

RACIAL AND ETHNIC DISPARITIES IN HOSPICE USE AFTER REFERRAL

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Abstract

JILL M. FORCINA HILL: Racial and Ethnic Disparities in Hospice Use after Referral
(Under the direction of Barbara Germino)

The efficacy of hospice in providing high quality end-of-life care has been substantially demonstrated in the scientific literature. The problem, however, is that hospice is vastly under-utilized among the terminally ill and particularly among racial and ethnic minorities; and no known studies have examined factors associated with hospice use while adjusting for patients who never had the opportunity to enroll. The purpose of this study was two-fold: 1) to develop a conceptual model to explore, describe and predict hospice utilization using a variety of patient, contextual and institutional factors, and 2) to test the model among a cohort of patients who have been referred to hospice, regardless of their utilization outcome. The newly developed model, the Behavioral Model of Hospice Use, was used to guide the extraction of variables from the administrative databases of two non-profit hospice agencies located in central North Carolina. Logistic regression determined which variables predicted both hospice utilization and the reasons patients did not use hospice when applicable. The final sample consisted of 3,825 patients referred to hospice from 2003-2006. Non-Whites were 3.1 times less likely to use hospice after referral than Whites ($p = .078$); and, when patients were referred by a physician (as compared to other source), those referred by female physicians were 6.6 times more likely to use hospice after referral than patients referred by male physicians ($p = .081$). The results of this study suggest that the patient's race/ethnicity is important even after referral. However, patient race/ethnicity may not be as

important as the characteristics of the referring physician, raising the question if the issue of under-utilization is not so much whether patients are referred *at all* but rather whether they are referred *appropriately* or *by whom*. The reasons for disparities in hospice use are more likely related to the characteristics of the institution and/or the referral process and not related to the characteristics of the patient. Future studies should expand on the Behavioral Model of Hospice Use by including additional concepts, such as the role of caregivers and individual beliefs and values related to end-of-life care.

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I. Background and Significance

Statement of the Problem

Only an estimated 43% of people eligible for hospice actually use hospice (Harrison, Ford, & Wilson, 2005), and this under-utilization is even more pronounced among racial and ethnic minorities. The benefits of using hospice are well-supported in the literature from economic, social and health care perspectives. Thus, the disparities in hospice utilization are cause for concern. Understanding and improving disparities in hospice use would offer opportunities to enable a more diverse population of dying patients and their families to receive comprehensive and individualized care that promotes comfort, peace and dignity at the end of life.

Significance

Numerous investigators have concluded that terminally ill patients in the United States prefer to die comfortably in their own home (Donaldson & Field, 1998; Koffman & Higginson, 2004; Lynn, 2004; Lynn, Schuster, & Kabcenell, 2000; Tang, 2003b); however, among the approximately 2.5 million people who died in the United States in 2003, 50% did so in the hospital (Hospice Facts and Figures, 2003). Of these deaths, 20% were in an intensive care unit (ICU) (Halcomb, Daly, Jackson, & Davidson, 2004; Rocker & Curtis, 2003), and 50% of those who died in the hospital had been in an ICU within the last three days of life (Ciccarello, 2003). Based on interviews with family members of 3,357 deceased patients, a study examining the end-of-life experience for seriously ill older adults revealed

that 40% of patients experienced severe pain during most of the 3 days prior to death; and 25% of patients experienced moderate to severe anxiety or depression prior to death (Lynn et al., 1997). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), the largest observational and interventional study on end-of-life care to date, including 9,105 patients, their physicians, and their family members, found that the final hospitalization for most patients included more than one week in an undesirable state of coma, mechanical ventilation or intensive care. In addition, family members of patients enrolled in this study reported that half of the patients who died in the hospital were unquestionably uncomfortable at least half the time during their final days of life - even after an intervention aimed at improving end-of-life care delivery (SUPPORT Principal Investigators, 1995).

Hospice care is an effective and compassionate way to deliver end-of-life health care services, addressing many of the problems reported in the studies described above. The goal of hospice is to provide comprehensive and individualized care in the setting of choice for terminally ill patients and their families while emphasizing comfort, peace and dignity as death approaches. As of 2006, the National Hospice and Palliative Care Organization (NHPCO) reported that an estimated 1.3 million patients were served by hospice, with only 8.8% of these patients ultimately dying in the hospital ("NHPCO Facts and Figures: Hospice Care in America," 2007). Among a sample of 29,292 family members of deceased hospice patients surveyed by the NHPCO in 2004, overall satisfaction with hospice care was rated as 47.1 on a 50-point scale, indicating very high satisfaction (Connor, Teno, Spence, & Smith, 2005). In a survey of 1,578 family members of recent decedents, family members of patients who died in hospice reported less concern about emotional support, more respectful

treatment of the patient, and greater satisfaction with overall quality of care than families of patients who died in hospitals, nursing homes, or with a home health agency (Teno et al., 2004). Also, patients under hospice care have reported good to very good quality of life within 20 days of admission (Steele, Mills, Hardin, & Hussey, 2005). A retrospective chart review comparing 209 hospice and 172 non-hospice nursing home residents found that those who were receiving hospice care had more frequent pain assessments and pain management interventions than non-hospice patients (Miller, Mor, & Teno, 2003). A recent comparative study of 66 terminally ill adults concluded that hospice patients were significantly more likely to report higher general quality of life and better physical well-being than non-hospice patients (Douglas, 2007). The benefits of hospice utilization are clear; thus, hospice is often considered by health care providers to be the “gold standard” for end-of-life care in the United States (Yabroff, Mandelblatt, & Ingham, 2004).

Studies have also looked at the potential cost-savings of hospice. While some of the studies have had flawed designs, most experts concur that hospice care is more cost effective than hospital and nursing home care for most patients. Hospital-affiliated hospices have been shown to increase organizational profitability and result in a larger return on investment (Harrison et al., 2005). Government expenditures during the last month of life are significantly less for hospice patients in nursing homes than non-hospice patients in nursing homes, particularly for short-stay patients (Miller et al., 2004). Among 8,700 Medicare beneficiaries studied in the years 1999-2000 and grouped into different diagnostic cohorts, most patient cohorts incurred lower mean and median costs when enrolled in hospice (Pyenson, Connor, Fitch, & Kinzbrunner, 2004). A study of 65,618 Medicare beneficiaries in two different states found that expenditures were 13-20% lower for cancer patients enrolled

in hospice than for other beneficiaries with cancer (Emanuel et al., 2002). A retrospective cohort study of 245,326 deceased Medicare beneficiaries found that hospice use resulted in cost savings for cancer patients, especially for those diagnosed with lung cancer or a more aggressive disease in the last year of life (Campbell, Lynn, Louis, & Shugarman, 2004). A recent, retrospective case control study comparing cost expenditures among 1,819 hospice Medicare decedents with 3,638 non-hospice controls indicated that hospice use reduced Medicare expenditures by an average of \$2,309 per person in the last year of life, with maximum savings occurring when hospice was utilized for the last 50-108 days of life (Taylor, Ostermann, Van Houtven, Tulskey, & Steinhauer, 2007). Despite some reports concluding that complex diagnoses or extended lengths of stay in hospice may increase costs (Campbell et al., 2004; Pyenson et al., 2004), most studies support that hospice provides better care at the same or lower cost for most patients who use the services.

Background

Given the benefits of hospice, the under-utilization of hospice services by terminally ill patients is unexpected and raises questions about factors influencing hospice use. While the research in this area is somewhat limited, empiric evidence supports that certain patient, contextual and institutional factors are associated with hospice utilization. The following sections provide an overview of hospice utilization patterns and common factors associated with hospice use at the level of the patient, context and institution.

Individual factors¹

Individual factors are the characteristics of patients that potentially influence their use of hospice services. According to the NHPCO, the “typical” hospice patient in 2006 was White (80.9%), had a cancer diagnosis (44.1%) and was over the age of 85 (33.2%) (“NHPCO Facts

¹ Parts of this section were published previously in Forcina Hill, 2008, p.241.

and Figures: Hospice Care in America," 2007). These data describe patients already enrolled in hospice; only three known studies have systematically examined individual factors associated with hospice utilization using a cohort of both hospice and non-hospice patients. In an early study of 251 people who died from lung cancer, investigators examined individual factors associated with the use of home hospice, inpatient hospice or hospitals as the last site of care for the patient and found that having higher income and older age predicted hospice use (Berry, Boughton, & McNamee, 1994). In a secondary analysis of the National Mortality Followback Survey which included data on 11,291 decedents, being married, relatively young, having higher income, having some college education, and having high levels of social support were all positively related to hospice use. Being female, not owning a home, not having a living will, having a non-cancer diagnosis, and not having health insurance were all negatively associated with hospice use (Greiner, Perera, & Ahluwalia, 2003). In their study of elderly patients newly diagnosed with lung cancer, colon cancer, stroke or heart attack from the 1993 Medicare claims data, Iwashyna and colleagues found that older, male, non-White, and patients who qualified for Medicaid were less likely to use hospice, while the more serious an individual's comorbidity score was, the more likely they were to receive hospice care (Iwashyna, Chang, Zhang, & Christakis, 2002). However, the researchers did not adjust for interaction effects between these variables. Additionally, none of these studies could say *why* some of the patients used hospice and others did not, because they did not differentiate between patients who had the opportunity to enroll in hospice and those who were not given the opportunity. They also did not adjust for all decedents who died suddenly or unexpectedly and, therefore, would not have been appropriate or realistic candidates for hospice.

The roles of caregiver support and patient preferences have also been shown to affect hospice use. For example, one study found that the patient's perception of their family's ability to provide care in the home was negatively associated with hospice use and that the patient's perception of home as a realistic place of death was positively associated with hospice use (Tang, 2003a). This study, however, was conducted with a small homogeneous sample, including only 127 participants, all with cancer diagnoses.

Contextual Factors

Hospice use varies substantially between geographical areas. Rates of hospice use vary between 3.5% and 39.7% among large metropolitan statistical areas (Virnig, Kind, McBean, & Fisher, 2000) and vary considerably across counties (Iwashyna et al., 2002). Thus, some researchers have focused on the potential influence that contextual factors, which include environmental and circumstantial characteristics, might have on hospice utilization. In their study, Iwashyna and colleagues (2002) found significant variations in hospice utilization rates across health care markets. The commonness of cancer deaths and the degree of White collar employment of a given market were positively associated with the rates of hospice use in those markets. They also reported that hospice utilization rates were negatively associated with the population density of a given area (rural counties had greater hospice utilization rates when hospice was available) and that the median income of an individual's immediate neighborhood was positively associated with hospice use (Iwashyna et al., 2002). Virnig and colleagues (2000) examined the national variation in the use of hospice among Medicare enrollees who died in 1996 and found that the rate of hospice use was higher for persons in wealthier and urban areas, and in areas with higher proportions of non-cancer diagnoses, fewer hospital beds per capita, more physicians per capita, higher reimbursement rates for

health care and higher HMO enrollment. Pritchard and colleagues (1998) reported that hospice use was negatively correlated with the in-hospital death rates in a community. All of these studies, however, used data from Medicare enrollees from more than a decade ago. None of these studies examined the contextual factors in hospice use by patients with other forms of payment.

Institutional Factors

Institutional factors are those characteristics of the health care system, organization, or agency that may influence hospice utilization rates. When examining the potential influence of institutional factors on hospice use, most researchers have focused on the effects of the physician. Admission to hospice requires a statement by two physicians, usually the patient's primary care physician and the hospice medical director, that the patient has 6 or fewer months to live. Therefore, the physician is considered the gatekeeper to hospice (Yabroff et al., 2004), and lack of physician referral is a frequently cited barrier to hospice use (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Gelfand, Balcazar, Parchowski, & Lenox, 2004; F. Jackson, Schim, Seely, Grunow, & Baker, 2000). Investigators who examined physician self-reported practices have found that physicians' referral practices varied by board certification status and specialty (Bradley et al., 2000), approval of hospice (Hyman & Bulkin, 1990), patients' diagnoses, and the number of terminally ill patients they served (Berry et al., 1994). However, self-report may not accurately represent actual physician practices, and no published studies have examined the effects of physician factors on a patient's decision to enroll in hospice once referred by that physician.

Other institutional factors, such as strict prognostic and treatment eligibility guidelines, may also influence hospice use. For eligibility in most hospices, a patient must be approved

and certified by their primary care physician and the hospice medical director to be terminally ill and have 6 months or less to live if the illness runs its natural course. This prognostic eligibility requirement is problematic because the disease trajectories of many illnesses, especially non-cancer life-limiting diseases, are ambiguous; and it is often difficult to estimate a 6-month prognosis (Christakis & Lamont, 2000). Further, the patient must be willing to forgo certain “cure-oriented” treatments to be eligible for enrollment in most hospices and pursue only “comfort-oriented”, or palliative, treatments if necessary. A survey of all California licensed hospice programs found that many hospices restricted admission for patients who were unwilling to relinquish future hospitalizations (29%), or were receiving chemotherapy (49%), radiotherapy (36%), blood transfusions (25%), total parenteral nutrition (38%), and tube feedings (3%) (Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004). However, this study only reported percentages of *hospices* that would not enroll patients if they were receiving these treatments. It did not address the percentages of *patients* who were unable to enroll because of the treatment eligibility guidelines and did not differentiate whether these treatments were being used for palliative purposes or curative purposes. A recent retrospective chart review of 50 patients concluded that, for many patients, the availability of second-line and beyond therapies in the treatment of cancer posed a significant delay to hospice referrals. They found that the last dose of chemotherapy was frequently given with the last 14 days of life, even after recognition that these therapies would pose little benefit to the patient’s disease progression (Mintzer & Zagrabbe, 2007).

The fragmentation of care is also a possible issue with hospice utilization. Caregivers of hospice patients in one qualitative study reported that the patient was often referred and transferred to several other settings before finally reaching hospice (Schulman-Green et al.,

2004), indicating that the health care system itself is a barrier to hospice services. Additional research is needed to determine whether these institutional factors are an influential barrier to hospice use for terminally ill patients.

Racial and Ethnic Disparities in Hospice²

While hospice is under-utilized by the terminally ill in general, racial and ethnic disparities in hospice use are even more pronounced. In the National Mortality Followback Survey study, Blacks were significantly less likely than Whites to use hospice, even after adjusting for age, gender, income, education, marital status, presence of a living will and access to health care (as measured by proxy next-of-kin questionnaire) (Greiner et al., 2003). Consequently, the proportion of racial and ethnic minorities in the United States population is much greater than the proportion of racial and ethnic minorities enrolled in hospice. About 14% of hospice admissions in 2004 were Black or Hispanic patients ("NHPCO Facts and Figures," 2004), while an estimated 12.3% of the United States' population is Black and 12.5% is Hispanic ("State & County Quick Facts," 2000). The racial and ethnic discrepancy becomes more distinct when the relative incidence of the top hospice admission diagnoses within these racial groups is considered. In 2006, the NHPCO reported that 44.1% of all hospice admissions were due to a cancer diagnosis ("NHPCO Facts and Figures: Hospice Care in America," 2007), and the incidence and death rates of most types of cancer are higher among Blacks than any other racial group (*Cancer Facts and Figures for African Americans 2007-2008*, 2007). The problem is not limited to Blacks; Hispanics, Asian Americans and Hawaiian/Pacific Islanders also use hospice in numbers that are disproportional to both their population size and the mortality/morbidity rates of the top hospice admission diagnoses.

² Portions of this section were previously published in Forcina Hill, 2008, pp.240-241.

Table 1 displays the percent of racial and ethnic minorities in the United States 2000 Census and the percent of racial and ethnic minorities who used hospice in 2004.

Table 1. *Racial and Ethnic Minority Population Estimates Comparison*

<i>Race/Ethnicity</i>	<i>U.S. Census 2000 Population Estimates</i>	<i>NHPCO 2004 Hospice Population Estimates</i>
White/Caucasian	75.1%	77.3%
Black/ African American	12.3%	8.1%
Hispanic/Latino	12.5%	6.2%
Asian/Hawaiian/ Pacific Islander	3.7%	1.7%
Multiracial/other race	8.8%	6.4%

Note. Statistics reported by ("NHPCO Facts and Figures," 2004; "State & County Quick Facts," 2000). The U.S. Census considers Hispanic/Latino to be an indication of ethnicity (not race); thus, patients may be Hispanic/Latino as well as some other race.

Factors Associated with Racial and Ethnic Disparities in Hospice³

Some researchers have begun to explore reasons for hospice under-utilization by racial and ethnic minorities. These studies have found that differences in values regarding medical care (Doorenbos, 2003; F. Jackson et al., 2000; Reese, Ahern, Nair, O'Farie, & Warren, 1999), language barriers (Born et al., 2004; Gelfand et al., 2004), differences in spiritual beliefs (Born et al., 2004; Doorenbos, 2003; F. Jackson et al., 2000; Reese et al., 1999), lack of knowledge of services (Born et al., 2004; Doorenbos, 2003; Gelfand et al., 2004; F. Jackson et al., 2000; Reese et al., 1999), economic factors (Born et al., 2004; Gelfand et al., 2004; Reese et al., 1999), lack of trust in the health care system (Born et al., 2004; Gelfand et al., 2004; F. Jackson et al., 2000; Reese et al., 1999), and lack of diversity among health care professionals (Doorenbos, 2003; Gelfand et al., 2004; F. Jackson et al., 2000; Reese et al., 1999) were barriers to hospice use. A recent study among 32 home health care patients who

³ Portions of this section were previously published in Forcina Hill, 2008, p. 241.

qualified for hospice care suggested that, although the majority of racial and ethnic minorities in the sample reported philosophies regarding end-of-life care similar to that of hospice, less than half of these patients had any knowledge of hospice services. Additionally, none of the participants had any prior discussions regarding hospice with their primary health care provider (Rosenfeld et al., 2007).

Studies that focused on differences in preferences for end-of-life care have shown that Blacks and Hispanics prefer more life-sustaining treatments than their White counterparts (Blackhall, Frank, & Murphy, 1999; Degenholtz, Thomas, & Miller, 2003; Hopp & Duffy, 2000; Kwak & Haley, 2005). For example, a study of 2,109 people admitted to the neurology/neurosurgery intensive care unit at a large academic tertiary care center found that Blacks were less likely than Whites to withdraw mechanical ventilation (Diringer, Edwards, Aiyagari, & Hollingsworth, 2001). Other studies have reported that racial and ethnic minority groups were less likely than Whites to have advance directives. Degenholtz and colleagues, for example, found that among 3,747 nursing home residents from around the country, Blacks were about one-third as likely as Whites to have living wills and one-fifth as likely to have Do Not Resuscitate (DNR) orders. Similarly, Hispanics were about one-third as likely as Whites to have DNR orders (Degenholtz, Arnold, Meisel, & Lave, 2002). In another survey of 1,447 decedents from 22 states, family members of Black decedents were 22% less likely than Whites to report that the deceased patient had a signed durable power of attorney or living will prior to death (Welch, Teno, & Mor, 2005). Race and ethnicity are characteristics of the individual that may be considered to represent their cultural beliefs. Thus, these studies suggest that racial and ethnic disparities in hospice use may be due to cultural differences in end-of-life preferences and planning.

Other studies, however, have suggested different explanations. For example, Troyer and McAuley (2006) found that the county characteristics of a patient's residence, specifically if the patient lived in a metropolitan area and area with greater poverty, had greater impact on the use of advance directives among Black nursing home patients than personal characteristics. Waters (2000) found that an educational program for 27 Black community members led to a significant increase in the number of those participants who would consider writing a living will, indicating that lack of knowledge or awareness of advance directives plays a major role in their completion. On a similar note, a survey of 179 elderly ambulatory care patients concluded that the difference in the rates of completion of health care proxies among racial and ethnic minorities was probably due to lack of knowledge or the belief that these documents are not necessary in a family-involved setting (Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). Black pastors have been reported to be unaware of hospice services. Given the importance of the church in Black communities, their lack of knowledge may indicate a lack of awareness of hospice in the Black community in general (Reese et al., 1999). Many of the studies of racial and ethnic minorities' use of hospice also suggest that lack of awareness and understanding of hospice among participants was a result of lack of provider knowledge, communication and referral (Born et al., 2004; Gelfand et al., 2004; F. Jackson et al., 2000). These studies have provided a wealth of information regarding the possible barriers to hospice for racial and ethnic minorities. However, most were qualitatively designed with little or no adjustment for participants who had previously encountered hospice services.

Summary

In summary, patients at the end of life may benefit significantly from the use of hospice services. Hospice is largely recognized as an indispensable tool for achieving optimal or quality end-of-life care with an economic advantage (Campbell et al., 2004; Connor et al., 2005; Emanuel et al., 2002; "Hospice Facts and Statistics," 2004; Pyenson et al., 2004; Steele et al., 2005; Teno et al., 2004). Hospices provide an environment of comfort and support while allowing patients to live their remaining time in the setting of their choice. However, hospice is largely under-utilized in the United States, and the disparities in hospice use among terminally ill patients and particularly among racial and ethnic minorities have generated much concern among practitioners and researchers.

The current research supports that certain patient, contextual and institutional factors are associated with hospice utilization. The age, gender, marital status, diagnosis, income and insurance status of an individual are all potential predictors of hospice use (Berry et al., 1994; Greiner et al., 2003; Iwashyna & Chang, 2002; Iwashyna et al., 2002); and the characteristics of the place in which an individual lives, such as the relative distribution of health services and providers, the population density and the wealth of a geographic area, have also been shown to affect hospice utilization (Iwashyna et al., 2002; Pritchard et al., 1998; Virnig et al., 2000). The training, education and experience of an individual's provider and the health policies regulating hospice admissions may also be large contributors to the under-utilization of hospice services (Berry et al., 1994; Bradley et al., 2000; Hyman & Bulkin, 1990; Lorenz et al., 2004). For racial and ethnic minorities, the research is even more in-depth, describing potential reasons for the disparities in hospice use, including lack of knowledge, differences in values and spiritual beliefs, lack of trust in the health care system and economic issues

(Born et al., 2004; Doorenbos, 2003; Gelfand et al., 2004; F. Jackson et al., 2000; Reese et al., 1999).

While these studies have provided information on the use of hospice services by those enrolled, no studies have examined the characteristics of patients who are offered hospice services but do not enroll or the influence of individual factors associated with hospice use in the context of both the contextual and institutional factors. Thus, more work is needed to ascertain why terminally ill patients, especially racial and ethnic minorities, are not enrolling in hospice.

Purpose and Specific Aims

The purpose of this study was to explore, describe and predict hospice utilization using a variety of patient, contextual and institutional factors that have been described in the hospice literature as correlates with hospice use and/or have been hypothesized in the general health care access literature as correlates with hospice use among a cohort of patients who have been referred to hospice, regardless of their utilization outcome. This study examined the characteristics of a cohort of patients who were referred to home hospice to identify patient, contextual and institutional factors that may affect hospice use. Particular attention was paid to the determinants of hospice use among referred racial and ethnic minorities. Three factors of interest based on the literature review and conceptual framework were: 1) individual factors, including age, gender, race/ethnicity, marital status, insurance, and diagnosis⁴; 2) contextual factors, including the age, gender, race/ethnicity, marital status, education and employment levels of the population, per capita income, rate of health insurance coverage,

⁴ The variables level of caregiver support and need for services were included in the original proposal but were not included in the study. The data that was to be used to represent level of caregiver support was not collected in the same manner for both hospices and would therefore have been invalid and unreliable; the data that was to be used to represent need for services was not collected by one of the hospices at all.

ratios of physicians and hospital beds to the population and the morbidity and mortality rates for the top 10 hospice diagnoses in the county of the patient's place of residence; and 3) institutional factors, including the age, gender, race/ethnicity, years licensed, specialty, primary practice location and hours spent in primary or clinical care for the patient's referring hospice physician, and the effects of hospice's eligibility requirements on utilization.⁵ A major purpose of this study was to test a predictive model of hospice utilization derived from the Behavioral Model of Health Services Use (Andersen & Davidson, 2001) and the Conceptual Model of Realized Access to End-of-Life Care (Yabroff et al., 2004). The proposed model, termed the Behavioral Model of Hospice Use, was designed to explain the variation in hospice use among referred patients as a function of the three factors.

The specific aims of this study were:

1. To determine individual factors associated with hospice use, contextual factors of a patient's place of residence associated with hospice use, and institutional factors associated with hospice use for all referred patients and for referred racial and ethnic minorities.
2. To determine whether individual factors associated with hospice use are conditional on contextual or institutional factors for all referred patients and for referred racial and ethnic minorities.
3. To test a predictive model of hospice utilization after referral, as derived from Andersen's Behavioral Model of Health Services Use and the Conceptual Model for Realized Access to End-of-Life Care.

⁵ The physician's board certification status was included as a variable in the original proposal; however, the data were not available on the individual level as anticipated.

II. Conceptual Framework and Review of the Literature

Conceptual Framework

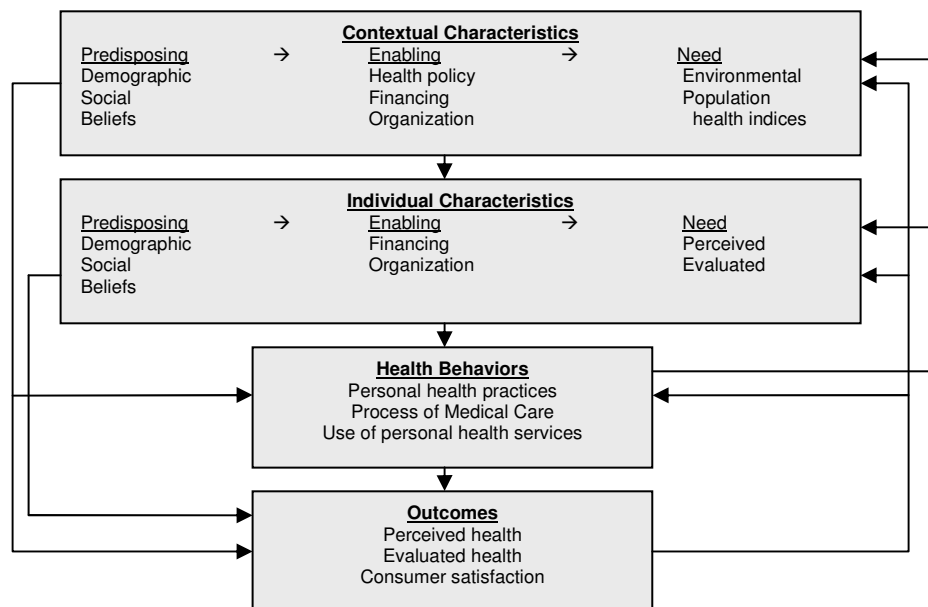
Hospice under-utilization has been conceptualized as a problem of health care services utilization for the purposes of this study, and the Behavioral Model of Hospice Use (“Hospice Model”) was used as a guide. The Hospice Model was derived from the synthesis of Andersen’s Behavioral Model of Health Services Use, the most frequently cited model in the study of health care services access and use (Andersen & Davidson, 2001), and the Conceptual Model for Realized Access to End-of-life Care, the only published model addressing the potential factors associated with the provision of optimal end-of-life care (Yabroff et al., 2004). Using the current literature, this chapter will describe and analyze the two conceptual frameworks that were used to develop the framework used in this study and present research that has been guided by each of the two frameworks. This chapter also includes a discussion of the synthesis of the frameworks into the derived conceptual model and a description of the variables and relationships in the Hospice Model.

Behavioral Model of Health Services Use

Most of the research focused on the access and utilization of health care services is conceptualized using Andersen’s Behavioral Model of Health Services Use (“Behavioral Model”; Figure 1) to guide the design. Andersen, a sociologist, developed this model as part of his dissertation research to study why individuals and families differ in the amount of health care they consume (Andersen, 1974). The concepts in the Behavioral Model were

included because they have potential to facilitate or impede access and utilization. These concepts have been well-defined in the literature and are: *contextual factors*, *individual factors*, *health behaviors* and *outcomes* of health behaviors. All of the concepts are considered dynamic and inter-relating in nature and are defined in Table 2 (Andersen & Davidson, 2001).

Figure 1. Behavioral Model of Health Services Use



Note. The figure shown is adapted from Andersen & Davidson, 2001.

Table 2. Concepts, Definitions and Common Examples of the Behavioral Model of Health Services Use

Concept	Sub-concepts		Definition	Common Examples
Contextual Characteristics	Predisposing	Demographics		Age, gender, marital status of community
		Social	How supportive or detrimental the community where people live or work are to their health and use of services	Ethnic/racial composition, proportion of recent immigrants, employment and educational levels
		Beliefs	Underlying community or organizational values and cultural norms and political perspectives regarding how health services should be organized, financed, and made accessible to the population	[Using surveys, interviews]
	Enabling	Health policy	Authoritative decisions pertaining to health or influencing the pursuit of health	Product lines, pricing, marketing influence of health products
		Financing	Resources potentially available to pay for health services	Per capita community income and wealth, per capita expenditures for health services
		Organization	The amount and distribution of health services facilities and personnel as well as how they are structured to offer services	Ratios of physicians and hospital beds to the population
	Need	Environmental	Health-related measures for the physical environment	Injury and death rates due to occupational accidents, homicides, firearms, motor vehicle accidents
		Population health indices	General indicators of community health	Infant mortality, cancer rates, prevalence of stroke, heart disease, etcetera
	Individual Characteristics	Predisposing	Demographics	
Social			The status of the individual in the community as well as his/her ability to cope with problems and command resources to deal with those problems	Race/ethnicity, education and employment levels of the individual
Beliefs			Attitudes, values, and knowledge people have about health and health services that can influence their health and use of services	[Using surveys, interviews]
Enabling		Financing	The income and wealth of the individual to pay for services	Effective price of health care services to the patients, determined by having insurance and cost-sharing requirements
		Organization	Whether or not the individual has a regular source of care and the nature of that source	Source of care (ED vs. private physician), means of transportation, travel time, waiting time for appointments
Need		Perceived	How people view their own general health and functional state	[Using surveys, interviews]
		Evaluated	Represents professional judgment and objective measurement about a patient's physical status and need for medical care	Blood pressure readings, temperature, blood cell count, prognoses, diagnoses
Health Behaviors		Personal Health Practices		Behaviors by the individual that affect health and health care use
	Process of medical care		The behavior of providers interacting with patients in the process of care delivery	Patient education and counseling, prescribing patterns, test ordering, quality of patient-provider communication
	Use of personal health services		Actual use of health care	Whether or not an individual uses a health care service
Outcomes	Perceived health		The extent to which a person can live a functional, comfortable, and pain-free existence	Reports of general perceived health status, symptoms of illness, disability [surveys, interviews]
	Evaluated health		The extent to which an individual needs health services dependent on the judgment of professionals	Tests of patient physiology and function, prognosis, diagnosis
	Consumer satisfaction		How individuals feel about the health care they receive	Patient ratings of waiting time, travel time, communication with providers, technical care received [using surveys, interviews]

Note. Adapted directly from Andersen & Davidson, 2001, pp. 4-10.

The *contextual factors* are the conditions of the environment and health care system that influence access and utilization (Andersen, 1995). These factors are measured at some aggregate level in which individuals are members or residents; and the aggregate levels used in Andersen's model range widely from the level of family to the geographical levels of zip code, county and metropolitan statistical area. The *individual factors* are the personal circumstances affecting health care access and utilization and are measured at the individual level. Within the contextual and individual characteristics are *predisposing*, *enabling* and *need* sub-concepts. *Predisposing* characteristics are existing conditions that make people more or less inclined to use health services. *Enabling* characteristics are the "conditions that facilitate or impede" health care utilization (Andersen & Davidson, 2001, p. 4), and *need* characteristics are conditions that are identified by health care providers and/or the patient as conditions that require the use of health services (Andersen & Davidson, 2001).

Within the contextual characteristics, the predisposing variables are the *demographics*, *social characteristics*, and *beliefs* at the contextual level of interest (i.e. family, zip code, county, and etcetera). *Demographics* include the age, gender, and marital composition of the designated area. *Social characteristics* are "how supportive or detrimental the communities where people live and work might be to their health and access to health services" (Andersen & Davidson, 2001, p. 6). They are commonly operationalized as the educational levels, ethnic and racial composition and employment levels of the contextual level of interest. *Beliefs* are the underlying community values and norms regarding health services. The contextual enabling variables are the *health policies*, *financing characteristics*, and *organization* of health services facilities and personnel that can influence health care use. These variables are commonly operationalized as the composition of resources that have

potential to pay for health services and the number and distribution of health care providers, institutions, and services in the contextual level of interest. The need component of the contextual characteristics includes *population health indices*, which are general measures of health at the contextual level of interest, and *environmental indices*, which are measures that reflect how the environment might be affecting health. Andersen has suggested the injury and death rates from occupational injuries, homicides, or motor vehicle accidents and infant mortality and mortality rates for cancer and heart disease at the contextual level of interest as examples of operationalizing the contextual need component (Andersen & Davidson, 2001).

Within the individual characteristics, the predisposing variables include *demographic factors*, such as an individual's age, gender and marital status; *social factors*, including an individual's race, occupation and educational level; and *health beliefs*, which are the attitudes and knowledge that individuals have regarding health and health care. The individual enabling characteristics include *financing* and *organization* of health services. *Financing* is operationalized as the individual resources available for health care services, which is measured by the cost of health services to the patient taking into account the presence of insurance. The *organization* of health services "describes whether or not an individual has a regular source of care and the nature of that source", including means of transportation and travel and waiting time (Andersen & Davidson, 2001, p. 7). The final sub-concept of the individual characteristics is the need component, which includes *evaluated* and *perceived* need. *Evaluated need* is how health care professionals judge an individual's state of health and need for medical care, and *perceived need* is how potential consumers view their present state of health (Andersen & Davidson, 2001).

The Behavioral Model includes two other major concepts. *Health behaviors* are the behaviors of both the individual and the health care professional that influence health status and access to health care. Health behaviors include *personal health services*, the *process of medical care*, and the *actual use of health care services*. *Personal health services* are the health behaviors of the individual, such as the individual's diet and exercise regimen. The *process of medical care* is the behavior of providers, such as their prescribing or referring patterns; and the *use of health services* is whether or not an individual actually draws on health care services. The fourth major concept is the *outcome* of health behaviors, which includes *perceived* and *evaluated health* as well as *consumer satisfaction*. *Perceived health status* is the extent to which a person can live his/her life according to his/her expectations for health and functional status, whereas *evaluated health status* is the extent to which a health care professional judges the health and quality of life of an individual. Finally, *consumer satisfaction* is how individuals perceive the health services they have received (Andersen & Davidson, 2001).

Andersen originally developed this model to both explain and predict utilization. Each component might make an individual contribution to predicting utilization. At the same time, the model suggests a causal order to which the predisposing factors can feed into the enabling factors which then can feed into whether or not a need for health services is defined. For example, the predisposing variables can influence utilization indirectly through their effect on enabling and need variables or they can influence use directly; the enabling variables can influence utilization through the need variables or they can do so directly; and the need variables influence utilization directly. The individual and contextual factors individually and together influence health behaviors, including the actual use of services and

personal health practices, and/or influence other outcomes, such as perceived and evaluated health status and consumer satisfaction. These outcomes (which were not in the original model but were added during the second and third phases of development as recognition that the use of health services and personal health practices had effects of their own) in turn can feed back to the individual factors, demonstrating that health care utilization has effects that can change previous predisposing, enabling, need, and health behaviors. For example, the use of health services may improve health and diminish an individual's need for health care (Andersen, 1995).

Access is a multidimensional, complex concept and is defined as the actual use of health services and everything that supports or hinders utilization (Andersen & Davidson, 2001). At least six different types of access are acknowledged by the Behavioral Model for Health Service Use: *potential* access, *realized* access, *equitable* access, *inequitable* access, *effective* access and *efficient* access. Andersen's Behavioral Model can also be used as a tool to quantify and to identify each type of access through measurement of the other concepts (Andersen, 1974). *Potential access* is indicated by both the contextual and individual enabling factors, whereas more enabling factors increase the possibility that access will occur. *Realized access* is the actual use of services (utilization of services), which is indicated by the use of the health services sub-concept of health behaviors. Equitable and inequitable access are defined by what factors in the model actually determine health services use. *Equitable access* occurs when contextual or individual demographic and need variables determine realized access, and *inequitable access* occurs when contextual or individual social characteristics and enabling resources determine the use of health services. *Effective access* is the use of health services for the best possible results. This type of access is denoted when

the use of health services results in enhanced outcomes such as improved perceived or evaluated health and satisfaction. Finally, *efficient access* is the use of health services in an appropriate and timely manner. Efficient access is indicated when the level of satisfaction or health status in outcomes increases relative to the number or amount of health services attained (Andersen & Davidson, 2001).

Supporting Literature

Many studies that utilize the Behavioral Model support the concepts and relationships set forth by Andersen. For example, Lieu and colleagues (2002) concluded that individual predisposing and enabling characteristics significantly affected health care use, health behaviors and evaluated health status of pediatric patients with asthma. Dobalian, Tsao and Duncan (2004) found that both evaluated and perceived needs were associated with health care use and that the presence of insurance, an individual enabling characteristic, was also significantly related to health care use. Haas and colleagues (2004) described support for the relationship between contextual predisposing characteristics and type of health care access. Another research group concluded that certain individual predisposing characteristics, specifically health beliefs, resulted in decreased health care use (Wallace, Scott, Klinnert, & Anderson, 2004). Hargraves and Hadley (2003) reported that enabling characteristics, specifically health insurance status and income, and predisposing characteristics, specifically demographics, were significantly related to an individual's health care use, health behaviors and organization. In addition, they concluded that contextual enabling characteristics accounted for a moderate portion of the variance in access and utilization. The findings from these studies consistently support the concepts in the Behavioral Model and the linkages between them; but, as Andersen expected, the way in which they interact to predict

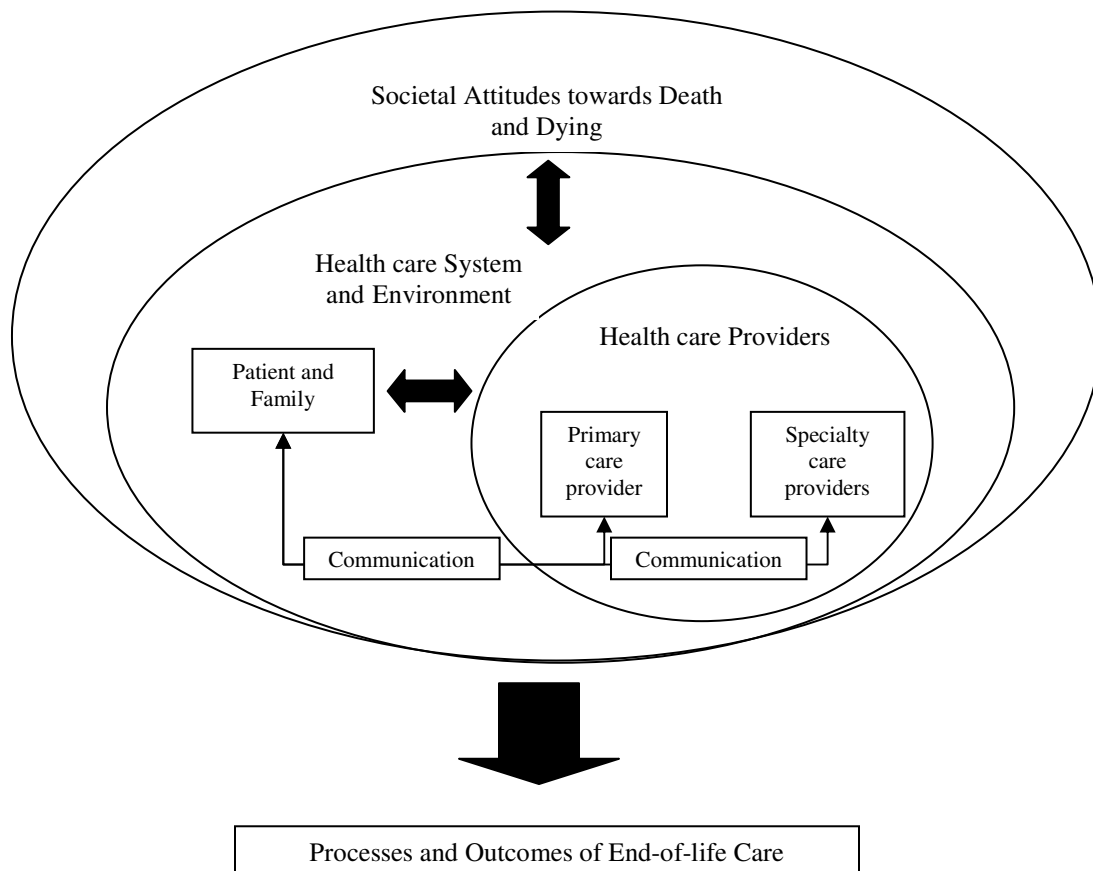
utilization may change according to the health service under study and the variables that represent each concept (Andersen, 1995). For example, one study concluded that HIV-positive subjects with the greatest need for antiretroviral treatments (operationalized as CD4 count) had the *greatest* utilization rates of that treatment (Andersen et al., 2000). In the examination of utilization patterns for children with asthma, however, those with a greater need (operationalized as severity of asthma status) used preventative services *less often* than those categorized with a lesser need (Lieu et al., 2002). Although these findings seem conflicting when considering the relationships between the components of the Behavioral Model, they are not surprising because Andersen expected that the impact of each component would vary when examining different health services (i.e. utilization of antiretroviral medications versus utilization of preventative asthma services).

Conceptual Model of Realized Access to End-of-Life Care

The Conceptual Model of Realized Access to End-of-Life Care (“Conceptual Model”; Figure 2) was developed deductively from the current literature on end-of-life care to explain the interactions between society, health care systems, health care providers, patients and families and their effect on achieving optimal end-of-life care (Yabroff et al., 2004). Optimal end-of-life care is defined as care that “provides patients and their families with sufficient understanding of prognosis, and risks and benefits of treatment to make treatment decisions; leads to the development of clear and informed treatment goals, features service delivery that addresses and is consistent with patient and family goals of care; and emphasizes and promotes quality of life, with practical, emotional and spiritual support, and minimization of symptomatic complaints and distress” (Yabroff et al., 2004, p. 203). The concepts in the model are *society*, the *health care system and environment*, the *health care provider*, the

patient and family, and the *processes and outcomes of end-of-life care*. Each concept is defined in terms of the barriers to optimal end-of-life care that were identified in the literature review (Yabroff et al., 2004). Table 3 displays the variables and the conceptual definitions provided by Yabroff and colleagues.

Figure 2. Conceptual Model of Realized Access to End-of-Life Care



Note. The figure above was adapted from Yabroff et al., 2004.

Table 3. *Concepts and Definitions in the Conceptual Model of Realized Access to End-of-Life Care*

Concepts	Definitions
Society	Societal attitudes towards death and dying
Health care System and Environment	Changes in health care delivery system, cost containment efforts, limited availability of coordinated end of life services, fragmented coverage of end-of-life care by insurers, increased reliance on informal caregiving, regulatory restrictions
Health care Provider	Poor provider-patient communication, under-referral to palliative care specialists and hospice services, limited ability to recognize terminal prognoses and manage symptoms associated with death and dying, lack of training in palliative care
Patient and Family	Ability to confront death, attitudes toward health care, lack of insurance coverage
Processes and Outcomes of End-of-life care	The subjective and objective experiences of individuals, caregivers, and populations and the net effects of health care delivery at the end of life, on the health, well-being, and dying experiences of individuals, caregivers and populations

Note. Definitions taken directly from Yabroff and colleagues (2004) and are defined in terms of barriers to optimal end-of-life care.

Potential *societal* effects on optimal end-of-life care are defined as the societal attitudes towards death and dying. This concept influences all other components in the model, from the health care system to individual patients – and all other components in the model influence this concept. Yabroff and colleagues characterize this concept as being particularly reflected in the mass media representation of death and dying. For example, they found in their literature review that repeated exposure to messages that depict cancer as a saddening illness to be feared and prevented contributes to the fear of a painful death among cancer patients. Additionally, they describe the mass media attention to the debates over physician-

assisted suicide and euthanasia as contributing to the societal expectation that the end of life and death are painful and uncomfortable. Perhaps most importantly, advanced medical technology, particularly the notion that advanced medical care is always appropriate, is viewed as a societal barrier to optimal end-of-life care and has led to a general misunderstanding and lack of awareness of the utility of palliative and comfort care treatments at the end of life (Yabroff et al., 2004).

According to the Conceptual Model, factors affecting optimal end-of-life care at the *health care system* level are numerous. Fragmentation of care at the end of life, both in the coordination of services for end-of-life care and in the disorganization of covered services for end-of-life care by insurance organizations, including Medicare, contribute to suboptimal end-of-life outcomes (Yabroff et al., 2004). Patients at the end of life often see many different health care professionals in many different settings, and coordination of care across these settings is complex and often overlooked (Lynn, 2004). Additionally, the inability of the formal health care system to accommodate the increasing number of people at the end of life who need care (which is itself a barrier) has placed unpaid family caregiving as an essential element of the delivery system and has contributed to the complexity in maintaining continuity of care, as well as in the provision of adequate care for complex patients (Lynn, 2004; Yabroff et al., 2004). The availability of palliative care experts in acute care and long term care settings is also less than sufficient to cover the number of patients who could benefit from such services. However, even when those services are available, other barriers become evident. For example, certain characteristics of hospice, which is the only organized end-of-life care system in the current reimbursement system, also contributes to the barriers to optimal end-of-life care at the health care system level. The eligibility restrictions

requiring patients to reject all life-sustaining treatments, even if they can sometimes be considered palliative, and to have a prognosis of less than 6 months, which is often difficult to estimate, represent barriers to optimal end-of-life care at the health care system level. The semi-capitated reimbursement system associated with most payers of hospice services also creates numerous financial barriers for hospice organizations to manage the care of terminal patients, thereby enhancing the difficulties represented by the hospice eligibility requirements.

The effects of the *health care provider* on optimal end-of-life care are well-documented in the literature. Many problems associated with barriers to end-of-life care at the health care provider level are associated with the physician because the physician is often considered the “gate-keeper to end-of-life services” (Yabroff et al., 2004, p. 206). Research indicates that many health care providers feel uncomfortable regarding care for the terminally ill; and much of this discomfort has been associated with a lack of training and education (Robinson et al., 2004). An overwhelming 67% of medical school deans support the accounts of medical students and resident physicians in their report that inadequate time is spent on end-of-life and palliative care in the current curriculum (Sullivan et al., 2004), and only four of 126 medical schools report offering a palliative care course for students (Porter-Williamson et al., 2004). While all 122 medical schools surveyed in a recent study report offering something on death and dying, the average number of hours spent on the subject in the entire curriculum was less than 12 hours. Interestingly, these medical schools also reported a heavy reliance on other disciplines, mainly nursing, to help with teaching end-of-life issues (Dickinson, 2007). An older study examining the end-of-life content in medical textbooks found that the vast majority of textbooks used by medical students and practicing physicians have little to no

information concerning end-of-life care; when the information is present, it is rarely helpful (Carron, Lynn, & Keaney, 1999).

Additionally, the ambiguities of non-cancer disease trajectories make it difficult for physicians to judge prognoses adequately enough for end-of-life care planning, and their prognostic estimates are usually overly optimistic (Christakis & Lamont, 2000; Mackillop & Quirt, 1997; Stuart, 1999; Teno & Coppola, 1999). Thus, patients are often referred for end-of-life care services too late for optimal care delivery to be possible, if they are even referred at all. For example, although patients may receive hospice services when they are expected to expire within 6 months, in 2006 the median length of stay for hospice care was only 20.6 days ("NHPCO Facts and Figures: Hospice Care in America," 2007). In 2003, close to 40% of hospice patients died within one week of admission (*Hospice Facts and Figures*, 2003), while 10% died on the same day of admission (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). These outcomes are often associated with physician reluctance to refer patients, lack of physician knowledge of hospice services, and physician discomfort with initiating conversations with their patients regarding death and dying (Yabroff et al., 2004).

Influential components of optimal end-of-life care at the *patient and family level* include the patient and/or family's ability (or inability) to accept a terminal prognosis and confront death and their attitudes towards health care. Although these patient and family characteristics may be influenced tremendously by the societal and health care provider barriers already discussed, the desire to continue with aggressive, curative treatments at the end of life is considered a critical issue at the patient and family level and represents a major barrier to optimal end-of-life care. Additionally, fears of being over-medicated or addicted to pain medications and a general mistrust of the health care system and/or of health care

providers constitute disadvantages within the processes and outcomes of end-of-life care. The inability to pay for health care services due to lack of insurance or under-insurance limits patient accessibility to many health care services and may lead to patients avoiding health care assistance at the end of life (Yabroff et al., 2004). On a similar note, lack of insurance is a large factor in the movement towards family caregiving, which results in numerous financial burdens for the entire family system (Lynn, 2004).

Processes are “the subjective and objective experiences of individuals, caregivers, and populations” and *outcomes of end-of-life care* are “the net effects of health care delivery at the end of life, on the health, well-being, and dying experiences of individuals, caregivers and populations” (Yabroff et al., 2004, p. 207). These components were purposefully included to make the Conceptual Model useful in measuring “realized” access to optimal end-of-life care services and all of its components. For example, Yabroff and colleagues (2004) recommend using patient and family self-report, as well as medical records, as evidence of accurate communication about prognosis (process) and patient and family satisfaction with provider communication about prognosis (outcome), both of which are considered essential elements for optimal end-of-life care.

A Combined Approach: Behavioral Model of Hospice Use

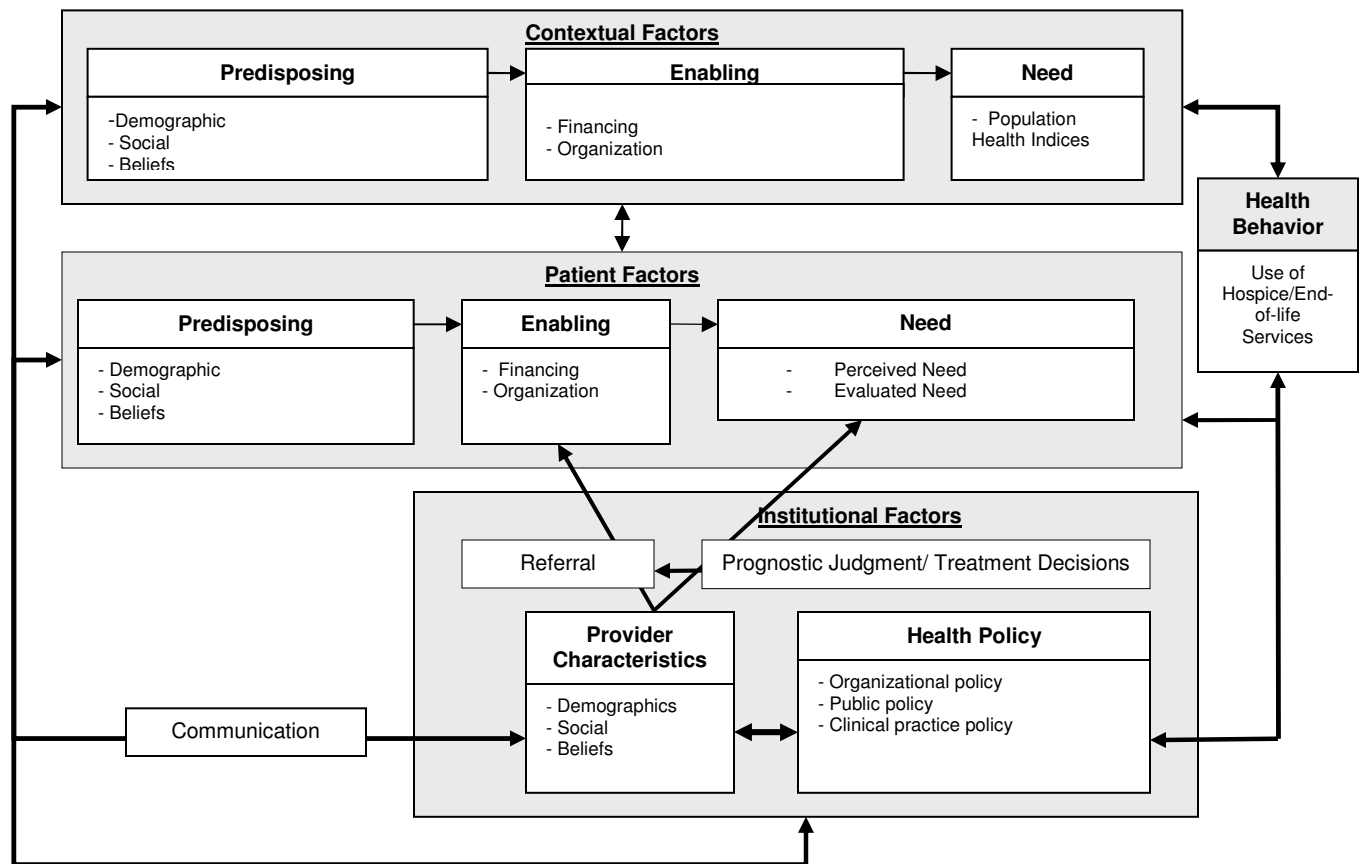
While Andersen’s Behavioral Model of Health Services Use has been widely used in the health care access and utilization literature and is well-supported, it was not developed with end-of-life care services in mind. Using this model to study end-of-life care, particularly hospice utilization, is complex because of the terminal nature of hospice users and the obvious methodological issues in end-of-life care research, such as the inability to measure satisfaction and perceived health status among deceased patients (Fowler, Coppola, & Teno,

1999). Therefore, operationalizing the outcomes variable in the Behavioral Model for end-of-life research is not especially realistic. On the other hand, while the Conceptual Model for Realized Access to End-of-life Care has not been used in any known published studies, it was developed deductively from a large literature base in end-of-life care. Two of the major advantages of the Conceptual Model are that it simplifies the Behavioral Model by focusing solely on Andersen's definition of *realized access*, or the actual utilization of services, and that it is specifically intended for the study of the provision of optimal end-of-life care. This model highlights important aspects of end-of-life care delivery that were discussed previously, including the emphasis of the role of the health care system and the health care provider in the processes and outcomes of end-of-life care and the description of optimal end-of-life care as the outcome of interest (Yabroff et al., 2004). A disadvantage of the Conceptual Model, aside from the lack of empirical evidence supporting the model, is that concepts are defined more conceptually than operationally, even though the intent of the model was to be used to measure barriers to optimal end-of-life care.

Thus, a new model was constructed using the above two described models. The model developed for this study, while mostly influenced by the Behavioral Model, is an integration of both the Behavioral Model and the Conceptual Model. The final model emphasizes the influence of individual, contextual and institutional factors, including the role of the provider and health policy, on hospice use. Contextual and individual factors were taken directly from the Behavioral Model. The outcome, optimal end-of-life care, was taken from the Conceptual Model. As discussed in Chapter I, much supportive evidence exists for the efficacy of hospice in providing high quality end-of-life care. Thus, the outcome in the new model is defined as the health behavior of hospice use. Figure 3 illustrates the model, termed the

Behavioral Model of Hospice Use (“Hospice Model”), with its concepts. The following sections provide a description of each concept and the literature supporting their inclusion in the new model; and Table 4 displays a summary of the concepts, sub-concepts, definitions and suggested operationalization of each concept.

Figure 3. Behavioral Model of Hospice Use



Note. Health behavior is the outcome.

Table 4. *Concepts, Definitions and Common Examples of the Behavioral Model of Hospice Use*

Concepts	Sub-concepts		Definitions	Common Examples
Contextual Factors	Demographics			Age, gender
	Predisposing	Social	How supportive or detrimental the community where people live and work are to their health and use of services ^a	Educational and employment levels, crime rates, racial and ethnic composition, proportion of recent immigrants, cultural prevalence, social network structures, marital composition
		Beliefs	Underlying community or organizational values and cultural norms and political perspectives regarding how health services should be organized, financed, and made accessible to the population ^a , as well as underlying values and beliefs regarding death and dying	[Using surveys, interviews; studying mass media communications]
	Enabling	Financing	Characteristics that reflect the amount and availability of resources available for health care use ^a	Income distribution per capita, rate and type of health insurance coverage in a community
		Organization	The amount and distribution of health services facilities and personnel as well as how they are structured ^a	Ratios of physicians (primary care and specialty), hospital beds, nursing home beds to the populations; number of hospital deaths in a given area; the number of inpatient hospice beds; the extent of service areas of local hospices
	Need	Population health indices	General indicators of community health ^a	Number of cancer vs. non-cancer diagnoses and deaths per capita; morbidity and mortality rates for the top hospice diagnoses; prevalence of terminal diagnoses
Individual Factors	Demographics			Age, gender, diagnosis
	Predisposing	Social	Characteristics that determine an individual's status in a community ^a and affect his/her ability to cope with death and dying	Education, race/ethnicity, occupation (of patient and caregiver), social network/social support system of the individual, marital status, communication
		Beliefs	Attitudes, values and knowledge ^a people have about health, health services, and death and dying that can influence their subsequent perception of need and use of health services	[Using surveys, interviews]
	Enabling	Financing	The income, wealth and resources of the individual to pay for/utilize services ^a	Health insurance status, wealth, income, referral status
		Organization	Whether or not the individual has a usual source of care and the nature of that source ^a	Source of care or source of referral (ED vs. private physician), means of transportation, travel time to health care resources in general and to hospice agencies
	Need	Perceived	How a patient views his/her health as it relates to quality of life and potential for death	Individual ratings of QOL and functional status, individual view of terminality of current health state
		Evaluated	The health care professional's judgment that death is approaching and that palliative care services are necessary	Prognostic judgment/treatment decisions, provider evaluation of patient QOL and functional status
Institutional Factors	Demographics			Age, gender
	Provider Characteristics	Social	How supportive or obstructive the physician is of end of life and palliative care services	Education, training, experience, race/ethnicity, physician's workplace, communication
		Beliefs	Attitudes, values and knowledge that the physician has regarding palliative care, death and dying, and hospice services	[Using surveys, interviews]
	Health policy	Organizational Policy	Authoritative decisions pertaining to health services or influencing the pursuit of health services	Comparing and contrasting organizational structures of different hospice/palliative care agencies
		Public Policy		Comparing and contrasting policies and regulations in different markets
		Clinical Practice		Comparing and contrasting different practice methods and ideologies between disciplines and specialties

Note. Table was published previously in Forcina Hill, 2008, pp.244-245.

^aDefinitions taken from Andersen & Davidson, 2001, pp.4-10.

Contextual and Individual Factors

As stated, contextual and individual factors in the Hospice Model were primarily influenced by the Behavioral Model of Health Services Use and are defined as they are defined by Andersen and Davidson (2001, p. 4):

1. Existing conditions that predispose people to use or not use services even though these conditions are not directly responsible for use;
2. Enabling conditions that facilitate or impede the use of services; *and*
3. Need or conditions recognized by lay people or health care professionals as requiring medical treatment.

The characteristic that differentiates these two major concepts is that contextual factors are concerned with the environment and circumstances surrounding health care access and use, while individual factors are concerned with individual characteristics that affect health care access and use. Additionally, the contextual factors are measured at some aggregate level, which can range from the individual's residential community to the individual's immediate family, while the individual factors are measured at the individual level.

Contextual Predisposing Factors. Similar to the definition in the Behavioral Model, the contextual predisposing factors in the Hospice Model are those factors of the environment that predispose people to utilizing hospice services. Andersen divides the contextual predisposing factors into *demographic characteristics*, *social characteristics* and *beliefs*. *Demographic characteristics* are the age and gender of a given area (Andersen & Davidson, 2001). *Social characteristics* are "how supportive or detrimental the communities where people live and work might be to their health and access to health services," (Andersen & Davidson, 2001, p. 6) and are often operationalized as the educational and employment

levels, crime rates, racial and ethnic composition, proportion of recent immigrants in a community and cultural prevalence and social network structures (Andersen, 1995; Andersen & Davidson, 2001). *Beliefs* are the underlying values and cultural norms in a given community (Andersen & Davidson, 2001). Beliefs are difficult to measure and may not be as important in predicting use as the other predisposing characteristics (Andersen, 1995).

Regardless, all of these characteristics are considered relevant to the study of hospice use. Although thus far no published studies have specifically examined contextual predisposing factors as they are associated with hospice use, variation in health care utilization in general across these factors has been well documented. This variation is likely to persist across all types of health care, including hospice services.

Demographically, the age and gender characteristics of a given community may affect the rate of hospice use in that community. For example, because the risk of morbidity and mortality increases with age, it might be hypothesized that areas with greater numbers of elderly inhabitants would have higher rates of hospice use. Similarly, because being female has been shown to negatively affect hospice use (Greiner et al., 2003), it might be hypothesized that areas with a greater number of females would have lower rates of hospice use.

Socially, rates of health care use have been shown to vary with the racial and ethnic composition of a community. For example, the degree of racial segregation in an individual's residential community has been shown to affect health and health care practices (Arcury et al., 2005; Fang, Madhavan, Bosworth, & Alderman, 1998; Haas et al., 2004; Hart, Kunitz, Sell, & Mukamel, 1998; S. A. Jackson, Anderson, Johnson, & Sorlie, 2000; Polednak, 1996). Members of the dominant racial or ethnic group in a given zip code area of New York City

were found to experience less all-cause and cardiovascular mortality than individuals in the same zip code who were in the minority (Fang et al., 1998). Using a nationally representative sample of U.S. households, Haas and colleagues (2004) found that Blacks reported fewer barriers to obtaining any type of health care or prescription medication when they lived in counties with a higher prevalence of Blacks. A similar finding was reported for Latinos: Latinos living in counties with a higher prevalence of Latinos reported less difficulty obtaining any type of health care they thought they needed than Latinos living in counties with a lower prevalence of Latinos (Haas et al., 2004). Because these findings have been consistent in the health care access literature and considering that lack of cultural diversity is a commonly reported barrier to hospice use (Doorenbos, 2003; Gelfand et al., 2004; F. Jackson et al., 2000; Reese et al., 1999), the racial and ethnic composition as well as the degree of residential segregation of an individual's geographic residential community may affect rates of hospice use. Because hospice is used much more by Whites than any other racial and ethnic group, minorities living in areas dominated by Whites might have more familiarity with hospice services and thus utilization could be higher. This hypothesis is supported in one recently published study. A retrospective analysis of over 70,000 Medicare beneficiaries with cancer resulted in the finding that hospice services were most commonly used by patients who lived in areas with fewer minority residents. They also concluded that racial and ethnic minorities were less likely to use hospice services if they lived in an area with higher concentrations of minorities (Haas et al., 2007).

Other social characteristics, such as the proportion of recent immigrants, crime rates, and educational and employment levels in a community, are also understudied as potential covariates of hospice use. However, these characteristics are closely tied to a community's

socioeconomic status, which is often associated with disparities in health care use in general (LaVeist, 2005). Additionally, the marital composition of a given community, although considered a demographic variable in the Behavioral Model (Andersen & Davidson, 2001), is considered a social variable in the Hospice Model. This change was made after consultation with Andersen (R.M. Andersen, personal communication, November 14, 2006) because the presence of others in the household to provide supportive services is particularly important for home hospice use and would therefore be considered more of a social variable than a demographic variable in the Hospice Model.

In the Behavioral Model, the contextual *beliefs* are closely tied to the societal attitudes towards death and dying included in the Conceptual Model. In general, American society has become accustomed to the idea that the physical body remains in relatively good condition for a very long time so much so that the loss of physical life is difficult to contemplate. Historically, death was often considered a part of life; and most deaths occurred rather quickly (Kalish, 1969). However, in the modern world of medicine, death is often a slow, drawn-out process that results after a “fight” with terminal illness. Fewer people die at home than ever before, and fewer people have had hands-on experience with death and dying. This new culture of dying is considered responsible for making death unknown and feared to many people, which subsequently leads to an overall feeling of death denial and death anxiety (Hallenbeck, 2003). In a qualitative study of 20 brain tumor patients and their next of kin, researchers found that almost all patients and their loved ones were preoccupied with death and fear of dying (Adelbratt & Strang, 2000). Perhaps this overall fear of death is why almost half of patients in one national study have reported that they do not want the responsibility to make their own end-of-life decisions (Hopp, 2000). Death denial and

anxiety in present-day society also maintain a notable presence (Byock, 1997; Nuland, 1993). Because one component of utilizing hospice is accepting the terminality of life, it is likely that this societal attitude affects hospice utilization. Thus, measures of community beliefs regarding death and dying are considered important variables in the Hospice Model.

Contextual Enabling Factors. Similar to the contextual enabling factors in the Behavioral Model, the contextual enabling factors in the Hospice Model are those environmental or circumstantial factors that facilitate or impede hospice use. Andersen and Davidson (2001) describe three different types of contextual enabling factors: *health policy*, *financing* and *organization*. *Health policy characteristics* are the legislative, judicial and/or executive decisions made that influence health and health care access and utilization in a given area. The decisions made by authorities regarding the marketing and pricing of health care services, as well as governing regulations set up by accrediting agencies are all considered health policy factors (Andersen & Davidson, 2001). However, in the Conceptual Model, health policy characteristics are described as more of an institutional factor than an environmental factor. For the Hospice Model, health policy characteristics are also considered an institutional factor as opposed to a contextual enabling factor. This decision was reached because changes in the health care delivery, cost containment efforts, limited availability of coordinated end-of-life services, fragmented coverage of end-of-life care by insurers, increased reliance on informal caregiving and regulatory restrictions are all related to health policy and arise contextually. More specifically they are also all issues that arise from the contextual health care system and, therefore, make conceptual sense under the institutional factors in the Hospice Model.

According to Andersen and Davidson (2001), *financing characteristics* are those characteristics that reflect the amount and availability of resources available for health care use in a given area. As described in Chapter I, certain financing characteristics have been explored as they pertain to hospice use. For example, the income distribution and the rate and type of health insurance coverage in a given area have been shown to affect the rate of hospice use in that area. These factors have also been well-documented in the general health care access literature. Studies of health and health services use have found that the concentration of poverty, wealth and insurance coverage, and the relative cost of medical equipment and services are associated with individual health, health care access and use (Arcury et al., 2005; Fang et al., 1998; Goodman, Fisher, Stukel, & Chang, 1997; Hargraves & Hadley, 2003; Klick & Satel, 2006, February 22; Nemet & Bailey, 2000; Ricketts, Savitz, Gesler, & Osborne, 1994; Waitzman & Smith, 1998). Among a nationally representative sample of 96,414 non-elderly persons, the income and insurance coverage rates of the population in a certain geographic area were a greater factor in health care use than the availability of health care services and providers (Hargraves & Hadley, 2003). Additionally, these factors may affect the general morbidity and mortality rates in a given area (Lynch et al., 1998; Shi et al., 2005), which could consequently affect the rates of hospice use in that area. For example, one study reported that counties with high income inequality had 11-13% greater mortality than counties with less inequality (Shi et al., 2005), which could possibly affect the rate of hospice utilization in those counties.

In the Behavioral Model, *organizational factors* are “the amount and distribution of health services facilities and personnel as well as how they are structured” (Andersen & Davidson, 2001, p. 6). As discussed in Chapter I, rates of hospice use are positively

associated with higher ratios of physicians and negatively associated with the number of hospital beds per capita and number of hospital deaths (Pritchard et al., 1998; Virnig et al., 2000). One study also found that individuals living in rural counties were more likely to use hospice services when available than individuals living in more populated counties (Iwashyna et al., 2002), suggesting that the availability of other health care resources in a given area could affect the utilization of hospice services. In the health services literature, it is evident that other organizational factors, particularly the supply of certain types of physicians, affect health and health services utilization. For example, researchers have found that counties with more primary care physicians have lower all-cause and heart disease mortality rates, regardless of socioeconomic and demographic characteristics; but counties with higher specialist to population ratios generally have higher mortality rates after risk adjustment (Starfield, Shi, & Macinko, 2005). In addition, the supply of primary care physicians in a given area has been shown to be associated with the reduction of racial disparities for specialty referral-sensitive procedures (Basu & Clancy, 2001). If the supply of certain types of physicians in a given area affect health and specialty referral, then it is possible that the supply of certain types of physicians in a given area also affect hospice referral and subsequent use. Thus, the contextual predisposing factors in the Hospice Model include both organizational factors and financing factors. These factors can be operationalized in several ways including, but not limited to, the income distribution of the population in a given area, the rate of health insurance coverage in a given area, the number of physicians per capita, the ratios of hospital beds to the population, the geographical locations of hospice services, the availability of inpatient versus outpatient hospice services and the extent of the service areas of local hospice agencies.

Contextual Need Factors. The contextual need factors in the Hospice Model are the health-related measures of the environment that may affect the utilization of hospice services. In the Behavioral Model, Andersen dichotomizes the contextual need factors into *environmental need* and *population health indices*. *Environmental need characteristics* are those that are related to the general health status of the environment, including the quality of air, water and housing as well as the rates of homicide, motor vehicle accidents, and occupational deaths (Andersen & Davidson, 2001). While environmental characteristics such as these may contribute to an ultimate terminal diagnosis in some circumstances, these characteristics are not considered particularly relevant to the Hospice Model for 2 reasons: 1) because the model is not designed to predict or prevent terminal diagnoses; and 2) because the majority of the above environmental characteristics (such as homicide, motor vehicle accident, etcetera) would result in a sudden or unexpected death that would make hospice utilization unrealistic and impractical. However, *population health indices*, which are more general indicators of health in a given community, have potential to affect the rate of hospice utilization in a community. For example, hospice use has been shown to be higher in areas with a high proportion of non-cancer diagnoses among hospice users and in areas with a higher concentration of cancer deaths (Iwashyna et al., 2002; Virnig et al., 2000). This is perhaps due to the fact that the majority of hospice users have a cancer diagnosis (as compared to other diagnoses categorized separately, not as compared to all non-cancer diagnoses grouped into one category). Thus, an increase in the number of hospice users with a non-cancer diagnosis and the number of deaths related to cancer in a given area may directly increase the overall rate of hospice use. Based on these findings, the contextual need factors in the Hospice Model are defined as population health indices and can be

operationalized as the number of cancer versus non-cancer diagnoses in a given area, the mortality rates for the top hospice diagnoses, or the prevalence of terminal diagnoses in a given community.

Individual Predisposing Factors. The individual predisposing factors in the Hospice Model are, similar to Andersen's Behavioral Model, the characteristics of the individual that predispose an individual to utilizing hospice services. These factors are divided into *demographic characteristics*, *social characteristics*, and *health beliefs* (Andersen & Davidson, 2001). *Demographic characteristics* represent the "biological imperatives suggesting the likelihood that people will need health services" (Andersen & Davidson, 2001, p. 7) and are often operationalized as the age and gender of an individual. As described in Chapter I, hospice use has been shown to vary across age and gender (Berry et al., 1994; Greiner et al., 2003; Iwashyna et al., 2002). Diagnosis is not specifically addressed by Andersen in the Behavioral Model as a predisposing demographic characteristic. However, it is considered an important factor that may also predispose individuals to seeking and utilizing hospice; and the current literature on hospice utilization supports including diagnosis as an individual predisposing characteristic in the Hospice Model. As discussed in Chapter I, almost half of all hospice patients have a cancer diagnosis ("NHPCO Facts and Figures," 2004), and having a cancer diagnosis and higher comorbidity scores have been identified as positive predictors of hospice use (Greiner et al., 2003; Iwashyna et al., 2002).

In the Hospice Model, *social characteristics*, similar to Andersen's description in the Behavioral Model, are those characteristics that determine an individual's status in a community and affect his/her ability to cope with death and dying. These characteristics are generally operationalized by measuring an individual's education, race/ethnicity, occupation

and an individual's social network or social support system (Andersen & Davidson, 2001). Supporting the inclusion of these variables in the Hospice Model, Greiner and colleagues (2003) found that having some college education and high levels of social support, operationalized by measuring the frequency of visits and telephone calls from friends and family, were positively associated with hospice utilization. Additionally, it is well documented in the literature (and described in depth in Chapter I) that hospice use varies significantly among different races and ethnicities. While no studies have examined the potential impact of an individual's occupation on hospice use, perhaps because it is likely that many terminal patients are no longer actively in the workforce, the occupational status of the patient's family caregiver may have a significant impact on hospice use. Yabroff and colleagues (2004) touch on this potential factor when they highlighted the issues associated with the increase in the use of informal caregivers. Many hospice organizations, particularly home hospice agencies, require the presence of a 24-hour caregiver in the home in order to utilize their services. If a caregiver has a flexible work schedule or is not working outside the home, then utilizing home hospice services is not as invasive as it would be for a caregiver who works full-time outside the home. Similarly, the individual's marital status may be an important factor on hospice use. The National Mortality Followback Survey found that being married was positively associated with hospice use (Greiner et al., 2003), suggesting that perhaps married individuals are better equipped or more apt to support each other in the process of death and dying, thus possibly reflecting the social support system of an individual. Although marital status is considered an individual *demographic* characteristic in Andersen's Behavioral Model (Andersen & Davidson, 2001), it is considered an individual *social* characteristic in the Hospice Model. Andersen states that "if the key issue is having the

presence of others in the household” (as in the case of home hospice use), then marital status could be regarded as a measure of the social variable for an individual (R.M. Andersen, personal communication, November 14, 2006).

Health beliefs are the “attitudes, values and knowledge people have about health and health services that can influence their subsequent perception of need and use of health services” (Andersen & Davidson, 2001, p. 7). According to the Contextual Model, a patient’s attitude and value system regarding death and dying and the health care system can greatly affect their use of palliative care services (Yabroff et al., 2004). Very few studies have examined health beliefs in terms of their impact on the actual utilization of hospice services. However, studies aimed at better understanding the under-utilization of hospice services, particularly among racial and ethnic minorities, have found that attitudes towards medical care and knowledge and awareness of hospice services may be significant contributors to the decision to use hospice services. A recent qualitative study with Black participants found that a lack of information and resultant assumptions regarding hospice and the importance of family and religion were strong influences in shaping end-of-life care choices (Taxis, 2006). Even in the White population, knowledge of hospice services could reportedly benefit from improvement. A study utilizing focus groups of bereaved family members of hospice patients found that participants wanted to facilitate the dissemination of knowledge regarding the availability of hospice (Burrs, 1995). Additionally, the role of spirituality in the patient’s life is considered part of the beliefs sub-concept. Spirituality has been shown to predict peacefulness at the end of life (Kruse, Ruder, & Martin, 2007), and patients at the end of life who report not having their spiritual needs met have reported lower satisfaction with their care (Astrow, Wexler, Texeira, He, & Sulmasy, 2007). Thus, an individual’s attitude, values

and knowledge regarding end-of-life care, while difficult to measure, are all considered major components of the individual predisposing factors in the Hospice Model.

Individual Enabling Factors. In Andersen's Behavioral Model, the individual enabling factors are the variables that facilitate or impede health care utilization. Andersen and Davidson (2001) describe these factors as *financing characteristics* and *organizational characteristics*. Both of these characteristics are considered important aspects of the Hospice Model as well. *Financing characteristics* are the individual's wealth and income that are potential resources for health services (Andersen & Davidson, 2001). An individual's resources, particularly health insurance status, have been shown to affect hospice use. For example, having higher annual income (greater than \$25,000) was positively associated with hospice use in the National Mortality Followback Survey study; and not having health insurance and not owning a home were negatively associated with hospice use in similar study (Greiner et al., 2003). Similarly, those who qualified for Medicaid, which, although understudied, offers the same hospice coverage as Medicare in most states and is often reflective of an individual's socioeconomic status, have been shown to have lower rates of hospice use (Iwashyna et al., 2002). It is also important to note in the Hospice Model that referral, while initiated as an institutional factor, is considered as individual enabling characteristic, as patients can not utilize hospice services without being referred, whether they refer themselves or are referred by a family member or health care provider (although they still need physician approval, regardless of referral source).

Organizational characteristics describe "whether or not the individual has a regular source of care and the nature of that source" (Andersen & Davidson, 2001, p. 7). Studies from the health care access literature have shown that people who do not have a usual source

of care are less likely to utilize beneficial health services and preventative services, which could lead to poorer health (DeVoe, Fryer, Phillips, & Green, 2001; Roberts, 2006).

Additionally, the relatively high mortality rates among Black women with breast cancer is thought to be at least partially associated with not having a usual source of care (Blackman & Masi, 2006). Hispanics are twice as likely as Whites to lack a usual source of care, and Hispanics are more likely than Whites to report having difficulty accessing specialty care (Weinick, Zuvekas, & Cohen, 2000). However, no known studies have examined whether an individual's usual source of care – or the nature of that source - is specifically associated with hospice. Because of the potential relationship between usual source of care and hospice utilization, organizational characteristics are still considered essential components of the Hospice Model, particularly when examining hospice disparities among racial and ethnic minorities. The patient-provider relationship and the communication that occurs between the patient and the provider are emphasized in the Conceptual Model as important aspects for achieving optimal end-of-life care. Individuals who do not have a usual source of care or whose usual source of care is an emergency room may miss the opportunity to develop good rapport and trusting relationships with their health care providers. The lack of opportunity to develop this kind of relationship with a health care provider has great potential to affect an individual's use of hospice services. Thus, an individual's usual source of care and the nature of that source are considered important elements of the organizational characteristics in the individual enabling factors of the Hospice Model.

Additionally, Andersen (2001) recommends including means of transportation and distance to and from medical care as potential predictors of health care use. While this aspect of organizational characteristics has not been examined specifically in the hospice utilization

research, the finding that individuals in rural areas have higher hospice utilization rates when available than individuals in more densely populated areas (Iwashyna et al., 2002) offers some support for including these characteristics in the Hospice Model. One explanation of this finding is that most hospice services are received by a patient in that patient's home. Thus, no travel is required for the individual or caregiver and distance to and from the agency may not be relevant. Nevertheless, distance to and from a hospice provider is relevant when examining inpatient hospice use; and distance to and from medical care in general is important when examining any kind of hospice use, as the lack of availability of acute care facilities may have an effect on the rates of hospice utilization. In the health services access literature, researchers have supported the hypothesis that distance to and from health services and providers affects utilization among rural residents and, more specifically, among rural elderly (Arcury et al., 2005; Fiedler, 1981; Nemet & Bailey, 2000). The empiric evidence supporting the potential influence of travel time and means of transportation in the use of health services provides more support for inclusion of the organizational characteristics in the individual enabling concept of the Hospice Model.

Individual Need Factors. The individual need factors are the conditions recognized by individuals that are important for deciding to seek and/or use hospice care. In the Behavioral Model, Andersen and Davidson (2001) identify two different kinds of individual need: *perceived* and *evaluated*. *Perceived need* is how individuals consider their own health status and need for care, and *evaluated need* is how health care professionals view an individual's health status and need for care (Andersen & Davidson, 2001). In the Hospice Model, perceived individual need is how a patient views his/her health as it relates to quality of life and potential for death. Perceived need is difficult to measure in the hospice population

because of their terminal and often fragile states. However, if an individual views their prognosis as terminal and perceives a need for support at the end of life, then hospice services might be utilized. Evaluated need, on the other hand, is the health care professional's judgment that death is approaching and that palliative care services are necessary. In the Conceptual Model, Yabroff and colleagues (2002) emphasize the importance of evaluated need, stating that a health care provider's accurate prognostic judgment is an essential component of the processes and outcomes of end-of-life care. Thus, in the Hospice Model, the evaluated need component is directly affected by the provider's prognostic judgment and any treatment decisions made by the patient and/or provider because receiving treatment likely influences prognosis. In other words, if a provider deems a patient to have more than 6 months to live (or believes a certain treatment he/she is receiving will extend the prognosis greater than 6 months), then he/she would not consider that patient to have a need for hospice services. In summary, both perceived and evaluated needs are included in the Hospice Model because of the supporting evidence that may impact hospice use.

Institutional Factors

While the contextual and individual factors were primarily influenced by Andersen's Behavioral Model of Health Services Use, the inclusion of institutional factors in the Hospice Model was influenced primarily by the Conceptual Model of Realized Access to End-of-Life Care. The institutional factors emphasize *provider characteristics* and *health policy characteristics*.

Provider Characteristics. The inclusion of provider characteristics as an institutional factor in the Hospice Model was influenced mainly by the Conceptual Model as well as by the general health care access and utilization literature. Lack of physician referral is a

frequently cited barrier to hospice use (Born et al., 2004; Gelfand et al., 2004; F. Jackson et al., 2000); and, as previously discussed, admission to hospice requires a statement by two physicians that the patient has 6 or fewer months to live. Thus, similar to the Conceptual Model, the physician is considered the gatekeeper to hospice in the Hospice Model (Yabroff et al., 2004). Physician characteristics can affect an individual's use of hospice through their communication with the patient, from their referral to hospice services, and by their evaluation of the patient's health status, prognosis and eligibility for treatment. Similar to the predisposing individual and contextual factors in the Behavioral Model, the provider characteristics are divided into three aspects: *demographics*, *social characteristics* and *beliefs*. The provider *demographics* are the age and gender of the physician. No known studies have examined the effects that a provider's age and gender have on hospice use or on health care use in general. However, these demographics are still incorporated into the Hospice Model for a few reasons. First, it is possible that a provider's age reflects his/her education, experience, and training in palliative care; particularly because medical education in palliative care has improved over time. Older physicians could also have more personal experience with death and thus more familiarity with hospice services or improved comfort with discussions regarding death and dying. Additionally, because gender is an individual predictor of hospice use (Greiner et al., 2003), it is possible that views on death and dying or roles in society are inherent in gender roles and might affect hospice utilization rates.

The *social characteristics* describe how supportive or obstructive the physician is of end-of-life and palliative care services, and this includes the resources that a provider has to care for individual patients. Although scant research has been conducted on physician factors associated with hospice utilization, social characteristics of the provider, such as training,

education, experience and race/ethnicity, are potential influences. For example, as discussed in Chapter I, the providers' board status certification, specialty, and experience with terminally ill patients have been associated with rates of hospice referral. None of these studies, however, examined how these characteristics affect the actual utilization of hospice after a referral was made. Because physicians with more hospice and end-of-life care experience may initiate a referral differently or have more accurate prognostic judgment than physicians who have little or no hospice experience, the training and experience of physicians may not only affect hospice referrals but may also affect hospice use following referral.

Additionally, the race and ethnicity of a provider may greatly affect how an individual patient utilizes health care services. Studies have found that, in general, patients prefer to be cared for by providers of similar appearances and cultural backgrounds (Bach, Hoangmai, Schrag, Tate, & Hargraves, 2004; Libby, Zhou, & Kindig, 1997; Saha, Taggart, Komarony, & Bindman, 2000). Black patients are more likely than Whites to visit Black physicians, and Hispanics tend to seek care from providers of their own ethnicity, regardless of geographic accessibility (Bach et al., 2004; Saha et al., 2000). Patients who are treated by physicians of the same race and ethnicity as themselves report higher satisfaction with their provider than patients treated by racially or ethnically different physicians (Gamst et al., 2003; Laveist & Nuru-Jeter, 2002). If race and ethnicity represent an individual's cultural beliefs, this suggests that the cultural match between patient and provider has a strong impact on the utilization of health care services and may affect the ability of providers to establish meaningful relationships, trust, and rapport with their patients, which are particularly important in the provision of end-of-life care (Lynn et al., 2000). Although mistrust in the

health care system (Born et al., 2004; Gelfand et al., 2004; F. Jackson et al., 2000; Reese et al., 1999) and lack of diversity among health care workers (Doorenbos, 2003; Gelfand et al., 2004; F. Jackson et al., 2000; Reese et al., 1999) are frequently cited barriers to hospice use, the impact of racial and ethnic concordance between patient and provider on hospice use has not been studied. Therefore, the education, training and experience of health care providers, as well as the race and ethnicity of providers, are considered essential elements of provider social characteristics in the Hospice Model.

Beliefs are the attitudes, values and knowledge that the physician has regarding palliative care, death and dying, and hospice services. Very few studies have examined the impact that the beliefs of providers regarding death and dying or hospice services might have on hospice utilization. Bradley and colleagues (2000) found that limited knowledge of hospice services and having a dissatisfying experience with hospice resulted in fewer hospice referrals among providers. Additionally, physicians have reported feeling uncomfortable working with dying patients (Schulman-Green, 2003). Because the physician is considered a key player in hospice use, more research on how their views on death and dying and hospice services is imperative to understanding the underutilization of hospice among terminally ill patients. Thus, provider beliefs are considered a major component of the provider characteristics in the Hospice Model.

Health Policy Characteristics. The major health policy characteristics in the institutional factors are the regulations and requirements set forth for hospice utilization within *organizations*, the general *public*, and *clinical practice*. Specifically, prognostic and treatment eligibility, as described in the Conceptual Model, are considered major public policy components in the Hospice Model. As previously discussed, most hospices require

that the patient be approved and certified by the patient's primary care physician and the hospice medical director to be terminally ill and have six months or less to live if the illness runs its natural course for hospice eligibility. Additionally, the patient must be willing to forgo any curative treatment of the terminal illness (*Medicare Hospice Benefits*, 2005). While these eligibility requirements were put in place to restrain costs by limiting the number of beneficiaries who can qualify to receive extensive services offered under hospice, they create numerous barriers at the clinical practice level. Physicians have reported that the six-month prognostic requirement, coverage of medications for symptom control only and complicated admission criteria are barriers to hospice referral (McGorty & Bornstein, 2003). Additionally, despite efforts from the NHPCO to publish prognostic criteria for non-cancer diagnoses, the illness trajectories are still not well understood, estimated or supported in the literature for accuracy (Stuart, 1999). Even if prognostic accuracy was enhanced, however, the literature supports numerous psychological barriers to hospice because of the eligibility requirements (Wiener & Tilly, 2003). Once a patient enrolls in hospice under the Medicare Hospice Benefit, they lose their coverage of other services for their terminal illness. Potentially related to this outcome, many patients have indicated that accepting hospice services is indicative of losing hope (Born et al., 2004); and many physicians have difficulty moving from the curative model of care, fear losing medical control of their patient, and worry about jeopardizing the patient-provider relationship if they refer the patient to hospice (Brickner, Scannell, Marquet, & Ackerson, 2004; Hyman & Bulkin, 1990). Thus, regulatory restrictions are included as elements of health policy in the Hospice Model.

Other health policy characteristics, organizational policies, included in the Hospice Model are influenced by the type of hospice organization under study. Because hospices are

generally reimbursed by insurance companies on a per diem basis, the high cost of providing advanced symptom control and the technological advances in palliative care have been a bittersweet advancement for end-of-life care. Medicare, which was the payment source for 83.7% of hospice patients in 2006, pays hospice agencies on a fixed, flat per diem basis based on the type of care that is provided (routine home care, continuous home care, general inpatient care, or inpatient respite care) ("NHPCO Facts and Figures: Hospice Care in America," 2007). For example, routine home care in fiscal year 2006 was paid at a rate of approximately \$130 per patient per day, regardless of the services utilized by the patient (Person, 2006). Thus, patients who will not forgo the use of expensive and more aggressive palliative treatments such as chemotherapy, radiation therapy or blood product transfusion, regardless of their palliative intention, may be precluded from admission into hospice because of the potential financial loss to the organization (Lorenz et al., 2004). The ability to cost shift varies between hospice organizations. For example, larger hospices are better able to recover from the financial punch of allowing the use of palliative chemotherapy and radiation for their hospice patients by shifting the cost from less expensive patients from whom they are getting reimbursed at the same rate but not utilizing the money in its entirety (Lorenz et al., 2004). Thus, cost containment efforts and agency-specific rules and regulations, including agency-specific policies regarding symptom control and "appropriate" palliative treatments, may greatly affect rates of hospice utilization. The impact of these agency-specific factors can be captured by applying the model to potential patients of different hospice organizations and determining whether or not factors at the organizational level affect hospice use. For example, differences in hospice use may vary among individuals if an individual is referred to a hospice agency that allows patients to receive palliative

chemotherapy or that requires/provides a 24-hour caregiver. Similarly, different outreach and educational programs on end-of-life care offered by different hospice organizations have the potential to affect hospice utilization rates; therefore, applying the Hospice Model to a variety of hospice settings is important to capture the influence of health policy characteristics.

Health Behavior

The inclusion of *health behavior* in the Hospice Model was a result of examining both the Behavioral Model of Health Services Use and the Conceptual Model of Realized Access to End-of-Life Care. Similar to the Conceptual Model, only “realized access” is considered in the Hospice Model because the purpose is to examine actual utilization of services. Realized access is defined by Andersen (2001) as the actual utilization of services and is a component of the health behavior concept. For reasons already discussed, hospice services are currently considered the most effective means (as well as the only organized means) of achieving high quality end-of-life care in the current health care system. In recognizing the provision of optimal end-of-life care services as the outcome in the Conceptual Model and as representing a potential health behavior in the Behavioral Model, the outcome in the Hospice Model is operationalized as hospice use versus non-use. The most important assumption of the Hospice Model, therefore, is that hospice utilization (as a health behavior) is equivalent to achieving high quality end-of-life care services. Whether or not hospice is suitable or “fits” a particular patient’s needs and values regarding appropriate end-of-life care is expected to be represented in the concept of the individual’s beliefs.

Relationships among Variables

Similar to Andersen's Behavioral Model, each component in the Hospice Model might make a direct individual contribution to the health behavior or they can indirectly affect the health behavior through the causal order between factors. The outcome (health behavior) may be influenced directly or indirectly by contextual, patient and institutional factors. Additionally, contextual, patient and institutional factors influence each other directly and indirectly. The outcome of hospice utilization can also feed back into the patient, contextual and institutional factors. For example, if residents in a community utilize hospice to its fullest potential, then perhaps the social and belief sub-concepts of the contextual predisposing variables will be altered. In other words, if terminally ill members of a particular social network use hospice, then perhaps the community beliefs about death and dying and hospice services would be positively influenced. Similarly, if a patient individually uses hospice services, then perhaps their beliefs about death and dying will change. A relationship is also evident between institutional factors and both patient and contextual factors because it is hypothesized that changes at the contextual and patient levels could influence changes at the level of the institution and vice versa. Within institutional factors, the provider, or perhaps providers in large numbers, could affect health policy; and health policies greatly affect provider characteristics, particularly the social characteristics and beliefs. Perhaps most notably, institutional factors specifically affect patient enabling factors through *referral* and patient need factors through *prognostic judgment and treatment decisions*, and a reciprocal relationship exists between individual factors and provider characteristics and is captured most importantly (although not exclusively) through *communication*. Individual factors can

also influence health policy directly; for example, agency specific rules and regulations may need to be adjusted to suit patients' needs and resources.

Referral. As Yabroff and colleagues (2004) emphasized, provider referral to specialty end-of-life services, particularly hospice services, is critical to the processes and outcomes of end-of-life care. Similarly, referral, operationalized dichotomously as being referred or not being referred for services, is considered a major component in the Hospice Model. Like many specialty agencies, it is impossible to be admitted to hospice services without a referral, even though the referral can be from the patient himself, his family or friends, or a health care provider and subsequent physician approval. In other words, realized access, or actual utilization of hospice services, cannot be achieved without some sort of referral. In the Hospice Model, referral is initiated from the provider in the institutional factors (because the focus of this model is currently on the role of the provider, not other referral sources) and feeds into the individual factors as an enabling characteristic. The actual source of the referral is considered a patient characteristic, as it likely reflects where the patient receives his/her medical care.

In order to improve the use of hospice among terminally ill patients, therefore, identifying the factors associated with hospice use *after referral* is imperative. Whether the underutilization of hospice is related to individual factors such as preferences for aggressive treatment, contextual factors such as health service accessibility, or institutional factors such as provider characteristics, lack of referral or strict eligibility guidelines is unknown.

Allowing the Hospice Model to focus on those patients who have been referred to hospice is advantageous in at least 2 ways: 1) it adjusts both for those patients who died suddenly or unexpectedly and were therefore never hospice appropriate, and 2) it adjusts for those

patients who never had any knowledge or communication of hospice services with their health care provider. The findings may contribute to the development of interventions aimed at increasing the use of hospice, improving the use of hospice among qualified minorities, and reducing the enormous health care resources expended on end-of-life care. Physicians may be referring terminally ill patients, including racial and ethnic minorities, at a rate that is proportionate to their numbers, but these patients may be refusing hospice. The next step then would be to continue to target individual factors associated with hospice use after referral and develop an intervention for patients and families. On the other hand, if the racial concordance between patient and provider is a strong predictor of hospice use after referral, then perhaps cultural competence and awareness interventions for providers and/or hospice organizations will increase use. If the availability of nursing home or hospital beds in a geographic area or strict eligibility guidelines are strong predictors in hospice use, then perhaps governmental involvement would be necessary to increase hospice utilization.

Prognostic Judgment and Treatment Decisions. Whether or not a patient is referred to hospice depends largely on the provider's prognostic judgment of the patient's illness and the treatment decisions made by both the patient and provider. As previously discussed, the provider's prognostic judgment is considered an important impact on individual evaluated need in the Hospice Model because a patient can not utilize hospice services if the provider does not support a 6-month-or-less prognosis. Additionally, the treatment decisions made by both the patient and the provider, which likely affect a patient's prognosis, are considered influential to an individual's need for hospice services. In other words, if a patient pursues aggressive treatment or a provider encourages/offers a patient to pursue aggressive treatments, then logically (or perhaps ideally) the patient's prognosis would be enhanced.

Thus, the linkage between the institutional factors and the individual need component through prognostic judgment and treatment decisions is an essential element in the Hospice Model.

Communication. In the Conceptual Model of Realized Access to End-of-Life Care, communication between patients and providers is considered essential. The development of treatment goals and care planning requires clear discussion of expectations from the patient, provider and caregiver (Yabroff et al., 2004). However, many providers report feeling uncomfortable or unprepared to initiate discussions regarding end-of-life care and prognoses (Lamont & Christakis, 2001; Schulman-Green, 2003). Additionally, patients and families may be reluctant to initiate conversations regarding end-of-life care planning because of a fear and mistrust in the health care system. Qualitative studies have found that many patients report difficulty getting health care providers to communicate prognosis and end-of-life care planning with them and even if communication does take place, often times patients felt “unheard” by doctors (Ekblad, Marttila, & Emilsson, 2000; F. Jackson et al., 2000) or that communication was “unclear” or “inconsistent” (Schulman-Green et al., 2004). These issues are also evident in the research concerning the completion of advanced directives. Discussion of advanced directives and DNR orders are infrequent and incomplete, which is thought to be a contributor to the lack of end-of-life care planning (Yabroff et al., 2004). With this evidence, communication is considered a key relational concept, although not the only relational concept, between the patient and provider factors in the Hospice Model.

III. Preliminary Study⁶

This study was built on a pilot study conducted by the investigator in 2005 to test the feasibility of data collection, entry and analysis of patient characteristics associated with hospice use. All patients referred to Hospice A⁷ between July 2003 and September 2005 were included in the pilot study. The sample was composed of 614 patients, 530 of whom enrolled in hospice after referral and 84 of whom did not enroll. The hospice database contained three standard classifications for not being admitted to hospice⁸: patient-driven reasons (e.g., the patient refused or was seeking active treatment), prognosis-driven reasons (e.g., the patient died before admission or had an estimated survival greater than 6 months), and other reasons (e.g., the patient's residence was not in the service area or the patient could be admitted to a closer hospice agency). Patients who were not admitted for an "other" reason were not included in this study. Variables analyzed for all patients included age, gender, race/ethnicity, marital status, diagnosis and type of insurance. For those not enrolled, the reason given was also analyzed.

The total sample included 258 males. The mean age of the group was 76.7 years (SD = 14.31), and the marital status was as follows: 43.8% were married, 41.6% were widowed,

⁶ The results of this study (and the majority of this section) were previously published in Forcina Hill, 2008.

⁷ Specific characteristics of Hospice A will be discussed in the Sample and Setting sub-section of Chapter IV.

⁸ Classifications completed by principal investigator based on the reasons for no admission listed and with guidance from the business administrator.

8.2% were single and 6.4% were divorced. Three hundred and twenty-four patients had an ICD-9 code indicating cancer, and 286 were non-cancer patients. Approximately 81.2% of referred patients were White and 18.8% were non-White. Insurance status broke down as follows: 83.8% had Medicare, 3.7% had Medicaid, 10.7% had private insurance, 1.0% were self pay, and 0.8% were indigent. A total of 530 referred patients were actually admitted to hospice after referral (hospice users), and 84 were not admitted (hospice non-users). Of the hospice non-users, 46 participants were not admitted because of a patient-driven reason and 38 were not admitted because of a prognosis-driven reason. Table 5 displays the descriptive findings for each group of patients: hospice users, hospice non-users, hospice non-users because of a patient-driven reason, and hospice non-users because of a prognosis-driven reason.

Table 5. *Characteristics of Sample in Preliminary Study*^a

	Variables	Hospice Users (N = 530)		Hospice Non-Users (N = 84)		Hospice Non- users with Patient-driven Reason for not enrolling (N = 46)		Hospice Non- users with Prognosis- driven Reason for not enrolling (N = 38)	
		N	%	N	%	N	%	N	%
Gender	Male	220	41.5	38	45.2	20	43.5	18	64.0
Age [*]	Median years (SD)	77.1 (13.65)		74.5 (17.85)		69.4 (20.54)		80.7 (11.37)	
Marital Status	Married	216	43.1	28	47.5	15	45.5	13	34.2
	Widowed	214	42.7	20	33.9	12	36.4	8	21.1
	Single	38	7.6	8	13.6	5	15.2	3	7.9
	Divorced	33	6.6	3	5.1	1	3.0	2	5.3
Insurance Status	Medicare	449	84.7	51	76.1	23	63.9	28	90.3
	Medicaid	18	3.4	4	6.0	4	11.1	-	-
	Private	54	10.2	10	14.9	7	19.4	3	9.7
	Self-pay or indigent	9	1.7	2	3.0	2	5.6	-	-
Race/Ethnicity ^{**}	White	438	82.6	42	68.9	26	72.2	16	64.0
Diagnosis	Cancer	285	53.8	36	46.2	21	51.2	15	40.5

Note. Parts of this table were published in Forcina Hill, 2008, p.247.

^aN = 614.

^{*} Statistically significant between hospice non-users with patient-driven reason and hospice users [$t(48.519) = 2.492$, $p = .016$]; between hospice non-users with a patient-driven reason and hospice non-users with prognosis-driven reason [$t(72.461) = -3.206$, $p = .002$]; marginally significant between hospice users and hospice non-users with a prognosis-driven reason [$t(45.026) = -1.898$, $p = .064$]. ^{**} Statistically significant between hospice users and hospice non-users ($\chi^2 = 6.819$, $p = .009$) and between hospice users and hospice non-users with prognosis-driven reason ($\chi^2 = 5.573$, $p = .018$).

The results of this study indicated that certain individual factors are associated with hospice utilization after referral and that, among hospice non-users, the prognostic and treatment eligibility restrictions of hospice are in turn related to these factors. Race was the only predictor of enrollment in hospice based upon results from the backward regression

model [2.154 (1.198, 3.872), $p = .010$]. White patients were 2.2 times more likely to enroll in hospice after referral than non-Whites. Non-White patients were more likely not to use hospice because of a prognosis-driven reason than White patients after adjusting for gender, age, diagnosis, insurance and marital status [8.190 (1.055, 63.547), $p = .044$]. In other words, they did not enroll in hospice because they had more than 6 months to live, they died before admission, or they were actively dying and inappropriate for home hospice services. The full model also suggested that female patients were more likely to use hospice after referral than male patients [0.417 (0.189, 0.923), $p = .031$], although a comparison of individual factors associated with hospice non-use for a patient-driven reason versus prognosis-driven reason did not indicate any differences among gender. No significant difference existed between Whites and non-Whites on gender.

The bivariate analyses indicated that although hospice users were not significantly different on age from the hospice non-users group in its entirety, they were significantly older than the hospice non-users with a patient-driven reason for not enrolling ($M = 77.1$, $SD = 13.65$ vs. $M = 69.4$, $SD = 20.54$; $t(48.495) = 2.495$, $p = .016$). Thus, younger patients appeared to be less likely to use hospice because they refused or were seeking active or curative treatment, as compared to not using hospice because of a prognosis-driven reason. A comparison of age and race and age and gender revealed that Whites were significantly older than non-Whites ($M = 77.84$, $SD = 13.46$ vs. $M = 72.19$, $SD = 15.10$; $t(152.947) = 3.625$, $p < .001$) and females were significantly older than males ($M = 79.1$, $SD = 13.27$ vs. $M = 73.4$, $SD = 15.05$). However, the results of the multivariate analyses indicated that race and gender

were the important factors. Thus, the apparent importance of age was actually due to confounding. Table 6 summarizes the results of the logistic regression.

Table 6. *Model of individual factors to determine hospice use vs. hospice non-use after referral in pilot study*^{a*}

Variable	Bivariate Analysis			Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Female [*]	-0.152 (0.236)	0.859 (0.541,1.365)	.520	-0.874 (0.405)	0.417 (0.189,0.923)	.031	-	-	-
Age	-0.012 (0.008)	0.988 (0.974,1.003)	.131	-0.026 (0.018)	0.975 (0.941,1.010)	.158	-	-	-
Non-White [*]	0.767 (0.299)	2.154 (1.198,3.872)	.010	0.856 (0.387)	2.355 (1.102,5.029)	.027	0.767 (0.299)	2.154 (1.198,3.872)	.010
Non-cancer	0.305 (0.243)	1.357 (0.842,2.186)	.209	0.615 (0.403)	1.850 (0.840,4.077)	.127	-	-	-
Marital Status									
Married					Reference				
Widowed	0.840 (0.718)	2.316 (0.567,9.452)	.242	0.501 (0.487)	1.650 (0.636,4.284)	.303	-	-	-
Single	0.355 (0.636)	1.426 (0.410,4.956)	.577	-0.008 (0.653)	0.992 (0.276,3.565)	.991	-	-	-
Divorced	0.028 (0.647)	1.028 (0.289,3.652)	.966	-0.204 (0.800)	0.816 (0.170,3.915)	.799	-	-	-
Insurance									
Medicare					Reference				
Medicaid	0.671 (0.572)	1.956 (0.637,6.005)	.241	-0.908 (1.237)	0.403 (0.036,4.552)	.463	-	-	-
Private	0.489 (0.375)	1.630 (0.782,3.398)	.192	0.460 (0.631)	1.584 (0.460,5.455)	.466	-	-	-
Self-pay or Indigent	0.671 (0.796)	1.956 (0.411,9.304)	.399	0.427 (1.170)	1.533 (0.155,15.187)	.715	-	-	-

Note. Table was published in Forcina Hill, 2008, p. 248. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; diagnosis = cancer; marital status = married; insurance = Medicare. Parsimonious model results based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 591. ^bFull model $R^2 = 0.075$. ^cParsimonious model $R^2 = 0.021$.

*Additional analyses were conducted to determine hospice non-use for a patient-driven reason vs. prognosis-driven reason (N = 37). The full model results indicate race as the important factor [8.190 (1.055, 63.547), $p = .044$; $R^2 = .449$]. The parsimonious model also indicated race as the important factor [4.250 (0.982, 18.395), $p = .053$; $R^2 = .137$]. Non-Whites were more likely to have a prognosis-driven reason to not use hospice after referral than Whites.

* $p \leq .05$ in full model.

The findings from this study provide some direction for determining why hospice services are under-utilized, particularly among racial and ethnic minorities. This study revealed that even *after referral*, race and ethnicity were strong predictors of hospice use. Thus, the notion that racial and ethnic minorities are under-represented in hospices because of a lack of referral was not necessarily supported. The answer to the problem then could be hidden in what takes place *after/during* the referral as opposed to *before* referral. Perhaps most importantly, however, this study indicated that among racial and ethnic minorities, the strict prognostic eligibility guidelines may be the strongest barrier. In other words, instead of cultural differences in medical care and values regarding the end of life, this population may be under-represented in hospice because they are referred too late for services and are either actively dying or die before they can enroll or are referred too early for services and are ineligible because they have a prognosis greater than 6 months. Thus, culture may not play as big of a role in end-of-life care choices as the current literature infers.

The results also suggested that gender is an important factor in hospice utilization after referral. Females were more likely to use hospice after referral than males, a finding that has been inconsistent throughout previous studies. Although females typically have a longer life expectancy than males, the importance of gender was captured after adjusting for age, as well as race, diagnosis, insurance and marital status. Additionally, the difference in life expectancy does not explain why males simply do not use hospice at an earlier age. Similar to the hypotheses regarding the disparities in hospice use among racial and ethnic minorities, the difference in utilization rates among males and females may be a result of differences in values regarding medical care. A recent study including 73 participants in 10 focus groups concluded that females were more likely than males to want touch, prayer and mental

awareness at the end of life (Duffy, Jackson, Schim, Ronis, & Fowler, 2006). Other studies have shown that females are less likely to want aggressive treatment at the end of life (Bookwala et al., 2001) and are more likely to experience pain than males at the end of life (Duffy et al., 2006), which could indicate a greater need for expert symptom control at the end of life among females.

Because the sample size and the resulting power were small, however, especially among the hospice non-user groups, the strength of the findings are limited. Determining whether or not racial and ethnic minorities are not enrolled in hospice after referral because they are referred too late and die before admission or are referred too early and have more than 6 months to live requires a larger sample size. With a larger sample size, other individual characteristics may also be found to be important in predicting hospice use among terminally ill patients. Further, individual factors associated with hospice use may be contingent on contextual and institutional factors, including the characteristics of referring providers; and these were not evaluated in the pilot study.

IV. Research Design and Methods

Design

A non-experimental quantitative cross-sectional design was used to determine whether patient, contextual and institutional factors predict hospice use after referral both in general and among racial and ethnic minorities. The study used the existing administrative databases from two hospice organizations, the North Carolina Health Professions Data Book, and data publicly available on several different state and federal websites. The demographic and socio-economic characteristics of individual patients (*individual factors*), the demographic and socio-economic characteristics of the patients' counties of residence (*contextual factors*), and the characteristics of the system, including the demographic and training characteristics of the patients' referring physicians and the comparison between two distinct hospice agencies (*institutional factors*), were analyzed to determine their influence on hospice use after referral (*health behavior*), as well as their influence on the reasons patients do not use hospice after referral (*institutional factors*).

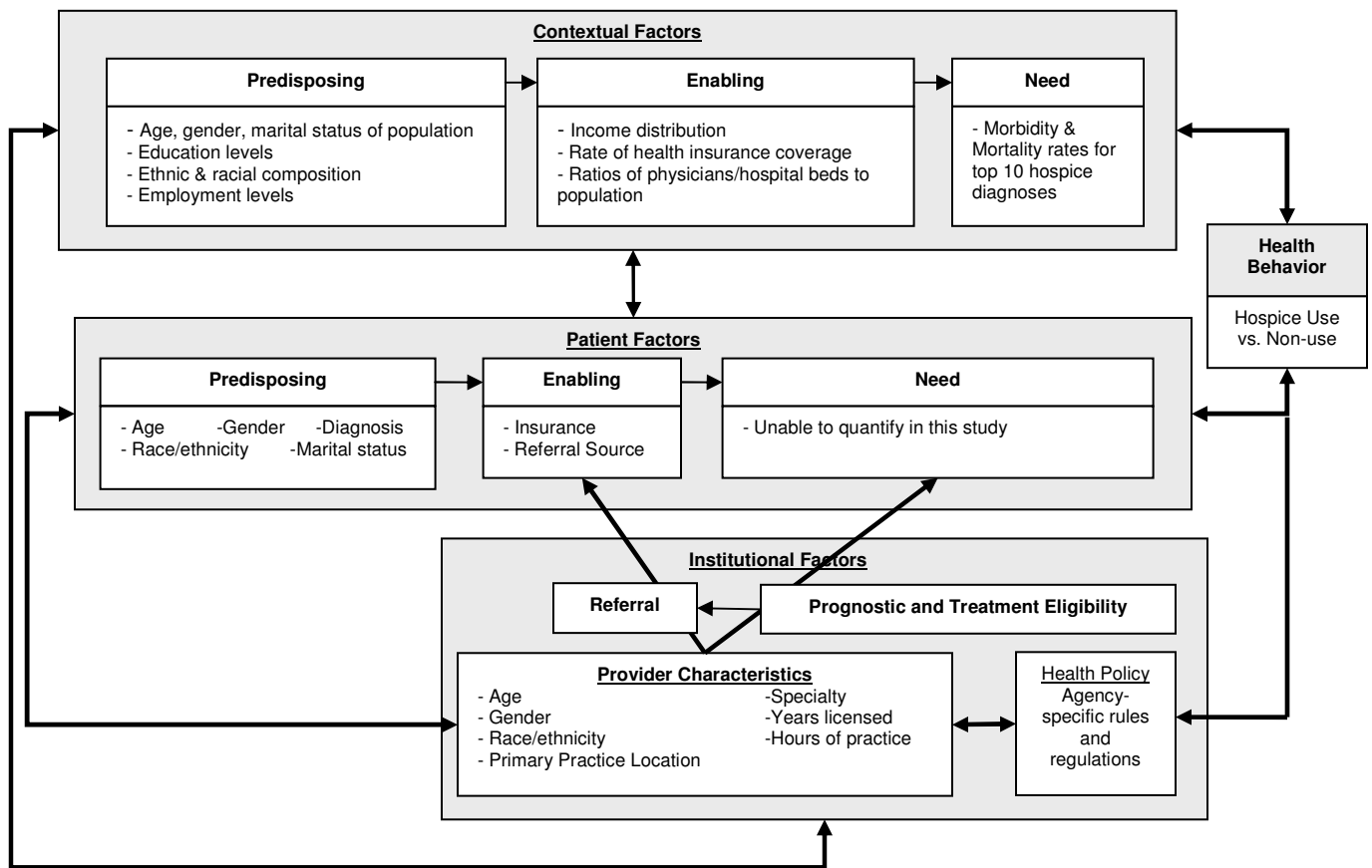
Variables and Measures

Variables were selected for inclusion based on the literature on hospice use, the Hospice Model, and the availability of data. The patient's county of residence was chosen as the level of analysis for contextual factors because the county is the lowest level of analysis that could be matched in both the individual and contextual data sources.⁹ Figure 3 illustrates the

⁹ The Census tract of each patient was not available, and the contextual variables were not all available at the zip code level.

Hospice Model with the variables that were examined in this study, and Table 7 lists the operational definitions of each variable. Not all the relationships depicted in Figure 3 were examined in this study.

Figure 3. Behavioral Model of Hospice Use with the Variables Used to Represent the Concepts in the Study



Note. Health behavior is the outcome. Parts of this figure were published previously by the author in Forcina Hill, 2008, p.243.

Table 7. *Operational Definitions of Variables Included in Study*

Major Concept	Level of Measurement	Sub-Groups	Variables	Operational Definitions/ Variable Levels ¹⁰
Individual factors	Individual level: Patients referred to both hospice organizations	Predisposing	Age	Age of patient, calculated from birth date
			Gender	Male; Female
			Race/Ethnicity	White; Non-White
			Marital Status	Married; Unmarried
Contextual Factors	Aggregate level: County of patient's place of residence		Diagnosis	Cancer; Non-cancer
		Enabling	Insurance Status	Medicare; Medicaid; Private insurance; Self-pay; Indigent
			Referral Source	Physician-referred; Referred by a source other than a physician
		Need		Unable to quantify in this study due to lack of data availability
		Predisposing	Age of population	Median age of population
			Gender of population	% of population that is male
			Marital status of community	% of population that is married
			Education levels	% of population with high school diploma
			Ethnic & racial composition	% of population that is White
			Employment levels	Unemployment rate
Institutional Factors	Individual level: Each patient's referring or approving provider and each hospice non-user's reason for no enrollment	Enabling	Income distribution	Income per capita; % of individuals below poverty level
			Rate of health insurance coverage	% of population that is uninsured
			Ratios of physicians & hospital beds to population	# of physicians per 10,000 population; # of hospital and Nursing facility beds; # of inpatient hospice beds; # of Hospice facilities serving population
		Need	Morbidity & Mortality statistics	Cancer death rate; Leading cause of death; # of deaths in population
		Provider Characteristics	Age	Age of physician, calculated from birth date
			Gender	Male; Female
			Race/ethnicity	White; Non-White
			Racial Match	Match; No match (Based on the following race/ethnicities of patients and providers: White, Black, Hispanic, American Indian/Alaskan, Asian, Other race)
			Experience	Years physician is medically licensed
			Specialty ¹¹	Hematology/Oncology; Family Practice; Internal Medicine; Other
Health Behavior	Outcome variable		Practice Location	Hospital-based; Clinic-based/Other
			Hours of practice	Total number of hours a week in clinical or care
		Health Policy	Agency specific rules and regulations	Evaluated through comparison of two hospice organizations; hospice A versus hospice B
			Hospice Utilization	Hospice Use: Patient enrolled in hospice, Hospice Non-use: Patient not enrolled in hospice after referral; Hospice Non-use for patient-driven reason vs. Hospice Non-use for prognosis-driven reason

Note. Parts of this table were published in Forcina Hill, 2008, p. 246.

¹⁰ Some of the operational definitions have changed since the original proposal due to the availability and accessibility of data, as well as to sample size considerations. These definitions represent what was actually used in the study.

¹¹ Specialty was categorized based on the groupings made in previous studies (Bradley et al., 2000).

Sample and Setting

Patient Data Sources. Individual data were extracted from the databases of two hospice organizations and drove the extraction of all other variables. Both organizations are long-standing home hospice agencies that have been an integral part of the community for over 20 years. Hospice A is located in rural, central North Carolina, and is a non-profit agency affiliated with a large academic tertiary care center. Hospice B is located in a large metropolitan area in North Carolina and is a private non-profit agency. Together, the two agencies receive approximately 1,500 referrals a year, with over 90% of referred patients enrolling in hospice. They jointly serve over 10 counties in North Carolina and carry an average daily census of over 200 patients. These two agencies were selected because their administrative databases and methods of collecting patient information are similar, they serve counties in the same region of North Carolina, their combined service area is large and demographically diverse, and working relationships already existed between the investigator and the organizations and between the two organizations themselves.

Individual data are collected by the organizations as part of their routine admission procedure. The variables for enrolled hospice patients in this study were: age, gender, race/ethnicity, marital status, diagnosis, type of insurance, the referral source, county of resident and the referring and authorizing physicians. Data on the same variables were extracted for patients who were referred but not admitted to hospice, along with the reason cited for not being admitted to hospice. Similar to the preliminary study, these reasons fell into one of three categories: patient-driven reasons, prognosis-driven reasons, and other reasons. If the patient refused hospice or was seeking aggressive treatment, they had a patient-driven reason to not enroll. If the patient was actively dying, died before admission or

had more than 6 months to live, they had a prognosis-driven reason for not enrolling. Patients who were not admitted because their insurance was contracted with a different hospice agency or they were not in the service area had an “other” reason for not enrolling. Patients in this category were not included in the analyses because whether they did or did not receive hospice services from other agencies could not be determined. All other patients referred to both agencies from July 2003, when the databases were established in both of the participating organizations, through the end of September 2005, when data extraction began for Hospice A, or through the end of July 2006, when data extraction began for Hospice B, were included in the analysis.¹²

Contextual Data Sources. Contextual data was obtained from a variety of publicly available sources including the United States Census for the year 2000 ("State & County Quick Facts," 2000), the North Carolina State Center for Health Statistics ("North Carolina State Center for Health Statistics,"), the North Carolina Health Professions Data Book at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill (Sheps Center at UNC-CH) ("North Carolina Health Professions Data Book," 2005), and the North Carolina Division of Facility Services ("The Division of Facility Services," 2006). Information was extracted after the individual data were obtained and included information at the county level so that data on every county in which patients in the sample resided were collected. The following data were obtained for each patient's county: racial/ethnic composition, gender composition, marital composition, age composition, income distribution, employment levels, educational levels, rate of health insurance

¹² Data extraction was attempted to cover July 2003 through July 2006 for both hospice agencies as the original proposal indicated. However, due to lack of technical support at Hospice A, as well as time and financial constraints, data could only be collected through September 2005 for this agency. Data for Hospice B spanned July 2003 through July 2006 as originally proposed.

coverage, the ratios of physicians and hospital beds to the population, and morbidity and mortality data.

Institutional Data Sources. Major institutional factors in this study were the characteristics of the referring physician. These data were also extracted after individual data were obtained because the names of the patient's referring physicians were used to guide compilation. Provider data was obtained on each physician who referred a patient during the study period using the North Carolina Health Professions Data Book at the Sheps Center at UNC-CH. Physician variables included in this study were age, gender, race/ethnicity, hours spent in primary or clinical practice, year of medical licensing, and primary specialty.

Other institutional factors, including eligibility guidelines, were captured in the hospice organizations' databases. Referred patients must have less than 6 months to live and be willing to forgo certain treatments in order to be eligible for enrollment in either organization. The reasons cited for patients not enrolling in hospice after referral were used to determine whether or not strict eligibility guidelines are major factors in hospice use. Patients who failed to enroll because of a prognosis greater than 6 months or because they were actively dying or died before admission were expected to reflect issues with prognostic eligibility guidelines. Patients who were not admitted because they were seeking aggressive or curative treatment were expected to represent issues with treatment eligibility guidelines. The health policy variable was operationalized by comparing the hospice organization rates of each hospice organization to determine if perhaps the organizational differences between the agencies affect the outcome. Table 8 summarizes each variable and its data source.

Table 8. *Data sources by variable*

Domain	Specific Variable	Source
Individual Variables	Age, gender, race/ethnicity,	Hospice A: manually extracted from face sheets printed from the administrative database
	marital status, diagnosis, insurance, referral source	Hospice B: electronically extracted from the administrative database
Contextual Variables	County of residence	Hospice A: manually extracted from face sheets printed from the administrative database Hospice B: electronically extracted from the administrative database
	Age composition, gender composition, marital composition	United States Census 2000
	Racial/ethnic composition, employment levels, income distribution, ratio of physicians and hospital beds to population	North Carolina Health Professions Data Book; North Carolina Division of Facility Services
	Morbidity/mortality data	North Carolina Health Professions Data Book; North Carolina State Center for Health Statistics
	Physician Characteristics	North Carolina Health Professions Data Book

Data Collection Procedures

For Hospice A, copies of the raw data in the form of “face sheets” for each patient (i.e., the front page of the patient record) were printed and given to the investigator for manual computer entry. Each patient face sheet contained all the patient variables listed in Table 7. Additional information, particularly for referred patients who were not enrolled in hospice, were obtained from the original hand-written referral forms that are used to alert the agency of potential patients.¹³ Individual data was imported electronically for Hospice B. Special

¹³ Data collection for Hospice A was completed as part of the preliminary study described in Chapter III.

attention was given to potential differences in the databases of the two hospice organizations by maintaining close communication with the business managers of both organizations.

The collected patient data was then used to determine the counties and providers on which to collect additional data for the contextual and institutional factors. These data were then coded and imported/entered into a data file by the investigator.

Data Analysis

The statistical software SPSS, version 12.0, was used to analyze the data using frequencies, correlations, probabilities and regression methods. The representativeness of the sample was determined by comparing the sample demographics of hospice users to the demographics of North Carolina hospices using the statistics reported by the Carolinas Center for Hospice and End-of-life care ("2004 National Summary Statistics and Trends,"). Additionally, the representativeness of the sample to the general population was determined by comparing the sample demographics of all referred patients to the demographics of the counties that each hospice serves. Unless otherwise specified, all analyses were performed at a 95% level of significance ($\alpha = .05$). Table 9 summarizes the statistical modeling methods that were used for each specific aim.

Table 9. *Statistical Modeling Plan*

Aim	Aim Description	#	Planned Statistical Models
Specific Aim 1	To determine individual factors associated with hospice use, contextual factors of a patient's place of residence associated with hospice use, and institutional factors associated with hospice use for all referred patients and for referred racial and ethnic minorities.	1A	Hospice Use vs. Non-use (including entire sample) = individual factors
		1B	Hospice Use vs. Non-use (including entire sample) = contextual factors
		1C	Hospice Use vs. Non-use (including entire sample) = institutional factors
		1D	Hospice Use vs. Non-use (including only racial and ethnic minorities in sample) = individual factors
		1E	Hospice Use vs. Non-use (including only racial and ethnic minorities in sample) = contextual factors
		1F	Hospice Use vs. Non-use (including only racial and ethnic minorities in sample) = institutional factors
		1G	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including entire sample of non-users) = individual factors
		1H	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including entire sample of non-users) = contextual factors
		1I	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including entire sample of non-users) = institutional factors
		1J	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including only racial and ethnic minority non-users) = individual factors
		1K	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including only racial and ethnic minority non-users) = contextual factors
		1L	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including only racial and ethnic minority non-users) = institutional factors
Specific Aim 2	To determine whether individual factors associated with hospice use are conditional on contextual or institutional factors for all referred patients and for referred racial and ethnic minorities.	2A	Hospice Use vs. Non-use (including entire sample) = significant main effects from 1A and 1B, and all interactions
		2B	Hospice Use vs. Non-use (including entire sample) = significant main effects from 1A and 1C, and all interactions
		2C	Hospice Use vs. Non-use (including only racial and ethnic minorities in sample) = significant main effects from 1D and 1E, and all interactions
		2D	Hospice Use vs. Non-use (including only racial and ethnic minorities in sample) = significant main effects from 1D and 1F, and all interactions
		2E	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including entire sample of non-users)= significant main effects from 1G and 1H, and all interactions
		2F	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including entire sample of non-users)= significant main effects from 1G and 1I, and all interactions
		2G	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including only racial and ethnic minority non-users) = significant main effects from 1J and 1K, and all interactions
		2H	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including only racial and ethnic minority non-users) = significant main effects from 1J and 1L, and all interactions
Specific Aim 3	To test a predictive model of hospice utilization after referral, as derived from Andersen's Behavioral Model of Health Services Use and the Conceptual Model for Realized Access to End-of-Life Care	3A	Hospice Use vs. Non-use (including entire sample) = main effects and interactions from 2A and 2B
		3B	Hospice Use vs. Non-use (including only racial and ethnic minorities in sample) = main effects and interactions from 2C and 2D
		3C	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including entire sample of non-users)= main effects and interactions from 2E and 2F
		3D	Hospice Non-use for patient-driven reason vs. prognosis-driven reason (including only racial and ethnic minority non-users) = main effects and interactions from 2G and 2H
		N/A	Factor analyses of individual variables, contextual variables and institutional variables

Note. All patient, contextual, and institutional factor variables listed in Table 7. Significant main effects/interactions defined as $p < .10$ in full model or $p \leq .05$ in parsimonious model. All interactions were two-way.

Analysis of Specific Aim 1

Individual factors associated with hospice use were identified by comparing hospice users to hospice non-users on each patient variable in Table 7. Descriptive statistics, including measures of central tendency for continuous variables and frequencies for categorical variables, were obtained for each variable in both the hospice users group and the hospice non-users group. Logistic regression was used to determine whether the demographic variables were significantly related to hospice use and to determine the bivariate relationships between the main effects and the outcome of hospice use. Additionally, multivariate logistic regression including all main effects was conducted with a backward elimination strategy.

Contextual factors associated with hospice use were determined by comparing hospice users to hospice non-users on county, entered as a fixed effect. If the fixed effect of county was significant ($p < 0.10$), a subsequent analysis using a logistic regression model and backward elimination strategy with each contextual variable in Table 7 was planned.¹⁴

Institutional factors associated with hospice use, specifically the provider factors, were identified by comparing the characteristics of the referring physicians of hospice users to the characteristics of the referring physicians of hospice non-users, in the same manner the individual factors were examined. Additionally, the role of health policy was analyzed by including a dichotomous variable for each hospice agency (each patient was either from Hospice A or Hospice B). The provider variables listed in Table 7 as well as the hospice agencies were the characteristics compared.

To determine what additional institutional factors, specifically treatment and prognostic eligibility guidelines, may be associated with hospice use, patients who did not use hospice

¹⁴ The second part of this analysis which was to include the detailed contextual variables (as compared to county entered as a fixed effect) was not implemented for reasons described in Chapter V: Results.

because of a patient-driven reason were compared to patients who did not use hospice because of a prognosis-driven reason. The factors to be included were the patient variables, including the specific reason given for no admission, and the contextual and institutional variables listed in Table 7. The analyses were completed in the same manners described above; however, instead of using hospice use versus non-use as the main outcome, patient-driven hospice non-use versus prognosis-driven hospice non-use was used as the main outcome (therefore, only hospice non-users were included in these analyses).

In order to address the differences between hospice users and non-users among racial and ethnic minorities, non-White hospice users were compared to non-White hospice non-users on the patient, contextual and institutional factors, in the same manners described above. The factors included in the comparisons were the patient, contextual and institutional variables listed in Table 7. Only non-White patients were included in this analysis. Further, non-White patients who did not use hospice because of a patient-driven reason were compared to non-White patients who did not use hospice because of a prognosis-driven reason, in the same manners as above. The factors included were the patient variables, including the specific reason given for no admission, and the contextual and institutional variables listed in Table 7. Only non-White hospice non-users were included in these analyses.

Analysis of Specific Aim 2

Multivariate logistic regression with backwards elimination was used to determine whether the individual factors associated with hospice use are contingent on the patient's contextual or institutional factors. The first model included the factors identified as significant ($p < .10$) from the patient-level model and the factors identified as significant from

the contextual-level model ($p < .10$). The second model was to include the factors identified as significant ($p < .10$) from the patient-level model and the factors identified as significant ($p < .10$) from the institutional-level model. All models included not only main effects but also two-way interactions.

In order to address whether the individual factors associated with hospice use are conditional on contextual or institutional factors among racial and ethnic minorities, a comparison of non-White hospice users and non-White hospice non-users using patient, contextual and institutional factors, was planned in the same manners described above. The same analyses were planned using hospice non-use for a patient-driven reason versus hospice non-use for a prognosis-driven reason as the outcome.

Analysis of Specific Aim 3

In order to test a predictive model for hospice use after referral, the significant main effects and interactions from the patient and contextual model and the significant main effects and interactions from the patient and institutional model were incorporated into one multivariate logistic regression model. This model was planned for implementation among hospice users, hospice non-users, and for racial and ethnic minorities with a backwards elimination strategy, in the same manners described above.

In addition to the above regression analyses, the model for hospice use after referral was tested by conducting factor analyses of the individual, contextual,¹⁵ and institutional variables to determine whether the variables in the data fit the underlying constructs in the Hospice Model. Methods for extraction and rotation were determined based on what appeared best in terms of simple structure.

¹⁵ Factor analysis of contextual variables was not completed for reasons described in Chapter V: Results.

Human Subjects Protection

This study involved the use of existing data in the form of patient records from the administrative databases of two hospice organizations. All patients referred to either of the participating hospice organizations during the period of study were planned for inclusion. The sample was estimated to consist of approximately 5,000 men and women of varying ages, races and ethnicities who were referred to one of two hospice organizations. The vast majority of the sample was considered terminally ill and included individuals of all age groups, including children. Because hospice is traditionally not used by children, however, it was expected that children would represent a very small portion of the sample, as was the case in the pilot study (refer to Table 5).

Because no direct interaction or contact between the investigator and subjects took place and because all direct identifiers were removed from the data, the risk to subjects was limited to breach of confidentiality. Patient records are the only available source of data on hospice utilization after referral because of the terminal nature of the patients referred to hospices; therefore, this research would not have been possible without patient records. The risk to privacy was minimal compared to the benefits to be gained. Quantitative examination of factors associated with hospice use after referral is necessary in order to improve hospice services, end-of-life care, and educational and outreach programs for terminally ill patients, including ethnic and racial minority groups, as well as providers.

As previously discussed, the individual data used in this study were kept in the administrative databases of the two participating hospice organizations. These two organizations collect data on every patient at the time of referral to hospice as part of their intake and admission procedures. No information was gathered specifically for the proposed

research. Identifiable information that was gathered as part of the study data included birth dates, counties and zip codes (for possible use at a later date). Other data that were collected included age, gender, race/ethnicity, marital status, diagnosis, type of insurance, acuity level (Hospice A only, not available for Hospice B), the number of emergency contacts and primary caregivers listed (collected from Hospice A as part of the preliminary study), the referral source, the authorizing physician and the reason for no admission (for patients who were not enrolled). No data were shared with anyone outside the immediate research team; and, when the face sheets were used to collect the data (in the case of Hospice A), all identifiers linked to subjects were blacked out from the face sheets by the investigator before removing them from the agency. Each patient was given a unique identification number for organization and data entry. During data entry and analysis for Hospice A, these face sheets were kept in a locked file box. When they were not being used by the investigator for data entry and cleaning, they were locked in a file cabinet. Once all data were coded, entered, verified, analyzed, and the current study has been approved by the investigator's research team, the face sheets were returned to the respective institution and destroyed following their regular procedures. The investigator obtained permission to use individual data from both hospice organizations, pending IRB approval, prior to beginning data extraction.

Contextual data were obtained from publicly available sources, including the United States Census for the year 2000 ("State & County Quick Facts," 2000), the North Carolina State Center for Health Statistics ("North Carolina State Center for Health Statistics,"), the North Carolina Health Professions Data Book ("North Carolina Health Professions Data Book," 2005), and the North Carolina Division of Facility Services ("The Division of Facility Services," 2006). These data were downloaded or copied from the respective websites.

Institutional data were obtained in two ways. Provider data are kept in the North Carolina Health Professions Data Book; however, the individual identifiers in the database are protected by the Sheps Center at UNC-CH and the North Carolina State Medical Board (NCSMB) and are not publicly available. The database includes information on health care providers from 17 different professions in North Carolina. The information is gathered by various professional organizations and provided to the Sheps Center for inclusion in the database. Physician information from the North Carolina Medical Board includes the name, mailing address, birth year, gender, race, information on basic professional education, specialty of practice, activity status, form of employment, and practice setting of every physician licensed in North Carolina. Provider names were collected from the patient data sources, entered into an Excel file, and then passed to the Sheps Center. Staff at the Sheps Center then extracted the needed variables on each provider. Provider variables included were age, gender, race/ethnicity, number of years licensed, primary practice location, specialty and hours spent in clinical care practice. Once the data were collected, each provider was given a unique identification code for organization and analysis. Provider names were not used in the study, and no new information was gathered on providers as part of the proposed study. The investigator obtained permission to extract provider data from the Sheps Center at UNC-CH and the NCSMB prior to initiation of this study. The reasons for no admission for hospice non-users, which were used to represent the influence of strict prognostic and treatment eligibility requirements, were obtained from the patient data sources. The health policy variable was simply included dichotomously as whether or not a patient was referred to Hospice A or Hospice B; thus, no additional data was collected for this variable.

Data entry and coding was completed by the investigator. Electronic copies of the data were kept on a secure network that requires password access both to the computer and to the electronic file. The data was backed up on a jump drive that requires password entry and was locked in a file cabinet when not in use.

The investigator claimed exemption of written consent because this study used data that had already been collected as part of the administrative procedures of participating hospice organizations by the beginning of the study period. The study would have been impossible without exemption because the majority of the patients in the database are deceased. IRB approval was obtained from the University of North Carolina at Chapel Hill prior to data extraction with this exemption.

V. Results

As discussed in Chapter IV, patient data from Hospice A, including the patient's referring physician and county of resident, were manually entered into SPSS 12.0 by the principal investigator. Patient data from Hospice B, including the patient's referring physician and county of residence, were electronically imported to SPSS 12.0 for analyses. The name and UPIN number of each patient's referring physician were provided to the Sheps Center at UNC-CH for electronic matching with the North Carolina Health Professions Data Book. The patients' counties of residence were manually matched with selected variables from the Census 2000, the North Carolina State Center for Health Statistics, the North Carolina Health Professions Data Book and the North Carolina Division of Facility Services.

Sample

Patient Data

The final sample extracted for analysis included 3,864 referred hospice patients, of which 3,571 were hospice users and 293 were hospice non-users. None of the hospice users were excluded. From the hospice non-users group, 134 of the non-users did not enroll in hospice because of a patient-driven reason¹⁶ and 120 did not enroll for a prognosis-driven reason.¹⁷ Nine of the non-users were excluded because they eventually did enroll in hospice

¹⁶ 110 patients in the patient-driven non-use group did not use hospice because they refused (and gave no specific reason for refusal), and 24 patients in this group were seeking curative/aggressive treatment at the time of referral and were not eligible for admission.

¹⁷ 18 patients in the prognosis-driven non-use group did not use hospice because they had a prognosis greater than 6 months, and 102 patients in this group died before admission or were actively dying and unrealistic candidates for home hospice.

after a second referral, and 30 of the non-users were excluded because they did not enroll in hospice for an “other” reason, indicating that they either enrolled in a different hospice or that the data were missing. Thus, the final number of non-users included in analyses was 254, and the final number of patients in the sample for analysis was 3,825. Significant differences existed between hospice users and non-users on race, diagnosis and referral source. More hospice users were White, had cancer, and were referred by a physician than hospice non-users. Table 10 summarizes characteristics of the patients in the sample along with the test statistics and p-values.

Table 10. *Selected Patient Characteristics*

Variable	Hospice Users ^a		Hospice Non-users ^b		Test statistics	
	N	%	N	%	Test statistic	p
Gender						
Male	1476	41.3	108	42.5	$\chi^2 = 0.138$.711
Race*						
White	2989	83.8	169	77.2	$\chi^2 = 6.549$.010
Marital Status						
Married	1519	43.9	92	44.2	$\chi^2 = 0.009$.926
Insurance						
Medicare	2794	79.2	183	78.5		
Medicaid	113	3.2	9	3.9		
Private	458	13.0	35	15.0	$\chi^2 = 3.078$.380
Self-pay	153	4.3	4	1.7		
Indigent	11	0.3	2	0.9		
Diagnosis*						
Cancer	1836	51.4	52	41.6	$\chi^2 = 4.655$.031
Referral Source**						
Physician-referred	984	27.6	40	16.3	$\chi^2 = 14.776$	<.001
Age	M = 77.2; SD = 14.50		M = 77.9; SD = 15.94		t (283.643) = -.650	.516

^aN = 3571. ^bN = 254.

*p≤.05. **p≤.001

To verify the representativeness of the sample, the demographics of hospice users in the sample were compared to the demographics of hospice users in North Carolina, as compiled by the Carolinas Center for Hospice and End-of-Life Care ("The Carolinas Center for Hospice and End-of-Life Care," 2004). As displayed in Table 11, significant differences on age, race and insurance status existed between the sample hospice users and hospice users in North Carolina. The sample contained more hospice users who were older, White, and were privately insured, self-pay or indigent than the documented hospice users in North Carolina. Data among hospice users in North Carolina were unavailable for gender and marital status.

Table 11. *Sample Characteristics Compared with Demographics of Hospice Users in North Carolina*

Variable	Hospice Users in Sample ^a		Hospice Users in North Carolina ^b		Test statistics	
	N	%	N	%	χ^2	p
Race**						
White	2989	83.3	17,267	79.9	$\chi^2 = 29.983$	<.001
Insurance**						
Medicare	2794	79.2	23,019	86.7	$\chi^2 = 347.382$	<.001
Medicaid	113	3.2	1,362	5.13		
Private	458	13.0	1,530	5.76		
Other	164	4.6	651	2.45		
Diagnosis						
Cancer	1836	51.4	11,117	49.75	$\chi^2 = 3.042$.065
Age**						
0-17	8	0.2	82	0.4	$\chi^2 = 168.602$	<.001
18-34	14	0.4	178	0.8		
35-64	651	18.2	4,511	20.3		
65-74	575	16.1	4,518	20.3		
75-84	1017	28.5	7,111	31.9		
85 & up	1304	36.5	5,869	26.4		

Note. Demographics compiled by The Carolinas Center for Hospice and End-of-Life Care (Accessed August 2, 2007). Available online: <http://www.carolinas.endoflifecare.org/Statistics2004.html>

^aN = 3571. ^bN ≈ 26,563, exact figure not available. This figure represents number of patients served by hospices in 2004, not number of patients reported in the data.

**p<.001.

Contextual Data

Patients in this sample were from a total of 12 counties in North Carolina. However, only 3 counties, named Counties A, B and C for the purposes of this study, had patients who were hospice users, hospice non-users for a patient-driven reason and hospice non-users for a prognosis-driven reason. All of the other counties had few to no patients in one or more of the outcome groups. Per recommendation of the population center at UNC-CH (telephone communication with Chris Weissen, statistical consultant, August 8, 2007), patients from the remaining 9 counties were combined and considered part of County D (or “Other” County) for the purposes of this study. This method of coding allowed for the planned statistical analyses to take place while not presenting a threat to the integrity of the remaining data. Of the 3,825 patients in the sample, 2,992 patients were from County A, 281 patients were from County B, 292 patients were from County C, and 245 patients were from County D. The characteristics of each county are shown in Table 12.

In order to explore whether racial and ethnic minorities in the sample were representative of racial and ethnic minorities in the geographic catchment area, the proportion of non-White patients in the entire sample (including hospice users and hospice non-users) was compared to the proportion of non-White hospice users in each county (as reported by the Carolinas Center for Hospice and End-of-Life Care). Non-White hospice users represented 16.4-17.8% of the hospice users in the sample, depending on the county from which they were referred, while non-Whites in the general population of each county represented 22.0-27.6% of the population in that county. The difference in proportions was statistically significant ($\chi^2 = 14.888$, $p < .001$).

Table 12. *Selected contextual characteristics in each county*

Variables	County A	County B	County C	County D
% Male	50%	47%	49%	47-53%
Median Age	32.9	30.4	38.8	32.2-36.5
Average Household Size	2.51	2.36	2.47	2.40-2.61
% Married	56.4%	45.3%	60.2%	47.0-60.9%
% High School Diploma	89.3%	87.6%	77.9%	68.1%-83.0%
% White	72.4%	78.0%	74.9%	48.2%-78.1%
Unemployment Rate	1.5	1.3	1.9	2.2-8.9
Per Capita Income	\$35,759	\$29,500	\$30,046	\$19,705-25,740
% Below Poverty Level	7.8%	14.1%	9.7%	11.1-20.5%
# Physicians per 10,000 population	22.2	87.1	6.9	6.1-64.2
# Hospital Beds	1197	578	68	62-1294
# Skilled Nursing Facility Beds	2060	443	340	232-1312
# Inpatient Hospice Beds	14	6	0	0-7
# Hospice Facilities Serving	20	8	9	3-14
# Deaths per year	3509	692	482	423-1843
Cancer Death Rate	180.5	188.2	176.7	196.8-244.5
Leading Cause of Death	Cancer	Cancer	Cardiovascular Disease	Cancer/ Cardiovascular Disease

Note. Because County D is a combination of multiple counties, ranges are given. Data were taken from the United States Census for the year 2000, the North Carolina State Center for Health Statistics, the North Carolina Health Professions Data Book (2005), and the North Carolina Division of Facility Services (2006).

Institutional Data

A total of 1024 patients (984 hospice users and 40 hospice non-users, representing 26.8% of the sample) were referred from one of 630 physicians. Although 699 physician names were collected from the individual data, 56 physicians were excluded because no data existed for them in the North Carolina Health Professions Data Book¹⁸ and 12 physicians were excluded because they were residents at the time of referral.¹⁹ One physician was excluded because he referred one patient to hospice before he graduated from medical school or had a medical license, causing validity concerns. The patients who were referred by excluded physicians were kept in the sample and were considered physician-referred, with the physician data treated as missing. Table 13 displays the sample physician characteristics stratified by the hospice users and hospice non-users groups. The only significant difference between groups was the hospice agency to which the patient was referred. More patients referred to Hospice B became hospice users than patients referred to Hospice A.

¹⁸ Potential reasons physicians were not found in the North Carolina Health Professions Data Book are: 1) the physician was a medical resident at the time of referral; 2) the physician's name/UPIN number were incorrectly entered into the administrative database.

¹⁹ In the state of North Carolina, medical residents may not legally refer patients for home services. These data were, therefore, considered an error in collection.

Table 13. *Selected institutional characteristics*

	Group	Hospice Users ^a		Hospice Non-users ^b		Test Statistics	
		N	%	N	%	Statistic	p
Hospice [*]							
	A	530	14.8	84	33.1	$\chi^2 = 7.671$.006
Physician Characteristics							
Gender							
	Male	716	76.3	29	82.9	$\chi^2 = 0.819$.366
Race							
	White	768	82.9	28	77.8	$\chi^2 = 0.082$.774
Specialty							
	Hematology/oncology	443	47.2	13	37.1	$\chi^2 = 1.365$.243
	Other	496	52.8	22	62.9		
Primary Practice Location							
	Hospital	151	16.4	5	15.2	$\chi^2 = 0.036$.849
	Age	M = 49.1, SD = 8.45		M = 50.5, SD = 9.64		t (35.972) = -0.850	.401
	Time licensed (years)	M = 16.5, SD = 9.59		M = 14.54, SD = 10.04		t (36.349) = 1.156	.228
	Clinical hours/week	M = 46.7, SD = 13.01		M = 45.4, SD = 11.74		t (34.880) = 0.603	.551

Note. The N is higher for the data given for hospice because all patients, regardless of whether they were referred by a physician, had potential data for this variable. Only patients referred by a physician had potential data for the physician characteristics. N given is for number of *patients* in each sample sub-group.

^aN = 3571 for hospice agency; N = 939 for physician characteristics. ^bN = 254 for hospice agency; N = 36 for physician characteristics.

*p ≤ .05.

In exploring the characteristics of the sample, two major unanticipated sub-samples emerged: 1) physician-referred patients (N = 1024) and 2) patients referred by a source other than a physician (namely social workers, nurses, family members, or friends; N = 2789). Only about one-fourth of the sample was referred by a physician; therefore, only about one-fourth of the sample had variables for physician characteristics. In an effort to obtain a more thorough description of the sample and to prepare for the model-building analyses, the characteristics of patients who were physician-referred were compared to the characteristics of patients who were referred by a source other than a physician. Significant differences existed between these groups on the patient's gender, marital status, diagnosis, and age. The group of patients referred by a physician contained more patients who were male, married, had cancer and were younger than the group containing patients referred by a source other than a physician. Table 14 compares the two groups on the patient variables.

Table 14. *Selected patient characteristics shown by referral source*

Patient Characteristic	Patients referred by a physician ^a		Patients referred by a source other than a physician ^b		Test Statistics	
	N	%	N	%	Statistic	p
Gender ^{**}						
Male	470	45.9	1107	39.7	$\chi^2 = 11.90$	<.001
Race						
White	862	84.7	2291	82.9	$\chi^2 = 1.607$.205
Marital Status ^{**}						
Married	504	51.4	1101	41.1	$\chi^2 = 30.91$	<.001
Diagnosis ^{**}						
Cancer	641	63.7	1242	46.4	$\chi^2 = 87.42$	<.001
Insurance						
Medicare	809	80.0	2159	78.8	$\chi^2 = 0.701$.402
Other	202	20.0	582	21.2		
Age ^{**}	M = 78.0, SD = 14.32		M = 81.0, SD = 14.64		$t(1858.639) = 0.509$	<.001

^aN = 1024. ^bN = 2789.^{**}p ≤ .001.

Other institutional factors that were examined in this study were operationalized through the reasons that patients did not use hospice after referral. Patients who did not enroll because they were actively dying, died before admission or did not meet the 6-month prognostic criteria were considered to have a prognosis-driven reason not to enroll. In an effort to further explore the issues related to the prognostic eligibility guidelines, patients who did not use hospice because they were actively dying or died before admission were compared to patients who did not use hospice because they had a prognosis greater than 6 months. The patients were significantly different both on age and marital status. Patients who did not use hospice because they were actively dying or died before admission were significantly more

likely to be married than patients who were referred with a prognosis greater than 6 months (51.1% vs. 11.1%; $\chi^2 = 5.246$, $p = .022$). Patients who were actively dying or died before admission were also significantly younger than those who had a prognosis greater than 6 months [$M = 80.1$, $SD = 12.33$ vs. $M = 85.3$, $SD = 7.36$, respectively [$t(21.290) = 2.197$, $p = .029$]. In addition, both the hospice to which the patient was referred and the county from which the patient was referred were significantly different between patients who did not use hospice because they were actively dying/died before admission and those who had a greater than 6-month prognosis. More patients referred to Hospice A did not use hospice because they had a prognosis greater than 6 months as compared to patients referred to Hospice B (28.9% vs. 2.4%) ($\chi^2 = 18.889$, $p < .001$). More patients referred from County A did not use hospice because they were actively dying or died before admission as compared to patients from Counties B, C or D (98.6% vs. 46.7%, 89.5% and 75.0%, respectively) ($\chi^2 = 34.910$, $p < .001$). The patient's marital status and age were moderately and significantly correlated ($r = .436$, $p < .001$).

Similarly, patients who did not use hospice because they refused or were pursuing aggressive treatment were considered to have a patient-driven reason not to use. In an effort to further explore the issues related to the treatment eligibility guidelines, the characteristics of patients who refused were compared to the characteristics of patients who were pursuing aggressive treatments. No significant differences existed between these patients on any of the individual factors; however, more patients referred to Hospice A did not use hospice because they were pursuing aggressive treatment as compared to patients referred to Hospice B (30.4% vs. 11.4%) ($\chi^2 = 7.473$, $p = .006$). A significant difference also existed on the county from which the patient was referred: fewer patients from County A did not meet the

treatment eligibility criteria as compared to patients referred from Counties B, C or D (9.9% vs. 29.4%, 35.0% and 33.3%, respectively) ($\chi^2 = 10.717$, $p = .013$).

Because it was possible that one physician in the sample referred more than one patient in the sample, additional analyses were conducted to learn if physicians with high rates of patient referrals in the sample were skewing the findings. Physicians who each referred greater than 1.0% of the sample were grouped together for a comparison with physicians who each referred less than 1.0% of the sample. The 19 physicians who each referred greater than 1.0% of the sample accounted for 47.7% of the patients in the sample. No significant difference existed on hospice use versus non-use status between patients referred by these physicians and patients referred by physicians with a low percentage of referrals (<1.0%), even when the sample was limited to racial and ethnic minority patients. Additionally, no significant difference existed on hospice non-use for a patient-driven reason versus prognosis-driven reason between physicians with many referrals versus few referrals, even when the sample was reduced to racial and ethnic minority patients.

The statistical modeling plan was described in Table 9. The results from each model are presented individually for Specific Aims #1, 2 and 3 in the following sections, and the corresponding tables include the results from both the full and parsimonious models within each specific aim. Nonetheless, because all of the variables included in the study were chosen based on previous studies of hospice services and/or the current literature in health services research, only the results of the full model will be discussed in detail throughout this chapter. Given that the results of the parsimonious model may evoke additional information regarding hospice utilization and may suggest direction for future research, pertinent findings will be referenced in the summary at the end of this chapter and in Chapter VI. Unless otherwise

indicated, results with p-values $\leq .05$ are considered statistically significant, and all results are presented with 95% confidence intervals. When applicable, power calculations were performed using the program offered by the University of Vanderbilt (Dupont & Plummer, 1990).

Specific Aim #1²⁰

1A: Hospice Use vs. Non-use = Individual factors

The results of the logistic regression for individual factors associated with hospice use are presented in Table 15. The results of the full model indicate that gender, race and diagnosis are significant predictors of hospice utilization after referral. Patients who were female [1.879, (1.143, 3.086), $p = .013$] or White [1.921, (1.123, 3.288), $p = .017$] were 1.9 times more likely to use hospice after referral, and patients who had cancer were 1.7 [(1.025, 2.819), $p = .040$] times more likely to use hospice. Gender, race and diagnosis were not highly correlated [$p = .002$ (gender/race), .139 (gender/diagnosis), -.104 (race/diagnosis)], although a significantly higher percentage of non-Whites (62.8%) had cancer than Whites (48.8%) [$\chi^2 = 39.545$, $p < .001$]. In addition, males had a significantly higher percentage of cancer diagnoses (59.4%) than females (45.2%) [$\chi^2 = 71.843$, $p < .001$].

Because the sample included two types of referred patients, those who were physician-referred and those who were referred by a source other than a physician, additional analyses had to be completed to help build the models that included institutional variables in Specific Aims #2 and #3. Thus, two additional models were run with the patient variables: 1) including only physician-referred patients and 2) including only patients referred by a source

²⁰ Specific Aim #1: To determine individual factors associated with hospice use, contextual factors of a patient's place of residence associated with hospice use, and institutional factors associated with hospice use for all referred patients and for referred racial and ethnic minorities.

other than a physician. The findings indicate no significant differences between hospice users and non-users on the patient variables for physician-referred patients. In the model of patients referred by a different source, however, gender was the only significant predictor of hospice use. Males were half as likely to use hospice after referral as females [0.538, (0.311, 0.934), $p = .027$].

Table 15. *Specific Aim #1A: Model of individual factors to determine hospice use vs. hospice non-use after referral, including entire sample of referred hospice patients^a*

Variable	Bivariate Analysis			Full Model ^{b,c}			Parsimonious Model ^d		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Female*	-0.049 (0.131)	0.952 (0.736,1.232)	.711	-0.631 (0.253)	0.532 (0.324,0.875)	.013	-0.552 (0.234)	0.576 (0.364,0.910)	.018
Age	0.003 (0.005)	1.003 (0.994,1.012)	.481	-0.004 (0.008)	0.996 (0.979,1.012)	.617	-	-	-
Non-White*	0.425 (0.167)	1.530 (1.102,2.124)	.011	0.653 (0.274)	1.921 (1.123,3.288)	.017	0.707 (0.266)	2.028 (1.203,3.419)	.008
Not married	-0.013 (0.144)	0.987 (0.744,1.308)	.926	0.224 (0.258)	1.251 (0.754,2.075)	.386	-	-	-
Non-cancer*	0.396 (0.185)	1.486 (1.035,2.133)	.032	0.530 (0.258)	1.700 (1.025,2.819)	.040	0.529 (0.238)	1.697 (1.064,2.706)	.026
Referred by non-physician	0.669 (0.177)	1.952 (1.380,2.760)	<.001	0.368 (0.295)	1.445 (0.811,2.575)	.211	-	-	-
Insurance									
Medicare				Reference					
Medicaid	0.196 (0.355)	1.216 (0.607,2.437)	.581	-0.906 (1.015)	.404 (.055,2.957)	.372	-	-	-
Private	0.154 (0.191)	1.167 (0.802,1.697)	.420	0.224 (0.324)	1.251 (0.663,2.360)	.490	-	-	-
Self-pay	-0.918 (0.512)	0.399 (0.146,1.089)	.073	-0.525 (0.725)	0.591 (0.143,2.448)	.469	-	-	-
Indigent	1.021 (0.772)	2.776 (0.611,12.617)	.186	1.568 (1.074)	4.798 (0.585,39.344)	.144	-	-	-

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; marital status = married; diagnosis = cancer; referral source = physician-referred; insurance = Medicare. Parsimonious model results are based on logistic regression with backwards elimination strategy; SLS = 0.05

^aN = 3490. ^bFull model $R^2 = 0.032$. ^cAdditional patient-level models were completed separately for only physician-referred patients and for patients who were referred by a source other than a physician. The findings indicated no significant differences in the variables for physician-referred patients; in the model of patients referred by a source other than a physician, gender and race were significant predictors of hospice non-use ($p = .027$ & $.065$, respectively, in the full model; $N = 2548$, $R^2 = .023$).

^dParsimonious model $R^2 = 0.022$.

* $p \leq .05$ in full model.

1B: Hospice Use vs. Non-use = Contextual Factors

As shown in Table 16, bivariate analyses indicate that county is a significant predictor for hospice use after referral. Patients from Counties B and C were about 2.4 (1.605, 3.592) and 2.9 (1.980, 4.189) times less likely to use hospice after referral than patients from County A, respectively ($p < .001$). Patients from County D were not significantly different than patients from Counties A or B on their hospice utilization status; however they were significantly different from County C [2.206 (1.200, 4.055), $p = .011$]. Patients from County D were more likely to use hospice after referral than patients from County C.

For the same reasons described above, the model of contextual factors to determine hospice use versus non-use was also tested with patients who were referred by a physician and with patients who were referred by another source. In the model of physician-referred patients, patients from County B were 3.5 (1.391, 9.222) times less likely to use hospice after referral than patients from County A ($p = .008$). In the model of patients referred by a source other than a physician, patients from Counties B and C were 1.9 (1.205, 3.129) and 3.0 (1.935, 4.557) times less likely to use hospice after referral than patients from County A ($p = .006, <.001$, respectively).

Table 16. *Specific Aim #1B: Model of contextual factors to determine hospice use vs. hospice non-use after referral, including entire sample of referred hospice patients^a*

Variable	β (SE)	Bivariate Analysis ^{b,c}	
		OR (95% CI)	p
A		Reference	
B ^{**}	0.876 (0.205)	2.401 (1.605,3.592)	<.001
C ^{**}	1.058 (0.191)	2.880 (1.980,4.189)	<.001
D	0.267 (0.272)	1.305 (0.767,2.223))	.327

Note. Odds ratio is for the probability of hospice non-use. County A is reference county for analysis.

^a N=3825. ^b R²=0.026. ^c Additional contextual-level models were completed separately for physician-referred patients and for patients referred by a source other than a physician. In the model of physician-referred patients, patients from County B were significantly different from patients from County A (p = .008; N = 975, R² = .027). In the model of patients referred by a source other than a physician, patients from Counties B and C were significantly different from patients from County A (p = .006, <.001, respectively; N = 2774, R² = .023).

^{**} p≤.001.

As described in the statistical modeling plan in Chapter IV, the contextual variables from each county were entered into the model because county was significant as a fixed effect; however, only the characteristics of 3 counties (Counties A, B and C) were available for further analysis. This small sample size of counties resulted in linear dependency. Linear dependency occurred because every patient from County A had the same values for the contextual variables, every patient from County B had the same values for the contextual variables, and every patient from County C had the same values for the contextual variables. This pattern resulted in every patient having only one of three combinations of contextual variables (because included patients were from one of three counties), making it impossible to determine which contextual variables could predict hospice utilization (Pett, Lackey, & Sullivan, 2003). Because the inclusion of the contextual variables (aside from the fixed effect of county) was no longer possible as planned with this limitation, additional analyses were completed to further describe the counties and are detailed in Appendices A and B.²¹

²¹ These analyses are included as appendices to avoid confusion in this Chapter.

1C: Hospice Use vs. Non-use = Institutional Factors

The results of the logistic regression for institutional factors associated with hospice use are presented in Table 17. The physician's gender and whether or not the physician's race was the same as the patient's race were significant. Patients who were referred by male physicians were less likely to use hospice than patients who were referred by female physicians [0.195 (0.043, 0.883), $p = .034$]. Patients who were referred by physicians who were of the same race/ethnicity as themselves [3.151 (1.303, 7.619), $p = .011$] were more likely to enroll in hospice after referral than patients who were referred by physicians of a different race than themselves. Additionally, the hospice agency to which the patient was referred was a marginally significant predictor of the patient's subsequent hospice use ($p = .056$). Patients referred to Hospice B were 2.7 (0.977, 7.519) times more likely to use hospice than patients referred to Hospice A [0.369 (0.133, 1.024)]. None of the significant variables were highly correlated ($\rho < 0.3$ for all relationships).

An analysis of institutional variables was conducted separately for patients who were referred by a source other than a physician and for the entire sample. Because not all of these patients were referred by a physician, the only institutional variable applicable (and available in the current data) was the hospice agency. The results indicate that, within the group of patients referred by a source other than a physician, the hospice agency did significantly predict hospice use versus non-use after referral [0.390 (0.285, 0.535), $p < .001$]. Patients who were referred to Hospice B were 2.6 (1.869, 3.509) times more likely to enroll in hospice than patients who were referred to Hospice A. The findings were similar when the entire sample of referred hospice patients was analyzed; patients from Hospice B were 2.8

(2.151, 3.755) times more likely to use hospice after referral compared to patients from Hospice A [0.353 (0.267, 0.465), $p < .001$].

Table 17. *Specific Aim #1C: Model of institutional factors to determine hospice use vs. hospice non-use after referral, including entire sample of referred hospice patients^a*

Variable	Bivariate Analysis			Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Hospice B [†]	-0.975 (0.365)	0.377 (0.185,0.771)	.008	-0.996 (0.520)	0.369 (0.133,1.024)	.056	-	-	-
Physician Variables									
Female [*]	-0.409 (0.455)	0.664 (0.272,1.621)	.369	-1.635 (0.771)	0.195 (0.043,0.883)	.034	-1.590 (0.745)	0.204 (0.047,0.878)	.033
Physician age	0.020 (.020)	1.020 (0.980,1.061)	.337	0.025 (0.016)	1.025 (0.993,1.059)	.131	-	-	-
Non-White	-0.142 (0.493)	0.868 (0.330,2.283)	.774	-0.868 (0.663)	0.420 (0.115,1.538)	.190	-	-	-
Racially un-matched [*]	0.645 (0.384)	1.906 (0.897,4.047)	.093	1.148 (0.450)	3.151 (1.303,7.619)	.011	0.852 (0.390)	2.344(1.092,5.031)	.029
Time licensed	-0.023 (0.019)	0.977 (0.942,1.014)	.228	-0.025 (0.021)	0.975 (0.935,1.017)	.244	-	-	-
Clinic-based	0.094 (0.494)	1.098 (0.417,2.889)	.850	0.852 (0.682)	2.345 (0.616,8.931)	.212	-	-	-
Clinical hours/week	-0.007 (0.013)	0.993 (0.967,1.019)	.584	-0.017 (0.016)	0.983 (0.953,1.014)	.278	-	-	-
Specialty									
Hematology/Oncology					Reference				
Internal medicine, including all subspecialties except hematology/oncology	0.292 (0.399)	1.339 (0.613,2.928)	.464	-0.348 (0.492)	0.706 (0.269,1.851)	.479	-	-	-
Family practice	0.529 (0.479)	1.697 (0.664,4.337)	.270	-0.693 (0.657)	0.500 (0.138,1.813)	.292	-	-	-
Other, including surgical specialties	0.655 (0.780)	1.925 (0.418,8.873)	.401	0.682 (0.870)	1.977 (0.359,10.887)	.433	-	-	-

Note. Odds ratio is for the probability of hospice non-use; References for analyses: hospice agency = A; physician gender = male; physician race = White; racial match = match; primary practice location = hospital-based; primary specialty = hematology/oncology. Parsimonious model results based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 946. ^bFull model R² = 0.086. ^cParsimonious model R² = 0.042.

*p ≤ .05 in full model. [†]Marginally significant (p < .10) in full model.

ID: Hospice Use vs. Non-use = Individual Factors (For Racial/Ethnic Minorities)

None of the variables in the full model were significant for any individual factors associated with hospice utilization after referral for racial and ethnic minorities. The results are displayed in Table 18. Power analyses were conducted to determine if the sample size was big enough to detect differences between groups. The results suggest that the variable of patient's gender was the most limiting variable, with a power of only 5.1% to detect the observed difference in gender. This was only enough power to detect a 27% difference between groups on gender. Power was also inadequate (<80%) for insurance status (13.0%), diagnosis (10.0%) and referral source (19.8%).

To prepare for the building of models that included both patient and institutional variables in the same model (Specific Aims #2 and #3), the models were re-run including only physician-referred patients and only patients referred by a different source. None of the variables were significant in either of these samples. Power was sufficient (>80%) to detect differences in gender, marital status, and age for patients referred by a physician; power was inadequate (<80%) to detect differences among all variables for patients referred by a source other than a physician.

Table 18. *Specific Aim #1D: Model of individual factors to determine hospice use vs. hospice non-use after referral, including only racial and ethnic minorities^a*

Variable	Bivariate Analysis			Full Model ^b			Parsimonious Model		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Female	-0.034 (0.299)	0.967 (0.538,1.736)	.910	-0.619 (0.509)	0.539 (0.199,1.460)	.224	-	-	-
Age	0.007 (0.009)	1.007 (0.989,1.026)	.432	0.009 (0.016)	1.009 (0.978,1.041)	.577	-	-	-
Not Married	-0.603 (0.318)	0.547 (0.293,1.021)	.058	-0.507 (0.500)	0.603 (0.226,1.604)	.310	-	-	-
Non-cancer	0.156 (0.401)	1.169 (0.533,2.566)	.696	0.048 (0.499)	1.050 (0.395,2.793)	.923	-	-	-
Referred by non-physician ^c	0.146 (0.356)	1.157 (0.576,2.322)	.682	0.324 (0.581)	1.383 (0.443,4.314)	.577	-	-	-
Other insurance (non-Medicare) ^d	0.372 (0.341)	1.450 (0.743,2.830)	.276	-0.381 (0.647)	0.683 (0.192,2.430)	.556	-	-	-

Note. Odds ratio is for probability of hospice non-use. References for bivariate analyses: gender = male; marital status = married; diagnosis = cancer; referral source = physician-referred; insurance = Medicare. Parsimonious model results based on logistic regression with backwards elimination strategy; SLS = 0.05. Power was only sufficient (>80%) for detecting differences in age and marital status.

^aN = 553. ^bFull model $R^2=0.033$. ^cAdditional analyses were run separately for physician-referred patients (N =131) and for patients referred by a source other than a physician (N = 417); none of the variables were significant. ^dDue to the absence of self-pay patients and limited indigent patients/patients with Medicaid in the hospice non-use group, insurance status was coded as Medicare vs. other source of payment (including Medicaid, private insurance, self-pay, and indigent).

1E: Hospice Use vs. Non-use = Contextual Factors (For Racial/Ethnic Minorities)

As shown in Table 19, county was a significant predictor of hospice utilization after referral for racial and ethnic minorities. Referred minority patients from County B were 2.5 (1.038, 6.031) times less likely to use hospice than referred minority patients from County A ($p = .041$). Minority patients from County C were about 4.2 (1.971, 9.060) times less likely to use hospice than minority patients from County A ($p < .001$). The referred patients from County D were not significantly different from referred patients from County A on their hospice utilization status ($p = .442$).

The model of contextual factors to determine hospice use for racial and ethnic minorities was also tested by referral source (physician-referred vs. referred by another source). In the model of physician-referred patients, too few patients were referred from County B to obtain reliable statistics. On the other hand, patients referred from Counties C and D were not significantly different from patients referred from County A ($p = .138$, $p = .430$, respectively); however, calculations suggest power was inadequate ($< 80\%$) to detect differences between Counties A and C (37.0%) and between Counties A and D (6.5%). In the model including patients referred by a source other than a physician, non-White patients from Counties B and C were 2.7 (1.045, 7.198) and 4.5 (1.736, 11.414) times less likely to use hospice after referral than non-White patients from County A ($p = .040$, $p = .002$, respectively). Too few patients were referred from County D to obtain reliable statistics.

Table 19. *Specific Aim #1E: Model of contextual factors to determine hospice Use vs. hospice non-use after referral, including only racial and ethnic minorities^a*

Variable	Bivariate Analysis ^{b,c}		
	β (SE)	OR (95% CI)	p
County			
A		Reference	
B [*]	0.917 (0.449)	2.502 (1.038,6.031)	.041
C ^{**}	1.441 (0.389)	4.226 (1.971,9.060)	<.001
D	-0.794 (1.032)	0.452 (0.060,3.416)	.442

Note. Odds ratio is for the probability of hospice non-use. County A is reference county for analysis

^aN = 627. ^bR² = .057. ^cAdditional contextual-level models were completed separately for physician-referred patients and for patients referred by a source other than a physician. The findings indicated no significant differences in county for physician-referred patients (N = 148); in the model of patients referred by a source other than a physician, Counties B and C were significantly different from County A (p = .040, p = .002; N = 470, R² = .074).

*p ≤ .05. **p ≤ .001.

1F: Hospice Use vs. Non-use = Institutional Factors (For Racial/Ethnic Minorities)

The results of the analyses to determine institutional factors associated with hospice use for racial and ethnic minorities are displayed in Table 20. None of the variables were significant predictors of hospice utilization in this model. Power calculations suggest that the variable representing the physician's race was the limiting variable with a power less than 5.0% to detect observed differences – only enough power to detect a 35% difference between groups. Power was also insufficient (<80%) for detecting differences between groups on the physician's gender (45.2%), age (56.6%), time licensed (5.9%), the racial match between the physician and the patient (5.9%), the physician's primary practice location (8.3%), and the hospice to which the patient was referred (9.8%).

For minority patients who were referred to hospice by a source other than a physician, the specific hospice agency was a significant predictor of hospice use versus non-use. Non-White patients who were referred to Hospice B were 3.5 (1.712, 7.092) times more likely to

use hospice than non-White patients who were referred to Hospice A ($p = .001$). Similarly, when the model was tested with the entire sample, patients referred to Hospice B were 2.8 (2.151, 3.743) times more likely to use hospice after the referral than those referred to Hospice A ($p < .001$).

Table 20. *Specific Aim #1F: Model of institutional factors to determine hospice use vs. hospice non-use, including only racial and ethnic minorities^a*

Variable	Bivariate Analysis			Full Model ^b			Parsimonious Model		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p	β (SE)	SE (95% CI)	p
Hospice B	-0.477 (0.721)	0.621 (0.151,2.551)	.508	-1.643 (1.019)	0.193 (0.026,1.424)	.107	-	-	-
Physician Variables									
Female	-0.382 (0.814)	0.682 (0.139,3.362)	.639	0.744 (1.073)	2.105 (0.257, 17.226)	.488	-	-	-
Physician age	0.014 (0.041)	1.014 (0.935,1.099)	.740	0.141 (0.103)	1.151 (0.941,1.409)	.172	-	-	-
Non-White ^c	-	-	-	-	-	-	-	-	-
Racial un-match	-0.249 (1.100)	0.780 (0.090,6.732)	.821	0.116 (1.310)	1.123 (0.086,14.647)	.929	-	-	-
Time licensed [†]	-0.023 (0.039)	0.977 (0.905,1.055)	.550	-0.143 (0.083)	0.867 (0.737,1.020)	.086	-	-	-
Clinic-based	1.019 (1.073)	2.769 (0.338,22.696)	.343	2.291 (1.415)	9.889 (0.617,158.411)	.105	-	-	-
Clinical hours/week	0.028 (0.027)	1.029 (0.976,1.085)	.290	0.026 (0.034)	1.026 (0.960,1.097)	.449	-	-	-
Primary Specialty other than Hematology/ Oncology ^d	-0.347 (0.668)	0.706 (0.191,2.614)	.603	-1.003 (0.905)	0.367 (0.062,2.164)	.268	-	-	-

Note. Odds ratio is for the probability of hospice non-use. References for analyses: hospice agency = A; physician gender = male; racial match = match; primary practice location = hospital-based; primary specialty = hematology/oncology. Parsimonious model results based on logistic regression with backwards elimination strategy; SLS = 0.05. Power was only sufficient (>80%) to detect differences in groups on specialty and clinical hours/week.

^aN = 146. ^bFull model R² = .139. ^cOnly one non-White physician referred a patient who did not use hospice, therefore, this variable could not be included. ^dDue to lack of/limited number of physicians specializing in internal medicine, family practice, and other/surgical specialties in the hospice non-use group, specialty was coded as hematology/oncology versus other specialties (including internal medicine, family practice, surgical services and other).

[†]Marginally significant (p < .10) in full model.

IG: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Individual Factors

The results of the logistic regression for individual factors associated with hospice non-use for a patient-driven reason versus a prognosis-driven reason are shown in Table 21. After adjusting for other variables, non-White patients were 7.1 (1.775, 28.319) times more likely to have a prognosis-driven reason not to use hospice after referral than White patients (p=.006).

The model was not run separately for patients referred by a physician due to sample size concerns and missing variables (N = 14). For patients referred by a source other than a physician, none of the patient variables were significant in the prediction of hospice non-use by reason (N = 206). Calculations suggest power was only adequate (>80%) to detect differences between groups on age.

Table 21. *Specific Aim #1G: Model of individual factors to determine hospice non-use for patient-driven reason vs. hospice non-use for prognosis-driven reason, including entire sample^a*

Variable	Bivariate Analysis			Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Female	-0.063 (0.254)	0.939 (0.570,1.545)	.804	-0.976 (0.712)	0.377 (0.093,1.522)	.171	-	-	-
Age	0.023 (0.009)	1.023 (1.006,1.041)	.010	0.013 (0.025)	1.014 (0.965,1.065)	.595	-	-	-
Non-White *	-0.015 (0.324)	0.985 (0.522,1.859)	.962	1.959 (0.707)	7.090 (1.775,28.319)	.006	1.612 (0.589)	5.011 (1.578,15.910)	.006
Not married	-0.243 (0.280)	0.785 (0.453,1.359)	.387	-0.500 (0.662)	0.607 (0.166,2.221)	.450	-	-	-
Non-cancer	0.126 (0.396)	1.135 (0.522,2.468)	.750	1.064 (0.712)	2.899 (0.719,11.699)	.135	-	-	-
Referred by non-physician	0.760 (0.365)	2.139 (1.045,4.376)	.037	-0.450 (0.762)	0.637 (0.143,2.839)	.555	-	-	-
Other insurance (Non-Medicare) ^d	-0.373 (0.324)	0.689 (0.365,1.301)	.251	0.373 (0.906)	1.452 (0.246,8.570)	.680	-	-	-

Note. Odds ratio is for the probability of hospice non-use for prognosis-driven reason. References for analyses: gender = male; race = White; marital status = married; diagnosis = cancer; referral source = physician-referred; insurance = Medicare. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=77. ^bFull model $R^2=0.248$. ^cParsimonious model $R^2=0.143$. ^d Due to the absence of indigent patients and limited self-pay patients/patients with Medicaid in prognosis-driven hospice non-use group, insurance status was coded as Medicare vs. other source of payment (including Medicaid, private insurance, self-pay, and indigent).

*p \leq .05 in full model.

1H: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Contextual Factors

The results of the logistic regression for contextual factors associated with hospice non-use for a patient-driven reason versus a prognosis-driven reason are listed in Table 22. The county of the patient's residence was not a significant predictor when the entire sample of non-users was included in the analysis. Calculations suggest power was inadequate (<80%) to detect differences in hospice utilization status between patients referred from County A and patients referred from Counties B (5.0%), C (5.0%), or D (5.7%).

Separate analyses were conducted for physician-referred patients and for patients referred by another source. The findings indicate that, while county was not a significant predictor of the reason for hospice non-use for patients referred by a different source, it was significant for patients who were referred by a physician. Patients who were referred from Counties B and C were 9.0 (1.031, 78.574) and 12.0 (1.482, 97.179) times more likely to have a prognosis-driven reason to not use hospice than patients who were referred from County A ($p = .020$ & $.047$, respectively). Calculations suggest power was inadequate to detect differences between patients referred by a source other than a physician from County A and patients referred by a source other than a physician from Counties B (5.2%), C (5.4%), and D (12.1%).

Table 22. *Specific Aim #1H: Model of contextual factors to determine hospice non-use for patient-driven reason vs. hospice non-use for prognosis-driven reason, including entire sample*

Sample	Variable	Bivariate Analysis		
		β (SE)	OR (95% CI)	p
Entire Sample ^a	County			
	A		Reference	
	B	0.007 (0.390)	1.007 (0.469,2.161)	.986
	C	0.080 (0.359)	1.084 (0.536,2.192)	.823
	D	-0.967 (0.600)	0.380 (0.117,1.232)	.107
Physician-referred ^b	A		Reference	
	B [*]	2.485 (1.067)	12.000 (1.482,97.179)	.020
	C [*]	2.197 (1.106)	9.000 (1.031,78.574)	.047
	D ^d	-	-	-
Referred by a source other than a physician ^c	A		Reference	
	B	-0.261 (0.464)	0.770 (0.310,1.911)	.573
	C	-0.273 (0.402)	0.761 (0.346,1.674)	.497
	D	-0.638 (0.651)	0.528 (0.147,1.894)	.327

Note. Odds ratio is for the probability of hospice non-use for prognosis-driven reason. County A is reference county for analysis.

^aN = 239; R² = .017. ^bN = 36; R² = .316. ^cN = 191. ^dToo few patients were referred from County D to be included in the analysis.

^{*}p ≤ .05.

II: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Institutional Factors

The results of the logistic regression for institutional factors associated with hospice non-use for a patient-driven reason versus a prognosis-driven reason are summarized in Table 23. After adjusting for all other variables, patients referred to Hospice B were 33.3 (1.081, 1,000.000) times more likely to have a patient-driven reason not to use hospice than patients referred to Hospice A ($p = .045$). Only 3 patients referred to Hospice B had a prognosis-driven reason not to use hospice, compared to 21 patients who had a patient-driven reason (only 12 patients were referred to Hospice A in this sample).

No significant differences existed between the groups on hospice agency when the entire sample was analyzed or when the sample was limited to patients who were referred by a source other than a physician. Calculations suggest power was inadequate ($<80\%$) to detect differences among hospice agency for both of these samples (6.3% for the entire sample; 23.4% for patients referred by a source other than a physician).

Table 23. *Specific Aim #II: Model of institutional factors to determine hospice non-use for patient-driven reason vs. hospice non-use for prognosis-driven reason, including entire sample^a*

Variable	Bivariate Analysis			Full Model ^b			Parsimonious Model		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Hospice B [*]	-0.282 (0.851)	0.102 (0.019,0.541)	.007	-3.514 (1.753)	0.030 (0.001,0.925)	.045	-	-	-
Physician Variables:									
Female	0.452 (0.969)	1.571 (0.235,10.491)	.641	1.970 (2.086)	7.171 (0.120,427.986)	.345	-	-	-
Age	0.026 (0.042)	1.026 (0.945,1.114)	.538	0.006 (0.112)	1.006 (0.808,1.253)	.956	-	-	-
Non-White ^c	-	-	-	-	-	-	-	-	-
Racially un-match	-0.743 (0.940)	0.480 (0.076,3.029)	.435	-2.210 (1.598)	0.110 (0.005,2.515)	.167	-	-	-
Time licensed	0.024 (0.038)	1.024 (0.951,1.103)	.529	0.039 (0.075)	1.040 (0.897,1.205)	.605	-	-	-
Clinic-based	-0.693 (1.012)	0.500 (0.069,3.633)	.493	-0.174 (1.931)	0.841 (0.019,36.972)	.928	-	-	-
Clinical hours/week	0.005 (0.034)	1.005 (0.940,1.074)	.888	0.081 (0.071)	1.084 (0.943,1.246)	.256	-	-	-
Primary specialty other than hematology/oncology ^d	-0.413 (0.787)	0.662 (0.141,3.097)	.600	-0.165 (1.345)	0.848 (0.061,11.844)	.903	-	-	-

Note. Odds ratio is for the probability of hospice non-use for prognosis-driven reason. References for analyses: hospice agency = A; physician gender = male; racial match = match; primary practice location = hospital-based; primary specialty = hematology/oncology. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 29. ^bFull model R² = 0.363. ^cDue to the absence of non-White physicians who referred patients to the prognosis-driven hospice non-use group, physician race was left out of analyses. ^dDue to lack of/limited number of physicians specializing in internal medicine, family practice, and other/surgical specialties in the prognosis-driven hospice non-use group, specialty was coded as hematology/oncology versus other specialties (including internal medicine, family practice, surgical services and other).

*p ≤ .05 in full model.

1J: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Individual Factors (For Racial/Ethnic Minorities)

The results of the patient model to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason for racial and ethnic minorities are shown in Table 24. None of the variables were significant in any of the models. The results of power calculations indicate that this sample size had approximately 5.0% power to detect differences on the patient's gender, age, marital status, insurance status and diagnosis. Power was also inadequate (<80%) to detect differences in referral source (28.4%).

None of the variables were significant when the model was completed for patients referred by a source other than a physician (N = 38). Calculations suggest that this sample size had between 5.0-9.5% power to detect differences on the patient's gender, age, marital status, insurance status and diagnosis. The model was not run for physician-referred patients due concerns with sample size (N = 11; only 2 patients referred by a physician had a prognosis-driven reason not to use hospice).

Table 24. *Specific Aim #1J: Model of individual factors to determine hospice non-use for patient-driven reason vs. hospice non-use for prognosis-driven reason, including only racial and ethnic minorities^a*

Variable	Bivariate Analysis			Full Model ^b			Parsimonious Model		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Female	0.080 (0.578)	1.083 (0.349,3.362)	.890	0.233 (0.806)	1.263 (0.260,6.133)	.772	-	-	-
Age	-0.004 (0.020)	0.996 (0.958,1.035)	.842	0.014 (0.023)	1.014 (0.968,1.061)	.565	-	-	-
Not Married ^c	-0.114 (0.613)	0.893 (0.268,2.970)	.853	-0.748 (0.826)	0.473 (0.094,2.391)	.365	-	-	-
Non-cancer ^c	0.606 (0.811)	1.833 (0.374,8.984)	.455	0.746 (0.975)	2.108 (0.312,14.260)	.445	-	-	-
Insurance other than Medicare ^d	0.018 (0.652)	1.018 (0.284,3.651)	.978	0.429 (0.822)	1.536 (0.307,7.698)	.601	-	-	-
Referred by non-physician	0.981 (0.751)	2.667 (0.612,11.614)	.191	1.302 (0.905)	3.677 (0.624,21.687)	.150	-	-	-

Note. Odds ratio is for the probability of hospice non-use for prognosis-driven reason. References for analyses: gender = male; marital status = married; diagnosis = cancer; referral source = physician-referred; insurance = Medicare. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05. Estimates indicate that power is inadequate (>80%) to detect difference on all variables.

^aN = 47. ^bR² = 0.145. ^cDue to small sample size, all missing values for this variable were coded as “unknown” and were included in the analyses. ^dDue to the absence of Medicaid, self-pay, and indigent patients in diagnosis/prognosis-driven hospice non-use group, insurance status was coded as Medicare vs. other source of payment (including Medicaid, private insurance, self-pay, and indigent).

1K: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Contextual Factors (For Racial/Ethnic Minorities)

As shown in Table 25, county was not significant in the model of contextual factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason by racial and ethnic minorities. Power calculations suggest this sample size had enough power to detect a 4.9% difference in the hospice non-use groups between Counties A and B, a 6.1% difference in the hospice non-use groups between Counties A and C, and a 6.9% difference in the hospice non-use groups between Counties B and C.

None of the variables were significant when the model was tested separately for patients who were referred by a source other than a physician (N = 38). Power calculations suggest this sample size had approximately 5.0% power to detect differences the hospice non-use groups between counties. A separate model for physician-referred patients was not analyzed due to the small sample size (N = 10; all physician-referred patients who did not use hospice for a prognosis-driven reason were referred from County C).

Table 25. *Specific Aim #1K: Model of contextual factors to determine hospice non-use for patient-driven reason vs. hospice non-use for prognosis-driven reason, including only racial and ethnic minorities^a*

Variable	B (SE)	Bivariate Analysis ^b OR (95% CI)	p
County A		Reference	
B	-0.019 (0.848)	0.981 (0.186,5.169)	.982
C	0.451 (0.709)	1.569 (0.391,6.295)	.525
D ^c	-	-	-

Note. Odds ratio is for probability of hospice non-use for prognosis-driven reason. County A is reference for analysis.

^aN = 48. ^bR²=0.012. ^cCounty D only added 1 additional patient and did not change the results; thus, County D was excluded from this analysis.

1L: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Institutional Factors (For Racial/Ethnic Minorities)

The model of hospice non-use for a patient-driven reason versus a prognosis-driven reason among racial and ethnic minorities referred by a physician was not tested due to concerns with sample size (N= 10; all patients in this sample who did not use hospice because of a prognosis-driven reason were referred to Hospice A).

For patients referred by a source other than a physician, however, the hospice agency to which the patient was referred was not a significant predictor of hospice non-use for a patient-driven reason versus a prognosis-driven reason [N = 39; 1.351 (0.370, 4.925), p = .649]. The results were similar when the entire sample was analyzed [N = 50; 0.802 (0.254, 2.531), p = .707]. Power calculations suggest that both samples had enough power to detect only about 6.0% difference in hospice agencies between the hospice non-use groups.

Specific Aim #1 Summary

In summary, four main models were examined separately for individual factors, contextual factors and institutional factors: 1) hospice use versus non-use, 2) hospice use versus non-use for racial and ethnic minorities, 3) hospice non-use for a patient-driven reason versus non-use for a prognosis-driven reason, and 4) hospice non-use for a patient-driven reason versus non-use for a prognosis-driven reason for racial and ethnic minorities. In addition, because the results from this section will be used to guide the analyses in the following sections (which combine patient and contextual factors with institutional factors such as provider characteristics), each model was examined separately for physician-referred patients and for patients referred by a source other than a physician.

Hospice Use versus Non-use. The patient's gender, race, and diagnosis were significant predictors of hospice use after referral when the entire sample was analyzed. Female patients, White patients, and patients with cancer were more likely to use hospice after referral than males, non-Whites and patients with non-cancer diagnoses. For patients referred by a source other than a physician, the patient's gender and race were significant predictors of hospice utilization in the same direction just described. For patients referred by a physician, no patient variables were significant predictors of utilization.

At the contextual level, the county from which the patient was referred was also significant. Regardless of referral source, patients from County A were more likely to use hospice after referral than patients from other counties. The planned additional analyses regarding the detailed variables within each county were not completed due to issues with linear dependency.

At the institutional level, the hospice to which the patient was referred was an important predictor of hospice utilization, regardless of referral source. Patients referred to Hospice B were more likely to use hospice after referral than patients referred to Hospice A. In addition, patients referred by female physicians and by physicians of the same race/ethnicity as themselves were more likely to use hospice after referral than patients referred by male physicians or by physicians of different races/ethnicities.

Hospice Use versus Non-use for Racial/Ethnic Minorities. No patient or institutional factors were significant in determining hospice use among racial and ethnic minorities, with the exception that minorities referred by a physician were more likely to use hospice if referred to Hospice B than minorities referred by a physician to Hospice A. At the contextual level, the county in which a racial/ethnic minority patient resided was significant. Non-White patients from County A were significantly more likely to use hospice after referral than non-White patients from Counties B or C.

Hospice Non-use for Patient-driven Reason versus Prognosis-driven Reason. The results of the patient model to determine factors associated with hospice non-use for a patient-driven reason versus a prognosis-driven reason suggest that non-Whites were more likely to have a prognosis-driven reason not to use hospice after referral than Whites. None of the patient variables were significant when the model was conducted for patients referred by a source other than a physician, and the model was not conducted separately for patients referred by a physician because of concerns with sample size.

At the contextual level, the county was a significant predictor of the hospice non-use subgroups only when the sample was analyzed with physician-referred patients. Physician-

referred patients from Counties B and C were more likely to have a prognosis-driven reason not to use hospice after referral than physician-referred patients from County A.

Similarly, at the institutional level, patients referred by a physician to Hospice A were more likely to have a prognosis-driven reason not to use hospice than patients referred by a physician to Hospice B. However, none of the institutional variables were significant when the entire sample or when the patients referred by a source other than a physician were analyzed separately.

Hospice Non-use for Patient-driven Reason versus Prognosis-driven Reason for Racial/Ethnic Minorities. When sample size was not a concern and the model of hospice non-use for a patient-driven reason versus a prognosis-driven reason was examined for racial and ethnic minorities, no patient, contextual or institutional variables were significant.

Review. To review, the findings from each model in Specific Aim #1 were applied to the proposed models in Specific Aim #2. Variables were included in the Specific Aim #2 models if they had p-values $\leq .05$ in the parsimonious model and/or values $< .10$ in the full model. With the intent to keep the analyses less complicated and confusing, the findings from the models that were run separately for patients referred by a physician and for patients referred by a source other than the physician were combined with the entire sample findings. For example, in analysis 1A, gender, race, and diagnosis were significant predictors of hospice use versus non-use when the patient characteristics of the entire sample of referred patients were included. No additional variables were significant when sub-samples of only physician-referred patients or only patients referred by a source other than a physician. Therefore, the variables of gender, race, and diagnosis were the independent variables used in the hospice

use models in Specific Aim #2 when analyzing the entire sample and the sub-samples of physician-referred patients and patients referred by another source. Similarly, the county was not significant in the model of contextual factors to determine patient-driven versus prognosis-driven hospice non-use when the entire sample was examined, but it was significant when the sample was reduced to include only physician-referred patients (analysis 1H). Thus, analysis 2E was conducted for the entire sample and for the referral subgroups with county included in the model.

Because the models examining the entire sample included both physician-referred patients and patients referred by a source other than a physician, the referral source variable was kept as a patient variable in all of the Specific Aim #2 models including the entire sample. This approach was expected to allow for better distinction of the two sub-groups within the sample. Table 26 summarizes the results for Specific Aim #1.

Table 26. *Summary of significant findings from Specific Aim #1 (single-level models) to be included in Specific Aim #2 analyses*

Variables	Sample: Outcome:	Entire Sample						Racial & Ethnic Minorities					
	Level:	Hospice Use vs. Hospice Non-use			Patient-driven non-use vs. Prognosis-driven non-use			Hospice Use vs. Hospice Non-use			Patient-driven non-use vs. Prognosis-driven non-use ^a		
		Patient	Contextual	Institutional	Patient	Contextual	Institutional	Patient	Contextual	Institutional	Patient	Contextual	Institutional
Patient Variables													
	Gender	*			-			-			-		
	Age	-			-			-			-		
	Race	*			*								
	Marital status	-			-			-			-		
	Diagnosis	*			-			-			-		
	Referral source	-			-			-			-		
	Insurance	-			-			-			-		
Contextual Variables													
	County		*			*			*			-	
Institutional Variables													
	Hospice agency			†		*			*				-
	Physician gender			-		-			-				-
	Physician age			-		-			-				-
	Physician race			-		-							
	Racial match			*		-			-				-
	Time licensed			*		-			†				-
	Primary practice location			-		-			-				-
	Clinical hours/week			-		-			-				-
	Primary specialty			-		-			-				-

^aFull/parsimonious models not conducted due to concerns with sample size.

*p ≤ .05 in full or parsimonious models. †p < .10 in full model.

Specific Aim #2²²

2A: Hospice Use vs. Non-use = Individual Factors Given Contextual Factors

The results of the logistic regression for individual factors given contextual factors to determine hospice utilization are summarized in Table 27. The main effects with a p-value < .10 from analyses 1A and 1B (results of both full and parsimonious models were considered for model-building), as well as all of their two-way interactions, were included in this model. The patient's diagnosis and county approached significance at the $p < .10$ level. Patients referred with a non-cancer diagnosis were over 3 (0.902, 10.033) times less likely to use hospice after referral than patients referred with a cancer diagnosis ($p = .073$). Patients referred from County D were 6.2 (1.073, 35.248) times less likely to use hospice than patients referred from County A ($p = .041$), and patients from County C were 3.6 (0.867, 14.795) times less likely to use hospice after referral ($p = .078$). None of the interactions were significant.

The model was run separately for physician-referred patients and for patients referred by another source. The patient's county of residence was a significant predictor of hospice use in the model of physician-referred patients. Patients from Counties C and D were 4.1 (1.304, 12.628) and 3.6 (0.954, 13.790) times less likely to use hospice compared to patients from County A ($p = .016$ and $.059$, respectively). No significant difference was noted between Counties A and B.

In the model of patients referred by a source other than a physician, race, diagnosis and county were significant. White patients were 2.0 (1.162, 3.348) times more likely to use hospice than non-Whites ($p = .012$), and cancer patients were 1.6 (1.018, 2.649) times more

²² Specific Aim #2: To determine whether individual factors associated with hospice use are conditional on contextual or institutional factors for all referred patients and for referred racial and ethnic minorities.

likely to use hospice than non-cancer patients ($p = .042$). Patients from Counties B and C were 5.4 (2.932, 10.087) and 9.7 (5.629, 16.792) times, respectively, less likely to use hospice after referral as compared to patients referred from County A ($p < .001$ for both Counties B and C). No significant difference existed between County A and County D.

Table 27. *Specific Aim #2A: Model of individual factors given contextual factors to determine hospice use vs. hospice non-use after referral, including entire sample of referred hospice patients^a*

Variable	Full Model ^{b,d}			Parsimonious Model ^c		
	B (SE)	OR (95% CI)	p	B (SE)	OR (95% CI)	p
Patient Variables						
Female	-0.745 (0.651)	0.474 (0.132,1.699)	.252	-	-	-
Non-White	1.003 (0.735)	2.726 (0.645,11.519)	.173	0.632 (0.239)	1.880 (1.176,3.006)	.008
Non-cancer [†]	1.102 (0.614)	3.009 (0.902,10.033)	.073	0.525 (0.211)	1.690 (1.690,2.556)	.013
Referred by non-physician	0.442 (0.576)	1.555 (0.503,4.806)	.443	-	-	-
Contextual Variables						
County						
A			Reference			
B	0.908 (0.944)	2.480 (0.390,15.770)	.336	1.675 (0.280)	5.337 (3.085,9.233)	<.001
C [†]	1.276 (0.724)	3.581 (0.867,14.795)	.078	2.099 (0.246)	8.161 (5.040,13.214)	<.001
D [*]	1.816 (0.891)	6.150 (1.073,35.248)	.041	0.613 (0.442)	1.846 (0.776,4.395)	.166
Interactions						
Female*Non-White	-0.163 (0.540)	0.850 (0.295,2.449)	.763	-	-	-
Female*Non-cancer	0.472 (0.478)	1.603 (0.628,4.095)	.324	-	-	-
Female*Referred by non-physician	-0.110 (0.548)	0.896 (0.306,2.624)	.841	-	-	-
Female*County A			Reference			
Female*County B	0.978 (0.657)	2.660 (0.733,9.647)	.137	-	-	-
Female*County C	.0306 (0.524)	1.358 (0.486,3.793)	.560	-	-	-
Female*County D	0.733 (0.950)	2.082 (0.323,13.397)	.440	-	-	-
Non-White*Non-cancer	-0.792 (0.547)	0.453 (0.155,1.324)	.148	-	-	-
Non-White*Referred by non-physician	-0.085 (0.668)	0.918 (0.248,3.402)	.898	-	-	-
Non-White*County A			Reference			
Non-White*County B	-0.023 (0.729)	0.978 (0.234,4.077)	.975	-	-	-
Non-White*County C	0.819 (0.589)	2.269 (0.716,7.194)	.164	-	-	-
Non-White*County D	18.293(6740.710)	<.001 (<.001,<.001)	.998	-	-	-
Non-cancer*Referred by non-physician	-0.358 (0.582)	0.699 (0.223,2.187)	.538	-	-	-
Non-Cancer*County A			Reference			
Non-cancer*County B	-1.035 (0.670)	0.355 (0.096,1.322)	.123	-	-	-
Non-cancer*County C	-0.272 (0.550)	0.762 (0.259,2.237)	.620	-	-	-
Non-cancer*County D	-1.397 (0.994)	0.247 (0.035,1.737)	.160	-	-	-
Referred by non-physician*County A			Reference			
Referred by non-physician*County B	0.783 (0.865)	2.188 (0.402,11.918)	.365	-	-	-
Referred by non-physician*County C	0.828 (0.637)	2.290 (0.656,7.986)	.194	-	-	-
Referred by non-physician*County D	-1.009 (0.944)	0.365 (0.057,2.321)	.285	-	-	-

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; diagnosis = cancer; referral source = physician-referred; county = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 3667. ^bR²=0.127. ^cR²=0.107. ^dAdditional analyses were run separately for patients who were referred by a physician and for patients who were referred by another source. The only significant variable for physician-referred patients was county (N = 957; R² = .061). In the model including patients referred by a non-physician, race, diagnosis and county were significant predictors (N = 2,672; R² = .122).

^{*}p≤.05 in full model. [†]Marginally significant (p<.10) in full model.

2B: Hospice Use vs. Non-use = Individual Factors Given Institutional Factors

Due to the presence of two sources of referral within the sample and the application these two sources have within the institutional level and upon the individual level of the Hospice Model, the model of individual factors given institutional factors was completed in 3 separate steps and is depicted in Tables 28-30.

The results of the model including the entire sample of referred patients are summarized in Table 28. As shown here, the hospice agency was the only predictor of hospice utilization in the full model at the $p \leq .05$ level. Patients referred to Hospice B were 3.4 (1.083, 10.638) times more likely to use hospice after referral than patients referred to Hospice A ($p = .036$).

Table 28. *Specific Aim #2B: Model of individual factors given institutional factors to determine hospice use vs. hospice non-use after referral, including entire sample of referred patients^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female	-0.133 (0.592)	0.875 (0.274,2.793)	.822	-	-	-
Non-White [†]	1.202 (0.680)	3.327 (0.878,12.607)	.077	0.610 (0.236)	1.841 (1.160,2.922)	.010
Non-cancer	0.498 (0.620)	1.645 (0.488,5.545)	.422	0.551 (0.208)	1.735 (1.155,2.608)	.008
Referred by non-physician	0.923 (0.598)	2.516 (0.779,8.123)	.123	-	-	-
Institutional Variables ^d						
Hospice B [*]	-1.225 (0.584)	0.294 (0.094,0.923)	.036	-1.941 (0.203)	0.144 (0.096,0.214)	<.001
Interactions						
Female*Non-White	-0.151 (0.510)	0.860 (0.317,2.335)	.767	-	-	-
Female*Non-cancer	0.198 (0.447)	1.219 (0.507,2.930)	.658	-	-	-
Female*Referred by non-physician	-0.067 (0.527)	0.936 (0.333,2.628)	.899	-	-	-
Female*Hospice B	-0.333(0.435)	0.717 (0.306,1.681)	.444	-	-	-
Non-White*Non-cancer	-0.574 (0.511)	0.563 (0.207,1.535)	.262	-	-	-
Non-White*Referred by non-physician	-0.016 (0.628)	0.984 (0.288,3.369)	.980	-	-	-
Non-White*Hospice B	-0.481 (0.508)	0.618 (0.228,1.673)	.344	-	-	-
Non-cancer*Referred by non-physician	-0.115 (0.550)	0.891 (0.303,2.622)	.835	-	-	-
Non-cancer*Hospice B	0.401 (0.455)	1.494 (0.613,3.642)	.377	-	-	-
Referred by non-physician*Hospice B	-0.780 (0.529)	0.459 (0.163,1.293)	.140	-	-	-

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; diagnosis = cancer; referral source = physician-referred hospice agency = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 3665. ^bR²=0.121. ^cR²=0.116. ^dNone of the other institutional variables were applicable because not all the patients were referred by a physician (and, thus, did not have any physician variables to include).

^{*}p≤.05 in full model. [†]Marginally significant (p<.10) in full model.

Table 29 reviews the findings from the model of individual factors given institutional factors to determine hospice utilization for physician-referred patients. Although the findings suggest the referring physician's gender is marginally significant (patients referred by female physicians were more likely to use hospice than patients referred by male physicians, $p = .074$), none of the variables were significant in the full model at the $p < .05$ level.

Table 29. *Specific Aim #2B: Model of individual factors given institutional factors to determine hospice use vs. hospice non-use after referral, including only physician-referred patients^a*

Variable	β (SE)	Full Model ^b OR (95% CI)	p	β (SE)	Parsimonious Model ^c OR (95% CI)	p
Patient Variables						
Female	-1.658 (1.370)	0.191 (0.013,2.793)	.226	-	-	-
Non-White	-0.733 (1.497)	0.481 (0.026,9.039)	.625	-	-	-
Non-cancer	0.547 (1.139)	1.728 (0.185,16.119)	.631	-	-	-
Institutional Variables						
Hospice B	-1.278 (1.063)	0.279 (0.035,2.236)	.279	-	-	-
Physician Variables						
Female [†]	-1.995 (1.115)	0.136 (0.015,1.210)	.074	-1.590 (0.745)	0.204 (0.047,0.878)	.033
Racial un-match	2.191 (1.531)	8.944 (0.445,179.845)	.152	0.852 (0.390)	2.344 (1.092,5.031)	.029
Interactions ^d						
Female*Non-White	0.807 (2.108)	2.241 (0.036,139.677)	.702	-	-	-
Female*Non-cancer	1.097 (1.208)	2.996 (0.281,31.961)	.364	-	-	-
Female*Hospice B	1.327 (1.200)	3.769 (0.359,39.628)	.269	-	-	-
Female*Racial un-match	0.180 (1.688)	1.197 (0.044,32.744)	.915	-	-	-
Non-White*Non-cancer	-1.757 (1.798)	0.173 (0.005,5.856)	.329	-	-	-
Non-White*Hospice B	0.665 (2.030)	1.945 (0.036,103.918)	.743	-	-	-
Non-cancer*Hospice B	-0.368 (1.313)	0.692 (0.053,9.068)	.779	-	-	-
Hospice B*Racial un-match	-2.523 (1.800)	0.080 (0.002,2.730)	.161	-	-	-

Note. Odds ratio is for the probability of hospice non-use; References for analyses: gender = male; race = White; diagnosis = cancer; hospice agency = A; racial match = match; primary practice location = hospital-based. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=943. ^bR²=0.123. ^cR²=0.042. ^dThe following interactions were omitted: racial match*race and racial match*diagnosis. Only 1 non-White hospice non-user racially matched their physician, and only 2 patients with non-users with a non-cancer diagnosis were racially un-matched from their physician. All interactions with the physician's gender were also omitted because only 6 female physicians referred non-users in the entire sample.

[†]Marginally significant ($p < .10$) in full model.

The third table, Table 30, recaps the findings from the model of individual factors given institutional factors to determine hospice use versus non-use for patients referred by a source other than a physician. The patient's race and the hospice agency to which the patient was referred were the only significant variables in the full model ($p = .044$ and $<.001$, respectively). Non-White patients were 2.9 (1.028, 7.911) times less likely to use hospice after referral than White patients. Patients referred to Hospice B were 6.8 (2.632, 17.544) times more likely to use hospice after referral than patients referred to Hospice A.

Table 30. *Specific Aim #2B: Model of individual factors given institutional factors to determine hospice use vs. hospice non-use after referral, including patients referred by a source other than a physician^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female	-0.059 (0.459)	0.942 (0.383,2.319)	.897	-	-	-
Non-White*	1.048 (0.521)	2.852 (1.028,7.911)	.044	0.604 (0.268)	1.830 (1.082,3.094)	.024
Non-cancer	0.376 (0.482)	1.456 (0.566,3.746)	.436	0.478 (0.238)	1.613 (1.012,2.570)	.044
Institutional Variables						
Hospice B**	-1.917 (0.485)	0.147 (0.057,0.380)	<.001	-2.053 (0.233)	0.128 (0.081,0.203)	<.001
Interactions						
Female*Non-White	0.015 (0.569)	1.015 (0.333,3.094)	.979	-	-	-
Female*Non-cancer	0.212 (0.517)	1.237 (0.449,3.0407)	.681	-	-	-
Female*Hospice B	-0.725 (0.497)	0.485 (0.283,1.284)	.145	-	-	-
Non-White*Non-cancer	-0.734 (0.569)	0.480 (0.157,1.465)	.197	-	-	-
Non-White*Hospice B	-0.186 (0.572)	0.830 (0.270,2.549)	.745	-	-	-
Non-cancer*Hospice B	0.492 (0.522)	1.635 (0.588,4.548)	.346	-	-	-

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; diagnosis = cancer; hospice agency = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=2662. ^bFull model $R^2=0.132$. ^cParsimonious model $R^2=0.123$.

* $p \leq .05$ in full model. ** $p \leq .001$ in full model

2C: Hospice Use vs. Non-use = Individual Factors Given Contextual Factors (For Racial/Ethnic Minorities)

The model of individual factors given contextual factors to determine hospice utilization for racial and ethnic minorities was not analyzed because none of the patient variables were significant from the previous analysis (analysis 1D).

2D: Hospice Use vs. Non-use = Individual Factors Given Institutional Factors (For Racial/Ethnic Minorities)

The model of individual factors given institutional factors to determine hospice use for racial and ethnic minorities was not tested because none of the patient variables were significant from the previous analysis (analysis 1D).

2E: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Individual Factors Given Contextual Factors

The model of individual factors given contextual factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason is summarized in Table 31. The interaction between county and referral source was significant for County C ($p = .031$). Patients from County C who had a prognosis-driven reason not to enroll in hospice after referral were significantly less likely to be referred by a source other than a physician compared to patients from County A who had a prognosis-driven reason not to enroll in hospice after referral (76.5% vs. 93.0%) ($\chi^2 = 7.007$, $p = .030$). The interaction is depicted in Figure 4.

Table 31. *Specific Aim #2E: Model of individual factors given contextual factors to determine hospice non-use for patient-driven reason versus hospice non-use for prognosis-driven reason, including entire sample of referred patients^a*

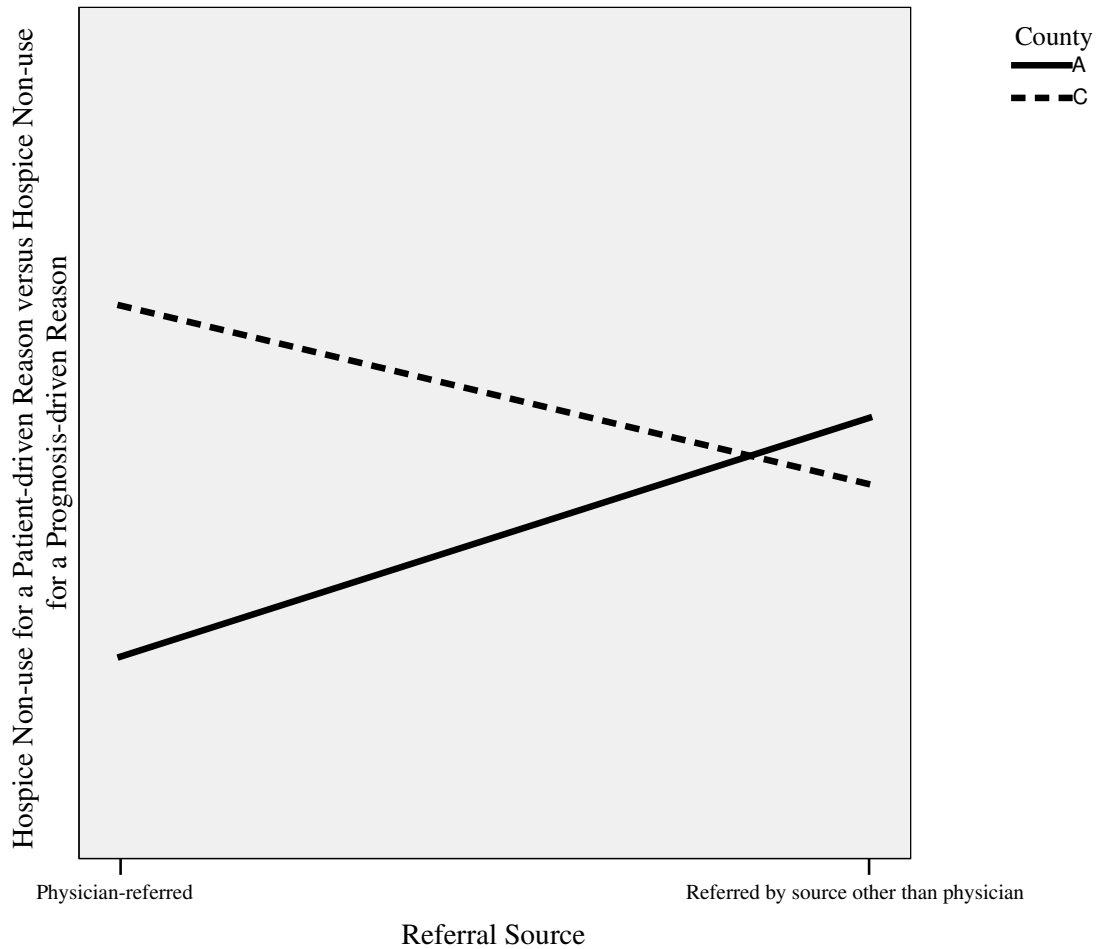
Variable	Full Model ^b			Parsimonious Model		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Non-White	-1.316 (1.265)	0.268 (0.022,3.200)	.298	-	-	-
Referred by non-physician [†]	1.070 (0.572)	2.915 (0.951, 8.934)	.061	-	-	-
Contextual Variables						
County A			Reference			
B	1.029 (1.513)	2.799 (0.144,54.350)	.497	-	-	-
C [†]	2.195 (1.328)	8.977 (0.665,121.265)	.098	-	-	-
D ^c	-	-	-	-	-	-
Interactions						
Non-White*Referred by non-physician	1.355 (1.290)	3.876 (0.309,48.563)	.294	-	-	-
Non-White*County A			Reference			
Non-White*County B	0.298 (1.100)	1.347 (0.156,11.634)	.787	-	-	-
Non-White*County C	0.635 (0.933)	1.887 (0.303,11.748)	.496	-	-	-
Referred by non-physician*County A			Reference			
Referred by non-physician*County B	-1.406 (1.634)	0.245 (0.010,6.026)	.389	-	-	-
Referred by non-physician*County C [*]	-2.895 (1.340)	0.055 (0.004,0.764)	.031	-	-	-

Note. Odds ratio is the probability of hospice non-use for prognosis-driven reason References for analyses: race = White; referral source = physician-referred; county = County A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 200. ^bR² = .069. ^cFew patients were referred from County D; the results did not change once County D was removed from the analysis.

^{*}p≤.05 in full model. [†]Marginally significant (p<.10) in full model.

Figure 4. Interaction between Referral Source and County



Note. The bottom of the graph represents hospice non-use for a patient-driven reason. The top of the graph represents hospice non-use for a prognosis-driven reason.

Due to sample size concerns, the model was not run separately for physician-referred patients (N=27; all non-White patients in the prognosis-driven non-use group including only physician-referred patients were referred from County C). None of the variables were significant when the model was run with patients referred by a source other than a physician (N=170). Power calculations suggest this sample size had enough power to detect only about 5.0% differences between groups on both county and race.

2F: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven reason = Individual Factors Given Institutional Factors

The model of individual factors given institutional factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason is reviewed in Table 31. The interaction between the hospice agency and the patient's referral source was significant ($p = .023$). In general, patients referred to Hospice A were slightly (although not significantly) more likely to be referred by a physician than patients referred to Hospice B (17.3% vs. 15.9%) ($\chi^2 = .080$, $p = .777$). More specifically, patients referred to Hospice A who had a prognosis-driven reason not to enroll were significantly more likely to have been referred by a physician compared to patients referred to Hospice B who had a prognosis-driven reason not to enroll (22.8% vs. 6.1%) ($\chi^2 = 6.976$, $p = .008$). Figure 5 illustrates the interaction.

None of the variables were significant when the model was run separately for physician-referred patients ($N=31$) or patients referred by a source other than a physician ($N=182$). For patients referred by a physician, power was adequate to detect differences between the hospice non-use groups in hospice agency (86.5%). Calculations suggest the sample of physician-referred patients had enough power to detect a 5.1% difference between groups on race. For patients referred by a source other than a physician, calculations suggest the sample had enough power to detect a 5.2% difference between groups on race and a 23.4% difference between groups on hospice agency.

Table 32. *Specific Aim #2F: Model of individual factors given institutional factors to determine hospice non-use for patient-driven reason vs. hospice non-use for prognosis-driven reason, including entire sample^a*

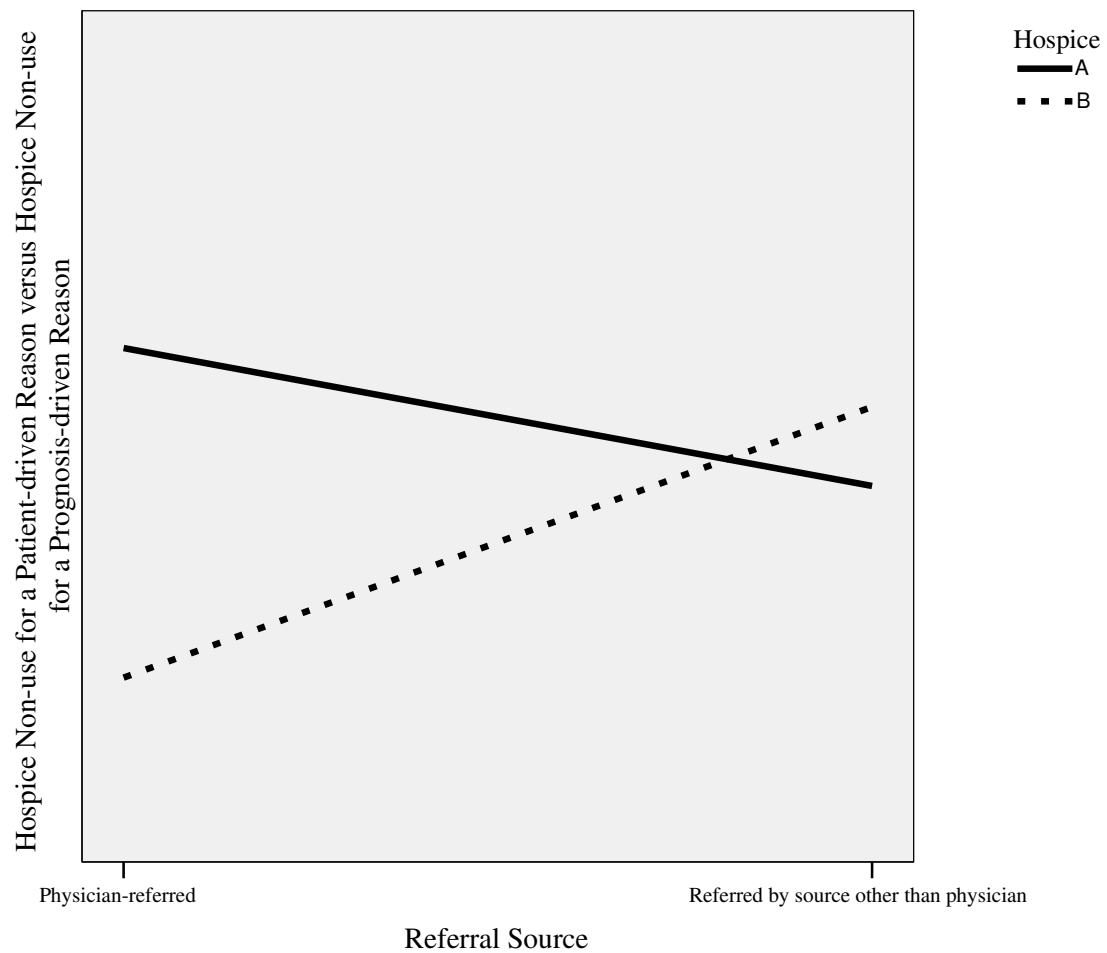
Variable	Full Model ^b			Parsimonious Model ^c		
	B (SE)	OR (95% CI)	p	B (SE)	OR (95% CI)	p
Patient Variables						
Non-White	-0.177 (1.001)	0.838 (0.118,5.962)	.860	-	-	-
Referred by non-physician	-0.813 (0.850)	0.444 (0.084,2.345)	.339	-0.595 (0.731)	0.522 (0.132,2.312)	.416
Institutional Variables						
Hospice B [†]	-1.585 (0.902)	0.205 (0.035,1.201)	.079	-1.658 (0.835)	0.190 (0.037,0.979)	.047
Interactions						
Non-White*Hospice B	-0.487 (0.721)	0.615 (0.150,2.523)	.499	-	-	-
Non-White*Referred by non-physician	0.652 (1.001)	1.919 (0.270,13.652)	.515	-	-	-
Hospice B*Referred by non-physician	2.128 (0.937)	8.398 (1.338,52.693)	.023	1.465 (0.527)	4.329 (1.541,12.166)	.005

Note. Odds ratio is for the probability of hospice non-use for prognosis-driven reason. References for analyses: race = White; hospice agency = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=216. ^bR²=0.067. ^cR²=0.061.

*p≤.05 in full model. [†]Marginally significant (p<.10) in full model.

Figure 5. Interaction between Referral Source and Hospice Agency



Note. The bottom of the graph represents hospice non-use for a patient-driven reason. The top of the graph represents hospice non-use for a prognosis-driven reason.

2G: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Individual Factors Given Contextual Factors (For Racial/Ethnic Minorities)

None of the patient variables were significant in the individual-level model (analysis 1J). County was also not significant (analysis 1K); therefore, the model of individual factors given contextual factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason for racial and ethnic minorities was not run.

2H: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Individual Factors Given Institutional Factors (For Racial/Ethnic Minorities)

The model of individual factors given institutional factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason for referred racial and ethnic minorities was also not tested. None of the patient variables were significant in the individual-level model (analysis 1J), and the sample was inadequate to obtain reliable results for the institutional-level model (analysis 1L).

Specific Aim #2 Summary

In summary, analyses of individual factors given contextual factors and of individual factors given institutional factors were planned with four main outcomes: 1) hospice use versus non-use, 2) hospice use versus non-use for racial and ethnic minorities, 3) hospice non-use for a patient-driven reason versus hospice non-use for a prognosis-driven reason, and 4) hospice non-use for a patient-driven reason versus hospice non-use for a prognosis-driven reason for racial and ethnic minorities; however, none of the models focusing on racial and ethnic minorities were conducted because none of the patient variables were significant from

the previous analyses in Specific Aim #1. When sample size allowed, each model was also conducted separately for physician-referred patients and for patients referred by another source.

Hospice Use versus Non-use. When the individual factors were examined in the framework of the contextual factors to determine hospice use versus non-use, the patient's diagnosis and county of residence were marginally significant predictors. Patients referred with a cancer diagnosis and patients referred from County A were significantly more likely to use hospice after referral than patients referred with a non-cancer diagnosis or from Counties C or D. Similarly, when physician-referred patients were examined separately, patients from County A were more likely to use hospice after referral than patients from Counties C or D although no patient variables were significant for physician-referred patients. In the model of patients referred by a source other than a physician, however, the patient's race, diagnosis and county were important. White patients, patients with cancer, and patients from County A were significantly more likely to use hospice after referral than non-White patients, patients with a non-cancer diagnosis, and patients from Counties B or C.

When the individual factors were examined in the context of the institutional factors, the patient's race and the hospice to which the patient was referred were at least marginally significant predictors for hospice use versus non-use. White patients and patients referred to Hospice B were more likely to use hospice after referral than non-White patients or patients referred to Hospice A. The results were similar for patients referred by a source other than a physician; however, when physician-referred patients were examined separately, only the physician's gender was marginally significant. Patients referred by a female physician were more likely to use hospice after referral than patients referred by a male physician.

Hospice Non-use for Patient-driven Reason versus Prognosis-driven Reason. When individual factors were examined in the framework of the contextual factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason, the interaction between referral source and county was significant. Patients in County C who were referred by a source other than a physician were less likely to have a prognosis-driven reason not to enroll in hospice after the referral than patients in County A who were referred by a source other than a physician. No variables were significant when the model was run separately for patients referred by a source other than a physician, and the model was not run separately for patients referred by a physician due to sample size concerns.

When individual factors were examined in the context of the institutional factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason, the interaction between the hospice agency and the referral source was significant. Patients referred to Hospice A by a physician were more likely to have a prognosis-driven reason not to use hospice after the referral than patients referred to Hospice B by a physician. None of the variables were significant when the model was run separately for physician-referred patients or for patients referred by another source.

Review. To review, the findings from Specific Aim #1 were used to build the models in Specific Aim #2. Similarly, the findings from Specific Aim #2 were used to build a complete model in Specific Aim #3 including individual factors, contextual factors, and institutional factors. Again, the findings from the models that were run separately for patients referred by a physician and for patients referred by a source other than the physician were combined with the entire sample findings for the models addressing Specific Aim #3. Because the models examining the entire sample included both physician-referred patients and patients referred

by a source other than a physician, the referral source variable was kept as a patient variable in all of the Specific Aim #3 models including the entire sample. This was the same approach used to address the Specific Aim #2 analyses.

Table 33 summarizes the findings from the models in Specific Aim #2 that were used in preparation for the models in Specific Aim #3.

Table 33. *Summary of Findings from Specific Aim #2 to be included in Specific Aim #3 analyses*

Variables	Sample:	Entire Sample				Racial and Ethnic Minorities ^a			
	Outcome:	Hospice Use vs. Hospice Non-use		Patient-driven Non-use vs. Prognosis-driven Non-use		Hospice Use vs. Hospice Non-use		Patient-driven Non-use vs. Prognosis-driven Non-use	
	Level:	Patient + Contextual	Patient + Institutional	Patient + Contextual	Patient + Institutional	Patient + Contextual	Patient + Institutional	Patient + Contextual	Patient + Institutional
Patient Variables									
Gender	-	-	-	-	-	-	-	-	-
Race	*	-	-	-	-	-	-	-	-
Diagnosis	*	-	-	-	-	-	-	-	-
Referral Source		-	†	b	-	-	-	-	-
Contextual Variables									
County	*		†			-		-	
Institutional Variables									
Hospice agency		*		*			-		-
Physician gender		*		-			-		-
Racial match		*		-			-		-

^aNo models were run due to insignificant findings in Specific Aim #1 or due to sample size concerns. ^bIncluded because of significant interaction.

*p≤.05 in full or parsimonious models. †p< .10 in full model.

Specific Aim #3²³

3A: Hospice Use vs. Non-use = Individual Factors Given Contextual and Institutional Factors

The results of the logistic regression for individual factors given contextual and institutional factors to determine hospice utilization after referral are displayed in Tables 34-36. Similar to the process implemented in Specific Aim #2, the model was run separately for the entire sample, for patients referred by a physician, and for patients referred by a source other than a physician. The significant main effects from analyses 2A and 2B, defined as variables having p-values < .10 in the full model and/or p-values \leq .05 in the parsimonious model, as well as most of their two-way interactions, were included in these models.

The results of the model including patient, contextual and institutional variables for the entire sample are displayed in Table 34. Although the patient's race was not significant at the $p \leq .05$ level, it was borderline significant at the $p < .10$ level ($p = .078$). In this case, the results suggest that non-White patients were 3.1 (0.883, 10.744) times less likely to use hospice after referral than White patients.

²³ To test a predictive model of hospice utilization after referral, as derived from Andersen's Behavioral Model of Health Services Use and the Conceptual Model for Realized Access to End-of-Life Care.

Table 34. *Specific Aim #3A: Model of individual factors given contextual and institutional factors to determine hospice use vs. hospice non-use after referral, including entire sample of referred patients^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Non-White [†]	1.125 (0.637)	3.080 (0.883,10.744)	.078	0.610 (0.236)	1.841 (1.160,2.922)	.010
Non-cancer	-0.636 (1.737)	0.529 (0.018,15.930)	.714	0.551 (0.208)	1.735 (1.155,2.608)	.008
Referred by non-physician	0.206 (1.694)	1.229 (0.044,33.996)	.903			
Contextual Variables						
County						
A			Reference			
B	-0.550 (1.620)	0.577 (0.024,13.815)	.734	-	-	-
C	-0.071 (1.505)	0.931 (0.049,17.801)	.962	-	-	-
D	1.324 (0.933)	3.757 (0.604,23.369)	.156	-	-	-
Institutional Variables						
Hospice B	-1.672 (1.386)	0.188 (0.012,2.846)	.228	-1.941 (0.203)	0.144 (0.096,0.214)	<.001
Interactions ^d						
Non-White*Non-cancer	-0.537 (0.509)	0.584 (0.25,1.586)	.292	-	-	-
Non-White*Referred by non-physician	-0.009 (0.632)	0.991 (0.287,3.419)	.989	-	-	-
Non-White*Hospice B	-0.493 (0.513)	0.611 (0.223,1.671)	.337	-	-	-
Non-cancer*Referred by non-physician	-0.255 (0.557)	0.775 (0.260,2.308)	.647	-	-	-
Non-cancer*County A			Reference			
Non-cancer*County B	1.018 (1.728)	2.767 (0.094,81.793)	.556	-	-	-
Non-cancer*County C	1.463 (1.696)	4.317 (0.155,119.972)	.389	-	-	-
Non-cancer*County D	-0.451 (1.120)	0.637 (0.071,5.721)	.687	-	-	-
Non-cancer*Hospice B	1.701 (1.636)	5.481 (0.222,135.437)	.299	-	-	-
Referred by non-physician*County A			Reference			
Referred by non-physician*County B	0.940 (1.822)	2.560 (0.072,90.920)	.606	-	-	-
Referred by non-physician*County C	0.812 (1.720)	2.251 (0.077,65.523)	.637	-	-	-
Referred by non-physician*County D	-1.310 (1.127)	0.270 (0.030,2.457)	.245	-	-	-
Referred by non-physician*Hospice B	0.099 (1.619)	1.104 (0.046,26.371)	.951	-	-	-

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; diagnosis = cancer; referral source = physician-referred; county = A; hospice agency = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 3661. ^bR²=0.119. ^cR²=0.116. ^dThe following interactions were excluded: race*county and county*hospice. Only 1 non-White hospice non-user was referred from County D; and no hospice non-users from County B or County C were referred to Hospice B and only 1 hospice user from County A was referred to Hospice A.

[†]Marginally significant (p<.10) in full model.

The results of the logistic regression model of individual factors given contextual and institutional factors to determine hospice use versus non-use after referral including only patients referred by a physician are shown in Table 35. The model included all significant main effects from analyses 2A and 2B, along with most two-way interactions. The physician's gender was approaching significance ($p = .081$), suggesting that patients referred by a female physician were 6.5 (0.018, 1.260) times more likely to use hospice after referral than patients referred by a male physician.

Table 35. *Specific Aim #3A: Model of individual factors given contextual and institutional factors to determine hospice use vs. hospice non-use after referral, including only physician-referred patients^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Non-White	-0.837 (1.342)	0.433 (0.031,6.011)	.533	-	-	-
Non-cancer	0.428 (0.975)	1.533 (0.227,10.363)	.661	-	-	-
Contextual Variables						
County						
A			Reference			
B	0.426 (1.525)	1.531 (0.077,30.420)	.780	-	-	-
C	0.786 (1.419)	2.195 (0.136,35.400)	.579	-	-	-
D	1.118 (0.808)	3.058 (0.627,14.906)	.167	-	-	-
Institutional Variables						
Hospice B	-0.655 (1.568)	0.519 (0.024,11.218)	.676	-	-	-
Physician Variables						
Female [†]	-1.886 (1.080)	0.152 (0.018,1.260)	.081	-1.590 (0.745)	0.204 (0.047,0.878)	.033
Racial Un-match	2.128 (1.441)	8.394 (0.498,141.397)	.140	0.852 (0.390)	2.344 (1.092,5.031)	.029
Interactions ^d						
Non-White*Hospice B	0.641 (1.900)	1.899 (0.046,78.680)	.736	-	-	-
Non-cancer*Hospice B	0.443 (1.087)	1.557 (0.185,13.116)	.684	-	-	-
Non-cancer*Racial un-match	-0.537 (1.170)	0.585 (0.059,5.790)	.646	-	-	-
Hospice B*Racial un-match	-1.911 (1.661)	0.148 (0.006,3.837)	.250	-	-	-

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; diagnosis = cancer; county = A; hospice agency = A; primary practice location = hospital-based. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=943. ^bR²=0.118. ^cR²=0.042. ^dNumerous interactions were omitted due to inadequate distributions within cells: race*diagnosis, race*racial match, race*county, diagnosis*county, hospice*county, racial match*county, and all interactions with physician gender.

[†]Marginally significant (p<.10) in full model.

The third table, Table 36, displays the findings from the logistic regression of individual factors given contextual and institutional factors to determine hospice use for patients referred by a source other than a physician. The patient's race was the only significant predictor in the full model ($p = .010$). Non-White patients were 3.1 (1.313, 3.125) times less likely to enroll in hospice after referral than White patients. None of the interactions were significant.

Table 36. *Specific Aim #3A: Model of individual factors given contextual and institutional factors to determine hospice use vs. hospice non-use after referral, including patients referred by a source other than a physician^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Non-White	1.140 (0.442)	3.125 (1.313,3.440)	.010	0.656 (0.264)	1.927 (1.148,3.232)	.013
Non-cancer	0.402 (0.368)	1.495 (0.727,3.073)	.274	0.505 (0.237)	1.657 (1.042,2.636)	.033
Contextual Variables						
County						
A			Reference			
B	0.653 (1.039)	1.921 (0.251,14.725)	.530	-	-	-
C	1.288 (1.030)	3.626 (0.481,27.322)	.211	-	-	-
D	-0.110 (0.732)	0.896 (0.213,3.763)	.880	-	-	-
Institutional Variables						
Hospice B	-1.172 (1.058)	0.310 (0.039,2.464)	.268	-2.055 (0.232)	0.128 (0.081,0.202)	<.001
Interactions ^d						
Non-White*Non-cancer	-0.530 (0.560)	0.588 (0.196,1.764)	.344	-	-	-
Non-White*Hospice B	-0.382 (0.562)	0.683 (0.227,2.053)	.497	-	-	-
Non-cancer*Hospice B	0.408 (0.502)	1.504 (0.563,4.022)	.416	-	-	-

Note. Odds ratio is for the probability of hospice non-use References for analyses: gender = male; race = White; diagnosis = cancer; county = A; hospice agency = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=2672. ^bR²=0.124. ^cR²=0.125. ^dThe following interactions were omitted: race*county, diagnosis*county, hospice*county. No non-Whites were hospice non-users from County D; only 2 non-users with cancer were from County D; and several cells had values of 0 when hospice and county were examined with the outcome.

3B: Hospice Use vs. Non-use = Individual Factors Given Contextual and Institutional Factors (For Racial/Ethnic Minorities)

The model of individual factors given contextual and institutional factors to determine hospice utilization after referral for racial and ethnic minorities was not tested because no variables were applicable from previous analyses (refer to analyses 2C and 2D).

3C: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Individual Factors Given Contextual and Institutional Factors

The results of the logistic regression including individual factors given contextual and institutional factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason are presented in Table 37. The interaction between the referral source and the hospice agency was significant ($p = .006$). As previously discussed in Analysis #2F and illustrated in Figure 5, patients referred to Hospice A who had a prognosis-driven reason not to enroll in hospice were significantly more likely to have been referred by a physician compared to patients referred to Hospice B who had a prognosis-driven reason not to enroll (22.8% vs. 6.1%) ($\chi^2 = 6.976$, $p = .008$).

Because of the similarity in findings from Analyses #2E and #2F, the relationship between county and hospice was examined. County and hospice were significantly related in this sub-sample of non-users ($\chi^2 = 217.424$, $p = <.001$). Therefore, two models were conducted separately to examine differences in the outcome with the inclusion of one or the other variable. The results of the models were similar: the interactions between referral source and either county or hospice were significant. The results of the model including hospice and not including county are shown in Table 37.

The model was not analyzed separately for patients referred by a physician or for patients referred by another source because no other patient variables were significant in previous analyses except referral source (which is a constant within each of these sub-groups).

Table 37. *Specific Aim #3C: Model of individual factors given contextual and institutional factors to determine hospice non-use for a patient-driven reason vs. hospice non-use for a prognosis-driven reason, including entire sample of referred patients^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Referred by non-physician	-0.925 (0.673)	0.397 (0.106,1.483)	.397	-0.925 (0.673)	0.397 (0.106,1.483)	.397
Contextual Variables						
County A			Reference			
B	-	-	-	-	-	-
C	-	-	-	-	-	-
D	-	-	-	-	-	-
Institutional Variables						
Hospice B	-2.028 (0.792)	0.132 (0.028,0.622)	.132	-2.028 (0.792)	0.132 (0.028,0.622)	.132
Interactions						
Referred by non-physician* Hospice B*	2.339 (0.859)	10.368(1.927,55.784)	.006	2.339 (0.859)	10.368 (1.927,55.784)	.006

Note. Odds ratio is for the probability of hospice non-use for a prognosis-driven reason. References for analyses: referral source = physician-referred; county = County A; hospice = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=215. ^bR²=0.063. ^cR²=0.063.

*p≤.05 in full model.

3D: Hospice Non-use for Patient-driven Reason vs. Prognosis-driven Reason = Individual factors Given Contextual and Institutional Factors (For Racial/Ethnic Minorities)

The model of individual factors given contextual and institutional factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason for racial and ethnic minorities was not analyzed because no variables were applicable from previous analyses (refer to analyses 2G and 2H).

Factor Analysis

Additional analyses were completed to further examine the concepts defined in the Hospice Model. Specifically, factor analyses were conducted to determine if the variables in the data set fit the underlying constructs in the data: individual predisposing factors, individual enabling factors, individual need factors, institutional predisposing factors, institutional enabling factors and institutional need factors. The physician-referred patients were the only patients who had the potential for values on all of the institutional variables; therefore, the sample was limited to physician-referred patients for these analyses. Factor analyses to examine the underlying constructs within the contextual variables (contextual predisposing factors, contextual enabling factors, and contextual institutional factors) were not feasible due to the limited number of counties ($N = 3$).

Individual Constructs. To determine if there might be some common constructs underlying the individual factors, six particular variables were included: gender, age, race, marital status, diagnosis and insurance status. The four-factor principal components analysis with direct oblimin (oblique) rotation appeared to be the best in terms of simple structure. The loadings on all factors were either high (0.3 or greater) or close to zero; each item loaded

onto only one factor; and each factor had high loadings. The factor correlation matrix showed a correlation ≤ 0.22 between all the factors, which means there was 4.8% or less shared variance between factors. Table 38 presents the loadings and eigenvalues, and the significance of each factor to the Hospice Model will be discussed in Chapter VI.

Table 38. *Factor groupings of individual variables*

Variables	Factors			
	1	2	3	4
Gender	-.129	.910*		
Age	.783*			
Race				.993*
Marital Status	.198	.751*		
Diagnosis	.860*			
Insurance Status			.999*	
Eigenvalues	1.794	1.214	.989	.844
% Variance Explained	29.906	20.239	16.479	14.074

Note. Principal components factoring based on observations from the scree plot. The 4 factors retained account for 80.70% of the variance. Values less than 0.1 were suppressed and are not shown.

*Loading.

To examine if the factors would differ with referral source added as a variable and with the entire sample analyzed, the analysis was also conducted with the entire sample. The simplest solution was a five-factor principal components analysis with direct oblimin rotation, and the findings were similar to those discussed above. Age and diagnosis loaded onto factor one, and gender and marital status comprised factor two. Insurance status, race and referral source were each their own individual factors.

Institutional Constructs. To determine whether there might be some common constructs underlying the institutional factors, nine particular variables were included: hospice agency,

whether the physician's race matched the patient's race, and the physician's gender, age, race, years licensed at the time of referral, specialty, primary practice location and number of hours per week in clinical care. The five-factor principal components analysis with direct oblimin rotation appeared to be the best in terms of simple structure. The loadings on all factors were either high (0.3 or greater) or close to zero; each item loaded onto only one factor, with the exception of one variable; and each factor had high loadings. The factor correlation matrix showed a correlation $\leq .275$, which means there was 7.5% or less shared variance between factors. Table 39 presents the loadings and the eigenvalues.

Table 39. *Factor groupings of institutional variables*

Variables	Factors				
	1	2	3	4	5
Hospice	.145		-.809*	.282	
Physician age	-.925*				
Physician gender	.106			.229	-.787*
Physician race		.886*			
Racial Match		.928*			
Years Licensed	-.969*				
Specialty	.130			-.933*	
Primary Practice Location	.202		.772*	.301	
Clinical Care Hours				.202	.854*
Eigenvalues	2.615	1.582	1.219	1.068	.931
% Variance Explained	29.054	17.577	13.549	11.870	10.345

Note. Principal components factoring based on observations from the scree plot. The 5 factors retained account for 82.40% of the variance. Values less than 0.1 were suppressed and are not shown.

*Loading.

Specific Aim #3 Summary

In summary, the results of Specific Aims #1 and #2 drove the analyses described in Specific Aim #3. Thus, individual factors were examined in the context of both contextual and institutional factors for two outcomes: 1) hospice use versus hospice non-use, and 2) hospice non-use for a patient-driven reason versus a prognosis-driven reason. No models were run separately for racial and ethnic minorities due to insignificant results from previous patient, contextual and institutional models, or, in some cases, due to sample size concerns. When feasible, each of the models was tested separately for physician-referred patients and for patients referred by a source other than a physician.

Hospice Use versus Non-use. In the model of individual factors given contextual and institutional factors, the patient's race was a marginally significant predictor of hospice utilization when the entire sample was analyzed ($p = .078$). When the sample was reduced to include only patients referred by a source other than a physician, race again was a significant predictor when adjusting for all the significant main effects and two-way interactions from previous patient, contextual and institutional models ($p = .010$). In both models, White patients were over 3 times more likely to use hospice after referral than non-White patients.

However, when the sample was limited to patients referred by a physician, the results differed. After adjusting for all the significant main effects from previous patient, contextual and institutional models and all two-way interactions, the physician's gender was a marginally significant predictor ($p = .081$). The findings suggest that patients referred by a female physician were more likely to use hospice after referral than patients referred by a male physician.

Hospice Non-use for Patient-driven Reason versus Prognosis-driven Reason. After adjusting for all the significant main effects from previous patient, contextual and institutional models and all two-way interactions, the interaction between the patient's referral source and the hospice to which the patient was referred was a significant predictor of hospice non-use for a patient-driven reason versus a prognosis-driven reason. Patients referred to Hospice A by a physician were more likely to have a prognosis-driven reason not to use hospice after referral compared to patients referred to Hospice B by a physician.

The full models include adjustment for all other variables that have previously been considered important (or potentially important) in hospice or health services research and are considered the definitive models for this study; however, the results of the parsimonious

model may add some insight to the full model findings, particularly because the findings of the full models for the entire sample and for the patients referred by a physician were marginal in significance. These findings will therefore be discussed in Chapter VI as an aside to the discussion of the full model findings in an effort to provide additional directions for forthcoming studies. To review briefly, the patient's race, diagnosis, and the hospice to which the patient was referred were significant in each of the parsimonious models to determine hospice use versus non-use including the entire sample and including patients referred by non-physician sources. Non-White patients, patients with a non-cancer diagnosis, and patients referred to Hospice A were less likely to use hospice after referral than White patients, patients with cancer, and patients referred to Hospice B. In the parsimonious model of patients referred by a physician, the physician's gender and whether the physician and patient matched racially were the only significant predictors of hospice utilization. Patients referred by female physicians and patients who racially matched their referring physician were more likely to use hospice than patients referred by male physicians and patients who did not racially match their referring physician.

The parsimonious models did not add to the full model findings for the models examining factors associated with hospice non-use for a patient-driven reason versus prognosis-driven reason.

Factor Analysis. Additional factor analyses were conducted to examine the representativeness of the variables to the concepts in the Hospice Model. The four-factor solution for the individual variables consisted of the following: 1) patients' age and diagnosis; 2) gender and marital status, 3) insurance status and 4) race. The five-factor solution for the institutional variables consisted of the following: 1) the physician's age and

how long the physician was licensed at the time of referral; 2) the physician's race and whether or not the patient and physician racially matched; 3) the hospice to which the patient was referred and the physician's primary practice location; 3) the physician's specialty; and 5) the physician's gender and weekly clinical care hours. A more thorough discussion of these factors can be found in the Chapter VI.

VI. Discussion

The objectives of this study were to explore, describe and predict hospice utilization using a variety of patient, contextual and institutional factors based on the published literature and to test the Hospice Model. When the entire sample was analyzed, the results suggested that the patient's race was a significant predictor of hospice utilization after referral; however, due to the ability to only examine physician characteristics for patients referred by a physician (who represented only about a quarter of the sample), the need for additional analyses emerged. Of particular interest, these analyses suggested that the patient's characteristics were not as important as the characteristics of the referral source. This chapter combines and describes in depth the findings from all of the modeling exercises within the following sections: 1) the importance of race; 2) the importance of referral source; 3) the importance of diagnosis; 4) the importance of the particular hospice to which the patient was referred; 5) the importance of other findings and 6) how representative the actual data were of the concepts in the Hospice Model. In addition, the limitations of the study and how the findings can be used for future research will be addressed.

*The Importance of the Patient's Race*²⁴

The results of the model tested to determine hospice use versus non-use suggested that the patient's race was one of the most important factors associated with hospice utilization after referral. After adjusting for all other variables and interactions, non-White patients were

²⁴ Because the data from preliminary study were included in this study, the section entitled *The Importance of the Patient's Race* was previously published by the author in Forcina Hill, 2008.

as much as 3.1 times less likely to use hospice after referral than White patients. In other words, racial and ethnic minorities appeared to underutilize hospice services *even after* they overcame the hurdle of receiving a hospice referral. These findings supplement the evidence from previous studies indicating that racial and ethnic minority patients are significantly less likely to use hospice than White patients (Greiner et al., 2003; Iwashyna et al., 2002). They are unique, however, because this study's sample provided an opportunity to determine whether minorities would have utilized hospice services if they were actually referred (consequently adjusting for patients who did not have an opportunity to enroll). While the comparison of the proportion of racial and ethnic minorities in the sample of referred patients and in the demographics of the counties represented in the study indicated that minorities were under-referred for services, the findings from the regression analyses suggested that increasing referral of non-Whites will *not* necessarily result in an increase in their hospice utilization.

Further, the results of this study imply that non-White patients are significantly more likely than White patients not to use hospice after referral for prognosis-driven reasons. In this study, patients who did not use hospice because they were actively dying or died before admission or because they had a prognosis greater than 6 months were considered to have prognosis-driven reasons not to enroll. This finding suggests that minorities are possibly either referred *too late* to be appropriate for in-home hospice services or they are referred *too early* to meet the hospice eligibility criteria for prognosis. Thus, framing the issue of racial and ethnic disparities in hospice as a function of the *lack* of referral may be off target. Instead, the issue might more accurately be described as a function of whether racial and ethnic minority patients are being referred *appropriately*.

Hospice non-users in the prognosis-driven group fell onto opposite ends of the spectrum (i.e. those who were actively dying or died before admission and, thus, referred too late versus those who had a prognosis greater than 6 months and, thus, referred too early); therefore, these findings must be interpreted from two different perspectives. First, potential reasons for referrals of racial and ethnic minorities occurring *too late* include: 1) minorities not having a usual source of care; 2) minorities posing a unique challenge to health care providers for making accurate prognoses (apart from diagnoses); 3) cultural or experiential factors that shape minority attitudes about not being open to hospice until the moments prior to death; or 4) minorities not being knowledgeable about hospice services. On the other hand, potential reasons for racial and ethnic minorities being referred *too early* include: 1) minorities not receiving the same opportunities as their White counterparts to pursue other forms of treatment or health service options for their terminal disease or 2) health care providers perceiving a need for sick minorities to obtain end-of-life care preparation or other at-home resources that they believe may not otherwise be obtained.

Referrals Occurring Too Late

As discussed in Chapter II, racial and ethnic minorities are less likely than Whites to have a usual source of health care, and this disparity seems to have negative effects on health (Blackman & Masi, 2006; LaVeist, 2005; Weinick et al., 2000). Without a usual source of health care, minorities may access health care services much later in their disease process. Thus, the time from diagnosis to the time when the patient is considered terminal may be shorter for racial and ethnic minorities than other patients. If these patients want to pursue all available treatments after the initial diagnosis, it is not surprising to find that they may be under-utilizing hospice services because they are referred too late to enroll. Additional

research is needed to determine if having a usual source of care and the nature of the source of care influence the use of hospice services. Future studies should determine whether non-Whites are referred to hospice at the same point in their terminal illness as Whites and if the timing of referral in the illness trajectory has any effect on the outcome of hospice utilization. Perhaps these findings would be different if considering inpatient hospice; future studies are needed to focus solely on factors associated with inpatient hospice use, as the current research focuses mostly on home hospice.

Another possible reason that minorities may be referred too late for hospice is related to previous discussion regarding the challenges that health care providers may have in estimating accurate prognoses. Currently, the research exploring prognostic accuracy focuses on diagnosis, with recognition that the often unpredictable nature of non-cancer diagnoses makes it particularly difficult to estimate a 6-month prognosis; however, the results of this study suggested that additional variables, aside from diagnosis, contribute to this problem. For example, racial and ethnic minorities may pose a unique challenge for health care providers. The signs and symptoms of impending death or end-stage disease may be different among different races and ethnicities. Similarly, health care providers may find it more challenging to diagnose terminal illnesses in minorities as compared to their White counterparts, as it is possible that their clinical presentation may not be what is considered “typical.” As previously discussed in Chapter I, minorities often report a general mistrust in the health care system and in health care providers. This mistrust may lead to the adoption of a telling-the-bare-minimum attitude that keeps health care professionals from obtaining all of the needed information to make accurate diagnoses and prognoses and that contributes to ineffective doctor-patient communications. This mistrust may also lead to the development of

a stoic outlook on health and, consequently, to the access of health care services at a later point in the disease trajectory. No known studies have explored the issues related to estimating prognoses or making diagnoses specifically for racial and ethnic minorities. In particular, qualitative work from the perspective of the health care provider may provide additional avenues to explore on this issue.

Some of the barriers to hospice utilization found in previous studies included differences in values regarding medical care and preferences for end-of-life care. In general, racial and ethnic minorities prefer more life-sustaining treatment and are less likely to plan for death than their White counterparts (Blackhall, Frank, & Murphy, 1999; Degenholtz, Thomas, & Miller, 2003; Hopp & Duffy, 2000; Kwak & Haley, 2005). The possibility that minorities are under-utilizing hospice because they are referred too late for services may be rooted in these patient preferences. Non-White patients simply may not be open to hospice until death is imminent, resulting in a referral that occurs too late to be practical. Only a few known studies have examined this issue from the perspective of the health care provider, and the findings support this interpretation (Ogle, Mavis, & Wang, 2003; Ogle, Mavis, & Wyatt, 2002; Sanders, Burkett, Dickinson, & Tournier, 2004). In the most recent survey-designed study, 337 physicians who made hospice referrals were asked why they thought hospice referrals often occurred late in the illness. The majority (67%) of responding physicians reported that the referral occurred late because the patient and family were reluctant to admit that the patient was dying (Sanders et al., 2004). This issue could be explored further with the family members of patients who are referred to hospice but die before admission, as well as exclusively with physicians who referred racial and ethnic minorities, to identify factors

associated with the “late” referral. Studies investigating the opinions of other referral sources, such as nurses and social workers, may also be beneficial.

In an increasingly patient-driven health care system, the lack of knowledge of hospice services, or even the lack of understanding of hospice, among racial and ethnic minorities could also be a significant factor as to why minorities might not be using hospice because of a late referral, as they may not be seeking a hospice referral. Combining this lack of knowledge with the cure-oriented focus of the current health care system, patients may not be aware of hospice as an option until the days prior to death. Not only do these findings support the need for community outreach programs that educate the public about hospice services, but they also support the need for increased end-of-life education for health care providers. Health care providers are responsible for assuring that patients receive information about all the relevant health care options regarding their illness. Notifying patients of their right to the provision of hospice care, the only organized end-of-life care option in the current health care system, is not exempt from this responsibility.

Referrals Occurring Too Early

Conceptualizing reasons as to why racial and ethnic minorities would be referred *too early* (and have more than eligible 6-month prognosis) to qualify for hospice services is more difficult. As previously discussed, despite the higher incidences of acute and chronic diseases in these populations, minorities in the United States are significantly less likely to receive what is considered the highest standard of medical care for a particular illness as compared to the majority White population. Racial inequalities have been observed in the screening and treatment of cancer, heart disease, organ transplantation, and AIDS treatment, among others (LaVeist, 2005). Thus, racial and ethnic minorities may be referred to hospice too early for

admission because they are not being treated or at least are not given the same options for treatment of their illness as their White counterparts. In other words, racial and ethnic disparities in hospice might actually be related to the under-treatment of their life-threatening diseases. More research is needed to determine if the patient's treatment history affects hospice utilization.

Health care providers may also perceive a particular need for their terminally ill racial and ethnic minority patients to receive end-of-life preparation before those patients meet the prognostic eligibility criteria. Providers may view hospice as the only option (or the best option) to obtain these resources and, consequently, make an early referral. This interpretation of the findings suggests that the current hospice eligibility criteria may not serve to identify patients who have the greatest need for hospice services, as terminally ill patients with a prognosis greater than 6 months may have an equal need for the resources offered by hospice as terminally ill patients with a prognosis less than 6 months. Although no known studies have explored whether the 6-month prognostic criteria identifies patients who have the greatest need for hospice, a recent study explored whether the treatment eligibility guidelines identify patients who have the greatest need for hospice. Patients who reported that they would not want cancer treatment even if it guaranteed a 6-month prognosis did not have a greater need for hospice services as compared to other patients. In fact, the researchers found that race was an independent predictor of patients' utilities for hospice services. Black patients were more likely than White patients to have a greater self-reported need for the resources offered by hospice, regardless of treatment choices (Casarett et al., 2008). In addition, Blacks and Hispanics are significantly more likely than Whites to report having unmet medical needs (Hargraves & Hadley, 2003). Hospice care provides patients with a

wealth of resources in the home, including medical supervision, nursing, social work, chaplain services, home health aides, durable medical equipment and prescription coverage, among other things. Health care providers (and even family and friends of patients) may recognize a need for these resources that can not be filled by other services outside hospice in the current health care system. Future studies that examine the outcomes, both in terms of mortality and disease coping, for patients who were precluded from hospice because they had more than 6 months to live could provide additional information regarding the actual needs of these patients and whether hospice eligibility guidelines identify patients who could benefit the most.

The finding that racial and ethnic minorities were more likely than Whites to have a prognosis-driven reason not to use hospice after referral supported the findings from the pilot study conducted by this investigator. However, interpretation of this finding is clouded because, when the model was adjusted for contextual and institutional factors, race was no longer a significant predictor of hospice non-use for a patient-driven reason versus a prognosis-driven reason. In the adjusted model, the interaction between the specific hospice agency and the patient's referral source was significant. Patients referred to Hospice A who had a prognosis-driven reason for not using hospice were more likely to have been referred by a physician compared to patients referred to Hospice B. This finding suggested that the reasons many patients are not enrolling in hospice go beyond simple racial identity or any *individual* predisposing characteristics the patient may possess. In fact, the specific combination of the referral source and the hospice agency to which the patient was referred may be a very important factor. The relationship between physicians and the specific hospice

agency and the outcomes of that relationship on hospice use should be explored in future studies, both in general and for racial and ethnic minorities in particular. Because the data for this study were administrative in nature, however, it is also possible that the process of referral differed for each hospice and is responsible for this interaction. Perhaps the intake coordinator at Hospice A simply indicated that the patient's approving physician was the referral source even though he/she was referred by another source, such as a social worker or a family member. Future studies with similar objectives as the current study need to be designed prospectively in an effort to assert some control over the referral process.

In addition, no variables were significant predictors of hospice non-use for a patient-driven reason versus a prognosis-driven reason when the sample was limited to racial and ethnic minorities. This finding was likely to have been an issue of inadequate power and/or sample size. Future studies with larger but manageable samples with sufficient power are needed to examine the patient, contextual and institutional factors associated with the reasons that racial and ethnic minority patients do not utilize hospice services after referral.

Further adding to the complexity of the findings, a comparison of the characteristics of patients who were referred too late to be realistic home hospice candidates (i.e. they were actively dying or died before admission) and the characteristics of patients who were referred too early and did not meet the prognostic criteria (i.e. they had greater than a 6 month prognosis) did not reveal any significant differences on race. In fact, these analyses suggested that the only differences between these groups were age and marital status. Patients who did not use hospice because of a late referral were more likely to be married and younger than patients who did not use hospice because of an early referral. Younger and married patients, and perhaps their health care providers, may have hopeful yet unrealistic expectations

regarding their terminal illness. For these patients, outcomes of treatment may sometimes be unexpected, delaying referral to hospice up until the hours prior to death. Younger patients may also have different values regarding medical care because they lack experience in the health care arena (and do not have a usual, trusted source of care) or are not knowledgeable about end-of-life care services because they lack the “life” experience. Married patients may have the additional pressure to continue to “fight” their terminal illness until all hope for life is gone because of the reliance or dependence of a significant other; however, the findings of the comparison of patients referred too late versus too early should be interpreted cautiously, as the sample was small and missing data were abundant. For example, only 13 patients in the sample did not use hospice because they had a prognosis greater than 6 months, and only 7 of those patients had values for race (in other words, 8 patients had missing data for race).

Additionally, no individual factors were significant predictors of hospice use versus non-use when the model was tested specifically for racial and ethnic minorities, even though power was adequate (>80%) to detect at least a 27% difference between hospice users and non-users on all of the individual variables. This finding suggested that race may have acted as a marker for some other factor in hospice utilization that was not measured or may not be measurable. On that note, the contextual and institutional factors should not be overlooked. For example, in the single-level contextual model (which did not include any individual or institutional factors), the county from which the patient was referred was a significant predictor of hospice utilization for non-Whites. Non-White patients from Counties B and C were significantly less likely to use hospice than non-White patients from County A; however, hospice patients in the sample may not have been completely representative of the

hospice patients in each county, as at least 20 hospice agencies serve County A, 8 serve County B and 9 serve County C ("The Division of Facility Services," 2006).²⁵ It is possible that each of these hospice agencies serving Counties A, B and C only recruit patients from certain, smaller catchment areas within that county. Future studies should use smaller geographical scales, such as census tract, to avoid this problem.

In the single-level institutional model (that did not include any individual or contextual variables), the particular hospice to which the patient was referred was a significant predictor of hospice use for non-White patients. Non-White patients referred to Hospice A were significantly less likely to use hospice after referral than non-White patients referred to Hospice B. Because the hospice agencies in this study were different in terms of organization, one explanation of these findings might be that the structure of the hospice agency affects the utilization of hospice services among racial and ethnic minorities. This study did not empirically examine the differences between the hospice agencies within the sample; however, Hospice B is a much larger organization than Hospice A. As discussed in Chapter I, larger hospice agencies may have a greater ability than smaller agencies to accommodate patients who want to pursue expensive palliative treatments (such as chemotherapy, radiation and blood transfusions) because of the semi-capitated billing method (Lorenz et al., 2004). Perhaps non-White patients would utilize hospice services at higher rates if they were allowed to continue pursuing palliative treatments. Future studies need to focus on the effect of the specific organizational characteristics of the hospice (such as the size, admission guidelines, policies for expensive palliative treatments and the referral process) to which racial and ethnic minority patients are referred.

²⁵ Multiple hospice agencies also served the counties combined into County D, which could explain why these counties were under-represented in the sample.

The findings from the single-level contextual and institutional models described above should be interpreted with the understanding that these models did not adjust for any individual factors. Therefore, no adjustments were made for the characteristics of the patients. It is also important to recognize that Blacks represented approximately 86.6% of the non-Whites in the sample. Thus, the findings related to race may be most beneficial for interpretation within the Black community and may not be generalizable to other minority groups. The majority of the published literature regarding cultural issues at the end of life is focused on issues with spirituality, mistrust, and attitudes and preferences among African Americans. Specific studies have shown that Blacks may fear sub-par medical care if they complete advance directives (Caralis, Davis, Wright, & Marcial, 1993) and have been shown to want more life-sustaining treatment than Whites near the end of life (Blackhall, Frank, & Murphy, 1999; McKinley, Garrett, Evans, & Danis, 1996). These documented preferences may be rooted in religious or spiritual attitudes among Blacks, which are often emphasized as a primary means of coping in this community (Born et al., 2004). In one study, Blacks reported a strong belief that only God had power over issues with life and death (Blackhall, Frank & Murphy, 1999), suggesting that physicians have no control over God's will (Crawley et al., 2000). The historical context of the experience of Blacks within the health care system, including the Tuskegee syphilis study, has festered a culture of mistrust in health care providers, the health care system in general, and, especially, a mistrust of research (Chadwick, 1997). Future studies should focus on specific races and ethnicities, instead of grouping all minorities into one category, as the issues for one group of minority patients at the end of life may differ dramatically from the issues of another minority group and should not be generalized to the entire non-White community.

The Importance of the Referral Source

Although the variable of referral source was not a significant predictor of hospice use, the findings for physician-referred patients differed greatly from the findings for patients referred by non-physicians. The findings for patients referred by non-physicians were similar to the findings for the entire sample: race was the only predictor of hospice utilization after adjusting for all other variables. However, none of the individual factors, *including the patient's race*, were significant predictors of hospice use for patients referred by a physician. After adjusting for all other variables, the gender of the patient's physician was marginally associated with the outcome, suggesting that patients referred by female physicians are more likely to utilize hospice than those referred by male physicians. The parsimonious model led to similar conclusions, adding only the variable of racial match between patient and physician. As hypothesized, patients who were of the same race and ethnicity as their referring physician were significantly more likely to use hospice after referral than patients who were referred by a physician of a different race.

The finding that patients referred by female physicians were more likely to utilize hospice is supported by previous research examining the characteristics of physicians and their attitudes towards end-of-life care services. Studies have shown that female physicians show a higher degree of empathy towards patients, have superior skills in therapeutic listening, are better able to communicate with sensitivity and are more receptive to psychosocial needs than male physicians (Arnold, Martin, & Parker, 1988; Bylund & Makoul, 2002; Dickinson & Tournier, 1993). Female physicians may also be more likely to refer their terminally ill patients to hospice than male physicians (Sanders et al., 2004). Future studies may also consider the gender match between the provider and the patient as a

potential factor in subsequent hospice utilization, as patients (particularly patients dealing with sensitive issues and difficult decisions) may feel more comfortable receiving care from physicians of the same gender. Additionally, studies examining the effect of gender when the referral source is not a physician may be beneficial.

Given the delicate nature of hospice and the current literature documenting the hesitancy of racial and ethnic minorities to trust the health care system, the finding that the racial match between the patient and the physician might be important was not surprising. A racial match between patient and physician may foster a more trusting, culturally-sensitive relationship than racially unmatched pairs. However, interpretation of this finding is somewhat ambiguous because racial match was not significant in the full model and because it was not possible to determine if the findings varied for different races in this study because of sample size. Additionally, the racial match between the patient and the physician was moderately correlated with the patient's race ($\rho = .619$). White patients were significantly more likely to racially match their referring physician than non-White patients (84.4% vs. 8.1%, $\chi^2 = 365.024$, $p < .001$). Future studies are necessary to further explore the importance of the racial match between the physician and the patient and the importance of the patient's race when the physician's characteristics are included in the model. Identifying if the racial match between the patient and any source of referral (e.g. the racial match between the patient and the social worker) is important and may provide direction for future work in alleviating hospice barriers for minorities. Qualitative research would be particularly helpful to examine if patients who are referred to hospice by professional sources of the same race and ethnicity as them have a different experience with the referral than patients who are referred by a provider of a different race and ethnicity.

Regardless, if the racial match between patients and providers represents an issue of cultural sensitivity and is an important factor in hospice utilization, the incorporation of cultural competency programs into hospices may need further exploration. If the racial match between patients and providers is important in the referral process, it is likely also important between patients and the intake nurses/coordinators of the hospice agency as well as between patients and their hospice providers once admitted. If the racial match is not always attainable, hospice agencies at the very least need to assure that all patients are treated with respect to their cultural values and beliefs when they are first introduced to hospice and that they receive care that is respectful and responsive to their beliefs and values when/if they are admitted. Additionally, building a diverse staff that is demographically representative of the served community of a particular health care organization has potential “to accentuate different knowledge and insights from varied cultures, to open the door for accessing culturally different markets, and to reduce the probability of discrimination based on race and ethnicity” (Forcina Hill, 2005, p.221). Only one known study has examined the current state of diversity in the hospice workforce, but it was conducted through surveys of hospice medical directors’ estimations of racial and ethnic representation of their employees and volunteers (Reese, Melton, & Ciaravino, 2004). While the staff racial mix appears to fairly represent the patient racial mix in this study, the researchers also did not statistically examine differences between the racial/ethnic representation of the patients they served and the racial/ethnic representation of the staff (Reese et al., 2004). Future work is needed to explore whether staff diversity and cultural competence training impacts the patient demographic characteristics of a particular hospice agency.

Perhaps the most interesting finding in the model examining physician-referred patients was the *lack* of certain findings. The patient's race was no longer an important factor in hospice utilization when the characteristics of the physician were included in the model. This is the first known study to examine patient characteristics in conjunction with the referring physician's characteristics. These findings are important in many ways, particularly for racial and ethnic minorities, because they suggest that the characteristics of the physician might be more important than specific patient characteristics. Further, because referral source was not a significant predictor of hospice utilization, this finding also suggests that the characteristics of the referral source – not simply the characteristics of the physician – are important. Studies are needed to corroborate if the characteristics of the patient's referral source, particularly for sources other than a physician, have an effect on subsequent hospice use. In addition, further exploration of the hospice referral process in general is essential to fully understand how an actual referral takes place in terms of how it is approached by the health care provider, how it is received or initiated by a patient or family member, whether a discussion takes place and how that discussion is facilitated, how the hospice agency approaches the patient and family, and the outcomes of these various measures on hospice use.

The Importance of the Patient's Diagnosis

The full models are considered the definitive models for this study, as previously discussed in Chapters IV and V; however, the results of the parsimonious models provide additional direction for future research. The parsimonious model to determine individual predictors of hospice use, given contextual and institutional factors, suggested that the patient's diagnosis was another important factor. Even though non-Whites were significantly more likely to have cancer than Whites ($\chi^2 = 39.545$, $p < .001$), patients referred to hospice

with a non-cancer diagnosis were less likely to use hospice after referral than patients referred with a cancer diagnosis. This finding is supported by findings from previous studies (Greiner et al., 2003). Malignant neoplasms are the leading admission diagnoses in hospices nationwide, accounting for the diagnoses of nearly 50% of hospice users ("NHPCO's Facts and Figures - 2005 Findings," 2006). Currently, very little empirical evidence exists to explain why non-cancer diagnoses are under-represented among hospice patients, although many researchers attribute the problem to issues with recognizing the signs and symptoms of terminality in non-cancer illnesses. As previously discussed, the disease trajectories of many non-cancer illnesses are ambiguous, and estimating an accurate prognosis is often very difficult (Christakis & Lamont, 2000). This finding supports the need for further research in improving prognostic accuracy. Numerous scales and disease-specific guidelines have been issued to assist in these efforts with little success (Elliott, Renier, & Palcher, 2007; "Medical Guidelines for determining prognosis in selected non-cancer diseases," 1996).

A different, although under-studied, option for prognostic improvement is the utility of illness trajectories. Lynn (2004) identified 3 illness trajectories for terminal illness: 1) short period of evident decline; 2) intermittent exacerbations and sudden dying; and 3) slow dwindling. These trajectories add to the current literature on prognostic estimation by recognizing that every disease has a different way of "ending." For example, many cancers result in a short period of decline, while many other chronic illnesses result in intermittent exacerbations and sudden dying. Future studies are needed to further explore the illness trajectories of life-ending diseases, validating these 3 or other categories and examining the utility of the knowledge of trajectories to appropriate and timely hospice referrals. Additionally, despite the recent nationwide growth of hospice admissions for patients with

non-cancer diagnoses, a new study found differences in this disease-specific growth rate by race, with larger disparities in hospice use among racial and ethnic minorities with non-cancer diagnoses than minorities with cancer diagnoses (Johnson, Kuchibhatla, Tanis, & Tulskey, 2007). This new study, in conjunction with the current study's findings, suggests that continued improvements in the accuracy of prognoses and the appropriateness of referrals of patients without cancer, perhaps with a focus on racial and ethnic minorities, may also improve the referral and utilization among racial and ethnic minorities.

On the other hand, the findings of this study do not suggest that the patient's diagnosis is an important predictor of hospice non-use for a patient-driven reason versus a prognosis-driven reason. If the prognostic difficulty in non-cancer diagnoses *is* truly an important barrier to hospice utilization, then one would have expected the patient's diagnosis to have been an important predictor in the model determining the hospice non-use subgroups. This study is the first known study to offer empirical evidence that issues in prognostic accuracy might hinder hospice utilization. Patients in this sample who were referred too early for hospice services and had prognoses greater than 6 months were grouped with patients who were referred too late for hospice services and were subsequently on the brink of death. Although both of these groups were not admitted to hospice because of some issue with prognosis, this method of coding may have affected the outcome. Patients who were not admitted because they had more than 6 months to live might have very different barriers to hospice use than patients who were not appropriate because they were actively dying. A comparison of hospice non-users who were referred too early and hospice non-users who were referred too late suggested significant differences on age and marital status; however,

the sample size was small with several missing values. Future studies in this realm should be powered so that each of these groups can be examined separately.

The Importance of the Hospice Agency

The parsimonious model of hospice use to determine individual factors given contextual and institutional factors also suggested that the particular hospice to which the patient was referred was an important factor in hospice use. Patients referred to Hospice B were significantly more likely to use hospice after referral than patients referred to Hospice A. This finding was similar to the findings from an earlier study of hospice programs suggesting that the specific hospice to which the patient was referred might affect the patient's utilization of services (Lorenz et al., 2004). Hospice B was a larger organization than Hospice A and may have had the ability to admit more patients preferring the more expensive palliative treatments (such as chemotherapy and radiation) because of its ability to spread the financial risk among more patients. Thus, it was not surprising to find that patients referred to Hospice B were more likely to utilize hospice after referral than patients referred to Hospice A. In contrast, the results of the parsimonious model to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason suggested that patients referred to Hospice B were also more likely than those referred to Hospice A to have patient-driven reasons not to use hospice. If Hospice B's larger size and presumed ability to admit more patients who were interested in pursuing aggressive treatments *was* indeed the reason that patients were more likely to utilize services when referred to Hospice B, one would have expected more patients from Hospice A to have a patient-driven reason not to use hospice than patients referred to Hospice B and not vice versa. On the other hand, when the two specific sub-groups of patients who had patient-driven reasons not to use hospice (those who

refused and those who were pursuing aggressive treatment) were examined separately, patients referred to Hospice A were more likely not to use hospice because they were pursuing aggressive treatment as compared to patients referred to Hospice B. Thus, because the subjects with patient-driven reasons not to use hospice were small in number, the effect of patients who refused may have masked the effect of patients who were pursuing aggressive treatment when the two groups were combined in the analysis.

The data for this analysis did not include detailed data on the differences between Hospice A and B's admission practices, particularly the extent to which patients pursuing the more expensive palliative treatments are admitted. The finding that the specific hospice agency was important could also have resulted from differences in data collection between agencies, particularly when considering how the data collectors determined the reasons for patients not to use hospice; therefore, confidently explaining this finding is not possible. This study appears to be the first known study to examine the patient's characteristics in the context of the hospice agency to which the patient was referred. Future studies need to focus on how the characteristics of the hospice agency to which the patient was referred affect the utilization of hospice services and to explore whether the individual factors associated with hospice use are conditional on characteristics of the hospice agency.

Other Findings of Interest

Unlike the findings in the pilot study, the findings of this study do not suggest any effect of age on hospice utilization after referral. Hospice users in the sample were only slightly younger ($M = 77.2$, $SD = 14.50$) than hospice non-users ($M = 77.8$, $SD = 15.94$). The fact that age did not emerge as an important factor was somewhat surprising, as it was expected that younger patients would be less likely to utilize hospice after referral, as younger people have

been shown to experience higher anxiety regarding death and may be concerned about dying too soon “before they have had the chance to do and experience all they have hoped for in life” (Kastenbaum, 2007). In the current study, the patient’s age might have been disregarded because all of the patients in the sample, in theory, had a terminal illness. In other words, having a terminal illness may “level the playing field” for patients of all ages when it comes to the utilization of hospice services.

Although the preliminary study suggested that the patient’s age affected the patient’s hospice utilization status, it also supported the current study’s findings by indicating that the patient’s race was the more important factor. It is interesting to note, however, that Whites in the sample were significantly older ($M = 78.4$, $SD = 13.83$) than non-Whites ($M = 71.5$, $SD = 16.61$) ($t = 9.653$, $df = 808.665$, $p < .001$) and that patients with non-cancer diagnoses were significantly older ($M = 83.3$, $SD = 12.24$) than patients with cancer diagnoses ($M = 71.4$, $SD = 14.26$) ($t = -27.197$, $df = 3648.759$, $p < .001$). Because the results of the multivariate analyses with backwards elimination indicated that diagnosis and race were the important factors, age does not appear to matter as much as the characteristics that are often associated with age (such as diagnosis and race) in the study of hospice utilization patterns. This finding represents a different conclusion than one might find in the study of other health services (Andersen & Davidson, 2001).

Previous studies have reported that the patient’s gender, health insurance status and marital status were all associated with hospice use (Berry et al., 1994; Greiner et al., 2003; Iwashyna et al., 2002). The findings from this study do not necessarily support the findings from these earlier studies. The patient’s marital status and insurance status were not significant predictors in any of the models in the current study. Similar to previous studies

and the preliminary study, the patient's gender was a significant predictor of hospice utilization when the patient's characteristics were examined by themselves, indicating that females were more likely to use hospice than males. Females in this sample were significantly older than males ($M = 79.2$, $SD = 14.47$ vs. $M = 74.4$, $SD = 14.33$) ($\chi^2 = 10.144$, $p < .001$). As noted in Forcina Hill (2008, p. 250), this finding is often explained by the longer life expectancy of females over males in the general population, an explanation that does not clarify "why males do not simply use hospice at an earlier age" than females. However, other published studies have not examined the importance of patient, contextual and institutional variables in one model; and the importance of the patient's gender disappeared when contextual and institutional variables were added.

Based on the literature, other individual factors that were not included in this study but may have some effect on hospice use after referral are the patient's income, educational level, social support and/or caregiver support, and comorbidity scores (as a measure of the patient's evaluated need). Additionally, although the referral source variable may have captured the patient's usual source of care in this study, more specific measures of the patient's source of care, including measurements of the trust between patient and provider as well as the length of the relationship, may lead to different findings. Inclusion of measurements of patients' perceived need for hospice services and their views regarding end-of-life and medical care is imperative for future studies. Another institutional factor that may have some effect on hospice use after referral is the physician's board certification status. On the contextual level, none of the variables that were planned for analysis were able to be examined because of the limited number of counties in the sample. Thus, future studies in

this area of research should include these missing variables, as well as other variables that were suggested throughout this chapter.

The Conceptual Model

Based on the Behavioral Model of Hospice Use, variables chosen for this study were expected to load onto one of three factors that could be named the predisposing, enabling and need constructs. Upon closer examination of the factors, however, it appears that many of the sub-concepts (within the predisposing, enabling and need constructs) in the Behavioral Model of Hospice Use were represented (refer to Figure 3 and Table 4 for details). Both the individual and institutional variables will be discussed. The contextual variables could not be factored due to the small number of counties ($N = 3$) within the data set.

Individual Constructs

Many of the individual concepts in the Hospice Model were borrowed from Andersen's Behavioral Model, and the results of the factor analysis support most of their operational definitions in this study. Among the individual constructs, factor one consisted of age and diagnosis. Both of these variables were chosen to represent the *demographic* sub-concept of the predisposing variables as guided by Andersen's Behavioral Model of Health Services Use. Thus, based on these data, the categorization of these variables appears to have been accurate. Andersen did not specifically address diagnosis as a variable in his model; therefore, the categorization of diagnosis into the demographic concept was based on the current literature on hospice utilization.

In contrast, the variables of gender and marital status were not initially regarded as part of the same concept; however, the factor analysis resulted with gender and marital status loading together onto factor two. Andersen originally categorized both gender and marital

status as part of the individual demographic characteristics within the predisposing variables; however, based on the hypothesis that marital status might represent a social aspect of end-of-life care and supported by Andersen himself (R.M. Andersen, personal communication, November 14, 2006), it was theorized that marital status would best be represented as a social characteristic of the individual predisposing domain in the Hospice Model. This hypothesis was not necessarily supported by the results of this factor analysis, as factor two could be viewed in two ways: 1) gender and marital status could be a different type of demographic sub-concept than age and diagnosis, or 2) gender and marital status could be categorized as part of the social sub-concept within the predisposing domain. Marital status is a strong indicator of the existence of a dying individual's emotional loneliness (Stroebe, Stroebe, Abakoumkin, & Schut, 1996); and women, in general, have a wider and more active social network than men (Antonucci, 1990; Umberson, Wortman, & Kessler, 1992); therefore, this factor seems to represent more of a *social* phenomenon (part of the social sub-concept within the predisposing domain) than a demographic description. Even though gender is almost always considered a demographic characteristic, the results of this analysis demonstrate that a patient's gender might represent more than biology in the study of hospice services. Future studies are needed to further examine how a patient's gender influences his/her perspective of hospice services and the consequence of these views on the subsequent utilization of end-of-life care services.

As the sole variable on factor three, insurance status was the only variable chosen to represent the *financing* aspect of the enabling concept based on Andersen's operational definitions. Thus, the a priori categorization of insurance status appears to have been accurate. The last factor, factor four, was comprised only of race, which reflects the

independence of race in conjunction with the other patient characteristics. Factor four was named *beliefs*.

When the analysis was conducted with the entire sample in order to include the variable of referral source, the factors were comprised in the same manner described above with referral source loading onto its own factor. This variable was categorized as an individual enabling characteristic in the Hospice Model. The sub-concept of *organization* within the individual enabling factors is defined as whether or not the patient has a usual source of care and the nature of that source of care. The variable of referral source in this study, i.e. whether the patient was referred by a physician or referred by a source other than a physician, is a potentially fitting proxy for the patient's usual source of care.

Institutional Constructs

Many of the institutional concepts in the Behavioral Model of Hospice Use were borrowed both from Andersen's Behavioral Model and the Conceptual Model of Realized Access to End-of-life Care; however, the results of the factor analysis reveal some possible gaps in the conceptualization of the Hospice Model in the realm of institutional factors. The first factor in this analysis consisted of the physician's age and how long the physician was licensed at the time of referral. These two characteristics together were not originally thought to represent a concept. Rather, the physician's age was chosen to represent the demographics of the provider characteristics and the time licensed was chosen to represent the social aspect of the provider characteristics. However, it is possible that a physician's age as well as how many years a physician was licensed at the time of referral reflect the physician's *experience* in death and dying instead. For example, the longer a physician is licensed, the more medical experience one would expect him/her to have with end-of-life care. While the age of the

physician may not accurately reflect his/her medical experience, it could act as an indication of his/her social or life experience with death or dying. The physician's time licensed, on the other hand, may also denote the kind of end-of-life training that he/she received during medical training.

The physician's race and the racial match between the physician and the patient loaded onto the second institutional factor, which was named culture. Initially, these two variables were thought to represent the *social* aspect of the provider characteristics, and the results of the factor analysis support this presumption. However, race may also represent the patient's cultural views and *beliefs* regarding death and dying. A racial match between the patient and provider, in turn, might foster a more appropriate relationship for the discussion of death and dying.

Factor three was comprised of the hospice to which the patient was referred and the physician's primary practice location. However, the hospice to which the patient was referred was hypothesized to represent the health policy variable in the Hospice Model, and the physician's primary practice location was hypothesized to represent part of the physician's social characteristics. The results of the factor analysis, however, indicated that both of these variables were part of the same domain. The effects of general health policy are reflected in health care providers' practices. Thus, the place where the physician practices is a fitting indicator of the resources the physician has available to him, cost containment efforts within the practice, the availability of alternate end-of-life services to the physician and his/her patients and coverage of care by insurers accepted by the physician's practice. For these reasons, the findings from the factor analysis support the placement of the physician's primary practice location with the *health policy* concept, with the physician's primary

practice location possible representing clinical practice policy and the hospice agency possibly representing organizational policy.

Specialty was the only variable to load onto factor four. The physician's specialty is an indication of his/her area of *expertise* and, perhaps even more importantly in end-of-life care, is an indication of the patient population that the physician serves. Because the patient's diagnosis was a significant predictor of hospice utilization in the parsimonious model and previous studies have suggested that the physician's specialty influences his/her referral practices (Bradley et al., 2000), the physician's specialty represents several aspects of the possible influence he/she has on the patient's utilization of hospice services.

The last factor, factor five, was comprised of the variables gender and clinical care hours and was labeled *availability*. Female physicians have been documented as working significantly fewer hours and seeing fewer patients than their male counterparts (Heiliger & Hingstman, 2000). This evidence helps to explain why the physician's gender loaded onto the same factor as the physician's clinical care hours. Similarly, female physicians in the current data set worked significantly fewer hours ($M = 37.3$, $SD = 12.10$) than male physicians ($M = 49.3$, $SD = 11.97$) ($t = 12.598$, $df = 331.027$, $p < .001$).

Model Testing Summary

In conclusion, few surprises were observed in the factor analysis of the patient variables, as the patient's age, diagnosis and insurance status seem to have accurately represented the intended concepts. The patient's gender and marital status were not expected to represent one concept, although it is quite possible that these two variables reflect the patient's social support system within the context of the dying process. The patient's race loaded onto its own factor, suggesting that race is an independent contributor to the structure of hospice

utilization, possibly representing the patient's beliefs. The analysis also demonstrated that the patient's referral source may reflect the organization sub-concept of the enabling characteristics.

On the other hand, the factor analysis of the institutional factors resulted in several unexpected findings. The four characteristics of the physician that seem to have representation in the data were social/beliefs, experience, expertise and availability. In future use of this model, the physician characteristics should be re-examined for their representation of these concepts. In addition, the hospice to which the patient was referred and the physician's primary practice location seem together to have represented the concept of health policy. Interestingly, none of the variables examined in this study appear to have represented the demographics of the physician. Table 40 displays the factors analysis results in comparison to the a priori classifications.

Table 40. *Factor analysis results in comparison to a priori variable classifications*

Individual Factor Analysis					
A priori			Results		
<i>Concepts</i>		<i>Variables</i>	<i>Concepts</i>		<i>Variables</i>
Predisposing	Demographics	Age, gender, diagnosis	Predisposing	Demographics	Age, diagnosis
	Social	Race/ethnicity, marital status		Social	Gender, marital status
	Beliefs	Not represented		Beliefs	Race/ethnicity
Enabling	Financing	Insurance status	Enabling	Financing	Insurance status
	Organization	Referral source		Organization	Referral source
Need		Not represented	Need		Not represented
Institutional Factor Analysis					
A priori			Results		
<i>Concepts</i>		<i>Variables</i>	<i>Concepts</i>		<i>Variables</i>
Provider characteristics	Demographics	Age, gender	Provider characteristics	Demographics	Not represented
	Social	Race/ethnicity, racial match, year licensed, clinical hours/week, primary practice location		Social	Race, racial match ^a
	Beliefs	Not represented		Beliefs	Race, racial match ^a
				Experience	Years licensed, age
				Expertise	Specialty
				Availability	Gender, clinical care hours
Health policy	-	Hospice agency	Health policy	-	Hospice agency, primary practice location

^aRace and racial match could have represented either the social concept or the beliefs concept.

While the results of the factor analyses should be interpreted with caution because of the relatively limited number of variables loading onto each factor (Pett et al., 2003), the analyses explained approximately 80% of the variance. Additionally, the final regression models of hospice use described in Specific Aim #3 explained approximately 12% of the variance in hospice utilization. Both of these figures suggest that the Hospice Model is acceptable for use in future studies of hospice utilization, with the improvements recommended here. As the health care system grows to accommodate more end-of-life and palliative care service options, this model might also be useful in the design and implementation of studies examining the utilization of these services.

Policy Implications

Although an in-depth analysis of the policy issues surrounding hospice services is not within the scope of this study, the findings reported here study provide some potential direction for policy improvement. The findings from this study support previous hypotheses that the current hospice treatment and prognostic eligibility guidelines are barriers to hospice utilization, particularly among racial and ethnic minorities. The current guidelines prevent patients with prognoses greater than 6 months and patients who are pursuing curative treatment from utilizing hospice, even though these may be the patients with the greatest need for hospice resources. Guidelines that focus more on a combination of the functional and emotional assessments of patients with terminal illness may be more reasonable. Studies to examine the economic, cultural and medical outcomes of changing the hospice restrictions on prognosis and treatment eligibility are essential to improving the utilization of hospice services and potentially the patient experience of end-of-life care in general.

However, changing the hospice eligibility guidelines may not be feasible any time in the near future. Considering the Hospice Benefit is the only true palliative care option under Medicare and most insurance companies, alternative methods to help patients access end-of-life care services should be explored. First, the reimbursement for end-of-life care services needs to be addressed both for hospices and hospitals alike. The current semi-capitated reimbursement system for hospice services does not allow for all patients to receive the most advanced palliative care due to expense. Similarly, the provision of palliative care services is not currently considered a legitimate, reimbursable reason to hospitalize a patient (Forcina Hill, 2005); and reimbursement for the provision of psychosocial services to terminally ill patients in a fee-for-service system outside the hospice benefit seems to be inadequate

(Wiener & Tilly, 2003). Researchers focusing on end-of-life care services in the United States need to appeal to policymakers to recognize the issues of reimbursement as a major barrier to optimal end-of-life care services and to explore methods to adequately address them.

Second, because the prognostic restriction of 6 months or less was identified as a potential barrier to hospice utilization, particularly among racial and ethnic minorities, the utility of pre-hospice or “bridge” programs needs further exploration. These programs are designed to offer the same comprehensive services offered by hospice through traditional home health services, without the eligibility restrictions of prognosis or treatment preference. The goal of a bridge program is to provide an effortless transition to hospice services when the patient is ready, while still providing the health care professionals with adequate time to foster a beneficial relationship with the patient and family (Casarett & Abraham, 2001). Few studies have examined the outcomes of utilizing these programs from a patient perspective, and no known studies have explored the economic advantages or disadvantages of this type of program. Whether these bridge programs truly represent a transition between aggressive care and hospice care or whether they simply act as a different model of end-of-life care provision is unclear. Of course, none of these proposed advancements – in eligibility guidelines, reimbursement rates or additional programs - can ultimately be addressed without detailed economic examination of their consequences for the patients, providers, third-party payers and the government.

The findings from this study also have specific implications for the community. Other research has suggested that barriers to hospice use based on race do exist, and this study suggests that these barriers continue even after referral. However, the data from this study

also suggest that the more important factors may lie within the referral process. Who makes the referral, how the referral is made, and the timing of the referral may be the most important areas for future exploration and may, in fact, be related to the disparities in health and health care in general. Factors associated with hospice use, as well as the referral process, may differ between communities, possibly even between agencies; therefore, researchers need to closely examine the factors associated with hospice use that are specifically related to the needs of their community.

Limitations

This study was conducted with secondary data of an administrative nature. Therefore, some limitations must be addressed. First and foremost, the data, and particularly the patient and provider data, were limited because they had been collected from numerous sources over a few years. It is possible that data collection methods could have changed over time or have varied between employees and institutions. Another common problem with the use of secondary data, particularly in this study, was missing data points. The data used here were collected administratively and not for research purposes; therefore, missing data were expected. All data missing from the databases were treated as such; and because the investigator was familiar with the database and the methods of data collection used by each institution, the limitations of the data set were minimized. A close working relationship with the business managers and technical support staff at each agency was maintained throughout this study, and these individuals were consulted whenever questions regarding the coding of the data arose.

Related to the source of the data, selection bias is another limitation. First, it is unclear how race was classified for both physicians and patients. That is, patients and physicians

could have identified their race during data collection or the data collectors could have determined patient and physician race/ethnicity. Secondly, this study assumed that the referral source actually made the referral; that is, the person listed as the referral source for the patient was presumed to have made contact with patient regarding the decision to enter hospice. It is possible, however, that the referral source, particularly if that source was a physician, simply filled out or had someone else fill out the paper work while another individual actually communicated with the patient. Therefore, interpretation of the meaning of how the physician characteristics affected the patient's actual utilization of hospice after referral (for those referred by a physician) should be made with caution.

The sample size was another limitation of the study. Some of the analyses, particularly when examining racial and ethnic minorities independently, were not sufficiently powered to detect differences between hospice users and non-users. In addition, the data set did not include enough patients who had a prognosis-driven reason not to use hospice after referral to detect if these patients were referred too late to be appropriate for home hospice or too early to qualify for hospice services. Many of the variables also had to be dichotomized into only two categories (instead of grouped into multiple categories) because the sample was not large enough to accommodate the heterogeneous mix. Additionally, the sample was not completely representative of hospice users in North Carolina, as statistical differences existed on several patient characteristics when the hospice users in the sample were compared to the characteristics of the hospice users of the region. According to the North Carolina Division of Facility Services ("The Division of Facility Services," 2006), 271 hospice facilities served patients in North Carolina in 2006, and only 2 of those hospices were included in this study, which may have been a factor in this discrepancy. Further, not all hospices in North Carolina

contribute data on their patients to the Carolinas Center for Hospice and End-of-Life Care (the agency from whom the comparison data was collected). Therefore, the findings from the study were not as specific as they may have been with a larger sample drawn from a larger number of hospices in the state.

Another major limitation was that the patient's county of residence was the smallest geographical area that could be obtained for data analysis. While this was a recognized issue at the beginning of the study, it was not expected to pose as complex of a problem as realized. Only 3 counties were available for analysis because most of the counties collected in the data did not have values for all of the outcome variables, and a sample size of 3 made it impossible to conduct the analyses as intended. If a smaller geographical area (such as census tract) could have been obtained, the number of geographical locations and the number of hospice agencies serving those locations, as well as the variation of characteristics within those areas, would have been more manageable and may have allowed for further exploration of the contextual characteristics with a more representative sample of patients. Gathering the individual data of hospice users by county as compared to gathering data of hospice users from hospice agencies may have resulted in a more complete sample.

In an effort to minimize the effect of these limitations, the data were analyzed and the results were interpreted with the described problems in mind. Most of these issues could not have been avoided; therefore, it was important to recognize the limitations throughout the study's process.

Implications for Future Research

This study provides a foundation for the development of a program of research in end-of-life care and aids in the advancement of knowledge pertaining to hospice use.

Understanding the barriers to hospice that terminally ill patients, particularly racial and ethnic minorities, face is the only way to move forward with ideas to improve realized access for patients who would benefit from this service or different end-of-life care services. As previously noted, the results of this study suggest several directions for future research. First, future studies need to be designed to enhance the Hospice Model based both on the findings from this study and from the growing literature on end-of-life care and hospice utilization. Not only will this study need to be replicated using different hospice agencies in different parts of the country (ideally in a prospective manner with smaller geographic areas of study such as census tract), but the model itself is expected to undergo refinement with continued investigation and empiric support. As there is no predictive model for hospice utilization in the current literature, a necessary first step was the development of the Hospice Model.

Second, further exploration of the impact of patients' beliefs is essential. In this regard, an instrument may need to be developed to examine how patients' underlying beliefs about death and dying, medical care, terminal illness, etcetera, impact their decision to utilize hospice services in context of the other factors explored here. Additionally, because the findings from this study indicated that institutional factors are particularly important in hospice use among referred patients, another study is needed to investigate the differences between the two hospice agencies further. Only one known study has explored where most hospice referrals are initiated (i.e. are they mostly referred by physicians, family members, social workers, or others?), and it concluded that most referrals are physician-initiated (Sanders et al., 2004). Additional research examining the current state of the referral process would be beneficial, particularly because the findings from this study suggest a difference in factors associated with hospice use based on the characteristics of the referral source.

Third, based on the current literature, the caregiver is hypothesized to play a major role in hospice utilization both in the entire referred population and in racial and ethnic minorities. This study did not include any representation of caregiver support or participation in the decision to use hospice; therefore, if or how caregiver support affects hospice utilization was not examined. Future studies are necessary to examine the role of the caregiver and caregiver satisfaction with hospice services and to incorporate these factors of the caregiver into the Hospice Model.

Fourth, further investigation of the patient-provider relationship, possibly using qualitative approaches to capture the referral experience of both the patient and the provider, is necessary because provider characteristics were important for hospice use in this study. An important area for future exploration is the “communication” concept in the Hospice Model that was only implicitly examined in this study.

Finally, it is anticipated that this research will lead to the development of interventions that will increase hospice utilization among the terminally ill and enhance hospice services. Findings from this study support the development of interventions aimed at improving community awareness of hospice, enhancing the education and training of health care professionals in the provision of end-of-life care and in prognostic estimation with diversity in mind, and integrating and monitoring cultural competency training into hospice organizations. Perhaps most importantly, these future endeavors are well within the realm of nursing practice. As noted in a prior publication by this author:

The provision of end-of-life care is considered a substantive part of nursing...Because nurses have a pivotal and critical role in the provision of optimal end-of-life care and hospice is [currently] considered the gold standard for optimal end-of-life care, hospice access and utilization for terminal patients is a health care service issue of great vested interest for nurses (Forcina Hill, 2005, p. 216-217).

On the forefront of bedside care, nurses are critical assets to improving end-of-life outcomes and may be in the most advantageous position to implement strategies to move forward with the findings from studies such as this one.

Summary

The issues encompassing the disparities in hospice utilization among terminally ill patients are grounded in the complexities of both health services and end-of-life care research. The findings from this study, while beneficial for providing direction for future research, are not exempt from these complexities. While the findings do not provide a clear-cut solution for resolving the problem of hospice under-utilization, they do highlight some important issues, particularly for racial and ethnic minorities. With the guidance of the Hospice Model, the results of this study shed some light on whether patient, contextual and institutional factors are associated with hospice use after referral and whether individual factors associated with hospice use are conditional on contextual and institutional factors. The findings indicate that the patient's race, referral source, diagnosis and the hospice agency to which the patient was referred are all important factors that predict hospice utilization after referral. However, the characteristics of the referring physician, such as the physician's gender, and the racial match between patient and provider may be just as important to consider as the characteristics of the patient. The findings from this study were also beneficial in identifying areas for improvement within the Hospice Model to enhance the use of this model in future research.

Appendix A: Additional Regression Analyses

Additional analyses were conducted including *all* of the variables from the patient, contextual, and institutional levels without regard to the findings from the one- and two-level models²⁶ (from the analyses completed in Specific Aims #1 and #2). Although many of the findings from both methods of analyses were the same, each technique has its own advantages and disadvantages that should be considered in interpretation. The first method (described in Chapter V and interpreted in Chapter VI), is considered a filtering method and is regarded as the definitive method of analysis for this study because of its efficiency, “simplicity, scalability and empirical success” (Guyon & Elisseeff, 2003), p. 1157). The method that will be described in the following pages, on the other hand, is advantageous because it includes all the variables in one model. This method is not as robust against over-fitting or as simple computationally, but it was thought to be potentially valuable in this analysis because it allowed variables that were useless in the single-level models (i.e. individual, contextual or institutional separately) to be considered potentially useful in the context of all the other variables from the other models (i.e. individual, contextual, institutional combined) (Guyon & Elisseeff, 2003). The results of these analyses are shown in Tables 41-45. No interactions were included in these analyses.

²⁶ Individual variables included gender, age, race/ethnicity, marital status, diagnosis, insurance status and referral source. Contextual variables included only the patient’s county of residence. Institutional variables included only the hospice to which the patient was referred when the entire sample and patients referred by another source were examined. Institutional variables for physician-referred patients included the hospice and the physician’s gender, age, race, racial match, time licensed, specialty, primary practice location and clinical hours/week.

Hospice Use versus Non-use for All Referred Patients

Table 41 summarizes the model of all patient, contextual and institutional factors for the entire sample of referred patients. The full model findings were slightly different from the findings in Chapter V. Significant predictors of hospice use versus non-use were the patient's gender, race and diagnosis. Female patients were 1.9 times more likely to use hospice after referral than males ($p=.017$). White patients were 1.9 times more likely to use hospice after referral ($p=.024$), and patients referred with a cancer diagnosis were 1.7 times more likely to use hospice after referral ($p=.044$). The results of the parsimonious model, however, were the same as the results described in Chapter V. In the parsimonious model, non-White patients, patients referred with a non-cancer diagnosis, and patients referred to Hospice A were significantly less likely to use hospice than White patients, patients with a cancer diagnosis, and patients referred to Hospice B ($p=.010$, $.008$, $<.001$, respectively). These findings support the findings from the previous analyses described in Chapters V and VI that race, diagnosis and the hospice to which the patient was referred are important factors in hospice utilization after referral. The full model results also provide support for the possible role of the patient's gender in hospice utilization, which was discussed briefly in Chapters IV and VI.

Table 41. *Model of all patient, contextual and institutional factors to determine hospice use vs. hospice non-use after referral, including entire sample of referred hospice patients^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female *	-0.620 (0.259)	0.538 (0.324,0.893)	.017	-	-	-
Age	-0.004 (0.009)	0.996 (0.979,1.013)	.650	-	-	-
Non-White *	0.625 (0.277)	1.869 (1.086,3.214)	.024	0.610 (0.236)	1.841 (1.160,2.922)	.010
Not married	0.287 (0.264)	1.332 (0.794,2.234)	.277	-	-	-
Non-cancer *	0.528 (0.262)	1.695 (1.015,2.830)	.044	0.551 (0.208)	1.735 (1.155,2.608)	.008
Source other than Medicare	0.137 (0.301)	1.147 (0.636,2.069)	.649	-	-	-
Referred by non-physician	0.473 (0.297)	1.605 (0.897,2.874)	.111	-	-	-
Contextual Variables						
County A			Reference			
B	-0.086 (0.915)	0.917 (0.153,5.508)	.925	-	-	-
C	0.661 (0.884)	1.937 (0.342,10.953)	.455	-	-	-
D	0.113 (0.603)	1.119 (0.343,3.649)	.852	-	-	-
Institutional Variables						
Hospice B	-1.197 (0.845)	0.302 (0.058,1.582)	.157	-1.941 (0.203)	0.144(0.096,0.214	<.001

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; marital status = married; diagnosis = cancer; insurance = Medicare; referral source = physician-referred; county = County A; hospice = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

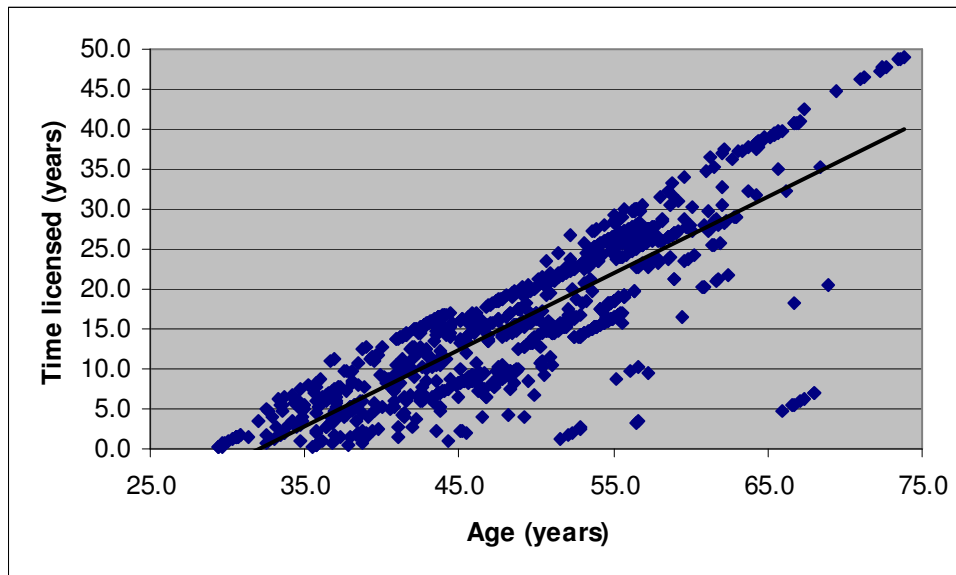
^aN=3489. ^bR² = 0.085. ^cR² = 0.116.

*p≤.05 in full model.

Hospice Use versus Non-use for Physician-referred Patients

Similar to the results described in Chapter V, none of the patient or contextual variables were significant in the model including all patient, contextual and institutional factors to determine hospice utilization for patients who were referred by a physician, but the physician's age and how long the physician was licensed at the time of referral were significant. However, Figure 6 illustrates that these variables were significantly, positively and highly correlated ($\rho = .846$, $p < .001$).

Figure 6. Scatter plot showing the relationship between physician age and time licensed.



Thus, the model was re-run with either one or the other of physician age or time licensed included. In both cases, none of the variables were significant. The results of the model including the physician's time licensed and excluding the physician's age are shown in Table 42. Similar to the findings described in Chapter V, none of the variables were significant at the $p \leq .05$ level in the full model, although the physician's gender and the racial match between the physician and patient were important in the parsimonious model.

Table 42. *Model of all patient, contextual and institutional factors to determine hospice use vs. hospice non-use after referral, including patients referred by a physician^a*

Variable	β (SE)	Full Model ^b OR (95% CI)	p	β (SE)	Parsimonious Model ^c OR (95% CI)	p
Patient Variables						
Female	-0.713 (0.657)	0.490 (0.0130,1.841)	.291	-	-	-
Age	0.004 (0.021)	1.004 (0.963,1.047)	.848	-	-	-
Non-White	-0.009 (0.963)	0.991 (0.150,6.543)	.993	-	-	-
Not married	0.817 (0.664)	2.263 (0.616,8.314)	.219	-	-	-
Non-cancer	1.033 (0.931)	2.809 (0.453,17.432)	.268	-	-	-
Source other than Medicare	-1.017 (0.931)	0.362 (0.044,2.979)	.345	-	-	-
Contextual Variables						
County A			Reference			
B ^d	-	-	-	-	-	-
C	0.185 (1.689)	1.203 (0.044,32.992)	.913	-	-	-
D	0.458 (1.136)	1.582 (0.171,14.654)	.686	-	-	-
Institutional Variables						
Hospice B	-1.540 (1.585)	0.214 (0.010,4.790)	.331	-	-	-
Physician Variables						
Female	-1.684 (1.087)	0.186 (0.022,1.564)	.121	-1.590(0.745)	0.204 (0.047,0.878)	.033
Age ^e	-	-	-	-	-	-
Non-White ^f	-	-	-	-	-	-
Racial Un-match	0.791 (0.824)	2.206 (0.439,11.085)	.337	0.852 (0.390)	2.344 (1.092,5.031)	.029
Time Licensed	-0.054 (0.036)	0.947 (0.882,1.017)	.137	-	-	-
Specialty other than hem/onc	-0.790 (0.958)	0.454 (0.069,2.964)	.409	-	-	-
Clinic-based	0.047 (0.833)	1.049 (0.205,5.371)	.955	-	-	-
Clinical Hours	-0.015 (0.024)	0.985 (0.939,1.033)	.530	-	-	-

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; marital status = married; diagnosis = cancer; insurance = Medicare; referral source = physician-referred; county = County A; hospice = A; physician gender = male; racial match = match; specialty = hematology/oncology; primary practice location = hospital-based. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=891. ^bR² = 0.161. ^cR² = 0.042 ^dDue to missing variables, too few patients from County B remained in the model; thus, it was removed from analyses. ^ePhysician age was excluded because of its high correlation with Time licensed. ^fDue to the redundancy of having physician race, patient race, and racial match in the same model, physician race was also excluded.

Hospice Use versus Non-use for Patients Referred by Another Source

Table 43 displays the results of the model of all patient, contextual and institutional variables to determine hospice use versus non-use after referral for patients referred by a source other than the physician. Similar to the results described in Chapter V, the patient's race was significant ($p = .029$). In addition, however, the patient's gender was significant with this method of modeling. Female patients were 1.9 (1.068, 3.279) times more likely to use hospice after referral than male patients ($p = .028$). These results, interpreted in context of the results in Chapter V, suggest that the effect of the patient's gender is only important when adjusting for the effects of all patient variables in this study. The results of the parsimonious model were the same as the results described in Chapter V: the patient's race, diagnosis and hospice agency were significant.

Table 43. *Model of all patient, contextual and institutional factors to determine hospice use vs. hospice non-use after referral, including patients referred by a source other than a physician^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female	-0.627 (0.286)	0.534 (0.305,0.936)	.028	-	-	-
Age	-0.004 (0.010)	0.996 (0.976,1.015)	.663	-	-	-
Non-White	0.667 (0.305)	1.949 (1.072,3.542)	.029	0.656 (0.264)	1.927 (1.148,3.232)	.013
Not married	0.155 (0.290)	1.168 (0.662,2.061)	.593	-	-	-
Non-cancer	0.522 (0.294)	1.685 (0.946,2.999)	.076	0.505 (0.237)	1.657 (1.042,2.636)	.033
Source other than Medicare	0.299 (0.321)	1.349 (0.718,2.532)	.352	-	-	-
Contextual Variables						
County A			Reference			
B	0.405 (1.080)	1.500(0.181,12.464)	.707	-	-	-
C	1.035 (1.061)	2.815(0.352,22.536)	.329	-	-	-
D	-0.093 (0.738)	0.912 (0.215,3.873)	.900	-	-	-
Institutional Variables						
Hospice B	-0.937 (1.025)	0.392 (0.053,2.919)	.360	-2.055 (0.232)	0.128 (0.081,0.202)	<.001

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; marital status = married; diagnosis = cancer; insurance = Medicare; referral source = physician-referred; county = County A; hospice = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 2547. ^bR² = 0.093. ^cR² = 0.125.

Hospice Use versus Non-use for Racial and Ethnic Minorities

The only significant predictor of hospice use for racial and ethnic minorities when all of the patient, contextual and institutional factors were included in the model was the specific hospice agency to which the patient was referred. After adjusting for all other variables, non-White patients referred to Hospice B were more likely to use hospice after referral than non-White patients referred to Hospice A [1.672 (0.524, 5.334), $p < .001$]. These results support the discussion in Chapter VI that larger hospices, which can accommodate more aggressive (and consequently more expensive) palliative treatments, might be more appealing to racial

and ethnic minorities; however, these results should be interpreted bearing mind that no interactions were included (and that no comparison model exists from this study because this model was not conducted in Chapter V due to previously insignificant results in the single-level models). Note that including both the hospice to which the patient was referred and the county from which the patient was referred in the same model due to issues with collinearity in this particular sample sub-group. Hospice and county in this sub-sample were significantly related ($\chi^2 = 561.585$, $p < .001$). Patients referred to Hospice B were more often referred from County A than patients referred to Hospice A. For this reason, the model was run twice: once including the variable of hospice and excluding the variable of county and once including the variable of county and excluding the variable of hospice. In both models, the included variable was the only significant predictor. The results of the model including hospice and excluding county are summarized in Table 44.

Table 44. *Model of all patient, contextual and institutional factors to determine hospice use vs. hospice non-use after referral, including entire sample of referred racial and ethnic minorities^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female	-0.585 (0.530)	0.557 (0.197,1.574)	.270	-	-	-
Age	0.007 (0.018)	1.007 (0.973,1.043)	.689	-	-	-
Not married	-0.515 (0.515)	0.597 (0.218,1.638)	.317	-	-	-
Non-cancer	-0.079 (0.527)	0.924 (0.329,2.594)	.880	-	-	-
Source other than Medicare	-0.609 (0.713)	0.544 (0.135,2.198)	.393	-	-	-
Referred by non-physician	0.514 (0.592)	1.672 (0.524,5.334)	.386	-	-	-
Contextual Variables						
County ^d						
A			Reference			
B	-	-	-	-	-	-
C	-	-	-	-	-	-
D	-	-	-	-	-	-
Institutional Variables						
Hospice B ^{**}	-1.960 (0.592)	1.672 (0.524,5.334)	<.001	-1.891 (0.465)	0.151 (0.061,0.375)	<.001

Note. Odds ratio is for the probability of hospice non-use. References for bivariate analyses: gender = male; race = White; marital status = married; diagnosis = cancer; insurance = Medicare; referral source = Physician-referred; county = County A; hospice = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN = 553. ^bR² = 0.140. ^cR² = 0.104. ^dUnable to include county in same model as hospice due to high correlation.

^{**}p ≤ .001 in full model.

Hospice Use versus Non-use for Racial and Ethnic Minorities Referred by Another

Source

The hospice agency to which the patient was referred was also the only predictor of hospice utilization for racial and ethnic minorities referred by a source other than a physician [0.150 (0.055, 0.413), p<.001].

Due to an inadequate number of racial and ethnic minorities who were referred by a physician (N = 129) and the accompanying missing values for the physician variables, a model including all patient, contextual and institutional factors for these patients was not feasible.

Hospice Non-use for Patient-driven Reason versus Prognosis-driven Reason

The results of the model of all patient, contextual and institutional factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason are shown in Table 44. These results differ from the results of the analysis described in Chapter V in that the patient's race and diagnosis were important. Similar to the single-level model findings from Specific Aim #1 and discussed in Chapter VI, non-White patients were significantly more likely to have a prognosis-driven reason not to use hospice after referral [15.719 (2.060, 119.958), $p = .008$]. Additionally, however, patients without a cancer diagnosis were significantly more likely to have a prognosis-driven reason not to use hospice after referral in this analysis [13.309 (1.514, 117.007), $p = .020$]. This finding supports the discussion in Chapter VI suggesting a need for further research in prognostic accuracy and a need to further investigate the differences between patients who are referred too early versus too late. The hospice to which the patient was referred was also important in this analysis, as it was in the parsimonious model of hospice non-use for a patient-driven reason versus a prognosis-driven reason described in Chapter V and discussed in Chapter VI.

Note that because hospice and county were significantly related in this sub-sample ($\chi^2 = 217.424$, $p < .001$), both variables were not included in the model at the same time. However, two models were conducted separately to examine differences in the outcome with the inclusion of one or the other of the variables. The results of the models were similar: the

patient's race and diagnosis were significant predictors along with the included variables of county or hospice. Table 45 displays the findings from the model including hospice and excluding county.

Table 45. *Model of all patient, contextual and institutional factors to determine hospice non-use for a patient-driven reason vs. hospice non-use for a prognosis-driven reason after referral, including entire sample of referred hospice patients^a*

Variable	β (SE)	Full Model ^b OR (95% CI)	p	β (SE)	Parsimonious Model ^c OR (95% CI)	p
Patient Variables						
Female	-1.295 (0.963)	0.274(0.041,1.810)	.179	-	-	-
Age	0.040 (0.029)	1.041(0.982,1.102)	.176	-	-	-
Non-White [*]	2.755 (1.037)	15.719(2.060,119.958)	.008	2.617 (0.958)	13.694 (2.094,89.549)	.006
Not married	-1.073 (0.973)	0.342(0.051,2.304)	.270	-	-	-
Non-cancer [*]	2.588 (1.109)	13.309 (1.514,117.007)	.020	2.109 (0.924)	8.242 (1.348,50.382)	.022
Source other than Medicare	0.292 (1.154)	1.339(0.139,12.858)	.800	-	-	-
Referred by non-physician	0.213 (1.266)	1.238(0.104,14.794)	.866	-	-	-
Contextual Variables						
County ^d						
A			Reference			
B	-	-	-	-	-	-
C	-	-	-	-	-	-
D	-	-	-	-	-	-
Institutional Variables						
Hospice B ^{**}	-5.025 (1.392)	0.007(<.001,.100)	<.001	-4.511 (1.258)	0.011 (0.001,0.129)	<.001

Note. Odds ratio is for the probability of hospice non-use for a prognosis-driven reason; References for bivariate analyses: gender = male; race = White; marital status = married; diagnosis = cancer; insurance = Medicare; referral source = physician-referred; county = County A; hospice = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = 0.05.

^aN=77. ^bR²= 0.663 ^cR²= 0.597. ^dUnable to include county in same model as hospice due to high correlation.

*p≤.05 in full model. **p≤.001 in full model.

*Hospice Non-use for Patient-driven Reason versus Prognosis-driven Reason for Patients
Referred by Another Source*

The findings from the model that included all patient, contextual and institutional factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason for patients referred by a source other than a physician did not differ from the above findings for the entire sample. Due to an inadequate number of hospice non-users in the sample who were referred by a physician and had completed data entry for all variables (N = 14), however, an additional model including all patient, contextual and institutional factors for these patients was not feasible.

No additional analyses were done to examine factors associated with hospice non-use for a patient-driven reason versus hospice non-use for a prognosis-driven reason for racial and ethnic minorities due to concerns with missing variables (N = 48).

Summary

In summary, the results of using this method of modeling hospice utilization were similar to the results of the model-building method described and discussed in Chapters V and VI. The most notable difference between these models is the magnitude of the importance of gender. Regardless, both methods of modeling suggested some importance of the patient's gender. However, the significance of gender only within the context of all the other patient variables is interesting and is an example of how the method of modeling described in this section can be advantageous in finding important variables that may have otherwise been unnoticed. The importance of the patient's gender in hospice utilization should not be overlooked; and, because previous studies have reported inconsistent results on

the effect of the patient's gender, analyses in future studies that stratify by gender may be useful.

This technique also provided some evidence for why racial and ethnic minorities are not using hospice services. The findings indicate that racial and ethnic minorities are more likely to have a prognosis-driven reason not to use hospice after referral than White patients.

Although no analyses of factors to determine hospice non-use for a patient-driven reason versus a prognosis-driven reason were done specifically for racial and ethnic minorities, the findings from other models in this section suggest that the patient's diagnosis and the hospice to which the patient is referred (or the patient's county of residence) may be at least part of the problem. However, patients with non-cancer diagnoses were more likely to have a prognosis-driven reason not to use hospice after referral, and non-Whites were significantly more likely to have *cancer* diagnoses than Whites (62.8% vs. 48.8%, $\chi^2 = 39.545$, $p < .001$). Therefore, it seems logical that the hospice to which the patient was referred (or the patient's county of residence) might be the more important factor for racial and ethnic minorities to have a prognosis-driven reason not to use hospice after referral. This finding provides support that individual hospice agencies have an important effect on hospice utilization and that the characteristics of the patient's geographical place of residence needs further investigation.

Appendix B: Additional County Analyses

Because the contextual analyses were limited to only using county as a fixed effect and in an effort to further examine the possible effect of county on hospice utilization patterns after referral, each model of patient and institutional variables was conducted within each county. In addition, a factor analysis of the individual variables was conducted within each county. The following sections describe the results of these analyses.

Regression Analyses Stratified by County

Tables 46-49 summarize the findings of the models of patient and institutional variables to determine hospice utilization, including the entire sample of referred patients as stratified by county. Due to sample inadequacy and missing variables, the models investigating hospice non-use for a patient-driven reason versus a prognosis-driven reason and the models limited to racial and ethnic minorities, patients referred by a physician and patients referred by another source within each county were not feasible.

County A

In County A (Table 46), both the patient's gender and diagnosis were significant predictors of hospice use versus non-use in the full model. After adjusting for other variables, females in County A were more likely to use hospice after referral than males [0.473 (0.237, 0.954), $p=.034$]. Patients referred with non-cancer diagnoses from County A were 2.1 [(0.995, 4.301), $p = .052$] times less likely to use hospice after referral than patients referred with cancer diagnoses.

Table 46. *Model of all patient and institutional variables to determine hospice use versus hospice non-use among patients referred from County A^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female *	-0.748 (0.353)	0.473 (0.237,0.945)	.034	-	-	-
Age	0.008 (0.013)	1.008 (0.982,1.034)	.561	-	-	-
Non-White	0.573 (0.396)	1.773 (0.816,3.853)	.148	-	-	-
Not married	0.328 (0.366)	1.388 (0.677,2.844)	.371	-	-	-
Non-cancer*	0.727 (0.373)	2.069 (0.995,4.301)	.052	0.741 (0.340)	2.098 (1.078,4.084)	.029
Source other than Medicare	-0.223 (0.420)	0.800 (0.351,1.824)	.596	-	-	-
Referred by non-physician	0.206 (0.406)	1.228 (0.554,2.722)	.613	-	-	-
Institutional Variables						
Hospice B ^d			-			

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; marital status = married; diagnosis = cancer; insurance = Medicare; referral source = physician-referred; Hospice = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = .05

^aN = 2,762. ^bR² = .032. ^cR² = .013. ^dVariable not included due to issues with sample size and distribution. Only 2 patients from County A were referred to Hospice A.

*p ≤ .05 in full model.

County B

The results of the model conducted in County B are summarized in Table 47. The only significant predictor of hospice utilization after referral was race. After adjusting for all other variables, non-White patients from County B were 3.9 [(1.106, 13.761), p = .034] times less likely to use hospice after referral than White patients.

Table 47. *Model of all patient and institutional variables to determine hospice use versus hospice non-use among patients referred from County B^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female	-0.403 (0.701)	0.668 (0.169,2.640)	.565	-	-	-
Age	0.028 (0.034)	1.029 (0.962,1.101)	.409	-	-	-
Non-White [*]	1.361 (0.643)	3.902 (1.106,13.761)	.034	1.386 (0.614)	4.000 (1.202,13.316)	.024
Not-married	0.516 (0.761)	1.675 (0.377,7.450)	.498	-	-	-
Non-cancer	0.385 (0.739)	1.470 (0.345,6.251)	.602	-	-	-
Source other than Medicare	1.509 (1.162)	4.522 (0.464,44.089)	.194	-	-	-
Referred by non-physician ^d			-			
Institutional Variables						
Hospice B ^e			-			

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; race = White; marital = married; diagnosis = cancer; insurance = Medicare. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = .05.

^aN = 243. ^bR² = .084. ^cR² = .024. ^dVariable not included due to issues with sample size and missing values. ^eAll patients (N = 4) referred to Hospice B from County B were hospice users.

^{*}p ≤ .05 in full model.

County C

In County C (Table 48), the patient's gender was a marginally significant predictor of hospice utilization after referral. Female patients from County C were more likely to use hospice after referral than referred male patients [0.393 (0.144, 1.074), p = .069]. Race was marginally significant in the parsimonious model. Referred non-White patients from County C were less likely to enroll in hospice after referral than White patients [2.615 (0.992, 6.898), p = .052].

Table 48. *Model of all patient and institutional variables to determine hospice use versus hospice non-use among patients referred from County C^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female [†]	-0.934 (0.513)	0.393 (0.144,1.074)	.069	-	-	-
Age	-0.030 (0.019)	0.971 (0.935,1.007)	.117	-	-	-
Non-White	0.855 (0.518)	2.352 (0.852,6.494)	.099	0.961 (0.495)	2.615 (0.992,6.898)	.052
Not married	0.313 (0.510)	1.368 (0.504,3.713)	.539	-	-	-
Non-cancer	0.679 (0.517)	1.972 (0.717,5.429)	.189	-	-	-
Source other than Medicare	-0.050 (0.754)	0.951 (0.217,4.171)	.947	-	-	-
Referred by non-physician	0.649 (0.549)	1.914 (0.652,5.619)	.237	-	-	-
Institutional Variables						
Hospice B ^d			-			

Note. Odds ratio is for the probability of hospice non-use; References for analyses: gender = male; race = White; marital status = married; diagnosis = cancer; insurance = Medicare; referral source = Physician-referred. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = .05.

^aN = 264. ^bR² = .109. ^cR² = .030. ^dVariable not included due to issues with sample size and/or distribution. All patients referred to Hospice B from County C (N = 6) were hospice users.

[†]Marginally significant (p < .10) in full model.

County D

Table 49 summarizes the results of the logistic regression to determine hospice use among patients referred from County D. The hospice agency to which the patient was referred was the only significant predictor of hospice utilization. Adjusting for other variables, patients referred to Hospice B from County D were 6.4 [(0.028, 0.895), p = .037] times more likely to use hospice after referral than patients referred to Hospice A from County D.

Table 49. *Model of all patient and institutional variables to determine hospice use versus hospice non-use among patients referred from County D^a*

Variable	Full Model ^b			Parsimonious Model ^c		
	β (SE)	OR (95% CI)	p	β (SE)	OR (95% CI)	p
Patient Variables						
Female	1.149 (1.031)	3.156 (0.418,23.846)	.265	-	-	-
Age	0.015 (0.034)	1.016 (0.949,1.087)	.655	-	-	-
Non-White ^d			-			
Not married	-0.157 (1.045)	0.854 (0.110,6.627)	.880	-	-	-
Non-cancer	-0.745 (1.032)	0.475 (0.063,3.588)	.471	-	-	-
Source other than Medicare	-0.737 (1.218)	0.478 (0.044,5.202)	.545	-	-	-
Referred by non-physician	-0.109 (0.904)	0.897 (0.153,5.271)	.904	-	-	-
Institutional Variables						
Hospice B [*]	-1.850 (0.887)	0.157 (0.028,0.895)	.037	-1.654 (0.837)	0.191 (0.037,0.987)	.048

Note. Odds ratio is for the probability of hospice non-use. References for analyses: gender = male; marital status = married; diagnosis = cancer; insurance = Medicare; referral source = Physician-referred; Hospice = A. Parsimonious model based on logistic regression with backwards elimination strategy; SLS = .05.

^aN = 224. ^bR² = .117. ^cParsimonious model R² = .072. ^dVariable not included due to issues with sample size and/or distribution. Only 1 non-White was a hospice non-user.

^{*}p ≤ .05 in full model.

Factoring the Individual Variables within County

In an effort to further characterize the counties, a factor analysis including all the individual variables was completed within each of the 4 counties. Specifically, seven variables were included: gender, age, race, marital status, diagnosis, insurance status and referral source. The four-factor principal components analysis with varimax rotation appeared to be the best solution in terms of simple structure for Counties A, B and C; and the five-factor principal components analysis with varimax rotation appeared to be the best solution for County D.

All 4 counties had 2 factors in common: one comprised of gender and marital status and one comprised of referral source. Counties A and D had one factor comprised only of insurance status, and Counties B, C and D had one factor comprised solely of race. The last

factor for County A was comprised of age, race, and diagnosis. The last factor for County B was comprised of age and insurance, and the last factor for County C was comprised of age, insurance and diagnosis. The last factor for County D was comprised of age and diagnosis. Because these factors differed between counties, they were not named. Table 50 summarizes the findings from each analysis, as stratified by county.

Table 50. *Factor groupings for individual variables in each county.*

Variables	County																
	A				B				C				D				
Factors	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	5
Gender	.820*				.128	.801*	.131			.842*			.882*			-.104	
Age	.269	.727*	.148		.900*				.858*	.109		-.114	.117	.754*	-.371		
Race	.196	-.705*	.356	-.141				.984*				.982*			.935*	.107	
Marital Status	.801*	.127				.809*		.146	.178	.785*	.164		.831*	.195	.137		
Diagnosis	.161	.636*	.431		.591	.276	-.123	-.105	.624	.267	-.192	.139	.134	.857*	.179	-.112	
Insurance				.984*	-.902*				-.834*						.101	.983*	
Referral Source			.880*				.984*				.975*						.994*
Eigenvalues	1.851	1.169	1.017	.999	2.237	1.282	.999	.898	2.047	1.282	1.084	.906	1.871	1.287	1.056	.897	.839
% Variance Explained	26.45	16.70	14.53	14.27	31.96	18.32	14.28	12.83	29.24	18.31	15.48	12.95	26.73	18.38	15.09	12.82	11.98
Total Variance	71.934				77.379				75.980				84.995				

Note. Principal components factoring based on observations from the scree plot. Values less than 0.1 were suppressed and are not shown.

*Loading.

Summary

Examining the models of hospice utilization within each county demonstrated that the counties included in this study differ from each other, as the findings within each county were different. In County A, the patient's gender and diagnosis were important. In County B, the patient's race was important. In County C, the patient's gender was marginally significant when adjusting for all other variables; but the patient's race was important in the parsimonious model. In County D, only the hospice to which the patient was referred was important. Because sample size concerns resulted in some variables being excluded from some of the analyses within each county and because no interactions were included, however, additional work is necessary to further capture the differences between these counties and how they might affect hospice utilization.

The factor analysis of the individual variables within each county support the perception that the counties involved in the analyses were distinctively different, making it highly possible that each county has some unmeasured impact on hospice utilization. An interesting outcome of the analysis, however, was that race consistently loaded onto its own factor in each county except County A. In County A, race loaded onto the same factor as age and diagnosis. This finding suggests the presence of some unobserved phenomena within County A related to race, age and diagnosis that affected County A's factor structure and perhaps is not present in Counties B, C or D. However, as already stated in Chapter VI, the results of all of the factor analyses in this study should be interpreted cautiously, as the number of variables on each factor may not be considered acceptable to many statisticians.

The factor analysis of the patient variables within each county also adds some understanding to the value of the Hospice Model. The results that each county had a different

structure imply that the model might act differently in different places or different environments. This attribute is not uncommon in health care access models and certainly is not an unrecognized characteristic of Andersen's Behavioral Model from which the Hospice Model was derived (Andersen, 1995). More work is needed to capture the performance of the Hospice Model within different samples from varying geographic locations and to closely examine the operationalization of the variables within the contextual factors. Determining if the characteristics of the geographic area of focus represent different concepts in the model would be an interesting and informative undertaking for the development of the Hospice Model.

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