POPULATIONS AT RISK

Differences in the Quality of the Patient–Physician Relationship Among Terminally Ill African-American and White Patients: Impact on Advance Care Planning and Treatment Preferences

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BACKGROUND: Little is known about the quality of the patient–physician relationship for terminally ill African Americans.

OBJECTIVE: To compare the quality of the patient–physician relationship between African-American and white patients and examine the extent to which relationship quality contributes to differences in advance care planning (ACP) and preferences for intensive life-sustaining treatment (LST).

DESIGN: Cross sectional survey of 803 terminally ill African-American and white patients.

MEASUREMENTS: Patient-reported quality of the patient–physician relationship (degree of trust, perceived respect, and joint decision making; skill in breaking bad news and listening; help in navigating the medical system), ACP, preferences for LST (cardiopulmonary resuscitation, major surgery, mechanical ventilation, and dialysis).

RESULTS: The quality of the patient–physician relationship was worse for African Americans than for white patients by all measures except trust. African Americans were less likely to have an ACP (adjusted relative risk [aRR]=0.66, 95%CI=0.52–0.84), and were more likely to have a preference for cardiopulmonary resuscitation and dialysis (aRR=1.28, 95%CI=1.03–1.58; aRR=1.25, 95%CI=1.07–1.47, respectively). Additional adjustment for the quality of the patient–physician relationship had no impact on the differences in ACP and treatment preferences.

CONCLUSIONS: Lower reported patient–physician relationship quality for African-American patients does not explain the observed differences between African Americans and whites in ACP and preferences for LST.

KEY WORDS: end-of-life care; race/ethnicity; trust; patient–physician relationship.
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INTRODUCTION

In recent years, multiple studies have reported a greater preference among African Americans than whites for life-sustaining treatment (LST) in the event of life-threatening illness.[1–5] Other studies have consistently found that African-American and other minority patients are less likely to have started the advance care planning (ACP) process by discussing preferences for future care with their physician and family, or codified their preferences with a document such as a living will or health care proxy.[1,6–8]

Communication and relational skills are an essential component of high quality care for terminally ill patients.[9] Of great concern, recent studies have found that, compared with white patients, African Americans report lower quality interactions with their physicians.[10–12] The impact of the quality of patient–provider relationships on patients' treatment preferences and ACP is unknown and may be magnified in the setting of terminal illness.[13]

Indicators of high quality patient–physician relationships include trust in the physician, feeling respected by the physician, and involving patients in decision making; physician skill at breaking bad news and listening; and helping patients to navigate the medical system. Finding that poor patient–physician relationships, a potentially modifiable factor, adversely affects end-of-life care would provide a compelling reason for a greater focus on improving physicians' relationships with patients. To our knowledge, no large, quantitative study has examined the impact of the relationship quality on the differences between terminally ill African-American and white patients in ACP or preferences for intensive LST.

Therefore, we examined the quality of patient–physician relationships as reported by terminally ill African-American and white patients. We then measured the extent to which quality contributes to the differences between African Americans and whites in ACP and treatment preferences.

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METHODS

Study Design and Subjects

We analyzed data from the Commonwealth–Cummings Project, a nationwide survey investigating the preferences of terminally ill patients, which has been described in detail elsewhere.[14] Patients were recruited through local physicians in 6 sites. Eligible patients were at least 18 years old, English-speaking, had a major chronic illness other than AIDS, and had a survival estimated by the primary physician to be 6 months or less. In-person interviews were completed between March 1996 and July 1997. Three hundred eighty-three physicians referred 1,472 patients, and 988 completed the initial interview. Our study sample consisted of the 803 of these 988 patients that self-identified as African American or white.

The Commonwealth–Cummings project research protocol was approved by the Institutional Review Boards of Harvard Medical School, Dana Farber Cancer Institute, and each local health care institution at which participating physicians practiced.

Measures

Our main factor of interest was the patient's self-identified ethnicity. Other covariates included patient-reported characteristics (age, gender, religion, income, education, health insurance type, and primary disease classification). Potential mediators were measures of the patient–physician relationship, including questions on trust in the physician, feeling respected by the physician, physician skill at breaking bad news, listening, allowing patient participation in care decisions, and help in navigating the health care system (factor loadings are reported in Table 2).[15] Responses to these questions ranged on a 4-point scale from "strongly agree" to "strongly disagree." Because of a low proportion of disagree responses, "strongly disagree" and "somewhat disagree" responses were combined and compared to "strongly agree" and "somewhat agree".

Our first primary outcome variable was the presence of an ACP, defined as the patient's report on one or more of the following: a living will, a health care proxy, or having talked with family or physician about plans for end-of-life care. Our second primary outcome variable focused on preferences for intensive LST. Patients were asked the single question: "If your current illness progressed so that it or a new problem is life threatening, and you are confused, then your goals and specific wishes—if medically reasonable—would be…" Patients were asked to indicate their wishes regarding 11 interventions. As was done previously,[16] we considered four of these (cardiopulmonary resuscitation [CPR], major surgery, mechanical ventilation, and dialysis) to be intensive. Potential responses included "I want", "I am undecided", and "I do not want". For the purposes of modeling, intervention choices were reclassified as "accepts treatment" ("I want" and "I am undecided") or "rejects treatment" ("I do not want treatment") to reflect clinical practice because physicians generally provide LST, at least initially, to those who have not decided.[16]

Statistical Analysis

We used bivariable analyses to compare the characteristics of African-American and white patients, presence of an ACP, and preference for LST. Next, we used sequential analyses to examine each outcome for African-American patients compared to white patients, first in unadjusted models, then in multivariable models adjusted for the potential confounders age, gender, education, terminal disease, and geographic recruitment site. These factors were selected for inclusion because they were shown to be related to ACP or treatment preferences in other studies.[1,17] We then added each measure of the patient–physician relationship to the model first individually and then combined to examine the extent to which these measures explained differences in outcomes. All analyses were conducted on models with a complete set of covariates. Because the outcomes were relatively common, we derived relative risks and 95% confidence intervals using a modified Poisson approach.[18,19] Data were analyzed with SAS version 9.1 (Cary, North Carolina).

RESULTS

The characteristics of our study population are shown in Table 1.

Table 1. Characteristics of Terminally Ill African-American and White Patients (*n*=803)

Characteristic	% African American (*n*=115)	% White (*n*=688)	*P* value
Age (y)			
≤50	18.3	13.2	0.009*
51–65	33.9	28.3	
66–80	42.6	46.1	
>80	5.2	12.4	
Gender			
Female	66.1	50.6	0.002†
Religion			
Christian	90.4	86.9	0.11†
Jewish	0.9	5.4	
Other	8.8	7.7	
Income			
<$15,000	62.9	31.2	<0.001*
$15,000–$24,999	16.5	23.6	
$25,000–$50,000	18.6	28.0	
>$50,000	2.1	17.3	
Education			
<8th grade	31.3	9.4	<0.001*
Some high school	23.5	16.7	
High school graduate	27.0	27.9	
Some college	13.9	25.2	
College graduate and higher	4.4	20.6	
Health insurance			
Medicare+secondary	31.3	31.0	<0.001†
Medicare alone	28.3	21.1	
Medicaid	9.1	4.9	
Other insurance	22.2	41.7	
No health insurance	9.1	1.4	
Primary disease			
Cancer	47.8	53.8	<0.001†
Heart disease	13.9	18.0	
COPD	5.2	12.5	
Renal disease	13.0	1.2	
Other	20.0	14.5	

Data are presented as percentages. Percentages may not add up to 100 as a result of rounding. Number of missing observations for variables with greater than 5% missing data—income (n=109).

*Chi-square test for trend.

†Pearson's chi-square test.

Table 2. Terminally Ill African-American and White Patients Report of the Quality of the Patient–Physician Relationship, Advance Care Planning and Preferences

All terminally ill patients, initial interview (n=803)	African American (n=115)	White (n=688)	P value
Quality of patient–physician relationship measures*			
Patient has complete trust in the physician (61)†			
Strongly agree	77.9	84.4	0.31
Somewhat agree	18.6	10.8	
Disagree	3.5	4.8	
Physician respects the patient as an individual (81)†			
Strongly agree	77.2	91.1	<0.001
Somewhat agree	19.3	7.7	
Disagree	3.5	1.2	
Physician tells bad news in a sensitive and caring manner (49)†			
Strongly agree	61.0	75.9	0.002
Somewhat agree	28.0	18.2	
Disagree	11.0	6.0	
Physician listens to what the patient has to say about illness (62) †			
Strongly agree	73.2	85.4	0.008
Somewhat agree	25.0	12.4	
Disagree	1.9	2.1	
Patient participates in decisions about care (66)†			
Strongly agree	74.1	85.8	0.01
Somewhat agree	25.0	12.2	
Disagree	0.9	1.9	
Physician helps the patient with the medical system (77)†			
Strongly agree	73.2	88.5	<0.001
Somewhat agree	24.1	10.0	
Disagree	2.7	1.5	
Has an advance care plan (any of 4 below)	47.0	79.5	<0.001
Has living will	14.9	54.9	<0.001
Has health care proxy	22.1	51.3	<0.001
Talked with family about plans for care near the end-of-life	40.2	64.9	<0.001
Talked with physician about plans for care near the end-of-life	21.1	25.9	0.29
Preferences for intensive life-sustaining treatment			
CPR			
Wants	42.1	26.5	0.001
Undecided	19.6	17.1	
Does not want	38.3	56.4	
Major surgery			
Wants	60.8	50.0	0.10
Undecided	13.1	19.4	
Does not want	26.2	30.6	
Mechanical ventilation			
Wants	33.6	17.1	<0.001
Undecided	15.0	15.7	
Does not want	51.4	67.2	
Dialysis			
Wants	66.7	32.2	<0.001
Undecided	16.2	24.0	
Does not want	17.1	43.8	

Data are presented as percentages. P values for the quality of patient–physician relationship measures are from the chi-square test for trend, all other P values are from Pearson's chi-square test. Number of missing observations for variables with greater than 5% missing data—physician tells bad news in a sensitive and caring manner (n=53); goal of "prolong life however possible" (n=51).

CPR: cardiopulmonary resuscitation.

*For the quality of the patient–physician relationship measures, the responses "strongly disagree" and "disagree" were collapsed into "disagree".

†Factor loading as reported by Emanuel et al.[15]

Terminally ill African-American patients gave lower ratings of the quality of the relationship with their physicians than whites (Table 2). All differences were statistically significant except trust.

After adjustment, compared to whites, African Americans were less likely to have an ACP (adjusted relative risk [aRR]= 0.66, 95%CI=0.52–0.84) and more likely to prefer CPR (aRR= 1.28, 95%CI=1.03–1.59) or dialysis (aRR=1.25, 95%CI=1.07–1.46), but no more likely to prefer major surgery (aRR=0.96, 95%CI=0.83–1.11) or mechanical ventilation (aRR=1.26, 95% CI=0.96–1.66). However, we found no change in the relative risk of these outcomes after adding all measures of the patient–physician relationship to the models. Examining individual patient–physician relationship factors similarly demonstrated little impact on the differences in ACP and preferences for LST.

DISCUSSION

In this large multisite study of terminally ill patients, we found that African-American patients reported significantly lower quality patient–physician relationships than white patients. We additionally found that, after adjustment, African Americans were nearly half as likely to have an ACP and were more likely to accept CPR or dialysis. Adding measures of the patient–physician relationship to the model had no impact on the differences in ACP and treatment preferences. Thus, patient-reported quality of the patient–physician relationship does not explain the differences in ACP and preferences for intensive LST between terminally ill African Americans and whites.

Our analysis confirms previously reported differences in preferences for end-of-life care between African Americans and whites. Our search for an explanation for these differences was motivated by the concern that, by accepting LST and eschewing ACP more often, African-American patients may more often endure the burdens of LST of questionable benefit, whereas missing the benefits of palliative and hospice care.[20] However, other intermediary factors that may explain the differences in ACP and treatment preferences were not measured. For example, lower ratings of the patient–physician relationship by African Americans may be a sign of a deeper lack of trust in a health care system to which African Americans have less access than whites despite poorer overall health and that, therefore, can reasonably be perceived as unjust and untrustworthy.[21–24] Holloway has described African Americans' "particular vulnerability to an early death",[25] and Crawley et al. has described the "ethic of struggle" against death within African-American culture in part as a healthy response to a legacy of unjust and unequal treatment within both the health care system and society as a whole.[26] Cykert et al. found African Americans assigned greater than threefold higher utility values to states of debility than whites.[27]

Whereas the determinants of ethnic differences in ACP and treatment preferences remain unknown, finding differences in relationship quality is itself a compelling reason to focus on improving physicians' relationship with African-American patients. Improving physician training in cultural sensitivity, communication, and relational skills such as building trust and communicating respect for patients will improve perceived health care quality regardless of patient preferences.

Our study has several limitations. First, data were collected in 1996–1997, and in the intervening years, differences between African Americans and whites may have changed. Second, physicians may have referred patients for the study with whom they had a strong relationship. Third, our measures of the quality of the patient–physician relationship were skewed toward the "agree" responses with <5% of the responses in the disagree categories for most measures. Fourth, other researchers have found that ethnic concordance/nonconcordance between patients and physicians influences trust and communication.[10,28] Unfortunately, we could not study this factor because of a high proportion of missing and uncharacterizable responses to the question on the ethnicity of the provider. Fifth, our measure of trust, a multidimensional construct,[29] was limited to a single question. Finally, the single question in our survey on ethnic category lacked precision; for example, it did not differentiate between Hispanic and non-Hispanic whites.

In conclusion, we found that the quality of the patient–physician relationship does not impact on the differences between terminally ill African Americans and whites in ACP and preferences for intensive LST. Unmeasured factors likely mediate these differences. We encourage future researchers to continue the search for these mediating factors for which "ethnic" and "racial" differences are a proxy.

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Conflict of Interest: *None disclosed.*

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