

Family Matters: Dyadic Agreement in End-of-Life Medical Decision Making

Bettina Schmid, PhD,^{2,3,4} Rebecca S. Allen, PhD,^{1,3,4} Philip P. Haley, MA,^{3,4}
and Jamie DeCoster, PhD^{4,5}

Purpose: We examined race/ethnicity and cultural context within hypothetical end-of-life medical decision scenarios and its influence on patient-proxy agreement. **Design and Methods:** Family dyads consisting of an older adult and 1 family member, typically an adult child, responded to questions regarding the older adult's preferences for cardiopulmonary resuscitation, artificial feeding and fluids, and palliative care in hypothetical illness scenarios. The responses of 34 Caucasian dyads and 30 African American dyads were compared to determine the extent to which family members could accurately predict the treatment preferences of their older relative. **Results:** We found higher treatment preference agreement among African American dyads compared with Caucasian dyads when considering overall raw difference scores (i.e., overtreatment errors can compensate for undertreatment errors). Prior advance care planning moderated the effect such that lower levels of advance care planning predicted undertreatment errors among African American proxies and overtreatment errors among Caucasian proxies. In contrast, no racial/ethnic differences in treatment preference agreement were found within absolute difference scores (i.e., total error, regardless of the direction of error). **Implications:** This project is one of the first to examine the mediators and moderators of dyadic racial/cultural differences in treatment preference agreement for end-of-life care in hypothetical illness scenarios. Future studies should use mixed method approaches to explore underlying fac-

tors for racial differences in patient-proxy agreement as a basis for developing culturally sensitive interventions to reduce racial disparities in end-of-life care options.

Key Words: End-of-life decision making, Race/ethnicity, Culture

When a patient is unable to communicate his or her wishes regarding medical care, a proxy may make decisions on behalf of the patient. In this circumstance, the ethical principle of substituted judgment is used (Allen-Burge & Haley, 1997; Chan, 2004; Hawkins, Ditto, Danks, & Smucker, 2005; Winzelberg, Hanson, & Tulskey, 2005) with the expectation that the proxy will communicate the same medical decision that the patient would have made if he or she were able to communicate. Advance directives (e.g., living will and durable power of attorney for health care) may be completed so that a person can give directions regarding treatment should he or she be deemed incompetent, become permanently unconscious, or suffer a terminal medical condition. Although familial advance care planning (Allen & Shuster, 2002; King, Kim, & Conwell, 2000) has been proposed as a method of facilitating proxy knowledge of autonomous patient wishes, research findings have shown mixed results regarding the efficacy of interventions to improve patient-proxy agreement. High agreement has been found using a formal advance care planning intervention called patient-centered advance care planning (PC-ACP; Briggs, 2003), wherein treatment groups of chronically ill patients and their proxies had higher agreement than controls (Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Song, Kirchhoff, Douglas, Ward, & Hammes, 2005). Additionally, Sulmasy, Haller, and Terry (1994) and Schwartz and colleagues (2002) found

¹Address correspondence to Rebecca S. Allen, PhD, Center for Mental Health and Aging, University of Alabama, Box 870315, Tuscaloosa, AL 35487-0315. E-mail: rsallen@ua.edu

²Psychology Service, Tuscaloosa Veterans Affairs Medical Center, Tuscaloosa, Alabama.

³Department of Psychology, The University of Alabama, Tuscaloosa.

⁴Center for Mental Health and Aging, The University of Alabama, Tuscaloosa.

⁵Institute for Social Science Research, The University of Alabama, Tuscaloosa.

that prior discussion between patients and their proxies or an extensive community-wide advance directive educational intervention both improved proxy predictions. However, Ditto and colleagues (2001) found that neither discussion interventions nor discussion interventions coupled with the availability of formal advance directives were successful in improving the agreement between patients and proxies in hypothetical illness scenarios.

Most proxy studies have found that proxy decisions are no better than chance, with proxies tending to make decisions based on their own treatment wishes (Fagerlin, Ditto, Danks, Houts, & Smucker, 2001; Karel & Gatz, 1996; Sulmasy et al., 1998). Many studies have found that proxies are conservative in their decisions, with more overtreatment than undertreatment errors (Ditto et al., 2001; Hare, Pratt, & Nelson, 1992; Suhl, Simons, Reedy, & Garrick, 1994; Zweibel & Cassel, 1989). Other studies have found a bias among proxies to undertreat (Allen et al., 2003; Diamond, Jernigan, Moseley, Messina, & McKeown, 1989) or no significant trends (Gerety, Chiodo, Kantan, Tuley, & Cornell, 1993; Sulmasy et al., 1998; Teno, Stevens, Spernak, & Lynn, 1998).

Only four proxy decision-making studies included samples consisting of close to 50% African Americans (Phipps et al., 2003 [56%]; Seckler, Meier, Mulvihill, & Paris, 1991 [50%]; Sulmasy et al., 1994 [48%]; Zweibel & Cassel, 1989 [56%]); yet, race/ethnicity and culture are crucial factors in end-of-life decision making (Kwak & Haley, 2005). Of these studies, Seckler and colleagues and Zweibel and Cassel did not report comparison of African Americans and Caucasians in their analyses, whereas Sulmasy and colleagues found that race was not significant. However, in their review, Kwak and Haley found that Caucasians are more likely than African Americans to choose palliative care, Caucasians are more likely than African Americans to possess a living will (Degenholtz, Arnold, Meisel, & Lave, 2002; Hopp & Duffy, 2000; Phipps et al., 2003), and African Americans are more likely than Caucasians to opt for life-sustaining treatments for themselves (Blackhall et al., 1999; Caralis, Davis, Wright, & Marcial, 1993; Phipps et al., 2003) or their older relatives (Allen-Burge & Haley, 1997; Hopp & Duffy).

Factors Potentially Associated With Race/Ethnicity and Treatment Preference Agreement

Four factors in the literature have been identified as possible mediators or moderators of the

relation between race/ethnicity and treatment preference agreement: religiousness/spirituality, decision-making style within the family, trust in the health care system, and prior advance care planning.

Religiousness/Spirituality.—Many authors mention religion or spirituality as a factor in end-of-life decision making, but only few have empirically examined its role. Crawley and colleagues (2000) proposed that African Americans have a spiritual view of death; yet, they may not opt for palliative care due to their values about enduring pain and suffering that conflict with the goals of palliative care (i.e., relieving physical pain). In support of this notion, True and colleagues (2005) found that cancer patients who rated high on measures of religiousness/spirituality were less likely to have a living will and more likely to opt for life-sustaining treatments, and more African Americans than Caucasians reported using religious/spiritual coping for their cancer.

Decision-Making Style.—Two basic approaches to decision making in health care are the patient autonomy model and the family-centered model. The patient autonomy model is based on the concept that an individual has the right to determine the course of his or her medical care and is the basis for the Patient Self-Determination Act (1990). The family-centered model recognizes that the individual operates within the context of the family system; the influence of family members must be taken into account in regard to making decisions about end-of-life care (Allen & Shuster, 2002; King et al., 2000). In a qualitative study, Moore, Sparr, Sherman, and Avery (2003) examined the decision-making process for older adults regarding end-of-life care and found prior experience with proxy decision making to be associated with preference for a family-centered approach. Waters (2000) found that many African American participants felt family should be involved in advance care planning and making decisions regarding end-of-life care.

Sehgal and colleagues (1992) examined how much family involvement patients were willing to allow in end-of-life medical treatment decisions in a diverse sample. They found variability in the amount of leeway people granted their proxies: 39% stated that they would give “no leeway,” 31% reported that they would grant “complete

leeway,” and the remaining 30% would give some measure of leeway.

Trust in the Health Care System.—Patients’ level of trust in the health care system may be a factor in their choices for end-of-life care. Boulware, Cooper, Ratner, LaVeist, and Powe (2003) examined race and trust in the health care system in a small national telephone survey ($N = 118$) and found that African Americans were less likely than Caucasians to trust their physicians and more likely to be concerned about privacy and potential for harm from undisclosed experiments. Corbie-Smith, Thomas, and St. George (2002) found that African Americans had significantly higher levels of distrust than Caucasians.

Prior Advance Care Planning.—Prior advance care planning has been proposed to facilitate patient-proxy treatment preference agreement. Caralis and colleagues (1993) found that African Americans were more likely than Caucasians or Hispanics to feel that they would be treated differently and cared for less if they had an advance directive. Phipps and colleagues (2003) found that African Americans were significantly less likely than Caucasians to have an advance directive, with the most commonly cited reason being “no one has brought it up to me.” Other reasons included not seeing formal documentation as necessary until the end of life, emotional distress associated with discussing end-of-life issues, and assuming that family members are already aware of one’s wishes.

Allen, Phillips, Pekmezi, Crowther, and Prentice-Dunn (2009) found no differences in intention to complete a living will among community-dwelling Caucasian and African American older adults but did find racial differences in coping with reactions to end-of-life medical decisions regarding treatments for a persistent vegetative state. Allen, Allen, Hilgeman, and DeCoster (2008) found that enhanced information regarding end-of-life medical choices reduced decisional conflict in both Caucasians and African Americans but only reduced desire for life-sustaining treatment among African Americans. Carr and Khodyakov (2007) explored predictors of possession of advance directives and informal discussions and found that recent hospitalizations, personal beliefs including death avoidance and the belief that doctors should control health care decisions, and recent experience with

the painful death of a loved one influence individual decision making.

Need for Study

Based on these findings, we hypothesized that religiousness/spirituality, decision-making style, trust in the health care system, and prior advance care planning may vary between Caucasian and African American families in ways that influence medical treatment decisions regarding end-of-life care. The tendency for African Americans to choose life-sustaining interventions over palliative care suggests that, perhaps culturally, African American patient-proxy dyads may be more homogeneous than Caucasian dyads regarding treatment preferences. Consequently, African Americans may have higher rates of concordance between patients and family proxies for end-of-life treatment decisions. We investigated whether African American family proxies were more accurate than Caucasian family proxies in predicting the treatment wishes of their healthy community-dwelling older relatives in hypothetical illness scenarios. We also examined religiousness/spirituality, decision-making style, trust in the health care system, and prior advance care planning as potential mediators or moderators of the relation between race/ethnicity and treatment preference agreement.

Design and Methods

Participants

The sample consisted of 64 family dyads (30 African American pairs and 34 Caucasian pairs) for a total of 128 individuals recruited from community and health care agencies, health fairs, informal networking, and the efforts of a paid recruiter who self-identified as African American. One hundred sixty community contacts were made with older adults, but the race of potential “patient” participants was not recorded at first contact. Seventeen of these individuals were excluded from the study due to an inability to identify a family member who could participate along with them.

Table 1 presents the demographic characteristics of the sample. Older adults were considered to be the “patient” and their family members the proxies. For spousal dyads ($n = 14$), researchers alternated in assigning husband and wife as patient and proxy. Volunteers were excluded if they did not meet age criteria (older adults 55 years or older, proxies 19 years or older), did not speak

Table 1. Patient and Proxy Demographic Data (N = 64 dyads, with 34 Caucasian dyads and 30 African American dyads)

Characteristic	Patients (N = 64)		Proxies (N = 64)	
	African American (n = 30)	Caucasian (n = 34)	African American (n = 30)	Caucasian (n = 34)
Age (years), M (SD)	70.60 (7.12)	73.32 (8.68)	48.23 (13.73)	52.12 (13.99)
MMSE (adjusted), M (SD)	26.63 (2.18)	28.18 (1.68)	27.69 (1.72)	29.11 (1.15)
Women, n (%)	22 (73)	27 (79)	23 (77)	25 (73)
Men, n (%)	8 (27)	7 (21)	7 (23)	9 (27)
Education, M (SD)	12.73 (3.21)	14.44 (3.78)	14.67 (3.75)	16.09 (3.06)
Annual income (\$), n (%)				
<15,000	13 (43)	8 (23)	5 (17)	3 (9)
15,000–30,000	10 (33)	8 (23)	9 (30)	3 (9)
30,000–45,000	3 (10)	6 (18)	10 (33)	7 (21)
≥45,000	4 (13)	12 (35)	6 (20)	20 (59)

Notes: N reflects the total number of patient-proxy dyads across race/ethnicity. Patients ranged in age from 59 to 92 years, in education from 6 to 22 years, and in education-adjusted MMSE from 22 to 30. Proxies ranged in age from 21 to 84 years, in education from 5 to 24 years, and in education-adjusted MMSE from 24 to 30. One Caucasian proxy declined to provide income information. MMSE = Mini-Mental State Examination.

English, or one member of the pair was unavailable. Additionally, patients and proxies were excluded who did not meet minimum criteria on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). Based on the percentile distribution developed by Crum, Anthony, Bassett, and Folstein (1993), the MMSE screening protocol was adjusted for education as follows: For those with a ninth-grade education or higher, the MMSE score had to be greater than or equal to 24, and for those with an educational level at or below eighth grade, the MMSE score had to be greater than or equal to 22 for inclusion. Of those who volunteered, none was excluded due to language and 13 people were unable to get a geographically local relative to participate as proxy in spite of initial interest. Additionally, two dyads were excluded because the older adult did not meet minimum criteria on the MMSE.

Measures

Mini-Mental State Examination.—The MMSE (Folstein et al., 1975) was used as a screening tool for inclusion and is an 11-item cognitive functioning assessment with scores ranging from 0 to 30. Test-retest correlations range from .83 to .98. The MMSE reliably differentiates between individuals with and without global cognitive impairments (Kafonek et al., 1989).

Illness Experience and Advance Planning Form.—Patients and proxies were asked about

current health status and prior experience with serious illness (i.e., “yourself as the patient or caring for an ill relative”). Patients and proxies were also asked whether they (e.g., the patient or the proxy himself or herself) (a) possessed a living will, (b) possessed a durable power of attorney for health care, or (c) had previous discussions with family members regarding end-of-life care. These three questions were summed to obtain a measure of total advance care planning for each participant with a possible score range of 0–3.

Life-Support Preferences/Predictions Questionnaire-Modified.—The Life-Support Preferences/Predictions Questionnaire (LSPQ; Bookwala et al., 2001) describes nine illness scenarios varying in severity of illness, prognosis, and level of pain. In this study, an abbreviated version of the LSPQ was used including (a) Alzheimer’s disease (AD), (b) emphysema, (c) coma with no chance of recovery, (d) cancer with no pain, and (e) cancer with constant pain. These five scenarios were chosen to provide a range of illness severity while reducing burden in completing the interviews. Coppola and colleagues (1999) found high internal consistency ($\alpha = .86-.96$) among preference for life-sustaining treatments by scenario for these illnesses.

Patients were asked to imagine themselves in each of the scenarios and indicate their preference for receiving (a) cardiopulmonary resuscitation (CPR), (b) artificial feeding and fluids (feeding tube), and (c) palliative care (comfort measures only). Proxies were asked to imagine their relative

in each of these scenarios and to indicate their relative's preference for receiving each treatment. The third treatment choice allowed the opportunity for patients and proxies to actively choose palliative care rather than passively select it by rejecting curative interventions. Patients indicated their treatment preferences along a 5-point Likert-type scale ranging from *definitely do not want* treatment (0) to *definitely want* treatment (4). Items were scored such that a higher number indicated preference for life-sustaining treatment (e.g., palliative care was reverse coded). Totals were calculated by summing all the items, with a possible score range of 0–60.

Measure of Understanding.—We measured understanding of the disease scenarios and treatment options through seven questions requiring the participant to provide definitions of AD, emphysema, coma, cancer, CPR, artificial feeding and fluids, and palliative care in their own words. Responses were recorded verbatim and scored at the time of administration to facilitate accuracy of coding. They were later reviewed by one of the authors (Bettina Schmid). Definition by example was accepted as correct. Responses to each item were scored 0, 1, or 2 points in a manner similar to scoring procedures for the Vocabulary subtest of the *Wechsler Adult Intelligence Scale—Fourth Edition* (Wechsler, Coalson, & Raiford, 2008). Two-point responses included any recognized meaning of the term reflecting good understanding (e.g., synonym, major use, definitive or primary feature, classification). One-point responses included a vague knowledge of the meaning of the term (e.g., vague synonym, minor use, correct but not definitive or distinguishing feature, example without elaboration). Zero-point responses were clearly incorrect definitions reflecting no real understanding of the term. For each item missed, the corresponding items in that participant's LSPQ were removed from the analysis.

Brief Multidimensional Measure of Religiousness/Spirituality.—We used seven subscales of the Brief Multidimensional Measure of Religiousness/Spirituality (29 Likert-type items; Fetzer Institute/National Institute on Aging Working Group, 1999): daily spiritual experiences ($\alpha = .91$), values/beliefs ($\alpha = .64$), forgiveness ($\alpha = .66$), private religious practices ($\alpha = .72$), religious and spiritual coping (positive $\alpha = .81$; negative $\alpha = .54$), religious sup-

port (congregation benefits $\alpha = .86$; congregation problems $\alpha = .64$), and organizational religiousness ($\alpha = .82$). Means for religiousness (e.g., private religious practices, religious and spiritual coping, religious support, and organizational religiousness; possible score range 1–5) and spirituality (e.g., daily spiritual experiences, values/beliefs, and forgiveness; possible score range 1–3) were calculated and used in all analyses.

Family Attachment and Changeability Index.—The Family Attachment and Changeability Index 8 (FACI8; McCubbin, Thompson, & Elver, 1996) is a 16-item scale specifically designed to be culturally sensitive that measures family communication and decision-making style. The instrument uses a 5-point Likert-type scale measuring how often the event occurs, ranging from 1 (*never*) to 5 (*always*). For the current project, one irrelevant question was deleted (“Discipline is fair in our family”). The FACI8 contains two questions that specifically address the family-centered decision-making model (no. 3 “Each family member has input in major family decisions” and no. 6 “Family members consult other family members on their decisions”). Two new questions were added to reflect the patient autonomy model (“Members are free to make important personal decisions without consulting others in the family” and “In our family, one person has the last word on family decisions”). The resulting questionnaire had a total of 17 items with high internal consistency ($\alpha = .827$ overall; African Americans $\alpha = .863$; Caucasians $\alpha = .763$). The mean score was calculated and used in all analyses, with a possible score range of 1–5.

Trust in the Medical Profession.—This 13-item questionnaire consists of the General Trust in Physicians Scale (Hall, Camacho, Dugan, & Balkrishnan, 2002; $\alpha = .89$) plus two items from a “distrust of research and the medical community” questionnaire developed by Corbie-Smith and colleagues (2002). Items were coded using a 5-point Likert-type scale that asked respondents to rate the degree to which they agree with statements about physicians ranging from *strongly agree* (1) to *strongly disagree* (5). The two items from Corbie-Smith and colleagues appeared to fit well with other items, with very high internal consistency ($\alpha = .928$ overall; African Americans: $\alpha = .920$; Caucasians: $\alpha = .935$). The mean score was calculated and used in all analyses, with a possible score range of 1–5.

Procedure

This study was approved by The University of Alabama Institutional Review Board. Patients were contacted by phone to determine interest in the study and eligibility, and to schedule a time for an interview in a convenient location, usually their home, a local senior citizens center, or the psychology clinic. Patients were asked to identify a relative living in the local area “for a study about how families make important decisions about health care.” Although not directly stated, this recruitment strategy implied that these relatives might serve as a surrogate decision maker for medical care. Further information about the study was provided during in person interviews as part of the consent process.

When the researchers met the dyad for the interview, informed consent was obtained and the MMSE was administered to each participant in separate private rooms. If both members of the dyad met minimum criteria on the MMSE, the other questionnaires were administered separately to each participant via interview. Patients and proxies were given a notebook containing hard copies of each questionnaire to facilitate understanding. If one or both members of the dyad did not meet minimum criteria, the dyad was thanked for their time and dismissed from the study ($n = 2$). The reason for exclusion was explained to the dyad and possible referrals for follow-up assessment and support were provided. Patients and proxies were compensated for their time and effort with a \$20.00 Wal-Mart gift certificate per person (i.e., \$40 per dyad).

Data Analysis

To compare patients and proxies, the data set was restructured so that each dyad represented a case ($N = 64$). Characteristics of the Caucasian and African American patients and proxies usually were compared using chi-square tests. Due to small samples in some cells, the Mann–Whitney test was used to compare patient and proxy subjective health and income data. Overall desire for treatment by race/ethnicity was compared using t tests. Patient–proxy agreement was calculated by obtaining a difference score for corresponding items (e.g., proxy rating – patient rating) as well as a total score on the patient’s LSPQ and the proxy’s LSPQ (referred to as “raw difference scores”). The sign of the difference score indicated overtreatment relative to the patient’s wishes if the answer was

positive and undertreatment relative to the patient’s wishes if the answer was negative. Although the direction of error is important, the different signs could potentially cancel each other out (e.g., calculating means). Thus, absolute values of these difference scores were also obtained to examine the magnitude of error in proxy predictions. Mixed analyses of variance (ANOVAs) consisting of a 5 (illness) \times 3 (treatment) \times 2 (race/ethnicity) design were conducted to examine differences in raw difference scores and absolute values of the difference scores, with illness and treatment analyzed as within-subjects factors and race analyzed as a between-subjects factor.

For mediation and moderation analyses, preferences for life-sustaining treatment were summed across scenarios to yield a total desire for treatment score, as in prior research (Ditto et al., 2001). The general linear model was used to predict raw difference scores (combining across illness and treatment) from race, the main effects of the proposed moderators, and the interaction between each moderator and race/ethnicity. Separate statistical analyses were conducted on raw difference scores and the absolute values of difference scores.

Results

Characteristics of the Sample

As shown in Table 1, patients ranged in age from 59 to 92 years, in education from 6 to 22 years, and in education-adjusted MMSE score from 22 to 30. Proxies ranged in age from 21 to 84 years, in education from 5 to 24 years, and in education-adjusted MMSE score from 24 to 30. A chi-square analysis indicated no significant differences between African Americans and Caucasians in regard to family status of the proxy, $\chi^2(4, N = 64) = 2.393, p = .664$. Seventy percent of African American and 74% of Caucasian proxies were adult children; 20% of African American and 24% of Caucasian proxies, spouses; and 10% of African American and 3% of Caucasian proxies, other family members.

As shown in Table 1, patient and proxy income differed significantly between race/ethnicity (Mann–Whitney $U = 341, p = .018$, and Mann–Whitney $U = 281, p = .002$, respectively). One Caucasian proxy declined to provide income information. Caucasian patients and proxies reported higher income than African American patients and proxies. Caucasians scored slightly higher than

Table 2. Illness Experience and Advance Care Planning (N =128 consisting of 64 dyads, with 34 Caucasian dyads and 30 African American dyads)

	Patients (n = 64), n (%)		Proxies (n = 64), n (%)	
	African American (n = 30)	Caucasian (n = 34)	African American (n = 30)	Caucasian (n = 34)
Description of personal health				
Excellent	1 (3)	8 (23)	3 (10)	12 (35)
Good	15 (50)	19 (56)	18 (60)	20 (59)
Fair	12 (40)	5 (15)	8 (27)	2 (6)
Poor	2 (7)	2 (6)	1 (3)	0 (0)
Personal experience with a life-threatening illness				
Yes	24 (80)	27 (79)	21 (70)	29 (85)
No	6 (20)	7 (21)	9 (30)	5 (15)
Possession of a living will				
Yes	7 (23)	18 (53)	6 (20)	14 (41)
No	23 (77)	16 (47)	24 (80)	20 (59)
Possession of a durable power of attorney for health care				
Yes	6 (20)	16 (47)	5 (17)	13 (38)
No	24 (80)	18 (53)	25 (83)	21 (62)
Talked with family about wishes for end-of-life medical care				
Yes	19 (63)	26 (76)	10 (33)	25 (73)
No	11 (37)	8 (24)	20 (67)	9 (27)

African Americans on the adjusted MMSE; however, this difference was not clinically significant.

Illness Experience and Advance Care Planning.—As shown in Table 2, African Americans reported worse health than Caucasians (patients: Mann–Whitney $U = 334, p = .009$; proxies: Mann–Whitney $U = 308, p = .002$). Most patients and proxies reported having some experience with life-threatening illness either as a patient or caring for an ill loved one. There were no racial/ethnic differences in levels of experience with life-threatening illness for patients or proxies. A minority of participants possessed a living will (35%) or durable power of attorney for health care (31%). Compared with Caucasian patients, significantly fewer African American patients reported having a living will, $\chi^2(1, N = 64) = 5.869, p = .015$, or durable power of attorney for health care, $\chi^2(1, N = 64) = 5.173, p = .023$. Among proxies, however, no significant differences were found by race/ethnicity.

Most patients and proxies (62.5%) reported that they had talked with at least one other family member about their end-of-life medical wishes (see Table 2). For patients, there were no significant

differences between African Americans and Caucasians in their reports of talking to family members about end-of-life wishes, $\chi^2(1, N = 64) = 1.318, p = .251$. However, among proxies, a greater number of Caucasians than African Americans reported engaging in such discussions with one or more family members, $\chi^2(1, N = 64) = 11.628, p = .009$.

Measure of Understanding.—To ensure that patients and proxies understood the questions on the LSPQ, they were asked to define each of the illnesses (AD, emphysema, coma, and cancer) and each of the treatments (CPR, artificial feeding and fluids, and palliative care) in their own words. Thirteen (10%; 6 African American, 7 Caucasian) participants included definition by example as an adjunct to at least one of their answers (e.g., the participant informed the interviewer that he or she was a caregiver for a relative living with AD). For each item missed, the corresponding items in that participant's LSPQ were removed from the analysis. Two Caucasian patients, three African American patients, and one African American proxy missed one definition each. Three missed the definition of emphysema and three missed a definition of one of

Table 3. Raw Differences on Life-Support Preferences/Predictions Questionnaire by Illness, Treatment, and Race

Illness/treatment	Caucasian, <i>M</i> (<i>SD</i>)	African American, <i>M</i> (<i>SD</i>)	Total sample, <i>M</i> (<i>SD</i>)
Alzheimer's disease			
CPR	0.71 (2.02)	-0.38 (1.93)	0.21 (2.04)
ANH	0.61 (1.73)	-0.50 (1.94)	0.08 (1.90)
Palliative care	0.94 (1.77)	-0.14 (1.77)	0.44 (1.84)
Emphysema			
CPR	1.18 (2.08)	0.18 (1.49)	0.72 (1.89)
ANH	0.84 (2.06)	0.21 (2.01)	0.54 (2.04)
Palliative care	0.94 (2.00)	0.21 (1.87)	0.61 (1.96)
Coma			
CPR	0.21 (.84)	-0.03 (1.57)	0.10 (1.23)
ANH	0.33 (1.61)	-0.30 (1.68)	0.03 (1.67)
Palliative care	0.03 (1.42)	-0.31 (1.56)	-0.13 (1.49)
Cancer (no pain)			
CPR	0.59 (1.91)	-0.21 (2.19)	0.22 (2.07)
ANH	0.48 (2.06)	0.07 (2.07)	0.29 (2.06)
Palliative care	0.38 (1.84)	0.07 (1.83)	0.24 (1.83)
Cancer with pain			
CPR	0.32 (1.93)	-0.66 (1.81)	-0.13 (1.93)
ANH	0.36 (2.00)	-0.30 (1.90)	0.05 (1.96)
Palliative care	0.15 (1.05)	-0.52 (1.66)	-0.16 (1.39)

Note: CPR = cardiopulmonary resuscitation; ANH = artificial feeding and fluids.

the treatment options (palliative care, CPR, and artificial feeding and fluids, respectively).

LSPQ Means by Family Status and Race/Ethnicity.—Overall desire for treatment among patients was significantly higher for African Americans, $t(57) = -4.539, p < .001$. Overall desire for treatment for patients as reported by proxies was also higher among African Americans compared with Caucasians, $t(52.488) = -2.176, p = .034$.

Outcome Variable: Patient-Proxy Agreement/Raw and Absolute Difference Scores

We conducted a 5 (illness) \times 3 (treatment) \times 2 (race) mixed ANOVA predicting the raw difference scores between patient and proxy, with illness and treatment analyzed as within-subjects factors and race analyzed as a between-subjects factor. The mean raw difference scores within this design are presented in Table 3. Within-subjects tests were analyzed using Wilk's lambda, a commonly used multivariate test that, unlike repeated measures analysis, does not make the assumption of sphericity. Post hoc analyses were only carried out on significant effects making the use of Fisher's least significant difference (LSD) measure appropriate. The only significant result was a main effect of race, $F(1, 57) = 5.304, p = .03$. Specifically, Caucasian

proxies indicated a tendency to overtreat in comparison with patients' wishes ($M = 0.54$), whereas African American proxies tended to undertreat ($M = -0.17$) their older family members. As hypothesized, this mean reflects better accuracy in predicting patients' end-of-life treatment preferences on the part of African Americans (perfect prediction would be represented by $M = 0$) when overtreatment and undertreatment errors are combined.

We next used the same 5 (illness) \times 3 (treatment) \times 2 (race) design to predict the absolute value of the differences between patient and proxy. The mean absolute values of the difference scores within this design are presented in Table 4. We observed a significant main effect of illness, Wilk's lambda = .703, $F(4, 54) = 5.714, p = .001$. LSD post hoc analyses indicate that the absolute value differences were significantly smaller for coma ($M = 0.957$) than for AD ($M = 1.46$), emphysema ($M = 1.53$), cancer without pain ($M = 1.48$), and cancer with pain ($M = 1.12$). None of the other mean comparisons was significant. We also observed a significant interaction between race and illness, Wilk's lambda = .838, $F(4, 54) = 2.61, p = .05$. LSD post hoc analyses showed that, for emphysema, African Americans had smaller absolute value differences than Caucasians ($M_s = 1.25$ and 1.81 , respectively) but that there were no significant racial differences for the other illnesses.

Table 4. Absolute Differences on Life-Support Preferences/Predictions Questionnaire by Illness, Treatment, and Race

Illness/treatment	Caucasian, <i>M (SD)</i>	African American, <i>M (SD)</i>	Total sample, <i>M (SD)</i>
Alzheimer's disease			
CPR	1.53 (1.48)	1.34 (1.42)	1.44 (1.45)
ANH	1.27 (1.40)	1.50 (1.31)	1.38 (1.30)
Palliative care	1.41 (1.42)	1.38 (1.08)	1.40 (1.26)
Emphysema			
CPR	1.91 (1.42)	0.96 (1.14)	1.48 (1.37)
ANH	1.72 (1.40)	1.52 (1.30)	1.62 (1.34)
Palliative care	1.79 (1.27)	1.36 (1.28)	1.59 (1.28)
Coma			
CPR	0.50 (.71)	1.00 (1.20)	0.73 (.99)
ANH	1.06 (1.25)	1.23 (1.17)	1.14 (1.20)
Palliative care	0.85 (1.13)	1.14 (1.09)	0.98 (1.11)
Cancer (no pain)			
CPR	1.53 (1.26)	1.59 (1.50)	1.56 (1.36)
ANH	1.58 (1.39)	1.47 (1.43)	1.52 (1.40)
Palliative care	1.44 (1.19)	1.31 (1.26)	1.38 (1.21)
Cancer with pain			
CPR	1.26 (1.48)	1.34 (1.37)	1.30 (1.42)
ANH	1.27 (1.57)	1.37 (1.33)	1.32 (1.45)
Palliative care	0.62 (.85)	1.28 (1.16)	0.92 (1.05)

Note: CPR = cardiopulmonary resuscitation; ANH = artificial feeding and fluids.

Mediators and Moderators of Race Effects

We investigated whether religiousness/spirituality, decision-making style, trust in the health care system, and prior advance care planning could possibly explain the observed relation between race/ethnicity and the patient-proxy difference scores. Using the guidelines proposed by Baron and Kenny (1986), we first investigated whether these variables had significant relations with patient-proxy difference scores. None of the relations with the difference scores was significant, so we concluded that none of these variables could be used as mediators to explain the effects of race.

Next, moderation analyses were conducted to explore the possible influences of religiousness/spirituality, decision-making style, trust in the health care system, and prior advance care planning on the relation between race/ethnicity and patient-proxy treatment preference agreement. The general linear model was used to predict raw difference scores (combining across illness and treatment) from race, the main effects of the proposed moderators, and the interaction between each moderator and race/ethnicity. The only significant interaction effect was found between race/ethnicity and advance care planning, $F(1, 47) = 4.15, p = .047$, accounting for 8% of patient-proxy agreement. Specifically, when advance care plan-

ning is high, African Americans and Caucasians display relatively high patient-proxy agreement on end-of-life decisions. When advance care planning is low, African American proxies tend to make more undertreatment errors and Caucasian proxies tend to make more overtreatment errors (Figure 1).

We conducted additional analyses to determine if the effect of race on the overall absolute value difference scores (again combining across illness and treatment) was moderated by religiousness/spirituality, decision-making style, trust in the health care

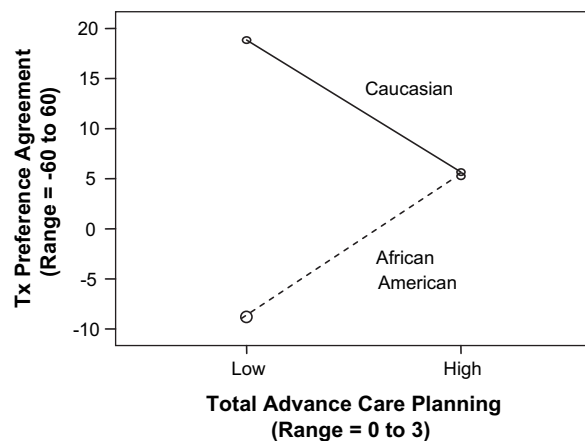


Figure 1. Overall difference score between patients and proxies for end-of-life treatment preferences as a function of the interaction of race/ethnicity and advance care planning.

system, or prior advance care planning. There were no significant effects in this model (all $ps > .14$).

Discussion

This study is one of the first to find that community-dwelling African American patient-proxy dyads displayed slightly better treatment preference agreement (measured by summed raw difference scores; Ditto et al., 2001) than Caucasian dyads regarding patients' hypothetical end-of-life treatment preferences. We also examined absolute value difference scores, which provided a measure of the total degree of error (e.g., overtreatment errors cannot compensate for undertreatment errors), and found no racial/ethnic differences using this measure.

Moreover, we examined potential mediators and moderators of the relation between race/ethnicity and dyadic treatment preference agreement: religiousness/spirituality, family decision-making style, trust in the medical profession, and prior advance care planning.

None of the hypothesized variables was found to mediate the relation between race/ethnicity and patient-proxy treatment preference agreement for end-of-life care. Family decision-making style and trust in the medical profession were unrelated to both race/ethnicity and treatment preference agreement. In contrast, religiousness/spirituality and advance care planning did not independently predict treatment preference agreement, although both were related to agreement on the bivariate level. It could be that the measures chosen to represent the constructs of interest were not sensitive enough to capture the complex relations between them and the end-of-life treatment preference agreement.

Only prior advance care planning was found to moderate the relation between race/ethnicity and treatment preference agreement. Low levels of advance care planning were associated with lower patient-proxy agreement in which African American proxies tended to make undertreatment errors and Caucasian proxies tended to make overtreatment errors. Identifying underlying issues influencing the direction of error of dyads with low levels of advance care planning may lead to the development of targeted interventions to improve patient-proxy agreement. One common issue that arose during debriefing in this study was the request of the dyad to see each other's responses; people wanted feedback on their accuracy and expressed concern about understanding each others'

end-of-life wishes. Although recent interventions to improve patient-proxy agreement between chronically ill patients and their proxies have shown promise (e.g., PC-ACP; Briggs et al., 2004; Song et al., 2005), they do not include the diversity in their samples that is needed in this area of research. Thus, it is unknown whether this intervention would be successful with other racial/ethnic groups.

Recent research is beginning to explore more nuanced differences in treatment preference and advance care planning among individuals from different racial/ethnic groups, but this research has yet to be extended to patient-proxy treatment preference agreement. For example, Allen and colleagues (2009) found that although Caucasians were more likely to seek health information in response to greater perceived threat, they were also more likely than African Americans to respond with maladaptive coping strategies, such as avoidance, fatalism, or wishful thinking. Allen and colleagues (2008) found that providing enhanced medical information reduced decisional conflict among Caucasian and African American older adults but influenced treatment preferences differently. Future research should incorporate mixed method approaches to explore more fully psychosocial issues found to be significant in individual treatment preference and advance care planning as they relate to patient-proxy decision making and treatment preference agreement.

Study Limitations

We acknowledge several limitations of this study. The relatively small sample size and geographic specificity of the sample reduced heterogeneity in some constructs of interest (e.g., religiousness/spirituality) and may limit generalizability of the findings. Second, our choice of quantitative measures to measure the constructs of religiousness/spirituality, family decision-making style, and trust in the medical profession may not have been sensitive enough to detect the subtle and complex relations of these constructs with medical decision making within a diverse sample. For example, the measure we used to assess family decision-making style focused on cohesiveness versus independence in decision making. A more sophisticated approach to examining race/ethnicity and family decision-making style might consist of a series of measures that tap into the structure of the family (e.g., number of first-order relatives, amount

of telephone and personal contact, whether patients and proxies share a home, observations about family members' interaction/social behavior during the interview) and the emotional functioning within the family (e.g., interaction styles, emotional connectedness, interdependence). The complexity inherent in the relations of religiousness/spirituality, decision-making style, and trust in the medical profession with individual treatment preference and dyadic treatment preference agreement lends itself to qualitative methods of inquiry.

Implications and Future Directions

In spite of these limitations, the finding that prior advance care planning moderates treatment preference agreement among Caucasian and African American "patient"–proxy dyads has implications for the development of future interventions to improve agreement. A thorough understanding of the needs and concerns of different groups (e.g., race/ethnicity, sex, age) in the end-of-life decision-making process will inform specific interventions and culturally sensitive approaches in practice, research, and policy (Duffy, Jackson, Schim, Ronis, & Fowler, 2006; Kwak & Haley, 2005). For those groups that already have relatively high agreement, suitable interventions may focus on education about the purpose of advance directives and the importance of having treatment wishes communicated in writing. By contrast, for those that have low patient–proxy agreement, an intervention strategy to improve communication and understanding of diverse cultural definitions for the meaning of quality of life may be in order.

Finally, the principle of substituted judgment, which is the basis of laws in the United States regarding advance directives, carries many assumptions, which may not apply to some patients depending on their backgrounds, beliefs, and values (Chan, 2004; Hawkins et al., 2005; Winzelberg et al., 2005). Substituted judgment emphasizes autonomy; however, for some patients, the needs of the family may be more important than one's own preferences. One avenue of study in need of attention is documenting the degree to which proxy accuracy is important to patients. This variable could potentially vary greatly depending on whether the patient is from a culture that emphasizes individualism (focus on personal welfare), familism (focus on welfare of immediate/extended family), and/or collectivism (focus on welfare of the larger community; Gaines et al., 1997).

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