

**NHPCO** *Original Article*

# African American Bereaved Family Members' Perceptions of the Quality of Hospice Care: Lessened Disparities, But Opportunities to Improve Remain

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**Abstract**

*Previous research has documented striking disparities in bereaved family members' perceptions of the quality of end-of-life care between African American and white decedents. Using data from the 2005 repository of the Family Evaluation of Hospice Care survey, we examined whether this disparity in quality of end-of-life care persists once an African American is enrolled in hospice. Of the 121,817 decedents whose proxies were surveyed, 4095 were non-Hispanic black (African American), and 97,525 were non-Hispanic white. There were no statistically significant differences with regard to decedents' gender. Length of stay on hospice was similar across racial groups. Although previous research has demonstrated striking disparities in the perceived quality of end-of-life care, we found that there were either no differences (quality ratings scores) or less of a disparity in perceptions of concerns with the quality of end-of-life care when compared to the results of a previously reported national mortality follow-back survey, suggesting that though disparities in perceptions of care at end of life persist, on hospice they improve to some degree. J Pain Symptom Manage 2007;34:472–479. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

**Key Words**

*Hospice, bereaved family members, perceptions, quality, disparities*

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**Introduction**

Multiple research studies report striking disparities between African Americans and Caucasians with regard to health care access and

utilization. These studies address disparities across the spectrum of health care, including treatment of depression, diagnosis of obesity, diagnosis of HIV/AIDS, and diagnosis and treatment of various malignancies.<sup>1–6</sup> Similarly, disparities have been found in perceived satisfaction with health care services. Studies suggest that racial and ethnic minorities are more likely than whites to have lower levels of trust and satisfaction with their physician.<sup>7</sup> Perceptions of racial barriers have been associated with lower likelihood of being satisfied

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*Accepted for publication:* June 27, 2007.

with care in African Americans.<sup>8</sup> African American colorectal cancer patients have been noted to have a higher rate of concerns with various aspects of health care when compared to Caucasian patients, and African American lung cancer patients have been found to have greater concerns with physician communication.<sup>9,10</sup> Although these studies suggest the presence of disparities, the nature of why these disparities exist has yet to be fully elucidated. Though studies have been done across the spectrum of health care, few studies focus on disparities in end-of-life care, and even fewer studies focus on disparities in the perceived quality of hospice care.

Recent research suggests that racial disparities persist in end-of-life care. The possibility of this disparity in end-of-life care was the focus of a recent study by Welch et al.<sup>11</sup> This study revealed that family members of African American decedents were more likely to report problems with absent or problematic physician communication than family members of white decedents. Furthermore, Welch et al. found that African American patients were less likely to have treatment wishes or advance care planning documents. This study also reported that family members of African American decedents reported more concerns with communication, higher rates of unmet needs, and lower satisfaction with care than did family members of white decedents. An important question is whether these differences persist once an African American is enrolled in a hospice program.

Though studies have documented that hospice improves quality at the end of life,<sup>12–16</sup> underutilization of hospice by members of the African American community continues to be documented,<sup>17,18</sup> and disparities in care at the end of life exist,<sup>11</sup> limited research has examined the quality of end-of-life care among African Americans when they are on hospice. Previously, Teno et al. developed the Brown Family Evaluation of Hospice Care (FEHC) survey to examine the quality of hospice services based on interviews with bereaved family members.<sup>19</sup> This survey examined whether hospices: 1) provide the desired physical comfort and emotional support; 2) treat the dying person with respect; 3) attend to the needs of family members for information and emotional support; and 4) provide assistance with coordination of care. Hospices that are

members of the National Hospice and Palliative Care Organization (NHPCO) submit surveys to an online repository.<sup>20</sup> This repository was used to examine the quality of care as perceived by the family members of African American and white hospice patients in 2005. The goal of this study was to examine whether racial differences in perceived quality of care exist, and to determine if previously noted disparities in perceived quality of care at the end of life persist once African Americans enroll in hospice by comparing our results to previously documented national data.

## Methods

A secondary analysis was done of an existing database maintained by the NHPCO. The FEHC survey is a 61-item questionnaire that surveys family members about care provided to decedents by various hospice programs. The NHPCO maintains a web-based repository of surveys that are submitted from hospice programs across the United States. Information is collected in terms of patient and family-centered outcomes that are measured in different domains. These domains include 1) provision of desired physical comfort and emotional support to the patient in terms of pain, dyspnea, and emotional support; 2) attending to the needs of the family in terms of providing them with information about the patient's symptoms, providing emotional and spiritual support to the patient's family, and giving the family information about what to expect when the patient died; and 3) coordination of care. Details regarding survey design and data collection have been published previously.<sup>20</sup> The FEHC is based on an instrument that was used in the 2001 national study of dying in America that characterizes these same domains. Previously, Welch et al. characterized the difference in perceptions of the quality of end-of-life care among the family members of African American and white decedents. The results of this study will be compared to the results noted by Welch et al. along similar domains of care. For the purposes of this study, race was defined as American Indian or Alaskan Native, Asian or Pacific Islander, Black or African American, and White. Responses such as "No answer" or "Don't know" were deemed invalid.

### Analysis

All analyses were conducted using STATA SE version 9 (College Station, Texas). A descriptive analysis was done to examine decedent baseline characteristics using the Chi-squared test ( $\chi^2$ ) for ordinal or dichotomous variables and the *t*-test for continuous variables. The nonparametric Wilcoxon rank-sum test was used to examine whether racial differences exist with regard to responses to patient and family-centered levels of care. To compare the results to those of Welch et al.,<sup>11</sup> crude odds ratios (OR) with 95% confidence intervals (CI) were calculated.

### Results

#### Sample Characteristics

Data used for this study were obtained from the NHPCO FEHC database for the year 2005. Eight hundred and nineteen hospices submitted surveys to the repository during this time period for a total of 121,817 respondents. Of the hospices represented, 35% were located in the South, 31% in the Midwest, 19% were located in the West, and 15% in the Northeast. Additionally, 87% of the facilities were located in urban areas, whereas 13% were located in rural areas. Of the 121,817 respondents, 16,946 potential respondents were eliminated because they did not have a valid response to the question about race. Given that this was a voluntary data collection, hospice programs could choose whether or not to include demographic questions. This accounted for the elimination of 9,767 respondents. The remaining cases were eliminated because the respondent did not answer the question on race. Overall, a total of 98,911 respondents were considered in this study. Of the total respondents, 3.9% were non-Hispanic black ( $n = 4095$ ), and 90.4% were white ( $n = 94,816$ ). Baseline characteristics of decedents by race are noted in Table 1. There were no statistically significant differences with regard to gender distribution by race. A greater percentage of white decedents died of heart disease (11.8% vs. 8.6%,  $P \leq 0.001$ ), whereas a greater percentage of African Americans died of cancers of all types (57.0% vs. 48.9%,  $P \leq 0.001$ ). White decedents were more likely to have completed high school than African American decedents (39.1% vs. 29.8%,  $P \leq 0.001$ ).

Table 1  
Baseline Characteristics of African American and White Decedents

Characteristic	Non-Hispanic Black <sup>a</sup> ( $n = 4095$ ) (%)	Non-Hispanic White <sup>a</sup> ( $n = 94,816$ ) (%)	<i>P</i> Value
Female	53.5	54.4	0.315
Age 65 years and older	75.9	85.7	<0.001
Leading cause of death			<0.001
Cancer	50.4	44.5	
Heart disease	7.7	10.7	
Dementia	8.2	8.4	
Level of education			<0.001
Eighth grade or less	26.4	13.6	
Some high school	17.8	12.9	
High school graduate	29.8	39.1	
One to three years of college	16.6	17.5	
Four-year college graduate	4.1	8.3	
More than four-year college degree	5.4	8.6	
Relationship of proxy to decedent			<0.001
Spouse	27.8	39.4	
Partner	1.1	1.0	
Child	35.9	39.8	
Parent	8.6	5.4	
Sibling	10.7	4.2	
Other	10.9	7.7	

<sup>a</sup>Data were not available for all decedents.

Additionally, respondents for white decedents were more often spouses (39.4% vs. 27.8%,  $P \leq 0.001$ ).

#### Patient and Family-Centered Outcomes

Racial differences in family members' perceptions of hospice quality were also measured across the domains previously mentioned. Table 2 describes the results across those domains in terms of percentages and crude ORs. Family members of African American decedents were less likely than those of whites to rate the overall quality of care received while on hospice as "excellent" or "very good" (OR = 0.7, CI = 0.6, 0.8). Of the patient and family-centered domains examined, family members of African American decedents expressed more concerns than those of whites in several areas. Family members of African American decedents were more likely to have one or more concerns with coordination of care (OR = 1.3, CI = 1.2, 1.4) and the amount of emotional support provided to the family (OR = 1.4, CI = 1.3, 1.5). Family members of

Table 2  
Patient and Family-Centered Outcomes by Race

Outcome	Non-Hispanic Black (n = 4095) (%)	Non-Hispanic White (n = 94,816) (%)	OR (95% CI)
Provide desired physical comfort and emotional support			
Unmet need—pain	8.2	5.6	1.5 (1.3, 1.7)
Unmet need—dyspnea	6.1	4.9	1.3 (1.1, 1.5)
Unmet need—emotional support	14.5	9.0	1.7 (1.5, 2.0)
Attend to the needs of the family			
At least one or more concerns about information regarding the patient's symptoms	16.4	10.6	1.7 (1.5, 1.9)
At least one or more concern(s) about emotional or spiritual support to family	15.3	11.6	1.4 (1.3, 1.5)
At least one or more concern(s) about information to family regarding patient's conditions and what to expect while the patient was dying	22.9	23.0	1.0 (0.9, 1.1)
Coordination of care			
At least one of more concerns(s) about coordination of care	21.7	17.9	1.3 (1.2, 1.4)
Timeliness of referral			
Referred "too early/too late"	10.8	12.6	0.8 (0.8, 0.9)
Satisfaction with services			
Rated as "Excellent/very good"	92.1	94.4	0.7 (0.6, 0.8)
Overall satisfaction ranking (0–50)	47.3	47.3	0.95 <sup>a</sup>

<sup>a</sup>Pvalue.

African American decedents were also more likely to have one or more concerns about being informed about the patient's symptoms (OR = 1.7, CI = 1.5, 1.9). There were no racial differences in perceived concerns about being informed about what to expect when the patient died (OR = 1.0, CI = 0.9, 1.1). There were also differences noted in terms of concerns about unmet needs. Family members of African American decedents were more likely to have concerns about unmet needs for their loved ones' pain (OR = 1.5, CI = 1.3, 1.7), dyspnea (OR = 1.3, CI = 1.1, 1.5), and emotional support (OR = 1.7, CI = 1.5, 2.0). There were no statistically significant differences in family members' overall rating of satisfaction on a 0–50 scale by race (African American 47.3, White: 47.3, and  $P = 0.96$ ).

#### *Length of Stay and Timeliness to Referral*

Fig. 1 details hospice length of stay by race. The percentages of patients on hospice in terms of length of stay were very similar. The greatest percentages of decedents, both African American and white, were found to have been on hospice for one to three months (27.9% vs. 25.4%). Table 2 also includes analysis of perceived timeliness to hospice referral. Family members of African American decedents were less likely to perceive that their

loved one was referred to hospice "too early" or "too late" (10.8% vs. 12.6%). Family members of African American decedents were 0.8 times less likely to believe that their loved one was referred to hospice too late or too early when compared to family members of white decedents (OR = 0.8, 95% CI = 1.1, 1.3).

#### *Discussion*

Multiple research studies have reported disparities in the quality of care between African American and Caucasian patients.<sup>7,8,21–23</sup> Welch et al. documented that these disparities extend to the quality of end-of-life care patients received. Using similar measures, we examined whether this disparity persists once African Americans are enrolled in hospice. Our results show lessening disparities, but important opportunities to improve the quality of care for African Americans enrolled in hospice. For instance, family members of African American hospice patients report fewer concerns about the emotional and spiritual support they receive, being informed about what to expect as their loved one nears the end of life, and overall satisfaction. Nevertheless, opportunities to improve the quality of care African American hospice patients receive with regard to provision of physical comfort and emotional support

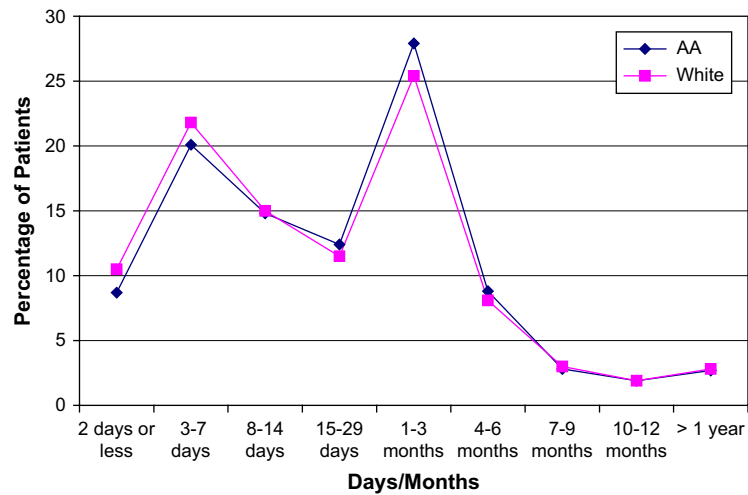


Fig. 1. Hospice length of stay, by race.

exist. Further research is needed to understand these disparities and how hospice can intervene to deliver individualized care that meets the need of the African American community.

In 2004, the NHPCO in collaboration with investigators at Brown University adopted the FEHC survey and created a repository by which hospice programs can submit their data online to receive a report on the quality of care. The goal of that repository is to provide actionable data that allow hospices to provide comprehensive services that meet the expectations and needs of dying persons and those who care for them. Additionally, the goal of the FEHC is to provide researchers and consumers with data that ensure that hospice strives to meet the goals so articulately outlined by Dr. Cicely Saunders: "We have never lost sight of the values that were so important to David: Commitment to openness, openness to challenge, and the absolute priority of patients' own views on what they need."<sup>24</sup>

Increasingly, perceptions of the quality of care by patients and family are an important measure of the quality of care. Although chart audits can determine whether an aspirin is prescribed in a myocardial infarction, only consumers can provide information on key processes (e.g., shared decision making, emotional support, etc.) that are fundamental to the patient-centered approach to medical care. Although multiple studies have documented disparities in the perception of health care quality,<sup>21-23</sup> few studies have documented racial

differences in the perceptions of the quality of care patients receive at the end of life. Of note, only the study conducted by Welch et al. reported racial differences in the perceptions of the quality of end-of-life care among a national sample of decedents.<sup>11</sup> This study used similar items as the present study.

Table 3 provides a comparison of the Welch et al. study of all deaths and our study that focused on those persons who died utilizing hospice. Disparities persisted; yet, they diminished once the dying person and the family were provided care by hospice. For example, Welch et al. found among all deaths regardless of the setting of care that African American family members reported a higher rate of concerns with emotional support (OR = 2.6).<sup>11</sup> Using similar items, our study found less of a disparity (OR = 1.4) in the rate of concerns with emotional support to the family. Similarly, there is improvement with regard to being informed about what to expect while the patient was dying (OR = 2.5 vs. OR = 1.0) and overall satisfaction with services (OR = 0.4 vs. OR = 0.7). One should also note that 92.2% of family members of African American decedents and 94.4% of family members of Caucasian decedents rated the care their loved one received as excellent or very good, showing that the quality of hospice care is perceived as being satisfactory by the vast majority of families—African American or Caucasian.

Although there is evidence of lessened disparities, important opportunities remain to

Table 3  
Comparison of Perceived Quality along Specific Domains: African American vs. White Respondents

Outcome	2005 FEHC OR (95% CI)	2001 MFBS <sup>11</sup> OR (95% CI)
Provide desired physical comfort and emotional support		
Unmet need—pain	1.5 (1.3, 1.7)	1.3 (0.7, 2.5)
Unmet need—dyspnea	1.3 (1.1, 1.5)	1.0 (0.5, 1.8)
Unmet need—emotional support	1.7 (1.5, 2.0)	1.1 (0.5, 2.4)
Attend to the needs of the family		
At least one or more concern(s) about emotional or spiritual support to family	1.4 (1.3, 1.5)	2.6 (1.6, 4.4)
At least one or more concern(s) about information to family regarding patient's conditions and what to expect while the patient was dying	1.0 (0.9, 1.1)	2.5 (1.5, 4.2)
Satisfaction with services "Excellent/very good"	0.7 (0.6, 0.8)	0.4 (0.3, 0.6)

improve the quality of care. An important next step is to better understand the concerns of bereaved family members through in-depth interviews and focus groups with participants of various ethnic backgrounds. Additionally, examining the variation among health care institutions will provide evidence of the opportunity to improve and, potentially, lead to organizational interventions to lessen the disparities. Previous qualitative research suggests a lack of trust in health care providers, and concerns over the lack of diversity may play a role in African Americans' satisfactions with the quality of care.<sup>25–28</sup> Similar to any ethnic group, the most important intervention may be simply asking about those persons' concerns and experiences, and this may be an important first step in understanding how to provide culturally sensitive care.

Certain limitations should be considered when interpreting the results of this study. First, the data repository maintained by the NHPCO is voluntary. When compared to Medicare beneficiaries who died while on hospice in 2000, the repository underrepresents African Americans (Table 4). These findings could be a function of sampling; however, the literature suggests that racial/ethnic minority population participation in health-related research is oftentimes low.<sup>29</sup> Second, the use of bereaved family members reflects their perceptions of the quality of end-of-life care. For some subjective symptoms such as pain, anxiety, and depression, previous research suggests that proxies are inaccurate in their reporting;<sup>30</sup> there is no evidence that the accuracy of proxies varies by the race of the respondent. Finally, the majority of hospices included in

the sample were located in the South and the Midwest (66%). Overrepresentation from these areas may have caused the results to be biased. Despite these limitations, this study is one of the few studies to date that examines whether or not racial differences in family members' perceptions of hospice care quality exist.

In conclusion, our findings suggest that a positive change occurs in racial differences in family members' perceptions of care once African Americans enroll in hospice. For family members of African American decedents, concerns about the provision of emotional and spiritual support to the family, being informed about what to expect when the patient died, and overall satisfaction were noted to improve when compared to previously documented findings along those domains. These findings suggest that hospice does improve the quality of care individuals receive at the end of life. However, there are important opportunities to improve quality of hospice care for African Americans. Hospice has been an

Table 4  
Comparison of FEHC Sample with Sample from Medicare Claims Files, Age ≥ 65

Characteristic	Medicare Claims	
	Files 2000	FEHC Database 2005
Sample size	386,468	92,862
Women (%)	56.0	55.5
Race/ethnicity (%)		
White	90.4	96.3
Black	6.5	3.7
Cause of death (%)		
Cancer	51.8	44.2
Heart disease	7.1	13.3
Dementia	6.7	10.7

innovative leader in providing high-quality end-of-life care. As the population of our country becomes more diverse, the challenge is to understand and meet the needs of all dying persons.

### Acknowledgments

The authors would like to thank the following individuals who reviewed earlier drafts of this manuscript, including David Dosa, MD, MPH, Patrick Vivier, MD, PhD, Marsha Rosenthal, PhD, and Melanie Wasserman, PhD. The authors would also like to thank the staff of the NHPCO, Brown University Center for Gerontology and Health Care Research, and Brown University Program in Public Health who have supported this project and provided administrative support.

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