

UCSF

UC San Francisco Electronic Theses and Dissertations

Title

Trends and predictors of quality, access, and cost in California's hospices. An examination of changes in quality in California's Medicare certified hospices from 2000-2005.

Permalink

<https://escholarship.org/uc/item/0b21k4n3>

Author

Dodd, Catherine Jean

Publication Date

2007-06-15

Peer reviewed|Thesis/dissertation

Trends and predictors of quality, access, and cost in California's hospices.
An examination of changes in quality in California's Medicare certified hospices from
2000-2005.

by

Catherine J. Dodd

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree for

DOCTOR OF PHILOSOPHY

in

Sociology

in the

ACKNOWLEDGEMENTS

This accomplishment would not have been possible without my family. I wish my mom, Eva Maria Lohmann Dodd, who encouraged me to continue learning throughout my life, and who during her final three years of life, and my first three years of doctoral study, often set aside her needs to allow me to study, could be here to see this in print. My life partner Mary Foley supported me, displayed patience beyond every expectation and encouraged me through some very challenging times in this six year journey. I am fortunate to have had Bonnie & Lee my lesbian mothers in my life who loved me unconditionally and without whom I cannot imagine enduring difficult times. I'm fortunate to have had a best friend, Mary McCutcheon who believed in me and so generously demanded little of our friendship as I put things on hold to study. And I'm grateful for mom's many friends who were there for her and for me when we needed them. Pali Cooper D.C. kept me upright when my back was aching from computer work and her partner Jeanne Rizzo, the Executive Director of the Breast Cancer Fund engaged me in real life meaningful activism as a wonderful distraction.

I have a great appreciation for the UCSF School of Nursing. The most highly regarded nursing school in the nation where I have been fortunate to receive three degrees. And, where, Margretta Madden Styles encouraged me as an undergraduate nursing student and throughout my career. I have only praise and gratitude for members of my dissertation committee and my third area exam committee. Charlene Harrington RN, PhD, a leader in health care and a voice for nursing home patients who are hidden from our view, who served as my dissertation committee chair. Charlene convinced me to come back and pursue this terminal degree and then with the patience of a mother hen waited and pushed and edited and pulled the dissertation out of me. Carroll L. Estes Ph.D., a scholar and translator of knowledge into action for social change, a wise sentinel of protection for social policy in aging and an agent of social change has been an inspiration to me and helped me find the sociologist within me. Betty Davies RN, PhD, world renown scholar on death and dying opened her door and gently welcomed me to study. Suzanne Dibble RN, PhD helped me conquer p values and much much more and Jeanne de Joseph RN, DNSc nursed me through qualitative study.

Dean Dracup, thank you for your kindness and confidence in me: Zina Mirsky, thank you for your patience. SBS faculty, I am grateful for your guidance and your patience and for the caring you showed when my mother died.

Many student colleagues have become dearest friends. Anne Hughes and I climbed this mountain together splashing all the way. Gail Dobell, your steadfast friendship provided incredible security; Tracy Weitz, you continue to inspire me; Mauro Hernandez, thank you for your good nature; Signy Judd thank you for getting pregnant to remind us all that there is life beyond graduate school; Brian Grossman, your genuine concern for others is unmatched; Erica Solway, your quiet voice is so important; Brooke Hollister, your enthusiasm is refreshing; Toby Adelman, thank you for reminding me that one day at a time we can do anything; MaryLouise, thank you for your refreshing optimism; Valerie Ruth, you are an amazing nurse and an amazing mother; Claire Hauser (and Fred), your generosity of heart renewed my soul and Michelle Tellez, your youthful spirit engaged the child in me. My IHPS fellows served as proof that it is possible to finish and many (Rosemary, Alexis, Meggi), provided me guidance and support.

School of Nursing staff and SBS staff especially Janis O'Meara, thank you for your help throughout this experience; I would not be here without your efforts and support.

House Speaker Nancy Pelosi encouraged me to follow my dream and allowed me to arrange my schedule as her District Director to accommodate school. I am grateful to her as a mentor and as an example of perseverance.

Zen Hospice Project has allowed me to return the love given to my mother through my board service. The Breast Cancer Fund board has cheered me on as they cheer on mountain climbers each year, Martha Ryan NP and the Homeless Prenatal Program has validated all my experience in health and politics and Cecil Williams and Janice Mirikitani from the Glide Foundation loved and encouraged my spiritual health.

I am grateful for funding from the Women's Health Care Executives, the UCSF Graduate Division, the Alpha Eta Chapter of Sigma Theta Tau, the Nurses Educational Foundation, the UCSF School of Nursing Alumni Association and to Association of California Nurse Leaders who awarded me the first Margretta Madden Styles scholarship.

In the words of Senator Hillary Rodham Clinton and my candidate for President in 2008, it does take a village and I am grateful to all the villagers.

ABSTRACT

TRENDS AND PREDICTORS OF QUALITY, ACCESS, AND COST IN
CALIFORNIA'S HOSPICES.
AN EXAMINATION OF CHANGES IN QUALITY IN CALIFORNIA'S MEDICARE
CERTIFIED HOSPICES FROM 2000-2005
Catherine J. Dodd R.N., PhD

This research examined trends in California Hospices during the period 2000-2005. The main aims were to describe trends in hospice characteristics, and quality, utilization and cost in California between 2000 and 2005 and to test the hypotheses that for-profit and chain hospices would be associated with longer lengths of stay, increased numbers of patients with non-cancer diagnoses, and decreased RN visits per patient.

Methods: Utilization and financial data from the California Office of Statewide Health Planning and Development for hospices filed annually from 2000-2005 and data from public sources. Descriptive statistics identified trends for approximately 200 hospices. Regression models examined quality, utilization and cost outcomes for 2005.

Results: The number of for-profit and chain hospices increased by 36% and 20% respectively. Sixty-six % of California's rural counties have no hospices. The percentage of female patients increased ½% per year, hospice patients over 81 years old increased by 2% per year. Longer lengths of stay (LOS) and greater percentages of patients with non-cancer diagnoses were associated with for-profit and chain hospices. Percent of Hispanic patients predicted decreased LOS and decreased visits by RNs. An Increased percentage of Hispanics in the county predicted decreased deficiencies by licensing agencies. For-profit hospices spent less on RNs care and chain hospices had more complaints. Increased

county per capita income predicted increased deficiencies identified by the state licensing agency.

Discussion: By 2020, 80% of hospice patients will be over 81 years old and 66% will be female. Chain hospices are associated with lower quality of care and for-profit hospices provided less professional care. These findings suggest the importance of the need for closer monitoring of quality and access to care. The recent CMS change allowing a longer 8 years rather than six years between required certification inspections for hospices this should be of concern to those concerned about quality of care and changes in the hospice model of care.

TABLE OF CONTENTS

| | |
|---|-----|
| Acknowledgements | iii |
| Abstract | v |
| Table of Contents | vii |
| Tables and Figures | x |
| Chapter One | 1 |
| Statement of the Problem | 2 |
| Significance | 5 |
| Specific Aims | 6 |
| Background | 8 |
| Historical Context and Origins of Hospice | 8 |
| Hospice Codified in U.S. Law | 17 |
| Chapter Two: Theoretical Frameworks | 20 |
| Classic and Neoclassic Economic Theory | 20 |
| State Theory | 26 |
| Economic Crisis of the State | 29 |
| Feminist Economic Theory | 31 |
| The Political Economy | 35 |
| Resource Dependency and Political Economy | 37 |
| Hospice as Shaped by Neoclassic, Neoliberal Ideologies | 39 |
| 1964 Passage of Medicare and Medicaid | 43 |
| The Hospice Benefit: The Only Social Program Added During Reagan's Presidency. | 53 |
| Challenges of Hospice in Today's Health Care System | 61 |
| The Transformation to For-Profit Health and Hospice Services | 63 |
| Chapter Three: Review of the Hospice Literature | 70 |
| Methods | 73 |
| Findings | 73 |
| Length of Stay/Survival: Diagnosis, Medicare Coverage Type | 73 |
| Ethnic Disparities in Hospice Use | 79 |
| Cost, Structure, Profit | 83 |
| Hospice Characteristics | 85 |
| Quality | 89 |
| Considerations and Questions | 92 |
| Chapter Four: Research Design and Methods | 94 |
| Research Design | 94 |
| Data Sources | 94 |
| Description of Variables | 96 |
| Missing Data | 96 |
| Hospice Organizational Characteristics as Independent Variables | 99 |
| Hospice Patient Characteristics as Independent Variables | 105 |
| Market Characteristics as Independent Variables | 106 |
| Outcome Variables | 109 |
| Data Cleaning | 112 |

| | |
|---|-----|
| Analysis | 113 |
| Aim 1 | 113 |
| Aim 2 | 114 |
| Analytic Model | 117 |
| Regression Analysis | 118 |
| Protection of Human Subjects | 122 |
| Chapter Five: Study Results | 123 |
| Aim 1 Trends in Hospice Characteristics 2000-2005 | 125 |
| Hospice Organizational Characteristics | 125 |
| Hospice Patient Characteristics | 133 |
| Summary Outcome Variable Measures of Central Tendency from 2000-2005 | 136 |
| Aim 2 Factors Associated with Quality, Utilization and Cost | 139 |
| Profit status, Chain affiliation, Size Relationships with other Independent Variables | 139 |
| Regression Analysis of Quality, Utilization and Cost | 147 |
| Regression Models | 149 |
| Average RN Visits | 153 |
| Average All Staff Visits | 154 |
| Average Length of Stay | 155 |
| Percent of Total Expenditures on Nursing Care | 157 |
| Cost Per Patient | 158 |
| Net Income Per Patient | 160 |
| Complaints and Deficiencies | 161 |
| Analysis of Hypotheses | 168 |
| Chapter Six: Discussion and Conclusion | 174 |
| Trends in Hospice Growth | 175 |
| Trends in Hospice Quality | 176 |
| Trends in Length of Stay | 179 |
| Trends in Hospice Cost | 180 |
| Ownership Characteristic Trends and Predictors of Quality, Utilization and Cost | 181 |
| Geographic Characteristic Trends and utilization of Hospice Services | 191 |
| Site of Care Characteristic Trends and Predictors of Quality, Utilization and Cost | 193 |
| Hospice Referral Characteristic Trends and Predictors of Quality, Utilization and Cost | 195 |
| Payer source Characteristic Trends and Predictors of Quality Utilization and Cost | 197 |
| Patient Characteristic Trends and Predictors of Quality, Utilization and Cost | 200 |
| Trends in Hospice Patients' Age and Predictors of Quality, Utilization and Cost | 200 |
| Patient Racial Characteristic Trends and Predictors of Quality, Utilization and Cost | 201 |

| | |
|--|-----|
| Trends in Gender Patient Characteristics and Predictors of Quality, Utilization and Cost | 203 |
| Trends in Diagnosis and Diagnosis as a Predictor of Quality, Utilization and Cost | 206 |
| Trends in Diagnosis and Diagnosis as a Predictor of Quality, Utilization and Cost | 206 |
| Market characteristics as Predictors of Hospice Quality, Utilization and Cost | 207 |
| Conclusion | 207 |
| Significance | 210 |
| Limitations | 211 |
| Implications for Future Research | 212 |
| Concluding Thoughts | 213 |
| References | 216 |
| Appendix | 248 |
| OSHPD Reporting Form | |
| Publishing Agreement | |

TABLES AND FIGURES

Tables

| | | |
|------------|--|-----|
| Table IV-1 | Variables and Sources California Hospices 2000-2005 | 97 |
| Table IV-2 | Hypothesis Chart | 116 |
| Table V-1 | California Hospice Patient Characteristics 2000-2005 | 131 |
| Table V-2 | California Hospice Patient Characteristics 2000-2005 | 135 |
| Table V-3 | Outcome Variables California Hospices 2000-2005 | 138 |
| Table V-4 | Ownership status and Hospice Characteristics | 140 |
| Table V-5 | Chain Affiliation and Hospice Characteristics | 142 |
| Table V-6 | Size and Hospice Characteristics in California 2005 | 144 |
| Table V-7 | Tests of significance between categorical variables in 2005 | 146 |
| Table V-8 | All Variables for California Hospices 2005 | 147 |
| Table V-9 | OLS Regressions Coefficients for: Average Visits by RN, Average Visits by All Staff, Average Length of Stay, Percent of Total Costs Spent on Nursing Care, Cost Per Patient, Income Per Patient in California Hospices 2005 | 150 |
| Table V-10 | Logistic Regression Model for Complaints for California Hospices 2000-2005 | 162 |
| Table V-11 | Negative Binomial Regression for Complaints for California Hospices 2000-2005 | 164 |
| Table V-12 | Logistic Regression Model for Deficiencies for California Hospices 2000-2005 | 166 |
| Table V-13 | Negative Binomial Regression for Deficiencies for California Hospices 2000-2005 | 167 |

Figures

| | | |
|--------------|---|-----|
| Figure IV- 1 | Average RN Visits | 120 |
| Figure IV-2 | Histogram for Complaints in California Hospices 2000-2005 | 121 |
| Figure IV-3 | Histogram for Deficiencies in California Hospices 2000-2005 | 121 |
| Figure V-1 | California Hospice Growth 2000-2005 | 125 |
| Figure V-2 | Ownership change in California Hospices 2000-2005 | 126 |
| Figure V-3 | Change in Size of California Hospices 2000-2005 | 127 |
| Figure V-4 | Change in California Hospice Diagnosis 2000-2005 | 134 |
| Figure V-5 | Log normal plot for RN visits | 153 |
| Figure V-6 | Log normal plot for All Staff Visits | 154 |
| Figure V-7 | Log normal plot for Average Length of Stay | 156 |
| Figure V-8 | Log normal plot for % Total Hospice expenditures on RN care | 157 |
| Figure V-9 | Log normal plot for Cost/Patient | 159 |
| Figure V-10 | Log normal plot for Income/Patient | 160 |

CHAPTER I

All of us hope for a long life with good quality, and we pray that our end is peaceful and without suffering. Most of us want to be involved in the decisions about our ultimate destiny on earth. And, no one wants to be a burden to his or her loved ones. These are universal truths and, more often than not, they are contrary to the way we leave this world. The Institute of Medicine report, “Approaching Death: Improving Care at the End of Life,” documented that many people experience needless suffering and distress at the end of life and that we have come to “fear a protracted death and to dread the prospect of abandonment and untreated physical and emotional distress” (Field & Cassel, 1997, p. 15). The report asserted that the care of individuals approaching death is an important part of health care and described a “good death” as one “free from avoidable stress and suffering for patients, families and caregivers; “as in general in keeping with the wishes of the patient and family; and, as consistent with clinical, cultural and ethical standards (Field & Cassel, 1997, p. 4).

Since hospice care began in the United States three decades ago, it has been considered a compassionate multidisciplinary philosophy of care for terminally ill patients for whom curative care is futile. The availability of hospice care was intended to provide for a comfortable and peaceful end. Although research on the quality of end-of-life care is in its gestational period, family members (proxies) of decedents have been highly satisfied with hospice care, as compared with patients (or their proxies) in similar settings who did not receive hospice care (Teno, J.M, Claridge, B.R., Casey, V., Welch, L.C., Wetle, T., Shield, R., Mor, V., 2004, (Teno et al., 2004; Wallston, Burger, Smith, & Baugher, 1988).

This dissertation posits that the conditions of our death and the end-of-life care that precedes it are increasingly constructed by the dominant political market ideology and the medical institutions are reflected in structural arrangements, specifically reimbursement mechanisms and other policies mandated by government, hereafter referred to as “the state”. The state is a term that broadly refers to all institutions that govern, and it functions at public expense (McKinlay & Marceau, 2004a). Hospice care is perhaps the final frontier for the Medical Industrial Complex (MIC), an institutional network of corporate investment entities, insurers, physicians, technology and pharmaceutical companies, health institutions, and consumers that emerged after the state adopted reimbursement of medical care from Medicare and Medicaid in 1965. In the transition of medical care from product for the social good to an economic product, two key institutional actors have been, and continue to be, the MIC and the “aging enterprise,” which has turned the social needs of the aging population into profit-making commodities (Estes, 1979, 1988, 1988, 2001b). These institutional actors remain key participants in a political economy wherein internal and external structures and processes in the economic and political arenas influence social and health policies. The resulting policies have directly or indirectly supported the growth of the “for-profit” hospice industry. The unintended consequences of the state’s policies, or lack of policies, are transforming hospice care provided in the final days and months of life for frail elderly women and for people of color from a social good into a market commodity.

Statement of the Problem

Published in the past decade with the support of the Robert Wood Johnson Foundation, *The Hastings Center Special Supplement*, “Access to Hospice Care:

Expanding Boundaries, Overcoming Barriers,” reported that more than half of the 2.5 million deaths in 2003 in the United States occurred in institutions and, of those, 70% occurred after a decision had been made to end treatment, yet fewer than 25% of those patients received hospice care (Jennings, Ryndes, D'Onofrio, & Baily, 2003). Based on the 1990 census, the Centers for Disease Control and Prevention (CDC) reported a national rate per 100,000 population for hospice use of 37.9% (Centers for Disease Control and Prevention National Center for Health Statistics, 2003a).

Because of demographic changes in the number of Medicare-eligible Americans (those 65 years of age and older), the demand for hospice care is anticipated to grow, even if the percentage of those using it does not significantly increase. At the turn of the last century, 80% of the 2.5 million people who died were Medicare beneficiaries (Jennings, Ryndes et al., 2003). The number of aging people born between 1946 and 1964, the so-called baby boomer generation, will increase dramatically in the next few decades. The number of Medicare beneficiaries is expected to increase by 5% each year, reaching 90 million in 2050 (Lunney, Foley, Smith, & Gelband, 2003). In 2003, cancer diagnoses made up 49% of hospice admissions, followed by dementia (9.6%) and lung disease (6.8%) (Locher, Kilgore, Morrissey, & Ritchie, 2006). Cancer is the second leading cause of death in persons aged 65 and older and is the primary cause of death in those aged 65 to 74. The number of cancer cases is anticipated to double in the next four decades. The projected number of patients with cancer and noncancer diagnoses who may choose hospice care is anticipated to increase dramatically.

Significant changes in the organizational characteristics of hospices have begun to be observed. Since its inception, hospice care has been dominated by nonprofit

organizations; however, this has begun to change during the past decade (Han, Remsburg, McAuley, Keay, & Travis, 2006). Concerns about corporate health care's market domination, creating a policy path for hospice care, are rarely voiced because of the presence and influence of for-profit hospices on the governing body of the national hospice trade organization, which sets national standards of hospice care and represents its interests before Congress and the public. The priority of profit versus compassion is not new. Florence Wald, a nurse and one of the original founders of hospice care in the United States, raised this issue during the debate on including a hospice benefit in Medicare.

If hospice care follows the path of voluntary hospitals and home health care agencies toward for-profit domination of the market, changes in its model of care and quality are assured. Many changes were observed in home health care when for-profit home health care agencies took over the industry (Estes, Swan, Bergthold, & Spohn, 1992). Lower levels of quality care in for-profit long-term-care institutions have been documented in the literature (Harrington, O'Meara, & Kang, 2006; Harrington, Wollhandler, Mullan, Carrillo, & Himmelstein, 2001; Harrington, Zimmerman, Karon, Robinson, & Beutel, 2000; Kitchner & Harrington, 2004). Concerns about hospice care quality and the availability of "charity care" are foremost in the minds of advocates as for-profit hospices increase their market share (Pietroburgo, 2006).

As a unique model of care created by law to contain health care costs (Hastings, 1993), hospice care has yet to be dominated by private for-profit economic interests because it is difficult to generate profits on per diem reimbursement that is capped per patient for complex care given in shorter and shorter lengths of stay. In the provision of

hospice services, documenting subtle changes over time is essential if the hospice care policy path is to be redirected before it subliminally becomes dependent and institutionalized.

With hospice care rapidly expanding in California during the next few decades, this study will examine the changes now occurring in the industry to determine if there is a need to protect the quality of care, to establish systems that will guarantee equity in access to care, and to ensure adequate income for hospice care services.

Significance

This is the first descriptive analytic study of California hospices to investigate changes in their quality, utilization, and costs over time. California is the largest state in the country with 15% of the nation's population and 12% of the nation's hospice patients (Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004). California often implements new and emerging health care models before they are adopted in other states. A case in point is that two of the three oldest hospices in the United States (Hospice of Santa Barbara and Hospice of Marin) were founded in California. The trends observed in California, one of five states with a majority of minorities, may not be generalizable to other states, but California's health care policies and patterns are influential in the national arena.

Within two decades, the elderly will constitute a larger proportion of the population than today, and the absolute number of people dying will be substantially higher. Systemic changes to expand and improve hospice policies and programs take decades to implement. It is essential, therefore, to evaluate those factors which affect hospice quality, utilization, and costs to assist in developing end-of-life care policies to

improve quality, to enhance access to and utilization of hospice care, and to ensure appropriate reimbursement for costs of care.

Specific Aims

This study has two specific aims. The first aim is to describe trends in hospice care quality, utilization, and cost in California from 2000 to 2005. The second aim is to examine factors associated with hospice quality, utilization, and cost in California in 2005. These factors fall into three categories: organizational characteristics, patient characteristics, and market factors. Of particular interest are the effects of ownership status and chain affiliation, referral sources, taking into account patient characteristics, and market factors, on the outcomes of quality, utilization, and costs.

Hypotheses

Three hypotheses, summarized in this paper's methods section, are related to the second aim.

H₁ Higher numbers of complaints and deficiencies, as measures of poor quality, will be associated with for-profit hospices that are affiliated with chain-operated systems. This is based on studies regarding quality of care in nursing homes (Harrington et al., 2000).

H₂ Increased hospice utilization will be associated with for-profit hospices, care provided in skilled nursing facilities, and care for patients with noncancer diagnoses. This is based on previous studies in selected states (McCarthy, Burns, Davis, & Phillips, 2003; Miller, Kinzbrunner, Pettit, & Williams, 2003; Miller, Teno, & Mor, 2004; Miller, Weitzen, & Kinzbrunner, 2003; Virnig, McBean, Kind, & Dholakia, 2002).

H₃ The lengths of stay and costs of hospice care will be higher in for-profit and chain-operated hospice programs. This is based on the mixed results of cost studies (Banaszak-Holl & Mor, 1996; Campbell, Lynn, Louis, & Shugarman, 2004).

Background

Historical and context of origins of Hospice

Medicalization of dying. In the United States, Elisabeth Kübler-Ross' best selling book, *On Death and Dying*, published in 1969, gave voice to the frustrations of families who have had to watch their loved ones dying in hospitals, alone and surrounded by technology and tubes. De Vries (1981) described the social construction of death as an "existence transition" (p. 1080). He cited Lofland's (1978) work on dying, which contrasted dying in the premodern world with low levels of medical technology, late detection of fatal conditions, simple definitions of death with "fatalistic passivity directed at dying people," and high death rates from acute illnesses and injuries, with dying in the modern world prolonged by sophisticated medical technology and bureaucratization (De Vries, 1981, p. 1083). According to De Vries, medicine transformed a "terminal condition which once naturally eventuated death" into a "struggle for control over the disease process where every available resource is mobilized to prolong life (p. 1083)."

Sociologists refer to the social construction of natural processes and illnesses as "medicalization." Zola (1972) and Freidson (1970) examined the process of medicalization and medicine's expansion as a profession and social institution to control the normal processes of everyday life, as well as the causes and treatments of deviance (Conrad, 2004; Freidson, 1970; Zola, 2004). Zola refers to medicine as a "new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts" (p. 432). Medicine's position of social and professional dominance grew with the scientific advances of the early twentieth century and combined with the monopolization of medical practice (Conrad & Schneider, 2004).

Conrad and Schneider (1980/1992) have suggested that medicalization occurs at three levels: (a) the conceptual level at which medical definitions are used to define problems; death is defined as a medical problem rather than a natural part of life; (b) the institutional level at which medical personnel serve as gatekeepers to benefits, including those provided by the state, such as Medicare-reimbursed care; the Medicare hospice benefit requires a medical referral and prognosis of death within 6 months for reimbursement; and (c) the individual level of interaction at which physicians treat problems that do not have a disease etiology as medical problems. Dying is equated with organ failure or respiratory failure. Physicians do not like to admit that their curative abilities have failed (Christakis & Iwashyna, 2000). Incurable disease is not a medical problem. Once curative care is no longer effective, comfort care, recently medicalized as the new medical specialty, palliative care, is prescribed to keep patients comfortable.

Medicalization was necessary to include the hospice benefit within Medicare; however, the cost containment it promised through limited per diem reimbursement further medicalized comfort care in the form of palliative care. According to Field and Cassel (1977), the hospice benefit challenged medicine with mutually exclusive goals: to cure disease and prolong life and to provide comfort care when expensive life-prolonging treatments were no longer beneficial. Medicare's hospice regulations require that patients forgo costly curative treatments; however today, medical advances have so improved comfort care that many symptoms can be controlled by radiation treatment or drugs (Wiener & Tilly, 2003). These treatments are too costly to be provided within the Medicare per diem reimbursement. Physicians who want to continue offering patients state-of-the-art palliative care might postpone hospice referral so that they can continue

billing Medicare for palliative care and in so doing deny patients and families the benefits of multidisciplinary hospice care (Raffa, 2004).

Waitzkin (2000) suggested that the individual level of interaction involves “not only social control, but the transmission of ideological messages that are communicated through the symbolism of medical science” (p. 124). Because of the professional expert position assigned to medical physicians, society is deferential to medical opinion of physicians. A physician’s professional recommendation or referral conveys an ideologic message of objectivity and the certainty of science. Illich (1976) was highly critical of the medicalization of death, describing it as a form of social control in which the patient is labeled *deviant*, if he or she rejects or fails to comply with physician orders for any intervention.

Conrad (2005) has posited that the social construction of medicalization has numerous contributions beyond medicine’s professional dominance. Social movements and interest groups have sought medical classifications and definitions for symptoms to legitimize the existence of their grievances, such as advocates for children with learning disabilities. Healing professions, such as complementary medicine and midwifery, have medicalized themselves to legitimize and to promote their medical claims. Technology, including pharmacologic advances (although often influenced by medicine) relies on medicalization for its legitimacy, and consumers have begun to demand specific medical treatments for human problems (Conrad, 2005).

Conrad and Leiter (2004) have considered the relationship of markets and medicalization. They cited the shift from a physicians’ traditional and ongoing role in the health care market, in which physicians are both the referral source for care (creating

demand) and the provider of goods and services (satisfying demand) as a conflict of interest. Because of patients' lack of medical information, the uncertainty their prognoses, and the emotional nature of illnesses, medicalization has permitted physicians to take advantage of patients' trust in their expert status, allowing physicians to order more services than necessary because third-party reimbursement for such services was assured (Conrad, 2005; Detsky, 1978; Folland, Goodman, & Stano, 2004a; Starr, 1982; Vogel, 1999). The increased corporatization of health care placed patients in "mediated" markets in which third party payers intervene between providers and consumers to determine what is medically necessary (Conrad & Leiter, 2004). Insurers, both public (the state) and private, constrain access to medicalized solutions. Working with medicine then, insurers have supposedly become the moral, neutral, and objective experts who decide if a patient is actually suffering from an illness or everyday life. Because Medicare eligibility regulations require a 6-month medicalized prognosis for referral to a hospice, the state itself has become the mediator, determining when terminal suffering begins and ends.

Consumer demand for the new terminal-condition therapies, promoted by corporately owned, developed and marketed technology and pharmacology, created an engine of medicalization within the MIC that has shaped the relationships between the state, corporate entities, insurers, physicians, health institutions and consumers. Media messages profess the miracles of the latest technology, whether curative or palliative. Advances in technology, fueled by corporate investment, are equated with greater certainty for cure or symptom control (Mahar, 2006). The medicalization of hope for a

cure has become a quasi social movement and is in stark contrast to the social movements from which hospice emerged in the late 1960s.

Early Hospice Care as a Social Movement. It is often said that hospice in the United States, and its addition as a benefit to Medicare in 1983, happened as the result of a social movement in which health professionals, spiritual ministers, and the public organized to promote change in the way people were dying. De Vries (1981) has suggested that the social movements associated with natural childbirth and natural death were motivated by the encroachment of medicine on these natural “existence transitions.” This professional encroachment was alluded to by Foucault (1973) who suggested that the 200–year-old institution of hospital medicine transformed a natural death into a pathological one. De Vries posited that “modernization created changes in the experience of birth and death in the role of the individual, the place of the family in transition, the control of information related to birth or death, the medical components of the experience, and in collective action (p. 1074).” Although the hospice movement did not seek medicalization, medicalization accompanied modernization and was required by the dominant hegemony of market-based policy in order to be legitimized for reimbursement.

Max Weber theorized about the nature of charismatic movements and posited that they alternate between charisma, a form of agency capable of producing innovative change in beliefs, and institutions and routinization through bureaucracy (Freund, 1969; James & Field, 1992). The hospice movement in the United States was ignited when Madame Cicely Saunders, a charismatic physician, visited from England where she had founded St. Christopher’s Hospice and inspired health professionals in Connecticut and

other leaders in the “death with dignity movement” who were dissatisfied with medicalized end-of-life care. Health professionals, ministers, and the public united to create a care environment for the terminally ill that was in sharp contrast to the institutionalized, highly technical care that had become – and continues to be - the norm in the United States by the late 1960s (McAdam, 1982).

Social movements have been defined as collective action to resist or create social change (Andersen & Taylor, 2000; Kuumba, 2001; Piven & Cloward, 1979; West, 1992). Social movements are defined, organized, conscious, strategic, and occur over time (Kuumba, 2001). Several approaches to social movements have emerged over time and integrating three of them provides a guide to the development of the hospice movement in the United States. The first approach, resource mobilization, refers to the gathering of vital resources such as knowledge, experts, money, and networks of people . The second approach, political opportunity, capitalizes on public awareness, seizes moments to solidify and raises protest or demands change. And, to take advantage of those opportune moments, the third approach, framing, is essential (McAdam, 1982). According to Brown, P., Zavestoske, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Altman, R. G., (2004), social movement actors framed illness or, in the case of the hospice movement, futile medical treatment and highly technical death “not only as a personal grievance, but as a social problem” (p. 59). The social movement in the United States that resulted in the establishment of hospice care as a unique kind of care for people at the end of life exemplifies an organized network of professionals with a unifying grievance who successfully mobilized resources. This network raised awareness and framed the issue by recounting dramatic stories of impersonal deaths in U.S. hospitals in

Congressional testimony (McAdam, 1982), and seized the moment of the public's frustration with the conditions of the dying and the state's desire to control hospital costs and the political opportunity of Medicare reform to propose changes to Medicare's package of benefits (Andersen & Taylor, 2000; Brown et al., 2004). That is how the history of the hospice movement is usually portrayed.

In her dissertation, Hastings (1993) posited that social movements can split into unique dynamic trajectories and that the hospice movement in the United States morphed into two distinct groups with differing goals. One group held to the initial ideological goal of expanding a philosophy of patient-centered care for the dying that integrated physical, psychological, and emotional care with spirituality, that emphasized volunteer caregivers, and that sought to demedicalize death throughout society. The other group was committed to institutionalizing a specific model of hospice care to receive Medicare reimbursement and to expand access to that model of professional care.

Buck's dissertation (2005) cited three separate paths for early hospice leaders: the idealist, the pragmatist, and the entrepreneur. Each path was embodied in three charismatic leaders of the same organization at different times. Like Hastings, Buck described the idealism of Florence Wald, the former Dean of the Yale School of Nursing, who spearheaded the establishment of the first hospice in New Haven, CT. Wald had studied with Dr. Saunders at St. Christopher's Hospice in England after Saunders visited Yale. Wald hoped to change societal views toward dying and create a "hospice that was total community, including staff, patients, their families and their social context, and the community at large (Buck, 2005, p. 151)," care was to be patient- and family- directed and provided in a facility like St. Christopher's Hospice. Wald embraced an

interdisciplinary approach with blended roles to create a sense of equality and interdependence and an ecumenical spiritual philosophy, unlike the uniformly Christian philosophy of St. Christopher's where the Church of England was part of the state. A feminist analysis would consider Wald a social movement leader because she valued all the roles within the movement equally (Kuumba, 2001).

Sylvia Lack, M.D., the first medical director of the New Haven Hospice, pursued a path quite different from that initially forged by Wald. Lack was committed to patient care, but her heart was in home care. She was a pragmatist who sought to put a hospice home care program in place, and she worked to "professionalize" (and in doing so medicalized) the organization with professional staff in an attempt to assure quality, accountability, and legitimacy (Hastings, 1993).

The entrepreneurial leadership of Dennis Rezendes, the New Haven Hospice's second executive director, brought academic and professional business credentials to the movement. He was committed to getting a form of hospice care reimbursed through Medicare. In 1977, Rezendes became the first President of the National Hospice Organization. Today's hospice benefit (although a restrictive one) is a testament to the dominant business and political savvy he brought to bear to incorporate a hospice model of care into the American health care system at a time when benefits were being cut rather than expanded. Today, the vast majority of hospices rely on Medicare reimbursement and some profit from it (Han, Remsburg, McAuley et al., 2006).

It was at that point in 1977 when the hospice movement divided. The majority within the NHO favored the of expansion and standardization, while many of the initial

founders joined Wald in protesting that the requirements associated with Medicare reimbursement were too restrictive (Paradis & Cummings, 1986).

Hospice care in the United States today is much different than what Florence Wald had envisioned in the early 1970s. It has become a movement with different leaders, different goals, and different paths, influenced by the state, the health care industry, and powerful interest groups. From the confluence of social movements in the 1970s, the death-and-dying movement emerged. Elisabeth Kübler-Ross' popular book, *On Death and Dying* (Kübler-Ross, 1969), moved the nation to focus on the needs and care of the dying. Euthanasia and right-to-die laws were being proposed in state legislatures throughout the country. And, women's reproductive rights were at the center of the women's movement. In response to these new movements, a powerful counter movement emerged, sponsored by right-to-life groups, which opposed women's reproductive freedom and the removal of life-support mechanisms and the right-to-die. At the same time, a consumerism movement that questioned medical authority was also beginning to emerge (Buck, 2005). The consumer advocates who supported patient self-determination countered by the right-to-life ideologues would prove to be key in the policy discourse that spanned the institutionalization of hospice the United States. Medicalization of when life begins and when life ends is at the center of the contestation today. The Medicare hospice benefit emerged from this confluence of social movements and the state's interest in cost effective care (Hastings, 1993; Paradis & Cummings, 1986).

In 1983, hospice care was eventually added to the Medicare benefit package, where it became rationalized and routinized as it was increasingly absorbed within the

bureaucratic health system run by medical professionals whose services were governed by regulations, audits, and evaluation. Field and Johnson (1993) cited Andreski's description (1984) of Weber's features of bureaucracy. Bureaucracies are characterized by: division of authority, laws, and regulations; hierarchy of communication channels; training required for work; and separation of official activities (Field & Johnson, 1993, p. 1368). All of these elements are part of hospice today. According to Weber, routinization is essential if movements are to survive their initial charismatic leadership (Andreski, 1984).

In England and the United States, concerns arose (and remain today) about retaining the ideology of the hospice movement: core ideals of holistic care that meld physical care with the emotional, social, and spiritual needs of patients; delivery of care by nonhierarchical multidisciplinary teams; inclusion of the family; and the creation and maintenance of a community of volunteers. Successful hospices are "characterized and sustained by an ethos of commitment and reward within which unpaid voluntary workers play a significant role (Field & Johnson, 1993, p. 215)." The motivation of volunteers is dependent on this ideology. In contrast to this approach, to a great extent, hospice care in the United States has become rationalized, routinized, and modified by the social institutions of medicine and commodified by the health care market with the assistance of the state, the main purchaser of hospice care through Medicare.

Hospice Codified in U.S. Law

The U.S. Congress discussed hospice benefits as part of the pilot project that created the New Haven Hospice in the 1970s. In 1982, the hospice benefit was amended into a comprehensive tax reform bill, the Tax Equity and Fiscal Responsibility Act

(TEFRA), during President Ronald Reagan's first term in office. The bill was intended to reduce the government's spending on social programs, including uncontrolled expenditures on Medicare, the state-sponsored program that covers hospitalization costs for the elderly (Brock & Foley, 1998). In the late 1970s and the early 1980s "neoliberalism" emerged in U.S. politics. It was reflected in dominant partisan ideologies that sought to curtail the state's spending on health care and to promote the market as a tool to control costs (Harvey, 2005). The hospice benefit was sold to Congress as a compassionate way to avoid costly hospitalizations and to save money during a person's last year of life. It is the only Medicare benefit that has the expectation of being cost-effective (Hastings, 1993; Mor, 1987).

The Medicare Conditions of Participation (COPs), written after passage of the hospice amendment, regulate hospices (Lynn, Shuster, & Kabcenell, 2000). They reflect a medicalized version of the interdisciplinary philosophical origin of hospice care, which includes a constellation of coordinated services led by a physician. The COPs have not been formally revised since their initial promulgation over 2 decades ago. However, the Centers for Medicare & Medicaid Services (CMS; formerly the Health Care Financing Administration (HCFA)) within the U.S. Department of Health and Human Services, formerly Health and Welfare (HEW) promulgated new COPS in 2002 and is currently engaged in the rulemaking process (Caring, 2002). The COPs include medical and nursing services, symptom management, spiritual care, homemaker services, social work services, and short-term inpatient care to provide respite care for caregivers and to treat a patient's symptoms. Volunteers are required to provide a minimum of 5% of the total

paid patient care hours, and bereavement services for family members are to be available for up to one year after a patient's death (Government Accounting Office, 2004).

Under the regulations, a physician must certify that a patient has a life expectancy of 6 months or less, if his or her terminal illness has run its normal course, and that the patient is willing to forgo any curative treatment to be eligible for the Medicare hospice benefit. This requirement has been identified as a barrier to physician referral for hospice care because of inaccurate medical prognostication (Jennings et al., 2003; Sherman, 2000). Patients are permitted to remain in hospice care beyond 6 months if they continue to show signs of decline. Patients are also permitted to revert to regular Medicare at any time.

The COPs define four levels of care that are reimbursed on a per diem basis. In 2001, routine home care (RHC), which accounted for 96% of Medicare hospice billing in 2001; continuous hospice care (CHC) of at least 8 hours of care within a 24-hour period delivered by a registered nurse, which accounted for 1.2% of Medicare billing; intermediate respite care for caregivers (IRC) covers up to 5 consecutive days in an inpatient setting, which made up 0.2% of billing; and, general inpatient care (GIC) for symptom control, which accounted for 2.6% of billing in 2001. Medicare also imposes an annual aggregate payment cap on hospices to ensure that hospice care costs do not exceed the commensurate cost to Medicare of inpatient care. The total annual Medicare payments to a hospice may not exceed a per-patient amount set annually by Medicare multiplied by the number of patients who received care from that hospice during the year (GAO, 2004).

CHAPTER II: THEORETICAL FRAMEWORKS

Classic and Neoclassic Economic Theory

Capitalist society in the United States is organized around an economic market in which prices are determined by interaction between buyers (purchasers or consumers) and sellers (producers or providers). In market terminology buyers, demand goods and services and sellers produce the supply of goods or capital and services or labor. In the United States, the “medical industrial complex” (MIC) is a system of economic markets subsidized by the government, where health care is bought, sold and traded by companies, corporations, and insurers all concerned with making a profit, or, in the case of the individual consumer of health care, with avoiding financial disasters by their illness. (Estes, 2001b; Light, 2004b; Starr, 1982; Waitzkin, 2001). Health care services and products are traded within our neoclassic economic market and theories applied to the economy, the market, and the state, help explain the allocation of scarce health care resources.

Classic Economic Markets were born in the late 1700s. Adam Smith fathered the concept of the classic “ideal market” and described an almost magical power of the market, “the invisible hand” that guides individuals to pursue their self-interest(s) and to produce the right kinds and amounts of goods and services that will compete with other producers of similar goods. According to Smith, all of society benefits from this competition in the market of goods and services. Consumers enjoy lower prices as a result of competition, and successful competitors profit (Hargrave & Ashwin, 1996). Smith warned against monopoly power of a limited number of sellers. A monopolist can raise prices and not lose customers because there is no alternative (Folland, Goodman, &

Stano, 2004c). Perfect competition is a market in which “the individual seller or buyer is so small relative to the total market that the actions of the seller or buyer have no effect on the market price” and that “each producer's output is indistinguishable from their competitors” (Fuchs, 1993, p. 166). Smith’s perfect market requires “perfect information on both the seller and buyer sides of the market.” Smith’s two conditions for success of the market’s magical slight of hand, were that the market had to be free of intervention by the state, and that competition among suppliers was essential (Hargrave & Ashwin, 1996).

While Smith is renowned for his “invisible hand,” he made other noteworthy contributions to the field of economics. He identified two types of value, the price or exchange value that goods or services (labor) could garner, and use value, the value of goods and services specific to individuals regardless of their exchange value. Hospice care relies on the “use value” of unpaid caregiving by wives, daughters, other family members and friends who save the state (Medicare) money.

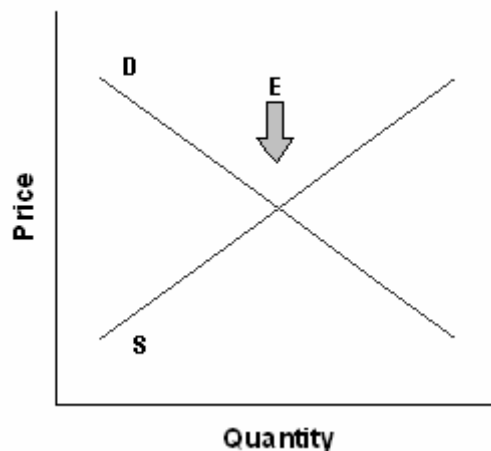
Smith also posited that economics must be concerned with ensuring access to (or “provisioning of”) the “creation and distribution of the necessities and conveniences of life” (Strober, 2003, p. 148). According to Callahan and Wasunna (2006), Smith cautioned that society could not flourish if members of society were poor and miserable. Callahan and Wasunna quote Smith (1776) as saying, “equity requires that those who help produce that which is needed by everyone should themselves be tolerably well fed, clothed and lodged” (p. 36). It would be logical to add the word “healthy” to this description. Achieving equity for those who help produce that which is needed, as Smith’s instruction describes, is unlikely; although, providing adequate food, clothing,

health care and lodging for those who produce the supply protects against social unrest and disharmony. In the U.S. health system, labor unions often negotiate for workers (the producers of health services) to be adequately paid so they can be clothed, lodged, and fed; thus avoiding the social unrest of a strike.

The neoclassic economist Jean-Baptiste Say, a protégé of Smith, posited “Say’s Law” that an increase in supply goods will lead to an increase in demand, or “supply creates demand” and so was born the phrase “supply-side economics.” As described previously, classic and neoclassic economists held that purchasers (who create demand) make rational and informed decisions to optimize their well-being. In an ideal market a point of equilibrium will eventually be reached where the mechanisms of supply and demand meet (see Figure III-1). This point determines the “price equilibrium” for goods or services (Hargrave & Ashwin, 1996).

Figure 1 Supply and Demand Equilibrium

x = Quantity y = Price S= supply D= demand E = price equilibrium



Source: (Samuelson & Nordhaus, 1985, p. 65)

The supply and demand economic model describes how prices vary as a result of the supply and demand for a product or service. The supply is the quantity of a product or service that the sellers or producers/providers of the product or service are willing to sell at a given price at a given time in a specific location. Supply requires “stock” of resources often called capital, such as labor, physical plant, and financial resources for production of output. Health care requires a supply of professionals, technology including pharmaceuticals, and health care facilities. Demand is the quantity of that product or service that buyers (purchasers or consumers) are willing to purchase at a specific price, and that they have the financial capacity and desire to purchase. Individuals, insurers and the state are the purchasers or demanders of health care services. Production of the supply of products and services is dependent on available stock or resources. A scarcity of supply of products or services will result in a price increase; a surplus of supply of products or services will cause prices to fall. The determination of price includes the cost to produce products or services and what the buyers are willing to pay.

In a market economy, economists expect that the supply and the demand will eventually reach equilibrium at a specific price. Price varies as a result of the balance between the availability (supply) of a product/service and the demand for the product/service. “Price” is an important measure in economics. Supply and demand analysis attempts to predict equilibriums with respect to supply, demand, price, and capital costs (Folland, Goodman & Stano, 2004b).

Price and supply or the quantity and availability of products and services are influenced by causes other than consumer demand that shift the price equilibrium. Technology and increased efficiencies due to economies of scale that reduce production

costs and increase supply result in suppliers decreasing price. Increased material or wage costs requiring increase production costs result in price increases. Impediments to provider supply, such as entry into the market (start-up) costs that increase production costs, also increase prices. The determination of the price is made by considering all the costs of making all the products (Folland et al., 2004a).

In hospice care, the state, through Medicare's reimbursement for hospice care, influences both supply and demand. The state provides a subsidy for the supply of hospice services as well as funding of medical, pharmacy and nursing schools (Feldstein, 1998). Say's law says "increased supply creates increased demand" (Hargrave & Ashwin, 1996). The state also creates barriers to supply such as a Medicare reimbursement rate that relies on the family to provide 24-hour care; and, Medicare regulations that "medicalized" hospice requiring physician referral and involvement in care. Many physicians are reluctant to refer patients to hospice because the regulations require physicians to give patients a six month prognosis. Limiting the supply limits access to care (Daugherty, 2004; Jennings et al., 2003; Lamont & Christakis, 2002; McCarthy, Burns, Davis et al., 2003; Naik & DeHaven, 2001; Sherman, 2000; Stillman & Syrjala, 1999).

Thomas Rice (1997) critiques the market approach to health policy suggesting that efficiency and equity require redistributing income because in a market, only the wealthy will be able to buy expensive technology, creating inequity. In addition, Donald Light (2000) joins Rice in a critique of the concept of buyer "choice" in health care because in health care markets, patients' choices are influenced by physician recommendations and advertising. Consumers do not have full information and are often not the best judge of

what will maximize their health or a peaceful death. In hospice care, there is variation in what services hospices provide. Some hospices provide just the minimum core services required by Medicare, while others provide more technology such as intravenous medication, radiation therapy for pain, massage and acupuncture (Gage, Miller, Mor, Jackson, & Harvell, 2000; Rosenau & Linder, 2001). As someone is dying, patients and families have limited knowledge regarding what care might be helpful and have limited ability to “comparison shop” for hospice care.

Light cites additional requirements markets must meet to function and why these requirements do not apply in health care (2000, p. 395-96). Among them are two additional requirements relevant to hospice care. The first is the requirement that there be many buyers and sellers, thus avoiding market control by one seller or one buyer. In the case of hospice care, as for-profit hospices acquire increasing market share, the models of care of for-profit hospices will become dominant. Small nonprofit hospices will change services to better compete and service diversity will be lost (DiMaggio & Powell, 1983; Schlesinger, 1998). Second, markets require that buyers and sellers be unrelated to each other to avoid influencing one another’s economic behavior. Many hospices today are affiliated with managed care, home health, hospital, and nursing home companies all of which make referrals to hospices with whom they are related, so they may influence one another’s economic decisions.

Light (2000b) insists that for the market competition to function in health care, regulatory and structural designs are necessary. The ultimate success or failure of health systems, according to Light (2000b), is determined by the norms and laws that socially construct markets. These socially constructed norms and laws are central to State Theory.

State Theory

In our advanced capitalist society, dominant classic and neoclassic economic theories and perspectives regarding the economy are at the center of theories of state (Estes, 2001a, 2001b; O'Connor, 1973). In democracies, societal values and norms are reflected in the decisions and laws made by the state. The state is made up of major social, political and economic institutions, elected and appointed politicians in every branch of government, the military, and educational, health and welfare organizations (Estes, 2001a; Estes, Biggs, & Phillipson, 2003; McKinlay & Marceau, 2004b; Waitzkin, 2001). The state is funded at public expense, through taxation, and it is dependent on the generation of income from private property and capital (Estes, 2001a; McKinlay & Marceau, 2004a; Offe & Ronge, 1982).

McKinlay and Marceau (2004b) describe the three general theories of the state as Marxist, Pluralist, and New Right. There are several iterations of each of these and personal values and perspectives determine which is most ideology is dominant. Estes (1997) calls these ideologies because each of these theories represent deeply held beliefs that provide an orientation for making sense for the world and what is right and wrong within the world. A pluralist perspective views the state as a neutral body protecting the public interest by establishing rules and ensuring that the democratic process reflects the public will through mediating and accommodating the clash of interest groups.

Pluralist theory has been critiqued by Estes (2001b) and Connolly (Estes, 1988) for several reasons, among them that pluralist theory implies that the public will can be represented by organized interests. They assert that all organized interest groups are not equal and suggest that interest groups do not reflect individual democratic participation of

all groups. In particular, the legitimate interests of oppressed and disadvantaged populations are not well represented (if at all) by organized structural interest groups.

Barr, Lee and Benjamin (2003), in explaining the role of special interests in pluralism, cite Peterson (1993), who described health policy formation until the last two decades of the 20th century as a process dominated by groups “characterized as an iron triangle including legislative committees, executive branch agencies and private interest groups such as the AMA” (p. 203). Neopluralists acknowledge that in western democracies, with advanced capitalist economies, major multinational corporations now exert significant influence on the state (McKinlay & Marceau, 2004b). Corporate health policy interests were successful in competing for the AMA’s position in the “iron triangle,” during the last 25 years of the last century and today, as a “counterveiling power” (Light, 2004a, 2004b).

McKinlay and Marceau (2004a) contend that evidence suggests that the United States is moving from a pluralist perspective to a New Right perspective. They suggest that “the medical profession thrived during the era of the pluralist state” as a major interest group with considerable public support granted by their expert position requiring extensive scientific knowledge (p. 195). In the creation of hospice policy in the late 1970s and early 1980s, the American Medical Association (AMA) ensured that physicians were “in charge” of the interdisciplinary hospice team.

The New Right perspective holds the state as the central independent actor in shaping behavior. In their recent chapter, “The End of the Golden Age of Doctoring,” McKinlay & Marceau (2004a) credit “the New Right (in combination with the business community) [as] portraying physicians as greedy and willing participants in fraud” (p.

194). They suggest that the support of the state is shifting from “protecting the interests of the medical profession to advancing the interest of financial and industrial owners of an ever more corporatized U.S. Health Care system (p. 195).” Estes (1997; 2001a) suggests that the New Right perspective combines free market ideology, which she calls the “neoliberal perspective,” with a “neoconservative perspective” that relies on “the emotional attachment to authority and imposed tradition” (p. 102). Neoliberals reject state intervention in economic and social life and support only market competition, privatized services and individual liberty. The New Right ideology makes maintaining the national defense the only justification for state intervention.

President Reagan’s legacy exemplifies the New Right/neoconservative ideology. It maintained dominant power relations via the country’s adoption of the ideologies of free market and the nuclear family. Reagan accomplished this by “creating cultural images” that were reproduced through the media and experts by focusing on the economic (budget) crisis and by implementing solutions that relied on familiar organizational structures and professions. Reagan’s solutions reified dominant power relations and had consequences for race, class, and gender inequities (Estes, 1997, p. 201). The Medicare hospice benefit was crafted in response to the budget crisis as a solution that would save the state money. It relied on the “traditional family” caring for dying loved ones. And, in doing so, it reproduced the role of women in the family providing care in the home rather having a career outside the home. The emotional attachment to this traditional role came at a time when the social movement against “medicalized” death was part of the mainstream.

The third state theory perspective, Marxist state theory, considers the state as acting to maintain the class system and the dominant class’s economic superiority and by

exploiting and subordinating certain groups. Capitalism as an economic system relies on the subordination and exploitation of classes of workers. The United States has historically rejected Marxist theory because capitalism is so embedded in the dominant values of the country.

Economic Crises of the State

There are few historical exceptions when the state has had a balanced economy and expenditures have not been higher than revenues. This pattern of “fiscal crisis of the state” (O'Connor, 1973) is characteristic of advanced capitalist societies. Decisions the state makes to accommodate fiscal crises are reflective of ideologies. O'Connor posited that the capitalist state has two functions: first, preserving its own existence by legitimating its existence and providing minimal benefits needed to contain social unrest and promote social harmony; and second, the accumulation of private wealth.

An economic Marxist, James O'Connor (1973) was concerned with “fiscal crisis of the state” in advanced capitalist societies, contending that the market was not the cause of government expenditures and the tax burden. He posited that government expenditures grew out of structurally determined economic conflicts between classes and groups. In advanced capitalist economies, the contradictory relationship between spending on the public sector and the private sector causes the state's fiscal crisis, and jeopardizes its survival. According to O'Connor, in advanced capitalist economies, the state is so dependent on tax revenue from large private capital that the power of large capital ultimately controls the state (O'Connor, 1973).

O'Connor posits that state policies, despite reflecting differing political ideologies, are described as administrative functions so they will not be drawn into the political

discourse. Hacker (2002, p. 15), calls this process “subterranean politics” because the political participants involved in the process represent the two branches of government which are removed from electoral institutions, the executive branch and the courts. The result of subterranean politics is that policies are formed in the domain of market relations. Hacker suggests that the public is unaware of policy making processes that privatize social welfare programs and it is difficult to mobilize the public because citizens cannot easily identify specific benefits that might be threatened.

Economic growth and ensuring private profit are considered a function of the state according to Alford and Friedland (1985), Estes (2001b), and O’Connor (1973). Without the taxes paid on the profit from increasing accumulation of private capital, the state would face fiscal crisis. The state spends social capital on the private sector in the form of investments designed to increase productivity including education, and on consumption of goods and services that lower the reproduction costs of labor, such as development of technology. Additionally, it spends on infrastructure to facilitate consumption, such as airports, seaports and roads, thus ensuring the successful private accumulation of wealth. As wealth accumulates to primarily one class, discontent and social disorder, in response to unemployment, poverty, and illness, emerge among the lower classes. The state must establish and ensure its continued legitimacy, preventing social unrest, and maintaining social harmony. To do so, the state subsidizes public sector social expenses that fund projects, such as welfare, health care, and community agencies, to alleviate some of the negative consequences of the accumulation of private capital that are born by the lower class and the environment, and to avoid the organization of contestation by the lower class against the state.

These two competing and contradictory, public versus private, functions along with the state appropriation of social capital to claims of special interest groups generated by the political system, lead to a fiscal crisis of the state (Alford & Friedland, 1985; Estes, 2001a, 2001b, 2001c; McKinlay & Marceau, 2004b; O'Connor, 1973). Estes (2001b) and Offe and Ronge (1982) posit the same contradictory functions of the state and suggest that the electorate is led to believe that it is their will in electing good fiscal managers and in paying their taxes, not the success of capital reinvestment, that ensures access to needed resources. In this way, if the economy fails, elected officials of the state are held accountable by the public. Estes (2001b) asserts that “ultimately how many resources are controlled by the state or the private economy is a political decision” and are subject to “political and economic struggle” (p. 8).

Feminist Economic Theories

Estes (2006), references the works of Connell (1987) and Acker (1998) who posit that through norms and social patterns the power of state extends beyond the distribution of resources and in fact reproduces the capitalist accumulation of wealth not only through property rights that lack parity for women, but also through caregiving responsibilities reproduced by the judicial system and welfare system. Gendered social norms are thus produced and reproduced by the state (Estes, 2006). Feminist theory examines how “male powerholders” define public and private concerns in ways that are of great importance to women (Mansbridge, 1998, p. 11). What is deemed to be in the public good is defined by male powerholders. This has relegated women’s work of informal caregiving to the private world of home and family. Informal care is unpaid care, e.g. husbands being cared for by their often frail wives during terminal illness and death. The

unpaid work of women caregivers makes access to hospice care possible for husbands and results in late admission to hospice for surviving widows who often spend their final days in poverty after all the family resources have been used up. And, when they can no longer live independently, they are institutionalized in private, state-subsidized long-term-care facilities, where they may or may not receive hospice care as they die (Emanuel et al., 1999). This example is a gendered norm of a public good.

Women's social movements and feminist organizations are often characterized by a sense of "collectivity" in which all members have equal voice in decision making (Kuumba, 2001). According to Alter (1998), the study of feminist organizations reveals a strength of ideological commitment, organizational goals and political resistance. Feminists believe that people can work together for common purposes without a hierarchy of command. Alter describes bureaucratic organizations as the primary means "by which women's oppression has been sustained" (p. 259).

Feminist theorists assert that the hegemonic theories of the state and the economy have historically been and continue to be dominated by men. Acker (1998) posits that gender plays a key role in the reproduction of the working class and that the demands of working-class daily life are predominantly women's work. Estes, Biggs, and Phillipson (2003) quote (Ciscel & Heath, 2001, p. 407) in their description of a "new form of patriarchy ... with women performing gendered labor in the service sector of the capitalist marketplace and the unpaid domestic labor of the home." Kuumba (2001) identifies structural ways in which social life and the division of labor are organized separately according to gender. Estes, Biggs, and Phillipson (2003) describe the social structures of marriage and kinship as preventing women from gaining access to networks

of power, money and culture. Feminist theorists suggest that the disadvantaged social, political and economic status of women is constructed, reproduced and maintained by gender regimes socially constructed by the division of labor and power in the dominant forces of the state, the market and the family (Connell, 1987; Estes, 2006). Estes and Weitz (2000) and Estes (2001b, p. 17), suggest that the disadvantaged power position of women has four major implications for women and health care:

1. There is a gendered relationship between socioeconomic structures and health over time.
2. There are gender specific implications of health care financing and policy.
3. There is a gender bias in the disease-based medical model of health
4. There are health consequences to the gendered nature [and responsibilities associated with] caregiving.

Hospice in the United States exemplifies all of these. Some examples include how socioeconomic structures reproduce the expectation that women's work outside the home is unimportant and can be abandoned to care for an ailing family member. Gender-specific health care financing and policies often result in institutionalization because women outlive their male counterparts. Gender bias often fails to recognize women's chronic illnesses as terminal illness eligible for hospice care and there exists an expectation that frail elderly women can care for dying husbands. And the health consequences of the caregiver are known to increase mortality (Schulz & Beach, 1999).

The Encyclopedia of Political Economy (O'Hara, 1999) suggests that feminist economists "view economic discourse as a social practice with concrete historical origins." Feminist economists argue "for transformation rather than reform" (p. 335). Feminist economists critique the worship of abstract individualism of neoclassical

economics (Dawson, Hatt, Watson-Brown, Baxter, & Bertaux, 2000; Estes et al., 2003; Hewitson, 1999). Estes (2006) emphasizes the persistent inequalities of power created and maintained by the market. In contrast to neoclassic market competition economists, feminist economic principles are based on cooperation rather than competition and consider gender, race and ethnicity as important concepts. Feminist economists look at how institutions and social norms evolve over time (Blank & Reimers, 2003) and challenge the male domination of the profession of economics (Dawson et al., 2000).

According to Dawson, Hatt, Watson-Brown, Baxter and Bertaux, (2000) feminist interpretations of science situate knowledge in the lives and values of those who produce knowledge. They posit that the economic science of the market is situated in a social context of income inequality reproduced by the state and capital which leads to the consolidation of wealth and the reproduction of economic social classes and the perpetuation of unequal power based on class, gender, race, sex and other groupings. Estes (2001b) references Collins (1990, 1991) description of these social structures as “interlocking systems of oppression (p. 13).”

Neoclassic economists suggest that in a perfect market rational choices are made, by completely informed buyers, based on tastes and preferences. A perfect market requires a balance of buyers and sellers, and consistent product quality (Budrys, 2005; Feldstein, 1998a). Feminist analysis suggests that the market itself influences tastes and that tastes can change through interactions and the media (England, 2003). Estes (2006) asserts that the choices available to women and other socially marginalized groups are constrained by the state, the market and the family. [Hospice care paid for by Medicare is by definition only given in the home (with the exception of short periods of respite care),

and is offered as a choice only to families who can afford to pay out of pocket for formal 24-hour-day home care, or who can afford to leave the workplace to provide care. Few women or marginalized groups have the financial resources to do either.]

England and Folbre (2003) insist that not every buyer is a rational actor making choices based on self-interest, but that feminist principles consider the community's well being because of emotional connections, empathy, and altruism rather than the individualist separate model of self. Dawson and colleagues (2000) suggest that the state is the institutional expression of the ways in which people value other people or have "ethical significance to one another."

Quadagno (2004) and Estes (1979, 1988; 2001b) suggest that public policies for income, health, long-term care, and social services come out of the social struggles and dominant power relations of the era. Both theorists use a political economy perspective to examine the broader social processes that determine how resources are distributed. Jacobs posits that the political economy is broader than the traditional "market place and examines exchanges between the producers, consumers, politicians and regulators" with "dimensions of self interest in each of the four groups," thus removing the protection of consumer interests as a responsibility of the state (Jacobs, 1980, p. 261).

The Political Economy

Estes (2001b) asserts that societal, institutional and individual interrelationships are inter-linked and proposes that the political economy perspective enables linkages between macro, meso, and micro levels of analysis. Embracing the perspectives of feminist economists, Estes includes evaluating the dominant social ideology and power struggles between interrelated systems of oppression as key to understanding social

policy. The process of gender domination, class domination and normative moral codes of society intertwine to form the dominant ideology (Estes et al., 2003). Dominant ideologies impose their will on others throughout society. The dominance of the medical model, reified by the state and the market, imposes decisions about what is best for patients at the end of life. The dominance of profit-motivated health care systems influence types of care available in the market place (Mahar, 2006). Hence, the availability of hospice care has been limited because it was not profitable (with the exception of hospice care for noncancer patients in nursing homes).

Like state theorists, Estes' political economy perspective considers the effects that public (state) spending has on protecting and enhancing the flow of capital for profits and investments in the private economy (Estes, 2001b). Estes' (2001a) perspective, based on O'Connor (1973) and others (Habermas, 1975; Offe & Ronge, 1982), suggests that the dominant ideology of the Reagan presidency continues through today for two reasons: first, it is a neoliberal ideology which is pro-market and anti-state in terms of domestic and social intervention. And second, the neoconservative ideology invokes "nature," and "appeals to tradition and authority" (Estes, 1997, p. 201) and is based on the traditional patriarchal family structure. According to Estes (2001a, p. 102), neoliberalism has "rekindled a gender war and laid the affective base for increased pressures of family responsibility". Neoconservative thought is consistent with the views that would consider women as the cause of a long-term care crisis because they live longer, become dependent, and need to rely on state supported welfare services (Estes, 2001c). Estes asserts that "policies created by the dominant power group made up of white males

[politicians among them], serve the needs of those who created them,” and such powerholders do not share with women the “benefits of the longevity revolution” (p. 103).

The evolution of health care in the United States has been shaped by the political economies of the time. Hospice care, and the addition of the hospice benefit to Medicare, can be viewed through the lens of all of these theories and perspectives.

Resource dependency and political economy.

The political economy perspective adds to the organizational theory of resource dependency. Resource dependency theory is useful in considering the influence of different elements in the environment and the extent to which an organization has the capacity maintain stability and to survive and gain a competitive advantage (Thompson, 1967). In the market, organizations must acquire resources by interacting with their social environments (Pfeffer & Salancik, 1978). In competitive markets, interorganizational relationships are more common (Zinn, Mor, Castle, Intrator, & Brannon, 1999).

Pfeffer and Salancik assert that organizations take actions to modify the environment and to influence the political, legal, and economic environment to establish functional stability. Hospice providers work together to influence and modify the environment in which they provide care. The hospice “trade organizations” set standards and lobby the state.

Pfeffer & Salancik posit that in order to reduce competitive uncertainty, organizations create “symbiotic interdependence” within industries (p. 123). In the nursing home industry, Zinn, Mor, Castle, Intrator, & Brannon (1999) suggested that in competitive markets, interorganizational relationships were more common. What Pfeffer

and Salancik would call “inter-organizational cooperation” (p. 152) between hospice providers and long-term care providers, was determined to be in violation of U.S. anti-trust law. an investigation known as: “Operation Restore Trust” launched in the late 1990s by the U.S Department of Health and Human Services, cited several home health agencies, nursing homes, and durable medical equipment suppliers (Morris, 2003) for violating anti-kickback laws in their referral processes (Herbst, 2004).

Hospices are dependent financially on Medicare as the primary purchaser of services (financial resource). Hospices are also dependent on referrals from hospitals and nursing homes (skilled nursing facilities). Interorganizational resource relationships are often accompanied by transaction costs and expectations (Zinn et al., 1999). When hospices seek Medicare reimbursement, they enter into an interorganizational relationship with the government and must agree to comply with the regulations set forth by Medicare which can be considered a “transaction cost.” Hospitals operating at capacity need rapid transfers of patients once referrals are made and hospices must decide if they can accommodate the transaction cost of patient admissions at any time of day or night. Referral source, payer source and site of care are variables that will be examined through the resource dependency lens.

Hospices must consider the availability of resources in a competitive market environment when making decisions such as where to locate of services, and from where to seek referrals. Environmental market demand factors such as the percentage of aged in the market (county), the number of deaths, the number of health facilities (hospitals, skilled nursing facilities and residential care facilities), sociodemographic factors and income levels all must be considered in making strategic decisions to reduce uncertainty.

In environments where resources (e.g. patient referrals) are abundant, interorganizational relationships are diminished.

The appearance of and increased number of: “chains” in hospice care could be considered an example of an organizational interdependent response to changes in the environment, to improve the ability to compete with larger organizations (Pfeffer & Salancik, 1978). Referrals by for-profit nursing facilities to for-profit hospices are an example of an interorganizational relationship in which both organizations benefit financially. Resource dependency theory would predict that large for-profit hospices located in urban areas carve out a market niche in skilled nursing facilities with large percentages of Medicare beneficiaries.

Pietroburgo (2004) in her article: *Joining forces, joining futures: hospice at the crossroads* poses a hypothesis that hospices restructure based on a) a hospice's economic resource base, b) their political resource base, and c) the decision making capacity of organization, (p. 212). She suggests that political economy and resource dependency theories explain the restructuring of hospice care from small community based nonprofit organizations to large, corporate investor owned chains. This emergence of the market influenced by the political economy in hospice care is better understood by considering how dominant economic and political ideologies shaped health care in the United States.

Hospice as Shaped by Neoclassic, Neoliberal Ideologies

Capitalism and Medicalization in the 20th Century

The rise of scientific medicine was fueled by corporate capitalism (Starr, 1982). The philanthropic foundations established by industrial (corporate) capitalists in the early twentieth century funded scientific medicine because it helped legitimize the inequalities

of capitalism by diverting attention from the social causes of diseases”. It also maintained the health of the workers, thereby increasing production and accumulation of wealth. Wealthy industrialists Carnegie and Rockefeller donated \$154 million to an elite group of physicians to reinvent medical care (Starr, 1982).

During the early decades of the 20th century, state by state, medical associations and their elite academic partners passed licensure laws which provided early legitimacy of medicine through codification, in statute and regulation, by the pluralist state, in which organized medicine was a powerful interest group influencing the election of politicians (McKinlay & Marceau, 2004a). These state promulgated policies that limited who could practice medicine, thus barring entry into the market, preventing competition, and creating a medical monopoly of elite licensed providers (Light, 2004b). Physicians became the dominant members of hospital boards and the goal of attracting insured patients or those who could afford to pay transformed hospitals from charitable organizations into medical centers. In order to dominate the treatment market, the AMA lobbied for, and the state granted, prescriptive authority only to physicians under the guise of protecting patients. Medicine controlled the profession through licensing boards, the hospitals, and pharmaceuticals and a monopoly was born with the assistance of the state (Light, 2004b).

Health care became inaccessible to many during the Great Depression. Hospitals could not afford to provide free care. The omnipresent poverty of the Depression, as well as lack of access to health care, were significant policy challenges during the administration of President Franklin Delano Roosevelt (D). In the early 1930s, Roosevelt did not include a proposal for national health insurance in the Social Security proposal

because it would have jeopardized passage of the act by incurring the wrath of two powerful interest groups, the AMA and organized labor (Starr, 1982). And so, the “market” continued to determine who received health care and who did not. Demand decreased because many people could not afford care and physician incomes dropped. The American Medical Association was forced to drop their opposition to private health insurance, and they created Blue Shield insurance to remain in control of their fees and their practices (Starr, 1982).

The first major state support for health care as a private industry was the Congressional authorization for the Hill-Burton program contained in the Hospital Survey Construction Act of 1946. The act appropriated funds for a massive building program for community hospitals that continued through 1971 (Starr, 1982). The state invested in expansion of the private sector medical care and its accompanying technology, or the accumulation of private capital. The construction produced jobs and reduced unemployment thus legitimating the actions of the state. The state created a government subsidy of supply of hospital beds which was followed by a demand for services; and Say’s Law proved itself. Congress also appropriated funds for biomedical research and medical education. Increased medical competence fueled by state-funded biomedical research resulted in medical specialties, reifying medical dominance and increasing consumer expectations of medical science. Hospitals grew and with them health expenditures. The Medical Industrial Complex was born (Starr, 1982).

During the first half of the 20th century, the population of people over 65 had grown from three million to twelve million. Two of every three people over 65 lived on less than \$1,000 per year and just over 10% had health insurance. Many attempted to

purchase health insurance and were denied because they were considered “bad health risks” (Corning, 2006). Dissatisfaction with access to health care was growing among the elderly and their families. Truman’s (D) administration began the work on what would eventually become Medicare. He made a strategic decision to narrow the proposal to cover only the aged because they were more “deserving” and to legitimize it by linking it to the popular Social Security program (Marmor, 2000). It would be another decade before the proposal would be heard by a Congressional committee.

After World War II, the U.S. population became more mobile and the concept of the nuclear family emerged. Cities and suburbs began to expand; women who were employed during the war continued to work outside of the home and hospitals and physicians were looked to for the latest technological cure (Buck, 2005). Medical science discovered and created “life sustaining” technology and death moved from the home to the hospital (Charmaz, 1980).

Additional state subsidy for the supply of health care to appease the growing unrest among the elderly and stave off a fiscal crisis was enacted during President Eisenhower’s administration, along with the passage of funding for construction of chronic-disease facilities and nursing homes, to provide care for the chronically ill (Corning, 2006). In doing this, the state again made a substantial investment in private industry, and assisted in private accumulation of wealth. The economy gained from new jobs in construction in the health-care industry, in technology, and in biomedical research. Unfortunately, the need to assist the elderly in paying for medical care continued to grow.

Health coverage was a central issue in the 1960 presidential race between Nixon (R) and Kennedy (D). Between 1950 and 1963, the number of elderly had grown from 12

million to 17.5 million and the cost of hospital care rose by over 6% per year (Corning, 2006). Although expansion of insurance coverage for the elderly and the poor did not occur before President Kennedy's assassination in 1963, it was a priority for President Johnson. Family health costs during the decade between 1953 and 1963 increased by 70% due to the 90% increase in the cost of hospitalization and the 37 % increase in physician fees. By the time Medicare passed in 1965, 70 % of the population had hospital insurance but the poor and the elderly, those in the greatest need, were excluded (Mahar, 2006; Stevens, 1996). The choices for the elderly needing to be hospitalized were to spend their life savings, rely on help from family, seek welfare which was very limited, or rely on charity from the hospitals; many avoided seeking care. In the 1962 best selling book, Harrington (1962) described the 40 to 50 million U.S. citizens who were poor and lacked access to health care, among them 18 million people over 65 years of age suffering from illness, invisibility and isolation. Many of these other Americans were minorities. This inequity, along with countless others, set the stage for the civil rights movement and the passage of the Civil Rights Act of 1964, one of the most important laws enacted in the twentieth century (Barr et al., 2003).

1964: The passage of Medicare and Medicaid.

According to Geyman, (2006)the passage of Medicare and Medicaid by Congress in 1964 reflected a great "corporate compromise." "Powerful private economic interests accepted government-financed [state] programs playing a larger role in return for acquiring new markets in their own self-interest" (p. 49). The "three-layer cake" proposal by then chairman of the House Ways and Means Committee, Wilbur Mills, included universal hospitalization for the elderly (Medicare Part A), physician coverage

for the elderly (Medicare Part B), and a state-federal program for the poor and indigent (Medicaid). The major opponents to universal health care had been insurers, hospitals, and physicians. This compromise allowed the insurance industry to concentrate market to a lucrative young, low-risk pool by eliminating the high-risk pool of the elderly and the poor, where illness was concentrated. Hospitals were promised reimbursement for care including care that would have previously been “charity care,” and physicians (represented by the AMA) could become well compensated for caring for the elderly many of whom, prior to the passage of Medicare and Medicaid, could not afford to pay for care (Geyman, 2006).

With the creation of Medicare and Medicaid, the state legitimized its role in protecting the public and avoided further social unrest, while committing substantial state investment in private health care and toward the accumulation of private capital while further reifying the dominance of medical science. The physician’s role in the market as the “dominant expert” was legitimized by the state’s reimbursement of medically-directed care. Patients who lacked medical expertise relied upon and trusted physicians. Physicians facilitated the demand for care by referring patients, prescribing medications and procedures, and also supplying the care (Starr, 1982). Physicians’ simultaneous role in both supply and demand is cited as one of the reasons the market fails to perform efficiently in health care. Further, without medical information and expertise, patients cannot determine the value or quality of treatment, leaving them dependent on the physician to determine what is valuable (Conrad & Leiter, 2004), thus demonstrating another reason that a market model is not applicable in health care.

The enactment of Medicare and Medicaid brought uncontrolled demand for care subsidized by the “state’s” purchase of cost based (or fee for service) care, provided by hospitals and physicians. Physicians had a financial incentive to treat people with insurance with expensive procedures and in hospitals because only slightly more than half of Americans with health coverage had coverage for physician office visits (Mahar, 2006). In 1966, the consumer price index rate of inflation was slightly over 3%. In the first year of operation of Medicare, physicians’ fees increased by 7.8% and hospital average daily service charge rose by 21.9% (Geyman, 2006). The state’s investment in biomedical research helped produce miracle drugs. The promise of pharmaceutical cures drove investment in the industry. By 1964 the amounts of antibiotics, sulfa drugs and tranquilizers produced in the United States had reached \$20 million and \$8 million respectively (Geyman, 2006). Heart attack patients had been brought back to life; and, patients in acute renal failure had been saved by artificial kidneys. The invention of Teflon in 1962 and its use in the newly invented dialysis machines offered hope to people with chronic renal disease, often referred to as End Stage Renal Disease (ESRD). Experimental organ transplants were being performed and physicians had begun to establish for-profit hospitals and the corporatization of medicine added fuel to the growth of the medical industrial complex (Light, 2004b).

Inflation accompanied this “uncontrolled demand” and the price of care increased. Third-party payers, or employers, through private health insurance coverage for employees, and the state through Medicare and Medicaid, were the primary payers of health care. Removing the individual consumers from the position of being the buyers of care created demand through the physicians who also supplied the services. Costs soared

and the state and insurers sought to control costs by manipulating reimbursement mechanisms to physicians and hospitals. State regulation post enactment of Medicare expanded the state's role in health care, and the state assumed a great proportion of the cost of health care (Barr et al., 2003). The state had legitimized itself by promulgating regulation to protecting consumers and subsidized the accumulation of private capital in the health industry (O'Connor, 1973; Offe & Ronge, 1982).

Although the state subsidized the supply of physicians via funding for medical education, the supply within the market, or entry into the profession, was controlled by the physicians themselves via professionally dominated regulatory boards that established criteria for medical licensure (Starr, 1982). Some hospital infrastructure continued to be subsidized by the state; however, technology and capital investment was controlled directly by the corporations.

By 1968, after only two years of Medicare and Medicaid implementation, federal funding for health care had more than tripled. Over 19.7 million people over 65 years of age had enrolled in the hospital insurance program known as Medicare Part A, and, of those, 18.6 million had subscribed and were paying a premium for Medicare Part B, which covered physician and other outpatient costs. The program had paid \$5.7 billion for inpatient hospital care (paying over 10.6 million bills), \$2.1 billion for physicians' care and other medical services (45 million bills), and \$420 million for extended care (1.3 million bills). During the two decades following its passage, the Hill-Burton hospital construction program built hospitals with the capacity of 413,800 beds (DHHS, 2006).

By the mid 1970s, the state's subsidy of unrestrained investment in the medically-dominated health industry began to generate distrust and the belief that health care,

professionally driven by medicine, had led to “greed, waste, inequalities and dubious quality” (Light, 2004a). Light (2004a) describes this as the beginning of a shift away from professional medical dominance, caused by the “countervailing powers of payers” the largest of which was the state. McKinlay and Marceau (2004a) described this as the beginning of the shift of the state from the pluralist to the New Right. Regardless, the state continued to subsidize the accumulation of private wealth.

The State’s Divestment of Responsibility to Private Enterprise

During the 1970s and 80s, the state began to “promote the sale of public goods” (Estes & Linkins, 2000, p. 161). Until the 1980s, privatization referred primarily to the state contracting with private nonprofits. The state had a long history as a partner a strong nonprofit sector providing public goods (services) which served as a safety net. The state directly subsidized the nonprofit sector in the form of grants in aid and indirectly through tax exemptions for individual and corporate charitable contributions (Bergthold, Estes, & Villanueva, 1990). The importance of the nonprofit sector at the time is reflected in the fact that “46 % of all publicly financed health dollars and more than 80 % of public social services dollars went to nonprofit organizations” at the time (Bergthold et al., 1990, p. 13). Gronbjerg (1998), along with Estes, Alford & Egan (2001) suggested that two forces in the political economy of the United States shaped changes in the non-profit sector:

[First was the] ideological dominance of the classic economical model which defines free markets and competing market organizations as the fundamental institutions of society, leaving government and nonprofits to play secondary and supportive roles; [and second, was] a deeply ingrained suspicion of virtually all public programs and authorities which are viewed as inefficient, subject to favoritism, and antagonistic to the much-preferred private initiative, unless carefully controlled and monitored (p. 138).

As a result, the public's skepticism about public programs led to the growth of nonprofits. Later, the pressure to decrease state expenditures combined with the emerging ideology of competition and individualism led to privileging of private enterprise.

Nonprofits are organizations which are legally prohibited from distributing profit, they are allowed to realize profit, but it must be reinvested in the organization. Nonprofits have significant regulatory constraints in exchange for their tax exempt status. There is a legal restriction, a "nondistribution constraint" on managerial compensation, which prohibits the distribution of profits in any form (Weisbrod, 1998, p. 73). Some nonprofits are considered "bonoficer" organizations that seek to generate revenue via the provision of private goods and services that have social value, such as the provision of health care, and they also seek resources in the form of time or money from donations. Revenue from donations depends on the organizations reputation as a provider of a "collective" good. This revenue allows the organization to engage in activities that are socially productive but privately unprofitable (Weisbrod, 1998, p. 74).

In contrast, private, proprietary organizations are "profit maximizers." They face different regulatory constraints. Proprietary firms pay taxes and cannot accept gifts or donations and rely on the constraints of consumer demand and competition to make profits (Weisbrod, 1998). Profits are distributed to owners whether individual companies, or "publicly owned" by shareholders and traded on the stock market.

Privatization uses public resources to secure profits as a priority, in addition to providing welfare. According to Estes and Linkins (2000), "the fundamental principle driving the development of the welfare state was for economic development to feed social development and, in so doing, to minimize inequality. [Yet,] privatization is an

example of an economic strategy that potentially escalates inequality” (p. 161). Estes and Alford (1990a) posit that, given the insatiable needs of private corporations for new markets in which their profits can accumulate, as well as the state’s increased budget problems and questioned legitimacy, the state is “promoting capitalist absorption of potentially profitable segments of the nonprofit health and social service sector” (p. 193).

Privatization of nonprofit services began in the Nixon administration and accelerated with the election of President Reagan (Bergthold et al., 1990). No national debate occurred as this privatization movement began. Nonprofit organizations do not have either the political clout, or, the economic clout to have signaled an alert when the move toward privatization was put on the subterranean policy track (Gronbjerg, 1998). According to Hacker (2002), politicians privatizing social welfare services rely on policy instruments that are difficult to quantify and are “produced through complex interactions among a vast range of actors” (p. 43). This makes it difficult to trace contracts with networks of private social benefit programs. These programs are easily entrenched and create policy paths that are difficult to redirect.

The privatization ideology favors competition and individualism. Privatization by replacement occurs in “two forms, the transfer of resources and responsibility from the nonprofit sector to the for-profit sector” and the “transfer of responsibility from the nonprofit service sector to the informal unpaid sector of home and family” (Bergthold et al., 1990, p. 14). Privatization also occurs by attrition where formerly nonprofit organizations convert to for-profit organizations (Bergthold et al., 1990). Privatization was advanced as a market solution to the inefficiencies of state bureaucracies. Corporate market vocabularies of “cost-effectiveness, downsizing and rightsizing and fiscal

restraint” are part of the discourse within the state and all sectors of the economy including the nonprofit sector (Estes & Linkins, 2000, p. 156).

“Privatization, or the administrative transfer of public goods and services to the private sector” was used by the neoliberals to “deregulate down (devolve) or even ... divest” the state’s “responsibilities to their citizenry” (Estes & Linkins, 2000, p. 161). This transfer of responsibility from the state to the individual is reflected in policies reforming Medicare and Medicaid since the 1980s.

During the decade between the Nixon Administration and 1980 when President Reagan was elected, the nation’s health care bill grew from \$73 billion to \$257 billion (Mahar, 2006). Reagan promised to reduce the role of the federal government and promised to control costs of public programs. Hecló (1986) described Reagan as “urging Americans to dream dreams, but these are dreams of private advantage, not public accomplishment” (p.60). Reagan spoke the “moral language of social obligation” (p. 53) and his free market was characterized as “a nation of neighbors and an economy of rugged individualists” (p.45).

Health policies of the Reagan administration, including the addition of hospice care to Medicare, were directed at reducing the federal medical care budget, restraining payments to Medicare providers, shifting payments to private enterprise, cutting benefits and claiming that health coverage causes over-utilization and inflation (Marmor, 2000). Estes and et al. (1992) described this period as a transformation from the ideals of “access and equity in health care” to those of “efficiency, competition, and profit” (p. 64). Stimulated by Reagan’s policies that encouraged competition and privatization, the size of the medical industrial complex tripled during his tenure (Estes, 2001c).

In 1981, Reagan used the omnibus budget reconciliation process to implement broad economic policy changes that involved dramatic cuts in domestic social services that had for over two decades been provided by the nonprofit sector (Estes, Alford et al., 2001, p. 62). According to Estes and Alford (1990b) and Estes and Linkins (1990b; Estes & Linkins, 2000) this was the beginning of an attack on the nonprofit sector that continues today. President Johnson had supported the development of the nonprofit sector. Reagan in contrast used the executive branch and the subterranean budget process to create investment opportunities for private capital in the areas that had been traditionally the domain of nonprofit health entities (Marmor, 2000).

The Reagan Administration implemented a new Medicare reimbursement mechanism in which hospitals were reimbursed based on patient diagnoses or Diagnostic Related Groupings (DRGs) rather than through fee-for-[every] service. This provided a financial incentive for hospitals to discharge patients sooner. Patients discharged early required home care. In addition, changes were also made in Medicare home health regulations that allowed referrals to for-profit home health agencies. These combined budgetary actions stimulated growth of for-profit home health agencies (Estes et al., 1992). Home health expenditures soon became the fastest growing segment within Medicare. For-profit home health agency growth increased by 4251% between 1972 and 1986 (Bergthold et al., 1990).

The 1981 Omnibus Budget Reconciliation Act (OBRA 81) and regulatory changes to the Older Americans Act included subsidy of for-profit home and community-based services that were traditionally provided by non-profit providers and promoted self-reliance through family care and informal care under the guise of reducing Medicaid

costs and reliance on institutional long-term care (Kitchner & Harrington, 2004). These policies were implemented without public debate through administrative procedures in a subterranean political process that created a “path dependence” for future welfare policy (Hacker, 2002).

Path dependence is a subtle process. The concept of path dependence in the setting of policy refers to: the institutionalization of a self-rewarding/reinforcing process, or a process that results in “increasing returns,” which because of its success, is repeated and creates a locked-in specific path. Path dependence creates a kind of inertia because changing processes, courses, policies, or market niches would be expensive (Pierson, 2000). These subterranean budget changes had implications related to quality and types of care that would later be documented. Research on the difference between for-profit and nonprofit home health agencies revealed a more stable workforce in nonprofit agencies; for-profit agencies were characterized by refusing service more frequently than nonprofits and as attempting to target their services to mostly profitable patients (Bergthold et al., 1990).

The Tax Equity and Fiscal Responsibility Act (TEFRA) in 1982 was a Reagan budget bill targeted at further reducing social spending. It sought to incentivize enrollment into for-profit, competitively-organized HMO plans, by increasing their payments because it was still being purported that managed care would save money. Geyman (2006) refers to Andrews (1995) book: *Profit Fever: the Drive to Corporatize Health Care and How to Stop It* in which he describes HMOs as generating sizable profits by marketing their health plans to healthy populations or “cherry-picking” less expensive patients through favorable risk selection. TEFRA included DRGs as a cost

saving measure (Paradis, 1984-85). It also included as an amendment the creation of the Medicare-funded hospice benefit. Reagan's tenure will be remembered as an era of domestic program cuts. Ironically, hospice was the only social program approved during Reagan's tenure and it was part of Reagan's legislating by budget technique.

The Hospice Benefit: The Only Social Program Added During Reagan's Presidency.

The hospice benefit was not an invention of the Reagan Administration; in fact President Reagan opposed the addition of hospice to Medicare. In the early 1970s, and 80s there were concerns that the "medicalization" of hospice would accompany the efforts to add the hospice benefit to Medicare because physicians and hospitals controlled what was reimbursed.

The National Cancer Institute had funded the New Haven hospice and hospices were growing throughout the country (Paradis & Cummings, 1986). The National Hospice Organization (NHO) was formed in 1977 and its first conference was held in 1978 and the word "hospice" was officially trademarked. Most hospice movement leaders in the U.S. believed that government reimbursement was essential for the viability of the service model and for establishing its legitimacy. President Carter's Secretary of Health Education and Welfare, Joseph Califano was supportive of the hospice concept and in 1978, created demonstration projects for organizations providing hospice services (Cohen, 1979). Professionalization accompanied the state's recognition of hospice. Licensure and the requirement for licensed staff and physician referral for hospice care, started the process of medicalization. The demonstration projects were required to evaluate the cost of hospice care. The plan was to introduce hospice legislation when the projects were complete and data analyzed, but the plan was sped up by the 1980 elections.

When President Carter lost the 1980 election, Dennis Rezendes, the chair of the NHO wanted to move ahead with Medicare reimbursement because the Reagan Administration was proposing major reforms in Medicare. The hospice amendment was added based on very preliminary data that hospice was a cost effective alternative to hospitalization, with a capped expenditure per patient and prospective per diem financing serving as a proxy for hospital costs during the last six months of life (Gage, 2000). The stipulation that the benefit would cover only care provided in the home, by informal family caregivers rather than hospitalization, was made to appease the Reagan Administration's opposition. This provision satisfied Reagan's and the neoconservative ideologues' insistence on reinforcing the patriarchal roles of the traditional nuclear family (Estes, 2006; Estes, Alford et al., 2001). By requiring unpaid caregiving this work by millions of American females, most of whom who were, of necessity, in the paid labor market, went unvalued.

The monetary value of the amount of care provided by informal caregivers in the U.S. was \$196 billion annually (Jennings et al., 2003), and has increased in subsequent years (Covinsky et al., 2001). Estes and Associates (1993) described this phenomenon as a "warring dualism of medicalization and informalization" (p. 79-80); hospice care was given formal status as "medical care" but informal unpaid caregivers were not compensated in anyway. Care provided by nurses, social workers and health aids, and ordered by physicians in the hospice plan of care was part of the hospice benefit; while, informal caregivers, usually female family members, if they worked outside the home, lost their wages, their Social Security benefits, retirement benefits, health benefits and career standing in their positions (Estes & Zulman, 2007).

Lastly, in order to pass the amendment, hospice advocates agreed to be governed by nursing home regulations and a sunset date for the legislation to expire based on ongoing evaluation of the cost-effectiveness of the benefit (Hastings, 1993). Another example of a subterranean budget action, through the Comprehensive Budget Reconciliation Act of 1985 (COBRA 85) was the removal of the sunset on the hospice benefit and the addition of nursing home facilities as a site of reimbursable care (Gage, 2000).

From a neoclassic economic perspective consumer demand was based on taste or demand for a substitute. And, from a state theorist analysis, the addition of the hospice benefit was not added just to address societal values or consumer tastes; it was agreed to because it would save money. Inequity was codified by requiring that the majority of care be provided in the home by family and informal caregivers because family caregiving is a middle-class and upper-class privilege.

State policy contributed to the commodification and medicalization of hospice by intervening in financing and delivery of hospice services after referral by a physician. Adding hospice care as a covered benefit within Medicare began the transition of hospice care from a socially based philosophy of how to best care for dying patients into a medically dominated and controlled model of care, a commodity to be purchased by the state after the referral of a licensed physician to a state regulated health care provider which may or may not be traded publicly for profit in the market.

Overall, Reagan's policies did not produce cost savings but functioned to solidify a policy ideology of privatization that has continued to grow. For-profit companies selling care in all settings to buyers (including the state) has become an institutionalized

part of all sectors of the U.S. health system. Private corporations whose accumulation of capital is funded by the state are instrumental in electing representatives who will continue to assist in their accumulation of wealth as O'Connor (1973) as well as Offe and Ronge (1982) predicted.

Reagan's administration relied on corporate market competition to reduce health costs by transferring the financial risk from the purchasers (the government and employers) to the suppliers, the physicians and hospitals (Feldstein, 1996; Light, 2004b). It was at this time that for-profit home care and for-profit Older American Act providers were allowed to be reimbursed with public funds (Estes, Wallace, Linkins, & Binney, 2001). This shift created uncertainty and economic incentives to search for suppliers (medical care providers) that would provide a quality product at the lowest price (Feldstein, 1996; Mahar, 2006). All providers sought to shift costs and to find the most lucrative markets and many did.

The Feminist Emergence of Hospice

In the midst of the 1960s and 1970s social forces for reform of the care of terminally ill patients had begun to question costly, aggressive interventions such as cancer therapies and surgeries which seemed to result in undue suffering (Charmaz, 1980). Rather than being a natural part of life, death came to be viewed as unnatural, and preventing death and prolonging life became the domain of medicine. Medicine as a form of social control of sickness (deviance) rendered patients and their families powerless over the physician's orders (Zola, 1972). Death had been "medicalized." Ivan Illich (1976) claimed that modern medicine had ended natural death. The institutionalization

and medicalization of death changed the social meaning of death by transforming it into an unnatural event.

Death had moved from the home to the hospital. The prolonged suffering that accompanied many medical treatments was publicized in the press and patients and their families began to question the “utility” of recommended treatments. A “cost benefit analysis” of futile treatment followed by death was measured by the public not in dollars but in patient outcomes of human suffering. Patients died in hospitals, isolated, in pain and surrounded by expensive technology that failed them.

As described previously, hospice care, a philosophy of caring for the terminally ill had been taken up as a crusade by Cecile Saunders in the United Kingdom in the 1960s and emerged as an alternative philosophy of treatment to traditional medical care. The seeds of the hospice philosophy of care in the US were nourished by the consumer discontent with the medicalization of death and this consumer demand grew into a social movement.

Florence Wald was successful in being funded to do nursing research on dying patients and subsequently funding for hospice care from major foundations. The project grew over a decade from a network of nurses, clergy and physicians into Hospice Inc. incorporated as a non-profit organization in 1971 in New Haven Connecticut. Wald and the early founders built a hospice facility similar to St. Christopher’s hospice in London based on a philosophy of nonhierarchical interdisciplinary care reflecting a feminist organizational philosophy (Alter, 1998).

Among the earliest known hospices were founded in Ireland by the Sisters of Charity in the late nineteenth century as a place for people with terminal incurable illness

to make the “passage from life to death a brief and happy one.” Compassionate care, comfort and symptom relief as well as spiritual care were the foundations of early hospices (McNulty & Holderby, 1983). These non-hierarchical organizations resemble the feminist principles of cooperation and transformation rather than reform. A qualitative study of founders of charitable hospice organizations in England revealed a high degree of communication and consensus decision making and leadership driving the organizational vision (Johnson, 1999). Wald demonstrated a feminist philosophy of shared leadership and collectivity at the management as well as patient care levels of the organization and the importance of involvement in the community (Buck, 2005). The value of community and the strength of ideological commitment are central to feminist ideology (Alter, 1998; Dawson et al., 2000; England & Folbre, 2003).

Wald separated from the mainstream hospice movement and started the American Society of Hospice Care when the NHO charged toward Medicare reimbursement and agreed to a medicalized benefit package at the lowest possible cost (Hastings, 1993). Wald believed, as did other nursing leaders, that guaranteed hospice care only if it saved money might possibly destroy the qualitative differences that are the essence of hospice (Hastings, 1993). And, as described in feminist theory, hospice would become mired in a medical hierarchy of command and in bureaucratic organizations which would ultimately sustain women’s oppression (Alter, 1998).

The provision requiring that hospice patients forgo all curative treatment in the hospice regulations was not supported by the hospice or home health advocates. In a 1983 Senate hearing on the proposed regulations, Wald expressed concern that hospice not be labeled a “model of care” but a philosophy. She referenced the principles of the

International Workgroup on Death, Dying and Bereavement (IWG), a group of international scholars and leaders in the death and dying movement. The IWG guidelines emphasized the complementary nature of curative and palliative care. In her testimony, Wald questioned the motivations behind the proposed regulations, accusing the Health Care Financing Administration (HCFA) of including these requirements only to reduce costs and predicting that the cost to society would be greater. Another major objection to the proposed “model of care” was that it was based solely on home care, because Congress (in an attempt to control costs) had embraced turning the responsibility of caregiving over to family members and informal caregivers (with very limited inpatient respite care available) rather than paying for caregivers in facilities (Buck, 2005). This requirement exemplifies the emerging neoconservative ideology and meets Ciscel and Heath’s (2001) description of the “new form of patriarchy” (p. 407). The hospice benefit saved the state money through the informal work of women through a confluence of capitalism and patriarchy.

HOSPICE IN THE UNITED STATES CODIFIED IN LAW

Hospice benefits had been discussed in Congress as part of the pilot project that created the New Haven Hospice. The hospice benefit was amended into a comprehensive tax reform bill in 1982 (Tax Equity and Fiscal Responsibility Act (TEFRA) during President Reagan’s first term in office. The bill was targeted at reducing the government’s spending on social programs including uncontrolled expenditures on Medicare, the state sponsored program that covered hospitalization costs for the elderly (Brock & Foley, 1998). The late 1970s and the early 1980s marked the beginning of a “neoliberal” turn in United States politics. Neoliberalism was reflected in dominant

partisan ideologies that sought to shrink the state's spending on health care and to promote the "market" as a tool for controlling costs (Harvey, 2005). The hospice benefit was sold to Congress as a compassionate way to avoid costly hospitalization and to save money during the last year of life. Until the implementation of Medicare managed care, it was the only Medicare benefit that has the expectation of being "cost-effective"(Hastings, 1993; Mor, 1987).

The Medicare Conditions of Participation (COPs), written after passage of the hospice amendment, constitute the legal regulations governing hospices (Lynn et al., 2000). They reflected a medicalized version of the interdisciplinary philosophical origins of hospice care which includes a constellation of coordinated services, led by a physician. The hospice Medicare COPS have not been formally revised since their initial promulgation over two decades ago; however, the Centers for Medicare and Medicaid Services (formally the Health Care Financing Administration (HCFA)) within the U.S. Department of Health and Human Services (formerly Health and Welfare (HEW)) promulgated new COPS in 2002 and is currently engaging in the rulemaking process (Caring, 2002). The COPs include medical and nursing services, symptom management, spiritual care, homemaker services, social work services, short term in-patient care both to provide respite care for caregivers and to treat a patient's symptoms. Volunteers are required to provide a minimum of 5 % of the total paid patient care hours and bereavement services for family members are to be available for up to one year after the patient's death (Government Accounting Office, 2004).

Under the regulations, patients must be certified by a physician as having a life expectancy of six months or less if his or her terminal illness runs its normal course; and

the patient must be willing to forgo any “curative” treatment, in order to be eligible for the Medicare hospice benefit. This requirement was identified as a barrier to physician referral for hospice care because of inaccurate medical prognostication (Jennings et al., 2003; Sherman, 2000). Patients are permitted to remain in hospice care beyond the six month period if they continue to show signs of decline. Patients are also permitted to exit hospice and return to regular Medicare at any time.

In addition to the four levels of care, reimbursed on a per diem basis, and described in the Medicare COPs: routine home care (RHC), continuous hospice care (CHC), intermediate respite care for caregivers (IRC), and, General inpatient care (GIC), hospices also have an annual aggregate Medicare payment cap intended to ensure that hospice care costs do not exceed the commensurate cost to Medicare of inpatient care. The total annual Medicare payments to a hospice may not exceed a per-patient amount set annually by Medicare multiplied by the number of patients who received care from that hospice during the year (Government Accounting Office, 2004).

Challenges of Hospice in Today’s Health Care System

Unfortunately, only a fraction of beneficiaries have taken advantage of the hospice benefit over the last 23 years for a variety of reasons, among them the supply barrier created by the capping of the “state subsidy.” Research has been done on other barriers which may influence choices based on “taste”, such as physician communication, stigma, educational background, and socio-economic-status which may influence whether there is a caregiver at home – a criteria for hospice services in the U.S. in most areas, and on cultural beliefs.

On the demand side, Medicare reimbursement of hospice services can be considered a subsidy of demand, because it serves to eliminate a financial barrier to the demand for care. However, hospice differs from other health care services in that Medicare is the primary third-party payer for the majority of hospice patients. Most health care services can move to markets with additional more lucrative third party insurers (buyers). Hospice services are sold in a “monopsony,” or a market with a single buyer, the state (*The Law Glossary of Terms*, 2006). The state limits its purchases by limiting the “state’s” subsidy via capped per diem reimbursement rates. The state drives prices down and provider underpayment in a monopsonistic market affects the quality of care for patients with complex illnesses and needs.

Research on hospitalization (Fisher et al., 2000) shows that in geographic areas with more hospital beds there is more hospitalization even when controlling for socioeconomic characteristics and illness burden. This leads to the conclusion that hospital utilization is “supply-driven” for Medicare beneficiaries. In contrast, Medicare’s low reimbursement rates for hospice care create a barrier to demand because the reimbursement rate does not adequately reward physician care and thus limits the supply of hospice services (Fisher et al., 2000). Another barrier to demand is that Medicare requires physicians to refer for hospice service and further requires physicians to predict a less than six month survival of patients being referred to hospice. This creates reluctance to enroll in hospice (to buy services) on the part of physicians, and patients because it requires acknowledging that death is imminent. Hospices are often reluctant to accept patients whose physical decline is not apparent because if patients live too long state oversight and audit might be triggered (Jennings et al., 2003). In addition, the

requirements that patients must select hospice care and forgo all curative treatments have been considered barriers since the beginning of the benefit.

The Transformation to For-Profit Health and Hospice Services

Nearly two decades ago, Estes, Swan, Berthgold and Spohn (1992) warned that “vocabularies of efficiency, competition and profit have replaced those of access and equality in health care” (p. 64). More recently, in his 2006 book *Shredding the Social Contract: The Privatization of Medicare*, John Geyman describes the “transformation of the health system by the medical industrial complex” with a list of facts, which are examples of what he refers to as “corporate profiteering” (p. 194). He begins the list with a comparison of the recently merged and converted for-profit Blue Cross and Blue Shield now owned by Indianapolis-based Anthem, and California’s Wellpoint Health Networks, and Kaiser’s nonprofit HMO. Blue Cross spent 76 % of each premium dollar on patient care in 2000 compared to nonprofit Kaiser’s 96%. That explains the 34% increase in net revenues for Anthem and Wellpoint in 2004. Other facts include:

- Medicare Modernization Act 2003, while providing a meager drug benefit and preventing price controls for prescription drugs, rewards the inefficiencies of private plans with large over payments and subsidies, and allocates \$139 billion over 10 years to private interests to administer the drug benefit
- For-profit, investor ownership now accounts for 85% of the nation’s renal dialysis facilities, 70% of nursing homes and home health agencies, and 64% of HMOs
- The distribution chain to hospitals for medical supplies is dominated by for-profit group purchasing organizations which pad their expenses and maximize profits with little oversight or disclosure (Geyman, 2006, p. 195-196).

Home health care was also early to the for-profit market race. As discussed earlier, the implementation of DRGs combined with Reagan’s budget proposals and with deregulation of the home health industry allowing unlicensed (and usually proprietary)

agencies to compete in the market challenged the existence of nonprofits. This specific type of “privatization” by replacement of public (nonprofit) organizations with proprietary organizations resulted in profound changes in the organizational structure of home health. In the three year period from 1984 to 1987, “chain” agencies increased from a 45% market share to a 66% market share, and independent agencies fell from 55% to 34 % respectively (Estes et al., 1993). Relman (2004) suggests that the expansion in home health to less governmental and third-party regulation provided opportunities for “commercial exploitation” (p. 269).

Rosenau and Linder (2001) compared for-profit and nonprofit home health care services in the United States and concluded that the organizational distinctions between for-profits and nonprofits are disappearing because market competition requires that nonprofits mimic for-profits and in doing so nonprofits pay less attention to social responsibilities (Consumer Reports, 1996; Rosenau & Linder, 2001). For-profit providers provide less charity care and their tax status does not obligate them to do so. Relman (2004) attributed the slowed growth in investor-owned hospitals during the 1990s to the implementation of DRGs by Medicare, and later hospital cost saving measures implemented by HMOs and other third-party-payers. However, competition for insured patients continued and hospitals added specialty services requiring new technologies, even if they already existed in the community, rather than adding quality and community service.

A gradual shift occurred as nonprofit voluntary hospitals behaved more and more like their investor-owned competitors; they focused on cutting costs and what is likely to be profitable rather than the priorities of the community’s health needs. As for-profit

hospitals raised prices, so too did nonprofits (Mahar, 2006). Many nonprofits created for-profit partners and sent diagnostic and therapeutic procedures outside the hospital to these for-profit vendors. In doing this, nonprofits made money and lowered their own costs (Relman, 2004). Between 1990 and 2003, the number of physician-owned ambulatory surgical centers providing outpatient care doubled (Casalino, 2003; Estes & Swan, 1994; Mahar, 2006). Estes and Swan (1994) suggest that all three types of isomorphism: coercive (competitive), normative (based on professional standards) and mimetic (the copying of practices of “successful” organizations), will push nonprofits to resemble for-profits and will lead to convergence of for-profits. Indeed, when observed over time, a “pervasive change in the ethos of the voluntary hospital system” ... “from a social service to a business” can be observed (Relman, 2004, p. 271; Schlesinger, 1998).

Until the early 1960s, nursing homes were a small cottage industry. The availability of state reimbursement via Medicare and Medicaid attracted investors and by 1985, 75% of the new 19,000 facilities, with 1.6 million beds, were proprietary. The implementation of prospective payment in the 1980s increased the demand for nursing home care in order to discharge patients from acute care before their DRG-capped reimbursement had been spent. Organizationally, the nursing home industry was the first to consolidate into chains and integrate horizontally (Estes et al., 1993); this trend was subsequently mimicked in the hospital and home health sectors of the industry and is beginning in the hospice sector. Today, two-thirds of nursing homes are owned by proprietary investors. And, the multibillion dollar nursing home business has been characterized by rapid growth in costs and by access and quality problems (Harrington, 1991; Harrington, O’Meara et al., 2006). Harrington et al. (2001) analyzed 1988 data

from inspections of 13,693 nursing homes and determined that investor-owned nursing homes had more care deficiency citations than nonprofit and public facilities; along with lower numbers of nursing staff (Harrington et al., 2001).

Research by Petrisek and Mor (1999) revealed the higher the percentage of nursing home residents receiving hospice benefits, the more likely the nursing home was to be for-profit or to belong to a chain. In 1997, U.S. News and World Report ran a story titled: *Death be not swift enough: fraud fighters begin to probe the expense of hospice care* (Shapiro, 1997). It suggested that “Medicare reimbursement transformed hospice away from its roots as a movement that relied primarily on volunteers” to a for-profit industry, just as Florence Wald had predicted. The article pointed to the fact that only 30% of hospices were independent community organizations with the rest being part of regional hospice chains, home care agencies or divisions of hospitals. Of the remaining 70%, 15% are for-profit hospices. Proprietary hospices care for larger numbers of patients than nonprofit hospices. The CDC’s National Center for Health Statistics reported that in 2000 proprietary hospices cared for 22.4% of hospice patients while making up only 15% of the hospices (Centers for Disease Control and Prevention National Center for Health Statistics, 2003a).

For-profit hospices have successfully carved out a niche by caring for patients in nursing homes who tend to have non-cancer diagnoses and longer lengths of stay in hospice care. Large for-profit hospices benefit from purchasing power. In selecting patient populations in long-term care, they are able to use economies of scale by having several patients in one place and eliminating travel time and costs, as well as avoiding

costly patients with complex diagnoses characterized by short lengths of stay (Lorenz et al., 2002).

In 2004, the more than 2,900 Medicare-certified hospice programs were reimbursed more than \$8.3 billion as compared to \$68.3 million in 1986. For-profit hospices controlled over 15% of the market. There is room for expansion and a 9.1% increase is predicted before this decade closes (Wharton Health Economics, 2006). Hospice care is shifting slowly and in a subterranean path as did hospital and home health care to a market-driven delivery model.

Claire Tehan, writing in the 1985 Hastings supplement on hospice in the United States, as hospice entered its second decade in the U.S., and just two years after Medicare reimbursement for hospice services began, described hospice as no longer a “fringe alternative led by an idealistic group of volunteers and professionals,” rather, hospice had become a “mainstream, industry-like approach to the care of the terminally ill (p. 10).” She said that with success came “uniformity and fiscal constraints” and she described hospice organizations as replacing their visionary leaders, with “professional health care managers with administrative, fiscal management, and fundraising skills.” She suggested that the focus must be on survival and less on the individual manager’s “commitment to the hospice concept.” Her final advice was that hospice programs “strive for balance between the humanistic, holistic traditions of hospice and the economic reality of national health policy” (Tehan, 1985, p. 13).

In 1990, Stoddard believed that “hospice, remaining essentially a grassroots concern of individual communities [would] continue to infiltrate and transform the rest of the medical establishment with its gentleness, its humane point of view, and its

continually developing technical expertise” (p. 29). She suggested that “the hospice interdisciplinary team is the wave of the future” because it promotes values of “individual initiative, inventiveness, responsibility, integrity, trust, a sense of community, open communication, decentralization and small is beautiful” (p. 30). She warned that: “hospice teams must not let the excellence of hospice programs be corrupted by the demands and restrictions of unimaginative business interests, or unenlightened insurance carriers.

Unfortunately, thirty years of neoliberalism has not only placed the power in the “capitalist class” of elites that dominated government at the dawn of the twentieth century, but the hegemony of neoliberalism has “produced concentrations of corporate power in energy, the media, pharmaceuticals and [the medical industrial complex], and retail” (Harvey, 2005, p. 38). The insidious and powerful concept of “freedom” defined only as free enterprise, has become unquestionably embedded in our everyday lives and will not be easily undone. As a society, our desire for “more,” is fulfilled by monopolies like Walmart, by unending medical technology; and, through our government’s monetary policies that promote tax cuts for the wealthiest and for corporations, and free trade, regardless of violations of human rights; as well as through our country’s military efforts to spread our form of “freedom” to other countries. The combination of neoconservative authoritarianism which emphasizes moral righteousness and cultural nationalism in response to social movements for women’s rights, gay rights, minority equality and environmentalism, with neoliberal values of “freedom” need to be challenged by a set of values that reflect social, economical, political and cultural equality and justice (Harvey, 2005, p. 206).

Hacker (2002) described “critical junctures” in policy formation as periods of significant change that are influenced by economic and political forces. Hospice was created in a critical juncture between a social movement to improve care for the dying, with feminist leadership, and political reform to make Medicare more cost effective. Unlike other social movements characterized by struggle with the dominant political and economic elite of the time, hospice included interdisciplinary care and the importance of spirituality as part of its philosophy. However, the movement failed to contest how the neoliberal neoconservative dominant powers were subjecting women. Perhaps a “critical juncture” of spiritual care and leadership can be created contrary to capitalism, with new feminist leadership. This new social movement will consider the everyday lives of women as patients and caregivers at the end-of-life and will acknowledge the grievance that the majority of hospice care is provided by women, both unpaid and paid, but largely invisible, and that the care received by women as patients is very often after they have cared for a spouse and are dying alone.

The next section of this paper provides a literature review of several aspects of hospice care. The review includes research that examines changes in the organization of hospice over time; and, research on hospice quality, utilization and cost.

CHAPTER III

Review of the Hospice Literature

Research regarding hospice care dramatically increased after the Institute of Medicine's 1997 publication of *Approaching Death* (Field & Cassel, 1997), Foley and Gelband's: *Improving Palliative Care for Cancer* (2001) and a substantial investment by the Robert Wood Johnson Foundation into the "Last Acts" campaign of 2002 which funded research examining the use of hospice in America (Johnson, 2002). Questions regarding who uses (and does not use) hospice in the United States and why, as well as why hospice length of stays have consistently declined since the inclusion of the hospice benefit in Medicare, have been explored in many articles and government reports (Centers for Disease Control and Prevention National Center for Health Statistics, 2003a, 2003b; Christakis, 1994; Christakis & Escarce, 1996; Conner, Tecca, LundPerson, & Teno, 2004; Enguidanos, Yip, & Wilber, 2005; Greiner, Perera, & Ahluwalia, 2003; Han, Remsburg, McAuley et al., 2006; Haupt, 2003; Iwashyna, Zhang, & Christakis, 2002; Jackson, Schim, Seely, Grunow, & Baker, 2000; Lorenz, Asch et al., 2004; Lorenz, Ettner et al., 2004b; McCarthy, Burns, Davis et al., 2003; Miller, Kinzbrunner et al., 2003; Miller, Weitzen et al., 2003; Robinson, Morris, Luck, & Pruitt, 2002; Virnig et al., 2002).

During the last decade, advances in computer technology have increased the quality and availability of national data. The Medicare claims denominator data file and hospice claims file have been used by many researchers. The Medicare claims denominator file includes diagnosis, age, race, marital status, and geographic location. The hospice claims file includes utilization and cost data. The National Mortality Followback Survey from the National Center for Health Statistics records location and

cause of death. These data have been useful in examining variables such as length of stay, utilization by age, race and diagnosis. The National Hospice and Palliative Care Organization (NHPCO) (formerly National Hospice Organization) has taken steps to promulgate national standards of care for hospice and to develop and advocate for data collection mechanisms to measure compliance with standards of care. In 1999, NHPCO began a national data collection process working with state member hospices. Its data includes much of the same information as the Medicare claims denominator file, such as program statistics including: free-standing, inpatient, residential care facility; ownership; location; Medicare certification, accreditation status; patient statistics such as payer mix; referrals; process statistics such as volunteer management, bereavement support, staffing (patient support and volunteer hours), productivity, average daily census; financial statistics, such as cost of care; revenue sources; and outcome statistics such as comfort in dying, self-determined life closer measures, safe dying measures, effective grieving.

National research provides insight into trends in utilization, hospice organization, and site of care. In 2003, the Centers for Disease Control's National Center for Health Statistics, published a Vital and Health Statistics Report based on year 2000 data from the National Health Care Survey which examined the hospice care in the United States (Haupt, 2003). Recently published national trends compared 1991/92 hospice data with 1998/99 data (Han, Remsburg, McAuley et al., 2006). Several statistics stand out. First, while the number of hospice patients increased over five times during the review period, hospice care was used by only 23% of Americans who died in the year 2001; second, the length of stay/service consistently declined; and, third, in all but one study, hospice use by minorities continues to lag behind that of non-Hispanic whites (Adams, Horn, &

Bader, 2006; Colon & Lyke, 2003; Enguidanos et al., 2005; Greiner et al., 2003; Jennings et al., 2003; Johnson et al., 2005; Rhodes, Teno, & Welch, 2006; Welch, Teno, & Mor, 2005).

In the United States, hospice care is provided in the home, in long-term-care facilities (skilled and residential), and in inpatient hospice units of acute care facilities. The majority of hospices are free standing hospice agencies. Some are part of home health agencies, and others are affiliated with a group or chain, operated by a hospital, operated by a nursing home, or operated by a health maintenance organization or managed care organization (HMO or MCO). Organizationally, hospices are categorized as: proprietary, voluntary nonprofit, or government and other. Core services required for Medicare certification require interdisciplinary care related to the terminal diagnosis including: nursing assessment, coordination and care, medical care and supervision, pharmaceutical and medical supplies, social work, spiritual care, nutrition consultation, home maker services, and volunteer care. Hospice care is available in every state; however it varies from county to county (Centers for Disease Control and Prevention National Center for Health Statistics, 2003a).

Hospice utilization, cost, and quality are important areas of research. Little research has been conducted on organizational structure and market effects on utilization, cost and quality. This review seeks to examine what has been studied to better understand the interaction of market and organizational characteristics of utilization, cost and quality.

Methods

A comprehensive search of the medical and social science online databases (PubMed, JSTOR, CINAHL and Google Scholar) was conducted to identify studies addressing factors affecting hospice utilization, cost, and quality of care. Key words for the search included: hospice AND economics, profit status, cost of care, quality of care, length of stay/service, ownership, organization, utilization, Medicare, Medicaid, survival, managed care/health maintenance organization, incentives, location/site of death, ethnicity/race, end-of-life. Palliative care was not included in the search because hospice is a distinct reimbursable service within a continuum of palliative care. Articles were excluded if: studies were limited only to nursing home care, the research was conducted outside the United States, the study was focused on patients with dementia or on children, the study variables were not included among data collected by California and/or Federal government sources, and/or if the study design was qualitative.

Although the hospice Medicare benefit has been in place since 1983, this review includes only studies published since 1990 because of the dramatic changes that have occurred in health care financing, organization, and delivery since that time. Fifty-seven studies satisfied the inclusion criteria and are summarized in the literature table (attached) organized under the categories of: Utilization: Length of Stay-Survival; Cost, and Quality.

Findings

Length of Stay/Survival: Diagnosis, Medicare Coverage Type

Since 1983, with the passage of the addition of the Medicare Hospice benefit, the United States Congress acknowledged that people who are dying and their families have special needs. In 1997, the Institute of Medicine reported that despite the fact that every

Medicare beneficiary is entitled to hospice care, less than one third of beneficiaries use the benefit and those who do are receiving the benefits for shorter and shorter periods of time (Field & Cassel, 1997). There is general agreement that at least a 30 day hospice stay provides maximum benefits for patients and families (Centers for Disease Control and Prevention National Center for Health Statistics, 2003b). Length of Stay/Survival (LOS) is also an important factor in the financial success of hospices because the intensity of care is front loaded on the intake process with assessments and back loaded on the actual direct care provided as patients actively die. Short lengths of stay are very labor intensive and the Medicare's per diem reimbursement does not cover the cost of professional services. There are a significant number of research studies on hospice LOS and factors that affect the timely referral of terminally ill patients to hospice.

Successful hospices anticipate the intensity of patient care requirements and admit patients based on criteria that will predict the length of stay, the intensity of care and hence the cost of patients in order to make effective use of limited reimbursement resources. Among the predictors of shortened length of stay are referral source and hospital utilization (Christakis, 1994; McCarthy, Burns, Davis et al., 2003; McCarthy, Burns, Ngo-Metzger, Davis, & Phillips, 2003; Miller, Kinzbrunner et al., 2003; Virnig, Fisher, McBean, & Kind, 2001; Virnig, Persily, Morgan, & DeVito, 1999; Wennberg et al., 2004). A study of referrals made to hospices in 1998/99, revealed that 55% of hospice referrals were from hospitals (Miller, Kinzbrunner et al., 2003) and in a small study, timing of referral to hospice was found to be the main determinant of length of stay (Christakis, 1994). Casarrett's (2001) work confirmed Christakis' early work and revealed shorter median lengths of stay for patients referred to hospice by academic

health center hospitals when compared to community hospitals (13 days v. 25 days) suggesting that academic health centers refer patients later in the course of illness. Other differences included that academic referrals tended to be younger with a mean age of 66 rather than 74, and less likely to live in a nursing home. They were more likely to be married and have private insurance and a cancer diagnosis with metastases at the time of referral. Overall academic referrals were more likely to have complex medical needs requiring higher levels of nursing care. Late hospice referrals often translate into greater support needs for the patient and family. Shorter stays make ensuring that patients and families receive the maximum benefit from hospice difficult and expensive.

No difference was found in the numbers of men and women who enroll in hospice; however, length of stay for women is longer than for men (Robinson et al., 2002; Virnig et al., 2002). Researchers posit that this is because men are referred to hospice later because they are cared for by wives and family, and because husbands predecease wives, women are referred for hospice care and assistance sooner because they lack a caregiver at home.

Many studies cite cancer diagnoses as an indicator of hospice use; 60% of hospice patients have cancer. However, hospice use varied widely across cancer diagnoses (McCarthy, Burns, Ngo-Metzger et al., 2003; Miller, Kinzbrunner et al., 2003; Virnig et al., 2002). Diagnosis was found to be an indicator of short length of stay for patients with leukemia or lymphoma, pancreatic, central nervous system, head and neck and liver or biliary cancer, renal failure, and cancer in general (Christakis & Escarce, 1996; Iwashyna, Zhang et al., 2002) with the exception of breast cancer (Christakis, 1994). Longer

lengths of stay were found in patients with diagnoses of breast cancer, dementia, chronic obstructive pulmonary disease (COPD), and depression (Christakis, 1994).

Higher utilization of hospitalization within six months of death and/or hospice referral was found to be associated with shortened survival and hospice stays. Hospice use was also found to be inversely associated with hospitalization during the last six months of life (Erickson et al., 2002; Iwashyna, Chang, Zhang, & Christakis, 2002; Miller, Weitzen et al., 2003; Wennberg et al., 2004).

Christakis' (1994) study found no relationship between religion, income, insurance type, and race on length of stay. This was the only study that included religion as a variable. Other studies, discussed later in this review, have had contrary findings related to income, insurance type, and race.

In most studies, the type of Medicare coverage (fee-for-Service versus Managed Care) was not examined. Managed care penetration of Medicare increased during the 1990s. Virnig, Fisher, McBean and Kind (2001) examined the one hundred U.S. counties in twenty-two states with the greatest number of Medicare deaths in managed care and found that rates of hospice use were higher for managed care enrollees. Managed care patients who selected hospice and palliative care yielded cost savings, received more home care visits, and were more likely to die at home than patients who received traditional Medicare certified home care at the end of life (Brumley, Enguidanos, & Cherin, 2003).

Several studies on hospice in managed care consistently found longer lengths of stay in hospice across diagnosis when compared with Medicare fee for service (FFS) (McCarthy, Burns, Ngo-Metzger et al., 2003; Virnig et al., 2001; Virnig, Persily et al.,

1999). Up to a median of one week longer stays were found in managed care and managed care patients were less likely to be enrolled in hospice within seven days of death (McCarthy, Burns, Ngo-Metzger et al., 2003). Across all cancer diagnoses, Medicare managed care hospice patients had a median one week longer stay than FFS patients; further, managed care hospice patients were less likely to have hospice stays of less than one week.

In managed care, when a Medicare patient chooses hospice, the managed care capitation covers the cost of medical care unrelated to terminal diagnosis and Medicare is billed the hospice per diem rate separately. During the 1980s and 90s, as managed care market penetration increased, concerns were raised that managed care organizations were referring patients into hospice early because the cost risk is transferred back to the government. Virnig et al. (2001) concluded that system level differences in hospice utilization in managed care reflected changes in provider behavior within managed care organizations, which were probably reflective of “organizational practice guidelines,” and not indicative of system level financial incentives resulting in earlier hospice enrollment.

Enguidamos, Yip and Wilbur (2005) recently published findings from a study in California that looked at both Medicare and Medicaid beneficiaries (also referred to as “dual eligibles”, who are both over 65 years of age and living below a federal poverty level) and hospice use using data from 1996-2000. Their findings provide rich data regarding ethnicity and hospice use and are discussed further under ethnic disparities. Of note in their findings related to Medicare coverage, they described the dual eligible beneficiary population as being made up of over two-thirds women, 55% were widowed,

21.6 % divorced and 21% married. Approximately 41% of these “dual eligible” women died in nursing homes, and overall, only about 10% used hospice, with nursing home use not being statistically significant in the use of hospice. Of dual eligibles, diagnostically, those dying of Alzheimer’s disease were twice as likely to be enrolled in hospice, and those dying of cancer were six times as likely to be enrolled in hospice as those dying of other conditions.

Miller and colleagues (Miller, 2004; Miller, Gozalo, & Mor, 2001; Miller, Gozalo, & Mor., 2000; Miller, Intrator et al., 2004; Miller, Kinzbrunner et al., 2003; Miller & Mor, 2004; Miller et al., 1998; Miller, Mor, Wu, Gozalo, & Lapane, 2002; Miller, Teno et al., 2004; Miller, Weitzen et al., 2003), have done extensive research on hospice in nursing homes. For the purposes of this review, articles with data on length of stay in nursing homes along with other settings, and quality of hospice care in nursing homes were included. One large study of 46,655 nursing home patients and 80,507 non-nursing home patients admitted to 21 hospices across seven states between 1994 and 1999 (Miller, Weitzen et al., 2003) revealed that, in 1995, a nursing home hospice patient had a 26% probability of less than an eight day length of stay and in 1999, probability increased to 33%. Non-nursing home patients in 1995 had a 32% probability of less than an eight day stay and, in 1999, the probability of shortened hospice stays occurred in patients being cared for in both nursing homes and non-nursing home settings. During that period, the number of patients admitted to hospice in nursing homes increased by 50% while the number of patients admitted to hospice not in nursing homes increased by only 44%.

More recent trend data (Han, Remsburg, McAuley et al., 2006) reports that the number of nursing home residents eighty-five and older, doubled between 1996 and 1999,

and there was a change from the trend of shorter hospice lengths of stay for patients in nursing homes to increased lengths of stay. Han and colleagues found that in 1996-97, 36% of nursing home hospice patients had greater than 90 day lengths of stay and in 1997-98, that increased to 43%.

It is noteworthy that the pre-1996 data trend toward shortened lengths of stay, occurred at the beginning of the Centers for Medicare and Medicaid Services' (CMS, formerly HCFA) Office of the Inspector General's (OIG) investigation titled "Operation Restore Trust" (ORT) which was launched in every state to find fraudulent home health and hospice practices. One of the data elements that triggered the investigation was unusually long lengths of stay in hospice ("Federal Register: OIG Special Fraud Alert: Fraud and Abuse in Nursing Home Arrangements With Hospice," 1998; Gage et al., 2000; Shapiro, 1997; Stanton, 2001).

Ethnic Disparities in Hospice Use

Hospice use has historically not matched the ethnic and racial breakdown of the U.S. population and has been the topic of much research using both qualitative and quantitative methods of analysis. While whites are more likely to use hospice (Han, Remsburg, & Iwashyna, 2006; Iwashyna, Chang et al., 2002; Virnig, Kind, & McBean, 2000), minorities are more likely to have longer lengths of stay (Christakis & Iwashyna, 2000; Colon & Lyke, 2003). Twenty-two studies were found that included data on "minority" utilization of hospice services (Adams et al., 2006; Banaszak-Holl & Mor, 1996; Christakis & Iwashyna, 2000; Colon & Lyke, 2003; Crawley & Kagawa-Singer, 2007b; Enguidanos et al., 2005; Goldstein, Concato, Bradley, O'Leary, & Fried, 2005; Gordon, 1996; Greiner et al., 2003; Han, Remsburg, & Iwashyna, 2006; Iwashyna, Chang

et al., 2002; Johnson et al., 2005; Kapo, Macmoran, & Casarett, 2005; Lacklan et al., 2004; Lorenz, Ettner et al., 2004b; Neubauer & Hamilton, 1990; Ngo-Metzger et al., 2003; Rhodes et al., 2006; Virnig et al., 2000; Virnig, Morgan, Persily, & DeVito, 1999; Welch et al., 2005). Only three studies included Asian American Pacific Islanders, and only eight included Hispanic Americans (Adams et al., 2006; Colon & Lyke, 2003; Crawley & Kagawa-Singer, 2007b; Enguidanos et al., 2005; Gordon, 1996; Greiner et al., 2003; Johnson et al., 2005; Lacklan et al., 2004; Ngo-Metzger et al., 2003).

The earliest study was done in 1990 by Neubauer and Hamilton (1990). It surveyed 253 decedent proxies (relatives or caregivers) by phone regarding their perceptions of the hospice care their relative had received. Thirty-four percent of respondents were African-American and 32.4% were white. The findings revealed that African-Americans were not less likely than whites to say they would want hospice care if they were terminally ill. However, numerous studies since then have provided different results and demonstrate that numerous factors contribute to the differences in utilization of hospice services. Recently, Rhodes, Teno and Welch (2006) conducted interviews from 1998 mortality follow-back data in twenty-two states; and the cross sectional analysis revealed that 53% of African-Americans were uninformed about the availability of hospice services. Thirty percent used hospice and of those patients, the majority had cancer diagnoses. Nine percent were informed and chose not to use hospice, and the remainder did not respond. Goldstein, Concato, Bradley, O'Leary, and Fried (2005) conducted interviews with 226 patients who qualified for end-of-life care and with 92 clinicians in Connecticut. They found that discussions about prognosis and end-of-life planning were more likely to have occurred when patients were poor and members of

ethnic minority groups. If those findings could be generalized beyond Connecticut, perhaps minorities would use hospice in greater numbers, but that is not the case.

In California (Lorenz, Ettner et al., 2004b), an annual survey of hospices revealed that 81% of the hospices provided translation, 63% had minority providers and 52% had culturally diverse spiritual services available; however, only 21% had marketing materials directed at minority communities. The most recent California study by Crawley and Kagawa-Singer (2007b) conducted both qualitative and quantitative analyses and concluded that the greatest barriers to hospice care in California were language and cultural limits of hospice providers.

Geographically, the proportion of nonwhite residents in the hospices' zip code was associated with the level of ethnically appropriate services offered. Seventy-two percent of the 832 hospices responding to the National Hospice Organization survey in 1996, Gordon reported that their service area was primarily white; 14% reported their service area was entirely white. In contrast, 2% (16 hospices in the country) had service areas that were greater than 50% African-American and similarly 2% report services areas with a greater than 35% Hispanic population. Given these statistics, findings of disparate hospice use is not surprising. From previously cited studies, reporting increased hospice utilization in areas with a high penetration of managed care translates to less pronounced differences in hospice enrollment across race and ethnicity (Ngo-Metzger et al., 2003; Virnig, Morgan et al., 1999). Late hospice enrollment was found to be associated with being of a race other than white or black by (McCarthy, Burns, Davis et al., 2003).

Asians are less likely to enroll in hospice than whites (Enguidanos et al., 2005), and foreign born Asians were found to be even less likely to use hospice care than Asians born in the U.S. (Crawley & Kagawa-Singer, 2007b; Ngo-Metzger et al., 2003). In comparing disparate use of hospice among people with terminal illness who are eligible for both Medicare and Medicaid (dual eligibles), Latinos showed no difference from whites in hospice utilization while African-American and Asians showed a 25% and 34% less likelihood of using hospice respectively.

Diagnosis specific data for pancreatic and breast cancer from 1996 revealed that 82% of African-American decedents received hospice care (Virnig et al., 2002); this is in contrast to findings that there was no greater likelihood of receiving hospice for African-Americans in the last year of life than for whites (Welch et al., 2005), and in contrast to other studies which all report a negative association with being African-American and hospice enrollment (Colon & Lyke, 2003; Enguidanos et al., 2005; Greiner et al., 2003; Kapo et al., 2005; Reese, Aherns, Nair, O'Faure, & Warren, 1999; Virnig et al., 2000). In analyses of where people died, Banaszak-Holl and Mor (1996), concluded that minorities are more likely to die in hospital based hospice. Johnson, Kuchibhatala, Sloane, Tanis, Galanos, and Tulsky(2005) had similar findings specifically for African-Americans. Hispanics in this study were most likely to die at home.

Recently published analyses of the Multiple Cause of Death files from all 50 states and the District of Columbia and the National Home and Hospice Care Surveys (NHCHS) conducted biennially from 1992 through 2000, revealed the importance of not using Medicare data (alone) in analyzing hospice use differences (Han, Remsburg, & Iwashyna, 2006). The most significant difference in black and white hospice patients

was age. Between 1992 and 1994, only 57% of black hospice patients were over 65 compared to 75% of white hospice patients; and between 1996 and 2000 53% of black hospice patients were over 65 compared to 77% of white hospice patients.

Han, Remsburg and Iwashyna (2006) identified dramatic changes in hospice use by African-Americans from 1992-2000. During this period, white hospice use rate doubled from 10% in 1992 to 23% in 2000 and black hospice use rate almost quadrupled 5% 1992 to 18% in 2000. While hospice use rates were lower among blacks than among whites in 1992, and 1994, they were not dissimilar in 1996, 1998, or 2000. Han et.al. found that Black hospice patients were more likely to be younger, have HIV/AIDS and have Medicaid as sole source of payment.

Cost, Structure, Profit

In many studies, length of stay was inversely correlated to the number of hospital admissions (Iwashyna, Chang et al., 2002; Miller, Kinzbrunner et al., 2003; Stuart, D'Onofrio, Boatman, & Feigelman, 2003; Wennberg et al., 2004). This finding is important because in evaluating the cost effectiveness of hospice, the cost of care in the last year of life is often considered.

Since before its addition to Medicare, hospice was touted as being a cost effective alternative to expensive, intensive end-of-life care. Kidder's early analysis (1992) compared patients who Medicare claims data of decedents from 1982-1986 who were not enrolled in hospice and who had had at least one malignant cancer, with claims data from hospice enrollees. She found hospice enrollees yielded an average expenditure ratio of 1.26 with the average length of benefit enrollment slightly longer than 30 days. This comparison of early data had significant selection biases because it included only cancer

patients and patients who chose not to pursue curative treatment; however, it was used to bolster the expansion of hospice care. The nature of shortened lengths of hospice stay mean that cost data comparisons of hospice utilization versus acute hospitalization should be limited to the last two weeks of life rather than the last thirty days.

Pyenson, Connor, Fitch and Kinzbrunner (2004) used 1999-2000 Medicare data and matched identical hospice and non-hospice cohorts with paired diagnoses and found that in most cases, for the mean and median Medicare costs, lower costs were associated with patients receiving hospice care, and were statistically significantly lower for patients with congestive heart failure (CHF), cancer of the liver and pancreatic cancer. Patients choosing hospice with a diagnosis of stroke, had significantly higher costs associated with hospice care. Patients who chose hospice had a longer mean and median survival than their non-hospice cohorts.

Campbell, Lynn, Louis and Shugarman (2004) published differing results using Medicare data from 1996-1999. Overall, they reported a mean expenditure of 4% higher costs for Medicare hospice enrollees after adjusting for gender, race, place of residence, duration of illness, comorbid conditions and year of death. From a diagnosis perspective, they found that adjusted mean expenditures were lower for patients with cancer who used hospice and as much as 11% higher for hospice enrollees without cancer. In distinct contrast to Pyenson et al. (2004), Campbell, Lynn Louis and Shugarman (2004) found up to 16% higher costs for hospice enrollees with CHF. This study also found that hospice costs increase with age.

Banaszak-Holl and Mor (1996) looked at expenditures among differing hospice providers and found that free standing hospice providers had the lowest costs. Hospice

enrollees receiving care in skilled nursing facilities (SNF's) were more likely to have short stays, have been hospitalized in the prior 180 days, and have the most expensive care.

Two studies on hospice cost and managed care confirmed that hospice care was cost effective. The first, although limited to a geographic area in Northern California, projected a reduction of \$6,580 in savings from an interdisciplinary palliative care model during the last year of life and a high level of patient (survivor proxy) satisfaction (Brumley et al., 2003). The second compared Medicare costs for the last 12 months of life between two states, one with low managed care penetration, Massachusetts, and California, a state with high managed care penetration. Overall cost of care for the last 12 months of life was \$774 lower in California. Like other studies, diagnosis influenced cost and decedents with cancer from both states who were enrolled in hospice had approximately 40% lower costs and these savings extended up to 90 days before death.

Hospice Characteristics

Hospice services have not been immune to the changes in health care delivery and financing that have occurred in the U.S. during the last two decades. Different characteristics of service delivery such as, profit status, location, length of stay, core v. non-core service availability, as well as type of insurance, have recently been studied.

The growth of managed care and competition from for profit hospices has challenged the economic survival of freestanding hospices in the last decade. Pietroburgo (2004) surveyed 116 hospices in six states in 2003. Findings showed that many hospices have restructured in response to the environmental changes. Older hospices with larger budgets and higher census were more likely to restructure by

integrating into other organizations or by forming “alliances.” Hospices located in rural areas with smaller budgets were more likely to create collaborative structures to share resources. The number of “for-profit” hospices has increased significantly over the last decade. The number of for-profit hospices quadrupled and outpaced nonprofit hospice growth six fold (Carlson, Gallo, & Bradley, 2004) with the greatest numbers in the southern part of the country. Some for-profit hospices are publicly traded and some are simply privately owned. Some are large, and some are small. Hospice “chains” are primarily “for-profit” although some are not-for-profit. Seven studies looked at profit status and service (Carlson et al., 2004; Hamilton, 1994; Lorenz et al., 2002; Lorenz, Ettner et al., 2004b; Lorenz, Rosenfeld, Asch, & Ettner, 2003; McCue & Thompson, 2005).

Hamilton’s early work analyzed 1991 Medicare cost data from 120 randomly selected hospices: 22 for-profit hospices (6 part of chain), twelve government hospices (Veteran’s Administration), and 90 nonprofit hospices. The study found no differences in costs per patient day or hours per patient day (a proxy measure for quality). She found that for-profit hospices served higher percentages of Medicare patients with chain hospices serving 13% more and nonchain for-profits serving 10% more than nonprofit hospices. In all settings, costs per patient decreased as length of stay increased. Hospice chains and large nonprofit hospices were larger and saw more patients per year thus increasing their revenue. Nonprofit hospices used revenue to cover costs of unreimbursed care for indigent patients who were cared for in far greater numbers than for-profits. Lorenz, Ettner, Rosenfeld, Carlisle, Leake, and Asch (2002) and Lorenz, Rosenfeld, Asch and Ettner (2003) used the National Home and Hospice Survey

discharge data set to confirm Hamilton's findings that not-for-profit hospices provide more unreimbursed care. Using California hospice only data, Lorenz et al. (2002) found a statistically significant higher percentage of Medicare patients cared for by for-profit hospices.

Using 2002/2003 data, McCue and Thompson(2005) examined financial reports on publicly traded companies and found some changes to Hamilton's early analysis. Unfortunately, they did not distinguish the profit status of chain and nonchain hospices to facilitate finding comparisons. They found that small publicly traded hospices admitted more patients, had lower operating expenses (including nursing cost/day), higher revenue per day, longer lengths of stay and a greater proportion of Medicare reimbursed days. In contrast to large publicly traded hospices and large non-profit hospices, small publicly traded hospices provided more core and non core hospice services. Large publicly traded hospices had more Medicare reimbursed days than large non-profit hospices and offered more core services and fewer non-core services. Revenues and lengths of stay were higher for larger publicly traded hospices when compared to large non-profit hospices.

Findings regarding range of services differed in research by Carlson, Gallo and Bradley (2004), who conducted the first national sample of hospice agencies and found that, after adjusting for diagnosis, disability, gender, location of care, certification, chain affiliation and geographic region, patients who received care from for-profit hospices were less likely to receive a range of non-core services. Demographically, the findings of this study found more for-profit services are provided to women in nursing homes by hospice chains.

In looking at California specific hospice data, Lorenz, Asch, Lui and Ettner (2004) discovered that hospice admission practices differed between chain and freestanding hospices. They found that 63% of hospices restricted admissions based on one or more criteria. Larger hospices had fewer admission restrictions except for TPN and tube feedings. Chain hospices (more likely to be for-profit) were less likely to restrict admissions to hospice. While this study was limited by its sample size it provides an important area for analysis of equity in hospice service availability.

The “market’s influence” on hospice has been examined in several studies (Christakis & Iwashyna, 2000; Erickson et al., 2002; Iwashyna, Chang et al., 2002; Ryan, 2000; Virnig et al., 2000). Early research from New York (Ryan, 2000) which examined inpatient deaths as a measure reflective of hospice ownership/affiliation, found that hospitals with inpatient units had the highest percentage of inpatient deaths, followed by hospices that were divisions of home health agencies. Hospices with no affiliation had the lowest number of inpatient deaths. These findings were most likely an indicator of resource availability with the majority of inpatient hospices located in hospitals in the state’s largest cities rather than individual choice. Many patients may have chosen inpatient settings if they existed near their homes. Erickson Fried, Cherlin, Johnson-Hurzeler, Horwitz and Bradley (2002), in a cross sectional study of a random sample of Medicare admissions of terminally ill patients in Connecticut, reported that patients admitted to a hospital with a hospice unit were more likely to use some kind of hospice. Findings from single states are useful for planning services in those states, but limit the generalizability to the rest of the country.

Christakis and Iwashyna (2000) used national data to examine the market effect on the timing of hospice referral and found earlier referral and enrollment in hospice in areas with more hospital beds, greater hospice capacity, or a higher proportion of physician generalists. They also found that areas with an increased population density and higher penetration of for profit hospices were associated with later enrollments. This contrast in shorter survival for for-profit hospices may be an indicator of hospice penetration in general, resulting in for-profit hospitals accepting more patients with complex illness and shorter prognoses in an attempt to maintain their market share.

Using national Medicare claims data from the beginning of the hospice Medicare benefit through 1997, Iwashyna, Chang, Zhang and Christakis (2002b) posited a lack of market impact on hospice use and their findings substantiated significant variation between counties (markets). Adjustments for individual characteristics of decedents and their diagnoses did not explain the county level variation. Demographics of the markets explained 2.5% of the difference between counties, while market factors explained some variance; however, combined, these two explained only 3.2% of the variation. The age of the data from 1993 – 1995 limit the generalizability of the findings but do suggest an area for additional research. The findings of Virnig et al., (2000) confirmed that local markets vary in hospice use rates and that hospice use is positively influenced by high managed care penetration and negatively influenced by high number of hospital beds per capita.

Quality

It is important to note that the only national examination by the government of hospice care has been “Operation Restore Trust” conducted by the Department of Health and Human Services Office of the Inspector General. Rather than the government

expressing concern about the quality of care, it examined only financial issues, searching for fraud and abuse (with abuse not relating to patient care but to financial abuse).

Quality of care in hospice has been defined in many ways and has not been measured consistently. A “quality of death” definition was suggested in 1988 by Wallston, Berger, Smith and Baugher as “experiencing in the last 3 days of life feelings and events that terminally ill patients reported they desired (p. 178).” By 1997, ten domains of quality had been identified: treatment for physical and emotional symptoms, support of functional autonomy, advance care planning, aggressive care near death, site of death, CPR, and hospitalization, patient and family satisfaction, global quality of life, family burden, survival time, provider continuity and skill, and bereavement (Lynn, 1997). The Institute of Medicine definition is more complex and covers domains of health status and functional outcomes including those mentioned (Field & Cassel, 1997). Donaldson (1998) suggests that measuring quality of care at the end of life is multidimensional and must include measurements of overuse (futile treatment), underuse of effective services, and poor practitioner skills or performance (p. 119). Practitioner skills should adhere to a standard of care that is sensitive to the needs of the patient and family, multicultural and institutional norms. The purposes of measurement include: external inspection, internal improvement, selective contracting with providers and informed patient/purchaser choice.

Only four articles were found in the hospice literature that analytically examined the quality of hospice care. Lorenz et al. (2002), suggested that standard measures of quality are not available and service intensity should not be a proxy for quality. However, Hamilton (1994) suggested that service intensity measured in hours per patient day was one legitimate measure of quality. Patrick, Curtis, Engelberg, Neilsen and McCown

(2003) in a study of two hospices in Seattle, Washington found higher Quality of Death scores were associated with the amount of time providers spent with patients which would validate the use of service intensity measurement.

Connor's summary of the National Hospice and Palliative Care Organization's (NHPCO) 2002 data set reported mean visits by clinical hospice staff as 4.5 and nursing staff as 2.2 during a stay of 20 days (national median length of stay); however, these were not suggested as measures of quality.

Whether or not family members received bereavement services and whether or not caregivers reported predeath preparation and emotional support pre and post death are considered measures of quality by NHPCO, the professional organization responsible for establishing standards of care. A survey of the 160 members of the California Hospice and Palliative Care Association conducted in 1999 revealed differences in bereavement practices categorized by hospice type. Foliart, Clausen and Siljestrom (2001) found "no clear relationship between the availability of professional counseling and the size or type of hospice" (p. 466). However, large hospices have more professional and Masters prepared staff; a greater percentage of large hospices and nonprofit hospices offer bereavement and support, than for-profits and small hospices.

Provision of "core services" and "non core services" were previously mentioned and might be considered a measure of quality (McCue & Thompson, 2005), as might the degree to which admission practices restrict access (Lorenz, Asch et al., 2004). However, these are not discussed in the standards of care possibly because the very hospice members of NHPCO who set the standards of care, restrict admissions and do not provide all core services.

Ethnic disparities in quality of hospice care were included in the analysis of end-of-life care for African-Americans (Welch et al., 2005). Their findings revealed that families of African-Americans decedents had concerns regarding physician communication more frequently than white families. Adams compared hospice care provided to Hispanics in El Paso, Texas and found that white patients received nearly twice as many volunteer services as Hispanic hospice patients in the same area.

No studies were found that considered “external inspection” by federal, state, or industry that compared care to established standards or to the Medicare Conditions of Participation. This is an area that needs much more research.

Considerations and Questions

Improving access to quality end-of-life care requires ongoing evaluation. Many of the articles reviewed were out of date because of the dramatic changes in life prolonging technology, and the financing and delivery of health care that occurred in the last decade of the twentieth century. As the health care industry continues to change and a substantial for-profit presence grows in hospice, systematic review of hospice organizational characteristics, length of stay, diagnoses, beneficiary insurance coverage and quality is essential in order to identify potential threats to access to quality hospice care. Research evaluating quality of care in the nursing home industry continues to reveal significant differences between for profit and nonprofit nursing homes (Harrington, O’Meara et al., 2006; Harrington & O’Meara, 2004; Harrington et al., 2001). Hospice care is far less regulated than nursing home care and the rapid changes in hospice structure should be monitored closely.

California, with foundation support, has created an environment of ongoing evaluation for nursing home and home health care. As the largest state in the country, trends in shifts toward for profit hospice and away from the interdisciplinary, volunteer based model of hospice care need to be monitored. If changes in access and quality are observed, it is essential that leaders and policy makers take advantage of the free enterprise sale of death, to redirect hospice toward its original community and spiritually centered philosophy. This study examines trends in California's hospices.

Chapter IV

Research Design and Methodology

Research Design

This dissertation uses secondary data to analyze trends and predictors of quality, utilization and cost in California's hospices over a 5-year time period (2000-2005). California was selected because it is one of the largest and most ethnically diverse states in the country with 15% of the nation's population and 12% of the nation's hospice patients (Lorenz, Asch et al., 2004). All of the data sources for this study come from United States (U.S.) government agencies and State of California databases that provide reliable sources of standardized data.

The sample for this study included data on California hospices from 2000 through 2005. Two aims guide this dissertation. The first aim is to describe hospice care in California and to examine trends in hospice quality, utilization and cost over the period of 2000 to 2005. The second aim is to examine the factors associated with hospice quality, utilization, and cost in California in 2005. To achieve the second aim, the study examined hospice organizational characteristics and hospice patient characteristics as predictors of specific outcomes related to quality, utilization and cost. Market characteristics at the county level were also examined as possible factors associated with quality, utilization, and cost outcomes.

Data Sources

This study used multiple data sources to describe California hospices. The primary source of data for this study is from the California Office of Statewide Health Planning and Development (OSHPD). The Office of Statewide Health Planning and

Development has been collecting data for over two decades for the purpose of analysis and planning. This public data base is regarded as a reliable source of data and has been used in many reports examining trends in health care utilization (Crawley & Kagawa-Singer, 2007b; Harrington, O’Meara et al., 2006; Harrington & O’Meara, 2004; Lorenz, Ettner et al., 2004a). This study uses the OSHPD data reported annually by all licensed hospices on a survey report titled: the “State Utilization Survey of Home Health Agencies and Hospices.” This survey (see Appendix 1) includes identifying business and organizational data including dates of operation, parent corporation, specification as branch or sole facility, Medicare and Medi-Cal accreditation status, ownership control (investor – for-profit v. nonprofit) as well as other data elements. The annual survey requires reporting all sources of financial income and all expenditures for licensed hospices. Numbers of patients and patient days, referral sources of patients, and payer sources are also reported. Client (patient) characteristics including, diagnosis, gender, race, age, types of services provided, types of personnel providing services, number of visits, and length of stay are included as well. The second dataset is from the California Department of Health Services, Licensing and Certification Program (CDDHS, L&C) Automated Certification and Licensing Administrative Information and Management Systems (ACLAIMS) data which contain organizational characteristics, complaints, and deficiencies at the hospice level.

Market level data at the county level were retrieved from the year 2000 U.S. Census Bureau and from the California Department of Health Services and Department of Social Services data on county population and health facility resources. The number of hospices and other health resources per county were calculated using the dataset.

Finally, internet websites for hospices and their parent corporations, as well as the U.S. Securities Exchange Commission website, were used as sources of data for describing profit and chain status. Individual hospice staffs were contacted by phone, by the investigator, to verify information gathered from websites and to clarify organizational name and address changes. Table III-1 contains a list of the variables, operational definitions and sources of the data.

Description of Variables

Independent variables were categorized as hospice organizational characteristics, hospice patient characteristics and county-level market characteristics. Data were standardized into counts (means, medians and proportions) per patient and per hospice. Dependent variables were categorized as quality variables including complaints, deficiencies, and visits by RNs and visits by all staff, average length of stay was the only utilization variable, and cost variables which included percent of total expenditures spent on RN care, cost per patient and income per patient. A more detailed description of how variables were standardized is described in the next section. A list of all variables, working definitions and their data source can be found on Table III-1.

Missing data

Estimates were made for missing data for independent variables using interpolation and extrapolation. If a hospice was open for at least three years and the middle year(s) were missing data, data were estimated by averaging the difference between the initial and subsequent years for which data were available. If hospices reported data in 2004 but not 2005, the investigator verified that the hospice was open in 2005 and missing data were extrapolated using linear regression.

Table IV-1 Variables and Sources California Hospices 2000-2005

| All Variables and Data Sources | Operational Definition | Data source |
|--|--|---|
| <i>Hospice Organizational Characteristics:</i> | | |
| Avg Patients/Year | Average Total Patients/Hospice/Year | OSHPD |
| Total Patient Days/year | Total Patient Days/Hospice/Year | OSHPD |
| Ownership | | |
| For-Profit | Investor owned individual + publicly owned | OSHPD |
| Nonprofit | Designated by Federal Government as Nonprofit + Government owned | OSHPD |
| Affiliation | | |
| Chain | 3 or more hospice branches in California and/or one or more branches in another state | Securities Exchange Filings & CA Dept of Corporations |
| NonChain | One or two hospice facilities in California | Securities Exchange Filings & CA Dept of Corporations |
| Size | | |
| Large | Greater than 75% percentile of patient days in specific year | OSHPD |
| Medium | 25 ^h -75 th percentile of patient days in specific year | OSHPD |
| Small | Less than 25 th percentile of patient days in specific year | OSHPD |
| Geography | | |
| Rural | Open county with fewer than 2,500 residents. | OSHPD |
| Non-Rural | Open county with greater than 2,500 residents. | OSHPD |
| Site of Care | | |
| % Days care at home | Days of care provided in patients' homes/total patient days | OSHPD |
| % Days of care in nursing home | Days of care provided in Skilled Nursing Facility/total patient days | OSHPD |
| % Days of care in RCFE (Residential Care Facility for the Elderly) | Days of care provided Residential Care for the Elderly Facilities/total patient days | OSHPD |
| Referral Source | | |
| % Referral by LTC facility (Long-Term Care Facility) | Number of referrals to hospice by Long Term Care Facilities/Total number of referrals to hospice | OSHPD |
| % Referral by insurer HMO (Health Maintenance Organization) | Number of referrals to hospice by Insurers or HMOs/Total number of referrals to hospice | OSHPD |
| % Referral by hospital | Number of referrals to hospice by Hospitals/Total number of referrals to hospice | OSHPD |
| <i>Hospice Patient characteristics</i> | continued | |

Hospice Patient characteristics

| | | |
|--|--|-------------|
| Age | | |
| <70 | Percentage of patients under 70 years of age | OSHPD |
| Age 71-80 | Percentage of patients between 71 and 80 | OSHPD |
| Age 81+ | Percentage of patients over 81 | OSHPD |
| Race | | |
| % Caucasian | Percentage of patients of Caucasian race | OSHPD |
| % African-American | Percentage of patients of African-American race | OSHPD |
| %Asian + other + unknown | Percentage of patients of Asian Pacific Islander, Native American, and "other" races | OSHPD |
| % Hispanic | Percent of patients answering "yes" to are you of Hispanic origin | OSHPD |
| Gender | | |
| % Female | Percent of female patients | OSHPD |
| % Male | Percent of male patients | OSHPD |
| Diagnosis | | |
| % Cancer | Percent of patients with diagnosis included in the combination of all cancer diagnoses | OSHPD |
| % Alzheimer's/dementia | Percent of patients with diagnosis of Alzheimer's and/or dementia | OSHPD |
| % Heart related | Percent of patients with diagnosis of heart related illness | OSHPD |
| Digestive/ Urinary system | Percent of patients with diagnosis of digestive tract or urinary system | OSHPD |
| Other diagnoses | Percent of other diagnoses | OSHPD |
| <i>Market Characteristic (County)</i> | | |
| Per Capita Income | Average county per capita income | Census 2000 |
| % Hispanic per 1000/population | Percent of Hispanics per 1000 population in county | Census 2000 |
| % African-American per 1000/population | Percent of African-Americans per 1000 population in county | Census 2000 |
| % Asian + unknown other per 1000/population | Percent of Asian Pacific Islander + Native American + other per 1000 population in county | Census 2000 |
| % Caucasian per 1000/population | Percent of Caucasian per 1000 population in county | Census 2000 |
| # hospital beds per 1000 population | Number of hospital beds in county/1000 population | OSHPD |
| # SNF beds per 1000 population | Number of Skilled Nursing Facility beds in county/1000 population | OSHPD |
| # RCFE beds per 1000 population | Number of Residential Care Facility for the Elderly beds/1000 population in county | OSHPD |
| Herfindahl-Hirshman Index | Sum of the squared market shares of all hospices in the county | OSHPD |
| <i>Outcomes:</i> | | |
| Complaints | Number of complaints filed with CA Dept. of Health Licensing and Certification Div. | ACLAIMSs |
| Deficiencies | Number of Deficiencies found on inspection by with CA Dept. of Health Licensing and Certification Div. | ACLAIMS |
| Average Visits RN/patient | Number of RN visits/Number of patients | OSHPD |
| Average Visits All Staff/pt | Total number of all staff visits/Number of patients | OSHPD |
| %RN Visits of Total Staff Visits | RN visits/Total staff visits | OSHPD |
| % Total Costs Spent on Nursing Care | Total operating costs/RN operating costs | OSHPD |
| Average Length of Stay | Total hospice days/total hospice patients | OSHPD |
| Cost/patient | Total operating costs/total patients | OSHPD |
| Income/patient | Total revenue/patient – Total operating costs/patient | OSHPD |

Hospice Organizational Characteristics as Independent Variables

Organizational characteristics include continuous independent variables that measure the number of California hospices, the average number of patients per hospice, and the average number of patient days per hospice. The number of hospices, patients and patient days are count variables for each year in the study period. The number of hospices was determined after all duplicates were removed in the data cleaning process (see data cleaning section). The numbers of patients were totaled and divided by the number of hospices to produce a mean number of patients per hospice each year. The number of patient days per year was totaled and divided by the total number of hospices each year.

Hospice size. The variable ‘size’ was created as a calculation of total patient days per hospice per year. Hospice size is measured by total patient days of care per year rather than by number of patients because of the differing lengths of patient stays. Size does not refer to the number of beds because hospice care is provided at the patient’s residence. Hospice size increases when more patients are cared for and requires only the addition of staff rather than capital infrastructure.

For the purposes of description and comparison, the hospices were divided into nominal variables referred to as 1) small, 2) medium and 3) large. The small hospices reported less than or equal to the first quartile (25%) of total patient days reported by California hospices in that year. Medium hospices reported patient days that included the second and third quartile, or between 25% and 75% of the average total patient days for all hospices per year. Large hospices reported total patient days in the fourth quartile or above 75% per year. Actual percentile values changed each year as the number of patient

days increased each year. Changes over time in the number of patient days are described further in Table V-1. This formula was taken from a Report to the House Ways and Means Committee: *Medicare hospice care: Modifications to payment methodology may be warranted* (Government, Accounting, & Office, 2004, p. 14).

Ownership. Ownership status is a nominal variable that describes the financial control of an organization. It is categorized as for-profit or nonprofit. Nonprofit hospices meet the nonprofit status criteria set out by the Internal Revenue Service of the United States. For-profit hospices are investor owned (both individually owned and publicly traded hospices). For-profit providers have a financial objective to maximize profits for the individual owner or for a group of investors. In contrast, nonprofit hospice providers are legally prohibited from distributing their earnings (McCue & Thompson, 2006). OSHPD data included for-profit, government operated and nonprofit categories. Nonprofit and government hospices were combined into one nonprofit category because there were so few government agency hospices. The number of government hospices did not change over the study period and did not provide adequate power for analysis using multivariate methods.

Affiliation. Until 2002, OSHPD collected and reported data on home health agencies and hospices together. Data were combined and described as “branches” of “parent” home health agencies. Since 2002, the designation of parent, branch, or sole facility describes a relationship with other hospices (rather than with home health agencies). Hospice data since 2002 were separated from home health data; the database continues to contain an element titled: ‘Name of Parent Corporation’. However since 2002, parent and branch refer to hospices with services in multiple locations or branches

(rather than hospice branches of home health agencies). This variable was eliminated from the dataset because several errors were found during the data cleaning process which were possibly related to confusion after the change in definitions.

Chain. The designation ‘chain’ was created by the investigator from multiple data sources. Previously published research using the OSHPD database defined chain as hospices that had parent organizations (including home health agencies described previously). The OSHPD definitions of parent and branch were confusing because of a change in the definition. In the nursing home literature, the definition of chain applies to more than one facility (Harrington, C., Carrillo, V., Wellin, V. Burdin, A., 2003). This dissertation defines ‘chain’ as hospices with three or more related hospices in California, or one or more hospices in another state. Three rather than one or more was chosen because many solely owned hospices add a second office because of federal guidelines requiring that the drive time from office to patient not exceed 40 minutes. As traffic congestion has increased, drive times have required the addition of additional offices (branches) in the same geographic area. When a third office is added, it represents an expansion of geographic service. Data were derived for hospices operating during the study period from the OSHPD dataset, hospice corporate websites, and the Securities Exchange Commission website.

Geographic location. Rural status is a nominal variable in the dataset that describes whether a hospice was located in one of the California’s 21 counties designated by the U.S. Office of Management as rural and listed on the Health Resources Services Agency (HRSA) rural health eligibility website (HRSA, 2005; US DHHS Health Resources Services Administration, 2005). Rural is defined as “open country and

settlements with fewer than 2,500 residents.” California is the third largest state, geographically in the country and almost half of the state’s 58 counties are considered rural.

The next set of organizational characteristic variables is related to the business organization of hospice services. These continuous variables include percentages of the days of care by site or location, the referral source and the payer source.

Site of Care. Site of care describes the percentage of days of care at one of three locations: 1) nursing homes, 2) residential care facilities for the elderly or 3) home. These data were not available for 2000 and 2001. The primary residential setting for hospice care in California remains at home. In many cases today, patients and their families cannot manage their care at home and instead reside in skilled nursing facilities or in residential care facilities. The OSHPD data show that nearly all of hospice care in California is provided where patients reside rather than in institutional settings, although some care is provided in institutions (nursing homes and Residential Care Facilities for the Elderly (RCFEs) where patients reside) by hospices that are licensed separately from the institution. There are very few institutional hospice beds because the per diem reimbursement rate of the Medicare benefit does not cover the cost of 24 hour care (see Chapter I).

Residential Care Facilities for the Elderly (RCFE) provide room and board and some assistance to people no longer able to live alone (often called ‘assisted living’). The patient (or in some cases government program including Medi-Cal) pays the RCFE fee and Medicare pays a hospice to provide hospice services to patients who reside in RCFEs.

Additional sites of care reported on the OSHPD database make up the reference category 'other' in the regression model.

Referral Source. Referral source is of interest as the market for hospice care changes. OSHPD collects data regarding the location or site from which the patient is referred. Referral source was measured as a continuous variable and describes the percent of patients referred from various sources. These data were not available on the OSHPD data base for 2000 and 2001. All hospice admissions require a physician referral attesting to a six month prognosis if the terminal illness runs its normal course without curative intervention. Patients can receive physician referrals when they are receiving care in both institutional and non-institutional settings. Three referral sources were selected for this study: referral by a long-term care facility, referral by a payer (insurer or health maintenance organization (HMO)), and referral by a hospital. The remainder combined into an "other" category for comparison in the regression models. These three reflected the most common referral sources, and included long-term care facilities which have begun to appear increasingly in the hospice literature (references previously cited).

Referrals from long-term care facilities are made for patients residing in skilled nursing facilities because they require some type of continuous care provided by a licensed nurse (RNs and LVNs). Patients who have a terminal diagnosis can be referred by a physician for hospice care. Room and board is then provided by the long-term care facility and the hospice care is provided by the hospice. The parent corporation of the long-term care facility and the hospice can be the same.

Referrals from payer sources (insurers and HMOs) reflect the increasing emphasis on planning for care and providing care in the most appropriate (and cost effective)

setting. Hospital referrals are made when patients are in the hospital and are referred through physicians. Patients are transferred from the hospital to hospice care at home or in a nursing home. Hospital prospective and diagnosis related reimbursement precludes keeping patients in acute care settings once treatment becomes only palliative because hospitals are not reimbursed for palliative care.

Payer Source. The percent of hospice revenue generated from Medicare, Medi-Cal (California's version of the Federal Medicaid insurance program) and other payers (the three primary payer sources) were considered in this study. Medicare is the federal insurance program for the elderly and disabled, Medi-Cal is a state/federal insurance program for the poor. The payers of hospice care are of interest for several reasons. Changes in financing of health care during the past two decades have placed a greater emphasis on managed care in the private sector as well as the public sector (Medicare and Medi-Cal managed care).

The federal and state governments are principal "payer sources" of hospice care. Payer source is measured as a continuous variable and reported in percentages. The OSHPD database did not include this information until 2002. Patients eligible for both Medicare and Medi-Cal have the portion of their hospice care not related to their terminal illness paid for by Medi-Cal. Nursing homes with non-Medi-Cal residents receiving hospice care are paid by Medicare for the hospice care related to their terminal illness. The patient pays for the room and board costs of the nursing home. Alternatively, the room and board portion of nursing home costs for patients eligible for both Medicare and Medi-Cal are paid for by Medi-Cal at 5% below the state Medi-Cal rate. Hospices are prohibited from paying 100 percent of the "board and care" costs to a nursing facility

unless the contract explicitly describes what additional services or products the hospice is buying from the facility.

Because fewer than 5 hospices did not accept Medicare and fewer than 20 did not accept Medi-Cal, the variable for accepting Medicare and Medi-Cal was eliminated from the data set. However, the percentage of Medicare and Medi-Cal revenue per hospice per year was included in multivariate analysis. .

The percentage of Medicare days (or days paid for by Medicare) describes the Medicare hospice benefit for all care related to the patient's terminal illness for patients over 65 years of age or disabled. Medicare is the primary payer for hospice care (Han, Remsburg, & Iwashyna, 2006). The percentage of Medi-Cal days describes the source of payment for patients meeting low income eligibility requirements for Medicaid. The percent of Medi-Cal patients is a proxy for the percentage of low income patients.

Hospice Patient Characteristics as Independent Variables

All the patient characteristic variables in this study are continuous variables measured as proportions. They include age, race/ethnicity, gender, and diagnosis.

Hospice Patient Characteristics.

Age. As the population ages, this categorical variable is of interest because hospice care is paid for largely by the age-related federal benefit Medicare. Medicare eligibility begins at age 65. The OSHPD dataset categorizes hospice patients by decade (51-60, 61-70, 71-80 etc.) so data comparisons for pre and post Medicare eligibility (age 65) could not be calculated. Three age intervals were used in this study. The percentage of hospice patients under age of 70 were combined into one variable to achieve adequate numbers for sufficient power in the regression model. The second age variable was the

percentage of hospice patients in the age range from age 71 to 80; and, finally the third age variable was the percentage of hospice patients over the age of 81. The percentage of hospice patients over the age of 81 served as the referent group in multivariate analyses.

Race/ethnicity is a variable of interest because ethnic disparities in health care are of concern to health providers, elected officials and ethnic minority groups themselves. Variables in this study include the percentages of African-Americans, Caucasians and an 'Other' category which combined Asian-Pacific-Islander, Native American, and unknown races. This category was created to achieve adequate power for regression modeling in which Caucasian is used as the comparison variable. The proportion of 'Hispanic' ethnicity was measured using a separate variable from the OSHPD data base (Hispanic/Non-Hispanic).

Gender is an important variable because of longer life spans experienced by women. Older women have fewer financial resources and are less likely to have a spouse at home to provide unpaid care required by hospice.

Diagnoses are the final patient characteristic. Some diagnoses were combined to limit the number of variables and to achieve adequate power for regressions. The four most common diagnoses include: cancer, heart related illnesses, digestive and urinary related illness and Alzheimer's/dementia. All cancers were combined into one variable because much of the literature differentiates between cancer and non-cancer diagnoses.

Market Characteristics

Market characteristics were added to the hospice characteristic variables previously described. The environment in which hospices operate was examined to evaluate market influences on outcomes. Market characteristics are described by county

as the unit of analysis. The county as a market measure was used in Iwashyna, Chang, Zhang and Christakis' (2002) study of the effect of market structure on the use of hospice services. The dataset for this study is abstracted from the U.S. Census Bureau 2000 data. Population demographic variables of age, race and gender and measures of health services available in the market, including the supply of hospital beds, skilled nursing facility beds and residential care for the elderly beds, as well as a measure of the competition in the market, were chosen as variables to explore the possible impact on "demand" for hospice services and competition among hospices and other health care service providers in the market area.

Population demographic measures. Population demographic measures include income, race, and gender. Average per capita income by county is included because Medicare does not pay for patient care unrelated to the terminal diagnosis. The ability of family members to care for patients and/or hire caregivers as required by the Medicare hospice benefit is related to income level. Racial categories are measured by percentages of Caucasians, African-Americans, Hispanics, Asian Pacific Islanders and other races combined per 1000 population per county. These racial/ethnic variables were defined by the US Census and included to evaluate demand and disparities in access.

When data across all 58 counties were combined, the average per capita income was \$22,221. African-Americans comprised 6.3% of the population; Caucasians 61.2% and 32.5% were Asian-Pacific Islander, Native American and unknown race combined. Nearly 32% of the population identified being of Hispanic origin. On average, women made up 50% of the population

The average per cent of people over age 65 per 1000 was 11%. This variable was considered for inclusion in multivariate analyses because this population makes up the largest demand for hospice care. However, this variable was not included in the dataset after it was found to be highly correlated with the hospice patient age category of 71-80 in Pearson product correlation analyses. The death rate for each county was obtained from State County Statistics as a measure of demand for hospice care. The average death rate per one thousand population was 6.3%. Again, this variable was not included in the final dataset because it was highly correlated with the study population age group of 71-80. Both of these variables were considered in analyzing trends related examine demand for hospice care in rural areas.

Measures of health care service intensity. Measures of health care service intensity for this study were available through the State of California Department of Health Services. Overall averages from county data collected in 2000 are summarized in Chapter IV, Table 1, along with the 2005 values of other independent variables.

The supply of hospital beds per 1000 population by county is a demand measure which has been examined in the literature. Hospice home care use has been higher in areas with fewer hospital beds per capita and in areas with lower in-hospital death rates (Tang, 2003). The supply of acute and long-term care beds represent market factors because both are referral sources for hospice care (Naik & DeHaven, 2001; Tang, 2003). Skilled Nursing Facility (SNF) beds per 1000 population by county provides a measure of demand for hospice services. Nursing home facility as a site of care for hospice has increased dramatically in the past decade (Neigh, 2004). The number of residential care facility for the elderly beds per 1000 population by county is also a potential hospice

demand factor. Although these facilities do not provide medical or nursing care services, they might include general supportive care and supervision for physically and/or mentally impaired people who can no longer live alone and have no caregivers.

The average number of hospital beds was 2.75 per one thousand population; the average number of skilled nursing facility beds was slightly higher at 4.44 per one thousand population and the average number of RCFE beds was 4.04 per thousand population.

Herfindahl-Hirshman Index The Herfindahl-Hirshman Index (HHI) is an economic measure of competition in a market (Baker, 2001; Banaszak-Holl, Zinn, & Mor, 1996). It is defined as the sum of the squares of the market share of each individual hospice. It can range from 0 to 1 and move from a very large number of very small hospices to a single large hospice. Decreases in the HHI index generally indicate a loss of monopolistic pricing power and an increase in competition, whereas an increase in the HHI index suggests increased pricing power, and increased concentration of service. To calculate the HHI, the total number of patient days for each hospice in California was divided by the total number of hospice patient days in each county. Furthermore, the proportions for each county were squared and summed to create an index for each county (Harrington, Swan, & Carrillo, 2006). The average HHI across the state was 0.06 across the counties in the state.

Outcome variables

Three types of outcome measures were examined to measure quality, utilization and cost of hospice care in California in 2005. These variables were chosen because they reflect three areas important to policy makers when regulating or subsidizing care. The

state is responsible for ensuring safety and quality in health care delivery services subsidized by the public. The state must also concern itself with accessibility to and utilization of services to ensure equity; and, the state as the primary payer for hospice care is concerned about the cost of care.

Quality. Quality of care in hospice has been defined in many ways and has not been measured consistently beyond compliance with the Medicare Conditions of Participation. Regulation of quality is limited to state agencies' inspection of hospices for licensure and investigation of complaints, which sometimes also requires inspection. For the purposes of this study, quality indicators include continuous count variables of deficiencies and complaints reported in the ACLAIMS data. Quality was also be measured by the number of skilled nursing visits (a proxy for quality), and the number of visits by all staff, both of which have been considered a proxy for quality (Gray, 1986, p. 135; Harrington et al., 2000).

Number of Complaints. Complaints are formal grievances filed with the licensing agency against the hospice by patients, families, friends or other people concerned about the safety and well-being of the patients admitted to the care of a licensed hospice. Hospices are licensed and certified using federal standards set forth in the Medicare Conditions of Participation (COPs). The COPs are intended to be standards that provide for both safety and quality. Recent research has found that nursing home consumer complaints used in combination with other quality measures have potential in evaluating quality of care (Stevenson, 2005).

Number of Deficiencies. Deficiencies are citations issued by state licensing agencies during routine surveys for licensure. Citations may also be found as a result of

surveys conducted to investigate complaints. The state of California inspects hospices shortly after they open to process licensure. After the initial inspection, they are only inspected every 6 years. The federal Centers for Medicare and Medicaid Services recently issued guidelines that increase the years between hospice routine certification inspections to 8 years (Office of the Inspector General, 2007).

Number of Skilled Nursing Visits. Nursing visits have been identified as a proxy for quality in hospice (Hamilton, 1993) and licensed staffing levels are frequently cited as an indicator for quality in the long-term care nursing facility literature (Harrington et al., 2000). And, higher quality of death scores have been found to be associated with the amount of time providers spent with patients which would validate the use of service intensity measurement (Patrick et al., 2003).

Number of visits by all staff. The hospice benefit was written to include interdisciplinary staff as well as nursing staff; this measure is included to evaluate service intensity for all staff. Hospice staff include social workers, chaplains, dieticians, physical therapists, home health aides, and counselors.

Utilization. Utilization is measured by the number of patients receiving hospice care, by the total number of patient days and by the average number of days per patient or average length of stay (ALOS). ALOS is a common measure of health utilization and is the outcome measure for this study. Utilization is considered a measure of access to hospice care. Three types of predictors of shortened lengths of stay have been examined in the literature: clinical characteristics (diagnosis and functional status upon admission), individual patient characteristics (age, race, and other comorbidities), and provider and institutional characteristics (Miller, Weitzen et al., 2003; Naik & DeHaven, 2001).

Costs. Costs may reflect length of stay and/or intensity of services needed by patients with advanced illness and high levels of co-morbid diagnoses or types of care provided. Three cost variables were included to evaluate both cost of care and income to the hospice. Cost and income are all continuous variables reported in dollars. The percentage of total hospice costs spent on nursing care is an important variable in this dissertation. It was calculated from total patient days and total number of patients per hospice and/or per year in California. The cost per patient was calculated by dividing total costs of the hospice by total number of patients. The income per patient was calculated by dividing total hospice income by total number of patients. Outcome variables requiring cost, income and expenditure data were only included for the years that data were available.

Data Cleaning

The California Office of Statewide Health Planning and Development collects data under provider numbers assigned to the address of the office out of which the hospice operates. Over the six year period there were a total of 40 hospice provider numbers with no data associated with them for more than one year and in all subsequent years (after the initial year of no data). Efforts were made to search the internet for these hospices and attempt to make contact with them were without success. Only after exhausting all potential avenues, the providers' numbers with missing data were removed from the dataset.

In addition, provider numbers assigned by OSHPD use "address" rather than license number or name as a unique identifier. When hospices offices move, a new provider number is assigned creating the appearance of some hospices closing and new

hospices opening. Often hospices report partial year data under two provider numbers during the same calendar year. This creates a false number of hospices providing care. In two instances, different hospices moved into the previous office of an entirely different hospice. The hospices took over the address and the previous hospice's provider number. Eliminating duplicate (and triplicate) provider numbers required an extensive search of the legal entity licensure data section of the CA database and attempts to contact hospices by phone to compare facility parent organizations, hospice names, license numbers, and addresses.

Seventy-five hospices with 159 different provider numbers moved and or joined other hospices during the study period and were combined into one provider number per hospice. Ownership status was checked for consistency across parent organizations and where questions arose, hospices were contacted. Additional data cleaning involved the ownership status of hospices (nonprofit or for-profit). Several hospices changed status from year to year and in all but one instance these were coding errors corrected via phone contact with hospice the administrator.

Analysis

The data analysis was conducted using SAS 7.0 software. Simple calculations were made using EXCEL. The sample for this analysis includes all hospices licensed in California operating at any time between 2000 and 2005. The sample size ranged from 179 to 210 so significance in all statistical analyses was considered from 0.1 to $\leq .0001$.

Aim 1: Describe Trends in California Hospice Characteristics, and in Hospice Quality, Utilization and Cost.

Descriptive statistics were used to describe trends in hospice quality, utilization and cost in California between 2000 and 2005. Statistical measures of central tendency were run on all independent and outcome variables. Means, standard deviations, medians, and confidence intervals were calculated for each continuous variable each year with the exception of deficiencies and complaints which were too small to calculate. Percentages were calculated for categories of nominal variables. Percentages were calculated to measure the change between 2000 and 2005, the years of the study. In order to better predict trends across years, a fixed regression model was performed with each predictor variable on unestimated data using the year as a fixed linear effect and a random hospice effect to account for correlations of values across the years. Estimated values were excluded from this regression model because the p-values and confidence intervals are not valid when the estimated values are included. Fixed regression is a multilevel model used to evaluate change. It considers change within each hospice and how changes differ across and between hospices. Data were summarized for each year 2000 through 2005 and compared across years.

Aim 2: Examine factors associated with hospice quality, utilization, and cost in California in 2005

Three hypotheses were associated with Aim 2.

H₁ Higher numbers of complaints and deficiencies as measures of poor quality will be associated with larger for-profit hospices that are affiliated with a parent corporation.

H₂ Increased hospice utilization will be associated with for-profit hospices, care provided in skilled nursing facilities, and care for patients with non-cancer diagnoses.

H₃ Lengths of stay and costs of hospice care will be higher in for-profit and chain operated hospice programs.

These three hypotheses posit that relationships will exist between the independent variables of chain, ownership and size with other independent variables. To evaluate possible relationships between chain and ownership profit status, Mann-Whitney U tests were performed on all the continuous variables to compare the means of the two groups (For-profit & Nonprofit, Chain & Nonchain). Mann-Whitney was used as a non-parametric alternative to a group t-test. It assumes that the distributions of variables are not normal. The Mann-Whitney U test is considered a 95% efficient test, which means it would be a little more powerful if the distributions were normal. If the Mann-Whitney “u” value, which is a sum of the ranked means of the variable, is significant, then the two groups come from different populations. To evaluate possible relationships between size and the other predictor variables, a Kruskal-Wallis one-way ANOVA (analysis of variance) test was performed because size was divided into three groups (small, medium and large). Kruskal-Wallis also presumes a non-normal distribution.

To examine the relationships between categorical variables, Fisher’s exact test of significance was performed with the affiliation variable (chain/nonchain) variable and ownership (for-profit/nonprofit) variables. The Fisher’s exact test is an alternative to a chi square test of significance that is used for categories with small numbers. The Kruskal-Wallis test was performed on the three size variables and the two groups of

affiliation variables (chain/nonchain) and ownership variables (for-profit/nonprofit). Significant p values (<0.05) reject the null hypothesis and infer that the groups come from different populations.

The three hypotheses also posit that relationships will exist between the independent variables: (hospice organizational and patient characteristics, and market characteristics) and the dependent variables (number of complaints, number of deficiencies, number of nursing visits, number of total visits, average length of stay, cost per patient, income per patient and percent of total hospice costs spent on nursing care).

Table IV-2 shows the specific hypothesized relationships between the 30 independent variables and the outcome variables examining quality, utilization and cost.

Table IV-2 Hypothesis Chart

| Predicted Findings | Quality | | | | Utiliza- tion | Costs | | | |
|---|----------------|------------------|--------------|-----------------|------------------|------------------------|--------------------------|------------------------|--|
| | Com plaints | Defi ciencies | RN visits | Total visits | LOS | Cost per patient | Income per patient | % costs for RN care | |
| <i>Organizational characteristics:</i> | | | | | | | | | |
| Ownership | | | | | | | | | |
| For-Profit | + | + | - | - | + | + | 0 | 0 | |
| Affiliation | | | | | | | | | |
| Chain | + | + | - | - | + | + | 0 | 0 | |
| Site of Care | | | | | | | | | |
| % days in Nursing Home | + | + | + | + | + | + | 0 | 0 | |
| % days in Residential Care Facility for the Elderly | - | - | - | - | + | + | 0 | 0 | |
| Referral Source | | | | | | | | | |
| % by Long-Term Care facility | + | + | + | - | + | + | 0 | 0 | |
| % by insurer HMO | 0 | 0 | + | 0 | + | + | 0 | 0 | |
| % by hospital | + | + | + | - | - | + | 0 | 0 | |
| Payer Source | | | | | | | | | |
| % Days: Medicare | + | + | - | 0 | + | + | + | + | |
| % Days: Medi-Cal | + | + | - | - | - | - | + | + | |
| Size | | | | | | | | | |
| Large | + | + | + | + | + | + | + | 0 | |
| Medium | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | |
| <i>Patient Characteristics</i> | | | | | | | | | |
| Age | | | | | | | | | |
| % <70 | 0 | + | + | 0 | + | + | 0 | 0 | |
| % 71-80 | + | + | + | + | + | + | + | + | |
| Race | | | | | | | | | |
| % African-American | 0 | 0 | + | + | + | + | 0 | 0 | |
| % Asian + other + unknown | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | |
| % Hispanic | 0 | 0 | + | + | + | + | 0 | 0 | |
| Gender | | | | | | | | | |
| % Female | + | + | + | + | + | 0 | 0 | 0 | |

| Diagnosis | | | | | | | | |
|-----------------------------|---|---|---|---|---|---|---|---|
| % cancer | - | - | - | - | + | - | 0 | 0 |
| % dementia/Alzheimer's | - | - | + | + | + | + | 0 | 0 |
| % Heart related | + | + | - | - | + | + | 0 | 0 |
| % Digestive/ Urinary system | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |

Analytic Model

Correlation Analysis. To determine what factors were associated with the outcomes, the independent variables were assessed for inclusion in regression models. Spearman Rank Correlations were used to examine associations between continuous independent (predictor) and dependent (outcome) variables. Kruskal-Wallis analysis was used for the categorical ‘size’ (small, medium and large) variable because it includes more than two groups. Mann-Whitney (previously described) was applied to compare categorical population variables and continuous variables. All tests were chosen because they assume non-normal or non-parametric distributions. Variables that reached the 0.25 level of significance were considered for inclusion in the regression model.

Pearson Product correlation analyses were conducted and correlation matrices were generated for all independent variables. Pearson correlation coefficients were compared to assess for evidence of multicollinearity. Pairs of variables with Pearson coefficients of 0.7 or greater were evaluated to determine which variable were removed from the analysis.

In the initial dissertation proposal, the percent of patients under 50 was intended to be the comparison group for age. However, the Pearson Correlation factor for age 51-70 and age 81+ was highly negatively correlated and the age category 81+ became the comparison variable. The initial proposal examined death rate per county, but in the Pearson Correlation analysis, it was found to be highly correlated with the percent of the

population in the county over 65 years of age, so the death rate was dropped from further analysis. The variable of percentage of Caucasian patients was highly correlated with African-American and 'Other' race. Therefore, Caucasian became the comparison variable rather than 'Other'.

Distributions were calculated on each of the outcome variables to examine for normality and possible skewness. The importance of normal distribution has been disproved by Lumley, Diehr, et al (2002) given adequate sample size. Moderately right skewed distributions were noted for six outcomes. Average Visits by all staff, percent of RN visits, cost per patient, percent of total costs spent on RN care, and complaints and deficiencies. These extremes were explained by the nature of hospice care which often allows for very limited care and significantly extended care dependent on stage of illness that patients were referred. The counts for complaints and deficiencies were cumulative over the five year period and included many hospices with zero complaints; therefore, they were tested separately as described later.

Regression Analysis

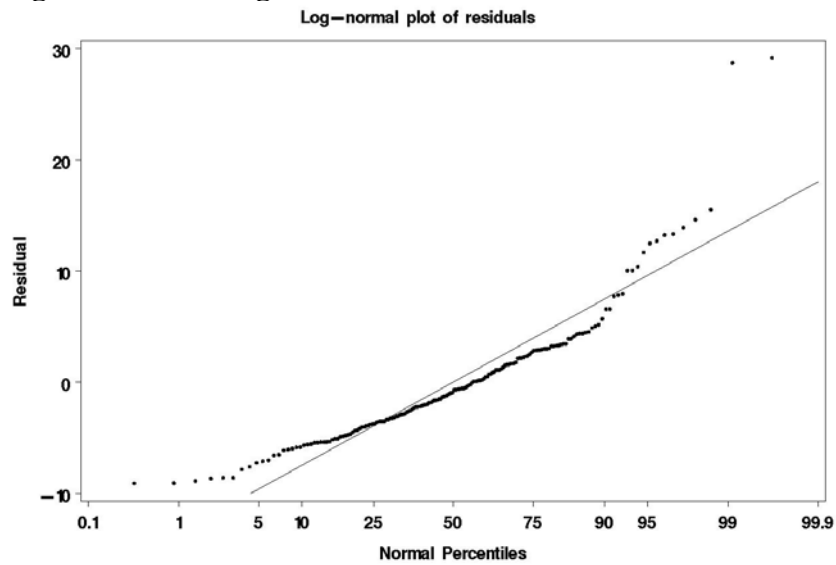
After removing highly correlated variables, 29 independent variables were selected for each model. All results had variable inflation factors (VIFs) of less than 4 as a measure of collinearity. Ordinary least squares regression (OLS) models were generated with the selected independent variables. Nominal variables (e.g. male, female, for-profit nonprofit) were assigned "dummy" values (0,1). The 2005 data with estimates were used in the regression analysis to predict quality, utilization and cost outcomes. The 2005 data were used for regression analysis because they were the most representative of the current field of California hospices. The outcome variables measured were: 1)

Average visits by RNs, 2) Average visits by all staff, 3) Average length of stay, 4) Percent of total costs spent on nursing care, 5) Hospice cost per patient and 6) Hospice income per patient. The following equation was used for each set of outcome variables.

$$\begin{aligned} \text{Quality (y)} &= (\text{Organizational characteristics}) + (\text{Patient characteristics}) + \\ & (\text{Market characteristics}) + e \\ \text{Utilization (y)} &= (\text{Organizational characteristics}) + (\text{Patient characteristics}) + (\text{Market} \\ & \text{characteristics}) + e \\ \text{Cost (y)} &= (\text{Organizational characteristics}) + (\text{Patient characteristics}) + \\ & (\text{Market characteristics}) + e \end{aligned}$$

Tolerance statistics were also performed in the regression analyses and variance inflation factors (VIF), which are considered the reciprocal of tolerance, were inspected for values of greater or equal to 4. The percent days of home care variable produced a VIF of 4 and new regression analyses were conducted for each outcome variable with home removed from the list of predictors and added to ‘other’ as the comparison variable. The regression models were re-evaluated for collinearity and none was observed. Models were assessed for normality of residuals produced on the residual versus predicted risk histograms and the log-normal plot of residuals. Normal distributions were confirmed with the exception of Average RN Visits which showed some deviation from normality for distribution of errors; however, it was not a large enough deviation to be problematic as shown below.

Figure IV-1 Average RN Visits



Adjusted R squared values were noted as measures of effect size used to explain the variance in the model. Regression coefficient estimates, standard errors and p-values for all six regressions were calculated. Significant predictor coefficients are in bold and identified. Intercept values, Adjusted R squared values, means, and final sample per model are also found in Chapter V Results on Table V-9.

Complaints and Deficiencies. As mentioned previously, the number of complaints and deficiencies reported during the six year study period was very small. In six years of data, only 50 hospices had deficiencies reported in the California Department of Health Services, Licensing and Certification Program (CDDHS, L&C) Automated Certification and Licensing Administrative Information and Management Systems (ACLAIMS) data. Only 55 hospices had complaints filed in the ACLAIMS data.

The distributions for the quality outcome variables of complaints and deficiencies were particularly small and skewed to the right. Because of the small number of complaints and deficiencies and the infrequency of licensure surveys, this analysis used

the cumulative number of complaints and deficiencies over the six year period (rather than only the 2005 data).

Figure IV-2 Histogram for Complaints in California Hospices 2000-2005

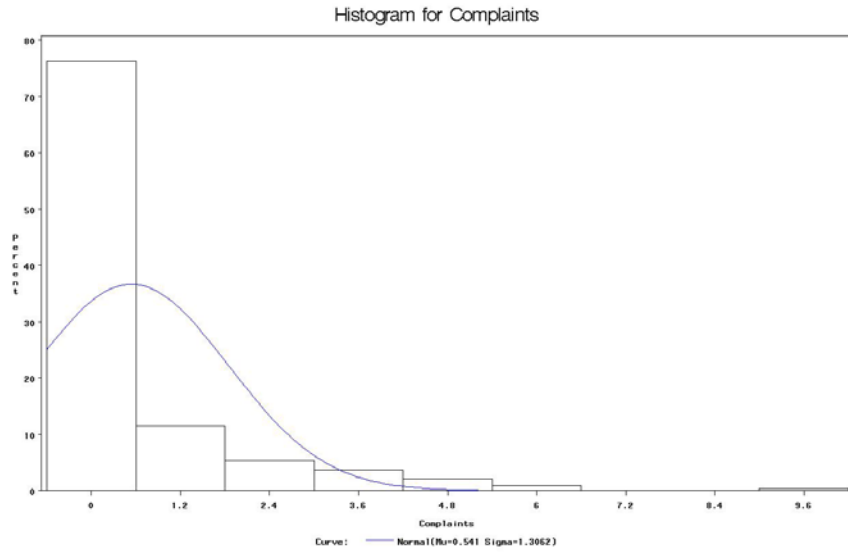
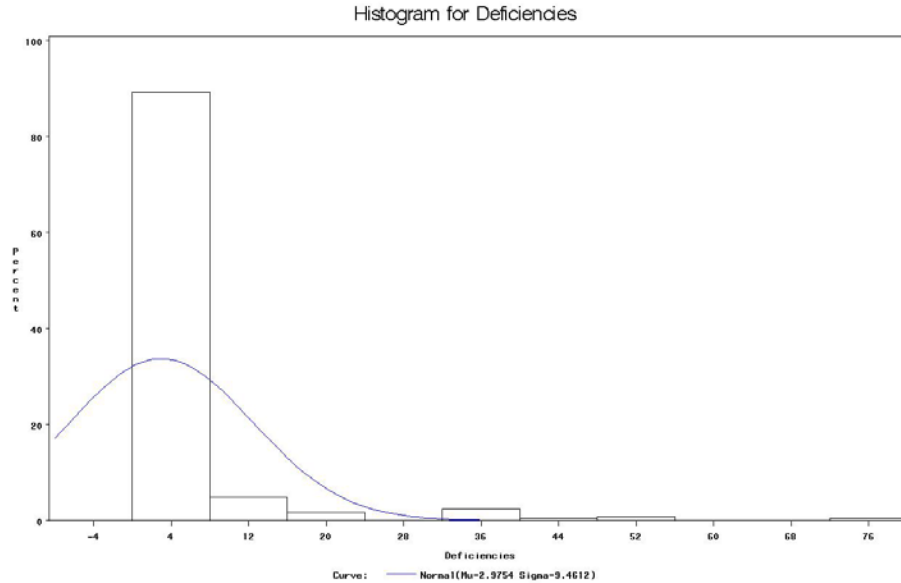


Figure IV-3 Histogram for Deficiencies in California Hospices 2000-2005



Poisson regression was considered as a possible approach to analyze these data because they are count measures. However, negative binomial regression analysis was a

better fit to identify predictors associated with complaints and deficiencies because there were so many 0 values.

First, the complaint data were fit to a logistic regression model. The 55 hospices that reported one or more complaints were assigned a 1=yes for complaints and the 146 hospices that reported 0 complaints were assigned a 0=no. Second the data were analyzed using a negative binomial regression model which is considered useful for tests where the distribution of the outcome is skewed (as this was to the right) and where there are many 0 values. Negative binomial regressions do not dichotomize the variables; therefore, they use more data in identifying significant predictors and are considered more powerful.

Next, deficiency data were fit to a logistic regression model. The 50 hospices that reported one or more deficiencies were assigned a 1=yes for deficiencies and the 151 hospices with 0 deficiencies were assigned 0=no. Finally, the data were analyzed using a negative binomial regression model.

Protection of Human Subjects

This dissertation research uses secondary analysis of publicly available data and meets the requirements for “exempt categories” of research (Category 4 - involving the collection of existing data that are publicly available) by the Human Research Protection Program at the University of California, San Francisco. No specific hospice identifiers were included in the dissertation. An exempt certification was received from the Office of Human Research Protection.

CHAPTER V STUDY RESULTS

The first aim of this study was to describe hospice care in California and to examine trends in hospice quality, utilization and cost during the period between 2000 and 2005. The first section of this chapter provides an overview of selected characteristics of California's hospices between 2000 and 2005, assembled from data retrieved from the California Office of Statewide Health Planning and Development's (OSHPD) data base and analyzed to identify trends in utilization of services. Changes in organizational and patient characteristics over the six year period are described in this chapter, including location of services and site of delivery, the organization of services as well as the types of patients and services used during the time period. Measures of central tendency, means, standard deviations, missing values, increases and decreases and percent change between 2000 and 2005, as well as the slope change per year with confidence intervals and predicted trends of change between 2000 and 2005 were calculated. Trend analysis of the counts for two of the quality outcome variables, complaints and deficiencies, were too small to calculate change over time.

Overall, the number of hospice patients and the number of days of hospice care grew significantly during the six year period. Access to hospice care in rural counties decreased. Residential Care Facilities for the Elderly (RCFEs) increased as a location for the provision of hospice care and there was an increase in the number of referrals to hospice by insurers and HMOs. The financing of hospice care showed increases in the percentage of Medicare paid days of care and a decrease in the percentage of days paid by Medi-Cal.

Hospice patient characteristics changed as well during the study period. The percentage of patients over 81 years of age increased, and the percentage of patients under 81 decreased. The percentage of Caucasian patients and African-American patients decreased and the percentage of female hospice patients increased. The diagnoses of hospice patients showed a significant increase in the percentage of patients with non-cancer diagnoses and a commensurate decrease in the percentage of cancer diagnoses.

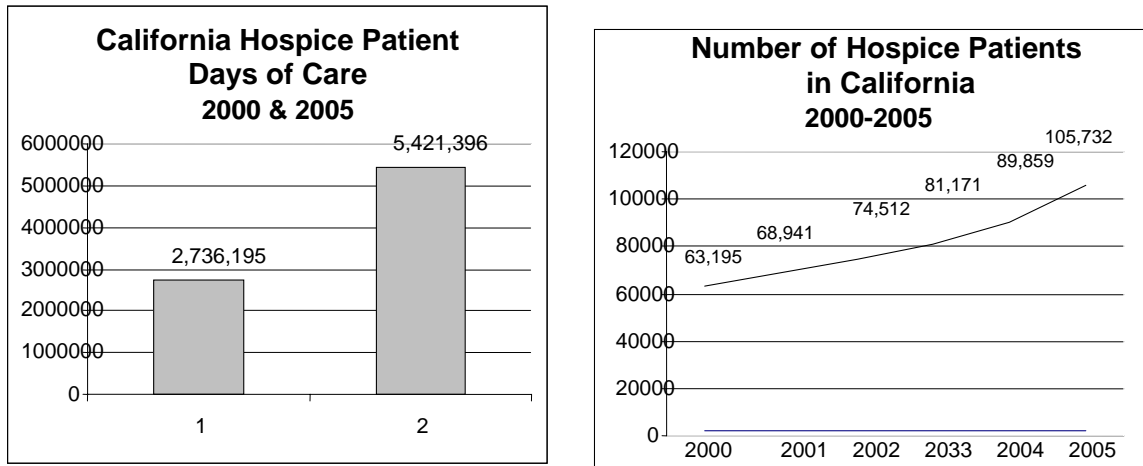
The second aim of this study was to examine factors associated with hospice quality, utilization and cost. The study explored possible relationships between hospice organizational and patient characteristics and quality, utilization and cost outcomes using Ordinary Least Squares (linear) regression. Outcomes requiring financial data were not included for the study years 2000 and 2001 because they were not available until 2002, when the OSHPD added these elements to the statewide utilization data set. Analysis of possible predictors of complaints and deficiencies used the cumulative number of complaints and deficiencies over the six year period modeling them using both logistic and negative binomial regressions. The 5 regression findings are summarized in Table V-4. Additional hypotheses were examined to identify relationships between independent variables and are summarized in Tables V- 4-7. All findings are described in detail in this chapter.

Aim 1 Hospice Characteristics 2000-2005
Organizational hospice characteristics

The organizational characteristics of California hospices examined in this study include counts of hospices, patients and patient days, type of ownership, chain affiliation, size, geographic location, site of care delivery, referral source and payer source. The number of hospices operating in California increased by 17% during the six year study period from 179 hospices in 2000 to 210 hospices in 2005 (see Table V-1).

Figure V-1 displays the increases in the number of patients and patient days of care during the study period. During this time, the number of patients increased by 67% from 63,195 in 2000 to 105,732 in 2005. The number of patient days of care nearly doubled, increasing from 2,736,195 to 5,421,396. The fixed regression model results revealed an increase per hospice of 38.8 patients per hospice per year, and an increase of 2,900 additional days of care per year per hospice per year (see Table V-1).

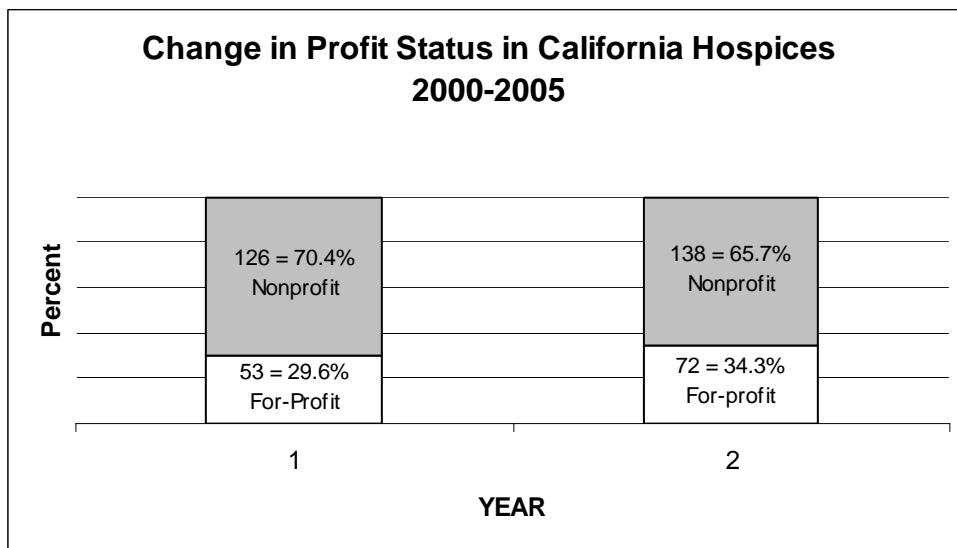
Figure V-1 California Hospice Growth 2000-2005



Hospice Ownership and Affiliation. The increased utilization of hospice care reported during the period between 2000 and 2005 was accompanied by changes in the ownership of California's hospices. In 2000, 53 of the 179 hospices, or 29.6% were for-

profit or owned by investors (see Figure V-2). By 2005, that number increased by 36% to 72, making up 34.3% of the state’s 210 hospices (see Figure 2 & Table V-1). The number of nonprofit hospices (including government hospices) which at the beginning of the study period made up 70.4% (126) of the state’s hospices increased by twelve hospices to a total of 138 in 2005 but dropped to 65.7% of the total number of hospices in the state (see Table V-1).

Figure V-2 Ownership change in California Hospices 2000-2005

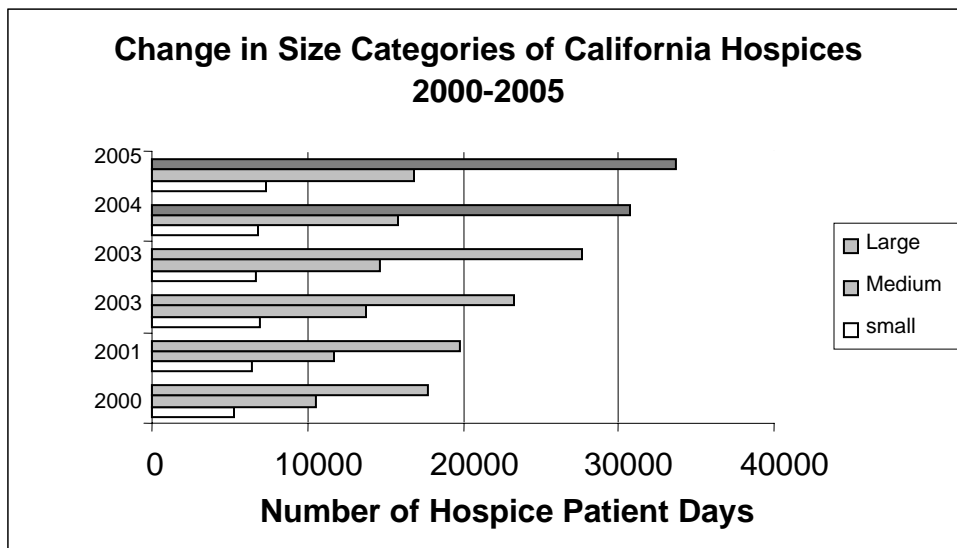


The number of hospices affiliated as part of a chain, or those with more than three affiliated hospices in California and/or one or more affiliated hospices in another state increased 20% over the study period, from 74 in 2000, to 89 in 2005, while the number of nonchain affiliated hospices remained increased by only 15% from 105 to 121 (see Table V-1).

Size(patient days of care). The sizes of California’s hospices are very diverse. The 2005 range data (not on table) show the smallest hospice in California reporting only three days of patient care and the largest reporting 244,367 patient days of care. The median number of patient days in 2005 was 16,800 days per hospice. For this study, size

is measured in total patient days per year and divided into three groups. For the purposes of comparison, hospices were divided into small, medium and large with the small hospices reporting less than or equal to the first quartile (25%) of average total patient days for all hospices in that year. Medium sized hospices reported patient days between 25% and 75% of the average total patient days for all hospices for that year, and large hospices reported total patient days above 75%. In 2000, small hospices reported fewer than 5,296 total patient days per hospice (see Figure V-3). Medium sized hospices reported between 5,297 and 10,499 total days per hospice and large hospices reported over 75% of total days per hospice, 17,808. Because of the rate of hospice growth, by 2005, the median quartile began at 16,801 days per hospice which was almost equal to the bottom of the large quartile in 2000 (17,808 days per hospice). Large hospices reported between 33,638 and 40,009 days per year in 2005 (see Table V-1).

Figure V-3 Change in Size Categories of California Hospices 2000-2005



Rural hospices. California is a large and geographically diverse state. California has 58 counties, and 21 of them are considered rural (or “nonmetro”) according to the US Office of Management and Budget (2004). Rural is defined as “open country and settlements with fewer than 2,500 residents” (USDA retrieved 2007). Because of the need to travel long distances to receive care, access to health care in rural areas is a challenge. During this study period, access to hospice care in rural California counties decreased (see Table V-1).

In 2000, 14 California counties had no hospice services. Twelve of the fourteen counties without hospices services were located in one of the state’s 21 rural counties. In 2005, 14 of the state’s 21 rural counties had no hospices. The total number of hospices in rural counties decreased from 14 to 12 during this study period. Further, by 2005, 15 California counties (both rural and non-rural) had no hospice services (county data not shown on tables).

The average death rate across California counties is 6.93 deaths per 1000 population per year. Of California’s 37 non-rural counties, 23 have a death rate below the state average. The death rate in California’s rural counties is much higher than non-rural counties. Nineteen of the 21 rural counties in California have death rates above 6.93. Twelve of the 21 rural counties have death rates above 10.

The percentage of people over 65 years of age, which is often considered retirement age because social security eligibility begins at age 66, is much higher in California’s rural counties, because of limited employment opportunities for work in rural areas. The state average percentage of the population over age 65 is 11%. There are 12 rural counties with greater than 15% of their residents over the age of 65, and fewer than

half of these counties have hospice care. The need for hospice care for people dying of age-related chronic illness is greater in rural counties than non-rural and rural counties.

Site of Care. The Medicare hospice benefit defined hospice care as care given in people's homes by family members. Home was the site of care for 70 per cent of hospice of days of hospice care in California; however, there was a significant decline in the percentage of hospice care provided in patients' homes during the period for which data were available, 2002 to 2005 (see Table V-1). The fixed regression model shows a decrease of 1% per year in hospice care provided in patients' homes. While some hospice care is provided in nursing homes and residential care facilities for the elderly (RCFEs), these facilities hold separate licenses, and if patients who reside there are referred for hospice care, separately licensed hospices (which may or may not have the same parent organization) provide the care. From 2002, when data were first reported to 2005, the smallest percentage of care was provided in RCFEs (see Table V-1). However, over the study period, the percentage of hospice days of care in RCFEs increased nearly 1% per year revealing a significant trend.

Referral source. Hospice referrals originate from many places, including friends, family, health providers, clergy, physicians, hospitals, insurers, and long-term care facilities (Jennings et al., 2003). This study considers three sources of hospice referrals. Referral for hospice care requires a physician's order, and a designation that the patient has less than six months to live. The location from where patients were referred during this study showed significant year to year changes in the percentage of patients referred by insurers/HMOs, and in referrals made by hospitals (see Table V-1).

Payer source. Medicare is the predominant payer of hospice services. The percent of hospice days paid for by Medicare increased by nearly 3% between 2002 and 2005. During the same period, the percent of days paid for by Medi-Cal decreased marginally. Combined, Medicare and Medi-Cal made up 91% of the payers for hospice care in 2002 and 92% in 2005. Other payer sources include private insurance and self-pay (see Table V-1).

Table V-1 California Hospice Organizational Characteristics 2000-2005

Means and (standard deviations), Percent Change, Predicted Trend Change

| | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | % change 2000-2005 N(+ or -) | Fixed Regression PER YEAR Slope-change CI (lower95%-upper 95%) | Predicted Trend 2000-2005 |
|--|-------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|------------------------------------|--|-------------------------------------|
| Organizational Characteristics | | | | | | | | | |
| Numbers hospices/Numbers patients | | | | | | | | | |
| Number of Hospices | 179 | 176 | 175 | 186 | 205 | 210 | 17.3% +31 | NC | NC |
| Total Patients/year | 63,195 | 68,941 | 74,512 | 81,171 | 89,859 | 105,732 | 67% +42,537 | NC | NC |
| Avg pts per hospice/yr | 353.04 (375.17) | 391.71 (410.92) | 425.78 (444.92) | 436.41 (466.98) | 442.66 (487.34) | 503 (977.32) | 42.6% +150 | 38.87**** CI(25.09/52.65) | 231.79**** (1034.94) |
| Total Patient Days/year | 2,736,195 | 2,975,022 | 3,401,401 | 4,157,389 | 4,881,516 | 5,421,396 | 98% +2,685,201 | NC | NC |
| Avg total patient days/hospice/year | 15,286.01 (18585.14) | 16,903.53 (19,571.72) | 19,548.28 (22,045.55) | 22,351.55 (26,290.16) | 24,046.88 (29,403.93) | 25,861.17 (31,116.11) | 69% +10,575.16 | 2,900.16**** CI(2559.5/3240.8) | 13,294.24**** (19,402.59) |
| Ownership/Affiliation | | | | | | | | | |
| | | | | | | | | | Period %change |
| For Profit | 53 29.6% | 54 30.7% | 57 32.6% | 62 33.0 % | 71 34. % | 72 34.3% | 36% +19 | NC | +5.3% |
| Nonprofit | 126 70.4% | 122 69.3% | 118 67.4% | 126 67% | 134 65.4% | 138 65.7% | 10% 12 | NC | -4.7% |
| Chain affiliation | 74 41.3% | 75 42.6% | 78 44.6% | 79 42% | 89 43.4% | 89 42.4% | 20% +15 | NC | +1.1% |
| Nonchain | 105 58.7% | 101 57.4% | 97 55.4% | 109 58% | 116 56.6% | 121 57.6% | 15% +16 | NC | -1.2% |
| Size | | | | | | | | | |
| Large | 44 24.6% | 46 26.1% | 47 26.9% | 48 25.5% | 48 23.4% | 48 22.9% | 10% +4 | NC | 1.5% |
| Med | 86 48% | 88 50% | 89 50.9% | 94 50.0% | 102 49.8% | 102 48.6% | 16 18% | NC | 0.6% |
| Small | 49 27.4% | 42 23.9% | 39 22.3% | 46 24.5% | 55 26.8% | 60 28.6% | 22% +11 | NC | 1.2% |
| Geographic location | | | | | | | | | |
| Rural | 14 (7.7%) | 14 (7.9%) | 10 (6.2%) | 14 (7.7%) | 13 (6.6%) | 12 (5.9%) | (-14.3%) -2 | NC | -6.6%NC |
| Non-rural | 165 (92.3%) | 162 (92.1%) | 165 (93.8%) | 172 (92.3%) | 192 (93.4%) | 198 (94.1) | (20%) 33 | NC | 1.8%NC |
| Site of Care | | | | | | | | | |
| % days Home | NA | NA | 77.45 (22.79) | 74.89 (24.89) | 73.54 (25.06) | 70.29 (27.67) | -9.6% -7.5 | -1.01** CI(-2.2/-0.41) | -2.59** (20.24) |

Table V-1 continued

| | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | % change 2000-2005 N(+or -) | Fixed Regression PER YEAR Slope-change CI (lower95%- upper 95%) | Predicted Trend |
|---|------|------|------------------|------------------|------------------|------------------|-----------------------------------|---|----------------------------|
| % days Nursing home | NA | NA | 15.16 (16.76) | 17.03 (20.54) | 18.02 (20.02) | 16.54 (18.75) | 9.1% +1.38 | 0.046 CI(-0.53/0.62)- | -0.08 (11.89) |
| % days Residential Care Facility for Elderly | NA | NA | 3.62 (8.19) | 4.61 (7.72) | 6.21 (11.81) | 8.69 (17.16) | 140% +5.07 | 1.046**** CI(0.56/1.53) | 1.77**** (6.66) |
| Referral Source | | | | | | | | | |
| % Long-Term Care Facility | NA | NA | 11.14 (13.27) | 11.22 (15.07) | 12.28 (16.8) | 11.45 (17.35) | 1.5% +0.17 | -0.16 CI(-0.9/0.55) | -0.87 (11.97) |
| % Insurer HMO | NA | NA | 2.87 (9.86) | 3.07 (8.75) | 3.52 (10.5) | 3.58 (10.25) | 20.6% +0.75 | 0.291* CI(-0.3/0.6) | 0.64 (7.82) |
| % Hospital | NA | NA | 26.48 (15.73) | 25.19 (15.37) | 25.35 (16.81) | 25.81 (17.24) | -2.5% -0.67 | 0.754*** CI(0.12/1.39) | 3.2*** (14.92) |
| Payer Source | | | | | | | | | |
| % days paid by Medicare | NA | NA | 83.03 (12.19) | 82.92 (15.03) | 83.25 (16.97) | 85.29 (12.83) | 2.7% +2.26 | 1.31**** CI(0.62/2.0) | 3.31**** (11.09) |
| % days paid by MediCal | NA | NA | 7.8 (9.4) | 7.54 (9.59) | 7.92 (11.13) | 7.67 (8.39) | -1.67% -1.3 | -0.09 CI(-0./0.3) | -0.47* (7.46) |

NA-Not Available NC-Not Calculated
2005

Fixed Regression Model year to year change

Wilcoxon Signed-Rank overall change between 2000 &

*Significant at 0.1 level

**Significant at .05 level

***Significant at \leq .01 level

****Significant at \leq .001 level

Hospice Patient Characteristics

Age. All age groups in the study showed significant changes over the six year study period. The largest change in characteristics of hospice patients in California during the study period was a 32.1% increase between 2000 and 2005 in the number of hospice patients over the age of 81 (Table V-1). On a year to year basis, this translated in the fixed regression model to an average rate of change of 2.11% per year and 11.38% over 6 years. This change was accompanied by a 27% decrease in the percentage of patients under 70 and a 14.5% decrease per year in patients between 71 and 80 during the study period.

Race. The racial/ethnic makeup of California's hospice patients changed significantly each year during the six year study period. The percentage of Caucasian hospice patients decreased from 75.18% in 2000 to 70.2% in 2005. This change is plotted as a downward slope of approximately 0.06% per year and 3% overall downward trend over the study period (see Table V-2). The racial category inclusive of Asian Pacific Islander, Native American and unknown race increased from 20.5% of hospice patients in 2000 to 25.6% in 2005. The percentage of African-Americans decreased slightly as did the percentage of hospice patients identifying themselves as 'Hispanic.'

Gender. The percentage of women using hospice services showed a significant increased trend of more than half a percent increase per year. The predicted trend over 6 years shows slightly over 2% increase for the study period (see Table V-2). By 2005 female patients made up 58% of all hospice patients. If this trend continues, in the next 15 years, women will make up over two-thirds of hospice patients in California.

Diagnosis. Not unlike national data, cancer made up the highest percentage of hospice patients' diagnoses. However, during this study period, there was a decrease in the percentage of hospice cancer diagnoses from 59% in 2000 to 43% in 2005, a significant 2.8% downward slope per year and a 12.35% downward trend over the 6 year period (see Table V-2). The variable of 'other diagnoses' more than doubled during the study period. Patients with heart related diagnoses made up 17.24% of California's hospice patients in 2005. This diagnosis showed a significant over all decrease and downward trend of 1.22% over the study period. Diagnoses related to the digestive and urinary system significantly decreased by over 2.43%. In contrast, the diagnoses of Alzheimer's or dementia increased significantly from 8.45% per cent of hospice patients in 2000 to 13.21% in 2005 (see Figure V- 4).

Figure V-4 Change in California Hospice Diagnosis 2000-2005

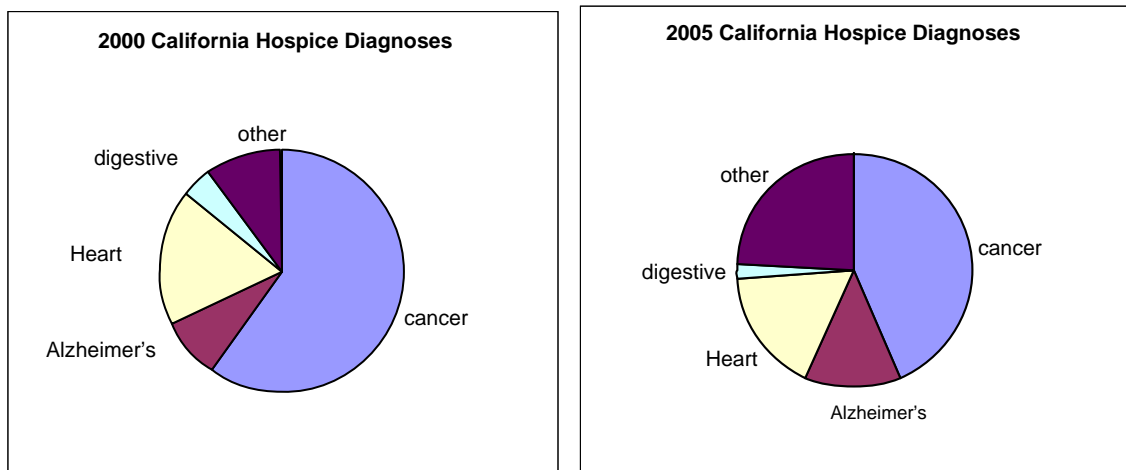


Table V-2 California Hospice Patient Characteristics 2000-2005
Means and (standard deviations), Percent Change, Predicted Trend Change

| | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | % change 2000-2005 (+ or -)N | Fixed Regression PER YEAR Slope-change CI (lower95%-/upper 95%) | Predicted Trend 2000-2005 |
|---------------------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------------------------|---|------------------------------|
| Age | | | | | | | | | |
| <70 years | 31.47 (13.79) | 29.67 (13.13) | 27.26 (11.28) | 25.91 (10.89) | 24.25 (11.25) | 22.98 (10.60) | -27% -8.49 | -1.11**** CI(-1.34/-0.88) | -5.59**** (9.3) |
| 71-80 years | 28.74 (7.07) | 27.62 (6.29) | 26.56 (6.33) | 26.09 (6.41) | 25.52 (8.87) | 24.56 (8.98) | -14.5% -4.18 | 0.929**** CI(-1.13/-0.74) | -5.73**** (6.75) |
| 81+ years | 39.76 (14.58) | 42.64 (12.8) | 46.12 (13.05) | 48.01 (13.14) | 50.19 (13.80) | 52.52 (13.26) | 32.1% +12.76 | 2.11**** CI(1.82/2.39) | 11.38**** (11.38) |
| Race/Ethnicity | | | | | | | | | |
| % Caucasian | 75.18 (24.51) | 72.72 (27.47) | 71.38 (28.36) | 71.95 (27.92) | 69.38 (27.58) | 70.2 (27.01) | -6.6% +4.98 | -0.61** CI(-1.1/0.14) | -3.06** (21.10) |
| % African-American | 4.29 (6.80) | 4.66 (8.45) | 4.61 (9.09) | 4.66 (8.77) | 4.95 (8.81) | 4.18 (8.11) | -2.6% -0.11 | -0.13**** CI(-0.23/-0.031) | -0.89** (3.62) |
| % Asian + other + unknown | 20.53 (23.97) | 22.59 (26.5) | 24.0 (27.58) | 23.39 (26.7) | 25.67 (26.12) | 25.61 (25.85) | 24.7% +5.08 | 0.75**** CI(0.26/1.23) | 3.95** (21.51) |
| % Hispanic | 9.93 (11.77) | 9.54 (10.92) | 9.22 (10.76) | 9.16 (10.57) | 9.31 (9.58) | 9.73 (11.50) | -2% -0.2 | 0.0245** CI(-0.45/-0.04) | -1.12 (9.77) |
| Gender | | | | | | | | | |
| %Female | 54.92 (8.31) | 55.75 (8.33) | 55.89 (7.51) | 56.89 (7.96) | 57.35 (8.99) | 58.03 (8.56) | 5.7% +3.11 | 0.548**** CI(0.31/0.78) | 2.06**** (6.47) |
| Diagnosis | | | | | | | | | |
| % Cancer | 59.1 (16.43) | 56.23 (15.37) | 52.39 (4.523) | 47.52 (17.65) | 44.50 (16.85) | 43.18 (16.32) | -26.9% -15.92 | -2.814**** CI(-3.18/-2.45) | -12.35**** (15.81) |
| % Alzheimer's/ Dementia | 8.45 (6.93) | 10.28 (8.04) | 9.22 (7.64) | 10.81 (10.56) | 12.01 (10.69) | 13.21 (10.54) | 56.33% +4.76 | 0.34**** CI(0.1/0.54) | 1.48*** (7.17) |
| %Heart illness | 17.80 (11.20) | 16.78 (9.02) | 14.07 (7.53) | 15.33 (9.93) | 16.68 (10.48) | 17.24 (9.32) | -3.15% -0.56 | 0.23* CI(-0.48/0.017) | -1.22** (8.35) |
| %Digestive & Urinary related | 4.3 (3.43) | 4.18 (2.39) | 1.95 (2.21) | 1.71 (1.64) | 1.98 (1.98) | 2.05 (2.41) | -52.3% -2.25 | 0.51**** CI(-0.59/0.43) | -2.43**** (3.9) |
| % other diagnoses | 10.3 (10.42) | 12.56 (12.31) | 22.33 (10.84) | 24.64 (15.57) | 24.94 (14.83) | 24.35 (13.89) | 136.4% +14.05 | 3.22**** CI(2.87/3.58) | 14.55**** (13.47) |

Fixed Regression Model year to year change Wilcoxon Signed-Rank overall change between 2000 & 2005
 *Significant at 0.1 level **Significant at .05 level ***Significant at \leq .01 level ****Significant at \leq .001 level

Summary of Outcome Variable Measures of Central Tendency from 2000-2005

Significant trends were found in 4 of the 6 outcome variables (excluding complaints and deficiencies which were too small to calculate). Table V-3 shows the measures of central tendency for the outcome measures.

Average length of stay. The average length of stay (ALOS), across California's hospices, increased by 37% from 43.44 days in 2000 to 59.89 days in 2005. This represents a significant predicted trend over the 6 year study period of 11.22% and an increase of 3.16% per year (see Table V-3).

Nursing visits. Although the average number of nursing visits per patient did not change significantly, the percent of all hospice visits that were made by a nurse decreased significantly by 0.11% from 0.65% to 0.56% over the 6 years. The distribution curve for the average number of nursing visits in 2005 was slightly skewed to the right because a small number of patients received more than 30 visits with the average being 13 visits (see Table V-3).

All staff visits. A significant trend in increased average numbers of visits by all hospice staff of 5.8 visits per patient was found over the 6 year study period. This increase may explain the decrease in the percent of nursing visits (see Table V-3).

Cost per patient. A trend of increased cost per patient was found for the 4 years financial data were reported (2002-2005). The average cost per patient increased from \$7056.30 per patient in 2002 to \$9537.56 per patient in 2005 representing an increase of 12% per year or \$763.68 per year. Patients requiring more complex care and having longer lengths of stay had higher costs; hence, the distribution of this outcome was also slightly skewed to the right because of small number of patients costing more than

\$30,000 with the average cost per patient at \$9,538 per patient in 2005. The percentage of total costs spent on nursing care decreased insignificantly from 27% in 2002 to 25 percent in 2005 (see Table V-3).

Table V-3

Outcome Variables California Hospices 2000-2005 Means and Standard Deviations, Percent change, and Predicted Trend Changes

| | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | % Change 2000 & 2005 (+ or -) N | Fixed Regression PER YEAR Slope-change (%/year change CI(lower 95%- upper 95%) | Predicted Trend 2000-2005 (SD) |
|-----------------------------------|------------------------|------------------------|------------------------------|------------------------------|------------------------------|------------------------------|---------------------------------------|---|---|
| Outcomes | | | | | | | | | |
| ALOS (in days) | 43.44 (15.02) | 43.27 (15.10) | 46.73 (19.24) M=1 | 51.12 (20.54) M=6 | 55.54 (36.89) M=3 | 59.89 (26.68) | 37% +16.5 | 3.161**** | 11.22**** (19.97) |
| AvgVisitsRN | 13.53 (9.98) M=5 | 12.54 (4.56) M=4 | 11.84 (6.36) | 12.63 (6.34) M=1 | 13.00 (5.88) | 13.25 (6.53) M=7 | -2% -.3 | 0.11 | .22 (12.19) |
| AvgVisitsStaff | 31.45 (26.32) | 29.54 (12.81) | 29.04 (15.88) M=1 | 32.56 (20.53) M=5 | 33.87 (16.09) M=1 | 37.28 (16.94) M=1 | 18.5% +5.8 | 1.235 | 4.29**** (26.84) |
| % RN visits | 0.65 (2.32) M=5 | 0.78 (5.14) M=4 | 0.24 (0.36) M=8 | 0.36 (0.69) M=13 | 0.74 (3.87) M=5 | 0.56 (2.59) M=13 | -13.8% -.09 | -0.037 | -0.11**** (0.46) |
| Cost per patient | data not available | data not available | 7056.30 (6121.49) M=20 | 7445.50 (4175.89) M=29 | 8743.74 (5134.58) M=42 | 9537.56 (5369.30) M=20 | 35% +2481.22 | 763.68**** 12% | 2174.04**** (3411.96) |
| % Costs for nursing care | data not available | data not available | 26.86 (11.95) M=27 | 25.47 (10.44) M=45 | 25.69 (11.20) M=47 | 25.09 (12.01) M=27 | -6.6% -1.77 | -0.385 | -1.33 (11.51) |
| Net Hospice Income per patient | data not available | data not available | 1908.28 (19032.30) | -154.46 (3397.68) | -64.10 (4806.16) | 23.92 (4346.99) | 98.7% -7878 | -1037.26**** | -1491.95 (19992.21) |
| Complaints | 0.13 (0.42) | 0.13 (0.41) | 0.10 (0.35) | 0.12 (0.44) | 0.14 (0.48) | 0.09 (0.44) | unable to calculate | unable to calculate | unable to calculate |
| Deficiencies | 0.00 (0.00) | 1.11 (6.32) | 1.59 (7.82) | 0.60 (3.45) | 0.66 (3.74) | 0.16 (0.88) | unable to calculate | unable to calculate | unable to calculate |

M=Missing

Fixed Regression Model year to year change

*Significant at 0.1 level

Wilcoxon Signed-Rank overall change between 2000 & 2005

**Significant at .05 level

***Significant at ≤.01 level

****Significant at ≤.001 level

Aim 2 The second aim of this study was to examine factors associated with hospice quality, utilization, and cost in California in 2005. The factors to be considered fall into three categories: organizational characteristics, patient characteristics, and market factors, in particular as they relate to hospice ownership, chain affiliation and size.

Profit status, Chain affiliation, Size Relationships with other Independent Variables

The 2005 data were examined in a univariate analysis to examine the differences in means between profit status, chain affiliation and size of the California hospices from the 2005 study sample. Comparisons with independent variables were made using univariate modeling. The means of the variables were compared using Mann-Whitney test of significance and Kruskal-Wallis tests. The results show significant differences in the means of several hospice organizational and patient characteristics between for-profit and nonprofit hospices.

Organizational characteristics and profit status

In comparing profit status and organizational characteristics, all three sites of care variables (home, nursing home, and RCFE) showed significantly different means when comparing the means of for-profit and nonprofit hospices (Table V-4). Nonprofit means were associated with lower means for percentage days of care in a nursing home, and RCFE, and a higher for percentage of days at home. Referral from long-term-care facility and referral by insurer had significantly higher means associated with for-profit hospices. MediCal as a payer source had significantly different means between for-profit and nonprofit hospices with the for-profit mean being higher.

Patient characteristics and profit status

Differences were also present in patient characteristics between for-profit and nonprofit hospices. There was a significant difference in the means of the percent of African-American patients cared for by for-profit hospices compared to the means of the nonprofit hospices as well as with the means of the per cent of patients identifying as Hispanic with for-profit means being higher for both. The means of the for-profit hospices were also significantly higher for the age of female patients and for patients with diagnoses of Alzheimer's/dementia as well as for heart related illnesses and other diagnoses. Nonprofit hospices had higher means for percentage of cancer patients.

Table V-4 Ownership status and Hospice Characteristics in California 2005
Mean, (Standard Deviation)

| <i>Organizational Characteristics</i> | Nonprofit | For-Profit | Mann-Whitney P-value |
|--|------------------------|------------------------|----------------------|
| Patients/Patient Days | | | |
| Avg Total Patient Days | 23804.02 (30121.59) | 29672.79 (32808.73) | 0.3133 |
| Avg pts per hospice/yr | 445.29 (507.18) | 615.03 (151.3) | 0.511 |
| Site of Care | | | |
| % days home | 74.4 (28.05) | 62.3 (25.23) | 0.001 |
| % days Nursing Home | 12.8 (17.4) | 23.6 (19.33) | <.0001 |
| % days Residential Care Facility for the Elderly | 7.57 (17.6) | 10.68 (16.17) | 0.011 |
| Referral Source | | | |
| % by Long-Term Care facility | 8.75 (13.86) | 16.89 (21.87) | 0.0002 |
| % by insurer HMO | 3.07 (10.55) | 4.75 (10.14) | <.0001 |
| % by hospital | 25.16 (17.4) | 27.12 (16.95) | 0.386 |
| Payer Source | | | |
| % days paid by Medicare | 84.81 (14.16) | 86.24 (9.71) | 0.64 |
| % days paid by MediCal | 6.96 (8.72) | 9.1 (7.56) | 0.002 |
| Patient Characteristics | | | |
| Age | | | |
| <70 | 23.08 (9.94) | 22.79 (11.83) | 0.141 |
| 71-80 | 24.69 (9.17) | 24.32 (8.68) | 0.225 |
| 81+ | 52.32 (13.05) | 52.91 (13.74) | 0.303 |

| | | | |
|------------------------------|----------------------|-----------------------|------------------|
| Race | | | |
| % Caucasian | 70.29 (28.11) | 71.03 (24.94) | 0.466 |
| % African-American | 3.32 (4.76) | 5.84 (12.06) | 0.042 |
| % Asian + other + Unknown | 26.39 (27.46) | 24.13 (22.57) | 0.882 |
| % Hispanic | 8.43 (11.64) | 12.21 (10.87) | 0.002 |
| Gender | | | |
| % Female | 56.53 (8.92) | 60.9 (7.02) | <.0001 |
| Diagnosis | | | |
| % Cancer | 44.87 (15.69) | 39.94 (17.11) | 0.0058 |
| % dementia/ Alzheimer's | 11.77 (10.91) | 15.98 (9.24) | 0.0001 |
| % Heart | 15.86 (8.43) | 19.89 (10.37) | 0.003 |
| % Digestive/ Urinary | 1.94 (2.46) | 2.26 (2.32) | 0.17 |
| % other Diagnoses | 25.6 (14.0) | 21.95 (13.48) | 0.0598 |
| Market | | | |
| Per Capita Income | 22556.01 (555.22) | 21248.75 (4112.72) | .542 |
| % African-American | 6.21 (4.14) | 6.97 (3.60) | 0.132 |
| % Asian + other | 35.18 (7.25) | 31.18 (10.80) | 0.029 |
| % Hispanic | 29.25 (13.44) | 36.54 (10.81) | 0.001 |
| % Female | 50.21 (1.04) | 50.42 (0.63) | 0.525 |
| # Beds/1000 population | 2.7 (.93) | 2.84 (0.7) | 0.079 |
| # SNF beds/1000 population | 4.58 (2.34) | 4.14 (0.99) | 0.129 |
| # RCFE beds/1000 population | 4.07 (1.15) | 3.97 (1.096) | 0.443 |

Chain affiliation and organizational characteristics

Chain hospices had higher means for the average number of total patient days, and the average number of patients per hospice when compared using Mann-Whitney analysis (Table V-5). Chain hospices had higher mean numbers of patients than nonchain hospices and also higher mean number of patient days than nonchain hospices.

Chain affiliation and patient characteristics

The mean for the percentage of patients between 71-80 years of age was slightly higher, yet significantly different, for chain hospices than nonchain hospices. Chain hospices had higher means for the percentage of African-American patients, the percentage of female patients and the percentage of patients with a diagnosis of Alzheimer's/dementia. Chain hospices had lower mean for percent of Caucasian patients (see Table V-5).

Market characteristics

The means for chain hospices were higher in counties with higher per capita incomes. Higher means for chain hospices were also found in counties with a higher percentage of Asian and other races (see Table V-5)

Table V-5 Chain Affiliation and Hospice Characteristics in California 2005 Mean, (Standard Deviation)

| <i>Organizational Characteristics</i> | Nonchain | Chain | Mann-Whitney P-Value |
|---|--------------------------|--------------------------|----------------------|
| Patients/Patient Days | | | |
| Avg Total Patient Days | 22,921.57 (31,628.73) | 29,751.53 (30,135.88) | 0.012 |
| Avg patients per hospice/yr | 406.65 (527.61) | 635.15 (13,63.26) | 0.0255 |
| Site of Care | | | |
| % days at home | 70.6 (27.38) | 69.85 (28.21) | 0.860 |
| % days in Nursing Home | 15.3 (17.59) | 18.24 (10.72) | 0.551 |
| % days in Residential Care Facility for the Elderly | 9.69 (18.94) | 7.31 (14.35) | 0.227 |
| Referral Source | | | |
| % by Long-Term Care Facility | 9.86 (14.64) | 13.62 (20.37) | 0.34118 |
| % by insurer HMO | 2.01 (6.56) | 5.64 (13.56) | 0.0001 |
| % by hospital | 25.26 (17.41) | 26.56 (17.69) | 0.513 |
| Payer Source | | | |
| % days paid by Medicare | 85.43 (14.38) | 85.09 (9.69) | 0.300 |
| % days paid by MediCal | 7.57 (8.34) | 7.83 (8.51) | 0.793 |
| Patient Characteristics | | | |
| Age | | | |
| <70 | 21.73 (10.33) | 24.67 (10.77) | 0.154 |

| | | | |
|-----------------------------|-----------------------|-----------------------|------------------|
| 71-80 | 25.47 (10.21) | 23.33 (6.85) | 0.0371 |
| 81+ | 52.86 (13.05) | 52.07 (13.61) | 0.919 |
| Race | | | |
| % Caucasian | 75.12 (25.97) | 63.52 (27.1) | 0.0001 |
| % African-American | 4.17 (9.48) | 4.2 (5.79) | 0.045 |
| % Asian + other+ Unknown | 20.71 (24.1) | 32.28 (26.79) | <.0001 |
| % Hispanic | 9.52 (12.29) | 10.01 (10.38) | 0.541 |
| Gender | | | |
| % Female | 57.21 (9.99) | 59.14 (5.97) | 0.0358 |
| Diagnosis | | | |
| % Cancer | 44.04 (16.67) | 42.01 (15.84) | 0.323 |
| % Dementia/ Alzheimer's | 12.38 (11.56) | 14.35 (8.91) | 0.0155 |
| % Heart | 17.47 (9.97) | 16.49 (8.4) | 0.902 |
| % Digestive/ Urinary | 1.98 (2.25) | 2.14 (2.62) | 0.495 |
| % other diagnoses | 24.17 (13.93) | 24.59 (13.92) | 0.764 |
| Market | | | |
| Per Capita Income | 21440.01 (4646.41) | 23420.20 (5506.05) | .007 |
| % African-American | 6.05 (3.85) | 7.04 (4.08) | 0.11 |
| % Asian + other | 31.39 (10.67) | 34.14 (8.55) | 0.069 |
| % Hispanic | 31.89 (13.22) | 31.56 (12.88) | 0.683 |
| % Female | 50.17 (1.06) | 50.28 (0.69) | 0.468 |
| # Beds/1000 population | 2.66 (0.86) | 2.87 (0.85) | 0.252 |
| # SNF beds/1000 population | 4.59 (2.47) | 4.22 (0.1) | 0.319 |
| # RCFE beds/1000 population | 3.99 (1.11) | 4.09 (1.16) | 0.401 |

Size and hospice characteristics

Kruskal-Wallis comparisons of means were used to determine differences in hospices of different sizes (Table V-6). Two variables had significant differences across ownership status (for-profit/nonprofit), chain relationship and size. The first was the organizational characteristic, referral from insurer or HMO, which had a significantly different and higher mean score when compared across the sizes of hospices. This was

also true in the profit and chain comparisons. The second was race, a patient characteristic. The means of the percentage of African-American patients was significantly different across hospice sizes as it was in the profit and chain comparisons.

Size, like chain, had a significantly higher rank mean for the mean of average total patient days and average total patients. Like the ownership comparison, hospice size showed significant differences across means for the percentage of days of care in nursing home with nursing home means largest for large hospices. Referral by a long-term care facility means were also higher and associated with large hospices. Other significant patient characteristic differences were found for Asian and other races and for Caucasian races and for the percentage of patients with heart-related illnesses. Lastly, market characteristics revealed significantly different means with medium sized hospices associated with the highest per capita income counties (see Table V-6).

Table V-6 Size and Hospice Characteristics in California 2005
Mean, (Standard Deviation)

| <i>Organizational Characteristics</i> | Large | Medium | Small | Kruskal-Wallis P-Value |
|--|------------------------|-----------------------|---------------------|---------------------------|
| Patients/Patient Days | | | | |
| Avg Total Patient Days | 65417.63 (43106.68) | 19509.82 (9235.15) | 4855.8 (3477.72) | <.0001 |
| Avg pts per hospice/yr | 1078.64 (706.62) | 469.96 (1219.30) | 100.87 (73.37) | <.0001 |
| Site of Care | | | | |
| % days at home | 65.67 (25.07) | 74.03 (25.70) | 67.57 (32.89) | 0.122 |
| % days Nursing Home | 22.65 (18.32) | 16.04 (17.64) | 12.44 (19.95) | <.0001 |
| % days Residential Care Facility for Elderly | 7.16 (10.19) | 5.38 (9.07) | 15.65 (27.54) | 0.196 |
| Referral Source | | | | |
| % by Long-Term Care Facility | 14.20 (17.48) | 12.66 (19.28) | 6.86 (12.16) | .0001 |
| % by insurer HMO | 5.75 (12.59) | 3.93 (11.1) | 1.07 (4.33) | .0025 |
| % by hospital | 31.13 (32.17) | 25.76 (16.05) | 21.28 (19.14) | 0.009 |
| Payer Source | | | | |
| % days paid by Medicare | 88.15 (8.59) | 86.02 (8.39) | 81.51 (19.98) | 0.2 |
| % days paid by MediCal | 6.89 (7.82) | 7.54 (7.93) | 8.59 (9.66) | 0.916 |

| Patient Characteristics | | | | |
|--------------------------------|-------------------------|-------------------------|-------------------------|---------------|
| Age | | | | |
| <70 | 23.12 (9.36) | 23.95 (10.41) | 21.23 (11.74) | 0.574 |
| 71-80 | 22.96 (3.93) | 23.98 (5.81) | 26.83 (14.42) | 0.304 |
| 81+ | 53.80 (11.03) | 52.21 (11.14) | 52.04 (17.67) | 0.590 |
| Race | | | | |
| % Caucasian | 73.42 (21.52) | 66.78 (26.70) | 73.44 (30.9) | 0.033 |
| % African-American | 4.39 (5.65) | 3.97 (4.89) | 4.31 (12.90) | 0.0019 |
| % Asian + other + unknown | 22.81 (21.40) | 29.25 (25.73) | 22.18 (28.72) | 0.012 |
| % Hispanic | 9.67 (6.66) | 8.9 (8.67) | 11.17 (17.35) | 0.173 |
| Gender | | | | |
| % Female | 58.03 (4.09) | 58.27 (5.52) | 57.58 (13.95) | 0.909 |
| Diagnosis | | | | |
| % Cancer | 43.06 (13.47) | 42.90 (15.41) | 43.75 (19.79) | 0.989 |
| % Dementia/ Alzheimer's | 13.04 (7.19) | 12.62 (9.71) | 14.37 (13.75) | 0.614 |
| % Heart | 19.22 (8.65) | 16.02 (8.55) | 17.75 (10.82) | 0.081 |
| % Digestive/ Urinary | 1.85 (1.9) | 2.09 (2.6) | 2.13 (2.81) | 0.484 |
| % other diagnoses | 22.85 (9.68) | 26.36 (13.09) | 22.13 (17.38) | 0.060 |
| Market | | | | |
| Per Capita Income | 227,121.08 (5110.57) | 229,924.53 (5361.31) | 20,683.00 (4,416.66) | .0437 |
| % African-American | 6.59 (3.64) | 6.33 (4.02) | 6.61 (4.18) | 0.830 |
| % Asian + other | 32.92 (7.61) | 32.81 (9.79) | 31.82 (11.66) | 0.870 |
| % Hispanic | 32.59 (10.0) | 31.44 (12.88) | 31.78 (15.44) | 0.96 |
| % Female | 50.19 (0.64) | 50.23 (0.98) | 50.22 (1.03) | 0.323 |
| # Beds/1000 population | 2.66 (0.54) | 2.81 (0.98) | 2.73 (0.86) | 0.776 |
| # SNF beds/1000 population | 4.36 (1.83) | 4.58 (2.44) | 4.23 (1.04) | 0.415 |
| # RCFE beds/1000 population | 4.19 (1.01) | 4.07 (1.13) | 3.84 (1.22) | 0.151 |

The Fisher's Exact Test was used to identify the relationships between ownership status (for-profit/nonprofit) and chain and nonchain hospices. A significant relationship was found between the whether hospices are part of a chain and their profit status (ownership) (Table V-7). The Kruskal-Wallis test (one way analysis of variance among the ranks) was used to examine ownership (profit status), size, and chains. The

relationship between size and profit was not significant; however, a significant relationship did exist between size and whether or not hospices were part of a chain. Nonprofit hospices were significantly less likely to be affiliated in a chain than for-profit hospices. And, small hospices were less likely to be affiliated in a chain when compared to medium and large hospices.

Table V- 7 Tests of significance between categorical variables in California Hospices 2005

| | | | | | | | | |
|-----------------------------|------------------|-------------------|-------|------------------|-------|--------------|-------------|--|
| Ownership: Chain | | For-Profit | | NonProfit | | Total | | Fisher's Exact P-Value <.0001 |
| | No Chain | 18 | 25.0% | 103 | 74.6% | 121 | 57.6% | |
| | Yes Chain | 54 | 75.0% | 35 | 25.4% | 89 | 42.4% | |
| | Total | 72 | 100% | 138 | 100% | 210 | 100% | |
| Ownership: Size | | For-Profit | | NonProfit | | Total | | Fisher's Exact P-Value 0.296 Kruskall- Walis $X^2=1.50$ P-Value0.225 |
| | Small | 19 | 26.4% | 41 | 29.7% | 60 | 28.6% | |
| | Med | 32 | 44.4% | 70 | 50.7% | 102 | 48.6% | |
| | Large | 21 | 29.2% | 27 | 19.6 | 48 | 22.9% | |
| | Total | 72 | 100% | 138 | 100% | 210 | 100% | |
| Chain: Size | | NonChain | | Chain | | Total | | Fisher's Exact P-Value 0.037 Kruskall-Wallis $X^2=6.65$ P-Value 0.0106 |
| | Small | 42 | 34.7% | 18 | 20% | 60 | 28.6% | |
| | Med | 57 | 47.1% | 45 | 50.6% | 102 | 48.6% | |
| | Large | 22 | 18.2% | 26 | 29.2% | 48 | 22.9% | |
| | Total | 121 | 100% | 89 | 100% | 210 | 100% | |

Regression Analyses of Quality, Utilization and Cost

The second aim of this study, was to examine factors associated with hospice quality, utilization and cost in California. The analyses used a linear regression (OLS) model for each of the outcome variables using hospice organizational, patient and market factors. Table V-8 shows the means, standard deviations and confidence intervals for the all variables used in the regression analyses.

Table V-8 All Variables for California Hospices 2005
Means, (Standard Deviations)

| | <i>Continuous Variables Mean (SD)</i> |
|--|---|
| | <i>Nominal Variables N (%)</i> |
| Organizational characteristics: | |
| Patients/Patient Days | |
| Total Patient Days/year/hospice | 25,861 (31,116.11) |
| Average Total Patients/Hospice | 505.3 (977.32) |
| Ownership | |
| For-Profit | 72 (34.3%) |
| NonProfit | 138 (65.9%) |
| NonChain | 121 (57.6%) |
| Chain | 48 (22.9%) |
| Size | |
| Large | 48 (22.9%) |
| Medium | 102 (48.6%) |
| Small | 60 (28.6%) |
| Site of Care | |
| % days Home | 70.29 (27.67) |
| % days in Nursing Home | 16.54 (18.75) |
| % days in Residential Care Facility for the Elderly | 8.69 (17.16) |
| Referral Source | |
| % by Long-Term Care Facility | 11.45 (17.35) |
| % by insurer | 3.58 |
| HMO | (10.25) |
| % by hospital | 25.81 (17.24) |

| | |
|---|-----------------------|
| Payer Source | |
| % Days: Medicare | 85.29 (12.83) |
| % Days: MediCal | 7.67 (8.39) |
| Patient Characteristics | |
| Age | |
| % <70 | 22.95 (10.60) |
| % 71-80 | 24.56 (8.98) |
| % 81+ | 52.52 (13.26) |
| Race | |
| % Caucasian | 70.2 (27.01) |
| % African-American | 4.18 (8.11) |
| % Asian + other + unknown | 25.61 (25.85) |
| % Hispanic | 9.73 (11.5) |
| Gender | |
| % Female | 58.03 (8.56) |
| Diagnosis | |
| % cancer | 43.18 (16.32) |
| % dementia/Alzheimer's | 13.21 (10.54) |
| % Heart related | 17.24 (9.32) |
| % Digestive/ Urinary system | 2.05 (2.41) |
| % Other diagnoses | 24.35 (13.89) |
| Market Characteristic (County)s | |
| Per Capita Income | 22221.48 (5139.62) |
| % Hispanic per 1000/population | 31.76 (13.07) |
| % African-American per 1000/population | 6.32 (3.96) |
| % Asian + unknown other per 1000/population | 32.48 (10.03) |
| % Female per 1000/population | 50.21 (0.92) |
| # hospital beds per 1000 population | 2.75 (0.86) |
| # SNF beds per 1000 population | 4.44 (2.00) |
| # RCFE beds per 1000 population | 4.04 (1.13) |
| Herfindahl Index | .06 (0.08) |

Regression Models

Table V-9 shows the results of OLS regression models for six outcome variables in 2005. Quality measures included: average visits by RNs, average visits by all staff (including RNs). The utilization measure was Average Length of Stay (ALOS). Cost measures included percent of total expenditures on nursing care, cost per patient and income per patient.

Table V-9 OLS Regressions Coefficients for: Average Visits by RN, Average Visits by All Staff, Average Length of Stay, Percent of Total Costs Spent on Nursing Care, Cost Per Patient, Income Per Patient in California Hospices 2005. (Standard Error) and (t Value)

| | <i>Average Visits by RNs</i> | <i>Average Visits by all staff</i> | <i>Average Length of Stay</i> | <i>Percent Total Costs Spent on Nursing Care</i> | <i>Cost Per Patient</i> | <i>Income per Patient</i> |
|--|----------------------------------|--|-----------------------------------|--|--------------------------------------|--------------------------------------|
| Organizational Characteristics | | | | | | |
| Ownership | | | | | | |
| For-Profit | -0.32 (1.54) (-0.21) | 3.51 (3.1) (1.12) | 11.81** (4.88) (2.42) | -7.56*** (2.74) (-2.75) | -727.66 (1146.89) (-0.64) | 764.77 (810.36) (0.94) |
| Chain | 1.69 (1.40) (1.21) | 1.35 (2.86) (0.47) | -2.32 (4.45) (-0.52) | 1.29 (2.5) (0.52) | 2017.42** (1039.36) (1.90) | -1263.65* (739.78) (-1.71) |
| Size | | | | | | |
| Large | -2.26 (1.60) (-1.41) | 0.41 (3.26) (0.13) | 12.35** (5.08) (2.43) | -0.80 (2.66) (-0.30) | 463.9 (1096.47) (0.42) | 1726.09** (845.51) (2.04) |
| Medium | -0.51 (1.30) (-0.39) | 3.30 (2.71) (1.22) | 7.64* (4.22) (1.81) | 1.0 (2.18) (0.46) | 707.47 (900.17) (0.79) | 1526.17** (702.13) (2.17) |
| Site of Care | | | | | | |
| Nursing Home | -0.0007 (0.04) (0.02) | 0.31**** (0.07) (4.47) | 0.02 (0.11) (0.22) | 0.04 (0.54) (0.8) | 37.61* (22.57) (1.67) | 10.12 (18.11) (0.56) |
| Residential Care Facility For the Elderly | 0.027 (0.036) (0.73) | 0.22*** (0.77) (2.87) | 0.134 (0.12) (1.14) | 0.13** (0.06) (2.05) | 37.36 (24.79) (1.51) | -32.50 (19.80) (-1.64) |
| Referral Source | | | | | | |
| Long-Term Care Facility | 0.05 (0.06) (0.83) | 0.007 (0.069) (0.1) | -0.022 (0.11) (-0.2) | 0.19**** (0.06) (3.22) | 2.89 (24.47) (0.12) | -3.40 (17.85) (-0.19) |
| Payer: Insurer or HMO | 0.07 (0.05) (1.43) | -0.024 (0.11) (-0.22) | -0.21 (0.17) (-1.29) | 0.095 (0.10) (0.98) | 11.26 (40.9) (0.28) | 40.51 (27.49) (1.47) |
| Hospital | -0.002 (0.035) (-0.07) | -0.067 (0.07) (-0.95) | -2.7** (0.11) (-2.44) | 0.15*** (0.06) (2.52) | -72.58*** (25.05) (-2.90) | 37.71** (18.35) (2.05) |
| Payer Source | | | | | | |
| % Days paid by Medicare | 0.0065 (0.047) (0.14) | 0.08 (0.10) (0.82) | 0.052 (0.15) (0.33) | 0.14* (0.08) (1.78) | -74.68** (33.0) (-2.26) | 163.50**** (25.61) (6.38) |
| % Days paid by MediCal | -0.07 (0.085) (-0.82) | 0.34* (0.17) (1.95) | 0.77*** (0.27) (2.89) | 0.12 (0.16) (0.76) | -44.17 (65.07) (-0.68) | 115.84*** (44.55) (2.60) |
| Hospice Patient Characteristics | | | | | | |
| Age | | | | | | |
| % 0-70 | 0.025 (0.08) (0.31) | 0.26 (0.17) (1.57) | 0.085 (0.26) (0.33) | -0.37 (0.14) (-0.26) | -34.93 (59.47) (-0.59) | 183.61**** (43.37) (4.23) |
| % 71-80 | -0.11 (0.09) (-1.26) | 0.04 (0.18) (0.24) | 0.088 (0.29) (0.31) | 0.02 (0.15) (0.16) | 52.05 (61.73) (0.84) | 21.37 (48.10) (0.44) |

Table V-9 continued

| | <i>Average Visits by RNs</i> | <i>Average Visits by all staff</i> | <i>Average Length of Stay</i> | <i>Percent Total Costs Spent on Nursing Care</i> | <i>Cost Per Patient</i> | <i>Income per Patient</i> |
|------------------------------------|-----------------------------------|--|-----------------------------------|--|-------------------------------------|-------------------------------------|
| Race | | | | | | |
| % African-American | -0.17** (0.07) (-2.40) | 0.01 (0.15) (0.07) | 0.51** (0.24) (2.14) | -0.21** (0.12) (-1.67) | 195.52**** (52.33) (3.74) | -94.44** (39.73) (-2.38) |
| % Asian & other race | -0.40* (0.023) (-1.72) | -0.006 (0.05) (-0.13) | 0.018 (0.75) (0.25) | -0.06 (0.04) (-1.63) | -4.11 (15.96) (-0.26) | 10.83 (12.61) (0.86) |
| % Hispanic | -0.146** (0.07) (-1.98) | -0.27** (0.16) (-1.75) | -0.51** (0.24) (-2.12) | -0.18 (0.12) (-1.51) | -59.26 (51.16) (-1.16) | -7.0 (40.11) (-0.17) |
| Gender | | | | | | |
| % Female | 0.11 (0.089) (1.26) | 0.48** (0.19) (2.61) | -0.4 (0.29) (-0.14) | 0.11 (0.15) (0.7) | -77.78 (61.52) (-1.22) | 162.60*** (47.91) (3.39) |
| Diagnosis | | | | | | |
| Cancer | 0.09* (0.05) (1.95) | 0.19* (0.10) (1.87) | -0.09 (0.15) (-0.59) | 0.26*** (0.91) (2.82) | 82.00** (34.29) (2.39) | -72.27*** (25.70) (-2.81) |
| Dementia or Alzheimer's | -0.01 (0.68) (-0.17) | 0.12 (0.13) (0.9) | 0.64*** (0.21) (3.10) | -0.09 (0.12) (-0.79) | 124.98*** (43.75) (2.86) | 16.18 (34.53) (0.47) |
| Dx: Heart related | 0.18*** (0.07) (2.70) | 0.61**** (0.14) (4.42) | 0.70*** (0.21) (3.30) | 0.26** (0.12) (2.29) | 67.59 (44.83) (1.51) | 25.75 (35.49) (0.73) |
| Digestive Urinary system | 0.27 (0.23) (1.19) | 1.03** (0.48) (2.16) | -0.14 (0.74) (-0.18) | -0.18 (0.38) (-0.48) | -260.48* (15.53) (-1.71) | -30.22 (123.75) (-0.24) |
| Market Characteristics | | | | | | |
| Per Capita Income | 0.0001 (0.0001) (0.77) | -0.000009 (0.0003) (-0.03) | 0.0004 (0.0004) (0.81) | -0.0003 (0.0002) (-1.59) | 0.069 (0.096) (0.72) | 0.019 (0.07) (0.26) |
| % African-American | 0.14 (0.17) (0.93) | -0.2 (0.35) (-0.57) | 0.35 (0.55) (0.64) | 0.46 (0.32) (1.44) | -42.03 (128.88) (-0.33) | 123.33 (90.97) (1.36) |
| % Hispanic | 0.055 (0.066) (0.83) | 0.13 (0.13) (0.97) | 0.13 (0.21) (0.6) | -0.08 (0.11) (-0.76) | (46.60) (45.17) (1.03) | -69.47** (34.85) (-1.99) |
| % Female | -0.49 (0.59) (-0.84) | -0.45 (1.22) (-0.38) | -0.81 (1.90) (-0.43) | -1.36 (0.96) (-1.42) | -24.79 (399.12) (-0.06) | 128.49 (315.43) (0.41) |
| # hospital beds/1000 population | 0.12 (0.68) (0.18) | -0.28 (1.39) (-0.20) | -1.59 (2.15) (-0.74) | 0.04** (1.10) (0.14) | -378.07 (458.80) (-0.82) | -205.55 (356.67) (-0.58) |
| # SNF beds/1000 population | 0.07 (0.26) (0.28) | 0.059 (0.54) (0.11) | -0.11 (0.84) (-0.14) | -0.24 (0.42) (-0.57) | -17.40 (173.69) (-0.10) | 170.12 (138.89) (1.22) |
| # RCFE beds/1000 population | -0.15 (0.61) (-0.24) | 0.36 (1.24) (0.29) | -1.18 (1.93) (-0.61) | -0.27 (1.05) (-0.26) | -158.36 (437.27) (-0.36) | -411.02 (321.27) (-1.28) |
| Herfindahl Index | 4.57 (14.85) (0.31) | -30.3 (29.65) (-1.02) | 9.78 (46.14) (0.21) | 26.74 (27.03) (0.99) | -5039.71 (10012) (-0.50) | 5203.68 (7675.87) (0.68) |

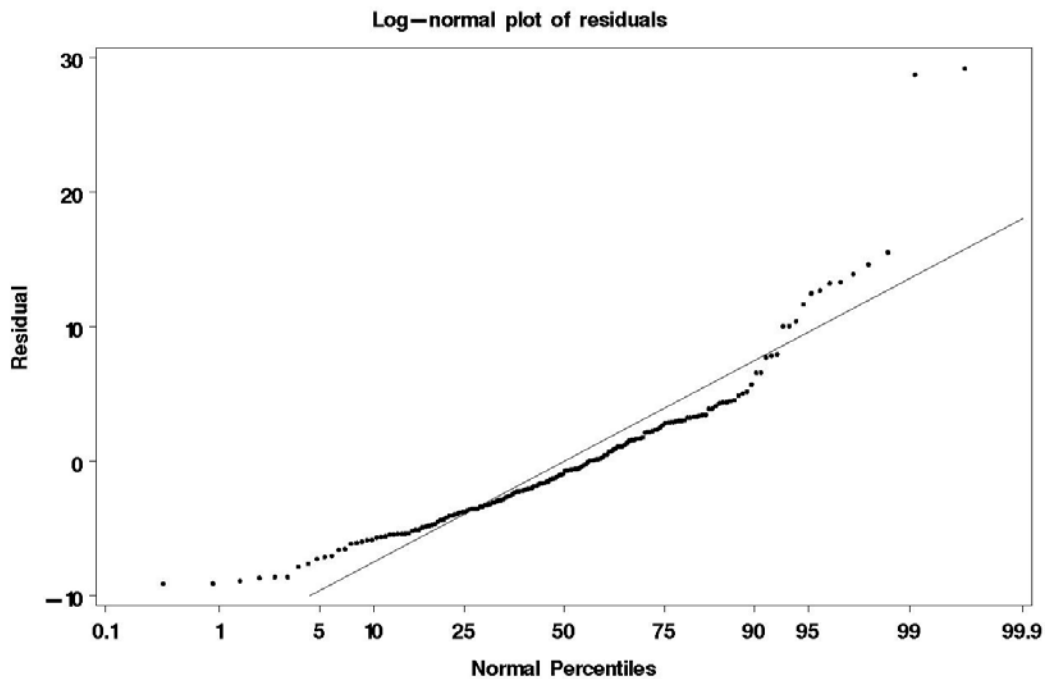
| | | | | | | |
|-------------------------|-------------------------|---------------------------|-------------------------|------------------------|------------------------|---------------------------|
| Intercept | 23.54 (31.14) (0.76) | -14.63 (63.91) (-0.23) | 66.85 (99.46) (0.67) | 50.89 (51.30) (1.4) | 1457 (20838) (0.70) | -32502 (16357) (-1.97) |
| Adjusted R ² | 4.04 | 35.06 | 37.03 | 24.27 | 25.86 | 35.33 |
| Mean | 13.54 | 37.548 | 60.02 | 25.6 | 9293.07 | 16.04 |
| N df | N=180 df=29 | N=193 df=29 | N=193 df=29 | N=167 df=29 | N=173 df=29 | N=193 df=29 |

Notes: Comparisons: Nonprofit, not chain, small, home+other, referral-other, small, other payer, 81+years, Caucasian, male, other diagnoses, Caucasian, Male.

*Significant at 0.1 level **Significant at .05 level ***Significant at ≤ 0.01 level ****Significant at ≤ 0.001 level

Predictors of the Average Visits by RNs were modeled in an OLS regression. The Adjusted R^2 value for this regression was .0411, so only 4% of the variance in the outcome was explained by the variables included in the model (see Table V-9). In addition, the log-normal plot of residuals showed some extreme observations (some patients with very large numbers of visits and some with very low) as seen Figure V- 5. Analysis did not show a normal distribution of standard errors; however, given the sample size, this deviation from normality does not pose a problem. Lumley, Diehr, Emerson and Chen assert that for sample sizes as small as 65, normal distributions are not essential for analyzing differences and trends. They suggest that “while large-sample properties of linear regression are well understood, there has been little research into the sample sizes needed for the Normality assumption to be unimportant” (2002). Further they posit that “it is not clear how the necessary sample size depends on the number of predictors in the model” (p. 167).

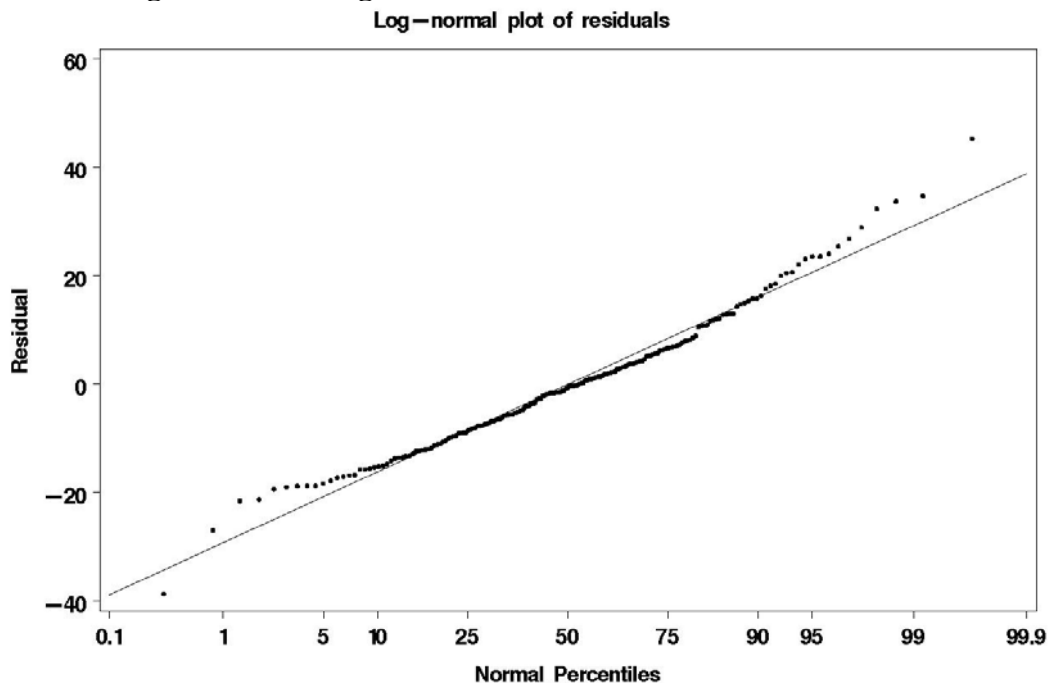
Figure V-5 Average RN Visits



None of the organizational variables significantly predicted the number of RN visits. However, patient characteristics included significant findings in two categories: race and diagnosis. Increased percentage of all the racial categories when compared to Caucasian significantly predicted small decreases in the average number of visits by RNs. Patients with a diagnosis of cancer and heart related illness, when compared to other diagnoses, were significantly associated with a 0.09 and 0.18 increase in RN visits (respectively).

The number of Visits by All Staff was predicted using an OLS regression. In this model, the adjusted R^2 value showed that 35% of the variance in the outcome was explained by the variables included in the model. The log-normal plot of residuals confirmed a normal distribution of errors as illustrated in Figure V-6.

Figure V-6 Average Visits All Staff



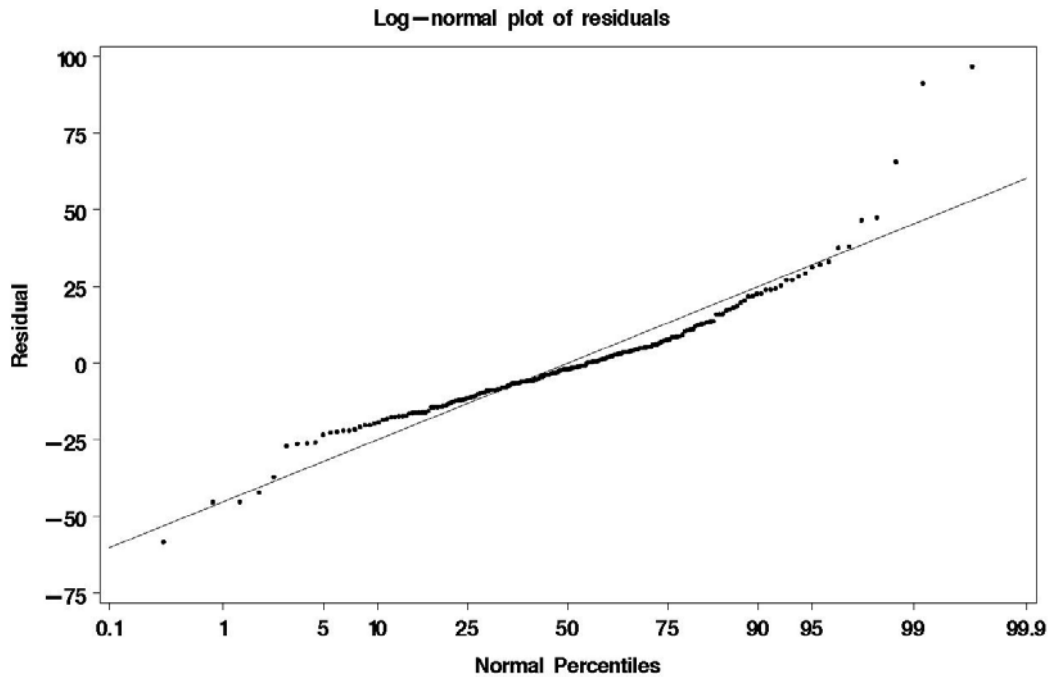
Eight hospice characteristics were significant when controlling for all other variables. A higher percentage of days paid by Medi-Cal when compared to other payers

was marginally associated with an additional 0.34 visits per patient. Site of care in a nursing home was associated with 0.32 additional staff visits when compared to the percentage of days at home and an increase in visits of 0.22 days per patient in a RCFE compared to the percentage of days at home and other locations (see Table V-9).

Patient characteristics were also significantly associated with increased numbers of visits by all staff. A higher percentage of female patients (compared to male patients) predicted 0.48 more visits by all staff. All diagnoses except Alzheimer's/Dementia were associated with increased visits by all staff. A higher percentage of patients with a diagnosis of cancer (compared to patients with other diagnoses) marginally predicted an increase of 0.19 visits per patient while a higher percentage of patients with heart related illnesses (compared to patients with other diagnoses) predicted an increase of 0.6 visits per patient (see Table V-9).

The outcome of average length of stay had a strong effect size as shown by adjusted R^2 value that accounted for 37% of the variance in the outcome explained by the variables in the model. The log-normal plot of residuals, with some outliers, confirmed a normal distribution of errors as illustrated on Figure 7.

Figure V-7 Average Length of Stay

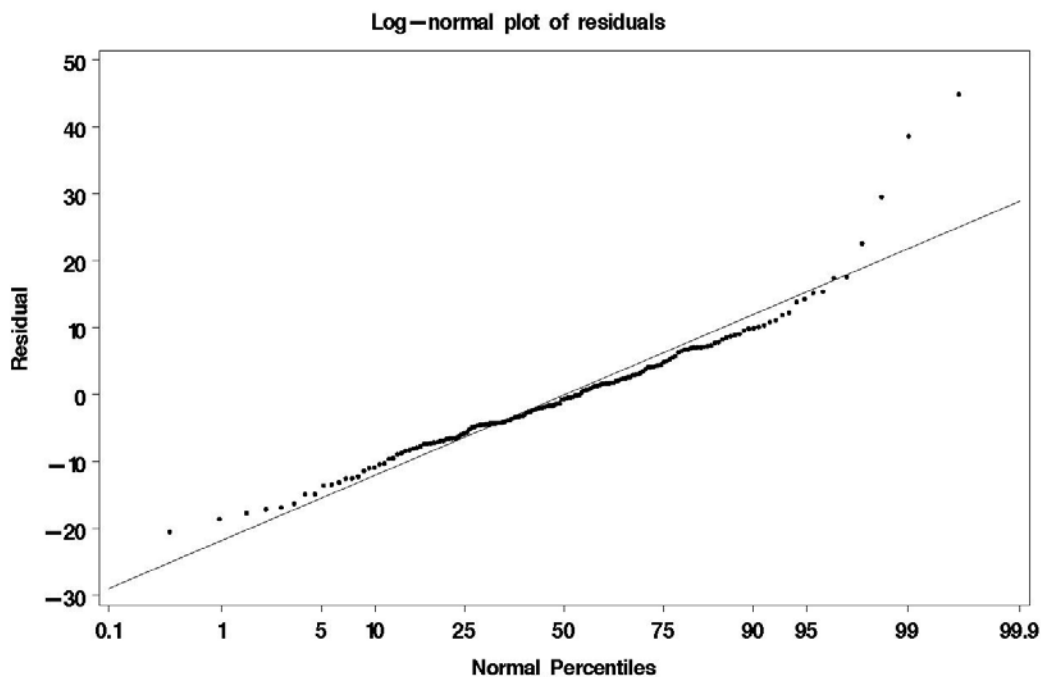


After controlling for all other variables in the model, for-profit hospices compared to non-profit hospices were associated with an increased length of stay of 11.81 days. In addition, when controlling for all other variables, the percent of days paid by MediCal was associated with an increase of 0.77 days in length of stay compared to other payers, and large or medium sized hospices compared to small hospices were associated with an increased stay of 12.35 days and 7.6 days, respectively (see Table V-9).

Four patient characteristics were associated with increases and decreases in length of stay. The percentage of African-Americans, compared to Caucasian patients, predicted an increase of half a day longer stay, while a higher percentage of Hispanic patients compared to Caucasian patients predicted a half day shorter average length of stay. Longer lengths of stay were predicted by a higher percentage of patients with Alzheimer's/dementia diagnoses (0.64 days) when compared to other diagnoses, and by a higher percentage of patients with heart related illnesses compared to other diagnoses (0.7 days) compared to other diagnoses (see Table V-9).

The percent of total hospice expenditures on RN care had seven hospice characteristics identified in the regression model. A strong effect size characterized by an adjusted R² value showed that 24.5% of the variance in the percent of total expenditures on RN care can be attributed to variables in the model. The log-plot of residuals confirmed a normal distribution of errors as illustrated on Figure 8.

FigureV-8 Percent of Total Hospice Expenditures Spent on Nursing Care



After controlling for all other variables, the only organizational characteristic with a significant negative partial regression coefficient was profit, meaning that the percent of total hospice costs spent on nursing care were predicted to be 7.56% less in for-profit hospices compared to nonprofit hospices. Organizational characteristics significantly associated with an increased percent of costs spent on nursing care included: the percentage of days paid for by Medicare (0.14) compared to other payers, and the percentage of days of care in a residential care for the elderly facility compared to other sites of care predicted an increased percent of costs spent on nursing care (0.13).

Referrals from long-term care facility and referrals from hospitals when compared to other referral sources were associated with percent increases of 0.19 and 0.15 respectively (see Table V-9).

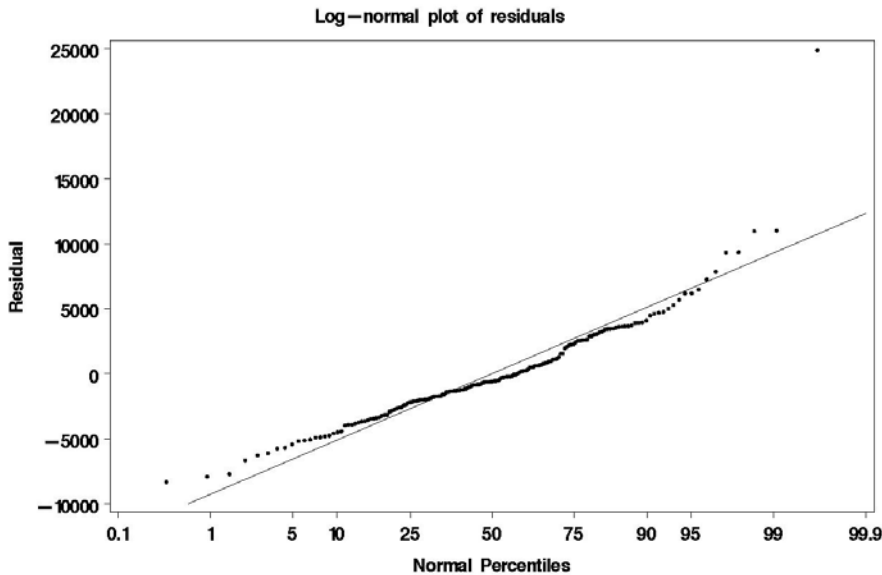
Three patient characteristics were significantly associated with the percent of total expenditures on nursing care. The percent of African-American patients was associated with a 0.21% decrease in the percent of costs spent on nursing care. Two diagnoses were associated with increased percentages of costs spent on nursing care. Cancer was significantly associated with a 0.26% increase in the percent of expenditure on nursing care compared to other diagnoses, and heart related illness was associated with an increase of 0.26% in the percent of total expenditure spent on RN care when compared to other diagnoses. The last characteristic of significance was a market characteristic. The number of hospital beds per 1000 population was associated with and 0.04% increase in the percent of the total hospice expenditures spent on nursing care (see Table IV-9).

Cost per patient is an outcome of concern to purchasers of hospice care.

Ordinary Least Squares regression was conducted on hospice characteristic predictors of cost per patient. The log-normal plot of residuals showed some extreme variants (some very expensive patients and some very inexpensive patients) as seen in Figure 9.

Adjusted R^2 indicated that nearly 26% of the variants of the cost per patient were accounted for by the variables in the model.

Figure V-9 Cost Per Patient



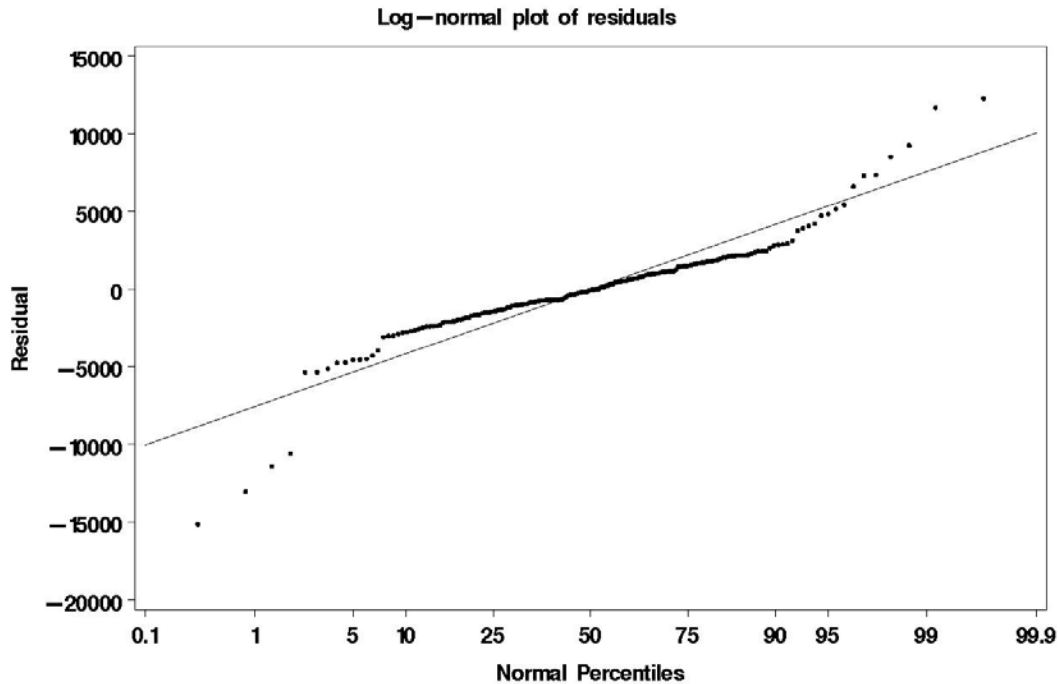
Three variables were significant predictors of decreases in the cost per patient. The percentage of days paid by Medicare was associated with a \$74.68 decrease in cost compared to all other payers. The percentage of hospice patients referred from a hospital predicted a decrease of \$72.58 per patient compared to other referral sources. And the percentage of patients with a diagnosis related to the digestive or urinary system was associated with a \$260.48 decrease in cost per patient. Several other organizational characteristics significantly predicted increased costs per hospice patient. The largest of these was chain affiliation which predicted an increased cost of \$2017.42 when compared to nonchain hospices. The percentage of patients receiving care in a nursing home was a marginal predictor of increased cost per patient (\$37.61 per patient) when compared to patients receiving care at home (see Table V-9).

Patient characteristics associated with increased cost per patient included the percentage of African-American patients when compared to all other races (\$195.52). The percent of patients with Alzheimer's/Dementia, when compared to all other

diagnoses, was associated with an increased cost of \$124.98 per patient and the percentage of patients diagnosed with cancer was associated with an increased cost of \$82 per patient compared to other diagnoses (see Table V-9).

The net income to the hospice per patient was the last outcome measure analyzed using an OLS regression. The adjusted R^2 for this model indicated that 35% of the variance in the outcome was accounted for by the variables in model. The log-normal plot of residuals showed some extreme variants, likely due to extremes in high incomes per patient and low incomes per patient, as seen in Figure 10.

Figure V-10 Hospice Net Income Per Patient



There were four significant predictors of decreases in income per hospice patient. Hospices affiliated with a chain were associated with a \$1263.65 decrease in income per patient. In addition, the percentage of African-American patients was associated with a decrease of \$94.44, when compared to Caucasians, and the percentage of patients with a cancer diagnosis was associated with a decrease in income per patient of \$73 compared to

other diagnoses. The last significant predictor of a decrease in income per hospice patient was the market characteristic of the percent of Hispanics in a county. This market characteristic was associated with a decrease in income per hospice patient of \$69.47 when compared to the percent of Caucasians in the county.

Several variables were associated with increased hospice income per patient. This was the only outcome in which age was a significant predictor variable. The percentage of patients between 0 and 70 years of age, when compared to the percentage of patients over 81 years of age, was a predictor of increased hospice income per patient or \$183.61. Compared to other payers, the percentage of days paid by Medicare and MediCal predicted increased incomes per hospice patient of \$163.50 and \$115.84 respectively. The only referral source that was a significant predictor of income per hospice patient was the percentage of patients referred from hospitals \$37.71. Large and medium hospices were both predictors of increased income per patient (\$1726.09, and \$1526.17, respectively). The final significant predictor of increased income per hospice patient is gender. The percentage of female patients is associated with increased income per patient of \$162.60.

Complaints and Deficiencies

Two quality measures (complaints and deficiencies) were analyzed using separate logistic and binomial regression models and are described. Results of these analyses can be found on Tables V-10, 11, 12 and 13 respectively.

Complaints. The number of complaints, for the purpose of this study, is considered a measure of quality. The number of complaints per year was very small, so a cumulative number over the six year study period (2000-2005) was analyzed. Both

logistic regression and negative binomial regression analyses were used to identify characteristics associated with complaints and deficiencies. Negative binomial regression is useful for tests where the distribution of the outcome is skewed (as this was to the right) and where there are many 0 values. Tables V-10, and IV-11 display results from the logistic regression and negative binomial regression approaches including regression odds ratios, rate ratios with confidence intervals and p-values.

A logistic regression was conducted on 55 hospices with more than one complaint and 146 hospices with no complaints, using 30 independent variables (Table V-10). Five characteristics were significantly associated with complaints in the logistic regression. Large and medium hospices had significant odds ratios for complaints which can be explained by their size (37.12 and 11.45 respectively) compared to small hospices; the larger the facility, the greater the number of patients and the odds of patients having complaints. When holding the values of other variables constant, the percentage of patients receiving hospice care in nursing homes showed an increase in the odds ratio for complaints of 1.04 compared to the percent of care at home. The percentage of patient days paid by Medicare as a payer source had an odds ratio of 0.97 and was associated with decreased complaints. The percentage of female patients was associated with a significant negative odds ratio (0.83) compared to males. As the percentage of women patients increase, the number of complaints decreases.

Table V-10
Logistic Regression Model for Complaints for California Hospices 2000-2005

| N = 55 hospices with 1 or more complaints and 146 hospices with 0 for the period 2000-2005 combined | Logistic Regression Odds Ratio Estimate | Lower 95% Confidence Limit for Odds Ratio | Upper 95% Confidence Limit for Odds Ratio Estimate | P-Value |
|---|---|---|--|---------|
| Organizational Characteristics | | | | |
| Ownership | | | | |
| For-Profit | 1.74 | 0.52 | 5.86 | 0.37 |
| Chain | 1.22 | 0.39 | 3.83 | 0.73 |

| | | | | |
|--|--------------|-------|---------|---------------|
| Size | | | | |
| Large | 37.12 | 6.1 | 225.48 | 0.0001 |
| Medium | 11.45 | 2.04 | 64.148 | 0.0056 |
| Site of Care | | | | |
| Nursing Home | 1.04 | 1.0 | 1.1 | 0.054 |
| Residential Care Facility For the Elderly Patient's Home | 1.00 | 0.95 | 1.06 | 0.89 |
| Referral Source | | | | |
| Long-Term Care Facility | 1.019 | 0.99 | 1.048 | 0.19 |
| Payer: Insurer or HMO | 0.98 | 0.945 | 1.02 | 0.42 |
| Hospital | 0.99 | 0.96 | 1.025 | 0.57 |
| Payer Source | | | | |
| % Days paid by Medicare | 0.965 | 0.93 | 1.01 | 0.09 |
| % Days paid by MediCal | 0.985 | 0.92 | 1.10 | 0.66 |
| Patient Characteristics | | | | |
| Age | | | | |
| % 0-70 | 1.01 | 0.94 | 1.085 | 0.75 |
| % 71-80 | 0.944 | 0.86 | 1.03 | 0.205 |
| Race | | | | |
| % African-American | 0.92 | 0.81 | 1.03 | 0.16 |
| % Asian & other race | 0.99 | 0.97 | 1.01 | 0.42 |
| % Hispanic | 1.05 | 0.98 | 1.12 | 0.17 |
| Gender | | | | |
| Female | 0.883 | 0.8 | 0.98 | 0.017 |
| Diagnosis | | | | |
| Cancer | 0.99 | 0.95 | 1.04 | 0.74 |
| Dementia or Alzheimer's | 0.96 | 0.9 | 1.03 | 0.27 |
| Heart related | 1.03 | 0.97 | 1.09 | 0.38 |
| Digestive | 0.94 | 0.73 | 1.19 | 0.58 |
| Urinary system | | | | |
| Market Characteristics | | | | |
| Per Capita Income | 1.000 | 1.000 | 1.000 | 0.49 |
| % African-American | 1.07 | 0.92 | 1.25 | 0.38 |
| % Hispanic | 1.04 | 0.98 | 1.11 | 0.19 |
| % Female | 1.32 | 0.74 | 2.35 | 0.35 |
| # hospital beds/1000 population | 0.69 | 0.34 | 1.41 | 0.31 |
| # SNF beds/1000 population | 0.87 | 0.62 | 1.22 | 0.41 |
| # RCFE beds/1000 population | 1.19 | 0.68 | 2.08 | 0.54 |
| Herfindahl Index | 171.32 | 0.002 | >999.99 | 0.39 |

Notes: Comparisons: Nonprofit, not chain, small, home+other, referral-other, small, other payer, 81+years, Caucasian, male, other diagnoses, Caucasian, Male. *Significant at 0.1 level **Significant at .05 level ***Significant at \leq .01 level ****Significant at \leq .001 level

A negative binomial regression was also conducted for complaints based on 55 hospices with one or more complaints and 151 hospices with no reported complaints. Like the logistic regression model results, large and medium sized hospices (as compared to small) had a greater likelihood of having complaints (relative rate ratios of: 22.9 and

9.5 respectively). Hospices that are part of a chain were predictors of a relative rate ratio greater than 2 for increased complaints when compared to nonchains. A greater percentage of days of care in nursing homes was a predictor of a greater likelihood of complaints being filed (relative rate ratio 1.03). The percentage of Hispanic patients was also associated with increased complaints (relative rate ratio: 1.05). Decreased numbers of complaints (relative rate ratio 0.99) were marginally associated with the percentage of patients in the Asian, other and unknown race category. The percentage of days paid by Medicare was also associated with decreased complaints (relative rate ratio: 0.97). No additional variables were associated with increases or decreases in complaints.

**Table V-11
Negative Binomial Regression for Complaints for California Hospices 2000-2005**

| N = 55 hospices with 1 or more deficiencies and 146 hospices with 0 deficiencies for the period 2000-2005 combined | Negative Binomial Relative Risk Rate Ratio | Lower 95% Confidence Limit for Risk Rate Ratio | Upper 95% Confidence Limit for Risk Rate Ratio | Probability ChiSquare Ratio |
|--|--|--|--|-----------------------------|
| Organizational Characteristics | | | | |
| Ownership | | | | |
| For-Profit | 1.46 | 0.66 | 3.23 | 0.351 |
| Chain | 2.08 | 1.05 | 4.13 | 0.036 |
| Size | | | | |
| Large | 22.89 | 6.10 | 85.86 | <.0001 |
| Medium | 9.46 | 2.55 | 35.06 | 0.001 |
| Site of Care | | | | |
| Nursing Home | 1.03 | 1.002 | 1.06 | 0.03 |
| Residential Care Facility For the Elderly Patient's Home | 1.02 | 0.98 | 1.05 | 0.3 |
| | 1.02 | 0.992 | 1.04 | 0.19 |
| Referral Source | | | | |
| Long-Term Care Facility | 1.01 | 0.99 | 1.03 | 0.173 |
| Payer: Insurer or HMO | 0.99 | 0.96 | 1.02 | 0.44 |
| Hospital | 1.003 | 0.98 | 1.02 | 0.734 |
| Payer Source | | | | |
| % Days paid by Medicare | 0.97 | 0.94 | 1.0 | 0.095 |
| % Days paid by MediCal | 0.99 | 0.95 | 1.04 | 0.688 |
| Patient Characteristics | | | | |
| Age | | | | |
| % 0-70 | 0.9954 | 0.95 | 1.04 | 0.844 |
| % 71-80 | 0.9755 | 0.92 | 1.04 | 0.429 |
| Race | | | | |
| % African-American | 0.967 | 0.899 | 1.04 | 0.374 |
| % Asian & other race | 0.986 | 0.97 | 1.00 | 0.074 |
| % Hispanic | 1.046 | 1.003 | 1.09 | 0.035 |

| | | | | |
|---------------------------------|-------|--------|----------|-------|
| Gender | | | | |
| Female | 0.95 | 0.887 | 1.02 | 0.138 |
| Diagnosis | | | | |
| Cancer | 0.996 | 0.965 | 1.03 | 0.776 |
| Dementia or Alzheimer's | 0.989 | 0.942 | 1.04 | 0.667 |
| Heart related | 1.03 | 0.984 | 1.07 | 0.227 |
| Digestive | 1.02 | 0.873 | 1.18 | 0.837 |
| Urinary system | | | | |
| Market Characteristics | | | | |
| Per Capita Income | 1.000 | 0.9999 | 1.00 | 0.464 |
| % African-American | 1.047 | 0.943 | 1.16 | 0.389 |
| % Hispanic | 0.987 | 0.947 | 1.03 | 0.543 |
| % Female | 1.09 | 0.704 | 1.66 | 0.723 |
| # hospital beds/1000 population | 0.97 | 0.603 | 1.56 | 0.902 |
| # SNF beds/1000 population | 0.898 | 0.672 | 1.17 | 0.406 |
| # RCFE beds/1000 population | 1.07 | 0.71 | 1.61 | 0.75 |
| Herfindahl Index | 4.04 | 0.0004 | 40759.03 | 0.767 |

Notes: Comparisons: Nonprofit, not chain, small, home+other, referral-other, small, other payer, 81+years, Caucasian, male, other diagnoses, Caucasian, Male. *Significant at 0.1 level **Significant at .05 level ***Significant at ≤ 0.01 level ****Significant at ≤ 0.001 level

Deficiencies. The number of deficiencies cited by licensing agencies per year was very small, because of the infrequency of inspections, so the cumulative number of deficiencies counted over the six year study period (2000-2005) was analyzed using both logistic regression and negative binomial regression models. As with complaints, negative binomial regression approach was used because it was a better fit for the data which had many 0 values and was skewed to the right.

A logistic regression of 50 hospices with one deficiency and 151 hospices with no deficiencies predicted an increase odds ratio of deficiencies associated with the market variable of increased percentage of Hispanics in the county of 1.08, compared to non-Hispanics when controlling for all other variables. A second market variable also predicted increased odds ratio of deficiencies. The average county "per capita income" calculated at a one dollar change was multiplied by 1000. For every one thousand dollar increase in average per capita income, the adjusted odds of deficiencies being cited increases by a 1.27. Size was a significant predictor in increased deficiencies and the

percentage of patients receiving care at home, compared to other locations was a marginal predictor of deficiencies being filed.

Table V-12
Logistic Regression Model for Deficiencies for California Hospices 2000-2005

| N=50 hospices with 1 or more deficiencies and 151 hospices with 0 deficiencies for the period 2000-2005 combined | Logistic Regression Odds Ratio Estimate | Lower 95% Confidence Limit for Odds Ratio | Upper 95% Confidence Limit for Odds Ratio Estimate | Pr>chisquare |
|--|---|---|--|-----------------|
| Organizational Characteristics | | | | |
| Ownership | | | | |
| For-Profit | 1.76 | 0.56 | 5.58 | 0.334 |
| Chain | 0.822 | 0.28 | 2.38 | 0.718 |
| Size | | | | |
| Large | 11.68 | 2.58 | 52.79 | <.001 |
| Medium | 3.62 | 0.89 | 14.76 | 0.073 |
| Site of Care | | | | |
| Nursing Home | | 0.99 | 1.08 | 0.177 |
| | 1.03 | | | |
| Residential Care Facility For the Elderly | 1.013 | 0.96 | 1.07 | 0.623 |
| Patient's Home | 1.03 | 0.99 | 1.073 | 0.099 |
| Referral Source | | | | |
| Long-Term Care Facility | 1.02 | 0.99 | 1.05 | 0.258 |
| Payer: Insurer or HMO | 1.01 | 0.98 | 1.05 | 0.514 |
| Hospital | 0.99 | 0.97 | 1.03 | 0.935 |
| Payer Source | | | | |
| % Days paid by Medicare | 0.98 | 0.94 | 1.02 | 0.242 |
| % Days paid by MediCal | 1.003 | 0.94 | 1.07 | 0.931 |
| Patient Characteristics | | | | |
| Age | | | | |
| % 0-70 | 1.01 | 0.95 | 1.08 | 0.684 |
| % 71-80 | 0.97 | 0.89 | 1.05 | 0.507 |
| Race | | | | |
| % African-American | 1.03 | 0.97 | 1.08 | 0.354 |
| % Asian & other race | 0.98 | 0.96 | 1.005 | 0.14 |
| % Hispanic | 0.992 | 0.94 | 1.05 | 0.789 |
| Gender | | | | |
| Female | 0.98 | 0.889 | 1.07 | 0.653 |
| Diagnosis | | | | |
| Cancer | 0.98 | 0.94 | 1.02 | 0.394 |
| Dementia or Alzheimer's | 0.99 | 0.92 | 1.06 | 0.66 |
| Heart related | 1.02 | 0.96 | 1.08 | 0.567 |
| Digestive Urinary system | 1.004 | 0.8 | 1.26 | 0.974 |
| Market Characteristics | | | | |
| Per Capita Income | 1.00027 | 1.000 | 1.000 | 0.018 |
| % African-American | 1.04 | 0.89 | 1.21 | 0.652 |
| % Hispanic | 1.076 | 1.01 | 1.15 | 0.025 |
| % Female | 0.93 | 0.55 | 1.59 | 0.796 |
| # hospital beds/1000 population | 0.94 | 0.49 | 1.82 | 0.85 |
| # SNF beds/1000 population | 1.21 | 0.91 | 1.61 | 0.182 |
| # RCFE beds/1000 population | 0.95 | 0.53 | 1.69 | 0.856 |
| Herfindahl Index | 414.78 | <0.001 | >999.999 | 0.408 |

Notes: Comparisons: Nonprofit, not chain, small, home+other, referral-other, small, other payer, 81+years, Caucasian, male, other diagnoses, Caucasian, Male.

*Significant at 0.1 level **Significant at .05 level ***Significant at ≤.01 level ****Significant at ≤.001 level

The negative binomial regression run on 50 hospices with one or more deficiencies cited by the state during the six year study period and the 151 hospices with no deficiencies shared the market variable of the percentage of Hispanics in the county with the logistic regression model (Relative Risk Rate Ratio 1.1). Size was also a significant predictor of increased deficiencies. Increased numbers of deficiencies were marginally associated with the percentage of hospice patients with a referral source as insurer/HMO in the negative binomial regression when compared to other referral sources. Decreased numbers of deficiencies were associated with the percentage of patients of Asian, other and unknown race when compared to Caucasian.

**Table V-13
Negative Binomial Regression for Deficiencies for California Hospices 2000-2005**

| N=50 hospices with 1+ deficiency and 151 hospices with 0 deficiencies for 2000-2005 combined | Negative Binomial Relative Risk Rate Ratio | Lower 95% Confidence Limit for Risk Rate Ratio | Upper 95% Confidence Limit for Risk Rate Ratio | Probability Chi Square |
|--|--|--|--|------------------------|
| Organizational Characteristics | | | | |
| Ownership | | | | |
| For-Profit | 6.26 | 0.65 | 59.89 | 0.112 |
| Nonprofit | 0.65 | 0.09 | 4.66 | 0.667 |
| Size | | | | |
| Large | 105.52 | 9.4 | 1185.03 | 0.0002 |
| Medium | 15.35 | 1.95 | 121.01 | 0.0095 |
| Site of Care | | | | |
| Nursing Home | 1.00 | 0.95 | 1.06 | 0.892 |
| Residential Care Facility For the Elderly | 0.95 | 0.88 | 1.03 | 0.231 |
| Patient's home | 1.03 | 0.98 | 1.08 | 0.299 |
| Referral Source | | | | |
| Long-Term Care Facility | 1.02 | 0.964 | 1.07 | 0.543 |
| Payer: Insurer or HMO | 1.05 | 0.99 | 1.10 | 0.082 |
| Hospital | 1.01 | 0.97 | 1.05 | 0.567 |
| Payer Source | | | | |
| % Days paid by Medicare | 0.97 | 0.89 | 1.06 | 0.487 |
| % Days paid by MediCal | 1.00 | 0.89 | 1.12 | 0.971 |
| Patient Characteristics | | | | |
| Age | | | | |
| % 0-70 | 0.99 | 0.90 | 1.09 | 0.858 |
| % 71-80 | 0.93 | 0.80 | 1.08 | 0.351 |
| Race | | | | |
| % African-American | 1.03 | 0.95 | 1.13 | 0.461 |
| % Asian & other race | 0.95 | 0.92 | 0.99 | 0.017 |
| % Hispanic | 1.05 | 0.96 | 1.14 | 0.301 |
| Gender | | | | |
| Female | 1.03 | 0.89 | 1.2 | 0.671 |

| | | | | |
|---------------------------------|-------------|--------|---------|-------------|
| Diagnosis | | | | |
| Cancer | 0.98 | 0.92 | 1.04 | 0.511 |
| Dementia or Alzheimer's | 0.97 | 0.87 | 1.09 | 0.64 |
| Dx: Heart related | 1.02 | 0.91 | 1.16 | 0.704 |
| Digestive Urinary system | 1.16 | 0.78 | 1.73 | 0.466 |
| Market Characteristics | | | | |
| Per Capita Income | 1.00 | 0.999 | 1.00 | 0.46 |
| % African-American | 1.15 | 0.87 | 1.5 | .324 |
| % Hispanic | 1.10 | 1.004 | 1.2 | 0.04 |
| % Female | 0.82 | 0.277 | 2.40 | 0.711 |
| # hospital beds/1000 population | 2.34 | 0.85 | 6.50 | 0.102 |
| # SNF beds/1000 population | 1.12 | 0.86 | 1.45 | 0.404 |
| # RCFE beds/1000 population | 1.63 | 0.622 | 4.25 | 0.322 |
| Herfindahl Index | 5826444.14 | 0.0006 | 5.86E16 | 0.185 |

Notes: Comparisons: Nonprofit, not chain, small, home+other, referral-other, small, other payer, 81+years, Caucasian, male, other diagnoses, Caucasian, Male. *Significant at 0.1 level **Significant at .05 level ***Significant at ≤ 0.01 level ****Significant at ≤ 0.001 level

Analysis of hypotheses

Hypothesis 1 of was that there would be higher numbers of complaints and deficiencies associated with larger for-profit hospices affiliated with a parent/chain corporation. Hypothesis 2 suggested that increased hospice utilization would be associated with for-profit hospices, care provided in nursing homes and care for patients with non-cancer diagnoses. Hypothesis 3 associated longer lengths of stay and higher costs of hospice care with for-profit and chain operated hospices.

Confirming Hypothesis 1, increased complaints were associated with hospices that are affiliated with a chain when examined using the negative binomial regression approach. However, contrary to the hypothesis, increased deficiencies were not predicted when comparisons were made between for-profit and nonprofit hospices in either the logistic or negative binomial regression models. As expected, size was a predictor of increased complaints and deficiencies because the more patients cared for, the greater the opportunity for complaints and deficiencies.

As predicted in Hypothesis 2, OLS regression revealed for-profit ownership status as a significant positive predictor of longer average lengths of stay length of stay. In

addition, the percentage of patients with non-cancer diagnoses, specifically Alzheimer's/dementia and heart related illnesses, were also significant positive predictors of length of stay.

Although not an outcome measure, the percentage of days of care in a nursing home was of interest and it was hypothesized that for-profit hospices would have more days of care provided in nursing homes and more patients with non-cancer diagnoses. A Mann-Whitney comparison of the sum of the means, for each site of care comparing profit and non-profit ownership, showed significant differences in the means with a higher mean percent days in a nursing home associated with for-profit hospices (see Table V-5). Higher means of the percent of patients with non-cancer diagnoses of Alzheimer's/dementia and heart related diagnoses were found associated with for-profit hospices. In contrast a higher mean for percent of patients with cancer was found in nonprofit hospices compared to for-profit hospices.

Consistent with Hypothesis 3, the OLS regression on cost per patient found that hospices affiliated with a chain predicted significantly higher costs per patient. However, chain affiliation was not a predictor of length of stay. Surprisingly, profit status was not a predictor of cost per patient.

Other findings

Many of the findings are consistent with the hypothesis chart found in Table IV-2. Organizational characteristics were significant predictors of outcomes. Surprisingly, for-profit ownership was not a significant predictor of increased complaints, deficiencies, decreased RN visits and staff visits, and increased cost. It was, however, a significant predictor of increased length of stay and decreased percent of total costs spent on nursing

care. As expected, chain affiliation when compared to nonchain affiliation, significantly predicted complaints and increased cost per patient; however, it also predicted decreased income per patient. It was not a predictor of deficiencies, decreased average RN visits, decreased total staff visits or increased length of stay. Nursing home as a site of care compared to home and other sites of care significantly predicted complaints but not deficiencies. It also was a significant predictor of increased cost of care, and increased total staff visits. However, the percent of days of hospice care provided in a nursing home did not significantly predict increased RN visits, or length of stay.

None of the hypotheses associated with the percent of days of hospice care provided in a residential care facility were correct. As compared to home and other sites of care, the percentage of hospice care provided in an RCFE significantly positively predicted total staff visits and the percent of total costs spent on nursing care. It significantly predicted increased percentage of costs spent on nursing care but had no effect on other outcomes. Referral source did not significantly predict any of the hypothesized outcomes. The percent of referrals from a skilled nursing facility when compared to other sources of referrals were a significant positive predictor of only one outcome: an increased percent of total costs spent on RN care and were not predictors of any other outcomes. As predicted, referrals to hospice care by hospitals when compared to other referral sources predicted a decrease in average length of stay. Contrary to hypothesis, referrals from hospitals were associated with decreased costs per patient and increased income per patient.

As predicted, the percent of days paid for by Medicare when compared to other payers was a significant predictor of cost per patient. Surprisingly, it was associated with

decreased complaints rather than the predicted increase. The percent of days paid by Medicare was not a significant predictor of any other outcome. Large and medium hospices were significant positive predictors of complaints and deficiencies as predicted. In addition, as expected, large hospices significantly predicted increased length of stay, as do medium sized hospices. Size of hospice was also associated with increased income per patient.

Patient characteristics included significant predictors of outcomes. Age predicted only one outcome. The percentage of patients under 70 years of age when compared to the percent of patients over 81, significantly predicted increased income per patient. No other outcomes were predicted by age. In contrast to hypothesis, the percent of African-American patients when compared to the percent of Caucasians was a significant predictor of decreased RN visits. Also in contrast to hypothesis, the percentage of African-American patients did not predict an increase in the numbers of visits by all staff. As expected, it was a positive predictor for increased length of stay by half a day; however, it was not associated with an increased cost per patient as hypothesized. An additional significant finding was that the percent of African-American patients was a significant predictor of decreased hospice income per patient. The percentage of Hispanic patients when compared to Caucasians had three findings contrary to the hypotheses. First, Hispanic patients were a significant predictor of decreased rather than increased visits by RNs. Similarly, an increased percentage of Hispanic patients predicted a decrease in all staff visits. Lastly, the percentage of Hispanic patients was found to be a significant predictor of decreased rather than increased length of stay. No

other outcomes were found to be significantly predicted by the percentage of Hispanic patients.

The prediction that the percent of female patients compared to male patients would positively predict total staff visits was affirmed. However, contrary to the hypotheses, the percentage of female patients predicted a decrease in complaints rather than an increase, and was not a significant predictor of deficiencies. It was found to be a significant indicator of positive income per patient and was not predictive of any other outcomes.

Hypotheses regarding the significance of the percentage of patients with a cancer diagnosis were contrary to all findings. Compared to other diagnoses, the percentage of patients with a cancer diagnosis is a significant predictor of increased (rather than decreased) RN visits, increased visits by all staff, and increased cost per patient. In addition, the percentage of cancer patients is a predictor of decreased income per patient and increased percent of costs spent on nursing care. No other outcomes were significantly predicted by the percentage of patients with a cancer diagnosis. The percentage of patients with Alzheimer's/dementia when compared to other diagnoses was a significant positive predictor of increased length of stay and increased cost per patient as expected. No other outcomes were significantly predicted by the percent of patients with this diagnosis. Increased length of stay was expected to be predicted by increased percentage of patients with heart related illness and it was significantly predicted. Complaints and deficiencies were not predicted as expected nor was an increased cost per patient. Contrary to expectations, decreased total visits and decreased RN visits were significantly predicted by the percentage of patients with heart related illness.

Only three market characteristics were significant predictors of outcomes. The first was that per capita income predicted an increase of deficiencies as income increases. Second, the percent of Hispanics per 1000 population in the county predicted an increase in deficiencies. In addition, as the percent of Hispanics per 1000 population in the county predicted a decrease in income per patient. Last, the percent of total costs spent on RN care was predicted by an increased number of hospital beds in the county. Surprisingly, the Herfindahl-Hirshman Index measure for competition in the market showed association with any outcomes.

CHAPTER VI

DISCUSSION AND CONCLUSION

This study analyzed trends in the organizational and patient characteristics, quality, utilization and costs of California hospices over a six year period to identify trends. It also examined selected predictors of quality, utilization and costs. As expected, the utilization of hospice rose during the study period, and the trend suggests continued growth in the future. The most significant trend was the rapid pace at which for-profit hospices are dominating the market share of hospice services in California. Additional changes and trends in organizational, patient, and market characteristics that predicted quality, utilization, and cost outcomes were also identified, some of which are associated with the trend of change in ownership. The findings raise policy implications for the regulators of health and hospice services in California.

This concluding chapter will review the trends in hospice characteristics found in the study and the hospice characteristics that were associated with quality, utilization, and cost in California hospices between 2000 and 2005. The discussion of the main findings will integrate what is known from the literature with economic, state, and feminist theoretical perspectives, which underlie this inquiry and analysis. The implications for policy development and future research will also be discussed. Finally, this study's limitations will be identified.

Trends in Hospice Growth

The trends in the growth of California hospices identified in this study signal major shifts in hospice care. The demand for hospice services found in this study documents a 40 percent increase in patients and a 50 percent increase in days of patient care when comparing 2000 and 2005 data. This growth trend has been reported on a national scale in several reports over the last 5 years (Jennings et al., 2003; MedPAC, 2006). Although hospice growth and utilization is monitored nationally by the Medicare Payment Advisory Commission (MedPAC, 2006), the literature does not report examination of the differences between national hospice data and hospice utilization and characteristics in California.

The growth of California hospices reflects an increased acceptance of hospice care by physicians and by the aging population. Over the 6-year study, there was a net increase of 31 new hospices in California; however, 30 hospices closed during that same period. Thus, the number of new hospices between 2000 and 2005 was 60. This study did not examine the organizational and patient characteristics of the hospices that closed, which presents an opportunity for future research. Research should consider examining the Herfindahl-Hirshman Index, an economic measure of competition, for hospice care, nursing home care and residential care for the elderly of areas where hospices closed. As increasing numbers of hospice days are provided outside the home, these measures may explain the success or failure of new and existing hospices. Examining the ethnic makeup of the counties where hospices closed may identify associations with hospice closures because of many cultural barriers to hospice care.

Trends in Hospice Quality

Hospice quality measured by complaints, deficiencies, nursing visits and visits by all staff showed mixed trends. The number of complaints filed was small and averaged fewer than 0.13 per year per hospice per year. Complaints are considered useful measures of quality but are often under reported because patients and families do not know how to file a formal complaint, or patients and families fear retaliation if they complain, as well as many hospice patients and their frail spouses lack the cognitive acuity to actively complain during an emotional time (Stevenson, 2005). Stevenson suggests evaluating all complaints not just those filtered through licensing agencies in order to increase the power of this important measurement. Inclusion of this measure in state licensure certification is unlikely because hospices will not want to make public every complaint that has been filed with their agency. The number of complaints filed with the Department of Health Services by patients, families or others, during the 6 years for which data was analyzed was too small to identify trends.

Similarly, the number of deficiencies was also small and averaged less than one per hospice per year. Deficiencies are citations by the California Department of Health Services Licensing and Certification (DHHS L&C) Division responsible for surveying hospices for California licensure and license renewal, as well as, for Medicare certification. Certification surveys determine whether or not hospices meet the Medicare Hospice program, health, and safety standards set forth in the Medicare Conditions of Participation (COPS). In May of 2005, the Centers for Medicare and Medicaid Services (CMS) published proposed new regulations modifying the current COPS which have not been updated since first written after the passage of the hospice benefit amendment in the

Tax Equity and Fiscal Responsibility Act of 1982 (Office of the Inspector General, 2007). These regulations are anticipated to be finalized sometime in 2008. Neither law nor regulation specifies the frequency of Medicare certification surveys for hospices. And, in August of 2005, the Centers for Medicare and Medicaid Services released the fiscal year 2006 Survey and Certification “budget call letter” with instructions for State agencies. In this document, in an administrative subterranean action, CMS lowered the required frequency of hospice certification, changing it from a minimum of every six years to a minimum of every eight years. This action was taken without any public debate or input. The reasons cited were related to reductions in President Bush’s budget (Office of the Inspector General, 2007). In contrast, nursing home certifications surveys are required by statute to be conducted at least every 15 months and home health agency certifications once every three years. Other industry hospice accreditation bodies (the Joint Commission for the Accreditation of Healthcare Organizations and the Community Health Accreditation Program) survey hospices every six years.

A personal communication with California DHHS L& C staff confirmed that hospices in California are inspected only once every six years for licensure and Medicare certification. However, the recent US DHHS Office of the Inspector General Report (2007) that evaluated the timeliness and results of hospice certification surveys performed by state agencies found California to be one of three states that accounted for 41% of all hospices (nationwide) with certification intervals of greater than six years (Office of the Inspector General, 2007).

In addition the California State Auditor released a report on the state DHHS Licensing and Certification Division responsible for oversight of skilled nursing facilities

and found the division inconsistent in its oversight processes, and questioned the integrity of the complaint tracking system (Howle, 2007). While the auditor's report did not evaluate hospice oversight, hospice licensing and certification is within the same division.

These shortcomings of the system of collecting and evaluating complaints and deficiencies helps explain the small numbers in this study's data. The study did find that complaints and deficiencies as measures of quality were predicted by some hospice and market characteristics which are discussed in greater detail in the next section.

This study showed that the number of hospice visits by nursing staff and by all the staff showed only a slight increase over the 6 years. The visits by all staff increased by 4.29 visits during the study period; however, the number of nursing visits decreased by 0.11 visits. It is unclear from the data whether these changes positively or negatively affected quality. A study of the number of hospice visits to patients in nursing homes in seven states (Miller, 2004) concluded that a different mix of services rather than volume of services was used to address hospice patient needs in nursing home settings. Fewer numbers of nursing visits and greater numbers of staff visits were found (Miller, 2004).

Additional quality measures were not examined because they were not available. The literature describes the difficulty in measuring what it means to "live well while dying" (Donaldson, 1998, p. 125) and suggests that suitable measures have not yet been validated to measure quality of care at the end of life because so many rely on proxy reporting (Donaldson, 1998; Donaldson & Field, 1998); proxies report objective states, such as mobility, more accurately than they report subjective states such as pain (National Institutes of Health, 2004). The National Institute of Health (NIH) State of the Science Conference on End-of-Life Care agreed that few tools had undergone rigorous

examination for measurement among groups from ethnically diverse populations (National Institutes of Health, 2004; NIH, 2005). The Conference Statement reported that communication among providers and patients and families is essential to improve care and relieve suffering. And, that the majority of studies on interventions to improve communication have been done outside the United States. In addition, the cultural diversity in the U.S. population makes communication effectiveness very difficult to measure. Donaldson and Field (1998) suggest that accreditation must include system and individual measures of quality and emphasize the importance of public oversight. This is an area where much work needs to be done in the policy arena given that CMS intends to lengthen the periods for Medicare recertification.

Trends in Hospice Length of Stay

Among the significant trends in the outcome findings, the average length of stay decreased by 3 days per year and 11 days over the 6-year study period. Documented during the past 2 decades, this trend concerns hospice care providers. The CDC acknowledges that a minimum stay of 1 month is necessary to receive maximum hospice benefits for a patient and family (Centers for Disease Control and Prevention National Center for Health Statistics, 2003a); however, lengths of stay continue to decline. Many contributing factors to length of stay have been identified (Christakis, 1994; Iwashyna, Zhang et al., 2002; Lorenz, Asch et al., 2004; McCarthy, Burns, Davis et al., 2003; McCue & Thompson, 2005; Stillman & Syrjala, 1999; Virnig et al., 2002). Besides diagnosis, age, and physician referral patterns, shorter lengths of stay have been attributed to government oversight of fraud and abuse by the USDHHS Office of Inspector General (OIG) investigation in the late 1990s (Jennings et al., 2003; Morris,

2003). While the OIG investigation uncovered only a couple of major incidents of fraud in hospices, the OIG warning “guidance” letters which were sent to all Medicare certified hospices resulted in hospices not accepting and or discharging patients whose physical status was not declining quickly enough ("Federal Register: OIG Special Fraud Alert: Fraud and Abuse in Nursing Home Arrangements With Hospice," 1998; Hoffman & Tarzian, 2005).

This study’s univariate analysis and regression analysis confirmed previous research that for-profit hospices have higher mean lengths of stay than nonprofit hospices (Miller et al., 2000; Miller, Weitzen et al., 2003). Length of stay is an important measure because a hospice is reimbursed on a per diem basis. Longer lengths of stay generate more income but may also require more services, depending on the patient diagnosis case mix.

Trends in Hospice Costs

From classic and neoclassic market economy perspective, the increased demand for hospice care should influence not only the supply but also the price of hospice care; however, because hospice care is provided in a monopsonistic model with Medicare as the primary purchaser of care, price competition has limited effect. Medicare controls costs by paying hospices a set amount “per day of service” (per diem) rather than per service. For the market to provide a return on investment, costs must be controlled and income maximized. Examining organizational and patient characteristics revealed the different strategies hospices use (or fail to use) to ensure not only adequate income to cover operating expenses but also profit. These strategies will be discussed later in this chapter.

The trends of this study showed the cost of hospice care increasing by \$763.68 per year per patient. This cost did not consider the cost of unpaid caregiving. Only one study from the literature investigated the cost of informal caregiving associated with end-of-life care in the elderly (Hayman et al., 2001). Hayman et al. (2001) examined costs associated with informal caregiving for elderly cancer patients who were receiving treatment with those not receiving treatment and found that cancer treatment was associated with 3 hours of care per week at a rate of \$8.17 per hour, which translates to an additional average yearly cost of \$1,200 per patient or just over \$1 billion nationally. Informal caregiving costs, therefore, are substantial and should be considered when estimating the cost of hospice care but unfortunately such information is not available from secondary data sources.

Hospice care is still not a large enough percentage of the Medicare budget to warrant a listing separate from home care in Centers for Medicare and Medicaid Services reports. So, year to year increases in the percent of the Medicare and Medicaid budget are not reported on annually published total health expenditure reports. The increase in California represents a 35% increase during a period when national growth in health care spending was approximately 30% (CHFC, 2007). The increased cost trend has not raised concerns possibly because hospice is still considered a cost effective alternative to hospitalization during the last 6 months of life.

Ownership Characteristic Trends and Predictors of Quality, Utilization and Cost

The most significant trends identified in this study were changes in the ownership and affiliation of California hospices. Similar to findings in the rest of the country, the

growth of for-profit hospices has outpaced the growth of nonprofit hospices in California. This study found that for-profit hospices increased their market share 4% over the 6-year period from just under 30% in 2000 (53 hospices) to just over 34% (72 hospices) in 2005. Adding the previous findings (Lorenz et al., 2002), the market share of for-profit hospices in California nearly doubled in 13 years from 13% in 1992 to 34% in 2005. For-profit hospices accounted for nearly two-thirds of the net hospice growth during the study period. The trend in hospice growth in California shows that for-profit hospices are growing faster than nonprofit hospices. These findings are congruent with the recent results of a national study (McCue & Thompson, 2006) that examined for-profit and nonprofit hospice growth.

In 2003, 56% of the more than 1,200 Medicare-certified hospices in the United States were nonprofit (McCue & Thompson, 2005). In 2006, MedPAC reported that for-profit hospices had increased nationally from 31% to 46% between 2001 and 2006. McCue and Thompson (2006) examined the ownership of freestanding hospices established between 2002 and 2003. They found that 91% of new hospices were for-profit in contrast to 60% of existing freestanding hospices. More than 70% of the new hospices were located in the southern United States. This trend has been reported in the national press for several years. In 1997, *U.S. News and World Report* published a story titled, "Death be not Swift Enough: Fraud Fighters Begin to Probe the Expense of Hospice Care" (Shapiro, 1997), which suggested that "Medicare reimbursement transformed hospice away from its roots as a movement that relied primarily on volunteers to a for-profit industry" (p. 34). Shapiro noted that only 30% of hospices are independent community organizations; the rest are part of regional hospice "chains,"

home health care agencies, or divisions of hospitals. Of the remaining 70%, 15% are for-profit hospices and these proprietary hospices care for more patients than nonprofit hospices.

This trend has just begun to surface in California hospices. After examining the California OSHPD data, Lorenz et al. (2002) reported that for-profit hospices grew from 13% in 1992 to 27% in 1999. This study's timeframe, 2000 to 2005, immediately follows that of Lorenz et al., providing an extended view of the trend change.

This study's findings also document a trend that California hospices affiliated with chains are continuing to grow but not at a rate to maintain the current chain market share. Fifteen new hospices that were affiliated with other hospices made up 50% of hospice growth in California during the study period compared with a total of 59% of the market share at the beginning of the study period. California's chain market share is already higher than national percentages. McCue and Thompson (2006), in their national study, found that 27% of the new hospices were owned by large, multi-state, for-profit hospice companies compared with only 12% of existing hospices.

The Home Health Care Market Transformation Applied to Hospice

The organizational trend toward for-profit hospices and chain affiliation is similar to the restructuring of home health care in the 1970s and 1980s when, in less than 2 decades, home health care was transformed into an industry dominated by for-profit corporations. The genesis of this transformation began in the late 1940s with a massive state investment in private health care expansion based on a free market ideology, which spawned the private medical industrial complex (MIC), an interrelated system of doctors, hospitals, technology companies and insurers. The passage of Medicare and Medicaid, in

1965, enabled the state to avoid creating its own government health system, and served to legitimize the state through the provision of medical care, in doing so, it also reified the dominance of medical expertise. The state's regulation of medical care fulfilled the state's role in consumer protection. It also subsidized the accumulation of private capital in the health care industry (O'Connor, 1973; Offe & Ronge, 1982).

By the 1970s, unlimited state subsidy of the MIC through Medicare and Medicaid, caused growing pains. Unfortunately, the state's subsidy of demand for medical care through funding of Medicare and Medicaid, combined with a complicit lack of fiscal regulation of the capitalist MIC, created a "fiscal crisis of the state" through uncontrollable hospital costs (O'Connor, 1973; Offe & Ronge, 1982). The state, rather than regulate the providers, relied on market competition, and the power shifted to the payers (corporations and insurers) who demanded shorter hospital stays, which in turn increased the demand for home health care.

Favoring deregulation in health care, President Ronald Reagan's Administration increased reimbursement for home health care as an alternative to costly inpatient care, further stimulating privatization (corporate ownership) and rationalization as well as subsidizing the accumulation of private capital in the health care industry (Estes & Swan, 1994). The Omnibus Budget Reconciliation Act (OBRA 81) included subsidy of for-profit home and community based services that were traditionally provided by non-profit providers and promoted self-reliance, family care and informal care under the guise of reducing Medicaid costs and reliance on institutional long-term care (Kitchner & Harrington, 2004). These policies were implemented without public debate, through

administrative procedures in a subterranean political process that created a “path dependence” for future welfare policy (Hacker, 2002).

The increased percentage of for-profit home health care agencies, accompanied by a decline and other changes in nonprofit agencies, initiated the increasing privatization of home health care. In the 14-year period beginning in 1972, “for-profit Medicare-certified home-health agencies moved from fourth to first place among the number of providers” ... “increasing their share of the home health market to 31.7%, while the market share of nonprofit agencies declined from 30.1% to 22.1%” (Estes & Alford, 1990b, p. 182).

This shift in the political economy toward a neoliberal competitive market ideology resulted in for-profit health care corporations investing in home health care. The dominant privatization/competitive market ideology of President Reagan’s executive branch of the state (responsible for regulating health care) promoted the efficiency and superiority of for-profit home health care agencies and in the co-modification of for-profit home health care by the state. Kitchner and Harrington (2004) described the process as the “colonization of home health care agencies by corporations seeking to maximize profits by skimming the ‘cream’ of the most profitable (least service intensive) clients” (p. 93).

The increased participation of for-profit home health care agencies caused the structure of nonprofit home health care agencies to change. In uncertain competitive environments, organizations attempt to secure their positions of domination and preserve “market share” through structural isomorphism, a process by which organizations become more and more alike (DiMaggio & Powell, 1983). Isomorphism in a competitive

environment promotes increasing complexity in organizations and integration both vertical and horizontal. Institutional isomorphism, in its coercive form, creates pressure to conform to corporate or regulated structures; in its mimetic form, it promotes the imitation of the structures that have been deemed legitimate by the dominant ideology; and, in its normative form, it emphasizes professional standards and norms. All of these isomorphic mechanisms were at work in the transformation of home health care into an industry dominated by for-profit agencies. Regulatory health and economic policies created a competitive environment in which nonprofit home health care providers began to resemble for-profit providers, and for-profit providers expanded and integrated vertically and horizontally. Spawned by the state and economic forces of the political economy, this increased privatization and rationalization (increased organizational complexity) created institutional isomorphism through corporate structures and changed the standards of care creating a home health care industry.

Hospices were not part of this structural isomorphism because their service was not added to Medicare's benefit package until 1983 and because hospice reimbursement was paid on a per diem rather than a per service basis, making it unattractive to for-profit agencies at that time. The infiltration of for-profit agencies into hospice care only began in the last decade.

The second organizational shift in home health care, now occurring in hospice care, was its affiliation and integration into larger organizations, described above as isomorphism. More than 10 years ago, the *Central New York Business Journal*, a trade publication providing coverage and analysis of economics, reported that most hospices were newly established subsidiaries of chains of home-health agencies, nursing homes or

health maintenance organizations (Harting, 1995). The definition of chain for this study referred only to affiliations between hospices themselves, not between hospices and home health agencies and hospitals etc. This study found that hospice chains in California are both for-profit and nonprofit. California has two large health care systems with nonprofit hospice chains. This study found that the trend of hospice chains to grow at the same rate as nonchain hospices, was similar to Estes, Swan, Berthgold and Spohn's (1992) examination of environmental factors and organizational characteristics as predictors of home health care agencies joining chains during a time of tremendous organizational growth and diversification between 1984 and 1987. Their study considered local market characteristics, including the Herfindahl-Hirshman Index and organizational characteristics, such as horizontal integration of chains or inter-organizational affiliations. The greatest growth, they found, was among hospital-based and for-profit home health care agencies or agencies affiliated with other organizations. This growth was spawned by regulatory policy changes in Medicare that allowed for-profit agencies to participate in home health care and that eliminated certification restrictions on for-profit companies in states that did not license home health care agencies.

Inaction has promoted the growth of for-profit hospices and hospice chains. Although no explicit regulatory changes have stimulated the growth of these proprietary organizations, the lack of regulatory intervention in response to their dramatic increase in providing care in nursing homes, is de facto policy. A Government Accounting Office report (2004) examining the possible need for payment methodology changes evaluated only proprietary (for-profit) hospices. The findings suggest that payment changes were not needed because profits were being made. The possibility of having different payment

rates for hospice services in skilled nursing facilities versus in homes was not considered, and different reimbursement methodologies for patients with different diagnoses were not considered.

Among the organizational theories that Estes et al. (2004) applied to the change in home health care was resource dependency theory, which posits that “organizations modify their structures and behaviors in response to the most powerful political and economic forces around them that control scarce resources” (Estes et al., 1992, p. 39). Oliver (1997) discussed the importance of an organization’s ability to manage the “institutional” context of its resource decisions. This institutional context for resource decisions operates at the individual, organizational, and inter-organizational level. Strategic inter-organizational “alliances allow organizations to access needed resources and capabilities” (Oliver, 1997, p. 707). Organizational affiliations are an example of a strategic alliance. Oliver, however, suggests that the organizational isomorphism described by DiMaggio and Powell (1983) results in decreased quality because there is an overall “reduction in structural strategic diversity when firms adopt similar approaches to product development and quality control” (p. 708). At the individual level, resource decisions reflect organizational norms and values; at the organizational level, resource decisions involve organizational culture and politics; and, at the inter-organizational level, resource decisions involve industry-wide norms and public and state regulatory oversight.

Hospices affiliated with a parent corporation, organization, or chain, reflect inter-organizational affiliation. Affiliation maximizes economies of scale in resource decisions regarding purchasing, marketing, and other business practices (Paradis and Cummings 1986; Hamilton 1994) and creates greater certainty for resources, although it limits

innovation (Oliver, 1997). A resource dependency perspective would suggest that the adding hospice care to a for-profit corporation's long-term care division exemplifies diversification in response to changing environmental conditions and such diversification, according to Banazak-Holl, Zinn and Mor, (1996), achieves a better balance. This study found a significant upward trend in the number of for-profit hospices and hospices affiliated with chains. In univariate analysis of means, for-profit and hospices affiliated with chains were associated with higher means of total patients and of total patient days, both of which could be considered measures of growth and security. Because of the limited hospice per diem reimbursement rate, hospices face economic incentives to select patients who do not require complex care. The univariate analysis comparing for-profit and nonprofit hospices across diagnoses revealed higher mean percentages of patients with noncancer diagnoses associated with for-profit hospices. This infers that for-profit hospices may "cherry pick" less service-intense and less costly patients to ensure their profit because per diem reimbursement determines whether a hospice makes or loses money on patients. Nonprofit hospices were associated with higher mean percentages of patients with cancer who have shorter lengths of stay and require more intense services. These findings are similar to those of Lorenz et al., (2002).

In the literature, studies of the differences between for-profit and nonprofit, affiliated and nonaffiliated hospices, have produced mixed results. Two recent studies report different findings after comparing the availability of core services of for-profit and nonprofit hospices. Carlson, Gallo and Bradley (2004) used a national data base to compare 422 for-profit and nonprofit hospices and found that the former provided a smaller range of services when adjusting for patient diagnosis, disability, gender, location

of care, certification, chain affiliation, and geographic region. Lorenz et al. (2004) found that California hospices that were part of a chain were less likely to restrict admission. Studies comparing quality were very limited.

Regression and negative binomial tests revealed only five significant findings in the outcomes predicted by for-profit and chain ownership. As expected, for-profit hospices had longer average lengths of stay (11.8 days). And, nursing care accounted for 7.6% less of for-profit hospices' total expenditures when compared to nonprofit hospices. These findings confirm that for-profit hospices admit patients who require less skilled care or who do not receive the skilled care they need. The chain affiliation for a hospice predicted a decreased income per patient of \$1,237 and an increase cost per patient of \$2,012. When comparing means across races, the Mann-Whitney *U* test associated greater percentages of African-American and Hispanic patients with for-profit hospices.

For hospice ownership characteristics (profit and affiliation), public policy - or its lack - fosters organizational change and/or inertia which are reflected in decisions about resources. The state's lack of regulation of the quality of hospice care and its lack of specificity regarding required core services, has complicity allowed for-profit hospices to provide services to patients who will have longer lengths of stay and require or receive less professional care resulting in shareholder profits paid from public Medicare trust funds and Medi-Cal tax dollars. This is an example of the implications of path dependence, in which policies and models of care are reproduced and become institutionalized through power dynamics, empowering one group at the expense of others (Mahoney, 2000).

Profit status has been examined in the nursing home industry; nursing homes that generated profits beyond a set threshold were associated with higher numbers of deficiencies (O'Neill, Harrington, Kitchner, & Saliba, 2003). In this study, profit status was not found to be a predictor of complaints or deficiencies. The number of for-profit hospices in California began to increase only within the past decade. In the nursing home industry, the for-profit market is more mature, and the nursing home literature documents that nonprofit nursing homes provide higher quality services than for-profit nursing homes (Aaronson, Zinn, & Rosko, 1994). As more for-profit hospices infiltrate the California market, changes in the quality of their care may be seen.

Geographic Characteristic Trends and utilization of Hospice Services

An unanticipated trend was found in examining access to hospice services in rural areas. California is a large and geographically diverse state. Unlike the national trend, in which access to hospice care in rural areas more than tripled between 1992 and 2000, increasing from 6% to 19% (MedPAC, 2004), access to hospice care in California's rural counties decreased during the study period. Many California counties are large and their highly populated cities define them as nonrural. Many people, however, reside in the rural areas of these vast counties, but these counties are not included in this analysis. California has 58 counties, and 21 of them are considered entirely rural according to the Health Resources Services Administration, (MedPAC, 2004; US DHHS Health Resources Services Administration, 2005).

In California, access to hospice care in rural areas decreased during the study period. In 2000, four counties had no hospice services, and nine were designated as rural. By 2005, 14 of the state's rural counties had no hospice

services. The total number of hospices in rural counties dropped from 14 to only 12 statewide in 6 years. No for-profit or chain-affiliated hospices were located in rural counties.

From a neoclassic economic perspective, rural counties have a higher demand for hospice care because they tend to have a higher population of older people. The mean death rate in California counties is 8.2 deaths per 1,000 population. The death rate in California's rural counties is much higher than nonrural counties. Twelve of the 21 rural counties in California have death rates above 10/1,000 population. Of California's 37 nonrural counties, all but 5 have a death rate below 8 deaths per 1,000 population, the exceptions being Shasta (10.2), Sutter (8.6), Napa (9.9), Placer (8.0), and Yuba (8.0) counties. That the percentage of people over 65 years of age is also much higher in California's rural counties is an added factor. Twelve rural counties have more than 15% of their residents over the age of 65, and fewer than half have hospices. The market fails in these rural areas because travel costs to reach people needing hospice care are greater than the reimbursement rate from Medicare. This inequity in access to care could be remedied if the reimbursement formula considered travel time. Or it could be addressed by higher hospice reimbursement rates for rural areas.

The lack of hospice care in California's rural areas, identified in this study, should concern policy makers. Although no research has been done on the availability of hospice care in rural areas, a 2004 analysis for home health care agencies (Dombi, 2004) suggests that payment reductions would jeopardize home health care in rural areas, and

while hospice is reimbursed separately from home health care, reimbursement rates determine the viability of hospice programs.

Future research might examine the lost productivity costs and increased mortality rates of unpaid caregivers in rural areas and the number of rural residents who die as inpatients in costly hospital settings. The policy implications of this disparity in care access are evident and must be addressed by increasing reimbursement for patients in rural areas to cover travel costs.

Site of Care Characteristic Trends and Predictors of Quality, Utilization and Cost

Unlike many other states, California has few institutionally designated hospice beds because Medicare's per diem reimbursement rate does not cover the cost of 24-hour care. Some hospitals are adding palliative-care comfort suites, which offer a homelike environment for patients who are near death and their families. These rooms are for short-term stays and are reimbursed through traditional Medicare, Medi-Cal, or private insurance, not through Medicare's hospice benefit. Some states have facilities with "hospice beds." Over the 4-year period for which data was available, the location where hospice care was provided changed, revealing a significant 7% decrease in the percentage of care provided in patients' homes and a significant increase of 1% per year in the percentage of hospice care provided in residential care facilities for the elderly (RCFE). This change may be attributed to changing family structures in which end-stage parents do not or cannot rely on their families for care. The Mann-Whitney *U* test associated a smaller percentage of days of hospice care provided in homes associated with for-profit hospices. Traveling to patients' homes is more resource intensive than seeing several patients in one place, which explains the finding that for-profit hospices were associated

with higher percentages of care provided in nursing homes and residential care facilities for the elderly in a Mann-Whitney *U* comparison of means testing.

The percentage of care in nursing homes as a percentage of all care increased only slightly. This trend is contrary to the findings in the literature, which report that the percentage of hospice care provided in skilled nursing facilities (SNFs) has increased since the passage of the Consolidated Omnibus Reconciliation Act of 1985 (Folland, Goodman, & Stano, 2004b; Neigh, 2004). Hospices contract with nursing homes and send their personnel into them to provide care. The market for nursing home care in general is predicted to grow because of the aging population. Feldstein (1998b) predicted a 59.2% likelihood that persons will have to enter a nursing home after spending down their personal assets on home care. In 2004, MedPAC reported to Congress that the percentage of hospice care provided in nursing homes increased from 11% to 36% between 1992 and 2000 and that the fastest rise in hospice use was among nursing home resident beneficiaries with noncancer diagnoses (Neigh, 2004). Petrisek and Mor (1999) found that the higher the percentage of nursing home residents receiving hospice benefits, the more likely a nursing home was to be for-profit or to belong to a chain.

The previously mentioned association of increased percentages of nursing home hospice days with for-profit hospices may also be related to strategic resource affiliation, in which hospices associate, formally and informally, with nursing homes that provide long-term care. Research which examined differences in hospice use in nursing homes in five states produced similar results (Miller et al., 2000). This research found that for-profit hospices had longer mean length of stays and a higher proportion of dementia patients and a lower proportion of cancer patients.

The increase in the percent of days of care in RCFEs is probably related to an increased availability of beds. The market analysis showed higher numbers of RCFE beds in wealthier counties, which may be attributed to the increase in retirement communities with assisted living. RCFEs recognize the value of hospice care and appear to be encouraging its use. Medicaid (Medi-Cal in California) waivers that reimburse care in RCFEs rather than nursing homes will soon be implemented in California and this may have an impact on increasing hospice use.

Research is needed to determine why the number of patients receiving hospice care in their homes has declined. Families who cannot afford 24-hour care for their loved ones may be hidden in this decline. Lack of family caregivers and frail family caregivers are cited in the literature as reasons for hospice ineligibility (Cassel & Demel, 2001; Neigh, 2004). Government policy must ensure equity in access to hospice care by providing home care assistance or reimbursement for families so they can continue working or by establishing Medicare- and Medi-Cal- reimbursed residential care beds for hospice care. These facilities exist in several other states.

Hospice Referral Characteristic Trends and Predictors of Quality, Utilization and Cost

During the 4 years for which data were available, only one trend in hospice referrals was evident, an increase in the percentage of referrals to hospice by insurers and health maintenance organizations (HMOs) or managed care organizations. The literature confirms this finding. Virning, Fisher McBean and Kind (2001) examined 100 counties in 22 states with the largest number of Medicare deaths in managed care settings and found that rates of hospice use were higher for managed care enrollees. Managed care patients who select hospice and palliative care yielded cost savings, received more home

care visits, and were more likely to die at home than patients who received traditional Medicare-certified home care at the end of life (Brumley et al., 2003). These findings were not confirmed in this study because no comparisons were made between patients in managed care and patients with traditional insurance. However, increased referrals from managed care organizations and insurers were among the few predictors of increased deficiencies as one of the outcome measures for quality. This may be related to the increased monitoring of managed care organizations by California's Department of Corporations and Department of Insurance. However, because there were so few predictors of deficiencies, the finding deserves further exploration.

The increased percentage of referrals to hospice from insurers and managed care organizations found in this study may reflect the extensive penetration of managed care health coverage in California. Managed care organizations may focus on hospital discharge planning to avoid costly hospital stays, and staff model HMOs often have their own internal hospice services, making referrals seamless. In the case of HMOs, Medicare reimbursement is based on a per diem rate rather than a per capita rate so there may be a financial incentive to enroll members in hospice. Medicare beneficiaries who can afford Medi-Gap insurance, which pays for services Medicare does not cover, may have more access to the hospice benefit as well because of care coordination systems insurers use to decrease expensive hospitalization.

Research is needed to determine if per diem payments are a financial incentive for managed care organizations to refer patients to a hospice. Research is also needed to evaluate the increased likelihood of deficiencies when there is a higher percentage of patients referred to hospice by insurers or managed care organizations. Some initial

research has been conducted on HMO use in hospices, and the findings confirm longer lengths of stay; however, no quality measures were evaluated (Virnig, Persily et al., 1999).

More research is needed to validate tools to measure hospice quality. The proposed Medicare Conditions of Participation, which are currently under revision for the first time since the hospice amendment was passed (1982), include quality improvement requirements. Such requirements will hopefully allow for modifications in quality measures over time as tools are developed to measure the effectiveness of different aspects of hospice care such as, interventions for symptom management, spiritual aspects of dying, withdrawal of life-sustaining treatments, family caregiving and bereavement (National Consensus Project for Quality Palliative Care, 2004; National Institutes of Health, 2004).

Payer source Characteristic Trends and Predictors of Quality Utilization and Cost

Medicare is the primary payer for hospice care (Han, Remsburg, & Iwashyna, 2006). Over the 4 years for which data were available, this study documented a trend in the increase of the percentage of days paid by Medicare. This may be due to the changing age demographic observed in California hospice care where more hospice patients are over 81 years of age and fewer are under 50 years of age. This study confirmed the findings of McCue and Thompson (2006), whose comparison of large and small publicly traded and nonprofit hospices found that publicly traded hospices served a greater proportion of Medicare patients relative to nonprofits, suggesting that they achieved higher earnings by serving patients insured by Medicare. The regression analysis of the percentage of Medicare-reimbursed days predicted a decreased cost per

patient (by \$75) and an increased income per patient (by \$164). Medicare was also associated with a modest increase (0.14%) in the percentage of total costs spent on nursing care and with decreased numbers of complaints.

These findings may alert for-profit corporations and their stockholders that the state's reimbursement of hospice care through Medicare is a lucrative investment opportunity. It is also an example of the state's participation in corporate accumulation of wealth. Indeed, Medicare is referenced in investor financial reports and recommendations. For example, consider the case of Chemed Corporation, Cincinnati, OH. In 2004, the company purchased the last 63% of Vitas[®] (a company that accounts for 11% of the hospice market in the United States) for \$324 million at a price revenue ratio of 1:2. Until this purchase, which established Chemed's total control of Vitas[®], Chemed was known for its largest subsidiary, Roto-Rooter (Shattuck & Hammond, 2004).

This study's trend analysis found a decrease in the percentage of Medi-Cal-covered days. Medi-Cal is federal-state insurance program for low income eligible people. (Medi-Cal provides coverage for the elderly whose incomes are less than \$926 a month). Decreased Medi-Cal use is considered a proxy measure of decreased access to hospice services by the poor. Hospices providing care to large Medi-Cal populations may have sicker patients because of comorbidities associated with poverty. People who are eligible for Medicare and Medicaid are known as "dual eligibles." Nationally, dual eligibles are 62% women. Dual eligibles tend to have poor health, more chronic illnesses, and difficulties performing activities of daily living (Kaiser Family Foundation, 2005). These conditions might make them higher users of care. This study found that a high percentage of Medi-Cal-reimbursed days of care predicted increased visits by all staff

and increased lengths of stay, suggesting that Medi-Cal beneficiaries have greater care needs.

The Kaiser Family Foundation reports that twenty-five percent of dual eligibles are in an institution, compared with 3% of their wealthier counterparts (Kaiser Family Foundation, 2004). No analysis considered the site of hospice care for dual eligibles; however, the Mann-Whitney *U* test revealed a higher mean percentage of Medi-Cal days associated with for-profit hospices and a higher percentage of days of care associated with care in nursing homes. Additional tests might examine where Medi-Cal patients receive hospice care. In 2001, 2.5% of dual eligibles used hospice care nationally (MedPAC, 2004).

In California, Medicare eligible (elderly) Medi-Cal enrollees (or dual eligibles) make up 8.7% of the state's Medi-Cal enrollees (Kaiser Family Foundation, 2004). This study's data examined only the percentage of hospice days paid by Medi-Cal; it does not show the percent of Medi-Cal beneficiaries using hospice care. Higher percentages of both state payer sources (Medicare and Medi-Cal) were associated with for-profit hospices.

Policy makers should re-evaluate the implications of California's continued legitimization of for-profit hospice services and ensure that the quality of hospice care is equitable. The relationship between increased 'all staff' visits and the percentage of Medi-Cal-reimbursed days compared with the predicted increase of the percent of costs spent on nursing care associated with the percentage of Medicare-reimbursed days may signal inequitable care.

Patient Characteristic Trends and Predictors of Quality, Utilization and Cost

This study identified significant trends in every characteristic of hospice patients, including, age, race, gender, and diagnosis. All have implications for future research, planning, and policy development. Many patient characteristics significantly predicted outcomes of quality, utilization, and cost.

Trends in Hospice Patients' Age and Predictors of Quality, Utilization and Cost

The percent of hospice patients under 50 years of age and between 70 and 80 years of age decreased during the 6-year study. The age group of patients under 70 was the only age category that significantly predicted any outcome. In the regression analysis, the percentage of patients under 70 years of age predicted an increase in hospice income per patient of \$184. This may be related to traditional private insurance coverage for hospice care, which pays at a higher rate than Medicare. An increasing number of third party payers are adding hospice as a covered benefit. Some states now require hospice coverage as a basic benefit. Aetna, a for-profit insurance company, expanded its hospice benefit in 2004 to include some treatments not considered palliative for two reasons: to make hospice care more attractive and to increase profits because hospice care reportedly reduced costs per day per patient to \$120 compared with an average of \$7,353 per day per patient for hospital care (Kaiser Family Foundation, 2004). From this outcome, market incentives seem to influence the use of hospice care.

In contrast to the decrease in the percentage of hospice patients under the age of 70, the percent of hospice patients over the age of 80 increased significantly from 9.76% to 52.52%. This study identified a significant trend in the increased age of hospice patients. In the 1970s and 1980s when hospice care began, life expectancy was shorter

than it is today. As medical technology has improved, people are living longer and people of advanced age are experiencing suffering associated with terminal illnesses.

This trend is important for women in particular. Increased life expectancy has a disproportionate impact on women because a woman's life expectancy is 5 years longer than a man's. In California, women make up 60% of people over 70 years of age (Public Policy Institute of California, 2004). Among persons aged 85 and older, men are four times as likely as women to live with a spouse (Collins, Estes, & Bradsher, 2001), which often means that a wife is the likely caregiver. Many elderly caregivers are frail themselves, caring for patients who are older and who have physical needs far more complex than 20 years ago. Some hospices in California refuse to admit patients who have only a frail caregiver at home (Lorenz, Asch et al., 2004).

There are many implications for research, clinical practice, and policy related to the trend of increasing age among hospice patients. Clinical research is needed to examine palliative treatment for conditions, other than pain, that cause discomfort late in life, such as anxiety and constipation. Pharmacists, physicians, and nurses must be trained about geriatric patients and their needs. Training providers to recognize the symptoms of caregiver stress is also essential. Reimbursement policy must address the increased need for in-home support, and compensation for caregivers is essential as the baby-boomer generation explodes in the next 3 decades when the percent of hospice patients over the age of 81 is anticipated to increase four-fold (Jennings et al., 2003).

Patient Racial Characteristic Trends and Predictors of Quality, Utilization and Cost

The trends identified in this study revealed a decrease in the percentage of Caucasian and African-American hospice patients in California, a slight increase in

Hispanic patients, and a significant increase in the category inclusive of Asian Americans, Native Americans, and others combined. The results of the regression analyses raised serious concerns about hospice care and the Hispanic population. The analysis found that the percentage of Hispanic patients was a predictor of fewer visits by all staff, increased complaints, increased deficiencies, and shorter average lengths of stay. And, the results of the market regression analysis predicted that decreased income per patient and increased deficiencies are associated with an increased percentage of Hispanics in the county.

The percentage of African-American patients was associated with fewer nursing visits, increased lengths of stay, increased cost per patient, and decreased income per patient. Increased lengths of stay and increased cost of care for African-American patients may be associated with complex illnesses associated with poverty. The combined-race category predicted decreased nursing visits, decreased complaints, and decreased deficiencies. One explanation for these findings is that language and cultural barriers may impede the filing of complaints and subsequent inspections by the state Department of Health Services resulting in possible deficiency citations.

Many of these findings may reflect the cultural and linguistic barriers identified by Crawley and Kagawa-Singer (2007). Their California-based research confirmed previous findings and the trends observed in this research that ethnically diverse populations use hospice less than Caucasian patients. They also found differences in priorities for end-of-life care among different races. Caucasians patients reported that pain control was a top priority; Hispanics, Asians, and Chinese-speaking Chinese cited affordability; and African-Americans identified cultural competence. The undertreatment

of pain in the elderly, poor, and racial/ethnic minorities was reported (Crawley & Kagawa-Singer, 2007a).

The literature has documented disparities in hospice utilization by African-Americans due to cultural beliefs, inadequate income to maintain a caregiver at home, and lack of information about hospice care. (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Colon & Lyke, 2003; Jackson et al., 2000; Kapo et al., 2005; Reese et al., 1999; Rhodes et al., 2006; Torke, Garas, Sexson, & Branch, 2005; Welch et al., 2005). Blacks and Hispanics are significantly more likely to die at home, less likely to receive hospice care, and have shorter lengths of stay if they receive hospice care (Adams et al., 2006; Colon & Lyke, 2003; Enguidanos et al., 2005; Gordon, 1995; Lackan et al., 2004; Talamantes, Lawler, & Espino, 1995).

A neoclassic economic perspective might evaluate why communities of color do not choose hospice care. Feminist economists might speculate that more patients of color would choose hospice care if family caregivers, who are culturally sensitive, were reimbursed for their services (Strober, 2003). The findings of this study show increased deficiencies related to higher percentages of Hispanics in the county. More research is needed to examine the quality of care for-profit hospices provide to different races. Feminist theorists would insist on exploring the intersections of race, gender, and class in hospice care (Ferber & Nelson, 2003).

Trends in Gender Patient Characteristics and Predictors of Quality, Utilization and Cost

The regression analyses unexpectedly found that an increased percentage of female patients predicted a 15% decrease in complaints. The reasons for this can only be surmised. Perhaps women have illnesses that preclude them from actively participating

in their care, and they have no survivors to advocate for them; or, perhaps this reflects the socialization of women to accept their circumstances. This reason places aging (and dying) as an individual experience. Future research should explore structural factors and the quality of hospice care, as well as considerations of how the powerful influences of gender, class, and race might influence older, female hospice patients' ability to file complaints.

The second most important trend identified by this study was the more than half a percent increase per year in the percent of hospice patients who are women. The trend of gender difference in hospice patient characteristics predicts that by 2020 two-thirds of hospice patients in the United States will be women. And, combining the age trend observed in this study suggests that by 2020, 80% of hospice patients will be over 81 years of age.

The trend toward increased age of hospice patients and the increased percentage of female patients is likely to have a great impact on the hospice care women receive. Considering that older women are more likely to live in poverty (Estes, 2001d), it is essential to consider the state and its policy role in shaping hospice-care. Widowhood and divorce have a negative economic impact on a female spouse because it changes her social class and her identification and, therefore, the way individuals, institutions, and society treat her (Estes, 2001c). Today, by age 85, 60% of women live alone (Public Policy Institute of California, 2004). If women need hospice care, and if they cannot afford 24-hour a day care at home, and if they do not have family members (usually daughters) to care for them, they are at risk of being institutionalized.

Nursing homes are a major component of the Medical Industrial Complex and they are an example of the “aging enterprise” that defines the needs of the elderly in terms of profit-making business opportunities or commodities (Estes, 1979, 1988, 2001b). This study’s regression analysis showed that the only patient characteristic predicting increased income per patient is gender. Female patients earn \$162 more income for hospices than male patients. It is not surprising then that the Mann-Whitney *U* tests showed that for-profit hospices provide a higher mean percent of care to women than nonprofit hospices and nearly twice the percent of nursing home days of hospice care. These findings confirmed the findings of Buchanan, Choi, Wang and Ju (2004), who examined marital status and found that hospice residents in nursing homes were more likely to be older widowed women; however, the only research that could explain this phenomenon used the OSHPD data base and found that 26% of hospices would not admit patients lacking a full-time care giver (Lorenz et al., 2004).

Hospice care in California is rapidly becoming part of the Medical Industrial Complex in which market-based and profit-driven institutions, legitimized and financed by the state through Medicare and Medi-Cal, promote and reproduce long-term institutional care for women. Women should not be expected to provide care for dying husbands and parents without some protection for their wage-earning ability, their social security status, their disability benefits, and most significantly their own health. According to the literature, the stress of caregiving increases mortality risk by 63% (Schulz & Beach, 1999). The current system of hospice care reproduces the patriarchal subordinate family role of women in which their caregiving is ignored and uncompensated. In 1997, the value of caregiving in the United States was estimated at

\$196 billion annually, at a wage of \$8.18 per hour (Estes, 2001c; Jennings et al., 2003). Hospice care is a cost effective alternative to hospitalization in large part because of the unrecognized and unpaid caregiving of women.

Hospice care is on a path to become another “gendered institution” within the MIC, not unlike for-profit nursing home care. The path is legitimized by state reimbursement through Medicare and Medicaid. Feminist theorists challenge the policy path and institutional trajectory on which hospice care is traveling, which supports institutions that facilitate the state’s role in the accumulation of wealth for for-profit health industries while ignoring women’s contributions, roles and unique needs (Estes, 2001c). Traditional gender roles in caring for the elderly must be challenged.

In the near future, it is unlikely that a policy agenda can or will be launched to eliminate the multiple sources of lifelong “interlocking oppression” that women experience, which contribute to the traditional gendered systems of care that seek to maximize profits rather than to provide service to the community. This goal, however, should not be overlooked and will only be achieved through research that identifies gender and racial inequities and that contributes to policy discourse. This research and policy agenda must become part of the policy dialogue on the aging lest dying become completely commodified by the market-driven for-profit hospice industry.

Trends in Diagnosis and Diagnosis as a Predictor of Quality, Utilization and Cost

Changing trends in diagnoses were significant, showing a decrease in the percentage of hospice patients with cancer and an increase in the number of patients with non-cancer diagnoses. This is considered a positive change and reflects greater acceptance of hospice care by physicians and patients. The increase in the percentage of

patients with Alzheimer's disease and other dementias underscores a need for research to recommend improved standards of care for this new hospice population. Alzheimer's disease and dementia were predictors for a slightly increased length of stay and increased cost per patient. Cancer was a predictor of increased visits by nurses and all staff, increased percent of costs spent on nursing care, increased cost per patient, and decreased income per patient. Heart related diagnoses had predictions similar to cancer, with the exception of decreased income per patient. Heart related diagnoses also predicted a slightly longer length of stay. Digestive related illness predicted increased visits by all staff and increased cost per patient.

Market characteristics as Predictors of Hospice Quality, Utilization and Cost

With the exception of per capita income and percent Hispanic, the most surprising finding was the insignificance of market variables. The prediction of increased deficiencies in counties with a higher per capita income may be related to a high level of social participation and understanding of how to use the system and report possible deficiencies.

Conclusion

For-profit hospices reflect the business values of efficiency and competition rather than the societal values of charity and compassion, upon which the hospice movement was founded. The ideological climate in health care today, characterized by efficiency and competition, has so influenced nonprofit hospices that they may be changing their structures to be more like for-profit hospices to stay competitive and stay in business. To date, research has shown differences in quality only in nursing homes. This finding may

be an artifact of increased scrutiny of nursing homes, which makes the hospices that provide care in nursing homes subject to higher scrutiny.

Not surprisingly, when compared with for-profit hospices, nonprofit hospices provided more days at home and cared for more cancer patients who had shorter lengths of stay. Tax law requires that nonprofit hospices have a social mission and are less likely than for-profit hospices to strategically select a case mix of patients who require less intense care.

Chain affiliated hospices include for-profit and nonprofit organizations and serve significantly more patients and have more patient days than freestanding hospices. This can be explained by their “branding” in the marketplace, resulting in an increased market share. In addition, they had more referrals from insurers and HMOs, the result no doubt of business practices that market to insurers. Hospices affiliated with chains, however, had an increased cost per patient, which might also be attributed to business costs unrelated to patient care. Hospice chains were 2.05 times as likely to have complaints filed; however, association with a chain was not found to be a predictor of deficiencies. This might be explained by systems within these chains that standardize preparation for inspections.

The growth of for-profit and hospice chains is supported by the resource dependency theory. This study found that for-profit hospices spent a smaller percentage of their total budget on nursing care. Motivated by efficiency and profitability, economic rationality, rather than rationality based on norms and traditions, provides for-profit hospices with a competitive advantage. For-profit hospices also have the advantage of organizational and interfirm strategic alliances that assist in procuring assets,

competencies, and capabilities. Strategic alliances explain the finding that for-profit hospices receive more referrals from long-term care facilities, which are also for-profit businesses.

In a 2004 report on investing in hospices, Shattuck and Hammond, an investment bank, suggested that once a hospice achieves an average daily census of 30 to 40 patients per month, 10% profit can be realized and profits will grow larger if the patient base increases. According to these investment experts, the potential margin for growth is significant because hospice does not require capital to expand services.

Changes in hospice patient characteristics including the increasing use of hospices by patients over 81 years old, the increase in the percentage of women in hospice care, and the disparities of hospice use by African-Americans and Hispanics, combined with the significant trend of new for-profit hospices requires that this study's findings be considered within a political economy framework (Estes, 2001). The policy interventions that emerge in the context of capitalist society along with the socio-economic determinants of access to appropriate care will construct the individual and family experience of end-of-life care.

In a capitalist society, political influence or dominance shapes health policies. For-profit hospices and their parent corporations donate considerable funds to political campaigns. In the 2004 election cycle, two of the major for-profit chains operating in California were among the top 20 contributors to federal candidates and parties (Open Secrets, 2007). Serving at the pleasure of elected officials, government regulators oversee (or fail to oversee) hospice care.

As suggested by Quadagno (2005) and Estes (2001), capitalist interests unduly influence the policy agenda. For example, the state (the government) has taken no action to improve access to care for minorities nor has it established regulations that measure the quality of hospice care. Formal complaints filed with the licensing agency are an inadequate measure of quality because they are most likely underreported because of the unequal power relations confronting patients and families seeking end-of-life care. The last thing a family needs is to struggle with the health care system over the care of their dying loved one. Further, the small number of deficiencies reported during this study's 6 years reflects the lack of licensure inspection of hospices in California. The lack of regulatory oversight of hospice care illustrates how little dying people are valued.

Significance

Medicare pays for over 80% of hospice care. Five percent of Medicare beneficiaries die each year. As the number of Medicare beneficiaries peaks during the next 20 years, the demand for hospice care will also peak. Quality, utilization, and the implications of the increasing demand for and rapid growth of hospice services in California should concern policymakers. The findings of this study confirm that there are significant differences between for-profit and nonprofit hospices. The lack of complaints and deficiency data underscores the need to increase monitoring of quality. It also confirms the trend of substantial growth in hospice care in California. This growth should stimulate more not less regulatory monitoring.

Because women are and will be the primary users of hospice care, the quality of hospice care is of utmost importance. Decreased quality, often associated with for-profit long-term care services, may well emerge as for-profit hospices begin to dominate the

market. The policies that regulate hospice care have ignored the fate of dying women and the lives of their caregivers (largely women both paid and unpaid). Finally, no research has addressed quality measurement in California hospices.

Limitations

First, the findings of this research are not generalizable outside of California, although they provide a basis for an ongoing analysis of changes in hospice characteristics within California. Second, the quality of the data can be questioned because OSHPD does not review data for accuracy or completeness. This was clear from the amount of cleaning that was required before analysis. In addition, the sample size of only 210 hospices limited power of analysis, which may explain the lack of identification of market characteristics as significant predictors.

The most significant limitation is the questionable legitimacy of the quality outcome definitions. The lack of standardized measures to evaluate quality end-of-life care across the functional scale draws into question the appropriateness of the selected outcome variables. The very small number of complaints and deficiencies are symptomatic of a system that lacks an efficient complaint process and lacks systematic inspection by regulators to identify deficiencies. In April 2007, the USDHHS OIG filed a report that ranked California among the top four states in which timely routine inspections were not conducted. The inspection standard for licensure compliance is at least every 6 years. This standard is twice as long as the standard for long-term care and three times as long as the standard for acute care. Although patients are subjected to dangerous conditions in acute and long-term care, quality, not just safety, should be the goal of licensure standards and inspections for complaints.

Complaints as a measure of quality are often questioned because most are filed by surrogates, often family members, rather than patients. And, although hospice care is the only Medicare-reimbursed benefit that includes the family, quality-of-care measures for patients need to be developed. Although services provided by professional and volunteer staff have been identified as potential indicators for quality (Donaldson, M.S., and Field, M.J., 1998), this study included only professional services.

Implications for future research

Several areas for future research are apparent. The study's findings recommend that market variables should be examined more closely to determine if a lack of power in the sample size precluded the identification of market variables as predictors of quality, utilization, and cost. Further study using a panel regression on the entire 6 years of data might reveal significant market variables. The size of this study's sample impeded the measurement of volunteer hours of care, spiritual and counseling care, and homemaker care. A panel regression over the 6-year period could include large enough samples of these components of care, which are so unique to hospices. It would also be useful to compare these outcomes with another large hospice market, such as Florida.

The definition of quality and how it should be measured in hospice care is currently under discussion at the state and national levels. National regulations, which for the most part articulate the processes by which physicians implement treatment orders, have not been changed since Medicare added the hospice benefit. California has a current workgroup on the quality of end-of-life care, and a pilot project might be considered. Further, comparisons between measures and monitoring of quality in

California and other states, including frequency of evaluation for licensure renewal, could contribute to the national body of standards for hospice care.

As hospice care grows, the importance of monitoring quality and preserving the interdisciplinary model of care, including spiritual, emotional, and volunteer care, may be jeopardized by the isomorphism that accompanies competition in health care settings. Increased oversight is essential during this time to preserve this unique care model.

Concluding thoughts

The prescient works of scholars Estes, Swan, Berthgold, Spohn, Swan, Binney, Alford, Egan, Schlesinger, Harrington, Pellow, and Kitchner have described the effects of the transformation of health services from the nonprofit sector to the for-profit sector. This study's findings confirm that for-profit hospices control - or manipulate - costs by selecting the types of patients they admit for services. For-profit hospices are more likely to admit patients with noncancer diagnoses in long-term care institutional settings. The neoliberal values of profit, efficiency, and competition are replacing the societal values of equitable access to compassionate and comprehensive hospice care, along with the values of charity and compassion upon which the hospice movement was founded. The market ideology in today's health care culture, characterized by competition and efficiency, has begun to seep into hospice care. To impede for-profit hospices from further infiltrating and colonizing hospice care in California, meaningful measurable quality standards with public reporting must be developed and enforced. End-of-life care services must include all needed services, provided by paid caregivers in whatever setting people choose to spend their final days.

Social struggles and dominant power relations result in public policies. While hospice is intended to assist in ending suffering at the end of life, it benefits capitalist interests because of the undue influence corporate interests exert on the policy agenda(s) (Estes, 1979, 1988; Quadagno, 1999) This is a critical time for California. It can choose not to follow the policy and organizational path of hospices in other states. California can join New York and set higher standards for hospice care and enforce them, which may deter the for-profit colonization of hospice care that has occurred in many other states. California can value the reproductive unpaid labor of women who are the predominant caregivers by giving them social benefits. California can create another path to ensure access to quality, compassionate, family-centered, end-of-life care for all its residents.

Public policy, or its lack, fosters and reifies organizational change. Hospice care in California is fertile ground for the growth of the Medical Industrial Complex as the aging enterprise adds to the growing MIC. This is a critical time for “Stage 3 feminism” or the “care movement,” which is organized around “the right of families to care for and be helped to care for their members; the right of paid care givers to give humane, high-quality care without compromising their own well-being; and the right for people who need care to get it’ (Matthaei, 2001) as quoted in Estes, Biggs, and Phillipson (2003, p. 61). Advocates for hospice care must wrest control of “old age policy” in California (and other states) from market forces to develop and to implement policies that value caregiving by rebalancing the gender-biased policies that have perpetuated public-private responsibilities for long-term and end-of-life care and that integrate caregiving into the

economy. This is the time for public sociologists and advocates to act, or the market will fill the void and irrevocably change hospice care.

REFERENCES

- Aaronson, W. E., Zinn, J. S., & Rosko, M. D. (1994). Do for-profit and not-for-profit nursing homes behave differently? *The Gerontologist*, *34*(6), 775-786.
- Acker, J. (1998). Class, gender and the relations of distribution. *Signs*, *13*(3), 473-493.
- Adams, C. E., Horn, K., & Bader, J. (2006). Hispanic access to hospice services in a predominantly Hispanic community. *American Journal of Hospice & Palliative Medicine*, *23*(1), 9-16.
- Alford, R. R., & Friedland, R. (1985). *Powers of theory: Capitalism, the state, and democracy*. New York: Cambridge University Press.
- Alter, C. (1998). Bureaucracy and democracy in organizations. In W. W. Powell & E. S. Clemens (Eds.), *Private Action and the Public Good* (pp. 258-271). New Haven: Yale University Press.
- Andersen, M. L., & Taylor, H. F. (2000). *Sociology: Understanding a diverse society*. Belmont, California: Wadsworth Thomson Learning.
- Andreski, S. (1984). *Max Weber's insights and errors*. London: RKP.
- Andrews, C. (1995). *Profit Fever: The drive to corporatize health care and how to stop it*. Monroe, ME: Common Courage Press.
- Baker, L. C. (2001). Measuring competition in health care markets. *Health Services Research*, *36*(1), 223-251.
- Banaszak-Holl, J., & Mor, V. (1996). Differences in patient demographics and expenditures among Medicare hospice providers. *Hospice Journal*, *11*(1-19).

- Banaszak-Holl, J., Zinn, J. S., & Mor, V. (1996). The impact of market and organizational characteristics on nursing care facility service: A resource dependency perspective. *Health Services Research, 31*(1), 97-117.
- Barr, D. A., Lee, P. R., & Benjamin, A. E. (2003). Health care and health care policy in a changing world. In P. R. Lee, C. L. Estes & F. M. Rodriguez (Eds.), *The Nation's Health* (Seventh ed., pp. 199-212). Boston: Jones and Bartlett Publishers.
- Bergthold, L. A., Estes, C. L., & Villanueva, A. (1990). Public light and private dark: the privatization of home health services for the elderly in the U. S. *Home Health Care Services Quarterly, 11*(3-4), 6-33.
- Blank, R. M., & Reimers, C. W. (2003). Economics, policy analysis and feminism. In M. A. Ferber & J. A. Nelson (Eds.), *Feminist Economics Today: Beyond Economic Man*. Chicago: University of Chicago Press.
- Born, W., Greiner, K. A., Sylvia, E., Butler, J., & Ahluwalia, J. S. (2004). Knowledge, attitudes and beliefs about end-of-life care among inner-city African Americans and Latinos. *Journal of Palliative Medicine, 7*(22), 247256.
- Brock, D. B., & Foley, D. J. (1998). Demography and epidemiology of dying in the U.S. with emphasis on deaths of older persons. *The Hospice Journal, 13*(1/2), 49-60.
- Brown, P., Zavestoske, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Altman, R. G. (2004). Embodied health movements: new approaches to social movements in health. *Sociology of Health and Illness, 26*(1), 50-80.
- Brumley, R. D., Enguidanos, S., & Cherin, D. A. (2003). Effectiveness of a home-based palliative care program for end-of-life. *Journal of Palliative Medicine, 6*(5), 715-724.

- Buchanan, R. J., Choi, M., Wang, S., & Ju, H. (2004). End-Of-Life Care in Nursing Homes: Residents in Hospice compared to Other End-Stage Residents. *Journal of Palliative Medicine*, 7(2), 221-232.
- Buck, K. J. (2005). *Rights of Passage: Reforming care of the dying 1956-1986*. Nursing, George Mason University, Fairfax, Virginia.
- Budrys, G. (2005). *Our unsystematic health care system* (2nd ed.). Lanham, Maryland: Rowman & Littlefield Publishers.
- Callahan, D., & Wasunna, A. A. (2006). *Medicine and the market: Equity v. choice*. Baltimore, MD: The Johns Hopkins University Press.
- Campbell, D. E., Lynn, J., Louis, T. A., & Shugarman, L. R. (2004). Medicare program expenditures associated with hospice use. *Ann Intern Med*, 140(4), 269-277.
- Caring. (2002). CMS releases new guidelines for hospice services to SNF residents. *Caring*, 21(7), 46-47.
- Carlson, D. A., Gallo, W. T., & Bradley, E. H. (2004). Ownership status and patterns of care in hospice: Results from the national home and hospice care survey. *Medical Care*, 42(5), 432-438.
- Casalino, L. P. (2003). Focused factories? Physician-owned special facilities. *Health Affairs*.
- Casarett, D. (2001). Differences between patients referred to hospice from academic vs. non-academic settings. *Journal of Pain and Symptom Management*, 21(3), 197-203.
- Cassel, C. K., & Demel, B. (2001). Remembering death: public policy in the USA. *Journal of the Royal Society of Medicine*, 94(September), 433-436.

- Centers for Disease Control and Prevention National Center for Health Statistics. (2003a, November 14, 2005). *Hospice Care*. Retrieved February 8, 2006, from <http://www.cdc.gov/nchs/fastats/hospice.htm>
- Centers for Disease Control and Prevention National Center for Health Statistics. (2003b, November 14, 2005). *Hospice Care*. Retrieved February 8, 2006, from <http://www.cdc.gov/nchs/fastats/hospice.htm>
- Charmaz, K. (1980). *The social reality of death: death in contemporary America*. Reading, MA: Addison-Wesley.
- CHFC. (2007). *Health Care Costs 101*. Retrieved March 12, 2007, 2007, from www.chfc.org
- Christakis, N. A. (1994). Timing of referral of terminally ill patients to an outpatient hospice. *Journal of General Internal Medicine*, 9, 314-320.
- Christakis, N. A., & Escarce, J. J. (1996). Survival of Medicare patients after enrollment in hospice programs. *The New England Journal of Medicine*, 335(3), 172-178.
- Christakis, N. A., & Iwashyna, T. J. (2000). Impact of individual and market factors on the timing of initiation of hospice terminal care. *Medical Care*, 38(5), 528-541.
- Ciscel, D. H., & Heath, J. H. (2001). To market, to market: imperial capitalism's destruction of social capital and the family. *Review of Radical Political Economics*, 33(4), 401-412.
- Cohen, K. P. (1979). *Hospice: Prescription for terminal care*. Germantown, Maryland: Aspen Systems Corporation.

- Collins, C. A., Estes, C. L., & Bradsher, J. E. (2001). Inequality and aging. In C. L. Estes & Associates. (Eds.), *Social policy & aging* (pp. 137-164). Thousand Oaks, California: Sage.
- Collins, P. H. (1990, 1991). *Black feminist thought: knowledge, consciousness, and the politics of empowerment*. Boston: Unwin-Hyman.
- Colon, M., & Lyke, J. (2003). Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *American Journal of Hospice & Palliative Care*, 20(3), 182-190.
- Connell, R. W. (1987). *Gender and power: Society, the person and sexual politics*. Sydney: Allen and Unwin.
- Conner, S. R., Tecca, M., LundPerson, J., & Teno, J. (2004). Measuring hospice care: The national hospice and palliative care organization national hospice data set. *Journal of Pain and Symptom Management*, 28(4), 316-328.
- Conrad, P. (2004). The medicalization of American society. In P. Conrad (Ed.), *The sociology of health and illness* (Seventh ed., pp. 430-431). New York: Worth Publishers.
- Conrad, P. (2005). The shifting engines of medicalization. *Journal of Health and Social Behavior*, 46(1), 3-14.
- Conrad, P., & Leiter, V. (2004). Medicalization, markets and consumers. *Journal of Health and Social Behavior*, 45(Extra Issue), 158-176.
- Conrad, P., & Schneider, J. W. (1980/1992). *Deviance and medicalization: From badness to sickness* (Expanded ed.). Philadelphia: Temple University Press.

- Conrad, P., & Schneider, J. W. (2004). Professionalization, monopoly, and the structure of medical practice. In P. Conrad (Ed.), *The sociology of health and illness* (Seventh ed., pp. 170-176). New York: Worth Publishers.
- Consumer Reports. (1996, October, 1006). Can HMOs help solve the health-care crisis? *Consumer Reports*, 28-35.
- Corning, P. (2006). *History of Medicare: The Fourth Round 1957-1965*. Retrieved July 28, 2006, from <http://www.ssa.gov/history/corningchap4.html>
- Covinsky, K. E., Eng, C., Lui, L.-Y., Sands, L. P., Sehgal, A. R., Walter, L. C., et al. (2001). Reduced employment in caregivers of frail elders: Impact of ethnicity, patient clinical characteristics, and caregiver characteristics. *Journal of Gerontology: Medical Sciences*, 56A(11), M707-M713.
- Crawley, L. M., & Kagawa-Singer, M. (2007a). *Racial, Cultural, and Ethnic Factors Affecting the Quality of End-of-Life Care in California*. Retrieved April 29, 2007, 2007, from <http://www.chcf.org/documents/chronicdisease/AHCJEOLBriefing.pdf>
- Crawley, L. M., & Kagawa-Singer, M. (2007b). *Racial, cultural, and ethnic factors affecting the quality of end-of-life care in California: findings and recommendations*. Oakland: California Health Care Foundation.
- Daugherty, C. K. (2004). Examining ethical dilemmas as obstacles to hospice and palliative care for advanced cancer patients. *Cancer Investigation*, 22(1), 123-131.
- Dawson, G., Hatt, S., Watson-Brown, L., Baxter, A., & Bertaux, N. (2000). *Market, state and feminism: The economics of feminist policy*. Northampton Massachusetts: Edward Elgar Publishing, Inc.

- De Vries, R. G. (1981). Birth and Death: social construction at the poles of existence. *Social Forces*, 59(4), 1074-1093.
- Detsky, A. S. (1978). *The economic foundations of national health policy*. Cambridge, MA: Ballinger Publishing Company.
- DHHS. (2006). *A Common Thread of Service: An Historical Guide to HEW*. Retrieved July 28, 2006, from <http://aspe.os.dhhs.gov/hewhistory.htm#Cohen>
- DiMaggio, P., & Powell, W. W. (1983). The iron cage revisited: Institutional isomorphism and collective rationality in organizational fields. *American Sociological Review*, 48, 147-160.
- Dombi, W. (2004). Profit margins projected to continue downward spiral. *Caring*, 34-38.
- Donaldson, M. S. (1998). The importance of measuring quality of care at the end of life. *The Hospice Journal*, 12(1-2), 117-138.
- Donaldson, M. S., & Field, M. J. (1998). Measuring quality of care at the end of life. *Archives of Internal Medicine*, 158, 121-128.
- Emanuel, E. J., Fairclough, D. L., Slutsman, J., Alpert, H., Baldwin, D., & Emanuel, L. L. (1999). Assistance from family members, friends, paid caregivers, and volunteers in the care of terminally ill patients. *New England Journal of Medicine*, 341(13), 956-963.
- England, P. (2003). Separative and soluable selves. In M. A. Ferber & J. A. Nelson (Eds.), *Feminist economics today: Beyond economic man*. Chicago: University of Chicago Press.

- England, P., & Folbre, N. (2003). Contracting for Care. In M. A. Ferber & J. A. Nelson (Eds.), *Feminist Economics Today: Beyond Economic Man*. Chicago: University of Chicago.
- Enguidanos, S., Yip, J., & Wilber, K. (2005). Ethnic variation in site of death of older adults dually eligible for Medicaid and Medicare. *Journal of the American Geriatrics Society*, 53(8), 1411-1416.
- Erickson, S. E., Fried, T. R., Cherlin, E., Johnson-Hurzeler, R., Horwitz, S., & Bradley, E. H. (2002). The effect of inpatient hospice units on hospice use post-admission. *Home Health Care Services Quarterly*, 21(2), 73-83.
- Estes, C. L. (1979, 1988). *The aging enterprise*. San Francisco: Jossey-Bass Publishers.
- Estes, C. L. (1988). *The Aging Enterprise*. San Francisco: Jossey-Bass Publishers.
- Estes, C. L. (1997). Privatization, The welfare state and aging: The Reagan-Bush legacy. In P. R. Lee, C. L. Estes & L. Close (Eds.), *The Nation's health* (Fifth ed., pp. 199-209). Boston: Jones and Bartlett Publishers.
- Estes, C. L. (2001a). Crisis, the welfare state, and aging. In C. L. Estes & Associates. (Eds.), *Social policy & aging* (pp. 95-117). Thousand Oaks, California: Sage.
- Estes, C. L. (2001b). Political economy of aging. In C. L. Estes & Associates. (Eds.), *Social policy & aging* (pp. 1-18). Thousand Oaks, California: Sage Publications.
- Estes, C. L. (2001c). Sex and gender in the political economy of aging. In C. L. Estes & Associates. (Eds.), *Social policy & aging* (pp. 119-136). Thousand Oaks, California: Sage.

- Estes, C. L. (2001d). Sex and Gender in the Political Economy of Aging. In Associates (Ed.), *Social Policy & Aging* (pp. 119-135). Thousand Oaks, California: Sage Publications.
- Estes, C. L. (2006). Critical feminist perspectives, Aging, and social policy. In J. Baars, D. Dannefer, C. Phillipson & A. Walker (Eds.), *Aging, globalization, and inequality*. Amityville, NY: Baywood Pub.
- Estes, C. L., & Alford, R. R. (1990a). Systemic crisis and nonprofit sector: Toward a political economy of the nonprofit health and social services sector. *Theory and Society*, 19(2), 173-198.
- Estes, C. L., & Alford, R. R. (1990b). Systemic crisis and the nonprofit field: toward a political economy of the nonprofit health and social services field. *Theory and Society*, 19(2), 173-198.
- Estes, C. L., Alford, R. R., & Egan, A. H. (2001). The transformation of the nonprofit sector: Systemic crisis and the political economy of aging services. In C. L. Estes & Associates. (Eds.), *Social policy & aging* (pp. 61-94). Thousand Oaks, California: Sage Publishing Inc.
- Estes, C. L., Biggs, S., & Phillipson, C. (2003). Social theory, social policy and ageing. In C. L. Estes & Associates. (Eds.). Berkshire, England: Open University Press.
- Estes, C. L., & Linkins, K. W. (2000). Critical perspectives on health and aging. In G. L. Albrecht, R. Fitzpatrick & S. Scrimshaw (Eds.), *Handbook of social studies in health and medicine* (pp. 154-172). Thousand Oaks, CA: Sage Publications.
- Estes, C. L., & Swan, J. H. (1994). Privatization, system membership, and access to home health care for the elderly. *The Milbank Quarterly*, 72(2), 277-298.

- Estes, C. L., Swan, J. H., & Associates. (1993). *The long term care crisis*. Newbury Park, CA: Sage Publications.
- Estes, C. L., Swan, J. H., Bergthold, L. A., & Spohn, P. H. (1992). Running as fast as they can: organizational changes in home health care. *Home Health Care Services Quarterly*, 13(1-2), 35-69.
- Estes, C. L., Wallace, S. P., Linkins, K. W., & Binney, E. A. (2001). The medicalization and commodification of aging and the privatization and rationalization of old age policy. In C. L. Estes & Associates. (Eds.), *Social Policy & Aging*. Thousand Oaks, California: Sage Publications Inc.
- Estes, C. L., & Weitz, T. A. (2000). Aging and gender: A new voice on the women's health agenda. In P. R. Lee & C. L. Estes (Eds.), *The nation's health* (6th edition ed., pp. 206-214). Boston: Jones & Bartlett.
- Estes, C. L., & Zulman, D. M. (2007). Informalization of long-term caregiving: A gendered lens. In C. Harrington & C. L. Estes (Eds.), *Health policy: Crisis and reform in the U.S. health care delivery system* (Fifth ed., pp. 142-151). Sudbury, MA: Jones and Bartlett Publishers.
- Federal Register: OIG Special Fraud Alert: Fraud and Abuse in Nursing Home Arrangements With Hospice, (1998).
- Feldstein, P. (1996). The emergence of market competition in the U.S. health care system. In P. Feldstein (Ed.), *The politics of health legislation* (2nd ed.). Chicago: Health Administration Press.
- Feldstein, P. (1998a). Introduction to the economics of medical care. In *Health care economics* (5th ed.). Albany: Delmar.

- Feldstein, P. (1998b). The market for long-term care services. In *Health care economics* (5th ed.). Albany: Delmar.
- Ferber, M. A., & Nelson, J. A. (Eds.). (2003). *Feminist economics today: Beyond economic man*. Chicago: University of Chicago Press.
- Field, D., & Johnson, I. (1993). Volunteers in the British hospice movement. In D. Clark (Ed.), *The sociology of death: Theory, culture, practice*. Cambridge, MA: Blackwell Publishers/The Sociological Review.
- Field, M. J., & Cassel, C. K. (Eds.). (1997). *Approaching death: Improving care at the end of life*. Washington, DC: National Academy Press.
- Fisher, E. S., Wennberg, J. E., Stukel, T. A., Skinner, J. S., Sharp, S. M., Freeman, J. L., et al. (2000). Associations among hospital capacity, utilization, and mortality of U.S. Medicare beneficiaries, controlling for sociodemographic factors. *Health Services Research, 34*(6), 1351-1362.
- Foley, K. M., & Gelband, H. (Eds.). (2001). *Improving palliative care for cancer*. Washington D.C.: National Academy Press.
- Folliart, D. E., Clausen, M., & Siljeström, C. (2001). Bereavement practices among California Hospices: Results of a statewide survey. *Death Studies, 25*(5), 461-467.
- Folland, S., Goodman, A., & Stano, M. (2004a). Basic economics tools. In *The economics of health and health care* (4th ed.). Upper Saddle River, New Jersey: Pearson/Prentice Hall.
- Folland, S., Goodman, A., & Stano, M. (2004b). Hospice and long-term care. In *The economics of health and health care* (4th ed.). Upper Saddle River, NJ: Pearson/Prentice Hall.

- Folland, S., Goodman, A., & Stano, M. (2004c). Microeconomic tools for health economics. In *The economics of health and health Care* (4th ed.). Upper Saddle River, NJ: Pearson/Prentice Hall.
- Foucault, M. (1973). *The birth of the clinic: An archaeology of medical perception*. London: Tavistock.
- Freidson, E. (1970). *Profession of medicine*. New York: Dodd, Mead.
- Freund, J. (1969). *The Sociology of Max Weber* (M. Ilford, Trans.). New York: Vintage Books Random House Inc.
- Fuchs, V. R. (1993). *The future of health policy*. Cambridge, MA: Harvard University Press.
- Gage, B. (2000). *Medicare's hospice benefit: Use and expenditures 1996 cohort*. Retrieved February 8, 2006, from <http://aspe.hhs.gov/daltcp/reports/96useesp.htm>
- Gage, B., Miller, S. C., Mor, V., Jackson, B., & Harvell, J. (2000, March 2000). *Synthesis and analysis of Medicare's hospice benefit: Executive summary and recommendations*. Retrieved February 8, 2006, from <http://aspe.hhs.gov/dalcp/reports/samhbes.htm>
- GAO. (2004). *Medicare hospice care: Modifications to payment methodology may be warranted* (Report to the Committee on Finance, US Senate, and Committee on Ways and Means, House of Representatives No. GAO-05-42). Washington D.C.: Government Accounting Office.
- Geyman, J. (2006). *Shredding the social contract: The privatization of Medicare*. Monroe, ME: Common Courage Press.

- Goldstein, N. E., Concato, J., Bradley, E. H., O'Leary, J. R., & Fried, T. R. (2005). Doctor - patient communication about prognosis: the influence of race and financial status. *Journal of Palliative Medicine*, 8(5), 998-1004.
- Gordon, A. K. (1995). Deterrents to access and services for blacks and Hispanics: the Medicare Hospice Benefit, healthcare utilization, and cultural barriers. *The Hospice Journal*, 10(2), 65-83.
- Gordon, A. K. (1996). Hospice and minorities: a national study of organizational access and practice. *The Hospice Journal*, 11(1), 49-70.
- Government, Accounting, & Office. (2004). *Medicare hospice care: Modifications to payment methodology may be warranted* (Report to the Committee on Finance, US Senate, and Committee on Ways and Means, House of Representatives No. GAO-05-42). Washington D.C.: Government Accounting Office.
- Government Accounting Office. (2004). *Medicare hospice care: Modifications to payment methodology may be warranted* (Report to the Committee on Finance, US Senate, and Committee on Ways and Means, House of Representatives No. GAO-05-42). Washington D.C.: Government Accounting Office.
- Gray, B. H. (Ed.). (1986). *For-Profit enterprise in health care*. Washington D.C.: National Academy Press.
- Greiner, K. A., Perera, S., & Ahluwalia, J. S. (2003). Hospice usage by minorities in the last year of life: results from the national mortality followback survey. *Journal of the American Geriatrics Society*, 51(7), 970-978.

- Gronbjerg, K. A. (1998). Markets, politics, and charity: Nonprofits in the political economy. In W. W. Powell & E. S. Clemens (Eds.), *Private Action and the Public Good* (pp. 137-162). New Haven: Yale University Press.
- Habermas, J. (1975). Crisis Tendencies in Advanced Capitalism. In t. T. McCarthy) (Ed.), *Legitimation Crisis* (pp. 33-94). Boston: Beacon Press.
- Hacker, J. S. (2002). *The divided welfare state: The battle over public and private social benefits in the United States*. New York: Cambridge University Press.
- Hamilton, V. (1993). The Medicare hospice benefit: The effectiveness of price incentives in health care policy. *The Rand Journal of Economics*, 24(4), 605-624.
- Hamilton, V. (1994). The impact of ownership form and regulatory measures on firm behavior: A study of hospices. *Nonprofit Management & Leadership*, 4(4), 415-431.
- Han, B., Remsburg, R. E., & Iwashyna, T. J. (2006). Differences in hospice use between black and white patients during the period 1992 through 2000. *Medical Care*, 44(8), 731-737.
- Han, B., Remsburg, R. E., McAuley, W. J., Keay, T. J., & Travis, S. S. (2006). National trends in adult hospice use: 1991-1992 to 1999-2000. *Health Affairs*, 25(3), 792-799.
- Hargrave, A., & Ashwin, A. (1996). *Economists - Theories*. Retrieved March 19, 2006, 2006, from <http://www.bized.ac.uk/virtual/economy/library/economists>
- Harrington, C. (1991). The nursing home industry: A structural analysis. In M. Minkler & C. L. Estes (Eds.), *Critical perspectives on aging: The political and moral economy of growing old* (pp. 153-164). Amityville, NY: Baywood.

- Harrington, C., O'Meara, J., & Kang, T. (2006). *Staffing and quality in California's nursing Homes*. Oakland, CA: California Health Care Foundation.
- Harrington, C., & O'Meara, J. (2004). *Report on California's nursing homes, home health agencies and hospice Programs* (Report). Oakland: California HealthCare Foundation.
- Harrington, C., Swan, J. H., & Carrillo, H. (2006). Nurse staffing levels and Medicaid Reimbursement rates in nursing facilities. *Health Research and Education Trust, in print*.
- Harrington, C., Wollhandler, S., Mullan, J., Carrillo, H., & Himmelstein, D. U. (2001). Does investor ownership of nursing homes compromise the quality of care? *American Journal of Public Health, 91*(9), 1452-1455.
- Harrington, C., Zimmerman, D., Karon, S., Robinson, J., & Beutel, P. (2000). Nursing home staffing and its relationship to deficiencies. *Journal of Gerontology, 55*(B), S278-287.
- Harrington, M. (1962). *The other America. Poverty in the United States*. New York: Macmillan.
- Harting, D. (1995, Feb. 06, 1995). Across America, more entrepreneurs are getting onto the hospice business. *CNY Business Journal*.
- Harvey, D. (2005). *A brief history of neoliberalism*. Oxford: Oxford University Press.
- Hastings, J. B. (1993). *A trajectory model of social movement development: The case of hospice in America*. Unpublished doctoral dissertation, Brown University, Providence, Rhode Island.

- Haupt, B. J. (2003). *Characteristics of hospice care discharges and their length of service: United States, 2000*. Washington D.C.: U.S. Department of Health and Humans Services Centers for Disease Control and Prevention National Center for Health Statistics.
- Hayman, J. A., Langa, K. M., Kabeto, M. U., Katz, S. J., DeMonner, S. M., Chernew, M. E., et al. (2001). Estimating the cost of informal caregiving for elderly patients with cancer. *Journal of Clinical Oncology*, 19(13), 3219-3225.
- Hecl, H. (1986). Reaganism and the search for a public philosophy. In J. L. Palmer (Ed.), *Perspectives on the Reagan years*. Washington D.C.: The Urban Institute.
- Herbst, L. (2004). Hospice care at the end of life. *Clinics in Geriatric Medicine*, 20, 753-765.
- Hewitson, G. (1999). *Feminist economics: Interrogating the masculinity of rational Man*: Edwin Elgar Publications.
- Hoffman, D. E., & Tarzian, A. J. (2005). Dying in America - An examination of policies that deter adequate end-of-life care. *The Journal of Law, Medicine & Ethics*, Summer, 294-309.
- Howle, E. M. (2007). *Department of Health Services: Its' Licensing and Certification Division is struggling to meet State and Federal oversight requirements for Skilled Nursing Facilities* (Auditor's Report No. 2006-106). Sacramento: California State Auditor.
- HRSA, U. D. (2005). <ftp://ftp.hrsa.gov/ruralhealth/eligibility>, March 2007, from <ftp://ftp.hrsa.gov/ruralhealth/eligibility>

- Illich, I. (1976). *Limits to medicine: Medical nemesis: The expropriation of health*.
London: Marion Boyars.
- Iwashyna, T. J., Chang, V. W., Zhang, J. X., & Christakis, N. A. (2002). The lack of effect of market structure on hospice use. *Health Services Research, 37*(6), 1531-1551.
- Iwashyna, T. J., Zhang, J. X., & Christakis, N. A. (2002). Disease-specific patterns of hospice and related healthcare use in an incidence cohort of seriously ill elderly patients. *Journal of Palliative Medicine, 5*(4), 531-538.
- Jackson, F., Schim, S. M., Seely, S., Grunow, K., & Baker, J. (2000). Barriers to hospice care for African Americans problems and solutions. *Journal of Hospice and Palliative Nursing, 2*(2), 65-72.
- Jacobs, P. (1980). *The economics of health and medical care*. Baltimore: University Park Press.
- James, N., & Field, D. (1992). The Routinization of hospice: charisma and bureaucratization. *Social Science and Medicine, 34*(12), 1363-1375.
- Jennings, B., Ryndes, T., D'Onofrio, C. N., & Baily, M. A. (2003). Access to hospice care: Expanding boundaries, overcoming barriers. *The Hastings Center Special Supplement, S1-S62*.
- Johnson, K. S., Kuchibhatala, M., Sloane, R. J., Tanis, D., Galanos, A. N., & Tulsky, J. A. (2005). Ethnic differences in the place of death of elderly hospice enrollees. *Journal of the American Geriatrics Society, 53*(12), 2209-2215.

- Johnson, M. W. (1999). Governing hospice projects: A review of governance, leadership, and management as seen in the foundation of the modern hospice movement. *Corporate Governance*, 7(1), 21-30.
- Johnson, R. W. (2002). *Last Acts: Means to a better end: A report on dying in America today*. Washington DC: Last Acts National Program.
- Joranson, D. (1994). *Are Health-Care Reimbursement Policies a Barrier to Acute and Cancer Pain Management?* Retrieved October 18, 2005, 2005, from <http://www.medsch.wisc.edu/painpolicy/publicat/94jpsma.htm>
- Kaiser Family Foundation. (2004). *Coverage & access / Aetna to launch new health plan covering hospice care*. Retrieved May 5, 2007, from http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=3&DR_ID=23470
- Kapo, J., Macmoran, H., & Casarett, D. (2005). "Lost to follow-up": Ethnic disparities in continuity of hospice care at the end of Life. *Journal of Palliative Medicine*, 8(3), 603-608.
- Kidder, D. (1992). Health Services Research
The effects of hospice coverage on Medicare expenditures., v27(n2), p195(123).
- Kitchner, M., & Harrington, C. (2004). The U.S. Long-term care field: A dialectic analysis of institutional dynamics. *Journal of Health and Social Behavior*, 45(Extra Issue), 87-101.
- Kübler-Ross, E. (1969). *On death and dying*. New York: Macmillan House.
- Kuumba, M. B. (2001). *Gender and social movements*. Walnut Creek, California: Alta Mira Press.

- Lackan, N. A., Ostir, G. V., Freeman, J. L., Kuo, Y. F., Zhang, D. D., & Goodwin, J. S. (2004). Hospice use by Hispanic and non-Hispanic white cancer decedents. *Health Services Research, 39*(4 Part 1), 969-983.
- Lacklan, N. A., Ostir, G. V., Freeman, J. L., Kuo, Y. F., Zhang, D. D., & Goodwin, J. S. (2004). Hospice use by Hispanic and non-Hispanic white cancer decedents. *Health Services Research, 39*(4 Pt 1), 969-983.
- Lamont, E. B., & Christakis, N. A. (2002). Physician factors in the timing of cancer patient referral to hospice palliative care. *Cancer, 94*(10), 2733-2737.
- The Law Glossary of Terms.* (2006). Retrieved 6/6/2006, 2006, from www.compcom.co.za/thelaw_glossary.asp?
- Light, D. W. (2000). The Sociological character of health care markets. In G. L. Albrecht, R. Fitzpatrick & S. Scrimshaw (Eds.), *Handbook of Social Studies in Health and Medicine* (pp. 394-408). Thousand Oaks, CA: Sage Publications.
- Light, D. W. (2004a). Countervailing Power: The changing character of the medical profession in the United States. In P. Conrad (Ed.), *The Sociology of Health and Illness* (pp. 215-224). New York: Worth Publishers.
- Light, D. W. (2004b). Ironies of success: A new history of the American health care "system". *Journal of Health and Social Behavior, 45*(Extra Issue), 1-24.
- Locher, J. L., Kilgore, M. L., Morrissey, M. A., & Ritchie, C. S. (2006). Patterns and Predictors of Home Health and Hospice Use by Older Adults with Cancer doi:10.1111/j.1532-5415.2006.00833.x. *Journal of the American Geriatrics Society, 54*(8), 1206-1211.
- Lofland, L. (1978). *The craft of dying*. Beverly Hills, CA: Sage.

- Lorenz, K. A., Asch, S. M., Rosenfeld, K. E., Liu, H., & Ettner, S. L. (2004). Hospice admission practices: Where does hospice fit in the continuum of care? *Journal of American Geriatrics Society*, 52(5), 725-530.
- Lorenz, K. A., Ettner, S. L., Rosenfeld, K. E., Carlisle, D. M., Leake, B., & Asch, S. M. (2002). Cash and compassion: Profit status and the delivery of hospice services. *Journal of Palliative Medicine*, 5(4), 507-514.
- Lorenz, K. A., Ettner, S. L., Rosenfeld, K. E., Carlisle, D. M., Liu, H., & Asch, S. M. (2004a). Accommodating ethnic diversity: A study of California hospice programs. *Medical Care*, 42(9), 871-874.
- Lorenz, K. A., Ettner, S. L., Rosenfeld, K. E., Carlisle, D. M., Liu, H., & Asch, S. M. (2004b). Accommodating ethnic diversity: A study of California hospice programs. *Medical Care*, 42(9), 871-874.
- Lorenz, K. A., Rosenfeld, K. E., Asch, S. M., & Ettner, S. L. (2003). Charity for the dying: Who receives unreimbursed hospice care? *Journal of Palliative Medicine*, 6(4), 585-591.
- Lumley, T., Dierh, S. E., & Chen, L. (2002). The Importance of the normality assumption in large public health data sets. *Annual Review of Public Health*, 23, 151-169.
- Lunney, J., Foley, K. M., Smith, T. J., & Gelband, H. (Eds.). (2003). *Describing death in America*. Washington D.C.: The National Academy Press.
- Lynn, J. (1997). Measuring quality of care at the end-of-life: A statement of principles. *Journal of the American Geriatrics Society*, 45(4), 526-527.

- Lynn, J., Shuster, J. L., & Kabcenell, A. K. (2000). Chapter 9: Medicare reimbursement. In *Improving Care for the End of Life* (pp. 151-168). Oxford: Oxford University Press.
- Mahar, M. (2006). *Money Driven Medicine - The real reason health care costs so much*. New York: Collins.
- Mahoney, J. (2000). Path dependence in historical sociology. *Theory and Society*, 29(4), 507-548.
- Mansbridge, J. (1998). On the contested nature of the public good. In W. W. Powell & E. S. Clemens (Eds.), *Private Action and the Public Good* (pp. 3-19). New Haven: Yale University Press.
- Marmor, T. R. (2000). *The politics of Medicare* (Second ed.). New York: Aldine De Gruyter.
- Matthaei, J. (2001). Healing ourselves, healing our economy: paid work, unpaid work, and the next stage of feminist economic transformation. *Journal of Radical Economics*, 33(1), 461-494.
- McAdam, D. (1982). *Political process and the development of black Insurgency*. Chicago: Chicago University Press.
- McCarthy, E. P., Burns, R. B., Davis, R. B., & Phillips, R. S. (2003). Barriers to hospice care among older patients dying with lung and colorectal cancer. *Journal of Clinical Oncology*, 21(4), 728-735.
- McCarthy, E. P., Burns, R. B., Ngo-Metzger, Q., Davis, R. B., & Phillips, R. S. (2003). Hospice use among medicare managed care and fee-for-service patients dying with cancer. *Journal of the American Medical Association*, 289(17), 2238-2245.

- McCue, M. J., & Thompson, J. M. (2005). Operational and financial performance of publicly traded hospice companies. *Journal of Palliative Medicine*, 8(6).
- McCue, M. J., & Thompson, J. M. (2006). Operational and financial performance of newly established hospices. *American Journal of Hospice & Palliative Care*, 23(4).
- McKinlay, J. B., & Marceau, L. D. (2004a). The end of the golden age of doctoring. In P. Conrad (Ed.), *The Sociology of Health and Illness* (Seventh ed., pp. 189-215). New York: Worth Publishers.
- McKinlay, J. B., & Marceau, L. D. (2004b). Mainstream healthy public policy: Lessons from the battle of tobacco. In V. Navarro & C. Muntaner (Eds.), *Political and economic determinants of population health and well-being: Controversies and developments*. Amityville, New York: Baywood Publishing Company, Inc.
- McNulty, E. G., & Holderby, R. A. (1983). *Hospice: A caring challenge*. Springfield, Illinois: Charles C Thomas.
- MedPAC. (2004). *Report to Congress: New approaches in Medicare*. Washington D.C.: Medicare Payment Advisory Commission.
- MedPAC. (2006). *Report to Congress: Data Book*. Washington D.C.: Medicare Payment Advisory Commission.
- Miller, S. C. (2004). Hospice care in nursing homes: Is site of care associated with visit volume. *Journal of American Geriatrics Society*, 52(8), 1331-1133;1336.
- Miller, S. C., Gozalo, P., & Mor, V. (2001). Hospice enrollment and hospitalization of dying nursing home patients. *The American Journal of Medicine*, 111(1), 38-44.

- Miller, S. C., Gozalo, P., & Mor, V. (2000). *Use of Medicare's hospice benefit by nursing facility residents*. Retrieved February 8, 2006, from <http://aspe.hhs.gov/daltcp/reports/nufares.htm>
- Miller, S. C., Intrator, O., Gozalo, P., Roy, J., Barber, J., & Mor, V. (2004). Government expenditures at the end of life for short- and long-stay nursing home residents: Differences by hospice enrollment status. *Journal of the American Geriatrics Society, 52*(8), 1284-1292.
- Miller, S. C., Kinzbrunner, B., Pettit, P., & Williams, J. R. (2003). How does the timing of hospice referral influence hospice care in the last days of life? *Journal of the American Geriatrics Society, 51*(6), 798-806.
- Miller, S. C., & Mor, V. (2004). The opportunity for collaborative care provision: the presence of nursing home/hospice collaborations in the U.S. *Journal of Pain and Symptom Management, 28*(6), 537-547.
- Miller, S. C., Mor, V., Coppola, K., Teno, J. M., Laliberte, L., & Petrisek, A. C. (1998). The Medicare hospice benefit's influence on dying in nursing homes. *Journal of Palliative Medicine, 1*(4), 367-376.
- Miller, S. C., Mor, V., Wu, N., Gozalo, P., & Lapane, K. (2002). Does Receipt of Hospice Care in Nursing Homes Improve the Management of Pain at the End of Life? *Journal of the American Geriatrics Society, 50*(3), 507-515.
- Miller, S. C., Teno, J. M., & Mor, V. (2004). Hospice and palliative care in nursing homes. *Clinics in Geriatric Medicine, 20*, 717-734.
- Miller, S. C., Weitzen, S., & Kinzbrunner, B. (2003). Factors associated with the high prevalence of short hospice stays. *Journal of Palliative Medicine, 6*(5), 725-736.

- Mor, V. (1987). *Hospice care systems*. New York: Springer Publishing Company.
- Mor, V., & Hiris, J. (1983). Determinants of site of death among hospice cancer patients. *Journal of Health and Social Behavior*, 24, 375-385.
- Morris, G. (2003). Hospice fraud and abuse: Operation Restore Trust and beyond. *American Journal of Hospice & Palliative Care*, 20(1), 1-8.
- Naik, A., & DeHaven, M. J. (2001). Short stays in hospice: A review and update. *Caring Magazine*, 20(2), 10-13.
- National Consensus Project for Quality Palliative Care. (2004). *Clinical practice guidelines for quality palliative care*. Pittsburgh, PA: National Consensus Project for Quality Palliative Care,.
- National Institutes of Health. (2004). *National Institutes of Health State-of-the-Science Conference Statement*. Paper presented at the Improving End-of-Life Care.
- Neigh, J. E. (2004). MedPAC's upcoming report to congress on the Medicare hospice benefit: Recommendations for a changing world. *Caring*, 62-63.
- Neubauer, B. J., & Hamilton, C. L. (1990). Racial Differences in attitudes toward hospice care. *The Hospice Journal*, 6(1), 37-48.
- Ngo-Metzger, Q., McCarthy, E. P., Burns, R. B., Davis, R. B., Li, F. P., & Phillips, R. S. (2003). Older Asian Americans and Pacific Islanders dying of cancer use hospice less frequently than older white patients. *American Journal of Medicine*, 115(1), 47-53.
- NIH. (2005). National Institutes of Health State-of-the-Science Conference Statement Conference Statement on Improving End-of-Life Care. *Journal of Pain & Palliative care Pharmacotherapy*, 19(3), 75-83.

- O'Connor, J. (1973). *The fiscal crisis of the state*. New York City: St. Martin's Press.
- Offe, C., & Ronge, V. (1982). Thesis on the theory of the state. In A. Giddens & D. Held (Eds.), *Classes, Power, and Conflict* (pp. 249-256). Berkeley: University of California Press.
- Office of the Inspector General. (2007). *Report on Medicare Hospice Certification and Oversight*. Retrieved May 5, 2007, 2007, from <http://oig.hhs.gov/0e9/reports/oei-06-05-00260.pdf>
- O'Hara, P. A. (Ed.). (1999). *Encyclopedia of political economy* (First ed. Vol. 1: A-K). London: Routledge.
- Oliver, C. (1997). Sustainable competitive advantage: Combining institutional and resource based views. *Strategic Management Journal*, 19(9), 697-713.
- O'Neill, C., Harrington, C., Kitchner, M., & Saliba, D. (2003). Quality of care in nursing homes: an analysis of relationships among profit, quality, and ownership. *Medical Care*, 41(12), 1318-1330.
- Paradis, L. F. (1984-85). Hospice: the first DRG. *Health Matrix*, 2(4), 32-34.
- Paradis, L. F., & Cummings, S. B. (1986). The evolution of hospice in America toward organizational homogeneity. *Journal of Health and Social Behavior*, 27(4), 370-386.
- Patrick, D. L., Curtis, J. R., Engelberg, R. A., Neilsen, E., & McCown, E. (2003). Measuring and improving the quality of death. *Annals of Internal Medicine*, 139(5), 410-416.
- Peterson, M. A. (1993). Political influence in the 1990s: From iron triangle to policy network. *Journal of Health Politics, Policy and Law*, 18(Summer), 395-438.

- Petrisek, A. C., & Mor, V. (1999). Hospice in nursing homes: A facility-level analysis of the distribution of hospice beneficiaries. *The Gerontologist*, 39(3), 279-290.
- Pfeffer, J., & Salancik, G. R. (1978). *The external control of organizations: A resource dependence perspective*. New York: Harper & Row Publishers.
- Pierson, P. (2000). Increasing returns, path dependence, and the study of politics. *The American Political Science Review*, 94(2), 251-267.
- Pietroburgo, J. (2004). Joining forces, joining futures: hospice at the crossroads. *American Journal of Hospice & Palliative Care*, 21(3), 209-215.
- Pietroburgo, J. (2006). Charity at the deathbed: impacts of public funding changes on hospice care. *American Journal of Hospice & Palliative Care*, 23(3), 217-223.
- Piven, F. F., & Cloward, R. A. (1979). *Poor people's movements: Why they succeed and how they fail*. New York City: Vintage Books.
- Public Policy Institute of California. (2004). *The economic status of women in California*. Retrieved May 3, 2007, from http://www.ppic.org/content/pubs/jtf/JTF_WomenEconomicStatusJTF.pdf
- Pyenson, B., Connor, s., Fitch, K., & Kinzbrunner, B. (2004). Medicare cost in matched Hospice and Non-Hospice cohorts. *Journal of Pain and Symptom Management*, 28(3).
- Quadagno, J. (1999). Creating a capital investment welfare state: The new American exceptionalism? *American Sociological Review*, 64(1), 1-11.
- Quadagno, J. (2004). *Aging and the life course, An introduction to social gerontology* (3rd ed.). Boston: McGraw Hill.

- Raffa, C. A. (2004, March 2004). Palliative care: The legal and regulatory requirements part II. *Caring*, 23, 34-37.
- Reese, D. J., Aherns, J., Nair, S., O'Faire, J., & Warren, C. (1999). Hospice access and use by African Americans: Addressing cultural and institutional barriers through participatory action research. *Social Work*, 44(6), 549-559.
- Relman, A. S. (2004). The health care industry: Where is it taking Us? In P. Conrad (Ed.), *The Sociology of Health and Illness* (Seventh ed., pp. 268-274). New York: Worth Publishers.
- Rhodes, R. L., Teno, J. M., & Welch, L. (2006). Access to hospice for African Americans: Are they informed about the option of hospice? *Journal of Palliative Medicine*, 9(2), 268-272.
- Rice, T. (1997). Can market forces give us the health system we want? *Journal of Health Politics, Policy and Law*, 22, 383-426.
- Robinson, W. R., Morris, K., Luck, M., & Pruitt, B. (2002). Hospice utilization by male and female cancer patients in an end-of-life transition program. *Journal of American Medical Women's Association*, 57(2), 82-84.
- Rosenau, P. V., & Linder, S. H. (2001). The comparative performance of for-profit and nonprofit home health care services in the U.S. *Home Health Care Services Quarterly*, 20(2), 47-59.
- Ryan, C. W. (2000). Association between administrative and ownership characteristics of hospices and their proportion of inpatient deaths. *The Hospice Journal*, 15(3), 63-74.

- Samuelson, P. A., & Nordhaus, W. D. (1985). *Economics*. New York: McGraw-Hill Book Company.
- Schlesinger, M. (1998). Mismeasuring the consequences of ownership. In W. W. Powell & E. S. Clemens (Eds.), *Private Action and the Public Good* (pp. 85-113). New Haven: Yale University Press.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality. The caregiver health effects study. *JAMA*, 282(23), 2215-2219.
- Shapiro, J. P. (1997, March 24, 1997). Death be not swift enough: fraud fighters begin to probe the expense of hospice care. (Industry overview). *U.S. News & World Report*, 122, 34(32).
- Shattuck, & Hammond. (2004). *Whitepaper*. Retrieved February 5, 2007
- Sherman, D. W. (2000). Access to hospice care. *Journal of Palliative Medicine*, 3(4), 407-411.
- Stanton, T. H. (2001). Fraud-and-abuse enforcement in Medicare: Finding middle ground. *Health Affairs*, 20(4), 28-42.
- Starr, P. (1982). *The social transformation of American medicine*. New York: Basic Books, Inc. Publishers.
- Stevens, R. A. (1996). Health care in the early 1960s. *Health Care Financing Review*, Winter.
- Stevenson, D. G. (2005). Nursing home consumer complaints and their potential role in assessing quality care. *Medical Care*, 43(2), 102-111.
- Stillman, M. J., & Syrjala, K. L. (1999). Differences in physician access patterns to hospice care. *Journal of Pain and Symptom Management*, 17(3), 157-163.

- Stoddard, S. (1990). Hospice: Approaching the 21st Century. *The American Journal of Hospice & Palliative Care*, 21(3), 209-215.
- Strober, M. (2003). The application of mainstream economics constructs to education: A feminist analysis. In M. A. Ferber & J. A. Nelson (Eds.), *Feminist Economics Today: Beyond Economic Man*. Chicago: University of Chicago Press.
- Stuart, B., D'Onofrio, C. N., Boatman, S., & Feigelman, G. (2003). Choices: promoting early access to end-of-life care through home-based transition management. *Journal of Palliative Medicine*, 6(4), 671-680.
- Talamantes, M. A., Lawler, W. R., & Espino, D. V. (1995). Hispanic American elders: caregiving norms surrounding dying and the use of hospice services. *The Hospice Journal*, 10(2), 35-49.
- Tang, S. T. (2003). Determinants of hospice home care use among terminally ill cancer patients. *Nursing Research*, 52(4), 217-225.
- Tehan, C. (1985). Has success spoiled hospice? *Hastings Center Report*, 5, 10-13.
- Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., et al. (2004). Family perspectives on end-of-life care at the last place of care. *JAMA*, 291(1), 88-93.
- Thompson, J. D. (1967). *Organizations in action*. New York: Mc Graw-Hill Book Company.
- Torke, A. M., Garas, N. S., Sexson, W., & Branch, W. T. (2005). Medical care at the end of life: Views of African American patients in an urban hospital. *Journal of Palliative Medicine*, 8(3), 593-602.

- US DHHS Health Resources Services Administration. (2005). *Rural health eligibility*. Retrieved March 2007, from <ftp://ftp.hrsa.gov/ruralhealth/eligibility>
- Virnig, B. A., Fisher, E. S., McBean, M. A., & Kind, S. (2001). Hospice use in Medicare managed care and fee-for-service systems. *The American Journal of Managed Care*, 7(8), 777-786.
- Virnig, B. A., Kind, S., & McBean, M. (2000). Geographic variation in hospice use prior to death. *JAGS*, 48, 1117-1125.
- Virnig, B. A., McBean, M. A., Kind, S., & Dholakia, R. (2002). Hospice use before death: variability across cancer diagnoses. *Medical Care Management Journal*, 40(1), 73-78.
- Virnig, B. A., Morgan, R. O., Persily, N. A., & DeVito, C. A. (1999). Racial and income differences in use of hospice benefit between Medicare managed care and Medicare fee-for-service. *Journal of Palliative Medicine*, 2(1), 23-31.
- Virnig, B. A., Persily, N. A., Morgan, R. O., & DeVito, C. A. (1999). Do Medicare HMOs and Medicare FFS differ in their use of the Medicare hospice benefit? *The Hospice Journal*, 14(1), 1-12.
- Vogel, R. J. (1999). *Medicare: Issues in political economy*. Ann Arbor Michigan: The University of Michigan Press.
- Waitzkin, H. (2000). *The second sickness* (Revised and Updated ed.). New York: Rowman & Littlefield Publishers, Inc.
- Waitzkin, H. (2001). *At the front lines of medicine: How the health care system alienates doctors and mistreats patients...and what we can do about it*. Lanham, Maryland: Rowman & Littlefield Publishers.

- Wallston, K. A., Burger, C., Smith, R. A., & Baugher, R. J. (1988). Comparing the quality of death for hospice and non-hospice cancer patients. *Medical Care*, 26(2), 177-182.
- Weisbrod, B. A. (1998). Institutional form and organizational behavior. In W. W. Powell & E. S. Clemens (Eds.), *Private Action and the Public Good* (pp. 60-84). New Haven: Yale University Press.
- Welch, L. C., Teno, J. M., & Mor, V. (2005). End-of-life care in black and white: race matters for medical care of dying patients and their families. *Journal of the American Geriatrics Society*, 53(7), 1145-1153.
- Wennberg, J. E., Fisher, E. S., Stukel, T. A., Skinner, J. S., Sharp, S. M., & Bronner, K. K. (2004). Use of hospitals, physician visits and hospice care during the last six months of life among cohorts loyal to highly respected hospitals in the United States. *British Medical Journal*, 328, 1-5.
- West, L. A. (1992). Feminist nationalist social movements: Beyond universalisms and towards a gendered cultural relativism. *Women's Studies International Forum*, 15(5), 563-579.
- Wharton Health Economics. (2006). *The business of hospice care*. Retrieved June 3, 2006, from <http://knowledge.wharton.upenn.edu/article/1493.cfm>
- Wiener, J. M., & Tilly, J. (2003). End-of-life care in the United States: Policy issues and model programs of integrated care. *International Journal of Integrated Care*, 3.
- Zinn, J. S., Mor, V., Castle, N. G., Intrator, O., & Brannon, D. (1999). Organizational and environmental factors associated with nursing home participation in managed care. *Health Services Research*, 33(6), 1753-1767.

Zola, I. (1972). Medicine as an institution of social control. *Sociological Review*, 4, 487-504.

Zola, I. K. (2004). Medicine as an institution of social control. In P. Conrad (Ed.), *The Sociology of Health and Illness* (Seventh ed., pp. 432-442). New York: Worth Publishers.

APPENDIX

- 1) OSHPD Annual Hospice Utilization Form

HOSPICE DESCRIPTION

ANNUAL UTILIZATION REPORT OF HOSPICES - 2005

Section 5

OSHPD Facility ID No. _____

DO NOT COMPLETE SECTIONS 5 THROUGH 10 UNLESS YOU HAVE A HOSPICE.

LICENSEE TYPE OF CONTROL

| | | |
|----------|---|-----|
| Line No. | | (1) |
| 1 | From the list below, select the ONE category that best describes the licensee type of control of your hospice. (There will be a drop down box in ALIRTS - see list of choices below.) | |

LICENSEE TYPE OF CONTROL CODES

| | | | |
|---|---|---|--------------------------------------|
| 1 | City and/or County | 6 | Investor - Individual |
| 2 | District | 7 | Investor - Partnership |
| 3 | Non-profit Corporation (incl. Church-related) | 8 | Investor - Limited Liability Company |
| 4 | University of California | 9 | Investor - Corporation |
| 5 | State | | |

MEDICARE/MEDI-CAL CERTIFICATION

| | |
|----------|---|
| Line No. | |
| 5 | Select: Medicare only <input type="checkbox"/> Medicare & Medi-Cal <input type="checkbox"/> Medi-Cal only <input type="checkbox"/> Neither <input type="checkbox"/> |

AGENCY ACCREDITATION STATUS (Check all applicable ones.)

| | |
|----------|--|
| Line No. | |
| 10 | Accredited by ACHC (1) Accredited <input type="checkbox"/> (2) Deemed <input type="checkbox"/> (3) None <input type="checkbox"/> |
| 11 | Accredited by CHAP (1) Accredited <input type="checkbox"/> (2) Deemed <input type="checkbox"/> (3) None <input type="checkbox"/> |
| 12 | Accredited by JCAHO (1) Accredited <input type="checkbox"/> (2) Deemed <input type="checkbox"/> (3) None <input type="checkbox"/> |
| 13 | Accredited by other: (1) Accredited <input type="checkbox"/> (2) Deemed <input type="checkbox"/> (3) None <input type="checkbox"/> |

AGENCY TYPE AS REPORTED ON MEDICARE COST REPORT

| | | |
|----------|--|-----|
| Line No. | | (1) |
| 20 | From the list below, select ONE category. (There will be a drop down box in ALIRTS.) | |

AGENCY TYPE CATEGORIES

| | | | |
|----------|-------------------|----------|-------------------------------|
| Line No. | | Line No. | |
| 1 | Free Standing | 4 | Long-Term Care Facility-based |
| 2 | Hospital-based | 5 | Veteran Administration-based |
| 3 | Home Health-based | 6 | Other |

LOCATION OF SERVICE DELIVERY (Check one)

| | |
|----------|--|
| Line No. | |
| 25 | Primarily Urban <input type="checkbox"/> Primarily Rural <input type="checkbox"/> Mixed Urban and Rural <input type="checkbox"/> |

HOSPICE SERVICES

ANNUAL UTILIZATION REPORT OF HOSPICES - 2005

Section 6

OSHPD Facility ID No. _____

BEREAVEMENT SERVICES

| Line No. | Bereavement Services | People Served (1) |
|----------|---|----------------------|
| 1 | Survivors of hospice patients | |
| 2 | Survivors of persons not receiving hospice care | |

VOLUNTEER SERVICES

| Line No. | Volunteer Services | No. of Volunteers (1) | Volunteer Hours (2) |
|----------|---|--------------------------|------------------------|
| 3 | Patient / Family Services | | |
| 4 | Bereavement | | |
| 5 | Administrative | | |
| 6 | Medicare Reportable Hours (sum lines 3-5) | | |
| 7 | Fundraising | | |
| 9 | Other | | |
| 10 | TOTAL | | |

ADDITIONAL AND SPECIALIZED SERVICES

Check all services directly provided by OR contracted for by the hospice.

| Line No. | Additional and Specialized Hospice Services | Services (1) |
|----------|---|-----------------|
| 11 | Hospice Designated Inpatient Facility / Unit | |
| 12 | Specialized Pediatric Program | |
| 13 | Bereavement services to survivors of persons not receiving hospice care | |
| 14 | Adult Day Care | |
| 15 | Specialized Palliative Care Program | |
| 16 | Other | |

VISITS BY TYPE OF STAFF (Include After-Hours and Bereavement Visits)

| Line No. | Type of Staff | Visits (1) |
|----------|--------------------------------|---------------|
| 21 | Nursing - RN | |
| 22 | Nursing - LVN | |
| 23 | Social Services | |
| 24 | Hospice Physician Services | |
| 25 | Homemaker and Home Health Aide | |
| 26 | Chaplain | |
| 29 | Other Clinical Services | |
| 30 | TOTAL | |

Section 7

OSHPD Facility ID No. _____

UNDUPLICATED HOSPICE PATIENTS BY GENDER AND AGE CATEGORY

| Line No. | Age Category | Male (1) | Female (2) | Other / Unknown (3) | Total (4) |
|----------|--------------|-------------|---------------|------------------------|--------------|
| 1 | 0-1 Years | | | | |
| 2 | 2-5 Years | | | | |
| 3 | 6-10 Years | | | | |
| 4 | 11-20 Years | | | | |
| 5 | 21-30 Years | | | | |
| 6 | 31-40 Years | | | | |
| 7 | 41-50 Years | | | | |
| 8 | 51-60 Years | | | | |
| 9 | 61-70 Years | | | | |
| 10 | 71-80 Years | | | | |
| 11 | 81-90 Years | | | | |
| 12 | 91 + Years | | | | |
| 15 | TOTAL | | | | |

UNDUPLICATED HOSPICE PATIENTS BY GENDER AND RACE

| Line No. | Race | Male (1) | Female (2) | Other / Unknown (3) | Total (4) |
|----------|------------------------|-------------|---------------|------------------------|--------------|
| 21 | White | | | | |
| 22 | Black | | | | |
| 23 | Native American | | | | |
| 24 | Asian/Pacific Islander | | | | |
| 25 | Other / Unknown | | | | |
| 30 | TOTAL | | | | |

UNDUPLICATED HOSPICE PATIENTS BY GENDER AND ETHNICITY

| Line No. | Ethnicity | Male (1) | Female (2) | Other / Unknown (3) | Total (4) |
|----------|--------------|-------------|---------------|------------------------|--------------|
| 31 | Hispanic | | | | |
| 32 | Non-Hispanic | | | | |
| 33 | Unknown | | | | |
| 35 | TOTAL | | | | |

Section 7 (Con't)

OSHPD Facility ID No. _____

HOSPICE PATIENT ADMISSIONS BY SOURCE OF REFERRAL

| Line No. | Source of Referral | Patients (1) |
|----------|------------------------------------|-----------------|
| 41 | Home Health Agency | |
| 42 | Hospital (Discharge Planner, etc.) | |
| 43 | Long-Term Care Facility | |
| 44 | Other Hospice | |
| 45 | Payer (Insurer, HMO, etc.) | |
| 46 | Physician | |
| 47 | RCFE / ARFCLHF | |
| 48 | Self / Family / Friend | |
| 49 | Social Service Agency | |
| 54 | Other | |
| 55 | TOTAL | |

HOSPICE PATIENT DISCHARGES BY REASON

| Line No. | Reason for Discharge | Patients (1) |
|----------|--------------------------------------|-----------------|
| 61 | Death | |
| 62 | Patient Moved Out of Area | |
| 63 | Patient Refused Service | |
| 64 | Transferred to Another Local Hospice | |
| 65 | Prognosis Extended | |
| 66 | Patient Desired Curative Treatment | |
| 69 | Other | |
| 70 | TOTAL | |

HOSPICE PATIENTS DISCHARGED BY LENGTH OF STAY

| Line No. | Length of Stay (Days) | Patients (1) |
|----------|-----------------------|-----------------|
| 71 | 0-5 Days | |
| 72 | 6-10 Days | |
| 73 | 11-15 Days | |
| 74 | 16-20 Days | |
| 75 | 21-30 Days | |
| 76 | 31-60 Days | |
| 77 | 61-90 Days | |
| 78 | 91-120 Days | |
| 79 | 121-150 Days | |
| 80 | 151-180 Days | |
| 84 | 181 + Days | |
| 85 | TOTAL | |

Section 7 (Con't)

OSHPD Facility ID No. _____

HOSPICE PATIENT ADMISSIONS BY COUNTY AND DISCHARGES BY DISPOSITION

| Line No. | County of Patient's Residence at Time of Admission (1) | No. of Admissions (2) | No. of Deaths (3) | No. of Non-Death Discharges (4) | No. of Patients Served (5) |
|----------|---|--------------------------|----------------------|------------------------------------|-------------------------------|
| 91 | | | | | |
| 92 | | | | | |
| 93 | | | | | |
| 94 | | | | | |
| 95 | | | | | |
| 96 | | | | | |
| 97 | | | | | |
| 98 | | | | | |
| 99 | | | | | |
| 100 | TOTAL | | | | |

HOSPICE UTILIZATION

Section 8

OSHPD Facility ID No. _____

Please provide the number of patients discharged during calendar year reported regardless of payment source. Count the patient only under the principal diagnosis for which the patient was admitted for hospice care. Report each patient only once. The ICD-9-CM codes are provided only as a guide for you. You may use your hospice's existing definitions for diagnosis groups or the LMRP diagnosis codes from your fiscal intermediary, provided they match in a general way with the ICD-9-CM codes.

DISCHARGED HOSPICE PATIENT'S VISITS AND PATIENT DAYS BY DIAGNOSIS

| Line No. | Diagnosis | ICD-9-CM Codes | No. of Patient Discharges (1) | Visits for Discharged Patients (2) | Discharged Patients Total Days of Care (3) |
|----------|------------------------------------|---|-------------------------------|------------------------------------|--|
| 1 | Cancer | 140.0 - 208.91 230.0 - 234.9 | | | |
| 2 | Heart | 391.0 - 392.0 393 - 402.91 404.0 - 404.9 with fifth digit 1 or 3 410.00-429.9 | | | |
| 3 | Dementia & Cerebral Degeneration | 290.0 - 294.9 331.0 - 331.9 | | | |
| 4 | Lung, excluding cancer | 460-519.9 | | | |
| 5 | Kidney, excluding cancer | 403.00 - 403.91, 404.0-404.9 with fifth digit 2 or 3, 405.0 - 405.9 with fifth digit 1 580.0 - 589.9 | | | |
| 6 | Liver, excluding cancer | 570-573.9 | | | |
| 7 | HIV | 042 | | | |
| 8 | Brain Stroke and late effects | 430 - 436 438.0 - 438.9 997.02 | | | |
| 9 | Coma, with or without brain injury | 780.01 - 780.09 850.4 851.0 - 854.1 with fifth digit 5 | | | |
| 10 | Diabetes | 250.00 - 250.93 | | | |
| 11 | ALS* | 335.20 | | | |
| 19 | Other | All other codes that are not in lines 1-11. | | | |
| 20 | TOTAL | | | | |

*Amyotrophic lateral sclerosis (ALS), also called Lou Gehrig's Disease

Section 9

OSHPD ID No. _____

Please provide patient days for all patients served, including those in nursing facilities during the calendar year reported. Patients who change primary pay source during the calendar year reported should be reported for each pay source with the number of days of care recorded for each source (count each day only once even if there is more than one pay source on any one day).

LEVEL OF CARE AND SOURCE OF PAYMENT

| Line No. | Source of Payment | No. of Patients Served (1) | Days of Routine Home Care (2) | Days of Inpatient Care (3) | Days of Respite Care (4) | Days of Continuous Care (5) | Total Patient Care Days (6) |
|----------|-----------------------|----------------------------|-------------------------------|----------------------------|--------------------------|-----------------------------|-----------------------------|
| 1 | Medicare | | | | | | |
| 2 | Medi-Cal | | | | | | |
| 3 | Medi-Cal Managed Care | | | | | | |
| 4 | Managed Care | | | | | | |
| 5 | Private Insurance | | | | | | |
| 6 | Self Pay | | | | | | |
| 7 | Charity | | | | | | |
| 9 | Other* | | | | | | |
| 10 | TOTAL | | | | | | |

* Other payment sources may include but not limited to Workers Comp., Home Health benefit, etc.

LOCATION OF CARE PROVIDED

| Line No. | Location of Care | Days of Routine Home Care (1) | Days of Inpatient Care (2) | Days of Respite Care (3) | Days of Continuous Care (4) | Total Patient Care Days (5) |
|----------|------------------|-------------------------------|----------------------------|--------------------------|-----------------------------|-----------------------------|
| 21 | Home | | | | | |
| 22 | Hospital | | | | | |
| 23 | SNF | | | | | |
| 24 | CLHF | | | | | |
| 25 | RCFE / ARF | | | | | |
| 29 | Other | | | | | |
| 30 | TOTAL | | | | | |

HOSPICE INCOME AND EXPENSES STATEMENT

ANNUAL UTILIZATION REPORT OF HOSPICES - 2005

Section 10

OSHPD Facility ID No. _____

DETAIL OF OPERATING EXPENSES

Use data from Medicare Cost Report where applicable.

| Line No. | | Total (1) |
|----------|--|--------------|
| | General Service Cost Centers | |
| 30 | Administrative and General | |
| | Inpatient Care Service | |
| 31 | Inpatient - General Care | |
| 32 | Inpatient - Respite Care | |
| | Nursing Home | |
| 33 | Room & Board SNF Medi-Cal Pass through Payments | () |
| 34 | Medi-Cal Room & Board Contractual Payments | |
| | Program Supervision | |
| 35 | Hospice Program / Team Supervision (Non-visit wages) | |
| | Visiting Services | |
| 36 | Physician Services | |
| 37 | Nursing Care | |
| 38 | Rehabilitation Services (PT, OT, Speech) | |
| 39 | Medical Social Services - Direct | |
| 40 | Spiritual Counseling | |
| 41 | Dietary Counseling | |
| 42 | Counseling - Other | |
| 43 | Home Health Aides and Homemakers | |
| 44 | Other Visiting Services | |
| | Hospice Service Cost Centers | |
| 45 | Drugs, Biologicals and Infusion | |
| 46 | Durable Medical Equipment / Oxygen | |
| 47 | Patient Transportation | |
| 48 | Imaging, Lab and Diagnostics | |
| 49 | Medical Supplies | |
| 50 | Outpatient Services (including ER Dept.) | |
| 51 | Radiation Therapy | |
| 52 | Chemotherapy | |
| 53 | Other Hospice Service Costs | |
| | Other Hospice Costs | |
| 54 | Bereavement Program Costs | |
| 55 | Volunteer Program Costs | |
| 56 | Fundraising | |
| | Other Costs | |
| 57 | Other Program Costs * | |
| 59 | Total Operating Expenses | |

* Program costs including community education and outreach program costs.

HOSPICE INCOME AND EXPENSES STATEMENT

ANNUAL UTILIZATION REPORT OF HOSPICES - 2005

Section 10 (Cont'd)

OSHPD Facility ID No. _____

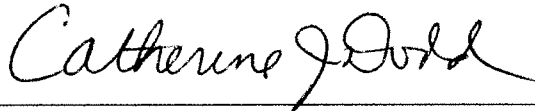
HOSPICE INCOME STATEMENT

| Line No. | | Total (1) |
|----------|---|--------------|
| | Gross Patient Revenue | |
| 101 | Medicare | |
| 102 | Medi-Cal (Excluding Room & Board) | |
| 103 | Medi-Cal Managed Care (Excluding Room & Board) | |
| 104 | Managed Care (Non Medi-Cal) | |
| 105 | Private Insurance | |
| 106 | Self-Pay | |
| 109 | Other Payers | |
| 110 | Total Gross Patient Revenue (sum of lines 101 through 109) | |
| | Write-offs and Adjustments | |
| 111 | Contractual Adjustments | |
| 112 | Denials / Bad Debt | |
| 113 | Charity | |
| 119 | Other Write-offs and Adjustments | |
| 120 | Total Write-offs and Adjustments (sum of lines 111 through 119) | |
| 125 | Net Patient Revenue (line 110 minus line 120) | |
| | Other Operating Revenue | |
| 131 | Grants | |
| 132 | Donations / Contributions | |
| 133 | Unrelated Business Income | |
| 139 | Other | |
| 140 | Total Other Operating Revenue (sum of lines 131 through 139) | |
| 145 | Total Operating Revenue (line 125 plus line 140) | |
| | Operating Expenses | |
| 151 | General Service Cost Centers | |
| 152 | Inpatient Care Service | |
| 153 | Nursing Home | |
| 154 | Program Supervision | |
| 155 | Visiting Services | |
| 156 | Hospice Service Cost Centers | |
| 157 | Other Hospice Costs | |
| 159 | Other Costs | |
| 160 | Total Operating Expenses (sum of lines 151 through 159) | |
| 165 | Net from Operations (line 145 minus line 160) | |
| 170 | Income Tax | |
| 175 | Net Income (line 165 minus line 170) | |
| | | |

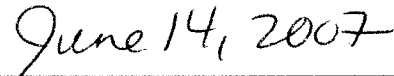
Publishing Agreement

It is the policy of the University to encourage the distribution of all theses and dissertations. Copies of all UCSF theses and dissertations will be routed to the library via the Graduate Division. The library will make all theses and dissertations accessible to the public and will preserve these to the best of their abilities, in perpetuity.

I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis or dissertation to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.



Author Signature (Catherine J. Dodd)



Date (June 14, 2007)