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RACIAL DIFFERENCES IN END-OF-LIFE PLANNING: WHY DON'T BLACKS AND LATINOS PREPARE FOR THE INEVITABLE?*

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ABSTRACT

I evaluate the extent to which ethnic disparities in advance care planning reflect cultural and religious attitudes and experience with the painful deaths of loved ones. Data are from a sample of 293 chronically ill older adults who are seeking care at one of two large medical centers in urban New Jersey. Blacks and Hispanics are significantly less likely than Whites to have a living will, a durable power of attorney for health care (DPAHC), and to have discussed their end of life treatment preferences. Multivariate analyses reveal that the Black-White gap in advance care planning is largely accounted for by Blacks' belief that God controls the timing and nature of death. The Hispanic-White gap is partially accounted for by the belief that one's illness negatively affects one's family. Ethnic disparities are starkest for living will and DPAHC use, and less pronounced for discussions. Implications for policy and practice are discussed.

At the end of life, most chronically ill older adults experience physical discomfort, limited mobility, and impaired cognitive functioning. Those who are mentally incapacitated and have not made plans for their own end-of-life care may receive

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unwanted costly medical interventions or the withdrawal of treatments they may have desired (Lambert, McColl, Gilbert, Wong, Murray, & Shortt, 2005). Difficult decisions about withholding or continuing treatment often fall upon health care providers or distressed family members who may disagree with one another (Breen, Abernathy, Abbott, & Tulsky, 2001). Recognizing the financial and emotional costs associated with unwanted, unnecessary, or contested end-of-life medical care, policy makers have established practices that enable patients to formally state their treatment preferences when they are still physically and mentally well.

The Patient Self-Determination Act, passed by Congress in 1990, requires that all federally funded hospitals and nursing homes give patients an opportunity to complete an advance directive, which comprises a living will and a durable power of attorney for health care (DPAHC). A living will is a legal document specifying the medical treatments a person would like to receive if incapacitated. A DPAHC permits a person appointed by the patient to make decisions about health care in the event the patient is incapable of making such decisions. Health care professionals also encourage patients to informally discuss their treatment preferences with family members and care providers to ensure that their preferences are known and understood (Doukas & Hardwig, 2003).

Although advance care planning is strongly encouraged by practitioners and policy makers, only one-third to one-half of all older Americans make such preparations (Carr & Khodyakov, 2007; Hopp, 2000). Further, research consistently documents a sizeable and intransigent Black-White gap in advance care planning. Studies based on large, nationally representative data sets 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 two to three times as likely as Blacks to have a living will, to have appointed a DPAHC, and to have discussed treatment preferences with loved ones (see also Degenholtz, Arnold, Meisel, & Lave, 2002). Although research on other ethnic groups is sparse, a number of small studies based primarily on hospital or nursing home samples reveal that Hispanics also are less likely than Whites to have living wills and health care proxies (Kwak & Haley, 2005).

Researchers have not yet explicated *why* such disparities exist, however. Thus, I examine the use of living wills, DPAHCs, and end-of-life discussions among Whites, Blacks, and Latinos; and evaluate five potential explanations for these ethnic disparities: socioeconomic status, satisfaction with one's doctor, attitudes toward death and dying, beliefs about autonomy versus interdependence, and direct experience with the deaths of significant others.

BACKGROUND

In the past decade, researchers have sought to understand why ethnic minorities are less likely than Whites to make formal preparations for end-of-life.

This is a critically important concern. Studies consistently show that Blacks receive 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, Whites are three times as likely as Blacks to receive treatments that are consistent with their preferences (Loggers, Maciejewski, Paulk, Desanto-Madeya, Nilsson, Viswanath, et al., 2009). Thus, it is essential that researchers identify the obstacles to Blacks' (and Latinos') formal articulations of their end-of-life treatment preferences.

Four broad explanations typically are set forth for racial disparities in advance care planning, although only one of the four has been assessed rigorously. First, the racial gap may reflect *socioeconomic factors*—including education that enables one to understand and seek out formal advance care planning and economic resources, including health insurance, that increase one's access to consistent, highly quality medical care (Carr & Khodyakov, 2007; Hopp, 2000). However, a number of multivariate studies reveal that the sizeable Black-White gap in advance care planning does not attenuate significantly even when income, education, health insurance, and access to care are controlled (Caralis, Davis, Wright, & Marcial, 1993; Gerst & Burr, 2008; Hopp & Duffy, 2000; Johnson, Kuchibhatia, & Tulsky, 2008; see also Kwak & Haley, 2005).

The limited explanatory power of structural obstacles to advance care planning has led researchers to propose three other plausible pathways: *attitudes toward the health care system* (including trust); *cultural or religious beliefs* pertaining to the nature and controllability of death; and one's *preferences for autonomous versus interdependent decision-making*. Blacks' distrust of the U.S. health care system has been widely documented, fueled in part by the legacy of the notorious Tuskegee Study, and perpetuated by actual and perceived experiences of discriminatory or poor quality care (Krakauer, Crenner, & Fox, 2002). Both survey-based studies of hospitalized patients (Caralis et al., 1993; Johnson, Kuchibhatia, & Tulsky, 2008; Perkins, Geppert, Gonzalez, Cortez, & Hazuda, 2002) and open-ended qualitative interviews with noninstitutionalized persons have found that Blacks report lower levels of trust in the health care system than Whites and Latinos. Blacks also are more likely to report absent or problematic communication with their physicians (Rhodes, Teno, & Connor, 2007; Welch, Teno, & Mor, 2005). Distrust and poor communication, in turn, may pose obstacles to advance care planning. Although advance care planning is intended to place decision-making power with patients, and to *protect* patients against discriminatory treatment, Blacks may perceive that the advance directive can be misinterpreted or it may give physicians license to withhold desired treatments (Caralis et al., 1993; Krakauer et al., 2002).

An emerging literature suggests that reluctance among ethnic minorities to engage in advance care planning may reflect cultural and religious beliefs pertaining to the nature and controllability of death. One qualitative study found that

Blacks tend to believe that life and death are beyond the control of the individual and that God or a higher power has such control (Bullock, McGraw, Blank, & Bradley, 2005; Waters, 2000). Similarly, a survey of 205 older adults seeking primary care at the Duke University Health System showed that Blacks held spiritual beliefs that conflicted with the goals of palliative care, and had high levels of discomfort when discussing death (Johnson et al., 2008). Death anxiety is a widely documented psychological obstacle to end-of-life care preparations (Wong, Reker, & Gesser, 1994).

Ethnic differences in advance care planning also may reflect personal beliefs about the desirability of autonomy versus interdependence. Autonomy, independence, and self-sufficiency are cherished goals in Western societies; as such, older adults often are reluctant to burden their loved ones (Cohler, 1983). Research based on samples of White middle-class older adults suggests that advance care planning is one strategy for minimizing burden on one's family; individuals who clearly state their preferences for care, or who legally appoint an advocate, are sparing their loved ones from the burden of making difficult—and potentially ill-informed—choices about life and death care (Carr & Khodyakov, 2007; see also Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tolsky, 2000).

It is plausible that Blacks and Latinos place greater priority on family interdependence than on individual-level autonomy; as such, they may feel less compelled to engage in advance care planning. For example, Blackhall and colleagues (1995) found that Mexican Americans believe that family members, and especially adult children, should minimize the burdens on the dying patient (rather than vice-versa). Among Latinos, end-of-life planning may be discouraged on the grounds that it is unnecessarily burdensome to the ailing older adult. Similarly, Morrison and colleagues (1998) found that older Hispanics viewed formal DPAHC appointments as irrelevant and unnecessary; family members should naturally participate in collaborative decision making without a legal document dictating so.

I propose that a fifth influence also may play an important role in advance care planning: one's prior experiences with the deaths of loved ones. Specifically, I propose that individuals who have witnessed the painful, prolonged, or unexpectedly sudden death of a significant other may be motivated to avoid a similarly distressing fate for self and loved ones. As such, those who witnessed a difficult death may be more likely to engage in advance care planning. Carr and Khodyakov (2007) analyzed data from the Wisconsin Longitudinal Study and found that persons who had witnessed the painful death of a spouse or parent were significantly more likely than non-bereaved persons to have a living will, a DPAHC appointment, or to have held discussions about their end-of-life preferences. Qualitative studies also suggest that older adults are more likely to make end-of- life preparations if they know someone suffering from severe cognitive impairment (Bravo, Dubois, & Paquet, 2003) or a serious illness or injury (Lambert et al., 2005). Given that Blacks and Latinos consistently

receive poorer quality care, less comfort care, and more invasive treatments at the end-of-life than Whites (Krakauer et al., 2002; Rhodes & Teno, 2009), they may be more likely than Whites to have witnessed significant others' distressing deaths and may turn to advance care planning to avoid a similar outcome.

In sum, I explore Black, White, and Hispanic differences in the likelihood that one has a living will, a DPAHC, and has held end-of-life discussions; evaluate the extent to which these differences are accounted for by socioeconomic characteristics, attitudes toward one's health care provider; beliefs pertaining to the nature and controllability of death; beliefs about autonomy versus interdependence; and direct observations of significant others' death. All analyses control for sociodemographic and health characteristics (age, gender, English language proficiency, marital and parental statuses, and self-rated health) that have been found elsewhere to affect advance care planning.

DATA

Data are from the New Jersey End of Life (NJEOL) study, a sample of 305 non-institutionalized adults ages 55 and older who are residing in New Jersey. To be eligible for study participation, individuals must be either English- or Spanish-speaking, have no cognitive limitations, and have been diagnosed by a physician with one or more of the following health conditions: colorectal cancer, Type II diabetes, or congestive heart failure (CHF). These disease groups are the focus of the study because each is a chronic illness with intrusive symptoms, and each affects both men and women in roughly equal proportions. A control group of "healthy" patients also was recruited; individuals in the control group are ages 55 and older, but have not been diagnosed with a major chronic illness including all forms of cancer and heart disease. Recruitment was conducted over the telephone from two large university hospitals and one comprehensive cancer center in New Jersey. The initial sampling frame consisted of 1,146 patients who were referred to the study through the University of Medicine and Dentistry of New Jersey's general internal medicine department. Three hundred five participants consented to participate in the study, representing 27% of the original sampling frame. This low response rate was due mainly to functional attrition rates, patients either being too ill to participate or having died during the recruitment period, cognitive limitations, and a reluctance to participate in a research study.

Data collection consisted of a 1.5 hour face-to-face structured interview with a trained interviewer; data were collected from 2006 through 2008. The survey obtained information on sociodemographics, health status and behaviors, end-of-life planning, and attitudes toward medical treatments, religion, and social relations. The average age is 69, and roughly two-thirds of participants are women.

MEASURES

Dependent Variables

The primary aim of this study is to explore the correlates of end-of-life preparations. Two formal preparations are considered: whether one has a *living will*; and whether one has appointed a *durable power of attorney for health care* (DPAHC). One informal preparation is considered: *discussions with loved ones*. Respondents are asked, "Have you discussed your future health care plans and preferences with any one? By future health care plans, we mean plans about the types of medical treatment you want or don't want to receive if you become seriously ill in the future."

Key Independent Variable

The key predictor variable is race/ethnicity. Individuals are asked to indicate their race and whether they are of Hispanic ethnicity. Sample members are classified as White non-Hispanic (n = 166), Black non-Hispanic (n = 80), or Hispanic (n = 47).

Potential Pathway Variables

I evaluate five potential pathways that may account for ethnic differences in end-of-life planning: socioeconomic characteristics, satisfaction with one's physician, beliefs about death and dying, beliefs about the intrusiveness of one's health on others, and direct experience with deaths of significant others.

Socioeconomic and Demographic Characteristics

Age (in years) and *gender* (1 = female; 0 = male) are controlled in all models. *Marital status* refers to whether one is married (reference group), separated/divorced, widowed, or never married. *Parental status* refers to the number of living children. *Physical health status* is assessed with a standard self-rated health measure, where responses of fair and poor are coded as 1, and good or better comprise the reference group. *Education* is the number of years of schooling completed. *Spanish-language speaker* is a dummy variable signifying those persons who completed the interview in Spanish. Nativity status was considered in preliminary analyses, yet was dropped due to multicollinearity with ethnicity; 89% of Latino but only 9% of White study participants were born outside the United States.

Satisfaction with One's Physician

Satisfaction with one's physician (α = .87) reflects one's level of agreement with two items: their physician is "a good listener" and is "emotionally

supportive." Response categories range from strongly agree to strongly disagree; responses are averaged and higher scores reflect greater satisfaction.

Beliefs about Death and Dying

Two beliefs about the nature and controllability of death are considered. First, *the belief that death is controlled by God* ($\alpha = .89$) is based on one's level of agreement with three statements: It is God's will when one's life will end; the length of one's life is determined by God; and I believe in turning my health problems over to God. Second, *death acceptance* ($\alpha = .70$) refers to one's level of agreement with two statements: death is simply a part of the process of life, and death should be viewed as a natural, undeniable, and unavoidable event. The latter two items are drawn from the Death Attitude Profile-Revised (Wong et al., 1994).

Beliefs about Intrusiveness of One's Health on Others

Beliefs about autonomy versus interdependence are captured with two measures. First, a single item is used to measure one's belief that "having a good quality of life means not being a burden on someone." Second, four items capture one's belief that their current health adversely affects the lives of significant others ($\alpha = .89$). Respondents indicate their level of agreement with the statements: my illness has serious financial consequences for me and my family; my illness causes difficulties for those who are close to me; the treatment for my illness has serious financial consequences for me and my family; and the treatment for my illness causes difficulties for those who are close to me. Items are adapted from the Revised Illness Perception Questionnaire (IPQ-R), originally developed to measure one's perceptions about the cause, timeline, controllability, and consequences of one's illness (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002; Weinman, Petrie, Moss-Morris, & Horne, 1996). Response categories for all attitudinal measures range from strongly disagree to strongly agree; higher scores indicate stronger agreement.

Direct Experience with Deaths of Significant Others

Participants who survived the *death of a significant other* in the 10 years prior to interview are asked about the death of the person with whom they were closest. Bereaved participants are asked: "During his/her last week of life, how much pain did your [significant other] have?" Response categories include no pain, slight pain, moderate pain, and severe pain. I constructed dichotomous variables to indicate: significant other died with no or slight pain; and significant other died in moderate or severe pain. Respondents also reported whether the decedent died suddenly or with some forewarning. The reference category includes persons who did not experience a recent death. Descriptive statistics for all measures are presented in Table 1.

Table 1. Descriptive Statistics by Ethnicity (N = 293)

	Total	White	Black	Latino
Dependent Variables				
Held discussions	.69	.85	.59***	.32***
Has living will	.47	.67	.26***	.09***
Appointed DPAHC	.41	.59	.25***	.04***
Independent Variables Sociodemographics				
Age	69.23 (8.74)	71.33 (8.39)	66.53*** (8.92)	66.39*** (7.67)
Gender (1 = female)	.64	.57	.71	.75*
Education (years)	13.76 (4.55)	15.89 (3.81)	11.69*** (3.48)	9.6*** (4.17)
Primary language: Spanish	.11	.006	.025	.59***
Self-rated health: fair/poor	.45	.31	.56***	.77***
Family Characteristics				
Currently married	.51	.65	.30***	.38***
Never married	.09	.07	.16***	.067
Separated/divorced	.16	.07	.19**	.38***
Widowed	.24	.21	.35*	.19
Number of children	3.21 (2.17)	2.63 (1.67)	4.04*** (2.66)	3.84*** (2.25)

Attitudes				
Satisfied with physician (range: 1-5)	4.45 (.77)	4.45 (.79)	4.38 (.78)	4.46 (.79)
Death acceptance (range: 1-5)	4.42 (.55)	4.45 (.56)	4.35 (.52)	4.42 (.54)
Believes God controls death (range: 1-5)	3.61 (1.17)	3.04 (1.14)	4.30*** (.71)	4.36*** (.79)
Importance of not being a burden (range: 1-5)	4.43 (.69)	4.54 (.63)	4.41 (.50)	4.11*** (.840)
Believes own health hurts family well-being (range: 1-5)	2.61 (1.12)	2.41 (1.16)	2.87** (.98)	2.77 (1.11)
Deaths to Significant Others				
No deaths, past 10 years	.17	.21	.10*	.17
Recent death, no pain	.26	.27	.30	.19
Recent death, slight pain	.18	.23	.13	.06**
Recent death, severe pain	.17	.13	.21	.25*
Recent death, DK pain level	.21	.16	.26*	.32*
Recent death, forewarning	.55	.61	.53	.36***
Recent death, sudden	.25	.17	.33**	.40***
N	293	166	.80	47

Notes: Means (and standard deviations) or proportions shown. Asterisks denote statistically significant mean differences, where White is the reference group.

*$p \leq .05$, **$p \leq .01$, ***$p \leq .001$.

Analytic Plan

Analyses are limited to the 293 persons who self-identify as White, Black, or Hispanic/Latino. Twelve persons of other ethnicity (i.e., Asian) are excluded because this is not a sufficient number for conducting comparative analyses. Logistic regression models are estimated to predict the three dichotomous end-of-life planning outcomes. The baseline models adjust for race/ethnicity only, subsequent models evaluate the extent to which the sizeable race gap in end-of-life planning is explained by socioeconomic characteristics; language; the belief that God controls the timing of death; death acceptance; satisfaction with one's doctor; beliefs about the intrusiveness of one's health conditions on significant others' lives; and direct experiences with others' deaths. A summary of the race coefficients for all models and model fit statistics are presented in Table 2. Final regression models for the three outcomes are presented in Table 3.

RESULTS

Bivariate Analysis

Table 1 presents descriptive statistics for all measures used in the analysis; *t*-tests and chi-square tests were conducted to evaluate whether Blacks and Hispanics differ significantly from Whites on all measures. The bivariate analyses reveal pronounced racial differences in end-of-life planning. The most commonly used preparation is informal discussions. Whereas 85% of Whites have discussed their end of life preferences, only 59% of Blacks and one-third of Latinos have done so. Similarly, two-thirds of Whites have a living will, compared to one in four Blacks, and one in ten Hispanics. DPAHC appointments are even less common; 59% of Whites, but only one-quarter of Blacks and 4% of Latinos have appointed a DPAHC.

The three ethnic groups also vary with respect to sociodemographic and attitudinal characteristics that may be associated with end-of-life planning. Blacks and Latinos report lower levels of educational attainment than Whites, and believe much more strongly than Whites that God should control the timing of one's death. Blacks believe more strongly than Whites that their health condition and expenses related to their health would negatively affect their family. Fear of being a burden on others is significantly less acute for Latinos than Whites. The three groups did not differ with respect to physician satisfaction or death acceptance, although this could reflect sample selection bias; only persons with relatively high levels of death acceptance would agree to participate in a study of end-of-life planning, whereas only those with a relatively good rapport with their physician would be successfully recruited to a hospital-based study.

Not surprisingly, Latinos are significantly more likely than Whites to speak Spanish as their primary language. However, Blacks and Latinos also possess a number of characteristics that have been found elsewhere to increase the odds of

Table 2. Summary Table: Relative Odds of Engaging in End-of-Life Planning by Blacks and Latinos, After Adjusting for Sociodemographic Characteristics and Potential Explanatory Variables

	Held Discussions			Named DPAHC			Has Living Will		
	Black	Hispanic	χ^2; *df*	Black	Hispanic	χ^2; *df*	Black	Hispanic	χ^2; *df*
Baseline Model: Unadjusted effects	.29***	.095***	49.6; 2	.231***	.03***	66.77; 2	.191***	.05***	69.94; 2
Model 1: BL + age, sex, education	.38**	.14***	58.5; 5	.376**	.06***	71.35; 5	.245***	.075***	77.43; 5
Model 2: 1 + self-rated health	.39**	.134***	54.5; 6	.326***	.047***	72.4; 6	.262***	.073***	77.03; 6
Model 3: 2 + family characteristics	.40*	.140***	56.1; 10	.34**	.039***	76.9; 10	.25***	.067***	80.83; 10
Model 4: 3 + Spanish language	.38*	.26*	61.4; 11	.34**	.059**	77.9; 11	.25***	.098***	81.89; 11
Model 5: 3 + belief that God controls death	.48	.17***	57.17; 11	.45*	.051***	82.2; 11	.29**	.079***	81.21; 11
Model 6: 3 + death acceptance	.41*	.13***	58.13; 11	.34**	.035***	86.7; 11	.26***	.066***	80.97; 11
Model 7: 3 + satisfaction with doctor	.32***	.19**	26.7; 11	.32**	.08**	49.3; 11	.23***	.099***	56.76; 11
Model 8: 3 + importance of not being a burden	.39*	.16***	62.4; 11	.34**	.042***	78.7; 11	.25***	.07	82; 11
Model 9: 3 + own health hurts family well-being	.35*	.27*	25.73; 11	.34**	.085**	43.7; 11	.25***	.12**	49.67; 11
Model 10: 3 + painful death of significant other	.38**	.13***	67.76; 14	.287**	.03***	89.7; 14	.24***	.066***	86.7; 14
Model 11: 3 + sudden versus expected death of significant other	.38*	.13***	59.82; 12	.31**	.033***	86.1; 12	.25***	.065***	84.2; 12

Notes: Results from binomial logistic regression model. Relative odds (exponentiated betas) are presented; omitted category is non-Hispanic White (OR = 1.0).

*$p \leq .05$, **$p \leq .01$, ***$p \leq .001$.

Table 3. Logistic Regression Predicting Odds of Engaging in End-of-Life Planning

	Discussions	DPAHC	Living Will
Ethnicity			
Black	.396†	.410*	.294**
Hispanic	.347	.090**	.171*
Sociodemographics			
Age	1.02	.507	1.04†
Gender (1 = female)	1.09	.672	.789
Education (years)	1.04	1.05	1.07
Primary language: Spanish	.824	.507	.536
Self-rated health: fair/poor	1.25	1.64	1.78
Family Characteristics			
Never married	.658	.493	1.92
Separated/divorced	.963	1.39	1.53
Widowed	1.32	.695	.846
Number of children	1.93	1.51	.945
Attitudes			
Death acceptance (range: 1-4)	1.46	2.69**	1.34
Believes God controls death (range: 1-5)	.798	.639**	.783†
Believes own health hurts family well-being (range: 1-5)	1.20	.999	1.06
Importance of not being a burden (range: 1-5)	1.96*	1.02	1.14
Deaths to Significant Others			
Recent death, forewarning	2.01†	3.48**	2.10†
Recent death, sudden	3.37*	6.89***	2.48†
–2 Log Likelihood; *df* (17)	275.70	327.51	327.17

Notes: Relative odds (exponentiated betas) are presented; omitted category is non-Hispanic White (OR = 1.0).
†$p < .10$; *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$.

end-of-life planning; they are more likely than Whites to be in fair or poor health, to have more children, and to have experienced the sudden death of a loved one. Hispanics are more likely than Whites to have witnessed a love one's painful death, and are far less likely to have been forewarned of a significant other's death.

Multivariate Analysis

The bivariate analyses reveal sizeable ethnic differences in rates of formal and informal end-of-life planning. The next step is to evaluate potential explanations; Table 2 presents a summary of multivariate binomial logistic regression results. Relative odds are shown for Blacks and Hispanics, and chi-square values are shown to enable comparisons of model fit. The baseline (unadjusted) model reveals that compared to Whites, Blacks have 29% the odds of having end-of-life discussions, 23% the odds of naming a DPAHC, and 19% the odds of having a living will; the relative odds for Latinos are .095, .03, and .05 respectively ($p < .001$). Consistent with prior studies, race gaps in each of the three outcomes attenuate but remain large and statistically significant after demographic, health, and family characteristics are controlled (in Model 3).

Ethnic differentials in the odds of advance care planning remain statistically significant when each potential explanatory pathway is controlled separately in Models 4 through 12, with one exception. In Model 5, the significant Black-White gap in the odds of holding discussions is no longer statistically significant when the belief that God controls one's death is adjusted. This measure also is the most powerful explanatory mechanism for the Black-White gaps in DPAHC and living will use; the gap remains statistically significant but its magnitude declines substantially between Models 3 and 5. By contrast, the belief that one's own health negatively affects family members is the single variable that accounts most heavily for the Hispanic-White gap in holding discussions, naming a DPAHC, and having a living will. Hispanics' odds of each of the three behaviors, relative to Whites, double when this belief is controlled (see Model 10 versus Model 4).

Table 3 presents the final logistic regression models for each of the three outcomes. This model includes all measures that are theoretically relevant, even if not statistically significant. The suddenness of a significant other's death explained more variance in the outcomes than the death pain measures, and thus were retained as the indicator of significant others' death quality. Satisfaction with one's doctor was dropped, as its inclusion was associated with significantly poorer model fit.

Several important findings emerge from the multivariate analyses. First, the race gap in each of the three outcomes declines considerably, and in the case of discussions is no longer statistically significant ($p <. 10$) net of all sociodemographics, attitudes, and deaths to significant others. In the fully adjusted models, Blacks are 41% as likely as Whites to have a DPAHC and only 30% as likely to

have a living will. Although these racial gaps are still stark, they are significantly narrower than in the unadjusted model in Table 2, where odds ratios were .23 and .19, respectively. Similarly, in the fully adjusted model, Hispanics are 9% and 17% as likely as Whites to have a DPAHC and living will respectively; these gaps are far narrower than the unadjusted odds ratios of .03 and .05 in the baseline models. The analyses also reveal different racial gaps for each of the outcomes: the Black-White gap is starkest for living wills, whereas the Hispanic-White gap is most pronounced for DPAHC appointments.

Each of the three outcomes also is linked significantly to different psychosocial predictors. Those with greater acceptance of death have significantly higher odds of naming a DPAHC, whereas those who do not want to burden others have significantly elevated odds of having discussions with loved ones. The more strongly one believes that God should control the timing of death, the less likely one is to have a DPAHC or a living will, although the latter association is only marginally significant.

Recent deaths to significant others are a powerful predictor of all three types of planning, where those who experienced loss are more likely to prepare for the end of life than the non-bereaved. However, the magnitude of the effect is larger for those whose loved one died suddenly (versus expectedly). Persons who had at least some forewarning of a loved one's death are twice as likely as non-bereaved persons to hold discussions or have a living will, yet these effects are only marginally significant. By contrast, those who were forewarned are 3.5 times as likely as non-bereaved persons to have a DPAHC. Those who lost a loved one suddenly are 3.4 times as likely as the non-bereaved to have held discussions, nearly 7 times as likely to name a DPAHC, and 2.5 times as likely to have a living will, although the latter effect is only marginally significant. The effects of others' deaths did not differ by ethnicity; in preliminary analyses I evaluated two-way interaction terms, and none were statistically significant ($p < .10$). Thus, those who experienced the sudden loss of a loved one are most likely to engage others in their end-of-life planning, whether through discussions or naming a family member as DPAHC.

DISCUSSION

This analysis confirmed that Blacks and Latinos are significantly less likely than Whites to make formal preparations for end-of-life care. Although ethnic minorities also are less likely to engage in informal practices that do not require contact with the formal health care system (i.e., discussions with loved ones), this difference was no longer statistically significant after sociodemographics, attitudes, and death experiences were controlled. These results suggest that ethnic minorities are not necessarily opposed to discussing or thinking about death, yet powerful obstacles persist with respect to formal, legal aspects of advance care planning.

Consistent with past studies, the ethnic disparities in living will and DPAHC appointments could not be explained away by socioeconomic, attitudinal, or experiential factors. However, two factors play a particularly important role in reducing the magnitude of the disparities. The belief that God controls the length of life accounted for a sizeable share of the Black-White gap in advance care planning, while the belief that one's health condition creates personal or financial difficulties for family members partially mediated the effect of Hispanic ethnicity. However, despite the rich range of measures controlled in this analysis, the fully adjusted models still reveal that Whites are 2.4 times (i.e., 1/.410) and 3.4 times as likely as Blacks to have a living will and DPAHC, respectively. Even more stark divides emerge among Latinos, where Whites are 11.1 times as likely to have a DPAHC and 5.8 times as likely to have a living will.

The question stands, then: why do Blacks and Latinos not prepare for their end-of-life health care needs? Some scholars have suggested that ethnic minorities may not perceive a need or a desire for advance care planning (Hicks & Lam, 1999). Current institutional practices for end-of-life preparations focus heavily on individual-level preferences, with the goal of preserving patient autonomy. However, this goal may not be desirable for all patients. Recent work suggests that many older adults prefer to either fully delegate or to share medical decision-making power with loved ones (Moorman, 2008). Consistent with this argument, several small studies have found that Hispanics and Asians are more likely than Whites to prefer family-centered decision-making (Kwak & Haley, 2005; Morrison et al., 1998). Morrison and colleagues (1998) have observed that Latinos' strong sense of family culture helps to ensure that individuals will work together to achieve a "good death" for their loved one, even in the absence of a legally-designated advocate.

My results suggest that further research is needed on how Latinos think about involving family in end-of-life care. The fully adjusted models presented here show that the Latino-White gap is statistically significant for DPAHC appointments, but not for discussions. This result suggests that Latinos may prefer to discuss their preferences with the entire family, rather than singling out one person to play the role of legal advocate. Just as Latinos have been found to explicitly or implicitly delegate decision-making to family members, African Americans may delegate this control to a higher power. As my analysis shows, Blacks score more than one-standard deviation higher than Whites on a scale assessing beliefs that a higher power controls the nature and timing of death. If God controls life and death decision-making, then legal documents specifying one's medical treatment preferences may be deemed irrelevant, undesirable, or as intruding upon God's plan.

Limitations and Future Directions

This study has a number of weaknesses that may limit its generalizability and impact. First, the response rate was low, reflecting the fact that chronic illness

was a pre-condition for participation. Further, the study participants may be over-representative of those who have strong feelings about end-of-life planning and thus agreed to participate. Second, the small sample size precludes the nuanced investigation of *within-ethnic group* differences in advance care planning. Ethnic identity alone is an incomplete indication of one's preferences, values, and attitudes. As Koenig and Gates-Williams (1995) have noted, "efforts to use racial or ethnic background as simplistic predictors of beliefs or behaviors will lead to harmful stereotyping of patients and culturally insensitive care of the dying." Future studies should explore the extent to which ethnic disparities are moderated by educational attainment, language ability, religious affiliation, and social integration.

Third, the study outcomes indicate only *whether* one has engaged in end-of-life preparations—and not the *content* of those preparations. Future studies should explore whether there are ethnic differences in whom one appoints as their DPAHC (e.g., physician vs. family member), one's specific preferences for sustaining or withholding treatment noted in the living will, and how well one's proxy understands the patient's specific preferences for end of life care.

Implications for Policy and Practice

Despite these limitations, the study shows persuasively that Hispanics and Blacks are far less likely than Whites to engage in legal preparations for end-of-life care. This disparity in formal advance care planning may contribute to well-documented racial disparities in the costs and quality of end-of-life care. When patients have not previously specified their treatment preferences, they are more likely to be over-treated than under-treated, which may create unnecessary discomfort, distress, and financial strain. For instance, roughly one-third of nursing home patients in the final stages of dementia are given feeding tubes, although the practice typically does not prolong patients' lives and may cause discomfort and infections (Mitchell, Teno, Roy, Kabumoto, & Mor, 2003). The financial costs of such care may be prohibitive; a recent analysis of Medicare data showed that costs of medical care in the last 6 months of life are 32% higher among Blacks ($26,704) and 57% higher among Hispanics ($31,702) than among Whites ($20,166) (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009). These stark racial gaps were almost fully explained by ethnic minorities' greater use of aggressive life-sustaining procedures.

At first blush, it may not seem problematic that Hispanics and Blacks receive more invasive treatments, given that they typically report stronger preferences for them than Whites (Johnson et al., 2008; Kwak & Haley, 2005). However, the failure to specify one's preferences may mean that desired treatments are not delivered (Loggers et al., 2009). As Rhodes and Teno (2009, p. 5498) observe: "preferences are meaningless without the care plan . . . in place to ensure that those wishes are respected and the patient receives patient-centered care."

Practitioners may need to develop innovative practices to ensure that dying Black and Latino patients receive care that is consistent with their personal desires, their family members' desires, and even their religious teachings. One possible strategy may be to discuss each component of the advance directive with patients, and to recognize that not all components are viewed as equally desirable or valuable by patients. As noted earlier, I find that Blacks are less likely to have a living will than a DPAHC, whereas Latinos are less likely to have a DPAHC than a living will. Blacks may perceive that the living will can be misinterpreted or it may give physicians license to withhold desired treatments (Caralis et al., 1993; Krakauer et al., 2002). Latinos, by contrast, may be uncomfortable appointing a single family member to represent their views, and thus may be opposed to making a formal DPAHC designation.

Health care providers, perhaps working in tandem with clergy or patient liaisons, could ask patients about their values, cultural practices, and family history of decision-making. Community and public health professionals also could develop culturally sensitive educational materials to teach about the potential costs and benefits to one's self *and one's kin* of being ill-prepared to make decisions about end-of-life care. Moreover, multiple family members—rather than a single legally appointed advocate—should be incorporated into doctor-patient discussions on end-of-life treatment options.

Given the importance of faith and family ties among all Americans (and especially Blacks and Latinos), two general lessons may be particularly important to convey to all patients. First, dying persons who have formally communicated instructions for late-life medical treatments may be better able to focus on their interpersonal, spiritual, or existential concerns—rather than symptom management—during their final weeks of life (Sulmasy, 2002). Second, by clearly specifying one's treatment preferences in advance, difficult decisions will not fall to family members. Making decisions about treatments, such as withdrawing a ventilator or withholding food and fluids from the patient, can create profound guilt or tension for family members (Barry, Kasl, & Prigerson, 2002; Pantilat, 1999)—and this distress may be far more severe and long-lasting than the anxiety temporarily provoked by making and discussing formal end-of-life preparations when the patient is still alive.

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