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THE EFFECTS OF RACE ON PATIENT PREFERENCES AND SPOUSE SUBSTITUTED JUDGMENTS

RACHEL PRUCHNO, PhD, FRANCINE P. CARTWRIGHT, B.S., MAUREEN WILSON-GENDERSON, PhD

University of Medicine & Dentistry of New Jersey—School of Osteopathic Medicine, Stratford

Abstract

Knowledge about the ways in which race affects decision-making at the end of life is minimal, yet this information is critical for providing culturally sensitive care at the end of life. Data matching socio-demographic characteristics of 34 black and 34 white patients with end-stage renal disease and their spouses reveal that there are no significant differences in the preferences to continue dialysis on the part of black and white patients. However, the substituted judgments of black and white spouses differ from one another, with black spouses being more likely to indicate that they believe that the patient would be more inclined to continue dialysis under a host of hypothetical conditions than white spouses. Structural equation modeling analyses revealed that differences in spouse substituted judgments between black and white spouses are explained as a direct function of race differences in perception of patient's health, and caregiver burden, and that indirect effects are associated with spouse's fear of death and participation in religious services. We conclude that these variables rather than race per se explain differences in end of life decision making.

INTRODUCTION

The importance of providing culturally sensitive care at the end of life will grow as the U.S. elderly population becomes increasingly diverse. Dilworth-Anderson, Williams, and Gibson (2002), using data from the U.S. Bureau of the Census (2001), project that between 2000 and 2050 the U.S. black elderly population will quadruple, while the white elderly population will double. A number of studies have found that black patients have less access to medical care, experience more problems regarding delivery of health care services, and endure poorer management of both acute and chronic life-threatening conditions (Blendon & Aiken, 1989; Ford, Cooper, Castaner, Simmons, & Mar, 1989; Vaccarino, Rathore, Wenger, Frederick, Abramson, & Barron, et al., 2005) than white patients. Knowledge regarding the similarities and differences in both the end of life experiences of blacks and whites and their preferences for care at the end of life is not yet well developed. Yet that knowledge is critical for the development of culturally appropriate, sensitive end of life care. This article examines the circumstances under which black and white dialysis patients and their spouses believe that the patient would prefer to continue this treatment and identifies variables that may explain race differences.

There is evidence in the literature that blacks prefer more aggressive life-sustaining treatment at the end of life than do whites, regardless of their stage of illness, and even when care is futile (Allen-Burge & Haley, 1997; Borum, Lynn, & Zhong, 2000; Caralis, Davis, Wright, & Marcial, 1993; Cicirelli, 1997; Degenholtz, Arnold, Meisel, & Lave, 2002; Degenholtz, Thomas, & Miller, 2003; Dula & Williams, 2005; Garrett, Harris, Norburn, Patrick, & Danis, 1993; Hopp & Duffy, 2000; King & Wolf, 1998; Kwak & Haley, 2005; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). Moreover, once aggressive life-sustaining treatments are begun, blacks are less likely than whites to discontinue them (Diringer, Edwards, Aiyagari, & Hollingsworth, 2001) and blacks express greater acceptance of life in worse health than do whites (Winter, Lawton, & Ruck-deschel, 2003). Recent evidence suggests that black patients are more likely than white patients to revoke hospice care in order to pursue life-prolonging therapies (Johnson, Kuchibhatla, Tanis, & Tulsky, 2008). Consistent with these trends, Duffy, Jackson, Schim, Ronis, and Fowler's (2006) report that black patients preferred receiving care in the intensive care unit, hospice, or nursing home (where care would be more aggressively provided) than at home. Together these findings suggest that black and white people may make different decisions about care at the end of life.

However, a closer look at this research reveals a more complex situation. First, many studies that have found race differences related to end of life care preferences have been conducted among persons who are not currently facing end of life issues (Carlais et al., 1993; Eleazer, Hornung, Egbert, Eng, & Hedgepeth, 1996; High, 1993; Stelter, Elliot., & Bruno, 1992). McKinley, Garrett, Evans, and Danis (1996), for example, asked ambulatory cancer patients age 40 and older about their preferences for ventilator support, cardiopulmonary resuscitation (CPR), feeding tubes, and intensive care monitoring, requesting that they respond assuming that they were so sick that they were dying and would never improve.

Second, despite consistent evidence that family members are unable to predict a patient's preferences at levels of accuracy beyond those expected by chance alone (Fried, Bradley, & Towle, 2003; Pruchno, Lemay, Feild, & Levinsky, 2005; Suhl, Simons, Reedy, & Garrick, 1994; Sulmasy, Terry, Weisman, Miller, Stallings, Vette, 1998), findings regarding race differences in end of life preferences often do not distinguish those based on family or proxy reports from those based on individual patient reports. When data from patients and family members have been distinguished from one another, there is inconsistent evidence regarding the effect of race on end of life decision making. Phipps et al. (2003), for example, report that black patients and their caregivers were more likely than white patients and their caregivers to desire CPR, tube feeding, and mechanical ventilation. Building on results from an earlier analysis in which we found that race affected spouse substituted judgments but was unrelated to patient preferences for dialysis continuation (Pruchno, Lemay, Feild, & Levinsky, 2006), we now seek to understand what factors explain these race differences.

Third, when studies have statistically controlled variables that may explain race differences, previously significant differences in end of life decision making often become insignificant. Evidence from the SUPPORT study (Borum et al., 2000), for example, finds that when questioned about CPR, 19% of non-white patients and 30% of white patients did not want it.

Multivariate analyses controlling for self-pay status and Medicaid eligibility, however, revealed that race was no longer associated with desire for CPR.

Reflecting the complexity of the issue is that some empirical studies have found that race continued to be a significant predictor of both advance care planning and treatment decisions even after controlling for age, gender, education level, marital status, and the presence of living children (Hopp & Duffy, 2000). McKinley et al. (1996), for example, report that even after controlling for socioeconomic variables, black cancer patients wanted more life-sustaining treatments and were less likely to want to complete a living will than white patients. They also found that these differences were neither related to lack of trust nor to fear of inadequate medical treatment.

Theoretical Model

Attempts to explain race differences in end of life preferences and planning efforts include the suggestion that they are the result of a history in which blacks were denied medical care and a general tendency for blacks to distrust the medical system (Blackhall, Frank, Murphy, Michel, Palmer, & Azen, 1999; Eleazer et al., 1996; Hallenbeck, Goldstein, & Mebane, 1996; Waters, 2001). Religious values (Eleazer et al., 1996; Hallenbeck et al., 1996; Kalish & Reynolds, 1976; Winter, Dennis, & Parker, 2007-2008), cultural beliefs (Garrett et al., 1993), and value differences (Dula & Williams, 2005) have also been offered as explanations. However, few studies have focused on decision making by surrogates of seriously ill persons (Heyland, Cook, Rocker, Dodek, Kutsogiannis, Peters, et al., 2003; Steinhauer, Christakis, Clipp, McNeilly, McIntyre, & Tulsy, 2000; Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006), and even rarer is attention to the way in which race affects surrogate decision making (Braun, Beyth, Ford, & McCullough, 2007; Hopp & Duffy, 2000). In their study of relatives of persons from the Asset and Health Dynamics Among the Oldest Old Study who died, Hopp and Duffy (2000) found that African Americans were significantly less likely than Whites to discuss treatment preferences before death, and less likely to complete a living will, or to designate a durable power of attorney for health care. However, the reasons behind these race differences remain unclear (Barrett, 2005-2006).

The analyses that follow seek to examine differences in the preferences for dialysis continuation on the part of black and white patients with end stage renal disease (ESRD) and their spouses, and to identify variables that may underlie race differences in these preferences. The incidence of ESRD varies markedly by race and ethnicity, with blacks having the highest incidence and whites the lowest in the United States (Lopes, 2004). Mortality rates also vary by race, with blacks having lower rates of mortality than whites (Lopes, 2004). Following Kwak and Haley's (2005) recent call for "greater emphasis on identifying cultural factors that provide explanatory mechanisms for racial or ethnic differences," we develop and test a model that incorporates knowledge regarding previously identified differences between blacks and whites and posit that it is these variables rather than race itself that are responsible for observed race differences. Our theoretical model predicting substituted judgments is depicted in Figure 1. In this model, all constructs reflect the perceptions and reports of spouses. Although we do not believe that there is a direct path from race to preferences, we include this path in our theoretical model in order to

empirically test it. Our conceptual model predicting patient preferences includes the perceptions and reports of patients. It is identical to the model predicting substituted judgments with the exception that it does not include caregiver burden.

A salient aspect of this model is the extent to which people have a fear of death. There is some evidence in the literature suggesting that blacks have more positive attitudes toward death than do whites. Cicirelli (2000), for example, found that older whites reported higher levels of death anxiety than older blacks. Depaola, Griffin, Young, and Neimeyer (2003) also found that whites displayed greater fear of death than blacks. Research by Lockhart et al. (2001) found that fear of death had a significant effect on preferences for end of life care, while a study by Cicirelli (1997) found positive associations between fear of the dying process and a preference for ending life and a negative association between fear of the dying process and maintaining life. Based on this literature, we hypothesize that white respondents will have a greater fear of death than black respondents and that patients and spouses who have a higher level of fear of death would be more likely to believe that the patient would want to discontinue dialysis under any circumstances than would those people who have lower levels of fear of death.

Another cultural factor likely to impact people's preferences for care at the end of life is the role of religion. The strong role of religion in the black culture has been well-documented. Blacks report higher levels of private religious activity and greater spirituality than do whites (Ferraro & Koch, 1994; Johnson, Elbert-Avila, & Tulskey, 2005; Roof & McKinney, 1987). In an analysis that explored race differences in religion across four national surveys, Levin, Taylor, and Chatters (1994) found that blacks report more religious involvement than whites on a host of dimensions including attending church, reading religious books, and feeling that religion is important in their lives. McKinley et al. (1996) found that stronger religious beliefs were associated with greater preference for life sustaining treatments. It is hypothesized that black respondents will report higher levels of religious participation and that patients and spouses who have stronger religious connections will believe that the patient would want to continue dialysis treatment longer than those with weaker religious ties.

Across a variety of studies, research has consistently indicated that the health of blacks is worse than that of whites (Manton, Patrick, & Johnson, 1987; Wilkinson & King, 1992). While some have argued that observed differences are due to race per se, most have focused instead on explanations emphasizing socially determined factors such as differences in access to medical care and differences in knowledge regarding health practice. Studies that have controlled for differences in socioeconomic status, however, often find race differences rendered insignificant (House, Kessler, & Herzog, 1990; House, Lepkowski, Kinney, Mero, Kessler, & Herzog, 1994; Mutchler & Burr, 1991; Schoenbaum & Waidmann, 1997). Cicirelli (1997) found that health had a small, but significant effect on desire to maintain life when other demographic variables were controlled, with people in better health being more likely to continue treatment. This literature suggests that black respondents will report poorer health on the part of the patient and that those patients and spouses who perceive the patient's health to be worse would be more likely to believe that the patient would prefer to stop dialysis treatment.

Caregiver burden has been viewed as the emotional reaction on the part of the caregiver to the demands of the caregiving situation (Sherwood, Given, Given, & von Eye, 2005). Research has consistently found that black caregivers report less subjective burden than do whites (Haley, West, Wadley, Ford, White, & Barnett, 1995; Janevic & Connell, 2001; Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007; Lawton, Rajagopal, Brody, & Kleban, 1992; Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2001; Pinquart & Sorensen, 2005). While the relationship between caregiving burden and end of life decision making has not been the subject of intense study, there is solid evidence that caregiving burden is a significant predictor of the decision to institutionalize a family member (Gaugler, Leach, Clay, & Newcomer, 2004; Gilley, McCann, Bienias, & Evans, 2005; Rozzini, Cornali, Chilovi, Ghiada, Pedovani, & Trabuochi, 2006; Spitznagel, Tremont, Davis, & Foster, 2006). Based on this literature, it is hypothesized that black spouses will report lower levels of caregiver burden than white spouses and that spouses who are more burdened would be more likely to indicate that their partner would want to stop dialysis treatment than those who feel less burdened.

Finally, although the relationship between patient health and caregiver burden has been the subject of much study, inconsistent conclusions have been reached depending on the population studied and the way in which patient health is operationalized. In their recent meta-analysis, Pinquart and Sorensen (2003) conclude that while behavior problems of the patient are consistently associated with caregiving burden, the evidence regarding other aspects of patient health, including functional ability and cognitive impairments, is equivocal. As such, a negative correlation between subjective perception of patient's health and caregiver burden is hypothesized.

METHODS

Data for the analyses that follow derive from a larger study involving telephone interviews with 315 patients with ESRD and their spouses. The national sample was recruited between May 2001 and June 2003 using a combination of convenience and population-based sampling strategies that are described in Feild, Pruchno, Bewley, Lemay, and Levinsky (2006). Convenience outreach efforts were concentrated in eastern Massachusetts and Rhode Island. They included: contacting local dialysis centers; purchasing paid newspaper advertisements; developing newsletter articles, press releases, and targeted mailings; canvassing the community; and following up on snowball referrals. These efforts were supplemented by a 2-stage informational mailing that was sent to 37,000 patients receiving financial assistance for dialysis treatment from the Centers for Medicare & Medicaid Services, were aged 55 and older, and had been on hemodialysis for at least 6 months. Medicare funded hemodialysis for all participating patients. Participants came from 39 states, including those in the Northeast (29.4%), Midwest (28.4%), South (23.5%), and West (18.6%). Preliminary analyses revealed that participants found through various recruitment strategies did not significantly differ on any of the focal variables in the current research.

Couples were eligible for inclusion in the study if patients:

1. had end-stage renal disease;

2. were on hemodialysis for at least 6 months;
3. were at least 55 years old; and
4. were married or partnered and cohabitating for at least 5 years.

Study eligibility required both patients and their spouses to be English speaking and to be free of cognitive, hearing, and speech impairments that would preclude their ability to answer questions on the phone. These characteristics were based on the screener's evaluation of the patient and spouse during the screening session. During the screening process, the recruiters determined that 28 patients or spouses had insufficient cognitive ability to participate and 16 patients or spouses had hearing impairments that would interfere with their ability to participate in the study. These couples were not enrolled in the study. In addition, one patient and one spouse each had more than four wrong answers to the Short Portable Mental Status Questionnaire (which was administered at the beginning of the interview), and these two couples were withdrawn from the study by staff.

The subset of participants included in these analyses was developed following the procedures used by Haley et al. (1995). Black and white patients were matched on key demographic variables known to influence treatment preferences, including age, patient gender, education, and per capita income. Matching on these demographic variables effectively eliminated the possibility that they explained race differences in treatment preferences. Matching enables a sample to be created where race is independent of characteristics known to distinguish black and white respondents in the population. Because our focus is on the cultural effects of race, matching allows us to concentrate on the theoretical model rather than untangling the relationship between race and other demographic characteristics.

The resulting sample included 34 couples in which both the patient and spouse was black and 34 couples in which both the patient and spouse was white for a total sample size of 136. Equal numbers of black and white patients were men (67.6%). In this matched subsample, race differences were not significant for patients' education ($t = -.55$, $df = 66$, $p = .59$), spouses' education ($t = -.04$, $df = 64$, $p = .97$), patients' age ($t = .23$, $df = 66$, $p = .82$), spouses' age ($t = .01$, $df = 66$, $p = .99$), or joint income ($t = .16$, $df = 57$, $p = .87$). Black and white patients did not differ from one another on number of health conditions ($t = .31$, $df = 66$, $p = .76$) and functional ability ($t = .04$, $df = 66$, $p = .97$). There were no statistically significant differences in the rate at which black and white patients identified their spouse as their health care proxy, with 91.2 % of the black patients and 85.3% of the white patients doing so ($t = .77$, $df = 64$, $p = .44$).

The average age for patients and spouses in the sample was 66.1 and 64.2 years, respectively. Average length of patients' treatment for end-stage renal disease was 86.4 months (7.2 years), including a mean of 63.9 months (5.32 years) of hemodialysis. Patients and spouses had been married for an average of 37.35 years ($SD = 14.25$). More of the patients (67.6%) were men. The mean income level was \$27,500. Highest level of education for the patients ranged from 3 years to post graduate study ($M = 12.96$, $SD = 3.8$). For all analyses race was coded as "0" for white and "1" for black.

Measures

All data were obtained from structured individual interviews by telephone with the patient and spouses separately. Patients and spouses within each couple were interviewed by different interviewers to protect confidentiality. The average patient and spouse interviews were 10.7 days ($SD = 44.0$) apart from each other. The average length of interview for patients and spouses were 78.1 minutes ($SD = 15.9$) and 85.0 minutes ($SD = 21.7$) respectively.

To assess patient preference and spouse substituted judgment for continuation of dialysis, respondents were presented with a series of seven hypothetical situations and asked about the likelihood of the patient continuing on dialysis given each condition. The hypothetical situations inquired about were conditions likely to characterize people with ESRD. They included those in which the patient developed mild and severe stroke, mild and severe dementia, permanent coma, and terminal illness, both with and without pain.

To ensure a common understanding of each condition, interviewers read descriptions developed by Singer et al. (1995) to the respondents prior to asking questions about the condition. For example, for the severe stroke scenario, respondents were told:

A stroke means that the patient would have damage to the brain causing permanent physical disability such as paralysis. S/he would have severe paralysis on one side of his/her body, be unable to walk and would need to be in a chair or bed. S/he would not have meaningful conversations, be unable to carry out routine daily activities, need a feeding tube for nourishment, and would be able to live at home with someone caring for him/her day and night; otherwise s/he would probably need to be cared for in a chronic care hospital.

Respondents were asked to assume, for the purposes of the research study, that these problems would stay the same for the rest of the patient's life; they would not get better.

After hearing each description, patients were asked the following question:

If you had [condition], how likely would you be to want to continue your dialysis treatments? Would you say: very likely (5), somewhat likely (4), not sure (3), somewhat unlikely (2), or very unlikely (1)?

The question posed to the spouse was:

If patient had [condition], how likely do you believe s/he would be to want his/her dialysis treatments continued? Would you say: very likely (5), somewhat likely (4), not sure (3), somewhat unlikely (2), or very unlikely (1)?

Responses to this question represent the substituted judgments that family members are often asked to make at the end of a loved one's life. Coefficient alpha for black and white patient preferences were .89 and .86, respectively. Coefficient alpha for black and white spouse substituted judgments were .94 and .89, respectively. Preference scores were summed across the seven scenarios for patients and for spouses yielding a separate summary score for each patient and spouse.

Fear of death was assessed using five items derived from existing inventories. We chose this measurement strategy because we could find no single scale at the time that captured the dimension (fear of dying before one's time) that we sought to understand. From the fear of death subscale of the Death Attitude Profile-Revised measure developed by Wong, Reker, and Gesser (1994), we included the following items: "The uncertainty of not knowing what happens after death worries me"; "I have an intense fear of death"; and "The fact that death will mean the end of everything as I know it frightens me." From the fear of premature death subscale, part of the Multidimensional Fear of Death Scale developed by Neimeyer and Moore (1994), we included the following items: "I have a fear of not accomplishing my goals in life before dying"; and "I am afraid I will not have time to experience everything I want to do." For each statement, patients and spouses were asked to rate their level of agreement on a 5-point scale, ranging from "5" (strongly agree) to "1" (strongly disagree). Responses were scored such that higher scores reflect greater fear of death. Patients and spouses reported on their own feelings regarding fear of death. Coefficient alpha was .88 for black patients, .78 for white patients, .86 for black spouses, and .80 for white spouses. Responses were summed across the five items.

Relative frequency of participation in religious services was measured with the single item: "Compared with other members of your religious group, do you attend much more frequently (3), about as frequently (2), or much less frequently (1)?" Patients and spouses reported on their own participation. This aspect of religiosity was selected over others because it is a relatively objective indicator and because blacks are known to have higher rates of participation in religious activities than whites.

Patients assessed their own health and spouses assessed the health of the patient with the following question: "Compared to other people your age (or patient's age), would you say that your health (your spouses' health) is: better (3), about the same (2), or not as good (1)?"

Spouse burden was measured using the 9-item caregiver burden scale developed by Lawton, Kleban, Moss, Rovine, and Glicksman (1989). This scale employs a 5-point rating scale to measure how frequently spouses experience each feeling, ranging from "1" (never) to "5" (nearly always). Higher scores indicated greater burden. Coefficient alpha for the scale was .90 for the black spouses and .88 for white spouses.

There was very little missing data, with no variable in the analyses missing more than 4% of data.

RESULTS

As indicated in Table 1, there were no significant differences between black and white patients in terms of their preferences for dialysis continuation. There were also no differences in the extent to which black and white patients experienced fear of death. Black patients, as contrasted with white patients, reported that they attended religious worship services more often than others in their religious group. They also reported better subjective health for themselves in comparison with their age peers than did white patients. Given the

lack of differences in preferences to continue dialysis treatments between black and white patients, our intent to test a model explaining race differences on this construct was halted.

There were, on the other hand, significant differences in the substituted judgments made by black and white spouses, with black spouses being significantly more likely than white spouses to believe that their partner would want to continue dialysis treatments. White spouses had significantly higher levels of fear of death than did black spouses. As was the case for patients, black spouses, when compared with white spouses, reported attending religious worship services more often than did other members of their religious group. Black spouses reported that their partner's health was significantly better than that of their age peers as contrasted with white spouses. White spouses reported significantly higher levels of caregiver burden than did black spouses.

Bivariate correlations of all variables for Black and White participants may be found in Table 2. Correlations for the black participants are reported above the diagonal, those for whites below. Consistent with the *t*-tests reported in Table 1, these data indicate that the relationship between spouse's substituted judgment and patient's preferences was not significant (.24) for the black sample, but was highly significant (.63) for the white sample. For black, but not white spouses, spouses' report of patient health vis-à-vis their age peers was significantly correlated with patient fear of death (.48), patient subjective health in relationship to their age peers (.53), and spouse's substituted judgment (.36). There was a significant negative correlation between spouse's substituted judgment and caregiver burden for both black (–.34) and white (–.39) spouses.

In order to more carefully examine the effects of race and variables associated with race on spouse substituted judgments, the model was tested using structural equation analysis (Arbuckle, 1995). Race, relative participation in religious worship services, and patient's subjective health were each modeled as manifest exogenous variables, making the assumption that these variables can be reliably measured with a single item that did not contain random error. Fear of death, caregiver burden, and substituted judgment were modeled as single indicators measured by scales. Procedures followed the recommendation made by Liang, Lawrence, Bennett, and White-aw (1990) when single scaled indicators are used, and the measurement error was adjusted using the formula developed by Werts, Linn, and Joreskog (1974) and Wheaton, Muthen, Alwin, and Summers (1997). As such, the measurement error variances of these constructs were fixed as variance times (1-reliability). These procedures result in squared multiple correlations that are equal to the reliability estimates and correct for known unreliability among measured variables.

The fit of the model predicting spouse substituted judgments was good. The chi square was 6.94 ($df=5$, $N=68$; $p=.22$), CFI was .96, and RMSE was .08. Support was found for the hypothesized paths between caregiver burden and substituted judgment and between patient's health and substituted judgment. The paths between relative religious participation and substituted judgments, between fear of death and substituted judgment, and between race and substituted judgment were not significant. In addition, while the hypothesized correlations between race and fear of death, religious participation, and patient's relative health were significant, the correlation between race and caregiver burden was not

significant. The final model explained 35.4% of the variance in substituted judgments. The standardized total effect of caregiver burden on substituted judgments was $-.32$; the standardized total effect of spouses' perception of patient health on substituted judgments was $.26$; and the standardized total effect of fear of death on substituted judgments was $-.17$. Significant covariances existed between race and relative participation in religious services, fear of death, and spouse's perception regarding patient's health relative to his/her age peers. Standardized results are depicted in Figure 2.

DISCUSSION

Findings from these analyses reveal that when black and white respondents were matched on age, patient gender, education, and per capita income there were no significant differences in the preferences of black and white patients regarding the likelihood that they would continue dialysis under various hypothetical situations. There were, however, significant differences in the beliefs that black and white spouses had about what the preferences of their partners would be, with black spouses believing that their partners would be more likely to want to continue dialysis treatment under various hypothetical conditions than white spouses. Our findings provide explanation for these observed race differences and suggest that variables known to be correlated with race, especially caregiver burden and perceptions of patient health, may lie behind observed differences in the substituted judgments of black and white spouses.

These data suggest that race differences in the spouses' subjective perceptions of the patient's health may help to explain some of the observed differences in the substituted judgments of black and white spouses. Although the broader literature suggests that the health of blacks is worse than that of whites (Manton et al., 1987; Wilkinson & King, 1992), a substantial body of literature indicates that these differences are often rendered insignificant when differences in socioeconomic status are controlled (House, et al., 1990; House et al., 1994; Mutchler & Burr, 1991; Schoenbaum & Waidmann, 1997). Our data suggest that although there are similarities in the more objective indicators of health (number of health conditions and functional ability) of black and white patients (as reported by both patients and spouses), black spouses perceived the health of their partner to be better than that of their peers when compared with white spouses. It is possible that this finding is unique to our sample either because of the matching procedures or because the Medicare End Stage Renal Disease Program, a national health insurance program for people with ESRD was designed to help to eliminate health disparities. Nonetheless, in these data black spouses perceive their partner's health to be better than that of their age peers when compared with white spouses. The data also support a direct link between perception of patient's relative health and substituted judgments, with spouses who perceive their partner's relative health to be better than that of their age peers being more likely to believe that the patient would want to continue on dialysis. As such, results from this study suggest that what appear to be race differences in substituted judgments may actually be attributed to differences in subjective perceptions of patient's relative health.

Data regarding the relationship between race, fear of death, and substituted judgments are not quite as clear. As hypothesized, black spouses have lower levels of fear of death than

white spouses. Like Cicirelli (1997), we found a negative association between fear of death and substituted judgments, suggesting that spouses with a greater fear of death would actually be more likely to discontinue dialysis than those with lower levels of fear of death. However, this path is not a significant one. Future study of the relationship between fear of death and substituted judgments would be wise to broaden measurement of the construct to tap other dimensions of death attitudes, including acceptance of death and death as an escape, as suggested by Lockhart et al. (2001).

Although our results indicate that black spouses report participating in religious services more than do others of their religion when compared with white spouses, there was no association between relative participation in religious services and substituted judgments. Future studies using measures that expand on different dimensions of religion and faith are important. For example, building on Cicirelli's (1997) finding that subjective religiosity had a positive association with the desire to maintain life and a negative correlation with desire to end life, as well as Lockhart et al.'s (2001) work examining the roles of multiple dimensions of religious behaviors, including self-perceptions of religiosity and spirituality, are likely to shed important light on this dimension. Similarly, because Braun et al. (2007) found that African-American surrogates emphasize faith and spirituality more than either white or Hispanic surrogates, the role of this resource for African-American surrogate decision makers requires greater study. Moreover, building on results of Braun et al.'s (2007) qualitative study, gaining a better understanding of the role of God in the end of life decision making process is likely to yield salient information regarding race differences. Studies such as that by Winter et al. (2007-2008) that examine the role of the will of God are likely to enhance our understanding of the role that religiosity plays at the end of life.

Our findings regarding the relationship between caregiver burden, race, and substituted judgments are interesting. There is a significant negative bivariate correlation between caregiver burden and substituted judgment for both black and white spouses. However, black spouses report lower levels of burden and higher predicted preference for continuing dialysis whereas white spouses report greater levels of caregiver burden and lower predicted preference for continuing dialysis. The significant bivariate relationship between race and caregiver burden, suggesting that black spouses report significantly lower levels of caregiver burden than do white spouses, is consistent with that found by others (Haley et al., 1995; Janevic & Connell, 2001; Kosberg et al., 2007; Lawton et al., 1992; Navaie-Waliser et al., 2001; Pinquart & Sorensen, 2005). However, the correlation between race and caregiver burden reduces to non-significance in the context of our theoretical model suggesting that when other variables are controlled for the race, difference in burden also diminishes. It is possible that these findings are unique to ESRD, a health condition more commonly experienced by blacks and one for which there is universal health insurance coverage, but future research should examine more closely the tendency for black caregivers to report experiencing less caregiver burden.

Our finding that greater caregiving burden is associated with a tendency for spouses to believe that their partner would be less likely to continue their dialysis treatment also deserves comment. Our earlier research (Pruchno et al., 2006) as well as that of Fagerlin, Ditto, Danks, Houts, and Smucker (2001) suggest that substituted judgments are more

highly related to spouses' own preferences than to patients' preferences. When caregiving spouses feel burdened by their role, they are more likely to want to change that role, as evidenced by research finding that caregiving burden is a significant predictor of the decision to institutionalize a family member (Gaugler et al., 2004; Gilley et al., 2005; Rozzini et al., 2006; Spitznagel et al., 2006). As such, our finding that when spouses experience high levels of caregiving burden they believe that the patient would not want to continue dialysis may be a projection of their own desire to cease the caregiver role. Further study should be made of the extent to which spouse preferences and their substituted judgments are influenced by caregiving burden, since spouse caregivers play a pivotal role in the care of their partners.

The significant negative association between spouse's perception of patient's health and caregiver burden adds to a burgeoning literature designed to understand caregiver burden and to develop strategies to mitigate it. While much of the literature regarding caregiver burden focuses on patients with dementia and finds that behavior problems rather than perceptions of health are associated with caregiver burden (Pinquart & Sorensen, 2003), results from our study of patients with ESRD find that when spouses perceive their partner's health to be poor they also feel more burdened. It is possible that the predictors of burden experienced by caregivers coping with physical conditions such as ESRD differ from those of caregivers coping with conditions such as dementia in which caregivers are faced with both cognitive and behavioral challenges.

The similarity of preferences expressed by black and white dialysis patients is somewhat inconsistent with previous research that has indicated that black patients want aggressive care at the end of life (Allen-Burge & Haley, 1997; Borum et al., 2000; Caralis et al., 1993; Cicirelli, 1997; Diringer et al., 2001; Dula & Williams, 2005; Garrett, et al., 1993; Gessert, Curry, & Robinson, 2001; Gessert, Mosier, & Brown, 2000; King & Wolfe, 1998; Morrison et al., 1998). There are several possible explanations for these discrepancies. First, it may be that the experience of black and white dialysis patients is more similar than the experience of black and white patients with other chronic diseases. The universal access to dialysis treatment provided by Medicare funding may help to level the playing field in terms of treatment options, thereby making the treatment experience more similar for black and white patients. For example, while others have found differences in the rate at which black and white patients have living wills or health care proxies (McKinley et al., 1996), in our sample there were no significant race differences in the rate at which black and white patients had identified their spouse as their health care proxy. As such, it may be that when actual treatment options are similar, preferences for continued use of these options may also be similar. Second, because this study included only patients in active treatment for end stage renal disease, the hypothetical nature of the end of life scenarios may have been perceived as more real than is the case when non-patients are studied. These findings are consistent with research by Lloyd, Nietert, and Silvestri (2004) who studied the extent to which seriously ill patients consented to life sustaining medical treatment and found no difference as a function of race. Third, because of the frequent hospitalizations associated with end stage renal disease, it is likely that these patients have had more opportunity to realistically think about their end of life treatment choices. As such, the similarity of patient experiences with

treatment options and realistic nature of the hypothetical situations they were asked to consider result in similar responses from black and white patients.

Together, these data have important implications for our understanding of the way in which end of life decisions are made. At the end of life when patient decision making is compromised, it is typically the spouse who is called upon to decide on treatment options. Data from this study suggests that black spouses, acting on their belief that patients would want to continue on dialysis, will request more aggressive treatment. It is likely, however, that this treatment may not be consistent with the actual preferences of the black patients. Clearly more attention should be paid to understanding the treatment preferences of black patients and to helping black spouses to understand what these preferences are.

While findings from this study are intriguing, generalization of results is limited for several reasons. First, while the matching strategy that generated the sample enabled controls for factors typically obfuscating the effects of race (e.g., education, income), the resulting sample was better educated and had higher income than the general population. Both the black and white subsamples included a preponderance of male patients and female spouses. Second, patients and spouses were asked to think about how decisions would be made regarding hypothetical situations. While these situations were selected to be as realistic as possible for patients on dialysis, it is not clear that actual decisions would mimic those reported here. Third, the study focused only on preferences regarding continuation of dialysis. Preferences regarding other forms of end of life treatment for patients with other diagnoses may vary. Fourth, this study included only black and white patients and spouses; hence generalizations cannot be made to other groups of people. Fifth, this research is limited in that it did not address variables such as mistrust of health care system, subjective perception of the health care system and health care professionals, and experience of racial discrimination in health care settings. Sixth, because these data are cross-sectional, and because modifications were made to the initial theoretical model, care must be taken regarding interpreting causality. Finally, because the sample size was relatively small, results from the structural equation modeling may be unstable. Although regression analyses yielded identical results, future work in this area should examine these relationships with larger samples.

As the number of older people who are members of minority groups increases, it becomes more important to understand the preferences that these people and their family members have regarding end of life care. Clinicians are challenged by the tremendous diversity within specific minority groups and often unsure about how end of life decisions should be made. As research in this area progresses, it is important that the perspectives of patients as well as those of family members most likely to be in the position of surrogate decision maker be included. Growth in the number of older Americans who are members of minority groups yields a multicultural society that is faced with a host of ethical and public policy challenges regarding end of life care. It is critical that the process of end of life decision making be grounded in the context of cultural background.

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REFERENCES

- Allen-Burge R, & Haley WE (1997). Individual differences and surrogate medical decisions: Differing preferences for life-sustaining treatments. *Aging and Mental Health*, 1, 121–131.
- Arbuckle J (1995). AMOS: Analysis of moment structures user's guide. Chicago: Small Waters.
- Barrett RK (2005-2006). Dialogues in diversity: An invited series of papers, advance directives, DNRs, and end-of-life care for African Americans. *Omega*, 52, 249–261.
- Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, & Azen S (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine*, 48, 1779–1789. [PubMed: 10405016]
- Blendon RJ, & Aiken LH (1989). Access to medical care for black and white Americans. *Journal of the American Medical Association*, 261, 278–281. [PubMed: 2909026]
- Borum ML, Lynn J, & Zhong Z (2000). The effects of patient race on outcomes in seriously ill patients in SUPPORT: An overview of economic impact, medical intervention, and end-of-life decisions. *Journal of the American Geriatrics Society*, 48, S194–S198. [PubMed: 10809475]
- Braun UK, Beyth RJ, Ford ME, & McCullough LB (2007). Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *Journal of General Internal Medicine*, 23, 267–274.
- Caralis PV, Davis B, Wright K, & Marcial E (1993). The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *Journal of Clinical Ethics*, 4, 155–165. [PubMed: 8334279]
- Cicirelli VG (1997). Relationship of psychosocial and background variables to older adults' end-of-life decisions. *Psychology and Aging*, 12, 72–83. [PubMed: 9100269]
- Cicirelli VG (2000). Older adults' ethnicity, fear of death, and end-of-life decisions In Tomer A (Ed.), *Death attitudes and the older adult: Theories, concepts, and applications* (pp. 137–153). Washington, DC: Taylor and Francis.
- Degenholtz HB, Arnold RA, Meisel A, & Lave JR (2002). Persistence of racial disparities in advance care plan documents among nursing home residents. *Journal of American Geriatrics Society*, 50, 378–381.
- Degenholtz HB, Thomas SB, & Miller MJ (2003). Race and the intensive care unit: Disparities and preference for end-of-life care. *Critical Care Medicine*, 31, S373–S378. [PubMed: 12771586]
- Depaola SJ, Griffin M, Young JR, & Neimeyer RA (2003). Death Anxiety and attitudes toward the elderly among older adults: The role of gender and ethnicity. *Death Studies*, 37, 335–354.
- Dilworth-Anderson P, Williams IC, & Gibson BE (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist*, 42, 237–272. [PubMed: 11914467]
- Diringer MN, Edwards DF, Aiyagari V, & Hollingsworth H (2001). Factors associated with withdrawal of mechanical ventilation in a neurology/neurosurgery intensive care unit. *Critical Care Medicine*, 29, 1792–1797. [PubMed: 11546988]
- Duffy SA, Jackson FC, Schim SM, Ronis DL, & Fowler KE (2006). Racial/ethnic preferences, sex preferences, and perceived discrimination related to end-of-life care. *Journal of the American Geriatrics Society*, 54, 150–157. [PubMed: 16420213]
- Dula A, & Williams S (2005). When race matters. *Clinics in Geriatric Medicine*, 21, 239–253. [PubMed: 15639049]
- Eleazer GP, Hornung CA, Egbert CB, Egbert JR, Eng C, & Hedgepeth J (1996). The relationship between ethnicity and advance directives in a frail older population. *Journal of the American Geriatrics Society*, 44, 938–943. [PubMed: 8708304]

- Fagerlin A, Ditto PH, Danks JH, Houts RM & Smucker WD (2001). Projection in surrogate decision about life-sustaining medical treatments. *Health Psychology*, 20, 166–175. [PubMed: 11403214]
- Feild ML, Pruchno RA, Bewley J, Lemay EP, & Levinsky NG (2006). Using probability vs. non-probability sampling to identify hard-to-access participants for health-related research: Costs and contrasts. *Journal of Aging & Health*, 18, 565–583. [PubMed: 16835390]
- Ferraro KF, & Koch JR (1994). Religion and health among black and white adults: Examining social support and consolidation. *Journal for the Scientific Study of Religion*, 33, 362–375.
- Ford E, Cooper R, Castaner A, Simmons B, & Mar M (1989). Coronary arteriography and coronary bypass surgery among whites and other racial groups relative to hospital based incidence rates for coronary artery disease: Findings from NHDS. *American Journal of Public Health*, 79, 437–440. [PubMed: 2784635]
- Fried TR, Bradley EH, & Towle VR (2003). Valuing the outcomes of treatment: Do patients and their caregivers agree? *Archives of Internal Medicine*, 163, 2073–2078. [PubMed: 14504121]
- Garrett J, Harris RP, Norburn JK, Patrick DL, & Danis M (1993). Life-sustaining treatments during terminal illness: Who wants what? *Journal of General Internal Medicine*, 8, 361–368. [PubMed: 8410396]
- Gaugler JE, Leach CR, Clay T, & Newcomer RC (2004). Predictors of nursing home placement in African Americans with dementia. *Journal of the American Geriatrics Society*, 52, 445–452. [PubMed: 14962163]
- Gessert CE, Curry NM, & Robinson A (2001). Ethnicity and end-of-life care: The use of feeding tubes. *Ethnicity and Disease*, 11, 97–106. [PubMed: 11289258]
- Gessert CE, Mosier MC, & Brown EF (2000). Tube feeding in nursing home residents with severe and irreversible cognitive impairment. *Journal of the American Geriatrics Society*, 48, 1593–1600. [PubMed: 11129748]
- Gilley DW, McCann JJ, Bienias JL, & Evans DA (2005). Caregiver psychological adjustment and institutionalization of persons with Alzheimer's disease. *Journal of Aging and Health*, 17, 172–189. [PubMed: 15750050]
- Haley WE, West CAC, Wadley VG, Ford GR, White FA, & Barrett JJ (1995). Psychological, social, and health impact of caregiving: A comparison of Black and White dementia family caregivers and noncaregivers. *Psychology and Aging*, 10, 540–552. [PubMed: 8749581]
- Hallenbeck J, Goldstein MK, & Mebane EW (1996). Cultural considerations of death and dying in the United States. *Clinics in Geriatric Medicine*, 12, 393–406. [PubMed: 8799356]
- Heyland DK, Cook DJ, Rocker GM, Dodek PM, Kutsogiannis DF, Peters S, et al. (2003). Decision-making in the ICU: Perspectives of the substitute decisionmaker. *Intensive Care Medicine*, 29, 75–82. [PubMed: 12528026]
- High DM (1993). Advance directives the elderly: A study of intervention strategies to increase use. *The Gerontologist*, 33, 342–349. [PubMed: 8325521]
- Hopp FP, & Duffy S (2000). Racial variations in end-of-life care. *Journal of the American Geriatrics Society*, 48, 658–663. [PubMed: 10855602]
- House J, Kessler R, & Herzog A (1990). Age, socioeconomic status, and health. *The Milbank Quarterly*, 68, 383–410. [PubMed: 2266924]
- House JS, Lepkowski JM, Kinney AM, Mero RP, Kessler RC, & Herzog AR (1994). The social stratification of aging and health. *Journal of Health and Social Behavior*, 35, 213–234. [PubMed: 7983335]
- Janevic MR, & Connell CM (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. *The Gerontologist*, 41, 334–347. [PubMed: 11405431]
- Johnson KS, Elbert-Avila KI, & Tulskey JA (2005). The influence of spiritual beliefs and practices on the treatment preferences of African Americans: A review of the literature. *Journal of the American Geriatrics Society*, 53, 711–719. [PubMed: 15817022]
- Johnson KS, Kuchibhatla M, Tanis D, & Tulskey JA (2008). Racial differences in hospice revocation to pursue aggressive care. *Archives of Internal Medicine*, 168, 218–224. [PubMed: 18227371]
- Kalish R, & Reynolds D (1976). *Death and Ethnicity: A Psychocultural Study*. Los Angeles: University of Southern California.

- King PA, & Wolf LE (1998). Empowering and protecting patients: Lessons for physician-assisted suicide from the African American experience. *Minnesota Law Review*, 82, 1015–1043. [PubMed: 11865911]
- Kosberg JI, Kaufman AV, Burgio LD, Leeper JD, & Sun F (2007). Family care giving to those with dementia in rural Alabama: Racial similarities and differences. *Journal of Aging and Health*, 19, 3–21. [PubMed: 17215199]
- Kwak J, & Haley WE (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45, 634–641. [PubMed: 16199398]
- Lawton MP, Kleban MH, Moss M, Rovine M, & Glicksman A (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences*, 44, P61–P71.
- Lawton MP, Rajagopal D, Brody E, & Kleban MH (1992). The dynamics of care giving for a demented elder among Black and White families. *Journal of Gerontology: Social Sciences*, 47, S156–S164.
- Levin JS, Taylor RJ, & Chatters LM (1994). Race and gender differences in religiosity among older adults: Findings from four national surveys. *Journal of Gerontology: Social Sciences*, 49, S137–S145.
- Liang J, Lawrence RH, Bennett JM, & Whitelaw NA (1990). Appropriateness of composites in structural equation models. *Journal of Gerontology: Social Sciences*, 45, S52–S59.
- Lloyd CB, Nietert PJ, & Silvestri GA (2004). Intensive care decision making in the seriously ill and elderly. *Critical Care Medicine*, 32, 649–654. [PubMed: 15090942]
- Lockhart LK, Bookwala J, Fagerlin A, Coppola KM, Ditto PH, Danks JH, et al. (2001). Older adults' attitudes toward death: Links to perception of health and concerns about end-of-life issues. *Omega: Journal of Death and Dying*, 43, 331–347. [PubMed: 12569924]
- Lopes AA (2004). Relationships of race and ethnicity to progression of kidney dysfunction and clinical outcomes in patients with chronic kidney failure. *Advances in Renal Replacement Therapy*, 11, 14–23. [PubMed: 14730535]
- Manton KG, Patrick CH, & Johnson KW (1987). Health differentials between Blacks and Whites: Recent trends in mortality and morbidity. *Milbank Quarterly*, 65, 129–199. [PubMed: 3327005]
- McKinley ED, Garrett JM, Evans AT, & Danis M (1996). Differences in end-of-life decision making among Black and White ambulatory cancer patients. *Journal of General Internal Medicine*, 11, 651–656. [PubMed: 9120650]
- Morrison RS, Zayas LH, Mulvihill M, Baskin SA, & Meier DE (1998). Barriers to completion of healthcare proxy forms: A qualitative analysis of ethnic differences. *Journal of Clinical Ethics*, 9, 118–126. [PubMed: 9750983]
- Mutchler JE & Burr JA (1991). Racial differences in health and health care service utilization in later life: The effect of socioeconomic status. *Journal of Health and Social Behavior*, 32, 342–356. [PubMed: 1765625]
- Navaie-Waliser M, Feldman PH, Gould DA, Levine C, Kuerbis AN, & Donelan K (2001). The experiences and challenges of informal caregivers: Common themes and differences among Whites, Blacks, and Hispanics. *The Gerontologist*, 41, 733–741. [PubMed: 11723341]
- Neimeyer RA, & Moore MK (1994). Validity and reliability of the multidimensional fear of death scale. In Neimeyer RA (Ed.), *Death anxiety handbook: Research, instrumentation, and application* (pp. 103–119). Washington, DC: Taylor & Francis.
- Phipps E, True G, Harris D, Chong U, Tester W, Chavin SI, et al. (2003). Approaching the end of life: Attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *Journal of Clinical Oncology*, 21, 549–554. [PubMed: 12560448]
- Pinquart M, & Sorensen S (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology: Psychological Sciences*, 58B, P112–P128.
- Pinquart M, & Sorensen S (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45, 90–106. [PubMed: 15695420]
- Pruchno RA, Lemay EP, Feild L, & Levinsky NG (2005). Spouse as health care proxy for dialysis patients: Whose preferences matter? *The Gerontologist*, 45, 812–819. [PubMed: 16326663]

- Pruchno RA, Lemay EP, Feild L, & Levinsky NG (2006). Predictors of patient treatment preferences and spouse substituted judgments: The case of dialysis continuation. *Medical Decision Making*, 26, 112–121. [PubMed: 16525165]
- Roof WC, & McKinney W (1987). *American mainline religion: Its changing shape and future*. New Brunswick: Rutgers University Press.
- Rozzini L, Cornali C, Chilovi BV, Ghiada D, Padovani A, & Trabucchi M (2006). Predictors of institutionalization in demented patients discharged from a rehabilitation unit. *Journal of American Medical Directors Association*, 7, 345–349.
- Schoenbaum M, & Waidmann T (1997). Race, socioeconomic status, and health: Accounting for race differences in health. *The Journal of Gerontology: Psychological Sciences & Social Sciences*, 52, 61–73.
- Sherwood PR, Given CW, Given BA, & von Eye A (2005). Caregiver burden and depressive symptoms: Analysis of common outcomes in caregivers of elderly patients. *Journal of Aging and Health*, 17, 125–147. [PubMed: 15750048]
- Singer PA, Thiel EC, Naylor CD, Richardson RMA, Llewellyn-Thomas H, Goldstein M, et al. (1995). Life-sustaining treatment preferences of hemodialysis patients: Implications for advance directives. *Journal of American Society of Nephrology*, 6, 1410–1417.
- Spitznagel MB, Tremont G, Davis JD, & Foster SM (2006). Psychosocial predictors of dementia caregiver desire to institutionalize: Caregiver, care recipient, and family relationship factors. *Journal of Geriatric Psychiatry and Neurology*, 19, 16–20. [PubMed: 16449755]
- Stelter KL, Elliot BA, & Bruno CA (1992). Living will completion in older adults. *Archives of Internal Medicine*, 152, 954–959. [PubMed: 1580721]
- Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, & Tulsky JA (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association*, 284, 2476–2482. [PubMed: 11074777]
- Suhl J, Simons P, Reedy T, & Garrick T (1994). Myth of substituted judgment: Surrogate decision making regarding life support is unreliable. *Archives of Internal Medicine*, 154, 90–94. [PubMed: 8267493]
- Sulmasy DP, Terry PB, Weisman CS, Miller DJ, Stallings RY, Vettese MA, et al. (1998). The accuracy of substituted judgments in patients with terminal diagnoses. *Annals of Internal Medicine*, 128, 621–629. [PubMed: 9537935]
- United States Census Bureau. (2001). *U.S. Census 2000*. Washington, D.C.
- Vaccarino V, Rathore SS, Wenger NK, Frederick PD, Abramson JL, Barron HV, et al. (2005). Sex and racial differences in the management of acute myocardial infarction, 1994–2002. *New England Journal of Medicine*, 353, 671–681. [PubMed: 16107620]
- Vig EK, Taylor JS, Starks H, Hopley EK, & Fryer-Edwards K (2006). Beyond substituted judgment: How surrogates navigate end-of-life decision-making. *Journal of American Geriatrics Society*, 54, 1688–1693.
- Waters CM (2001). Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. *Qualitative Health Research*, 11, 385–398. [PubMed: 11339081]
- Werts CF, Linn RL, & Joreskog KG (1974). Intraclass reliability estimates: Testing structural assumptions. *Educational and Psychological Measurement*, 34, 25–33.
- Wheaton B, Muthen B, Alwin DF, & Summers GF (1997). Assessing reliability and stability in panel models. In Heise DR (Ed.) *Sociological methodology* (pp. 84–136). San Francisco: Jossey-Bass.
- Wilkinson DY, & King G (1992). Conceptual and methodological issues in the use of race as a variable: Policy implications. *Milbank Quarterly*, 65, 56–71.
- Winter L, Dennis MP, & Parker B (2007–2008). Religiosity and preferences for life-prolonging medical treatments in African-American and White elders: A mediation study. *Omega: Journal of Death and Dying*, 56, 273–288.
- Winter L, Lawton MP, & Ruckdeschel K (2003). Preferences for prolonging life: A prospect theory approach. *The International Journal of Aging and Human Development*, 56, 155–170. [PubMed: 14533855]

Wong PTP, Reker GT, & Gesser G (1994). Death attitudes profile-revised: A multidimensional measure of attitudes toward death In Neimeyer RA (Ed.), *Death anxiety handbook: Research, instrumentation, and application* (pp. 121–148). Washington, DC: Taylor & Francis.

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Figure 1.
Theoretical model.

Figure 2.
Final model.

Table 1.

Means and (Standard Deviations) Comparing Black and White Patients and Spouses.

Patient Comparisons	Black		White		<i>t</i> (df = 64)
Preferences for Dialysis Continuation	26.9	(9.8)	25.1	(8.1)	0.82
Fear of Death	12.2	(4.6)	12.2	(3.6)	0.03
Religious Participation	1.97	(.76)	1.44	(.67)	3.02 **
Subjective Health	2.12	(.78)	1.50	(.71)	3.42 **
Spouse Comparisons	Black		White		<i>t</i> (df = 64)
Preferences for Dialysis Continuation	35.1	(10.0)	27.5	(8.9)	-3.32 **
Fear of Death	11.1	(4.4)	13.7	(4.3)	-2.41 *
Religious Participation	2.09	(0.75)	1.50	(0.72)	3.24 **
Spouse's Report of Patient's Health	2.24	(0.71)	1.59	(0.78)	3.58 **
Caregiver Burden	13.9	(6.4)	17.1	(6.4)	-2.03 *

Note:

*
 $p < .05$.**
 $p < .01$.

Table 2.
Correlations for Black (Above the Diagonal) and White (Below the Diagonal) Respondents

	1	2	3	4	5	6	7	8	9
1. Preference (P)	1.0	-.15	.49**	.18	.24	-.34*	.08	-.04	.13
2. Fear of Death (P)	.08	1.0	-.04	.28	.29	.29	.06	.48**	.19
3. Religious Participation (P)	.12	-.13	1.0	.00	.19	-.21	.27	.09	-.03
4. Subjective Health (P)	.24	-.12	-.23	1.0	.16	-.02	.08	.53**	-.29
5. Substituted Judgment (S)	.63**	.06	.01	.28	1.0	-.21	.06	.36*	-.39*
6. Fear of Death (S)	.07	.13	-.01	.13	-.02	1.0	.12	.10	.18
7. Religious Practice (S)	-.06	-.05	.50**	-.34	-.03	.17	1.0	.02	-.09
8. Spouse's Report of Patient Health (S)	.27	.17	-.17	.33	.21	.31	.03	1.0	-.25
9. Caregiver Burden (S)	-.24	-.22	.07	-.01	-.34*	-.05	-.26	-.26	1.0

Note:

* $p < .05$

** $p < .01$

(P) Patient Report; (S) Spouse Report.