihood that elderly patients will execute formal or informal advance directives?
2. What is the relationship between the presence of advance directives and the decision of healthcare providers to:
    a. Treat the patient in the intensive care unit (ICU)?
    b. Use life-sustaining treatments?
    c. Initiate the use of comfort care plans?
    d. Use cardiopulmonary resuscitation (CPR)?

Need for the Study

Over the past century, the human experience of dying has changed. Before the twentieth century, medicine could do little to extend life by preventing or curing illness. Dying, like being born, was considered a family, communal, and religious event, not a medical one. Most deaths occurred at home; most caregivers were family members (Institute of Medicine (IOM), 1997).

During the last century, death moved out of homes and into institutions. Deaths are now "medicalized" (Kyba, 2002, p. 141). In 1949, 49.5% of deaths occurred in institutions. By 1980 that number had risen to 74% (IOM, 1997). Advances in technology have prolonged life; in doing so, these same advances have prolonged death by allowing an existence beyond the point of a conscious, meaningful life (Tilden, 2000).

When asked, most people will say they want to die quickly in their sleep. The fact is that only 10% of people in this country will die suddenly. Most will die as a result of a slow decline, with episodes of organ or organ system failure (Modern Maturity, 2000). A recent study found that at least half of those who were dying experienced moderate to severe pain at least half of the time during their last three days of life. Many spent their last days in the intensive care unit receiving mechanical ventilation (SUPPORT Principal Investigators, 1995).

In the United States today, it is considered responsible to set money aside for a future retirement. The government mandates contributions to the Social Security system. In addition, many people participate in retirement plans through their places of employment. It is common to buy life insurance to take care of others after death.

It is not, however, customary in our society to plan for the process of death. Since the PSDA became effective in 1991, people in the United States have been given the legal means to accept or reject medical care in accordance with their wishes, whether or not they are physically or mentally able to speak for themselves (Goodwin, Kiehl, & Peterson, 2002). In spite of this opportunity to take control of their deaths, recent research has revealed that written advance directives were in place for only 1.5% (Eleazer, Hornung, Egbert, Egbert, Eng, Hedgepeth, McCann, Strothers, Sapir, Wei, & Wilson, 1996) to 20.4% (Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000) of subjects studied.

Unfortunately, even when advance directives were in place, researchers have found that they may not be respected. A survey of subscribers to a professional nursing journal revealed that 25% of nurses had seen other healthcare providers (either physicians or nurses) deliberately disregard a patient's advance directives when planning his or her care. When only nurses working in the intensive or critical care units were considered, those witnessing such an occurrence increased to more than 50% (Wolfe, 1998). A survey of physicians found that 34% had continued life-sustaining treatment despite patient or proxy wishes that it be discontinued (Asch, Hansen-Flaschen, & Lanken, 1995).

Last Acts, a national coalition promoting quality end-of-life care, published a national report card grading each state on their provision of end-of-life care. Their survey found that people in the United States "at best have no better than a fair chance of finding good care for their loved ones or for themselves when facing a life-threatening illness" (Last Acts, 2002, p. 3). The investigators polled 1,002 residents of the U.S. and found that for the total group, 60% rated care for the dying as fair or lower, including a quarter who rated it as poor. When reviewing specific states, the state of Tennessee was given a "D" based on the quality of laws addressing advance directives, an "E" based on the percentage of people over age 65 who spent seven or more days in the ICU during the last six months of life, and a "C" based on the percentage of nursing home patients in persistent pain (Last Acts, 2002).

Past researchers have designed studies aimed at better understanding how end-of-life decisions are made. Several of those studies have confirmed the discrepancy between the care dying patients would like to receive and the care they are being provided. Most of the studies have been conducted in large research and teaching hospitals in metropolitan areas. At present, there are no data to support the generalizability of past study findings to populations in other geographic and practice settings, including the community hospital. Researchers have recommended the study of the end-of-life choices of other populations of elderly and their healthcare providers as they may be significantly different from the choices made by populations found in metropolitan teaching hospital settings. It is with that recommendation in mind that this study has been designed and implemented.

Theoretical Framework

This research effort draws its support from two areas: the study of biomedical ethics supported by the theories of Kant and Mill and the emerging practice of evidence-based medicine (EBM). Respect for individual autonomy is a principle of biomedical ethics. It was the intent of the PSDA to “foster prospective autonomous decision-making, thereby reducing suffering and loss of individual dignity related to unwanted health care” (Collins, 1999, p. 29). The principle of individual autonomy is a basic foundation of the history and culture of the United States. Originally referring to the self-governance of ancient independent city-states, the word *autonomy* is derived from the Greek *autos* (“self”) and *nomos* (“rule,” “governance,” or “law”) (Beauchamp & Childress, 2001).

Respect for the autonomy of others provided the foundation for the theories of Immanuel Kant and John Stuart Mill. Kant argued that respect for autonomy flowed from the recognition that all persons have unconditional worth, each having the capacity to determine his or her own moral destiny. Mill argued that society should permit individuals to develop according to their convictions, as long as they do not interfere with the expressions of freedom by others (Beauchamp & Childress, 2001). Medical ethicists Beauchamp and Childress (2001) stated that, in today's context, personal autonomy can be interpreted to be:

> At a minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice. The autonomous individual acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories or sets its policies. (p. 58)

Kant equated the concepts of autonomy and self-determination (Suber, 1992). The authors of the PSDA cited the principle of self-determination as a "fundamental right of patients to accept or refuse medical treatment" (Levin, 1990, p. E943). Beauchamp and Childress (2001) concluded that "respect for autonomy is not a mere ideal in health care; it is a professional obligation" (p. 63).

This study is also grounded by the discipline of evidence-based medicine. EBM is defined as "the conscious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. Practicing evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research" (Sackett, Rosenberg, Gray, Haynes, & Richardson, n.d., p.1). The practice of evidence-based medicine has as its purpose the improvement of health outcomes (Schultz, 2004).

A major way in which EBM has impacted the practice of medicine has been through the development, dissemination, and use of clinical practice guidelines (Rosoff, n.d.). Evidence-based clinical practice guidelines have been published by the United States Government Agency for Healthcare Research and Quality, the Department of Defense and Veterans Administration, and by numerous medical and professional organizations around the world. Both society and courts of law agree that it has become the expected standard of care for healthcare providers to use evidence-based clinical practice guidelines to provide state-of-the-art care for their patients (Rosoff, n.d.).

Those providing care at the end of life have embraced their opportunity to provide a quality of life for those who are dying, allowing the dying to live until the moment of their death. The specialty care that reflects this philosophy is called *palliative care*. Palliative care has been defined as "the comprehensive management of physical, psychological, social, spiritual, and existential needs of patients, in particular those with incurable, progressive illnesses" (Vachon, 2001, p. 648).

Evidence-based guidelines have been developed for the practice of palliative care by the National Consensus Project for Quality Palliative Care. The National Consensus Project is a consortium of the following organizations: American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, Hospice and Palliative Nursing Association, Last Acts Partnership, and National Hospice and Palliative Care Organization. Representing 20 years of research, the guidelines were developed in response to the urgent need for high quality palliative care for our aging population with serious, chronic and advanced illnesses. The National Consensus Project (2004) defines the goal of palliative care as:

> To relieve suffering and to support the best possible quality of life for patients with advanced chronic and life-threatening illnesses and their families. (Palliative care) focuses on treating pain, symptoms and stress, providing support for daily living, helping patients and families make difficult medical decisions and ensuring that patient and family wishes for care are followed. (Fact Sheet)

This care specialty is growing rapidly in both the medical and nursing professions.

Basic Assumptions

The following assumptions were made regarding this study:

1. The formal and informal advance directives of the patients were accurately recorded in the patients' medical records.
2. The "Chart Abstraction Instrument" (Fins, Miller, Acres, Bacchetta, Huzzard, & Rapkin, 1999) used to collect data from the medical record was valid and reliable.
3. The chart entries made by healthcare providers were accurate, truthful, and complete.

Delimitations

This study was delimited to elderly patients who had died in a community hospital and to the healthcare providers practicing in that community hospital during the study period.

Limitations

This study was limited by a lack of control over the manner in which the healthcare providers wrote their reports. There may be omissions of data which may have injected bias.

Definition of Terms

For the purposes of this study, the following terms were operationally defined:

Advance Directives (Formal): Written legal documents (generally living wills and durable powers of attorney for healthcare (DPOA-HC)) that expressed a person's preferences for end-of-life care and designed to guide medical treatment should the person become incompetent to make his or her own end-of-life choices.

Advance Directives (Informal): Patient or proxy preferences directing end-of-life care that were not formalized in a living will or durable power of attorney for healthcare; an informal durable power of attorney for healthcare. Preferences were communicated to healthcare providers during the hospitalization and documented by the providers of care in the Physician's Progress Notes or Nurses' Notes in the patient's medical record.

Comfort Care Plan: A medical plan of care that accepted the patient's terminal prognosis and promoted aggressive pain management, but discouraged cardiopulmonary resuscitation, antibiotic administration, routine blood draws, mechanical ventilation, and artificial nutrition and hydration unless it was desired by the patient or proxy to promote the comfort of the patient. If a comfort care plan was in place, documentation was found in the Physician's Progress Notes in the patient's medical record.

Community Hospital: A hospital serving a group of people living in the same locality, in this case a 155-bed multi-service hospital which served a primarily rural five county area in Tennessee.

Durable Powers of Attorney for Healthcare: A written advance directive that designated another person (proxy) to make decisions about medical treatment in the event that the person writing the advance directive was unable to make such decisions.

Elderly Patients: Patients admitted to the hospital age 65 or older.

End–of-Life Care: Care provided to patients by healthcare providers at the end of life.

End-of-Life Choices of Healthcare Providers: Choices made by the physicians and nurses directing and implementing medical treatment at the end of the patient's life. This information was documented in the Physician's Orders and Nurses' Notes in the patient's medical record.

End-of-Life Choices of Patients: Care preferences for end-of-life care conveyed to the healthcare providers either by the patient or the proxy and documented in the medical record. These choices were communicated in either formal or by informal advance directives.

Healthcare Providers: Physicians and nurses providing care to the patient.

Informal Durable Power of Attorney for Healthcare: A person (or persons) without formal legal responsibility for the patient who was (were) recognized by healthcare providers as speaking on behalf of the patient. Input into care decisions was documented in the Physician's Progress Notes or in the Nurses' Notes.

Living Will: A written advance directive that allowed a person to state his or her wishes about accepting or refusing life-sustaining medical treatments in the event of a terminal illness.

Terminal Hospitalization: The episode of hospitalization that began with admission to the hospital and ended with the death of the patient.

Summary

This chapter addressed the need for continued analysis of the situation regarding the care being provided to elderly patients at the end of their lives. The current study was designed to determine whether or not patients were exerting their autonomy by executing formal advance directives in advance of or during their terminal hospitalization. It was also designed to analyze whether or not the end-of-life choices of patients were being respected. Need for the study was established through a review of the literature which revealed that the majority of patients in large teaching hospitals did not have written advance directives in place. The literature review also revealed that even when advance directives were present, some caregivers did not respect the end-of-life choices of patients.

This chapter presented the statement of the problem, the need for the study, theoretical framework, basic assumptions, delimitations and limitations of the study, and definitions of terms. The remainder of this study is organized as follows:

Chapter II: Review of Related Literature
Chapter III: Method and Procedures
Chapter IV: Analysis and Interpretation of the Data
Chapter V: Summary of Findings, Conclusions, and Recommendations

Chapter II

Review of Related Literature

Prompted by popular interest, researchers have been busy searching for the elements of a *good death*. This review of related literature presents literature and research conducted to determine what patients want at the end of their lives and what healthcare providers can do to facilitate a good death for their elderly, terminal patients. In the first section, Research and Literature Related in Content, the concepts of death with dignity and quality of life are discussed. The second section, Research Related in Content and Methodology, presents studies identifying the factors that contribute to a good death, the characteristics of those who complete advance directives, and the impact of advance directives on patient care. Research Related in Methodology, the third section, presents examples of research utilizing the retrospective record review to gather data investigating other phenomena. A summary concludes this chapter.

Research and Literature Related in Content

The purpose of this section of the literature review is to discuss the research and literature related to the study in content. This section discusses two seemingly contradictory concepts: Death with Dignity and Quality of Life. This section begins by presenting information from the Institute of Medicine's (IOM) comprehensive publication that urges healthcare professionals to redefine how they care for their dying patients (IOM, 1997). By facilitating a death with dignity, it is possible for healthcare providers to maintain a quality of life to the very end of life.

Death with Dignity

The Institute of Medicine (1997) reviewed the existing literature and research addressing the process of dying in the United States today. The purpose of the project was to strengthen the popular and professional understanding of what constitutes good care at the end of life and to encourage a wider societal commitment to "caring well" (pp. 1-2) for people as they die. The IOM committee identified four broad deficiencies in the current care of people with life-threatening and incurable illnesses (1997):

1. Too many people are suffering needlessly at the end of life, from errors of omission (when healthcare providers fail to provide palliative and supportive care known to be effective) and errors of commission (when healthcare providers do what is known to be ineffective or even harmful).
2. Legal, organizational, and economic obstacles obstruct reliably excellent care at the end of life. Laws regulating drug prescriptions are outdated and misinterpreted by state medical boards, in turn intimidating and frustrating physicians who are trying to effectively relieve their patients' pain. Also, incentives remain in place leading physicians to overuse available procedural services.

3. Physicians and other health care professionals continue to graduate without the knowledge, attitudes, and skills required to care for the dying patient.
4. Current knowledge and understanding of the end stages of diseases and the physiological bases of symptoms is insufficient to support the consistent practice of evidenced-based practice at the end of life. Past research has focused almost exclusively on the development of knowledge contributing to the prolongation of life.

The IOM (1997) has defined a *good death* as one that is:

> Free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards. A *bad death*, in turn, is characterized by needless suffering, dishonoring of patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended. Bad deaths include those resulting from or accompanied by neglect, violence, or unwanted and senseless medical treatments. (p. 24)

The term *death with dignity* has been interpreted in several ways. To some it implies the right to request and receive physician intervention to promote the dying process. To others it implies dying accompanied by "respectful and skillful caregiving" (IOM, 1997, p. 25). To still others it implies a death free from the physical and psychological discomforts often associated with dying. According to the IOM (1997), death with dignity is a worthy and achievable goal.

Toward that end, the IOM committee redefined death with dignity as end-of-life care that honors and protects those who are dying and helps them to preserve their integrity while coping with unavoidable losses and physical insults.

Quality of Life

When healthcare providers deliver end-of-life care that promotes death with dignity, they add quality of life to the patient's remaining days of life. Researchers have found that people with life-threatening illnesses are not so much afraid of dying, as they are afraid they will not be able to live until they die (Super, 2001).

The concept of quality of life emphasizes health as perceived and valued by people for themselves. Quality of life is multidimensional and includes the domains of physical, psychological, social, and spiritual well-being of the patient before death and of the family before and after the patient's death (Ferrell, 1995). The physical domain includes the patient's functional ability, strength, and symptoms such as pain, nausea, dyspnea, and constipation. The psychological domain includes the patient's perceived control, level of anxiety, depression, fear, and cognition. The social domain includes caregiver burden, roles and relationships, and perceived appearance. The spiritual domain includes the patient's religiousity and suffering.

The dying patient's quality of life is promoted by quality end-of-life care. Good quality end-of-life care is also a multidimensional construct that is best characterized as individualized care that is holistic in nature and strives to ensure optimal functioning as death approaches (Thompson & McClement, 2002). To deliver quality care at the end of life, healthcare providers must acknowledge the values and preferences of patients and their families. This communication of the end-of-life wishes of the patients is achieved through a process of shared decision-making between patient, family, and caregiving staff (Steinhauser, Clipp, McNeilly, Christakis, McIntyre, & Tulsky, 2000).

The popular press has begun to address the healthcare consumer's right to quality care at the end of life. A *Time* magazine article (Cloud, 2000) reported that available technology can extend the length of life but cannot extend the quality of life. Recognizing this, many people are taking control of their own lives through the execution of advance directives. According to a Time/CNN poll, 55% of those over 65 year-old have advance directives in place. The poll found, however, that only 6% of those people worked with a doctor to prepare the document.

An article in *Modern Maturity* (2000) cited a lower figure. Although 75% of people in this country say they are in favor of advance directives, it was reported that only 30-35% have advance directives in place. The article also reported that an estimated 35% of the people who have advance directives could not find them when needed. The authors cautioned the reader that without an advance directive, the hospital staff is legally bound to do everything to keep a person alive as long as possible, or until a family member decides otherwise. They recommended starting the conversation outlining end-of-life choices with family and physician while still enjoying good health to ensure the end-of-life care given is the end-of-life care desired.

Encouraging and then enabling patients and families to express their wishes regarding end-of-life care is a part of promoting the experience of dignity and respect. Soliciting and then respecting the end-of-life wishes of patients regarding the provision of pain medication, cardiopulmonary resuscitation (CPR), or placement on the ventilator are paramount in providing quality end-of-life care.

In summary, the Institute of Medicine reviewed research and literature addressing end-of-life care in the United States today and observed: needless suffering among patients; overuse of procedural services; lack of physician knowledge, attitudes, and skills; and insufficient knowledge and understanding of end-of-life symptoms by all healthcare providers (IOM, 1997). The IOM has recommended facilitating a death with dignity for dying patients that recognizes and respects the physical, psychological, social, and spiritual needs and wishes of those who are dying. Although seemingly contradictory, death with dignity and quality of life are related constructs. Care that promotes death with dignity also promotes quality of life during the remaining days of life, allowing patients to live their life as fully as possible until they die.

Research Related in Content and Methodology

The purpose of this section is to present the research related in content and methodology. This section has been divided into three subsections. The first subsection, Factors Identified as Contributing to a Good Death, presents the research of several groups of investigators and offers the patients' perspective of end-of-life care. Through interviews and surveys, investigators have elicited responses from their subjects, identifying the broad domains that define quality end-of-life care. In the second section, Characteristics of Those Who Complete Advance Directives, the research of those investigating the demographic profile of people who complete advance directives is presented. The third section, The Impact of Advance Directives on Patient Care, presents important studies investigating how healthcare providers are caring for the elderly and dying. The retrospective record review has been used by many researchers to collect data for their analyses of the use of advance directives and the impact advance directives have on patient care.

Factors Identified as Contributing to a Good Death

Singer, Martin, and Kelner (1999) surveyed chronically ill patients in search of quality end-of-life care. The objective of their study was to fill a void in the research by identifying and describing elements of quality end-of-life care from the patient's perspective. Their subjects were 126 participants who were dialysis patients, people with human immunodeficiency virus (HIV), or residents of a long-term care facility. In-depth interviews were conducted face-to-face. The dialysis and HIV patients were asked questions addressing whether they had initiated advance directives or advance care planning. The long-term care residents were asked questions related to their perceived control over decision-making at the end of life. Content analysis of the interviews identified five domains of quality end-of-life care. They were: (1) avoiding inappropriate prolongation of dying (61.1%); (2) strengthening relationships with loved ones (38.9%); (3) achieving a sense of control (38.1%); (4) relieving burden on their loved ones (provision of their physical care, witnessing their death, and substitute decision making for life-sustaining treatments) (38.1%); and (5) receiving adequate pain and symptom management (22.2%).

Steinhauser, Clipp, McNeilly, Christakis, McIntyre, and Tulsky (2000) also identified domains that healthcare providers may address to ensure the quality of end-of-life care. The investigators utilized focus groups comprised of patients, families, and providers to gather descriptions of the components of a good death. Discussions and in-depth interviews were conducted over a four-month period with 75 participants including physicians, nurses, social workers, chaplains, hospice volunteers, patients, and recently bereaved family members. All were recruited from a university medical center, a Veterans Affairs (V.A.) medical center, and a community hospice. Interviews were audiotaped, transcribed, and coded. During the coding, four investigators independently read the transcripts and analyzed them for common and recurrent themes pertaining to the qualities of a good death. More than 70 attributes were collapsed into six broad domains. Six clear themes emerged. Participants desired opportunities for pain and symptom management, clear decision making, preparation for death, completion of activities, contributing to others, and affirmation of their whole person.

Recognizing that patients want to prepare for their end of life, Fried, Bradley, Towle, and Allore (2002) conducted a study that evaluated the desire of patients to weigh the burden of treatment options against possible negative outcomes. To do this, investigators administered a questionnaire to 226 subjects age 60 years or older. Subjects had a limited life expectancy due to cancer, congestive heart failure, or chronic obstructive pulmonary disease. They were recruited from the outpatient clinics of two V.A. hospitals, medical practices in the metropolitan areas of southern Connecticut, and inpatient units of a university teaching hospital, a community hospital, and a V.A. hospital. The subjects were asked whether they would want to receive a given treatment in four situations. The risk of adverse outcomes increased over the four scenarios. In the first scenario, the outcome was known with certainty. The likelihood of functional or cognitive impairment increased over the next three scenarios. For all scenarios, the outcome without treatment was specified as death from the underlying disease. Frequencies were used to describe the characteristics of the study population and the subjects' treatment preferences according to the diagnosis. Chi square tests were used to determine the significance of differences in preferences when the scenarios had a dichotomous outcome. The log-rank test was used to determine the statistical significance of differences in preferences as the likelihood of adverse outcome increased across the four scenarios.

Study participants had a mean age of 72.8 years. For the choice between a low burden treatment that would restore the participant's current state of health and no treatment, 98.7% of subjects stated that they would want the treatment. For scenario 2 in which the burden of treatment was higher, 11.2% of subjects who wanted to receive the treatment in scenario 1 did not want the treatment in scenario 2. For scenarios 3 and 4, in which the burden of treatment was low but the outcome was survival with impairment, 74.4% and 88.8% of subjects, respectively, who wanted the treatment in scenario 1 no longer wanted it. Preferences did not differ according to diagnosis. According to the investigators, their findings suggested that the possibility of functional or cognitive impairment played a greater part than mortality in the preferences of seriously ill patients. They concluded by stating that the provision of care at the end of life should honor the preferences of patients. Advance care planning should take into account the patients' attitudes toward the burden of treatment and the likelihood of each possible outcome (Fried, et al., 2002).

Nahm and Resnick (2001) also addressed treatment burden in their study. Rather than address possible broad domains of end-of-life care, these investigators evaluated the patient acceptance or rejection of the specific treatment components of traditional living wills. Subjects were 191 older adult residents of a continuing care retirement community who had reported their treatment preferences the year before. The subjects were asked if, in the event of medical necessity, they were willing to receive CPR, have major surgery, receive mechanical ventilation, artificial nutrition or hydration, undergo diagnostic tests, receive antibiotics, or receive pain medication. A total of 140 subjects completed surveys two years in a row. Investigators utilized descriptive statistics to consider demographics, cognitive status, health status, the number of chronic illnesses, and the end-of-life preferences of subjects. Correlations were carried out to test the relationship between the end-of-life preferences, age and gender, health status, and number of chronic illnesses. Chi square tests were used to determine differences in advance directives between the two years of surveys.

Results from the second survey showed that the majority of subjects were female, unmarried, with a mean age of 85.3 years. The majority of subjects did want to receive antibiotic treatment (95%), undergo diagnostic testing (94%), receive pain medications as needed (84%), receive blood transfusions (71%), and undergo major surgery, if needed (55%). Just over one-third (36%) wanted to receive artificial hydration and nutrition, 15% wanted it started but stopped if there was no improvement, and 40% did not want to receive any hydration or nutrition at all. Approximately one-half of subjects did not want CPR (53%), to receive mechanical ventilation (49%), or to undergo dialysis (51%). Comparing the second survey with the first, there was a statistically significant increase (although slight) in the percentage of subjects who wanted CPR or to receive blood. There was a slight decrease in the percentage of those who wanted to be placed on mechanical ventilation (Nahm & Resnick, 2001).

Characteristics of Those Who Complete Advance Directives

Inman (2002) designed a descriptive study to determine the reasons given by a convenience sample of older adults for discussing or completing advance directives. A total of 55 adults, aged 50 and older participated in the study. Participants completed an investigator-constructed self-report questionnaire containing 31 open- and closed-ended questions addressing participant experiences with advance directives. The questionnaire was pilot tested, establishing its readability, clarity, and content validity. The investigator also collected demographic information about the subjects. The mean age of the participants was 70. Eighty percent of the subjects were women; the majority of the subjects were white (89%). Almost half had completed high school (47%). Most participants (78%) reported having discussed their end-of-life wishes with someone, most frequently their child or children (58%). The most prominent motivating factor influencing participants to discuss their end-of-life wishes with others was the death or serious illness of a friend or significant other (27%).

Hamel, Guse, Hawranik, and Bond (2002) interviewed a convenience sample of community-dwelling older adults in Canada to determine whether an individualized intervention would lead to increased completion of advanced directives. The investigators used an experimental posttest only control and randomized group design to evaluate the effect of a phone call that responded to questions about advance directives and offered more information. All potential subjects attended an educational session addressing advance directives. Seventy-four older adults volunteered for the study. Study participants were randomly divided between control and intervention groups. Participants in the intervention group received a phone call from the investigator one month after the educational session to ask if they had any questions about advance directives and to offer more information. At the end of the three-month study period, all study participants in both groups received a follow-up phone call to see whether they had completed advance directives or had discussed their wishes with someone.

The mean age of the participants was 72.6 years. There were no significant differences between intervention and control groups in demographic characteristics. Of the 74 subjects, 19 (25.7%) completed advanced directives (12 in the intervention group and 7 in the control group). Of the 72 participants who provided responses, 28 in the intervention group and 22 in the control group reported talking to someone about advance directives. Bivariate comparisons indicated no significant differences between the intervention and control groups for the completion of advance directives. There was, however, a significant positive relationship between the discussion of advance directives with someone and the subsequent completion of the written document. Content analysis revealed perceived barriers to the completion of advance directives to be: a present orientation to life and a tendency toward procrastination (62.3%), a reluctance to think about one's death (18.9%), trusting others to decide (11.3%), feeling healthy (11.3%), and needing help (5.7%). Of the 19 participants who completed advance directives, reasons for doing so included wanting to be in control of those decisions (52.6%), wanting others to know the type of care they desired (31.6%), wanting to decrease the burden on loved ones (15.8%), having no relatives (10.5%), and having witnessed the suffering or death of a loved one (10.5%). The investigators also noted that, for the total sample, those individuals who had more medical conditions tended to want to complete or had completed advance directives (27.8%) (Hamel, et al., 2002).

Mezey, Leitman, Mitty, Bottrell, and Ramsey (2000) surveyed patients discharged from four tertiary care hospitals in New York to determine the characteristics of patients who did or did not execute advance directives. Patients were excluded from the study if they were younger than 18 years old, unable to answer questions in either English or Spanish, admitted to obstetrics, gynecology, psychiatry, or drug and alcohol services, and admitted from or discharged to a nursing home. The investigators administered the Patient Survey Instrument developed for the study by telephone to 1,016 eligible patients discharged from the four hospitals within the previous three months. The instrument collected basic demographic data and explored three content areas: knowledge about advance directives before hospitalization, recall of receiving information about directives while in the hospital, and reasons for having or not having an advance directive. In addition to the patient survey, in-depth interviews with hospital nurses, physicians, patient representatives, social workers, admission personnel, and administrators were conducted. Percentages for each response were computed for the total sample. Chi square tests were used to compare proportions among the various subgroups.

The mean age of the sample was 52 years. Of the 1,016 patients, 207 (20.4%) had advance directives at the time of the survey. Almost half of the directives were formulated during or since the hospitalization. Of those patients with advance directives, 187 (90.3%) were English speaking; 17 (8.2%) spoke Spanish. White respondents were more likely than black or Hispanic respondents to have an advance directive. Patients who were Hispanic, Spanish-speaking, had a high school education or less, low income, and no health insurance were significantly less likely to have advance directives when compared with white, English-speaking, college-educated patients with higher incomes and health insurance. The reasons for writing advance directives given most frequently by the patients that had them were: wanting to make up their own mind (92%); the desire to help their family by letting them know what they wanted (89%); the desire for peace of mind (85%); and not wanting to be kept alive with tubes, wires, or in a coma (81%). Among those patients without advance directives (n = 779), 47% thought they needed more information, 38% thought that their family should decide what to do, and 33% thought that they were too sick to think about it. After reviewing their findings, the investigators suggested that level of education rather than race was the most important factor in differentiating among patients who did or did not execute advance directives (Mezey, et al., 2000).

In a study designed to determine the use of living wills at the end of life, Hanson and Rodgman (1996) relied on data from the 1986 National Mortality Followback Survey, a 1% random sample of all U.S. death certificates for persons aged 25 years and older. Information was collected on the use of living wills, social and health status, and use of medical services for 13,883 patients. Decedents with and without living wills were compared for differences in age, gender, race, education, income, and insurance status. They were also compared on health status, cognitive impairment, and primary cause of death. Univariate comparisons were made using Chi square tests for categorical variables and two-tailed *t* tests for continuous variables. To identify independent predictors of living wills, all sociodemographic and health status variables were included in a logistic regression model in which the presence or absence of a living will was the dependent variable. Associations between having a living will and the use of health services were also determined.

Only 9.8% of the subjects had prepared living wills prior to their deaths. Rates of completion of advance directives were higher for decedents who were white (10.7%), female (11.0%), had private insurance (13.8%), had higher incomes (14.5%), or had a college education (18.7%). The use of living wills was lower among blacks (2.7%), Medicaid recipients (6.3%), those with lower incomes (7.5%), and those with less than eight years of education (4.0%). Functionally independent persons were less likely to have a written a living will; frequency of use increased with dependency. Cognitive impairment made it less likely that the person had a living will (6.7%). Persons who died of cancer (16.4%) or pulmonary diseases (11.4%) were more likely to have one. Controlling for health status, the investigators found that decedents with living wills were half as likely to receive CPR or ventilatory support. The investigators justified the use of this pre-Patient Self-Determination Act data by stating that more recent data shows only a minimal increase in the acceptance of living wills and similar demographic patterns of use (Hanson & Rodgman, 1996).

Eleazer, Hornung, Egbert, Egbert, Eng, Hedgepeth, McCann, Strothers, Sapir, Wei, and Wilson (1996) specifically assessed the relationship between ethnicity and advance directives in a sample of frail elderly. Subjects were drawn from participants in a national demonstration project, Program of All-Inclusive Care for the Elderly (PACE). A total of 1,193 older adults participated. All participants met state criteria for nursing home level of care. The ethnic heritage of subjects was 385 non-Hispanic whites, 364 blacks, 156 Hispanics, and 288 Asians. Investigators determined the presence or absence of advance directives (living will or durable power of attorney for healthcare (DPOA-HC)) or health care wishes (verbally expressed wishes about end-of-life decisions) for all subjects. Quantitative variables were assessed using the Student *t* test or ANOVA. Comparisons of the proportion of patients with expressed health care wishes in each ethnic group were made using Chi square tests. The impact of demographic variables on the decision to express health care wishes was evaluated using multiple logistic regression analysis.

The average age for study participants was 79 years. Seventy-three percent of subjects were female. More than three quarters (77.2%) of the subjects had documented health care wishes in their records; most, however, were informal verbal expressions of their directives. Considering formal declarations of advance directives, only 12% were expressed as a written DPOA-HC, 20% had designated a health care proxy, and only 1.5% had written a living will. The investigators found that nearly all of the Asians (95.5%), 76.4% of the whites, 80% of the blacks, and 39.1 % of the Hispanics had recorded healthcare wishes in their chart. Blacks, however, rarely used legal instruments. Use of the durable power of attorney for healthcare was most common among white patients and healthcare proxies were most common among Asians. More than 95% of Asians but only 41% of Hispanics specified a code status in their health care wishes. More than 80% of Asians but only 16% of Hispanic patients requested a do-not-resuscitate (DNR) order; in contrast, 19% of blacks, 10% of whites, and 3.9% of

Hispanics requested a “full code.” In reviewing their findings, the investigators noted that blacks were particularly unlikely to select written health care instruments such as living wills and durable powers of attorney when compared with whites and Asians. Blacks were most likely to select aggressive inventions. Hispanics were most likely to refuse to give any form of advance directives. Investigators attributed this to the importance of religiosity as well as the importance of the daughter as primary caregiver. White subjects were most likely to have written advance directives. They were less likely to have selected a surrogate to express their health care wishes. Whites selected “no code” more often than blacks or Hispanics, but less often than Asians. Asians (mostly Chinese) were reluctant to sign legal written documents; this was thought to be a reflection of the cultural importance the Chinese place on the honor of verbal agreements. The investigators concluded that ethnicity has a significant impact on each patient’s choices and may be more important than other sociodemographic factors (Eleazer, et al., 1996).

The Impact of Advance Directives on Patient Care

The landmark study, The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (SUPPORT Principal Investigators, 1995), identified that there was much room for improvement in how patients died. With the objective of improving the end-of-life decision making opportunities for patients and reducing the frequency of a mechanically supported, painful, and prolonged death, the investigators designed a two-part study. Phase I was a two-year prospective observational study that included 4,301 patients. Phase I was followed immediately by Phase II, a two-year controlled clinical trial with 4,804 patients and their physicians. Phase II patients and physicians were randomized by specialty group; there were 2,652 patients assigned to the intervention group and 2,152 assigned to the control group. All subjects were patients in one of five teaching hospitals in the United States and in the advanced stages of one or more of nine illnesses any time from 1989 to 1991. Data were collected by reviewing the medical record retrospectively for discussions or decisions concerning issues such as the use of dialysis, withdrawal from the ventilator, and initiation of DNR orders. Interview data were also gathered from patients and designated surrogates twice during the hospitalization. Surrogates were interviewed again after the patient's death. The interview process collected information on patient demographics, functional status, self-assessed quality of life, communication with physicians, frequency and severity of pain, satisfaction with medical care, and the patient's preferences for CPR. Phase II interventions were aimed at improving communication and decision-making by providing timely and reliable information regarding the patient's prognosis and by determining and documenting patient and family preferences and understanding of the disease prognosis and treatment. A specially trained nurse coordinated and facilitated the discussions.

Investigators chose five measures to evaluate the intervention. They were: (1) the timing of the written DNR order, (2) patient and physician agreement on preferences to withhold resuscitation, (3) days spent in the intensive care unit

(ICU), (4) frequency and severity of pain, and (5) hospital resource use. Regression analyses were performed to interpret the data. Data analysis revealed that Phase I patients had a median age of 65 years. Thirty-one percent of Phase I patients preferred that CPR be withheld, but only 47% of their physicians reported knowing this preference. Nearly half (47%) of those who indicated a desire for CPR to be withheld did not have a DNR order written during their hospitalization. Nearly one-third (29%) of those patients died before discharge. Of those Phase I patients who died during their hospitalization, 79% did have a DNR order in place. Many of the DNR orders (46%), however, were written within two days of death. Among all patients who died during Phase I, the median number of days spent in an ICU, comatose, or receiving mechanical ventilation was eight. More than one-third (38%) spent at least ten days in the ICU and 46% received mechanical ventilation within three days of death. Conscious patients reported that they were in moderate to severe pain at least half of the time. During interviews conducted after the patient died, surrogates reported that 50% of conscious patients experienced moderate or severe pain during their last three days of life at least half the time (SUPPORT Principal Investigators, 1995).

During the intervention phase of the study, the SUPPORT nurse communicated with both the patient and the physician about the patient's prognosis, pain, likely outcomes, resuscitation, or advance directives. Phase II results did not differ significantly with the results of Phase I. The prevalence and timing of DNR orders was the same for both intervention and control groups. The number of days spent in an ICU, comatose, or receiving mechanical ventilation also did not differ significantly between intervention and control groups. When compared with the control group, reported pain actually increased for the intervention patients and surrogates. The investigators concluded that they “are left with a troubling situation. The picture we describe of the care of seriously ill or dying persons is not attractive” (p. 1597). They went on to say that their vision was one where, when confronted with a life-threatening illness, the patient and the family would be included in the discussions with the physician, realistic estimates of prognosis would be considered and valued by all, pain would be treated, and dying would not be prolonged (SUPPORT Principal Investigators, 1995).

Fins, Miller, Acres, Bacchetta, Huzzard, and Rapkin (1999) utilized a retrospective record review to describe the pattern of end-of-life decision-making by hospitalized dying patients and their healthcare providers. The charts of 200 of 205 patients that died at a large, urban teaching facility in New York City during the first four months of 1996 were abstracted using an 83-item investigator-constructed instrument. The instrument was pilot tested; validity and reliability were established. The instrument gathered data including demographic statistics and the main outcome measures which were identified as recognition of the patient as dying, presence and timing of DNR orders, and presence of comfort care plans. In determining the presence of comfort care plans, the following items were audited: the use of antibiotics, blood draws, mechanical ventilation, and artificial nutrition and hydration. Chi square tests and logistic regression were used to analyze the relationships between the dependent variables (DNR, recognition of the patient as dying, and comfort care plans) and the independent variables (age, gender, race, insurance status, the presence of a prior physician-patient relationship with the attending physician, primary diagnosis, presence of health care proxy, patient preferences, capacity on admission, length of stay, and unit of admission).

The mean age of the patients was 68 years of age. The majority of patients (60%) suffered from cardiovascular diseases or cancer. Decision-making capacity on admission was noted for 62% of the patients; however, 71% of these patients lost capacity during their hospitalization. Seventy-seven percent had a prior physician-patient relationship. Fifty-five percent of the patients were admitted or transferred to the intensive care unit. The mean length of stay in the ICU was 10.7 days; 41% of the patients died there. Forty-six percent of the patients were placed on a ventilator at some time during their hospitalization; 37% died while on the ventilator. Artificial nutrition and hydration were provided for 30% of the patients. Only 13% of those patients on the ventilator and 19% of those patients receiving artificial nutrition and hydration were withdrawn from those life-sustaining treatments prior to death. Thirteen percent of the patients had DNR orders in place prior to admission, 77% of the patients had orders in place prior to death, and 90% of patients with a length of stay longer than three weeks had DNR orders in place. Twenty-five percent of all patients underwent CPR prior to death. Comfort care plans were put in place a mean of 15 days after admission; the overall mean length of stay was 17 days. Antibiotics were provided for 41% of the patients; 30% of the patients received routine diagnostic or monitoring blood draws. Morphine infusions were begun on 31% of all patients prior to death; the mean length of time on a morphine infusion was 67 hours (Fins, et al., 1999).

Advance planning and evidence of patient preferences were significantly associated with end-of-life decision-making. A health care proxy (DPOA-HC) was completed by 28% of all patients. Almost all of these patients had a DNR order (94.6%). Seventy percent of these patients also had a comfort care plan in place as compared with only 37% of those patients who did not have evidence of advance directives (Fins, et al., 1999).

Hammes and Rooney (1998) utilized a retrospective record review to document the effectiveness of an extensive, collaborative education program addressing advance directives that was conducted approximately two years prior to their study. Participants in the study included two nonuniversity, nonprofit teaching hospitals, three medical clinic systems, six nonprofit long-term care facilities, three nonprofit home health agencies with hospice programs, and a county health department with home care. Excluded from the study were decedents with age less than18 years, those who lacked mental competence, and those who died outside the care of the participating healthcare organizations. All eligible decedents were included in the study. Data collection included the decedent’s exposure to advance directive education and the presence of an oral and/or written advance directive. The decedent’s physician and proxy were also contacted for survey or interview. Data were coded and univariate and multivariate analyses were performed using either parametric or nonparametric methods, depending on the variable.

A total of 540 decedents qualified for the study. The mean age was 82 years. Four hundred fifty-nine of the decedents (85%) had written advance directives. Almost all of these (81%) were found in the decedent's medical record; the other 22 documents were identified through interviews with the identified proxy. A power of attorney for health care was used by 77% of the decedents. Decedents who did not have written advance directives were younger, more likely to die of sudden causes, and more likely to die in a hospital. Among those with written advance directives, the most common reason given not to use life-sustaining treatments was a permanent change in quality of life (35%). The next most common reasons were limited survival (17%), death expected soon despite treatment (12%), the possibility of a persistent vegetative state (9%), and if the burdens outweighed the benefits (9%). A request that CPR not be attempted at some point was included in the directives of 271 of the decedents. Comfort care was requested in 209 documents and pain management was requested in 185. Aggressive treatment was limited near the time of death for 528 (98%) of the decedents. Treatment preferences expressed in the decedents' advance directives were consistently followed by the physicians. Investigators determined that 53% of the decedents had been exposed to advance directive education and credited the program with the increased prevalence of advance planning and the number of documents in the medical records (Hammes & Rooney, 1998).

In summary, this section presented research related to the study in content and methodology. This section had been divided into three subsections. The first subsection, Factors Identified as Contributing to a Good Death, presented the findings of researchers investigating the elements of quality end-of-life care from the patient's perspective. Through interviews and surveys, researchers have found that patients desire to: avoid the inappropriate prolonging of life, have an opportunity to strengthen relationships, have time to prepare for death, complete tasks, contribute to others, achieve or maintain a sense of control, relieve the burden on caregivers, and receive adequate pain and symptom management (Singer, Martin, & Kelner, 1999; Steinhauser, et al., 2000). Researchers have also determined that patients are influenced in their end-of-life choices by the possibility of functional or cognitive impairment. The possibility of impairment may play a greater role in end-of-life decisions than actual known mortality (Fried, et al, 2002; Nahm & Resnick, 2001).

In the second section, Characteristics of Those Who Complete Advance Directives, the research of those investigating the motivating factors and demographic profiles of people who complete advance directives was presented. Factors identified as motivating people to execute advance directives include the death or serious illness of a friend or significant other, desiring to make their own decision and be in control, wanting others to know of the care they desired, and wanting to decrease the burden on loved ones (Hamel, et al., 2002; Inman, 2002; Mezey, et al., 2000). Demographic characteristics of those who completed advance directives included being white, female, and having private insurance, a higher income, and a college education (Hanson & Rodgman, 1996; Mezey, et.al., 2000).

The third section, The Impact of Advance Directives on Patient Care, presented important studies investigating how healthcare providers are caring for the elderly and dying. The findings of the SUPPORT study illustrated the poor communication between patients and their healthcare providers with regard to end-of-life care (SUPPORT Principal Investigators, 1995). The SUPPORT findings were confirmed by Fins, et al. (1999). The investigators of several studies noted that when advance directives were present, they did impact the patient care provided, making healthcare providers less likely to use CPR or treat the patient in the ICU and more likely to use comfort care plans (Fins, et al., 1999; Hammes & Rooney, 1998; Hanson & Rodgman, 1996; SUPPORT Principal Investigators, 1995). The retrospective record review has been used by several of the cited researchers to analyze the use of advance directives and the impact of the directives on patient care (Fins, et al., 1999; Hammes & Rooney, 1998; SUPPORT Principal Investigators, 1995).

Research Related in Methodology

The purpose of this section is to present research related in methodology. The retrospective record review has also been utilized successfully in other areas of study. This methodology allows significant data to be collected and analyzed efficiently and reliably. The research presented here includes studies utilizing the retrospective record review to gather data from hospital inpatient settings.

Lawrence, Hilsenbeck, Noveck, Poses, and Carlson (2002) designed their study to map the incidence and outcomes of a broad spectrum of medical complications after hip fracture repair. To do this, they designed “the largest study in a single surgical setting comprehensively evaluated for postoperative complications and their outcomes” (p. 2056) and performed a retrospective record review of the hospital records of 8,930 patients who had undergone surgical repair of a hip fracture. The subjects had been patients in one of 20 hospitals in New Jersey, Texas, Pennsylvania, and Virginia between the years 1982 and 1993. Of the 8,930 patients, 1,737 were found to have experienced postoperative medical complications. To further evaluate these patients, investigators documented the length of stay, medical comorbid conditions, tobacco and alcohol use, medications used before admission and during hospitalization, preoperative physical examination data, laboratory data, cointerventions, intraoperative data, independence of daily living, and mortality. Statistical comparisons of complication rates, mortality, and time to complication, death, and discharge were limited to the largest patient groups. Data were evaluated utilizing an analysis of variance (ANOVA) for categorical data or Kruskal-Wallis tests for independence for continuous data.

Investigators found that the mean age of the population was 80.2 years. The majority of patients were white (87%), female (79%), and living at home at the time of the fracture (73%). The vast majority of patients (81%) had no postoperative medical complications. Of the patients that experienced medical complications, cardiac and pulmonary complications were most frequent (8% and 4%, respectively) (Lawrence, et al., 2002).

Timms, Parker, Fallat, and Johnson (2002) also utilized a retrospective record review to analyze the characteristics of elderly (> 65 years old) readmissions to the hospital within 30 days of discharge. They desired to correlate the common reasons for readmissions with selected demographic data and to compare the readmission data with the top ten diagnostic-related groups. To do this, the investigators reviewed the hospital records of a convenience sample of 127 patients who met readmission criteria during a three-month period. The demographic data collection included age, race, marital status, gender, pay source, length of time between discharge and readmission, primary admitting diagnosis, secondary diagnoses, operative or diagnostic procedures performed, number of medications at the time of discharge, and the number of health problems other than the primary and secondary diagnoses. To analyze the strength of the relationships between the number of days since last discharge and the length of stay and the variables age, number of operative or diagnostic procedures, number of other health problems, and number of medications prescribed, the Spearman Rank correlation was utilized. The only significant relationship was found between the number of procedures and length of stay. The investigators noted a number of gaps in the documentation. They recommended a qualitative analysis of what was missing from the care during the index hospitalization followed by an evaluation of what may not have been readily available to patients and families on discharge that may have made a difference in their post-hospital course.

Vincent, Neale, and Woloshynowych (2001) utilized a methodology of retrospective record review to make preliminary estimates of the incidence and costs of adverse events in British hospitals. They reviewed 1,014 records of patients admitted to two acute care hospitals in the greater London area. The review team used 18 predefined screening criteria to assess the patient records. In all, 110 (10.8%) of the 1,014 patients experienced an adverse event. Of those, 63 (66%) had a resultant minimal impairment or recovered within one month. Moderate impairment was noted in 21 (19%) of patients and permanent impairment was noted in seven patients (6%). The adverse event contributed to the patient's death in nine cases (8%). Investigators found that overall, 53 (48%) of the adverse events were preventable.

In summary, the purpose of this section was to present research related in methodology. The retrospective record review has been utilized successfully to map the incidence and outcomes of complications after hip surgery (Lawrence, et al., 2002), to investigate the readmission of elderly patients back into the hospital (Timms, et al., 2002), and to review the incidence and cost of adverse medical events (Vincent, Neale, & Woloshynowych, 2001). This methodology was shown to result in the efficient and reliable collection of data for analysis in a variety of situations involving patients in inpatient settings.

Summary

Healthcare providers have been charged with providing quality care for their dying patients. The IOM (1997) recommended that healthcare providers facilitate a death with dignity for all terminal patients. By facilitating this process, healthcare providers can ensure quality of life for the dying patient. In order to discover what kind of care people want at the end of their lives, researchers have used interviews and focus groups to collect the personal definitions of subjects addressing the components of quality end-of-life care. When subjects were asked to describe what those components were, most identified: the inappropriate prolongation of dying (Hamel, et al., 2002; Inman, 2002; Singer, Martin & Kelner, 1999); communication facilitating informed decision-making and a sense of control (Fried, et al., 2002; Hamel et al., 2002; Nahm & Resnick, 2001; Steinhauser, et. al., 2000); and receiving adequate pain and symptom management (Nahm & Resnick, 2001; Singer, Martin, & Kelner, 1999; Steinhauser, et. al., 2000). The execution of advance directives has been identified as a way to ensure that the care desired at the end of life is the care that is provided.

With one exception (Hammes & Rooney, 1998), it appeared as if the percentage of those writing advance directives had not changed much over the past decade. A study using data from 1986 found that 9.8% of subjects had written advanced directives (Hanson & Rodgman, 1996). Later research revealed that written directives were in place for anywhere from 1.5% (Eleazer, 1996) to 20.4% (Mezey, et al., 2000) of subjects studied. The popular press cited higher figures (Cloud, 2000; *Modern Maturity*, 2000).

The characteristics of those writing advanced directives have been identified by several researchers. Subjects who were white, female, had private insurance, higher incomes, and more years of education were more likely to have written advance directives in place (Eleazer, et al., 1996; Hanson & Rodgman, 1996; Mezey, et al., 2000). Nonetheless, researchers continued to recommend further studies to evaluate the relationships among health insurance, education, language preferences, income, and ethnic background on end-of-life planning and treatment decisions (Mezey, et al., 2000).

Reinforcing the concerns shared in the IOM report, recent research has demonstrated that patients are not always receiving the kind of care they want at the end of their lives. Data provided by SUPPORT confirmed that communication between physicians and patients is limited, facilitating missed opportunities for patient input into their own care. More than one-third of the patients who died spent at least ten days in the intensive care unit; 46% of those received mechanical ventilation to within three days of death. A survey of both the medical records and the patients' surrogates found that the dying patients were in moderate to severe pain at least half of the time. (SUPPORT Principal Investigators, 1995). Fins, et al. (1999) reported similar findings. Investigators found, however, that when the advance directives were in place, evidence of patient preferences did have a positive impact on the end-of-life decision making by healthcare providers. Retrospective medical record reviews were used successfully to collect the data described in the SUPPORT (1995) and Fins (Fins, et al., 1999) studies.

Studies to date have provided a snapshot of how people are dying. Investigators have recommended continued research to determine if the care desired by dying patients is the care they are being provided. The following research questions have been asked in the past and can be asked in the future to determine if quality care is being provided to the dying. Are more people taking advantage of their opportunities to execute advance directives to direct their end-of-life care? What other relationships exist between the demographic characteristics of patients and their end-of-life decisions? Are terminal patients still receiving unwanted, uncomfortable, and expensive care at the end of their lives? Are the findings of past investigators who designed and implemented their studies in large teaching facilities consistent with findings obtained in smaller facilities? And ultimately, are healthcare providers any closer to facilitating a *good death* for their patients? It is with these questions in mind that this study has been designed.

Chapter III

Method and Procedures

This chapter outlines the procedures employed to address the research questions proposed in this study. It includes a discussion of the study population, procedure, design, instrumentation, and collection and analysis of data.

Selecting the Research Population

The study sample was comprised of 160 hospital patients age 65 or older drawn from the population of a small Tennessee city (population approximately 25,000) and its surrounding five county area. All patients who died in this community hospital located within the city during the year 2002 were selected for the study.

Healthcare providers in this study were the physician and nursing staff who provided care for the patients during their terminal hospitalizations. The physician staff practiced independently and had staff privileges at the hospital. They were either doctors of medicine (M.D.s) or doctors of osteopathy (D.O.s) and represented many specialties, including family practice, internal medicine, pulmonology, cardiology, and oncology. The nurses were employed by the hospital and were either registered nurses (R.N.s) or licensed practical nurses (L.P.N.s). They practiced in nursing units that were designated as general medical-surgical units, a geropsychiatric unit, or in one of two intensive care specialty areas (ICUs) that cared for critically ill patients.

Study Procedure

The purpose of this study was to analyze the end-of-life choices of elderly patients and their healthcare providers in a community hospital setting. A 155-bed facility located in Tennessee was selected for the study. Permission to conduct research in the facility was granted by the hospital association after the study proposal was reviewed and approved by the Executive Director of Human Resources and the Chief Executive Officer.

In compliance with the requirements of the University of Tennessee, Knoxville, permission to conduct research was requested from the University of Tennessee, Knoxville Institutional Review Board (IRB). Institutional Review Board Form B was completed and submitted to the University of Tennessee, Knoxville Compliance Section. The application was approved in April, 2004. Copies of the approval letters from both the hospital and the University of Tennessee, Knoxville IRB are included in Appendix A.

At the request of the investigator, the Director of Medical Records ran a list of the names, ages, account and medical record numbers of all patients who died in the hospital during the proposed study period. Medical records of the patients who met the study sample requirements were accessed using the hospital's online medical record retrieval system. Chart information was extracted by the investigator onto copies of the data collection instrument. Patient account numbers were cross-referenced with anonymous consecutive study numbers. To maintain patient confidentiality, the only study number was placed on the instrument. The document with the cross-referenced data was destroyed.

Study Design

This study was designed as a quantitative, descriptive study. Patients were assigned to three groups: those with a living will in their medical records, those with a formal durable power of attorney for healthcare (DPOA-HC) in their medical records, and those with recognition of an informal DPOA-HC documented in their medical records. It was possible for subjects to belong to both the living will group and the formal DPOA-HC group, if they possessed both documents. Subjects could also belong to the living will group and the informal DPOA-HC group, if they had evidence of both in their records. It was not possible for patients to belong to both the formal and informal DPOA-HC groups; those groups were considered to be mutually exclusive. The research questions were answered based on calculations utilizing this three-group design.

Inherent in this study was the opportunity for a case-control analysis. Case-control analyses are retrospective studies that begin with a group of people who have a defining characteristic and compare them with people who do not have that characteristic (Neutens & Rubinson, 2002). The patients with either type of written document were hypothesized to be proactive in their approach to their end-of-life care; patients with no written documents but with an identified family or friend designated as their advocate were hypothesized to be passive in their approach to their end-of-life care. Those with formal advance directives were considered the “cases;” those without written advance directives were considered “controls.”

Instrumentation

The instrument selected for use in this research project was developed and used by Fins, Miller, Acres, Bacchetta, Huzzard, and Rapkin (1999) to collect data for their study entitled "End-of-Life Decision-Making in the Hospital: Current Practice and Future Prospects," published in the *Journal of Pain and Symptom Management*. This instrument was used to abstract data from the charts of their subjects at the New York Hospital and Cornell University Medical College (now named New York Presbyterian Hospital and Weill Medical College of Cornell University). Permission was granted by Dr. Fins to use the instrument in this study; the letter of permission is included in Appendix B.

The original instrument surveyed 81 items, including demographic characteristics, diagnoses, circumstances of admissions, types of hospital units caring for the patients, occurrence and timing of end-of-life decisions, symptoms, and time and place of death. Two survey questions involving key end-of-life decisions were also included in the original instrument. The first question determined whether a clinician considered a patient to be dying. The second question determined whether a comfort care plan had been implemented.

Prior to beginning the study, researchers pilot tested the instrument to establish and document agreement between the two nurses who were selected to abstract chart data. Ease of use and percentage of agreement on survey items was evaluated. The initial mean agreement between the chart abstractors was 0.76. Each discrepancy was critically reviewed, leading to modification of the instrument and clarification of the rules for completing it. Interrater reliability using the finalized survey instrument between the same nurse abstractors was found to be 0.91. There was complete agreement between the two abstractors when the two survey questions were considered.

Fins, et al. (1999) organized their chart abstraction instrument as follows:

- Demographic data: age, sex, race, religion, language, and insurance status;
- Admission data: date of admission, number of prior admissions to the hospital for the six months preceding the date of admission, place of origin, presence of a note from the outpatient admitting provider, primary diagnosis, admitting diagnosis, admission through emergency room, and involvement of family or significant other;
- Hospital unit data: unit of admission, patient admitted or transferred to intensive care unit, number of admissions to the intensive care unit (ICU), and length of stay in the ICU;
- Information regarding end-of-life decision making for the patient: DPOA-HC recognized by staff, when DPOA-HC was signed, living will recognized by staff, when living will was signed, presence of patient preferences in the chart other than living will or health care proxy, decision-making capacity on admission, capacity lost during hospitalization, psychiatric consult requested to determine capacity, living will or DPOA-HC invoked during hospital course, undocumented living will or DPOA-HC used, chaplain visit documented;
- Information regarding end-of-life decision making for the healthcare providers: presence of evidence that the patient was considered dying,

determination of when the patient was first identified as dying, presence of comfort care plan, determination of when comfort care plan first noted, treatments/procedures provided to patient, presence of do-not-resuscitate (DNR) order prior to admission, DNR order written during current hospitalization, determination when patient became DNR, person consenting to DNR order, placement on ventilator during hospitalization, length of time patient was on the ventilator, intubation during hospitalization, presence of tracheostomy, length of time before death tracheostomy was placed, patient withdrawn from ventilator prior to death, length of time before death ventilator withdrawn, artificial nutrition and hydration received, length of time patient received artificial nutrition/hydration, patient agreement with artificial nutrition/hydration, withdrawal from nutrition/hydration prior to death, length of time before death nutrition/hydration withdrawn, chemotherapy received during hospitalization, withdrawal from antibiotics during hospitalization, length of time before death antibiotics withdrawn, other life-sustaining treatment withdrawn prior to death, morphine drip during hospitalization, patient agreement to morphine drip, length of time before death patient on morphine, involvement of Ethics Committee, number of consultants, evidence of symptoms within two days of death; and

- Information describing the patient’s death: date of death, site of death, patient transfer within 48 hours of death, location of patient prior to transfer, patient to operating room within 48 hours of death, and cardiopulmonary resuscitation (CPR) prior to death.

Instructions for the completion of the two survey questions were specific. For the first question to determine whether there was any evidence in the chart that the patient was considered to be dying, the abstractor would answer "yes" only when the following language was used: "end stage," "dying," "terminally ill," "moribund," "situation hopeless" or "grave," or "prognosis grim." For the second question to determine whether the patient had a comfort care plan in place, the abstractor would answer "yes" only if the following phrases were used: "comfort care," "palliative care," or "supportive care."

The original instrument was altered slightly for the present study. Based on the findings of Hanson and Rodgman (1996) and Mezey, Leitman, Mitty, Bottrell, and Ramsey (2000), level of education was added to the data collection instrument. An entry, "Level of Education," was inserted into the instrument as item 6. In addition, the two survey questions appeared to be redundant their content was incorporated into the questions addressing whether the patient was considered dying and whether a comfort care plan was present. Finally, questions addressing the presence of a note from the outpatient admitting provider and the number of prior admissions to the hospital for the six months preceding the date of admission were deleted. They were thought to be neither necessary nor appropriate in the current study as they reflected information sought by the original investigators in their specific setting. Other than those modifications, care was taken to collect and organize the data in the same way as the original investigators to facilitate the comparison of data collected in the two settings. The original Fins instrument (Fins, et al., 1999) is included in Appendix C. The modified chart abstraction instrument utilized in this study is included in Appendix D.

Collection of Data

As the medical records were accessed online, data collection took place at the convenience of the researcher over a period of approximately six weeks. Redacted chart information for 160 patients was abstracted by the researcher on copies of the instrument.

Data Analysis

The information was entered into and analyzed by the Statistical Package for the Social Sciences (SPSS) software for Windows, version 12.0. Descriptive statistics were tabulated and provided a detailed description of the sample. Means and frequencies for each dependent and independent variable were obtained, as appropriate. Calculation of Chi square and binary logistical regression statistics utilizing the data collected by the Chart Abstraction Instrument facilitated the analysis of the relationships between the variables. The following research questions were addressed:

In a sample of elderly patients admitted for their terminal hospitalization:

1. What is the likelihood that elderly patients will execute formal or informal advance directives?
2. What is the relationship between the presence of advance directives and the decision of healthcare providers to:

a. Treat the patient in the ICU?

b. Use life-sustaining treatments?

c. Initiate the use of comfort care plans?

d. Use CPR?

An alpha level of 0.05 was selected as the criterion of significance for all statistical data. The 0.05 level of significance reduces the chance of a Type I error and has been defended by past researchers and used in past related research involving similar subjects (Fins, et al., 1999; Nahm & Resnick, 2001; SUPPORT Principal Investigators, 1995).

Summary

This chapter presented the method and procedures used in this study. Selection of the research population, study procedure and design, instrumentation, and the collection and analysis of data were discussed.

A modified chart abstraction instrument based on the Chart Abstraction Instrument developed by Fins, et al. (1999) was used to abstract information from the medical records of 160 elderly patients who died in a community hospital during the year 2002. Appropriate statistical procedures were performed to address the research questions proposed in this study. Frequency data facilitated a description of the elderly patient subjects. More sophisticated statistical manipulation of data provided for analysis of the relationship between the presence of formal and informal advance directives and the variables of interest.

Data were viewed from two perspectives: a three-group descriptive study design and a two-group, case-control design.

Chapter IV

Analysis and Interpretation of the Data

In this chapter, the sample and the findings of the study are described, analyzed, and interpreted. The chapter is divided into two sections: Description of the Sample and Analysis and Interpretation of the Data. Frequency data is used to describe the sample. Characteristics of the sample are presented with emphasis on the use of advance directives and life-sustaining treatments. The second section includes an analysis and interpretation of the data in order to answer the research questions central to this study. Statistical manipulations used to process the data include the Chi square, binary logistic regression, Cohen's Kappa, and Kruskal-Wallis H tests. A presentation and analysis of recoded data utilizing the case-control study design is also included. A summary concludes the chapter.

Description of the Sample

This section contains a discussion of the characteristics of the sample. Frequency data are used to describe the following: the patient's terminal hospitalization, presence of advance directives, use of life-sustaining treatment, identification as dying, presence of comfort care plans, do-not-resuscitate (DNR) orders, terminal symptoms, and status at the time of death.

Characteristics of the Sample

The sample was comprised of 160 elderly patients who died in a community hospital in Tennessee during the year 2002. According to the hospital database, there were 166 elderly patients who died during that period but six records had not been placed on the computerized record retrieval system. Reasons offered by medical records personnel for the exclusion of those six records were that the records had been lost or that they were not available (i.e., being used on the nursing units) at the time the 2002 records were scanned into the system.

The average age of the patient admitted for his or her terminal hospitalization was 81 years of age. Patients were admitted to the study if they were 65 years of age or older. Two of the patients died at 98 years of age and defined the upper limit. There were 72 males and 88 females included in the sample. The majority of the patients were white (n = 151) as compared with African-Americans (n = 9). No other ethnic groups were represented.

Fifty-seven percent (n = 92) of the patients indicated a religious affiliation. Eighty of the patients were of the Baptist faith (one-half of the entire sample). There were six (3.8%) among the sample who identified their religion as Episcopalian, Lutheran, Methodist, or Presbyterian. There were three (1.9%) who identified themselves as practicing a fundamentalist Christian religion such as Pentecostal. Two (1.3%) subjects were Catholic. The religion was identified as "unknown" for two (1.3%) of the subjects. No documentation was provided in the record to identify religious preference for 17 (10.6%) of the sample.

All of the patients (100%; n = 160) spoke English as their primary language. There was no documentation describing the level of education found in the medical record for 125 (78.1%) of the patients. Of the patients with level of education documented in their records, those patients who left formal education before graduating from 8th grade numbered six (3.8%). Twelve (7.5%) graduated from 8th grade. Six (3.8%) completed some high school. Seven (4.4%) graduated from high school. Three (1.9%) graduated from college. One (0.6%) had a post-graduate degree.

Most of the patients were covered by Medicare. Eighty-one (50.6%) listed Medicare with a private supplement as their insurance. Seventeen (10.6%) listed Medicare alone. Fifty-eight (36.3%) listed Medicare plus Medicaid (TennCare) as their insurance. Four patients (2.5%) listed a private payor exclusively.

The majority of patients (60.6%; n = 97) entered the hospital from a private home. Fifty-one (31.9%) were admitted from a nursing home. Three (1.9%) were transferred from another acute care facility. Eight (5%) came from an assisted living facility. One (0.6%) patient was identified as being followed by hospice/homecare prior to admission.

Description of the Terminal Hospitalization

The majority of patients were admitted to the hospital through the emergency room (88.1%; n = 141). Those admitted directly to the facility by their physicians numbered 19 (11.9%). The diagnoses on admission were as follows: cardiovascular disease (23.8%; n = 38), cancer (6.3%; n = 10), neurological disorders (6.9%; n = 11), sepsis (11.3%; n = 18), pulmonary disease (30%; n = 48), metabolic disorder (10%; n = 16), GI disease or disorder (5%; n = 8), orthopedic disorder (4.4%, n = 7), and genitourinary disease or disorder (2.5%; n = 4).

Advance Directives

The majority of patients (96.9%; n = 155) had evidence of family involvement on admission noted in their medical records. The nursing and/or medical staff recognized an informal durable power of attorney for healthcare (DPOA-HC) for 122 patients (76.3%). Only 33 patients (20.6%) had a formal DPOA-HC in their records. A formal written living will was in the records of 43 patients (26.9%). There was evidence in the medical record that a written living will or DPOA-HC was used to guide care during the hospitalization of 51 (31.9%) of the patients. An undocumented living will or informal DPOA-HC was used to guide the decisions of healthcare providers for 108 (67.5%) of the patients. Decision-making capacity was noted on admission for 45 patients (28.1%). Thirty-six of those patients (83.7%) had documented loss of capacity noted during their final hospitalization.

Life-Sustaining Treatment

One hundred and two (63.8%) of the patients were either admitted or transferred to the intensive care units (ICU) during their hospitalization. Of those patients, 89 (87.3%) had one admission to intensive care; 11 (10.8%) had two admissions. One patient (1%) was readmitted to intensive care three times; another (1%) was readmitted four times. The average length of stay in the ICU was 4.49 days although the total number of days in the ICU ranged from one day (n = 31) to 43 days (n = 1). Ninety-five patients (59.4%) were admitted to general medical-surgical units. One patient (0.6%) was admitted to the geropsychiatric unit.

Thirty-six patients (22.5%) were placed on mechanical ventilation during their hospital stay. The mean number of hours on the ventilator was 48.6 (SD = 79.6); seven patients (19.4% of those placed on the ventilator) spent more than nine days each receiving mechanical ventilation. Only two patients (1.3%) had evidence in their record that they had agreed to the intubation. Only one patient (0.6%) received a tracheostomy to support the ventilation. Mechanical ventilation was withdrawn before death for 23 patients (63.9% of ventilated patients). The average time between withdrawal of mechanical ventilation and death was 10.78 hours (SD = 6.3; range from one hour (n = 3) to 11 days (n = 2)).

Thirty-two patients (20%) received artificial nutrition (tube feedings) prior to their death. The average time receiving the feedings was 6.34 days (SD 6.6). The days receiving artificial nutrition ranged from one day (n = 7) to 30 days (n = 1). Fourteen of the patients receiving artificial nutrition (43.8%) were withdrawn from the feedings prior to death. The average time between withdrawal of artificial nutrition and death was 13.2 hours (SD = 6.1; range from 1 hour (n = 1) to 10 days (n = 1)).

None of the patients received dialysis during their terminal hospitalization. Fifty-seven patients (35.6%) received a vasopressor medication to maintain their blood pressure at some point. The majority of the patients (83.1%; n = 133) received antibiotics. Only three of those patients (2.3%) had their antibiotics withdrawn prior to death. Thirty-one patients (19.4%) received blood transfusions during their hospital stay. All but five (96.9%; n = 155) received blood draws for laboratory studies. Invasive studies performed on these terminal patients included: bone marrow biopsies, thoracentesis, or paracentesis (3.1%; n = 5); central line or port-a-cath placement (18.1%; n = 29); endoscopy or bronchoscopy (4.4%; n = 7); and cardiac catheterization (2.5%; n = 4).

Patients Identified as Dying

There was evidence in the medical record that the patient was considered to be dying for 120 (75%). The mean number of days from admission until the patient was noted to be dying was 4.97 (SD = 7.6). Thirty-six patients (22.5%) were noted to be dying on the day of their admission; one patient was not identified as dying until the 29th day of hospitalization. The mean number of days from the time the patient was identified as dying until death was 4.93 (SD = 7.0). Twenty-nine patients (24.2% of those identified as dying) were not identified as dying until the day of their death. One patient was considered "dying" for 33 days. Forty subjects (25%) were never identified as dying.

Comfort Care Plans

A comfort care plan was in place for 86 (53.8%) of all patients prior to their death. The average number of days from admission until comfort care plan and comfort care plan until death were 4.95 days (SD = 6.6) and 2.99 days (SD = 6.6), respectively. Morphine sulfate was ordered for 51.9% (n = 83) of the patients. The time between the writing of the morphine order and death ranged from one hour to 23 days. Other medications that were prescribed for symptom relief (most commonly pain and anxiety) were meperidine (*Demerol*), ketorolac (*Toradol*), and lorazepam (*Ativan*). It is worth noting that these medications were used in place of morphine, not as an adjuvant therapy. A chaplain's visit was documented in the medical record of only three of the 160 patients (1.9%).

Do-Not-Resuscitate Orders

Forty-one patients (25.6%) were designated as do-not-resuscitate patients prior to admission. One hundred forty-nine (93.1%) were designated by order as a DNR patient during the hospitalization. The mean number of days between admission and DNR designation and DNR designation and death were 3.38 (SD = 5.1; range from the day of admission (n = 68) to 30 days (n = 1)) and 4.33 (SD = 4.9; range from the day of the DNR (n = 36) to 29 days (n = 1)), respectively. Table 4.1 summarizes the timing of the major decisions made at the end of life.

A surrogate consented to the DNR order for 116 (72.5%) of the subjects. Nine subjects (5.6%) requested the DNR order themselves. The person designated by a written DPOA-HC consented for 12 patients (7.5%) and the physician accepted

Table 4.1

The Timing of Decisions Made at the End of Life

	Mean (Days)	SD	Median (Days)
Length of Stay	7.29	7.382	5
Number of Days from Admission until Identified as Dying	4.97	7.606	3
Number of Days from Identified as Dying until Death	4.93	6.963	3
Number of Days from Admission until Comfort Care Plan	4.95	6.574	3
Number of Days from Identified as Dying until Comfort Care Plan	2.99	6.66	0
Number of Days from Comfort Care Plan until Death	3.45	3.560	2
Number of Days Between Admission and DNR	3.38	5.106	2

the responsibility for another 12 patients (7.5%). None of the patients was referred to the Ethics Committee.

One hundred thirteen patients (70.6%) were provided the services of at least one consultant. The number of physicians consulted ranged from one (31.9%; n = 51) to seven (0.6%; n = 1).

Terminal Symptoms

Documentation in the medical record reflected that 90 (56.3%) of the patients experienced pain during the last 48 hours of their life. Other terminal symptoms reported included: shortness of breath (58.8%; n = 94), nausea and/or vomiting

(15.6%; n = 25), constipation (3.8%; n = 6), diarrhea (4.4%; n = 7), anxiety (33.1%; n = 53), depression (1.9%; n = 3), and change in mental status (69.4%; n = 111).

Status at the Time of Death

Ninety-three (58.1%) patients died on a medical-surgical unit. The remaining 67 (41.9%) patients died in the intensive care units. Thirty-five patients (21.9%) were transferred to the unit where they died within 48 hours of their death. Twenty-one patients (60%) were transferred from the intensive care units to the medical-surgical floors. Fourteen subjects (40%) were moved from the medical-surgical areas to the intensive care units. Only four patients (2.5%) went to surgery within 48 hours of their death.

Twelve patients (7.5%) received and survived cardiopulmonary resuscitation (CPR) at some point during their hospitalization. Twelve patients (7.5%) received CPR at the end of their lives.

The mean length of stay for this sample was 7.29 days (SD = 7.3). Lengths of stay ranged from 1 day (n = 17) to 47 days (n = 1).

Diagnoses at death varied slightly from admission diagnoses. They were: cardiovascular disease (23.8%; n = 38), cancer (7.5%; n = 12), neurological disorder (10.6%; n = 17), sepsis (14.4%; n = 23), pulmonary disease (32.5%; n = 52), metabolic disorder (6.3%; n = 10), gastrointestinal disease or disorder (1.9%; n = 3), and orthopedic disorder (3.1%; n = 5).

Analysis and Interpretation of the Data

This section presents the analysis of the data and attempts to interpret the data to answer the research questions posed in Chapter I. The research questions were:

1. What is the likelihood that elderly patients will execute formal or informal advance directives?
2. What is the relationship between the presence of advance directives and the decision of healthcare providers to:
   a. Treat the patient in the ICU?
   b. Use life-sustaining treatments?
   c. Initiate the use of comfort care plans?
   d. Use CPR?

To analyze the data, patients were assigned to one of three groups, depending on the variable being analyzed. The three groups were: patients with a living will in their medical record, patients with a formal DPOA-HC in their medical record, and patients with recognition of an informal DPOA-HC documented in their medical records. Patients could belong to both the living will group and the formal DPOA-HC group, if they possessed both documents. Patients could also belong to both the living will group and the informal DPOA-HC group, if evidence of both were present. The formal DPOA-HC and informal DPOA-HC groups were considered mutually exclusive.

The Frequency of the Writing of Advance Directives

Among this sample of 160 elderly patients hospitalized at a community hospital in Tennessee, 26.9% (n = 43) patient subjects had a copy of their written living will placed in their medical records. Formal durable powers of attorney for healthcare were placed in the charts of 20.6% (n = 33) of the patients. An informal DPOA-HC was recognized by staff for 76.3% (n = 122) of the patients.

There was a significant relationship between the presence of a formal living will and a formal DPOA-HC ($\chi^2 = 44.477$, df = 1, $p < 0.001$) suggesting that patients who had prepared a living will were likely to have also prepared a formal DPOA-HC. This was confirmed by the calculation of an odds ratio which found that the odds of having a formal DPOA-HC in their chart were 15.158 times larger for those who had a formal living will than for those who did not have a formal living will. Table 4.2 illustrates the differences between the proportions and table 4.3 illustrates the odds ratio.

The Relationship of the Presence of Advanced Directives and Selected Variables

In looking for relationships between those who wrote advance directives and their demographic variables, a binary logistic regression was performed and there were no significant relationships found with regard to patient age, sex, race, religion, or type of insurance. Because the number of patients with a documented level of education in their medical record was so small (n = 35), education was not considered in the regression equation but was considered in a separate Chi

Table 4.2

Frequencies and Percentages of Patients with Formal Living Wills and Formal DPOA-HC

		Formal DPOA-HC in Chart				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Formal Living Will in Chart	Yes	24	55.8	19	44.2	43	100.0
	No	9	7.7	108	92.3	117	100.0
Total		33	20.6	127	79.4	160	100.0

$\chi^2 = 44.477$, df = 1
$p < 0.001$

Table 4.3

Odds Ratio Between Patients with Formal Living Wills and Formal DPOA-HC

	Value	95% Confidence Interval	
		Lower	Upper
Odds Ratio for Formal Living Will in Chart (Yes / No)	15.158	6.113	37.586
For cohort Formal DPOA-HC in Chart = Yes	7.256	3.670	14.347
For cohort Formal DPOA-HC in Chart = No	.479	.341	.673
N of Valid Cases	160		

square analysis. The data suggested that as the level of patient education increased, the likelihood that the patient or family had prepared a formal DPOA-HC also increased ($\chi^2 = 6.522$, df = 2, p = 0.038). Table 4.4 compares the differences in proportions between the level of education and the presence of a formal DPOA- HC. The same relationship to the level of education was not found when the preparation of living wills was considered.

When the presence of a formal living will was considered with the care situation prior to admission, a significant relationship was found ($\chi^2 = 7.726$, df = 2, p = 0.021). Those coming from private homes were found to have completed living wills less frequently than expected when compared with those patients admitted from a nursing home. Conversely, those patients coming from a

Table 4.4

Frequencies and Percentages Between Level of Patient Education and Presence of a Formal DPOA-HC

		Formal DPOA-HC in Chart				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Education of Patient	Elementary	1	5.6	17	94.4	18	100.0
	Secondary	5	38.5	8	61.5	13	100.0
	College	2	50.0	2	50.0	4	100.0
Total		8	22.9	27	77.1	35	100.0

$\chi^2 = 6.522$, df = 2
$p < 0.05$

nursing home were found to have completed living wills more frequently than expected. The relationship is illustrated in Table 4.5. No significant differences were found when the care situation prior to admission was evaluated with the presence of a formal ($\chi^2 = 3.531$, df = 2, $p = 0.171$) or informal ($\chi^2 = 2.322$, df = 2, $p = 0.313$) DPOA-HC.

The patient's admission diagnosis was evaluated to see if there was a relationship between the type of illness the patient was experiencing and the likelihood that he or she would prepare advance directives. The Chi square procedure revealed that no significant relationships existed between the patient's

Table 4.5

Frequencies and Percentages of Care Situation Prior to Admission and the Presence of a Living Will

		Formal Living Will in Chart				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Care Situation Prior to Admission	Private Home	19	19.6	78	80.4	97	100.0
	Nursing Home	18	35.3	33	64.7	51	100.0
	Other (another hospital, homecare, assisted living)	6	50.0	6	50.0	12	100.0
Total		43	26.9	117	73.1	160	100.0

$\chi^2 = 7.726$, df = 2
$p < 0.05$

admission diagnosis and the presence of a living will ($\chi^2 = 11.670$, df = 8, p = 0.161) or formal DPOA-HC (χ^2 = value, df = 8, p = 0.214).

The Patient's Relationship with Family

The majority of patients had family involvement on admission documented in their medical records (n = 155). When the relationship between the presence of advance directives and family involvement at the time of admission was considered, the data suggested a strongly significant relationship between family involvement and the respect by staff of the family's wishes (i.e., the informal DPOA-HC) ($\chi^2 = 16.570$, df = 1, $p < 0.001$). Table 4.6 illustrates the differences between the proportions of patients with family involvement on admission and the presence of an informal DPOA-HC. Documentation found in one patient's medical record illustrated the conflict between family members that occurs occasionally. The physician recorded the following in the patient's admission history and physical:

> Son was contacted and says he wants everything done. When pt was in the emergency room, her granddaughter was contacted and also her daughter. They wish DNR be reissued as son does not understand her condition. They have already decided just to make her comfortable.

A DNR order for this patient was written on admission. The patient died the following day. The relationships between family involvement on admission and

Table 4.6

Frequencies and Percentages of Family Involvement on Admission and the Presence of an Informal DPOA-HC

		Informal DPOA-HC Recognized by Staff					
		Yes		No		Total	
		Count	%	Count	%	Count	%
Family Involvement on Admission	Yes	122	78.7	33	21.3	155	100.0
	No	0	0.0	5	100.0	5	100.0
Total		122	76.3	38	23.8	160	100.0

$\chi^2 = 16.570$, df = 2
$p < 0.001$

the presence of a formal DPOA-HC ($\chi^2 = 1.897$, df = 1, $p = 0.168$) or living will ($\chi^2 = 1.341$, df = 1, $p = 0.247$) were found not to be significant.

The Relationship of Life-Sustaining Treatments to the Presence of Advance Directives

The healthcare provider's decision to admit the patient to an intensive care unit, a medical-surgical unit, or the geropsychiatric unit was found to be independent of the presence of either formal or informal advance directives. No significant relationship was found when the variable of unit of admission was evaluated with the presence of a living will ($\chi^2 = 0.598$, df = 2, $p = 0.742$), formal

DPOA-HC ($\chi^2 = 1.094$, df = 2, p = 0.579), or informal DPOA-HC ($\chi^2 = 1.074$, df = 2, p = 0.584).

In this study, life-sustaining treatments were considered to be placement of the patient on mechanical ventilation, artificial nutrition, or dialysis; the use of vasopressors, antibiotics, blood transfusions, or blood draws for laboratory studies; and invasive procedures such as bone marrow biopsies, thoracentesis, or paracentesis, central line or port placement, endoscopy or bronchoscopy, or cardiac catheterization. When the life-sustaining variables were evaluated to find the effect of the presence of formal and informal advance directives upon them, only one significant relationship was found. Patients with a person recognized by staff as an informal DPOA-HC were found to be more likely to have undergone any invasive procedure except for cardiac catheterization ($\chi^2 = 13.460$, df = 4, p = 0.009). Table 4.7 illustrates the association between the performance of invasive procedures and the presence of an informal DPOA-HC. The presence of a formal living will or DPOA-HC was found not to be significantly related to whether or not the procedures were performed by healthcare providers ($\chi^2 = 4.365$, df = 4, p = 0.0.359; $\chi^2 = 7.627$, df = 4, p = 0.106, respectively).

The Relationship Between the Presence of Advance Directives and the Use of Comfort Care Plans

The implementation of comfort care plans was found to be independent of either formal or informal advance directives. No significant relationships were found when patients with comfort care plans were evaluated with those patients

Table 4.7

Frequencies and Percentages of the Performance of Invasive Procedures and the Presence of an Informal DPOA-HC

		Informal DPOA-HC Recognized by Staff				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Other Invasive Procedures Performed	Bone marrow biopsy, thoracentesis, or paracentesis	4	80.0	1	20.0	5	100.0
	Central line or port placement	23	79.3	6	20.7	29	100.0
	Endoscopy, bronchoscopy, or PEG tube placement	6	85.7	1	14.3	7	100.0
	Cardiac catheterization	0	0.0	4	100.0	4	100.0
	No	89	77.4	26	22.6	115	100.0
Total		122	76.3	38	23.8	160	100.0

$\chi^2 = 13.460$, df = 4
$p < 0.05$

with a living will ($\chi^2 = 1.067$, df = 1, p = 0.302), formal DPOA-HC ($\chi^2 = 0.245$, df = 1, p = 0.621), or informal DPOA-HC ($\chi^2 = 0.025$, df = 1, p = 0.874) documented in their medical records.

Morphine was found to be the drug of choice for patients with a comfort care plan. A strong relationship was found between patients with an order for "comfort care" in their medical records and patients receiving morphine either continuously or "as needed" ($\chi^2 = 27.045$, df = 1, $p < 0.001$). This association is illustrated in Table 4.8. Review of the medical records revealed that the presence of a morphine order did not necessarily mean that the patient did not die in pain. Ninety patients (56.3%) had evidence of terminal pain found in their medical records. The nurses' notes for one patient vividly illustrated that fact. Although

Table 4.8

Frequencies and Percentages of the Presence of a Comfort Care Plan and the Decision to Administer Morphine

		Did Patient Receive Morphine Continuously or "As Needed"				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Comfort Care Plan Noted	Yes	61	70.9	25	29.1	86	100.0
	No	22	29.7	52	70.3	74	100.0
Total		83	51.9	77	48.1	160	100.0

$\chi^2 = 27.045$, df = 1
$p < 0.001$

it was ordered to be administered every hour, morphine was not administered until the patient was “thrashing about,” “moaning,” “crying out in pain,” or “yelling out.” During the last two days of this patient’s life, the intervals between morphine doses ranged from two to nearly four hours.

A strong and interesting significant relationship was found between the patient’s admission diagnosis and the likelihood the healthcare provider would order a comfort care plan. Patients with cardiovascular disease, cancer, neurological disorders, and gastrointestinal diseases or disorders were more likely to have comfort care plans in place than patients with sepsis, pulmonary disease, metabolic disease, orthopedic disorders, or genitourinary diseases or disorders ($\chi^2 = 22.714$, df = 8, p = 0.004). Table 4.9 illustrates the differences between the proportions.

In a search for possible explanations for the above findings, an additional procedure was done to evaluate whether or not patients in specific diagnostic groups were recognized as dying at all. Although the relationships were nonsignificant ($\chi^2 = 11.300$, df = 8, p = 0.185), patients with an admitting diagnosis of cardiovascular disease, cancer, or neurological disorders were somewhat more likely to be recognized as dying than patients admitted with a diagnosis of sepsis, pulmonary disease, metabolic disorders, or orthopedic disorders.

The majority of patients (n = 133) received antibiotics during their hospitalization. A relatively weak but significant relationship was found, however, between those patients who did not receive antibiotics and the

Table 4.9

Frequencies and Percentages of the Patient’s Admission Diagnosis and the Presence of a Comfort Care Plan

		Comfort Care Plan Noted				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Admission Diagnosis	Cardiovascular disease	26	68.4	12	31.6	38	100.0
	Cancer	8	80.0	2	20.0	10	100.0
	Neurological disorder	10	90.9	1	9.1	11	100.0
	Sepsis	8	44.4	10	55.6	18	100.0
	Pulmonary disease	18	37.5	30	62.5	48	100.0
	Metabolic disorder	6	37.5	10	62.5	16	100.0
	GI disease/ disorder	6	75.0	2	25.0	8	100.0
	Orthopedic disorder	3	42.9	4	57.1	7	100.0
	Genitourinary disease/ disorder	1	25.0	3	75.0	4	100.0
Total		86	53.8	74	46.3	160	100.0

$\chi^2 = 22.714$, df = 8
$p < 0.05$

presence of a comfort care plan ($\chi^2 = 5.397$, df = 1, $p = 0.020$). Table 4.10 illustrates the differences in proportions.

When the presence of a comfort care plan was evaluated with those patients who were considered dying, a significant positive relationship was found ($\chi^2 = 45.891$, df = 1, $p < 0.001$). The comparison of the proportions is presented in Table 4.11.

The terminal symptoms considered in this study were: pain, shortness of breath, nausea and vomiting, constipation, diarrhea, anxiety, depression, and a change in mental status. There were significant differences found between the documentation of a comfort care plan and the presence of terminal symptoms when a binary logistical regression was performed. When specific terminal symptoms were evaluated with the use of morphine, however, there were

Table 4.10

Frequencies and Percentages of the Presence of a Comfort Care Plan and the Use of Antibiotics

		Did Patient Receive Antibiotics				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Comfort Care Plan Noted	Yes	66	76.7	20	23.3	86	100.0
	No	67	90.5	7	9.5	74	100.0
Total		133	83.1	27	16.9	160	100.0

$\chi^2 = 5.397$, df = 1
$p < 0.05$

Table 4.11

Frequencies and Percentages of Evidence the Patient is Considered Dying and the Presence of a Comfort Care Plan

		Comfort Care Plan Noted				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Evidence in Chart Patient Considered Dying	Yes	83	69.2	37	30.8	120	100.0
	No	3	7.5	37	92.5	40	100.0
Total		86	53.8	74	46.3	160	100.0

$\chi^2 = 45.891$, df = 1
$p < 0.001$

significant differences found. Morphine was prescribed more often for patients with documented terminal pain ($\chi^2 = 23.853$, df = 1, $p < 0.001$) and shortness of breath ($\chi^2 = 5.411$, df = 1, $p = 0.02$). The differences between the proportions are illustrated in Tables 4.12 and 4.13.

With the exception of anxiety, all of the other terminal symptoms (pain, shortness of breath, nausea or vomiting, constipation, diarrhea, depression, and change in mental status) were not significantly related to the presence of a living will, formal DPOA-HC, and informal DPOA-HC ($p > 0.05$). When terminal anxiety was evaluated with the presence of a formal DPOA-HC, a seemingly significant relationship was found ($\chi^2 = 4.191$, df = 1, $p = 0.041$). This relationship was found to be weak and nonsignificant by Fisher's Exact Test ($p = 0.060$). Recognition of an informal DPOA-HC was found to be weakly but

Table 4.12

Frequencies and Percentages of the Presence of Terminal Pain and the Prescription of Morphine

		Did Patient Receive Morphine Continuously or "As Needed"					
		Yes		No		Total	
		Count	%	Count	%	Count	%
Evidence of Terminal Pain	Yes	62	68.9	28	31.1	90	100.0
	No	21	30.0	49	70.0	70	100.0
Total		83	51.9	77	48.1	160	100.0

$\chi^2 = 23.853$, df = 1
$p < 0.001$

Table 4.13

Frequencies and Percentages of the Presence of Terminal Shortness of Breath and the Prescription of Morphine

		Did Patient Receive Morphine Continuously or "As Needed"					
		Yes		No		Total	
		Count	%	Count	%	Count	%
Evidence of Terminal Shortness of Breath	Yes	56	59.6	38	40.4	94	100.0
	No	27	40.9	39	59.1	66	100.0
Total		83	51.9	77	48.1	160	100.0

$\chi^2 = 5.411$, df = 1
$p < 0.05$

significantly related to the terminal symptom of anxiety ($\chi^2 = 4.864$, df = 1, p = 0.027). Significance was confirmed by the Exact Test (p = 0.031). This association between the variables is presented in Table 4.14.

The Relationship Between the Presence of Advance Directives and the Use of CPR

Only 12 patients (7.5%) received cardiopulmonary resuscitation at the end of their lives. Although the number was small and the strength of the relationship not impressive ($\chi^2 = 4.768$, df = 1, p = 0.029), it is significant to note that no patients with a living will in their medical records received CPR at the end of life. This relationship is illustrated in Table 4.15. There were no significant

Table 4.14

Frequencies and Percentages of Evidence of Terminal Anxiety and the Recognition of an Informal DPOA-HC

		Informal DPOA-HC Recognized by Staff					
		Yes		No		Total	
		Count	%	Count	%	Count	%
Evidence of Terminal Anxiety	Yes	46	86.8	7	13.2	53	100.0
	No	76	71.0	31	29.0	107	100.0
Total		122	76.3	38	23.8	160	100.0

$\chi^2 = 4.864$, df = 1
$p < 0.05$

Table 4.15

Frequencies and Percentages of the Presence of a Formal Living Will and the Use of CPR at the End of Life

		Did Patient Receive CPR at the End of Life				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Formal Living Will in Chart	Yes	0	0.0	43	100.0	43	100.0
	No	12	10.3	105	89.7	117	100.0
Total		12	7.5	148	92.5	160	100.0

$\chi^2 = 4.768$, df = 1
$p < 0.05$

relationships found when either formal ($\chi^2 = 3.371$, df = 1, $p = 0.066$) or informal ($\chi^2 = 0.658$, df = 1, $p = 0.417$) durable powers of attorney for healthcare were considered.

The Relationship Between Advance Directives and Do-Not-Resuscitate Orders

One hundred and forty-nine patients (93.1%) had do-not-resuscitate orders in their medical records. The presence of a DNR order was found not to be significantly related to the life-sustaining treatments evaluated in this study ($p > 0.05$ for each variable). The presence of a formal living will was found to be significantly related to whether or not a DNR order was written ($\chi^2 = 4.341$, df = 1, $p = 0.037$). The 43 patients with a living will in their medical records all had written DNR orders. The proportions are compared in Table 4.16.

Table 4.16

Frequencies and Percentages of the Presence of a Formal Living Will and a Do-Not-Resuscitate Order

		DNR Order Written				Total	
		Yes		No			
		Count	%	Count	%	Count	%
Formal Living Will in Chart	Yes	43	100.0	0	0.0	43	100.0
	No	106	90.6	11	9.4	117	100.0
Total		149	93.1	11	6.9	160	100.0

$\chi^2 = 4.341$, df = 1
$p < 0.05$

The same significance was not found when either a formal or informal DPOA-HC was considered ($\chi^2 = 3.069$, df = 1, p = 0.080 and $\chi^2 = 1.038$, df = 1, p = 0.308, respectively).

It was expected that there would be a strong inverse relationship between those patients with a DNR order in their medical record and those who received CPR at the end of their lives. This was confirmed when the relationship was evaluated ($\chi^2 = 145.682$, df = 1, $p < 0.001$) and is presented in Table 4.17. It is of interest to this study, however, that there was one patient who had a DNR order written in his medical record but received CPR at the end of life in spite of the order. When the data collection instrument for that patient was reviewed, it was found that the family requested the attempted resuscitation be discontinued after it had begun. There was no notation as to why it was begun with a written DNR order in the

Table 4.17

Frequencies and Percentages of the Presence of a Written DNR Order and the Performance of CPR at the End of Life

		Did Patient Receive CPR at the End of Life				Total	
		Yes		No			
		Count	%	Count	%	Count	%
DNR Order Written	Yes	1	0.7	148	99.3	149	100.0
	No	11	100.0	0	0.0	11	100.0
Total		12	7.5	148	92.5	160	100.0

$\chi^2 = 145.682$, df = 1
$p < 0.001$

chart. Another patient subject almost suffered a similar fate. The nurse's entry reads:

> Dr. __ at bedside. V-fib noted on monitor. MD requests to shock pt and give epi. Informed MD that pt is DNR and son does not want resuscitation of any kind. Precordial thump x 2 by MD. No changes noted (in patient condition).

No significant differences were found when the presence of a DNR order was evaluated with the unit site of death ($\chi^2 = 0.779$, df = 1, $p = 0.377$) or whether or not the patient was transferred within 48 hours of death ($\chi^2 = 0.201$, df = 1, $p = 0.654$). No significant differences were found between the presence of any advance directive and the unit site of death (formal living will ($\chi^2 = 3.275$, df = 1,

$p = 0.070$); formal DPOA-HC ($\chi^2 = 0.105$, df = 1, $p = 0.746$); and informal DPOA-HC ($\chi^2 = 0.001$, df = 1, $p = 0.974$)).

The Relationship Between The Patient's Length of Stay and Selected Variables

The patient's admission diagnosis differed from the diagnosis at death for some patients. Nonetheless, Cohen's Kappa test revealed that the relationship between admission and death diagnoses was strongly significant (Kappa = 0.561, $p < 0.001$). Four patients with genitourinary disorders on admission were excluded from the equation because there were no deaths attributed to genitourinary disorders or diseases and a requirement of Kappa calculations is that the underlying table be squared. The relationship is illustrated in Table 4.18.

Table 4.18

Measure of Agreement Between the Patients' Diagnosis at the Time of Admission and the Diagnosis at the Time of Death

		Value	Asymp. Std. Error(a)	Approx. T(b)	Approx. Sig.
Measure of Agreement	Kappa	0.561	0.047	15.296	0.000
N of Valid Cases		156			

a Not assuming the null hypothesis.
b Using the asymptotic standard error assuming the null hypothesis.
Kappa = 0.561
$p < 0.001$

Patient length of stay was found to be unrelated to the patient's diagnosis at death. A Kruskal-Wallis H test found that the relationship between the patients' length of stay and their diagnosis at death was not found to be significant ($\chi^2 = 2.933$, df = 3, $p = 0.402$).

The patient's length of stay was directly related to the number of consulting physicians. When a Kruskal-Wallis H test was performed, a strong significant relationship was found between the two variables ($\chi^2 = 27.510$, df = 3, $p < 0.001$).

Case-Control Analysis

To evaluate the benefits of approaching this study as a case-control analysis, the data were recoded and reexamined as cases and control. The cases were those patients who had either or both of the formal advance directive documents in their medical record. Having prepared a formal document was hypothesized to mean that these patients were proactive in their approach to the care they received at the end of their lives. There were 24 patients who had both a formal living will and a formal DPOA-HC. There were 19 patients who had only a living will and there were 9 patients who had only a formal DPOA-HC, making the number of cases 52. In the original data examination, those patients who had both a living will and a recognized formal DPOA-HC were considered in either group, depending on the variable being analyzed.

The control group became the 104 patients who had documentation of an informal DPOA-HC in their medical records. This group was hypothesized to be more passive in their approach to their end-of-life care, leaving end-of-life decisions to their significant others. There were four patients who had neither formal document in their medical records, nor any family member or friend who was recognized as speaking on their behalf. These patients were thought to represent yet another group and could not be assumed to have the characteristics of either the cases or the controls. They were excluded from this case-control analysis.

The Relationship of the Presence of Advance Directives and the Selected Variables

There were no significant relationships found when binary logistic regressions were performed with regard to the demographic variables with either the cases or the controls. When the care situation prior to admission was considered, a significant relationship was found between the presence of an advance directive and the care situation prior to admission ($\chi^2 = 7.158$, df = 2, p = 0.028). Patients coming from private homes were once again found to be less likely and patients coming from nursing homes more likely to have completed formal documents. Table 4.19 illustrates those relationships. When the directives were considered separately in the original data examination, significance was found with only the living will ($\chi^2 = 7.726$, df = 2, p = 0.021).

The Patient's Relationship with Family

When the relationship between family involvement on admission and the presence of the formal documents was considered, no significant differences were

Table 4.19

Frequencies and Percentages of Care Situation Prior to Admission and the Type of Advance Directive in Place

		Type of Advance Directive in Place					
		Formal Advance Directives in Place		Informal DPOA-HC Recognized		Total	
		Count	%	Count	%	Count	%
Care Situation Prior to Admission	Private Home	24	25.8	69	74.2	93	100.0
	Nursing Home	21	41.2	30	58.8	51	100.0
	Other (another hospital, homecare, assisted living)	7	58.3	5	41.7	12	100.0
Total		52	33.3	104	66.7	156	100.0

$\chi^2 = 7.158$, df = 2
$p < 0.05$

found ($\chi^2 = 503$, df = 1, p = 0.478). This was also the case when the formal documents were considered separately in the original data analysis, as family involvement on admission was the norm in both groups.

Unlike the original data analysis, when the cases were compared with the controls and the four patients without either type of advance directive were excluded from the data, there was essentially no difference between the groups as all but one patient had documentation in their medical records that reflected family involvement ($\chi^2 = 2.013$, df = 1, p = 0.156). In the three-group comparison, the differences between family involvement on admission and the recognition of an informal DPOA-HC were found to be significant ($\chi^2 = 16.570$, df = 1, $p < 0.001$).

The Relationship of Life-Sustaining Treatments to the Presence of Advance Directives

There were no significant differences found between the case and control groups when the unit of admission was considered ($\chi^2 = 1.686$, df = 2, p = 0.430). When the differences between the life-sustaining treatment variables and the cases and controls were examined, no significant differences were found with any variable. In the case-control comparison, there continued to be a trend suggesting that patients with a recognized informal DPOA-HC were more likely to undergo invasive procedures (with the exception of cardiac catheterization), however this relationship did not achieve significance ($\chi^2 = 8.932$, df = 4, p = 0.063).

The Relationship Between the Presence of Advance Directives and the Use of CPR

As with the original data configuration, there was a significant difference found between the type of advance directives in the patients' medical records and the decision of healthcare providers to use CPR at the end of life ($\chi^2 = 4.776$, df = 1, p = 0.029). None of the patients who received CPR at the end of their lives had formal documents in their records.

In summary, the case-control configuration provided another perspective from which to view the subjects in this study. The recoding and rerunning of the data in a case-control design confirmed the findings of the three-group design and did not make a difference in the statistically significant findings of this study.

Summary

This chapter included a description of the sample and an analysis and interpretation of the data. The medical records of 160 elderly patients were reviewed to answer the research questions posed in this study.

In the three-group study design, it was found that 26.9% (n = 43) of the patients had a copy of their written living will placed in their medical records. Formal durable powers of attorney for healthcare were placed in the charts of 20.6% (n = 33) of the patients. An informal DPOA-HC was recognized by staff for 76.3% (n = 122) of the patients.

One hundred and two (63.8%) of the patients were either admitted or transferred to the intensive care areas during their hospitalizations. There was no relationship found between the presence of a written living will, formal DPOA-HC, or informal DPOA-HC and the unit of admission. Likewise, there was no relationship found between the presence of any advance directive and the unit site of death.

Thirty-six patients (22.5%) were placed on mechanical ventilation during their hospital stay. Mechanical ventilation was withdrawn before death for 23. Thirty-two patients (20%) received artificial nutrition prior to their death. Fourteen of those patients were withdrawn from their feedings before death. Fifty-seven patients (35.6%) received a vasopressor medication to maintain their blood pressure at some point during their hospitalization. Most (83.1%; n = 133) received antibiotics; the majority (n = 130) continued to receive them until they died. One hundred and fifty-five patients (96.9%) had blood drawn for laboratory studies. Forty-five patients (28.1%) underwent invasive procedures. A positive relationship was found between the recognition of an informal DPOA-HC and the performance of invasive procedures (with the exception of cardiac catheterizations). No other relationships were found between the recognition of an informal DPOA-HC, formal DPOA-HC, or living will and the use of life-sustaining treatments.

No relationship was found between the presence or recognition of any type of advance directive and the presence of a comfort care plan. Morphine was found to be the drug of choice for patients with a comfort care plan, although the presence of a morphine order did not mean the patient did not die in pain. Ninety patients (56.3%) experienced pain during the two days before their death.

An interesting relationship was found between the patient's admission diagnosis and the initiation of a comfort care plan. Data suggested that comfort care plans were ordered more often for patients with cardiovascular disease, cancer, neurological disorders, and gastrointestinal diseases or disorders than for patients with sepsis, pulmonary disease, metabolic disease, orthopedic disorders, or genitourinary diseases or disorders.

Patient length of stay was found to be unrelated to the patient's diagnosis at death. The number of consultants, however, was significantly related to the patient's length of stay.

Patients with a formal living will in their medical records were found to be less likely to receive CPR at the end of their lives than those who did not have the document in their records. The presence of a living will was also found to be significantly related to the writing of a DNR order. There were no significant differences found when formal or informal durable powers of attorney were considered. Even though there was a written DNR order, CPR was initiated for one patient and, if not for the nurse at the bedside, would have been initiated for a second.

When the data were reanalyzed in the case-control design, study findings were similar to the three-group design. No advantage was found to viewing the subjects from this perspective.

Chapter V

Summary of Findings, Conclusions, and Recommendations

The purpose of this study was to analyze the end-of-life choices of elderly patients and their healthcare providers in a community hospital setting. This chapter presents a summary of the findings followed by a discussion of the findings as they relate to the research questions. A presentation of conclusions, implications, and recommendations based on the findings of this and other studies concludes the chapter.

Findings of the Study

The medical records of 160 elderly patients were reviewed to answer the research questions posed in this study. The research questions were:

1. What is the likelihood that elderly patients will execute formal or informal advance directives?
2. What is the relationship between the presence of advance directives and the decision of healthcare providers to:
   a. Treat the patient in the intensive care unit (ICU)?
   b. Use life-sustaining treatments?
   c. Initiate the use of comfort care plans?
   d. Use cardiopulmonary resuscitation (CPR)?

A modified form of the Chart Abstraction Instrument developed by Fins, Miller, Acres, Bacchetta, Huzzard, and Rapkin (1999) was used to abstract data from a sample of medical records. The instrument was altered only slightly to adapt it to the community population and setting used in this study. Based on the findings of others (Hanson & Rodgman, 1996; Mezey, Leitman, Mitty, Bottrell, and Ramsey, 2000), level of education was added to the demographic data collected. All but six of the patients who died in the selected community hospital during the year 2002 were included in the sample.

The analysis of the data was completed using the Statistical Package for the Social Sciences (SPSS) software for Windows, version 12.0. Descriptive statistics were used to define the sample and included frequency counts and measures of central tendencies. Chi square procedures, binary logistical regression, Cohen's Kappa, and Kruskal-Wallis H tests were calculated to analyze relationships between the variables.

The study was approached from two directions. Data were analyzed using a three-group design. Patients were grouped according to whether they had a living will, formal durable power of attorney for healthcare (DPOA-HC), or informal DPOA-HC in their medical record. For comparison, the data were reanalyzed using a case-control design. Patients were grouped according to whether they had either of the written advanced directives (the cases) or whether they had a recognized informal DPOA-HC (the controls). There was no benefit found to utilizing the case-control design.

Summary of Findings

1. Forty- three patients (26.9%) had a living will in their medical records. Formal durable powers of attorney for healthcare were found in the medical records of 33 patients (20.6%). An informal DPOA-HC was recognized by staff for122 patients (76.3%).
2. There was a significant relationship found between the presence of a formal living will and a formal DPOA-HC ($p < 0.001$).
3. There was no relationship found between those with formal or informal advance directives and any of the demographic variables, with the exception of education. Although the number was small, data seemed to confirm that those with higher levels of education were more likely to prepare a formal DPOA-HC ($p < 0.05$).
4. Patients admitted from a nursing home were found most likely to have completed a living will. Patients admitted from private homes were least likely to have completed one ($p < 0.05$).
5. No relationship was found between the types of illness the patient was experiencing and the presence of a living will or formal DPOA-HC.
6. One hundred and fifty-five patients (96.9%) had evidence of family involvement on admission. An informal DPOA-HC guided the actions of healthcare workers caring for 108 patients (67.5%). There was a strong, significant relationship found between the presence of family involvement at the time of admission and the recognition by staff of an informal DPOA-HC ($p < 0.001$).

7. There was no relationship found between the presence of formal or informal advance directives and admission or transfer to the ICU or the unit site of death.
8. There was no relationship found between the presence of formal or informal advance directives and life-sustaining measures, except for invasive procedures. There was a significant relationship found between the presence of an informal DPOA-HC and invasive procedures (with the exception of cardiac catheterizations) ($p < 0.05$).
9. There was no relationship found between the presence of a formal or informal advance directive and the presence of a comfort care plan or the prescription of morphine.
10. Ninety patients (56.3%) had documentation of terminal pain found in their medical record.
11. Patients with a comfort care plan were more likely to receive morphine than were patients without a comfort care plan ($p < 0.001$). Morphine was prescribed more often for patients with terminal pain ($p < 0.001$) and shortness of breath ($p < 0.05$) than for those without.
12. Data suggested that comfort care plans were ordered more often for patients with cardiovascular disease, cancer, neurological disorders, and gastrointestinal diseases or disorders ($p < 0.05$).
13. Of those with a comfort care plan in place, 25 (29.1%) did not have morphine ordered for them.

14. Those patients who did not receive antibiotics were more likely to have comfort care plans in place ($p < 0.05$).
15. There was a strong significant relationship found between those patients who were considered dying and the initiation of a comfort care plan ($p < 0.001$).
16. The presence of terminal anxiety was found to be significantly related to the presence of an informal DPOA-HC ($p < 0.05$).
17. Only three patients (1.9%) had documentation reflecting a visit by a chaplain.
18. Patients with a living will in their medical records were less likely to receive CPR at the end of their lives ($p < 0.05$).
19. The presence of a living will was found to be significantly related to the writing of a do-not-resuscitate (DNR) order ($p < 0.05$).
20. Patients with a DNR order in their medical records were less likely to receive CPR at the end of their lives ($p < 0.001$).
21. There was a strong significant relationship between the admission diagnosis and the diagnosis at death ($p < 0.001$).
22. There was a significant relationship found between the patient's length of stay and the number of consultants who saw the patient ($p < 0.001$).
23. There were no advantages found to arranging the study as a case-control investigation. There appeared to be differences between patients who wrote living wills and those who prepared a formal DPOA-HC. These differences were missed when the data was pooled.

Discussion of Findings Related to the Research Questions

The findings of the study can be related to the research questions.

1. ***What is the likelihood that elderly patients will execute formal or informal advance directives?***

The Patient Self-Determination Act had been in effect for over 10 years when the patients of this study died as patients in a community hospital. Since 1991, the federal government has mandated that hospitals receiving federal reimbursement (i.e., Medicare and Medicaid) document whether or not each patient has advance directives in place. On arrival to the hospital for their terminal hospitalization, each of the patients who became subjects in this study was asked to provide a copy of a living will or a durable power of attorney for healthcare for the medical record, if these documents were written.

Less than 27% (26.9%; n = 43) of the patients in this study had a copy of their written living will placed in their medical records. Formal durable powers of attorney for healthcare were placed in the charts of 20.6% (n = 33) of the patients. An informal DPOA-HC was recognized by staff for 76.3% (n = 122) of the patients. Among this sample of elderly, there was a significant relationship between the presence of a formal living will and a formal DPOA-HC ($p < 0.001$). This finding suggests that patients who prepared one document were likely to have prepared the other. This is not surprising as many of those who prepare the documents for their elderly clients prepare the living will and the DPOA-HC together.

Patients admitted from nursing homes were found to be most likely to have completed a living will. A possible explanation could be that many long-term care institutions require the completion of advance directives on admission to the facility. It is interesting that the same significant relationship did not exist with formal durable powers of attorney for healthcare.

Fins, et al. (1999) reported that 28% of their sample had completed a DPOA-HC, a higher percentage than the 20.6% found in this study. Unfortunately, they did not present the frequency data describing the presence of a living will in the medical record in the report of their study. A comparison of the findings of the SUPPORT study, Fins study, and this study are presented in Table 5.1.

In a sample of 135 patients, Gilbert, Counsell, Guin, O'Neill, and Briggs (2001) found that 35 (25.9%) had advanced directives in place. To gain perspective, a review of pre-PSDA data revealed that only 9.8% of 14,000 subjects had completed living wills by the time of their deaths in 1986 (Hanson & Rodgman, 1996). When the findings of post-PDSA researchers are compared with the findings of the current study, no real increase in the preparation of advance directives is apparent.

The results of the scientific research endeavors described above make the claims of the popular press appear inflated. Articles in *Time* Magazine (Cloud, 2000) and *Modern Maturity* (2000) claimed that popular polls have found some 30-55% of U.S. citizens with advance directives in place.

Table 5.1

A Comparison of the Findings of Three Studies

	SUPPORT (1995)	Fins, et al. (1999)	Current Study
Sample Size	4,301 (Phase 1) Mean age 65	200 Mean age 68	160 Mean age 81
Setting	5 teaching hospitals	Large, urban academic medical center	155-bed community hospital
DPOA-HC	*	28%	20.6%
Days in ICU	38% had 10 days or more Median = 8 days	55.3% were admitted or transferred to ICU Median = 5 days	63.8% were admitted or transferred to ICU Median = 2 days
Patients Identified as Dying	*	72%	75%
Patients Placed on Vent	46%	46%	22.5%
Pain Reported	22-50%	*	56.3%
Comfort Care Plans	*	46%	53.8%
Morphine Used	*	31%	51.9%
DNR Order Written	79%	77%	93.1%
CPR at the End of Life	*	25%	7.5%

* Not included in the study report

Past researchers have attempted to clarify the reasons why people chose to complete or not complete advance directives. Hamel, Guse, Hawranik, and Bond (2002) reported that barriers to completion of advance directives included a present orientation to life and a tendency to trust others to decide. Inman (2002) reported that 78% of her sample had discussed their end-of-life wishes with someone, most often their child (or children). Nearly 97% of the subjects in this study had evidence of family involvement on admission in their medical record. During the hospitalization, the decisions of healthcare providers were influenced by an informal durable power of attorney for healthcare for 67.5% of the subjects.

When the relationship between the presence of family involvement at the time of admission and the recognition by staff of an informal DPOA-HC was considered, a strongly significant positive relationship was found ($p < 0.001$). No significant relationships were found between the presence of family involvement on admission and the presence of the formal documents. The possibility of strong family support as a barrier to the completion of formal advance directives must be recognized, although there is no way to confirm it using the data gathered in this study. Investigation into the presence and importance of family at the end of life provides an opportunity for future study.

There was no significant relationship found between patients who wrote advance directives and their demographic variables in this study. The variable of interest, education, proved to be problematic in data analysis because the number of patients with a documented level of education in their medical record was so small ($n = 35$). When the level of education was considered outside of the logistic regression model, Chi square analysis revealed a significant direct relationship between those with higher levels of education and the preparation of a formal DPOA-HC ($p < 0.05$). The same significant relationship was not found, however, between level of education and the preparation of a living will. The results of this study confirm (at least partially) the findings of past researchers who demonstrated that level of education was an important demographic factor. Those with higher levels of education do appear to be more likely to prepare the formal documents (Hanson & Rodgman, 1996; Mezey, et al., 2000).

Care situation prior to admission was found to be significantly related to the presence of a living will ($p < 0.05$). Those subjects admitted from a nursing home were found to have completed living wills more frequently than expected when compared with other pre-admission care situations. Conversely, and possibly confirming the importance of the presence of family on the decision of the person not to complete the document, those coming from private homes were found to have completed living wills less frequently than expected when compared with other pre-admission situations. The relationship between care situation and the presence of a DPOA-HC was not found to be significant.

No significant relationship was found in this study between the patient's admission diagnosis and the likelihood that the patient would prepare advance directives. In contrast, Hanson and Rodgman (1996) found that persons who died with cancer or pulmonary diseases were more likely to have advance directives in place than those with other diseases or disorders.

2. a. What is the relationship between the presence of advance directives and the decision of healthcare providers treat the patient in the ICU?

One hundred and two (63.8%) of the patients were either admitted or transferred to the intensive care areas during their hospitalizations. Sixty-seven (41.9%) of the patients died there. The mean length of stay in the intensive care areas was 4.49 days. There was no significant relationship found between the presence of a written living will, formal DPOA-HC, or informal DPOA-HC and admission or transfer to the ICU. There was also no significant relationship found between the presence of any advance directive and the unit site of death.

In the SUPPORT study, 38% of the subjects spent at least 10 days in the ICU; the median number of days spent in ICU, comatose, or receiving mechanical ventilation was eight (SUPPORT Principle Investigators, 1995). Fins, et al. (1999) reported that the mean length of stay in the ICU for patients in their study was 10.7 days. Although the length of stay in the intensive care units was higher than in the current study, the percentage of patients who died there was nearly the same (41% vs. 41.9%).

In the past, the ICU has been defined by technology. Healthcare providers who worked there have been portrayed as promoting the extension of life, often in exchange for quality of life. In reaction to this perception and accepting the fact that nearly 20% of those who die each year in this country die in the ICU, there is a growing body of literature addressing the use of ICU as an appropriate environment for end-of-life care. One nurse author proposed that nurses in ICU "have the knowledge and time to provide good end-of-life care, particularly for older adults" (Trossman, 2004, p. 1).

The argument remains that ICU care is expensive. Although more than 95% of SUPPORT patients had health insurance, about one third (31%) of the families reported losing a considerable portion of their savings as a result of direct or indirect healthcare expenses (Lynn, 1996). Nationwide, the cost of care during the patient's last year of life varies widely but averages $26,000 per patient. For all Medicare recipients, the last year of health care accounts for 28% of Medicare total costs (Center to Advance Palliative Care, 2002).

2. b. What is the relationship between the presence of advance directives and the decision of healthcare providers to use life-sustaining treatments?

There were no significant relationships found between the presence of formal or informal advance directives and the life-sustaining variables of mechanical ventilation, artificial nutrition, the use of vasopressors, antibiotics, blood transfusions, or blood draws for laboratory studies. Thirty-six patients (22.5%) were placed on mechanical ventilation during their hospital stay. Mechanical ventilation was withdrawn before death for 23 patients. Thirty-two patients (20%) received artificial nutrition during their hospitalization. Fourteen of those patients were withdrawn from their feedings before death. Fifty-seven patients (35.6%) received a vasopressor medication to maintain their blood pressure at some point. Most (83.1%; n = 133) received antibiotics; the majority (n = 130) continued to receive them until they died. Thirty-one patients (19.4%) received blood transfusions and 155 (96.9%) had blood drawn routinely for laboratory studies.

In the SUPPORT study, 46% of patients received mechanical ventilation within three days of their death (SUPPORT Principle Investigators, 1995). Fins, et al. (1999) also reported that 46% of the patients in their study were mechanically ventilated at some point during their hospitalization; 13% of those patients were withdrawn before death. Artificial nutrition and hydration were provided for 30%; 19% of those patients were withdrawn before death. Antibiotics were provided for 41% of patients and blood was collected for routine laboratory tests for 30% of the patients, both much lower percentages than found in the current study.

In their study, Nahm and Resnick (2001) found that the majority of participants questioned about possible treatments offered at the end of life were willing to receive antibiotics and blood transfusions. A large number of patients in this study did receive antibiotics and transfusions.

In the current study, 45 patients (28.1%) underwent invasive procedures. A positive significant relationship was found between the recognition of an informal DPOA-HC and the performance of invasive procedures (with the exception of cardiac catheterizations) ($p < 0.05$), suggesting that patients with a person recognized by healthcare providers as the patients' representative were found to be more likely to have undergone invasive procedures than those patients who did not have someone recognized as speaking on their behalf. There were no relationships found between the recognition of the formal documents and the use of invasive procedures.

Past research has demonstrated that the desirability of the treatment intervention depends greatly on its outcome. Fried, Bradley, Towle, and Allore (2002) found that the burden of treatment (such as the length of hospital stay, extent of testing, and invasiveness of the interventions) inversely influenced the treatment preferences in a sample of elderly persons. The situation found in the current study, however, was that those recognized as speaking on behalf of the patient (the informal DPOA-HC) agreed to the invasive (and most likely futile) procedures, not the patient. A possible reason for this finding may be the desire of family and friends to "do everything possible" for the patient, perhaps at the recommendation of the patient's physician.

2. c. What is the relationship between the presence of advance directives and the decision of healthcare providers to initiate the use of comfort care plans?

In contrast to the findings of Fins, et al. (1999) who found a significant relationship between the presence of a DPOA-HC and a comfort care plan, there was no significant relationship found in this study between the presence or recognition of any type of advance directive and the presence of a comfort care plan. There was also no significant relationship found between the presence of any advance directive and the prescription of morphine. Patients with a comfort care plan in place, however, were found to be more likely to have morphine ordered to control their pain ($p < 0.001$). Ninety patients (56.3%) had documentation describing terminal pain found in their medical record. Morphine was prescribed significantly more often for patients with documented terminal pain and ($p < 0.001$) and shortness of breath ($p < 0.05$) than for patients who did not have those symptoms. The presence of a morphine order, however, did not did not mean the patient did not die in pain. Sixty-two of the 83 patients who received morphine had evidence of terminal pain during the last two days of their lives, suggesting that the pain of those 62 patients was never effectively controlled.

An interesting finding was that 25 of the patients with a comfort care plan (29.1%) did not have morphine ordered for them. They received medications such as meperidine (*Demerol*), ketorolac (*Torodol*), and lorazepam (*Ativan*) in its place. Morphine sulfate, an opiod, is considered a mainstay of pain treatment at the end of life and, in addition, is the standard treatment for the relief of dyspnea (Hospice and Palliative Nurses Association, 1996; World Health Organization, 1996).

Past researchers have also documented that the presence of terminal pain is common. The SUPPORT Investigators (1995) found that half of the conscious patients in their study experienced moderate or severe pain during their last three days of life at least half of the time. Unfortunately, the findings of this study confirm that at least half of terminal patients can continue to expect pain during their last days of life.

Since the SUPPORT study, adequate pain and symptom management have been found to be a significant concern of dying patients and qualitative studies have been consistent in identifying the management of pain as paramount in end-of-life care (Singer, Martin, & Kelner, 1999; Steinhauser, Clipp, McNeilly, Christakis, McIntyre, and Tulsky, 2000). In the quest for the *good death*, a painful death is identified as a *bad death* (Vig & Pearlman, 2004).

As noted in the previous section, most patients (83.1%) received antibiotics. There was a relatively weak but significant relationship found between those patients who did not receive antibiotics and the presence of a comfort care plan ($p < 0.05$). In a discussion why such a high percentage of their patients continued to receive antibiotics and phlebotomy procedures (41% and 30%, respectively), Fins, et al. (1999) stated that "the uncertainty of short-term prognosis for acutely ill patients of advanced age with progressive, terminal conditions may make appropriate a mixed management strategy involving both life-prolonging and palliative measures" (p. 11).

The presence of anxiety was found to be significantly related to the presence of an informal DPOA-HC ($p < 0.05$). Past researchers have found that the elderly do not want to become a burden to their loved ones (Hamel, et al., 2002; Singer, Martin, & Kelner, 1999) and it can be hypothesized that anxiety may have resulted from the perception that the patients in this study felt they were a burden to their family or friends.

A positive significant relationship was found in the current study between those patients who were considered dying and the initiation of a comfort care plan

($p < 0.001$). This implies at least a recognition by healthcare providers of the need to change the focus of patient care from curative to palliative.

An interesting significant relationship was found between the patient's admission diagnosis and the initiation of a comfort care plan. Data suggested that comfort care plans were ordered significantly more often for patients with cardiovascular disease, cancer, neurological disorders, and gastrointestinal diseases or disorders than for patients with sepsis, pulmonary disease, metabolic disease, orthopedic disorders, or genitourinary diseases or disorders ($p < 0.05$). An exploration into whether the patients grouped according to their admission diagnoses were recognized as dying at all displayed a trend, but no significance.

An interesting (but disappointing) finding was that only three of the patients (1.9%) in this study had visits by a chaplain documented in their medical record. On admission, 92 (57%) identified a religious affiliation. The importance of spirituality or meaningfulness at the end of life has been found to be important to elderly patients when they considered their end-of-life care (Ferrell, 1995; Steinhauser, et al., 2000). Spirituality is one of the dimensions included in the Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project, 2004). It is possible that the chaplains' visits were not being captured in the medical record as the chaplains could have entered and left the patients' rooms without being seen by the nurses. If this finding reflects the practice at this community hospital, an important component of quality end-of-life care is missing.

2. d. *What is the relationship between the presence of advance directives and the decision of healthcare providers to use CPR?*

Patients with a formal living will in their medical records were found to be less likely to receive CPR at the end of their lives than those who did not have the document in their records ($p < 0.05$). The presence of a living will was also found to be significantly related to the writing of a DNR order ($p < 0.05$). There were no significant relationships found when formal or informal durable powers of attorney were considered with each of the variables.

The majority of patients in this study (93.1%) had a DNR order in place at the time of their death. The mean number of days between the writing of the DNR order and death was 4.33 days.

There was a strong inverse significant relationship found between those patients with a DNR order in their medical records and those who received CPR at the end of their lives ($p < 0.001$). Although a written DNR order was in place, CPR was initiated for one patient and, if not for the nurse at the bedside, would have been initiated for a second.

The SUPPORT Investigators (1995) found that 79% of their study patients who died before discharge had a DNR order in place, nearly one-half (46%) written within two days of death. Fins, et al. (1999) reported that 77% of their study patients had DNR orders in place prior to their death. The mean time between DNR order and death was 9.1 days. Nonetheless, they reported that 25% of their patients underwent CPR prior to death.

In this study, the presence of a living will was significantly related to having a written DNR order in the medical record and not having CPR performed at the end of life. It is commendable that the living wills of the patients in this study appear to have been respected. Other researchers have found that 25-50% of nurses had seen other healthcare providers deliberately disregard a patient's advance directives (Wolfe, 1998). When physicians were considered, 34 % of physicians had continued life-sustaining treatment despite patient or proxy wishes that it be discontinued (Asch, Hansen-Flaschen, & Lanken, 1995).

As noted above, in this study there was no significant relationship found between the presence of a formal or informal DPOA-HC and a written DNR order. This may once again indicate the reluctance of family or friends to give up on the patient's treatment.

Although there was a perception that the admission and death diagnoses differed, a strong significant relationship between the admission diagnosis and the diagnosis at death did exist ($p < 0.001$). There was no significant relationship found between the patient's length of stay and diagnosis at death. Finally, there was a significant relationship found between the patient's length of stay and the number of consultants who saw the patient ($p < 0.001$).

Conclusions and Implications

The following conclusions are offered:

1. The percentage of people in this country completing formal advanced directives has not changed much since the findings of the SUPPORT study were released.
2. Patients who completed one formal document were found to be likely to complete the other, indicating effectiveness of the “combined approach” to completing advance directives used by senior citizen groups and lawyers.
3. Family support appeared to be a substitute for preparing the formal documents, although family members were often found to expose the patient to additional suffering. Patients with a strong family presence (as noted by the recognition of an informal DPOA-HC) were found to be more likely to undergo invasive procedures and experience more anxiety than those without an acknowledged family presence. This may represent the family’s reluctance to “let go” of the patient, perhaps at the recommendation of the healthcare provider.
4. Healthcare providers were not influenced by the presence of any advance directives in their decisions involving the unit of treatment, the use of life-sustaining treatments, or the initiation of comfort care plans.
5. Healthcare providers appeared to be influenced by the presence of a living will in their decisions to write DNR orders more often and use CPR less often for patients possessing the document.

6. Healthcare providers did not appear to acknowledge the multidimensionality of end-of-life care, neglecting to support the spiritual needs of their patients.
7. At least half of dying patients continued to experience pain during their last days of life, unchanged over the past decade, in spite of increased public concern and the published research-based protocols available. More than one-quarter of the patients with a "comfort care plan" in place were not treated with medications accepted as standard of care.

The findings of this study demonstrate that only slight improvements in the quality of care that dying patients receive have taken place over the last decade. On first glance it appears as if not much has changed since SUPPORT (SUPPORT Principle Investigators, 1995). As the investigators concluded:

> We are left with a troubling situation. The picture we describe of the care of seriously ill or dying persons is not attractive. One would certainly prefer to envision that, when confronted with life-threatening illness, the patient and family would be included in discussions, realistic estimates of outcome would be valued, pain would be treated, and dying would not be prolonged. (p. 1597)

The intent of the Patient Self-Determination Act has not yet been realized. Based upon the findings of this study, it appears that formal advance directives, when written at all, were often ignored, except at the very end of life. Educational efforts to raise both community and professional awareness of the importance of these documents continue to be needed.

The future does hold promise for improvement. Many members of today's older generation believe that end-of-life decision-making is the prerogative of their families or their physicians (Palker & Nettles-Carlson, 1995). The Baby Boomers, however, are the next generation. Currently, this largest of generations is watching their parents grow old and die. Hamel, et al. (2002) found that one of the reasons for completing advance directives was having witnessed the suffering and death of a loved one.

The death of a loved one has been identified as a "disorienting dilemma" which provides the opportunity to initiate the process of transformational learning (Mezirow, 1991). Transformational learning, a theory of adult learning, provides a promising framework for present and future educational programs addressing the end-of-life issues central to this study. The process of transformational learning follows a series of three steps: the experience of the disorienting dilemma; self-examination and critical assessment of assumptions; and the engagement in reflective discourse, a recognition that others have gone through a similar process. This third step leads to the formulation of a plan of action, not merely seeing, but living the new perspective (Baumgartner, 2001). A benefit of transformational learning has been identified as the development of greater autonomy as a person (Mezirow, 1997).

Metaphors, role playing, case studies, and literature offer ways to stimulate transformational learning and critical reflection (Mezirow, 1997). Since the disturbing findings of the Institute of Medicine were published in 1997, the quest for the *good death* has included efforts by the media to support end-of-life care reform. Written in 1993 by Margaret Edson, the Pulitzer Prize winning play *Wit* chronicled a professor's experience with advanced ovarian cancer. The play was produced on Broadway and was made into a popular film in 2001. Since then, the play has been performed more than 100 times by professional and amateur theaters in every state in the country. The play has had such a lasting effect on audiences that a *Wit* educational initiative has been created and funded to bring *Wit* readings or full performances to medical students, residents, and medical school faculty (Blacksher & Christopher, 2002).

Several programs produced for television have also helped to increase awareness the need for end-of-life reform. *On Our Own Terms* was a four-part series produced for the Public Broadcasting Service, hosted by Bill Moyers, and seen by some 20 million viewers. Likewise, Mitch Albom's *Tuesdays with Morrie* became a television movie in 1999 and touchingly portrayed the slow death of the writer's mentor (Blacksher & Christopher, 2002).

Raising community awareness is important, but raising professional awareness is key to improving the care provided to our dying. In the past, many physician-related attitudes and behaviors were identified that perpetuated poor care for the dying. Researchers studying barriers to the improvement of care identified a physician lack of knowledge regarding advance directives, physician lack of knowledge regarding care at the end of life, and physician belief that death is an inappropriate outcome of care (General Accounting Office, 1995).

Healthcare providers have been trained for generations to cure their patients. The latest generation of providers, however, is being trained differently. The most promising educational initiatives designed to change the attitudes and behaviors of healthcare providers have been funded by the Robert Wood Johnson (RWJ) Foundation. Through a grant from the RWJ Foundation, the American Medical Association developed a program to promote positive reform in end-of-life care. Created in 1998, the Education on Palliative and End-of-Life Care (EPEC) Project is designed to equip medical students with the basic knowledge and skills needed to appropriately care for dying patients, with the aim of avoiding needless suffering “in order to permit experiences that will have positive meaning” (EPEC Project, 1999, p. P3-1).

A comparable program has been developed for nurse educators. The End-of-Life Nursing Education Consortium (ELNEC) is a comprehensive, national education program to improve the end-of-life care that nurses provide to their dying patients. Formed as a partnership between the American Association of Colleges of Nurses (AACN) and the City of Hope National Medical Center, it is also funded by a grant from the RWJ Foundation. Since the project began in February, 2000, the Consortium has sponsored 13 courses to develop a core of expert nursing educators with the goal of coordinating national education efforts in end-of-life care. To date, over 1,500 nurse educators representing all 50 states (including the writer of this dissertation) have received ELNEC training and have taken their materials back to their nursing programs, hospitals, nursing homes, and hospices (AACN, n.d).

Nurses, by their defined role, are patient educators and advocates. At the bedside, they are in a position to provide support and information and to make referrals related to end-of-life decisions (Brown, 2003). Nurse practitioners working with geriatric populations have also been described as well-suited to encourage patients to consider end-of-life treatment options before they become critically ill or cognitively incapable of making decisions (Goodwin, Kiehl, & Peterson, 2002; Resnick & Andrews, 2002). Several researchers have documented the success of such educational efforts (Hamel, et. al., 2002; Hammes & Rooney, 1998).

The efforts to publicize the specialty of palliative care are slowly making a difference. Instead of caring for the dying in the ICU, the Center for Palliative Care promotes caring for patients in Palliative Care Units, focusing on patient comfort, not patient cure (Center to Advance Palliative Care, 2002). Currently, fewer than 20% of hospitals in the United States have such units, but the number is growing. In 2002, there were palliative care programs in 844 community hospitals, but that reflects an increase of 18% when compared with the previous year. A report published in the Wall Street Journal describing the state-of-the-art palliative care unit at Virginia Commonwealth University (VCU) Medical Center stated,

> A typical five-day stint for a cancer patient cost $5,312 in the palliative wing-57% less than it cost to house a similar patient elsewhere in the hospital. VCU officials calculate that the 11-bed unit, which opened in May, 2000, saved the hospital $1 million last year. (Naik, 2002, p. 2)

All people in this country today should be encouraged to consider their end-of-life choices before the end of their lives. They should execute the formal documents, if they feel comfortable doing so. At a minimum, they should discuss their end-of-life choices with their family, friends, and healthcare providers so that their choices are known and can be respected if they are unable to speak for themselves. On the other hand, healthcare providers should inquire about and then respect their patients' advance directives; it is their moral and professional obligation to do so (Beauchamp & Childress, 2001).

As the Baby Boomers themselves grow older, the number of people in the U.S. over the age of 85 is expected to swell to 8.9 million by the year 2030 (U.S. Census Bureau, n.d.). It is the task of future researchers to quantify and qualify the effectiveness of past, present, and future educational initiatives directed at tomorrow's consumers of end-of-life care. Hopefully, the researchers will find that the aging Boomers realize that they have a choice in how they die, acknowledging that the PSDA has empowered them with a voice to accept or reject the options technology offers. Hopefully, the researchers will also find that healthcare providers respect the autonomous decisions of their patients and empower and enable them to die in comfort and with dignity.

Recommendations

Based upon the findings of this study, the following recommendations are offered:

1. To replicate this study using samples drawn from multiple facilities from this and other regions of the country to confirm generalizability to other populations.

2. To investigate further the importance of the presence of family in the decision to write formal documents.
3. To continue the education of both healthcare consumers and their healthcare providers on the writing and respect of advance directives and to continue research as to the effectiveness of educational efforts.
4. To promote the development and implementation of evidence-based protocols to enable healthcare providers to more effectively address the multidimensional domains of end-of-life care, ultimately contributing to a death with dignity.

REFERENCES

American Association of Colleges of Nursing (AACN) (n.d.). ELNEC Project: ELNEC fact sheet. Retrieved October 9, 2004, from http://www.aacn.nche.edu/elnec/factsheet.htm

Asch, D. A., Hansen-Flashen, J., & Lanken, P. N. (1995). Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: Conflicts between physicians' practices and patients' wishes. American Journal of Respiratory and Critical Care Medicine, 151, 288-292.

Baumgartner, L. M. (2001). An update on transformational learning. *The new update on adult learning theory, 89,* 15-24.

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics* (5th ed.). New York: Oxford University Press.

Blacksher, E., & Christopher, M. (2002). On the road to reform: Advocacy and activism in end-of-life care. *Journal of Palliative Medicine, 5,* 13-22.

Brown, B.A. (2003). The history of advanced directives: A literature review. *Journal of Gerontological Nursing, 29* (9), 4-14.

Center to Advance Palliative Care. (2002). The case for hospital-based palliative care. Retrieved October 30, 2002, from http://www.capc.org

Chambers, C. V., Diamond, J. J., Perkel, R. L., & Lasch. L. A. (1994). Relationship of advance directives to hospital charges in a Medicare population. *Archives of Internal* Medicine, 154, 541-547.

Cloud, J. (2000, September 18). A kinder, gentler death. *Time, 156*, 60-67.

Collins, S. E. (1999). Rethinking the Patient Self-Determination Act: Implementation without effectiveness. *Journal of Nursing Law, 6,* 29-46.

Eleazer, G. P., Hornung, C. A., Egbert, C. B., Egbert, J. R., Eng, C., Hedgepeth, J., McCann, R., Strothers, H., Sapir, M., Wei, M., & Wilson, M. (1996). The relationship between ethnicity and advance directives in a frail older population. *Journal of the American Geriatrics Society, 44,* 938-943.

EPEC Project (1999). EPEC Participant's Handbook: Plenary 3: Elements and models of end-of-life care. Retrieved October 9, 2004, from http://www.ama-assn.org/ama/pub/category/2910.html

Ferrell, B. R. (1995). The impact of pain on quality of life. *Nursing Clinics of North America, 30*, 609-624.

Fins, J. J., Miller, F. G., Acres, C. A., Bacchetta, M. D., Huzzard, L. L., & Rapkin, B. D. (1999). End-of-life decision-making in the hospital: Current practice and future prospects. *Journal of Pain and Symptom Management, 17*, 6-15.

Fried, T. R., Bradley, E. H., Towle, V. R., & Allore, H. (2002). Understanding the treatment preferences of seriously ill patients. *New England Journal of Medicine, 346,* 1061-1066.

General Accounting Office (1995). *Patient Self-Determination Act: Providers offer information on advanced directives but effectiveness uncertain.* Letter Report 95-135. Washington, DC: Author.

Gilbert, M., Counsell, C.M., Guin, P., O'Neill, R., & Briggs, S. (2001). Determining the relationship between end-of-life decisions expressed in advance directives and resuscitation efforts during cardiopulmonary resuscitation. *Outcomes Management for Nursing Practice, 5* (2), 87-92.

Goodwin, Z., Kiehl, E. M., & Peterson, J. Z. (2002). King's theory as foundation for an advance directive decision-making model. *Nursing Science Quarterly, 15,* 237-241.

Hamel, C. F., Guse, L. W., Hawranik, P. G., & Bond, J. B. (2002). Advance directives and community-dwelling older adults. *Western Journal of Nursing Research, 24,* 143-158.

Hammes, B. J., & Rooney, B. L. (1998). Death and end-of-life planning in one midwestern community. *Archives of Internal Medicine, 158,* 383-390.

Hanson, L. C., & Rodgman, E. (1996). The use of living wills at the end of life: A national study. *Archives of Internal Medicine, 156,* 1018-1022.

Hecht, M. B. (1996-2003). Advance medical directives (Living will, power of attorney, and health care proxy). Retrieved November 23, 2003, from http://www.medicinenet.com/script/main/art.asp?articlekey=7813&pf=3&track=qpa7813

Hospice and Palliative Nurses Association (1996). *Clinical practice protocol: Dyspnea*. Pittsburgh: Author.

Inman, L. (2002). Advance directives: Why community-based older adults do not discuss their wishes. *Journal of Gerontological Nursing, 28* (9), 40-46.

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

Karen Ann Quinlan (n.d.). Retrieved March 8, 2003, from http://www.who2.com/karenannquinlan.html

Kyba, L. (2002). Legal and ethical issues in end-of-life care. *Critical Care Nursing Clinics of North America, 14,* 141-155.

Last Acts. (2002). *Means to a better end: A report on dying in America today.* Retrieved November 21, 2002, from http://www.lastacts.org

Lawrence, V. A., Hilsenbeck, S. G., Noveck, H., Poses, R. M., & Carlson, J. L. (2002). Medical complications and outcomes after hip fracture repair. *Archives of Internal Medicine, 162,* 2053-2057.

Levin, S. M. (1990). Patient Self-determination Act of 1990- Hon. Sander M. Levin (Extension of remarks, April 3, 1990). Retrieved October 25, 2003, from http://thomas.loc.gov/cgi-bin/query/F?r101:1:./temp/~r101Gw1OOG:e0:

Lynn, J. (1996). Care and cost savings at the end of life. *Journal of the American Medical Association, 276*, 1217.

Mezey, M. D., Leitman, R., Mitty, E. L., Bottrell, M. M., & Ramsey, G. C. (2000). Why hospital patients do and do not execute an advance directive. *Nursing Outlook, 48,* 165-171.

Mezirow, J. (1991). *Tranformative dimensions of adult learning*. San Francisco: Jossey-Bass.

Mezirow, J. (1997). Transformative learning: Theory to practice. *New Directions for Adult and Continuing Education, 74,* 5-12.

Modern Maturity (2000, September/October). Start the conversation: The Modern Maturity guide to end-of-life care. In K. L. Freiberg (Ed.), Annual Editions: *Human Development 2002/2003* (pp. 194-200). Guilford, CT: McGraw-Hill/Dushkin.

Nahm, E., & Resnick, B. (2001). End-of-life treatment preferences among older adults. *Nursing Ethics, 8,* 533-543.

Naik, G. (2004, March 10). Unlikely way to cut hospital costs: Comfort the dying. *Wall Street Journal Online*. Retrieved September 6, 2004, from http://webreprints.djreprints.com/1036690089843.html

National Consensus Project (2004). *Clinical practice guidelines for quality palliative care*. New York: Author.

Neutens, J. J., & Rubinson, L (2002). *Research techniques for the health sciences* (3rd ed.). San Francisco: Benjamin Cummings.

Palker, N., & Nettles-Carlson, B. (1995). The prevalence of Ads: Lessons from a nursing home. *Nurse Practitioner, 20* (2), 7-21,

Resnick, B., & Andrews, C. (2002). End-of-life treatment preferences among older adults: A nurse practitioner initiated intervention. Journal of the American Academy of Nurse Practitioners, 14, 517-522.

Rosoff, A. J. (n.d.). Evidenced –based medicine and the law: The courts confront clinical practice guidelines. Retrieved September 6, 2004, from http://www.ahrq.gov/clinic/jhppl/rosoff1.htm

Sackett, D. L., Rosenberg, W. M., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (n.d.). Evidence-based medicine: What it is and what it isn't. Retrieved September, 11, 2004, from http://www.cebm.net/ebm_is_isnt.asp

Schultz, A. A. (2004). Role of research in reconstructing global healthcare for the 21st century. *Nursing Administration Quarterly, 28,* 133-143.

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *JAMA, 281,* 163-169.

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, 132,* 825-832.

Suber, P. (1992). Self-determination and selfhood in recent legal cases. Retrieved October 16, 2003, from http://www.earlham.edu/~peters/writing/emerson.htm

Super, A. (2001). The context of palliative care in progressive illness. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of Palliative Nursing* (pp. 27-36). New York, NY: Oxford.

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatment (SUPPORT). *JAMA, 274,* 1591-1598.

Thompson, G., & McClement, S. (2002). Defining and determining quality in end-of-life care. *International Journal of Palliative Nursing, 8,* 288-293.

Tilden, V. P. (2000). Policy perspectives: Advance directives. *AJN, 100* (12), 49, 51.

Timms, J., Parker, V. G., Fallat, E. H., & Johnson, W. H. (2002). Documentation of characteristics of early hospital readmission of elderly patients: A challenge for inservice educators. *Journal for Nurses in Staff Development, 18* (3), 136-145.

Title 42, Chapter 7, Subchapter XVIII, Sec. 1395cc (1990). Retrieved November 23, 2003, from http://www4.law.cornell.edu/uscode/42/1395cc.html

Trossman, S. (2004). Critical initiatives: Palliative care services complement, not contradict ICU care. *American Nurse, 36* (4), 1, 7.

U.S. Census Bureau (n.d.). Projections of the total resident population by 5-year age groups, and sex with special age categories: Middle series, 2025 to 2045. Retrieved November 17, 2002, from http://www.census.gov/population/projections/nation/summary/np-t3-f.txt

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

Vig, E.K., & Pearlman, R.A. (2004). Good and bad dying from the perspective terminally ill men. Archives of Internal Medicine, 164, 977-981.

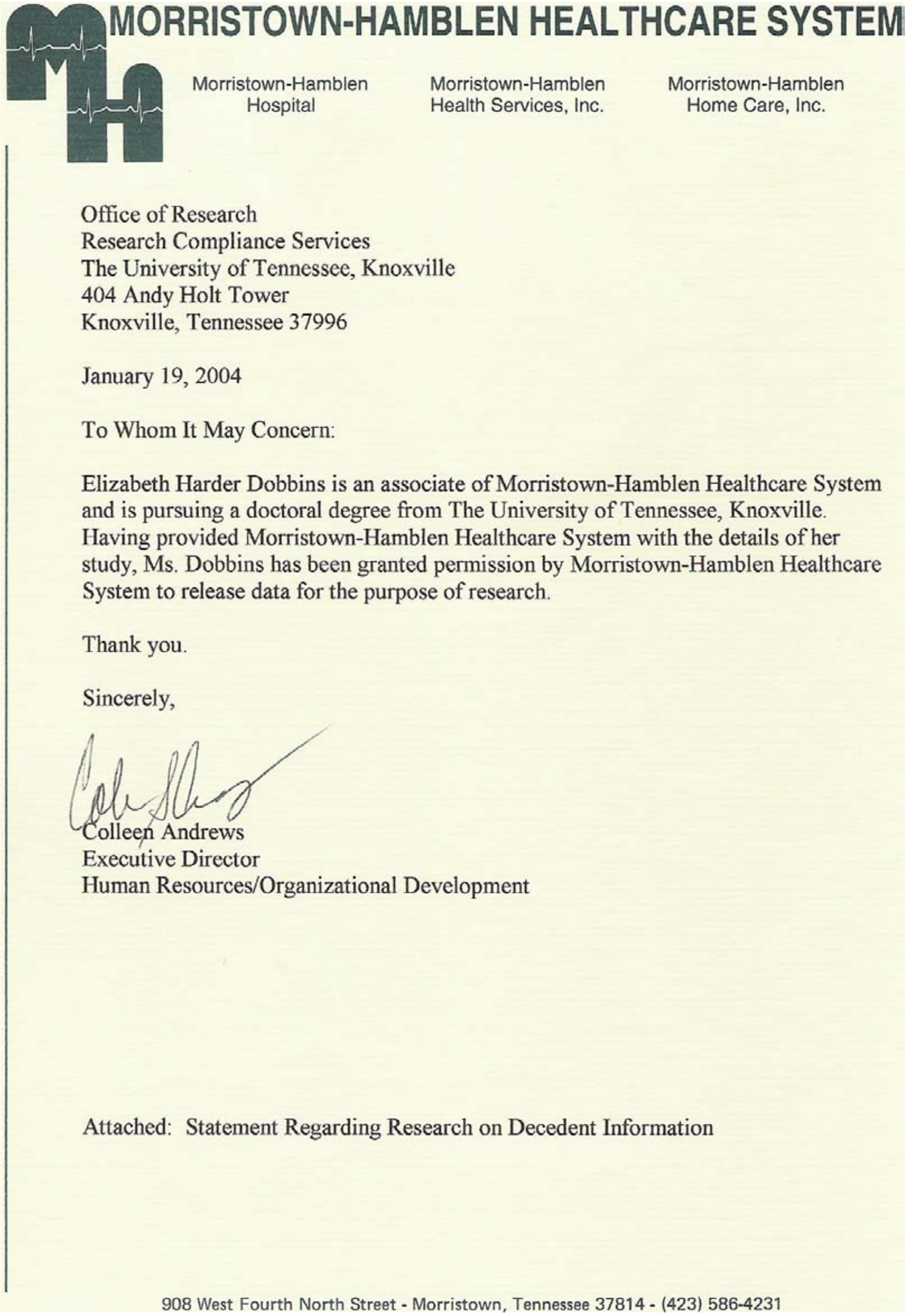
Vincent, C., Neale, G., Woloshynowych, M. (2001). Adverse events in British hospitals: Preliminary retrospective record review. *BMJ, 322,* 517-519.

Wolfe, S. (1998). When is it time to die? *RN, 61* (11), 50-54, 56.

World Health Organization (WHO) (1996). *Cancer pain relief and palliative care. Report of a WHO expert committee* (WHO Technical Support Series, No. 804). Geneva: Author.

APPENDICES

APPENDIX A: Letters of Permission to Conduct Research



MORRISTOWN-HAMBLEN HEALTHCARE SYSTEM

Morristown-Hamblen
Hospital

Morristown-Hamblen
Health Services, Inc.

Morristown-Hamblen
Home Care, Inc.

Office of Research
Research Compliance Services
The University of Tennessee, Knoxville
404 Andy Holt Tower
Knoxville, Tennessee 37996

January 19, 2004

To Whom It May Concern:

Elizabeth Harder Dobbins is an associate of Morristown-Hamblen Healthcare System and is pursuing a doctoral degree from The University of Tennessee, Knoxville. Having provided Morristown-Hamblen Healthcare System with the details of her study, Ms. Dobbins has been granted permission by Morristown-Hamblen Healthcare System to release data for the purpose of research.

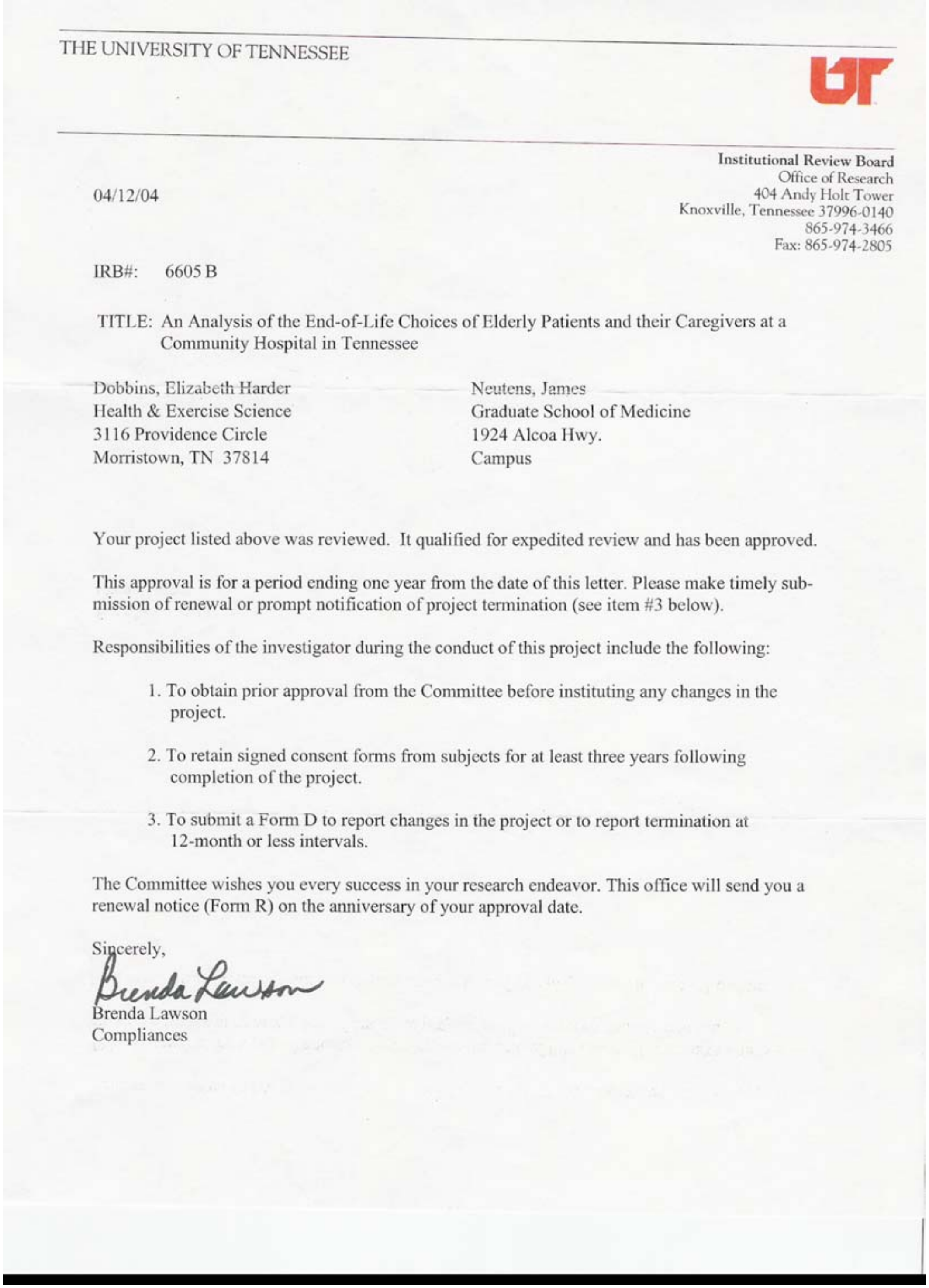
Thank you.

Sincerely,

Colleen Andrews
Executive Director
Human Resources/Organizational Development

Attached: Statement Regarding Research on Decedent Information

908 West Fourth North Street - Morristown, Tennessee 37814 - (423) 586-4231



THE UNIVERSITY OF TENNESSEE

Institutional Review Board
Office of Research
404 Andy Holt Tower
Knoxville, Tennessee 37996-0140
865-974-3466
Fax: 865-974-2805

04/12/04

IRB#: 6605 B

TITLE: An Analysis of the End-of-Life Choices of Elderly Patients and their Caregivers at a Community Hospital in Tennessee

Dobbins, Elizabeth Harder
Health & Exercise Science
3116 Providence Circle
Morristown, TN 37814

Neutens, James
Graduate School of Medicine
1924 Alcoa Hwy.
Campus

Your project listed above was reviewed. It qualified for expedited review and has been approved.

This approval is for a period ending one year from the date of this letter. Please make timely submission of renewal or prompt notification of project termination (see item #3 below).

Responsibilities of the investigator during the conduct of this project include the following:

1. To obtain prior approval from the Committee before instituting any changes in the project.
2. To retain signed consent forms from subjects for at least three years following completion of the project.
3. To submit a Form D to report changes in the project or to report termination at 12-month or less intervals.

The Committee wishes you every success in your research endeavor. This office will send you a renewal notice (Form R) on the anniversary of your approval date.

Sincerely,

Brenda Lawson

Brenda Lawson
Compliances

APPENDIX B: Letter of Permission to Use Instrument

MSN Hotmail

Page 1 of 1

Hotmail@ dobbinsbetsy@hotmail.com

Inbox I Previous Page

From: "Joseph Fins" <jjfins@med.comell.edu>
To: "Betsy Dobbins" <dobbinsbetsy@hotmail.com>
Subject: Re: Request for Permission to Use the 1996 Chart Survey Instrument
Date: Tue, 21 Jan 2003 11:50:07 -0500

I'd be delighted if you used the instrument. I'll send you a hard copy by regular mail. PIs just cite the source if you use it. Thanks for your interest.

Best, Joe

Dr. Fins,
I am a doctoral student at the University of Tennessee. My dissertation interest is how hospitalized elderly people are dying today- fully 10 years after being given an opportunity for voice through their advance directives. My suspicions are that things haven't changed much- from SUPPORT, through your 1996 study, to today. I am requesting your permission to use the 83-item instrument that you and your colleagues developed to audit the charts in that study of 200 deaths at The New York Hospital-Cornell Medical Center. I am also requesting a copy of the instrument.
I thank you, in advance, for your time and consideration of my request.
Sincerely,
Elizabeth H. Dobbins
3116 Providence Circle
Morristown, TN 37814

Joseph J. Fins, M.D., F.A.C.P.
Chief, Division of Medical Ethics
Associate Professor
Departments of Public Health and Medicine
Weill Medical College of Cornell University

Director of Medical Ethics
New York Presbyterian Hospital-Weill
525 East 68th Street F-173
NY NY 10021 USA
tel: 212-746-4246
fax:212-746-8738
jjfins@mail.med.comell.edu

`Cornell Center`

APPENDIX C: Chart Abstraction Instrument (Original Instrument)

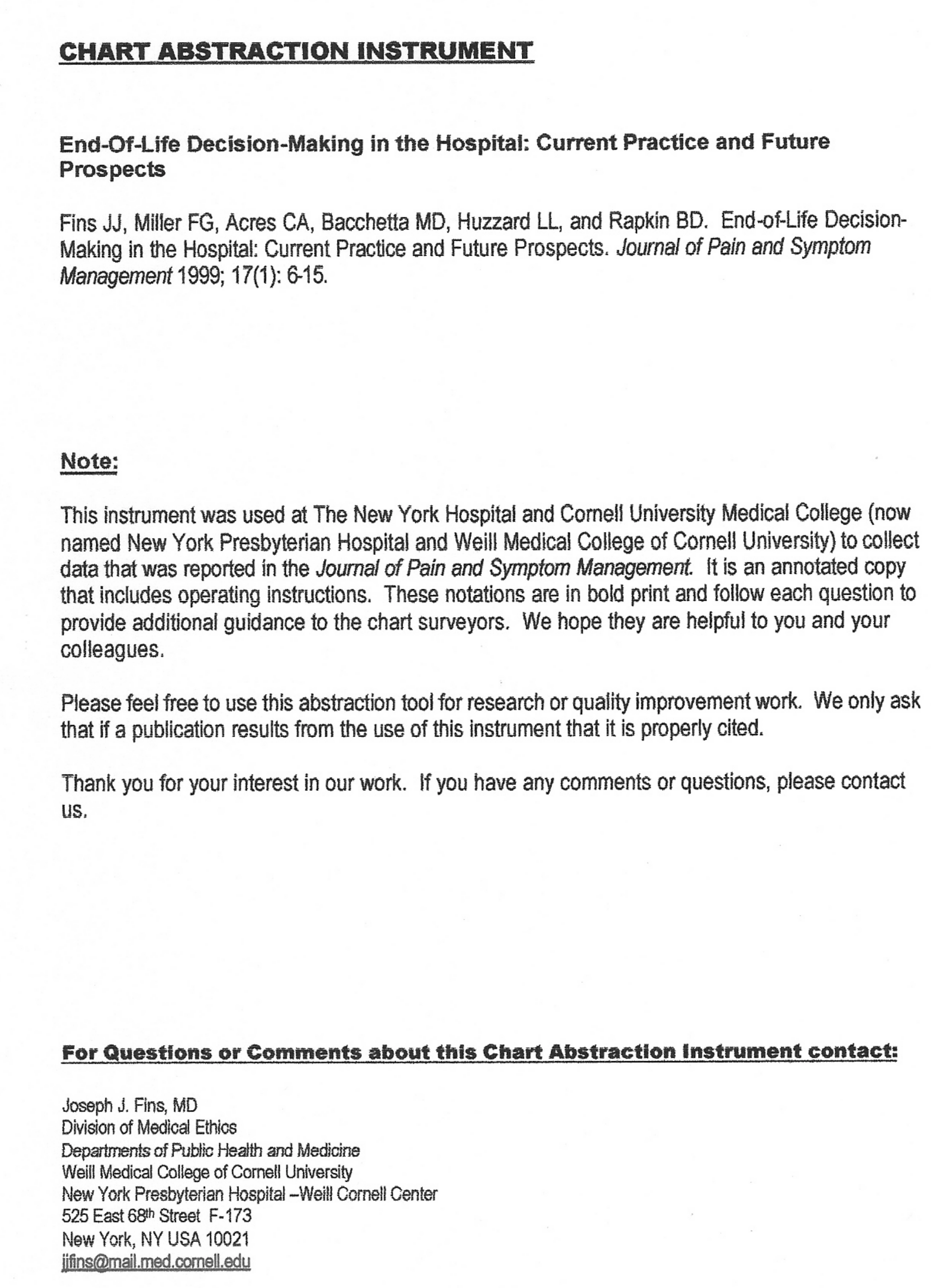


CHART ABSTRACTION INSTRUMENT

End-Of-Life Decision-Making in the Hospital: Current Practice and Future Prospects

Fins JJ, Miller FG, Acres CA, Bacchetta MD, Huzzard LL, and Rapkin BD. End-of-Life Decision-Making in the Hospital: Current Practice and Future Prospects. *Journal of Pain and Symptom Management* 1999; 17(1): 6-15.

Note:

This instrument was used at The New York Hospital and Cornell University Medical College (now named New York Presbyterian Hospital and Weill Medical College of Cornell University) to collect data that was reported in the *Journal of Pain and Symptom Management*. It is an annotated copy that includes operating instructions. These notations are in bold print and follow each question to provide additional guidance to the chart surveyors. We hope they are helpful to you and your colleagues.

Please feel free to use this abstraction tool for research or quality improvement work. We only ask that if a publication results from the use of this instrument that it is properly cited.

Thank you for your interest in our work. If you have any comments or questions, please contact us.

For Questions or Comments about this Chart Abstraction Instrument contact:

Joseph J. Fins, MD
Division of Medical Ethics
Departments of Public Health and Medicine
Weill Medical College of Cornell University
New York Presbyterian Hospital –Weill Cornell Center
525 East 68th Street F-173
New York, NY USA 10021
jjfins@mail.med.cornell.edu

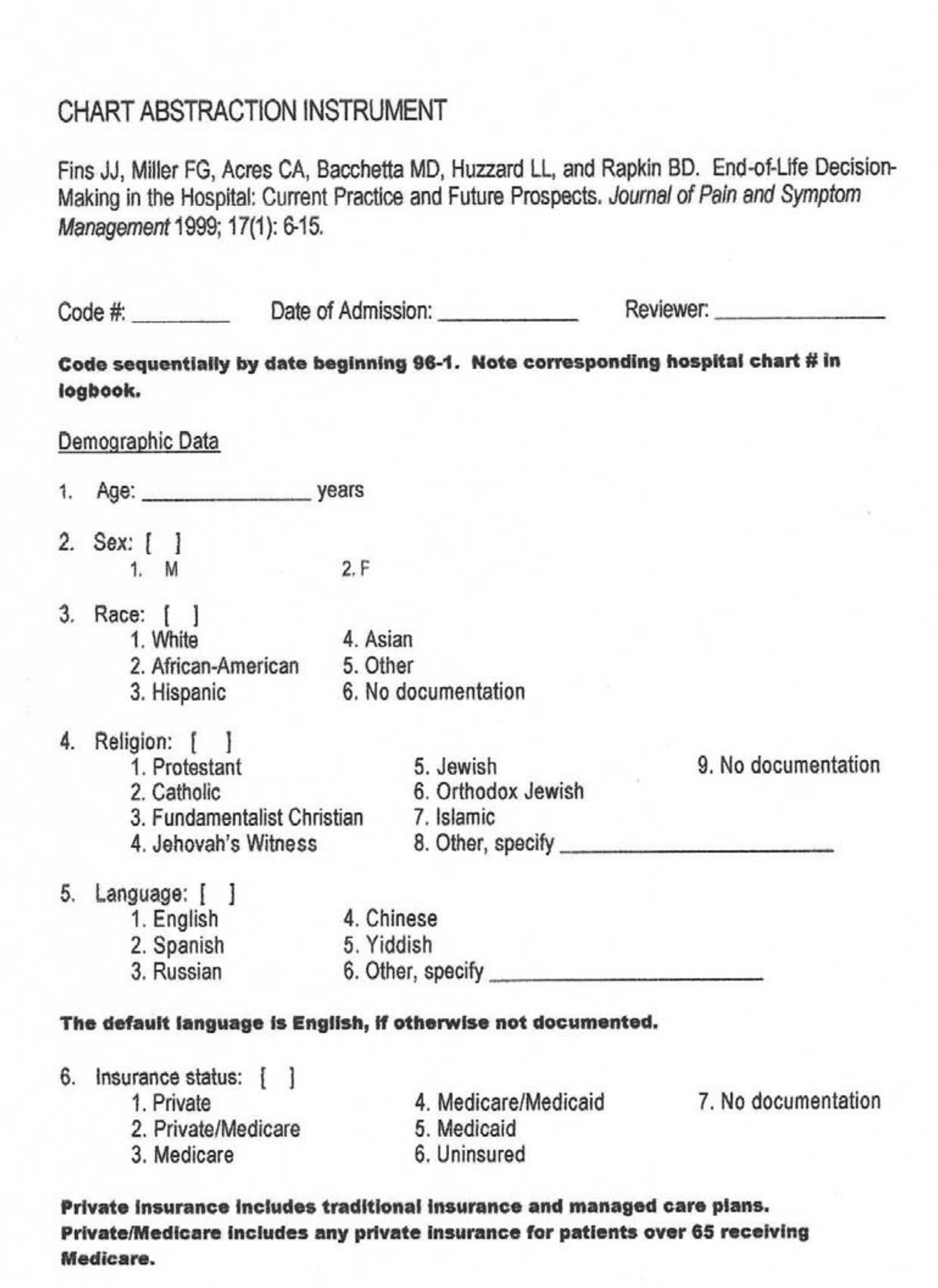


CHART ABSTRACTION INSTRUMENT

Fins JJ, Miller FG, Acres CA, Bacchetta MD, Huzzard LL, and Rapkin BD. End-of-Life Decision-Making in the Hospital: Current Practice and Future Prospects. *Journal of Pain and Symptom Management* 1999; 17(1): 6-15.

Code #: ________ Date of Admission: ____________ Reviewer: ______________

Code sequentially by date beginning 96-1. Note corresponding hospital chart # in logbook.

Demographic Data

1. Age: ______________ years

2. Sex: [ ]
    1. M 2. F

3. Race: [ ]
    1. White 4. Asian
    2. African-American 5. Other
    3. Hispanic 6. No documentation

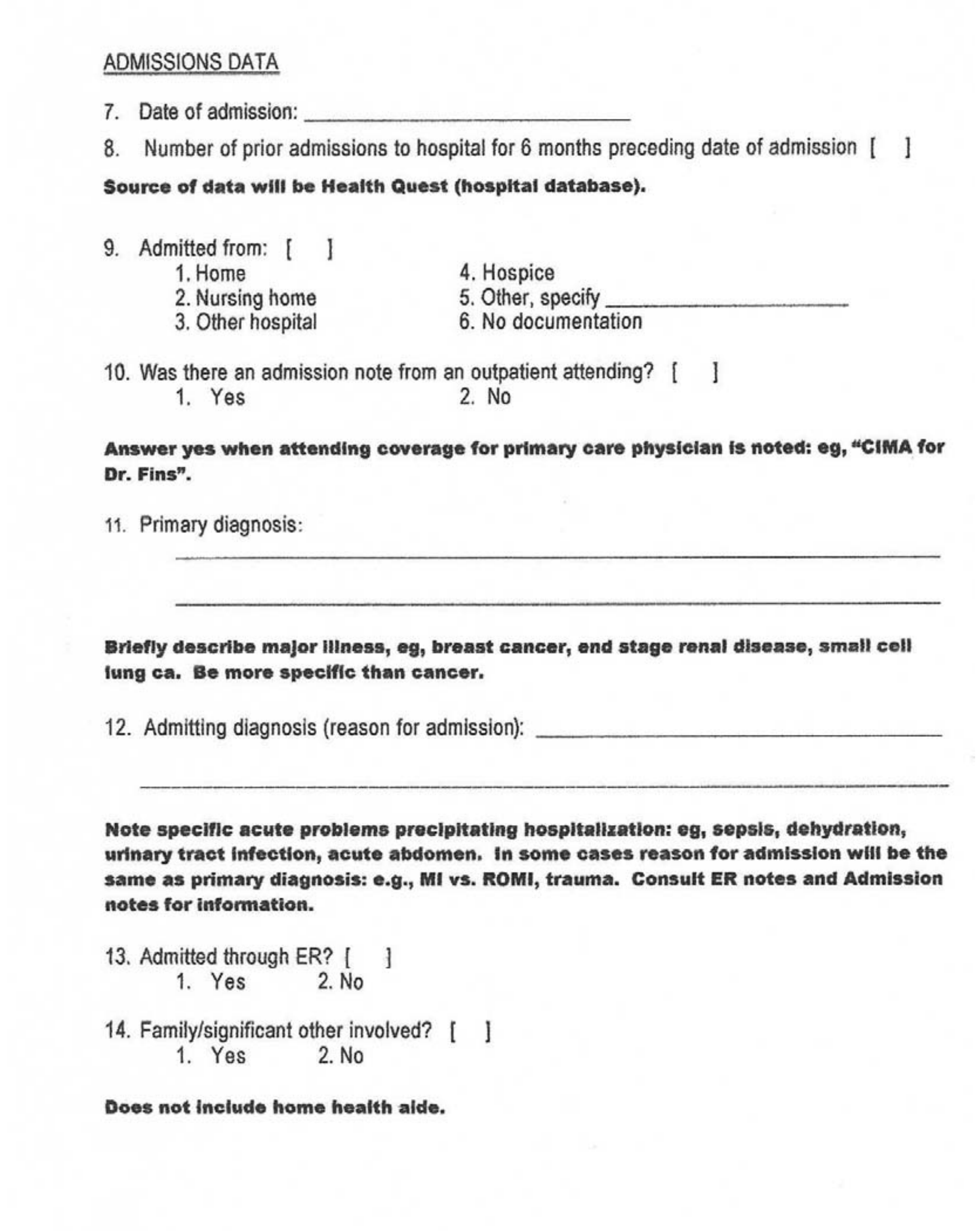
4. Religion: [ ]
    1. Protestant 5. Jewish 9. No documentation
    2. Catholic 6. Orthodox Jewish
    3. Fundamentalist Christian 7. Islamic
    4. Jehovah's Witness 8. Other, specify ______________________

5. Language: [ ]
    1. English 4. Chinese
    2. Spanish 5. Yiddish
    3. Russian 6. Other, specify ______________________

The default language is English, if otherwise not documented.

6. Insurance status: [ ]
    1. Private 4. Medicare/Medicaid 7. No documentation
    2. Private/Medicare 5. Medicaid
    3. Medicare 6. Uninsured

Private insurance includes traditional insurance and managed care plans. Private/Medicare includes any private insurance for patients over 65 receiving Medicare.



ADMISSIONS DATA

7. Date of admission: ______________________________

8. Number of prior admissions to hospital for 6 months preceding date of admission [ ]

Source of data will be Health Quest (hospital database).

9. Admitted from: [ ]

1. Home	4. Hospice
2. Nursing home	5. Other, specify ____________________
3. Other hospital	6. No documentation

10. Was there an admission note from an outpatient attending? [ ]
    1. Yes   2. No

Answer yes when attending coverage for primary care physician is noted: eg, "CIMA for Dr. Fins".

11. Primary diagnosis:
    ____
    ____

Briefly describe major illness, eg, breast cancer, end stage renal disease, small cell lung ca. Be more specific than cancer.

12. Admitting diagnosis (reason for admission): ______________________________
    ____

Note specific acute problems precipitating hospitalization: eg, sepsis, dehydration, urinary tract infection, acute abdomen. In some cases reason for admission will be the same as primary diagnosis: e.g., MI vs. ROMI, trauma. Consult ER notes and Admission notes for information.

13. Admitted through ER? [ ]
    1. Yes   2. No

14. Family/significant other involved? [ ]
    1. Yes   2. No

Does not include home health aide.

HOSPITAL UNITS

15. Unit admitted to: [ ]

1. MICU
2. SICU
3. CCU
4. Gen Med
5. AIDS
6. Gen Surgical
7. Neuro
8. Step-down

SICU includes F9 ICU, F11 ICU, and burn unit. Gen Med includes Payson, Whitney and Baker general medicine floors. Step-down includes all telemetry units, Payson 4 step-down unit and burn step-down. Gen Surgical includes Payson, Whitney and Baker surgical floors.
Note the unit pt is admitted to if a boarder: eg, AIDS pt on Baker 16 followed by CSS team is a Baker 16 pt.

16. Was patient admitted or transferred to MICU, SICU or CCU [ ]

1. Yes
2. No

17. Number of admissions to ICU: ______________

ICU means all intensive care units: MICU, SICU, CCU.

18. Length of stay in ICU: _________________days

Note total length of stay of all ICU admissions.

Count unit days based on the daily progress note. If the progress note is written while the pt is in the ICU, then that day counts as an ICU day, even if the pt is transferred and spends more time on the new unit.

END-OF-LIFE DECISION MAKING

19. Health Care Proxy (HCP) in chart or recognized by staff? [ ]

1. Yes
2. No

By "recognized by staff" we mean that in the absence of HCP document in chart, a patient's surrogate is treated by staff as if he or she were a designated health care agent: eg, use of health care agent category on DNR form when there is no clear evidence of HCP designation.

20. When was HCP signed ? [ ]

1. Prior to admission
2. On admission (first 24 hours)
3. During hospital course
4. Not applicable

Answer "not applicable" when HCP is recognized but not found or documented in chart.

21. Living will in chart or recognized by staff? [ ]
1. Yes 2. No

Answer "yes" if living will is believed to exist, not placed in chart, but still guides medical decision making.

22. When was living will signed? [ ]
1. Prior to admission
2. On admission (first 24 hours)
3. During hospital course
4. Not applicable

Answer "not applicable" if living will is recognized by staff but not found or documented in chart.

23. Evidence of patient preferences in chart other than living will or HCP? [ ]
1. Yes 2. No

Answer "yes" if staff notes or quotes pt's articulated preferences or the recollections of pt preferences by family, nurse or physician.

24. Did patient have decision-making capacity on admission? [ ]
1. Yes
2. No
3. Lack of adequate information in chart

This pertains to the first 24 hours of hospitalization. Look at whether pt signs consent forms for evidence of decision-making capacity. Also note formal assessments of capacity. The default answer is "yes". Answer #3 if unclear.

25. Did capacitated patient lose capacity during hospital course? [ ]
1. Yes
2. No
3. Lack of adequate information
4. Not applicable

This pertains to pt who had capacity on admission but subsequently loses capacity and loss of capacity is noted in chart when a medical decision needs to be made. Do not include loss of consciousness associated with a terminal event.

26. Was a psychiatric consult to assess capacity requested during current admission? [ ]
1. Yes 2. No

27. Was living will or HCP invoked during hospital course? [ ]
1. Yes 2. No 3. Not applicable

Answer "yes" if documented living will or HCP determined or influenced medical decision-making. Answer "no" if documented living will or HCP did not determine or influence medical decision making: e.g., pt with a health care proxy dies without loss of decision making capacity or there is no opportunity to invoke living will or HCP. Answer "not applicable" if pt did not have living will or HCP or if these were not documented.

28. Was an *undocumented* living will or HCP used to guide medical decision-making? [ ]
1. Yes 2. No 3. Not applicable

See instructions for #19 and #21.

29. Was chaplain visit to patient and/or family documented in medical record? [ ]
1. Yes 2. No

30. Any evidence in chart that patient was considered dying? [ ]
1. Yes 2. No

Answer "yes" only when language such as the following is found in chart: "end stage", "dying", "terminally ill", "moribund", "situation hopeless/grave", "prognosis grim", etc.

31. When was patient first identified as dying? ________________(date)

Enter date when language in #30 first appears in chart.

32. Did patient have a plan of comfort care? [ ]
1. Yes 2. No

Answer "yes" only if the following phrases are used: "comfort care", "palliative care" or "supportive care".

33. When was comfort care plan noted? ____________(date)

Enter date when key phrases in #32 are first used.

For patients who have a plan of comfort care, indicate whether the following treatments/procedures were provided to the patient 24 hours or more after the comfort care plan was noted in the chart. (Write 1 for yes and 2 for no. Leave blank for patients without a comfort care plan).

34. Mechanical ventilation [ ]

35. Artificial nutrition and hydration [ ]

36. Dialysis [ ]

37. Pressors [ ]

38. Antibiotics [ ]

39. Transfusions [ ]

40. Blood draws [ ]

41. Other invasive treatments or procedures [ ]
If yes, specify ______________________

42. Was patient DNR prior to admission? [ ]
1. Yes 2. No

Consult admission notes and DNR redesignation.

43. Did patient become DNR during current admission? [ ]
1. Yes, with order 2. Yes, no order 3. No

Answer "yes with order" only if DNR order is written as an order in the order book. Answer "yes, no order" if the chart reflects DNR status but no order exists.

44. When did patient become DNR? _______________date

45. Who consented to DNR order? [ ]
1. Patient
2. Health care agent
3. Surrogate
4. Legal guardian
5. Physician
6. Not applicable

Consult DNR forms. Answer "not applicable" for DNR without written order: see #43

46. Was patient on a ventilator during admission? [ ]
1. Yes 2. No

47. How long was patient on ventilator? ____________________days

Count progress notes with vent settings and use respiratory therapy notes for corroboration.

48. Did patient agree to intubation? [ ]
1. Yes
2. No
3. No documentation
4. Not applicable

49. Was a tracheotomy placed? [ ]
1. Yes 2. No 3. Not applicable

50. How long before death was trach placed? _______________days

51. Was patient withdrawn from ventilator prior to death? [ ]
1. Yes 2. No 3. Not applicable

52. How long before death was patient withdrawn from ventilator? ____________ hours

53. Was patient receiving artificial nutrition and hydration (N & H) during admission? [ ]
1. Yes 2. No

Answer "yes" only for PEG, PEJ, TPN and NGT feeds. This does not include IV fluids alone.

54. How long was patient on N & H? ________________days

55. Did patient agree to N & H? [ ]
1. Yes
2. No
3. No documentation
4. Not applicable

56. Was patient withdrawn from N & H prior to death? [ ]
1. Yes 2. No 3. Not applicable

57. How long before death was patient withdrawn from N & H? ______________days

58. Did patient receive chemotherapy during admission? [ ]
1. Yes 2. No

59. Was patient withdrawn from antibiotics during admission? [ ]
1. Yes 2. No 3. Not applicable

Answer "yes" if course of therapy is intentionally stopped.

60. How long before death was patient withdrawn from antibiotics? ____________days

61. Was other life -sustaining treatment withdrawn prior to death? [ ]
1. Yes, specify ____
2. No

62. Was patient on morphine drip during admission? [ ]
1. Yes 2. No

63. Did patient agree to morphine drip? [ ]
1. Yes
2. No
3. No documentation
4. Not applicable

64. How long was patient on morphine drip prior to death? ________________hours

65. Was Patient Services/Ethics Committee involved during patient's current hospital course? [ ]
1. Yes 2. No

Consult Patient Services database.

66. How many consults were called during hospital course? [ ]

Do not include ER consults upon admission. Count only in-patient consults.

Was there evidence in the chart that within 2 days prior to death the patient experienced the following symptoms? (Write 1 for yes and 2 for no).

67. Pain [ ]
68. Shortness of breath [ ]
69. Nausea/vomiting [ ]
70. Constipation [ ]
71. Diarrhea [ ]
72. Anxiety [ ]
73. Depression [ ]
74. Change in mental status [ ]

Nursing notes may be an important source of information

DEATH DATA

75. Date of death: ____________________

76. Site of death: [ ]
   1. General Medicine
   2. MICU
   3. SICU
   4. CCU
   5. Step-down
   6. AIDS
   7. General Surgical
   8. Neuro
   9. Other, specify ____________

Answer to reflect where patient died not service they are on: eg, answer "SICU" when patient followed by CSS dies in burn unit.

77. Was patient transferred within 48 hours of death? [ ]
   1. Yes
   2. No

OR procedures do not count as transfers if patient returns to original unit.

78. Where was patient prior to transfer? [ ]
   1. General Medicine
   2. MICU
   3. SICU
   4. CCU
   5. Step-down
   6. AIDS
   7. General Surgical
   8. Neuro
   9. Other, specify ____________

79. Did patient go to OR within 48 hours of death? [ ]
   1. Yes
   2. No

80. If patient went to OR within 48 hours of death, was it for palliation? [ ]
   1. Yes
   2. No
   3. Not applicable

Answer yes if the intention is not to cure but to relieve symptoms. Examples of palliative surgery include: diverting colostomy for obstructing colon cancer, placement of broviac for access, nerve blocks, epidurals, PCA devices, etc. If in doubt, answer "no".

81. Did patient receive CPR prior to death? [ ]
   1. Yes
   2. No

Consult arrest note, if no arrest note, answer "no".

Discharge diagnosis: ____

____

Note cause of death and relationship to primary diagnosis: eg, nadir sepsis secondary to chemotherapy for acute myelogenous leukemia.

COMMENTS:

Note any details of case history that seem interesting or unusual, including quotes from chart.

We are especially interested in capturing the dying process as experienced by patients, family and staff in their own voices. Note cases in which you believe end of life care is managed well and poorly and give your reasons for your assessment.

APPENDIX D: Modified Chart Abstraction Instrument

The Chart Abstraction Instrument was adapted for this study from the instrument originally constructed and used by the following authors in their study:

Fins, J. J., Miller, F. G., Acres, C. A., Bacchetta, M. D., Huzzard, L. L., and Rapkin, B. D. (1999). End-of-life decision-making in the hospital: Current practice and future prospects. *Journal of Pain and Symptom Management, 17* (1), 6-15.

Code #: ____________ Date of Admission: ________________________

Code sequentially by data beginning 02-1. Note corresponding medical record number in logbook.

DEMOGRAPHIC DATA

1. Age (years): [ ]

    1. 65-75
    2. 76-85
    3. 86+

2. Sex: [ ]

    1. M 2. F

3. Race: [ ]

    1. White
    2. African American
    3. Hispanic
    4. Asian
    5. Other, specify: ___________
    6. No documentation

4. Religion: [ ]

1. Protestant (Baptist)
2. Protestant (Episcopal, Lutheran, Methodist, Presbyterian)
3. Other Fundamentalist Christian
4. Catholic
5. Jehovah's Witness
6. Seventh Day Adventist
7. Jewish
8. Other, specify: ______________
9. No documentation
10. No religious preference
11. Unknown

5. Primary Language: [ ]

1. English
2. Spanish
3. Other, specify: ________________________________

6. Education: [ ]

1. No formal education
2. Some elementary school (through grade 8)
3. Graduated from 8th grade
4. Some high school
5. Graduated from high school
6. Some college
7. Graduated from college
8. Post-graduate degree
9. No documentation

7. Insurance status: [ ]

1. Private
2. Private/Medicare
3. Medicare
4. Medicare/Medicaid (TennCare)
5. TennCare
6. Uninsured

<u>ADMISSION DATA</u>

8. Date of admission: ______________________________

9. Admitted from: [ ]

1. Home
2. Nursing home
3. Other hospital
4. Hospice/Homecare
5. Other, specify: ________________________
6. No documentation

10. Admitted through the ER? [ ]

1. Yes 2. No

11. Admitting diagnosis: ____

Note specific acute problem that precipitated hospitalization, e.g., sepsis, dehydration, urinary tract infection, acute abdomen, etc.

12. Primary diagnosis: ____

Briefly describe specific major illness, e.g., breast cancer, end stage renal disease, small cell lung cancer, etc. In some cases, the primary diagnosis will be the same as the admitting diagnosis.

13. Family or significant other involved? [ ]

1. Yes 2. No

<u>HOSPITAL UNITS</u>

14. Unit admitted to: [ ]

1. ICU/CCU
2. General medical/surgical
3. Geropsychiatric

15. Was the patient admitted or transferred to ICU/CCU? [ ]

1. Yes 2. No

16. Number of admissions to ICU/CCU? ________________

17. Length of stay in ICU/CCU: _______________ days

Note the total length of stay of all ICU/CCU admissions. Count unit days based on the daily progress notes. If the progress note is written while the patient is in the ICU/CCU, then that day counts as an ICU/CCU day, even if the patient is transferred that day.

<u>END-OF-LIFE DECISION-MAKING (PATIENT)</u>

18. Durable Power of Attorney for Healthcare (DPOA-HC) in chart? [ ]

1. Yes 2. No

By “recognized by staff” we mean that in the absence of DPOA-HC document in chart, a patient’s surrogate is treated by staff as if he or she were a designated health care agent.

19. When was the DPOA-HC signed? [ ]

1. Prior to admission	3. During hospital course
2. Within first 24 hours of admission	4. Not applicable

Answer “Not applicable” when DPOA-HC is recognized but not found or documented in the chart.

20. Living Will in chart? [ ]

1. Yes 2. No

Answer “Yes” if living will is believed to exist, not placed on chart, but still guides medical decision-making.

21.When was the Living Will signed? [ ]

1. Prior to admission	3. During hospital course
2. Within first 24 hours of admission	4. Not applicable

Answer “Not applicable” if living will is recognized by staff but not found or documented in chart.

22. Is there evidence of patient preferences in the chart other than a Living Will or DPOA-HC? [ ]

1. Yes 2. No

Answer “ Yes” if staff notes or quotes patient’s articulated preferences or the recollections of patient preferences by family, nurse, or physician.

23. Did the patient have decision-making capacity on admission? [ ]

1. Yes	3. Lack of adequate information in the chart
2. No	

This pertains to the first 24 hours of hospitalization. Look at whether patient signs consent form for evidence of decision-making capacity.

24. Did the patient lose capacity during hospital course? [ ]

1. Yes
2. No
3. Lack of adequate information
4. Not applicable

This pertains to a patient who had capacity on admission but subsequently loses capacity and loss of capacity is noted in the chart when a medical decision needs to be made. Do not include loss of consciousness associated with a terminal event.

25. Was Living Will or DPOA-HC invoked during hospital course? [ ]

1. Yes 2. No 3. Not applicable

Answer “Yes” if documented living will or DPOA-HC determined or influenced medical decision-making. Answer “No” if documented living will or DPOA-HC did not determine or influence medical decision-making: e.g., a patient with a health care proxy dies without loss of decision-making capacity or there is no opportunity to invoke living will or DPOA-HC. Answer “Not applicable” if patient did not have a living will or DPOA-HC or if these were not documented.

26. Was an undocumented living will or DPOA-HC used to guide medical decision-making? [ ]

1. Yes
2. No
3. Not applicable

See instructions #18 and #19.

27. Was a chaplain visit to patient and/or family documented in the medical record? [ ]

1. Yes 2. No

<u>END-OF-LIFE DECISION-MAKING (HEALTHCARE PROVIDERS)</u>

28. Any evidence in the chart that the patient was considered dying? [ ]

1. Yes 2. No

Answer “Yes” only when language such as the following is found in the chart: “end stage,” “dying,” “terminally ill,” moribund,” “situation hopeless/grave,” “prognosis grim,” etc.

29. When was the patient first identified as dying? ______________________
(date)

Enter date when language in #28 first appears in chart.

30. Did the patient have a plan of comfort care? [ ]

1. Yes 2. No

Answer "Yes" only if the following phrases are used: "comfort care," "palliative care," or "supportive care."

31. When was comfort care plan noted? ____________________________
(date)

Enter date when key phrases in #30 are first used.

For patients who have a plan of comfort care, indicate whether the following treatments/procedures were provided to the patient 24 hours of more after the comfort care plan was noted in the chart. Write 1 for Yes, 2 for No. Leave blank for patients without a comfort care plan.

32. Mechanical ventilation [ ]

33. Artificial nutrition/hydration [ ]

34. Dialysis [ ]

35. Pressors [ ]

36. Antibiotics [ ]

37. Transfusions [ ]

38. Blood draws [ ]

39. Other invasive treatments or procedures [ ]
If yes, specify:
____

For All Patients

DNR

40. Was patient a DNR prior to admission? [ ]

1. Yes 2. No

Consult admission notes.

41. Did the patient become DNR during current admission? [ ]

1. Yes, with order 2. Yes, no order 3. No

Answer, “Yes, with order” only if DNR order is written as an order in the Physician Order’s. Answer, “Yes, no order” if the chart reflects DNR status but no order exists.

42. When did patient become a DNR? ______________________________ (date)

43. Who consented to the DNR order? [   ]

1. Patient
2. Person designated by DPOA-HC
3. Surrogate
4. Legal guardian
5. Physician
6. Not applicable

Answer “not applicable” for DNR without written order; see #41.

Ventilator

44. Was the patient on a ventilator during hospitalization? [   ]

1. Yes 2. No

If the answer to #44 is “Yes,” complete questions #45 through #50.

45. How long was the patient on a ventilator (days)? [   ]

1. 1-3
2. 4-5
3. 6-8
4. 9+

Count progress notes with vent settings and use respiratory therapy notes for corroboration.

46. Did the patient agree to intubation? [   ]

1. Yes 2. No

47. Was a tracheostomy placed? [   ]

1. Yes 2. No

48. How long before death was the trach placed? __________________ days

49. Was the patient withdrawn from the ventilator prior to death? [   ]

1. Yes 2. No

50. How long before death was the patient withdrawn from the ventilator?
__________ hours

ARTIFICIAL NUTRITION AND HYDRATION (N & H)

51. Did the patient receive artificial nutrition and hydration during hospitalization? [ ]

1. Yes 2. No

Answer "Yes" only for PEG, PEJ, TPN, and NGT feedings. This does not include IV fluids alone.

If the answer to #51 is "Yes," complete questions #52 through #55.

52. How long was patient on N & H? __________ days

53. Did the patient agree to N & H? [ ]

1. Yes	3. No documentation
2. No	4. Not applicable

54. Was the patient withdrawn from N & H prior to death? [ ]

1. Yes 2. No

55. How long before death was the patient withdrawn from N & H? _______ days

CHEMOTHERAPY

56. Did the patient receive chemotherapy during the hospitalization? [ ]

1. Yes 2. No

ANTIBIOTICS

57. Was the patient withdrawn from antibiotics during the hospitalization? [ ]

1. Yes 2. No

Answer "yes" if the course of antibiotics was intentionally stopped.

58. How long before death was the patient withdrawn from antibiotics? ________ days

OTHER

59. Was other life-sustaining treatment withdrawn prior to death? [ ]

1. Yes, specify: ____
2. No

PAIN MANAGEMENT

60. Did the patient receive morphine continuously or on an "as needed" basis during the hospitalization? [ ]

1. Yes 2. No

61. Did the patient agree to the morphine? [ ]

1. Yes
2. No
3. No documentation
4. Not applicable

62. How long was the patient on morphine prior to death? ____________ hours

ETHICS COMMITTEE INVOLVEMENT

63. Was the Ethics Committee involved during the patient's hospitalization? [ ]

1. Yes 2. No

CONSULTANTS

64. How many consultants were called during the hospital course? [ ]

Enter the total number of physician consultants while the patient was an in-patient.

TERMINAL SYMPTOMS

Was there evidence in the chart that within 2 days prior to death the patient experienced the following symptoms? Write 1 for Yes and 2 for No.

65. Pain [ ]
66. Shortness of breath [ ]
67. Nausea/vomiting [ ]
68. Constipation [ ]
69. Diarrhea [ ]
70. Anxiety [ ]
71. Depression [ ]
72. Change in mental status [ ]

DEATH DATA

73. Date of death: ________________________________

74. Site of death: [ ]

1. ICU/CCU
2. General medical/surgical
3. Geropsychiatric

75. Was the patient transferred within 48 hours of death? [ ]

1. Yes 2. No

OR procedures do not count as transfers if the patient returns to the original unit.

76. Where was the patient prior to transfer? [ ]

1. ICU/CCU
2. General medical/surgical
3. Geropsychiatric

77. Did the patient go to the OR within 48 hours of death? [ ]

1. Yes 2. No

78. If the patient went to the OR within 48 hours of death, was it for palliation? [ ]

1. Yes 2. No

Answer "Yes" if the intention is not to cure but to relieve symptoms. Examples of palliative surgery include: diverting colostomy for obstructing colon cancer, placement of a broviac for access, nerve blocks, pain-relieving pumps, etc. If in doubt, answer "No."

CPR

79. Did the patient survive CPR during the hospitalization? [ ]

1. Yes 2. No

80. Did the patient receive CPR at the end of life? [ ]

1. Yes 2. No

81. Discharge (death) diagnosis: ____

Note the cause of death and relationship to primary diagnosis.

VITA

Elizabeth Harder Dobbins was born in Davenport, Iowa but raised in Milwaukee, Wisconsin. She attended Pius XI High School, graduating in 1971. She went on to fulfill her childhood dream of becoming a nurse, graduating from the University of Wisconsin-Milwaukee, in 1975. Her life between then and now has been punctuated by periods of formal education. She received a Masters Degree in Nursing from the University of Alabama at Birmingham (clinical nurse specialist tract, gerontological focus) in 1986 and a second Masters Degree in Nursing from East Tennessee State University (family nurse practitioner tract) in 1994. Her nursing career has been varied. She has held positions as a hospital staff nurse, home health nurse, employee health nurse, family nurse practitioner, and nurse educator.

Ms. Dobbins is currently the director of the Department of Organizational Development at Morristown-Hamblen Healthcare System, Morristown, Tennessee. She is currently pursuing a doctorate in Human Ecology with a concentration in Health Education from the University of Tennessee, Knoxville.