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# Profiling the Quality of End of Life Care

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PROFILING THE QUALITY OF END OF LIFE CARE

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A Thesis  
Presented to  
the Graduate School of  
Clemson University

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Science  
Nursing

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by  
Catherine S. Murton  
August 2007

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Accepted by:  
Dr. Janet Craig, Committee Chair  
Dr. Nancy Meehan  
Dr. Hugh Spitler

## ABSTRACT

Despite increased national debate regarding quality of life and quality of care at the end of life, patients in the United States continue to die primarily in hospitals experiencing a myriad of distressing symptoms, leaving caregivers and healthcare professionals wondering if caring for the dying will ever change in this country. There are alternatives available, but it is necessary to assess current conditions for dying patients in order to change the status quo in end of life care. Profiling how patients experience the last few months of life, as well as their terminal hospital stay, is a starting point for just such an assessment.

The following manuscript outlines the purpose of profiling dying populations and provides a framework for compiling profile data for patients who expire in an institutional setting. Utilizing Myra Levine's four conservation principles of nursing care, the following study examines quality indicators identified for end of life care and discusses these domains with regard to specific decline-to-death disease trajectory groups identified in the study.

## DEDICATION

I dedicate the following manuscript to my amazing family...my husband Pete, and children, Stephen and Lina...who have sacrificed much in their support of my educational goals, and will undoubtedly continue to do so for many years to come.

## ACKNOWLEDGMENTS

There are many people to thank for their invaluable assistance on this research project. First, I would like to thank Dr. Janet Craig for initiating the project in my behalf and for her assistance throughout the study period. She has been a friend, colleague, and mentor throughout my graduate education and I am deeply indebted to her. I would also like to thank my other committee members, Dr. Nancy Meehan and Dr. Hugh Spitler, for their time, assistance, and wonderful senses of humor while developing what I believe to be a noteworthy manuscript.

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## CHAPTER 1

### INTRODUCTION

There is a need to define quality and efficacy in the field of end of life (EOL) care since significant gaps exist between how people would like to die and how they actually die in this country (Last Acts, 2002; Lynn, 1997; Lamont, 2005). In the past, families consisted primarily of multi-generational groups living together under one roof, with children growing up observing their parents care for dying elders. The activities associated with caring for the dying were a normal part of life, and children witnessed the realities of the life cycle early on (Anderson, 2002). Today, families have scattered, often living long distances apart, so the responsibility of caring for ill and elderly loved ones has shifted towards utilizing trained personnel in institutionalized settings, such as nursing homes or hospitals.

Meanwhile, in the competitive US healthcare market now focused on customer satisfaction, administrators and practitioners alike are feeling unrelenting pressure to identify factors representative of quality efficacious care, particularly for the typically expensive care associated with dying. Unfortunately, current medical practices appear to offer little in the way of quality to patients during the last six months of life, since practitioners continue to focus on curative interventions in spite of the fact that “cure” is an ultimately futile goal for the vast majority of patients suffering with serious chronic conditions before death.

## Dying in the United States

For a burgeoning legion of Americans living with debilitating medical conditions, our healthcare system obstinately focuses on preventing or curing acute illness (Lorenz, 2004). The current system has not evolved to serve the needs of patients dying from chronic illnesses for whom dying is just a slow succession of decreasing functional and/or cognitive abilities (Lunney, 2003; Lynn, 2000; Teno, 2004). Dying is no longer an event, but a process of decline experienced through aging. In spite of the obvious inadequacies of the prevention and cure model, the medical community has thus far been either unable or unwilling to change; yet a glance at population trends indicates that the time for change is long overdue.

## The Impact of an Aging Population

Population trends indicate that the number of people over age 65 is growing and will continue to grow for decades, from 12% of the population in 2000 to a projected 20% by the year 2030, and the number of individuals living with activity-limiting or life-limiting chronic illnesses will similarly climb (Lorenz, 2004). Ninety percent of the elderly population has one or more of the following chronic conditions in the year preceding their death: cancer, chronic heart or lung disease, dementia, liver failure, renal failure, or stroke (Lorenz, 2004). With fifty percent of the population dying in hospitals and another 20-25% dying in nursing homes (Last Acts, 2002), a shift in focus with respect to EOL care is necessary, since neither prevention nor cure are realistic goals for this rising tide of chronically ill elderly (Lorenz, 2004).

With nearly three-quarters of the population dying in institutional settings, it is alarming that national polls indicate that most people want to die at home (Last Acts, 2000; Pritchard, 1998) and that families report a more favorable death experience when it occurs in the home (Teno, 2004; Lamont, 2005, Phipps, 2004). The current healthcare system seems capable of only perpetuating the institutionalized death and continues to remain unresponsive to this preference. In fact, only 25 percent of Americans die at home, even though 70 percent express it as their desired place of death (Last Acts, 2002). In addition to dying at home, studies indicate that most people hope to experience death free of physically distressing symptoms and with their family and friends nearby, yet the truth is that a majority of people will die alone, in a hospital, experiencing a myriad of distressing symptoms (Last Acts, 2002). Despite increasing national debate regarding issues such as quality of life and quality of care at the EOL, little has actually changed since patients continue to die primarily in hospitals with many of their needs unmet (Lynn, 1997).

### South Carolina and the Upstate Region

A 2004 state survey on attitudes regarding EOL issues in South Carolina reveals that a majority of South Carolinians would prefer to die at home (63%) and that over a third (36%) are concerned about the costs of terminal care (Carolina Center, 2004). However, state data indicates that SC has a higher percentage (55%) of hospitalized deaths than the national average of fifty percent (Facts on Dying, 2004). In 1989, SC ranked 20<sup>th</sup> for the highest percentage of hospital deaths, and rose to the 13<sup>th</sup> state with the largest proportion of hospital based deaths in 1997 and 2001, even though the

percentage of hospitalized deaths for the state declined from 66% in 1989 to 55% in 2001 (Facts on Dying, 2004). Likewise, the percentage of Medicare patients dying in SC hospitals has decreased 2%, keeping pace with the national decline for this population (Dartmouth Atlas, 2004).

The most alarming SC statistic was the increased utilization of Intensive Care Units (ICU) and Coronary Care Units (CCU) for patients during the last six months of life. There was a 4% increase in SC Medicare patients admitted to ICU/CCU at least once during the last six months of life from 1999 to 2003, and in the upstate region of SC (HSA368), admissions to ICU/CCU during the last six months of life increased 7.8 % (Dartmouth Atlas, 1999-2003). This increased utilization of aggressive care areas translated into an additional \$3000/patient spent during the last six months of life, totaling an estimated \$6.7 million dollars additional spending during 2003 in the upstate region of SC alone (calculated from Dartmouth Atlas data, 1999-2003).

In order to understand the gaps that exist in caring for individuals at the EOL, researchers have examined a wide array of patient, caregiver, and provider characteristics associated with EOL care. The following discussion, based on a review of current literature, portrays the present state of dying in the United States, examines the EOL period in light of varying rates of decline towards death, and identifies factors that define quality care at the EOL.

## CHAPTER 2

### REVIEW OF THE LITERATURE

Even though the field of EOL care is relatively new, literature has proliferated over the past decade on a wide assortment of topics. Topics in EOL care cover the full expanse of the human experience, with studies examining the physiologic, psychosocial, spiritual, cultural, legal, ethical, and economic conditions associated with dying.

In the 1990s, researchers began to amass data from all fifty states using statistics available from the Centers for Medicare and Medicaid Services (CMS) and Minimum Data Sets (MDS). Additionally, the Study to Understanding Prognoses and Preferences for Outcome and Risk of Treatment (SUPPORT) study began to examine EOL care and tested an intervention that ultimately failed to improve the identified shortcomings in care provided to the dying. Over the ensuing years, the data collected and synthesized by these groups and others has produced a large and diverse volume of literature (Lorenz, Lynn, 2005), and through this volume of work the foundations for quality in EOL care emerge.

#### Search Criteria

For the purposes of this review, keyword searches using terms such as end of life, end of life care, quality care, quality improvement, quality indicators, disease trajectories, medical futility, resuscitation mortality, palliative care, and hospice care using the Medline and CINAHL databases netted the bulk of initial material. Additionally, it was necessary to obtain early, repeatedly cited studies to understand the historical developments in EOL research. Inclusion factors focused on studies conducted in the United States, dying population for those 45 years old and older, and studies related to



quality patient care at the EOL or decline-to-death trajectories. Exclusionary criteria included studies with pediatric subjects, redundant articles, editorial formats, and lack of specificity to dying or EOL care. Studies focused on either ethical or legal concerns related to dying were also outside the scope of this discussion and therefore excluded, yet they are unquestionably aspects to discussions regarding end of life care.

### Identifying Dying Populations

Technological advances have transformed numerous medical conditions that were once fatal into treatable chronic health states. Every breakthrough contributes further to the collective American perception that doctors and hospitals can ‘make it better’. The unfortunate by-product of this technology is the creation of a population living with chronic and debilitating conditions that the medical community now revolves around. Patients often have little hope of getting better; and at best, they receive extensive medical management to control recurring periods of exacerbation. Therefore, identifying patterns of patient care and survival rates for various diagnostic populations as a means of defining and recognizing the EOL timeframe has met with varying degrees of success, due in part to ambiguous EOL definitions. Researchers involved in a recently published comprehensive systematic review of literature regarding care delivered to the terminally ill noted that time frames varied from imminent death (usually the last 48 hours) to expansive interpretations encompassing the entire length of time a person lives with, and finally succumbs to, a fatal condition (Lorenz, Lynn, 2004).

To date, the most common operational definition for the EOL period is the one established by CMS, which defines it as the last six months of life. It is unclear how CMS

arrived at this definition, but the result has been that physicians must now recognize this period in order for patients to receive hospice services. This definition fails to define how, or with what degree of confidence, practitioners actually arrive at this prognostic determination (Lorenz, Lynn, 2004). Therefore, there is a need to produce valid prospective algorithms that measure EOL (Lamont, 2005).

Studies indicate that patients, families, and healthcare providers all feel that the care provided to patients at the EOL should be different from that provided to patients suffering from acute ailments (Lamont, 2005), yet being able to prognosticate the dying process and identify populations who would benefit from palliative care has proven difficult beyond those groups diagnosed with cancer. Multiple studies have identified characteristics that predict survival time among cancer patients (Lamont, 2005), due largely to the predictable short period of decline-to-death experienced by this group (Lunney, 2003). However, large segments of the population suffer from illnesses that do not follow precise and extrapolative patterns of decline, notably those with congestive heart failure (CHF), dementia, (Lorenz, & Lynn, 2005), or chronic obstructive pulmonary disease (COPD) (Lunney, 2003). Yet many of these patients benefit greatly from care delivered from a palliative care perspective.

A bulk of the foundational research on EOL prognosis relates to cancer diagnostic groups, with prospective and retrospective studies identifying survival predictors related to functional decline, signs and symptoms of decline, physician prediction of clinical decline, and other indicators that are then calculated into prognostic scores (Lamont, 2005, Porock, 2005; Lorenz, Lynn, 2004, Teno, 2000). The SUPPORT study was one of

the first well-developed large studies (Lorenz, Lynn, et al., 2004) producing models that calculated survival curves for cancer as well as non-cancer diagnoses (Lorenz, Lynn, et al., 2004). Although some consider the SUPPORT model useful, limitations primarily relate to the numerous tests it requires and its limited ability to predict six-month survival for patients with non-malignant conditions, particularly CHF and COPD (Lorenz, Lynn, et al., 2004).

### Disease Predicated Decline Trajectories

More recent prognostication research trends have focused on the concept of illness decline-to-death trajectories and these studies are influencing the direction of many future research recommendations. Lunney, et al., (2003) identified four disease trajectory patterns using the International Classification of Diseases, Ninth Edition (ICD-9) codes and functional decline. The authors discovered that patients in a sudden death trajectory had no functional impairment prior to death, while those dying in a cancer group had predictable short-term rates of decline. Additionally, patients with chronic conditions leading to end stage organ failure, such as those diagnosed with CHF or chronic lung diseases, experienced multiple cycles of exacerbation and stability. Lastly, a frailty trajectory group, consisting primarily of patients residing in nursing homes and frequently diagnosed with dementia, declined very slowly over months and years towards death. The study further revealed that demographic characteristics such as age, sex, race, education, and marital status, along with disease co-morbidities produced discernable differences between the groups (Lunney, 2003). A major shortcoming of the study was the large group of subjects (25%) that did not meet the criteria for these four

groups, and therefore classified as ‘others’. Although CHF and COPD are undeniably significant debilitating diseases, the decline patterns related to other conditions such as stroke, liver failure, and kidney failure, are equally relevant.

### Communication and Futility at the End of Life

Although physicians are under no obligation to initiate futile care, the standard in this country is to perform cardiopulmonary resuscitation (CPR) on anyone who experiences a cessation of cardiac or pulmonary function, even if there is no reasonable hope of it being effective. In the absence of expressed wishes otherwise, or a physician order explicitly stating “do not resuscitate” (DNR), CPR is initiated, and if successful it often leads to a stressful and painful phase for families and providers, as discussions commence regarding withdrawing the ineffective treatments (Norton, 2003).

Older studies indicated that there were dismal survival rates following hospital initiated CPR, particularly for patients over 70 years of age and those suffering with comorbidities (Bialecki & Woodward, 1995; de Vos, 1999). In contrast, a more recent study of similar design and size showed a much higher survival to discharge rate of 32.2% (Zoch, 2000), compared to earlier studies with survival to discharge rates of 17% (Bialecki & Woodward, 1995) to 20% (de Vos, 1999). Authors of the Zoch, et al. study admit however, that during the 8-year study period there was an increased tendency for physicians to write DNR orders, which probably contributed to the improved survival rates by naturally, yet selectively, removing the sickest subjects that were most prone to unsuccessful resuscitative efforts (2000). In spite of these results, they also found that patients over 70 years old, with or without functional limitations prior to admission,

experienced significantly limited long-term survival after CPR (Zoch, 2000). Therefore, the readily identifiable factors of age and functional status should propel clinicians to initiate communications with both patients and families regarding appropriate levels of care, prior to the onset of arrest events.

Lesser studied influences affecting communication and decision-making with respect to aggressive treatments at the EOL include the influence of the media on perpetuating unrealistic expectations held by the public regarding medical treatments (Jones, Brewer, & Garrison, 2000), and the influence of the Medicare hospice benefit on perceptions about hospice and palliative care. One study found that factors such as age, using television as a source of medical information, and having medical training all contributed to overly optimistic views on the effectiveness of CPR, with 96% of the participants holding unrealistically high expectations (Jones, Brewer, & Garrison, 2000). Although sample collection techniques flaw this study, it never the less presents an intriguing avenue of influence affecting patient-provider communication that is worthy of further investigation.

National census data regarding hospice and end of life care illuminates the under representation of African Americans in this area of healthcare delivery, leading some to examine the racial differences that could account for so few AA seeking hospice services at the EOL. One noteworthy study found significant differences between ethnicities, as well as gender disparities concerning levels of care at the end of life (Duffy, et al., 2006) and others have found that African American (AA) physicians tended to choose more aggressive treatment options than Caucasian physicians (Mebane, et al., 1999).

Complicating the issue of ethnic and cultural differences were the findings of gender variation within cultural groups (Duffy, et al., 2006). Since spouses are common surrogate decision makers at the EOL (Hines, et al., 2001), gender differences could possibly account for the disparity noted between patient preferences and actual EOL practices, particularly among AAs. Duffy, et al. (2006) did in fact find that AA males were less interested in aggressive care, yet AA females sought aggressive care for loved ones in their desire to have everything possible done. AAs were also more comfortable with utilizing hospitals and nursing homes as places of death, compared to Caucasians who had a distinct preference to die at home (Duffy, et al., 2006), which would correlate with low levels of hospice utilization since the primary venue for American hospice care is in the home. The variation found between races and genders in these studies illuminates the need to study this area more thoroughly.

In order to curb the injudicious utilization of healthcare resources on futile medical efforts, and advance the science of delivering appropriate levels of care to diverse patient populations, the medical community must communicate honestly among themselves and with the public about the goals and efficacy of medical interventions.

#### Hospital-Based Deaths

Dying in a hospital is unsatisfactory for patients and families (Lynn, 1997; Pritchard, 1998; Last Acts, 2000; Teno, 2005) and the costs are escalating, ultimately depleting healthcare resources that are already scarce. One large study found that where patients die has little to do with personal preferences or clinical status, but is highly correlated to healthcare utilization patterns in a given area, and the number of hospital

beds available in the vicinity (Pritchard, 1998). Additionally, other large-scale national studies found extensive variation in EOL spending in different U.S. regions that were statistically unrelated to population, or per capita wealth (Wennberg, 2004; Fisher, 2003). In fact, the variations in spending were once again highly correlated to utilization patterns and the availability of healthcare providers (Wennberg, 2004; Fisher, 2003). In other words, areas with more hospitals, hospital beds, and physicians spend more on patients at the EOL, yet there is no evidence to indicate that the increased utilization (and inherent increased expense) led to decreased mortality rates or improved quality of care (Wennberg, 2004; Fisher, 2003; Teno, 2005).

### Quality Care at the End of Life

#### *The need for quality indicators*

As recently as 2002, Virginia Tilden declared that the “American way of death [is] fragmented, expensive, and insensitive to patient and family preferences” (p.71), and several significant large studies reveal recurring themes of dissatisfaction with regard to the American dying experience. These themes include a lack of continuity between care settings, patients experiencing unrelieved distressing symptoms in the last days of life, a lack of respect for the dying, inadequate emotional support for patients and families, and poor communication with physicians related to a lack of shared decision-making (Lynn, 1997; Teno, 2004, Paice, 2004, Lorenz, Lynn, et al., 2005).

Today’s increasingly hostile economic environment, created by tighter constraints on healthcare dollars and coupled with increased demand for proof of quality care by consumer groups, has led several national organizations to recommend the use of quality

indicators to track and measure care at the EOL (Tilden, 2002; Jennings, 2005). The use of performance and outcome measures of care are gaining support and momentum. Numerous areas in healthcare already employ their use, and a growing number of healthcare venues identify and use indicators to evaluate quality patient care for nursing (ANA, 1996; Kuhlthau, 2004), medicine (AHA, 2000), and in-patient hospital care (AHRQ, 2004). This trend has led several national groups interested in improving EOL care to declare that identifying quality indicators is necessary to bring about meaningful change in the EOL arena (Tilden, 2002).

In the mid 1990s, researchers with the Dartmouth Atlas Project began to collect data from all fifty states using statistics available from CMS, while others started to compile EOL data on nursing homes using the MDS data. The data collected by these groups and synthesized in numerous studies have formed the foundation for identifying quality indicators for EOL care. To date, they are the largest ongoing databases tracking EOL care and the quality indicators identified in these studies are elemental to monitoring any appreciable change achieved in this area. The fundamental indicators of quality that recurrently surface in the literature are (a) continuity of care; (b) physical comfort; (c) respect for the dying; (d) emotional support for patients and family; and (e) communication and shared decision-making with providers (Last Acts, 2002; Teno, 2004; Lorenz, 2004; Lorenz, Lynn, et al., 2004; Lorenz, Lynn, et al., 2005).

#### Quality Indicators for End of Life Care

A preponderance of the evidence in the literature reveals positive patient and caregiver outcomes associated with palliative care (Lorenz, Lynn, et al., 2004).



Consistently, five dimensions of quality care mirroring the themes of dissatisfaction unfold throughout the literature. These include care delivery that provides (a) continuity of care; (b) physical comfort; (c) respect for the dying; (d) emotional support for patients and family; and (e) communication with shared decision-making (Last Acts, 2002; Teno, 2004; Lorenz, 2004; Lorenz, Lynn, et al., 2004; Lorenz, Lynn, et al., 2005). Other groups, such as the National Consensus Project for Quality Palliative Care (2004), identified separate domains for imminently dying patients, spirituality, and ethical or legal issues, yet these distinctions are not uniform throughout the literature. For this reason, the five themes of quality mentioned earlier are an important focus and therefore built into the theoretical model for profiling EOL care discussed in detail to follow.

## CHAPTER 3

### THEORETICAL FRAMEWORK FOR PROFILING THE END OF LIFE

The conceptual model designed to profile EOL care specifically encompasses the numerous variables that contribute or detract from that experience, as it unfolds in hospitals. The construction of the conceptual model for profiling hospital deaths necessitated abandoning traditional evaluative tools of patient care that are formulated from the medical model, which historically directs its goals towards cure. The growing population living with chronic illnesses that slowly erode the quality of life requires a cultural shift regarding how the medical community and public view death and dying.

The proposed Model for Profiling EOL Care serves as a framework for collecting and analyzing hospital-specific data (see Appendix A), incorporating disease predicated decline trajectories (Lunney, 2003), and an orientation for assessing care interventions based on the principles of conservation first introduced by Myra Levine in the 1960s (Levine, 1967,1989). These broad principles are the philosophical structure that organize five outcome criteria: continuity of care, physical comfort, respect for the dying, communication with shared decision-making, and emotional support (Teno, 2004; Paice, 2004), which are well documented and relevant measures of quality in EOL care.

#### Disease Predicated Decline Trajectories

One of the key components of the profiling model is the knowledge that different disease processes produce different rates of functional decline. In this country a great deal of EOL care is focused on patients with cancer, due primarily to its predictable short-term trajectory from initial decline-to-death, however research illuminating the

remarkably different rates of decline among clusters of chronic illnesses has tremendous implications for healthcare delivery at the EOL (Lunney, 2003).

The model utilizes demographic and disease diagnosis data (ICD-9 codes) to classify patients into groups largely based on the research conducted by Lunney on decline-to-death trajectories (2004). Similar to the groups identified by Lunney, the model identifies patients that fall into four decline-to-death clusters, which are Sudden Death, Cancer, Chronic Disease, and the Frail Elderly.

#### *Sudden Death*

Characteristics associated with those in the Sudden Death group are high levels (or stable levels) of functional ability brought to an abrupt end due to a sudden and unexpected terminal event. Patients experiencing acute hemorrhage, acute myocardial infarct (AMI), or pulmonary embolism (PE) are examples of the Sudden Death trajectory. These patients may, or may not suffer from multiple chronic conditions in the months preceding death, yet the sudden onset of death during their terminal admission is the identifiable indicator for patients assigned to this cluster.

#### *Cancer*

Patients in the Cancer group include all those that have a diagnosis of cancer at the time of death. Patients in this group usually experience a predictable short-term, very steep rate of functional decline prior to death, and are readily identifiable by their diagnostic group. For the following study, there was no attempt made to differentiate decline patterns for different forms of cancer.

### *Chronic Disease*

Patients in the Chronic Disease group are those with chronic diseases typified by multiple periods of exacerbation, such as chronic obstructive pulmonary diseases (COPD), congestive heart failure (CHF), end-stage renal disease (ESRD), diabetes mellitus (DM), or stable stroke patients. Using primary and secondary diagnoses, patients in this group suffer with one or more of the aforementioned chronic diseases, and researchers can stratify the cluster into sub-groups to determine differences between patients with a single chronic illness to those suffering with multiple chronic co-morbidities.

### *Frail Elderly*

The Frail Elderly group consists primarily of patients who are severely impaired, either functionally and/or cognitively, and defined in the model as persons greater than 70 years of age who do not have a diagnosis of cancer at the time of death. Typically, this group declines very gradually over time towards death.

Given that rates of decline experienced by patients influences healthcare interactions, interventions, and family communication, data using the decline-to-death trajectories are expected to reveal differences in EOL experiences among the groups, since needs vary dramatically based on individual circumstances.

### A Conservation Orientation to Profiling the End of Life

The conceptual model for profiling hospital death builds on the four conservation principles of patient care identified by Myra Levine in the late 1960s, which are conservation of energy, conservation of structural integrity, conservation of personal

integrity, and conservation of social integrity (Levine, 1967, 1989). The conservation principles are holistic in their orientation to patient care and sensitive to the complex web of interactions that exists between patients and the healthcare system. Conservation is a term derived from Latin meaning to “keep together”, and the goal of conservation is the preservation of individual wholeness (Levine, 1989).

Conservation of energy refers to the “identifiable, measurable, and manageable” (Levine, 1989, p.331) aspects of patient care. Conservation of structural integrity refers to the balance and order of human physiologic processes (1989). Conservation of personal integrity incorporates all the components of behavior and recognizes the value of self, and conservation of social integrity defines all the social components and interactions an individual identifies with, including the established social systems of family, community, and religious affiliation, as well as the unfamiliar environment of a hospital (Levine, 1969).

#### Profiling Based on End of Life Quality Indicators

Embedded in the broad principles of conservation are decline trajectories of Sudden Death, Cancer, Chronic Disease, and Frail Elderly adapted from the work of others (Lunney, 2003), and the five dimensions of quality EOL care identified by others as continuity of care, physical comfort, respect for the dying, emotional support, and communication with shared decision-making (Teno, 2004).

#### *Conservation of Energy: Continuity of Care*

Chronically and critically ill patients along with the frail elderly are shuttled between interfaces of care at an alarming rate and number, as evidenced by the

tremendous utilization of resources expended during the last six months of life (Wennberg, 2004; Fisher, 2003). Therefore, in an effort to conserve energy at the EOL, healthcare professionals must provide continuity of care, smooth transitions from setting to setting, or optimally minimize the number of transfers that take place. To profile continuity of care during the last six months of life the model assesses the volume and location of transitions of care before, during, and after each hospital stay and examines the size of the multidisciplinary team that consists of physicians, specialists, nurses, and numerous ancillary service departments. The profile will assist with identifying medical services and disease processes prone to high utilization in expensive areas of care that contribute to less than satisfactory EOL experiences for patients and families alike.

*Conservation of Structural Integrity: Physical Comfort*

Extensive evidence exists that dying patients experience distressing physical symptoms (Lorenz, 2004) at the time of their death. Preserving structural integrity is the theoretical realm that examines physical comfort by profiling provider responsiveness to a variety of symptoms during the last 48 hours of life and the intensity of treatments ordered during the last six months of life.

Profiling distressing symptoms encompasses all biological systems and often requires an astute provider to detect. Profiling the level of treatment intensity during the last six months of life provides insight into the efficacy of aggressive treatments, particularly with regard to the frail elderly and chronically ill. Items of interest include invasive procedures, resuscitation efforts, and the use of artificial hydration or nutrition, along with other physically depleting interventions such as chemotherapy, radiation,

dialysis, and ventilator support, all of which potentially require the use of physical restraints to perform (Lorenz, Lynn, et al., 2004).

*Conservation of Personal & Social Integrity: Respect, Support, and Communication*

Lastly, conservation of personal and social integrity requires that healthcare providers show respect for the dying by listening and honoring their wishes. Profiling personal integrity encompasses the degree to which healthcare professionals are respectful to advanced directives or personal preferences. Profiles therefore assess for evidence of living wills, healthcare powers of attorney, and congruence between medical treatment and expressed EOL wishes, and examines resuscitation efforts and the use of restraints at the EOL.

Providing emotional support to patients and families maintains social integrity, and contributes to communication and shared decision-making. Profiling communication and shared decision making examines for meaningful interactions between patients, families, and providers particularly during the active dying process, and assesses how it influences the treatment plan. The profile for emotional support assesses for evidence of family involvement during the last 48 hours of life, including family visiting patterns, and whether a patient died alone, or in the company of loved ones.

The Model for Profiling End of Life Care

Although a large and diverse volume of literature has gathered in the field of EOL care over the past decade, a comparative dearth exists for studies pertaining to measures on a local or regional scale. Yet, it is at this level that Americans actually experience death. One exception is a study conducted in response to the SUPPORT study that

retrospectively examined the EOL care delivered to decedents who expired in a large metropolitan hospital during a single calendar year (Dendaas, 2001).

The findings were similar to those reported by SUPPORT investigators, with a majority of deaths occurring in the ICU and physicians writing most DNR orders one to three days prior to death (Dendaas, 2001). Consistent with previous studies, this study also found that decedents were medically unstable and had at least one chronic illness at the time of admission (Dendaas, 2001). This particular study was valuable in that it provided hospital leadership with information that could change the trend of care delivered to its dying patients. Conceivably, all healthcare delivery systems will discover the need to evaluate current EOL practices in a systematic manner in order to design programs that improve consumer satisfaction with dying in this country.

In order to affect any meaningful change regarding EOL care, comprehensive assessments are necessary as a starting point. The EOL Profiling Model (Appendix A) is a tool developed to enable assessment of EOL care delivered to hospitalized patients at site-specific locations.

The model serves as not only an assessment tool for examining current EOL care, but a theoretical framework for developing new programs of care for dying patients and a methodology for evaluating the effectiveness of EOL care programs. The body of knowledge gained from analyzing EOL profile data will provide the information necessary to formulate policies using methodologies that focus on decreasing the human and economic costs associated with futile care. Additionally, there is hope that individual profile studies from different facilities will ultimately combine and generate a regional



database on EOL care to facilitate the development of policies that can positively influence the quality of dying for larger populations.

A key characteristic of the Model for Profiling EOL Care is how it builds on the well-established research started by others in the specialty of palliative care. The literature reveals that a great deal of EOL care is focused on patients with cancer, due primarily to the predictable short-term trajectory from initial decline-to-death, yet the need for research to illuminate the decline among clusters of chronic illnesses has tremendous implications for the future of healthcare delivery (Lunney, 2003). The uncertain knowledge regarding EOL declines with diseases other than cancer is a need recognized by several studies (Lorenz, Lynn, et al., 2004; Lamont, 2003), and the Model for Profiling EOL Care will attempt to discern decline patterns as a means of filling that void.

## CHAPTER 4

### RESEARCH METHODS & PROCEDURES

#### Study Design & Purpose

The aim of the EOL profiling study is to collect and analyze pertinent baseline data to portray the present state of dying at a county hospital serving the citizens of Anderson, Oconee, and Pickens counties, located in the Upstate region of South Carolina. The study retrospectively examined the hospital medical records for a randomized sample of decedents ages 45 years and older (n=100), who expired while hospitalized during 2003. The study selected 2003 because comparative baseline data from another facility is available for future use, and to avoid potential bias from a palliative care program initiated the following year. The study examined data for all the admissions experienced by the sample subjects during their last six months of life. Although the study is primarily exploratory and descriptive in design, the study extracted quantitative data sets for selected variables. Since the study was not of an experimental design that identifies independent and dependent variables, the research identified no extraneous variables.

#### The Study Setting

The study setting for this research project was a 461-bed acute-care facility located in the Upstate region of South Carolina. The hospital offers a full range of medical services to citizens living predominantly in the three counties of Anderson, Oconee, and Pickens. The facility is located in an urban center, yet the service area is predominantly rural.

## Research Objectives

Utilizing the Model for Profiling EOL Care, data collected addressed the following questions to reveal the conditions related to dying and end of life care at the acute care medical facility described above:

- 1) What are the demographic characteristics of patients dying in an acute care hospital in Upstate South Carolina?
- 2) What proportions of the sample fall into readily identifiable decline trajectory groups (Sudden Death, Cancer, Chronic Disease, and Frail Elderly) and what are the demographic characteristics of these groups?
- 3) What are the current conditions regarding continuity of care as evidenced by admission frequencies, medical service, care transitions, and the volume of professionals interacting with patients, noting patterns of care for the decline-to-death trajectory groups?
- 4) Does the intensity of treatment delivered during the last admission, and how healthcare professionals respond to common symptoms experienced by dying patients affect how patients physically experience the dying process?
- 5) Is there respect for the dying as evidenced by relationships between documented EOL preferences, the presence of advanced directives, do not resuscitation (DNR) orders, and changes in resuscitation orders while hospitalized?
- 6) Is there documented evidence of emotional support, communication, and shared decision-making with patients and/or families related to unit of death,

degree of family presence at the end of life, and decisions to forego or withdrawal treatment?

### The Study Sample

The subjects selected for the EOL Profiling study were patients who expired while hospitalized in an acute care medical facility located in Anderson, South Carolina during the calendar year 2003. All subjects were 45 years old or older and deaths related to suicide and homicide were excluded, since the goal of this study was to depict the last six months of life for persons experiencing more complex medical needs, such as those suffering with chronic diseases or the frail elderly. The initial pool of decedents meeting the above criteria was N=273, from which a randomized sample of patients (n=100) was selected using a computer generated random number list.

### The Study Instrument

The development of the profiling instrument (see Appendix B) evolved from the Model for Profiling EOL Care and the organization of the instrument was in accordance with that of the medical records at the study facility in order to facilitate the data retrieval process. The study instrument integrated items used on instruments from similar studies at other nearby institutions. Researchers have not established the reliability or validity of the instrument at this time.

### The Data Collection Process

A graduate student investigator collected the data for the sample of decedents selected for this study using the facility's electronic medical records system. The Medical Records Department at the study facility provided training in the use of the system, a

password protected login to the sample of subjects, and on site assistance as needed. The graduate student investigator retrieved 100% of the data using a data collection protocol to insure consistency. The collection period extended from June 2006 to May 2007, and data collection procedures were pilot-tested and refined prior to implementation of the data collection process for the project.

### Data Management & Data Analysis

The software used to organize and analyze the data extracted from the electronic medical records was SPSS Version 15.0. Additionally, the investigator employed the use of Microsoft Excel to summarize various population characteristics. Graphs and charts generated in this report used both of the above-mentioned software packages. Due to the predominantly descriptive nature of the study, the majority of analyses detailed in this report are frequencies, with means, medians, range, and standard deviations reported for selected variables where appropriate.

### Study Limitations

#### *Threats of Validity*

The instrument developed for profiling the last six months of life for the sample of hospitalized patients extracted information regarding demographics, units of care, diagnostic procedures and tests undertaken, and the type and quantity of medical treatments initiated. The medical records reviewed were those of deceased individuals and the investigator made no attempt to contact any surviving family members to validate the accuracy of the information documented in the medical records, since this was outside the scope of the study parameters. Additionally, the researcher made no effort to contact

the healthcare providers identified in the records to validate the interpretation of their documentation. It is conceivable that patients and their families experienced their loved ones death quite differently from the vision depicted in the medical record, and that documented interactions between medical staff, nursing staff, patients, and families do not adequately paint a portrait of dying from the patient and family perspective.

### *Limitations*

During the course of data collection, the principal investigator encountered several limitations that are common to retrospective chart reviews, while others are unique to the medical facility where the data collection took place. All the medical records were digitally stored and accessible via a computer storage system maintained by the hospital, and some computer summary data were available such as primary and secondary diagnoses, medical service, physicians and consultants, hospital charges, insurance payors, and certain medical procedures. The coded information sometimes varied slightly from the handwritten notes or typed reports in the actual medical record. When this occurred, information from the medical record took precedent over the digitally coded information following a standard protocol set by the investigator. Since much of the information extracted from the medical records required the researcher to decipher handwritten notes entered by physicians, nursing staff, or others; an obvious limitation existed related to the legibility of these notes, and this might have led to misinformation or omissions of data due to an inability to read it correctly.

Another limitation encountered by the examiner began with records in October of 2003, when the hospital began to phase in electronic nursing documentation on several of

the nursing units, and nearly all the hospital units were documenting via the computer by the end of the sample year. During the phase-in period, omissions and oversights in the admission process were likely to have occurred, particularly regarding obtaining patient EOL preferences, which was well documented earlier using the traditional paper and pen admission form. At the same time, the hospital laboratory transitioned to a new reporting system, resulting in charts having duplicate lab results on file. This duplication increased the risk of incorrectly tabulating laboratory studies performed, although the researcher took care to minimize this risk when encountering charts of this type by methodically accounting for dates and collection times.

Lastly, within a fifty to seventy mile radius of the study hospital are several medical facilities of comparable size, reputation, and ability to serve the sample population. Therefore, the patients in the study sample might have sought care at one of these facilities and those encounters are not included in the six-month EOL review period. It is unknown how many persons this might affect, and places a limitation on any estimation made in this study regarding the analysis of the six months prior to death.

#### Significance of the Study

Historically, serious efforts to collect EOL data began over a decade ago, and there is a sizable amount of literature describing EOL care at the national and state levels. However, a comparative dearth exists for literature pertaining to measures on a local or regional scale. Hospital-specific EOL profiling will generate data to compare and contrast against existing data and will aid in establishing regional databases for EOL care. EOL

profiling will assist in assessing trends and variances in the quality of care provided to dying patients, and will contribute to the growing national database on EOL care.

The EOL profile data from this project will facilitate the development of programs by healthcare professionals and policymakers to improve conditions for dying patients in Upstate SC. Additionally, the study results and model for profiling EOL care provide administrators with tools to assess current EOL care practices and the means to evaluate the effectiveness of any implemented programs or policy changes in the future. A comprehensive hospital-based EOL profile is essential if existing healthcare delivery systems sincerely desire a meaningful change in the way our local citizenry experience death. Through profiling the status quo in EOL care, knowledge is garnered that will ultimately improve the kind of care offered to patients approaching the end of life. Research will identify the frequency and utilization patterns that are inconsistent with optimal measures for continuity of care, physical comfort, respect for the dying, communication efforts, and emotional well-being for patients and families.

Utilizing demographic and diagnostic data, the study classifies patients into groups based on decline trajectories first identified by Lunney, et al. (2004), and referred to in this study as the Sudden Death, Cancer, Chronic Disease, and Frail Elderly decline-to-death trajectory groups. Primary and secondary diagnoses as indicated by ICD-9 codes will provide the basis for analyzing decline trajectories for various diseases as well as for patients with multiple co-morbidities. This will add to the body of knowledge by documenting the relationships between disease diagnoses, patterns of decline in health, and approaches currently employed to handle the EOL.



## CHAPTER 5

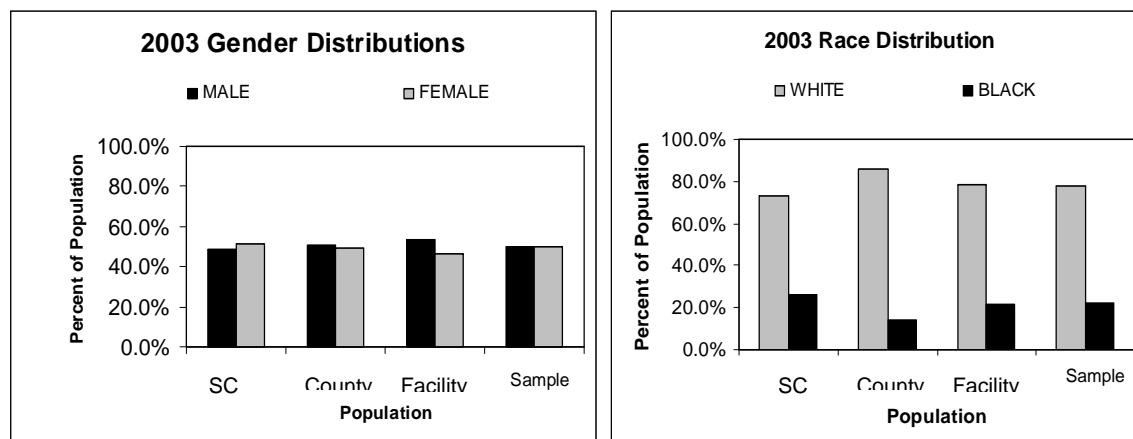
### RESULTS

The following results pertain to the randomized sample of 100 patients, 45 years old or older, who expired in an acute care medical facility during 2003 from non-traumatic causes of death in Anderson, South Carolina. To determine how representative the sample was of the general patient population, the investigators compared the random sample to similar populations in South Carolina, Anderson County, and the pool of patients that expired in the study facility that met the study parameters. The following graph (Figure 5.1) illustrates the demographic composition of gender and race comparing the populations in South Carolina, Anderson County, the study facility, and the study sample. Although the state and county both had very small percentages of residents of other ethnic origins (0.3% and 0.1% respectively), the sample, and the population of 2003 hospitalized deaths at the study facility had no other ethnicities represented.

There were 276 persons who expired while hospitalized in the study facility during 2003 (age  $\geq 45$  years and excluding homicides or suicides) with a mean age of 74.6 years (s.d. =11.32). The random sample (n=100) from the population of inpatient deaths had a mean age of 73.18 years (s.d. =11.38). A statistical comparison of age for the sample and facility population reveal that there is no significant difference between the two populations ( $t = -1.07$ ,  $p = .286$ ) when performing t-test for differences. Statistical analysis indicates that state, county, hospital, and sample are comparable, so that generalizations regarding the sample are pertinent to the larger population sets.

Figure 5.1

Gender and Race Distributions of Sample  
Compared to like Populations in South Carolina, Anderson County, and Facility



From: <http://scangis.dhec.sc.gov/scannet/tables/death2table.aspx>

Profile: Demographic Characteristics

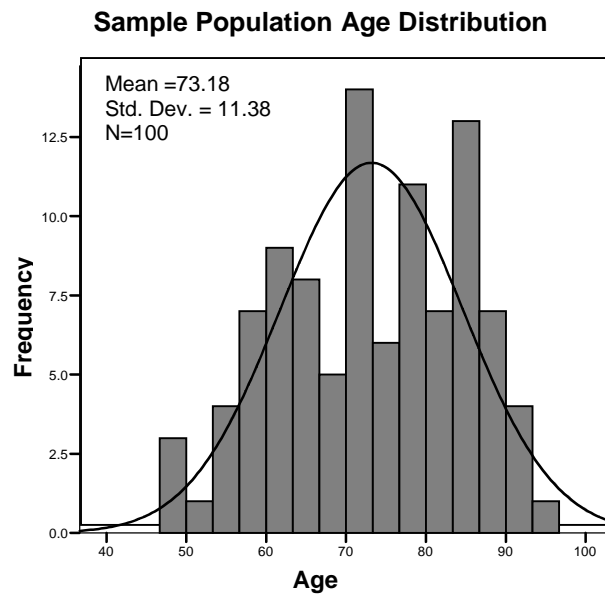
*Research Question 1 (Q1):*

*What are the demographic characteristics of patients dying in an acute care hospital in Upstate South Carolina?*

The gender and race distributions for the decedent sample were evenly split for gender, with 50% males and females alike, while the proportion of Caucasians were 78% compared to 22% African Americans (Figure 5.1). The mean age for decedents in the study was 73.18 years (s.d. =11.38), with a range extending from 48 to 94 years old (Figure 5.2). Caucasians averaged 74.08 years of age, compared to African American (AA) with a mean age of 70 years. Females were slightly older on average at 73.98 years, compared to their male counterparts who had a mean age of 72.38 years.

Additional demographic information collected from decedent charts included marital status, county of residence, and the next of kin identified at the time of admission. Other demographic information collected included employment status, as well as primary and secondary insurance payors. The following summarizes the frequency results in these areas.

Figure 5.2  
Age Distribution of Sample

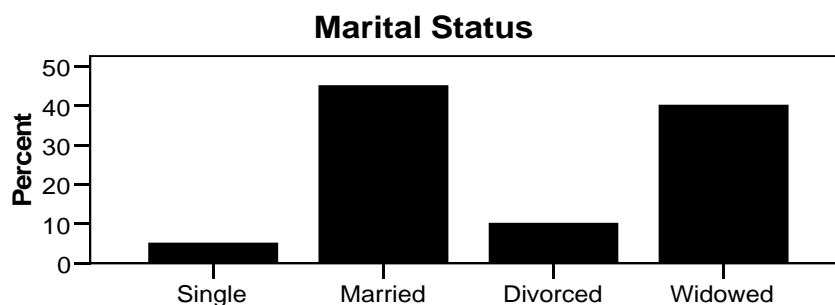


### *Marital Status*

The majority of decedents were married (45.0%), yet almost equal proportions (40.0%) were either widows or widowers. Ten percent (10.0%) of the sample was divorced, while 5.0% indicated at the time of admission that they were single. No decedent changed their marital status during the last six months of their life.

Figure 5.3

Distribution of Sample by Marital Status



#### *County of Residence*

Not surprisingly, the vast majority of decedents reported residency in Anderson County (87.0%), while the remaining 13.0% lived in the adjacent counties of Pickens, Oconee, or neighboring counties in Georgia. All these counties have urban hubs surrounded by predominantly rural, less populated areas of residential and agricultural land use. It is outside the scope of this study to assess whether decedents resided in urban or rural areas in these counties. It is of interest to note that all these bordering counties have hospitals, yet the study hospital is larger and has more specialties available than do the hospitals in the other counties.

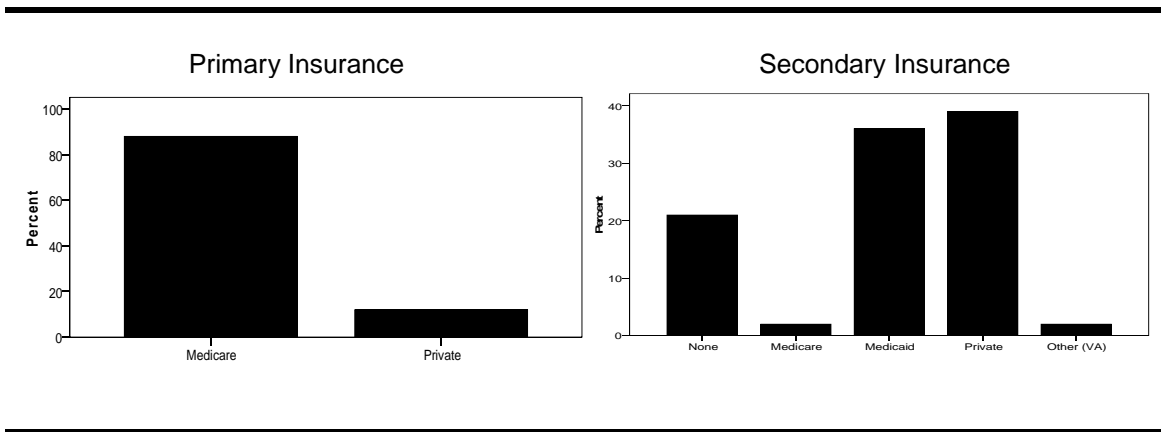
#### *Next-of-Kin*

Of nearly equivalent proportion, decedents named either their spouse or children as the next of kin (43.0% and 42.0% respectively). A majority of (95.6%) indicated that their next of kin was their spouse, while 4.4% identified their son or daughter as the next of kin. Widows and widowers overwhelmingly named children as their next of kin

(82.5%), but 2.5% each identified that an in-law or sibling as their next of kin and 12.5% indicated that other people such as grandchildren, nieces or nephews, or person of no relation were their next of kin at the time of admission. Males favored their wives as next of kin (58.0%), while women indicated that their children were the next of kin 56.0%. Again, the next of kin identified did not change during any of the subsequent admissions during the last six months of life.

Figure 5.4

Distribution of Sample by Primary and Secondary Insurance



### *Insurance and Employment*

As depicted in Figure 5.4, the overwhelming majority of decedents had Medicare as their primary payor for hospital services (88.0%), and 12.0% had insurance via the private sector. There were no cases of indigent care in the sample. The presence of secondary insurance was high, due to the percentage of Medicare patients. Secondary insurance included policies in the private sector (39.0%), Medicaid recipients (36.0%), and 21% had no secondary insurance. Two percent (2%) each claimed either Medicare or the Veterans Administration as secondary payors of medical services. As expected, the

majority of decedents were retired (70.0%), while 21.0% were disabled. Only 5.0% were employed and 4.0% unemployed (Figure 5.4).

#### Profile: Decline-to-Death Trajectory Groups

##### *Research Question 2 (Q2):*

*What proportions of the sample fall into readily identifiable decline trajectory groups (Sudden Death, Cancer, Chronic Disease, and Frail Elderly) and what are the demographic characteristics of these groups?*

The study placed decedents into one of four decline-to-death groups, which others identified in previous research efforts as relevant decline trajectory clusters. The four groups in this study are Sudden Death, Cancer, Chronic Disease, and Frail Elderly. While reviewing the terminal medical records, the investigator was able to place each decedent into one of the four decline-to-death groups.

Patient characteristics associated with Sudden Death are those whose demise was abrupt and unforeseen, such as from hemorrhage, acute myocardial infarct, or pulmonary embolus. Patients in the Cancer group included all those with a diagnosis of cancer, except for those who met with a sudden and unanticipated death. Patients in the Chronic Disease decline group are those diagnosed with one or more diseases that are chronic in nature and typified by periods of exacerbation such as chronic cardio-pulmonary diseases, and debilitating conditions such as end-stage renal disease, diabetes, or stable stroke patients. The Frail Elderly group consists of elderly persons greater than age 70, from either nursing homes or home, who have documented functional and/or cognitive impairment at the time of admission.

### *Sudden Deaths*

Sudden Deaths were those decedents who had either a high or a stable level of functional ability at the time of death, and the records described their demise along the lines of “the patient suddenly collapsed”. Eleven (n=11) cases met the criteria for the Sudden Death group. The cases ranged in age from 58 to 88 years of age, with a mean age of 74.09 years (s.d. =10.44).

Nearly twice as many females (63.6%) as males (36.4%) experienced a sudden death, and 54.5% decedents were AA (n=6), compared to 45.5% that were Caucasian (n=5). The majority in this category were widowed (45.5%), while 27.3% were married, 18.2% divorced, and 9.1% were single. Almost half (45.5%) the patients who experienced an unexpected death had one chronic disease on previous admissions (diabetes n=2; CHF n=1; COPD n=1; and CVA n=1). They also had a low frequency of falls (18.2%), and were the least likely to chair bound or bed bound (27.3%) at the time of their last admission.

### *Cancer Deaths*

Deaths due to cancer are very recognizable by diagnosis (ICD-9 code 140-239 & 284-289) and researchers have studied their decline-to-death extensively. For the purposes of this report, decedents assigned to the Cancer cluster had to have a primary or secondary IDC-9 diagnosis of cancer and not meet the criteria for sudden death during their last admission.

Thirty-two (n=32) decedents in the study qualified for this death trajectory group, with 62.5% (n=20) having cancer as a primary diagnosis, while the remaining had cancer

as a secondary diagnosis. The mean age for this group was 66.56 years (s.d. = 9.76), with a range from 48 years to 84 years of age. The majority of decedents in the cluster were male (65.6%) versus female (34.4%), and predominantly Caucasian (84.4%) versus AA (15.6%). Unlike the previously discussed Sudden Death group, decedents in this category were predominantly married (78.1%), versus widowed (15.6%), divorced (3.1%), or single (3.1%). The Cancer cluster had the fewest falls documented in the last 6 months at 16.1%, yet 67.7% had documented decline at the onset of their last admission and less than half (43.3%) were chair or bed bound and a very small percentage (3.1%) at the time of the terminal admission.

#### *Chronic Disease Group*

This is by far the most complex and least understood group of the decline-to-death trajectories. In order to understand the complexity of this group better, decedents with any readily identifiable chronic illnesses such as chronic pulmonary diseases (ICD-9 490-496), congestive heart failure (ICD-9 428), end-stage renal disease (ESRD) (ICD-9 585), diabetes (ICD-9 250), or non-acute stroke patients (ICD-9 438) qualified for inclusion in this category. The investigator placed each qualified decedent into sub-groups depending on whether they had one, two, or three or more documented chronic diseases. For subjects with only one chronic disease, they entered a sub-group based on which one of the five identified chronic disease groups was appropriate. The remaining sub-groups in this category were for patients with multiple co-morbidities, either with two of the five chronic diseases or having three or more of the five chronic diseases.



Thirty-five (n=35) subjects met the criteria for the Chronic Disease cluster, with the vast majority in this group having two or more chronic diseases at the time of their death. Forty percent (40%) of the decedents had two of the 5 chronic diseases and 37.1% had three or more at the time of death. Only eight cases (22.9%) had a single chronic disease during their terminal admission, and all the patients had the same single chronic disease category in previous admissions, which distributed as three (3) with chronic obstructive pulmonary disease (COPD), two (2) each had ESRD and CHF, and a single case of diabetes.

The Chronic Disease cluster had 45.7% male subjects and 54.3% female, 74.3% were Caucasian compared to 25.7% African American, and the mean age for this group was 71.37 years old, with a range of 50-91 years of age. A majority of the decedents in this group were widowed (51.4%), followed by 22.9% who were married, 20.0% who were divorced, and 5.7% that were single at the time of their death.

### *Frail Elderly*

In sharp contrast to the Chronic Disease group, the Frail Elderly are probably the most readily identifiable group, since the first criterion for inclusion is that subjects had to be 70 years old or older. Decedents meeting the age criteria then had to have documented physical impairment requiring assistance with activities of daily living (ADLs) and/or having cognitive impairment identified by ICD-9 codes for dementia (ICD-9 331), Alzheimer's (ICD-9 331.8), or Parkinson's disease (ICD-9 332). Type of residence had no bearing on whether the investigator identified a decedent as a frail elder, since nursing home elders are often mobile and independent, while other elders that are

completely dependent for all their needs are cared for by family members in private homes.

Table 5.5  
Demographic Distribution of Disease Trajectory Groups

Disease Group		Gender (% of total sample)		Race (% of total sample)		Marital Status (% of total sample)			
		M	F	W	B	Single	Married	Divorce	Widowed
Chronic Disease Organ Failure	ESRD	1.0	1.0	0.0	2.0	0.0	1.0	0.0	1.0
	CHF	1.0	1.0	2.0	0.0	0.0	0.0	0.0	2.0
	COPD	1.0	2.0	3.0	0.0	0.0	0.0	2.0	1.0
	DM	1.0	0.0	0.0	1.0	0.0	1.0	0.0	0.0
	2 Chronic	7.0	7.0	12.0	2.0	2.0	1.0	1.0	10.0
	3+ Chronic	5.0	8.0	9.0	4.0	0.0	5.0	4.0	4.0
Chronic Disease		<b>16.0</b>	<b>19.0</b>	<b>26.0</b>	<b>9.0</b>	<b>2.0</b>	<b>8.0</b>	<b>7.0</b>	<b>18.0</b>
Cancer		<b>21.0</b>	<b>11.0</b>	<b>27.0</b>	<b>5.0</b>	<b>1.0</b>	<b>25.0</b>	<b>1.0</b>	<b>5.0</b>
Frail Elderly		<b>9.0</b>	<b>13.0</b>	<b>20.0</b>	<b>2.0</b>	<b>1.0</b>	<b>9.0</b>	<b>0.0</b>	<b>12.0</b>
Sudden death		<b>4.0</b>	<b>7.0</b>	<b>5.0</b>	<b>6.0</b>	<b>1.0</b>	<b>3.0</b>	<b>2.0</b>	<b>5.0</b>
% of Total		50%	50%	78%	22%	5%	45%	10%	40%

The Frail Elderly cluster consisted of 22 subjects (n=22) who met the study criteria for this disease trajectory. Due to the age restriction inherent in this group, the mean age is at least 10 years higher than that of the other three groups, at 85.23 years old, with a range from 73 years to 94 years of age. Males composed 40.9% of the frail elders and females 59.1%, and the majority in this group were Caucasian (90.9%) leaving less than ten percent (9.1%) African American, the smallest proportion compared to the other trajectory groups. At the time of the last admission, 81.8% of the medical records for this

group had documented a decline in patient health status, while 13.6% (n=3) documented no decline, and one case (4.5%) had no documentation on this subject.

It is not surprising that over half in this category were widowed (54.5%), but a large portion of them were still married (40.9%). No subject in the Frail Elderly group was divorced, however 4.5% indicated upon admission that they were single. The following table summarizes the demographic characteristics of gender, race, and marital status for four disease trajectory groups, and includes the sub-groups within the Chronic Disease group.

#### Profile: Continuity of Care

##### *Research Question 3 (Q3):*

*What are the current conditions regarding continuity of care as evidenced by admission frequencies, medical service, care transitions, and the volume of professionals interacting with patients, noting patterns of care for the decline trajectory groups?*

#### Admission Frequencies & Medical Services

During the last six months of life, the sample population (n=100) experienced 281 admissions to the hospital, for an average of 2.81 admissions over 6 months, with an average length of stay each admission of 8.94 days. For their last admission, a majority (86.0%) came through the Emergency Department (ED), 10.0% came to the hospital from the doctor's office, and only 4.0% gained admission from other locations such as directly from home or from the dialysis clinic.

The majority of decedents lived at home prior to their last admission (57.0%), while another 15.0% were living at home receiving home health services (13.0%) or home hospice care (2.0%). Over a quarter (28.0%) of the decedents resided in nursing care facilities prior to their last admission.

The most frequently utilized admissions medical specialty during the study period was Internal Medicine, which accounted for 63% of all the terminal admissions (n=100), and 56.9% of all the admissions experienced during the last six months of life (n=281). Surgical services admitted 18.0% of the patients for their last hospital stay, and 24.6% during the preceding 6-month period. The Oncology specialty admitted nearly the same percentage of patients to their terminal hospital stay as it did for the 6-month period (15.0% and 14.9% respectively). The smaller specialty services of Neurology and Orthopedics admitted 3.0% and 1.0% (respectively) of the decedents for their last hospitalization, and 1.8% and 1.1% (respectively) during the last six months of life. A very small percentage of patients used the Urology medical service during the six months prior to death (0.7%), yet no patients used this service as an admitting service during their terminal hospital stay.

For discussing patterns of care during the six month of life the sample size is n=281, representing the total volume of admissions reviewed. Most of the cases held the same trajectory group classification throughout all their admissions, but occasionally a Cancer patient was in a chronic disease category during earlier admissions, or a frail elder was an alert elder without chronic disease in prior admissions. Similarly, the Sudden Death group could only gain entry into this category during their last admission. Therefore, for the purposes of this section the analysis will primarily focus on the last admission, due to a few decedents falling into different groups over the last six months of life.

### *Sudden Death*

For the majority of patients who experienced an unexpected death (72.7%), the internal medicine service was the admitting service of record, followed by equal proportion admitting to surgery, oncology, and orthopedics (9.1% each). The Sudden Death group averaged 2.18 admissions in the last 6 months of life (range 2-3), and an average LOS of 4.14 days their last admission. The entire Sudden Death group came through the ED prior to their last admission to the hospital, with the majority coming from home without any home health or hospice services in use (72.7%), and the rest (27.3%) lived in nursing homes or assisted living prior to their untimely demise.

### *Cancer*

Not surprisingly, the oncology unit was the admitting service of choice for 43.8% of the patients with a diagnosis of cancer. The Cancer group had an average of 3.0 admissions during the last 6 months of life (range 2-8), and an average LOS of 10.95 days for their last admission. Most of the decedents in the group came through the emergency room (71.9%), but this group had the largest proportion of admissions made directly from the physician's office (15.6%). A majority of the cancer decedents lived at home (81.3%), and 9.4% were receiving home health services prior to their terminal admission. This cluster had the smallest percentage of subjects living in nursing care facilities (6.3%) prior to the terminal admission, and a single case (3.1%) was receiving hospice services when the family opted for more aggressive treatment as the patient declined.

### *Chronic Disease*

Admissions for the Chronic Disease group were primarily to Internal Medicine (74.3%), with the surgery service admitting 22.9%, and Neurology admitting 2.9%. Similar to that of the other trajectory groups, they came through the ED (85.7%), yet 14.3% of the decedents came directly from the physician's office for their last admission. The Chronic Disease group experienced an average of 3.0 admissions during the last 6 months of life (range 2-6), and an average LOS of 10.19 days for their terminal admission. Over half (54.3%) the decedents with chronic disease lived at home, and 31.4% came from nursing care facilities prior to their last admission. The remaining patients were living at home with either home health support (11.4%) or hospice services (2.9%) prior to their last admission to the hospital.

### *Frail Elderly*

All (100.0%) of the decedents in the Frail Elderly group came to the hospital via the ED for their terminal admission, most (81.8%) were admitted to the Internal Medicine service. The group averaged 2.55 admissions during the last six months of their lives (range 2-4), and had an average LOS their last admission of 7.61 days. Over half (54.5%) of the decedents in the group lived in a nursing care facility prior to their last admission, while 27.3% lived at home receiving home health services, and 18.2% at home without any identified services in use.

### Care Transitions and the Interdisciplinary Team

For the purposes of this study, the definition of a care transition is the number of setting changes a patient experiences including where he/she lived prior to admission and

location of discharge disposition. For example, a patient admitted to the hospital from home via the ED to a medical floor, and then discharged back home would total three transitions of care. However, if the same patient discharged to a nursing care facility or returned home with home health service, the number of care transitions would be four in each case. Likewise, during each hospital stay, transfers from one unit type to another counted as a single care transition. The sum of care transitions within the hospital did not account for every bed transfer a patient made, but rather the different nursing units encountered during a hospital stay. Differentiating hospital units for this study included medical/surgical units, intensive care units, telemetry monitoring units, oncology, and stays on the orthopedic or neurology units counted as ‘other’ in the data coding process.

To assess the volume of healthcare professionals that interacted with a patient, the profile first counted the number of physicians on the case during each admission, and then calculated the interdisciplinary team (IDT) members by adding the number of other healthcare services providing care to a patient during their hospitalization. Other healthcare services included nursing, respiratory, physical therapy, occupational therapy, speech therapy, and nursing specialists such as diabetic educators, wound specialists, mental health personnel, or oncology counselors. IDT tallies also included representative from the chaplain’s office and the social work department, which included social workers, case managers, and/or discharge planners. Calculating the sum of individuals providing care to any one patient during a hospital stay was outside the scope of this project, and therefore IDT members were service departments and not necessarily individuals.

During the last six months of life, the decedents experienced an average of 9.90 care transitions, with a range of 5-25 transitions of care experienced during this six-month period (s.d. = 4.05). During their last admission, the decedents had a mean number of 12.62 diagnoses for which they experienced an average of 3.52 transitions of care, (range of 3-5; s.d. = 0.67). The mean number of physicians seeing decedents during their terminal admission was 3.57 (range of 1-12; s.d. = 1.88), while the mean number of IDT members was 5.07 (range 1-10; s.d. = 1.80). All of the trajectory groups had a range of 3-5 transitions of care during their last admission.

### *Sudden Death*

The Sudden Death group experienced a mean number of 9.45 transitions of care during their last six months (range 6-18; s.d. = 4.01). On their final hospital stay, they had the least number of diagnoses, with a mean of 10.09 diagnoses their last admission and experienced 3.55 transitions of care. As a group, they saw the fewest physicians, at an average of 3.36, and had the smallest IDT with a mean of 4.55 members their terminal stay in the hospital.

### *Cancer*

The Cancer group had an average of 9.91 transitions of care during their last six months of life (range 5-25; s.d. = 4.40), and a mean of 3.47 transitions of care their last admission with an average of 12.66 diagnoses at the time of their death. Additionally, the Cancer group had the highest average of medical doctors on their cases at 3.81 (range 1-8; s.d. = 1.87), and the highest average of IDT members at 5.34 (range 2-10; s.d. = 1.89).



### *Chronic Disease*

The Chronic Disease group had the highest mean number of transitions during the last six months of life at 10.51 (range 6-23; s.d. = 4.20), the highest average transitions of care during their last admission at 3.63, and had the highest mean diagnoses at 13.74. The group saw an average of 3.69 physicians during their terminal admission, and had an average of 5.11 IDT members on their case.

### *Frail Elderly*

The Frail Elderly group had the fewest number of transitions of care during the last six months at 9.14. They also had the fewest transitions during their last admission with an average of 3.41 transitions of care, and a mean of 12.05 diagnoses during their terminal admission. Frail Elders had an average of 3.14 physicians managing their care during their last admission and an average of 4.86 services on their IDT.

### Profile: Physical Comfort

#### *Research Question 4 (Q4):*

*Does the intensity of treatment delivered during the last admission, and the way healthcare professionals respond to common symptoms experienced by dying patients affect how patients physically experience the dying process?*

#### Intensity of Treatment

The variables measuring the intensity of treatment expended on dying patients included the number of invasive procedures performed, resuscitation efforts and outcomes, and the number of days patients received various treatments typically associated with aggressive care during their terminal admission. Procedures included in the profile were all invasive efforts performed by physicians that took place in an

operating room (surgery), procedural suite (example endoscopy), or procedures performed at the bedside. Also included in the volume of procedures is whether a patient received a transfusion of red blood cells, platelets, or plasma, but not the number of units transfused. A coded procedure list was readily available for all the decedents and compared against the medical record for completeness and accuracy.

Various treatments are indicative of aggressive care, which many feel are inappropriate at the conclusion of life. Typically aggressive treatments included in the profile are ventilator support, intravenous fluids (IVF), vasoactive medications, artificial nutrition (either intravenous or enteric), along with chemotherapy, radiation, dialysis, and advance cardiopulmonary resuscitation (CPR). Therefore, the profile examines not only the number of days aggressive forms of treatment are provided, but also the number of times patients required CPR and the outcome of those efforts.

#### *Invasive Procedures*

The number and type of invasive procedures performed varied, but 64% of the decedents experienced anywhere from 1-16 invasive procedures during their final admission. Thirty percent (30%) had 1-2 procedures, while the remaining 34% had three or more aggressive/invasive procedures performed. Thirteen percent (13%) of decedents had surgery during their last admission.

The Cancer and Chronic Disease groups had the higher mean numbers of procedures performed, with means of 3.13 and 2.80 invasive procedures performed respectively for the two groups. These groups also had the highest percentage of surgeries with 14.3% in the Chronic Disease group and 12.5% in the Cancer group.

### *Treatments and Interventions*

Of the aggressive forms of treatments listed above and profiled, the most widely used was IVF. Eighty-seven percent (87%) of decedents received fluids during their last admission (range of 0.5-50 days), and the highest frequency of IVF delivery was for 1 day (29%) and the mean number of days they had IVF was 5.58 days. A majority (93.7%) of the Cancer group received IVF from 0.5 days to 29 days, for a mean of 7.92 days of IVF. The Sudden Death and Frail Elderly each had 90.9% of their group receiving IVF, while the Chronic Disease group had only 77.1% receiving IVF for a mean of 1.34 days. The most likely explanation for the lower use of IVF in the Chronic Disease group is the high incidence of congestive heart failure within this diagnostic group.

The initiation of ventilator support occurred for 35% of the decedents for a mean of 1.6 days, with ventilator support including B-PAP, C-PAP, or intubation. Ventilator support was most prevalent among the Frail Elderly, with an average use of 3.3 days, and least used among the Sudden Death group, with a mean use of only 0.27 days.

The use of vasoactive medications often required that a patient transfer to a specialized unit authorized to administer them, and 50% of the decedent received one or more vasoactive intravenous medication during their last hospitalization, for an average of 1.5 days. The Chronic Disease group was the most likely to receive vasoactive medications, for an average of 2.6 days compared to the least likely group, Sudden Death, who received these medications for an average of only 0.5 days.

Table 5.6

## Common Aggressive Treatments by Group

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<b>Mean Number of Days of Aggressive Treatment by Group</b>				
<b>Population</b>	<b>IVF</b>	<b>Vent/BPAP/ CPAP</b>	<b>Vasoactive gts</b>	<b>Artificial Nutrition</b>
All Decedents	5.58	1.60	1.50	3.58
Sudden Death	2.86	0.27	0.50	1.00
Cancer	7.92	1.05	1.02	4.38
Chronic Disease	4.01	1.44	2.60	2.97
Frail Elderly	6.02	3.30	0.93	4.68

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When severely ill or terminally ill patients are no longer able to swallow, it is common medical practice to place an artificial feeding tube, using a naso-gastric tube (NGT) or a gastric tube (PEG). Another route of administration for artificial nutrition is intravenously via total parental nutrition (TPN). Twenty-three percent (23%) of the subjects in the study had naso-gastric tubes (NGT) placed when they could no longer swallow effectively, 11% had PEG tubes (either new or existing), 3% received TPN, and 6% had a combination of the above nutritional support. Sixteen percent (16%) were receiving nothing by mouth (NPO), 12% were refusing to eat, and 17% were feeding themselves during some portion of their last admission. Forty-three percent (43.0%) of the decedents received artificial nutrition in some form, for an average of 3.6 days during their terminal admission. The group most likely to receive artificial nutrition was the Frail

Elderly for a mean of 4.68 days, whereas the Sudden Death group was least likely to undergo this treatment with a mean of 1.0 day of nutritional support.

Only 4% of the study sample received chemotherapy for anywhere from 1 to 16 days during their last admission. Five percent (5%) received from 1 to 11 radiation treatments, and 11% had dialysis treatments from 1 to 11 times during their last admission.

### Common Symptoms at the End of Life

Lastly, to assess physical comfort at the EOL the investigator examined the last forty-eight hours preceding death for patterns of provider responsiveness to distressing symptoms commonly reported at the end of life, such as pain, shortness of breath, nausea, disrupted bowel patterns, fevers, and congestion. The profile revealed that patients experience a myriad of uncomfortable symptoms in the last 48 hours of life. The most prevalent was pain, which 66% of the decedents experienced to some degree. Only 1% (n=1) had pain that went untreated and the majority received morphine (36%) for their pain, with 20% requiring more than three doses in the last days of life. Twelve percent (12%) had narcotic analgesia by continuous infusion or patient controlled analgesia (PCA), 10% received other medications, and 7% wore a fentanyl patch for primary pain control. The group most frequently complaining of pain was the Sudden Death group (81.8%), followed by Cancer (78.1%), Frail Elderly (63.6%), and lastly the Chronic Disease group at 54.3%.

Forty-three percent (43.0%) of the decedents had documented episodes of dyspnea, orthopnea, or other episodes of shortness of breath. Most were treated with

oxygen and morphine (12%), followed by oxygen alone (9%). Six percent (6%) received intubation and ventilator support, and 2% received no treatment change for their respiratory symptoms. The remaining 14% received a combination of oxygen, diuretics, and other treatments in response to respiratory distress. The group suffering the highest frequency of shortness of breath was the Sudden Death group (63.6%), followed by those in the Chronic Disease group (51.4%), Cancer (34.4%), and the Frail Elderly (31.8%).

Table 5.7

Distressing Symptoms Experienced the Last 48 Hours by Group

<b>Symptoms Experienced the Last 48 Hours by Group</b> (percent within each group)			
<b>Population</b>	<b>Pain</b>	<b>SOB</b>	<b>Anxiety</b>
All Decedents	66.0%	43.0%	35.0%
Sudden Death	81.8%	63.6%	27.3%
Cancer	78.1%	34.4%	46.9%
Chronic Disease	54.3%	51.4%	31.4%
Frail Elderly	63.6%	31.8%	27.3%

Over a third of the decedents (34.0%) experienced congestion at the end of life. Congestion was most prevalent in the Chronic Disease group (40.0%) and Frail Elderly group (40.9%). In the Frail Elderly group, treatment for congestion was primarily naso-tracheal (NT) suctioning or oral suction with a Yankar suction device, whereas in the Chronic Disease group, congestion was most often not treated (14.3%) with suction or medications.

Thirty-five percent (35%) of decedents experienced anxiety or restlessness near to their deaths, and the most frequent treatments employed were the use of lorazepam or haloperidol, which nursing administered to 25% of the decedents, while 5% of the subjects received various other medications for periods of agitation. Two percent (2%) received no treatment, and 3% had restraints applied due to agitation during the last 48 hours before death. The Cancer group had the highest frequency of anxiety or restlessness documented at 46.9%, followed by those in the Chronic Disease group (31.4%). The Frail Elderly and Sudden Death group each had a frequency of 27.3% for episodes of anxiety or restlessness.

There were a group of diverse symptoms classified as “other” in the study, and these included symptoms such as edema, bladder spasms, mouth sores, and complaints of generalized itching or rashes. The most common of these symptoms was edema (including ascites), which 14.0% of the study cases experienced during the last days of their life.

#### Profile: Respect for the Dying

*Research Question 5 (Q5):*

*Is there respect for the dying as evidenced by relationships between documented preferences, the presence of living wills, healthcare powers of attorney, do not resuscitate orders, and changes in resuscitation orders while hospitalized.*

#### Advanced Directives

In spite of the well-publicized need for advanced directives (AD) or legally designated healthcare decision makers via healthcare powers of attorney (HCPOA), the vast majority of decedents in the study had no such documentation available when they came to the hospital. During the last six months of life, even through repeated inquiries

regarding AD and HCPOA, the overwhelming majority had no designated healthcare proxy (90%), living will (81.5%), or HCPOA (82.1%). Even by their last admission, the proportion without this documentation was high at 89% without a designated healthcare proxy, and 85% having neither a living will nor HCPOA.

Of the patients who claimed to have living wills or HCPOA on their last admission (15%), only 9.0% actually had copies of these documents in the medical record. These findings were similar to the ones found when examining all admission during the last 6 months of life; with approximately 18% indicating they had these documents, yet only 8.6% actually having them on the chart.

#### Preferences and Actual Code Status

Another method for profiling the degree of respect that healthcare providers have for patients approaching death is to compare EOL personal preferences to actual code status. Hospitals have responded to the variety of patient wishes on this issue by stratifying resuscitation preferences. At the study hospital, there were four levels of code status in effect during the study period:

1. Full Code (FC): continue all medical management and resuscitate in the event of cardio-pulmonary arrest
2. DNR 2: do not intubate, but continue all medical management and initiate CPR in the event of cardiac arrest
3. DNR 3: do not perform CPR or intubate, but continue all other medical management



4. DNR 4: comfort measures only, with medical management restricted to treatments aimed at providing comfort

Although do not resuscitate (DNR) order stratification is common among the area hospitals, it is unknown whether patients and family members understood or were aware of the designated levels of code status outlined above.

Upon admission to the hospital for the last time, a majority of the subjects (48.0%) had a DNR 3 order, 6.0% had orders not to intubate (DNR 2), and another 6.0% had orders for comfort care (DNR 4). The remaining 40.0% were Full Code (FC) patients, with 32.0% having written orders to be FC and 8.0% being designated FC by default, due to an absence of any physician order to the contrary. During the course of their last hospital stay, the majority (47.0%) of patients had no order to change their code status. One subject (1.0%) changed to FC, and another 1.0% changed to DNR 2. Five percent (5.0%) had multiple changes in code status during their last hospitalization. However, most of the patients who experienced a code status change converted to a DNR 3 (30%), or DNR 4 (16%) prior to their death.

Sixteen (16) patients expressed a desire to be a full code (FC) at the onset of their terminal admission, and 81.3% had written orders that correlated with this preference, 6.3% had no order making them a FC by default, and 12.5% had orders to be DNR 3. Twenty-five percent (25%) had no change in code status, 56.3% converted to DNR 3 during the course of their admission, 12.5% converted to a DNR 4, and 6.3% had multiple changes made until being declared a DNR4 by the time of their death.

Thirteen (13) patients verbalized a desire to be a DNR 2 (do not intubate), yet only 15.4% had orders written reflecting this wish. Most were DNR 3 (46.2%), while the remaining percentage were FC, of which 23.1% had written FC orders. Only 7.7% of these patients converted to DNR 2 or had multiple changes in code status during their hospital stay, while equal frequencies of 30.8% each converted to DNR 3 or DNR 4 prior to their death.

Twenty-four (24) decedents expressed a preference to be a DNR 3, and their wishes were respected 62.5% of the time with written orders, and 58.3% of these patients experienced no change in their code status during the course of their hospitalization. Of these patients, 25% were initially FC by either order or default, and 4.2% were DNR 2. However, all 29.4% converted to DNR 3 at some point during their hospital stay.

A relatively large proportion of the subjects (31.0%) had no documented EOL preference. These patients had orders predominantly to be DNR 3 (54.8%), another 32.3% were FC by either order or lack of orders, and a few were DNR 2 (9.7%) or DNR 4 (3.2%) upon admission. During the course of their last hospital stay, 45.1% ultimately had their code status changed to DNR 3 or DNR 4 by the time they expired.

Six (6) of the decedents expressed a desire to be comfort care only at the onset of their last admission. Half of these patients were made DNR 3, and the other half were DNR 4 honoring their wishes. None of these patients had their code status changed during the course of their hospital stay.

Another small segment of the sample (7.0%) were unclear regarding their EOL resuscitation wishes and these patients predominantly had written orders to be FC

(71.4%), with the remaining 28.6% of them having orders to be DNR3. The vast majority of these patients (57.2%) converted to a DNR 4 status by the time of their death. Only 14.3% in this group had no code level change during their terminal admission.

For the small group of patients (n=3) who presented a living will, HCPOA, or had an emergency transport DNR order required by the Department of Health and Environmental Control of South Carolina, all these patients had written orders to be DNR 3 and had no change in their code status.

#### Resuscitation Efforts

Of the patients who received CPR, all had it performed during their terminal admission and obviously none survived to discharge. The decedents experienced twelve (12) instances of the commonly referred to “Code Blue”, for which ten percent (10%) received CPR once and expired, and the remaining 2% had CPR performed twice and expired. Almost half of the Sudden Death group received CPR at 45.5% (n=5), representing a majority of the code cases (41.7%), followed by the Cancer group with 33.3% and 25% performed on the Chronic Disease group. No patients in the Frail Elderly group received CPR.

#### Decline-to-Death Trajectory Groups

##### *Sudden Death*

The Sudden Death group had the largest portion of FC patients (72.7%) and the smallest portion of DNR orders (27.3%) at the time of admission. This group also spent the fewest mean number of days with DNR orders at 3.23 days. The Sudden Death group

had the largest proportion of patients who desired to be FC (45.5%) or preference that was not documented (36.4%).

### *Cancer*

The Cancer group split nearly evenly between having orders to be FC at 46.9% or DNR 3 status at 40.6%, yet only 25.0% of the Cancer group indicated a preference to be a DNR 3 at the time of admission and 37.6% either had no documentation of preference or a preference to be FC. The Cancer group spent a mean of 5.56 days with DNR orders during their last admission to the hospital.

### *Chronic Disease and Frail Elderly*

Chronic Disease patients and the Frail Elderly were the least likely groups to be designated FC (by commission or omission) at the time of admission (34.3% and 22.7% respectively). The Chronic Disease group had the longest mean number of days with DNR orders (8.26 days) and this group was most likely to be DNR 3 at admission (57.1%) along with the Frail Elderly (54.5%). The bulk of the Chronic Disease group (31.4%) indicated that they preferred to be a DNR 3, while another 28.6% had no documented preference, and only 11.4% indicated that they wished to be designated FC. Surprisingly, 50.0% of the Frail Elderly had no documented preference at the time of admission, while 18.2% preferred to be DNR 3, and only 4.5% indicated a preference to be FC when admitted to the hospital.

## Profile: Emotional Support, Communication, and Shared Decision-Making

### *Research Question 6 (Q6):*

*Is there documented evidence of emotional support, communication, and shared decision-making with patients and/or families related to unit of death, degree of family presence at the end of life, and decisions to forego or withdrawal treatment?*

### Emotional Support

Identifying emotional support in the medical record presented challenges due to the cultural norm for physicians and nurses alike to focus on factual content, not emotional content. The graduate student investigator therefore identified any documented interactions or conversations regarding the terminal prognosis or support at the time of death as positive for evidence of emotional support. Even with the liberal leeway given to this variable, the majority of patient records (68.4%) had no documented evidence of emotional support provided to either patients or family members. For the study sample as a whole, 49.0% had family continuously at the bedside during the last 48 hours, while 43.9% had intermittent visitors during the last days of life. Very few patients (5.1%) had no family visiting, and most patients had family present at the actual time of death (72.2%).

### Racial Differences and Emotional Support

There appears to be racial differences in the levels of documented emotional support, with 36.8% of the Caucasian charts showing support, compared to 13.6% of those in the African American (AA) group. Additionally, AAs are more apt to visit intermittently (77.3%) versus continuously (18.2%), while Caucasians are at the bedside continuously more than intermittently (57.9% and 34.2% respectively). Both groups have

about the same portion of decedents in which no family members visited, with 5.3% of the Caucasian patients and 4.5% for AA patients having no visiting family.

Even when patients are gravely ill, it is often difficult for family members to recognize or accept that death as imminent. Nearly twice as many AAs were surprised by the death of their loved one (18.2%) than Caucasians (9.2%), but this might be related to the higher proportion of AAs who suffered a sudden death (27.3%) versus Caucasians at 6.4%. Yet, the records indicate that in a higher proportion of African American cases (13.6%), only the healthcare team seemed to know that death was imminent compared to that of the Caucasian community (2.6%). Additionally, Caucasians patients were more likely to have family at the bedside at the time of their death (77.6%), while AA patients had family present at the death 52.4% of the time.

#### Unit of Death and Family Presence the Last 48 hours

Some hospital units are more amenable to dying than others. Therefore, it is necessary to examine where disease clusters die, paying particular attention to the rates of ICU/CCU death since these units have the most restrictive policies regarding family visitation. Over a quarter of the decedents (26.0%) died on medical-surgical units, while 18.0% each expired on the oncology or telemetry units in the facility. A very large proportion of the study sample (78.0%) spent time in intensive care units during the last 6 months of life, and 55.0% spent an average of 5.66 days in the ICU during their terminal hospital stay. Thirty-five percent (35.0%) of the decedents died in the ICU/CCU, which is comparable to the high-end averages reported by others (Wennberg, et al., 2004; Barnato, et al., 2004) of 9-36%.

### *Sudden Death*

Over half of the sudden death group expired in the ICU/CCU (54.5%, n=6), with a mean LOS of 2.0 days (range 0.5-6 days), yet the majority of these patients (71.5%) spent one day or less in the ICU/CCU during their terminal admission. Medical/surgical units saw 18.2 % of these patients expire, and an even distribution of 9.1% each expired on telemetry, oncology, or neurology units (9.1% each).

This group had the least amount of documented emotional support, with only 10% of the charts showing signs of support rendered at the time of death or before. For patients in this group, there was evidence that family visited intermittently for 54.5% of the decedents and continuously for 27.3%. Forty percent (40.0%) had family at the bedside at the time of death.

Although the group succumbed to a rapid demise, death was not always immediate due to medical interventions, therefore in the last 48 hours 40% of the families and healthcare providers alike expected the death. It is interesting to note that this is the only group where nursing documentation indicated that a family expected death, yet there was no indication that clinicians managing the case did.

### *Cancer Group*

Not surprising, 53.1% of the cancer patients died on the oncology unit, while 21.9% expired in an ICU/CCU setting, 15.6% on a medical/surgical unit, and 9.4% on one of the 3 telemetry units located within the medical facility. The average length of stay in the ICU/CCU for this group was 5.77 days (range 0.5 to 27 days), with the highest portion in the ICU/CCU for 3 days (26.7%).

When examining emotional support by disease trajectory groups, the group with the highest levels of support documented was the cancer cluster, with 50% of the medical records positive for signs of emotional support. This is possibly due to the documentation of an oncology counselor who regularly interacted with both patients and families on the unit. Family was continuously at the bedside for a majority of the patients with cancer (62.5%), or intermittently for 34.4% of decedents. In 84.4% of the cases of cancer, both healthcare providers and family expected death, and family was at the bedside at the time of death for 83.9% of the patients in this category.

#### *Chronic Elderly*

The group with the second highest proportion of ICU/CCU deaths was the Chronic Disease group, with 48.6% dying in this aggressive care area. The mean LOS in the ICU/CCU area for these decedents was 5.71 days (range 0.5 to 17 days). This group also had the largest percentage of telemetry deaths (28.6%), therefore 77.2% died in expensive, restrictive, aggressive care areas.

A quarter (26.5%) of the medical records for the Chronic Disease group showed evidence of emotional support, and family for this group visited continuously with 40.0% of the decedents and intermittently in 48.6% of the cases. Only 5.7% had no visiting family members, yet 70.6% had family at the bedside at the time of death. Both healthcare professionals and family (67.6%) expected most of the deaths in the chronic disease group, however healthcare providers alone appeared to expect death with 11.8% of the chronic disease patients, and 17.6% of the patient deaths seemed to surprise everyone in spite of the well-documented co-morbidities in this pool of patients.



### *Frail Elderly*

The average LOS for the frail elderly was 7.6 days for their last admission and the most frequent unit of death was on a medical/surgical unit (54.5%), yet 22.7% expired in the ICU/CCU areas and had the highest mean LOS in the ICCU/CCU of 7.77 days (range 0.5 to 50 days). It is important to note that, the high mean LOS in ICU/CCU for the group is probably a result of an outlier who spent 50.0 days in the Neurological ICU prior to expiration. The affect of this outlier is apparent when noting that 45.5% of the frail elderly actually spent one day or less in ICUs during their terminal admission. The remaining portion of the frail elders died while on telemetry units (18.2%) or the neurology unit (4.5%).

In 22.6% of the medical records for Frail Elderly, there was evidence of emotional support provided to patients and/or family members. Fifty percent (50%) had family at the bedside continuously and another 40.9% had family visiting intermittently, with 72.7% having family at the bedside at the time of death. The Frail Elderly group had the highest percentage of cases in which both the family and providers expected death at 90.9%, which may be due to their advanced age and debility, leading to improved acceptance of the inevitable in this group of patients.

### Communication and Shared Decision Making

Communication and shared decision making ideally begins long before the onset of the dying process. To profile communication and shared decision making at the EOL, the study examined the medical records for conversations regarding prognosis, and then

examined whether the discussions led to the foregoing of aggressive treatment or the withdrawal of treatment.

For the study sample (n=100), conversations took place with family members or the designated power of attorney (POA) 62.0% of the time, with the patient and family 11%, and with the patient alone in 4.0% of the cases reviewed. Nearly a quarter of the patient charts had no documented conversations between providers, patients, and families regarding prognosis.

There was no change in treatment plans for 42.0% of the cases reviewed and the most common result of conversations regarding prognosis was that patients/family wanted to forego aggressive treatment for comfort (24.0%) or change in code status (20.0%). Five percent (5%) wanted aggressive care to continue, two patients each refused surgery and dialysis, and three medical records indicated that the families refused tube feedings or the placement of a feeding tube. One patient refused intubation, against the strong objection of the physicians, and another refused any additional chemotherapy treatments. Conversations regarding prognosis also resulted in 12 patients being extubated from the ventilator, eleven withdrew other forms of aggressive care, and one family requested the cessation of resuscitation efforts (“code blue”) in progress on their loved one.

#### Racial Differences and Communication

Discussion regarding prognosis occurred with similar frequencies between the racial groups, with 73.0% of the Caucasian patients or family and 72.7% of their AA counterparts. Over twice the number of AAs documented a desire for aggressive

treatment (9.1%), compared to only 3.8% of the Caucasian patients/families requesting aggressive care, and Caucasians were more apt to refuse aggressive care (10.3%) compared to AAs (4.5%). However, a majority in both groups sought to change code status or pursue comfort care measures during the final days of the terminal admission, 46.1% for Caucasians, and 36.3% for African Americans.

#### Decline-to Death Trajectory Groups

The group most likely to have no documented discussions was the Sudden Death group, (45.5%), followed by those in the Chronic Disease group (31.4%), and the Frail Elderly (18.2%). Providers in the Cancer group were most likely to have discussions with patients and/or families regarding prognosis (90.7%).

For patients in the Sudden Death cluster, the only change in treatment that resulted from conversations was to change the code status and this occurred nearly half the time (45.5%). Almost a third of both the Cancer group and Frail Elderly group had families wanting to change the treatment focus to comfort care (31.3% and 36.4% respectively), and 13.5% of the patients/families in the Frail Elderly group refused aggressive treatments compared to 6.2% in the Cancer group. The Chronic Disease group appeared to be somewhat ambivalent regarding the foregoing of aggressive treatments with only 20.0% changing their code status and 17.1% seeking comfort care. 5.7% wanted to continue aggressive care, yet another 11.6% refused aggressive treatments such as surgery, feeding tubes, dialysis, and intubation.

Withdrawal of treatment occurred infrequently for all the decline trajectory groups, with no withdrawal of aggressive treatments occurring at frequencies of 68.2% to

82.9%. The Frail Elderly group was most apt to withdrawal ventilator support (18.2%) and other aggressive treatment (13.6%), and the Cancer group withdrew ventilator support for 15.6% of the patients and other aggressive care with 12.5% of the patients. The group least likely to withdrawal any type of treatment was the Chronic Disease group who withdrew ventilator and other care at frequencies of 8.6% each.

## CHAPTER 6

### DISCUSSION & IMPLICATIONS

#### Demographic Characteristics

*Q1: What are the demographic characteristics of patients dying in an acute care hospital in Upstate South Carolina?*

Demographically, the sample is primarily Caucasian; either married or widowed, and of the Baptist or other Christian faith. They name either their spouse or child as their next of kin, and since the sample splits evenly between males and females, it is interesting to view the demographics from the gender perspective. The men were twice as likely to be married at the time of their death (60.0% compared to 30.0% for women), and therefore named their spouse as the next of kin more frequently (58.0%). On the other hand, the women were more frequently widowed (52.0%), and consequently named their children as the next of kin more often (56.0%). These gender shifts with regard to who becomes the next of kin decision-maker, points to the importance of clinicians being sensitive to the gender disparities noted by others (Duffy, et al. 2006) related to EOL preferences verbalized by patients and the decisions made in actual practice. It is therefore highly recommended that future research efforts focus on male-female differences in EOL preferences and the degree to which decision-makers honor EOL wishes of others.

#### Decline-to-Death Trajectories

*Q2: What proportions of the sample fall into readily identifiable decline trajectory groups (Sudden Death, Cancer, Chronic Disease Organ Failure, and Frail Elderly) and what are the demographic characteristics of these groups?*

The study results indicate that there are readily identifiable characteristics for four

decline-to-death trajectory groups, which compare to the findings of others regarding decline trajectories. These groups differ in composition, and therefore most probably differ in their response to medical management, as well as expectations of the healthcare system. By studying profile data for these decline trajectory groups, clinicians could develop appropriate levels of care for each patient cluster, versus treating all patients and their diseases in the same manner. These decline-to-death profiles would permit adjusting EOL treatment protocols to improve the quality of EOL care.

Table 6.1

Summary of Decline-to-Death Trajectory Group Characteristics

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<b>Summary of Decline-to-Death Trajectory Group Characteristics</b>				
<b>Characteristic</b>	<b>Sudden Death</b>	<b>Cancer</b>	<b>Chronic</b>	<b>Frail Elderly</b>
Size	n = 11	n = 32	n = 35	n = 22
Age	74.09	66.56	71.37	85.23
Gender	M > F	M > F	M = F	F > M
Race	W = B	W > B	W > B	W > B
Marital Status	W > M, D, S	M > W, D, S	M > W, D, S	W > M, S
Falls	Low	Low	Low	High
Decline	Low	High	High	High
Bed/Chair Bound	Low	Moderate	Moderate	High

---

The groups are recognizable using a variety of characteristics, which the table above summarizes. In this study, decedents of the Sudden Death group represented the smallest trajectory group (n=11), and it is unknown whether this represents the proportion of unexpected deaths for the population of hospitalized patients in general. When

admitted to the hospital. The Sudden Death decedents had a decline pattern typified by low frequencies of documented falls in the past 6-months, low levels of documented decline, and were least likely to be chair or bed bound when compared to the other groups.

The Cancer group is readily identifiable by diagnosis, and oncology units can use profiling techniques to improve their efforts at meeting the needs of the unique population they serve. The Chronic Disease population is the largest and most complex trajectory group, with a varied composition of sub-groups measuring co-morbidities, yet again they are almost exclusively identifiable by their diagnoses. The Cancer and Chronic Disease group exhibited similar patterns of decline documented on their last admission, and over the last six month of life differed only in that the Chronic Disease group was more likely to be bed bound or chair bound at some point during their last six months. Since the Chronic Disease and Cancer groups also had high levels of repeat admissions occurring during the last six months of life, frequent readmission patterns can cue clinicians into initiating discussions prior to the onset of a crisis or impending death.

Lastly, the Frail Elderly are easily identifiable to practitioners by age and functional status, and it is likely that this group will increase substantially in the years ahead. It is critical that clinicians be able to recognize these often-defenseless patients and adjust utilization patterns accordingly, in order to make the limited time left as meaningful to them and their families, and to prevent any one group from overwhelming the healthcare system. It is therefore recommended that future research focus on developing palliative care protocols unique for each group of decline patients.

## Continuity of Care

*Q3: What are the current conditions regarding continuity of care as evidenced by admission frequencies, medical service, care transitions, and the volume of professionals interacting with patients, noting patterns of care for the decline trajectory groups?*

### Admission Frequencies & Medical Service

As more specialties and specialized departments emerge, the healthcare system fragments further and navigating through the system becomes more difficult. The vast majority of today's admissions into the hospital are via the Emergency Department (ED), which begins the cascade of diagnostic tests that are often the prelude to aggressive care. Aggressive care patterns ultimately lead to many patients dying in the ICU, surrounded by technology versus family.

Table 6.2

### Admissions by Decline-to Death Trajectory Group

Population	Total # 6m Admits	6m LOS	Last Admit LOS	Admitted Via		Admitted From		Medical Service		
				ED	MD	Home (w/ & w/o support)	Nursing Home	Internal Medicine	Surgery	Oncology
All Decedents	2.81	8.94	9.20	86.0%	10.0%	57.0%	28.0%	63.0%	18.0%	9.0%
Sudden Death	2.18	3.73	4.14	100.0%	0%	72.7%	27.3%	72.7%	9.1%	9.1%
Cancer	3.00	9.32	10.95	71.9%	15.6%	93.8%	6.3%	34.4%	18.8%	43.8%
Chronic Dis.	3.00	9.07	10.19	85.7%	14.3%	68.6%	31.4%	74.3%	22.9%	0%
Frail Elderly	2.55	9.24	7.61	100.0%	0%	45.5%	54.5%	81.8%	13.6%	4.5%

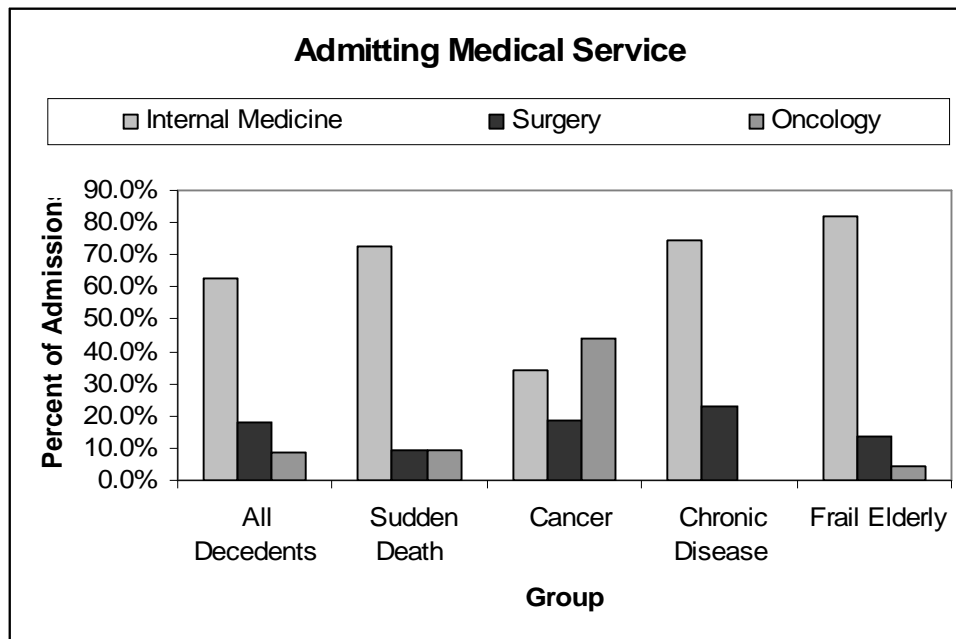
Shaded areas represent groups with the highest frequency for a given category.



The profile reveals that most patients gain admission to the hospital via the ED, similar to findings in national studies, with the Frail Elderly group exclusively using the ED as their hospital gatekeeper (Table 6.2). The Cancer group has the highest level of admissions and the longest LOS of the trajectory groups (Table 6.2), most likely due to hospital-based chemotherapy regimens or post chemotherapy side-affects. Meanwhile, the Sudden Death group has the lowest average of admissions during the last six months of life as well as the shortest length of stays (Table 6.2), which presumably relates to the unexpected and rapid decline this group experienced during their terminal diagnosis.

Figure 6.3

Admitting Frequencies by Medical Service



The profile also reveals that the Internal Medicine service is responsible for the bulk of admissions at the study facilities, regardless of diagnostic group other than cancer, and almost exclusively responsible for overseeing the care of the frail elderly (Figure 6.3).

### Care Transitions and the Interdisciplinary Team

The profile reveals high frequencies of care transitions, particularly for the Chronic Disease and Cancer groups, while the group with the lowest number of transitions and fewest members of the medical team are the Frail Elderly (Table 6.4).

Table 6.4

Care Transitions and Interdisciplinary Team by Group

Population	6m Transitions	Last Admit Transitions	Mean # MDs	Mean # IDT	Mean # ICD-9 Diagnosis Codes
All Decedents	9.90	3.52	3.57	5.07	12.62
Sudden Death	9.45	3.55	3.36	4.55	10.09
Cancer	9.91	3.47	<b>3.81</b>	<b>5.34</b>	12.66
Chronic Disease	<b>10.51</b>	<b>3.63</b>	3.69	5.11	<b>13.74</b>
Frail Elderly	9.14	3.41	3.14	4.86	12.05

Shaded areas with bold text represent group with the highest level or frequency for category, while shaded areas with regular text represent groups with the lowest frequencies.

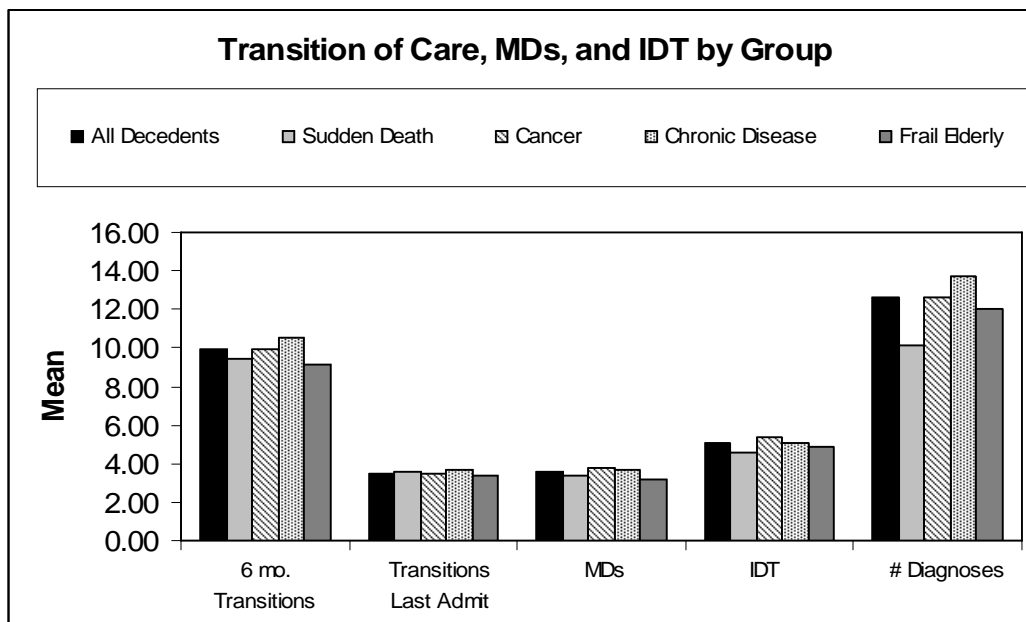
Non-parametric analysis found no statistical differences between the trajectory groups in terms of number of diagnoses, physicians, volume of IDT members, or transitions of care, which confirms the homogeneous tendency of current treatment

methodologies. Figure 6.5 illustrates this homogenous character noted between trajectory groups.

By examining and understanding the current utilization patterns, practices, and environment of care provided to patients in different decline trajectory populations, clinicians may be enabled to tailor their medical interventions to appropriate levels of care and to focus their communication efforts towards establishing realistic goals with both the patient and family.

Figure 6.5

Care Transitions and Interdisciplinary Team



## Physical Comfort

*Q4: Does the intensity of treatment delivered during the last admission, and the way healthcare professionals respond to common symptoms experienced by dying patients affect how patients physically experience the dying process?*

### Intensity of Treatments

As found in the admitting patterns discussed above, there was also homogeneity in the frequencies found among the decline trajectory groups in terms of number of invasive procedures, treatments ordered, as well as symptoms experienced during the last 48 hours of life. The inability to distinguish one group from another in terms of intensity suggests a general lack of sensitivity to declining and terminally ill patients. There was no statistical difference found among the groups regarding the number of procedures performed ( $p=0.133$ ), mean number of days of IVF use ( $p=0.190$ ), mean days on a ventilator ( $p=0.388$ ), or mean days of artificial nutrition ( $p=0.546$ ). There is a degree of variation noted between the groups regarding the days of vasoactive medication use ( $p=0.078$ ), with the Chronic Disease group receiving over twice the mean number of days of these medications than the other groups. Given the differences noted to exist between these groups demographically, it is illuminating that their medical management does not vary more.

### Symptom Management

Others have researched and reported extensively regarding the frequency with which distressing symptoms occur at the EOL (Teno, 2005; Lorenz, Lynn, et al., 2005; Lorenz, Lynn, et al., 2004). Pain, shortness of breath, anxiety/restlessness were symptoms experienced with high frequencies by the study subjects, particularly pain. Practitioners

in the study records utilized a variety of medications to treat EOL symptoms, yet morphine was by far the most frequently utilized medication for both pain and shortness of breath. This trend is in keeping with the research suggesting their effective use in both these areas (Lorenz, Lynn, et al., 2004).

### Respect for the Dying

*Q5: Is there respect for the dying as evidenced by relationships between documented preferences, the presence of living wills, healthcare powers of attorney, do not resuscitate orders, and changes in resuscitation orders while hospitalized.*

### Advanced Directives

An ever-increasing amount of evidence suggests that advanced directives (AD) do not function as intended and are therefore underutilized. In spite of all fifty states having advanced directive statutes, including South Carolina, communicating EOL preferences via these legally sanctioned means has been less than satisfactory, and the study profile illuminates that fact clearly by having less than 10.0% of the sample submitting AD at the time of admission. Advanced directives are legal documents that initiate action in legal, political, and business circles, but in the healthcare environment, physician orders are the force behind medical interventions. The ineffectiveness of these documents therefore resides in a system unable to translate the language and format of the legal world into the language and format for the healthcare world. Future policy and research efforts must therefore direct their attention towards bridging the chasm between the intent of AD and the reality of effectively communicating preferences across all transitions of care.

## Resuscitation Efforts

There appears to be a slight difference between groups with regard to use of CPR, since none of the Frail Elderly had CPR performed during their last admission. Only 12% of the sample received CPR at the end of life, which is lower than other studies have reported (Zoch et al., 2000), due probably to an increased tendency to write DNR orders prior to the onset of arrest. Survival to discharge following hospital initiated CPR was also much lower than others have reported (Zoch et al., 2000). There was a high frequency of CPR initiated for patients in the Sudden Death group and an absence of resuscitation efforts in the Frail Elderly group, which may indicate a growing awareness regarding the futility of CPR at the end of life.

## Congruence between EOL Preferences and Ordered Code Status

There appears to be a concerted effort on the part of practitioners to order code status stratification in accordance to patient preferences, yet there continues to be a large percentage of patients for whom there is no documented preference (31.0%), or have unclear documentation regarding their preference (7.0%). In these instances, there seems to be a preference for clinicians to order DNR 3 stratification (54.8%) or full code status (32.3%).

In general, physicians tended to write DNR 3 orders most often (48.0%), or full code orders (32.0%). Only 8.0% of the decedents had no code stratification order, while 6.0% each had orders to be DNR 2 or DNR 4. The prevalence for writing full code or DNR 3 orders might be due in part to these levels being widely understood by healthcare professionals and laypersons alike, and they each offer physicians the greatest amount of

control and range regarding medical treatments.

Table 6.6

Comparison between Patient Code Preferences and Actual Code Status

Patient Preference	Pt. Preference (% of Sample)	Code Status Order				% changed to DNR 3 or DNR 4
		FC (order or default)	DNR 2	DNR 3	DNR 4	
Full code	16.0%	87.6%	0.0%	12.5%	0.0%	75.1%
DNR 2	13.0%	38.5%	15.4%	46.2%	0.0%	69.3%
DNR 3	24.0%	25.0%	4.2%	62.5%	8.3%	41.7%
DNR 4	6.0%	0.0%	0.0%	50.0%	50.0%	0.0%
Unclear	7.0%	71.4%	0.0%	28.6%	0.0%	57.2%
Not documented	31.0%	32.3%	9.7%	54.8%	3.2%	

Emotional Support, Communication, and Shared Decision Making

*Q6: Is there documented evidence of emotional support, communication, and shared decision-making with patients and/or families related to unit of death, degree of family presence at the end of life, and decisions to forego or withdrawal treatment?*

The profile confirms that EOL discussions between physicians and patients and/or families occur with Cancer patients more often than with other trajectory groups. This is presumably due to an increased level of comfort and experience that oncologists typically have with discussions regarding death and dying. A possible area for further research is assessing the level of support provided to Cancer patients and their families and developing a model for providing similar levels of support to other decline trajectory populations.

A formidable challenge for healthcare providers is developing programs for the

chronically ill population, especially those with multiple co-morbidities. The profile indicates what many healthcare providers suspected, that patients and families suffering with chronic diseases are reluctant to give up hope. By researching the behaviors and attitudes of this group further, and by profiling the outcomes of aggressive care in this group, clinicians will be able to communicate honestly about the benefits and burdens of aggressive treatment. Lastly, patients and families often claim that they want everything done, yet clinicians must inquire about what patients and families expect to achieve with such measures in order to address unrealistic expectations that often produce heartache for so many.



## CHAPTER 7

### CONCLUSIONS

End of life care in the United States can trace its origins to the hospice philosophy initiated in this country in the 1970s. Today, the Hospice Medicare Benefit defines hospice care by delineating the parameters of eligibility. The benefit defines ‘terminal’ as a life expectancy of six months or less, yet this narrow vision precludes patients with long-term debilitating illnesses from receiving the benefits of symptom management and emotional support. Future endeavors in EOL care must adopt holistic approaches that are sensitive to appropriate uses of healthcare resources, and therefore must create a healthcare culture that embodies quality of life as part of the treatment montage.

Further investigation and research regarding decline-to-death trajectories and development of medical and nursing protocols unique to each cluster offer potentially valuable additions to medical and nursing educational curricula. At a minimum, educational programs that reorient their focus towards patient populations versus the treatment of disease conditions will likely benefit patients at the EOL. Patients have a right to expect appropriate treatment and relief of troubling symptoms, along with advanced planning, so that complications and decline do not become emergencies (Lynn, 2004). Furthermore, they have a right to have their wishes respected and their resources used thoughtfully, as well as receiving the help they need to make the best of every day (Lynn, 2004). It is the responsibility of every healthcare professional to ensure these rights, and every educator to instill these principles into the practice of tomorrow’s practitioners.

Death is not the enemy; it is often the predictable conclusion to a protracted terminal disease process. In 1997, the Institute of Medicine (IOM) defined a good death as one “free of 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” (IOM, 2002, p. 24). Providing good death experiences are possible if healthcare professionals make them a priority to provide. Developing healthcare delivery systems that are philosophically respectful of death will allow practitioners to guide patients and families through this inevitable process, and order treatments in accordance with goals established between themselves, the patient, and family and avoid treatments that are based solely on doing everything medically possible to prolong life. By wisely sparing dying patients the over zealous utilization of medical services, millions of dollars would be potentially available to improve symptom control for patients with chronic diseases.

It is the fervent belief of many who toil in the EOL field that quality improvements for the dying, and appropriate allocation of resources, will not only produce greater levels of satisfaction expressed by the public, but greater levels of professional satisfaction as well, due to heightened sensitivity and responsiveness to fellow citizens at a vulnerable juncture in life. Many hope that a heightened sensitivity and awareness to fellow citizens traversing the vulnerable juncture in life called dying will produce the impetus for such a change to occur.

## APPENDICES

## Appendix A

### Theoretical Concepts of Interest in Profiling End of Life Care

<b>EOL Profiling: Concepts of Interest</b>
<b>Q1: Profiling Demographics:</b> Age, Sex, Race, Marital status, County of residence, Employment
<b>Q2: Profiling Decline-to-Death Trajectories:</b> By ICD-9 codes, Functional & Cognitive ability
<i>Sudden Death:</i> Unexpected or untimely death due AMI, hemorrhage, PE or other unforeseeable events <i>Cancer:</i> Death related to a diagnosis of cancer or metastatic disease process <i>Chronic Disease:</i> Illnesses with multiple exacerbations before death (CHF, COPD, DM, ESRF, CVA) <i>Frail Elderly:</i> > 70 years old, requiring maximum assist with ADLs; cognitively and/or physically impaired
<b>Holistic Care:</b> Levine's Conservation Principles for Patient Care
<i>Energy:</i> Manageable and measurable aspects of care that contribute or deplete personal energy <i>Structural Integrity:</i> physiologic processes associated with patient care <i>Personal Integrity:</i> all the components of behavior and recognizes the value of self <i>Social Integrity:</i> all of the social components and interactions (family, community, religious, hospital, etc)
<b>Profiles of Care: Dimensions of Quality End of Life Care</b>
<b>Q3: Profiling Continuity of Care</b>
<i>Transitions of Care:</i> Frequency of admissions by medical service, care transitions <i>Multidisciplinary Team:</i> Complexity of medical team and healthcare team
<b>Q4: Profiling Physical Comfort</b>
<i>Symptom Control:</i> Frequency of treatment to unpleasant symptoms experienced the last 48 hrs of life <i>Intensity of Treatment:</i> Frequency of invasive procedures and treatments performed at the EOL
<b>Q5: Profiling Respect for the Dying</b>
<i>Advanced Directives:</i> Evidence of advanced care planning and adherence to patient preferences <i>Resuscitation Preferences:</i> Documented preferences other than above <i>Resuscitation Efforts:</i> Code status on admit and changes in code status
<b>Q6: Profiling Emotional Support, Communication, and Shared Decision-Making</b>
<i>Emotional Support:</i> Documentation of support by healthcare professionals <i>Family/Social Involvement:</i> Frequency of family or social visitation, presence at time of death <i>Documented discussions on prognosis:</i> documented communication on prognosis and care decisions <i>Forego/Withdrawal Treatment:</i> Documented decisions regarding foregoing or withdrawal of treatment



## Appendix C

### Literature Review Chart

#### I. The Dying Experience

Author/Year Level of Evidence Profile Categories	Study Design and Goal	Results, Conclusions, Recommendations
Last Acts 2002  <i>Level IV</i>  Respect for dying	Describe the state of dying in the US Descriptive Well organized analysis of state statistics EOL care measured in 8 categories: <ul style="list-style-type: none"> <li>• State policy (2)</li> <li>• MD/RN/Hospital policy (1)</li> <li>• Hospice use (1)</li> <li>• Patient oriented (4)</li> </ul> Well defined criteria measuring categories 74 references, Evidence tables and maps	Findings <ul style="list-style-type: none"> <li>• Discrepancy btw. preferences &amp; practice at EOL</li> <li>• Over utilization of ICU, aggressive care at EOL</li> <li>• Majority die in a hospital</li> <li>• Under utilization of hospice care</li> <li>• Wide spread unrelieved pain at EOL</li> <li>• State policies inconstant w/ quality EOL care</li> </ul> Recommendations presented for <ul style="list-style-type: none"> <li>• Policy makers, HC professionals, and public</li> </ul>
Lynn, J., et al. 1997  <i>Level IV</i>  Respect for Dying	Death of elderly and family perceptions Prospective cohort study MR review, Surrogate interviews 9 cohorts of serious illness and age > 80y Large sample (n=9105) Subjects from SUPPORT & HELP studies	Findings <ul style="list-style-type: none"> <li>• Most elderly &amp; seriously ill pts die in acute care hospitals w/ pain and other symptoms commonplace</li> <li>• Families report pt wish was comfort care, yet life-sustaining treatment provided</li> </ul> Conclusions: There are opportunities to improve EOL care
Duffy, S., et al. 2006  Respect for dying	Highlights racial/ethnic preferences, gender preferences, and religious differences in decision making at the EOL	Findings <ul style="list-style-type: none"> <li>• Gender differences in EOL preferences exist within ethnicities</li> <li>• These differences can affect how families respond to EOL issues and decision making</li> </ul>

#### II. Illness Trajectories to Death: Futility and Predicting EOL

Bialecki, L. 1995  <i>Level IV</i>  Communication Decision-making	CPR survival r/t functional ability Identify variables r/t death & in-hospital CPR Retrospective, observational design Sample n=289 APACHE II, Glasgow coma, Unit of CPR 47 references	Findings <ul style="list-style-type: none"> <li>• Low survival to discharge rates after CPR (16.5%)</li> <li>• APACHE &gt;20 was 96% predictive of death after CPR</li> </ul> Conclusion: <ul style="list-style-type: none"> <li>• CPR outcomes can be predicted early in hospitalization</li> <li>• May assist MDs in DNR discussions with family</li> </ul>
De Vos, R. et al. 1999  <i>Level IV</i>  Communication Decision-making	CPR survival and quality of survival Cohort study Samples Initially (n=827), Survivors (n=90) Limitation: included all ages >18y old	Findings <ul style="list-style-type: none"> <li>• Initial survival was good (47%)</li> <li>• Survival to d/c (20%; 1% in a vegetative state)</li> <li>• 6 mo. survival (16%)</li> <li>• Mortality after d/c r/t age (&gt;70y), ADL depend. before CPR</li> </ul> Conclusions <ul style="list-style-type: none"> <li>• CPR often unsuccessful</li> <li>• Factors before CPR sig. determine survival &amp; QOL after</li> </ul>

<p>Zoch, T., et al. 2000 <i>Level IV</i> Communication Decision-making</p>	<p>Long &amp; Short term survival after CPR Retrospective MR review; longitudinal survival 8y study at 2 Midwestern sites Outcomes: survival, D/C survival, LT survival Large sample (n=948; w/ f/u n=298) Limitations include age range 18- &gt;80y, DNR order Increase during study period 31 references</p>	<p>Findings</p> <ul style="list-style-type: none"> <li>• 61% survived arrest, 49% survived 24h, 32.2% to D/C</li> <li>• PEA, asystole, bradycardia, resp. arrests had lowest survival to d/c</li> <li>• Age not predictor of survival to d/c</li> <li>• 1y post D/C, 25% f/u sample died, regardless of age</li> <li>• LT survival worst for &gt;70y, NH care need on admit, and impaired ADLs at d/c</li> </ul>
<p>Norton, S. et al. 2003 <i>Level VI</i> Communication Decision-making</p>	<p>Treatment withdrawal communication conflict Qualitative descriptive analysis Limitations: Sample size (n=20) 20 family members representing 12 decedents</p>	<p>Findings: Families expressed the following needs from MDs</p> <ul style="list-style-type: none"> <li>• Give information to families</li> <li>• Give it honestly and use lay terms</li> <li>• Get together as a team with the family</li> <li>• Listen to the family</li> </ul>
<p>Jones, G., et al. 2000 <i>Level VI</i> Communication Decision-making</p>	<p>Unrealistic expectations about CPR success Descriptive, survey Limitation:  <ul style="list-style-type: none"> <li>• Voluntary participation</li> <li>• Randomly distributed to local church congregations</li> </ul> </p>	<p>Findings</p> <ul style="list-style-type: none"> <li>• 96% expected CPR to be unrealistically effective</li> <li>• Factors increasing predicted CPR survival included <ul style="list-style-type: none"> <li>◦ &lt;50y old</li> <li>◦ TV as a source of CPR information</li> <li>◦ personal medical training</li> </ul> </li> </ul> <p>Conclusions: Public not accurate about CPR survival</p>
<p>Lunney, J., et al. 2003 <i>Level IV</i> Communication Decision-making</p>	<p>EOL Trajectory r/t functional decline Cohort (12) analysis Prospective Longitudinal study: 4 US regions Large sample (n=14,456 age 65y and older) 23 references</p>	<p>Findings</p> <ul style="list-style-type: none"> <li>• Identified 4 cohorts of decline-to-death r/t functional ability (ADL dependency)</li> <li>• Sudden death, Cancer death, Organ Failure, Frailty</li> </ul>
<p>Porock, D., et al. 2005 <i>Level IV</i> Communication Decision-making</p>	<p>Predict NH deaths Retrospective cohort study Large sample (n=43,510) Limitations: data from a single state</p>	<p>Found predictive factors of EOL r/t</p> <ul style="list-style-type: none"> <li>• Age, sex, recently to NH, Dx (Ca, CHF, RF, dementia)</li> <li>• S/S (SOB, deteriorating, wt loss, poor appetite, dehydration, ADL assist, cognitive score)</li> </ul> <p>Conclusion: Usable scoring system, easy to apply clinically</p>
<p>Teno, J., et al. 2000 <i>Level III</i> Communication Decision-making Respect for dying</p>	<p>Predict survival hospitalized pts over 80y old Prospective cohort study w/ NDI mortality follow-back Large sample hospitalized elderly (n=1266) Goal: estimate survival time pt &gt; age 80 in hosp Validated</p>	<p>Findings Important prognostic factors include</p> <ul style="list-style-type: none"> <li>• APACHE III score on 3<sup>rd</sup> day, Mod. Glasgow score</li> <li>• Dx, age, ADLs, exercise capacity, wt loss, QOL</li> </ul> <p>Conclusions</p> <ul style="list-style-type: none"> <li>• Calculated estimated survival; accuracy improved w/ MD prognosis &amp; perceptions of preferred care</li> </ul>

<p>Lamont, E. 2005</p> <p><i>Level I</i></p> <p>Communication Decision-making Respect for dying</p>	<p>Predict Death r/t functional decline</p> <p>Literature Review of survival predictors</p> <p>Performance status/Functional ability</p> <p>Clinical signs and symptoms (136 variables from 22 articles)</p> <p>MD prediction of patient survival time</p> <p>Identified problems: operational definition of EOL = prognosis &lt;6m dictated by insurance (M/C hospice benefit)</p> <p>75 references</p>	<p>Findings</p> <ul style="list-style-type: none"> <li>• MDs/Pts overly optimistic w/ survival time; Pts &gt; MDs</li> <li>• Correlation btw. functional ability and survival time</li> <li>• Dyspnea, dysphagia, wt loss, dry mouth, anorexia, cognitive impairment highly correlated to survival time</li> <li>• Models using S/S w/ Function status were prognostic &amp; improved w/ MD predictive input</li> </ul> <p>Recommendations for future research</p> <ul style="list-style-type: none"> <li>• Study disparity btw MD/Pt prognostication</li> <li>• Dx. survival algorithms to improve comm. &amp; decisions</li> </ul>
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### III. Quality of Care Indicators: Communication, Shared Decision-Making, Respect for the Dying

<p>Wennberg, J. et al. 2004</p> <p><i>Level IV</i></p> <p>Communication Decision-making Respect for dying</p>	<p>HC Utilization at he EOL</p> <p>Retrospective cohort study measuring HC resources used during last 6m of life</p> <p>US Medicare data "follow-back" design</p> <p>Large sample (n=115,089) died in 77 "best" hospitals by <i>US News &amp; World Report</i></p> <p>Large geographic area</p> <p>Limitations: only acute care, MD visits, hospice; Design exclude pts &lt;1 admit in last 2y life</p> <p>20 references</p>	<p>Findings</p> <ul style="list-style-type: none"> <li>• Wide variation among 77 hospital cohorts</li> <li>• Variables included LOS, ICU LOS, #MD visits, %Hospital deaths, %ICU deaths, %Pts w/ &gt;10 MDs, %Hospice use</li> <li>• Variation strongly r/t supply of MDs &amp; beds in region</li> <li>• Increased hospice use not correlated w/ less ICU use</li> <li>• Includes data on dx, age, chronic dx, functional impair</li> </ul> <p>Recommends:</p> <ul style="list-style-type: none"> <li>• Hospital specific data to improve QOC at the EOL</li> </ul>
<p>Teno, J. et al. 2005</p> <p><i>Level IV</i></p> <p>Communication Decision-making Respect for dying</p>	<p>HC Utilization and Pt/CG Satisfaction</p> <p>Mortality follow-back design, observational</p> <p>2 strata: High and low ICU use</p> <p>Needs, concerns, QOC in 5 domains:</p> <ul style="list-style-type: none"> <li>• Physical comfort</li> <li>• Treat the dying w/ respect</li> <li>• Support shared decision-making</li> <li>• Continuity of care</li> <li>• Emotional support to pt and family</li> </ul> <p>Limitations: proxies, cooperation r/t ethnicity</p> <p>15 references</p>	<p>Findings</p> <ul style="list-style-type: none"> <li>• Dying in areas w/ high ICU utilization at EOL is not associated with improved perceptions of quality</li> <li>• High ICU areas were significantly associated with Insufficient emotional support for pt</li> <li>• MD communication concerns</li> <li>• Lack of respect for decedent</li> <li>• Lack of knowing what to expect w/ dying process</li> <li>• Overall less satisfied with QOC at EOL</li> </ul>
<p>Dendaas, N. 2001</p> <p><i>Level V</i></p> <p>Communication Decision-making Respect for dying</p>	<p><i>Hospital Audit of EOL Care</i></p> <p>Retrospective descriptive design</p> <p>Chart review of decedent final hospitalization</p> <p>Random proportional by service</p> <p>Variables: Demographic, Medical data, Hospital data, AD, EOL care</p> <p>4 references</p>	<p>Findings similar to SUPPORT and others</p> <ul style="list-style-type: none"> <li>• Majority of deaths in ICU (medical service); short LOS</li> <li>• Majority of DNR orders 1-3 days prior to death</li> <li>• Unstable health status on admit</li> <li>• Majority with at least 1 chronic illness</li> </ul> <p>Conclusions: audit useful to leadership to assess care</p>
<p>Tilden, V., et al. 2002</p> <p><i>Level V</i></p> <p>Communication Decision-making Respect for dying</p>	<p>QOC and QOL</p> <p>Literature review focus: IoM's HC quality &amp; EOL care process</p> <ul style="list-style-type: none"> <li>• Conceptual frameworks</li> <li>• Measure selection</li> <li>• Data sources</li> </ul> <p>75 references</p>	<p>Recommendations</p> <ul style="list-style-type: none"> <li>• Test models for interrelated variables (i.e. symptom clusters)</li> <li>• Add to or adapt the existing collection of EOL measures</li> <li>• Develop multi-dimensional measures</li> <li>• Study EOL related to different settings, trajectories of decline, symptom fluctuation</li> <li>• Study validity of proxy reports and use of Nat'l data sets</li> </ul>



<p>Pritchard, R. [Abstract] 1998</p> <p>Communication Decision-making</p> <p>Respect for Dying</p>	<p>HC Utilization Place of death (hospital vs. non-hospital) Large samples Subjects: SUPPORT &amp; Medicare decedents Comparison of the two populations Multivariate analysis Peer reviewed</p>	<p>Findings SUPPORT</p> <ul style="list-style-type: none"> <li>• Preferred home death, yet most died in hospital</li> <li>• % hospital deaths varied greatly (29-66%) across 5 sites</li> </ul> <p>M/C beneficiaries</p> <ul style="list-style-type: none"> <li>• % hospital deaths varied greatly (23-54%) in US</li> </ul> <p>Conclusions</p> <ul style="list-style-type: none"> <li>• EOL care may require changing MD practice patterns</li> <li>• In-hospital death influenced by HC, not pt preferences or pt characteristics</li> <li>• Variation is not r/t pt preference, social, economic, or clinical factors</li> <li>• Increased hospital deaths in areas with increased bed availability &amp; use</li> <li>• Decreased hospital deaths in areas with &gt;NH &amp; hospice availability and use</li> </ul>
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#### IV. Quality of Care Indicators: Physical Comfort, Continuity of Care, Respect for the Dying

<p>1) Lorenz, K., et al. 2004</p> <p>2) Lorenz, K. &amp; Lynn, J., et al. 2004</p> <p><i>Level I</i></p> <p>Physical Comfort Continuity of Care Respect for Dying</p>	<p>EOL Care &amp; Outcomes</p> <ol style="list-style-type: none"> <li>1. Summary of the systematic review</li> <li>2. Full Report of the systematic review</li> </ol> <p>Expansive review on end of life care Well delineated inclusion &amp; exclusion criteria Inclusion: SR/MA, I/O studies w/ evidence tables Goal: identify evidence for:</p> <ul style="list-style-type: none"> <li>• Valid variables as QOC indicators</li> <li>• Pt, CG, HC factors r/t better outcomes</li> <li>• Interventions r/t to better outcomes</li> <li>• EOL research needs</li> </ul> <p>269 articles reviewed (search results = 24,423 citations) MEDLINE®, NCPQPC, DARE, TIME, and recommended citations by int'l expert panel Peer Reviewed 17 references for summary 376 references in full report</p> <p><i>Details of the SR methodology</i> See (Lorenz, Lynn, 2005)</p>	<p>Findings for specific areas of focused review:</p> <p><i>Satisfaction</i></p> <ul style="list-style-type: none"> <li>• SR/MA: Satisfaction strongly r/t pain control, CG support, communication, spiritual support, continuity</li> <li>• I/O studies support satisfaction r/t comfort, comm., emotional support, respect, continuity</li> <li>• CG support: focused on burdens, inconsistent results</li> </ul> <p><i>Measurements</i></p> <ul style="list-style-type: none"> <li>• Quality instruments for satisfaction, QOL, QOC, symptoms, continuity of care (See Teno [TIME], 2000)</li> </ul> <p><i>Symptoms</i></p> <ul style="list-style-type: none"> <li>• Strong evidence for treating cancer pain, depression</li> <li>• Small studies suggest opiates effective for dyspnea</li> </ul> <p><i>Continuity of Care</i></p> <ul style="list-style-type: none"> <li>• Strong evidence: continuity of care w/ cancer, moderate for HIV (CHF limited: no multi-site studies)</li> </ul> <p><i>Advanced Care Planning</i></p> <ul style="list-style-type: none"> <li>• Little reliable evidence that AD improve outcomes, some indication of improving Pt/CG satisfaction</li> <li>• Studies often measure utilization, not Pt/CG outcomes</li> </ul> <p><i>Research needed to study:</i></p> <ul style="list-style-type: none"> <li>• EOL definitions r/t diagnosis using s/s, CG needs, continuity, communication gaps</li> <li>• Continuity between care settings such as Amb Care, NH, AL, hospital, and between units</li> <li>• Test measures of continuity across care settings such as ICU to medical floor, NH to Hospital</li> <li>• Epidemiology of non-cancer pain &amp; symptoms</li> <li>• Large studies on interventions alleviating dyspnea</li> <li>• Economic and social dimensions of CG and EOL care</li> <li>• Process of Adv. Care Planning to meet pt/CG goals</li> </ul>
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LOS- Length of stay; I/O-Interventional/Observational studies; SR/MA-Systematic review/Meta-analysis; AD-Advanced Directives; Ca-Cancer; EOL-End of Life; D/C or d/c-discharge; QOC-Quality of care; QOL-Quality of life; DNR-Do not resuscitate; Dx-Diagnosis; Tx-Treatment, PEA-Pulseless Electrical Activity

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