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# A national study of racial/ethnic differences in end-of-life care planning : an application of the Integrated Behavioral Model

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A Dissertation

entitled

A National Study of Racial/Ethnic Differences in End-of-Life Care Planning: An  
Application of the Integrated Behavioral Model

by

Colette McAfee

Submitted to the Graduate Faculty in partial fulfillment of the requirements for the  
Doctor of Philosophy Degree in Health Education

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August 2015

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An Abstract of

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**Purpose:** The purpose of this study was to determine if the Integrated Behavioral Model (IBM) was useful in explaining and predicting American adults' behavioral intentions to complete end-of-life care planning. Of specific interest was whether the IBM could help to explain racial/ethnic differences in end-of-life care planning.

**Methods:** The study featured a theory-based, non-experimental, cross-sectional, survey research design. Participants were American adults between the ages of 40 and 80 years old. A geographically proportional sample based on the US census regions was randomly selected. An *a priori* sample size estimate indicated that a minimum of 384 completed surveys was needed to generalize the results to the US population of adults ages 40-80. Oversampling of racial/ethnic minorities was done to ensure that Blacks and Hispanics were adequately represented in the sample. To compensate for non-responses, a total of 1,650 American adults were included in the final sample. The IBM and the Precaution Adoption Process Model (PAPM) were used to design a valid and reliable survey. Prior to data collection, an elicitation phase featuring interviews and focus groups was conducted to ensure that the survey items were based on attitudes, beliefs, and

perceptions that were highly salient to the priority population. After the survey was designed, it was pilot tested to ensure that the survey was readable, culturally acceptable, valid, and reliable. Data were collected via a four-wave postal mailing method that used best practices in survey research to ensure the optimum return rate.

**Results:** A total of 386 surveys were completed and returned (25% response rate). The respondents were non-Hispanic White (65%), married (61%), male (52%), with a post-secondary degree (59%), and with a total household income of \$70,000 and above (32%). The majority of participants (75%) had not completed end-of-life care planning. Approximately 1 in 3 respondents (36%) had completed a living will, 32% had completed a durable power of attorney for health care (DPAHC), 60% had discussed end-of-life care wishes with at least one family member, and 18% had discussed end-of-life care wishes with their physician.

Statistically significant differences in the completion rates of the three key planning behaviors were found by race/ethnicity ( $X^2(2) = 18.90, p < .001$ ). One in three Whites (33%) had completed end-of-life care planning versus 18% of Hispanics and 8% of Blacks. Specifically, more Whites (43%) than Hispanics (26%) or Blacks (16%) were likely to have completed a living will. Similarly, more Whites (39%) than Hispanics (25%) or Blacks (14%) were likely to have completed a Durable Power of Attorney for Health Care (DPAHC). Likewise, more Whites (68%) than Hispanics (59%) or Blacks (38%) were likely to have had discussions with family members. Finally, more Whites (21%) than Hispanics (15%) or Blacks (9%) were likely to have had discussions with a health care provider.

The IBM constructs of *direct attitudes* and *indirect attitudes* were statistically significant predictors of behavioral intention. Attitude scores differed significantly by race/ethnicity. Whites were more likely to have positive direct attitudes toward advance directives ( $M = 23.85, SD = 5.37$ ) than Blacks ( $M = 22.36, SD = 5.20$ ) and Hispanics ( $M = 21.84, SD = 5.50$ ) ( $F(2, 338) = 4.15, p < .05$ ). As direct attitudes toward advance directives increased/improved, respondents' behavioral intentions to complete end-of-life care planning also increased [ $r = .446, n = 197, p < .001$ ]. Likewise, direct attitudes were significantly and positively associated with discussing wishes with family members and intention to complete end-of-life care planning [ $r = .323, n = 198, p < .001$ ]. Indirect attitudes were also significantly and positively associated with end-of-life care planning and intention to complete end-of-life care planning [ $r = .457, n = 200, p < .001$ ].

The IBM construct of *perceived norms* was also influential. Respondents reported that they would be more likely to complete end-of-life planning if their physician, loved ones, and best friend wanted them to complete it. Statistically significant differences were noted by race/ethnicity for direct perceived norms ( $F(2, 364) = 4.18, p < .05$ ) and indirect perceived norms ( $F(2, 359) = 15.39, p < .001$ ). Whites were more likely to have higher levels of direct perceived norms ( $M = 7.57, SD = 1.94$ ) than Blacks ( $M = 7.00, SD = 2.79$ ) and Hispanics ( $M = 6.76, SD = 2.38$ ). In addition, Whites were more likely to have higher levels of indirect perceived norms for end-of-life care planning ( $M = 16.99, SD = 3.39$ ) than Blacks ( $M = 14.90, SD = 4.20$ ) and Hispanics ( $M = 14.48, SD = 4.39$ ).

The IBM construct of *personal agency* may also help to explain the differences noted by race. Respondents' level of self-efficacy impacted their PAPM stage of readiness to take action to complete end-of-life care planning. Those with the lowest level

of self-efficacy were more likely to decide they did not want to complete end-of-life care planning, while those with the highest self-efficacy level were more likely to decide they did want to complete end-of-life care planning ( $F(4,254) = 15.32, p < .001$ ). Self-efficacy was also positively and significantly associated with behavioral intentions [ $r = .312, n = 202, p < .001$ ]. Whites had higher self-efficacy ( $M = 24.17, SD = 5.12$ ) to complete end-of-life care planning than Blacks ( $M = 23.48, SD = 5.46$ ) and Hispanics ( $M = 21.96, SD = 5.81$ ) ( $F(2, 262) = 3.17, p < .05$ ).

Other factors outside of the IBM (e.g., racial disparities in education and income) likely played a role in the differences in end-of-life care planning and behavioral intention by race. Respondents with higher education and household income levels were more likely to have completed end-of-life care planning. Racial/ethnic minorities had lower education levels and lower household incomes than Whites. Sixty-six percent of Whites in the current study had a post-secondary degree compared to 51% of Hispanics and 38% of Blacks. Similarly, nearly 50% of Blacks, 34% of Hispanics, and only 10% of Whites had total household incomes less than \$30,000 per year.

**Conclusion:** Health care providers, patient educators, hospice organizations, and health educators should use the Integrated Behavioral Model and the Precaution Adoption Process Model as a framework for the design, implementation, and evaluation of custom tailored messages, social marketing campaigns, and other educational initiatives to increase awareness, knowledge, and completion of end-of-life care planning among American adults, particularly among racial/ethnic minorities.

*Key words:* end-of-life care planning, advance care planning, advance directives, racial and ethnic disparities, death and dying, Integrated Behavioral Model

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## List of Abbreviations

DPAHC.....	Durable Power of Attorney for Health Care
EOL.....	End-of-Life
IBM.....	Integrated Behavioral Model
LW.....	Living Will
PAPM.....	Precaution Adoption Process Model

# Chapter 1

## Introduction

This chapter will state the purpose of the study and will review the problems associated with underutilization of end-of-life care planning among adults in the United States. The following sections will be included in this chapter: 1) The Problem, 2) The Significance of the Problem, 3) Statement of Purpose, 4) Research Questions, 5) Hypotheses, 6) Definitions of Terms, 7) Delimitations of the Study, and 8) Limitations of the Study.

### 1.1 The Problem

End-of-life care planning (i.e., completing a living will, completing a durable power of attorney for health care document, and discussing end-of-life wishes with loved ones) is an important activity in which all adults should participate. Engaging in end-of-life care planning has been shown to improve end-of-life care for the patient by ensuring that patients' wishes are established, documented, respected, and followed at the end-of-life (Detering, Hancock, Reade, & Silvester, 2010). End-of-life care planning gives patients the opportunity to make health care decisions cooperatively with their health care providers and gives patients a sense of control over their health care decisions (Hilliard, Washington, Hines, & McGill, 2013). Engaging in end-of-life care planning can help to

prevent unnecessary prolongation of the dying process, futile treatment for patients, high medical costs from aggressive and unnecessary care, and excess burden on patients and family (Coustasse, Quiroz, & Lurie, 2008). Since patients and their families can convey their cultural or religious beliefs about treatment proactively, end-of-life care planning can also help to prevent conflicts between health care at the end of one's life and the patient's values, beliefs, and culture (Hilliard et al., 2013). Engaging in end-of-life care planning also has health benefits for patients and their family members including reducing stress, lessening anxiety, and reducing depression among surviving relatives after death occurs (Detering et al., 2010).

Although completing end-of-life care does have multiple benefits, many people still do not complete this task (Institute of Medicine, 2015). In the United States, past research indicates that a range of 18% to 36% of the adult population has completed an advance directive, which can be described as a written health care directive and/or appointment of an agent, or a written refusal to appoint an agent or execute a directive (U.S. Department of Health and Human Services, 2008). Those with serious medical conditions have completed advance directives at a slightly higher rate (U.S. Department of Health and Human Services, 2008). Many times when advance directives are completed, physicians are unaware that their patients have them (U.S. Department of Health and Human Services, 2008).

Although there is a lack of end-of-life care planning among Americans, research has demonstrated that African Americans and Hispanics are even less likely to complete end-of-life care planning than Caucasians. The size of this difference by race/ethnicity depends on the type of planning that the person completes (Burdson, 2013). In a study by

Burdsall (2013), when controlling for cause of death and region, both African Americans and Hispanics had approximately 74% lower odds of completing any type of formal end-of-life planning than Caucasians. Burdsall (2013) defined formal end-of-life planning as completing a living will, assigning a Durable Power of Attorney for Health Care (DPAHC), and writing a financial will. Furthermore, African Americans and Hispanics had approximately 86% to 88% lower odds than Caucasians of completing both a written advance directive and assigning a proxy (Burdsall, 2013). Carr (2012) also demonstrated that Latinos were significantly less likely than Whites to have a living will (13% vs. 25%) and a DPAHC appointment (17% vs. 28%). Likewise, Carr (2012) found that a significantly higher proportion of Caucasians had discussions with loved ones about their preferences for end-of-life care, in comparison to African Americans and Latinos (60% vs. 44% and 60% vs. 37%, respectively).

Research has demonstrated a clear association between a lack of end-of-life care planning and being an African American or Hispanic, but few research studies have attempted to explain why these racial and ethnic differences exist. Even fewer studies have used any type of behavioral theory to explain or predict these racial and ethnic differences.

## **1.2 Significance of the Problem**

Many assume that performing more medical tests and procedures results in better health outcomes for patients. However, there is evidence to suggest otherwise (Grudzen & Grady, 2011). A palliative care approach can offer patients near the end of life a better likelihood of maintaining the highest possible quality of life for the longest possible time (Institute of Medicine, 2015). Palliative care is a type of care that is centered on the

patient and his/her family members. It is provided by an interdisciplinary team to optimize quality of life by alleviating suffering (National Consensus Project, 2013). Palliative care can begin early in the course of treatment for any serious illness that requires management of pain or other afflicting symptoms, such as difficulty breathing or swallowing (Institute of Medicine, 2015). Research suggests that using palliative care to treat the pain and symptoms of patients with life threatening illnesses is associated with improvements in physical status and may even lengthen survival (Grudzen & Grady, 2011). Temel et al. (2010) demonstrated that early palliative care among lung cancer patients led to significant improvements in both quality of life and mood. In addition, in comparison to patients who received standard care, patients who received early palliative care had less aggressive care at the end-of-life and longer survival (Temel et al., 2010). Palliative care has also been associated with reduced medical costs. Morrison et al. (2008) calculated that a palliative care service completing 500 consults annually would save a 400-bed hospital approximately \$1.3 million.

In order for a patient to obtain early palliative care, he or she should complete end-of-life care planning and discuss wishes with family and physicians. When end-of-life care planning is not completed, it can be costly to the patient, family, health care system, and society. A disproportionate amount of health care dollars are spent at the end-of-life. Approximately 30% of Medicare expenditures are used by the 5% of beneficiaries who die each year (Zhang et al., 2009). Approximately one third of the expenditures in the last year of life is spent in the last month of life, with most of these costs resulting from life-sustaining care, such as ventilator support and resuscitation (Zhang et al., 2009). Minorities tend to spend even more during the last months of life

than Caucasians (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009). In a study of patients in the last six months of life, Medicare expenditures amounted to an average of \$20,166 for Caucasians, \$26,704 for African Americans (32% more), and \$31,702 for Hispanics (57% more) (Hanchate et al., 2009).

One way to avoid unwanted medical care at end of life is for patients and their physicians to discuss the patient's preferences and values. However, a small percentage of patients have discussed end-of-life care wishes with their physician or with family members (Institute of Medicine, 2015). End-of-life care conversations between patients and physicians are associated with less aggressive medical care near death, earlier hospice referrals, and lower rates of ICU admission (Wright, Zhang, Ray, & et al., 2008). Such discussions may reduce health care expenditures by reducing patients' use of non-beneficial, intensive and aggressive care at the end-of-life (Zhang et al., 2009). In addition to reducing medical costs, end-of-life care planning can reduce burden and emotional distress for family members and loved ones. Nearly half of patients lose decision-making capacity near the end of their life, and over two thirds of these face choices on specific end-of-life treatment options (Tejwani et al., 2013). Because these choices are typically made by the patient's surrogate and family (Tejwani et al., 2013), such choices can create emotional distress for loved ones who make these decisions. Therefore, having already discussed end-of-life care wishes with the family members can potentially help to alleviate this burden and distress.

### **1.3 Statement of Purpose**

The purpose of this study is to determine if the Integrated Behavioral Model (IBM) is useful in explaining and predicting American adults' intentions to complete end-

of-life planning. Of specific interest is whether the IBM can help to explain the racial/ethnic disparities in end-of-life planning.

#### **1.4 Research Questions and Hypotheses**

##### **Research Question # 1: What proportion of American adults has completed end-of-life care planning?**

- 1.1: There is no difference in end-of-life care planning completion by race/ethnicity.
- 1.2: There is no difference in end-of-life care planning completion by age.
- 1.3: There is no difference in end-of-life care planning completion by marital status.
- 1.4a: There is no difference in end-of-life care planning completion by religiosity/spirituality [attending religious organization].
- 1.4b: There is no difference in end-of-life care planning completion by religiosity/spirituality [personal time].
- 1.4c: There is no difference in end-of-life care planning completion by religiosity/spirituality [overall].
- 1.5: There is no difference in end-of-life care planning completion by SES [education].
- 1.6: There is no difference in end-of-life care planning completion by SES [income].
- 1.7: There is no difference in end-of-life care planning completion by gender.
- 1.8: There is no difference in end-of-life care planning by racial distrust.

**Research Question # 2: At what PAPM stage of readiness to complete end-of-life care planning are adults in the United States?**

- 2.1: There will be no difference in stage of readiness to complete end-of-life care planning by having a history of a life threatening illness.
- 2.2: There will be no difference in stage of readiness to complete end-of-life care planning by having a family member with a history of being diagnosed with a life threatening illness.
- 2.3: There will be no difference in stage of readiness to complete end-of-life care planning by direct attitudes toward completing an advance directive.
- 2.4: There will be no difference in stage of readiness to complete end-of-life care planning by direct attitudes toward discussing end-of-life wishes with family members.
- 2.5: There will be no difference in stage of readiness by level of indirect attitude regarding end-of-life care planning (e.g. low versus high attitude scores).
- 2.6a: There will be no difference in stage of readiness to complete end-of-life care planning by direct perceived norms toward end-of-life care planning.
- 2.6b: There will be no difference in stage of readiness to complete end-of-life care planning by indirect perceived norms toward end-of-life care planning.
- 2.6c: There will be no difference in stage of readiness to complete end-of-life care planning by motivation to comply toward end-of-life care planning.
- 2.7: There will be no difference in stage of readiness to complete end-of-life care planning by personal agency regarding end-of-life care planning.

- 2.8: There will be no difference in stage of readiness to complete end-of-life care planning by having a family member with a history of being a coma or persistent vegetative state.

**Research Question # 3: Which socio-demographic factors are associated with end-of-life care planning by adults in the United States?**

- 3.1: There is no difference in intention to complete end-of-life care planning by race/ethnicity.
- 3.2: There is no difference in intention to complete end-of-life care planning by age.
- 3.3: There is no difference in intention to complete end-of-life care planning by gender.
- 3.4: There is no difference in intention to complete end-of-life care planning by SES [education].
- 3.5: There is no difference in intention to complete end-of-life care planning by SES [income].
- 3.6: There is no difference in intention to complete end-of-life care planning by marital status.
- 3.7a: There is no difference in intention to complete end-of-life care planning by religiosity/spirituality [attending religious services/meetings].
- 3.7b: There is no difference in intention to complete end-of-life care planning by religiosity/spirituality [personal time].
- 3.7c: There is no difference in intention to complete end-of-life care planning by religiosity/spirituality [overall].

- 3.8: There is no difference in intention to complete end-of-life care planning by racial distrust.

**Research Question # 4: Does the Integrative Behavioral Model help explain and/or predict adults' behavioral intentions to complete end-of-life care planning?**

- 4.1: There is no difference in behavioral intentions by level of direct attitude regarding completing advance directives (living will and durable power of attorney for health care) (e.g., low versus high attitude scores).
- 4.2: There is no difference in behavioral intentions by level of direct attitude regarding discussing end-of-life wishes with family members (e.g., low versus high attitude scores).
- 4.3: There is no difference in behavioral intentions by level of indirect attitude regarding end-of-life care planning (e.g., low versus high attitude scores).
- 4.4a: There is no difference in behavioral intentions by level of direct perceived norms regarding end-of-life care planning (e.g., low versus high perceived norms).
- 4.4b: There is no difference in behavioral intentions by level of indirect perceived norms regarding end-of-life care planning (e.g., low versus high perceived norms).
- 4.4c: There is no difference in behavioral intentions by level of motivation to comply regarding end-of-life care planning (e.g., low versus high motivation to comply).
- 4.5: There is no difference in behavioral intentions by level of personal agency to conduct end-of-life care planning (e.g., low versus high personal agency).

- 4.6: There is no statistically significant difference in the predictive ability of the IBM constructs to predict behavioral intentions to complete end-of-life care planning.

### **1.5 Definitions of Terms**

**Advance Care Planning:** The process of discussing, determining and/or executing treatment directives, appointing a proxy decision maker, and periodically reviewing those plans (U.S. Department of Health and Human Services, 2008).

**Advance Directive:** A written health care directive and/or appointment of an agent, or a written refusal to appoint an agent or execute a directive (U.S. Department of Health and Human Services, 2008). This includes a living will document and a durable power of attorney for health care document.

**Durable Power of Attorney for Health Care:** This is a type of advance directive where a grantor can appoint someone as a proxy to make decisions about medical treatment if the grantor is unable to do so. This appointed person may be a relative, friend, or someone with whom the grantor discussed his or her preferences. This person acts in accordance with the grantor's previously discussed wishes or the wishes that are stated in other advance directive forms (Despelder & Strickland, 2015).

**End-of-Life Care:** Quality end-of-life care is described as alleviating physical and emotional symptoms, supporting function and autonomy to help the patient maintain his or her dignity, guarding against inappropriate and aggressive care near death, and working to minimize financial burden that care places on the family (Virani, 2003).

**End-of-Life Care Planning:** End-of-life care planning typically involves making decisions about the goals of care, where to spend a person's final days, which treatments

a person would like to receive, and which types of end-of-life care a person would like to receive. This can also include discussing these preferences with family members, caregivers, and friends (U.S. National Library of Medicine, 2014). For this study, end-of-life care planning will be defined as completing three specific behaviors: 1) completing a living will document, 2) completing a durable power of attorney for health care document and, 3) discussing end-of-life care wishes with a family member.

**Hospice:** Hospice is a concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments. The goal is to improve the quality of a patient's final days. A special emphasis is placed on pain control and offering comfort and dignity using a team-oriented group of trained professionals, volunteers, and family members (Yancu, Farmer, & Leahman, 2010).

**Integrated Behavioral Model (IBM):** This theory is an extension of Fishbein and Ajzen's Theory of Reasoned Action (TRA) (1975, 1980) and Theory of Planned Behavior (TPB) (1988, 1991) that includes components from other major behavioral theories (Ajzen, 1991; Glanz, Rimer, & Viswanath, 2008). With IBM, the most important determinant of behavior is intention to perform the behavior. Behavioral intention is driven by three construct categories including: attitude toward the behavior, perceived norms, and personal agency (Glanz et al., 2008).

**Living Will:** A legal document that allows a person to refuse life-sustaining treatment in the event that he or she is terminally ill and life-sustaining procedures would only extend life unnecessarily (Despelder & Strickland, 2015).

**Palliative Care:** Also called "comfort care," a comprehensive approach to treating

serious illness that focuses on the physical, psychological, and spiritual needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, controlling pain and symptoms, and enabling the patient to achieve maximum functional capacity. Respect for the patient's culture, beliefs, and values is an essential component (U.S. Department of Health and Human Services, 2008).

**Precaution Adoption Process Model (PAPM):** The Precaution Adoption Process Model (PAPM) (Weinstein & Sandman, 1992) is a model used to explain how a person makes a decision to take action and how he or she puts the decision into action. The PAPM has categories or stages, which are defined in terms of mental states, as opposed to external factors. The PAPM applies to the deliberate steps taken to adopt a new precaution or stop a risky behavior, and it does not apply to actions that result from the development of habitual patterns of behavior (Glanz et al., 2008).

### **1.6 Delimitations**

Several delimitations exist for this study. First, the questionnaire is closed-formatted. Therefore, additional information regarding adult beliefs about end-of-life planning was not collected. Second, study participants were restricted to those between the ages of 40 and 80, and those who were Caucasian, African American, or Hispanic. Hence, the views, actions, and attitudes of people from other races/ethnicities were not collected or analyzed. Third, the study was restricted to only those who speak English.

### **1.7 Limitations**

The results of the current study should be viewed with its limitations in mind. One possible limitation is that the sample was taken from a commercial mailing list compiler. This is a limitation because low-income racial/ethnic minority populations may have

been underrepresented in the database purchased by the investigator. To overcome this potential limitation, the investigator over-sampled both the African American and Hispanic populations. A second potential limitation with using commercial mailing lists is that the list may not have represented all geographical areas of the United States. To avoid this potential limitation, the investigator used stratified random sampling to ensure that all US census regions of the United States were represented. In addition, because the study was cross-sectional, no cause and effect relationship can be assumed from the results. Long-term follow up of participants is needed to determine whether IBM constructs and behavioral intentions are true predictors of completing end-of-life care planning. A fourth possible limitation was the potential for response bias because the participants were self-reporting their responses. Participants may have responded in a certain way due to the topic of the study. A fifth potential limitation was the 25% response rate. The 75% of subjects who were contacted and chose not to respond may have been different in systematic ways from those who responded, thus creating potential limitations with external validity of the results. Also, the racial/ethnic demographics of respondents were comparable to the racial/ethnic composition of the US population. Another limitation was the low test-retest coefficient for the following scales: self-efficacy, attitude evaluation, direct perceived norms, and racial distrust 2. Although these were low, other scales had a medium to high test-retest reliability. Finally, there is the possibility of response set bias due to all questions involving end-of-life care planning.

# Chapter Two

## Literature Review

This chapter will provide a background on end-of-life care planning and factors related to it. In addition, it will also provide a review of studies that have explored end-of-life care planning and its association with race and ethnicity. Specifically, the following sections are presented in this chapter: 1) Changes in Death and End-of-Life Care Planning Over Time; 2) Medical Technology and End-of-Life Care Planning; 3) Patient Preferences and Concerns at End-of-Life; 4) End-of-Life Care; 5) Palliative Care; 6) Palliative Care; 7) Hospice; 8) Advance Directives; 9) Importance and Consequences of End-of-Life Care Planning; 11) End-of-Life Care Planning Completion; 11) Factors Associated with End-of-Life Care; 12) Barriers to End-of-Life Care Planning; 13) Reasons for Differences in End-of-Life Care; 14) Integrated Behavioral Model; 15) Precaution Adoption Process Model; and 16) Summary.

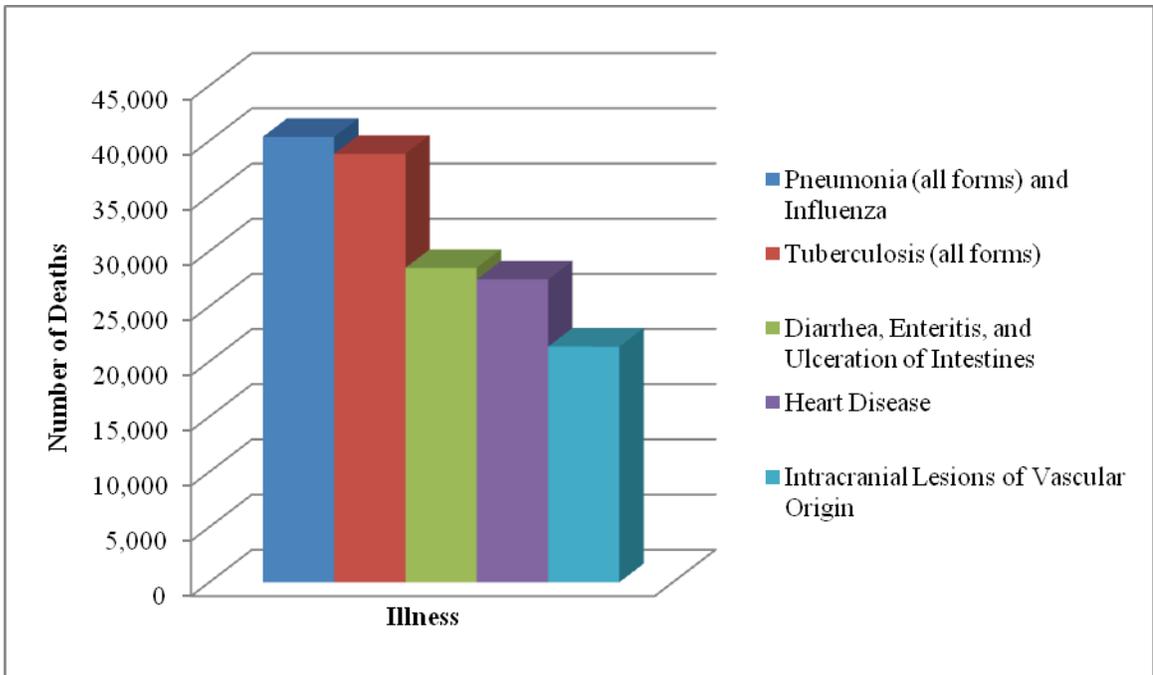
### 2.1 Changes in Death and End-of-Life Care Planning Over Time

Since the early 1900's, the average life expectancy at birth in the United States has increased from 47 years of age to approximately 78 years of age (Fries, 2002; Kung, Hoyert, Xu, & Murphy, 2008). In 1900, infectious respiratory diseases accounted for approximately a quarter of all deaths (Guyer, Freedman, Strobino, & Sondik, 2000) and

30.4% of all deaths occurred among children less than five years old (Centers for Disease Control and Prevention, 1999). At the turn of the century, acute and infectious diseases (e.g., tuberculosis, diphtheria, smallpox, acute rheumatic fever) were the leading causes of mortality (Fries, 2002). In 1900, pneumonia and influenza, tuberculosis (all forms), diarrhea, enteritis, and ulceration of the intestines, heart disease, and intracranial lesions of vascular origin were the top five leading causes of death (Figure 2-1) (Hagger, Chatzisarantis, & Biddle, 2002). Advancements in public health and improvements in medicine (e.g., antibiotics) have reduced the rates of incidence and mortality from infectious diseases (Fries, 2002). The leading causes of death now are primarily chronic/lifestyle diseases such as heart disease and cancer.

According to Hoyert (2012), the crude death rate fell 27% from 1935 and 2010. When the effect of aging in the population is removed by adjusting the death rate by age, the risk of dying decreases by 60% over this time period. For all except those 85 years old and over, mortality risk fell more than 50% during this time period, with the greatest reduction among those between one and four years of age. In those over 85 years old, the death rate declined from 440.9 to 26.6 deaths per 100,000. A decline in death rates was also seen among the older adult population (Hoyert, 2012). Between 1900 and 2010, the death rates for the leading causes of death also decreased (Table 2.1) (Hagger et al., 2002; Murphy, Xu, & Kochanek, 2013).

Today, chronic illness is now responsible for more than 80% of all deaths, and even more disability (Fries, 2002). In 2011, the leading causes of death were heart disease, malignant neoplasms, chronic lower respiratory disease, cerebrovascular disease, and unintentional injuries (Figure 2-2) (Hoyert & Xu, 2012). Seven out of ten deaths



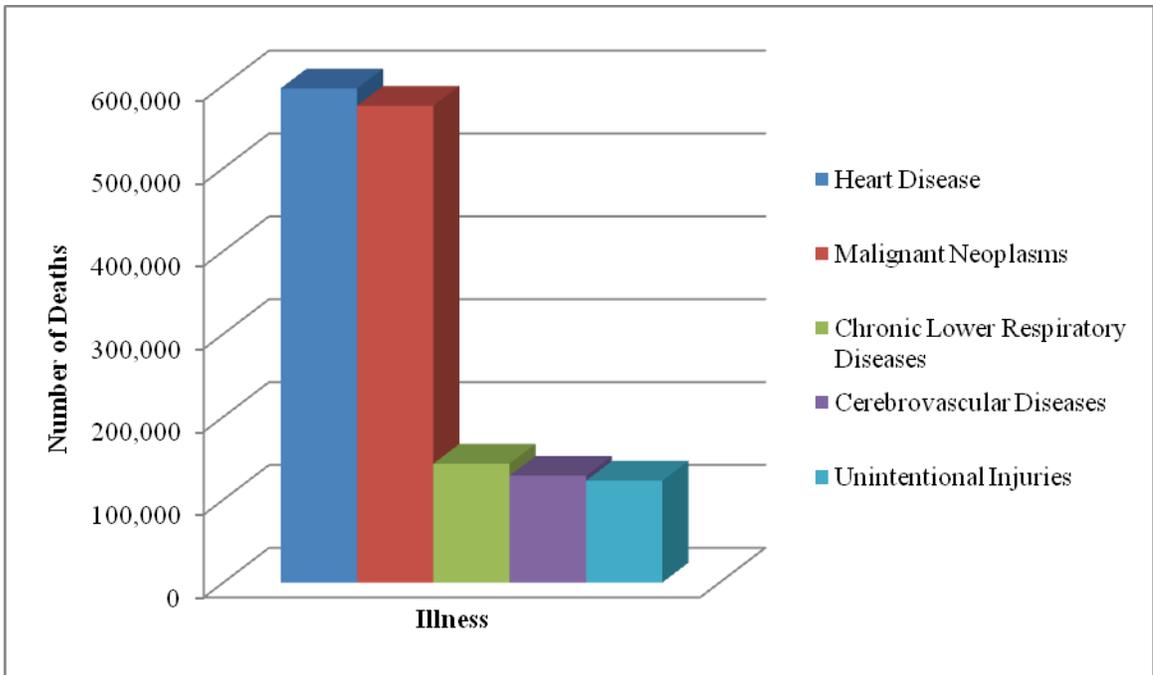
Source: Hagger et al. (2002)

Figure 2-1: Leading causes of death in 1900

Table 2.1  
Mortality Rates for Leading Causes of Death in 1900 and 2010

<b>1900</b>		<b>2010</b>	
Illness	Crude Mortality Rate*	Illness	Crude Mortality Rate*
Pneumonia (all forms) and Influenza	202.2	Heart Disease	193.6
Tuberculosis (all forms)	194.4	Malignant Neoplasms	186.2
Diarrhea, Enteritis, and Ulceration of Intestines	142.7	Chronic Lower Respiratory Diseases	44.7
Heart Disease	137.4	Cerebrovascular Diseases	41.9
Intracranial Lesions of Vascular Origin	106.9	Unintentional Injuries	39.1

\*Crude death rates on an annual basis per 100,000 population  
Sources: Hagger et al. (2002) and Murphy et al. (2013)



Source: Hoyert and Xu (2012)

Figure 2-2: Leading causes of death 2011

among Americans each year result from chronic diseases, with heart disease, stroke, and cancer representing more than 50 percent of those deaths (Kung et al., 2008). Nearly one out of every two adults in the United States has at least one chronic illness (Wu & Green, 2000), and about one out of every four people with chronic conditions has one or more limitations to daily activities (Anderson, 2004).

## **2.2 Death Location**

Near the end of the 19<sup>th</sup> century, a transition in the location of death began to occur. Historically, death was a household-family experience. Members of the family actively participated in and witnessed the death process of loved ones in the home (Despelder & Strickland, 2015; Fonseca & Testoni, 2011). In the past, death was an event that was shared by the family and community, and it was comforting to the dying and their relatives to be able to share the death experience with others (Fonseca & Testoni, 2011).

As society changed, the location of death changed. One reason for the transition in the location of death was because hospitals began to adopt a secondary function of receiving the dying, rather than being solely focused on healing the living (Fonseca & Testoni, 2011). With this transition, the death experience lost much of its ceremony and ritual, which further distanced families from the dying process (Fonseca & Testoni, 2011). Death is now viewed as a hospital or medical establishment experience (Dean-Lee, 2005; Institute of Medicine, 2015).

Although there has been a reduction in hospital deaths in recent years (Gruneir et al., 2007), the last few months of life typically include frequent stays in the hospital or other long-term care institutions (Institute of Medicine, 2015). Among Medicare fee-for-

service beneficiaries, the percentage of individuals who died in acute care hospitals declined from 33% in 2000 to 25% in 2009 (Institute of Medicine, 2015; Teno, Gozalo, Bynum, & et al., 2013). However, only 34% of Medicare deaths occurred in the home, with 28% occurring in nursing homes, and approximately 14% elsewhere (Institute of Medicine, 2015; Teno et al., 2013). The percentage of people who die in each setting varies depending on the area's conditions and the availability of nonhospital services, such as nursing homes (Gruneir et al., 2007; Institute of Medicine, 2015).

The “epidemiological transition” in causes of death, the age of death, and the location of death created a situation where members of Western societies became less familiar with death over time. In addition, other macro-level forces such as urbanization, secularization, and an emphasis on medical technology also caused members of Western societies to become less familiar with death (Fonseca & Testoni, 2011). With urbanization, family members became more dispersed throughout the country, leading to fewer intergenerational families living within the same geographical area (Despelder & Strickland, 2015). As a result, individuals became more distanced from death, as fewer older relatives were living in the same household.

A displacement of cemeteries from urban to rural areas also occurred, further distancing peoples' familiarity with death and funeral rituals (Fonseca & Testoni, 2011). As Westerners became more distanced from the dying process, their attitudes and views of death began to change. Rather than viewing death as a natural event to be accepted, Westerners have become more death-denying and death-defying, with the general view that old age could be “treated,” and that death was merely a failure of the body and a failure in medical technology (Fonseca & Testoni, 2011).

### **2.3 Medical Technology and Death Changes**

Advancements in medical technology have influenced the general population's views of death over the years (Despelder & Strickland, 2015; Fonseca & Testoni, 2011). Ultimately, these changes have forced industrialized societies to change their definition of death to match technological advances. The changing landscape of medical technology also creates ethical dilemmas not faced in the past when death was defined more simply as the irreversible cessation of respiration and cardiac function (Caldwell & Freeman, 2009). With modern technology, even when someone is near death and has little chance of recovery, life can be prolonged (Caldwell & Freeman, 2009). With this ability comes the ethical decision to either maintain this person's life on life support or end this person's life by withholding or withdrawing treatment. This decision can be difficult for many people and demonstrates the need for the completion of end-of-life care planning.

Although many view advancements in medical technology as beneficial, some may view it negatively as something that may prolong death unnecessarily. In the past, many people died from infectious diseases, war, accidents, or in childbirth (Hardwig, 2009). These types of deaths can be described as "quick." In contrast, many deaths today are often "slow motion." People often die slowly today over longer periods of time due to the debilitating effects of chronic disease that typically are manifest during old age (Hardwig, 2009).

Due to the rapid advancements in medical technology, societal and personal ethics have not had time to respond and adjust effectively (Hardwig, 2009). Western medicine still focuses on extending life at all costs, even when such care may bring little benefit to the patient (Hardwig, 2009; Institute of Medicine, 2015). Although many people try to

extend life as long as possible, others fear that death will come too late after quality of life is lost (Hardwig, 2009). To avoid this situation, people need to plan for their end-of-life medical care to ensure that their wants and needs are met as death approaches (Hardwig, 2009).

#### **2.4 Patient Preferences and Concerns at End-of-Life**

Patients have various concerns about care and quality of life as they approach the end of their lives. Commonly reported concerns include being an emotional and financial burden on family and friends (Givens & Mitchell, 2009). Specifically, patients report that they worry about the emotional burden that their families could have while making end-of-life care decisions, in addition to the economic burden that a terminal illness might cause their families (Givens & Mitchell, 2009). Patients also report being concerned about depleting their funds due to medical treatment and about receiving “second-class” health care if they do not have health insurance (Givens & Mitchell, 2009). Other reported preferences by patients include the desire to receive adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, strengthening relationships with loved ones, having trust in the treating physician, communicating effectively, and avoiding unwanted life support (Heyland et al., 2006; Singer, Martin, & Kelner, 1999).

Being prepared for death and completing important tasks are also common themes regarding patient concerns at end-of-life (Steinhauser et al., 2001). Preparation, or being prepared for the end-of-life and knowing that one’s family is prepared, includes various components, such as naming someone to make decisions, knowing what to expect about one’s physical condition, having financial affairs in order, knowing that one’s doctor is

comfortable talking about death and dying, feeling the family is prepared for one's death, and feeling prepared to die (Steinhauser et al., 2001). Preparation and making treatment preferences known is also reported as a method of relieving burden on the patient, as well as helping family members feel relieved in knowing that they are fulfilling the patient's wishes (Steinhauser et al., 2001). Patients also report that if they are able to prepare for end-of-life, then they may be able to engage in the process of achieving completion. Components of completion that are highly valued by patients include saying goodbye to important people, finding peace with God, resolving unfinished business with family or friends, praying, and remembering personal accomplishments (Steinhauser et al., 2001).

In addition to preferences for care, preferences for location of death have also been expressed by patients. Although many patients die in the hospital setting, the majority of patients have expressed that they would like to die at home or in a hospice facility (Aoun & Skett, 2013; Gomes, Calanzani, Gysels, Hall, & Higginson, 2013), and approximately four-fifths of patients did not change their preferences as their illnesses progressed (Gomes et al., 2013). For those who do spend their final days in the hospital, they identify privacy, proximity (physically and emotionally) to loved ones, proximity to home and nature, and features of the physical environment as important characteristics of the hospital environment (Brereton et al., 2012). Proximity to home is important because it has an influence on the family's ability to visit the patient frequently. Proximity to nature is important because patients and caregivers report having access to garden areas and patios as beneficial (Brereton et al., 2012). Features of the physical environment that contribute to patient and caregiver satisfaction include cleanliness and homeliness of the environment, familiarity with the environment, and size, accessibility, and atmosphere of

the hospital (Brereton et al., 2012). In addition, noise levels influence patient satisfaction. Loud noises such as other patients are complaining of pain or loud conversation among patients in shared rooms are typically viewed as a negative factor (Brereton et al., 2012).

## **2.5 End-of-Life Care**

Various terms are used when describing end-of-life care and practices. Some frequently used terms include active dying, terminally ill, end-of-life, end-of-life-care, terminal care, and transition of care. These terms are frequently used in clinical settings and research articles, but the exact meaning of these terms is often unclear (Hui et al., 2014). Although these terms are imprecise, it is important to understand their meaning and significance.

“End-of-life” has been described using two different perspectives: 1) a disease-centered perspective based on a period of irreversible decline before death and 2) a time-based perspective related to the hospice admission criteria of six months or less time left to live (Hui et al., 2014). “Terminal illness” is often described as a state of having an irreversible fatal illness, usually with a timeframe of six months or less left to live, but different sources use different time frames ranging from “days to weeks,” “nine months left to live,” and “24 months left to live” (Hui et al., 2014).

When one defines “end-of-life care,” various aspects of care should be included: 1) place of care (e.g., home or hospital), 2) qualifications and training of the health care professionals (e.g., palliative care teams, oncologists, etc.), and 3) goals of care (e.g., no further active treatments, palliative treatments, etc.) (Hui et al., 2014). More specifically, quality end-of-life care has been described as alleviating physical and emotional symptoms, supporting function and autonomy to help the patient maintain his or her

dignity, guarding against inappropriate and aggressive care near death, and working to minimize financial burden that care places on the family (Virani, 2003). Quality end-of-life care is also described as making the time left at end-of-life precious to the patient and family, educating patients in the length of time insurance companies cover treatment of a terminal illness, and ensuring that the patient's quality of life is good despite declining health (Virani, 2003).

Inadequate end-of-life care can be described as the overuse of medical care, such as unwanted treatments or hospitalizations, or poor technical performance, such as errors in surgical techniques or inadequate administration of pain medications (Virani, 2003). It also includes poor interpersonal communication skills, or the under use of care, such as late referral to hospice care or failure to assess and treat pain (Virani, 2003).

In addition to the preferences for end-of-life expressed by patients, family members of patients have also identified various elements of end-of-life care that are important. The three elements that family members rate as extremely important include having trust and confidence in the doctors treating the patient, not keeping the patient alive on life support when there is little hope for meaningful recovery by the patient, and having information about the patient and his or her disease communicated to the family member in an honest manner (Heyland et al., 2006). In addition, family members express such preferences as making sure that the patient has relief from physical symptoms, having the opportunity to strengthen or maintain the relationship with the family member, and having trust and confidence in the nurses caring for the family member (Heyland et al., 2006).

End-of-life care planning allows individuals to make decisions about care that best suit their needs. End-of-life care planning typically involves making decisions about the goals of care, where to spend a person's final days, which treatments a person would like to receive, and which types of end-of-life care a person would like to receive (U.S. National Library of Medicine, 2014). This should also include discussing these preferences with family members, caregivers, and friends. The National Hospice and Palliative Care Organization (2014) describes end-of-life care planning as getting information on the types of life-sustaining treatments that are available, deciding which types of treatments a person would like to use if diagnosed with a life-limiting illness, sharing personal views with loved ones, and completing advance directives. Sharing end-of-life preferences with loved ones and completing advance directives helps to ensure that everyone is aware of the patient's wishes, which aids in fulfilling them when the time is appropriate.

## **2.6 Palliative Care**

Palliative care is described as a type of care provided to address patient symptoms such as physical pain, psychosocial pain, and anxiety (Bray, 2013). Palliative care provides relief from pain and other symptoms, supports quality of life, and focuses on patients with serious advanced illness and their families (Institute of Medicine, 2015). Palliative care is typically provided by an interdisciplinary team with the goal to relieve suffering and improve quality of life for patients with a serious illness or for their families (Bray, 2013). This interdisciplinary team should ideally consist of physicians, a nurse practitioner, a social worker, and a chaplain, and it may also include a nutritionist, a pharmacist, or a physical therapist (Bray, 2013). Palliative care can begin early in the

course of treatment for any serious illness that requires management of pain or other symptoms (Institute of Medicine, 2015). It can also be provided in conjunction with treatments for several illnesses (Institute of Medicine, 2015). Palliative care can be given to the patient in various settings, including the home setting, the outpatient office setting, and the inpatient setting, and it is usually provided to severely ill patients who are not yet at end-of-life, and still involved in active and curative therapies (Bray, 2013; Quill et al., 2006). Palliative care is frequently provided through hospital-based consultation programs and outside the hospital through hospice programs in the home, nursing home, assisted living facility, or long-term acute care facility (Institute of Medicine, 2015).

Guidelines for quality palliative care were created by several organizations. In 2007, the following organizations formed the Hospice and Palliative Care Coalition: the Nurses and Palliative Nurses Association, the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, and the National Hospice and Palliative Care Organization (Callaway, 2012). A subcommittee of this coalition established the Clinical Practice Guidelines for Quality Palliative Care, which were revised and released as the third edition in 2013.

These national guidelines for quality palliative care include eight domains: 1) structure and processes of care, 2) physical aspects of care, 3) psychological and psychiatric aspects of care, 4) social aspects of care, 5) spiritual, religious, and existential aspects of care, 6) cultural aspects of care, 7) care of the patient at the end-of-life, and 8) ethical and legal aspects of care (National Consensus Project, 2013). Domain one emphasizes interdisciplinary team engagement and collaboration with patients and families. Domain two describes the management of symptoms with validated and

appropriate methods. Domain three focuses on the collaborative assessment process of psychological concerns and psychiatric diagnoses. Domain four emphasizes collaboration with patients and families to identify and support patient and family strength. Domain five defines spirituality and staff collaboration in addressing spiritual concerns. Domain six addresses cultural competence. Domain seven addresses quality communication with the patient and family, managing pain, providing guidance to the patient and family regarding expectations, and offering bereavement support. Finally, domain eight addresses issues regarding advance care planning, ethics, and legal aspects of care (National Consensus Project, 2013).

Consultation is also an important component of palliative care and should include goal setting with the patient and family (Bray, 2013; Quill et al., 2006). Other components of palliative care include pain and symptom management, prognostication, spiritual support, and psychosocial support (Bray, 2013).

Patients have expressed their desire for several components of palliative care which can be divided into four major categories: 1) improving quality and meaning of life, 2) achieving relief or comfort, 3) altering the trajectory of the illness, and 4) preparing for dying (Quill et al., 2006). Improving quality and meaning of life encompasses a variety of goals that patients want to achieve before they die, such as wanting to be able to go home or leave the hospital, regaining a lost function, supporting significant others, and improving quality of life in general (Quill et al., 2006). The second category, achieving relief or comfort, includes wanting relief from physical distress such as pain or inability to breathe, wanting relief from emotional distress such as anxiety or fear, and wanting to be comfortable (Quill et al., 2006). Altering the trajectory of the

illness is described as hoping to recover, be cured, improve, or look for potentially effective treatments for the disease, living until important personal and family milestones can be realized, making important medical decisions about treatment, and wanting to die sooner or stop living in the current condition (Quill et al., 2006). The final category, preparing for dying, includes wanting help with emotional or family-directed “unfinished business,” achieving a peaceful, comforting, and pain-free death, and fulfilling spiritual or religious hopes (Quill et al., 2006).

Nurses have described effective palliative care as being able to connect with patients by listening to the patient, facilitating communication, providing information, acknowledging barriers to communication, building rapport, spending time with the patients, and supporting the patient and family (Johnston & Smith, 2006). Nurses also state that effective palliative care provides comfort to the patients and manages pain and symptoms, and that the palliative care team should have exemplary interpersonal skills and qualities such as compassion and kindness (Johnston & Smith, 2006).

## **2.7 When Patients Should Seek Palliative Care**

Growing evidence shows that palliative care improves quality of life, survival, and lowers costs (McCormick, Chai, & Meier, 2012). Unfortunately, various health care providers are slow to initiate palliative care interventions, which can contribute to unrelieved symptoms for patients, more distress for bedside providers, and increased medical costs for health care institutions (Callaway, 2012). The evidence supports that early palliative-care interventions for patients with serious illnesses should be used (McCormick et al., 2012).

For oncological care, it is recommended that palliative care be integrated in standard oncological care at initial diagnosis (McCormick et al., 2012). This recommendation is supported by the Clinical Practice Guidelines for Quality Palliative Care, which stress the importance of implementing palliative care at the time of diagnosis of a life-limiting or chronic illness (Callaway, 2012). When using palliative care alongside oncology care when a patient is newly diagnosed with advanced cancer, patients often report improvements in mood and quality of life (McCormick et al., 2012). In addition to this, early palliative-care interventions used with patients with lung cancer have been shown to improve survival even with less aggressive end-of-life care treatments. Patients with lung cancer have also been shown to have increased quality of life, less likelihood of receiving aggressive end-of-life treatments, less depression, and more likelihood to have end-of-life preferences documented when using early palliative-care interventions (McCormick et al., 2012). For terminally ill patients with chronic obstructive pulmonary disease, congestive heart failure, and cancer, early-intervention palliative care has improved family and patient satisfaction, reduced medical costs, and increased opportunities for dying at home (McCormick et al., 2012).

Although many benefits of palliative care exist, various barriers impede patients' use of these services. One barrier is that many patients do not have direct access to palliative care services due to hospitals not having hospital-based palliative care programs (Callaway, 2012). Many patients and providers also do not accept palliative care options when making decisions regarding how to provide and receive care (Callaway, 2012). Some reasons for this lack of acceptance include overwhelming numbers of choices given to terminally ill patients and their families, lack of

conversations regarding patients' statuses prognoses, confusion between scientific and cultural facts, providers viewing palliative care referrals as a personal failure, and the belief that palliative care is only used for "death imminent" patients (Callaway, 2012). Although it is encouraged to have clinicians counsel patients about palliative care, too few patients and families receive this support in a timely manner (Institute of Medicine, 2015). To help integrate palliative care into practice, it is important to have palliative care consults initiated as part of a integrative management plan at the time of diagnosis (Callaway, 2012), and also improve provider and patient education on the use and implementation of palliative care.

## **2.8 Hospice**

Hospice is often viewed as the model for quality compassionate care that provides medical care, pain management, spiritual support, and emotional support to a terminally-ill patient and the patient's loved ones (National Hospice and Palliative Care Organization, 2013). The first hospice program was opened in 1974, and the number of hospice programs continues to increase (National Hospice and Palliative Care Organization, 2013). Over 5,500 hospice programs exist today (including primary locations and satellite offices), and approximately 1.5 to 1.6 million patients received hospice care in 2012 (National Hospice and Palliative Care Organization, 2013).

Cancer diagnoses account for more than a third of all hospice admissions, followed by unspecified debilities, dementia, heart disease, and lung disease (National Hospice and Palliative Care Organization, 2013). The predominant source of payment for hospice care is the Medicare Hospice benefit, followed by managed care or private

insurance, the Medicaid Hospice benefit, and then uncompensated or charity care (National Hospice and Palliative Care Organization, 2013).

Hospice care is provided in a variety of settings including inpatient hospice facilities, hospitals, skilled nursing facilities, acute hospice facilities, and patients' homes. In addition, hospice care is not limited to any single disease, and it is provided to people of any age, race, or religion (National Hospice and Palliative Care Organization, 2013).

Usually a family member serves as the primary caregiver to the patient, and the hospice team works with the patient and family to meet their specific needs (National Hospice and Palliative Care Organization, 2013). Ideally, a hospice team is interdisciplinary and is composed of physicians, nurses, therapists, home health aides, bereavement counselors, social workers, and spiritual counselors (National Hospice and Palliative Care Organization, 2013). Volunteers, speech therapists, physical therapists, and occupational therapists can also be part of the team, if needed (National Hospice and Palliative Care Organization, 2013).

Various services are provided to patients and families including managing the patient's pain and symptoms, instructing the family on how to care for the patient, providing bereavement care and counseling, assisting the patient with psychosocial, emotional, and spiritual aspects of dying, and providing needed drugs and medical supplies (National Hospice and Palliative Care Organization, 2013).

## **2.9 Advance Directives**

Advance directives are any statements made by a competent person about choices for medical treatment if he or she cannot make these decisions or communicate them in the future (Despelder & Strickland, 2015). Advance directives go into effect when a

person is unable to communicate his or her wishes and medical intervention is needed. Several types of advance directives exist, including a living will, a durable power of attorney for health care, and do-not-resuscitate (DNR) orders.

A living will is a legal document that allows a person to refuse life-sustaining treatment in the event that he or she is terminally ill and life-sustaining procedures would only prolong death unnecessarily (Despelder & Strickland, 2015). This type of advance directive was proposed in 1967 and was first adopted by California under the Natural Death Act, giving recognition to the living will, and by the end of the 20<sup>th</sup> century, all states adopted some form of living will legislation (Despelder & Strickland, 2015).

Durable power of attorney for health care, also known as health care proxy, is another type of advance directive where a grantor can appoint someone as a proxy to make decisions about medical treatment if the grantor is unable to do so (Despelder & Strickland, 2015). This appointed person may be a friend, relative, or someone with whom the granter discussed his or her preferences. This person acts in accordance with the grantor's previously discussed wishes or the wishes that are stated in other advance directive forms (Despelder & Strickland, 2015).

A do-not-resuscitate (DNR) order is an advance directive stating that a person does not want to be resuscitated. Unless otherwise stated, hospital and emergency personnel will start CPR to help patients whose hearts have stopped or who have stopped breathing, and a DNR can be used to prevent this. However, one should be specific when requesting this order from his or her physician because it can be unclear which life-saving interventions this order can include (Despelder & Strickland, 2015).

For all advance directives, the person completing them must be specific in stating which treatments he or she would like to receive if mentally incompetent or unable to communicate. To have this specificity, an individual needs to be educated on the different types of treatment options that are available for those at end-of-life. Copies of the documents should be given to family, friends, caregivers, and care providers. Documents should also readily available for emergency personnel who are called to the scene (Despelder & Strickland, 2015).

In addition to completing advance directives, individuals with life-threatening illnesses or those approaching death may wish to complete a will. In contrast to a living will, a will is a legal document expressing a person's intentions for the disposition of his or her property after death; it is a declaration of how a person's estate will be distributed to heirs or beneficiaries upon death (Despelder & Strickland, 2015).

## **2.10 Importance and Consequences of End-of-Life Care Planning**

End-of-life care planning is an important task in which people should engage before they die. Engaging in end-of-life planning has been associated with various benefits, such as improving quality of life at end-of-life (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). Those who complete end-of-life planning are less likely to have an in-hospital death, and they have an increased use of hospice services (Bischoff et al., 2013). Patients who prepare advance directives are also more likely to receive care associated with their preferences (Silveira, Kim, & Langa, 2010). Silveira et al. (2010) demonstrated that 83.2% of patients who requested limited care received it and 97.1% who requested comfort care received it.

Not only does end-of-life care planning help the patient, but it also is beneficial for families and caregivers of the patient. Research demonstrates that when end-of-life wishes are written, relatives report lower levels of emotional distress at the end of life (Vandervoort, Houttekier, Vander Stichele, van der Steen, & Van den Block, 2014). Advance directives also assist the caregiver or surrogate decision maker with deciding which treatment should be given to the patient (Tejwani et al., 2013). This helps the surrogate decision maker to have realistic expectations about the prognosis and goals of care for the patient. These advance directives can also help prevent futility disputes. Futility disputes are strong disagreements about whether treatment would offer reasonable benefits to the patient, or would be futile for the patient (Tejwani et al., 2013). These futility disputes occur when the physician and the patient's family or surrogate have opposing views on what type of care is appropriate for the patient (Tejwani et al., 2013). During these disputes, the physician typically thinks that aggressive care is futile and palliative care is appropriate, while the family or surrogate disagrees with this (Tejwani et al., 2013). Having completed advance directives can aid in avoiding these situations and prevent families from worrying about keeping the patient alive on futile life-extending treatment.

### **2.11 End-of-Life Care Planning Completion**

Although completing end-of-planning care does have various benefits, many people still do not complete this task (Institute of Medicine, 2015). In a 2013 national survey of Americans aged 18 and older, 9 in 10 Americans believed it was important to talk about their wishes for end-of-life care with loved ones, but less than 3 in 10 had actually engaged in such discussions (The Conversation Project, 2013). The National Council on

Aging (2014) reported that 62% of those aged 60 and older have discussed end-of-life wishes with a loved one. In addition, in a nationally representative study of those aged 40 and older, 41% discussed end-of-life wishes with a loved one (Tompson et al., 2013). In a 2012 study of a representative sample of 1,669 Californians aged 18 and above, 42% of respondents reported having a discussion about end-of-life issues with a loved one (California Health Care Foundation, 2012). The groups most likely to have had a discussion about end-of-life issues with a loved one were those aged 65 and older, people with higher education and income, Whites, and those with one or more chronic conditions (California Health Care Foundation, 2012). In addition, more than 75% of respondents said they would definitely or probably want to talk with their doctor about their wishes for end-of-life medical treatment if they were seriously ill. However, 92% said a doctor had never asked them about end-of-life medical preferences (California Health Care Foundation, 2012).

Regarding advance directives, past research indicates that a range of 18% to 36% of the entire American adult population has completed an advance directive (U.S. Department of Health and Human Services, 2008). However, the rate of completion among adults aged 60 and older has increased over time (Silveira, Wiitala, & Piette, 2014). In a study of those who died between 2000 and 2010 aged 60 and above, the proportion of decedents with an AD increased from 47% in 2000 to 72% in 2010 (Silveira et al., 2014). However, this conflicts with a study by the National Council on Aging (2014) that reported that 54% of adults in the United States aged 60 and older had completed an advance directive. Tompson et al. (2013) revealed that among those aged 40 and older, 47% had completed an advance directive. Furthermore, among those aged

18 and older, only 23% completed an advance directive (California Health Care Foundation, 2012).

One would think that those with a terminal illness would certainly have completed an advance directive. However, past research indicates that fewer than half of severely or terminally ill patients had an advance directive in their medical record, and among individuals with chronic illnesses, only one in three completed an advance directive (U.S. Department of Health and Human Services, 2008). In addition, more than 60% of physicians whose patients had advance directives were unaware of the existence of those documents (U.S. Department of Health and Human Services, 2008).

### **2.12 Factors Associated with End-of-Life Care**

Various factors are associated with participation in end-of-life care planning and end-of-life care use. Positive attitudes toward hospice have been shown to be associated with older age, having prior knowledge of living wills, having prior knowledge of hospice services, and having a higher level of education (Ruff, Jacobs, Fernandez, Bowen, & Gerber, 2011). In addition, older age, having no religious affiliation, and having prior knowledge of living wills were associated with preferences for less intensive medical interventions at the end-of-life (Ruff et al., 2011). Participation in end-of-life care planning has also been shown to be associated with those having greater disease burden, higher socioeconomic status, knowledge about advance directives or end-of-life treatment options, a positive attitude toward end-of-life discussions, a long-standing relationship with a primary care physician, and having a diagnosis of cancer (U.S. Department of Health and Human Services, 2008). Type and acuity of condition has been shown to be associated with end-of-life care planning participation as well; for example,

patients with greater disease burden are more likely to complete end-of-life planning, and patients with cancer have been shown to be more likely to complete advance directives than severely ill patients with a different condition (U.S. Department of Health and Human Services, 2008). The factors of gender, age, religiosity, socioeconomic status, marital status, and race and ethnicity are described below in more detail.

### *Gender*

Women are more likely than men to engage in some aspect of advance care planning (Bischoff et al., 2013). Women are more likely than men to share their preferences for end-of-life care with others and to know more about hospice. Women are more likely than men to want pain control, to be at home when dying, and to be off machines that prolong life. Men are more likely to value having financial matters settled and having their spouse initiate conversations about end-of-life (Schrader, Nelson, & Eidsness, 2009). In addition, when looking at the distribution of medical end-of-life decisions, non-treatment decisions are more frequently used among women whereas palliative sedation and life-ending without explicit request are found less often (Rietjens, Deschepper, Pasman, & Deliens, 2012).

In a study of Medicare cancer patients, in the last 30 days of life, women received less aggressive in-hospital care than men. In addition, women were less likely to receive chemotherapy than men (Miesfeldt et al., 2012).

### *Age*

Age has been shown to be associated with some aspects of end-of-life care planning and use. Regarding end-of-life care planning, as a person ages, the more likely he or she is to complete some aspect of end-of-life care planning (Institute of Medicine,

2015). Those aged 65 and older are more likely to discuss end-of-life preferences with loved ones than those under 65 (California Health Care Foundation, 2012). Adults aged 60 and older are also more likely to complete an advance directive than adults under 60 years old (Institute of Medicine, 2015).

Individuals 85 years old or older had increased odds of being in a long-term care institution and also dying there than individuals 65-74 years old (Menec, Lix, Nowicki, & Ekuma, 2007). Individuals 85 years old or older also have lower odds of being hospitalized and being admitted to an ICU (Menec et al., 2007). Non-treatment decisions, or decisions to withdraw or withhold potential life-prolonging treatments no longer considered beneficial, are more frequently practiced among patients older than 80 (Rietjens et al., 2012). In addition, life-ending without explicit request and palliative care sedation are practiced less often amongst the very old (Rietjens et al., 2012). Furthermore, Parr et al. (2010) described that middle-aged patients wanted less life-prolonging care in comparison to younger patients, and in the last week of life, older patients were less likely to undergo ventilation than younger patients.

Regarding pain medication use in end-of-life care, use of opiates, NSAIDS, and adjuvant medications are all shown to decrease with increasing age (Zerzan, Benton, Linnebur, O'Bryant, & Kutner, 2010). In addition, the administration of medication with a potential or certain life-shortening effect has been shown to be practiced less often among the elderly, females, and less well-educated patients compared with younger, male, or more educated patients (Rietjens et al., 2012). However, decisions that include the withdrawal or withholding of treatments appear to be more common among the elderly, females, and less educated individuals (Rietjens et al., 2012).

Regarding high medical care use, defined as having seven or more intensive care unit (ICU) days in the last 90 days of life, among older adults over the age of 67 who have cognitive impairment, those who are younger and non-white are more likely to have high medical care use (Haller & Gessert, 2007). In addition, high medical care users are also more likely to lack DNR directives when compared to controls (Haller & Gessert, 2007).

In a study of Medicare cancer patients, in the last month of life, compared with the younger age group, those who were 75 years old and above received less acute care as measured by multiple admissions, multiple ED visits, ICU admissions, and in-hospital deaths (Miesfeldt et al., 2012). Comparing chemotherapy across subgroups in the last 14 days of life, older patients were less likely to receive chemotherapy than younger patients. When observing hospice use during the last six months of life, older patients aged 75 and older were more likely to die with hospice care than those under 75 years old. Hospice enrollment was less common among older cohort members as well (Miesfeldt et al., 2012).

### *Religiosity*

Patients reporting high intrinsic religiosity have been shown to be more likely to have specified a decision maker than those reporting low intrinsic religiosity, and the same is true for those with high compared with low spirituality (Karches, Chung, Arora, Meltzer, & Curlin, 2012). Some research has also demonstrated that religious characteristics are not significantly associated with having an advance directive or DNR order (Karches et al., 2012), while other research has stated that those who describe themselves as very religious are more likely to be prepared for death by completing a will

and advance directive (Schrader et al., 2009). In addition, those who describe themselves as very religious are more likely to report the importance of being in a spiritual community, which included seeking spiritual peace at end-of-life, attending funerals, rejecting assisted suicide, and relying on clergy (Schrader et al., 2009).

Those who self-identify as somewhat religious have been shown to be more likely to fear sudden death, dying alone, or abandonment, and are less likely to have discussed their end-of-life preferences with others. Those who are not at all religious have been shown to be more likely to convey fears about pain, institutionalization, and physical dependency at end-of-life (Schrader et al., 2009).

#### *Socioeconomic Status*

Individuals with greater net worth have been shown to be more likely to engage in advance care planning (Bischoff et al., 2013). Highly-educated patients are more likely to use physician assisted suicide and intensified symptoms alleviation (Rietjens et al., 2012). In addition, differences in the circumstances surrounding death, such as location of death or treatment used, exist between different socioeconomic groups for several reasons (Rietjens et al., 2012). One reason is because the place of death and well-being during the dying process are often associated with financial resources, and although most cancer patients prefer to die at home, the ability to do so depends on the patient's socioeconomic status (Rietjens et al., 2012). Highly-educated individuals tend to receive more social support from others, which might influence the care resources and end-of-life decision making (Rietjens et al., 2012). In addition, patients with a lower level of education are less involved in treatment decisions (Rietjens et al., 2012).

Individuals with more education are also more likely to talk to their spouse and

lawyer about end-of-life preferences, complete a financial will and organ donor card, and be more receptive to having others initiate end-of-life conversations (Schrader et al., 2009). Those with more education are also more likely to complete an advance directive (Carr & Khodyakov, 2007). Those with less education have been shown to be more likely to have engaged in pre-planning their funeral and burial, and be concerned about being off machines, controlling pain, and knowing how to say goodbye (Schrader et al., 2009).

#### *Marital Status*

Unpartnered and unmarried individuals are more likely to engage in some aspect of end-of-life care planning (Bischoff et al., 2013). Those who have never married are more likely to express fears related to dying and to have discussed end-of-life wishes with friends (Schrader et al., 2009). In addition, long-term residents of nursing homes are more likely to have engaged in advance care planning (Bischoff et al., 2013). Also, widows have been shown to be more likely to be prepared for death regarding discussions with family members and actions (Schrader et al., 2009). Those who have separated or divorced have been shown to be more likely to be open to the idea of assisted suicide (Schrader et al., 2009).

#### *Race and Ethnicity*

Caucasians are more likely to engage in some aspect of advance care planning as compared to other racial groups (Bischoff et al., 2013). More specifically, Caucasian patients are more likely than African American patients to have an advance directive and a DNR order (Karches et al., 2012). In addition, Latinos are significantly less likely than Whites to have a living will (13% vs. 25%) and a DPAHC appointment (17% vs. 28%), and a significantly higher proportion of Caucasians hold discussions about their

preferences for end-of-life care, in comparison to African Americans and Latinos (60% vs. 44% and 60% vs. 37%, respectively) (Carr, 2012). Caucasians also scored significantly higher on the Hospice Beliefs and Attitudes Scale than African Americans, with an average of 3.2 points higher on the scale than African Americans (Johnson, Kuchibhatla, & Tulsky, 2008). This indicates that Caucasians have more favorable attitudes toward hospice care than African Americans (Johnson et al., 2008).

Regarding end-of-life care planning and minorities, African Americans have been shown to be less likely than Caucasians to have completed a living will or a DPAHC (35.5% vs. 67.4%), and in an unadjusted multivariate analysis of race as a predictor of possession of an advance directive, Caucasians had nearly four times greater odds of having an advance directive than African Americans (Johnson et al., 2008). Carr (2011) demonstrated that only 25% of African Americans and 10% of Latinos have completed a living will, compared to approximately 65% of Caucasians. Regarding DPAHC appointments, 25% of African Americans and 4% of Latinos have appointed a DPAHC, compared to 59% of Caucasians (Carr, 2011). Discussing end-of-life care wishes was more common among all three groups, with 59% of African Americans and 33% of Latinos having discussed their end-of-life care preferences, compared to 85% of Caucasians (Carr, 2011).

African Americans and Latinos also tend to have over-utilization of futile therapeutic treatment and underutilization hospice and palliative care as a whole (Noah, 2012). African Americans and other racial minorities in the United States use palliative care and hospice significantly less frequently than white Americans, and these minority populations also tend to abstain from completing advance care planning and choose more

life-prolonging care at end-of-life, even when prognosis is poor (Noah, 2012). In a study by Barnato, Anthony, Skinner, Gallagher, and Fisher (2009), minorities were more likely to prefer intensive treatment options than whites; specifically, more Blacks (28.1%) and Hispanics (21.2%) than Whites (15%) would want life-extending drug treatment with uncomfortable side effects, and fewer Blacks (49.3%) and Hispanics (56.6%) than Whites (74.2%) would want palliative medications that might be life shortening. More Blacks (36.1%, 23.5%) and Hispanics (29%, 21.6%) than Whites (19.3%, 10.8%) also reported that they would want to receive ventilator support for 1 month's or 1 week's life extension, respectively (Barnato et al., 2009).

In addition, older African American adults are more likely to express discomfort discussing death, want aggressive care at the end of life, have spiritual beliefs that conflict with the goals of palliative care, and distrust the health care system (Johnson et al., 2008). A number of studies document that African Americans utilize hospice services at lower rates than white patients, even when controlling for variables such as insurance coverage (Noah, 2012). In 2012, 93.1% of hospice patients were of non-Hispanic or non-Latino origin, while only 6.9% were of Hispanic or Latino origin (National Hospice and Palliative Care Organization, 2013). In that same year, the statistics for hospice utilization also showed disproportionately low use by African Americans, with only 8.6% of hospice patients being African American, in contrast to 81.5% of hospice patients being Caucasian (National Hospice and Palliative Care Organization, 2013).

Furthermore, in a study of Medicare cancer patients, African American patients received more aggressive acute care in the last month of life than non-African American patients, and African American patients were more likely to die without hospice care than

non-African American patients (Miesfeldt et al., 2012). Compared with non-African American patients, fewer African American patients received chemotherapy. Despite lower overall hospice use, late enrollment was less common among African American hospice patients compared with non-African American hospice patients (Miesfeldt et al., 2012).

### **2.13 Barriers to End-of-Life Care Planning**

There are numerous barriers to completing end-of-life care planning. Common barriers include Americans' discomfort discussing death, reluctance of physicians to discuss advance care planning with their patients, beliefs about the utility or relevance of an advance directive, lack of information, and having difficulty with stating specific care preferences in response to potential specific clinical scenarios (U.S. Department of Health and Human Services, 2008). Patients also report barriers such as concerns with relationships such as having a poor relationship with family or friends, not wanting to burden family or friends, or not having family or friends. Other barriers include patients perceiving end-of-life care planning as irrelevant, lacking awareness and information about health and possible treatment choices for the future, preferring to leave health in God's hands, perceiving themselves as being "too healthy" to need to complete end-of-life planning, and needing help with understanding and completing the documents (Schickedanz et al., 2009). Among adults who had not spoken with loved ones about end-of-life care preferences, common reasons for not having these end-of-life discussions included having too many other things to think about, not wanting to think about death or dying, and loved ones not wanting to talk about death or dying (California Health Care Foundation, 2012).

The health professions most involved in care near the end of life are physicians, nurses, and social workers (Institute of Medicine, 2015). Primary care plays an important role for many people with advanced serious illnesses. Primary care providers are often best able to coordinate the patient's health services and ensure continuity of care (Institute of Medicine, 2015). Although these providers are often in the best position to coordinate care, burdensome transitions at the end of life still occur. In addition to this, there are repeated miscommunications with the family, poor communication with the patient, and failure to implement advance directives (Institute of Medicine, 2015). There is a lack of attention to developing providers' ability to communicate effectively with patients about dying and teaching them to listen to patients' expression of their concerns, values, and goals (Institute of Medicine, 2015).

Health literacy has also been shown to predict end-of-life care preferences (Vollandes et al., 2008). In study of patients over 40 years old, subjects were asked their preferences for end-of-life care after they heard a verbal description of advanced dementia (Vollandes et al., 2008). The results from this study demonstrated that health literacy was an independent predictor of end-of-life care preferences after hearing a verbal description of advanced dementia (Vollandes et al., 2008). Low health literacy affects certain population subgroups disproportionately including people of lower socioeconomic status, racial and ethnic minorities, people with disabilities, those with psychiatric and other cognitive disorders, and the elderly (Institute of Medicine, 2015). Research has shown that health literacy affects health care utilization, outcomes, and costs (Berkman et al., 2011), and those with low health literacy whose difficulties are

worsened by the burden of an advanced illness may have difficulty reading or comprehending advance directive documents (Institute of Medicine, 2015).

African Americans and Hispanics have expressed different barriers to utilization of end-of-life care services and end-of-life planning. Some common barriers include lack of awareness of hospice services, prohibitive cost of health care, language barriers, and distrust of the health care system (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004). Lack of health insurance and difficulty paying for health services and medications has also been identified among these common barriers (Born et al., 2004).

#### **2.14 Reasons for Differences in End-of-Life Care Use**

Various reasons exist why there are differences in the end-of-life care use by race/ethnicity. Lack of insurance or under-insurance partially explains the racial differences in use of hospice and end-of-life care, as many African Americans and other racial minorities are uninsured in disproportionate numbers in comparison to Caucasians (Noah, 2012). However, even when African American patients have adequate insurance coverage for hospice care and have similar rates of end-of-life discussions with their physicians as Caucasian patients, research shows that African Americans receive more life-prolonging care in the last week of life (Noah, 2012). Other studies also demonstrate that African Americans and Hispanics are more likely to request expensive interventions such as cardiopulmonary resuscitation, mechanical ventilation, intensive care, and artificial feeding, regardless of prognosis (Noah, 2012).

Even when African Americans choose hospice care, they are 70% more likely than Caucasian patients to leave hospice to resume curative treatment (Noah, 2012). Several other factors influence the use of end-of-life care by African Americans and

Latinos including religious beliefs, cultural differences from the Western norm, and distrust in the medical system and its providers (Bullock, 2006; Johnson et al., 2008; Noah, 2012; Winston, Leshner, Kramer, & Allen, 2004; Yancu et al., 2010). Research suggests that African Americans are more likely to consider themselves religious than Caucasians and these religious beliefs are associated with higher use of care at end-of-life (Noah, 2012). In addition, patients who are religious or spiritual may feel that it is inappropriate to leave decisions about life or death with the doctor or to make these decisions themselves, and may also feel compelled to undergo potentially painful or futile treatments in order to demonstrate moral strength in preparation for life after death (Noah, 2012).

Distrust in the health care system and health care providers can obviously impact the use of health services. African Americans and other racial minorities express significantly more distrust in the health care system (Cort, 2004; Institute of Medicine, 2015; Johnson et al., 2008; Noah, 2012). Minority patient populations' lack of trust in the predominately white medical system discourages these patients from seeking early medical attention or using hospice care, even when care is available and affordable (Cort, 2004; Noah, 2012). Research also suggests African American and Hispanic patients are less likely to trust their physicians because of perceived discrimination, the legacy of racial discrimination in medicine and medical research, and social distance between physicians and their minority patients (Duffy, Jackson, Schim, Ronis, & Fowler, 2006; Noah, 2012).

Other reported reasons that African Americans are less likely to engage in end-of-life care planning include previous experiences with death and those who have used end-

of-life care, and barriers to complete end-of-life planning (Bullock, 2006). These barriers include lack of knowledge about end-of-life care documents, lack of involvement of others in end-of-life planning, perceived negative effect with regard to planning for a terminal illness and death, and the feeling of being pushed by health care providers to make end-of-life decisions (Bullock, 2006).

Lack of knowledge about hospice care has also been shown to be a barrier to use these services. In a study of older adults recruited from the Duke Health Care System, compared to Caucasians, African Americans were shown to have less exposure to hospice information; nineteen percent of African Americans and 4% of Caucasians had never heard of hospice, and 47.6% of African Americans and 71.6% of whites had heard a lot about hospice (Johnson, Kuchibhatla, & Tulsky, 2009). In addition, African Americans were twice as likely to report that they had never heard of hospice or heard only a little about hospice versus heard a lot about hospice (Johnson et al., 2009). This is problematic since greater exposure to hospice information has been shown to be associated with more favorable beliefs about hospice care (Johnson et al., 2009).

### **2.15 Integrated Behavioral Model**

The Integrated Behavioral Model (IBM) is an extension of Fishbein and Ajzen's Theory of Reasoned Action (TRA) (1975, 1980) and Theory of Planned Behavior (TPB) (1988, 1991) that includes components from other major behavioral theories (Figure 2-3) (Ajzen, 1991; Glanz et al., 2008). With IBM, the most important determinant of behavior is intention to perform the behavior. Behavioral intention is determined by three construct categories including: attitude toward the behavior, perceived norms, and personal agency (Glanz et al., 2008).

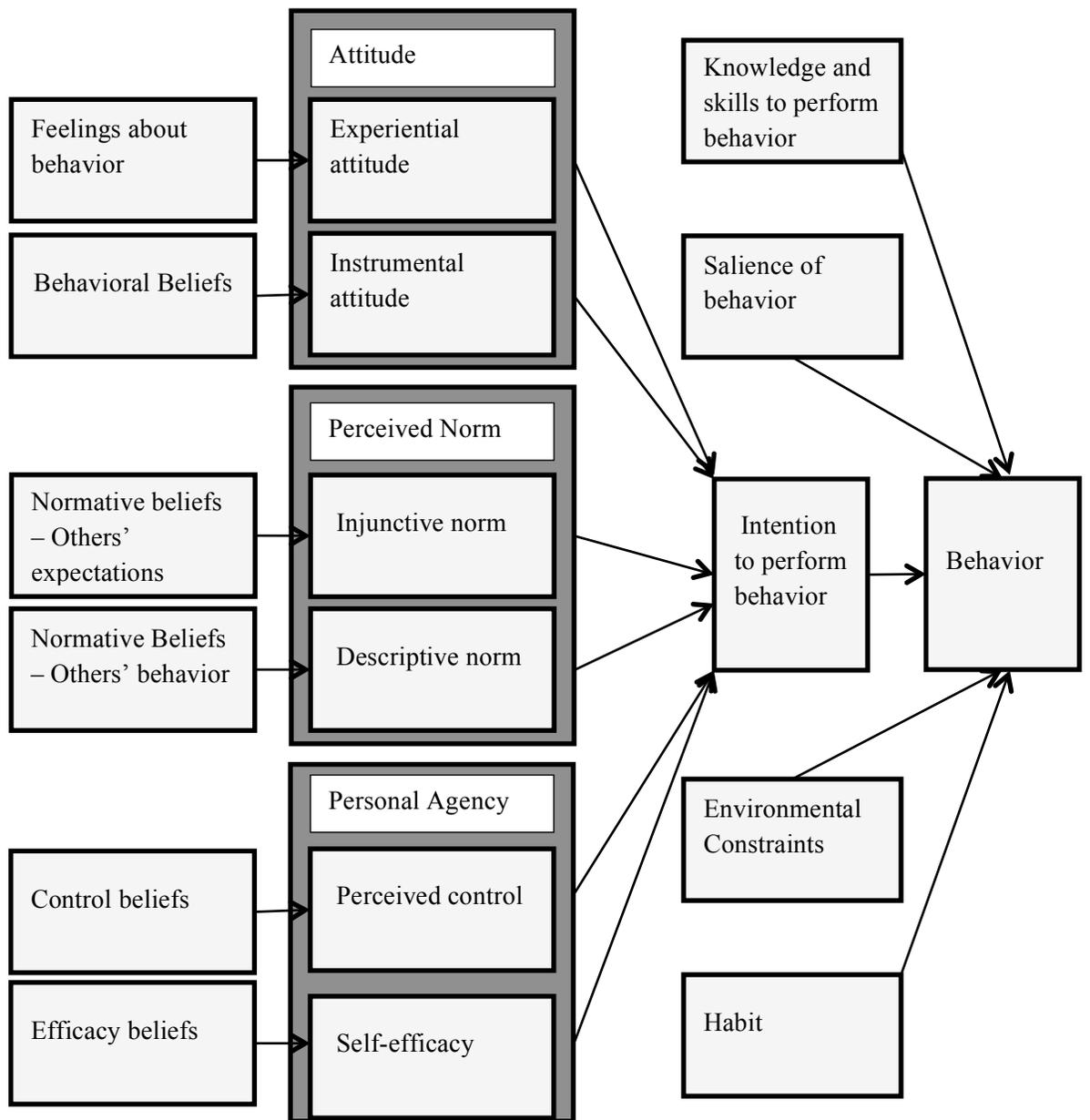


Figure 2-3: Integrated Behavioral Model (IBM)

The first construct category, attitude toward the behavior, is defined as a person's overall favorableness or unfavorableness toward performing a behavior, which is composed of experiential attitude or instrumental attitude (Ajzen, 1991; Fishbein, 2004; Glanz et al., 2008). Experiential attitude is the person's emotional response to the idea of performing a behavior, while instrumental attitude is cognitive response to performing a behavior, and is determined by beliefs about outcomes of behavioral performance (Glanz et al., 2008). With these constructs, a person is more likely to perform a behavior if he or she has a strong positive emotional reaction to it, and a person who believes that a behavior will produce positive outcomes and prevent negative outcomes is more likely to engage in that behavior as well (Fishbein, 2004).

The second construct category, perceived norms, represents the social pressure that one feels to perform or not perform a specific behavior (Ajzen, 1991; Fishbein, 2004). The construct of perceived norms is comprised of both injunctive norms and descriptive norms. Injunctive norms are described as the normative beliefs about what others think one should do and motivation to comply, while descriptive norms are described as the perceptions about what others in one's social or personal networks are doing (Fishbein, 2004; Glanz et al., 2008).

Finally, personal agency is bringing one's influence to bear on one's own functioning and environmental events (Fishbein, 2004; Glanz et al., 2008). Personal agency is also composed of two constructs, being perceived control and self-efficacy. Perceived control is described as one's perceived ease or difficulty of performing the behavior of interest, and is determined by one's perception of the degree to which various available resources or opportunities make it easy or difficult to engage in the behavior

(Ajzen, 1991). Self-efficacy is described as one's degree of confidence in the ability to perform a specific behavior in the face of challenges or barriers (Fishbein, 2004).

These three construct categories all influence intention to perform a behavior, but the importance in determining intention may vary for one behavior, and also for different populations (Ajzen, 1991; Fishbein, 2004). Due to this, it is necessary to determine the degree to which intention is influenced by each of these categories (Fishbein, 2004). In addition, each of these categories is a function of underlying beliefs; instrumental attitudes are a function of beliefs about outcomes or performing the behavior, experiential attitudes are a function of feeling about a behavior, injunctive norms are a function of normative beliefs about others' expectations, descriptive norms are a function of normative beliefs about others' behaviors, perceived control is a function of control beliefs, and self-efficacy is a function of efficacy beliefs (Fishbein, 2004; Glanz et al., 2008). This is important when implementing interventions because these specific underlying beliefs should be targeted when trying to change a behavior (Fishbein, 2004; Glanz et al., 2008).

The IBM constructs have been used to predict various health related behaviors and understand intention and behavior for condom use among high HIV risk groups, as well as other HIV/STD prevention behaviors (Kasprzyk, Montaño, & Fishbein, 1998; Kenski, Appleyard, von Haefen, Kasprzyk, & Fishbein, 2001; von Haefen, Fishbein, Kasprzyk, & Montano, 2001). It has also been used with college students to predict leisure time physical activity (Beville et al., 2014).

## **2.16 Precaution Adoption Process Model**

The Precaution Adoption Process Model (PAPM) is a model used to explain how a person makes a decision to take action and how he or she puts the decision into action (Weinstein, Sandman, & Blalock, 2008). Work on the PAPM was initially performed by Irving Janis and Leon Mann in 1977, as they tried to explain people's responses to threats by using different categories determined by the people's beliefs about their capacity to cope with the threat (Weinstein et al., 2008). The PAPM has these categories or stages, which are defined in terms of mental states, as opposed to external factors.

The PAPM applies to the deliberate steps taken to adopt a new precaution or stop a risky behavior, and it does not apply to actions that result from the development of habitual patterns of behavior (Weinstein et al., 2008). This model has been applied to various health behaviors such as cancer screening (Costanza et al., 2005; Sifri et al., 2010), osteoporosis prevention (Blalock et al., 2000), home radon testing (Weinstein & Sandman, 1992), and smoking cessation (Borrelli et al., 2002), and it may be used for many other health behaviors as well (Weinstein et al., 2008).

The current formulation of the PAPM was published by Weinstein and Sandman in 1992, and this version identifies seven stages including: unaware of issue, unengaged by issue, undecided about acting, decided not to act, decided to act, acting, and maintenance (Weinstein & Sandman, 1992). Stage one, or unaware of issue, is when people are unaware of a health issue, while stage two, unengaged by issue, is when people are no longer unaware of the issue, but they are not yet engaged by it (Weinstein & Sandman, 1992; Weinstein et al., 2008). Stage three, undecided about acting, describes those who are engaged by the issue and are considering their response to it. This can

result in different outcomes, being that they stay in stage three, they decide to take no action (stage four), or they decide to adopt the precaution (stage five) (Weinstein & Sandman, 1992; Weinstein et al., 2008). Next, the person would move to stage six and initiate the behavior, and then the final stage seven would indicate that the person has maintained this behavior over time, if applicable (Weinstein & Sandman, 1992; Weinstein et al., 2008). Movement between stages is not always necessarily linear or sequential, as movement backward toward an earlier stage can occur without going back through all intermediate stages (Weinstein et al., 2008).

### **2.17 Summary**

End-of-life care planning is an important activity in which people should partake to ensure that their wishes are fulfilled at the end-of-life. In addition to ensuring that a person's wishes are kept at the end-of-life, completing end-of-life care planning has many benefits, including preventing futility disputes between family members and care providers, relieving emotional and financial burden on family and friends, and reducing medical costs.

Although these benefits exist, many people do not complete end-of-life care planning. As previously discussed, African Americans and Hispanics are significantly less likely than Caucasians to complete any type of end-of-life care planning. Various reasons have been explored for why these populations do not frequently engage in this behavior, but few studies use a health behavior theory to explain and predict these racial and ethnic differences in end-of-life care planning. The Integrated Behavioral Model and Precaution Adoption Process Model are both respected and frequently used models that can be applied to this study to help explain these differences in end-of-life care planning.

# Chapter Three

## Methods

This chapter will include the following sections: 1) Purpose of the Study, 2) Participants, 3) Instrument Development, 4) Instrument Testing, 5) Procedures, and 6) Data Analysis. This chapter discusses the design, development and implementation of the survey to examine adults' attitudes, beliefs, and perceptions on end-of-life care planning and use of end-of-life care.

### 3.1 Purpose of the Study

The primary objective of this study was to determine if the Integrated Behavioral Model was helpful in explaining and predicting end-of-life care planning behaviors among American adults, especially explaining differences by race/ethnicity. For this study, "end-of-life care planning" was defined as completing a Durable Power of Attorney for Health Care (DPAHC) document, completing a living will, and discussing end-of-life wishes with at least one relative or loved one.

### 3.2 Participants

A national sample of US adults was randomly selected through a commercial mailing list compiler with a consumer database comprised of more than 118 million households. An *a priori* sample size estimate was conducted to determine the necessary

sample size for adequate external validity to generalize the results to the adult population in the United States, ages 40 to 80. With a 95% confidence level and a 5% margin of error, the sample size needed was 384 participants (i.e., completed surveys).

To adjust for an anticipated 40% return rate, the required sample size was adjusted upwards. Therefore, 1,000 names and addresses were purchased. Since minority groups are often under-represented among commercial mailing list compilers, the investigator over-sampled African American and Hispanic adults between the ages of 40 and 80. Over sampling and proportional allocation was used to ensure that the sample represented the proportions of these race/ethnicity groups in the United States: Caucasians (74%), Hispanic/Latino (17%), and African Americans (13%) (U.S. Census Bureau, 2012). Proportional allocation was also used to ensure that the sample was representative of the general population within each region within the United States based on US Census Bureau statistics: Northeast (18%), Midwest (22%), South (37%), and West (23%) (U.S. Census Bureau, 2012).

### **3.3 Instrument Development**

The survey instrument for the current study was four pages in length and featured mostly closed-ended responses to assess adults' end-of-life care planning behaviors, attitudes, beliefs, and perceptions. The survey was formulated based upon a review of the published research literature. In addition, prior to the development of the final survey, an elicitation phase of formative research was conducted by the investigator. Focus groups and interviews were conducted with a convenience sample of adults from NW Ohio to elicit their most salient perceptions, beliefs, and attitudes regarding end-of-life care planning. The questions used for this elicitation phase were based on the Integrated

Behavioral Model and the Precaution Adoption Process Model. The three focus groups were composed of 31 participants, with 9 Blacks (29%) and 22 non-Hispanic Whites (71%). The groups were comprised of 8 males and 23 females.

Results of the elicitation phase were used to inform the final development of the survey instrument. The items in the instrument were formulated based on the Integrated Behavioral Model and the Precaution Adoption Process Model. The survey included measures for each of the four major IBM constructs, including attitude, perceived norms, personal agency, and intention to complete the behavior. In addition, questions regarding the stages within the PAPM were included. The survey also included demographic items to identify gender, age, race/ethnicity, educational background, annual income, and personal experience with life threatening illnesses.

Since some experts suggest that religiosity and racial distrust of the health care system may also impact adults' end-of-life-care planning, the investigator included a religiosity scale and a racial distrust scale. These scales were both adopted and modified from previous research. The religiosity scale was based upon the Duke University Religion Index (DUREL) (Koenig & Büssing, 2010). This is a 5-item scale assessing three dimensions of religiosity: 1) organizational religious activity, 2) non-organizational religious activity, and 3) intrinsic religiosity. In its past use, the overall scale had high test-retest reliability (intra-class correlation = 0.91), high internal consistence ( $\alpha = 0.78-0.91$ ), and high convergent validity with other measures of religiosity ( $r$ 's = 0.71–0.86) (Koenig & Büssing, 2010). For the current study, the wording of the items was altered slightly to improve clarity, and a sixth item was added that related more directly to end-of-life care planning.

The racial distrust scale was adopted from the 7-Item Medical Mistrust Index (MMI) (LaVeist, Isaac, & Williams, 2009) and the Group-Based Medical Mistrust Scale (GBMMS) (Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004). During past use, the test-retest reliability Pearson correlation coefficient for the 7-item MMI ranged from 0.35 to 0.70. This scale was also predictive of underutilization of health services (LaVeist et al., 2009). During past use, the GBMMS was shown to assess three factors: 1) suspicion, 2) group disparities in health care, and 3) lack of support from health care providers. In past use, internal consistency for the total GBMMS was high ( $\alpha = 0.83$ ,  $M = 28.32$ ,  $SD = 9.43$ ). Reliability coefficients for the subscales were 0.80 for factor 1, 0.76 for factor 2, and 0.55 for factor 3 (Thompson et al., 2004). For the current study, six items were based upon the MMI and the GBMMS, and the final item was tailored more specifically around end-of-life care planning.

### **3.4 Instrument Testing**

#### *Acceptability and Readability*

A small convenience sample of adults that matched the characteristics of the priority population was used to assess readability of the survey instrument. Readability was assessed using the SMOG and Flesch-Kincaid readability tests. The Flesch-Kincaid analysis was performed using the Microsoft Word grammar tools. The grade for this survey was 6.2, which represents a sixth grade level readability. A SMOG test revealed a reading level of 5.6, which equates to a fifth grade reading level.

#### *Validity*

A review of the current literature was conducted to establish face validity for the items on the survey. A panel of content experts (based on their publication records) with

expertise in minority health, adult health, end-of-life planning, and survey research evaluated the survey to establish content validity. The panel was given a draft version of the survey instrument with a cover letter explaining the nature of the study. Suggested revisions from the expert panel were incorporated into the questionnaire.

Construct validity of the theoretical subscales on the survey was established by conducting a principal component analysis (PCA) with Varimax rotation (Table 3.1). The minimal factor loading for individual items that was considered acceptable was 0.5. Listed below are the a priori subscales and a description of the final subscales created based on the results of the PCA analysis.

### *Subscales*

#### **Factor 1:**

- **Indirect attitudes:** *Before PCA:* Part D, items 17, 18, 19, 20, and 21. The possible range of this subscale was 5 to 30. *After PCA:* No changes necessary.
  - **Interpretation:** The higher the mean score, the higher respondents' indirect attitudes toward end-of-life care planning.
- **Attitude evaluation:** *Before PCA:* Part D, items 22, 23, 24, 25, 26. The possible range of this subscale was 5 to 30. *After PCA:* No changes necessary.
  - **Interpretation:** The higher the mean score, the higher respondents' indirect attitudes evaluation toward end-of-life care planning.

Table 3.1  
Principal Components Analysis (PCA) with corresponding theoretical subscales

Theoretical Subscale	PCA Factors (Eigen values)	Factor Loadings
<b>Indirect Attitudes</b>	<b>Factor 1 – D17, D18, D19, D20, D21</b>	#
	<b>Item D17:</b> How likely it is that completing end-of-life care planning would make you feel better prepared for the end of your life?	.715
	<b>Item D18:</b> How likely it is that completing end-of-life care planning would make you feel more at peace in the final days of your life?	.661
	<b>Item D19:</b> How likely it is that completing end-of-life care planning would ensure that your health care wishes for end-of-life medical care are followed?	.673
	<b>Item D20:</b> How likely it is that completing end-of-life care planning would reduce stress and burden on your loved ones when you are at the end of your life?	.583
	<b>Item D21:</b> How likely it is that completing end-of-life care planning would help you avoid unwanted medical treatment at the end of your life?	.653
<b>Attitude Evaluation</b>	<b>Factor 1 – D22, D23, D24, D25, D26</b>	#
	<b>Item D22:</b> How important is it for you to feel prepared for the end of your life?	.842
	<b>Item D23:</b> How important is it for you to feel more at peace in the final days of your life?	.856
	<b>Item D24:</b> How important is it for you to ensure that your health care wishes for end-of-life medical care are followed?	.875
	<b>Item D25:</b> How important is it for you to reduce stress and burden on your loved ones?	.853
	<b>Item D26:</b> How important is it for you to avoid unwanted medical treatment at the end of your life?	.818

Table 3.1 Continued

Direct Attitude	Factor 2 – F31a, F31b, F31c, F32a, F32b, F32c, F33a, F33b, F33c	#
	<b>Item F31a:</b> Completing my living will was or would be comfortable for me to do.	.811
	<b>Item F31b:</b> Completing my living will was or would be easy for me to do.	.830
	<b>Item F31c:</b> Completing my living will was or would be beneficial for me.	.548
	<b>Item F32a:</b> Completing my durable power of attorney for health care was or would be comfortable for me to do.	.787
	<b>Item F32b:</b> Completing my durable power of attorney for health care would be easy for me to do.	.805
	<b>Item F32c:</b> Completing my durable power of attorney for health care would be beneficial for me.	.521
	<b>Item F33a:</b> Discussing my wishes with family members was or would be comfortable for me to do.	.859
	<b>Item F33b:</b> Discussing my wishes with family members was or would be easy for me to do.	.828
	<b>Item F33c:</b> Discussing my wishes with family members was or would be beneficial for me.	.644
<b>Racial Distrust</b>	<b>Factor 3 – Items I45, I46, I47, I48, I49, I51</b>	#
	<b>Item I45:</b> People of my racial/ethnic group should be careful when dealing with doctors and health care workers.	.724
	<b>Item I46:</b> People of my racial/ethnic group have sometimes been deceived or misled by doctors and health care workers.	.801
	<b>Item I47:</b> People of my racial/ethnic group should not trust doctors and health care workers.	.828

Table 3.1 Continued

	<b>Item I48:</b> People of my racial/ethnic group should be suspicious of information from doctors and health care workers.	.873
	<b>Item I49:</b> People of my racial/ethnic group should not confide in doctors and health care workers because the information provided will probably be used against us.	.747
	<b>Item I51:</b> People of my racial/ethnic group should not complete end-of-life planning because if we do, doctors will give up on us and not give us full medical treatment.	.646
<b>Religiosity</b>	<b>Factor 4 – Items G34, G35, G36, G37, G38</b>	#
	<b>Item G34:</b> How often do you attend church, mosque, temple or other religious meetings?	.762
	<b>Item G35:</b> How often do you spend time in private spiritual activities such as prayer, meditation, or reading sacred books?	.803
	<b>Item G36:</b> In my life, I experience the presence of the Divine (i.e., God, Allah, Jehovah, other gods).	.891
	<b>Item G37:</b> My religious/spiritual beliefs help shape my approach to life.	.894
	<b>Item G38:</b> I try hard to apply my spiritual beliefs and values to my decisions, attitudes, and actions.	.906
<b>Intention</b>	<b>Factor 5 – Items E27, E28, E29, E30</b>	#
	<b>Item E27:</b> In the next 6 months, I plan to complete a living will.	.883
	<b>Item E28:</b> In the next 6 months, I plan to complete a durable power of attorney for health care.	.904
	<b>Item E29:</b> In the next 6 months, I plan to discuss my end-of-life wishes with at least one family member.	.694

Table 3.1 Continued

	<b>Item E30:</b> In the next 6 months, I plan to discuss my end-of-life wishes with my physician or health care provider.	.859
<b>Motivation to Comply</b>	<b>Factor 6 – Items B10, B11, B12</b>	#
	<b>Item B10:</b> How likely is it that you would complete end-of-life care planning if your physician/health care provider recommended it?	.771
	<b>Item B11:</b> How likely is it that you would complete end-of-life care planning if your loved ones wanted you to do it?	.779
	<b>Item B12:</b> How likely is it that you would complete end-of-life care planning if your best friend wanted you to do it?	.784
<b>Self Efficacy</b>	<b>Factor 7 – items C13, C14, C15, C16</b>	#
	<b>Item C13:</b> How certain are you that you could complete a living will?	.768
	<b>Item C14:</b> How certain are you that you could complete a durable power of attorney document for health care?	.788
	<b>Item C15:</b> How certain are you that you could discuss your wishes with your family?	.620
	<b>Item C16:</b> How certain are you that you could discuss your wishes for end-of-life medical care with your doctor?	.634
<b>Indirect Perceived Norms</b>	<b>Factor 8 – Items H42, H43, H44</b>	#
	<b>Item H42:</b> My physician approves or would approve of me completing my end-of-life planning.	.674

Table 3.1 Continued

	<b>Item H43:</b> My loved ones approve or would approve of me completing my end-of-life planning.	.787
	<b>Item H44:</b> My best friend approves or would approve of me completing my end-of-life planning.	.785
<b>Direct Perceived Norms</b>	<b>Factor 9 – Items H40, H41</b>	#
	<b>Item H40:</b> Most people that I know complete end-of-life planning.	.884
	<b>Item H41:</b> Most people in my community complete end-of-life planning.	.846
<b>Racial Distrust</b>	<b>Factor 10 – Item I50</b>	#
	<b>Item I50:</b> People of my racial/ethnic group receive the same quality of medical care from doctors and health care workers as people from other racial/ethnic groups.	.817

**Factor 2:**

- **Direct attitude:** *Before PCA:* Part F, items 31a, 31b, 31c, 32a, 32b, 32c, 33a, 33b, and 33c. The possible range of this subscale was 9 to 45. *After PCA:* No changes necessary.
  - **Interpretation:** The higher the mean score, the higher respondents' direct attitudes toward end-of-life care planning.

**Factor 3:**

- **Racial distrust:** *Before PCA:* Part I, items 45, 46, 47, 48, 49, 50, and 51. Item 50 reverse coded. The possible range of this subscale was 7 to 35. *After PCA:* The only change necessary was removing item 50 from this subscale, which was then established as its own factor. This changed the possible range to be 6 to 30.
  - **Interpretation:** The higher the mean score, the higher respondents' racial distrust.

**Factor 4:**

- **Religiosity:** *Before PCA:* Part G, Items 34, 35, 36, 37, 38, and 39. The possible range of this subscale was 7 to 37. *After PCA:* Item 39 was deleted from the analysis, changing the range from 6 to 32.
  - **Interpretation:** The higher the mean score, the higher respondents' religiosity.

**Factor 5:**

- **Intention:** *Before PCA:* Part E, items 27, 28, 29, and 30. The possible range of this subscale was 4 to 28. *After PCA:* No changes necessary.

- **Interpretation:** The higher the mean score, the higher respondents' intention to complete end-of-life care planning.

**Factor 6:**

- **Motivation to Comply:** *Before PCA:* Part B, items 10, 11, and 12. The possible range of this subscale was 3 to 21. *After PCA:* No changes necessary.
  - **Interpretation:** The higher the mean score, the higher respondents' motivation to comply to complete end-of-life care planning.

**Factor 7:**

- **Self-efficacy:** *Before PCA:* Part C, items 13, 14, 15, and 16. The possible range of this subscale was 4 to 28. *After PCA:* No changes necessary.
  - **Interpretation:** The higher the mean score, the higher respondents' self-efficacy to complete end-of-life care planning.

**Factor 8:**

- **Indirect perceived norms:** *Before PCA:* Part H, items 42, 43, and 44. The possible range of this subscale was 3 to 21. *After PCA:* No changes necessary.
  - **Interpretation:** The higher the mean score, the higher respondents' indirect perceived norms toward end-of-life care planning.

**Factor 9:**

- **Direct perceived norms:** *Before PCA:* Part H, items 40 and 41. The possible range of this subscale was 2 to 14. *After PCA:* No changes necessary.

- **Interpretation:** The higher the mean score, the higher respondents' direct perceived norms toward end-of-life care planning.

**Factor 10:**

- **Racial distrust 2:** *Before PCA:* Part I, items 45, 46, 47, 48, 49, 50, and 51. Item 50 reverse coded. The possible range of this subscale was 7 to 35. *After PCA:* Item 50 was removed from the first racial distrust factor and created as its own factor. The range for this subscale is 1 to 5.
  - **Interpretation:** The higher the score, the higher respondents' racial distrust.

*Reliability*

The survey was pilot-tested to establish stability reliability. To procure at least 25 matched pairs of surveys, a convenience sample of adults in Northwest Ohio was used. The survey was administered on two separate occasions, ten days apart. Pearson product moment correlation coefficients were calculated for each subscale to determine the consistency of responses over time (Table 3.2). The internal reliability of the subscales was assessed using Cronbach's alpha method based on responses obtained from the final sample (Table 3.2).

**3.5 Procedures**

A cover letter explaining the voluntary nature and potential risks and benefits of participation served as the informed consent for this study. The University of Toledo's Institutional Review Board (IRB) approved the study design and protocol prior to the initial mailing.

Table 3.2  
Reliability Analysis of Survey Instrument Subscales

Subscales	Number of Items	Internal Consistency Alpha Coefficient*	Test-Retest Stability Coefficient**
Self-Efficacy	4	.88	.52
Intention	4	.92	.61
Indirect Attitudes	5	.93	.79
Attitude Evaluation	5	.95	.29
Direct Attitude	9	.94	.64
Motivation to Comply	3	.85	.75
Religion 1	1	-	.98
Religion 2	1	-	.95
Religion 3	3	.92	.86
Direct Perceived Norms	2	.81	.57
Indirect Perceived Norms	3	.81	.84
Racial Distrust 1	6	.88	.65
Racial Distrust 2	1	-	.54

\*Cronbach's alpha method (N=386; Categories with less than N=386 due to unreported data.)

\*\*Survey administered twice to same sample 10 days apart (N=25)

A four-wave postal mail survey procedure was used for this study. The first wave consisted of a hand-signed letter on University of Toledo stationery informing potential participants of the study and informing them that a survey would be arriving soon. One week following the announcement letter, the second wave was mailed. The second wave mailing consisted of a personalized hand-signed cover letter explaining the purpose of the study, a copy of the survey, a self-addressed stamped envelope, and an incentive of one dollar. Response to the survey served as consent to participate. No additional incentives were provided after the second wave. After two weeks, the third wave was mailed with a follow up letter and a second copy of the survey. After two more weeks, a fourth wave mailing consisting of a reminder postcard was sent to those who did not complete the survey during the previous waves.

### **3.6 Data Analysis**

#### *Variables in the Study*

Variables in the study are listed below in Table 3.3. Descriptive statistics (e.g., means, standard deviations, percentages) were used to describe the findings of the individual items. Inferential statistical tests such as t-tests, ANOVA, and logistic regression were also used. Due to the fact that multiple hypotheses were tested, the investigator used the Benjamini-Hochberg correction method to reduce the odds of making a Type 1 error (Table 3.3).

Table 3.3  
Data Analysis

<b>Hyp.</b>	<b>Independent Variable</b>	<b>Dependent Variable</b>	<b>Statistical Procedure</b>
1.1	Race/ethnicity (A2-A3)	EOL planning (A6-A9)	Chi-square
1.2	Age (J52)	EOL planning (A6-A9)	Chi-square
1.3	Marital Status (J57)	EOL planning (A6-A9)	Chi-square
1.4a	Religiosity/spirituality (G34)	EOL planning (A6-A9)	Logistic regression
1.4b	Religiosity/spirituality (G35)	EOL planning (A6-A9)	Logistic regression
1.4c	Religiosity/spirituality (G36-G38)	EOL planning (A6-A9)	Logistic regression
1.5	SES [Education] (A4)	EOL planning (A6-A9)	Chi-square
1.6	SES [Income] (J53)	EOL Planning (A6-A9)	Chi-square
1.7	Gender (A1)	EOL Planning (A6-A9)	Chi-square
1.8	Racial Distrust (I45-I51)	EOL Planning (A6-A9)	Logistic Regression
2.1	History of life threatening illness (J55)	Stage of readiness (B5)	Chi-square
2.2	Family member history with life threatening illness (J56)	Stage of readiness (B5)	Chi-square
2.3	Direct attitude toward completing advance directive documents (F31-F32)	Stage of readiness (B5)	One-way ANOVA
2.4	Direct attitude regarding discussing EOL wishes with family members (F33)	Stage of readiness (B5)	One-way ANOVA

Table 3.3 Continued

2.5	Indirect attitude regarding completing end-of-life planning (D17-D26)	Stage of readiness (B5)	One-way ANOVA
2.6a	Direct perceived norms regarding EOL planning (H40-H41)	Stage of readiness (B5)	One-way ANOVA
2.6b	Indirect perceived norms regarding EOL planning (H42-H44)	Stage of readiness (B5)	One-way ANOVA
2.6c	Mot to comply regarding EOL planning (B10-B12)	Stage of readiness (B5)	One-way ANOVA
2.7	Personal Agency (Self-Efficacy) regarding EOL planning (C13-C16)	Stage of readiness (B5)	One-way ANOVA
2.8	Family history with coma or PVS (J54)	Stage of readiness (B5)	Chi-square
3.1	Race/ethnicity (A2-A3)	Intention to complete EOL planning (E27-E30)	One-way ANOVA
3.2	Age (J52)	Intention to complete EOL planning (E27-E30)	One-way ANOVA
3.3	Gender (A1)	Intention to complete EOL planning (E27-E30)	Independent t-test
3.4	SES [Education] (A4)	Intention to complete EOL planning (E27-E30)	One-way ANOVA
3.5	SES [Income] (J53)	Intention to complete EOL planning (E27-E30)	One-way ANOVA
3.6	Marital Status (J57)	Intention to complete EOL planning (E27-E30)	Independent t-test
3.7a	Religiosity/spirituality (G34)	Intention to complete EOL planning (E27-E30)	Pearson correlation
3.7b	Religiosity/spirituality (G35)	Intention to complete EOL planning (E27-E30)	Pearson correlation

Table 3.3 Continued

3.7c	Religiosity/spirituality (G36-G38)	Intention to complete EOL planning (E27-E30)	Pearson correlation
3.8	Racial Distrust (I45-I51)	Intention to complete EOL planning (E27-E30)	Pearson correlation
4.1	Direct attitude toward completing advance directive documents (F31-F32)	Intention to complete EOL planning (E27-E30)	Pearson correlation
4.2	Direct attitude regarding discussing EOL wishes with family members (F33)	Intention to complete EOL planning (E27-E30)	Pearson correlation
4.3	Indirect attitude regarding completing end-of-life planning (D17-D26)	Intention to complete EOL planning (E27-E30)	Pearson correlation
4.4a	Direct perceived norms regarding EOL planning (H40-H41)	Intention to complete EOL planning (E27-E30)	Pearson correlation
4.4b	Indirect perceived norms regarding EOL planning (H42-H44)	Intention to complete EOL planning (E27-E30)	Pearson correlation
4.4c	Motivation to comply regarding EOL planning (B10-B12)	Intention to complete EOL planning (E27-E30)	Pearson correlation
4.5	Personal Agency (Self-Efficacy) regarding EOL planning (C13-C16)	Intention to complete EOL planning (E27-E30)	Pearson correlation
4.6a	Direct attitude toward completing advance directive documents (E18-E19)	Intention to complete EOL planning (E27-E30)	Linear regression
4.6b	Direct attitude regarding discussing EOL wishes with family members (E20)	Intention to complete EOL planning (E27-E30)	Linear regression
4.6c	Indirect attitude regarding completing end-of-life planning (F21-F30)	Intention to complete EOL planning (E27-E30)	Linear regression

Table 3.3 Continued

4.6d	Direct perceived norms regarding EOL planning (H40-H41)	Intention to complete EOL planning (E27-E30)	Linear regression
4.6e	Indirect perceived norms regarding EOL planning (H42-H44)	Intention to complete EOL planning (E27-E30)	Linear regression
4.6f	Motivation to Comply regarding EOL planning (B10-B12)	Intention to complete EOL planning (E27-E30)	Linear regression
4.6g	Personal Agency (Self-Efficacy) regarding EOL planning (B10-B12)	Intention to complete EOL planning (E27-E30)	Linear regression

# Chapter 4

## Results

This chapter describes the results of the current study. The following sections are included in this chapter: 1) Description of Response, 2) Demographics and Background Characteristics, 3) End-of-life Care Planning Behaviors, 4) Integrated Behavioral Model Constructs, 5) Racial Distrust, 6) Religiosity, and 7) Summary.

### 4.1 Description of Response

Surveys were mailed to 1,650 adults randomly selected from across the United States. A total of 89 surveys were not completed due to being undeliverable by mail and one survey was returned due to the death of the listed recipient. Therefore, the study population consisted of 1,561 randomly selected adults from the United States. A total of 386 adults responded, providing a response rate of 25% (386/1,561).

### 4.2 Demographics and Background Characteristics of Respondents

The respondents can be described as non-Hispanic White (65%), married (61%), with a post-secondary degree (59%), male (52%), and with a total household income of \$50,000 and above (51%). A plurality of respondents was between the ages of 51 and 60 (29%), with the average age being 59 years old (SD=10.5) (Table 4.1). Respondents

Table 4.1  
Demographics and Background Characteristics

Characteristics	n	(%)
<b>Age (years)</b>		
40-50	90	(23.3)
51-60	113	(29.3)
61-70	100	(25.9)
71-80	53	(13.7)
<b>Race</b>		
Non-Hispanic White	249	(64.5)
Black	64	(16.6)
Hispanic	61	(15.8)
Other	12	(3.1)
<b>Gender</b>		
Male	199	(51.6)
Female	187	(48.4)
<b>Highest Level of Education</b>		
Less than high school	16	(4.1)
High school/GED	140	(36.3)
Associate's degree	51	(13.2)
Bachelor's degree	98	(25.4)
Post-Bachelor's degree	78	(20.2)
<b>Relationship Status</b>		
Married	234	(60.6)
Divorced	53	(13.7)
Never married	50	(13.0)
Widowed	27	(7.0)
Domestic partnership	15	(3.9)
<b>Total Household Income (per yr.)</b>		
<\$10,000	21	(5.4)
\$10,000 to \$29,000	60	(15.5)
\$30,000 to \$49,000	80	(20.7)
\$50,000 to \$69,000	70	(18.1)
≥\$70,000	125	(32.4)

n=386      \*Categories with less than n=386 due to unreported data.

came from the following geographic regions based on the US census: South (35%), Midwest (26%), West (24%), and Northeast (15%). The racial and geographical distributions of respondents were not statistically significantly different than the racial and geographic distributions of the United States adult population.

### **4.3 Completed End-of-Life Care Planning Behaviors**

The majority of participants (75%) did not complete end-of-life care planning as defined in the current study. When looking at the three key planning behaviors separately, approximately 1 in 3 respondents (36%) had completed a living will and a durable power of attorney for health care (DPAHC) (32%). In contrast, 60% had discussed their end-of-life care wishes with at least one family member, yet only 18% had discussed their end-of-life care wishes with their physician (Table 4.2).

Statistically significant differences in the three key planning behaviors were found by race/ethnicity ( $\chi^2(2) = 18.90, p < .001$ ). One in three Whites (33%) had completed end-of-life care planning versus 18% of Hispanics and 8% of Blacks. Specifically, more Whites (43%) than Hispanics (26%) and Blacks (16%) were likely to have completed a living will. Similarly, more Whites (39%) than Hispanics (25%) and Blacks (14%) were likely to have completed a DPAHC. Likewise, more Whites (68%) than Hispanics (59%) and Blacks (38%) were likely to have had discussions with family members. Finally, more Whites (21%) than Hispanics (15%) and Blacks (9%) were likely to have had discussions with a health care provider.

Past completion of end-of-life care planning also differed in a statistically significant way by selected demographic variables. Those 65 and older were more likely to have completed end-of-life care planning (39%) than those younger than 65 (21%)

Table 4.2  
Completed End-of-Life Care Planning Behaviors and Background

Behaviors	Total n (%)	Race n (%)			Age n (%)		Gender n (%)	
		White	Black	Hisp.	<65	≥65	M	F
<b>Completed End-of-Life Care Planning</b>	<b>97 (25)</b>	<b>81 (33)</b>	<b>5 (8)</b>	<b>11 (18)</b>	<b>52 (21)</b>	<b>41 (39)</b>	<b>47 (24)</b>	<b>50 (27)</b>
Completed Living Will	138 (36)	108 (43)	10 (16)	16 (26)	80 (32)	51 (48)	74 (37)	64 (34)
Completed DPAHC	122 (32)	97 (39)	9 (14)	15 (25)	67 (27)	50 (47)	63 (32)	59 (32)
Discussed Wishes w Loved Ones	233 (60)	170 (68)	24 (38)	36 (59)	149 (60)	72 (68)	113 (57)	120 (64)
Discuss Wishes w Physician	68 (18)	52 (21)	6 (9)	9 (15)	37 (15)	28 (26)	34 (17)	34 (18)

n=386      \*Categories with less than 386 due to unreported data.

( $X^2(1) = 12.33, p < .001$ ). Those who were married (27%), in a domestic partnership (33%), or widowed (44%) were more likely to have completed end-of-life care planning than those who were never married (12%) or divorced (17%) ( $X^2(4) = 12.88, p = .012$ ). In addition, those who had an annual income of \$70,000 or above were more likely to have completed end-of-life care planning (34%) than those who made under \$70,000 per year (5% to 25%) ( $X^2(4) = 9.61, p = .048$ ), and those who had a bachelor's degree (28%) or post-bachelor's degree (36%) were more likely to have completed end-of-life care planning than those who had an associate's degree or less (20% to 26%) ( $X^2(4) = 12.37, p = .015$ ) (Table 4.2).

The majority of respondents (68%) had a family member who had previously been diagnosed with a life threatening illness, and 13% of the respondents had been diagnosed with a life-threatening illness themselves. Those respondents who had been diagnosed with a life-threatening illness (e.g. cancer) were more likely to have completed end-of-life care planning (42%) than those who had not experienced such a diagnosis (23%) ( $X^2(1) = 8.38, p = .004$ ). Likewise, those who have had a family member diagnosed with a life-threatening illness were more likely to have completed end-of-life care planning (28%) than those who had not experienced such a diagnosis among their loved ones (19%) ( $X^2(1) = 4.27, p = .039$ ). Almost a third (30%) of the respondents previously had a loved one in a coma or persistent vegetative state. However, having a loved one diagnosed in a coma or PVS state did not make a difference in past end-of-life care planning ( $X^2(1) = 3.52, p = .061$ ).

#### 4.4 Behavioral Intention

Of those who had not yet completed end-of-life care planning, 36% intended to complete a living will in the next six months, 35% intended to complete a DPAHC in the next six months, and 33% intended to discuss end-of-life care wishes with their physician in the next six months. A higher percentage (51%) planned to discuss end-of-life care wishes with at least one family member in the next six months. In contrast, a range of 49% to 68% of respondents were either *not* planning to complete end-of-life care planning in the next six months or were not sure about doing so (Table 4.3). More specifically, in the next six months, 35% who had not completed end-of-life care planning reported that they did *not* intend to complete a living will; 33% did *not* intend to complete a DPAHC; 25% did *not* intend to discuss wishes with family members; and 40% did *not* intend to discuss their end-of-life wishes with their physician (Table 4.3).

##### *Differences in Behavioral Intention by Selected Demographic Variables*

The investigator was interested in determining whether there were differences in behavioral intentions to complete end-of-life care planning in the next six months by selected demographic variables. Contrary to the differences noted above in the past completion of end-of-life planning by selected demographic variables, no statistically significant differences in behavioral intentions were noted across the following demographic variables: race/ethnicity ( $F(2,196) = 1.56, p = .212$ ), age ( $F(1,186) = 1.03, p = .312$ ), gender ( $F(1,204) = .389, p = .533$ ), education ( $F(4,199) = .220, p = .927$ ), income ( $F(4, 188) = .340, p = .851$ ), and marital status ( $F(4, 198) = .276, p = .893$ ).

Table 4.3  
Behavioral Intentions of Those Who Have Not Completed End-of-Life Care Planning

Intention Items	Unlikely n (%)	Unsure n (%)	Likely n (%)	Mean (SD)
<b>In the next 6 months, I intend to...</b>				
Complete a living will.	87 (35)	71 (29)	88 (36)	3.8 (2.0)
Complete a durable power of attorney for health care.	88 (33)	85 (32)	92 (35)	3.9 (2.0)
Discuss my end-of-life wishes with at least one family member.	58 (25)	54 (24)	117 (51)	4.5 (2.0)
Discuss my end-of-life wishes with my physician or health care provider.	108 (40)	75 (28)	88 (33)	3.7 (2.0)

\*Note: Behavioral Intention was assessed using 7-point Likert style scale  
 Unlikely = values of 1 to 3 combined into one category  
 Unsure = 4  
 Likely = values of 5 to 7 combined into one category

### *Behavioral Intention and the Integrated Behavioral Model (IBM)*

A multiple linear regression was calculated to determine which of the constructs of the IBM predicted the greatest amount of the variance in behavioral intention to complete end-of-life care planning. A statistically significant regression equation was found ( $F(7, 178) = 9.94, p < .001$ ), with an adjusted  $R^2$  of .253. Participants' predicted intention to complete end-of-life care planning was equal to  $-2.46 + .465$  (Direct Attitude toward Documents)  $- .162$  (Direct Attitude toward Discussing with Family)  $+ .171$  (Indirect Attitude)  $- .047$  (Direct Perceived Norms)  $+ .202$  (Indirect Perceived Norms)  $+ .002$  (Motivation to Comply)  $- .136$  (Self-Efficacy). The results indicated that direct attitudes toward advance directives ( $p = .002$ ) and indirect attitudes toward end-of-life care planning ( $p < .001$ ) were significant predictors of behavioral intention.

#### **4.5 Self-Efficacy**

Although the majority of respondents had not completed end-of-life care planning, they were confident in their ability to do so in the future (Table 4.4). More than 6 in 10 (64%) reported certainty in their ability to complete a living will; 59% reported certainty in ability to complete a DPAHC; 70% reported certainty in ability to discuss wishes with family; and 61% reported certainty in their ability to discuss wishes with a physician. It was interesting to note that self-efficacy differed by race. Whites had higher self-efficacy ( $M = 24.17, SD = 5.12$ ) to complete end-of-life care planning than Blacks ( $M = 23.48, SD = 5.46$ ) and Hispanics ( $M = 21.96, SD = 5.81$ ) ( $F(2, 262) = 3.17, p < .05$ ).

Table 4.4  
Self-Efficacy of Those Who Have Not Completed End-of-Life Care Planning

Self-Efficacy Items	Certain Could Not n (%)	Unsure n (%)	Certain Could n (%)	Mean (SD)
<b>How certain are you that you could...</b>				
Complete a living will?	14 (5)	45 (16)	223 (79)	6.0 (1.5)
Complete a durable power of attorney for health care?	25 (9)	50 (18)	205 (73)	5.7 (1.7)
Discuss your wishes with your family?	14 (5)	21 (7)	247 (88)	6.2 (1.4)
Discuss your wishes for end-of-life medical care with your doctor?	28 (10)	38 (14)	213 (76)	5.7 (1.7)

\*Note: Self-Efficacy was assessed using 7-point Likert style scale

Unlikely = values of 1 to 3 combined into one category

Unsure = 4

Likely = values of 5 to 7 combined into one category

### *Self-Efficacy and PAPM Stage of Readiness*

Self-efficacy impacted respondents' PAPM stage of readiness to take action to complete end-of-life care planning. Those with the lowest level of self-efficacy were more likely to decide they did not want to complete end-of-life care planning, while those with the highest self-efficacy level were more likely to decide they did want to complete end-of-life care planning ( $F(4,254) = 15.32, p < .001$ ).

### *Self-Efficacy and Intention to Complete End-of-Life Care Planning*

Self-efficacy also impacted respondents' behavioral intentions to complete end-of-life care planning in the next six months. A moderate, statistically significant positive correlation was detected between self-efficacy and behavioral intentions. As a person's self-efficacy increased, so did his/her behavioral intentions [ $r = .312, n = 202, p < .001$ ].

## **4.6 Attitudes**

The majority of participants had favorable direct attitudes toward each end-of-life care planning behavior (Table 4.5). Respondents reported that completing a living will would be beneficial (81%), comfortable (71%), and easy (65%). Similar results were noted for attitudes toward completing a DPAHC (70% beneficial, 61% comfortable, 56% easy) and discussing end-of-life care wishes with family members (74% beneficial, 65% comfortable, and 60% easy) (Table 4.5).

It was interesting to note that direct attitudes toward end-of-life care planning differed in a statistically significant way by race/ethnicity. Whites were more likely to have positive direct attitudes toward advance directives ( $M = 23.85, SD = 5.37$ ) than Blacks ( $M = 22.36, SD = 5.20$ ) and Hispanics ( $M = 21.84, SD = 5.50$ ) ( $F(2, 338) = 4.15, p < .05$ ).

Table 4.5  
Direct Attitudes of All Respondents

Attitude Items	Disagree n (%)	Unsure n (%)	Agree n (%)
<b>Completing my living will was or would be...</b>			
Comfortable for me.	37 (10)	70 (19)	258 (71)
Easy for me to do.	40 (11)	88 (24)	235 (65)
Beneficial for me.	20 (6)	50 (14)	292 (81)
<b>Completing my durable power of attorney for health care was or would be...</b>			
Comfortable for me.	37 (10)	91 (25)	237 (65)
Easy for me to do.	42 (12)	105 (29)	217 (60)
Beneficial for me.	23 (6)	71 (20)	270 (74)
<b>Discussing my end-of-life wishes with family members was or would be...</b>			
Comfortable for me.	45 (12)	68 (19)	253 (69)
Easy for me to do.	48 (13)	72 (20)	243 (67)
Beneficial for me.	19 (5)	49 (14)	295 (81)

\*Note: Attitudes were assessed using 5-point Likert scale  
 Disagree = 1 to 2  
 Unsure = 3  
 Agree = 4 to 5

Respondents also reported generally positive indirect attitudes toward end-of-life care planning (Table 4.6). Respondents reported that end-of-life care planning had various benefits associated with completing it and that they valued the importance of these benefits/outcomes. Seventy nine percent of respondents reported that completing end-of-life care planning would reduce stress and burden on their loved ones, and 87% reported that this was important for them. Seventy seven percent reported that completing the behavior would help them avoid unwanted medical treatment at the end-of-life, and 82% reported this as being important to them (Table 4.6).

#### *Attitudes and PAPM Stage of Readiness*

Direct attitudes toward end-of-life care planning had an impact on respondents' PAPM stage of readiness to take action. Those with the lowest level of direct attitudes were more likely to decide they did not want to complete end-of-life care planning, while those with the highest level of direct attitude were more likely to decide they did want to complete end-of-life care planning. These differences were statistically significant for direct attitudes toward advance directives ( $F(4,318) = 23.89, p < .001$ ), direct attitudes toward discussing wishes with family members ( $F(4,321) = 8.79, p < .001$ ), and indirect attitudes ( $F(4,252) = 20.45, p < .001$ ).

#### *Attitude and Intention to Complete End-of-Life Care Planning*

Direct attitudes toward end-of-life care planning were also associated with behavioral intentions. As respondents' direct attitudes toward advance directives increased/improved, their intention to complete end-of-life care planning also increased [ $r = .446, n = 197, p < .001$ ]. In addition, there was a statistically significant positive correlation between direct attitudes toward discussing wishes with family members and

Table 4.6  
Indirect Attitudes of Those Who Have Not Completed End-of-Life Care Planning

Attitude Items	Unlikely n (%)	Unsure n (%)	Likely n (%)	Mean (SD)
<b>How likely is it that completing end-of-life planning would ...</b>				
make you feel better prepared for the end of your life?	34 (12)	50 (18)	198 (70)	5.4 (1.8)
make you feel more at peace in the final days of your life?	33 (12)	55 (20)	194 (69)	5.4 (1.8)
ensure that your health care wishes for end-of-life medical care are followed?	25 (9)	42 (15)	214 (76)	5.6 (1.6)
reduce stress and burden on your loved ones when you are at the end of your life?	22 (8)	38 (14)	220 (79)	5.8 (1.6)
help you avoid unwanted medical treatment at the end of your life?	19 (7)	45 (16)	217 (77)	5.7 (1.5)
	Unimportant n (%)	Unsure n (%)	Important n (%)	Mean (SD)
<b>How important is it for you to...</b>				
feel prepared for the end of your life?	26 (9)	37 (13)	219 (78)	5.6 (1.6)
feel more at peace in the final days of your life?	27 (10)	31 (11)	223 (79)	5.7 (1.7)
ensure that your health care wishes for end-of-life medical care are followed?	20 (7)	28 (10)	233 (83)	5.9 (1.5)
reduce stress and burden on your loved ones?	19 (7)	17 (6)	242 (87)	6.1 (1.5)
avoid unwanted medical treatment at the end of your life?	19 (7)	32 (11)	229 (82)	5.9 (1.6)

\*Note: Attitudes were assessed using 7-point Likert style scale  
 Unlikely; Unimportant = 1 to 3  
 Unsure = 4  
 Likely; Important = 5 to 7

intention to complete end-of-life care planning [ $r = .323, n = 198, p < .001$ ]. As a respondent's direct attitude toward discussing wishes with family members increased, his or her intention to complete end-of-life care planning increased as well. Finally, there was a statistically significant positive correlation between indirect attitude towards end-of-life care planning and intention to complete end-of-life care planning [ $r = .457, n = 200, p < .001$ ]. As a respondent's indirect attitude toward end-of-life care planning increased, his or her intention to complete end-of-life care planning increased.

#### *Salience of the Behavior*

Since the IBM posits that the salience of the behavior is a factor outside of the model that directly influences behavioral intentions, the investigator conducted an exploratory analysis by treating the indirect attitudes items as a measure of salience. The results indicated that there was a moderate, statistically significant positive correlation between salience and intention to complete end-of-life care planning [ $r = .414, n = 202, p < .001$ ]. As the importance of end-of-life care planning increased for respondents, so did their intention to complete such planning.

#### **4.7 Perceived Norms**

Respondents reported that they would be more likely to complete end-of-life planning if their physician, loved ones, and best friend wanted them to complete it. Statistically significant differences were noted by race/ethnicity for direct perceived norms ( $F(2, 364) = 4.18, p < .05$ ) and indirect perceived norms ( $F(2, 359) = 15.39, p < .001$ ). Whites were more likely to have higher levels of direct perceived norms ( $M = 7.57, SD = 1.94$ ) than Blacks ( $M = 7.00, SD = 2.79$ ) and Hispanics ( $M = 6.76, SD = 2.38$ ). In addition, Whites were more likely to have higher levels of indirect perceived norms for

end-of-life care planning ( $M = 16.99$ ,  $SD = 3.39$ ) than Blacks ( $M = 14.90$ ,  $SD = 4.20$ ) and Hispanics ( $M = 14.48$ ,  $SD = 4.39$ ).

It was interesting to note that many respondents were unsure if these specific significant others listed in the survey would approve of them completing the behavior (Table 4.7). Sixty percent of respondents who had not completed end-of-life care planning reported that they would complete end-of-life care planning if their physician or health care provider recommended it. However, 41% of all respondents were unsure if their physician or health care provider would approve of doing this. The majority (77%) of respondents reported that their loved ones would approve of completing end-of-life care planning, and 72% reported that they would complete the behavior if their loved ones wanted them to do it. In addition, 61% of respondents were unsure if most people they know complete end-of-life care planning, and 70% were unsure if most people in their community complete end-of-life care planning (Table 4.7).

#### *Perceived Norms and PAPM Stage of Readiness*

Statistically significant differences in PAPM stage of readiness to complete end-of-life care planning were noted by the level of perceived norms. Those with the lowest direct perceived norm levels were more likely to decide they did not want to complete end-of-life care planning, while those with the highest direct perceived norm levels were more likely to decide they did want to complete end-of-life care planning or had never heard about end-of-life care planning. Those with the lowest indirect perceived norm levels were more likely to decide they did not want to complete end-of-life care planning or had never heard about end-of-life care planning, while those with the highest indirect perceived norm levels were more likely to decide they did want to complete end-of-life

Table 4.7  
Perceived Norms for All Respondents

Perceived Norms Items	Unlikely n (%)	Unsure n (%)	Likely n (%)	Mean (SD)
<b>How likely is it that you would complete end-of-life planning if...</b>				
your physician/health care provider recommended it?	50 (18)	58 (21)	165 (60)	4.9 (1.9)
your loved ones wanted you to do it?	39 (14)	38 (14)	199 (72)	5.4 (1.9)
your best friend wanted you to do it?	70 (26)	81 (30)	120 (44)	4.3 (1.9)
	Disagree n (%)	Unsure n (%)	Agree n (%)	Mean (SD)
<b>Do you agree or disagree?</b>				
Most people that I know complete end-of-life care planning.	99 (26)	233 (61)	49 (13)	3.7 (1.3)
Most people in my community complete end-of-life care planning.	86 (23)	265 (70)	29 (8)	3.7 (1.1)
My physician approves or would approve of me completing my end-of-life care planning.	16 (4)	154 (41)	208 (55)	5.2 (1.5)
My loved ones approve or would approve of me completing end-of-life planning.	15 (4)	73 (19)	290 (77)	5.8 (1.4)
My best friend approves or would approve of me completing my end-of-life care planning.	24 (6)	147 (39)	205 (55)	5.2 (1.6)

\*Note: Perceived Norms were assessed using 7-point Likert style scale

Unlikely; Disagree = 1 to 3

Unsure = 4

Likely; Agree = 5 to 7

care planning. Those with the lowest motivation to comply levels were more likely to decide they did not want to complete end-of-life care planning, while those with the highest motivation to comply levels were more likely to decide they did want to complete end-of-life care planning. These differences were statistically significant for direct perceived norms ( $F(4,344) = 12.58, p < .05$ ), indirect perceived norms ( $F(4,340) = 22.11, p < .001$ ), and motivation to comply ( $F(4,248) = 26.16, p < .001$ ).

#### *Perceived Norms and Intention to Complete End-of-Life Care Planning*

The researcher investigated the relationship between perceived norms and intention to complete end-of-life care planning. There was a positive correlation between direct perceived norms and intention to complete end-of-life care planning, but it was not statistically significant [ $r = .111, n = 206, p = .112$ ]. However, there was a statistically significant positive correlation between indirect perceived norms towards end-of-life care planning and intention to complete end-of-life care planning [ $r = .271, n = 205, p < .001$ ]. As indirect perceived norms increased, intention to complete end-of-life care planning increased as well. Finally, there was a statistically significant positive correlation between motivation to comply and intention to complete end-of-life care planning [ $r = .320, n = 199, p < .001$ ]. As a respondent's motivation to comply with significant others increased, his or her intention to complete end-of-life care planning increased.

#### **4.8 Racial Distrust**

Overall, African Americans and Hispanics reported more distrust of the medical system than Caucasians (Table 4.8). African Americans had the highest level of distrust compared to Hispanics and Caucasians. Just under half of African Americans (44%) agreed that people of their racial/ethnic group have sometimes been misled or deceived

Table 4.8  
Racial Distrust

Racial Distrust Items	Disagree %			Unsure %			Agree %		
	C	A	H	C	A	H	C	A	H
<b>People of my racial/ethnic group...</b>									
should be careful when dealing with doctors and health care workers.	51	48	42	16	19	25	33	32	32
have sometimes been deceived or misled by doctors and health care workers.	53	31	49	20	25	25	27	44	25
should not trust doctors and health care workers.	80	66	71	13	19	17	7	15	12
should be suspicious of information from doctors and health care workers.	75	57	70	15	22	15	11	22	15
should <b>not</b> confide in doctors and health care workers because the information provided will probably be used against us.	83	65	71	13	23	22	5	13	7
receive the same quality of medical care from doctors and health care workers as people from other racial/ethnic groups.	19	30	25	24	31	31	57	39	44
should <b>not</b> complete end-of-life care planning because if we do, doctors will give up on us and not give us full medical treatment.	78	56	59	17	33	24	4	12	17

Note: C = Caucasian, A = African Americans, H = Hispanic  
Racial Distrust was assessed on a 5-point Likert Scale

Disagree = 1 to 2

Unsure = 3

Agree = 4 to 5

by doctors and health care workers, while 27% of Caucasians and 25% of Hispanics agreed with this statement. Nearly one in four African Americans (22%) reported that people of their racial/ethnic group should be suspicious of information from doctors and health care workers, while 15% of Hispanics and 11% of Caucasians. Almost a third of all three racial/ethnic groups reported that people of their racial/ethnic groups should be careful when dealing with doctors and health care workers (Table 4.8). When comparing racial and ethnic groups, racial distrust significantly differed among the groups ( $F(2,360) = 6.42, p < .01$ ), with Blacks ( $M = 15.00, SD = 5.71$ ) and Hispanics ( $M = 14.58, SD = 5.46$ ) having more racial distrust in the medical system than Whites ( $M = 12.76, SD = 4.83$ ).

#### *Racial Distrust and End-of-Life Care Planning*

Surprisingly, racial distrust did not significantly influence past end-of-life care planning completion ( $OR = 1.00; 95\% CI [.956, 1.05]$ ) nor did racial distrust influence behavioral intentions to do such planning in the future [ $r = -.092, n = 203, p = .191$ ].

#### **4.9 Religiosity**

The investigator examined the impact of self-reported religiosity on end-of-life care planning (Table 4.9). One in five respondents reported that they never attend formal religious services or meetings and 32% reported that they attend religious services or meetings once to a few times a year. Regarding private religious activities, 32% reported that they rarely or never spend time in private spiritual activities, while 12% reported engaging in these activities a few times a month, and 7% reported doing so once a week. However, 44% of the respondents did report that they experience the presence of a Divine being and 47% reported that religious/spiritual beliefs help shape their approach

Table 4.9  
Religiosity

Religiosity Items	Never n (%)	Once a year or less n (%)	A few times a year n (%)	A few times a month n (%)	Once a week n (%)	More than once a week n (%)	Mean (SD)
How often do you attend church, mosque, temple or other religious meetings?	77 (20)	52 (14)	68 (18)	47 (12)	92 (24)	45 (12)	3.4 (1.7)
	Rarely or Never n (%)	A few times a month n (%)	Once a week n (%)	Two or more times a week n (%)	Daily n (%)	More than once a day n (%)	Mean (SD)
How often do you spend time in private spiritual activities such as prayer, meditation, or reading sacred books?	121 (32)	47 (12)	27 (7)	49 (13)	92 (24)	44 (12)	3.2 (1.9)
	Definitely not true n (%)	Tends not to be true n (%)	Unsure n (%)	Tends to be true n (%)	Definitely true n (%)	Mean (SD)	
In my life, I experience the presence of the Divine (e.g., God, Allah, Jehovah, other gods).	47 (13)	26 (7)	46 (12)	91 (24)	167 (44)	3.8 (1.4)	
My religious/spiritual beliefs help shape my approach to life.	37 (10)	29 (8)	27 (7)	107 (28)	177 (47)	3.9 (1.3)	
I try hard to apply my spiritual beliefs and values to my decisions, attitudes, and actions.	39 (10)	25 (7)	31 (8)	125 (33)	159 (42)	3.9 (1.3)	
I do not need to plan for end-of-life care because God/a higher power will take care of that for me.	168 (45)	67 (18)	72 (19)	30 (8)	35 (9)	2.2 (1.3)	

to life. Regarding end-of-life care planning behaviors, 9% reported that they do not need to plan of end-of-life care because a higher power will take care of that for them. In contrast, 45% disagreed with this statement (Table 4.9).

#### *Religiosity and Intention to Complete End-of-Life Care Planning*

The researcher investigated the association between religiosity and intention to complete end-of-life care planning. In sum, religiosity did not influence behavioral intentions. There was no statistically significant correlation between frequency of religious meeting attendance and intention to complete end-of-life care planning [ $r = .074$ ,  $n = 206$ ,  $p = .288$ ]. Likewise, there was no statistically significant correlation between time spent in private spiritual activities and intention to complete end-of-life care planning [ $r = -.088$ ,  $n = 206$ ,  $p = .206$ ]. Similarly, there was no statistically significant correlation between intrinsic religiosity/spirituality and intention to complete end-of-life care planning [ $r = -.004$ ,  $n = 201$ ,  $p = .958$ ].

#### **4.10 Summary**

A total of 386 individuals completed surveys, providing a response rate of 25% (386/1,561). The respondents can be described as follows: non-Hispanic White (64%), married (61%), with a post-secondary degree (59%), male (52%), with a total household income of \$70,000 and above (32%), Black (17%), and Hispanic (16%). A plurality of respondents was between the ages of 51 and 60 (29%), with the average age being 59 years old.

The majority of participants (75%) did not complete end-of-life care planning as defined in the current study. When looking at the three key planning behaviors separately, approximately 1 in 3 respondents had completed a living will and completed a

durable power of attorney for health care (DPAHC) (32%). In contrast, 60% had discussed their end-of-life care wishes with at least one family member, yet only 18% had discussed their end-of-life care wishes with their physician.

Several statistical tests were used with a Benjamini-Hochberg correction to analyze the data. Significant differences in the three key planning behaviors were noticed by race/ethnicity. Whites were more likely to complete end-of-life care planning than Blacks and Hispanics. When comparing age groups, those 65 and older were more likely to complete end-of-life care planning than those younger than 65. In addition, statistically significant differences in end-of-life care planning completion were noted for marital status, education, and income. Those who were married, in a domestic partnership, or widowed were more likely to have completed end-of-life care planning than those who were never married or divorced. In addition, those who had an annual income of \$70,000 or above were more likely to have completed end-of-life care planning than those who made under \$70,000 per year, and those who had a bachelor's degree or post-bachelor's degree were more likely to have completed end-of-life care planning than those who had an associate's degree or less. However, differences in end-of-life care planning completion by gender were not statistically significant.

None of the selected demographic variables were significantly associated with intention to complete end-of-life care planning. However, direct attitudes toward advance directives and indirect attitudes toward end-of-life care planning were significant predictors of intention to complete end-of-life care planning.

Respondents reported confidence in their ability to complete end-of-life care planning, in addition to generally positive direct and indirect attitudes toward end-of-life

care planning. Although respondents were confident in their abilities and had positive attitudes toward end-of-life care planning, a range of 49% to 68% of respondents who had not yet completed end-of-life planning were either not planning to complete end-of-life care planning in the next six months or were not sure about doing so. In addition, respondents reported that they would be more likely to complete end-of-life planning if their physician, loved ones, and best friend wanted them to complete it, but many respondents were unsure if these people would approve of them completing the behavior.

Overall, African Americans and Hispanics reported more distrust of the medical system than Caucasians. In addition, African Americans had the highest level of distrust when compared to Hispanics and Caucasians. However, racial distrust did not significantly influence end-of-life care planning completion. In addition, there was not a statistically significant correlation between racial distrust and intention to complete end-of-life care planning.

Although the investigator hypothesized that religiosity would influence end-of-life care planning, it did not. One in five respondents reported that they never attend formal religious services or meetings and 32% reported that they attend religious services or meetings once to a few times a year. Regarding private religious activities, 32% reported that they rarely or never spend time in private spiritual activities, while 12% reported engaging in these activities a few times a month, and 7% reported doing so once a week. However, 44% of the respondents did report that they experience the presence of a Divine being, and 47% reported that religious/spiritual beliefs help shape their approach to life.

# Chapter 5

## Conclusions

The following sections are included in this chapter: 1) Summary, 2) Discussion and Implications, and 3) Recommendations for future research.

### 5.1 Summary

This national study was conducted to answer the following questions:

1. What proportion of American adults has completed end-of-life care planning?
2. At what stage of readiness to complete end-of-life care planning are adults in the United States?
3. Which socio-demographic factors are associated with end-of-life care planning by adults in the United States?
4. Does the Integrative Behavioral Model help explain and/or predict adults' behavioral intentions to complete end-of-life care planning, especially differences by race/ethnicity?

A four-page questionnaire was developed to assess adults' attitudes, perceptions, and behaviors regarding end-of-life care planning. The Integrated Behavioral Model (Glanz et al., 2008) and the Precaution Adoption Process Model (Weinstein & Sandman, 1992) were used as the framework for the study.

The investigator surveyed 1,650 Americans randomly selected by a commercial mailing list compiler. The response rate was 25%. Descriptive statistics (e.g., means, standard deviations, percentages) were used to describe the findings of the individual items. Other statistical procedures included chi-square statistics, t-tests, Pearson correlations, linear regression, and logistic regression. There were four (4) research questions with a total of thirty-nine (39) null hypotheses (Tables 5.1 and 5.2).

## **5.2 Discussion**

This was the first national study to use behavioral models (i.e., the IBM and PAPM) to explain and predict American adults' behavioral intentions to complete end-of-life care planning. This was also the first national study to use behavioral models to explain racial differences in end-of-life care planning. According to IBM, the most important determinant of behavior is intention to perform the behavior. The IBM posits that a person's intention to complete end-of-life care planning is driven by attitude toward the behavior, perceived norms, and personal agency (Ajzen, 1991; Glanz et al., 2008).

The Precaution Adoption Process Model (PAPM) was used in the current study to explain and predict respondents' stage of readiness to complete end-of-life care planning. The PAPM helps to explain how individuals make decisions to take action and how decisions are put into action (Weinstein et al., 2008).

In the current study, only 1 in 4 respondents (25%) had completed end-of-life care planning in the past as defined by three key behaviors: a) completing a living will, b) completing a DPHAC appointment, and c) discussing one's wishes with family members. This percentage is on the lower end of what past research has reported for Americans

Table 5.1  
Accepted Null Hypotheses

Null Hypothesis	Test Statistic
1.4a: There is no difference in end-of-life care planning completion by religiosity/spirituality [attending institution].	Logistic Regression
1.4b: There is no difference in end-of-life care planning completion by religiosity/spirituality [personal time].	Logistic Regression
1.4c: There is no difference in end-of-life care planning completion by religiosity/spirituality [overall].	Logistic Regression
1.7: There is no difference in end-of-life care planning completion by gender.	Chi-square
1.8: There is no difference in end-of-life care planning by racial distrust.	Logistic Regression
1.7: There is no difference in intention to complete end-of-life care planning by racial distrust.	Pearson Correlation
2.8: There will be no difference in stage of readiness to complete end-of-life care planning by having a family member with a history of being a coma or persistent vegetative state.	Chi-square
3.1: There is no difference in intention to complete end-of-life care planning by race.	One-way ANOVA
3.2: There is no difference in intention to complete end-of-life care planning by age.	One-way ANOVA
3.3: There is no difference in intention to complete end-of-life care planning by gender.	Independent T-test
3.4: There is no difference in intention to complete end-of-life care planning by SES [Education].	One-way ANOVA
3.5: There is no difference in intention to complete end-of-life care planning by SES [Income].	One-way ANOVA
3.6: There is no difference in intention to complete end-of-life care planning by marital status.	Independent T-test

Table 5.1 Continued

Null Hypothesis	Test Statistic
3.7a: There is no difference in intention to complete end-of-life care planning by religiosity/spirituality [attending institution].	Pearson correlation
3.7b: There is no difference in intention to complete end-of-life care planning by religiosity/spirituality [personal time].	Pearson correlation
3.7c: There is no difference in intention to complete end-of-life care planning by religiosity/spirituality [overall].	Pearson correlation
3.8: There is no difference in intention to complete end-of-life care planning by racial distrust.	Pearson correlation
4.4a: There is no difference in behavioral intentions by level of direct perceived norms regarding end-of-life care planning (e.g. low versus high perceived norms).	Pearson correlation

Table 5.2  
Rejected Null Hypotheses

Null Hypothesis	Test Statistic
1.1: There is no difference in end-of-life care planning completion by race.	Chi-square
1.2: There is no difference in end-of-life care planning completion by age.	Chi-square
1.3: There is no difference in end-of-life care planning completion by marital status.	Chi-square
1.5: There is no difference in end-of-life care planning completion by SES [Education].	Chi-square
1.6: There is no difference in end-of-life care planning completion by SES [Income].	Chi-square
2.1: There will be no difference in stage of readiness to complete end-of-life care planning by having a history of a life threatening illness.	Chi-square
2.2: There will be no difference in stage of readiness to complete end-of-life care planning by having a family member with a history of being diagnosed with a life threatening illness.	Chi-square
2.3: There will be no difference in stage of readiness to complete end-of-life care planning by direct attitudes toward completing an advance directive (living will or durable power of attorney for health care).	One-way ANOVA
2.4: There will be no difference in stage of readiness to complete end-of-life care planning by direct attitudes toward discussing end-of-life wishes with family members.	One-way ANOVA
2.5: There will be no difference in stage of readiness to complete end-of-life care planning by indirect attitudes regarding end-of-life care planning.	One-way ANOVA
2.6a: There will be no difference in stage of readiness to complete end-of-life care planning by direct perceived norms toward end-of-life care planning.	One-way ANOVA

Table 5.2 Continued

Null Hypothesis	Test Statistic
2.6b: There will be no difference in stage of readiness to complete end-of-life care planning by indirect perceived norms toward end-of-life care planning.	One-way ANOVA
2.6c: There will be no difference in stage of readiness to complete end-of-life care planning by motivation to comply regarding end-of-life care planning.	One-way ANOVA
2.7: There will be no difference in stage of readiness to complete end-of-life care planning by personal agency (self-efficacy) regarding end-of-life care planning.	One-way ANOVA
4.1: There is no difference in behavioral intentions by level of direct attitude regarding completing advance directives (living will and durable power of attorney for health care) (e.g. low versus high attitude scores).	Pearson correlation
4.2: There is no difference in behavioral intentions by level of direct attitude regarding discussing end-of-life wishes with family members (e.g. low versus high attitude scores).	Pearson correlation
4.3: There is no difference in behavioral intentions by level of indirect attitude regarding end-of-life planning (e.g. low versus high attitude scores).	Pearson correlation
4.4b: There is no difference in behavioral intentions by level of indirect perceived norms regarding end-of-life care planning (e.g. low versus high perceived norms).	Pearson correlation
4.4c: There is no difference in behavioral intentions by level of motivation to comply regarding end-of-life care planning (e.g. low versus high perceived norms).	Pearson correlation
4.5: There is no difference in behavioral intentions by level of personal agency (self-efficacy) to conduct end-of-life care planning (e.g. low versus high personal agency).	Pearson correlation
4.6: There is no statistically significant difference in the IBM constructs' predictive power for behavioral intentions to complete end-of-life care planning.	Linear regression

who have completed an advance directive (i.e., 18% to 36%) (U.S. Department of Health and Human Services, 2008). Tompson et al. (2013) reported that 47% of those 40 and older had completed an advance directive, and 41% had discussed care preferences with a loved one. The National Council on Aging (2014) found that 53% of those 60 and older had completed an advance directive and 58% had discussed care preferences with a loved one.

The lower rate of end-of-life care planning in the current study may be due to the fact that the investigator defined “completion” as three specific behaviors rather than simply completing an advance directive document. If “completion” is defined as the completion of an advance directive (and not discussing it with family members), the completion rate in the current study was 36% for living wills and 32% for a DPAHC.

The lower rate of advance care planning in the current study could also be reflective of the fact that 36% of the respondents were racial/ethnic minorities. Past research has indicated that fewer racial/ethnic minorities than Caucasians have completed end-of-life care planning (Carr, 2011, 2012; Johnson et al., 2008; Phipps et al., 2003; U.S. Department of Health and Human Services, 2008). In past research, Caucasian patients were more likely than African American patients to have an advance directive and a DNR order (Karches et al., 2012). In addition, Latinos were significantly less likely than Whites to have a living will (13% vs. 25%) and a DPAHC appointment (17% vs. 28%). Likewise, a significantly higher proportion of Caucasians were reported to hold discussions about their preferences for end-of-life care, in comparison to African Americans and Latinos (60% vs. 44% and 60% vs. 37%, respectively) (Carr, 2012).

### *Racial and Ethnic Differences*

Significant differences in end-of-life planning completion rates by race and ethnicity were noted in the current study. While 33% of non-Hispanic Whites completed end-of-life care planning, only 8% of Blacks and 18% of Hispanics had done so. Whites in the current study completed each end-of-life care planning behavior at a higher rate than Blacks and Hispanics, which was consistent with past research (Carr, 2011, 2012; Johnson et al., 2008; Phipps et al., 2003; U.S. Department of Health and Human Services, 2008). However, among respondents who had not yet completed end-of-life care planning, race/ethnicity was not predictive of behavioral intention.

Differences in scores by race/ethnicity on several of the IBM construct scales may help to explain the racial/ethnic differences in end-of-life care planning in the current study. Differences by race/ethnicity were found in direct attitudes, direct perceived norms, indirect perceived norms, and self-efficacy. Blacks and Hispanics reported lower (i.e. more negative) direct attitudes toward advance directives, lower indirect and direct perceived norms, and lower self-efficacy than Whites. Past research also corroborates that Blacks and Hispanics have more negative attitudes toward advance directives than Whites (Ko & Lee, 2014). Attitudes have previously been shown to be strong predictors of end-of-life care planning completion (Institute of Medicine, 2015). Those with more positive attitudes toward advance directives are more likely to complete end-of-life care planning (Ko & Lee, 2014).

Another factor that may help to explain the differences by race/ethnicity in the current study is potential differences in awareness and knowledge. According to the IBM, knowledge is a factor outside of the model that directly influences behavior. Lack of

awareness and knowledge about end-of-life care planning is frequently cited as a reason why people do not complete it (Rao, Anderson, Lin, & Laux, 2014). Research has demonstrated that barriers such as lack of knowledge and lack of social support for advance care planning are possible reasons that African Americans are less likely than Whites to engage in end-of-life care planning (Bullock, 2006).

Racial/ethnic disparities in education and income may also help to explain the differences in end-of-life care planning by race/ethnicity that were found in the current study. Results of the current study demonstrated that those with higher education and income levels were more likely to have completed end-of-life care planning.

Racial/ethnic minorities in the current study had lower education levels and lower household incomes than Whites. Sixty-six percent of Whites in the current study had a post-secondary degree, while 38% of Blacks and 51% of Hispanics had a post-secondary degree.

Past research corroborates these results. Education level has been shown to influence end-of-life care planning completion rates (Carr & Khodyakov, 2007; Institute of Medicine, 2015). Those with higher education and income are also more likely to have a discussion about end-of-life issues with a loved one (California Health Care Foundation, 2012), and those with higher education are also more likely to have an advance directive (Carr & Khodyakov, 2007). Moreover, highly educated individuals tend to receive more social support and have more elaborated social networks that may influence end-of-life care planning behaviors (Rietjens et al., 2012). Those with lower levels of education are also typically less involved in the medical decision making process with their health care providers (Rietjens et al., 2012).

### *Other Factors Outside the IBM*

Another factor outside of the IBM that may help to explain racial differences in end-of-life care planning is distrust of the health care system and health care practitioners (Johnson et al., 2008; Lepore, Miller, & Gozalo, 2011; West & Hollis, 2012). Distrust has been shown to reduce people's use of medical care, even when care is available and affordable (Cort, 2004; Noah, 2012). African Americans and other racial minorities have expressed more distrust in the health care system (Cort, 2004; Johnson et al., 2008; Noah, 2012). This lack of trust in the health care system may be one reason why African Americans may prefer intensive life-sustaining treatment near the end of life and believe that end-of-life care planning may exclude them desired treatment (Johnson et al., 2008; Lepore et al., 2011; West & Hollis, 2012). Surprisingly, the results from this study showed that although Blacks and Hispanics expressed significantly more distrust in the health care system than Whites, racial distrust did not significantly influence end-of-life care planning completion or intention to complete end-of-life care planning. The fact that racial distrust was not associated with end-of-life care planning may have to do with additional factors outside the IBM.

In addition to knowledge, awareness, and racial distrust, another factor outside of the IBM that may influence the decision to complete end-of-life care planning is environmental constraints. This factor may have also played a role in the differences noted by race. One significant environmental constraint is income level and access to resources. In the current study, income level significantly influenced whether or not someone completed end-of-life care planning, which is corroborated by other research that shows that individuals with greater net worth have been shown to be more likely to

engage in advance care planning (Bischoff et al., 2013). In the current study, nearly half of Blacks and 34% of Hispanics had a total household income *less than* \$30,000 per year. In contrast, nearly 9 of 10 Whites had income levels higher than this. Those with lower net worth typically have lower socioeconomic status, lower education, and lower health literacy. Health literacy affects health care utilization (Berkman et al., 2011). Those with low health literacy may have difficulty gaining access to and comprehending advance directive documents (Institute of Medicine, 2015). In addition, lower income among minority respondents may have led to environmental constraints, such as lack of Internet access to the advance planning documents, lack of access to printing the documents, or lack of a primary care medical home. Those without a primary care medical home would obviously not have a primary care physician with which to discuss end-of-life care planning issues. Research shows that minorities have lower rates of health care utilization than Whites, both among healthy and unhealthy populations (Zheng & Zimmer, 2009). This lower rate of utilization of health care services includes office-based physician visits, office-based non-physician visits, outpatient department visits, and hospital discharges. Furthermore, lower rates of having a medical home are typically found among racial/ethnic minorities (Strickland, Jones, Ghandour, Kogan, & Newacheck, 2011). Lower rates of having a medical home and lower rates of health care service utilization among racial and ethnic minorities would likely be an environmental constraint to discussing end-of-life care planning with physicians and health care providers.

Socio-demographic factors may have also played a role in the differences noted by race/ethnicity. For example, marital status and age influenced end-of-life care

planning completion among respondents in the current study. Married (27%) and widowed (44%) respondents were more likely to complete end-of-life care planning than those who were never married (12%) or divorced (17%). Marital status may have interacted with race since a higher proportion of Whites (70%) were married than Hispanics (52%) or Blacks (41%). Furthermore, a higher proportion of Whites was aged 65 or above (33%) than Hispanics (24%) or Blacks (22%). Results from the current study show that those aged 65 and above were more likely to complete end-of-life care planning, which has been demonstrated in other studies as well (California Health Care Foundation, 2012; Tompson et al., 2013). Although research has shown that women are more likely than men to engage in some aspect of advance care planning (Bischoff et al., 2013), this was not the case in the current study.

#### *The Predictive Validity of the IBM with PAPM Stage of Readiness*

Results of the current study indicate several constructs within the IBM were predictive of stage of readiness within the PAPM. Attitudes toward advance care planning, perceived norms, and personal agency seem to influence whether someone is ready to complete end-of-life care planning. Not only were IBM constructs associated with PAPM stage of readiness, but outside factors were associated with stage of readiness as well. For example, stage of readiness differed by whether respondents had been previously been diagnosed with a life threatening illness or had a family member previously diagnosed with a life threatening illness. Those who had experienced such diagnoses were more likely to have decided they want to complete end-of-life care planning.

Surprisingly, stage of readiness did not significantly differ by whether a family member had ever been in a coma or persistent vegetative state. Since past research indicates that people perceive being in a PVS state as “worse” than death (Gray, Anne Knickman, & Wegner, 2011), one might expect that having a relative in such a state would strongly motivate family members to complete end-of-life care planning. However, this was not the case. Perhaps the medical complexities surrounding coma and persistent vegetative state were more difficult for respondents to understand versus being diagnosed with cancer or another life threatening illness, which respondents may associate with impending death.

#### *The Predictive Validity of the IBM with Intentions*

Several of the IBM constructs were significantly associated with intention to complete end-of-life care planning. Direct attitudes toward completing advance directives, direct attitude toward discussing end-of-life wishes with family members, indirect attitudes, indirect perceived norms, motivation to comply, and personal agency were significantly associated with intention to complete end-of-life care planning. In addition, direct attitudes toward advance directives and indirect attitudes were significant predictors of intention to complete end-of-life care planning.

In general, respondents had favorable attitudes toward the behavior. Overall, respondents believed that end-of-life care planning was associated with positive outcomes that they valued highly. A range of 69% to 79% of the respondents believed that end-of-life care planning would make them more prepared for end of life, feel more at peace in final days, ensure that their EOL wishes were followed, would reduce stress

on loved ones, and would help them avoid unwanted medical treatment. Likewise, a range of 78% to 87% reported that these outcomes were important to them.

Although respondents generally had positive attitudes toward end-of-life care planning, only 25% had done it. Furthermore, only 33% to 51% (depending on the end-of-life care planning behavior) intended to do so in the next six months. This may be due to the intention time frame of six months. Some respondents may not have been planning to do end-of-life care planning within the next six months, but rather later in life when confronted with some type of medical emergency. People have been shown to be more likely to complete end-of-life care planning in older age, and also when they have been recently admitted to a hospital (Carr & Khodyakov, 2007; Institute of Medicine, 2015).

It could be that some people perceive themselves as being “too healthy” to feel the need to complete end-of-life planning (Schickedanz et al., 2009), especially among those in younger age brackets. This was corroborated by findings in the current study that those who had been diagnosed with a life threatening illness or who had a loved one diagnosed with a life threatening illness were more likely to have completed end-of-life care planning. Those without such a medical history in the current study may not have felt the urgency or believed in the importance of completing end-of-life care planning within the next six months time frame of the behavioral intention scale.

There was also a significant association between indirect perceived norms and intention to complete end-of-life care planning. Although 44% to 72% of respondents stated that they would likely complete end-of-life care planning if their physician, loved ones, or best friend recommended it, a range of 19% to 41% respondents were unsure if these significant others would actually recommend end-of-life care planning. In addition,

61% to 70% were unsure if other adults around them had completed end-of-life care planning. Such results suggest that adults need to discuss end-of-life care planning with their primary care physician, best friends, and family members. Open and respectful communication between patients and health care professionals is a prerequisite for effective end-of-life care planning (Institute of Medicine, 2015). Research has demonstrated that the most effective advance directive interventions include interactive patient-provider communication over several visits (Bravo, Dubois, & Wagneur, 2008; Jezewski, Meeker, Sessanna, & Finnell, 2007; Ramsaroop, Reid, & Adelman, 2007), and that repeated end-of-life care planning discussions relevant to the patient's life stage can improve end-of-life care planning completion (Sudore & Fried, 2010; Wittink, Morales, Meoni, & et al., 2008).

Many patients often wait on their health care providers to raise this issue rather than raising it proactively with their health care providers (Keating et al., 2010). Therefore, it is vital that future physicians and other health care providers are provided with adequate death and dying education during their undergraduate and graduate training programs. Unfortunately, some physicians are not trained adequately in end-of-life care. Research has shown that physicians often fall short in areas of patient-physician communication, explaining treatment options, and end-of-life care planning (SUPPORT, 1995). Many medical students and residents report feeling unprepared to deal with these issues in practice, and medical faculty members report feeling unprepared to teach important components related to quality end-of-life care (Sullivan, Lakoma, & Block, 2003). Less than one fifth of medical students reported having taken a death and dying course or a class in end-of-life care, and one third rated the quality of their end-of-life

care education as fair or poor (Sullivan et al., 2003). It appears that medical students across the United States lack comprehensive education about end-of-life care, specifically aspects of communication and empathy (Billings, Engelberg, Curtis, Block, & Sullivan, 2010). However, when medical students are exposed to more coursework in this area and more teaching from attending physicians at the bedside of patients, students report a greater sense of preparedness for end-of-life care and higher ratings of educational quality (Billings et al., 2010). Therefore, it is important that all future health care providers and members of the health care team be adequately educated in death and dying and advance care planning.

Contrary to the researcher's hypothesis, self-efficacy for end-of-life care planning was high among respondents. A majority of respondents (73% to 88%) of those who had yet to do end-of-life care planning reported that they were certain they would be able to complete a living will, DPAHC, and discuss end-of-life wishes with loved ones and their doctor. Although respondents were confident in their ability to complete end-of-life care planning, a relatively small proportion of them intended to do so in the next six months. It is possible that other factors outside the IBM may have influenced intentions to complete end-of-life care planning (e.g., knowledge, salience of the behavior, environmental constraints).

#### *Religiosity and End-of-Life Care Planning*

Some research suggests that those who are highly religious are less likely to participate in aspects of end-of-life care planning and more likely to desire intensive life-sustaining treatment (Karches et al., 2012; Phelps et al., 2009; True et al., 2005). In contrast, other research suggests that those who describe themselves as very religious are

more “death accepting” and are more likely to complete a will and advance directive (Schrader et al., 2009). Results of the current study showed that religiosity/spirituality was not significantly associated with end-of-life care planning completion or intention to complete end-of-life care planning.

A strong belief that a higher power controls one’s destiny, including meeting his health care needs at end-of-life, may influence end-of-life care planning (Balboni et al., 2013; Johnson et al., 2008). Blacks have been shown to be more likely to possess this belief (Johnson et al., 2008). The results of the current study showed that Blacks were significantly more religious than Whites or Hispanics, which is consistent with other studies (Levin, Taylor, & Chatters, 1994; Taylor, Mattis, & Chatters, 1999). However, religiosity was not associated with end-of-life care planning, no matter the race of the respondents. The lack of association between end-of-life care planning and religiosity in the current study could be due to the small sample size of Blacks and Hispanics in relation to Caucasians.

### **5.3 Implications**

The findings from this study suggest some potentially important implications. First, the study was consistent with previous research and revealed that a low percentage of American adults between the ages of 40 and 80 complete end-of-life care planning. The study also demonstrates that a low percentage of people intend to complete end-of-life care planning in the next six months. This is troubling, as end-of-life care planning has many positive benefits, no matter the person’s stage of life or age.

This study also supported research stating that racial and ethnic disparities exist regarding end-of-life care planning. These differences may exist for several reasons

including demographic factors, lack of knowledge and awareness, environmental constraints, and differences in the constructs of the IBM. Blacks and Hispanics appear to have lower attitudes, lower self-efficacy, and lower perceived norms than Whites, which demonstrates the impact of the IBM on end-of-life care planning completion. However, racial distrust and religiosity did not have a significant influence on end-of-life care planning completion, as reported in other studies.

The results point to the need for future interventions to focus on these IBM constructs by improving attitudes, perceived norms, and personal agency related to this behavior, especially among minority populations. This could potentially be done through reducing the taboo nature of talking about death, and increasing knowledge and awareness of end-of-life care planning, particularly by emphasizing the benefits to loved ones and family members. Lack of communication about end-of-life care planning is a major barrier to completing the activity, which was demonstrated by the results related to perceived norms. Many respondents were not sure if their physician, loved ones, or best friend would recommend the behavior, which demonstrates a lack of past communication about this topic.

The results of this study will likely be helpful to health care providers as they consider how to tailor and customize their method of communication and the content of their messages to the specific age, race, ethnicity, and values of their patients. Tailoring messages about end-of-life care planning is especially important for racial/ethnic minority patients. As the US population becomes more racially diverse, learning how to communicate with patients in a culturally acceptable way becomes more important.

The current study may also help to increase the number of health care providers

who increase their education in this area and participate in discussions with their patients regarding end-of-life care planning. Lack of educational training among health care providers in death and dying and advance care planning is an important issue that needs to be addressed. Death and dying education should be provided at every level of professional preparation for physicians – undergraduate, medical school, and residency. Likewise, other members of the health care team such as nurses should be required to take a death and dying course at both the undergraduate and graduate levels.

Educating the general public on the importance of end-of-life care planning is also an important priority and implication, especially for racial and ethnic minorities. Addressing racial and ethnic end-of-life care planning disparities will have a positive impact in multiple areas, including helping minority families obtain care that is in alignment with their values, reducing burden on family members, and helping families to address death in a proactive way.

#### **5.4 Future recommendations**

Based on the findings from this study, the investigator would make the following recommendations:

- 1) Investigate further the linkage between the IBM constructs and factors including attitudes, perceived norms, self-efficacy, knowledge, and environmental constraints and end-of-life care planning;
- 2) Conduct long-term follow up of respondents to determine whether IBM constructs and behavioral intentions are true predictors of completing end-of-life care planning;

- 3) Discover methods to improve attitudes, perceived norms, and self-efficacy toward end-of-life care planning among racial and ethnic minorities, in addition to the rest of the adult population;
- 4) Discover to what extent knowledge and awareness of end-of-life care planning influences completion of the behavior and intention to complete the behavior;
- 5) Promote the difficult, but essential, conversations about death and end-of-life care planning between loved ones and patients;
- 6) Improve the quality of education for health care providers so that it includes more death and dying education at undergraduate and graduate levels;
- 7) Stress the need for continuing medical education regarding end-of-life care among graduate faculty members in residency programs;
- 8) Encourage the completion of end-of-life care planning at earlier ages; and finally,
- 9) Promote conversations and open communication about death and end-of-life care planning between medical personnel and patients.

## References

- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179-211. doi: [http://dx.doi.org/10.1016/0749-5978\(91\)90020-T](http://dx.doi.org/10.1016/0749-5978(91)90020-T)
- Anderson, G. (2004). *Chronic conditions: making the case for ongoing care*. Baltimore, MD: John Hopkins University.
- Aoun, S. M., & Skett, K. (2013). A longitudinal study of end-of-life preferences of terminally-ill people who live alone. *Health & Social Care in the Community*, 21(5), 530-535. doi: 10.1111/hsc.12039
- Balboni, T. A., Balboni, M., Enzinger, A. C., Gallivan, K., Paulk, M. E., Wright, A., . . . Prigerson, H. G. (2013). Provision of Spiritual Support to Patients With Advanced Cancer by Religious Communities and Associations With Medical Care at the End of Life. *JAMA internal medicine*, 173(12), 1109-1117. doi: 10.1001/jamainternmed.2013.903
- Barnato, A. E., Anthony, D. L., Skinner, J., Gallagher, P. M., & Fisher, E. S. (2009). Racial and Ethnic Differences in Preferences for End-of-Life Treatment. *JGIM: Journal of General Internal Medicine*, 24(6), 695-701. doi: 10.1007/s11606-009-0952-6

- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., . . .  
. Viswanathan, M. (2011). Health literacy interventions and outcomes: an updated  
systematic review. *Evid Rep Technol Assess (Full Rep)*(199), 1-941.
- Beville, J. M., Umstattd Meyer, M. R., Usdan, S. L., Turner, L. W., Jackson, J. C., &  
Lian, B. E. (2014). Gender Differences in College Leisure Time Physical  
Activity: Application of the Theory of Planned Behavior and Integrated  
Behavioral Model. *Journal of American College Health, 62*(3), 173-184. doi:  
10.1080/07448481.2013.872648
- Billings, M. E., Engelberg, R., Curtis, J. R., Block, S., & Sullivan, A. M. (2010).  
Determinants of medical students' perceived preparation to perform end-of-life  
care, quality of end-of-life care education, and attitudes toward end-of-life care.  
*Journal of Palliative Medicine, 13*(3), 319-326. doi: 10.1089/jpm.2009.0293
- Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. K. (2013). Advance  
Care Planning and the Quality of End-of-Life Care in Older Adults. *Journal of the  
American Geriatrics Society, 61*(2), 209-214. doi: 10.1111/jgs.12105
- Blalock, S. J., Currey, S. S., DeVellis, R. F., Giorgino, K. B., Anderson, J. J. B., Dooley,  
M. A., & Gold, D. T. (2000). Effects of educational materials concerning  
osteoporosis on women's knowledge, beliefs, and behavior. *American Journal of  
Health Promotion, 14*(3), 161-169.
- Born, W., Greiner, K. A., Sylvia, E., Butler, J., & Ahluwalia, J. S. (2004). Knowledge,  
Attitudes, and Beliefs about End-of-life Care among Inner-City African  
Americans and Latinos. *Journal of Palliative Medicine, 7*(2), 247-256. doi:  
10.1089/109662104773709369

- Borrelli, B., McQuaid, E. L., Becker, B., Hammond, K., Papandonatos, G., Fritz, G., & Abrams, D. (2002). Motivating parents of kids with asthma to quit smoking: the PAQS project. *Health Education Research, 17*(5), 659-669.
- Bravo, G., Dubois, M. F., & Wagneur, B. (2008). Assessing the effectiveness of interventions to promote advance directives among older adults: a systematic review and multi-level analysis. *Soc Sci Med, 67*(7), 1122-1132. doi: 10.1016/j.socscimed.2008.06.006
- Bray, S. H. M. D. M. B. E. F. (2013). Palliative care: What is it and why should an otolaryngologist care? *Ear, Nose & Throat Journal, 92*(7), 284.
- Brereton, L., Gardiner, C., Gott, M., Ingleton, C., Barnes, S., & Carroll, C. (2012). The hospital environment for end of life care of older adults and their families: an integrative review. *Journal of Advanced Nursing, 68*(5), 981-993. doi: 10.1111/j.1365-2648.2011.05900.x
- Bullock, K. (2006). Promoting Advance Directives among African Americans: A Faith-Based Model. *Journal of Palliative Medicine, 9*(1), 183-195. doi: 10.1089/jpm.2006.9.183
- Burdsall, T. D. L. (2013). *The Effects of Race, Socioeconomic Status, and Religion on Formal End-of-Life Planning*. (3568035 Ph.D.), Portland State University, Ann Arbor. Retrieved from <http://linksource.ebsco.com/linking.aspx?sid=ProQuest+Dissertations+%26+Theses+A%26I&fmt=dissertation&genre=dissertations+%26+theses&issn=&volume=&issue=&date=2013-0101&spage=&title=The+Effects+of+Race%2C+Socioeconomic+Status%2C+and+Religion+on+Formal+End-ofLife+Planning&>

atitle=&au=Burdsall%2C+Tina+Dawn+Lillian&isbn=9781303216350&jtitle=&bt  
title=&id=doi: ProQuest Dissertations & Theses A&I database.

Caldwell, C. D., & Freeman, S. J. (2009). End-of-Life Decision Making: A Slippery Slope. *Journal of Professional Counseling: Practice, Theory & Research*, 37(2), 21-33.

California Health Care Foundation. (2012). Final chapter: Californians' attitudes and experiences with death and dying.

Callaway, C. (2012). Timing is everything: When to consult palliative care. *Journal of the American Academy of Nurse Practitioners*, 24(11), 633-639. doi: 10.1111/j.1745-7599.2012.00746.x

Carr, D. (2011). Racial Differences in End-of-Life Planning: Why Don't Blacks and Latinos Prepare for the Inevitable? *Omega: Journal of Death & Dying*, 63(1), 1-20. doi: 10.2190/OM.63.1.a

Carr, D. (2012). Racial and ethnic differences in advance care planning: Identifying subgroup patterns and obstacles. *Journal of Aging and Health*, 24(6), 923-947.

Carr, D., & Khodyakov, D. (2007). Health Care Proxies: Whom Do Young Old Adults Choose and Why? *Journal of Health and Social Behavior*, 48(2), 180-194.

Centers for Disease Control and Prevention. (1999). Control of infectious diseases, 1900-1999. *JAMA*, 282(11), 1029-1032. doi: 10.1001/jama.282.11.1029

Cort, M. A. (2004). Cultural Mistrust and Use of Hospice Care: Challenges and Remedies. *Journal of Palliative Medicine*, 7(1), 63-71. doi: 10.1089/109662104322737269

- Costanza, M. E., Luckmann, R., Stoddard, A. M., Avrunin, J. S., White, M. J., Stark, J. R., . . . Rosal, M. C. (2005). Applying a stage model of behavior change to colon cancer screening. *Preventive Medicine, 41*(3-4), 707-719. doi: <http://dx.doi.org/10.1016/j.yjmed.2004.12.013>
- Coustasse, A., Quiroz, T., & Lurie, S. G. (2008). To the Bitter End: Disparities in End-of-Life Care. *Journal of Hospital Marketing & Public Relations, 18*(2), 167-185. doi: 10.1080/15390940802232473
- Dean-Lee, J. B. (2005). Rest in Peace: A Cultural History of Death and the Funeral Home in Twentieth-Century America. *Conversations in Religion & Theology, 3*(2), 192-203. doi: 10.1111/j.1479-2214.2005.00070.x
- Despelder, L. A., & Strickland, A. L. (2015). *The Last Dance: Encountering Death and Dying* (10th ed.). New York, NY: McGraw-Hill Education.
- Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ, 340*. doi: 10.1136/bmj.c1345
- Duffy, S. A., Jackson, F. C., Schim, S. M., Ronis, D. L., & Fowler, K. E. (2006). Racial/Ethnic Preferences, Sex Preferences, and Perceived Discrimination Related to End-of-Life Care. *Journal of the American Geriatrics Society, 54*(1), 150-157. doi: 10.1111/j.1532-5415.2005.00526.x
- Fishbein, M. (2004). Intentional Behavior. In C. D. Spielberger (Ed.), *Encyclopedia of Applied Psychology* (pp. 329-334). New York: Elsevier.
- Fonseca, L. M., & Testoni, I. (2011). The Emergence of Thanatology and Current Practice in Death Education. *Omega: Journal of Death & Dying, 64*(2), 157-169.

- Fries, J. F. (2002). Aging, natural death, and the compression of morbidity. *Bulletin of the World Health Organization*, 80, 245-250.
- Givens, J. L., & Mitchell, S. L. (2009). Concerns about end-of-life care and support for euthanasia. *Journal of Pain and Symptom Management*, 38(2), 167-173. doi: 10.1016/j.jpainsymman.2008.08.012
- Glanz, K., Rimer, B., & Viswanath, K. (2008). *Health Behavior and Health Education: Theory, Research, and Practice* (4th ed.). San Francisco, CA: Jossey-Bass.
- Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care*, 12(1), 7-19. doi: 10.1186/1472-684X-12-7
- Gray, K., Anne Knickman, T., & Wegner, D. M. (2011). More dead than dead: Perceptions of persons in the persistent vegetative state. *Cognition*, 121(2), 275-280. doi: <http://dx.doi.org/10.1016/j.cognition.2011.06.014>
- Grudzen, C., & Grady, D. (2011). Improving care at the end of life. *Archives of Internal Medicine*, 171(13), 1202-1202. doi: 10.1001/archinternmed.2011.132
- Gruneir, A., Mor, V., Weitzen, S., Truchil, R., Teno, J., & Roy, J. (2007). Where people die: a multilevel approach to understanding influences on site of death in America. *Med Care Res Rev*, 64(4), 351-378. doi: 10.1177/1077558707301810
- Guyer, B., Freedman, M. A., Strobino, D. M., & Sondik, E. J. (2000). Annual summary of vital statistics: trends in the health of Americans during the 20th century. *Pediatrics*, 106(6), 1307-1317.
- Hagger, M. S., Chatzisarantis, N. L. D., & Biddle, S. J. H. (2002). A meta-analytic review of the theories of reasoned action and planned behavior in physical

- activity: predictive validity and the contribution of additional variables. *Journal of Sport & Exercise Psychology*, 24(1), 3-32.
- Haller, I. V., & Gessert, C. E. (2007). Utilization of medical services at the end of life in older adults with cognitive impairment: focus on outliers. *Journal of Palliative Medicine*, 10(2), 400-407.
- Hanchate, A., Kronman, A. C., Young-Xu, Y., Ash, A. S., & Emanuel, E. (2009). Racial and Ethnic Differences in End-of-Life Costs. *Archives of Internal Medicine*, 169(5), 493-501.
- Hardwig, J. (2009). Going to meet death. *Hastings Center Report*, 39(4), 37-45.
- Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., . . . Lam, M. (2006). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ: Canadian Medical Association Journal*, 174(5), O1-O9. doi: 10.1503/cmaj.050626
- Hilliard, T. S., Washington, T., Hines, C., & McGill, T. (2013). Wishes left unspoken: engaging underserved populations in end-of-life advance care planning. *Journal Of Health Care For The Poor And Underserved*, 24(3), 979-986. doi: 10.1353/hpu.2013.0130
- Hoyert, D. L. (2012). 75 years of mortality in the United States, 1935-2010 *NCHS data brief* (Vol. 88). Hyattsville, MD: National Center for Health Statistics.
- Hoyert, D. L., & Xu, J. Q. (2012). Deaths: Preliminary data for 2011. *National Vital Statistics Report*, 61(6).
- Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., De La Cruz, M., Kim, S. H., . . . Bruera, E. (2014). Concepts and Definitions for “Actively Dying,” “End of Life,”

- “Terminally Ill,” “Terminal Care,” and “Transition of Care”: A Systematic Review. *Journal of Pain and Symptom Management*, 47(1), 77-89. doi: <http://dx.doi.org/10.1016/j.jpainsymman.2013.02.021>
- Institute of Medicine. (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.
- Jezewski, M. A., Meeker, M. A., Sessanna, L., & Finnell, D. S. (2007). The effectiveness of interventions to increase advance directive completion rates. *J Aging Health*, 19(3), 519-536. doi: 10.1177/0898264307300198
- Johnson, K. S., Kuchibhatla, M., & Tulsky, J. A. (2008). What Explains Racial Differences in the Use of Advance Directives and Attitudes Toward Hospice Care? *Journal of the American Geriatrics Society*, 56(10), 1953-1958. doi: 10.1111/j.1532-5415.2008.01919.x
- Johnson, K. S., Kuchibhatla, M., & Tulsky, J. A. (2009). Racial Differences in Self-Reported Exposure to Information about Hospice Care. *Journal of Palliative Medicine*, 12(10), 921-927. doi: 10.1089/jpm.2009.0066
- Johnston, B., & Smith, L. N. (2006). Nurses' and patients' perceptions of expert palliative nursing care. *Journal of Advanced Nursing*, 54(6), 700-709. doi: 10.1111/j.1365-2648.2006.03857.x
- Karches, K. E., Chung, G. S., Arora, V., Meltzer, D. O., & Curlin, F. A. (2012). Religiosity, spirituality, and end-of-life planning: a single-site survey of medical inpatients. *Journal of Pain and Symptom Management*, 44(6), 843-851. doi: 10.1016/j.jpainsymman.2011.12.277

- Kasprzyk, D., Montaña, D. E., & Fishbein, M. (1998). Application of an Integrated Behavioral Model to Predict Condom Use: A Perspective Study Among High HIV Risk Groups. *Journal of Applied Social Psychology, 28*(17), 1557-1583.
- Keating, N. L., Landrum, M. B., Rogers, S. O., Jr., Baum, S. K., Virnig, B. A., Huskamp, H. A., . . . Kahn, K. L. (2010). Physician factors associated with discussions about end-of-life care. *Cancer, 116*(4), 998-1006. doi: 10.1002/cncr.24761
- Kenski, K., Appleyard, J., von Haefen, I., Kasprzyk, D., & Fishbein, M. (2001). Theoretical determinants of condom use intentions for vaginal sex with a regular partner among male and female injecting drug users. *Psychology, Health & Medicine, 6*(2), 179-190. doi: 10.1080/13548500120035436
- Ko, E., & Lee, J. (2014). Completion of advance directives among low-income older adults: Does race/ethnicity matter? *American Journal of Hospice & Palliative Medicine, 31*(3), 247-253. doi: 10.1177/1049909113486170
- Koenig, H. G., & Büssing, A. (2010). The Duke University Religion Index (DUREL): A Five-Item Measure for Use in Epidemiological Studies. *Religions, 1*(1), 78.
- Kung, H. C., Hoyert, D. L., Xu, J. Q., & Murphy, S. L. (2008). Deaths: final data for 2005. *National Vital Statistics Reports 2008, 56*(10).
- LaVeist, T. A., Isaac, L. A., & Williams, K. P. (2009). Mistrust of health care organizations is associated with underutilization of health services. *Health Serv Res, 44*(6), 2093-2105. doi: 10.1111/j.1475-6773.2009.01017.x
- Lepore, M. J., Miller, S. C., & Gozalo, P. (2011). Hospice Use Among Urban Black and White U.S. Nursing Home Decedents in 2006. *The Gerontologist, 51*(2), 251-260. doi: 10.1093/geront/gnq093

- Levin, J. S., Taylor, R. J., & Chatters, L. M. (1994). Race and gender differences in religiosity among older adults: findings from four national surveys. *J Gerontol*, 49(3), S137-145.
- McCormick, E., Chai, E., & Meier, D. E. (2012). Integrating Palliative Care Into Primary Care. *Mount Sinai Journal of Medicine*, 79(5), 579-585. doi: 10.1002/msj.21338
- Menec, V. H., Lix, L., Nowicki, S., & Ekuma, O. (2007). Health care use at the end of life among older adults: does it vary by age? *Journals of Gerontology: Series A: Biological Sciences and Medical Sciences*, 62A(4), 400-407.
- Miesfeldt, S., Murray, K., Lucas, L., Chang, C.-H., Goodman, D., & Morden, N. E. (2012). Association of Age, Gender, and Race with Intensity of End-of-Life Care for Medicare Beneficiaries with Cancer. *Journal of Palliative Medicine*, 15(5), 548-554. doi: 10.1089/jpm.2011.0310
- Morrison, R. S., Penrod, J. D., Cassel, J. B., Caust-Ellenbogen, M., Litke, A., Spragens, L., & Meier, D. E. (2008). Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*, 168(16), 1783-1790. doi: 10.1001/archinte.168.16.1783
- Murphy, S. L., Xu, J. Q., & Kochanek, K. D. (2013). Deaths: Final data for 2010. *National Vital Statistics Report*, 61(4).
- National Consensus Project. (2013). Clinical practice guidelines for quality palliative care. [http://www.nationalconsensusproject.org/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf)
- National Council on Aging. (2014). The United States of Aging Survey.

- National Hospice and Palliative Care Organization. (2013). NHPCO's facts and figures: Hospice care in America.
- National Hospice and Palliative Care Organization. (2014). Advance care planning. Retrieved March 16, 2014, from <http://www.nhpco.org/advance-care-planning>
- Noah, B. A. (2012). The Role of Race in End-of-Life Care (Vol. 15, pp. 349-378): University of Maryland School of Law.
- Parr, J. D., Baohui, Z., Nilsson, M. E., Wright, A., Balboni, T., Duthie, E., . . . Prigerson, H. G. (2010). The Influence of Age on the Likelihood of Receiving End-of-Life Care Consistent with Patient Treatment Preferences. *Journal of Palliative Medicine, 13*(6), 719-726. doi: 10.1089/jpm.2009.0337
- Phelps, A. C., Maciejewski, P. K., Nilsson, M., Balboni, T. A., Wright, A. A., Paulk, M. E., . . . Prigerson, H. G. (2009). Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA, 301*(11), 1140-1147. doi: 10.1001/jama.2009.341
- Phipps, E., True, G., Harris, D., Chong, U., Tester, W., Chavin, S. I., & Braitman, L. E. (2003). Approaching the End of Life: Attitudes, Preferences, and Behaviors of African-American and White Patients and Their Family Caregivers. *Journal of Clinical Oncology, 21*(3), 549-554. doi: 10.1200/jco.2003.12.080
- Quill, T., Norton, S., Shah, M., Lam, Y., Fridd, C., & Buckley, M. (2006). What is Most Important for You to Achieve?: An Analysis of Patient Responses When Receiving Palliative Care Consultation. *Journal of Palliative Medicine, 9*(2), 382-388. doi: 10.1089/jpm.2006.9.382

- Ramsaroop, S. D., Reid, M. C., & Adelman, R. D. (2007). Completing an advance directive in the primary care setting: what do we need for success? *J Am Geriatr Soc*, 55(2), 277-283. doi: 10.1111/j.1532-5415.2007.01065.x
- Rao, J. K., Anderson, L. A., Lin, F.-C., & Laux, J. P. (2014). Completion of Advance Directives Among U.S. Consumers. *American Journal of Preventive Medicine*, 46(1), 65-70. doi: 10.1016/j.amepre.2013.09.008
- Rietjens, J. A. C., Deschepper, R., Pasma, R., & Deliens, L. (2012). Medical end-of-life decisions: Does its use differ in vulnerable patient groups? A systematic review and meta-analysis. *Social Science & Medicine*, 74(8), 1282-1287. doi: 10.1016/j.socscimed.2011.12.046
- Ruff, H., Jacobs, R. J., Fernandez, M. I., Bowen, G. S., & Gerber, H. (2011). Factors associated with favorable attitudes toward end-of-life planning. *American Journal of Hospice & Palliative Medicine*, 28(3), 176-182.
- Schickedanz, A. D., Schillinger, D., Landefeld, C. S., Knight, S. J., Williams, B. A., & Sudore, R. L. (2009). A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers. *Journal of the American Geriatrics Society*, 57(1), 31-39.
- Schrader, S. L., Nelson, M. L., & Eidsness, L. M. (2009). Dying to Know: A Community Survey about Dying and End-of-Life Care. *Omega: Journal of Death and Dying*, 60(1), 33-50.
- Sifri, R., Rosenthal, M., Hyslop, T., Andrel, J., Wender, R., Vernon, S. W., . . . Myers, R. E. (2010). Factors associated with colorectal cancer screening decision stage.

*Preventive Medicine*, 51(3–4), 329-331. doi:

<http://dx.doi.org/10.1016/j.ypmed.2010.06.015>

Silveira, M. J., Kim, S. Y. H., & Langa, K. M. (2010). Advance Directives and Outcomes of Surrogate Decision Making before Death. *New England Journal of Medicine*, 362(13), 1211-1218. doi: 10.1056/NEJMsa0907901

Silveira, M. J., Wiitala, W., & Piette, J. (2014). Advance Directive Completion by Elderly Americans: A Decade of Change. *Journal of the American Geriatrics Society*, 62(4), 706-710. doi: 10.1111/jgs.12736

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *JAMA*, 281(2), 163-168. doi: 10.1001/jama.281.2.163

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., Grambow, S., Parker, J., & Tulsky, J. A. (2001). Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *Journal of Pain and Symptom Management*, 22(3), 727-737.

Strickland, B. B., Jones, J. R., Ghandour, R. M., Kogan, M. D., & Newacheck, P. W. (2011). The Medical Home: Health Care Access and Impact for Children and Youth in the United States. *Pediatrics*, 127(4), 604-611. doi: 10.1542/peds.2009-3555

Sudore, R. L., & Fried, T. R. (2010). Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Ann Intern Med*, 153(4), 256-261. doi: 10.7326/0003-4819-153-4-201008170-00008

Sullivan, A. M., Lakoma, M. D., & Block, S. D. (2003). The status of medical education in end-of-life care: a national report. *Journal Of General Internal Medicine*, 18(9), 685-695.

SUPPORT. (1995). A controlled trial to improve care for seriously iii hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (support). *JAMA*, 274(20), 1591-1598. doi: 10.1001/jama.1995.03530200027032

Taylor, R. J., Mattis, J., & Chatters, L. M. (1999). Subjective Religiosity among African Americans: A Synthesis of Findings from Five National Samples. *Journal of Black Psychology*, 25(4), 524-543. doi: 10.1177/0095798499025004004

Tejwani, V., YiFan, W., Serrano, S., Segura, L., Bannon, M., & Qian, Q. (2013). Issues surrounding end-of-life decision-making. *Patient Preference & Adherence*, 7, 771-775. doi: 10.2147/PPA.S48135

Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., . . . Lynch, T. J. (2010). Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine*, 363(8), 733-742. doi: 10.1056/NEJMoa1000678

Teno, J. M., Gozalo, P. L., Bynum, J. W., & et al. (2013). Change in end-of-life care for medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*, 309(5), 470-477. doi: 10.1001/jama.2012.207624

The Conversation Project. (2013). New Survey Reveals ‘Conversation Disconnect’: 90 percent of Americans know they should have a conversation about what they want at the end of life, yet only 30 percent have done so.

- Thompson, H. S., Valdimarsdottir, H. B., Winkel, G., Jandorf, L., & Redd, W. (2004). The Group-Based Medical Mistrust Scale: psychometric properties and association with breast cancer screening. *Prev Med, 38*(2), 209-218.
- Tompson, T., Benz, J., Agiesta, J., Junius, D., Nguyen, K., & Lowell, K. (2013). Long-term care: Perceptions, experiences, and attitudes among Americans 40 or older. *The Associated Press*. NORC Center for Public Affairs Research.
- True, G., Phipps, E., Braitman, L., Harralson, T., Harris, D., & Tester, W. (2005). Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. *Annals of Behavioral Medicine, 30*(2), 174-179. doi: 10.1207/s15324796abm3002\_10
- U.S. Census Bureau. (2012). American Community Survey Demographic and Housing 1-Year Estimates. American FactFinder  
<http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>
- U.S. Department of Health and Human Services. (2008). *Advance Directives and Advance Care Planning: Report to Congress*. Retrieved from  
<http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>
- U.S. National Library of Medicine. (2014). End of life issues. from  
<http://www.nlm.nih.gov/medlineplus/endoflifeissues.html>
- Vandervoort, A., Houttekier, D., Vander Stichele, R., van der Steen, J. T., & Van den Block, L. (2014). Quality of Dying in Nursing Home Residents Dying with Dementia: Does Advanced Care Planning Matter? A Nationwide Postmortem Study. *PLoS ONE, 9*(3), 1-8. doi: 10.1371/journal.pone.0091130

- Virani, R. (2003). Improving the Quality of End-of-Life Care. *American Journal of Nursing, 103*(5), 52.
- Volandes, A. E., Paasche-Orlow, M., Gillick, M. R., Cook, E. F., Shaykevich, S., Abbo, E. D., & Lehmann, L. (2008). Health Literacy not Race Predicts End-of-Life Care Preferences. *Journal of Palliative Medicine, 11*(5), 754-762. doi: 10.1089/jpm.2007.0224
- von Haften, I., Fishbein, M., Kasprzyk, D., & Montano, D. (2001). Analyzing data to obtain information to design targeted interventions. *Psychology, Health & Medicine, 6*(2), 151-164. doi: 10.1080/13548500120035409
- Weinstein, N. D., & Sandman, P. M. (1992). A model of the precaution adoption process: evidence from home radon testing. *Health Psychology: Official Journal Of The Division Of Health Psychology, American Psychological Association, 11*(3), 170-180.
- Weinstein, N. D., Sandman, P. M., & Blalock, S. J. (2008). The precaution adoption process model. In K. Glanz, B. K. Rimer & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice (4th ed.)*. (pp. 123-147). San Francisco, CA, US: Jossey-Bass.
- West, S. K., & Hollis, M. (2012). Barriers to completion of advance care directives among African Americans ages 25-84: a cross-generational study. *Omega, 65*(2), 125-137.
- Winston, C. A., Leshner, P., Kramer, J., & Allen, G. (2004). Overcoming barriers to access and utilization of hospice and palliative care services in African-American communities. *Omega: Journal of Death & Dying, 50*(2), 151-163.

- Wittink, M. N., Morales, K. H., Meoni, L. A., & et al. (2008). Stability of preferences for end-of-life treatment after 3 years of follow-up: The Johns Hopkins precursors study. *Archives of Internal Medicine*, *168*(19), 2125-2130. doi: 10.1001/archinte.168.19.2125
- Wright, A. A., Zhang, B., Ray, A., & et al. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, *300*(14), 1665-1673. doi: 10.1001/jama.300.14.1665
- Wu, S. Y., & Green, A. (2000). *Projection of chronic illness prevalence and cost inflation*. Santa Monica, CA: RAND Health.
- Yancu, C., Farmer, D., & Leahman, D. (2010). Barriers to hospice use and palliative care services use by African American adults. *American Journal of Hospice and Palliative Medicine*, *27*(4), 248-253.
- Zerzan, J., Benton, K., Linnebur, S., O'Bryant, C., & Kutner, J. (2010). Variation in pain medication use in end-of-life care. *Journal of Palliative Medicine*, *13*(5), 501-504. doi: 10.1089/jpm.2009.0406
- Zhang, B., Wright, A. A., Huskanip, H. A., Nilsson, M. E., Maciejewski, M. L., Earle, C. C., . . . Prigerson, H. G. (2009). Health Care Costs in the Last Week of Life. *Archives of Internal Medicine*, *169*(5), 480-488.
- Zheng, X., & Zimmer, D. M. (2009). Racial differences in health-care utilization: Analysis by intensity of demand. *Contemporary Economic Policy*, *27*(4), 475-490. doi: 10.1111/j.1465-7287.2009.00151.x