

End-of-life care planning and its implementation

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BOSTON COLLEGE
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END-OF-LIFE CARE PLANNING AND ITS IMPLEMENTATION

A dissertation
by

Megumi Inoue

Submitted in partial fulfillment
of the requirements for a degree of
Doctor of Philosophy

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Dissertation Chair: Dr. James Lubben, Dr. Sara M. Moorman

Abstract

End-of-life care planning is an opportunity for people to express how they want to spend the final stage of their lives by directing what type of medical treatment they wish or do not wish to receive. The completion of such planning is a way to exercise their autonomy, which is one of the fundamental ethical principles in medicine in the United States. Many older adults in the U.S., however, do not have such a plan or even discuss the topic with anyone. In order to understand the circumstances in which end-of-life planning is enacted, this study investigated two important research questions: (1) What are the sociodemographic and psychosocial factors that enhance or impede the completion of end-of-life planning? (2) How consistent is the content of a living will with the person's actual dying experience? These research questions were developed and examined as an application of expectancy theory, which explains the concepts of motivation and action. A series of logistic regression analyses were conducted.

This study analyzed data from the Health and Retirement Study (HRS), which is a nationally representative sample of Americans over the age of 50. The analytic subsample included those who died between 2000 and 2010 ($N = 6,668$). The study found that persons who were older, who identified themselves as White, who had higher

levels of income and education, and who were widowed or separated were more likely to be motivated to complete end-of-life planning. A higher level of sense of mastery was specifically relevant to documentation of living wills. On the other hand, a lower level of religiosity was specifically associated with having a durable power of attorney for health care. In addition, there was a clear connection between a request for palliative care and less troubling pain.

Implications include conducting a community- or workplace-based public educational campaign, incorporating a culturally tailored approach for racial/ethnic minorities (e.g. faith-based interventions), using advance directives written in easy to understand language (e.g. Five Wishes), and funding Medicare provision for end-of-life care consultations between doctors and patients during annual physical exams.

DEDICATION

This dissertation is dedicated to the patients that I had opportunities to work with during the final days of their lives. This work is also dedicated to my late grandparents who taught me the virtues of hard work and the importance of family. Their deaths motivated me to study end-of-life issues.

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Chapter I. Introduction

Purpose of the Study

The dying process is an important part of human life. End-of-life care planning is an opportunity for people to express how they want to spend this inevitable, final stage of their lives by directing what type of medical treatment they wish or do not wish to receive. Many older adults in the U.S., however, do not have such a plan or even discuss the topic with anyone (Carr & Khodyakov, 2007; Curtis, Patrick, Caldwell, & Collier, 2000; Moorman & Inoue, 2013; Schickedanz et al., 2009). Distressing symptoms such as pain, depression, confusion, fatigue, and breathlessness are prevalent among patients who are at the end-of-life stage (Solano, Gomes, & Higginson, 2006). Thus, when people become terminally ill, they are often unable, physically or cognitively, to articulate their treatment preferences. About 30% of recent decedents aged 50 or older needed treatment decisions when they no longer had decision-making capacity (Silveira, Kim, & Langa, 2010). A lack of end-of-life planning has been reported as a barrier to the improvement of end-of-life care (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007).

Prior research has examined people's sociodemographic characteristics and psychosocial circumstances to identify factors that promote legal planning for end-of-life care as well as informal discussion with families and physicians. Such factors include older age (e.g. Alano et al., 2010; Braun, Onaka, & Horiuti, 2001; Bravo, Dubois, & Pâquet, 2003; Moorman & Inoue, 2013), being White (e.g. Johnson, Kuchibhatla, & Tulsky, 2008; Pollack, Morhaim, & Williams, 2010; Moorman & Inoue, 2013), being married (Carr & Khodyakov, 2007) higher socioeconomic status (e.g. Carr & Khodyakov, 2007; Dobalian, 2006; Rosnick & Reynolds, 2003), and the experience of

recently losing a loved one (Carr & Khodyakov, 2007). However, many of these previous studies used geographically constrained or institutionalized populations, which yield limited generalizability. Greater generalizability enables research findings and conclusions to be applicable to a larger population. In addition, compared to the number of studies that investigate persons' sociodemographic characteristics in relation to the completion of end-of-life planning, there is little research examining psychosocial circumstances, such as one's sense of control and religiosity. Because individuals' thoughts, feelings, and values are affected by their psychosocial circumstances, it is important to understand such circumstances. Another underdocumented area of research on end-of-life planning is the question of whether the wishes of deceased persons were actually carried out during the dying process. While many studies focus on the prevalence of end-of-life planning and factors that promote such planning, it is also important to investigate the conditions in which persons' end-of-life plans are carried out in the way they were specified because the purpose of end-of-life planning is to respect one's wishes.

This study aims to fill in these gaps existing in literature. The data for this study are from the Health and Retirement Study (HRS), which is a nationally representative sample of Americans over the age of 50 (University of Michigan, 2012). The use of the HRS allows the study findings to be generalizable to a broad population of older adults in the U.S., in contrast to many other previous studies whose participants were geographically constrained or whose focus was limited to institutionalized populations. The HRS includes psychosocial variables that have been understudied in relation to the completion of end-of-life planning. Furthermore, the HRS conducts proxy interviews

after panel participants died and collects information on whether the deceased had end-of-life planning, and if so, what were the contents of such plans. The HRS also asks proxies about actual medical treatment the deceased received during the last year of their lives, as well as their statuses in the days before death, such as their pain level, the type of illness that caused death, and the duration of the illness.

In sum, with an attempt to fill in gaps existing in literature, the purposes of this study are (a) to identify sociodemographic and psychosocial factors that enhance or impede the completion of end-of-life planning, using a nationally representative sample; and (b) to examine consistency between end-of-life treatment preferences the deceased specified in plans and actual care they received.

Definitions of End-of-Life Planning

Advancement in medical technology offers a wide variety of treatment choices for terminally ill patients as end-of-life care. Even when curative treatments are no longer effective, patients can still receive aggressive, life-prolonging interventions. On the other hand, patients can choose palliative care, which focuses on providing comfort and relief in order to enhance quality of life for dying persons (Meier, 2006). These treatment choices include the use or withholding of a number of different medical interventions, such as cardiopulmonary resuscitation, tube feeding, artificial hydration, mechanical ventilation, and dialysis.

End-of-life planning, also called advance care planning, is the process of planning for future medical care in the event that a person become unable to make decisions or speak for oneself in the last year of life (Emanuel, Von Gunten, & Ferris, 2000). It is an opportunity for individuals to identify and express which treatments they do or do not

want for their end-of-life care so that health care providers can give appropriate care. It has three types: a living will, a durable power of attorney for health care (DPAHC), and informal discussion.

A living will specifies in writing the types of medical care a person does or does not want to receive under certain circumstances during a terminal illness (Annas, 2011). For example, a person can specify whether he or she would want to have life-support treatment when he or she is in a coma and not expected to wake up or recover. A living will goes into effect only when the person has a terminal illness or irreversible condition declared by medical doctors and is no longer able to make or communicate his or her health care decisions. A DPAHC is a designated individual permitted to make health care decisions for an incapacitated person should decisions arise that are not covered in the living will. A living will and DPAHC are both legal documents, and together they are called an advance directive. Research has documented that a small proportion of individuals complete advance directives without discussing their contents with the family members or health care providers who will carry out those contents (Carr & Khodyakov, 2007). Although such discussions are not legally binding, they are helpful for informing those persons (Mack, Weeks, Wright, Block, & Prigerson, 2010). Talking about one's thoughts, values, and preferences for end-of-life care will help one's surrogate decision makers understand the values and preferences of a person so that they can make the right decisions when needed. Surrogates are legally obligated to apply the standard of substituted judgment, which is to choose the treatment that they believe the dying person would choose, if competent (Sabatino, 2010). When a surrogate has previously been

involved in a dying family member's end-of-life planning, the surrogate's substitute judgment is more accurate (Inoue & Moorman, forthcoming).

Importance of the Completion of End-of-Life Planning

The completion of end-of-life care planning has been encouraged by policy makers and health care professionals (American Medical Association, 1998; Gillick, 2004; Hopp, 2000). Researchers have been investigating the prevalence of end-of-life planning and factors that are associated with it (e.g. Alano et al., 2010; Braun et al., 2001; Carr & Khodyako, 2007; Dobalian, 2006; Johnson et al., 2008; Moorman & Inoue, 2013; Pollack et al., 2010; Rosnick & Reynolds, 2003). There are broadly four reasons for encouraging the completion of end-of-life planning: respect for one's autonomy, family members' well-being, reduction of futile, unnecessary, or unwanted medical treatment, and reduction of care expenses (American Medical Association, 1998; Gillick, 2004; Hopp, 2000). The current study is particularly relevant to respect for one's autonomy and reduction of unwanted care.

Respect for Autonomy

One of the fundamental ethical principles in medicine in the United States is respect for patient autonomy, which is a patient's right to direct his or her medical treatment. A medical ethicist, Raanan Gillon, even argues that autonomy is the most important principle in medical ethics and defines autonomy as "the ability and tendency to think for oneself, to make decisions for oneself about the way one wishes to lead one's life based on that thinking, and then to enact those decisions" (Gillon, 2003, p. 310).

When terminally-ill patients are too physically or cognitively incapacitated to speak for themselves, they require surrogate decision makers. A surrogate could have been legally appointed by a patient in advance, but if the patient does not have a designated decision maker, most states appoint one by default (Sabatino, 2010).

Therefore, the surrogate is usually a family member, and typically the spouse if the dying person is married (Fagerlin, Ditto, Ganks, Houts, & Smucker, 2001). Having completed end-of-life planning will help surrogates speak for a dying person. In this way, even when terminally-ill patients are unable to make decision for themselves, their autonomy can be still preserved.

Family Members' Well-Being

Surrogate decision-making is a stressful process, and family conflicts related to end-of-life care decisions occur in more than half of the families who have a dying family member (Kramer, Boelk, & Auer, 2006). Previous research has documented that at least one third of surrogate decision-makers experience a negative emotional burden due to making treatment decisions for their loved one (Wendler & Rid, 2011). Such negative emotions reported by surrogates include enormous stress, feelings of guilt over the decisions, and doubt regarding whether the decisions they made were right (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Braun, Beyth, Ford, & McCullough, 2008; Colclough & Young, 2007; Handy, Sulmasy, Merkel, & Ury, 2008; Hansen, Archbold, & Stewart, 2004; Hansen, Archbold, Stewart, Westfall, & Ganzini, 2005; Radwany et al., 2009). Furthermore, the negative emotional effects often last months or sometimes years (Wendler & Rid, 2011).

Research also suggests that knowing a dying person's treatment preferences or having advance directives in place is associated with reduced emotional burden among surrogate decision-makers (Abbott et al., 2001; Braun et al., 2008; Colclough & Young, 2007; Handy et al., 2008; Hansen et al., 2004; Hansen et al., 2005). Making decisions based on the dying person's wishes cause surrogates less burden than making decisions without knowing their loved one's preferences. Therefore, the completion of end-of-life planning not only promotes dying persons' autonomy, but also protects family members who have to make treatment decisions for their loved one.

Reduction of Futile, Unnecessary, or Unwanted Medical Treatment

The absence of end-of-life planning is associated with aggressive, life-prolonging treatment in terminal care, such as blood transfusion, mechanical ventilation, and chemotherapy (Hinkka, Kosunen, Metsänoja, Lammi, & Kellokumpu-Lehtinen, 2002; Mack et al., 2012). Extensive treatment often causes pain and suffering without offering much benefit (Earle et al., 2008; Matsuyama, Reddy, & Smith, 2006). What is worse is that such aggressive care may not be consistent with dying persons' treatment preferences (Covinsky et al., 2000; Lynn & Goldstein, 2003; Mack, Weeks, Wright, Block, & Prigerson, 2010). Therefore, completing end-of-life planning and having one's preferences known is a way to avoid receiving unnecessary or unwanted treatment (Lynn & Goldstein, 2003; Mack et al., 2010). In contrast, terminally-ill patients who have completed end-of-life planning are more likely to die at home and receive hospice care, which offers quality of life during individuals' final days (Mack et al., 2012; Nicholas, Langa, Iwashyna, & Weir, 2011; Teno et al., 2007).

Reduction of Care Expenses

Medical expenditures for the last year of life among persons aged 65 or older are far more expensive than those for non-terminal years. Expenses for the last year of life account for 22% of all medical, 26% of Medicare, 18% of all non-Medicare, and 25% of Medicaid expenditures (Hoover, Crystal, Kumar, Sambamoorthi, & Cantor, 2002). The completion of end-of-life planning is associated with lower health care costs in terminally-ill patients' final days of life (Gade et al., 2008; Zhang et al., 2009). This is because those who have such planning are less likely to wish for costly, intensive interventions and more likely to receive palliative care (Gade et al., 2008; Zhang et al., 2009). Especially, when a person's end-of-life planning specifies limited care, Medicare spending is significantly lower (Nicholas et al., 2011). In addition, a study with 627 advanced cancer patients has reported that high health care costs were not associated with better survival outcomes, and higher health care costs were actually associated with worse quality of life (Zhang et al., 2009). Smith and Hillner (2011) point out that the lack of discussions on end-of-life care precipitates the rising cost of cancer treatment in the terminal care settings because dying patients are not aware of treatment choices. From a standpoint of preventing rising health care costs and avoiding unnecessary or unwanted medical treatment in end-of-life care, it is important to complete advance care planning.

Concerns over Advance Directives

Despite the documented favorable outcomes of end-of-life planning, there are some concerns over the effectiveness of advance directives addressed by bioethicists and researchers who question their usefulness. Their concerns can be broadly divided into

three groups: accessibility of completed advance directives at the time of decision-making, effectiveness of advance directives in increasing surrogates' knowledge of a dying person's preferences, and levels of health literacy advance directives require. Some studies have investigated reasons that advance directives are not initiated and found that they are often inaccessible when needed (Douglas & Brown, 2002; Morrison, Olson, Mertz, & Meier, 1995). Douglas and Brown (2002) found that only 31% of patients who completed advance directives had them on their medical charts.

Surrogate decision-makers' lack of knowledge of a dying person's treatment preferences has also been reported (Fagerlin & Schneider, 2004; Moorman & Carr, 2008; Shalowitz, Garrett-Meyer, & Wendler, 2006). A study examining 2,750 couples from the Wisconsin Longitudinal Study found that having been appointed as a DPAHC by a dying person or keeping the dying person's living will does not improve surrogates' knowledge (Moorman & Carr, 2008). There is only one study that found the effectiveness of surrogates' involvement in multiple types of end-of-life planning in increasing their knowledge (Inoue & Moorman, forthcoming). The majority of prior research, however, has failed to find the evidence that supports the idea that advance directives will improve surrogates' ability to make substitute judgments (Fagerlin & Schneider, 2004; Shalowitz et al., 2006).

The last concern involves persons' health literacy that is required to execute advance directives (Fagerlin & Schneider, 2004). Fagerlin and Schneider (2004) argue that it is very difficult for people to know what they would want for their end-of-life care. They further point out that people do not know enough about illnesses and treatment options in order to specify their preferences for unspecifiable future situations.

Focus on the Older Adult Population

This study population is older adults. Because the meanings of and attitudes toward death vary among different age groups, it is important to study age groups separately in relation to end-of-life planning. Death occurs more frequently among older adults, although death certainly occurs in all age groups; the death rate in the U.S. in 2010 for people aged 25-29 was 96.0 per 100,000 as compared to 1,527.6 for people aged 65-69 (Murphy, Xu, & Kochanek, 2013). In addition, socioemotional selectivity theory, a life span theory of motivation, suggests that one's subjective sense of remaining time in life influences one's motivation and goal setting (Carstensen, 2006). Consequently, older people are more likely than younger people to be in a position to contemplate their own end-of-life contingencies because they recognize that they are approaching death (Cicirelli, 2001). Therefore, having an end-of-life plan is particularly important for those older adults who are approaching the end-of-life stage in which they can meaningfully conclude their lives, especially when a variety of treatment choices are available with medical advancement.

Specific Aims and Significance of the Study

This study will add to previous research and advance knowledge in two important ways. First, the study aims to examine both sociodemographic and psychosocial factors that enhance or impede the completion of end-of-life planning by using a nationally representative sample of Americans over the age of 50, the HRS data. Second, the study aims to analyze the consistency between the content of living wills and the actual care that the deceased received, which has been underdocumented. By investigating the issue

of end-of-life planning from its completion to actual receipt of care, the end-of-life planning process can be examined in a more comprehensive manner.

This study can contribute to the lives of older adults and their families as well as our knowledge of end-of-life planning. With advances in medicine and technology, there are more choices available for terminally-ill people in terms of what type of treatment they would like to receive and how they would like to spend the final days of their lives. With careful planning, people can have control over the care they receive. The study findings will inform the goals of interventions in practice as well as policy implications surrounding end-of-life planning.

Research Questions

This study was guided by two primary research questions and 12 related hypotheses. The research questions are outlined below. The related hypotheses are outlined in Chapter II, following a review of the existing literature related to the study variables.

The first research question was guided by this study's focus on identifying factors that could enhance or impede the completion of end-of-life planning. Identification of such factors will inform us of how to promote end-of-life planning and with whom to intervene. For example, if people with certain characteristics are less likely to complete end-of-life planning, special approaches may be needed to these people. Therefore, the first research question is as follows:

- (1) What are the sociodemographic and psychosocial factors that enhance or impede the completion of end-of-life care planning?

The second research question was guided by this study's focus on identifying whether treatment preferences that are specified in living wills are associated with the actual dying experience and treatment choices. Examination of the association between the contents of living wills and the actual end-of-life treatment experience inform us whether the completion of end-of-life planning has an influence on the treatment that a person receives. For example, if a person wishes for comfort care only, then the person should not suffer from excessive pain. If the content of living wills does not influence the actual treatment, the completion of such planning will be meaningless; thus people will not be motivated to engage in end-of-life planning. Therefore, the second research question is as follows:

- (2) How consistent is the content of living wills and the person's actual dying experience?

Chapter II. Literature Review

Theoretical Framework: Expectancy Theory

This study is guided by expectancy theory, which explains the concept of motivation and action. According to expectancy theory, individuals choose a specific behavior or performance that they believe will lead to a desired outcome (Porter & Lawler, 1968; Vroom, 1964). Vroom (1964) introduced three components of the theory: *expectancy*, *instrumentality*, and *valence*. These three components influence an individual's motivation force, which directs a person to take a particular course of action. Expectancy theory can be presented using the formula as follows:

$$\text{Motivation Force} = \text{Expectancy} \times \text{Instrumentality} \times \text{Valence}$$

Expectancy

Expectancy refers to the degree to which one believes a particular behavior is achievable (Vroom, 1964). It is the perceived probability that a certain effort will lead to the intended performance. Conditions that affect the individual's *expectancy* perception include whether a person has support from others, materials, equipment, skills, and information, as well as whether a person has previous experience that reinforces his or her perception regarding the achievability of a certain behavior (Swenson, n.d.). If the person is resourceful in terms of taking a certain course of action, he or she is more likely to perceive that a particular behavior is attainable. In addition to these conditions, the individual's level of perceived control can also affect the *expectancy* perception (Scholl, 2002). According to Rodin (1986), "sense of control" is the degree to which individuals feel able to influence their behavior and are responsible for the consequences of it.

Therefore, individuals who believe that they have some degree of control over their behavior or performance have higher levels of *expectancy*.

Instrumentality

Instrumentality is the level of one's belief that a particular behavior will result in a desired outcome (Vroom, 1964). The *instrumentality* perception can be affected by the level of trust toward the system in which a particular behavior is linked to a desired outcome (Scholl, 2002). If a person trusts the connection between a certain behavior and outcome, he or she is more likely to be motivated to choose that behavior. Similarly, if there are policies that link desired outcomes to a certain behavior, *instrumentality* is increased. Therefore, *instrumentality* is high when a person sees a clear path between a certain performance and a desired goal.

Valence

Valence is described as the extent to which one finds the expected outcome valuable or attractive (Vroom, 1964). The *valence* perception can be affected by an individual's value system because each person has different value levels that are associated with specific outcomes (Scholl, 2002). For a person who values the outcome of the behavior or who is in great need of such an outcome, *valence* is high. Therefore, the person is more likely to take a certain course of action that leads him or her to the desired outcome.

Motivation Force

An individual's motivation force, directing a specific behavior, is determined by the combination of expectancy, instrumentality, and valence (Vroom, 1964). Individuals

will choose a specific behavior that has the greatest motivational force among behavioral options.

Application of Theory to End-of-Life Planning

Expectancy theory is one of the most widely accepted motivation theories and is frequently used to explain people's behavioral intentions (Liao, Liu, & Pi, 2011).

Although previous studies have not used this theory to examine end-of-life planning, the theory can provide an insightful framework on this matter by explaining what motivates people to have an end-of-life conversation or to document advance directives. When applying expectancy theory to end-of-life planning, *expectancy* indicates whether a person thinks having an informal end-of-life discussion or completing advance directives is achievable. As the theory explains, one's skills, resources, competencies, and past experiences influence one's perception toward attainability of end-of-life care planning.

Instrumentality measures the strength of association between end-of-life planning and actual end-of-life care, or decisions that happen during the final stage of life. In order for a person to have high instrumentality, the person needs to see the clear connection between end-of-life care preferences that are specified in plans and the actual treatment or dying experience. *Valence* refers to how much value the individual places on having control over one's end-of-life care by completing advance directives. This study focuses on *expectancy* and *instrumentality* components of the theory. The first research question is guided by the *expectancy* component, investigating an individual's sociodemographic and psychosocial factors that are associated with the completion of end-of-life planning.

The second research question is guided by the *instrumentality* component, examining the association between the content of living wills and the actual dying experience. Due to the unavailability of variables that can measure one's *valence*, this study assesses the first two components. Figure 1 represents the application of the theory to end-of-life planning.

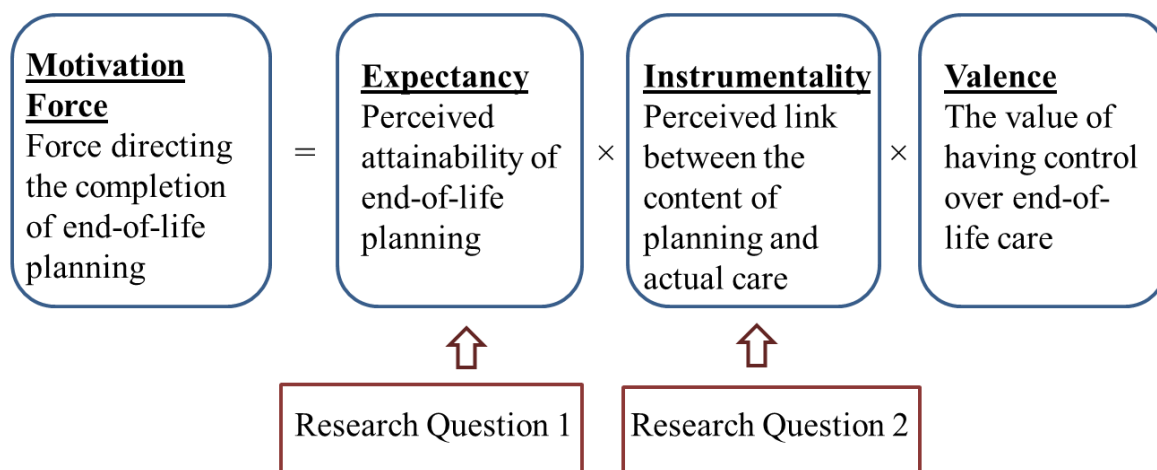


Figure 1. Application of Expectancy Theory to End-of-Life Planning.

Previous Studies

A review of existing literature provides a summary of current knowledge on end-of-life care planning and its implementation. The literature review shows the relevance of this study's research questions and how these research questions have built upon previous research. Implementation of the Patient Self-Determination Act in 1990 and its effects on the completion rates of end-of-life care planning are presented in the first section. The second section examines the literature on the effects of sociodemographic characteristics on the completion of end-of-life planning. The third section focuses on

psychosocial factors that have been examined in relation to such planning. The fourth section discusses the relationship between health conditions and end-of-life planning. The last section introduces current knowledge on the relationship between advance care planning and actual care.

Patient Self-Determination Act & the Prevalence of End-of-Life Planning

In an attempt to encourage citizens to plan their end-of-life care to protect their autonomy, Congress passed the Patient Self-Determination Act (PSDA) in 1990. Under the PSDA, all Medicare and Medicaid funded facilities, such as hospitals, nursing homes, hospice agencies, home health agencies, and HMOs, are required to provide patients with written information on advance directives, living wills and DPAHC, at the time of enrollment (Baker, 2002). Research findings indicate that the PSDA seems to have been successful at increasing public awareness and the use of advanced care planning, particularly among certain high-risk populations, such as older adults and persons in declining health (Resnick, Schuur, Heineman, Stone, & Weissman, 2009). This is because mandating that Medicare and Medicaid funded facilities to provide their service users with information on advance directives has contributed to the higher prevalence rates of end-of-life planning among such service users, compared to the general population.

Bradley, Wetle, and Horwitz (1998) examined the prevalence of advance directives among nursing home residents before and after the enactment of the PSDA. They found a significant increase in documentation of advance directives from 4.7% in 1990 before PSDA to 34.7% in 1994 after PSDA. A study using a nationally representative survey of US nursing home residents found that 70% of those who were

aged 65 years or older documented advance directives in 2004, which is a notable increase from 53% in 1996 (Resnick et al., 2009). Hammes, Rooney, and Gundrum (2010) examined the prevalence rates of advance directives among those who died under the care of a healthcare organization that provided a systematic end-of-life planning intervention. They found that 90% of the deceased had advance directives. In a study with 520 community-dwelling adults aged 70 or older, only 49% reported having a conversation about health care preferences, and 37% had advance directives in 1995 (Hopp, 2000). A study using a sample of 3,838 respondents who graduated from Wisconsin high schools in 1957 reported that slightly more than half of respondents had either a living will (56%) or a DPAHC (53%) in 2003-2004 (Carr & Khodyakov, 2007). In a 2007 survey of 1,195 randomly chosen Maryland residents, Pollack et al. (2010) found a higher prevalence rate of advance directive among older adults compared to younger adults. However the completion rate of advance directives among those aged 65 or older was still only 45%. In sum, the prevalence of end-of-life planning among people who receive health care services is higher than the prevalence among community dwelling, healthier populations.

Healthier older persons may believe that end-of-life planning is necessary only once they become sick (Pollack et al., 2010). However, serious illness or accidents can happen at any time. Chronic conditions can afford individuals time to plan for end-of-life care, but unexpected accidents or sudden deaths do not. In addition, completing end-of-life planning involves a series of steps that take time, such as contemplation, preparation, and action (Schickedanz et al., 2009). Thus, having end-of-life care plans in place is

important for healthier persons as well. Without having such plans, they may miss the opportunity to direct their medical care.

Sociodemographic Characteristics and End-of-Life Planning

Age. One of the variables most frequently documented to strongly predict having end-of-life care planning is a person's age. Older age is associated with higher completion rates of both end-of-life discussion and advance directives (Alano et al., 2010; Braun et al., 2001; Bravo et al., 2003; Moorman & Inoue, 2013; Pollack et al., 2010; Rosnick, & Reynolds, 2003). For example, a study examining 2,150 individuals aged 18-64 who belonged to one of 1,075 married or cohabiting heterosexual couples found that an additional one year of age was associated with a 3% increase in the odds of having an informal discussion, as well as a 4% increase in the odds of having either a living will or DPAHC (Moorman & Inoue, 2013). Another study conducting interviews with 200 hospitalized and community-dwelling older patients in New York reported an increasing completion rate of advance directives as people age (Alano et al., 2010). By age 65, 30% of participants had advance directives, but this number reached 65% by age 75 and 96% by age 85. These trends are understandable considering higher death rates among the older population compared with the younger one; thus, as people get older, they may become more aware of their approaching death, which can lead them to make plans. In addition, as people age, they may utilize health care services more frequently, which will give them an opportunity to learn about advance directives through their health care providers, by virtue of the PSDA.

Gender. Findings on gender in prior research are inconsistent. Studies conducted by Bravo et al. (2003) and Alano et al. (2010) reported significantly higher

completion rates of advance directives among women. Bravo et al. (2003) analyzed the survey data of 300 community-dwelling people in Quebec, Canada, who were 65 years of age or older and found that the odds of having advance directives for women were 74% higher than men. Similarly, by investigating 200 older patients in New York, Alano et al. (2010) found that women were 11 times more likely to have completed advance directives than men. In contrast, using a sample of 3,838 Wisconsin high school graduates, Carr and Khodyakov (2007) found that women were less likely to have completed a living will (55% of women vs. 57% of men) although they were more likely to have engaged in an informal end-of-life discussion (78% of women vs. 71% of men). Although the empirical findings on the effects of gender are inconsistent, considering that women are more likely than men to live longer (National Center for Health Statistics, 2012), women may have more opportunities to experience their partners' death or loss of their friends, which may make them think about the importance of end-of-life planning eventually. Moreover, women are more likely than men to be sick and utilize medical services (Bertakis, Azari, Helms, Callahan, & Robbins, 2000; Owens, 2008). Feeling sick or communicating with health care providers may offer more opportunities for women to learn and think about end-of-life planning.

Race. Race is a robust predictor of end-of-life care planning. The completion rates of both informal discussions and advance directives are consistently higher among Whites than African Americans (Alano et al., 2010; Braun et al., 2001; Degenholtz, Arnold, Meisei, & Lave, 2002; Eleazer et al., 1996; Hopp, 2000; Hopp & Duffy, 2000; Johnson et al., 2008; Kiely, Mitchell, Marlow, Murphy, & Morris, 2001; Kwak & Willima, 2005; Phipps et al., 2003; Pollack et al., 2010). The lower completion rates of

end-of-life planning among African Americans is consistent regardless of whether the study populations are community-dwelling older adults, institutionalized persons, or cancer patients. For example, by examining 1,195 Maryland residents, Pollack et al. (2010) found two times as many Whites as African Americans reporting having advance directives (43% vs. 23%). Hopp and Duffy (2000) interviewed family members of 540 persons who died between 1993 and 1995 and reported that Whites were significantly more likely to discuss treatment preferences and to complete advance directives than African Americans.

The number of studies that examined other racial or ethnic minority groups is smaller than the number of studies that investigated the difference between Whites and African Americans. In addition, findings on Hispanic, Asian, and Native American groups varied depending on study settings. In general, Hispanics have lower completion rates of advance directives than Whites (Eleazer et al., 1996; Kiely et al., 2001; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). Kiely and colleagues (2001) investigated nursing home residents in the states of California, Massachusetts, New York, and Ohio. They reported that Asians were less likely to have a living will than Whites and Native Americans, but they were more likely than Hispanics and Native Americans and as likely as Whites to have a surrogate decision-maker. In contrast, a study examined community-dwelling frail older adults participating in the Program for All-Inclusive Care of the Elderly (PACE) found that Asians were more likely than Whites to have recorded health care wishes (Eleazer et al., 1996).

Some reasons behind lower completion rates among racial and ethnic minority groups have been investigated and proposed. Distrust of the medical system and fear that

advance directives may be used to deny the medical treatments that they desire were found to be prevalent among African Americans (Bullock, 2006; Eleazer et al., 1996; Johnson et al., 2008; Waters, 2001). African Americans also perceive that their spiritual or religious beliefs conflict with end-of-life planning and the goals of palliative care (Johnson et al., 2008; Waters, 2001). Water (2001) conducted focus group interviews with 27 noninstitutionalized African Americans and found that they believe how they die is determined by God and that end-of-life care planning specifying no medical intervention is viewed as a form of assisted suicide.

Carrese and Rhodes (1995) found that Native Americans in the Navajo reservation consider advance directives as the discussion of negative information, which is considered as a violation of their traditional values. Bowman and Singer (2001) reported that older Chinese immigrants residing in Canada who embrace Confucianist, Buddhist, or Taoist traditions have negative views on advance directives because they consider direct reference to death as taboo. Murphy et al. (1996) also documented more negative attitudes toward advance directives among older Korean American and Mexican adults compared with their White and African American counterparts. These different perspectives and attitudes toward end-of-life planning among racial and ethnic minority groups are influential.

Income. Income has also been reported as a strong predictor for the completion of end-of-life care planning; a person with a higher income is more likely to have advance directives (Carr, 2012b; Dobalian, 2006; Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000; Moorman & Inoue, 2013; Rosnick & Reynolds, 2003). For example, Rosnick and Reynolds (2003) analyzed data from 451 healthy adults in Florida and found

that the odds of having a DPAHC for persons who had an income more than \$50,000 were 2.3 times higher than those who did not. In the same study, persons whose income was less than \$30,000 were found to be 66% less likely to have a living will than those whose income was \$30,000 or more. Similarly, a study examining a nationally representative sample of US nursing home residents reported that persons with household incomes below 400% of the Federal Poverty Level (FPL) were less likely to have a living will (Dobalian, 2006). Wissow et al. (2004) claim that it is important to provide interventions targeting people on a low-income because they may have doubt that their best interests are respected by health care providers. Using data from the Wisconsin Longitudinal Study ($n = 4,971$), Carr (2012b) found that people were more likely to complete end-of-life planning when they documented a financial will; therefore, persons with low assets were less likely to have end-of-life planning.

Education. Education is another robust predictor of end-of-life planning; higher educational attainment is also related to higher completion rates of advance directives (Alano et al., 2010; Carr & Khodyakov, 2007; Hopp, 2000; Moorman & Inoue, 2013) and informal discussions about end-of-life care (Carr & Khodyakov, 2007). A study examining 2,150 individuals aged 18-64 who belonged to one of 1,075 married or cohabiting heterosexual couples found that persons whose educational attainment was a college degree or higher were more likely to have advance directives than those who had high school level or less education (Moorman & Inoue, 2013). Another study with 3,838 Wisconsin high school graduates found that the odds of having completed an informal discussion about end-of-life planning for persons with 16 or more years of education were 31% higher than those with 12 years of education (Carr & Khodyakov, 2007).

Persons with lower educational attainment may not be aware of the importance and availability of end-of-life planning, and for them, the technical language used in advance directives may be difficult to understand (Hopp, 2000). It is suggested that additional interventions for those with limited education are needed in order to help them understand end-of-life planning (Hopp, 2000).

Marital Status. The effects of marital status on end-of-life planning are inconclusive. Hopp (2000) reported that persons who were not married but had children were more likely to have advance directives and informal discussions when compared with those who are married and have children. Moorman and Inoue (2013) examined 2,150 individuals aged 18-64 and found that the odds of having an informal discussion for cohabiting persons were 30% lower compared to married persons. Other studies reported null results regarding marital status and end-of-life planning (Bravo et al., 2003; Dobalian, 2006). Geographically constrained or relatively smaller sample sizes may have been responsible for the varied findings. Variables that have yielded inconclusive results need to be examined with a nationally representative sample.

Psychosocial Factors and End-of-Life Planning

Painful Death of a Significant Other. Compared with prior studies investigating the effects of sociodemographic characteristics on end-of-life planning, few studies have examined psychosocial factors. A study analyzing the data from the Wisconsin Longitudinal Study conducted by Carr and Khodyakov (2007) is one of those studies that examined psychosocial factors. They investigated 3,838 community-dwelling persons who graduated from Wisconsin high schools in 1957 and found that the experience of a loved one who died in pain was associated with the completion of end-of-life planning.

More specifically, those who had experienced the painful death of a significant other in the past ten years had 33% to 46% significantly higher odds of having advance directives and engaging in informal discussions than those who did not have such an experience. Carr and Khodyakov (2007) discuss that people may learn and think more about end-of-life issues when witnessing their loved one's dying. As a matter of fact, a study examining 305 noninstitutionalized adults aged 55 and older who live in New Jersey reported that 19% of those who had documented advance directives answered their significant other's death as a reason for their own end-of-life planning (Carr, 2012a).

Death Avoidance. In the same study, Carr and Khodyakov (2007) also examined the relationship between one's desire to avoid thinking about death and the completion of end-of-life planning. They found that those who avoided thinking about death were less likely to have any type of end-of-life planning. Carr and Khodyakov (2007) discussed that reducing one's fear of death by carefully targeted interventions or cognitive therapy may result in increasing one's self efficacy over end-of-life decision making.

Sense of Control. An individual's sense of control is an important psychosocial aspect that has been extensively examined as a predictor of people's health-related intentions and behavior, such as receiving medical checkups, engaging in regular exercise, limiting salt consumption, and being a non-smoker (Gale, Batty, & Deary, 2008; Lachman, & Firth, 2004; Steptoe & Wardle, 2001; Ziff, Conrad, & Lachman, 1995). A person's sense of control is a strong predictor of motivation (e.g. Skinner, 1995), and it is an important factor that affects the *expectancy* perception in expectancy theory (Scholl, 2002).

Although not many studies have used this concept when examining end-of-life planning, there is a study that examines the relationship between one's sense of control and the completion of advance directives. Rosnick and Reynolds (2003) examined 451 community-dwelling, healthy, older adults aged 60 to 84 in Florida, but they were unable to find an association between perceived control in daily life and the completion of a DPAHC or a living will. Their measure of perceived control was derived from only one item, which asked participants how much control they had over their own lives. This probably did not fully assess individuals' perceptions of their ability to choose their own behavior and the following consequences, because when measuring complex psychological constructs, a single-item question is less reliable than a multi-item scale (Churchill, 1979; Peter, 1979).

Carr and Khodyakov (2007) investigated one's beliefs that physicians rather than patients should make health care decisions. This concept is not exactly the same as one's sense of control; however, the degree to which persons want their physicians to make medical decisions for them is related to one's desire to have control over health care decisions. As they hypothesized, persons who had such beliefs were less likely to engage in end-of-life planning than those who did not have such beliefs (Carr & Khodyakov, 2007). Another study analyzing data from the Wisconsin Longitudinal Study reported the significant association between the completion advance directives and individuals' preferences of independent decision-making rather than physician decision-making (Moorman, 2012). End-of-life planning is used to realize one's wishes during the final stage of life; in other words, it is a way for a person to control one's dying process.

Therefore, sense of control is an important factor to be tested for in relation to end-of-life planning.

Religiosity. Although the number of studies that investigated the effects of religiosity is small, some studies have reported its influence on end-of-life planning (Allen et al., 2003; Bullock, 2006; Smith et al., 2008). A lower degree of religiosity has been found to be associated with having end-of-life planning. Smith et al. (2008) examined 468 patients with advanced cancer and found that patients who reported that religion was not important were 23% more likely to have advance care planning than patients reporting that religion was very important. Allen et al. (2003) reported the effects of proxy decision makers' religiosity on nursing home residents' advance care planning. They found that proxies with a greater degree of religiosity were less likely to have advance directives for their residents. A study with 143 general medicine patients in San Francisco identified barriers to completing advance care planning (Schickedanz et al., 2009). One of the barriers endorsed by the study participants was that they "preferred to leave their health in God's hands." Although its focus was not the completion of end-of-life planning, there is a study examined the effects of religious denomination on end-of-life treatment preferences (Sharp, Carr, & Macdonald, 2012). Analyzing Wisconsin Longitudinal Study data, Sharp et al. (2012) found that fundamentalist Catholics and fundamentalist Protestants were significantly more likely to prefer life-prolonging medical treatment than their nonfundamentalist counterparts.

Status of Health and End-of-Life Planning

Multiple studies have documented that a person's health status influences his or her decisions to engage in advance care planning. People often think they are too healthy

to need end-of-life plans (Pollack et al., 2010; Schickedanz et al., 2009). Therefore, persons who perceive their health status as worse are more likely to complete end-of-life planning (Douglas & Brown, 2002; Moorman & Inoue, 2013; Pollack et al., 2010). For instance, Moorman and Inoue (2013) found that persons who perceived their health status as fair or poor had 85% greater odds of having a discussion than those who perceived it as good, very good, or excellent.

If a person's poor health motivates him or her to complete end-of-life planning, duration of illness may affect the completion of advance care planning; the longer period a person perceives his or her health as poor, the higher the odds of completing end-of-life planning. Although there is no prior research supporting this hypothesis, it is reasonable to assume this based on the previous findings on the association between perceived health status and planning. Some studies also found that type of illness influences one's motivation to engage in end-of-life planning (Bradley, Zia, & Hamilton, 1996; Mansell, Kazis, Giantz, & Heeren, 1999; Mansell, Poses, Kazis, & Duefield, 2000). For example, using hypothetical scenarios, Bradley et al. (1996) found that cancer patients desired to participate in medical decisions, such as do-not-resuscitate orders. Another study found that patients with severe and chronic illnesses are more likely than those with less severe or acute illnesses to have an advance directive (Mansell et al., 1999). In addition, advance care planning is perceived as an important aspect of care in the field of oncology (Walling et al., 2008). Considering these potential influences of status of health, it is important to investigate whether and to what extent certain types of illness and duration of illness motivate persons to engage in advance care planning.

Advance Care Planning and Actual Care

As previously mentioned in Chapter I, end-of-life planning is strongly associated with hospice use and palliative care (Mack et al., 2012; Nicholas et al., 2011; Teno et al., 2007). In contrast, the absence of end-of-life planning is often related to aggressive, life-prolonging treatment in terminal care (Hinkka et al., 2002; Mack et al., 2012). Limited research, however, has looked at specific treatment requests made in advance care planning and examined whether such requests are implemented during the dying process. Using the HRS data between 2000 and 2006, Silveira et al. (2010) reported that treatment preferences that were specified in the deceased's living wills were consistent with decisions that surrogates made. What is still unknown is whether the actual treatment the deceased received and his or her dying experience corresponded to what was specified in their living wills.

Prior research has found that people's treatment preferences change as their health condition changes (Ditto, Jacobson, Smucker, Danks, & Fagerlin, 2006; Messinger-Rapport, Baum, & Smith, 2009). Therefore, a periodic review of living wills has been recommended to keep them up-to-date (Emanuel et al., 2000; Happ et al., 2002). Family members and health care providers may not respect living wills that were documented in the distant past as much as recent ones. Therefore, it is important to take the recency of living wills into consideration when examining the consistency between the content of living wills and the actual care that the deceased received. This study investigates this topic by taking into account potentially important factors, including the types of illness the deceased died from, the duration of the illness, and timing of the documentation of a living will.

Hypotheses

Based on the theoretical framework guided by expectancy theory and the review of literature, the following two research questions and the 12 related hypotheses with conceptual models are outlined below:

Research Question 1:

What are the sociodemographic and psychosocial factors that enhance or impede the completion of end-of-life care planning?

Hypothesis 1a. Older persons are more likely than younger persons to have completed an informal discussion and advance directives.

Hypothesis 1b. Women are more likely to have completed an informal discussion and advance directives than men.

Hypothesis 1c. Persons from racial/ethnic minority groups are less likely to have completed any types of end-of-life planning than Whites.

Hypothesis 1d. Persons with higher incomes are more likely to have completed any types of end-of-life planning than those with lower incomes.

Hypothesis 1e. Persons who have higher educational attainment are more likely to have completed any types of end-of-life planning than those who have limited education.

Hypothesis 1f. Married persons are more likely to have completed any types of end-of-life planning than those who are not married.

Hypothesis 1g. Persons who have experienced the death of a spouse are more likely to have completed any types of end-of-life planning than who did not.

Hypothesis 1h. Persons who have a higher sense of control are more likely to

have completed any types of end-of-life planning than who did not.

Hypothesis 1i. Persons who have a higher degree of religiosity are less likely to have completed any types of end-of-life planning than who did not.

Conceptual Model for Research Question 1

Figure 2 exhibits the conceptual model for research question 1.

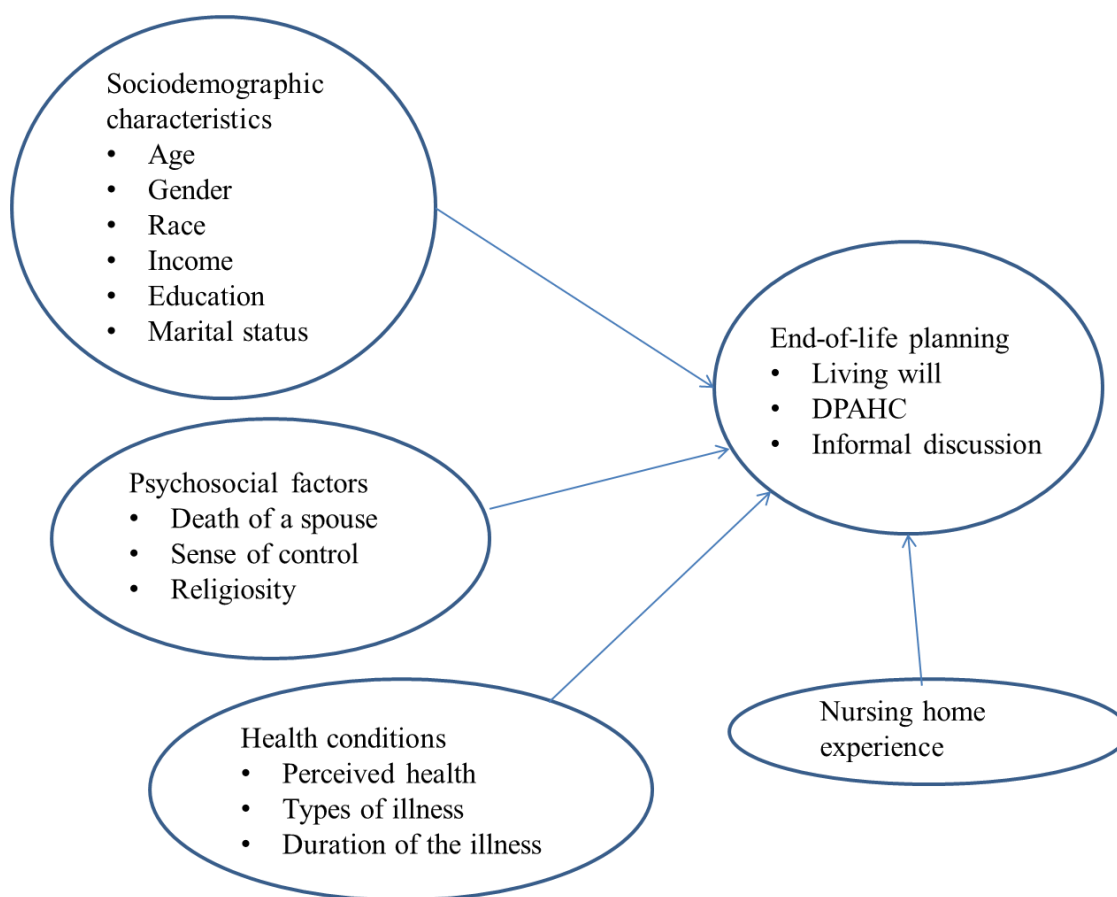


Figure 2. Conceptual Model for Research Question 1.

Research Question 2:

How consistent is the content of a living will with the person's actual dying experience?

Hypothesis 2a. Persons who requested all care possible in their living wills are more likely to receive life-prolonging treatment than those who did not.

Hypothesis 2b. Persons who requested palliative care only in their living wills are less likely to suffer from severe pain.

Hypothesis 2c. Recently documented living wills strengthen the relationship between what is requested in a living will and actual end-of-life care during the last year of the deceased's lives.

Conceptual Model for Research Question 2

Figure 3 exhibits the conceptual model for research question 2.

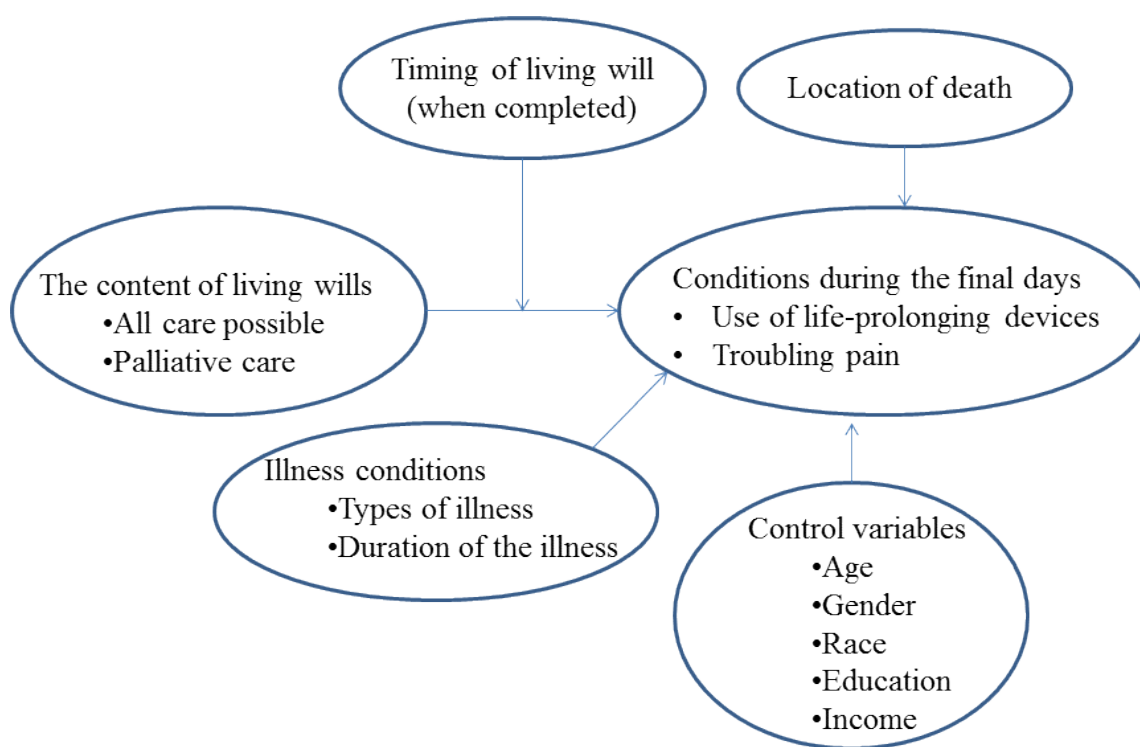


Figure 3. Conceptual Model for Research Question 2.

Chapter III. Methods

Data

This study uses data from the Health and Retirement Survey (HRS), a biennial longitudinal survey launched in 1992. The HRS is funded by National Institute on Aging and designed, administered, and conducted by the Institute for Social Research (ISR) at the University of Michigan (University of Michigan, 2012). The original HRS cohort is a nationally representative sample of individuals who were born between 1931 and 1941 ($N=12,652$) aged 51-61 at the time of the first interview in 1992. This original HRS cohort oversampled African Americans, Latinos, and residents of the state of Florida (Heeringa & Connor, 1995). The HRS added the Asset and Health Dynamics among the Oldest Old (AHEAD) cohort in 1993, a sample of individuals who were born before 1923 ($N=8,222$) and aged 70 or older at the first interview. In 1998, the original HRS and AHEAD were merged and combined with new respondents born between 1924 and 1930 (Children of the Depression Age) and between 1942 and 1947 (War Babies) to create a fully representative sample of American population over age 50 (Hauser & Willis, 2005). The HRS has low attrition rates and high response rates. For example, less than 7% of participants in the age group of 55-64 dropped out of the survey between 2002 and 2006, and a total of 88% of the respondents in this age group responded to all three waves (Banks, Muriel, & Smith, 2010).

The HRS collects a wide range of information over years, such as employment, financial status, physical and mental health status, health service use, health behaviors, living and housing arrangements, and family structures. In 2004, the HRS added a psychosocial questionnaire which evaluates respondents' psychosocial functioning in

relation to health and well-being. Therefore, the HRS data are extremely rich and complex, which allow researchers to investigate how one dimension of older adults' lives is associated with other dimensions. This study focuses on the data related to participants' sociodemographic characteristics, psychosocial aspects, health status, content of advance care planning, and conditions of death.

Sample for Research Question 1

In order to answer the first research question (What are the sociodemographic and psychosocial factors that enhance or impede the completion of end-of-life care planning?), the study uses the HRS data from Wave 6 (2002) to the most recent Wave 10 (2010). This is because the information about the deceased panel participants' end-of-life discussions and advance directives, as well as the health care they received during the final years of their lives, has been available since Wave 6. Each wave consists of information concerning those who have passed away since the previous wave. Therefore, the sample includes those who died between 2000 and 2010 ($N = 6,668$).

Many of the deceased's sociodemographic and psychosocial variables used in this study are drawn from their final personal interviews when they were still alive. Approximately 64% of participants reported for the last time within two years of their death. The variable of one's sense of control is either from the survey in 2006 or 2008. This is because the HRS began collecting respondents' psychosocial information in Wave 7 (2004) and added questions about one's sense of control in Wave 8 (2006). After a participant of the HRS has died, an exit interview is conducted with a proxy informant who was familiar with the deceased. The proxy informant is usually a widow, widower, or some other family member. Whether or not the deceased had advance directives or

informal discussions is answered by proxy. The information about the types of illness that led to a participant's death and the duration of the terminal illness are also from proxy interviews. The number of exit cases due to death has fluctuated around 1,500, and the response rate of proxy interviews has ranged between 84% and 92% (University of Michigan, 2011). Table 1 summarizes the number of proxy interviews conducted between waves.

Table 1: *The Number of Proxy Interviews Conducted Organized by the Year of Death*

Year	# of proxy interviews
W5 (2000) – W6 (2002)	1,427
W6 (2002) – W7 (2004)	1,218
W7 (2004) – W8 (2006)	1,300
W8 (2006) – W9 (2008)	1,326
W9 (2008) – W10 (2010)	1,434
Total	6,705

Sample for Research Question 2

In order to answer the second research question (How consistent is the content of living wills and the person's actual dying experience?), the study also uses the HRS data from Wave 6 (2002) to Wave 10 (2010). Most of the variables used to examine the second research question are obtained from the proxy interviews. Some variables such as education and income are obtained from the participants' final personal interviews when they were still alive. Because the second research question focuses on the content of living wills, only the deceased who had a living will at the time of death are included in the sample. Further, among those who had a living will, only the cases in which

instructions in living wills were applicable to the actual situation were included ($N = 2,158$). This applicability is determined by the proxy after a series of question regarding the content of living will. The proxy was asked the following question: “Were these instructions applicable to the actual situation?” For example, persons who died suddenly in an accident or who were found dead unexpectedly are not included in the sample because their living wills did not go into effect prior to their death. Table 2 summarizes the number of deceased who had a living will and the number of the deceased with applicable living wills.

Table 2: *The Number of Decedents Who Had a Living Will and Whose Wills Were Applicable*

Year	# of decedents with a living will	# of decedents whose living wills were applicable
W5 (2000) – W6 (2002)	500	362 (72%)
W6 (2002) – W7 (2004)	508	391 (77%)
W7 (2004) – W8 (2006)	580	446 (77%)
W8 (2006) – W9 (2008)	576	437 (76%)
W9 (2008) – W10 (2010)	667	522 (78%)
Total	2,831	2,158 (76%)

Measures for Research Question 1

Dependent Variables for RQ 1

The dependent variables for the first research question are based on proxy interviews from an exit survey. The variables are: *informal discussion* about end-of-life care, *living will*, and *DPAHC*. Whether the deceased had an informal discussion before death is assessed with the following question: “Did [the deceased] ever discuss with you or anyone else the treatment or care he/she wanted to receive in the final days of his/her life?” Whether the deceased had a living will is evaluated from the following question: “Did [the deceased] provide written instructions about the treatment or care he/she wanted to receive during the final days of his/her life?” Similarly, whether the deceased had a DPAHC is assessed with the following question: “Did [the deceased] make any legal arrangements for a specific person or persons to make decisions about his/her care or medical treatment if he/she could not make those decisions himself/herself?” Response options for these dependent variables include “yes,” “no,” “don’t know,” and “refused.” The answer “yes” is coded as 1, and “no” is coded as 0. The responses of “don’t know” and “refused” are coded as missing values. Approximately 1 to 3% of the proxy answered “don’t know” and less than 0.2% refused to answer. These three dependent measures are all binary variables.

Independent Variables for RQ 1

Sociodemographic Variables. Sociodemographic characteristics included in the analyses are *age*, *gender*, *race*, *education*, and *income*. *Age* is a continuous variable measured at death; *gender* is a dichotomous measure, which is coded 1 for *female* and 0 for *male*. *Race* is categorized into three groups: *White* (reference group), *African*

American, and *Other*. The “Other” category included respondents whose ethnicity is other than non-Hispanic White or African American, as well as respondents who reported belonging to two or more racial categories. *Income* was originally a continuous variable in dollars. It was a combined value of the following sources: income from work for pay, pension, supplemental security income (SSI), social security disability insurance (SSDI), social security income, worker’s compensation, unemployment insurance, and other government transfers, such as veteran’s benefits, welfare, and food stamps. This income variable is highly skewed in each wave with the skew statistics ranging from 5.7 to 39.0. Therefore, it is categorized into three groups, using the 25th and 75th percentiles as cut-off points: low income (\$0-\$7,788), middle income (\$7,789-\$19,823) (reference group), and high income (\$19,824 or greater). *Education* is a continuous variable measuring years of education completed. *Marital status* has four categories: *married* (reference group), *separated/divorced*, *widowed*, and *never married*. Information on income and marital status is obtained from the last wave in which the participants were still alive.

Psychosocial Variables. Psychosocial variables include *experience of a spouse’s death*, *sense of control*, and *religiosity*, and they are obtained from the last survey in which the participants were interviewed while they were alive. *Experience of a spouse’s death* in the past ten years is included as one of the psychosocial variables examined. The HRS asks respondents whether their spouse is still alive. If the answer is no, then they are asked when the spouse died. For example, a respondent is asked “Is your spouse still living?” If the respondent’s answer is no, then he/she is asked “In what month and year did he/she die?” Those who have experienced a spouse’s death in the past ten years are coded as 1, and those who have not are coded as 0.

The variable, *sense of control*, is measured by the following ten items: (1) I often feel helpless in dealing with the problems of life; (2) other people determine most of what I can and cannot do; (3) what happens in my life is often beyond my control; (4) I have little control over the things that happen to me; (5) there is really no way I can solve the problems I have; (6) I can do just about anything I really set my mind to; (7) when I really want to do something, I usually find a way to succeed at it; (8) whether or not I am able to get what I want is in my own hands; (9) what happens to me in the future mostly depends on me; and (10) I can do the things that I want to do. Response categories range from 1 (strongly agree) to 6 (strongly disagree). Negative items are re-coded so that higher values indicate higher levels of sense of control. The items 2, 3, 6, and 7 were written by Lachman and Weaver (1998a), and the remaining items were adopted from Pearlin and Schooler's (1978) mastery scale. The first five items are related to the concept of *constraints*, and the latter five items to the concept of *mastery* (Lachman & Weaver, 1998a). *Constraints* refer to "[the] extent one believes there are obstacles beyond one's control that interfere with reaching goals," and *mastery* means "one's sense of efficacy or effectiveness in carrying out goals" (Lachman & Weaver, 1998b, p. 765). Each index of *constraints* and *mastery* is created by averaging the scores across the items; therefore, the lowest value is 1, and the highest value is 6. The Cronbach alpha values for *constraints* and *mastery* ranged from 0.86 to 0.89.

Religiosity is measured by the following question: "How important would you say religion is in your life; is it very important, somewhat important, or not too important?" Respondents who answered that religion is "very important" and "somewhat important"

were coded as 1 and those who answered “not too important” were coded as 0 to create a binary variable.

Health Related Variables. Variables that are related to the deceased’s health conditions are controlled for in the analysis. Health related variables include *perceived health, types of illness, duration of illness, and experience of nursing home institutionalization*. *Perceived health* is derived from the last interview while the participants were still alive. It is assessed with the following question: “Would you say your health is excellent, very good, good, fair, or poor?” This variable is originally an ordinal variable ranging from 1 (excellent) to 5 (poor). The majority of the responses (61%) were “fair” or “poor.” Therefore, response categories of “excellent,” “very good,” and “good” are combined and coded as 1. The other categories of “fair” and “poor” are combined and coded as 0. Based on the assumption that the timing of when this variable was assessed relative to participant’s death would influence the analysis (e.g. just before the death vs. many years before the death), the time at which this variable was documented is controlled. The year in which this variable was documented is subtracted from the year of death, which creates a continuous variable that shows how many years prior to death the deceased’s perceived health status was reported. This variable, *health status reported year*, ranged 0 to 16 with a mean of 1.38 ($SD = 1.38$) and was highly skewed. Therefore, it was top-coded at 5 years.

The types of illness that lead to a person’s death and *the duration of the terminal illness* are based on the proxy interviews. *The types of illness* are assessed with the following question: “What was the major illness that led to [his/her] death? By taking illness categories that had at least 250 observations, *the types of illness* are categorized

into the following dichotomous, mutually-exclusive categories: *cancer*, *heart disease*, *respiratory disease*, *kidney disease*, *old age*, and *other* (reference group). The *other* category includes illnesses such as allergies, neurological conditions, reproductive system diseases, and endocrine diseases.

The duration of the terminal illness is evaluated with the following question:

“About how long was it between the start of the final illness and the death: was it one or two hours, less than a day, less than a week, less than a month, less than a year, or was it more than a year?” The categories of one or two hours and less than a day are combined into one group and treated as a reference group. Therefore, this variable has five categories: *less than a day* (reference group), *less than a week*, *less than a month*, *less than a year*, and *more than a year*. Each category is dummy coded.

Experience of nursing home institutionalization is also controlled because people who are institutionalized in a nursing home are supposed to be informed about advance directives under the PSDA. Persons who have been patients overnight in a nursing home (including convalescent homes and other long-term health care facilities) in the past two years are coded as 1 and those who have not are coded as 0. This variable is obtained from the last personal interview when the participants were still alive.

Measures for Research Question 2

The outcomes variables and key independent variables used to answer research question 2 are all based on proxy interviews from an exit survey.

Dependent Measures for RQ 2

Two separate outcomes are examined: *troubling pain* and *life-prolonging equipment use*. The variable of *troubled pain* is a binary variable and is derived from the question: “Was [he/she] often troubled with pain during the last year or so of life?” Yes is coded 1 and no is coded 0. *Life-prolonging equipment use* is a binary variable that is examined among the deceased who had a hospitalization experience between their last interview and their death. It is derived from the following question to proxies: “([During any of those hospital stays/During [her/his] hospital stay]) did [he/she] use life support equipment, such as a respirator?” Yes is coded 1 and no is coded 0.

Independent Measures

Key Independent Measures. Key independent variables related to the content of a living will are *all care possible* and *palliative care*. *All care possible* is derived from the question: “Did the instructions express a desire to receive all care possible under any circumstances in order to prolong life?” *Palliative care* is assessed with the question: “Did these instructions express a desire to keep him/her comfortable and pain free but to forgo extensive measures to prolong life?” These two independent variables are both binary variables: yes is coded 1 and no is coded 0.

Moderating Measures. The *recency* of a living will is a moderating variable. A proxy was asked the question: “About when were these written instructions dated (approximately)?” Based on the year that is specified by the proxy, the number of years is calculated, and it is used as a continuous variable. This variable ranged from 0 to 49 years and is skewed ($M = 5.5$, $SD = 6.3$); therefore, it is top-coded at 10.

Health Related Measures. *The types of illness and the duration of the terminal illness* are controlled for in the analyses. These variables are the same variables that are used for the first research question. *The types of illness* are assessed with the following question: “What was the major illness that led to [his/her] death? *The types of illness* are categorized into the following categories and each category is dummy-coded: *cancer, heart disease, respiratory disease, kidney disease, old age, and other* (reference group).

The duration of the terminal illness is evaluated with the following question: “About how long was it between the start of the final illness and the death?” Response categories are *one or two hours* (or no warning), *less than a day, less than a week, less than a month, less than a year, and more than a year*. The categories of *one or two hours* and *less than a day* are combined into one group since both are considered as sudden death and treated as a reference group. Each category is dummy coded.

The location of death is also controlled in the analyses. It is reasonable to assume that the available medical treatment would vary by location. For example, aggressive and intensive treatment would be more available in a hospital setting than in a home. This accessibility to certain treatment types would affect patients’ dying process. The variable of *location of death* is derived from the question: “At the time of death, was [she/he] in a hospital, in a nursing home, at home, in a hospice, or what?” Death that occurred in a hospital or nursing home is coded as 0 and used as a reference group. Because only 2% of the deaths were in assisted living or other places, these categories are combined with home and hospice and coded as 1.

Sociodemographic Control Measures. *Age, Gender, race, education, and income* are also controlled for. *Age* is a continuous variable measured at death. *Gender*

is a dichotomous measure, which is coded 1 for *female* and 0 for *male*. *Race* is categorized differently from the analyses for the first research question. For the second research question, race is divided into two categories: *White* (reference group) and *other race/ethnicity*. Therefore, the variable *race* is a binary variable. Consistent with prior research, the majority of the deceased who had a living will were White, consisting of 89.8% the study population. The remaining 6.6% were African Americans and 3.6% were other than White or African Americans. Because of the small representation of persons from racial minority groups who had a living will, they are combined together.

The variables of *income* and *education* are the same variables that are used for the first research question. *Income* is originally a continuous variable presented in dollar amounts. It was the combined value of the following sources: income from work for pay, pension, supplemental security income (SSI), social security disability insurance (SSDI), social security income, worker's compensation, unemployment insurance, and other government transfers, such as veteran's benefits, welfare, and food stamps. This income variable is divided into three categories and dummy coded: high income, middle income (reference group), and low income. *Education* is a continuous variable measuring years of education completed.

Analytic Strategies

Analyses begin with descriptive statistics to summarize the sample's characteristics. Frequencies and percentages are presented for categorical variables. Means and standard deviations will be assessed for continuous variables. A series of bivariate analyses, such as independent t-tests and chi-square tests, are conducted to examine the relationship between each independent variable and outcome variable. In

order to test the hypotheses, binary logistic regressions are executed, regressing each of the outcome variables (having an informal end-of-life discussion, a living will, and a DPAHC, as well as use of life-prolonging devices and troubling pain) on a set of predictor variables.

In terms of missing data, the variable of *type of illness* had the most missing observations at 538 (8.0%). Because of the unpatterned nature of missing observations and the limited amount of missing data, listwise deletion is used. Approximately 79% of the cases are complete. The variance inflation factor (VIF) values indicate that there is no problematic multicollinearity; the mean VIF for each model ranges from 1.4 to 1.8. All statistical analyses are performed using the statistical software package STATA 12.

Specific Strategies for Research Question 1

One of the independent variables, *sense of control* (*mastery* and *constraints*), is obtained from the HRS psychosocial and lifestyle questionnaire. Following the 2004 pilot study of the psychosocial and lifestyle questionnaire, the HRS administered this questionnaire and collected data from a randomly selected 50% of the panel participants in 2006 (Smith et al., 2013). The remaining 50% of the panel participants were surveyed with the same psychosocial and lifestyle questionnaire in 2008. The overall response rates were 74% and 71% in 2006 and 2008, respectively (Smith et al., 2013). Because there is no information on *sense of control* prior to 2006, and not all panel participants have values on this variable, the inclusion of *sense of control* necessitates losing a significant number of observations with listwise deletion, which is roughly 80% of the sample. Therefore, this study executes two separate logistic regression analyses for each outcome variable (*informal discussion* about end-of-life care, *living will*, and *DPAHC*) to

answer the first research question. The first logistic regression model excludes the variable of *sense of control* in order to retain as many observations as possible. The second model includes this variable in order to examine the effects of *sense of control* on the outcome variables. The sample size for the first model (without sense of control) for each outcome ranges from 5,404 to 5,453. The sample size for the second model (including sense of control) for each outcome ranges from 1,073 to 1,094.

Specific Strategies for Research Question 2

The analyses to answer the second research question only include the observations in which living wills of the deceased were applicable to the actual end-of-life treatment situation. The HRS asks proxies the following question: “Were these instructions applicable to the actual situation?” In order to include the cases that the content of living wills was relevant, those who answered “yes” to this question are included. About 77% of proxies of the deceased with a living will answered yes.

Interaction terms are created between the content of a living will (*all care possible* and *palliative care*) and the *recency* of a living will to examine the moderation effects of *recency*. After the main effects are examined, interaction terms will be included in models testing each hypothesis.

One of the outcome variables for the second research question is *life-prolonging equipment use*. As previously explained in the measurement section, this variable assesses the use of life-prolonging devices between the last interview and the death. Therefore, the analysis includes only those participants whose living wills were documented prior to the last interview ($N = 923$) in order to make sure that living wills were in place before the medical decisions.

Chapter IV: Findings for Research Question 1

Description of Sample and Univariate Analysis Results

Trends in End-of-Life Planning Over Time

As shown in Figure 4, the proportion of the deceased who had end-of-life plans has increased over time. Among participants who died between the year 2000 and 2002, only 44% had a DPAHC when they died; however, this number has reached 64% of those who died between 2008 and 2010. Likewise, the proportion of the people who died between 2000 and 2002 and had a living will was 36%. This number has gradually increased and reached 48% of the people who died between 2008 and 2010. Those who had any type of end-of-life planning, either an informal discussion, DPAHC, or living will, represented 80% of the deceased between 2008 and 2010.

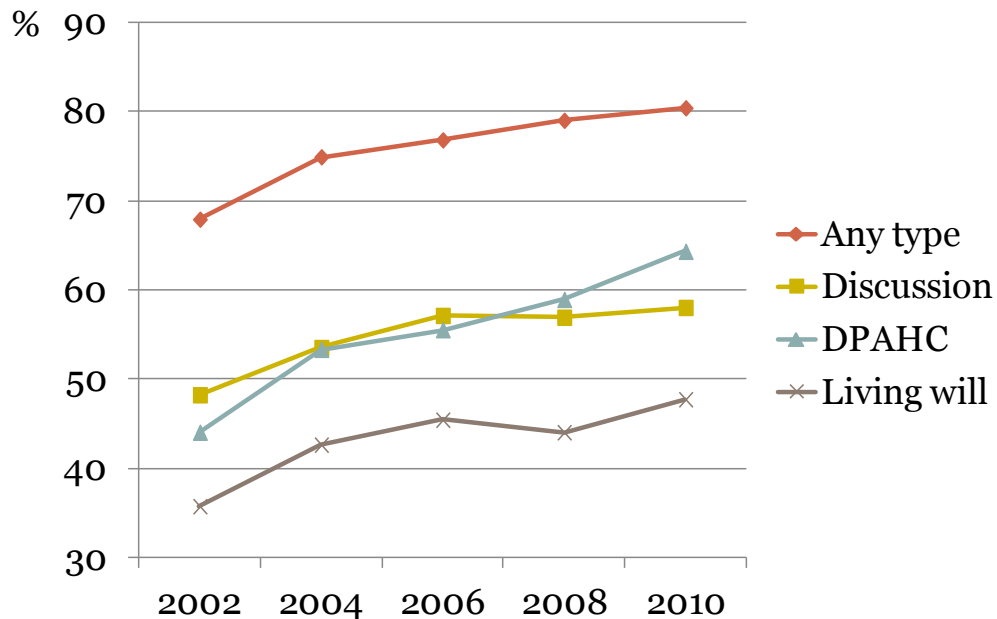


Figure 4. Trends in EOL Planning Over Time.

Sample Characteristics

End-of-Life Planning. Table 3 summarizes sample characteristics averaged across all waves. A little more than half of the deceased (54.8%) had an informal discussion before their death. Similarly, more than half (55.2%) had a designated decision maker. The completion rate for a living will is the lowest among three types of end-of-life planning; 43.1% had a living will documented when they died.

Sociodemographic characteristics. Panel participants' age at the time of death ranged from 40 to 111 years old with a mean of 80.2 ($SD = 10.6$). Slightly more than half (53.9%) were female. The majority of the deceased were White (75.5%), followed by African American (15.5%) and other race/ethnicity (9.0%). The average educational attainment was 11.1 years ($SD = 3.6$); the minimum and maximum values were 0 and 17. A quarter of the deceased fell into the low income category, with earnings ranging from \$0 to \$7,788. Income for the middle 50th percentile ranged from \$7,789 to \$19,823. The remaining 25% had incomes of \$19,824 or greater. The majority were either married (46.6%) or widowed (40.1%) followed by those separated/divorced (9.6%) and never married (3.7%).

Psychosocial characteristics. Approximately a fifth (20.8%) had the experience of losing a spouse in the past ten years. The "constraints," or perceived obstacles aspect of sense of control, ranged from 1 to 6 with a mean of 4.1 ($SD = 1.4$). Higher values are associated with lower perceived constraints, which means higher sense of control. Similarly, the "mastery" or sense of efficacy aspect ranged from 1 to 6 with a mean of 4.3 ($SD = 1.3$). Higher values are related to higher sense of control. In terms of religiosity, the majority (87.6%) of the deceased answered in the last personal interviews that religion was very important or somewhat important.

Health Related Characteristics. In the last personal interviews when the participants were still alive, a little less than two thirds (61.5%) reported their health status as fair or poor. This perceived health status was reported on average 1.3 years prior to their death ($SD = 1.1$). Two major illnesses that lead to a person's death were heart disease (38.2%) and cancer (24.0%). Those who died of respiratory disease, kidney disease, and old age, accounted for 12.5%, 4.4%, and 4.5%, respectively, while the rest (16.7%) died of other illnesses. The duration of the terminal illness varied as follows: 16.2% were ill for a day; 16.9% were ill for more than a day but less than a week; 20.1% were ill for more than a week but less than a month; 25.5% were ill for more than a month but less than a year; and 21.3% were ill for more than a year. Approximately one fourth (24.2%) had a nursing home institutionalization experience.

Table 3 *Sample Characteristics for Research Question 1 (N = 6,705)*

Variable	<i>n</i> (%)	Mean (range; <i>SD</i>)
End-of-life planning		
Informal discussion		
<i>Yes</i>	3,627 (54.8%)	
<i>No (ref)</i>	2,993 (45.2%)	
Living will		
<i>Yes</i>	2,826 (43.1%)	
<i>No (ref)</i>	3,732 (56.9%)	
DPAHC		
<i>Yes</i>	3,584 (55.2%)	
<i>No (ref)</i>	2,912 (44.8%)	
Sociodemographic variables		
Age		80.2 (40-111; 10.6)
Gender		
<i>Female</i>	3,610 (53.9%)	
<i>Male (ref)</i>	3,083 (46.1%)	
Race		
<i>White (ref)</i>	5,050 (75.5%)	

<i>African American</i>	1,035 (15.5%)	
<i>Other race/ethnicity</i>	606 (9.0%)	
Education		11.1 (0-17; 3.6)
Income		
<i>Low income</i>	1,625 (25.0%)	
<i>Middle income (ref)</i>	3,249 (50.0%)	
<i>High income</i>	1,621 (25.0%)	
Marital status		
<i>Married (ref)</i>	2,946 (46.6%)	
<i>Separated/divorced</i>	605 (9.6%)	
<i>Widowed</i>	2,539 (40.1%)	
<i>Never married</i>	235 (3.7%)	
Psychosocial variables		
Loss of spouse		
<i>Yes</i>	1,392 (20.8%)	
<i>No (ref)</i>	5,313 (79.2%)	
Sense of control		
<i>Constraints</i>		4.1 (1-6; 1.4)
<i>Mastery</i>		4.3 (1-6; 1.3)
Religiosity		
<i>High</i>	5,681 (87.6%)	
<i>Low (ref)</i>	808 (12.4%)	
Health related variables		
Perceived health		
<i>Healthy</i>	2,571 (38.5%)	
<i>Unhealthy (ref)</i>	4,109 (61.5%)	
Health reported year		1.3 (0-5; 1.1)
Types of illness		
<i>Cancer</i>	1,476 (24.0%)	
<i>Heart disease</i>	2,355 (38.2%)	
<i>Respiratory disease</i>	773 (12.5%)	
<i>Kidney disease</i>	255 (4.1%)	
<i>Old age</i>	279 (4.5%)	
<i>Other (ref)</i>	1,029 (16.7%)	
Duration of illness		
<i>Less than a day (ref)</i>	1,067 (16.2%)	
<i>Less than a week</i>	1,112 (16.9%)	
<i>Less than a month</i>	1,328 (20.1%)	

<i>Less than a year</i>	1,678 (25.5%)
<i>More than a year</i>	1,404 (21.3%)
Nursing home experience	
<i>Yes</i>	1,563 (24.2%)
<i>No (ref)</i>	4,909 (75.8%)

Bivariate Analyses

Informal Discussion

Bivariate findings on the relationship between each independent variable and the outcome variable of informal discussion are summarized in Table 4. Age was not associated with the completion of informal discussion. Gender was significantly associated with having had a discussion; women were more likely to have engaged in a discussion ($\chi^2 = 5.6, p < 0.05$). The effects of race were also apparent. Whites were more likely than non-whites to have had a discussion ($\chi^2 = 218.9, p < 0.001$). Those who had engaged in discussion had a significantly higher level of education than those who had not engaged in it ($t = -11.0, p < 0.001$). Persons with a lower income were less likely ($\chi^2 = 52.2, p < 0.001$) and a higher income were more likely ($\chi^2 = 28.1, p < 0.001$) to have had a discussion, compared with persons with moderate income. Widowed persons had a significantly higher completion rate of discussion than persons with other marital statuses, including those who were married, separated/divorced, and never married ($\chi^2 = 16.2, p < 0.001$). In contrast, persons who were never married were less likely to have had a discussion than those who were married, separated/divorced, or widowed ($\chi^2 = 10.1, p < 0.01$).

None of the psychosocial variables was associated with having had a discussion. Perceived health was not significant, either, suggesting that those who perceived their

health as excellent, very good, or good were as likely to have engaged in discussion as those who perceived their health as fair or poor. Specific illnesses were associated with having a discussion. Persons who died of cancer ($\chi^2 = 19.1, p < 0.001$) and respiratory disease ($\chi^2 = 6.0, p < 0.05$) were more likely than those who died of an “other” illness to have engaged in discussion. In contrast, persons who had a heart disease were less likely to have had a discussion ($\chi^2 = 5.6, p < 0.05$). The duration of illness was significantly related to having discussion. Persons who had more than a week but less than a month from onset of terminal illness to death were more likely than those who died within a day to have engaged in discussion ($\chi^2 = 6.2, p < 0.05$). In addition, persons who had an experience of nursing home stay were less likely to have had a discussion than those who did not have such an experience ($\chi^2 = 4.9, p < 0.05$).

Table 4 *Bivariate Analyses for Informal Discussion (N = 6,620)*

	Had discussion <i>n</i> = 3,627 (54.8%) <hr/> <i>n</i> (%) / Mean (SD)	No discussion <i>n</i> = 2,993 (45.2%) <hr/> <i>n</i> (%) / Mean (SD)	χ^2 / t
Sociodemographic variables			
Age	80.4 (10.3)	79.9 (11.0)	-1.8
Gender			
<i>Female</i>	1,997 (55.2%)	1,559 (52.2%)	6.2*
<i>Male (ref)</i>	1,622 (44.8%)	1,430 (47.8%)	
Race			
<i>White (ref)</i>	2,989 (82.6%)	2,000 (66.9%)	218.9***
<i>African American</i>	397 (11.0%)	624 (20.9%)	122.8***
<i>Other race/ethnicity</i>	231 (6.4%)	365 (12.2%)	67.7***
Education	11.6 (3.3)	10.6 (3.9)	-11.0***
Income			
<i>Low income</i>	758 (21.4%)	844 (29.3%)	52.2***
<i>Middle income (ref)</i>	1,804 (51.0%)	1,410 (48.9%)	2.8
<i>High income</i>	974 (27.6%)	628 (21.8%)	28.1***
Marital status			

<i>Married (ref)</i>	1,567 (45.8%)	1,352 (47.9%)	2.9
<i>Separated/divorced</i>	307 (9.0%)	291 (10.3%)	3.6
<i>Widowed</i>	1,448 (42.3%)	1,052 (37.3%)	16.2***
<i>Never married</i>	101 (2.9%)	126 (4.5%)	10.1**
Psychosocial variables			
Loss of spouse			
<i>Yes</i>	777 (21.4%)	599 (20.0%)	2.0
<i>No (ref)</i>	2,850 (78.6%)	2,394 (80.0%)	
Sense of control			
<i>Constraints</i>	4.2 (1.4)	4.1 (1.4)	-0.9
<i>Mastery</i>	4.3 (1.3)	4.3 (1.3)	0.7
Religiosity			
<i>High</i>	3,077 (87.1%)	2,535 (88.1%)	1.3
<i>Low (ref)</i>	456 (12.9%)	344 (11.9%)	
Health related variables			
Perceived health			
<i>Healthy</i>	1,362 (37.7%)	1,166 (39.1%)	1.4
<i>Unhealthy (ref)</i>	2,251 (62.3%)	1,816 (60.9%)	
Health reported year	1.3 (1.0)	1.3 (1.1)	-0.8
Types of illness			
<i>Cancer</i>	882 (26.1%)	578 (21.3%)	19.1***
<i>Heart disease</i>	1,243 (36.8%)	1,079 (39.7%)	5.6*
<i>Respiratory disease</i>	458 (13.6%)	311 (11.5%)	6.0*
<i>Kidney disease</i>	152 (4.5%)	99 (3.6%)	2.8
<i>Old age</i>	139 (4.1%)	136 (5.0%)	2.8
<i>Other (ref)</i>	505 (14.9%)	512 (18.9%)	16.6***
Duration of illness			
<i>Less than a day (ref)</i>	489 (13.7%)	571 (19.5%)	40.2***
<i>Less than a week</i>	610 (17.0%)	491 (16.7%)	0.1
<i>Less than a month</i>	760 (21.2%)	549 (18.7%)	6.2*
<i>Less than a year</i>	943 (26.3%)	717 (24.5%)	3.0
<i>More than a year</i>	781 (21.8%)	604 (20.6%)	1.4
Nursing home experience			
<i>Yes</i>	815 (23.1%)	731 (25.5%)	4.9*
<i>No (ref)</i>	2,713 (76.9%)	2,137 (74.5%)	

* $p < .05$, ** $p < .01$, *** $p < .001$

Living will

Table 5 presents bivariate analysis results between each independent variable and the completion of living will. Age was positively related to documentation of a living will ($t = -12.5, p < 0.001$), and females were more likely than men to have completed a living will ($\chi^2 = 23.1, p < 0.001$). The bivariate findings on race, education, and income with the completion of living will were the same as the findings with an informal discussion. Being White ($\chi^2 = 597.8, p < 0.001$), having higher educational attainment ($t = -18.7, p < 0.001$), and having a high income ($\chi^2 = 72.8, p < 0.001$) were associated with the completion of a living will. Widowed persons were more likely to have had a living will ($\chi^2 = 53.5, p < 0.001$) than those who were married, separated/divorced, or never married.

Some psychosocial variables were found to be significantly associated with having a living will. Persons who lost their spouse in the past ten years were more likely than those who did not ($\chi^2 = 14.5, p < 0.001$) and those who had high religiosity were less likely than those with low religiosity ($\chi^2 = 15.5, p < 0.001$) to have a documented living will. The same types of illness that were associated with having a discussion also were significant in their relationship with the completion of living wills in the same direction. Persons who died of cancer ($\chi^2 = 18.5, p < 0.001$) and respiratory disease ($\chi^2 = 4.9, p < 0.05$) were more likely but those who died of heart disease ($\chi^2 = 11.1, p < 0.01$) were less likely to have had a living will than those who died of an “other” illness. In terms of the duration of illness, persons who died suddenly, whose illness lasted less than a day, were less likely to have documented a living will ($\chi^2 = 59.0, p < 0.001$). When the period between illness onset and death was more than a day but less than a week ($\chi^2 = 5.5, p < 0.05$) as well as when the period was more than a year ($\chi^2 = 6.3, p < 0.05$), people were

likely to have a living will. Persons who had a nursing home stay were more likely to have documented a living will ($\chi^2 = 35.7, p < 0.001$).

Table 5 *Bivariate Analyses for Living will (N = 6,558)*

	Had living will <i>n</i> = 2,826 (43.1%) <i>n</i> (%) / Mean (SD)	No living will <i>n</i> = 3,732 (56.9%) <i>n</i> (%) / Mean (SD)	χ^2 / t
Sociodemographic variables			
Age	82.0 (9.7)	78.7 (11.1)	-12.5***
Gender			
<i>Female</i>	1,614 (57.2%)	1,907 (51.2%)	23.1***
<i>Male (ref)</i>	1,208 (42.8%)	1,817 (48.8%)	
Race			
<i>White (ref)</i>	2,552 (90.4%)	2,398 (64.2%)	597.8***
<i>African American</i>	168 (6.0%)	843 (22.6%)	342.5***
<i>Other race/ethnicity</i>	102 (3.6%)	490 (13.2%)	177.9***
Education	12.1 (3.0)	10.4 (3.8)	-18.7***
Income			
<i>Low income</i>	503 (18.2%)	1,083 (30.1%)	117.0***
<i>Middle income (ref)</i>	1,416 (51.4%)	1,759 (48.9%)	3.8
<i>High income</i>	839 (30.4%)	758 (21.0%)	72.8***
Marital status			
<i>Married (ref)</i>	1,186 (44.1%)	1,712 (49.0%)	15.0***
<i>Separated/divorced</i>	208 (7.7%)	384 (11.0%)	18.7***
<i>Widowed</i>	1,216 (45.2%)	1,257 (36.0%)	53.5***
<i>Never married</i>	81 (3.0%)	139 (4.0%)	4.2*
Psychosocial variables			
Loss of spouse			
<i>Yes</i>	648 (22.9%)	712 (19.1%)	14.5***
<i>No (ref)</i>	2,178 (77.1%)	3,020 (80.9%)	
Sense of control			
<i>Constraints</i>	4.2 (1.4)	4.1 (1.4)	-1.0
<i>Mastery</i>	4.3 (1.3)	4.2 (1.3)	-1.5
Religiosity			
<i>High</i>	2,360 (85.6%)	3,198 (88.9%)	15.5***
<i>Low (ref)</i>	396 (14.4%)	398 (11.1%)	
Health related variables			

Perceived health			
<i>Healthy</i>	1,102 (39.1%)	1,405 (37.8%)	1.2
<i>Unhealthy (ref)</i>	1,714 (60.9%)	2,313 (62.2%)	
Health reported year	1.3 (1.0)	1.3 (1.1)	-0.1
Types of illness			
<i>Cancer</i>	696 (26.7%)	751 (21.9%)	18.5***
<i>Heart disease</i>	931 (35.7%)	1,367 (39.9%)	11.1**
<i>Respiratory disease</i>	358 (13.7%)	405 (11.8%)	4.9*
<i>Kidney disease</i>	105 (4.0%)	144 (4.2%)	0.1
<i>Old age</i>	120 (4.6%)	148 (4.3%)	0.3
<i>Other (ref)</i>	400 (15.3%)	614 (17.9%)	7.1**
Duration of illness			
<i>Less than a day (ref)</i>	338 (12.1%)	705 (19.2%)	59.0***
<i>Less than a week</i>	508 (18.2%)	587 (16.0%)	5.5*
<i>Less than a month</i>	590 (21.2%)	721 (19.7%)	2.2
<i>Less than a year</i>	719 (25.8%)	916 (25.0%)	0.6
<i>More than a year</i>	632 (22.7%)	737 (20.1%)	6.3*
Nursing home stay			
<i>Yes</i>	765 (27.8%)	763 (21.3%)	35.7***
<i>No (ref)</i>	1,990 (72.2%)	2,820 (78.7%)	

* $p < .05$, ** $p < .01$, *** $p < .001$

DPAHC

Table 6 shows bivariate analysis results between each independent variable and the documentation of DPAHC. Sociodemographic and psychosocial variables that were found to be significant for a living will were also significant for a DPAHC in the same direction. Older age was associated with having a DPAHC ($t = -15.6, p < 0.001$).

Persons who were more likely to have had a DPAHC were predominantly females ($\chi^2 = 23.9, p < 0.001$). Persons who identified themselves as White ($\chi^2 = 505.6, p < 0.001$), who had a higher level of education ($t = -16.6, p < 0.001$), whose income level was high ($\chi^2 = 65.1, p < 0.001$), who were widowed ($\chi^2 = 132.8, p < 0.001$), who had experience of losing their spouse in the past ten years ($\chi^2 = 17.7, p < 0.001$), and whose religiosity was low ($\chi^2 = 20.6, p < 0.001$) were more likely to have had a DPAHC. In contrast, persons

who identified themselves as African American ($\chi^2 = 267.6, p < 0.001$) or other race/ethnicity ($\chi^2 = 171.9, p < 0.001$) were significantly less likely to have had a DPAHC compared with those who identified themselves as White. Persons whose income was low were less likely to have had a DPAHC than those with moderate or high income ($\chi^2 = 145.1, p < 0.001$). Persons who were married ($\chi^2 = 73.0, p < 0.001$), separated/divorced ($\chi^2 = 8.2, p < 0.01$), or never married ($\chi^2 = 8.4, p < 0.01$), were less likely to have had a DPAHC, compared with other marital statuses.

Some health-related variables were also found to be significantly associated with having a DPAHC. Persons who died of heart disease were less likely ($\chi^2 = 7.8, p < 0.01$) and those who died of old age were more likely ($\chi^2 = 7.2, p < 0.01$) to have had a DPAHC than those who died of other illnesses. Persons who had only less than a day between onset of their illness and death were less likely ($\chi^2 = 51.1, p < 0.001$) and those who had more than a month but less than a year were more likely to have had a DPAHC ($\chi^2 = 6.4, p < 0.05$). Persons who had a nursing home stay were more likely to have documented a DPAHC ($\chi^2 = 94.9, p < 0.001$).

Table 6 *Bivariate Analyses for DPAHC (N = 6,496)*

	Had DPAHC <i>n</i> = 3,584 (55.2%) <i>n</i> (%) / Mean (SD)	No DPAHC <i>n</i> = 2,912 (44.8%) <i>n</i> (%) / Mean (SD)	χ^2 / <i>t</i>
Sociodemographic variables			
Age	82.0 (10.0)	78.0 (10.9)	-15.6***
Gender			
<i>Female</i>	2,018 (56.4%)	1,463 (50.3%)	23.9***
<i>Male (ref)</i>	1,559 (43.6%)	1,444 (49.7%)	
Race			
<i>White (ref)</i>	3,089 (86.4%)	1,809 (62.3%)	505.6***
<i>African American</i>	316 (8.8%)	686 (23.6%)	267.6***

<i>Other race/ethnicity</i>	171 (4.8%)	411 (14.1%)	171.9***
Education	11.8 (3.2)	10.3 (3.9)	-16.6***
Income			
<i>Low income</i>	666 (19.1%)	908 (32.3%)	145.1***
<i>Middle income (ref)</i>	1,809 (51.9%)	1,335 (47.5%)	11.8**
<i>High income</i>	1,013 (29.0%)	567 (20.2%)	65.1***
Marital status			
<i>Married (ref)</i>	1,434 (42.0%)	1,439 (53.0%)	73.0***
<i>Separated/divorced</i>	293 (8.6%)	292 (10.8%)	8.2**
<i>Widowed</i>	1,582 (46.4%)	865 (31.9%)	132.8***
<i>Never married</i>	101 (3.0%)	118 (4.3%)	8.4**
Psychosocial variables			
Loss of spouse			
<i>Yes</i>	807 (22.5%)	532 (18.3%)	17.7***
<i>No (ref)</i>	2,777 (77.5%)	2,380 (81.7%)	
Sense of control			
<i>Constraints</i>	4.1 (1.4)	4.2 (1.4)	0.8
<i>Mastery</i>	4.3 (1.3)	4.4 (1.3)	1.5
Religiosity			
<i>High</i>	2,992 (85.9%)	2,518 (89.7%)	20.6***
<i>Low (ref)</i>	492 (14.1%)	290 (10.3%)	
Health related variables			
Perceived health			
<i>Healthy</i>	1,379 (38.6%)	1,096 (37.8%)	0.5
<i>Unhealthy (ref)</i>	2,192 (61.4%)	1,804 (62.2%)	
Health reported year	1.3 (1.0)	1.3 (1.1)	-1.6
Types of illness			
<i>Cancer</i>	815 (24.8%)	619 (23.0%)	2.5
<i>Heart disease</i>	1,198 (36.4%)	1,075 (39.9%)	7.8**
<i>Respiratory disease</i>	427 (13.0%)	329 (12.2%)	0.8
<i>Kidney disease</i>	140 (4.2%)	109 (4.1%)	0.2
<i>Old age</i>	170 (5.2%)	100 (3.7%)	7.2**
<i>Other (ref)</i>	541 (16.4%)	460 (17.1%)	0.4
Duration of illness			
<i>Less than a day (ref)</i>	465 (13.2%)	566 (19.8%)	51.1***
<i>Less than a week</i>	610 (17.3%)	480 (16.8%)	0.3
<i>Less than a month</i>	740 (20.9%)	548 (19.1%)	3.2
<i>Less than a year</i>	940 (26.6%)	682 (23.8%)	6.4*
<i>More than a year</i>	777 (22.0%)	586 (20.5%)	2.2

Nursing home stay			
Yes	1,007 (29.0%)	514 (18.4%)	94.9***
No (ref)	2,471 (71.0%)	2,286 (81.6%)	

* $p < .05$, ** $p < .01$, *** $p < .001$

Multivariate Analyses with the Entire Sample (without Sense of Control)

Table 7 presents the logistic regression results without including the sense of control variable. The exclusion of this variable enables the analysis to retain a substantial number of observations as previously described. This section explains how each variables is related to all three outcomes: informal discussion, living will, and DPAHC.

Sociodemographic Characteristics

Age had significant effects on the completion of advance directives, a living will and DPAHC. As a person's age at death increased by one year, the odds of having executed a living will or DPAHC increased 3% (OR = 1.03, $p < 0.001$). Women were more likely than men to have completed each of three types of end-of-life planning. Being female was associated with a 24% increase in the odds of engaging in a discussion ($p < 0.01$), a 31% increase in the odds of documenting a living will ($p < 0.001$), and a 17% increase in the odds of having a DPAHC ($p < 0.05$). Race was found to be a significant predictor of all the types of planning. Compared with Whites, African Americans were far less likely to have engaged in every type of end-of-life planning; 53% (1.00-0.47) lower odds of having a discussion (OR = 0.47, $p < 0.001$), 74% lower odds of having a living will (OR = 0.26, $p < 0.001$), and 65% lower odds of having a DPAHC (OR = 0.35, $p < 0.001$). Similarly, compared with Whites, persons whose race was other than African American had 46%, 66%, and 57% lower odds of having a

discussion (OR = 0.54, $p < 0.001$), living will (OR = 0.34, $p < 0.001$), and DPAHC (OR = 0.43, $p < 0.001$), respectively. Higher levels of education were significantly related to increased odds of having each type of end-of-life planning (range of odds ratios = 1.05 – 1.11, $p < 0.001$). Income levels were also related to having every types of planning. Compared to those whose income was moderate, the deceased with low income had 22% to 31% lower odds of having each of three types of planning. In contrast, compared to those with moderate income, the odds of having a living will and DPAHC for those with high income were 25% ($p < 0.01$) and 27% ($p < 0.01$) higher, respectively. Regarding one's marital status, compared with being married, being divorced/separated was associated with 33% higher odds of having a DPAHC ($p < 0.01$). Widowed persons were more likely than married persons to have a discussion (OR = 1.19, $p < 0.05$), a living will (OR = 1.17, $p < 0.05$), and a DPAHC (OR = 1.57, $p < 0.001$).

Psychosocial Characteristics

The experience of losing a spouse in the past ten years was not associated with any type of end-of-life planning. One's religiosity significantly predicted having a DPAHC; compared with those whose religiosity was low, persons with high religiosity were 17% less likely to have had a DPAHC (OR = 0.83, $p < 0.05$). However, a person's religiosity was not associated with either having a discussion or living will.

Health-Related Characteristics

Perceived health status when participants were still alive was found to be a significant predictor of each of three types of end-of-life planning. Better perceived health status was associated with reduced odds of having a discussion (OR = 0.79, $p < 0.001$), living will (OR = 0.86, $p < 0.05$), and DPAHC (OR = 0.81, $p < 0.01$). The longer

duration between the time at which the deceased's perceived health was reported and their death was associated with increased odds of having a discussion (OR = 1.09, $p < 0.01$), living will (OR = 1.07, $p < 0.01$), and DPAHC (OR = 1.15, $p < 0.001$). Some illness types were associated with end-of-life planning. Compared with persons with other types of illness, those who died of cancer were more likely to have had a discussion (OR = 1.40, $p < 0.001$) and living will (OR = 1.60, $p < 0.001$). Heart disease was associated with greater odds of having a discussion (OR = 1.23, $p < 0.05$), and respiratory disease was related to greater odds of having a discussion (OR = 1.42, $p < 0.01$) and living will (OR = 1.28, $p < 0.05$). Those who died of kidney disease were more likely to have had a discussion (OR = 1.63, $p < 0.01$). In terms of the duration of terminal illness, overall, longer periods were associated with the completion of every type of end-of-life planning. For example, compared with the deceased who suffered from the illness less than a day, those who suffered more than a year were more likely to have completed a discussion (OR = 1.30, $p < 0.01$), living will (OR = 1.46, $p < 0.001$), and DPAHC (OR = 1.32, $p < 0.01$). Lastly, experience of nursing home stay was associated with reduced odds of having as discussion (OR = 0.84, $p < 0.01$), but it was associated with greater odds of having a living will (OR = 1.25, $p < 0.01$) and DPAHC (OR = 1.52, $p < 0.001$).

Table 7 *Logistic Regression Analyses for End-of-Life Planning (excluding sense of control)*

	Discussion ($n = 5,453$)	Living will ($n = 5,404$)	DPAHC ($n = 5,354$)
	Odds ratio (95% CI)	Odds ratio (95% CI)	Odds ratio (95% CI)
Sociodemographic variables			
Age	1.00	1.03***	1.03***

	(0.99-1.01)	(1.02-1.03)	(1.02-1.03)
Female	1.24**	1.31***	1.17*
	(1.09-1.42)	(1.14-1.51)	(1.02-1.34)
African American ^a	0.47***	0.26***	0.35***
	(0.40-0.55)	(0.21-0.31)	(0.29-0.41)
Other race/ethnicity ^a	0.54***	0.34***	0.43***
	(0.44-0.67)	(0.26-0.44)	(0.35-0.54)
Education (years)	1.05***	1.11***	1.09***
	(1.03-1.07)	(1.09-1.13)	(1.07-1.11)
Low income ^b	0.78**	0.77**	0.69***
	(0.68-0.90)	(0.66-0.90)	(0.60-0.81)
High income ^b	1.07	1.25**	1.27**
	(0.93-1.24)	(1.08-1.45)	(1.09-1.48)
Separated/divorced ^c	1.02	1.06	1.33**
	(0.83-1.24)	(0.85-1.32)	(1.07-1.64)
Widowed ^c	1.19*	1.17*	1.57***
	(1.03-1.38)	(1.01-1.36)	(1.35-1.83)
Never married ^c	0.84	1.06	1.13
	(0.61-1.15)	(0.75-1.50)	(0.80-1.57)
Psychosocial variables			
Loss of spouse	0.98	1.05	1.09
	(0.85-1.13)	(0.91-1.22)	(0.94-1.27)
Religiosity	0.96	0.88	0.83*
	(0.81-1.14)	(0.73-1.05)	(0.68-0.99)
Health related variables			
Healthy at last report	0.79***	0.86*	0.81**
	(0.70-0.89)	(0.76-0.97)	(0.72-0.92)
Health reported year	1.09**	1.07*	1.15***
	(1.03-1.16)	(1.01-1.14)	(1.08-1.23)
Cancer ^d	1.40***	1.60***	1.21
	(1.16-1.68)	(1.32-1.94)	(0.99-1.47)
Heart disease ^d	1.23*	1.05	0.97
	(1.04-1.45)	(0.88-1.25)	(0.82-1.16)
Respiratory disease ^d	1.42**	1.28*	1.03
	(1.15-1.74)	(1.03-1.59)	(0.82-1.27)
Kidney disease ^d	1.63**	1.24	1.22
	(1.19-2.21)	(0.90-1.72)	(0.88-1.69)

Old age ^d	0.99 (0.73-1.33)	0.92 (0.67-1.27)	0.98 (0.71-1.37)
Less than a week ^e	1.30** (1.07-1.57)	1.55*** (1.26-1.91)	1.21 (0.99-1.49)
Less than a month ^e	1.45*** (1.20-1.75)	1.38** (1.12-1.69)	1.20 (0.98-1.47)
Less than a year ^e	1.35** (1.12-1.62)	1.37** (1.12-1.67)	1.43*** (1.17-1.74)
More than a year ^e	1.30** (1.08-1.58)	1.46*** (1.19-1.80)	1.32** (1.08-1.62)
Nursing home stay	0.84* (0.73-0.96)	1.25** (1.08-1.45)	1.52*** (1.30-1.77)
χ^2 (df)	329.64 (24)***	889.26 (24)***	845.21 (24)***
Pseudo R ²	0.04	0.12	0.12

^a White is the reference category. ^b Moderate income is the reference category. ^c Married is the reference category. ^d Other illnesses are the reference category. ^e Death less than a day is the reference category.

* $p < .05$, ** $p < .01$, *** $p < .001$

Multivariate Analyses with Sub-Sample (with Sense of Control)

Table 8 summarizes the logistic regression results which included the sense of control variable. The inclusion of this variable necessitated omitting a large number of observations; however, the sample size for each model was still slightly over 1,000 observations.

Sociodemographic Characteristics

In this model, older age was associated with increased odds of having a discussion (OR = 1.02, $p < 0.05$) in addition to living will (OR = 1.03, $p < 0.001$) and DPAHC (OR = 1.04, $p < 0.001$). Gender was a significant predictor for having a discussion and living will, but not for a DPAHC; women were more likely than men to have had a discussion (OR = 1.67, $p < 0.01$) and living will (OR = 1.76, $p < 0.01$). Race and education stayed as significant predictors for each outcome in the same direction from the previous model.

The only difference was that being other race/ethnicity did not predict the odds of having a DPAHC in this model. In terms of income, the only significant relationship was found between having high income and the documentation of a living will; compared with persons with moderate income, those high income were more likely to have completed a living will ($OR = 1.49, p < 0.05$). Regarding the effects of marital status, widowed persons had higher odds of having a DPAHC compared with married persons ($OR = 1.47, p < 0.05$). However, widowhood did not significantly predict other types of planning, and other marital statuses were not associated with any type of planning.

Psychosocial Characteristics

One's experience of losing a spouse and religiosity were not significantly related to any type of planning. The mastery aspect of sense of control was the only significant predictor; higher levels of mastery were associated with greater odds of the completion of a living will ($OR = 1.14, p < 0.05$), but were not associated with either having a discussion or DPAHC.

Health-Related Characteristics

Better perceived health was associated with reduced odds of having a discussion ($OR = 0.75, p < 0.05$), but it was not associated with having a living will or DPAHC. The odds of having a discussion was 64% and 77% higher when persons died of cancer ($OR = 1.64, p < 0.05$) or respiratory disease ($OR = 1.77, p < 0.05$) than those who died of other types of illness. None of the types of illness predicted the completion of a living will or DPAHC. The longer period of time the deceased suffer between onset of illness and death was associated with greater odds of having planning. For example, those who had a more than a week and less than a month until death were more likely to have had a

discussion than those who died within a day ($OR = 1.63, p < 0.05$). In similar fashion, persons who suffered more than a year were more likely to have had a living will ($OR = 1.58, p < 0.05$) and DPAHC ($OR = 1.62, p < 0.05$) than those who suddenly died within a day. One's experience of nursing home stay only predicted the documentation of a DPAHC; those who had experience of nursing home stay were more likely than those who did not to have had a DPAHC ($OR = 1.81, p < 0.05$).

Table 8 *Logistic Regression Analyses for End-of-Life Planning (including sense-of-control)*

	Discussion ($n = 1,094$)	Living will ($n = 1,086$)	DPAHC ($n = 1,073$)
	Odds ratio (95% CI)	Odds ratio (95% CI)	Odds ratio (95% CI)
Sociodemographic variables			
Age	1.02* (1.01-1.03)	1.03*** (1.02-1.05)	1.04*** (1.02-1.06)
Female	1.67** (1.23-2.26)	1.76*** (1.29-2.41)	1.18 (0.86-1.64)
African American ^a	0.50** (0.34-0.74)	0.33*** (0.21-0.51)	0.39*** (0.26-0.59)
Other race/ethnicity ^a	0.50** (0.30-0.83)	0.26*** (0.14-0.48)	0.65 (0.39-1.10)
Education (years)	1.06** (1.02-1.11)	1.08** (1.03-1.13)	1.15*** (1.09-1.20)
Low income ^b	0.84 (0.58-1.22)	0.89 (0.60-1.31)	1.01 (0.69-1.49)
High income ^b	1.11 (0.80-1.53)	1.49* (1.07-2.06)	1.39 (0.98-1.98)
Separated/divorced ^c	1.03 (0.65-1.64)	1.16 (0.72-1.86)	1.43 (0.89-2.33)
Widowed ^c	0.90 (0.64-1.27)	0.92 (0.65-1.31)	1.47* (1.01-2.14)
Never married ^c	0.59 (0.27-1.27)	0.90 (0.39-2.06)	1.21 (0.54-2.68)

Psychosocial variables			
Loss of spouse	0.94 (0.64-1.36)	1.00 (0.69-1.44)	1.34 (0.88-2.05)
Sense of control			
Constraints	1.03 (0.93-1.15)	0.99 (0.89-1.10)	0.92 (0.82-1.03)
Mastery	0.98 (0.87-1.09)	1.14* (1.01-1.28)	0.97 (0.85-1.09)
Religiosity	0.95 (0.63-1.42)	0.74 (0.50-1.11)	0.70 (0.45-1.11)
Health related variables			
Healthy at last report	0.75* (0.57-0.99)	0.88 (0.67-1.17)	0.88 (0.65-1.18)
Health reported year	1.20* (1.01-1.42)	0.99 (0.83-1.18)	0.96 (0.80-1.16)
Cancer ^d	1.64* (1.06-2.53)	1.30 (0.83-2.03)	1.47 (0.92-2.33)
Heart disease ^d	1.22 (0.81-1.83)	0.99 (0.65-1.52)	0.99 (0.64-1.53)
Respiratory disease ^d	1.77* (1.05-2.99)	1.35 (0.80-2.28)	1.03 (0.60-1.78)
Kidney disease ^d	1.48 (0.73-2.99)	0.86 (0.42-1.77)	1.11 (0.53-2.35)
Old age ^d	0.86 (0.41-1.80)	0.82 (0.37-1.82)	1.46 (0.57-3.73)
Less than a week ^e	1.63* (1.06-2.52)	2.15** (1.36-3.39)	1.65* (1.03-2.64)
Less than a month ^e	1.92** (1.22-3.01)	1.68* (1.06-2.65)	1.23 (0.77-1.98)
Less than a year ^e	1.37 (0.90-2.07)	1.70* (1.10-2.64)	1.66* (1.06-2.61)
More than a year ^e	1.49 (0.97-2.31)	1.58* (1.01-2.48)	1.62* (1.07-2.58)
Nursing home stay	0.94 (0.62-1.41)	1.18 (0.78-1.77)	1.81* (1.11-2.95)
$\chi^2 (df)$	101.12 (26)***	179.80 (26)***	189.67 (26)***
Pseudo R ²	0.07	0.12	0.14

^a White is the reference category. ^b Moderate income is the reference category. ^c Married is the reference category. ^d Other illnesses are the reference category. ^e Death less than a day is the reference category.

* $p < .05$, ** $p < .01$, *** $p < .001$

Summary of Hypothesis Testing

Since the model that retains a bigger sample size has more statistical power, the results of hypothesis testing is summarized based on the results using the bigger model, which excluded one's sense of control. Only the hypothesis testing for sense of control is summarized based on the smaller model, which included one's sense of control.

Hypothesis 1a. Older persons are more likely than younger persons to have completed an informal discussion and advance directives.

Older age was associated with greater odds of having completed each of the three types of planning: an informal discussion, living will, and DPAHC.

Hypothesis 1b. Women are more likely to have completed an informal discussion and advance directives than men.

Women were more likely than men to have completed each of the three types of planning.

Hypothesis 1c. Persons from racial/ethnic minority groups are less likely to have completed any types of end-of-life planning than Whites.

Persons from racial/ethnic minority groups were less likely to have completed any types of end-of-life planning than Whites.

Hypothesis 1d. Persons with higher incomes are more likely to have completed any types of end-of-life planning than those with lower incomes.

Compared with persons with a moderate income, those who had a lower income were less likely to have completed each of the three types of planning, and those

who had a higher income were more likely to have documented a living will or DPAHC.

Hypothesis 1e. Persons who have higher educational attainment are more likely to have completed any types of end-of-life planning than those who have limited education.

The higher educational attainment was significantly associated with greater odds of having completed each of the three types of planning.

Hypothesis 1f. Married persons are more likely to have completed any types of end-of-life planning than those who are not married.

Against the hypothesis, compared with married persons, widowed persons were more likely to have completed each of the three types of planning, and separated/divorced persons were more likely to have had a DPAHC.

Hypothesis 1g. Persons who have experienced the death of a spouse are more likely to have completed any types of end-of-life planning than who did not.

Against the hypothesis, experience of losing a spouse did not predict end-of-life planning.

Hypothesis 1h. Persons who have a higher sense of control are more likely to have completed any types of end-of-life planning than who did not.

The hypothesis was partially supported: only one's mastery predicted the completion of a living will. Those with a higher mastery level were more likely to have documented a living will.

Hypothesis 1i. Persons who have a higher degree of religiosity are less likely to have completed any types of end-of-life planning than who did not.

One's religiosity predicted the documentation of a DPAHC. Those who had a higher level of religiosity were more likely to have had a DPAHC compared with those who had a lower level of religiosity.

Chapter V: Findings for Research Question 2

Description of Sample and Univariate Analysis Results

Table 9 summarizes the sample characteristics for the second research question. This sample includes the deceased participants who had a living will at the time of death and whose living will was applicable to the dying situation. Slightly more than half of the deceased suffered from troubling pain during the last year of their lives (60.2%). Approximately a quarter used life-prolonging equipment between their last interview wave and death (26.9%).

Only 5% of the deceased had expressed a desire to receive all care possible in their living wills. In contrast, 94.2% of the deceased had expressed a desire to be kept comfortable and pain free but to forgo extensive measures to prolong their lives. The recency of living will, expressed in years, ranged from 0 to 10 with a mean year of 4.2 ($SD = 3.7$). The value zero means that a living will was filed in the same year that a participant died.

Two major illnesses that lead to a person's death were heart disease (32.5%) and cancer (29.1%) followed by respiratory disease (14.5%), kidney disease (4.6%), and old age (4.5%), while the rest (14.8%) died of other illnesses. The duration of the terminal illness varied; 7.6% had less than a day from onset of illness until death; 19.0% had more than a day but less than a week; 23% had more than a week but less than a month; 27.9% had more than a month but less than a year; and 22.4% had more than a year. Approximately two thirds of deaths occurred in a hospital or nursing home (61.6%).

Age at the time of death ranged from 44 to 108 with a mean age of 82.1 ($SD = 9.6$). The majority were females (58.5%) and Whites (89.8%). Years of education

ranged from 0 to 17 ($M = 12.0$, $SD = 3.0$). Slightly less than a fifth had low income (18.4%) and a little less than a third had high income (31.1%).

Table 9 *Sample Characteristics for Research Question 2* ($N = 2,155$)

Variable	<i>n</i> (%)	Mean (range; <i>SD</i>)
Experience of death		
Troubling pain		
<i>Yes</i>	1,281 (60.2%)	
<i>No (ref)</i>	847 (39.8%)	
Life-prolonging equipment use		
<i>Yes</i>	467 (26.9%)	
<i>No (ref)</i>	1,271 (73.1%)	
Content of living will		
All care possible		
<i>Yes</i>	107 (5.0%)	
<i>No (ref)</i>	2,028 (95.0%)	
Palliative care		
<i>Yes</i>	2,003 (94.2%)	
<i>No (ref)</i>	124 (5.8%)	
Moderating variable		
Recency of living will		4.2 (0-10; 3.7)
Illness-related variables		
Types of illness		
<i>Cancer</i>	582 (29.1%)	
<i>Heart disease</i>	650 (32.5%)	
<i>Respiratory disease</i>	289 (14.5%)	
<i>Kidney disease</i>	91 (4.6%)	
<i>Old age</i>	90 (4.5%)	
<i>Other (ref)</i>	296 (14.8%)	
Duration of illness		
<i>Less than a day (ref)</i>	163 (7.6%)	
<i>Less than a week</i>	406 (19.1%)	
<i>Less than a month</i>	489 (23.0%)	
<i>Less than a year</i>	595 (27.9%)	
<i>More than a year</i>	477 (22.4%)	
Location of death		

<i>Hospital/nursing home (ref)</i>	1,328 (61.6%)	
<i>Home/hospice/assisted living</i>	827 (38.4%)	
Sociodemographic control variables		
Age		82.1 (44-108; 9.6)
Gender		
<i>Female</i>	1,259 (58.5%)	
<i>Male (ref)</i>	892 (41.5%)	
Race		
<i>White (ref)</i>	1,932 (89.8%)	
<i>Other race/ethnicity</i>	219 (10.2%)	
Education		12.0 (0-17; 3.0)
Income		
<i>Low income</i>	387 (18.4%)	
<i>Middle income (ref)</i>	1,063 (50.5%)	
<i>High income</i>	653 (31.1%)	

Bivariate Analyses

Troubling Pain

Table 10 presents the bivariate findings on the relationship between each independent variable and the outcome variable of troubling pain. One's desire to receive all care possible was not related to troubling pain, but requesting palliative care was negatively associated with having troubling pain. The deceased who requested palliative care were less likely to have had troubling pain than those who did not ($\chi^2 = 7.9, p < 0.01$). Older living wills were associated with having no troubling pain ($t = 3.2, p < 0.01$). Cancer was significantly associated with having troubling pain compared with other types illness ($\chi^2 = 10.8, p < 0.01$). On the other hand, persons who died of heart disease were less likely to have had troubling pain ($\chi^2 = 5.5, p < 0.05$). No significant relationship was found between other types of illness and troubling pain. The duration of

illness was not associated with troubling pain, but death that occurred in home or hospice was associated with having troubling pain ($\chi^2 = 7.5, p < 0.01$). All sociodemographic characteristics were significantly related to having troubling pain at the bivariate level. Older age ($t = 5.9, p < 0.001$) and higher education ($t = 3.4, p < 0.001$) were significantly associated with not having troubling pain. Whites compared with non-whites ($\chi^2 = 9.7, p < 0.01$) and persons with moderate income compared with those with low or high income ($\chi^2 = 3.9, p < 0.01$) were less likely to have had troubling pain. Women were more likely than men ($\chi^2 = 11.3, p < 0.01$) and persons with low income than persons with moderated or high income ($\chi^2 = 9.0, p < 0.01$) to have had troubling pain.

Table 10 *Bivariate Analyses for Troubling Pain (N = 2,128)*

	Had troubling pain <i>n</i> = 1,281 (60.2%) <hr/> <i>n</i> (%) / Mean (SD)	No troubling pain <i>n</i> = 847 (39.8%) <hr/> <i>n</i> (%) / Mean (SD)	χ^2 / <i>t</i>
Content of living will			
All care possible			
<i>Yes</i>	67 (5.3%)	39 (4.6%)	0.5
<i>No (ref)</i>	1,198 (94.7%)	804 (95.4%)	
Palliative care			
<i>Yes</i>	1,174 (93.0%)	805 (95.9%)	7.9**
<i>No (ref)</i>	88 (7.0%)	34 (4.1%)	
Moderating variable			
Recency of living will	4.0 (3.7)	4.5 (3.8)	3.2**
Illness-related variables			
Types of illness			
<i>Cancer</i>	385 (31.9%)	193 (25.0%)	10.8**
<i>Heart disease</i>	369 (30.6%)	275 (35.6%)	5.5*
<i>Respiratory disease</i>	162 (13.4%)	124 (16.1%)	2.7
<i>Kidney disease</i>	52 (4.3%)	37 (4.8%)	0.3
<i>Old age</i>	55 (4.6%)	35 (4.5%)	0.0

<i>Other (ref)</i>	184 (15.2%)	108 (14.0%)	0.6
Duration of illness			
<i>Less than a day (ref)</i>	85 (6.7%)	74 (8.8%)	3.2
<i>Less than a week</i>	252 (20.0%)	152 (18.1%)	1.1
<i>Less than a month</i>	284 (22.5%)	200 (23.9%)	0.5
<i>Less than a year</i>	348 (27.5%)	240 (28.6%)	0.3
<i>More than a year</i>	295 (23.3%)	173 (20.6%)	2.2
Location of death			
<i>Hospital/nursing home (ref)</i>	756 (59.0%)	550 (64.9%)	7.5**
<i>Home/hospice/assisted living</i>	525 (41.0%)	297 (35.1%)	
Sociodemographic control variables			
Age	81.1 (9.7)	83.5 (9.2)	5.9***
Gender			
<i>Female</i>	784 (61.3%)	456 (54.0%)	11.3**
<i>Male (ref)</i>	495 (38.7%)	389 (46.0%)	
Race			
<i>White (ref)</i>	1,127 (88.1%)	780 (92.3%)	9.7**
<i>Other race/ethnicity</i>	152 (11.9%)	65 (7.7%)	
Education	11.8 (3.0)	12.3 (3.0)	3.4***
Income			
<i>Low income</i>	255 (20.4%)	126 (15.2%)	9.0**
<i>Middle income (ref)</i>	608 (48.7%)	440 (53.1%)	3.9*
<i>High income</i>	385 (30.9%)	262 (31.6%)	0.1

* $p < .05$, ** $p < .01$, *** $p < .001$

Use of Life-Prolonging Equipment

Table 11 shows the bivariate analysis findings on the relationship between each independent variable and the use of life-prolonging equipment. The deceased who had expressed a desire to receive all care possible were more likely than those who did not to have used life-prolonging equipment ($\chi^2 = 6.5, p < 0.05$). Persons who died of old age ($\chi^2 = 5.5, p < 0.05$), who suffered from the terminal illness for more than a month but less than a year ($\chi^2 = 6.0, p < 0.05$), and who had more than a year until death after the onset of illness ($\chi^2 = 3.9, p < 0.05$) were less likely to have used life-prolonging equipment. In

contrast, those who died of respiratory diseases ($\chi^2 = 4.7, p < 0.05$) and who suffered from the terminal illness for more than a day but less than a week ($\chi^2 = 10.3, p < 0.01$) were more likely to have used life-prolonging equipment. Deaths that occurred in the hospital and nursing home were associated with use of such equipment ($\chi^2 = 11.8, p < 0.01$). Older persons were less likely to have used life-prolonging equipment ($t = 4.2, p < 0.001$). Gender, race, education, and income did not have a significant relationship with use of equipment.

Table 11 *Bivariate Analyses for Use of Life-Prolonging Equipment (N = 923)*

	Use of life- prolonging equipment <i>n</i> = 235 (25.5%)	No life-prolonging equipment <i>n</i> = 688 (74.5%)	
	<i>n</i> (%) / Mean (SD)	<i>n</i> (%) / Mean (SD)	χ^2 / <i>t</i>
Content of living will			
All care possible			
<i>Yes</i>	15 (6.4%)	19 (2.8%)	6.5*
<i>No (ref)</i>	219 (93.6%)	666 (97.2%)	
Palliative care			
<i>Yes</i>	217 (93.5%)	662 (96.5%)	3.8
<i>No (ref)</i>	15 (6.5%)	24 (3.5%)	
Moderating variable			
Recency of living will	6.4 (3.0)	6.5 (3.1)	0.2
Illness-related variables			
Types of illness			
<i>Cancer</i>	42 (18.8%)	140 (22.6%)	1.4
<i>Heart disease</i>	80 (35.9%)	241 (38.9%)	0.6
<i>Respiratory disease</i>	40 (17.9 %)	75 (12.1%)	4.7*
<i>Kidney disease</i>	7 (3.2%)	29 (4.7%)	0.9
<i>Old age</i>	4 (1.8%)	35 (5.6%)	5.5*
<i>Other (ref)</i>	50 (22.4%)	100 (16.1%)	4.4*
Duration of illness			
<i>Less than a day (ref)</i>	17 (7.3%)	53 (7.8%)	0.1

<i>Less than a week</i>	69 (29.8%)	133 (19.6%)	10.3**
<i>Less than a month</i>	71 (30.6%)	180 (26.5%)	1.5
<i>Less than a year</i>	39 (16.8%)	167 (24.6%)	6.0*
<i>More than a year</i>	36 (15.5%)	146 (21.5%)	3.9*
Location of death			
<i>Hospital/nursing home (ref)</i>	179 (76.2%)	440 (64.0%)	11.8**
<i>Home/hospice/assisted living</i>	56 (23.8%)	248 (36.0%)	
Sociodemographic control variables			
Age	81.6 (8.3)	84.3 (8.7)	4.2***
Gender			
<i>Female</i>	140 (59.6%)	404 (58.9%)	0.0
<i>Male (ref)</i>	95 (40.4%)	282 (41.1%)	
Race			
<i>White (ref)</i>	215 (91.5%)	648 (94.5%)	2.6
<i>Other race/ethnicity</i>	20 (8.5%)	38 (5.5%)	
Education	12.2 (3.0)	12.2 (2.9)	-0.2
Income			
<i>Low income</i>	46 (19.7%)	122 (17.9%)	0.4
<i>Middle income (ref)</i>	109 (46.6%)	335 (49.1%)	0.4
<i>High income</i>	79 (33.8%)	225 (33.0%)	0.0

* $p < .05$, ** $p < .01$, *** $p < .001$

Logistic Regression Analyses

Table 12 shows logistic regression analysis results for troubling pain and use of life-prolonging equipment. The interaction terms between the recency and the content of living wills were not significant; therefore, they were not included in the final models for parsimony. Having expressed a desire to receive palliative care was a significant predictor for troubling pain; the odds of having troubling pain for the deceased who requested palliative care were 56% lower than the odds for those who did not (OR = 0.44, $p < 0.01$). In contrast, having specified a desire to receive all care possible was not associated with the use of life-prolonging device after controlling for other variables.

Death due to old age was associated with reduced odds of having used a device (OR = 0.24, $p < 0.05$). The odds of having used life-prolonging equipment for persons who died in home/hospice/assisted living were 47% lower than those who died in the hospital or nursing home (OR = 0.53, $p < 0.01$). A one year increase in age was associated with 3% decreased odds of having troubling pain (OR = 0.97, $p < 0.001$) and 5% decreased odds of using life-prolonging devices (OR = 0.95, $p < 0.001$). The odds of having troubling pain for women were 1.48 times more compared with men (OR = 1.48, $p < 0.001$). Lastly, one year increase in education was associated with 4% decreased odds of having troubling pain (OR = 0.96, $p < 0.05$).

Table 12 *Logistic Regression Analyses for Consistency between the Content of Living Wills and Dying Experience*

	Troubling pain ($n = 1,694$)	Life-prolonging device ($n = 817$)
	Odds ratio (95% CI)	Odds ratio (95% CI)
Content of living will		
All care possible	0.93 (0.56-1.55)	1.95 (0.83-4.60)
Palliative care	0.44 (0.26-0.74)**	0.55 (0.25-1.18)
Moderating variable		
Recency of living will	0.99 (0.96-1.02)	1.01 (0.96-1.07)
Illness-related variables		
Types of illness		
Cancer ^a	1.05 (0.75-1.49)	0.73 (0.42-1.26)
Heart disease ^a	0.79 (0.58-1.10)	0.70 (0.45-1.10)
Respiratory disease ^a	0.74 (0.51-1.08)	1.19 (0.69-2.05)
Kidney disease ^a	0.72 (0.42-1.24)	0.38 (0.14-1.03)
Old age ^a	0.98 (0.56-1.71)	0.24 (0.07-0.87)*
Duration of illness		
Less than a week ^b	1.43 (0.93-2.20)	1.59 (0.80-3.16)
Less than a month ^b	1.31 (0.86-2.00)	1.23 (0.62-2.44)
Less than a year ^b	1.15 (0.76-1.76)	0.78 (0.38-1.61)

<i>More than a year^b</i>	1.19 (0.77-1.84)	0.69 (0.33-1.44)
Death in home/hospice	1.12 (0.90-1.39)	0.53 (0.36-0.78)**

Sociodemographic control variables

Age	0.97 (0.96-0.98)***	0.95 (0.93-0.97)***
Female	1.48 (1.19-1.84)***	1.32 (0.92-1.89)
Other race/ethnicity	1.03 (0.71-1.49)	1.10 (0.54-2.22)
Education (years)	0.96 (0.92-0.99)*	0.99 (0.93-1.05)
Low income ^c	1.16 (0.87-1.54)	0.99 (0.63-1.56)
High income ^c	1.13 (0.89-1.44)	1.05 (0.71-1.56)
$\chi^2 (df)$	77.11 (19)***	71.61 (19)***
Pseudo R ²	0.03	0.08

^a Other illnesses are the reference category. ^b Death less than a day is the reference category. ^c Moderate income is the reference category.

* $p < .05$, ** $p < .01$, *** $p < .001$

Summary of Hypothesis Testing

Hypothesis 2a. Persons who requested all care possible in their living wills are more likely to receive life-prolonging treatment than those who did not.

Against the hypothesis, there was no relationship found between a person's request for all care possible and the provision of life-prolonging treatment.

Hypothesis 2b. Persons who requested palliative care only in their living wills are less likely to suffer from severe pain.

The hypothesis was supported; persons who had expressed a desire to receive only palliative care were more likely to have been pain free than those who had not made such a request.

Hypothesis 2c. Recently documented living wills strengthen the relationship between what is requested in a living will and actual end-of-life care during the last year of the

deceased's lives.

Against the hypothesis, the recency of living wills did not moderate the relationship between one's content of a living will and treatment experience.

Chapter VI: Discussion

The primary aim of this study was to understand the circumstances in which end-of-life planning is enacted by investigating two important research questions: (1) What are the sociodemographic and psychosocial factors that enhance or impede the completion of end-of-life planning? (2) How consistent is the content of a living will with the person's actual dying experience? These research questions were developed and examined as an application of expectancy theory, which explains the concepts of motivation and action.

This chapter is organized in five sections. The first section focuses on findings related to the first research question. The second section addresses results related to the second research question. The third section discusses overall understanding about end-of-life planning within expectancy theory, followed by limitations in the fourth section, and finally implications of the study in the last section.

Research Question 1: Factors Associated with End-of-Life Planning

Sociodemographic Factors

A number of previous studies have examined persons' sociodemographic characteristics in relation to their completion of end-of-life planning. Few studies, however, have investigated this relationship with a nationally representative sample. Although overall results of this study regarding sociodemographic aspects have confirmed previous findings, one of this study's significant contributions to knowledge in the field of end-of-life planning is having produced results based on a generalizable sample.

A person's age, race, education, and income are robust predictors for the completion of end-of-life planning as consistent with prior research; older age, White race, and higher socioeconomic status were positively associated with the completion of any type of planning (e.g. Alano et al., 2010; Carr & Khodyakov, 2007; Moorman & Inoue, 2013; Pollack et al., 2010). The effects of age are understandable because as people age, they are more likely to experience health problems and receive information about advance care planning from medical facilities that have responsibilities to explain about advance directives under the PSDA (Baker, 2002). Older people are also more likely to experience the loss of their family members or friends. Such experiences probably afford older people opportunities to think about their death and learn about end-of-life planning.

The more alarming result is that racial minorities and those with less education are less likely to complete end-of-life planning. This has been repeatedly reported by previous studies as well. Considering end-of-life planning as an opportunity to exercise one's autonomy, this finding may suggest that a right to direct one's medical treatment is undermined among certain subpopulations. As previous research suggests, if distrust of the medical system and culturally rooted perspectives or attitudes are the reasons for the lower completion rates among racial minority groups, then delivering accurate information about end-of-life planning, including its purposes and benefits, to this population would be important. For those with limited education, the technical language used in advance directives may be difficult to understand and they may not be aware of the importance and availability of end-of-life planning (Hopp, 2000). Similarly, because of the fact that advance directives are often completed along with a financial will (Carr,

2012b), persons with low income and assets may have fewer opportunities to access end-of-life planning. Therefore, improving the accessibility and availability of end-of-life planning is critical for those with limited education and income.

Gender was found to be a strong predictor in this study; women were more likely than men to have engaged in every type of end-of-life planning. The findings on gender are consistent with the findings of the previous studies conducted by Bravo et al. (2003) and Alano et al. (2010), but not with the findings of Carr and Khodyakov (2007). The study samples for Bravo et al. (2003) and Alano et al. (2010) were at least 65 years old, including many people who were older than 75. On the other hand, the sample in the study of Carr and Khodyakov (2007) was comprised of persons aged 64 or 65. This study's population ranged from 40 to 111. Inconsistent findings on gender might be due to the effects of age or cohort. Since women live longer than men (National Center for Health Statistics, 2012), they are more likely to experience loss of their spouse and friends, which may offer them opportunities to think about planning their end-of-life care. This study examined the completion of end-of-life planning among the deceased at the time of their death unlike previous studies that examined persons who were still alive. Therefore, although some studies find higher completion rates of plans among men in relatively younger age groups, women may turn out to be more likely to have completed end-of-life planning by the time of their death.

Regarding marital status, this study found that widowed persons were more likely than married persons to have engaged in each of the three types of planning. Divorced or separated persons were more likely than married persons to have had a DPAHC. These findings are consistent with the findings from the study conducted by Hopp (2000); end-

of-life planning was more common among unmarried persons. Persons who do not have a spouse may perceive the necessity to have end-of-life planning in place while married persons may have an assumption that their spouse would know their treatment preferences (Hopp, 2000; Moorman, 2011).

Psychosocial Factors

The “mastery” aspect of one’s sense of control significantly predicted the completion of a living will; persons who had higher levels of perceived mastery were more likely to have documented a living will than those who had lower levels. The “mastery” aspect, however, was not associated with having an informal discussion or appointing a DPAHC. This may be because unlike having an informal discussion or designating someone to make decisions on one’s behalf, documenting a living will requires a lot of thought regarding what types of medical treatment one would like to have when one has certain medical conditions. Therefore, the process requires a higher level of mastery, which means higher self-efficacy in carrying out goals (Lachman & Weaver, 1998b).

One’s religiosity was found to be a significant predictor of having a DPAHC in the model that did not include sense of control (the model with larger sample size). Persons with higher levels of religiosity were less likely to have had a DPAHC than those with lower levels of religiosity. Religious persons may think that end-of-life treatment decisions need to be made by a higher power or God rather than a surrogate decision maker, as prior research has pointed out (Schickedanz et al, 2009). The experience of losing a spouse was not associated with any of the three types of planning. Carr and Khodyakov (2007) have reported that persons who witnessed their loved one dying in

pain were more likely to engage in informal discussion and complete advance directives. This study, however, did not have a measure that could assess whether a person's spouse died in pain. This lack of measurement might be the reason for the null findings of the loss of a spouse.

Other Significant Factors

Some health related variables were found to be significant in their relation to the completion of end-of-life planning. Controlling for the time since the deceased's last self-reported health was documented, one's better perceived health was associated with decreased odds of completing end-of-life planning, which confirmed previous research findings. Poor health status motivates people to engage in such planning (Pollack et al., 2010). Certain types of illness were associated with the completion of planning, such as cancer, respiratory disease, and kidney disease. This is probably due to the chronic nature of these illnesses. The symptoms and the course of chronic diseases are well known, and they offer people time to think about their dying process and end-of-life medical treatment. Not surprisingly, persons who suffered from a terminal illness for a longer period of time were more likely to have engaged in end-of-life planning in general. A prolonged illness would afford individuals time to plan for their end-of-life care.

Research Question 2: Consistency between Living wills and Dying Experience

Content of Living Will

This study investigated the degree to which one's wishes as specified in a living will influenced his or her actual dying experience, by examining the relationship between

the request for palliative care and pain as well as the relationship between the request for all care possible and the use of life-prolonging devices. The study found that persons who expressed a desire to be kept comfortable and pain-free yet forgo extensive measures to prolong their lives were significantly less likely to suffer from troubling pain during their last year of life. Thus, their wishes were respected.

On the other hand, persons' requests to receive all care possible under any circumstances in order to prolong life were not associated with the use of life-prolonging devices between the previous wave and their death. There are a couple of potential explanations for this. Of course, there is a possibility that the deceased persons' requests were not respected. Families and physicians usually agree about the dying patient's care, but they do not always know the patient's preferences (Moorman & Inoue, 2013) and sometimes have different opinions (Luce, 2010). For example, families may demand extensive care while physicians view such treatment as inappropriate or futile. In that case, even if the dying patient has expressed a desire to receive rigorous life-prolonging treatment, physicians and families discussing the course of treatment may decide to withhold life-sustaining treatment. The more common scenario may be that although the dying patients did not ask for extensive treatment, they receive extra care at the request of the family. There is also a possibility that the dying person's living will was not accessible when needed; therefore, the person's preferences for treatment were not recognized. This trouble of accessibility has been pointed out as a problem of living wills (Fagerlin & Schneider, 2004). The HRS does not have this information regarding accessibility of advance directives. Another potential reason for the null finding might be due to the proxy's perceptions toward life-prolonging devices. Whether life-support

equipment had been used was assessed by the proxy, and the HRS questions include only a respirator as an example of such equipment. Life support equipment can include various items, such as a kidney dialysis machine, infusion feeding pump, oxygen concentrator, or ventilator. Therefore, the proxy's understanding of what life-support equipment is may have influenced their answer. The recency of living wills did not have a moderating effect, indicating that the time when one's living will was documented did not influence the relationship between the content of the will and actual treatment.

Other Significant Factors

Older age was associated with reduced odds of having troubling pain and using a life-prolonging device. This may be because as people age, they become more aware of approaching death and prefer treatment that improves quality of life rather than going through aggressive treatment (Hamel et al., 2000). Physicians' attitudes may have an influence as well. Physicians tend to offer more extensive treatment to younger patients than older patients (Pang, Ho, & Lee, 2013). Other unexpected findings include the effects of gender and education on troubling pain. Women were found to be more likely than men to have had troubling pain. On the other hand, persons with a higher educational background were less likely than those without to have had troubling pain. Some previous studies report that women are more likely to experience a variety of pain than men (Keogh, 2008; Unruh, 1996). The reason for gender differences in pain has not been identified, but some researchers suggest gender role expectations (femininity and masculinity) as an explanation (Robinson et al., 2001). Robinson et al. (2001) claim that women are more socialized to express emotions of pain. The relationship between lower educational attainment and greater pain has been reported by some literature (Dionne et

al., 2001; Platts-Mills et al, 2012). There is no concrete explanation for this relationship, but persons with higher educational attainment may have better knowledge about available medical treatment and health care services, as well as better communication skills with health care providers. This may help them to manage their pain.

End-of-Life Planning and Expectancy Theory

The first research question examined factors that affect the individual's *expectancy* perception. Expectancy theory explains that influential factors include whether a person has support from others, materials, equipment, skills, and information, as well as whether a person has previous experience that reinforces his or her perception regarding the attainability of a certain behavior (Swenson, n.d.). This study identified some influential factors regarding a person's perception toward end-of-life planning. Persons who are older, who identify themselves as White, who have higher levels of income and education, and who are widowed or separated are more likely to be motivated to complete end-of-life planning. A higher level of mastery is specifically relevant to documentation of living wills. Persons with a greater level of perceived mastery may find completing a living will easier than those whose mastery level is low. On the other hand, a lower level of religiosity was specifically associated with having a DPAHC. Appointing someone as a decision maker may be easier for non-religious persons, compared with religious persons. As previous research found, religious people may think that medical decisions should be in the hands of God (Schickedanz et al., 2009). Persons who have a slowly advancing illness, such as cancer and respiratory disease, who suffer from the illness for a long period of time, and who have stayed in a nursing home may be more informed about the availability and accessibility of end-of-life planning (Resnick et

al., 2009), and as a result, completion of end-of-life planning may become easier for them.

The second research question assessed the *instrumentality* component of the theory. According to the theory, in order for people to be motivated to engage in a certain behavior, they need to see a connection between the behavior and the outcome (Vroom, 1964). Therefore, this study examined the association between treatment preferences that are specified in living wills and actual treatment experience of the deceased. There was a clear connection between a request for palliative care and less troubling pain. However, the study was not able to find an association between a request for extensive care and the use of life-prolonging equipment. This may be due to confounding factors that were not measured in this study. Using more detailed information regarding dying patients' medical conditions and treatment decision situations, this relationship between a request for extensive care and a provision of such care needs to be investigated in future research.

Limitations

Several limitations of the study should be noted. The first limitation of this study is its cross-sectional design. Although the HRS is a longitudinal study, the information about participants' end-of-life planning is collected only at the exit survey after their death. Therefore, it is impossible to assess how an individual's changes in the sociodemographic and psychosocial status influence his or her end-of-life planning over the course of their lives. The use of cross-sectional design prevents this study from establishing causal relationships among the variables of interest.

The second limitation is the reliance on proxy interview data. This study used the data collected from the HRS participants themselves while they were still alive, as well as the data from proxy interviews after the HRS participants died. In addition, it is important to be aware that proxy reports may not be as accurate as self-reports. Also, there might be difference between the deceased who had a proxy willing to report and the deceased who did not have a proxy or whose proxy refused to answer. The third limitation is a lack of some variables of interest due to the use of secondary data. Although previous research suggests that the implementation of advance directives is affected by the place where the documents are stored and whether they are accessible needed (Douglas & Brown, 2002; Morrison et al., 1995), this information was not available in the HRS data. Therefore, this study was not able to test the effects of how advance directives are kept or whether they were accessible when needed. Direct measurements or ideal questions to test the valence component of the expectancy theory were not available, either. An example of such a question is asking the HRS participants about their degree of desire to have a say about their own dying process in the form of advance directives or informal discussions with their families and physicians. Another example would be asking the degree to which they think end-of-life planning has effects on actual treatment.

Implications

Practice Implications

In order to inform healthy, working-age and retired older adults of end-of-life planning and establish easier access to such planning for them, conducting a public

educational campaign is recommended. The study findings as well as the findings from prior research present the significant relationship between one's health condition and the completion of end-of-life planning; until people become sick and suffer from an illness for a longer period of time, they are less likely to think about or plan for their end-of-life care. Therefore, community- or workplace-based public education and outreach campaigns can be effective in accessing healthier, older adult populations.

Incorporating a culturally tailored approach for racial/ethnic minorities is essential when informing them of end-of-life planning. The study results confirmed previous findings that racial minorities are significantly less likely to complete end-of-life planning. Previous studies suggest distrust of the medical system and fear that advance directives may be used to deny the desired medical treatments as reasons for the lower completion rate of such planning among African Americans (Bullock, 2006; Eleazer et al., 1996; Johnson et al., 2008; Waters, 2001). Because religion and religious institutions play important roles in African American communities, faith-based interventions may be more effective for this population (Taylor, Ellison, Chatters, Levin, & Lincoln, 2000). As a matter of fact, there is a study implementing a program that facilitates the discussion and documentation of advance directives in faith-communities, and the study found the effectiveness of faith-based interventions, including African American and Hispanic congregations (Medvene et al., 2003).

Another practice implication is to use advance directives written in language that is easy to understand. The study findings suggest that unless persons have a higher sense of mastery, they are less likely to document a living will. Furthermore, those with limited education are less likely to complete any type of planning. As Hopp (2000) suggests, the

technical language used in advance directives makes it difficult for people to complete end-of-life planning unless one has a strong educational background or a greater motivation. Thus, using an advance directive document that is easy to understand for everyone may increase accessibility to such legal documents among people with limited education or a lower sense of mastery. An example of such a document is “Five Wishes” developed by the non-profit organization, Aging with Dignity. This document meets the legal requirements for advance directives in 42 states and includes the appointment of a surrogate decision maker, the instruction of end-of-life care, and the description of spiritual and emotional needs (see Appendix).

Policy Implications

Under the proposed Patient Protection and Affordable Care Act, which was eventually enacted in 2010, Medicare would pay for end-of-life care consultations between doctors and patients during annual physical exams. However, this coverage was removed from the bill following the “death panel” controversy, which claimed that such coverage would encourage bureaucrats to determine who were worthy to live and in turn, promote euthanasia (Nyhan, 2010). However, end-of-life care is not only about less intensive care or palliative care. Persons can request rigorous treatment as well. End-of-life planning is about directing one’s medical treatment, and the conversation facilitated by physicians during a routine doctor visit is an ideal way for people to start thinking about or re-examining their end-of-life care preferences. Such planning also helps inform their physicians of their preferences. Therefore, funding this Medicare provision is strongly recommended.

Research Implications

Potentially influential variables that were not examined in this study due to the lack of information need to be investigated in future research. Such variables include one's desire to have a say about their end-of life care, which is related to the *instrumentality* component of the expectancy theory, and availability of advance directives when needed. In addition, the small representation of racial/ethnic minority populations prevents this study from examining the variation within the minority groups. Therefore, future research needs to include a larger minority population and examine the extent to which variations between racial/ethnic groups exist in relation to end-of-life planning and its implementation. Lastly, more detailed and objective information about a person's symptoms and treatment during the dying process is necessary to be included in future research in order to more fully examine the effects of having end-of-life planning on the receipt of care.

Conclusion

The importance of having end-of-life planning has been extensively discussed by researchers, policy makers, and practitioners. However, there are still concerns over the low completion rate of such planning, and family members and physicians of the dying persons often do not know what the dying persons would want for their end-of-life care. This study presented factors that influence people's motivation to engage in end-of-life planning. The findings suggest a mastery aspect of sense of control is a motivation factor. Those who are less likely to engage in planning include persons who are younger and healthier, who have lower socioeconomic status, and who are racial/ethnic minorities. Helping professionals including social workers should be aware of this fact and need to

pay special attention to this population when promoting the completion of end-of-life care planning. This study also partially identified the consistency between the content of living wills and one's dying experience. An expressed desire to be kept comfortable and pain free was associated with less pain. However, the study was not able to find a relationship between a desire to receive all care possible and the use of life-prolonging devices. Although this null finding might be due to the proxy's understandings of what the life-support devices are or the availability/accessibility of the living will at the time of death, health care providers should make sure that the dying person's preferences are known and respected. Promoting persons' right to direct their medical care is critical because autonomy is such an important ethical principle in medicine in the United States.

References

- Abbott, K. H., Sago, J. G., Breen, C. M., Abernethy, A. P., & Tulsky, J. A. (2001). Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. *Critical Care Medicine*, 29, 197-201. doi: 10.1097/00003246-200101000-00040
- Alano, G. J., Pekmezaris, R., Tai, J. Y., Hussain, M. J., Jeune, J., Louis, B., . . . Wolf-Klein, G. P. (2010). Factors influencing older adults to complete advance directives. *Palliative and Supportive Care*, 8, 267-275. doi: 10.1017/S1478951510000064
- Allen, R. S., DeLaine, S. R., Chaplin, W. F., Marson, D. C., Bourgeois, M. S., Dijkstra, K., & Burgio, L. D. (2003). Advance care planning in nursing homes: Correlates of capacity and possession of advance directives. *The Gerontologist*, 43, 309-317. doi: 10.1093/geront/43.3.309
- American Medical Association. (1998). *Opinion 2.225: optimal use of orders-not-to-intervene and advance directives*. Retrieved January 20, 2014, from <http://www.ama-assn.org//ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2225.page>.
- Annas, G. J. (2011). The health care proxy and the living will. In D. E. Meier, S. L. Isaacs, & S. R. Hughes (Eds.), *Palliative care: Transforming the care of serious illness* (pp. 167-175). San Francisco: Jossey-Bass.
- Baker, M. E. (2002). Economic, political, and ethnic influences on end-of-life decision making: A decade in review. *Journal of Health and Social Policy*, 14, 27-39. doi: 10.1300/J045v14n03_02

- Banks, J., Muriel, A., & Smith, J. P. (2010). *Attrition and health in ageing studies: Evidence from ELSA and HRS*. Retrieved February 18, 2014, from http://www.rand.org/content/dam/rand/pubs/working_papers/2010/RAND_WR784.pdf
- Bertakis, K. D., Azari, R., Helms, J., Callahan, E. J., & Robbins, J. A. (2000). Gender differences in the utilization of health care services. *The journal of Family Practice, 49*(2), 147-152.
- Bowman, K. W., & Singer, P. A. (2001). Chinese seniors' perspectives on end-of-life decisions. *Social Science & Medicine, 53*, 455-464. doi: 10.1016/S0277-9536(00)00348-8
- Bradley, E. H., Wetle, T., & Horwitz, S. M. (1998). The Patient Self-Determination Act and advance directive completion in nursing homes. *Archives of Family Medicine, 7*, 417-423. Doi: 10.1001/archfami.7.5.417
- Bradley, J. G., Zia, M. J., & Hamilton, N. (1996). Patient preferences for control in medical decision making: A scenario-based approach. *Family Medicine, 28*(7), 496-501.
- Braun, U. K., Beyth, R. J., Ford, M. E., & McCullough, L. B. (2008). Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *Journal of General Internal Medicine, 23*, 267-74. doi: 10.1007/s11606-007-0487-7
- Braun, K. L., Onaka, A. T., & Horiuchi, B. Y. (2001). Advance directives completion rates and end-of-life preferences in Hawaii. *Journal of the American Geriatrics Society, 49*, 1708-1713. doi: 10.1046/j.1532-5415.2001.49284.x

- Bravo, G., Dubois, M., & Pâquet, M. (2003). Advance directives for health care and research: Prevalence and correlates. *Alzheimer Disease and Associated Disorders*, 17(4), 215-222. doi: 10.1097/00002093-200310000-00004
- 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
- Carr, D. (2012a). "I don't want to die like that. . .": The impact of significant others' death quality on advance care planning. *The Gerontologist*, 52(6), 770-781. doi: 10.1093/geront/gns051
- Carr, D. (2012b). The social stratification of older adults' preparations for end of life health care. *Journal of Health and Social Behavior*, 53(3), 297-312. doi: 10.1177/0022146512455427
- Carr, D., & Khodyakov, D. (2007). End-of-life health care planning among young-old adults: An assessment of psychosocial influences. *Journal of Gerontology: Social Sciences*, 62B(2): 135-S141. doi: 10.1093/geronb/62.2.S135
- Carrese, J. A., & Rhodes, L. A. (1995). Western bioethics on the Navajo reservation: Benefit or harm? *Journal of the American Medical Association*, 274, 826-829. doi: 10.1001/jama.1995.03530100066036
- Carstensen, L. L. (2006). The influence of a sense of time on human development. *Science*, 312, 1913-1915. doi: 10.1126/science.1127488
- Churchill, G. A. (1979). A paradigm for developing better measures of marketing constructs. *Journal of Marketing Research*, 16(1), 64-73.

- Cicirelli, V. G. (2001). Personal meaning of death in older adults and young adults in relation to their fears of death. *Death Studies*, 25(8), 663-683. doi: 10.1080/713769896
- Colclough, Y. Y., & Young, H. M. (2007). Decision making at end of life among Japanese American families. *Journal of Family Nursing*, 13, 201-225. doi: 10.1177/1074840707300761
- Covinsky, K. E., Fuller, J. D., Yaffe, K., Johnston, C. B., Hamel, M. B., Lynn, J., . . . Phillips, R. S. (2000). Communication and decision-making in seriously ill patients: Findings of the SUPPORT project. The study to understand prognoses and preferences for outcomes and risks of treatments. *Journal of the American Geriatrics Society*, 48, S187-193.
- Curtis, J. R., Patrick, D. L., Caldwell, E. S., & Collier, A. C. (2000). Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Archives of Internal Medicine*, 160(11), 1690-1696. doi: 10.1001/archinte.160.11.1690
- Degenholtz, H. B., Arnold, R. A., Meisel, A., & Lave, J. R. (2002). Persistence of racial/ethnic disparities in advance care plan documents among nursing home residents. *Journal of the American Geriatrics Society*, 50, 378-381. doi: 10.1046/j.1532-5415.2002.50073.x
- Dionne, C. E., Korff, M. V., Koepsell, T. D., Deyo, R. A., Barlow, W. E., & Checkoway, H. (2001). Formal education and back pain: A review. *Journal of Epidemiology & Community Health*, 55, 455-468. doi: 10.1136/jech.55.7.455

Ditto, P. H., Jacobson, J. A., Smucker, W. D., Danks, J. H., & Fagerlin, A. (2006).

Context changes choices: A prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Medical Decision Making*, 26, 313-322. doi: 10.1177/0272989X06290494

Dobalian, A. (2006). Advance care planning documents in nursing facilities: Results from a nationally representative survey. *Archives of Gerontology and Geriatrics*, 43, 193-212. doi: 10.1016/j.archger.2005.10.007

Douglas, R. & Brown, H. N. (2002). Patients' attitudes toward advance directives. *Journal of Nursing Scholarship*, 34(1), 61-65. doi: 10.1111/j.1547-5069.2002.00061.x

Earle, C. C., Landrum, M. B., Souza, J. M., Neville, B. A., Weeks, J. C., & Ayanian, J. Z. (2008). Aggressiveness of cancer care near the end-of-life: Is it a quality-of-care issue? *Journal of Clinical Oncology*, 26(23), 3860-3866. doi: 10.1200/JCO.2007.15.8253

Eleazer, G. P., Hornung, C. A., Egbert, C. B., Egbert, J. R., Eng, C., Hedgepeth, J.,... Wilson, M. (1996). The relationship between ethnicity and advance directives in a frail older population. *Journal of the American Geriatrics Society*, 44, 983-943.

Emanuel, L. L, von Gunten, C. F., & Ferris, F. D. (2000). Advance care planning. *Archives of Family Medicine*, 9, 1181-1187. doi: 10.1001/archfami.9.10.1181

Fagerlin, A., Ditto, P. H., Ganks, J. H., Houts, R. M., & Smucker, W. D. (2001). Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychology*, 20(3), 166-175. doi: 10.1037//0278-6133.20.3.166

- Fagerlin, A., & Schneider, C. E. (2004). Enough: The Failure of the Living Will. *Hastings Center Report* 34(2), 30-42. doi: 10.2307/3527683
- Gade, G., Venohr, I., Conner, D., McGrady, K., Beane, J., Richardson, R. H., . . . Penna, R. D. (2008). Impact of an inpatient palliative care team: A randomized controlled trial. *Journal of Palliative Medicine*, 11(2), 180-190. doi: 10.1089/jpm.2007.0055
- Gale, C. R., Batty, D., & Deary, I. J. (2008). Locus of control at age 10 years and health outcomes and behaviors at age 30 years: The 1970 British Cohort Study. *Psychosomatic Medicine*, 70, 397-403. doi: 10.1097/PSY.0b013e31816a719e
- Gillick, M. R. (2004). Advance care planning. *The New England Journal of Medicine*, 350, 7-8. doi: 10.1056/NEJMp038202
- Gillon, R. (2003). Ethics needs principles – four can encompass the rest – and respect for autonomy should be “first among equals.” *Journal of Medical Ethics*, 29, 307-312. doi: 10.1136/jme.29.5.307
- Hamel, M. B., Lynn, J., Teno, J. M., Covinsky, K. E., Wu, A. W., Galanos, A., . . . Phillips, R. S., (2000). Age-related differences in care preferences, treatment decisions, and clinical outcomes of seriously ill hospitalized adults: Lessons from SUPPORT. *Journal of American Geriatrics Society*, 48, S176-182.
- Hammes, B. J., Rooney, B. L., & Gundrum, J. D. (2010). A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *Journal of the American Geriatrics Society*, 58(7), 1249-1255. doi: 10.1111/j.1532-5415.2010.02956.x

- Handy, C. M., Sulmasy, D. P., Merkel, C. K., & Ury, W. A. (2008). The surrogate's experience in authorizing a do not resuscitate order. *Palliative & Supportive Care*, 6, 13-19. doi: 10.1017/S1478951508000035
- Hansen, L., Archbold, P. G., Stewart, B., Westfall, U. B., & Ganzini, L. (2005). Family caregivers making life-sustaining treatment decisions: Factors associated with role strain and ease. *Journal of Gerontological Nursing*, 31, 28-35.
- Hansen, L., Archbold, P. G., Stewart, B. J. (2004). Role strain and ease in decision-making to withdraw or withhold life support for elderly relatives. *Journal of Nursing Scholarship*, 36, 233-238. doi: 10.1111/j.1547-5069.2004.04043.x
- Happ, M. B., Capezuti, E., Strumpf, N. E., Wagner, L., Cunningham, S., Evans, L., & Maislin, G. (2002). Advance care planning and end-of-life care for hospitalized nursing home residents. *Journal of the American Geriatrics Society*, 50, 829-835. doi: 10.1046/j.1532-5415.2002.50207.x
- Hauser, R. M. & Willis, R. J., (2005). "Survey Design and Methodology in the Health and Retirement Study and the Wisconsin Longitudinal Study." In L. J. Waite (Ed.), *Aging, Health, and Public Policy: Demographic and Economic Perspectives*, pp. 209-235. New York: The Population Council, Inc.
- Heeringa S. G., & Connor J. H. (1995). *Technical description of the Health and Retirement Survey sample design*. Ann Arbor, MI: ICPSR, University of Michigan.
- Hinkka, H., Kosunen, E., Metsänoja, R., Lammi, U-K., & Kellokumpu-Lehtinen, P. (2002). Factors affecting physicians' to forgo life-sustaining treatments in terminal care. *Journal of Medical Ethics*, 28, 109-114. doi 10.1136/jme.28.2.109

- Hoover, D. R., Crystal, S., Kumar, R., Sambamoorthi, U., & Cantor, J. C. (2002). Medical expenditures during the last year of life: Findings from the 1992-1996 Medicare current beneficiary survey. *Health Services Research, 37*(6), 1625-1642. doi: 10.1111/1475-6773.01113
- Hopp, F. P. (2000). Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: Results from a national study. *The Gerontologist, 40*(4), 949-957. doi 10.1093/geront/40.4.449
- Hopp, F. P., & Duffy, S. A. (2000). Racial variations in end-of-life care. *Journal of the American Geriatrics Society, 48*, 658–663.
- Inoue, M., & Moorman, S. M. (forthcoming). Does end-of-life planning help partners become better surrogates? *The Gerontologist*.
- 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
- Keogh, E. (2008). Sex differences in pain. *Reviews in Pain, 2*, 4-7. doi: 10.1177/204946370800200203
- Kiely, D. K., Mitchell, S. L., Marlow, A., Murphy, K., & Morris, J. N. (2001). Racial and state differences in the designation of advance directives in nursing home residents. *Journal of the American Geriatric Society, 49*, 1346-1352. doi: 10.1046/j.1532-5415.2001.49263.x

- Kramer, B. J., Boelk, A. Z., & Auer, C. (2006). Family conflict at the end of life: Lessons learned in a model program for vulnerable older adults. *Journal of Palliative Medicine*, 9(3), 791-801. doi: 10.1089/jpm.2006.9.791
- Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45(5), 634-641. doi: 10.1093/geront/45.5.634
- Lachman, M. E., & Firth, K. M. (2004). The adaptive value of feeling in control during midlife. In O. G. Brim, C. D. Ryff, & R. Kessler (Eds.), *How healthy are we?: A national study of well-being at midlife* (pp. 320–349). Chicago: University of Chicago Press.
- Lachman, M. E., & Weaver, S. L. (1998a). The sense of control as a moderator of social class differences in health and well-being. *Journal of Personality and Social Psychology*, 74, 763-773. doi: 10.1037/0022-3514.74.3.763
- Lachman, M. E., & Weaver, S. L. (1998b). Sociodemographic variations in the sense of control by domain: Findings from the MacArthur studies of midlife. *Psychology and Aging*, 13(4), 553-562. doi: 10.1037/0882-7974.13.4.553
- Liao, H., Liu, S., & Pi, S. (2011). Modeling motivations for blogging: An expectancy theory analysis. *Social Behavior and Personality*, 39(2), 251-264. doi: 10.2224/sbp.2011.39.2.251
- Luce, J. (2010). A history of resolving conflicts over end-of-life care in intensive care units in the United States. *Critical Care Medicine*, 38(8), 1623-1629. doi: 10.1097/CCM.0b013e3181e71530

- Lynn, J., & Goldstein, N. E. (2003). Advance care planning for fatal chronic illness: Avoiding commonplace errors and unwarranted suffering. *Annals of Internal Medicine*, 138, 812-818. doi 10.7326/0003-4819-138-10-200305200-00009
- Mack, J. W., Cronin, A., Keating, N. L., Taback, N., Huskamp H. A., Malin, J. L., . . . Weeks, J. C. (2012). Association between end-of-life discussion characteristics and care received near death: A prospective cohort study. *Journal of Clinical Oncology*, 30(35), 4387-4395. doi 10.1200/JCO.2012.43.6055
- Mack, J. W., Weeks, J. C., Wright, A. A., Block, S. D., & Prigerson, H. G. (2010). End-of-life discussions, goal attainment, and distress at the end-of-life: Predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology*, 28(7), 1203-1208. doi: 10.1200/JCO.2009.25.4672
- Mansell, D., Kazis, L., Glantz, L., & Heeren, T. (1999). Roles of physicians, attorneys, and illness experience in advance directives. *Southern Medical Journal*, 92, 197-203. doi 10.1097/00007611-199902000-00007
- Mansell, D., Poses, R. M., Kazis, L., & Duefield, C. A. (2000). Clinical factors that influence patients' desire for participation in decisions about illness. *Archives of Internal Medicine*, 160, 2991-2996. doi 10.1001/archinte.160.19.2991
- Medvene, L. J., Wescott, J. V., Huckstadt, A., Ludlum, J., Langel, S., Mick, K. . . .Base, M. (2003). Promoting signing of advance directives in faith communities. *Journal of General Internal Medicine*, 18(11), 914-920. doi: 10.1046/j.1525-1497.2003.20351.x
- Matsuyama, R., Reddy, S., & Smith, T. J. (2008). Why do patients choose chemotherapy bear the end-of-life? A review of the perspective of those facing death from

- cancer. *Journal of Clinical Oncology*, 24(21), 3490-3496. doi: 10.1200/JCO.2005.03.6236
- Meier, D. E. (2006). Palliative care in hospitals. *Journal of Hospital Medicine*, 1(1), 21-28. doi: 10.1002/jhm.3
- Messinger-Rapport, B. J., Baum, E. E., & Smith, M. L. (2009). Advance care planning: Beyond the living will. *Cleveland Clinic Journal of Medicine*, 76(5), 276-285. doi: 10.3949/ccjm.76a.07002
- Mezey, M. D., Leitman, R., Mitty, E. L., Bottrell, M. M., & Ramsey, G. C. (2000). Why hospital patients do and do not execute an advance directive. *Nursing Outlook*, 48(4), 165-171. doi: 10.1067/mno.2000.101772
- Moorman, S. M. (2011). The importance of feeling understood in marital conversations about end-of-life health care. *Journal of Social and Personal Relationships*, 28(1), 100-116. doi: 10.1177/0265407510386137
- Moorman, S. M. (2012). Older adults' preferences for independent or delegated end-of-life medical decision making. *Journal of Aging and Health*, 23(1), 135-157. doi: 10.1177/0898264310385114
- Moorman, S. M., & Carr, D. (2008). Spouses' effectiveness as end-of-life health care surrogates: Accuracy, uncertainty, and errors of overtreatment or undertreatment. *The Gerontologist*, 48(6), 811-819. doi: 10.1093/geront/48.6.811
- Moorman, S. M., & Inoue, M. (2013). Persistent problems in end-of-life planning among young and middle-aged American couples. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 68(1): 97-106. doi: 10.1093/geronb/gbs103

- Morrison, R.S., Olson, E., Mertz, K.R., & Meier, D.E. (1995). The inaccessibility of advance directives on transfer from ambulatory to acute care settings. *Journal of the American Medical Association*, 274(6), 478-482. doi: 10.1001/jama.1995.03530060052033
- Morrison, R. S., Zayas, L. H., Mulvihill, M., Baskin, S. A., & Meier, D. E. (1998). Barriers to completion of health care proxies: An examination of racial/ethnic differences. *Archives of Internal Medicine*, 158, 2493–2497. doi: 10.1001/archinte.158.22.2493
- Murphy, S. T., Palmer, J., Azen, S. P., Frank, G., Michel, V., & Blackhall, L. (1996). Ethnicity and advance directives. *Journal of the American Medical Association*, 274(10), 820-825. doi: 10.1111/j.1748-720X.1996.tb01843.x
- Murphy, S. L., Xu, J. Q., & Kochanek, K. D. (2013). Deaths: Final data for 2010. *National Vital Statistics Reports*, 61(4). Hyattsville, MD: National Center for Health Statistics.
- National Center for Health Statistics. (2012). *Health, United States, 2012*. Retrieved September 20, 2013, from <http://www.cdc.gov/nchs/data/hus/hus12.pdf#017>.
- Nicholas, L. H., Langa, K. M., Iwashyna, T. J., & Weir, D. R. (2011). Regional variation in the association between advance directives and end-of-life Medicare expenditures. *The Journal of the American Medical Association*, 306(13), 1447-1453. doi: 10.1001/jama.2011.1410
- Nyhan, B. (2010). Why the “death panel” myth wouldn’t die: Misinformation in the health care reform debate. *The Forum*, 8(1), Article 5. doi: 10.2202/1540-8884.1354

- Owens, G. M. (2008). Gender differences in health care expenditures, resource utilization, and quality of care. *Journal of Managed Care Pharmacy*, 14(3), S2-S6.
- Pang, A., Ho, S., & Lee, S. (2013). Cancer physicians' attitude towards treatment of the elderly cancer patient in a developed Asian country. *BMC Geriatrics*, 13, 35. doi: 10.1186/1471-2318-13-35
- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19, 2-21. doi: 10.2307/2136319
- Peter, P. J. (1979). Reliability: A review of psychometric basics and recent marketing practices. *Journal of Marketing Research*, 16(1), 6-17.
- 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, 549-554. doi: 10.1200/JCO.2003.12.080
- Platts-Mills, T. F., Hunold, K. M., Bortsov, A. V., Soward, A. C., Peak, D. A., Jones, J. S., . . . McLean, S. A. (2012). More educated emergency department patients are less likely to receive opioids for acute pain. *Pain*, 153, 967-973. doi: 10.1016/j.pain.2012.01.013
- Pollack, K. M., Morhaim, D., & Williams, M. A. (2010). The public's perspectives on advance directives: Implications for state legislative and regulatory policy. *Health Policy*, 96(1) 57-63. doi: 10.1016/j.healthpol.2010.01.004
- Porter, L. W., & Lawler, E. E. (1968). *Managerial attitudes and performance*. Homewood, IL: Richard D. Irwin, Inc.

- Radwany, S., Albanese, T., Clough, L., Sims, L., Mason, H., & Jahangiri, S. (2009). End-of-life decision making and emotional burden: Placing family meetings in context. *American Journal of Hospice and Palliative Care*, 26, 376-83. doi: 10.1177/1049909109338515
- Resnick, H. E., Schuur, J. D., Heineman, J., Stone, R., & Weissman, J. S. (2009). Advance directives in nursing home residents ≥ 65 years: United States 2004. *American Journal of Hospice and Palliative Medicine*, 25(6), 476-482. doi: 10.1177/1049909108322295
- Robinson, M. E., Riley, J. L., Myers, C. D., Papas, R. K., Wise, E. A., Waxenberg, L. B., & Fillingim, R. B. (2001). *The Journal of Pain*, 2(5), 251-257. doi: 10.1054/jpai.2001.24551
- Rodin, J. (1986). Aging and health: Effects of the sense of control. *Science*, 233, 1271-1276. doi: 10.1126/science.3749877
- Rosnick, C. B., & Reynolds, S. L. (2003). Thinking ahead: Factors associated with executing advance directives. *Journal of Aging and Health*, 15(2), 409-429. doi: 10.1177/0898264303015002005
- Sabatino, C. P. (2010). The evolution of health care advance planning law and policy. *The Milbank Quarterly*, 88(2), 211-239. doi: 10.1111/j.1468-0009.2010.00596.x
- 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. doi: 10.1111/j.1532-5415.2008.02093.x

- Scholl, R. W. (2002). *Motivation: Expectancy theory*. Retrieved February 9, 2012, from the University of Rhode Island, Labor Research Center website, http://www.uri.edu/research/lrc/scholl/webnotes/Motivation_Expectancy.htm
- Shalowitz, D. I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers. *Archives of Internal Medicine*, 166(5), 493-497. doi: 10.1001/archinte.166.5.493
- Sharp, S., Carr, D., & Macdonald, C. (2012). Religion and end-of-life treatment preferences: Assessing the effects of religious denomination and beliefs. *Social Forces*, 91(1), 275-298. doi: 10.1093/sf/sos061
- Silveira, M. J., Kim, S. Y. H., & Langa K. M. (2010). Advance directives and outcomes of surrogate decision making before death. *The New England Journal of Medicine*, 362, 1211-1218. doi: 10.1056/NEJMsa0907901
- Skinner, E. A. (1995). *Perceived control, motivation, & coping*. Thousand Oaks, CA: Sage Publications, Inc.
- Smith, J., Fisher, G., Ryan, L., Clarke, P., House, J., & Weir, D. (2013). *Psychosocial and lifestyle questionnaire 2006 - 2010*. Ann Arbor, MI: Survey Research Center Institute for Social Research.
- Smith, T. J., & Hillner, B. E. (2011). Bending the cost curve in cancer care. *The New England Journal of Medicine*, 364(21), 2060-2065. doi: 10.1056/NEJMs1013826
- Smith, A. K., McCarthy, E. P., Paulk, E., Balboni, T. A., Maciejewski, P. K., Block, S. D. & Prigerson, H. G. (2008). Racial and ethnic differences in advance care planning among patients with cancer: Impact of terminal illness acknowledgment,

- religiousness, and treatment preferences. *Journal of Clinical Oncology*, 26(25), 4131-4137. doi: 10.1200/JCO.2007.14.8452
- Solano, J. P., Gomes, B., & Higginson, I. J. (2006). A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *Journal of Pain and Symptom Management*, 31(1), 58-69. doi: 10.1016/j.jpainsymman.2005.06.007
- Step toe, A., & Wardle, J. (2001). Locus of control and health behavior revisited: A multivariate analysis of young adults from 18 countries. *British Journal of Psychology*, 92, 650-672. doi: 10.1348/000712601162400
- Swenson, D. (n.d.). *Expectancy and equity theories of motivation*. Retrieved February 9, 2012, from the College of St. Scholastica website, <http://faculty.css.edu/dswenson/web/OB/VIetheory.html>
- Taylor, R. J., Ellison, C. G., Chatters, L. M., Levin, J. S., & Lincoln, K. D. (2000). Mental health services in faith communities: The role of clergy in black churches. *Social Work*, 45(1), 73–87. doi: 10.1093/sw/45.1.73
- Teno, J. M., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T. (2007). Association between advance directives and quality end-of-life care: A national study. *Journal of the American Geriatrics Society*, 55(2), 189-194. doi: 10.1111/j.1532-5415.2007.01045.x
- University of Michigan. (2011) *Health and Retirement Study: Sample size and response rates*. Retrieved February 17, 2014, from <http://hrsonline.isr.umich.edu/sitedocs/sampleresponse.pdf>

- University of Michigan. (2012). *Health and Retirement Study*. Retrieved February 15, 2012, from <http://hrsonline.isr.umich.edu/>
- Unruh, A. M. (1996). Gender variations in clinical pain experience. *Pain*, 65, 123-167. doi: 10.1016/0304-3959(95)00214-6
- Vroom, V. H. (1964). *Work and motivation*. New York, NY: Wiley.
- Walling, A., Lorenz, K. A., Dy, S. M., Naeim, A., Sanati, H., Asch, S. M., & Wenger, N. S. (2008). Evidence-based recommendations for information and care planning in cancer care. *Journal of Clinical Oncology*, 26(23), 3896-3902. doi: 10.1200/JCO.2007.15.9509
- Water, C. M. (2001). Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. *Qualitative Health Research*, 11(3), 385-398. doi: 10.1177/104973201129119172
- Wendler, D., & Rid, A. (2011). Systematic review: The effects on surrogates of making treatment decisions for others. *Annals of Internal Medicine*, 154, 336-346. doi: 10.7326/0003-4819-154-5-201103010-00008
- Wissow, L. S., Belote, A., Kramer, W., Compton-Phillips, A., Kritzler, R., & Weiner, J. P. (2004). Promoting advance directives among elderly primary care patients. *Journal of General Internal Medicine*, 19, 944-951. Doi: 10.1111/j.1525-1497.2004.30117.x
- Zhang, B., Wright, A. A., Huskamp, 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. doi: 10.1001/archinternmed.2008.587

Ziff, M. A., Conrad, P., & Lachman, M. E. (1995). The relative effects of perceived personal control and responsibility on health and health-related behaviors in young and middle-aged adults. *Health Education & Behavior*, 22(1), 127-142.
doi: 10.1177/109019819502200111

Appendix

FIVE WISHES[®]

MY WISH FOR:

The Person I Want to Make Care Decisions for Me When I Can't

The Kind of Medical Treatment I Want or Don't Want

How Comfortable I Want to Be

How I Want People to Treat Me

What I Want My Loved Ones to Know

print your name

birthdate

Five Wishes

There are many things in life that are out of our hands. This Five Wishes document gives you a way to control something very important—how you are treated if you get seriously ill. It is an easy-to-complete form that lets you say exactly what you want. Once it is filled out and properly signed it is valid under the laws of most states.

What Is Five Wishes?

Five Wishes is the first living will that talks about your personal, emotional and spiritual needs as well as your medical wishes. It lets you choose the person you want to make health care decisions for you if you are not able to make them for yourself. Five Wishes lets you say exactly how you wish to be

treated if you get seriously ill. It was written with the help of The American Bar Association's Commission on Law and Aging, and the nation's leading experts in end-of-life care. It's also easy to use. All you have to do is check a box, circle a direction, or write a few sentences.

How Five Wishes Can Help You And Your Family

- It lets you talk with your family, friends and doctor about how you want to be treated if you become seriously ill.
- Your family members will not have to guess what you want. It protects them if you become seriously ill, because they won't have to make hard choices without knowing your wishes.
- You can know what your mom, dad, spouse, or friend wants. You can be there for them when they need you most. You will understand what they really want.

How Five Wishes Began

For 12 years, Jim Towey worked closely with Mother Teresa, and, for one year, he lived in a hospice she ran in Washington, DC. Inspired by this first-hand experience, Mr. Towey sought a way for patients and their families to plan ahead and to cope with serious illness. The result is Five Wishes and the response to it has been

overwhelming. It has been featured on CNN and NBC's Today Show and in the pages of *Time* and *Money* magazines. Newspapers have called Five Wishes the first "living will with a heart and soul." Today, Five Wishes is available in 26 languages.

Who Should Use Five Wishes

Five Wishes is for anyone 18 or older — married, single, parents, adult children, and friends. More than 15 million people of all ages have already used it. Because it

works so well, lawyers, doctors, hospitals and hospices, faith communities, employers, and retiree groups are handing out this document.

Five Wishes States

If you live in the **District of Columbia** or one of the **42 states** listed below, you can use Five Wishes and have the peace of mind to know that it substantially meets your state's requirements under the law:

Alaska	Illinois	Montana	South Carolina
Arizona	Iowa	Nebraska	South Dakota
Arkansas	Kentucky	Nevada	Tennessee
California	Louisiana	New Jersey	Vermont
Colorado	Maine	New Mexico	Virginia
Connecticut	Maryland	New York	Washington
Delaware	Massachusetts	North Carolina	West Virginia
Florida	Michigan	North Dakota	Wisconsin
Georgia	Minnesota	Oklahoma	Wyoming
Hawaii	Mississippi	Pennsylvania	
Idaho	Missouri	Rhode Island	

If your state is not one of the 42 states listed here, Five Wishes does not meet the technical requirements in the statutes of your state. So some doctors in your state may be reluctant to honor Five Wishes. However, many people from states not on this list do complete Five Wishes along with their state's legal form. They find that Five Wishes helps them express all that they want and provides a helpful guide to family members, friends, care givers and doctors. Most doctors and health care professionals know they need to listen to your wishes no matter how you express them.

How Do I Change To Five Wishes?

You may already have a living will or a durable power of attorney for health care. If you want to use Five Wishes instead, all you need to do is fill out and sign a new Five Wishes as directed. As soon as you sign it, it takes away any advance directive you had before. To make sure the right form is used, please do the following:

- Destroy all copies of your old living will or durable power of attorney for health care. Or you can write "revoked" in large letters across the copy you have. Tell your lawyer if he or she helped prepare those old forms for you. *AND*
- Tell your Health Care Agent, family members, and doctor that you have filled out a new Five Wishes. Make sure they know about your new wishes.

WISH 1

The Person I Want To Make Health Care Decisions For Me When I Can't Make Them For Myself.

If I am no longer able to make my own health care decisions, this form names the person I choose to make these choices for me. This person will be my Health Care Agent (or other term that may be used in my state, such as proxy, representative, or surrogate). This person will make my health care choices if both of these things happen:

- *My attending or treating doctor finds I am no longer able to make health care choices, AND*
- *Another health care professional agrees that this is true.*

If my state has a different way of finding that I am not able to make health care choices, then my state's way should be followed.

The Person I Choose As My Health Care Agent Is:

First Choice Name

Phone

Address

City/State/Zip

If this person is not able or willing to make these choices for me, *OR* is divorced or legally separated from me, *OR* this person has died, then these people are my next choices:

Second Choice Name

Third Choice Name

Address

Address

City/State/Zip

City/State/Zip

Phone

Phone

Picking The Right Person To Be Your Health Care Agent

Choose someone who knows you very well, cares about you, and who can make difficult decisions. A spouse or family member may not be the best choice because they are too emotionally involved. Sometimes they are the best choice. You know best. Choose someone who is able to stand up for you so that your wishes are followed. Also, choose someone who is likely to be nearby so that they can help when you need them. Whether you choose a spouse, family member, or friend as your Health Care Agent, make sure you talk about these wishes and be sure that this person agrees to respect

and follow your wishes. Your Health Care Agent should be **at least 18 years or older** (in Colorado, 21 years or older) and should **not** be:

- Your health care provider, including the owner or operator of a health or residential or community care facility serving you.
- An employee or spouse of an employee of your health care provider.
- Serving as an agent or proxy for 10 or more people unless he or she is your spouse or close relative.

I understand that my Health Care Agent can make health care decisions for me. I want my Agent to be able to do the following: (Please cross out anything you don't want your Agent to do that is listed below.)

- Make choices for me about my medical care or services, like tests, medicine, or surgery. This care or service could be to find out what my health problem is, or how to treat it. It can also include care to keep me alive. If the treatment or care has already started, my Health Care Agent can keep it going or have it stopped.
- Interpret any instructions I have given in this form or given in other discussions, according to my Health Care Agent's understanding of my wishes and values.
- Consent to admission to an assisted living facility, hospital, hospice, or nursing home for me. My Health Care Agent can hire any kind of health care worker I may need to help me or take care of me. My Agent may also fire a health care worker, if needed.
- Make the decision to request, take away or not give medical treatments, including artificially-provided food and water, and any other treatments to keep me alive.
- See and approve release of my medical records and personal files. If I need to sign my name to get any of these files, my Health Care Agent can sign it for me.
- Move me to another state to get the care I need or to carry out my wishes.
- Authorize or refuse to authorize any medication or procedure needed to help with pain.
- Take any legal action needed to carry out my wishes.
- Donate useable organs or tissues of mine as allowed by law.
- Apply for Medicare, Medicaid, or other programs or insurance benefits for me. My Health Care Agent can see my personal files, like bank records, to find out what is needed to fill out these forms.
- Listed below are any changes, additions, or limitations on my Health Care Agent's powers.

If I Change My Mind About Having A Health Care Agent, I Will

- Destroy all copies of this part of the Five Wishes form. *OR*
- Tell someone, such as my doctor or family, that I want to cancel or change my Health Care Agent. *OR*
- Write the word "Revoked" in large letters across the name of each agent whose authority I want to cancel. Sign my name on that page.

WISH 2

My Wish For The Kind Of Medical Treatment I Want Or Don't Want.

I believe that my life is precious and I deserve to be treated with dignity. When the time comes that I am very sick and am not able to speak for myself, I want the following wishes, and any other directions I have given to my Health Care Agent, to be respected and followed.

What You Should Keep In Mind As My Caregiver

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means that I will be drowsy or sleep more than I would otherwise.
- I do not want anything done or omitted by my doctors or nurses with the intention of taking my life.
- I want to be offered food and fluids by mouth, and kept clean and warm.

What "Life-Support Treatment" Means To Me

Life-support treatment means any medical procedure, device or medication to keep me alive.

Life-support treatment includes: medical devices put in me to help me breathe; food and water supplied by medical device (tube feeding); cardiopulmonary resuscitation (CPR); major surgery; blood transfusions; dialysis; antibiotics;

and anything else meant to keep me alive.

If I wish to limit the meaning of life-support treatment because of my religious or personal beliefs, I write this limitation in the space below.

I do this to make very clear what I want and under what conditions.

In Case Of An Emergency

If you have a medical emergency and ambulance personnel arrive, they may look to see if you have a **Do Not Resuscitate** form or bracelet. Many states require a person to have a **Do Not Resuscitate** form filled out and

signed by a doctor. This form lets ambulance personnel know that you don't want them to use life-support treatment when you are dying. Please check with your doctor to see if you need to have a **Do Not Resuscitate** form filled out.

Here is the kind of medical treatment that I want or don't want in the four situations listed below. I want my Health Care Agent, my family, my doctors and other health care providers, my friends and all others to know these directions.

Close to death:

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- ☐ I want to have life-support treatment.
- ☐ I do not want life-support treatment. If it has been started, I want it stopped.
- ☐ I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

In A Coma And Not Expected To Wake Up Or Recover:

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up or recover, and I have brain damage, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- ☐ I want to have life-support treatment.
- ☐ I do not want life-support treatment. If it has been started, I want it stopped.
- ☐ I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

Permanent And Severe Brain Damage And Not Expected To Recover:

If my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but I can not speak or understand) and I am not expected to get better, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- ☐ I want to have life-support treatment.
- ☐ I do not want life-support treatment. If it has been started, I want it stopped.
- ☐ I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

In Another Condition Under Which I Do Not Wish To Be Kept Alive:

If there is another condition under which I do not wish to have life-support treatment, I describe it below. In this condition, I believe that the costs and burdens of life-support treatment are too much and not worth the benefits to me. Therefore, in this condition, I do not want life-support treatment. (For example, you may write "end-stage condition." That means that your health has gotten worse. You are not able to take care of yourself in any way, mentally or physically. Life-support treatment will not help you recover. Please leave the space blank if you have no other condition to describe.)

The next three wishes deal with my personal, spiritual and emotional wishes. They are important to me. I want to be treated with dignity near the end of my life, so I would like people to do the things written in Wishes 3, 4, and 5 when they can be done. I understand that my family, my doctors and other health care providers, my friends, and others may not be able to do these things or are not required by law to do these things. I do not expect the following wishes to place new or added legal duties on my doctors or other health care providers. I also do not expect these wishes to excuse my doctor or other health care providers from giving me the proper care asked for by law.

WISH 3

My Wish For How Comfortable I Want To Be.

(Please cross out anything that you don't agree with.)

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means I will be drowsy or sleep more than I would otherwise.
- If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my care givers to do whatever they can to help me.
- I wish to have a cool moist cloth put on my head if I have a fever.
- I want my lips and mouth kept moist to stop dryness.
- I wish to have warm baths often. I wish to be kept fresh and clean at all times.
- I wish to be massaged with warm oils as often as I can be.
- I wish to have my favorite music played when possible until my time of death.
- I wish to have personal care like shaving, nail clipping, hair brushing, and teeth brushing, as long as they do not cause me pain or discomfort.
- I wish to have religious readings and well-loved poems read aloud when I am near death.
- I wish to know about options for hospice care to provide medical, emotional and spiritual care for me and my loved ones.

WISH 4

My Wish For How I Want People To Treat Me.

(Please cross out anything that you don't agree with.)

- I wish to have people with me when possible. I want someone to be with me when it seems that death may come at any time.
- I wish to have my hand held and to be talked to when possible, even if I don't seem to respond to the voice or touch of others.
- I wish to have others by my side praying for me when possible.
- I wish to have the members of my faith community told that I am sick and asked to pray for me and visit me.
- I wish to be cared for with kindness and cheerfulness, and not sadness.
- I wish to have pictures of my loved ones in my room, near my bed.
- If I am not able to control my bowel or bladder functions, I wish for my clothes and bed linens to be kept clean, and for them to be changed as soon as they can be if they have been soiled.
- I want to die in my home, if that can be done.

WISH 5

My Wish For What I Want My Loved Ones To Know.

(Please cross out anything that you don't agree with.)

- I wish to have my family and friends know that I love them.
- I wish to be forgiven for the times I have hurt my family, friends, and others.
- I wish to have my family, friends and others know that I forgive them for when they may have hurt me in my life.
- I wish for my family and friends to know that I do not fear death itself. I think it is not the end, but a new beginning for me.
- I wish for all of my family members to make peace with each other before my death, if they can.
- I wish for my family and friends to think about what I was like before I became seriously ill. I want them to remember me in this way after my death.
- I wish for my family and friends and caregivers to respect my wishes even if they don't agree with them.
- I wish for my family and friends to look at my dying as a time of personal growth for everyone, including me. This will help me live a meaningful life in my final days.
- I wish for my family and friends to get counseling if they have trouble with my death. I want memories of my life to give them joy and not sorrow.
- After my death, I would like my body to be (circle one): buried or cremated.
- My body or remains should be put in the following location_____.
- The following person knows my funeral wishes: _____.

If anyone asks how I want to be remembered, please say the following about me:

If there is to be a memorial service for me, I wish for this service to include the following (list music, songs, readings or other specific requests that you have):

(Please use the space below for any other wishes. For example, you may want to donate any or all parts of your body when you die. You may also wish to designate a charity to receive memorial contributions. Please attach a separate sheet of paper if you need more space.)

Signing The Five Wishes Form

Please make sure you sign your Five Wishes form in the presence of the two witnesses.

I, _____, ask that my family, my doctors, and other health care providers, my friends, and all others, follow my wishes as communicated by my Health Care Agent (if I have one and he or she is available), or as otherwise expressed in this form. This form becomes valid when I am unable to make decisions or speak for myself. If any part of this form cannot be legally followed, I ask that all other parts of this form be followed. I also revoke any health care advance directives I have made before.

Signature: _____

Address: _____

Phone: _____ Date: _____

Witness Statement - (2 witnesses needed):

I, the witness, declare that the person who signed or acknowledged this form (hereafter "person") is personally known to me, that he/she signed or acknowledged this [Health Care Agent and/or Living Will form(s)] in my presence, and that he/she appears to be of sound mind and under no duress, fraud, or undue influence.

I also declare that I am over 18 years of age and am NOT:

- The individual appointed as (agent/proxy/surrogate/patient advocate/representative) by this document or his/her successor,
- The person's health care provider, including owner or operator of a health, long-term care, or other residential or community care facility serving the person,
- An employee of the person's health care provider,
- Financially responsible for the person's health care,
- An employee of a life or health insurance provider for the person,
- Related to the person by blood, marriage, or adoption, and,
- To the best of my knowledge, a creditor of the person or entitled to any part of his/her estate under a will or codicil, by operation of law.

(Some states may have fewer rules about who may be a witness. Unless you know your state's rules, please follow the above.)

_____ Signature of Witness #1	_____ Signature of Witness #2
_____ Printed Name of Witness	_____ Printed Name of Witness
_____ Address	_____ Address
_____ Phone	_____ Phone

Notarization • Only required for residents of Missouri, North Carolina, South Carolina and West Virginia

- If you live in Missouri, only your signature should be notarized.

- If you live in North Carolina, South Carolina or West Virginia, you should have your signature, and the signatures of your witnesses, notarized.

STATE OF _____

COUNTY OF _____

On this _____ day of _____, 20____, the said _____, _____, and _____, known to me (or satisfactorily proven) to be the person named in the foregoing instrument and witnesses, respectively, personally appeared before me, a Notary Public, within and for the State and County aforesaid, and acknowledged that they freely and voluntarily executed the same for the purposes stated therein.

My Commission Expires: _____

Notary Public

What To Do After You Complete Five Wishes

- Make sure you sign and witness the form just the way it says in the directions. Then your Five Wishes will be legal and valid.
- Talk about your wishes with your health care agent, family members and others who care about you. Give them copies of your completed Five Wishes.
- Keep the original copy you signed in a special place in your home. Do NOT put it in a safe deposit box. Keep it nearby so that someone can find it when you need it.
- Fill out the wallet card below. Carry it with you. That way people will know where you keep your Five Wishes.
- Talk to your doctor during your next office visit. Give your doctor a copy of your Five Wishes. Make sure it is put in your medical record. Be sure your doctor understands your wishes and is willing to follow them. Ask him or her to tell other doctors who treat you to honor them.
- If you are admitted to a hospital or nursing home, take a copy of your Five Wishes with you. Ask that it be put in your medical record.
- I have given the following people copies of my completed Five Wishes:

Residents of WISCONSIN must attach the WISCONSIN notice statement to Five Wishes.

More information and the notice statement are available at www.agingwithdignity.org or 1-888-594-7437.

Residents of Institutions In CALIFORNIA, CONNECTICUT, DELAWARE, GEORGIA, NEW YORK, NORTH DAKOTA, SOUTH CAROLINA, and VERMONT Must Follow Special Witnessing Rules.

If you live in certain institutions (a nursing home, other licensed long term care facility, a home for the mentally retarded or developmentally disabled, or a mental health institution) in one of the states listed above, you may have to follow special "witnessing requirements" for your Five Wishes to be valid. For further information, please contact a social worker or patient advocate at your institution.

Five Wishes is meant to help you plan for the future. It is not meant to give you legal advice. It does not try to answer all questions about anything that could come up. Every person is different, and every situation is different. Laws change from time to time. If you have a specific question or problem, talk to a medical or legal professional for advice.

Five Wishes Wallet Card

Important Notice to Medical Personnel:
I have a Five Wishes Advance Directive.

Signature _____

Please consult this document and/or my Health Care Agent in an emergency. My Agent is:

Name _____

Address _____ City/State/Zip _____

Phone _____

My primary care physician is:

Name _____

Address _____ City/State/Zip _____

Phone _____

My document is located at:

Cut Out Card, Fold and Laminate for Safekeeping

Here's What People Are Saying About Five Wishes:

"It will be a year since my mother passed on. We knew what she wanted because she had the Five Wishes living will. When it came down to the end, my brother and I had no questions on what we needed to do. We had peace of mind."

Cheryl K.
Longwood, Florida

"I must say I love your Five Wishes. It's clear, easy to understand, and doesn't dwell on the concrete issues of medical care, but on the issues of real importance—human care. I used it for myself and my husband."

Susan W.
Flagstaff, Arizona

"I don't want my children to have to make the decisions I am having to make for my mother. I never knew that there were so many medical options to be considered. Thank you for such a sensitive and caring form. I can simply fill it out and have it on file for my children."

Diana W.
Hanover, Illinois

To Order:

Call (888) 5-WISHES to purchase more copies of Five Wishes, the Five Wishes DVD, or Next Steps guides. Ask about the "Family Package" that includes 10 Five Wishes, 2 Next Steps guides and 1 DVD at a savings of more than 50%. For more information visit Aging with Dignity's website, or call for details.

(888) 5-WISHES or (888) 594-7437

www.agingwithdignity.org



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