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Predictors and Outcomes of Hospice Use among Medicare and Medicaid Dual-Eligible
Nursing Home Residents in Florida: A Comparison of Non-Hispanic Blacks and Non-
Hispanic Whites

by

Jung Kwak

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Aging Studies
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Dedication

I would like to dedicate this dissertation research to my parents, Dr. Soo-Young and Mi-Soon K. Kwak. Dad and Mom, I love you more than I could ever express in words. How grateful and lucky I am to have parents like you. Your unconditional love, encouragement, support and guidance helped me get through numerous moments of self-doubts, and sometimes despair. Thank you for loving and believing in me.

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Predictors and Outcomes of Hospice Use among Medicare and Medicaid Dual-Eligible
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ABSTRACT

This research investigated the racial/ethnic differences in hospice utilization and the effect of hospice in reducing the risk of hospital death at the end of life among non-Hispanic Black and non-Hispanic White dual-eligible (Medicare and Medicaid) older adults residing in a nursing home setting. The final study population included 30,765 non-Hispanic Black and non-Hispanic White nursing home residents who died between state fiscal years 2000-2002 in Florida.

The behavioral model of health services use successfully predicted group membership in hospice use. In the full model, seven variables - female gender, non-Hispanic White race/ethnicity, being married, urban area of residence, and cancer and dementia/Alzheimer's disease as causes of death – predicted increased likelihood of hospice use. This study also found that race/ethnicity moderates the strength of the effect of the illness on the likelihood of using hospice. Among residents who died of cancer, no difference in hospice use was found between the two racial/ethnic groups while hospice utilization rate among non-cancer residents was lower for non-Hispanic Blacks than non-Hispanic Whites.

The same predisposing, enabling and need factors tested in predicting hospice use were examined for association with the probability of survival time since hospice admission. The poor model fit and the small number of factors found to significantly affect the probability of survival time from the initial hospice enrollment suggest that the survival time might be influenced by external factors other than covariates examined in this study.

This study found hospice to be a powerful predictor of place of death among nursing home residents. After controlling for other factors, hospice nursing home residents were 91 percent less likely to die in a hospital. At the same time, non-Hispanic Black residents were still 76 percent more likely to die in a hospital even after adjusting for the effect of hospice use and other variables.

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Chapter One: Background

Overview

A growing body of literature suggests that hospice is a critical service for individuals with terminal illness because it leads to such better outcomes as reduced hospitalization, better pain management and better satisfaction with care (Baer & Hanson, 2000; Teno et al., 2004). Given better outcomes, the underutilization of hospice services and late entrance to hospice, especially among older adults in nursing homes and members of racial/ethnic minority backgrounds, has been a growing concern since the Medicare hospice benefit was created in 1982 (Gorden, 1996; Medicare Payment Advisory Commission [MedPAC], 2004; Reese, Ahern, Nair, Schrock, & Warren-Wheat, 1999).

The study presented in this dissertation research focuses on racial/ethnic differences in hospice utilization and the effect of hospice in reducing the risk of hospital death at the end of life among non-Hispanic Black and non-Hispanic White dual-eligible (Medicare and Medicaid) older adults residing in a nursing home setting. When studying the effects of race/ethnicity on hospice use during the last year of life, Blacks are of special interest since they make up one of the largest ethnic minority groups, at 12.3 percent of the U.S. population (U.S. Census, 2000). In addition, disparities in access and in the use of medical services including end-of-life care between White and Black groups have been reported by a number of studies (see Krakauer, Crenner & Fox, 2002 for

review of this issue). The present study specifically examines not only differences between the two racial/ethnic groups in question, but also individual differences within each group in hospice use. The reason for the within-group examination is that previous studies have reported that there is more variability within each racial/ethnic group than across groups (e.g., Dilworth-Anderson, Williams, & Gibson, 2002). In addition to examining the predictors of hospice use, factors associated with survival time from enrollment in hospice are also examined since late entrance to hospice (e.g. shorter survival after admission for the same disease state) has been a serious concern for practitioners and policy makers. The study also addresses an important end-of-life care outcome, place of death, as a result of hospice use.

For studying utilization of hospice services, duration of hospice use, and outcomes of hospice use, the expanded version of the behavioral model of health services use (Andersen, 1995) originally developed by Andersen in 1968 was adopted. The behavioral model of health service utilization has been used extensively in research, and in particular has been used to identify access disparity among racial/ethnic groups (Aday & Awe, 1997; Gabbe et al., 1995). According to the model, three categories of individual determinants covering predisposing, enabling, need factors and psychosocial factors, as well as health care system determinants affect health services utilization and outcomes (Aday & Andersen, 1974; Andersen, 1968; Andersen & Newman, 1973; Bradley et al., 2002). In order to increase the model's salience to end of life issues, selected theoretical models from the death and dying and literature on the role of race/ethnicity on end-of-life decision making were reviewed to facilitate use of the behavioral model of health service utilization in this research.

Chapter 1 begins with a brief overview of health service utilization at the end of life, followed by a review of the literature on theories on health services utilization and death and dying, and a synopsis of predictors of hospice use, hospice length of stay and place of death. Specific research questions regarding predisposing, need, and enabling factors predicting hospice use, hospice length of stay, and place of death are presented.

In both the reviews and research questions, the central focus is on the implications for race and ethnicity. The purpose of the literature review is to provide a critical and comprehensive background on theories and research findings on end-of-life services use with a specific focus on the role of race/ethnicity in hospice, length of stay in hospice and place of death to identify the gaps in the current literature which led to development of research questions for this dissertation research. The review pays particular attention to theoretical frameworks relevant to the research effort, since theoretical frameworks facilitate both the selection and the examination of the effects of multiple variables (George, 2002). A review of the current medical and long-term care services available in the U.S. is also necessary to better understand the context in which people choose treatment options and services which often represent competing goals of treatment and care at the end of life (i.e., treatments with curative vs. palliative treatment purpose).

In the review of the literature, findings from studies with varying methods of conceptualization and operationalization of “end-of-life” issues are included, ranging from studies that examine the last few days before death to studies examining the last three years before death. Such a broad time frame for defining the end-of-life period is used in this review because there is no consensus on when the dying process actually is initiated – indeed much may depend on the illness and the individual - and there are many

variations of definition of the end of life in the literature (Field & Cassel, 1997). As a report by the Institute of Medicine (IOM) (1997) recognizes, the dying process can take from days to several months or even for years due to varying trajectories and progression of different illnesses. It thus appears to be appropriate to examine health service utilization patterns during a wide span of time before death.

Introduction

End-of-life service utilization among older adults is an increasingly important area of research due to the complex needs for care at the end of life, and the high costs associated with such care. During the final months, older adults have special needs that are distinct from younger individuals. In part the differences arise because older adults are more likely to manifest multiple comorbidities, greater levels of functional impairment, and generally greater needs for care (World Health Organization [WHO], 2004). As a result, many older individuals die after a prolonged period of chronic illnesses and after spending time in a nursing home (Hogan, Lynn, Gabel, Lunney, O'Mara, & Wilkinson, 2000). A substantial portion of medical treatment and supportive services at the end of life is related to caring for older adults with declining health and functional status and increasing comorbidity (Culler, Callahan, & Wolinsky, 1995; Stump, Johnson, & Wolinsky, 1995; Hogan et al., 2000) and cost of end-of-life care is highest during the final few months of life (Yang, Norton, & Stearns, 2002). Costs of caring for older dying patients on average are six to seven times of those for survivors (Levinsky, Ash, Yu, & Moskowitz, 1999; Lubitz & Riley, 1993; Riley, Lubitz, Prihoda, & Rabey, 1987).

The high cost is associated with the many types of medical and social services are used by older adults during the last year of life, including hospital care, physician services, skilled nursing care, and hospice care. Alone among these services, hospice is a program specifically designed to meet various medical, psychosocial, and spiritual needs of patients at the end of life.

Hospice services are reimbursed by Medicare, the primary source of insurance for almost all older Americans aged 65 and older, and Medicaid, the primary payment source for long-term care for dual-eligible older adults, [National Hospice and Palliative Care Organization (NHPCO), 2002]. Despite the support of medical insurers, and the increasing empirical evidence supporting the benefits of hospice use (Christakis & Iwashyna, 2003; Miller, Gozalo, & Mor, 2001; Miller, Mor, Wu, & Lapane, 2002; Teno et al., 2004), underutilization of hospice has been reported among Medicare beneficiaries. This is especially the case for racially and ethnically diverse older adults and nursing home residents (Hoffmann & Tarzian, 2005; Iwashyna, Chang, Zhang, & Christakis, 2002; MedPAC, 2004; Virnig, Kind, McBean, & Fisher, 2000). Although timely access to hospice would provide better opportunities for patients, families and hospice providers to develop and coordinate an appropriate plan of care, persistent pattern of short duration of hospice use remains as a serious concern.

Health Services Utilization by Older Adults at the End of Life

Health services use by older Medicare beneficiaries in the last years of life have been studied extensively. With declining functional ability, deteriorating health and increasing severity of illnesses, older adults utilize various types of medical and long-term care services as they approach the end of life. These services are accessed at

various health care and long-term care settings. Many older adults transition in and out of different health care institutions including hospital and nursing homes as their illnesses progress near the end of life. Among health care institutions, hospitals are the most frequent site of death: from 50 to 60 percent of all deaths occur in hospitals (Hogan et al., 2000; Weitzen, Teno, Fennell, & Mor, 2003). Hospitals are also used more frequently by older adults after they receive a diagnosis of serious progressive illnesses (Field & Cassel, 1997). A recent study of decedents enrolled in the Program of All-Inclusive Care for the Elderly (PACE) (Mukamel, Bajorska, & Temkin-Greener, 2002) shows that hospitalization use increases as early as 7 months before death and continues to increase until the last month of life; there was an increase of almost 250 percent in the last month among this group of older adults.

Many patients, who spend time at hospitals during the last year of life, or during the last few days before death, are transferred from nursing homes. At the same time, nursing homes are another common site of death; this is where 20 percent of all U.S. deaths occur (Mezey, Dubler, Mitty, & Brody, 2002). A significant minority of older adults spend varying periods of time at a nursing home in their last year of life. An analysis of the 1993 National Mortality Followback Survey by Hogan and colleagues (2000) showed that in 1993 about 38 percent of older adults resided in a nursing home for either a full (22 percent) or partial year (16 percent) and 59 percent of older adults resided at home during the last year of life. The same analysis (Hogan et al., 2000) indicated that the majority of nursing home decedents who spent a full year in a nursing home died in a nursing home (67 percent) while about 28 percent died in hospitals and 1 percent died at home. Of those who stayed part of the year 1993 in a nursing home, 48 percent, 35

percent and 10 percent died in a nursing home, hospital and home respectively. These results suggest that older adults who enter a nursing home for a short-term stay are more likely to be transferred to hospitals and die at hospitals than long-term nursing home residents.

The literature on hospitalization of nursing home residents reveals the complex process of decision making on hospitalization of nursing home residents and both beneficial and harmful effects of hospitalization of nursing home residents at the end of life. Hospitalization is often inevitable and also potentially appropriate for older adults who die of organ failure (Mezey et al., 2002). On the other hand, a number of studies report that hospitalization is not necessarily appropriate for all dying nursing home residents (Engle, 1998; Mezey et al., 2002). The literature documents that transfer from skilled nursing facilities to hospitals can lead to adverse outcomes such as sudden death, disruption of care plan, disorientation, and unnecessary financial costs associated with transfer (Creditor, 1993; Fried, & Mor, 1997; Sanders & Morley, 1993).

Hospice has been found to not only provide better pain and symptom management (Baer & Hanson, 2000; Teno et al., 2004) but also to reduce overall hospitalization rates at the end of life and to facilitate dying in place (Miller et al., 2001; Teno et al., 2004). In the U.S., hospice is the main source of palliative care - which has been identified as one of the most important services that can be provided to terminally ill patients and their families [Gage et al., 2000; NHPCO, 2002; WHO, 2004]. For hospice care, Medicare provides the bulk of financing. It was the primary payer for 80 percent of all patients served by hospice organizations in 2002 (NHPCO, 2002). Medicaid plays a somewhat smaller role: it covers hospice care for Medicaid beneficiaries without other sources of

insurance and in 45 states and the District of Columbia it reimburses for nursing home care for dual-eligible nursing home residents who elect hospice care. (Tilly & Wiener, 2001). Therefore, it is important to review some of the major features and requirements of the Medicare hospice benefit (MHB) and Medicaid hospice benefit.

Overview of the Medicare and Medicaid Hospice Benefits

The Medicare hospice benefit (MHB) was created under the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) (Gage et al., 2000). A new type of formal service that specializes in the care of the dying, the Medicare hospice benefit covers a broad set of palliative services for beneficiaries with a diagnosed terminal illness who are expected to die within six months if their illness runs a normal course (Gage et al., 2000). Since 1974 when hospice was first introduced in the United States, the number of health care organizations providing hospice services and public recognition of patient preferences to receive palliative care at home has grown rapidly (Greer & Mor, Sherwood, & Birnbaum, 1983). By adding the hospice benefit to the Medicare, Congress allowed beneficiaries with a terminal illness to choose between comprehensive palliative care and conventional care (MedPAC, 2004; Moon & Boccuti, 2002).

Under the 1982 Medicare hospice legislation, all Medicare Part A beneficiaries became eligible to receive hospice benefits if the Medicare beneficiary met both of the following criteria: (a) certification by both an attending physician and the hospice medical director (or other physician affiliated with the hospice) that the individual has a terminal illness with a likely prognosis of six months' or less anticipated survival if the disease runs its normal course; and (b) beneficiary's agreement in writing to a care plan focused on palliative care of their terminal illness while forgoing curative treatment

(Gage et al., 2000). Thus, to receive the Medicare hospice benefit, beneficiaries must waive all Medicare coverage of non-palliative care related to their terminal illness.

Every state except for Connecticut, Nebraska, New Hampshire, Oklahoma, and South Dakota provides a hospice benefit under Medicaid (Tilly & Wiener, 2001). Although there are some variations in the overall structure and design of Medicaid hospice programs across states, the eligibility, benefit coverage, and payment rate structure of Medicaid hospice programs are designed similarly to the MHB (Tilly & Wiener, 2001). A few notable differences between the Medicaid and Medicare hospice programs need to be mentioned however. Medicaid programs cannot impose co-payments on hospice patients while the MHB does; instead, the programs must pay Medicare hospice co-payments for dually eligible beneficiaries (Tilly & Wiener, 2001). In addition, when a dual-eligible nursing facility resident chooses hospice in the nursing home, Medicaid allocates funds to the hospice, which is responsible for paying the nursing home 95 percent of the Medicaid nursing facility room and board rate.

Hospice as a Model of Care

Hospice care is considered as a model of care for the dying in terms of comprehensiveness of services provided and its focus on patient- and family-centered care and continuity of care by practitioners, consumers, and researchers (Lynn, 2001). Hospice care represents a patient- and family-centered approach that is provided by an interdisciplinary team of health care providers including physician, registered nurse, social worker, pastoral or other counselor, and volunteers (NHPCO, 2002). The MHB and Medicaid hospice benefit programs provide a comprehensive coverage for medical care (focusing on symptom and pain management), prescription drugs, bereavement

counseling, respite care, and other services not ordinarily covered by Medicare. Continuity and coordination of care are considered key strengths of hospice care (Lynn, 2001). This is because hospice staff take responsibility for all aspects of a Medicare beneficiary's care related to the terminal illness. Family members also receive education and support from hospice providers during caregiving and bereavement and hospice appears to decrease the burden of bereavement among surviving spouses (Christakis & Iwashyna, 2002). While the exact numbers of patients receiving hospice service in different settings are not clear, according to the 2002 NHPCO National Data Set Summary Report, the majority (58 percent) of terminally ill patients were at home (i.e., private residence) at the time of enrollment while 22 percent of hospice patients were in a nursing home at the time of enrollment in 2002 (NHPCO, 2003).

Recent empirical studies also provide evidence that hospice care leads to better end-of-life outcomes. These outcomes include lower hospitalization (Miller et al., 2001) among nursing home residents and better pain management among both community dwelling patients and nursing home residents (Greer et al., 1986; Miller et al., 2002; Teno et al., 2004), better satisfaction among patients and families (Kane et al., 1984; Teno et al., 2004) and a greater likelihood of dying at home (Hogan et al., 2000; Iwashyna et al., 2002; Moinpour & Polissar, 1989).

Although strengths of hospice care are supported by empirical evidence and recognized by patients and families and practitioners, recent studies demonstrate that cost savings due to hospice service are found only among a selected group of dying patients (Campbell, Lynn, Louis, & Shugarman, 2004) and cost saving is sensitive to time frame of assessment (Miller, Intrator, Gozalo, Roy, Barber, & Mor, 2004). One recent study of

Medicare decedents (Campbell, Lynn, Louis, & Shugarman, 2004) found cost saving among patients who were younger or diagnosed with cancer. Campbell and colleagues (2004) also found that costs increased for older patients, especially those who were diagnosed with non-cancer illnesses. Another study among dual-eligible nursing home residents by Miller and colleagues (2004) found that regardless of length of stay among all nursing home residents, mean total public expenditures in the last month of life were significantly less for hospice than non-hospice residents. In the last six months of life, however, total mean public expenditures were significantly greater for hospice than non-hospice residents.

Underutilization of Hospice

Since the MHB benefit was created in 1982, the number of MHB beneficiaries has grown rapidly. In 2001, 580,000 Medicare beneficiaries enrolled in hospice compared to only slightly more than 150,000 in 1992 (MedPAC, 2004). Many beneficiaries who are eligible for and benefit from hospice, however, do not utilize it. Using 1996 data, Virnig and colleagues (2000) found that only about 15.5 percent of Medicare decedents used hospice. One important caveat lies in their approach to calculating the utilization rate of hospice: using all Medicare decedents as a denominator may underreport utilization rate among eligible beneficiaries since some beneficiaries experience sudden, unexpected death. Still, Lunney and colleagues (2002) estimated that hospice use rate was less than 50 percent even among decedents who died of identifiable clinical causes other than sudden death or unidentifiable cause of death. Moreover, among cancer patients who are characterized with relatively predictable trajectory of illness progression, and therefore prime candidates for hospice use (Lunney et al., 2003),

Lunney and associates (2002) found that less than half used hospice. Of important note is that the utilization rate of hospice differs across states. In the state of Florida, for example, approximately 35 percent of eligible adults aged 65 and older are served by hospice organizations (NHPCO, 2003). In addition, 60 percent of hospice enrollees in Florida are diagnosed with illnesses other than cancer (NHPCO, 2003).

Overall, the results suggest that hospice services are underutilized even among those beneficiaries who have relatively better access to hospice due to their disease characteristics. Moreover, short length of stay in hospice is another serious issue related to hospice utilization. In 2003, over 30 percent of hospice enrollees died within 7 days of admission and the median length of stay in hospice was 22 days (NHPCO, 2005).

Although underutilization of hospice benefit and short durations of hospice stay among terminally ill patients have become a focus of increasing research, most of the research examining predictors of and potential barriers to hospice use employ exploratory study designs. The absence of a theoretical basis for most of the existing empirical studies on end-of-life care and end-of-life decision making has been identified as another major limitation of current end-of-life research (George, 2002; Tilden, Tolle, Drach, & Hickman, 2002).

For a better understanding of the complex processes by which a number of demographic, clinical, organizational and health care market area factors influence hospice use, more research with a theoretical framework is needed (George, 2002). Without a theoretical or conceptual model, it is difficult to identify appropriate constructs and their specific relationships to one another (Dilworth-Anderson et al., 2002). The next section of the literature review, therefore, discusses the behavioral model of health

service use and several theories on death and dying, in the context of end-of-life. The behavioral model of health service utilization was chosen as the centerpiece of the review because it has been used extensively in service utilization research and also to identify access disparity among racial/ethnic groups. The behavioral model of health service utilization's strengths lie in its adaptability in conceptualizing and categorizing the myriad of correlates of use of health and social services (Grabbe et al., 1995) and identifying utilization of subgroups, especially racial/ethnic minority groups (Aday & Awe, 1997). Thus, this model can be applied to studying diversity and disparity in access to end of life care services such as hospice. In addition, theories on death and dying provide contextual information that is specific to the experience at the end of life. The literature suggests that the complex process of making the decision to use hospice is influenced by many factors including knowledge and perception of the severity of illness and the possibility of recovery by the patient, physician and family during which race/ethnicity plays an important role.

Literature on Health Services Use, Death and Dying, and Racial/Ethnic Diversity in End-of-Life Decision Making

Behavioral Model of Health Service Utilization

The behavioral model of health service utilization was initially developed by Andersen in 1968 to explain use of health services by families and to define and measure access to health care (Andersen, 1968). Since the initial model was introduced, it has been modified and expanded by Andersen and colleagues (Aday & Andersen, 1974; Andersen & Newman, 1973; Andersen, Davidson, & Ganz, 1994; Andersen, 1995; Bradley et al., 2002; Evans & Stodart, 1990). The four major components of the

behavioral model of health service utilization (Aday & Andersen, 1974; Andersen, 1968; Andersen & Newman, 1973; Andersen, 1995) include the individual determinants, health care system determinants, health behavior, and outcomes. Each includes several categories.

The individual determinant component consists of three categories of factors - predisposing, enabling and need factors (Aday & Andersen, 1974; Andersen, 1968; Andersen & Newman, 1973). Predisposing characteristics are characteristics of an individual that would either predispose or deter the person from using the service and include demographic characteristics (i.e. age, gender), social structure (i.e. education, occupation, race/ethnicity), and health beliefs (i.e. attitudes, beliefs, knowledge of medical care, provider and disease). Health beliefs can be shaped by culture and social group.

The enabling resources component includes the means by which an individual could use services such as personal (i.e. income, insurance coverage, having a regular source of care, the nature of the regular source of care, and the accessibility of the source), family (i.e. social network and social support) and community (i.e. availability of health personnel and facilities, geographic location – rural or urban nature – of the community in which the individual lives) resources. The need component, in turn, refers to illness level or need for care and is often the most immediate cause of health service use (Andersen, 1995). The need component has two parts: illness level perceived by the individual and illness evaluated by the delivery system. Two versions of the model (Aday & Andersen, 1974; Andersen & Newman, 1973), however, do not make a conceptual distinction between need for services and illness level or measurement approaches to

these concepts. Instead, illness level perceived by individuals (e.g., days of disability) or evaluated illness (e.g., diagnoses) are used.

Health care system determinants refer to the arrangements made to provide care to potential consumers and include volume and distribution of resources, access to resources, structure of resource organization, and health policy (Andersen, 1995).

Volume and distribution of resources refer to personnel/population ratios for types of personnel or facilities and the way in which resources are distributed within a geographic area. The access component of the health care system refers to the means by which the patient gains entry to the medical care system and continues the treatment process (e.g., diagnostic criteria for receiving certain treatments or out-of-pocket cost). The structure component is defined as characteristics of the organization (e.g., medical facility) that the patient deals with following entry (e.g., means of admission to the hospital or processes of referral to other sources of care). However, Andersen and Newman (1973) acknowledged that the structural component is difficult to define and measure due to the many facets of structure and its high correlation with other components in the model such as policy variables.

Health policy factors (Aday & Andersen, 1974) include financing, education, manpower, and organization. State-to-state variability of public health policy variables such as financial and need eligibility criteria for national programs such as Medicaid services is an example of the policy variable.

Health service utilization is the health behavior component and refers to actual utilization of services measured by examining type (e.g. hospital, physician, nursing home, etc), purpose (i.e. primary care, secondary care, tertiary care, custodial care) and

unit of service (i.e. contact, volume, episodic care) (Aday & Andersen, 1974; Andersen & Newman, 1973). Several studies published during the 1990s suggested inclusion of personal health behavior as one of subcomponents, along with use of health services, in the health behavior component and perceived health status, evaluated health status and consumer satisfaction as outcome measures (Andersen et al., 1994; Evans & Stodart, 1990).

According to the behavioral model of services utilization (Aday & Andersen, 1974; Andersen & Newman, 1973; Andersen, 1995), health service use behavior is determined directly by individual determinants and indirectly by health care system factors. Health care system factors directly influence Individual determinants and outcomes and indirectly influence health services use through individual determinants (Andersen, 1995). Within the individual determinant components, predisposing factors precede the enabling factors which are followed by need factors (Aday & Andersen, 1974; Andersen & Newman, 1973). However, the expanded model by Bradley and colleagues (2002) conceptualizes psychosocial determinants such as health beliefs, knowledge and attitudes as related but separate construct from predisposing factors and posits that psychosocial factors may be mechanisms by which race and ethnicity (one of the predisposing variables) may influence use. This version of the behavioral model of services utilization (Bradley et al., 2002) suggests that psychosocial factors follow rather than precede enabling and need factors and serve as mediating factors. Lastly, health services use directly influence outcomes.

The behavioral model of services utilization has been utilized by and applied to a wide range of health services use among older adults including general health services

utilization (e.g., hospital and physician services), long-term care (e.g., nursing home and home care use), social services, adult day care and dental services for older adults (see Aday and Awe, 1997, for a review of this issue). The behavioral model of services utilization was also recently used as a framework for studying hospice visit volume across nursing home and non-nursing home settings (Miller, 2004). Moreover, a number of studies examining racial/ethnic disparities in service utilization among older adults have been based on this model (e.g., Bradley et al., 2002; Dunlop, Manheim, Song, & Chang, 2002; Kart, 1991; Mui & Burnette, 1994; Wallace, Levy-Storms, Kington, & Andersen, 1998; White-Means & Rubin, 2004). The behavioral model of health service utilization's concept of equitable access provides a framework for examining the role of potential access measures (enabling resources) in predicting different groups' actual rate of utilization or health care outcome (Aday & Awe, 1997). By identifying mutable (i.e., being amenable to changes such as public policy, health care beliefs and attitudes, knowledge and sources of health care information, insurance coverage, regular source of care, ease of getting care) and immutable population characteristics such as predisposing and need factors, the model offers a systematic approach to examining the relative effect of each component of the model and the opportunity to determine whether subgroups with distinct immutable attributes experience equitable access to health services (Andersen, 1995).

Keeping in mind the strengths of and contributions made by the behavioral model of services utilization in health services research, it is nonetheless important to recognize potential weaknesses of the model. Several investigators have raised concerns about the conceptualization and operationalization of the major model constructs, the specification

and testing of relationships among constructs, and the robustness and generalizability of findings based on the various versions of the model (e.g., Aday & Awe, 1997; Porter, 2000). One criticism relates to the concern that predictors may not have been adequately captured due to inconsistent conceptualization and measurement of concepts such as need and illness. A second general criticism of the Andersen model is that the original and modified versions of the model do not specify the relationships between psychosocial variables (e.g., beliefs and knowledge regarding illness), enabling (e.g., social network), need and service use (Bradley et al., 2002; Kart, 1991). A third general criticism concerns the Andersen model's overall predictive and explanatory capacity and the prioritizing of need as the dominant predictor (Aday & Awe, 1997). The model tends to explain a small amount of variability in predicting service utilization, with need consistently being the dominant predictor (Aday & Awe, 1997).

Notwithstanding the several limitations of the behavioral model of health service use, the flexibility of the model suggests that improvements can be made. Many researchers have expanded the Andersen model by adding explanatory variables that are relevant and specific to the type of utilization behavior explored in their studies. For example, some studies have added variables measuring characteristics of kin or caregiver of the individual that may affect the service utilization (Bass & Noelker, 1987; Coulton & Frost, 1982; Counte & Glandon, 1991; Freedman, 1993; Mutran & Ferraro, 1988).

Theories on Death and Dying

Major theories on death and dying developed in the last three decades include the stage of dying theory (Kubler-Ross, 1969), the context of awareness theory (Glaser & Strauss, 1965), dying trajectories (Glaser & Strauss, 1968), the living- dying

interval/phase theory of dying (Pattison, 1977), the task-based approach to coping with dying (Corr, 1992), and the readiness-to-die theory (Copp, 1996) (see the review by Copp, 1998). Of these theories, the dying trajectories idea introduced by Glaser and Strauss (1968) and the readiness-to-die theory (Copp, 1996) are particularly useful in understanding the clinical and psychological context in which people make decisions on treatments and services to use at the end of life.

Dying trajectories (Glaser & Strauss, 1968) provides a framework for understanding two important elements in an individual's dying trajectory: duration and shape. Glaser and Strauss (1968) proposed that depending on the type of major illness, individuals may experience different durations (e.g., rapid or slow progression toward death) of clinical and functional changes of varying trajectories (e.g., short term improvements and relapses, crisis, plateaus, etc). According to the dying trajectories theory (Glaser and Strauss, 1968; Lunney et al., 2002; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003), there are four modal trajectories: sudden death, terminal illness, organ failure, and frailty. Some people die suddenly without experiencing any significant change in functional ability (i.e., sudden death). Individuals in the terminal illness category are characterized with a reasonably high functional status that rapidly declines within 6 weeks to three months before death, which is typically shown among some types of cancer patients. The organ failure group has serious organ system failure related to illnesses such as congestive heart failure or chronic obstructive disease and they experience gradually decreasing functional ability that is often accompanied by periodic exacerbations of conditions. The last category is the frailty group in which individuals experience slow decline of functional ability with steadily progressive disability due to

illnesses such as stroke or dementia. Lunney and colleagues (Lunney et al, 2003) have found support for the idea of different functional trajectories of dying in older adults with different main illnesses. Understanding different trajectories of illnesses is important in the context of hospice use at the end of life. For older adults to receive the hospice benefit through Medicare in the U.S., a physician must certify that they have less than 6 months to live (Gage et al., 2000). However, the majority of older adults die of serious illnesses without clear functional trajectories that indicate whether the patient is in terminal phase. According to the analysis of Medicare beneficiaries who died between 1993 and 1998 (Lunney et al., 2002), the majority of decedents experienced organ system failure or frailty trajectories and only about 20 percent of decedents died of cancer which follows more predictable terminal trajectory mode of dying. Physicians have been found in numerous studies to greatly overestimate likely survival time (Lamont & Christakis, 2001), and non-cancer diagnoses present particular challenges. Indeed, the clinical characteristic of the patient appears to be a strong predictor of hospice use as studies consistently have shown cancer diagnosis as a significant predictor of hospice use (Iwashyna et al., 2002; MedPAC, 2004; Moon & Boccuti, 2002; Virnig et al., 2000).

Even if serious physical and functional decline may indicate impending death, the person may not be psychologically ready to accept the poor prognosis. The readiness-to-die theory (Copp, 1996) argues that while the body (i.e. biological state) is approaching death, the person (i.e. psychological state) may not be psychologically ready to die. The state of readiness of the person can be influenced by a number of factors, especially by previous treatment history of the illness. If the initial diagnosis of the illness is made at an advanced stage of the illness, the person may not be able to move to the ready state as

quickly as the person who has received and pursued curative treatments during earlier stages of the illness and/or has simply had time to think about the seriousness of the problem.

The person may also appraise the illness as curable despite poor prognosis due to such reasons as religious belief in miracle, or may perceive the hospice option as a form of denial of care rather than an appropriate care approach. This latter perception may result from previous experience of discrimination in the health care system. In this case, the coping response of the person may focus on tasks of survival and cure rather than tasks of dying. Thus, coping responses can be either pursuing curative treatment or palliative treatment depending on the appraisal of the illness.

The Role of Race and Ethnicity in End-of-Life Decision Making

The literature details the importance of the cultural norms and behaviors of a racial/ethnic group in influencing the individual response to the terminal illness and decision to use hospice (Ersek et al., 1998; Kalish & Reynolds, 1976; Reese et al., 1999). A classic study on death and dying among ethnic groups by Kalish and Reynolds (1976) suggests that ethnic variation is an important factor influencing attitudes, beliefs and expectations regarding death and dying although individual differences within any racial/ethnic groups also exist. Persons of ethnic minority backgrounds may be more likely to turn to traditional norms and practices at the end of life because religious and cultural beliefs and norms can provide them with meaning for their illnesses and guide them in making decisions regarding treatment and care options (Ersek et al., 1998; Reese et al., 1999). Thus, a careful examination of the role of culture associated with

racial/ethnic groups in health care decision making is needed to better understand how individuals make decisions to use health services such as hospice.

A recent review of the role of race and ethnicity in end-of-life decision making by Kwak and Haley (2005) documents that race/ethnicity plays an important role in shaping preferences for and actual decisions in end-of-life care planning and use of treatments. Among 33 empirical studies, including both qualitative and quantitative studies that were published between 1992 and 2003, Kwak and Haley (2005) found multiple potential explanatory factors for racial/ethnic diversity in end-of-life decisions, including cultural values and norms regarding death and dying, individual level of acculturation and assimilation as well as sociodemographic characteristics, and shared history within the U.S health care system among older adults of racial/ethnic minority backgrounds.

Kwak and Haley (2005) also report that Blacks were the most frequently studied racial/ethnic group (28 studies out of 33 studies included Blacks in their study samples) and were consistently found to prefer more aggressive treatments than other racial/ethnic groups as indicated by: (a) advance directive documents (Degenholtz et al., 2002; Eleazer et al., 1996; Hopp, 2000; Hopp & Duffy, 2000; Kiely, Mitchell, Marlow, Murphy, & Morris, 2001; McKinley et al., 1996; Mebane et al., 1999; Murphy et al., 1996; Phipps, True, Harris, Chong, Tester, Chavin et al., 2003); (b) interviews (Allen-Burge & Haley, 1997; Blackhall et al., 1999; Caralis et al., 1993; Cicirelli, 1997; Garrett et al., 1993; Klessig, 1992; McKinley et al., 1996; Mebane et al., 1999; O'Brien et al., 1995; Phillips et al., 2000; Phipps et al., 2003; Waters, 2001); and (c) actual use (Gessert, et al., 2001; Hopp & Duffy, 2000).

The review by Kwak and Haley (2005) reports distrust of the health care system as one of the most frequently mentioned explanation for racial/ethnic differences in advanced care planning and preferences for end-of-life care treatments. It is suggested that low level of trust in Blacks in the U.S. health care system is due to personal experience with poor access to medical care and awareness of abuses in medical research in the past, for example, the Tuskegee syphilis study (Berger, 1998; Krakauer et al., 2002; Murphy et al., 1996; Waters, 2001).

One of the key issues that needs to be addressed in future research is individual variation regarding end-of-life related issues within a single racial/ethnic group (Kwak & Haley, 2005). As within-group differences among diverse groups are influenced by sociodemographic factors such as age, gender, education, acculturation and location (e.g. rural vs. urban) (Barker, 1992), it is suggested that these factors and a greater awareness of their potential theoretical significance should be more frequently incorporated into research designs for the study of end-of-life care (Kwak & Haley, 2005).

Summary

The current literature on health services use suggests that the Andersen model's strengths lie in its usefulness in conceptualizing and categorizing the myriad of correlates of use of health and social services (Grabbe et al., 1995) and identifying patterns of service use by subgroups, and its flexibility and openness to modification (Aday & Awe, 1997). Moreover, explanatory power of the model can be improved by inclusion of additional variables and further specification of relationships between individual determinants which can be informed by dying trajectories, readiness-to-die theory, and the literature on end-of-life decision making. Dying trajectories (Glaser & Strauss, 1968),

and readiness-to-die theory (Copp, 1996) provide the social and clinical context for understanding end-of-life decision making process while the literature on end-of-life decision making across diverse racial/ethnic groups suggests the importance of recognizing the diversity across racial/ethnic groups. Illness and need factors, such as the principal illness and associated trajectory, and psychosocial factors, are likely to have strong effects on the decision making process and service utilization.

Factors Associated with Hospice Use

Underutilization of hospice among terminally ill patients who can potentially benefit from its comprehensive benefit package of services has led to an increase in research efforts in identifying predictors of hospice use. A literature review of empirical research, expert opinions, and commentaries on this topic identified a number of potential determinants of hospice enrollment. These consist of (a) individual determinants including predisposing, enabling, need and psychosocial factors; (b) hospice service provider related factors; and (c) Medicare policy and organizational practice of nursing home factors. The literature on factors associated with length of stay in hospice is less extensive, but many factors that have been studied are also predictors of hospice use. Although most empirical studies that examined predictors of hospice use reviewed here are atheoretical, factors identified by these studies reflect many elements of the behavioral model of health service use. Therefore, the review of the literature on hospice use is organized within the framework of the behavioral model of health service use and factors associated with hospice length of stay are also summarized.

Individual Determinants of Hospice Use

Predisposing factors. Among predisposing factors, age, gender, education and race have been identified to be associated with hospice use. Two studies examining Medicare decedents (Iwashyna, Chang, Zhang, & Christakis, 2002; Virnig et al., 2000) and a study of Medicaid and Medicare dual-eligible decedents in California (Enguidanos, Yip, & Wilber, 2005) found that being older was significantly associated with higher likelihood of using hospice after controlling for gender, race, and main principal diagnosis. Some studies suggest that older patients are treated differently in health care settings. Even after adjusting for disease severity and patient preferences, older adults are less likely to receive intensive treatments than younger patients (Lubitz & Riley, 1993; Riley, Lubitz, Prihoda, & Rabey, 1987; Spector & Mor, 1984). Thus, it is possible that health care providers such as physicians may see it as more appropriate for older patients with severe illnesses to receive hospice care than younger patients, or older adults are more willing to forego life sustaining treatments to enhance quality of life. The same studies (Enguidanos et al., 2005; Iwashyna et al., 2002; Virnig et al., 2000) also found that women were more likely to use hospice. Other studies reported that among both community dwelling and nursing home residents, older women were less likely to receive intensive treatments or care such as hospitalization (Barker, Zimmer, Hall, Ruff, Freundlick, Eggert, & Rates, 1994; Fried & Mor, 1997), dialysis, transplantation, timely diagnosis of lung cancer, and specific interventions for heart disease adjusting for disease type and severity (American Medical Association, 1991). However, a recent study by Bird and colleagues (2002) on health care utilization and spending of Medicare beneficiaries in the last year of life demonstrates that gender differences in hospice care may be in part due to women's greater longevity and the tendency to treat younger adults

more aggressively by physicians. It is also possible that differential use of hospice between women and men may reflect treatment preference difference between genders. However, treatment preferences among men and women in this study are unknown.

Two studies found education level to be associated with hospice use (Chen, Haley, Robinson, & Schonwetter, 2003; Greiner, Perera, & Ahluwalia, 2003), but the studies reported the associations to be in opposite directions. Chen and colleagues (2003) found lower education to be associated with hospice use after controlling for other demographic characteristics whereas Greiner and colleagues (2003) found that increased level of education increased the probability of receiving hospice at the end of life. Inconsistent findings from these two studies may be due to difference in characteristics of study samples. The study by Chen and colleagues (2003) was based on a convenience sample of older patients (i.e., aged 65 and older) with selected types of cancer diagnoses while Greiner and colleagues (2003) examined a random, probability national sample of decedents aged 15 and older in 1993 using the 1993 National Mortality Followback Survey (NMFS). Although it may be hypothesized that higher level of education allow the person greater access to information about hospice service, the small number of studies examining this issue precludes any conclusion on the role of education.

Older Whites have been consistently found to use hospice more than older adults from other race/ethnic groups, especially Blacks. This is true for older adults with differing diagnostic characteristics at the end of life (Enguidanos et al., 2005; Greiner et al., 2003; Iwasyna et al., 2002; Lackan, Ostir, Freeman, Kuo, Zhang, & Goodwin, 2004; Lackan, Ostir, Freeman, Mahnken, & Goodwin, 2004; Virnig, McBean, Kind, & Dholakia, 2002; Virnig, Morgan, Persily, & DeVito, 1999; Welch, Teno, & Mor, 2005).

Five studies using multivariate analyses (Enguidanos et al., 2005; Iwasyna et al., 2002; Lackan, Ostir, Freeman, Mahnken et al., 2004; Virnig et al., 1999; Virnig et al., 2002) report that Blacks are less likely to use hospice. One multivariate study by Greiner and colleagues (2003) found that the role of race/ethnicity is attenuated by presence of a living will and another recent study using univariate analysis by Welch and colleagues (2005) found no difference in hospice use between Blacks and Whites.

The complexity of the relationship between race/ethnicity and hospice use is illustrated by the work of Virnig and colleagues (2002). Examining Medicare cancer patients who died in 1996, Virnig and colleagues (2002) report that Blacks are 25 percent less likely to use hospice compared with people from other racial/ethnic groups after adjusting for age and gender. Similar findings were reported by studies adjusting for various sociodemographic and clinical characteristics. Adjusting for age, gender, and income, Virnig and colleagues (1999) found that Black Medicare decedents in South Florida were less likely to use hospice. Virnig and associates (1999) also found that the racial difference in hospice use was reduced among Medicare decedents in managed care programs compared to those in fee-for-service programs. Iwashyna and colleagues (2002) found results similar to Virnig and colleagues (1999) after adjusting for the age, gender, income and Medicaid insurance status of Medicare decedents with diagnosis of lung cancer, colorectal cancer, stroke, and heart attack. Lackan and colleagues (2004) found that Black Medicare decedents with breast, colorectal, lung, or prostate cancer who died between 1991 and 1999 were less likely to use hospice in all years between 1991 and 1999 after adjusting for age, gender, and education. Enguidanos and colleagues

(2005) reported that Blacks were less likely to use hospice after controlling for age, gender, marital status, nursing home stay, and cause of death.

The findings by the study by Greiner and colleagues (2003) using the 1993 NMFS data provide additional insights into the role of race/ethnicity and other factors in predicting hospice use. Greiner and colleagues (2003) initially found that the rate of hospice use was significantly different between Black and White groups after controlling for a number of sociodemographic and clinical characteristics. However, Greiner and associates also found that the negative relationship between Black race/ethnicity and hospice use was reduced when the presence of a living will was controlled for. Examining only decedents who were aged 55 and older, the investigators found that the role of Black race/ethnicity was no longer significant when income, education, homeownership, and presence of a living will were included in the final model. Moreover, they found a significant interaction between race/ethnicity and access to care difficulties on hospice use. Blacks were less likely to use hospice when they experienced difficulty accessing health care while Whites and Hispanics showed increased hospice use when experiencing difficulty in accessing health care. It may be the case that Blacks are more likely to experience difficulty in accessing all health care in general including hospice, than for other racial/ethnic groups. It is also possible that the difficulties in accessing health care in general may prompt Blacks to pursue aggressive care. Findings from this study suggests that while the effect of race/ethnicity is not independent of income or access to care variables, the significant effect of the presence of a living will in explaining the racial/ethnic difference in hospice use may indicate cultural differences toward end-of-life decision making. The investigators hypothesized that lower hospice

use by Blacks results from the same forces that lead to the frequent Blacks' aversion toward completing advance directives or treatments limiting choices.

Enabling factors. Several studies have examined the role of individual, family, and community resource factors on hospice use. Enabling factors examined in these studies include income, marital status, caregiver availability, social support, living arrangement, rural/urban location of the primary residence and health care provider availability. On individual and family resource factors, however, much a smaller number of studies are available (Chen et al., 2003; Enguidanos et al., 2005; Greiner et al., 2003; Iwashyna et al., 2002; Virnig et al., 1999). Of four studies examining the role of income in hospice use, one study (Virnig et al., 1999) used the average or median household income per zip code from the 1990 U.S. Census data as a proxy for income, another study (Iwashyna et al., 2002) used the same method as Virnig and colleagues (1999) in addition to Medicaid status as a second proxy for the income status and the other two studies (Chen et al., 2003; Greiner et al., 2003) measured household income by interviewing the patient or the proxy for the decedent.

In the multivariate analysis controlling for age, gender, race, primary diagnosis and comorbidity, Iwashyna and colleagues (2002) found little effect of income on hospice use when examining the median income alone. However, Iwashyna and associates found that Medicaid recipients were 0.69 time less likely to use hospice than those without Medicaid insurance, suggesting that poor Medicare recipients (i.e., Medicare and Medicaid dual-eligible beneficiaries) were less likely to use hospice. Virnig and colleagues (1999) found that the higher the income was, the more likely Medicare beneficiaries were to use hospice after controlling for age, gender and race.

Greiner and colleagues (2003) also found having a household income of more than \$25,000 significantly increased the likelihood of using hospice in their multivariate analysis of all decedents in the 1993 NMFS sample. In contrast, Chen and colleagues (2003) did not find any significant effect of income on hospice use in their multivariate analysis. Given the small number of studies examining the role of income and variability in the method of measuring income across these studies, the role of income on hospice use is unclear. It may be that income is not a significant enabling factor for access to hospice care among older adults since all terminally ill Medicare and most Medicaid beneficiaries are eligible to receive it.

Findings on the role of social support are also inconclusive due to few studies available on this issue. Chen and colleagues (2003) found a positive association between the number of individuals living in the same household and hospice use but did not find marital status or caregiver relationship to the patient to be significant in predicting hospice use. Chen and colleagues (2003) also found that the final decision to use hospice was made largely by family members (42 percent of hospice patients) followed by patients themselves (28 percent) and physicians (27 percent). Enguidanos and colleagues (2005) did not find a significant role of marital status on predicting hospice use among Medicare and Medicaid dual-eligible older adults either. At the same time, Greiner and colleagues (2003) found that being never married significantly increased the likelihood of receiving hospice while being widowed significantly reduced the chance of receiving hospice.

It is possible that such difference found by Greiner and associates (2003) may be due to age differences between these two groups in this study. It is also possible that a

significant proportion of never married decedents were younger adults while older adults disproportionately represented widowed individuals who were also likely to have fewer social support resources and more likely to be in nursing homes and thus, they may have less access to hospice. In addition, Greiner and associates (2003) found the increased social support measured by frequency of phone calls was positively associated with likelihood of hospice use. An implication of these findings is that marital status may not be as significant as the availability of caregiver residing in the same household in predicting hospice use since most of hospice care is provided at home and informal caregivers are needed to provide substantial levels of care for hospice patients (Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004).

The role of rural/urban location of residence has been studied and found to be significant in predicting hospice use. Although it is estimated that 20 to 25 percent of Americans live in rural areas and over 18 percent of rural residents are over the age of 65, compared to 15 percent in metropolitan areas (MedPAC, 2001), the availability of hospice in rural areas is more limited than in urban areas. Virnig and colleagues found that a higher proportion of counties in urban areas (69 percent) had a hospice agency physically located within them than did rural counties (34 percent) (Virnig, Moscovice, Kind, & Casey, 2002). Virnig and associates also found that the rate of hospice use was lower among rural decedents. Among the Medicare beneficiaries who died in 1999, Virnig and colleagues (2004) reported that after controlling for age, sex, and race that the hospice use rate was 22.2 percent for those living in urban areas and 15.2 percent for those living in rural non-adjacent areas. Although the percentage of rural beneficiaries enrolled in hospice increased from 1992 to 2000, rural beneficiaries still used hospice at

75 percent of the urban rate (MedPAC, 2002). Thus, it is expected that residents in rural areas have less access to hospice and consequently, are less likely to use hospice.

Three studies examined the role of availability of certain types of physicians in predicting hospice use. Virnig and colleagues (2000) report that the number of hospitals per Health Service Area (HSA) is negatively associated with hospice use while the number of generalists and number of doctors per capita increased hospice use. The study by Iwashyna and colleagues (2002), however, did not find the effects of the number of hospitals and generalists in predicting hospice use at county level. The findings of this study (Iwashyna et al., 2002) suggested that when individual-level differences in diagnosis and wealth are taken into a consideration, market variables at the county level did not explain intercounty variability in hospice use rate whereas the study of Virnig and colleagues (2002) which only adjusted for age, sex, and race and examined market variables at the HSA level did find significant effects of market variables.

A study examining differences in attitudes toward hospice between physicians with different specialties (Bradley, Cramer, Bogardus, Kasl, Johnson-Hurzeler, & Horwitz, 2002) provides an insight into the role of physician specialty. Bradley and colleagues (2002) found that physicians' positive attitudes toward hospice care and increased communication about hospice care increased referral for hospice. Bradley and colleagues (2002) also found differences in self knowledge of and attitude toward hospice by physicians' specialty: oncologists with the least favorable attitude toward hospice and cardiologists with the least knowledge of hospice.

Need/illness factors. Studies have consistently shown that having a cancer diagnosis is one of the strongest predictors of hospice use (Iwashyna, Zhang, &

Christakis, 2002). Recent studies examining disease trajectories of varying illnesses document the limited current knowledge base to understand trajectories of different illnesses and to identify the point where the prognosis slips below 6 months (Field & Cassel, 1997; Lunney et al., 2002). Studies report that physicians experience the difficulties inherent in accurate prognostication of life expectancy and are reluctant to identify patients as dying (Christakis & Lamont, 2000; Mahoney, 2002 as cited in MedPAC, 2002). Among all major diagnostic groups, however, cancer has a relatively predictable disease trajectory that is characterized by a precipitous decline of function as the patient approaches death (Teno, Weitzen, Fennel, & Mor, 2001). Therefore, the six-month prognosis rule of the MHB is usually appropriate for patients with cancer diagnosis but it is much more difficult to furnish a e six month prognosis for patients dying of other illnesses.

Psychosocial factors. Knowledge and accurate understanding of what hospice is and what type of services offered by hospice providers is clearly an important factor in order for the utilization to take place. However, the lack of knowledge or misconceptions about hospice has been frequently cited as one of major barriers to hospice enrollment by commentators and reviewers on this issue, although very few studies have examined this issue empirically. Of the few empirical studies that explore this issue, a recent study about hospice decision making among patients and families (Casarett, Crowley, Stevenson, Xie, & Teno, 2005) found that only 40 percent of 237 patients and family members who were interviewed reported they knew anything about hospice and only 27 participants knew that the focus of hospice was on comfort care and symptom management. Although this study was based on a convenience sample of patients and

families who were recruited from hospice information visits, the result suggests that the misconception and lack of knowledge about hospice may be common among terminally ill patients.

The literature also suggests that forced choice between palliative and curative treatment required by the MHB makes it difficult for individual patients and families to choose hospice care. Case studies and reviews on hospice utilization report that many patients and families as well as physicians find it difficult to accept poor prognosis and are willing to seek curative treatment despite poor prognosis (Schulman-Green, McCorkle, Cherlin, & Bradley, 2005). According to a Gallup poll in 1996, most Americans are willing to seek curative care if faced with a terminal illness although a majority expresses an interest in hospice care (GAO, 2000). Preference to seek curative treatment even in terminal phases of an illness may be even stronger among minority groups. Due to differences in cultural beliefs and practice regarding death and dying, members of minority groups are less likely to choose hospice care; differences in religion, socialization and education and disparities in access to healthcare in general also play a role (Crawley et al., 2000). Consistent findings that Blacks prefer more aggressive care and treatment at the end of life compared with Whites provides support for this hypothesis (Kwak & Haley, 2005).

Hospice Service Provider Related Factors

A recent study examined the role of hospice organization admission practices (Lorenz et al., 2004). Based on a statewide survey of hospice organizations in California, Lorenz and colleagues (2004) found that a significant minority of hospices restricted admission on criteria such as lack of caregiver (26 percent), and unwillingness to forgo

hospitalization (29 percent); in addition many hospices were unwilling to accept patients with complex medical care needs such as total parenteral nutrition (TPN) (38 percent), tube feeding (3 percent), transfusions (25 percent), radiotherapy (36 percent), and chemotherapy (48 percent). Lorenz and associates also found that larger hospices were less likely to restrict admission based on these criteria, except for TPN or tube feeding, suggesting that eligible beneficiaries living in areas served by smaller hospices may be likely to experience provider-related barriers to hospice. As one of the goals of hospice care is to promote home-based care, and hospice organizations stress the need for a family member or someone else to serve as a primary caregiver for the patient who wants to receive home-based hospice care, some hospices do not accept patients without a designated caregiver (NHO, 1996b). However, it appears that the use of such restrictions imposed by hospice organizations may vary across states. The state of Florida for instance, has a higher proportion of hospice organizations with freestanding hospice inpatient or residential beds (12 percent) than the national average (8 percent) (Miller & Lima, 2004). The implication of the higher level of availability of inpatient or residential hospice beds in states such as Florida is that patients who are unable to stay in their homes in the community due to lack of caregiver may experience fewer barriers to access to hospice because they may be able to receive hospice care in these hospice residential beds. For nursing home resident, however, lack of available caregiver may not function as a barrier. In a nursing home facility, hospice and other long-term care are coordinated between hospice and nursing home staff if a nursing home resident elects a hospice care.

Medicare policy and organizational practice of nursing homes in referring nursing home patients to hospice

Nursing home residents are one of the most rapidly growing segments of hospice beneficiaries, with representation going from 11 percent of hospice enrollees in 1992 to 36 percent in 2000 (Hogan, 2002; MedPAC, 2002). Nevertheless, the rate of hospice enrollment among nursing home residents is reported to be lower than the enrollment rate among community-dwelling residents (Hoffmann & Tarzian, 2005). Some studies and commentaries suggest several major barriers to hospice in nursing home exist (Hoffmann & Tarzian, 2005; Mezey et al., 2002; Miller et al., 2003; Zerzan, Stearn, & Hanson, 2000). Jones and colleagues (1997) report that differential use of hospice in nursing homes is influenced by the nursing home administrator's attitude toward and knowledge of hospice care. Another potential barrier is that the major goal of care in nursing homes is to promote functional maximization and rehabilitation while hospice care focuses on palliative care, not curative care (Hoffmann & Tarzian, 2005; Mezey et al., 2002; Zerzan, Stearn, & Hanson, 2000). The potential conflicts of care philosophy between nursing home and hospice care may prevent enrollment of nursing home residents in hospice.

The six-month prognosis rule of MHB and Medicare nursing home reimbursement rates are reported to be other potential barriers to hospice enrollment among nursing home residents. The majority of nursing home residents can be characterized as having chronic illnesses related to organ system failure or frailty (Mezey et al., 2001), types of illnesses in which the dying trajectory is difficult to be determined (Lunney et al., 2003). Thus, it is more difficult to identify nursing home residents as dying by clinical measures at the end of life. In addition, there is often a financial incentive to choose skilled nursing care over hospice for both nursing facilities and Medicare beneficiaries. This is especially the case for Medicare beneficiaries with a need

for nursing home placement following hospitalization, since Medicare does not cover skilled nursing care and hospice care simultaneously.

For Medicare beneficiaries without Medicaid or other supplemental insurance coverage for nursing home care, there is a financial disincentive for them to choose hospice and to forgo the skilled nursing care benefit. A potential financial disincentive also exists for the facility with respect to Medicare and Medicaid dual-eligible nursing home residents. When a dual-eligible nursing facility resident chooses hospice, Medicaid allocates funds to the hospice, which is responsible for paying the nursing home 95 percent of the Medicaid nursing facility room and board rate. It has been suggested that this “pass thru” practice not only creates confusion for the nursing facility regarding the source of payment for the room and board, but also creates financial disadvantages (Miller & Mor, 2002). Also, the Medicare nursing home per diem payment rate for skilled nursing care is higher with an average per diem rate of \$265 than for Medicaid nursing home care (\$118) (Hoffmann & Tarzian, 2005). Thus, even for Medicare and Medicaid dual-eligible beneficiaries, nursing home facilities have financial incentives to enroll their residents under the skilled nursing benefit rather than hospice care since reimbursement rate under Medicare skill nursing benefit is higher than hospice room and board rate under Medicaid.

The presence of financial disincentives does seem to have an impact. Two recent studies suggest that there is at least a delay in access to hospice care if not implicit denial of access to hospice care due to the nursing home care reimbursement rate policy. One of these studies examined nursing home residents and hospice use in five states. Miller, Gozalo and Mor (2000) found that about 26 percent of nursing home residents who

received hospice were admitted to hospice within 1 day after being discharged from a skilled nursing facility using the Medicare skilled nursing benefit. It is possible that due to the fact that skilled nursing benefit is covered under Medicare, albeit for a limited period of time, some older adults (without Medicaid) with nursing home care need may opt to choose nursing home benefit over hospice care and other older adults who are dually eligible for Medicare and Medicaid, nursing home facility may find a financial incentive to enroll residents under Medicare skilled nursing benefit instead of under Medicaid hospice room and board benefit.

The second study (Moon & Boccuti, 2002) found that hospice use was higher among Medicare decedents who entered a nursing facility during the calendar year of death (19 percent) than decedents who resided in a nursing home from the start of the calendar year of death (11 percent). Combined, these findings indicate a need for further assessment of the process of hospice enrollment among both short-term and long-term nursing home residents. That is because a significant minority of older adults are admitted into a nursing home for a short duration of time using the Medicare skilled nursing benefit during the last few months of life (Miller, Intrator, Gozalo et al., 2004; Miller, Intrator, Laiberte, & Cang, 2004). Such transition from community to nursing facilities for example may occur when an acutely-ill older adult is discharged to a nursing facility following hospitalization (Mukamel, Bajorska, & Temkin-Greener, 2002). These short-term nursing home residents may experience access barriers to hospice during the last few months.

Factors Associated with Hospice Length of stay

Timely access to hospice would provide better opportunities for patients, families and hospice providers to develop and coordinate an appropriate plan of care. Short length of stay among hospice enrollees has become a major concern for hospice providers and policy makers. The analysis by the Government Accountability Office (2000) on the length of enrollment under hospice care shows that the average length of hospice use per hospice enrollee declined from 74 days in 1992 to 59 days in 1998. Although patients become eligible during 6 months before expected time of death, half of hospice users now receive care for 19 or fewer days, and care for one week or less is common (NHPCO, 2004).

The literature on the factors associated with shorter length of stay include diagnoses such as renal failure, leukemia or lymphoma, and liver or biliary cancer (Christakis & Escarce, 1996), male gender (Miller et al., 2000; Somova, Somov, Lawrence, & Frantz, 2000; Christakis & Iwashyna, 2000), White race (Christakis & Escarce, 1996; Christakis & Iwashyna, 2000), private insurance status (Somova et al., 2000), enrollment in Medicare's fee-for-service program (Virnig et al., 2000), living with a caregiver (Somova et al., 2000), having a hospital referral sources (Somova et al., 2000), and states and health care market characteristics (Christakis & Iwashyna, 2000; Virnig et al., 2000). Of particular interest among these factors is race/ethnicity. Although two previous studies (Christakis & Escarce, 1996; Christakis & Iwashyna, 2000) found Whites to be more likely to use hospice, among hospice users non-Whites are likely to have a longer stay than Whites. However, these studies do provide clear reasons for differences in the rate of hospice use and length of stay between these White and non-White racial/ethnic groups.

Factors Associated with Place of Death

The place of death has been considered as one of important end-of-life care outcomes as increasing number of studies have documented the gaps between the preferred places of death and actual deaths of place. Most of studies that examined the issue of site of death vary greatly in sample characteristics – cancer patients (Bruera et al., 2003), individuals enrolled in specialized programs such as hospice or the PACE programs (Fried, Drickamer, & Tinetti, 1999; Tempkin-Greener & Mulamel, 2002), seriously ill patients who were hospitalized (Pritchard et al., 1998), skilled nursing facility residents (Levy, Fish, & Kramer, 2004), Medicare beneficiaries of selected states (Emanuel et al., 2002), dual-eligible older adults from a western state (Enguidanos et al., 2005) and U.S. decedent population (Iwashyna & Chang, 2002; Mitchell, Teno, Miller, & Mor, 2005; Weitzen et al., 2003).

Despite tremendous variations in sampling and methods of these studies, two factors are consistently found to influence location of death: race/ethnicity and hospice use. Studies report Black race/ethnicity to be associated with higher odds of in-hospital death (Iwashyna & Chang, 2002; Pritchard et al., 1998; Weitzen et al., 2003). In addition two studies, although based on convenience samples of community dwelling residents, found that Blacks were more likely to prefer to die in a hospital than their White counterparts (Kalish & Reynolds, 1976; Neubauer & Hamilton, 1990).

Another factor in place of death is hospice use. Hospice use has been associated with greater likelihood of home deaths and lower likelihood of in-hospital deaths (Emanuel et al., 2002; Enguidanos et al., 2005; Moinpour & Polissar, 1989; Pritchard et al., 1998). Some studies have suggested that the higher rate of in-hospital deaths among

racial/ethnic groups may be due to the lack of resources that may help them receive end-of-life care at home since minority groups are less likely to use hospice. However, it is not clear how hospice use and race/ethnicity may affect place of death among nursing home residents, particularly among dual-eligible nursing home residents.

Limitations of Previous Research

The present review of the literature on health services use by ethnically/racially diverse older adults at the end of life, specifically hospice use, suggests areas of further research and areas of methodological improvement that this dissertation research seeks to address. Areas of further research include: (a) hospice utilization among Medicare and Medicaid dual-eligible older adults; (b) within- and between-group differences in hospice utilization among racial/ethnic groups; (c) hospice utilization among nursing home residents; and (d) the effects of hospice use on place of death between and within racial/ethnic groups of nursing home residents.

Dual-eligible Medicare and Medicaid Beneficiaries

Little is known about hospice use within special populations such as older adults eligible for both Medicare and Medicaid. Although it has been shown that dual-eligible older adults are less likely to use hospice than Medicare-only beneficiaries (Iwashyna et al., 2002; Moon & Boccuti, 2002), reasons for the lower utilization by dual-eligibles are unclear. Studies that found differential rates of hospice use between these two groups (i.e., dual-eligible and non-dual-eligible Medicare beneficiaries) suggest that the difference may be due to income differences. Nevertheless, given the unique characteristics of dual-eligibles, the role of predictors of hospice use previously identified

among general Medicare population may be different within the dual-eligible population from those of the non-dual-eligible older adult population.

Dual-eligibles are considered a vulnerable subgroup of Medicare beneficiaries as they tend to be poor, are more likely to be members of non-White minority groups, and report lower health status than other beneficiaries (MedPAC, 2004). A report on dual-eligibles provided by Medicare Payment Advisory Commission (2004) shows a detailed profile of dual-eligibles on multiple characteristics. According to the analysis of dual-eligibles based on the 2001 Medicare Current Beneficiary Survey by MedPAC (2004), 60 percent of them live below the poverty level and 94 percent live below 200 percent of poverty. Blacks and individuals with less than a high school level of education make up more than 20 percent and 60 percent of the dual-eligible population respectively while of Medicare beneficiaries without Medicaid only seven percent are Blacks and 28 percent have less than high school education. Sixty two percent of the dual-eligible group are female while only 55 percent of the non-dual eligible Medicare group are female.

Dual-eligibles are also more likely to have poor health compared to non-dual eligibles and to suffer from cognitive impairment, mental disorders, diabetes, pulmonary disease, stroke, and Alzheimer's disease than are non-dual eligibles (MedPAC, 2004). Moreover, between 1993 and 1998, dual-eligibles comprised 21 percent of all Medicare decedents while they made up for 13 percent of survivors during these years (Hogan et al., 2000) indicating higher mortality rate among dual-eligible beneficiaries. Furthermore, dual-eligibles are also more likely to receive care in long-term care facilities than other Medicare beneficiaries with almost one-quarter of dual-eligibles residing in an institution, compared with three percent of non-dual eligibles (MedPAC, 2004).

Racial/Ethnic Differences between Blacks and Whites

Although a few recent studies examine the role of race/ethnicity in hospice use, all empirical studies examining hospice use reviewed examined between-group differences only. Blacks have been consistently found to use hospice less frequently than Whites as discussed previously. The end-of-life literature suggests that cultural and institutional barriers may be reasons for underutilization of hospice by Blacks. Suggested institutional barriers include a lack of knowledge, trust of hospice and the health care system, and the lack of a full time primary caregiver. Cultural barriers include Black spiritual and religious values, and cultural values that are often in conflict with hospice philosophy and medical care.

There are at least five areas in which institutional and cultural barriers have been explored. The first is that Blacks are suggested to be less knowledgeable about hospice services than Whites. While a lack of knowledge concerning hospice services has been suggested as a barrier to hospice access and use among the general population (Reese et al., 1999), it is also suggested that Blacks may be even less likely than the general population to know of such services. Reese and colleagues found in focus groups that most community leaders such as pastor were not familiar with hospice and most Blacks who are religious often seek advices regarding health care from their ministers (Reese et al., 1999).

Moreover, Blacks are likely to have a lower socioeconomic status: Blacks in general have lower levels of education and income compared to Whites (MedPAC, 2004). Socioeconomic status (SES), typically measured in income and education, affects access to health services because knowledge and financial resources affect the ability to

obtain health information about innovative services such as hospice. Thus, it is possible that the lower SES among Blacks contributes to some of the differences in hospice use between Blacks and Whites. In fact, a multivariate analysis of the national sample of adult population who were aged 55 and older and died in 1993 by Greiner and colleagues (2003) supports this. Greiner and associates (2003) found that the negative relationship between Black race/ethnicity and hospice use was attenuated and became statistically insignificant when income was controlled for.

Second, mistrust among Blacks toward health care system is another potential barrier to hospice. It can be hypothesized that Blacks may perceive hospice service as a care option that will prevent them from receiving adequate care. Some speculate that the historical experience of receiving inadequate and disrespectful treatment by the medical and health care community has lead Black group to distrust the overall medical system and serve as a barrier to hospice (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Burrs, 1995; Gorden, 1995; Neubauer & Hamilton, 1990). The infamous Tuskegee Syphilis Study is often cited as a major influence on Black opinions concerning medical care. Distrust toward medical system has been found to be associated with Blacks' attitude toward other end-of-life care options such as life support and advance directives (see the review by Kwak & Haley, 2005 on this issue).

Third, Blacks may seek or obtain access to care at later stages than do Whites, and therefore may present with illnesses at advanced stages during encounters with health care providers. Among patients with cancer or stroke, Blacks are more likely to be diagnosed at later stages of the disease than Whites (American Cancer Society, 2003; Manderblatt, Andrews, Kao, Wallace, & Kerner, 1996). It also may be that in the

context of having serious illnesses such as a cancer diagnosis, the later entry point into the health care system for Blacks results in the patient and family having less time to contemplate the significance of the diagnosis. Difficulties in accessing care can also have a ripple effect: Greiner and colleagues (2003) report that the more health care access problems Blacks experienced, the less they were likely to use hospice. As a result, Blacks may be likely to be more focused on pursuing all possible curative treatment with a goal of recovery rather than pursuing palliative care.

Lastly, traditional Black spiritual and religious and cultural values are often in disagreement with hospice philosophy of giving up curative treatment (Burrs, 1995; Gorden, 1995; Reese et al., 1999). The traditional hospice philosophy is often in disagreement with their preferences for life-sustaining treatment and against advance care planning such as completing advance directives (Blackhall et al., 1995, 1999; Caralis, 1993; Klessig, 1992; Waters, 2001). Such perspectives on end-of-life care options are often related to spiritual/religious values (Burrs, 1995; Reese et al., 1999). Traditionally, Blacks believe in God's omnipotence and miracles especially regarding medical care decisions and Blacks rely on their religious faith for recovery or cure at the end-of-life rather than accept terminality (Reese et al., 1999). Through their quantitative study, Reese and colleague (1999) found that Blacks were less likely to agree with hospice philosophy controlling for gender, age, education and income.

Overall, the literature suggests that Blacks are less likely to use hospice due to different sociodemographic and their unique historical and cultural experiences in the medical system. Such results should be considered in the context of the diversity of Blacks and there is a need for further examination of individual variation within each

racial/ethnic group in addition to between-differences to better understand the mechanism by which race/ethnicity affects hospice use.

Another related issue regarding the role of race/ethnicity in hospice use is length of stay. Two previous studies (Christakis & Escarce, 1996; Christakis & Iwashyna, 2000) found that non-Whites are likely to enter hospice sooner, measured by survival time from the time of initial hospice enrollment. The reason for such finding is not clear. Comparing the predictors of use of and length of stay under hospice across racial/ethnic group may help identify factors that may facilitate hospice use as well as timely access to hospice service.

Hospice Utilization in Nursing Homes

Better understanding of end-of-life experiences, particularly hospice utilization and its outcomes, among nursing residents is needed. The current literature on hospice utilization among nursing home residents is limited by a small number of studies that have comprehensively examined two different types of nursing home residents: short-term and long-term nursing home residents. Although a study of dual-eligibles in California by Enguidanos and colleagues (2005) included a variable indicating long-term nursing home admission in their analysis, their conceptualization of long-term nursing home admission is limited in capturing a subgroup of nursing home residents, short-term nursing home residents. Enguidanos and colleagues (2005) defined individuals in a custodial nursing facility as having a minimum of 90 consecutive days in their last year of life. However, a significant minority of older adults enter into a nursing home for a short duration of time using the Medicare skilled nursing benefit (Miller, Intrator, Laliberte et al., 2004). Miller and colleagues (Miller, Intrator, Laliberte et al., 2004)

found that 31 percent of all nursing home residents who died in Florida were enrolled in the Medicare skilled nursing benefit during the last 60 days before death.

The literature also suggests that there may be unique differences among short-term and long-term nursing home residences at the end of life. Among nursing home residents, short-term nursing home residents are more likely to be younger and have a cancer diagnosis (Miller, Intrator, Gozalo et al., 2004). Similar to hospice use, Blacks are in general less likely to use nursing homes after adjusting for other confounders (Salive, Collins, Foley, & George, 1993; Stevens, Owen, Roth, Clay, Bartolucci, & Haley, 2004). Therefore, it is important to account for the unique differences between subpopulations of nursing home residents when examining hospice use at the end of life. Moreover, few studies comprehensively examine how hospice use affects outcomes within and between racial/ethnic groups residing in nursing homes.

The Effects of Hospice Use on Place of Death

One of the key issues in end-of-life care is where people die because place of death shows where the person was receiving care at the very end of life and suggests areas of improvement for that particular setting of care (Flory, Young-Xu, Gurol, Levinsky, Ash, & Emanuel, 2004). In addition, there is a gap between preferred place of death and actual place of death. A national survey shows that the majority (65 percent) of older adults aged 65 and older prefer to die at home or in a hospice (Gallup, 2000) while over 50 percent of older adults actually died in acute care hospitals (Hogan et al., 2000). Although hospitalization at the end of life can be both necessary and unnecessary depending on the clinical needs of the patient, the experts on end-of-life care generally agree that hospitalization at the end of life should be avoided if possible (Engle, 1998;

Mezey et al., 2002; Mor, Papandonatos & Miller, 2005). Early studies on home and inpatient-based models of hospice care have found that hospice reduces hospitalization among non-nursing home residents and facilitates home death among community-dwelling terminally ill patients (Kidder, 1992; Mor & Kidder, 1985). Among nursing home residents, a recent study shows that hospice reduces hospitalization during the last month of life (Miller et al., 2001). However, more research is needed to replicate these study findings among dual-eligible older adults in a nursing home setting. Of particular interest is to explore patterns of hospital death between Blacks and non-Hispanic Whites and how they are affected by hospice use.

A recent study of nursing home residents in two states, New York and Mississippi, by Mor, Papandonatos and Miller (2005) holds important implications for a study of site of death among nursing home residents. Mor and colleagues (2005) found that Blacks were more likely to be hospitalized during the last 90 days of life than Whites after adjusting for demographic and clinical characteristics, patient preference (using do-not-resuscitate order) and facility resources. Mor and colleagues (2005) also found interactions between race and age and race and functional impairment on hospitalization rates. They found that the oldest and most impaired Blacks experienced significantly higher rates of hospitalization than non-Hispanic White counterparts. Mor and colleagues also speculated that these findings might be attributed to racial segregation in nursing homes and/or cultural effects. Their study found that Black residents resided in nursing facilities with fewer resources and therefore, these nursing facilities might be predisposed to discharge to hospital those patients with high levels of clinical needs. Mor

and associates (2005) also recognized that higher rate of hospitalization by Black residents might be due to their preference for aggressive treatments at the end of life.

For nursing home residents, particularly long-term nursing home residents, nursing homes can be considered as an appropriate place of death. With increased functional impairment and physical deterioration along with diminished capacity of informal caregivers to provide adequate care in a community setting, many frail older adults enter nursing homes to receive long-term care that otherwise may not be available in a community setting. For these nursing home residents, some of the important goals of end-of-life care are to minimize unnecessary transfers to hospitals while providing adequate medical care that is appropriate for terminally ill patients, and to reduce hospital death. In fact, a recent randomized controlled study of a hospice educational and referral interventions for nursing home residents and their families (Casarett, Kwalawish, Morales, Crowley, Mirsch, & Asch, 2005) shows that a simple communication studies significantly improved referral of eligible nursing home residents to hospice with better outcomes such as fewer acute care admissions and higher ratings on quality of care. Thus, providing hospice care for nursing home residents appear to make significant improvement in quality of care and facilitate nursing home residents experience dying in place at the end of life.

Measurement issues

The operationalization of key concepts such as race and ethnicity is critical in understanding disparities and variations in access to and quality of health care services (Arispe, Holmes, & Moy, 2005). Race classification and selection of variables influence almost all aspects of the research including methodological approach, analysis, and the

presentation and framing of results (Arispe et al., 2005). Yet, it is generally recognized that there is tremendous variations in the availability, reliability and validity of racial and ethnic-related variables across data systems (Arispe et al., 2005). Chen, Chen and Mehra (2005) for example found that while the identification of Whites and Blacks in a statewide Medicaid data set was over 90 percent accurate, accuracy was substantially lower for other groups.

Limitations in using administrative record or vital statistics records should be noted because many studies examining the end-of-life health services utilization (e.g., Enguidanos et al., 2005) use such records as their data sources. Generally, administrative data contain enrollment files with information on eligibility of the person for a health plan and demographic characteristics and encounter or claims data including information on individual services or sets of services (Iezzoni, 2002). Since administrative data are usually generated from billing records or discharge data provided by health service providers who are not required to collect information on race and ethnicity, rates of missing data are relatively higher than what is found in population-based surveys. Quality of data is also often in question because designation of race and ethnicity may reflect patient, proxy or provider report. Moreover, large data sources such as Medicare or Medicaid do not provide readily available information regarding enrollees other than age, race, and gender and certain proxies for income and ethnicity (Fisher et al., 1992; Iwashyna, Brennan, Zhang, & Christakis, 2002). While the literature suggests the importance of the characteristics of family members in the household of the patient in medical decision making, Medicare claims data, for example, do not provide reliable information concerning such variables as marital status although there have been some

efforts to improve the accuracy of sociodemographic information in the claims data set and to identify social information such as marital status (Iwashyna et al., 2002).

Furthermore, there are limitations of using diagnostic and procedure codes recorded in the administrative data. Differing systems of diagnostic categorization (e.g., International Classification of Diseases, ICD-9-CM vs. ICD-10 or DSM-IV-R) and procedure codes (Current Procedure Terminology, CPT-4) and inconsistent accuracy and completeness of coding of administrative data are well documented (Iezzoni, 2002; Iezzoni, Daley, Heeren, Foley, Fisher, Duncan et al., 1994; McCarthy et al., 2000). Different diagnosis and procedure codes may describe the same event, and diagnostic codes do not allow researchers to determine the severity of illness of the patient (Iezzoni, 2002; McGlynn, Damberg, Kerr, & Brook, 1998). Moreover, substantial variability is found in the accuracy of diagnostic coding across hospitals and physicians and up-coding practices (i.e., using codes to ensure the highest payment and not the condition that is the most clinically salient) by some hospitals has been found to occur in an effort to maximize reimbursement through Medicare's Prospective Payment System (PPS) (Iezzoni, 1997; Iezzoni, 2002; McGlynn et al., 1998). Yet another problem is the validity of coding of cause of death on death certificates, which has also been questioned (Hogan et al., 2000). There is some evidence, however, that the accuracy of cause of death codes has improved in recent years (Hoyert and Rosenberg, 1999).

Summary

This dissertation research seeks to fill the gap in the end-of-life literature in the areas addressed above. Specifically, this dissertation research investigates the role of multiple determinants of hospice use among dual-eligible older adults in nursing homes

to provide implications for practice and policy to improve access to hospice among this unique population of older adults by identifying potential access barriers to hospice that may be unique to dual-eligible nursing home residents. Another major aim of this study is to explore individual variation within each racial/ethnic group in addition to between-group differences to better understand the mechanism by which race/ethnicity affects hospice use and length of stay in hospice. Finally, the place of death as an outcome of hospice use is examined between and within each racial/ethnic group, non-Hispanic Whites and non-Hispanic Blacks. In an effort to contend with measurement issues, this study uses demographic and clinical data of decedents from multiple data sources such as Florida Medicaid eligibility and claims data sets and Florida Death Certificate record set to improve accuracy of race/ethnicity and cause of death variables.

The decisions to focus on dual-eligible individuals and residents of nursing homes were made for several important reasons. First, dual-eligibles are a group that is of special importance to policy makers, due to their very high utilization of public funds (both Medicaid and Medicare). Second, using dual-eligibles is advantageous in studying racial/ethnic differences, because this group includes a restricted range of financial assets, minimizing some of the problems typically encountered in such comparisons because of the large disparities in income in the general population of older NHW and NHB. Since nursing homes are an increasing site of death, and use of hospice use in nursing homes has not been extensively studied, research focused in this setting can also provide useful policy information. Finally, because of the complex nature of Medicare and Medicaid funding for hospice care for dual eligibles, and limitations of the available administrative data sets, we have a much better accuracy of ascertaining whether hospice care was

utilized among a nursing home population than in a community-dwelling group. For all of these reasons, the project focuses on dual-eligible individuals who were nursing home residents.

Research Questions

The Conceptual Model

Within the framework of the behavioral model of health service utilization (Andersen, 1995), the relationships between race/ethnicity, nursing home use, hospice, and hospital death are examined systematically in this study. The behavioral model of health service utilization is modified to include predisposing, enabling and need factors predicting hospice service use which is expected to reduce the risk of hospital death as identified in the literature (Figure 1). Thus, the final outcome in this model is hospital death.

For hospice, three sets of individual determinants – predisposing, enabling and need factors - will predict the use of this service. Among predisposing factors, older age, female gender, and Black race/ethnicity have been consistently found to predict hospice use while the role of education is not clear. As enabling factors, marital status, rural/urban location of the primary residence, and short-term nursing home status have been found to predict higher likelihood of hospice use while a cancer diagnosis is found to be the strongest predictor of hospice use among need factors.

The literature on place of death suggests that Black race, presence of the principal diagnosis other than cancer, and hospice use are associated with hospital death (Miller et al., 2001; Mor et al, 2005). In this study, the use of hospice, in turn, is expected to reduce

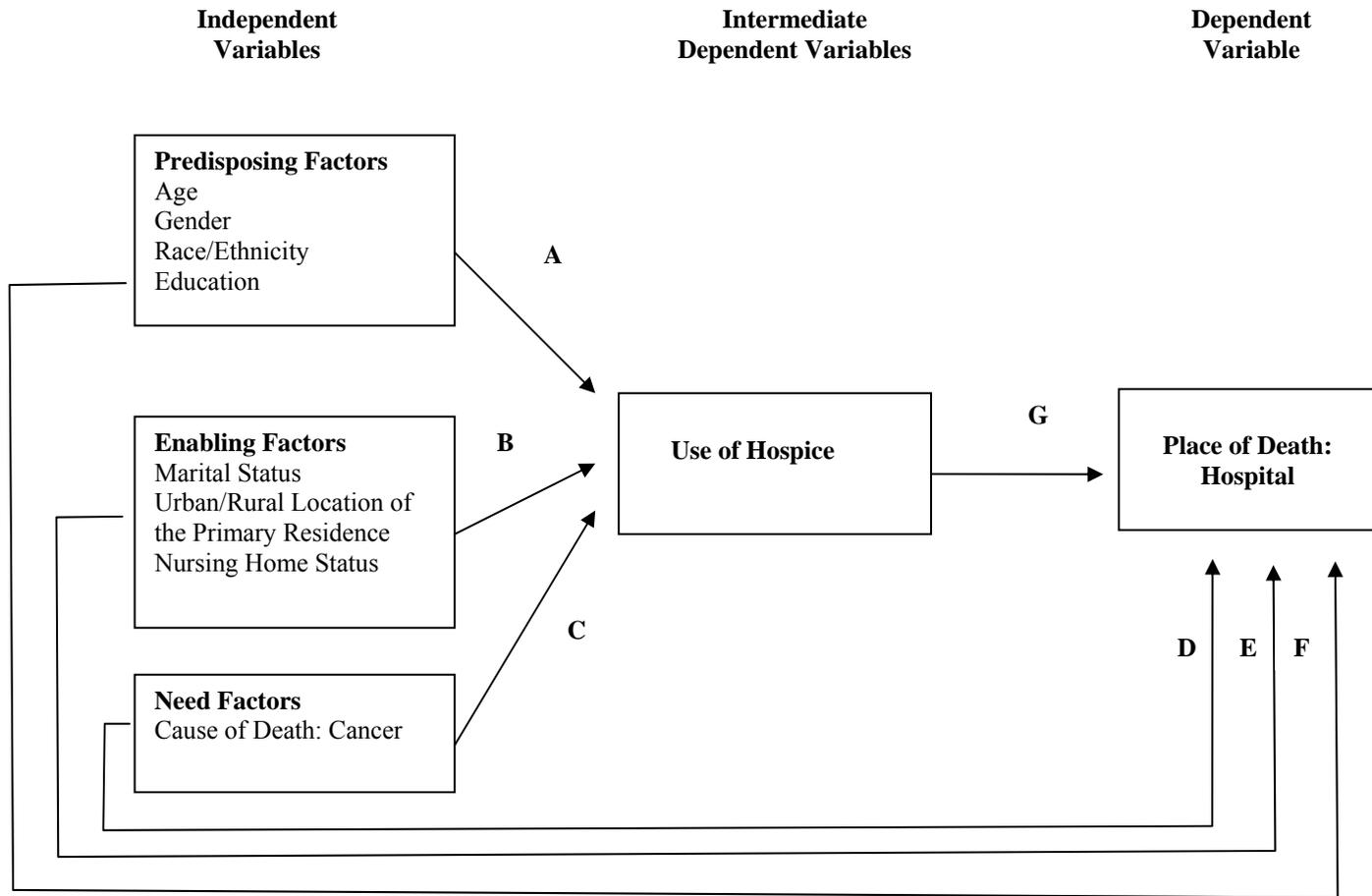


Figure 1. Conceptual Model

the risk of hospital death. In predicting hospital death, some of predisposing, enabling and need factors predicting hospice are expected to directly influence hospital death and hospice use is expected to reduce the risk of hospital death after controlling for these covariates.

In this study, not only between- but also within-group differences across racial/ethnic groups are examined. In addition, factors associated with the length of stay in hospice will be studied among individuals who use hospice. This is an exploratory component of the dissertation study; the exploratory component has been added because there is no substantial theoretical base in the literature to explain the timing of hospice use, and thus, the same predictors identified for hospice use will be assessed in predicting the length of stay in hospice.

Research Questions and Hypotheses

Research question 1. Do predisposing, need, and enabling factors have significant associations with hospice use in the last year of life among dual-eligible nursing home residents?

Hypothesis 1: Four predisposing factors – age, race, education, and gender - are significantly associated with hospice use (Figure 1, A).

- Older age, non-Hispanic White race, higher educational level, and female gender are significantly associated with increased likelihood of using hospice.
- Race/ethnicity is significantly associated with hospice use after controlling for other variables: non-Hispanic Blacks are less likely to use hospice compared with non-Hispanic Whites.

Hypothesis 2. Enabling factors –marital status, geographic location of the primary residence (i.e., rural or urban area code), and short-term nursing home status significantly predict hospice use (Figure 1, B).

- Being married, urban residence, and long-term nursing home status are significantly associated with increased hospice use.

Hypothesis 3: An illness-need factor, diagnosis of cancer directly influences hospice use (Figure 1, C).

- Having a diagnosis of cancer of any type is significantly and positively associated with hospice use.
- *Hypothesis 4:* Race/ethnicity moderates the impacts of education, marital status, and cancer diagnoses on hospice use. This is an exploratory component of the analysis of predictors of hospice use. The moderating effect of race/ethnicity on other enabling factors with hospice use has not been explored extensively by previous research on hospice utilization. However, the literature on racial/ethnic differences in end-of-life decision making and service utilization documents a strong influence of race/ethnicity. Thus, it is possible that race/ethnicity and its associated cultural norms and expectations may influence the strength or direction of effects of other enabling and need factors known to facilitate use of hospice. In this sub-analysis, potential interaction effects between race/ethnicity and education, marital status and cancer as a cause of death with hospice use are explored.

Hypothesis 5: The same predictors identified by Hypotheses 1-3 with the exception of the direct effect of race/ethnicity will affect hospice use within each of the racial/ethnic groups. The same predictors include predisposing (older age, higher educational level, female gender), enabling (being married, urban residence, long-term nursing home status), and need (cancer as a cause of death) characteristics will be associated with higher likelihood of hospice use within each racial/ethnic group. Little is known about within racial/ethnic group difference on predictors of hospice use, but there is no evidence that the elements of the Andersen Model should function differently across the two groups being studied.

Research question 2. Do major predisposing, need, and enabling factors have significant associations with length of stay in hospice in the last year of life among dual-eligible nursing home residents?

Hypothesis 1. The same predictors identified from the Research Question 1 are tested in their roles in predicting longer length of stay. Specifically, predisposing (older age, higher educational level, female gender, non-Hispanic White), enabling (being married, urban residence, long-term nursing home status), and need (cancer as a cause of death) characteristics will be associated with longer survival time from the time of initial hospice enrollment for the overall nursing home residents enrolled in a hospice program. Due to limited theoretical understanding on the effects of multiple factors on predicting the short length of stay in hospice, the same predisposing, enabling and need factors predicting hospice use will be assessed in this analysis. Among predisposing, enabling and need factors, characteristics associated with longer survival time identified in previous research are hypothesized to be associated with longer survival time.

Hypothesis 2. The same predisposing, enabling and need predictors for longer survival time from the *Hypothesis 2 of the Research Question 2* are tested within each of the racial/ethnic groups. There is no clear evidence in the literature that indicates the factors influencing length of stay will be different within each racial/ethnic group. Thus, relative importance of these factors will be explored within each racial/ethnic group, with the guiding hypothesis being that factors influencing length of stay will be the same across both groups.

Research question 3. Does hospice use reduce hospital death after controlling for covariates?

Hypothesis 1. Among predisposing, enabling and need factors, female gender, non-Hispanic White race/ethnicity, presence of cancer, and hospice use are significantly associated with lower risk of hospital death (Figure 1, D - G).

- Hospice use is significantly associated with lower risk of hospital death after controlling for covariates.

In addition, the potential moderating effect of race/ethnicity on age with hospital death is tested as a previous study of hospitalization rates among nursing home residents (Mor et al., 2005) found a moderating effect of race/ethnicity on age with hospitalization rates and hospitalization precedes in-hospital death.

Hypothesis 2. Among predisposing, enabling and need factors, female gender, presence of cancer, and hospice use are significantly associated with non-hospital death within each of the racial/ethnic groups. The effect of hospice use on lower risk of hospital death after controlling for other covariates is not significantly different for non-Hispanic Blacks compared with non-Hispanic Whites. There is no evidence found in the

literature to suggest that there will be differential effects of hospice use across race on hospital death.

Chapter Two: Research Methods

Sample

This doctoral research consists of a series of analyses of secondary data utilizing a Florida Medicaid Long-Term Care analysis file which was built from Florida Medicaid eligibility and claims records and Florida Department of Health Death Certificates stored and managed at the State Data Center on Aging at the Florida Policy Exchange Center on Aging, School of Aging Studies, University of South Florida. In addition, an extended hospice claims file from Medicaid Program Analysis data file was provided by the Agency for Health Care Administration. Those desiring further information on hospice claims should contact the Agency for Health Care Administration for additional information on the nature and type of hospice services that were utilized.

The sampling frame consists of dual-eligible nursing home residents aged 65 and older who died between three state fiscal years (SFY) 2000-2001, 2001-2002, and 2002-2003 in Florida. To be included in the final sample of this study of decedents, individuals needed to be dually eligible for nine consecutive months during the last 12 months of life and be either non-Hispanic Blacks or non-Hispanic Whites. Individuals with traumatic or sudden death were excluded from the analysis since these individuals would not have been eligible for hospice service.

The data sources were linked by a probabilistic record matching method. The probabilistic matching method is a statistically validated technique that uses multiple

passes combined with clerical review of candidate matches (G. E. Mitchell, personal communication, October 12, 2004). Social security number was a common identifier variable for all three data sources (i.e., Florida Medicaid Long-Term Care analysis file, extended hospice claims file, death certificate record file) while Medicaid data files also included a unique Medicaid recipient identification number for each recipient. Thus, first, Medicaid recipient identification number and social security number were used to match and merge a Medicaid Long-Term Care analysis file and an extended hospice claims file. The merged Medicaid file was matched and merged with death certificate record file using social security number.

The initial study population included a total of 118,703 Medicaid beneficiaries aged 18 and older, who died between SFY 2000 and 2002 (see Appendix A). From the 118,703 Medicaid decedents during those three state fiscal years, there were 117,667 beneficiaries who had a death certificate record and manner of death recorded as natural or unknown. A further 1,036 Medicaid recipients were excluded from analyses, since individuals with traumatic or sudden death would not have been eligible for hospice service.

Of 117,667 Medicaid decedents, 67,562 (57 percent) were dually eligible for Medicare and Medicaid being eligible for both Medicare and Medicaid for at least 9 months. Of 67,562 dual-eligible beneficiaries, 61,137 (90 percent) were aged 65 and older and 34,081 (50 percent) were identified as either long-term or short-term nursing home residents. Among 34,081 dual-eligible nursing home residents aged 65 and older, 30,765 residents were identified as either non-Hispanic Black or non-Hispanic White and thus, there were 30,765 nursing home residents in the final study population.

Measures

Dependent Variables

The dependent variable for the *Research Question 1* was hospice use. Any use of hospice room and board care during the last year of life recorded in the Medicaid claims record was considered as use of hospice (hospice vs. no hospice use). Hospice utilization information among the study population (i.e., dual-eligible nursing home residents in Florida) is based on Florida Medicaid claims record file. However, nearly all dual-eligible nursing home residents receive hospice room and board care reimbursed by Medicaid. Although dual-eligible nursing home residents may receive hospice or nursing home care reimbursed by private sources other than Medicare or Medicaid, the author is not aware of actual or estimated number or percentage of such cases in Florida or in the U.S. Thus, hospice utilization rate reported in this study is likely to reflect overall hospice utilization experience of dual-eligible nursing home residents in Florida.

For *Research Question 2*, the dependent variable was survival from hospice enrollment until death in days. Since identifying factors that affect timing of initiation of hospice service is a major interest in this study, number of days from the beginning date of hospice service recorded in the Medicaid Program Analysis file and the date of death from the death certificate record was calculated and used as a dependent variable for the *Research Question 2*. The dependent variable for *Research Question 3* was place of death recorded in the death certificate record and includes: hospital - inpatient, emergency room, outpatient medical facilities, dead on arrival; nursing home; private residence and others. This variable was recoded into three discrete variables: death at hospital (1=yes, 0=no), death at nursing home and death at other (1=yes, 0=no).

Predictor Variables

For all three research questions, independent variables included predisposing factors (age, gender, race, education), enabling factors (marital status, urban/rural location of the primary residence, nursing home status), and need factors (principal diagnosis - cancer, non-cancer- COPD, CHF, stroke, dementia, or other non-cancer illness). For the *Research Question 3*, an additional independent variable, hospice use, was included. All these variables except education and Hispanic ethnicity were available from the Medicaid Long-Term Care Analysis file. While Hispanics were not included in the study, the Hispanic ethnicity variable was used to identify Black and White nursing home residents who were not of Hispanic ethnicity. The variable for education and Hispanic ethnicity were available from the death certificate record.

Predisposing factors. Age and education were continuous variables. Categorical variables included gender (female=1 and male=0) and race/ethnicity (non-Hispanic Black=1, non-Hispanic White=0).

Enabling factors. Marital status was recoded and categorized into two groups: married as 1 and non-married as 0. The zip code was reviewed based on the Rural-Urban Commuting Areas (RUCA) code developed for the state of Florida by Bill Kearns at the Department of Aging and Mental Health of the Louis de la Parte Florida Mental Health Institute at the University of South Florida and recoded into two categories: urban as 1 and rural as 0.

To be considered as a long-term nursing home resident, the decedent had to have a documented record of nursing home stay identified in the nursing home variable in the Medicaid Long-Term Care file during the last three consecutive months of life. If a

recipient had a record of nursing home stay identified in that file during any of the last three consecutive months of life without meeting the above duration criterion, the person was considered as a short-term nursing home resident.

The nursing home variable in the Medicaid long-term care file is based on a complex algorithm that considers multiple combinations of different types of nursing home stays and determines the nursing home status based on the total number of nursing home stays during three consecutive months. However, the nursing home status algorithm identifies Medicaid recipients who elect hospice in a nursing home setting as a hospice recipient and not as a nursing home resident during a given month because the priority is given to hospice status over nursing home stay in the administrative data. Thus, if the person elects hospice, his/her nursing home status is not captured by the nursing home variable in the data. Data regarding the nature and location of hospice services – nursing home room and board and other hospice services - was obtained from the Medicaid Program Analysis file for all Medicaid decedents in this study. The flowchart of the decision making process for assigning nursing home status is described in the Appendix B.

Need factors. The principal diagnosis of cancer or non-cancer condition as a cause of death was determined by examining the reported cause of death in the death certificates. The principal cause of death variable was categorized and recoded into eight discrete variables: cancer, heart, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), stroke, dementia, renal failure, dementia/Alzheimer's disease, and other. Among principal causes of death, CHF was distinguished from other health disease group. CHF has been identified as a condition characterized with a

trajectory that consists of abrupt changes in functional status which is similar to COPD (Lunney et al., 2002).

Statistical Approach

Descriptive Analyses and Bivariate Correlations for Research Questions 1-3

Descriptive analyses were conducted of all predisposing, enabling and need factor variables and dependent variables - hospice use, hospice length of stay, and hospital death – by hospice use, race/ethnicity, and nursing home status. Descriptive analysis results include means with standard deviations and percentages and are described in Chapter 3. Pearson's correlations were performed on all independent and dependent variables for the overall study population (Table 1) and the sub-group of hospice users (Table 2). Although 10 out of 14 variables are dichotomous variables, Pearson's correlations were chosen to examine the strength of relationship between variables because studies have shown that variant forms of correlation for dichotomous variables such as point-biserial correlation rarely affect research conclusions (Tabachnik & Fidell, 2001). Significance levels were not included since these analyses used a population, and not a sample.

Table 1 is a display of the results of the full correlation matrix for the overall study population including two dependent variables, hospice use and place of death. Pearson's correlations analyses for both hospice and non-hospice groups found no evidence for multicollinearity among variables except for a very high negative correlation, $r = -0.91$, between hospital death and nursing home death. However, the high negative correlation between nursing home death and hospital death is due to other places of death accounting for only four percent of all deaths. Hospice use was negatively correlated

Table 1. Correlations among Variables for the population of Medicaid Nursing Home Residents

	2	3	4	5	6	7	8	9	10	11	12	13
1 Age	.24	-.11	-.07	-.23	-.12	.02	-.09	.07	-.15	.15	.00	.02
2 Female		-.07	.00	-.37	-.05	.00	-.05	.05	-.06	.05	.02	.02
3 Non-Hispanic Black			-.25	-.02	.10	.02	.04	-.08	.14	-.12	.00	-.06
4 Education				.09	-.04	.09	.00	.04	-.04	.03	.00	.04
5 Married					.00	-.01	-.01	.03	.01	-.01	-.01	.02
6 Short-term Nursing Home						.00	.00	-.07	.18	.19	.02	-.25
7 Urban area of residence							-.01	.00	-.02	.00	.01	.04
8 Cause of Death: Cancer								-.10	-.05	.05	.00	.11
9 Cause of Death: Dementia									-.15	.13	.00	.09
10 Hospital death										-.91	-.08	-.33
11 Nursing home death											-.19	.32
12 Home death												.01
13 Any hospice use												

Table 2. Correlations among Variables for Medicaid Nursing Home Decedents Who Used Hospice

	2	3	4	5	6	7	8	9	10	11	12	13
1 Age	.23	-.10	-.10	-.25	-.07	.04	-.15	.06	-.06	.06	.00	-.03
2 Female		-.06	-.03	-.41	-.04	.03	-.07	.06	-.03	.00	.04	.00
3 Non-Hispanic Black			-.25	-.02	.05	-.02	.09	-.07	.09	-.03	-.03	.04
4 Education				.11	-.03	.09	-.02	.03	-.03	.00	.00	-.04
5 Married					-.01	-.02	-.03	.05	.02	-.01	-.04	-.02
6 Short-term Nursing Home						.00	.07	-.04	.02	-.02	.01	.03
7 Urban area of residence							-.04	.01	-.03	-.01	.02	-.03
8 Cause of Death: Cancer								-.16	.00	.00	-.01	.00
9 Cause of Death: Dementia									-.05	.03	.00	-.04
10 Hospital death										-.07	-.03	.11
11 Nursing home death											-.05	-.09
12 Home death												-.09
13 Length of Stay in Hospice												

with short-term nursing home status ($r=-.25$) and hospital death ($r=-.33$) and positively correlated with cancer as a cause of death ($r=.11$). Hospital death was positively correlated with non-Hispanic Black race/ethnicity ($r=.14$) and short-term nursing home status ($r=.18$) and negatively associated with age ($r=-.15$) and dementia as a cause of death ($r=-.15$). No variable except for death in a hospital ($r=.11$) showed a correlation of .10 or greater (e.g. accounting for 1 percent of more of variance) with hospice length of stay.

Multivariate Analyses

Research Question 1. The choice of multivariate analysis method for examining the role of multiple factors in predicting hospice use for this analysis was a sequential binomial (or binary) logistic regression. Binomial logistic regression was used since the dependent variable is dichotomous (1=hospice use, 0=no hospice use) (Tabachnick & Fidell, 2001). Unlike ordinary least square (OLS) regression, the logistic regression does not assume linearity of the relationship between the independent variables and dependent variable, normal distribution of variables, and homoscedasticity. A sequential binomial model is used over a direct model when the underlying theoretical model being tested suggests a sequence of events (Tabachnick & Fidell, 2001). In the behavioral model of service utilization, predisposing factors precede enabling factors both of which are underlying factors that are triggered by need factors.

The model described took the form of: $\{\log (P/1-P) = \alpha + \beta_1X_1 + \beta_2X_2 + \beta_3X_3 + \beta_4X_4 + e\}$, where P represents the probability of using hospice during the last year of life, X_1 represents a set of predisposing factors (age, gender, race, education), X_2 represents a set of enabling factors (urban/rural residence, short-term nursing home

status), X_3 represents a set of need factors (cancer, dementia), XZ_4 represents interaction terms (non-Hispanic Black race/ethnicity*being married; non-Hispanic Black race/ethnicity*cancer) while e represents an error term. The model was tested by entering each set of individual determinant in sequence. Each variable within predisposing, enabling and need factors was assessed for main effect on hospice use first, and then, for potential interaction effects of marital status, and cancer diagnosis on hospice use. The multivariate analysis result revealed no meaningful (odds ratio of 1.01) effect of education on the likelihood of hospice use while non-Hispanic Black race/ethnicity (odds ratio of 0.77), being married (odds ratio of 1.16) and cancer (odds ratio of 3.2) had meaningful direct effects on hospice use after controlling for other factors. Thus, only two interaction effect models were tested in the final model: interaction between non-Hispanic Black race/ethnicity and being married and interaction between non-Hispanic Black race/ethnicity and cancer as a cause of death.

For multivariate analysis results, upper and lower confidence intervals are provided, and results are not interpreted if confidence intervals cross or include 1.0. However, confidence intervals should not be interpreted for the purpose of significance testing since this study is based on a population of dual-eligible nursing home residents in Florida. Model fit statistics are presented in the $-2\log$ likelihood, the adjusted R^2 , the receiver operating curve (roc) statistic and the Hosmer-Lemeshow test for model fit. The same analysis was repeated to identify predictors of hospice use for each racial/ethnic group excluding race/ethnicity variable.

Research Question 2

The main goal of this analysis was to examine the relative risk of predictor variables in predicting the timing of the hospice enrollment among all hospice users with the focus on the role of race/ethnicity. As a choice of multivariate analysis method, a Cox proportional-hazards model was performed to assess the multiple factors determining survival from hospice enrollment until death in days. In a sequential Cox regression, covariates enter the equation in an order specified by the researcher (Tabachnik & Fidell, 2001). In this analysis, the same assumptions were made regarding the order of entering predisposing, enabling and need factors since the literature does not suggest otherwise. The assumptions regarding normality distribution, proportionality of hazards, and multicollinearity were assessed by examining the interactions between each variable and the natural logarithm of the time variable. No violation of these assumptions was found. Also, no censoring was involved since all individuals by definition of the population experienced death within 12 months of time period.

The association between a variable and length of stay in hospice was assessed by examining the odds ratios (or hazard ratio or risk ratio) indicated as in Exp (B). An odds ratio greater than unity is associated with a higher risk of death and therefore represents a shorter survival time after hospice enrollment, which is interpreted as shorter length of stay. Upper and lower confidence intervals are provided. The significant change as a result of entering additional sets of factors (predisposing, enabling, and need) was assessed by examining the Wald test and the likelihood ratio test. The inverse was tried to reduce severe positive skewness of the survival time. However, the transformation of the dependent variable did not change the outcome of the Cox regression survival analysis, and thus, the results are based on the model with the untransformed dependent

variable. The model fit did not improve by sequentially entering predisposing, enabling and need factors and the overall model fit was poor: -2 log likelihood of the model fit without covariate was 134313 while -2 log likelihood of the model fit with covariate was 134285. Thus, only the final model is presented for the overall nursing home hospice population and for each racial/ethnic group.

Research Question 3

The main goal of a series of analyses for Research Question 3 was to determine the unique effect of hospice use on hospital death after controlling for other potential covariates. The choice of multivariate analysis method for examining the effects of multiple factors on hospital death was a sequential binomial (or binary) logistic regression since the dependent variable is dichotomous (1=hospital death, 0=no hospital death) (Tabachnick & Fidell, 2001). The model described took the form of: $\{\log(P/1-P) = \alpha + \beta_1X_1 + \beta_2X_2 + \beta_3X_3 + \beta_4X_4 + \beta_5XZ_5 - e\}$, where P represents the probability of hospital death, X_1 represents a set of predisposing factors (age, gender, race, education), X_2 represents a set of enabling factors (urban/rural residence, short-term nursing home status), X_3 represents a set of need factors (cancer, dementia), X_4 represents hospice use, and XZ_5 represents the interaction term for non-Hispanic Black race/ethnicity and age on hospital death while e represents an error term. The model was tested by entering each set of individual determinant in sequence. Each variable within predisposing, enabling and need factors were assessed for main effect on hospital death and hospice use was entered in the final model to examine the effect of hospice on reducing hospital death after controlling for other covariates. As the direct effect of age on in-hospital death was

not found, interaction effect of race/ethnicity and age on hospital death was not entered in the final model.

For multivariate analysis results, upper and lower confidence intervals are provided. Model fit statistics are presented in the $-2\log$ likelihood, the adjusted R^2 , the receiver operating curve (roc) statistic and the Hosmer-Lemeshow test for model fit. The same analysis was repeated to identify predictors of hospice use for each racial/ethnic group excluding race/ethnicity variable.

Chapter Three: Findings

Population Characteristics

The dual-eligible nursing home residents in this study (n=30,765) were on average 86 years old, female (73 percent), non-Hispanic White (85 percent), not married (82 percent), residing in a urban area, a long-term nursing home residents (74 percent) and had 11 years of formal education (Table 3). About five percent of the nursing home residents died of cancer while 37 percent and 15 percent died of heart disease and or some form of dementia respectively. The most common place of death was nursing home (69 percent) followed by hospital (27 percent) and home (1.5 percent). Twenty eight percent of nursing home residents used any hospice service and of those who used hospice, the average days between the date of enrollment and the date of death was 53 days. For those who used hospice, the average length of stay was 48 days while the median length of stay was 21 days (data not shown).

Hospice nursing home residents, compared with non-hospice residents, were more likely to be female (74 percent vs. 72 percent), married (19 percent vs. 18 percent), living in an urban area (90 percent vs. 86 percent), to have died of cancer (10 percent vs. 4 percent) and dementia or Alzheimer's disease (20 percent vs. 13 percent), and to die in a nursing home (93 percent vs. 60 percent) compared with non-hospice nursing home residents. Non-hospice nursing home residents, compared with hospice residents, were more likely to be non-Hispanic Black (16 percent vs. 11 percent) and short-term nursing

Table 3. Nursing Home Residents Aged 65 and Older by Hospice Use, Race/Ethnicity, and Nursing Home Status (N=30,765)

	All	Hospice	Non-Hospice	Non-Hispanic White Number (%) or Mean ± SD	Non-Hispanic Black	LTNH ¹	STNH ²
PREDISPOSING							
Age	85.9±8	86±8	85.8±8	86.3±7.9	83.7±8.9	86.5±8	84±8
Gender: Female	73	74	72	72.6	73.9	74	69
Education	10.8±2.9	11±2.8	10.7±2.9	11.1±2.7	9±3.3	11±3	11±3
Race: Non-Hispanic Black	14.6	11.3	15.9	0	100	13	21
ENABLING							
Marital status: Married	18.1	19.4	17.7	18.5	16.2	18	18
Area of Residence Urban	87.3	89.5	86	87	88	88	88
STNH ²	25.9	8	32.8	24.1	36.6	0	100
NEED							
Cause of Death							
Cancer	5.4	9.6	3.9	5.1	7.7	5	6
Heart	36.7	32.9	38.2	37	37	37	37
Dementia	14.9	20.3	12.9	16	8.4	16	11
DEPENDENT VARIABLES							
Any Hospice use	27.7	100	0	28.8	21.4		
Time from hospice enrollment until death	53±68	53±68	0	53±68	51±67	51±66	78±101
Place of death							
Hospital	26.9	3.6	35.8	24.4	41.7	22	41
Nursing home	69	93	60	71.4	55.5	74	54
Home	1.5	1.8	1.4	1.6	1.3	1.4	2

Note: ¹ LTNH: Long-term nursing home. ² STNH: Short-term nursing home.

home resident (33 percent vs. 8 percent), to die of heart disease (38 percent vs. 33 percent), and to die in a hospital (36 percent vs. 4 percent). Compared with non-Hispanic White nursing home residents, non-Hispanic Black nursing home residents were likely to be younger (84 years old vs. 86 years old) and have lower level of education (9 years vs. 11 years). Non-Hispanic Black nursing home residents were also less likely to be married (16 percent vs. 19 percent), to die of dementia or Alzheimer's disease (8 percent vs. 16 percent), and use hospice. They were more likely to be short-term nursing home resident, to die of cancer (8 percent vs. 5 percent) and to die in a hospital (42 percent vs. 24 percent). Mean length of stay in hospice was somewhat shorter for non-Hispanic Black nursing home residents compared with non-Hispanic White (45 days vs. 47 days) nursing home residents, although the variance was quite large compared to the magnitude of difference.

Length of stay in facility yielded generally expectable results. Long-term nursing home residents were likely to be older (87 years vs. 84 years), female (74 percent vs. 69 percent), to die of dementia/Alzheimer's disease (16 percent vs. 11 percent) and to die in a nursing home (74 percent vs. 54 percent).

Major Findings

The major findings for each of three research questions are presented next.

Research question 1. Do major predisposing, need, and enabling factors have significant associations with hospice use in the last year of life among dual-eligible nursing home residents?

The first step of the sequential binomial logistic regression model was to enter four predisposing characteristics (i.e., age, gender, race/ethnicity, education). The second

step included three characteristics (i.e., marital status, urban/rural status of residence, nursing home status) which were followed by third step of entering two major causes of death: cancer and dementia/Alzheimer's disease. The final step was to enter the interaction terms between race/ethnicity and marital status and race/ethnicity and cancer as a cause of death. All steps for the overall nursing home population are displayed in Table 4. All steps of analysis were repeated for each racial/ethnic group and displayed in Table 5 for the non-Hispanic White group and Table 6 for the non-Hispanic Black group. The race/ethnicity variable, however, was excluded from entering into the model for within-group analysis.

For the nursing home population (Table 4), there was a good model fit based on improved chi-square statistic for the $-2\log$ likelihood parameters which were significant ($p \leq .001$) at each step. In addition, the Hosmer and Lemeshow goodness-of-fit test was not significant at each step, so the null hypothesis (that there is a better model than this one) was rejected. Finally, adjusted R^2 of the final model was 0.14. The odds ratio provides the relative likelihood that a characteristic contributes to a nursing home resident receiving hospice care. Odds ratios that are greater than one suggest that the characteristics increases the likelihood of receiving hospice care while odds ratios that are less than one suggests that the characteristic decreases the likelihood of receiving hospice care. Where confidence intervals cross or include 1.0, results are considered to be of low magnitude and are not interpreted.

When just predisposing characteristics were entered (Model 1 in the Table 4), being non-Hispanic Black was negatively associated with hospice use. Non-Hispanic Blacks were 29 percent less likely to use hospice after controlling for other predisposing

factors. Age, gender, and education had limited effects on the likelihood of hospice use, odds ratio of 1.01, 1.07, and 1.02 respectively.

When predisposing and enabling factors were entered together (Model 2 in the Table 4), short-term nursing home residents were 82 percent less likely to use hospice, while being married and resident of urban areas increased the likelihood of receiving hospice by 15 percent and 34 percent respectively. After controlling for these predisposing and enabling factors, non-Hispanic Black nursing home residents were still 20 percent less likely to use hospice.

When cancer and dementia/Alzheimer's disease were entered in the third step (Model 3 in the Table 4) along with predisposing and enabling characteristics, having died from cancer increased the likelihood of using hospice more than threefold and dementia/Alzheimer's disease as a cause of death increased the likelihood by 69 percent. The relative likelihood of using hospice among non-Hispanic Black remained the same (odds ratio of .80) in the third model.

The final model (Model 4 in the Table 4) revealed a relatively strong interaction effect of race/ethnicity and cancer as a cause of death on hospice use (odds ratio of 1.35). However, the interaction effect between race/ethnicity and marital status was found to be relatively small (odds ratio of .97). The regression line for non-Hispanic Black and non-Hispanic White nursing home residents with cancer and non-cancer causes of death was calculated and is displayed in Figure 2. Non-Hispanic Black nursing home residents were less likely than White residents to use hospice if they had a non-cancer cause of death but non-Hispanic Black nursing home resident with cancer as a cause of death were

Table 4. Multiple Logistic Regression Models Predicting Hospice Use by Race/Ethnicity (N=30,765)

	Model 1		Model 2		Model 3		Model 4	
	Odds Ratio (95% Confidence Interval)							
PREDISPOSING								
Age	1.01	(1.00-1.01)	0.99	(0.99-1.00)	0.99	(1.00-1.00)	0.99	(1.00-1.00)
Gender: Female	1.07	(1.00-1.13)	1.08	(1.02-1.16)	1.09	(1.02-1.16)	1.09	(1.02-1.16)
Race: Non-Hispanic Black	0.71	(0.66-0.77)	0.80	(0.74-0.87)	0.80	(0.73-0.86)	0.80	(0.65-0.98)
Education	1.02	(1.01-1.03)	1.02	(1.01-1.02)	1.01	(1.00-1.02)	1.01	(1.00-1.02)
ENABLING								
Marital status: Married			1.15	(1.06-1.23)	1.16	(1.07-1.25)	1.16	(1.07-1.25)
Area of Residence Urban			1.34	(1.23-1.46)	1.36	(1.25-1.48)	1.36	(1.25-1.48)
Short-Term Nursing Home Resident			0.18	(0.17-0.20)	0.18	(0.17-0.20)	0.18	(0.16-0.20)
NEED								
Cause of Death								
Cancer					3.4	(3.07-3.8)	3.01	(2.65-3.42)
Dementia					1.69	(1.56-1.81)	1.69	(1.56-1.81)
INTERACTION								
NHBlack * Marital Status - Married							0.97	(0.78-1.21)
NHBlack*Cancer							1.35	(1.03-1.77)
-2 log likelihood		36183		33891		33246		33241
Hosmer and Lemeshow		0.24		0.13		0.37		0.55
Max-rescaled R-square		0.01		0.11		0.14		0.14
c		0.54		0.65		0.68		0.68

as likely as non-Hispanic White nursing home residents to use hospice. The race effect remained the same at this step.

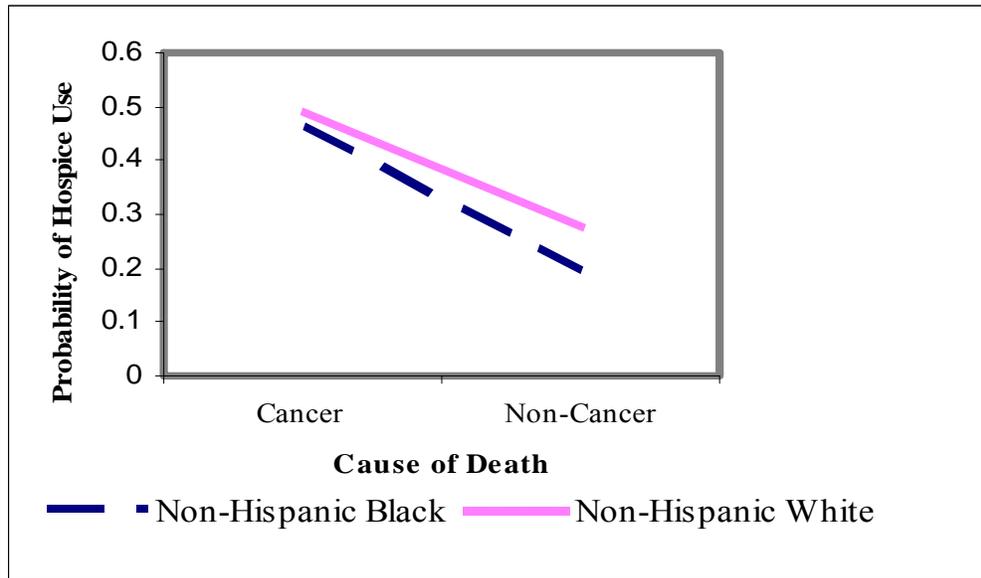


Figure 2. Interaction Effect of Race/Ethnicity on Cause of Death – Cancer with Hospice Use

The results of sequential binomial logistic regression model for the non-Hispanic White and non-Hispanic Black groups are found in Table 5 and Table 6. For non-Hispanic White nursing home residents, female gender, being married, and two causes of death – cancer and dementia increased the likelihood of receiving hospice care while short-term nursing home status decreased the likelihood of hospice use. However, only short-term nursing home status and two causes of death, cancer and dementia, predicted the likelihood of hospice use among non-Hispanic Black nursing home residents (all three results with the same direction). Specifically, urban location of residence led to greater likelihood of using hospice for non-Hispanic Whites (odds ratios of 1.39 vs. 1.01)

Table 5. Multiple Logistic Regression Models Predicting Hospice Use For Non-Hispanic Whites (n=26,271)

	Model 1		Model 2		Model 3	
	Odds Ratio (95% Confidence Interval)					
PREDISPOSING						
Age	1	(1.00-1.01)	1	(0.99-1.00)	1	(0.99-1.00)
Gender: Female	1.07	(1.00-1.14)	1.09	(1.01-1.16)	1.08	(1.01-1.16)
Education	1.02	(1.01-1.03)	1.01	(1.00-1.02)	1.01	(1.00-1.02)
ENABLING						
Marital status: Married			1.16	(1.08-1.26)	1.15	(1.07-1.25)
Area of Residence Urban			1.39	(1.28-1.53)	1.4	(1.29-1.55)
Short-Term Nursing Home Resident			0.18	(0.17-0.20)	0.18	(0.17-0.20)
NEED						
Cause of Death						
Cancer					3.21	(2.85-3.62)
Dementia					1.67	(1.56-1.80)
	-2 log likelihood	31516		29578		29076
	Hosmer and Lemeshow	0.05		0.85		0.57
	Max-rescaled R-square	0.00		0.10		0.13
	c	0.52		0.64		0.67

Table 6. Multiple Logistic Regression Models Predicting Hospice For non-Hispanic Blacks (n=4,494)

	Model 1		Model 2		Model 3	
	Odds Ratio (95% Confidence Interval)					
PREDISPOSING						
Age	1	(0.99-1.01)	1	(0.99-1.01)	1	(0.99-1.01)
Gender: Female	1.08	(0.92-1.26)	1.08	(0.92-1.26)	1.17	(0.98-1.40)
Education	0.99	(0.98-1.02)	0.99	(0.98-1.02)	0.99	(0.97-1.02)
ENABLING						
Marital status: Married			1.12	(0.91-1.39)	1.17	(0.94-1.46)
Area of Residence Urban			1.01	(0.80-1.27)	1.06	(0.83-1.33)
Short-Term Nursing Home Resident			0.18	(0.15-0.22)	0.18	(0.14-0.22)
NEED						
Cause of Death						
Cancer					4.41	(3.44-5.64)
Dementia					1.82	(1.43-2.33)
-2 log likelihood		4662		4304		4157
Hosmer and Lemeshow		0.09		0.61		0.99
Max-rescaled R-square		0.00		0.12		0.17
c		0.52		0.67		0.71

compared with non-Hispanic Blacks. The two causes of death studied, cancer and dementia/ Alzheimer's disease, had greater association with the likelihood of hospice use (odds ratio of 4.41 and 1.82 vs. 3.21 and 1.7) within the non-Hispanic Black group than non-Hispanic White group.

Research question 2. Do major predisposing, need, and enabling factors have significant associations with length of stay in hospice in the last year of life among dual-eligible nursing home residents?

The multivariate analysis result of the full model for the overall hospice user population, the non-Hispanic White, and non-Hispanic Black groups (Table 7) suggests that the covariates (i.e., predisposing, enabling and need factors) included in the model do not explain the model very well. The factors that significantly increased the probability of survival time were female gender (hazard ratio, .93) and urban area of residence (hazard ratio, .92) while stroke (hazard ratio, 1.09) reduced the probability of survival time. The poor model fit and the small number of factors significant affect the probability of survival time suggest that the survival time might be influenced by external factors other than covariates examined in this study. Some differential effects of covariates within each group included increased probability of survival time associated with female gender for non-Hispanic Blacks and stroke as a cause of death associated with decreased probability of survival time for non-Hispanic Whites. Nonetheless, poor model fit and low explanatory power of all three full models suggest that external factors other than covariates entered in this group of nursing home population may explain the timing of hospice enrollment.

Table 7. Cox Regression Model to Examine the Days of Hospice Length of Stay

	All		Non-Hispanic White		Non-Hispanic Black	
	Hazard Ratio	<i>P</i> -value	Hazard Ratio	<i>P</i> -value	Hazard Ratio	<i>P</i> -value
PREDISPOSING						
Age	1.00	0.27	1.00	0.75	1.01	0.07
Gender: Female	0.93	0.007	0.95	0.05	0.84	0.02
Race: Non-Hispanic Black	1.00	0.94	N/A	N/A	N/A	N/A
Education	1.00	0.21	0.99	0.14	1.00	0.64
ENABLING						
Marital status: Married	0.99	0.80	0.99	0.88	1.04	0.87
Area of Residence Urban	0.92	0.03	0.94	0.08	0.88	0.14
Short-Term Nursing Home Resident	1.03	0.42	1.03	0.59	1.10	0.35
NEED						
Cause of Death						
Cancer	0.97	0.43	0.93	0.25	0.94	0.96
Heart	1.02	0.51	1.02	0.24	0.81	0.14
CHF or COPD	0.94	0.83	0.96	0.88	0.68	0.09
Stroke	1.09	0.01	1.10	0.02	0.96	0.64
Dementia/Alzheimer's Disease/Senility	0.96	0.96	0.97	0.99	0.82	0.84
	-2 log likelihood					

Research question 3. Does hospice use reduce hospital death after controlling for covariates?

For the overall nursing home resident population (Table 8), when predisposing factors were entered, a one unit increase of age and education led nursing home residents to be 4 percent and 2 percent less likely to die in a hospital. Similarly, a female nursing home resident was 9 percent less likely to die in a hospital. At the same time, a non-Hispanic Black nursing home resident was 96 percent more likely to experience in-hospital death.

When enabling factors were entered along with predisposing factors, being married and residing in an urban area was negatively associated with the likelihood of in-hospital death. The odds ratios were 0.89 and 0.88, respectively. On the other hand, short-term nursing home residents were twice as likely as to experience in-hospital death. As shown in the Model 3 of the Table 8, those who died of cancer and dementia/Alzheimer's disease were 62 percent and 66 percent less likely to die in a hospital. Hospice use, which was entered in the final, substantially reduced the likelihood of in-hospital death (after controlling for all other factors) with an odds ratio of 0.08: nursing home residents who used hospice were 92 percent less likely to die in a hospital. At the same time, the relative influence of urban location of residence, short-term nursing home status, and cancer and dementia/Alzheimer's disease as causes of death were reduced. After controlling for all other predisposing, enabling and need factors and hospice use, non-Hispanic Black race/ethnicity was still strongly and positively associated with in-hospital death (odds ratio of 1.76) which suggests that despite the powerful effect of hospice

preventing hospitalization and subsequent in-hospital death, non-Hispanic Blacks were more likely to die in a hospital.

Within-group analyses of non-Hispanic White and non-Hispanic Black groups (Table 9, Table 10) found that variables such as gender, marital status, urban location of residence, dementia/Alzheimer's disease as a cause of death and use of hospice have differential effects on the likelihood of in-hospital death within the two racial/ethnic groups. Comparing the results of the final model from each racial/ethnic group suggests that female non-Hispanic Whites are 11 percent less likely to experience in-hospital death while the effect of gender appears to be minimal in Blacks. Dying from dementia/Alzheimer's disease reduces the likelihood of in-hospital death by 63 percent in Whites while it reduces the likelihood by 57 percent among non-Hispanic Blacks. Lastly, hospice appears to have a stronger influence among non-Hispanic Whites (odds ratio of 0.07) than non-Hispanic Blacks (odds ratio of 0.10). Of note is that hospice use has similar effects in reducing the likelihood of hospital death across race/ethnicity.

Table 8. Multiple Logistic Regression Models Predicting Hospital Death by Race/Ethnicity and Hospice Use

	Model 1		Model 2		Model 3		Model 4	
	Odds Ratio (95% Confidence Interval)							
PREDISPOSING								
Age	0.96	(0.96-0.97)	0.96	(0.96-0.97)	0.96	(0.96-0.97)	0.96	(0.96-0.97)
Gender: Female	0.91	(0.86-0.96)	0.9	(0.84-0.95)	0.9	(0.84-0.95)	0.9	(0.84-0.95)
Race: Non-Hispanic Black	1.96	(1.82-2.10)	1.84	(1.71-1.97)	1.81	(1.68-1.94)	1.80	(1.67-1.94)
Education	0.98	(0.92-0.99)	0.99	(0.98-0.99)	0.99	(0.98-1.00)	0.99	(0.98-1.00)
ENABLING								
Marital status: Married			0.89	(0.82-0.95)	0.9	(0.84-0.97)	0.94	(0.87-1.01)
Area of Residence Urban			0.88	(0.82-0.95)	0.88	(0.81-0.95)	0.94	(0.87-1.2)
Short-Term Nursing Home Resident			2.13	(2.02-2.26)	2.08	(1.97-2.20)	1.44	(1.36-1.53)
NEED								
Cause of Death								
Cancer					0.38	(0.34-0.44)	0.57	(0.49-0.66)
Dementia					0.34	(0.31-0.38)	0.38	(0.34-0.42)
							0.08	(0.07-0.08)
HOSPICE								
-2 log likelihood		34699		33982		33228		30000
Hosmer and Lemeshow		0.16		0.02		0.37		0.03
Max-rescaled R-square		0.05		0.08		0.12		0.25
c		0.62		0.65		0.682		0.76

Table 9. Multiple Logistic Regression Models Predicting Hospital Death for Non-Hispanic Whites

	Model 1		Model 2		Model 3		Model 4	
	Odds Ratio (95% Confidence Interval)							
PREDISPOSING								
Age	0.96	(0.96-0.97)	0.96	(0.96-0.97)	0.97	(0.96-0.97)	0.96	(0.96-0.97)
Gender: Female	0.87	(0.84-0.95)	0.89	(0.81-0.93)	0.88	(0.82-0.94)	0.89	(0.83-0.95)
Education	0.98	(0.97-0.99)	0.98	(0.97-0.99)	0.99	(0.98-1.00)	0.99	(0.98-1.00)
ENABLING								
Marital status: Married			0.85	(0.79-0.92)	0.87	(0.80-0.95)	0.9	(0.83-0.99)
Area of Residence Urban			0.84	(0.77-0.91)	0.83	(0.76-0.90)	0.9	(0.82-0.98)
Short-Term Nursing Home Resident			2.16	(2.03-2.29)	2.09	(1.97-2.23)	1.45	(1.35-1.54)
NEED								
Cause of Death								
Cancer					0.39	(0.33-0.46)	0.57	(0.48-0.67)
Dementia					0.34	(0.30-0.37)	0.37	(0.33-0.41)
HOSPICE								
-2 log likelihood		28653		28050		27409		24686
Hosmer and Lemeshow		0.2832		0.643		0.668		0.39
Max-rescaled R-square		0.03		0.06		0.10		0.23
c		0.592		0.64		0.09		0.754

Table 10. Multiple Logistic Regression Models Predicting Hospital Death For non-Hispanic Blacks

	Model 1		Model 2		Model 3		Model 4	
	Odds Ratio (95% Confidence Interval)							
PREDISPOSING								
Age	0.97	(0.97-0.98)	0.97	(0.97-0.98)	0.97	(0.97-0.98)	0.97	(0.97-0.98)
Gender: Female	0.96	(0.84-1.09)	0.96	(0.86-1.12)	0.96	(0.83-1.10)	0.99	(0.86-1.15)
Education	1.00	(0.98-1.02)	1.00	(0.98-1.02)	1.00	(0.98-1.02)	1.00	(0.98-1.02)
ENABLING								
Marital status: Married			1.05	(0.88-1.25)	1.04	(0.87-1.24)	1.09	(0.91-1.32)
Area of Residence Urban			1.19	(0.98-1.44)	1.18	(0.97-1.44)	1.22	(0.99-1.50)
Short-Term Nursing Home Resident			2.03	(1.79-2.30)	2	(1.76-2.27)	1.42	(1.24-1.62)
NEED								
Cause of Death								
Cancer					0.38	(0.29-0.49)	0.57	(0.43-0.75)
Dementia					0.4	(0.31-0.51)	0.43	(0.33-0.56)
HOSPICE								
							0.10	(0.08-0.13)
-2 log likelihood		6033		5905		5794		5288
Hosmer and Lemeshow		0.53		0.06		0.34		0.84
Max-rescaled R-square		0.02		0.06		0.09		0.22
c		0.57		0.62		0.65		0.72

Chapter Four: Discussion and Conclusions

Identifying and reducing barriers to quality end-of-life care among diverse older adults has become an increasingly important area of research. The findings from this study provide implications for theory, research, practice and policy in regard to improving access to and outcomes of hospice services for frail nursing home residents at the end of life. These findings and implications are addressed in terms of: (a) the utility of the behavioral model of health services use (Andersen, 1995); (b) racial/ethnic differences in utilization of hospice services; (c) the limited contribution of individual characteristics to length of stay in hospice; and (d) the role of race/ethnicity and hospice in in-hospital death.

The Behavioral Model of Health Services Use

The first question raised by this research was aimed at identifying characteristics that facilitate hospice use among dual-eligible nursing home residents. Analyses were guided by the behavioral model of health services use (Andersen, 1995). The behavioral model of health services use successfully predicted group membership in hospice use. With each sequential step of the model, the model fit improved compared to the Intercept only and all improvements were significant. In the full model, seven variables - female gender, non-Hispanic White race/ethnicity, being married, urban area of residence, and cancer and dementia/Alzheimer's disease as causes of death – predicted increased hospice use.

Although it was hypothesized that older age and higher level of education would be associated with the increased likelihood of hospice use, this study did not find any meaningful effects of these two predisposing characteristics. At the same time, as predicted, race/ethnicity was the prevailing predisposing characteristic contributing to the model. Non-Hispanic Black nursing home residents were 20 percent less likely to use hospice after controlling for all other factors. This finding is discussed further with findings on within-group differences later in this chapter.

All three enabling factors tested in this study affected the likelihood of hospice use. Married and urban nursing home residents were more likely to use hospice by 16 percent and 36 percent, respectively, whereas short-term nursing home residents were 82 percent less likely to use hospice. The role of marital status is of particular note since, while it is consistent with the behavioral model followed in this research, the relationship has not been found in other research. Two studies (Chen et al., 2003; Enguidanos et al., 2005) found no significant effect of marital status while a study by Greiner and colleagues (2003) found that being never married significantly increased the likelihood of receiving hospice while being widowed significantly reduced the chance of receiving hospice.

One of the reasons for the discrepancy in findings for marital status may lie in the unique nature of the population under study. Dual-eligible individuals, who are in fact eligible for both Medicare and Medicaid benefits, have generally not received much attention in past research. The study population of the study by Enguidanos and colleagues (2005) resemble the characteristics of the population of the present study the most, as Enguidanos and colleagues examined hospice use among dual-eligible decedents

in California. However, this dissertation examined the experiences among nursing home residents while the study by Enguidanos and colleagues included both community-dwelling and nursing home residents. It is possible that the decision to use hospice is influenced by preferences and influence of spouses of nursing home residents in the current study. However, information on spouses of nursing home residents is not available from the data sources used for this study.

The finding that urban residents were more likely to use hospice is consistent with previous research findings that the availability of hospice in rural areas is more limited than in urban areas and the rate of hospice use is correspondingly lower among rural decedents (Virnig, Moscovice, Kind, & Casey, 2002). Although Florida serves a higher percentage of terminally ill patients than most of other states (Miller and Lima, 2004), it may be that hospice services remain less available in rural areas than in urban areas and nursing home residents in rural area still experience access barriers to hospice care.

As predicted, short-term nursing home residents in this study were less likely to use hospice. Short-term nursing home residents in this study were different from long-term nursing home residents. Short-term nursing home residents were, on average, younger, more likely to be males, and more likely to be non-Hispanic Blacks. Short-term nursing home residents may be a unique sub-group of nursing home residents who enter nursing home with different demographic characteristics under different circumstance from long-term nursing home residents. It is also possible that short-term nursing home residents were more likely to be receiving Medicare skilled nursing benefit which does not allow simultaneous enrollment in hospice. Further examination of end-of-life experiences of short-term nursing home residents, particularly on their experience in

transitions in and out of health and long-term care institutions will help us to better understand end-of-life experiences of this unique sub-population of nursing home residents. Better understanding of the factors that facilitate and prevent short-term nursing home residents from hospice use will help identify barriers to hospice care and develop policy initiatives such as reimbursement policy to reduce such barriers that may exist at individual and health care facility levels.

As previous research testing the behavioral model of health services use has shown, the primary need factor used in this study, cause of death, was the strongest predictor of hospice use. Nursing home residents dying from cancer were three times more likely to use hospice than those who died of illnesses other than cancer. Another unexpected need factor found in this study was dementia/Alzheimer's disease as a cause of death leading to increase in the likelihood of using hospice by 69 percent. It is not clear as to why dementia/Alzheimer's disease as a cause of death would predict higher likelihood of hospice use compared to non-dementia causes of death, since historically dementia patients have vastly underutilized hospice care (Christakis & Escarce, 2001).

However, Florida is a state with the highest proportion of dying older adults receiving hospice care, 35 percent. It also has a high proportion of non-cancer hospice patients (60 percent), second only to Arizona (Miller & Lima, 2004). In addition, a higher proportion of nursing home residents is served by hospice providers in Florida than in 44 of the 48 states studied by Miller and colleagues (Miller & Lima, 2004). Given a high level of penetration of hospice service providers in the state of Florida and that a significant proportion of nursing home residents have dementia or other cognitive impairment, it is possible that nursing home residents with dementia/Alzheimer's disease

are more likely to be identified as appropriate candidates for hospice care than those with illnesses other than cancer or dementia/Alzheimer's disease. In addition, the guidelines for determining 6-month prognosis, originally developed by National Hospice and Palliative Care Organization and subsequently adopted by Medicare, includes guidelines for not only cancer diagnoses but also dementia diagnoses. Such guidelines for dementia patients may have made it easier for nursing home care providers, physicians and hospice providers to identify and refer and enroll nursing home residents with dementia into a hospice program.

This finding is encouraging given that hospice services have historically been utilized primarily by terminally ill patients with a cancer diagnosis. Although recent data from NHPCO reports that an increasing number of patients with non-cancer diagnoses receive hospice care, cancer patients still made up 46 percent of all hospice patient population in 2004 (NHPCO, 2005), while cancer causes 23 percent of deaths in the U.S. (Anderson & Smith, 2005). Further examination of how the decision of hospice enrollment is made among nursing home residents with different clinical characteristics at individual, family, nursing home provider, physician, and hospice provider levels will improve our understanding of the effects of principal illness.

Racial/Ethnic Differences in Utilization of Hospice Services

This study found a significantly lower level of hospice utilization rate in non-Hispanic Black as compared to non-Hispanic White nursing home residents, even after controlling for other factors. This finding is consistent with previous research. The explanation for this finding may be twofold.

First, the racial/ethnic difference in hospice utilization may reflect cultural differences in preferences for end-of-life care between the two groups as race/ethnicity was viewed as a proxy for culture in this study. The literature suggests that non-Hispanic Blacks are less likely to use hospice due to different sociodemographic characteristics and their unique historical and cultural experiences in the medical system. However, the fact that non-Hispanic Black nursing home residents were less likely to use hospice even among dual-eligible nursing home residents (with low income and poorer health) after controlling for the level of education suggests that the racial/ethnic difference found in this study is not likely to be a result of differential socioeconomic status of the two groups. Furthermore, this study excluded from the study White and Black nursing home residents who were identified as Hispanic. Thus, the unique historical and cultural experiences of non-Hispanic Blacks may attribute, at least partially, to the differential rates of hospice use.

A second reason for racial/ethnic difference may be the potential effect of residential segregation reported in the nursing home literature. A recent national study of nursing homes (Mor, Zinn, Angelelli, Teno, & Miller, 2004) found that Black nursing home residents were significantly overrepresented in poor-quality nursing home facilities measured by quality of care indicators including staffing and pain control. It is conceivable that poor-quality nursing facilities are less likely to facilitate residents' use of hospice care. Poor-quality nursing facilities are more likely to experience the shortage of highly trained health care staff who can monitor the progress of the illness and functional decline of the residents and identify and refer residents for whom hospice care may be appropriate compared with high-quality nursing facilities.

Poor-quality facilities also may be less able to coordinate comprehensive end-of-life care with hospice providers for their dying nursing home residents. If a higher proportion of non-Hispanic Black residents in the current study were living in poor-quality facilities than non-Hispanic White residents, it is possible that non-Hispanic Black nursing home residents experienced an access barrier to hospice care due to the facility effect. However, the current study is limited to examining only individual level characteristics and hospice use due to the data limitations. Ideally, residents in poor quality facilities should be more likely to receive hospice care because poor-quality facilities are more likely to lack the capacity to provide quality pain control and symptom management on their own.

The results of the interaction effect of race/ethnicity and cancer as a cause of death with hospice use, and within-group analyses, also suggest unique differences in the role of predisposing, enabling and need factors in predicting hospice use. This study found that race/ethnicity moderates the strength of the effect of the illness on the likelihood of using hospice. Among residents who died of cancer, no difference in hospice use was found between the two racial/ethnic groups while hospice utilization rate was lower for non-Hispanic Blacks than non-Hispanic Whites among non-cancer residents. It may be that cultural differences in the perception of illness may exist between the two groups. As cancer has a relatively predictable illness trajectory compared to other illnesses, and is generally recognized to be a lethal illness, it is possible that there may not be a significant difference in accepting a prognosis of terminal cancer between the two groups and thus, cancer may not lead to differential use of hospice between the two groups. However, for other illnesses with less predictable

illness trajectories, non-Hispanic Blacks may be more likely to pursue curative treatments than hospice care.

Further analysis of predictors of hospice use within each group, an exploratory component of the study, found that marital status and urban/rural location of primary residence influenced the likelihood of using hospice. This was the case only for the non-Hispanic White group. In addition, the two causes of death studied, cancer and dementia/Alzheimer's disease, exerted a stronger influence on the likelihood of using hospice among non-Hispanic Blacks compared with non-Hispanic Whites. These findings may imply that the current behavioral model of health service use does a better job of predicting the likelihood of use of hospice for the non-Hispanic White group compared with non-Hispanic Black group. Incorporating psychosocial factors in the model may enhance the predictive function of the behavioral model of health services use model for non-Hispanic Black nursing home residents.

In sum, this study found that a significant racial/ethnic difference in hospice utilization exists among dual-eligible nursing home residents. Such differences may be due to cultural preferences for types of end-of-life care and treatment of each racial/ethnic group or other external factors such as facility effects. At the individual level, better understanding of the mechanisms by which race/ethnicity affects the decision-making process and access to hospice is needed. Race/ethnicity is only a proxy for culture. Further research is needed to better understand racial/ethnic differences by incorporating psychosocial measures in the theoretical model that examines the expectations and views regarding specific illnesses, coping methods, death and dying, and the role of health and long-term care providers. Moreover, examining the effects of

nursing home facility and hospice service provider will help better understand the broader, more complex process of access to and utilization of hospice among nursing home residents. Furthermore, nursing home and hospice staff may need to acknowledge racial/ethnic disparity in utilization of hospice and gain a better understanding of the historical and cultural differences among members of various racial/ethnic groups which may help them to develop effective strategies for nursing home community outreach and education.

Limited Contribution of Individual Characteristics to Length of Stay in Hospice

Another exploratory part of the overall study was the examination of the factors associated with length of stay in hospice among a sub-group of nursing home residents who used hospice. However, as the multivariate results shows, the behavioral model of health service did not fit well and explained little variance. There may be two potential explanations for this result. First, because of the limited accuracy of the current prognostic criteria and tools and the six month prognosis rule, physicians may prefer to err on the side of overestimating survival time. As a result, many, if not most, nursing home residents may not be referred to hospice until death is imminent. This is illustrated by the fact that the mean and median lengths of hospice stay among nursing home residents in the current study were 47 days and 21 days, respectively.

Second, it is also possible that factors other than individual characteristics may affect the length of stay in hospice. As a study of hospice survival time of Medicare beneficiaries (Christakis et al., 2000) reports, both nursing home and hospice provider level factors as well as health care market factors may affect the length of stay among nursing home residents. Further study of nursing home residents that include facility and

health care market level characteristics may improve the model fit and better explain the factors associated with hospice length of stay.

The Role of Race/Ethnicity and Hospice in Predicting In-Hospital Death

The third question explored in this study was to examine the effect of race/ethnicity and hospice use in determining place of death. This dissertation research found that hospice is a powerful predictor of place of death among nursing home residents. Ninety-three percent of nursing home residents who used hospice died in a nursing home compared with 60 percent of non-hospice nursing home residents dying in a nursing home. After controlling for other factors, hospice nursing home residents were 92 percent less likely to die in a hospital. At the same time, non-Hispanic Black residents were still 80 percent more likely to die in a hospital even after adjusting for the effect of hospice use and other variables.

The findings from the current study are partially consistent with the finding of a recent study of dual-eligible decedents from California (Enguidanos et al., 2005). Enguidanos and colleagues (2005) found that among dual-eligible decedents in California (including both community-dwelling and nursing home residents) hospice users were three times more likely to die at home. At the same time, Enguidanos and colleagues found that Blacks were significantly more likely to die at home although they were less likely to receive hospice care. However, different results between this current dissertation study and the study by Enguidanos et al. may be due to the fact that the study population of the current dissertation study only examines the experiences of nursing home residents in Florida. Moreover, the main outcome of the current study is in-hospital death while the main outcome of the study by Enguidanos and colleagues was

home death and thus, the findings cannot be directly compared with each other. Despite these differences, a similar conclusion to the study of Enguidanos and colleagues (2005) can be drawn: hospice significantly reduces in-hospital death. Nursing homes often represent the last “home” for older adults with substantial long-term care needs and hospice is effective in facilitating nursing home residents to die in place in this study population.

Summary

This dissertation research found racial/ethnic differences in utilization of hospice services among dual-eligible nursing home residents in Florida. The significantly lower hospice use among non-Hispanic Black nursing home residents in Florida, a state with high level of penetration and availability of hospice service providers, suggests that further outreach and education efforts are needed to increase communication and knowledge among nursing home residents, physicians and hospice providers about the hospice program. Decision making, access and utilization of health services at the end of life are complex processes which are influenced not only by individual characteristics, but also service provider and health care market characteristics. Better understanding of this process will be achieved by further examining not only predisposing, enabling and need factors but also psychosocial factors that influence the individual’s perceptions of illness and prognosis attitudes and beliefs about health care providers and system. Given the powerful effect of hospice reducing in in-hospital death and the competency and skills of hospice care professionals in providing quality end-of-life care, further efforts in reducing the gap in hospice utilization among minority nursing home residents through culturally sensitive strategies are needed.

Study Limitations

This dissertation study has several limitations. First, although individuals with any record of Medicaid claims in this study can be expected to represent the population of dual-eligible older adults who died in Florida during a certain time period, SFY 2000-2001, SFY 2001-2002, and SFY 2002-2003, it is also recognized that the study population may not accurately represent all dual-eligible older adults who received nursing home care. Not all dual-eligible older adults receive nursing home care reimbursed through the Medicaid program. It is possible that some minority of older adults in this group may have had their nursing home care paid by a private long-term insurance benefit or other private resources, although the dual eligible group is highly unlikely to have such resources available. These nursing home residents would not be captured in the data sources for this study. Although the majority of dual-eligible nursing home residents receive hospice care reimbursed by Medicare first and then by Medicaid for the room and board part of hospice care and this study specifically focuses on the dual-eligible nursing home population in Florida, there may be unknown number of dual-eligible nursing home residents who receive hospice care or nursing home care reimbursed by private sources such as long-term care insurance or private pay. The hospice utilization of these nursing home residents are not captured in this study.

Second, although one of the major objectives was to examine the role of race/ethnicity, this study does not have information on personal preferences for hospice service or individual orientation toward the self-identified race/ethnicity. Thus, the potential effects of cultural norms and individual psychosocial factors were not assessed in this study. Moreover, it should be recognized that there may be sub-ethnic groups

within each of the racial/ethnic groups studied. For example, there are various subgroups within non-Hispanic Whites such as Italian or Irish Americans who may have different cultural norms. In addition, the data set does not include any self-identification of race or ethnicity by the patient or their family, and relied on the so-called “race” variable in Medicaid administrative files. As shown by Chen, Chen and Mehra (2005), there is a possibility that up to 7 or 8 percent of the Medicaid enrollees could have been misclassified.

Third, certain types of nursing home residents may not have been captured in this study due to the methodology chosen for this study. To be considered as a long-term nursing home resident in this study, the decedent had to have a documented record of nursing home stay identified in the nursing home variable in the Medicaid Long-Term Care file during the last three consecutive months of life. If a recipient had a record of nursing home stay identified in that file during any of the last three consecutive months of life without meeting the above duration criterion, the person was considered as a short-term nursing home resident. However, there may be other long-term nursing home residents who were not categorized as long-term nursing home residents. For instance, as the hospitalization increases toward the end of life, some long-term nursing home residents (who may have spent most of their last year of life as nursing home residents) may experience hospitalization and may spend the last month of life and die in a hospital. Although these residents should be considered as long-term nursing home residents, they were captured as short-term nursing home residents in this study. Thus, the effects of the short-term nursing home status on the outcomes need to be interpreted with caution.

Fourth, there may be other potential factors affecting hospice use, timing of hospice initiation and place of death which are not included in this study. They include health care market factors, physician factors and organizational factors of hospice providers and nursing homes. The effects of these factors were not assessed in this study due to data limitations.

Lastly, the study population in this research is dual-eligible older adults in Florida. Findings from this study regarding factors associated with hospice use, timing of initial hospice enrollment, and the effects of hospice use on place of death may not be generalizable to the national population of dual-eligible older adults. Due to several unique characteristics of Florida such as the state's high level of hospice availability and high proportion of residential or inpatient beds of hospice organizations, the rate of hospice may be higher and barriers to access to hospice may be lower among dual-eligible older adults studied in this research compared to dual-eligible older adults in other states.

Future Directions

This study found racial/ethnic differences in both hospice use and in –hospital death among dually eligible nursing home residents in Florida. In order to better understand the effect of race/ethnicity on end-of-life experiences of older adults, additional study on this topic should be conducted utilizing Medicare and Medicaid claims and eligibility data and other facility level data such as On-Line Survey Certification And Reporting (OSCAR). These types of data sources will provide additional important information on factors that may influence end-of-life services

utilization experience of dual-eligible older adults. In addition, comparison of end-of-life experiences across different long-term care settings can be examined.

Addressing ethnic/racial diversity and disparity in end-of-life service utilization is an important and challenging task. Although review of the literature and findings from this dissertation study suggest clearly distinct patterns of services use by different racial/ethnic groups, the pathway by which the race/ethnicity influences services use is unclear. Incorporating psychosocial factors such as cultural norms and values regarding illness and dying, attitudes toward the health care system, and knowledge of the purpose and availability of hospice in addition to provider and organization factors affecting actual service use in the Andersen model will help identify mechanisms by which race/ethnicity influence the decision to use and actual use of hospice.

An increasing number of studies have found strong evidence for the effectiveness of hospice care in improving end-of-life care outcomes and the efficiency of simple, feasible interventions that can improve hospice referral among community-dwelling and nursing home residents. The doctoral dissertation research reported here finds a strong evidence for the efficacy of hospice in reducing in-hospital death among dually eligible nursing home residents in Florida. At the same time, the current study also found that racial/ethnic disparities in hospice use exist among nursing home residents. Given that these findings are based on a large sub-population of nursing home residents, further efforts should be made in developing and providing hospice education and communication interventions for nursing home residents of diverse cultural backgrounds. A recent randomized controlled study of nursing home residents (Casarett et al, 2005) shows that a simple educational and communication intervention can significantly

improve appropriate referral of nursing home residents to hospice care even among racially/ethnically diverse nursing home residents. Replicating such a simple intervention as an intervention used in the study by Casarett and colleagues (2005) with additional efforts in improving cultural sensitivity and awareness of nursing home and other medical staff may help end-of-life decision-making processes among nursing home residents and their families and health care staff. Casarett and colleagues (2005) found that at both the beginning and 6-month follow-up, hospice referral rates were significantly higher in the intervention group compared with the control group. In addition, this study did not find significantly different hospice enrollment rates between the two racial/ethnic groups. This finding suggests that when an effective communication and referral intervention is employed, racial/ethnic differences in hospice use among nursing home residents may be significantly reduced if not all differences may be reduced.

Ensuring that nursing home residents and their family members receive appropriate and timely information on all feasible and appropriate end-of-life care options will be a critical step toward improvement in theoretical understanding of racial/ethnic differences in end-of-life decision making and service utilizations. Identifying institutional barriers such as lack of information or knowledge of end-of-life care options such as hospice care will be an important task that is needed for better understanding the role of cultural norms and expectations in perceptions and decision making processes by older adults and their family members of diverse backgrounds at the end of life. With a better understanding of institutional and cultural factors influencing end-of-life care preferences and decision making processes, culturally sensitive and

effective interventions can be developed to reduce racial/ethnic disparities in end-of-life care access, utilization and outcomes among diverse older adults and their families.

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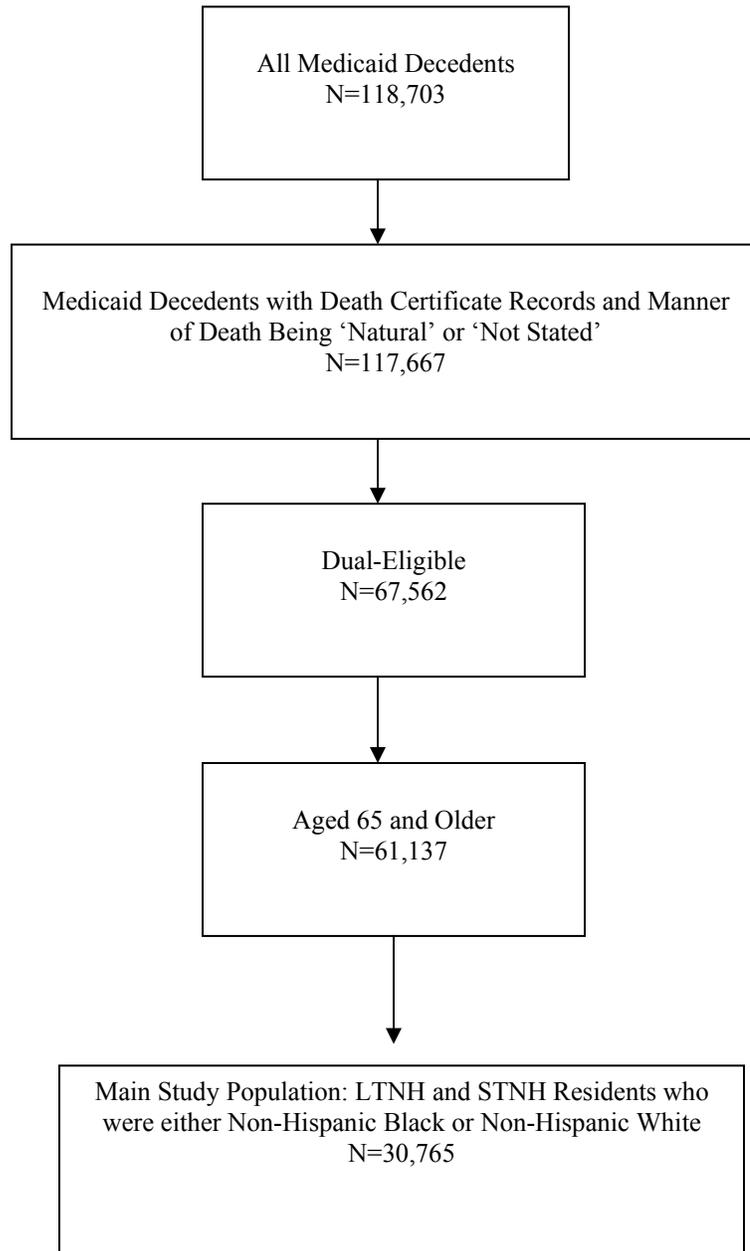
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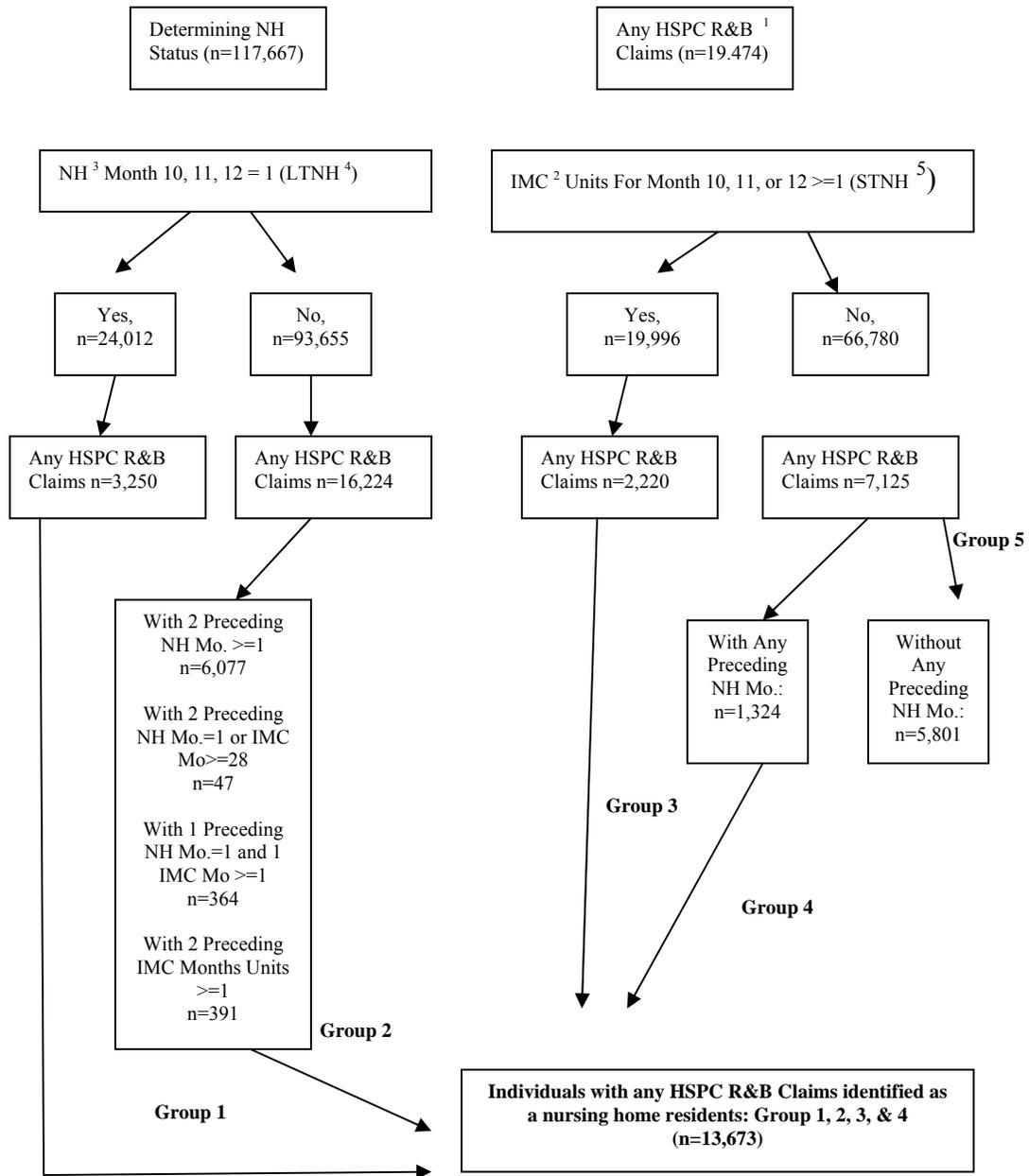
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Appendices

Appendix A: Flow Chart of the Study Population Selection



Appendix B: Determining Nursing Home Status



¹ HSPC R&B: Hospice Room & Board

² IMC : Intermediate Care Units Month variable

³ NH Month: Nursing Home Month variable

⁴ LTNH: Long-Term Nursing Home

⁵ STNH : Short-Term Nursing Home

About the Author

Jung Kwak received her Bachelor's of Science Degree in Business Administration from University of South Carolina in August of 1998 and Master of Social Work Degree from University of South Carolina in May of 2001. She entered the Ph.D. in Aging Studies program at the University of South Florida in the Fall of 2001. Ms. Kwak's scholarly work include research articles published in journals including The Gerontologist and the Journal of Pain and Symptom Management, and a number of technical reports prepared for Florida Agency for Health Care Administration. Ms Kwak is also a recipient of AARP Scholarship, Grantmakers in Aging Fellowship, Institute on Aging Fellowship and Center for Hospice, Palliative Care, and End-of-Life Studies Pilot Grant.