

Racial/Ethnic Variation in Care Preferences and Care Outcomes

among United States Hospice Enrollees

By

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Dedication

This work, and all that led to it, is dedicated to the two most amazing people I have ever known: my father, Richard J. Laguna, and my mother, Jodie M. Laguna. You have always been there to love me, support me, challenge me, guide me, and motivate me. I would not be who I am today if it were not for you two.

I am, because of you.

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Abstract

Despite the rapid growth of hospice care in the United States over the past several decades, racial/ethnic minorities continue to utilize higher levels of aggressive life-prolonging interventions at end of life, often resulting in poorer care experiences. While previous research has expanded understanding of racial/ethnic end-of-life disparities outside of hospice, an in-depth analysis of the relationship between patient care preferences and key end-of-life outcomes within a racially/ethnically diverse hospice population remains to be conducted.

Using the 2007 wave of the National Home Health and Hospice Care Survey (NHHCS), a retrospective analysis of clinical and service use outcomes was conducted to test for racial/ethnic variation following hospice enrollment. Key outcomes of interest included advance care planning, emergent care utilization, hospice length of stay, and site of death. In total, 3,661 White, Black, and Hispanic Medicare hospice patients were analyzed, representing approximately 788,872 older Americans. Results indicated that advance care planning varied by race/ethnicity, with Blacks less likely to complete an advance directive, Hispanics more likely to elect a do not resuscitate order, and both Blacks and Hispanics less likely to designate a healthcare proxy. Findings also indicated that Blacks were less likely to utilize emergent care following adjustment for advance care planning. While Hispanics were more likely to die in the first week of hospice care, Blacks were more likely to die in the first month of hospice care. Concerning site of death, Blacks and Hispanics were more likely to die in a home-like setting, and Hispanics were also more likely to die in a hospital. Results also indicated that advance care planning reduced the likelihood of emergent care utilization, death in the first week of

hospice care, death in the first month of hospice care, and death in a hospital. Lastly, patients engaging in advance care planning were also more likely to die in a home-like setting.

Findings support racial/ethnic variation following hospice enrollment, but suggest that differences within hospice contrast with those in the larger healthcare system. Furthermore, results support the protective effect of advance care planning among hospice enrollees. The data presented have substantial clinical and policy implications for improving the care of all patients at end of life. Additional research is needed to better understand and address reported racial/ethnic differences following hospice enrollment.

Chapter 1: The Problem and Its Underlying Framework

Background of the Problem

Although high-quality care for the dying is available, racial/ethnic minorities continue to have poor end-of-life (EOL) care experiences. During the last year of life, racial/ethnic minorities utilize less palliative-based care and more aggressive, acute interventions that do little to extend life while negatively impacting patient symptom management, quality of life, emotional support, and care satisfaction (Barnato, Chang, Saynina, & Garber, 2007; Earle et al., 2008; Goldstein, Elliott, Lehrman, Hambarsoomian, & Giordano, 2010; Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009; Mazanec, Daly, & Townsend, 2010; A. K. Smith, Earle, & McCarthy, 2009; Teno et al., 2004; Zhang et al., 2009). Although differences are due in part to a decreased willingness among racial/ethnic minorities to forgo curative treatments (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Casarett, Van Ness, O'Leary, & Fried, 2006; Duffy, Jackson, Schim, Ronis, & Fowler, 2006), care disparities exist (Hanchate et al., 2009). To address these disparities, research has focused on improving racial/ethnic minority patient knowledge of and access to EOL care programs; however, research investigating minority outcomes within hospice, the most widely used form of EOL care in the United States, is scarce.

Hospice is designed to meet the unique needs of dying patients in the last six months of life. Studies of hospice have documented effective pain management (Hanlon, Perera, Sevvick, Rodriguez, & Jaffe, 2010), higher care satisfaction among patients and families (Dy et al., 2008; Teno et al., 2004), and an increased likelihood of dying in-place (Hogan, Lunney, Gabel, & Lynn, 2001; Teno et al., 2004). Despite these benefits,

hospice remains widely underutilized by racial/ethnic minorities (Enguidanos, Yip, & Wilber, 2005; Givens, Tjia, Zhou, Emanuel, & Ash, 2010; K. S. Johnson, Kuchibhatla, Tanis, & Tulsky, 2008; Kwak, Haley, & Chiriboga, 2008; Lepore, Miller, & Gozalo, 2011; Ngo-Metzger, Phillips, & McCarthy, 2008). Among the minorities who elect hospice, care experiences following enrollment remain unclear largely due to outdated studies and sample limitations. For example, research suggests that hospice length of stay (LOS), an important care quality indicator, is longer for Blacks and Hispanics compared to Whites, but findings are limited due to non-representative samples (Cólón & Lyke, 2003; Hardy et al., 2012; K. S. Johnson, Kuchibhatla, & Tulsky, 2011). Similarly, hospice decedent racial/ethnic variation in site of death (SOD), another key indicator of EOL care quality, has been examined only once since the Medicare Hospice Benefit was established in 1983, and significant sample limitations constrain the generalizability of findings (K. S. Johnson et al., 2005). Thus, while racial/ethnic differences in EOL care preferences and medical service use have been documented outside of hospice, and although research suggests that that hospice patient care experiences currently differ by race/ethnicity, an in-depth analysis of racial/ethnic variation in key EOL outcomes following hospice enrollment remains to be conducted.

Purpose of the Study

This purpose of this study was to investigate racial/ethnic variation in clinical and service use outcomes among U.S. hospice patients enrolled in Medicare, the largest payment provider of U.S. hospice care. Specifically, the study examined racial/ethnic differences in advance care planning and its influence on emergent care utilization, hospice LOS, and SOD. Research was conducted using secondary data analysis of the

2007 wave of the National Home Health and Hospice Care Survey (NHHCS), a nationally representative survey of 1,036 agencies. A total of 3,661 hospice patients over the age of 65 were analyzed who when weighted, represent 788,872 older adults enrolled in the Medicare Hospice Benefit. This study offers a novel approach to examining racial/ethnic minority EOL care experiences by investigating care preferences, utilization, and outcomes within hospice, one of the fastest growing sectors of the U.S. health care system. Given the rapidly growing segment of U.S. minority elders who require high-quality EOL care, and increasing national focus on eliminating disparities in the U.S. healthcare system (USDHHS, 2012), findings are both timely and critical.

Research Questions

The primary research questions guiding the study were as follows:

1. Is there a difference between White, Black, and Hispanic hospice enrollees in the completion of advance care plans and care choices?
2. Does race/ethnicity influence emergent care utilization among hospice enrollees? Does engaging in advance care planning affect this relationship?
3. Among patients who die under the care of hospice, how does race/ethnicity influence hospice length of stay and site of death?

Significance of the Problem

Numerous studies have documented disparities in access to hospice (Connors et al., 1995; Greiner, Perera, & Ahluwalia, 2003; Haber, 1999; Laguna, Enguידanos, Siciliano, & Coulourides-Kogan, 2012; O'Mahony et al., 2008), poorer provider-level care (Enguidanos et al., 2005; Huskamp et al., 2009; Loggers et al., 2009; Mack, Paulk,

Viswanath, & Prigerson, 2010; Muni, Engelberg, Treece, Dotolo, & Curtis, 2011), and worse patient-level outcomes (Goldstein et al., 2010; Hanchate et al., 2009; Mazanec et al., 2010; A. K. Smith, Earle, et al., 2009; Young, Meterko, & Desai, 2000) for racial/ethnic minorities at EOL. Among racial/ethnic minority hospice enrollees, little is known about their experience under the care of hospice. Of the few studies examining hospice disenrollment rates, racial/ethnic minorities have been found to be more likely than Whites to disenroll from hospice (K. S. Johnson, Kuchibhatla, Tanis, et al., 2008; Unroe, Greiner, Johnson, Curtis, & Setoguchi, 2012), suggesting that hospice patient care experiences may differ by race/ethnicity. Identifying differences in care planning, use of medical services, and care outcomes within a diverse hospice population is needed to improve understanding of minority care at EOL, and critical to reducing disparities and improving the quality of care among seriously ill populations. Information gathered can also inform policy (e.g., Medicare Hospice Benefit) to improve equitable access to and continuity of hospice care for an increasingly diverse group of older adults.

Definition of Terms

To promote clarity in the diffusion of study findings, several pre-defined constructs were employed throughout this investigation. Those constructs, along with commonly abbreviated terms referenced in this manuscript, are listed below.

- *ANOVA* is an abbreviation of “analysis of variance.”
- *Blacks* represents patients who are non-Hispanic Black.
- *CAPI* is an abbreviation of “computer-assisted personal interviewing” system, one of the primary data collection tools utilized for the 2007 wave of the National Home and Hospice Care Survey.

- *DNR* is an abbreviation of “do not resuscitate.”
- *Emergent care* represents unplanned emergency medical care, including hospital emergency department use, doctor’s office emergency visits, and outpatient department/clinic use (including urgent care sites).
- *EOL* is an abbreviation of “end of life.”
- *Hispanics* represents patients who identify with the Hispanic ethnicity (all races included).
- *Home-like setting* represents two potential care settings: 1) a private home or apartment, and 2) a residential care place. Moreover, a residential care place was defined as an assisted living facility, a board and care home, or a life care/continuing care retirement community.
- *ICC* is an abbreviation of “Intraclass Correlation Coefficient.”
- *LOS* is an abbreviation of “length of stay.”
- *Minorities* represents racial and ethnic minorities.
- *NCHS* is an abbreviation of the “National Center for Health Statistics,” the center within the Centers for Disease Control and Prevention that conducted the survey analyzed in this study.
- *NHHCS* is an abbreviation of “National Home Health and Hospice Care Survey,” the national survey utilized in this study.
- *QOL* is an abbreviation of “quality of life.”
- *SOD* is an abbreviation of “site of death.” For the purpose of this study, site of death was operationalized as the location of where the decedent was staying on the last day of hospice care.

- *Whites* represents patients who are non-Hispanic White.

Organization of the Study

Chapter 1 provides an overall background of the problem, reviews the research questions that guided the study, discusses the significance of addressing the identified problem, introduces key definitions that were operationalized in the study, and presents a general overview of the manuscript's structure.

Chapter 2 examines the research literature addressing the identified problem. Key topics covered include 1) hospice care in the United States, 2) hospice LOS, 3) advance care planning, 4) emergent care utilization, 5) SOD, and 6) determinants of racial/ethnic variation in hospice use. Research is presented for both hospice enrollees as well as the general population. Lastly, the overall importance of the study topic is discussed.

Chapter 3 presents the research methodology of the study. The hypotheses driving the study are proposed, data sources are discussed, and variable operationalization is reviewed. In addition, the conceptual model that guided the analysis plan is proposed, and the bivariate and multivariable statistical analyses utilized in the study are discussed.

Chapter 4 provides a general overview of the analytic samples that were utilized in the study. Univariate descriptives are presented, and bivariate examination of racial/ethnic variation in demographic characteristics and health indicator variables is discussed.

Chapter 5 presents an in-depth examination into the advance care planning hypotheses. Results that are discussed include bivariate and multivariable analyses testing for racial/ethnic variation in 1) advance directive completion, 2) do not resuscitate (DNR) order election, and 3) healthcare proxy designation.

Chapter 6 examines variation in emergent care utilization. Bivariate findings are presented first, followed by multivariable tests for 1) racial/ethnic differences, and 2) variation by advance care planning decisions.

Chapter 7 provides an in-depth examination into racial/ethnic differences in hospice LOS. Bivariate and multivariable models are utilized to test for relative variation in 1) the length of the full care episode, 2) death within the first week of hospice care, and 3) death within the first month of hospice care.

Chapter 8 investigates racial/ethnic variation in SOD. Specifically, racial/ethnic differences in dying in a 1) home-like setting, and 2) hospital are reviewed. As with Chapters 5-7, bivariate findings are discussed first, followed by multivariable results.

Chapter 9 presents an integrated discussion of study findings in relation to existing literature, examines clinical implications, reviews study limitations, and proposes recommendations for future research.

Chapter 2: Review of the Literature

Developed to meet the unique medical, palliative, and socioemotional needs of patients with life-limiting illness, hospice care is both the most widely utilized, as well as the highest regarded, model of end-of-life (EOL) care in the United States (National Hospice and Palliative Care Organization, 2013). Since the introduction of the Medicare hospice benefit in 1982, U.S. hospice programs have expanded rapidly, with current estimates indicating that approximately 45% of all U.S. deaths each year are under the care of hospice (National Hospice and Palliative Care Organization, 2012).

Notwithstanding, hospice remains widely underutilized by racial/ethnic minorities, and care disparities have been identified as a significant contributor (L. L. Cohen, 2008).

Given recent calls by the U.S. Department of Health and Human Services for the elimination of healthcare disparities by 2020 (USDHHS, 2012), comprehensive examination of care disparities within the hospice system is both timely and critical.

Research investigating racial/ethnic disparities in access to and utilization of U.S. hospice care has focused on several key topics, including advance care planning, care utilization, and care outcomes. This literature review presents a general overview of the U.S. hospice care model, followed by a background on racial/ethnic variation in hospice length of stay (LOS), advance care planning, emergent care utilization, and site of death (SOD). Next, proposed empirically-based determinants for racial/ethnic variation are discussed. The review concludes with a discussion on the importance of addressing current gaps in research to improve the lives of seriously ill vulnerable populations at EOL.

Documentation

Research findings reported in this comprehensive literature review were obtained by searching several research databases, including PubMed, Medline, and ProQuest. Database search terms included hospice, end-of-life, race/ethnicity, disparities/differences/variation, palliative care, advance care planning, advance directives, do not resuscitate/dnr, healthcare proxy/durable power of an attorney/dpoa, aggressive/acute/emergent care, length of stay, and site/place of death. Additional content was also obtained by searching U.S. government and non-profit reports.

Hospice: A Model for End-of-Life Care

Originating from calls to improve the care of those life-limiting illness, as well as reduce costs at EOL, formal U.S. hospice care was established as an official Medicare benefit in 1982 under the Tax Equity and Fiscal Responsibility Act. Over thirty years later, it remains the only model of EOL care covered as an official Medicare benefit. To be eligible for the Medicare Hospice Benefit, patients must be enrolled in Medicare Part A (Hospital Insurance), and certified by a physician as having a terminal illness with a prognosis of six months or less to live, given expected illness progression (CMS, 2014). Hospice care is unique in that it represents a transition from curative, life-prolonging treatments to care that focuses on patient comfort and quality of life (QOL). Patients enrolled in hospice services are entitled to several key benefits. First, pain and symptoms are managed by palliative specialists, and short-term inpatient care is made available when pain or symptoms are exacerbated. Second, patients and their families receive supplementary psychological, socioemotional, and spiritual support (as well as other support, as needed) from an interdisciplinary care team. Third, costs associated with

prescribed medication, supplies, and durable medical equipment (DME) are fully covered. Lastly, families and caregivers are provided with additional respite support as well as bereavement counseling following the patient's death (National Hospice and Palliative Care Organization, 2013).

Hospice has grown substantially in the United States over the past two decades (Christakis & Escarce, 1996; Connor, 2007; Huskamp, Buntin, Wang, & Newhouse, 2001; National Hospice and Palliative Care Organization, 2013; U.S. General Accounting Office, 2000). Between 1990 and 2005, the number of active hospice programs in the United States grew from 1,604 to 4,160 (Connor, 2007). Since 2005, the number of active hospice programs has risen above 5,500, and estimates indicate that hospice care will become one of the fastest-growing sectors of the U.S. health care system for years to come (National Hospice and Palliative Care Organization, 2013; C. Smith, Cowan, Heffler, & Catlin, 2006). As of 2012, hospice programs provided care to approximately 1.5 million people in the United States, and represented approximately 45% of all U.S. deaths (National Hospice and Palliative Care Organization, 2013). Recent data also suggests that nearly a third of all Medicare decedents access hospice for three or more days in the months preceding death, an 11% increase over the past decade (National Hospice and Palliative Care Organization, 2013).

Research has linked hospice with improved pain control (Hanlon et al., 2010; Miller, Mor, & Teno, 2003), improved QOL (Greer et al., 1986; Wallston, Burger, Smith, & Baugher, 1988), higher patient and family satisfaction with care (Dy et al., 2008; Kane, Bernstein, Wales, Leibowitz, & Kaplan, 1984; Teno et al., 2004), increased likelihood of dying in place (Hogan et al., 2001; Teno et al., 2004), and in some cases increased

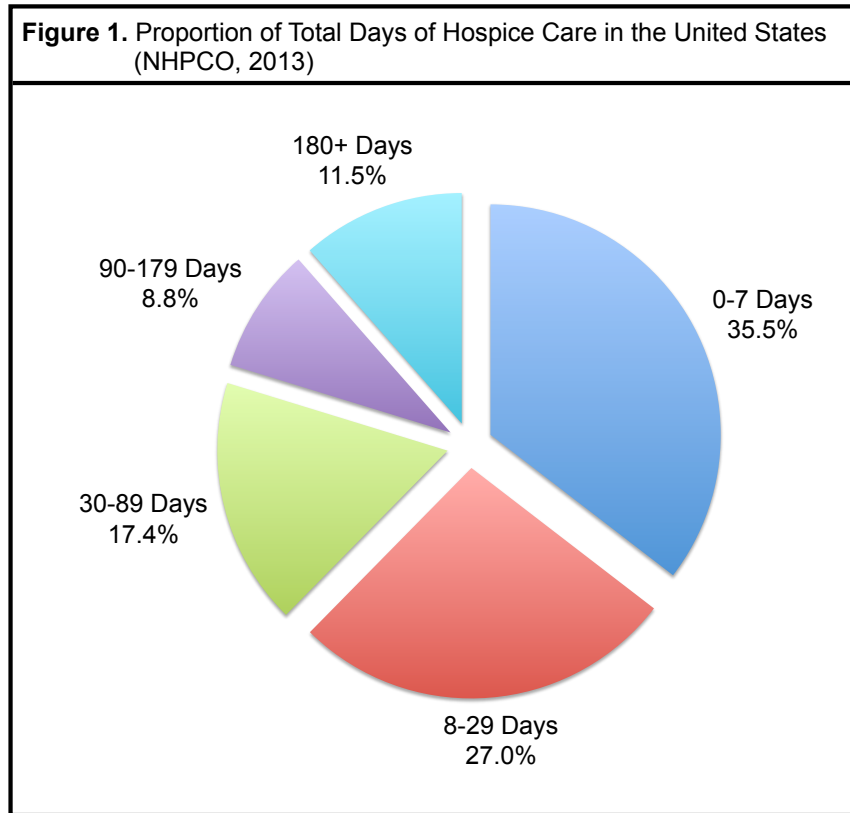
survival rates (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007; Pyenson, Connor, Fitch, & Kinzbrunner, 2004; Taylor, Ostermann, Van Houtven, Tulskey, & Steinhauer, 2007). Hospice is also associated with reduced healthcare costs in the last months of life (Pyenson et al., 2004; Stevenson & Bramson, 2009; Taylor et al., 2007; Teno et al., 2004), specifically through reductions in hospitalizations (Gozalo & Miller, 2007).

Despite these benefits, studies have consistently documented the under-use of hospice by racial/ethnic minorities (L. L. Cohen, 2008; C3lon & Lyke, 2003; Connor, Elwert, Spence, & Christakis, 2008; Enguidanos et al., 2005; Givens et al., 2010; Greiner et al., 2003; Hackbarth, Reischauer, & Miller, 2009; Han, Remsburg, & Iwashyna, 2006; K. S. Johnson, Kuchibhatla, Tanis, et al., 2008; Kwak et al., 2008; Lepore et al., 2011; Ngo-Metzger et al., 2003; Ngo-Metzger et al., 2008; A. K. Smith, Earle, et al., 2009). In a recent study of over 98,000 Medicare beneficiaries, Givens and colleagues (2010) found that Black and Hispanic heart failure patients were less likely than Whites to enroll in hospice following diagnosis. Similarly, a 2011 study of over 115,000 older adults reported that urban-dwelling Blacks and Hispanics were approximately 20% less likely to receive hospice services than Whites (Hardy et al., 2012). Factors associated with racial/ethnic variation in hospice utilization include patient unwillingness to forgo curative measures (Barnato et al., 2009; Borum, Lynn, & Zhong, 2000; Casarett, Crowley, & Hirschman, 2004; Casarett et al., 2005; Casarett et al., 2006; Duffy et al., 2006; Earle et al., 2004; Prigerson, 1991; Weeks et al., 1998; Weggel, 1999), discomfort discussing death with health care providers (K. S. Johnson, Kuchibhatla, & Tulskey, 2008) contributing to fewer conversations with physicians about hospice care (Huskamp et al., 2009; McGorty & Bornstein, 2003), an assumed lack of minority hospice care providers

(Washington, Bickel-Swenson, & Stephens, 2008; Yancu, Farmer, & Leahman, 2010), a lack of awareness of advance directives and/or hospice programs, misunderstanding the severity of one's prognosis, and other culturally-related issues including beliefs about death and familial expectations of caring for the dying (Burrs, 1995; Gordon, 1995; Neubauer & Hamilton, 1990; Talamantes, Lawler, & Espino, 1995). While much of the research concerning racial/ethnic minority healthcare at EOL has focused on issues pertaining to access to hospice, and outcomes associated with reduced access to hospice, examination of racial/ethnic minority patient care preferences, utilization, and outcomes following hospice enrollment is lacking.

Length of Hospice Stay

Although the Medicare Hospice Benefit provides care for patients in the last six months of life, research indicates that enrollment often occurs late in the disease trajectory, resulting in short hospice care episodes (Kapo, Harrold, Carroll, Rickerson, & Casarett, 2005). While an established benchmark does not exist for the number days of hospice care that elicit the most favorable outcomes, researchers (Byock, Forman, & Appleton, 1996; Daugherty & Steensma, 2003; McGorty & Bornstein, 2003), clinicians (Christakis & Iwashyna, 1998), families (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005), and government agencies (Haupt, 2003) agree that fewer days under hospice care limit patients from receiving the full benefits of hospice. Notwithstanding, over one-third (36%) of hospice patients continue to die within the first week of enrollment (National Hospice and Palliative Care Organization, 2013). For a proportional illustration of the total days of hospice care provided in the United States, see Figure 1.



Median trends are also particularly useful in understanding hospice LOS, as they are not influenced by extreme cases (i.e., outliers). Data on median trends indicate that despite the rapid growth of hospice care in the United States, LOS has been declining for the past several years (Christakis & Escarce, 1996; Head, Ritchie, & Smoot, 2005; National Hospice and Palliative Care Organization, 2008, 2010, 2012, 2013), suggesting that late referral to hospice may be an increasingly important issue (Rickerson et al., 2005). Most recently, median hospice LOS has declined from 21.1 days in 2009 to just 18.7 days in 2012 (National Hospice and Palliative Care Organization, 2010, 2013), far below the thirty days of care that many experts believe are necessary for hospice providers to fully address patient and family needs (Christakis & Escarce, 1996; Christakis & Iwashyna, 2000; Han, Remsburg, McAuley, Keay, & Travis, 2007; Haupt,

2003; Huskamp et al., 2001; McCarthy, Burns, Ngo-Metzger, Davis, & Phillips, 2003; Quill, 2007; Stillman & Syrjala, 1999; U.S. General Accounting Office, 2000).

Racial/Ethnic variation in hospice length of stay. Current understanding of racial/ethnic differences in hospice LOS is primarily based on a limited number of studies. Since 2000, only four identified studies have examined racial/ethnic variation in hospice LOS (Cólón & Lyke, 2003; Hardy et al., 2012; K. S. Johnson et al., 2011; Rhodes, Teno, & Connor, 2007). Results from this more recent body of research suggest longer LOS for Blacks and Hispanics, compared to Whites (Cólón & Lyke, 2003; Hardy et al., 2012; K. S. Johnson et al., 2011), with the exception of one study, a family questionnaire, which reported no racial/ethnic variation in hospice LOS (Rhodes et al., 2007). Other factors that have been associated with a shorter hospice LOS include gender (Christakis & Iwashyna, 2000; Somova, Somov, Lawrence, & Frantz, 2000), primary diagnosis (Christakis & Escarce, 1996; Miller, Weitzen, & Kinzbrunner, 2003), Medicare enrollment (Somova et al., 2000), nursing home placement (Somova et al., 2000), hospice agency characteristics (Carlson et al., 2009; Wachterman, Marcantonio, Davis, & McCarthy, 2011), and referral source (i.e., referral during hospitalization and subsequent hospice enrollment; Han et al., 2007; K. S. Johnson et al., 2011; McCarthy, Burns, Davis, & Phillips, 2003; Miller, Kinzbrunner, Pettit, & Williams, 2003; Miller, Weitzen, et al., 2003; Somova et al., 2000). Importantly, a complete analysis hospice LOS among a diverse patient population has not been conducted using a nationally representative sample in over a decade (Han et al., 2006). Given that Medicare is the largest payer of hospice care in the United States (Lubitz & Riley, 1993), it is critical that these data be

re-analyzed at a national level in order to better inform policy guiding interventions and cost-savings plans.

Advance Care Planning

Advance care planning is the process by which patients can specify, usually through a document called an advance directive, their preferred care plans should they become incapacitated. Often involving family, significant others, and care providers, advance care planning provides a medium by which patients can state general EOL preferences, indicate the level of care aggressiveness that they would like to receive, give specific orders concerning resuscitation, and designate others as proxy decision-makers in the event that they are no longer able to communicate their preferences. Equally important, advance care planning offers providers with a forum to ensure that their patients are fully aware of their prognosis and treatment options, and gain improved understanding of their patients' core values, beliefs, and goals of care (Detering, Hancock, Reade, & Silvester, 2010).

Advance care planning is fundamental to the delivery of high-quality EOL care (Lynn et al., 1997), as clarification of goals improves patient satisfaction (Kumar, Markert, & Patel, 2011) and ensures that patients receive care that is consistent with their wishes (Mack, Weeks, Wright, Block, & Prigerson, 2010). Furthermore, research indicates that advance care planning reduces family stress, anxiety, and depressive symptoms (Detering et al., 2010). However, substantial challenges must first be overcome in order to ensure the benefits advance care planning. First, patients should have a solid understand their illness and prognosis in order to properly represent their wishes in an advance directive (Fischer, Tulsky, Rose, Siminoff, & Arnold, 1998;

Hoffmann, Zimmerman, & Tompkins, 1996; Thorevska et al., 2005). Similarly, healthcare proxies should also understand the illness and prognosis, as well as patient preferences, in order to adequately fulfill their role (Fagerlin & Schneider, 2004; Lo & Steinbrook, 2004; Teno, Stevens, Spernak, & Lynn, 1998; Volicer et al., 2002). Lastly, care providers have an obligation to ensure that care adheres to documented preferences, as research has indicated that advance directives are not always followed due to several reasons, including document availability, perceived conflict with family preferences, and organizational policies (Galambos, 1998; Perkins, 2007; Volicer et al., 2002). Identified challenges aside, advance care planning remains an essential aspect of high-quality EOL care, with Medicare-certified hospices mandated to inform patients of their right to complete an advance directive (Omnibus Reconciliation Act of 1990), although patients make the final decision as to whether or not they document their preferences in a formal advance directive.

Non-hospice-specific population. Most research examining racial/ethnic differences in advance care planning is among non-hospice-specific populations. These studies indicate that racial/ethnic minorities are less likely than Whites to have advance directives (Eleazer et al., 1996; Greiner et al., 2003; K. S. Johnson, Kuchibhatla, & Tulsky, 2008; Kwak & Haley, 2005; McKinley, Garrett, Evans, & Danis, 1996), and often prefer more aggressive interventions, compared to Whites. In a comprehensive review of the literature, Kwak and Haley (2005) reported that racial/ethnic minorities often lacked knowledge about advance directives, and were less likely to support advance directives. Furthermore, while Blacks have consistently been found to prefer more aggressive, acute interventions (e.g., ICU treatment, resuscitation, mechanical ventilation;

Barnato et al., 2009; Borum et al., 2000; Duffy et al., 2006; K. S. Johnson, Kuchibhatla, & Tulsky, 2008; Mitchell & Mitchell, 2009), Hispanics often prefer less aggressive interventions at EOL, but few document this preference in advance directives (Kelley, Wenger, & Sarkisian, 2010; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). Studies of non-hospice-specific populations also indicate that Blacks and Hispanics are less likely than Whites to know about or designate a healthcare proxy, frequently citing beliefs that a healthcare proxy is unnecessary, difficulty identifying a potential proxy, and discomfort discussing such issues with their healthcare providers (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Hopp & Duffy, 2000; Kwak & Haley, 2005; Morrison et al., 1998).

Hospice enrollees. Few identified studies have examined advance care planning among racial/ethnic minority hospice users (Jones, Moss, & Harris-Kojetin, 2011; Resnick, Hickman, & Foster, 2012). A recent study by Resnick and colleagues (2012) found that Black hospice patients were less likely than White hospice patients to complete advance directives, but the exclusion of theoretically-driven predictors limit study interpretation (e.g., age, gender, primary diagnosis, and comorbidity count were all excluded from multivariable analyses). Concerning hospice patient care preferences among those who document advance directives, only one article, a descriptive data brief, has been published (Jones et al., 2011); however, its lack of analytic testing greatly restricts the applicability of reported findings. Thus, while hospice minority care preferences remain widely understudied, existing research suggests that Blacks and Hispanics complete advance directives less often than Whites, Blacks prefer aggressive interventions more often than Whites and Hispanics, and Blacks and Hispanics designate healthcare proxies less often than Whites.

Emergent Care Utilization

Emergent care utilization, or unplanned emergency medical service use, is an important quality indicator of EOL care. Although it most commonly involves emergency department use, emergent care can also involve an emergency doctor's visit, and utilization of acute outpatient services (e.g., urgent centers). Unplanned utilization of emergent care services is contrary to the philosophy of hospice because it jeopardizes care quality and patient experiences, often at a critical point in the dying process (Olsen, Bartlett, & Moynihan, 2011). Not surprisingly, research of non-hospice-specific populations has found that patients with advance directives utilize less emergent care at EOL (Degenholtz, Rhee, & Arnold, 2004; Gozalo et al., 2011; Silveira, Kim, & Langa, 2010; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). In a 2011 study of 474,829 nursing home decedents, Gozalo and colleagues (2011) reported that decedents without an advance directive were at an increased risk of experiencing a burdensome transition (i.e., multiple hospitalizations or late-stage hospitalization). The same study also found that patients who experienced a burdensome transition before death were also more likely to experience other markers of poor EOL care quality (e.g., feeding tube, ICU visit in the last month of life; Gozalo et al., 2011). While enrollment in hospice has been found to decrease hospitalization rates (Hughes et al., 1997; McCusker & Stoddard, 1987; Miller, Gozalo, & Mor, 2001), some hospice users still seek acute care following hospice enrollment (Legler, Bradley, & Carlson, 2011; Olsen et al., 2011), and risk compromising hospice benefits, namely quality of death. In a 2007 study of patients enrolled in the Mayo Hospice Program, Olsen and colleagues (2011) found that the majority of

hospitalized hospice patients received moderately-intense care, escalating costs and increasing the likelihood of dying in a hospital.

Racial/Ethnic differences in emergent care utilization at end of life. Most research examining racial/ethnic differences in emergent care utilization does not differentiate between hospice and non-hospice users, leaving significant gaps in the understanding of care use patterns among hospice enrollees. Regardless, these studies indicate that Blacks and Hispanics often utilize emergent EOL care more often than Whites (Barnato et al., 2007; Goldstein et al., 2010; Gozalo et al., 2011; Hanchate et al., 2009; A. K. Smith, Earle, et al., 2009). A 2009 study (A. K. Smith, Earle, et al.) of over 40,000 Medicare beneficiaries with advanced stage cancer found that Blacks were more likely than Whites to be 1) hospitalized two or more times, 2) hospitalized for two or more weeks, and 3) admitted to the intensive care unit (ICU) in the last month of life. Similarly, Hanchate and colleagues (2009) reported that among 158,780 Medicare decedents, Blacks and Hispanics were more likely than Whites to utilize intensive life-sustaining interventions at EOL, resulting in significantly higher costs. Increased utilization of more aggressive interventions at EOL also places racial/ethnic minorities at a greater risk of multiple poor EOL outcomes, including reduced care quality (Casarett et al., 2005; Earle et al., 2008; Patrick, Curtis, Engelberg, Nielsen, & McCown, 2003; Steihauser et al., 2000), lower satisfaction with care (Baker et al., 2000; Billings & Kolton, 1999; Teno et al., 2004), decreased QOL (Mazanec et al., 2010; Wright et al., 2008; Zhang et al., 2009), debilitating procedures that do little to prolong life (Engle, 1998; Mezey, Dubler, Mitty, & Brody, 2002), and increased healthcare costs (Hanchate

et al., 2009; Hogan et al., 2001; Levinsky et al., 2001; Shugarman et al., 2004; Wennberg, Fisher, Goodman, & Skinner, 2008; Wennberg et al., 2004).

Hospice enrollees. Few studies have examined racial/ethnic variation in emergent care utilization following hospice enrollment. Of this body of research, findings suggest that hospice-electing racial/ethnic minorities also utilize emergent care at higher rates than Whites (Cintron et al., 2003; Loggers et al., 2013; Schonwetter et al., 2008; Unroe et al., 2012). In a 2012 study conducted by Unroe and colleagues (2012), non-White Medicare beneficiaries were more likely than White beneficiaries to visit the emergency department, be hospitalized, and be admitted into an ICU. Moreover, the authors also reported that among hospice decedents, racial/ethnic minorities remained significantly more likely than Whites to utilize emergent care at higher rates. Similarly, a review of Medicare records between 1988-1998 found that Blacks were more likely than Whites to seek hospitalization following hospice enrollment (Cintron et al., 2003). Thus, while emergent care utilization among hospice-electing racial/ethnic minorities remains widely understudied, existing research suggests that Blacks and Hispanics are at an increased risk of utilizing emergent care following hospice enrollment.

Site of Death

Numerous studies have demonstrated that the majority of seriously ill patients prefer to die at home (Higginson & Sen-Gupta, 2000; Tang, 2003; Townsend et al., 1990); however, most do not achieve this aim and instead, die in other settings (Burge, Lawson, Johnston, & Cummings, 2003; Higginson, Astin, & Dolan, 1998). Current statistics indicate that while approximately seven out of ten Americans prefer to die in their home (Cloud, 2000), only 25% do so, with the majority dying in hospitals (45%),

and nursing home/long-term care facilities (22%; CDC, 2008). Research investigating in-home death has established links with fewer medical complications (Leff et al., 2005), reduced costs (Leff et al., 2005), less physical and emotional distress (Wright et al., 2010), improved QOL (Wright et al., 2010), greater satisfaction with care (Leff et al., 2006), and lower levels of complicated grief and other bereavement-related distress for surviving family members (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2010; Wright et al., 2010). Conversely, dying in a hospital has been associated with increased pain and symptoms (Nelson et al., 2001), reduced care quality (Meier, 2003), poorer patient QOL (Wright et al., 2010), and increased psychological disorders among survivors (Wright et al., 2010).

Racial/ethnic variation in site of death. Studies of non-hospice-specific populations have consistently reported an increased likelihood among racial/ethnic minorities to die acute hospital settings more often than Whites (Gruneir et al., 2007; Hanchate et al., 2009; Hansen, Tolle, & Martin, 2002; National Center for Health Statistics, 2011; A. K. Smith, Earle, et al., 2009; Weitzen, Teno, Fennell, & Mor, 2003; Zheng, Mukamel, Caprio, Cai, & Temkin-Greener, 2011). A 2009 study of terminally ill Medicare beneficiaries (A. K. Smith, Earle, et al.) found that non-Whites were significantly more likely than Whites to die in a hospital setting. While this increased likelihood may be due in part to a greater preference for in-hospital death among minorities (Neubauer & Hamilton, 1990), research also suggests that other factors such as geographic location, socioeconomic status, and morbidity differences may also be in operation (Hanchate et al., 2009).

Hospice enrollees. In-home death is both supported and fostered by hospice (K. S. Johnson et al., 2005). Research on SOD among hospice patients has reported that hospice users are more likely than non-hospice users to die in their homes rather than in an acute setting (Moinpour & Polissar, 1989; Pritchard et al., 1998). Among those enrolled in hospice in 2010, 67% died in their home and 11% died in an acute setting (National Hospice and Palliative Care Organization, 2012), compared to approximately 24% dying in-home and 40% dying in acute settings among non-hospice users over 65 (National Center for Health Statistics, 2011). Hospice patients who die in their homes have lower rates of unmet needs, fewer concerns about being treated with respect, higher levels of emotional support, and greater satisfaction with care, compared to non-hospice users (Teno et al., 2004). Since the introduction of the Medicare Hospice Benefit in 1982, only one identified study has examined racial/ethnic differences in SOD among hospice patients (K. S. Johnson et al., 2005). Findings indicated that Blacks and Hispanics were more likely than Whites to die in an inpatient hospice setting; however, nearly three quarters of the sample utilized inpatient hospice services, and thus the sample represented only a small subsample (22%; National Hospice and Palliative Care Organization, 2012) of the larger hospice population. The study also reported an increased likelihood among Hispanics to die in a home versus an inpatient hospice setting; however, the study did not differentiate between death in an acute hospital setting and death in a hospital-based hospice unit, greatly restricting finding implications. Thus, while hospice minority SOD remains widely understudied, EOL research in general suggests that Blacks and Hispanics may be more likely than Whites to die in an acute setting following hospice enrollment (Gruneir et al., 2007; Hanchate et al., 2009; Hansen et al., 2002; National

Center for Health Statistics, 2011; A. K. Smith, Earle, et al., 2009; Weitzen et al., 2003; Zheng et al., 2011).

Determinants of Racial/Ethnic Variation in Hospice Use

In addition to identifying existing racial/ethnic disparities in the U.S. healthcare system, research has also focused on determining the contributing mechanisms to enrollment disparities. Key patient-level factors that have been identified include patient 1) cultural beliefs, 2) religious values, 3) knowledge and education, and 4) communication and trust.

Cultural beliefs. For the purposes of this manuscript, culture is defined as the complete cultural background (including previous and current cultural identities) that shape one's lens through which they see the world. As such, while ethnicity is an inherent component of one's cultural beliefs, culture is proposed to encompass the larger historical cultural landscape of each individual's unique identity. Under this framework, 1) race is proposed to account for the biological, genetically-determined, characteristics or traits of an individual, 2) ethnicity is proposed to encompass the non-biological factors, largely representative of one's culture of origin, that differentiate people within racial groups (Egede, 2006), and 3) cultural beliefs are proposed to be the product of the full cultural history of individuals (i.e., ethnic background, previous cultures, current culture).

Numerous studies have identified cultural factors that contribute to racial/ethnic differences in healthcare utilization at EOL (Blackhall et al., 1999; Del Gaudio et al., 2013; Searight & Gafford, 2005; A. K. Smith, Sudore, & Pérez-Stable, 2009). First, fundamental differences in beliefs about truth-telling and decision-making appear to contribute significantly to racial/ethnic variation in advance care planning. While the U.S.

healthcare system emphasizes patient autonomy, some cultures value more collectivist approaches, often looking to the family to share in the care decision-making process, or in some cases even make care decisions on behalf of patients while concealing diagnoses from patients out of respect (Searight & Gafford, 2005). Research has found that compared to African American and White elderly patients, half as many Korean-Americans and Mexican-Americans report wanting to be told the truth about their diagnosis, with many Korean-Americans and Mexican-Americans preferring the family, not the patient, to be the key decision-maker concerning EOL choices (Blackhall et al., 1999; Blackhall et al., 1995). These cultural beliefs contrast sharply with the prevailing U.S. preference for patient autonomy, and present significant challenges with advance care planning for racial/ethnic minorities. Additionally, substantial within-culture variation, often resulting from acculturation to the United States, further contributes the complexity of the issue.

In addition to cultural differences in preferences for truth-telling and decision-making, culture-specific beliefs, such as the Latino values of *Machismo*, *Fatalismo*, and *Marianismo*, also shape the attitudes and care decisions of many patients (Del Gaudio et al., 2013; A. K. Smith, Sudore, et al., 2009). For example, it is conceivable that Latino patients valuing *Fatalismo*, or the belief that one's fate is predetermined, may be less likely to engage in the care planning process, and ultimately receive more aggressive life-prolonging interventions. Similarly, men valuing *machismo*, or the belief that men are the primary protectors and decision-makers of the household, may be more likely to perceive election of hospice (and the forgoing of curative efforts) as a sign of weakness or defeat. Moreover, even for those Latino men who do elect hospice, there still may be a latent

cultural propensity to not show weakness to family or care providers. As a result, care decisions and utilization patterns of these men may differ from other non-Latino groups. Although still in its infancy, this growing body of research suggests that culture-specific values significantly contribute to racial/ethnic variation in healthcare decision-making, and that these differences are magnified at EOL (Del Gaudio et al., 2013; A. K. Smith, Sudore, et al., 2009).

Religious values. For the purposes of this manuscript, religion is defined as either individually-identified (e.g., patients who identify themselves as such) or the participation in formal religious activities (e.g., attending church, prayer).

Patient religious beliefs have a strong influence on EOL decision-making, with more religious individuals often preferring more aggressive interventions at EOL (Balboni et al., 2007; Phelps et al., 2009). In a rare study examining the relationship between religion and views of patient autonomy, Blackhall and colleagues (1995) reported that Protestants were more likely to believe that patients should be told the truth about a terminal prognosis and that patients should be the primary decision-maker for their EOL care choices. Conversely, Buddhist and Jewish participants did not support telling patients the truth about a terminal prognosis (Blackhall et al., 1995). Interestingly, patient race/ethnicity appears to partially moderate the relationship between religiosity and EOL care planning and behaviors. That is, among racial/ethnic minorities, high religiosity has been associated with a preference against advance care planning (K. S. Johnson, Kuchibhatla, & Tulsky, 2008) and decisions not to enroll in hospice, with highly religious African Americans maintaining more negative views toward hospice (Kagawa-Singer & Blackhall, 2001; Reese, Ahern, Nair, O'Faire, & Warren, 1999).

Strong religious beliefs among non-terminal African American men have also been associated with preferences for more aggressive interventions, regardless of prognosis, as a means of fighting for god's gift of life (Blocker et al., 2006). A recent study found that many Blacks choose not to engage in advance care because "...a higher power controls the nature and timing of death" (Carr, 2011, p. 15). Research suggests there is a preference among some Latinos to endure suffering at EOL, wherein suffering is viewed as a necessary and even fundamental aspect of dying (Krause & Bastida, 2011). When understood in the context of religion/spirituality, these Latinos conceive suffering as a means to atone for one's sins, and ultimately deepen one's faith in god (Braun, Beyth, Ford, & McCullough, 2008; A. K. Smith, Sudore, et al., 2009). Collectively, this body of literature suggests that the influence of religiosity on healthcare decision-making differs across racial/ethnic groups and may contribute to racial/ethnic variation in care decisions and utilization patterns at EOL.

Knowledge and education. Racial/Ethnic differences in patient knowledge and education are also associated with variation in healthcare utilization patterns. Throughout the past decade, multiple studies have demonstrated the effectiveness of brief educational interventions in shifting racial/ethnic minority patient knowledge and understanding of healthcare options (Casarett et al., 2005; Chung, Essex, & Samson, 2009; Enguidanos, Kogan, Lorenz, & Taylor, 2011; Volandes, Ariza, Abbo, & Paasche-Orlow, 2008; Volandes, Barry, Chang, & Paasche-Orlow, 2010; Volandes et al., 2007; Volandes, Paasche-Orlow, et al., 2008). In a study of Spanish-speaking Latino patients, Volandes and colleagues (2008) found that after viewing a two-minute video of an individual with advanced dementia, preference for comfort care nearly doubled, and desire for life-

prolonging care reduced from 40% of patients to just 8%. Similarly, African Americans have demonstrated improved knowledge of hospice and an increased willingness to enroll in hospice after reviewing a targeted educational brochure describing positive patient experiences of hospice care (Enguidanos et al., 2011). Improved racial/ethnic minority caregiver knowledge has also been associated with patient willingness to engage in advance care planning, preferences for comfort care over aggressive care at EOL, enrollment in hospice earlier in the disease trajectory, and more active caregiver involvement in monitoring the quality of hospice services (Chung et al., 2009). Interestingly, in a study of over 30,000 dual-eligible nursing home residents, Kwak and colleagues (2008) found that while formal years of education was associated with patient willingness to enroll in hospice, this relationship was moderated by race/ethnicity. That is, for Whites, formal education appears to affect patient willingness to enroll in hospice; however, this relationship does not appear to be true for Blacks (i.e., formal education has no association; Kwak et al., 2008).

Communication and trust. While some minorities may prefer higher levels of aggressive care (Barnato et al., 2009; Borum et al., 2000; Duffy et al., 2006), others report challenges communicating comfort care preferences to providers (Kelley et al., 2010; Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002), potentially resulting in care that is not consistent with the patient's wishes (Barnato et al., 2009). Studies of non-terminal patients have reported that African Americans are less likely to be actively involved in the decision-making process and more likely to experience difficulty in physician-patient communication (Cene, Roter, Carson, Miller, & Cooper, 2009; Cooper-Patrick et al., 1999; Ghods et al., 2008; R. L. Johnson, Roter, Powe, & Cooper, 2004).

Huskamp and colleagues (2009) found that healthcare providers were less likely to discuss hospice care with seriously ill Black and Hispanic patients, compared to White patients. Similarly, in a study of 981 physicians, Modi and colleagues (2007) found Black physicians were nearly twice as likely to recommend percutaneous endoscopic gastrostomy (PEG) tube placement to their Black patients, compared to White patients, suggesting that physician-patient race concordance is also a factor affecting communication between patients and healthcare providers at EOL.

Research has demonstrated that historical prejudices and discriminatory acts, such as the Tuskegee study and the U.S. sterilization campaign targeting Puerto Ricans, have contributed to racial/ethnic minority distrust of medical professionals as well as the larger healthcare system (Braunstein, Sherber, Schulman, Ding, & Powe, 2008; Gamble, 1997; Harris, Gorelick, Samuels, & Bempong, 1996; Payne, 2001). In a comprehensive focus group study of 73 Arab Muslim, Arab Christian, Hispanic, Black, and White older adults, Duffy and colleagues (2006) found that Blacks often cited past inequities (e.g., medical mistreatment, provider abandonment) as a barrier to hospice care. In a survey of 236 physicians, 88% of U.S.-born African American physicians, compared to 35% of White physicians, believed that the Tuskegee study has negatively impacted medical decision-making among African Americans (M. P. Wallace et al., 2007). These findings suggest that even at the provider-level, the ramification of these past events has had a significant impact on racial/ethnic minorities. Moreover, ongoing societal policies (e.g., Medicaid's race-neutral long-term care policies) that limit racial/ethnic minority access to care have also likely played a significant role in promoting continued distrust, with African Americans significantly more likely than Whites to report higher levels of racism and

distrust of the healthcare system (Fowler-Brown, Ashkin, Corbie-Smith, Thaker, & Pathman, 2006). Overall, this body of research indicates that race/ethnicity-specific factors related to communication and healthcare provider trust further contribute to racial/ethnic variation in healthcare care preferences and utilization.

Importance of the Topic

Demographic projections indicate that the U.S. population will age significantly throughout the next fifty years (Lutz, Sanderson, & Scherbov, 2008), with a sharp increase in the proportion of racial/ethnic minorities (Ortman & Guarneri, 2009). As the population shifts, a widely diverse group of older adults will require high-quality EOL care. Since the landmark SUPPORT study found that dying patients often receive inadequate or overly aggressive care that is inconsistent with preferences (Connors et al., 1995), patients and their families have continued to report reduced participation in the decision-making process (Azoulay et al., 2004; Selman et al., 2007; White, Braddock, Bereknyei, & Curtis, 2007; Winzelberg, Hanson, & Tulsky, 2005), insufficient emotional support (Kunik et al., 2005; Teno et al., 2004; Thornton, Pham, Engelberg, Jackson, & Curtis, 2009; Wenrich et al., 2003), low satisfaction with care (Baker et al., 2000; Billings & Kolton, 1999; Teno et al., 2004), poor QOL (Blinderman, Homel, Billings, Portenoy, & Tennstedt, 2008; Blinderman, Homel, Billings, Tennstedt, & Portenoy, 2009; Lackan, Eschbach, Stimpson, Freeman, & Goodwin, 2009; Wright et al., 2008), increased aggressive care (Mack, Weeks, et al., 2010; Parr et al., 2010; Teno, Fisher, Hamel, Coppola, & Dawson, 2002), in-hospital death despite patient preferences (Lackan et al., 2009; Mularski et al., 2009), poorly treated pain and dyspnea (Goodlin, Winzelberg, Teno, Whedon, & Lynn, 1998; Lynn et al., 1997; Teno et al., 2004; Tolle,

Tilden, Hickman, & Rosenfeld, 2000), and inadequate bereavement support (Billings & Kolton, 1999; Wright et al., 2008). Currently, Medicare spending during the last year of life accounts for nearly a quarter of total annual expenditures (Hogan et al., 2001). Research suggests that as much of 78% of the costs incurred during the last year of life result from care received during the final thirty days (Yu, 2008), with racial/ethnic minority utilization of aggressive interventions and underuse of hospice serving as significant contributors (Hanchate et al., 2009; Hogan et al., 2001; Levinsky et al., 2001; Shugarman et al., 2004; Teno et al., 2002; Wennberg et al., 2008; Wennberg et al., 2004). Existing research focuses almost exclusively on increasing racial/ethnic minority access to hospice care; however, it remains unclear if racial/ethnic differences in care preferences, utilization, and outcomes persist following hospice enrollment. With increasing national focus on improving care quality and cost-containment ("The Patient Protection and Affordable Care Act, Pub. L. No. 111-148," 2010) as well as eliminating healthcare disparities (USDHHS, 2012), research investigating racial/ethnic minority healthcare at EOL, a time when such disparities are particularly significant, is critical.

Chapter 3: Research Methodology

In this chapter, the research questions and hypotheses are proposed, and the overall research approach is described.

Research Questions and Hypotheses

Research questions. The study was guided by the following key research questions:

1. Is there a difference between White, Black, and Hispanic hospice enrollees in the completion of advance care plans and care choices?
2. Does race/ethnicity influence emergent care utilization among hospice enrollees? Does engaging in advance care planning affect this relationship?
3. Among patients who die under the care of hospice, how does race/ethnicity influence hospice length of stay and site of death?

Hypotheses. The primary purpose of this investigation was to provide an in-depth examination into hospice care preferences, utilization, and outcomes among racial/ethnic minorities in the United States. In testing for differences in care utilization and outcomes, patient care preferences and Medicaid enrollment (as a proxy for socioeconomic status) were included to account for potential explanatory variability between racial/ethnic groups. Hypotheses in this study tested for racial/ethnic variation following hospice enrollment in advance care planning decisions, emergent care utilization, hospice length of stay (LOS), and site of death (SOD). Tested hypotheses are as follows.

1. White hospice patients will be more likely than Black and Hispanic hospice patients to have a documented advance directive (H1).

- a. Among those with documented advance directives, White and Hispanic hospice patients will be more likely than Black hospice patients to document a do not resuscitate order (H1A).
 - b. Among those with documented advance directives, White and Hispanic hospice patients will be more likely than Black hospice patients to document a healthcare proxy (H1B).
- 2. Black and Hispanic hospice patients will be more likely than White hospice patients to utilize emergent care (i.e., unplanned emergency medical care; H2).
 - a. Hospice patients without documented advance care plans (i.e., advance directive, do not resuscitate order) will be more likely than those with documented advance care plans to utilize emergent care (H2A).
- 3. Hospice length of stay will be longer for Black and Hispanic decedents, compared to White decedents (H3).
- 4. White hospice decedents will be more likely than Black and Hispanic hospice decedents to die in a home-like setting (H4).
 - a. Black and Hispanic hospice decedents will be more likely than White hospice decedents to die in a hospital (H4A).

Research Design

This study is a retrospective analysis of clinical and service use outcomes among Medicare-enrolled U.S. hospice patients using secondary data from the 2007 wave of the National Home Health and Hospice Care Survey (NNHCS). Using a complex two-stage sampling design, NNHCS 2007 data are representative of the U.S. hospice patient

population. Although six previous waves of the NHHCS were conducted from 1992-2000, NHHCS 2007 represents a significant shift in the sampling frame, study design, and data collected within the NHHCS survey family. Accordingly, NHHCS 2007 is the first study in its family to provide detailed data on racial/ethnic minority hospice enrollees, and much of its patient-level data are not available in previous waves.

Data Sources

NHHCS 2007 data were collected between August 2007 and February 2008 using a two-stage probability sampling design of agencies providing home health and/or hospice care in the United States. The sampling frame of 15,488 U.S. home health and hospice agencies was derived from three sources: 1) the National Hospice and Palliative Care Organization (NHPCO), 2) Verispan, L.L.C., and 3) the Centers for Medicare & Medicaid Services Provider of Services file.

Agency selection. In the first sampling stage of NHHCS 2007, all agencies in the sampling frame were grouped into strata based on agency-type (i.e., home health care only, hospice care only, both home health care and hospice care) and metropolitan statistical area (MSA; i.e., metropolitan, micropolitan, neither metropolitan nor micropolitan), and then sorted by census region (i.e., Northeast, Midwest, South, West), ownership type (i.e., proprietary, nonprofit, government, unknown), certification status (i.e., Medicare, Medicaid, both Medicare and Medicaid), state, county, and ZIP code. Following agency stratification and sorting, 1,545 agencies were randomly selected with probability proportional to agency size (i.e., number of employees). Of these, 84 were excluded for being out of survey scope, and 425 refused to participate, yielding a final agency sample of 1,036.

Patient selection. In the second sampling stage, interviewers visited each of the selected agencies and collected a census of all home health and/or hospice patients. The patient sampling pool consisted of 1) all home health patients serviced by the agency the day before the interview, and 2) all hospice discharges during a 3-month period four months before the interview. Patients discharged more than once during the 3-month period of data collection were treated as distinct episodes of care (i.e., separated hospice discharges). As such, hospice patients could be represented more than once in NHHCS 2007 data. Following agency censuses, a final sample of ten patients from each agency was randomly selected using the computer-assisted personal interviewing (CAPI) system. If agencies serviced less than ten patients, all patients were included, and if an agency serviced both home health and hospice patients, two samples of five patients were included (i.e., five home health and five hospice patients). In all, 4,733 hospice discharges and 4,683 home health patients were selected for participation in the study.

Data collection. Patient-level and agency-level data were collected from in-person interviews with agency directors, and self-administered staffing questionnaires. Study personnel first contacted agencies to setup in-person data collection visits. Next, agency directors were asked to complete a paper questionnaire describing agency characteristics two-weeks prior to the scheduled in-person visit. Finally, on the day of the scheduled in-person visit, trained interviewers collected additional data using the CAPI system on agency characteristics, as well as data on patient characteristics and care received. Several steps (e.g., audio recording, in-person observation, debriefing calls) were utilized to ensure data were collected consistently and reliably across agencies.

Data use. The data utilized in this study were cleaned by the Inter-university Consortium for Political and Social Research (USDHHS, 2010). Data were accessed on March 16, 2013, and subsequently maintained by the principal investigator.

Human Subjects Protection

An application for Exempt Review was submitted to the University of Southern California's Institutional Review Board on June 22, 2011. Study approval was obtained on June 29, 2011.

Sampling Plan

The study sample consisted of 3,661 White, Black, and Hispanic Medicare-enrolled hospice patients 65 years of age and older at the time of death/discharge. Patients were drawn from nine strata and 657 hospice-providing agencies. When weighted for national representation, the data represent 788,872 hospice patients in the United States. Patients from other racial/ethnic groups were excluded due to low sample sizes (unweighted $n = 53$; Pacific Islanders, Native Americans, Asians). Since Medicare covers 84% of hospice care in the United States, this study examined the discrete Medicare population to maximize research translatability and add national policy implications to the analyses.

Operationalization of the Variables and Measures

All patient-level data were collected from hospice agency administrators during in-person interviews.

Demographic and health indicator variables. Patient demographic and health indicator variables included age (continuous), gender (binary), race/ethnicity (White, Black, Hispanic), marital status (married/living with partner, widowed,

divorced/separated, never married), primary diagnosis (Cancer, Congestive Heart Failure/Heart Disease, Lung Disease, neurological diseases, other), and the total number of comorbidities (continuous). In care utilization (i.e., emergent care utilization) and outcome models (i.e., LOS, SOD), Medicaid enrollment (binary) was included as a proxy for patient/decedent socioeconomic status (Bach, Guadagnoli, Schrag, Schussler, & Warren, 2002; Gross, Filardo, Mayne, & Krumholz, 2005).

Outcome variables included 1) advance directive completion, 2) do not resuscitate (DNR) order election, 3) healthcare proxy designation, 4) emergent care utilization, 5) hospice LOS, and 6) SOD. Outcome data coded as missing were excluded from all bivariate and multivariable analyses.

Advance directive completion. Completion of an advance directive was measured using agency binary data on the documented preference of any of the following pre-defined advance directive categories: 1) living will, 2) DNR order, 3) do not hospitalize order, 4) preferences for comfort measures only, 5) feeding restrictions, 6) medication restrictions, 7) durable power of attorney, 8) healthcare proxy/surrogate, and 9) other treatment restrictions. Each of the above pre-defined categories were collected separately and recoded into the following binary variable: 1) patients with any pre-defined documented preference (positive binary indicator outcome), and 2) patients with no pre-defined documented preferences (negative binary indicator outcome).

Do not resuscitate order election. Preference against resuscitation was measured using agency binary data on the documented election of a DNR order. Responses were recorded into two categories: 1) patient has elected to document a DNR order (positive binary indicator outcome), and 2) patient has not elected to document a DNR order

(negative binary indicator outcome). Only patients with a documented advance directive (i.e., valid advance directive completion response) were included in bivariate and multivariable analyses of DNR election.

Healthcare proxy designation. Healthcare proxy designation was measured using agency binary data on the documented designation of 1) a durable power of attorney (DPOA), or 2) healthcare proxy or surrogate decision-maker. Using data from these two recorded variables, responses were recoded into two categories: 1) patient has elected to designate a healthcare proxy (positive binary indicator outcome), and 2) patient has not elected to designate a healthcare proxy (negative binary indicator outcome). Given the duplicative nature of a designated DPOA and healthcare proxy (Ouslander, Tymchuk, & Rahbar, 1989), responses to both of these originally-recorded variables were treated as equivalent during recoding. Only patients with a documented advance directive (i.e., valid advance directive completion response) were included in bivariate and multivariable analyses of healthcare proxy designation.

Emergent care utilization. Emergent care utilization was measured using agency binary data on patient unplanned emergency medical care use while enrolled in hospice. Emergent care was selected over other potential outcomes (e.g., emergency department use) to model more comprehensively any unplanned emergency service use by hospice patients. Data were originally recorded as three separate binary outcomes: 1) hospital emergency department use (including 23-hour holding), 2) doctor's office emergency visit/house call, and 3) outpatient department/clinic use (including urgent care sites). For each of the above binary outcomes, positive responses were only recorded if care utilization occurred during the 60 days prior to data collection, per survey data collection

guidelines. Using the above recorded variables, data were recoded into the following emergent care utilization binary outcome: 1) patient utilized any of the three originally recorded unplanned emergency care outcomes (positive binary indicator outcome), and 2) patient did not utilize any of the originally recorded unplanned emergency care outcomes (negative binary indicator outcome).

Hospice length of stay. Given previous research documenting racial/ethnic variation in hospice revocation (K. S. Johnson, Kuchibhatla, Tanis, et al., 2008), hospice LOS was examined using the subsample of patients who died under the care of hospice. This was done to further understanding of potential racial/ethnic differences in the total length of the care episode specifically among those who elected to continue hospice services throughout the dying process. Using agency documentation, hospice LOS was calculated as the difference between patient discharge (i.e., death) and enrollment dates. As such, the variable level was continuous.

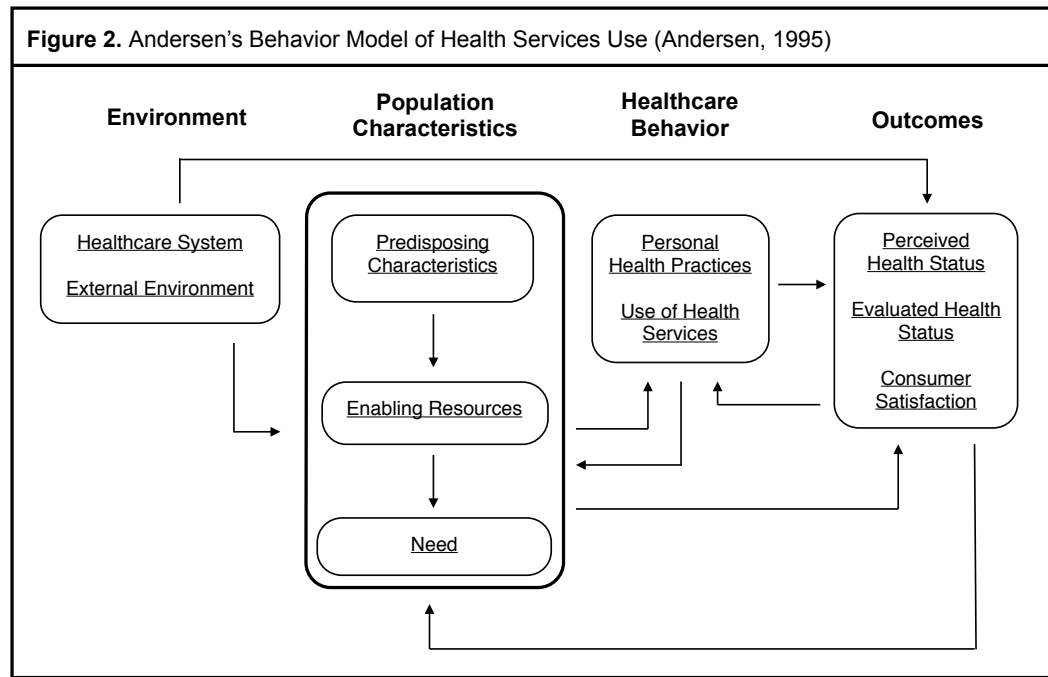
Site of death. Patient SOD was measured using agency data on where the patient was staying on the last day of care. Pre-defined locations included: 1) the agency's inpatient or residential facility, 2) private home or apartment, 3) residential care place, 4) nursing home, 5) skilled nursing facility, 5) hospital, and 6) other. Residential care place was operationalized as an assisted living facility, a board and care home, or a life care/continuing care retirement community. Although data on the final site of care are available for all discharged patients, only patients who died under the care of hospice were included in models of hospice SOD, and thus the originally recorded final site of care was re-operationalized as SOD.

Two separate outcomes were tested to determine racial/ethnic variation in death in a 1) home-like setting, and 2) hospital. Death in a home-like setting was analyzed by recoding the above pre-defined locations into two categories: 1) death in a private home or apartment or residential care place (positive binary indicator outcome), and 2) death in all other locations (negative binary indicator outcome). Death in a hospital was examined by recoding the above pre-defined locations to 1) death in a hospital (positive binary indicator outcome), and 2) death in all other locations (negative binary indicator outcome).

Conceptual Model

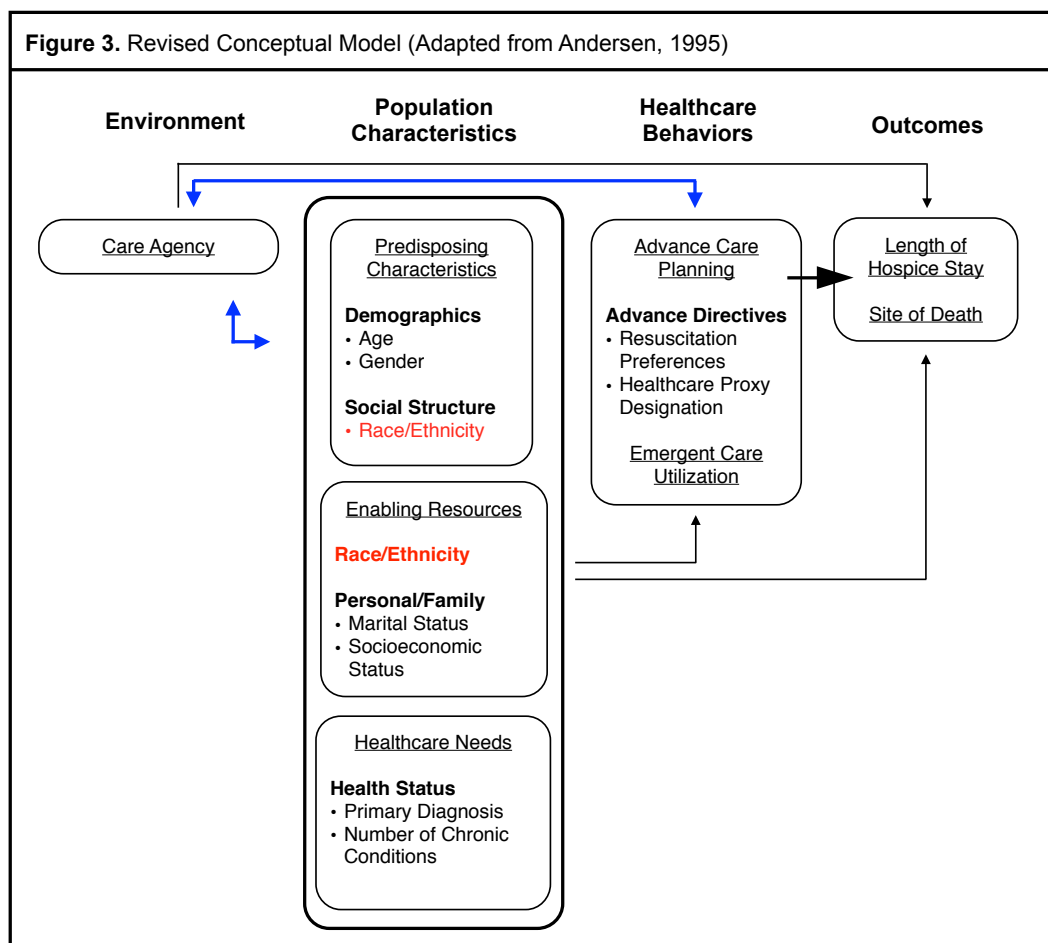
Andersen's Behavior Model of Health Services Use. The Behavior Model of Health Services Use proposed by Andersen (1995) provided a solid initial framework to guide the study. Initially developed to explain health service use, Andersen's model (Figure 2) posits that patient health outcomes result from a dynamic interaction between population characteristics, health behavior, and the larger environment. Specifically, Andersen proposes that aspects of the greater healthcare system (e.g., policy, practices, care settings) influence patient predisposing characteristics (e.g., demographics, social structure, health beliefs), enabling resources (e.g., personal, family, medical insurance), and overall need. These in turn affect patient health behaviors (i.e., utilization of health services), which ultimately influence health outcomes. The model also includes feedback loops to represent the dynamic relationship between outcomes and patient predisposing factors, overall need, and health behaviors. Prior research has drawn from Andersen's model to examine and explain racial/ethnic variation in 1) healthcare utilization in the larger healthcare system (LaVeist, Nuru-Jeter, & Jones, 2003), 2) overall care at end of

life (EOL; Bradley et al., 2002; S. P. Wallace, Levy-Storrs, Kington, & Andersen, 1998), and 3) hospice access and utilization (Conner, 2012; Miller, Kinzbrunner, et al., 2003).



Revised model. This study proposes an adaptation of Andersen's model (Figure 3) to explain within-hospice racial/ethnic variation in care planning, utilization, and outcomes. Specifically, hospice patient healthcare behaviors (i.e., advance directive completion, resuscitation preferences, healthcare proxy designation, emergent care utilization) and outcomes (i.e., LOS, SOD) are proposed to be a function of population characteristics (predisposing characteristics, enabling resources, healthcare needs) and the greater health environment (i.e., care agency). In the proposed model, patient predisposing characteristics include age, gender, and race/ethnicity (social structure). Furthermore, to emphasize the unique sociocultural contribution of patient race/ethnicity

on health behaviors and outcomes, it is also included in the model as an enabling resource. In doing so, the model more accurately explains the multifaceted nature of race/ethnicity (beyond social structure) on the identified outcomes of interest. Marital status and socioeconomic status are also operationalized as enabling resources, and patient healthcare needs are explained using data on primary diagnosis, and number of chronic conditions (i.e., comorbidity count). Agency random effects on endogenous factors are denoted by blue double-arrow feedback loops. Lastly, race/ethnicity is noted in red text to identify it as the key predictor variable of interest.



To emphasize the importance of EOL care choices and behaviors, an important distinction is made between the original Andersen model and the proposed model: patient health behaviors in the proposed model (e.g., advance care planning, emergent care utilization) are considered both an outcome as well as a factor contributing to other outcomes (e.g., LOS, SOD). This relationship between EOL health behaviors and outcomes is represented in the proposed model by a bolded arrow. To represent the EOL care philosophy of patient self-determination (Center to Advance Palliative Care, 2007), advance care planning is proposed to directly affect within-hospice outcomes in the adapted model. Building on previous research, this study investigated the independent effect of patient race/ethnicity on advance care planning, emergent care utilization, hospice LOS, and SOD, following adjustment for the other variables identified in the adapted model.

Analysis Plan

Due to the complex sampling design of NHHCS 2007, additional steps were taken to ensure accurate data representation in study analyses. Sample recruitment employed a two-stage probability sampling design in which 1) agencies were first randomly selected from the U.S. home health and hospice provider network, and 2) home health and hospice patients were randomly selected from within the sampled agencies. The National Center for Health Statistics (NCHS) recommends (Dwyer, Harris-Kojetin, Branden, & Shimizu, 2010) that data analyses include appropriate survey modeling techniques to account for the clustered nature of the data, and that sampling weights be applied for national representativeness. Added effort was made throughout the study to ensure that all analyses accounted for sampling design, survey weights were correctly applied, and

results from hypothesis tests incorporated robust standard errors. Descriptive analyses of all study variables were initially conducted. Fixation indices (i.e., F -statistics) estimated from survey-adjusted chi-square tests (discrete variables) and one-way analysis of variance (ANOVA) tests (continuous variables) were employed to investigate bivariate relationships between non-missing outcome variables and patient demographic variables. To improve variable transparency in bivariate analyses, continuous variables (i.e., age, comorbidity count) were cut into balanced, mutually-exclusive groups based on the number of valid responses.

Multivariable logistic models were tested using unconditional (i.e., random second-level intercept) multilevel regression models. Unconditional multilevel regression was selected to correctly model the observation dependence of patient-level data within the hospice agencies. The model assumes fixed effects on the hypothesized relationships, and random effects on agency intercepts. The approach can be illustrated as a two-level procedure. The first level consists of patient-level regressions that test the hypothesized relationships within agencies. The second level estimates agency-level regressions that account for between-agency variation in patient-level outcomes. Given the exclusion of level-two predictors in analyses, this model is considered an intercept-only approach where possible interactions between variables in different levels are not modeled. An unreduced example of the multivariable models employed to test study hypotheses, accounting for full patient-level predictor variation between agencies, is illustrated in Figure 4.

Figure 4. Multilevel Regression Models***Level 1 Regression***

$$y_{ij} = \beta_{0j} + \beta_{1j}x_{1ij} + \beta_{2j}x_{2ij} + \beta_{3j}x_{3ij} + \beta_{4j}x_{4ij} + \beta_{5j}x_{5ij} \\ + \beta_{6j}x_{6ij} + \beta_{7j}x_{7ij} + \beta_{8j}x_{8ij} + \beta_{9j}x_{9ij} + \beta_{10j}x_{10ij} + e_{ij}$$

Level 2 Regressions

$$\beta_{0j} = \gamma_{00} + u_{0j}$$

$$\beta_{1j} = \gamma_{10} + u_{1j}$$

$$\beta_{2j} = \gamma_{20} + u_{2j}$$

$$\beta_{3j} = \gamma_{30} + u_{3j}$$

$$\beta_{4j} = \gamma_{40} + u_{4j}$$

$$\beta_{5j} = \gamma_{50} + u_{5j}$$

$$\beta_{10j} = \gamma_{100} + u_{10j}$$

$$\beta_{7j} = \gamma_{70} + u_{7j}$$

$$\beta_{8j} = \gamma_{80} + u_{8j}$$

$$\beta_{9j} = \gamma_{90} + u_{9j}$$

$$\beta_{10j} = \gamma_{100} + u_{10j}$$

In this illustrated model formula, the level 1 regression resembles a standard regression model where the link function of patient-level outcome y_{ij} is related to a linear combination of an estimated intercept (β_{0j}), patient-level predictors x_{1ij} , x_{2ij} , x_{3ij} , x_{4ij} , x_{5ij} , x_{6ij} , x_{7ij} , x_{8ij} , x_{9ij} , x_{10ij} , and a degree of patient-level error (e_{ij}). In the level 1 regression, subscript i is included to model fixed patient-level variation, and subscript j is included to model random agency-level variation. Level 2 regressions are intercept-only models that estimate coefficients to account for between-agency differences in level 1 factors. Specifically, between-agency variation estimates are produced for the level 1 regression intercept, and each level 1 predictor. In these series of regressions, predicted coefficient outcomes β_{xj} are related to a linear combination of a level 2 intercept (γ_{x0}), and an

agency-level error term (u_{xj}). Agency-level residuals of patient-level predictors (u_{xj}) are included to model the potential level 2 variation for all level 1 predictors; however, such residuals were excluded in the final models due a lack of theoretical support in the existing literature. Notwithstanding, level 1 intercepts included agency-level residuals to model the nested nature of the data. In their reduced forms, estimated multilevel regression models substitute level 2 regressions in the level 1 equation (Figure 5). The resulting equation estimates a patient-level predicted outcome from an intercept (random at level 2), a series of level 1 predictors (in the illustrated example, random at level 2), and a degree of estimated error at levels 1 and 2.

Figure 5. Reduced Form Multilevel Regression Model

***Model Reduced Form (Incorporates Regressions
for both Levels)***

$$\begin{aligned}
 y_{ij} = & \gamma_{00} + \gamma_{10}x_{ij} + \gamma_{20}x_{ij} + \gamma_{30}x_{ij} + \gamma_{40}x_{ij} + \gamma_{50}x_{ij} + \gamma_{60}x_{ij} \\
 & + \gamma_{70}x_{ij} + \gamma_{80}x_{ij} + \gamma_{90}x_{ij} + \gamma_{100}x_{ij} + u_{0j} + u_{1j}x_{ij} \\
 & + u_{2j}x_{ij} + u_{3j}x_{ij} + u_{4j}x_{ij} + u_{5j}x_{ij} + u_{6j}x_{ij} + u_{7j}x_{ij} \\
 & + u_{8j}x_{ij} + u_{9j}x_{ij} + u_{10j}x_{ij} + e_{ij}
 \end{aligned}$$

$$i = 1, \dots, n \text{ (level 1 cases)}$$

$$j = 1, \dots, n \text{ (level 2 cases)}$$

Logistic regressions. Adjusting for patient-level predictors and agency-level variation, unconditional multilevel generalized linear models with logit link functions

were applied for study outcomes to test hypotheses 1, 1A, 1B, 2, 2A, and 4. Intraclass Correlation Coefficients were calculated to assess the proportion of observed variance between agencies (Singer, 1987), and given the large number level 2 units, between-group variance significance was determined using the asymptotic chi-squared Wald test (Maas & Snijders, 2003). Compared to the likelihood ratio test, the more conservative Wald test draws from the approximate Satterthwaite degrees of freedom (Satterthwaite, 1946; Welch, 1947), which are proportionally-adjusted to provide a more accurate p-value estimate for the test. Only patients who died while receiving hospice care ($n = 3,043$) were included in SOD analyses.

Cox proportional hazards regression. Hospice LOS models employed censoring to account for patients who withdrew from hospice prior to death. Although NHHCS 2007 data were collected at one time point, data provided by the hospice agencies, namely the total number of days under hospice care, spanned the entire hospice stay, allowing for analysis of patient survival following hospice enrollment. Preliminary patient-level analyses were conducted using mean bivariate comparisons, and the Kaplan-Meier estimator with Log-rank statistics to determine unadjusted racial/ethnic differences in hospice LOS. Adjusting for patient-level predictors and agency-level variation (random intercept approach), survival analysis was conducted to determine racial/ethnic differences in hospice LOS using Cox Proportional Hazards with the Breslow estimator. By testing for relative risk differences (among all decedents), the Cox Proportional Hazards model permitted examination of whether one racial/ethnic group was at a significant risk of dying earlier in the hospice care trajectory, relative to other decedents (Hypothesis 3).

All data management was performed using R v.3.0.1, and all analyses were conducted and Stata v.13 (StataCorp, 2013) with appropriate survey weights applied, and robust standard errors employed, to account for complex survey design (Rabe-Hesketh, Skrondal, & Pickles, 2005). Significant alpha levels were set at .05. Previous NCHS publications using NHHCS 2007 data (Jones et al., 2011) guided appropriate alpha-level selection. Statistical power to detect a small effect size (< 0.2) in the full and decedent samples was greater than 0.95 for all hypothesized relationships (J. Cohen, 1977).

Chapter 4: Description of Analytic Sample

In this chapter, a descriptive overview of the analytic samples is presented, and bivariate comparisons by race/ethnicity are reported.

The 2007 wave of the National Home Health and Hospice Care Survey (NNHCS) was analyzed to test the proposed hypotheses. Two primary analytic samples were utilized for this study. The first sample (Full Sample; $n = 3,661$; *weighted* $n = 788,872$) consisted of all cases specified in the *Sampling Plan*, and was used to test Hypotheses 1, 1A, 1B, 2, 2A, and 3. The second analytic sample (Decedent Sample; $n = 3,006$; *weighted* $n = 667,820$) was a sub-sample of patients who died during the hospice care episode. The second analytic sample was utilized to test Hypotheses 4, and 4A.

Given the complex nature of the sampling design, problems with estimate precision arise when presenting both unweighted and survey-adjusted weighted descriptives and statistics. An example of the substantial percentage shifts that can occur when accounting for the complex survey design is illustrated in Appendix A. Accordingly, when reporting descriptive and bivariate findings from complex data such as NNHCS 2007 data, researchers regularly present only percentages and test statistics (Sengupta, Park-Lee, Valverde, Caffrey, & Jones, 2013); however, for complete transparency, results from this study are also presented alongside the weighted sample size that is represented for each univariate and bivariate finding. For unweighted descriptions of the Full Sample and Decedent Sample, see Appendices B and C, respectively.

Full Sample

The full analytic sample consisted of 3,341 White, 219 Black, and 101 Hispanic hospice patients. When weighted for national representation, these patients represent 711,284 White, 51,368 Black, and 26,220 Hispanic hospice patients in the United States (Table 1).

Table 1. Full Sample Size ($n = 788,872$)				
	White	Black	Hispanic	Total
Unweighted Sample	3,341	219	101	3,661
Weighted Sample	711,284	51,368	26,220	788,872

A descriptive summary of the full analytic sample can be found in Table 2. The mean age of the sample was 82.8 ± 8.3 . Forty-three percent of the sample was female. Forty percent of the sample was married or living with a partner, 46% widowed, 5% divorced or separated, and 4% never married. Thirty-six percent of the sample had a primary diagnosis of Cancer, 13% Congestive Heart Failure or Heart Disease, 16% Lung Disease, 21% a neurological disease, and 13% another primary diagnosis. The mean comorbidity count for the sample was 3.4 ± 2.4 . Sixteen-percent of the sample was enrolled in Medicaid. Bivariate analysis indicated significant racial/ethnic differences in gender ($F(1.88, 1219.15) = 3.85$; $p = .024$), and Medicaid enrollment ($F(1.93, 1247.18) = 22.26$; $p < .001$). Specifically, relative to Whites, Blacks had a higher percentage of females (58%), Hispanics had a lower percentage of females (34%), and both Blacks (37%) and Hispanics (36%) had higher Medicaid enrollment rates. No significant racial/ethnic differences were observed for age ($F(2.00, 647.00) = 2.75$; $p = .065$), marital

status ($F(4.98, 3213.92) = 1.82$; $p = .106$), primary diagnosis ($F(6.51, 4220.89) = 0.85$; $p = .542$), or comorbidity count ($F(2.00, 647.00) = 1.60$; $p = .202$).

Table 2. Weighted Full Sample Description ($n = 788,872$)

Characteristics	Total ($n = 788,872$)	White ($n = 711,284$)	Black ($n = 51,368$)	Hispanic ($n = 26,220$)	Sig.
Age, Mean \pm SD	82.82 \pm 8.30	83.00 \pm 8.33	80.72 \pm 8.36	82.03 \pm 6.83	.065
Female, No. (%)	338,468 (42.91)	299,860 (42.16)	29,752 (57.92)	8,856 (33.78)	.024
Marital Status, No. (%)					.106
Married/Living with Partner	313,820 (39.78)	287,064 (40.36)	20,756 (40.41)	6,000 (22.88)	
Widowed	362,512 (45.95)	325,040 (45.70)	21,328 (41.52)	16,144 (61.57)	
Divorced/Separated	42,144 (5.34)	36,392 (5.12)	3,972 (7.73)	1,780 (6.79)	
Never Married	29,524 (3.74)	25,888 (3.64)	3,188 (6.21)	448 (1.71)	
Missing	40,872 (5.18)	36,900 (5.19)	2,124 (4.14)	1,848 (7.05)	
Primary Diagnosis, No. (%)					.542
Cancer	287,308 (36.42)	258,308 (36.32)	19,732 (38.41)	9,268 (35.35)	
CHF/Heart Disease	100,376 (12.72)	91,180 (12.82)	5,764 (11.22)	3,432 (13.09)	
Lung Disease	128,028 (16.23)	120,336 (16.92)	5,260 (10.24)	2,432 (9.28)	
Neurological Diseases	168,156 (21.32)	147,512 (20.74)	12,696 (24.72)	7,948 (30.31)	
Other	104,140 (13.20)	93,084 (13.09)	7,916 (15.41)	3,140 (11.98)	
Missing	864 (0.11)	864 (0.12)	0 (0.00)	0 (0.00)	
Comorbidity Count, Mean \pm SD	3.39 \pm 2.40	3.40 \pm 2.42	3.07 \pm 2.03	3.65 \pm 2.33	.202
Medicaid Enrollee, No. (%)	125,224 (15.87)	96,912 (13.62)	18,960 (36.91)	9,352 (35.67)	<.001
Missing	8,744 (1.11)	8,744 (1.23)	0 (0.00)	0 (0.00)	

Footnotes

SD: Standard Deviation

CHF: Congestive Heart Failure

Percentages are presented by column

Discharge reasons. Patients in the full analytic sample were discharged from hospice for a variety of reasons (Table 3), including death (85%), improved health (6%), revocation for more aggressive treatment (5%), unspecified revocation (2%), and relocation (2%). Racial/Ethnic differences were found in reasons for discharge ($F(6.07, 3935.11) = 2.15$; $p = .045$), with the most substantial differences among death (White 86%; Black 72%; Hispanic 76%), revocation for more aggressive treatment (White 4%; Black 11%; Hispanic 10%), and unspecified revocation (White 1%; Black 4%; Hispanic 5%).

Table 3. Reasons for Hospice Discharge (*n* = 788,872)

Documented Reason, No. (%)	Total	White	Black	Hispanic	Sig. .044
Died	667,820 (84.66)	610,820 (85.88)	37,076 (72.18)	19,924 (75.99)	
Stabilized or Improved	46,148 (5.85)	39,688 (5.58)	4,672 (9.10)	1,788 (6.82)	
More Aggressive Treatment	39,664 (5.03)	31,356 (4.41)	5,704 (11.10)	2,604 (9.93)	
Moved	17,196 (2.18)	15,388 (2.16)	1,688 (3.29)	120 (0.48)	
Revoked (Unspecified)	13,820 (1.75)	10,284 (1.45)	2,116 (4.12)	1,420 (5.42)	
Other	2,764 (0.35)	2,672 (0.38)	92 (0.18)	0 (0.00)	
Missing	1,460 (0.19)	1,076 (0.15)	20 (0.04)	364 (1.39)	

Footnotes

Percentages are presented by column

Decedent Sample

Derived from the full analytic sample, the decedent sample consisted of 2,787 White, 139 Black, and 80 Hispanic hospice patients. When weighted for national representation, these patients represent 610,820 White, 37,087 Black, and 19,924 Hispanic U.S. hospice decedents.

Table 4. Weighted Decedent Sample Description (*n* = 667,820)

Characteristics	Total (<i>n</i> = 667,820)	White (<i>n</i> = 610,820)	Black (<i>n</i> = 37,087)	Hispanic (<i>n</i> = 19,924)	Sig.
Age, Mean \pm SD	82.58 \pm 8.37	82.77 \pm 8.40	79.91 \pm 7.95	81.55 \pm 7.45	.068
Female, No. (%)	291,012 (43.58)	262,660 (43.00)	21,216 (57.22)	7,136 (35.82)	.126
Marital Status, No. (%)					.166
Married/Living with Partner	273,588 (40.97)	252,992 (41.42)	16,064 (43.33)	4,532 (22.75)	
Widowed	273,589 (45.29)	275,356 (45.08)	15,260 (41.16)	11,860 (59.53)	
Divorced/Separated	273,590 (4.88)	28,340 (4.64)	2,908 (7.84)	1,356 (6.81)	
Never Married	273,591 (3.83)	23,100 (3.78)	2,124 (5.73)	328 (1.65)	
Missing	273,592 (5.03)	31,032 (5.08)	720 (1.94)	1,848 (9.28)	
Primary Diagnosis, No. (%)					.167
Cancer	255,580 (38.27)	231,428 (37.89)	16,336 (44.06)	7,816 (39.23)	
CHF/Heart Disease	83,996 (12.58)	81,440 (13.33)	1,444 (3.90)	1,112 (5.58)	
Lung Disease	105,364 (15.78)	98,720 (16.16)	4,336 (11.69)	2,308 (11.58)	
Neurological Diseases	138,632 (20.76)	122,256 (20.02)	9,508 (25.64)	6,868 (34.47)	
Other	83,384 (12.49)	76,112 (12.46)	5,452 (14.70)	1,820 (9.14)	
Missing	864 (0.13)	864 (0.14)	0 (0.00)	0 (0.00)	
Comorbidity Count, Mean \pm SD	3.41 \pm 2.42	3.43 \pm 2.45	3.01 \pm 1.96	3.64 \pm 2.14	.223
Medicaid Enrollee, No. (%)	98,680 (14.78)	78,268 (12.81)	13,660 (36.84)	6,752 (33.89)	<.001
Missing	7,556 (1.13)	7,556 (1.23)	0 (0.00)	0 (0.00)	

Footnotes

SD: Standard Deviation

CHF: Congestive Heart Failure

Percentages are presented by column

A descriptive summary of the decedent analytic sample is presented in Table 4. The mean age of the decedent sample was 82.6 ± 8.4 . Forty-four percent of decedents were female. Forty-one percent were married or living with a partner, 45% widowed, 5% divorced or separated, and 4% never married. Thirty-eight percent of the decedent sample had a primary diagnosis of Cancer, 13% Congestive Heart Failure or Heart Disease, 16% Lung Disease, 21% a neurological disease, and 13% another primary diagnosis. The mean comorbidity count was 3.4 ± 2.4 . Fifteen-percent of decedents were enrolled in Medicaid. As with the full analytic sample, bivariate analysis indicated significant racial/ethnic differences in Medicaid enrollment among decedents ($F(1.74, 1090.50) = 15.16$; $p < .001$). Specifically, relative to Whites (13%), Blacks (37%) and Hispanics (34%) had higher rates of Medicaid enrollment. No significant racial/ethnic differences were observed for age ($F(2.00, 629.00) = 2.70$; $p = .068$), gender ($F(1.83, 1154.96) = 2.11$; $p = .126$), marital status ($F(6.30, 3971.58) = 1.51$; $p = .166$), primary diagnosis ($F(6.67, 4203.87) = 1.50$; $p = .167$), or comorbidity count ($F(2.00, 629) = 1.51$; $p = .223$).

Chapter 5: Advance Care Planning Decisions

In this chapter, bivariate comparisons by advance care planning decisions are presented, and multivariable results are reported. The full analytic sample was utilized to investigate racial/ethnic variation in advance directive completion. Subsequent analyses examining 1) do not resuscitate (DNR) order election, and 2) healthcare proxy designation were conducted using the subsample of patients with a documented advance directive. For frequencies and relative percentages of missing and excluded data for all advance care planning analyses, see Appendices D (advance directive completion), E (DNR election), and F (healthcare proxy designation).

Bivariate Comparisons

Advance care planning decisions were examined using three dependent variables: 1) advance directive completion, 2) DNR election, and 3) healthcare proxy designation. As such, bivariate comparisons are presented separately below for each dependent variable.

Advance directive completion. A summary of patient characteristics for those with and without an advance directive is presented in Table 5. Bivariate analyses indicated significant differences in advance directive completion by race/ethnicity ($F(1.67, 1078.21) = 8.98; p < .001$). As hypothesized, advance directive completion rates were significantly lower among Black patients (80%), relative to White patients (93%); however, advance directive completion rates were not significantly lower among Hispanic patients (96%), relative to White patients. No significant differences in advance directive completion were observed by age ($F(2.69, 1735.08) = 1.36; p = .256$), gender ($F(1.00, 645) = 0.60; p = .438$), marital status ($F(2.51, 1612.88) = 2.14; p = .105$),

primary diagnosis ($F(3.65, 2354.37) = 0.72$; $p = .566$), or comorbidity count ($F(1.60, 1033.78) = 1.14$; $p = .310$).

Table 5. Advance Directive Completion Bivariate Comparisons ($n = 778,520$)

Characteristics, No. (%)	Documented Advance Directive		Sig.
	No	Yes	
Age			.256
65-75	15,244 (9.54)	144,556 (90.46)	
76-82	16,456 (9.03)	165,684 (90.97)	
83-87	13,856 (7.46)	171,992 (92.54)	
88+	14,928 (5.95)	235,804 (94.05)	
Gender			.438
Female	27,852 (8.32)	307,088 (91.68)	
Male	32,632 (7.36)	410,948 (92.64)	
Race/Ethnicity			.004
White	49,164 (7.01)	652,144 (92.99)	
Black	10,312 (20.08)	41,044 (79.92)	
Hispanic	1,008 (3.90)	24,848 (96.10)	
Marital Status			.105
Married/Living Together	26,056 (8.41)	283,880 (91.59)	
Widowed	20,536 (5.69)	340,156 (94.31)	
Divorced/Separated	5,136 (12.19)	37,008 (87.81)	
Never Married	2,360 (8.00)	27,152 (92.00)	
Missing	6,396 (17.65)	29,840 (82.35)	
Primary Diagnosis			.566
Cancer	23,128 (8.11)	262,060 (91.89)	
CHF/Heart Disease	10,528 (10.68)	88,016 (89.32)	
Lung Disease	7,916 (6.27)	118,380 (93.73)	
Neurological Diseases	10,692 (6.43)	155,616 (93.57)	
Other	7,960 (7.85)	93,440 (92.15)	
Missing	260 (33.16)	524 (66.84)	
Comorbidity Count			.310
0-1	17,572 (8.45)	190,464 (91.55)	
2-3	23,060 (9.31)	224,692 (90.69)	
4+	19,852 (6.15)	302,880 (93.85)	

Footnotes

CHF: Congestive Heart Failure

Percentages are presented by row

Do not resuscitate order election. A summary of patient characteristics for those with and without a DNR order is presented in Table 6. Reported frequencies and percentages comprise the subsample of patients who completed an advance directive. Bivariate analyses indicated no significant differences in DNR order election by race/ethnicity ($F(1.99, 1274.64) = 0.78$; $p = .459$). Contrary to what was hypothesized,

DNR order election rates were not significantly lower among Black patients (91%), relative to White (91%) and Hispanic patients (96%). Significant differences in DNR order election were observed by primary diagnosis ($F(3.63, 2317.87) = 3.28$; $p = .014$). Specifically, those with neurological diseases (95%), or other primary diagnoses (96%) were more likely to elect a DNR order than patients with Cancer (89%), Congestive Heart Failure or Heart Disease (90%), or Lung Disease (89%). No significant differences in DNR order election were observed by age ($F(2.77, 1771.98) = 0.58$; $p = .614$), gender ($F(1.00, 639) = 0.53$; $p = .467$), marital status ($F(2.91, 1851.35) = 1.00$; $p = .390$), or comorbidity count ($F(1.87, 1196.49) = 0.83$; $p = .429$).

Table 6. Do Not Resuscitate Order Election Bivariate Comparisons (*n* = 718,036)

Characteristics, No. (%)	Documented DNR Order		Sig.
	No	Yes	
Age			.614
65-75	13,888 (9.61)	130,668 (90.39)	
76-82	12,820 (7.74)	152,864 (92.26)	
83-87	11,872 (6.90)	160,120 (93.10)	
88+	23,516 (9.97)	212,288 (90.03)	
Gender			.467
Female	24,212 (7.88)	282,876 (92.12)	
Male	37,884 (9.22)	373,064 (90.78)	
Race/Ethnicity			.459
White	57,472 (8.81)	594,672 (91.19)	
Black	3,748 (9.13)	37,296 (90.87)	
Hispanic	876 (3.53)	23,972 (96.47)	
Marital Status			.390
Married/Living Together	23,224 (8.18)	260,656 (91.82)	
Widowed	28,048 (8.25)	312,108 (91.75)	
Divorced/Separated	4,356 (11.77)	32,652 (88.23)	
Never Married	3,944 (14.53)	23,208 (85.47)	
Missing	2,524 (33.16)	27,316 (66.84)	
Primary Diagnosis			.014
Cancer	27,764 (10.59)	234,296 (89.41)	
CHF/Heart Disease	9,244 (10.50)	78,772 (89.50)	
Lung Disease	13,468 (11.38)	104,912 (88.62)	
Neurological Diseases	8,236 (5.29)	147,380 (94.71)	
Other	3,364 (3.60)	90,076 (96.40)	
Missing	20 (3.82)	504 (96.18)	
Comorbidity Count			.429
0-1	19,852 (10.42)	170,612 (89.58)	
2-3	16,520 (7.35)	208,172 (92.65)	
4+	25,724 (8.49)	277,156 (91.51)	

Footnotes

CHF: Congestive Heart Failure

Percentages are presented by row

Healthcare proxy designation. A summary of patient characteristics for those with and without a designated healthcare proxy is presented in Table 7. As with the bivariate analyses examining DNR order election, reported frequencies and percentages comprise the subsample of patients who completed an advance directive. Bivariate analyses indicated significant differences in healthcare proxy designation by race/ethnicity ($F(1.83, 1167.93) = 5.28$; $p = .007$). As hypothesized, healthcare proxy designation rates were significantly lower among Black patients (39%), relative to White patients (55%); however, healthcare proxy designation rates were also significantly lower

among Hispanic patients (31%), relative to White patients. Significant differences in healthcare proxy designation were also observed by age ($F(2.92, 1864.84) = 3.75$; $p = .011$), gender ($F(1.00, 639) = 4.13$; $p = .043$), marital status ($F(2.94, 1874.01) = 6.44$; $p < .001$), and comorbidity count ($F(1.87, 1196.27) = 4.15$; $p = .018$). Specifically, healthcare proxy designation rates were higher among 1) patients in the oldest age group (60%), relative to the youngest age group (47%), and 2) males (56%), relative to females (50%). Conversely, healthcare proxy designation rates were lower among 1) patients who were married or living with a partner (45%), relative to widowed (58%), divorced or separated (56%), and never married patients (59%), and 2) patients with 0-1 comorbidities (45%), relative to patients with 2-3 comorbidities (56%), and four or more comorbidities (56%). No significant differences in healthcare proxy designation were observed by primary diagnosis ($F(3.84, 2454.64) = 1.40$; $p = .234$).

Table 7. Healthcare Proxy Designation Bivariate Comparisons (*n* = 718,036)

Characteristics, No. (%)	Documented Healthcare Proxy		Sig.
	No	Yes	
Age			.011
65-75	77,220 (53.42)	67,336 (46.58)	
76-82	82,376 (49.72)	83,308 (50.28)	
83-87	82,752 (48.11)	89,240 (51.89)	
88+	94,880 (40.24)	140,924 (59.76)	
Gender			.043
Female	154,624 (50.35)	152,464 (49.65)	
Male	182,604 (44.43)	228,344 (55.57)	
Race/Ethnicity			.007
White	294,744 (45.20)	357,400 (54.80)	
Black	25,244 (61.50)	15,800 (38.50)	
Hispanic	17,240 (69.38)	7,608 (30.62)	
Marital Status			<.001
Married/Living Together	155,304 (54.71)	128,576 (45.29)	
Widowed	141,268 (41.53)	198,888 (58.47)	
Divorced/Separated	16,376 (44.25)	20,632 (55.75)	
Never Married	11,228 (41.35)	15,924 (58.65)	
Missing	13,052 (43.74)	16,788 (56.26)	
Primary Diagnosis			.234
Cancer	135,172 (51.58)	126,888 (48.42)	
CHF/Heart Disease	38,336 (43.56)	49,680 (56.44)	
Lung Disease	54,064 (45.67)	64,316 (54.33)	
Neurological Diseases	69,344 (44.56)	86,272 (55.44)	
Other	39,788 (42.58)	53,652 (57.42)	
Missing	524 (100.00)	0 (0.00)	
Comorbidity Count			.018
0-1	105,612 (55.45)	84,852 (44.55)	
2-3	99,276 (44.18)	125,416 (55.82)	
4+	132,340 (43.69)	170,540 (56.31)	

Footnotes

CHF: Congestive Heart Failure

Percentages are presented by row

Multivariable Models

Racial/Ethnic differences in advance care planning were tested using multivariable models that were conducted in three waves: 1) multilevel model predictions of advance directive completion (Hypothesis 1), 2) multilevel model predictions of DNR order election (Hypothesis 1A), and 3) multilevel model predictions of healthcare proxy designation (Hypothesis 1B). All models included patient-level (level 1) predictors to adjust for key demographic and health characteristics, and random agency-level (level 2) intercepts to account for between-agency variation.

Advance directive completion. A multilevel logistic regression was conducted to test if White hospice patients were more likely than Black and Hispanic hospice patients to have an advance directive. Results of this model are presented in Table 8.

Table 8. Predictors of Advance Directive Completion

Model Predictors	OR (Std. Err.)	95% CI	Sig.
Race/Ethnicity			
Black	0.20 (0.20)	0.14, 0.30	<.001
Hispanic	1.04 (0.09)	0.87, 1.24	.703
Age	1.01 (0.01)	0.99, 1.03	.504
Female	0.44 (0.12)	0.35, 0.55	<.001
Marital Status			
Widowed	1.60 (0.06)	1.42, 1.80	<.001
Single/Divorced/Separated	1.75 (0.25)	1.08, 2.85	.024
Primary Diagnosis			
CHF/Heart Disease	0.34 (0.22)	0.22, 0.53	<.001
Lung Disease	1.06 (0.59)	0.33, 3.38	.920
Neurological Disease	2.40 (0.38)	1.15, 5.01	.020
Other Primary Diagnosis	0.71 (0.23)	0.46, 1.10	.127
Comorbidity Count	1.05 (0.02)	1.01, 1.10	.015
Random Intercept	14.67 (0.78)	3.19, 67.49	.001
Model Summary	1.01 (0.14)		
Level 2 Variance	1.29 (0.17)		
Akaike Information Criterion	217664.92		
Bayesian Information Criterion	217714.24		
Patient Observations	3,517		
Agency Observations	651		

Footnotes

CHF: Congestive Heart Failure

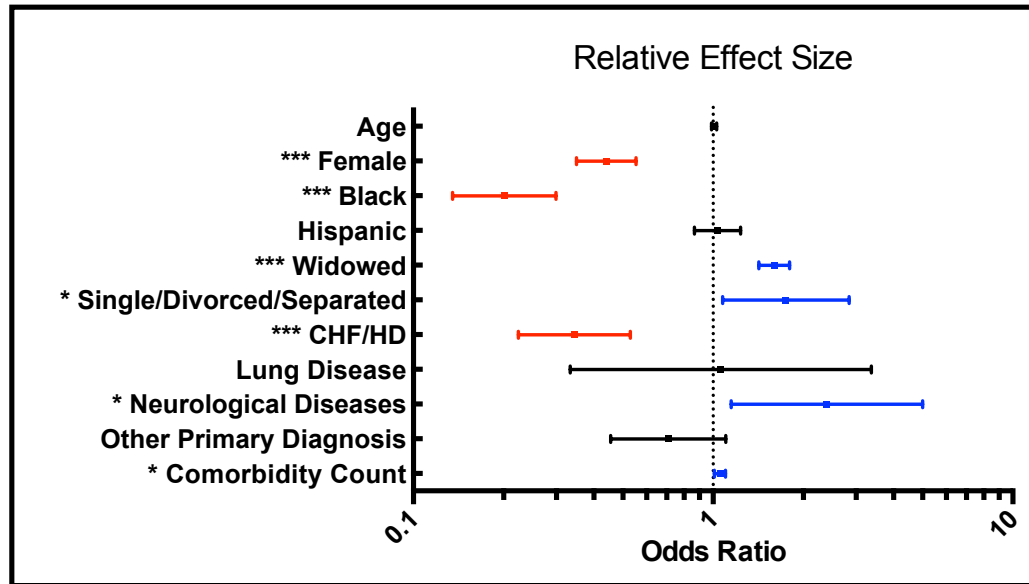
Reference Variables

White (Race)

Married/Living with Partner (Marital Status)

Cancer (Primary Diagnosis)

Preliminary multilevel analysis of the null model (agency-level $n = 654$; patient-level $n = 3,639$) revealed an Intraclass Correlation Coefficient of 0.423 (95% CI: 0.346-0.503), indicating that approximately 42% of the observed variation in advance directive completion was due to differences between agencies. Subsequent analysis further confirmed significant between-group variance ($\chi^2 = 7.59$, $df = 1$; $p = .006$), suggesting significant variation across agencies. Therefore the multilevel random intercept methodological approach was employed to account for unexplained level 2 variance. The adjusted model (Level 1 $n = 3,517$; Level 2 $n = 651$) revealed an *AIC* fit criteria of 217664.92, and a *BIC* fit criteria of 217714.24. As hypothesized, Black patients ($OR = 0.20$; $p < .001$) were less likely than White patients to have an advance directive; however, Hispanic patients ($OR = 1.04$; $p = .703$) were not less likely than White patients to have an advance directive. Female patients ($OR = 0.44$; $p < .001$), and those with Congestive Heart Failure/Heart Disease ($OR = 0.34$; $p < .001$) were significantly less likely than the associated referents to have an advance directive. Conversely, widowed patients ($OR = 1.60$; $p < .001$), single/divorced/separated patients ($OR = 1.75$; $p = .024$), and those with a neurological disease ($OR = 2.40$; $p = .020$) were significantly more likely than the associated referents to have an advance directive. Finally, comorbidity count was positively associated with having an advance directive ($OR = 1.05$; $p = .015$). See Figure 6 for a blobbogram illustrating the relative effect of each predictor for advance directive completion.

Figure 6. Relative Effects of Predictors for Advance Directive Completion**Footnotes**

CHF: Congestive Heart Failure
 HD: Heart Disease
 DNR: Do Not Resuscitate Order

Reference Variables

White (Race)
 Married/Living with Partner (Marital Status)
 Cancer (Primary Diagnosis)
 No Advance Directive (Advance Care Planning)

Do not resuscitate order election. A multilevel logistic regression was employed to test if White and Hispanic hospice patients were more likely than Black hospice patients to elect a DNR order. Model results can be found in Table 9.

Table 9. Predictors of Do Not Resuscitate Order Election

Model Predictors	OR (Std. Err.)	95% CI	Sig.
Race/Ethnicity			
Black	1.09 (0.14)	0.83, 1.43	.553
Hispanic	3.68 (0.02)	3.52, 3.86	<.001
Age	0.99 (0.01)	0.96, 1.01	.287
Female	0.66 (0.12)	0.52, 0.84	.001
Marital Status			
Widowed	1.12 (0.07)	0.98, 1.27	.090
Single/Divorced/Separated	0.29 (0.13)	0.23, 0.38	<.001
Primary Diagnosis			
CHF/Heart Disease	1.13 (0.18)	0.79, 1.62	.492
Lung Disease	1.86 (0.19)	1.29, 2.69	.001
Neurological Disease	4.73 (0.12)	3.75, 5.96	<.001
Other Primary Diagnosis	6.82 (0.37)	3.32, 14.00	<.001
Comorbidity Count	0.90 (0.04)	0.83, 0.98	.016
Random Intercept	62.45 (1.21)	5.89, 662.01	.001
Model Summary			
Level 2 Variance	1.77 (0.23)		
Akaike Information Criterion	196256.58		
Bayesian Information Criterion	196305.12		
Patient Observations	3,187		
Agency Observations	646		

Footnotes

CHF: Congestive Heart Failure

Reference Variables

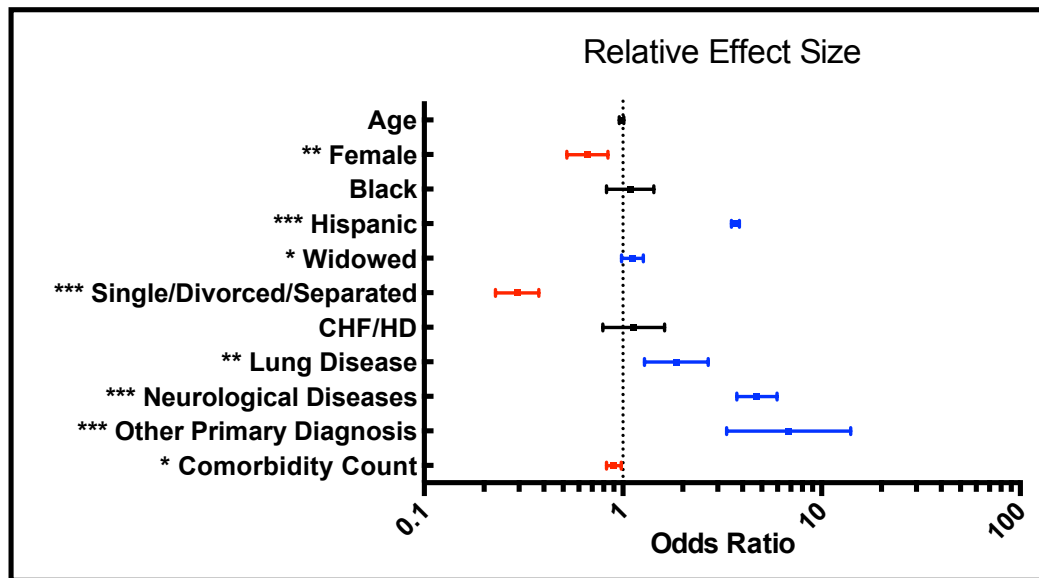
White (Race)

Married/Living with Partner (Marital Status)

Cancer (Primary Diagnosis)

Preliminary analysis of the null model (agency-level $n = 648$; patient-level $n = 3,293$) indicated that approximately 53% of the variation in DNR order election was due to between-agency differences ($ICC = 0.530$, 95% CI: 0.448-0.610; $\chi^2 = 7.61$, $df = 1$; $p = .006$), thus justifying the multilevel approach. The adjusted model (Level 1 $n = 3,187$; Level 2 $n = 646$), revealed AIC and BIC model fit criteria were 196256.58, and

196305.12, respectively. Contrary to what was hypothesized, Black patients ($OR = 1.09$; $p = .553$) were equally as likely as White patients to elect a DNR order. Additionally, Hispanic patients ($OR = 3.68$; $p < .001$) were 3.68 times as likely as White patients to elect a DNR order. Subsequent analyses (not shown), further indicated that Hispanic patients ($OR = 3.67$; $p < .001$) were also more likely than Black patients to elect a DNR order. Patients with Lung Disease ($OR = 1.86$; $p < .001$), a neurological disease ($OR = 4.73$; $p < .001$), or other primary diagnoses ($OR = 6.82$; $p < .001$) were significantly more likely than patients with Cancer to elect a DNR order. Conversely, female patients ($OR = 0.66$; $p < .001$), and those single/divorced/separated ($OR = 0.29$; $p < .001$) were significantly less likely than the associated referents to elect a DNR order. Lastly, patients with more comorbidities ($OR = 0.90$; $p = .016$) were less likely to elect a DNR order than patients with fewer comorbidities. See Figure 7 for a blobbogram illustrating the relative effect of each predictor for a documented DNR order.

Figure 7. Relative Effects of Predictors for Do Not Resuscitate Order Election**Footnotes**

CHF: Congestive Heart Failure
 HD: Heart Disease
 DNR: Do Not Resuscitate Order

Reference Variables

White (Race)
 Married/Living with Partner (Marital Status)
 Cancer (Primary Diagnosis)
 No Advance Directive (Advance Care Planning)

Healthcare proxy designation. To test if White and Hispanic hospice patients were more likely than Black hospice patients to designate a healthcare proxy, a multilevel logistic regression was conducted (Table 10).

Table 10. Predictors of Healthcare Proxy Designation

Model Predictors	OR (Std. Err.)	95% CI	Sig.
Race/Ethnicity			
Black	0.58 (0.13)	0.46, 0.75	<.001
Hispanic	0.16 (0.22)	0.11, 0.24	<.001
Age	1.01 (0.00)	1.01, 1.01	<.001
Female	1.04 (0.07)	0.90, 1.19	.597
Marital Status			
Widowed	1.05 (0.06)	0.93, 1.18	.463
Single/Divorced/Separated	1.71 (0.24)	1.08, 2.72	.022
Primary Diagnosis			
CHF/Heart Disease	1.67 (0.10)	1.26, 2.04	<.001
Lung Disease	1.10 (0.21)	0.74, 1.64	.646
Neurological Disease	2.70 (0.27)	1.60, 4.55	<.001
Other Primary Diagnosis	2.20 (0.20)	1.49, 3.24	<.001
Comorbidity Count	1.08 (0.01)	1.06, 1.10	<.001
Random Intercept	0.18 (0.18)	0.13, 0.26	<.001
Model Summary			
Level 2 Variance	1.15 (0.17)		
Akaike Information Criterion	552471.57		
Bayesian Information Criterion	552520.10		
Patient Observations	3,187		
Agency Observations	646		

Footnotes

CHF: Congestive Heart Failure

Reference Variables

White (Race)

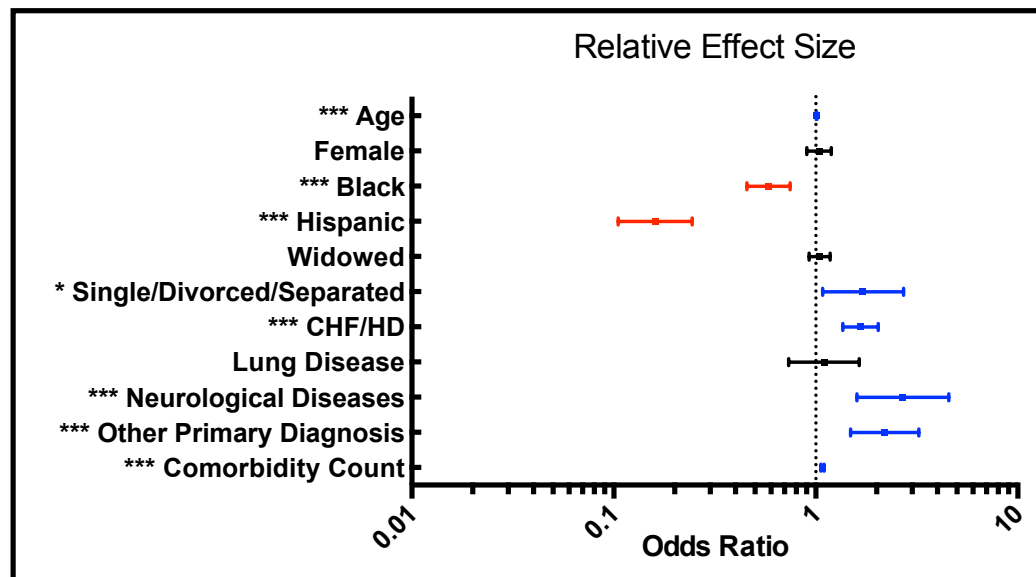
Married/Living with Partner (Marital Status)

Cancer (Primary Diagnosis)

Analysis of the null model (agency-level $n = 648$; patient-level $n = 3,293$) indicated that 49% of the variance in healthcare proxy designation was due to differences between agencies ($ICC = 0.494$, 95% CI: 0.438-0.550; $\chi^2 = 19.62$, $df = 1$; $p < .001$). The *AIC* and *BIC* fit criteria for the adjusted model (Level 1 $n = 3,187$; Level 2 $n = 646$), were 552471.57, and 552520.10, respectively. As hypothesized, Black patients ($OR = 0.58$; $p <$

.001) were less likely than White patients to designate a healthcare proxy; however, contrary to what was hypothesized, Hispanic patients ($OR = 0.16$; $p < .001$) were also significantly less likely than White patients to designate a healthcare proxy. Single/Divorced/Separated patients ($OR = 1.71$; $p = .022$), and those with Congestive Heart Failure/Heart Disease ($OR = 1.67$; $p < .001$), a neurological disease ($OR = 2.70$; $p < .001$), or other primary diagnoses ($OR = 2.20$; $p < .001$) were significantly more likely than the associated referents to designate a healthcare proxy. Both age ($OR = 1.01$; $p < .001$) and comorbidity count ($OR = 1.08$; $p < .001$) were positively associated with designating a healthcare proxy. For a blobbogram illustrating the relative effect of each predictor for healthcare proxy designation, see Figure 8.

Figure 8. Relative Effects of Predictors for Healthcare Proxy Designation



Footnotes

CHF: Congestive Heart Failure
 HD: Heart Disease
 DNR: Do Not Resuscitate Order

Reference Variables

White (Race)
 Married/Living with Partner (Marital Status)
 Cancer (Primary Diagnosis)
 No Advance Directive (Advance Care Planning)

Chapter 6: Emergent Care Utilization

In this chapter, bivariate comparisons by emergent care utilization are presented, and multivariable results are reported. To test all hypotheses associated with emergent care utilization, the full analytic sample was utilized. Frequencies and relative percentages of missing and excluded data for emergent care planning analyses can be found in Appendix G.

Bivariate Comparisons

Emergent care utilization following hospice enrollment was examined using binary outcome data. A summary of patient characteristics for those who did and did not utilize emergent care utilization is presented in Table 11. Contrary to the hypothesis, bivariate analyses indicated that emergent care utilization rates were not significantly higher among Black patients (10%), relative to White patients (6%) and Hispanic patients (7%; $F(1.86, 1194.72) = 0.89$; $p = .403$). Significant differences in emergent care utilization were observed by Medicaid enrollment ($F(1.00, 642) = 6.22$; $p = .013$), and advance care planning ($F(1.79, 1149.73) = 5.02$; $p = .009$). Specifically, emergent care utilization rates were higher among 1) patients enrolled in Medicaid (10%), relative to patients not enrolled in Medicaid (5%), and 2) patients without an advance directive (14%), relative to patients with an advance directive (DNR order not elected; 7%), and patients with a do not resuscitate (DNR) order (5%). No significant differences in emergent care utilization were observed by age ($F(2.90, 1864.80) = 1.33$; $p = .265$), gender ($F(1.00, 644) = 0.16$; $p = .691$), marital status ($F(2.71, 1737.64) = 0.76$; $p = .503$), primary diagnosis ($F(3.84, 2475.29) = 1.89$; $p = .113$), or comorbidity count ($F(1.88, 1212.50) = 1.80$; $p = .168$).

Table 11. Emergent Care Utilization Bivariate Comparisons (*n* = 773,572)

Characteristics, No. (%)	Emergent Care Utilization		Sig.
	No	Yes	
Age			.265
65-75	147,996 (93.05)	11,056 (6.95)	
76-82	168,232 (93.23)	12,220 (6.77)	
83-87	179,260 (96.11)	7,260 (3.89)	
88+	230,892 (93.27)	16,656 (6.73)	
Gender			.691
Female	315,420 (94.17)	19,536 (5.83)	
Male	410,960 (93.69)	27,656 (6.31)	
Race/Ethnicity			.403
White	656,592 (94.18)	40,568 (5.82)	
Black	45,328 (90.31)	4,864 (9.69)	
Hispanic	24,460 (93.29)	1,760 (6.71)	
Marital Status			.503
Married/Living Together	292,140 (94.41)	17,292 (5.59)	
Widowed	334,636 (93.40)	23,636 (6.60)	
Divorced/Separated	38,816 (92.12)	3,320 (7.88)	
Never Married	28,636 (97.16)	836 (2.84)	
Missing	32,152 (93.85)	2,108 (6.15)	
Primary Diagnosis			.113
Cancer	265,140 (94.31)	15,996 (5.69)	
CHF/Heart Disease	88,776 (90.00)	9,864 (10.00)	
Lung Disease	117,868 (93.00)	8,876 (7.00)	
Neurological Diseases	158,956 (96.19)	6,292 (3.81)	
Other	95,516 (93.94)	6,164 (6.06)	
Missing	124 (100.00)	0 (0.00)	
Comorbidity Count			.168
0-1	197,024 (95.49)	9,316 (4.51)	
2-3	226,048 (92.22)	19,076 (7.78)	
4+	303,308 (94.16)	18,800 (5.84)	
Enrolled in Medicaid			.013
Yes	112,236 (90.04)	12,416 (9.96)	
No	606,904 (94.58)	34,776 (5.42)	
Missing	7,240 (100.00)	0 (0.00)	
Advance Care Planning			.009
No AD, No DNR order	51,832 (86.46)	8,116 (13.54)	
Yes AD, No DNR order	56,756 (92.74)	4,440 (7.26)	
Yes AD, Yes DNR order	614,244 (94.66)	34,624 (5.34)	
Missing	3,548 (99.66)	12 (0.34)	

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row

Multivariable Models

Racial/Ethnic variation in emergent care utilization was analyzed using a two-step multilevel modeling approach. The first step investigated emergent care utilization, adjusting for key demographic and health indicators (Hypothesis 2), whereas the second

step introduced additional predictors pertaining to care planning behaviors (Hypothesis 2A). This approach was selected to determine the overall effect of race/ethnicity, and the relative effect of advance care planning, on the hypothesized relationships. Both steps included patient-level (level 1) predictors with random agency-level (level 2) intercepts to account for between-agency variation. Finally, preliminary multilevel analysis of the null model (agency-level $n = 653$; patient-level $n = 3,624$) indicated that approximately 34% of the observed variation in emergent care utilization was due to between-agency differences ($ICC = 0.344$, 95% CI: 0.268-0.430; $\chi^2 = 11.68$, $df = 1$; $p < .001$).

Step 1: Demographics and health indicator variables. To test if Black and Hispanic hospice patients were more likely than White hospice patients to utilize emergent care, a multilevel logistic regression was conducted. Results are presented under *Step 1* in Table 12. The adjusted (Level 1 $n = 3,480$; Level 2 $n = 649$), revealed an *AIC* of 205206.42, and a *BIC* of 205255.66. Contrary to the hypothesis, Black patients ($OR = 0.81$; $p = .150$) were equally as likely as White patients to utilize emergent care, and Hispanic patients ($OR = 0.56$; $p < .001$) were less likely than White patients to utilize emergent care. Widowed patients ($OR = 1.24$; $p = .004$), those with Congestive Heart Failure/Heart Disease ($OR = 2.49$; $p < .001$), and patients enrolled in Medicaid ($OR = 2.16$; $p = .036$) were significantly more likely than the associated referents to utilize emergent care. Age ($OR = 0.98$; $p < .001$), and comorbidity count ($OR = 0.94$; $p < .001$) were negatively associated with emergent care utilization.

Table 12. Predictors of Emergent Care Utilization

Model Predictors	Step 1			Step 2		
	OR (Std. Err.)	95% CI	Sig.	OR (Std. Err.)	95% CI	Sig.
Race/Ethnicity						
Black	0.81 (0.14)	0.61, 1.08	.150	0.50 (0.14)	0.38, 0.66	<.001
Hispanic	0.56 (0.15)	0.42, 0.76	<.001	0.70 (0.23)	0.45, 1.09	.117
Age	0.98 (0.00)	0.98, 0.99	<.001	0.99 (0.00)	0.98, 0.99	<.001
Female	0.86 (0.11)	0.69, 1.07	.178	0.78 (0.19)	0.54, 1.13	.188
Marital Status						
Widowed	1.24 (0.07)	1.07, 1.43	.004	1.23 (0.09)	1.04, 1.46	.018
Single/Divorced/Separated	0.82 (0.40)	0.38, 1.78	.619	0.68 (0.37)	0.33, 1.41	.298
Primary Diagnosis						
CHF/Heart Disease	2.49 (0.19)	1.73, 3.59	<.001	1.80 (0.09)	1.53, 2.13	<.001
Lung Disease	0.98 (0.43)	0.42, 2.29	.954	0.89 (0.38)	0.42, 1.86	.751
Neurological Disease	0.72 (0.46)	0.29, 1.77	.475	0.67 (0.49)	0.26, 1.75	.410
Other Primary Diagnosis	1.78 (0.34)	0.92, 3.43	.088	1.67 (0.33)	0.87, 3.19	.123
Comorbidity Count	0.94 (0.02)	0.91, 0.98	.001	1.01 (0.01)	1.00, 1.02	.131
Medicaid Enrollee	2.16 (0.37)	1.05, 4.44	.036	1.72 (0.41)	0.78, 3.82	.182
Advance Care Planning						
Yes AD, No DNR order				0.47 (0.24)	0.30, 0.75	.002
Yes AD, YES DNR order				0.36 (0.40)	0.16, 0.78	.010
Random Intercept	0.04 (0.31)	0.02, 0.07	<.001	0.13 (0.42)	0.06, 0.30	<.001
Model Summary						
Level 2 Variance	1.18 (0.09)			1.46 (0.11)		
Akaike Information Criterion	205206.42			201953.59		
Bayesian Information Criterion	205255.66			202002.82		
Patient Observations	3,480			3,475		
Agency Observations	649			648		

Footnotes

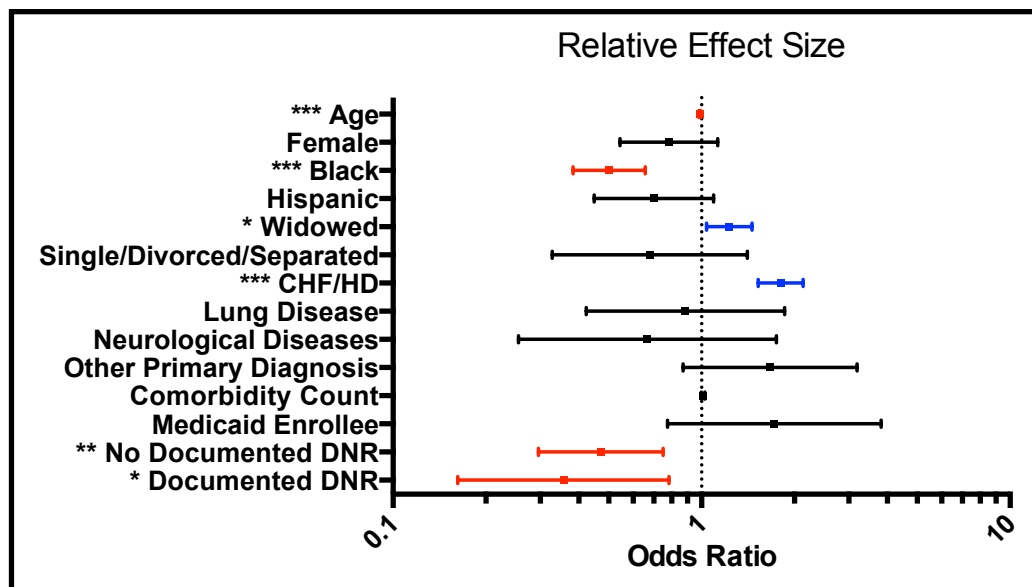
CHF: Congestive Heart Failure
AD: Advance Directive
DNR: Do Not Resuscitate

Reference Variables

White (Race)
Married/Living with Partner (Marital Status)
Cancer (Primary Diagnosis)
No Advance Directive (Advance Care Planning)

Step 2: Inclusion of advance care planning decisions. To determine the relative effect of advance care planning on emergent care utilization, a second model was estimated. Results are presented under *Step 2* in Table 12. The second adjusted model

(Level 1 $n = 3,475$; Level 2 $n = 648$) was an improved fit over the first model ($AIC = 201953.59$; $BIC = 202002.82$). Consistent with what was hypothesized, patients with an advance directive ($OR = 0.47$; $p = .002$) or DNR order ($OR = 0.36$; $p = .010$) were significantly less likely than those without an advance directive to utilize emergent care. Black patients ($OR = 0.68$; $p = .031$) were also found to be less likely than White patients to utilize emergent care, and Hispanic patients ($OR = 0.70$; $p = .117$) were equally as likely as White patients to utilize emergent care. Additionally, widowed patients ($OR = 1.23$; $p = .018$), and those with Congestive Heart Failure/Heart Disease ($OR = 1.80$; $p < .001$) were significantly more likely than the associated referents to utilize emergent care. Older patients ($OR = 0.99$; $p < .001$) were also less likely to utilize emergent care, compared to younger patients. Finally, following inclusion of care planning covariates, Black race/ethnicity, comorbidity count, and Medicaid enrollment all lost significance, whereas Hispanic race/ethnicity gained significance. See Figure 9 for a blobbogram illustrating the relative effect of each model 2 predictor for emergent care utilization.

Figure 9. Relative Effects of Predictors for Emergent Care Utilization**Footnotes**

CHF: Congestive Heart Failure
 HD: Heart Disease
 DNR: Do Not Resuscitate Order

Reference Variables

White (Race)
 Married/Living with Partner (Marital Status)
 Cancer (Primary Diagnosis)
 No Advance Directive (Advance Care Planning)

Chapter 7: Hospice Length of Stay

In this chapter, bivariate comparisons by hospice length of stay (LOS) are presented, multivariable results are reported, and posthoc ancillary bivariate comparisons and multivariable models are also presented. Bivariate tests of the LOS hypothesis were conducted using the decedent analytic sample, whereas multivariable LOS survival models utilized the full sample, censoring patients who did not die under the care of hospice. Results of the initial analyses testing for differences in the total days of care before death are presented first, followed two ancillary binary outcomes that were subsequently investigated: 1) hospice LOS: 0-7 days (1 week), and 2) hospice LOS: 0-30 days (1 month). Recent data indicates that approximately 36% of U.S. hospice patients die within the first week of care, and 63% die within the first month (National Hospice and Palliative Care Organization, 2013). Given that shorter hospice stays limit the full benefits of care (Byock et al., 1996; Christakis & Iwashyna, 1998; Rickerson et al., 2005), time windows for ancillary analyses were selected to test for racial/ethnic variation in shorter lengths of stay among decedents. Previous studies investigating key hospice LOS outcomes have also investigated similar hospice LOS time windows (Sengupta et al., 2013). Frequencies and relative percentages of missing and excluded data for LOS analyses can be found in Appendix H.

Bivariate Comparisons

Hospice LOS was examined using continuous outcome data on the total days of hospice care received prior to death. A summary of decedent characteristics by LOS is presented in Table 13. Additional data on median differences in LOS among the decedent sample is also available in Appendix I.

Bivariate analyses indicated no significant differences in decedent LOS by race/ethnicity ($F(1.00, 630.00) = 0.03$; $p = .862$). Contrary to the study hypothesis, days of care prior to death were not significantly greater for Black (59.53 ± 148.48) and Hispanic decedents (60.99 ± 92.90), relative to White decedents (58.43 ± 120.52). Significant differences in LOS were observed by age ($F(3.00, 628.00) = 3.91$; $p = .009$), gender ($F(1.00, 630.00) = 6.50$; $p = .011$), primary diagnosis ($F(1.00, 630.00) = 6.06$; $p = .014$), and Medicaid enrollment ($F(1.00, 628.00) = 4.66$; $p = .031$). Specifically, LOS before death was longer for 1) decedents in the oldest age group (77.27 ± 141.71), relative to the youngest age group (47.49 ± 107.32), 2) females (66.26 ± 131.95), relative to males (48.53 ± 105.57), 3) decedents with Lung Disease (71.90 ± 140.11), or a neurological disease (88.93 ± 164.91), relative to decedents with Cancer (44.07 ± 94.61), or Congestive Heart Failure/Heart Disease (58.59 ± 109.57), and 4) decedents enrolled in Medicaid (75.60 ± 125.73), relative to decedents not enrolled in Medicaid (54.59 ± 117.30). No significant differences in hospice LOS were observed by marital status ($F(1.00, 627.00) = 0.37$; $p = .545$), comorbidity count ($F(1.00, 630.00) = 0.50$; $p = .480$), or advance care planning ($F(1.00, 628.00) = 3.70$; $p = .055$).

Table 13. Decedent Hospice Length of Stay (Full Care Episode)
Bivariate Comparisons ($n = 638,412$)

Characteristics	Length of Stay: Full Episode		Sig.
	<i>n</i>	Mean \pm SD	
Age			.009
65-75	144,880	47.49 \pm 107.32	
76-82	150,860	54.63 \pm 110.68	
83-87	147,548	48.76 \pm 113.43	
88+	195,124	77.27 \pm 141.71	
Gender			.011
Female	361,604	66.26 \pm 131.95	
Male	276,808	48.53 \pm 105.57	
Race/Ethnicity			.862
White	583,124	58.43 \pm 120.52	
Black	36,304	59.53 \pm 148.48	
Hispanic	18,984	60.99 \pm 92.90	
Marital Status			.545
Married/Living Together	262,216	50.08 \pm 106.77	
Widowed	286,640	66.43 \pm 130.72	
Divorced/Separated	31,956	32.73 \pm 81.99	
Never Married	24,920	51.25 \pm 101.72	
Missing	32,680	88.65 \pm 174.40	
Primary Diagnosis			.014
Cancer	247,300	44.07 \pm 94.61	
CHF/Heart Disease	80,536	58.59 \pm 109.57	
Lung Disease	96,788	71.90 \pm 140.11	
Neurological Diseases	133,176	88.93 \pm 164.91	
Other	79,748	36.55 \pm 76.83	
Missing	864	69.41 \pm 227.24	
Comorbidity Count			.480
0-1	174,004	57.11 \pm 135.21	
2-3	194,320	53.03 \pm 108.36	
4+	270,088	63.50 \pm 121.05	
Enrolled in Medicaid			.031
Yes	95,952	75.60 \pm 125.73	
No	534,904	54.59 \pm 117.30	
Missing	7,556	124.39 \pm 258.14	
Advance Care Planning			.055
No AD, No DNR order	39,456	47.85 \pm 94.78	
Yes AD, No DNR order	47,744	42.96 \pm 105.51	
Yes AD, Yes DNR order	542,360	59.29 \pm 121.12	
Missing	8,852	146.67 \pm 246.69	

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Log-rank tests. Differences in time-to-death between 1) White and Black decedents ($n = 2,825$), 2) White and Hispanic decedents ($n = 2,765$), and 3) Black and Hispanic decedents ($n = 212$), were also tested using the log-rank test for equality of

survivor functions. Results of bivariate mean comparisons further indicated no significant difference in time-to-death between White and Black decedents ($\chi^2 = 0.90$; $p=.344$; Figure 10), White and Hispanic decedents ($\chi^2 = 0.32$; $p=.574$; Figure 11), or Black and Hispanic decedents ($\chi^2 = 0.03$; $p=.864$; Figure 12),

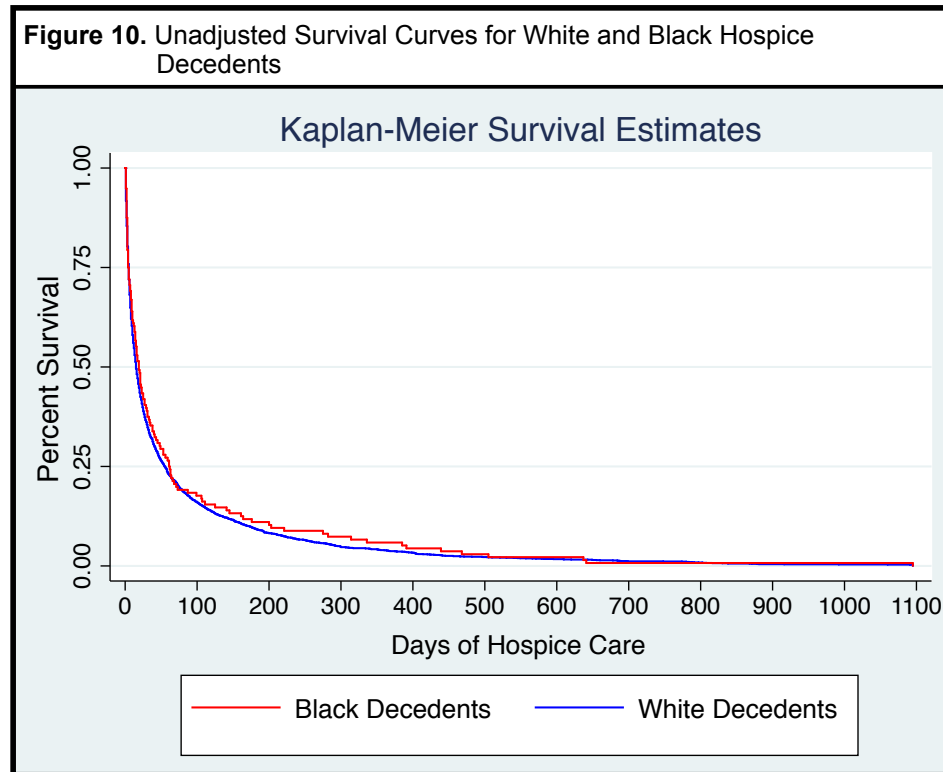


Figure 11. Unadjusted Survival Curves for White and Hispanic Hospice Decedents

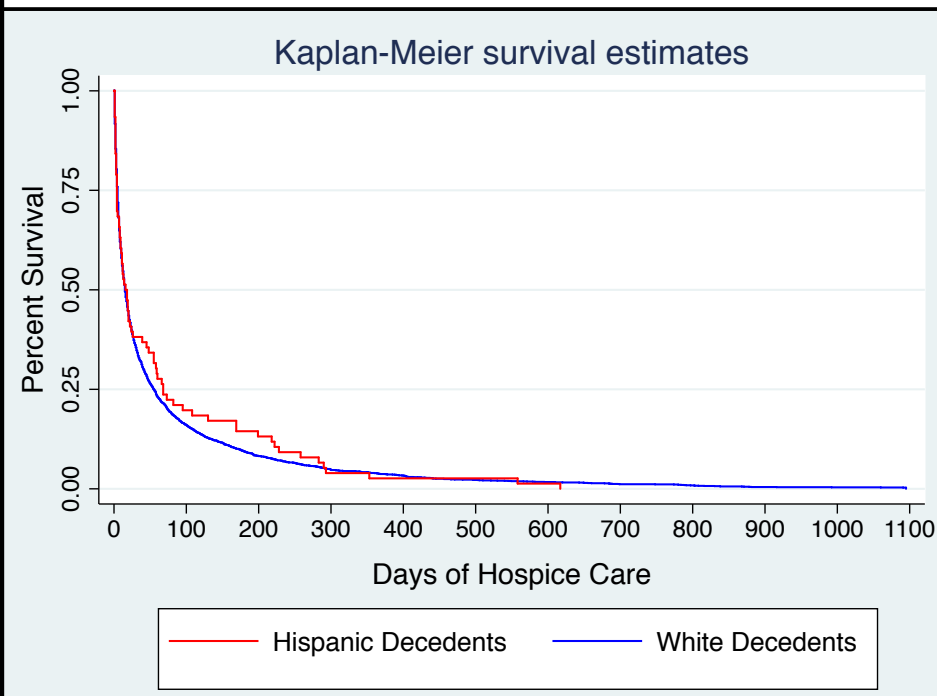
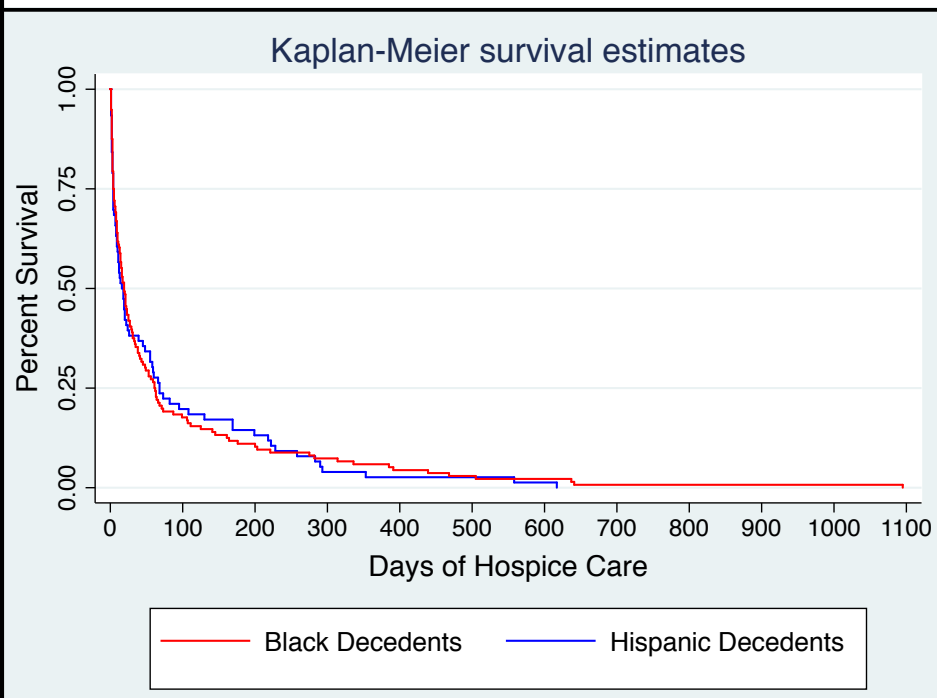


Figure 12. Unadjusted Survival Curves for Black and Hispanic Hospice Decedents



Multivariable Models

Racial/Ethnic differences in hospice LOS were analyzed using a two-step Cox Proportional Hazards multivariable model. As with emergent care utilization multivariable analyses, the first step adjusted for key demographic and health indicators, whereas the second step introduced additional predictors pertaining to care planning. Both steps were employed to test relationships proposed in Hypothesis 3, and patients who were discharged for any reason other than death were censored in survival analysis models.

Step 1: Demographics and health indicator variables. To test if hospice LOS was longer for Black and Hispanic decedents, compared to White decedents, a Cox Proportional Hazards regression was conducted. Results of this model can be found under *Step 1* in Table 14. The adjusted model was significant (Level 1 $n = 3,400$; Level 2 $n = 652$; $F(12.00, 632.00) = 6.13$; $p < .001$). Contrary to study hypotheses, neither Black ($HR = 0.82$; $p = .216$) nor Hispanic ($HR = 0.86$; $p = .318$) decedents were more likely to experience a longer LOS than White decedents prior to death. Decedents with Lung Disease ($HR = 0.75$; $p = .003$), a neurological disease ($HR = 0.72$; $p < .001$), or those enrolled in Medicaid ($HR = 0.79$; $p = .008$) were at significantly reduced risk of dying before decedents with Cancer. Similarly, older decedents ($HR = 0.99$; $p = .001$) were at a reduced risk of an earlier death during the hospice stay, compared to younger decedents.

Table 14. Predictors of Decedent Hospice Length of Stay: Full Care Episode

Model Predictors	Step 1	95% CI	Sig.	Step 2	95% CI	Sig.
	HR (Std. Err.)			HR (Std. Err.)		
Race/Ethnicity						
Black	0.82 (0.16)	0.60, 1.12	.216	0.86 (0.16)	0.63, 1.16	.325
Hispanic	0.86 (0.15)	0.64, 1.16	.318	0.85 (0.15)	0.63, 1.15	.279
Age	0.99 (0.00)	0.98, 1.00	.001	0.99 (0.00)	0.98, 0.99	<.001
Female	0.91 (0.07)	0.80, 1.03	.145	0.92 (0.07)	0.80, 1.04	.187
Marital Status						
Widowed	0.98 (0.03)	0.92, 1.05	.563	0.97 (0.03)	0.91, 1.04	.409
Single/Divorced/Separated	1.00 (0.12)	0.79, 1.27	.996	1.01 (0.12)	0.80, 1.27	.959
Primary Diagnosis						
CHF/Heart Disease	0.82 (0.11)	0.66, 1.01	.065	0.84 (0.11)	0.68, 1.04	.106
Lung Disease	0.75 (0.10)	0.62, 0.90	.003	0.74 (0.10)	0.61, 0.90	.002
Neurological Disease	0.72 (0.09)	0.60, 0.86	<.001	0.73 (0.10)	0.61, 0.88	.001
Other Primary Diagnosis	0.92 (0.11)	0.73, 1.15	.458	0.92 (0.12)	0.73, 1.16	.481
Comorbidity Count	1.00 (0.01)	0.98, 1.03	.812	1.00 (0.01)	0.98, 1.03	.881
Medicaid Enrollee	0.79 (0.09)	0.66, 0.94	.008	0.78 (0.09)	0.66, 0.93	.007
Advance Care Planning						
Yes AD, No DNR order				1.38 (0.21)	0.92, 2.09	.122
Yes AD, YES DNR order				1.35 (0.16)	0.98, 1.85	.063
Model Summary						
Survey-Adjusted F-Statistic	6.13			5.61		
Design Degrees of Freedom	643.00			641		
Model Significance	<.001			<.001		
Patient Observations	3,400			3,392		
Agency Observations	652			650		

Footnotes

CHF: Congestive Heart Failure
AD: Advance Directive
DNR: Do Not Resuscitate

Reference Variables

White (Race)
Married/Living with Partner (Marital Status)
Cancer (Primary Diagnosis)
No Advance Directive (Advance Care Planning)

Step 2: Inclusion of advance care planning decisions. To determine the relative effect of advance care planning on decedent hospice LOS, a second model was estimated (see *Step 2* in Table 14). The adjusted model was significant (Level 1 $n = 3,392$; Level 2

$n = 650$; $F(14.00, 628.00) = 5.61$; $p < .001$). As with the first model, neither Black ($HR = 0.86$; $p = .325$) nor Hispanic decedents ($HR = 0.85$; $p = .279$) were more likely to experience a longer LOS prior to death, compared to White decedents. Those with Lung Disease ($HR = 0.74$; $p = .002$), a neurological disease ($HR = 0.73$; $p = .001$), or those enrolled in Medicaid ($HR = 0.78$; $p = .007$) were at significantly reduced risk of dying before decedents with Cancer. Age ($HR = 0.99$; $p < .001$) was also found to be negatively associated with an earlier death. Lastly, following inclusion of care planning covariates, none of the variables lost or gained significance.

Ancillary Bivariate Comparisons

To further investigate racial/ethnic variation in hospice LOS, two ancillary binary outcomes were examined within the original LOS variable: 1) hospice LOS: 0-7 days (1 week; coded as positive/negative indicator), and 2) hospice LOS: 0-30 days (1 month; coded as positive/negative indicator). The ancillary outcomes were analyzed to determine if there were racial/ethnic differences in shorter hospice stays among decedents. As with prior LOS analyses, the decedent sample was utilized for ancillary analyses. For frequencies and relative percentages of missing and excluded data for ancillary LOS analyses, see Appendices J (0-7 days) and K (0-30 days).

Hospice length of stay: 0-7 Days. A summary of decedent characteristics by a hospice LOS of seven days or less is presented in Table 15. Bivariate analyses indicated no significant differences in death within the first week by race/ethnicity ($F(1.89, 1193.79) = 0.74$; $p = .472$), with 39% of White decedents, 31% of Black decedents, and 33% of Hispanic decedents enrolled in hospice for seven days or less prior to death. No significant differences in decedent LOS of 0-7 days were observed by age ($F(2.98,$

1876.31) = 2.42; $p = .065$), gender ($F(1.00, 630.00) = 0.37$; $p = .542$), marital status ($F(2.95, 1849.34) = 1.27$; $p = .283$), primary diagnosis ($F(3.73, 2351.23) = 0.68$; $p = .599$), comorbidity count ($F(1.96, 1235.92) = 0.64$; $p = .523$), Medicaid enrollment ($F(1.00, 628.00) = 3.82$; $p = .051$), or advance care planning ($F(1.94, 1220.85) = 0.30$; $p = .733$).

Table 15. Decedent Hospice Length of Stay (0-7 Days) Bivariate Comparisons
(*n* = 638,412)

Characteristics, No. (%)	Length of Stay: 0-7 Days		Sig.
	No	Yes	
Age			.065
65-75	86,480 (59.69)	58,400 (40.31)	
76-82	94,544 (62.67)	56,316 (37.33)	
83-87	81,284 (55.09)	66,264 (44.91)	
88+	128,756 (65.99)	66,368 (34.01)	
Gender			.542
Female	166,252 (60.06)	110,556 (39.94)	
Male	224,812 (62.17)	136,792 (37.83)	
Race/Ethnicity			.472
White	353,252 (60.58)	229,872 (39.42)	
Black	25,084 (69.09)	11,220 (30.91)	
Hispanic	12,728 (67.05)	6,256 (32.95)	
Marital Status			.283
Married/Living Together	156,908 (59.84)	105,308 (40.16)	
Widowed	181,028 (63.16)	105,612 (36.84)	
Divorced/Separated	16,288 (50.97)	15,668 (49.03)	
Never Married	13,792 (55.35)	11,128 (44.65)	
Missing	23,048 (70.53)	9,632 (29.47)	
Primary Diagnosis			.599
Cancer	156,852 (63.43)	90,448 (36.57)	
CHF/Heart Disease	46,412 (57.63)	34,124 (42.37)	
Lung Disease	60,076 (62.07)	36,712 (37.93)	
Neurological Diseases	81,892 (61.49)	51,284 (38.51)	
Other	45,016 (56.45)	34,732 (43.55)	
Missing	816 (94.44)	48 (5.56)	
Comorbidity Count			.523
0-1	105,876 (60.85)	68,128 (39.15)	
2-3	114,652 (59.00)	79,668 (41.00)	
4+	170,536 (63.14)	99,552 (36.86)	
Enrolled in Medicaid			.051
Yes	65,908 (68.69)	30,044 (31.31)	
No	320,420 (59.90)	214,484 (40.10)	
Missing	4,736 (62.68)	2,820 (37.32)	
Advance Care Planning			.733
No AD, No DNR order	22,288 (56.49)	17,168 (43.51)	
Yes AD, No DNR order	29,392 (61.56)	18,352 (38.44)	
Yes AD, Yes DNR order	332,020 (61.22)	210,340 (38.78)	
Missing	7,364 (83.19)	1,488 (16.81)	

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row

Hospice length of stay: 0-30 Days. A summary of decedent characteristics by a hospice LOS one month or less can be found in Table 16. Bivariate analyses indicated no significant differences in a hospice LOS of 0-30 days by race/ethnicity ($F(1.96, 1234.62) = 2.63$; $p = .074$), with 66% of White decedents, 76% of Black decedents, and 65% of

Hispanic decedents dying within the first thirty days of hospice care. Significant differences in a hospice LOS of 0-30 days were observed by age ($F(2.89, 1822.58) = 3.03$; $p = .030$), marital status ($F(2.92, 1829.66) = 2.64$; $p = .049$), primary diagnosis ($F(3.78, 2383.51) = 2.70$; $p = .032$), and Medicaid enrollment ($F(1.00, 628.00) = 3.87$; $p = .049$). Specifically, rates of dying within the first thirty days of hospice care were lower among 1) decedents in the oldest age group (60%), relative to the youngest age group (68%), 2) widowed decedents (64%), relative to decedents who were married or living with a partner (69%), divorced or separated (79%), or never married (73%), and 3) decedents enrolled in Medicaid (60%), relative to decedents who were not enrolled in Medicaid (67%). Additionally, rates of dying within the first thirty days of hospice care were higher among decedents with Cancer (69%) and other primary diagnoses (75%), relative to decedents with Congestive Heart Failure/Heart Disease (63%), Lung Disease (60%), or a neurological disease (61%). No significant differences in a hospice LOS of 0-30 days were observed by gender ($F(1.00, 630.00) = 2.57$; $p = .109$), comorbidity count ($F(1.98, 1246.76) = 2.61$; $p = .075$), or advance care planning ($F(1.90, 1190.44) = 0.26$; $p = .763$).

Table 16. Decedent Hospice Length of Stay (0-30 Days) Bivariate Comparisons
(*n* = 638,412)

Characteristics, No. (%)	Length of Stay: 0-30 Days		Sig.
	No	Yes	
Age			0.030
65-75	45,828 (31.63)	99,052 (68.37)	
76-82	50,548 (33.51)	100,312 (66.49)	
83-87	41,284 (27.89)	106,264 (72.02)	
88+	78,420 (40.19)	116,704 (59.81)	
Gender			0.109
Female	85,952 (31.05)	190,856 (68.95)	
Male	130,128 (35.99)	231,476 (64.01)	
Race/Ethnicity			0.074
White	200,956 (34.46)	382,168 (65.54)	
Black	8,540 (23.52)	27,764 (76.48)	
Hispanic	6,584 (34.68)	12,400 (65.32)	
Marital Status			0.049
Married/Living Together	81,348 (31.02)	180,868 (68.98)	
Widowed	104,348 (36.40)	182,292 (63.60)	
Divorced/Separated	6,800 (21.28)	25,156 (78.72)	
Never Married	6,736 (27.03)	18,184 (72.97)	
Missing	16,848 (51.55)	15,832 (48.45)	
Primary Diagnosis			0.032
Cancer	76,204 (30.81)	171,096 (69.19)	
CHF/Heart Disease	30,112 (37.39)	50,424 (62.61)	
Lung Disease	38,300 (39.57)	58,488 (60.43)	
Neurological Diseases	51,748 (38.86)	81,428 (61.14)	
Other	19,592 (24.57)	60,156 (75.43)	
Missing	124 (14.35)	740 (85.65)	
Comorbidity Count			0.075
0-1	53,936 (31.00)	120,068 (69.00)	
2-3	58,812 (30.27)	135,508 (69.73)	
4+	103,332 (38.26)	166,756 (61.74)	
Enrolled in Medicaid			0.049
Yes	38,844 (40.48)	57,108 (59.52)	
No	174,328 (32.59)	360,576 (67.41)	
Missing	2,908 (38.49)	4,648 (61.51)	
Advance Care Planning			0.763
No AD, No DNR order	12,136 (30.76)	27,320 (69.24)	
Yes AD, No DNR order	14,712 (30.81)	33,032 (69.19)	
Yes AD, Yes DNR order	182,596 (33.67)	359,764 (66.33)	
Missing	6,636 (74.97)	2,216 (25.03)	

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row

Ancillary Multivariable Models

Racial/Ethnic variation in binary hospice LOS outcomes were analyzed using multivariable models conducted in two waves: 1) death in the first week (0-7 days), and

2) death in the first month (0-30 days). As with previous study analyses, two-step multilevel models were estimated to first adjust for key demographic and health indicators, followed by the inclusion of additional care planning predictors. All models included patient-level (level 1) predictors with random agency-level (level 2) intercepts to account for between-agency variation.

Hospice length of stay: 0-7 days. Preliminary analyses of the null model (agency-level $n = 639$; patient-level $n = 2,901$) found that 5% of the observed variation in death within the first week was due to between-agency differences ($ICC = 0.047$, 95% CI: 0.021, 0.100; $\chi^2 = 27.21$, $df = 1$; $p < .001$). Despite the low Intraclass Correlation Coefficient, previous research has suggested that between-level 2 unit variation should still be accounted for in study design (Nezlek, 2008) and thus, the hierarchical analytical design was modeled to the data.

Step 1: Demographics and health indicator variables. To test for racial/ethnic variation in dying within the first seven days of hospice care, a multilevel logistic regression was conducted. Results of this model are presented under *Step 1* in Table 17. The adjusted model (Level 1 $n = 2,776$; Level 2 $n = 634$), revealed an *AIC* fit criteria of 616693.63, and a *BIC* fit criteria of 616746.99. Hispanic decedents ($OR = 1.15$; $p = .036$) were significantly more likely than White decedents to die within the first seven days of hospice care. Conversely, Black decedents ($OR = 0.71$; $p = .019$) were significantly less likely than White decedents to die within the first week. Single/Divorced/Separated decedents ($OR = 1.37$; $p = .008$), and those with Congestive Heart Failure/Heart Disease ($OR = 1.35$; $p < .001$), a neurological disease ($OR = 1.53$; $p < .001$), or other primary diagnoses ($OR = 1.97$; $p = .007$) were significantly more likely than the associated

referents to die within the first seven days of hospice care. Lastly, age was negatively associated with dying within the first seven days of hospice care ($OR = 0.98$; $p < .001$).

Table 17. Predictors of Decedent Hospice Length of Stay: 0-7 Days

Predictors	Step 1			Step 2		
	OR (Std. Err.)	95% CI	Sig.	OR (Std. Err.)	95% CI	Sig.
Race/Ethnicity						
Black	0.71 (0.14)	0.54, 0.95	.019	0.78 (0.12)	0.62, 0.97	.027
Hispanic	1.15 (0.07)	1.01, 1.32	.036	1.18 (0.05)	1.07, 1.30	.001
Age	0.98 (0.00)	0.97, 0.98	<.001	0.98 (0.00)	0.98, 0.99	<.001
Female	0.96 (0.06)	0.85, 1.09	.552	0.99 (0.08)	0.85, 1.15	.886
Marital Status						
Widowed	0.93 (0.15)	0.69, 1.26	.635	0.93 (0.16)	0.69, 1.27	.658
Single/Divorced/Separated	1.37 (0.12)	1.09, 1.73	.008	1.37 (0.08)	1.17, 1.59	<.001
Primary Diagnosis						
CHF/Heart Disease	1.35 (0.09)	1.14, 1.60	<.001	1.37 (0.11)	1.10, 1.71	.005
Lung Disease	1.41 (0.23)	0.90, 2.20	.138	1.38 (0.16)	1.00, 1.90	.050
Neurological Disease	1.53 (0.03)	1.43, 1.64	<.001	1.53 (0.04)	1.41, 1.66	<.001
Other Primary Diagnosis	1.97 (0.25)	1.20, 3.22	.007	2.06 (0.26)	1.24, 3.43	.005
Comorbidity Count	1.01 (0.01)	0.99, 1.03	.531	0.98 (0.01)	0.96, 1.01	.126
Medicaid Enrollee	0.82 (0.11)	0.66, 1.00	.054	0.75 (0.13)	0.58, 0.97	.031
Advance Care Planning						
Yes AD, No DNR order				0.61 (0.18)	0.43, 0.87	.007
Yes AD, YES DNR order				0.61 (0.09)	0.51, 0.73	<.001
Random Intercept	2.71 (0.31)	1.47, 4.98	.001	4.04 (0.38)	1.94, 8.42	<.001
Model Summary						
Level 2 Variance	0.80 (0.11)			0.79 (0.08)		
Akaike Information Criterion	616693.63			614667.00		
Bayesian Information Criterion	616746.99			614714.42		
Patient Observations	2,776			2,771		
Agency Observations	634			633		

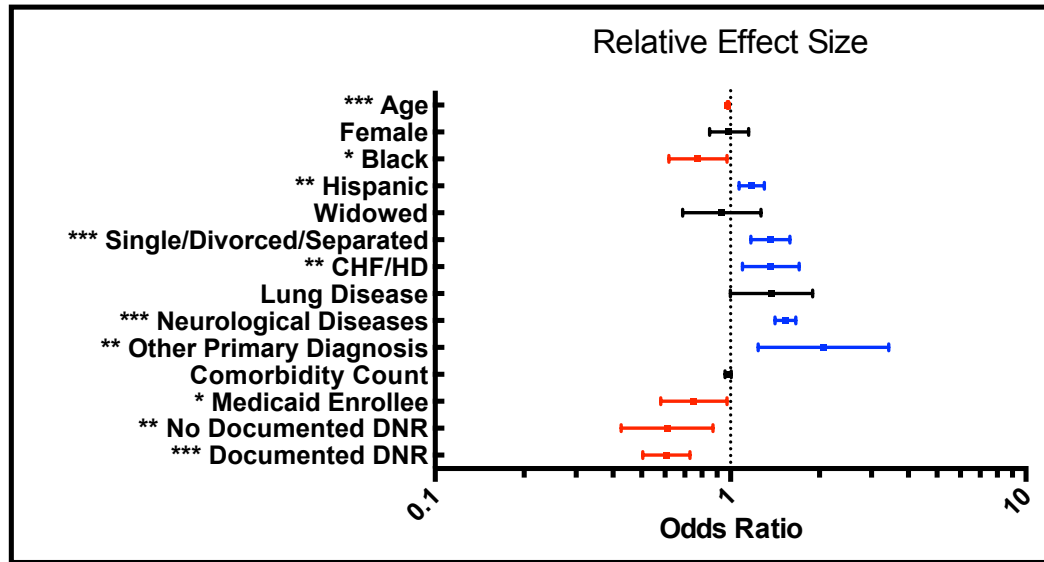
Footnotes

CHF: Congestive Heart Failure
AD: Advance Directive
DNR: Do Not Resuscitate

Reference Variables

White (Race)
Married/Living with Partner (Marital Status)
Cancer (Primary Diagnosis)
No Advance Directive (Advance Care Planning)

Step 2: Inclusion of advance care planning decisions. The second multilevel model predicting death within the first seven days of hospice care added advance care planning decisions to the previous model (see *Step 2* in Table 17). The second adjusted model (Level 1 $n = 2,771$; Level 2 $n = 633$), indicated an improved fit over the first model ($AIC = 614667.00$; $BIC = 614714.42$). As with the first model, Hispanic decedents ($OR = 1.18$; $p < .001$) were significantly more likely than White decedents to die within the first week of hospice care, and Black decedents ($OR = 0.78$; $p = .027$) were significantly less likely than White decedents to die within the first week. The change in effect size between the first and second models was 0.71 vs. 0.78 for Black decedents, and 1.15 vs. 1.18 for Hispanic decedents. Similarly, single/divorced/separated decedents ($OR = 1.37$; $p < .001$), and those with Congestive Heart Failure/Heart Disease ($OR = 1.37$; $p = .005$), a neurological disease ($OR = 1.53$; $p < .001$), or other primary diagnoses ($OR = 2.06$; $p = .005$) were significantly more likely than the associated referents to die within the first seven days of hospice care. Conversely, decedents enrolled in Medicaid ($OR = 0.75$; $p = .031$), and those with an advance directive ($OR = 0.61$; $p = .007$), or do not resuscitate (DNR) order ($OR = 0.61$; $p < .001$) were significantly less likely than the associated referents to die within the first seven days of hospice care. Age ($OR = 0.98$; $p < .001$) was also negatively associated with dying within the first seven days of hospice care. Finally, Medicaid enrollment was the only predictor that changed significance between the two models. See Figure 13 for a blobbogram illustrating the relative effect of each *Step 2* predictor for dying within the first seven days of hospice care.

Figure 13. Relative Effects of Predictors for Decedent Length of Stay: 0-7 Days**Footnotes**

CHF: Congestive Heart Failure
 HD: Heart Disease
 DNR: Do Not Resuscitate Order

Reference Variables

White (Race)
 Married/Living with Partner (Marital Status)
 Cancer (Primary Diagnosis)
 No Advance Directive (Advance Care Planning)

Hospice length of stay: 0-30 days. Analysis of the null model (agency-level $n = 639$; patient-level $n = 2,901$) suggested that 3% of the variance in dying within the first thirty days of care was due to between-agency variation ($ICC = 0.026$ (95% CI: 0.007, 0.093; $\chi^2 = 13.93$, $df = 1$; $p < .001$). As with the previous model, random effects modeling was maintained.

Step 1: Demographics and health indicator variables. To test for racial/ethnic variation in dying within the first thirty days of hospice care, a multilevel logistic regression was conducted. Results of this model are presented under *Step 1* in Table 18. The adjusted model (Level 1 $n = 2,776$; Level 2 $n = 634$), revealed *AIC* and *BIC* model fit criteria were 578290.89, and 578338.32, respectively. While Black decedents ($OR = 2.55$; $p < .001$) were significantly more likely than White decedents to die in the first

thirty days of hospice care, Hispanic decedents ($OR = 1.19$; $p = .278$) were equally likely as White decedents to die during the first month. Decedents with other primary diagnoses ($OR = 1.70$; $p = .002$) were significantly more likely than those with Cancer to die in the first thirty days of hospice care. Conversely, female decedents ($OR = 0.84$; $p = .041$), and those with Lung Disease ($OR = 0.73$; $p = .024$) were significantly less likely than the associated referents to die within the first month of hospice care. Lastly, older decedents ($OR = 0.98$; $p = .034$), and those with more comorbidities ($OR = 0.90$; $p < .001$) were less likely to die during the first month of hospice care.

Table 18. Predictors of Decedent Hospice Length of Stay: 0-30 Days

Predictors	Step 1			Step 2		
	OR (Std. Err.)	95% CI	Sig.	OR (Std. Err.)	95% CI	Sig.
Race/Ethnicity						
Black	2.55 (0.23)	1.64, 3.96	<.001	2.54 (0.23)	1.62, 3.99	<.001
Hispanic	1.19 (0.16)	0.87, 1.62	.278	1.20 (0.12)	0.94, 1.52	.148
Age	0.98 (0.01)	0.96, 1.00	.034	0.98 (0.01)	0.96, 0.99	.007
Female	0.84 (0.09)	0.71, 0.99	.041	0.80 (0.10)	0.66, 0.97	.021
Marital Status						
Widowed	0.99 (0.13)	0.77, 1.27	.911	1.00 (0.14)	0.76, 1.31	.981
Single/Divorced/Separated	1.56 (0.23)	1.00, 2.44	.050	1.55 (0.21)	1.04, 2.32	.032
Primary Diagnosis						
CHF/Heart Disease	0.65 (0.25)	0.40, 1.08	.094	0.69 (0.28)	0.40, 1.18	.175
Lung Disease	0.73 (0.14)	0.56, 0.96	.024	0.86 (0.08)	0.74, 1.01	.067
Neurological Disease	0.84 (0.15)	0.62, 1.13	.253	0.91 (0.13)	0.70, 1.18	.476
Other Primary Diagnosis	1.70 (0.17)	1.22, 2.35	.002	1.71 (0.17)	1.21, 2.40	.002
Comorbidity Count	0.90 (0.02)	0.88, 0.93	<.001	0.89 (0.02)	0.85, 0.92	<.001
Medicaid Enrollee	0.97 (0.17)	0.70, 1.34	.838	0.96 (0.15)	0.72, 1.29	.800
Advance Care Planning						
Yes AD, No DNR order				0.99 (0.19)	0.68, 1.45	.958
Yes AD, YES DNR order				0.51 (0.25)	0.31, 0.83	.007
Random Intercept	31.45 (0.81)	6.49, 152.43	<.001	74.48 (0.56)	24.67, 224.87	<.001
Model Summary						
Level 2 Variance	0.82 (0.09)			0.73 (0.08)		
Akaike Information Criterion	578290.89			576066.63		
Bayesian Information Criterion	578338.32			576114.04		
Patient Observations	2,776			2,771		
Agency Observations	634			633		

Footnotes

CHF: Congestive Heart Failure
AD: Advance Directive
DNR: Do Not Resuscitate

Reference Variables

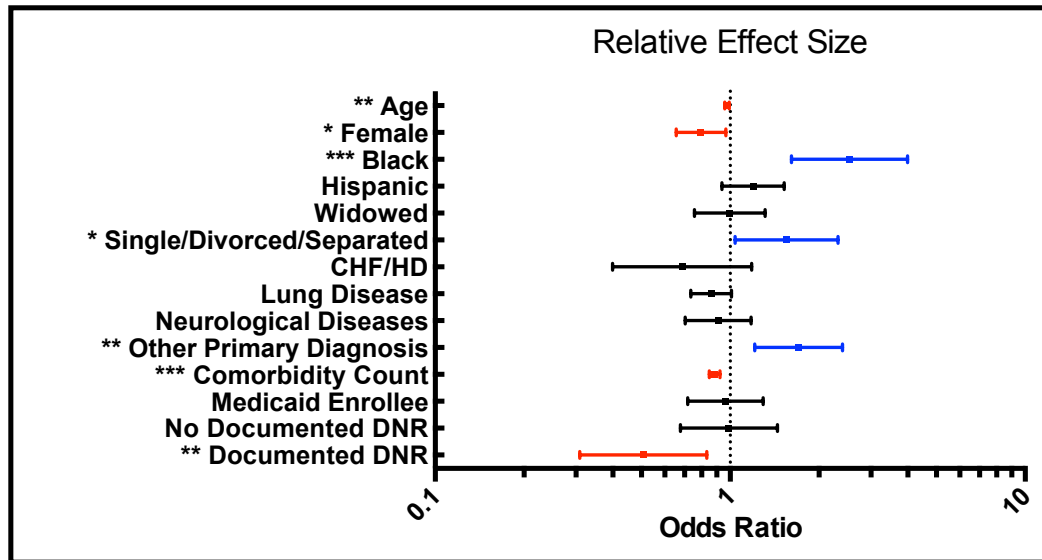
White (Race)
Married/Living with Partner (Marital Status)
Cancer (Primary Diagnosis)
No Advance Directive (Advance Care Planning)

Step 2: Inclusion of advance care planning decisions. The second multilevel model predicting death within the first thirty days of hospice care included advance care planning covariates. Results from this model are presented under *Step 2* in Table 18. The

second adjusted model (Level 1 $n = 2,771$; Level 2 $n = 633$) demonstrated improved fit over the first model ($AIC = 576066.63$; $BIC = 576114.04$). Black decedents ($OR = 2.54$; $p < .001$) were still found to be more likely than White decedents to die in the first thirty days of hospice care, and Hispanic decedents ($OR = 1.20$; $p = .148$) remained as likely as White decedents to die in the first month of care. The relative effect size difference between the first and second models for Black decedents was 2.55 vs. 2.54.

Single/Divorced/Separated decedents ($OR = 1.55$; $p = .032$), and those with other primary diagnoses ($OR = 1.71$; $p = .002$) were significantly more likely than the associated referents to die within the first thirty days of hospice care. Female decedents ($OR = 0.80$; $p = .021$), and those with a DNR order ($OR = 0.51$; $p = .007$) were significantly less likely than the associated referents to die within the first month of hospice care. As with the first model, age ($OR = 0.98$; $p = .007$), and comorbidity count ($OR = 0.89$; $p < .001$) remained negatively associated with dying within the first thirty days of hospice care.

Lastly, the primary diagnosis of Lung Disease lost significance following inclusion of care planning covariates, and the marital status of single/divorced/separated gained significance. For a blobbogram illustrating the relative effect of each *Step 2* predictor for dying within the first thirty days of hospice care, see Figure 14.

Figure 14. Relative Effects of Predictors for Decedent Length of Stay: 0-30 Days**Footnotes**

CHF: Congestive Heart Failure
 HD: Heart Disease
 DNR: Do Not Resuscitate Order

Reference Variables

White (Race)
 Married/Living with Partner (Marital Status)
 Cancer (Primary Diagnosis)
 No Advance Directive (Advance Care Planning)

Chapter 8: Site of Death

In this chapter, bivariate comparisons by site of death (SOD) are presented, and multivariable results are reported. To test the hypothesis associated with SOD, the decedent analytic sample was utilized. For frequencies and relative percentages of missing and excluded data for SOD analyses, see Appendices L (home-like setting) and M (hospital).

Overall Site of Death

A descriptive summary of decedent SOD by race/ethnicity is presented in Table 19. Inpatient hospice agencies were excluded from study analyses due to operationalization concerns with the survey questionnaire; however, a full summary of frequencies and associated percentages of decedent SOD by race/ethnicity, including inpatient hospice agencies, is provided in Appendix N. Forty-three percent of decedents died in a private home or apartment, 26% died in a nursing home or skilled nursing facility, 9% died in a hospital, 5% died in a residential care place (i.e., assisted living facility, board and care home, continuing care retirement community), and 1% died in other locations. No significant differences in SOD by race/ethnicity were observed ($F(5.40, 3340.02) = 0.55$; $p = .749$).

Table 19. Overall Site of Death ($n = 667,820$)

	Total	White	Black	Hispanic	Sig.
Private Home/Apartment	289,900 (43.41)	262,260 (42.94)	18,392 (49.61)	9,248 (46.42)	.749
Residential Care Place	36,596 (5.48)	36,008 (5.90)	588 (1.59)	0 (0.00)	
Nursing Home/SNF	176,572 (26.44)	162,232 (26.56)	9,316 (25.13)	5,024 (25.22)	
Hospital	57,236 (8.57)	52,744 (8.63)	2,280 (6.15)	2,212 (11.10)	
Other	492 (0.07)	492 (0.08)	0 (0.00)	0 (0.00)	
Missing	107,024 (16.03)	97,084 (15.89)	6,500 (17.53)	3,440 (17.27)	

Footnotes

SNF: Skilled Nursing Facility

Percentages are presented by column

Bivariate Comparisons

Hospice decedent SOD was examined using two dependent variables: 1) death in a home-like setting (i.e., private home or apartment, and residential care place), and 2) death in a hospital. As such, bivariate comparisons are presented below separately for each dependent variable.

Site of death: Home-like setting. A summary of patient characteristics by death in a home-like setting is presented in Table 20. Bivariate findings were discordant with the hypothesis, as rates of death in an home-like setting were not significantly higher for White decedents (58%), relative to Black (62%) or Hispanic decedents (56%; $F(1.57, 972.13) = 0.15$; $p = .814$). Analyses indicated significant differences in death in a home-like setting by age ($F(2.83, 1751.78) = 6.91$; $p < .001$), gender ($F(1.00, 618.00) = 13.97$; $p < .001$), marital status ($F(2.93, 1799.80) = 12.13$; $p < .001$), primary diagnosis ($F(3.77, 2329.87) = 17.97$; $p < .001$), Medicaid enrollment ($F(1.00, 616.00) = 57.95$; $p < .001$), and advance care planning ($F(1.93, 1191.30) = 4.15$; $p = .017$). Specifically, rates of dying in a home-life setting were lower for 1) decedents in the oldest age group (49%), relative to the youngest age group (69%), 2) males (52%), relative to females (66%), 3)

widowed (51%), or never married decedents (39%), relative to decedents who were married or living with a partner (69%), or divorced or separated (67%), 4) decedents with Congestive Heart Failure/Heart Disease (55%), or Lung Disease (55%), relative to decedents with Cancer (76%), a neurological disease (41%), or other primary diagnoses (43%), 5) decedents enrolled in Medicaid (27%), relative to decedents not enrolled in Medicaid (64%), and 6) decedents with an advance directive (74%), relative to decedents without an advance directive (56%), or do not resuscitate (DNR) order (57%). No significant differences in death in a home-like setting were observed by comorbidity count ($F(2.00, 1233.01) = 0.90$; $p = .406$).

Table 20. Site of Death (Home-Like Setting) Bivariate Comparisons (*n* = 560,592)

Characteristics, No. (%)	Site of Death: Home		Sig.
	No	Yes	
Age			<.001
65-75	35,648 (30.70)	80,480 (69.30)	
76-82	51,060 (38.67)	80,996 (61.33)	
83-87	55,936 (41.88)	77,624 (58.12)	
88+	91,452 (51.13)	87,396 (48.87)	
Gender			<.001
Female	82,536 (34.06)	159,756 (65.94)	
Male	151,560 (47.62)	166,740 (52.38)	
Race/Ethnicity			.814
White	215,264 (41.92)	298,268 (58.08)	
Black	11,596 (37.93)	18,980 (62.07)	
Hispanic	7,236 (43.90)	9,248 (56.10)	
Marital Status			<.001
Married/Living Together	68,996 (30.56)	156,780 (69.44)	
Widowed	130,128 (49.30)	133,836 (50.70)	
Divorced/Separated	8,508 (33.45)	16,928 (66.55)	
Never Married	11,800 (61.26)	7,460 (38.73)	
Missing	14,664 (55.12)	11,492 (44.88)	
Primary Diagnosis			<.001
Cancer	51,080 (24.38)	158,424 (75.62)	
CHF/Heart Disease	32,188 (44.61)	39,972 (55.39)	
Lung Disease	38,888 (44.80)	47,916 (55.20)	
Neurological Diseases	72,988 (59.05)	50,624 (40.95)	
Other	38,932 (57.16)	29,176 (42.84)	
Missing	20 (4.95)	384 (95.05)	
Comorbidity Count			.406
0-1	66,376 (43.19)	87,304 (56.81)	
2-3	64,116 (37.65)	106,192 (62.35)	
4+	103,604 (43.79)	133,000 (56.21)	
Enrolled in Medicaid			<.001
Yes	64,008 (72.85)	23,852 (27.15)	
No	169,340 (36.03)	300,712 (63.97)	
Missing	748 (27.91)	1,932 (72.09)	
Advance Care Planning			.017
No AD, No DNR order	15,960 (43.90)	20,392 (56.10)	
Yes AD, No DNR order	11,300 (25.91)	32,320 (74.09)	
Yes AD, Yes DNR order	206,808 (43.12)	272,848 (56.88)	
Missing	28 (2.90)	936 (97.10)	

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row

Site of death: Hospital. A summary of patient characteristics by death in a hospital is presented in Table 21. As with death in a home-like setting, bivariate findings were incongruent with the hypothesis, as no racial/ethnic variation in hospital death was observed ($F(1.85, 1142.84) = 0.41$; $p = .648$). Specifically, rates of hospital death were

10% for White decedents, 7% for Black decedents, and 13% for Hispanic decedents.

Significant differences in hospital death were only observed by comorbidity count

($F(1.98, 1223.51) = 5.24$; $p = .006$), with higher rates for decedents with 0-1

comorbidities (15%), relative to decedents with 2-3 comorbidities (9%), or four or more

comorbidities (8%). No significant differences in death in a hospital were observed by

age ($F(2.92, 1803.74) = 1.91$; $p = .128$), gender ($F(1.00, 618.00) = 0.25$; $p = .615$),

marital status ($F(2.48, 1522.27) = 1.39$; $p = .248$), primary diagnosis ($F(3.76, 2326.06) =$

1.80 ; $p = .131$), Medicaid enrollment ($F(1.00, 616.00) = 3.23$; $p = .073$), or advance care

planning ($F(1.98, 1224.57) = 1.35$; $p = .259$).

Table 21. Site of Death (Hospital) Bivariate Comparisons (*n* = 560,592)

Characteristics, No. (%)	Site of Death: Hospital		Sig.
	No	Yes	
Age			.128
65-75	100,184 (86.27)	15,944 (13.73)	
76-82	116,236 (88.02)	15,820 (11.98)	
83-87	121,508 (90.98)	12,052 (9.02)	
88+	165,428 (92.50)	13,420 (7.50)	
Gender			.615
Female	218,928 (90.36)	23,364 (9.64)	
Male	284,428 (89.36)	33,872 (10.64)	
Race/Ethnicity			.648
White	460,788 (89.73)	52,744 (10.27)	
Black	28,296 (92.54)	2,280 (7.46)	
Hispanic	14,272 (86.58)	2,212 (13.42)	
Marital Status			.248
Married/Living Together	200,460 (88.79)	25,316 (11.21)	
Widowed	240,212 (91.00)	23,752 (9.00)	
Divorced/Separated	21,632 (85.04)	3,804 (14.96)	
Never Married	18,288 (94.95)	972 (5.05)	
Missing	22,764 (87.03)	3,392 (12.97)	
Primary Diagnosis			.131
Cancer	191,356 (91.34)	18,148 (8.66)	
CHF/Heart Disease	65,012 (90.09)	7,148 (9.91)	
Lung Disease	74,464 (85.78)	12,340 (14.22)	
Neurological Diseases	114,104 (92.31)	9,508 (7.69)	
Other	58,036 (85.21)	10,072 (14.79)	
Missing	384 (95.05)	20 (4.95)	
Comorbidity Count			.006
0-1	129,988 (84.58)	23,692 (15.42)	
2-3	155,252 (91.16)	15,056 (8.84)	
4+	218,116 (92.19)	18,488 (7.81)	
Enrolled in Medicaid			.073
Yes	82,412 (93.80)	5,448 (6.20)	
No	418,332 (89.00)	51,720 (11.00)	
Missing	2,612 (97.46)	68 (2.54)	
Advance Care Planning			.259
No AD, No DNR order	30,492 (83.88)	5,860 (16.12)	
Yes AD, No DNR order	40,316 (92.43)	3,304 (7.57)	
Yes AD, Yes DNR order	431,584 (89.98)	48,072 (10.02)	
Missing	964 (100.00)	0 (0.00)	

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row

Multivariable Analyses

Racial/Ethnic differences in SOD were investigated using multivariable analyses conducted in two waves: 1) multilevel model predictions of dying in a home-like setting (Hypothesis 4), and 2) multilevel model predictions of dying in a hospital (Hypothesis

4A). Both waves were conducted using two-steps multilevel models, with the first step adjusting for key demographic and health indicators, and the second step further adjusting for advance care planning decisions. All models included patient-level (level 1) predictors with random agency-level (level 2) intercepts to account for between-agency variation.

Site of death: Home-like setting. Preliminary multilevel analysis of the null model (agency-level $n = 627$; patient-level $n = 2,680$) revealed that approximately 26% of the observed variation in dying in a home-like setting was due to differences between agencies ($ICC = 0.259$, 95% CI: 0.205, 0.321; $\chi^2 = 17.32$, $df = 1$; $p < .001$).

Step 1: Demographics and health indicator variables. To test for racial/ethnic variation in dying in a home-like setting, a multilevel logistic regression was conducted. Results of this model are presented under *Step 1* in Table 22. The adjusted model (Level 1 $n = 2,570$; Level 2 $n = 622$), revealed an *AIC* fit criteria of 409665.85, and a *BIC* fit criteria of 409712.66. Model findings were inconsistent with what was hypothesized, as Black ($OR = 1.90$; $p = .019$), and Hispanic decedents ($OR = 1.21$; $p = .026$) were both significantly more likely than White decedents to die in a home-like setting. Conversely, widowed decedents ($OR = 0.69$; $p < .001$), single/divorced/separated decedents ($OR = 0.60$; $p = .020$), those with Congestive Heart Failure/Heart Disease ($OR = 0.40$; $p < .001$), Lung Disease, ($OR = 0.55$; $p = .024$), a neurological disease ($OR = 0.14$; $p < .001$), or other primary diagnoses ($OR = 0.25$; $p = .003$), and decedents enrolled in Medicaid ($OR = 0.18$; $p < .001$) were significantly less likely than the associated referents to die in a home-like setting.

Table 22. Predictors of Site of Death: Home-Like Setting

Predictors	Step 1			Step 2		
	OR (Std. Err.)	95% CI	Sig.	OR (Std. Err.)	95% CI	Sig.
Race/Ethnicity						
Black	1.90 (0.27)	1.11, 3.24	.019	2.14 (0.27)	1.27, 3.60	.004
Hispanic	1.21 (0.09)	1.02, 1.43	.026	1.20 (0.08)	1.03, 1.39	.017
Age	0.98 (0.01)	0.96, 1.00	.103	0.98 (0.01)	0.96, 1.00	.016
Female	0.99 (0.10)	0.81, 1.21	.937	1.13 (0.12)	0.90, 1.41	.291
Marital Status						
Widowed	0.69 (0.10)	0.56, 0.84	<.001	0.70 (0.09)	0.58, 0.84	<.001
Single/Divorced/Separated	0.60 (0.22)	0.39, 0.92	.020	0.57 (0.29)	0.33, 0.99	.047
Primary Diagnosis						
CHF/Heart Disease	0.40 (0.17)	0.29, 0.56	<.001	0.47 (0.18)	0.33, 0.67	<.001
Lung Disease	0.55 (0.27)	0.32, 0.92	.024	0.65 (0.24)	0.41, 1.04	.072
Neurological Disease	0.14 (0.12)	0.11, 0.18	<.001	0.15 (0.10)	0.12, 0.18	<.001
Other Primary Diagnosis	0.25 (0.47)	0.10, 0.62	.003	0.25 (0.38)	0.12, 0.54	<.001
Comorbidity Count	1.00 (0.02)	0.96, 1.05	.963	1.02 (0.03)	0.97, 1.07	.430
Medicaid Enrollee	0.18 (0.14)	0.13, 0.23	<.001	0.15 (0.08)	0.13, 0.18	<.001
Advance Care Planning						
Yes AD, No DNR order				2.91 (0.38)	1.39, 6.07	.005
Yes AD, YES DNR order				1.57 (0.07)	1.37, 1.80	<.001
Random Intercept	28.77 (0.64)	8.20, 100.91	<.001	45.08 (0.57)	14.72, 138.06	<.001
Model Summary						
Level 2 Variance	1.20 (0.07)			1.26 (0.07)		
Akaike Information Criterion	409665.85			407270.15		
Bayesian Information Criterion	409712.66			407316.96		
Patient Observations	2,570			2,568		
Agency Observations	622			622		

Footnotes

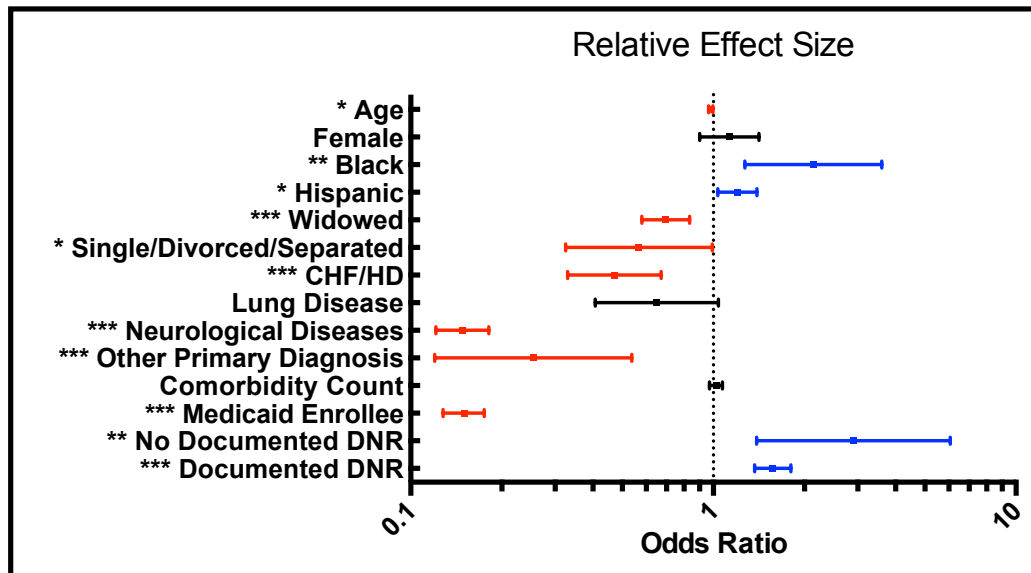
CHF: Congestive Heart Failure
AD: Advance Directive
DNR: Do Not Resuscitate

Reference Variables

White (Race)
Married/Living with Partner (Marital Status)
Cancer (Primary Diagnosis)
No Advance Directive (Advance Care Planning)

Step 2: Inclusion of advance care planning decisions. To determine the relative effect of advance care planning on dying in a home-like setting, a second model was estimated. Results are presented under *Step 2* in Table 22. The second adjusted model

(Level 1 $n = 2,568$; Level 2 $n = 622$) was an improved fit over the first model ($AIC = 407270.15$; $BIC = 407316.96$). As with the first model, Black ($OR = 2.14$; $p = .004$) and Hispanic decedents ($OR = 1.20$; $p = .017$) were more likely than White decedents to die in a home-like setting. Relative effect size differences between the first and second models was 1.90 vs. 2.14 for Black decedents, and 1.21 vs. 1.20 for Hispanic decedents. Those with an advance directive ($OR = 2.91$; $p = .005$), or DNR order ($OR = 1.57$; $p < .001$) were significantly more likely than those without an advance directive to die in a home-like setting. Conversely, widowed decedents ($OR = 0.70$; $p < .001$), single/divorced/separated decedents ($OR = 0.57$; $p = .047$), those with Congestive Heart Failure/Heart Disease ($OR = 0.47$; $p < .001$), a neurological disease ($OR = 0.15$; $p < .001$), other primary diagnoses ($OR = 0.25$; $p < .001$), and decedents enrolled in Medicaid ($OR = 0.15$; $p < .001$) were significantly less likely than the associated referents to die in a home-like setting. Following inclusion of care planning covariates, Lung Disease lost significance in the model. See Figure 15 for a blobbogram illustrating the relative effect of each *Step 2* predictor for dying in a home-like setting.

Figure 15. Relative Effects of Predictors for Site of Death: Home-Like Setting**Footnotes**

CHF: Congestive Heart Failure
 HD: Heart Disease
 DNR: Do Not Resuscitate Order

Reference Variables

White (Race)
 Married/Living with Partner (Marital Status)
 Cancer (Primary Diagnosis)
 No Advance Directive (Advance Care Planning)

Site of death: Hospital. Analysis of the null model (agency-level $n = 627$; patient-level $n = 2,680$) suggested that 31% of the variance was accounted for by agency-level differences $ICC = 0.319$, 95% CI: 0.234, 0.420; $\chi^2 = 15.699$, $df = 1$; $p < .001$).

Step 1: Demographics and health indicator variables. To test for racial/ethnic variation in dying in a hospital, a multilevel logistic regression was conducted. Results of this model are presented under *Step 1* in Table 23. The adjusted model (Level 1 $n = 2,570$; Level 2 $n = 622$), revealed *AIC* and *BIC* model fit criteria were 189611.79, and 189658.60, respectively. As hypothesized, Hispanic decedents ($OR = 7.93$; $p < .001$) were significantly more likely than White decedents to die in a hospital; however, Black decedents ($OR = 0.54$; $p = .447$) were not more likely than White decedents to die in a hospital. Those with Congestive Heart Failure/Heart Disease ($OR = 2.11$; $p = .023$), Lung

Disease ($OR = 3.18$; $p < .001$), or other primary diagnoses ($OR = 6.24$; $p < .001$) were significantly more likely than those with Cancer to die in a hospital. Conversely, single/divorced/separated decedents ($OR = 0.67$; $p < .001$), and those enrolled in Medicaid ($OR = 0.44$; $p < .001$) were significantly less likely than the associated referents to die in a hospital. Lastly, both age ($OR = 0.97$; $p < .001$), and comorbidity count ($OR = 0.83$; $p < .001$) were negatively associated with in-hospital death.

Table 23. Predictors of Site of Death: Hospital

Predictors	Model 1			Model 2		
	OR (Std. Err.)	95% CI	Sig.	OR (Std. Err.)	95% CI	Sig.
Race/Ethnicity						
Black	0.54 (0.81)	0.11, 2.63	.447	0.46 (0.86)	0.09, 2.46	.364
Hispanic	7.93 (0.29)	4.50, 13.98	<.001	6.12 (0.24)	3.85, 9.75	<.001
Age	0.97 (0.01)	0.96, 0.99	<.001	0.97 (0.01)	0.96, 0.98	<.001
Female	1.09 (0.10)	0.90, 1.32	.378	1.17 (0.09)	0.97, 1.40	.097
Marital Status						
Widowed	0.90 (0.10)	0.74, 1.10	.300	0.92 (0.12)	0.72, 1.18	.521
Single/Divorced/Separated	0.67 (0.09)	0.56, 0.80	<.001	0.65 (0.12)	0.52, 0.82	<.001
Primary Diagnosis						
CHF/Heart Disease	2.11 (0.33)	1.11, 4.00	.023	1.82 (0.36)	0.89, 3.71	.101
Lung Disease	3.18 (0.31)	1.74, 5.81	<.001	2.73 (0.25)	1.66, 4.50	<.001
Neurological Disease	1.03 (0.30)	0.58, 1.84	.920	1.02 (0.33)	0.53, 1.94	.962
Other Primary Diagnosis	6.24 (0.23)	4.01, 9.69	<.001	4.78 (0.27)	2.80, 8.15	<.001
Comorbidity Count	0.83 (0.03)	0.78, 0.87	<.001	0.84 (0.03)	0.80, 0.88	<.001
Medicaid Enrollee	0.44 (0.24)	0.28, 0.70	.001	0.38 (0.33)	0.20, 0.72	.003
Advance Care Planning						
Yes AD, No DNR order				0.47 (0.26)	0.28, 0.78	.003
Yes AD, YES DNR order				0.46	0.41, 0.52	<.001
Random Intercept	3.60 (0.08)	3.09, 4.18	<.001	3.43 (0.04)	3.14, 3.74	<.001
Model Summary						
Level 2 Variance	1.64 (0.20)			1.52 (0.11)		
Akaike Information Criterion	189611.79			188717.65		
Bayesian Information Criterion	189658.60			188764.46		
Patient Observations	2,570			2,568		
Agency Observations	622			622		

Footnotes

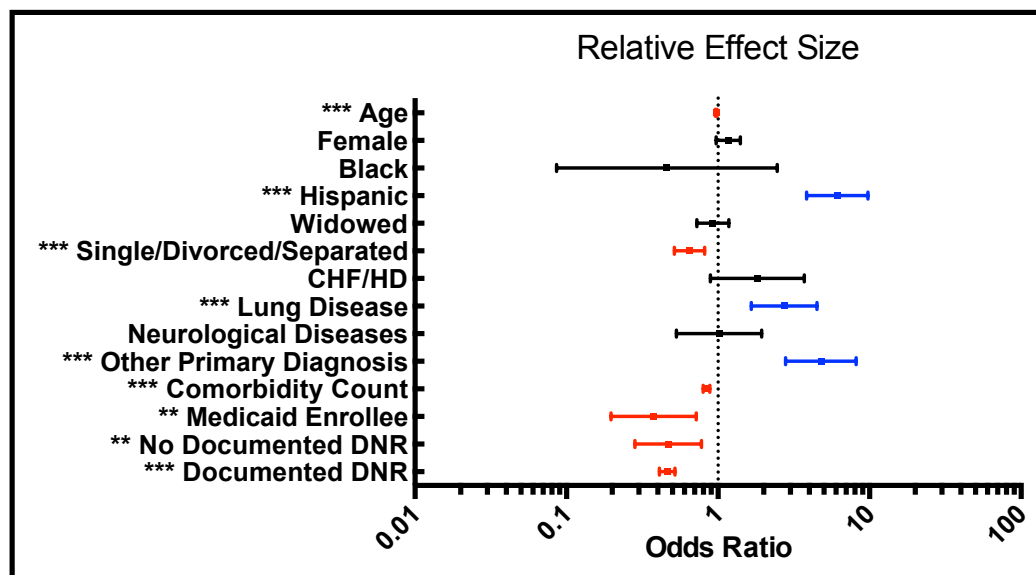
CHF: Congestive Heart Failure
AD: Advance Directive
DNR: Do Not Resuscitate

Reference Variables

White (Race)
Married/Living with Partner (Marital Status)
Cancer (Primary Diagnosis)
No Advance Directive (Advance Care Planning)

Step 2: Inclusion of advance care planning decisions. The second multilevel model predicting death in a hospital included advance care planning covariates (see Step 2 in Table 23). The adjusted model (Level 1 $n = 2,568$; Level 2 $n = 622$) was found to be

a better fit to the data, compared to the first model ($AIC = 188717.65$; $BIC = 188764.46$). Following inclusion of advance care planning covariates, Hispanic decedents ($OR = 6.12$; $p < .001$) remained significantly more likely than White decedents to die in a hospital (a effect size change from 7.93 in the first model). Furthermore, Black decedents ($OR = 0.46$; $p = .364$) also remained as likely as White decedents to die in-hospital. Decedents with Lung Disease ($OR = 2.73$; $p < .001$), or other primary diagnoses ($OR = 4.78$; $p < .001$) were significantly more likely than decedents with Cancer to die in a hospital. Single/Divorced/Separated decedents ($OR = 0.65$; $p < .001$), those enrolled in Medicaid ($OR = 0.38$; $p = .003$), and decedents with an advance directive ($OR = 0.47$; $p = .003$) or DNR order ($OR = 0.46$; $p < .001$) were significantly less likely than the associated referents to experience in-hospital death. Furthermore, older decedents ($OR = 0.97$; $p < .001$), and those with more comorbidities ($OR = 0.84$; $p < .001$) were significantly less likely to die in a hospital. Lastly, predictor significance was lost for Congestive Heart Failure/Heart Disease following inclusion of advance care planning covariates. For a blobbogram illustrating the relative effect of each *Step 2* predictor for dying in a hospital, see Figure 16.

Figure 16. Relative Effects of Predictors for Site of Death: Hospital**Footnotes**

CHF: Congestive Heart Failure
 HD: Heart Disease
 DNR: Do Not Resuscitate Order

Reference Variables

White (Race)
 Married/Living with Partner (Marital Status)
 Cancer (Primary Diagnosis)
 No Advance Directive (Advance Care Planning)

Chapter 9: Discussion

This is the first known in-depth investigation of racial/ethnic variation in care preferences and outcomes following hospice enrollment. Examined outcomes included advance directive completion, do not resuscitate (DNR) order election, healthcare proxy designation, emergent care utilization, decedent length of stay (LOS), and site of death (SOD). In this chapter, hypotheses are revisited with respect to study findings, contributions to the existing literature are discussed, limitations are considered, and recommendations for future research are proposed.

Hypothesis 1 Findings

White hospice patients will be more likely than Black and Hispanic hospice patients to have a documented advance directive.

Relatively few previous studies have examined racial/ethnic variation in advance directive completion following hospice enrollment (Jones et al., 2011; Resnick et al., 2012). Drawing from findings of these studies, it was hypothesized that Black and Hispanic hospice patients would be less likely than White hospice patients to have a documented advance directive. Results of this study were semi-consistent with this hypothesis. Specifically, as hypothesized, Black hospice patients were estimated to be 80% less likely than White hospice patients to complete an advance directive ($OR = 0.20$; $p < .001$); however, Hispanic patients were not found to be less likely, but instead equally as likely as, White patients to complete an advance directive ($OR = 1.04$; $p = .703$). The finding that Black hospice patients are less likely than White hospice patients to complete an advance directive is consistent with both of the previously identified studies of hospice samples, which reported that Blacks were less likely than Whites to complete advance

directives (Jones et al., 2011; Resnick et al., 2012). This finding is also consistent with studies examining the non-hospice population (Eleazer et al., 1996; Greiner et al., 2003; K. S. Johnson, Kuchibhatla, & Tulsky, 2008; Kwak & Haley, 2005; McKinley et al., 1996). Concerning Hispanic patients, findings are not consistent with studies of the non-hospice population, which have reported reduced advance directive completion among Hispanic, compared to White, patients (Kelley et al., 2010; Morrison et al., 1998). No previously identified study has examined variation in advance directive completion among Hispanic hospice patients.

Hypothesis 1A Findings

Among those with documented advance directives, White and Hispanic hospice patients will be more likely than Black hospice patients to document a do not resuscitate order.

Only one identified study has examined racial/ethnic differences in DNR order election following hospice enrollment (Jones et al., 2011). Drawing from this study, as well as studies of the non-hospice population, it was hypothesized that Black hospice patients would be less likely than White and Hispanic hospice patients to elect a DNR order. Results were semi-consistent with this hypothesis. That is, Black hospice patients were estimated to be equally as likely as White hospice patients to elect a DNR order ($OR = 1.09$; $p = .553$). Furthermore, while Hispanic hospice patients were 3.68 times more likely than White hospice patients to elect a DNR order ($OR = 3.68$; $p < .001$), they were also 3.67 times more likely than Black hospice patients to elect a DNR order ($OR = 3.67$; $p < .001$). The finding that Black hospice patients are equally as likely as White hospice patients to elect a DNR order contrasts with previous studies of hospice (Jones et al.,

2011), and non-hospice populations (Barnato et al., 2009; Borum et al., 2000; Duffy et al., 2006; K. S. Johnson, Kuchibhatla, & Tulsky, 2008; Mitchell & Mitchell, 2009), which have reported stronger preferences among Blacks for more aggressive end-of-life (EOL) treatments, and reduced likelihood of electing a DNR order. Conversely, the finding that Hispanic patients were more likely than Black patients to elect a DNR order is consistent with literature indicating that Hispanics often prefer less aggressive care, despite lower documentation levels (Kelley et al., 2010; Morrison et al., 1998); however, the finding that Hispanic patients were also more than White patients to elect a DNR order has not been previously documented in the hospice- or non-hospice-electing literature.

Hypothesis 1B Findings

Among those with documented advance directives, White and Hispanic hospice patients will be more likely than Black hospice patients to document a healthcare proxy.

Research investigating healthcare proxy designation among racially/ethnically diverse populations is scarce (Blackhall et al., 1995; Hopp & Duffy, 2000; Kwak & Haley, 2005). Drawing from the few existing studies, it was hypothesized that White and Hispanic hospice patients would designate healthcare proxies at higher rates than Black hospice patients. Hispanic hospice patients were hypothesized to designate healthcare proxies at similar rates as Whites given studies suggesting that environments encouraging advance care planning would facilitate documentation of informal preferences (Kelley et al., 2010; Morrison et al., 1998). Results of this study were semi-consistent with this hypothesis. Although Black hospice patients were estimated to be 42% less likely ($OR = 0.58$; $p < .001$) than White hospice patients to designate a healthcare proxy, Hispanic

hospice patients were also estimated to be 84% less likely ($OR = 0.16$; $p < .001$) than White hospice patients to designate a healthcare proxy. The finding that Black hospice patients are less likely than White hospice patients to designate a healthcare proxy is consistent with the small body of previous research of non-hospice samples (Blackhall et al., 1995; Hopp & Duffy, 2000; Kwak & Haley, 2005). However, despite being in an environment that encourages advance care planning, Hispanic hospice patients remained less likely than White hospice patients to designate healthcare proxies. No prior identified study has investigated racial/ethnic variation in healthcare proxy designation rates following hospice enrollment.

Hypothesis 2 Findings

Black and Hispanic hospice patients will be more likely than White and hospice patients to utilize emergent care (i.e., unplanned emergency medical care).

As with previously discussed outcomes, racial/ethnic variation in emergent care utilization following hospice enrollment is limited to a few studies (Cintron et al., 2003; Schonwetter et al., 2008; Unroe et al., 2012). Drawing from this existing literature, it was hypothesized that both Black and Hispanic hospice patients would be more likely than White hospice patients to utilize emergent care. Results of this study were inconsistent with this hypothesis. Black hospice patients were estimated to be equally as likely as White hospice patients to utilize emergent care ($OR = 0.81$; $p = .150$), and Hispanic hospice patients were estimated to be 44% less likely than White hospice patients to utilize emergent care ($OR = 0.56$; $p < .001$). The finding that neither Black nor Hispanic hospice patients were more likely than White hospice patients to utilize emergent care is inconsistent with prior research reporting significantly higher utilization among

minorities, both within hospice the system (Cintron et al., 2003; Schonwetter et al., 2008; Unroe et al., 2012), as well as throughout the larger U.S. healthcare system (Barnato et al., 2007; Goldstein et al., 2010; Gozalo et al., 2011; Hanchate et al., 2009; A. K. Smith, Earle, et al., 2009). Additionally, the finding that Hispanic patients were significantly less likely than White patients to utilize emergent care following hospice enrollment has not been previously documented.

Hypothesis 2A Findings

Hospice patients without documented advance care plans will be more likely than those with documented advance care plans to utilize emergent care.

No identified study has examined the association between advance care planning and emergent care utilization following hospice enrollment. Drawing from prior studies of non-hospice-electing patients, it was hypothesized that patients engaging in advance care planning would be less likely than those not engaging in such planning to utilize emergent care following hospice enrollment. Results were consistent with this hypothesis, as hospice patients with an advance directive were 53% less likely ($OR = 0.47$; $p = .002$) to utilize emergent care following hospice enrollment. Likewise, hospice patients with a DNR order were 64% less likely ($OR = 0.36$; $p = .010$) to utilize emergent care following hospice enrollment. These findings match those of previous studies of non-hospice-specific populations, which have consistently reported lower levels of emergent care use among those who engage in advance care planning (Degenholtz et al., 2004; Gozalo et al., 2011; Silveira et al., 2010; Teno, Gruneir, et al., 2007).

Findings also indicated that racial/ethnic variation in emergent care utilization persisted following adjustment for advance care planning. Specifically, Black hospice

patients were found to be 32% less likely than White hospice patients to utilize emergent care following hospice enrollment ($OR = 0.68$; $p = .031$), whereas Hispanic hospice patients were estimated to be equally as likely ($OR = 0.70$; $p = .117$). As with the previous hypothesis testing, the finding that Black and Hispanic hospice patients were not more likely than White hospice patients to utilize emergent care following adjustment for advance care planning is inconsistent with previous research (Barnato et al., 2007; Cintron et al., 2003; Goldstein et al., 2010; Gozalo et al., 2011; Hanchate et al., 2009; Schonwetter et al., 2008; A. K. Smith, Earle, et al., 2009; Unroe et al., 2012).

Hypothesis 3 Findings

Hospice length of stay will be longer for Black and Hispanic decedents, compared to White decedents

Racial/Ethnic variation in hospice LOS is largely understudied (Cólón & Lyke, 2003; Hardy et al., 2012; K. S. Johnson et al., 2011; Rhodes et al., 2007). Drawing from the four identified studies in the past decade, Black and Hispanic decedents were hypothesized to report longer stays under the care of hospice, relative to White hospice decedents. Results were not consistent with this hypothesis, as neither Black ($HR = 0.06$; $p = .626$) nor Hispanic ($HR = 0.02$; $p = .850$) hospice decedents were estimated to be more likely than White hospice decedents to experience longer hospice LOS. This finding also persisted following adjustment for advance care planning. Results contrast with the majority of existing studies, which have reported longer LOS among hospice patients (Cólón & Lyke, 2003), and decedents (Hardy et al., 2012; K. S. Johnson et al., 2011). However, results correspond with one previous study by Rhodes and colleagues (2007) which reported no difference in hospice LOS among White and Black decedents.

Hypothesis 4 Findings

White hospice decedents will be more likely than Black and Hispanic hospice decedents to die in a home-like setting.

While several previous studies have examined racial/ethnic variation in SOD among non-hospice-specific populations, only one identified study has examined SOD differences following hospice enrollment among Whites, Blacks, and Hispanics (K. S. Johnson et al., 2005). Drawing from this body of literature, it was hypothesized that White hospice decedents would be more likely than Black or Hispanic hospice decedents to die in a home-like setting. Results were inconsistent with this hypothesis. Black hospice decedents were estimated to be 2.14 times more likely than White hospice decedents to die in a home-like setting ($OR = 2.14$; $p = .004$), and Hispanic hospice decedents were found to be 20% more likely than White hospice decedents to die in a home-like setting ($OR = 1.20$; $p = .017$). These differences persisted following adjustment for advance care planning. Given that the one previously identified study of SOD among hospice decedents utilized significantly different comparison settings (i.e., death in an inpatient setting, including inpatient hospice), results are difficult to compare. Regardless, findings were inconsistent with the previous study which reported no difference between Black and White decedents in dying in a home setting, relative to an inpatient hospice setting (K. S. Johnson et al., 2005). Conversely, Hispanic decedent findings were similar with those of the previous study which reported a decreased likelihood among Hispanic, compared to White, decedents to die in an inpatient hospice setting, relative to a home (K. S. Johnson et al., 2005). Findings from this study are discordant with studies of the larger U.S. healthcare system, which have repeatedly found

an increased likelihood among Blacks and Hispanics to die in acute settings (Gruneir et al., 2007; Hanchate et al., 2009; Hansen et al., 2002; National Center for Health Statistics, 2011; A. K. Smith, Earle, et al., 2009; Weitzen et al., 2003; Zheng et al., 2011).

Hypothesis 4A Findings

Black and Hispanic hospice decedents will be more likely than White hospice decedents to die in a hospital.

Although only one identified study has examined racial/ethnic variation in SOD following hospice enrollment, death in an acute setting was not included in the reported analyses. Therefore, drawing from research of non-hospice-specific populations, Black and Hispanic hospice decedents were hypothesized to be more likely than White hospice decedents to die in a hospital. Findings were semi-consistent with this hypothesis.

Specifically, Hispanic decedents were estimated to be 6.12 times more likely than White decedents to die in a hospital ($OR = 6.12$; $p < .001$). Conversely, Black decedents were found to be equally as likely as White decedents to die in a hospital ($OR = 0.46$; $p = .364$). Numerous studies of the non-hospice population have documented an increased risk among Blacks and Hispanics, relative to Whites, to die in a hospital (Gruneir et al., 2007; Hanchate et al., 2009; Hansen et al., 2002; National Center for Health Statistics, 2011; A. K. Smith, Earle, et al., 2009; Weitzen et al., 2003; Zheng et al., 2011). While the Hispanic findings in this study are consistent with this body of literature, the finding that Black hospice decedents are equally as likely as White decedents to die in a hospital contrasts with what has been previously reported.

Contributions to the Literature

By investigating racial/ethnic variation in care preferences, utilization, and outcomes following hospice enrollment, this study addresses several gaps in the existing literature. When considered alongside previous research, multiple factors can be identified to inform understanding of racial/ethnic variation following hospice enrollment.

Advance care planning. Findings indicate that racial/ethnic variation in advance care planning behaviors persist following hospice enrollment. While some of the reported differences mirror what has been documented outside of the hospice system, findings also suggest substantial differences between minorities enrolling in hospice and their non-hospice-utilizing counterparts.

Advance directive completion. Hispanic patients were found to be equally as likely as White patients to complete an advance directive. This finding illustrates the potential value of advance care planning education for Hispanic populations. Previous studies have documented the effectiveness of educational programs in overcoming Hispanic barriers to advance care planning (Vollandes, Ariza, et al., 2008; Vollandes et al., 2010; Vollandes et al., 2007). It is possible that the existing structure of hospice provides improved access to advance care planning among Hispanics, resulting in advance directive completion rates comparable with White populations. This would also explain why Hispanics were equally as likely as Whites to document an advance directive, but Blacks remained significantly less likely to document, as non-hospice-specific studies suggest that many Hispanics prefer less aggressive EOL interventions, but that few document the preference (Kelley et al., 2010; Morrison et al., 1998). The hospice

philosophy facilitates patient education of advance care planning so that well-informed decisions can be made, and thus it is possible that existing programs within hospice increase advance directive completion rates among Hispanics. This study also found that Black hospice patients were less likely than White hospice patients to complete an advance directive, suggesting that hospice-based advance care planning educational interventions, in their current form, do not influence advance directive development among Black hospice patients. Bullock (2006) found that following an advance care planning educational intervention, religious beliefs still significantly affected willingness to engage in advance care planning for many Blacks. The study found that among healthy Black older adults, most participants refused to complete advance directives following intervention, citing no perceived benefits to having an advance directive, valuation of enduring suffering and fighting until the end, beliefs that god can cure illnesses beyond medical intervention, and general distrust of service providers and the larger healthcare system (Bullock, 2006). These findings in conjunction with those reported in this study suggest that religious beliefs could have contributed to some of the observed racial/ethnic variation in advance directive completion. It is also possible that patient-provider communication, as well as trust in healthcare providers, may have also influenced decisions to complete advance directives for Black hospice patients (Kelley 2010, Perkins 2002; Duffy 2006; Braunstein 2008; Gamble 1997; Harris 2001). As non-hospice-specific studies have reported, communication and trust remain a significant healthcare issue in the United States for many patients and providers (Braunstein et al., 2008; Gamble, 1997; Harris et al., 1996; Perkins et al., 2002). Challenges associated with

communication and trust may persist in the hospice system, and contribute to the differences observed in this study.

Do not resuscitate order election. This study also found that among the racial/ethnic minorities who engage in advance care planning, preferences for resuscitation that are well-documented outside of hospice are not present within the hospice system. First, Hispanic hospice patients were more likely than White hospice patients to elect a DNR order. Although this finding could be the result of selection bias (i.e., Hispanic patients who prefer more aggressive care do not enroll in hospice), it also potentially illustrates the value of the hospice experience. Under the care of hospice, patients experience many of the benefits associated with an integrated care approach that addresses holistic needs, often including religio-cultural components. Following hospice intervention, patients are able to focus more of their time, energy, and resources to consider their care choices. It is conceivable that as Hispanic patients in this study experienced the benefits of palliative patient-centered care, the perceived need for more aggressive interventions decreased, and patients documented less aggressive preferences at higher rates. Finally, the increased likelihood among Hispanics to elect a DNR order could also be a function of hospices accurately documenting patient preferences. Loggers and colleagues (2013) found that among a non-hospice-specific sample, similar proportions of Hispanics and Whites preferred less aggressive EOL interventions; however, Whites were more likely to document this preference through a DNR order. Given that the current study did not find such differences in DNR election, it is possible that among those hospice-enrollees choosing to engage in advance care planning, hospices are effective at ensuring that DNR preferences are accurately documented.

This study also found that among those engaging in advance care planning, Black hospice patients were equally as likely as White hospice patients to elect a DNR order, a finding that contrasts with the existing literature (K. S. Johnson, Kuchibhatla, & Tulsky, 2008; Kwak & Haley, 2005; McKinley et al., 1996). Previous research suggests two possible explanations to account for this finding. First, it is possible that this trend arises from self-selection, with Black hospice patients who prefer less aggressive interventions more likely to complete an advance directive and thus, elect DNR orders at a similar rate as their White counterparts. It is also possible that for some Black hospice patients, the timing of advance care planning education, as well as the hospice experience, may support more favorable views for comfort-based interventions following hospice enrollment. Although previous research has found that educational interventions often do little to shift views of advance care planning among healthy Black patients (Bullock, 2006), a recent study has reported that seriously ill Black patients are willing to reconsider DNR election preferences following a palliative-based intervention (Sacco, Carr, & Viola, 2013). Sacco et al. (2013) reported that while none of the Black patients in their study ($n = 1,113$) had documented a DNR order prior to palliative care intervention, 65% of Black patients ($n = 724$) had elected a DNR order following palliative care consultation. When considered with findings reported in this manuscript, it is possible that after experiencing the palliative and patient-centered benefits of hospice care, some Black hospice patients elected to document a DNR order. However, additional time-ordered investigation is needed to confirm this hypothesis. Finally, when considering DNR election findings with advance directive completion findings of this study, the fact that Black hospice patients were less likely than White hospice patients to document an

advance directive, but equally as likely as Whites to elect a DNR order (among those completing advance directives) suggests that formal documentation of DNR orders may not be important to Black patients who elect hospice care; however, data from this study restrict examination of this possibility.

Although several factors are certainly in operation, overall DNR election findings from this study highlight the potential value of healthcare settings that encourage advance care planning. Namely, of the racial/ethnic minorities who engaged in advance care planning, the stronger preferences for resuscitation that have been well-documented outside of hospice were not observed. While this may be due in-part to patient self-selection (i.e., only those who preferred less aggressive care completed advance directives), results support the general hospice philosophy of encouraging all patients to document their preferences, regardless of aggressiveness, and suggest that potential value of advance care planning education and palliative-based patient-centered care in reducing existing racial/ethnic disparities.

Healthcare proxy designation. Results also indicated racial/ethnic variation in healthcare proxy designation rates following hospice enrollment. Specifically, both Black and Hispanic hospice patients were found to be less likely than White hospice patients to document a formal healthcare proxy. These findings are congruent with previous research studies, which have found that many racial/ethnic minorities value informal over formal healthcare proxy designation (Carr, 2011; Cruz-Oliver, Talamantes, & Sanchez-Reilly, 2014; Morrison et al., 1998). Morrison and colleagues (1998) reported that the prevailing family-centered culture of many Hispanics fosters the belief that the family will work closely together as a unit to ensure that the dying loved one will receive adequate and

appropriate care. Accordingly for these Hispanics, formal designation of a healthcare proxy is often considered to be unnecessary, given existing informal family designation (Morrison et al., 1998). Likewise, in a study of chronically ill older adults, Carr (2011) found that for some Black patients, beliefs in a higher power often shape views concerning the nature and timing of death, and thus ultimately affect decisions regarding healthcare proxy designation. The author illustrates this concept with the contention, “If God controls life and death decision-making, then legal documents specifying one’s medical treatment preferences may be deemed irrelevant, undesirable, or as intruding upon God’s plan” (Carr, 2011, p. 15). Furthermore, given that this study also found a reduced likelihood among Blacks to engage in any advance care planning (through the documentation of an advance directive), it is also possible that the lower rates of healthcare proxy designation is a function of a wider view among Blacks in this study that the documentation of care preferences is generally unnecessary. Considering the strong trend toward lower rates of healthcare proxy designation among both Black and Hispanic hospice patients, it could be reasoned that while education may help overcome educational barriers to advance care planning, others factors, such as cultural preferences, may not be impacted. Additional investigation into the cultural context of EOL decision-making is needed to better understand these findings.

Finally, results suggest that advance care planning, specifically advance directive completion and DNR order election, significantly influences care utilization and outcomes following hospice enrollment. Patients who engaged in advance care planning were found to have 1) lower emergent care utilization rates (patients completing advance directives, and patients electing DNR orders), 2) reduced likelihood of dying within the

first week of hospice care (patients completing advance directives, and patients electing DNR orders), 3) reduced likelihood of dying within the first month of hospice care (patients electing DNR orders), 4) increased likelihood of dying in a home like setting (patients completing advance directives, and patients electing DNR orders), and 5) reduced likelihood of dying in a hospital (patients completing advance directives, and patients electing DNR orders). Although some of these findings may relate to the timing of advance directive completion (e.g., perhaps the advance directive was in-place earlier in the dying process), these findings as a whole strongly support the value of advance care planning on multiple key EOL outcomes within the hospice system.

Emergent care utilization. Results of this study suggest that the racial/ethnic variation in emergent care utilization observed outside of hospice care differs from trends observed within hospice care. Research of the larger healthcare system has consistently documented higher rates of emergent care utilization for racial/ethnic minorities, compared to Whites (Barnato et al., 2007; Goldstein et al., 2010; Gozalo et al., 2011; Hanchate et al., 2009; A. K. Smith, Earle, et al., 2009). In contrast, the current study found that racial/ethnic minorities enrolled in hospice care were not more likely to utilize emergent care. In fact, Blacks were less likely, and Hispanics equally as likely, as Whites to utilize emergent care, following adjustment for advance care planning. Similar results were also observed when examining emergency department utilization rates within the same sample utilized in this study (not shown). Two possible explanations to account for this divergent finding are discussed below.

First, it could be conceived that hospice-electing racial/ethnic minorities differ significantly in their care utilization patterns from those who do not elect hospice. It is

possible that those who prefer less aggressive interventions naturally elect hospice care, and thus utilize less emergent care following hospice enrollment. As a result of this self-selection, racial/ethnic minorities would not be expected to utilize emergent care at a higher rate than Whites, as observed in this study. Moreover, it is also possible that hospice enrollees who prefer more aggressive care may be disenrolling from hospice in order to pursue more aggressive interventions, and thus skewing the findings. Previous studies of higher hospice disenrollment rates among racial/ethnic minorities further support this possibility (K. S. Johnson, Kuchibhatla, Tanis, et al., 2008; Kapo, MacMoran, & Casarett, 2005; Unroe et al., 2012). Second, it is possible that the hospice system elicits less aggressive care decisions by patients and thus, contributes to comparable emergent care utilization patterns across race/ethnicity. This protective effect of advance care planning against utilization of emergent services was also reported in a recent systematic literature review of 113 studies over the past decade (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). As purported earlier, the value of the hospice experience may be functioning as a key contributor to study findings, with patients shifting care preferences and decisions after experiencing the many benefits of hospice care. The shift from standard acute care to patient-centered hospice care could promote improved understanding and awareness of the negative outcomes associated with aggressive, futile care, thus reducing minority patients' desire for aggressive interventions.

Interestingly, the effect of race/ethnicity on emergent care utilization changed considerably following adjustment for advance care planning decisions. Specifically, prior to adjustment, Hispanics were found to be less likely than Whites to utilize emergent care, and Blacks were found to be equally as likely as Whites to utilize

emergent care. However, when advance care planning decisions were added to the analytic model, Blacks were found to be less likely than Whites to utilize emergent care, and Hispanics were found to be equally as likely as Whites to utilize emergent care. Previous studies examining emergent care utilization among hospice enrollees offers a potential explanation. In a study of 292 stage IV cancer hospice enrollees, Loggers and colleagues (2013) found that Hispanic hospice patients were less likely than White hospice patients to utilize intensive EOL care. The authors of this study concluded that patient documentation against resuscitation played a critical role in study findings (Loggers et al., 2013). Thus, it may be possible that the increased likelihood of Hispanics in this study to elect a DNR order may have also influenced emergent care utilization models. This hypothesis is substantiated by the fact that the Hispanic effect went away following adjustment for DNR order election (i.e., Hispanics became equally as likely as Whites as DNR order election became significant in predicting a reduced likelihood of utilizing emergent care). Conversely, given that Black hospice patients were less likely than White hospice patients to complete an advance directive, it is conceivable that the relative effect of Black vs. White race/ethnicity on emergent care use would shift following adjustment for advance care planning decisions. Not surprisingly, this is what was observed in this study, with Black hospice patients becoming less likely than White hospice patients to utilize emergent care following inclusion of care planning covariates. This study also found that patients who preferred less aggressive care often received it, indicating good patient-provider communication. Loggers and colleagues (2009) previously reported that among Black non-hospice enrollees, preferences for less aggressive EOL were not associated with the type of care received (i.e., acute

interventions remained prevalent), suggesting poor provider-patient communication.

However, findings from this study suggest congruency between patient preferences and the type of care received, and support hospice providers' effectiveness in maintaining the central value of patient-guided care.

Hospice length of stay. Hospice LOS was examined in this study using three distinct outcomes: 1) the full care episode, 2) survival of one week or less, and 3) survival of one month or less. Results from models examining the full care episode indicate no racial/ethnic variation in hospice LOS. This finding persisted following adjustment for advance care plans. These results are inconsistent with most of the previous literature (Cólón & Lyke, 2003; Hardy et al., 2012; K. S. Johnson et al., 2011), which has reported longer hospice LOS for racial/ethnic minorities; however, it is consistent with one previous study reporting no racial/ethnic variation in hospice LOS following analysis of over 120,000 hospice decedents (Rhodes et al., 2007). Although the initial LOS finding from this study indicates no racial/ethnic variation in hospice LOS, the divergence of this finding from the larger empirical literature prompted a second wave of analyses examining racial/ethnic variation in shorter care episodes (Byock et al., 1996; Christakis & Iwashyna, 1998; Rickerson et al., 2005). Results from the additional analyses indicated that, compared to White hospice patients, Black hospice patients were significantly less likely to die in the first week ($OR = 0.78$; $p = .027$), but more likely to die in the first month of hospice care ($OR = 2.54$; $p < .001$). Similarly, compared to White hospice patients, Hispanic hospice patients were significantly more likely to die in the first week ($OR = 1.18$; $p < .001$), and equally as likely to die in the first month of hospice care ($OR = 1.20$; $p = .148$). All findings remained relatively unchanged following adjustment for

advance care planning decisions. Taken together, these findings suggest that racial/ethnic minorities enter hospice later in the disease trajectory compared to Whites, a finding previously documented in the empirical literature (K. S. Johnson et al., 2011).

Several implications can be drawn from the finding that racial/ethnic minorities are at an increased risk of dying within the first month of care. First, racial/ethnic minorities may experience late referral to hospice. It is possible that poor patient-provider communication about EOL care options and preferences prior to hospice enrollment may be contributing to delayed hospice enrollment for Blacks and Hispanics (Kelley et al., 2010; Perkins et al., 2002), and ultimately resulting in shorter hospice care episodes for minorities. Similarly, patient lack of trust in healthcare providers (Braunstein et al., 2008; Duffy et al., 2006; Gamble, 1997) may also influence timely enrollment, with some patients insisting on more aggressive interventions in order to ensure that they are not under-treated by healthcare providers. Racial/Ethnic minorities may also be deferring hospice enrollment for religio-cultural reasons. As previously discussed, cultural values such as Machismo/Fatalismo (Del Gaudio et al., 2013; A. K. Smith, Earle, et al., 2009) can influence racial/ethnic minority decision-making at EOL. Similarly, other factors, such as the perceived value of suffering (Krause & Bastida, 2011), and the belief that a higher being determines one's health outcomes (Blocker et al., 2006; Carr, 2011), may also be influence the timing of hospice enrollment.

Timely enrollment in hospice is important to ensure receipt of adequate hospice benefits. Studies indicate that at least thirty days of care are necessary for hospice providers to fully address the needs of their patients (Christakis & Iwashyna, 2000; Han et al., 2007; Haupt, 2003; Huskamp et al., 2001; McCarthy, Burns, Ngo-Metzger, et al.,

2003; Quill, 2007). Although study findings suggest both Black and Hispanic hospice patients are at-risk of not experiencing the full benefits of hospice care, additional research is also needed to ascertain patient and family views of the hospice experience. A growing body of research suggests that actual enrollment is more important than the number of days enrolled in hospice (Rickerson et al., 2005; Schockett, Teno, Miller, & Stuart, 2005; Teno, Shu, et al., 2007). These studies found that many patients who receive care for less than one month still report positive views of hospice and describe their needs as being met. Thus, although racial/ethnic minorities may be experiencing shorter hospice care episodes, it is possible that these patients are receiving the preferred duration of hospice care, and benefiting from this care. Additional studies are needed to test this hypothesis, and improve understanding of the relative effect of late hospice enrollment on racial/ethnic minority populations.

Site of death. This study, one of the first comprehensive examinations of racial/ethnic differences in SOD among Medicare hospice beneficiaries, found significant racial/ethnic variation, with both Black and Hispanic patients more likely than White patients to die in a home-like setting. These findings are in sharp contrasts with those found in the larger healthcare system, where racial/ethnic minorities are more likely than Whites to die in an acute setting (Gruneir et al., 2007; Hanchate et al., 2009; A. K. Smith, Earle, et al., 2009; Zheng et al., 2011). Given research documenting that hospice patients who prefer to die at home often do (Jeurkar et al., 2012), it is possible that many racial/ethnic minorities who elect hospice care favor in-home death and thus, are not representative of the larger population. The fact that similar proportions of Whites, Blacks, and Hispanics died in nursing homes ($\approx 25\%$) further indicates that this

population of racial/ethnic minorities is unique and not necessarily representative of the general population. Nevertheless, it is also conceivable that the value of the hospice experience, as described previously, also influences patient preferences concerning SOD. Accordingly, following hospice enrollment, patients who would traditionally prefer to die in more acute settings, may revise their preferences after experiencing high quality hospice care in the home. Notwithstanding, additional longitudinal studies that include patients' preferred location of death are needed to test these assertions, and further understanding of racial/ethnic variation in hospice SOD.

This study also found that Hispanic hospice patients were more likely than White hospice patients to die in a hospital setting, a finding that speaks to the diversity of the U.S. Hispanic population. Studies have documented significant variation in medical decision-making within Hispanic samples (Barnato et al., 2009; Cruz-Oliver et al., 2014), demonstrating how a single racial/ethnic group (of multiple countries of origin) could have significant within-group variation in healthcare preferences and usage. The finding that Hispanic hospice patients were more likely than White hospice patients to die in both home-like and hospital settings may serve as an illustration of this phenomenon. Similar studies of non-hospice-specific samples have also observed this trend (Barnato et al., 2009; Kalish & Reynolds, 1976). In a study of community-dwelling Medicare beneficiaries, Barnato and colleagues (2009) found that Hispanics were more likely than Whites to die in a home as well as a hospital setting. The authors concluded that although Hispanics were more likely than Whites to die in a hospital, most preferred and experienced in-home death. Although this manuscript was not able to examine patient SOD preferences, it is also possible that a small portion of Hispanics in this study

preferred to die in a hospital setting, and the majority preferred death in a home-like setting, as observed by Barnato and colleagues. The fact that 46% of Hispanics in this study died in a home-like setting, and only 11% died in a hospital setting supports this hypothesis; however, additional investigation that incorporates patient preferred location of death is needed to test this assertion, and will likely contribute to the understanding of potential subgroups within the Hispanic population.

Limitations and Research Recommendations

Despite the significant contributions of this study, limitations must be considered. First, as a result of the recent redesign of the National Home Health and Hospice Care Survey (NHHCS), data on key variables are only available for the 2007 wave and thus, the cross-sectional nature of the study restricts time order and causality-based conclusions. Additional studies that follow patients across the entire hospice stay will provide added insight into causal relationships suggested by this study. Second, nominal care preference data restrict in-depth exploration into complex constructs that guide patient decision-making at EOL. In the future, additional measures of care preferences, such as preferred location of death, will expand understanding of the association of these preferences on subsequent patient outcomes. Similarly, qualitative measures beyond simple binary responses may reveal additional aspects of patients' preferences that are lost in binary data collection. For example, inclusion of patient measures of religious views, acculturation, cultural beliefs, knowledge/education, and provider communication/trust will provide added context and explanatory power to the variation revealed by this study. This added richness will likely improve understanding of the relationship between patient's preferences, care utilization, and ultimately care outcomes.

both within and outside the hospice system. The coding structure of emergent care utilization following hospice enrollment was extremely limited, as data was only collected as occurred versus not occurred. Although beneficial in exploring general differences in care use, this type of data collection prevents an in-depth examination into the type of care that is utilized, as well as specification on the location and length of the unplanned care episode. Emergent care utilization was also only recorded if the episode occurred during the 60 days prior to data collection, as specified in survey data collection guidelines. As a result, additional emergent care episodes that are beyond the 60-day scope are lost. Furthermore, data on multiple acute care episodes are lost and thus, little is known regarding potential cases of multiple emergent care use episodes under the care of hospice. Future studies would benefit from data collection that accounts for these emergent care descriptive characteristics. Finally, given the unique nature of the emergent care use variable (i.e., atypical operationalization accounting for service use beyond hospitalization and/or emergency department use), results from this study, particularly comparisons between findings from this study and other studies, should be considered cautiously. NHHCS data rely on hospice agency records, and as such patient-data were never collected directly from the patients. Two potential complications arise from this limitation. Given that patient-level data is based on agency medical records, it is only as good as the record keeping system for each agency. While some agencies may have a well-structured record system established, other agencies may rely on less effective methods. With the large number of agencies utilized in the study ($n = 657$), it is reasonable to assume that agency-level variation in record-keeping accounted for some of the variance in missing data. Another potential complication arising from agency-level

record data collection is that some data may have never been collected. For example, some patients may have formally designated a healthcare proxy, but not documented this designation with the hospice agency, resulting in skewed data. Prospective studies would benefit from using a combined agency- and patient-level data collection technique. Such an approach would help account for variance in missing data. While significant consideration was given to variable selection and analysis, it is possible that results from death in a home-like setting are skewed due to operationalization issues. That is, it is possible that some patients died in a setting that they considered to be their *home*, such as nursing facility, but data coding prevented the correct assignment of this outcome. Future studies investigating hospice SOD should consider utilizing patient self-identified home settings to ensure proper representativeness. This study also did not account for agency-level predictors that could affect outcomes of interest. For example, research suggests that hospice characteristics, such as for-profit status, hospice size, years of certification, and geographic location all influence patient-level outcomes (Carlson et al., 2009; Sengupta et al., 2013; Wachterman et al., 2011). Additional studies that account for these agency-level characteristics will likely expand understanding of the association between patient race/ethnicity and care utilization and outcomes. As indicated above, previous studies have documented an increased likelihood among racial/ethnic minorities to disenroll from hospice. It is possible that this trend could be contributing to biased results in this study, as the racial/ethnic minorities who prefer more aggressive interventions could be disenrolling from hospice care, and thus leaving only a subset of minorities who prefer and utilize less aggressive EOL care. Follow-up studies that longitudinally account for disenrollment will help determine the relative effect of this trend on study outcomes.

While this study examined the influence of advance directive completion and DNR order election on care utilization and outcomes, it is possible that healthcare proxy designation may have also influenced these outcomes. Accordingly, additional examination of the relative effect of healthcare proxy designation on racial/ethnic within-hospice variation is needed to further understand the role of advance care planning on hospice patient care utilization and outcomes. Although socioeconomic status was modeled through Medicaid enrollment status in this study, a more accurate examination of socioeconomic status that includes information on patient education and income will likely provide a more precise estimate of the relative effect of the construct on the investigated outcomes. Lastly, as with all national hospice data, there is limited representation of all racial/ethnic minority groups, notably Asian/Pacific Islanders, and Native Americans/Alaska Natives. Future investigation of potential variation across other racial/ethnic groups will increase understanding of preferences and outcomes for other potentially vulnerable populations, and likely lead to improved hospice care for all patients.

Conclusion

Recent calls by the United States Department of Health and Human Services for the elimination of healthcare disparities by 2020 (USDHHS, 2012) highlights a significant need for equitable care within the U.S. healthcare system. Studies have repeatedly documented racial/ethnic disparities in access to and utilization of health services across multiple settings, and despite significant improvements over the past decade, important gaps remain. It is widely-understood that EOL decisions, and subsequent care outcomes, substantially impact several quality indicators at EOL. As a result, considerable effort has been made to improve racial/ethnic minority access to

hospice care in the United States; however, relatively few studies have investigated racial/ethnic differences among hospice enrollees. Given known EOL disparities outside of hospice care, further examination of disparities within the hospice system is needed to ensure equitable care for all hospice enrollees, and address government petitions to end disparities in the United States. This study provides the first in-depth investigation of racial/ethnic variation in care preferences, utilization, and outcomes following hospice enrollment. Results indicate that race/ethnicity is a significant contributor of patient-level variation in EOL decision making and care outcomes following hospice enrollment. As such, this study highlights an important need for future studies to advance understanding of care differences following hospice enrollment to ultimately ensure adequate quality of care for all patients. Equally-important, this investigation also underscores a potential need for Medicare Hospice Benefit policy adjustments, as the current structure of the benefit may disservice some racial/ethnic minorities who could benefit substantially from hospice care, but do not elect it due to current restrictions (e.g., requirement to forgo curative care). As researchers, healthcare providers, and policy makers, we have an obligation to ensure equity throughout the healthcare system. By identifying key differences in care preferences, utilization, and outcomes among U.S. hospice patients, this manuscript represents a concerted step toward ensuring that that all people are cared for equally at end of life.

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Appendices

Appendix A. Weighted and Unweighted Example Description				
Characteristics, No. (%)	White	Black	Hispanic	Sig.
Gender (Unweighted)				.613
Female	1,425 (42.65)	95 (43.38)	48 (47.52)	
Male	1,916 (57.35)	124 (56.62)	53 (52.48)	
Gender (Weighted)				.024
Female	299,860 (42.16)	29,752 (57.92)	8,856 (33.78)	
Male	411,424 (57.84)	21,616 (42.08)	17,364 (66.22)	

Footnotes

Sample size: 3,661

Unweighted sample size: 788,872

Percentages are presented by column

Appendix B. Unweighted Full Sample Description (*n* = 3,661)

Characteristics	Total (<i>n</i> = 3,661)	White (<i>n</i> = 3,341)	Black (<i>n</i> = 219)	Hispanic (<i>n</i> = 101)	Sig.
Age, Mean \pm SD	82.30 \pm 8.37	82.37 \pm 8.39	81.52 \pm 8.56	81.42 \pm 7.13	0.197
Female, No. (%)	1,568 (42.83)	1,425 (42.65)	95 (43.38)	48 (47.52)	0.613
Marital Status, No. (%)					0.019
Married/Living with Partner	1,476 (40.32)	1,370 (41.01)	63 (28.77)	43 (42.57)	
Widowed	1,706 (46.60)	1,543 (46.18)	118 (53.88)	45 (44.55)	
Divorced/Separated	200 (5.46)	183 (5.48)	12 (5.48)	5 (4.95)	
Never Married	151 (4.12)	130 (3.89)	17 (7.76)	4 (3.96)	
Missing	128 (3.50)	115 (3.44)	9 (4.11)	4 (3.96)	
Primary Diagnosis, No. (%)					0.012
Cancer	1,391 (38.00)	1,286 (38.49)	69 (31.51)	36 (35.64)	
CHF/Heart Disease	527 (14.39)	479 (14.34)	33 (15.07)	15 (14.85)	
Lung Disease	580 (15.84)	541 (16.19)	26 (11.87)	13 (12.87)	
Neurological Diseases	645 (17.62)	563 (16.85)	62 (28.31)	20 (19.80)	
Other	512 (13.99)	466 (13.95)	29 (13.24)	17 (16.83)	
Missing	6 (0.16)	6 (0.18)	0 (0.00)	0 (0.00)	
Comorbidity Count, Mean \pm SD	3.55 \pm 2.52	3.56 \pm 2.52	3.48 \pm 2.40	3.59 \pm 2.49	0.883
Medicaid Enrollee, No. (%)	740 (20.21)	599 (17.93)	104 (47.49)	37 (36.63)	<.001
Missing	30 (0.82)	30 (0.90)	0 (0.00)	0 (0.00)	

Footnotes

SD: Standard Deviation

CHF: Congestive Heart Failure

Percentages are presented by column

Appendix C. Unweighted Decedent Sample Description (*n* = 3,006)

Characteristics	Total (<i>n</i> = 3,006)	White (<i>n</i> = 2,787)	Black (<i>n</i> = 139)	Hispanic (<i>n</i> = 80)	Sig.
Age, Mean ± SD	82.07 ± 8.38	82.18 ± 8.41	80.45 ± 7.96	81.34 ± 7.39	0.043
Female, No. (%)	1,325 (44.08)	1,215 (43.60)	70 (50.36)	40 (50.00)	0.163
Marital Status, No. (%)					0.855
Married/Living with Partner	1,260 (41.92)	1,175 (42.16)	51 (36.69)	34 (42.50)	
Widowed	1,357 (45.14)	1,257 (45.10)	65 (46.76)	35 (43.75)	
Divorced/Separated	166 (5.52)	154 (5.53)	8 (5.76)	4 (5.00)	
Never Married	120 (3.99)	109 (3.91)	8 (5.76)	3 (3.75)	
Missing	103 (3.43)	92 (3.30)	7 (5.04)	4 (5.00)	
Primary Diagnosis, No. (%)					0.370
Cancer	1,237 (41.15)	1,148 (41.19)	58 (41.73)	31 (38.75)	
CHF/Heart Disease	398 (13.24)	379 (13.60)	10 (7.19)	9 (11.25)	
Lung Disease	454 (15.10)	424 (15.21)	18 (12.95)	12 (15.00)	
Neurological Diseases	492 (16.37)	443 (15.90)	32 (23.02)	17 (21.25)	
Other	419 (13.94)	387 (13.89)	21 (15.11)	11 (13.75)	
Missing	6 (0.20)	6 (0.22)	0 (0.00)	0 (0.00)	
Comorbidity Count, Mean ± SD	3.55 ± 2.53	3.55 ± 2.53	3.58 ± 2.48	3.56 ± 2.47	0.991
Medicaid Enrollee, No. (%)	564 (18.76)	478 (17.15)	59 (42.45)	27 (33.75)	<.001
Missing	25 (0.83)	25 (0.90)	0 (0.00)	0 (0.00)	

Footnotes

SD: Standard Deviation

CHF: Congestive Heart Failure

Percentages are presented by column

Appendix D. Advance Directive Completion Sample Descriptives
(*n* = 788,872)

Characteristics, No. (%)	Documented Advance Directive	
	Yes	Missing
Age		
65-75	144,556 (86.16)	7,980 (4.76)
76-82	165,684 (90.62)	688 (0.38)
83-87	171,992 (91.83)	1,456 (0.78)
88+	235,804 (93.96)	228 (0.09)
Gender		
Female	307,088 (90.73)	3,528 (1.04)
Male	410,948 (91.24)	6,824 (1.52)
Race/Ethnicity		
White	652,144 (91.69)	9,976 (1.40)
Black	41,044 (79.90)	12 (0.02)
Hispanic	24,848 (94.77)	364 (1.39)
Marital Status		
Married/Living Together	283,880 (90.46)	3,884 (1.24)
Widowed	340,156 (93.83)	1,820 (0.50)
Divorced/Separated	37,008 (87.81)	0 (0.00)
Never Married	27,152 (91.97)	12 (0.04)
Missing	29,840 (73.01)	4,636 (11.34)
Primary Diagnosis		
Cancer	262,060 (91.21)	2,120 (0.74)
CHF/Heart Disease	88,016 (87.69)	1,832 (1.83)
Lung Disease	118,380 (92.46)	1,732 (1.35)
Neurological Diseases	155,616 (92.54)	1,848 (1.10)
Other	93,440 (89.73)	2,740 (2.63)
Missing	524 (60.65)	80 (9.26)
Comorbidity Count		
0-1	190,464 (88.00)	8,396 (3.88)
2-3	224,692 (90.46)	628 (0.25)
4+	302,880 (93.46)	1,328 (0.41)

Footnotes

CHF: Congestive Heart Failure

Percentages are presented by row among the full sample

Appendix E. Do Not Resuscitate Order Election Sample
Descriptives (*n* = 788,872)

Characteristics, No. (%)	Documented DNR Order	
	Yes	Missing
Age		
65-75	130,668 (77.88)	23,224 (13.84)
76-82	152,864 (83.61)	17,144 (9.38)
83-87	160,120 (85.49)	15,312 (8.18)
88+	212,288 (84.59)	15,156 (6.04)
Gender		
Female	282,876 (83.58)	31,380 (9.27)
Male	373,064 (82.83)	39,456 (8.76)
Race/Ethnicity		
White	594,672 (83.61)	59,140 (8.32)
Black	37,296 (72.61)	10,324 (20.10)
Hispanic	23,972 (91.43)	1,372 (5.23)
Marital Status		
Married/Living Together	260,656 (83.06)	29,940 (9.54)
Widowed	312,108 (86.10)	22,356 (6.17)
Divorced/Separated	32,652 (77.48)	5,136 (12.19)
Never Married	23,208 (78.61)	2,372 (8.03)
Missing	27,316 (66.83)	11,032 (26.99)
Primary Diagnosis		
Cancer	234,296 (81.55)	25,248 (8.79)
CHF/Heart Disease	78,772 (78.48)	12,360 (12.31)
Lung Disease	104,912 (81.94)	9,648 (7.54)
Neurological Diseases	147,380 (87.64)	12,540 (7.46)
Other	90,076 (86.50)	10,700 (10.27)
Missing	504 (58.33)	340 (39.35)
Comorbidity Count		
0-1	170,612 (78.83)	25,968 (12.00)
2-3	208,172 (83.81)	23,688 (9.54)
4+	277,156 (85.53)	21,180 (6.54)

Footnotes

CHF: Congestive Heart Failure

Percentages are presented by row among the full sample

Appendix F. Healthcare Proxy Designation Sample Descriptives
(*n* = 788,872)

Characteristics, No. (%)	Documented Healthcare Proxy	
	Yes	Missing
Age		
65-75	67,336 (40.13)	23,224 (13.84)
76-82	83,308 (45.57)	17,144 (9.38)
83-87	89,240 (47.64)	15,312 (8.18)
88+	140,924 (56.15)	15,156 (6.04)
Gender		
Female	152,464 (45.05)	31,380 (9.27)
Male	228,344 (50.70)	39,456 (8.76)
Race/Ethnicity		
White	357,400 (50.25)	59,140 (8.32)
Black	15,800 (30.76)	10,324 (20.10)
Hispanic	7,608 (29.02)	1,372 (5.23)
Marital Status		
Married/Living Together	128,576 (40.97)	29,940 (9.54)
Widowed	198,888 (54.86)	22,356 (6.17)
Divorced/Separated	20,632 (48.96)	5,136 (12.19)
Never Married	15,924 (53.94)	2,372 (8.03)
Missing	16,788 (41.07)	11,032 (26.99)
Primary Diagnosis		
Cancer	12,6888 (44.16)	25,248 (8.79)
CHF/Heart Disease	49,680 (49.49)	12,360 (12.31)
Lung Disease	64,316 (50.24)	9,648 (7.54)
Neurological Diseases	86,272 (51.30)	12,540 (7.46)
Other	53,652 (51.52)	10,700 (10.27)
Missing	0 (0.00)	340 (39.35)
Comorbidity Count		
0-1	84,852 (39.20)	25,968 (12.00)
2-3	125,416 (50.49)	23,688 (9.54)
4+	170,540 (52.63)	21,180 (6.54)

Footnotes

CHF: Congestive Heart Failure

Percentages are presented by row among the full sample

Appendix G. Emergent Care Utilization Sample Descriptives
(n = 788,872)

Characteristics, No. (%)	Emergent Care Utilization	
	Yes	Missing
Age		
65-75	11,056 (6.59)	8,728 (5.20)
76-82	12,220 (6.68)	2,376 (1.30)
83-87	7,260 (3.88)	784 (0.42)
88+	16,656 (6.64)	3,412 (1.36)
Gender		
Female	19,536 (5.78)	3,512 (1.04)
Male	27,656 (6.14)	11,788 (2.62)
Race/Ethnicity		
White	40,568 (5.70)	14,124 (1.99)
Black	4,864 (9.47)	1,176 (2.29)
Hispanic	1,760 (6.71)	0 (0.00)
Marital Status		
Married/Living Together	17,292 (5.51)	4,388 (1.40)
Widowed	23,636 (6.52)	4,240 (1.17)
Divorced/Separated	3,320 (7.88)	8 (0.02)
Never Married	836 (2.83)	52 (0.18)
Missing	2,108 (5.16)	6,612 (16.18)
Primary Diagnosis		
Cancer	15,996 (5.57)	6,172 (2.15)
CHF/Heart Disease	9,864 (9.83)	1,736 (1.73)
Lung Disease	8,876 (6.93)	1,284 (1.00)
Neurological Diseases	6,292 (3.74)	2,908 (1.73)
Other	6,164 (5.92)	2,460 (2.36)
Missing	0 (0.00)	740 (85.65)
Comorbidity Count		
0-1	9,316 (4.30)	10,092 (4.66)
2-3	19,076 (7.68)	3,256 (1.31)
4+	18,800 (5.80)	1,952 (0.60)
Enrolled in Medicaid		
Yes	12,416 (9.92)	572 (0.46)
No	34,776 (5.31)	13,224 (2.02)
Missing	0 (0.00)	1,504 (17.20)
Advance Care Planning		
No AD, No DNR order	8,116 (13.42)	536 (0.89)
Yes AD, No DNR order	4,440 (7.15)	900 (1.45)
Yes AD, Yes DNR order	34,624 (5.28)	7,072 (1.08)
Missing	12 (0.12)	6,792 (65.61)

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row among the full sample

Appendix H. Decedent Hospice Length of Stay (Full Care Episode)
Sample Descriptives (*n* = 3,006)

Characteristics, No. (%)	Length of Stay: Full Episode	
	Valid Cases	Missing
Age		
65-75	689 (96.77)	23 (3.23)
76-82	788 (97.16)	23 (2.84)
83-87	598 (96.14)	24 (3.86)
88+	826 (95.93)	35 (4.07)
Gender		
Female	1,277 (96.38)	48 (3.62)
Male	1,624 (96.61)	57 (3.39)
Race/Ethnicity		
White	2,689 (96.48)	98 (3.52)
Black	136 (97.84)	3 (2.16)
Hispanic	76 (95.00)	4 (5.00)
Marital Status		
Married/Living Together	1,213 (96.27)	47 (3.73)
Widowed	1,311 (96.61)	46 (3.39)
Divorced/Separated	160 (96.39)	6 (3.61)
Never Married	117 (97.50)	3 (2.50)
Missing	100 (97.09)	3 (2.91)
Primary Diagnosis		
Cancer	1,209 (97.74)	28 (2.26)
CHF/Heart Disease	380 (95.48)	18 (4.52)
Lung Disease	433 (95.37)	21 (4.63)
Neurological Diseases	474 (96.34)	18 (3.66)
Other	399 (95.23)	20 (4.77)
Missing	6 (100.00)	0 (0.00)
Comorbidity Count		
0-1	734 (94.71)	41 (5.29)
2-3	904 (97.10)	27 (2.90)
4+	1,263 (97.15)	37 (2.85)
Enrolled in Medicaid		
Yes	2,328 (96.32)	89 (3.68)
No	548 (97.16)	16 (2.84)
Missing	25 (100.00)	0 (0.00)
Advance Care Planning		
No AD, No DNR order	216 (95.58)	10 (4.42)
Yes AD, No DNR order	234 (96.69)	8 (3.31)
Yes AD, Yes DNR order	2,436 (96.59)	86 (3.41)
Missing	15 (93.75)	1 (6.25)

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row among the decedent sample

Appendix I. Decedent Hospice Length of Stay (Full Care Episode) Median Comparisons (*n* = 638,412)

Characteristics	Decedent Length of Stay: Full Episode		
	<i>n</i>	Median	Sig.
Age			0.628
65-75	144,880	15.00	
76-82	150,860	15.00	
83-87	147,548	15.00	
88+	195,124	17.00	
Gender			0.190
Female	361,604	15.00	
Male	276,808	16.00	
Race/Ethnicity			0.428
White	583,124	15.00	
Black	36,304	19.00	
Hispanic	18,984	17.00	
Marital Status			.316
Married/Living Together	262,216	15.00	
Widowed	286,640	16.00	
Divorced/Separated	31,956	14.50	
Never Married	24,920	12.00	
Missing	32,680	18.50	
Primary Diagnosis			<.001
Cancer	247,300	18.00	
CHF/Heart Disease	80,536	21.00	
Lung Disease	96,788	13.00	
Neurological Diseases	133,176	14.00	
Other	79,748	9.00	
Missing	864	16.50	
Comorbidity Count			0.695
0-1	174,004	15.00	
2-3	194,320	16.00	
4+	270,088	15.00	
Enrolled in Medicaid			0.849
Yes	95,952	15.00	
No	534,904	16.00	
Missing	7,556	10.00	
Advance Care Planning			0.849
No AD, No DNR order	39,456	14.50	
Yes AD, No DNR order	47,744	12.00	
Yes AD, Yes DNR order	542,360	16.00	
Missing	8,852	52.00	

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Appendix J. Decedent Hospice Length of Stay (0-7 Days) Sample Descriptives (n = 667,820)

Characteristics, No. (%)	Length of Stay: 0-7 Days	
	Yes	Missing
Age		
65-75	58,400 (38.78)	5,704 (3.79)
76-82	56,316 (36.13)	5,004 (3.21)
83-87	66,264 (42.89)	6,940 (4.49)
88+	66,368 (32.08)	11,760 (5.68)
Gender		
Female	110,556 (37.99)	14,204 (4.88)
Male	136,792 (36.30)	15,204 (4.04)
Race/Ethnicity		
White	229,872 (37.63)	27,696 (4.53)
Black	11,220 (30.26)	772 (2.08)
Hispanic	6,256 (31.40)	940 (4.72)
Marital Status		
Married/Living Together	105,308 (38.49)	11,372 (4.16)
Widowed	105,612 (34.92)	15,836 (5.24)
Divorced/Separated	15,668 (48.06)	648 (1.99)
Never Married	11,128 (43.55)	632 (2.47)
Missing	9,632 (28.67)	920 (2.74)
Primary Diagnosis		
Cancer	90,448 (35.39)	8,280 (3.24)
CHF/Heart Disease	34,124 (40.63)	3,460 (4.12)
Lung Disease	36,712 (34.84)	8,576 (8.14)
Neurological Diseases	51,284 (36.99)	5,456 (3.94)
Other	34,732 (41.65)	3,636 (4.36)
Missing	48 (5.56)	0 (0.00)
Comorbidity Count		
0-1	68,128 (36.73)	11,472 (6.19)
2-3	79,668 (39.37)	8,044 (3.98)
4+	99,552 (35.56)	9,892 (3.53)
Enrolled in Medicaid		
Yes	30,044 (30.45)	2,728 (2.76)
No	214,484 (38.19)	26,680 (4.75)
Missing	2,820 (37.32)	0 (0.00)
Advance Care Planning		
No AD, No DNR order	17,168 (41.21)	2,208 (5.30)
Yes AD, No DNR order	18,352 (37.55)	1,128 (2.31)
Yes AD, Yes DNR order	210,340 (37.01)	26,044 (4.58)
Missing	1,488 (16.76)	28 (0.32)

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row among the decedent sample

Appendix K. Decedent Hospice Length of Stay (0-30 Days) Sample Descriptives (*n* = 667,820)

Characteristics, No. (%)	Length of Stay: 0-30 Days	
	Yes	Missing
Age		
65-75	99,052 (65.78)	5,704 (3.79)
76-82	100,312 (64.36)	5,004 (3.21)
83-87	106,264 (68.78)	6,940 (4.49)
88+	116,704 (56.41)	11,760 (5.68)
Gender		
Female	190,856 (65.68)	14,204 (4.88)
Male	231,476 (61.43)	15,204 (4.04)
Race/Ethnicity		
White	382,168 (62.57)	27,696 (4.53)
Black	27,764 (74.88)	772 (2.08)
Hispanic	12,400 (62.24)	940 (4.72)
Marital Status		
Married/Living Together	180,868 (66.11)	11,372 (4.16)
Widowed	182,292 (60.27)	15,836 (5.24)
Divorced/Separated	25,156 (77.16)	648 (1.99)
Never Married	18,184 (71.16)	632 (2.47)
Missing	15,832 (47.12)	920 (2.74)
Primary Diagnosis		
Cancer	171,096 (66.94)	8,280 (3.24)
CHF/Heart Disease	50,424 (60.03)	3,460 (4.12)
Lung Disease	58,488 (55.51)	8,576 (8.14)
Neurological Diseases	81,428 (58.74)	5,456 (3.94)
Other	60,156 (72.14)	3,636 (4.36)
Missing	740 (85.65)	0 (0.00)
Comorbidity Count		
0-1	120,068 (64.74)	11,472 (6.19)
2-3	135,508 (66.96)	8,044 (3.98)
4+	166,756 (59.56)	9,892 (3.53)
Enrolled in Medicaid		
Yes	57,108 (57.87)	2,728 (2.76)
No	360,576 (64.21)	26,680 (4.75)
Missing	4,648 (61.51)	0 (0.00)
Advance Care Planning		
No AD, No DNR order	27,320 (65.57)	2,208 (5.30)
Yes AD, No DNR order	33,032 (67.59)	1,128 (2.31)
Yes AD, Yes DNR order	359,764 (63.29)	26,044 (4.58)
Missing	2,216 (24.95)	28 (0.32)

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row among the decedent sample

Appendix L. Site of Death (Home-Like Setting) Sample
Descriptives (n = 667,820)

Characteristics, No. (%)	Site of Death: Home	
	Yes	Missing
Age		
65-75	80,480 (53.45)	34,456 (22.88)
76-82	80,996 (51.97)	23,808 (15.27)
83-87	77,624 (50.25)	20,928 (13.55)
88+	87,396 (42.24)	28,036 (13.55)
Gender		
Female	159,756 (54.90)	48,720 (16.75)
Male	166,740 (44.25)	58,508 (15.53)
Race/Ethnicity		
White	298,268 (48.83)	97,288 (15.93)
Black	18,980 (51.19)	6,500 (17.53)
Hispanic	9,248 (46.42)	3,440 (17.27)
Marital Status		
Married/Living Together	156,780 (57.31)	47,812 (17.48)
Widowed	133,836 (44.25)	38,512 (12.73)
Divorced/Separated	16,928 (51.92)	7,168 (21.99)
Never Married	7,460 (29.20)	6,292 (24.62)
Missing	11,492 (34.20)	7,444 (22.15)
Primary Diagnosis		
Cancer	158,424 (61.99)	46,076 (18.03)
CHF/Heart Disease	39,972 (47.59)	11,836 (14.09)
Lung Disease	47,916 (45.48)	18,560 (17.62)
Neurological Diseases	50,624 (36.52)	15,020 (10.83)
Other	29,176 (34.99)	15,276 (18.32)
Missing	384 (44.44)	460 (53.24)
Comorbidity Count		
0-1	87,304 (47.07)	31,796 (17.14)
2-3	106,192 (52.48)	32,056 (15.84)
4+	133,000 (47.50)	43,376 (15.49)
Enrolled in Medicaid		
Yes	23,852 (53.55)	91,532 (16.30)
No	300,712 (24.17)	10,820 (10.96)
Missing	1,932 (25.57)	4,876 (64.53)
Advance Care Planning		
No AD, No DNR order	20,392 (48.94)	5,312 (12.75)
Yes AD, No DNR order	32,320 (66.13)	5,252 (10.75)
Yes AD, Yes DNR order	272,848 (48.00)	88,748 (15.61)
Missing	936 (10.54)	7,916 (89.14)

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row among the decedent sample

Appendix M. Site of Death (Hospital) Sample Descriptives
(*n* = 667,820)

Characteristics, No. (%)	Site of Death: Hospital	
	Yes	Missing
Age		
65-75	15,944 (10.59)	34,456 (22.88)
76-82	15,820 (10.15)	23,808 (15.27)
83-87	12,052 (7.80)	20,928 (13.55)
88+	13,420 (6.49)	28,036 (13.55)
Gender		
Female	23,364 (8.03)	48,720 (16.75)
Male	33,872 (8.99)	58,508 (15.53)
Race/Ethnicity		
White	52,744 (8.63)	97,288 (15.93)
Black	2,280 (6.15)	6,500 (17.53)
Hispanic	2,212 (11.10)	3,440 (17.27)
Marital Status		
Married/Living Together	25,316 (9.25)	47,812 (17.48)
Widowed	23,752 (7.85)	38,512 (12.73)
Divorced/Separated	3,804 (11.67)	7,168 (21.99)
Never Married	972 (3.80)	6,292 (24.62)
Missing	3,392 (10.10)	7,444 (22.15)
Primary Diagnosis		
Cancer	18,148 (7.10)	46,076 (18.03)
CHF/Heart Disease	7,148 (8.51)	11,836 (14.09)
Lung Disease	12,340 (11.71)	18,560 (17.62)
Neurological Diseases	9,508 (6.86)	15,020 (10.83)
Other	10,072 (12.08)	15,276 (18.32)
Missing	20 (2.32)	460 (53.24)
Comorbidity Count		
0-1	23,692 (12.77)	31,796 (17.14)
2-3	15,056 (7.44)	32,056 (15.84)
4+	18,488 (6.60)	43,376 (15.49)
Enrolled in Medicaid		
Yes	5,448 (9.21)	91,532 (16.30)
No	51,720 (5.52)	10,820 (10.96)
Missing	68 (0.90)	4,876 (64.53)
Advance Care Planning		
No AD, No DNR order	5,860 (14.06)	5,312 (12.75)
Yes AD, No DNR order	3,304 (6.67)	5,252 (10.75)
Yes AD, Yes DNR order	48,072 (8.46)	88,748 (15.61)
Missing	0 (0.00)	7,916 (89.14)

Footnotes

CHF: Congestive Heart Failure

AD: Advance Directive

DNR: Do Not Resuscitate

Percentages are presented by row among the decedent sample

Appendix N. Original Site of Death: Full Responses (*n* = 667,820)

	Total	White	Black	Hispanic
Inpatient Hospice Agency ^β	100,012 (14.98)	90,072 (14.75)	6,500 (17.53)	3,440 (17.27)
Private Home/Apartment	289,900 (43.41)	262,260 (42.94)	18,392 (49.61)	9,248 (46.42)
Residential Care Place	36,596 (5.48)	36,008 (5.90)	588 (1.59)	0 (0.00)
Nursing Home/SNF	176,572 (26.44)	162,232 (26.56)	9,316 (25.13)	5,024 (25.22)
Hospital	57,236 (8.57)	52,744 (8.63)	2,280 (6.15)	2,212 (11.10)
Other	492 (0.07)	492 (0.08)	0 (0.00)	0 (0.00)
Missing	7,012 (1.05)	7,012 (1.15)	0 (0.00)	0 (0.00)

Footnotes

^β Inpatient Hospice Agency excluded from study analyses due to operationalization problems

SNF: Skilled Nursing Facility

Percentages are presented by column