ORIGINAL ARTICLES

Differences in End-of-Life Decision Making Among Black and White Ambulatory Cancer Patients

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OBJECTIVE: **African-American (black) and white individuals have been shown to differ in their desire for life-sustaining treatments and their use of living wills for end-of-life care, but the reasons for these differences are unclear. This study was designed to test the hypothesis that these ethnic differences exist because black patients trust the health care system less, fear inadequate medical treatment more, and feel less confident that living wills can give them more control over their terminal care.**

DESIGN: **Cross-sectional, in-person survey conducted from November 1993 to June 1994.**

SETTING: **Two medical oncology clinics with 40% to 50% black patient representation.**

PARTICIPANTS: **Ambulatory cancer patients, 92 black and 114 white, who were awaiting their physician visits and agreed to participate (76% of those eligible). Patients were excluded if they were under age 40 or if they had nonmelanoma skin cancer only.**

MEASUREMENTS AND MAIN RESULTS: **Black ambulatory cancer patients wanted more life-sustaining treatments (odds ratio [OR] 2.8; 95% confidence interval [CI] 1.4–5.3), and were less likely to want to complete a living will at some time in the future (OR 0.36; 95% CI 0.17–0.75) than were white patients after controlling for socioeconomic variables. However, these differences were not related to lack of trust or fear of inadequate medical treatment in this study population. Both groups of patients trusted the health care system and felt that physicians treated patients equally well. Neither group feared inadequate or excessive medical care, and the majority of both groups agreed that living wills would help them keep control over their terminal care.**

CONCLUSIONS: **Black and white cancer patients make different end-of-life choices, even after adjusting for likely explanatory variables. The other factors that influence decision making remain unclear and need to be further explored if physicians are to understand and help their patients make choices for end-of-life care.**

KEY WORDS: **living wills; life-sustaining treatments; ethnic differences.**
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Living wills and other advance care documents were developed to increase patient autonomy and decrease unwanted life-sustaining treatments at the end of life. Although there is tremendous interest in advance care documents among the general public and a federal law has been enacted to promote their use, less than a quarter of Americans polled have actually completed such a directive.[1] There are few predictors of who will complete a living will, but one such predictor appears to be race.

Ethnic differences in desire for living wills and life-sustaining treatments have been noted repeatedly in the medical literature, but the reasons for these differences remain largely unknown.[2–7] Studies have consistently shown that African-American (black) participants want more life-sustaining treatments, have discussed life-sustaining treatments less often with physicians, and have or want to have fewer living wills than their white counterparts. For example, Haas found that HIV-positive patients were less likely to discuss life-sustaining treatments if they were black (26% vs 42%) even after controlling for education, income, severity of illness, age, and physician's gender.[4] Garrett also found that black Medicare recipients had fewer living wills and wanted more life-sustaining treatments (42% vs 15%) than their white counterparts after controlling for likely explanatory variables.[3]

Several possibilities have been suggested to explain these ethnic differences, yet none has been systematically studied. Perhaps we have inadequately measured or not yet identified important confounding variables that may explain these differences. Perhaps black and white patients truly have different perspectives on end-of-life issues.

We developed several hypotheses based on the clini-

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cal experience of several black and white physicians, literature on trust and alienation,[8–11] and medical literature on racial disparities in medical treatments.[12–18] We believed that a cultural history including discrimination, experimentation, unequal medical care, and poor access to medical care might make black patients feel that the health care system does not work in their best interest. They may be reluctant to forgo medical treatments when given the choice, and they may feel unsure about signing a document that allows a physician to withhold medical treatments. We also hypothesized that some black patients may feel more comfortable not having a living will so that they or their families control important end-of-life treatment decisions rather than physicians.

The purpose of this study was first to describe whether black and/or white differences in desire for life-sustaining treatments and living wills were present in a group of ambulatory cancer patients after controlling for likely confounding variables such as education, income, insurance status, knowledge of living wills and life-sustaining treatments, stage of cancer, and strength of religious beliefs. Second, we hypothesized that ethnic differences, if found, might be explained in part because more black patients (1) trust the health care system less, (2) fear inadequate medical care more, and (3) feel less confident that a living will would give them more control over their terminal health care.

We chose ambulatory cancer patients as the study population because they have ready access to ongoing care and a diagnosis that suggests the possibility of death. Therefore, they may have heard about, thought about, and made informed choices about their end-of-life medical care.

METHODS

Study Population

From November 1993 to June 1994, we enrolled consenting ambulatory cancer patients from one university-based medical oncology clinic and one private medical oncology clinic in North Carolina. To be enrolled, patients had to be over age 40 and be under treatment by a medical oncologist. Patients were excluded if they had nonmelanoma skin cancer only, and if they had not seen an oncologist at least once previously for their current cancer diagnosis. This provision allowed at least some time for thought and discussion of end-of-life issues.

Study Subjects and Recruitment

In-person interviews were conducted in private by trained interviewers while patients awaited their oncology clinic appointments. The interviewers reviewed the list of scheduled appointments each day to identify patients eligible for the 35-minute survey consisting of 90 closed-ended and several open-ended questions. We suspected that patients might be more likely to give same-race interviewers more frank information about sensitive issues[19]; to explore this issue further, our two black and two white interviewers surveyed both black and white patients to allow for a comparison of responses.

Data Sources

After signing an informed consent form, enrolled patients were asked whether they had a living will at the time of the interview, whether they intended to complete a living will if one had not already been completed, and whether they desired more or less life-sustaining treatments in the event of terminal illness. A scale, similar to that used by Garrett,[3] was developed to measure patients' preferences for life-sustaining treatments. The same question was asked about each of four life-sustaining treatments: ventilator support, cardiopulmonary resuscitation (CPR), feeding tubes, and intensive care unit (ICU) monitoring. For example, the ICU question read, "If you were so sick that you were dying and would never improve, would you definitely, possibly, or never want to be in the ICU?" To create the life-sustaining treatment (LST) preference scale, responses for all four LST questions were quantified so that a response of "never" received a 0, "possibly" received a 1, and "definitely" received a 2. Each patient's responses were summed for the four questions resulting in a possible range of scores from 0 to 8. The scale had excellent reliability with a Cronbach's α of 0.83.

Patients were also asked questions exploring their beliefs about (1) the trustworthiness of the medical system, (2) the possibility of receiving inadequate or excessive medical care, and (3) whether having a living will would increase their sense of being in control of their medical care when terminally ill. These questions were developed from social psychology literature on scales of interpersonal trust and alienation,[20] and from the medical literature addressing ethnic differences in medical treatments.[12–18] All questions were asked as statements, and patients were asked how much they agreed or disagreed with each statement using a 4-point Likert scale from *strongly agree* to *strongly disagree*. For example, sample questions addressing trust read, "Generally speaking, doctors can be trusted" and "You trust your doctor to do what's best for you," among others. A question about receiving inadequate medical care read, "You are sometimes afraid that you will get *less* medical care than you want," and a question about control over terminal care read, "Signing a living will would help you keep control over what happens to you at the end of your life."

The ethnicity of the participants was established by asking patients to identify the ethnic group they belonged to, not by visual assessment. Other selected items asked on the questionnaire included age, gender, marital status, income, education level, health insurance coverage, type of cancer, stage of disease, cancer treatments, perceived health status, and questions addressing choices for life-prolonging versus comfort care if terminally ill, communication about LSTs, knowledge of living wills, and beliefs about living wills increasing hopelessness or decreasing the quality of medical care to be received. From four survey questions asking about religious beliefs, we created a variable assessing strength of religious beliefs based on a similar scale developed and validated by Sherrill and Larson.[21] All survey questions were reviewed by a medical sociologist, a health behaviorist, and a physician-ethicist for content validity, and the questionnaire was pretested for comprehension on a broad group of patients (the study questionnaire is available on request).

Charts of all study patients were reviewed by one of the authors (EDM) to corroborate cancer diagnosis, previous cancer treatments, and stage of disease. All solid tumors were categorized as either advanced stage (metastatic) or not (all other stages). Hematologic cancers were combined and considered a separate stage.

Statistical Analysis

To examine black/white differences in desire for life-sustaining treatments, we dichotomized the LST preference scale at the median to create two categories (desire for more or less treatments). Linear regression models using the LST preference scale as a continuous variable were not significantly different from the logistic models using the dichotomized variable; therefore, we present only the logistic models for the LST preference scale. Our second outcome was a dichotomous variable assessing intent to complete a living will in the future (yes, no). Bivariate analyses of the relations between these two outcomes and patient race were assessed using Pearson's χ^2 test. Variables potentially confounding these relationships were identified using stratified analyses, and included income, education, insurance status, gender, age, type and severity of cancer, interviewer race, knowledge of living wills, and strength of religious beliefs.

After looking at these bivariate comparisons, we fit two logistic regression models using desire for more or less LSTs as the outcome for the first model and intent or lack of intent to complete a living will as the outcome for the second. The initial models included race and all of the potential confounding variables. Starting with all variables in the models, we removed variables that were not statistically significant ($p > .10$) and that did not affect the relation between race and the outcome measures. Odds ratios [ORs] and 95% confidence intervals [CIs] for race of patients desiring more life-sustaining treatments and intending to complete living wills were calculated using the β estimates for race in the final logistic regression models.

In addition to these outcomes, we assessed the relationships between race and the questions relating to trust in the medical system, fear of inadequate medical care, and whether living wills increase patients' sense of being in control of their terminal health care. We then included these new variables in the logistic models above to see if they explained any of the remaining ethnic differences in desire for LSTs and intention to complete living wills.

We used qualitative analysis to examine open-ended questions. The texts for all open-ended questions were transcribed and read independently by an investigator and a research assistant trained in qualitative analysis. Texts were coded and reviewed, and major themes were identified and reported.

RESULTS

Patient Characteristics

Of the 270 subjects approached for the study, 206 (76%) agreed to participate. The 64 subjects who refused to participate were similar to study subjects in age, type of cancer, and stage of disease. A slightly greater proportion of these subjects were black, but the difference was not statistically significant. The study sample was composed of 92 black patients and 114 white patients, and the majority of study subjects were women (Table 1). Black cancer patients were significantly more likely to make less than $25,000 per year, to have less than a high school education, to have nonprivate or no health insurance, and to have no living will. The most common diagnosis was breast cancer in both blacks and whites, and although there was a trend toward more advanced stages in black patients, this trend was not statistically significant. Other types of cancer and cancer treatments were

Table 1. Patient Characteristics*

Characteristic	Black, % (n = 92)	White, % (n = 114)
Female	68	59
Income < $25,000/yr†	74	39
High school graduate†	53	86
Private health insurance†	54	88
Diagnosis		
Breast cancer	42	36
Colon cancer	22	11
Hematologic cancer	21	32
Other cancers	15	21
Stage		
Metastatic	47	38
Not metastatic	34	36
Hematologic	19	26
Previous cancer treatment		
Chemotherapy	73	81
Surgery	67	71
Radiation	43	42
Perceived good/excellent health	58	60
MD-patient relationship > 2 yr	70	70
Have a living will†	3	34

*Mean age (±SD): black, 59(±11.9) white; 60(±10.4).
†p < .05.

Table 2. Desire for Individual Life-Sustaining Treatments When Terminally Ill

Life Sustaining Treatment*	Black, % (n = 92)	White, % (n = 114)
ICU monitoring	27	6
CPR	37	16
Nasogastric feeding	13	6
Ventilator support	15	5

*$p \le .05$.

distributed equally among black and white patients. Two thirds of all study subjects considered themselves in good or excellent health, and over 70% had a long-standing relationship with a primary care physician or an oncologist.

Preferences for End-of-Life Care

When patients were asked whether they would want each of four LSTs, black patients were significantly more likely to want each LST than were white patients (Table 2). When questions regarding the four LSTs were combined into the LST preference scale, 47% of whites wanted no LSTs at all compared with 27% of black patients.

In bivariate comparisons, black race, stronger religious beliefs, and lower income were strongly associated with preference for LSTs. White race, more education, higher income and younger age were associated with the intent to complete a living will (Table 3).

Table 3. Patient Characteristics by Desire for More Life-Sustaining Treatments and Intent to Complete a Living Will

	Desire for More Life-Sustaining Treatments		Intent to Complete a Living Will	
Characteristics	n (%)	p	n (%)	p
Race				
White	47 (41)	.000	39 (53)	.000
Black	61 (67)		21 (24)	
Education				
<High School	35 (60)	.155	11 (21)	.003
≥High school	72 (49)		49 (45)	
Income				
<$25,000/yr	59 (58)	.029	24 (28)	.001
≥$25,000/yr	36 (42)		33 (56)	
Religion				
Low importance	2 (14)	.002	2 (40)	.075
Medium importance	15 (42)		17 (55)	
High importance	91 (59)		41 (33)	
Gender				
Male	35 (46)	.159	21 (36)	.703
Female	72 (56)		39 (39)	
Age				
<59 yr	48 (49)	.340	38 (46)	.025
≥59 yr	59 (56)		22 (29)	
Stage				
Metastatic	48 (55)		24 (32)	
Nonmetastatic	37 (50)	.805	21 (39)	.418
Hematologic	23 (52)		15 (45)	

Logistic regression modeling used to estimate the ORs of black and white patients (1) selecting more or less LSTs, and (2) intending or not intending to complete a living will showed that even after controlling for income, strength of religious beliefs, and age, black and white patients differed significantly. Black patients were more likely to desire more LSTs than whites (OR 2.8; 95% CI 1.4–5.3). Conversely, blacks were less likely than whites to plan on completing a living will at some time in the future (OR 0.36; 95% CI 0.17–0.75).

Trust, Fear of Inadequate Medical Care, and Control over Future Medical Care

Black and white patients answered all of our questions addressing trust in the health care system identically. For example, 96% of both groups felt the medical system was trustworthy, 94% felt doctors can be trusted, and 96% felt doctors generally treat all patients equally well. In addition, less than 20% of either group feared inadequate medical care. Although whites were more likely to believe that living wills would help them keep control over their terminal health care, this difference was not statistically significant. The great majority of black patients agreed that living wills would help them keep control over their terminal care (Table 4).

In addition, a small number of mostly black patients did feel that a living will would increase their feeling of hopelessness and would decrease the quality of medical care that they would receive at the end of their lives (Table 4). No one in this group had a living will and over two thirds of both these black and white patients wanted more LSTs.

Reasons for Having or Not Having a Living Will: Qualitative Assessment

Patients were read a short statement explaining living wills, and they were then asked whether or not they had a living will. Next, patients were asked why they did or did

Table 4. Beliefs about Trust, Fear of Inadequate Medical Care, and Control over Future Medical Care by Race

	Black, % (n = 91)	White, % (n = 113)
Trust the health care system	96	96
Fear inadequate medical care	16	19
Feel living wills help maintain control over future care	84	92
Living wills increase hopelessness	18	9
Living wills decrease quality of medical care	14	4

not have a living will at the time of the interview. Four major themes emerged from patients' answers about why they did not have a living will ($n = 169$). These included: "I haven't gotten around to it yet" (38% black, 57% white); "I object to them" (11% black, 6% white); "I don't know about them" (29% black, 7% white); and "I don't need one" (22% black, 30% white).

The themes that emerged from the 37 patients who had living wills at the time of the interview were less clear, but included wanting to have a dignified death, to relieve family of financial and emotional burdens, to make sure things are taken care of, and to have final control over decisions about terminal care. Only three black patients had living wills; therefore, we could not compare black and white responses.

Communication about Life-Sustaining Treatments

Of the white participants, 78% had discussed their preferences for LSTs with their families compared with 37% of the black participants. However, only 8% of blacks and 24% of whites had discussed their preferences for end-of-life care with their physicians. Interestingly, over 50% of both black and white patients felt confident or very confident that their physicians knew their wishes for LSTs.

DISCUSSION

Black ambulatory cancer patients preferred to receive more LSTs than did their white counterparts, even after controlling for likely explanatory variables. In addition, black study patients had fewer living wills before our interviews, and they were less likely to want to complete a living will in the future. Once again, this study supports previous data suggesting that black and white subjects differ in their desire for LSTs and in their use of living wills for end-of-life care.

Of great interest to us was the fact that our hypotheses could not explain these persistent ethnic differences. Although we asked a number of questions addressing the trustworthiness of the medical system, black and white patients answered all of these questions identically. Therefore, our questions addressing trust could explain none of the remaining differences in desire for LSTs and intent to complete a living will. Moreover, study patients uniformly denied any fear of inadequate or excessive medical care and most felt that a living will would assist them in maintaining control over their terminal health care, not take such control away.

Several limitations of this study and potential explanations for these results warrant further discussion. Our questionnaire was limited to a mostly quantitative design; although we incorporated several open-ended questions into the survey, patients only rarely had the opportunity to explore questions in detail. Because patients were interviewed in oncology clinics, they may have felt pressure to answer questions the way they thought their care providers would want them to. To minimize this possibility, the interviewers were trained in nondirective interview techniques, were careful to tell patients that the information gathered was strictly confidential, and conducted all interviews in a private room out of sight of the waiting rooms. Although we suspected that patients might be more likely to give same-race interviewers more frank information about sensitive issues, the patients' responses where shown to be unaffected by the race or gender of the interviewer in stratified analyses.

Although we quantified several complex concepts—trust in the health care system, fear of inadequate medical care, and control over terminal care—there was little variation in the responses to questions addressing these issues. This may indicate that the questions did not adequately address these concepts. Our questions about the trustworthiness of the medical system were developed from several scales of interpersonal trust from the social psychology literature,[9,22] but there is scant medical literature validly measuring any of these concepts.

This lack of variability in responses may also indicate that these concepts truly did not play a part in the disparities in preferences for living wills and LSTs in this unique patient sample. We chose to study ambulatory cancer patients because their diagnosis suggests the possibility of death and may stimulate thought and discussion about choices for end-of-life care by patients, families, and physicians. Yet cancer patients in an oncology clinic by definition have good access to medical care, and they may therefore have less reason to mistrust the system or fear inadequate care.[23,24] What we found, however, was that even among this group of patients with excellent access to care, for whom mistrust of the medical system and fear of inadequate care had been minimized, the black patients were still much less likely to use living wills to plan for their terminal care and were much more likely to want more LSTs when terminally ill than were their white counterparts. These results suggest that there may be as yet unmeasured factors responsible for these differences.

We had hoped that looking more closely at ethnicity would help us understand some of the factors that lead to disparities in desire for LSTs and use of living wills for terminal care planning; instead we have raised more questions than we have answered. We suspect that these differences persist due to some mix of the previously mentioned reasons—imperfect survey instruments, potentially biased study samples, and as yet unidentified confounding factors. But there has also been an ongoing discussion about whether there is a unique black perspective on biomedical ethics.[11,25] Clearly "black" is a broad and ill-defined descriptor, but a shared cultural history of discrimination and disadvantage might cause an otherwise heterogeneous group of people who identify themselves as black to share similar beliefs about medicine, ethical issues surrounding death, and medical choices at the end of life.

These are complex issues, but it is clear that ethnicity is a multidimensional concept that has attained a prominent place in medical literature,[26] and encompasses some combination of societal and cultural factors.[27] It is also clear that we do not fully understand how these factors interact to affect how our patients make medical decisions and how they communicate their wishes with and to family and physicians.

We found substantial gaps in knowledge and communication about future medical choices in our study patients. These gaps were persistently wider for black patients; indeed, almost 20% of black patients without living wills said they had never heard of them. There seems to be a need for improved patient education and communication about advance care planning and LSTs, but how much the importance of these issues and the dissemination of such knowledge is influenced by the cultural context in which our patients live is unknown.

We urge researchers to continue the work of refining the concept of ethnicity as it applies to health services research and health policy. Beginning to more clearly conceptualize the factors for which race is believed to be a proxy will help us to better understand our patients' diverse health beliefs and to create health policies that are ethical and acceptable to our multiethnic patients.

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