Racial and Ethnic Differences in Advance Care Planning: Identifying Subgroup Patterns and Obstacles

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Abstract

Objectives: The author investigated (a) whether Whites, Blacks, Latinos, and Asians differ in their rates of advance care planning (ACP; that is, living will, health care proxies, discussions), (b) sources of within-racial group heterogeneity, and (c) racial differences in the explanations offered for not doing ACP. **Methods:** The author estimated logistic regression models with data from a national sample of married and cohabiting adults ages 18 to 64 in the Knowledge Networks study (*N* = 2,111). **Results:** Latinos are less likely than Whites to discuss preferences and to have a living will, although the latter gap is fully accounted for by education. Asians are less likely than Whites to have discussions, but more likely to have living wills. Black-White differences emerge only among low SES (socioeconomic status) subgroups. Each group noted distinctive obstacles to planning. **Discussion:** Public policies should target increasing rates of ACP for all adults prior to onset of major health concerns.

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At the end of life, most chronically ill persons experience physical discomfort, limited mobility, and impaired cognitive functioning (Field & Cassel, 1997). Patients who are incapacitated and have not previously stated their treatment preferences may receive unwanted, futile, and costly medical interventions, or the withdrawal of treatments they may have desired (Detering, Hancock, Reade, & Silvester, 2010; Silveira, Kim, & Langa, 2010). Difficult decisions about withholding or continuing treatment often fall upon distressed family members who may not know the patient's preferences or may disagree with one another (Breen, Abernathy, Abbott, & Tulsky, 2001).

In response to the financial and emotional costs associated with problematic end-of-life care, policy makers have established practices that enable patients to formally state their treatment preferences when they are still cognitively intact. The Patient Self-Determination Act (PSDA), passed by Congress in 1990, requires that federally funded hospitals and nursing homes give patients an opportunity to complete an advance directive, which comprises a living will and durable power of attorney for health care (DPAHC). A living will is a legal document specifying the treatments a person would like to receive if incapacitated. A DPAHC permits a person appointed by the patient to make health care decisions if the patient is incapable of doing so (i.e., a "proxy"). Living wills and DPAHC appointments have widely recognized limitations (Fagerlin & Schneider, 2004), so health care professionals urge patients to also convey their preferences and values to significant others via informal conversations (Doukas & Hardwig, 2003).

Advance care planning (ACP) is strongly encouraged by practitioners, yet only one third to one half of older Americans make such preparations (Hopp, 2000; Silveira et al., 2010). Furthermore, research consistently documents a sizeable and intransigent Black-White gap in ACP. Studies based on large, nationally representative samples of older adults, including the Health and Retirement Study (Gerst & Burr, 2008; Hopp, 2000) and Asset and Health Dynamics Among the Oldest Old (Hopp & Duffy, 2000) show that Whites are 2 to 3 times as likely as Blacks to have a living will, appoint a DPAHC, and discuss treatment preferences with significant others (see also Degenholtz, Arnold, Meisel, & Lave, 2002). Research on Latinos is sparser, yet most conclude that they are less likely than Whites to do ACP (Carr, 2011a; Eleazer et al., 1996; Muni, Engelberg, Treece, Dotolo, & Curtis, 2011; Smith et al., 2008).

However, studies have not fully explicated why these disparities exist or the extent to which within-racial category differences persist. Furthermore, nearly all studies focus on older adults or chronically ill persons only (see Kwak & Haley, 2005, for review). Practitioners recognize that planning

done at age 65 or above may be "too late," especially given that Blacks and Latinos (to a lesser extent) are more likely than Whites to have early onset of major health conditions, including hypertension, diabetes, heart disease, Alzheimer's disease, and some forms of cancer (Cowie et al., 1989; Jones & Hall, 2006; Livney et al., 2011; Newman, 2005). As such, it is essential that researchers also explore disparities in and obstacles to ACP among young and midlife adults. Identifying the prevalence of and obstacles to ACP among ethnic minorities will become increasingly important in the future, as the U.S. population grows more diverse. The proportion of the U.S. population that is White is projected to decline from roughly 67% today to 47% in 2050; by contrast, the Asian and Hispanic populations are expected to increase from 5% to 9%, and 14% to 29%, respectively (Passel & Cohn, 2008).

Thus, this study has four goals:

1. Evaluate whether White, Black, Latino, and Asian adults aged 18 to 64 differ in their rates of three types of ACP (i.e., living will, DPAHCs, and informal discussions);
2. Assess the extent to which these subgroup differences persist net of potential confounds, including demographic, socioeconomic status (SES), and health characteristics;
3. Examine whether racial and ethnic differences in ACP are moderated by age, health status, and two aspects of SES: college education and home ownership; and
4. Describe racial and ethnic differences in the accounts offered for why one does not engage in each of the three types of planning. Data are from the Knowledge Networks (KN) panel, a large national sample of married and cohabiting adults aged 18 to 64.

Background

Understanding the extent to which ethnic groups differ in their rates of ACP and the reasons for such disparities is an important public health issue. Blacks receive consistently poorer quality health care than Whites over the life course (Smedley, Stith, & Nelson, 2003), including at the end of life (Rhodes & Teno, 2009). For example, among cancer patients who desire aggressive treatments, Blacks are one third as likely as Whites to receive treatments that are consistent with their preferences (Loggers et al., 2009). One possible reason for this disparity is that Whites are more likely to formally articulate their preferences; unstated preferences cannot be heeded. As

Rhodes and Teno (p. 5498) observe, "Preferences are meaningless without the care plan . . . in place to ensure that those wishes are respected."

Mounting research also documents that end of life health care expenditures are considerably higher for Blacks and Latinos relative to Whites (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009; Kelley et al., 2011; Nicholas, Langa, Iwashyna, & Weir, 2011). One analysis of Medicare expenditures in 2001 found that the average cost of care in the past 6 months of life ranged from US$20,166 among Whites, to US$26,704 among Blacks, and US$31,702 among Latinos (Hanchate et al., 2009). Fully 85% of the observed higher costs for Blacks and Hispanics were accounted for by their greater usage of intensive (and costly) invasive treatments. This usage pattern partially reflects preferences, where Blacks and Hispanics are more likely than Whites to desire aggressive treatments (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Kwak & Haley, 2005). However, an additional explanation may be that ethnic minorities are less likely to formally specify those treatments they would like (or not like) at the end of life. In the absence of such formal statements, health care providers typically default to the use of all available treatments (Field & Cassel, 1997). ACP is encouraged precisely so that patients have the opportunity to reject intensive and often futile medical treatments, even if one is mentally incapacitated at the moment the decision is required.

In the past decade, several studies have evaluated potential explanations for ethnic disparities in ACP among older and terminally ill adults. One study of advanced cancer patients found persistent Black-White and Latino-White differences in rates of ACP, and these differences were not explained by clinical or demographic factors, terminal illness acknowledgment, importance of religion, or treatment preferences (Smith et al., 2008). Similarly, an analysis of chart data from 3,000 patients who recently died in hospital intensive care units (ICUs) found that stark racial differences in ACP were not accounted for by sociodemographic characteristics (Muni et al., 2011). By contrast, research based on 305 terminally ill older adults in New Jersey showed that Black-White and Latino-White gaps in the use of formal ACP documents (i.e., living will or DPAHC) were largely explained by Blacks' and Latinos' very low rates of estate planning—an action that often triggers health-related planning. Given Blacks' and Latinos' lower levels of wealth accumulation and lower rates of home ownership relative to Whites, they are less likely to have wills; thus, they do not engage in the action that often triggers formal health-related planning (Carr, 2011b).

Distinctive psychosocial explanations also have been found for Black and Latino older adults; Carr (2011a) found that Latinos' very low rates of DPAHC (compared to living will) usage reflected their view that families as

a unit—rather than a single appointed individual—should carry out the patient's treatment preferences at the end of life. Small qualitative studies have similarly found that Mexican American families believe that important care decisions should be made by consensus rather than a single individual (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). Among older Blacks, by contrast, low rates of formal and informal ACP were largely accounted for by the belief that death timing is in God's hands (Carr, 2011a).

Although recent studies have started to shed light on the magnitude of and possible explanations for racial disparities in ACP, a number of important research gaps remain. First, nearly all studies focus on current cohorts of old and oldest-old adults who were born during the first three decades of the 20th century. This focus partly reflects data availability, where the most widely used data resources for studying patients' ACP are large population-based sample surveys of older adults such as the Health and Retirement Study (Gerst & Burr, 2008; Hopp, 2000) and Asset and Health Dynamics Among the Oldest Old (Hopp & Duffy, 2000). Among these birth cohorts, who entered adulthood prior to the Civil Rights movements of the 1960s, racial and ethnic gaps in education, literacy, income, wealth, home ownership, and access to care are far wider than they are for young and midlife adults today (U.S. Census Bureau, 2006). Ethnic minority status may be confounded with low levels of educational attainment, income, and assets, given historical patterns of race-based stratification in the United States, especially among cohorts who came of age, completed their schooling, and began their work lives in the decades prior to implementation of Federal equal opportunity policies during the Civil Rights era. Studies that do not adjust for these potential confounds may overstate the effect of race and ethnicity on ACP.

Second, ACP research typically focuses on clinical populations who, by design, are seeking care at hospitals (e.g., Smith et al., 2008) or nursing homes (e.g., Degenholtz et al., 2002; Rhodes & Teno, 2009). Institution-based samples may generate disproportionately high estimates of ACP, given that the PSDA (1990) mandates that persons seeking care in federally funded hospitals or nursing homes be offered the opportunity to complete an advance directive.

Third, most studies focus on Black-White and Latino-White contrasts, to a lesser degree. However, relatively few studies examine Asian-White differences. Several small qualitative studies suggest that some Asian cultures believe that discussing unpleasant topics, such as death, will bring such troubles upon one's family (Frank et al., 1998; Kalish & Reynolds, 1981). Furthermore, given that many Asian cultures are patriarchal and hierarchical, formal planning may be done—even in the absence of discussions (Lee,

2009). One family member, usually the eldest male, is expected to make health care decisions on behalf of family members. Such findings are intriguing and invite further exploration in a large-scale study that can reveal the distinctive ways that race and ethnicity affect both formal and informal preparations for end-of-life care.

Finally, most empirical studies identify post hoc the reasons why one does not engage in planning, by documenting those variables that mediate the statistical association between race and ethnicity and ACP. This strategy is reasonable and well justified; it is important for researchers to identify those factors that account for all or some of the effects of ethnicity on planning. However, an equally valuable approach is to ask individuals directly why they did not engage in ACP. Particular subgroups may name distinctive obstacles and may cite different obstacles for each component of ACP (i.e., living will, DPAHC, and discussions).

I use data from a national sample of more than 2,000 White, Black, Latino, Asian, and multiracial persons aged 18 to 64 to explore differences in two aspects of formal (i.e., living will, DPAHC) and one informal aspect (i.e., discussions) of end-of-life planning. All analyses are controlled for demographic (age, gender), family (marital and parental statuses), SES (income, education, employment status, home ownership) and health (self-rated) characteristics that are correlated with both ACP (e.g., Hopp, 2000) and race and ethnicity (U.S. Census Bureau, 2006). I also conduct moderation analyses to evaluate potential sources of within-race heterogeneity in ACP. First, I explore whether the magnitude of race disparities in ACP differ for midlife versus younger adults, and healthy versus unhealthy participants. These analyses enable me to partially explore cohort differences, given stark changes in the socioeconomic composition of ethnic minority cohorts in recent decades (U.S. Census Bureau, 2006), as well as subgroup differences in the timing and severity of major health conditions (Cowie et al., 1989; Jones & Hall, 2006; Livney et al., 2011; Newman, 2005).

I also evaluate whether the effects of race and ethnicity are moderated by two components of SES: home ownership and educational attainment. Prior research shows that home owners are more likely than non-home owners to do ACP, because they engage in estate planning to protect their financial assets, and then complete advance directives at the same time (Carr, 2011b). Given the strong correlation between race and home ownership (e.g., Keister & Moller, 2000; Oliver & Shapiro, 2006) studies that fail to look at the independent and interactive effects of both variables may overstate the magnitude of the race gap in ACP. I also explore whether the effects of race vary by educational attainment; advanced education is associated with higher literacy

rates, greater access to legal and financial professionals who may assist one with their ACP, better quality jobs that carry richer health insurance benefits, and a fuller knowledge of health behaviors and practices (Phelan, Link, & Tehranifar, 2010). Finally, I explore individuals' accounts of why they do not engage in each type of ACP. These reports may enable practitioners to develop targeted interventions that facilitate the use of strategies individuals deem desirable and consistent with their cultural beliefs and practices.

Data and Methods

Sample

Analyses are based on data from an internet survey conducted by Knowledge Networks (KN), in conjunction with the National Center for Family and Marriage Research (NCFMR) at Bowling Green State University, between July and October 2010. This cross-sectional study included a sample of 2,150 participants between 18 and 64 years of age who belonged to one of 1,075 married or cohabiting heterosexual couples residing in the United States. Seventy percent of the couples were married and 30% were cohabiting.

In 1999, KN established the first online research panel (Knowledge Panel [KP]) that is representative of the U.S. population, using probability-based sampling methods that include computer user and nonuser populations. If the panel members did not have access to the internet, they were provided computer equipment to participate in the study. A recent evaluation found that a survey using the KP was comparable to a nationally representative random digit dial (RDD) telephone survey sample, and the data obtained from the KP internet component were superior to the RDD sample with respect to reliability and validity (Chang & Krosnick, 2009).

Couples in my analytic sample were recruited primarily from the KP. Of the married persons, all participants were in the KP. Of the cohabiting persons, one third of participants were panelists. Two additional sources were used to generate the remaining sample of cohabiting couples: 10% of cohabiting couples include one KP member and one partner who was not on the panel, and the remaining 57% of cohabiting couples comprise two partners recruited through online advertisements (i.e., an off-panel nonprobability sample). This strategy was used so that the final sample would roughly approximate the marital status breakdown of partnered Americans, where married couples significantly outnumber cohabiting couples.

Response rates varied by recruitment method. Recruitment within the panel yielded a 50% response rate from married couples and a 41% response

rate from cohabiting couples. Response rates are not calculable for the off-panel nonprobability sample because response to the web advertisement is unknown. Because my analysis is focused on individuals rather than couples as the unit of analysis, the data are weighted to account for potential nonindependence of measures (see Moorman & Inoue, 2011, for further detail).

Dependent Variables

Study participants are introduced to the ACP module with the question stem: "We now have some questions about health care planning and decisions that people may make for their end-of-life medical care." *Formal ACP* is assessed with two questions: "Have you made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself? This is sometimes called a durable power of attorney for health care," and "Do you have a living will or advance directive? These are written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate." I consider both outcomes separately because prior studies show that ethnic minorities are more likely than Whites to adopt only one of the two strategies (Carr, 2011a). However, rates of overlap are very high at the population level. In the overall KN sample, 87% of persons with a living will also named a DPAHC, and 80% with a DPAHC also have a living will.

End-of-life discussion is a dichotomous variable based on the question: "Have you discussed with anyone plans about the types of medical treatment you want or don't want if you become seriously ill in the future?" Those who had had a discussion were coded as 1 and those who had not were coded as 0.

Persons who do not engage in each type of planning are asked their *reasons for not doing so*. They were provided eight closed-ended responses and could endorse as many reasons as applied. Response categories were as given below:

1. "I do not believe this measure affects treatment."
2. "I have not thought about my treatment preferences."
3. "My preferences are already known to others."
4. "I did not know this measure existed."
5. "I do not know how to go about doing this."

6. "My health is currently good."
7. "I do not want to burden anyone with this responsibility."
8. "I do not want to think about dying and illness."

Independent Variables

The key independent variable is *race/ethnicity*; respondents self-identify as non-Hispanic White, non-Hispanic Black, Hispanic/Latino, and Asian. Thirty nine of the original 2,150 respondents self-identified as multiracial; this cell size is too small to conduct sufficiently powered logistic regression analyses; thus. they are dropped from the analytic sample. Preliminary analyses reveal that multiracial persons in the KP do not differ significantly from Whites with respect to their rates of living will completion, DPAHC appointments, or holding end-of-life discussions.

All multivariate analyses are adjusted for demographic, SES, and health characteristics. Demographic characteristics include *age* (in years), *gender* (1 = female, 0 = male), *marital status* (1 = cohabiting, 0 = married), and *parental status* (1 = has children, 0 = does not).

SES characteristics include *employment* (1 = employed, 0 = not), education, income, and *home ownership* (1 = owns home, 0 = not). *Education* refers to the highest level of schooling one has completed: less than high school, high school diploma (reference category), some college, and college degree. *Income* refers to total household income. For the 2% of cases for whom income is missing, I imputed the mean and used a dummy variable to indicate missing data. *Physical health* is assessed with a standard self-rated health measure ("How would you rate your health at the present time?"); fair and poor are coded as 1, and good or better comprise the reference group.

Analytic Plan

Descriptive statistics for all variables, by race and ethnicity are presented in Table 1. I conducted ANOVA (analysis of variance) with post hoc comparisons to identify statistically significant differences between the racial categories. Second, I estimated logistic regression models to identify the extent to which the racial differences in ACP documented in the bivariate analyses persist net of demographic, SES, and health characteristics. Third, I evaluated whether the effects of race and ethnicity on ACP are moderated by age, health, education, and home ownership. Finally, I present descriptive results contrasting the explanations offered by Whites, Blacks, Latinos, and Asians for why they do not engage in each of the three types of ACP.

Table 1. Descriptive Statistics for All Variables Used in Multivariate Analyses, Knowledge Networks Study, 2010

	Total	White	Black	Latino	Asian	F statistic (df = 3)	Significant subgroup differences
Dependent variables							
Has living will	.24	.25	.16	.13	.32	6.72***	WL, BA, AL
Named DPAHC	.27	.28	.21	.17	.29	3.65*	WL
Had discussions	.57	.60	.44	.37	.45	16.15***	WB, WA, WL
Independent variables							
Demographic characteristics							
Age (years)	43.18 (11.89)	44.2 (11.7)	30.1 (12.4)	37.4 (11.1)	39.8 (12.2)	25.19***	WB, WA, WL
Female	.50	.51	.42	.49	.53	1.16	
Cohabiting	.30	.27	.69	.39	.27	33.05***	WB, WL, BA, BL
Has children	.40	.38	.42	.55	.57	10.37***	WA, WL
Socioeconomic status							
Less than high school	.054	.046	.065	.11	.076	34.29*	WL
High school diploma	.23	.24	.25	.25	.15	1.49	
Some college	.36	.36	.48	.38	.28	3.11*	BA
College graduate	.35	.36	.21	.26	.49	8.41***	WB, WA, BA, AL
Total household income	68,675	70,801	49,404	58,263	71,851	18.17***	WB, WL, BA, AL
Income missing	.021	.02	.028	.036	.00	1.59	
Owns home	.71	.76	.34	.55	.61	44.08***	WB, WA, WL, BA, BL
Currently employed	.70	.70	.66	.72	.64	.831	
Health							
Self-rated health, fair/poor	.11	.11	.12	.10	.13	.223	
N	2111	1731	107	167	106		
%	100	82.0	5.1	7.9	5.0		

Note: N = 2,111. DPAHC = durable power of attorney for health care. Means (and standard deviations) are shown for continuous measures and proportions are shown for categorical measures. ANOVA (analysis of variance) with post hoc tests were conducted to assess subgroup contrasts. Specific contrasts that are statistically significant at the $p < .05$ level are indicated where W = White, B = Black, L = Latino, and A = Asian.

Results

Bivariate Analysis

The descriptive statistics in Table 1 reveal significant racial and ethnic differences in each of the three ACP outcome measures, yet they also point out how rare ACP is in a relatively young and healthy sample of partnered adults. (The mean sample age is 43, and 89% rate their health as "good" or better). Overall, 24% have a living will, and 27% have named a DPAHC. Informal discussions are much more common; 57% have discussed their preferences for end-of-life medical care. The ANOVA analyses reveal that Latinos are significantly less likely than Whites to have a living will (13% vs. 25%) and a DPAHC appointment (17% vs. 28%). Asians are more likely than Hispanics and Blacks (32% vs. 13% and 16%, respectively) to have a living will. A significantly higher proportion of Whites held discussions, relative to Blacks, Latinos, and Asians (60% vs. 44%, 37%, and 45%, respectively).

The sample reveals stark racial differences in marital, parental, and SES, consistent with prior work on race and ethnic differences in family and status attainment processes (e.g., U.S. Census Bureau, 2006). Blacks and Latinos are less likely than Whites and Asians to be married (relative to cohabiting) and also have consistently lower levels of education, household income, and home ownership rates.

Multivariate Analysis

I next evaluate the extent to which the race and ethnic differences in ACP, as shown in Table 1, persist when a range of potential explanatory factors are controlled. I estimated a series of nested models, where I sequentially controlled for demographics, family statuses, SES factors, and health. The White-Latino gap in DPAHC appointments was wholly accounted for after entering the first block of demographic characteristics. Although the baseline (unadjusted model) showed that Latinos had 55% the odds of Whites of appointing a DPAHC, that effect is no longer significant after age and gender are controlled. This pattern likely reflects the significantly younger mean age of Latinos versus Whites in the sample (37 vs. 44 years, $p < .001$), as young people are less likely to engage in ACP. I do not present models for the outcome of DPAHC because I did not find statistically significant ethnic differences in the adjusted models. The logistic regression models, presented in Table 2, show that some racial and ethnic differences in living will use and discussions persist, though these attenuate in the fully adjusted models. I present only the fully adjusted models for living will (left-hand column) and

Table 2. Logistic Regression Models Predicting the Odds of Having a Living Will and Holding End-of-Life Discussions, by Race and Ethnicity; Demographic, Socioeconomic, and Health Characteristics; Knowledge Networks Panel

	Has living will (odds ratio)	Discussed preferences (odds ratio)
Black	0.89	0.72*
Latino	0.73	0.53****
Asian	1.56*	0.58***
Demographic characteristics		
Age (years)	1.06***	1.03****
Female	0.94	1.14
Cohabiting	0.86	0.83
Has children	1.18	0.98
Socioeconomic status		
Less than high school	0.84	0.77
Some college	1.38	1.09
College graduate	2.88***	1.16
Total household income	1.001***	1.001***
Income missing	0.35†	0.58
Owns home	0.97	1.06
Currently employed	1.05	0.76**
Health		
Self-rated health, fair/poor	1.56*	1.35**
Chi-square (df)	257.89 (15)	167.11 (15)
Nagelkerke pseudo R^2	0.172	0.102

Notes: N = 2,111.
*$p < .10$. **$p < .05$. ***$p < .01$. ****$p < .001$.

discussions (right-hand column), although I describe results for the nested models.

The baseline model (not shown), like the descriptive statistics, reveals that Blacks (OR = 0.55, $p < .05$) and Latinos (OR = 0.45, $p < .001$) are less likely and Asians (OR = 1.39, $p < .10$) more likely than Whites to have a living will. The Black-White difference is no longer statistically significant after age is controlled, reflecting the lower age of Blacks than Whites in the sample. By contrast, the large gap between Whites and Hispanics, where Hispanics are about half as likely as Whites to have a living will, is no longer statistically significant after educational attainment is controlled. Asians' greater likelihood
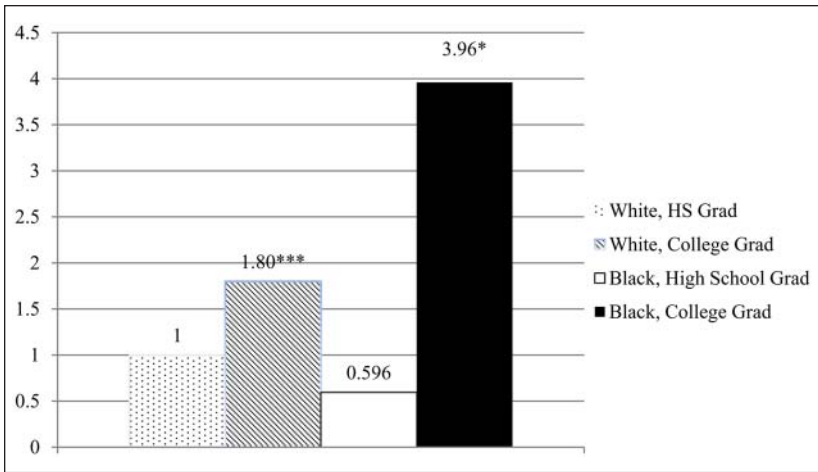
of having a living will relative to Whites persists in the fully adjusted model. After health, SES, and demographics are controlled, Asians are 1.56 times as likely as Whites to have a living will. This is the only ethnic gap in formal planning that remains statistically significant in the fully adjusted models.

Pronounced racial and ethnic differences persist for discussions, however. In the fully adjusted model, the odds of discussing one's treatment preferences are 0.72 ($p < .10$) for Blacks, 0.53 ($p < .000$) for Hispanics, and 0.58 ($p < .01$) for Asians, relative to Whites. The full models reveal several other important influences on end-of-life preparations. With each additional year of age, the odds of having a living will and discussing one's preferences increase by 6% and 3%, respectively ($p < .000$). A college education is associated with a greater likelihood of having a living will (OR = 1.88, $p < .000$), yet does not affect the odds of having discussions (OR = 1.16, $p = .24$). Household income is positively and significantly associated with both outcomes. Consistent with prior studies, persons in fair or poor health are 56% ($p < .05$) and 35% ($p < .05$) more likely than persons in good or better health to have executed a living will and held discussions, respectively. The full model explains a greater amount of variance in living will usage than in discussions (i.e., pseudo R^2 values of .172 and .102, respectively).
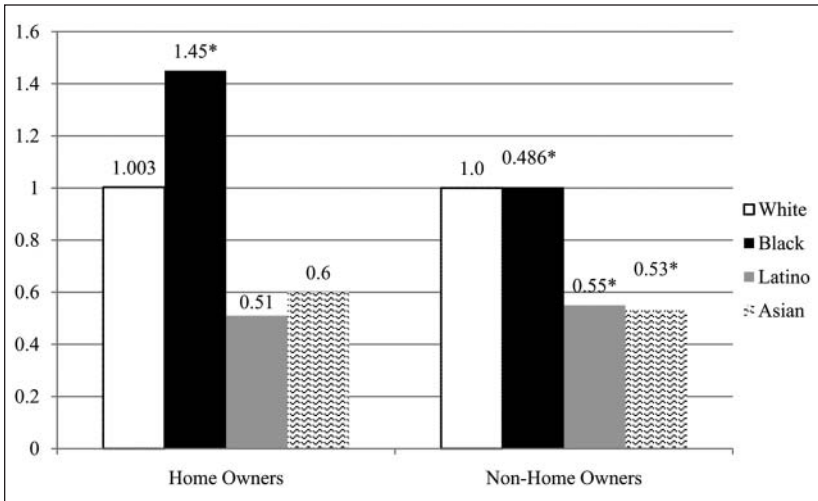
Moderation Analyses

I next evaluate whether the effects of race and ethnicity on ACP differs significantly by health (fair/poor vs. good or better), age (a dichotomous measure indicating whether one is younger or older than age 50), home ownership (owns home vs. not), and whether one has a college degree. A Bonferroni correction was used to account for multiple comparisons. I estimated two-way interaction terms between each potential moderator and the racial categories of Black, Hispanic, and Asian. Of the 36 interactions tested (i.e., three racial categories, by four potential moderators, for three outcomes), just two were statistically significant at the $p < .05$ level. The Black-White gap in living will usage is moderated by education, and the Black-White gap in discussions is moderated by home ownership. For ease of presentation, the statistically significant interaction terms (net of all controls) are plotted in Figures 1 and 2.

Figure 1 shows the relative odds of having a living will. College graduates are significantly more likely than high school graduates to have a living will, yet the disparity is significantly larger among Blacks than among Whites. Whites with a college degree are 1.8 times as likely as their counterparts with a high school diploma to have a living will ($p < .001$), whereas the difference

Figure 1. Relative odds of having a living will, by race and educational attainment (adjusted for all study independent variables)

Figure 2. Relative odds of discussing end-of-life treatment preferences, by race and home ownership status (adjusted for all study independent variables)
Note: Statistically significant main and interaction effects denoted as *p* values below.
*$p < .05$. **$p < .01$. ***$p < .001$.

is nearly sevenfold (3.96/0.596 = 6.64) among Blacks. Of the four subgroups plotted here, Black high school graduates are least likely to have a living will (OR = 0.596, relative to Whites with a high school diploma).

Similarly, Figure 2 reveals that socioeconomic resources moderate the effects of race on discussions. Among those who do not own homes, stark racial and ethnic disparities are documented—gaps that are consistent with other studies of ACP among older samples of ethnic minorities. Blacks (OR = 0.486, $p < 0.05$), Latinos (OR = 0.55, $p < .05$), and Asians (OR = 0.53, $p < .05$) are about half as likely as Whites to have discussed end-of-life issues, in the subsample of those who do not own homes; these effects are net of age, income, education, and all other study independent variables. Among home owners, by contrast, only one race and ethnic difference is statistically significant; Blacks are more likely than Whites to have discussed end-of-life issues (OR = 1.45, $p < .05$). The interaction term of Black by homeowner was statistically significant ($p < .05$), yet the comparable interaction terms for Hispanic and Asian ethnicity were not statistically significant. Thus, among Blacks, social class differentiates those who do and do not make end-of-life preparations; however, the Asian-White and Latino-White differences documented do not differ significantly based on educational attainment or home ownership.

What Accounts Are Offered for Not Preparing for the End of Life?

The results thus far suggest that ethnic minorities are less likely than Whites to do ACP, but these effects are not as pronounced as found in past studies, and the Black-White gap is limited to socioeconomically disadvantaged sub-populations. The final aim is to describe the reasons why one did not engage in planning. Among those without a living will ($n = 1,578$, 76% of sample) or a DPAHC ($n = 1,530$, 73%), the most common explanations were, "My health is currently good" (28% and 33%), "My preferences are already known by others" (29% and 31%), "I have not thought about my preferences" (25% and 29%), and "I don't want to think about dying" (26% and 27%), respectively. Three of these reasons were also the most common explanations for why one has not had discussions ($n = 893$, 43%): "haven't thought about preferences" (38%), "health is good" (32%), and "don't want to think about death and dying" (35%).

The most rarely endorsed explanations were the belief that the measure would be ineffective (3%-4% across all outcomes) and not knowing the measure existed (3%-4% across all outcomes). However, the rarely endorsed

explanations evidence the starkest racial and ethnic differences. I conducted ANOVA with post hoc tests to evaluate race and ethnic differences in each of the eight reasons, for each of the three outcomes. Of the 24 analyses, 11 yielded statistically significant differences; I detected more racial and ethnic differences in the explanations offered for formal versus informal planning. These results are plotted in Figures 3a to 3c.
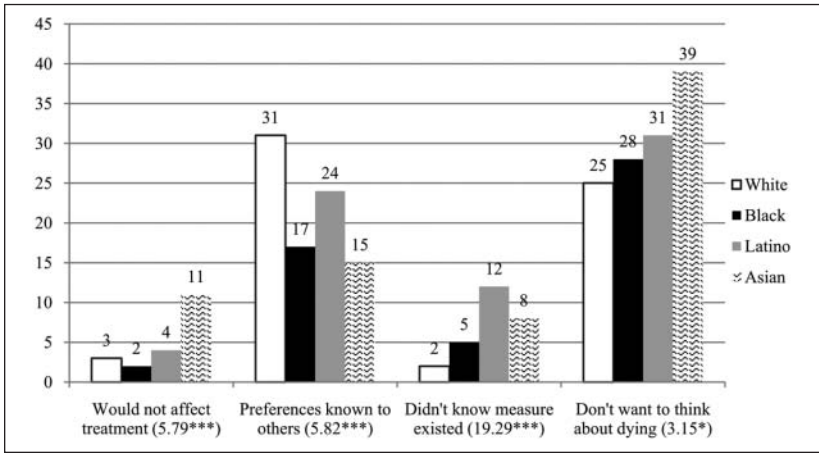
Figure 3a displays the reasons why one does not have a living will. Asians are most likely to say that it would not affect treatment and that they don't want to think about dying. By contrast, Whites are most likely to say that their preferences are known by others. The most commonly cited reason among Blacks, like Asians, was they didn't want to think about dying. Although it was rare for any ethnic group to say they didn't know the measure existed, Latinos are significantly more likely than others to offer this response. Generally similar findings emerge for DPAHC appointments, as shown in Figure 3b. Asians believe that it will not affect treatment, whereas Whites are most likely to say that their preferences are known to others. Asians are far more likely than the other three groups to say they don't want to burden family and don't want to think about dying.

Finally, Figure 3c focuses on discussions. Latinos are significantly more likely than Whites to say they didn't know they had this option, whereas Latinos and Asians are most likely to say that they don't know how to broach such discussions. No statistically significant ethnic differences were found in endorsements of the other four reasons. In sum, the results suggest that the obstacles to planning are based more on denial and avoidance, especially among Asians and less on cognitive or knowledge obstacles—although knowledge obstacles were often cited by Hispanics. Few said they were afraid of burdening others, although this view was most commonly endorsed among Asians.
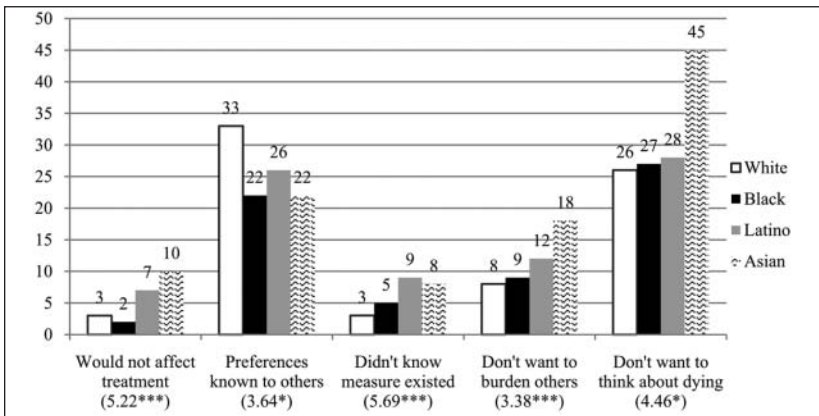
Discussion

The study results shows that race and ethnicity are neither uniformly nor negatively associated with end-of-life planning. These findings stand in stark contrast with qualitative studies (e.g., Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002), national surveys based on samples of older adults (e.g. Hopp, 2000), and clinical samples (e.g., Carr, 2011a; Smith et al., 2008), which show pronounced Black-White and Latino-White gaps that persist net of SES, demographic, health, and religious characteristics. The discrepancy in findings could reflect distinctive aspects of the KN sample. By design, all persons are in stable romantic partnerships; thus, sample members are likely "positively" selected on SES, especially African Americans. In the general
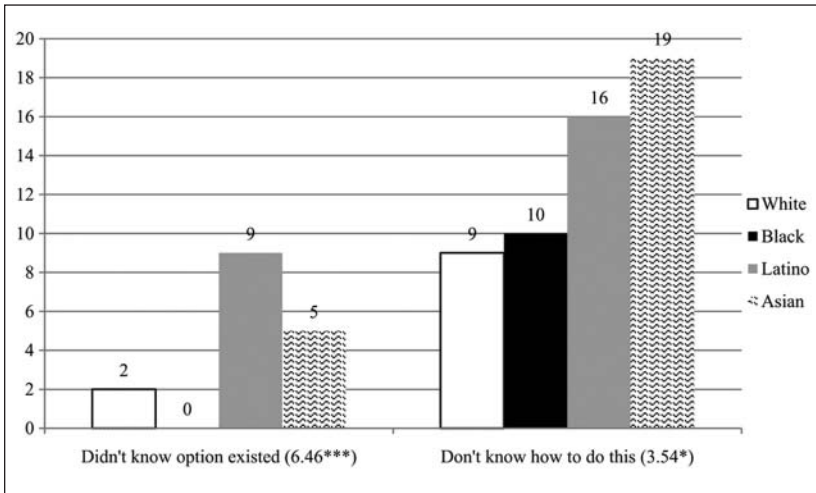
Figure 3a. Proportion of persons without a living will (*n* = 1,578) naming each explanation
Note: No statistically significant differences for proportions saying, "haven't thought about preferences," "don't know how to do this," "health is good," and "don't want to burden others." Results are presented from analysis of variance (ANOVA; *df* = 3). Chi-square values and significance levels are presented in parentheses, whose *p* values are provided below.
*p < .05. **p < .01. ***p < .001.

Figure 3b. Proportion of persons without a DPAHC (*n* = 1,530) naming each explanation
Note: No statistically significant differences for proportions saying, "haven't thought about preferences," "don't know how to do this," and "health is good." Results are presented from analysis of variance (ANOVA; *df* = 3). Chi-square values and significance levels are presented in parentheses, whose p values are provided below.
*p < .05. **p < .01. ***p < .001.

Figure 3c. Proportion of persons who have not had discussions (*n* = 893) naming each explanation

Note: No statistically significant differences for proportions saying, "it would not affect treatment," "haven't thought about preferences," "preferences known to others," "health is good," "don't want to burden others," and "don't want to think about dying." Results are presented from analyses of variance (ANOVA; *df* = 3). Chi-square values and significance levels are presented in parentheses whose *p* values are provided below.
*p < .05. **p < .01. ***p < .001.

population, African Americans have much lower rates than Whites in the categories marrying and staying married; marriage is both a consequence and predictor of economic standing. The discrepancy also may reflect the relatively young age and good health of the KN sample.

Although the race differences documented here are not as steep or sweeping as detected elsewhere, several clear patterns emerge. First, Latinos are less likely than Whites to do all three types of planning, although the gap in DPAHC usage was fully accounted for by their relatively young age and the gap in living will usage was accounted for by their lower educational attainment, relative to Whites. Latinos remain only half as likely as Whites to discuss their treatment preferences in the fully adjusted models. Moderation analyses showed that this difference was not significantly different for higher- versus lower SES Latinos; two-way interaction terms between home ownership and college education, by Hispanic ethnicity, were not statistically significant.

However, Latinos also are more likely than other sample members to mention cognitive or informational obstacles to ACP. They are significantly more likely than Whites to say that they didn't know about each of the three ACP options and also were more likely to say they didn't know how to broach a discussion about end-of-life issues. These results suggest that informational campaigns targeted at Latino communities would be useful in encouraging ACP, although this information would need to be presented in a nonthreatening manner, given that about a third of Latinos attributed their lack of ACP to their desire to avoid thoughts of death.

Asians also are more likely than Whites to say that they do not do ACP because they don't want to think about dying. Interestingly, Asians are only 58% as likely as Whites to hold discussions, but are 56% more likely to have a living will. These findings are consistent with prior qualitative work showing that Asians are more likely than other ethnic groups to rely on formal documents, yet do not want to discuss issues related to death due to a fear that such a conversation will bring on a death (e.g., Lee, 2009). Interventions targeted at Asian communities should convey that formal planning in the absence of discussions may not be effective in conveying one's preferences (Fagerlin & Schneider, 2004).

Finally, I did not find statistically significant differences between Blacks and Whites for formal planning in the initial regression models, yet moderation analyses revealed that such racial differences emerge only in lower SES populations. Black college graduates are more likely than their White counterparts to have a living will, whereas Black high school graduates are less likely than their White counterparts to have a living will. The Black-White gap in discussions is statistically significantly only among those who do not own homes. Prior research suggests that one reason why Blacks do not engage in ACP is that they are less likely to own homes and hold assets, and thus, are less likely to do estate planning—an action that often triggers the writing of ACP documents (Carr, 2011b). Consistent with this finding, my results show that among homeowners, Blacks are slightly more likely than Whites to own a home. These findings are broadly consistent with prior studies of the role of education, acculturation, and the accumulation of economic resources in minimizing historical subgroup disparities in health outcomes ranging from cancer to birth rates to health behaviors (Balcazar, Castro, & Krull, 1995; Mosher, Williams, & Johnson, 1992).

Limitations

Several limitations may weaken the generalizability of the study findings. By design, the sample includes only those in marital or cohabiting relationships.

As noted early, the sample is likely positively selected for Blacks in particular, given very low rates of marriage among young and midlife Black Americans today (U.S. Census Bureau, 2006). I compared socioeconomic characteristics of the analytic sample with 2010 U.S. Census data and found that the average household income and proportion who graduated college were similar for Whites and Asians in the two samples, yet much more disparate for Blacks and Latinos.

For instance, 14% of all Latinos in the United States reported having a college degree in 2010, compared to 26% in the analytic sample. Although the proportions of Blacks with a college degree were nearly identical in the two data sources (21% vs. 20%), the average household income showed a clear positive bias in the KN study (US$49,000 vs. US$32,500 in the Census). Despite this positive selection bias in the composition of the KN, it is important to recall that the moderation analyses still revealed steep racial disparities in ACP among those with fewer economic assets, measured in terms of home ownership. Thus, we can reasonably conclude that ACP racial disparities exist among disadvantaged populations.

A second limitation is that interviews were conducted in English, thus non-English speakers were excluded. This could potentially bias the subsamples of Asians and Latinos in particular, as those who are fluent in English may be more acculturated and thus more likely to engage in ACP than their peers who do not speak English. However, this bias is presumably small. According to 2007 American Community Survey data, of persons who spoke Spanish or Asian languages at home, only 10.7% and 5.4%, respectively, reported that they could not speak English (Shin & Kominski, 2010).

Third, the KN study includes only a single indicator of health; the study would be strengthened by considering a broader range of health characteristics, especially early-life risk factors such as body mass index (BMI) and blood pressure, as well as an indicator of access to health care. However, the simple self-rated health measure is widely regarded as a highly effective predictor of adult mortality and is a more accurate predictor of mortality than physician assessments of a patient's health (Ferraro & Farmer, 1999).

Fourth, KN includes only basic demographic, SES, and health information; a broader range of psychological, religious, and experiential factors would be useful to further explicate subgroup differences in ACP. Such factors might include religious and cultural beliefs regarding death and specific medical treatments, communication and problem-solving styles, language and literacy measures, and past experience with significant others' deaths. The multivariate models presented here had fairly weak explanatory power (pseudo R^2 values < .20); a fuller range of influences should be considered.

Finally, although sample members were given the opportunity to say why they did not do ACP, they had only a limited set of response categories. Open-ended interviews asking people to provide their own accounts for why they did or did not engage in ACP would provide further insights into the obstacles to and facilitators of ACP.

Despite these limitations, this study is the only one I know of to investigate three aspects of ACP among an ethnically and racially diverse sample of adults aged 18 to 64; other studies draw on either population-based samples of older adults (aged 65 and older; for example, Hopp, 2000) or clinical and/or nursing home–based samples of older adults (Carr, 2011a; Smith et al., 2008). It is essential to document patterns of and obstacles to ACP among adults when they are still relatively young and healthy, especially in ethnic minority populations. Given the early onset of major health conditions, including heart disease, dementia, and cancer, among Blacks and Latinos relative to Whites, and especially among Blacks and Latinos of low SES (Cowie et al., 1989; Jones & Hall, 2006; Livney et al., 2011; Newman, 2005), it is critical that obstacles to ACP among young and midlife adults are recognized. ACP interventions targeted to persons aged 65 and older may be "too late" for persons who become incapacitated at younger ages.

Conclusion

In sum, this study documented modest racial and ethnic differences in ACP and showed that particular ethnic groups are partial (or resistant) to different aspects of planning. Although Asians have particularly high levels of formal planning, they are less likely than Whites to have discussions. Latinos are least likely to engage in any of the four types of planning. The Black-White gap, by contrast, is revealed only for low SES populations.

However, this attention to ethnic differences should not draw attention away from the study's most jarring finding: Less than one third of any ethnic group has engaged in formal ACP. These low rates are even more disheartening when one considers that the sample includes only partnered persons; prior work shows that married persons are more likely than their unmarried counterparts to do ACP (Hopp, 2000). Although slightly more than half have held discussions, discussions in the absence of formal documents are of limited value, if a loved one must convey an incapacitated patient's treatment preferences in a clinical setting (Rhodes & Teno, 2009).

These findings suggest that broad, population-level programs should be implemented to increase rates of ACP, especially among younger and midlife adults. One way to ensure that older adults specifically have access to ACP

tools is to revitalize the original Patient Protection and Affordable Care Act (PPACA) proposal to include one voluntary ACP session as an option included in the annual wellness visit for Medicare beneficiaries. This benefit would give all older patients the opportunity to discuss their treatment preferences with a health care provider. However, political uproar regarding (unsubstantiated) fear of "death panels" contributed to President Barack Obama's deletion of the proposed benefit from PPACA in January 2011 (Pear, 2011). This relatively low-cost aspect of the proposed health care reform may be one step toward ensuring a better quality death for older adults. However, given the earlier onset of major illnesses among Blacks and Hispanics relative to Whites—and a likely amplification of this pattern among future cohorts of adults given high rates of childhood obesity and diabetes among these populations—the proposed PPACA benefit may be too little, too late. The expansion of this benefit to also cover Medicaid populations and ACP information programs delivered in community centers, houses of worship, and workplaces also may be effective strategies.

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