PLANNING AHEAD: WHAT WILL I DO?

by

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(Under the Direction of Pamela Orpinas and Anne Glass)

ABSTRACT

As a natural part of life, older adults and their families must eventually confront death and end-of-life care decisions. Multiple studies documented that hospice and palliative care are optimal models of quality and compassionate care for the end of life. Nevertheless, hospice services are underutilized in the United States and the majority of patients enroll for short periods of times.

The primary objective of this study was to identify the significant predictors of intentions to use hospice in older adults in general population. Secondary objectives were to assess if hospice knowledge differed by race, gender, education, and income; and compare the levels of palliative care and hospice knowledge. The Theory of Planned Behavior was used as the theoretical framework. The sample included 169 community-dwelling older adults (mean age 69±7.8; 69% females; 95% White). Spearman correlation, analyses of variance, and multiple linear regression were used for the analyses. Results indicated that hospice knowledge (β=0.31, p<.001), subjective norms (β=0.19, p=.003), perceived control (β=0.36, p<.001), and preferences of end-of-life care (β=0.17, p=.002) were significant predictors of intentions to use hospice. Together these variables explained 55.5% of the variance in intentions to use hospice. Though overall hospice knowledge scores were high, only 56% of the participants knew that Medicare

pays for hospice. Additionally, 47% did not know that the most common place for hospice care to be provided is at home. Participants with low hospice knowledge were more likely to be older and lower income. Older adults reported less knowledge of palliative care than hospice.

Based on a theoretical framework and empirical results, the current study supports the hypothesis that intentions to use hospice in older adults are influenced by hospice knowledge, preferences for quality of life rather than aggressive treatments, normative beliefs towards hospice and perceived control to use hospice if faced with a terminal illness. These results provide better understanding of where to focus while developing interventions to educate older adults about hospice care options before a crisis happens, when patients and families are forced to comprehend complex information about hospice and make health care decisions within a short timeline.

INDEX WORDS: hospice, palliative care, older adults, end-of-life care decision making

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DEDICATION

This dissertation is dedicated to my parents, brother, and my friend Snizhana Radzetska for being role models of exceptional strength, inspiration, and appreciation of beauty in life.

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TABLE OF CONTENTS

Page

LIST OF TABLES

Page

LIST OF FIGURES

Page

CHAPTER 1

INTRODUCTION

The population in the United States is aging. According to the U.S. Census Bureau (2011) estimates, adults 60 years and older comprise 19% and adults 65 years and older comprise 13.3% of total US population. As a natural part of life, older adults and their families must eventually confront death, dying, and end-of-life care decisions. The end-of-life care decisions that older adults make, affect their own quality of life as well as their family and society. Different options and combinations of these options for end-of-life care are available to older adults: 1) wait until death comes naturally; 2) request all available treatments that medical science and technology can currently offer (cardiopulmonary resuscitation, use of ventilators, use of feeding tubes and artificial hydration, organ transplants, etc.); or 3) refuse all curative treatment and accept only comfort care provided by hospice at a place they consider home (Cicirelli, 2002). Palliative Care and hospice are regarded as optimal models for end-of-life care (Meier, 2011; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2010). According to the World Health Organization, palliative care is "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual"(World Health Organization, 2002). Palliative care philosophy regards dying as a normal process; the goal is to neither hasten nor postpone death. In the United States, palliative care can be started early in the

course of a serious illness, in combination with other curative therapies that intend to prolong life (chemotherapy, radiation therapy, etc.) (Health Team Works, 2011; Meier, 2011).

Similar to palliative care, the major goal of hospice is to achieve the best possible quality of life for patients and their families. The control of pain and other distressing symptoms is central to the philosophy of hospice so that patients can remain as comfortable as possible. Patients' families are also an important focus of hospice care, and services are designed to provide them with the assistance and support they need (Saunders, 1997). In contrast to palliative care, hospice services are available only to persons who can no longer benefit from curative treatment and have a prognosis of 6 months or less to live.

In a random sample of 7,258 Medicare decedents Lunney, Lynn, and Hogan (2002) have identified four distinct illness trajectories leading to death in older adults: 1) sudden death when people progressed from normal functioning to death within a short time; 2) terminal illness or cancer, when patients functioned fairly well before the disease became nonresponsive to treatment, leading to a rapid decline and death within a 6-week terminal phase; 3) organ system failure, when people had a slow progressive illness for years with exacerbations and remissions eventually leading to death; and 4) frailty, when patients had a very slow decline with progressive disability before dying. The proportion of individuals following the trajectory leading to sudden death was only 7%, whereas frailty (47%), cancer (22%) and organ system failure (16%) were dominant trajectories of illness leading to death. Individuals following the last three trajectories would benefit considerably at the end of their lives from hospice care (Murray, Kendall, Boyd, & Sheikh, 2005).

Multiple studies have shown that hospice provides high-quality care at the end of life, with high satisfaction for both patients and their family (Candy, Holman, Leurent, Davis, &

Jones, 2011; Casarett, Hirschman, Crowley, Galbraith, & Leo, 2003; Kiely, Givens, Shaffer, Teno, & Mitchell, 2010; Teno et al., 2004). Nevertheless, hospice services are underutilized in the United States. Although the utilization of hospice has continuously increased in the last decade, less than half of all deaths (44.6%) in 2011 were under the care of hospice (National Hospice and Palliative Care Organization, 2012) . Additionally, over half of the patients tend to enroll in hospice only for short periods of times. In 2011, 36% of hospice patients died or were discharged within seven days and 27% within 8-29 days of admission (National Hospice and Palliative Care Organization, 2012). Hospice and palliative care clinicians and researchers recommend a hospice enrollment of at least 3 months to provide optimal services and offer maximum benefits for both patients and families (Christakis & Iwashyna, 2000; Teno et al., 2007).

Goal of the Study and Research Questions

The majority of research to understand the reasons for underutilization of hospice services is targeted towards assessing the characteristics, knowledge, attitudes, and beliefs of the patients that qualified for hospice at the end of their lives and/or their caregivers (Carrion, 2010; Cohen, Ruthazer, & Germain, 2010; Csikai & Martin, 2010; Hardy et al., 2010; Johnson et al., 2005; Johnson, Kuchibhatla, & Tulsky, 2011; Kreling, Selsky, Perret-Gentil, Huerta, & Mandelblatt, 2010; Lepore, Miller, & Gozalo, 2011; Teno et al., 2004; Torke, Garas, Sexson, & Branch, 2005; Vig et al., 2010). Very few studies have focused on evaluating the knowledge, attitudes, subjective norms, perceived control, and intentions to use hospice in general older adult population who are not currently in need of hospice services.

The goal of this study is to advance the understanding of the attitudes, subjective norms, and perceived control related to hospice, as well as knowledge of hospice and palliative care in

older adults who are not currently in need of hospice services. The objective of this study is to empirically evaluate the predictors of intentions to use hospice among older adults (60 years and older) in the general population. The Theory of Planned Behavior (TPB) was used as the theoretical model to understand the main predictors of intentions to use hospice if faced with a terminal illness in the future (Ajzen, 1991). This study targets older adults because patients with cancer, dementia, and organ system failure will significantly benefit from hospice, and these diseases are the leading causes of death in the 60 year and older population in the United States (Centers for Disease Control and Prevention, 2010).

The research questions guiding this study are:

1) What is the level of hospice knowledge in older adults who currently do not have a diagnosis of a terminal illness (such as stage 4 cancer, end-stage renal disease, end-stage congestive heart failure, etc.)? Does hospice knowledge in older adults differ by race, gender, education levels, and income?
2) What proportions of older adults who currently do not have a diagnosis of a serious illness have some degree of palliative care knowledge? Do older adults know more about hospice compared to palliative care?
3) Based on the TPB, what are the main predictors of intentions to use hospice in the older adults?

To answer these research questions, a cross-sectional non-experimental survey design and a convenience sample were used. Data were collected from 169 older adults in the general population. To be included in the study, participants were 1) 60 years or older; 2) not currently undergoing cancer treatment (except treatment for cancerous skin moles that are removed in one session in the doctor's office); and 3) not receiving hospice care. The primary outcome measure

was intentions to use hospice if faced with a terminal illness. Predictor variables were hospice knowledge, attitudes towards hospice, subjective norms related to hospice, and perceived control to use hospice if faced with a terminal illness. Additional predictor variables were demographic characteristics (age, gender, race, marital status, education, income), perceived health status, preferences for end-of-life care, social support, and having an advanced directive and durable power of attorney.

This study advances science in several ways. First, it contributes to the understanding of the main predictors of intentions to use hospice in the general older adult population. Gaining an understanding of the main psychosocial variables that predict intentions to use hospice can help develop interventions to educate older adults about hospice before a crisis happens, when patients and families are forced to comprehend complex information about hospice and make health care decisions within a short timeline. Improving the understanding of the psychosocial variables involved in intentions to use hospice is important not only for patients and their families, but also for the physicians and health-care agencies to increase effective communication and planning for end-of-life care. An innovation of this study is that it proposes to empirically evaluate the predictors of intentions to use hospice among the older adults in general population.

Second, this study used the TPB as a theoretical framework for the design of the survey questions and the analyses of the data. The TPB has been used to predict a wide variety of health behaviors including health services utilization, smoking, drinking, substance use, HIV/STDs and condom use, and screening behaviors. Several studies and meta-analyses provided support that the TPB can account for a significant amount of variance in behavior and intention and found that changing TPB constructs (attitude, subjective norm, and perceived control) leads to change

in behavior (Albarracin et al., 2005; Albarracin, McNatt, et al., 2003; Armitage & Conner, 2001; F. Rhodes, Stein, Fishbein, Goldstein, & Rotheram-Borus, 2007). The research using the TPB to predict intentions to use hospice in older adults is limited. This study quantitatively assessed which constructs within the TPB (attitudes, normative beliefs, perceived control) are strongly and significantly related to the intention to use hospice in older adults, and thus, most important to develop interventions to increase hospice use in older adults.

CHAPTER 2

REVIEW OF LITERATURE

The review of literature is organized in ten subsections. Section one explores the characteristics of a "good death." Sections two and three discuss definitions and main characteristics of palliative care and hospice in the United States. Section four explores the effect of palliative care and hospice on the quality of life. Section five discusses the utilization of hospice in the United States. Section six explores the societal and cultural barriers to hospice. Section seven explores factors affecting the hospice utilization at individual and interpersonal level. Section eight describes the theoretical model for the proposed study. The final section describes how the Theory of Planned Behavior can be used to explain intentions to use hospice and underlines the rationale for the proposed study.

Characteristics of Good Death

Older adults and their families must eventually confront death, dying, and end-of-life care choices. The inevitability of death raises such questions as what are the characteristics of "good death" and what are the best practices for providing end-of-life care?

Although the meaning of a "good death" will vary for each patient, several definitions of a good death generated from qualitative research apply to the majority of people in many countries. Steinhauser et al. (2000) identified six major components of good death: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. According to the Debate of the Age Health and Care Study Group (1999), principles of a good death include: 1) knowing when death is coming, and

understanding what can be expected, 2) being able to retain control of what happens, 3) having dignity and privacy, 4) having control over pain relief and other symptoms, 5) having choice and control over where death occurs (at home or elsewhere), 6) having access to information and necessary expertise, 7) having access to any spiritual or emotional support required, 8) having access to hospice care in any location, 9) having control over who is present and who shares the end, 10) being able to issue advance directives to ensure wishes are respected, 11) having time to say goodbye and control over other aspects of timing, 12) being able to leave when it is time to go and not to have life prolonged pointlessly. As Smith (2000) highly recommended, these principles should be incorporated into the provision of health care services to improve the end of life experiences of both patients and their families. It is certainly challenging for the health care systems to translate all the components of "good death" into practice; however, the World Health Organization and many countries worldwide have accepted certain approaches and philosophies of care – hospice and palliative care – as optimal models of quality and companionate care for the end of life.

Definition and Characteristics of Palliative Care

According to the World Health Organization, palliative care is "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"(World Health Organization, 2002). The major goal of palliative care is the achievement of the best possible quality of life for patients and their families. Control of pain control and management of other distressing symptoms are central to palliative care so that patients can remain as comfortable as possible. Palliative care philosophy regards dying as a

normal process; the goal is to neither hasten nor postpone death. Additionally, palliative care incorporates psychological and spiritual dimensions of patient care and offers support system for both patients and families. In the United States, palliative care can be started early in the course of a serious illness, in combination with other curative therapies that intend to prolong life (chemotherapy, radiation therapy, etc.).

Over the past decade, palliative care services grew steadily in the United States. The number of palliative care teams within hospital settings has increased from more than 600 in the year 2000 to more than 1,600 in 2012. The southern region of the US has the lowest prevalence of hospital palliative care teams (52.7% of hospitals reporting a palliative care team) and the Northeast region has the highest prevalence of hospital palliative care teams (75.8%) (Center to Advance Palliative Care, 2012). However, according to a recent study, these numbers may be overestimated. For the state of Georgia, Glass and Burgess (2011) reported that overall only 18% of all hospitals had palliative care programs, with larger (300+ beds) hospitals reporting the highest percentage of palliative care programs. Additionally, the authors of the study found that there was some confusion among hospital staff regarding the differences between hospice and palliative care. Furthermore, the need for training and specialization in palliative care was highlighted by the majority of respondents (Glass & Burgess, 2011). Contributing to the rise of palliative care are the aging of the population, the increasing number of people living with serious and chronic diseases (cancer, organ system failure, frailty and dementia), and the concomitant caregiving burden of families. In the United States, palliative care addresses the fragmented traditional healthcare model for serious illnesses, where patients receive life-prolonging curative treatment up to the terminal stage of the disease. Only after a patient gets to

the terminal stage with a life expectancy of 6 months or less, they can be offered an opportunity to abruptly shift to a hospice care focusing on quality of life and comfort care (Health Team Works, 2011; Meier, 2011).

Definition and Characteristics of Hospice

Hospice as a philosophy and model of end-of-life care was developed by Dame Cicely Saunders in 1967 in the United Kingdom. Saunders (1997) laid out seven basic principles of hospice care (Table 2.1). These principles are still implemented by hospices worldwide.

The first hospice service in the United States was established in 1974 in Connecticut. For the health care delivery model in the United States, hospice can be defined as a type of palliative care that, under current regulations, is provided in the final months of life and focuses on patient comfort and quality of life rather than cure of disease.

Table 2.1. Basic Principles of Hospice Care

	Hospice Principles
1.	Skilled control of symptoms and total pain (defined holistically)
2.	Multidisciplinary team
3.	Maximize the potential remaining to a patient or family
4.	The whole family is the focus and unit of care
5.	Peer groups to help support the caregivers
6.	Defined research to enable the spread of palliative care
7.	Not only may the patients and families be in a quest to search for meaning, but so may the workers

Source: (Saunders, 1997)

Hospice services are available only to patients who can no longer benefit from curative treatment, must have a life expectancy of six months or less and must be willing to stop curative treatments (Casarett, 2011; Merrik, 2005; National Hospice and Palliative Care Organization,

2012). Some larger hospices and insurance companies (Capital Hospice in Washington, DC, UnitedHealth, etc.) offer "open-access care" programs that allow patients to continue curative treatments, while enrolled in hospice. However, the number of open access hospices is very limited in the United States, as open access is much more expensive than the regular hospice services and only larger hospices are able to dilute the expenses among many patients. For example, the cost of oral chemotherapy, radiation, blood and blood products transfusions can exceed $10,000 per month. Similarly, the costs of life-sustaining therapies for congestive heart failure towards end of life can be as high as $1,300 per day. In contrast, the approximate cost for outpatient hospice care in 2006 was $126 daily, not exceeding $4000 per month (Wright & Katz, 2007). Despite significant differences between the costs of aggressive treatments and hospice care, many studies reported high patient and family satisfaction with hospice care compared to the care in institutions (Candy et al., 2011; Casarett et al., 2003; Kiely et al., 2010; Teno et al., 2004). Open-access hospice care is a relatively new phenomenon and further research is needed to understand if offering open-access significantly improves hospice utilization and patient and family satisfaction, while reducing health-care costs by decreasing unnecessary hospitalizations near end-of-life crisis situations. The descriptions of the terms palliative care, hospice, and open-access hospice are summarized in Table 2.2.

Table 2.2. Definition of Terms Related to Hospice and Palliative Care

Term	Definition
Palliative care	Specialized medical care for patients with a serious illness. The focus is on providing relief from pain, symptoms and stress of a serious illness. The goal is to improve quality of life for patients and family. Often is provided along with curative treatment and can be started anytime in the course of a serious illness.
Hospice	Medical care provided to patients and their families when patient life expectancy is 6 months or less. Patients must agree to forgo curative treatments. Hospice provides comprehensive, interdisciplinary, team-based palliative care in a place the patient calls home. Maximizes comfort and quality of life, when curative treatment is no longer beneficial. Provides respite care for caregivers and bereavement services to family after the patient's death.
Open-access hospice	Allows patients to add hospice care to their current medical treatment that can slow or change disease progression

Source: Aldridge Carlson, Barry, Cherlin, McCorkle, and Bradley (2012), Center to Advance Palliative Care (2011), National Hospice and Palliative Care Organization (2012)

The provision of hospice care in the United States is organized in various settings: at home, hospice centers, hospitals, or skilled nursing facilities. However, the most common form of hospice in the U.S. is the provision of services at the home of patients (National Hospice and Palliative Care Organization, 2012). Commonly, a family member serves as a primary caregiver. Hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff is available 24 hours a day, 7 days a week. For many hospice models, the interdisciplinary team provides physical, social, spiritual, and emotional care and is composed of the patient's personal physician, hospice physician or medical director, nurses, home health aides, social workers, bereavement counselors, clergy or other spiritual counselors, trained volunteers, and, if necessary, speech, physical, and occupational therapists. Services are provided to patients and families during 1) the last stages of illness, 2) the dying process, and 3) the bereavement period. According to the National Hospice and Palliative Care Organization,

hospice services are available to all individuals and their families without regard to age, gender, race, diagnosis, availability of a primary caregiver, or ability to pay (National Hospice and Palliative Care Organization, 2012).

Hospice is covered under Medicare, Medicaid, and most private insurance plans, and patients can receive hospice care regardless of ability to pay. Currently, Medicare is the major source of payment for hospice care. In 2011, the percentage of hospice patients covered by the Medicare hospice benefit versus other payment sources was 84.1%. Medicaid hospice benefit covered 5.2% of patients. Centers for Medicare and Medicaid Services certify most of the hospice agencies to provide services under the Medicare hospice benefit (National Hospice and Palliative Care Organization, 2012).

To summarize, hospice and palliative care share the same core values and philosophy. In the United States, palliative care is targeted towards a broader population of people facing a serious illness who could benefit from receiving multidisciplinary care earlier in the disease process. Under current regulations, hospice is provided in the final months of life, is available only to patients who can no longer benefit from curative treatment, and focuses on patient comfort and quality of life rather than cure of disease.

The Effect of Palliative Care and Hospice on the Quality of Life

Previous research has identified four distinct trajectories of illness leading to death in older adults: 1) sudden death when people progressed from normal functioning to death within a short time; 2) terminal illness or cancer, when patients functioned fairly well before the disease became nonresponsive to treatment leading to a rapid decline and death within a 6-week terminal phase; 3) organ system failure, defined as slow progressive illness for years with exacerbations and remissions eventually leading to death; and 4) frailty, defined as very slow decline (Lunney

et al., 2002; Lynn, 2001). The proportion of individuals following to the trajectory leading to sudden death was only 7%, whereas frailty (47%), cancer (22%) and organ system failure (16%) were dominant trajectories. Individuals following the last three trajectories will benefit considerably at the end of their lives from hospice care (Murray et al., 2005).

Multiple studies have shown that hospice provides high-quality care at the end of life, with high satisfaction for patients and their families (Candy et al., 2011; Casarett et al., 2003; Kiely et al., 2010; Teno et al., 2004). Teno and colleagues (2004) found that many people dying in institutions have unmet needs for controlling their symptoms, communicating with their physician, receiving emotional support, and being treated with dignity. This national study also found that family members of decedents who received care at home with hospice services reported a more favorable experience than patients who died in institutions (hospitals and nursing homes). In another study, the health care proxies of patients with advanced dementia that used hospice in nursing home reported fewer unmet needs for symptom management, communication, information, emotional support, and help with personal care during the last 7 days of the residents' life (Kiely et al., 2010). Bereaved family members of people with dementia who received hospice reported higher perceptions of the quality of care and quality of dying than family members of patients who did not use hospice (Teno et al., 2011). Black et al. (2011) reported that hospice care had a positive impact on pain severity and related suffering of cancer patients, as well as patient quality of life near death.

Other studies found similar positive impacts for palliative care, when physicians incorporated palliative care into the treatment strategy of patients. In a randomized controlled trial, Gade et al. (2008) found that patients with life-limiting diagnosis (cancer, congestive heart failure, chronic obstructive pulmonary disease, end stage renal disease, stroke and dementia)

who received palliative care reported greater satisfaction with their care, had fewer intensive care unit admissions, and lower total health care costs following hospital discharge. Similarly, another randomized controlled trial found that compared with participants receiving usual oncology care, patients receiving a palliative care-focused intervention that addressed physical, psychosocial, and care coordination with oncology care had higher quality of life and mood (Bakitas et al., 2009). Based on the analyses of literature examining the impact of hospice and palliative care on the quality of life, Meier (2011) reported that palliative care and hospice services lessened pain, depression, and other symptoms, as well as increased patient and family satisfaction.

Utilization of Hospice in the United States

The number of hospice programs in the United States has increased dramatically during past three decades, since the first hospice program opened in 1974. In 2011, there were approximately 5,300 hospices in the United States (National Hospice and Palliative Care Organization, 2012). Although the utilization of hospice in the United States has continuously increased in the last decade, even in recent years less than half of all deaths (44.6%) in the United States in 2011 were under the care of hospice (National Hospice and Palliative Care Organization, 2012). Additionally, while the number of patients receiving hospice care increased over past decade, majority of the patients tend to consistently enroll in hospice only for short periods of times. In 2011, 36% of hospice patients died or were discharged within 7 days and 27% within 8-29 days of admission (National Hospice and Palliative Care Organization, 2012). A hospice enrollment of at least 3 months is recommended by clinicians and researchers to provide optimal services and offer maximum benefits for both patients and families (Christakis & Iwashyna, 2000; Teno et al., 2007). The majority of patients (62%) who used hospice in 2011 had non-cancer diagnoses. The top five diagnoses for patients enrolled in hospice in 2011 were:

cancer (38%), unspecified debility (14%), dementia (13%), heart disease (11%), and lung disease (9%).

Hospice is available in all states and most communities in the United States. A study examining access to hospice services concluded that, overall, the large majority of population in the United States lived in close distance to a hospice; therefore, underutilization of hospice services should be due to other barriers and not geographic access. However, the study did identify state and community variations. Urban areas had more access than rural areas. Community characteristics independently associated with greater access to hospice included higher population density, higher median income, higher educational attainment, and higher percentage of black residents (Carlson, Bradley, Du, & Morrison, 2010).

Barriers to hospice use are multiple. This study explores the effect of some individual and interpersonal characteristics on the intentions to use hospice. However, to provide a broader context for underutilization, the next section discusses societal and cultural barriers that can influence individual and interpersonal level predictors.

Societal and Cultural Barriers for Hospice

Societal and cultural views of death can have profound impact on people's personal meanings and fears of death, views on dying process, and decisions to prepare for the end-of-life. America has a death-denying culture and discussions about death are a taboo subject for many people (Cloud, 2000). Additionally, many physicians are poorly prepared to counsel dying patients and their families. Deficiencies in medical school curricula and continuing education for end-of-life care generated a medical culture that defines death as failure and ignores care for dying people as a source of professional accomplishment. Advances in medicine frequently lead to a "do everything" approach to health care despite a large amount of evidence on the low

effectiveness of many aggressive interventions. For example, numerous studies have documented low survival rates and serious complications (multiple rib fractures, neurologic sequelae, etc.) after cardiopulmonary resuscitation (CPR) for older patients (Gordon & Cheung, 1993; Hamill, 1995). In a meta-analysis of 21 studies examining predictors of survival after CPR, Cohn, Lefevre, Yarnold, Arron, and Martin (1993) reported that only 4% to 24% of patients receiving CPR survived to be discharged from hospital. A recent study reported an overall survival rate after CPR as low as 6.1% (Bigham et al., 2011). Despite these statistics, research indicates that many patients and even healthcare professionals significantly overestimate the success and underestimate the negative consequences of CPR in older patients (Adams & Snedden, 2006; Hayward, 1999). The lay public largely base their perceptions of the effectiveness of CPR on its portrayal in media and television (Adams & Snedden, 2006). Medical television dramas depict unrealistically high long-term survival after CPR, which may generate a falsely high expectation in the lay public, especially in the older adults (Harris & Willoughby, 2009).

Overall, a substantial group of older adults are willing to have aggressive treatments to prolong life even for a short time, despite acknowledging that aggressive treatments will significantly reduce their quality of life (Cicirelli, 2002). For some terminally ill patients it may be difficult to accept that death is approaching. Others would like more time to settle their affairs, and others hope for cure. The percentage of older adults who will refuse aggressive treatments depends on the aggressiveness of the treatment. Older adults are more likely to refuse a respirator and tube feeding than cardiopulmonary resuscitation (CPR) and intravenous fluids, and less likely to refuse antibiotics and oxygen (Cicirelli, 1998; Henderson, 1990; Yung, Walling, Min, Wenger, & Ganz, 2010). A study examining the response of patients and their families to a severe illness, highlighted that effective communication among patients, families,

and clinicians is important and can help jointly develop a treatment that respects patient and family values and in consideration of what is medically possible (Quill, Arnold, & Back, 2009). The promotion of public discussion of death and end-of life care is very important: If people openly discuss the end-of-life issues and understand the effectiveness and side effects of aggressive interventions, they will be more likely to think about what type of care they would want if faced with a life-limiting illness and will take action to make their end-of-life care wishes known before a crisis happens. Further education of the older adults about advance directives, living wills, designation of health care proxy and legal guardian, hospice and palliative care is essential to ensure that patients know all options and make informed choices,

Factors Affecting Hospice Utilization at Individual and Interpersonal Level

The majority of research to understand the individual level factors for underutilization of hospice services has focused predominantly on assessing the characteristics, knowledge, attitudes, and beliefs of the patients who were enrolled or qualified for hospice at the end of their lives and of their caregivers (Carrion, 2010; Cohen et al., 2010; Csikai & Martin, 2010; Hardy et al., 2010; Johnson et al., 2005; Johnson et al., 2011; Kreling et al., 2010; Lepore et al., 2011; Teno et al., 2004; Torke et al., 2005; Vig et al., 2010). Race is a major determinant of hospice services underutilization in the United States with minority adults having considerably and consistently lower utilization rates compared to White adults (Connor, Elwert, Spence, & Christakis, 2008; Givens, Tjia, Zhou, Emanuel, & Ash, 2010; Greiner, Perera, & Ahluwalia, 2003; Hardy et al., 2010; Johnson et al., 2011; Kapo, MacMoran, & Casarett, 2005; Lepore et al., 2011). The effect of race on the utilization of hospice is complex and multilevel. Overall, the effects of race can be categorized into two broad domains: 1) health care access and 2) culture. Limited access to health care overall and hospice services in particular due to lack of health

insurance was acknowledged by several studies as an important barrier for both African Americans and Latinos (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Carrion, 2010; Reese, Ahern, Nair, O'Faire, & Warren, 1999).

Many studies have documented that African American and Latino older adults have significantly less knowledge of hospice and end-of-life care preparation compared to White older adults (Carrion, 2010; Johnson, Kuchibhatla, & Tulsky, 2009; Reese et al., 1999; R. L. Rhodes, Teno, & Welch, 2006; Zapka et al., 2006). Religious, spiritual, and cultural beliefs and attitudes of African American older adults were in conflict with the hospice philosophy. For African American adults, accepting death was not an option and spirituality/religion was the main coping mechanism. For these reasons, African American participants experienced higher discomfort discussing death and hospice referral, and preferred aggressive care at the end-of-life. Additionally, there was a preference to have the family to make decisions and provide care at the end-of-life (Ache, Shannon, Heckman, Diehl, & Willis, 2011; Born et al., 2004; C. Jenkins, Lapelle, Zapka, & Kurent, 2005; Johnson, Kuchibhatla, & Tulsky, 2008; Reese et al., 1999; Torke et al., 2005; Waters, 2001). A unique and profound cultural barrier in African American older adults is the distrust of health care system (Born et al., 2004; Cort, 2004; Johnson et al., 2008; Reese et al., 1999; Torke et al., 2005; Waters, 2001). Similarly, cultural values of denial and secrecy about prognosis, collective, family-centered system influenced hospice decisions and experience in Latino men and women (Carrion, 2010; Kreling et al., 2010). Therefore, developing culturally tailored interventions for educating African American and Latino older adults can have potential to increase utilization of hospice in these populations.

Patients, families, and their physicians are reluctant to consider hospice care for several reasons. Some of the reasons for refusing to use hospice are reluctance by patients as well as

their physicians to accept that the patient is in a phase of illness where the goals of care cannot be curative any longer (Russell & LeGrand, 2006). Refusal to acknowledge that chemotherapy cannot overcome incurable cancers is not an uncommon phenomenon. In a large national prospective study of 1,193 patients with stage IV metastatic lung and colorectal cancer, the authors found that the large majority of the patients (69% of patients with lung cancer and 81% of patients with colorectal cancer) did not understand that their chemotherapy treatment was unlikely to cure their cancer. The misunderstanding of the effectiveness of chemotherapy can impede patients' ability to make truly informed treatment decisions (Weeks et al., 2012). In another study, concerns about continuity of care after hospice enrollment (such as concerns about losing current health care providers) were identified as factors for declining hospice enrollment(Vig et al., 2010). A study exploring appropriate timing for and communication about hospice found that the majority of hospice admissions occur during final stage of illness and are shorter than the available 6-month benefit period. The authors concluded that improved communication among families, physicians, and hospice teams is essential to ensure that patients are referred to hospice earlier (Waldrop & Rinfrette, 2009). Vig et al. (2010) reported that how hospice is presented during the initial visit and delays in obtaining physician order for hospice were reasons precluding enrollment in hospice. Csikai and Martin (2010) explored the communication between patients, caregivers, and health care professionals for hospice decision-making. The authors concluded that there is a need for a more coordinated approach to discussing end-of-life care options with seriously ill patients and their families. To ensure timely referrals to hospice and high quality care towards the end-of-life, efforts to improve patient-provider communications about end-of-life care options should be implemented, including

changes in medical school curricula to better prepare physicians for encounters with dying patients.

It should be highlighted that hospice enrollment decision is not an easy one for patients, because the current regulations require a physician signature that patient is within 6 months of end and for the patient to give-up life-sustaining treatment. Casarett (2011) argues that such rigid eligibility criteria are not based on needs for care, create delays in hospice enrollment, and shorten the median length of stay in hospice. A new demonstration project within the Affordable Care Act of 2010 (pp. 363-364) is under way to reevaluate the current eligibility criteria for hospice. As Casarett (2011) strongly recommended, the new hospice eligibility criteria should be established based on how well these criteria can guarantee that the right patients receive the right services at the right time. Additional to the hospice enrollment regulations by the government, different hospices have their own restrictive enrollment practices, which may further contribute to underuse. Although some larger hospices offer open-access care programs that allow patients to continue curative treatments while enrolled in hospice, numbers of open access hospices are very limited in the United States (Wright & Katz, 2007). In a recent study, the authors explored national trends in hospice enrollment practices and reported that only 29% of hospices had an open-access enrollment policy and 78% of hospices had at least one enrollment policy that could limit access to care for patients with high-cost treatments (chemotherapy, total parenteral nutrition, transfusions, intrathecal catheter, palliative radiation, and tube feeding)(Aldridge Carlson et al., 2012). Most of these high-cost treatments were considered curative, when the Medicare hospice benefit was enacted in 1981. However, as medicine evolved during the last three decades, many of these treatments can benefit patients for palliative rather than curative purposes. However, because of the high costs, most hospices have financial incentives to restrict

enrollment of patients who will require such treatments. Smaller hospices, hospices in Mountain and Pacific regions, and for-profit hospices were more likely to have restrictive enrollment policies (Aldridge Carlson et al., 2012). One of the main reasons for the restrictions in hospice enrollment is that Medicare hospice benefit reimbursement is on a per diem basis (fixed fees regardless of services provided) and is considered to be too low to allow hospices offer open access programs or have less restrictive enrollment policies. As Aldridge Carlson et al. (2012) recommended, Medicare hospice per diem reimbursement rates for patients who require complex palliative treatment should increase to enable more hospices to expand their enrollment. However, currently policy makers do not agree on the best, cost-effective ways of changing reimbursement structure without potentially bankrupting Medicare.

In addition to eligibility criteria, even though hospice offers important benefits and support to patients and their families, the hospice enrollment decision frequently requires patients and their families to comprehend and process complex information in a short period of time and under very challenging circumstances. Patients are typically referred by their physicians to hospice near the very end of life, often within days of death, thus making the time to process the information about hospice very short (National Hospice and Palliative Care Organization, 2012; Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005; Schockett, Teno, Miller, & Stuart, 2005). Older adults may benefit more from hospice and make more informed decisions if they are educated about hospice *before* they become terminally ill and near the end of life.

Few studies have examined the knowledge, attitudes about hospice, and intentions to use hospice among older adults in general population, who are not currently in need of hospice services. Several studies have found that lack of knowledge of hospice is an important barrier to

hospice services and end-of-life discussions in general population. In a study of 71 surrogate decision makers of older and chronically ill veterans, Vig et al. (2006) found that those who had a knowledge of hospice (who hospice cares for, where the care is provided, and the goal of the care) were inclined to use hospice for loved ones in the future. Conversely, the surrogates who had less accurate knowledge hospice were less likely to consider using it. The authors recommended that clinicians discuss the key aspects of hospice during routine advance care planning sessions with patients and their future surrogate decision makers. Casarett, Crowley, Stevenson, Xie, and Teno (2005) found that many patients and families who are referred for a hospice information visit had little prior knowledge about hospice and, therefore, had significant information needs. According to this study, most patients wanted to know about the frequency of visits, payment options, and practical support that hospice provides. In a cross-sectional study of adults (18 -- 84 year old) in general population, Ruff, Jacobs, Fernandez, Bowen, and Gerber (2011) found that prior knowledge of living wills and hospice services was associated with more positive attitudes toward hospice care, preference for limited medical interventions at end of life, and more comfort in communicating about death and dying. A study of home health clients who are eligible for hospice, but not currently receiving it, found that a high proportion of both African American and White home health clients held erroneous ideas about hospice care and had not discussed this option with their providers (Rosenfeld et al., 2007). Another study examining perceptions and awareness of hospice among 148 adults in community aged 43 and older found that respondents overall had favorable opinions about hospice and would recommend its services for their family members. However, older participants reported more negative impressions about hospice than younger respondents. Additionally, the authors reported

that majority of participants did not know whether hospice is covered by Medicare, Medicaid, and private insurance (Dussen, Culler, & Cagle, 2011).

Several studies have documented that there are many misconceptions and negative attitudes about hospice in the general population. Some of the misconceptions are: hospice is only for people with cancer, hospice is for the last hours or days of life, hospice is for patients who do not need high technology care, hospice starves patients, hospice keeps patients on high doses of opioids and hastens death (Rogers, 2009; Vig et al., 2010). There is a widespread belief in the population and even among some health care providers that medications used to alleviate symptoms may accelerate death in hospice patients. Although further research examining survival rates for patients receiving hospice and palliative care is necessary, several recent studies have reported that hospice and palliative care prolong life. Connor, Pyenson, Fitch, Spence, and Iwasaki (2007) found that the survival rate for hospice patients was 29 days longer than for non-hospice patients. Another randomized study comparing the quality of life and survival of patients with metastatic non-small-cell lung cancer reported that median survival was significantly longer among patients receiving early palliative care (11.6 months) compared to patients in the standard care group (8.9 months) (Temel et al., 2010). Because of the discussed misconceptions, many families initially often have negative attitudes toward hospice, but when they experience hospice philosophy and the interdisciplinary approach to care, those negative attitudes generally resolve (Rogers, 2009).

Theoretical Framework

The Theory of Planned Behavior (TPB) was used as a theoretical framework in this study. The aim of the TPB is to explain rationally motivated, intentional health behavior. Based on research aimed to understand why attitudes did not always initiate behavior, Ajzen and

Fishbein (1980) initially developed the Theory of Reasoned Action (TRA). Ajzen (1991) expanded the TRA into the Theory of Planned Behavior by adding a new construct – perceived control – to accommodate lack of complete control over the decision to exercise some behaviors. TPB focuses on the constructs of attitude, subjective norm, and perceived control to explain and predict behavioral intentions and behavior. According to the TPB, *behavioral intention* is the most important determinant of *behavior*. Individual's behavioral intention has three direct determinants: 1) attitude towards performing behavior, 2) subjective norm related to the behavior, and 3) perceived control over the behavior. According to the TPB, the more favorable are the attitude and subjective norm, and the higher is the perceived control over the behavior, the stronger are person's intention to perform the behavior and the higher is the likelihood of performing the behavior (Ajzen, 1991; Ajzen & Fishbein, 1980; Montano & Kasprzyk, 2008). Such external variables as demographic characteristics, personality traits, other individual difference variables can have moderating effects on model constructs (attitude, subjective norm, and perceived control) but do not independently contribute to explain the probability of performing the behavior (Ajzen, 1991; Ajzen & Fishbein, 1980; Glanz, Rimer, & Viswanath, 2008).

According to the TPB, attitudes are determined by the personal beliefs about benefits of performing the behavior, as well as evaluation of the outcomes of the behavior (Ajzen & Fishbein, 1980). Subjective norms are determined by the individual's normative beliefs (whether significant individuals in a person's life approve/disapprove the behavior) weighted by the individual's motivation to comply with the approval or disapproval (Montano & Kasprzyk, 2008). Perceived control is determined by control beliefs about the facilitators and barriers to behavioral performance, weighted by their perceived power (impact of each control factor) to

facilitate or inhibit the behavior. According to Ajzen (1991), a person's perception of control over behavioral performance coupled with his/her intentions, is expected to have a direct independent effect on behavioral intention and behavior. This effect will be especially prominent when perceived control is a correct estimate of actual control over the behavior (Ajzen, 1991; Montano & Kasprzyk, 2008).

The Theory of Planned Behavior and Theory of Reasoned Action have been used to predict a wide variety of health behaviors including health services utilization (Andrykowski & Burris, 2010; Enguidanos, Kogan, Lorenz, & Taylor, 2011), smoking, drinking(Trafimow, 1996), exercise (Blue, 1995), substance use (Morrison, Spencer, & Gillmore, 1998), HIV/STDs and condom use (Albarracin, Johnson, Fishbein, & Muellerleile, 2001), and screening behaviors (Jalilian & Emdadi, 2011; Montano & Taplin, 1991). Weinstein (2007) has criticized the use of correlation data to test theories of health behavior including the TPB, underscoring that most such tests overestimate the accuracy of theories in explaining health behaviors. However, many studies and meta-analyses support that TPB can account for a significant amount of variance in behavior and intention. Intervention studies showed that changing TRA and TPB constructs (attitude, subjective norm, and perceived control) is effective in achieving a positive change in different health behaviors (Albarracin et al., 2005; Albarracin, McNatt, et al., 2003; Armitage & Conner, 2001; Kamb et al., 1998; F. Rhodes et al., 2007). The research using the TPB as a theoretical framework shows that some behaviors are heavily influenced by attitudes (Albarracin, Cohen, & Kumkale, 2003; Trafimow, 1996), while for other behaviors subjective norms (Fishbein & Cappella, 2006) or perceived control may be most important predictors (Albarracin et al., 2005).

Using the Theory of Planned Behavior to Explain Intentions to Use Hospice

The research to use the TPB to predict intentions to use hospice in older adults is very limited. Enguidanos et al. (2011) used the Theory of Reasoned Action and Social Cognitive Theory (Bandura, 1986) constructs to develop a hospice brochure containing role model stories of African Americans' experience with hospice, their initial attitudes and beliefs about hospice, factors influencing their enrollment in program, and outcomes following enrollment. After the development of the educational brochure, the authors tested the impact of the brochure on knowledge, attitudes and intentions to enroll in hospice in a sample of community-dwelling older African American adults. The authors used a pre-post, no control intervention design. The knowledge, attitudes, and intentions to enroll in hospice were measured in older adults before and after the intervention. The authors reported significant improvement in knowledge of, attitudes towards, and intentions to use hospice after the intervention.

Another study conducted in Korea used the Theory of Reasoned Action as a theoretical framework to examine how individual characteristics, attitudes, and subjective norms towards hospice explained choice intention regarding hospice in general public. The study reported that attitudes and subjective norms related to hospice care had moderate effect on intentions to use hospice. Overall, the adults who intended to use hospice had more positive attitudes and subjective norms towards hospice than nonintenders. Additional factors that influenced intentions to use hospice were gender (females), religion (Catholics and Buddhist), experiences of medical treatment, ill news of acquaintances, and notice to patients of incurable disease upon diagnosis. The authors suggested that the development of strategies for hospice publicity should be based on prevailing attitudes and subjective norms towards hospice in population (Park & Lee, 2012). A limitation of the study was that the authors examined only univariate associations

between hospice choice intention and other variables. It is possible that the effects of different variables may be diminished if multivariate associations were examined.

In a cross-sectional study examining the associations between cultural values, social acculturation, hospice knowledge, and intentions to use hospice for cancer care, researchers reported low levels of knowledge and intentions to use hospice among Latino adults living in the United States. Collectivist views, endorsing family-centric values, and higher education were associated with greater hospice knowledge. Greater social ties were also independently associated with greater knowledge. Interestingly, knowledge was not related to hospice intentions in this study. Individuals who believed in maintaining secrecy about prognosis were less likely to choose hospice. The most socially acculturated individuals were significantly more likely to choose hospice than those with less acculturation. This study highlighted that hospice knowledge may be necessary but is not sufficient to increase hospice use among Latinos (Selsky et al., 2012).

Although the research using the TPB constructs to examine intentions to use hospice and hospice utilization in older adults is limited, there is a significant body of research on the association between hospice enrollment and patients' and health care professionals' attitudes towards hospice. Ford, Nietert, Zapka, Zoller, and Silvestri (2008) found that one of the main reasons for refusing hospice enrollment in patients with advanced lung cancer was the belief that hospice means giving up hope. Similarly, other studies found that most common barriers to hospice were unwillingness of a patient or the patient's family to accept hospice philosophy and discontinue active treatment, as well as nurses' desire to maintain hope among patients and families (Becker, 2004; Boyd, Merkh, Rutledge, & Randall, 2011; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). Several studies highlighted that attitudes of

physicians (Ache et al., 2011; Casarett & Quill, 2007; Ogle, Mavis, & Wyatt, 2002), nurses (Boyd et al., 2011; Cramer, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2003) and nursing home staff (Dobbs, Hanson, Zimmerman, Williams, & Munn, 2006; Welch, Miller, Martin, & Nanda, 2008) strongly influenced hospice referrals and timing of referrals. Overall, the results of these studies highlighted that health care professionals' negative attitudes towards hospice (hospice does not add a value to care, hospice is for crisis only, hospice is only for the "very end") precluded and delayed hospice referrals.

Research that evaluated the impact of social influence or subjective norms on hospice utilization is limited and has focused mainly on the influence of physicians on their patients' decisions to enroll in hospice. Overall, the results indicate a direct relation between hospice utilization and physician willingness to provide a hospice referral: if there is a positive social influence from physicians towards using hospice, hospice utilization increases and if there is a negative social influence towards using hospice, hospice utilization decreases. For example, how hospice is presented during the initial visit and delays in obtaining physician order for hospice were reasons precluding enrollment in hospice (Vig et al., 2010). Further, the patients' and physicians' reluctance to accept that the patient is in a terminal phase of illness strongly influenced low hospice enrollment (Russell & LeGrand, 2006). Several studies reported that difficulty of physicians to predict that a patient has a life-expectancy of six months or less was a reason for postponing hospice discussions with patients and families (Brickner, Scannell, Marquet, & Ackerson, 2004; T. M. Jenkins et al., 2011; Thomas, O'Leary, & Fried, 2009). Other studies have reported a strong family influence and a preference to have the family make decisions and provide care at the end-of-life for African Americans and Latinos (Ache et al., 2011; Born et al., 2004; Carrion, 2010; C. Jenkins et al., 2005; Johnson et al., 2008; Kreling et

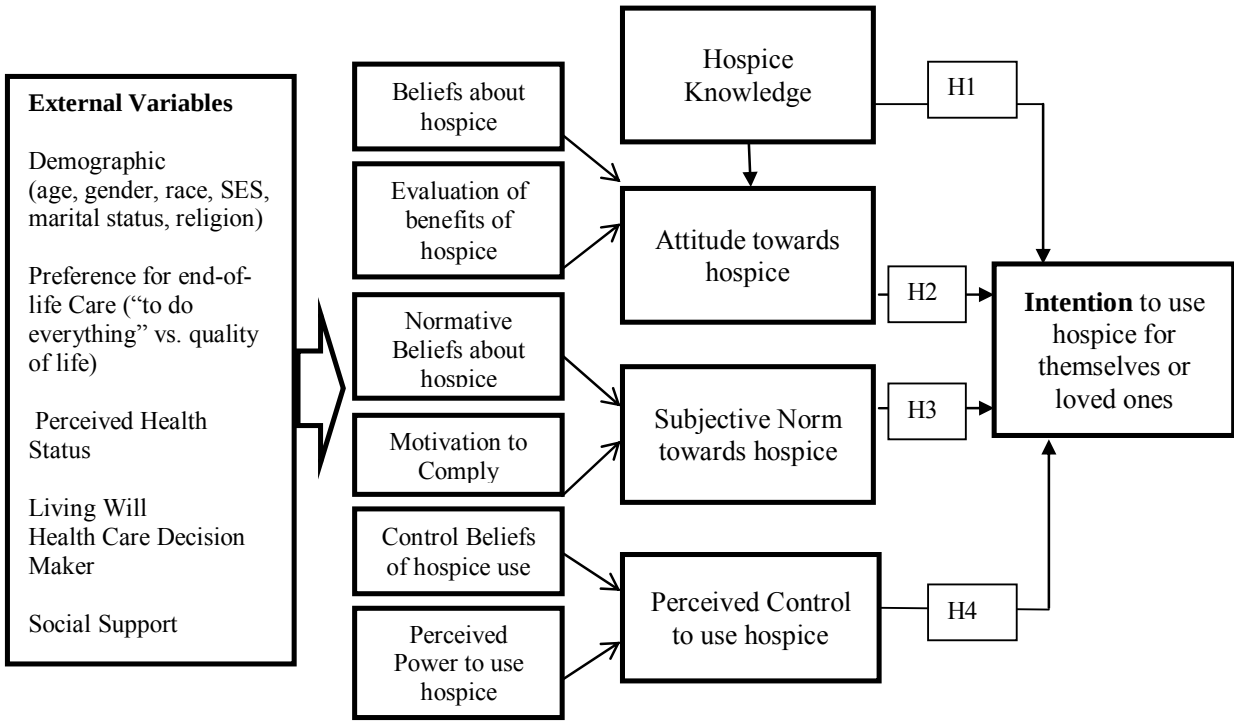
al., 2010; Reese et al., 1999; Torke et al., 2005; Waters, 2001). No study to date has examined the association of perceived control and intention to use hospice or hospice enrollment in older adults.

The Theory of Planned Behavior was criticized for indirect measurement of the effect of demographics, personality traits and other external variables on the behavioral intention and behavior (Montano & Kasprzyk, 2008). In response to such criticism, Ajzen (1991) stated that external variables operate through main constructs of the model (attitude, subjective norm, perceived control) and do not independently contribute to predict the likelihood of performing a behavior. However, in the research examining hospice utilization, multiple studies reported low levels of hospice knowledge and have found that lack of knowledge or incomplete knowledge of hospice is an important barrier to hospice services and end-of-life discussions in general population (Casarett, Karlawish, et al., 2005; Colon, 2012; Dussen et al., 2011; Enguidanos et al., 2011; Johnson et al., 2009; Rosenfeld et al., 2007; Ruff et al., 2011; Selsky et al., 2012; Vig et al., 2006). Since the knowledge of hospice is a perquisite for forming attitudes, subjective norms, and perceived control, hospice knowledge was added to the theoretical model as an independent predictor of intentions to use hospice.

As already discussed, the TPB assumes a causal relation that links attitudes, subjective norms, and perceived control to behavior through behavioral intention. Therefore, the theory requires *highly specific* behavioral intention measures that closely match the intended behaviors. The primary outcome measure for this study is *intentions to use hospice if faced with a terminal illness*. Based on the Theory of Planned Behavior, the main predictor variables are hospice knowledge, attitudes towards hospice, subjective norms related to hospice, and perceived control to use hospice if faced with terminal illness. Based on the literature review examining hospice

utilization, additional variables that can be associated with intention to use hospice are demographic variables, perceived health status, having a living will or health care decision maker, preferences of care if faced with a life-limiting illness, and social support. The model depiction is provided in the Figure 2. 1.

Figure 2. 1. A Model to Predict Intentions to Use Hospice Informed by the Theory of Planned Behavior



CHAPTER 3

METHODS

This chapter describes the methodology of this study. The chapter is divided into four subsections. Section one describes the goals, design, and research questions. Section two describes how the sample was obtained. Section three details the measures, and section four explains the data management and analyses.

Goals, Design, and Research Questions

Goals and Design

The goal of this study is to advance the understanding of the attitudes, subjective norms, and perceived control related to hospice, as well as knowledge of hospice and palliative care in older adults who are not currently in need of hospice services. The objective of this study is to empirically evaluate the predictors of intentions to use hospice among older adults (60 years and older) in general population. The Theory of Planned Behavior was used as a theoretical framework to understand the main predictors of intentions to use hospice if faced with a terminal illness in future.

A cross-sectional non-experimental design was used. Data were collected over 8 months from 169 adults 60 years and older. The survey included questions related to the personal characteristics of participants (age, gender, race, income, education, and marital status), preferences for end-of-life care, preparation for end-of-life care (having advanced directives and durable power of attorney), social support, knowledge about hospice and palliative care, attitudes and social norms towards hospice, perceived control for using hospice if faced with a terminal

illness, and intentions to use hospice if faced with a terminal illness. Appendix A contains the survey questionnaire. Participants completed the survey in one of two forms: 1) online or 2) paper-and-pencil. This latter form was completed as an interview or alone.

Primary Research Questions and Hypothesis

The purpose of this study was to answer the following research questions:

1) What are the main predictors of intentions to use hospice in older adults if they are faced with a terminal illness?

   Hypothesis 1: Older adults with higher knowledge of hospice will be more likely to have higher intentions to use hospice compared to older adults with less or no knowledge

   Hypothesis 2: Older adults who have positive attitudes toward hospice will be more likely to intend to use hospice if faced with a terminal illness.

   Hypothesis 3: Older adults who have normative beliefs that support the use of hospice will be more likely to intend to use this service.

   Hypothesis 4: Older adults who have higher perceived control to use hospice will be more likely to intend to use this service.

Secondary Research Questions and Hypothesis

2) What is the level of hospice knowledge in older adults who currently do not have a diagnosis of a terminal illness (such as stage 4 cancer, end-stage renal disease, end-stage congestive heart failure, etc.)? Does hospice knowledge in older adults differ by race, gender, education levels, and income?

   Hypothesis 5: Minority older adults and older adults with lower education levels and lower income will have significantly lower knowledge about hospice.

3) What proportions of older adults who currently do not have a diagnosis of a serious illness have some degree of palliative care knowledge? Do older adults know more about hospice compared to palliative care?

   Assessment of palliative care knowledge in older adults is exploratory in this study. Therefore, no specific hypothesis was formulated for question three.

Sample and Data Collection Procedures

The population for this study were adults 60 years and older. This study targeted older adults because the population in the United States is aging and currently adults 60 years and older comprise 19% of the total U.S. population and adults 65 years and older comprise 13.3% (U.S. Census Bureau, 2011). Cancer, dementia, and organ system failure are leading causes of death in the 60 year and older population in the United States and patients with these conditions will benefit considerably from hospice care (Centers for Disease Control and Prevention, 2010). The following were the inclusion and exclusion criteria for the sampling. *Inclusion criteria*: participants must be 1) 60 years or older, 2) not currently undergoing cancer treatment (except treatment for cancerous skin moles that are removed in one session in the doctor's office), and 3) not receiving hospice care. *Exclusion criteria:* 1) participants who cannot communicate in written and spoken English, and 2) participants who are not able to provide informed consent.

Sample Size Calculations

To calculate the necessary sample size for the study, statistical power analyses applicable to studies using multiple regression and analyses of variance were used. For multiple regression analyses, this study has four primary predictor variables (hospice knowledge, attitudes towards hospice, subjective norms towards hospice, and perceived control to use hospice) and additional six external variables. Using a medium effect size of 0.15, 80% power to detect differences,

5% of chance of incorrectly rejecting the null hypothesis (α =0.05), and 10 predictors to be entered into multiple regression models, the minimum sample size is 118 participants (Faul, Erdfelder, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007).

Data Collection

A combination of convenience sampling and snowball sampling (non-probability sampling) was used to recruit participants in the community. Part of the recruitment efforts included sending recruitment announcements to the Osher Lifelong Learning Institute (OLLI) at the University of Georgia, the Athens Community Council on Aging (ACCA), and the Centers for Disease Control and Prevention (CDC) Parents Network. To increase the diversity of the sample, older adults in a low-income independent living community in Metro Atlanta area (Calvin Court) were invited to participate. Based on the research on the recruitment of older adults, the expected response rate was approximately 40-45%. Additionally, since death and end-of-life decisions are a taboo subject in the United States, the expected response rate could be lower than 40% (Kaldenberg, Koenig, & Becker, 1994; Klein et al., 2011).

Data were collected with a combination of online survey and paper-and-pencil survey. The majority of responses (n=146) were from online surveys. Compared to paper-and-pencil surveys—a well-established data collection methodology—online surveys have both advantages and disadvantages. Gosling, Vazire, Srivastava, and John (2004) reported that the data provided by online surveys are of comparable quality to those provided by traditional paper-and-pencil methods. For paper-and-pencil surveys, the sampling frames can be clearly established, there is no risk of multiple responses, and response rates can be calculated. However, paper-and-pencil surveys are costly, may generate less diverse samples and may not allow access to hard to reach populations. In contrast, online surveys allow obtaining larger and more diverse samples, are

lower cost, allow access to hard-to-reach populations who may be reluctant to discuss difficult and sensitive topics, and allow participants discontinue their involvement at any time, without feeling any pressure from the researcher. However, sampling frames and response rates are more difficult to determine for online surveys. A potential challenge to online survey methodology is receiving multiple responses from the same person. Multiple responses can be a concern if high monetary incentives are offered. However, since no monetary incentive was offered in this study, possibility of receiving multiple responses is unlikely to bias the results of this study (Gosling et al., 2004; Pequegnat et al., 2007).

Participants provided informed consent before answering the survey "Planning Ahead: What Will I Do?" Participants completing the paper-and-pencil surveys met with one of two of the researchers conducting the study (Nahapetyan and Binkow) and completed the surveys during a face-to-face interview. To facilitate the completion of both online and paper surveys, researchers were available in person, by phone or by email to answer questions about the survey. In appreciation for helping identify the factors that influence older adults' decisions and preferences of care if they would be faced with a serious illness, participants received educational materials about hospice and palliative care after completing the survey. The University of Georgia's Institutional Review Board approved all research activities.

Sample Description

Table 3.1 summarizes the demographic characteristics of the sample.

Table 3.1. Sample Demographics

Demographic Characteristics	N	%
Age		
60-69 years	101	59.8
70 – 79 years	38	22.5
80 years and older	23	13.6
Gender		
Men	52	30.8
Women	117	69.2
Race		
White	161	95.3
Black	7	4.1
Other	1	0.6
Marital Status		
Single, never married	9	5.3
Married	101	59.8
Separated	1	0.6
Divorced	33	19.5
Widowed	25	14.8
Education		
Less than high school	2	1.2
High school or GED	9	5.3
Some college or technical training	18	10.7
College graduate	39	23.1
Postgraduate or professional degree	100	59.2
Income		
Less than $ 25,000	14	8.3
$ 25,000 - $ 50,000	35	20.7
$ 50,000 - $ 75,000	24	14.2
More than 75,000	85	50.3
State		
Georgia	145	85.8
Other	21	12.4

The sample consisted of 169 older adults. A large proportion of the sample was female (69%). It is important to note that due to higher life expectancy of women compared to men, after age 60 the proportion of women in general population is higher than men. According to the US Census Bureau (2010), the gender distribution of 60 years and older population in Georgia

was 56% female and 44% male. Therefore, even though women are oversampled in this study, the gender distribution of the sample is not highly skewed. The mean age of participants was 69 years (SD = 7.8), median age was 67 years, and range was from 60 to 93 years. Almost 60% were in the age category of 60 to 69 years. The majority of participants were White (95.3%), were highly educated (23.1% completed college and 59.2% completed a postgraduate or professional degree), and reported high income (54.5% had income more than $ 50,000). Additionally, a large proportion of the sample was married (59.8%) followed by participants who were divorced (19.5%) and widowed (14.8%).

Measures

Instrument Development

The survey consisted of: 1) demographic information section; 2) questions about preferences for care, social support, and end-of-life care preparation; and 3) scales measuring hospice knowledge, palliative care knowledge, attitudes towards hospice, subjective norms towards hospice, perceived control to use hospice, and intentions to use hospice. The demographic information assessed in the survey was age, gender, race (Black, White, Latino, Asian, Other), current marital status, having living children, highest level of education completed, self-reported health status, and if participant ever had a life-threatening disease/injury.

Prior research using the TPB to predict intentions to use hospice in older adults is very limited. Therefore, a significant challenge was the lack of reliable and validated measures of TPB constructs specifically related to hospice. The scales measuring preferences for care, social support, hospice knowledge, palliative care knowledge, attitudes towards hospice, and intentions to use hospice were adapted and modified from three previous studies: 1) “Racial Differences in

the use of advance directives and attitudes toward hospice" (Johnson et al., 2008, 2009); 2) "Use of Role Model Stories to Overcome Barriers to Hospice among African Americans" (Enguidanos et al., 2011); and 3) "2011 Public Opinion Research on Palliative Care"(Center to Advance Palliative Care, 2011).

The scales measuring subjective norms towards hospice and perceived control to use hospice were constructed specifically for this study. The operationalization and measurement of the TPB constructs is considered more work-intensive compared to other theories as the TPB suggests both direct and indirect ways of measuring the constructs (Montano & Kasprzyk, 2008). The direct measures are generally more strongly associated with intentions and behaviors than indirect measures (Montano & Kasprzyk, 2008). Additionally, according to Ajzen (2002), few studies have operationalized perceived control using the indirect measures of control beliefs and perceived power; instead, researchers have mostly used direct measures of perceived control (Ajzen, 2002). For this study, direct measures were used to operationalize the TPB constructs. A *direct measure* of subjective norms generally asks the respondent to rate 'Most people important to me think I should' perform the behavior. The rating uses a bipolar unlikely–likely or agree–disagree scale. A *direct measure* of perceived control assesses capacity and autonomy aspects and asks the respondent to rate 'I am confident that I can' perform the behavior. The *direct measures* of perceived control use semantic differential scale items (under my control–not under my control, agree–disagree) (Ajzen, 2006).

Scale development for subjective norms and perceived control was based on the recommendations of Ajzen (2006) for construction of the TPB questionnaire. First, the behavior of interest was clearly defined as: hospice use if faced with a terminal illness. Second, the population of interest was clearly defined as: older adults 60 years and older. Third, five to six

items for each direct measure were formulated to assess the constructs. The TPB measures can use either 5- or 7-point scales (Ajzen, 2006; Montano & Kasprzyk, 2008). Five-point bipolar scales were employed for this study. Participants circled the answer that best described their personal opinions.

The prevalence of mild cognitive impairment and dementia increases with advancing age (Petersen et al., 1999; Reisberg et al., 2008). Therefore, questions were checked for clarity and simplicity. After construction of the questionnaire, it was reviewed by an end-of-life care researcher in the University of Georgia, Institute of Gerontology for face validity. Additionally, two experts on the Theory of Planned Behavior reviewed the questionnaire to examine if the items represent the constructs correctly. The questionnaire was further tested with a lay person in her 50s for ease of completion and understandability of the questions. Later, eight doctoral students in the Health Promotion Department reviewed the questionnaire for clarity. All suggestions were incorporated into the final questionnaire.

Description of the Scales

Table 3.2 summarizes the scales and describes the constructs, number of items each scale contains, and scoring of the scale items in the study. Each scale is described in detail in this section. Internal consistency was measured using Cronbach's alpha (refer to appendix A).

Preferences for End-of-Life Care scale (Johnson et al., 2008) assessed the beliefs about the kind of medical care the participant would want at the end-of-life (requesting everything to be done to be kept alive as long as possible vs. having more comfort and higher quality of life). Response categories were measured on a 5-point scale and ranged from *Strongly Disagree* (1) to *Strongly Agree* (5).

Table 3.2. Psychometric Properties of Survey Scales: Current Study

Construct	Scale	Number of items, Cronbach's alpha	Scoring in Current Study
Preferences for End-of-Life Care	Preferences for End-of-Life Care scale (Johnson et al., 2008)	8 items (Alpha 0.74)	*Strongly Disagree* (1), *Disagree* (2), *Neutral* (3), *Agree* (4), *Strongly Agree* (5). Higher scores indicate higher preference for being comfortable and having better pain and other symptom control
Hospice knowledge	Hospice knowledge scale (Enguidanos et al., 2011)	10 items	*True/False* scale (0 to 1) with "*don't know*" option (score of 0). Higher score indicates higher levels of hospice knowledge
Attitudes towards hospice	Attitudes toward hospice(Enguidanos et al., 2011); Hospice Beliefs and Attitudes (Johnson et al., 2008)	9 items (Alpha 0.76)	*Strongly Disagree* (1), *Disagree* (2), *Neutral* (3), *Agree* (4), *Strongly Agree* (5). Higher scores indicate positive attitudes towards hospice
Subjective norms towards hospice	Subjective norms towards hospice	5 items (Alpha 0.80)	*Strongly Disagree* (1), *Disagree* (2), *Neutral* (3), *Agree* (4), *Strongly Agree* (5). Higher scores indicate positive subjective norms towards hospice
Perceived control to use hospice	Perceived control to use hospice	5 items (Alpha 0.80)	*Strongly Disagree* (1), *Disagree* (2), *Neutral* (3), *Agree* (4), *Strongly Agree* (5). Higher scores indicate higher perceived control to use hospice
Intentions to use hospice	Intentions to use hospice if faced with terminal illness (Ajzen, 2006; Enguidanos et al., 2011)	3 items (Alpha 0.94)	*Strongly Disagree* (1), *Disagree* (2), *Neutral* (3), *Agree* (4), *Strongly Agree* (5). Higher scores indicate higher intentions to use hospice
Palliative Care knowledge	Palliative Care Knowledge (Center to Advance Palliative Care, 2011)	7 items	*True/False* scale (0 to 1) with "*don't know*" option (sore of 0). Higher scores indicate higher levels of palliative care knowledge
Social Support	Social Support (Johnson et al., 2008)	6 items (Alpha 0.66)	*Strongly Disagree* (1), *Disagree* (2), *Neutral* (3), *Agree* (4), *Strongly Agree* (5). Higher scores indicate higher social support

Negatively worded questions were recoded to reflect that a higher score indicated stronger preference for being comfortable and having better pain and other symptom control. The scale score was calculated as the average of the eight items. The internal consistency of this scale was 0.72 in the Racial Differences in the Use of Advance Directives and Attitudes toward Hospice study and 0.74 for this study (Johnson et al., 2008).

Hospice Knowledge scale (10 items) was adapted from a study assessing hospice knowledge in older adults (Enguidanos et al., 2011). Items reflected common myths about hospice, such as location of care, eligibility, and insurance coverage. The question 'Hospice benefits pay for medications' was replaced by 'Medicare pays for hospice' to assess this important knowledge related to Medicare coverage. Response categories were measured on a true or false scale (scored 1 for correctly answering the item and 0 for incorrect or *don't know* response). The total score reflected the number of correctly answered questions, ranging from 0 to 10. A higher score indicated higher levels of hospice knowledge.

Hospice Attitudes scale measured older adult's attitudes towards hospice and combined items from two scales in two studies: Hospice Beliefs and Attitudes scale (Johnson et al., 2008; alpha = 0.74) and Hospice Attitude Scale (Enguidanos et al., 2011; alpha not reported). Items that reflected hospice knowledge or perceived control to use hospice rather than attitudes towards hospice were removed from both scales. Examples of removed items were: "I know what hospice is", "I know how long hospice cares for a patient", "I know the types of services hospice provides", "Even if I wanted hospice care, I could not afford hospice", "I wouldn't need hospice if I were dying because my family would take care of me". The remaining items were combined into a nine-item scale. Response categories were measured on a 5-point Likert scale and range from *Strongly Disagree* (1) to *Strongly Agree* (5). Negatively worded questions were

recoded to reflect that a higher score indicated more positive attitudes towards hospice. The scale score was calculated as the average of the 9 items. A higher score indicated more positive attitudes towards hospice.

Subjective Norms towards Hospice scale measured whether significant individuals in an older adult's life approve or disapprove of hospice, weighted by the older adult's motivation to comply with the approval or disapproval. The scale contained five questions. Response categories are measured on a 5-point Likert scale and range from *Strongly Disagree* (1) to *Strongly Agree* (5). Responses to negatively worded questions were recoded to reflect that a higher score indicated more positive subjective norms towards hospice. The scale score was calculated as the average of the five items. A higher scale score indicated more positive subjective norms towards hospice.

Perceived Control to use Hospice scale measured control beliefs about the facilitators and barriers to hospice weighted by their perceived power (impact of each control factor) to facilitate or inhibit the behavior. The scale consisted of five items. Response categories were measured on a 5-point Likert scale and ranged from *Strongly Disagree* (1) to *Strongly Agree* (5). Responses to negatively worded items were recoded to reflect that a higher score indicated higher perceived control to use hospice. The scale score was calculated as the average of the five items. A higher scale score indicated higher perceived control over using hospice.

Intentions to use Hospice scale was adapted from Enguidanos et al. (2011) and modified based on the suggestions of Ajzen (2006). The scale consisted of three items. Two items assessed participant's intentions to enroll in hospice if faced with a terminal illness. One item asked if the participant would consider enrolling a family member in hospice if the family member was extremely ill. Response categories were measured on a 5-point scale and ranged from *Strongly*

Disagree (1) to *Strongly Agree* (5). The scale score was calculated as the average of the three items. A higher score indicated a stronger intention to enroll in hospice.

Palliative Care Knowledge scale was constructed based on the Center to Advance Palliative Care (2011) Public Opinion Research in Palliative Care that explored public's awareness and understanding of palliative care. The Public Opinion Research in Palliative Care survey tested language, terminology, definitions and messaging for discussing palliative care with consumers. The palliative care knowledge scale contained items that reflect knowledge about philosophy, goals, provisions, and applicability of palliative care in end-of-life care continuum. Response categories were measured on a true or false scale (score of 1 for correctly answering the item and 0 for incorrect or *don't know* response). The total score reflected the number of correctly answered questions, ranging from 0 to 7. A higher score indicated higher levels of palliative care knowledge.

Social Support scale (Johnson et al., 2008) measured older adults' perceptions of the support they will receive from children, spouse, other family members, friends, and church members if they face a terminal illness. The scale consisted of six items. Response categories were measured on a 6-point scale and ranged from *Strongly Disagree* (1) to *Strongly Agree* (5) with an additional category of *Not Applicable* (score of 0). Responses to negatively worded items were recoded to reflect that a higher score indicated higher levels of social support. The scale score was calculated as the average of the six items. A higher scale score indicated higher levels of social support.

Data Management and Data Analyses

Data Management

Data were collected from March 2013 to January 2014 over 8 months until the desirable sample size was reached. Online survey data were collected using Qualtrics software (Qualtrics, 2013), which allows options to download the survey responses into either Excel or SPSS datasets. The online data were received with no personal identifiers. Microsoft Excel was used to build a database for the completed paper surveys. Item descriptives, histograms with normal distribution curves and bar graphs were generated to identify potential outliers. After reviewing the output, extreme values were rechecked against raw data in paper questionnaire. Particularly, there were anomalous values (n=5) for palliative care knowledge on paper surveys, when participants indicated that they never heard about palliative care, but nevertheless answered the questions assessing palliative care knowledge. These values for palliative care knowledge were cross-checked against the corresponding answers on paper questionnaire, and, when appropriate, codes were replaced with the correct value. Electronic data files were maintained on computer and backed up regularly on electronic disk. After the data collection was completed and accuracy of data entry was ensured, the Excel spreadsheet was imported into SPSS and merged with the data from the online surveys.

Reliability analyses

Internal consistency of scale scores were assessed by using Cronbach's alpha. Internal consistency measures the extent to which the items of a scale are interrelated and are measuring the same construct (Green, Lissitz, & Mulaik, 1977). Therefore, if the scale has high internal consistency, it is expected that all items should be moderately correlated with each other and each item should correlate with the total score. Cronbach's alpha or coefficient α is a measure of

internal consistency and can be used for scales with dichotomous and multiple response levels. If the coefficient alpha increases when removing a specific item, then excluding that item will increase the internal consistency of the scale (Cronbach, 1951). Generally, the higher is the Cronbach's alpha, the better is the internal consistency of the scale. However, there are at least two potential problems with this measure that should be taken into consideration. First, α depends not only on the strength of the correlation among items, but also on the *number of items* in the scale (Cortina, 1993; Green et al., 1977). Second, if α is too high, then it is likely that some items are asking the same question and are redundant (Boyle, 1991). Overall, α should be above 0.7, but not higher than 0.9 (Streiner & Norman, 2003). As Cortina (1993) suggests, coefficient alpha is useful for estimating internal consistency of a scale scores when item-specific variance in a unidimensional test is of interest. While conducting reliability analyses, I examined if any items contributed to very high or low internal consistency scores of the scales, removed problematic items, and reran the scale scores. The score distributions of final items and scales used in this study are summarized in Table 3.2 and in Appendix B. The reliabilities of all study scales had moderate to high internal consistency (Cronbach's alpha = 0.74 - 0.94) except for the social support (alpha = 0.66). There were very few missing values for different items of the scales with overall 92.9% (social support) to 99% completion rates (intentions and knowledge). Since there were very few missing data, no procedures were applied to impute the missing values.

Examination of the Primary Research Questions

First, frequency analyses and descriptive statistics (mean, median, standard error, and range, degree of skewness and kurtosis) were used to examine the distributions of the categorical and scale variables used in the study. Second, univariate analyses (chi-square tests, Spearman

correlation, and one-way analyses of variance (ANOVA)) were used to examine significant associations between the intentions to use hospice (outcome variable) and independent (predictor and moderator) variables. For the purposes of univariate analyses, particularly analyses of variance, the "intentions to use hospice" variable was recoded from a continuous distribution into interval level response categories: 1) low intentions (participants who scored < 4), 2) high intentions (participants who scored from 4 to 5), and 3) very high intentions (participants who scored 5). The choice of combining scores of 1, 2, and 3 into one group is justified if the points within the lower end of the scale have few cases (Warner, 2008). ANOVA was used to examine if mean scores of hospice knowledge, attitudes towards hospice, subjective norms towards hospice, perceived control to use hospice, preferences for end-of-life care, and social support were different for the three intentions to use hospice groups. To examine if equal variances assumption for ANOVA was violated, Levene's homogeneity of variance test was used. For pairwise comparison tests, Bonferroni (equal variances) and Tamhane (unequal variances) corrections were used.

Third, multiple linear regression models were used to identify the significant predictors of intentions to use hospice in older adults. The construction of regression models was based on the relationships specified in the Theory of Planned Behavior (TPB). According to the TPB, hospice knowledge, attitudes towards hospice, subjective norms towards hospice, and perceived control to use hospice are the main predictor variables. Therefore, a forced entry was used to ensure that these variables will enter the regression models. For the remaining variables (demographic characteristics, social support, preferences for care if faced with a serious illness, having a living will and health care decision maker, religious and spiritual beliefs), stepwise and

forward selection methods (entry $p = .05$ and removal $p = .1$) were used to eliminate the variables that did not have significant effect on the intentions to use hospice.

All predictor variables, regardless of their significant associations with the intentions to use hospice in univariate models, were entered into multiple regression models. The main assumptions of the multiple linear regression models are: 1) linearity: the relationship between the dependent variable and each independent variable should be linear; 2) normality: for each value of independent variable, the distribution of dependent variable must be normal; 3) homoscedasticity: the variance of the distribution of the dependent variable should be constant for all values of the independent variable; and 4) independence: all observations should be independent. Normal Q-Q plots of studentized residuals were used to assess the normality assumption. Studentized residual plots were used to examine linearity and homoscedasticity assumptions. It is important to note that for large sample size ($n - k > 30$ where n is the sample size and k is the number of variables), the inference of multiple regression is robust to violations of normality assumption. Additionally, violation of homoscedasticity assumption gives unbiased estimation of regression coefficients but can provide erroneous inference.

Multiple models were tested to identify significant predictors of intentions to use hospice. Adjusted R-square as well as parameter p-values were used to assess the fit of different models. Variance Inflation Factors (VIF) and tolerance were used for multicollinearity analyses.

Examination of the Secondary Research Questions

First, frequency analyses were used to examine proportions of the sample that responded correctly to each knowledge item and descriptive statistics to examine the distribution of the hospice and palliative care knowledge scales. Second, chi-square tests and ANOVA were used to

examine whether hospice and palliative care knowledge differed by gender, education levels, marital status, religiosity/spirituality, place where participants prefer to die, and income.

Third, to examine and compare the levels of hospice and palliative care knowledge, participants were divided into four categories: No knowledge (score of 0), low knowledge (lowest 30^{th} percentile cut-off score: score of ≤ 3 for hospice and score of ≤ 2 for palliative care), average knowledge (30^{th} to 70^{th} percentile cut-off score: score of 4 to 7 for hospice and score of 3 to 5 for palliative care) and high knowledge (highest 30^{th} percentile cut-off score: score of ≥ 8 for hospice and score of ≥ 6 for palliative care). Wilcoxon signed rank test was used to examine if there were significant differences in palliative care and hospice knowledge levels.

Analyses were conducted with SPSS version 21.

CHAPTER 4

RESULTS

The results chapter consists of three subsections. Section one provides the descriptive statistics (frequency, mean, median, standard deviation) of the measures used in the study. Section two provides the results of primary research questions and hypothesis related to the predictors of intentions to use hospice. Section three examines the secondary research questions and hypothesis related to hospice and palliative care knowledge.

Preliminary Data Analyses

Appendix B summarizes the scale items. Overall, intentions to use hospice was high and skewed to the right side of the scale (mean = 4.4, SD = 0.72; skewness = -1.047; kurtosis = 0.49). After categorical transformation, frequency analyses showed that 18.6% of the sample had low intentions, 30.5% had high intentions, and 50.9% had very high intentions to use hospice. Additionally, average attitudes, subjective norms, perceived control, and preferences for comfort care towards the end of life were above 4 on a 1 to 5 scale. The most important people that could influence older adults' health care decisions were spouse or partner (67.5%), children (76.3%), doctor or nurse (72.2%), friends (34.3%), relatives (29%), and religious official (17.8%).

Table 4.1 summarizes the frequency and proportions of categorical independent variables. Half of the sample belonged to a church. Approximately one in three described themselves as very religious/spiritual and a similar proportion described themselves as somewhat religious/spiritual. The large majority (71.9%) reported that they never had a life threatening illness. Only 6.6 % of the sample reported fair or poor health; 26.9% reported excellent, 42.5%

reported very good and 24% reported good health status. The large majority (76.6%) said they would prefer to die home rather than in hospital, nursing home or other institution. Overall, the study participants reported high levels of preparation for health care decision-making: 75.6% had a living will and 68.9% had a health care decision maker.

Table 4.1. Characteristics of Categorical Independent Variables

Variables	N	%
Spiritual/religious		
Very religious/spiritual	53	31.4
Somewhat religious/spiritual	64	37.9
Not very religious/spiritual	25	14.8
Not at all religious/spiritual	27	16.0
Belongs to a church	87	51.5
Never had a life threatening illness	120	71.9
Self-rated health status		
Excellent health	45	26.9
Very good	71	42.5
Good	40	24.0
Fair	8	4.8
Poor	3	1.8
Place would like to die		
Home	128	76.6
Hospital	11	6.6
Nursing home	2	1.2
Other	26	15.6
Living will		
Never heard of living will	1	0.6
Have heard of living will, but does not have one	38	22.9
Have a living will	127	75.6
Health care decision maker		
Never heard	8	4.8
Have heard of health care decision maker , but does not have one	44	26.3
Have a health care decision maker	115	68.9

Primary Research Questions and Hypothesis

The primary purpose of this study was to examine the main predictors of intentions to use hospice in older adults if they are faced with a terminal illness. Four hypotheses were tested. The first hypothesis stated that older adults with higher knowledge of hospice will be more likely to have higher intentions to use hospice compared to older adults with less or no knowledge. The second hypothesis posited that older adults who have positive attitudes toward hospice will be more likely to intend to use hospice if faced with a terminal illness. The third hypothesis stated that older adults who have normative beliefs that support the use of hospice will be more likely to intend to use this service. The fourth hypothesis stated that older adults who have higher perceived control to use hospice will be more likely to intend to use this service. First, univarite analyses were used to examine the associations of different predictors with the intentions to use hospice. After examining the univariate associations, multiple linear regression analyses were used to test the hypotheses.

Univariate Analyses

Examination of associations of intention to use hospice and categorical independent variables showed that only two variables were significantly associated with intentions to use hospice: Having a living will ($F(2,162)= 4.48$, $p = .013$) and having a health care decision maker ($F(2,163) = 4.038$, $p =.019$). The associations of intentions to use hospice with education ($F(4,161) = 2.25$, $p = .066$) and income ($F(3,153) = 2.3$, $p = .077$) reached borderline significance. There were no significant associations of intentions to use hospice with gender ($F(1,165) = 0.008$, $p = .93$), age ($r = 0.025$, $p = .75$), religiousness/spirituality ($F(3,163) = 0.76$, $p = .52$), marital status ($F(4,162) = 0.21$, $p = .93$), place where would like to die ($F(3,161) = 0.77$, $p = .51$), and current health status ($F(4,160) = 0.94$, $p = .44$). Table 4.2 shows the means

and standard deviations (SD) of the continuous independent variables by the three intentions to use hospice groups. The mean scores of all variables ($p < .001$) differed by the three intention groups except social support. Pairwise comparison results are summarized in Appendix C. Levene's homogeneity of variance tests indicated that variances were equal for attitudes towards hospice ($p = .176$), subjective norms towards hospice ($p = .251$), preferences for end-of-life care ($p = .379$), and social support ($p = .633$). Therefore, Bonferroni correction was used for pairwise comparisons for these variables. Levene's homogeneity of variance tests indicated unequal variances for hospice knowledge ($p < .001$) and perceived control to use hospice variables ($p =.034$). Therefore, Tamhane's correction was used for post-hoc tests for these variables. As pairwise comparison tests indicated, hospice knowledge, subjective norms, and preferences for end-of-life care were significantly different only between low and very high intention groups. Perceived control and attitudes towards hospice were significantly different between all three intention groups.

Table 4.2. Distribution of the means and standard deviation of the predictor variable scale scores by intentions to use hospice

Scales	N	Low Intention (n=31) Mean (SD)	High Intention (n=51) Mean (SD)	Very High Intention (n=85) Mean (SD)	F (d.f.)	*p*-value
Hospice knowledge	166	4.3 (2.9)	5.8 (2.5)	7.3 (1.7)	22.2 (2, 164)	<.001
Attitudes towards hospice	166	3.8 (0.5)	4.1 (0.4)	4.5 (0.4)	24.5 (2, 164)	<.001
Subjective norms towards hospice	165	3.8 (0.4)	4.0 (0.5)	4.6 (0.5)	35.9 (2, 163)	<.001
Perceived control to use hospice	166	3.9 (0.4)	4.2 (0.5)	4.7 (0.4)	49.7 (2, 164)	<.001
Preferences for End-of-Life Care	166	4.0 (0.6)	4.2 (0.5)	4.5 (0.5)	14.4 (2, 164)	<.001
Social Support	160	2.8 (0.9)	2.7 (1.0)	2.8 (0.9)	0.09 (2, 158)	.91

Table 4.3 provides the correlations among intention to use hospice (as a scale) and continuous independent variables. Intentions to use hospice variable was significantly correlated with hospice knowledge, subjective norms towards hospice, perceived control to use hospice, preferences for comfort care at the end-of-life care. Additionally, most of the predictor variables (except social support) were significantly correlated with each other. Particularly, moderate correlations were noted between attitudes and subjective norms towards hospice (r = 0.52), attitudes towards hospice and perceived control to use hospice (r = 0.58), attitudes towards hospice and preferences for end-of-life care (r = 0.54), and subjective norms towards hospice and perceived control to use hospice (r = 0.6). Due to high correlations between predictor variables, multicollinearity may influence multiple regression results. Variance Inflation Factor (VIF) was used to assess multicollinearity. Stepwise selection methods were used to address potential multicollinearity in regression models.

Table 4.3. Correlation coefficients among predictor variables and intentions to use hospice based on the Theory of Planned Behavior

Variables	1	2	3	4	5	6
1. Hospice knowledge	--					
2. Attitudes towards hospice	0.29**	--				
3. Subjective norms towards hospice	0.26**	0.52**	--			
4. Perceived control to use hospice	0.29**	0.58**	0.60**	--		
5. Preferences for end-of-life care	0.11	0.54**	0.36**	0.38**	--	
6. Social support	0.06	0.09	-0.038	0.06	-0.008	--
7. Intentions to use hospice	0.44**	0.51**	0.61**	0.64**	0.41**	-0.011

**Correlation is significant at the 0.01 level (2-tailed).

Multiple Linear Regression Analyses

After examining the univariate associations of predictor variables with the intentions to use hospice, all predictor variables were entered into multiple linear regression models. The reported results are based on forced entry for the hospice knowledge, hospice attitudes, subjective norms towards hospice and perceived control to use hospice variables, and stepwise selection for the remaining predictor variables. The model fit summary and results of different models are presented in Table 4.4 and Table 4.5, respectively. As the results show, preferences for end-of life care was the first variable to enter into regression model one, followed by health care decision maker in model two, and perceived control, hospice knowledge, attitudes towards hospice, and subjective norms towards hospice in model three. All other independent variables were removed for the multiple regression models based on the stepwise selection criteria (entry p = .05 and removal p = .1).

Table 4.4. Model Fit Summary for Multiple Regression Models

Model	R	R-Square	Adjusted R- Square	Std. Error of the Estimate
Model 1	.461	.212	.207	.645
Model 2	.496	.246	.235	.633
Model 3	.750	.562	.543	.489

The adjusted R-square increased from model one to model three. Model one explained only 21% of the variance (R-square = .212); model 2 explained 24.6% of the variance (R-square = .246); model three explained 56.2% of the variance (R-square = .562).

Table 4.5. Initial Variable Entry Steps into the Multiple Regression Models

Model		Unstandardized Coefficients		Standardized Coefficients	t	*p*-value
		B	Std. Error	Beta		
Model 1	(Constant)	1.746	.437		3.996	.000
	Preferences for end-of life care	.612	.100	.461	6.100	.000
Model 2	(Constant)	1.287	.467		2.757	.007
	Preferences for end-of life care	.565	.100	.426	5.635	.000
	Health Care Decision Maker	.249	.100	.188	2.490	.014
Model 3	(Constant)	-.766	.436		-1.756	.081
	Preferences for end-of life care	.220	.096	.165	2.283	.024
	Health Care Decision Maker	-.020	.083	-.015	-.241	.810
	Hospice Attitudes	.150	.126	.106	1.196	.234
	Subjective Norms	.255	.084	.211	3.016	.003
	Perceived Control	.483	.119	.330	4.067	.000
	Hospice Knowledge	.065	.018	.223	3.536	.001

Note: Intentions to use hospice is the dependent variable

In model three (Table 4.5), though the health care decision maker variable was initially entered by stepwise selection, the *p* value indicated highly nonsignificant effect ($p = .81$). Therefore, the health care decision maker variable was removed and the regression model was rerun. The results of the new model are summarized in Table 4.6.

Table 4.6. Predictors of Intentions to Use Hospice based on the Relationships Specified by the Theory of Planned Behavior

Model	Unstandardized Coefficients		Standardized Coefficients	t	*p*-value
	B	Std. Error	Beta		
(Constant)	-.559	.394		-1.42	.158
Preferences for end-of-life care	.186	.082	.141	2.258	.025
Hospice Attitudes	.132	.105	.095	1.261	**.209**
Subjective Norms	.228	.078	.191	2.933	.004
Perceived Control	.495	.101	.349	4.896	.000
Hospice Knowledge	.072	.016	.253	4.438	.000

The results in Table 4.6 show that after removing the health care decision maker variable, the attitudes towards hospice variable was still not significantly associated with intentions to use hospice (($\beta = 0.09$, $p = .209$). Additionally, the examination of the histogram with normal distribution curve, Q-Q and residual plots of this model (Appendix D, figures 1a, 2a, and 3a) showed that there was some violation of normality and equal variance assumptions. Examination of standardized residuals, Cook's distance and leverage values indicated that one case (#1100) had a residual = -3.8 and was an outlier and a potentially influential point. Therefore, this case was removed and the regression model was rerun without attitudes towards hospice variable (as this variable did not show a significant effect). The histogram, Q-Q and residual plots showed improvement with approximately normal distribution and equality of variances (Appendix D, figures 1b, 2b, and 3b). The results of the final selected regression model are summarized in Table 4.7.

Table 4.7. Predictors of Intentions to Use Hospice: The Final Selected Regression Model

Model	Unstandardized Coefficients		Standardized Coefficients	t	*p*-value
	B	Std. Error	Beta		
(Constant)	-.183	.377		-.486	.627
Preferences for end-of-life care	.219	.071	.174	3.082	.002
Perceived Control	.494	.090	.361	5.505	.000
Hospice Knowledge	.085	.015	.314	5.544	.000
Subjective Norms	.222	.072	.193	3.071	.003

Note: N = 165; Intentions to use hospice is the dependent variable

For the final selected model reported in Table 4.7, R square was 0.566 and adjusted R square was 0.555, indicating that the 55.5% of the variance in intentions to use hospice was explained by preferences for end-of-life care, perceived control, hospice knowledge, and

subjective norms. Based on the multiple regression analyses results, the first hypothesis that higher knowledge of hospice in older adults will be associated with higher intentions to use hospice was confirmed ($\beta = 0.31$, $p < .001$). The third hypothesis that older adults who have normative beliefs that support the use of hospice will be more likely to intend to use this service was also confirmed ($\beta = 0.19$, $p = .003$). Additionally, the fourth hypothesis that higher perceived control to use hospice will be associated with higher intentions to use hospice was confirmed ($\beta = 0.36$, $p < .001$). Finally, the results showed that preferences for end-of-life care was also significantly associated with the intentions to use hospice ($\beta = 0.17$, $p = .002$).

The second hypothesis that older adults who have positive attitudes towards hospice will be more likely to intend to use hospice if faced with a terminal illness was not confirmed. Though more positive attitudes towards hospice were significantly associated with higher intentions to use hospice in univariate analyses ($r = 0.44$; $p = 0.01$), this association was not found in multiple regression models ($p > 0.1$). The reason for attitudes towards hospice variable becoming a non-significant predictor in the multivariate model is multicollinearity (variance inflation factor (VIF) for the attitude variable was 2.4; a VIF > 2 is indicative of multicollinearity). Particularly, significant correlations of attitudes towards hospice with other predictor variables such as hospice knowledge, subjective norms and perceived control to use hospice as well as preferences for end-of-life care contributed to the multicollinearity in the multiple regression model.

Secondary Research Questions and Hypothesis

There were two secondary research questions. The first question examined the level of hospice knowledge in older adults and whether hospice knowledge differed by race, gender, education levels, and income. The hypothesis related to this question stated that minority older

adults and older adults with lower education levels and lower income will have significantly lower knowledge about hospice. The second question examined what proportions of older adults who currently do not have a diagnosis of a serious illness had some degree of palliative care knowledge and whether older adults knew more about hospice compared to palliative care. Assessment of palliative care knowledge in older adults is exploratory in this study. Therefore, no specific hypothesis was formulated for this question.

The average hospice knowledge on a 10 point scale was 6.3 (SD = 2.5). Participants with low hospice knowledge were more likely to be older (80 years and above), $F(2, 159) = 3.83$, p = .024; r = -0.164, p =.037; in fair health, $F(4, 162) = 3.55$, p = .008; and lower income, $F(3, 154)$ = 5.17, p = .002. Hospice knowledge did not differ by gender, education level, marital status, spirituality/religiosity, and place where participants prefer to die. Associations with race were not examined as there were only seven African American participants in the sample.

First, participants answered separate questions if they have ever heard about 1) hospice and 2) palliative care. If the participants answered that they have ever heard about hospice and palliative care, then they answered the scale items measuring hospice and palliative care knowledge. Only 1.2% of the participants reported that they never heard about hospice. Approximately a third of the sample (30%) reported that they have heard a little about hospice and two third (65%) reported that they have heard a lot about hospice. Conversely, 18% of the sample reported that they never heard about palliative care, half of the sample (50%) reported that they have heard a little and only a third of the sample reported that they have heard a lot about palliative care. Approximately half of the sample reported that they would like to learn more about hospice (44%) and palliative care (51%). The comparisons of hospice and palliative care knowledge scales (Table 4.8) showed similar results to the participant's self-reported

hospice and palliative care exposure: Significantly more participants scored zero on palliative care than hospice knowledge scales (20.1% vs. 3.6%; z=-4.4, p<0.001). However, the overall knowledge scores were only marginally different for hospice and palliative care (z= -1.77, p = .077).

Table 4.8. Comparison of Palliative Care and Hospice Knowledge

Knowledge	Hospice (%)	Palliative Care (%)
None	3.6	20.1
Low	11.8	2.4
Average	45.0	29.0
High	39.6	48.5

Analyses of correct responses to the individual items of hospice and palliative care knowledge scales are summarized in Table 4.9. Among hospice knowledge items, the lower responses were in the items reflecting knowledge about hospice payment by Medicare (56.2% correct), most common place of hospice care being at home (52.7% correct), eligibility criteria related to being within 6 months of end of life (43.8% correct), and requirement for the patient to forgo curative treatments (40.8% correct).

Among palliative care items, the lower responses were in knowledge about palliative care difference from hospice (53% correct), palliative care provision with curative treatment in contrary to hospice (43% correct), and palliative care appropriateness at any age and stage of serious illness (60% correct). Participants with low palliative care knowledge were more likely to be in fair health, $F(4,163) = 4.5$, $p = .002$; less educated, $F(4, 163) = 9.65$, $p < .001$; and lower income, $F(3, 154) = 4.57$, $p = .004$. There were no significant age, gender, and marital status differences in palliative care knowledge.

Table 4.9. Correct Responses for Hospice and Palliative Care Knowledge

Variable	N	% responded correctly
Palliative Care Knowledge		
Palliative care is specialized medical care for people with serious illnesses.	169	63.3
Palliative care is focused on providing patients with relief from the pain, symptoms, and stress of a serious illness.	169	78.1
The goal of palliative care is to improve quality of life for both the patient and the family.	169	76.3
Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.	169	74.0
Palliative care cannot be provided together with treatment to cure the illness.	169	43.2
Palliative care is appropriate at any age and at any stage in a serious illness.	169	60.4
Palliative care is the same as hospice.	169	53.3
Hospice Knowledge		
All adults who have an illness that cannot be cured can get hospice services, not just those with cancer.	169	82.2
Patients can stop hospice services and start them again at a later time if they want to.	169	71.0
Patients must have health insurance to get hospice services.	168	61.5
Patients must be told by their doctor that they have 6 months to live or less to be allowed to get hospice care.	169	43.8
If a patient on hospice lives more than 6 months, hospice services must be stopped.	169	64.5
Hospice workers are available by phone 24-hours a day, every day.	169	73.4
Hospice provides medical, psychological, and spiritual care for patients and patients' family.	168	84.5
Most patients who are in hospice receive care at home.	169	52.7
Hospice can be provided with curative treatment.	168	40.8
Medicare pays for hospice.	169	56.2

CHAPTER 5

DISCUSSION, IMPLICATIONS FOR PRACTICE, AND RECOMMENDATIONS

The primary focus of this study was to empirically evaluate the predictors of intentions to use hospice if faced with a terminal illness in older adults. The Theory of Planned Behavior was used as the theoretical framework for the study. A cross-sectional non-experimental survey was conducted with 169 adults 60 years and older living in community. This chapter is divided into four sections: discussion of the findings, limitations of the study, implications for practice and translation of results into practice, and suggestions for further research.

Findings of the Study

Primary Research Questions and Hypothesis

The primary research question in this study was to identify the significant predictors of intentions to use hospice in older adults in general population. The majority of research to understand the factors affecting use of hospice focused predominantly on assessing the characteristics, knowledge, attitudes, and beliefs of the patients who were enrolled or qualified for hospice at the end of their lives and of their caregivers (Carrion, 2010; Cohen et al., 2010; Csikai & Martin, 2010; Hardy et al., 2010; Johnson et al., 2005; Johnson et al., 2011; Kreling et al., 2010; Lepore et al., 2011; Teno et al., 2004; Torke et al., 2005; Vig et al., 2010). Very few studies have focused on evaluating the knowledge, attitudes, subjective norms, perceived control, and intentions to use hospice in general older adult population who are not currently in need of hospice services. A strength of this study is that an established behavioral theory–the Theory of Planned Behavior–was used as a theoretical framework for examining predictors of intentions to

use hospice. To my knowledge, this study was the first to incorporate the TPB to examine predictors of intentions to use hospice in older adults. The TPB has been used to predict a variety of health behaviors including health services utilization, smoking, alcohol use, substance use, HIV/STDs and condom use, and screening behaviors. Several studies and meta-analyses support that the TPB can account for a significant amount of variance in behavior and intention and found that changing TPB constructs (attitude, subjective norm, and perceived control) leads to change in behavior (Albarracin et al., 2005; Albarracin, McNatt, et al., 2003; Armitage & Conner, 2001; F. Rhodes et al., 2007).

Results of this study indicated that hospice knowledge, subjective norms, perceived control and preferences of end-of-life care were significant predictors of intentions to use hospice. Together these predictor variables explained 55.5% of the variance in intentions to use hospice for this sample. Though research examining the predictors of intentions to use hospice based on the Theory of Planned Behavior is very limited, there is some support for the findings in this study.

The first hypothesis that older adults with higher hospice knowledge would have higher intentions to use hospice was confirmed. After controlling for the effects of demographic variables, attitudes towards hospice, perceived control to use hospice, subjective norms and preferences for end-of-life care, hospice knowledge was a significant predictor of intentions to use hospice. Several studies have found that lack of knowledge or incomplete knowledge of hospice is an important barrier to hospice services and end-of-life discussions in general population (Casarett, Karlawish, et al., 2005; Colon, 2012; Dussen et al., 2011; Enguidanos et al., 2011; Johnson et al., 2009; Rosenfeld et al., 2007; Ruff et al., 2011; Selsky et al., 2012; Vig et al., 2006). For example,Vig et al. (2006) have found that people with more knowledge about

hospice (who hospice cares for, where the care is provided, and what is the goal of the care) were more inclined to use hospice for loved ones in the future. A study of home health clients who are eligible for hospice, but not currently receiving it, found that a high proportion of both African American and White home health clients held erroneous ideas about hospice care and had not discussed this option with their providers (Rosenfeld et al., 2007). Ruff et al. (2011) found that prior knowledge of living wills and hospice services were associated with more positive attitudes toward hospice care, preference for limited medical interventions at end of life, and more comfort in communicating about death and dying. Hospice knowledge is a prerequisite to form attitudes, subjective norms, perceived control, and intentions to use hospice. However, it is important to note that hospice knowledge alone may not be sufficient to increase intentions to use hospice. In a study examining the associations between hospice knowledge, cultural values, social acculturation, and intentions to use hospice for cancer care among Latino adults living in the United States, the authors found that hospice knowledge may be necessary but was not sufficient to increase hospice use among Latinos. However, it is important to note that the levels of hospice knowledge and intentions to use hospice were low among the study participants and it is possible that higher hospice knowledge could have led to higher intentions to use hospice among Latinos (Selsky et al., 2012).

The second hypothesis that older adults with more positive attitudes towards hospice will have higher intentions to use hospice if faced with a terminal illness was only confirmed in univariate models. However, after adjusting for the effects of hospice knowledge, subjective norms, perceived control and preferences of end-of-life care, the attitudes towards hospice variable was not a significant predictor of intentions in this study population. The reason for attitudes towards hospice variable becoming a non-significant predictor in the multivariate model

was multicollinearity. Particularly, moderate positive correlations were noted between attitudes and subjective norms towards hospice ($r = 0.52$), attitudes towards hospice and perceived control to use hospice ($r = 0.58$), attitudes towards hospice and preferences for end-of-life care ($r = 0.54$), and subjective norms towards hospice and perceived control to use hospice ($r = 0.60$), attitudes towards hospice correlation with knowledge ($r=0.29$, $p<0.01$). Other studies have also found similar positive correlations between hospice attitudes and hospice knowledge (Johnson et al., 2009; Ruff et al., 2011) and hospice attitudes and greater preferences for life-sustaining therapies (Johnson et al., 2008).

In contrast to findings of this study, other studies have reported that positive hospice attitudes were significantly associated with higher intentions to use hospice and negative hospice attitudes were associated with low hospice use. For example, a study examining perceptions and awareness of hospice among middle aged and older adults in community found that respondents overall had favorable opinions about hospice and would recommend its services for their family members (Dussen et al., 2011). Ford et al. (2008) found that one of the main reasons for refusing hospice enrollment in patients with advanced lung cancer was having negative attitudes towards hospice and believing that hospice means giving up hope. Another study conducted in Korea used the Theory of Reasoned Action as a theoretical framework to examine how individual characteristics, attitudes, and subjective norms towards hospice explained choice intention regarding hospice in general public. This study reported that the adults who intended to use hospice had more positive attitudes and subjective norms towards hospice than nonintenders (Park & Lee, 2012). However, it is important to highlight that many of the previous studies examined only univariate associations of attitudes with intentions and did not assess simultaneous impact of multiple variables on the intentions to use hospice. For example, Park

and Lee examined only univariate associations between hospice attitudes, subjective norms, and intention to use hospice. It is possible that the effect of attitudes towards hospice could have diminished if multivariate associations of demographics, hospice attitudes and subjective norms towards hospice had been examined.

Overall, participants in this study had highly positive attitudes towards hospice which is in contrast to other studies. Several studies have documented that there are many negative attitudes about hospice in the general population, such as hospice is only for people with cancer, hospice is for the last hours or days of life, hospice is for patients who do not need high technology care, hospice starves patients, hospice keeps patients on high doses of opioids and hastens death (Rogers, 2009; Vig et al., 2010). In the current study, some reasons for such highly positive attitudes towards hospice could be that the study sample was highly educated, and high proportions of participants reported having a living will and a health care decision maker. These sample characteristics indicate that the participants could have had a high interest in hospice and end-of-life care preparation, and therefore, more positive attitudes towards hospice compared to the general population. The nonsignificant effect of positive hospice attitudes on intentions to use hospice in multivariate models in this study suggests that when the attitudes towards hospice are already highly positive in older adults, other variables such as normative beliefs and perceived control to use hospice may become more important factors than attitudes towards hospice, particularly for older adults with high income and high education.

The third hypothesis that older adults with more positive subjective norms towards hospice will have higher intentions to use hospice was confirmed. In this study, subjective norms were conceptualized as the individual's normative beliefs (whether important individuals in a person's life, including doctors, would approve or disapprove the person's interest in and use of

hospice) weighted by the individual's motivation to comply with the approval or disapproval (Ajzen & Fishbein, 1980). First, a question was asked about who are important people to the older adult that could influence his/her health-care decisions (possible answeres were spouse/partner, children, relatives, religious official, doctor/nurse, friends, and other). Then, a question stated: "Most people who are important to me probably think I should use hospice if I had exhausted all other treatment options" followed by "if most people who are important to me supported hospice, I would likely use it." Another question stated: "I think my doctor would approve of me using hospice if I had a terminal illness" followed by "If my doctor supported hospice, I would likely use it." The results showed that for the large majority of the sample the most important people who could influence older adults' health care decisions were spouses or partners (67.5%), children (76.3%), and doctor or nurse (72.2%). Additionally, approximately one third of the sample reported relatives and friends and one-in-five reported religious officials as important influences in health care decision making. After controlling for the effects of demographic variables, hospice knowledge, attitudes towards hospice, perceived control to use hospice, and preferences for end-of-life care in the multiple linear regression models, the results showed that increasing subjective norms towards hospice will significantly increase intentions to use hospice in older adults.

Research evaluating the impact of subjective norms or social influence on hospice utilization is limited and has focused mainly on the influence of physicians on their patients' decisions to enroll in hospice. Therefore, comparing the results related to the subjective norms in the current study with other studies is challenging. The results from literature indicate a direct relation between hospice use and physician willingness to provide a hospice referral: If there is a positive social influence from physicians towards using hospice, hospice utilization increases and

if there is a negative social influence towards using hospice, hospice utilization decreases. For example, how hospice is presented during the initial visit and delays in obtaining physician order for hospice were reasons precluding enrollment in hospice (Vig et al., 2010). Several studies highlighted that attitudes of physicians (Ache et al., 2011; Casarett & Quill, 2007; Ogle et al., 2002), nurses (Boyd et al., 2011; Cramer et al., 2003) and nursing home staff (Dobbs et al., 2006; Welch et al., 2008) strongly influenced hospice referrals and timing of referrals. Overall, the results of these studies highlighted that health care professionals' negative attitudes towards hospice (hospice does not add a value to care, hospice is for crisis only, hospice is only for the "very end") precluded and delayed hospice referrals. Further, the patients' and physicians' reluctance to accept that the patient is in a terminal phase of illness strongly influenced low hospice enrollment (Russell & LeGrand, 2006). Additionally, several studies have focused on examining the effect of family influence among other factors on hospice and end-of-life care decisions. For example, one of the most common barriers to hospice was unwillingness of the patient's family to accept hospice philosophy and discontinue active curative treatment for patients (Becker, 2004; Schulman-Green et al., 2005). Other studies that examined racial differences have reported a strong family influence and a preference to have a family member make decisions and provide care at the end-of-life for African Americans and Latinos (Ache et al., 2011; Born et al., 2004; Carrion, 2010; C. Jenkins et al., 2005; Johnson et al., 2008; Kreling et al., 2010; Reese et al., 1999; Torke et al., 2005; Waters, 2001).

The results of this study highlight that to increase intentions to use hospice in older adults, it is important to change not only older adults' attitudes but also subjective norms and normative beliefs of important people in the social network of older adults who can influence their health-care decision making. For the large majority of the participants in this study, the

most important people who could influence older adults' health care decisions were children (76.3%), doctor or nurse (72.2%), and spouses or partners (67.5%). Therefore, educational efforts should focus on educating family members of older adults including younger generations as well as physicians/nurses about the benefits that hospice can provide.

The fourth hypothesis that older adults with higher perceived control to use hospice will have stronger intentions to use hospice was confirmed. After controlling for the effects of demographic variables, hospice knowledge, hospice attitudes, subjective norms towards hospice, and preferences for end-of-life care, the results showed that increasing perceived control to use hospice significantly increased intentions to use hospice in older adults. Based on the current review of the literature, no study to date has examined the association of perceived control and intention to use hospice or hospice enrollment in older adults. In this study, perceived control was conceptualized as older adults' overall confidence and perception of control to use hospice if they wanted to (Ajzen, 1991). Participants were asked to rate their confidence in being able to discuss hospice choice with family and doctors and being able to access hospice. As such, the percevied control construct takes into account both older adult's perceived self-efficacy in expressing their wishes as well as their confidence to overcome environmental constraints such as access to hospice. Ability to pay for hospice care and health insurance coverage of hospice can be perceived as environmental constraints by older adults and are important determinants of access to hospice. Hospice is covered under Medicare (major source of payment), Medicaid, and most private insurance plans. In 2011, the percentage of hospice patients covered by the Medicare hospice benefit versus other payment sources was 84.1%. Medicaid hospice benefit covered 5.2% of patients. Most importantly, patients can receive hospice care regardless of ability to pay (National Hospice and Palliative Care Organization, 2012). It is important to

underscore that only 56% of the participants in this study knew that Medicare pays for hospice, which can potentially lower the perceived control to use hospice.

Among other independent variables, having a living will and a health care decision maker were significantly associated with intentions to use hospice in univariate but not multivariate models. Preference for comfort care at the end of life was a significant predictor of intentions to use hospice in both univariate and the multiple regression models. Societal and cultural views of death can have a profound impact on people's preferences for care at the end of life. America has a death-denying culture and many patients and their physicians are reluctant to accept that the patient is in a phase of illness where the goals of care cannot be curative any longer (Cloud, 2000; Russell & LeGrand, 2006). Refusal to acknowledge that chemotherapy cannot overcome incurable cancers is not an uncommon phenomenon. In a large national prospective study of 1,193 patients with stage IV metastatic lung and colorectal cancer, the authors found that the large majority of the patients (69% of patients with lung cancer and 81% of patients with colorectal cancer) did not understand that their chemotherapy treatment was unlikely to cure their cancer. The misunderstanding of the effectiveness of chemotherapy can impede patients' ability to make truly informed treatments decisions (Weeks et al., 2012). Additionally, the costs of aggressive treatments towards the end of life can be staggering without significantly improving the quality of life for the patients and families. For example, the cost of oral chemotherapy, radiation, blood and blood products transfusions can exceed $10,000 per month. Similarly, the costs of life-sustaining therapies for congestive heart failure towards end of life can be as high as $1,300 per day. In contrast, the approximate cost for outpatient hospice care in 2006 was $126 daily, not exceeding $4000 per month (Wright & Katz, 2007). Despite significant differences between the costs of aggressive treatments and hospice care, many studies reported

high patient and family satisfaction with hospice care compared to the care in institutions (Candy et al., 2011; Casarett et al., 2003; Kiely et al., 2010; Teno et al., 2004).

Advances in medicine frequently lead to a "do everything" approach to health care despite a large amount of evidence on the low effectiveness of many aggressive interventions in older adults. For example, numerous studies have documented low survival rates and serious complications (multiple rib fractures, neurologic sequelae, etc.) after cardiopulmonary resuscitation (CPR) for older patients (Bigham et al., 2011; Cohn et al., 1993; Gordon & Cheung, 1993; Hamill, 1995). Despite these statistics, research indicates that many patients and even healthcare professionals significantly overestimate the success and underestimate the negative consequences of CPR in older patients (Adams & Snedden, 2006; Hayward, 1999). Overall, a substantial group of older adults are willing to have aggressive treatments to prolong life even for a short time, despite acknowledging that aggressive treatments will significantly reduce their quality of life (Cicirelli, 2002). For some terminally ill patients it may be difficult to accept that death is approaching. Others would like more time to settle their affairs, and others hope for cure. Additionally, the percentage of older adults who will refuse aggressive treatments depends on the aggressiveness of the treatment. Older adults are more likely to refuse a respirator and tube feeding than cardiopulmonary resuscitation (CPR) and intravenous fluids, and even less likely to refuse antibiotics and oxygen (Cicirelli, 1998; Henderson, 1990; Yung et al., 2010).

Additionally, preferences for end-of-life care are associated with preferences for place of death. In this study, I found that the majority of participants (77%) reported that they would prefer to die at home. This result is similar to other studies. Most Americans report that they would prefer to die at home; however, a smaller proportion of patients are able to realize their preference for place of death (Flory et al., 2004; Muramatsu, Hoyem, Yin, & Campbell, 2008;

Tang, 2003; Tang & McCorkle, 2003). In 2001, the proportion of people who died at home differed significantly by state. The Western part of the United States had higher rates of at home death, whereas upper Midwest and Eastern states had the lower rates (Center for Gerontology and Health Care Research, 2001b). In Georgia in 2001, only 20.5 % of patients died at home (23.2% average for the United States), whereas the majority died at hospital (55.2%) and nursing home (15.9%) (Center for Gerontology and Health Care Research, 2001a). Some of the major considerations in decision making for the place of death are quality of life and quality of healthcare, availability and ability of family caregivers, concerns of being a burden to others, and long-standing relationships with healthcare providers (Tang, 2003). Importantly, hospice facilitates dying at home as the most common form of hospice in the United States is the provision of services at the home of patients (National Hospice and Palliative Care Organization, 2012). A study examining the response of patients and their families to a severe illness, highlighted that effective communication among patients, families, and clinicians is important and can help jointly develop a treatment that respects patient and family values and takes into consideration of what is medically possible (Quill et al., 2009). The promotion of a public discussion of death and end-of life care is very important: If people openly discuss the end-of-life issues and understand the effectiveness and side effects of aggressive interventions, they will be more likely to think about what type of care they would want if faced with a life-limiting illness and will take action to make their end-of-life care wishes known before a crisis happens. For example, in a study with 1,231 patients with lung or colorectal cancer, the authors found that patients who had early end-of-life care discussions with their physicians were less likely to receive aggressive care (chemotherapy in last 14 days of life, intensive unit care, and acute hospital-based care) and were more likely to receive hospice care and started hospice earlier

during the eligibility period (Mack et al., 2012). Further education of the older adults about advance directives, living wills, designation of health care proxy and legal guardian, hospice and palliative care is essential to ensure that patients know all options and make informed choices. To summarize, the results of this study showed that older adults with higher knowledge of hospice, normative beliefs that support the use of hospice, higher perceived control to use hospice, and preferences of comfort care at the end of life were more likely to have higher intentions to use hospice compared to older adults with less or no knowledge, lower normative beliefs, lower perceived control to use hospice, and preferences for aggressive treatments at the end of life. It is important to highlight that the study sample was a relatively restricted group based on race, income, level of education and high preparation for end of life (living wills and health care decision maker). The restriction of the sample could be the reason why most of the demographic variables were not significantly associated with intentions to use hospice. It is possible that demographic characteristics will impact intentions to use hospice in African American, Latino, and Asian older adults, as well as older adults with lower income and lower levels of education. For example, several studies have found that minority adults had considerably and consistently lower hospice utilization rates compared to White adults (Connor et al., 2008; Givens et al., 2010; Greiner et al., 2003; Hardy et al., 2010; Johnson et al., 2011; Kapo et al., 2005; Lepore et al., 2011). Race was associated with limited health care access, lower knowledge of hospice, lower end of life care preparation, higher discomfort discussing death and hospice referral, and preference of aggressive care at the end-of-life, preference to have the family to make decisions and provide care at the end-of-life in African Americans and Latinos (Ache et al., 2011; Born et al., 2004; Carrion, 2010; Frost, Cook, Heyland, & Fowler, 2011; C. Jenkins et al., 2005; Johnson et al., 2008; Kreling et al., 2010; Reese et al., 1999; Torke

et al., 2005; Waters, 2001). Additionally, a recent study reported that income was associated with hospice choice and place of death: Patients with limited income and support beyond what routine hospice care can offer were less likely to die at home (Barclay, Kuchibhatla, Tulsky, & Johnson, 2013). Some of the mechanisms associated with lower income and death in institutions reported by other studies were poorer access to health care, lower knowledge of resources, less communication with providers about care preferences, and lack of resources to assist with caregiving (Koffman et al., 2007; Volandes et al., 2008). Interestingly, the authors of the TPB stated that external factors such as demographic and environmental characteristics operate through the main constructs of the theory - attitude, subjective norm, perceived control - and do not independently contribute to predict the likelihood of performing a behavior (Ajzen, 1991).

Hospice Knowledge

There were two secondary research questions. The first question examined the level of hospice knowledge in older adults and whether hospice knowledge differed by race, gender, education levels, and income. The results showed that hospice knowledge was high both on the self-reported exposure to hospice information question (only 1.2% of the participants reported that they never heard about hospice) and hospice knowledge scale scores (only 3.6% scored zero). The majority of the sample had average (45%) or high (39.6%) hospice knowledge scores. However, though overall hospice knowledge scale scores were high, there were notable deficits in certain areas. Particularly, only 56% of the participants knew that Medicare pays for hospice. This result is consistent with a recently published study, where the authors reported that the majority of participants did not know whether hospice is covered by Medicare, Medicaid, and private insurance (Dussen et al., 2011).

Additionally, approximately half of the sample (47%) did not know that the most common site for hospice care is provision of services at home. The lack of knowledge of this important information is particularly significant as the majority of participants (77%) reported that they would prefer to die home, and hospice facilitates dying at home (National Hospice and Palliative Care Organization, 2012). Other studies have also found that many patients and families who are referred for a hospice information visit had significant information needs, wanted to know about the frequency of visits, payment options, and practical support that hospice provides (Casarett, Crowley, et al., 2005).

Other deficit areas in hospice knowledge were in the eligibility criteria: 56% of the sample did not know that to be eligible for hospice, the patient needs to be within 6 months of end of life, and 59% did not know that the patient must forgo curative treatments. It is important to highlight that the definition of curative treatments may not be the same for different hospice facilities in different parts of the US, and some hospices offer radiation therapy and chemotherapy if these treatments can help alleviate symptoms. Some larger hospices and insurance companies (Capital Hospice in Washington, DC, UnitedHealth, etc.) offer "open-access care" programs that allow patients to continue their current medical treatments that can slow or change disease progression, while enrolled in hospice. However, numbers of open access hospices are very limited in the United States, as open access is much more expensive than the regular hospice services and only larger hospices are able to dilute the expenses among many patients (Wright & Katz, 2007). Open-access hospice care is a relatively new phenomenon and further research is needed to understand if offering open-access significantly improves hospice utilization and patient and family satisfaction.

The results showed that participants with low hospice knowledge were more likely to be older (80 years and above), in fair health, and lower income. A study by Colon (2012) found that higher income and higher levels of education were associated with higher knowledge of hospice and more positive hospice attitudes. The finding that older adults with lower income are less likely to know about hospice is particularly relevant as a recently published study found that patients with lower incomes are less likely to enroll in hospice or more likely to enroll late (Fairfield et al., 2012). Conversely, the hypothesis that older adults with lower education levels will have lower hospice knowledge was not confirmed. Additionally, hospice knowledge did not differ by gender, marital status, spirituality/religiosity, and place where participants prefer to die. Associations of hospice knowledge with race were not examined as there were only seven African American participants in the sample.

Slightly less than half of the sample (44%) reported that they would like to learn more about hospice. It is important to note that even though hospice offers important benefits and support to patients and their families, the hospice enrollment decision frequently requires patients and their families to comprehend and process complex information in a short period of time and in very challenging circumstances. Patients are typically referred by their physicians to hospice near the very end of life, often within days of death, thus making the time to process the information about hospice very short (Ackard, Eisenberg, & Neumark-Sztainer, 2007; Rickerson et al., 2005; Schockett et al., 2005). Older adults may benefit more from hospice and make more informed decisions if they are educated about hospice *before* they become terminally ill and near the end of life. Additionally, physicians may need to be educated to discuss hospice and palliative care with their patients and refer the patients earlier to hospice in the course of a serious illness.

Palliative Care Knowledge

The second question examined what proportions of older adults who currently do not have a diagnosis of a serious illness had some degree of palliative care knowledge and whether older adults knew more about hospice compared to palliative care. Approximately half of the sample (47%) did not know that palliative care is different than hospice and 40% did not know that palliative care is appropriate at any age and stage of serious illness. A notable deficit in palliative care knowledge was that 57% of the sample did not know that palliative care can be provided with curative treatment in contrast to hospice. This information is very important for older adults as palliative care addresses the fragmented traditional healthcare model for serious illnesses. In the traditional model, patients receive life-prolonging curative treatment up to the terminal stage of the disease; only after patients get to the terminal stage with a life expectancy of 6 months or less, they can be offered an opportunity to abruptly shift to a hospice care focusing on quality of life and comfort care. It is important to educate older adults that palliative care is different from hospice and can be provided with curative treatments and to encourage physicians and older adults to incorporate palliative care treatments early in the course of a serious illness. Palliative care has been associated with greater satisfaction with care, higher quality of life and mood, fewer intensive care unit admissions, and lower total health care costs following hospital discharge (Bakitas et al., 2009; Gade et al., 2008; Meier, 2011).

Importantly, palliative care knowledge was overall fairly high for this study sample, which likely can be explained by high educational attainment of the majority of the participants as well as high proportions reporting having a living will and a health care decision maker compared to the general population. In the present study, participants with low palliative care knowledge were more likely to be in fair health, less educated, and lower income. There were no

significant age, gender, and marital status differences in palliative care knowledge. On the self-reported exposure to palliative care information question, 18% of the participants reported that they had never heard about palliative care. Similarly, palliative care knowledge scale scores showed that 20% of the sample had no knowledge of palliative care**.** The comparisons of hospice and palliative care knowledge scales showed that significantly older adults had no knowledge of palliative care than hospice. This difference in hospice and palliative care knowledge among older adults is expected as palliative care services started to expand in the United States only over the past decade whereas hospice was first introduced in the 1970s. Importantly, approximately half of the sample reported that they would like to learn more about palliative care. These results show that educational interventions are needed to increase palliative care knowledge in older adults in the general population to help with smoother transition from curative to comfort care at the end of life.

Limitations of the study

This study has some limitations. First, it described the decision making process of a sample of older adults who were recruited from the community by using snowball sampling and purposeful sampling. The study sample consisted of primarily White, high income and highly educated older adults; thus, the results are not generalizable to other races or ethnic groups, as well as low income and less educated older adults. Overall, since death and end-of-life care preparation is a taboo subject in American society, it is challenging to recruit older adults to participate in studies about hospice and end-of-life care. Furthermore, it is more difficult to recruit minority older adults than White older adults. Other researchers have also reported low participation rates for African Americans in studies examining the end-of-life care preferences and attitudes (Johnson et al., 2008; Stahl & Vasquez, 2004).

Second, there is a potential participation bias in the study sample. High proportions of participants reported having a living will and a health care decision maker, which is an indication that the participants could have had a high interest in the subject of death and end-of-life care preparation compared to the general population. Third, a possible limitation is that intent may not be strongly associated with future behavior. There is high level of anxiety related to death and end-of-life care decision making; therefore, it is difficult to predict how high intentions to use hospice will translate into a use of hospice when older adults are faced with a terminal illness in the future.

Fourth, the study is based on self-reports that can lead to potential misreporting of the information. However, most of the survey responses were collected online and were anonymous. Additionally, the contents of the survey are not related to possible social stigma and therefore, there is no social pressure on participants to provide misinformation. Thus, it is unlikely that participants would over or underreport their knowledge, attitudes, subjective norms, perceived control, and intentions to use hospice.

Finally, the measures to assess subjective norms towards hospice, perceived control to use hospice and palliative care knowledge were constructed by the authors of this study and were not previously tested for reliability and validity. However, it is important to highlight that currently there are no reliable and valid measurement instruments for assessing these constructs in older adults.

Implications and Recommendations

Based on a theoretical framework and empirical results, the current study supports the hypothesis that intentions to use hospice in older adults are influenced by hospice knowledge, preferences for quality of life rather than aggressive treatments, normative beliefs towards hospice and perceived control to use hospice if faced with a terminal illness. These results provide a better understanding on where to focus while developing interventions to educate older adults about hospice *before a crisis* happens, when patients and families are forced to comprehend complex information about hospice and make health care decisions within a short timeline.

Educational interventions targeted to increase intention to use hospice and eventually hospice use should target several areas. First, interventions are needed to increase hospice knowledge among older adults. Particularly, Medicare coverage of hospice, hospice services availability regardless of ability to pay, most common place of hospice care being at home, and eligibility criteria are some of the areas that should be incorporated in educational interventions for older adults. Second, interventions need to focus on increasing perceived control in older adults. To increase perceived control, older adults need to be educated that hospice services are accessible to them regardless of gender, race, income, insurance coverage and ability to pay. Also, interventions need to empower older adults to feel confident about their end-of-life care choices and teach them strategies how to bring up hospice conversations to their family, physicians, and friends. Third, interventions need to focus on increasing subjective norms and changing the normative beliefs about hospice. The results of this study showed that the efforts must focus not only on older adults but also on important people in the social network of older adults such as family members including younger generations, physicians/nurses, friends, and

religious officials about the philosophy and benefits that hospice can provide. Particularly, physicians should discuss hospice and palliative care during routine advance care planning with patients and important people in older adults' social environment.

Fourth, interventions need to focus on educating older adults, as well as their physicians, about different choices available to them towards the end of life and helping them make informed decisions about the care they want to have at the end of their life. It is important to note that these results come from older adults who had higher interest in hospice compared to general population. Researchers and practitioners need to reach those older adults for whom the topics of death, hospice and end-of-life preparations are a taboo. Promoting a public discussion of death and end-of life care is very important: If people openly discuss the end-of-life issues and understand the effectiveness and side effects of aggressive interventions, they will be more likely to think about what type of care they would want if faced with a life-limiting illness and will take action to make their end-of-life care wishes known *before a crisis happens*. Further education of the older adults about advance directives, living wills, designation of health care proxy and of a legal guardian, hospice and palliative care is essential to ensure that patients know their options and make informed choices.

Further Research

This study provides the basis for intervention research studies examining the efficacy and effectiveness of different types of educational materials about hospice and palliative care (brochures, video, in person lectures, etc.). Educational materials are needed to improve intentions to use hospice and, ultimately, the use of hospice in older adults. However, this study needs to be repeated with a more diverse older adult population, specifically racial minorities who may have lower intentions to use hospice. Additionally, the study should be replicated with

less educated and lower income older adult groups to examine whether the results of this study are consistent across different older adult population groups. Additionally, further research should focus on not only estimating the knowledge of palliative care but also attitudes, subjective norms, and perceived control to use palliative care in older adults. Overall, there are not many measurement instruments that can be used to assess the attitudes, subjective norms, perceived control to use palliative care, and palliative care knowledge in older adults. Thus, more research is needed to refine the existing scales and develop new scales that have high reliability and validity for hospice and palliative care psychosocial research.

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APPENDIX A

SURVEY: Planning Ahead: What Will I Do?

Thank you for taking time to complete this survey. It should take about 20 minutes to complete this survey.

We appreciate your participation!

Section 1 of 5 has general questions about you and your health. Place a "X" in the blank space next to the response that best describes you.

1. Gender

   _____a. Man
   _____b. Woman

2. Race (mark all that apply)

   _____a. African American
   _____b. White
   _____c. Latino
   _____d. Asian
   _____e. Other _____

3. How old are you? _____

4. What is your current marital status?

   _____a. Single, never married
   _____b. Married
   _____c. Separated
   _____d. Divorced
   _____e. Widowed

5. Do you have living children?

   _____ Yes
   _____ No

6. Do you consider yourself

   _____a. Very religious/spiritual
   _____b. Somewhat religious/spiritual
   _____c. Not very religious/spiritual
   _____d. Not at all religious/spiritual

7. Do you belong to a church?

   _____a. I do not belong to a church
   _____b. I belong to a church. My church is _____

8. What is the highest level of education you completed?

_____a. Less than high school
_____b. High school graduated or GED
_____c. Some college or technical training beyond high school
_____d. College graduate
_____e. Post-graduate or professional degree

9. What country are you from? _____

10. If you live in the United States, in which state do you live?_____

11. In general, how would you rate your health right now?

_____a. Excellent health
_____b. Very good health
_____c. Good health
_____d. Fair health
_____e. Poor health

12. Have you ever had a life-threatening disease/injury?

_____ No
_____ Yes. If yes, when and what type? _____

Section 2 of 5: We are interested in your beliefs about the medical care you would want if you had a serious illness that doctors could not cure. These questions are not about your current health; we are simply interested in your thoughts and feelings. There is no right or wrong answer.

13. If you were seriously ill with a disease that could not be cured and you could choose where to die, where would you want to die?

_____a. Home
_____b. Hospital
_____c. Nursing Home
_____d. Other _____

Indicate how much you <u>agree or disagree</u> with the following statements.

14. **If I had a disease that could not be cured:**

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	I would want to live as long as possible, even if I had to be on life support or a breathing machine.					
b.	Being out of pain would be more important to me than living as long as possible.					
c.	I would want to live as long as possible, even if I had to be fed through a tube.					
d.	I would want to live as long as possible, even if I were in severe pain.					
e.	Being comfortable would be more important to me than living as long as possible.					
f.	Living as long as possible would be most important.					
g.	I would want to live as long as possible, even if my brain had stopped working.					
h.	Being at home would be more important to me than being in the hospital.					

Section 3 of 5 contains questions and statements about hospice. Hospice is a program that provides care to people with illnesses that cannot be cured when they are at the end of their lives. The goal of hospice care is to keep terminally ill patients as comfortable as possible.

Please place an **"X"** in the blank space next to the response.

15. Have you ever heard of hospice?

_____a. I have <u>never</u> heard of hospice and I do not know anything about it.
_____b. I have heard <u>a little</u> about hospice.
_____c. I have heard <u>a lot</u> about hospice.

16. How did you learn about hospice services? Tell us if what you heard or experienced gave you a good or a bad impression overall. (mark all that apply)

		YES, good impression	YES, bad impression	Does not apply
a.	I know someone who used hospice services.			
b.	I have used hospice services myself.			
c.	I heard about hospice from the radio, television, or newspaper			
d.	I heard about hospice from my minister or pastor.			
e.	I heard about hospice from others.			
f.	I know someone who works for hospice			

17. **When thinking about hospice, indicate if the following statements are true or false.**

		True	False	Don't Know
a.	All adults who have an illness that cannot be cured can get hospice services, not just those with cancer.			
b.	Patients can stop hospice services and start them again at a later time if they want to.			
c.	Patients must have health insurance to get hospice services.			
d.	Patients must be told by their doctor that they have 6 months to live or less to be allowed to get hospice care.			
e.	If a patient on hospice lives more than 6 months, hospice services must be stopped.			
f.	Hospice workers are available by phone 24-hours a day, every day.			
g.	Hospice provides medical, psychological, and spiritual care for patients and patients' family.			
h.	Most patients who are in hospice receive care at home.			
i.	Hospice can be provided with curative treatment.			
j.	Medicare pays for hospice.			

18. **The following questions are NOT about your current state of health. Indicate how much you <u>agree or disagree</u> with these statements.**

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	I would be comfortable talking about hospice with my doctor.					
b.	When there is little hope for curing a patient, doctors should always talk about hospice as an option.					
c.	In all circumstances I prefer hospital care over hospice care.					
d.	Hospice care means giving up hope.					
e.	Doctors should generally try to keep their patients alive on machines for as long as possible.					
f.	If my doctor recommended hospice care, I would feel that he/she is giving up on me.					
g.	Hospice care causes people to die before their time.					
h.	Talking about hospice services should be done with patients before they are in the last stages of their disease.					
i.	Patients and families do not want to have strangers in their home, even if the strangers are with hospice.					

19. Who are the people important to you that could influence your health-care decisions? (choose all that apply)

_____a. Spouse or Partner
_____b. Children
_____c. Relatives
_____d. Religious Official (e.g., church minister, priest, rabbi)
_____e. Doctor or Nurse
_____f. Friends
_____g. Other _____

20. **Next, when thinking about people important to you and how you feel about hospice, rate how strongly you agree or disagree with the following statements.**

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	Most people who are important to me probably think I should use hospice if I had exhausted all other treatment options.					
b.	Most of the important people in my life would not support my interest in hospice.					
c.	I think my doctor would approve of me using hospice if I had a terminal illness.					
d.	Other people I know used hospice when they had a terminal illness.					
e.	If most people who are important to me supported hospice, I would likely use it.					
f.	If my doctor supported hospice, I would likely use it.					

21. When thinking about how you feel about hospice, rate how strongly you agree or disagree with the following statements.

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	I am confident that I can ask my doctor for hospice care if I decide to use it.					
b.	My family or others close to me will honor my wishes about using or not using hospice.					
c.	My use of hospice is up to me.					
d.	I am confident that I will have access to hospice care if I decide to use it.					

e.	My family or others close to me will make the right decision for me if I am unable.					
f.	If a family member had a terminal disease and had less than 6 months to live, I would strongly recommend hospice care for them.					
g.	If I had a terminal disease and had less than 6 months to live, I would enroll in hospice.					
h.	I intend to use hospice care if I am faced with a terminal illness in the future.					

22. Below are concerns related to end of life that have been expressed by people age 60 and older. Rate how strongly you agree or disagree with the following statements.

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	I feel comfortable talking about death and dying with my loved ones.					
b.	Accepting that you are going to die means you do not have faith.					
c.	It is a good idea to plan for end-of-life care.					
d.	I find it difficult to think about my death.					

23. On a scale of 1 to 7, where:

    1 = We've barely touched on the subject
    7 = We've talked about it at length and taken action

    How would you describe your discussions with your family about your preferences about end-of-life care?

1	2	3	4	5	6	7
We have barely touched on the subject					We've talked about it at length and taken action	

Section 4 of 5: We are interested to learn what you know about <u>Palliative Care</u>. Place an "X" in the blank space next to the response.

24. Have you ever heard of palliative care?

_____a. I have <u>never</u> heard of palliative care.
_____b. I have heard <u>a little</u> about palliative care.
_____c. I have heard <u>a lot</u> about palliative care.

25. How did you learn about palliative care? (mark all that apply)
_____a. I know someone who used palliative care services.
_____b. I have used palliative care services myself.
_____c. I heard about palliative care from radio, television, or newspaper.
_____d. I heard about palliative care from my pastor.
_____e. I heard about palliative care from others.
_____f. I know someone who works in palliative care

26. When thinking about palliative care, indicate if the following statements are true or false.

		True	False	Don't Know
a.	Palliative care is specialized medical care for people with serious illnesses.			
b.	Palliative care is focused on providing patients with relief from the pain, symptoms, and stress of a serious illness.			
c.	The goal of palliative care is to improve quality of life for both the patient and the family.			
d.	Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.			
e.	Palliative care cannot be provided together with treatment to cure the illness.			
f.	Palliative care is appropriate at any age and at any stage in a serious illness.			
g.	It is important that patients with serious illness and their families be educated about palliative care options available to them together with curative treatment.			
h.	Palliative care is the same as hospice.			

Section 5 of 5: These statements are about who would take care of you if you had a serious illness that could not be cured and you could not take care of yourself. Additionally, the section has general questions that will help describe survey respondents.

27. Indicate how much you agree or disagree with the following statements.

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
a.	My children would take care of me.						
b.	My spouse would take care of me.						
c.	Other family members would take care of me.						
d.	Friends would take care of me.						
e.	Members of my church would take care of me.						
f.	There would be no one to take care of me.						

28. A "living will" is a written document that states the kind of medical care you would want if you could not speak for yourself. Have you heard of a living will and do you have one?

_____ a. I have never heard of a living will

_____ b. I have heard of a living will, but I do not have one

_____ c. I have a living will

29. A Durable Power of Attorney for Health Care or a Health Care Decision Maker is a written document naming a person to make medical decisions for you if you are unable to make decisions for yourself. Have you heard of a Health Care Decision Maker and do you have one?

_____ a. I have never heard of a Health Care Decision Maker

_____ b. I have heard of a Health Care Decision Maker, but I do not have one

_____ c. I have a Health Care Decision Maker

The following question about income will help describe survey respondents.

30. What is your annual household income?
    _____a. less than $25,000
    _____b. $25,000 to under $50,000
    _____c. $50,000 to under $75,000
    _____d. $75,000 or more

31. How did you hear/learn about this study?
    _____a. Friend
    _____b. Family member
    _____c. OLLI
    _____d. Athens Community Council on Aging
    _____e. UGA Retired Educators
    _____f. Other. Who or where?_____

32. Is there anything else you would like to add?

    _____

    _____

33. Would you be interested in learning more about hospice services?
    _____a. YES
    _____b. NO
    _____c. Not Sure

34. Would you be interested in learning more about palliative care?
    _____a. YES
    _____b. NO
    _____c. Not Sure

If you are interested in learning more about hospice services and palliative care, the website Health Team Works provides excellent information:
http://www.healthteamworks.org/guidelines/palliative-care.html

THANK YOU
For Your Valuable Information!

APPENDIX B

DESCRIPTIVE STATISTICS FOR SCALE ITEMS

Variable	N	Mean	SD	α if item deleted
Dependent Measure				
Intentions to use hospice if faced with a terminal illness **(α = 0.94)**	167	4.4	0.72	
1. If I had a terminal disease and had less than 6 months to live, I would enroll in hospice.	164	4.44	.74	.94
2. I intend to use hospice care if I am faced with a terminal illness in the future.	166	4.43	.74	.89
3. If a family member had a terminal disease and had less than 6 months to live, I would strongly recommend hospice care for them.	167	4.39	.81	.89
Independent Measures				
Attitudes **(Cronbach's α = 0.76)**	168	4.25	.51	
1. I would be comfortable talking about hospice with my doctor.	166	4.63	.51	.75
2. When there is little hope for curing a patient, doctors should always talk about hospice as an option.	166	4.46	.74	.75
3. In all circumstances I prefer hospital care over hospice care.	166	4.13	.92	.73
4. Hospice care means giving up hope.	166	3.87	1.10	.73
5. Doctors should generally try to keep their patients alive on machines for as long as possible.	166	4.50	.83	.74
6. If my doctor recommended hospice care, I would feel that he/she is giving up on me.	166	3.78	1.12	.72
7. Hospice care causes people to die before their time.	166	4.51	.73	.72
8. Talking about hospice services should be done with patients before they are in the last stages of their disease.	166	4.37	.89	.77
9. Patients and families do not want to have strangers in their home, even if the strangers are with hospice.	166	4.02	.86	.75
Subjective Norms **(α = 0.80)**	167	4.28	.60	
1. Most people who are important to me probably think I should use hospice if I had exhausted all other treatment options.	165	4.28	.70	.80
3 I think my doctor would approve of me using hospice if I had a terminal illness.	165	4.32	.80	.77
4 Other people I know used hospice when they had a terminal illness.	165	4.40	.81	.78
5 If most people who are important to me supported hospice, I would likely use it.	165	4.23	.84	.73
6 If my doctor supported hospice, I would likely use it.	165	4.18	.86	.71

Perceived Control **(α = 0.80)**	167	4.41	0.5	
1. I am confident that I can ask my doctor for hospice care if I decide to use it.	163	4.44	.65	.75
2. My family or others close to me will honor my wishes about using or not using hospice.	163	4.51	.64	.76
3. My use of hospice is up to me.	163	4.48	.69	.76
4. I am confident that I will have access to hospice care if I decide to use it.	163	4.34	.72	.76
5. My family or others close to me will make the right decision for me if I am unable.	163	4.31	.71	.79
Preferences for end of Life Care **(α =0.74)**	169	4.32	.56	
If I had a disease that could not be cured:				
1. I would want to live as long as possible, even if I had to be on life support or a breathing machine.	163	4.48	.88	.70
2. Being out of pain would be more important to me than living as long as possible.	163	4.21	1.1	.70
3. I would want to live as long as possible, even if I had to be fed through a tube.	163	4.39	.92	.69
4. I would want to live as long as possible, even if I were in severe pain.	163	4.56	.71	.68
5. Being comfortable would be more important to me than living as long as possible.	163	4.33	.92	.67
6. Living as long as possible would be most important.	163	4.21	1.04	.68
7. I would want to live as long as possible, even if my brain had stopped working.	163	4.78	.62	.72
8. Being at home would be more important to me than being in the hospital.	163	3.80	1.07	.79
Social Support **(α = 0.66)**	162	2.79	.97	
1. My children would take care of me.	157	3.17	1.59	.64
2. My spouse would take care of me.	157	2.95	2.10	.67
3. Other family members would take care of me.	157	2.63	1.52	.57
4. Friends would take care of me.	157	2.67	1.26	.60
5. Members of my church would take care of me.	157	1.80	1.49	.61
6. There would be no one to take care of me.	157	3.54	1.49	.59

APPENDIX C

ANOVA COMPARISONS

Test of Homogeneity of Variances

	Levene Statistic	df1	df2	Sig.
Hospice Knowledge	9.553	2	164	.000
Social Support	.459	2	158	.633
Perceived Control	3.457	2	164	.034
Subjective Norms	1.394	2	163	.251
Hospice Attitudes	1.757	2	164	.176
Preferences for end-of life care	.976	2	164	.379

Dependent Variable: Hospice Knowledge

	(I) INTENTIONS	(J) INTENTIONS	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Tamhane	Low Intentions	High Intentions	-1.51360	.63617	.061	-3.0794	.0522
		Very High Intentions	-3.02732*	.56205	.000	-4.4311	-1.6235
	High Intentions	Low Intentions	1.51360	.63617	.061	-.0522	3.0794
		Very High Intentions	-1.51373*	.40079	.001	-2.4914	-.5360
	Very High Intentions	Low Intentions	3.02732*	.56205	.000	1.6235	4.4311
		High Intentions	1.51373*	.40079	.001	.5360	2.4914

*. The mean difference is significant at the 0.05 level.

Dependent Variable: Perceived Control

	(I) INTENTIONS	(J) INTENTIONS	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Tamhane	Low Intentions	High Intentions	-.29092*	.09346	.008	-.5192	-.0627
		Very High Intentions	-.76818*	.07717	.000	-.9584	-.5779
	High Intentions	Low Intentions	.29092*	.09346	.008	.0627	.5192
		Very High Intentions	-.47725*	.07701	.000	-.6648	-.2897
	Very High Intentions	Low Intentions	.76818*	.07717	.000	.5779	.9584
		High Intentions	.47725*	.07701	.000	.2897	.6648

*. The mean difference is significant at the 0.05 level.

Dependent Variable: Subjective Norms

	(I) INTENTIONS	(J) INTENTIONS	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Bonferroni	Low Intentions	High Intentions	-.19516	.11619	.285	-.4762	.0859
		Very High Intentions	-.77497*	.10724	.000	-1.0344	-.5156
	High Intentions	Low Intentions	.19516	.11619	.285	-.0859	.4762
		Very High Intentions	-.57980*	.08944	.000	-.7962	-.3635
	Very High Intentions	Low Intentions	.77497*	.10724	.000	.5156	1.0344
		High Intentions	.57980*	.08944	.000	.3635	.7962

*. The mean difference is significant at the 0.05 level.

Dependent Variable: Attitudes towards Hospice

	(I) INTENTIONS	(J) INTENTIONS	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Bonferroni	Low Intentions	High Intentions	-.29041*	.10328	.017	-.5402	-.0406
		Very High Intentions	-.63050*	.09515	.000	-.8607	-.4003
	High Intentions	Low Intentions	.29041*	.10328	.017	.0406	.5402
		Very High Intentions	-.34009*	.08033	.000	-.5344	-.1458
	Very High Intentions	Low Intentions	.63050*	.09515	.000	.4003	.8607
		High Intentions	.34009*	.08033	.000	.1458	.5344

*. The mean difference is significant at the 0.05 level.

Dependent Variable: Preferences for End-of-life Care

	(I) INTENTIONS	(J) INTENTIONS	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Bonferroni	Low Intentions	High Intentions	-.19153	.11492	.292	-.4695	.0864
		Very High Intentions	-.51814*	.10588	.000	-.7742	-.2621
	High Intentions	Low Intentions	.19153	.11492	.292	-.0864	.4695
		Very High Intentions	-.32661*	.08938	.001	-.5428	-.1104
	Very High Intentions	Low Intentions	.51814*	.10588	.000	.2621	.7742
		High Intentions	.32661*	.08938	.001	.1104	.5428

*. The mean difference is significant at the 0.05 level.

Dependent Variable: Social Support

	(I) INTENTIONS	(J) INTENTIONS	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Bonferroni	Low Intentions	High Intentions	.06111	.22378	1.000	-.4804	.6026
		Very High Intentions	-.01514	.20710	1.000	-.5163	.4860
	High Intentions	Low Intentions	-.06111	.22378	1.000	-.6026	.4804
		Very High Intentions	-.07626	.17428	1.000	-.4980	.3454
	Very High Intentions	Low Intentions	.01514	.20710	1.000	-.4860	.5163
		High Intentions	.07626	.17428	1.000	-.3454	.4980

*. The mean difference is significant at the 0.05 level.

APPENDIX D

MULTIPLE LINEAR REGRESSION DIAGNOSTICS

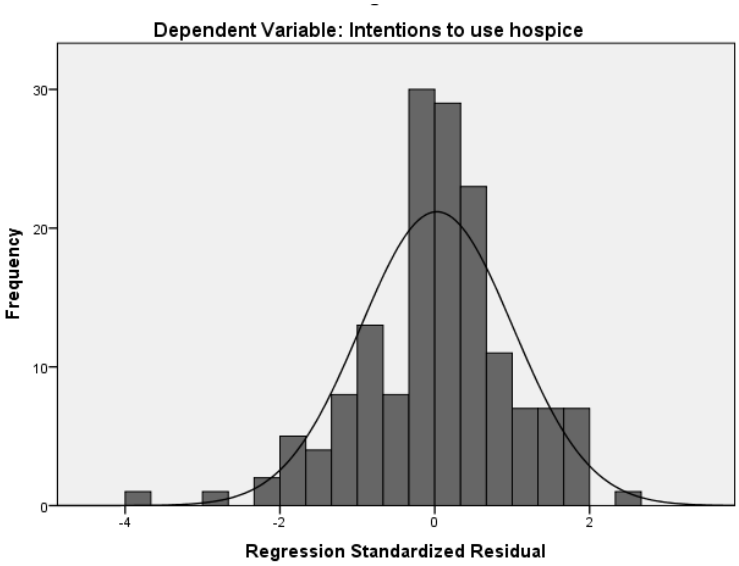

Figure 1a. Histogram of standardized residuals with normal distribution curve based on regression model suggested by stepwise selection

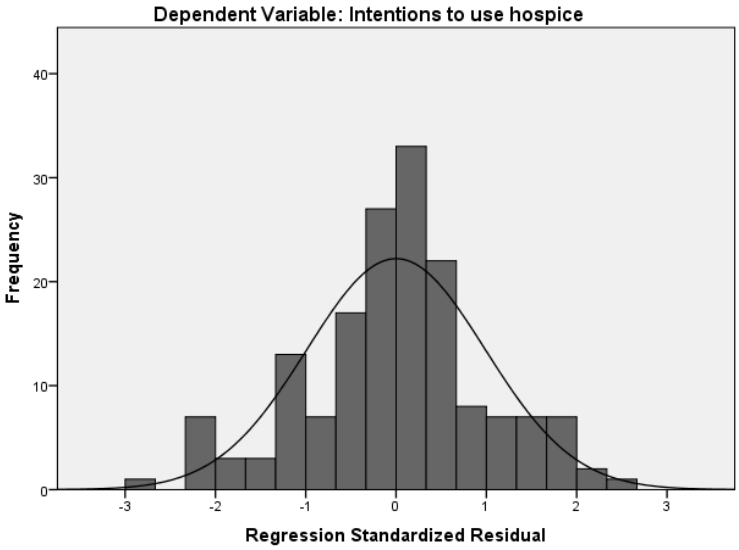

Figure 1b. Histogram of standardized residuals with normal distribution curve after removing an outlier and an influential case

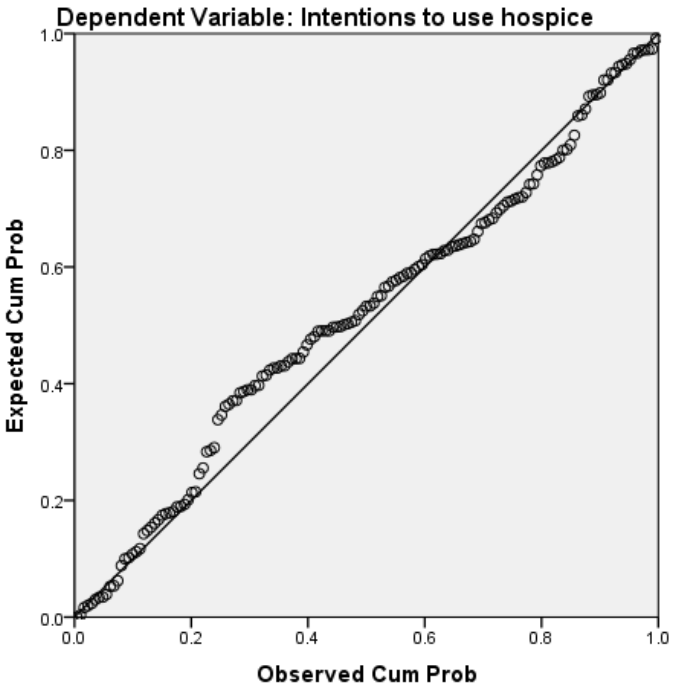

Figure 2a. Q – Q plot based on regression model suggested by stepwise selection

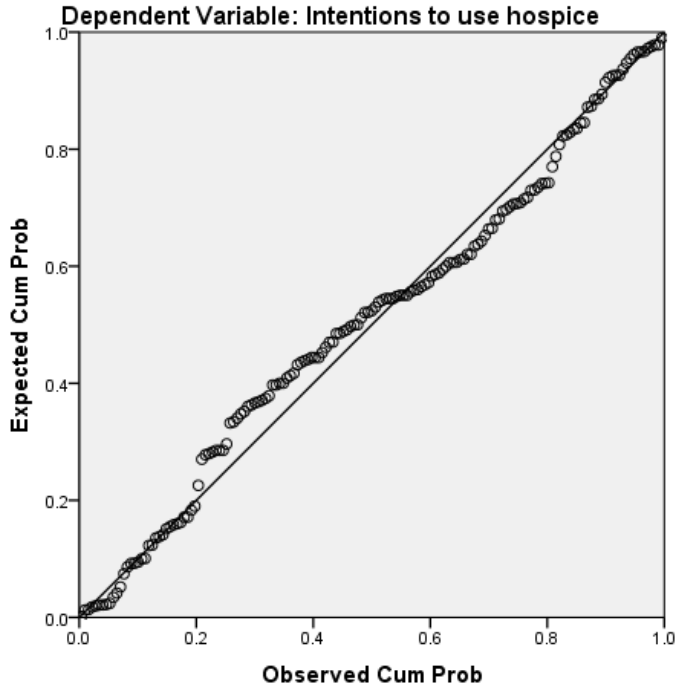

Figure 2b. Q – Q plot after removing an outlier and an influential case

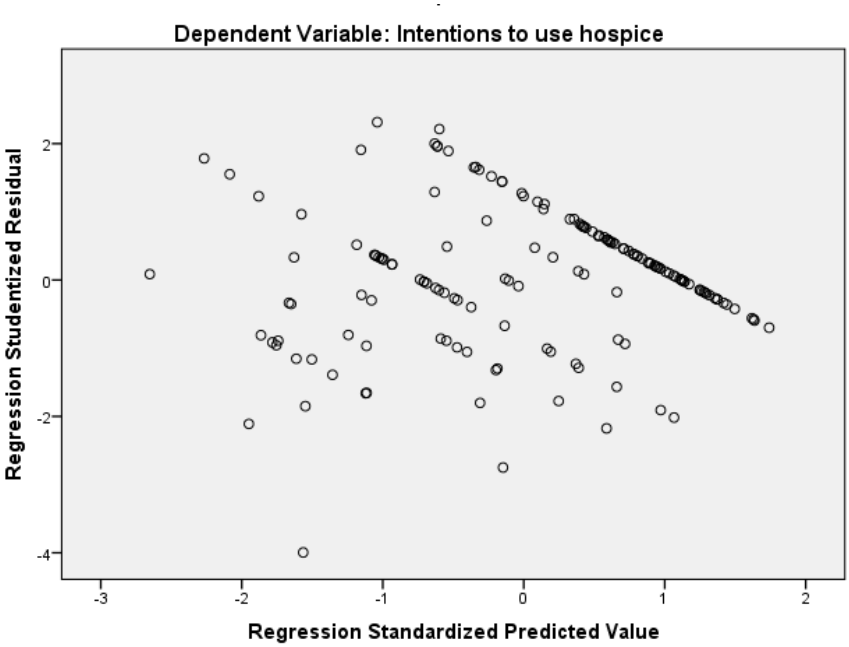

Figure 3a. Residual plot based on regression model suggested by stepwise selection

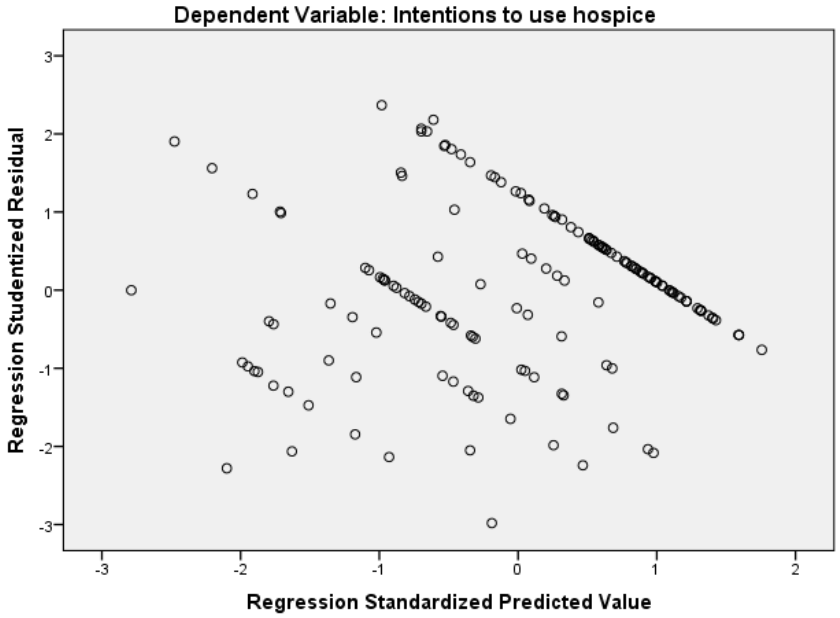

Figure 3b. Residual plot after removing an outlier and an influential case