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What explains racial differences in the use of advance directives and attitudes toward hospice care?

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Abstract

Cultural beliefs and values are thought to account for differences between African Americans and Whites in the use of advance directives and beliefs about hospice care. However, little data clarifies which beliefs and values explain these differences.

We surveyed 205 older adults (≥ age 65) who received primary care in the Duke University Health System. The survey included five scales: Hospice Beliefs and Attitudes, Preferences for Care, Spirituality, Healthcare System Distrust, and Beliefs about Dying and Advance Care Planning. Compared to Whites, African Americans were less likely to have completed an advance directive (35.5% vs. 67.4%, $P<.001$) and had less favorable beliefs about hospice care (Hospice Beliefs and Attitudes Scale score, $P<.001$). African Americans were more likely to express discomfort discussing death, want aggressive care at the end of life, have spiritual beliefs which conflict with the goals of palliative care, and distrust the healthcare system. In multivariate analyses, none of these factors alone completely explained racial differences in either possession of an advance directive or beliefs about hospice care. However, when all of these factors were combined, race was no longer a significant predictor of either of the two outcomes.

Our findings suggest that ethnicity is a marker of common cultural beliefs and values which in combination influence decision-making at the end of life. This study has implications for the design of healthcare delivery models and programs which provide culturally-sensitive end-of-life care to a growing population of ethnically diverse older adults.

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Keywords

race; end-of-life care; hospice; advance directives

INTRODUCTION

Cultural beliefs are central to perceptions of illness and may influence healthcare utilization. As such, understanding how culture impacts healthcare is essential to efforts to reduce racial and ethnic disparities in healthcare outcomes.[1] Because of the influence of culture on the meaning and experience of death and dying, cultural beliefs, values, and traditions may be of particular relevance at the end of life.[2]

A number of studies have examined racial differences in end-of-life care and have documented lower rates of advance directives and hospice use among African Americans compared to Whites.[3–7] While there is evidence that these disparities are decreasing, cultural beliefs among African Americans may influence their willingness to use advance directives or access hospice care.[8, 9] For example, preferences for life-sustaining therapies, spirituality, beliefs about death and dying, and mistrust of the healthcare system have all been suggested as explanations for the decision-making of African Americans at the end of life.[10–14] However, to what extent these factors explain the relationship between African-American culture and either the use of advance directives or attitudes toward hospice has not been well-described.

Much of the literature on African Americans and the use of advance directives or attitudes toward hospice has included focus groups, interviews, surveys, or database analyses exploring attitudes toward advance care planning, hospice use, and end-of-life care in general, or documenting racial differences in rates of advance directives or hospice enrollment after controlling for demographic factors.[3–7, 9–15] Only a few studies have examined the association between racial differences in the completion of advance directives or willingness to use hospice care and specific factors other than demographic variables, such as preferences for life-sustaining therapies, patient-physician relationship, trust in the healthcare system, and knowledge of hospice or advance directives.[4, 8, 16–18]

The purpose of this study was to determine whether differences between African-American and White older adults in the use of advance directives and attitudes toward hospice care were explained by differences in cultural beliefs and values. Like other studies, we examined racial differences in the use of advance directives, attitudes toward hospice care, and cultural beliefs which may impact end-of-life care. However, in addition to documenting these differences, we specifically examined the extent to which racial differences in the completion of advance directives and beliefs about hospice were individually or collectively explained by specific cultural beliefs, including preferences for end-of-life care, beliefs about dying, spiritual beliefs, and mistrust of the healthcare system. Our findings have implications for the development of programs which meet the needs of a growing population of culturally diverse older adults.

METHODS

This study was a cross-sectional survey of community-dwelling older adults (≥ age 65). The Institutional Review Board of the Duke University Health System approved the study protocol.

Subjects

We recruited participants from two primary care practices in the Duke Health System. Patients were eligible if they were African-American or White, ≥ age 65, cognitively able to provide informed consent, and able to complete a 30-minute telephone interview. We excluded those who were living in a nursing home, receiving hospice care, or undergoing active treatment for cancer. From master lists of all African Americans and Whites ≥ age 65 seen at either of the two practices between April 1, 2004 and April 30, 2006, we selected a random sample of older adults stratified by race. The goal was to recruit 200 older adults.

Potential subjects received a letter describing the study and a self-addressed, stamped postcard for return by those who did not wish to be contacted further. Two weeks after the mailing, a research assistant telephoned those who did not return the postcard and scheduled a telephone interview with those who agreed to participate. All participants received $10.

Questionnaire

We developed a questionnaire exploring beliefs which may impact decision-making at the end of life. The final instrument included questions taken or modified from the Hospice Values and Barriers Scales, Healthcare System Distrust Scale, and AARP North Carolina End-of-Life Care Survey which was based on the Missoula Demonstration Project's Community Survey, along with additional questions developed from a review of the literature.[13, 19, 20] The questionnaire included scales exploring social support, preferences for end-of-life care, trust in the healthcare system, spirituality and beliefs about pain management, dying, advance care planning, and hospice. Questions were reviewed by a panel of end-of-life care researchers and clinicians for face validity, and each scale was tested for reliability using Cronbach's alpha. Participants used a five-point Likert scale (strongly agree, agree, neither agree or disagree, disagree, strongly disagree) to respond to statements from each of the scales. Sections of the questionnaire relevant to this analysis are described below. The full questionnaire can be found at http://palliativecare.medicine.duke.edu.

Demographic Characteristics, Use of Advance Directives—This section included multiple-choice questions about race, marital status, education, income, health status, and use of advance directives--living will and Durable Power of Attorney for Healthcare (DPOA).

Preferences for End-of-Life Care—This scale included 8 statements exploring beliefs about the desire to live as long as possible with a terminal illness even if on life support, brain dead, receiving tube feeds, or in severe pain. Statements were developed by the authors based on a review of the literature or taken with minor modification from the AARP North Carolina End-of-Life Care Survey.[20] Higher scores (possible range 8 to 40) indicated a greater preference for life-sustaining therapies in the event of a terminal illness. Cronbach's Alpha for the scale was 0.71.

Beliefs about Dying and Advance Care Planning—This scale included 7 statements exploring beliefs about the inevitability of death and comfort discussing death. Statements were developed by the authors based on a review of the literature or taken with minor modification from the AARP North Carolina End-of-Life Care Survey.[20] Lower scores (possible range 7 to 35) indicated greater comfort discussing death. Cronbach's Alpha for the scale was 0.75.

Trust in the Healthcare System—We used the previously validated Health Care System Distrust Scale.[19] The scale included 10 items exploring perceptions of healthcare system honesty, competence, and fidelity. Higher scores (possible range 10 to 50) indicated greater distrust in the healthcare system. Cronbach's Alpha for the scale was 0.75.

Spirituality—
This scale included 7 statements exploring spiritual beliefs about suffering and death, the use of life-prolonging therapies, advance care planning, and hospice. The statements were developed by the authors based on a review of the literature. Lower scores (possible range 7 to 35) indicated spiritual beliefs which were more likely to conflict with the goals of hospice and palliative care. Cronbach's alpha for the scale was 0.72.

Hospice Beliefs and Attitudes—
This scale included 8 statements examining attitudes toward hospice care, including desire for hospice care and beliefs about the type of care hospice provides. Statements were developed by the authors based on a review of the literature or taken from the Hospice Barriers and Hospice Values Scales, previously published scales which have been tested for face validity and reliability.13 Higher scores (possible range 8 to 40) indicated more favorable beliefs about hospice. Cronbach's alpha for the scale was 0.74.

Analyses

Bivariate Analyses—
We used Chi square (χ^2) tests to compare African Americans and Whites across categorical demographic variables and nonparametric Wilcoxon tests to compare mean scores by race on each of the scales described above. Differences were considered statistically significant at $P < .05$.

Multivariate Analyses—
We conducted multivariate analyses for two different outcomes. In the first group of analyses, we used logistic regression to determine if race was an independent predictor of possession of an advance directive--either a living will and/or a DPOA. In the second group of analyses, we used linear regression to determine if race was an independent predictor of attitudes and beliefs about hospice; the outcome for these analyses was the Hospice Beliefs and Attitudes Scale score. We chose covariates for the models a priori based on their relevance as potential confounders of the relationship between race and the two outcomes.

To determine to what extent differences between African Americans and Whites in each outcome (possession of an advance directive and Hospice Beliefs and Attitudes Scale score) were explained by cultural beliefs, we ran 5 separate models for each outcome: (1) base model which included demographic characteristics and self-reported health; (2) base model + Preferences for End-of-Life Care Scale; (3) base model + Beliefs about Dying and Advance Care Planning Scale; (4) base model + Healthcare System Distrust Scale; (5) base model + Spirituality Scale. We also ran a final model for each outcome which included all of the independent variables--demographic characteristics, self-reported health, and all four scales. Except income which was missing for 6% of the sample, all other variables were missing for < 1% of the sample. Sensitivity analyses with and without the income variable did not change the results. All analyses were conducted using SAS Statistical Software, Version 9.1 (SAS Institute Inc, Cary, North Carolina).

RESULTS

We mailed letters to 817 older adults. We were unable to contact 206 of the 817 (25.2%) because of an incorrect address, invalid phone number, or no answer to the phone call which followed the mailing. Of the 611 contacted, 19.1% (n =117) returned the postcard indicating that they did not want to be contacted further, and 47.3% (n=289) declined participation by telephone. One third (205/611) of those contacted agreed to participate; 41.5% (205/494) of those contacted by telephone (those who did not return postcard) agreed to participate. Compared to participants, a greater proportion of those who declined participation were African-American (68% vs. 32%, *P* <.001). There were no significant differences in gender or mean age among those who completed the study or those who declined participation.

The sample characteristics by race are listed in Table 1. Compared to Whites, African Americans were less likely to have completed either a living will or DPOA (35.5% vs. 67.4%, *P*<.001). Based on their scores on the scales described above, African Americans expressed a greater preference for life-sustaining therapies in the event of a terminal illness, less comfort discussing death, greater distrust of the healthcare system, spiritual beliefs which were more likely to conflict with the goals of palliative care or hospice, and less favorable attitudes toward hospice care.

Possession of an Advance Directive and Beliefs about Hospice

The results of the multivariate analyses are listed in Tables II and III. In the unadjusted analysis, Whites had almost a four times higher odds of having an advance directive than African Americans (Table II) and scored an average of 3.2 points higher on the Hospice Beliefs and Attitudes Scale than African Americans (Table III), indicating more favorable attitudes toward hospice care. When added individually to the base model, each of the scales to varying degrees reduced but did not extinguish the relationship between race and either possession of an advance directive (Table II) or beliefs about hospice (Table III). However, in the final models which included all four scales, there was no longer a statistically significant association between race and either possession of an advance directive (OR = 2.05 [0.87, 4.37] from Table II) or beliefs about hospice care (*P* = 0.53 from Table III).

DISCUSSION

As in other studies, African Americans in our sample were less likely than Whites to have an advance directive and had less favorable beliefs and attitudes about hospice.[3, 4, 10, 11, 13 – 16] We identified beliefs and values among African Americans which may explain these differences, including greater preferences for life-sustaining therapies, less comfort discussing death, greater distrust of the healthcare system, and spiritual beliefs which may conflict with the goals of hospice care. None of these factors alone explained racial differences in either possession of an advance directive or attitudes toward hospice, rather these differences were explained by a combination of beliefs and values.

These findings suggest that frequently documented racial differences in approaches to end-of-life care are a proxy for a combination of shared beliefs, preferences, and values. Although some expert groups recommend the use of advance directives, and there is data supporting improvements in end-of-life care among hospice enrollees, including better management of pain and emotional needs and greater satisfaction with care, our results suggest that advance directives and hospice may not be congruent with the cultural beliefs of some older African Americans.[21 – 25] This work has implications for the development of culturally-competent policies and programs which may improve end-of-life care.

In this study, African Americans were less comfortable discussing death, more likely to want life-prolonging therapies and more likely to agree that those who believe in God do not have to plan for end-of-life care; these factors partly explained the relationship between race and possession of an advance directive. Although interventions in church or community settings have increased dialogue around and comfort discussing end-of-life care, many of these programs have not increased the number of African Americans completing advance directives.[10, 26] This is not surprising since they only partly address potential cultural barriers. Further, given the lack of data supporting the effectiveness of advance directives in improving end-of-life care and the cultural beliefs identified in this study and others, emphasis on the process of advance care planning rather than the completion of documents seems more likely to result in the desired outcome—opportunities for those who want to do so to express their preferences for end-of-life care should they become incapacitated.[27] For African Americans, in addition to community and church-based discussions, culturally sensitive advance care planning should consider the importance of family in decision-making and the value of informal ways of expressing preferences, including oral and written instructions or even deferral of decisions to family, and greater emphasis on understanding and respecting preferences for care whatever they are and however they are expressed in the context of patients' values and goals.

Although a number of studies document lower rates of hospice enrollment among African Americans, very little has been published regarding interventions to increase access to hospice for African Americans.[6, 7] African Americans in our study expressed less favorable beliefs about hospice, including the belief that "hospice care means you get no treatment". These beliefs were partly explained by distrust of the healthcare system, preferences for life-sustaining therapies, and spiritual beliefs. Not surprisingly, issues of trust may be especially important in determining attitudes toward hospice since the hospice philosophy of care focuses on palliative rather than more traditional cure-directed therapies.

In one study, a home-based palliative care program for patients with advanced serious illness resulted in an increase in the number of African Americans hospice enrollees.[28] The authors speculate that the program's success was due to the promotion of unrestricted choice in treatment modalities in the home-based palliative care program. These findings and those of this analysis emphasize the need for healthcare delivery models which support a range of values, beliefs, and preferences while ensuring access to high quality palliative and supportive care. Such programs may not only more readily accommodate patients' preferences but may also cultivate trust in the healthcare system by allowing on-going cure-directed therapies. Hospice bridge programs and open access hospice programs, both of which allow patients to receive palliative care while continuing to receive life-prolonging therapies, are examples of healthcare delivery models which may be more attractive to some older African Americans although currently data regarding their effectiveness in meeting the needs of African Americans is lacking.[29, 30]

Common to other successful programs designed to improve palliative care for African Americans is an emphasis on community partnerships.[31, 32] These partnerships foster sensitivity to many of the cultural beliefs identified in this study by recognizing the importance of spirituality through church involvement, facilitating access to medical and nonmedical services, respecting patients' preferences, and showing sensitivity to beliefs about death and dying by focusing on family involvement and advance care planning as a process of comprehensive care.

This study has some limitations. Our sample included older adults receiving primary care at two clinic sites affiliated with one academic medical center in the southeast. These results may not be generalizable to other populations of older adults. Another concern is the response rate. Only one-third of those contacted agreed to participate and African Americans made up 2/3 of those who declined participation. Although all African Americans were contacted by an African-American interviewer, interviewer-subject race concordance did not appear to improve our response rate as noted in previous studies.[33, 34] Other studies have also documented lower rates of research participation among African Americans.[34, 35]. It is possible that older African Americans and Whites who participated were more similar than in the general population with respect to their comfort discussing end-of-life care and beliefs about participating in research which are thought to relate to trust in the healthcare system.

If this is true, our results may underestimate the true differences that exist in the general population between the two racial groups in cultural beliefs and values related to end-of-life care. Another limitation is the absence of validated measures examining cultural differences in approaches to end-of-life care. When possible, we used or modified existing measures; however, to address our study objectives, we developed many questions based on published literature. Questions were reviewed for face validity and reliability. The differences in cultural beliefs found in our study are consistent with those reported in other studies.

We attempted to identify a common set of cultural beliefs among African Americans which may influence end-of-life care. However, individual differences in beliefs exist within any culture due to differences in socioeconomic status, age, gender, location, and experiences. These within-culture differences are evident in our results. Although there were statistically significant differences in mean survey scores between the African-American and White samples, there was a wide range of scores with some overlap among individuals in the two different racial groups (Table I). These findings highlight the need for healthcare providers to be sensitive to cultural differences while avoiding stereotyping based on race and ethnicity.

In the absence of a one-size-fits all approach to end-of-care, one-size-fits all healthcare delivery models, programs, and policies will exclude large numbers of patients facing life-limiting illness, especially in an increasingly ethnically diverse and aging society. The challenge is for healthcare providers, researchers, and policy makers to design, test, and implement programs which accommodate a range of individual and cultural beliefs, values, and preferences.

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Table I

Sample Characteristics by Race

Variable	African Americans N = 110	Whites N = 95	*P* Value
Mean Age (years) (Range)	73.4 (65 – 90)	72.5 (65 – 91)	0.43
Gender			0.55
Male	43 (39.1%)	41 (43.2%)	
Marital Status			<.001
Married	43 (39.1%)	65 (68.4%)	
Education			<.001
Less than High School	46 (41.8%)	10 (10.5%)	
Annual Household Income			<.001
Less than $30,000	77 (75.5%)	38 (42.2%)	
Self-rated Health			0.006
Good to Excellent	57 (51.8%)	67 (70.5%)	
Poor to Fair	53 (48.2%)	28 (29.5%)	
Advance Directives			
Living Will	32 (29.1%)	57 (60.0%)	<.001
DPOA	28 (25.5%)	55 (57.9%)	<.001
Living Will and/or DPOA	39 (35.5%)	64 (67.4%)	<.001
Preferences for End-of-Life Care Scale			<.001
Mean ± SD Range	19.8 ± 4.2 (12 – 33)	16.1 ± 4.8 (8 – 28)	
[†]**Beliefs About Dying and Advance Care Planning Scale**			<.001
Mean ± SD Range	16.8 ± 3.6 (7 – 26)	13.8 ± 3.7 (7 – 22)	
[‡]**Healthcare System Distrust Scale**			<.001
Mean ± SD Range	21.5 ± 3.9 (11 – 28)	18.5 ± 3.9 (10 – 28)	
[§] **Spirituality Scale**			<.001
Mean ± SD Range	22.1 ± 3.1 (14 – 31)	25.4 ± 4.2 (11 – 35)	
[¶]**Hospice Beliefs and Attitudes Scale**			<.001
Mean ± SD Range	26.2 ± 4.0 (16 – 38)	29.4 ± 4.3 (18 - 39)	

[*] Preferences for End-of-Life Care Scale: Scores may range from 8 to 40. Higher scores indicate greater preferences for life-sustaining therapies if diagnosed with a terminal illness.

[†] Beliefs About Dying and Advance Care Planning Scale: Scores may range from 7 to 35. Lower scores indicate greater comfort discussing death and a greater likelihood of informal advance care planning.

[‡] Healthcare System Distrust Scale: Scores may range from 10 to 50. Higher scores indicate greater distrust of the health care system.

[§] Spirituality Scale: Scores may range from 7 to 35. Lower scores indicate spiritual beliefs which are more likely to conflict with the goals of hospice and palliative care.

[¶] Hospice Beliefs and Attitudes Scale: Scores may range from 8 to 40. Higher scores indicate more favorable attitudes toward hospice use.

Table II

Multivariate Analyses of Race as a Predictor of Possession of an Advance Directive

Odds Ratios and 95% Confidence Intervals are for Whites; African Americans are the Reference

Unadjusted	[*]Model 1	[†]Model 2	[‡]Model 3	[§]Model 4	[¶]Model 5	[#]Model 6
3.76	3.01	2.94	2.62	2.43	2.32	2.05
[2.10, 6.71]	[1.54, 5.90]	[1.47, 5.90]	[1.30, 5.29]	[1.21, 4.87]	[1.14, 4.69]	[0.97, 4.37]

Model 6 Fit Statistics: Likelihood Ratio Test -- $X^2 = 50.68$, $P<.0001$; C-index = 0.79

[*] Base Model: Demographic Variables (Age, sex, race, marital status, education, income) + Self-reported Health

[†] Base Model + Healthcare System Distrust Scale

[‡] Base Model + Spirituality Scale

[§] Base Model + Preferences for End-of-Life Care Scale

[¶] Base Model + Beliefs About Dying and Advance Care Planning Scale

[#] Base Model + Preferences for End-of-Life Care Scale + Beliefs About Dying and Advance Care Planning Scale + Healthcare System Distrust Scale + Spirituality Scale

Table III

Multivariate Analyses of Race as a Predictor of the Hospice Beliefs and Attitudes Scale

Mean Difference in Scores Between Whites and African Americans (Reference); Higher Scores Indicate More Favorable Beliefs and Attitudes About Hospice Care

Unadjusted	[*]Model 1	[†]Model 2	[‡]Model 3	[§]Model 4	[¶]Model 5	[#]Model 6
3.23	2.06	1.68	1.51	1.37	1.34	0.38
P< .001	*P*=0.001	*P*= 0.008	*P*=0.02	*P*=0.03	P=0.03	*P*=0.53

Model 6 fit Statistics: F = 13.40, $P<.0001$; $R^2= 0.42$

[*] Base Model: Demographic Variables (Age, race, gender, marital status, education, income) + Self-reported Health

[†] Base Model + Preferences for End-of-Life Care Scale

[‡] Base Model + Spirituality Scale

[§] Base Model + Healthcare System Distrust Scale

[¶] Base Model + Beliefs About Dying and Advance Care Planning Scale

[#] Base Model + Preferences for End-of-Life Care Scale + Spirituality Scale + Beliefs About Dying and Advance Care Planning Scale + Healthcare System Distrust Scale