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ABSTRACT

JUSTIN B. DAVIS

Examining Disparities Related to the Use of Hospice Care: Cancer vs. Non-cancer Diagnoses

(Under the direction of BRUCE C. PERRY, MD, MPH)

Americans often face end-of-life with ineffective pain/symptom control. While hospice care prevents suffering for the terminally ill, only around 40% of individuals access services. Although few studies describe differences in terms of cancer vs. non-cancer diagnoses, hospice utilization/access disparities appear to exist. Analyzing 14 sociodemographic and clinical variables for 3,905 hospice discharge cases, this study highlights observed disproportions between cancer and non-cancer groups, identifying significant relationships amongst patient characteristics and hospice diagnosis. Factors found significantly related to diagnosis include components of the following: age, primary payment source, mortality status at discharge, hospice initiation location, length of stay, physical function, cognitive function, and presence of pain symptoms. Results confirm low overall hospice utilization rates, while validating diagnosis-specific differences driven by individual and population-based characteristics. In order to increase utilization/access rates and eliminate current disparities, patients presenting with certain terminal diseases may require greater provider flexibility in terms of hospice eligibility requirements.

INDEX WORDS: hospice care, palliative care, health disparities, cancer, chronic disease, death and dying, end-of-life

EXAMINING DISPARITIES RELATED TO THE USE OF HOSPICE CARE:
CANCER VS. NON-CANCER DAIGNOSES

by

JUSTIN B. DAVIS

BBA, EMORY UNIVERSITY

A Thesis Submitted to the Graduate Faculty
of Georgia State University in Partial Fulfillment
of the
Requirements for the Degree

MASTER OF PUBLIC HEALTH

ATLANTA, GEORGIA
30302

EXAMINING DISPARITIES RELATED TO THE USE OF HOSPICE CARE:
CANCER VS. NON-CANCER DAIGNOSES

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Without the love and encouragement of my partner, Will, the past two years would have been exponentially more difficult. No matter the circumstance, he continues to exhibit tolerance and offer reassurance, even when my life decisions are not the most convenient for him. I am thankful for his unwavering companionship and look forward to equally supporting his future educational ambitions.

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AUTHOR'S STATEMENT

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Chapter I Introduction

1.1 Background

Over at least the past six decades, the world's human population has significantly transformed, experiencing record-breaking growth rates. In addition to birthrate increases partially responsible for progress during the 20th century, the human lifespan also continues to lengthen, further compounding the rise in population and leading to momentous advances in aging (Schoeni & Ofstedal, 2010). Evidence of the aging population includes not only longer life expectancies, but also the increase in the proportion of the elderly in today's society. Particularly, in the United States (U.S.), the percentage of individuals aged 65 and older is expected to comprise 20% of the total population by mid-21st century – a notable difference from roughly 4% in the early 1900's (McLaughlin, Connell, Heeringa, Li, & Roberts, 2010).

Paralleled by the evolving aging structure in the U.S., the conditions associated with living longer, along with the end-of-life experience, have also changed considerably in the past 100 years. Due to advances in the fight against infectious disease, coupled with lower mortality rates, aging Americans now suffer from mostly lingering chronic conditions (Lehning & Austin, 2010). Consequently, ailments such as heart, pulmonary, and cerebrovascular diseases currently prevail as leading causes of death (Mokdad, Marks, Stroup, & Gerberding, 2004). Related primarily to the long-term nature of chronic diseases and the uncertainty regarding the multiple paths of decline that often lead to death, anticipating and approaching end-of-life issues and planning has

become increasingly challenging (Batchelor, 2010). Certainly, Americans' tendency to avoid the topic of death also complicates the ability and willingness to address such sensitive issues (Wasserman, 2008).

Although evidence-based models providing quality end-of-life care exist, a shocking proportion of Americans currently face death in undesirable settings, increasing their chances of experiencing inadequate pain and symptom control (Galanos, Morris, Pieper, Poppe-Ries, & Steinhauer, 2012). Offering holistic care for those who are terminally ill, hospice services are generally regarded as superior in promoting comfort and quality of life; however, more than half of dying Americans lack the benefits that hospice provides ("NHPCO Facts," 2012). Furthermore, of those in the minority that do access hospice care at the end-of-life, most are referred too late in the disease process, as approximately 62% of hospice patients only receive 30 days or less of the potential 180+ days of care available ("NHPCO Facts," 2012). While the U.S. significantly outspends other developed nations in terms of medical advancement, unfortunately, most Americans suffer at end-of-life with underfunded care and low quality-of-death ratings (Hoefler, 2010).

1.2 Purpose of Study

Although commonly indicated by public health efforts, the promotion of health does not always involve prolonging life. According to the World Health Organization, "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" ("Preamble to the Constitution," 1946). Fittingly, when a disease process can no longer be prevented or reversed, well-being should translate to the absence of pain and suffering and overall quality of life remaining. However,

previous research has shown that the American health care system is flawed in regards to the promotion of well-being at end-of-life (Bern-Klug, 2009; O'Mahony et al., 2008; Resnick, Foster, & Hickman, 2009; Walling et al., 2010). While the hospice model of care remains backed by a considerable evidence base regarding efficacy, particularly in response to holistic well-being, a shocking majority of the U.S. population continues to face death without its benefits ("NHPCO Facts," 2012).

Attempting to pinpoint answers concerning low hospice enrollment rates, numerous studies have indicated that significant disparities related to hospice access and utilization exist (Carrion, Park, & Lee, 2011; duPreez et al., 2008; Givens, Tjia, Zhou, Emanuel, & Ash, 2010; Silveira, Connor, Goold, McMahon, & Feudtner, 2011). However, since hospice was originally introduced as care for terminally ill cancer patients, much of the available research does not include cases with non-cancer diagnoses (Cohen, 2008). Of the studies that do include the latter, most seem to focus on one particular disease (duPreez et al., 2008; Givens et al., 2010). Consequently, relatively few studies attempt to describe hospice use disparities between general cancer and non-cancer diagnosis groups, which remains concerning given the fact that the majority of hospice patients no longer suffer from cancer ("NHPCO Facts," 2012). By further expanding knowledge regarding hospice use disparities, a better understanding of methods to reach greater proportions of the American population with critical end-of-life services will emerge. Likewise, the emergence of new knowledge creates the potential to improve care for those individuals who are already likely to access hospice services. Therefore, the purpose of this study is to describe hospice use statistics from a nationally representative sample of cancer and non-cancer hospice discharges, as well as explore the

relationship between diagnosis and patient/population characteristics in an attempt to illuminate factors that may play a role in imbalanced hospice utilization and access rates in the U.S.

1.3 Research Questions

1. What are characteristics (sociodemographic and clinical) of a nationally representative sample of hospice patients?
2. What are differences between patients with cancer vs. non-cancer hospice diagnoses?
3. To what extent do patient/population characteristics (sociodemographic and clinical) relate to hospice diagnosis?

Chapter II Review of Literature

2.1 Aging

2.1.1 Aging Global Population

The 20th century brought about unprecedented growth in the world's population. In the 18 years after World War II alone, the baby boomer generation multiplied, creating around 400 million new human lives (Olshansky, Goldman, Zheng, & Rowe, 2009). While many factors contributed to the dramatic increase in population, rises in fertility and improvements in mortality played large roles (Cherlin, 2010). In particular, successes in infectious disease control and management of chronic disease have significantly affected lifespan (Schoeni & Ofstedal, 2010). For example, those born in 2010 will live around 17 years longer than their elders of 50 years, enjoying an average estimated lifespan of 69 years, worldwide (Schoeni & Ofstedal, 2010). The success of aging is evident, especially when examining the world's older population, aged 65 years plus (65+). Between 2008 and 2040, it is estimated that this group will almost double in size, from 7.8% to 14.7% of the total population, which will equal around 1.3 billion older people by 2040 (Schoeni & Ofstedal, 2010). Additionally, the world's oldest-old population continues to increase. Growing more quickly than the 65+ age group, the subset aged 80 plus (80+) is expected to represent 24% of the older population by 2040 (Schoeni & Ofstedal, 2010).

2.1.2 Aging U.S. Population

Although developed countries are aging at slower rates than those in the developing world, the U.S. continues to experience significant growth (Schoeni & Ofstedal, 2010). As with the world population, the U.S. also benefits from both increased longevity and decreased mortality. The Social Security Administration estimates that overall mortality will decline until 2032 by .86% per year (Olshansky et al., 2009). The reduction in death rates leads to estimates of average life expectancy at birth ranging from 80.9 to 85.9 years for males and 85.3 to 93.3 for females by the year 2050 (Olshansky et al., 2009). Combining the effects of increased life expectancy and decreased mortality, there exists evidence that entire U.S. population will increase from 304.2 million in 2008 to between 410 and 439 million by 2050 (Olshansky et al., 2009). Much of the overall estimated U.S. population growth is attributed to the increasing proportion of the old, those aged 65+. Estimated to rise to 20% of the total population by 2050, this group will have grown from a mere 4% at the beginning of the 20th century (McLaughlin et al., 2010). The 16% increase in growth means that around 84 million Americans will comprise the 65+ population (Baernholdt, Hinton, Yan, Rose, & Mattos, 2012). Within the 65+ age group, the proportion of Americans reaching advanced old age has also become more commonplace, further contributing to the overall U.S. population growth rate. Of those men and women born in 1900 who lived until at least 65 years of age, 41% and 62% also reached age 80, respectively (Ailshire, Beltrán-Sánchez, & Crimmins, 2011). Of the approximately 84 million Americans estimated to be age 65+ by 2050, nearly 21 million will be over the age of 85 (Baernholdt et al., 2012). Considering that only 5.4 million Americans were 85 years or older in 2008, it is

apparent that great strides in aging are expected to continue (Olshansky et al., 2009). Looking at subsets of Americans within the 65+ age group, racial and ethnic minority populations are also expected to grow, increasing from 16.4% of the elderly in 2000 to 25.4% by 2050 (Trask, Hepp, Settles, & Shabo, 2009). Comparing 2000 statistics to 2050 estimates, White individuals will decrease from representing 84% of the 65+ population to 64%, while African American individuals will increase from 8% to 12%, Asian individuals will increase from 2% to 7%, and Hispanic individuals will increase from 6% to 16% (Trask et al., 2009). Although minority elder populations are expected to grow, inequalities in aging are still evident. For instance, in 2002, life expectancy for African Americans and Whites differed by almost six years, with an expected lifespan of 72.3 and 77.7 years, respectively (Weaver & Rivello, 2006).

2.1.3 Conditions of Aging in U.S.

As the U.S. elderly population continues to grow, much concern is being directed toward the fulfillment of living longer healthier, happier lives. One of the leading concepts in the field involves the notion of successful aging, which includes components such as avoiding disease and disability, maintaining high levels of physical and cognitive function, and staying involved in social activities (Hank, 2011). A recent study reports that as of 2004, only about 11% of Americans age 65+ meet the criteria of successful aging. Furthermore, the prevalence of successful aging has shown decline since 1998, according to their analysis (McLaughlin et al., 2010). Much of the disease faced by the older U.S. population consists of lingering chronic conditions. As of 2009, statistics provide that 80% of adults over age 50 suffer from at least one chronic diagnosis (Lehning & Austin, 2010). In addition to chronic disease, many older Americans also

face the risk of generally limiting conditions. Research shows that in 2005, 40% of older adults lived with some type of disability (Lehning & Austin, 2010). Moreover, in 2006, studies suggest that 20% of older adults were disabled due to chronic disease alone (McLaughlin et al., 2010). Higher levels of chronic conditions and disability create extreme difficulties in maintaining physical function. Assessment of functioning often involves an individual's ability to engage in activities of daily living (ADL's), such as eating, toileting, dressing, bathing, and walking (Berlau, Corrada, & Kawas, 2009). By age 90, up to 51% of elders have been shown to struggle with five or six ADL's, with 28% completely relying on others for help when performing such activities (Berlau et al., 2009). Existing with the alarmingly low successful aging rates in the U.S. are disparities that remain disconcerting. For example, individuals with lower incomes are 62% more likely to face moderate to severe disability than those with higher incomes (Huguet, Kaplan, & Feeny, 2008). Additionally, studies report that aging White individuals tend to maintain better physical health and cognitive function than aging African Americans (Ailshire et al., 2011). Generally, it appears that the odds of aging successfully are higher for White individuals, those with higher socioeconomic status (SES), and women (McLaughlin et al., 2010).

2.2 Death and Dying in the U.S

2.2.1 Mortality

Over the past 40 years, the U.S. has experienced a significant decline in overall death rates. Compared to the 1,242 per 100,000 age-standardized death rate in 1970, there was a 32% decrease by 2002, resulting in a 845 per 100,000 age-standardized death rate (Jemal, Ward, Hao, & Thun, 2005). As of 2000, the leading causes of death were

heart disease, malignant neoplasms, cerebrovascular diseases, chronic lower respiratory disease, and unintentional injuries (Mokdad et al., 2004). It is important to note, however, the underlying leading actual causes of death: tobacco, poor diet and physical inactivity, alcohol consumption, microbial agents, and toxic agents (Mokdad et al., 2004). Related primarily to changes in lifestyle associated with chronic illness, studies suggest that around 50% of deaths that year may have been preventable (Mokdad et al., 2004). From 1990 to 2000, deaths attributable to smoking increased almost 9%, while deaths attributable to diet and inactivity increased by 33%, and deaths attributable to alcohol consumption decreased by almost 18% (Mokdad et al., 2004). Such staggering statistics highlight the influence of behavior on overall mortality. Although death rates have declined, certain factors have been linked to increased mortality, particularly race and ethnicity. For example, data shows that throughout the 20th century there was an African American-White male mortality difference of around 17-18% (Sloan, Ayyagari, Salm, & Grossman, 2010). Additionally, as evidenced by 2002 data, the age-adjusted mortality rate for Whites was 829, as opposed to 1083.3 for African Americans (Weaver & Rivello, 2006). Also closely related to race and ethnicity, death rates by cause differ between populations. In 2002, African Americans and Whites were similar in regards to the ranking of the top three leading causes of death (heart disease, malignant neoplasms, and cerebrovascular disease); however, diabetes mellitus ranked fourth for African Americans, instead of chronic lower respiratory disease (Weaver & Rivello, 2006). Compared to both African Americans and Whites in the same year, Hispanic or Latino, Asian or Pacific Islander, and American Indian or Alaska Native populations all

experienced lower overall mortality rates, at 629.3, 474.4, and 677.4, respectively (Weaver & Rivello, 2006).

In addition to race, SES and sex have also been shown to play a major role in disparities related to mortality. For instance, 2001 data illustrates that African American males with less than 12 years of education have an age-standardized death rate of 1211, while African American males with greater than 16 years of education are affected by a lower rate of 386.5 (Jemal et al., 2008). African American females in the same education scenario experience death rates of 577.6 versus 318.7 (Jemal et al., 2008).

Correspondingly, inequalities connected to mortality and both sex and education hold true for the White population, albeit at lower rates than in the African American population. White males with less than 12 years versus those with more than 16 years of education experience mortality rates of 914.6 and 216.2, while White females experience rates of 539.5 and 147.4, in the same situation (Jemal et al., 2008). Ultimately, evidence suggests that each year the following populations experience more deaths than their counterparts: men, African Americans, and individuals having lower SES.

2.2.2 Onset of Death

Unfortunately, in the U.S., death largely remains a taboo topic. Research documents that death is not only feared by Americans, but that both historic and current cultures support the denial of death (Wasserman, 2008). Furthermore, academics submit that medical and pharmacological technologies have played a large role in attempts to postpone and renounce death; however, at some point, death becomes unavoidable (Bern-Klug, 2009). With the rise in chronic disease-related deaths, assessing approaching death and end-of-life matters proves increasingly difficult. One popular concept addressing

such challenges is the “ambiguous dying syndrome”, which clearly identifies social and medical factors related to the health status of patients who are healthy or compromised versus those who are terminally ill (Bern-Klug, 2004). The difficulty arises when considering patients who fall in the middle of the spectrum, the severely compromised – those experiencing conditions that are not quite recoverable or in the earliest stages, but at the same time, are not in advanced or final stages (Bern-Klug, 2004). Data shows that around 60% of contemporary deaths may involve levels of ambiguity, creating confusion related to the appropriate medical approach, expectation of death, expectation of recovery, and patient’s social role (Bern-Klug, 2004). Another theory related to assessing end-of-life matters takes into consideration differing courses of degeneration. The “trajectories of decline” model insinuates that those with chronic illness follow one of three paths: long-term decent functioning with a quick decline to death in weeks or months, slow decline with sudden death during an episode of exacerbation, or long-term diminishing function necessitating years of personal care (Batchelor, 2010). Estimates propose that 20% of individuals experience the first trajectory, while 25% and 40% experience trajectory two and three; only about 15% of deaths appear to relate to sudden illness or accidents (Batchelor, 2010). The difficulties involved in anticipating death for Americans requiring long-term care, along with uncertainties regarding methods of treatment and the tendency to ignore end-of-life matters until it is too late, creates the need for urgent improved attention to the process of dying.

2.2.3 Conditions of Death

While the majority of Americans report a preference for home death, many face end-of-life in less desirable surroundings. Systematic literature reviews illustrate the

importance of dying at home for 59% to 81% of the general population; however, around half of all chronic disease-related deaths in 2001 still occurred in acute care hospitals (Gruneir et al., 2007). Avoiding death in the acute care setting does not necessarily translate to the desired home death for the remaining half of the population, though. The proportion of nursing home deaths has grown rapidly in the past 12 years, with around 25% of Americans facing end-of-life in such institutions (Gruneir et al., 2007). Like many other aspects of healthcare, disparities related to place of death are well documented. For example, one U.S. study reports that only about 16% of dementia patients die in the acute care setting, as compared to the 50% average rate experienced by most chronic patients, and that, instead, 67% experience dementia-related death in nursing homes (Mitchell, Teno, Miller, & Mor, 2005). In addition to disease-related disparities, other factors have also been linked to place of death. Studies show that being White or living in less racially diverse areas predicts a home death, whereas being a minority predicts death in the acute care setting (Gruneir et al., 2007). Also, higher odds of hospital death are cited for less educated individuals or those who have less access to social support (Gruneir et al., 2007).

Regarding preference, place of death is not the only important factor influencing the end-of-life experience. Research, both domestic and abroad, demonstrates that a meaningful death includes important concepts such as timeliness and lack of pain, and that emphasizing the value of personal relationships and promoting feelings of connectedness remain priorities for dying patients and their families (Long, 2004). The “meaningful death”, however, is only one of many definitions related to the notion of dying well. Another popular framework, the “good death”, promotes physical and

psychological comfort, awareness, agency, and autonomy and acceptance, ending in peaceful closure (Watts, 2012). Additionally, the “dignified dying” concept stresses psychological and spiritual care, patient autonomy and control, quality of interactions, and privacy boundaries during the end-of-life journey (Coenen, Doorenbos, & Wilson, 2007). Moreover, the “respectful death model” focuses more broadly on professional caregivers building personal, close relationships with patients and families to provide overall support during end-of-life (Wasserman, 2008). Although many of the concepts fostering positive end-of-life experiences contain slight variations, overall, they generally define aspects that lead to the avoidance of negative or bad death situations.

Evidence suggests that place of death and the odds of a positive death experience may be strongly correlated, which, for many Americans, translates to undesirable circumstances. Much of the literature regarding hospital-based deaths demonstrates overaggressive measures and lack of comfort care, as perceived by family members, with loved ones experiencing end-of-life symptoms like pain, shortness of breath, and dysphoria (Galanos et al., 2012). Research supports the view that hospitals often offer surroundings incompatible with a good death. For example, one study estimates that around 50% of hospital staff and over 70% of nurses know their dying patients for less than two days, and that attending physicians, nurses, and other medical staff rarely ever agree on proper end-of-life care protocol (Galanos et al., 2012). Likewise, research also validates that end-of-life care in the nursing home is deemed less than exemplary and is the institution with, perhaps, the greatest room for improvement (Bern-Klug, 2009). Well-documented complaints portray nursing home physicians as “missing in action” and criticize hospice enrollment rates that occur too late, as well as the tendency for residents

to be transferred to hospital intensive care units as they near death (Bern-Klug, 2009). Accordingly, uncertainty remains regarding the ability of institutions to facilitate positive death experiences by providing necessary components such as education and explanations for family members, grief work facilitation, and advocacy of patient wishes (Coenen et al., 2007).

Considering the statistics related to disparities in place of death and the lack of evidence regarding the potential for a positive death experience in institutions, racial minorities or individuals of lower SES seem to exhibit an unfair disadvantage in terms of dying well. A multitude of analyses have not only validated disparities, but at the same time have also exposed unsettling data. For instance, one study illustrated that cancer-diagnosed African Americans have increased odds for under treatment of pain, while another report documented the likelihood of greater wait times for pain medication administration for African American patients, regardless of diagnosis (Hazin & Giles, 2011). Analogously, an additional article declares that patients in facilities having primarily minority residents are three times more likely to be under medicated than those in institutions with residents of a majority population (Hazin & Giles, 2011). Along with race and ethnicity and SES, other determinants of quality end-of-life care, like age and expected death, have also been explored. A recent study looking at end-of-life care in the hospital setting shows that patients under 75 years of age received worse overall care than those 75 or older (Walling et al., 2010). Moreover, patients whose charts indicated expected death three or more days before the actual occurrence experienced more effective pain control than those with no such documentation (Walling et al., 2010). The realities of widespread disparities in end-of-life care, together with the flawed institution-

centered death model, leave much to be desired during Americans' final days of life. Although the U.S. spends almost twice as much per capita on healthcare than the 23 most developed nations worldwide spend on average, end-of-life medical care remains severely underfunded; the Economist Intelligence Unit ranks the U.S. 31 out of 40 countries in this regard (Hoefer, 2010). Disturbingly, according to the same report, the U.S. ranks 9th for overall quality of death, followed closely by Hungary and Poland (Hoefer, 2010).

2.3 End-of-Life Care in the U.S.

2.3.1 Palliative Care

In response to the fragmented end-of-life medical care most Americans receive, the palliative care movement has recently gained momentum. Keeping the focus on quality of life, regardless of diagnosis, palliative care is intended to provide comfort and support to patients and families, irrespective of whether they choose to pursue curative treatments (Meier, 2011). The palliative care model may be delivered in multiple settings – the home, hospital, nursing home, or assisted living facility – and consists of an interdisciplinary team of healthcare professionals who address disease, mental health, family and social relationships, and spiritual needs (Meier, 2011). Proponents advocate that palliative care should be practiced simultaneously with therapeutic efforts from the moment a life-threatening illness is diagnosed, taking the form of primary, secondary, or tertiary care (Meier, 2011). At the primary level, all physicians should strive to control pain and symptoms; however, at the secondary level, many times the services of a palliative care specialist are required for more complex situations. Additionally, palliative care efforts may involve research or teaching at the tertiary level (Meier, 2011).

Patients most often benefiting from palliative care services include those that are struggling with a chronic disease that will one day lead to death or the elderly suffering from overall debility and distress; nevertheless, few restrictions regarding patient-related aspects of qualification exclude anyone in need of service (Batchelor, 2010). Conversely, most of the limitations affecting access to palliative care services stems from the issue of reimbursement on the provider side of the spectrum. While many professionals support the notion of palliative care, reimbursement for certain services through Medicaid, Medicare, and private insurance is not always guaranteed, forcing the institution to bear any uncovered costs (Lubell, 2010). Currently, providing palliative care in the hospital setting is the only way to ensure the most comprehensive reimbursement for healthcare providers' services; still, assistance from team members like chaplains, social workers, and bereavement counselors is never considered billable in the palliative setting (Lubell, 2010).

Due to the restrictions placed on palliative care reimbursement, most programs providing such services focus on the in-patient hospital environment. Estimates suggest that at least 80% of hospitals with 300 or more beds offer formal palliative care programs (Galanos et al., 2012). Even with availability of services in larger hospitals, one study, examining end-of-life care at a well-respected university medical center, highlights the truths associated with access to palliative care – only 7% of patients hospitalized for three or more days were engaged in a palliative care consultation (Walling et al., 2010). Similarly, in another study enrolling almost 1600 patients across 35 university hospitals, palliative care consults were ordered for only about 13% of patients meeting end-of-life criteria (O'Mahony et al., 2008). Given the difficulties related to reimbursement outside

of the hospital, it is not uncommon to find poorer access to formal palliative care or end-of-life programs in the nursing home setting. A nationally representative study recently reported that out of nearly 1200 nursing homes, only about 17% of facilities even offered a formal palliative care program at all (Resnick et al., 2009). Furthermore, the data suggests that patients have a greater chance of being offered specialty end-of-life programs in independent nursing homes, as well as in facilities that have fewer than 50 beds (Resnick et al., 2009).

When examining evidence addressing the efficacy of palliative care treatment at end-of-life, it becomes apparent that few Americans receive holistic comfort care, regardless of their diagnosis and decisions to pursue curative or restorative measures. The literature presents little evidence suggesting that palliation is ineffective. On the contrary, a recent systematic review looking at specialist palliative care teams and cancer patients found that out of eight relevant randomized controlled trials, seven merited a ranking of moderate to high evidence, providing significant outcome improvements for pain and symptom control, reduced anxiety, and reduced hospital admissions (Higginson & Evans, 2010). Combined with the substantiation regarding the efficacy of palliative care in cancer patients, a recent study looking at differences between cancer and non-cancer patients in palliative care programs in Germany indicates that patients with non-cancer diagnoses benefit as much from palliation – or in some cases, even more – as their cancer-diagnosed counterparts (Ostgathe et al., 2011). Compared with cancer patients, those with non-cancer diagnoses had significantly worse functional status, significantly higher needs for nurse support, and died significantly more often (Ostgathe et al., 2011). Furthermore, the non-cancer patients were significantly more likely to suffer from

dyspnea, weakness, and tiredness, as well as require more wound care and assistance with ADL's (Ostgathe et al., 2011).

2.3.2 Hospice Care

Another option for Americans facing terminal illness, hospice care offers most of the same services associated with palliative care, with a more distinct focus on approaching end-of-life. While palliative care provides the opportunity to continue restorative treatments simultaneously, hospice care is intended for those individuals who are estimated to have six months or less to live and wish to forego curative efforts, concerned mainly with comfort, dignity, and quality of life remaining (Furman, Doukas, & Reichel, 2010). Like the interdisciplinary team that oversees palliative care, the hospice team provides much needed support including physician and nursing care, as well as social work, counseling, chaplain and bereavement services (Lutz, 2011). In addition to care services, the hospice benefit provides palliative medications, durable medical equipment (e.g., wheelchairs and hospital beds), and supplies (e.g., adult diapers and mouth care swabs) (Lutz, 2011). According to patient preference and level of required support, hospice care is generally provided at a private residence, an in-patient hospice unit, or in the hospital setting. As of 2010, at the time of death, 41.1% of patients received hospice services at their private residence, while 18% and 7.3% received care at nursing homes and residential facilities, respectively ("NHPCO Facts," 2012). Additionally, at the time of death, 21.9% of patients received care in hospice in-patient facilities, and 11.4% of care was delivered in the hospital setting ("NHPCO Facts," 2012). Outside of the in-patient setting, hospice services are generally regarded as supplementary, since the interdisciplinary team visits the home regularly, but also

requires the patient have a primary caregiver. While hospice staff are not typically able to provide around-the-clock or even daily care, most agencies offer on-call services, in case any issues arise (“NHPCO Facts,” 2012). Similar to the evidence regarding effectiveness of palliative care, hospice has been shown to dramatically improve the end-of-life experience. For instance, families exposed to hospice describe less unmet needs, higher quality of death, and less anxiety regarding quality of care (Teno et al., 2011).

Since 1982, when Congress created a national hospice benefit, many Americans have qualified for services under Medicare part A (Lutz, 2011). Upon election of the Medicare Hospice Benefit, patients relinquish their access to the regular Medicare Benefit for any care related to their terminal condition (Furman et al., 2010).

Accordingly, the Hospice Medicare Benefit covers the cost of hospice care at 100%, but patients are still able to access their standard Medicare Benefit for unrelated health care issues (Furman et al., 2010). For Americans not enrolled in Medicare, many state Medicaid programs and private insurance plans also offer hospice care benefits, varying in their levels of out of pocket-costs, deductibles, and covered services. As of 2010, almost 84% of hospice patients were covered under Medicare, with around 5% covered through a Medicaid program and nearly 8% covered by managed care or private insurance (“NHPCO Facts,” 2012). The remaining 3% of hospice patients served in 2010 were covered as charity cases, through self-pay, or through other similar sources (“NHPCO Facts,” 2012).

Even though there was a network of almost 5,000 U.S. hospice agencies as of 2008, the majority of Americans still face death without the comfort and support provided by a qualified hospice team (Silveira et al., 2011). Of the approximately 2.45

million U.S. deaths occurring in 2010, only around 1 million involved hospice services, signifying that nearly 58% of Americans most likely lack appropriate pain control and psychosocial care during their final days (“NHPCO Facts,” 2012). Although the total number of Americans seeking hospice services over the past 20 years has multiplied at least six times, additional progress related to end-of-life care remains necessary (Johnson, Kuchibhatla, Tanis, & Tulsky, 2007). In addition to increasing the reach of hospice to the proportion of dying Americans who are currently lacking, more work is required to assure that the nearly 42% of patients using hospice services take full advantage of the benefits. Though the hospice benefit provides 180 days of care and potentially more, if the patient continues to meet terminal qualifications, roughly 62% of hospice patients in 2010 utilized services for less than one month (“NHPCO Facts,” 2012). Sadly, short lengths of service create challenges for caregivers attempting to build trusting relationships with patients and families, in order to foster positive deaths and provide the highest level of end-of-life care.

Akin to the theme of disparities in service access and utilization in other areas of health care, the literature confirms that the likelihood of receiving hospice care is not uniformly distributed throughout the American population. Research shows important differences regarding the probability of a hospice admission in relation to many other crucial factors, such as sex, for example. Not only have previous studies cited females’ increased odds of hospice enrollment as compared to males, but the most recent statistics regarding hospice use further substantiate this inconsistency (duPreez et al., 2008). In 2010, the majority of all hospice patients were female, with male patients representing only 43.9% of the total hospice patient population (“NHPCO Facts,” 2012). In addition

to sex, research highlights variances in hospice utilization by age group. In general, older Americans remain more likely to engage hospice services than their younger counterparts (Carrion et al., 2011). More specifically, according to 2010 data, almost 39% of all hospice patients were 85 years or older, while around 28% were 75-84 years, roughly 16% were 65-74 years, and about another 16% were 35-64 years of age (“NHPCO Facts,” 2012).

Another important factor appearing to influence the odds of enrolling in hospice care is the nature of a patient’s diagnosis. Upon the introduction of hospice to the U.S., providers were focused on serving primarily individuals living with terminal cancer; nevertheless, there has been a recent shift in the growing number of patients receiving care for non-cancer terminal diseases (Johnson et al., 2007). In fact, as of 2010, almost 64% of all hospice patients were diagnosed with life-limiting diseases other than cancer (“NHPCO Facts,” 2012). The top four non-cancer diagnoses, by percentage of hospice admissions, in 2010 included heart disease (14%), debility unspecified (13%), dementia (13%), and lung disease (8%) (“NHPCO Facts,” 2012). Diagnoses such as stroke, end-stage renal disease, liver disease, ALS, and HIV/AIDS comprised the remainder of non-cancer related hospice admissions (“NHPCO Facts,” 2012).

Closely paralleling the probability that Americans with lower SES will face less positive death experiences, income, wealth, and education have all been documented as key hospice use indicators. For example, a study found that each \$1000 increment in median household income corresponded to a 3% increase in hospice services supply in counties across the U.S., potentially creating less access to end-of-life care for those individuals living in more poverty-stricken areas (Silveira et al., 2011). Another study

discusses their sample's 20% hospice utilization rate for patients with incomes 300% or greater than the federal poverty level, as opposed to a 14% utilization rate for those with incomes less than 100% of the federal poverty level (O'Mahony et al., 2008). Also emphasizing the issues related to SES, access to end-of-life care, and potential hospice utilization, the authors of one study found that populations with a lower median household income or lower educational attainment were significantly more likely to be located more than 30 minutes from a hospice than their counterparts (Carlson, Bradley, Du, & Morrison, 2010).

Perhaps the most pronounced disparities, race and ethnicity seem to play a vital role in the acceptance and utilization of hospice services at the end-of-life. As of 2010, estimates suggest nearly 77% of all hospice patients were White, while the remaining patients identified as African American (8.9%), Asian/Hawaiian/Pacific Islander (2.5%), American Indian/Alaskan Native (.3%), or multiracial/other (11%). Additionally, only around 6% identified as Hispanic/Latino ("NHPCO Facts," 2012). Confirming the accuracy of such estimates, numerous studies report the troubling underuse of hospice care by racial and ethnic minorities. In one study looking at almost 23,000 hospice patients in Florida, around 81% of the sample was White, while around 10% were African American, around 9% were Hispanic, and only about 1% were Asian/Pacific Islander (Carrion et al., 2011). In another analysis, assessing hospice utilization for stroke victims, the authors found that African Americans were significantly less likely to use hospice services when compared to Whites (duPreez et al., 2008). Furthermore, another investigation determined that non-Whites diagnosed with heart failure were also

significantly less likely to enroll in hospice, as compared to their White counterparts (Givens et al., 2010).

Despite the fact that African Americans exhibit the highest mortality rates in the U.S., a considerable portion of the literature focuses on their underrepresentation in hospice care. Although African American patients tend to report a greater need for the types of services provided by hospice, research clearly indicates that they do not embrace end-of-life care in the same manner as Whites (Fishman et al., 2009). While many factors most likely result in such an outcome, treatment preferences appear to play an important role in the hospice utilization gap. Opting for more aggressive care than Whites, African Americans have been shown to have higher rates of artificial nutrition, blood transfusions, and mechanical ventilation (Connolly, Sampson, & Purandare, 2012). Moreover, in a study looking at cancer patients, African Americans were more likely than Whites to continue treatment for a smaller chance of six-month survival (Fishman et al., 2009). Overall, the idea of giving up curative treatment treatments to enroll in hospice may very well create discordance with African American beliefs (Hazin & Giles, 2011).

Chapter III Methods and Procedures

3.1 Background

The data analyzed in this study were obtained from the cross-sectional 2007 National Home and Hospice Care Survey (NHHCS), conducted by the Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS). This nationally representative data set, collected between August 2007 and February 2008, offers descriptive information regarding home health and hospice agencies, staff, services, and patients (“NHHCS - National Home and Hospice Care Survey Homepage,” n.d.). As part of a continuing series of surveys, the NHHCS has been conducted at varying intervals since 1992. All participating hospice agencies were certified by at least one of the following: Medicare, Medicaid, or the state in which patients were served.

3.2 Data Collection

Utilizing a stratified two-stage probability sample design, the NCHS first systematically and randomly selected 1,545 home health and hospice agencies from a sample frame of over 15,000 agencies (“NHHCS - National Home and Hospice Care Survey Homepage,” n.d.). Then, during interviews, staff randomly selected current home health patients and hospice discharges from agency census lists, with the assistance of a computer algorithm. After eliminating agencies outside of the scope of the survey, information was collected in-person from a total of 1,036 hospice and home health

agencies via directors and staff – no patients or patient representatives were interviewed. Agency interviews, along with information collected from medical records, provided details for a total of 9,416 current home health patients and hospice discharges after eliminating those outside of the survey scope. Of the 9,416 final patients/discharges surveyed, 4,733 were hospice cases. Data available for these cases include details such as age, sex, race and ethnicity, diagnoses, and medications taken.

3.3 Variables Selected

From the available data, the following sociodemographic (independent) variables were chosen for this analysis: sex, age at time of discharge, Hispanic/Latino ethnicity, race, primary source of payment for hospice care, and deceased status upon discharge. Regarding sex, response options were limited to male or female. The data set treated age at time of discharge as a continuous variable; therefore, responses were recoded into the following categorical groups for the purposes of this study: 18-34, 35-64, 65-74, 75-84, and 85+. The question regarding Hispanic/Latino ethnicity was answered with a simple yes or no response. Regarding race, options included White, Native Hawaiian/Pacific Islander, African American, Asian, American Indian/Alaska Native, and other. Discharges could be classified as more than one race, and those with an “other” response were treated as missing. Regarding source of payment, discharges were primarily covered by one of the following: Medicare, Medicaid, TRICARE (formally CHAMPUS), Department of Veterans Affairs, CHAMPVA, other government, private insurance, long-term care insurance, self-pay (patient/family), no charge for care, payment source not determined, or other. In order to make results more manageable, the variable was recoded into the following options: no charge/other, self-pay, private insurance, other

government, Medicaid, or Medicare. For deceased status upon hospice discharge, responses included a simple yes or no answer.

In addition to selected sociodemographic variables, clinical (independent) variables were also analyzed in this study, including location hospice was initiated, length of stay in days, level of care at discharge, number of ADL's requiring help, cognitive function at admission/currently, and symptoms of dyspnea, depression, or pain at last visit. Categorical options for the question, "where was patient staying when (he/she) first began receiving hospice care?" (location hospice initiated), were: agency's inpatient/residential facility, private home or apartment, residential care place, skilled nursing facility (nursing home), hospital, or other. The data set treated "number of days patient received hospice care" (length of stay) as a continuous variable, which, for the purpose of this study, was recoded into five corresponding categories: 180+, 90-179, 30-89, 8-29, and < 7.

Categorical possibilities regarding level of care at discharge included routine home care, continuous home care, general inpatient care, and respite care. Cases classified as unknown, refused, or inapplicable were treated as missing. Regarding the number of ADL's requiring help, which includes assistance with bathing, dressing, transferring, walking, or eating, available categorical responses were zero to five. Again, those cases classified as unknown, refused, or inapplicable were treated as missing. For mental status (cognitive function at admission/currently), categorical responses included no cognitive impairment, requires occasional reminders, requires situational assistance, requires routine assistance, or severe cognitive impairment; unknown, refused, or inapplicable selections were treated as missing. Symptoms of dyspnea, pain, and

depression at last visit were treated as simple categorical yes or no responses. Cases with unknown, refused, or inapplicable selections were treated as missing, as well.

The dependent variable in this analysis – hospice diagnosis – was determined from the response to each discharge’s primary admission diagnosis when first beginning hospice service. Potential responses included any valid International Classification of Diseases (ICD-9) code. For comparison purposes, all ICD-9 diagnosis codes were recoded into a main categorical variable, producing two independent groups: cancer vs. non-cancer.

3.4 Statistical Analysis

All statistical analysis was performed using PASW Statistics 18 (SPSS, Inc., 2009, Chicago, IL). In order to determine the distribution of diseases for the sample of discharges, ICD-9 codes were recoded into their corresponding categorical diagnosis groups. Prevalence of disease was then determined by running descriptive frequencies. Additionally, descriptive frequencies were also run for all sociodemographic and clinical variables, in order to determine the prevalence of each. Next, the two diagnosis groups (cancer vs. non-cancer) were compared by each sociodemographic and clinical variable through chi-square tests of independence, evaluating the existence of any between-group differences. Differences were considered significant for p-values less than 5%. In order to better describe relationships between the sociodemographic and clinical variables and hospice diagnosis, logistic regression was performed. Any independent variables that differed significantly during chi-square testing were evaluated for association with hospice diagnosis through univariate logistic regression procedures. Finally, in an attempt to control for potential confounders, all independent variables with significant

chi-square results were combined in one multivariate logistic regression model. Overall relationships were determined by odds ratios, and significance was indicated by 95% confidence intervals.

Chapter IV Results

4.1 Distribution of Diseases

The 2007 NHHCS dataset contained a total of 9,416 patient cases. Of those, 3,905 cases met study inclusion criteria: having a hospice discharge, being a patient age 18 or over, and detection of complete survey responses for selected variables. In terms of disease prevalence (Table 1), 1,865 (47.8%) discharges entered hospice care with a cancer diagnosis. The remaining 2,040 (52.2%) discharges entered with a non-cancer diagnosis. The top non-cancer diagnoses were comprised of discharges exhibiting diseases of the circulatory system; 614 (15.7%) individuals suffered from illnesses such as heart disease, heart failure, or cerebrovascular disease. The second most common non-cancer group, “other”, included mainly those diagnosed with failure to thrive or debility unspecified and contained 485 (12.4%) discharges. Respiratory system illnesses ranked third, as 304 (7.8%) discharges were diagnosed with diseases such as pulmonary fibrosis or chronic airway obstruction. Ranking fourth, 234 (6%) discharges were diagnosed with nervous system disorders, including Parkinson’s disease, multiple sclerosis, and muscular dystrophy. The fifth most common non-cancer diagnosis included organic psychotic conditions such as dementia – 206 (5.3%) discharges exhibited these types of terminal diseases. Other less common non-cancer diagnoses represented were HIV/AIDS and diseases of the digestive, genitourinary, and musculoskeletal systems.

4.2 Comparison of Cancer/Non-cancer Diagnoses by Sociodemographics

Evaluating the prevalence of selected sociodemographic variables in relation to hospice diagnosis (Table 2), the majority of the non-cancer group, 1,228 (60.2%) discharges, identified as female, while the majority of the cancer group, 959 (51.4%) discharges, identified as male. Accordingly, a significant difference regarding sex prevailed between the two hospice diagnosis groups ($X^2 (1) = 53.052, p < .001$). For non-cancer diagnoses, an age of 85 years or older was most common, with 1,011 (49.6%) discharges classified in the corresponding age range. In contrast, the most common age for a cancer diagnosis ranged between 75 and 84 years, with this category including 605 (32.4%) discharges. A significant age difference between the two hospice diagnosis groups was discovered ($X^2 (4) = 612.399, p < .001$). Comparing ethnicity between the two hospice diagnosis groups, 52 (2.5%) non-cancer discharges and 54 (2.9%) cancer discharges were reported as having a Hispanic/Latino origin. No significant difference between the two diagnosis groups was found in regards to ethnicity ($X^2 (1) = .443, p = .506$).

The majority of both non-cancer and cancer hospice discharges were White, totaling 1,842 (90.3%) and 1,727 (92.6%), respectively. Analysis showed a significant difference in White racial status between the two diagnosis groups ($X^2 (1) = 6.591, p = .010$). The second most common racial status was African American, with 154 (7.5%) non-cancer discharges and 108 (5.8%) cancer discharges represented. Results exposed a significant difference in African American racial status between the two diagnosis groups, as well ($X^2 (1) = 4.811, p = .028$). No significant differences between diagnosis groups were discovered regarding Native Hawaiian/Pacific Islander, Asian, and

American Indian/Alaska Native racial status. For primary source of payment, most utilized Medicare benefits – 1,909 (93.6%) non-cancer discharges and 1,341 (71.9%) cancer discharges. However, a significant difference was noted when comparing the two diagnosis groups in terms of primary payment source ($X^2 (5) = 343.545, p < .001$). Upon discharge, 1,511 (74.1%) non-cancer diagnosed hospice patients and 1,641 (88%) cancer diagnosed hospice patients were deceased, highlighting a significant difference between the two groups' prevalence of death ($X^2 (1) = 121.302, p < .001$).

4.3 Comparison of Cancer/Non-cancer Diagnoses by Clinical Characteristics

Upon assessment of the prevalence of selected clinical variables in relation to hospice diagnosis (Table 3), private residences and nursing homes were the most common locations hospice was initiated for both diagnosis groups. For the non-cancer group, 1,058 (51.9%) discharges began hospice service at home, while 585 (28.7%) discharges were served in a nursing home. In the cancer group, 1,459 (78.2%) discharges also received care at their home, and 179 (9.6%) discharges participated in a hospice program in a nursing home facility. Overall, a statistically significant difference was detected in the location of hospice service initiation between the two groups ($X^2 (5) = 358.319, p < .001$). Regarding length of stay, 1,015 (49.8%) non-cancer discharges and 1,144 (61.4%) cancer discharges received 29 days or less of hospice care services. Correspondingly, only 376 (18.4%) non-cancer and 120 (6.4%) cancer discharges received hospice services for at least 180 days. The between group differences related to length of stay were found to be statistically significant ($X^2 (4) = 171.772, p < .001$). Examining the level of care at time of discharge, most non-cancer and cancer discharges

were classified as routine homecare, and the difference between both groups did not hold significance ($X^2 (3) = .704, p = .872$).

Most discharges in both diagnosis groups required assistance with three to five ADL's. Assistance with four ADL's was the most common response, as evidenced by 649 (31.8%) non-cancer and 520 (27.9%) cancer discharges' needs. Results indicate significant differences between the two groups and their requirement of assistance with ADL's ($X^2 (5) = 148.092, p < .001$). In terms of level of cognitive function at admission/currently, the most common response for the non-cancer diagnosed group was the need for routine assistance, with 626 (30.7%) discharges included. However, the most common response for the cancer diagnosis group was no cognitive impairment, with 880 (47.2%) discharges included. Differences in cognitive function at admission/currently significantly differed between the two diagnosis groups ($X^2 (4) = 524.468, p < .001$). Upon assessment of symptoms that were present at the most recent hospice visit, 872 (42.7%) non-cancer discharges experienced dyspnea, as opposed to the 894 (47.9%) cancer discharges exhibiting the same issue. This symptomatic difference between the two groups proved statistically significant ($X^2 (1) = 10.596, p < .001$). With 181 (8.9%) non-cancer discharges and 138 (7.4%) cancer discharges reported as depressed, such between group differences remained insignificant ($X^2 (1) = 2.818, p = .093$). Finally, when addressing pain, 521 (25.5%) non-cancer discharges and 708 (38%) cancer discharges faced challenges. Like dyspnea, analysis of pain presence during the previous hospice visit resulted in significant differences between the two diagnosis groups ($X^2 (1) = 69.721, p < .001$).

4.4 Univariate Logistic Regression

Univariate logistic regression analysis revealed quite a few important predictive relationships between the classification of terminal hospice diagnosis (cancer vs. non-cancer) and selected sociodemographic and clinical variables (Table 4). Regarding the relationship with sex, females appeared significantly less likely to enter hospice with a cancer diagnosis than males (OR = 0.625; 95% CI: 0.550, 0.709). Considering a link with age, hospice discharges in the 75-84 age range were significantly less likely to enter hospice care with a cancer diagnosis, as compared to other age groups (OR = 0.226; 95% CI: 0.064, 0.797). Similarly, the 85+ age group also proved significantly less likely to have a cancer diagnosis at time of admission (OR = 0.072; 95% CI: 0.020, 0.256). Concerning an association with race, White hospice discharges were significantly more likely to admit with a cancer diagnosis (OR = 1.345; 95% CI: 1.072, 1.688), while African American's were significantly less likely to do so (OR = 0.753; 95% CI: 0.584, 0.971). Examining a potential relationship with primary payment source, results indicated that hospice discharges with private insurance were significantly more likely to have a cancer diagnosis (OR = 3.246; 95% CI: 1.809, 5.824), and that those with Medicare were significantly less likely to enter hospice care with cancer (OR = 0.337; 95% CI: 0.206, 0.551). Also, discharges that were deceased were significantly more likely to have been diagnosed with cancer (OR = 2.565; 95% CI: 2.161, 3.044).

Results proved significant for three of the six categories related to place of hospice service initiation. Hospice discharges beginning care in their private homes were more likely to have a cancer diagnosis (OR = 1.915; 95% CI: 1.400, 2.619), whereas those initiating care in a nursing home were less likely to have cancer (OR = 0.425; 95%

CI: 0.301, 0.601). Additionally, hospice discharges beginning services in residential care facilities were even less likely to have a cancer diagnosis (OR = 0.313; 95% CI: 0.196, 0.500). Regarding length of stay, hospice discharges receiving less than 180 days of services were all significantly more likely to belong to the cancer diagnosis group. However, discharges receiving only 8-29 days of hospice care were significantly most likely to be admitted with cancer (OR = 4.238; 95% CI: 3.345, 5.370). In terms of needing help with ADL's, hospice discharges requiring assistance with two to five activities were all significantly less likely to have a cancer diagnosis documented. Hospice discharges that struggled with five ADL's were least likely to be diagnosed with cancer (OR = 0.284; 95% CI: 0.220, 0.366). Looking at cognitive function upon admission/currently, hospice discharges with any level of impairment whatsoever were deemed significantly less likely to belong to the cancer diagnosis group. Particularly, discharges with severe cognitive impairment were the least likely to enter hospice care with cancer (OR = 0.095; 95% CI: 0.073, 0.124). Lastly, significant associations were found in relation to both dyspnea and pain symptoms and hospice diagnosis. Discharges that experienced dyspnea were more likely to have cancer (OR = 1.233; 95% CI: 1.087, 1.399), as were those patients who faced pain (OR = 1.784; 95% CI: 1.556, 2.045).

4.5 Multivariate Logistic Regression Model

When controlling for potential confounders in the multivariate logistic regression model (Table 5), many of the associations between hospice diagnosis and sociodemographic and clinical variables remained significant; however, noteworthy changes occurred. One of the relationships no longer considered significant, females were found only very slightly less likely to admit to hospice with a cancer diagnosis

when compared to males (OR = 0.920; 95% CI: 0.787, 1.074). Another adjustment, the only significant relationship between age and diagnosis was found in the 85+ group, as they continued to be much less likely to enter hospice care with a cancer diagnosis (OR = 0.254; 95% CI: 0.066, 0.976). In addition to sex, race was determined to be of no significant relation to hospice diagnosis for both White (OR = 1.664; 95% CI: 0.930, 2.975) and African American discharges (OR = 1.273; 95% CI: 0.667, 2.430). Regarding primary source of payment, multivariate regression indicated that the only significant association with hospice diagnosis remained private insurance, which led to a greater likelihood of having cancer (OR = 2.458; 95% CI: 1.268, 4.765). While still proving significantly related to the chance of a cancer diagnosis, the odds ratio for being deceased upon hospice discharge increased slightly (OR = 3.041; 95% CI: 2.440, 3.790).

The only significant association between hospice diagnosis group and location of hospice initiation was found for those discharges located at a private residence. Beginning hospice service in one's own home predicted a much greater chance of cancer diagnosis (OR = 1.806; 95% CI: 1.243, 2.625). Like the results from univariate analysis, all lengths of stay shorter than 180 days were significantly associated with increased chances for a cancer diagnosis. Moreover, a length of stay ranging from 8-29 days carried the highest odds of being linked to a cancer diagnosis (OR = 3.043; 95% CI: 2.296, 4.033). Also similar to univariate results, the relationship between the number of ADL's requiring help and type of cancer diagnosis continued to exist. Hospice discharges requiring assistance with two to five ADL's were found significantly less likely to admit with a cancer diagnosis when compared to individuals who needed help with zero to one activity. Specifically, those discharges relying on assistance with three

ADL's were least likely to be classified with a cancer hospice diagnosis (OR = 0.471; 95% CI: 0.339, 0.655). Additionally, the association in regards to level of cognitive function at admission/currently and hospice diagnosis continued to show significance. All levels of cognitive function involving any impairment, even if only slight, predicted less chance for a cancer diagnosis, with severe cognitive impairment being the least likely (OR = 0.148; 95% CI: 0.108, 0.201). Finally, while pain symptoms still proved significantly related to hospice diagnosis, predicting an increased chance that a discharge admitted for cancer (OR = 1.583; 95% CI: 1.338, 1.872), the association between diagnosis and dyspnea lost significance (OR = 0.855; 95% CI: 0.731, 1.002).

Chapter V

Discussion and Conclusion

This study explores potential disparities related to the use of hospice care, as observed between individuals who presented with terminal cancer diagnoses versus those who presented with other non-cancer terminal diseases. Of particular interest were details regarding main differences between the two hospice diagnosis groups and the degree to which hospice patient characteristics are related. After controlling for both sociodemographic and clinical variables in a multivariate logistic regression model, results confirmed significant relationships between a cancer vs. non-cancer hospice diagnosis classification and multiple patient characteristics, largely those of clinical nature. However, important differences concerning sociodemographics also emerged.

Descriptive analysis showed that the majority of hospice discharges involved in this study were seeking comfort care for a non-cancer related disease. The most common non-cancer diagnoses consisted of conditions such as heart disease, cerebrovascular disease, failure to thrive, debility unspecified, and pulmonary disease. While results do parallel other data suggesting a non-cancer majority, findings from this study regarding estimated proportions of cancer vs. non-cancer diagnoses differ slightly. Another U.S. study, looking at racial differences and non-cancer hospice diagnoses, found that only around 40% of their sample presented with cancer, in comparison to the nearly 48% in this study (Johnson et al., 2007). Although not entirely nationally representative, their sample did include patients from eight states in differing geographic locations.

Accordingly, it is more likely that their observation of less cancer patients relates to a larger sample size, including approximately 162,000 more cases than this study. In terms of distribution of non-cancer terminal disease, results from this study generally agree with the National Hospice and Palliative Care Organization's most recent findings from 2010 data ("NHPCO Facts," 2012).

Descriptive analysis also revealed that over 90% of all hospice discharges included in this study identified as White, racially. In comparison, only about 7% of total discharges identified as African American. The remaining minority identified racially as American Indian or Alaska Native (~1%), Asian (~1%), or Native Hawaiian or Pacific Islander (.2%). In terms of ethnicity, only about 3% of discharges were considered to be of Hispanic or Latino origin. While certainly concerning, the racial divide found in this study is not a new concept. In a study conducted in Florida around the same time, authors reported their sample to be primarily represented by White patients (~81%), while African Americans accounted for almost 10%, Asian Americans or Pacific Islanders accounted for .5%, and around 9% were of Hispanic ethnicity (Carrion et al., 2011). It is quite possible that the minimal differences in terms of racial composition between the two studies may be attributed to their less-generalizable sample, gathered from only one agency in central Florida. While differences in comfort care utilization likely stem from multiple causes, research has shown that some races, particularly African Americans, often have misconceptions about hospice services or lack awareness of such care altogether (Enguidanos, Kogan, Lorenz, & Taylor, 2011). Also related to race, culture and spirituality/religion have been found to shape end-of-life decisions, remarkably those addressing treatment options (Bosma, Apland, & Kazanjian, 2010).

The comparison of cancer to non-cancer hospice discharges in this study revealed significant sociodemographic and clinical differences between the two diagnosis groups, potentially pointing to important hospice utilization disparities. Thus, each significant between-group difference was further examined in an attempt to more concretely describe relationships between variables. Addressing sex, women comprised the majority of non-cancer diagnoses and males dominated the cancer group, as comparably noted in other palliative care research (Ostgathe et al., 2011). It is possible that observed sex differences in hospice utilization might stem from inherent biological processes affecting disease epidemiology – those that also play a role in the average life expectancy gap between American males and females. Interestingly, although unadjusted odds of a cancer diagnosis were significantly lower for females during regression analysis, final adjusted odds resulted in no significant relationship between sex and hospice diagnosis.

Though all racial minorities utilized hospice much less than Whites, there were no significant racial differences found between non-cancer and cancer diagnoses for American Indians/Alaska Natives, Asians, or Native Hawaiians/Pacific Islanders. Nevertheless, African Americans admitted significantly more for non-cancer diagnoses, while Whites were significantly more often diagnosed with cancer. Since hospice services generally require patients to forego curative efforts for comfort care, this observation is logical, as research has shown African Americans many times elect more aggressive measures than Whites, expressly when continuing cancer treatments (Fishman et al., 2009). Much like the analysis of sex, unadjusted odds of a cancer diagnosis were significantly higher for Whites and lower for African Americans, but no significant relationship resulted when examining adjusted odds in regards to race and diagnosis. It is

important to note, however, that the 95% confidence intervals were very close to significance for both sex and White race variables. The listwise method utilized in cleaning data for this study could be one potential explanation for the barely insignificant adjusted results, depending on whether a disproportionate number of African American cases were missing data and excluded from analysis.

Examining differences in age, the non-cancer group was mostly comprised of discharges 75 years and older. On the other hand, the majority of cancer diagnoses occurred in discharges ages 35-84. Similarly, one study reported a majority of non-cancer patients over the age of 65 and majority of cancer patients age 65 or under, which suggests that cancer may more often affect those in adulthood or middle age than those considered old (Johnson et al., 2007). In this study, regression analysis produced adjusted odds indicating that discharges 85 and older are significantly less likely to enroll with a cancer hospice diagnosis. The Johnson study found the same significant relationship for age; however, it applied to hospice patients 65 and older. The conflicting age results may be related to the number of categories included in each analysis – this study contained five age categories, while theirs only utilized two.

In terms of medical coverage, the results of this study agree with previous research. Even though the majority of all discharges used Medicare as a primary payment source, private insurance or Medicaid covered those with cancer diagnoses more often than their non-cancer counterparts. Such a finding may be substantiated by the fact that nearly 30% of all cancer discharges were between the ages of 18 and 64, creating increased likelihood for Medicare ineligibility. Ultimately, adjusted odds signify that private insurance increases the chances of admitting with cancer, which has also been

shown in other studies looking at health maintenance organizations and hospice diagnoses (Johnson et al., 2007).

Regarding status upon hospice discharge, fewer non-cancer diagnosed individuals were deceased when compared to those with cancer. Additionally, adjusted odds validated the relationship between discharge status and diagnosis, showing that cancer diagnoses are significantly more likely to be deceased at the end of their hospice stay. Compared with other research, this finding certainly makes sense. Estimates exist claiming that live discharges occur anywhere from 6-15% of the time, due to improved or stabilized conditions or the decision to pursue more aggressive treatment. Furthermore, studies show that live discharge status and a non-cancer diagnosis are related (Enck, 2011).

While more cancer than non-cancer discharges began hospice services at their private homes, the opposite was observed with regards to beginning services at residential care facilities and nursing homes. Accordingly, multivariate regression specified a significant relationship between location of hospice initiation and diagnosis, providing that discharges beginning hospice at home were more likely to have cancer. Such a finding seems appropriate, due to the fact that facilities offer additional services unavailable in the home, and research has shown that non-cancer hospice patients exhibit poorer functional status and higher needs for nursing support (Ostgathe et al., 2011). Moreover, results from this study also support a functionality difference – more cancer discharges required assistance with zero to one ADL's and had little to no cognitive impairment, whereas more non-cancer discharges needed help with three to five ADL's and displayed significantly less cognitive function. Along the same lines, adjusted odds

showed that needing assistance with more than one ADL, as well as exhibiting cognitive impairment at any level, led to decreased chances of a cancer diagnosis.

In addition to the majority of all discharges receiving hospice services for less than three months, this study provided that those with non-cancer diagnoses more often had greater length of stays, while those with cancer diagnoses were more often enrolled for eight days to three months. Not only has evidence validated that most hospice referrals occur too late in the dying process, but studies also show that the problem is further compounded by the physician reimbursement incentives related to continuing curative treatments, as often seen with cancer patients (Hoefler, 2010). In this study, multivariate regression results indicated a significantly greater chance of a cancer diagnosis for any length of stay less than 180 days; however, a length of stay of 29 days or less held the highest predictive value.

Finally, assessing differences in symptoms between the two diagnosis groups, pain and dyspnea were indicated more often for cancer patients, but no significant difference existed for depression. Although another study comparing cancer and non-cancer patients reported no significant difference in pain and a significantly greater amount of non-cancer patients suffering from dyspnea, conflicting results may be attributed to potential variance of specific cancer diagnoses included in each sample, as some malignancies have the ability to cause more pain and symptoms than others (Given, Given, Azzouz, Kozachik, & Stommel, 2001). In this sample, final adjusted odds indicated that discharges with pain symptoms were significantly more likely to admit with a cancer diagnosis. While regression revealed a non-significant relationship

between hospice diagnosis and dyspnea symptoms, 95% confidence intervals came very close to demonstrating a significantly protective association with cancer diagnosis.

When comparing this study to others that also focus on disparities and hospice utilization, important strengths are evident. First, this analysis includes nationally representative data, as provided by the CDC, National Center for Health Statistics. The agencies surveyed were chosen systematically and randomly, with probability proportional to size, from a sample frame of over 15,000 agencies across the U.S. (“NHHCS - National Home and Hospice Care Survey,” n.d.). Although it is important to take caution when referring to the results as generalizable, this study likely represents the U.S. population to a greater degree than other studies in the literature utilizing data from one specific hospice agency with multiple locations or vice-versa. Another strength lies in the data and methods allowing for the control of confounders. Because of a multitude of available variables in the data set, it was possible to analyze independent variables’ relationships to the dependent variable in light of several sociodemographic and clinical characteristics.

While strong in some aspects, this study certainly poses its own limitations. Perhaps most importantly, the analysis was based on cross-sectional survey data, making it impossible to evaluate true “causality”. Since such data is gathered at only one point in time, prevalence odds ratios only provide potential evidence of relationships or associations between variables. Another limitation of this study relates to the use of the listwise deletion method. Of the original 4,733 hospice cases included in the data set, only 3,905 were used during final analysis, due to the fact that data was missing for key variables. Although still a large sample size, the reduction in cases may have affected the

significance of results through changes in statistical power. Other limitations involve the inability to control for religion/spirituality and SES (income and education), both of which have been shown to play a role in hospice utilization. Primary payer source was used as proxy variable for income, as health care coverage has been directly linked with poverty status; however, the substitution is far from a perfect choice (Collins, Robertson, Garber, & Doty, 2012). Finally, although research has pinpointed links between characteristics (e.g., size and location) of the agency providing care and hospice use and diagnosis, controls for agency differences were not included in this analysis (Johnson et al., 2007). Further research is needed to more comprehensively build a multivariate regression model that better predicts patient characteristics' relationships with diagnosis.

Overall, this study highlights important implications related to continuing “business as usual” in the end-of-life health care field. Not only do results further confirm statistics exposing the alarmingly low utilization of hospice services in general, but they also validate diagnosis-specific differences in use and required care, seemingly driven by both individual and population-based characteristics. In order to increase utilization and access rates and eliminate current disparities, patients presenting with certain terminal diseases may require greater provider flexibility in terms of hospice eligibility requirements and services offered. Consequently, in addition to health education promoting general awareness of hospice benefits, it is necessary to consider addressing end-of-life care systematic and policy standards that may be strengthening hospice use disparities, such as those emphasized in this analysis.

Some critics suggest moving from a prognosis-based eligibility system to one that is needs based, for example, which may increase length of stay and allow for more

comprehensive care for those that are not 100% ready to give up hope for their curative treatment (Carlson, Morrison, & Bradley, 2008). Another suggestion that may impact a reduction in hospice use disparities requires changes on the educational side of the U.S. health care system. Research shows that although most medical and nursing schools offer some training on end-of-life matters, the average student spends less than 15 hours focused on the topic, and that only one-tenth of programs offer a complete palliative care course. Furthermore, only about half of students spend time with a hospice patient (Dickinson, 2007). Reconsidering medical education requirements may be an effective way to encourage physician comfort concerning the topic of death, thereby potentially increasing the likelihood that hospice services are addressed more frequently with patients. While many possible reform options exist, each ignites its own, fueled debate and requires additional research to determine feasibility from both cost and logistical viewpoints.

In conclusion, this study revealed several important disparities related to the use of hospice between cancer and non-cancer discharges. As determined through multivariate logistic regression, the following factors were found significantly associated with primary hospice diagnosis: age of 85+ at discharge, private insurance as a primary payment source, deceased status upon discharge, hospice initiation at primary residence, length of stay less than 180 days, requiring assistance with two to five ADL's, level of cognitive function, and presence of pain. Although not shown to be associated with primary diagnosis in light of the final results, sex and White racial status came extremely close to reaching significance. While additional research is required to more meticulously describe relationships shaping cancer vs. non-cancer hospice disparities, the

differences that emerged from this study offer further insight to aid in the fight against end-of-life care inequalities in the U.S.

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**Appendix
Statistical Summary Tables**

Table 1. Distribution of Terminal Diseases, *n* = 3905

Terminal Disease	<i>n</i>	%
HIV/AIDS	7	.2
Organic Psychotic Conditions (including Dementia)	206	5.3
Nervous System (including Parkinson's, Multiple Sclerosis, Muscular Dystrophy)	234	6.0
Circulatory System (including Ischemic Heart Disease, Heart Failure, Cerebrovascular Disease)	614	15.7
Respiratory System (including Pulmonary Fibrosis, Chronic Airway Obstruction)	304	7.8
Digestive System (including Chronic liver disease, Cirrhosis)	72	1.8
Genitourinary System (including Renal Failure, Chronic Kidney Disease)	112	2.9
Musculoskeletal System/Connective Tissue (including Systemic Sclerosis, Bone Infections)	6	.2
Other (including Failure to Thrive, Debility Unspecified)	485	12.4
Total Non-Cancer	2040	52.2
Cancer	1865	47.8

Table 2. Comparison of Sociodemographic Variables Between Discharges with Cancer vs. Non-cancer Hospice Diagnoses

Variable	Non-Cancer (n = 2040)	Cancer (n = 1865)	Difference <i>p</i>
Sex			< .001
Male	812 (39.8%)	959 (51.4%)	
Female	1228 (60.2%)	906 (48.6%)	
Age			< .001
18-34	3 (.1%)	13 (.7%)	
35-64	143 (7%)	530 (28.4%)	
65-74	265 (13%)	400 (21.4%)	
75-84	618 (30.3%)	605 (32.4%)	
85+	1011 (49.6%)	317 (17%)	
Hispanic/Latino	52 (2.5%)	54 (2.9%)	.506
Race			
White	1842 (90.3%)	1727 (92.6%)	.010
Native Hawaiian/Pacific Islander	6 (.3%)	2 (.1%)	.293
African American	154 (7.5%)	108 (5.8%)	.028
Asian	18 (.9%)	14 (.8%)	.648
American Indian/Alaska Native	20 (1%)	13 (.7%)	.334
Primary Payment Source			< .001
No Charge/Other	24 (1.2%)	50 (2.7%)	
Self-pay	9 (.4%)	22 (1.2%)	
Private Insurance	42 (2.1%)	284 (15.2%)	
Other Government	13 (.6%)	54 (2.9%)	
Medicaid	43 (2.1%)	114 (6.1%)	
Medicare	1909 (93.6%)	1341 (71.9%)	
Deceased	1511 (74.1%)	1641 (88%)	< .001

Table 3. Comparison of Clinical Variables Between Discharges with Cancer vs. Non-cancer Hospice Diagnoses

Variable	Non-Cancer (n = 2040)	Cancer (n = 1865)	Difference p
Location Hospice Initiated			< .001
Agency Inpatient/Residential Facility	100 (4.9%)	72 (3.9%)	
Private Residence	1058 (51.9%)	1459 (78.2%)	
Residential Care Facility	164 (8%)	37 (2%)	
Nursing Home	585 (28.7%)	179 (9.6%)	
Hospital	120 (5.9%)	105 (5.6%)	
Other	13 (.6%)	13 (.7%)	
Length of Stay in Days			< .001
180+	376 (18.4%)	120 (6.4%)	
90-179	235 (11.5%)	151 (8.1%)	
30-89	414 (20.3%)	450 (24.1%)	
8-29	485 (23.8%)	656 (35.2%)	
< 7	530 (26%)	488 (26.2%)	
Level of Care at Discharge			.872
Routine Homecare	1668 (81.8%)	1508 (80.9%)	
Continuous Homecare	87 (4.3)	82 (4.4%)	
GIP	265 (13%)	258 (13.8%)	
Respite	20 (1%)	17 (.9%)	
Number of ADL's Requiring Help			< .001
0	109 (5.3%)	277 (14.9%)	
1	57 (2.8%)	127 (6.8%)	
2	198 (9.7%)	184 (9.9%)	
3	451 (22.1%)	342 (18.3%)	
4	649 (31.8%)	520 (27.9%)	
5	576 (28.2%)	415 (22.3%)	
Cognitive Function at Admission			< .001
No Cognitive Impairment	410 (20.1%)	880 (47.2%)	
Requires Occasional Reminders	265 (13%)	331 (17.7%)	
Requires Situational Assistance	342 (16.8%)	303 (16.2%)	
Requires Routine Assistance	626 (30.7%)	270 (14.5%)	
Severe Cognitive Impairment	397 (19.5%)	81 (4.3%)	
Dyspnea	872 (42.7%)	894 (47.9%)	.001
Depression	181 (8.9%)	138 (7.4%)	.093
Pain	521 (25.5%)	708 (38%)	< .001

Table 4. Unadjusted Odds Ratios and 95% Confidence Intervals for Variables Predicting Cancer Hospice Diagnosis (vs. Non-Cancer Hospice Diagnosis), $n = 3905$

Variable	Odds Ratio	95% CI
Sex		
Male	1	
Female	0.625*	(0.550, 0.709)
Age		
18-34	1	
35-64	0.855	(0.240, 3.042)
65-74	0.348	(0.098, 1.234)
75-84	0.226*	(0.064, 0.797)
85+	0.072*	(0.020, 0.256)
Race		
White	1.345*	(1.072, 1.688)
African American	0.753*	(0.584, 0.971)
Primary Payment Source		
No Charge/Other	1	
Self-pay	1.173	(0.470, 2.931)
Private Insurance	3.246*	(1.809, 5.824)
Other Government	1.994	(0.917, 4.336)
Medicaid	1.273	(0.698, 2.319)
Medicare	0.337*	(0.206, 0.551)
Deceased	2.565*	(2.161, 3.044)
Location Hospice Initiated		
Agency Inpatient/Residential Facility	1	
Private Residence	1.915*	(1.400, 2.619)
Residential Care Facility	0.313*	(0.196, 0.500)
Nursing Home	0.425*	(0.301, 0.601)
Hospital	1.215	(0.814, 1.814)
Other	1.389	(0.608, 3.173)
Length of Stay in Days		
180+	1	
90-179	2.013*	(1.507, 2.690)
30-89	3.406*	(2.666, 4.351)
8-29	4.238*	(3.345, 5.370)
< 7	2.885*	(2.271, 3.666)
Number of ADL's Requiring Help		
0	1	
1	0.877	(0.598, 1.286)
2	0.366*	(0.271, 0.493)
3	0.298*	(0.230, 0.388)
4	0.315*	(0.246, 0.405)
5	0.284*	(0.220, 0.366)
Cognitive Function at Admission		
No Cognitive Impairment	1	
Requires Occasional Reminders	0.582*	(0.477, 0.711)
Requires Situational Assistance	0.413*	(0.340, 0.501)
Requires Routine Assistance ³	0.201*	(0.167, 0.242)
Severe Cognitive Impairment	0.095*	(0.073, 0.124)
Dyspnea	1.233*	(1.087, 1.399)
Pain	1.784*	(1.556, 2.045)

Table 5. Adjusted Odds Ratios and 95% Confidence Intervals for Variables Predicting Cancer Hospice Diagnosis (vs. Non-Cancer Hospice Diagnosis), $n = 3905$

Variable	Odds Ratio	95% CI
Sex		
Male	1	
Female	0.920	(0.787, 1.074)
Age		
18-34	1	
35-64	0.994	(0.263, 3.764)
65-74	0.778	(0.203, 2.990)
75-84	0.671	(0.175, 2.574)
85+	0.254*	(0.066, 0.976)
Race		
White	1.664	(0.930, 2.975)
African American	1.273	(0.667, 2.430)
Primary Payment Source		
No Charge/Other	1	
Self-pay	1.161	(0.408, 3.309)
Private Insurance	2.458*	(1.268, 4.765)
Other Government	2.121	(0.874, 5.148)
Medicaid	1.426	(0.718, 2.832)
Medicare	0.716	(0.403, 1.272)
Deceased	3.041*	(2.440, 3.790)
Location Hospice Initiated		
Agency Inpatient/Residential Facility	1	
Private Residence	1.806*	(1.243, 2.625)
Residential Care Facility	0.655	(0.384, 1.118)
Nursing Home	0.846	(0.564, 1.269)
Hospital	1.302	(0.817, 2.074)
Other	1.025	(0.375, 2.802)
Length of Stay in Days		
180+	1	
90-179	1.622*	(1.151, 2.286)
30-89	2.347*	(1.755, 3.138)
8-29	3.043*	(2.296, 4.033)
< 7	2.881*	(2.147, 3.867)
Number of ADL's Requiring Help		
0	1	
1	0.972	(0.624, 1.513)
2	0.541*	(0.376, 0.779)
3	0.471*	(0.339, 0.655)
4	0.499*	(0.365, 0.680)
5	0.547*	(0.396, 0.755)
Cognitive Function at Admission		
No Cognitive Impairment	1	
Requires Occasional Reminders	0.725*	(0.576, 0.912)
Requires Situational Assistance	0.569*	(0.454, 0.713)
Requires Routine Assistance	0.305*	(0.244, 0.381)
Severe Cognitive Impairment	0.148*	(0.108, 0.201)
Dyspnea	0.855	(0.731, 1.002)
Pain	1.583*	(1.338, 1.872)