African American Bereaved Family Members' Perceptions of Hospice Quality: Do Hospices with High Proportions of African Americans Do Better?

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Abstract

Background: Research suggests that racial differences in end-of-life care persist even among patients enrolled in hospice.

Objective: The objective of the study was to examine the association between bereaved family members' satisfaction with hospice services and the proportion of African American (AA) patients in hospice.

Methods: The 2007 and 2008 Family Evaluation of Hospice Care (FEHC) Survey examined family members' perceptions of the quality of care on several dimensions including: unmet need for pain, dyspnea, and emotional support; being informed about the patient's condition and what to expect as the patient was dying; being informed about medications and treatments for symptoms; coordination of care; and overall satisfaction with care. We examined the association between family members' perception along each domain and the proportion of AAs served by hospices surveyed.

Results: Of the 11,892 AA decedents in 678 hospice programs, 53.7% were female. The leading cause of death was cancer (51.6%). On univariate analysis, family members of decedents who died in hospices that had higher proportions of AAs were less likely to have concerns about unmet pain needs (odds ratio [OR] 0.84, 95% confidence interval [CI] 0.72–0.98), more likely to have concerns about coordination of care (1.28, 1.17–1.40), and less likely to perceive care as excellent or very good (0.73, 0.63–0.84). Coordination-of-care concerns and lower overall rating of care persisted in multivariable analyses. There were no other significant associations between family perceptions and proportions of AAs in hospice.

Conclusions: Among hospices with higher proportions of AAs, family members have more concerns about coordination of care and have lower overall perceptions of quality.

Introduction

PREVIOUS RESEARCH has identified racial differences in use of hospice and palliative care.^{1–7} Differences in perceptions hospice quality have also been identified. In a prior study of the 2005 Family Evaluation of Hospice Care (FEHC) Survey, bereaved family members of African American (AA) patients were more likely to have one or more concerns along certain patient and family-centered domains of care, including pain management, treatment of dyspnea, and provision of emotional support.⁸ These differences were also noted in the setting of family-centered domains of care. For example, bereaved family members were more likely to have concerns about being informed about patients' symptoms, being provided with emotional and spiritual support, and coordination of care. AA bereaved family members were also less likely to

rate the care they received as excellent or very good. Although these findings improved when compared with perceptions of family members of patients not in hospice, opportunities for improvement still exist, and the reasons for these differences have not been fully identified.

Studies have shown that organizational characteristics and patient demographics may influence differences in the quality of care that patients receive in the long-term care setting. In a study of nonhospital-based long-term care facilities, nursing homes serving predominantly Medicaid patients were found to have fewer nurses, lower occupancy rates, and more health-related deficiencies. These facilities were also more likely to serve AA residents than other facilities.⁹ Additional research has indicated that blacks are much more likely than whites to be cared for in nursing homes that have serious deficiencies, lower staffing ratios, and greater financial

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vulnerability.¹⁰ Furthermore, more recent data suggest that elderly Hispanics are more likely than their non-Hispanic white peers to reside in nursing homes that are characterized by severe deficiencies in performance, understaffing, and poor care; and a facility's concentration of Hispanic residents has been associated with prevalent pressure ulcers after adjustment for resident characteristics.^{11,12} Whether similar patterns are seen regarding the perceived quality of care received by patients in hospice and their and family members remains to be seen. The aim of this study was to assess if hospices with higher proportions of AAs had better or worse perceptions of care quality by AA family members using data from a nationwide survey of AA bereaved family members.

Methods

Data

This study involved a secondary analysis of data obtained from a repository of the FEHC Survey maintained by the National Hospice and Palliative Care Organization (NHPCO). The FEHC Survey is a 61-item survey that measures bereaved family members' perceptions of the quality of care provided by various U.S. hospice agencies.¹³ Completion of the survey by family members and caregivers is voluntary, and the results are maintained by NHPCO. Questions asked in the survey cover several patient and family-centered domains of hospice care: pain management, management of dyspnea, provision of emotional and spiritual support to the patient, provision of emotional and spiritual support to the family, informing the family of what to expect as the patient was dying, informing the family about the patient's symptoms, coordination of care, and overall perception of hospice quality. The sample consists of respondents who represented AA decedents who died while receiving hospice services. The hospices considered were U.S. hospices that had at least one AA patient during the study time period.

Analysis

Descriptive analyses were done to examine baseline characteristics of decedents and respondents. A contingency table analysis was used for comparison of ordinal or dichotomous variables, with the Student's *t*-test used for continuous variables. Hospices were divided into quartiles based on the proportion of AA decedents. These quartiles were used to create the variable used to identify AA patient concentration. Simple logistic regression was conducted to examine univariate associations between AA patient concentration and bereaved family members' perceptions of care along the patient and family-centered domains in the FEHC Survey described above. A multivariable logistic regression analysis was conducted to further evaluate the association between the proportion of AA hospice patients and bereaved family members' perceptions of care along the FEHC survey domains. Adjustment was made for patient-level characteristics including: age, gender, and leading causes of death such as cancer, heart disease, lung disease, stroke, dementia, and AIDS (acquired immune deficiency syndrome). Generalized estimating equations were used to account for clustering by hospice. To simplify the presentation of results, the final statistical analysis dichotomized AA concentration into high (the third and fourth quartiles) and low (the first and second

quartiles); however, our results were similar in analyses done with AA patient concentration analyzed as a dichotomous, categorical, or continuous variable. Analyses were conducted using the statistical software SAS version 9.2 (SAS Institute, Inc., Cary, NC).

Results

Decedent and respondent characteristics

The sample consisted of respondents representing 11,892 AA decedents who died while receiving care from 679 hospices in the United States. About half (53.7%) of the total AA decedents were female (Table 1). The majority of decedents (75.9%) were 65 years of age or older. More than half of the decedents (51.6%) died of cancer, with other prominent primary causes of death including dementia (9.9%), heart disease (8.1%), lung disease (6.5%), and frailty (6.1%). One-third (33%) of decedents received their care in the nursing home setting.

TABLE 1. BASELINE CHARACTERISTICS OF DECEDENTS AND SURVEY RESPONDENTS

<i>Decedent characteristics</i>	<i>N = 11,892 (%)</i>
Female	53.7
Age	
65 and older	75.9
45–64	20.7
25–44	2.9
24 and younger	0.5
Level of education	
Less than high school	41.6
High school graduate	31.0
Some college	16.7
College graduate	10.7
Primary cause of death	
Cancer	51.6
Dementia	9.9
Heart disease	8.1
Lung disease	6.5
Frailty/Old age	6.1
Other	17.8
Place of care, nursing home	33.0
<i>Respondent characteristics</i>	<i>N = 11,892 (%)</i>
Female	81.7
Age	
65 and older	33.5
45–64	52.5
25–44	13.4
24 and younger	0.6
Level of education	
Less than high school	12.4
High school graduate	29.7
Some college	31.6
College graduate	26.3
Relationship to patient	
Spouse	27.1
Child	35.5
Parent	10.4
Sibling	11.1
Other	15.9

The majority of respondents (81.7%) were women, and 35% of respondents were the children of the decedents they represented.

Concentration of African Americans in hospice

Overall, the proportion of AAs in the hospices ranged from 0.9 to 37.5%. The lowest quartile consisted of hospice organizations that had percentages of AA patients ranging from 0.9% to 1.8% of all patients. The second quartile had between 1.9 and 8.9% of AA patients, the third quartile had a range of 9.0 to 13.1% AAs, and the fourth quartile had between 13.2% and 37.5% AA patients.

Rating of quality of hospice by domain

Differences were noted in the perceived quality of hospice by bereaved family members stratified by hospice concentration. A greater percentage of bereaved family members whose loved ones were in hospices with higher concentrations of AAs felt that their loved ones received the right amount of pain control (92.9% versus 91.6%, $p=0.03$). However, higher percentages of family members of patients who received care in hospices with higher concentrations of AAs had unmet needs in terms of coordination of care (24.7% versus 20.5%, $p<0.001$), and lower percentages in the high

concentration group rated overall care as excellent or very good (91.3% versus 93.5%, $p<0.001$) (Table 2).

Univariate association between African American concentration and perception of quality

On univariate analysis, bereaved family members of AA patients who died while receiving services from hospices with higher concentrations of AAs were less likely to have unmet needs for pain (OR=0.84, 95%CI 0.72–0.98). However, family members of AA patients in high AA concentration hospices were more likely to have one or more concerns about coordination of care (OR=1.28, 1.17–1.40), and less likely to rate the care patients received as excellent or very good (OR=0.72, 0.84–0.53). Otherwise, there were no statistically significant associations between the patient and family-centered domains of care and AA hospice patient concentration.

Multivariable logistic regression analysis

After adjustment for patient-level factors and clustering of patients by hospices, bereaved family members of AAs who died while receiving services from hospices with higher concentrations of AAs continued to be more likely to have concerns about coordination of care (AOR=1.33, 95% CI 1.09–1.61) and were less likely to rate the care they received as excellent or very good (AOR=0.75, 0.91–0.61). There were no other statistically significant associations between AA patient concentration and the other patient and family centered domains of care (Table 3).

Discussion

In this study using a national survey of bereaved family members whose loved ones died in hospice, we explored whether racial composition (in this case, proportion of AAs) had any impact on the perceptions of hospice quality had

TABLE 2. RATING OF QUALITY OF HOSPICE BY DOMAIN

Domain of care	Low concentration AA (%) N=5969	High concentration AA (%) N=5923	P value*
<i>One or more concerns about:</i>			
Unmet need: pain			
Right amount	91.6	92.9	0.03
Less/more than wanted	8.4	7.2	
Unmet need: dyspnea			
Right amount	95.6	94.6	0.07
Less/more than wanted	4.4	5.4	
Unmet need: emotional support			
Right amount	87.3	86.0	0.24
Less/more than wanted	12.7	14.0	
Being informed about patient's symptoms			
No need	86.7	86.8	0.87
Unmet need	13.3	13.2	
Amount of emotional support provided to family			
No need	86.0	85.5	0.48
Unmet need	14.0	14.5	
Being informed about what to expect as patient is dying			
No need	75.2	74.5	0.39
Unmet need	24.8	25.5	
Coordination of care			
No need	79.5	75.3	<0.001
Unmet need	20.5	24.7	
Overall Excellent/Very good rating			
Yes	93.5	91.3	<0.001
No	6.5	8.7	

*P value from χ^2 test.

TABLE 3. PATIENT AND FAMILY-CENTERED DOMAINS OF CARE BY CONCENTRATION OF AFRICAN AMERICANS, SIMPLE AND MULTIVARIABLE LOGISTIC REGRESSION ANALYSIS

Domain of care	OR (95% CI)	AOR (95% CI) ^a
<i>Patient-centered</i>		
Unmet need: pain	0.84 (0.72, 0.98)	0.96 (0.70, 1.32)
Unmet need: dyspnea	1.24 (0.98, 1.58)	1.17 (0.80, 1.71)
Unmet need: emotional support	1.12 (0.93, 1.34)	1.20 (0.95, 1.52)
<i>Family-centered</i>		
Being informed about the patient's symptoms	1.00 (0.85, 1.17)	0.95 (0.75, 1.22)
Emotional support provided to family	1.04 (0.93, 1.16)	1.01 (0.83, 1.23)
Being informed about what to expect as patient is dying	1.06 (0.98, 1.16)	0.99 (0.83, 1.18)
Coordination of care	1.28 (1.17, 1.40)	1.33 (1.09, 1.61)
Overall rating of excellent or very good	0.73 (0.63, 0.84)	0.75 (0.61, 0.91)

^aControlling for patient age, patient gender, cancer (all types), heart disease, lung disease, stroke, dementia, and AIDS.

AOR, adjusted odds ratio; CI, confidence interval; OR, odds ratio.

by bereaved family members of AA hospice patients. We found that AA family members whose loved ones received care from hospices with higher proportions of AA patients were more likely to have concerns about coordination of care and less likely to rate the care they received as excellent or very good. This study confirms and expands our previous research that revealed that although some improvements are noted in perceptions of quality once AA patients receive hospice services, improvement along some domains of care is still needed.⁸

Although concerns exist in terms of coordination of care and overall rating of care for AAs receiving care in hospices with higher proportions of AAs, other findings suggest that the care received by AA patients and their families is continuing to improve. Despite the differences identified above, one should note that the percentage of AA family members rating hospice as excellent or very good among hospices with both low and high proportions of AAs was above 90%, and ratings were above 80% in several of the other domains of care. This suggests, again, that although racial differences exist in certain domains of care, the majority of AA family members in this sample continue to perceive the care they receive positively.

Previous work has identified racial differences in end-of-life care and in perceptions of care on hospice, and this work expands on that very important area of research.^{8,14–17} When comparing the findings in this study with previous research on black and white differences, our findings show positive perceptions of effective pain and symptom management, being informed about a loved ones symptoms, and provision of emotional and spiritual support. Coordination care, which is defined in the FEHC survey as information continuity and being able to identify one hospice nurse in charge of care, and overall satisfaction with care remained of concern for AA family members. Other research also suggests that factors including coordination of care influence how family members rate the care they receive.¹⁸ Identifying specific domains of care that may be of concern to bereaved family members makes continued evaluation of this interesting dynamic and creation of targeted interventions areas for future research.

In our study bereaved AA family members of patients who received care in hospices with higher concentrations of AAs were less likely to have concerns about unmet needs for pain. This finding is contrary to research that relates to disparities in end-of-life care. In fact, our previous work revealed that bereaved family members of AA decedents were 1.5 times more likely than white bereaved family members to have concerns about unmet needs for pain.⁸ A possible explanation for this could be that an even greater emphasis is now being placed on pain and symptom management, particularly given evidence that racial differences in this domain of care have been identified. One should note, however, that in this cohort this finding did not carry forward after adjustment was made for important patient-level characteristics, including age, gender, and cause of death.

Certain limitations should be taken into consideration when interpreting the results of this study. First, although the FEHC dataset used in this study represented more than 11,000 AA decedents and their family members cared for at almost 700 hospices nationwide, participation by bereaved family members and hospices was voluntary and may not be representative of all organizations. Some would argue that the

perceptions of bereaved family members are not as reliable as the patient themselves. We feel, however, that although this research relies on self-report from bereaved family members, the perceptions of care noted by the family members are important, and are oftentimes the only source of information among patients who die. Family members commonly serve as the voice for their loved ones, particularly those who are nearing death.

In this study of AA hospice patients and their family members, we found that the coordination and overall quality of hospice care among them was rated lower in hospices with higher proportions of AA patients. Our study and previous research suggests that racial differences in perceptions of end-of-life care improve when patients enroll in hospice, but there are certain opportunities for continued improvement along specific domains of care. Future work will be needed to understand the underlying causes of these racial differences so that interventions can be designed to overcome them.

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Author Disclosure Statement

No competing financial interests exist.

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