Racial and Ethnic Differences in Advance Care Planning Among Patients With Cancer: Impact of Terminal Illness Acknowledgment, Religiousness, and Treatment Preferences

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ABSTRACT

Purpose

Despite well-documented racial and ethnic differences in advance care planning (ACP), we know little about why these differences exist. This study tested proposed mediators of racial/ethnic differences in ACP.

Patients and Methods

We studied 312 non-Hispanic white, 83 non-Hispanic black, and 73 Hispanic patients with advanced cancer in the Coping with Cancer study, a federally funded multisite prospective cohort study designed to examine racial/ethnic disparities in ACP and end-of-life care. We assessed the impact of terminal illness acknowledgment, religiousness, and treatment preferences on racial/ethnic differences in ACP.

Results

Compared with white patients, black and Hispanic patients were less likely to have an ACP (white patients, 80%; black patients, 47%; Hispanic patients, 47%) and more likely to want life-prolonging care even if he or she had only a few days left to live (white patients, 14%; black patients, 45%; Hispanic patients, 34%) and to consider religion very important (white patients, 44%; black patients, 88%; Hispanic patients, 73%; all $P < .001$, comparison of black or Hispanic patients with white patients). Hispanic patients were less likely and black patients marginally less likely to acknowledge their terminally ill status (white patients, 39% v Hispanic patients, 11%; $P < .001$; white v black patients, 27%; $P = .05$). Racial/ethnic differences in ACP persisted after adjustment for clinical and demographic factors, terminal illness acknowledgment, religiousness, and treatment preferences (has ACP, black v white patients, adjusted relative risk, 0.64 [95% CI, 0.49 to 0.83]; Hispanic v white patients, 0.65 [95% CI, 0.47 to 0.89]).

Conclusion

Although black and Hispanic patients are less likely to consider themselves terminally ill and more likely to want intensive treatment, these factors did not explain observed disparities in ACP.

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INTRODUCTION

Culturally sensitive end-of-life (EOL) care is a national priority. The National Quality Forum and National Consensus Project for Quality Palliative Care both identify provision of culturally sensitive care as one of eight core domains of high-quality palliative care.^{1,2} Yet little information exists on the ways in which different sociocultural beliefs, expectations, and behaviors influence EOL care, and the absence of such information limits a clinician's ability to provide culturally sensitive care. In this context, an Institute of Medicine report called for more research to examine underlying

causes of variation in attitudes and practices toward EOL care across racial and ethnic groups.³

Advance care planning (ACP) is the process by which patients, in conjunction with their physicians and loved ones, establish goals and preferences for future care and codify these preferences in written documents such as a living will, durable power of attorney for health care decision making (health care proxy), or Do-Not-Resuscitate (DNR) order.^{4,5} Despite well-documented racial and ethnic differences in ACP,⁶⁻¹³ we know little about why these differences exist. Previous research suggest that differences in acknowledgment of terminal illness, religiousness, and treatment preferences are important in ACP, but none

of these studies has evaluated the influence of these factors on racial/ethnic differences in ACP.¹⁴⁻²⁰ Formal evaluation of these proposed mediators is important because finding a significant mediator could provide a starting point for a targeted intervention to reduce racial/ethnic differences in ACP, whereas finding a lack of mediation would encourage researchers to search for other potential mediating factors.

The Coping with Cancer study is a National Cancer Institute–funded, multisite, longitudinal investigation that was designed to fill these gaps in research on racial/ethnic disparities in EOL care. The present report uses data from the Coping with Cancer study to examine the impact of terminal illness acknowledgment, religiousness, and treatment preferences on racial/ethnic variation in ACP.

PATIENTS AND METHODS

Sample

Patients were recruited from February 8, 2002, through December 20, 2006, as part of the Coping with Cancer study, a multi-institutional study of patients with advanced cancer and their primary caregivers. Participating sites include the Dana-Farber Cancer Institute/Harvard Cancer Center (Boston, MA), Yale Cancer Center (New Haven, CT), Veterans' Affairs Connecticut Healthcare System Comprehensive Cancer Clinics (West Haven, CT), Memorial Sloan-Kettering Cancer Center (New York, NY), Simmons Comprehensive Cancer Care Center (Dallas, TX), Parkland Hospital Palliative Care Service (Dallas, TX), and New Hampshire Oncology and Hematology (South-Central NH).

Inclusion criteria were diagnosis of advanced cancer (clinician's estimate that the patient would live < 6 months and failure of first-line chemotherapy); age ≥ 20 years; having an unpaid caregiver; and adequate stamina to complete the interview. Patient-caregiver dyads in which either met criteria for dementia or delirium (by neurobehavioral cognitive status examination²¹) or could not speak English or Spanish were excluded. Potentially eligible patients were identified by clinicians. Interviews were conducted between February 2002 and December 2006 at a location chosen by the patient. All study participants provided written informed consent according to protocols approved by each institutional review board.

Of 928 eligible patients, 654 enrolled. Reasons for nonparticipation were "not interested" (n = 120), "caregiver refuses" (n = 36), "too upset" (n = 27), and other reasons (n = 91). Of participants, 593 self-identified as white, black, or Hispanic. Hispanic patients were more likely to participate than white or black patients (83% v 67% v 64%, respectively; overall $P = .007$). Nonparticipants were similar to participants in age, sex, and high school graduation status. On a 5-point rating of current distress (1 = "minimal, nonexistent," 5 = "distraught"), nonparticipants reported higher ratings of distress than participants (3.8 v 2.5, respectively; $P \leq .001$). Our analyses included the 449 white, black, and Hispanic patients with complete data on ACP, terminal illness acknowledgment, religion, and treatment preferences.

Measures

After informed consent was obtained, patients participated in a baseline interview (\$25 compensation). Interviews were conducted by trained research staff in either English (91%) or Spanish (9%). Patient's race/ethnicity was self-reported as non-Hispanic white, non-Hispanic black, and Hispanic (hereafter referred to as white, black, and Hispanic for brevity). Our primary outcome variable was the presence of an ACP, defined as patient's report of one or more of the following: living will or durable power of attorney for health care decision making (health care proxy), completed DNR order, or having discussed wishes for EOL care with their physician. Measures assessing the potential mediators of terminal illness acknowledgment, religiousness, and treatment preferences were drawn from other studies.^{22,23} Terminal illness acknowledgment was assessed using the question, "How would you describe your current health status?" Participants selecting the response "seriously and terminally ill" were compared with those selecting "relatively healthy" or "seriously but

not terminally ill." Importance of religion (religiousness) was assessed using the question, "How important is religion to you?" Potential responses were "very important," "somewhat important," and "not important." Treatment preferences for EOL care were assessed with the question, "Would you want the doctors here to do everything to keep you alive even if you were going to die in a few days anyway?" We considered those who responded "yes" as preferring life-prolonging care. Because terminal illness acknowledgment and preferences for life-prolonging treatment may be influenced by their understanding of their prognosis, we explored participants' preference for prognostic disclosure using the question, "If your doctor knew how long you had left to live, would you want him or her to tell you?"

Other patient-reported characteristics included age (continuous), sex, marital status (married v not married), education (less than high school diploma v high school diploma or higher), insurance status, and native language. Type of cancer and Zubrod performance score were obtained from chart review (range, 0 [asymptomatic] to 4 [100% bedridden]). Participating sites were grouped by region (Southwestern and Northeastern) rather than by individual sites because not all sites had sufficiently large sample sizes to permit comparisons by site.

Statistical Analysis

Baseline demographic factors, ACP, terminal illness acknowledgment, religiousness, and treatment preferences were compared by race/ethnicity (white race as reference group) using student's t test for age and Fisher's exact test for all other variables. We used the method of Barron and Kenny to assess for mediation.²⁴ In this method, after determining that the factor of interest (race/ethnicity) is associated with the outcome (ACP) and the potential mediator (terminal illness acknowledgment, religiousness, or treatment preferences), the potential mediator is then regressed on the outcome. If the potential mediator is significantly associated with the outcome, then a final model is fit to examine the association between race/ethnicity and the outcome after adjusting for the potentially mediating factor. Mediation holds if we find that no racial/ethnic differences in ACP after adjusting for the potential mediator. By comparing the estimated effect of race/ethnicity in models with and without the mediating factor, we examined the relative contribution of each mediating factor to racial/ethnic differences in ACP. All models adjusted for age, sex, education, health insurance status, geographic region, cancer diagnosis, and Zubrod performance score. These variables were selected for inclusion because they were shown to be clinically relevant to EOL care in other studies.^{18,25-29}

Because many of these outcomes were common (> 10%), and in such cases the odds ratio may deviate substantially from the relative risk, we derived relative risks using a modified Poisson approach as recommended by Spiegelman, McNut, and Zou.³⁰⁻³² We examined multiple outcomes and wanted to adjust the critical value. Recognizing that these outcomes are not strictly independent, we considered a two-sided P value of $\leq .01$ to be statistically significant. All analyses were performed using SAS version 9.1 (SAS Institute, Cary, NC).

RESULTS

Sample Characteristics

Characteristics of the 449 participants are listed in Table 1. Black and Hispanic participants tended to be younger than white participants, were more likely to come from a Southwestern site, and were less likely to have a high school diploma or health insurance.

Table 2 lists bivariable associations of race/ethnicity with ACP and each potential mediator (terminal illness acknowledgment, religiousness, and treatment preferences). In unadjusted analysis, black and Hispanic patients were less likely than white patients to have an advance directive or durable power of attorney for health care or to have a DNR order. Overall, 29% of patients discussed plans for EOL

Racial/Ethnic Differences in Advance Care Planning

Table 1. Characteristics of Sample Patients (n = 449)*

Characteristic	White (n = 312)		Black (n = 75)		Hispanic (n = 62)		P, Black v White†	P, Hispanic v White†
	No.	%	No.	%	No.	%		
Age, years							.005	< .001
Mean	61		57		53			
SD	12		11		15			
Male sex	155	50	39	52	33	53	.79	.68
Married	198	65	23	31	35	59	< .001	.76
Education							< .001	< .001
Less than high school graduate	49	15	33	44	45	73		
High school graduate and beyond	266	85	42	56	17	27		
Has health insurance	252	81	29	39	10	16	< .001	< .001
English is native language	303	97	74	99	13	21	1.00	< .001
Geographic recruitment region							< .001	< .001
Southwestern	71	23	53	72	56	90		
Northeastern	236	77	21	28	6	10		
Diagnosis information							.36	.005
Lung cancer	78	25	26	35	6	10		
Colorectal cancer	40	12	12	16	6	10		
Breast cancer	25	8	6	8	7	11		
Pancreatic cancer	29	9	2	3	3	5		
Other cancers‡	140	45	29	39	40	65		
Zubrod performance score§							.80	.76
0 or 1	156	51	36	48	28	46		
2	98	32	27	36	21	34		
3 or 4	53	17	12	16	12	20		

Abbreviation: SD, standard deviation.

*Percentages may not add up to 100 as a result of rounding. All characteristics had < 5% missing.

†P values for age are from Student's *t* test; all other P values are from Fisher's exact test.

‡The remaining patients had cancer types representing < 5% of the total sample. Most common other cancers for Hispanics were stomach, gall bladder, and sarcoma.

§Zubrod performance score: 0, asymptomatic; 1, symptomatic, fully ambulatory; 2, symptomatic, in bed < 50% of day; 3, symptomatic, in bed 50% of day, not bedridden; 4, 100% bedridden.

care with their physician, which did not differ by race/ethnicity. Compared with white patients, both black and Hispanic patients were less likely to want to be told their prognosis by a physician (black patients, 58% v white patients, 77%, $P = .001$; Hispanic patients, 61% v white patients, $P = .01$).

Racial/ethnic differences in terminal illness acknowledgment and preference for life-prolonging treatment persisted after adjustment for age, sex, marital status, education, health insurance status, geographic region, type of cancer, and Zubrod performance score. Compared with white participants, black and Hispanic participants were less

Table 2. Unadjusted Racial/Ethnic Differences in Advance Care Planning, Terminal Illness Acknowledgment, Religiousness, and Treatment Preferences (n = 449)*

Factor	White (n = 312)		Black (n = 75)		Hispanic (n = 62)		P, Black v White†	P, Hispanic v White†
	No.	%	No.	%	No.	%		
Has advance care plan (any of the following)	249	80	35	47	29	47	< .001	< .001
Has a living will or durable power of attorney	232	74	17	23	13	21	< .001	< .001
Completed a DNR order	136	44	19	25	12	20	.004	< .001
Discussed wishes for end-of-life care with physician	94	31	19	25	19	31	.40	1.00
Acknowledges terminal illness	122	39	20	27	7	11	.05	< .001
Religion								
Very important	138	44	66	88	45	73		
Somewhat important	109	35	8	11	12	19	< .001	< .001
Not important	65	21	1	1	5	8		
Wants life-prolonging care even if only a few days to live	43	14	34	45	21	34	< .001	< .001

Abbreviation: DNR, do not resuscitate.

*Percentages may not add to 100 as a result of rounding. All factors had < 5% missing.

†P values from Fisher's exact test.

likely to acknowledge they were terminally ill (adjusted relative risk [aRR], black ν white patients, 0.56 [95% CI, 0.36 to 0.86]; Hispanic ν white patients, 0.24 [95% CI, 0.10 to 0.54]) and more likely to prefer life-prolonging care, although differences between white and Hispanic patients were not significant (aRR, black ν white patients, 3.24 [95% CI, 2.05 to 5.12]; Hispanic ν white patients, 1.95 [95% CI, 0.95 to 4.03]). Differences in religiousness persisted after adjustment for black patients compared with white patients, but differences for Hispanic patients compared with white patients were no longer statistically significant (aRR, religion considered “very important” ν other responses, black ν white patients, 1.65 [95% CI, 1.35 to 2.01]; Hispanic ν white patients, 1.12 [95% CI, 0.82 to 1.52]).

We examined the relationship between ACP and each mediator. After adjustment, participants who acknowledge their terminal illness status were 26% more likely to have an ACP as those who did not (aRR, 1.26; 95% CI, 1.12 to 1.41). No difference in ACP was observed between participants reporting that religion was very important and those reporting that religion was somewhat important to them (aRR, 1.04; 95% CI, 0.90 to 1.21), but those who reported religion was not important were 23% more likely than

those reporting religion was very important to have an ACP (aRR, 1.23; 95% CI, 1.04 to 1.44). Participants who preferred life-prolonging treatment even if they only had a few days to live were 23% less likely to have an ACP than those who did not prefer life-prolonging treatment (aRR, 0.77; 95% CI, 0.62 to 0.92).

Table 3 lists unadjusted and adjusted associations of race/ethnicity, confounders, and potential mediators with ACP. Table 4 lists adjusted associations of race/ethnicity with ACP in models with and without each potential mediator. In the base model, adjusted for known confounders, black patients were 41% and Hispanic patients 40% less likely than white patients to have an ACP (aRR, black ν white patients, 0.59 [95% CI, 0.46 to 0.77]; Hispanic ν white patients, 0.60 [95% CI, 0.45 to 0.82]). Further adjustment for terminal illness acknowledgment had a modest impact on the aRR (black ν white patients, 0.61 [95% CI, 0.47 to 0.79]; Hispanic ν white patients, 0.63 [95% CI, 0.47 to 0.86]). Similar reductions in aRR were observed for the other two mediators examined (religiousness and treatment preferences). None of the mediators examined met criteria for mediation. Examining a model with all three potential mediators included simultaneously

Table 3. Bivariable and Multivariable Models of Advance Care Planning (n = 426)*

Variable	Has Advance Care Plan			
	Unadjusted		Adjusted†	
	RR	95% CI	RR	95% CI
Age, years (increasing)	1.01‡	1.00 to 1.01	1.00	1.00 to 1.01
Male sex	0.94	0.83 to 1.06	0.99	0.87 to 1.12
Race/ethnicity				
White	1.00		1.00	
Black	0.57‡	0.44 to 0.74	0.64‡	0.49 to 0.83
Hispanic	0.56‡	0.42 to 0.75	0.65‡	0.47 to 0.89
Married	0.96	0.85 to 1.09	0.86	0.76 to 0.97
Education more than high school graduate	1.37‡	1.15 to 1.64	1.11	0.94 to 1.31
Has health insurance	1.34‡	1.15 to 1.56	1.18	0.97 to 1.43
Southwestern recruitment region	0.81‡	0.70 to 0.93	1.13	0.94 to 1.35
Diagnosis				
Lung cancer	1.00		1.00	
Colorectal cancer	1.18	0.95 to 1.46	1.21	1.00 to 1.48
Breast cancer	1.17	0.91 to 1.49	1.22	0.96 to 1.55
Pancreatic cancer	1.12	0.85 to 1.48	1.08	0.85 to 1.38
Other cancers	1.14	0.96 to 1.35	1.20	1.02 to 1.41
Zubrod performance score 2, 3, and 4 (reference, 0 and 1)§	0.89	0.79 to 1.01	0.91	0.81 to 1.04
Terminal illness acknowledgment				
Does not acknowledge terminal illness	1.00		1.00	
Acknowledges terminal illness	1.28‡	1.14 to 1.44	1.18‡	1.05 to 1.32
Religiousness				
Religion is very important	1.00		1.00	
Religion is somewhat important	1.10	0.95 to 1.27	0.96	0.83 to 1.11
Religion is not important	1.31‡	1.14 to 1.51	1.15	0.99 to 1.33
Treatment preferences				
Does not want life-prolonging care	1.00		1.00	
Wants life-prolonging care	0.71‡	0.58 to 0.87	0.85	0.70 to 1.03

Abbreviation: RR, relative risk.

*Fifteen observations were not included in these analyses because of missing data on one or more covariates (16 white patients, three black patients, and four Hispanic patients).

†Adjusted for all factors in the model.

‡ $P \leq .01$.

§Zubrod performance score: 0, asymptomatic; 1, symptomatic, fully ambulatory; 2, symptomatic, in bed < 50% of day; 3, symptomatic, in bed 50% of day, not bedridden; 4, 100% bedridden.

Table 4. Multivariable Models of Racial/Ethnic Differences in Advance Care Planning Adjusted for Individual Potential Mediators (n = 426)*

Model	Has Advanced-Care Plan			
	Black v White		Hispanic v White	
	aRR	95% CI	aRR	95% CI
Base model†	0.58	0.45 to 0.75	0.59	0.43 to 0.81
Mediational models				
Base model + terminal illness acknowledgment	0.60	0.46 to 0.78	0.62	0.45 to 0.85
Base model + religiousness	0.60	0.46 to 0.78	0.59	0.43 to 0.81
Base model + treatment preferences	0.62	0.48 to 0.81	0.61	0.44 to 0.83

Abbreviation: aRR, adjusted relative risk.

*Fifteen observations were not included in these analyses because of missing data on one or more covariates (16 white patients, three black patients, and four Hispanic patients).

†All models adjusted for age, sex, marital status, education, health insurance status, geographic region, diagnosis, and Zubrod performance score.

similarly demonstrated modest impact on racial and ethnic differences in ACP (Table 3).

DISCUSSION

Although we found important racial and ethnic differences in terminal illness acknowledgment, religiousness, and treatment preferences among patients with advanced cancer, none of these factors accounted for observed racial and ethnic differences in ACP. We found that black patients were nearly half and Hispanic patients nearly one quarter as likely as white patients to acknowledge their illness was terminal, black patients were nearly 70% more likely to consider religion very important, and black patients were three and Hispanic patients two times more likely than white patients to prefer life-prolonging care. Compared with white patients, black and Hispanic patients were 40% less likely to have an ACP. Yet this study was negative: these differences in ACP were not impacted by proposed mediators.

Previous research suggests that patients who acknowledge their terminal prognosis experience less aggressive EOL care than those who do not.³³ We found that black and Hispanic patients were significantly less likely to acknowledge their terminal illness status or to want a physician to disclose their prognosis as compared with white patients. Yet terminal illness acknowledgment had no appreciable impact on racial/ethnic differences in ACP. Evidently, although racial/ethnic disparities in terminal illness acknowledgment and ACP exist, the lower rates of ACP by the minority patient groups cannot be explained by differences in understanding of life expectancy. Taken together, these findings suggest that efforts to improve ACP by informing patients of their terminal prognosis may not be sensitive to racial/ethnic differences in preferences for prognostic disclosure and acknowledgment.

Religious views within the African American community of the value or sanctity of life have been suggested as explanatory factors for differences in attitudes toward EOL care.^{20,34,35} Nevertheless, we did not find support for religiousness as a mediator of racial/ethnic differences in ACP. Several possible explanations exist. Our measure of religiousness was based on a single question and may not have captured differences in particular religious beliefs and values between black, Hispanic, and white participants, such as a belief in miracles, that God's power supersedes that of physicians, or that suffering is to be endured as part of a spiritual commitment.^{20,35-37} This measure also had only three possible

response categories ranging from not at all important to very important and may have lacked sufficient variation or power to detect a difference. Therefore, future studies are warranted to confirm our findings with regard to religiousness.

A greater preference for life-sustaining treatment among African American and Hispanic patients compared with white patients has been described previously,^{7,8,28,38-41} although to our knowledge, this is the first study to describe differences between Hispanic and white patients with advanced cancer. We were surprised to find that treatment preferences had no appreciable impact on the observed racial and ethnic differences in ACP. These findings suggest that although important racial/ethnic differences in treatment preferences exist, they are unlikely to be major explanatory factors in racial/ethnic differences in ACP.

Several limitations should be considered when interpreting these results. Most importantly, the number of black and Hispanic patients enrolled was low (83 black and 73 Hispanic participants), and the overwhelming majority of black and Hispanic patients were recruited from Texas. The extent to which these findings generalize to other areas of the country is unclear and requires further exploration in future studies. Furthermore, as mentioned previously, our measure of religiousness was limited and may not reflect the multidimensional nature of this construct. However, use of other measures such as church attendance is also problematic, because church attendance may decrease in states of ill health.

Our overarching goal in conducting this research was to develop more culturally sensitive approaches to ACP. After establishing that racial/ethnic differences exist, searching for potential mediators is the next step in advancing the field. In light of our negative findings, future research is needed to evaluate the impact of other factors on racial/ethnic differences in ACP and EOL care. Recent scholarship has uncovered a number of other promising and potentially explanatory factors. First, several recent studies highlighted the importance of health literacy in establishing preferences for care and ACP. Volandes et al⁴² demonstrated that use of video images of advanced dementia improved older patients' choices for dementia care, and in a randomized controlled trial, Sudore et al⁴³ demonstrated the effectiveness and usefulness of an advance directive redesigned for a fifth-grade reading level. Second, mistrust is often discussed as a potential mediator of disparities.^{44,45} Interpersonal trust in the patient-physician relationship does not seem to mediate racial differences in ACP⁴⁶; however, the impact of distrust in the health care system on racial/ethnic

differences in ACP has not been examined. Third, of great concern, implicit or unconscious racial bias has been shown to influence physician treatment of patients in hypothetical scenarios.⁴⁷ However, the degree to which implicit bias influences physician attitudes and communication around ACP and EOL care is unknown.

In conclusion, we found that although black and Hispanic patients were less likely to consider themselves terminally ill and were more likely to want intensive and potentially futile treatment, these factors did not mediate the observed disparities in ACP, suggesting the need to identify other factors to promote patient-centered, culturally appropriate EOL care among black and Hispanic patients with cancer.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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