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The Effects of Race, Socioeconomic Status, and Religion on Formal End-of-Life Planning

by

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requirements for the degree of

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ABSTRACT

Individuals who are facing death today are doing so in an environment that is significantly different than it was in the past. Medical technology is increasingly able to keep people alive even with multiple complex chronic conditions. While these advances in medicine are beneficial to many, it can also unnecessarily prolong inevitable deaths. Concerns over the ability to have a death that is in alignment with personal values has increased the interest in the use of formal end-of-life planning including writing an advance instructional directive and assigning a durable power of attorney for health care. Although research has indicated that the use of these formal planning strategies is beneficial, not everyone completes them. Using a current nationally representative sample, the three specific aims of this study were to examine whether there are racial and ethnic differences in formal end-of-life planning done by older African American, Hispanic, and White adults; to examine socioeconomic factors including education and income in formal end-of-life planning as well as assess the contribution of these factors in explaining racial and ethnic differences in formal end-of-life planning; and to examine the role of religiosity in formal end-of-life planning and to assess its influence on racial and ethnic differences in explaining formal end-of-life planning.

Logistic regression was run on data from the Health and Retirement Study (HRS) in order to analyze the completion of formal end-of-life plans by African American, Hispanic, and White decedents. Exit interviews conducted with knowledgeable proxies in 2008 or 2010 were combined with data from earlier waves of the HRS survey in order to analyze the completion of formal end-of-life plans, race and ethnicity, socioeconomic status, and religion.

Both Blacks and Hispanics were less likely to complete a written advance directive, assign a proxy, or complete both forms of formal planning than were Whites. Group differences remained after controlling for region of death and cause of death. Both Blacks and Hispanics were less likely to complete any form of formal planning than Whites. Group differences remained after additionally controlling for gender, age, marital status, whether the decedent had children, income, education, religious preference, importance of religion, and frequency of attending religious services. Higher levels of income and education both increased the odds that formal advance planning would take place. Religious preference was not significant, but decedents who had stated that religion was very important were less likely to plan while those that attended services frequently were more likely to plan.

I speculate that the role of cultural capital may partially explain the persistent racial and ethnic disparities and the importance of income and education. Additionally the dominant religious doctrines of Christianity may have a greater influence than the different religious teachings of Protestant and Catholics around end-of-life medical care. Contrary to expected findings, reference groups of those who attend religious services frequently may assist in formal planning. These finding may help guide interventions that can diminish disparities in the end-of-life experience. Understanding who are completing formal plans can help ensure end-of-life care that is in alignment with personal beliefs and values.

ACKNOWLEDGMENTS

When I started this dissertation I did not think through all of the ramifications. Immersing myself in literature around death and dying had challenges: dreams were at times difficult and pleasantries with people who innocently asked what I was studying were often difficult. But slowly, I realized that whether people were fascinated and wanted to talk about death or ran away because they did not want to talk about it, their reactions showed how important the topic is.

I need to thank those who not only saw the importance of the topic but who also were willing to see and develop the parts of me that most needed it. My dissertation chair, Matt Carlson, in addition to his unwavering academic support deserves many awards for talking me down when my stress would get the better of me. He helped keep my head together and my motivation going throughout the whole process. Hyeyoung Woo was instrumental to my confidence that I could manage analysis from such a large and often unwieldy data set. Her attention to detail is truly and greatly appreciated. Thanks also go to both Margaret Everett and Pam Miller for reading drafts, offering suggestions, and being all-around generous with their time and positive energy.

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CHAPTER ONE: INTRODUCTION

Medical care and the decisions necessary at the end of life have changed rapidly in recent decades. Medical technology is increasingly able to ward off death for both young and old, and keep people alive even with multiple complex chronic conditions. While this medical ability is seen as a triumph for many, it also can have the unintended consequence of prolonging deaths that are inevitable or even desired. It is now common to die in a hospital with aggressive medical interventions after having lost the ability to make medical decisions for oneself (Hiltunen et al. 1999, Silveira, Kim and Langa 2010). Because of these changes in the nature of dying, there has been an increase in concern over a dying patient's ability to have a death that is in alignment with their personal values. The last twenty years has seen increases in legal protection for both patients and physicians that are meant to encourage people to plan for their deaths. The use of these formal end-of-life planning strategies, which can include both writing an advance instructional directive and assigning a legal power of attorney for health care, has been associated with a more positive death in that patients who have made formal plans tend to experience less aggressive medical care, earlier referral to hospice, decreased likelihood of dying in a hospital, decreased cost, decreased family conflict, increased satisfaction with physician communication, and greater acceptance of impending death (Degenholtz, Rhee and Arnold 2004, Jeong, McMillan and Higgins 2012, Kahana, Lovegreen and Kahana 2012, Silveira, Kim and Langa 2010, Teno et al. 2007, Wright et al. 2008).

Research on end-of-life decision-making has been increasing, but there is still a great deal that is not known about those that are not completing formal plans. Race and ethnicity, demographic factors such as age, gender, and family structure, socioeconomic status, and religiosity may directly affect the completion of formal advance directives. Demographic factors, socioeconomic status and religion may additionally help explain racial and ethnic differences the completion of formal end-of-life plans.

Most studies on the end-of-life experiences of racial and ethnic minorities in the United States have focused on African Americans, with little done on other racial and ethnic groups. The studies that have been done point to health and health care disparities continuing into the final phases of life. Racial and ethnic minorities are less likely to participate in formal end-of-life planning and more likely to experience worse deaths than their White peers (Carr 2011, Hazin and Giles , Rhodes and Teno 2009). Socioeconomic status is a robust indicator of health care utilization (Braveman et al. 2010) and also has significant implications for how one experiences death and dying (Moller 2004). Those who are socioeconomically disadvantaged have multiple obstacles to completing formal plans including lower health literacy, fewer connections with the medical field, and a lack of continuity of care that could provide information and support for end-of-life planning (Moller 2004, Tarzian, Neal, and O'Neil 2005). Because of historic and personal experiences of discrimination and racism, racial and ethnic minorities are more likely to be socioeconomically disadvantaged (Williams and Jackson 2005), and therefore may experience greater obstacles in completing formal end-of-life plans than Whites. Furthermore, the role that religion plays in the decision to complete end-of-life plans has had little attention, although it has been indicated that people who report that they are not religious are more likely to complete advance directives than those who report higher levels of religiosity (Rurup et al. 2006). However, qualitative studies have also indicated the importance of religiosity for many people who are facing the end of their lives

(Sessanna 2008, Smith, Sudore and Pérez-Stable 2009). As research has indicated the significant importance of religion to many racial and ethnic minorities (Lincoln and Mamiya 1990, Lujan and Campbell 2006, Taylor, Chatters and Levin 2004), religion may additionally help explain the racial and ethnic differences in end-of-life planning.

Prior research has indicated that there are differences in who completes formal end-of-life plans, but there are no current nationally representative studies that examine both the direct influence of race and ethnicity, socioeconomic factors, and religion, as well as the mediating role that demographic factors, socioeconomic factors, and religion may have in racial and ethnic differences in advance care planning. This study explores the relationship between race, socioeconomic status, and religion, and formal advance care planning including what forms of advance care planning are taking place.

In order to understand end-of-life planning, the remainder of this chapter will discuss what a "good death" is and some history of advance care planning. The chapter will wrap up with the specific aims and research questions as well as their implications.

What is a Good Death?

Measuring a "good" death is difficult. By most standards, death is the "bad" outcome, the outcome that is considered undesirable. Most end-of-life research has focused on the medical aspects of dying, such as the progression of kidney failure or cancer response to treatment, because most health researchers received their training in a health care system that focuses on a medical model of care (Blevins and Papadatou 2006) where physicians are trained to view death as an enemy to be avoided at any cost (Wold 1992). This way of thinking has led to many breakthroughs in ways to keep people alive, but it has not always encouraged physicians and researchers to consider much beyond biomedical indicators (Wenger 1988).

A good death, just like a good life, is a subjective concept, but there have been attempts to define a good death through goals that are considered appropriate for managing the end of life. In a study done to understand factors that are important at the end of life, Steinhauser et al. (2000a) found some broad agreements between patients, family members, physicians, and other care providers on what contributes to a good death. Things such as freedom from pain, anxiety, and shortness of breath as well as being kept clean were widely held as important. Physicians tended to also focus on the importance of the physical aspects of dying, such as being kept comfortable, where patients and families had a broader conceptualization that included being mentally aware, being at peace with God, not being a burden on family, and being able to help others.

In another study by Steinhauser et al. (2000b), six primary domains were identified as the most important dimensions for the quality of dying: symptom and pain management, clarity of decision making, preparation for death, completion, contribution to others, and affirmation of the whole person. Additionally, being free of pain, issues of control, autonomy, and independence have consistently been reported as important to a good death (Smith 2000).

Finally, a similar definition was agreed upon in the Institute of Medicine report "Approaching Death":

> "a decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards. A bad death, in turn, is characterized by needless suffering, dishonoring of patient or family wishes or values, and

> a sense among participants or observers that norms of decency have been offended" (Committee on Care at the End of Life, 1997, p 24).

End-of-Life Planning Strategies

The demographic shift in the United States towards a larger older population which lives further away from family combined with the ability of physicians to help people survive increasingly complex illnesses is impacting how people die (Kellehear 2007). It is more common to die in a hospital while receiving aggressive interventions than in the past (Kellehear 2007) and it is more common for people to lose the ability to make health care decisions for themselves. It has been estimated that approximately 70% of adults over the age of 60 will lose the ability to make their own health care decisions prior to death (Hiltunen et al. 1999, Silveira, Kim and Langa 2010). Knowledge of prolonged, over-medicalized deaths, whether through personal experience (Lambert et al. 2005) or through exposure to the media (Sudore et al. 2008a), have led many people to consider the use of advance care planning for their own deaths. Concerns over the potential of experiencing a prolonged and over-medicalized death has led many to support informed consent and self-determination over the timing and experience of death, believing that the patient involved can and should make important end-of-life decisions that are in alignment with their values (Bottles 2001, Moorman 2011). Without end-of-life planning, when a medical crisis occurs it is often too late to properly consider all options (Pinquart, Sörensen and Peak 2005).

Formal end-of-life planning includes writing an advance directive for health care (also known as an instructional directive or a living will), assigning a durable power of attorney for health care (also known as a DPAHC, proxy directive, or medical proxy), and writing a financial will. An instructional directive indicates what care a person does, or does not, want to receive if they are unable to make decisions for themselves. A DPAHC assigns another person the right to make medical decisions on the patient's behalf when the patient is no longer able to make those decisions. Informal end-of-life planning, such as discussions with family, is important not only as a step in formal planning, but for the people who do not complete formal plans. Unfortunately there is much that is unknown about the form, frequency, and efficacy of informal planning (Glass and Nahapetyan 2008). The current research therefore focuses on formal planning behaviors with the acknowledgment that more research needs to be done to understand the role of informal end-of-life planning behaviors.

Informed Consent and Self Determination

Years ago most medical decisions were made by physicians. Their experience and training were seen as a legitimate reason for people to give decision making ability over to them (also known as medical paternalism) (Starr 1982, Will 2011a). At the end of life, most people experienced an acute episode of illness or injury and died at home. As medical technology increased, so did the ability of physicians to keep people in a state of 'living.' Most physicians believed that it was unethical to do anything less than the most that technology and medicine was capable of (Wold 1992). As this medical imperative to aggressively treat all patients collided with the realities of illness and dying, ethicists and family members began to challenge the assumption that 'life' at any cost was worthwhile. Cases that had shown up in court in the early 1900's signifying the idea that people had the right to refuse unwanted surgery began to be used to discuss end-of-life care almost seventy years later (Cerminara 2011, Olick 2012b, Will 2011a, Will 2011b).

Informed consent and self-determination refer to the right of individuals to consider the risks and benefits of medical procedures and to determine what is done to his or her own body (Will 2011a). Although informed consent and self-determination have not always been considered important at the end-of-life, they began to be seriously discussed with a landmark court case in the mid-1970s. In this case, the parents' of Karen Quinlan fought to have their daughter, who was in a persistent vegetative state with no hope of recovery, removed from a ventilator and allowed to die (Veatch 2009). This case was important as it brought the idea of the "right to die" into both the public thought and the legal purview. In response to this high profile case, the growing belief in patient autonomy in medical ethics, and the increasing complexity of end-of-life care, state legislatures began to enact Advance Directive or Living Will laws beginning with California in 1976 (Olick 2012a). These laws stated that clearly written end-of-life wishes would be honored after the person was no longer able to make decisions for themselves. In other words, it extended the right to self-determination to after a person was decisionally impaired.

Shortcomings to written advance directives became apparent quickly. Few people completed them, and even if they were completed, the range of decisions that they covered was limited (Pope 2012, Sabatino 2010). These shortcomings left many people facing the end of their lives still experiencing end-of-life care that was out of alignment with their values or desires. One solution was for people to assign someone who could speak on their behalf if they were unable to communicate for themselves. Although

California passed a durable power of attorney for health care statute in 1983, the concept of who had the right to make decisions for a person who was unable to make decisions regarding the maintenance or withdrawal of life-sustaining treatments was not considered by the Supreme Court until 1990. In 1983, a young woman named Nancy Cruzan was in a car accident. Once it became clear that their daughter would not recover, her parents wanted the hospital to remove the feeding tubes that were keeping her alive. The hospital refused. Although the family stated that Nancy had informally discussed her wished with them, they were unable to prove that Nancy would want the feeding tubes removed. In the case of Nancy Cruzan, the Supreme Court upheld the state's authority to require "clear and convincing evidence" to determine an incompetent person's desires regarding life sustaining treatments (Miles and August 1990).

By 1997, every state had some form of power of attorney for health care statute (Olick 2012a). These statutes are supplemented in forty-four states and the District of Columbia with default surrogate laws that list permissible surrogates if a patient did not assign one (Sabatino 2010). While these lists help decision-making in many situations, they vary from state to state in both who is included in the list and the power that these surrogates have. Two challenges with the default surrogate list is that the most appropriate person to make decisions may not be at the top of the list, or even on the list in the case of domestic partners, and it does not help patients who do not have close family or friends (Sabatino 2010).

A third important end-of-life court case was related to the life of Terri Schiavo. In 1990, Terri experienced a cardiac arrest and was left in a persistent vegetative state with no evidence of higher cortical functioning (Quill 2005). She had left no written advance directive nor had she assigned a medical power of attorney for health care. Her husband was made her legal surrogate based on the default surrogate law in Florida. After three years, her husband believed that Terri would not recover and would not want to be kept alive in her condition. Terri's parents disagreed with both the diagnosis that Terri would not recover and that she would want to have her feeding tube removed. Supported by a variety of religious groups, Terri's family successfully involved the state legislature and ultimately Congress and the President in an attempt to overturn the Supreme Court of Florida's ruling to remove the feeding tube (Annas 2005, Quill 2005). Ultimately, the feeding tube was removed and Terri died, 15 years after her cardiac arrest. Terri Schiavo's case is important as it not only signaled politics entering what had previously been seen as a medical and legal issue, but it also exemplifies the challenge of surrogate decision-making if there is family disagreement and no written advance directive that clearly indicates personal values towards end-of-life care.

Patient Self Determination Act

Supported by the Cruzan decision that states had the authority to require "clear and convincing evidence" to determine an incompetent person's desires regarding life sustaining treatments (Miles and August 1990), Congress passed the Federal Patient Self-Determination Act (PSDA) in 1990. According to the PSDA, any institution that is supported in any way by Medicare or Medicaid funding must inform patients of their right to consent to or refuse treatment, their state determined rights regarding advanced directives, and the policies of the institution regarding the withholding or withdrawing of life-sustaining treatments. The institutions that fall under this requirement include hospitals, HMOs, extended care facilities, nursing homes, hospices, and home health services. This information must be provided to patients or their designated representative upon admission to the facility or enrollment in the HMO. The PSDA also requires that the institutions provide ongoing training and education for both employees and the general public about advance directives and the act itself.

The PSDA left deciding substantive rights regarding advance directives up to the individual states, but all fifty states and the District of Columbia agree that individuals who are over the age of 18 and who are deemed competent have the right to provide direction for health care decisions at the end-of-life through some form of advance directive which may take the form of the instructional directive, the durable power of attorney for health care, or a combination of the two (Olick 2012b). One form of advance directives is the instructional directives (also known as living wills) where a person indicates in a written document what care they do or do not want to receive if they are no longer able to make decisions for themselves. Another form of advance directive is the durable power of attorney for health care (also known as a DPAHC, proxy directive, or medical proxy) where a person designates another person who is allowed to make medical decisions on the patient's behalf if the patient is unable to make these decisions themselves. These formal advance directives for health care have been developed as a way to protect individuals' rights to self-determination and as a way to protect proxy decision makers from legal liability.

Medical Orders

Other commonly used types of end-of-life planning strategies are medical orders. The first medical order that allowed physicians to stop care was the do-not-resuscitate (DNR) order. When a physician determines that a patient is in a terminal condition, if the patient or the proxy agrees, a do-not-resuscitate (DNR) order can be written. A DNR order, once signed by a physician, authorizes the withholding of life-sustaining treatments such as cardiopulmonary resuscitation (CPR). DNR orders make explicit the care that is going to be withheld so that the decision to resuscitate does not depend on the individual health care respondent.

Another medical order is the Physician Orders for Life Sustaining Treatment (POLST). The POLST originated in Oregon in 1991 to provide a coordinated system for patient's end-of-life treatment decisions (Citko et al. 2011). The POLST is an order that converts an individual's end-of-life treatment wishes into immediately active medical orders that are transferable across all care settings. This means that the order is valid whether the person is at a care facility, gets moved to a hospital, or returns home. A primary difference between the POLST and written advance directives are that the POLST is a medical order signed by a physician that is put into a patient's medical chart and followed by medical professionals whereas a written advance directive is a legal document that can be contested within the medical field. Additionally, the POLST is specifically for people who are expected to die, where a written advance directive can be created at any time whether a person is healthy or ill.

Medical orders for end-of-life treatments, such as DNR orders or POLST orders, are important for the care and treatment of dying individuals. Since these are medical orders, they are instigated and completed by physicians and therefore do not encourage the same level of personal agency that is involved in completing a written directive or assigning a proxy. Although there is still much research to be done on who is having medical orders completed for them and what those orders are, this research focuses on formal planning behaviors that are completed by patients.

Advanced Care Planning

The ideal end-of-life situation would be for a dying person to be taken care of by a trusted family physician. This physician would know the patient as an individual, and be aware of the patient's values and desires for the end-of-life. Unfortunately, according to a report published by Robert Wood Johnson Foundation (2004), the reality is that many patients first contact for end-of-life care is with an emergency department. This means that the physicians must make decisions and recommendations without knowing the patient as an individual. If the patient is competent to make decisions but has not thought about their desires or values for the end-of-life, they may take the advice of the physician even if it is not in alignment with their desires or values (Dixon-Woods et al. 2006). If the patient is not competent to make decisions and they have not done any formal advance care planning, they risk having medical care that they do not want. Having an advance directive provides the format to receiving the care that they value when they are not capable of expressing their own intensions and desires.

While formal advance care planning has its critics who believe that the concepts behind formal advance directives are flawed (e.g. Perkins 2007), studies are beginning to indicate that having advance directives does have an effect on the care received at the end of life (Silveira, Kim and Langa 2010) and that discussions around advance directives increase satisfaction with care for terminal patients (Tierney et al. 2001). Having a written instructional directive has been associated with dying in place rather than being taken to the hospital at the end of life for both those who are living in a nursing home and those who are living in the community (Degenholtz, Rhee and Arnold 2004). In a follow-back study of 1,587 people who died non-traumatic deaths in 2000, decedents who had planned for their deaths were more likely to die in a nursing home or at home with hospice services than those who did no planning. Those who did not have a written advance directive were more likely to die in a hospital, at home with no formal services, or in an intensive care unit. Additionally, those with no planning were more likely to have been on a respirator or to have had a feeding tube during the last month of life (Teno et al. 2007). In addition, hospital based physicians, emergency and critical care physicians report that having advance directives may contribute to end-of-life decisions that are more accurately aligned with patient desires (Coppola et al. 2001).

Overall, the slow change in healthcare from medical paternalism to patient autonomy has been greeted with support by many patients and physicians, but there are still many people who do not complete formal end-of-life plans. While the number of people who are completing some form of advance directive appears to be increasing, the actual number is under debate. It has often been estimated that advance directive completion ranges from 15% - 20% in the general population (Last Acts 2002, Salmond and David 2005) however some recent studies have indicated that an increasing number of people complete some form of formal advance care planning, especially among those who are older and those who know that they have a condition that could lead to death. In a survey of 203 adults over the age of 65 in the state of Florida, 78.6% of the respondents reported that they had assigned a durable power of attorney for health care and 81.1% had a living will (Black, Reynolds and Osman 2008). Similarly, a nationally representative study found that of 999 deceased older adults who had needed decisions made prior to death but lacked decision-making capacity at the time, 67.5% had either a living will, a DPAHC, or both (Silveira, Kim and Langa 2010). In another study of adults who died non-traumatic deaths in 2000, 70.8% had completed either a living will or had assigned a durable power of attorney for health care (Teno et al. 2007). While there may be an increase in the number of people who are completing advance directives, not everyone completes them and the reasons why they are not completed are not entirely clear. Race and ethnicity, demographics, socioeconomic status, and religiosity have all been indicated as having possible influences on formal end-of-life planning.

One argument that has been posited as to why minorities are less likely to make end-of-life care plans is that they are less knowledgeable about formal planning (Gerst and Burr 2008, Salmond and David 2005). While there have been studies that have indicated that African American adults may be more unfamiliar with advance care planning that White adults (Gerst and Burr 2008, Salmond and David 2005), other studies have found that 96% of African Americans had heard of living wills, and two-thirds could accurately define the circumstances where a living will would be applied (Waters 2001). Equally interesting, interviews with African American, Hispanic, and White adults between the ages of 50 and 79, Perkins et al. (2002) found that there were significant misperceptions about advance care planning among all three groups.

The experience of poverty may negatively influence the likelihood of completing formal plans due to different experiences with the medical field compared to those who have more advantages. Focus groups with twenty inner-city homeless individuals indicated a significant deficit in the relationship that they had with the medical field in general, and compassionate health care providers in specific (Tarzian et al. 2005). Lacking continuity of care due to insurance status, lower levels of health literacy, and distrust of medical providers makes understanding and completing advance care plans less likely.

Most studies on the role of religion in health behaviors have neglected the end-of-life planning although there have been a few qualitative studies documenting the important role of religiosity at the end-of-life for racial minorities, especially for African Americans. Because religion plays a prominent role in many racial and ethnic minorities' lives (Pew Research center 2007, Hill et al. 2005, Lincoln and Mamiya 1990, Taylor, Chatters and Levin 2004), it is possible that religious involvement exposes racial and ethnic minorities to a reference group that does not support official end-of-life planning behaviors, although it may support other informal planning, such as talking to family and friends about the care that they desire.

To summarize, many people are uneasy about dying - they fear being both under-treated and over-treated at the end of life. Because of some high profile cases, there are now legal protections in place for patients to turn to in order to have their end-of-life desires and values followed. The use of formal end-of-life plans appears to be increasing, but racial and ethnic minorities are still less likely to create advance care plans and are still more likely to experience worse deaths than their White peers. It is possible that socioeconomic factors and religion play a role in planning for death and may also mediate whether racial and ethnic minorities plan for death.

Goals and Objectives

The purpose of this study was to explore how older African-American, Hispanic, and White adults plan for the end-of-life as well as to investigate some potential mechanisms that might explain the likelihood of formal end-of-life planning. While there have been a few nationally representative studies on end-of-life planning (Gerst and Burr 2008, Teno et al. 2007), there have been none that have included Hispanics or that have examined the direct and mediating roles that religion may have on formal end-of-life planning. Using a current nationally representative data set, this study compared the completion of formal advance directives (both written instructional directives and assigning a durable power of attorney for health care) across the three racial and ethnic groups of non-Hispanic Black, non-Hispanic White, and Hispanic in the United States. Additionally, socioeconomic status and religiosity were investigated both for their direct influence on end-of-life planning as well as for potential mediating influence on racial and ethnic differences in formal planning. Additionally, other factors known to influence end-of-life planning such as age, gender, family structure, region of death, and cause of death will be investigated. Understanding factors that influence end-of-life planning is of growing importance as a larger number of older adults face progressively complex choices prior to death. As racial and ethnic minorities suffer a disproportionate burden of health disparities, it is important to identify and understand mechanisms that influence health behaviors such as formal advance care planning. The expectation was that by exploring the role that race, socioeconomic status, and religion have on end-of-life planning, it is possible to gain a better understanding of who may be at risk of being inadequately prepared for the decisions and challenges that they will face at the end-of-life.

The three specific aims of this study were:

- To examine whether there are racial and ethnic differences in formal end-of-life planning done by older African American, Hispanic, and White adults.
- To examine socioeconomic factors including education and income in formal end-of-life planning as well as assess the contribution of these factors in explaining racial and ethnic differences in formal end-of-life planning.
- To examine the role of religion in formal end-of-life planning and to assess the influence of religiosity in racial and ethnic differences in formal end-of-life planning.

Implications for Practice, Policy, and Health Disparities Research

This research helps explain differences in the use of formal end-of-life planning. By using a nationally representative sample that included an oversample of African Americans and Hispanics, this study supports and expands previous research that examines racial and ethnic disparities in formal end-of-life planning. I also include demographic factors, socioeconomic status, and religion to examine differences in planning and help point to reasons why some groups who are at an increased risk of experiencing poor end-of-life care are not taking advantage of formal means of planning. Understanding patterns in end-of-life planning is useful for all professionals working with people who are traveling towards their deaths. Support and assistance can be provided to those who are the least likely to prepare for their death and interventions can be directed at the planning strategies that are most palatable to various groups. This can help improve the completion of formal advance care plans, but also can help people engage in the other planning behaviors such as financial and informal personal preparations. The more that death is planned for, the more likely the person will die in accordance to their values and to have a "good" death. In addition, this research challenges disparity researchers to look more closely at the end-of-life. Since the dying are not able to advocate for change, it is up to others to do so.

The next chapter reviews the relevant literature on end-of-life planning as well as the conceptual model used in this study. Chapter three presents the data and methodology used to answer the specific aims of this research. Chapter four addresses results and findings of the research. The final chapter, five, summarizes the findings and conclusions of the study and discusses the implications, limitations, and future directions of study.

CHAPTER TWO: LITERATURE REVIEW AND THEORY

This literature review is divided into seven major sections. The first section discusses how death has changed in the recent past and the medical model of dying that currently influences the most common death. The second section addresses racial and ethnic minorities and what is currently known about their experiences planning for death. The third section considers the role that socioeconomic status has on end-of-life planning. The fourth section discusses the role that religion plays in end-of-life planning. The fifth section addresses additional factors that are important to consider such as age, gender, and family structure. The sixth section will discuss the conceptual model used to help explain the expected relationship between racial and ethnic minorities, socioeconomic status, religion, and end-of-life planning. The seventh and final section of this chapter will discuss the specific aims and research questions of this study.

The Experience of Death

The way that death is experienced in the United States today is very different from deaths even a century ago. Shifts in demographics, technology, medicine, and socio-political factors have changed the context in which people die and therefore the experience of death. The primary causes of death have changed from acute illnesses and accidents to chronic diseases and progressive conditions with no known cure primarily experienced at an older age. Improvements in both social conditions and medical technology have not only allowed people to survive to an older age, but to survive increasingly difficult illnesses and combinations of illnesses. These improvements in successfully warding off death have led many to strive for medical cures for themselves, their loved ones, or their patients, even at advanced stages of illness. Although many of these advances in medical technology do allow the sick and dying to prolong their lives, the process often has serious physical, financial, and psychological consequences for the patient (Last Acts 2002, Teno et al. 2004) and the surviving community including family (Brock, Foley and Salive 1996, Institute of Medicine 1997, Teno et al. 2004), friends (Parsons et al. 2010), and even the medical community (Casey and Walker 2011, Parsons et al. 2010). For the dying individual, the final stage of life is often experienced with disability, physical pain, isolation from family and friends, and loss of autonomy (Last Acts 2002, Teno et al. 2004). Surviving family members may experience physical, psychological, and financial strains as a result not only of the death of their loved one, but of the way their loved one dies (Kapp 2001, Webb and Guarino 2011).

In the 1900's, the life expectancy of was an average of 47.3 years (Center for Disease Control). Most people died from acute infectious illnesses such as tuberculosis, influenza, pneumonia, and typhus (Weitz 2004). Death often came quickly, but the dying person usually had enough time to realize that it was coming and to prepare for it (Kellehear 2007). In this context, a good death was achieved when the dying person and those around were able to address religious, medical, and personal preparations for death at the death bed in the home.

By 2009 life expectancy had reached 78.2 years (Kochanek et al. 2011) and the main killers are now chronic diseases: major cardiovascular diseases, cancer and stroke (Center for Disease Control 2009). A good death is no longer accomplished in the short time around the death bed. The new realities of increasing old age and complex chronic diseases, as well as the proliferation of new medical technology, have changed how we experience death. The new typical death of our time is to die in a hospital with often aggressive interventions (Kellehear 2007). For example, the payment strategies for hospice by Medicare and Medicaid mean that many people who would benefit from palliative or hospice care do not have access to it unless they are willing and able to pay for it themselves. In moments of crisis, instead of being able to get relief and information from someone trained in palliative care, they end up turning to hospitals and medical management by those trained in acute rescue care.

Between 1989 and 1997, Robert Wood Johnson Foundation funded the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a large, two phased, multi-site research project to investigate dying in American hospitals. In Phase One, the investigators enrolled over 9,000 patients who had been diagnosed with a life-threatening illness in one of five U.S. teaching hospitals. The goal of this phase was to detail what was happening to those dying in hospitals. Phase Two had the purpose of designing and implementing an intervention that directly addressed the findings in Phase One. This intervention was intended to improve the outcomes for seriously ill hospitalized patients by improving timely medically relevant information for physicians, improving communications between physicians and patients or proxies, and encourage end-of-life decision making. The results of this study were disappointing - the intervention had little impact on how hospitals were treating dying patients. The dying experience was found to be unnecessarily painful, isolating, and costly, even with interventions specifically put in place to reduce these outcomes (Moskowitz and Lin demann Nelson 1995).

In response to the finding from SUPPORT, improvement of end-of-life care became a priority. The American Medical Association (AMA) and the Institute of Medicine (IoM) both developed goals for improving end-of-life care. The Robert Wood Johnson Foundation (RWJF) founded the Last Acts initiative, a national coalition of more than 800 health and consumer groups in order to improve end-of-life care. The goals of the Last Acts program were to improve dying in America by improving communication and decision making by the dying, changing the culture of health care institutions, and changing American culture and attitudes towards death and dying. Unfortunately, even with their goals in place, Last Acts claimed:

> "Despite many recent improvements in end-of-life care and greater public awareness about it, ... Americans at best have no better than a fair chance of finding good care for their loved ones or for themselves when facing a life-threatening illness" (Acts 2002).

The program was closed, along with its website, in 2005.

The Medical Model of Dying

While most people want to be healthy until the day that they die, the reality for the majority of people in the United States is that they will face chronic illness and disability in the final years of their life (Smedley, Stith and Nelson 2003). Experiences of pain, multiple physical symptoms, as well as changes in social and family roles, financial concerns, and dependence, often are the reality for people during the final years of life. Unfortunately the medical model that most people find themselves in is not well equipped to handle the wide range of issues that dying patients and their families experience. The medical establishment ultimately prioritizes conventional treatment, focusing on physical symptoms, over a holistic treatment of the dying experience.

Palliative care, which focuses on the management of symptoms as well as psychosocial support for both the patient and the family, has the potential to improve the quality of life of the dying individual, decrease the use of invasive medical services, and ultimately provide a better death than the medical model (Last Acts 2002).

The medical model's dominance is clearly shown in the Medicare payment models. Under the traditional benefit package, Medicare pays for nursing home placements if “skilled care” is needed, but does not pay for nursing home when “unskilled” care is needed, so a dying person can only receive assistance for nursing home placement if they are receiving medically managed care, not palliative care. Medicare can only reimburse for hospice care if the physician estimates that a patient has less than six months to live and if the patient is willing to sign paperwork stating that they are electing to enroll in the hospice benefit instead of the regular Medicare benefits, therefore relinquishing curative treatment options (Furman, Doukas and Reichel 2010). This policy has two potential challenges for dying individuals who would benefit from palliative care. First, the physician, who is the gatekeeper to hospice care, must be willing and able to prognosticate when the patient will die. And second, the patient must be ready to stop curative treatment.

Unfortunately, these Medicare eligibility criteria also mean that terminal patients with uncertain prognoses are often excluded from hospice and palliative care. Conditions such as chronic heart failure, emphysema, and Alzheimer's, often have disease trajectories that are difficult to predict and physicians are often unable or unwilling to claim that a patient has less than six months to live even though the patient may benefit from hospice. Other patients may be excluded from hospice care such as the homeless, socially or geographically isolated patients, or those who do not have documentation of citizenship (Moller 2004). Racial and ethnic minorities may also be excluded, either through their own preferences or through language and education barriers. For those that do not enter hospice, health care and community services are not currently organized to meet the needs of the growing number of people who face progressive illnesses and disability before death. When faced with a health crisis, many people have nowhere to turn except for the emergency room and the hospital. According to a recent study of 235,821 Medicare patients who died from a poor prognosis cancer between 2003 and 2007, the use of high-intensity care was common. Within 30 days of death, 61.3% of patients were hospitalized at least once, 23.7% were admitted to an ICU, and 28.8% died while in a hospital (Miesfeldt et al. 2012).

Even though the medical model of care focuses on the management of physical symptoms, most dying patients experience inadequately treated physical symptoms even in a hospital. Pain, dyspnea, fatigue, and anxiety are common symptoms experienced at the end-of-life with most patients who die in the hospital suffering moderate to severe symptoms (Cantor et al. 2003, Desbiens et al. 1999, Desbiens et al. 1996, Lynn et al. 2000). The SUPPORT study found that 50% of patients who were conscious prior to death in the hospital experienced moderate to severe pain at least half of the time. While dyspnea (difficulty breathing) is not well documented, it is likely to be experienced by half of all dying persons and is considered by Truog et al. to be "the most important symptom that must be relieved for patients dying in the ICU" (2001: 2339). Other symptoms that are common in those that are actively dying are nausea, vomiting, fevers, infections, skin ulcerations, anxiety and delirium (Truog et al. 2001). In a study of the symptom experience of seriously ill hospitalized patients near the end of life it was found that the highest symptom scores for all patients were for pain, shortness of breath, difficulty sleeping, dry mouth, and feeling worried. The results of this study indicate that seriously ill, hospitalized patients at the end of their lives experience many symptoms that are frequent, moderately severe, and moderately distressful (Tranmer et al. 2003). All of these studies support the idea that even in hospitals or in the ICU, where patients are surrounded by medical technology, many die with treatable pain (Truog et al. 2001). These troubling deaths are not only a problem for the person dying, but for family members as well. Family members of decedents who have had more aggressive medical care and worse patient quality of life have been shown to be at higher risk of major depressive disorder six months after the death (Wright et al. 2008).

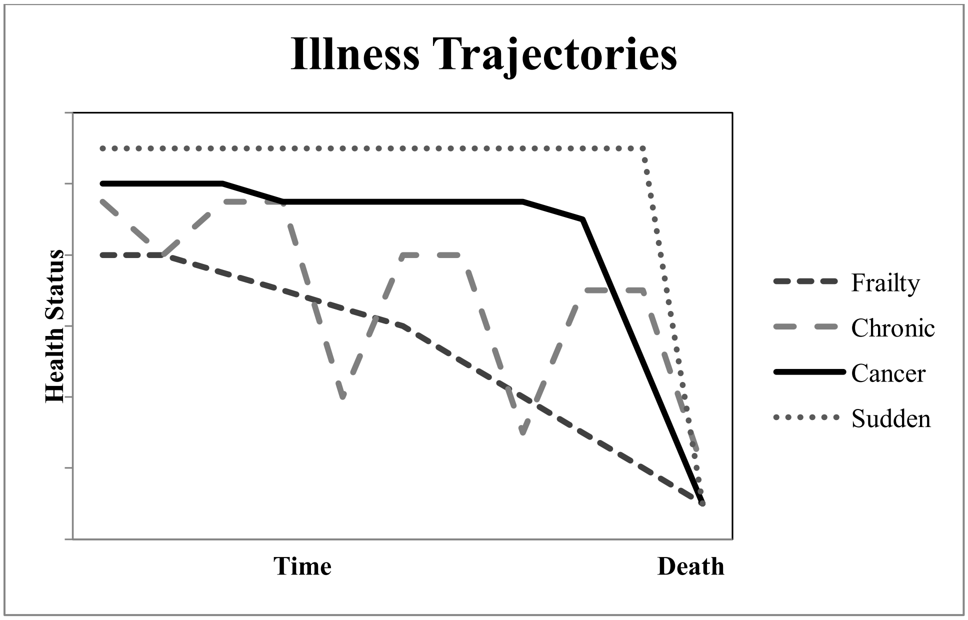
For those who are able to leave the hospital but do not enter into hospice care, the experience of physical symptoms is still troubling. According to the Center to Advance Palliative Care's 2011 Report Card on America's Care of Serious Illness, one-in-three patients who were able to leave the hospital report that they did not receive education on how to treat pain and other symptoms and one-in-three patients did not have any follow-up arrangements with a physician for after their hospital stay (Morrison and Meier 2011). Because of the structure of care that has developed in the United States, the majority of people facing the end of their lives who are not enrolled in hospice experience fragmented care with no one specifically in charge of coordinating palliation and all that it involves. Care coordination, or lack thereof, has important ramifications for patient outcomes as well as costs. Palliative care specialists are a recent addition to the end-of-life experience. In fact, the palliative medicine specialty only received formal recognition from the AMA in 2007. Although the number of accredited training programs has increased, the numbers are still too low to produce enough specialists for the needs. In 2010 there were only 73 programs in the United States which produce approximately 86 new palliative medicine physicians per year (Morrison and Meier 2011). This leaves most of the day-to-day palliative care to be provided by family members, friends, and other volunteer workers (such as church members or neighbors).

Illness Trajectories

Although each person's experience with death is unique, there are some commonalities in disease trajectories (Lunney et al. 2003, Lynn 2004, Lynn 2005). Diseases such as most cancers have a trajectory that is relatively predictable. Most people with these illnesses are able to maintain functioning and relative comfort until the illness overwhelms the body. At that point the person experiences a rapid decline. This trajectory is very compatible with current approaches in hospice and hospice payments: physicians can fairly accurately predict the decline, the decline is rapid, and cure at that point is unlikely making refusal of curative treatments more acceptable to many patients and families. Organ failures, such as liver failure and congestive heart failure, have a trajectory that is marked by periods of relative stability interrupted by acute episodes. While there may be a slow decline between episodes, it is difficult to know which acute episode may lead to death. Death in this trajectory is often 'surprising' even if the person, the family, and the physician are aware that the patient has a terminal condition. The third trajectory is one that is common among patients experiencing dementia and Alzheimer's. This trajectory is a slow decline and the person experiences greater and greater general frailty. Death is not easy to predict in this trajectory because it may come about through various means such as an infection (especially if there has been the decision to not use antibiotics) or another illness that the frail body is unable to fight off. The last trajectory, sudden deaths, is not predictable. People who die because of an accident or injury are generally healthy enough prior to the incident that death is not expected. Although each of these trajectories have significant differences, and there are individual differences within each trajectory, there are enough similarities that it is possible to encourage end-of-life planning for everyone and as well as to encourage thinking about specific concerns based on the illness trajectory one is facing.

Figure 1: Illness trajectories

(Based onLunney et al. 2003, Lynn 2004, Lynn 2005)



Racial and Ethnic Minorities and End-of-Life Planning

Despite years of research reporting racial and ethnic disparities in health and healthcare in the United States, individuals from racial and ethnic minority groups continue to lack access to health care, receive poorer quality of health care, have worse health outcomes, and more frequently die from treatable conditions than Whites do (Smedley, Stith and Nelson 2003). Although the reasons for these disparities are complex, the sources include patient-level, provider-level, and health system-level issues including medical staff and physician biases, lack of cultural familiarity within medical encounters, the time and physical conditions of the medical encounter, language barriers, access to care, financial barriers, socioeconomic status, and neighborhood segregation (Smedley, Stith and Nelson 2003, Williams and Jackson 2005). According to the Institute of Medicine report (1997), of these different factors the patient-level factors such as preferences and treatment refusals contribute the least to health disparities.

Minorities continue to receive poorer quality of care at the end-of-life (Barnato et al. 2006, Loggers et al. 2009, Rhodes and Teno 2009). Although there are significant differences between minority groups, both Hispanics and African Americans experience some similarities in the disparities they face at the end of life. Patient-physician communication, utilization of hospice, and utilization of advance directives are more problematic for both Hispanics and African Americans compared to Whites (Born et al. 2004, Carr 2011, Huskamp et al. 2009, Smith, Sudore and Pérez-Stable 2009, Thomas et al. 2008). Huskamp et al. (2009) found that Hispanics and African Americans who were diagnosed with metastatic lung cancer were less likely than their White peers to have had a physician discuss hospice with them. In a nationally representative sample of patients who were participating in home health care or hospice, it was found that Black and Hispanic home health patients were less likely to have advance directives than were White patients, and although hospice patients had overall higher levels of advance directives, Black hospice patients were less likely than their White peers to have one (Resnick, Hickman and Foster 2011). In a qualitative study, Volker and Wu (2011) interviewed African American, Hispanic, and White patients who had been diagnosed with advanced cancer and were no longer receiving curative treatments. Interestingly, they found that all three groups expressed similar values in regards to autonomy and control. All three groups expressed preference for personally controlling treatment decisions in the final days of their lives.

African Americans are more likely than Whites to use emergency services, as well as to use life-sustaining interventions such as being on a respirator or having a feeding tube, all of which are associated with a worse quality of death (Hanchate et al. 2009, Welch, Teno and Mor 2005). Although racial and ethnic minorities are more likely to die in a hospital (Gruneir et al. 2007), they do not have better outcomes in social or emotional support, pain management, or respect for treatment desires (Loggers et al. 2009, Rhodes and Teno 2009).). In a study of Medicare patients who died from poor prognosis cancers, Blacks were more likely to receive more aggressive acute care than Whites but they were less likely to receive late chemotherapy which is sometimes used as a way alleviate distressing symptoms (Miesfeldt et al. 2012). In addition, African American families are more likely to report lower satisfaction with physician communication, especially regarding being informed about possible treatments and what to expect during the dying process (Welch, Teno and Mor 2005).

There has been fairly consistent evidence that African Americans are more likely to want aggressive care at the end-of-life and less likely to request lower levels of care than White Americans. As an African American participant in a focus group stated:

> "I'm not going to accept it if he (the doctor) tells me I have only 2 years to live.... My grandmother always told me 'illness is the devil - you rebuke him.' I'll be the one to prove them wrong" (Born et al. 2004:250).

Partly because of the higher use of intensive care, African Americans have higher costs at the end-of-life than White Americans (Hogan et al. 2001). Additionally, the effect of paying for this medical care has been found to be more troubling for African Americans than for Whites. Welch et al. (2005) found that African Americans were twice as likely as Whites to have depleted their savings in order to pay for end-of-life care of a family member. Although there were similar rates of somebody quitting a job in order to care for a dying family member, African American families were twice as likely as White families to report that covering the cost of care was difficult.

African Americans have been found to be less likely to write an advance directive than Whites (Carr 2011, Gerst and Burr 2008, Kwak and Haley 2005). In a qualitative study using focus groups of African Americans, Waters (2001) found that themes emerged including that death is outside of personal control and therefore religiosity or spirituality and end-of-life planning is a contradiction, distrust that the health care system will behave in their best interests, and that family and friends will make sure that they are cared for appropriately. But while that research found that African American patients who are facing end-of-life medical decisions tend to rely on trusted family members, friends, or clergy members (Waters 2001) and are therefore less likely to rely on written instructions, this has not been supported in other research. Using data from a nationally representative survey conducted in 2000, Gerst and Burr (2008) found that African Americans were not only less likely than Whites to have a written health directive or assign a durable power of attorney for health care, but they were also less likely to have discussed end-of-life wishes with others. Unfortunately, this study did not consider Hispanics or any other racial or ethnic minority group.

Concerns over discrimination are a common theme found in studies of end-of-life care and African Americans (Duffy et al. 2006, Loggers et al. 2009, Waters 2001). Distrust in the health care system has a long history based on racism and discrimination. This distrust is not unfounded - even when African Americans express their preferences for end-of-life care, it is often not followed. A multicenter prospective cohort study found that the preferences of African American patients in end-of-life care settings were ignored or overlooked by physicians more often than the preferences of White patients (Loggers et al, 2009). In fact, the Caucasian patients who expressed desire for aggressive treatment were three times more likely to receive it than African Americans who expressed the same preferences. Among 302 patients with stage IV cancer, Black patients were less likely to receive the care that they wanted than White patients, even when they had end-of-life discussions with their physicians and Do-Not-Resuscitate orders written.

There have been far fewer studies regarding Latino's end-of-life experiences and preferences, with no nationally representative studies. One commonly cited barrier to care, not surprisingly, is not having a physician who speaks Spanish (Born et al. 2004, Randall and Csikai 2003, Smith, Sudore and Pérez-Stable 2009). Discussions of terminal prognosis and end-of-life decisions are complex enough when both parties speak the same language, but when there is both a cultural and a language barrier, these discussions may be almost impossible. Additionally, lack of familiarity with the health care system, including the use of hospices or pain relief, create barriers to accessing end-of-life care (Randall and Csikai 2003). Latinos have additional difficulties if they are recent immigrants or undocumented, such as being separated from their family, being uninsured, and being fearful of deportation (Smith, Sudore and Pérez-Stable 2009). The use of advance directives by Hispanics has been studied even less frequently than general end-of-life care and hospice utilization, and the resulting studies often do not agree with one another. One telephone survey of 82 Whites and 67 Latinos found that while the Latino respondents were less likely to complete advance directives or talk to family members about advance directives, there was no significant differences between the groups on having heard about advance directives or their attitudes towards their use (Wittenberg-Lyles, Villagran and Hajek 2008). In another study, after exposure to information about advance directives, Latinos were more likely than their White peers to discuss issues around end-of-life planning with their family, friends, and medical doctors (Sudore et al. 2008b). Similarly, in a study using cross sectional interviews of older Latinos in the greater Los Angeles area, the majority (84%) reported preference towards comfort care rather than care to extend life yet only 24% had an advance directive and 47% never discussed their preferences with either their family or their physician (Kelley, Wenger and Sarkisian 2010). These studies suggest that observed rates of more aggressive care at the end of life for Hispanics may not represent actual preferences.

Socioeconomic Status and End-of-Life Planning

Because of the belief that upward mobility is within everyone's reach, social class has generally been underemphasized as a determinant of health outcomes in the United States, although two of the traditional components of socioeconomic status (SES), income and education, are often associated with health outcomes. Having a lower SES is associated with lower health care use as well as lower health care quality (Fiscella et al. 2000). People in low SES groups receive fewer mammograms and fewer influenza immunizations (Hahn et al. 2009), and are less likely to plan for their deaths (Moller 2005). Additionally, socioeconomic status is one of the factors that may explain racial and ethnic differences in end-of-life planning.

Link and Phelan have theorized that SES is a "fundamental cause" of health disparities (Link 2008, Link and Phelan 1995, Phelan et al. 2004, Phelan, Link and Tehranifar 2010). According to their research, higher SES is protective of health regardless of the mechanisms of illness because SES includes access to a variety of resources including money, knowledge, prestige, power, and beneficial social connections (Link 2008, Phelan, Link and Tehranifar 2010). People who have higher SES use these to both keep themselves healthy as well as to minimize damage if they do become ill.

While death comes to everyone regardless of their SES, having access to money, knowledge, and beneficial social connections may be the difference between a "good" and a "bad" death. The amount of suffering experienced while dying is not only caused by disease progression. Experiences of deprivation and disadvantage, such as lack of air conditioning or heating or social isolation, make suffering worse (Moller 2004). In addition to the emotional and physical stressors that most dying patients experience, the dying poor face the compounding stress of their poverty. Poverty shapes the process of dying through interactions with medical and financial bureaucracies often in ways that are not experienced by the more affluent (Kellehear 2007, Moller 2004, Moller 2005).

Access to resources also may make the difference between a death that is alignment with a person's wishes and one that is not. Gruneir et al. (2007) found that in addition to being white and having cancer, people who were financially better-off and those with social support were more likely to die at home rather than in a nursing home or in a hospital. Education, as a part of SES, may also play a part in whether people are able or willing to fill out an advance directive. While health literacy is considered a foundational element for quality health care and the Institute of Medicine has had a roundtable organized to address health literacy since 2007 (Institute of Medicine 2012) there are indications that end-of-life care still suffers from significant health literacy issues. A study published in 2010 that explored the readability of advance directive forms found that no state supplied forms were readable at the recommended 5th grade level and only 5 of the 47 states had forms that were readable at the 8th grade level, which is the average reading level for adults in the United States (Mueller, Reid and Mueller 2010). Similarly, a 2009 article that reviewed end-of-life educational materials from five prominent palliative care websites found that almost one third of the educational materials required a university level of literacy skills, which is far more advanced than the average (Ache and Wallace 2009).

Because of the close ties between racial and ethnic minority groups and lower SES in the United States, it is often difficult to disentangle their role in health disparities.

While racial and ethnic minorities, the poor, and the less educated are less likely to plan for the end-of-life, the impact of SES on racial differences in formal end-of-life planning has not been explored.

Religion and End-of-Life Planning

From Marx's assertion that religion is created by those in power to keep the masses pacified (Marx 1967) to Durkheim's "Elementary Forms of the Religious Life" (Durkheim 1965) the influence of religion on society has been a frequent premise in sociology. Durkheim believed that religion not only influenced the thinking and behavior of individuals but that social solidarity, uniting beliefs, and values were created through religious rituals and ceremonies (Durkheim 1965). While one may question Durkheim's functional perspective on religion, the concept that religion is important to people and society can hardly be denied. In the United States, 92% of respondents to a 2011 Gallup poll expressed a belief in God, 80% state that religion is at least fairly important to them, and 79% consider the Bible the actual or inspired word of God (Gallup 2009).

It is common for people to search for meaning in their lives when they are dying, and in the process turn to religion (Kemp 2002, Lloyd-Williams, Cobb and Taylor 2006, Sulmasy 2006b). Studies have supported the importance of religion to individuals considering treatment decisions. In 1997, 177 adult patients were surveyed at a pulmonary outpatient practice. Fifty-one percent described themselves as religious and 45% of respondents indicated that spiritual or religious beliefs would influence their treatment decisions if they were seriously ill (Ehman et al. 1999). Lambert et al. (2005) found that among long-term-care residents, spiritual considerations were important to their decision-making. This means that for end-of-life care, religion is likely to play a role for a majority of people, yet the role that religion plays in end-of-life planning is unclear. Some studies indicate that religion is negatively associated with completing formal planning (Balboni et al. 2007) while other studies have indicated that those who are more religious are more likely to have written advance directives (DeLuca Havens 2000) or have assigned a durable power of attorney for health care (Karches et al. 2012).

Most religions maintain specific beliefs concerning life and death. Although the dominant religious traditions in the United States (Protestant and Catholic) are both based on Christian traditions, there are some significant differences between them. While Catholics have a uniformity of practice and moral thought through the historical role of the papal leadership, the Protestant faith is linked only through adherence to common doctrine (Low 1997). This has created variations in teachings that may impact end-of-life decisions. In general, Protestants do not have moral opposition to stopping medical treatments and allowing someone to die when the treatments are deemed ineffective (Sharp, Carr and Macdonald 2012). On the other hand, Catholic leaders have supplied formal statements regarding the sanctity of human life. For example, The United States Conference of Catholic Bishops stated that care must be taken against advance directives that encourage actions that may shorten life since this goes against Catholic teachings regarding the sanctity of life (Activities 2011, Bishops 2009, Bishops 2001, Bradley 2009). While the right of the patient to direct their own care if they wish to avoid ‘extraordinary care’ through advance directives was supported, directives that do not follow the teachings of the Catholic Church regarding ‘ordinary care’ that supports life are not to be followed (Activities 2011, Bishops 2009, Bishops 2001).

Religious coping, described as how a patient uses religious beliefs to understand illness and adapt to stress, has a surprising effect on end-of-life experiences. Although religious coping has been associated with positive psychological adjustment for people facing stressors, it also is associated with receiving intensive life-prolonging medical care prior to death (Balboni et al. 2007, Phelps et al. 2009, Sulmasy 2006a). Although the mechanism for this relationship is unclear (Phelps et al. 2009), religious beliefs may decrease the likelihood of written advance directives. In one focus group study, participants likened planning that declined medical intervention to assisted suicide:

> "In the Bible, you're not supposed to take your life. True Christians would leave it up to God. And there's that contradiction again. Signing a living will would be a death warrant, and one would go to hell." (Waters 2001)

The importance of clergy to the dying is often cited in research articles (Duffy et al. 2006, Waters 2001) but little research has actually been done on the impact that religious advisors have on the dying. Unfortunately in studies done exploring how the clergy interact with parishioners it appears that the clergy are not well equipped for the corporal aspects this important work. One study by Doka and Jendreski indicated that not only do clergy receive little formal education on end-of-life issues, but they had considerable misperceptions of the nature and process of grief (Doka and Jendreski 1985 as described in Abrams et al. 2005). While pastoral care for the dying and bereaved is a core activity for parish clergy, the majority of the clergy report a need for further training in how to help the dying as well as what services are available (Lloyd-Williams, Cobb and Taylor 2006, Reese et al. 1999).

Religion is a complex variable with multiple dimensions that can be measured to capture different ways that religion may help guide decisions and behaviors in everyday life (Fetzer Institute 2003). Religious preference, or the identification with a religious community or tradition, provides information about not only a person's belief system but also provides information about the surrounding social environment (Ellison 2003, Flannelly, Ellison and Strock 2004). Each religion has beliefs, teachings, customs and rituals that impact the individuals who support that faith as well as the surrounding cultural environment. This dimension is commonly asked in large surveys (e.g. General Social Surveys), and is frequently a single question with those who report being Protestant being asked to further specify a denomination (Ellison 2003).

Organizational religiousness, or the involvement with a formal public religious institution (Idler 2003), has consistently been shown to have a positive impact on health (Levin and Chatters 1998, Lucchetti, Lucchetti and Koenig 2011, Wink, Dillon and Larsen 2005). Frequent attendance at religious services may indicate stronger conformity to religious teachings as well as greater connections with the religious social network (Ellison and Levin 1998, Gillum et al. 2008, Levin 2009). The single item question of frequency of attending religious services is considered a reliable indicator and is also commonly asked in large surveys such as the General Social Surveys and Gallup Polls (Idler 2003). Religious commitment, or the personal importance of religion, captures the salience of religion in daily life. Although this dimension has received less attention in health research than the previous dimensions, the single item measure of importance of religious beliefs has been used in some studies (Williams 2003).

While severe illness could possibly prevent someone from attending religious services, studies have found that negative stressors of aging, such as poor health, generally do not significantly impact religious involvement (Wink, Dillon and Larsen

2005). In fact, religious involvement may become particularly important during times of stress.

While it seems clear that religion likely impacts preferences for end-of-life care, there is little information about the role that religion has in shaping whether these preferences and decisions get turned into formal plans. Nor do we understand racial and ethnic differences in the role that religion has for formal planning. The differing role that religion has on various racial and ethnic groups for end-of-life care has been implied in qualitative research studies and in some limited samples of "non-White" participants. For example, in one study exploring the factors that may inhibit the use of hospice among poor African Americans and Latinos, all of the groups discussed the major role that religion plays in coping with dying (Born et al. 2004), but the issue of advance care planning was not addressed.

The church plays an important role in both the African American and Hispanic communities in ways that are different than the role that the church plays for White communities (Pew Research Center 2007, Lincoln and Mamiya 1990). Because of the historical experience of racial discrimination and segregation, the church grew to provide political, economic, emotional, and spiritual assistance and leadership to the African American community in ways different than in the dominant White community (George 1988). African Americans report higher levels of many dimensions of religiosity, such as religious practice, importance of religion, religious membership, comfort found in religion, and subjective religiosity, compared to their White peers (Ferraro and Koch 1994, Levin, Taylor and Chatters 1994, Taylor, Chatters and Levin 2004). Hispanics also report high levels of religiosity, with the majority reporting that they pray every day and attend religious services at least once a month (Pew Research Center 2007). In addition, significant majorities of Hispanics believe that miracles happen today just as they did in ancient times (Pew Research Center 2007). Because the mystery of death lies solidly in the purview of religion, the historically and culturally grounded sense of identity that religion and the church provide may help explain racial and ethnic differences in approaches to death and end-of-life planning.

Other Factors that May Influence Formal End-of-Life Planning

The demographic factors of age, gender, and family structure, as well as the region where death occurs, and the illness trajectory itself may influence formal end-of-life planning. The impact that these factors have may also help explain racial and ethnic differences in end-of-life planning.

Age

Today, the majority of deaths occur in people who are over the age of 65. In 2007 the life expectancy was 77.9 years (Arias 2011), but the "oldest old" (over the age of 85) are the most rapidly growing elderly age group in the United States. In 2009 they were 11.6% of the elderly (US CensusBureau "Sixty-Five Plus in the United States") and it is expected that by 2050 that percentage will climb to 24% of the elderly and 5% of all people in the United States will be over the age of 85. This aging population is an important research area for gerontologists, but there is a trend in the gerontology research to focus on an agenda of “positive" or "successful" ageing and leaving medical researchers to address end-of-life issues in the context of chronic illness (Kahana, Lovegreen and Kahana 2012). The tendency to neglect death and dying in gerontology literature may indicate a belief that there are few opportunities for older adults to be engaged and involved in their own well-being (Seymour, Witherspoon and Gott 2005). It is also possible that there is a belief that conversations about well-being and dying are mutually exclusive, but this paradoxically leaves something that significantly impacts the elderly out of the realm of gerontology discussions.

While many older adults remain healthy into late old age, some experience the challenges of chronic illness, reduced income and resources, loss of spouses and other social support, and "fundamental inequalities in health and social care provisions" (Seymour, Witherspoon and Gott 2005:viii). Much research and many policies focused on the end-of-life have been left to medical specialists who deal with specific diseases and conditions and a wide age range. Therefore, the specific needs of dying older adults have often been neglected (Moss 2000, Seymour, Witherspoon and Gott 2005). As a society we tend to assume that death in old age is 'natural' or 'timely' (Howarth 1998) and therefore less worthy of concern than deaths of those who are younger. Combining this assumption with the lack of research on the experience of the dying elderly, many older people do not receive the care and support that is provided to younger dying patients (Bowling 1999, Kapp 2002, Pedersen et al. 2008).

One of the earliest public discussions about how age is involved in health care rationing was in 1987 when Daniel Callahan's published "Setting Limits: Medical Goals in an Aging Society." In this book Callahan puts forward the notion that medical care rationing based on age would be both ethically and fiscally responsible. Many people found this notion problematic (see Homer and Holstein 1990) and believed that it was a dangerous step towards eugenics (Neuhaus 1988). Unfortunately, significant evidence has been found that there is de-facto age-based rationing by health care providers. The older that patients are, the less likely they are to receive specialty care or intensive medical care even when other explanatory variables have been taken into account (Bowling 1999, Kapp 1998). Jones et al. (1996) found that elderly patients with isolated long-bone fractures were less likely than younger patients to receive pain medication, and when they did receive pain medication they waited for longer times and received lower doses. Seymour, Witherspoon, and Gott (2005) in research in the UK found that older patients were less likely to enter hospice than younger patients and older patients were also more likely to be taken to the emergency room than younger patients even when they had requested not to be transported.

Although older patients are more likely to engage in end-of-life planning than their younger peers (Ai 2006, Black, Reynolds, and Osman 2008), there have been no studies that have explicitly explored the reasons that advanced age increases formal planning. One recent study indicated that patients who were older, had gone through a major surgery or were encouraged by their medical provider to complete an advance directive were more likely to do so (Alano et al 2010). As a person ages, the reality of personal death may become more real due to increasing physical limitations and the experience of the deaths of family or friends. Additionally, it is possible that the older a person is, the more likely that they have been exposed to formal planning through discussions with family or physicians. These sensitizing experiences may increase the likelihood of completing formal end-of-life plans as a person ages.

There is a paucity of studies that specifically explore the age related experiences of racial and ethnic minority elders around formal end-of-life planning. The studies that are available indicate that many older people, regardless of race or ethnicity, experience disadvantage and discrimination because of their age (Bowling 1999, Hamel et al. 1999, Pedersen et al. 2008).

Gender

While disparities in the experience of illness and healthcare between men and women have been documented throughout the lifespan, little research has been done on end-of-life care. Women are overrepresented among the elderly: in 2009, 12.5% of the population was 65 or older (n= 37,788), of these 56.8% were female. As they enter late old age, the percentage of surviving women increases with women accounting for 66% of those over the age of 85 (United States Census Bureau). As both the largest and poorest section of the elderly, women should account for the majority of public spending in end-of-life care, but this has generally not been found. Some studies indicate that this may be because women are less likely to prefer, as well as less likely to receive, aggressive treatments such as CPR, artificial nutrition and hydration, or surgery at the end of life (Bookwala et al. 2001). Other studies indicate that there may be other reasons for the lower spending: women are also less likely to receive expensive, high-tech procedures such as transplantation or dialysis, have later diagnosis of lung cancer, and are less likely to have therapeutic interventions for heart disease (American Medical Association 1991).

While multiple studies have shown that women receive less aggressive care they are more likely to spend more time living in a care facility. Women represent three quarters of all nursing home residents (Agency for Health Care Research and Quality, 2003). For some older people, entering a care facility can be a positive experience. They may experience decreased social isolation, increased personal care and overall well-being. Unfortunately, for some patients this is not the case. Gender differences in living in care facilities are influenced by other variables such as marital status which can act as a proxy for the availability of informal caregivers (Arber and Thomas 2004). Older women are less likely to have a living spouse that can take care of them should they become ill or disabled. Therefore a short term stay to recover from an acute episode of illness may become permanent because of the lack of support or services needed to return home. Additionally, Medicare generally will pay for nursing home care but not for home care, which may make returning home infeasible for some.

In addition to those who enter nursing homes after a hospital stay, it is not uncommon for nursing home patients to enter the hospital at the end of life. Many nursing homes do not feel that they are adequately prepared to handle actively dying patients and routinely transfer them to a hospital (Moss 2000). The fact that many care facilities regularly refer their residents to a hospital when they are close to death means that women are potentially more likely to die in an environment and situation that they do not want.

Differences in end of life planning strategies could be expected to exist given the well-established pervasiveness of gender differences in other health related behaviors and experiences. For example, while men are more likely to be hospitalized, women are more likely to visit a doctor on a regular basis and have a medical home (Lorber 2000). Given persistent gender inequalities in health and health behaviors, there may also be differences in the approach that men and women take to end-of-life planning.

Social Support and Family Structure

Numerous studies have found that social support is a factor influencing responses to stress and illness (House, Landis and Umberson 1988, Thoits 1995, Umberson et al. 1996). Ertel et al. (2008) found that older adults with low social integration had memory decline that was twice that of the most integrated elders. Marriage, as a form of social support, has consistently been found to decrease mortality risks (Idler, Boulifard and Contrada 2012), which is possibly stronger for men (Umberson et al. 1996). The mechanism for how social support influences health is unclear. It appears to have both a physiological impact as well as a psychological response. One of the more accepted theories that could be relevant to this research is that social support acts as a stress-buffer (Thoits 2011). In this, social support can function through emotional, informational, and instrumental assistance (Thoits 2011). Emotional support includes activities that demonstrate care such as providing encouragement or sympathy. Informational support includes giving advice and information, such as discussing difficult situations and possible solutions. Instrumental support includes practical assistance, such as providing money or physical labor.

The involvement of family and friends in medical care includes helping with patient / physician communication, linking the patient with services, and helping to understand and navigate the care system (Ai, Hopp and Shearer 2006). Less is known about how support systems created within the family structure affect end-of-life care planning behaviors, especially the role that children play. In one study done on patients undergoing major cardiac surgery it was found that patients with greater social support were more likely to have done some form of end-of-life planning than those with less social support. It was posited that social support may have played two roles for the patients. The first is that social support may have provided emotional support as well as problem-solving support to the patient which allowed the patient at the end of their life to cope with the attendant stress and consider end-of-life planning. The second is that those with more social support may prepare for death out of concern that their family and friends will be negatively impacted if there is no plan in place and the surgery had complications (Ai, Hopp and Shearer 2006). Conversely, social isolation has been linked to not planning for the end-of life, often due to the lack of an available proxy (Morrison et al. 1998).

The Patient Self Determination Act regulates that information is provided to patients when they enter a facility, so it may be important to not only look at the number of times that a patient is exposed to it (discrete contacts with facilities covered by PSDA), but also who the patient subsequently talks to about advanced directives. Understanding how social support influences end-of-life planning behaviors will allow for the design of effective interventions by targeting potential points of where assisting social support may be the most effective.

Region of Death

Where a person dies can influence not only what is available for end-of-life care, but what is considered normal or appropriate care. One recent study found that hospitals in the MidWest and the West were more likely to have hospital palliative care programs than hospitals in the NorthEast, but that access to palliative care services are especially limited in Mississippi, Alabama, and Oklahoma (Goldsmith et al. 2008). Areas with higher levels of medical specialists tend to have higher use of specialist services (Starfield, Shi, Grover, and Macinko 2005) and areas with more palliative services tend to have more people who use palliative services (Goldsmith et al. 2008).

Community-level religiosity may also influence what is considered appropriate medical care. Religious ecology, in its simplest form, refers to religion as a "structural property of communities" (Blanchart et al 2008, p 1503). In other words, the dominant religious environment will impact the overall culture and structure of the community which in turn impacts health, health care services, and orientations towards the use of these services (Bartkowski, Xu and Garcia 2011).

Illness Trajectories

Although each death is unique, there are some commonalities among disease trajectories that can influence how a person dies and the likelihood that a person will complete formal end-of-life planning (Lunney et al. 2003, Lynn 2004, Lynn 2005). Cancer's relatively predictable trajectory and compatibility with current approaches to hospice and hospice payments increases the likelihood that end-of-life desires will be documented. Death following the organ failure trajectory, with periods of stability broken by acute episodes, are often less expected even if there is acknowledgment that the person has a potential life limiting condition. Planning may not be addressed since the timing of death is uncertain. The slow decline experienced by those following the frailty or dementia trajectory allows the time for discussions to take place, but since death is difficult to predict in this trajectory, people may postpone decision making until they do not have the capacity to execute it. The sudden death trajectory is the least expected death and therefore is the category of death that is least likely to have completed formal plans.

Conceptual Model for Understanding Differences in Formal End-of-Life Planning

Much of the legal and academic discussions about end-of-life decisions have focused on individual behaviors that are believed to lead to formal end-of-life planning. This focus often assumes a rational and linear decision-making process and minimizes contextual factors. These models indicate that people choose behaviors that are in their best interest when they are provided with the necessary information. The Patient Self Determination Act is premised on the concept that if individuals are provided with the information regarding formal end-of-life, they will make the decision to complete formal plans. Since end-of-life planning is not completed by everyone, the reasons and mechanisms of these differences need to be explored.

Based on a review of relevant literature, I created a conceptual model to ground this research (Figure 2). The factors that appear to be important in determining the likelihood of end-of-life planning are race, socioeconomic status, and the demographic factors of age, gender, family structure, location of death and cause of death. Studies have also found that religion is an important mechanism to understand differences in end-of-life planning. These factors are conceptualized to both independently influence formal end-of-life planning as well as influence racial and ethnic differences in formal end-of-life planning.

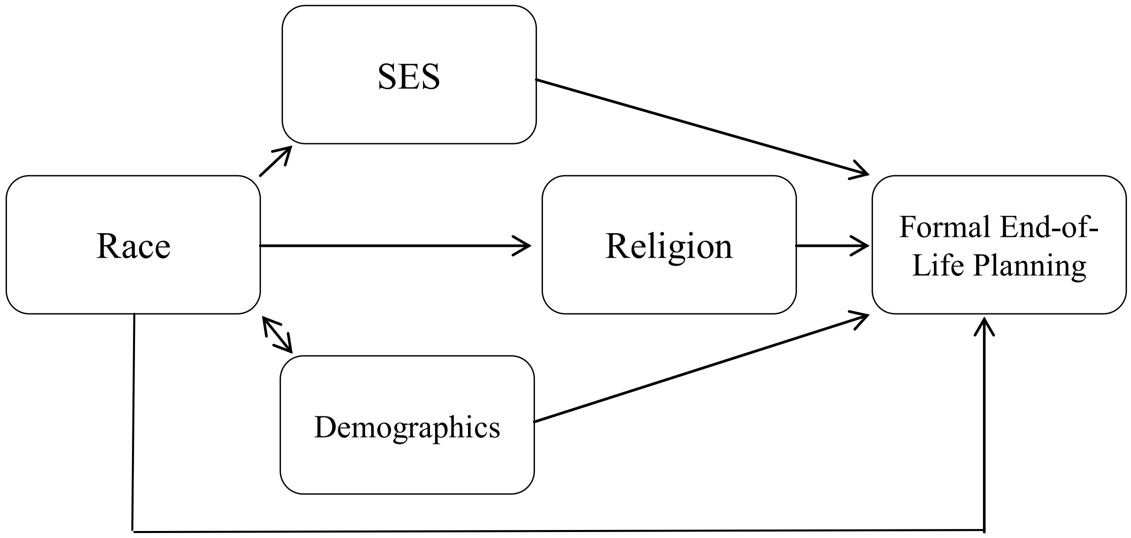


Figure 2: Conceptual model

How Does Race Influence Formal End-of-Life Planning?

In this model, race is expected to have a direct effect on formal end-of-life planning as well as through three pathways where race can influence the completion of plans. The direct effect is due to personal and historical experiences with racism, prejudice, and discrimination which dissuade racial and ethnic minorities from engaging with both the medical and legal fields involved with end-of-life planning. Experiences such the federally funded Tuskegee Syphilis Study which kept African American males from receiving medically known and available treatment for syphilis, have left many Blacks mistrusting the medical field and concerned that that they will receive less care because of their race (Boulware et al. 2003, Lang et al. 2013). Since the medical model of end-of-life care considers aggressive care to be the standard, racial and ethnic minorities may believe that it is not in their best interest to complete formal plans that encourage less care.

Another possible pathway for racial and ethnic disparities in end-of-life planning is through disparities in socioeconomic status. Because society is hierarchically structured, where a person is positioned in the social structure influences resources that are available (Grusky and Ku 2008). Socioeconomic status generally includes three domains of stratification: education, occupation, and income. Racial segregation creates differences in the quality of education received with minorities receiving lower quality elementary education and fewer opportunities to complete higher education. Additionally, racial segregation limits the job opportunities available to minorities and the security and benefits that are available (Oliver and Shapiro 1997). Even with comparable education, Blacks are less likely to be hired and are paid less than Whites (Bertrand and Mullainathan 2004). This impacts not only their income level, but also their overall wealth. Because race is associated with income through segregation, education, and job opportunities, access to medical care is worse for racial and ethnic minorities than for Whites. This provides minorities with fewer opportunities to get consistent medical care, relevant and accurate information regarding their health from providers that they have developed trust in, and information regarding the implications of medical care at the end of life.

Another possible pathway for racial and ethnic disparities in end-of-life planning is through the different role that religion has for African Americans, Hispanics, and Whites. There are significant racial differences in religious preferences with Blacks being predominantly Protestant, Hispanics predominantly Catholic, and Whites being more evenly distributed (although the majority of Whites are Protestant). Additionally, the role that both religion and the church itself have is different for Blacks, Hispanics, and

Whites. Because of the experiences of racism and segregation, the Black Protestant church fulfills a different role than the White Protestant church or the Catholic Church for the community. Whereas most religious people turn to their church for spiritual support, Black parishioners turn to their church for guidance and assistance with political, economic, emotional, spiritual and leadership matters (Chatters et al. 2009, Lincoln and Mamiya 1990).

As with socioeconomic status and religion, there are race differences in the demographic characteristics in old age. Blacks tend to die younger than Whites or Hispanics but Black women outlive Black men (Miniño 2013). Whites and Hispanics are more likely to be married than Blacks (Copen et al. 2012) but Hispanics and Blacks are more likely to have children than Whites (Martin et al. 2012).

How Does SES Influence Formal End-of-Life Planning?

In this model socioeconomic status is expected to have a direct influence on formal end-of-life planning. Socioeconomic status (SES) generally includes three domains of social stratification: income, education, and occupational social class. While each of these three domains act as indicators of position within the stratified structure of society, they each exert separate effects.

Income is a direct indicator of economic position. Higher income allows for higher purchasing power which may include better health insurance or specialist health care. Access to these benefits increases the likelihood that a person will be exposed to the idea of formal end-of-life planning. Additionally, people with higher incomes are more likely to have financial wills in order to distribute financial resources after their death.

The process of completing a financial will may sensitize the person to the need to make other end-of-life plans or their legal guide may encourage the completion of formal end-of-life plans.

Education is expected to have an impact on the decision to complete formal planning primarily through the mechanism of increased health literacy. Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Health Literacy 2004:32). Health literacy encompasses more than the ability to read. It includes skills in reading, listening, analyzing, and decision-making, as well as the ability to appropriately apply these in health related situations. Although health literacy is not directly taught in higher education, skills such as the ability to find and evaluate relevant information are.

While income and education may have independent influences on formal planning, to frame the underlying mechanisms of socioeconomic positions on health care decisions and behaviors it is helpful to consider the differences in the acquisition of economic, cultural, and social capital. Socioeconomic disparities in end-of-life planning can be understood as differences in the acquisition of capital, specifically in capital that is relevant to the medical field. Economic, social, and cultural capital all help shape social stratification (Bourdieu 1986) and can be usefully employed to understand differences in end-of-life care and planning.

Economic capital are resources that can easily be converted into money. For those that are ill, economic capital provides access to specialist care that may not be available to those with less economic capital. Income, although only one measure of economic capital, functions as an indicator of economic position within the social hierarchy. Those with greater income have access to resources that will directly and indirectly encourage and promote formal end-of-life planning. Because race is associated with income through community segregation, education, and job opportunities, access to medical care and the resulting promotion of formal end-of-life planning may be worse for racial and ethnic minorities than for Whites.

Social capital consists of the resources that are within a network of family, friends, and acquaintances. Social capital includes not only the size of the network, but the resources that those in the network themselves possess. Those with a higher degree of social capital may have physicians or lawyers within their social network which can provide information or referrals regarding formal end-of-life planning. Due to segregation and lower levels of economic capital, racial and ethnic minorities have access to different social networks than Whites and therefore may not have the resources within their networks to encourage formal end-of-life planning. Cultural capital refers to cultural resources and the corresponding dispositions and practices of the individual. In other words, cultural capital consists of context specific skills, dispositions, and competencies that can be deployed for an advantage within a field. A field, as used by Bourdieu, is a structured system of social positions where actors struggle for the ability to both define and accumulate relevant capital (Bourdieu and Wacquant 1992, Williams 1995), such as the medical field. Therefore, cultural capital that is relevant in the medical field may take the form of understanding medical terminology, reducing risky health behaviors based on current medical knowledge, and using a future-oriented approach to health decisions (Shim 2010).

There are systemic inequalities in the ability to accrue capital as well as the ability to convert capital to be used for advantage within the relevant field. Higher levels of economic, social, and cultural capital can influence end-of-life planning decisions directly through differential access to resources (such as the ability to pay for specialized care or greater access to information), or more indirectly through effective interactions with, and navigation through, the health-care field. Due to segregation, racial and ethnic minorities are less able to accrue economic capital and may be less likely to have social networks who are savvy regarding the medical and legal management of end-of-life care. This limits the social capital available to racial minorities that could promote end-of-life planning and decreases the accrual of the cultural capital that would be relevant to navigating the medical field. This in turn reduces the ability to use relevant cultural capital to increase the quality of interactions between the patient and medical personnel. This may result in racial minorities not understanding the purpose or importance of formal planning, not having support for the decision to complete one, or not having the information needed on how to complete one. Lower levels of capital important to the medical field, whether it is economic, social, or cultural, may help explain why racial and ethnic minorities are less likely to plan for their deaths.

How Does Religion Influence Formal End-of-Life Planning?

One way to understand how religion exerts an influence on formal end-of-life planning is by considering how an individual comes to understand themselves and their place in the world. Identity theory posits that individuals come to understand themselves, including their values, through categorizing other people, as well as themselves, based on the interactions that they have (McCall and Simmons 1966). This then suggests that people will come to understand themselves as mortal (i.e. will die) and may make decisions regarding end-of-life decisions based on their interactions with physicians, medical personnel, peers, and other significant people.

Stryker and Serpe (1982) use the concepts of identities, identity salience and commitment to understand the choices individuals make when there are multiple reasonable courses of action that can be taken. Identities are created through reflexively applied cognitions regarding role interactions in social relations, or to put it more simply, through involuntary reflection of the experience of interacting with others. Identity salience refers to the order of importance that individuals place their identities in. The higher the salience, the more likely a person is to enact that particular identity. Commitment refers to how much a relationship with a social group or other individuals depends upon the person adopting that identity (Stryker and Serpe 1982). High commitment levels encourage the creation of relevant social groups or networks and limit interaction with irrelevant groups.

As there are multiple reference groups that a person could use to create identities, the particular reference group an individual uses is important. For many people in the United States, religion plays an important role in many aspects of life and has been touted by many classical theorists as a significant reference group for providing moral messages to its members (e.g. Durkheim 1965). Several researchers have found that there appears to be a religion-health link, with people who are more religious being healthier (Marks et al. 2005, Wink, Dillon and Larsen 2005). One possible explanation of this religion-health link is that most religions encourage activities and beliefs that promote health and discourage activities that can negatively impact health (e.g. excessive drinking, non-monogamous sexual relations) (Benjamins et al. 2011). Involvement in a religion creates an environment for socialization that reinforces the norms of the group as well as provides potential social support during difficult times. The more frequently a person attends religious activities, the greater the opportunity for association with people who share specific norms and the greater the likelihood of using these people as an important reference group. Since many people will turn to religion in times of health trials (Ferraro and Koch 1994), it is reasonable to assume that religious reference groups could have an impact on the decision to complete advance directives. The importance of religion in life indicates the salience that an individual places on that identity. The higher the salience the more likely that the identity is enacted and the reference group is used. This may be especially true for racial and ethnic minorities who tend to be more religious than their white peers (Ferraro and Koch 1994).

The role of a religious reference group as a person deliberates about end-of-life planning can influence how, and whether, any formal planning takes place. If a person has a religious identity, they are more likely than someone who does not have a religious identity to claim a religious preference (i.e. Catholic, Protestant, etc). This religious preference will determine the messages that are received around end-of-life concerns and planning based on the core beliefs of the religion. In the case of Catholics, this may include the belief that all human life is sacred and that it is not acceptable to stop basic life support, such as feeding tubes (Bishops 2001) and that they must be careful of advance directives may indicate the acceptance of limiting this care at the end of life (Activities 2011). For Protestants, there is more diversity in teachings since there is not a single leadership authority, but the message may be more amenable towards end-of-life planning based around core teachings of autonomy and individual choice (Pauls and Hutchinson 2002).

If the religious identity is salient to a person, it is likely that person will place greater importance on religion in their daily life. The teachings of the particular religion may take on a greater role in the deliberation process. Therefore it could be expected that a Catholic who finds religion very important is more likely to subscribe to the concerns around formal end-of-life planning than a Catholic who does not find religion very important.

A person who is highly committed to the religious identity may attend religious services more frequently and therefore have greater exposure to both the social support and the moral teaching of the church. If the social support includes informational support in the form of getting advice and discussing possible solutions, the person considering end-of-life planning will have the moral teachings of the religion reinforced. Additionally the social component of commitment to this identity may create additional social pressure to conform to the norms of the group. During the decision making process, discussions with co-religionists may help a person understand their own personal relationship with their end-of-life plans, or may reproduce beliefs around the role and uses of advance directives that are in opposition to their completion (Ubel, Jepson and Baron 2001).

Other Characteristics that May Influence Formal End-of-Life Planning

I included age, gender, marital status, children living and in contact with the decedent, cause of death, and region of death in the conceptual model because these variables are known or suspected to have a direct influence on end-of-life planning. There are also known racial and ethnic differences in these characteristics. Therefore these characteristics may help explain racial and ethnic differences in formal end-of-life planning. Since these variables were not the focus of this study they are treated as control variables in most of the analysis.

Specific Aims and Research Questions

Using data from the Health and Retirement Survey this study explored of the role of race, socioeconomic status, and religion in end-of-life planning within a nationally representative sample of older adults with the following specific aims:

Specific Aim One

To examine whether there are racial and ethnic differences in formal end-of-life planning done by older African American, Hispanic, and White adults.

Research Question 1.1: Are there racial and ethnic differences in who completes a written advance directive?

Research Question 1.2: Are there racial and ethnic differences in who assigns a durable power of attorney for health care?

Research Question 1.3: Are there racial and ethnic differences in who completes a written advance directive and assigns a durable power of attorney for health care?

Research Question 1.4: Are there racial and ethnic differences in who completes any formal end-of-life planning?

Research Question 1.5: Do demographic factors such as age, gender, family structure, region of death, and cause of death help explain racial and ethnic differences in completion rates of any formal end-of-life planning?

Specific Aim Two

To examine socioeconomic factors including education and income in formal end-of-life planning as well as assess the contribution of these factors in explaining racial and ethnic differences in formal end-of-life planning.

Research Question 2.1: Does education help explain differences in the completion of any formal end-of-life planning?

Research Question 2.2: Does income help explain differences in the completion of any formal end-of-life planning?

Research Question 2.3: Does education help explain racial and ethnic differences in who completes any formal end-of-life planning?

Research Question 2.4: Does income help explain racial and ethnic differences in who completes any formal end-of-life planning?

Specific Aim Three

To examine the role of religion in formal end-of-life planning and to assess the influence of religiosity in racial and ethnic differences in formal end-of-life planning.

Research Question 3.1: Does religious preference help explain differences in the completion of any formal end-of-life planning?

Research Question 3.2: Does belief in the importance of religion help explain differences in the completion of any formal end-of-life planning?

Research Question 3.3: Does frequency of attending religious services help explain differences in the completion of any formal end-of-life planning?

Research Question 3.4: Does religious preference help explain racial and ethnic differences in who completes any formal end-of-life planning?

Research Question 3.5: Does belief in the importance of religion help explain racial and ethnic differences in who completes any formal end-of-life planning?

Research Question 3.6: Does frequency of attending religious services help explain racial and ethnic differences in who completes any formal end-of-life planning?

Significance

While it is known that end-of-life planning is often inadequate, we do not fully understand the factors that influence whether any formal planning takes place. Racial and ethnic minorities have been shown to complete fewer formal plans for the end-of-life than Whites, but the reasons are not clear. Cultural differences such as mistrust in the medical and legal fields, differences in age, gender, family structure, socioeconomic status, and religiosity may all influence the decisions of African Americans and Hispanics to complete formal plans. Advantages in socioeconomic status may also directly influence the desire to complete formal end-of-life plans through access to economic, social, and cultural capital. Religious participation and the salience of a religious identity may influence decisions about completing formal end-of-life planning. Additionally, demographic factors such as age, gender, and family structure may play a role. The proposed study has the potential to add significantly to the literature as it will help determine who is most at risk for inadequate end-of-life planning, and therefore who is at risk for a death that may not be in alignment with personal values and desires. This is important not only for those involved in improving end-of-life care, but for every person who cares about someone who is dying and every person who is facing their own death.

CHAPTER THREE: METHODS

This chapter provides an overview of the data source that was used for the study, information on the variables of choice, and a description of the analysis used.

Data Source

The Health and Retirement Survey (HRS) is a bi-annual survey conducted by the Survey Research Center at the Institute for Social Research (ISR), University of Michigan, Ann Arbor. The HRS collects data from the aging population in the United States regarding physical and mental health, insurance coverage, financial status, family support systems, labor market status, and retirement planning. The HRS is sponsored by the National Institute on Aging (NIA) (grant number NIA U01AG009740) and the Social Security Administration. Because the HRS data is an extremely complex longitudinal study, with new cohorts being added in, multiple supplemental surveys, and a very large amounts of interview data, the RAND Center for the Study of Aging was given funding and support from both the National Institute on Aging and the Social Security Administration to create some user-friendly variables from a some of the HRS data. Both of these data are used in this study.

The HRS is a large panel survey that was started in 1992. The first interviews were with a nationally representative sample of those born between 1931 and 1941 (the original HRS cohort) and their spouses and were conducted in either English or Spanish. This cohort has been interviewed every two years since. In 1993 another survey was given to a nationally representative sample of those born before 1921 (the AHEAD cohort) and their spouses. This cohort was interviewed again in 1995 and then merged with the HRS cohort in 1998. In 1998 two other cohorts were added as well: those born between the HRS cohort and the AHEAD cohort (born between 1924 and 1930), and the first cohort brought in to supplement the early 50s age range as the original HRS aged out. Other refresher cohorts were added in 2004 and 2010. Core surveys, those surveys done every two years, requests information regarding the aging population's physical and mental health, insurance coverage, financial statue, family support systems, labor market status, and retirement planning.

The death of a sample member is discovered in one of three ways. Sometimes a family member contacts the HRS study team to let them know of the death. Sometimes the death is discovered when an interviewer attempts to contact them for a core interview. HRS also uses the Social Security Death Index, Insight (a subscription based database), and the National Death Index. When members of the sample die, the HRS conducts an "Exit" interview with the person who is considered to be the most knowledgeable about the deceased individual’s situation at the end-of-life. This is typically a spouse or child, but may be another relative (such as a sibling or grandchild), a friend, or a professional caregiver. The emphasis is on trying to identify the person who is the most knowledgeable about the deceased. At the end of every core survey (non-exit interviews) information on two alternate contacts is provided in case the study is unable to reach the respondent. These are often the people who are called first for an exit interview, but they are asked if they are comfortable completing the interview or if there is someone else who would be more knowledgeable about the deceased person (Personal communication, Institute of Social Research, University of Michigan, “MBO”, Feb 9, 2012). If an exit interview is incomplete because financial or legal matters have not been settled, a short post-exit interview is done at the next interview wave to finalize the information in the exit interview. In 2008, the response rate for exit interviews was 91.7% (HRS 6/27/2011).

As a large and nationally representative data set, HRS data provides an opportunity to provide reliable estimates of variables and to disaggregate data along key variables of end-of-life planning. Because the data from the HRS study are extremely rich and complex, both HRS and RAND created data files to increase the usability of the raw HRS data. HRS created a tracker file to facilitate the use of data within and across waves. This data includes information on the numerical identifiers of the respondents as well as demographic characteristics such as race and gender on every person who was ever eligible to be interviewed in any of the survey or interview formats conducted by the HRS study (HRS 2011). For clarity, I will refer to this data as the cross-wave data. RAND created files that included respondent-level data that had been merged from multiple years, and if necessary merged or imputed from household-level data.

For this study I used exit interviews, core surveys, cross-wave data, and data from RAND. The exit interviews that I used were conducted in 2008 and 2010. These interviews were completed by proxies as described above. The core surveys were conducted with the respondent prior to their deaths in previous waves of the survey. The cross-wave data was used for some of the demographic information. These data were also collected in previous surveys, but were compiled by HRS staff and verified during each survey wave for accuracy.

This study includes those decedents who had an exit interview completed in either 2008 or 2010. A total of 2748 exit surveys were completed in 2008 and 2010. There was missing data in 189 of them in either the dependent or key independent variables and were therefore excluded from the final analysis. This included 128 who did not answer both of the formal end-of-life planning questions, 6 who did not have a year of death, 52 who did not have enough information to determine a poverty ratio, 3 who had missing information on children, and 3 who had missing information on the region where they died. Those with missing information were less likely to be white or to have died in the West South Central area and were more likely to be black or from the South Atlantic / East South Central area. However, there was no significant differences in what type of formal advance care planning they had (no formal planning, advanced directives only, proxy only, both advance directive and proxy). The final number of respondents included in this analysis is 2559.

Measures

Dependent Variables

Formal End-of-Life Planning

Two questions, both of which provide a dichotomous response option (yes/no) measure formal health care plans. The first question asked whether the decedent provided written instructions about the treatment or care that he/she wanted to receive during the final days of life. The second question asked whether the decedent had made legal arrangements for a specific person or persons to make medical decisions if the decedent was unable to make those decisions personally (assigning a durable power of attorney for health care). Both of these items come from the exit survey. Respondents must have answered both of these questions in order to be included in the final sample.

There were five dependent variables created in order to consider whether there were differences in the type of planning done or whether any planning was done. In order to explore the different types of formal planning, four dichotomous variables were created: those who did not have any form of formal end-of-life planning, those that only had a written advance directive, those that only had a proxy, and those that had both an advance directive and a proxy. When using these variables, those that did not have any form of formal end-of-life planning was the reference category.

The fifth dependent variable was a dichotomous variable indicating whether there was any formal planning done. This variable coded anyone who answered positively to having written instructions or to having legal arrangements for a durable power of attorney as having some formal planning and those that answered negatively to both of the survey questions as not having formal plans. Not having formal plans was the reference category when this variable was used.

Independent Variables

Three categories of independent variables were included in this study. The first was race and ethnicity, which includes non-Hispanic Whites, non-Hispanic Blacks, and Hispanics. The second was socioeconomic status, which includes education and poverty ratio. The third category was religion, which includes religious preference, frequency of attending religious services, and importance of religion.

Race and Ethnicity

Race and ethnicity data came from two cross-wave variables in the HRS tracking file. The questions on self-assessed race questions were changed in the 2006 interview wave allowing respondents to identify themselves as more than one racial category. In that wave and subsequent waves, every respondent was asked the new version of the question. Respondents who chose multiple racial categories were also asked what racial category they primarily considered themselves to be and this answer was used to calculate the racial category. In order to protect the confidentiality of the participants, all race data was collapsed by HRS down to three categories: White/Caucasian, Black/African American, and Other. The variables of race and ethnicity were combined so that anyone who identified as Hispanic, regardless of the race that they selected, was coded as Hispanic. The Other category, once the Hispanic category was identified, was excluded from the final sample (n=25). While the end-of-life planning of other racial and ethnic categories are important to research, there were too few in this dataset and they were excluded from the final sample. The final categories were: non-Hispanic White, non-Hispanic Black, and Hispanic.

Socioeconomic Status

Socioeconomic status (SES) is complex, as there is no consistent definition or measure of SES. Common indicators that are used as proxies for SES include education, income, and job category. Because the advanced age that most deaths occur at, the majority of the participants in this study were retirement age and likely no longer working. Additionally, because they were sick enough to die, it is likely that many were no longer working because of illness. This means that both the job category and income variables are less reliable for determining socioeconomic status for this population. An education variable and a poverty threshold variable that can capture meaningful social and economic differences were therefore used as proxies for SES.

Education

The education variable was created from the HRS tracker file's variable that assessed the highest degree of education that the respondent had achieved. The original categories included 'no degree,' 'GED,' 'High school diploma,' 'Two year college degree,' 'Four year college degree,' 'Master's degree,' and 'Professional degree (PhD, MD, JD).' There were no missing values. These categories were recoded into a series of dichotomous variables for 'less than a high school diploma,' 'High school diploma or GED,' and 'Two year college degree or more.' Those with less than a high school diploma are the reference category.

Poverty Ratio

Poverty threshold data was obtained from the RAND data. This ratio compares the HRS data for before-tax income and family size to the U.S. Census Bureau’s poverty threshold. The poverty threshold is the minimum level of income deemed necessary to afford the minimum standards of shelter, food, and clothing which was originally set at three times the cost of sustenance food for 1963 and is updated annually for inflation using the Consumer Price Index. Income includes before-tax income from earnings, unemployment, workers’ compensation, Social Security, SSI, public assistance, veterans benefits, pension and retirement income, interest, dividends, rents, royalties, income from estates and trusts, educational assistance, alimony, child support, assistance from outside the household, other sources, income of all resident and institutionalized family members. Income does not include noncash benefits (e.g., food stamps), or capital gains and losses. A poverty ratio of 1 indicates that the person was living at the poverty threshold for that year, anything less than 1 indicates that they were living below poverty threshold, and above one indicates that they were above the poverty threshold for that year. A poverty ratio of 2.5 would indicate that the person's family income was 2.5 times the federal poverty threshold level. Because the respondent may have been ill or in a nursing home at that time, the data included the information for institutionalized family members. The data from the most recent year prior to death was used unless it was missing. If it was missing, the prior interview year's data was used. Poverty ratios were available for 2002 through 2008. Fifty two decedents did not have information and were therefore excluded from the final sample.

Religion

Religion is a complex variable with multiple dimensions that can be measured to capture different ways that religion may help guide decisions and behaviors in everyday life (Fetzer Institute 2003). Three dimensions of religion were used in this study: religious preference, frequency of attending religious services, and the personal importance of religion.

Religious Preference

The religious preference variable was created from the RAND data. This data had the religious preference listed for ten waves of interviews as well as a combined variable. My variable was created by first using the last non-missing value in the ten waves, in other words, the religious preference that was given closest to time of death. Any missing values were then taken from the combined RAND variable that listed the first non-missing value from the ten waves and the AHEAD interviews in 1993 and 1995.

The religious preference question was a single item question. From the second wave forward the question asked was “What is your religious preference; Is it Protestant, Catholic, Jewish, some other religion, or do you have no preference?” In the first wave of interviews the question was “What is your religious preference: Protestant, Roman Catholic, Jewish, or something else?” Due to the limited number of people who reported being Jewish (n=66) or another religion (n=23), these groups were included in the group of 'none, no preference, or other.' The final dichotomous variables were ‘Protestant,’ ‘Catholic,’ and ‘none, no preference, or other.’ Catholics were the reference category.

Church Attendance

The church attendance variable was created from the question "About how often have you attended religious services during the past year?" asked of the respondents in the 2008 core interview, 2006 core interview, and the 2004 core interview. The last non-missing variable was used in order to capture the answer given closest to death. The decision was made to not include the proxy responses to this question after the respondent had passed away in order to capture the answer closest to the truth for the respondent as well as to minimize the impact that serious physical constraints created by illness at the end-of-life would have on attending services.

While it is not possible to counteract all of selection bias of those healthy enough to attend services, using the respondent's answer in previous surveys as well as combining the most frequent attendance answers may help minimize it. The original answer categories included 'more than once a week,' 'one time a week,' 'two to three times a month,' 'one or more times a year,' 'not at all,' 'don't know or non-applicable,' and 'refused to answer.' These response categories were combined to four dichotomous variables of 'two or more times a month,' 'one or more times a year,' 'not at all,' and 'did not answer.' Attending 'not at all' was used as the reference category.

Religious Commitment

The religious commitment variable was created from the question "How important would you say religion is in your life; is it very important, somewhat important, or not too important?" The last non-missing variable from the 2008 core interview, 2006 core interview, 2004 core interview, and 2002 core interview, was used to capture the answer provided by the responded closest to death. Four dichotomous variables were created: 'not important,' 'somewhat important,' 'very important,' and ' did not answer.' 'Not important' was used as the reference category.

Demographic Predictors

Demographic variables that may influence end-of-life planning were included in the analysis. These factors include age, gender, family structure (measured by marital status and having any living children in contact), cause of death, and region of death.

Age at death

The age variable was created from the month and year or birth and the month and year of death. The month and year of birth came from the HRS cross-wave tracker file and had no missing data. The month and year of death came first from the HRS tracker file which used the exit interviews. There were 48 missing either a month of death or a year of death. I was able to use RAND data for 27 of these, and imputed 15 based on Rand recommendations, which left 6 missing and excluded from the final sample. The RAND data used dates as ascertained by the HRS via the exit interview or the surviving spouse's report and then used National Death Index (NDI) dates. If the month was missing but year was given, and the year was the same as the last live interview, the month was set using the mean date between the last interview date and the last day of the year. Otherwise if the month was missing, the death date is set to July 1st of the death year. If the year was missing, the death date was considered missing and excluded from the sample. From these data, the scale variable of age at death was created by using the century month for both birth and death (see Appendix A).

Gender

The gender variable comes from the HRS a cross-wave data. While it was asked at the first interview, it was updated during subsequent interviews or in the exit interview if it had not been answered previously or if there were any corrections to be made. The response options were limited to the dichotomous responses of male and female. Male is used as the reference category.

Contact with Children

The children variable was constructed from the RAND data which included the number of living children who were in contact with the parent from the HRS data. The most recent year that had data, beginning in 2008, was used. If the data was missing the prior interview year was used all the way back to the beginning of the surveys in 1992. These data were then dichotomized to whether or not the decedent had any children who were in contact with the decedent prior to death. No children in contact was used as the reference category.

Marital Status

This variable is based on the calculations done by HRS in the cross-wave data file on whether a decedent had previously been married, living with a partner as if married, divorced, separated, widowed, or never married or partnered and if the proxy respondent states that the decedent has, or has not, changed in status since the previous interview. The 2006 data was used if the death occurred in 2007 or earlier and the 2008 data was used if the death occurred in 2008 or later. The final variable consists of two categories: married or living with partner as if married, and not married. The not married category includes those who were divorced, widowed, or had never married at the time of death. Not married was used as the reference category.

Region of Death

This variable was created from the HRS exit data which included 11 regions where the death could have taken place (see figure 3). There were 13 decedents who died while in a foreign country and 3 with missing information as to their location of death.

The three who had missing information were excluded from the final sample. The eleven regions were combined to five regions based on census regions and the amount of religious diversity. Due to the expectation that beliefs about end-of-life planning expressed by Catholic leadership may influence the death discourse, the rate per 1000 Catholics as found in the Association of Religion Data Archives (ARDA) was used to determine regional religious diversity. This data indicated variability in the South census region which led to dividing it into two separate regions, based on the available HRS regional groupings. The final five dichotomous variables were NorthEast, MidWest, South Atlantic / East South Central, West South Central, and West. The South Atlantic / East South Central variable was used as the reference category.

NorthEast
- NE Region, New England Division (ME, NH, VT, MA, RI, CT)
- NE Region, Mid Atlantic Division (NY, NJ, PA)

MidWest
- MidWest Region, East North Central Div (OH, IN, IL, MI, WI)
- MidWest Region, West North Central Div (MN, IA, MO, ND, SD, NE, KS)

South Atlantic / East South Central
- South Region, South Atlantic Div (DE, MD, DC, VA, WV, NC, SC, GA, FL)
- South Region, East South Central Div (KY, TN, AL, MS)

West South Central
- South Region, West South Central Div (AR, LA, OK, TX)

West
- West Region, Mountain Div (MT, ID, WY, CO, NM, AZ, UT, NV)
- West Region, Pacific Div (WA, OR, CA, AK, HI)

**Foreign Country, Not in a census division (includes U.S. territories) was not included into any of the five regions*

Table 1: New regions of death based on HRS categories

Cause of Death / Illness Trajectory

During the exit interview, the respondent was asked what the major illness that led to death was. Up to two answers were recorded. If the answer for the first cause of death was 'do not know,' 'no health condition,' or 'other health condition' and there was a condition listed in the second cause of death, the second cause of death was used. These causes of death were categorized according to the International Classification of Disease (ICD_10 Version 2010) into broad categories. Although each person's experience with death is unique, there are some commonalities in disease trajectories (Lunney et al. 2003, Lynn 2004, Lynn 2005) which allows for the further categorization of the cause of death into three dichotomous categories (cancer, organ failure, and frailty) and a fourth 'other' category. Cancer is used as the reference category.

The first category, 'cancer,' consists of illnesses that have a trajectory of basic health until the illness overwhelms the body and then there is a fairly rapid and predictable decline. This category included people whose cause of death was listed as cancers or tumors. The second category, 'organ failure,' consists of chronic health conditions that tend to have acute phases of illness but can usually be overcome with appropriate care, especially in the early stages. While many know that the health condition can lead to death, predicting when death will occur is much more difficult. This category included people whose cause of death was categorized as heart conditions, respiratory system conditions, or digestive system conditions. The third category, 'frailty,' consists of those whose health has a slow but fairly consistent decline. This category included people whose cause of death was categorized such as Alzheimer's disease, dementia, or old age. The last category is 'other' which incorporates both those who died from accidents as well as those who died from conditions that are currently not classified in one of the other trajectories. These include those whose cause of death was categorized as a problem with the musculoskeletal system, neurological or emotional conditions. While accidental deaths (i.e. suicide, murder, accidents) are usually placed into their own category, there were too few (n=32) in the sample to populate a category. These people were therefore incorporated into the 'other' category.

Statistical Methods

All analysis were done using IBM SPSS Statistics 19. The first step in the analysis was to describe the sample. This includes the proportion or the mean, range, and standard deviation as appropriate for all variables that are included in the analysis. In order to determine if there was a bivariate relationship between end-of-life planning and race, chi-square or spearman correlations are reported.

Statistical Methods: Aim One

Multinomial logistic regression models was used to estimate the odds of having completed formal end-of-life planning based and race and ethnicity. In the first model, the polytomous dependent variable of 'no formal planning,' 'written advance directive only,' 'proxy only,' and 'both written and proxy' are modeled with the race and ethnicity categories of 'non-Hispanic white,' 'non-Hispanic black,' and 'Hispanic.' The model explores how the race and ethnicity of the decedent affects the odds that the decedent completed the different forms of formal planning using 'no formal planning' as the reference category. In addition, the bivariate dependent variable of 'any formal planning' will be considered in a similar logistic regression.

The second logistic model adds in the control variables of region of death and cause of death first with the polytomous dependent variable of type of formal planning and then with the bivariate dependent variable of any formal planning. South Atlantic / East South Central and cancer are the respective reference categories.

Lastly, I ran a logistic model with the dependent variable of any formal planning, the control variables of region of death, cause of death, age at death, gender, children, and marital status and the independent variables of race/ethnicity.

Statistical Methods: Aim Two

Logistical regression was used to estimate the odds that a decedent completed any form of formal end-of-life planning, and specifically whether the addition of sociodemographic factors make a significant contribution to whether race or ethnicity affect whether formal end-of-life planning took place. Models include the dependent variable of whether any formal end-of-life planning took place, the control variables of region of death, cause of death, age at death, gender, children, and marital status and the independent variables of race/ethnicity, education, and poverty ratio.

Statistical Method: Aim Three

Logistical regression was again used to determine the odds that a decedent completed any form of formal end-of-life planning and whether the addition of religious variables make a significant contribution to whether formal end-of-life planning took place. Models include the dependent variable of whether any formal end-of-life planning took place, the control variables of region of death, cause of death, age at death, gender, children, and marital status and the independent variables of race/ethnicity, education, poverty ratio, religious preference, importance of religion, and frequency of attending religious services.

CHAPTER FOUR: RESULTS

This chapter addresses the results of the research. In the first section, descriptive characteristics of the sample are provided. The second section addresses the results for Aim One, specifically whether there are racial and ethnic differences in what type of formal planning occurs as well as whether any formal end-of-life planning takes place after controlling for demographic factors. The third section addresses the results for Aim Two, specifically the role that sociodemographic factors play in racial and ethnic differences in formal end-of-life planning. The fourth section addresses the results for Aim Three: the role that religion has on racial and ethnic differences in formal planning with demographic factors adjusted.

Descriptive Characteristics of the Sample

Demographics

As described in Table 2, the largest racial and ethnic category was non-Hispanic White (76.8%; n=1965). Non-Hispanic Black was the second largest category (15.7%; n=403), and Hispanic was the smallest category (7.5%; n=191).

The mean age for the decedents was 80.75 years old with the youngest decedent being 44 years old and the oldest being 110 years old. Females accounted for 55.5% of the sample (n=1419), and males the remaining 44.5% (n=1140).

Family structure was measured in two ways: whether the decedent had been married or living as married at the time of death and whether the decedent had any children who were still alive and in contact. Forty three percent (n=1089) had been married or partnered as married prior to death and 57% (n=1470) had not been married or partnered as married prior to death. These include those who were divorced, widowed, or never married. The majority (91.2%; n=2334) had at least one living child who was in contact. The range in number of children who were alive and in contact with the parent was between zero and nineteen, with a mean of 3.23 (SD 2.42).

As shown in Table 2, almost 20% (n=500) of the decedents died in the Northeast, 23.4% (n=598) died in the Midwest, 34.7% (n=889) in the South Atlantic / East South Central, 11.4% (n=292) died in West South Central, and 10.4% (n=267) died in the West. Please refer to Table 1 for clarification on which states were included in each region.

The most common cause of death was organ failure, with 57.4% (n=1468) of the respondents reporting that as the primary cause of death. The second most reported cause of death was cancer, with 22.3% (n=570). There were 15.5% (n=396) whose cause of death fell into the 'other' category, and 4.9% (n=125) whose cause of death followed the frailty trajectory.

Socioeconomic Status

Socioeconomic status indicators were measured in two ways: educational attainment and poverty level. Thirty-seven percent (n=947) of the decedents had less than a high school degree, 47.1% (n=1205) had a high school degree or GED, and 15.9% (n=407) had a two-year college degree or higher. A poverty ratio, which measures adjusted family income compared to the poverty threshold established by the census, ranged between 0 and almost 58 (please refer back to the Poverty Ratio section in the previous chapter for more information on how the poverty ratio was constructed). A score of 1 indicates that the family was living at the poverty threshold established for that year, below one indicates that the family's income was below the minimum standard set, above one the family's income was above the minimum standard. The mean was 3.324 (SD 3.909), indicating that the mean fell between three and four times the poverty threshold level.

Religion

In order to approach the multiple layers of religious behaviors and beliefs, religion was measure in three ways: religious preference, frequency of attending religious services, and importance of religion.

As shown in Table 2, the majority of decedents reported having a religious preference compared to not having any religious affiliation. Protestant was the most common religious preference with 64.9% of the sample reporting this preference (n=1660). The second most common response was Catholic, with 26.2% (n=670), and the remaining 8.9% (n=229) consisted of Jewish (n=66; 2.6%), other religions (n=23; .9%), and no religion or no preference (n=140; 5.5%).

Over half of the decedents reported attending religious services in the year prior to the last interview that they completed. There were 38.9% (n=995) who reported attending services two or more times a month, and 15.9% (n=408) who attended one or more times a year. There were 36.6% (n= 937) who reported that they did not attend at all, and 8.6% (n=219) who did not answer this question. Those that did not answer this question consisted of members of all three religious preference categories (see Appendix D).

The majority of decedents reported that religion was important in their lives. There were 64.1% (n=1641) who reported that it was very important and 19% (n=486) who said that it was somewhat important. Only 12.5% (n=319) reported that religion was not too important to them, and there were 4.4% (n=113) who did not answer this question. Those that did not answer this question consisted of members of all three religious preference categories (See Appendix E).

Table 2: Descriptive characteristics of sample

(N=2,559)	n	%	Mean	SD	Range
Race/Ethnicity					
Non-Hispanic White	1965	76.8			
Non-Hispanic Black	403	15.7			
Hispanic	191	7.5			
Region where death occurred					
South Atlantic / East South Central	889	34.7			
North-East	500	19.5			
Mid-West	598	23.4			
West	267	10.4			
West South Central	292	11.4			
Illness trajectory / cause of death					
Cancer	570	22.3			
Organ Failure	1468	57.4			
Frailty	125	4.9			
Other	396	15.5			
Age			80.75	10.626	44-110
Gender					
Female	1419	55.5			
Family Structure					
Children					
Had living children in contact	2334	91.2			
Marital status					
Married or partnered as married	1089	42.6			
Socioeconomic Status (SES)					
Education					
No degree	947	37			
High School degree or GED	1205	47.1			
2-year college degree or more	407	15.9			
Poverty Ratio			3.324	3.909	0-57.945
Religion					
Religious Preference					
Protestant	1660	64.9			
Catholic	670	26.2			
None, no preference, other	229	8.9			
Frequency of attending religious services					
Two or more times a month	995	38.9			
One or more times a year	408	15.9			
Not at all	937	36.6			
Did not answer	219	8.6			
Importance of religion in life					
Very Important	1641	64.1			
Somewhat Important	486	19			
Not Too Important	319	12.5			
Did not answer	113	4.4			

Results for Specific Aim One - Race and Types of Formal End-of-Life Planning

For the whole sample, 32.1% (n=821) of the decedents had no formal end-of-life plans while 67.9% (n=1738) had some form of formal plan. Of those that had a formal plan, the fewest (5.8%; n=149) had a written advance directive only, 21.1% (n=541) had a proxy only, and the majority (41%; n=1048) had both a written advance directive and a proxy.

Table 3: Formal planning

	n	%
Any Planning		
No Planning	821	32.1
Any Planning	1738	67.9
Type of Formal End-of-Life Planning		
No Formal Planning	821	32.1
Written Advance Directive Only	149	5.8
Proxy Only	541	21.1
Both Written and Proxy	1048	41

Figure 3 shows a visual depiction of the types of formal planning completed. Approximately one-third of the sample completed no planning. Relatively fewer did only one type of planning. Only 5.8% had only a written advance directive, and 21.1% had only a proxy. The largest group (41%) had both a written advance directive and assigned a proxy.

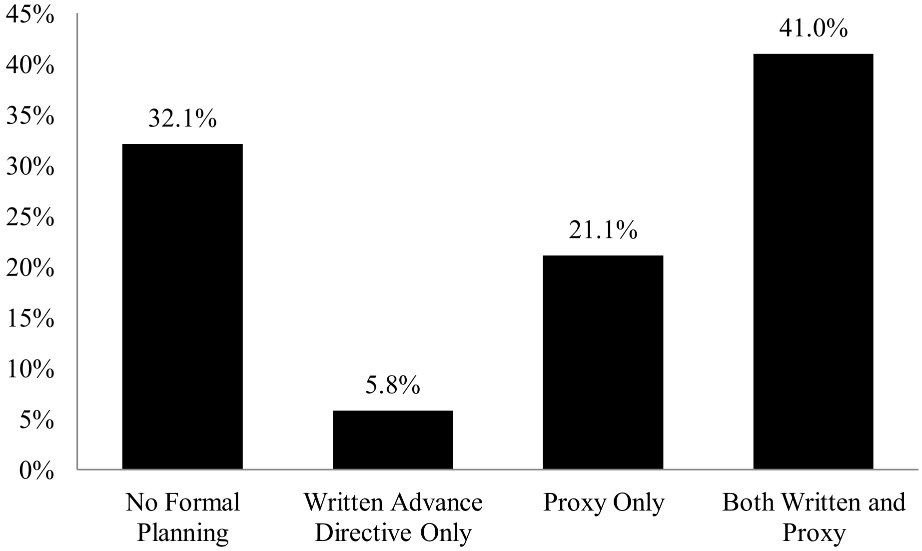
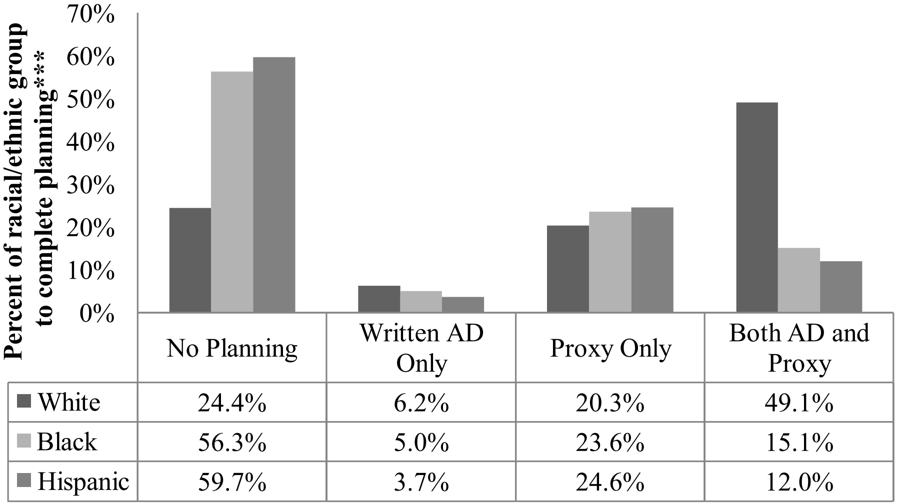


Figure 3: Types of formal planning

To examine whether non-Hispanic Blacks, Hispanics, and non-Hispanic Whites differ in their use of formal planning and to better understand what explains the differences, both crosstabs and multinomial logistic regression were conducted. There were statistically significant differences between the type of formal planning that non-Hispanic Whites, non-Hispanic Blacks, and Hispanics engaged in ($p \leq .001$). Table 4 shows the results in graph format for the percent within each racial / ethnic group that completed the various forms of formal planning. Within the non-Hispanic White decedents, almost half (49.1%) completed both a written advance directive and assigned a proxy, while almost a quarter (24.4%) completed no planning. Non-Hispanic whites were more likely to have only assigned a proxy (20.3%) than they were to only write an advance directive (6.2%). Within the non-Hispanic Black decedents, over half (56.3%) did no formal planning, and only 15.1% completed both a written advance directive and assigned a proxy. Fewer than a quarter (23.6%) assigned a proxy only, and 5% completed a written advance directive only. Hispanics had similar numbers to non-Hispanic Blacks, with 59.7% having completed no planning and 12% who completed both a written advance directive and assigned a proxy. Almost a quarter (24.6%) of the Hispanics assigned a proxy only, and 3.7% only had a written advance directive.

Table 4: Types of formal planning by race/ethnicity



	No Planning	Written AD Only	Proxy Only	Both AD and Proxy
■ White	24.4%	6.2%	20.3%	49.1%
■ Black	56.3%	5.0%	23.6%	15.1%
■ Hispanic	59.7%	3.7%	24.6%	12.0%

Note: Chart shows row totals ***Chi-square p≤.001

I used multinomial logistic regression models to examine the type of formal end-of-life planning completed, using those that did no formal planning as the reference group. This yielded comparisons between those who wrote an advance directive only versus those who did no planning, those that assigned a proxy only versus those who did no planning, and those that both wrote an advance directive as well as assigned a proxy versus those that did no planning. All logistic regression tables present the odds ratio (Exp(β)) and the significance level of the variables in the model. All models included race with non-Hispanic Whites as the reference category.

The first model in Table 5 demonstrates the influence that race / ethnicity had on the type of formal planning that took place compared to no planning. Considering each of the types of planning individually, Blacks and Hispanics were less likely to have completed any of the types of planning compared to no planning, but the difference was greatest between those that did no planning and those that completed both written advance directives and assigned a proxy. In that instance, Blacks had 87% lower odds and Hispanics had 90% lower odds compared to Whites of having completed both a written advance directive and assigned a proxy versus no planning. Blacks had 65% lower odds of a written advance directive only, and 50% lower odds of having assigned a proxy only versus no planning. Hispanics had 76% lower odds of having a written advance directive only, and 50% lower odds of having assigned a proxy only versus no planning.

Model 2 (Table 5) added the control variables of region of death and cause of death. For the region of death, the South Atlantic / East South Central area was the reference (see Table 1 for listing of the states in each region). For cause of death, cancer was the reference group. Race and ethnicity stayed significant for each form of planning, and stayed similar to the initial model. Blacks had 66% lower odds of having had a written advance directive only, 48% lower odds of having had a proxy only, and 86% lower odds of having had both a written advance directive and an assigned proxy compared to no planning. Hispanics had 73% lower odds of having a written advance directive only, 44% lower odds of having a proxy only, and 88% lower odds of having both a written advance directive and an assigned proxy compared to no planning.

The type of planning completed varied by region of death. None of the regions were significantly different from the reference region (South Atlantic / East South Central) for those with a written advance directive only. Those in the Mid-West were almost twice as likely to have only a proxy compared to having no planning than the reference region. Having both a written advance directive and an assigned proxy was significant for both those in the Mid-West and those in the West South Central, but those in the Mid-West had 52% greater odds and those in the West South Central had 57% lower odds of having both a written advance directive and an assigned proxy versus having no planning compared to the reference region.

Cause of death accounted for some of the differences in the type of planning that was completed. Compared to the reference group (cancer), those that died from 'organ failure' or 'other' were less likely to have had a written advance directive only. Those with frailty compared to those with cancer had greater odds of having a proxy only than having no planning. Interestingly, none of the causes of death were significant for those that had both a written advance directive and an assigned proxy.

Table 5: Multinomial logistic regression for type of planning by race and control variables

	Model 1			Model 2		
	Written AD Only	Proxy Only	Both AD and Proxy	Written AD Only	Proxy Only	Both AD and Proxy
	O.R.	O.R.	O.R.	O.R.	O.R.	O.R.
Race (White)						
Black	0.347***	0.503***	0.134***	0.339***	0.522***	0.137***
Hispanic	0.242***	0.496***	0.100***	0.273**	0.561**	0.122***
Region of Death (South Atlantic / East South Central)						
North-East				0.916	0.875	0.767
Mid-West				1.553	1.939***	1.518**
West				0.776	1.083	1.194
West South Central				0.775	0.938	0.431***
Cause of Death (Cancer)						
Organ Failure				0.558**	0.914	0.790
Frailty / Old Age				0.777	1.875*	1.291
Other				0.562*	0.789	0.729
-2LL		52.348			560.137	

***p≤.001 **p≤.01 *p≤.05 note: values in parentheses are reference categories

Table 6 shows the logistic regression odds ratios of completing any formal planning compared to completing no formal planning. Across all four models, Black and Hispanic decedents, compared to White decedents, had significantly lower odds of completing any formal planning than no planning. Model 1 shows that without any additional controls, Blacks had 75% lower odds and Hispanics had 78% lower odds of having completed any form of planning. Model 2 added in the control variables of region of death and cause of death. Even controlling for region of death and cause of death, both Blacks and Hispanics had 74% lower odds of completing any form of formal planning. Model 3 controls for age at death and gender. With these controls, Blacks had 72% lower odds of completing any formal planning and Hispanics had 73% lower odds than their White peers. Model 4 additionally controls for whether the decedent had any children that were in contact and whether the decedent had been married or partnered as married prior to death. With these additional controls, both Blacks and Hispanics had 73% lower odds of completing any formal end-of-life plans. While many of the control variables were significant, they did not drastically change the effect of being Black or Hispanic on the odds of completing formal planning across any of the four models.

Whether any planning was completed varied by region of death. Controlling for demographic variables of race, age, gender, children in contact, marital status, and cause of death, decedents in the Mid-West had 63% higher odds of completing some form of formal end-of-life plan compared to those in the reference group (South Atlantic / East South Central). With the same controls, those in the West South Central had 39% lower odds of completing any formal plans. Planning also varied by cause of death. Decedents who died from organ failure had 35% lower odds of completing some form of formal end-of-life plan compared to those who died from cancer. Those who died from other causes (which include accidental deaths and uncategorized deaths) had 44% lower odds of completing any formal plans compared to those who died from cancer. Age at death was a significant predictor, with every year older the decedents had approximately 4% greater odds of completing some form of formal advance planning. Gender was significant in Model 3, with women having 24% greater odds of having planned prior to death, but this significance dropped out in Model 4 when children and marriage were also controlled for. Model 4 included whether the decedent had any children who were in contact prior to death. This was not significant. This model also included whether the decedent had been coupled or partnered prior to death. This was significant, with those that were coupled or partnered having 32% lower odds of having completed any formal planning.

Table 6: Logistic regression for any planning by race with demographics

	Model 1	Model 2	Model 3	Model 4
	O.R.	O.R.	O.R.	O.R.
Race (White)				
Black	.251 ***	.257 ***	.285 ***	.271 ***
Hispanic	.218 ***	.258 ***	.269 ***	.267 ***
Region of Death (South Atlantic / East South Central)				
North-East		.817	.754 *	.751 *
Mid-West		1.659 ***	1.635 ***	1.631 ***
West		1.133	1.112	1.097
West South Central		.632 **	.620 ***	.607 ***
Cause of Death (Cancer)				
Organ Failure		.800 *	.661 ***	.653 ***
Frailty / Old Age		1.416	.805	.781
Other		.728 *	.561 ***	.557 ***
Age at Death			1.040 ***	1.037 ***
Gender (Male)				
Female			1.240 *	1.126
Children (No)				
Yes				1.011
Coupled or Partnered (No)				
Yes				.740 **
-2LL	19.836	239.430	2736.892	2838.192

***p≤.001 **p≤.01 *p≤.05 note: values in parentheses are reference categories

Results for Specific Aim Two - Socioeconomic Factors and Formal End-of-Life Planning

Logistic regression was performed to consider the role that the socioeconomic factors of education and poverty may have played in formal planning and whether they may help explain the racial and ethnic differences in formal end-of-life planning. 'No formal planning' was used as the reference group. Table 7 Table 7 includes three models. The first model included the same variables as Model 4 in Table 6 (race, region of death, cause of death, age, gender, children, and married or partnered). Model 2 added in the socioeconomic variable of education. Model 3 included a poverty ratio variable.

These models indicate that non-Hispanic Blacks and Hispanics were less likely to participate in any formal planning, even after controlling for the other demographic and socioeconomic factors. Hispanics stay constant between Model 3 and Model 4 with 66% lower odds of completing any formal plans compare to Whites. Blacks have between 67% and 68% lower odds of completing any formal plans compared to Whites.

In order to determine whether the impact of race on formal planning varied by poverty status or education, separate analysis was conducted using the interaction between race and poverty status, and race and education. Surprisingly neither of these interactions were significant and are thus not reported here. This may in part be an artifact of low numbers, especially when looking at the interaction between Hispanic and college education.

Education was a significant independent predictor of formal planning. Decedents that had at least a high school degree had 57% (Model 2) and 51% (Model 3) greater odds of completing any formal planning than their peers that had less than a high school education. The odds were even greater for those that had at least a two-year college degree. Taking the demographic factors into account, those with at least a two-year college degree had 99% greater odds of having completed any formal plans than their peers that had less than a high school education (Model 2). Living above the poverty threshold helped explain some of the benefits of a college education for formal planning, but a college education remained significant with 75% greater odds of completing formal planning after controlling for poverty (Model 3). Interactions between race and education were not significant and are thus not shown here.

Income was also a significant predictor for formal planning. The better off the decedent was, the more likely they were to have done some form of formal planning. Every percent increase in the poverty ratio increased the odds that formal planning had taken place by 4.3% (Model 3). Interactions between race and poverty ratio were not significant and are therefore not shown here.

Table 7: Logistic regression of any planning by race with SES

	Model 1	Model 2	Model 3
	O.R.	O.R.	O.R.
Race (White)			
Black	.271 ***	.308 ***	.317 ***
Hispanic	.267 ***	.329 ***	.336 ***
Region of Death (South Atlantic / East South Central)			
North-East	.751 *	.753 *	.741 *
Mid-West	1.631 ***	1.619 ***	1.617 ***
West	1.097	1.013	1.011
West South Central	.607 ***	.633 **	.645 **
Cause of Death (Cancer)			
Organ Failure	.653 ***	.657 ***	.668 ***
Frailty / Old Age	.781	.791	.802
Other	.557 ***	.551 ***	.557 ***
Age at Death	1.037 ***	1.040 ***	1.041 ***
Gender (Male)			
Female	1.126	1.117	1.121
Children (No)			
Yes	1.011	1.024	1.024
Coupled or Partnered (No)			
Yes	.740 **	.712 ***	.677 ***
Education (Less than High School)			
High School		1.570 ***	1.514 ***
College or more		1.986 ***	1.751 ***
Poverty Ratio			1.043 **
-2LL	2838.192	2816.495	2809.246

***p≤.001 **p≤.01 *p≤.05 note: values in parentheses are reference categories

Results for Specific Aim Three - Religion and Formal End-of-Life Planning

As is shown in Table 8, the majority of White, Black, and Hispanic decedents claimed a religious preference. Almost 90% of the Black decedents were Protestant while 81% of the Hispanic decedents were Catholic. Whites were dominantly Protestant (65%) but 25% had claimed to be Catholic. Whites had the highest percentage who claimed no religion or another religion, with 10% belonging to this category.

The majority of White, Black, and Hispanic decedents also reported that religion was 'very important' to them, with 83% of Blacks, 75% of Hispanics, and 59% of whites making this claim. White decedents had the highest proportion who reported that religion was 'not too important' with 15%. Just over half (51%) of Blacks reported attending religious services two or more times a month, while 44% of Hispanics, and 36% of Whites reported attending this frequently. Again, Whites were the most likely to report not attending religious services at all with 40%.

Table 8: Race and religion

		White	Black	Hispanic
Religious Preference	Protestant	64.6%	89.8%	14.7%
	Catholic	25.2%	5.0%	80.6%
	None, other	10.1%	5.2%	4.7%
Importance of religion	Very Important	59.3%	82.6%	74.9%
	Somewhat Important	22.1%	7.2%	12.0%
	Not Too Important	14.7%	3.7%	8.4%
	Did not answer	4.0%	6.5%	4.7%
Frequency of attending religious services	Two or more times a month	35.9%	50.9%	44.0%
	One or more times a year	16.3%	15.4%	13.6%
	Not at all	39.7%	23.3%	32.5%
	Did not answer	8.0%	10.4%	9.9%

note: percents are column percents

Logistic regression was performed to consider whether religion could account for whether any formal end-of-life planning was done (Table 9). No formal planning was used as the reference group. Model 1 included the religious preference of the decedent, with Catholic as the reference group. Neither Protestant nor those who reported having 'no religious preference or other' were significantly different from those who reported being Catholic. Race and ethnicity was still significant, with Blacks having 68.1% lower odds of formal planning and Hispanics 66.6% lower odds of formal planning compared to Whites.

Model 2 included the importance of religion to the decedent, with not important as the reference group. There was no significant difference between those who reported religion as 'very important,' 'somewhat important,' or did not answer the question and those that reported religion as 'not important.' Race and ethnicity was still significant, with Blacks having 67% lower odds of completing formal planning and Hispanics having 66% lower odds of completing formal planning compared to Whites.

Model 3 includes the frequency of religious service attendance, with those who did not attend at all as the reference group. There was no significant difference between those who reported attending services two or more times a month, one or more times a year, or did not answer the question, and those that did not attend any religious services. Race and ethnicity was still significant, with Blacks having 69.4% lower odds of completing formal planning and Hispanics having 67.3% lower odds of completing formal planning compared to Whites.

Model 4 includes religious preference, importance of religion, and frequency of attending services. In this model, religious preference is still not significant, but both frequency of attending services and importance of religion become significant. Those that reported religion as very important had 31.2% lower odds of completing any formal planning. Those that reported going to religious services two or more times a month had 31.7% higher odds of completing any formal end-of-life planning. Those that did not answer either the importance of religion or the frequency of attending questions were also significantly different. Race and ethnicity was still significant, with Blacks having 68.4% lower odds of completing formal planning and Hispanics having 67.0% lower odds of completing formal planning compared to Whites.

Model 5 (Table 9) included all three of the religion variables and the interaction between religious preference and importance of religion. In this model, race and ethnicity was still significant with Blacks having 68.0% lower odds and Hispanics having 67.7% lower odds than Whites of having completed any formal end-of-life plans. While race and ethnicity did not change in this model, the impact of religion did. Protestants had 117.7% greater odds than Catholics of completing formal planning. Additionally, those that attended services two or more times a month had 31.1% greater odds of completing formal planning. The interaction between religion and importance shows a significant interaction between Protestants and importance of religion, with those Protestants who found religion very important having 60.1% lower odds of completing formal plans and those Protestants who found religion somewhat important having 56.6% lower odds of completing formal plans than Catholics who felt that religion was not important. Interactions between religious preference and frequency of attending religious services were tested but were not significant (results not shown).

Across all of the models, race and ethnicity remained significant and were not significantly changed or explained by the addition of religious variables. When sociodemographic factors were controlled for, both Blacks and Hispanics had significantly lower odds (66% to 68%) of completing any formal planning compare to Whites. This was not changed significantly for either group when adding in the religion variables of preference, frequency, or importance, with Blacks and Hispanics still having significantly lower odds (66% to 69%) of completing formal planning compared to Whites. Interactions between race and religious preference, race and frequency of attending services, and race and importance of religion were all tested but the interactions were not significant (results not shown). This indicates that the effects of race and ethnicity on completing formal end-of-life planning is independent of sociodemographic and religious factors.

Table 9: Logistic regression for any planning with religion variables

	Model 1	Model 2	Model 3	Model 4	Model 5
	O.R.	O.R.	O.R.	O.R.	O.R.
Race (White)					
Black	.319 ***	.326 ***	.306 ***	.316 ***	.320 ***
Hispanic	.334 ***	.340 ***	.327 ***	.330 ***	.323 ***
Region of Death (South Atlantic / East South Central)					
North-East	.740 *	.736 *	.744 *	.741 *	.739 *
Mid-West	1.617 ***	1.603 ***	1.631 ***	1.625 ***	1.626 ***
West	1.008	.984	1.043	1.017	1.029
West South Central	.647 **	.649 **	.645 **	.648 **	.647 **
Cause of Death (Cancer)					
Organ Failure	.669 ***	.671 ***	.667 ***	.672 ***	.670 ***
Frailty / Old Age	.799	.801	.820	.832	.844
Other	.556 ***	.562 ***	.557 ***	.567 ***	.562 ***
Age at Death	1.041 ***	1.041 ***	1.040 ***	1.040 ***	1.040 ***
Gender (Male)					
Female	1.119	1.147	1.121	1.160	1.157
Children (No)					
Yes	1.025	1.025	1.025	1.026	1.027
Coupled or Partnered (No)					
Yes	.676 ***	.677 ***	.677 ***	.677 ***	.674 ***
Education (<High School)					
High School	1.512 ***	1.513 ***	1.502 ***	1.493 ***	1.510 ***
College or more	1.745 ***	1.735 ***	1.725 ***	1.678 ***	1.684 ***
Poverty Ratio	1.043 **	1.044 **	1.041 **	1.041 *	1.041 *
Importance of Religion (Not Important)					
Somewhat Important		.813		.760	1.272
Very Important		.780		.688 *	1.246
Did not answer		.679		.345 **	.450
Frequency of Attending Services (Not at all)					
1 or more times a year			1.182	1.247	1.250
2 or more times a month			1.192	1.317 *	1.311 *
Did not answer			1.332	2.125 **	2.154 **
Religion * Importance					
Protestant * Somewhat Important					.434 *
None/Other * Somewhat Important					.711
Protestant * Very Important					.399 **
None/Other * Very Important					.553
Protestant * Did Not Answer					.562
None/Other * Did Not Answer					1.495
-2LL	2809.045	2806.024	2805.072	2794.286	2786.158

***p≤.001 **p≤.01 *p≤.05 note: values in parentheses are reference categories

CHAPTER FIVE: DISCUSSION, LIMITATIONS, AND CONCLUSION

The purpose of this study was to explore how older non-Hispanic Black, non-Hispanic White, and Hispanic adults plan for the end-of-life as well as to investigate the potential mechanisms of SES and religion to help explain differences in formal end-of-life planning. Using a current nationally representative data set, the completion of formal advance directives (written instructional directives and/or assigning a durable power of attorney for health care) was compared across the three racial and ethnic groups in the United States. Additionally, socioeconomic status and religiosity were investigated along with other demographic characteristics both for their direct influence on end-of-life planning as well as for potential mediating influence on racial and ethnic differences in formal planning.

Racial and Ethnic Differences in Formal End-of-Life Planning

The first aim of this research was to explore whether disparities exist in who completes formal planning and to examine whether there are differences in the type of formal planning that takes place. The finding that 68% of the decedents in this sample completed some form of formal end-of-life planning is consistent with other recent research on advance planning for those that have an illness that could lead to death. Teno et al. (2007) found that 70.8% of non-traumatic deaths in 2000 had completed some form of advance planning, while Black et al. (2008) found a higher proportion of their sample had completed formal end-of-life planning. Of the 203 older adults that were surveyed in Florida in 2006, 78.6% had a durable power of attorney for health care and 81.1% had a written advance directive.

Breaking the forms of formal planning out, it is interesting to note that 41% of people in this study completed both a written advance directive and assigned a proxy, whereas only 5.8% only had a written advance directive and 21.1% only had a proxy. This indicates that among those who did any formal end-of-life planning, the majority approached planning in more than one way. Just considering these numbers, there is reason to be optimistic that the majority of people are completing some form of advance directive, whether it be a written advance directive only, assigning a proxy only, or doing both.

Similar to previous studies, racial and ethnic disparities in formal planning were found (Carr 2011, Gerst and Burr 2008). This study found that Blacks and Hispanics were less likely to complete any form of formal planning than Whites, but the size of the disparity depended on the type of formal planning. Both Hispanics and Blacks were more likely to have assigned a proxy than they were to have a written advance directive. As has been claimed in some previous research (Kwak and Haley 2005), the idea of assigning a proxy may be more acceptable to Hispanics and non-Hispanic Blacks because of strong norms regarding the role of family in health care decisions. Hispanics were slightly less likely to have a written advance directives compared to Whites than were Blacks. This could be explained by language barriers, which I was unable to control for.

This study finds slightly better results for Blacks writing advance directives and assigning a proxy than an earlier study that used HRS exit interviews from 2000 (Gerst and Burr 2008). That study found in their basic logistic models the likelihood of Blacks assigning a proxy were 66% lower and having a completed written advance directive were 80% lower than Whites. By contrast, the current study found that Blacks had 48%

lower odds for assigning a proxy and 66% lower odds of completing a written advance directive. These numbers are not directly comparable due to differences in the models, but the smaller Black / White difference found in this study may indicate more usage of formal planning by Black elders over time. Unfortunately, Gerst and Burr did not consider Hispanics in their study.

After controlling for region and cause of death, non-Hispanic Blacks and Hispanics were significantly less likely to complete formal end-of-life plans than non-Hispanic Whites. Both Blacks and Hispanics had approximately 74% lower odds of completing any formal planning than Whites, and that was reduced to 86-88% lower odds of completing both a written advance directive and assigning a proxy. While, there are no comparable studies examining the completion of both forms of formal end-of-life planning, Gerst and Burr (2008) considered both formal and informal end-of-life planning and found that Blacks were 63% less likely than Whites to engage in additional end-of-life planning activities.

Both Blacks and Hispanics had significantly lower odds of completing both a written directive and assigning a proxy than Whites. Almost 50% of Whites completed both a written advance directive and a proxy compared to 15% of Blacks and 12% of Hispanics. Although there is no empirical evidence that having both a written advance directive and a proxy is better than either alone, it seems reasonable that the two forms support and benefit each other. While an assigned proxy has the benefit of being able to make decisions based on the specific circumstances that their loved one is in, the written advance directive indicates some of the specific desires and values that the patient has. Having this document may help alleviate some of the anxiety and strain that proxies experience, while having a proxy who is able to speak for the patient can help physicians better understand the fears, values, and desires of their patient. Additionally, having two forms of planning may increase the likelihood that the plan will be followed. Based on the finding in a previous study that even when African Americans had stated preferences for end-of-life care it was less likely to be followed than the preferences of White patients (Loggers et al. 2009), the additional legal support of having multiple formal plans may be beneficial.

Similar to previous studies, the demographic factors of age and marital status were both related to formal planning, with being older increasing the odds of formal planning and being married decreasing the odds of formal planning (Alano et al. 2010, Boerner et al. 2013). Gender and having children did not influence the odds of completing formal plans. These findings are important and add to the literature as they support previous research findings but are based on a recent nationally representative sample.

Similar to previous studies, increasing age improves the odds of formal planning. As people age, they have greater exposure to death as their friends and family die. In this way, death becomes more real and therefore planning for it may become more important. Issues of personal health and physical deterioration may also make planning more salient. In 2011, the life expectancy for Blacks was 4 years lower than the life expectancy for Whites and 6.6 years lower than Hispanics (Miniño 2013). Death at a younger age accounts for some of the difference seen in planning between Blacks and Whites.

People who were married had lower odds of completing formal planning compared to those who were not married at the time of their death. This is in line with another study (Carr 2007). Since most states have passed statutes that list spouses as the first person to turn to if a person is unable to make decisions for themselves (Cerminara 2011), people may not make formal plans expecting that their spouse will be consulted. It is possible that informal discussions between the spouses have taken place, or there may be the assumption that the spouse will know what is wanted without any discussion. Both of these possibilities have potentially serious repercussions for the incapacitated person as well as the default proxy. In the legal battle over Nancy Cruzan's care, the Supreme Court upheld the state's authority to require evidence of an incompetent person's desires for removing life sustaining treatments (Miles and August 1990). Without a written advance directive, a spouse may be unable to prove informal discussions about care. Additionally, in a study done on married couples, designated surrogates were incorrect in their understanding of their spouses treatment desires 13% of the time in scenarios involving cognitive impairment and 26% of the time in scenarios involving physical pain (Moorman, Hauser, and Carr 2009).

The finding that having children was not significant is interesting, but more challenging to explain. Although previous studies have indicated that married persons tend to assign their spouses as their durable power of attorney for health care, those that do not have a spouse will frequently select a child as a proxy (Boerner, 2013, Carr, 2007). Considering that in this sample, 91% had at least one living child in contact with the decedent but only 43% were married or living with someone as married prior to death, it is reasonable to assume that many children took on the role of proxy. While this study did not determine who was the proxy for the decedent and there were not many decedents who did not have children in contact with them, the lack of significance in this case signifies the need for further study to understand the roles that children play in their parent's formal end-of-life planning.

Race, Socioeconomic Status, and Formal End-of-Life Planning

This study also had the aim of examining whether socioeconomic factors influenced formal planning. Consistent with previous studies, this study found that socioeconomic factors influenced the completion of formal end-of-life planning (Black, Reynolds and Osman 2008, Gerst and Burr 2008, Kwak and Haley 2005). Education and poverty both significantly influenced the odds of completing formal plans, with higher levels of either increasing the likelihood of formal plans being completed. Interestingly, although these factors had strong influences on planning, they did not significantly account for the large racial and ethnic differences.

Comparative studies of advance directives have primarily used the racial categories of Black and White, so the findings that Hispanics were similar to Blacks in a nationally representative sample is of interest. After controlling for the demographic characteristics of age, gender, children in contact, and marital status but prior to controlling for socioeconomic factors, both Blacks and Hispanics had approximately 73% lower odds of completing any formal planning. Once the socioeconomic factors of education and poverty were controlled for, the odds improved for both Blacks and Hispanics, but they still had significantly lower odds (68% and 66% respectively) of completing any formal planning compare to Whites. The effect of education was greater for Hispanics than it was for Blacks, with Hispanics having a 9% improvement in their odds for completing any formal end-of-life plan and Blacks improving 5.8%. Based on the age of the decedents, the effects of segregated schools and racial barriers to higher education may have been especially relevant. Fewer racial and ethnic minorities of this age range completed high school or attended college than Whites (see Appendix C) which indicates that racial and ethnic minorities were less likely to have received the skills that form the basis of health literacy. As the available information on end-of-life planning is relatively complex, having lower levels of health literacy skills in reading and analyzing health related information is a barrier to completing formal end-of-life plans.

Poverty had a significant implication for end-of-life planning, with those who were better off financially being more likely to complete formal plans. As indicated in other research, people with very low incomes do not have access to the same quality of health care services as those with higher levels of income (Moller 2004, Moller 2005). Although this study was not able to control for the type or quality of medical providers, studies have shown that people with lower levels of income are less likely to have an ongoing relationship with a medical provider (Oster and Bindman 2003). They therefore may be getting information regarding serious illness from multiple sources, none of which are primarily responsible for the health and wellbeing of the patient. If information regarding the need for formal end-of-life planning is provided at all, it may not be trusted since the patient and medical provider would not have a developed relationship. Additionally, those who live in impoverished neighborhoods are more likely to use the emergency department for health care needs (Schappert and Rechtsteiner 2011). The emergency department is designed to treat acute medical issues and is not designed around the time and knowledge needed to have discussions about end-of-life planning.

While both income and education are indicators of position within a socially stratified society (Grusky 2008), they may not be capturing differences in social and cultural capital. Lower levels of health cultural capital may partially explain why racial and ethnic minorities were less likely to complete any formal plans, as well as the significantly lower percent that completed both a written advance directive and assign a proxy. Economic capital may provide greater access to care, but the activation of cultural capital may help patients choose a consistent medical home, develop a beneficial relationship with their provider, and ultimately plan for their own deaths. Health care providers of patients with lower levels of medical cultural capital may believe that the patient does not want, or will not understand, information around end-of-life treatment options. They therefore may not provide the same quality of discussions about end-of-life planning to these patients as they do to patients with higher levels of medical cultural capital. Racial and ethnic minorities are likely to have lower levels of medical cultural capital, which can lead to increased levels of distrust in the medical field.

Although most people want to use medical technology and medical advances while there is still hope, nine out of ten people in the United States also claim that they want to die at home (Institute of Medicine 1997). Using Bourdieu's concepts of fields, the subfield of end-of-life care can be understood as the location where patients, family, medical professionals, and others struggle for the right to make decisions about death. The higher use of formal end-of-life plans by Whites, those with higher levels of education, and those with more money (in other words, those with greater economic and cultural capital) can be understood as resulting from a greater ability to activate their capital to their advantage. Additionally, the use of formal plans, which are recognized and legitimized methods of planning, is an activation of a form of symbolic capital in an attempt to achieve a death in alignment with personal values. Using two forms of formal planning may indicate a more sophisticated deployment of symbolic capital available to those with greater medical cultural capital in order to achieve the advantage of a desired death experience.

Race, Religion, and Formal End-of-Life Planning

The third aim of this study was to explore three dimensions of religiosity on the creation of formal end-of-life plans as well as the influence of religiosity on racial and ethnic differences in planning. Religious preference, importance of religion, and frequency of attending religious services were each considered.

When considering any of the religious variables independently of each other, none of them were significant. But, interestingly, more frequent attendance of religious services and higher reported levels of importance of religion are both significant and appear related when included in the same model. Those who believed that religion was very important in life were less likely to plan while those who attended religious services two or more times a month were more likely to plan. The odds were nearly equal for these two indicators of religion, but in opposite directions. This supports the argument for the importance of using multidimensional measurements to capture religiosity (Flannelly, Ellison and Strock 2004).

The finding that those who attend services more frequently are more likely to plan indicates that having a religious reference group has a different outcome than expected for end-of-life planning. Rather than reinforcing the norms and moral messages provided by the official stance of the church, the reference group may include people who have firsthand experience with the bad death of a loved one or who have other relevant information. Since religious teachings are intimately connected to the experience and meaning of death, the general taboo towards talking about death may not apply to people who attend services together frequently. Therefore the reference groups found at religious services may help spread the information, skills, and support needed for formal planning rather than discourage it.

The influence of religious identity salience on formal end-of-life planning was partially supported by the findings in this study. Those who claimed that religion was very important to them had lower odds of completing formal planning when frequency of attending religious services was held constant. In many Christian teachings the experience of suffering brings believers closer to God or is even considered redemptive (Mellor 1991, Shilling and Mellor 2010), so those who have a strong religious identity may be more likely to believe that the timing and method of death is in God's hands and resist planning, especially planning that may limit care (Braun et al. 2008). Alternatively, physicians of patients who have strong religious identities may be less likely to bring up formal end-of-life planning. A recent case study indicated that medical teams may be less likely to discuss hospice with patients who believe that God will perform a miracle and heal them (Sulmasy 2006). If a patient tells her medical provider that she believes that her health is in God's hands, it is possible that the physician will assume that the patient will not be open to end-of-life planning.

Once the interaction of religious preference and importance of religion was considered, Protestants who did not feel that religion was very important were more likely to complete formal end-of-life planning than Catholics. This is in line with the expected influence of Catholic doctrine regarding the sanctity of life. Conversely, Protestants who felt that religion was somewhat or very important were less likely to plan than Catholics who felt that religion was not very important. This further supports the idea that the importance of a religion based on the Christian tradition in the United States, whether it is Protestant or Catholic, influences formal end-of-life planning. Unfortunately due to the small numbers of non-Christians in the sample, this study was unable to investigate religious traditions not based on Christianity.

Although religiosity has been shown to be associated with wanting more aggressive medical care (Balboni et al. 2007, Phelps et al. 2009), most studies have not considered the influence of multiple dimensions of religion on actual planning behaviors. While the exact mechanism that occurs to encourage formal planning when people frequently attend religious services needs further study, the findings from this study indicate that religious social support has the potential to positively influence the use of formal end-of-life plans.

None of the dimensions of religiosity influenced racial and ethnic disparities in the creation of formal end-of-life plans, even when I conducted interactions between race and any of the three dimensions of religiosity. This was surprising based on the literature that indicates that religion plays a larger role in racial and ethnic minorities health behaviors (Ferraro and Koch 1994, Krause 2002) as well as in their beliefs toward end-of-life care (Born et al. 2004, Braun 2008, Carr 2011). These findings differ from a recent study of 293 chronically ill older adults in New Jersey which found that much of the difference between Blacks and Whites in advance care planning was related to Black's belief that God controls the timing of death (Carr 2011). This suggests that while religiosity itself may not differ, there may be racial differences in the belief about specific religious doctrines that influence formal planning.

Implications for Policy

If the United States was actually moving towards the majority of people completing formal end of life plans, time would bridge the differences in who was planning for their deaths and who was not. But, if the use of formal plans are on different trajectories based on race, demographic factors, or socioeconomic status then policy must be created to diminish or stop increasing disparities.

Health Policy

Since advance care planning is a relatively low cost way to increase the chance that people can experience a death that is in alignment with their values, policies that encourage formal planning should be strengthened. The current trend toward patient activation by health plans should include considerations of how patients can be involved in decisions about their deaths. Patient-centered care has been shown to be increase patient and provider satisfaction, improve health outcomes, reduce health care usage, and lower malpractice rates (Maizes, Rakel and Niemiec 2009). There is no reason that the benefits of patient-centered care should stop during the end-of-life. At a minimum, hospitals and medical schools should provide training to staff and students regarding the legal rights of patients to plan for their deaths and how to talk to patients about planning. Additionally, health plans should encourage physicians to take the time to develop patients' understanding of the death process, including what to expect and the value of formal end-of-life planning. Furthermore, insurance (including Medicare and Medicaid) should pay for physicians to have periodic discussions about advance directives with their patients. Although Obama attempted to include Medicare payments for physicians to have periodic discussions about advance directives with their patients in the Affordable Care Act in 2009, it was removed from the final bill due to the popular misconception that a "death panel" would decide if a person would be allowed to live. If doctors were encouraged to sensitively have these discussions with plenty of time for questions, racial and ethnic fears around end-of-life plans may begin to be assuaged. If these discussions happen early enough, patient's cultural health competency can be augmented. Allowing physicians to get paid for their time discussing end-of-life planning is a first and necessary step towards diminishing disparities in those who experience a "bad" death.

Education Policy

Other broad policy that could assist in decreasing disparities in end-of-life planning is improving education. Education that included a complete life-course perspective as well as health literacy skills could ultimately improve the likelihood of end-of-life planning. Additionally, improving education would encourage more racial and ethnic minorities to enter the medical field as professionals. Diversifying the medical field could go a long way towards increasing the trust of racial and ethnic minority patients.

Marriage Equality

People who were coupled or partnered had 32% lower odds of completing formal planning. While this is in line with other studies (Carr and Khodyakov 2007), the finding is interesting due to the potential policy ramifications. Since most states have passed statutes that list the people that can make medical decisions for an incapacitated patient if no other person has been formally designated (Cerminara 2011), it may be assumed that the spouse will be turned to at that time of need and therefore no formal planning is necessary. People who are in significant relationships without the benefit of a formal marriage certificate do not have the same benefits of having their significant other on the top of the list for medical decisions. People who are not completing formal plans but assuming that the person that they are living with will be allowed a place at the decision-making table may ultimately have their end-of-life experience dictated by a different family member than they expected or wanted.

Implications for Sociology

Sociology has much to offer those that are, or will be, facing death. Social and cultural factors play a large role in how people experience the end of their lives. While social forces should be irrelevant in life or death situations, sociological research has shown that sociodemographic factors such as race, class, and gender, all have implications for treatment and outcomes and it is unlikely that the dying process is exempt.

Most end-of-life research is done by medical researchers, not sociologists (Kahana, Kahana and Wykle 2010). Many researchers who study both the dying and the end-of-life experience therefore neglect the social and social structural implications involved. This study adds a sociological voice to formal end-of-life planning, and in the process hopefully encourages further exploration of end-of-life issues with a sociological lens. End-of-life struggles around the medical imperative, medical paternalism, patient rights, palliative care, and diverse patient values are ripe areas to study sociology. People who are dying are extremely vulnerable to disparities in care since they are unable to seek redress. Those that are most vulnerable to systemic problems are those that live in the margins of the system. Racial and ethnic minorities are greatly underrepresented in the professional medical field, are the least likely to have 'health capital' and are therefore the most likely to be vulnerable to problems at the end-of-life. While some see the decision making process at the end-of-life as highly personal (Lambert et al. 2005) if we fail to look for the social and environmental influences on how death is experienced, we will fail to understand the disparities that are there and fail in efforts to eliminate them.

Limitations

As in most research, there are limitations to this study that need to be acknowledged.

In most research, the use of proxy respondents would be considered a significant limitation. Because of the nature of end-of-life research, the use of proxies is a common method due to difficulties involved with interviewing dying patients as well as the general belief that families play a large role in the end-of-life care and can therefore accurately answer most questions. This use of proxy respondents is appropriate provided that the patient is unable to participate (George, 2002). That said, while it is appropriate to use proxies in this case, it is important to remember that proxies answered questions regarding having completed formal end-of-life plans, cause of death, region of death, and timing of death, and if there was a change in marital status prior to death. The proxy limitation was minimized in this research by using answers that the decedent provided during earlier waves of the HRS longitudinal study for all other variables.

While this study did control for region of death, the size of these regions may not have been sensitive enough to adequately control for regional variations in religious ecology or the availability of palliative services and support that may play a significant role in patient's exposure to and acceptance of formal end-of-life planning (Grunier et al. 2007). Regional expectations may be important at a smaller regional levels because areas that have a high number of ICU beds and high technology hospitals may have people who are more likely to expect medical technology at the end of life. Conversely, areas that have the social support in place for home care will likely have more patients and families who are familiar with that care and therefore may be more inclined to use them. Although these regional differences may be experienced differently by racial and ethnic minorities, interactions between race and region of death did not produce any significant results. This may have been partly due to the size of the regions included in the study.

Other limitations of this research include lack of information on other health care dimensions that may impact willingness to complete formal end-of-life plans. These include insurance coverage, relationships with health care professionals, and previous experiences with the medical establishment. Additionally, although this study found that 68% of the decedents had completed some form of formal end-of-life plan, this finding cannot be generalized to younger or healthier people. This study focuses on an older population that had been sick enough to die. The findings are therefore not generalizable to younger or healthier populations. Studies are needed to see how younger decedents have used formal end-of-life planning.

There are many other groups whose experiences are missing in this research. Other racial and ethnic groups have different experiences and are important to consider when looking at end-of-life planning. There are also a number of intersecting identities that may make a difference in formal end-of-life planning. Statuses and identities that may impact formal planning and need further research include immigrant status, acculturation, sexual orientation, gender identity, developmental disabilities, physical disabilities, and mental illness. There are also issues that are specific to rural populations, homeless, those in prison, and newer immigrants to the United States that have implications for racial and ethnic experiences with end-of-life care and planning which were not approached in this research.

Acknowledging the previously stated limitations, this study adds to the conversation by considering the patterns within socioeconomic, demographic, and religious variables and formal end-of-life planning. Although other racial and ethnic groups need to be studied, this study had the benefit of exploring the differences in formal end-of-life planning between Black, Hispanic, and Whites rather than assuming either that all end-of-life experiences were similar, or that all racial and ethnic minorities experiences were similar. Additionally, most studies that consider religion typically use a single indicator such as denomination which fails to address the multiple avenues of impact that religiosity may have. The use of multiple domains of religiosity in this study brings a more nuanced understanding of the role of religion in formal end-of-life planning.

Future Research

Ultimately it is important to distinguish between those who complete formal planning and the use of these plans by physicians and hospitals. Even if everyone is completing end-of-life plans, if physicians and hospitals are not following them in ways that are equitable and just, then the plans mean little. Additionally, studies that explore the change in the use of formal planning by racial and ethnic groups over time are needed to see if the disparity in formal planning is increasing or decreasing. While this would not provide a solution to existing disparities, it is important to know if the gap between racial groups is widening.

There is a need for a cost-benefit analysis of formal end-of-life planning, but that recommendation comes with the major caveat that care must be taken with the research. While this study was more rooted in issues of social justice than of economics, deep discussions about the medical model of death and the resulting economic, personal and social costs of dying could help move end-of-life care towards a more holistic approach. Additionally, encouraging people to consider their end-of-life values could lead to cost savings for families, medical providers, and insurance companies. I am making this recommendation with great caution though for two reasons. The first is that this form of end-of-life research has the potential to move the conversation away from being about social justice in how people experience their death and toward a cost-cutting approach. Approaching death with only costs in mind would significantly increase disparities rather than reduce them. Additionally, if people came to believe that end-of-life planning is a cost-cutting measure rather than a social justice issue, a cost-benefit analysis could create a backlash and harm the movement toward better end-of-life planning.

Another study that would be important would include qualitative research around the impact that race and religion have on formal planning. Exploring both similar and different religious beliefs around formal planning by racial and ethnic groups could help clarify what aspects of religiosity impact end-of-life planning. Focus groups with religious congregations could help explicate the role that religious reference groups have on formal planning.

Lastly, more research is needed on the roles of both medical cultural capital and health literacy in formal end-of-life planning. If, as has been suggested by this research, medical cultural capital influences end-of-life planning and may also have implications for reducing racial and ethnic differences in planning, it is important to determine the specific mechanisms such as health literacy.

As larger numbers of older adults face progressively complex choices prior to death, understanding the factors that influence end-of-life planning is of growing importance. The fact that there is a diverse aging population that will be facing death in hospital systems that are not ready for them makes formal end-of-life planning an important topic from both a sociological and a policy perspective. Medical care, especially at the vulnerable time at the end-of-life, can hide existing social and economic inequalities with the claim of medical legitimacy. Social determinants of health researchers have a lot to offer, as well as a lot to gain from studying the end-of-life.

Although more research is needed to determine whether people who are dying are receiving care that is alignment with their desires and values, one of the first steps in identifying problematic deaths is to examine the differences in who is completing formal planning. As medical technology continues to progress and as the population ages, the urgency to have discussions around end-of-life treatment desires will only increase. The use of sociologically informed evidence will help build interventions that can diminish disparities in the end-of-life experience. While formal plans are not the only or the complete answer, they are an essential step to ensuring end-of-life care that is in alignment with personal beliefs and values.

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APPENDIX A: CENTURY MONTH

Table A.1: Century Month

To get the date of birth century month:
DOBCenturyMonth=(BIRTHYR-1900) * 12+BIRTHMO.
↓
To get the date of death century month:
DODCenturyMonth=(DeathYr-1900)*12+DeathMo
↓
To get age century month:
CenturyMoAGE = DODCenturyMo-DOBCenturyMo
↓
Age at death=CenturyMoAGE/12

APPENDIX B: MARITAL STATUS BY RACE

Table A.2: Marital Status by Race

	White	Black	Hispanic	Total
No	56.6%	64.3%	51.3%	57.4%
Yes	43.4%	35.7%	48.7%	42.6%

Note: Percents shown are column percents
** Chi-square p≤.01

APPENDIX C: RACE AND EDUCATION

Table A.3: Race and Education

	White	Black	Hispanic
Less than high school diploma	29.1%	57.3%	75.9%
High school diploma or GED	52.5%	33.7%	19.4%
Some college or more	18.4%	8.9%	4.7%

note: Percents shown are column percents

***Chi-square $p \leq .001$

APPENDIX D: FREQUENCY OF ATTENDING RELIGIOUS SERVICES BY RELIGIOUS PREFERENCE

Table A.4: Religious Service Frequency and Preference

	Protestant	Catholic	None, no pref, other	Total
2 or more times a month	39.9%	44.2%	15.7%	38.9%
One or more times a year	16.3%	14.3%	17.9%	15.9%
Not at all	35.8%	31.8%	56.8%	36.6%
Did not answer	8.0%	9.7%	9.6%	8.6%

Note: Percents shown are column percents

*** Chi-square $p \leq .001$

APPENDIX E: IMPORTANCE OF RELIGION BY RELIGIOUS PREFERENCE

Table A.5: Importance of Religion and Preference

	Protestant	Catholic	None, no pref, other	Total
Very Important	67.3%	65.2%	37.6%	64.1%
Somewhat Important	18.5%	18.4%	24.5%	19.0%
Not Too Important	10.3%	11.2%	31.9%	12.5%
Did not answer	3.9%	5.2%	6.1%	4.4%

Note: Percents shown are column percents

***Chi-square p≤.001