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Original Article

# Racial Differences in Self-Reported Exposure to Information about Hospice Care

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## Abstract

*Background:* Previous research suggests that lack of knowledge of hospice is a barrier to the use of hospice care by African Americans. However, there is little data examining racial differences in exposure to hospice information.

*Objectives:* Examine racial differences in self-reported exposure to hospice information and determine how this exposure impacts beliefs about hospice care.

*Methods:* We surveyed 200 community-dwelling older adults (65 or older). We used Spearman's correlations to examine the relationship between responses to individual items on the Hospice Beliefs and Attitudes Scale (HBAS) and self-reported exposure to hospice information (never heard of hospice, heard a little, or heard a lot). We used multivariate analyses to examine predictors of exposure to hospice information and beliefs about hospice care (total score on HBAS).

*Results:* Compared to whites ($n = 95$), African Americans ($n = 105$) reported significantly less exposure to hospice information ($p = 0.0004$). Nineteen percent of African Americans and 4% of whites had never heard of hospice; 47.6% of African Americans and 71.6% of whites had heard a lot about hospice. In multivariate analysis controlling for demographics and health status, African Americans had a two times higher odds of reporting that they had never heard of hospice or heard only a little about hospice versus heard a lot about hospice (odds ratio [OR] = 2.24 [1.17, 4.27]. Greater exposure to hospice information was associated with more favorable beliefs about hospice care (outcome: total score on HBAS; parameter estimate 1.34, standard error 0.44, $p = 002$).

*Conclusions:* African Americans reported less exposure to information about hospice than whites. Greater exposure to hospice information was associated with more favorable beliefs about some aspects of hospice care. Because knowledge is power, educational programs targeting older African Americans are needed to dispel myths about hospice and to provide minorities with the tools to make informed choices about end-of-life care.

## Introduction

Over the last decade, there has been enormous growth in the use of hospice due, in part, to educational campaigns informing the public about the availability of hospice services for the care of those at the end of life.[1] Beginning in the 1990s, the National Hospice Foundation along with other organizations launched initiatives, including art, public service announcements via television and radio, documentaries, and widespread distribution of printed materials to educate consumers about options for end-of-life care.[2]

Although these public education campaigns have reached millions of consumers, there are still significant knowledge gaps and misconceptions about hospice. Many Americans know little about the hospice philosophy of care, services provided, or payment for services by Medicare, Medicaid, and private insurers.[3–5] Additionally, the extent to which information about hospice has reached vulnerable populations, such as minorities, is unclear. For example, studies suggest that African Americans, a group historically underrepresented in hospice, may know less about hospice than whites.[6–12] Because awareness of a service is a prerequisite for its use, understanding whether information about hospice is reaching the African American community could inform the development of targeted interventions to improve knowledge about and access to hospice care.

Currently, there is little empiric research examining racial differences in exposure to information about hospice and how

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this exposure impacts beliefs and attitudes. Of the existing research, one small study, which included only 19 African Americans cared for by a visiting nurse service, found that over half of African Americans in the sample had not heard of hospice.[13] A larger study of 220 black adults (92% under age 65) found that blacks who trusted their physicians and had prior positive exposure to hospice (use of hospice by a family, friend, or self) were more willing to use hospice in the future than blacks who had not been exposed to hospice.[14]

The purpose of this study was to examine differences between older African Americans and whites in self-reported exposure to information about hospice. This work extends previous research by focusing on: (1) exposure to hospice information; (2) those 65 or older, a group that makes up over 80% of hospice enrollees; and (3) the association between the degree of self-reported exposure to hospice information and beliefs and attitudes that may impact willingness to use hospice in the future.

## Methods

### *Study design*

This study was a cross-sectional survey of community-dwelling older adults (65 or older). The Institutional Review Board of the Duke University Health System approved the study protocol. A complete description of the study protocol, including questionnaire (see below), can be found in a previously published analysis.[15]

### *Subjects*

We recruited participants from two primary care practices in the Duke University Health System. Patients were eligible if they were African American or white, 65 or older, cognitively able to provide informed consent, and able to complete a 30-minute telephone interview. We excluded those who were living in a nursing facility, receiving hospice care, or undergoing active treatment for cancer. We obtained a list of all African Americans and whites 65 or older with a clinic visit at either of the two practice sites between April 1, 2004 and April 31, 2006. From the master list, we selected a random sample of older adults stratified by race. The goal was to recruit approximately 200 older adults.

Potential subjects received a letter from their primary care provider describing the study. The mailing contained 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 contacted those who did not return the postcard and scheduled a telephone interview with those who agreed to participate. All participants received $10.

### *Questionnaire*

As part of a larger study, we developed a questionnaire exploring beliefs and values which may impact decision-making at the end of life. The final instrument included questions taken or modified from the Hospice Values Scale, Hospice Barriers Scale, the AARP North Carolina End-of-Life Care Survey, and the Healthcare System Distrust Scale, along with additional questions developed by the authors from a review of the literature.[11,16,17] The questionnaire included a series of scales exploring social support, preferences for end-of-life care, trust in the health care 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 $\alpha$. 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, self-reported health.** This section included multiple-choice questions about race, marital status, education, and health status.

**Self-reported exposure to hospice information.** Participants were read the following statement describing hospice care: "Hospice is a program that provides care to people with illnesses that cannot be cured when they are at the end of their lives. The goal of hospice care is to keep terminally ill patients as comfortable as possible." They were then asked, "Have you ever heard of hospice?" Participants could respond that they had "never heard of hospice, heard a little about hospice, or heard a lot about hospice." Those who had heard either a little or a lot about hospice were then asked to identify the source of information from a list read by the interviewer (used hospice in the past; knew someone who used hospice; media; church).

**Hospice Beliefs and Attitudes Scale (HBAS).** This scale included 8 statements exploring beliefs about and attitudes toward hospice care (Table 1). Statements were developed by the authors based on a review of the literature or taken/modified from the Hospice Barriers Scale, a previously published scale which has been tested for face validity and reliability.[11] Total score may range from 8 to 40 with higher scores indicating more favorable beliefs about hospice care. Cronbach $\alpha$ for the scale was 0.74.

## Analyses

### *Bivariate analyses*

We used $\chi^2$ analyses to compare African Americans and whites across categorical demographic variables, self-reported health, and self-reported exposure to hospice information. Additionally, after combining responses to the individual statements of the HBAS into two categories: disagree (strongly disagree + disagree) versus all others (strongly agree, agree, or neither) or agree (strongly agree + agree) versus all others, we used $\chi^2$ analyses to compare responses by race. We used agree versus all others to compare responses to only one of the statements—"If I were dying, I would want hospice care"—and disagree versus all others to compare responses to all other statements; this categorization was based on the response which reflected the most favorable beliefs about hospice care.

We used Spearman correlations to examine the relationship between self-reported exposure to hospice information (never heard of hospice, heard a little, or heard a lot about hospice) and responses to individual statements from the HBAS (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree). Based on our coding, positive correlations

Table 1. Correlations between Self-Reported Exposure to Hospice Information and Beliefs about Hospice Care by Race

| | *African Americans* n = *105* | | | | *Whites* n = *95* | | | |
|---|---|---|---|---|---|---|---|---|
| *Statements from Hospice Beliefs and Attitudes Scale* | *Never heard* n = *20* | *Heard a little* n = *35* | *Heard a lot* n = *50* | *Correlation* p *value* | *Never heard* n = *4* | *Heard a little* n = *23* | *Heard a lot* n = *68* | *Correlation* p *value* |
| If I were dying, I would want hospice care. | | | | −0.26 $p = 0.008$ | | | | −0.29 $p = 0.004$ |
| Strongly agree/Agree | 9 (45.0%) | 30 (85.7%) | 40 (80.0%) | | 4 (100%) | 64 (73.9%) | 17 (94.1%) | |
| Even if I wanted hospice care, I could not afford hospice. | | | | 0.06 $p = 0.55$ | | | | 0.32 $p = 0.001$ |
| Strongly disagree/Disagree | 7 (35.0%) | 10 (28.6%) | 22 (44.0%) | | 0 (0%) | 7 (30.4%) | 44 (64.7%) | |
| I wouldn't need hospice if I were dying because my family would take care of me. | | | | 0.23 $p = 0.02$ | | | | 0.05 $p = 0.65$ |
| Strongly disagree/Disagree | 4 (20.0%) | 17 (48.6%) | 28 (56.0%) | | 4 (100%) | 13 (56.5%) | 45 (66.2%) | |
| Hospice is a place where people go to die. | | | | −0.13 $p = 0.18$ | | | | −0.09 $p = 0.38$ |
| Strongly disagree/Disagree | 4 (20.0%) | 5 (14.3%) | 9 (18.0%) | | 2 (50.0%) | 6 (26.1%) | 16 (23.5%) | |
| Hospice care means you get no treatment. | | | | 0.11 $p = 0.28$ | | | | 0.21 $p = 0.04$ |
| Strongly disagree/Disagree | 7 (35.0%) | 23 (65.7%) | 31 (62.0%) | | 1 (25.0%) | 19 (82.6%) | 62 (91.2%) | |
| Hospice treatment is not as good as treatment in the hospital. | | | | 0.26 $p = 0.008$ | | | | 0.38 $p = 0.0002$ |
| Strongly disagree/Disagree | 6 (30.0%) | 14 (40.0%) | 33 (66.0%) | | 2 (50.0%) | 13 (56.5%) | 60 (88.2%) | |
| Hospice care means giving up. | | | | 0.10 $p = 0.32$ | | | | 0.14 $p = 0.17$ |
| Strongly disagree/Disagree | 9 (45.0%) | 20 (57.1%) | 32 (64.0%) | | 4 (100%) | 13 (56.5%) | 49 (72.1%) | |
| Hospice care causes people to die before their time. | | | | 0.28 $p = 0.004$ | | | | 0.27 $p = 0.009$ |
| Strongly disagree/Disagree | 9 (45.0%) | 25 (71.4%) | 42 (84.0%) | | 3 (75.0%) | 20 (87.0%) | 62 (91.2%) | |

indicated that with greater exposure to hospice information, participants were more likely to disagree with the statement; negative correlations indicated that with greater exposure to hospice information, participants were more likely to agree with the statement. Differences were considered statistically significant at $p < 0.05$.

### Multivariate analyses

We used logistic regression to determine if race was an independent predictor of self-reported exposure to hospice information. For this analysis, the outcome was never heard of hospice or heard a little about hospice versus heard a lot about hospice. We used linear regression to determine if self-reported exposure to hospice information (from never heard of hospice to heard a lot about hospice) predicted beliefs and attitudes toward hospice care as measured by the total score on the HBAS. We chose covariates for the models a priori based on their relevance as potential confounders. These included age, gender, marital status, education, and self-reported health. All analyses were conducted using SAS Statistical Software, Version 9.1 (SAS Institute Inc., Cary, NC).

## Results

We contacted 611 older adults to request their participation in the study. Nineteen percent ($n = 117$) returned the postcard in the initial mailing 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 the postcard) agreed to participate. Compared to participants, a greater proportion of those who declined participation were African American (32% versus 68%, $p < 0.001$). A total of 205 older adults completed the study. This analysis includes the 200 participants, 105 African Americans and 95 whites, who provided information about prior exposure to hospice information.

### Self-reported exposure to information about hospice by race

Table 2 lists sample demographics by race. African Americans reported significantly less exposure to information about hospice care $p = 0.0004$). Nineteen percent of African Americans had never heard of hospice compared to only 4% of whites; 71.6% of whites reported that they had heard a lot about hospice compared to 48.6% of African Americans. In multivariate analysis controlling for age, gender, marital status, education, and self-reported health, compared to whites, African Americans had a two times higher odds of reporting that they had never heard of hospice or only heard a little about hospice versus heard a lot about hospice (odds ratio [OR] = 2.24 [1.17, 4.27]. Among those who had heard of hospice, the most common source of information was someone who used hospice as reported by over 80% of those with prior exposure in both racial groups.

### Self-reported exposure to hospice information and beliefs about hospice care by race

There were differences by race in responses to the individual items of the HBAS. African Americans were significantly less likely than whites to agree that they would want hospice care in the future (75.2% versus 89.5%, $p = 0.01$) and significantly less likely to disagree with 5 of the remaining 7 items of the HBAS describing unfavorable beliefs about hospice care. For example, compared to whites, a smaller proportion of African Americans disagreed that they would not be able to afford hospice (37.1% versus 53.7%, $p = 0.02$); would not need hospice in lieu of family care (46.7% versus 65.3%, $p = 0.01$; hospice care means you get no treatment (58.1% versus 86.3%, $p < 0.0001$) and is not as good as treatment in the

Table 2. Sample Characteristics by Race

| *Variable* | *African Americans* n = *105 (52.5%)* | *Whites* n = *95 (47.5%)* | p *value* |
|---|---|---|---|
| Mean age (years) | 72.8 | 72.5 | 0.68 |
| (Range) | (65–90) | (65–91) | |
| Gender | | | 0.65 |
| Male | 42 (40.0%) | 41 (43.2%) | |
| Marital status | | | <.0001 |
| Married | 41 (39.1%) | 65 (68.4%) | |
| Education | | | <.0001 |
| Less than high school | 43 (41.0%) | 10 (10.5%) | |
| Self-rated health | | | 0.009 |
| Good to Excellent | 55 (52.4%) | 67 (70.5%) | |
| Poor to fair | 50 (47.6%) | 28 (29.48%) | |
| Have you heard of hospice? | | | 0.0004 |
| Never | 20 (19.1%) | 4 (4.2%) | |
| A little | 35 (33.3%) | 23 (24.2%) | |
| A lot | 50 (47.6%) | 68 (71.6%) | |
| How did you learn about hospice?[a] | | | |
| Someone who used hospice | 70 (82.4%) | 75 (82.4%) | 0.99 |
| Used hospice for loved one | 23 (27.1%) | 20 (22.0%) | 0.48 |
| Media | 40 (47.1%) | 52 (57.1%) | 0.16 |
| Church | 13 (15.3%) | 12 (13.2%) | 0.73 |

[a] $n = 85$ for African Americans, $n = 91$ for Caucasians.

hospital (50.5% versus 79.0%, $p < 0.0001$); and hospice causes people to die before their time (72.4% versus 89.5%, $p = 0.002$).

Table 1 summarizes responses to the individual items from the HBAS by race and self-reported exposure to hospice information. Greater exposure to information about hospice was significantly correlated with more favorable beliefs about the desire for hospice care if dying, whether hospice treatment is as good as treatment in the hospital or if hospice care causes people to die before their time for both racial groups. Among African Americans only, greater exposure to hospice information was correlated with more favorable beliefs about the need for hospice in lieu of family care. Among whites only, greater exposure to hospice information was correlated with more favorable beliefs about affordability of hospice and whether hospice care means you get no treatment. There was no correlation between exposure to hospice information and the other items on the HBAS for either racial group.

In multivariable analysis, controlling for age, gender, marital status, race, education, and self-reported health, greater exposure to hospice information was associated with more favorable beliefs about hospice care as measured by the total score on the HBAS (parameter estimate 1.34, standard error 0.44, $p = 0.002$).

## Discussion

In this analysis, older African Americans reported significantly less exposure to information about hospice than whites. Additionally, greater exposure to information about hospice was associated with more positive beliefs about some aspects of hospice care. These findings have implications for the design of educational interventions which may increase access to hospice for older African Americans.

Nineteen percent of older African Americans compared to only 4% of older Caucasians reported that they had never heard of hospice. Although other studies document less knowledge about hospice among African Americans, we were surprised to find that such a large proportion of African Americans in our sample had not heard of hospice especially given how ubiquitous hospice care is throughout the United States.[1,9–12,14] Because African Americans use hospice at lower rates than whites, older African Americans may have less opportunity to interact with someone who has used hospice services.[6–8] Furthermore, formal educational programs focusing on end-of-life care may be less prevalent in African American communities and less effective at reaching older African Americans compared to similar programs in predominantly white communities. In addition to targeting providers and healthcare organizations who care for large numbers of African Americans, educational and outreach initiatives that involve less conventional groups such as churches, civic groups, and other organizations of importance in the community, as well as public service announcements on African American media, may improve the dissemination of information about hospice and other options for end-of-life care among older African Americans.[18–21]

In addition to documenting less exposure to information about hospice among African Americans, our results suggest that exposure to information impacts beliefs about hospice care. With greater exposure to information about hospice, both racial groups endorsed more favorable beliefs about some aspects of hospice care. However, there were notable racial differences. For example, only among African Americans was there a correlation between exposure to hospice information and beliefs about the need for hospice in lieu of family care. This may reflect beliefs about the central role of family in caring for ill and dying loved ones.[12] With greater exposure to hospice information, African Americans may realize that hospice does not exclude but encourages and supports families caring for their loved ones at the end of life. Also, greater exposure to hospice information was associated with more favorable beliefs about whether hospice means you get no treatment among whites but not African Americans. This may reflect a difference in beliefs about the value of cure-directed versus palliative care in the African American community and how this type of care is discussed given greater preferences for life-prolonging therapies at the end of life.[22–24]

Although greater exposure to hospice information was associated with more favorable beliefs about hospice care, the sizes of the correlations (0.21–0.38) are noteworthy. These correlations are considered small in the social science literature suggesting that even among those who report prior exposure to information about hospice, there may be considerable misinformation. For example, only 20% of those who reported some prior exposure to hospice information disagreed that hospice is a place where people go to die. As in other studies, the majority of older adults in our sample reported learning about hospice from someone who had used hospice.[5,25] Lay sources of information may not be accurate. In one study of surrogate decision-makers, those without hospice experience who had heard of hospice from friends or colleagues provided incomplete or inaccurate information about key aspects of hospice.[5] Formal educational programs may be more likely than friends or family to provide complete, accurate information about hospice and address the specific information needs of older adults.

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. Additionally, only one third of those contacted agreed to participate, and African Americans made up two thirds of those who declined participation. Other studies have also documented lower rates of research participation among African Americans.[26–28] Another limitation is the absence of a single validated measure examining beliefs about hospice care. We used/modified existing measures from previously published analyses, and all measures were reviewed for face validity and reliability.[11,13,16,17] Despite the response rate and the measures used, the fact that our findings are consistent with those of other studies exploring beliefs and attitudes of African Americans toward end-of-life care is reassuring.

Our study is also limited by the sample size resulting in some subgroups with a small number of participants and the use of multiple comparisons leading to the possibility of a type I error. These analyses are exploratory, and tests of significance should be interpreted with caution. Nevertheless, our results provide important information about racial differences in exposure to information about hospice care and should inform the design of future studies with larger samples that test community-based educational interventions.

While a combination of beliefs are likely to impact decisions to enroll in hospice, including spiritual beliefs, preferences for end-of-life care, beliefs about dying, and trust in the healthcare system, knowledge is an important piece of the decision-making process and perhaps the most modifiable. Some older African Americans will have beliefs and preferences that are compatible with the hospice philosophy of care and knowledge of hospice along with physician referral will allow them to access the services that hospice provides.[12,29] Future research should design and test the effectiveness of educational interventions to increase access to hospice care for older African Americans. These interventions should identify both information that may be important to the majority of older adults and information that may address the specific concerns of some older African Americans based on their cultural beliefs, values, and preferences.

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## Author Disclosure Statement

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