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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

MORTALITY PROGNOSTICATION IN LONG-TERM CARE RESIDENTS:
THE MDS-CHESS SCALE

By

Caroline Etland, MSN, CNS

A Dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
UNIVERSITY OF SAN DIEGO

In partial fulfillment of the requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING

April, 2008

Dissertation Committee

Cynthia D. Connelly, PhD, RN, FAAN, Chairperson

Jane M. Georges, PhD, RN

Mary Ellen Dellefield, PhD, RN

ABSTRACT

Quality end of life (EOL) care for the elderly continues to be a challenge, in part due to late referral for palliative and/or hospice services. The purpose of this study was to determine the accuracy of the MDS-CHESS scale (Hirdes, Frijters & Teare, 2003) in predicting 6-month mortality in a stable American nursing home (NH) population. A secondary aim was to determine any differences in mortality between the 2 sites.

A sample of 191 residents of two NHs was analyzed in a retrospective, correlational cohort study, using data collected from the federal MDS database. Correlational statistics and logistic regression were utilized to determine relationships between predictive variables, and to examine the overall quality of the regression model. The items that comprise the MDS-CHESS scale (DNR status, daily pain, IV site, IV medications, oxygen, suctioning, Physician's visits, Physician's orders and abnormal labs) demonstrated weak relationships among some of variables, although p-values were significant.

The predictive model was analyzed on a final sample of 81 subjects who died during the evaluation period. Regression coefficients were generally low (range 0.09-0.46) and none demonstrated significance in the likelihood ratio test. Odds ratios were uniformly low (range 0.52-2.26) as well. Differences between the 2 NH were negligible in the correlational analysis, as well as the logistic regression statistics and overall mortality.

This study examined the accuracy of the MDS-CHESS scale in predicting death in a cohort of NH residents, and determined differences between the two NH. Early identification of elderly NH residents at risk of dying can improve the quality of care by promoting palliative care and hospice referral in a timely manner. Reduction of suffering through determination of goals of care and appropriate therapeutic interventions remains an important priority in all settings.

DEDICATION

I would like to dedicate this dissertation to the patients and families who have shared their experiences with me throughout my nursing career. They have been the most powerful teachers.

Equally important, I dedicate this effort to my parents, Jimmy and Carolyn, who have always loved my brother and me without reservation, taught us to love others well, and to contribute however we were able to making the world just a little bit better. We miss you Dad.

ACKNOWLEDGEMENTS

I would like to extend my heartfelt gratitude to my dissertation chair, Cynthia Connelly, PhD, RN, FAAN, for her unceasing support and guidance through the many challenges, surprises and successes throughout the entire academic program. The commitment, courage and pragmatism she has brought to this endeavor, and to me personally cannot ever be repaid, only honored in future work.

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I would also like to acknowledge the ARCS Foundation, San Diego Chapter, for their kindness, support and interest in the work of nurse scientists. Their commitment to advancing nursing science has made a huge difference in the ability of doctoral students to embark upon and complete work that ultimately benefits us all. They are very dear to me as individuals as well.

I have been honored to be a part of a group of doctoral nursing students who have inspired me and helped me progress through a profound time in my life. Their humanity and encouragement showed me the way when I could not see the path clearly. Together we helped each other stretch into new territory.

Without the support of the nurse leaders at the healthcare organizations at which I have worked during my doctoral program, completion of the dissertation would not have been possible. Their commitment to higher education and preparation of nurse scientists is a reflection of their futuristic thinking, as they have a profound understanding of the need to close the gap between practice and research to help patients and families cope with health challenges, and to improve nursing practice for the benefit of all. My immediate supervisor, Linda Urden, DNSc, RN, CNA-BC, FAAN, Executive Director of Nursing Education and Research at Palomar Pomerado Health has demonstrated unrivaled support and encouragement to me throughout our association. Lorie Shoemaker, RN, MSN, CNAA-BC, Chief Nurse Executive for Palomar Pomerado Health, has provided the inspiration and setting necessary to complete the research study. Her consistent and public support of nursing research has elevated the image of PPH nurses internally and throughout the community. Maryann Cone, RN, MS, NEA-BC, Vice-President, Chief Nursing Officer, Sharp Grossmont Hospital, provided much appreciated support and encouragement as I began the nursing doctoral program, and encouraged me to continue my studies during major life transitions. These nurse leaders offered me invaluable assistance that cannot be measured, only acknowledged.

Without the assistance and infinite patience of Faith Asper from ResDAC and Debbie Dean from IFMC, it would have taken a much longer period of time to acquire the MDS data and proceed with my study. They are truly well-suited for their roles as navigators, and have a thorough understanding of the data they help investigators to access.

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USD IRB Approval

Chapter One

INTRODUCTION

Overview of the Problem

The Institute of Medicine (IOM) report, *Approaching Death: Improving Care at the End of Life* (1997) created ripples of thought and action in healthcare when it was published. This monograph was the first comprehensive summary of end of life (EOL) practices, perceptions and recommendations that detailed how Americans experienced debility and decline prior to death. The report identified gaps in health care and community support for elders and others dealing with life-limiting illness. Although the hospice movement was well established in America by that time, curative treatment remained the standard of care for people with serious, life-limiting illness.

The Last Acts Coalition report, *Means to a Better End* (2002) examined regulatory directives and laws throughout America, as well as EOL practices in a variety of healthcare settings. Of particular note in this report was the significant lack of adequate EOL care in nursing homes (NH). Health care professionals and people in mainstream America were beginning to openly confront the idea that dying is a part of life and failure to discuss personal wishes with loved ones creates profound problems and an avoidable burden of decision making during times of emotional stress.

As clinical, legal and ethical experts contributed to the knowledge base through publications and presentations at professional conferences, as well as recommendations to government organizations, momentum grew to create a vision for improving care of the dying in all healthcare and community settings. Several consensus reports followed the IOM report that broadened the scope of understanding of different aspects of care of people with terminal and life-limiting illness, and made recommendations for future action and research (*Describing Death in America*, 2003).

In subsequent years, much progress has been made in America with regard to discussion of EOL wishes and understanding of the dying process. Regulatory requirements have increased inquiries regarding Advanced Directives when people are hospitalized (Hawes et al., 1997). Social movements and non-profit organizations have successfully raised awareness of the importance of discussing end of life wishes and identification of alternate decision-makers. Less common is a discussion of quantity versus quality of life. Medical advances have resulted in many fatal illnesses (e.g. cancer, renal failure) becoming chronic diseases. As functionality decreases over time, treatment morbidity increases. Organ damage, fatigue and psychological alterations become part of the everyday life, requiring additional medications and interventions. Yet, too seldom is there a discussion between physician and patient that presents treatment withdrawal with aggressive comfort management as the best option for care.

There are many reasons for this deficit; among them is the difficulty in predicting with accuracy an estimated time left to live. Withdrawal of treatment is often seen as a failure by the physician and by the patient as abandonment (Christakis, 1999a). Failure to promote the option of aggressive supportive care during the terminal phase of illness

influences the decision to continue futile, aggressive treatment. People fear pain, suffering and abandonment. Although healthcare professionals cannot guarantee freedom from symptoms or loss of function, physical, emotional and spiritual support is available that can ease the transition into the terminal phase of illness. The availability of gerontology specialists has also improved NH care and promoted realistic expectations regarding decision-making and autonomy, as well as promoted the inherent value of the elderly. Understanding the concerns and fears of NH residents is essential to promoting good quality of life and self-determination.

Improving EOL care of the elderly is a problem of immense proportions. More than 2.4 million Americans die each year of various causes; 1% of the GNP is spent on ICU care and 23% die in nursing homes (Esserman, Belkora, & Lenert, 1995). Upon admission to a NH, 35% will die within one year (van Dijk, et al., 2000). Less than 30% of Medicare patients with serious illnesses die while utilizing the hospice benefit, resulting in a large proportion of terminally ill people dying with poorly controlled symptoms (Christakis, Iwashnya & Zhang, 2002). These data point to a tremendous human and financial cost to patients and organizations because EOL care is not well-managed.

Prognostication

The process of estimating a patient's future health status can be complex and intimidating not only to the novice but to the experienced physician as well. Nurses do not view prognostication as within the scope of their practice, yet are engaged in conversations with patients and families on a routine basis regarding when a loved one is expected to die.

The terms prognosis and prognostication overlap, yet are quite different in meaning. Stedman's Medical Dictionary (2007) defines the term prognosis as "a prediction of the probable course and outcome of a disease", as well as the "likelihood of a recovery from a disease". These definitions represent two distinctly different constructs; that of a prediction and outcome, and that of recovery. It is not difficult to understand the confusion that exists because of lack of specificity in terminology.

Christakis (1999a) developed a more refined definition, stating that prognosis was an objective reality; "... the actual prospect of a recovery from a diagnosis given the nature of the disease and the special features in question." This definition is from the patient's perspective, and arose out of patient inquiries about severity of illness and possible proximity to death. Relying only on one perspective (that of the patient) undermines this complex process because understanding of a new clinical diagnosis occurs through mutual conversation, and interpretation of clinical information in the context of the situation. In this spirit, Christakis also defines prognosis from the subjective point of view as being the physician's impression of what might happen; "... the acts of foreseeing and foretelling the course and outcome of a disease" (p. 19). It is the physician's perception of the patient's experience. Prognostication is thought to be a forecast or prediction (Stedman, 2007) and is used broadly throughout the business world as well as in healthcare, to respond to industry changes and planning mandates. This definition is too simplistic and fails to acknowledge the nature of the physician-patient relationship. Christakis deems the act of prognostication as "... an intellectual process whereby the physician moves from knowledge about disease in patients in general to knowledge about its expression in an individual" (Christakis, p. 20). This is an

important basis for subsequent communication as disease advances. If the act of prognostication is not done with restraint, perspective and knowledge of the limits of medical care, then “disrespectful overtreatment” is a risk during times of crisis (Christakis, p. xiv).

Avoidance of overtreatment is a common theme of dialogue in clinicians caring for people with advanced illness. Many clinicians lack knowledge about how to balance comfort with desired goals of care. Some of the barriers to providing comfort through the use of hospice and palliative care services include the availability of consultation services, poorly identified goals of care, and difficulties with prognosis. The majority of NH residents are clinically stable, with multiple co-morbidities. Exacerbations and remissions of chronic illness are normal events and death is often sudden and unexpected, but not surprising. Prognostication is difficult, and few instruments can accurately predict death within a certain time frame. Several instruments can predict risk of complications or mortality if certain illnesses are present, such as the Functional Assessment Staging (FAST) scale for dementia (Volicer et al., 1993). However, the multiple chronic illnesses that are present with most NH residents might make use of such instruments less reliable. Several instruments are more broad-based and will be discussed in greater detail in Chapter Two.

The Minimum Data Set (MDS) for Nursing Homes

As a culture, Americans are less likely in the 21st century to care for aging loved ones at home. The demise of the nuclear family and economic necessity of working outside of the home has resulted in fewer extended families residing within the same home. Insufficient retirement funds prevent many elders from living independently with

assistance as needed. The increased availability of nursing homes (NH) in the last century has meant that institutional or group living is the only viable option for many sick and elderly people. Because of the potential for poor quality care, the NH industry has become highly regulated in an effort to ensure resident safety and to minimize fraud.

Among the regulatory requirements are the routine and systematic assessment of NH residents, and the evaluation of quality indicators on a routine basis. To participate in state and federal Medicare reimbursement programs, NHs must collect resident data and submit it to a federal database for analysis. Reports are returned to the NH after several months, care deficits are identified and improvement plans created. Many researchers have utilized the Minimum Data Set (MDS) database to conduct research on the care of NH residents and identify trends within certain geographic areas. The information collected for submission to the MDS database provides a valuable sample with adequate power to demonstrate statistical significance. The MDS is the database from which the sample was derived for this study.

Conceptual Framework

A long-standing problem with healthcare is the gap between research and clinical practice. Clinicians lack the time to absorb research advances, and it has only been in the past decade that researchers are beginning to partner with clinicians to implement and evaluate evidence-based practices outside of pharmaceutical studies. The advent of large national administrative databases has facilitated the refinement of health outcomes research design, however, the process is slow and many barriers exist for implementation of novel tools for quality improvement. One driving force that is closing the research-clinical gap is the quality initiatives inherent to healthcare facilities and regulatory

organizations. The Joint Commission (JC), states' Department of Health Services (DHS), and the Institute for Healthcare Improvement (IHI) all communicate the need for a supporting quality program to monitor and improve patient outcomes.

One conceptual framework that supports quality and research initiatives in healthcare organizations is the Quality Health Outcomes Model (QHOM), first described by Mitchell, Ferketich, and Jennings (1998). This model arose from a collaboration of researchers and policy-makers, under the auspices of the Agency for Health Care Policy and Research (now the AHRQ). An evolution of Donebedian's quality model, the QHOM broadened the understanding of nursing outcomes by illustrating the bi-directional influence that the patient and organization have on outcomes. There is no direct effect of interventions on outcome, but rather, all are impacted by the characteristics of each (Radwin & Fawcett, 2002).

The QHOM supports the metaparadigm of nursing by incorporating the concepts of person, health, environment and nursing into the framework (Radwin & Fawcett, 2002). This is ideally suited for nursing research, as the influence of nurses on patient care and outcomes is readily visible. The study design described here addresses all four paradigms as they relate to identifying NH residents with poor prognosis, so that discussions regarding goals of care can be initiated.

Significance of the Study

The significance of this study lays in the potential for healthcare providers to have available an accurate instrument that predicts mortality in NH residents. In the past, the clinical experience of physicians and nurses has provided direction for discussions regarding goals of care and recommendations for palliative treatment of people in the last

stages of advanced disease. An accurate prognostic instrument has the potential to be incorporated into decision-making as part of evaluating a person's clinical status holistically. For many patients and families, there is uncertainty regarding a shift to comfort care and away from curative or life-sustaining treatments. There is a great fear of abandoning a loved one, or stopping life-sustaining treatment when there is still hope of a reversal of clinical decline. Prognostication “. . . allows patients to make the most effective use of their emotional, fiscal and temporal resources and to regain a sense of control over lives thrown into disarray by serious illness” (Christakis, 1999a).

Prognostication for treatment purposes is a medical responsibility, and not within the scope of practice of nursing practice. However, nurses routinely use predictive indexes to score patients for risk of an event (e.g. falls, pressure ulcers) and initiate activities to address these risks. Nurse ratings of a NH resident's mortality risk using a validated prognostic scale is therefore within the scope of nursing practice. The nature of this activity is data collection, assessment, and collaboration with physicians to communicate clinical condition, and to trigger discussions about goals of care, rather than to communicate prognosis to patients and families.

Nurses receive no training in prognostication, or in the use of predictive models in basic academic curriculums. Yet, nurses spend more time with residents than any other discipline, and are able to contribute valuable insights to the interdisciplinary team (IDT). Use of validated prognostic tools to communicate risk does not in itself determine treatment. This author believes that there is minimal risk involved when trained nurses identify NH residents who meet criteria for palliative care or hospice referral, and communicate that information to the IDT. However, there are ethical and professional

considerations that provide some caveats to this perspective. These considerations will be discussed in greater detail in Chapter 5. Of the prognostic tools examined, the MDS-CHESS has good utility and is simple to use.

In future research, it may be shown that the MDS-CHESS scale can facilitate discussions regarding end of life care in this population. Indeed, the intent stated by virtually all investigators who have created prognostic models for NH residents is for the prognostic models to be used in this fashion. Having a prognostic tool that can predict mortality in NH residents and generate discussion of goals of care would provide valuable information with which a physician can offer realistic treatment options aimed at maintaining function, while minimizing suffering. The ultimate hope is that more residents will receive palliative and/or hospice support in the last six to twelve months of life, rather than aggressive interventions that will not improve that quality of life.

Statement of the Problem

The problem this study is designed to examine is that predicting death in NH residents can be difficult and complex, and delays in referral to appropriate supportive care results in undesired medical intervention and unnecessary suffering when clinical decline occurs.

Purpose of the Study

This study is undertaken to retrospectively determine survival of a cohort of NH residents and to determine whether the MDS-CHESS scale accurately predicts mortality within six months. Using an existing data set, relationships between mortality and scores on the MDS-CHESS scale will be evaluated.

Study Aims

The focus of this study design is to replicate a previous research study in another patient population outside of the United States. With consideration of differences between healthcare systems, study elements were modified slightly during data collection and analysis to accommodate those differences.

Aim #1: Determine the accuracy of the MDS-CHESS scale for predicting six-month mortality in two American nursing homes.

Aim #2: Determine whether there are differences in six-month post-admission mortality between two NH populations operated under identical regulatory and organizational rules.

Implications for Nursing

Nursing knowledge can be advanced by this study in several ways. Clinical nursing practice in NH is facilitated by use of evidence-based tools to evaluate risk and plan interventions. MDS nurses can screen for mortality risk during the admission assessment, without duplication of activities. Trained nurses with knowledge of the MDS-CHESS items could also score residents in the absence of a recent Resident Assessment Instrument (RAI) and obtain prognostic information. In daily clinical practice, this would be a valuable baseline to complete upon admission, and with any clinical changes. Since physicians are required to see NH residents only once a month, nursing use of this scale would assess relative risk and can prompt goals of care discussions on a more frequent basis. In this regard, nurses can have a direct effect on preventing unnecessary ED visits or hospitalizations by advocating for care appropriate to the resident's stated wishes.

Nursing education can be impacted on a variety of levels. Instruction of the NH nurses, supervisors and MDS coordinator on the value of accurate data entry and concurrent mortality risk assessment is likely to improve EOL quality indicators, and can decrease perceived liability as communication is enhanced. Supervisors have the responsibility and authority to mandate and monitor process changes that are expected to improve resident outcomes. Increased nurse comfort with the resident's transition to the active dying phase facilitates resident and family support and bereavement. Ancillary staff and other disciplines also benefit from this knowledge. Whenever additional eyes are trained on the NH resident, changes can be detected more readily, and modifications to the treatment plan are more likely.

Nursing research on EOL care in NH has gained momentum in the last decade. Most studies concentrate on some aspect of hospice services or on the nursing staff providing EOL care. Additional studies are necessary to determine the effect of nurses on promoting good EOL outcomes. This study may have implications for nursing research as the basis for follow-up investigations of interventions and quality program modifications. Improving end-of-life care in the elderly is dependent on a number of complex factors including availability of fiscal and human resources, adequate organizational structure and effective care processes. Uncertainty regarding expected length of life and reluctance to address practical considerations often results in prolonged dying and avoidable suffering. The impact of sustaining life in the face of advanced disease is felt at all levels of care, and is just recently being evaluated more comprehensively from a population-based perspective. Much research remains to be done on identifying how and when to intervene for people with serious, chronic illness.

This investigation is informed by previous research and literature on administrative national databases, the MDS, clinical prognostication and the Quality Health Outcomes Model. Each of these topics will be explored to provide the framework for this study in the following chapter.

Chapter Two

REVIEW OF THE LITERATURE

The purpose of this study is to determine the accuracy of the MDS-CHESS scale in estimating six-month prognosis in long-term care residents. Numerous studies and initiatives have suggested that the ability to predict mortality in people with advanced disease can minimize futile treatment, and refocus goals toward palliation at the end of life. Few predictions of mortality are absolute, and prognostic tools are best used to supplement clinicians' knowledge of patients' quality of life, and psychosocial and spiritual outlook.

Improving end-of-life care in the elderly is dependent on a number of complex factors including availability of fiscal and human resources, and adequate organizational structure and effective care processes. Uncertainty regarding expected length of life and reluctance to address practical considerations often results in prolonged dying and avoidable suffering. The impact of sustaining life in the face of advanced disease is felt at all levels of care, and is just recently being evaluated more comprehensively from a population-based perspective. Much research remains to be done on identifying how and when to intervene for people with serious, chronic illness. This investigation is informed by previous research and literature on administrative national databases, the MDS, clinical prognostication and the Quality Health Outcomes Model. Each of these topics will be explored to provide the framework for the proposed study.

End-of Life Research Using National Administrative Databases

National administrative databases were originally created for billing and documentation purposes, and are only recently being explored for uses such as quality of care studies, population-based clinical outcome evaluation, and analysis of predictive measures. The use of databases for research must be considered in the context of whether the desired information is contained in the database, and how to link a sample with other databases to analyze endpoints or outcomes. One limitation of database studies is that the information submitted for inclusion may contain missing data, may be inaccurate, and is certainly dependent on the competency of person entering the data. Therefore, validation studies of national databases strengthen support for research use and ultimately, can guide interventions. Another barrier is the timeliness of access to electronic data from state or federal databases (Rantz & Connolly, 2004). Collated reports from the databases to the providers are usually not available for several months after data submission, limiting the opportunity to improve care for individuals and minimize adverse outcomes in a timely manner.

Several investigators have utilized national databases to describe end-of-life care. Grunfield et al. (2006) described population-based indicators of quality of end-of-life care by linking the Canadian Vital Statistics database with cancer registries and other provincial databases. The investigators retrospectively measured 19 quality indicators and determined that seven indicators met the necessary criteria for inclusion in the study. Validation of the indicators was accomplished through concurrent chart abstraction of a random sample of study subjects (p. 773). This study added to the body of knowledge about quality of care at the end of life for breast cancer patients, and the usefulness of

retrospective design in a population that is difficult to research during the terminal stage of illness.

Research measuring quality of life outcomes is seldom able to evaluate the contributions of nurses in promoting quality of life for seriously ill people. Doran, et al. (2006) analyzed nursing-sensitive outcomes in Ontario hospitals and long-term care facilities. One purpose of the study was to determine reliability of instruments measuring nursing-sensitive outcomes in hospital administrative databases and the MDS. The results revealed that, “. . . data collection by nurses on a broad set of outcomes . . . can be conducted reliably and validly” (p. S80).

The investigators cautioned that data collection on nursing-sensitive outcomes should be considered carefully, and a plan should be created for establishing their utility in care planning and quality monitoring. This study had added significance because of the conceptual framework that informed its design. Using the Quality Health Outcomes Model and the Nursing Role Effectiveness Model, the investigators identified a broad set of outcomes that were already recorded during the normal course of patient care. Previous studies had identified an underrepresentation of nursing-sensitive outcomes in administrative databases. In summary, use of large national databases for health research has been shown to be an efficient and reliable method of evaluating and describing patient and population characteristics.

Retrospective and prospective study designs both have merit in determining elements of good EOL care. Information from a sample of individuals can be applied to a similar clinical situation to provide guidance about an individual's present and future situation (Teno, 2005). By examining a cohort of individuals with common clinical

problems and diagnoses, studies can be designed to test hypotheses and answer questions with live participants, rather than through proxy or documentation in the medical record. Retrospective analyses eliminate the need for concurrent chart audit to identify those at risk of dying, as the time to event (death) has already occurred. This cost-effective method of conducting research also eliminates the patient burden of describing experiences and perceptions at a time of advanced illness near death.

In discussing the methodological issues surrounding retrospective EOL studies, a noted expert in the field cited the need for “Mortality Follow-Back Surveys” (MFBS) to provide “. . . information on the dying experience including functional trajectory and the site of death, quality of life in the last year of life, and the use of hospice services” (Teno, 2005). There have been six MFBS conducted in America thus far, the last done in 1993. These studies have provided data regarding access to healthcare and disparities between populations, and quality of life measures. Retrospective studies have provided compelling evidence that EOL care can be improved, and identified specific areas on which to concentrate research efforts.

However, unresolved issues make retrospective database studies on EOL care problematic. First, there is no standard definition for the concepts of “terminally ill”, “dying”, “end-of-life”, or “frailty” (Christakis, 1999a). Investigators do not always include a working definition of these terms in the study report. Therefore, minimizing risk of internal bias is more complicated. Triangulation of methods and using multiple sources of information has been recommended to understand EOL care more comprehensively (Teno, 2005).

Prospective studies are more difficult to conduct and should incorporate subjective data from patient or proxy in the research design. Few prospective studies have been conducted to date because of data collection difficulties. Patients are weary from prolonged illness and treatment, and may not be able to complete the necessary interviews or surveys. A proxy is beset by numerous functional and emotional responsibilities, and is providing responses that may not be an accurate reflection of the patient's experience. Identification of potential study participants is also problematic. Physician prognostication is a highly variable activity prior to the last stage of illness before death. Capturing patients and families in transition to an advanced stage of illness would yield information essential to knowing when to time discussions regarding a shift in priorities of care (Steinhauser, 2005).

A central feature of prospective studies of people with serious illness is the focus on quality of life (QOL). Existing, validated QOL instruments measure constructs that are grounded in the present, rather than evaluating concerns about the future (Steinhauser, 2005). This is not a realistic use of such instruments in the terminally ill population. Instead, quality of dying (QOD) instruments are necessary to capture the unique features of experiences prior to death (Steinhauser, p. S37). Improvements in prognostic accuracy can identify optimal timing of discussions about goals of care, and ultimately increase opportunities to measure quality of dying. This analysis does not have to be restricted to the last six months of life; it could begin with a baseline measurement at the time of diagnosis. Of particular concern is the length of time seriously ill patients spend in hospitals and care facilities as a result of aggressive treatment in the last stages of advanced illness.

The Dartmouth Atlas of Healthcare (2006) recently published a retrospective review describing the care of patients with severe chronic illness in the last two years of life. This was a comprehensive review of care at the end of life across the nation, as well as across the care spectrum. The focus of this report was to analyze care intensity and resource utilization in the Medicare population. National statistics were compared with state-specific data in 306 geographic regions across the United States.

With mortality as an end point, investigators were able to evaluate resource utilization and quality of care at intervals in the two years prior to death. Figure 2.1 delineates the number of hospital days per state in the last six months of life. It was revealing that people spent fewer hospital days in states that were less populous and therefore, had fewer hospitals and resources.

Figure 2.1

Variation, by State, in Average Numbers of Hospital Days During the Last Six Months of Life (Center for Evaluative Studies, Dartmouth Medical School, 2006).

Interestingly, the report determined that more intense care and utilization did not improve outcomes. In fact, regions with the highest intensity of utilization also had the highest mortality rates (Dartmouth Atlas, p. 16). Regions with the lowest resources and care intensity had less hospital days in the last months of life, possibly because facilities operated more efficiently or because there were fewer physicians available to admit patients. Another important measure of aggressiveness of care is the time spent in the Intensive Care Unit (ICU). A summary by state shows the number of days spent in the ICU in the last six months of life (Figure 2.2).

Figure 2.2

Variation, by State, in Average Numbers of ICU Days During the Last Six Months of Life
(Center for Evaluative Studies, Dartmouth Medical School, 2006).

Fragmentation of care and lack of communication between healthcare professionals decreases the quality of care. With advancing illness and frequent hospitalizations, different physicians are providing therapeutic direction to patients. Commonly, no one physician is in charge of directing a person's care when advanced illness is present, creating confusion and increasing the chance of conflicting medical orders.

The primary care physician who usually knows the patient best is often uninformed about treatment decisions made when patients are hospitalized. The amount of physicians involved in treatment decision-making in the last two years of life is well

demonstrated by this study. Figure 2.3 shows the percentage of patients who had more than ten physicians in the last six months of life.

Figure 2.3.

Variation, by State, in the Percentage of Decedents Seeing Ten or More Physicians During the Last Six Months of Life (Center for Evaluative Studies, Dartmouth Medical School, 2006).

In addition to the altruistic desire to improve care and decrease suffering at the EOL, there is an urgent need to approach resource utilization as a data-driven endeavor. Medicare spending for hospitalization and Part B ranged from \$21,000 to \$60,000 in the last two years of life, according to a study of calendar years 2000-2003 (Dartmouth Atlas, 2006). Alarming increases have been noted in the intensity of care this decade (Dartmouth Atlas, p. 80). The demographic profile of hospitalized patients has not shifted radically in the last decade, with the majority of admissions continuing to be elderly

people (excepting obstetrical admissions). Therefore, more intense care is being delivered to the elderly, who traditionally have more co-morbidities and are frailer. Figure 2.4 illustrates the rise in care intensity from 2000-2003.

Resource	2000	2001	2002	2003	% Increase in 4 years
Intensive care beds	12.4	12.9	13.5	14.0	13.6%
Medical specialists	7.9	8.1	8.5	8.9	12.4%
Primary care physicians	8.4	8.6	8.7	9.0	7.7%

Table 5.1. Increases in the Average Inputs of Intensive Care Beds, Medical Specialist Physicians, and Primary Care Physicians per 1,000 Chronically Ill Medicare Enrollees (2000-03)

Figure 2.4

Increases in the Average Inputs of Intensive Care Beds, Medical Specialist Physicians, and Primary Care Physicians per 1,000 Chronically Ill Medicare Enrollees (Center for Evaluative Studies, Dartmouth Medical School, 2006).

The data from the Dartmouth atlas reveals the fiscal impact of failure to identify realistic goals of care in elders with chronic illness and provides a baseline from which improvements can be measured.

The use of national databases will continue to provide valuable information regarding the care of populations, as well as identifying measures of care quality and benchmarks to aid in organizational decision-making. Further efforts should be expended understand and time interventions in prospective studies. A necessary evolution of research design is the conduct of studies that follow patients through the continuum. Optimal EOL care cannot occur in the vacuum of one care setting (e.g. acute care). Because people with serious chronic illness repeatedly cycle through all care settings, interrupting the cycle to reevaluate goals of care is a worthy effort. A person who is in the terminal trajectory of illness, responding to clinical crisis by providing adequate

supportive care can prevent unnecessary interventions that ultimately do not ease suffering, but prolong it. One logical point at which to interrupt the care cycle is in the nursing home (NH) setting, where the frailest patients are cared for. An examination of the NH database research on EOL care follows in the next section.

The Minimum Data Set

The Omnibus Reconciliation Act of 1987 mandated “. . . that Medicare and Medicaid-certified nursing facilities complete a comprehensive, accurate and standardized reproducible assessment . . .” for nursing home residents using the Minimum Data Set (MDS) (Carter, et al., 2006). The MDS is a survey of more than 550 items used to assess Nursing Home (NH) residents upon admission, quarterly, and with significant changes in clinical condition. The first version of the MDS was implemented nationally in 1991; MDS version 2.0 was launched in 1995. A third version is currently under construction, and includes assessments related to palliative care.

Originally developed for assessment and care planning purposes, the use of the MDS expanded rapidly to include provision of data for reimbursement, evaluation of quality indicators and health services research (Dellefield, 2007). The operations manual used by NHs to guide data collection contains Resident Utilization Guidelines (RUGs) and Resident Assessment Protocols (RAPs) to identify and organize information about common clinical problems, and provide direction regarding data collection and submission. Not exclusive to nursing care, this tool greatly facilitates interdisciplinary care planning.

Original validation studies of the reliability of the MDS included multiple field trials and revision or deletion of some items (Morris et al., 1990; Hawes, Morris, Phillips,

Fries, & Mor, 1991). After several years of use nationally, questions emerged regarding the reliability of the data for research. Hawes et al. (1995) conducted small scale field trials and concluded that intraclass reliability was adequate for research purposes, provided the MDS RN Coordinators utilized the RAPs properly.

Other investigators have validated different elements of MDS as quality indicators or to compare with existing clinical measurement instruments. Bates-Jensen et al. (2004) examined 15 nursing homes to determine the prevalence of bedfast residents and the effect on activity levels and mobility care. Results of this study surprisingly revealed that a higher prevalence of bedfast time did not equate with fewer activity interventions by nursing home staff. The significance of this study lies in the unexpected finding on a key quality indicator for NH. Traditionally it has been thought that more time in bed equates with less activity, and the reverse was found to be true. This study is valuable in addressing assumptions about NH processes and potential modifications to measure the bedfast quality indicators.

Frederiksen, Tariot and De Jonghe (1996) conducted a cross-sectional correlational study of the criterion-related validity of the MDS with five existing rating scales. This study added to the validity of MDS data in assessing behavior, function, mood, communication, and cognition of NH residents. The correlation of functional scores with the Physical Signs and Symptoms Scale was high, as were the dementia scores with the Brief Psychiatric Rating Scale (BPRS) and the Mini-Mental Status Scale (MMSS). The MDS communication scores also correlated highly with the Mini-Mental Status Scale and the Psychogeriatric Dependency Rating Scale (PGDRS). Mood and behavior MDS items were less well correlated with the MMSS and the PGDRS scales.

The investigators attributed these negative correlations to the limited number of MDS items for mood and behavior. Standard ratings scales such as the MMSS, PGDSR and BPRS “. . . by design, encompass psychopathology more broadly in their description of psychiatric symptom characteristics” (Frederiksen, Tariot & De Jonghe, p. 308). The authors acknowledge that the MDS is not intended to be a diagnostic tool, but has validity when compared to standard research rating scales.

Burrows, Morris, Simon, Hirdes and Phillips (2000) advanced knowledge of MDS utility further with a study that identified MDS items that correlated with the Hamilton Depression Rating Scale (HDRS) and the Cornell Scale for Depression in Dementia (CSDD). The MDS Depression Rating Scale (MDSDRS) had high sensitivity with the HDRS and CSDD (95% and 78%, respectively) and minimal loss of specificity (72% and 77%, respectively). The implication for practice was to use the MDSDRS to screen for depression in residents, rather than completing an additional screening instrument.

Fries, Simon, Morris, Flodstrom and Bookstein (2001) studied 95 NH residents to determine whether use of the Visual Analogue Scale (VAS) correlated with MDS pain items, and suggested that the MDS Pain Scale was easier to use. This is an important consideration with cognitively impaired residents who are not able to use the VAS to rate pain. Pain, depression and cognition influence chronic illness and the dying process, and the previous descriptions of validation studies of MDS as a research tool serve to support its use for researching prognostication of death. In summary, the MDS has been shown to be a versatile source of information on NH residents.

Prognosis and Prognostication

Since the late 1800s, medical journals have provided a forum for discussion on the nature of disease and the patient's response to it. Underlying this discourse is the physician's role as the guide into the unknown realm of illness and uncertainty. As far back as 1934, physicians were lamenting prognosis as being difficult (Christakis, 1999a). In *Death Foretold: Prophecy and Prognosis*, an ethical code regarding prognosis becomes apparent in the following quote:

"The ability of physicians to prognosticate is equated with showing restraint, maintaining a sense of perspective, and knowing one's own limits. Acting on predictions to avoid such disrespectful overtreatment required assiduous data collection, substantial learning, excellent judgment, and considerable courage. It also requires a commitment not to abandon the patient" (p. xiv).

Physicians' estimates of prognosis vary widely, depending on the physician specialty and familiarity with the patient. This results in a prolonged dying process brought about by extended medical treatment that will not produce a long-lasting solution. When there is little treatment available for a particular illness, prognosis by the physician is a prominent influence on treatment decision-making. When there are available treatments, "... physicians will blithely neglect prognosis" (Christakis, p. xix).

The ability to sustain life when catastrophic cardiac or pulmonary failure occurs was greatly increased with the advent of cardiopulmonary resuscitation (CPR) in the 1960s. Since that time, advances in therapeutic interventions and diagnostic technology have prevented death and organ failure in countless people. Intensive care units (ICUs) and emergency departments (ED) have improved the care of critically ill people through

coordinated efforts of medical specialists (e.g. trauma, cardiology), the Emergency Medical System (EMS) network, and hospital support systems. These advances have also created significant ethical dilemmas because the dialogue surrounding death and dying has not matured along with technological capabilities into effective communication between patients, families and healthcare professionals. To ameliorate this gap, national experts, research entities and the government have collaborated to produce guiding documents that disseminate research and make recommendations for policy and regulatory changes (IOM, 1997; 2003).

Improved management of progressive, chronic illness has prolonged life and allowed Americans to retain productivity and quality of life through various stages of disease and disability. These advances have also resulted in a prolonged dying process that has impact beyond the personal suffering that occurs. The financial and emotional toll of disease remissions and exacerbations is felt by loved ones as they respond to the changes brought about by increased dependency. Patients fear losing control and suffering needlessly (Connors, et al., 1995). The cultural shift in our society that brought about the Right-to-Die movement has produced encouraging progress. Healthcare professionals are engaging with ethicists and consumers to discuss when to prolong life, and the relative benefits of life-sustaining treatments. A significant barrier that creates uncertainty in this discussion is the difficulty in determining prognosis.

As a result, there has been an increased emphasis on discovering methods and support tools that will aid in reliable prognostication. Many clinicians rely on biophysical data as well as intuitive insights to communicate recommendations and timing of treatments. Often, these discussions occur during crisis, or do not happen at all. Studies of

physicians reveal that they pursue treatment for patients that they would not choose for themselves or their loved ones (Connors, et al., 1995). Other research has provided conflicting information regarding whether physicians' prognosis is overly optimistic or pessimistic (Connors, et al., p. 1592). In general, it has not been observed that prognostic models are widely used in the hospital setting to aid in treatment determination, with a few exceptions (e.g. burn and intensive care patients). It is postulated that this is because physicians receive very little training in using prognostic systems in medical school and residency, and nurses are unlikely to receive any training on prognostication in their entire career (Christakis, 1999a).

Prognostic Models

Several systematic reviews of prognostic models, tools, or other predictive measures have contributed to understanding the scope of research that has been completed in the past. This organized approach is done within several contexts; that of palliative care and terminal cancer. Vigano and colleagues (2000) reviewed major literature databases until 1999 and found that there were five independent predictors of survival in the terminal cancer population: performance status, presence of cognitive failure, weight loss, dysphasia, anorexia, and dyspnea. Physicians' estimations of patient survival only showed an association of small magnitude. This review added valuable information by identifying specific criteria to describe the terminal phase of cancer, and substantiating support for the Terminal Cancer Syndrome Theory, previously described in related literature, but not supported by research. These predictors crossed many types of cancer, and helped to explain the subpopulation of cancer patients who die despite only a moderate stage of cancer.

Other investigators evaluated survival studies through the palliative care perspective. Coventry, Grande, Richards, and Todd (2005) reviewed studies of prognosis in hospitalized and community-dwelling elders. Because the prognostic models that exist have poor discrimination in non-cancer patients, it was necessary to identify independent predictors in non-cancer populations that generally are thought to have poor prognoses.

Six independent predictors were identified:

- Increased dependence in activities of daily living;
- Presence of co-morbidities;
- Poor nutritional status;
- Weight loss;
- Abnormal vital signs;
- Abnormal lab values.

These data are easily obtainable from the patient's medical record, and can serve to make available palliative or hospice services to maintain comfort of a physical, psychosocial and spiritual nature. However, the authors note, “. . . uncertainty about the onset of palliation and time to death in older, non-cancer patients is, undoubtedly, compounded by problems of prognostication in this group” (Coventry, et al., p. 226). They suggest that a mixed model of active and palliative treatment may serve this population better than one or the other. The unpredictable nature of non-malignant, terminal disease makes delivery of quality EOL care difficult. Identification of independent predictors can be of great use to clinicians involved in the care of such patients.

Although survival time is one of the first concerns expressed by patients receiving a life-threatening diagnosis, clinicians often provide inaccurate estimates of prognosis. One would think that the availability of supportive tools would enhance prognostic estimates. It is clear that there is no famine of evidence-based prognostic instruments. In a recently published systematic review of prognostic tools for palliative care, over 20 examples were identified from the literature (Lau, Downing, Lesperance, Shaw, and Kuziemy, 2007). The tools were disease-specific, or non-disease specific. Limitations of the reviewed tools, such as the need for further validation in different populations, and lack of consistent reporting of prognosis and its interpretation, will be further discussed.

One problem with prognostic systems is that they were created from a patient sample at one point in time, and then tested for internal reliability. It was not known whether a prognostic system was generalizable to future patient samples. In an article about assessing generalizability, one study from 1987 was cited that addressed the problem of the degradation of such systems in subsequent patient populations and created some baseline criteria for judging longitudinal rigor (Justice, Covinsky, & Berlin, 1999).

Justice and colleagues (1999) outlined essential factors for consideration of the utility of a prognostic system. Accuracy is determined by measures of calibration and discrimination. Calibration is demonstrated by plotting of predicted and observed outcomes. Discrimination is measured by the Receiver-Operating Characteristic (ROC) curve. Generalizability is evaluated by reproducibility and transportability. Resampling methods can determine reproducibility in a sample similar to the sample in the original study. Transportability is analyzed depending on the intended application to the system, and is tested in a sample that is non-identical or homogenous to the original study sample.

The preceding concepts are significant considerations in the current quest for evidence-based healthcare and outcome measurement. Treatment recommendations for serious illnesses arise from staging and prognostic systems that may have degraded over time or were not ever formally tested for external validity. It is possible that the same perspective holds true for prognostic systems that inform goals of care. Testing the external validity of the MDS-CHESS scale will add to the body of knowledge regarding estimating prognosis in NH residents.

The following section will provide an overview of prognostic models and tools as they relate to prediction of mortality and desired influence on determination of goals of care. Disease-based prognostic methods will be discussed, as well as models used in acute and long-term care to enhance understanding of this complex, imprecise process. A discussion of the value of prognostication in advanced disease will complete this section.

Disease-Based Prognostication

It is important to distinguish between disease-based prognosis for treatment purposes, and prognosis determination to inform goals of care. When delivering a new diagnosis to a patient, a physician must be prepared to interpret the meaning of an individual's clinical information in the context of a global understanding of that disease, its natural history, and expected responses to current treatment. Disease-based prognostic systems have been created to “. . . generate predictions for patients whose outcome is not yet known” (Justice, et al., 1999).

One of the most comprehensive and mature uses of disease-based prognosis exists within the field of oncology. Development and refinement of staging systems by the American Joint Commission on Cancer (AJCC) has provided clinicians with a template

for evaluating degree of disease and a baseline for treatment (AJCC, 2008). Diagnostic testing can accurately pinpoint the primary source of tumors and most metastatic sites. Extensive research studies on multimodal cancer treatments have identified which stage of disease is most likely to respond to a given treatment plan. Much attention is given to survival percentages (as determined by the Kaplan-Meier curve) that are based on one stage of a specific type of cancer and its response to a treatment approach. As cancer treatments have improved and patients survive longer, equally important is the attention given to managing the sequelae of disease and treatment. From this origination point, researchers began investigating prognostic systems for advanced illnesses to facilitate appropriate care, improve communication with patients and families, and minimize suffering during the last stages of life.

Within the literature on specific diseases there are prognostic indicators designed to evaluate time to event, such as death. In the terminal cancer population, estimates of time remaining prior to death can be inaccurate, potentially leading to continuation of therapy, or less aggressive comfort measures. One such prognostic indicator is the measurement of uric acid levels in the last weeks of life. It has been shown that uric acid levels greatly increase between the first and second weeks prior to death (Shin et al., 2006). This information can be quite useful in predicting time of death with some accuracy. Families wish to know with as much certainty as possible, how long a loved one may linger before dying. This is an indication of achieving some measure of control over a difficult process, in addition to more practical considerations such as funeral planning and gathering of family.

Other investigators have stratified terminal cancer patients into homogenous risk categories in order to minimize over- or undertreatment, and to stage the terminal phases of cancer for estimation of survival. Pirivano et al. (1999) created the Palliative Prognostic Score (PaP) which resulted in three risk categories for survival. Statistical significance was determined for survival in Group A (64 days), Group B (32 days), and Group C (11 days), based on simple clinical measures. These risk categories were thought to have utility in clinical practice for treatment and to support decision-making.

A similar prognostic index for palliative cancer patients was developed by Morita and colleagues (1999), with some overlapping variables. Efforts to develop the Palliative Prognostic Index (PPI) in Japan progressed almost simultaneously with the Pirovano group work in Italy. This study sought to group patients into survival risk categories and successfully demonstrated that distinct patient profiles, or “bands” emerged from the data. By contrast, subsequent researchers found conflicting results in replication studies. A British Columbia research group found distinct survival curves but no profiles or “banding” (Lau et al., 2006), while Australian researchers confirmed broad applicability in a different setting (Glare & Virik, 2001). This can be interpreted to mean that although the PPI had validity for survival prognosis, it is unclear whether the generalizability across different samples is consistent. This is an important point to resolve in future studies. Categorization of terminally ill patients into groups with distinctly different survival curves can allow clinicians to tailor therapeutic and care needs in congruence with the expected prognosis of each group (Glare & Virik, p. 894).

This type of prognostication for treatment purposes has advanced the knowledge of response to cancer therapy, and shifted the diagnosis from a terminal disease to one

that is more chronic, albeit life-limiting. Similar methods of staging and prognostication are utilized in the cardiology, rheumatology, pulmonology and infectious disease specialties. The progression of chronic, life-limiting diseases may be slowed or put into remission by medical therapies and lifestyle modification. In this way, prognosis can be modified and quality of life improved. As a disease advances over time and the effects of aging influence response to treatment, it becomes prudent for the healthcare provider to determine with the patient which medical measures continue to be meaningful.

It is not the focus of this study to examine disease-based prognosis. However, it is necessary to consider the underlying principles of prognostication in chronic disease management in order to understand the trajectory of an illness, perceptions of quality of life, and what informs people in making decisions regarding goals of care. Disease-based prognostic models have been primarily used during the diagnostic phase of treatment. During a healthcare crisis, it becomes necessary to evaluate prognosis from a mortality perspective, rather than a response-to-treatment perspective. The next section will examine the literature on prognostication in the acute care setting, which in turn influenced subsequent studies in long-term care.

Acute Care Prognostic Models

One of the first attempts to classify critically ill patients was the creation of the Acute Physiology and Chronic Health Evaluation (APACHE) prognostic model. This model predicts risk of death by measuring severity of illness in the ICU population and assigning a score. From information readily available in the medical record, investigators compared mortality and outcomes of ICU patients to physiologic measures for each day in the ICU. Validity was confirmed, as well as sensitivity to all measures (Knaus, Draper,

Wagner, & Zimmerman, 1985). In a validation study of a revised version of the APACHE, Knaus, et al. (1991) found that a five-point increase of the patient's APACHE score was associated with a significant increase in hospital death. Overall, risk estimates were within 3% of actual mortality in this study. This has proven to be a valuable tool for estimation of risk of death when completed on the first day of ICU admission. Figure 2.5 below illustrates the survival curve for a sample population of patients with subdural hematomas, sepsis, pneumonia, and gastrointestinal perforation.

Figure 2.5

Relationship Between APACHE III Score and Predicted Risk of Hospital Death (Knaus, W., et al., 1991).

Other authors have studied the APACHE model to determine utility in patient populations such as abdominal sepsis (Bohnen, Mustard, Oxholm, & Shouten, 1998); Multiple Organ Failure Syndrome (Cerra, Negro, & Abrams, 1999); resource utilization and mortality in Coronary Artery Bypass Graft (CABG) patients (Becker et al., 1995); and renal failure (Maher et al. 1989). In conjunction with physicians' predictions, the

APACHE model has proven useful in prognosis of critically ill patients, although it is not used in all hospitals.

Even in the presence of available prognostic models, it was clear that patterns of treatment were not changing. It was theorized that creation of support mechanisms in addition to prognostic systems would influence the delivery of inappropriate care to patients who were expected to die within a short time frame. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) trial was a pivotal study of five academic medical facilities that sought to examine outcomes and clinical decision-making in ICU and non-ICU patients (Knaus et al., 1995). One aim of the study was to determine if prognostication could be improved upon, beyond existing tools and clinician experience. Unique to other studies on prognosis, patients were followed for 180 days after hospitalization and were not severely physiologically imbalanced or critically ill (Knaus et al., 1995). This study was conducted in two phases, and observed the process of decision-making and patient outcomes. The first phase consisted of the development of a prognostic model and phase two compared the SUPPORT model to an existing prognostic model and to individual physician's prognoses for their patients.

The phase one SUPPORT prognostic score was based on the disease category, degree of physiologic abnormality, estimates of the patient's long-term health, and the number of hospital days before entry into the study (Knaus, et al., 1995). The SUPPORT prognostic score was calculated on day three of the study, and proved to be the important predictor of survival. The Glasgow Coma Scale score was the most significant predictor of death. Most patients want to know their prognosis and current thought supports use of

prognostic estimates due to “. . . evolving professional and societal consensus...that prognostic data should be shared in the context of the patient-physician relationship, which is based on trust” (Knaus et al., p. 196). The investigators concluded that the SUPPORT prognostic score should be used in conjunction with the physician’s estimate of an individual’s mortality risk. This was an important step forward in creating tools for clinicians to guide patients and families in decision-making.

Phase two of the SUPPORT study utilized an intervention to conduct a cluster randomized controlled trial based on the prognostic model developed in phase one. Study nurses reviewed hospital admissions and ICU patients daily to determine eligibility of patients, and facilitated discussions and patient care conferences. Discussions included appropriate diagnostic and prognostic information, and determination of patient and family understanding of disease prognosis and treatment. Study outcomes were 1) timing of written Do Not Resuscitate (DNR) orders; 2) patient or proxy discussions with the physician occurring in the first interview on preferences for withholding resuscitation; 3) days spent in the ICU; 4) pain analyses; and 5) resource utilization. These outcomes were chosen as they represented common EOL quality of care indicators.

Four of the five outcome measures showed no difference between the experimental and control groups. Pain analysis was the only outcome that showed a difference, with the intervention group having slightly higher reports of pain than the control group. This could be explained by the increased awareness of pain as a priority of care in the intervention group. Unfortunately, half of the conscious patients in the study reported moderate or severe pain in the last days of life. All other interventions were not statistically significant for improvement. The findings were surprising; as it was

commonly thought that more focused resources on complex EOL decision-making would improve outcomes. This was not the case. It is disappointing that prior recommendations from EOL experts for improved processes and communication failed to produce the desired outcomes. However, patients, families and physicians reported high satisfaction scores with the personnel and processes that supported care. One of the strengths of the SUPPORT study was demonstration of a study design that reflected the many elements involved in care of the seriously chronically ill patient.

Soon after the initial SUPPORT studies were published, researchers at Stanford University Hospital in San Francisco shifted the perspective from predicting mortality calculated from scores of abnormal physiology (as determined by the APACHE III model) to estimates of ICU care that is potentially ineffective (Esserman, Belkora, Jeffery, & Lenert, 1995). They reasoned that mortality was not necessarily an indicator of ineffective care. Retrospectively analyzing APACHE III scores from day one and day five in the ICU, the investigators constructed a model predictive of Potentially Ineffective Care (PIC). Threshold levels were calculated from the APACHE III scores that were sensitive and specific enough to categorize subjects into PIC or non-PIC groups. Early identification of PIC patients was necessary to shift clinical efforts to a supportive focus. If patients had not responded to treatment by day five, then they were grouped into the PIC category.

Effectiveness of the model also depends on resource utilization savings. The investigators applied a supportive care guideline to the database sample after determination of PIC was made. This allowed interventions of high care intensity to be limited and cost savings projected. 12.9% of the ICU patients in the sample used 32% of

the resources. Implementation of a supportive care guideline in PIC patients was projected to save \$1.7 million over the six-month study period. As compelling as the results of the PIC study were, it was clear that physician behavior change needed to accompany use of the model in order to realize resource savings and the shift to supportive care for PIC patients.

One of the strengths of the SUPPORT study was that it followed patients beyond a short-term time frame, and analyzed mortality at 180 days. This was significant, as prior studies concentrated on survival until discharge from the intensive care setting or from the hospital. It was suspected that long-term survival was not realized despite aggressive measures during hospitalization, which was validated by the SUPPORT study. Another surprising finding was that age was not a significant factor in survival, which was contrary to popular thought.

The SUPPORT study generated a number of other research studies based on the same sample of participants. Hamel and colleagues (1999) examined the effect of age on short-term survival, independent of aggressiveness of care and patient characteristics. It was demonstrated in this sample that elderly people receive less aggressive treatment than younger patients with the same diagnoses. This was not, however, due to less intensive care care. Contrary to popular thought, age had only a small effect toward increasing short-term mortality; more influential were diagnosis and severity of illness. The investigators concluded that age was not an independent factor in short-term mortality.

In a follow-up to the previous study, Teno and colleagues investigated hospitalized elders (80 years and older) to develop a predictive model that estimated

mortality at ten months post-hospital admission (Teno et al., 2000). The investigators coordinating the Hospitalized Elderly Longitudinal Project (HELP) were able to predict survival by analysis of routine hospital admission data. In addition to hospital-generated database information, the study elicited patients' and families' preferences for life-extending or life-foregoing treatment in the future. Physicians were asked a similar question about patient preferences, in addition to offering an opinion about whether they thought the patient would survive for two months following enrollment. The authors cited previous research confirming that congruent patient and physician preferences for treatment resulted in shorter life spans. In this study, only the physician's perception of patient preference predicted survival time. This area of interest requires further research to explain any correlation between mortality and physician's perceptions of patient preferences for life-extending treatment. This added to the body of knowledge of survival prediction by identifying a potential confounding variable (the physician's perceptions), and by demonstrating that age has only a modest relationship to mortality in the seriously ill. These findings are relevant to the proposed study, as nurses collect prognostic data during the course of normal assessment processes in NH. Therefore nurses have access to information that informs prognosis, and can facilitate goals of care discussions upon screening evaluation of mortality risk.

The final study to be discussed related to acute care is the Veterans Administration study by Walter et al. (2001) that examined one-year mortality in older patients after hospitalization. Using data accessible at time of discharge, investigators identified risk factors that were hypothesized to be associated with one-year mortality and measured each risk factor against mortality in a derivation and a validation cohort (from a

local community hospital). The final set of six risk factors was developed into a bedside tool with a simple point-scoring system. Upon completion of the tool, points were totaled and the score evaluated for placement in each of the quartile risk designations. The prognostic index demonstrated validity and stratified patients into risk categories. The model was shown to have good calibration and discrimination, as well as generalizability. This tool can be useful across care settings, provided access to data at discharge is available. For those patients who are discharged to NH, this information can guide discussions regarding treatment decisions and subsequent hospitalizations, or serve as additional validation of future assessments and alterations in the treatment plan.

Prognostic Models in Nursing Homes

The development of prognostic models in NH has followed a similar path as that of the acute care models. In numerous studies, retrospective samples from the MDS have been cross-referenced to state and national databases or the Medicare database to validate survival within a certain time frame, or to stratify risk of death (Abicht-Swensen & Debner, 1999; Hirdes, Frijters & Teare, 2003; Mehr et al., 2001; Mitchell et al., 2004; Porock, et al., 2003; and van Dijk et al., 1999). Residents of NH usually have comorbidities, poor functional status, and are frail but stable. Detecting subtle instabilities of health can be challenging in any patient population. NH caregivers are familiar with variations in mood and communication of the residents, and therefore, may not detect changes until they are more pronounced, and require more intense care. Instabilities of health can be thought of as a consequence of frailty, which makes a person more vulnerable to stressors of a medical, environmental or psychosocial nature (Hirdes, Frijters, & Teare, 2003). Given the common scenario of catastrophic decline or failure to

rehabilitate after an adverse event (e.g. falls, pneumonia) in NH residents, it is logical to proactively evaluate risk of death in a fashion that is efficient and accurate. The following descriptions of prognostication research in NH residents demonstrate that there are overlapping variables, and several methods of accomplishing this outcome.

Most retrospective survival studies in NH residents focus on specific diseases and have an end-point set at the six-month mark. That is, survival is calculated six months from the date of the first MDS assessment. This time frame coincides with the criteria for hospice admission, which requires that patients receiving the hospice benefit are thought to have six months or less to live. It is hoped that identification of reliable prognostic indicators can support the decision to forego aggressive care in people who do not have long to live, and facilitate hospice admission.

An international group of investigators examined the correlation between mortality and multiple comorbidities in NH residents (van Dijk et al., 2000). Because functional status, disease, gender and age are common influences on mortality, van Dijk and colleagues used regression analysis to determine which comorbidities had a synergistic effect on mortality. The sample was followed out to one year to determine survival. Contrary to expectations, no disease combinations demonstrated synergistic effects, after controlling for age, gender, and functional status. Not unexpectedly, cancer, heart failure, renal failure, Chronic Obstructive Pulmonary Disease (COPD) and diabetes were strongly related to one-year mortality.

This study is unique in design among other NH survival models, as it utilized regression analysis rather than the Cox Proportional Hazards analysis. However, the authors stated that the results were not essentially different from the proportional hazards

model. The value that this study added in the evolution of prognostic models for NH residents was that there was no demonstrable merit to comorbidities in a survival analysis. Subsequent investigators have included diseases into their models, but not the presence of multiple diseases in the scoring systems.

Other researchers have focused on using the MDS to estimate short-term mortality of NH residents in specific situations. Abicht-Swensen and Debner (1999) analyzed NH residents on hospice to determine indicators of short-term mortality. They found that a decrease in functional status resulted in death within 15 days for 74% of the sample. Functional status decrease was defined as a significant decline in communication, ADLs, incontinence and nutrition. These were strong predictors regardless of age, gender and diagnosis. Although this information can be valuable to staff and families, it does not add significant knowledge to the body of work on estimating prognosis to reassess goals of care.

Several years later, Mehr and colleagues (2001) examined NH residents with Lower Respiratory Infections (LRI), a common cause of mortality and functional status decline. The purpose of the study was to determine 30-day survival in residents with the diagnosis of LRI. A point-scoring system allowed the investigators to stratify the sample into risk categories. More than half of the sample had a relatively low risk of mortality. The value of these results lies in the ability to identify NH residents with a higher risk, in order to approach the treatment plan in a manner that improves chances of survival or a shift to comfort care.

Another diagnosis with a perplexing prognosis is that of dementia. In recent years, hospices have expanded their scope of admission diagnoses to include advanced

dementia. Many people with dementia enter NH because of behavioral and safety problems, rather than a serious decline in functional status. Yet, this patient population has a great need for symptom management and comfort, and individuals are not able to communicate their needs. Families experience great distress as well, and need support as their loved one becomes less and less accessible. Thus, patients are appropriate for hospice support. More recently, hospices have been challenged by regulatory bodies to demonstrate that advanced dementia patients have a six-month prognosis (L. H. Sumner, personal communication, January 18, 2007).

Studies that have evaluated dementia and its correlation to mortality have shown that it is not an independent predictor of survival (Glare, Eychmueller, & Virik, 2003; Hamel et al., 1999; Lau et al. 2006; and Van Dijk et al., 2000). Even in residents with advanced dementia, time to death has been difficult to estimate. Use of the Functional Assessment Staging (FAST) scale has been the standard of care for dementia assessment, and has been incorporated into several prognostic models. A subset of the MDS, the Cognitive Performance Scale (CPS) has also been used in this manner. Neither tool was created for, or is primarily used to estimate survival but rather, is intended to stage dementia.

A multi-state, longitudinal study sought to create a prognostic model to evaluate NH residents with advanced dementia for survival. Resident data from the MDS for New York and Michigan NH were analyzed to stratify risk, using a derivation and a validation cohort (Mitchell et al., 2004). Results from both cohorts were statistically similar, and the Area Under the Receiver Operating Characteristic (AUROC) scores were 0.74 and 0.70 for the derivation and validation samples, results which indicate good specificity and

sensitivity. AUROC scores are utilized to demonstrate probability of an event, and have been used in healthcare for many years to aid in decision-making (Wikipedia, 2007). The risk score from this MDS-derived index was shown to be superior to the FAST scale for predicting mortality in residents with dementia.

The preceding studies were based on data derived from the MDS and addressed disease-specific conditions, or were created to estimate mortality when NH residents were already known to be dying. As prognostic models have evolved over the last decade, more sophisticated methods have been employed to refine and strengthen the studies. Of interest is that the MDS is used outside of the United States with populations similar to American NH. Validation of prognostic models elsewhere increases the generalizability of such models, and provides more decision-making tools to clinicians. Some of these studies have provided baseline data for NH residents regarding survival in certain circumstances, but are sophisticated in design, and may require data retrieval from several sources. Some models require a learning curve to implement in the organizational support structure because they must be built into the routine of care and documentation. Most of the models assert that they are simple tools to use, and rely on readily retrievable data. Two recent studies demonstrate a simple scoring system that supports the claim of utility (Hirdes, Firjters, & Teare, 2003; and Porock et al., 2005), and truly rely on readily available data from MDS items.

In 2005, researchers in Missouri further refined the analysis of mortality using the MDS, and corrected for limitations noted by investigators in prior studies (Porock et al., 2005). Using a retrospective design, MDS items with a potential to correlate with dying or poor prognosis were isolated into the categories of demographics, diseases, clinical

signs and symptoms, and adverse events (Porock, et al., p. 492). Cognitive performance and functional status were represented by MDS items known from previous research to be reliable indicators for these constructs.

The sample consisted of all Missouri NH residents over 65 years of age who were admitted to NH in 1999. Files that were missing last name, sex, or Social Security Numbers (SSN) were excluded from the data set. Seventy-five percent of the sample became the developmental or derivation cohort, and twenty-five percent was designated for the validation cohort. This allowed testing of the model testing from a similar sample. Fourteen variables were determined to comprise the MDS Mortality Risk Index (MMRI), whose items were calculated through stepwise regression. Discrimination and calibration were demonstrated by distribution of the Kaplan-Meier survival graph and a satisfactory match of expected and observed deaths in each decile, respectively (Porock et al., p. 494). One limitation of this study was the lack of ethnic diversity. The study proposed by this author addresses that limitation by developing the study sample from an ethnically diverse NH population in southern California.

Prior to the Porock et al. study (2005), Hirdes, Frijters & Teare (2003) conducted a retrospective analysis of residents of a Complex Continuing Care (CCC) hospital in Toronto, Canada. CCC hospitals are similar to American NH, but house patients with far more complex medical conditions, including neurological and degenerative disorders. Residents typically stay for years, post-hospitalization, or are admitted from the community due to clinical deterioration (Hirano, 2003). The Canadian Institute for Healthcare Improvement has required CCCs to utilize an assessment system similar to the

MDS requirement from OBRA '87 for American NH. As a result, Canadian long-term care facilities utilize the MDS for assessment and quality trending purposes (CIHI, 2004).

In this retrospective study, investigators sought to explore whether subtle instabilities of health could be detected prior to imminent catastrophic decline. Instability of health was thought to be a component of frailty, which is difficult to observe, but is a common description of institutionalized patients. The study was designed to determine whether health instabilities were correlated with survival.

Using the MDS database, a sample was created from residents admitted to CCCs from July, 1996, to May, 1999. MDS items that were thought to be indicators of changing health status were derived from three sections of the MDS – Changing Health, End-stage Disease, and Symptoms and Signs of Medical Problems (Hirdes, Frijters & Teare, 2003). This was a novel approach to estimating prognosis, as most other prognostic models incorporate functional and cognitive status as key indicators. The MDS-CHESS scale does not do so.

The proportional hazards model was used to examine the relationships between the items constituting the MDS-CHESS scale and mortality. Items were required to achieve a hazard ratio of at least 1.5, and a p-value of less than 0.05 for inclusion in the scale. Six score levels were identified from stratification, ranging from 0 (no instability) to 5 (highest level of instability) (Hirdes, Frijters, & Teare, p. 98). Associations with functional and cognitive status, as well as depression, were weak, indicating a distinctly different domain was being measured in the MDS-CHESS scale.

The MDS-CHESS scale was determined to be a brief, simple scoring system that has use in daily practice to detect health instabilities. MDS assessments are done upon

admission to long-term care, quarterly, and with a significant change in health status. Therefore, there may be changes that go undetected for some time before another assessment is done, and data can be retrieved for scoring in a prognostic index. The MDS-CHESS scale contains nine items, all of which can easily be determined by a brief chart review, or in conversation with NH caregivers.

The investigators of this study recommended that it be replicated in a typical long-term care facility containing a more stable, chronically ill population than the higher-intensity residents of the CCCs. A limitation of this study was that there was no mechanism to determine if residents discharged from the CCCs had died within the six-month time frame. Therefore, there is missing data of an undeterminate volume, as the authors did not include the actual percentage of residents for whom survival could not be confirmed after discharge. The investigators were unable to cross-reference missing resident data with a vital statistics database for unstated reasons. Therefore, a replication design would have to include cross-referencing with a governmental database that includes mortality statistics.

This study seeks to replicate the Canadian study by Hirdes and colleagues (2003), rather than the Porock et al. study of 2005. Testing of the MDS-CHESS scale rather than the MMRI has several practical rationales. First, the settings from which the sample will be derived is more ethnically diverse and medically stable than that of the Canadian CCC hospital, but are hospital-based and have post-acute short-term rehabilitation patients. This approach follows a research recommendation of the Canadian investigators. Secondly, the items on the MDS-CHESS scale reflect instability of health, which can alert NH practitioners to conditions that are potentially reversible, or to those conditions

for which interventions can improve comfort in those residents who are not actively dying. The MDS-CHESS scale items are also fewer in number than those on the MMRI. The items that comprise the MDS-CHESS scale are predictive and

independent of age, gender, and disease. With the MMRI and other prognostic scales, common diseases like cancer and heart failure are built into the scoring systems.

American NH routinely provide interventions such as intravenous fluids, and the sample settings have attentive physician presence routinely (both are MDS-CHESS items). It is reasonable to expect that physician change orders and visits will accurately reflect clinical decline. Many NH do not have the level of physician presence because they are not hospital-based as the sample NH are in the proposed study. This could be a confounding variable if samples were derived from hospital-based and non-hospital-based settings. Broader sampling may be included in the design of a follow-up study.

In summary, the literature regarding prognostic models provides a diverse menu of research opportunities. Refinement of design has proceeded more rapidly than implementation of prognostic models in clinical practice. Virtually all investigators engaged in this line of inquiry recommend testing in alternate settings to confirm generalizability of the model. However, it is unknown whether these predictive models are routinely used in practice after the research study. Many research instruments are created to meet specific clinical needs, yet are not implemented systematically, or evaluated for long-term utility and ease of use. The next section of the literature review addresses the significance of structure and process in adding to the value of prognostic models.

Quality Health Outcomes Model

The Quality Health Outcomes Model (QHOM) was originally described by Mitchell, et al. in 1998 and was a refinement of Donebedian's quality framework. The main elements of this classic quality model are structure, process and outcomes. Many healthcare organizations have used this model as the basis for quality programs. Rather than one element of Donebedian's framework producing a change in another, the QHOM reflects a dynamic, interrelated system that flows in many directions, and whose elements all affect each other. A unique feature of the QHOM is the lack of direct flow between interventions and outcomes (see Figure 2.6).

Figure 2.6

Quality health outcomes model. (Mitchell, P., Ferketich, S., Jennings, B., 1998)

Several investigators have used the QHOM as a framework for nursing research design. Radwin and Fawcett (2002) approached model integration in a unique way. With the aid of a theoretician (Fawcett), Radwin retrospectively reviewed her own previous studies on disparate topics and retrofitted the QHOM into the research design. The

researcher concluded that the model was a good fit for her program of research (p. 360). The model was incorporated into a proposed study and several other future studies were designed to examine different constructs of quality oncology nursing care.

This application of the QHOM is relevant to the study described here.

Prognostication of mortality in the NH and subsequent goals of care discussions rely on the flow of information between the involved parties. Interventions will not necessarily result in the desired outcome; much depends on the interrelationship between patient and organizational characteristics as well as timing.

Mayberry and Gennaro (2001) used the QHOM to describe using the QHOM framework for research and quality activities with second-stage labor patients. The interdisciplinary nature of the setting and multiple possible outcomes from the labor were explained clearly with integration of the model into nursing practice. The interrelationships between the patient, system, interventions and outcomes provided ideas for future research studies. The authors concluded that research studies based on the QHOM have the ability to influence health policy in the future.

Chapter Three

METHODOLOGY

The purpose of this study was to examine the survival of a cohort of nursing home residents and to determine whether the MDS-CHESS scale accurately predicts mortality within six months after admission to a nursing home. This chapter provides a description of the research design, sample and sampling, instrumentation, data collection procedures and data analytic techniques. The protection of human subjects is also discussed.

Research Design

This retrospective correlational cohort study was conducted to examine mortality in residents of two nursing homes (NH) in southern California. Retrospective design is useful when working with large national sample, as the data has already been collected and can be accessed at any given point in time. Publicly reported data, such as that in the Minimum Data Set (MDS) database also allows evaluation of a construct at time intervals to determine selected endpoints. Additionally, with large samples, a representative sample of the population is more likely, as is adequate power for the study. Of added benefit, this type of research lends itself to addressing nursing concerns. The sample for this study was derived from two NH that are situated within the same comprehensive healthcare organization. The rationale for selecting organizationally-linked NH is to have the ability to determine variance among the cohorts if possible, given that they are governed by identical regulatory and procedural rules. Understanding any differences may be of benefit in future intervention studies.

Sample and Sampling

Data was obtained from the MDS 2.0 database, which is the federal database for NH that was first implemented in 1991, becoming a computerized process in 1998. Version 2.0 is an upgrade of the original software that contains modifications that support data analysis by making assessment items less ambiguous. Hawes et al. (1995) conducted reliability testing of the MDS in an effort to, “. . . enhance the reliability of the MDS, [provide] the results of the final reliability testing of the MDS items, and [discuss] the usefulness of the MDS in research efforts” (p. 173).

The items of the MDS-CHESS subscale were compared to actual mortality rates to determine the accuracy of the scale in predicting death within six months of admission to a nursing home. The sample was comprised of all residents admitted to two NH facilities, who had an admission RAI submitted to the MDS during the calendar year 2005. Working with a large national data set is advantageous when using a study design that includes multivariate analyses (Zeni & Kogan, 2007).

The sample for this study was taken from the MDS database of nursing homes that receive Medicare reimbursement. The sample was derived from all residents over 65 years of age that were admitted to two LTC facilities in a large urban area in the southwestern United States during the calendar year 2005. The advantage of this sampling method is that it is theoretically convenient and accessible, with less risk of missing data and adequate power. The disadvantage of this sampling method is that the data may be skewed by atypical LTC residents, such as post-acute residents who had a short-term stay in the NHs for rehabilitation after hospitalization. No published studies

were found that derived the sample from less than several thousand subjects and multiple nursing homes.

The sample consisted of NH residents with completed MDS admission assessments during the calendar year 2005. Data on mortality was also collected during the time period of 2005-2006. In this study, the completion of the first Resident Assessment Instrument (RAI) was compared to the death date. Because a discharge from the NH is not necessarily linked to death, this study required alternate methods of determining whether a resident was, in fact, still alive. Residents may die in a hospital, be transferred to another jurisdiction, or may survive beyond the end of the data collection period. From previous studies on death in NHs, it is expected that some residents would be unaccounted for, and would have to be eliminated from the study sample. To gather accurate mortality data, Medicare claims data was collected to determine date of death. Regardless of the setting in which a Medicare beneficiary died, a date of death can be linked to Medicare claims.

Power, Effect and Sample Size

In order to determine significance of statistical results, one must have an adequate sample size and minimize the possibility of “. . . drawing the wrong conclusion . . . with an errors of inference” (Munro, 2005). The chance of making a type I error is minimized by setting an adequate alpha level, or level of significance (Munro, p. 88). For this study, the significance level was set at 0.05; p -values less than or equal to the alpha level are considered statistically significant. Power is defined as the probability of detecting a difference or relationship if such a difference or relationship exists (Munro, p. 92). Providing adequate power in the sampling decreases the chance of making a type II error.

A power of .80 has been chosen as an adequate level to prevent this error (Munro, p. 100). Effect size was set at 0.5 for this study to determine the magnitude of the influence of the independent variable on the dependent variable. Using the power table provided in Hinkle, Weirsmas and Jurs (2000), a minimum sample size of 155 was required for this study for correlation testing.

In logistic regression, however, an estimate of the probability of a certain event occurring is made, rather than detecting the difference or relationship that may be present, such as in linear regression. No assumptions are made about the DV and IV, the relationship is non-linear, and is not normally distributed (Munro, 2005). In linear regression, the significance level is usually set at 0.05., as was the case in this study. P-values less than or equal to the alpha level are considered statistically significant.

Inclusion and Exclusion Criteria

Inclusion criteria were residents over the age of 65 who had an admission Resident Assessment Instrument (RAI) completed in the MDS database sometime in calendar year 2005, and who died between June 30, 2005, and June 30, 2006. Exclusion criteria were residents under age 65 and those without a date of death in the Medicare claims database.

Data Collection Procedures

Although aggregate Medicare claims and patient care information is considered to be publicly reported and accessible in the United States, the information is not readily available to the general public through visitation to an internet web site or other direct methods. In order to collect data using one of the Medicare data sets, an investigator must progress through several phases of development, assisted by two agencies designated by

the federal government to prepare the data request and create the data files. This section of the paper describes data collection procedures implemented by the investigator to obtain MDS data, and the phases of development that accompanied the data collection procedures.

The Research Data Assistance Center (ResDAC) specializes in the “conversion of raw data into usable data sets” and assists the investigator to understand “Medicare and Medicaid program policies and coverage issues”

(http://resdac.umn.edu/aboutus/resdac_services.asp#free, 2008). Their services are essential in determining which data files and variables to request, and whether additional data is needed from another source. ResDAC staff assisted the investigator to create the data request and complete the necessary documentation to submit to the CMS Privacy Board. The purpose of the CMS Privacy Board is to ensure that data requests are for the purpose of improving the quality of care or decreasing costs for Medicare beneficiaries, and that there are adequate safeguards for protected health information (PHI) after receipt by the investigator. For this study, MDS assessment and demographic data was requested, as well as mortality data. Assessment data was required from January to December, 2005, and mortality data from June, 2005 to June, 2006. Because not all of the NH residents died during their stay at the two facilities, information across the continuum of care was needed. CMS contracts with another agency to provide access to beneficiary data across the care continuum.

The Chronic Conditions Warehouse (CCW) was created in response to the Medicare Modernization Act of 2003, as part of the CMS plan to “. . . improve the quality of care and reduce the cost of care for chronically ill Medicare beneficiaries”

(<http://www.ccwdata.org/about.php>, 2008). Assessment and claims data on chronic illnesses are collected and linked by a unique beneficiary identification number, which allows analysis of care across the continuum. The Iowa Foundation for Medical Care (IFMC) contracts with CMS to establish and maintain the CCW. Assessment and claims data on 21 chronic conditions is collected at the CCW, and custom data requests are also completed on an individual basis.

A custom request was submitted for this study and the IFMC created data files in SAS[®] software once the CMS Privacy Board approved the data request and payment was received. A CD-ROM containing compressed, encrypted data files was mailed to the investigator. A separate electronic communication was sent from IFMC containing decryption instructions and a secure password for accessing the data files. Support files, such as a user's manual, were also included on the CD-ROM. Technical support from IFMC was available throughout the data transfer and analysis process.

Another feature of acquiring data from a federal database that is worthy of discussion are the distinct phases of progress identified by the investigator. Phase One involves knowledge acquisition regarding the components and syntax of that particular database. In this study, knowledge of the MDS instruments and terminology was acquired over a period of several months as data request documents were completed. Previously published studies provided valuable information regarding data elements included in the sample and related terminology. Without prior working knowledge of the MDS instruments and Medicare claims terminology, the learning curve was steep and necessitated multiple reference sources to dialogue with support staff.

Phase Two was characterized by identification of potential barriers from the technological perspective, such as availability of computer hardware considered to be secure by the CMS Privacy Board. For example, plans to place the study data on an organizational network such as a hospital system or university had to include detailed descriptions of Information Technology (IT) security at a level unknown to the average user. Discussions with the IT Security Officer at the healthcare system for the two NH revealed that additional security measures for the organizational network would have been necessary in order to meet the required CMS standards. This barrier was overcome by the decision to locate the data on an independent computer system without internet access in the investigator's home. The password-protected computer met the CMS security standards, as the risk of computer hacking and obtaining access to PHI was negated by lack of internet access.

Phase Three of the data collection process was that of data acquisition and delivery from the IFMC. Adequate time must be allotted for data request review by the CMS Privacy Board, receipt of payment by CMS and delivery of the data files. This may involve four to six months from submission of data request documents. This timeline must be carefully considered to coordinate with other activities such as grant submission, study funding, and availability of support staff. For this study, approval of the data request was delayed for several months due to the volume of requests to the CMS Privacy Board. In summary, knowledge of data documentation requirements, familiarity with requested data elements and adequate time for approval of the data request must be carefully considered throughout the research process.

Data Analysis

Hirdes, Frijters and Teare (2003) suggested in their original study on the MDS-CHESS scale, that validity of the instrument be evaluated in an alternate setting that includes stable LTC residents. The original study was conducted in a Canadian Chronic Care (CCC) hospital, where the residents had complex and somewhat acute needs, unlike the typical American NH resident. The prognostic value of the scale was demonstrated in the CCC population. Prognostication is inherently difficult, and existing instruments can have a substantial variance with actual mortality rates. A validated screening tool that accurately predicts mortality in NH residents can assist the clinician to quickly evaluate a patient's burden of illness during an acute health crisis and guide discussion regarding goals of care. The ability to evaluate the crisis within the context of the individual's overall health can be an important part of decision making regarding goals of care and treatment.

Dependent Variable

The dependent or outcome variable in this study was mortality. Specifically, the evaluation measured the point in time from completion of the RAI (upon admission to the NH in 2005) to six months in the future. This measurement occurred within the confines of the 2005-2006 calendar years for these two LTC facilities. Therefore, the outcome (death) could have occurred anywhere from June 30, 2005 to June 30, 2006.

Independent Variables

Descriptive statistics were computed on the demographic variables of age, gender, and ethnicity. The MDS-CHESS instrument consists of nine items from the MDS RAI, and was used to analyze: Do-Not-Resuscitate (DNR), daily pain, parenteral I.V. access,

I.V. medications, oxygen, suctioning, any physician visit in the last two weeks, any physician change order in the last two weeks, and any abnormal lab values in the last 90 days. Using the definitions provided below the MDS nurse entered assessment items according to documentation requirements.

- **DNR Order** – in the event of respiratory or cardiac failure, the resident, family , or legal guardian has directed that no cardiopulmonary resuscitation (CPR) or other life-saving methods will be used to attempt to restore the resident's respiratory or circulatory function; either present or absent in the medical record.
- **Daily Pain** – any type of physical pain or discomfort in any part of the body; either present or absent.
- **Parenteral or Intravenous (I.V.) access** – device to permit intravenous medication or nutritional support delivery; either present or absent in the last seven days.
- **I.V. medications** – any drug or biological given by intravenous push or drip through a central or peripheral port. Does not include heparin or saline flush to keep a heparin lock patent but does include epidural and intrathecal pumps and total parenteral nutrition (TPN). This item does not include I.V. medications administered only during dialysis or chemotherapy treatments. Item is either present or absent in the last 14 days.
- **Oxygen** – continuous or intermittent oxygen via a mask, nasal cannula or other device; either present or absent in the last 14 days.
- **Suctioning** – nasopharyngeal or tracheal suctioning is either present or absent in the last 14 days.

- **Physician visits** – any visit in the last 14 days by an MD, DO, podiatrist or dentist who is either the primary Physician or Consultant; also includes authorized Physician Assistant, Nurse Practitioner, or Clinical Nurse Specialist working in collaboration with the Physician, and excludes Medicine Men and licensed Psychologists. An examination described by this coding may be a full or partial exam at the facility or in the Physician's office, or an unscheduled examination by an Emergency Room Physician, for which frequency is recorded in the last 90 days. The actual number of visits is documented.
- **Physician change orders** – any orders for new or altered treatment in the last 14 days by an MD, DO, podiatrist or dentist who is either the primary Physician or Consultant; also includes authorized Physician Assistant, Nurse Practitioner, or Clinical Nurse Specialist working in collaboration with the Physician. Orders include telephone, fax, or consultation orders, even those new or altered orders given on the day of admission that fall outside of standard admission orders. The number of days on which Physician orders were changed is recorded.
- **Abnormal lab values** – any lab values that are abnormal when compared to standard values that are recorded in the last 90 days or since admission to the nursing home. This item includes abnormal fingerstick glucose values and is either present or absent.

MDS assessments have been validated in numerous studies since its inception, and a variety of research studies have been conducted since that time (Fredericksen, Tariot & De Jonghe, 1996; Hawes et al., 1991, 1995, & 1997; and Morris et al., 1990). Items for the MDS-CHESS scale were derived from the MDS RAI, which is completed

within 14 days of admission to the NH, quarterly, annually and when changes in clinical condition occur. The MDS-CHESS items were identified from “. . . bivariate analysis of their relationships with mortality in the proportional hazards model” (Hirdes, Frijters, & Teare, 2003). Items that met an acceptable hazard ratio were included in the model and were validated to measure independent constructs. Since the MDS-CHESS items were validated in the original study, the analysis in this study focused on determination of whether the scale was an appropriate instrument to predict mortality in the two sample nursing homes.

Descriptive and multivariate statistics were calculated to perform a secondary data analysis. Demographic variables such as age, gender and ethnicity were used to create a profile of the sample using descriptive measures. Age, sex and ethnicity were compared to mortality and items on the MDS-CHESS scale and are reported as an aggregate. Interestingly, age and Do-Not-Resuscitate status were not correlated with six-month prognosis in the original study (Hirdes, Frijters & Teare, 2003).

Several statistical approaches were utilized to analyze the data. Correlational statistics were computed to determine relationships among and between the IVs and DV. Logistic regression statistics provided information about the predictive model and how well it fit with the sample. Multicollinearity was analyzed to ensure that variables were measuring different constructs. A demographic profile was created using descriptive statistics.

The Pearson r correlation coefficient was used to determine the index, or strength, and direction of relationships between the IVs and DV (Hinkle, Weirsmas & Jurs, 2003). The correlation coefficient (r) can range from +1.00 to -1.00, indicating a positive or a

negative (inverse) relationship. A value of 0.00 indicates no relationship exists. The strength of the relationship can range from .00-.25 (little, if any relationship) to .90-1.00 (very high relationship). The strength of the relationship is also evaluated with a two-tailed level of significance test at the 0.05 and 0.01 levels, which is reflected in the p-value (p. 245). The p-value is an indication of the probability that the relationship (r) occurred by chance (p. 249). A Spearman rho was used to analyze relationships between the variables, and is similar to the Pearson r. This is useful to analyze curvilinear relationships, in which Pearson r may underestimate the strength of the relationship. While Pearson r requires interval or ratio level data; Spearman rho requires only ordinal data, and is based on the rank order of the values, rather than on the values themselves (<http://www.sfu.ca/~richards/Zen/Pages/Chap18.htm>, 2008). All correlational statistics were computed using SPSS 14.0 Graduate software.

Binary logistic regression analysis was conducted to determine the relationship between each IV and the DV, and therefore, the predictor ability of each IV on the DV. Logistic regression is a useful and appropriate analytic strategy for this study because of the ability to predict the effect of the IV on the DV, as well as the flexibility of using any level of measurement (Munro, 2005). Mertler and Vannata (2005) note that logistic regression techniques can analyze predictor variables of all types - continuous, categorical or dichotomous. Like discriminant analysis, logistic regression can classify subjects into groups, or predict group membership from a probability of zero to one, but does so without the assumptions or linear nature of discriminant analysis (Mertler & Vannata, 2005). Values produced in logistic regression computations are positive, and can be considered probabilities of a particular outcome.

The SAS data files provided by the IFMC were converted into Excel spreadsheets and logistic regression was computed using R software (R Development Core Team, 2008). When analyzing predictor variables, several methods can be employed to create the regression model. Since the predictive model already existed (the MDS-CHESS scale), stepwise, forward or backward entry methods were not used, because the IVs were previously identified in the original study. For the IVs that comprised the model, correlation coefficients were computed, and odds of death occurring versus not occurring were calculated to ascertain the predictability of each independent variable in the model (Mertler & Vannata, 2005).

Munro (2005) describes the concept of relative risk as how many occurrences exist in the total number of occurrences calculated for several conditions (p. 305). The ability to estimate risk is related to predictability of the outcome. Calculating odds ratios for each IV is at least equivalent to relative risk in the logistic regression model (p. 305). Odds ratios less than “1” indicate a decreased risk of an outcome; values greater than “1” are reflective of an increased risk of the outcome (Katz, 2006). The confidence interval (CI) for the odds ratios demonstrate a reasonable range of values expected. A large CI indicates that the sample size may be too small for the analysis being conducted (p. 130). In this study, the odds ratios were calculated for each IV and adjusted for age, ethnicity and gender.

Once it has been determined or confirmed which IVs contribute to the regression model, an evaluation of the overall predictive ability of the model is completed. The likelihood ratio statistic is computed to measure the overall model fit and is reported as a p-value for each IV, given the other predictors already in the model. When results

demonstrate significance ($p < 0.05$) for an IV in the regression model, then the Wald test is done to determine the significance that the IV has on the model when it is either present or absent (Katz, 2006).

Data analysis was designed to either support or not support the prognostic utility of the MDS-CHESS scale and if so, whether it was equivalent to that which is noted in the original study. Alternately, results that do not support correlation between the MDS-CHESS scale and mortality might still be of value in the care planning process.

Additional discussion on this topic is included in Chapter Five.

Human Subjects Protection

In order to ensure the protection of each subject's freedom from intrinsic risk or injury, and to ascertain rights to privacy and dignity, a variety of human subject protective mechanisms was utilized in this study. Approval for the proposed study was obtained from the University of San Diego Investigational Review Board, and the Palomar Pomerado Health Investigational Review Committee. Since this retrospective study was conducted on medical records, no participant informed consent was required.

CMS requires a thorough description of data management procedures in the Data Use Agreement (DUA), a required document for the data request. Since data analysis and results are performed and reported as an aggregate, no Social Security Numbers (SSN) were required. A unique beneficiary identification number permitted comparison of NH admission to date of death. With these safeguards, protection of individual health information was maximized. Data files were provided as compressed, encrypted files on electronic media, and computer security was approved by CMS prior to the provision of data to the investigator.

In this chapter, study design was explored with rationales for sampling and determination of power, effect and sample size. An extensive outline of data collection procedures was given to provide readers with an overview of steps for consideration in future studies. Data analysis procedures were described with a brief explanation of statistical tests used for correlation and logistic regression. Results of the analysis will be discussed in the Chapter Four.

Chapter Four

STUDY RESULTS

The purpose of this study was to determine survival rates of a cohort of NH residents and to determine whether the MDS-CHESS scale accurately predicts mortality within six months. The assessment items from the MDS that comprise the MDS-CHESS scale are DNR orders, daily pain, presence of parenteral IV line, IV medications, oxygen use, suctioning, physician visits in the two weeks prior to assessment, any physician change order in the last two weeks prior to assessment, and abnormal lab values. The presence of these items in the resident's assessment was evaluated for prediction of mortality. Other covariates were age, gender and ethnicity. In this chapter, study results will be presented. First, a descriptive profile of the sample will be presented, followed by the results specific to the research questions.

Sample Characteristics

The dataset provided by the Iowa Institute for Medical Care (IFMC) contained multiple assessment entries, so only admission assessments were used to look forward in time to date of death. After eliminating subjects that did not meet the inclusion criteria, the sample of 212 was further reduced by including only those over 65 years of age who had a death date and those who did not from both facilities. The final sample used for analysis was 191 residents. During the study period, 42 residents from Nursing Home A died, and 39 residents from Nursing Home B died.

The mean age of the sample was 82.35 years, with a standard deviation of 7.04 years, ranging from 65-98 years; 34.5% of the sample (N=66) were male and 65.5% (N=125) were female. The majority of the sample was Caucasian (91.1%, n=174), followed by Asian/Pacific Islander (4.2%, n=8), Hispanic (3.1%, n=6) and African American (1.6%, n=3). Table 4.1 summarizes the demographic profile of the sample.

Table 4.1 *Demographic Profile of Sample*

N = 191	Nursing Home A	Nursing Home B
Sample	110	81
Age*		
Mean	82	82.8
Range	66-98	66-96
Standard Deviation	+/- 7.5	+/- 6.4
Gender		
Male	49 (44.5%)	17 (21%)
Female	61 (55.5%)	64 (79%)
Ethnicity	Asian/ Pacific Islander 5 (4%) Black 2 (1%) Hispanic 4 (4%) Caucasian 99 (91%)	Asian/ Pacific Islander 3 (4%) Black 1 (1%) Hispanic 2 (3%) Caucasian 75 (92%)

* No significant differences were found between the two NH related to age with One-Way ANOVA ($p=.479$)

Descriptive Findings

The primary focus of the study was to determine the accuracy and utility of the MDS-CHESS scale at the two nursing homes from which the sample was derived. Evaluation of the scale in a stable nursing home population can provide insight into future expectations of health decline and the need for interventions that decrease suffering and prolong the dying process. In this study, the intent was to evaluate the model against the population, rather than re-validation of the scale.

Aim #1 Determine the accuracy of the MDS-CHESS scale for predicting six-month mortality in two American nursing homes.

Frequencies were computed on the items comprising the MDS-CHESS scale. Less than 25% of residents in the sample experienced daily pain, used oxygen, had IVs, received IV medication, or were suctioned. Most residents had at least one Physician change order in the 14 days preceding the admission assessment, peaking at 17% (n=33), and 56 residents (29%) had Physician's visits in the two weeks preceding the assessment. Overwhelmingly, residents had abnormal lab values in the 90 days prior to the admission assessment. Only 57 (34%) had a DNR order in the medical record. Table 4.2 includes a summary of the MDS-CHESS variable frequencies and the predictor values for each IV. Because none of the predictor variables demonstrated significance, the Wald statistic was not computed.

Table 4.2 Predictor Variable Descriptives

Variable Name	23	n(%) or mean±SD	Likelihood Ratio (p-value) ^a
<u>Do Not Resuscitate</u> 0 (not present on chart) 1 (present on chart)		57(30%) 134(70%)	0.56
<u>Pain Frequency</u> 0 (no pain) 1 (pain less than daily) 2 (pain daily)		65(34%) 78(41%) 48(25%)	0.96
<u>Parenteral IV</u> 0 (no) 1 (yes)		178(93%) 13(7%)	0.37
<u>IV Medication</u> 0 (no) 1 (yes)		42(78%) 12(22%)	0.18
<u>Oxygen Therapy</u> 0 (no) 1 (yes)		159(82.3%) 32(16.8%)	0.49
<u>Suctioning</u> 0 (no) 1 (yes)		174(91%) 17(9%)	0.53
<u>Physician Visits</u> (actual number) mean±SD		2.92±1.84	0.44
<u>Physicians Orders</u> (number of orders) mean±SD		6.53±2.32	0.31
<u>Abnormal Labs</u> 0 (no) 1 (yes)		198(99%) 2(1%)	0.83
<u>Age</u>		82.35±7.04	0.57
<u>Gender</u> 1 (male) 2 (female)		66 (34.5%) 125 (65.5%)	0.76
<u>Ethnicity</u> 1 (American Indian/ Alaskan Native) 2 (Asian/Pacific Islander) 3 (African American) 4 (Hispanic) 5 (Caucasian)		0 8 (4.2%) 3 (1.6%) 6 (3.1%) 174 (91.1%)	0.13

a. The p-value is from the likelihood ratio test for testing the overall effect of the predictor.

The null hypothesis is that the nine variables on the MDS-CHESS scale do not predict mortality in this sample of nursing home residents. Several statistical approaches were utilized to analyze the data including correlations and logistic regression.

Correlations between the IVs and DV were performed in the original study, and were

repeated in this sample. Additionally, IVs were evaluated for multicollinearity to ensure that different constructs were being analyzed. Logistic regression was used to determine whether presence of the IV predicted the DV, death. The main outcome of this analysis was that 81 out of 191 residents (42.2%) died between June 30, 2005 and June 30, 2006.

Correlation

A correlation matrix was computed to determine the relationships between the IVs (DNR status, daily pain, IV access, IV Medications, oxygen use, suctioning, physician's change orders, physician's visits, and abnormal lab values), co-variables (age, gender, ethnicity and site) and the DV (death). Correlation coefficients demonstrate relationships between IVs, as well as the differences in variance of each IV that can be associated with variance differences in another IV (Hinkle, Weirsma & Jurs, 2003). Correlations between items on the MDS-CHESS scale were significant as noted in the Table 4.3, and demonstrated statistical significance in the p-values for each relationship. All correlations in Table 4.3 were positive, with the exception of DNR/suctioning, DNR/MD orders, and suctioning/abnormal labs, which were inversely related.

Table 4.3 *Pearson Correlation Coefficients of MDS-CHESS Variables*

<i>Pearson Correlation Coefficient</i>			
Variable	<i>r, p values</i>	Variable	<i>r, p values</i>
DNR/suctioning	-.164(*), .024	IV/IV meds	.213(**), .003
DNR/MD orders	-.166(*), .021	IV/suctioning	.208(**), .004
O2/suctioning	.489(**), .000	IV/MD orders	.168(*), .020
O2/MD visits	.178(*), .014	Suctioning/MD visits	.404(**), .000
MD visits/MD orders	.363(**), .000	Suctioning/MD orders	.181(*), .012
		Suctioning/abn labs	-.148(*), .040

*Correlation is significant at the 0.05 level (2-tailed)

**Correlation is significant at the 0.01 level (2-tailed)

These data infer that although the relationships between certain variables are likely to be found in the population, they are not considered to be of substantial importance (Munro,

2005) in a predictive model. Spearman rho correlation coefficients were almost identical to Pearson r and are therefore, not reported in this chapter. No correlation or statistical significance was demonstrated between the DV (death) and any of the IVs, as shown in the Correlation Matrix.

Table 4.4 *Correlation Matrix of Dependent and All Independent Variables*

	Death	A10B	AA2	AA4	J2A	K5A	P1AC	P1AG	P1AI	P7	P8	P9	site	age
death	1.000													
DNR (A10B)	.042	1.000												
Gender (AA2)	.022	.161	1.000											
Ethnicity (AA4)	.068	-.091	.026	1.000										
PAIN (J2A)	.003	-.059	.074	.081	1.000									
IV (K5A)	-.064	-.131	-.066	-.143	.004	1.000								
IV Meds (P1AC)	.097	-.078	-.116	.064	.034	.213**	1.000							
Oxygen (P1AG)	.050	-.010	-.107	-.017	-.045	.126	.022	1.000						
Suction (P1AI)	-.045	.164*	-.160	-.022	-.084	.208**	.057	.489**	1.000					
MD Visits (P7)	-.056	-.134	.005	.053	-.050	.046	.019	.178*	.404**	1.000				
MD Orders (P8)	-.072	.166*	-.083	.036	-.092	.168*	.094	.075	.181*	.363**	1.000			
Abnormal Lab (P9)	-.016	.067	.033	-.029	.055	.028	.046	-.078	.148*	-.060	-.021	1.000		
Site	-.078	-.181	-.245	-.036	-.169	.148	.073	.162	.231	.090	.433	-.088	1.000	
Age	.041	.164	.131	-.027	-.117	-.061	-.196	-.122	-.168	-.099	-.148	.035	-.052	1.000

*Correlation is significant at the 0.05 level (2-tailed)

**Correlation is significant at the 0.01 level (2-tailed)

Collinearity

Multicollinearity is a problem that can occur when there are moderate to high correlations between variables, indicating that they could be measuring the same construct (Mertler & Vanatta, 2005). Collinearity analysis is evaluated by several measures, Tolerance and the Variance Inflation Factor (VIF), which are analyzed as part of the regression procedure. Generally, if there is a high tolerance, only a small percentage of the variance in a variable is shared with the other predictors (p. 288). In this study, oxygen use (P1AG) shares 25% variance with other predictor variables; suctioning

(P1AI) shares 31% variance with other predictor variables. Physician's Visits (P7) and Physician's Change Orders (P8) share 28% and 33% of variance respectively, with other predictor variables. Because the Inflation Factors remain small for these predictor variables and the Tolerance values all exceed 0.1, multicollinearity is not a problem, as shown in Table 4.5 below.

Table 4.5 *Collinearity Statistics*

Model		Collinearity Statistics	
		Tolerance	VIF
1	(Constant)		
	A10B	.882	1.134
	AA2	.891	1.123
	AA4	.940	1.064
	J2A	.928	1.077
	K5A	.857	1.167
	P1AC	.895	1.117
	P1AG	.746	1.341
	P1AI	.588	1.701
	P7	.717	1.394
	P8	.669	1.496
	P9	.960	1.042
	site	.604	1.656
	age	.875	1.143
	■	.816	1.225

a Dependent Variable: death

Note: Constant VI is unique beneficiary number assigned to each set of assessment variables. Site denotes one of the two long-term care facilities. Neither are predictor variables.

Logistic Regression

Logistic regression was then computed to determine which of the IVs affected the probability of the outcome, death (Munro, 2005). The sample analyzed was 191 subjects, which provided enough power to reduce the chance of a Type I error in linear regression calculations. However, in logistic regression, power is less important than the relative risk of a particular outcome occurring. Relative risk is evaluated by computation of Odds

Ratios (OR) with the desired Confidence Interval (CI). Bivariate association between each IV and the DV were analyzed with the likelihood ratio test, which compares observed to predicted values and determines significance (p. 307). Although none of the variables achieved statistical significance, it is difficult to draw any conclusions from the statistics. Lack of significance could be due to the number of variables in the model – nine predictive variables and four demographic variables. Mertler and Vannata (2005) caution investigators regarding limiting the ratio of cases to predictor variables to ensure that an adequate sample is analyzed to demonstrate significance. One of the features of analyzing a data set from an administrative database is that there will be missing data, for which subjects must be excluded in the sample. Once the missing and inaccurate data had been removed from the data set, too few beneficiaries remained in the sample for the number of variables being tested.

Aim #2: Determine whether there are differences in six-month post-admission mortality between two NH populations operated under identical regulatory and organizational rules.

The logistic regression model was analyzed with all the predictor variables, demographics and the SITE variable to determine differences between the two facilities. The only predictors that approached statistical significance were IV medication use and ethnicity. Those who were administered IV medications had a higher risk (OR=2.26, 95%CI 0.97, 5.28) of dying than those who did not. African Americans were more likely to die (OR=18.16, 95%CI - 1.12, 292.41) than American Indians and other ethnic groups. However, the wide CI (95%) for the odds ratio indicates small cell counts, which makes

this inference unreliable. Table 4.6 presents data computed from the regression analysis.

The complete Logistic Regression Coefficients table is included in Appendix A.

Table 4.6 *Logistic Regression Analysis*

Variable Name	Regression Coefficient	OR, 95% CI	p-value ^b
<i>Do Not Resuscitate</i>			
0	----- ^a		
1	0.09	1.09 (0.54,2.18)	0.62
<i>Pain Frequency</i>			
0	----- ^a		
1	-0.02	0.98 (0.48,1.99)	
2	-1.23	0.88 (0.39,1.99)	0.93
<i>Parenteral IV</i>			
0	----- ^a		
1	-0.58	0.56 (0.14,2.17)	0.63
<i>IV Medication</i>			
0	----- ^a		
1	-0.85	2.26 (0.97,5.28)	0.06
<i>Oxygen Therapy</i>			
0	----- ^a		
1	0.46	1.58 (0.66,3.79)	0.38
<i>Suctioning</i>			
0	----- ^a		
1	-0.34	0.71 (0.18,2.80)	0.53
<i>Abnormal Labs</i>			
0	----- ^a		
1	-0.64	0.52 (0.03,9.07)	0.66
<i>Physician Visits</i> mean±SD	-0.031	0.97 (0.79,1.17)	0.61
<i>Physicians Orders</i> mean±SD	-0.032	0.96 (0.82,1.14)	0.68
<i>Age</i>	0.016	1.02 (0.97,1.06)	0.60
<i>Gender</i>			
1	----- ^a		
2	-0.011	0.98 (0.51,1.93)	0.98
<i>Ethnicity</i>			
2 (Asian/Pacific Islander)	----- ^a		
3 (African American)	2.50	12.23 (0.41,358.92)	0.13
4 (Hispanic)	2.89	18.16 (1.12,292.41))	
5 (Caucasian)	1.59	4.90 (0.55,43.55)	
<i>SITE</i>	-0.32	0.73 (0.35,1.51)	0.28

a. Reference level of the categorical variable

b. The p-value is from the likelihood ratio test for testing whether the predictor is significant given the other predictors were already in the model.

Summary of Results

Results presented in this chapter were an analysis of correlation and logistic regression. None of the predictor variables were shown to be statistically significant in predicting the outcome of mortality, likely due to an inadequate number of cases per predictor variable. Logistic regression revealed that the overall model was not a good fit, which was supported by the results of the odds ratios. Further discussion of results and interpretation will be done in Chapter Five.

Chapter Five

DISCUSSION OF FINDINGS

The purpose of this study was to retrospectively determine six-month mortality of a cohort of NH residents and the relationships between mortality and the variables comprising the MDS-CHESS scale. The sample was derived from a data set of Medicare beneficiaries who were admitted to two nursing homes in the calendar year 2005 which contained assessment and demographic information. The two nursing homes were part of a public healthcare system in southern California. One facility was free-standing and the other was located on the grounds of a hospital within the healthcare system.

The original dataset for the two nursing homes of 238 subjects was decreased to 212 subjects to eliminate duplicate beneficiary identification numbers. Of those 212 subjects, 191 had death dates documented in the dataset. Since six-month mortality was the DV, only deaths that occurred between June 30, 2005 and June 30, 2006 were included in the analysis. The study sample was composed primarily of females with a mean age of 82.35 years. Most residents were Caucasian, followed by Asian/Pacific Islanders, Hispanics and African Americans.

Of the NH 191 residents 65 years of age or over who died within the time interval of June 30, 2005 to June 20, 2006, 42 were in Nursing Home A (22%) and 39 were in Nursing Home B (20%). There was little difference in the mortality rates between the two nursing. Other studies have excluded hospital-based NH, as the post-acute population served there usually returns to home after rehabilitation from surgery, resulting in sample

bias. Both nursing homes studied are part of a larger healthcare organization that maintains continuity of care by discharging hospital patients to the nursing homes for post-surgical or functional rehabilitation. For this reason, mortality may actually be less than in a non-hospital-based nursing home. This could have attributed to the small sample size.

The overwhelming majority of residents were Caucasian in both nursing homes. The ethnic profile of the sample does not reflect the ethnic profile of the geographic area in which the nursing homes are located. The San Diego Association of Governments (SANDAG) tracks and forecasts census, housing and economic data, which has been used for strategic planning by healthcare organizations, government, and other businesses. According to SANDAG (2008), 44% of the population in the geographic location of Nursing Home B is Hispanic, followed by Caucasian, then Asian. Nursing Home A is located in a geographic area in which Caucasians account for 74% of all residents, followed by 12% Hispanics, then 8% Asians. Differences in ethnicity among the residents are most likely due to the family caregiving practices of the ethnic subgroups evaluated. Asian/Pacific Islanders, Hispanics and American Indian/Alaskan Native populations typically do not admit family members to nursing homes, preferring to provide personal and health-related support within the home or community (Lipson & Dibble, 2005). This could account for the skewed ethnic mortality profile in the sample as compared to the geographic ethnic profile.

Aim #1 Determine the accuracy of the MDS-CHESS scale for predicting six-month mortality in two American nursing homes.

The study sample included residents admitted to the two nursing homes in calendar year 2005. It is possible that some of the residents died more than or less than six months from admission to the nursing home, and therefore outside of the analyzed time period. Since survival rather than survival time was measured in the study, this should not have affected results. However, beneficiary death outside of the defined time frame (June 30, 2005 to June 30, 2006) could have resulted in a smaller sample size while confirming the overall prognostic ability of the model, though with a few calendar days difference.

Studies that derive the sample population from large administrative databases have several advantages as described in Chapter Two, including the ability to retrospectively study large numbers of subjects and more efficiently evaluate outcomes of care. All databases potentially have missing data points for individual variables, excluding those subjects from analysis. Other reasons for excluding subjects are values with unusable codes and duplicate identifiers. Regardless of whether government-controlled or private databases are utilized for a study, thorough understanding of the coding, definitions, variables and process for access cannot be underestimated. For many studies, a data manager is included in the study team for the purpose of cleaning the dataset prior to analysis.

One of the challenges to acquiring the Medicare data used in this study was the process for obtaining the data set. Many revisions to the data request were submitted over

a period of five months before the data request was accepted for approval. A significant barrier was the taxonomy used for both the Medicare data and the data request process. Multiple communications with the contracted data management agencies were necessary to maximize mutual understanding of the specifics of the individual data request for this study. Investigators wishing to study some aspect of the continuum of care must have a basic understanding of tools and taxonomy of each database, as well as billing and documentation structure that ultimately influences data collection for any study of this type.

Another challenge was that of estimating how much data to request. Admission assessments were requested from calendar year 2005, with mortality data from 2005 and 2006. Despite adequate anecdotal admission volume, the study ultimately was underpowered after excluding unusable data. Maintaining focus on two nursing homes in the same healthcare organization could have been accomplished by requesting data from additional calendar years, rather than from 2005 only. Each additional year's data increases the cost of the data request, thus requiring some source of funding to complete the study. Thus, only one calendar year was requested. Previous studies of this design have been funded through grants and have support personnel such as data managers, or investigators in academic healthcare centers to ensure adequate support and expertise. Despite acquisition of an initial data file of over 2,200 subjects from the MDS database, many were excluded for reasons previously detailed, resulting in a sample of 191.

All residents in the sample were evaluated for the presence of each of the nine variables in the MDS-CHESS scale, as well as three demographic variables and the site variable. While IV medications ($p=.18$) and ethnicity ($p=.13$) had the lowest p value on

the likelihood ratio test, the two items did not meet the threshold for significance. Other items ranged from p -values of 0.31 (Physician's orders) to 0.96 (daily pain) for the overall effect of each predictor. In the original study by Hirdes, Frijters and Teare (2003) significance of 0.001 was achieved on all scale items. It is possible that in a future study with additional calendar years included in the data set, statistical significance could be computed for the nursing homes in this study.

Logistic regression was conducted to determine whether the statistical model derived from the MDS-CHESS scale fit the sample population. Bivariate analysis using the likelihood ratio test demonstrated the nine items that comprise the MDS-CHESS scale (DNR, pain, IV, IV meds, oxygen, suctioning, Physician's orders, Physician's visits, and abnormal labs) did not individually affect mortality, as evidenced by significance levels greater than 0.05 (range 0.06 to 0.98). Because of the overwhelmingly positive findings in the original study, there is reason to believe that with additional subjects, significance can be achieved with relation to the IVs predicting mortality.

Aim #2: Determine whether there are differences in six-month post-admission mortality between two NH populations operated under identical regulatory and organizational rules.

Initially, there was a desire to compare differences between the two nursing homes, and possibly to offer explanations for any differences in mortality rates or IVs. The relative importance of determining differences between two organizationally-related facilities has not been demonstrated in the literature. Rather, quality indices are used to benchmark sister organizations for ensure similar outcomes of care. Porock, et al., studied nursing homes in the state of Missouri as an aggregate (2005), with a sample size of over

40,000 NH residents. Recommendations from other investigators studying prognostic scales suggest determining accuracy of the scale variables in a homogenous population, or in a different geographic region. However, smaller sample sizes run the risk of not having enough power for statistical significance. Once the dataset was decreased to reflect only the inclusion criteria, the sample size was not powered to demonstrate significance in correlation analyses. Indeed, mortality rates were very similar between the two facilities. Of greater value to a healthcare organization would be to determine rehospitalization and/or Emergency Department visits for NH residents who have advanced illness and are positive for assessment items on one of the validated scales that predict mortality.

Implications for Nursing

Implications for Nursing Practice

The first duty that healthcare providers have to patients is to do no harm. The concept of failure to rescue applies not only to patients who are receiving curative treatment, but also to patients who require aggressive management of symptoms related to their disease. As chronic diseases advances, the downward trajectory is somewhat predictable. Assessing for, correctly identifying and intervening when prognostic signs appear over time can be considered the prevention of harm and undesirable outcomes. Nurses place great value on physical and psychosocial support of patients and families, which positions the individual nurse to identify current Advance Directives, prepare patients and loved ones for transitions in health status, and ensure that physicians' orders are consistent with the patient's wishes. Participation in interdisciplinary team meetings

or patient care conferences provides an opportunity for the nurse to access information and resources for patients that may not have been made available in past interactions.

Physicians are reluctant to prognosticate, and nurses may see this process as outside the scope of nursing practice. State Nurse Practice Acts are clear that medical prognostication is outside the realm of nurses. However, knowledge of research-based prognostic indicators for selected populations is certainly within acceptable nursing practice. Prognostic indexes for medical conditions or organ transplantation serve to activate a series of steps, or to evaluate candidacy for a procedure; these indexes or screens are used routinely by nurses to communicate information and implement previously established research-based protocols.

Interdisciplinary Teams (IDT) function as forums to discuss plans of care and overall patient situations, and are consistent part of the structure of nursing homes, home health, hospice, and other specialized services. Practice implications from this study for nursing homes include using a prognostic scale in the evaluation of newly admitted residents, as well as disease-specific prognostic tools to alter the plan of care when warranted or desired by the resident or family. In home health, recognition of severity of prognosis can lead to front-loading home visits to prevent rehospitalization or emergency department visits. Additionally, the home environment may be more conducive to information gathering and referrals in the absence of a crisis-oriented hospitalization. Palliative care or hospice informational visits can provide a measure of comfort for patients and families who are at high risk of exacerbation of illness and subsequent suffering. The value of supporting family members who must provide caregiver services cannot be underestimated, as the caregivers often experience altered decision making

skills under duress. The previously mentioned sequelae of support can arise out of the nurse's knowledge of a realistic prognosis.

Nursing Education

Nursing academic curriculums have shown great improvement in educating students regarding EOL topics during the course of studies. Many hospital-based training programs also include EOL content in their orientation process. However, a significant missing element of EOL nursing education in all settings is discussion of the strategies necessary to communicate with physicians regarding patients' prognoses. Nurses are affected by the professional norms regarding prognostication that exist among physicians. These barriers were recently described Glare and Sinclair (2008) and consist of the following tenets:

- Do not make predictions
- Keep what predictions you make to yourself
- Do not communicate predictions to patients unless asked
- Do not be specific
- Do not be extreme
- Be optimistic

Such covert directives are seldom effective and do not observe the right to self-determination for patients, nor do they provide truly informed consent. Nurses play a key role in identifying crisis points at which direct communication about prognosis is necessary to prevent adverse outcomes or unwanted decisions about prolonging life.

Education of experienced and novice nurses in eliciting information regarding what the future holds for specific patients can be compared to patients' and families'

perspectives to identify gaps in understanding that impede decision making. A related nursing education topic is the practical application of how to intervene during a short hospital stay versus intervention with a patient known throughout the illness trajectory. For shorter stay patients, key patient care areas that can benefit from additional training include the Emergency Department, Intensive Care, Step-Down/Intermediate Care, and Home Health, which are entry and exit points during crisis. Targeting nurses that work in these areas has the potential to interrupt the cycle of readmission and aggressive treatment in the advanced stages of illness. The ultimate goal would be the amelioration of suffering and psychosocial and spiritual support.

For nurses familiar with patients because of repeated care episodes (e.g. oncology, long-term care, dialysis, neurological services), education may include methods that assist patients and families to adjust to transitions in the disease process. The relationships that are built with repeated care episodes engender trust and reassurance of support. Therefore, goals of care discussions may be perceived as less threatening and part of normal operations. Yet, even experienced nurses shy away from overt dialogue about prognostication, contributing to a collaboration of withholding the truth. Educational emphasis on discussing predictions about future health outcomes as a normal activity can only enhance communication between patients, families and healthcare providers. Additionally, education at networking forums with other palliative care and hospice providers also offer the opportunity to discuss the various prognostic scales and advantages of each.

Finally, education on individualizing care discussions that recognize and honor cultural differences is gaining more priority throughout healthcare. Few hospitals, nursing

homes or other care settings have incorporated meaningful cultural sensitivity and competency into the workforce. Despite regulatory mandates to improve cultural competence, no easy solution for doing so has appeared. In the geographic region of the study, cultural differences account for much miscommunication and conflict among patients, nurses and physicians related to EOL care. Because of the different cultural compositions of healthcare providers and patient populations for each care facility, individual solutions must be identified, as well as educational approaches. A supportive strategy for engaging nurses and physicians in this learning dialogue is to embed cultural concepts into forums and processes in which treatment planning and ethical decision making occur. Nurses have the ability to change perspectives regarding the value of cultural awareness if they are educated on strategies for doing so. Too often, the influence of culture on treatment decisions and EOL care is devalued if patient/family opinions differ from those of the healthcare team, and is thought to be too complicated to explore, setting the stage for additional conflict. Many educational approaches are necessary to alleviate these perspectives and improve care.

Nursing Research

Implications for nursing research will be discussed from two perspectives, that of nursing at the sample organization, and nursing as a whole. Within the healthcare organization the two NH represent, a follow-up study could select and test use of a prognostic index to screen for mortality risk, and its correlation to actual referral to hospice or palliative care services. Currently, in palliative care the basic screening question is, “Would you be surprised if this patient died within the next year?” Using such minimal referral criteria produces the desired goals of care conversation, but does answer

the central question of uncertainty (estimated/predicted time until death), and prognosis is not speculated upon systematically. During IDT meetings at NH, a decision is made regarding when to rediscuss a resident at IDT. Sometimes rediscussions by the team are set months in the future if a resident is stable. Knowledge of prognostic indicators can alter the rediscussion schedule, and perhaps to detect increased frailty or clinical decline. A prospective trial to incorporate prognostic information for new admissions or regularly scheduled assessments could yield valuable insights regarding effects of bringing prognosis into open discussion.

In nursing as a whole, future research studies should include the nurse's role, influence and comfort in participating in prognostic discussions, and the effects on providing quality EOL care in a variety of settings. Globally, nurses have different comfort and competency levels related to participating in patient care conferences. The phenomenological perspective of nurses distressed by care they provide to seriously ill patients is important, insofar as their personal viewpoint often influences the care and support that is provided to patients and families. This is never truer than when a patient's religious or cultural norms conflict with those of the nurse. Future research should explore methods of expanding understanding of conflict resolution within the scope of nursing practice, as well as how best to access and incorporate prognostic information into treatment decision making and support of patients, families and the entire healthcare team.

Conclusion

In this study, a previously validated prognostic scale was evaluated for accuracy in a sample of nursing home residents. Statistical analysis failed to demonstrate

significance for items on the MDS-CHESS scale for predicting mortality. In his sociological dissertation, Christakis (1995) stated that prognosis serves to “. . .organize clinical knowledge, [influence] conceptions of ‘complications’, and [order] diagnostic possibilities.” In an effort to manage uncertainties of the future (p. 293). It has been well-demonstrated that physicians often provide an overly optimistic prognosis to patients for a variety of reasons (Christakis & Lamont, 2000; Coventry, Grande, Richards & Todd, 2005; Farquhar, Grande, Todd & Barclay, 2002). In a study by Christakis and Lamont (2000), physicians reported to investigators overly optimistic estimates of survival by a factor of five in patients newly admitted to hospice. This leads one to believe that even in the absence of emotional reactions from patients and families to the bad news, there is a large margin of error that cannot be attributed to characteristics of the physician or patient.

Demystifying prognostication and educating physicians and nurses to use prognostic tools within the interdisciplinary team is likely to raise awareness of high-risk patients for whom a priority must be established to determine goals of care and advance directives. An important part of this education is the timing and style of communication used with patients and families. A cultural shift among healthcare disciplines is necessary to focus efforts on systematic methods of planning care for seriously ill individuals, and preventing harm that results when medical interventions contrary to goals of care are performed.

Prognostication is essentially an attempt to gaze into the future and determine the best course of action for a given individual. Foreseeing and foretelling in healthcare can be thought of as ethical actions that are an attempt to provide a truthful picture of what

the future is likely to hold (Christakis, 1999). Both patients and physicians are reluctant to engage in or accept prognosis because of the perceived power of stating bad news as it relates to health. Instead, optimistic views of the future are provided if there are therapies that can alter the course of illness. This “ritualization of optimism” creates a barrier to ethical decision making and rationalizes the concept of futility for those with serious, advanced illness (p. 204-205). For seriously ill patients, the nature of their vulnerability obligates prognostic, as well as clinical and therapeutic responsibility (p. 210).

This deeply affects nurses at different levels of awareness. An experienced nurse can speculate about prognosis due to knowledge of disease and treatment modalities. This seasoned nurse who is distressed by providing care deemed futile to patients with advanced illness may request an ethics committee consult. An essential element of ethical decision making (regardless of the model is used) is that of the patient’s prognosis, which is often unclear in the medical record. For nurses wanting to facilitate communication between physicians and patients and families, this is a significant barrier.

Knowledge of disease trajectories and prognostic indicators strengthens the professional role of the nurse in moderating perspectives that are often divergent. Novice nurses can be supported through feelings of moral distress in providing aggressive care to end-stage patients by establishing an accurate prognosis and through dialogue with patients and families about quality of life. None of these interventions is to be taken lightly, but serve the purpose of gaining knowledge of the individual patient, and advocating for their autonomy despite uncertainty of future outcomes.

Just as there is a moral obligation of physicians to prognosticate as accurately as possible, there is a moral obligation of nurses to raise questions about the course of

treatment as it relates to the presence of suffering, religious or spiritual concerns.

Addressing concerns from a transcendent perspective becomes essential when discussing the possibility of death or disability. Although all patients and families cannot tolerate dialogue of this nature, attempts must be made for ethical and moral reasons. Acute care nurses may be unable to know the outcome of their attempts to incorporate prognostic indicators into goals of care discussion; hospital stays are too short and patients move to a different location before the end result is known. In long-term care, however, NH residents may be observed until time of death or transfer to a hospital where they die. Communication within the IDT at NH usually notes the death of residents who are transferred to the hospital and subsequently die. For NH nurses and other members of the IDT, a self-calibration is possible regarding the accuracy of prognostication, hopefully with improved success of interventions aimed at decreasing suffering and preventing unwanted therapeutics.

APPENDIX A

COEFFICIENTS TABLE

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	.160	.678		.236	.814	-1.178	1.497					
	A10B	.012	.085	.011	.146	.884	-.155	.180	.042	.011	.011	.882	1.134
	AA2	.011	.081	.011	.137	.891	-.149	.172	.022	.010	.010	.891	1.123
	AA4	.042	.057	.056	.733	.465	-.071	.154	.068	.055	.054	.940	1.064
	J2A	-.009	.050	-.013	-.173	.863	-.106	.089	.003	-.013	.013	.928	1.077
	K5A	-.130	.157	-.066	-.830	.407	-.439	.179	-.064	-.062	.061	.857	1.167
	P1AC	.170	.103	.129	1.649	.101	-.033	.374	.097	.123	.122	.895	1.117
	P1AG	.127	.106	.103	1.199	.232	-.082	.336	.050	.090	.089	.746	1.341
	P1AI	-.083	.167	-.048	-.497	.619	-.413	.247	-.045	-.037	.037	.588	1.701
	P7	-.010	.023	-.038	-.437	.663	-.057	.036	-.056	-.033	.032	.717	1.394
	P8	-.006	.020	-.025	-.282	.778	-.045	.034	-.072	-.021	.021	.669	1.496
	P9	-.132	.366	-.027	-.361	.719	-.854	.590	-.016	-.027	.027	.960	1.042
	site	-.058	.095	-.058	-.606	.546	-.245	.130	-.078	-.046	.045	.604	1.656
	age	.004	.006	.053	.669	.504	-.007	.015	.041	.050	.049	.875	1.143
	V1	-2.06E-005	.000	-.018	-.226	.822	.000	.000	-.044	-.017	.017	.816	1.225

a Dependent Variable: death

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