ATTITUDES TOWARD LIFE-SUSTAINING INTERVENTIONS AMONG AMBULATORY BLACK AND WHITE PATIENTS

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Objectives: The purpose of this study was to evaluate racial differences in preference for life-sustaining interventions in the context of various physical and mental health scenarios.

Design: Data were collected by using an investigator-administered survey.

Setting and Patients: Consecutive patients who self-identified as African American or Caucasian were recruited from two private primary care practices in Rochester, New York.

Main Outcome Measures: Patients were asked to decide whether they would accept or decline life-sustaining intervention in eight scenarios, each involving a different combination of mental and physical disability. Information on religiousness, family integration, and experience with creating a healthcare proxy was also collected, as these variables were believed to be potential confounders of the relationship between race and preference.

Results: Data from 77 patients (50 Black patients and 27 White patients) were analyzed. In multivariate log linear modeling, race was a significant predictor of preference for life-sustaining therapy, even after controlling for degree of mental and physical disability. Religiousness, family integration, and experience with creating a healthcare proxy did not explain racial differences in preference for life-sustaining therapy.

Conclusions: We have shown that ambulatory Black patients aged ≥50 years are more likely than White patients to prefer life-sustaining care, and that these preferences persist across a wide range of mental and physical disabilities. This attitude conflicts with the prevailing ethic regarding end-of-life care, and Black patients and their families may consequently find have difficulty obtaining medical care that is consistent with their cultural values and beliefs. Policy decisions regarding end-of-life care must reflect a culturally diverse perspective. (*Ethn Dis*. 2006;16:914–919)

Key Words: African Americans, Aged, Attitude to Death, Cross-Cultural Comparison, Decision Making, Life Support Care, Multivariate Analysis

INTRODUCTION

As technology continues to enhance our ability to extend life, terminal care issues have taken a prominent position in the American healthcare dialogue.[1,2] Another prominent discussion concerns disparities in approaches to care across ethnic and racial spectra.[3,4] Our clinical experience has been that significant differences exist between Black patients and White patients in their approach to end-of-life (EOL) care. In the hospital setting, we have observed a pattern of conflict between Black families' desires to continue life-sustaining care and the largely White caregiving staffs' desires to discontinue that care. In the outpatient care of Black patients, we have repeatedly seen a positive, family-oriented approach to life-sustaining care at home, even in the setting of severe dementia and terminal disease.

Several studies have confirmed these observations that Blacks have a more positive view of life-sustaining measures in EOL situations. Blackhall and colleagues[5] noted a more positive attitude toward cardiopulmonary resuscitation and mechanical ventilation in elderly (>65 years old) Black patients in Los Angeles, compared to White patients. Similar results were obtained by Hopp and Duffy[6] in a survey of elderly (>70 years old) patients in Michigan. In North Carolina, Black respondents showed a more positive attitude toward interventions in the setting of a terminal illness.[7] Differences in attitudes toward treatment have been demonstrated in ambulatory cancer patients[8,9] and also in the attitudes of Black physicians compared to White physicians.[10] Other studies have suggested that Black patients receive more life-sustaining care than White patients. A survey of nursing homes has shown that the use of feeding tubes is almost four times as frequent with Black patients as compared to White patients.[11] A Medicare analysis indicated that the cost of care in the last year of life was significantly higher for Black patients that for White patients, even though expenditures for care prior to the last year of life were significantly lower for Black patients.[12]

Our clinical experience has been that significant differences exist between Black patients and White patients in their approach to end-of-life (EOL) care.

Previous investigations generally have focused on elderly (>65 years) patients who are seriously ill, and these investigations have been limited to a small number of EOL scenarios. We could not find studies located in the northeastern United States. We have sought in our study to confirm the hypothesis that Blacks have a more positive attitude than Whites toward life-sustaining care and to analyze more closely its different parameters through extended interviews of ambulatory

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Black patients and White patients over the age of 50 in two family practice offices in Rochester, NY. In particular, we have sought to determine if the differences in attitude extended across eight hypothetical EOL settings, representing different levels of mental and physical status. The second purpose of this investigation was to investigate the roles of religiousness, family integration, and healthcare proxy experience in accounting for any observed racial differences in preferences for life-sustaining therapy.

Table 1. Definitions used in patient survey

Term	Definition
Brain Death	Irreversible loss of brain function.
Cardiopulmonary Resuscitation	Treatment to try to restart a person's breathing or heartbeat. CPR may be done by pushing on the chest, by inserting a tube down the throat or by other treatment.
Chemotherapy	The treatment of cancer using specific chemical agents or drugs that are selectively destructive to malignant cells and tissues.
Coma	A state of deep, often prolonged unconsciousness in which an individual is incapable of sensing or responding to external stimuli and internal needs.
Life-sustaining treatment	Any medical treatment that is used to keep a person from dying. A breathing machine, CPR, and artificial nutrition/hydration are examples of life-sustaining treatments.
Senile Dementia	A progressive deterioration of mental abilities in old age (common in Alzheimer's disease).
Terminal Condition	An ongoing condition caused by injury or illness that has no cure and from which doctors expect the person to die even with medical treatment.

METHODS

Procedures

Before beginning data collection, approval for this study was obtained from the University of Rochester Internal Review Board. Patients were recruited from two private primary care practices in Rochester, NY, one of which was located in the inner city and one of which was located in a neighboring suburb. Only Black patients were recruited from the inner-city practice, which serves a patient population that is 95% Black, and only White patients were recruited from the suburban practice, which serves a patient population that is 90% White. Patients were eligible for the study if they were ≥50 years of age and if they self-identified as either African American or Caucasian.

Between June 2002 and August 2002, a description of the study was presented to consecutive eligible patients at the time of a regularly scheduled office visit. The treating physician assessed patients' interest in the study and obtained consent to release interested patients' names to the study coordinator. The study coordinator subsequently contacted interested patients by phone to provide additional information about the study. For patients who chose to enroll in the study, the study coordinator set up an in-person meeting to obtain consent and administer the questionnaire. The questionnaire took ≈30–45 minutes to administer.

From the inner-city practice, 50 Black patients expressed interest in the study, and all 50 enrolled. From the suburban practice, 27 White patients expressed interest in the study, and again, all 27 patients enrolled. None of the patients withdrew from the study; therefore, our final sample was 77 people. Unfortunately, the participating practices could not track the number of patients who were given information about the study. Therefore, we cannot determine the response rate for this study.

Measures

Before the questionnaire was administered, participants were given specific, concise definitions for the terms that would be used during the interview (see Table 1). These written definitions remained available to the participant for the duration of the interview.

Social and Demographic Characteristics

Patients' race, age, sex, and education level were assessed by self-report. Patients were also asked to report, on seven-point Likert scales, their health status, their overall religiousness, and their closeness to their immediate family. Based on clinical experience, the investigators felt that these variables were likely to influence an individual's feelings about life-sustaining treatment. For example, patients who are more religious may be less likely to prefer interventions that interfere with the "normal course" of life and death. Patients who are closer to their family members may also be less likely to prefer life-sustaining interventions out of concern for the prolonged mourning of the family members.

Patients were also asked whether they currently had a living will, healthcare proxy, or do not resuscitate (DNR) order. The investigators also felt that this variable would be related to preferences for life-sustaining treatment, as the process of formally considering EOL options may influence feelings toward life-sustaining care.

Health Scenarios

In order to understand the complexity of the relationships between physical and mental health status and their relationship to preferences for life-sustaining treatments, the investigators developed two physical health scenarios and four mental health scenarios. The physical health scenarios represented: 1) a terminal illness, such as cancer; and 2) a chronic illness, such as a stroke. The mental health scenarios represented: 1) current (full) mental capabilities; 2) senile dementia; 3) coma; and 4) brain death. The physical and mental health scenarios were crossed, so that a total of eight health scenarios were presented to participants. Participants were asked to decide whether they would want life-sustaining therapies in each of the eight scenarios.

Analyses

Univariate statistics were generated for all variables in the dataset. For bivariate and multivariate analyses, conservative nonparametric tests were used because of the small sample size and non-normally distributed data. Fisher exact tests were used to test the bivariate relationships between race and preference for life-sustaining treatment for each health scenario. Fisher exact tests (for dichotomous variables) and Wilcoxon rank-sum tests (for continuous variables) were performed to test for differences in sociodemographic characteristics based on preferences for life-sustaining treatment in each scenario. Because of the exploratory nature of this study, no correction was made for multiple comparisons.

Multivariate log linear analysis was used to model the likelihood that a patient would prefer life-sustaining treatment based on: 1) physical state – terminal or chronic illness; 2) mental state – four levels, described previously; 3) race; and 4) covariates. Mental state was represented in the multivariate model by using indicator variables to eliminate the assumption of linearity. Because of the large number of available variables relative to the study sample size and the exploratory nature of this study, the decision was made to include in the multivariate model only those covariates that had a significant bivariate association with preference for life-sustaining treatment. All analyses were conducted by using SAS, version 8.02 (SAS Institute, Inc., Cary, NC).

Table 2. Characteristics of the sample*

	Black	White
	n (%)	*n* (%)
Sex		
Male	18 (36)	9 (33)
Female	32 (64)	18 (67)
Education†		
Less than high school	31 (63)	0 (0)
High school	9 (18)	13 (48)
Some college	7 (14)	4 (15)
College or graduate	2 (4)	10 (37)
Current healthcare proxy		
Yes	13 (26)	9 (33)
No	37 (74)	18 (67)
	Mean (SD)	Mean (SD)
Age‡	63.7 (9.0)	57.7 (5.6)
Health‡	4.2 (1.8)	5.3 (1.0)
Religiousness‡	6.0 (1.5)	4.9 (1.6)
Family closeness	6.5 (1.1)	6.7 (.4)

* Health, religiousness, and family closeness were rated on a 7-point Likert scale; higher numbers represent more of the attribute.
† $P<.05$
‡ $P<.01$
SD= standard deviation

RESULTS

Patient Characteristics

Data from 50 Black patients and 27 White patients were analyzed. Black patients and White patients did not differ in terms of sex, likelihood of having a proxy report, or closeness to family. However, White patients were significantly more likely to be younger, to have more education, to rate their health as better, and to rate themselves as less religious (Table 2).

Preferences for Life-Sustaining Therapy and Race

Bivariate analysis was performed to determine whether, for each of the eight scenarios, race was associated with preference for intervention. Results of the Fisher exact tests demonstrate that in most scenarios, Black patients are statistically significantly more likely than White patients to want life-sustaining therapy (Table 3). In general, the magnitude of the differences between the races was largest in scenarios involving terminal illness, while differences were less pronounced in scenarios involving chronic illness. In the setting of coma, statistical significance of the differences was not reached, though Blacks did trend toward wanting more intervention in this setting. Almost all patients, regardless of race, preferred life-sustaining therapy in the scenario involving a chronic illness and current mental state.

Sociodemographic Correlates of Preference for Life-Sustaining Treatment

None of the covariates were associated with preference for life-sustaining treatment in all eight scenarios. However, several covariates were associated with preference in some of the scenarios (Table 4). For example, in the scenario involving terminal illness and concomitant brain death, patients who wanted life-sustaining treatment were slightly older than those who did not (65.7 years vs 60.7 years, $P=.06$).

Table 3. Percentage of patients reporting that they would want life-sustaining therapy for each health scenario

	Current State	Senile Dementia	Coma	Brain Death
Terminal illness				
White	29.6	22.2	29.6	0.0
Black	72.0	73.5	53.2	26.1
P value	<.0001	<.0001	.06	.003
Chronic illness				
White	100.0	70.4	73.1	11.1
Black	98.0	94.0	90.0	51.0
P value	1.0	.01	.09	<.0001

Table 4. Summary of significant bivariate relationships between preference for life-sustaining treatment and covariates*

	Current State	Senile Dementia	Coma	Brain Death
Terminal illness				
Sex†	NS	NS	NS	NS
Education†	***P*=.06**	***P*=.06**	NS	***P*=.11**
Proxy/DNR†	NS	***P*=.04**	NS	NS
Age‡	NS	NS	NS	***P*=.06**
Health‡	NS	NS	NS	NS
Religiousness‡	***P*=.06**	***P*=.08**	NS	NS
Family closeness‡	NS	NS	NS	NS
Chronic illness				
Sex†	NS	NS	NS	NS
Education†	NS	NS	NS	***P*=.003**
Proxy/DNR†	NS	NS	***P*=.003**	***P*=.003**
Age‡	NS	NS	NS	NS
Health‡	NS	NS	NS	NS
Religiousness‡	NS	***P*=.02**	NS	NS
Family closeness‡	NS	NS	NS	NS

* *P* values≤.15 are shown; NS=not significant at α=.15.
† Fisher exact test.
‡ Wilcoxon rank sum test.

Some evidence of an association was also seen between education and preference for life-sustaining treatment. For example, in the setting involving a chronic illness and brain death, those with a high school diploma were again less likely to want life-sustaining treatment than those with less education (23% vs 58%, *P*=.003).

Having a proxy report or DNR order was associated with lower likelihood of wanting life-sustaining treatment in the scenarios involving terminal illness with dementia (*P*=.04), chronic illness with coma (*P*=.003), and chronic illness with brain death (*P*=.003). Religiousness was also moderately associated with preference for life-sustaining treatment in three of the eight scenarios. In the scenario involving terminal illness with either current mental state or dementia, those who wanted life-sustaining treatment rated themselves as slightly more religious (mean=5.9 for current mental state and 5.3 for dementia) than those who did not want intervention (mean=6.0 for current mental state and 5.2 for dementia; *P*=.06 and *P*=.08, respectively). No differences in preference for life-sustaining treatment were seen in bivariate analyses by sex, self-rated health, or family closeness.

Multivariate Analysis

The three factors that were most consistently associated with preference for life-sustaining treatment were education, previous completion of a proxy report or DNR order, and religiousness; these three covariates were thus selected for inclusion in the multivariate log linear model. The outcome modeled was the binary variable representing preference for life-sustaining therapy. As shown in Table 5, type of illness, mental state, race, and having a proxy report were all strongly associated with preference for life-sustaining treatment. Patients were more likely to want life-sustaining treatment for a chronic illness (as compared to a terminal illness) and in situations involving less mental incapacitation. Patients who already had a proxy report or DNR order were less likely to want life-sustaining treatment. Most important to our research question, findings from the multivariate analysis indicate that Black patients are more likely than White patients to want life-sustaining treatment even after controlling for physical and mental health variables.

DISCUSSION

Our study, looking at ambulatory Black and White patients over the age of 50, in Rochester, NY, has confirmed previous reports that Black patients anticipate choosing more life-sustaining measures than White patients in EOL situations. We were further able to demonstrate that Black patients' and White patients' preferences differed most significantly in the settings of dementia and brain death. While more than half of the Black patients wanted life-sustaining treatment in the scenario involving a chronic condition and brain death, only 11% of the White patients

Table 5. Multivariate log linear regression predicting likelihood that a patient will want life-sustaining intervention

Variable	Parameter Estimate	Standard Error	*P* value
Chronic illness	.34	.03	<.0001
Mental status			
Current	.50	.04	<.0001
Senile dementia	.44	.04	<.0001
Comatose	.38	.05	<.0001
Brain dead (referent)	–	–	–
White race	−.33	.06	<.0001
High school diploma	.08	.06	.16
Has proxy report	−.18	.06	.003
Religiousness	.00	.02	.97

While more than half of the Black patients wanted life-sustaining treatment in the scenario involving a chronic condition and brain death, only 11% of the White patients preferred intervention in this scenario.

preferred intervention in this scenario. Our regression analysis indicated that the positive attitudes toward life-sustaining measures among Black patients persisted after controlling for education, prior completion of a proxy report or DNR order, and religiousness. We did not obtain income data, and this may be a factor that would benefit from further analysis in a larger study.

The attitudes of most of our Black respondents conflict with the prevailing ethic regarding EOL care. In the United States, current physician attitudes and practices may reflect a northern European approach to senescence and EOL care. In England, for example, dialysis is often denied to patients over the age of 60.[13] In the Netherlands in 1995, 2.7% of all deaths were as a result of euthanasia or physician-assisted suicide, and 14.7% of deaths were aided by the use of opioids in large doses.[14] Northern European physicians in the intensive-care setting forego life-sustaining care more frequently than their southern European counterparts.[15] Some have suggested that the use of life-sustaining measures in terminally ill or brain dead patients is an unwise allocation of resources.[16]

By contrast, a large number of Black older adults appear to feel that extensive life-sustaining measures are appropriate for demented, comatose, and brain-dead patients. This more positive attitude concerning life-sustaining measures may, at first, seem to conflict with the value placed on religion among our Black respondents. Why wouldn't patients want to "let nature take its course" or "let God decide the future"? When asked about this seeming contradiction, one Black participant denied that these views were inconsistent. She stated her belief that "none of us will live a second longer than God desires. All of our efforts won't change His decision." In this woman's view, it is our duty to try and stay alive, not to hasten death. This philosophy may have an influence on the historically low Black suicide rate.[17]

Several limitations of this study must be noted. First, our analyses make multiple comparisons between Black patients and White patients based on several health scenarios. Our positive findings may be due to chance rather than to true differences between groups. However, given the strength and consistency of our findings, the problem of multiple comparisons does not likely present a significant bias in this study. A second limitation of this study is that results may not be generalizable to all patients. White study subjects were drawn from a suburban medical practice, while Black study subjects were drawn from an inner-city medical practice. We cannot draw conclusions from this study about groups other than those represented in our study sample. That is, our study may compare groups that are fundamentally different in socioeconomic characteristics other than race. If this is the case, our findings may be due to confounding factors such as education or religiousness. For example, persons with less education or who are more religious may be more likely to want life-sustaining interventions. Although our multivariate analyses control for such potentially confounding factors, caution should be taken in extrapolating our findings to groups other than those represented in our sample. Ideally, future studies will draw patients of both races from diverse practice settings in order to better elucidate the independent effects of race and other sociodemographic factors on preferences for life-sustaining interventions.

A final limitation of this study is that patients were asked to understand and make subtle distinctions between complex medical conditions, such as dementia, coma, and brain death. While patients were provided with comprehensive definitions and were offered the opportunity to ask and receive answers to their questions, some patients may have had difficulty comprehending the distinctions between the health scenarios. This could introduce bias in our findings, although the magnitude and direction of such bias cannot be determined from our results. In future similar research, the survey instrument should be pilot tested to determine health literacy level and patient comprehension.

We hope that the findings of this and previously cited studies will serve as a launching point for future interaction and dialogue. For example, studies have noted the relatively low utilization of hospice by Black patients, which is entirely congruent with the attitudes evidenced in our survey. Without acknowledging these differences in attitudes, efforts to increase hospice use in Black patients may be fruitless and possibly harmful. The attitudes of Black and other minority groups should be incorporated into a new dialogue concerning care at the end of life. Perhaps hospice is not a reasonable choice for many terminally ill patients who do not want to die.

Some have suggested that prolonging life results in greater costs to the healthcare system. However, the predicted savings from surrogate decision-making, HMO supervision, and hospice care have yet to be realized. Costs for terminal care are not significantly different between California, where hospice and managed care are used extensively, and New York, where these measures are used much less frequently.[18,19] We posit that the minimal demonstrated economic savings of hospice care are more than counterbalanced by the loss that a patient and family may feel at not having been afforded a maximum effort at the end of life.

More people of all racial and ethnic backgrounds are dying in institutional settings today than at any other time in history. In these settings, where cultures intermingle, a greater appreciation of diverse approaches to death and dying is needed. Developing sensitive approaches to helping patients and their families at the end of life may ease the passing of a loved one.

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AUTHOR CONTRIBUTIONS

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Acquisition of data: Silver, Williams
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Manuscript draft: Silver, Williams, Macario
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Acquisition of funding: Silver
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