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**The Roles of Estate Planning and Social Support in Racial/Ethnic
Disparities in Advance Care Planning and End-of-Life Care**

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**The Roles of Estate Planning and Social Support in Racial/Ethnic
Disparities in Advance Care Planning and End-of-Life Care**

by

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The Roles of Estate Planning and Social Support in Racial/Ethnic Disparities in Advance Care Planning and End-of-Life Care

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Advance Care Planning (ACP)– completing advance directives, discussing end of life care preferences, and assigning a durable power of attorney for healthcare – may be associated with improvements in quality of end of life care and more specifically with receiving care congruent with one’s wishes. Despite this, stark differences in completion rates by Non-Hispanic Blacks and Hispanics compared to Non-Hispanic Whites are observed. Much of the research on ACP has focused on describing associations between sociodemographic factors and planning completion or planning completion and health care received at the end of life (End-of-Life). However, few studies have proposed testable hypotheses and investigated causal relationships for ACP completion, particularly among Hispanic subgroups, and effects on end of life care received. This study uses nationally representative data from the Health and Retirement Study to investigate explanatory causal pathways in ACP completion and its effects on End-of-Life healthcare with a focus on Hispanics. Results from this study will help providers better understand sociodemographic factors that predispose patients to high risk for failing to plan for the end of life, health systems identify target areas for system change, and policy makers understand the role socioeconomic disparities play in end of life planning.

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List of Abbreviations

ACP	Advance Care Planning
EoL	End of Life
HRS	Health and Retirement Study
CMS	Centers for Medicare and Medicaid Services
SES	Socioeconomic Status
NHW	Non-Hispanic White
NHB	Non-Hispanic Black
OR	Odds Ratio
CI	Confidence Interval
RR	Relative Risk
C-stat	C Statistic
HL-P	Hosmer Lemeshow p Value

Chapter 1 Research Proposal

SPECIFIC AIMS

Advance Care Planning (ACP), defined here as completing advance directives, having a medical power of attorney, or discussing end of life care preferences can result in improved quality of care at the end of life. However, participation in ACP varies by race/ethnicity and other sociodemographic factors like education and income or wealth. Despite disparities in ACP completion (Catheryn & Tamara, 2017; Gerst & Burr, 2008; Catheryn S. Koss & Baker, 2017c), causal pathways that influence completion and facilitation of end of life care preferences are understudied. Estate planning plays a mediating role between social determinants and ACP (Catheryn & Tamara, 2017). The effects of ACP may be dependent on social support, like family living nearby, to facilitate alternative treatment options (Dixon, Matosevic, & Knapp, 2015; Klingler, in der Schmitten, & Marckmann, 2016; Riley & Lubitz, 2010).

A recent systematic review on facilitators and barriers for ACP among racial/ethnic minorities highlights the need to further describe the mechanism of race/ethnicity in ACP completion, specifically among Hispanics, which are culturally distinct from Non-Hispanic Blacks and Whites (Hong, Yi, Johnson, & Adamek, 2017). In the review, only 7 of 26 studies specifically include Hispanics in their samples and analyses and of those 7 only 2 utilized nationally representative samples despite the literature consistently demonstrating racial/ethnic disparities between Non-Hispanic Whites and Non-Hispanic Blacks. Therefore, there is a need to understand ACP completion rates and determinants among Hispanics due to their growing number in the U.S. and unique cultural differences compared to Non-Hispanic Blacks and Whites. In addition, studies described bivariate relationships between various sociodemographic factors and ACP (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; C. Koss, 2018; Narang, Wright, & Nicholas, 2015; Ornstein et

al., 2018; Portanova, Ailshire, Perez, Rahman, & Enguidanos, 2017; Silveira, Kim, & Langa, 2010; Silveira, Wiitala, & Piette, 2014; Tschirhart, Du, & Kelley, 2014), but few modeled their analyses such that mediating or moderating pathways may be investigated (Catheryn & Tamara, 2017; C. S. Koss, 2017; Catheryn S. Koss & Baker, 2017a). Understanding these relationships may shift the focus of interventions from the individual to the system level for broader reach and impact. The following aims are investigated to address these gaps.

Aim 1: To describe the association between sociodemographic factors (ex. age, race/ethnicity, education, etc.) and level of participation in end of life planning (ACP and estate planning). HRS core interviews for living respondents (2014) are analyzed to describe the prevalence and adjusted associations of community dwelling adults 65 and older participating in end-of-life preparatory activities (ACP and estate planning). Variation across ethnic groups (Non-Hispanic White, Non-Hispanic Black, and Hispanic) and socioeconomic levels and co-occurrence of ACP elements is examined.

Aim 2: To test for possible mediating relationship between race/ethnicity, socioeconomic status, estate planning, and advance care planning. HRS Exit interviews for deceased respondents (2002-2016) are used to investigate the possible mediating effect of socioeconomic status (education and wealth) and estate planning (having a written and witnessed will) on the relationship between race/ethnicity and ACP (advance directives, discussing End-of-Life care, and having a medical power of attorney).

Aim 3: To test for possible mediating relationship between race/ethnicity, advance care planning, social support, and end of life (End-of-Life) care. HRS Exit interviews for deceased respondents (2002-2016) are used to investigate the possible mediating effect of advance care planning and social support on the relationship between race/ethnicity and 1) decisions to limit care at the End-of-Life, hospital death, and complex care and 2) having one's End-of-Life preferences honored.

BACKGROUND AND SIGNIFICANCE

Many older adults needing to make medical decisions at the end of their life are unable to do so (Medicine, Committee on Approaching Death: Addressing Key End of Life, & Institute of Medicine . Committee on Approaching Death: Addressing Key End-of-Life, 2015; Silveira et al., 2010). End of life planning is associated with improved quality of life at the end of life measured by out of hospital death, increased hospice use, and decreased life sustaining treatments (Brinkman-Stoppelenburg, Rietjens, & Heide, 2014; Detering, Hancock, Reade, & Silvester, 2010; Wright et al., 2008). Advance care planning (ACP) may also be associated with decreased medical expenditures at the end of life (L. H. Nicholas, K. M. Langa, T. J. Iwashyna, & D. R. Weir, 2011). Population-level research on ACP has largely relied on the Health and Retirement Study, a representative sample of non-institutionalized U.S. adults age 50 and older and focused on bivariate or adjusted associations between sociodemographic factors and planning completion.

This dissertation adds to the ACP literature by investigating specific hypotheses for the pathways through which socioeconomic status affects end of life planning and care decisions with a focus on racial/ethnic disparities. Three areas of the literature are reviewed to present the contribution of this research: (1) the definition and components of Advance Care Planning and the currently reported U.S. completion rates, (2) factors associated with end of life planning completion, and (3) the role of advance care planning in quality of care at the end of life. An overview of each of these areas is presented in its own sub-section below, with a final sub-section that summarizes the gaps in the existing literature that this proposal is meant to fill.

DEFINING ADVANCE CARE PLANNING AND PREVALENCE OF COMPLETION

Definition. Advance Care Planning (ACP) encompasses a broad set of tasks involved in the process of informing others of one's wishes for health care at the end of life (Carr & Luth, 2016). The ideal timing of ACP is well before terminal illness when a

person has decision making capacity and can communicate their preferences for various types of life sustaining care including cardiopulmonary resuscitation (CPR), intubation, intravenous antibiotics, and feeding tubes (Carr & Luth, 2017). Instructions about which of these treatments the patient would decline if given the choice are usually documented in an advance directive or living will. Informal or formal designation of a durable power of attorney for health care (DPAHC) may also be involved. This is an individual who may make decisions on behalf of an incapacitated patient who is unable to guide treatment. State laws determine whether these shared decision makers need to be designated through legal documentation or if informal conversations between the patient and decision makers are sufficient (Sabatino, 2010).

Development of the various elements of advance care planning began in the late 1970s and continues to this day (Sabatino, 2010). The United States Federal Government demonstrated its support for ACP in 1990 by passing the Patient Self Determination Act (Carr & Luth, 2016; Carr & Luth, 2017; Sabatino, 2010). The act mandated that institutions receiving reimbursement from the Centers for Medicare and Medicaid Services (CMS) inform patients of their right to have advance directives and offer to document those advance directives in the medical record. With healthcare reform in 2008, congress tried to support ACP again by incorporating Medicare coverage for provider consultations. However, reimbursement for ACP discussions was not approved until 2016 (Sabatino, 2010; Tuller, 2016).

Prevalence. Completion of advance care planning has been low among minorities. Many studies report unadjusted completion rates for Non-Hispanic Whites, Non-Hispanic Blacks, and Hispanics. In one HRS study of 4,761 deceased respondents from 1998-2007, non-whites completed treatment-limiting advance directives 12.55% of the time compared to 44.39% for whites ($p < 0.001$) (L. H. Nicholas et al., 2011). Similar disparities are reported in another study using exit interviews for 4,394 respondents from 1993-2007 (Bischoff et al., 2013). The authors define advance care planning as having discussed end

of life care, completed advance directives, or assigned a medical power of attorney. Whites (77.58%) were more likely than Hispanics (43.56%) or Blacks (47.83%) to have completed any ACP activities ($p < 0.001$). A third study on 1,985 HRS decedents with cancer reported lower ACP rates (defined as discussing end of life care, completing advance directives, or assigning a medical power of attorney) among Blacks (58.96%) and Hispanics (53.13%) compared to Whites (83.89%) (Narang et al., 2015).

Non-Hispanic Blacks and Hispanics consistently have lower rates of completion than Non-Hispanic whites, even after multivariate analyses controlling for many sociodemographic confounders. For example, among 7,177 exit interview proxy respondents in the Health and Retirement Study from 1998-2013, Whites were more likely to have completed advance directives than Non-Hispanic Blacks (OR = 0.23, 95% CI: 0.19-0.29) and Hispanics (OR = 0.30, 95% CI: 0.22-0.40) after controlling for factors like age, gender, marital status, education, and income (Portanova et al., 2017). Another study of 6,946 HRS core interview respondents from 2012 demonstrated similar findings. In multivariate logistic regression modeling controlling for factors like age, gender, education, marital status, income, and self-rated health, Whites were more likely to have had an advance care discussion (OR = 1.75, 95% CI: 1.50-2.03) (Catheryn & Tamara, 2017). In a 2008 summary statement of the current state of advance care planning in the United States, the department of Health and Human Services reported one-third to one-half of American adults have completed advance directives (Services, 2008).

FACTORS ASSOCIATED WITH END-OF-LIFE PLANNING COMPLETION

Sociodemographics. Age and age at death have consistently been associated with ACP completion with older individuals generally being marginally more likely to complete planning activities likely due to proximity to the end of life. Small, positive associations with age in years have been reported (OR = 1.03, 95% CI: 1.02-1.04) (Catheryn S. Koss & Baker, 2017c) (Bischoff et al., 2013; Gerst & Burr, 2008; Khosla, Curl, & Washington,

2015). Some studies have reported *gender* differences in end of life planning (Bischoff et al., 2013; Carr, 2012; Catheryn & Tamara, 2017), while others have not (Gerst & Burr, 2008; Catheryn S. Koss & Baker, 2017c). Findings of gender differences generally indicate females are more likely than males to complete planning activities and that they are more likely to discuss the care they would like to receive. For example, in a study of 6,946 HRS respondents from 2012, women were more likely than males to have had an advance care discussion (OR = 1.71, 95% CI: 1.49-1.96) (Catheryn & Tamara, 2017).

Racial/ethnic minorities, namely Non-Hispanic Blacks and Hispanics consistently have lower rates of ACP (Catheryn & Tamara, 2017; Gerst & Burr, 2008; Catheryn S. Koss & Baker, 2017a, 2017c). The differences are substantial and generally prevail after adjusting for various sociodemographic factors. For example, in one study of 1,102 community dwelling and institutionalized individuals from the nationally representative HRS in 2000, Blacks were less likely than Whites to discuss care preferences (OR = 0.49), assign a durable power of attorney for health care (OR = 0.45), and have written advance directives (OR = 0.26) after controlling for factors like gender, education, marital status, and religious attendance (Gerst & Burr, 2008). Another study of 6,946 HRS respondents from 2012 reported Whites were significantly more likely to participate in advance care discussions than Blacks (OR = 1.75, 95% CI: 1.50-2.03) (Catheryn & Tamara, 2017). A third study using HRS data for 7,177 respondents from 2000-2012 to increase the sample size of Hispanics reported Non-Hispanic Blacks (OR = 0.23, 95% CI: 0.19-0.29) and Hispanics (OR = 0.30, 95% CI: 0.22-0.40) were less likely than Non-Hispanic Whites to complete advance directives (Portanova et al., 2017).

Marital status has not been operationalized consistently in the literature making interpretation of any association with ACP less straight forward. For example, one study of 7,177 respondents from the HRS in 2000-2012 defined four categories: married, divorced or separated, widowed, and never married (Portanova et al., 2017). Results of multivariate analyses showed significantly increased odds of having advanced directives

for those who were widowed (OR = 1.38, 95% CI: 1.19-1.61) or never married (OR = 1.45, 95% CI: 1.04-2.01) compared to those who were married. Other studies have used an alternative approach to define marital status, but not reported findings for this factor limiting interpretability of the association between marital status and planning completion (L. H. Nicholas et al., 2011; Silveira et al., 2010; Silveira et al., 2014).

Socioeconomic Factors. The association between *education* and advance care planning has been mixed. For example, in the 2004 Wisconsin Longitudinal Study interview using data for 4,971 White respondents education was not significantly associated with any ACP component (living will, power of attorney, discussing care) (Carr, 2012). In the HRS (2000) responses from 1,102 respondents demonstrated a significant association between education and having a power of attorney (OR = 1.06) and advance directives (OR = 1.13) (Gerst & Burr, 2008). Another HRS study from 2002-2010 with 6,052 respondents did not find a significant association between ACP and education (Khosla et al., 2015). Differences in sample size and characteristics may have contributed to the mixed results. For example, the Wisconsin Longitudinal Study is a survey of majority Non-Hispanic White high school graduates and the HRS is a nationally representative survey of community dwelling older adults. The samples in the HRS studies are also different with one including nursing home residents and the other excluding any non-community dwelling respondents.

Income has inconsistently been shown to have an association with ACP. For example, in one study using HRS core data from 6,946 respondents the association between income and ACP activities were different for each activity (Catheryn & Tamara, 2017). The odds of having an advance directive were not associated with household income in fully adjusted models (OR = 0.90, 95% CI: 0.80-1.01), but the odds of advance care discussion were significantly higher with higher household income (OR = 1.21, 95% CI: 1.09-1.35). In another study using HRS data from 2002-2010 for 6,052 respondents, household income was not associated with discussing care preferences, or having written

advance directives, but it was significantly associated with having a medical power of attorney (OR = 1.11) (Khosla et al., 2015). *Wealth* commonly measured with a summative value of assets minus debts provided by RAND in conjunction with the HRS also has mixed findings. One study using HRS data from 2000 for 1,102 respondents reported a significant association between wealth and informal care discussions (OR = 1.35) and having a medical power of attorney (OR = 1.32) (Gerst & Burr, 2008). Another HRS study using data for 6,946 respondents from 2012 reported a significant relationship between wealth and advance directives (OR = 1.15, 95% CI: 1.10-1.21) but not for advance care discussions (OR = 0.98, 95% CI: 0.95-1.02) (Catheryn & Tamara, 2017). These differences may be related to the different measurements of financial status. Household income for older adults likely lacks variability due to retirement. Wealth is a different measurement provided by the RAND corporation and calculated by summing assets and subtracting any debts. This variable is a better measurement of financial status in older age and likely to be associated with legal documentation of ACP (advance directives and power of attorney) (Carr, 2012; Catheryn & Tamara, 2017).

Health conditions, hospitalizations, and complex hospitalizations have been associated with completion of advance care planning documentation. Health conditions like cancer and memory problems have been associated with an increased rate of participation in ACP. In one study of 7,177 HRS respondents from 2000 to 2012, those with cancer were more likely to complete an advance directive (OR = 1.41, 95% CI: 1.25-1.60) (Portanova et al., 2017). Another study of respondents from 2002 to 2010 found similar associations for cancer (OR = 1.33, $p < 0.01$) and also reported a significant association with memory problem diagnosis and medical power of attorney (OR = 1.52, $p < 0.01$) (Khosla et al., 2015). Other indicators of health like recent and complex hospitalizations or expected death have been shown to be associated with ACP. Data from the HRS in 1998 and 2000 for 1,102 deceased respondents used to investigate ACP showed increased odds of having advance directives (OR = 1.77, $p < 0.001$) and power of attorney

(OR = 1.95, 95% CI: <0.001) when death was expected (Gerst & Burr, 2008). In a study of 6,946 HRS respondents from 2012 being hospitalized in the last 2 years was associated with an increased odds of having an advance directive (OR = 1.23, 95% CI: 1.11-1.37) (Catheryn & Tamara, 2017). A small study of low-income, community dwelling older adults demonstrated a significant association between previous ICU admission and completion of advance directives (OR = 4.33, 95% CI: 1.69-1.11) (Eunjeong & Jaehoon, 2013). In a study using data from the Wisconsin Longitudinal Study with 4,971 Non-Hispanic White respondents, spending a night in the hospital in the past year was significantly associated with completing an advance directive or having a medical power of attorney (OR = 1.82, $p < 0.01$) (Carr, 2012).

Potential causal relationships. Estate Planning has been proposed as a mediator of the association between socioeconomic status and advance care planning (Catheryn & Tamara, 2017). Koss and Baker hypothesize that legal documentation of advance care planning (living will or advance directives and durable power of attorney for health care) is prompted by lawyers during estate planning and that if this is the case it may account for SES disparities in ACP completion. Using HRS data for Whites and Blacks from 2012 for 6,946 respondents, the strong main effect of race/ethnicity on advance directive completion (OR = 1.96, 95% CI: 1.70-2.25, ref = Black) is completely mitigated when estate planning (having a will or trust) is added to the multivariate model (OR = 0.96, 95% CI: 0.82-1.12) (Catheryn & Tamara, 2017). They do not include Hispanics in their analysis. Social support has been suggested to play a role in the relationship between advance care planning and care received at the end of life (Riley & Lubitz, 2010). Despite indicators of social and familial support being included in some studies (Carr, 2012; Eunjeong & Jaehoon, 2013; Gerst & Burr, 2008; A. S. Kelley et al., 2011; Silveira et al., 2010; Tschirhart et al., 2014), there has not been much emphasis on results for the association between social support and advance care planning or end of life care outcomes (Exhibit 1). For example, two studies using the HRS have included a yes/no indicator of relatives living nearby (A. S. Kelley et

al., 2011; Tschirhart et al., 2014). One investigated health care costs in the last 6 months of life for 2,394 HRS respondents from 2000-2006 and reported a significant association between having relatives that live nearby and end of life expenses (A. S. Kelley et al., 2011). The second utilized HRS data from 2002-2008 and reported no association with the type of end of life treatment received (Tschirhart et al., 2014). Three studies have included an indicator of the number of children, living children, or grandchildren an HRS respondent had (Carr, 2012; Gerst & Burr, 2008; Silveira et al., 2010). Gerst and Burr reported significant associations between having one or more grandchildren and discussing End-of-Life care (OR = 1.58, $p < 0.01$) or having a medical power of attorney (OR = 1.47, $p < 0.05$) in a sample of 1,102 HRS respondents from 1998-2000 (Gerst & Burr, 2008). Carr found similar results for 4,971 respondents in the Wisconsin Longitudinal Study with those that had 3 or more children being more likely to have a living will (OR = 1.16, $p < 0.05$), written will (OR = 1.35, $p < 0.001$), or complete any end of life planning activity (ACP or estate planning; OR = 1.34, $p < 0.01$) (Carr, 2012). The operationalization of social support and subsequent findings are mixed and further work needs to be done to understand the role it plays in planning for the end of life.

THE ROLE OF ACP ON QUALITY OF END-OF-LIFE CARE

The association between advance care planning and quality of care at the end of life has been mixed with findings suggesting it may improve care or make no difference (Brinkman-Stoppelenburg et al., 2014; Carr & Luth, 2016; Detering et al., 2010; Ratner, Norlander, & McSteen, 2001; Teno et al., 2004; Wright et al., 2008). Patients who participated in ACP were more likely to receive care congruent with their preferences (Brinkman-Stoppelenburg et al., 2014; Detering et al., 2010). In one randomized controlled trial of 309 participants aged 80 and older at a single hospital wishes for care at the end of life were significantly more likely to be known and followed in those completing ACP (25/29 vs. 8/27 deaths, $p < 0.001$) (Detering et al., 2010). The treatment group received an

advance care planning intervention from a trained facilitator. A strength of this study is the randomized controlled trial design, although the study was conducted at a single institution and utilized a unique, complex ACP intervention that may not be generalizable to all settings.

Studies using HRS data linked to Medicare claims data have found mixed results for the role of ACP components on End-of-Life care. One study using HRS data from 1993 to 2007 for 4,394 respondents reported that those who stated a preference for comfort care had a decreased likelihood of dying in the hospital (OR = 0.78, 95% CI: 0.71-0.86), decreased hospital length of stay (OR = 0.65, 95% CI: 0.50-0.85), and that those with a preference for limited care were more likely to be admitted to hospice (OR = 1.83, 95% CI: 1.35-2.48) compared to those who preferred all care possible (Bischoff et al., 2013). However, the same study did not demonstrate significant associations between advance directives and medical power of attorney alone and hospital death. Related results are reported in a study using HRS responses from 2002-2008 linked to CMS data for 3,069 respondents. In this study having advance directives was associated with decreased odds of intensive procedures (ex. intubation, ICU admission, CPR) at the end of life (OR = 0.71, 95% CI: 0.57-0.89) (Tschirhart et al., 2014). A third study of 4,761 respondents who died from 1998-2007 reported those with an advance directive were less likely to die in the hospital (37% vs 43%, $p < 0.0001$) (L. H. Nicholas et al., 2011). The findings in these studies highlight the robustness of the HRS data for investigating end of life care with results similar to those reported using CMS data and also demonstrates the inconsistency of the role of ACP in end of life care.

One systematic review looked at 113 papers on ACP defined as do not hospitalize (52 studies) or do not resuscitate (16 studies) orders, advance directives or power of attorney (45 studies), and complex ACP intervention (20 studies) (Brinkman-Stoppelenburg et al., 2014). Studies focusing on legal documentation (advance directives or durable power of attorney for health care) showed either a decrease in life sustaining

treatment (10/22 studies) or no difference (11/22 studies) and increased use of hospice care (5/7 studies). Studies investigating complex ACP interventions reported increased compliance with patient's wishes for care at the end of life (3/4 studies), decreased hospitalization (3/4 studies), and decreased life sustaining treatment (3/5 studies).

GAPS IN THE LITERATURE

The current literature on advance care planning and quality of care at the end of life rely on either small sample, institution-level studies (not emphasized in the review above (Detering et al., 2010; Eunjeong & Jaehoon, 2013; Hlubocky Fay, 2014; Hong et al., 2017; Huang, Neuhaus, & Chiong, 2016; Ratner et al., 2001; Shen et al., 2016; Wright et al., 2008)) with limited generalizability or large, population-based surveys like the Health and Retirement Study (HRS) linked to Medicare data. Many studies analyze racial/ethnic minorities, but most of these studies, even those using national surveys like the HRS, excluded Hispanics as a subgroup due to limited sample size in exit interviews and concerns about statistical power (Brinkman-Stoppelenburg et al., 2014; Dixon et al., 2015; Hong et al., 2017; Klingler et al., 2016). It is important to understand this racial/ethnic minority that is culturally distinct from Non-Hispanic Whites and Blacks. Additionally, many studies focus on describing the association between an array of sociodemographic factors (age, gender, race/ethnicity, marriage status, self-reported health, income, wealth, etc.) and advance care planning completion, adherence to ACP treatment preferences, quality of end of life care, or cost outcomes without testing specific mediating or moderating hypotheses (Byhoff, Harris, Langa, & Iwashyna, 2016; Amy S. Kelley et al., 2011; Lauren Hersch Nicholas, Kenneth M. Langa, Theodore J. Iwashyna, & David R. Weir, 2011; Nidhi, Angela, & Karla, 2015). While this is useful, it limits the identification of specific proximal targets for intervention to improve ACP completion.

Some studies have proposed and tested specific hypotheses. For example, one study using 6,946 proxy-respondents from the HRS hypothesized that estate planning mediated

the relationship between race/ethnicity and advance care planning (Catheryn & Tamara, 2017). The authors reported that the higher completion rates of advance directives in Whites compared to Blacks was mitigated when estate planning was taken into account (OR: 0.96, 95%CI: 0.82-1.12). This study did not include Hispanics but did utilize hierarchical modeling to test and demonstrate a mediating relationship. Another study focusing on 4,971 Non-Hispanic Whites from the Wisconsin Longitudinal Study hypothesized that estate planning (having a signed and witnessed will) mediated the relationship between socioeconomic status (education and assets) and advance care planning (Carr, 2012). The results suggest the relationship is partially mediated by estate planning and the author notes this is supported by the stronger effect on legal documentation (living will and durable power of attorney for health care) compared to informal planning (discussions). For example, after adding estate planning to multivariate models, the effect size for those in the lowest asset group decreased for those having a living will (29%), power of attorney (29%), and end of life care discussions (15.7%). A weakness of this study is the lack of racial/ethnic subgroups in the sample and a strength is the hierarchical modeling allowing for assessment of the mediating role estate planning has on the relationship between socioeconomic status and advance care planning. These studies demonstrate the ability to use large samples to investigate specific mediating hypotheses and highlight the need to include Hispanics as a racial/ethnic subgroup.

This dissertation addresses two gaps in the literature using the Health and Retirement Study (HRS). The HRS is a survey with a nationally representative sample of U.S. adults aged 50 and older. Respondents are interviewed every two years in a core interview and after passing a proxy familiar with the respondent's last year of life is interviewed in an exit interview. Responses range from basic sociodemographic variables like age, gender, race/ethnicity, and education to specific details related to advance care planning like completion of an advance directive/living will, discussing end of life care, and the details of preferences for care outlined in advance care planning. The core

interviews also collect information related to health care expenditures, insurance status, and self-reported health. Exit interviews can provide information on the care setting and types of care received at the end of life. Given all the measures available and the large sample sizes that can be generated when interview waves are combined and assessed cross-sectionally, this dataset is ideal for investigating causal relationships between documented factors associated with advance care planning and planning completion. The data also provides sufficient numbers of Hispanic respondents to include this subgroup in all analyses. Despite its utility for investigating the role of advance care planning in end of life care, the data has largely been used to investigate bivariate associations with few studies proposing testable hypotheses for the causes or pathways of those associations (Exhibit 1).

A first aim addressed by this research is the lack of population-level information on all three major ethnic groups, Whites, Blacks, and Hispanics. Hispanic subsamples are included in all analyses to expand the evidence on advance care planning participation by this minority of interest. A second aim that is addressed is the lack of specific, testable hypotheses to investigate causal pathways of advance care planning completion and effects. Specific hypotheses were investigated for the relationship between advance care planning and end of life quality of care outcomes. The first hypothesis was based on the work of Koss, Baker, and Carr (Carr, 2012; Catheryn & Tamara, 2017). It proposes a mediating relationship between socioeconomic status (SES), estate planning, and advance care planning. This hypothesis investigated the role estate planning plays in mediating the relationship between race/ethnicity and advance care planning. The second hypothesis addresses the gap in the literature on quality of care outcomes associated with advance care planning. It proposes that the relationship between SES and limited care at the end of life is mediated by ACP and social support. Testing this hypothesis provides clarity on the relationship between ACP and care received at the end of life.

EXHIBIT 1.1- HEALTH AND RETIREMENT STUDIES ON ADVANCE CARE PLANNING

Author	Year	Sample (n)	Hypotheses	R/E	Outcome Measures	Independent Variables of interest	Covariates
Gerst & Burr	2008	2000 HRS Exit (1,102; community dwelling and institutionalized)	1) Race/Ethnicity moderates the association between personal characteristics and End-of-Life planning	W, B	discuss care (y/n), living will (y/n), DPAHC (y/n)	Race: White/Black; social connectedness: marital status (married, not married), presence of grandchildren (one or more, none); social class: education (years of school completed (0-17), net worth (subtracting debts from total assets, natural log); religiosity: religious service attendance (attended at least once a year, did not attend at least once a year)	age at time of death, gender, self-rated health (excellent/very good/good, fair/poor), number of health conditions in previous year (0-7; cancer, chronic lung disease, heart condition, stroke, diabetes, other or mental illness); exposure to health care system: hospitalization in last 2 years (y/n), residence in LTC, death was expected (y/n), enrollment in managed care (y/n), death location (LTC, community), lived in hospice (y/n)
Silveira, et al.	2010	2000-2007 HRS Exit (3,746)		W, B, H, O	living will or DPAHC, decision-making capacity, need for decision-maker at End-of-Life	location of death (hospital (38.9%), home (27.3%), nursing home (24.5%))	age, gender, race/ethnicity (white, black, other), marital status (married, living with partner, other) education (<HS, HS, some college+), cognitive impairment ('fair' or 'poor' memory 1 mo. pre-death), chronic conditions (cancer, lung disease, heart disease, cerebrovascular disease, depression), pain (often troubled with pain in last year of life), duration of illness, year of death

Kelley, et al.	2011	2000-2006 HRS Exit linked to CMS and Dartmouth Atlas of Health Care data (2,394 aged 65.5 years +)		NHW, AA, H, O	total Medicare expenditures in the last 6 months of life (inpatient, outpatient, SNF, hospice and home care, durable medical equipment)	family member living nearby	age, gender, race/ethnicity, education level, net worth, religiosity, urban residence, self-rated health, having relatives nearby, marital status, residential status (living in nursing home, alone, or with others), non-Medicare insurance (Medicaid, VA, Medigap), completion of advance directive or discussion of End-of-Life care, functional status (ADL core and proxy to determine functional stability or decline over time), chronic medical conditions (ICD9), # hospital beds/10,000 residents, # primary care & specialists/100,000 residents
Nicholas, et al.	2011	1998-2007 HRS Exit linked to CMS and National Death Index (3,302)	1) association between AD and End-of-Life Medicare expenses moderated by hospital referral region Medicare spending	W, B, O	total Medicare expenditures in the last 6 months of life (inpatient, outpatient, carrier, durable medical, hospice, home health and SNF), End-of-Life Tx (intubation and mechanical ventilation, tracheostomy, gastrostomy tube, hemodialysis, enteral and parenteral nutrition, CPR), any hospice use	Hospital Referral Region average per-decedent Medicare spending in the last 6 months (Dartmouth Atlas of Health Care)	age (5-year categories), gender, race (B, W), highest tertile of household wealth (y/n), education (<HS, HS, some college+), marriage status (widowed/single, separated/divorced, married), self-reported chronic conditions, Elixhauser's comorbidity index

Bischoff, et al.	2013	1993-2007 HRS Exit linked with CMS (4,394)		W, B, H, O	quality metrics in last month of life (hospital admission, in-hospital death, >14 days in the hospital, ICU admission, >1 ED visit, hospice admission, length of hospice 3+ days)	ACP, care preferences (all care possible, some limits (desire to limit care in certain situations), comfort care (desire to keep respondent comfortable and pain free, but forego extensive measures to prolong life)	age at death, gender, race/ethnicity, marital status, net worth, year of death, comorbidities (cancer, hypertension, diabetes mellitus, lung disease, heart disease, stroke, cognitive impairment), functional limitation score (0-6 based on number of assisted ADLs in last 3 months)
Nicholas, et al.	2014	1998-2007 HRS Exit linked to Medicare (3,876)	1) moderating effect of location (nursing home vs. community dwelling) on the relationship between advance directives and intensity of End-of-Life care for those with varying levels of cognitive impairment	--	total End-of-Life Medicare spending (6 mo. pre-death), in-hospital death, use of ICU, and use of life-sustaining Tx (intubation/mechanical ventilation, tracheostomy, gastrostomy feeding tube, hemodialysis, enteral and parenteral nutrition)	dementia (HRS survey + 3/6 ADL limitations), CIND/mild dementia, reference is normal cognition	Not explicitly provided: sociodemographic characteristics, Elixhauser comorbidities, geographic region (nursing home capacity, end-of-life spending levels)
Silveira, et al.	2014	2000-2010 HRS Exit (6,122)		W, B, H	completion of living will or appointed DPAHC (AD, y/n), hospitalization at least once in 2 years pre-death (y/n), number of hospitalizations and hospital days in 2 years pre-death, in-hospital death (y/n)	Advance Directives	age, gender, race (NHW, NHB, other), marital status (married, partnered, other), education (<HS, HS, some college+), nursing home status (overnight stay at SNF in last 2 years)

Tschirhart, et al.	2014	2002-2008 HRS Exit linked to Dartmouth Atlas of Health Care and CMS (3,069)		NHW, B, H	intensive procedures in last 6 mo.: intubation & mechanical ventilation, tracheostomy, gastrostomy tube, enteral and parenteral nutrition, or CPR	Advance Directive	Individual variables: age, gender, race/ethnicity, educational level, marital status, net worth, religiosity, presence of a relative living nearby, residential status (nursing home vs. community dwelling), functional status (any help with ADLs y/n), chronic medical conditions (modified Elixhauser Index), Regional variables: number of acute care hospital beds per 1,000 residents, number of specialists per 100,000 residents, hospital care intensity index (HCI)
Narang, et al.	2015	2000-2012 HRS Exit (1,985)		NHB, NHW, H, O	ACP, End-of-Life Tx intensity (all care possible, Tx limited or withheld, terminal hospitalization)	ACP, time	age at death, gender, race/ethnicity (NHW, NHB, other), education (<HS, HS, some college +), marital status (married, widowed, separated/divorced, single), type of religion (protestant, catholic, Jewish, no preference, other), importance of religion (very, somewhat, not too important), time from Ca Dx to death, medical co-morbidities (heart disease, chronic lung disease, prior stroke, memory-related disease), veteran status, residence in nursing home, geographic region (new England, mid-Atlantic, east north central, west north central, south Atlantic, east south central, west south central, mountain, pacific), year of death, relationship of proxy to decedent

Byhoff, et al.	2016	1998-2012 HRS Exit linked to CMS and Dartmouth Atlas (7,105)	1) sociodemographic factors mediate the relationship between R/E and medical expenditures in the last 6 mo. of life	NHW, NHB, H, O	discuss care (y/n), living will (y/n), durable power of attorney for health care (y/n)	time (exit interview year), SES: years of education (0-17+), household income (annual), nominal value of \$250 added to all responses before natural log	age at death, gender, race (black or other, white), ethnicity (Hispanic/Latino, non-Hispanic), household wealth (logged), memory problems (Dx by medical professional, y/n), location of death (home, institution or other location), death expected (y/n), primary cause of death (cancers/tumors/skin conditions, heart/stroke/circulatory/blood conditions, respiratory system conditions, other (diabetes, kidney failure, acute infections, suicide, murder, accidents) = reference), frequency of religious service attendance (one or more times in past year, none),
Khosla, et al.	2016	2002-2010 HRS Exit (6,052)	1) ACP engagement increased over time 2) higher SES (higher education, higher household income) predicts greater odds of engaging in ACP 3) SES moderates engagement in ACP over time	NHW, NHB, H	Medicare expenditures in the last 6 mo. of life (all: inpatient, outpatient, SNF, DME, HH, physician supplier, hospice care)	AD, discussed End-of-Life Tx preferences, expected death (y/n)	age at death, gender, education (<12 years, 12 years, 13-15 years, 16 years +), marital status (married, never married, divorced, widowed, other), net worth (quartile), residential situation (lives at home, at home with others, in nursing home), birth cohort (based on HRS codebook), non-Medicare insurance (Medicaid, VA, private/Medigap), urban residency, END-OF-LIFE-EI (quintile), Elixhauser comorbidities, cognitive function (normal, mild cognitive impairment, dementia), functional status (no impairment, moderate (1-3 ADL deficiencies), severe impairment (4+ ADL deficiencies)

Koss	2017	2004-2012 HRS (2,243)	1) associations between demographic factors and AD completion differ by gender	--	Advance Directives (LW or DPAHC)		age, education (<HS, HS/GED, some college, bachelor's or higher), self-rated health (excellent, very good, good, fair, poor) , at least one night in hospital or outpatient surgery in last 10 years, regular place of care other than ED, net household assets (log-transformed)
Koss & Baker	2017	2001-2012 HRS Exit (5,832)	1) the effect of race on having AD differs over time	NHW, NHB	Advance Directives (LW or DPAHC)	time (death year)	age at death, gender, education (< HS, HS/GED, > HS), marital status (married, widowed, separated/divorced, never married), geographic region (MW, NE, S, W), living in nursing home or health care facility at time of death (y/n), death expected (y/n)
Koss & Baker	2017	HRS 2012 Core (699; 2,736)	1) discrimination mediates the association between R/E and AD completion	NHW, NHB	AD completion (y/n)	study 1: trust in doctors and care providers (worry about judgement: y/n, trust doctor's judgement: y//n); study 2: non-medical everyday discrimination (never, rarely, more than rarely), medical everyday discrimination (ever vs never), non-medical lifetime discrimination (y/n), medical lifetime discrimination (y/n)	age, gender, education (< HS, HS/GED, some college, bachelors+), marital status (married/partnered, widowed, separated/divorced, never married), self-rated health (poor - excellent, 5 point Likert), composite indicator (hospitalization, outpatient surgery, nursing home admission in last 2 years (y/n)), regular provider other than ER (y/n), annual HH income (log transformed), total HH net wealth (log transformed), BMI, current smoker (y/n)

Portanova, et al.	2017	HRS 2000-2012 Exit (7,177)		White, B, H	AD completion (y/n), preference for aggressive care among those completing AD (all care possible, limited care, comfort care; recoded as aggressive (all care) vs. all others)	time	age, gender, marital status (married, divorced or separated, widowed, never married), education ($\leq$ HS, $>$ HS), income (quartiles), health conditions (lung disease, heart condition, depression, stroke, memory impairment, cancer), religious attendance (service attendance in last year of life (y/n)), death expected (y/n), year of death
Koss	2018	2012-2014 HRS (3,752)		NHW, NHB, H, O	Advance Directives (LW or DPAHC)	at least one night in hospital (y/n), outpatient surgery (y/n), home health care (y/n), at least one night in nursing home (y/n)	age, gender, education ($<$ HS, HS/GED, some college +), race (NHW, NHB, Hispanic, other), marital status (married, divorced, widowed, never married), death between waves
Koss & Baker	2018	HRS 2012 Core (6,946)	1) financial disparities mediate the relationship between race/ethnicity and estate planning 2) estate planning mediates the relationship between race/ethnicity and advance directives completion 3) estate planning mediates the relationship between race/ethnicity and	NHW, NHB	estate planning (will or trust), advance care planning, advance directives, advance care discussion	Estate planning (will or trust), HH wealth (sum assets minus debts averaged over 2006-2012 waves; negative values changed to 0 and nominal value of \$250 added before natural log), HH income (same as wealth, but just summed income), home ownership (y/n), Race (NHW, NHB (ref))	age, gender, education ($<$ HS, HS/GED, some college, college +), marital status (married/partnered, widowed, separated/divorced, never married), self-rated health (1 = poor, 5 = excellent), at least one night in hospital or nursing home in previous 2 years (y/n)

			advance care discussion				
Ornstein, et al.	2018	2000-2012 HRS linked to CMS and Dartmouth Atlas (1,348)		NHW, NHB, H, O	total Medicare expenditures for the surviving spouse in the 12 months post-death (all payments: inpatient, outpatient, SNF, hospice and home care, DME)	in-hospital death (hospital death vs. other (home, assisted living, nursing home, hospice, other)	spousal: age, gender, race/ethnicity, education, net worth, self-rated health, functional status, level of comorbidity, primary helper with ADLs/iADLs; decedent: insurance coverage, functional status (difficulty with 1+ ADL), residential status (NH, community-dwelling), self-reported health, probable dementia, self-reported illness (cancer & level of comorbidity), AD completion, expected death; HRR, END-OF-LIFE-EI
Orlovic, et al.	2019	2002-2014 HRS Exit (9,228)	1) AA and Hispanics are more likely to die in hospitals than NHW 2) AA/Hispanics more likely to be exposed to aggressive End-of-Life Tx 3) AA/Hispanics less likely to participate in End-of-Life	NHW, NHB, H, O	Place of death (outcome) = proxy for End-of-Life care intensity (home, nursing home, hospice, hospital (ref)); short stay in hospital (outcome) = <1 wk (y/n), use of life support (y/n), use of dialysis (y/n), time spent in ICU, End-of-Life instructions (all care, withheld Tx),		age, gender, education (< HS, HS, graduate), income (quintiles), cohabitation, # resident children, # ADL difficulties, duration of terminal illness (<1 mo., <1 yr., >1 yr.), underlying cause of death (cancer, cardio, pulm, digestive, other), health insurance (y/n), Medicare FFS (y/n), Medicare HMO (y/n), written End-of-Life instructions (y/n), census region (NE, Midwest, S, E), wave dummy variable; religious adherence (often, sometimes, never), religious

			planning 4) religion is an important factor for engagement in End-of-Life planning; testing mediation of religion and interaction of R/E with religious importance		End-of-Life Decisions (withhold Tx), End-of- Life legal-care arrangement (y/n), discuss End-of-Life care (y/n), time of End-of-Life planning		importance (very important, not very important)
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RESEARCH ACCOMPLISHMENTS TO DATE

Prior research. I completed a descriptive manuscript using the Health and Retirement Study to investigate levels of completion of advance directives, durable power of attorney for healthcare, and written will. *Introduction:* Rates of advance care planning are lower among older Non-Hispanic Blacks and Hispanics than Non-Hispanic Whites. Estate planning has been proposed as a possible mechanism that explains this disparity. *Methods:* The Health and Retirement Study, a nationally representative survey of U.S. adults aged 50 and older was used to investigate the completion rates of advance care planning (having an advance directive or power of attorney). Exit interview data from proxies reporting on the last year of life of deceased loved ones from 2006 through 2014 was used to test whether the relationship between race/ethnicity and advance care planning completion was mediated by estate planning. *Results:* Unadjusted bivariate associations demonstrated significant racial/ethnic disparities in completion rates of written will (NHW: 62.6%, NHB: 26.3%, and Hispanics: 15.4%), durable power of attorney for healthcare (NHW: 64.9%, NHB: 37.0%, and Hispanics: 33.1%), and advance directives (NHW: 53.7%, NHB: 20.7%, and Hispanics: 20.4%). In multivariate logistic regression modeling adjusted odds ratios demonstrated significantly lower completion rates of durable power of attorney for health care and advance directives for Non-Hispanic Blacks (OR: 0.38, 95% CI: 0.31-0.46, and OR: 0.27, 95% CI: 0.22-0.34, respectively) and Hispanics (OR: 0.34, 95% CI: 0.26-0.43, and OR: 0.28, 95% CI: 0.21-0.37, respectively) compared to Non-Hispanic Whites. *Conclusions:* Results from this study are similar to other findings (Catheryn & Tamara, 2017) and improve the understanding of the association between wealth, education, and end of life planning. Profound and prevailing disparities for racial/ethnic minorities in full, adjusted models are observed and warrant further study into the mechanisms and potential causal pathways of these associations.

Courses/Other Experience. Classes in quantitative analysis have prepared me for the statistical analyses that will be performed in this research. Specifically, I completed linear models and categorical data analysis. I also have experience using the Health and Retirement study for a class project in the Aging in Minorities class. Working with a mentor, I have gained additional experience analyzing large data sets using SAS.

METHODS

Aim 1: To describe the association between sociodemographic factors (ex. age, race/ethnicity, education, etc.) and level of participation in end of life planning (ACP and estate planning). HRS core interviews for living respondents (2014) are analyzed to describe the prevalence and adjusted associations of community dwelling adults 65 and older participating in end-of-life preparatory activities (ACP and estate planning). Variation across ethnic groups (Non-Hispanic White, Non-Hispanic Black, and Hispanic) and socioeconomic levels and co-occurrence of ACP elements is examined.

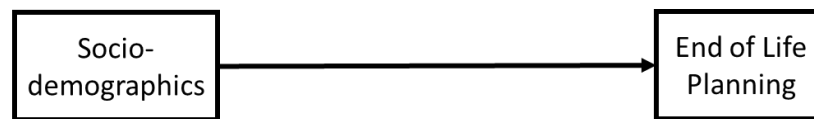
CONCEPTUAL MODEL

Aim 1 describes levels of participation in activities to prepare for the end of life including age, gender, race/ethnicity, educational level, and income/wealth. There are currently no studies using HRS data that report the rates of estate planning (completing a written will) for Hispanics. This aim replicates previous work while also investigating these associations for Hispanics and served to guide further analyses in this proposal.

It is hypothesized that relationships previously described in the literature (Carr, 2012; Eunjeong & Jaehoon, 2013; Gerst & Burr, 2008; Khosla et al., 2015; Portanova et al., 2017) will be demonstrated in this analysis. For example, age will have a small, but statistically significant positive association with ACP and Non-Hispanic Blacks and Hispanics will be significantly less likely than Non-Hispanic Whites to participate in any end of life planning. The association between age and advance directive completion has

been reported using HRS data from 2012 for 6,946 respondents (OR = 1.04, 95% CI: 1.03-1.05) (Catheryn & Tamara, 2017). Portanova et al. used HRS data from 2000-2013 for 7,177 respondents and reported significantly lower odds of completing an advance directive for non-Hispanic Blacks (OR = 0.23, 95% CI: 0.19-0.29) and Hispanics (OR = 0.30, 95% CI: 0.22-0.40) compared to non-Hispanic Whites (Portanova et al., 2017).

Figure 1.1- Conceptual Model for Specific Aim 1



DATASET

The Health and Retirement Study (HRS) will be used to describe the levels of participation in end of life planning activities (ACP: completing advance directives, discussing end of life care preferences, and assigning a durable power of attorney for healthcare and Estate Planning: having a written and witnessed will).

The HRS is a U.S. nationally representative, longitudinal study of adults age 50 and older supported by the National Institute on Aging. The questionnaire is broad and covers topics like income and wealth, work and retirement, and family connections. It was established in 1992 and the questionnaire is administered to approximately 20,000 living respondents every 2 years (core interviews). Respondents were selected with a complex sampling design that oversampled Mexican Americans and Non-Hispanic Blacks. When sampling weights are used, estimates are representative of the U.S. non-institutionalized population. After a respondent dies, a close family member, relative, or friend is interviewed to obtain information about the final year of life (exit interviews). This study will use publicly available data from both the HRS and RAND HRS. These files can be accessed freely and downloaded from the respective websites. They do not require an agreement for their use.

For the aims in this dissertation, two analytic files will be used. The first, used in Aim 1, will include only 2014 HRS core data from HRS and the RAND Corporation for living respondents. The second file, used in Aims 2-4, will be generated by merging 9 waves (2000-2016) of HRS core and exit interview data for deceased respondents.

The analytic file for Aim 1 will utilize the RAND Core data (2014 wave), which includes general sociodemographic factors, most responses to HRS core and exit interviews, and newly computed variables that utilize the HRS raw data (Image 1.1a). RAND has imputed values for missing responses. As an example, if gender was not recorded, data from a previous wave was used to complete the record. Total wealth was computed by RAND as the difference between all assets and debts from responses in the HRS Core interview data. An inclusion criterion for this sample will be having a record of a 2014 core interview. Exclusion criteria will include age < 65 years old and nursing home residency. Those missing responses for all end of life planning activities are also excluded from the sample with listwise deletion.

Image 1.1- Aim 1 Analytic File Composition

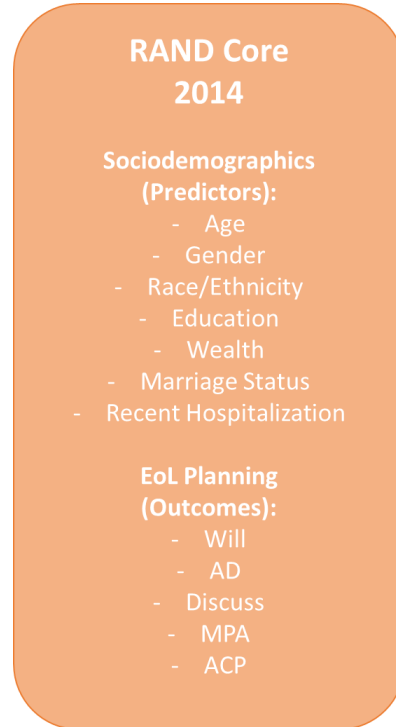


Table 1.1a provides the sample characteristics for the first analytic file using the HRS Core data that will be used to investigate end of life planning outcomes in Aim 1. Sample size estimates provided in the proposal for this research indicated there are 17,004 observations from the core interview in 2014. Notably, there are many missing values for health-related end of life planning activities (discussing End-of-Life care (12,143), medical power of attorney (7,105), advance directives (7,108), and advance care planning (8,116)) due to the questionnaire skip sequence that limits these core interview questions to those 65 years of age and older. There are 2,287 Hispanics in this sample, which provides a sufficient sample for the analysis in Aim 1.

Table 1.1a- Full HRS Core Analytic Sample Characteristics (Core)

Characteristic	%	fi/n
Gender (female)		
Male	42.41	7,211/17,004
Female	57.59	9,793/17,004
Missing		0
Race/Ethnicity		
NHW	66.26	10,860/16,391
NHB	19.79	3,244/16,391
Hispanic	13.95	2,287/16,391
Missing		613
Education		
< HS	18.46	3,138/17,000
HS/GED	52.62	12,084/17,000
Any College+	28.92	4,916/17,000
Missing		4
Discussed End-of-Life Care*		
No	59.97	2,915/4,861
Yes	40.03	1,946/4,861
Missing		12,143
Medical Power of Attorney*		
No	46.35	4,588/9,899
Yes	53.65	5,311/9,899
Missing		7,105
Advance Directive*		
No	48.84	4,833/9,896
Yes	51.16	5,063/9,896
Missing		7,108
ACP*		
No	24.59	2,186/8,888
Yes	75.41	6,702/8,888
Missing		8,116
Written Will		
No	52.80	8,943/16,939
Yes	47.20	7,996/16,939
Missing		65

*only available for those aged 65+ due to HRS skip sequence

Abbreviations: NHW- Non-Hispanic White, NHB- Non-Hispanic Black, HS- High School, End-of-Life- End-of-Life, ACP- Advance Care Planning

Specific sample size estimates for Aim 1 are provided in Table 1.1b. The total sample size is approximately 17,000. Of note, the smallest sample for Hispanics is for the ‘discuss End-of-Life care’ outcome (n = 202), but when all three advance care planning activities are considered together, there are 416 observations for Hispanics, which allows for adequate statistical power to assess this racial/ethnic subgroup of interest.

ESTIMATED SAMPLE SIZE FOR SPECIFIC AIM 1

Table 1.1b- Bivariate Results for Aim 1 (Core)

		Outcomes 1-3				
		Discuss End-of-Life Care*		Medical Power of Attorney*		Advance Directive*
		% Yes	N = 4,709	% Yes	N = 9,651	% Yes N = 9,648
Race/Ethnicity						
NHW		46.08	1,403/3,045	60.39	4,373/7,241	59.99 4,342/7,238
NHB		30.53	290/950	38.48	553/1,437	29.11 418/1,436
Hispanic		28.29	202/714	28.67	279/973	21.05 205/974
Missing			12,295		7,353	7,356

		Outcomes 4-5			
		ACP*		Will	
		% Yes	N = 8,667	% Yes	N = 16,327
Race/Ethnicity					
NHW		82.54	5,380/6,518	86.74	6,769/10,819
NHB		59.58	762/1,279	62.57	684/3,224
Hispanic		47.82	416/870	15.37	351/2,284
Missing			8,337		677

*Only available for those aged 65+ due to HRS skip sequence

Abbreviations: End-of-Life- End-of-Life, ACP- Advance Care Planning, NHW- Non-Hispanic White, NHB- Non-Hispanic Black

MEASURES

Predictor(s): Predictors (sociodemographic factors) for Aim 1 include age (65-74, 75-84, 85+), gender (male/female), race/ethnicity (NHW/NHB/Hispanic), educational level (less than high school, high school or equivalent, and any college or greater), wealth (quintiles), marriage status (married/partnered), and recent hospitalization (yes/no). Total

wealth is calculated by taking the difference of the sum of all reported assets minus the sum of all reported debts. The final wealth variable is a continuous number that includes negative values. This wealth variable will be categorized into quintiles for analysis. Marriage status was dichotomized into married/partnered (“married”, or “partnered”) or divorced/single (“married, spouse absent”, “separated”, “divorced”, “widowed”, or “never married”). Recent hospitalization is defined as any self-reported hospitalization in the last 2 years.

Outcome(s): The outcomes for specific Aim 1 will be the four end of life preparatory activities: ACP (advance directives (yes/no), discussing End-of-Life care (yes/no) and durable power of attorney for health care (yes/no)) and estate planning (written will (yes/no)). Respondents with ‘unknown’ or missing responses will be excluded from analyses through listwise deletion. Chapter 2 will explore the relationship among the ACP variables to operationalize the outcome for successive chapters.

ANALYSIS

Descriptive statistics will be reported for the variables in this analysis. Means and standard deviations will be calculated for continuous variables and assessed for normality. Frequencies and chi-square values will be reported for categorical variables. In this aim, bivariate correlations between predictors and ACP components will be assessed prior to multivariate modeling in the next aims to check for multicollinearity. The intercorrelation of the three ACP components will be explored with bivariate 2-by-2 tables, a correlation matrix, and Cronbach’s alpha. A correlation matrix for all covariates will be assessed for collinearity issues before multivariate modeling.

First (1a) co-occurrence of end of life planning activity completion will be investigated. Correlations between the ACP outcome variables will be reviewed to determine if the three indicators should be collapsed into one measure. Next (1b) bivariate associations between race/ethnicity, ACP, and estate planning will be used to investigate

the population prevalence of end of life planning. Third (1c) multivariate logistic regression modeling for Aim 1 will investigate the adjusted association of end of life planning as defined in 1a for each of the predictors of interest.

Aim 2: To test for possible mediating relationship between race/ethnicity, socioeconomic status, estate planning, and advance care planning. HRS Exit interviews for deceased respondents (2002-2016) are used to investigate the possible mediating effect of socioeconomic status (education and wealth) and estate planning (having a written and witnessed will) on the relationship between race/ethnicity and ACP (advance directives, discussing End-of-Life care, and having a medical power of attorney).

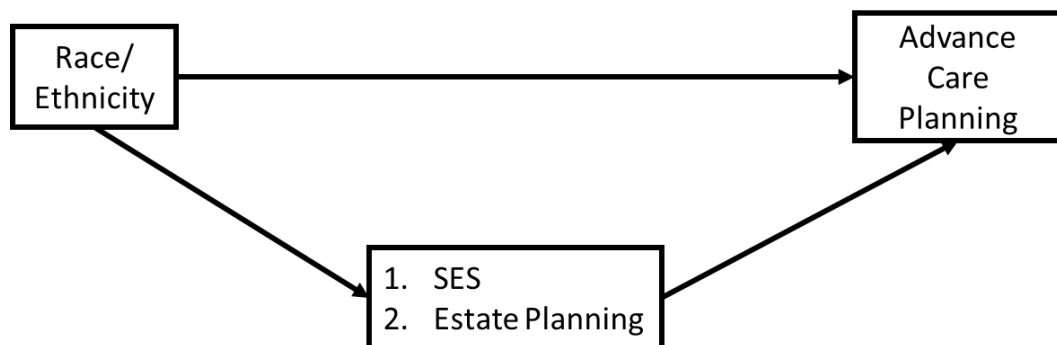
CONCEPTUAL MODEL

Aim 2 investigates the mediation model presented in Figure 1.2. In this model, the effect of race/ethnicity on completion of advance care planning is hypothesized to be mediated by both socioeconomic status and estate planning. The objective of this aim is to investigate the relationships proposed in the conceptual model. Confounders are excluded from the figure but described in the text.

It is hypothesized that Non-Hispanic Blacks and Hispanics will be less likely to participate in advance care planning, but that the main effect of this relationship will be reduced when socioeconomic status and estate planning are accounted for. This is a modified replication of previous work by Koss and Baker (Catheryn & Tamara, 2017) with the consideration of socioeconomic status and addition of Hispanics to the analyses. Koss and Baker have described the relationship between estate planning and ACP for non-Hispanic Whites and Blacks using data from the HRS in 2012 for 6,946 respondents. They reported that the disparity in advance directive completion rates for non-Hispanic Whites and Blacks was completely mediated by estate planning (OR = 0.96, 95% CI: 0.82-1.12) (Catheryn & Tamara, 2017). A similar relationship was demonstrated using data from the Wisconsin Longitudinal Study for 4,971 White respondents with the odds of having an

advance directive much higher for those who had participated in estate planning (OR = 7.78, $p < 0.001$) (Carr, 2012). Each of these studies investigated the mediating effect of estate planning and included socioeconomic status as a covariate. In the Koss and Baker study, education (OR = 1.21, 95% CI: 1.11-1.32) and household assets (OR = 1.39, 95% CI: 1.32-1.47) were associated with estate planning. The same SES indicators were also significantly associated with legal ACP and may be mediating the main effect of race/ethnicity on advance care planning. Carr's findings were similar with wealth being associated with both estate planning and legal ACP. However, there was no association with education and legal ACP, possibly due to the difference in sample with all participants having completed high school.

Figure 1.2- Conceptual Model for Specific Aim 2



DATASET

Image 1.2- Aim 2 Analytic File Composition

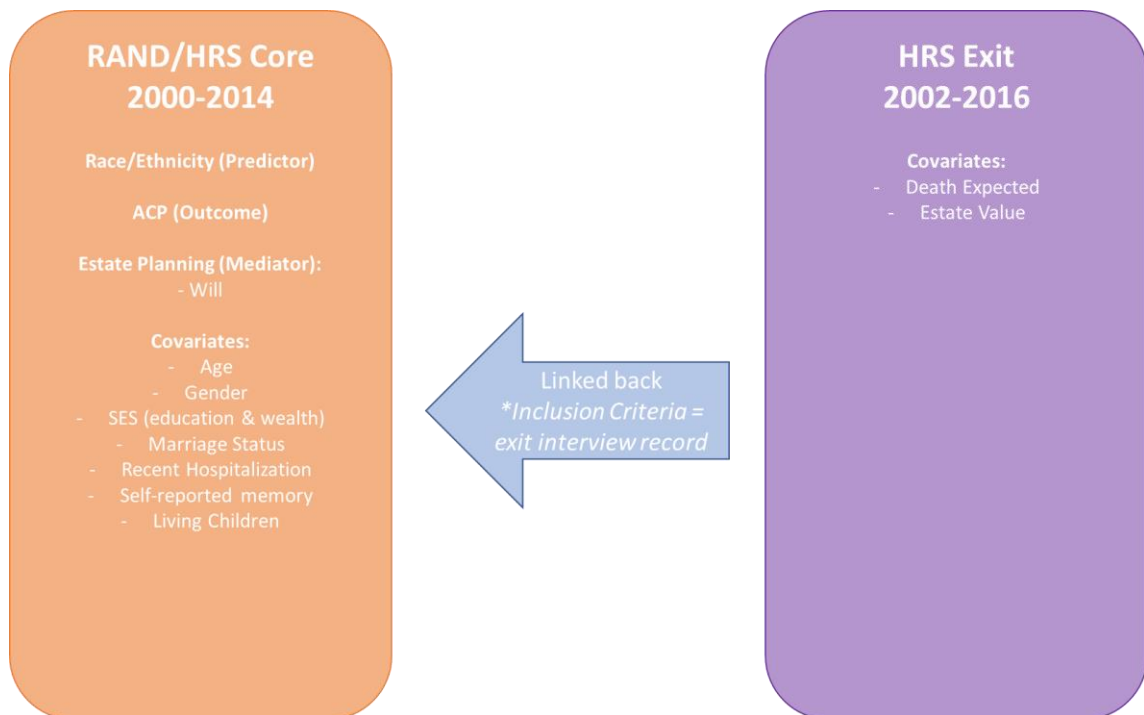


Table 1.2a provides the sample characteristics estimated in the proposal for the second analytic file using the HRS Exit data linked to Core data that will be used to investigate end of life outcomes in Aims 2-4. There were 7,665 observations from exit interviews for 2002-2016. Notably, there are many missing values for social support (2,917) due to the questionnaire skip sequence that limits the interview questions to those with children. There are 599 Hispanics available in this analytic file, which provides a sufficient sample for the analyses in Aims 2 and 3.1.

Table 1.2a- Full HRS Exit Analytic Sample Characteristics (Exit)

Characteristic	%	fi/n
Gender		
Male	49.93%	3,827/7,665
Female	50.07%	3,838/7,665
Race/Ethnicity		
NHW	75.37%	5,667/7,519
NHB	16.66%	1,253/7,519
Hispanic	7.97%	599/7,519
Missing		146
Education		
< HS	34.24%	2,624/7,664
HS/GED	48.92%	3,749/7,664
Any College+	16.84%	1,291/7,664
Discussed End-of-Life Care		
No	42.32%	3,212/7,590
Yes	57.68%	4,378/7,590
Missing		75
Medical Power of Attorney		
No	44.01%	3,274/7,440
Yes	55.99%	4,166/7,440
Missing		225
Advance Directive		
No	55.85%	4,188/7,499
Yes	44.15%	3,311/7,499
Missing		166
ACP		
No	22.58%	1,693/7,498
Yes	77.42%	5,805/7,498
Missing		167
Social Support		
No	25.27%	1,285/5,086
Yes	74.73%	3,801/5,086
Missing		2,579
Hospital Death		
No	62.50%	4,786/7,658
Yes	37.50%	2,872/7,658
Missing		7
End-of-Life Pref. Honored		
No	7.64%	44/576
Yes	92.26%	532/576
Missing		7,089

Abbreviations: NHW- Non-Hispanic White, NHB- Non-Hispanic Black, HS- High School, End-of-Life- End-of-Life, ACP- Advance Care Planning

Specific sample size estimates for Aim 2 are provided in Table 1.2b. The total sample size is approximately 7,700. Of note, the smallest sample for Hispanics is for the advance directive outcome ($n = 112$), but when all three advance care planning activities are considered together, there are 326 observations for Hispanics, which should allow for adequate statistical power to assess this racial/ethnic subgroup of interest.

ESTIMATED SAMPLE SIZE FOR SPECIFIC AIM 2

Table 1.2b- Bivariate Results for Aim 2 (Exit)

Race/Ethnicity	Discuss End-of-Life Care		Medical Power of Attorney		Advance Directive		ACP	
	% Yes	N = 7,445	% Yes	N = 7,297	% Yes	N = 7,357	% Yes	N = 7,355
NHW	62.93	3,531/5,611	63.14	3,479/5,510	52.49	2,912/5,548	83.71	4,657/5,563
NHB	41.28	511/1,238	36.21	437/1,207	19.08	232/1,216	59.44	718/1,208
Hispanic	42.62	254/596	31.38	182/580	18.89	112/593	55.82	326/584
Missing		220		368		308		310

Abbreviations: End-of-Life- End of Life, ACP- Advance Care Planning, NHW- Non-Hispanic White, NHB- Non-Hispanic Black

MEASURES

Predictor(s): For Aim 2, a mediating model will be investigated. Race/ethnicity (NHW, NHB, Hispanic) will be the main predictor as defined in Aim 1.

Outcome(s): For Aim 2, the outcome for the mediating model was advance care planning, previously described. Here, ACP will be operationalized as defined in Aim 1 after investigating cooccurrence of ACP components.

Mediator(s): Socioeconomic status and estate planning are the hypothesized mediators. Socioeconomic status is a combination of education and wealth. Both variables were standardized and summed. The summed socioeconomic status variable was then divided into quintiles. As described in Aim 1, estate planning is a dichotomous (yes/no) response to the HRS questionnaire item asking living respondents about having a written and witnessed will.

Covariate(s): Covariates for Aim 2 include age, gender, marriage status, recent hospitalization, self-reported memory, living children, death expected, and estate value. All covariates previously listed for Aim 1 are operationalized identically as described above.

Self-reported memory is part of the core interview with living respondents. Answers are on a 5-point Likert scale ranging from excellent to poor. For this study, self-reported memory was dichotomized (excellent/very good/good, fair/poor). Unknown responses will be recorded as a third unknown category and missing responses excluded from analyses.

Living children is obtained from core interview responses to a follow-up question to the number of children the respondent has. In this analysis, the indicator was dichotomized to indicate whether a respondent had any living children. Death expected is obtained from exit interviews and will be dichotomized for 'yes' and 'no' responses. Don't know responses will be coded as missing and missing responses excluded from analyses.

Estate value is obtained from an exit interview question asking the proxy if the deceased respondent's assets have been distributed. Answers indicating there was 'nothing of much value' will be coded as 'none' and all other responses coded as 'some'. Missing responses will be excluded from analyses.

ANALYSIS

Data for this sample was gathered over 14 years. So, prior to multivariate modeling, the main outcome variables will be reviewed for adjusted secular trends. Completion rates for all end of life planning activities (ACP: as defined in aim 1 and estate planning: having a written and witnessed will) will be reviewed and compared for the years 2002-2006, 2008-2012, and 2014-2016. If there are no significant trends, the analysis will proceed as described below. If there are meaningful differences over time an indicator for HRS wave will be included in multivariate modeling.

Descriptive statistics will be reported for the variables in this analysis. Means and standard deviations will be calculated for continuous variables and assessed for normality. Frequencies and chi-square values will be reported for categorical variables. A correlation matrix will also be assessed for collinearity issues before multivariate modeling.

Prior to modeling the hypothesized mediation relationships, model assumptions will be checked. Specifically, adjusted main effects and mediating effects will be checked using multivariate logistic regression models. First the main effect adjusted for basic demographics (age, gender, and socioeconomic status) will be assessed. Next, the association between the predictor and mediator will be assessed with the same adjusted model. Last, the relationship between the mediator and outcome variable will be assessed. If these assumptions of mediation are upheld, multivariate modeling will proceed.

The mediating model will utilize multivariate logistic regression modeling. To investigate the hypothesized relationship, four models will be generated. Model 1 will include the main predictor adjusted for age, gender, marriage status, living children, and

estate value. Model 2 will add recent hospitalization, self-reported memory, and death expected to Model 1. Model 3 will add SES (education and wealth) to Model 2. Model 4 will add estate planning to Model 3. Model fit will be assessed with Hosmer-Lemeshow p-values and c-statistics.

After assessing mediation assumptions and multivariate modeling, the SAS causal mediation procedure will be used to determine the size of any mediating effects. Stepwise mediation will be investigated by first reviewing the mediating effect of socioeconomic status and then the effect of estate planning after controlling for socioeconomic status.

Aim 3: To test for possible mediating relationship between race/ethnicity, advance care planning, social support, and end of life (End-of-Life) care. HRS Exit interviews for deceased respondents (2002-2016) are used to investigate the possible mediating effect of advance care planning and social support on the relationship between race/ethnicity and 1) decisions to limit care at the End-of-Life, hospital death, and complex care and 2) having one's End-of-Life preferences honored.

CONCEPTUAL MODEL

Aim 3.1 proposes the mediation model presented in Figure 1.3a. In this model, the effect of race/ethnicity on care received at the end of life is hypothesized to be mediated by advance care planning and social support. The objective of this aim is to investigate the relationships proposed in the conceptual model. Confounders are excluded from the figure but described in the text.

It is hypothesized that Non-Hispanic Whites will be more likely than Non-Hispanic Blacks or Hispanics to have proxies report decisions to limit care at the end of life, hospital death, and complex care procedures, but that the main effect of these relationships will be facilitated by the presence of advance care planning and social support. These relationships have not been previously investigated using HRS data.

Aim 3.2 proposes the mediation model presented in figure 1.3b. The aim investigates the mediating effect of advance care planning and social support on the relationship between race/ethnicity and having one's end of life preferences honored. Confounders are excluded from the figure but described in the text.

It is hypothesized that Non-Hispanic Whites will be more likely than Non-Hispanic Blacks and Hispanics to have their End-of-Life preferences honored at the end of life, but that this relationship will be facilitated by the presence of advance directives and social support. This relationship has not been previously investigated using HRS data.

Figure 1.3a- Conceptual Model for Specific Aim 3.1

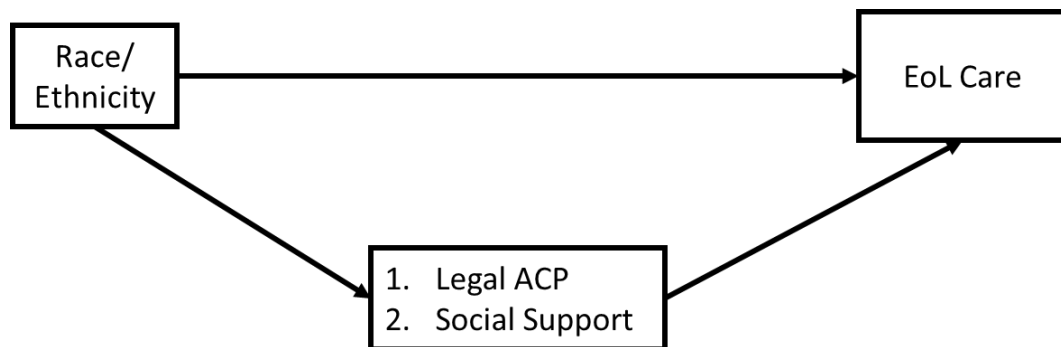
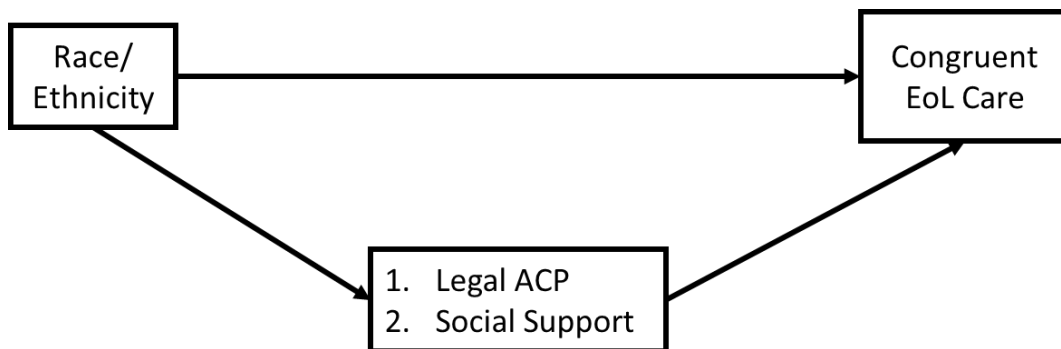


Figure 1.3b- Conceptual Model for Specific Aim 3.2

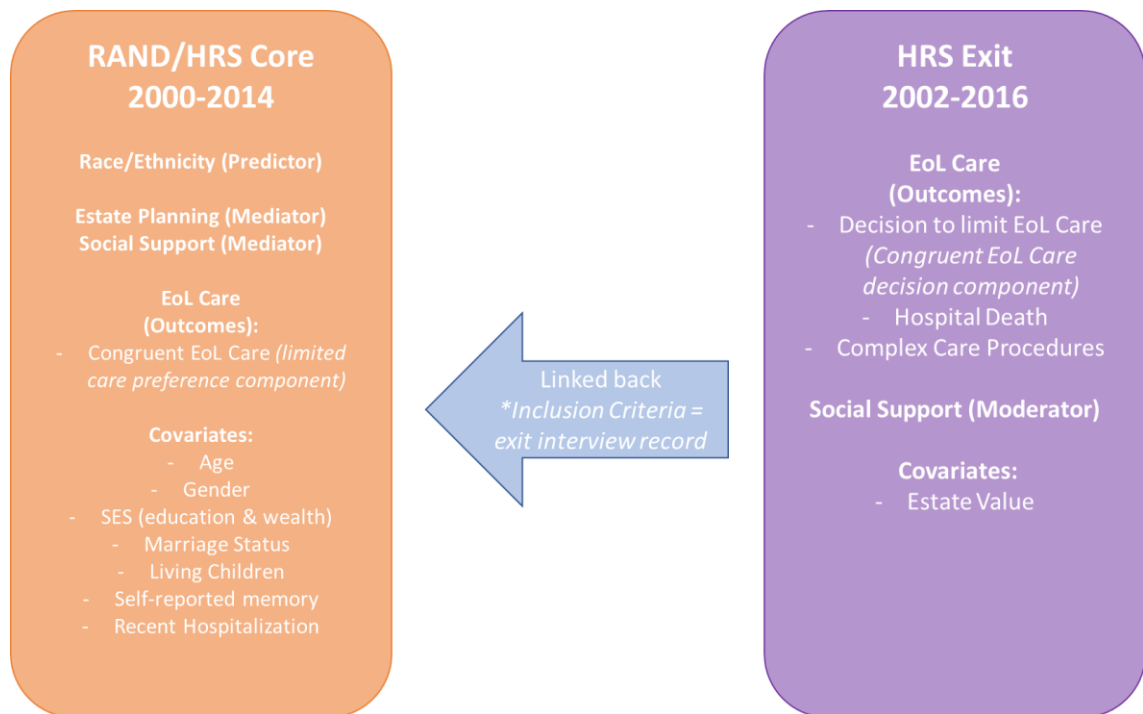


DATASET

The dataset for Aim 3 is identical to that used in Aim 2, and the dataset for Aim 3.2 is a subset of this data (Image 1.3). For Aim 3.1, an additional inclusion criterion is having

a proxy report about decisions to limit care at the end of life. For Aim 3.2, additional inclusion criteria are having both a proxy report about decisions to limit care at the end of life from 2014 and 2016 exit interviews and respondent report about preferences to limit care at the end of life from the 2012 and 2014 core interviews. Because the ‘preferences honored’ outcome is determined using both proxy and respondent answers to decisions and preferences to limit care, respectively, any cases with missing responses for these questions are excluded from the sample.

Image 1.3- Aim 3 Analytic File Composition



Specific sample size estimates from the proposal for this research for Aim 3.1 are provided in Table 1.3a. The total sample size is approximately 7,700. Of note, the outcome with the most limited sample for Hispanics is a decision for limited End-of-Life care ($n = 118$). Statistical power will be limited for analyses of this outcome. The sample size of Hispanics for the hospital death outcome is larger ($n = 263$) and allows for comparisons between racial/ethnic groups.

ESTIMATED SAMPLE SIZE FOR SPECIFIC AIM 3.1

Table 1.3a- Bivariate Results for Aim 3.1 (Exit)

Race/Ethnicity	Social Support		Limited Care Decision		Hospital Death	
	% Yes	N = 4,992	% Yes	N = 3,179	% Yes	N = 7,513
NHW	72.83	2,734/3,754	73.66	1,829/2,483	35.49	2,010/5,663
NHB	80.95	680/840	59.97	276/468	44.04	551/1,251
Hispanic	78.64	313/398	51.75	118/228	43.91	263/599
Missing		2,673		4,486		152

Abbreviations: NHW- Non-Hispanic White, NHB- Non-Hispanic Black

Sample size estimates from the proposal for this research for Aim 3.2 are provided in Table 1.3b. The total sample size is approximately 1,900 with only 12 Non-Hispanic Blacks and 10 Hispanics for the preference honored outcome. Due to the small sample size, racial/ethnic differences will not be investigated for this aim.

ESTIMATED SAMPLE SIZE FOR SPECIFIC AIM 3.2

Table 1.3b- Bivariate Results for Aim 3.2 (Exit)

	Social Support		Pref. Honored	
	% Yes	N = 1,278	% Yes	N = 566
Race/Ethnicity				
NHW	71.75	668/931	55.05	289/525
NHB	77.45	182/235	80.77	21/26
Hispanic	84.82	95/112	80.00	12/15
Missing		609		1,321

Subsample with Core and Exit interview components for End-of-Life Preferences Honored
Abbreviations: NHW- Non-Hispanic White, NHB- Non-Hispanic Black

MEASURES

Predictor(s): The predictor for specific Aims 3.1 and 3.2 is race/ethnicity as described in previous aims (NHW, NHB, Hispanic).

Outcome(s): The outcomes for specific Aim 3.1 will be proxy-reported decisions to limit End-of-Life care, hospital death, and complex care procedures. Hospital death is a general quality indicator frequently investigated in the End-of-Life literature.

Missing values will be excluded from analyses. Limited End-of-Life care is generated from a single HRS exit interview item asking the proxy if decisions to limit End-of-Life care were made. The final variable will be a dichotomous indicator (yes/no) of whether a decision to limit End-of-Life care was made. Hospital death is defined by one question indicating the location of the respondent's death. The final variable will be a dichotomous indicator of death location in the hospital or another location. Complex care procedures are not specific to end of life care due to the questionnaire skip sequence. Three dichotomous questions (intensive care unit admission, use of dialysis, and use of life support) are used to generate this indicator and all are follow-up

questions to positive responses of a recent hospitalization (since the last core interview before death). The final complex procedures variable is a dichotomous indicator of a positive response to any of the three questions and indicates any use of those services in approximately 2 years leading up to the respondent's death. Unknown and missing responses will be excluded from analyses.

The outcome for Aim 3.2 will be an indicator of End-of-Life care preference being honored. 'Preference honored' is defined as the receipt of end of life care consistent with patients' wishes. This variable is specifically an indicator of preferences for limited care at the end of life and whether these preferences were honored. It is generated from two variables. The first variable is the respondent's core interview answer indicating a preference to limit care at the end of life. The second variable is an exit interview proxy response to an end of life care decisions follow-up question asking, "Did those last decisions involve limiting care in certain situations?" (yes/no). For both questions, missing and "don't know" responses are excluded from analyses. The preference honored variable is generated as 1 if the respondent and proxy responses match, 0 if they do not.

Mediator(s): For both Aims 3.1 and 3.2 advance care planning and social support are hypothesized as the mediators. Advance care planning is defined as described in aim 1. Social support is defined as any financial or relocation support from family or friends. A series of HRS questions are used to determine if any or no support was provided to the respondent. The questions are often in a sequence, first asking about a type of support in general (moving close, financial, etc.) and then following up with a question about who specifically provided the support.

The first questioning sequence asks about financial support. The first question is part of the exit interview and asks if any of the respondent's children provided financial help in the last 2 years. Positive responses are recorded as positive child financial support. Negative responses are recorded as negative child financial support and missing responses excluded from analyses. The second question is part of the core interview and asks if the respondent received financial help from family or friends in the last 2 years. Responses indicating financial support was received are

recorded as positive financial support. Don't know and missing responses are excluded from analyses.

The second questioning sequence asks about general support. The first question is part of the core interview and asks if a child lives within 10 miles of the respondent. Positive responses are recorded as positive child support. Negative responses are recorded as no child support. Missing values are excluded from analyses. The next question is part of the exit interview and asks if any of the respondent's children moved close but did not live in the same house or apartment prior to death. Positive responses are recorded as positive child support and negative responses were coded as no child support. Missing and don't know responses are excluded from analyses. The last two questions ask if the respondent moved in with someone and if someone moved close to be with the respondent before death. Responses indicating the respondent or someone else moved to support the respondent will be recorded as positive relocation support. Don't know and missing responses will be excluded from analyses.

The responses to all these questions were limited. For example, 72 out of 1,310 proxies indicated the primary respondent moved in with someone. Therefore, to increase the sensitivity of these markers for social support, a final support variable is generated from the above-mentioned questions. Any positive response to the listed questions was considered social support and those with all negative responses are considered to not have had social support.

Covariate(s): In the mediation model for both Aims 3.1 and 3.2, the following covariates are considered for inclusion: age, gender, socioeconomic status, estate value, marriage status, religious importance, living children, self-reported memory, and recent hospitalization. These variables are coded as described in Aims 1 and 2.

Religious importance is acquired from core interview respondent answers to a question about how important religion is to the respondent. Response choices are on a 3-point Likert scale and range from very important to not too important. For this study, religious importance will be grouped into 3 categories (very important, somewhat important, not important). Those reporting

“don’t know” will be recorded as missing and those with missing responses will be excluded from analyses.

ANALYSIS

Descriptive statistics will be reported for the variables in this analysis. Means and standard deviations will be calculated for continuous variables and assessed for normality. Frequencies and chi-square values will be reported for categorical variables. A correlation matrix will also be assessed for collinearity issues before multivariate modeling.

For both Aims 3.1 and 3.2, the mediating model will utilize multivariate logistic regression modeling. To investigate the hypothesized relationship, a fully adjusted model (controlling for all covariates with significant bivariate relationships) will be generated. Model fit will be assessed with Hosmer-Lemeshow p-values and c-statistics.

Prior to modeling the hypothesized mediation relationships, model assumptions will be checked. Specifically, adjusted main effects and mediating effects will be checked using multivariate logistic regression models. First the main effect adjusted for basic demographics (age, gender, and socioeconomic status) will be assessed. Next, the association between the predictor and mediator will be assessed with the same adjusted model. Last, the relationship between the mediator and outcome variable will be assessed. If these assumptions of mediation are upheld, multivariate modeling will proceed.

The mediating model will utilize multivariate logistic regression modeling. To investigate the hypothesized relationship, four models will be generated. Model 1 will include the main predictor adjusted for age, gender, socioeconomic status, and estate value. Model 2 will add marriage status, religious importance, and living children Model 1. Model 3 will add self-reported memory and recent hospitalization to Model 2. Model 4 will add ACP and/or social support to Model 3 depending on the mediation assumptions being upheld. Model fit will be assessed with Hosmer-Lemeshow p-values and c-statistics.

After assessing mediation assumptions and multivariate modeling, the SAS causal mediation procedure will be used to determine the size of any mediating effects. If both candidate mediators meet the requirements, stepwise mediation will be investigated by first reviewing the mediating effect of ACP and then the effect of social support after controlling for ACP.

SUPERVISION AND FACILITIES

My immediate supervisor for this dissertation will be Dr. Susan Weller. No specialized facilities were required for this research.

HUMAN SUBJECTS

Data used in this dissertation is publicly available online and did not require access to restricted or confidential information.

Chapter 2: Aim 1- Prevalence of End of Life Planning

RATIONALE

Purpose

Aim 1: To describe the association between sociodemographic factors (ex. age, race/ethnicity, education, etc.) and level of participation in end of life planning (ACP and estate planning). HRS core interviews for living respondents (2014) are analyzed to describe the prevalence and adjusted associations of community dwelling adults 65 and older participating in end-of-life preparatory activities (ACP and estate planning). Variation across ethnic groups (Non-Hispanic White, Non-Hispanic Black, and Hispanic) and socioeconomic levels and co-occurrence of ACP elements is examined.

Significance

Advance Care Planning (ACP) is the ongoing process of making healthcare decisions prior to acute, life-threatening illnesses. It involves informal discussions with health care providers, family members, and decision makers. Legal documentation formalizes the discussions and delineates care preferences so that medical professionals and healthcare proxies can make informed decisions on behalf of an incapacitated individual (Carr & Luth, 2016). For these conversations and documents to have a meaningful impact on decision making, they must be completed in advance of terminal illnesses when a person has decision making capacity and can communicate their preferences for life sustaining therapy including cardiopulmonary resuscitation (CPR), intubation, intravenous antibiotics, and feeding tubes (Carr & Luth, 2017). Legal documents include advance directives, sometimes referred to as a living will, and durable power of attorney for healthcare, sometimes referred to as a medical power of attorney or healthcare proxy. The directives aim to clarify which procedures a patient would decline if given the choice. Durable power of attorney for healthcare documents designate a decision maker responsible for

navigating healthcare choices when a patient is unable to make decisions for themselves (Sabatino, 2010).

The development and implementation of advance care planning has been emphasized in the United States since the 1970s (Sabatino, 2010). The Patient Self Determination Act was passed by the United States Federal Government in 1990 in support of ACP (Carr & Luth, 2016; Carr & Luth, 2017; Sabatino, 2010). This act requires institutions and providers reimbursed by the Centers for Medicaid and Medicare Services (CMS) to inform patients of their right to participate in ACP and offer to document their preferences in the patient's medical record. Medicare reimbursement for ACP discussions during routine healthcare visits was approved in 2016 (Tuller, 2016).

The association between ACP and improved quality of life at the end of life is unclear with some studies reporting improvements in End-of-Life care like decreased in hospital death and utilization of complex care procedures and others demonstrating no difference (Brinkman-Stoppelenburg et al., 2014; Carr & Luth, 2016; Detering et al., 2010; Ratner et al., 2001; Teno et al., 2004; Wright et al., 2008). A systematic review assessed results in 113 studies on ACP looking at research focusing on do not hospitalize (52 studies) or do not resuscitate (16 studies) orders, advance directives or power of attorney (45 studies), and complex ACP intervention (20 studies) (Brinkman-Stoppelenburg et al., 2014). Studies focusing on legal components of ACP (advance directives or durable power of attorney for healthcare) showed decreased use of life sustaining treatment (10/22 studies) or no difference (11/22 studies), and increased hospice use (5/7 studies). Studies investigating complex ACP interventions reported improved adherence to patient preferences for care (3/4 studies), decreased hospitalization (3/4 studies), and decreased life sustaining treatment (3/5 studies). A randomized controlled trial of 309 participants 80 years of age and older at a single hospital reported that preferences for care at the end of life were more likely to be known and honored among those completing ACP (25/29 vs. 8/27 deaths, $p < 0.0001$) (Detering et al., 2010). In the study, the intervention group participated in an extensive ACP discussion lead by a trained facilitator. However, this study's strength in RCT design must be weighed against the complex ACP intervention that may not be applicable in other settings.

Studies using data from the Health and Retirement study that were not included in the review above have shown similar results. For example, one study using HRS data from 1993 to 2007 for 4,394 respondents linked to Medicare claims data reported decreased likelihood of dying in the hospital (OR = 0.78, 95% CI: 0.71-0.86) and decreased hospital length of stay (OR = 0.65, 95% CI: 0.50-0.85) among those with a stated preference for comfort care. In the same study, those with a preference for limited care were more likely to be admitted to a hospice than those with a preference for all care possible (OR = 1.83, 95% CI: 1.35-2.48) (Bischoff et al., 2013). All outcomes in this study were obtained from deceased HRS respondents' billing data.

Another study linked HRS proxy exit interviews for deceased respondents from 2002-2008 to CMS data for 3,069 respondents and found that those who reported having advance directives were less likely to undergo intensive procedures like intubation, CPR, and ICU admission at the end of life (OR = 0.71, 95% CI: 0.47-0.89) compared to those without a directive (Tschirhart et al., 2014). Non-Hispanic Blacks were more likely than Non-Hispanic Whites to have an intensive procedure at the end of life (OR = 2.02, 95% CI: 1.52-2.69), but there was no difference for Hispanics compared to Whites (OR = 1.53, 95% CI: 1.00-2.34). Education (OR = 1.01, 95% CI: 0.81-1.26), marriage status (OR = 0.95, 95% CI: 0.71-1.21), and net worth were not associated with receiving intensive procedures. However, those who had completed advance directives were less likely to undergo an intensive procedure like intubation and mechanical ventilation, parenteral nutrition, or cardiopulmonary resuscitation (OR = 0.71, 95% CI: 0.57-0.89).

Many studies of HRS data linked to CMS claims data have produced insignificant results. In one study of 2,394 decedents from 2002-2006 neither advance directives (RR = 1.04, 95% CI: 0.94-1.14) or discussing end of life preferences (RR = 0.95, 95% CI: 0.88-1.04) were associated with end of life Medicare expenditures (A. S. Kelley et al., 2011). A second study of 4,394 HRS decedents from 1993-2007 failed to find a significant association between advance directives or medical power of attorney and hospital death (RR = 0.86, 95% CI: 0.73-1.01 and RR = 0.88, 95% CI: 0.78-1.00) or ICU admission (RR = 0.81, 95% CI: 0.55-1.18 and RR = 0.90, 95% CI: 0.72-1.14) (Bischoff et al., 2013). A third study did not find a significant association between end of

life Medicare spending and advance directives (OR = 1.01, 95% CI: 0.95-1.06) or discussing end of life care preferences (OR = 0.98, 95% CI: 0.92-1.04) (Byhoff et al., 2016). With mixed results for the associations between ACP and end of life care further study is needed to describe the potential impacts of end of life healthcare planning.

Despite the potential influence of ACP on end of life care, completion rates among U.S. adults remain low, particularly for minorities. A 2008 statement from the U.S. Department of Health and Human Services reported one-third to one-half of U.S. adults have completed advance directives (Services, 2008). HRS studies have also demonstrated low completion among minorities compared to Whites. One study of 4,761 proxy interviews for respondents who died between 1998 and 2007 reported treatment limiting advance directives for 44.39% of Whites compared to 12.55% of non-Whites ($p < 0.001$) (L. H. Nicholas et al., 2011). A second study of 4,394 deceased HRS respondents from 1992-2007 demonstrated disparities in advance care planning completion, defined as discussing end of life care, completing advance directives, or having a medical power of attorney with Whites (77.58%) being more likely than Hispanics (43.56%) or Blacks (47.83%) to complete ACP ($p < 0.0001$) (Bischoff et al., 2013). Another HRS study using exit interviews for 1,985 decedents reported lower rates of ACP (discussing End-of-Life care, advance directive, or medical power of attorney) for Blacks (58.96%) and Hispanics (53.13%) compared to Whites (83.89%) (Narang et al., 2015).

Multivariate modeling has consistently demonstrated lower completion rates among Non-Hispanic Blacks and Hispanics compared to Non-Hispanic Whites even after controlling for key sociodemographic confounders. A study using HRS exit interview data from 1998-2013 for 7,177 deceased respondents reported that Non-Hispanic Blacks (OR = 0.23, 95% CI: 0.19-0.29) and Hispanics (OR = 0.30, 95% CI: 0.22-0.40) were less likely than Non-Hispanic Whites to complete advance directives even after controlling for factors like age, gender, marital status, education, and income (Portanova et al., 2017). Another study using 6,946 HRS core interview responses for living respondents in 2012 reported similar findings. Whites were more likely than Blacks to complete advance directives even after adjusting for age, gender, education, marital status, income,

and self-rated health (Catheryn & Tamara, 2017). Despite a fair amount of evidence on advance directives specifically, there is limited data for the broader concept of advance care planning which includes assigning a medical power of attorney and informally discussing care preferences, specifically among Hispanics. Given the unique cultural perspectives of Hispanics and their growing proportion of the U.S. population, it is important to further the understanding of ACP completion in this racial/ethnic minority compared to Non-Hispanic Whites and Blacks.

Association with Sociodemographic Factors

Studies have consistently shown that *age* and *age at death* are associated with completion of ACP with older age being associated with increased likelihood of completion. Positive associations with age in years have been small, but statistically significant (OR = 1.03, 95% CI: 1.02-1.04) (Catheryn S. Koss & Baker, 2017c) (Bischoff et al., 2013; Gerst & Burr, 2008; Khosla et al., 2015; Catheryn S. Koss & Baker, 2017c). Associations with *gender* have been mixed, with some studies reporting females being more likely to discuss the care they would like to receive and complete ACP activities and others reporting no difference (Bischoff et al., 2013; Carr, 2012; Catheryn & Tamara, 2017; Gerst & Burr, 2008; Catheryn S. Koss & Baker, 2016). For example, one study of 6,946 HRS respondents in 2012 reported that females were more likely than males to have discussed the type of care they would like to receive (OR = 1.71, 95% CI: 1.49-1.96) (Catheryn & Tamara, 2017).

As stated above, *Non-Hispanic Blacks* and *Hispanics* have lower rates of ACP than Non-Hispanic Whites (Catheryn & Tamara, 2017; Gerst & Burr, 2008; Catheryn S. Koss & Baker, 2017a, 2017c). Stark differences prevail after adjusting for a variety of sociodemographic factors. After controlling for gender, education, marital status, and religious attendance, one study of 1,102 community dwelling and institutionalized respondents from the 2000 wave of the HRS reported that Blacks were less likely than Whites to discuss care preferences (OR = 0.49), assign a medical power of attorney (OR = 0.45), and have written advance directives (OR = 0.26) (Gerst & Burr, 2008). Similar findings were reported for 6,946 HRS respondents in 2012 with Whites more likely

to participate in care discussions than Blacks (OR = 1.75, 95% CI: 1.50-2.03) (Catheryn & Tamara, 2017). In a third HRS study using data from 2000-2012 for 7,177 respondents, Hispanics (OR = 0.30, 95% CI: 0.22-0.40) and Non-Hispanic Blacks (OR = 0.23, 95% CI: 0.19-0.29) were less likely than Non-Hispanic Whites to complete advance directives (Portanova et al., 2017).

Marital status may play a role in ACP completion, but interpretation of the association is challenging due to variability in operationalization of this factor in analyses. One study of 7,177 HRS respondents from 2000-2012 defined four categories (married, divorced or separated, widowed, never married) and reported significantly increased odds of having advance directives among those who were widowed (OR = 1.38, 95% CI: 1.19-1.61) or never married (OR = 1.45, 95% CI: 1.04-2.01) compared to those who were married (Portanova et al., 2017). Other studies have defined marriage status differently, but not provided results for this factor of interest (L. H. Nicholas et al., 2011; Silveira et al., 2010; Silveira et al., 2014).

Associations between *education* and *income* and ACP have been inconsistent. Findings from data using the Wisconsin Longitudinal Study for 4,971 Whites did not demonstrate an association between education and any ACP component (discussing care, living will, or power of attorney) (Carr, 2012). Another study using HRS data from 2002-2012 for 6,052 respondents did not find a significant association between education and ACP (Khosla et al., 2015). However, HRS data from 2000 for 1,102 respondents demonstrated a significant association between education and medical power of attorney (OR = 1.06) and having an advance directive (OR = 1.13) (Gerst & Burr, 2008). Mixed findings may be a result of differences in samples. The Wisconsin Longitudinal Study is a sample of mostly Non-Hispanic White high school graduates and the HRS is a nationally representative survey of the U.S. non-institutionalized population. HRS samples can also vary significantly depending on inclusion/exclusion criteria. For example, nursing home residents can be included where weights are provided, and some samples may use proxy responses for deceased respondents. The Gerst & Burr (2008) and Khosla et al. (2015) studies had significantly different samples and included different confounders in multivariate models, which may account for differences in the association between planning activities and education. Gerst

and Burr (2008) used one wave of exit interview data for deceased respondents and controlled for *social factors* like religious attendance and grandchildren. Khosla et al. (2015) used HRS exit interview data for 5 waves and controlled for specific comorbidities like cancer, cardiovascular conditions, respiratory problems, and memory problems.

Income has been operationalized in a variety of ways including household income and person-level wealth making it difficult to compare results across studies. In one HRS study using 6,946 core survey responses household income was uniquely associated with each ACP component (Catheryn & Tamara, 2017). Advance directives were not associated with income (OR = 0.90, 95% CI: 0.80-1.01), but advance care discussion was (OR = 1.21, 95% CI: 1.09-1.35) in fully adjusted models. Some HRS studies have used the *wealth* variable provided by RAND, but results have been mixed. One study using data from 2000 for 1,102 respondents found significant associations between wealth and care discussions (OR = 1.35) and medical power of attorney (OR = 1.32) (Gerst & Burr, 2008), but another study failed to reproduce the findings for care discussions using data from 2012 (OR = 0.98, 95% CI: 0.95-1.02) (Catheryn & Tamara, 2017). These results may be explained by a few methodological differences. First, Gerst & Burr (2008) used exit interview data, while Carr & Baker (2017) used core interview responses. Related to the differences in sample selection, Carr & Baker (2017) also applied sampling weights to obtain population estimates.

Health conditions, hospitalizations, and complex hospitalizations have been associated with completion of ACP documents. Cancer and memory problems like dementia have been shown to increase participation in ACP. In a study using HRS data from 2000 to 2012 for 7,177 respondents, those with cancer were more likely to have advance directives compared to those without cancer (OR = 1.41, 95% CI: 1.25-1.60) (Portanova et al., 2017). Another study using HRS from a similar timeframe (2002-2010) reported similar associations for cancer (OR = 1.33, $p < 0.01$) and diagnosis of a memory problem (OR = 1.52, $p < 0.01$) with having a medical power of attorney (Khosla et al., 2015). Complex hospitalizations and expected death have been shown to be associated with ACP. HRS exit interview data from 1998 and 2000 for deceased respondents

demonstrated increased likelihood of having advance directives (OR = 1.77, $p < 0.001$) and medical power of attorney (OR = 1.95, $p < 0.001$) when death is expected (Gerst & Burr, 2008). Similarly, recent hospitalization has consistently been associated with increase odds of ACP legal documentation. Researchers using the Wisconsin Longitudinal Study reported spending the night in hospital at least once in the last year increased the odds of having an advance directive or medical power of attorney (OR = 1.82, $p < 0.01$) (Carr, 2012). Another study using a convenience sample of community dwelling older adults found a significant association between previous ICU admission and advance directives completion (OR = 4.33, 95% CI: 1.69-1.11) (Eunjeong & Jaehoon, 2013).

The objective of the analyses in this chapter is to describe the prevalence of end of life planning and associations with sociodemographic factors like age, gender, education, and income among U.S. adults age 65 and older. End of life planning activities include advance care planning (discussing care preferences, having advance directives, and assigning a medical power of attorney) and estate planning (written will). First, ACP components are assessed to determine how to operationalize the outcome variable in the next chapters. Next, prevalence of planning activity participation is estimated while adjusting for sociodemographic variables including age, gender, race/ethnicity, education, wealth, marriage status, and recent hospitalization.

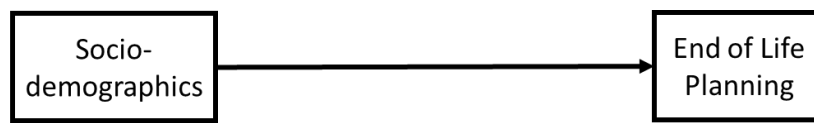
METHODS

Conceptual Model: Aim 1 describes levels of population prevalence of participation in end of life planning activities and associations with various sociodemographic factors including age, gender, race/ethnicity, educational level, and income/wealth. This aim replicates work by previous authors that have described prevalence rates and associations for Non-Hispanic Whites and Blacks and builds on the work by investigating the same associations in Hispanics.

It is hypothesized that relationships previously described in the literature for Non-Hispanic Whites and Blacks will be reproduced in this analysis. (Carr, 2012; Eunjeong & Jaehoon, 2013; Gerst & Burr, 2008; Khosla et al., 2015; Portanova et al., 2017) For example, consistent with other

studies, one using HRS data from 2012 for 6,946 respondents described a small, statistically significant association (OR = 1.04, 95% CI: 1.03-1.05) between age and ACP (Catheryn & Tamara, 2017). Results are also expected to demonstrate lower completion rates for Non-Hispanic Blacks and Hispanics compared to Non-Hispanic Whites. The same study above reported significant differences in completion rates of advance directives and advance care discussion between Blacks (36%, 40%) and Whites (63% and 65%) (Catheryn & Tamara, 2017). Adjusted associations in one HRS study investigating completion rates for advance directives among 7,177 respondents from 2000-2013 reported significantly lower odds of completion among non-Hispanic Blacks (OR = 0.23, 95% CI: 0.19-0.29) and Hispanics (OR = 0.30, 95% CI: 0.22-0.40) compared to non-Hispanic Whites (Portanova et al., 2017).

Figure 2.1- Conceptual Model for Specific Aim 1



Dataset: The Health and Retirement study core interview in 2014 will be used to estimate population prevalence of participation in end of life planning activities including (1) discussing end of life care preferences, (2) completing advance directives, (3) assigning a durable power of attorney for healthcare, and (4) having a written and witnessed will. The first three collectively are components of advance care planning and the last considered estate planning.

The HRS utilizes a complex sampling design to generate a study sample that is representative of the U.S. population. It is a longitudinal study of adults aged 50 and older supported by the National Institute on Aging. The broad questionnaire covers topics like income and wealth, work and retirement, and family connections. Established in 1992, the survey is administered to approximately 20,000 living respondents bi-annually in core interviews. The complex design oversampled Floridians, Mexican Americans and Non-Hispanic Blacks. Using sampling weights in analyses produces estimates that are representative of the U.S. non-institutionalized population.

The analytic file for Aim 1 utilized data from multiple sources for 2014 HRS core interview responses. The RAND corporation provides processed data files that have been cleaned and imputed. The RAND HRS 2014 core data file contains general sociodemographic factors, many responses to HRS core and exit interviews, and newly computed variables generated from HRS raw data. RAND has imputed values for missing responses. As an example, if gender was not recorded, data from a previous wave is used to complete the record. Additionally, RAND computed a total wealth variable that takes the difference between all assets and debts from HRS core interview responses. Responses for end of life planning activities are acquired from raw HRS 2014 Core interview data files.

Inclusion criteria for this sample includes age ≥ 65 and having a response to all three advance care planning questions (discuss end of life care preferences, complete advance directive, and assign a durable power of attorney for health care). Age is an inclusion criterion due to the skip pattern of the HRS core interview. Questions related to ACP components are only asked for those 65 years of age and older. An exclusion criterion for this sample is nursing home residency, because nursing home residents experience with ACP is inherently different from the non-institutionalized population. Additionally, respondents with missing covariates are excluded from analyses with listwise deletion.

Measures

PREDICTORS: Key sociodemographic factors are included in Aim 1 as predictors and include age (65-74, 75-84, 85+), gender (male/female), race/ethnicity (Non-Hispanic White, Non-Hispanic Black, and Hispanic), educational level (less than high school, high school or equivalent, and any college or greater), wealth (quintiles), marriage status (married/partnered, separated/divorced/single), and recent hospitalization (yes/no). Wealth is a continuous value provided by RAND derived from adding all assets and debts and taking the difference of the two. The final variable provided by RAND includes negative values. For this study, the total wealth variable is categorized into quintiles. Marriage status is recoded dichotomously as

married/partnered (“married”, or “partnered”) or separated/divorced/single (“married, spouse absent”, “separated”, “divorced”, “widowed”, or “never married”). Recent hospitalization is defined as any self-reported overnight hospitalization in the last 2 years.

Table 2.1- Aim 1 Sociodemographic Variables, Predictors

<i>Predictor</i>	<i>HRS Question</i>	<i>Coding</i>
Age	Calculated from the respondent’s birthdate	1 = 65-74, 2 = 75-84, 3 = 85+ years old
Gender	Is [R’s first name] male or female? (coverscreen)	1 = male, 2 = female
Race/Ethnicity	Do you consider yourself to be Hispanic or Latino? What race do you consider yourself to be: White, Black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, or something else?	1 = Non-Hispanic White, 2 = Non-Hispanic Black, 3 = Hispanic
Educational Level	What is the highest grade of school or year of college you completed?	1 = less than high school, 2 = high school/GED, 3 = any college or more
Wealth	Total non-housing wealth (RAND imputed) = sum of wealth components less debt	Quintiles (1 = lowest, 5 = highest)
Marital Status	Just to clarify, are you currently separated, divorced, widowed, or have you never been married?	1 = married; partnered, 0 = married, spouse absent; divorced; separated/divorced; widowed; never married
Recent Hospitalization	Since your last interview, have you been a patient in a hospital overnight?	1 = yes, 0 = no

OUTCOMES: Outcomes for Aim 1 include four end of life preparatory activities: discussing preferences for end of life care, having advance directives, having a durable power of attorney for healthcare, and having a written will (estate planning). All responses were reported directly by each respondent and are coded dichotomously (yes/no). A fifth outcome variable will be defined by the intercorrelation of the ACP components. Candidate operationalization approaches for the ACP variable include: a dichotomized variable indicating any positive response to the three ACP components or no positive responses, a dichotomized variable indicating positive responses on all 3 ACP components or any combination of ACP components with at least one negative response,

generating an index score of the 3 components, developing a scale for the components, or creating a typology for response categories.

Table 2.2- Aim 1 End of Life (End-of-Life) Planning Variables, Outcomes

<i>Outcome</i>	<i>HRS Question</i>	<i>Coding</i>
Discussing end of life care preferences	Have you ever discussed with anyone the care or medical treatment you would want to receive if you were to become seriously ill in the future?	1 = yes, 0 = no
Completing advance directives	Have you provided written instructions about the care or medical treatment that you would want to receive if you can not make those decisions yourself? This is sometimes called a "Living Will".	1 = yes, 0 = no
Assigning a medical power of attorney	Have you made any legal arrangements for a specific person or persons to make decisions about your care or medical treatment if you can not make those decisions yourself? This is sometimes called a "Durable Power of Attorney for Health Care".	1 = yes, 0 = no
Completing a written will (estate planning)	Do you currently have a will that is written and witnessed?	1 = yes, 0 = no

For all predictor and outcome variables, “don’t know”, “refused”, and blank responses are recoded as missing.

Analysis: First, after a review of the data for coding errors, the sample is described with univariate descriptive statistics. Frequencies and weighted percentages are provided for categorical variables.

Second, the outcome variables were described with bivariate statistics. The ACP components were first assessed for intercorrelation and then with Cronbach’s alpha. The alpha

value for all three components was compared to the alpha value with each component removed. If the alpha value stayed the same when a factor was removed, it was considered to measure the same ACP construct. If the alpha value increased when the factor was removed it was considered to measure a different construct, and alternatively, if the alpha value decreased it was considered to measure the ACP construct. This assessment of the ACP construct and operationalization will inform analyses in the next aims.

Unadjusted bivariate statistics were run for each outcome variable followed by adjusted bivariate statistics with logistic regression modeling controlling for all covariates. Significance of unadjusted bivariate statistics was determined with chi-square statistics for categorical variables. Adjusted odds ratios and 95% confidence intervals are reported for predictors and each outcome variable.

All analyses were performed using weights provided by the HRS. Results are reported for these weighted analyses so that generalizations can be made to the U.S. non-institutionalized adult population greater than 65 years old in 2014.

RESULTS

Data from the 2014 Health and Retirement Study core interview with living respondents for 43,224 participants was used to generate the analytic sample for aim 1 (Figure 2.2). There were 32,836 respondents less than age 65 who were excluded from the sample. Those living in a nursing home ($n = 418$) and with missing data for all the advance care planning component variables ($n = 40$) were also excluded. Listwise deletion excluded 286 respondents with missing covariates. The final sample size is 9,644.

Figure 2.2- Aim 1 Sample Flow Chart

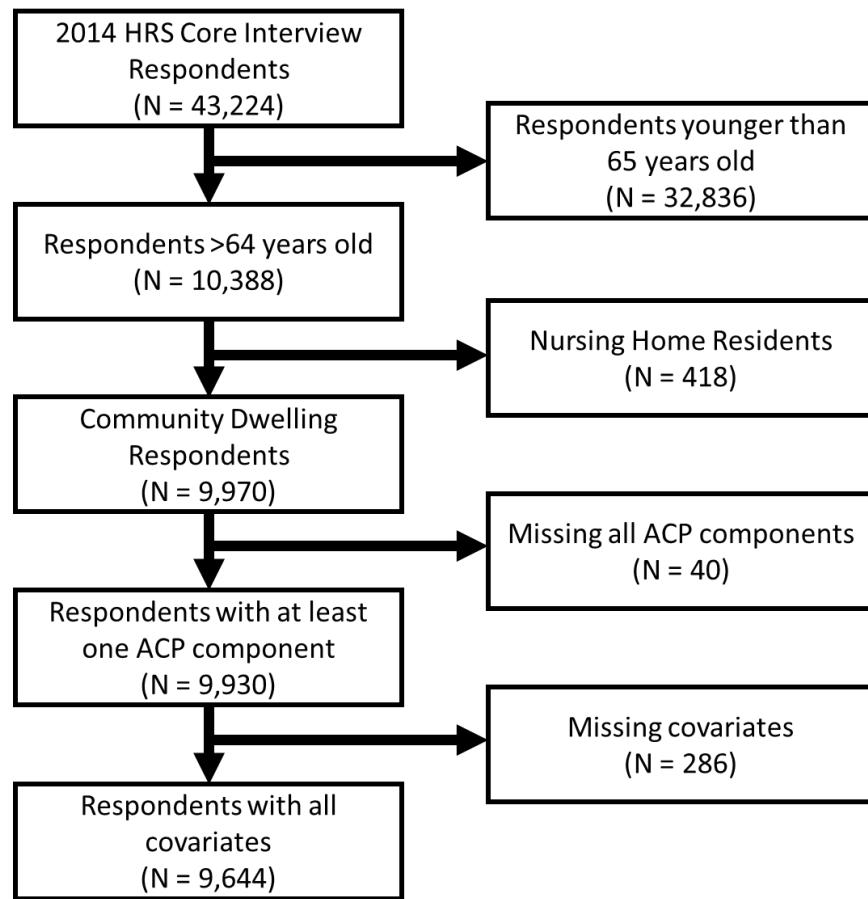


Table 2.3 provides sample characteristics for the 2014 HRS Core sample used in Aim 1. The total sample size is 9,644 and represents approximately 43 million U.S. adults aged 65 and older. Majority of participants were aged 65-74 years old (57.79%). Most respondents were female (55.84 %) and Non-Hispanic White (83.06%). Most interview respondents reported having completed at least a high school education (53.31%) and fewer reported completing less than a high school education (16.35%) or greater than a high school education (30.34%). After weighting, more respondents were in the highest wealth quintile (23.30%) and fewer in the lowest quintile (17.22%). Most HRS participants in the sample were married or partnered (59.90%) and had not been hospitalized since their last interview (71.79%).

End of life planning variables included ACP components related to health care decisions (discussing End-of-Life care preferences, advance directives, and medical power of attorney) and

estate planning (written will). Completion of any ACP component was high at 77.02%. Few respondents participated in discussing end of life care preferences (19.57%). This is due to a skip pattern that limits this question to those who have not answered in previous wave. For the 2014 core interview, 51.62% of participants did not have a response recorded. Approximately half of respondents completed legal ACP documentation including advance directives (51.31%) and medical power of attorney (53.75%). Most of the respondents completed estate planning (63.02%).

Table 2.3- HRS Core Weighted Sample Characteristics (Core)

Characteristic	Unweighted		Weighted	
	Mean or %	SD or n	Mean or %	SE or n
Age, n (%)				
65-74	47.18	4,550	57.79	25,108,853
75-84	39.73	3,832	30.27	13,153,669
85+	13.09	1,262	11.94	5,186,130
Gender, n (%)				
Male	41.41	3,994	44.16	19,188,147
Female	58.59	5,650	55.84	24,260,505
Race/Ethnicity, n (%)				
Non-Hispanic White	74.99	7,232	83.06	36,089,909
Non-Hispanic Black	14.88	1,435	8.93	3,880,007
Hispanic	10.13	977	8.01	3,478,736
Education, n (%)				
< High School	20.18	1,946	16.35	7,102,616
High School/GED	53.83	5,191	53.31	23,163,323
Any College +	26.00	2,507	30.34	13,182,713
Wealth Quintiles, n (%)				
Q1	19.92	1,921	17.22	7,480,128
Q2	20.15	1,943	18.41	8,001,031
Q3	19.94	1,923	19.88	8,638,951
Q4	20.00	1,929	21.19	9,205,953
Q5	19.99	1,928	23.30	10,122,589
Marriage Status, n (%)				
Married/Partnered	57.43	5,539	53.82	23,128,849
Sep./Div./Single/Widowed	42.57	4,105	46.18	19,843,816
Recent Hospitalization, n (%)				
No	70.54	6,803	71.79	31,191,713
Yes	29.46	2,841	28.21	12,256,939
Advance Care Planning (any), n (%)				
No	21.36	2,060	22.98	8,848,667
Yes	67.77	6,536	77.02	29,657,930
Missing	10.87	1,048		
Discuss End-of-Life Care, n (%)				
No	28.82	2,779	55.96	11,911,437
Yes	19.57	1,887	44.04	9,373,339
Missing	51.62	4,978		
Advance Directive, n (%)				
No	47.34	4,565	47.47	20,345,013
Yes	51.31	4,948	52.53	22,512,642
Missing	1.36	131		
Medical Power of Attorney, n (%)				
No	45.24	4,363	46.18	19,843,816

Yes	53.75	5,184	53.82	23,128,849
Missing	1.01	97		
Legal ACP, n (%)				
No	38.41	3,704	60.74	16,886,243
Yes	60.69	5,853	39.26	27,249,507
Missing	0.90	87		
Written Will, n (%)				
No	38.75	3,737	36.98	15,986,658
Yes	60.68	5,852	63.02	27,249,507
Missing	0.57	55		

Abbreviations: ACP- Advance Care Planning

The intercorrelation of ACP components was assessed with a correlation matrix and Cronbach's alpha (Tables 2.4a and 2.4b). Discussing End-of-Life care was weakly correlated with medical power of attorney ($r = 0.37$) and advance directives ($r = 0.41$). Medical power of attorney and advance directives were moderately correlated ($r = 0.63$). Additional bivariate associations of the three ACP components are provided in tables 2.5a-2.5c. The ACP construct was assessed with a standardized Cronbach's alpha by deleting each component one at a time and evaluating the effect on the alpha value. Deleting the discussion component increased the standardized alpha value (0.77) compared to when all three components were included (0.73) suggesting this variable is not measuring the same ACP construct. Removing the medical power of attorney or advance directives component reduced the standardized alpha (0.58 & 0.54, respectively) compared to when all three components were included (0.73) suggesting these two components measure the same construct.

Table 2.4a- ACP Component Assessment (Correlation Matrix), unweighted (Core)

	Medical Power of Attorney	Advance Directives
Discuss End-of- Life Care	0.37	0.41
Medical Power of Attorney		0.63

Abbreviations: End-of-Life- End of Life

Table 2.4b- ACP Component Assessment (Cronbach's Alpha), unweighted (Core)

	Correlation with Total	Standardized Alpha
All 3 components		0.727542
Discuss End-of-Life Care Deleted	0.43	0.772196
Medical Power of Attorney Deleted	0.59	0.584578
Advance Directives Deleted	0.63	0.541051

Abbreviations: End-of-Life- End of Life

Table 2.3 and tables 2.5a and 2.5b highlight problems with sample size when including the discussion component in analyses. Approximately half (51.62%) of the responses for discussing End-of-Life care are missing due to the HRS skip sequence. Due to this sample size limitation and the previous correlation results, discussing End-of-Life care preferences was not included in the

final ACP variable. The final advance care planning variable is a dichotomized outcome called legal ACP. Any positive response to advance directives or medical power of attorney is recorded as yes (1) and those without advance directives and medical power of attorney are recorded as no (0) legal ACP.

Table 2.5a- Bivariate Association: Discuss & MPA, weighted (Core)

	No MPA	MPA
	% (n)	% (n)
No Discussion	47.84 (2,211)	10.10 (548)
Discuss	21.54 (829)	21.72 (1,043)
Missing	30.62 (1,323)	68.18 (3,593)

Abbreviations: Discuss- Discussed End-of-Life Care, MPA- Medical Power of Attorney

Table 2.5b- Bivariate Association: Discuss & AD, weighted (Core)

	No AD	AD
	% (n)	% (n)
No Discussion	49.12 (2,338)	8.00 (412)
Discuss	20.67 (862)	22.43 (997)
Missing	30.20 (1,365)	69.57 (3,539)

Abbreviations: Discuss- Discussed End-of-Life Care, AD- Advance Directives

Table 2.5c- Bivariate Association: MPA & AD, weighted (Core)

	No AD	AD
	% (n)	% (n)
No MPA	83.38 (3,704)	12.77 (636)
MPA	16.62 (839)	87.23 (4,279)

Abbreviations: Discuss- Discussed End-of-Life Care, AD- Advance Directives, MPA- Medical Power of Attorney

Prevalence of legal ACP in the sample was 61% (Figure 2.3a). Among Non-Hispanic Whites, more respondents completed legal ACP (65%). The opposite is observed for Non-Hispanic Blacks (43%) and Hispanics (33%) with fewer completing legal ACP. Similar disparities are observed for education and wealth (Figures 2.3b and 2.3c). There was a graded response for education with rates increasing from 45% among those with less than a high school education to 61% in those completing high school and 69% among those completing any college education. The rates of legal ACP also increased with increasing wealth with 43% of those in the lowest

quintile compared to 75% of those in the highest completing an advance directive or assigning a medical power of attorney.

Figure 2.3a- Legal ACP by Race/Ethnicity, weighted (Core)

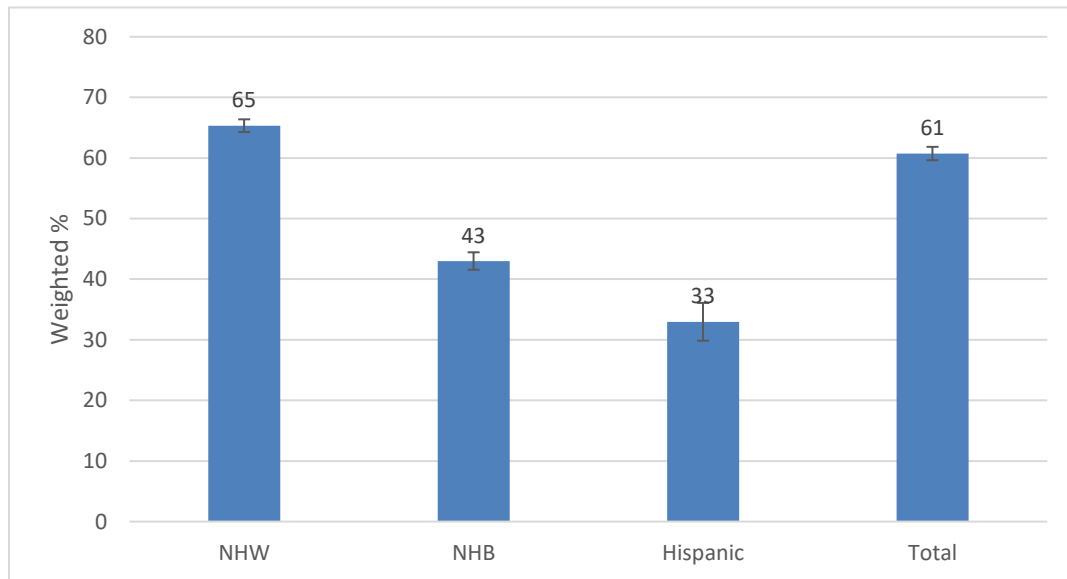


Figure 2.3b- Legal ACP by Education, weighted (Core)

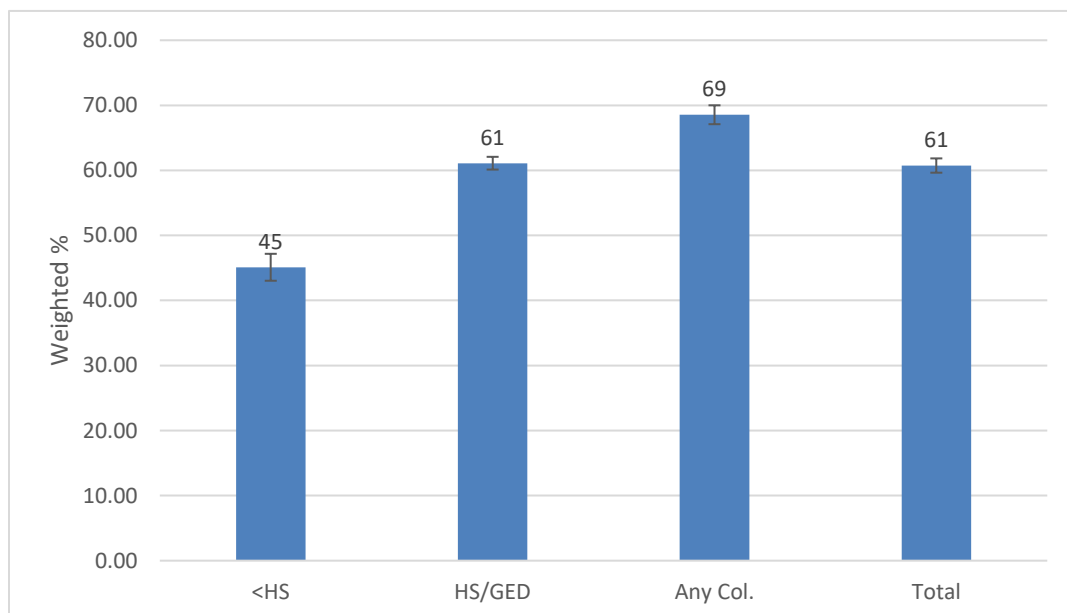
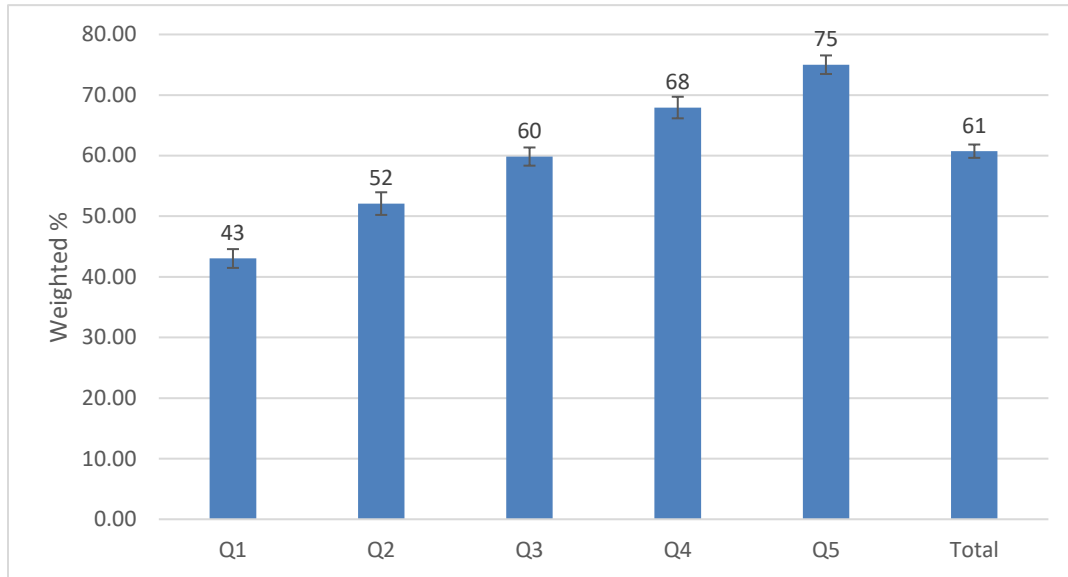


Figure 2.3c- Legal ACP by Wealth, weighted, (Core)



Weighted, unadjusted bivariate associations for legal ACP are presented in Table 2.5. Without adjusting for other variables, all bivariate relationships were statistically significant. Those completing legal ACP were older than those who did not. Legal planners were more often female and Non-Hispanic White. They had higher educational attainment and income. Those that were married and had been hospitalized recently completed legal ACP more often.

Table 2.6- Bivariate and Multivariate Associations with Legal ACP, weighted (Core)

Characteristic	Unadjusted Bivariate	Adjusted Multivariate		
	Legal ACP = Yes	Legal ACP = Yes		
	Mean (SE)/n (%)	Chi-square	OR, 95% CI	p
Age, n (%)		*****		
65-74	2,301 (51.90)			
75-84	2,551 (69.82)		2.26 (2.03-2.50)	*****
85+	1,001 (80.54)		4.10 (3.42-4.91)	*****
Gender, n (%)		*****		
Male	2,324 (57.72)			
Female	3,529 (63.13)		1.29 (1.16-1.43)	*****
Race/Ethnicity, n (%)		*****		
Non-Hispanic White	4,910 (65.33)			
Non-Hispanic Black	635 (43.00)		0.60 (0.52-0.70)	*****
Hispanic	308 (32.97)		0.46 (0.35-0.60)	*****
Education, n (%)		*****		
< High School	857 (45.10)		0.53 (0.45-0.63)	*****
High School/GED	3,233 (61.10)		0.80 (0.69-0.93)	0.0037
Any College +	1,763 (68.55)			
Wealth Quintiles, n (%)		*****		
Q1	814 (43.03)		0.27 (0.22-0.34)	*****
Q2	1,025 (52.09)		0.40 (0.32-0.49)	*****
Q3	1,188 (59.85)		0.48 (0.39-0.60)	*****
Q4	1,351 (67.94)		0.69 (0.55-0.87)	0.0018
Q5	1,475 (75.01)			
Marriage Status, n (%)		0.006		
Married/Partnered	3,274 (58.93)			
Sep/Div/Single/Widowed	2,579 (63.39)		1.31 (1.10-1.55)	0.0026
Recent Hospitalization, n (%)		*****		
No	3,937 (58.20)			
Yes	1,916 (67.21)		1.55 (1.34-1.80)	*****
Model Statistics				
c statistic			0.731	
R-square (Nagelkerke)			0.1876	

Abbreviations: ACP- Advance Care Planning, Legal ACP- Advance Directives or Medical Power of Attorney

*p < 0.05, **p < 0.01, ***p < 0.001, ****p < 0.0001

Results of weighted, multivariate binary logistic regression modeling of legal ACP are also presented in Table 2.5. Legal ACP completion was highest among the oldest respondents (OR = 4.10, 95% CI: 3.42-4.91) and was more likely among females (OR = 1.29, 95% CI: 1.16-1.43) than males. Non-Hispanic Blacks (OR = 0.60, 95% CI: 0.52-0.70) and Hispanics (OR = 0.46, 95% CI: 0.35-0.60) were significantly less likely to complete legal ACP compared to Non-Hispanic Whites. Those with lower educational attainment were less likely to complete legal ACP with those completing less than high school being half as likely as those with any college education (OR = 0.53, 95% CI: 0.45-0.63). The odds of participation in legal ACP increased with increasing wealth, but all wealth quintiles less than the highest quintile were significantly less likely to complete advance directives or medical power of attorney documents. The greatest difference is observed for those in the lowest quintile (OR = 0.27, 95% CI: 0.22-0.34), but those in the fourth quintile were also less likely to complete either activity (OR = 0.69, 95% CI: 0.55-0.86) compared to those in the fifth quintile. Those who were separated or divorced (OR = 1.31, 95% CI: 1.11-1.55) were more likely than those who were married or partnered to complete planning activities. Recent hospitalization was also associated with increased likelihood of legal ACP (OR = 1.55, 95% CI: 1.34-1.80).

Prevalence of estate planning in the sample was 63% (Figure 2.4a). Among Non-Hispanic Whites, more respondents completed estate planning (70%). The opposite is observed for Non-Hispanic Blacks (27%) and Hispanics (26%) with fewer completing estate planning. Similar disparities are observed for education and wealth (Figures 2.4b and 2.4c). There was a graded response for education with rates increasing from 39% among those with less than a high school education to 62% in those completing high school and 78% among those completing any college education. The rates of estate planning also increased with increasing wealth with 30% of those in the lowest quintile compared to 86% of those in the highest completing a written will.

Figure 2.4a- Estate Planning by Race/Ethnicity, weighted (Core)

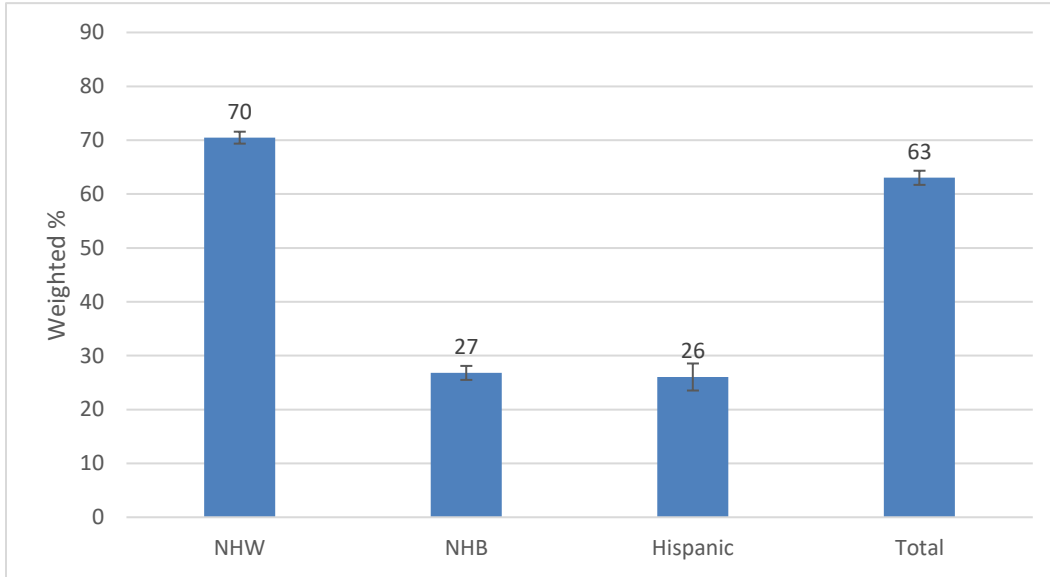


Figure 2.4b- Estate Planning by Education, weighted (Core)

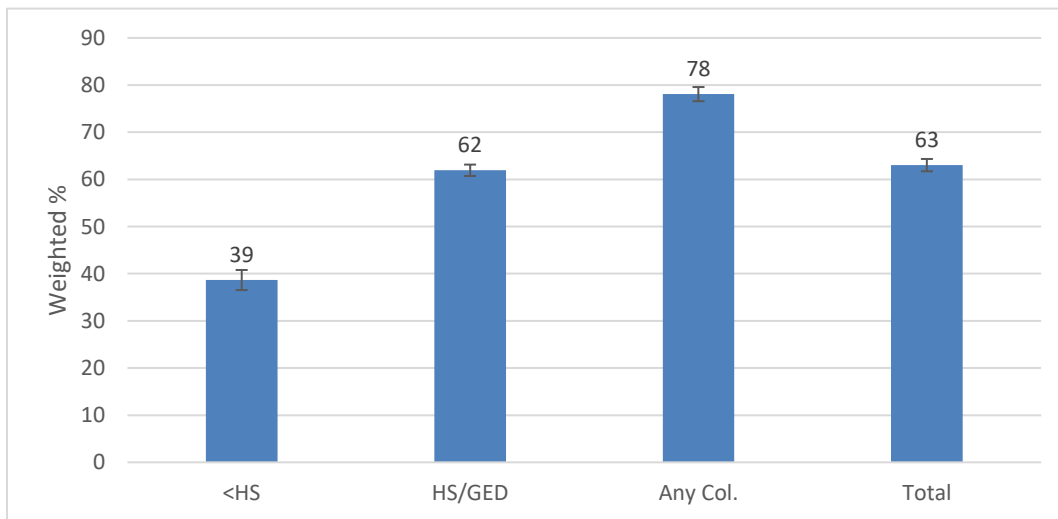
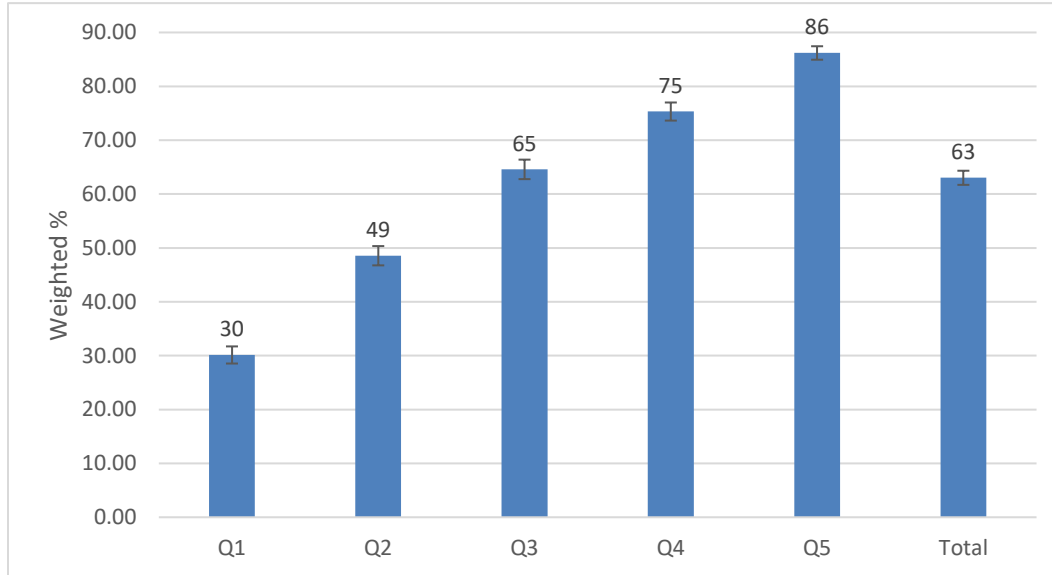


Figure 2.4c- Estate Planning by Wealth, weighted (Core)



Weighted, unadjusted bivariate associations for estate planning are presented in Table 2.6. Without controlling for other variables, all bivariate relationships except gender and recent hospitalization were statistically significant. Those completing estate planning, having a written will, were older than those who did not. Estate planners were more likely to be Non-Hispanic White and have some college education. Those with greater wealth and who were married were more likely to participate in estate planning. The weighted percentage of those completing a written will were approximately equal for those with and without a recent hospitalization.

Table 2.7- Bivariate and Multivariate Associations with Estate Planning, weighted (Core)

Characteristic	Unadjusted Bivariate	Adjusted Multivariate		
	Estate Planning (Yes)	Estate Planning (Yes)		
	Mean (SE)/n (%)	Chi-square p	OR, 95% CI	p
Age, n (%)		****		
65-74	2,379 (56.35)			
75-84	2,512 (70.30)		2.34 (2.05-2.67)	****
85+	961 (77.10)		4.00 (3.22-4.98)	****
Gender, n (%)		0.8961		
Male	2,426 (62.94)			
Female	3,426 (63.09)		1.22 (1.07-1.39)	0.004
Race/Ethnicity, n (%)		****		
Non-Hispanic White	5,208 (70.47)			
Non-Hispanic Black	408 (26.80)		0.29 (0.25-0.34)	****
Hispanic	236 (26.04)		0.33 (0.25-0.42)	****
Education, n (%)		****		
< High School	712 (38.66)		0.40 (0.30-0.51)	****
High School/GED	3,212 (61.93)		0.61 (0.50-0.74)	****
Any College +	1,928 (78.08)			
Wealth Quintiles, n (%)		****		
Q1	531 (30.13)		0.11 (0.09-0.14)	****
Q2	940 (48.55)		0.22 (0.17-0.28)	****
Q3	1,244 (64.58)		0.34 (0.26-0.44)	****
Q4	1,478 (75.32)		0.52 (0.40-0.67)	****
Q5	1,659 (86.19)			
Marriage Status, n (%)		****		
Married/Partnered	3,541 (66.29)			
Sep/Div/Single/Widowed	2,311 (58.23)		0.93 (0.80-1.09)	0.3777
Recent Hospitalization, n (%)		0.8157		
No	4,088 (62.94)			
Yes	1,764 (63.23)		1.13 (1.01-1.28)	0.0392
Model Statistics				
c statistic			0.806	
R-square (Nagelkerke)			0.3203	

*p < 0.05, **p < 0.01, ***p < 0.001, ****p < 0.0001

Results of weighted, multivariate binary logistic regression modeling of estate planning, having a written will, are also presented in Table 2.6. The observed associations are similar to those for legal ACP. Participation was highest among those in the oldest age category (OR = 4.03, 95% CI: 3.24-5.01) and was more likely among females (OR = 1.22, 95% CI: 1.07-1.39). Non-Hispanic Blacks (OR = 0.29, 95% CI: 0.25-0.34) and Hispanics (OR = 0.33, 95% CI: 0.25-0.42) were approximately one-third as likely to complete a will than Non-Hispanic Whites. Those with lower educational attainment were less likely to complete a will with those completing less than high school education being about one-third as likely as those with any college education (OR = 0.39, 95% CI: 0.30-0.51). The odds of completing a will increased with increasing wealth, but all wealth quintiles were significantly less likely than the highest group to complete estate planning. The greatest difference is observed for those in the lowest quintile (OR = 0.11, 95% CI: 0.09-0.15), but those in the fourth quintile were also less likely to complete a will (OR = 0.52, 95% CI: 0.40-0.67) compared to those in the fifth quintile. There was no difference in estate planning for marriage status. Those who had been hospitalized since their last HRS interview were more likely to have a will (OR = 1.13, 95% CI: 1.01-1.28).

DISCUSSION

In this study, advance care planning was defined as having a medical power of attorney or advance directive completed and overall prevalence was 61% in a representative sample of non-institutionalized US adults aged 65 and older in the HRS 2014 core interview data. Prevalence rates of legal ACP in the literature are mixed and dependent on the sample used and definitions of advance care planning. Many studies report associations for advance directives or medical power of attorney alone (Byhoff et al., 2016; Gerst & Burr, 2008; A. S. Kelley et al., 2011; Tschirhart et al., 2014). Other studies use a combination of advance care planning activities like discussing care preferences, having an advance directive, or having a medical power of attorney as the outcome (Bischoff et al., 2013; Catheryn & Tamara, 2017; Catheryn S. Koss & Baker, 2017c; Narang et al., 2015). Completion of advance directives is reported anywhere from 38% in a study of 1,102

White and Black HRS exit interview respondents in 2000 (Gerst & Burr, 2008) to 76% in 7,177 White and Black HRS exit interview respondents from 2000 to 2012 (Portanova et al., 2017). Prevalence rates for having a medical power of attorney are rarely reported, but range from 44% in adult decedents of all ages (Gerst & Burr, 2008) to 65% (Khosla et al., 2015). Prevalence rates for various multi-component ACP outcomes range from 59% (Catheryn & Tamara, 2017) to 81% (Narang et al., 2015). Studies defining ACP as having a medical power of attorney or advance directive reported completion rates of 70% (Catheryn S. Koss & Baker, 2017c) and 59% (Catheryn & Tamara, 2017). The overall completion rate (61%) in this study is close to those reported by one of the Koss and Baker papers. The higher rates of the second paper may be due to the study design, which was longitudinal and used data from 2001-2012 for 5,832 White and Black HRS participants aged 65 to 99 at death (Catheryn S. Koss & Baker, 2017c).

Completion rates by race/ethnicity, education, or wealth are reported less often than overall rates. In this study from the HRS core interview in 2014, prevalence ranged from 65% for Non-Hispanic Whites, to 43% for Non-Hispanic Blacks, to 33% for Hispanics. A study of 7,105 deceased respondents aged 65+ reported completion rates of advance directives alone among Hispanics (31%), which is similar to the rates of legal ACP in this study (33%) (Byhoff et al., 2016). For papers defining ACP the same as this chapter, rates are slightly different from the results here. In a cross-sectional study of 6,946 HRS respondents from 2012 63% of Whites and 36% of Blacks completed legal ACP (Catheryn & Tamara, 2017). These completion rates are similar to those in Table 2.5 for Non-Hispanic Whites (65%) and Non-Hispanic Blacks (43%). A second paper by Koss and Baker with a sample of HRS respondents from 2002-2012 reported higher completion rates for Whites (74%) and similar rate for Blacks (38%) (Catheryn S. Koss & Baker, 2017c).

There are no studies with the same ACP definition reporting completion rates by education or wealth. In this study of HRS core respondents from 2014, completion rates increased with increasing education (<high school 38.7%, High school/GED 62%, Any college+ 78%) and wealth (first quintile 30% vs fifth quintile 86%). In a study of treatment limiting advance directives among

3,302 HRS decedents from 1998-2007 about one-third of those with less than a high school education (31%) and at least a high school education (35%) had a treatment limiting advance directive (L. H. Nicholas et al., 2011). These rates are much lower than those presented in Table 2.5 (< High School: 45% and High School/GED: 61%) and may be due to the Nicholas sample being limited to Medicare fee for service beneficiaries. Another study of 1,985 HRS decedents from 2000-2012 with cancer reported higher completion rates than the results in this chapter for those with less than a high school degree (72%) and who were high school graduates (84%) (Narang et al., 2015). Differences here are likely due to sample selection and the inclusion of only those with a history of cancer.

Bivariate prevalence by wealth is reported in one study of 4,399 HRS decedents with ACP defined as having discussed End-of-Life care, advance directives, or a medical power of attorney (Bischoff et al., 2013). Net worth in quartiles demonstrated a positive association between wealth and ACP with those in the lowest quartile (66%) completing ACP less often than those in the second (71%), third (76%), and fourth quartiles (82%). Rates in this chapter are reported by quintile and demonstrate a similar positive trend (Table 2.5).

Prevalence rates of estate planning, having a written will, are lacking in the literature. Two papers referenced above provide overall prevalence rates for completion. The first describes the rate for White high school graduates from Wisconsin (Carr, 2012). Among 4,971 respondents to the Wisconsin Longitudinal Survey, 75% had completed a will. This is higher than the rates for whites found in this study (70.5%) and may be due to the lack of participants who did not graduate from high school. The second study reported rates for Whites (73%), Blacks (27%), and overall (69%) among 6,946 HRS respondents (Catheryn & Tamara, 2017). These rates are comparable to those in this study (NHW: 70.5%, NHB: 26.8%, overall: 63%). The overall rate is lower in this study likely due to the inclusion of Hispanics in analyses.

Estate planning prevalence rates by education and wealth are not described in the literature. However, adjusted associations demonstrate similar relationships to those of this study. In the study by Carr, education was categorized into 12, 13-15, 16, and 17 or more years (Carr, 2012). In

multivariate analyses, those with 16 (OR = 1.35, $p < 0.05$) and 17 or more years of education (OR = 1.41, $p < 0.05$) were more likely to have a will. Koss and Baker used a continuous indicator of years of education and also report a significant adjusted association with having a written will (OR = 1.21, 95% CI: 1.11-1.32) (Catheryn & Tamara, 2017). These adjusted associations are similar to the results in Table 2.6 with those completing less education being less likely to participate in estate planning.

Adjusted associations for wealth demonstrate similar trends. Participants in the Wisconsin Longitudinal Study were increasingly more likely to complete a will as their assets increased (no or negative assets: OR = 0.36, $p < 0.001$, 0-25th percentile: OR = 0.34, $p < 0.001$, 25th-50th percentile: OR = 0.59, $p < 0.001$, 50th-75th percentile: OR = 0.83, $p > 0.05$) (Carr, 2012). Koss and Baker report similar findings using household net assets as a continuous indicator of wealth (Catheryn & Tamara, 2017). In their study of White and Black HRS respondents, each unit increase in household net assets was associated with a 39% greater likelihood of participating in estate planning (OR = 1.39, 95% CI: 1.32-1.47). These adjusted associations are similar to the results in Table 2.6 with increasing wealth being associated with greater odds of completing a written will.

This study adds to the literature meaningfully by including Hispanics in the investigation of the role race/ethnicity plays in completion of end of life planning. The two main studies that propose a pathway and testable hypothesis for the completion of advance care planning exclude Hispanics from analysis. In the paper by Carr, the data was limited to White high school graduates. Koss and Baker chose to exclude Hispanics from their subsample due to concerns about sample size. The results of this chapter demonstrate the similarities in end of life planning completion rates among Non-Hispanic Blacks and Hispanics (Tables 2.5 and 2.6).

This chapter highlights similarities and key differences in the predictors for legal ACP and estate planning. As expected, age is strongly associated with both outcomes. Interestingly racial/ethnic disparities are greater for estate planning than legal ACP. This is likely due to the accessibility of legal ACP documents, which should be made available by health care providers, especially those reimbursed by the Centers for Medicaid and Medicare Services. Socioeconomic

status indicators (education and wealth) are also more strongly associated with estate planning, which is expected, because those with more assets are more likely to complete a written will. Although the relationship for recent hospitalization is statistically significant for both legal ACP (OR = 1.55, 95% CI: 1.34-1.80) and estate planning (OR = 1.13, 95% CI: 1.01-1.28) the relationship is stronger for ACP. This is consistent with what would be expected as a recent hospitalization may prompt advance health care planning and to a lesser extent end of life estate planning. Similar findings were reported by both Carr and Koss and Baker, with the associations for health planning being significant (OR = 1.82, $p < 0.001$ and OR = 1.23, 95% CI: 1.11-1.37, respectively) and those for estate planning being insignificantly associated with recent hospitalization (OR = 1.14, $p > 0.05$ and OR = 1.10, 95% CI: 0.96-1.27, respectively) (Carr, 2012; Catheryn & Tamara, 2017).

Findings in this chapter are consistent with the literature. Notably, there are significant differences in end of life preparation for the three major racial/ethnic groups in the United States. Non-Hispanic Blacks and Hispanics are much less likely to participate in legal ACP or estate planning. Including Hispanics in the analyses adds to the literature on this minority group that is culturally distinct from non-Hispanic Blacks and Whites. Describing these racial/ethnic disparities is the first step in understanding causal pathways that may contribute to differences in end of life planning.

Other sociodemographic factors were significantly associated with end of life planning and will need to be considered in the next chapters as potential confounders. Importantly, socioeconomic factors (education and wealth) were significantly associated with both legal ACP and estate planning. These predictors are associated with race/ethnicity and will be included in the next chapters as the relationship between race/ethnicity and end of life planning is described further.

Strengths of this analysis include the representative sample provided by the HRS that can provide population estimates when used with sampling weights. Another strength is the large sample size that allows for subgroup analyses of Hispanics. A weakness of aim 1 was the limited

sample size for discussing end of life care preferences due to the HRS skip sequence. However, the sample was large enough to investigate the intercorrelation of the three ACP components of interest and determine that discussing End-of-Life preferences measured a different construct than advance directives and medical power of attorney. Another weakness is that the HRS is a survey prone to recall bias, so some responses may not reflect the true experience of participants.

This chapter has highlighted the stark differences in End-of-Life planning between racial/ethnic minorities and those with low SES compared to Non-Hispanic Whites and higher SES groups, respectively. The prevalence rates of healthcare planning are less than ideal and demonstrate the need to expand engagement in this process that can facilitate improvements in the quality of the end of life experience.

Chapter 3: Aim 2- Mediating Effect of Socioeconomic Status and Estate

Planning on Legal Advance Care Planning

RATIONALE

Purpose

Aim 2: To test for possible mediating relationship between race/ethnicity, socioeconomic status, estate planning, and advance care planning. HRS Exit interviews for deceased respondents (2002-2016) were used to investigate the possible mediating effect of socioeconomic status (education and wealth) and estate planning (having a written and witnessed will) on the relationship between race/ethnicity and ACP (advance directives, discussing End-of-Life care, and having a medical power of attorney).

Significance

Advance care planning is the ongoing process of defining the decisions one would make if terminally ill. It includes informally discussing care preferences with friends, family members, and medical providers as well as formal, legal documentation of preferences for care and assigned decision makers in advance directives and a medical power of attorney, respectively (Carr & Luth, 2016). Aim 1 examined the co-occurrence of these planning activities in the HRS core sample using respondents' own responses to estimate these activities in the entire population. The intercorrelation between ACP activities indicated that advance care planning could be defined as any reported legal documentation of end of life health care preferences including having written advance directives or assigned a medical power of attorney.

Participation in advance care planning has been encouraged in the United States medical system and is highlighted by policies promoting engagement in planning activities (Sabatino, 2010). For example, the Patient Self Determination Act of 1990 required health care providers and institutions receiving reimbursement from the Centers for Medicare and Medicaid Services to

inform patients of their right to participate in Advance Care Planning and have their preferences documented in the health record (Carr & Luth, 2016; Carr & Luth, 2017). Additionally, in 2016 The Centers for Medicare and Medicaid Services approved reimbursement for advance care planning discussions (Tuller, 2016).

Advance care planning is promoted, because engagement in planning activities may be associated with improved quality of health care outcomes for patients and their family members. For example, participation in advance care planning is associated with decreased in-hospital death, increased hospice use and duration of use, and decreased life sustaining treatments including cardiopulmonary resuscitation (CPR), intubation, intravenous antibiotics, and feeding tubes (Brinkman-Stoppelenburg et al., 2014; Detering et al., 2010; Wright et al., 2008). When patients document preferences for end of life care and assign decision makers through ACP activities, they are more likely to have their preferences for care known and honored (Brinkman-Stoppelenburg et al., 2014; Carr & Luth, 2016; Detering et al., 2010; Ratner et al., 2001; Teno et al., 2004; Wright et al., 2008).

Despite indications of improvement in quality of care at the end of life for those with advance care planning compared to those without highlighted in chapters 1 and 2, few studies tested hypotheses concerning factors contributing to planning completion. This is important for understanding the racial/ethnic differences in advance care planning completion demonstrated in aim 1.

One hypothesis proposes that estate planning mediates socioeconomic disparities in advance care planning and was tested in two large samples focusing on Non-Hispanic Whites and Blacks (Carr, 2012; Catheryn & Tamara, 2017).

The first study investigating this relationship used core interview data for living respondents from the Health and Retirement Study for 6,946 community dwelling Whites and Blacks 65 years of age and older from 2012 and reported that the effect of race/ethnicity on completion of advance directives (OR = 1.96, 95% CI: 1.70-2.25) was completely mitigated when estate planning was included as a mediator in the multivariate model (OR = 0.96, 95% CI: 0.82-

1.12) (Catheryn & Tamara, 2017). The authors proposed that these results suggest advance care planning is mediated by estate planning because completion of advance directives and medical power of attorney documents, both legal forms, is promoted by lawyers during estate planning. The second study used data from the Wisconsin Longitudinal Study for 4,971 Non-Hispanic Whites who graduated from Wisconsin high schools in the mid-1900s. The study reported a reduced main effect of wealth on advance directives (29% reduction) and medical power of attorney (29% reduction) for the lowest wealth categories after estate planning was added to multivariate models (Carr, 2012). The odds of completing an advance directive for those with no or negative assets and those in the 0 to 25th percentile were shifted toward the null (from 0.43* to 0.55* and from 0.41* to 0.53*, respectively) after accounting for estate planning. Similar mediating effects were observed for the same wealth categories' odds of assigning a medical power of attorney (from 0.58* to 0.75, and from 0.47* to 0.59*, respectively).

Results in the previous studies were consistent using both a nationally representative and large survey-based sample. However, neither study included Hispanics in their sample. The HRS study was limited to community dwelling Non-Hispanic Whites and Blacks age 65 and older and the Wisconsin Longitudinal Study focused on Non-Hispanic White high school graduates. Racial/ethnic disparities in advance care planning need to be investigated with testable hypotheses and Hispanics need to be included. It is important to understand the potential mediating role of estate planning in the relationship between race/ethnicity and advance care planning especially among Hispanics, a racial/ethnic minority that is culturally distinct from Non-Hispanic Whites and Blacks.

Associations with Sociodemographic Factors

Although Chapters 1 and 2 described the association of various sociodemographic factors with advance care planning, a review of studies linking age, race/ethnicity, marital status, children, education, wealth, and health status with advance care planning is presented below.

Older *age* is associated with advance care planning completion. With each additional year in age, HRS respondents are marginally more likely to complete planning activities (OR = 1.03, 95% CI: 1.02-1.04 (Catheryn S. Koss & Baker, 2017c)). The association with age is demonstrated consistently in the literature (Bischoff et al., 2013; Gerst & Burr, 2008; Khosla et al., 2015). In aim 1, age was significantly associated with legal advance care planning (OR = 2.26, 95% CI: 2.03-2.51 and OR = 4.10, 95% CI: 3.42-4.91) and estate planning (OR = 2.34, 95% CI: 2.05-2.67 and OR = 4.03, 95% CI: 3.24-5.01) among those aged 75-84 and 85+ compared to those aged 65-74. The association between *gender* and advance care planning has been mixed. Some studies report that females are much more likely to complete planning activities like having advance care discussions (OR = 1.71, 95% CI: 1.49-1.96 (Catheryn & Tamara, 2017)) (Bischoff et al., 2013; Gerst & Burr, 2008) while others report no association (OR = 1.00, 95% CI: 0.88-1.14) (Catheryn S. Koss & Baker, 2017c). Results in aim 1 demonstrated that females were more likely to participate in legal advance care planning (OR = 1.30, 95% CI: 1.17-1.44) and estate planning (OR = 1.23, 95% CI: 1.08-1.40). Differences are likely due to sample selection with the first Koss and Baker study including Non-Hispanic White and Black decedents and the second including living respondents. Additionally, the outcome in the two studies is different with the first investigating associations with advance care discussions and the second associations with advance directives.

Racial/ethnic minorities, specifically Non-Hispanic Blacks and Hispanics complete advance care planning activities less often than Non-Hispanic Whites (Catheryn & Tamara, 2017; Gerst & Burr, 2008; Catheryn S. Koss & Baker, 2017b, 2017c). This association is significant and maintained in multivariate models controlling for other sociodemographic factors including age, gender, education, marital status, and religious attendance. For example, one study using responses from 6,946 core respondents in the Health and Retirement study from a single interview in 2012 reported Non-Hispanic Whites were significantly more likely to have end of life care discussions than Blacks (OR = 1.75, 95% CI: 1.50-2.03) (Catheryn & Tamara, 2017). Another study included multiple waves of data from the Health and Retirement Study allowing for the inclusion of Hispanics in analyses. The study included 7,177 exit interview respondents from 2000-2012 and

reported Non-Hispanic Blacks (OR = 0.23, 95% CI: 0.19-0.29) and Hispanics (OR = 0.30, 95% CI: 0.22-0.40) were less likely than Non-Hispanic Whites to complete advance directives (Portanova et al., 2017). In aim 1, living Non-Hispanic Black and Hispanic respondents were less likely than Non-Hispanic Whites to complete legal advance care planning (OR = 0.60, 95% CI: 0.52-0.70 & OR = 0.46, 95% CI: 0.35-0.60, respectively, N = 9,557) and estate planning (OR = 0.29, 95% CI: 0.25-0.34 & OR = 0.33, 95% CI: 0.25-0.42, respectively).

The association with having a marital partner has been unclear. The operationalization of *marital status* is not consistently reported across studies investigating advance care planning making it difficult to interpret any associations. For example, in a study of 4,394 HRS decedents from 1993-2007 dichotomized marriage status into married or partnered and other and did not report multivariate associations with ACP (Bischoff et al., 2013). Another study also dichotomized marriage status (married or not married) and found a significant adjusted association (OR = 0.71) with married respondents being more likely to complete ACP, but the outcome was an ordinal indicator of ACP component completion (Gerst & Burr, 2008). However, in aim 1 those who were separated or divorced were 25% more likely to complete legal advance care planning (OR = 1.25, 95% CI: 1.06-1.47) but 13% less likely to participate in estate planning (OR = 0.87, 95% CI: 0.74-1.02) compared to those who were married or partnered, although the latter association was not significant.

Having more *living children* is associated with advance care planning and estate planning. In a study of 4,971 participants in the Wisconsin Longitudinal Study number of living children, having 3 or more children was associated with a greater likelihood of having an advance directive (OR = 1.61) and completing a living will (OR = 1.35) compared to those with 2 children (Carr, 2012). The same study reported a nonsignificant association with having a medical power of attorney. Other investigators used data for 9,228 HRS decedents from 2002-2014 and reported significantly lower associations for advance directives (OR = 0.82) and medical power of attorney (OR = 0.83) with increasing number of resident children (Orlovic, Smith, & Mossialos, 2019). Results in these two studies are dramatically different with one showing a positive trend for

planning with number of living children and the other showing a negative trend for number of resident children and warrant further investigation. The samples are different with one including only White high school graduates and the other including Non-Hispanic Whites, Non-Hispanic Blacks, Hispanics, and Non-Hispanic others of all educational backgrounds. However, the modeling and definitions may also contribute to the observed differences. In the Carr paper, number of living children is categorized and includes all reported living children. In the Orlovic paper, resident children is continuous and represents those children living in the same home as the respondent.

The association between *education* and advance care planning is also not clear. Differences in sample characteristics of studies reporting a relationship between higher educational level and advance care planning (Gerst & Burr, 2008) and those reporting no association (Carr, 2012; Khosla et al., 2015) may account for the mixed results. One study was limited to one exit interview (2000) and included only Whites and Blacks (Gerst & Burr, 2008). Another used a sample of Non-Hispanic White high school graduates from Wisconsin limiting variability and representativeness of the sample (Carr, 2012). In aim 1, those with less than a high school education were half as likely to complete legal advance care planning (OR = 0.50, 95% CI: 0.52-0.59) and about 2/3 less likely to participate in estate planning (OR = 0.37, 95% CI: 0.28-0.48) compared to those with any college education.

Inconsistencies for *income* and *wealth* are observed with some studies suggesting greater household income is associated with greater likelihood of various advance care planning activities (Catheryn & Tamara, 2017; Khosla et al., 2015), but less of an association for wealth (Catheryn & Tamara, 2017; Gerst & Burr, 2008). In an older population, wealth is a better indicator of socioeconomic status, because the variability in household income will be limited due to retirement. In aim 1, wealth in quintiles was significantly associated with both legal advance care planning and estate planning. Those in the lowest quintile were one-third as likely to complete legal advance care planning (OR = 0.28, 95% CI: 0.22-0.35) and 90% less likely to participate in estate planning (OR = 0.11, 95% CI: 0.09-0.15) compared to those in the highest quintile.

Associations between *health status indicators* like memory problems (Khosla et al., 2015), cancer (Khosla et al., 2015; Portanova et al., 2017), recent hospitalization (Carr, 2012), expected death (Gerst & Burr, 2008), and ICU admission (Eunjeong & Jaehoon, 2013) and advance care planning have been reported in the literature. In aim 1, a recent hospitalization was associated with higher likelihood of legal advance care planning (OR = 1.53, 95% CI: 1.32-1.77) and estate planning, but the association was not significant for estate planning (OR = 1.11, 95% CI: 0.99-1.25).

The objective of the analyses in this chapter is to investigate the possible mediating roles of socioeconomic status and estate planning on the relationship between race/ethnicity and completion of legal advance care planning among adults aged 65 and older. HRS exit interviews for deceased respondents were used, because they provide information about the end of life experience for respondents. Estate value, recent hospitalization, and death expected are factors of interest available in exit interviews with proxies that are important to consider when investigating end of life planning. First, mediation assumptions were assessed by testing for the main effect of race/ethnicity on legal ACP, the association between race/ethnicity, SES, and estate planning, and the association between SES, estate planning, and legal ACP. Next, multivariate binary logistic regression modeling was used to investigate the mediating effect of estate planning while controlling for sociodemographic and health variables including age, gender, marriage status, living children, estate value, self-reported memory, recent hospitalization, and death expected.

METHODS

Conceptual Model: Aim 2 investigates the mediation model presented in Figure 3.1. In this model, the effect of race/ethnicity on completion of legal advance care planning is hypothesized to be mediated by SES and estate planning. The objective of this aim is to investigate the relationships proposed in the conceptual model. Confounders are excluded from the figure but described in the text. This aim replicates work by previous authors that have described this

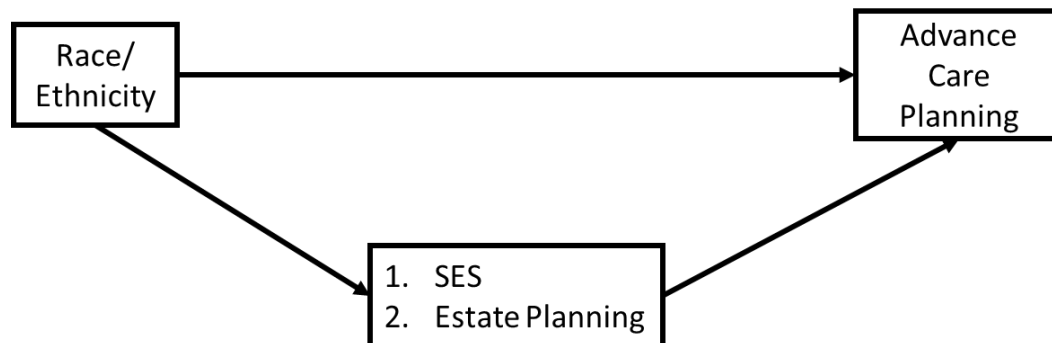
association for Non-Hispanic Blacks and Whites and builds on that work by investigating the associations in Hispanics and the role of SES.

It is hypothesized that Non-Hispanic Blacks and Hispanics will be less likely to participate in legal ACP, but that the main effect of this relationship will be reduced when SES and estate planning are accounted for. This is a replication of previous work by Koss and Baker (2017) with the addition of Hispanics to the analyses and SES to the hypothesis. Koss and Baker have described the relationship between estate planning and ACP for non-Hispanic Whites and Blacks using data from the HRS in 2012 for 6,946 living respondents. They reported that the disparity in advance directive completion rates for non-Hispanic Whites and Blacks was completely mediated by estate planning (OR = 0.96, 95% CI: 0.81-1.12) (Catheryn & Tamara, 2017). A similar relationship was demonstrated using data from the Wisconsin Longitudinal Study for 4,971 living White respondents with the odds of having an advance directive much higher for those who had participated in estate planning (OR = 7.78, $p < 0.001$) (Carr, 2012). Neither study considered SES as an additional mediator of the main effect. However, both reported significant associations between SES indicators, estate planning, and ACP. Koss and Baker demonstrated significant relationships between education in years (OR = 1.21, 95% CI: 1.11-1.32) as well as household net assets (OR = 1.39, 95% CI: 1.32-1.47) and estate planning (Catheryn & Tamara, 2017). Education (OR = 1.15, 95% CI: 1.08-1.22) and assets (OR = 1.15, 95% CI: 1.10-1.21) were also significantly associated with completion of advance directives. Carr also reported a significant association for education and assets with having a written will (Carr, 2012). However, in this study education was not associated with having advance directives or a medical power of attorney. This is likely due to a difference in sample with the Carr paper including only White high school graduates.

The two studies mentioned above utilized data from living respondents only. The current study aims to investigate the end of life experience and the role of both socioeconomic status and estate planning in completion of legal ACP. Unique questions in exit interviews provide information about the end of life experience, like whether the respondent had much of an estate, was hospitalized before death, or if their death was expected when it occurred. These factors may

influence completion of estate and health care planning at the end of life. The results presented in this aim are similar to those in the two previous studies and observed differences may be attributed to the different samples.

Figure 3.1- Conceptual Model for Specific Aim 2



Dataset: The Health and Retirement Study is a survey with complex sampling design that interviews adults aged 50 and older bi-annually. The HRS core and exit interview from 2000 through 2016 will be used to investigate the mediating relationship described above based on all deaths among respondents in that time period. The HRS core interview data is from living respondents and includes general sociodemographic factors like gender, race/ethnicity, marital status, and wealth. Exit interviews are performed with an immediate family member, close relative, or friend familiar with the respondent's last year of life after an HRS core interview respondent has died. Exit interviews occur once per deceased respondent. Utilizing exit interview data facilitates a cross-sectional investigation of respondents' end of life experience.

Multiple waves of data can be combined to increase the sample size permitting subgroup analyses for Hispanics. The sample for aim 2 combines raw HRS exit interview data for deceased respondents from 2002-2016 with earlier reported information in core interviews. The raw exit file is merged with matched, imputed RAND and raw HRS core data files from 2000-2014. These files contain general sociodemographic variables, legal ACP components, estate planning, and recent hospitalization. RAND files are used, because they are cleaned files with imputed values for some variables. The files are generated from raw HRS data and may utilize responses from previous

waves to complete a record. For example, if gender is not recorded in a particular wave, responses on a previous wave may be used to replace the missing value. RAND also computes a total wealth variable that is the difference of all assets and debts collected in HRS core interviews.

Due to the questionnaire skip sequence, which limits questions related to ACP, an inclusion criterion for this sample includes age ≥ 65 at the last core interview with the living respondent. Another inclusion criterion is death, indicated by the presence of an exit interview record. An exclusion criterion is nursing home residency, because the ACP experience for these individuals is different from that of community dwelling older adults. Listwise deletion is utilized in multivariate modeling excluding respondents with missing values from analyses.

Measures

PREDICTORS: Race/ethnicity (Non-Hispanic White, Non-Hispanic Black, and Hispanic) is the main predictor for aim 2 and is operationalized as defined in aim 1.

Table 3.1- Aim 2 Race/Ethnicity, Predictor

<i>Predictor</i>	<i>HRS Question</i>	<i>Coding</i>
Race/Ethnicity	Do you consider yourself to be Hispanic or Latino? [respondent] What race do you consider yourself to be: White, Black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, or something else? [respondent]	1 = Non-Hispanic White, 2 = Non-Hispanic Black, 3 = Hispanic

OUTCOMES: The outcome for aim 2 is legal ACP (yes, no). Defined in aim 1, this variable is a dichotomous indicator of either (1) completing an advance directive or medical power of attorney documentation or (2) completing neither documentation.

Table 3.2- Aim 2 Legal Advance Care Planning, Outcome

<i>Outcome</i>	<i>HRS Question</i>	<i>Coding</i>
Legal ACP (advance directive or medical power of attorney)	Have you provided written instructions about the care or medical treatment that you would want to receive if you can not make those decisions yourself? This is sometimes called a "Living Will". [respondent] Have you made any legal arrangements for a specific person or persons to make decisions about your care or medical treatment if you can not make those decisions yourself? This is sometimes called a "Durable Power of Attorney for Health Care". [respondent]	1 = yes to either, 0 = no to both

MEDIATORS: The mediators for aim 2 are socioeconomic status and estate planning. SES is a composite score of education and wealth. Each variable was standardized and then summed together. After an SES sum was calculated respondents were categorized into SES quintiles. Estate planning is defined as having a written and witnessed will (yes, no).

Table 3.3- Aim 2 Socioeconomic Status (SES) & Estate Planning, Mediators

<i>Mediator</i>	<i>HRS Question</i>	<i>Coding</i>
Socioeconomic Status (standardized, summed, and categorized into quintiles)	Education- What is the highest grade of school or year of college you completed? (no degree, high school/GED, Associate's degree/less than Bachelor's, Bachelor's, Master's/MBA/Law/MD/PhD) [respondent] Wealth- Total non-housing wealth (RAND imputed) = sum of wealth components less debt [respondent]	quintiles
Completing a written will (estate planning)	Do you currently have a will that is written and witnessed? [respondent]	1 = yes, 0 = no

COVARIATES: Covariates for aim 2 include age, gender, marriage status, living children, estate value, cognition status, recent hospitalization, and death expected. Age (continuous), gender (male, female), marriage status (married/partnered, separated/divorced/single/married, spouse absent) and recent hospitalization (yes, no) are operationalized as described in aim 1.

Number of living children is obtained from the RAND core interview data file. RAND has used multiple questions to create a composite indicator of number of living children. This variable is categorized (0, 1, 2, 3 or more). Whether or not death was expected was acquired from exit interviews and is dichotomized (yes, no).

Estate value is available in exit interview data. The proxy is asked if the deceased respondent's assets have been distributed. The variable is an indicator of an estate with little or no value and dichotomized as none (estate has nothing of much value) or some (all other responses). This variable is included as a covariate, because those with nothing of much value are less likely to prepare a written will. The estate value variable is weakly correlated with wealth ($r = 0.18$) and SES ($r = 0.16$) quintiles.

Cognition score is calculated and provided by RAND and is coded consistently for all HRS waves used in this aim. Respondents are asked to complete various recall and memory tasks. Scores range from 0-35 and are grouped into quintiles for analyses.

Table 3.4- Aim 2 Sociodemographic Variables, Covariates

<i>Covariate</i>	<i>HRS Question</i>	<i>Coding</i>
Age	Calculated from the respondent's birthdate [respondent]	1 = 65-74, 2 = 75-84, 3 = 85+ years old
Gender	Is [R's first name] male or female? (coverscreen)	1 = male, 2 = female
Marriage Status	Just to clarify, are you currently separated, divorced, widowed, or have you never been married? [respondent]	1 = married; partnered, 0 = married, spouse absent; divorced; separated/divorced; widowed; never married
Living Children	How many living children or step-children do you have? [respondent]	0, 1, 2, 3+
Estate Value	The next questions are about [respondent's first name]'s assets and possessions, excluding any life insurance. Have they been divided up among the heirs, have they not yet been distributed, was there nothing of much value to distribute, what? [proxy]	1 = nothing of much value, 0 = divided or retained/not yet divided
Total Cognition Score	Scale calculated by RAND, includes items like word recall, serial counting, and word associations (range = 0-35) [respondent]	Quintiles (low score = bad, high score = good)
Recent Hospitalization	Since your last interview, have you been a patient in a hospital overnight? [respondent & proxy]	1 = yes, 0 = no
Death Expected	Was the death expected about the time it occurred, or was it unexpected? [proxy]	0 = not expected, 1 = expected

For all variables, “don’t know”, “refused”, and blank responses are recoded as missing.

Analysis: First, because data for this sample represents 16 years, the key variables were assessed for secular trends. Rates of legal ACP and estate planning were compared for the years 2002-2006, 2008-2012, and 2014-2016.

Next, descriptive statistics were performed. Frequencies and chi-square statistics are reported for categorical variables. Assumptions of mediation modelling were then checked. Associations adjusted for age, gender, and socioeconomic status were assessed between 1) the predictor and outcome, 2) the predictor and mediator, and 3) the mediator and outcome. Both race/ethnicity, and living children were reviewed to inform the recoding for mediation analyses. Intercorrelation of covariates was assessed with a correlation matrix.

Multivariate, binary logistic regression modeling proceeded after mediation assumptions were checked. To investigate the hypothesized mediating relationship logistic regression and the SAS causal mediation procedure were used. Logistic regression included four models. Model 1 included the main predictor (race/ethnicity) adjusted for age, gender, marriage status, living children, and estate value. Model 2 added recent hospitalization, death expected, and cognition score to model 1. Model 3 added socioeconomic status (education and wealth) to model 2. Model 4 added estate planning to model 3. Model fit was assessed with Hosmer-Lemeshow p-values and c-statistics.

The SAS causal mediation procedure was then used to determine the size of the mediating effects. Stepwise mediation was investigated by considering SES first followed by estate planning adjusted for SES. A limitation of this procedure is that the variables included must be continuous or dichotomous. Therefore, sensitivity analyses were performed to determine 1) if Non-Hispanic Blacks and Hispanics be combined into a ‘minority’ group for dichotomized race/ethnicity (Non-Hispanic White, Minority) and 2) if SES quintiles can be treated as continuous variable. First, the fully adjusted model 4 above was used with Non-Hispanic Blacks as the reference to determine if there were differences in legal ACP compared to Hispanics. Next, the full sequence of models was run for 1) minorities compared to Non-Hispanic Whites, 2) Non-Hispanic Blacks compared to Non-Hispanic Whites, and 3) Hispanics compared to Non-Hispanic Whites all with SES in

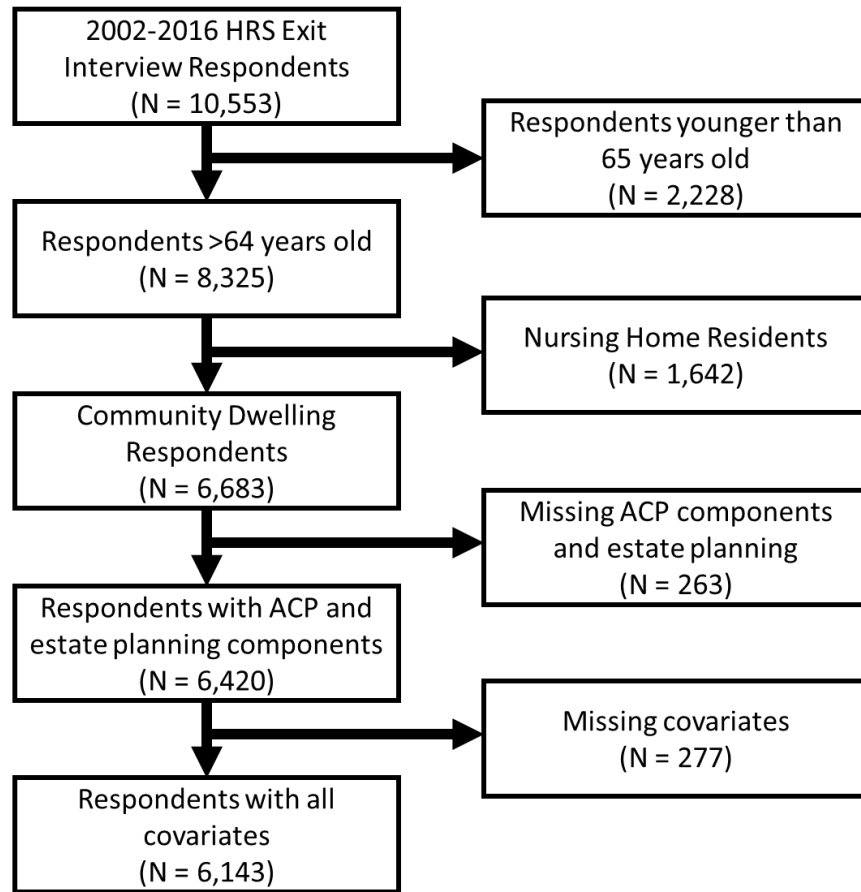
quintiles. Last, the full sequence of models was run for minorities compared to Non-Hispanic Whites with SES quintiles treated as a continuous variable. The mediation procedure was run for 1) Non-Hispanic Whites compared to minorities, 2) Non-Hispanic Whites compared to Non-Hispanic Blacks, and 3) Non-Hispanic Whites compared to Hispanics.

All analyses were unweighted. HRS uses a complex sampling design for core interviews and provides weights for generalizing to the U.S. population. However, unique weights for exit interviews are not provided. Therefore, analyses using exit interview data in this dissertation are unweighted.

RESULTS

Data from the 2002-2016 Health and Retirement Study exit interview with proxies of deceased respondents for 10,553 participants was used to generate the analytic sample for aim 2 (Figure 3.2). There were 2,228 respondents less than age 65 who were excluded from the sample. Those living in a nursing home ($n = 1,642$) and with missing data for all the advance care planning component variables and estate planning ($n = 263$) were also excluded. Listwise deletion was used to exclude an additional 277 respondents with missing values for covariates. The final sample size was 6,143.

Figure 3.2- Aim 2 Sample Flow Chart



Sample Characteristics

Table 3.5 provides sample characteristics for the 2002-2016 HRS Exit interview sample used in Aim 1. The total unweighted sample size is 6,143 decedents aged 65 and older. Majority of respondents were 75-84 years old (40.03%). There were approximately the same number of males (49.47%) and females (50.53%). Non-Hispanic Whites make up the majority of the sample (78.20%) and more respondents were separated/divorced/single (51.36%) rather than married/partnered (48.64%). Most respondents had at least one living child (92.28%) and unknown estate value (40.96%). Among those with known estate value, about the same amount had something of value (31.79%) or nothing of much value (27.75%). Fewer respondents had fair/poor

self-reported memory (31.79%), most respondents had been hospitalized since their last HRS interview (81.07%), and in most cases the respondent's death was expected (57.72%).

As expected, end of life planning variables including estate planning (written will) and legal ACP (advance directives or medical power of attorney) were more common in this exit interview sample compared to the core interview sample. In this subsample of deceased respondents over 8 interview waves 65% had completed a written will and 66% had completed legal ACP. In the sample of living respondents from the 2014 core interview used in the previous chapter 61% (unweighted) of respondents had completed a written will and 61% (unweighted) had participated in legal ACP. Figure 3.3 shows the concordance of living respondent (HRS Core 2014) and proxy responses (HRS Exit 2016) to legal ACP. HRS core respondent's healthcare planning status matched proxy reports 76% of the time. About 24% of proxies reported information that did not match living respondents. Those reporting new legal ACP where there previously was none (11.8%, positive discordance) and no legal APC where the living respondent reported positively (12.2%, negative discordance) were approximately equal. The latter group likely represents misinformed proxies who were unaware of legal ACP documents.

Figure 3.3- Living Respondent (HRS 2014) and Proxy Legal ACP Concordance (Core & Exit)

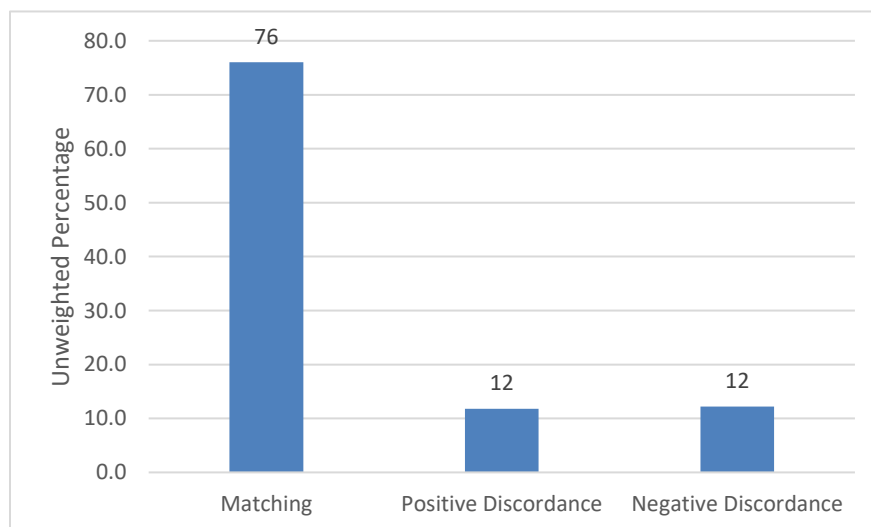


Table 3.5- HRS Exit Unweighted Sample Characteristics (Exit)

Characteristic	%	n
Age, n (%)		
65-74	27.20	1,671
75-84	40.03	2,459
85+	32.77	2,013
Gender, n (%)		
Male	49.47	3,039
Female	50.53	3,104
Race/Ethnicity, n (%)		
Non-Hispanic White	78.20	4,804
Non-Hispanic Black	14.15	869
Hispanic	7.65	470
SES Quintiles, n (%)		
Q1	19.40	1,192
Q2	20.06	1,232
Q3	19.52	1,199
Q4	20.56	1,263
Q5	20.46	1,257
Marriage Status, n (%)		
Sep/Div/Single/Widowed	52.40	3,219
Married/Partnered	47.60	2,924
Living Children, n (%)		
0	7.72	474
1	12.08	742
2	23.33	1,433
3+	56.88	3,494
Estate Value, n (%)		
Any	31.79	1,953
None	27.75	1,674
Unknown*	40.96	2,516
Cognition Score, n (%)		
Q1 worst	15.92	978
Q2	17.13	1,052
Q3	16.49	1,013
Q4	16.33	1,003
Q5 best	15.01	922
Unknown*	19.13	1,175
Recent Hospitalization, n (%)		
No	18.93	1,163
Yes	81.07	4,980
Death Expected, n (%)		
No	42.28	2,597
Yes	57.72	3,546

Written Will, n (%)		
No	34.64	2,128
Yes	65.36	4,015
Legal ACP, n (%)		
No	34.01	2,089
Yes	65.99	4,054

Abbreviations: SES- Socioeconomic Status, ACP- Advance Care Planning

Bivariate Associations

Unweighted and unadjusted bivariate associations for legal ACP are presented in Table 3.6. Weights are not used, because unique sampling weights are not provided for exit interviews. Without adjusting for other variables, all bivariate relationships are statistically significant. Given the different sample compared to the previous analysis for aim 1, some relationships are different from previously presented results. In this sample of deceased respondents, a larger percent of Non-Hispanic White participants completed legal ACP (73%). Those in the oldest age category (85+ years) were more likely to have completed advance directives or medical power of attorney. Women and those who were separated/divorced were more likely to participate in legal ACP. Among those with known estate value, respondents with greater value were more likely to complete legal ACP. Recent hospitalization and death expected were both significantly associated with health care planning. Those with legal ACP were more likely to have better cognitive function. Higher SES quintiles were more likely to complete legal ACP. Having completed a written will was significantly associated with legal ACP.

Table 3.6- Bivariate Associations with Legal ACP, unweighted (Exit)

Characteristic	Legal ACP = Yes	
	Mean (SD)/n (%)	Chi-square p
Race/Ethnicity		<0.0001
NHW	3,512 (73.11)	
NHB	367 (42.23)	
Hispanic	175 (37.23)	
Age, n (%)		<0.0001
65-74	909 (54.40)	
75-84	1,621 (65.92)	
85+	1,524 (75.71)	
Gender, n (%)		<0.0001
Male	1,931 (63.54)	
Female	2,123 (68.40)	
Marriage Status, n (%)		<0.0001
Sep/Div/Single/Widowed	2,284 (70.95)	
Married/Partnered	1,770 (60.53)	
Living Children		0.0453
None	317 (66.88)	
1	489 (65.90)	
2	987 (68.88)	
3+	2,261 (64.71)	
Estate Value		<0.0001
Some	1,221 (62.52)	
None	816 (48.75)	
Unknown	2,017 (80.17)	
Recent Hospitalization, n (%)		<0.0001
No	636 (54.69)	
Yes	3,418 (68.63)	
Death Expected, n (%)		<0.0001
No	1,522 (58.61)	
Yes	2,532 (71.40)	
Cognition Score, n (%)		0.0002
Q1 worst	604 (61.76)	
Q2	687 (65.30)	
Q3	686 (67.72)	
Q4	687 (68.49)	
Q5 best	648 (70.28)	
Unknown	742 (63.15)	
SES Quintiles, n (%)		<0.0001
Q1	567 (47.57)	
Q2	755 (61.28)	
Q3	795 (66.31)	
Q4	964 (76.33)	

Q5	973 (77.41)	
Estate Planning		<0.0001
No	982 (46.15)	
Yes	3,072 (76.51)	

Abbreviations: ACP- Advance Care Planning, Legal ACP- Advance Directives or Medical Power of Attorney
 *p<0.05, **p < 0.01, ***p < 0.001, ****p < 0.0001

Secular Trends

Data for this study was obtained from 18 years of HRS interviews. Secular trends for completion of estate planning and legal ACP were reviewed prior to multivariate analyses to determine if an indicator for interview wave should be included as a covariate to control for variation over time. The timeframe was divided into 3 periods (2002-2006, 2008-2012, and 2014-2016). Table 3.7a presents unadjusted trends and Table 3.7b presents trends adjusted for age, gender, race/ethnicity, and socioeconomic status. Unadjusted trends demonstrated an insignificant association ($p = 0.0539$) for estate planning with rates slightly higher in 2002-2006 (67%) compared to 2014-2016 (64%). The unadjusted trend for legal ACP was significant ($p < 0.0001$) with rates increasing from 2002-2006 (60%) to 2014-2016 (72%). After adjusting for sociodemographic factors (age, gender, race/ethnicity, SES) there were significant differences over time for both estate planning and legal ACP. The odds of having a written will were decreased in both 2008-2012 (OR = 0.79, 95% CI: 0.69-0.91) and 2014-2016 (OR = 0.69, 95% CI: 0.59-0.81) compared to 2002-2006. Legal ACP increased over time with those in 2008-2012 (OR = 1.52, 95% CI: 1.34-1.73) and 2014-2016 (OR = 1.66, 95% CI: 1.43-1.93) being more likely to complete an advance directive or have assigned a medical power of attorney. Based on these analyses showing some changes over time, an indicator for HRS wave was included in all multivariate modeling.

Table 3.7a- Unadjusted Secular Trends in End-of-Life Planning (Exit)

	2002-2006	2008-2012	2014-2016	
	n (%)	n (%)	n (%)	p
Written Will	1,571 (67.22)	1,482 (64.07)	962 (64.43)	0.0539
NHW	1,427 (77.09)	1,324 (73.72)	853 (73.73)	
NHB	93 (29.43)	102 (30.09)	69 (32.24)	
Hispanic	51 (30.00)	56 (31.46)	40 (32.79)	
Legal ACP	1,395 (59.69)	1,589 (68.70)	1,070 (71.67)	<0.0001
NHW	1,261 (68.13)	1,356 (75.50)	895 (77.36)	
NHB	94 (29.75)	157 (46.31)	116 (54.21)	
Hispanic	40 (23.53)	76 (42.70)	59 (48.36)	

Abbreviations: End-of-Life- End of Life, NHW- Non-Hispanic White, NHB- Non-Hispanic Black
 * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$, **** $p < 0.0001$

Table 3.7b- Adjusted Secular Trends in End-of-Life Planning (Exit)

	2008-2012		2014-2016	
	aOR	95% CI	aOR	95% CI
Written Will	0.79	0.69-0.91	0.69	0.59-0.81
Race/Ethnicity (ref = NHW)				
NHB	0.25	0.19-0.33	0.25	0.18-0.36
Hispanic	0.31	0.22-0.45	0.32	0.21-0.51
Legal ACP	1.52	1.34-1.73	1.66	1.43-1.93
Race/Ethnicity (ref = NHW)				
NHB	0.36	0.28-0.47	0.44	0.31-0.61
Hispanic	0.34	0.24-0.47	0.37	0.24-0.57

Abbreviations: End-of-Life- End of Life

Adjusted for: Age, Gender, Race/Ethnicity, SES

Reference Period is 2002-2006

Mediation Assumptions

Prior to multivariate modeling, mediation assumptions were also checked. For a candidate variable to be considered a mediator, 3 assumptions must be upheld. First, there must be a main effect between the proposed independent variable and the outcome variable. Second, there must be an association between the independent variable and proposed mediating variable. Last, there must be an association between the proposed mediating variable and the outcome variable. Two potential mediators were considered in this study, socioeconomic status and estate planning. The independent variable is race/ethnicity and the outcome variable legal ACP.

Table 3.8a- Adjusted Mediation Assumptions (SES, Exit)

	aOR	95% CI
Race/Ethnicity (Ref: NHW) → ACP		
Non-Hispanic Black	0.35	0.30-0.41
Hispanic	0.31	0.25-0.39
Race/Ethnicity (Ref: NHW) → Median SES		
Non-Hispanic Black	0.26	0.21-0.33
Hispanic	0.20	0.15-0.28
SES Quintiles → ACP	1.44	1.38-1.50

Abbreviations: ACP- Advance Care Planning, NHW- Non-Hispanic White

Adjusted for: Age, Gender

Table 3.8a presents the results of binary logistic regression analyses adjusted for age and gender to test the assumptions of SES as a mediator of the main effect of race/ethnicity on legal

ACP. The first assumption of a main effect between the independent variable and outcome was upheld with Non-Hispanic Blacks (OR = 0.35, 95% CI: 0.30-0.41) and Hispanics (OR = 0.31, 95% CI: 0.25-0.39) being significantly less likely to complete legal ACP. To test the second assumption SES was dichotomized at the median for ease of interpretability. Non-Hispanic Blacks (OR = 0.26, 95% CI: 0.21-0.33) and Hispanics (OR = 0.20, 95% CI: 0.15-0.28) were much less likely than Non-Hispanic Whites to be at the median SES or greater. For the third assumption the association between ordinal SES quintiles and legal ACP was tested. There was a positive association between SES and completion of end of life healthcare planning (OR = 1.44, 95% CI: 1.38-1.50). With all three assumptions upheld, SES will be tested for a mediating effect on the relationship between race/ethnicity and legal ACP.

Table 3.8b- Adjusted Mediation Assumptions (Estate Planning, Exit)

	aOR	95% CI
Race/Ethnicity (Ref: NHW) → ACP		
Non-Hispanic Black	0.35	0.30-0.41
Hispanic	0.31	0.25-0.39
Race/Ethnicity (Ref: NHW) → Estate Planning		
Non-Hispanic Black	0.23	0.19-0.27
Hispanic	0.28	0.23-0.35
Estate Planning (Ref: No Will) → ACP	2.70	2.39-3.06

Abbreviations: ACP- Advance Care Planning, NHW- Non-Hispanic White
Adjusted for: Age, Gender, SES

Table 3.8b presents the results of binary logistic regression analyses adjusted for age, gender, and SES to test the assumptions of estate planning as a mediator of the main effect of race/ethnicity on legal ACP. SES is included, because it is hypothesized that this factor plays a proximal role in mediating the main effect and should be adjusted for when testing the mediating role of estate planning. The first assumption was upheld with the main effect of race/ethnicity (NHB: OR = 0.35, 95% CI: 0.30-0.41, Hispanics: OR = 0.31, 95% CI: 0.25-0.39) on legal ACP being significant. The independent variable and potential mediator were also significantly associated with Non-Hispanic Blacks (OR = 0.23, 95% CI: 0.19-0.27) and Hispanics (OR = 0.28, 95% CI: 0.22-0.35) significantly less likely to have a written will than Non-Hispanic Whites. The

third assumption was upheld with those having a written will being significantly more likely to also complete legal ACP (OR = 2.70, 95% CI: 2.39-3.06). All three assumptions were met, and estate planning was tested for a mediating effect on the relationship between race/ethnicity and legal ACP.

Table 3.9- Multivariate Assessment of Race/Ethnicity and Living Children (Exit)

Characteristic	Legal ACP = Yes	
	aOR	95% CI
Race/Ethnicity (ref = NHB)		
Hispanic	0.78	0.58-1.05
Living Children (ref = 0)		
1	0.94	0.70-1.26
2	1.07	0.82-1.40
3	1.19	0.90-1.58
4	1.28	0.96-1.71
5	1.18	0.85-1.64
6+	1.06	0.79-1.42

Abbreviations: NHB- Non-Hispanic Black

Table 3.9 presents results of assessing the coding for race/ethnicity and number of living children. In a fully adjusted model, the differences in legal ACP between Non-Hispanic Blacks and Hispanics was not significant (OR = 0.78, 95% CI: 0.58-1.05). Therefore, these two groups were collapsed into one minority group for the SAS causal mediation procedure. There were also no significant differences in legal ACP based on the number of children a respondent had. Thus, this variable was collapsed into fewer groups in analyses (0, 1, 2, 3+).

Table 3.10- Multicollinearity Assessment between Variables (Exit)

Variable 1	Variable 2	r
Marital Status	Gender	-0.39
Death	Recent	
Expected	Hospitalization	0.15
SES	Race/Ethnicity	-0.36
SES	Marital Status	0.17
SES	Estate Value	0.16
Will	Race/Ethnicity	-0.36
Will	Age	0.22
Will	Estate Value	0.20
Will	SES	0.36

Abbreviations: SES- Socioeconomic Status

Multicollinearity Assessment

Table 3.10 presents some of the results from an 11x11 correlation matrix for all variables included in the fully adjusted logistic regression models. The correlation table was used to investigate intercorrelation between study factors. The highest correlations were seen among marital status and gender ($r = -0.39$). Other notable correlations were observed for SES and race/ethnicity ($r = -0.36$), SES and estate planning ($r = 0.36$), and estate planning and race/ethnicity ($r = -0.36$). There were no meaningful concerns for intercorrelation among covariates.

Mediation Modeling: Binary Logistic Regression

Results of unweighted, multivariate binary logistic regression modeling of legal ACP are presented in table 3.11. The results of interest are the main effect of race/ethnicity on completion of legal APC, which are presented in the top rows. In model 1, adjusted for key sociodemographic variables (age, gender, marriage status, living children, and estate value), Non-Hispanic Blacks (OR = 0.32, 95% CI: 0.27-0.37) and Hispanics (OR = 0.25, 95% CI: 0.20-0.31) were much less likely to complete legal ACP compared to Non-Hispanic Whites. After adjusting for health-related variables in Model 2, the main effect of race/ethnicity is unchanged. R-squared increased from 22% in model 1 to 24 % in model 2. Model 3 added the first potential mediator, socioeconomic

status. Compared to the first quintile all other groups were more likely to complete legal ACP, but the difference between the first and second quintiles was not significant. The main effect of race/ethnicity was shifted toward the null with Non-Hispanic Blacks (OR = 0.35, 95% CI: 0.30-0.42) and Hispanics (OR = 0.30, 95% CI: 0.24-0.37) becoming more likely to complete legal ACP compared to model 2. R-squared increased to 25% in model 3. The final model added estate planning, the second mediator of interest. In model 4, the effect of SES was reduced such that the effect of each quintile was shifted toward the null and the effect of the third quintile became insignificant. The effect of estate planning on legal ACP was significant with those completing estate planning being more than twice as likely to complete legal ACP (OR = 2.07, 95% CI: 1.80-2.38). The main effect of race/ethnicity on legal ACP was also reduced for Non-Hispanic Blacks (OR = 0.42, 95% CI: 0.35-0.50) and Hispanics (OR = 0.34, 95% CI: 0.27-0.43). R-square increased to 27% in the final model. The addition of SES in model three contributed to 3% of the total estimated variance explained and the addition of estate planning contributed 7%, but the change in total variance explained before and after adding the mediators was negligible. There were no issues with model fit, as the Hosmer-Lemeshow p values for all models were insignificant. R-square (Nagelkerke) values also increased indicating the addition of variables in each model improved the variance explained. Although, the total variance explained was small (27%).

Associations in model 4 for covariates are worth noting. Increasing age was associated with increased odds of legal ACP completion. Those 75-84 years old were 19% more likely to complete planning activities (OR = 1.19, 95% CI: 1.03-1.37) and those in the oldest age group, 85+, were 50% more likely to complete legal ACP (OR = 1.50, 95% CI: 1.26-1.79) compared to those 65-74 years old. Respondents who were separated/divorced were more likely than those married/partnered to complete End-of-Life healthcare planning (OR = 1.92, 95% CI: 1.67-2.21). Among those with known estate value respondents with nothing of much value were 19% less likely to complete legal ACP (OR = 0.81, 95% CI: 0.70-0.95). Those in poorer health as indicated by recent hospitalization (OR = 1.71, 95% CI: 1.48-1.99) and death expected (OR = 1.55, 95% CI: 1.37-1.75) were more likely to have advance directives or medical power of attorney documents

completed. The associations for gender, living children, and self-reported memory ability were insignificant.

Table 3.11- Multivariate Associations with Legal ACP, unweighted (Exit)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3		Multivariate Model 4	
	Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)								
NHB	0.32	0.27-0.37	0.32	0.27-0.38	0.35	0.30-0.42	0.42	0.35-0.50
Hispanic	0.25	0.20-0.31	0.25	0.20-0.32	0.30	0.24-0.37	0.34	0.27-0.43
Age (ref = 65-74)								
75-84	1.32	1.15-1.52	1.34	1.16-1.54	1.32	1.14-1.52	1.19	1.03-1.37
85+	1.82	1.55-2.12	1.79	1.52-2.12	1.77	1.50-2.10	1.50	1.26-1.79
Gender (ref = male)	1.09	0.96-1.23	1.07	0.94-1.22	1.09	0.96-1.24	1.09	0.96-1.24
Sep/Div/Single/Widowed (ref = married/partnered)	1.69	1.48-1.93	1.72	1.50-1.96	1.86	1.62-2.14	1.92	1.67-2.21
No Living Children (ref = 0)								
1	0.96	0.73-1.25	0.94	0.72-1.23	0.94	0.71-1.23	0.94	0.71-1.23
2	1.06	0.83-1.35	1.04	0.82-1.33	1.03	0.80-1.31	1.02	0.80-1.31
3+	1.10	0.88-1.38	1.08	0.86-1.35	1.12	0.89-1.41	1.14	0.90-1.43
Estate Value (ref = some)								
None	0.65	0.56-0.75	0.65	0.56-0.75	0.73	0.63-0.85	0.81	0.70-0.95
Unknown	2.09	1.82-2.41	2.07	1.80-2.39	1.96	1.70-2.27	1.76	1.52-2.04
Recent Hospitalization (ref = no)			1.70	1.47-1.96	1.72	1.48-1.99	1.71	1.48-1.98
Death Expected (ref = no)			1.58	1.41-1.79	1.57	1.39-1.77	1.55	1.37-1.75
Cognition Score (ref = Q5 best)								
Q1 worst			0.86	0.69-1.08	1.03	0.82-1.30	1.08	0.85-1.36
Q2			0.92	0.74-1.15	1.06	0.85-1.32	1.10	0.88-1.37
Q3			0.91	0.74-1.13	1.00	0.80-1.24	1.01	0.81-1.25
Q4			0.93	0.75-1.15	0.97	0.79-1.20	1.00	0.81-1.25
Unknown			0.88	0.71-1.08	1.01	0.81-1.25	1.04	0.83-1.30
SES Quintiles (ref = Q1)								
Q2					1.20	1.00-1.46	1.10	0.91-1.33

Q3					1.29	1.06-1.57	1.17	0.96-1.43
Q4					1.89	1.52-2.35	1.62	1.29-2.02
Q5					1.90	1.53-2.38	1.60	1.27-2.00
Estate Planning (ref = no)							2.07	1.80-2.38
Wave	1.14	1.11-1.17	1.14	1.11-1.17	1.13	1.10-1.16	1.14	1.11-1.17
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.740	0.4969	0.752	0.4573	0.758	0.8537	0.768	0.8783
R-square (Nagelkerke)		0.2170		0.2410		0.2502		0.2693

Abbreviations: ACP- Advance Care Planning, Legal ACP- Advance Directives or Medical Power of Attorney, C-stat- C Statistic, HL-p- Hosmer Lemeshow p value

*p < 0.01, **p < 0.01, ***p < 0.001, ****p < 0.0001

Mediation Modeling: SAS Causal Mediation Procedure

Results of the SAS causal mediation procedure are presented in Table 3.12. Due to the limitations of this new procedure, race/ethnicity was dichotomized (Non-Hispanic White, Minority (Non-Hispanic Black or Hispanic)) and SES quintiles were assumed to represent a continuous scale. Tables 3.14a and 3.14b present results for Non-Hispanic Blacks and Hispanics, respectively. The procedure tests the percentage of the total effect that is due to the indirect, or mediating effect. Odds ratios for the total, direct, and indirect effects are presented for consistency with other results. Total Excess Relative Risk, Excess Relative Risk (NDE), and Excess Relative Risk (NIE) are presented because the procedure uses these values, which are on an additive scale, to calculate the percent mediated rather than the odds ratios.

A stepwise approach was used to test for the mediating effects of SES and then estate planning. For each mediator, unadjusted and adjusted results are presented. The modeling for SES included all covariates in Model 3 from Table 3.11 (age, gender, marriage status, living children, estate value, recent hospitalization, death expected, and self-reported memory). The modeling for estate planning included all covariates in Model 4 from Table 3.11 (addition of SES).

The adjusted total effect of race/ethnicity on legal ACP was significant (OR = 0.30, 95% CI: 0.26-0.35) with minorities being less than one-third as likely to complete legal ACP compared to Non-Hispanic Whites. The direct effect of race/ethnicity was also significant (OR = 0.35, 95% CI: 0.30-0.40). The indirect effect of race/ethnicity mediated by SES was statistically significant (OR = 0.87, 95% CI: 0.83-0.90). A small percentage (6.60%) of the main effect of race/ethnicity on legal ACP is mediated by SES ($p < 0.0001$).

When testing the mediating effect of estate planning while controlling for SES, the total effect of race/ethnicity on legal ACP was significant (OR = 0.34, 95% CI: 0.29-0.39) with minorities being about one-third as likely as Non-Hispanic Whites to participate in healthcare planning. The direct effect was also significant (OR = 0.41, 95% CI: 0.35-0.47). The indirect effect of race/ethnicity mediated by estate planning was statistically significant (OR = 0.84, 95% CI:

0.80-0.87). One-tenth (10.07%) of the main effect of race/ethnicity on legal ACP is mediated by estate planning after controlling for SES ($p < 0.0001$). Taken together, less than 20% of the main effect of race/ethnicity on legal ACP is mediated by SES (6.6%) and estate planning (10.1%).

Table 3.12- Stepwise Mediation Effects on Legal ACP, unweighted (Exit)*

	SES**				Estate Planning			
	unadjusted		adjusted		unadjusted		adjusted	
	OR/RR	95% CI	OR/RR	95%CI	OR/RR	95% CI	OR/RR	95% CI
Total Effect (OR)	0.24	0.21-0.28	0.30	0.26-0.35	0.25	0.21-0.28	0.34	0.29-0.39
Direct Effect (OR)	0.32	0.28-0.37	0.35	0.30-0.40	0.37	0.32-0.43	0.41	0.35-0.47
Indirect Effect (OR)	0.76	0.71-0.80	0.87	0.83-0.90	0.66	0.62-0.69	0.84	0.80-0.87
Total Excess RR	-0.76	-0.78,-0.72	-0.7	-0.74,-0.65	-0.75	-0.79,-0.72	-0.66	-0.71,-0.61
Excess RR (NDE)	-0.68	-0.72,-0.63	-0.65	-0.70,-0.60	-0.63	-0.68,-0.57	-0.59	-0.65,-0.53
Excess RR (NIE)	-0.08	-0.10,-0.06	-0.05	-0.06,-0.03	-0.13	-0.16,-0.10	-0.07	-0.08,-0.05
% Mediated	10.43****	7.58-13.28	6.60****	4.32-8.87	17.00****	13.33-20.66	10.07****	6.88-13.26

Abbreviations: SES- Socioeconomic Status

*Non-Hispanic Whites vs. Minorities, **SES Quintiles

Adjusted for: age, gender, marriage status, living children, estate value, recent hospitalization, death expected, cognition score, and SES (estate planning only)

****p < 0.0001

Sensitivity Analyses

Prior to utilizing the new causal mediation procedure in SAS, sensitivity analyses were performed to determine variable operationalization. The causal mediation procedure became available in the latest version of SAS in late 2019. The new procedure is limited in applicability and can only assess dichotomous or continuous independent and dependent variables and mediators. Tables 3.13a-d present a series of logistic regression analyses to determine whether 1) race/ethnicity can be dichotomized (NHW, Minority (NHB or Hispanic)) and 2) SES quintiles can be treated as an ordinal variable.

MEDIATION MODELING: BINARY LOGISTIC REGRESSION- NON-HISPANIC WHITES VS. MINORITIES

Table 3.13a presents the same modeling as Table 3.11 with race/ethnicity dichotomized. Prior to modeling, a fully adjusted model comparing Non-Hispanic Blacks and Hispanics demonstrated that there was not a statistically significant difference in legal ACP between these two minorities (Table 3.9 [OR = 0.78, 95% CI: 0.58-1.05]). The associations with race/ethnicity dichotomized are similar to those presented in Table 3.11. SES has a graded effect with higher quintiles being more likely to complete legal ACP and estate planning is significantly associated with the outcome (OR = 2.07, 95% CI: 1.80-2.37). The reduction and prevailing main effect of race/ethnicity is also observed with minorities being 40% as likely to complete legal ACP compared to Non-Hispanic Whites (OR = 0.39, 95% CI: 0.33-0.46) in the fully adjusted Model 4.

MEDIATION MODELING: BINARY LOGISTIC REGRESSION- NON-HISPANIC WHITES VS. NON-HISPANIC BLACKS/HISPANICS

Tables 3.13b and 3.13c present results comparing Non-Hispanic Whites to Non-Hispanic Blacks and Hispanics, respectively. Similar associations are observed and relationships for each of these minorities in isolation can be seen. The fully adjusted main effect for Non-Hispanic Blacks (OR = 0.42, 95% CI: 0.35-0.50) and Hispanics (OR = 0.35, 95% CI: 0.28-0.44) are not statistically

different. With the main effect of race/ethnicity maintained and no significant differences between Non-Hispanic Blacks and Hispanics, race/ethnicity was dichotomized for the causal mediation procedure.

MEDIATION MODELING: BINARY LOGISTIC REGRESSION- CONTINUOUS SES

Table 3.13d presents results for dichotomized race/ethnicity and ordinal SES quintiles treated as a continuous measure. The association for SES is statistically significant with each higher quintile being 14% more likely to complete legal ACP (OR = 1.14, 95% CI: 1.00-1.20). With the significant association for SES maintained, ordinal SES quintiles treated as a continuous variable were used in the causal mediation procedure.

Table 3.13a- Multivariate Associations with Legal ACP, unweighted (Exit) (NHW & Minorities; SES Quintiles)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3		Multivariate Model 4	
	Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)								
Minority (NHB or Hispanic)	0.29	0.25-0.33	0.3	0.26-0.34	0.33	0.29-0.39	0.39	0.33-0.46
Age (ref = 65-74)								
75-84	1.32	1.15-1.52	1.33	1.16-1.54	1.32	1.14-1.52	1.19	1.03-1.37
85+	1.81	1.55-2.12	1.79	1.52-2.12	1.77	1.50-2.10	1.50	1.26-1.79
Gender (ref = male)	1.09	0.96-1.24	1.07	0.94-1.22	1.09	0.96-1.24	1.09	0.96-1.24
Sep/Div/Single/Widowed (ref = Married/Partnered)	1.70	1.49-1.94	1.72	1.51-1.97	1.87	1.63-2.15	1.93	1.68-2.22
No Living Children (ref = 0)								
1	0.95	0.73-1.24	0.93	0.71-1.22	0.93	0.71-1.22	0.93	0.71-1.22
2	1.05	0.82-1.34	1.03	0.81-1.32	1.02	0.80-1.30	1.01	0.79-1.29
3+	1.09	0.87-1.37	1.07	0.85-1.34	1.11	0.88-1.40	1.13	0.90-1.42
Estate Value (ref = some)								
None	0.65	0.56-0.75	0.64	0.56-0.75	0.73	0.63-0.85	0.81	0.70-0.95
Unknown	2.09	1.81-2.40	2.06	1.79-2.38	1.95	1.69-2.26	1.76	1.52-2.04
Recent Hospitalization (ref = no)			1.70	1.47-1.97	1.72	1.49-2.00	1.72	1.48-1.99
Death Expected (ref = no)			1.58	1.40-1.78	1.56	1.39-1.76	1.54	1.37-1.74
Cognition Score (ref = Q5 best)								
Q1 worst			0.87	0.69-1.09	1.04	0.83-1.31	1.09	0.86-1.37
Q2			0.92	0.75-1.15	1.06	0.85-1.33	1.10	0.88-1.38
Q3			0.91	0.74-1.13	1.00	0.80-1.24	1.01	0.81-1.25
Q4			0.93	0.76-1.15	0.97	0.79-1.20	1.01	0.81-1.25
Unknown			0.87	0.70-1.08	1.01	0.81-1.25	1.04	0.83-1.30
SES Quintiles (ref = Q1)								
Q2					1.22	1.01-1.47	1.11	0.91-1.34
Q3					1.31	1.01-1.59	1.19	0.97-1.45

Q4					1.91	1.54-2.38	1.64	1.31-2.04
Q5					1.93	1.55-2.41	1.62	1.29-2.03
Estate Planning (ref = no)							2.07	1.80-2.37
Wave	1.14	1.10-1.17	1.14	1.11-1.17	1.12	1.10-1.15	1.13	1.10-1.17
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.740	0.6548	0.752	0.6912	0.758	0.9435	0.768	0.9184
R-square (Nagelkerke)		0.2163		0.2404		0.2498		0.2689

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Table 3.13b- Multivariate Associations with Legal ACP, unweighted (Exit) (NHW & NHB; SES Quintiles)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3		Multivariate Model 4	
	Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)								
NHB	0.32	0.27-0.37	0.33	0.28-0.39	0.36	0.30-0.42	0.42	0.35-0.50
Age (ref = 65-74)								
75-84	1.36	1.17-1.57	1.37	1.18-1.59	1.35	1.16-1.57	1.21	1.04-1.41
85+	1.91	1.62-2.25	1.89	1.59-2.26	1.87	1.57-2.23	1.58	1.32-1.90
Gender (ref = male)	1.13	1.00-1.29	1.12	0.98-1.28	1.14	0.99-1.30	1.15	1.00-1.31
Sep/Div/Single/Widowed (ref = Married/Partnered)	1.63	1.42-1.87	1.65	1.43-1.90	1.79	1.55-2.06	1.84	1.60-2.13
No Living Children (ref = 0)								
1	0.96	0.73-1.26	0.94	0.71-1.24	0.94	0.71-1.24	0.94	0.71-1.25
2	1.04	0.81-1.34	1.02	0.79-1.32	1.01	0.79-1.31	1.00	0.78-1.30
3+	1.11	0.88-1.40	1.09	0.86-1.38	1.13	0.89-1.43	1.15	0.90-1.45
Estate Value (ref = some)								
None	0.65	0.56-0.76	0.65	0.56-0.76	0.73	0.62-0.86	0.81	0.69-0.95
Unknown	2.13	1.84-2.47	2.11	1.82-2.44	1.99	1.72-2.31	1.81	1.55-2.10
Recent Hospitalization (ref = no)			1.62	1.40-1.89	1.65	1.41-1.92	1.64	1.40-1.91
Death Expected (ref = no)			1.61	1.42-1.82	1.59	1.40-1.80	1.57	1.39-1.79
Cognition Score (ref = Q5 best)								
Q1 worst			0.85	0.68-1.08	1.01	0.79-1.28	1.05	0.82-1.34
Q2			0.94	0.75-1.17	1.07	0.85-1.34	1.11	0.88-1.39
Q3			0.93	0.74-1.15	1.01	0.80-1.26	1.01	0.81-1.27
Q4			0.93	0.75-1.15	0.97	0.78-1.20	1.00	0.80-1.24
Unknown			0.86	0.69-1.07	0.98	0.78-1.22	1.01	0.81-1.27
SES Quintiles (ref = Q1)								
Q2					1.20	0.98-1.47	1.1	0.90-1.36
Q3					1.23	1.00-1.52	1.13	0.92-1.39

Q4					1.80	1.44-2.27	1.56	1.23-1.96
Q5					1.84	1.46-2.33	1.57	1.24-1.99
Estate Planning (ref = no)							2.01	1.73-2.32
Wave	1.13	1.10-1.16	1.12	1.09-1.16	1.11	1.08-1.15	1.12	1.09-1.16
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.727	0.7687	0.739	0.9599	0.745	0.8348	0.755	0.8108
R-square (Nagelkerke)		0.1892		0.2132		0.2218		0.2398

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Table 3.13c- Multivariate Associations with Legal ACP, unweighted (Exit) (NHW & Hispanics; SES Quintiles)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3		Multivariate Model 4	
	Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)								
Hispanic	0.26	0.21-0.32	0.26	0.21-0.32	0.30	0.24-0.38	0.35	0.28-0.44
Age (ref = 65-74)								
75-84	1.33	1.14-1.55	1.33	1.14-1.56	1.30	1.12-1.52	1.16	0.99-1.36
85+	1.93	1.62-2.29	1.89	1.57-2.28	1.85	1.54-2.23	1.55	1.28-1.88
Gender (ref = male)	1.08	0.94-1.24	1.07	0.93-1.23	1.09	0.95-1.26	1.08	0.94-1.25
Sep/Div/Single/Widowed (ref = Married/Partnered)	1.68	1.46-1.95	1.71	1.47-1.97	1.87	1.61-2.17	1.93	1.65-2.24
No Living Children (ref = 0)								
1	0.94	0.69-1.27	0.9	0.67-1.23	0.91	0.67-1.23	0.88	0.65-1.20
2	1.03	0.79-1.36	1.01	0.77-1.33	1.01	0.76-1.33	0.98	0.74-1.30
3+	1.11	0.86-1.43	1.07	0.83-1.39	1.12	0.86-1.46	1.12	0.86-1.46
Estate Value (ref = some)								
None	0.59	0.50-0.69	0.58	0.49-0.68	0.67	0.56-0.79	0.74	0.62-0.89
Unknown	2.01	1.73-2.33	1.99	1.71-2.32	1.87	1.60-2.18	1.67	1.43-1.96
Recent Hospitalization (ref = no)			1.70	1.45-1.98	1.73	1.47-2.02	1.71	1.46-2.01
Death Expected (ref = no)			1.53	1.34-1.74	1.51	1.32-1.73	1.49	1.31-1.71
Cognition Score (ref = Q5 best)								
Q1 worst			0.88	0.69-1.13	1.07	0.83-1.37	1.10	0.85-1.42
Q2			0.94	0.75-1.18	1.10	0.87-1.39	1.15	0.91-1.46
Q3			0.95	0.76-1.19	1.05	0.83-1.31	1.06	0.84-1.33
Q4			0.93	0.75-1.16	0.98	0.78-1.22	1.01	0.81-1.27
Unknown			0.91	0.72-1.14	1.06	0.84-1.34	1.10	0.87-1.39
SES Quintiles (ref = Q1)								
Q2					1.16	0.93-1.45	1.01	0.81-1.27
Q3					1.30	1.04-1.62	1.14	0.91-1.44

Q4					1.94	1.53-2.47	1.60	1.25-2.05
Q5					2.01	1.57-2.58	1.61	1.25-2.08
Estate Planning (ref = no)							2.21	1.90-2.57
Wave	1.12	1.09-1.15	1.12	1.08-1.15	1.11	1.07-1.14	1.12	1.09-1.15
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.722	0.2551	0.734	0.9796	0.743	0.9431	0.755	0.5546
R-square (Nagelkerke)		0.1817		0.2047		0.2164		0.2396

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Table 3.13d- Multivariate Associations with Legal ACP, unweighted (Exit) (NHW & Minorities; Continuous SES)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3		Multivariate Model 4	
	Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes		Legal ACP = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)								
Minority (NHB or Hispanic)	0.29	0.25-0.33	0.30	0.26-0.34	0.33	0.29-0.39	0.39	0.34-0.46
Age (ref = 65-74)								
75-84	1.32	1.15-1.52	1.33	1.16-1.54	1.32	1.15-1.53	1.19	1.03-1.38
85+	1.81	1.55-2.12	1.79	1.52-2.12	1.78	1.50-2.11	1.51	1.27-1.79
Gender (ref = male)	1.09	0.96-1.24	1.07	0.94-1.22	1.09	0.96-1.24	1.10	0.96-1.25
Sep/Div/Single/Widowed (ref = Married/Partnered)	1.70	1.49-1.94	1.72	1.51-1.97	1.84	1.61-2.11	1.91	1.66-2.19
No Living Children (ref = 0)								
1	0.95	0.73-1.24	0.93	0.71-1.22	0.93	0.71-1.23	0.93	0.71-1.23
2	1.05	0.82-1.34	1.03	0.81-1.32	1.02	0.80-1.31	1.01	0.79-1.30
3+	1.09	0.87-1.37	1.07	0.85-1.34	1.11	0.88-1.39	1.13	0.90-1.42
Estate Value (ref = some)								
None	0.65	0.56-0.75	0.65	0.56-0.75	0.72	0.62-0.84	0.8	0.69-0.94
Unknown	2.09	1.81-2.40	2.06	1.79-2.38	1.95	1.69-2.25	1.76	1.52-2.03
Recent Hospitalization (ref = no)			1.70	1.47-1.97	1.72	1.48-1.99	1.71	1.48-1.98
Death Expected (ref = no)			1.58	1.40-1.78	1.56	1.38-1.76	1.54	1.36-1.74
Cognition Score (ref = Q5 best)								
Q1 worst			0.87	0.69-1.09	1.04	0.83-1.31	0.99	0.80-1.22
Q2			0.92	0.75-1.15	1.06	0.85-1.32	0.91	0.74-1.12
Q3			0.91	0.74-1.13	1.00	0.81-1.24	0.92	0.74-1.13
Q4			0.93	0.76-1.15	0.98	0.79-1.21	0.91	0.73-1.13
Unknown			0.87	0.70-1.08	1.01	0.81-1.26	0.95	0.78-1.16
SES Quintiles					1.19	1.13-1.25	1.14	1.09-1.20
Estate Planning (ref = no)							2.07	1.80-2.38
Wave	1.14	1.11-1.17	1.14	1.11-1.17	1.12	1.10-1.15	1.13	1.10-1.16

Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.74	0.6548	0.752	0.6912	0.757	0.9831	0.767	0.8034
R-square (Nagelkerke)		0.2163		0.2404		0.2489		0.2681

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$, **** $p < 0.0001$

***MEDIATION MODELING: SAS CAUSAL MEDIATION PROCEDURE- NON-HISPANIC WHITES
VS. NON-HISPANIC BLACKS/HISPANICS***

Tables 3.14a and 3.14b present causal mediation procedure results for Non-Hispanic Whites compared to Non-Hispanic Blacks and Hispanics, respectively. The percentage of the main effect mediated by SES for Non-Hispanic Blacks (5.59%, 95% CI: 3.31-7.87) is less than that for Hispanics (7.69%, 95% CI: 4.48-10.91). The percentage mediated by estate planning is greater for Non-Hispanic Blacks (10.58%, 95% CI: 6.70-14.47) than Hispanics (8.22%, 95% CI: 4.68-11.76). The small differences are not likely statistically significant given the confidence intervals, and the total mediating effect for both factors taken together is approximately equal.

Table 3.14a- Stepwise Mediation Effect on Legal ACP, unweighted (Exit) (NHW & NHB; SES Quintiles)

	SES				Estate Planning			
	unadjusted		adjusted		unadjusted		adjusted	
	OR/RR	95% CI	OR/RR	95%CI	OR/RR	95% CI	OR/RR	95% CI
Total Effect (OR)	0.26	0.22-0.30	0.33	0.28-0.39	0.27	0.22-0.31	0.36	0.30-0.43
Direct Effect (OR)	0.34	0.28-0.39	0.37	0.31-0.43	0.40	0.34-0.47	0.43	0.35-0.51
Indirect Effect (OR)	0.78	0.74-0.82	0.9	0.87-0.93	0.66	0.62-0.70	0.84	0.81-0.88
Total Excess RR	-0.74	-0.78,-0.70	-0.67	-0.72,-0.61	-0.73	-0.78,-0.69	-0.64	-0.70,-0.57
Excess RR (NDE)	-0.66	-0.72,-0.61	-0.63	-0.69,-0.57	-0.60	-0.66,-0.53	-0.57	-0.65,-0.49
Excess RR (NIE)	-0.07	-0.10,-0.05	-0.04	-0.05,-0.02	-0.14	-0.17,-0.11	-0.07	-0.09,-0.05
% Mediated	10.10****	6.97-13.24	5.59****	3.31-7.87	18.65****	13.94-23.35	10.58****	6.70-14.47

Abbreviations- NHW: Non-Hispanic Whites, NHB: Non-Hispanic Blacks, SES: Socioeconomic Status (Education & Wealth)

Adjusted for: age, gender, marriage status, living children, estate value, recent hospitalization, death expected, self-reported memory, and SES (estate planning only)

***p < 0.0001

Table 3.14b- Stepwise Mediation Effect on Legal ACP, unweighted (Exit) (NHW & Hispanics; SES Quintiles)

	SES				Estate Planning			
	unadjusted		adjusted		unadjusted		adjusted	
	OR/RR	95% CI	OR/RR	95%CI	OR/RR	95% CI	OR/RR	95% CI
Total Effect (OR)	0.21	0.17-0.25	0.26	0.20-0.32	0.21	0.17-0.26	0.31	0.24-0.38
Direct Effect (OR)	0.3	0.24-0.36	0.32	0.25-0.39	0.33	0.26-0.40	0.37	0.28-0.45
Indirect Effect (OR)	0.71	0.66-0.76	0.82	0.78-0.87	0.65	0.60-0.69	0.84	0.80-0.89
Total Excess RR	-0.79	-0.83,-0.75	-0.74	-0.80,-0.68	-0.79	-0.83,-0.74	-0.69	-0.76,-0.62
Excess RR (NDE)	-0.7	-0.76,-0.64	-0.68	-0.75,-0.61	-0.67	-0.74,-0.60	-0.63	-0.72,-0.55
Excess RR (NIE)	-0.09	-0.11,-0.06	-0.06	-0.08,-0.04	-0.12	-0.15,-0.09	-0.06	-0.08,-0.04
% Mediated	11.04****	7.29-14.79	7.69****	4.48-10.91	14.80****	10.40-19.20	8.22****	4.68-11.76

Abbreviations- NHW: Non-Hispanic Whites, NHB: Non-Hispanic Blacks, SES: Socioeconomic Status (Education & Wealth)

Adjusted for: age, gender, marriage status, living children, estate value, recent hospitalization, death expected, self-reported memory, and SES (estate planning only)

***p < 0.0001

DISCUSSION

The purpose of this chapter was to test for possible mediating relationship between socioeconomic status, estate planning, race/ethnicity, and legal ACP. The hypothesis was that the main effect of race/ethnicity on legal ACP would be reduced or eliminated when SES and estate planning were taken into account and results using two alternative analytical approaches indicate the hypothesis was supported for both SES and estate planning. This study builds on work by two previous authors that have described a mediating role for estate planning among living Whites alone and Blacks compared to whites. The first study demonstrated disparities in ACP (advance directives, medical power of attorney, or discussing End-of-Life care preferences) by wealth that were partially mediated by estate planning among living HRS respondents (Carr, 2012). The second reported that the disparities in advance directives completion between Whites and Blacks was fully mediated by estate planning in living respondents (Catheryn & Tamara, 2017).

This study has added to what is known about racial/ethnic disparities in legal advance care planning (advance directives or medical power of attorney). There are only two studies that have proposed a testable hypothesis for healthcare planning disparities, and neither included Hispanics in their samples. This study also utilized the new SAS causal mediation procedure. Although this new procedure has its limitations, it provides statistics for the size of the mediating effect of SES and estate planning in the relationship between race/ethnicity and legal ACP. Although main results are presented comparing Non-Hispanic Whites to minorities, sensitivity analyses were run comparing Non-Hispanic Whites to Non-Hispanic Blacks and Hispanics independently.

The results from the logistic regression modeling demonstrated a limited mediating effect for SES (3% of total variance explained) and stronger effect for estate planning (7% of total variance explained). However, the change in R-square from models without (24%) to those with the mediators (27%) was negligible suggesting a limited mediating effect. The main effect of race/ethnicity was also reduced when each mediator was added supporting the mediation hypotheses. The new SAS causal mediation procedure demonstrated a significant mediating effect

from both mediators. Socioeconomic status accounted for 7% and estate planning 10% of the total effect of race/ethnicity on legal ACP. Both approaches indicated SES and estate planning play a small mediating role in the completion of legal healthcare planning. Other studies to date have not formally quantified or tested the statistical significance of the mediating effect of SES or estate planning on ACP.

Results in this study are consistent with the two main studies testing similar hypotheses. Among living Non-Hispanic Whites in the Wisconsin Longitudinal Study, Carr found that the main effect of wealth on both advance directives and medical power of attorney was reduced when estate planning was taken into account (Carr, 2012). The greatest effect was for the lowest wealth categories. The main effect of wealth on advance directives for participants with no or negative assets (OR = 0.43* to 0.55*, *p < 0.05) and those in the 0 to 25th percentile (OR = 0.41* to 0.53*, *p < 0.05) was reduced by 29% for both groups when estate planning was added to the modelling. Similar results are observed for medical power of attorney with the effect for those in the lowest wealth category (OR = 0.58* to 0.75, *p < 0.05) and the second lowest category (OR = 0.47* to 0.59*, *p < 0.05) being reduced by 29% and 27% respectively. The effect on both outcomes was smaller for higher wealth categories. Formal mediation testing was not presented. Results in the Carr paper and this study are similar despite the different samples. This study used responses from proxies of deceased respondents and included Hispanics. The Carr paper included only living Non-Hispanic White high school graduates. Tables 3.13b and 3.13c demonstrate similar associations between SES and legal ACP for Non-Hispanic Blacks and Hispanics, respectively. Estate planning also played a significant role for both racial/ethnic minority groups of interest with those completing a written will being about twice as likely to participate in legal ACP. Koss and Baker report results testing the mediating role of estate planning in the disparities in advance directives between Non-Hispanic Whites and Blacks among HRS respondents (Catheryn & Tamara, 2017). In their study, Whites were significantly more likely to complete advance directives (OR = 1.53, 95% CI: 1.34-1.75). After estate planning was taken into account the effect was reduced and became insignificant (OR = 0.96, 95% CI: 0.82-1.12). The results in this study demonstrate similar

mediating effects, but to a lesser extent than what is seen in the Koss and Baker paper. This is likely due to sample differences including sample size and respondent type (living vs. deceased). The Koss and Baker paper only included Non-Hispanic White and Black living respondents from one HRS interview, resulting in a relatively small sample. The sample size prevented the inclusion of Hispanics in their analyses. The current study used exit interview responses from proxies of deceased respondents over a period of 16 years and was able to include Hispanics. The main effect of race/ethnicity is significant throughout the analyses. Comparing models 3 and 4 in Table 3.13d, the disparities between whites and non-whites ($OR = 0.30$, 95% CI: 0.26-0.34) are reduced when SES ($OR = 0.33$, 95% CI: 0.29-0.39) and estate planning ($OR = 0.39$, 95% CI: 0.34-0.46) are taken into account. This is consistent with the Carr paper where estate planning reduced the main effect of wealth for Whites and the Koss and Baker paper that reported racial/ethnic disparities mediated by estate planning.

An addition to the literature made by this chapter is the inclusion of formal mediation analyses performed with the new SAS causal mediation procedure. The adjusted mediating effects of SES and estate planning were significant. When considering both factors together, approximately half of the relationship between race/ethnicity and legal ACP is accounted for. This supports the hypothesis that those with higher SES are likely to complete a will and are prompted by their lawyers to also complete legal health care planning documents like advance directives and medical power of attorney paperwork. However, given the size of the effect that remains unexplained, it is likely cultural differences and other unmeasured factors may contribute to completion of ACP.

Additional analyses in Table 3.13c and Table 3.14b provide results for Hispanics compared to Non-Hispanic Whites. Neither of the two studies mentioned above included Hispanics in their sample. This minority subgroup is of interest because it is a growing segment of the U.S. population with unique cultural attributes. The reduction of the main effect of race/ethnicity on legal ACP when SES and estate planning are taken into account is observed for Hispanics. Although the breakdown of the percent mediated by SES and estate planning is slightly different

for Hispanics compared to the full sample of Non-Hispanic Whites compared to minorities (Non-Hispanic Blacks and Hispanics) and the subsample of Non-Hispanic Whites compared to Non-Hispanic Blacks, the differences are not likely statistically significant based on the confidence intervals. Additionally, the overall effect of SES and estate planning is comparable between Hispanics (15.91%), Non-Hispanic Blacks (16.17%), and both minorities considered together (16.67%).

The main hypothesis in this chapter was supported by the results presented. The effect of race/ethnicity on legal ACP is partially mediated by SES and estate planning. Strengths of this study include the large sample size that permits the subgroup analyses of Hispanics and Non-Hispanic Blacks. A weakness of the specific statistical analyses used in this study is the limitation of the SAS causal mediation procedure to using dichotomous or continuous variables. To address this, sensitivity analyses were performed to determine if race/ethnicity could be dichotomized and SES quintiles could be treated as an ordinal variable. Limitations of the HRS data include those associated with survey research including recall bias, reliability of proxies, and issues with temporality.

Results in this chapter are consistent with the proposed mechanism for completion of end of life planning. Namely, there are prevailing and significant racial/ethnic disparities in end of life planning with minorities (Non-Hispanic Blacks and Hispanics) completing planning less often than Non-Hispanic Whites. These disparities are partially due to socioeconomic disparities among the three major racial/ethnic groups in the United States. These SES disparities are associated with estate planning, which serves as a first step for end of life healthcare planning. So, racial/ethnic minorities are less likely to have high SES and participate in estate planning resulting in lower rates of healthcare planning among Non-Hispanic Blacks and Hispanics.

This chapter has demonstrated the mediating role of socioeconomic status and estate planning in end of life healthcare planning. Though the associations are not as strong as might be expected, they support the hypothesis that those who have more assets and plan for distribution of those assets before passing are more likely to also participate in legal advance care planning. The

smaller than expected effect of mediation is likely due to the complex, multi-step advance care planning process and unmeasured cultural differences. These findings suggest minorities and those in low SES groups may benefit from targeted interventions to facilitate ACP.

Chapter 4: Aim 3- Mediating Effect of Legal Advance Care Planning and Social Support on End of Life Care

RATIONALE

Purpose

Aim 3: To test for possible mediating relationship between race/ethnicity, advance care planning, social support, and end of life (End-of-Life) care. HRS Exit interviews for deceased respondents (2002-2016) are used to investigate the possible mediating effect of advance care planning and social support on the relationship between race/ethnicity and 1) decisions to limit care at the End-of-Life, hospital death, and complex care and 2) having one's End-of-Life preferences honored. Decisions to limit care at the End-of-Life is an indicator of any decision to limit care rather than receive all care possible. Hospital death denotes death in a hospital instead of at home or in a hospice or other care facility. The complex care outcome includes dialysis, life support, or ICU admission since the last core interview. Having one's End-of-Life preferences honored is determined by comparing a living respondent's preferences to limit care at the end of life to care decisions that were made at the end of life. Where the previous chapters have examined predictors of legal ACP (advance directive or medical power of attorney), this chapter looks at actual end of life care.

Significance

Advance care planning is the ongoing process of discussing one's preference for end of life care, documenting those preferences in an advance directive, and assigning an individual to make decisions in the event a person becomes incapacitated (Carr & Luth, 2016). Aim 1 investigated the co-occurrence of ACP components (discussing end of life care, preparing an advance directive, and assigning a medical power of attorney) and determined that the construct would be best defined as having an advance directive or medical power of attorney, legal ACP.

Chapters 2 and 3 demonstrated significant associations between race/ethnicity, socioeconomic status (education and wealth), estate planning (having a written will), and legal ACP. Racial/ethnic minorities (Non-Hispanic Blacks and Hispanics) and those in lower SES quintiles are less likely to participate in legal ACP compared to Non-Hispanic Whites and those with higher SES. The main association between race/ethnicity and ACP is partially mediated by both SES and estate planning. The next step is to determine whether legal ACP plays a role in the type of care individuals receive at the end of their life. Thus, this chapter examines the mediating effects of legal ACP on end of life care including hospital death, limited End-of-Life care decisions, complex care procedures, and congruent End-of-Life care.

Advance care planning has been encouraged in the United States since the late 1900s. Policies like the Patient Self Determination act of 1990 (Sabatino, 2010) encourage engagement in ACP by requiring providers reimbursed by the Centers for Medicaid and Medicare Services to inform patients of their right to participate in ACP and have their preferences formally documented in their medical record (Carr & Luth, 2016; Carr & Luth, 2017). A more recent policy added CMS reimbursement to providers for facilitating ACP discussions with their patients in 2016 (Tuller, 2016).

The role of ACP in end of life care and reducing complex and costly life sustaining therapies is mixed with some studies demonstrating positive effects and others reporting no difference in outcomes like intensive procedures, hospital death and limited care at the end of life for those participating in ACP. As an example, one study of intensive medical procedures in the last 6 months of life among 3,069 HRS decedents with linked CMS billing data found a 30% reduction (OR = 0.71, 95% CI: 0.57-0.89) in the odds of intensive procedure use for those who had completed an advance directive (Tscherhart et al., 2014). Another study of 3,746 HRS respondents also found a 30% reduction in hospital deaths in those who had completed an advance directive, although the association was not significant (OR = 0.71, 95% CI: 0.47-1.07), and found a similar 79% increase in preferences for limited care in certain situations at the end of life (OR =

1.79, 95% CI: 1.28-2.50) (Silveira et al., 2010). These studies support the influence of ACP on end of life care.

The role of ACP in end of life care is unclear and dependent on which outcomes are investigated. In a systematic review 10 out of 22 studies reported a statistically significant decrease in life sustaining treatment for those with legal ACP documents and 11 demonstrated no difference (Brinkman-Stoppelenburg et al., 2014). The same review reported mixed results for increased hospice use (5/7 studies) and decreased hospitalization/length of stay (2/8 studies) among those with legal ACP. Among studies in the review with complex ACP interventions, 3 out of 5 studies reported a decrease in life sustaining treatment and 2 had mixed results. The review of associations below will highlight some of the differences observed in the systematic review. All the studies below failed to propose testable hypotheses and only describe adjusted associations for some key relationships.

Association with Sociodemographic Factors

Chapters 1 and 2 describe the association of various sociodemographic factors with legal ACP. A brief review of key factors is presented below as well as a more detailed review of factors associated with end of life care. The literature on this topic is lacking and studies that are available often omit presenting sociodemographic associations with outcomes of interest. The information that is available is presented below.

Older *age* and female *gender* are both associated with higher likelihood of legal ACP. Chapter 2 presented prevalence rates for legal ACP and adjusted associations. In fully adjusted models, those aged 75-84 were twice as likely (OR = 2.26, 95% CI: 2.03-2.51) and those 85+ were four times as likely (OR = 4.10, 95% CI: 3.42-4.91) as those aged 65-74 to complete an advance directive or medical power of attorney. Females were 30% more likely than males to complete end of life health care planning (OR = 1.29, 95% CI: 1.16-1.43).

Most studies investigating the role of ACP in end of life outcomes fail to report associations for age. One paper presents results of a multinomial logistic regression comparing death in the

hospital to death in another location (home, nursing home, hospice) for 9,228 HRS decedents from 2002 to 2014 (Orlovic et al., 2019). Those dying at home were no different in years of age from those dying in a hospital and those dying in a nursing home (RRR = 1.06, $p < 0.001$) or in a hospice (RRR = 1.03, $p < 0.001$). The same paper reported significant associations between years of age and the use of life support (OR = 0.96, 95% CI: 0.96-0.97), dialysis (OR = 0.94, 95% CI: 0.93-0.95), and time spent in the ICU (OR = 0.96, 95% CI: 0.95-0.97) before death. In a study of 3,069 HRS decedents linked to Medicare claims data, there was a 33% decrease in intensive procedures among those 85-94 (OR = 0.67, 95% CI: 0.51-0.90) and 45% reduction among those 95+ years old (OR = 0.55, 95% CI: 0.35-0.85) compared to respondents aged < 75 (Tschrhart et al., 2014). A third study of 7,177 HRS decedents found no difference in age (continuous) among those who opted for aggressive end of life care (OR = 0.98, 95% CI: 0.96-1.00) (Portanova et al., 2017).

Minority race/ethnicity is associated with lower likelihood of legal ACP and a higher likelihood of complex care and a hospital death. Chapters 2 and 3 presented adjusted results with Non-Hispanic Blacks (OR = 0.60, 95% CI: 0.52-0.70) and Hispanics (OR = 0.46, 95% CI: 0.35-0.60) being about half as likely to complete legal health care documents as Non-Hispanic Whites. Two studies have reported associations between race/ethnicity and end of life outcomes. The first reported significant differences in location of death with Non-Hispanic Blacks (44%) and Hispanics (43%) being more likely to die in the hospital compared to Non-Hispanic Whites (34%) (Orlovic et al., 2019). In the same study, Non-Hispanic Blacks and Hispanics were more likely than Non-Hispanic Whites to be given life support (OR = 1.49, 95% CI: 1.24-1.79 and OR = 2.44, 95% CI: 1.87-3.18, respectively) and dialysis (OR = 1.79, 95% CI: 1.35-2.39 and OR = 1.83, 95% CI: 1.20-2.79, respectively) but equally likely to spend time in the ICU (OR = 1.04, 95% CI: 0.87-1.23 and OR = 1.15, 95% CI: 0.89-1.49, respectively). In another study of 3,069 HRS decedents Blacks were twice as likely (OR = 2.02, 95% CI: 1.52-2.69) and Hispanics equally likely (OR = 1.53, 95% CI: 1.00-2.34) as Whites to have an intensive procedure (intubation and mechanical ventilation, gastrostomy tube, enteral or parenteral nutrition, cardiopulmonary resuscitation, or tracheostomy) in the last 6 months of life (Tschrhart et al., 2014).

Chapters 2 and 3 demonstrated the associations between higher *socioeconomic status* and legal ACP. Weighted analyses in chapter 2 for 9,557 HRS core respondents demonstrated that those with higher education and wealth were significantly more likely to complete an advance directive or medical power of attorney. Aim 2 demonstrated that higher SES (education and wealth) quintiles treated as an ordinal variable was significantly associated with higher rate of legal ACP after adjusting for sociodemographic factors like age, gender, race/ethnicity, and health indicators (OR = 1.18, 95% CI: 1.13-1.24).

SES is associated with location of death and not intensive procedures at the end of life. Orlovic et al found that those in the 3rd through 5th income quintiles were 28-35% more likely to die at home rather than in a hospital (ORs = 1.28-1.35), but did not find a significant association for education (< high school, high school, college) (Orlovic et al., 2019). In the same study of 9,228 deceased HRS respondents neither education nor income was associated with receiving intensive end of life procedures like life support, dialysis, OR ICU admission. Similar results are reported in a second study that failed to find an association between education (less than high school, completed high school), net worth quartiles, and End-of-Life procedures including intubation, feeding tubes, and CPR. (Tschirhart et al., 2014). The association for estate value has not been reported in the literature.

Indicators of *social support* including marital status and number of living children have mixed associations with legal ACP. Aim 2 investigated the mediating role of estate planning on the relationship between race/ethnicity and legal ACP. In the fully adjusted model, those who were separated/divorced were 83% more likely than married/partnered respondents to complete legal ACP (OR = 1.83, 95% CI: 1.60-2.11) and there was no difference between those with and without children (OR = 0.94, 95% CI: 0.75-1.18).

In a study of 9,228 HRS decedents from 2002-2014, living with a partner was not associated with a difference in the likelihood of dying at home compared to in a hospital (RRR = 0.97), but the number of resident children was (RRR = 1.34, $p < 0.001$) (Orlovic et al., 2019). Two additional studies have failed to report a significant association between marriage status and

aggressive end of life care. One study included four groups (married (ref), divorced or separated, widowed, never married) and reported a significant difference only for those who were widowed (OR = 0.48, 95% CI: 0.26-0.88) (Portanova et al., 2017). The second study of 3,069 HRS decedents from 2002 to 2008 reported an insignificant association for marriage status (OR = 0.95, 95% CI: 0.75-1.21) (Tschirhart et al., 2014). This study also reported an insignificant adjusted association for relatives living nearby (OR = 0.89, 95% CI: 0.72-1.09).

In the literature, results for support from family members is unclear. An HRS study of 1,102 decedents in 2000 reported a 35% higher proportion had completed a medical power of attorney among those with grandchildren compared to those without (OR = 1.35, $p < 0.05$), but there was no association between grandchildren and having advance directives (Gerst & Burr, 2008). Another study failed to find a significant association between the number of living children a respondent has defined as zero, one, two, or three or more and legal ACP (Carr, 2012). A third study reported that those who had a relative living nearby were less likely to receive an intensive procedure in the last 6 months of life (Tschirhart et al., 2014). However, the adjusted association was not statistically significant (OR = 0.89, 95% CI: 0.72-1.09).

Markers of *health status* demonstrated mixed associations with legal ACP in fully adjusted models in chapter 3. Being hospitalized since their last HRS interview increased a respondent's likelihood of completing an advance directive or assigning a medical power of attorney (OR = 1.72, 95% CI: 1.48-1.99). In the same analysis, cognition score categorized in quintiles was not significantly associated with legal ACP.

Two studies include adjusted associations between specific health conditions and aggressive end of life care and found those with cognitive impairment received less aggressive care. The first study investigated the likelihood of choosing aggressive end of life care among 7,177 HRS decedents from 2000 to 2012 and included conditions like cancer, lung disease, heart conditions, and depression, but only found a significant association for memory problems (defined as memory impairment) – those with memory problems were less likely to receive aggressive care (OR = 0.49, 95% CI: 0.29-0.82) (Portanova et al., 2017). The second study of 3,069 HRS decedents

from 2002 to 2008 investigated the likelihood of receiving an intensive procedure like intubation, parenteral nutrition, and cardiopulmonary resuscitation in the last 6 months of life and included conditions like chronic kidney disease, chronic obstructive pulmonary disease, congestive heart failure, and diabetes (Tschirhart et al., 2014). In this study, those with Alzheimer's disease were 30% less likely to receive aggressive care (OR = 0.71, 95% CI: 0.54-0.94).

Associations between legal ACP and end of life care are mixed and dependent on the definitions of ACP and outcomes investigated. In a study of 1,985 HRS decedents with cancer who died between 2000 and 2012 those with a medical power of attorney were 30% less likely to die in a hospital (OR = 0.70, 95% CI: 0.52-0.94) but those with an advance directive were equally as likely to die in the hospital than those without a directive (OR = 0.93, 95% CI: 0.69-1.25) (Narang et al., 2015). Those with advance directives were 251% more likely to limit or withhold treatment at the end of life (OR = 2.51, 95% CI: 1.52-4.11) compared to only a 52% higher limitation among those with a medical power of attorney (OR = 1.52, 95% CI: 0.78-2.66). With an alternate definition for ACP (discussing end of life care, completing an advance directive, or assigning a medical power of attorney), one paper using data for 4,399 HRS decedents from 1993 to 2007 found that those with ACP were less likely to die in the hospital (OR = 0.87, 95% CI: 0.80-0.94) and equally likely to be admitted to the intensive care unit (OR = 0.92, 95% CI: 0.76-1.08) compared to those without ACP (Bischoff et al., 2013). In a study of 3,069 HRS decedents, having an advance directive was associated with a decreased likelihood of receiving an intensive procedure in the last 6 months of life (OR = 0.71, 95% CI: 0.57-0.89) (Tschirhart et al., 2014).

It is hypothesized that Non-Hispanic Blacks and Hispanics will be more likely to receive aggressive care at the end of life compared to Non-Hispanic Whites but that the main effect of this relationship will be reduced when legal ACP and social support are accounted for. For the outcomes in this investigation, it is expected that these two minorities will be less likely to have decisions made to limit End-of-Life care and more likely to die in the hospital and receive complex care leading up to their death. In a recent study of 9,228 HRS decedents from 2002-2014, Non-Hispanic Blacks (OR = 0.37, 95% CI: 0.27-0.52) and Hispanics (OR = 0.52, 95% CI: 0.30-0.89)

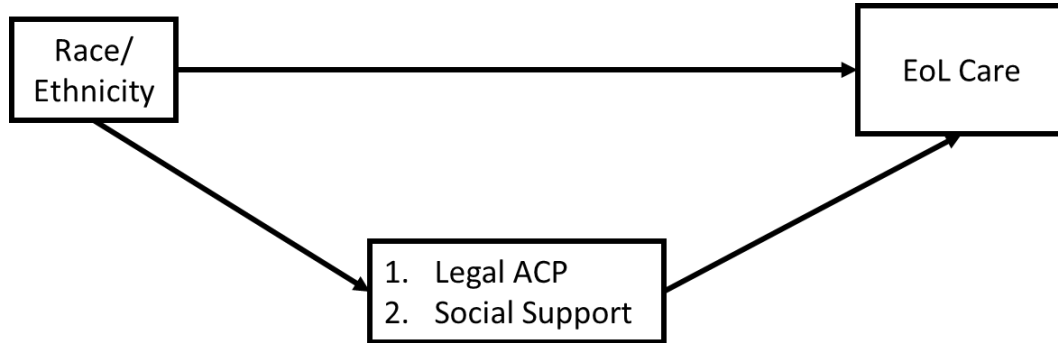
were significantly less likely to express a desire to have treatment withheld at the end of life (Orlovic et al., 2019). Blacks (OR = 0.52, 95% CI: 0.42-0.66) and Hispanics (OR = 0.46, 95% CI: 0.33-0.65) were also less likely to have end of life care decisions involve withholding treatment. A smaller study of 3,069 HRS decedents with data linked to Medicare claims reported similar findings with Non-Hispanic Blacks (OR = 2.02, 95% CI: 1.52-2.69) and Hispanics (OR = 1.53, 95% CI: 1.00-2.34) being more likely to receive intensive procedures (ex. Intubation, cardiopulmonary resuscitation, and tracheostomy) compared to Non-Hispanic Whites (Tschirhart et al., 2014).

The objective of this chapter is to further describe sociodemographic associations with end of life care and investigate the possible mediating effects of legal ACP and social support on the relationship between race/ethnicity and end of life care. First, the mediating hypothesis will be tested in the full exit interview sample investigating the mediating role for three outcomes: decisions to limit care at the end of life, hospital death, and complex care. Next, the hypothesis will be investigated in a subsample testing for the mediating effect on receipt of end of life care that is congruent with the respondent's wishes. For each outcome, mediation assumptions are assessed prior to modeling. Next, multivariate binary logistic regression modeling is used to investigate the role of the two potential mediators (legal ACP and social support).

METHODS

Conceptual Model: Aim 3.1 investigates the mediation model presented in Figure 4.1a. In this model, the effect of race/ethnicity on end of life care is hypothesized to be mediated by legal ACP and social support. The objective of this aim is to investigate the relationships proposed in the conceptual model. Three outcomes will be investigated: decisions to limit care at the end of life, hospital death, and complex care in the time between the respondent's last core interview and death. Confounders are excluded from the figure but described in the text. This aim adds to the literature on ACP and end of life care by proposing a testable hypothesis for the disparities in end of life care.

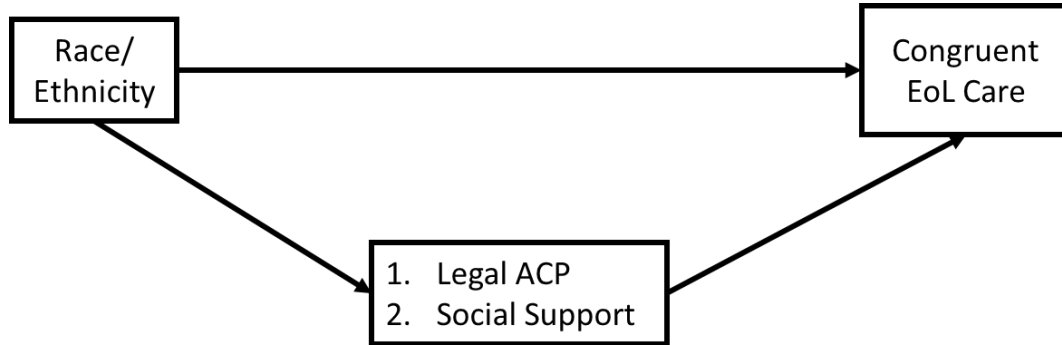
Figure 4.1a- Conceptual Model for Specific Aim 3.1



Aim 3.2 investigates the mediation model presented in Figure 4.1b. In this model, the effect of race/ethnicity on receipt of end of life care that is congruent with the respondent's wishes is hypothesized to be mediated by legal ACP and social support. The objective of this aim is to investigate the relationships proposed in the conceptual model. The outcome is an indicator of a respondent's core interview answers to a desire to receive limited care, have care withheld, or receive comfort care only and whether that preference was honored by decisions at the end of life to limit care. Confounders are excluded from the figure but described in the text. This aim adds to the literature by proposing a specific, testable hypothesis.

It is hypothesized that Non-Hispanic Blacks and Hispanics will be less likely to receive care congruent with their preferences compared to Non-Hispanic Whites, but that the main effect of this relationship will be reduced when legal ACP and social support are accounted for. There is no literature using HRS data with respondent preferences matched to end of life decisions investigating the likelihood of preferences being honored. One study presents results comparing preferences for care expressed in an advance directive and end of life outcomes for 4,399 HRS decedents, but does not provide results for racial/ethnic differences (Bischoff et al., 2013). Findings were mixed with those expressing a preference for comfort care only (OR = 0.78, 95% CI: 0.71-0.86) being less likely to die in the hospital compared to those without ACP. However, those expressing a preference for comfort care only (OR = 0.86, 95% CI: 0.74-1.01) and limited care (OR = 0.72, 95% CI: 0.43-1.21) were equally likely to be admitted to an intensive care unit compared to those without ACP.

Figure 4.1b- Conceptual Model for Specific Aim 3.2



Dataset: The Health and Retirement Study is a nationally representative survey completed with U.S. adults aged 50 and older every 2 years. Respondents and their spouses are included in the interviews and when a respondent dies a spouse, close family member, or friend is interviewed in an exit interview to gather information about the respondent's end of life experiences. For this study, two samples are used. Aim 3.1 uses the full exit sample described in the previous chapter. It includes exit interview data from 2002 through 2016 merged with matched core interview data for 2000-2014. The core interview data is included for sociodemographic factors provided by the living respondent including gender, race/ethnicity, marital status, and wealth. Exit interview data provides information about the end of life experience and includes information like location of death, decisions made at the end of life, and type of care received at the end of life. Multiple waves of data are used to increase the sample size and provide enough Hispanics for subsample analyses. Due to the questionnaire skip sequence limiting ACP questions to those older than 65 years in core interviews, an inclusion criterion is age ≥ 65 at the last core interview before death. A second inclusion criteria is death in the study period as indicated by an exit interview in HRS waves from 2002-2016. Respondents living in nursing homes prior to death are excluded from analyses, because ACP experiences are different from that of the community dwelling population. Respondents with missing information are excluded from the sample through listwise deletion.

Aim 3.2 uses a subset of the HRS exit data for exit interviews in 2014 and 2016 merged with core data from 2012-2014. These years are used because they contain respondent preferences

for end of life care in core interviews and similarly worded questions for proxies about the end of life experience in exit interviews.

Measures

PREDICTORS: Race/ethnicity (Non-Hispanic White, Non-Hispanic Black, and Hispanic) is the main predictor for aims 3.1 and 3.2. In analyses with sample size concerns or SAS limitations, race/ethnicity is dichotomized with main tables presenting results for Non-Hispanic Whites compared to minorities (Non-Hispanic Black and Hispanic) and sensitivity analyses tables including results for each minority group individually compared to Non-Hispanic Whites.

Table 4.1- Aim 3 Race/Ethnicity, Predictor

<i>Predictor</i>	<i>HRS Question</i>	<i>Coding</i>
Race/Ethnicity	Do you consider yourself to be Hispanic or Latino? [respondent] What race do you consider yourself to be: White, Black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, or something else? [respondent]	1 = Non-Hispanic White, 2 = Non-Hispanic Black, 3 = Hispanic

OUTCOMES: Three outcomes are investigated for aim 3.1 (hospital death, limited care decision, complex care procedures) and one outcome for aim 3.2 (congruent end of life care). Hospital death is an indicator of the respondent's death being in the hospital. A proxy exit interview question is used with responses indicating the location of death was in the hospital coded as 1 and any other location coded as 0.

Limited end of life care decision is a composite indicator of any decisions to limit care at the end of life rather than to unconditionally provide all care possible to prolong life. Responses from 3 proxy exit interview questions are dichotomized for positive responses (1) and negative responses (0). The three questions are listed in Table 4.2. The final variable is coded as 1 if there was a positive response to any of the three questions and 0 if all responses were negative.

The complex care procedures variable is a composite of recent hospitalizations with any of three life sustaining procedures including ICU admission, life support, and dialysis. The variable

is a dichotomized indicator of any procedure (yes) or no reported procedures or hospitalizations (no). The timeline for this variable is not necessarily closely tied to the hospitalization at death. This question sequence in the interview refers to the timeframe between the last HRS core interview with the living respondent and death. The complex care procedure could have occurred up to 2 years before death and may not be associated with the last hospitalization before death.

Congruent End-of-Life care is a composite indicator of whether a respondent's preferences for limited care at the end of life were honored. A core interview follow-up question after asking about advance directives was used to determine if the respondent expressed a desire to have limited end of life care. A series of exit interview questions following a question about whether decisions needed to be made about the care and treatment of the respondent in the final days of their life were used to determine the type of care received at the end of life. Respondents answering positively in the core interview were coded as having a preference for limited care (1) and others coded as no preference for limited care (0). In contrast to a question asking if decisions were made to give all care possible unconditionally to prolong life, the three exit interview questions used are indicators of decisions to limit end of life care in some way. All three are considered together as one indicator of any decisions to limit care. Each question was dichotomized (yes = 1, no = 0). The final limited care decision variable is an indicator of any positive response to the three questions (limited care decision = 1) or all negative responses (no limited care decision = 0). The final congruent End-of-Life care variable is 1 if the proxy's response matched the respondent's preference and 0 if not.

Table 4.2- Aim 3 End-of-Life Care, Outcome

<i>Outcome</i>	<i>HRS Question</i>	<i>Coding</i>
Hospital Death	At the time of death, was (respondent) in a hospital, in a nursing home, at home, in a hospice, or what? [proxy]	1 = hospital death, 0 = death in other location
Limited End-of-Life Care Decision	Did those last decisions involve limiting care in certain situations? [proxy] (limited care decision) Did those last decisions involve withholding any treatment? [proxy] (decision to withhold treatment) Did those last decisions rest largely on keeping (respondent) comfortable and pain free without taking extensive measures to prolong life? [proxy] (decision for comfort care)	1 = decision to limit care at End-of-Life, 0 = no decision to limit End-of-Life care
Complex Care Procedure	During any of those hospital stays did [respondent's first name] spend any time in an intensive care unit? [proxy] During any of those hospital stays did [she/he] use life support equipment, such as a respirator? [proxy] During any of those hospital stays did [she/he] use kidney dialysis services? [proxy]	1 = yes to any intensive care unit, life support, or dialysis; 0 = no hospitalizations or uncomplicated hospitalizations
Congruent End-of-Life Care (Aim 3.2)	Do these instructions express a desire to limit the care or medical treatment that you receive in certain situations? [respondent] (limited care preference) Did those last decisions involve limiting care in certain situations? [proxy] (limited care decision) Did those last decisions involved withholding any treatment? [proxy] (decision to withhold treatment) Did those last decisions rest largely on keeping (respondent) comfortable and pain free without taking extensive measures to prolong life? [proxy] (decision for comfort care)	1 = care congruent with patient's preference, 0 = care discordant with patient preference

MEDIATORS: The first hypothesized mediator is legal ACP (yes, no) as defined in aim 1. Legal ACP is a dichotomous indicator of completing an advance directive or assigning a medical power of attorney or completing neither. The second proposed mediator is an ordinal (quintiles) of any financial or relocation support from family or friends and living family members (children, siblings, or spouse). A series of HRS questions are used to determine how much social support was available to the respondent.

Due to HRS skip sequences and limited responses to financial and relocation support questions, three RAND variables and seven core and exit interview questions were used together as an indicator of number of living supporters and support provided by family or friends (Table 4.3). The RAND variables are generated from multiple HRS questions and provide the number of living children (including stepchildren), number of living siblings, and presence of a spouse of the respondent. The HRS core and exit interview questions are about financial or relocation support and asked about children, family, and friends. Some of the HRS interview questions are skipped if the respondent did not report any living children. If the number of living children in the RAND variable is 0, social support from children is coded as zero rather than missing.

Three core interview responses from living respondents were used to generate a support-received subscale. The first asks if a child lived within 10 miles of the respondent. The second and third ask about financial support greater than \$500 provided to the respondent by children (or grandchildren) and friends, respectively. Four exit interview responses from proxies are also used. The first asks about financial support (at least \$500) provided by the respondent's children (or grandchildren) in the last two years before death. The next three questions ask about relocation in the last two years before death. One asks if any children moved close and the other two ask if the respondent moved in with someone or if someone move in with the respondent.

The HRS skip sequence results in many missing responses for the financial and relocation support variables. All the variables are considered together in one composite indicator of financial or relocation support to increase the sample size for analyses. Responses for each question are coded as positive (1), negative (0), and don't know or missing (.). A sum is calculated separately for living supporters and support received. Each subscale is standardized before summing the two subscales and grouping respondents into quintiles of social support. Lower scores indicate less social support. Those missing responses for all questions are coded as missing and later excluded from analyses.

Table 4.3- Aim 3 Legal ACP & Social Support, Mediators

<i>Mediator</i>	<i>HRS Question</i>	<i>Coding</i>
Legal ACP (advance directive or medical power of attorney)	Have you provided written instructions about the care or medical treatment that you would want to receive if you cannot make those decisions yourself? This is sometimes called a "Living Will". [respondent] Have you made any legal arrangements for a specific person or persons to make decisions about your care or medical treatment if you can not make those decisions yourself? This is sometimes called a "Durable Power of Attorney for Health Care". [respondent]	1 = yes to either, 0 = no to both
Social Support	Do any of your children live within 10 miles of you? [respondent] Since your last interview did you receive financial help totaling \$500 or more from any of your children (or grandchildren)? [respondent] Did you receive financial help totaling \$500 or more since your last interview from friends or relatives other than (children, grandchildren, great grandchildren, or parents/children, grandchildren, or parents/children or parents)? [respondent] In the last two years before (respondent's) death did they receive financial help totaling \$500 or more from any of their children (or grandchildren)? [proxy] In the two years preceding (respondent's) death, did they or any of their children move in order to be closer to each other but not living in the same house or apartment? [proxy] In the two years preceding (respondent's) death, did they move into and then out of someone else's house or apartment? [proxy] In the two years preceding (respondent's) death, did anyone move into the house or apartment where (respondent) was living to help them but then move out before they died? [proxy] How many living children or step-children do you have? [RAND: respondent] Just to clarify, are you currently separated, divorced, widowed, or have you never been married? [RAND: respondent] (1 = married/partnered, 0 = married, spouse absent, separated, divorced, separated/divorced, widowed, never married) Number of living siblings [RAND: respondent]	Items 1-7 summed and standardized (subscale 1-support received), items 8-10 summed and standardized (subscale 2-living supporters). Subscales 1 and 2 summed and collapsed into quintiles

COVARIATES: Covariates for aims 3.1 and 3.2 include age, gender, SES, estate value, cognition score, and recent hospitalization. Age (65-74, 75-84, 85+), gender (male, female), SES (quintiles), estate value (some, none, unknown), cognition score (quintile 1 = worst, quintile 5 = best), and recent hospitalization (yes, no) are operationalized as described in previous aims.

Table 4.4- Aim3 Sociodemographic Variables, Covariates

<i>Covariate</i>	<i>HRS Question</i>	<i>Coding</i>
Age	Calculated from the respondent's birthdate [respondent]	1 = 65-74, 2 = 75-84, 3 = 85+ years old
Gender	Is [R's first name] male or female? (coverscreen)	1 = male, 2 = female
Socioeconomic Status (standardized, summed, and categorized into quintiles)	Education- What is the highest grade of school or year of college you completed? (no degree, high school/GED, Associate's degree/less than Bachelor's, Bachelor's, Master's/MBA/Law/MD/PhD) [respondent] Wealth- Total non-housing wealth (RAND imputed) = sum of wealth components less debt [respondent]	Education and wealth standardized, summed, and collapsed into quintiles
Estate Value	The next questions are about [respondent's first name]'s assets and possessions, excluding any life insurance. Have they been divided up among the heirs, have they not yet been distributed, was there nothing of much value to distribute, what? [proxy]	1 = nothing of much value, 0 = divided or retained/not yet divided
Total Cognition Score	Scale calculated by RAND, includes items like word recall, serial counting, and word associations (range = 0-35) [respondent]	quintiles (1 = worst, 5 = best)
Recent Hospitalization	Since your last interview, have you been a patient in a hospital overnight? [respondent & proxy]	1 = yes, 0 = no

Analysis: First, because data for this sample represents 16 years, key variables were assessed for secular trends. Rates of hospital death, decisions to limit End-of-Life care, and complex care procedures were compared for the years 2002-2006, 2008-2012, and 2014-2016.

For both aim 3.1 and 3.2, descriptive statistics were performed with frequencies and chi-square statistics reported for categorical variables. Unadjusted bivariate prevalence of outcomes by race/ethnicity were calculated. Mediation assumptions adjusted for age, gender, and SES were checked prior to multivariate modeling. Associations adjusted for age, gender, and socioeconomic

status were assessed between 1) the predictor and outcome, 2) the predictor and mediator, and 3) the mediator and outcome. Intercorrelation of covariates was assessed with a correlation matrix.

Multivariate, binary logistic regression modeling was used to test for mediation effects. To investigate the hypothesized mediating relationship logistic regression and the SAS causal mediation procedure were used. For aim 3.1, four models were generated. Model 1 includes the main independent variable (race/ethnicity) adjusted for sociodemographics (age, gender, SES, and estate value). Model 2 adds health indicators (recent hospitalization and cognition score). Model 3 adds legal ACP and model 4 adds social support. A different approach is taken for aim 3.2 due to the smaller sample size. First, bivariate associations are reviewed. Important demographic covariates (ex. age, gender) and those with significant bivariate associations are then included in subsequent models to determine the adjusted mediating effect of the hypothesized mediators meeting modeling assumptions. Model fit was assessed with Hosmer-Lemeshow p-values and c-statistics.

For hypothesized mediators with appropriate associations, the SAS causal mediation procedure is used to determine the size of the mediating effect. There are limitations to this procedure that have been addressed in the previous chapter (dichotomous or continuous variables only). In the analyses here, the same adjustments are made to key variables so the procedure can be used. Race/ethnicity will be dichotomized (Non-Hispanic White, minority (Non-Hispanic Black and Hispanic)) and social support quintiles treated as a continuous variable.

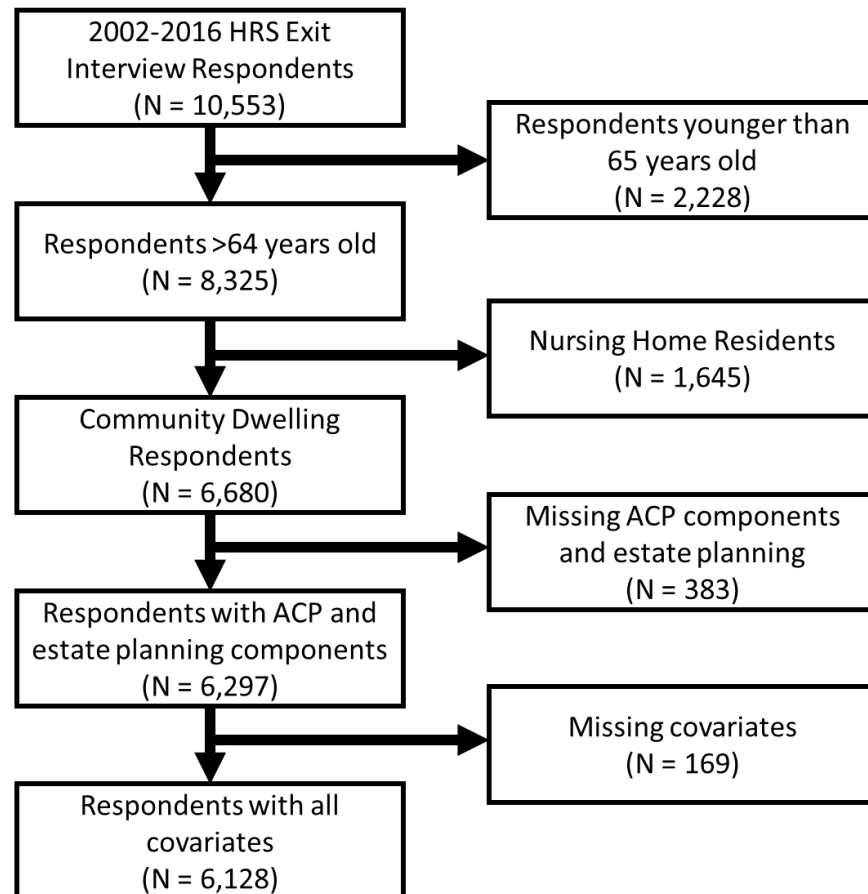
All analyses are unweighted. Although the HRS uses a complex sampling design for core interviews and provides weights for generalizing to the U.S. population, unique exit interview weights were not provided.

RESULTS

Data from the 2002-2016 HRS Exit interview with proxies of deceased respondents for 10,553 participants was used to generate the analytic sample for aim 3.1 (Figure 4.2a). There were 2,228 respondents less than age 65 at their last core interview that were excluded from the sample.

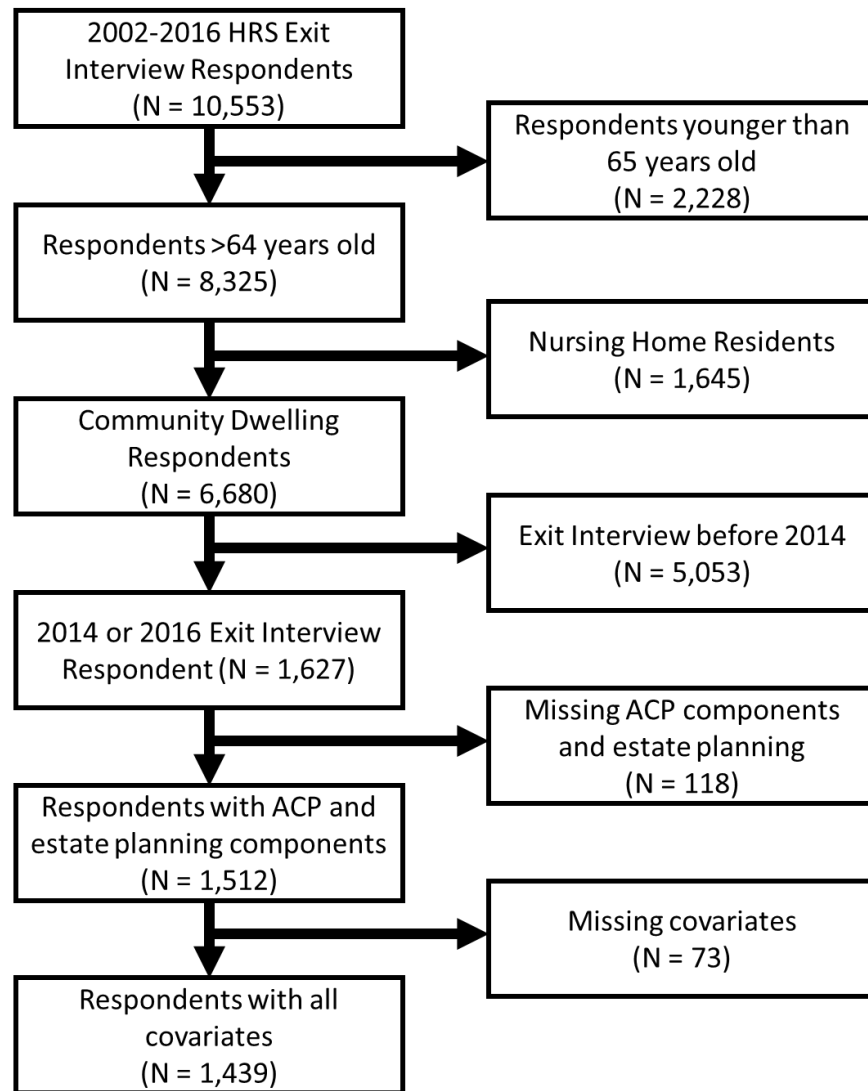
Those living in a nursing home ($n = 1,645$) and with missing data for all the advance care planning component variables and estate planning ($n = 383$) were also excluded. Listwise deletion was used to exclude an additional 169 respondents with missing values for covariates. The final sample size is 6,128.

Figure 4.2a- Aim 3.1 Sample Flow Chart



The sample for aim 3.2 is a subset of the sample used in aim 3.1 that includes respondents with exit interviews for 2014 and 2016 only (Figure 4.2b). Respondents with interviews prior to 2014 ($n = 5,053$) are excluded. Those with missing data for all advance care planning component variables and estate planning ($n = 118$) were excluded. Listwise deletion was used to exclude an additional 73 respondents with missing values for covariates. The final sample size is 1,439.

Figure 4.2b- Aim 3.2 Sample Flow Chart



Sample Characteristics

AIMS 3.1 & 3.2

Table 4.5 provides sample characteristics for aims 3.1 and 3.2. The total unweighted sample size used to investigate end of life care (hospital death, limited care decisions, and complex care procedures) is 6,128 decedents.

Most respondents were aged 75-84 years old (40%) and Non-Hispanic White (78%). Many respondents had an unknown estate value (41%). Among those with a known estate value, more

had something of value (32%). Among those with known cognition score, most were in the second quintile (17%). Majority of respondents had been hospitalized since their last core interview (81%) and had completed an advance directive or assigned a medical power of attorney (66%). There were more respondents in the lowest quintile of social support than the other groups (22%). There were minimal differences for gender.

Most respondents died in the hospital (63%) compared to another location. More proxies reported decisions to limit care at the end of life (57%). More than half (57%) of those interviewed reported that the respondent had received a complex care procedure (life support, ICU admission, or dialysis) in the time leading up to the respondent's death.

Aim 3.2 uses a subsample of respondents with matching core interview preferences for end of life care and exit interview responses for end of life care decisions. These were only available for 2 waves of HRS interviews. Sample characteristics for aim 3.2 are comparable to those for aim 3.1 described above with minor differences. For example, the subsample was slightly older with fewer respondents aged 65-74, the youngest age group (22% compared to 27%). Respondents in the subsample also reported higher completion of legal ACP (71%). Respondents in the subset were marginally more likely to receive end of life care congruent with their preferences (51%).

Table 4.5 HRS Exit Unweighted Sample Characteristics (Aims 3.1 & 3.2, Exit)

Characteristic	End-of-Life Care Sample (N = 6,128)		Congruent End-of-Life Care Sample (N = 1,439)	
	% or mean	n or SD	% or mean	n or SD
Age, n (%)				
65-74	26.75	1,639	21.82	314
75-84	40.06	2,455	43.15	621
85+	33.19	2,034	35.02	504
Gender, n (%)				
Male	49.04	3,005	50.24	723
Female	50.96	3,123	49.76	716
Race/Ethnicity, n (%)				
Non-Hispanic White	78.07	4,784	77.00	1,108
Non-Hispanic Black	14.44	885	14.52	209
Hispanic	7.49	459	8.48	122
SES Quintiles, n (%)				
Q1	19.48	1,194	20.01	288
Q2	19.92	1,221	20.01	288
Q3	19.71	1,208	19.53	281
Q4	20.53	1,258	20.22	291
Q5	20.35	1,247	20.22	291
Estate Value, n (%)				
Some	31.64	1,939	28.21	406
None	27.45	1,682	28.98	417
Unknown	40.91	2,507	42.81	616
Cognition Score, n (%)				
Q1 worst	15.96	978	14.11	203
Q2	17.25	1,057	19.46	280
Q3	16.50	1,011	17.44	251
Q4	16.02	982	16.33	235
Q5 best	14.82	908	14.38	207
Unknown	19.45	1,192	18.28	263
Recent Hospitalization, n (%)				
No	18.88	1,157	17.30	249
Yes	81.12	4,971	82.70	1,190
Legal ACP, n (%)				
No	33.84	2,074	28.56	411
Yes	66.16	4,054	71.44	1,028
Social Support, n (%)				
Q1 least	22.49	1,378	18.62	268
Q2	16.33	1,001	19.81	285
Q3	20.41	1,251	20.43	294
Q4	20.99	1,286	20.29	292

Q5 most	19.78	1,212	20.85	300
Hospital Death, n (%)				
No	63.02	3,862		
Yes	36.98	2,266		
Decision to Limit End-of-Life				
Care, n (%)				
No	57.11	3,500		
Yes	42.89	2,628		
Complex Care Procedures, n (%)				
No	57.23	3,507		
Yes	42.77	2,621		
Congruent End-of-Life Care, n				
(%)				
No			48.51	698
Yes			51.49	741

Abbreviations- ACP: Advance Care Planning, End-of-Life: End of Life

Bivariate Associations

AIM 3.1

Unweighted and unadjusted bivariate associations for End-of-Life care are presented in Table 4.6a. Outcomes include hospital death (37%), decisions to limit End-of-Life care (43%), and complex care procedures (43%), which include life support, dialysis, or ICU admission. Weights are not used, because unique sampling weights are not provided for exit interviews. All three outcomes were significantly associated with race/ethnicity with minorities (Non-Hispanic Blacks and Hispanics) being more likely to die in a hospital and complex care procedures and less likely to receive limited end of life care. Age was also associated with all three outcomes with younger respondents more likely to die in the hospital and undergo complex care procedures and less likely to receive limited care at the end of life. Men were more likely to die in a hospital and less likely to receive limited End-of-Life care, but there was no gender difference in complex care procedures. SES quintiles were significantly associated with hospital death and limited End-of-Life care, but there were no clear trends. Respondents with some estate value were less likely to die in a hospital and receive complex care procedures, but more likely to receive limited End-of-Life care. The two health measures (cognition score and recent hospitalization) were significantly associated with the three outcomes, apart from cognition score, which was not associated with limited End-of-Life care. There were no distinct associations between social support and hospital death or limited End-of-Life care decisions. Those with higher levels of social support were increasingly more likely to undergo complex care procedures. Those with legal ACP were less likely to die in a hospital and more likely to receive limited End-of-Life care. Legal ACP was not associated with complex care procedures in the time leading up to death.

Table 4.6a- Bivariate Associations with End-of-Life Care, unweighted (Exit)

Characteristic	Limited End-of-Life					
	Hospital Death = Yes		Care = Yes		Complex Care = Yes	
	Mean (SD)/n (%)	Chi-square p	Mean (SD)/n (%)	Chi-square p	Mean (SD)/n (%)	Chi-square p
Race/Ethnicity		<0.0001		<0.0001		<0.0001
NHW	1,679 (35.10)		2,125 (44.42)		1,989 (41.58)	
NHB	397 (44.86)		325 (36.72)		393 (44.41)	
Hispanic	190 (41.39)		178 (38.78)		239 (52.07)	
Age, n (%)		<0.0001		0.0009		<0.0001
65-74	687 (41.92)		658 (40.15)		815 (49.73)	
75-84	946 (38.53)		1,033 (42.08)		1,072 (43.67)	
85+	633 (31.12)		937 (46.07)		734 (36.09)	
Gender, n (%)		0.0307		<0.0001		0.2202
Male	1,152 (38.34)		1,200 (39.93)		1,309 (43.56)	
Female	1,114 (35.67)		1,428 (45.73)		1,312 (42.01)	
SES Quintiles, n (%)		0.0148		0.0013		0.2375
Q1	472 (39.53)		466 (39.03)		542 (45.39)	
Q2	482 (39.48)		497 (40.70)		516 (42.26)	
Q3	432 (35.76)		528 (43.71)		517 (42.80)	
Q4	428 (34.02)		556 (44.20)		513 (40.78)	
Q5	452 (36.25)		581 (46.59)		533 (42.74)	
Estate Value		<0.0001		<0.0001		0.0081
Some	744 (38.37)		875 (45.13)		827 (42.65)	
None	686 (40.78)		635 (37.75)		769 (45.72)	
Unknown	836 (33.35)		1,118 (44.60)		1,025 (40.89)	
Cognition Score, n (%)		<0.0001		0.9679		<0.0001
Q1 worst	330 (33.74)		423 (43.25)		379 (38.75)	
Q2	406 (38.41)		454 (42.95)		470 (44.47)	
Q3	397 (39.27)		438 (43.32)		451 (44.61)	
Q4	384 (38.10)		429 (43.69)		445 (45.32)	

Q5 best	366 (40.31)		383 (42.18)		455 (50.11)	
Unknown	383 (32.13)		501 (42.03)		421 (35.32)	
Recent Hospitalization, n (%)		<0.0001		<0.0001		<0.0001
No	547 (47.28)		380 (32.84)		289 (24.98)	
Yes	1,719 (34.58)		2,248 (45.22)		2,332 (46.91)	
Legal ACP		<0.0001		<0.0001		0.7462
No	937 (45.18)		702 (33.85)		893 (43.06)	
Yes	1,329 (32.78)		1,926 (73.29)		1,728 (42.62)	
Social Support		0.6753		0.169		<0.0001
Q1 least	499 (36.21)		554 (40.20)		526 (38.17)	
Q2	358 (35.76)		423 (42.26)		410 (40.96)	
Q3	479 (38.29)		557 (44.52)		536 (42.85)	
Q4	486 (37.79)		562 (43.70)		599 (46.58)	
Q5 most	444 (36.63)		532 (43.89)		550 (45.38)	

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Rates of the three end of life outcomes by Race/Ethnicity in aim 3.1 are presented in Figures 4.3a-c. Hospital death was less common among respondents (37%) than death in another location (63%). Non-Hispanic Whites (35%) experienced death in a hospital less often than Non-Hispanic Blacks (45%) and Hispanics (41%). Decisions to limit care at the end of life were made less than half the time (43%) with Non-Hispanic Whites (44%) more likely than Non-Hispanic Blacks (37%) or Hispanics (39%) to have that decision made. Receipt of complex care procedures leading up to death also occurred about half the time (43%) with Hispanics (52%) and Non-Hispanic Blacks (44%) being more likely to receive these treatments than Non-Hispanic Whites (42%).

Figure 4.3a- Hospital Death by Race/Ethnicity, unweighted (Exit)

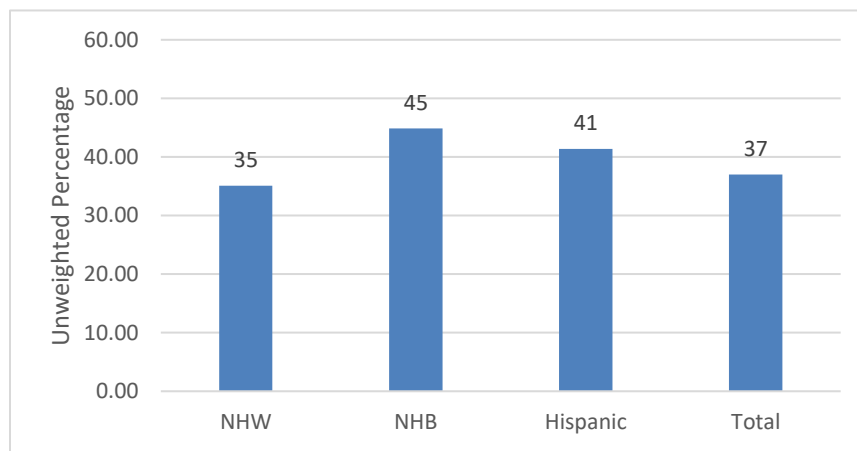


Figure 4.3b- Limited End-of-Life Care Decision by Race/Ethnicity, unweighted (Exit)

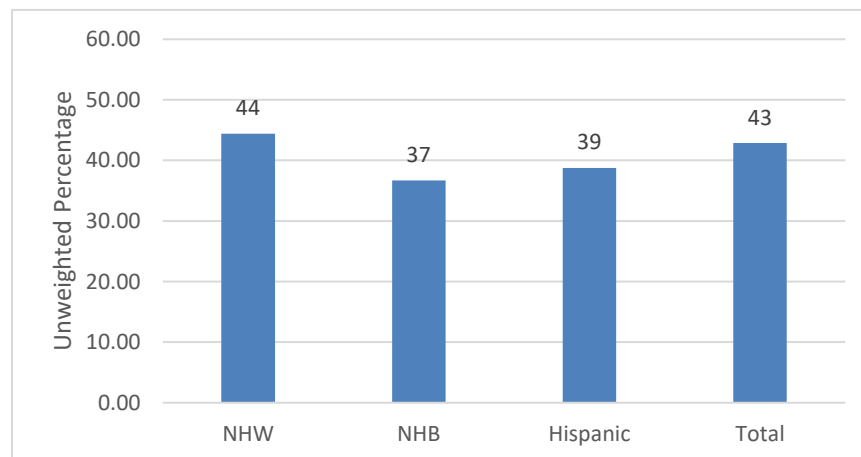
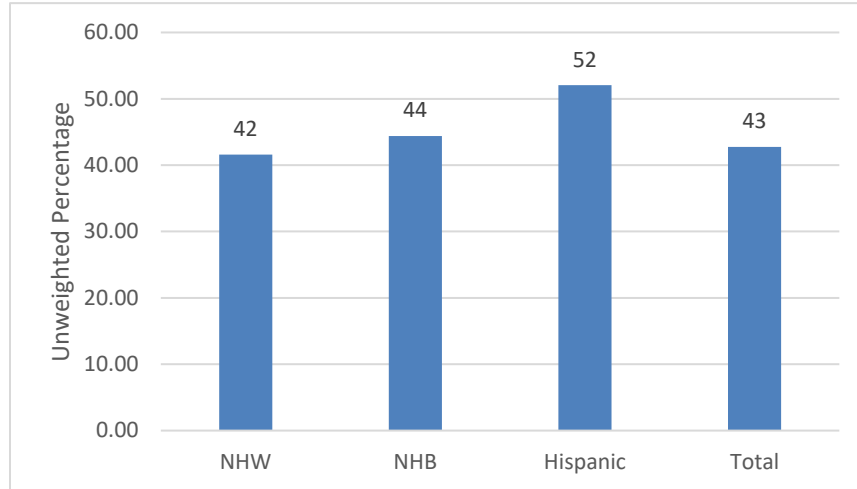


Figure 4.3c- Complex Care by Race/Ethnicity, unweighted (Exit)



AIM 3.2

Information on congruent care was only available for a subsample of HRS respondents in two waves of interviews (n=1439). Unweighted and unadjusted bivariate associations for congruent End-of-Life care are presented in Table 4.6b. The only statistically significant relationship observed was for legal ACP. Those without legal ACP were more likely to have their preferences for end of life care honored, which is opposite of what would be expected. Additionally, minorities were more likely to have their preferences honored than Non-Hispanic Whites, but the relationship was not statistically significant. The smaller sample size resulted in small cell sizes and likely a contributor to the lack of statistically significant associations.

Table 4.6b- Bivariate Associations with Congruent End-of-Life Care, unweighted (Exit)

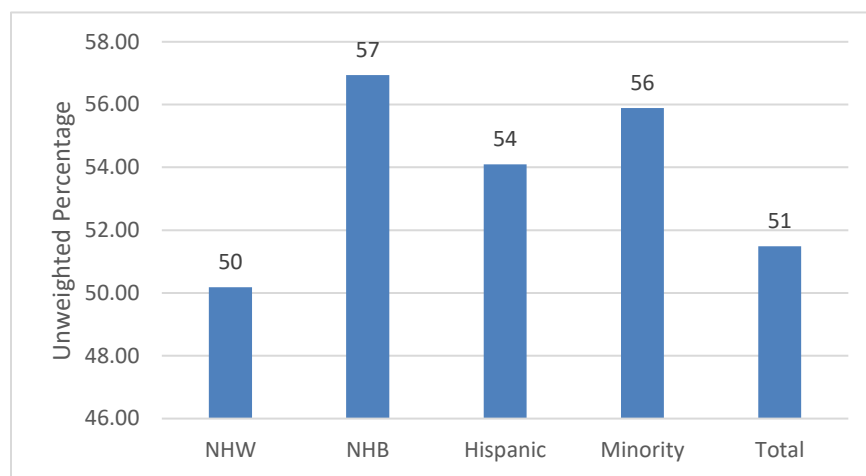
Characteristic	Congruent Care = Yes	
	Mean (SD)/n (%)	Chi-square p
Race/Ethnicity		0.0681
NHW	556 (50.18)	
Minority	185 (55.89)	
Age, n (%)		0.3259
65-74	170 (54.14)	
75-84	324 (52.17)	
85+	247 (49.01)	
Gender, n (%)		0.9746
Male	372 (51.45)	
Female	369 (51.54)	
SES Quintiles, n (%)		0.968
Q1	152 (52.78)	
Q2	150 (52.08)	
Q3	141 (50.18)	
Q4	151 (51.89)	
Q5	147 (50.52)	
Estate Value		0.2518
None	195 (48.03)	
Some	222 (53.24)	
Unknown	324 (52.60)	
Cognition Score, n (%)		0.7637
Q1 worst	109 (53.69)	
Q2	151 (53.93)	
Q3	128 (51.00)	
Q4	119 (50.64)	
Q5 best	98 (47.34)	
Unknown	136 (51.71)	
Recent Hospitalization, n (%)		0.1727
No	138 (55.42)	
Yes	603 (50.67)	
Legal ACP		0.0174
No	232 (56.45)	
Yes	509 (49.51)	
Social Support		0.1511
Q1 least	138 (51.49)	
Q2	135 (47.37)	
Q3	163 (55.44)	
Q4	140 (47.95)	
Q5 most	165 (55.00)	

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Although minority groups were more likely to receive congruent care, this difference was not statistically significant ($p=0.07$). Rates of congruent end of life care by race/ethnicity are presented in Figure 4.4. Overall, 51% of respondents received end of life care congruent with their preferences. The highest rates are among Non-Hispanic Blacks (57%) and lowest among Non-Hispanic Whites (50%). When Non-Hispanic Blacks and Hispanics are considered together, 56% of respondents received the care they desired.

Figure 4.4- Congruent End-of-Life Care by Race/Ethnicity, unweighted (Exit)



Secular Trends

Data for this study was obtained from 18 years of HRS core and exit interviews. Secular trends for hospital death, decisions to limit End-of-Life care, and complex care procedures were reviewed prior to multivariate modeling to determine if time should be included as a covariate to control for changes over the study period. The timeframe was grouped into 3 periods (2002-2006, 2008-2012, and 2014-2016). Table 4.7a presents unadjusted trends and Table 4.7b presents trends adjusted for age, gender, race/ethnicity, and socioeconomic status. Unadjusted trends demonstrated significant changes over time for all three outcomes. Hospital death decreased over time from 43% to 21%, limited care decisions were decreased (25%) in 2014-2016 compared to 2002-2006 (36%), and complex care was also decreased in the final time period compared to the first (24% vs. 36%, respectively).

After adjusting for sociodemographic factors (age, gender, race/ethnicity, SES) the significant differences over time for all three outcomes remained. Those in the later years were 31% (OR = 0.69, 95% CI: 0.60-0.79) less likely to die in a hospital, 18% (OR = 1.18, 95% CI: 1.03-1.34) more likely to make decisions to limit care at the end of life, and 15% (OR = 1.15, 95% CI: 1.03-1.34) more likely to receive complex care near the end of life.

Table 4.7a- Unadjusted Secular Trends in End-of-Life Care (Exit)

	2002-2006	2008-2012	2014-2016	
	n (%)	n (%)	n (%)	p
Hospital Death	968 (42.51)	828 (36.36)	481 (21.12)	<0.0001
NHW	714 (38.57)	626 (34.89)	351 (30.36)	
NHB	168 (53.33)	134 (38.53)	88 (41.12)	
Hispanic	86 (50.59)	68 (38.20)	42 (34.43)	
Limited Care Decision	931 (35.70)	1,020 (39.11)	657 (25.19)	0.0027
NHW	755 (40.94)	827 (46.46)	535 (46.85)	
NHB	120 (38.10)	123 (36.39)	71 (33.65)	
Hispanic	56 (33.53)	70 (40.00)	51 (41.80)	
Complex Care	946 (36.16)	1,032 (39.45)	638 (24.39)	0.0169
NHW	732 (39.55)	779 (43.37)	477 (41.23)	
NHB	130 (41.14)	153 (45.13)	102 (47.66)	
Hispanic	84 (49.41)	100 (56.18)	59 (48.36)	

Abbreviations: End-of-Life- End of Life, NHW- Non-Hispanic White, NHB- Non-Hispanic Black

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Table 4.7b- Adjusted Secular Trends in End-of-Life Care (Exit)

	2008-2012		2014-2016	
	aOR	95% CI	aOR	95% CI
Hospital Death	0.79	0.70-0.89	0.69	0.60-0.79
Race/Ethnicity (ref = NHW)				
NHB	1.23	0.95-1.59	1.41	1.02-1.95
Hispanic	1.15	0.82-1.61	1.02	0.67-1.57
Limited Care	1.19	1.06-1.34	1.18	1.03-1.34
Race/Ethnicity (ref = NHW)				
NHB	0.70	0.54-0.91	0.62	0.45-0.86
Hispanic	0.87	0.62-1.22	0.91	0.60-1.37
Complex Care	1.21	1.07-1.36	1.15	1.00-1.31
Race/Ethnicity (ref = NHW)				
NHB	1.01	0.79-1.31	1.18	0.86-1.61
Hispanic	1.61	1.16-2.24	1.18	0.78-1.77

Abbreviations: End-of-Life- End of Life, NHW- Non-Hispanic White, NHB- Non-Hispanic Black

Adjusted for: Age, Gender, Race/Ethnicity, SES

Reference period is 2002-2006

Mediation Assumptions

AIM 3.1

Prior to multivariate modeling, mediation assumptions were checked. A candidate mediator needs to meet three conditions to be evaluated in testing for mediation effects. First, the independent variable (race/ethnicity) must be associated with the outcome variable (hospital death, limited care decisions, and complex care procedures). Next, the independent variable and potential mediator (legal ACP and social support) must be associated. Third, the potential mediator must be associated with the outcome. Results are presented for each minority (Non-Hispanic Blacks and Hispanics) individually and combined compared to Non-Hispanic Whites.

Table 4.8a- Adjusted Mediation Assumptions (Legal ACP) (Exit)

	Hospital Death		Limited Care		Complex Care	
	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (Ref: NHW) → Outcome						
Stratified						
Non-Hispanic Black	1.45	1.24-1.69	0.77	0.66-0.90	1.07	0.91-1.25
Hispanic	1.23	1.00-1.51	0.87	0.71-1.08	1.43	1.16-1.75
Combined (Minorities)	1.37	1.20-1.58	0.80	0.70-0.92	1.17	1.02-1.34
Race/Ethnicity (Ref: NHW) → Legal ACP						
Stratified						
Non-Hispanic Black	0.35	0.30-0.42	0.35	0.30-0.41	0.35	0.30-0.41
Hispanic	0.33	0.27-0.41	0.33	0.26-0.40	0.33	0.26-0.40
Combined (Minorities)	0.35	0.30-0.40	0.35	0.30-0.40	0.35	0.30-0.40
Legal ACP (Ref: No) → Outcome	0.63	0.57-0.71	1.67	1.49-1.88	1.10	0.99-1.23

Abbreviations: ACP- Advance Care Planning, NHW- Non-Hispanic White

Adjusted for: Age, Gender, SES

Table 4.8b- Adjusted Mediation Assumptions (Social Support) (Exit)

	Hospital Death		Limited Care		Complex Care	
	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (Ref: NHW) → Outcome						
Stratified						
Non-Hispanic Black	1.45	1.24-1.69	0.77	0.66-0.90	1.07	0.91-1.25
Hispanic	1.23	1.00-1.51	0.87	0.71-1.08	1.43	1.16-1.75
Combined (Minorities)	1.37	1.20-1.58	0.80	0.70-0.92	1.17	1.02-1.34
Race/Ethnicity (Ref: NHW) → Social Support						
Stratified						
Non-Hispanic Black	1.22	1.04-1.43	1.22	1.04-1.43	1.22	1.04-1.43
Hispanic	1.54	1.24-1.90	1.54	1.24-1.90	1.54	1.24-1.90
Combined (Minorities)	1.31	1.14-1.51	1.31	1.14-1.51	1.31	1.14-1.51
Social Support (Ref: No) → Outcome	0.98	0.95-1.02	1.06	1.03-1.10	1.06	1.02-1.10

Abbreviations: ACP- Advance Care Planning, NHW- Non-Hispanic White

Adjusted for: Age, Gender, SES

Minorities were statistically more likely to die in a hospital, less likely to limit care at the end of life, and more likely to undergo a complex care procedure. Tables 4.8a and 4.8b present results of logistic regression modeling controlling for age, gender, and SES to test for the mediation assumptions. The first assumption of a main effect had mixed results with Hispanics being equally likely as Non-Hispanic Whites to experience death in the hospital (OR = 1.23, 95% CI: 1.00-1.51) and limited care decisions (OR = 0.87, 95% CI: 0.71-1.08), but more likely to receive complex care procedures (OR = 1.43, 95% CI: 1.16-1.75). Different associations were observed for Non-Hispanic Blacks who were more likely than Non-Hispanic Whites to die in the hospital (OR = 1.45, 95% CI: 1.24-1.69), less likely to make limited care decisions (OR = 0.77, 95% CI: 0.66-0.90), and equally likely to receive complex care procedures (OR = 1.07, 95% CI: 0.91-1.25). When Non-Hispanic Blacks and Hispanics are considered together the main effect for all three outcomes is statistically significant.

As demonstrated in the previous chapters, race/ethnicity is significantly associated with legal ACP fulfilling the second requirement for mediation for all outcomes. Non-Hispanic Whites are significantly more likely to complete healthcare planning documents compared to Non-Hispanic Blacks (OR = 0.35, 95% CI: 0.30-0.42) and Hispanics (OR = 0.33, 95% CI: 0.27-0.41). The third assumption was met for both hospital death and limited care decisions with those completing legal ACP being significantly less likely to die in the hospital (OR = 0.63, 95% CI: 0.57-0.71) and more likely to receive limited care (OR = 1.67, 95% CI: 1.49-1.88). Legal ACP meets the assumptions for the hospital death and limited care outcomes and will proceed with mediation testing in aim 3.1.

The relationship between race/ethnicity and social support was mixed for the two minority groups. When considered together, Non-Hispanic Blacks and Hispanics are more likely to die in the hospital (OR = 1.37, 95% CI: 1.20-1.58), less likely to have decisions made to limit care (OR = 0.80, 95% CI: 0.70-0.92), and more likely to undergo complex care procedures (OR = 1.17, 95% CI: 1.02-1.34). In these analyses, the first mediation assumption is met for all three outcomes. The second assumption was met with minorities being more likely than Non-Hispanic Whites to have

social support (OR = 1.31, 95% CI: 1.14-1.51). The third assumption was met for both limited care decisions and complex care procedures with each increasing quintile of social support increasing the odds of both outcomes by 6%.

AIM 3.2

Tables 4.9a and 4.9b present the results of mediation assumption testing for the outcome of congruence in END-OF-LIFE care. It was hypothesized that legal ACP and social support would play a mediating role in the main effect of race/ethnicity on congruent End-of-Life care. In adjusted logistic regression modeling, there were no significant associations for the main effect of race/ethnicity on the outcome. With the first assumption failing to be demonstrated, neither factor was considered as a mediator. Multivariate modeling preceded with unadjusted bivariate analyses. The original analysis plan was to only include covariates with significant bivariate associations ($p < 0.05$) in multivariate models. However, there were no significant bivariate associations except for legal ACP. Therefore, model 1 was adjusted for basic sociodemographic factors (race/ethnicity, age, gender, and SES), model 2 added legal ACP, and model 3 added social support.

Table 4.9a- Adjusted Mediation Assumptions (Legal ACP) (Exit)

	Congruent Care	
	aOR	95% CI
Race/Ethnicity (Ref: NHW) → Congruent Care		
Non-Hispanic Black	1.32	0.96-1.80
Hispanic	1.15	0.76-1.72
Race/Ethnicity (Ref: NHW) → Legal ACP		
Non-Hispanic Black	0.43	0.31-0.61
Hispanic	0.39	0.26-0.61
Legal ACP (Ref: No) → Congruent Care	0.78	0.61-1.00

Abbreviations: ACP- Advance Care Planning, NHW- Non-Hispanic White

Adjusted for: Age, Gender, SES

Table 4.9b- Adjusted Mediation Assumptions (Social Support) (Exit)

	Congruent Care	
	aOR	95% CI
Race/Ethnicity (Ref: NHW) → Congruent Care		
Non-Hispanic Black	1.32	0.96-1.80
Hispanic	1.15	0.76-1.72
Race/Ethnicity (Ref: NHW) → Social Support		
Non-Hispanic Black	1.44	1.04-1.99
Hispanic	1.49	1.04-2.43
Social Support (Ref: No) → Congruent Care	1.02	0.95-1.11

Abbreviations: ACP- Advance Care Planning, NHW- Non-Hispanic White

Adjusted for: Age, Gender, SES

Table 4.10- Multicollinearity Assessment between Variables (Exit)

<i>Aim 3.1</i>		
Variable 1	Variable 2	r
SES	Race/Ethnicity	-0.36
Will	Race/Ethnicity	-0.27
Will	Age	0.17
Will	SES	0.22
Will	Estate Value	0.17
Social Support	Race/Ethnicity	0.15
Social Support	SES	-0.20
<i>Aim 3.2</i>		
SES	Race/Ethnicity	-0.38
Estate Value	Age	0.17
ACP	Race/Ethnicity	-0.22
ACP	Age	0.25
ACP	SES	0.19
ACP	Estate Value	0.16
Social Support	Race/Ethnicity	0.19
Social Support	SES	-0.24

Abbreviations: SES- Socioeconomic Status, ACP- Legal Advance Care Planning (Advance Directives or Medical Power of Attorney)

Multicollinearity Assessment

Table 4.10 presents some of the results from an 9x9 correlation matrix for all variables included in the fully adjusted logistic regression models. The correlation table was used to investigate intercorrelation between study variables. For aim 3.1 the highest correlations were seen among race/ethnicity and SES ($r = -0.36$) and will ($r = -0.27$). For aim 3.2 two of the highest correlations were between SES and race/ethnicity ($r = -0.38$) and social support ($r = -0.24$). The correlation between legal ACP and race/ethnicity ($r = -0.22$) and age ($r = 0.25$) were also among the highest. There were no meaningful concerns for intercorrelation among covariates.

Mediation Modeling: Logistic Regression

Aim 3.1

Table 4.11 presents summary results for multivariate logistic regression modeling of the three end of life outcomes considered in aim 3.1. Tables 4.12a-c present multivariate adjusted models 1-4 for all three outcomes. After mediation assumptions were checked logistic modeling proceeded to test the mediating effects of legal APC. Model 1 included sociodemographics (age, gender, SES, and estate value). Model 2 added health indicators including cognition score and recent hospitalization. Model 3 added the first hypothesized mediator, legal ACP. Model 4 added the second potential mediator social support. Table 4.11 presents the fully adjusted model for all three outcomes.

Table 4.11- Multivariate Associations with End-of-Life Care, unweighted (Exit)

Characteristic	Hospital Death = Yes		Limited End-of- Life Care = Yes		Complex Care = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)						
NHB	1.46	1.24-1.72	0.84	0.71-1.00	1.12	0.95-1.32
Hispanic	1.22	0.98-1.51	0.97	0.78-1.20	1.56	1.26-1.93
Age (ref = 65-74)						
75-84	0.99	0.87-1.13	0.99	0.87-1.13	0.82	0.72-0.94
85+	0.81	0.69-0.94	1.11	0.96-1.28	0.65	0.56-0.75
Gender (ref = male)	0.92	0.82-1.02	1.25	1.13-1.39	0.94	0.84-1.04
SES Quintiles (ref = Q1)						
Q2	1.10	0.92-1.32	0.99	0.83-1.18	0.89	0.75-1.06
Q3	0.96	0.80-1.15	1.06	0.89-1.27	0.87	0.72-1.04
Q4	0.95	0.78-1.15	1.05	0.87-1.27	0.84	0.69-1.02
Q5	1.05	0.86-1.28	1.19	0.98-1.45	0.86	0.70-1.05
Estate Value (ref = some)						
None	1.06	0.92-1.23	0.79	0.68-0.91	1.07	0.93-1.24
Unknown	0.90	0.79-1.03	0.86	0.76-0.98	0.95	0.83-1.08
Cognition Score (ref = Q5 best)						
Q1 worst	0.70	0.57-0.86	1.18	0.96-1.44	0.62	0.50-0.76
Q2	0.89	0.73-1.08	1.12	0.92-1.35	0.81	0.67-0.98
Q3	0.96	0.79-1.16	1.11	0.92-1.34	0.85	0.70-1.02
Q4	0.94	0.78-1.14	1.12	0.93-1.35	0.85	0.71-1.03
Unknown	0.65	0.53-0.79	1.11	0.92-1.35	0.55	0.45-0.67
Recent Hospitalization (ref = no)	0.62	0.54-0.71	1.59	1.38-1.82	2.74	2.36-3.17
No Legal ACP (ref = yes)	1.38	1.22-1.56	0.64	0.57-0.73	0.97	0.86-1.10
Social Support (ref = Q1 least)						
Q2	0.98	0.82-1.16	1.10	0.93-1.31	1.06	0.89
Q3	1.09	0.93-1.28	1.22	1.04-1.43	1.11	0.95-1.31
Q4	1.04	0.88-1.23	1.19	1.01-1.39	1.26	1.07-1.48
Q5 most	0.95	0.80-1.13	1.24	1.05-1.46	1.10	0.93-1.30
Wave	0.94	0.92-0.96	1.03	1.00-1.05	1.04	1.01-1.06
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.624	0.4003	0.602	0.2318	0.636	0.2582
R-square (Nagelkerke)		0.0558		0.0455		0.0777

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Hospital death. Of the two hypothesized mediators, legal ACP was the only one to meet mediation assumptions for the hospital death outcome. Non-Hispanic Blacks were 46% significantly more likely (OR = 1.46, 95% CI: 1.24-1.72) and Hispanics 22% more likely (OR = 1.22, 95% CI: 0.98-1.51) to experience death in a hospital compared to Non-Hispanic Whites (Table 4.12a). There was a positive trend for cognition score with those in higher quintiles being progressively more likely to die in the hospital. Those who had been hospitalized since their last core interview were 38% less likely to die in a hospital (OR = 0.62, 95% CI: 0.54-0.71). Those without legal ACP were 38% more likely to die in the hospital compared to those with either advance directives or medical power of attorney (OR = 1.38, 95% CI: 1.22-1.56).

The inclusion of legal ACP in Model 3 did reduce the main effect of race/ethnicity on hospital death. Non-Hispanic Blacks were still more likely to die in a hospital (OR = 1.45, 95% CI: 1.23-1.71), but the effect was reduced compared to model 3 (OR = 1.55, 95% CI: 1.32-1.83). The effect for Hispanics was marginally significant in model 3 (OR = 1.31, 95% CI: 1.06-1.62), and adding legal ACP to the modeling decreased the effect (OR = 1.21, 95% CI: 0.97-1.50). There was little change in the main effect between models 3 and 4 with the addition of social support. The change in estimated R-square from model 2 (0.049) to model 3 (0.055) was negligible as was the overall variance explained in the fully adjusted model (Table 4.12a). This means a small proportion of the variance in hospital death was accounted for by the variables included in the multivariate model suggesting factors that were not included may play a more meaningful role.

Limited End-of-Life care decision. Both hypothesized mediators met the assumptions of mediation for the limited care decisions outcome. Non-Hispanic Blacks were 16% less likely (OR = 0.84, 95% CI: 0.71-1.00) and Hispanics equally as likely (OR = 0.97, 95% CI: 0.78-1.20) as Non-Hispanic Whites to make decisions to limit care at the end of life (Table 4.12b). Women were more likely than men to receive limited care at the end of life (OR = 1.25, 95% CI: 1.13-1.39). Those with estates with nothing of much value were 21% less likely to make limited care decisions (OR = 0.79, 95% CI: 0.68-0.91). Decedents who were hospitalized since their previous interview were more likely to make decisions to limit care at the end of life (OR = 1.59, 95% CI: 1.38-1.82).

Those who failed to complete legal ACP were 36% less likely to receive limited care (OR = 0.64, 95% CI: 0.57-0.73). Those in higher social support quintiles were about 20% more likely to receive limited care at the end of life.

The inclusion of legal ACP reduced the main effect of race/ethnicity in model 3 compared to model 2. Non-Hispanic Blacks were 23% less likely than Non-Hispanic Whites to receive limited care in model 3 (OR = 0.77, 95% CI: 0.65-0.90) and this relationship became marginally significant after adding legal ACP. Although the main effect for Hispanics was reduced in model 3, after adjusting for sociodemographic variables in model 1, they were equally as likely as Non-Hispanic Whites to receive limited care (OR = 0.88, 95% CI: 0.71-1.08). There was little change in the main effect between models 3 and 4 with the addition of social support. The change in estimated R-square from model 2 (0.032) to model 4 (0.044) was negligible as was the total estimated variance explained (Table 4.12b). This means there are likely other, more important factors that influence the likelihood of making decisions to limit care at the end of life.

Complex care procedures. Of the two hypothesized mediators, only social support met the assumptions for the complex care procedures (life support, dialysis, or ICU admission) outcome. Modeling was identical to the other two outcomes. Those in the older age groups were less likely to undergo complex care procedures. Respondents in the two lowest quintiles for cognition score were less likely to receive life support, dialysis, or ICU admission. Those with a recent hospitalization were more than twice as likely to have received complex care procedures (OR = 2.74, 95% CI: 2.36-3.17).

The main effect was essentially unchanged in models 3 and 4 with the addition of legal ACP and social support, respectively. Similarly, the change in estimated R-square was negligible from model 2 (0.076) to model 4 (0.078). The low estimate for variance explained means there are other unaccounted factors influencing the receipt of complex care procedures.

Table 4.12a- Multivariate Associations with Hospital Death, unweighted (Exit)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3		Multivariate Model 4	
	Hospital Death = Yes		Hospital Death = Yes		Hospital Death = Yes		Hospital Death = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)								
NHB	1.44	1.23-1.69	1.55	1.32-1.83	1.45	1.23-1.71	1.46	1.24-1.72
Hispanic	1.25	1.02-1.55	1.31	1.06-1.62	1.21	0.97-1.50	1.22	0.98-1.51
Age (ref = 65-74)								
75-84	0.92	0.81-1.05	0.97	0.85-1.11	0.99	0.87-1.13	0.99	0.87-1.13
85+	0.69	0.60-0.80	0.77	0.67-0.90	0.81	0.70-0.94	0.81	0.69-0.94
Gender (ref = male)	0.91	0.82-1.01	0.90	0.81-1.00	0.92	0.82-1.02	0.92	0.82-1.02
SES Quintiles (ref = Q1)								
Q2	1.14	0.95-1.35	1.09	0.92-1.30	1.11	0.93-1.32	1.10	0.92-1.32
Q3	1.02	0.86-1.22	0.95	0.79-1.14	0.97	0.80-1.16	0.96	0.80-1.15
Q4	1.01	0.84-1.22	0.92	0.76-1.12	0.95	0.78-1.16	0.95	0.78-1.15
Q5	1.13	0.93-1.36	1.02	0.84-1.24	1.06	0.87-1.29	1.05	0.86-1.28
Estate Value (ref = some)								
None	1.06	0.92-1.23	1.08	0.93-1.25	1.06	0.92-1.23	1.06	0.92-1.23
Unknown	0.86	0.76-0.98	0.87	0.76-0.99	0.91	0.80-1.03	0.90	0.79-1.03
Cognition Score (ref = Q5 best)								
Q1 worst			0.70	0.57-0.86	0.70	0.57-0.86	0.70	0.57-0.86
Q2			0.89	0.73-1.08	0.89	0.73-1.08	0.89	0.73-1.08
Q3			0.96	0.79-1.16	0.95	0.79-1.16	0.96	0.79-1.16
Q4			0.94	0.78-1.16	0.94	0.78-1.13	0.94	0.78-1.14
Unknown			0.65	0.53-0.79	0.64	0.53-0.78	0.65	0.53-0.79
Recent Hospitalization (ref = no)			0.60	0.52-0.68	0.62	0.54-0.71	0.62	0.54-0.71
No Legal ACP (ref = yes)					1.39	1.23-1.56	1.38	1.22-1.56
Social Support (ref = Q1 least)								
Q2							0.98	0.82-1.16

Q3							1.09	0.93-1.28
Q4							1.04	0.88-1.23
Q5 most							0.95	0.80-1.13
Wave	0.93	0.91-0.95	0.93	0.91-0.95	0.94	0.92-0.96	0.94	0.92-0.96
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.584	0.3729	0.613	0.3808	0.623	0.301	0.624	0.4003
R-square (Nagelkerke)		0.0293		0.049		0.0551		0.0558

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Table 4.12b- Multivariate Associations with Limited End-of-Life Care Decisions, unweighted (Exit)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3		Multivariate Model 4	
	Limited End-of- Life Care = Yes		Limited End-of- Life Care = Yes		Limited End-of- Life Care = Yes		Limited End-of- Life Care = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)								
NHB	0.79	0.67-0.92	0.77	0.65-0.90	0.85	0.72-1.00	0.84	0.71-1.00
Hispanic	0.88	0.71-1.08	0.88	0.71-1.09	0.98	0.79-1.22	0.97	0.78-1.20
Age (ref = 65-74)								
75-84	1.04	0.91-1.18	1.01	0.89-1.16	0.99	0.86-1.12	0.99	0.87-1.13
85+	1.19	1.04-1.36	1.15	0.99-1.32	1.08	0.93-1.24	1.11	0.96-1.28
Gender (ref = male)	1.28	1.16-1.42	1.29	1.16-1.43	1.26	1.14-1.40	1.25	1.13-1.39
SES Quintiles (ref = Q1)								
Q2	0.99	0.83-1.18	1.00	0.84-1.19	0.98	0.82-1.17	0.99	0.83-1.18
Q3	1.06	0.89-1.27	1.07	0.90-1.29	1.05	0.88-1.26	1.06	0.89-1.27
Q4	1.04	0.86-1.25	1.06	0.88-1.29	1.02	0.84-1.23	1.05	0.87-1.27
Q5	1.17	0.97-1.41	1.21	1.00-1.46	1.15	0.95-1.40	1.19	0.98-1.45
Estate Value (ref = some)								
None	0.78	0.67-0.89	0.77	0.67-0.89	0.79	0.68-0.91	0.79	0.68-0.91
Unknown	0.92	0.82-1.04	0.91	0.80-1.03	0.86	0.76-0.98	0.86	0.76-0.98
Cognition Score (ref = Q5 best)								
Q1 worst			1.17	0.96-1.43	1.17	0.96-1.43	1.18	0.96-1.44
Q2			1.11	0.92-1.35	1.11	0.92-1.35	1.12	0.92-1.35
Q3			1.10	0.91-1.33	1.11	0.91-1.34	1.11	0.92-1.34
Q4			1.12	0.93-1.35	1.12	0.93-1.35	1.12	0.93-1.35
Unknown			1.11	0.91-1.34	1.11	0.92-1.34	1.11	0.92-1.35
Recent Hospitalization (ref = no)			1.68	1.46-1.92	1.60	1.39-1.83	1.59	1.38-1.82
No Legal ACP (ref = yes)					0.64	0.57-0.72	0.64	0.57-0.73
Social Support (ref = Q1 least)								

Q2							1.10	0.93-1.31
Q3							1.22	1.04-1.43
Q4							1.19	1.01-1.39
Q5 most							1.24	1.05-1.46
Wave	1.04	1.02-1.07	1.04	1.02-1.06	1.03	1.01-1.06	1.03	1.00-1.05
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.569	0.5515	0.587	0.2264	0.6	0.2597	0.602	0.2318
R-square (Nagelkerke)		0.0194		0.0323		0.0436		0.0455

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Table 4.12c- Multivariate Associations with Complex Care, unweighted (Exit)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3		Multivariate Model 4	
	Complex Care = Yes		Complex Care = Yes		Complex Care = Yes		Complex Care = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)								
NHB	1.04	0.89-1.22	1.11	0.94-1.30	1.11	0.94-1.31	1.12	0.95-1.32
Hispanic	1.39	1.13-1.71	1.56	1.26-1.92	1.57	1.26-1.94	1.56	1.26-1.93
Age (ref = 65-74)								
75-84	0.79	0.70-0.90	0.82	0.72-0.94	0.82	0.72-0.93	0.82	0.72-0.94
85+	0.57	0.50-0.66	0.64	0.55-0.74	0.63	0.55-0.73	0.65	0.56-0.75
Gender (ref = male)	0.97	0.87-1.07	0.94	0.85-1.05	0.94	0.85-1.05	0.94	0.84-1.04
SES Quintiles (ref = Q1)								
Q2	0.93	0.78-1.10	0.89	0.74-1.06	0.89	0.74-1.06	0.89	0.75-1.06
Q3	0.95	0.80-1.13	0.86	0.72-1.03	0.86	0.72-1.03	0.87	0.72-1.04
Q4	0.91	0.75-1.09	0.82	0.68-1.00	0.82	0.67-0.99	0.84	0.69-1.02
Q5	0.96	0.79-1.15	0.84	0.69-1.02	0.84	0.69-1.02	0.86	0.70-1.05
Estate Value (ref = some)								
None	1.05	0.91-1.21	1.07	0.92-1.23	1.07	0.92-1.24	1.07	0.93-1.24
Unknown	0.98	0.87-1.11	0.95	0.84-1.08	0.95	0.84-1.08	0.95	0.83-1.08
Cognition Score (ref = Q5 best)								
Q1 worst			0.62	0.50-0.76	0.62	0.50-0.76	0.62	0.50-0.76
Q2			0.80	0.66-0.97	0.80	0.66-0.97	0.81	0.67-0.98
Q3			0.84	0.70-1.02	0.84	0.70-1.02	0.85	0.70-1.02
Q4			0.85	0.70-1.02	0.85	0.70-1.02	0.85	0.71-1.03
Unknown			0.55	0.45-0.66	0.55	0.45-0.66	0.55	0.45-0.67
Recent Hospitalization (ref = no)			2.75	2.38-3.19	2.74	2.37-3.18	2.74	2.36-3.17
No Legal ACP (ref = yes)					0.94	0.86-1.10	0.97	0.86-1.10
Social Support (ref = Q1 least)								
Q2							1.06	0.89

Q3							1.11	0.95-1.31
Q4							1.26	1.07-1.48
Q5 most							1.10	0.93-1.30
Wave	1.05	1.02-1.07	1.04	1.02-1.07	1.02	1.02-1.07	1.04	1.01-1.06
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.575	0.0358	0.635	0.568	0.635	0.3621	0.636	0.2582
R-square (Nagelkerke)		0.0227		0.0759		0.076		0.0777

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

Mediation Modeling: SAS Causal Mediation Procedure

The SAS causal mediation procedure was used to test for the mediating effect of legal ACP on hospital death and decisions to limit care at the end of life. Table 4.13 presents the percent mediated for each outcome and Tables 4.14a-c present more output from the procedure. Legal ACP was a significant mediator of the relationship between race/ethnicity and hospital death and limited End-of-Life care accounting for 27% and 46% of the total effect, respectively. Using the causal mediation procedure social support failed to have a total effect on limited End-of-Life care (Table 4.14b). Therefore, its mediating effect was not evaluated. Social support mediated 6% of the effect of race/ethnicity on complex care procedures, but the mediating effect was not statistically significant.

Table 4.13- Legal ACP Mediation Effects on End-of-Life Care, unweighted (Exit)

Mediator	Hospital Death %	Limited End-of-Life Care %	Complex Care %
Legal ACP			
% Mediated	26.87****	46.34*	--
Social Support			
% Mediated	--	--	6.25

Abbreviations: ACP- Advance Care Planning, End-of-Life- End of Life

*p < 0.05, **p < 0.01, ***p < 0.001, ****p < 0.0001

Hospital death. Results of the causal mediation procedure describe the magnitude of the mediation effect observed in the logistic regression modeling above (Table 4.12a). The logistic regression modeling demonstrated a main effect that shifted toward the null with the addition of legal ACP. However, the R-square in the logistic regression modeling was low (0.06). The adjusted total effect of race/ethnicity on hospital death was significant (OR = 1.44, 95% CI: 1.24-1.65) with minorities being 44% more likely to die in a hospital than Non-Hispanic Whites. The direct effect of race/ethnicity was also significant (OR =

1.32, 95% CI: 1.13-1.52). The indirect effect of race/ethnicity mediated by legal ACP was statistically significant (OR = 1.09, 95% CI: 1.06-1.12). About one-fourth (26.9%) of the total effect of race/ethnicity on hospital death is mediated by legal ACP ($p < 0.0001$).

Limited End-of-Life care decision. The causal mediation procedure demonstrates a large and statistically significant mediation effect. This is consistent with the logistic regression modeling above (Table 4.12b). The adjusted total effect of race/ethnicity on decisions to limit care at the end of life was significant (OR = 0.82, 95% CI: 0.70-0.93). The direct effect of race/ethnicity was not significant (OR = 0.90, 95% CI: 0.77-1.03). The indirect effect of race/ethnicity mediated by legal ACP was statistically significant (OR = 0.91, 95% CI: 0.88-0.93). Almost half (46.3%) of the total effect of race/ethnicity on limited End-of-Life care decisions is mediated by legal ACP ($p < 0.05$). Although the initial review of mediation assumptions indicated social support met the criteria for a mediating relationship, logistic regression modeling (Table 4.12b) demonstrated no change in the main effect of race/ethnicity on limited End-of-Life care after social support was added to the multivariate model. The total effect of race/ethnicity on limited End-of-Life care mediated through social support was insignificant (OR = 0.90, 95% CI: 0.77-1.03) further supporting its disqualification as a mediator.

Complex Care Procedures. Although the social support met the mediation assumptions checked above (Table 4.8), multivariate logistic regression modeling demonstrated almost no change in effect size when social support was added to the multivariate model. This is supported by the causal mediation results presented in Tables 4.13 and 4.14c. The adjusted total effect of race/ethnicity on complex care procedures was significant (OR = 1.27, 95% CI: 1.08-1.45). The direct effect of race/ethnicity was also significant (OR = 1.25, 95% CI: 1.07-1.43). The indirect effect of race/ethnicity mediated by social support was marginally statistically significant (OR = 1.01, 95% CI: 1.00-1.03). A small proportion (6.3%) of the total effect of race/ethnicity on complex care procedures is mediated by social support, but the mediating effect is not statistically significant.

Table 4.14a- Mediation Effect of Legal ACP on Hospital Death,
unweighted (Exit)

	Legal ACP			
	unadjusted		adjusted	
	OR/RR	95% CI	OR/RR	95%CI
Total Effect (OR)	1.44	1.26-1.62	1.44	1.24-1.65
Direct Effect (OR)	1.23	1.08-1.39	1.32	1.13-1.52
Indirect Effect (OR)	1.17	1.12-1.21	1.09	1.06-1.12
Total Excess RR	0.44	0.26-0.62	0.44	0.24-0.65
Excess RR (NDE)	0.23	0.08-0.39	0.32	0.13-0.52
Excess RR (NIE)	0.21	0.15-0.26	0.12	0.07-0.17
% Mediated	46.72****	29.95-63.49	26.87****	14.37-39.38

Abbreviations- NHW: Non-Hispanic Whites, NHB: Non-Hispanic Blacks

Adjusted for: age, gender, marriage status, religious importance, living children,
estate value, recent hospitalization, and self-reported memory

*p < 0.05, **p < 0.01, ***p < 0.001, ****p < 0.0001

Table 4.14b- Mediation Effect of Legal ACP and Social Support on Limited End-of-Life Care, unweighted (Exit)

	Legal ACP				Social Support			
	unadjusted		adjusted		unadjusted		adjusted	
	OR/RR	95% CI	OR/RR	95%CI	OR/RR	95% CI	OR/RR	95% CI
Total Effect (OR)	0.75	0.66-0.85	0.82	0.70-0.93	0.75	0.65-0.84	0.90	0.77-1.03
Direct Effect (OR)	0.89	0.77-1.00	0.90	0.77-1.03	0.73	0.64-0.82	0.89	0.76-1.02
Indirect Effect (OR)	0.85	0.82-0.88	0.91	0.88-0.93	1.03	1.01-1.05	1.02	1.00-1.03
Total Excess RR	-0.25	-0.34,-0.15	-0.18	-0.30,-0.07	-0.25	-0.35,-0.16	-0.10	-0.23,0.03
Excess RR (NDE)	-0.11	-0.23,0.00	-0.10	-0.23,0.03	-0.27	-0.36,-0.18	-0.11	-0.25,0.02
Excess RR (NIE)	-0.13	-0.17,-0.10	-0.09	-0.11,-0.06	-0.27	-0.36,-0.18	0.01	0.00,0.03
% Mediated	54.07***	24.02-84.12	46.34*	8.26-84.42	-7.63*	-14.27,-0.99	-14.82	-39.37,9.72

Abbreviations- NHW: Non-Hispanic Whites, NHB: Non-Hispanic Blacks, SES: Socioeconomic Status (Education & Wealth)
Adjusted for: age, gender, marriage status, religious importance, living children, estate value, recent hospitalization, and self-reported memory

*p < 0.05, **p < 0.01, ***p < 0.001, ****p < 0.0001

Table 4.14c- Mediation Effect of Social Support on Complex Care Procedures, unweighted (Exit)

	Social Support			
	unadjusted		adjusted	
	OR/RR	95% CI	OR/RR	95%CI
Total Effect (OR)	1.25	1.10-1.40	1.27	1.08-1.45
Direct Effect (OR)	1.20	1.05-1.35	1.25	1.07-1.43
Indirect Effect (OR)	1.04	1.02-1.06	1.01	1.00-1.03
Total Excess RR	0.25	0.10-0.40	0.27	0.08-0.45
Excess RR (NDE)	0.20	0.05-0.35	0.25	0.07-0.43
Excess RR (NIE)	0.05	0.02-0.07	0.02	0.00-0.03
% Mediated	19.11**	5.95-32.27	6.25	-0.14,12.65

Abbreviations- NHW: Non-Hispanic Whites, NHB: Non-Hispanic Blacks

Adjusted for: age, gender, marriage status, religious importance, living children, estate value, recent hospitalization, and self-reported memory

*p < 0.05, **p < 0.01, ***p < 0.001, ****p < 0.0001

Multivariate Modeling

Aim 3.2

The mediation assumptions for aim 3.2 were not met and analyses proceeded without assessing a mediating hypothesis. Results of unweighted, adjusted multivariate logistic regression modeling are presented in Table 4.15. There were no significant associations in model 1. Minorities (Non-Hispanic Blacks and Hispanics) were more likely to receive congruent End-of-Life care, but the association was not statistically significant in any model. Model 2 added legal ACP. Those with legal healthcare planning documents were 25% more likely to receive care congruent with their preferences, but the association was not statistically significant (OR = 1.25, 95% CI: 0.98-1.60). Social support was added in model 3. There were not significant associations with social support or meaningful trends.

Table 4.15- Multivariate Associations with Congruent End-of-Life Care, unweighted (Exit)

Characteristic	Multivariate Model 1		Multivariate Model 2		Multivariate Model 3	
	Congruent Care = Yes		Congruent Care = Yes		Congruent Care = Yes	
	aOR	95% CI	aOR	95% CI	aOR	95% CI
Race/Ethnicity (ref = NHW)	1.25	0.95-1.65	1.20	0.91-1.59	1.17	0.88-1.55
Age (ref = 65-74)						
75-84	0.94	0.72-1.24	0.97	0.74-1.28	0.98	0.74-1.29
85+	0.84	0.63-1.12	0.89	0.66-1.19	0.88	0.65-1.18
Gender (ref = male)	1.00	0.81-1.24	1.01	0.82-1.24	1.01	0.81-1.24
SES Quintiles (ref = Q1)						
Q2	1.02	0.73-1.43	1.02	0.73-1.43	1.04	0.74-1.46
Q3	1.00	0.70-1.42	1.00	0.70-1.43	1.03	0.72-1.47
Q4	1.07	0.76-1.52	1.09	0.77-1.55	1.11	0.78-1.59
Q5	1.03	0.72-1.46	1.06	0.74-1.51	1.08	0.75-1.55
Legal ACP (ref = no)			1.25	0.98-1.60	1.26	0.99-1.61
Social Support (ref = Q1 least)						
Q2					0.83	0.59-1.16
Q3					1.15	0.82-1.60
Q4					0.83	0.59-1.17
Q5 most					1.08	0.76-1.53
Wave	0.98	0.80-1.21	0.99	0.80-1.22	1.00	0.81-1.23
Model Fit	C-stat	HL-P	C-stat	HL-P	C-stat	HL-P
	0.533	0.0458	0.539	0.3712	0.558	0.974
R-square (Nagelkerke)		0.0049		0.0079		0.0136

Abbreviations- ACP: Advance Care Planning, Legal ACP: Advance Directives or Medical Power of Attorney, C-stat: C Statistic, HL-p: Hosmer Lemeshow p value

* p < 0.05, ** p < 0.01, *** p < 0.001, **** p < 0.0001

DISCUSSION

The purpose of this chapter was to test for the possible mediating relationship between legal ACP, social support, race/ethnicity, and end of life care. Two aims were presented. In the first, the hypothesis was that the main effect of race/ethnicity on end of life care (hospital death, limited care decisions, and complex care procedures) would be reduced or eliminated when legal ACP and social support were taken into account. In the sub aim with a smaller sample, it was hypothesized that the main effect of race/ethnicity

on congruent end of life care (respondent's preference for limited end of life care honored by decisions to limit care at the end of life as reported by proxies) would be reduced or eliminated when legal ACP and social support were considered. Results in this study indicated that legal ACP partially mediates the differences in hospital death and limited end of life care observed between minorities (Non-Hispanic Blacks and Hispanics) and Non-Hispanic Whites. Social support did not play a mediating role in the relationships investigated.

Aim 3.1 was proposed because there are relationships between the type of end of life care a person receives and their participation in ACP. However, there have not been studies investigating testable hypotheses to explain the associations. Most results in aim 3.1 are consistent with the literature.

Terminal hospitalizations are associated with legal ACP components. In this study, terminal hospitalizations were more likely to occur among those without legal ACP documents (OR = 1.38, 95% CI: 1.22-1.56). Three previous studies reported an association between hospital death and having assigned a medical power of attorney with adjusted associations ranging from 13% in a sample of 4,399 HRS decedents aged 65+ from 1993 to 2007 (OR = 0.87, 95% CI: 0.80-0.94) (Bischoff et al., 2013) to 30% in a sample of HRS decedents from 2000 to 2012 with cancer (OR = 0.70, 95% CI: 0.52-0.94) (Narang et al., 2015) for those with this legal document (Silveira et al., 2010). Results in the current study demonstrated consistent findings with those failing to complete legal ACP documents being 38% more likely (OR = 1.38, 95% CI: 1.22-1.56) to experience death in a hospital.

The overall rate of hospital death in this sample of 6,128 HRS decedents from 2002-2016 is 37%. Non-Hispanic Blacks (45%) and Hispanics (41%) were more likely ($p < 0.0001$) to die in the hospital than Non-Hispanic Whites. In fully adjusted models, this association remained significant for Non-Hispanic Blacks (OR = 1.46, 95% CI: 1.24-1.72) but became insignificant for Hispanics (OR = 1.22, 95% CI: 0.98-1.51). There was limited evidence in the literature about the association between race/ethnicity and hospital death.

Many studies include race/ethnicity as a covariate but fail to report prevalence rates or adjusted associations. One study reported that Non-Hispanic Blacks (RRR = 0.77, $p = 0.006$) and Hispanics (RRR = 0.86, $p = 0.276$) were less likely to die at home than in a hospital compared to Non-Hispanic Whites, although the association was not significant for Hispanics (Orlovic et al., 2019). The results in this chapter add to literature by describing both prevalence rates and multivariate associations for hospital death by race/ethnicity.

Another addition to the literature is the testing of a specific hypothesis for disparities in hospital death. Legal ACP significantly mediated the main effect of race/ethnicity on location of death (27%, $p < 0.0001$). As described above, the main effect was reduced for both Non-Hispanic Blacks and Hispanics, with the association for Hispanics becoming statistically insignificant.

The second outcome investigated was decisions to limit care at the end of life. In this study, those without legal ACP were less likely to make decisions to limit care at the end-of-life (OR = 0.64, 95% CI: 0.57-0.73). Two papers presented a significant increase in the likelihood of receiving limited care for those with advance directives. The first reported that decedents with an advance directive were 80% more likely (OR = 1.79, 95% CI: 1.28-2.50) and the second that decedents were more than twice as likely (OR = 2.51, 95% CI: 1.53-4.11) to forgo some treatments at the end of life (Narang et al., 2015; Silveira et al., 2010).

Most studies investigating end of life outcomes fail to report bivariate prevalence rates or adjusted associations for racial/ethnic groups. One study found Non-Hispanic Blacks (OR = 0.52, 95% CI: 0.42-0.66) and Hispanics (OR = 0.46, 95% CI: 0.33-0.65) less likely to make decisions to withhold treatment at the end of life compared to Non-Hispanic Whites (Orlovic et al., 2019). This study adds to the literature by providing both prevalence rates and adjusted associations for decisions to limit end of life care. Overall prevalence rates of decisions to limit care in this study were 43%. Non-Hispanic Blacks (37%) and

Hispanics (39%) were less likely than Non-Hispanic Whites (44%) to report limited care decisions at the end of life ($p < 0.0001$).

Adjusted associations for limited End-of-Life care demonstrated Non-Hispanic Blacks were less likely (OR = 0.84, 95% CI: 0.71-1.00) and Hispanics equally likely (OR = 0.97, 95% CI: 0.78-1.20) to make decisions to limit care. The mediating role of legal ACP in that relationship was significant and accounted for almost half of the total effect (46%, $p < 0.05$). There have been no previous studies proposing a testable hypothesis for the role of ACP in decisions to limit care at the end of life.

It is worth noting that the associations between the first two end of life outcomes in the literature demonstrate a unique pattern. Having a medical power of attorney is associated with decreased hospital death whereas having an advance directive is associated with greater likelihood of choosing to limit care at the end of life (Narang et al., 2015; Silveira et al., 2010) suggesting these two documents play a different role in end of life care. The current study combines these two ACP components into legal ACP and does not comment on the unique associations for each legal document. Given that these documents are generally completed at the same time it may make more sense to consider them together rather than separately.

Complex care procedures was the last outcome investigated in aim 3.1. These procedures were not limited to the terminal hospitalization and could have occurred up to two years prior to the respondent's death. In this study, those without legal ACP were about equally likely to receive complex care procedures (OR = 0.97, 95% CI: 0.86-1.10). Results presented in this chapter are different from those described in the literature. Differences may be attributed to sample selection and methods. The first two studies used HRS data linked to Medicare claims and reported associations for end of life outcomes limited to the last month or 6 months of life (Bischoff et al., 2013; Tschirhart et al., 2014). In the first study there was no significant association between advance directives (OR = 0.81, 95% CI: 0.55-1.18) or medical power of attorney (OR = 0.90, 95% CI: 0.72-1.14) and ICU

admission compared to those without ACP (Bischoff et al., 2013). Results for racial/ethnic groups were not presented. The second study only considered advance directives and reported a significant reduction in the likelihood of intensive procedures in the last 6 months of life (OR = 0.71, 95% CI: 0.57-0.89) (Tschirhart et al., 2014). The current study failed to find a significant association between legal ACP (OR = 0.97, 95% CI: 0.86-1.10) and receiving complex care procedures in the final years before death. The observed differences may be due to the more accurate data available in claims data, which was used in the two other studies.

Racial/ethnic disparities in complex care procedures were demonstrated in this study with Hispanics 50% more likely (OR = 1.56, 95% CI: 1.26-1.93) than Non-Hispanic Whites to receive life support, be admitted to the ICU, or have dialysis. The association for Hispanics is consistent with the literature, but studies have also found Non-Hispanic Blacks to be significantly more likely than Non-Hispanic Whites to undergo intensive treatment at the end of life. In one study of 3,069 HRS decedents from 2002-2008 with linked Medicare claims data Non-Hispanic Blacks were twice as likely to receive an intensive procedure in the last 6 months of life (OR = 2.02, 95% CI: 1.52-2.69) as Non-Hispanic Whites (Tschirhart et al., 2014). A second study of 9,228 HRS decedents from 2002-2014 found Non-Hispanic Blacks and Hispanics to be significantly more likely than Non-Hispanic Whites to use life support, dialysis, or be admitted to the ICU before death (Orlovic et al., 2019). However, this second study did not include advance care planning components in multivariate modeling.

The sample size for aim 3.2 was limited reducing statistical power and the likelihood of detecting differences when present. The limited availability of data may be the reason for a lack of available information on the topic of end of life care consistent with decedents' preferences. This exploratory analysis aimed to test for associations between sociodemographics like age, gender, race/ethnicity, and congruent end of life care. A mediating hypothesis was also proposed and tested. However, there were no significant

results for this investigation. About half (51%) of HRS decedents received limited care when they expressed a preference to limit end of life care. Congruent care was most common among Non-Hispanic Blacks (57%) and least common for Non-Hispanic Whites (50%), though this was not statistically significant. There are no studies providing rates for congruent end of life care by race/ethnicity.

One investigation reported adjusted associations between ACP preferences to provide comfort care or limited care compared to those without ACP and found mixed results (Bischoff et al., 2013). Respondents with ACP preferences for comfort care were less likely to die in the hospital (OR = 0.78, 95% CI: 0.71-0.86) while there was not statistical difference for those with a preference for limited care (OR = 0.80, 95% CI: 0.61-1.06). In the current study, those with legal ACP documents were more likely to receive congruent care, but the relationship was not statistically significant (OR = 1.26, 95% CI: 0.99-1.61). Differences are likely due to the way key variables were operationalized with the Bischoff study considering comfort care and limited care preferences separately and the current study combining the two into one measure.

The main hypothesis for aim 3.1 was partially supported with legal ACP mediating the effect of race/ethnicity on hospital death and limited End-of-Life care. Social support did not play a mediating role. The analyses for this aim provide prevalence estimates and adjusted associations for racial/ethnic groups of interest. These results add to the limited information available in the literature. Disparities in end of life care are not as clear as might be expected with differences observed between minority groups of interest. Outcomes for complex care procedures are inconsistent with the literature, but this is likely due to the limitations of the HRS data when not linked to CMS claims.

The main hypothesis for aim 3.2 was not supported and may be due to the limited sample size. The results above provide the first available estimates for congruent end of life care by race/ethnicity. Given a larger sample size, it is possible the effect for legal ACP

may be significantly associated with increasing the likelihood that a respondent's preferences for end of life care are honored.

A strength of this study is the sample size for aim 3.1, which was large enough to report results for Non-Hispanic Blacks and Hispanics in multivariate analyses. Another strength is that a specific hypothesis was tested rather than only presenting multivariate adjusted associations for some or all covariates. Limitations include the SAS causal mediation procedure requiring continuous or dichotomous variables. The sample size for aim 3.2 was also small limiting power for analyses. A weakness of the HRS data is that it is a survey with potential for recall bias and for this study in particular errors in proxy reports. Due to the cross-sectional nature of this study, it is also not possible to determine temporality, such as whether ACP documents were completed before, during, or after the outcomes of interest.

This chapter has demonstrated the complexity of the role of legal ACP and social support in end of life care. Legal ACP plays a significant mediating role in death being experienced in a location other than the hospital and in the decision to limit care at the end of life. These findings suggest legal ACP may be useful for limiting hospital deaths and aggressive care at the end of life. Social support as defined in this study did not play a major mediating role in any of the outcomes investigated. However, studies with more robust measures of social support may find that this factor influences end of life care.

Chapter 5: The Roles of Estate Planning and Social Support in Racial/Ethnic Disparities in Advance Care Planning and End-of-Life Care

PURPOSE

The purpose of this chapter is to summarize the findings of this research on advance care planning and end of life care. A review of the main hypotheses of this study will be presented. Key findings from each aim will be reviewed considering the proposed hypotheses. After the outcomes of individual hypotheses are presented a broad overview of the results within the context of the theoretic framework will be examined. Lastly, strengths and limitations of the study will be reviewed.

AIM 1

The purpose of aim 1 was to describe the association between sociodemographic factors (ex. Age, race/ethnicity, education, etc.) and level of participation in end of life planning (ACP and estate planning). The aim replicated work by previous authors (Gerst & Burr, 2008; Khosla et al., 2015; Narang et al., 2015; Silveira et al., 2010) and expanded the evidence by investigating associations for Hispanics. It was hypothesized that sociodemographic associations in the literature would be observed. For example, older adults would be more likely to plan for the end of life. A specific hypothesis was that Non-Hispanic Blacks and Hispanics would be less likely than Non-Hispanic Whites to complete end of life planning (ACP or estate planning). The association between Hispanic ethnicity and estate planning has not been previously investigated.

Chapter 2 presents the full methods and results for aim 1. HRS core interview data from 9,644 living respondents in 2014 was used in weighted analyses to estimate U.S. community dwelling older adult (65+) prevalence rates for end of life planning.

Sociodemographic associations were generally similar to those in the literature. Direct comparisons were hard to make, because there are three potential activities included in advance care planning (discussing preferences for end of life care, advance directives, medical power of attorney) and definitions vary across studies. Some studies define ACP as having done any of the three activities while others focus on advance directives alone or any combination of the three components. Estate planning is not commonly investigated (Carr, 2012; Catheryn & Tamara, 2017), but results in the literature were generally consistent with findings in this study.

Legal ACP (advance directives or medical power of attorney) is significantly associated with age, gender, race/ethnicity, education, wealth, marriage status, and recent hospitalization and these associations remained significant in fully adjusted models. Prevalence rates demonstrate expected relationships. Minorities (Non-Hispanic Blacks and Hispanics) are less likely than Non-Hispanic Whites to participate in legal ACP. Education and wealth, both indicators of SES display positive trends with those in higher education categories and wealth quintiles being more likely to participate in healthcare planning.

Estate planning (having a written will) is significantly associated with age, gender, race/ethnicity, education, wealth, and marriage status, but not gender or recent hospitalization in bivariate analyses. After controlling for confounders, the associations for gender and recent hospitalization became significant, but marriage status was no longer significantly associated with having a will. Prevalence rates highlight key trends. Minorities (Non-Hispanic Blacks and Hispanics) are less likely to complete a will than Non-Hispanic Whites. Socioeconomic status is associated with estate planning such that those with higher educational attainment and wealth are more likely to make plans for their assets before death.

Specific associations were similar for the two end of life planning activities. Older respondents and females were more likely to plan for the end of life. As expected, health indicators (recent hospitalization) were more strongly associated with healthcare planning

than estate planning, and SES indicators were more strongly associated with having a will than with participating in legal ACP.

Hypotheses of aim 1 were supported. Sociodemographic associations were similar to those observed in the literature and most consistent with those defining the same ACP outcome (Catheryn & Tamara, 2017; Catheryn S. Koss & Baker, 2017c). Specifically, Hispanics and Non-Hispanic Blacks were significantly less likely to plan for the end of life even after multivariate modeling adjusting for potential confounders. Population prevalence estimates are presented in the chapter adding to the literature on end of life planning, especially for Hispanics. Results from aim 1 set the foundation for further investigations in this study. With profound and prevailing racial/ethnic disparities in end of life planning, it is important to develop specific hypotheses to investigate why these associations exist.

AIM 2

The purpose of aim 2 was to test for possible mediating relationship between race/ethnicity, socioeconomic status, estate planning, and advance care planning. The aim reproduced work done by previous authors and expanded the evidence by investigating the associations for Hispanics (Carr, 2012; Catheryn & Tamara, 2017). It was hypothesized that the effect of race/ethnicity on legal ACP would be mediated by SES and estate planning such that when these factors were included in the analyses the main effect of race/ethnicity on health care planning would be reduced or eliminated.

Theoretical assumptions were met for both socioeconomic status and estate planning to be considered as mediators in multivariate analyses. Logistic regression modeling supports the hypotheses that each factor mediates the main effect of race/ethnicity on legal ACP. As each mediator was added independently, there was a reduction in the disparities between Non-Hispanic Whites, Non-Hispanic Blacks, and Hispanics. Although, the differences persisted in fully adjusted models indicating the effect

was not fully mediated by SES and estate planning. Using the new SAS causal mediation procedure, each mediator was added in a stepwise fashion to investigate the role each plays independently. SES mediated 6% of the main effect and estate planning 10%. Taken together less than one-fifth of the relationship between race/ethnicity and legal ACP is accounted for by socioeconomic status and estate planning.

These findings are consistent with the limited literature on this topic (Carr, 2012; Catheryn & Tamara, 2017) and expand the evidence on the relationship between SES, estate planning, and ACP for Hispanics. Previous authors have hypothesized that adults who consult a lawyer to complete a last will and testament are prompted to complete legal healthcare documents. They propose that this could explain racial/ethnic and socioeconomic differences in ACP. The same hypothesis investigated here is supported with the findings in chapter 3. Racial/ethnic minorities (Non-Hispanic Black and Hispanic) are less likely to participate in legal ACP, and this relationship was partially mediated by both SES and estate planning. However, the extent of the mediating effect of SES and estate planning was less in the current study. The observed differences may be due to sample selection. Koss and Baker used a sample of living Non-Hispanic Whites and Blacks from one HRS Core interview and Carr used a sample of Non-Hispanic White Wisconsin high school graduates. (Carr, 2012; Catheryn & Tamara, 2017). The current study used a sample of deceased Non-Hispanic Whites, Blacks, and Hispanics from multiple waves of HRS exit interviews.

AIM 3

The purpose of aim 3 was to test for possible mediating relationship between race/ethnicity, advance care planning, social support, and end of life (End-of-Life) care. A key objective of this aim was to expand the literature on the association between ACP and end of life care, specifically by adding to the detail of results reported in the literature (Bischoff et al., 2013; Orlovic et al., 2019; Portanova et al., 2017; Tschirhart et al., 2014).

It was hypothesized that the effect of race/ethnicity on end of life care outcomes would be mediated by legal ACP and social support such that when these factors were included in the analyses the main effect of race/ethnicity would be reduced or eliminated. Aim 3.1 investigated three outcomes: hospital death, limited care decision, and complex care procedures. Sub aim 3.2 investigated congruent end of life care defined as proxy reported decisions to limit care at the end of life when the respondent indicated a preference for limiting end of life care.

Theoretical assumptions were met for legal ACP for hospital death and limited End-of-Life care decisions. Social support met assumptions for the limited End-of-Life care decisions and complex care procedures outcomes in aim 3.1. Neither hypothesized mediator met the assumptions for mediation analyses in aim 3.2. Multivariate modeling supported the hypothesis that legal ACP mediates the effect of race/ethnicity on hospital death and limited care decisions. The main effect of race/ethnicity on hospital death was reduced for Non-Hispanic Blacks and Hispanics when legal ACP was added to the model. The effect for Non-Hispanic Blacks remained statistically significant, but for Hispanics became nonsignificant. A similar mediating effect was observed with decisions to limit care at the end of life. However, the main effect for Hispanics was non-significant after controlling for sociodemographic factors (age, gender, SES, and estate value). The hypothesis that the racial/ethnic differences in complex care procedures is mediated by social support was not supported in multivariate modeling.

Although the mediating effect of legal ACP and social support was not consistently demonstrated for the four end of life outcomes, this chapter adds to the literature on disparities in end of life care. Associations between sociodemographics and end of life care are rarely reported in the literature. There are limited results for racial/ethnic minorities with three studies reporting findings for intensive procedures at the end of life (Orlovic et al., 2019; Portanova et al., 2017; Tschirhart et al., 2014) and one reporting rates of decisions to limit care at the end of life (Orlovic et al., 2019). Findings in this study were not

completely consistent with those reported in the three papers. All three papers found significant disparities between Non-Hispanic Whites, Non-Hispanic Blacks, and Hispanics. In this study, Non-Hispanic Blacks were more likely to die in the hospital, but the association for Hispanics was insignificant compared to Non-Hispanic Whites. The same discrepant findings were observed for decisions to limit end of life care with Non-Hispanic Blacks being less likely and Hispanics equally likely to make decisions to limit care at the end of life compared to Non-Hispanic Whites. Differences were likely due to the operationalization of ACP. In two studies advance directives alone were considered (Portanova et al., 2017; Tschirhart et al., 2014) and in the other ACP was not included in multivariate models (Orlovic et al., 2019).

The results for complex care procedures were also different from those reported in the literature. In the current study, Hispanics were more likely to undergo a complex procedure, but the association for Non-Hispanic Blacks was not significant when compared to Non-Hispanic Whites. Others using more precise data with HRS responses linked to CMS billing information have reported significant associations for both Non-Hispanic Blacks and Hispanics.

The objective of sub aim 3.2 was to expand the evidence on the role of ACP in honoring preferences for end of life care. The sample size was limited, because only two waves of HRS core data are available with core interview questions about care preferences. Although there were no significant associations after adjusting for sociodemographics (age, gender, SES, and legal ACP), bivariate analyses demonstrated a significant association between legal ACP and congruent end of life care. Surprisingly, those without legal ACP were more likely to receive care congruent with their preferences. Unweighted prevalence estimates for congruent end of life care were also not as expected. Non-Hispanic Blacks and Hispanics were more likely than Non-Hispanic Whites to receive limited care when that was their preference. This may be due to cultural differences between minorities and Non-Hispanic Whites.

THEORETIC FRAMEWORK

The overall theoretic framework of this research is built off the work of two papers investigating the role of estate planning in facilitating healthcare planning (Carr, 2012; Catheryn & Tamara, 2017). These authors demonstrated a mediating role for estate planning on the main effects of wealth and race/ethnicity in advance care planning. Building on their initial work, this investigation focused on racial ethnic disparities and the roles of both SES and estate planning in ACP. ACP was then linked to end of life care.

The framework can be broken down into two main steps. The first step is communicating preferences for end of life care and making these preferences known to others through legal documentation. Aim 1 demonstrated that those with legal ACP documents are more likely to be Non-Hispanic White, have a higher education, and more wealth. This is consistent with the theory that those with more social capital are likely to participate in estate planning before completing legal healthcare documents. Aim 2 demonstrated that those who have participated in estate planning are significantly more likely to complete legal ACP documents. Furthermore, SES and estate planning individually are significant mediators of the main effect of race/ethnicity on legal ACP and together account for about one-fifth of the observed disparities. So, although there is a mediating effect it may be smaller than expected.

The second step of the overall framework is the link between ACP, social support, and end of life care. Bivariate and adjusted analyses in aims 3.1 and 3.2 highlight racial/ethnic disparities in hospital death, limited end of life care decisions, complex care procedures, and congruent end of life care. For the two main outcomes in aim 3.1 most proximally associated with end of life care (hospital death and limited End-of-Life care), ACP was a significant mediator of the main effect of race/ethnicity on end of life care accounting for 27% and 46% of the observed disparities. Social support did not play a mediating role in care received at the end of life.

Results in this investigation support the overall theoretical framework demonstrating significant mediating effects of SES and estate planning on the relationship between race/ethnicity and legal ACP. Legal ACP is also a mediator of the effect of race/ethnicity on care received at the end of life.

LIMITATIONS

Sample. Data for this study was obtained from the Health and Retirement Study. When used with sampling weights, population estimates for U.S. adults 50 years of age and older can be produced. Aim 1 utilized a single wave of HRS core data allowing for prevalence estimates for advance care planning and estate planning. Aims 2 and 3 used exit interview data for deceased respondents. Weights were not applied in these analyses, meaning the results cannot be generalized to the entire U.S. population.

Another limitation is the reliance on interview data – proxy interviews – to estimate end of life care, rather than actual Medicare billing data. Recall bias may be an issue for this self-reported and proxy data. However, results in this study were comparable to those that linked HRS and CMS billing data for end of life outcomes. Non-response bias has been minimal in the HRS study with response rates for the years in this study ranging from 81.0-89.1% (mean = 86.9%) (Staff, 2017). Another issue is the utilization of proxy responses for exit interviews and the end of life experience. However, this cannot be avoided without using billing data which also has limitations.

A limitation of the measures available in the HRS data is the complexity of the questionnaire design. Skip sequences throughout the interview limit responses in each wave for some variables. This was an issue for ACP components, which were asked only to those 65 or older in core interviews. Other variables with a substantial amount of missing data were estate value and cognition score. Listwise deletion was used to exclude respondents with missing information. However, to preserve the sample size an unknown category was generated for both of these variables.

Measures. Although the concept of advance care planning is appropriately broad including informal discussions and legal documentation, lack of a clear definition makes it hard to compare outcomes across studies. The current study assessed the intercorrelation of ACP components to define the construct as having legal documents (advance directive or medical power of attorney). Much of the literature defines ACP as advance directives alone, medical power of attorney alone, or all three components together. Due to differences in operationalizing this variable, some associations were not exactly consistent with what is observed in the literature.

Defining Hispanic ethnicity is problematic. The HRS oversamples Mexican Americans and Floridians and the questionnaire asks about Hispanic ethnicity. Sample sizes for the entire subgroup of Hispanics are large enough to compare this minority of interest. However, Hispanic/Latino subgroups are culturally distinct. For example, treating Cuban and Mexican Americans as a homogenous group oversimplifies cultural differences. Despite this, the HRS does not have a large enough sample to explore associations for unique subsets of the Hispanic population.

Another limitation is the social support index that was created. The social support index used in this study has not been validated. A validated scale is available in the HRS leave behind questionnaire, but the sample size is inadequate for the analyses here. The scale used in this study was informed by the literature and included items like number of living children and actual support received. The correlation between the scale used in this study and the subsample of respondents who completed and returned the leave behind survey was low ($r = 0.20$), but was the best logical approximation of an indicator of social support given the variables available.

Design. The cross-sectional design of this study was used to increase the sample size for racial/ethnic minorities. This is a major limitation of this research that prevents the interpretation of causality. Due to this weakness, it is impossible to say whether the pathways described in the overall conceptual framework are supported temporally. Reverse

causality cannot be ruled out. For example, estate planning could precede legal ACP or legal ACP facilitated by a health care provider may prompt estate planning. This could be addressed using approximate dates of ACP documentation by proxies in exit interviews. However, this approach is not without issue. Proxies may not know the date ACP documents were completed and could provide inaccurate information. Additionally, dates for completion of estate planning would also be needed and this is not collected in the HRS.

Combining core interview responses from living respondents and matched exit interview answers from proxies posed a problem with sample size and statistical power for aim 3.2. Concordant questions in the two interviews are limited to HRS core interviews in 2012 and 2014. One additional wave of data may provide a large enough sample to detect differences in congruent end of life care, but at this time the HRS has not released newer data.

Methods. This dissertation utilizes a new SAS procedure released in late 2019. The causal mediation procedure is limited to independent, dependent, and mediator variables that are dichotomous or continuous. Therefore, mediation analyses could not be performed with Non-Hispanic Blacks and Hispanics compared to Non-Hispanic Whites in one model. Sensitivity analyses in chapter 3 demonstrated that there were no significant differences between Non-Hispanic Blacks and Hispanics for legal ACP. These two groups were combined, and the mediation procedure used to compare Non-Hispanic Whites to minorities (Non-Hispanic Blacks and Hispanics) throughout aims 2 and 3. Socioeconomic status in quintiles also posed an issue and was treated as a continuous variable in the mediation procedure. Results for key mediation procedures were also performed comparing Non-Hispanic Whites to Non-Hispanic Blacks and Hispanics alone and presented in sensitivity analyses tables.

Complexity. Advance care planning is a complex, multi-stage process. An individual must be aware of the process to engage it. Once an individual is aware and actively participating, it is up to the healthcare team to clarify treatment goals and

document them in the medical record. Later, when medical decisions are being made, the preferences communicated must be readily accessible and utilized. It is challenging to investigate such a complex issue with the limited information available in the HRS dataset. Improvements can be made with more complex datasets that link the HRS to CMS billing data, but important information will still be missing.

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