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Racial/Ethnic Perspectives on the Quality of Hospice Care

Cathy L. Campbell, PhD, ANP-BC¹, Marianne Baernholdt, PhD, MPH, RN², Guofen Yan, PhD³, Ivora D. Hinton, PhD¹, and Erica Lewis, PhD, MSN, RN⁴

¹ The University of Virginia, School of Nursing, Charlottesville, VA, USA

² The University of Virginia, School of Nursing and the School of Public Health Sciences, Charlottesville, VA, USA

³ The University of Virginia, School of Public Health Sciences, Charlottesville, VA, USA

⁴ Eastern Mennonite University, School of Nursing, Harrisonburg, VA, USA

Abstract

Diversity in the US population is increasing, and evaluating the quality of culturally sensitive hospice care is important. A survey design was used to collect data from 743 patients enrolled in hospice or their family members or caregivers. Race/ethnicity was not significantly associated with any of the hospice interventions or outcomes. Patients were less likely to be satisfied with the overall hospice care (OR = 0.23, 95% CI = 0.065-0.796, $P = .021$) compared to other type of respondents. Satisfaction with emotional support was substantially associated with the increased likelihood of satisfaction with pain management (OR = 3.82, 95% CI = 1.66-8.83, $P = .002$), satisfaction with other symptom management (OR = 6.17, 95% CI = 2.80-13.64, $P < .001$), and of overall satisfaction with hospice care (OR = 20.22, 95% CI = 8.64-47.35, $P < .001$).

Keywords

hospice; quality; racial–ethnicity; satisfaction; symptom management; emotional support

Introduction

The National Hospice Palliative Care Organization (NHPCO)¹ estimated that the racial/ethnic composition of people using hospice services is as follows: 80.5% white, 8.7% African American, 8.7% multiracial, 1.9% Asian/Hawaiian/Pacific Islander, and 0.2% Native American/Alaskan Native. Of the people receiving hospice care in 2009, 68.6% of people received care at their place of residence, 21.2% were cared for in a hospice inpatient facility, and 10.1% received care in an acute care hospital.¹ To date, national statistics affirm that there is limited racial/ethnic diversity in people using hospice programs. In contrast, results from the latest census suggest that the demographic picture in the United States is changing. The US Census Bureau predicts that in less than a century racial and ethnic minorities will become the majority in the United States.² Given the increasing diversity in the US population, providing and evaluating the quality of culturally sensitive hospice care is important.³⁻⁵

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Corresponding Author: Cathy L. Campbell, PhD, ANP-BC, University of Virginia, School of Nursing, Charlottesville, VA 22908, USA clc5t@virginia.edu.

Declaration of Conflicting Interests

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Racial/ethnic disparities in the use of hospice have been well documented, especially the disparity between African Americans and Whites.⁶⁻¹⁰ Barriers to the use of hospice care by African Americans include, ethical conflicts with the hospice philosophy,⁷ current and historical health disparities,^{11,12} limited physician access,¹³ and a lack of knowledge about the services available under the Medicare Hospice Benefit.^{12,14,15}

Furthermore, with the aging of the generation of baby boomers, hospice and palliative care services are playing a greater role in the nation's health care system.¹⁶ Therefore, in 2008, the Centers for Medicare and Medicaid Services (CMS) mandated as a condition of receiving reimbursement for hospice care that US hospice providers have to initiate quality assessment and performance improvement (QAPI) programs.¹⁷ The QAPI programs should span all settings of care from patients' homes to inpatient facilities and measure quality indicators that link hospice delivery directly to palliative care outcomes for individuals and their caregivers. Multiple quality indicators exist for hospice and palliative care such as symptom management, patient, family member, or caregiver satisfaction with communication from the hospice team, and overall satisfaction with hospice care. These indicators should be used by hospice providers for benchmarking and quality improvement.^{16,18,19}

Hospice and palliative care providers face 4 major challenges when collecting data about quality of care from patients/caregivers. First, 34.4% people who enroll in hospice do so within the last week of life and the median length of stay in hospice programs is 21.1 days.¹ Given that approximately 34% of the patients die within a week of admission and 50% die within 3 weeks of admission, hospice providers are not able to collect data to evaluate the quality of their services from a large number of the patients. Second, the patients who may be available to provide feedback often have severe physical and cognitive limitations that will impact their ability to provide information about the quality of services provided. Third, caregivers are often too busy with the physical demands of their role as well as coping with the emotional experience of caring for a dying relative, intimate partner, or close friend and therefore may be reluctant to participate in surveys.^{20,21} Thus, the majority of the studies that evaluate quality of hospice care are done retrospectively. Caregivers may be surveyed from one month to as many as 13 months after the death or discharge of a patient²²⁻²⁵ (See p. 3). Finally, gathering data from racial/ethnic minorities is difficult because of the aforementioned disparities in the use of hospice.^{1,5-7,9,10}

In one of the seminal studies that compared outcomes between African American and white hospice patients, Rhodes and colleagues conducted a secondary data analysis on data from NHPCO's Family Evaluation of Care Survey (FEHC).²³ Compared to white family members, African American families were more likely to report that their family member had unmet symptom management needs (pain and dyspnea) and not enough emotional support.²³ While the study did highlight the differences between African American and white families on important hospice outcomes, all of the data were collected from bereaved family members 13 months or longer after the death and not during the period of hospice care. Given the unmet needs for symptom management and emotional support expressed by African American families who have used hospice services, the increasing diversity in the US population, and the greater role for hospice and palliative care in the US health care system, there is clearly a need for studies that explore how race/ethnicity influences hospice outcomes. These studies will provide the evidence base for culturally sensitive care for patient/families enrolled in hospice.

Both patient, family members, or caregiver characteristics and hospice interventions are factors that influence hospice outcomes. Satisfaction with hospice and palliative care for people at the advanced phase of disease is influenced by patient diagnosis, race-ethnicity,⁵

length of time enrolled in hospice, geographic location of care,^{5,26} and socioeconomic status.⁵ Family or caregiver characteristics that influence satisfaction with hospice care are race/ethnicity,²³ the family member's relationship with the patient, and working status of the caregiver (retired vs being employed outside of the home).²⁶ Researchers have also studied the impact of interventions by the interdisciplinary team on patient, family member, or caregiver satisfaction. Hospice interventions that have been positively associated with patient, family member, or caregiver satisfaction are providing emotional support,^{22,23} accurate information about medical treatment,²² regular information about the patient's condition,^{22,27,5} and assigning one nurse to be in charge of the plan of care.^{22,5} Less attention has been given to exploring associations between race/ethnicity, hospice interventions, and outcomes.⁵

The current study was designed to answer two research questions: (1) Is the race/ethnicity of patient or family member associated with satisfaction ratings of 3 hospice interventions: explanation of plan of care, information about patient's condition, and emotional support and 3 hospice outcomes: satisfaction with pain management, satisfaction with other symptom management, and overall satisfaction with hospice care? (2) What patient/family characteristics (race/ethnicity and relationship to patient) are associated with the 3 hospice outcomes (satisfaction with pain management, satisfaction with other symptom management, and overall satisfaction with hospice care)? (3) What hospice interventions (explanation of plan of care, information about patient's condition, and emotional support) are associated with the 3 hospice outcomes (satisfaction with pain management, satisfaction with other symptom management, and overall satisfaction with hospice care)?

Materials and Methods

Design and Setting

For this cross-sectional study, data were collected from a large hospice organization in the Southeastern part of the United States. At the time of data collection, the hospice had an average daily census of over 630 patient/families per day. Patient care was provided by 7 teams geographically located across the service area. Of the 7 teams, 4 had a dedicated hospice inpatient facility. The study received Social Sciences Institutional Review Board approval from the researchers' university prior to data collection.

Selection of Participants and Data Collection

All patients who were admitted for hospice care at home or in the hospice inpatient units over an 8-month period were invited to participate in the study. Hospice patients, family members, or caregivers were always given the option to not participate in the survey. Data were collected by phone using a demographic form and a patient satisfaction questionnaire designed by the hospice program and modified by the researchers was administered to evaluate patient, family member, or caregiver satisfaction with care received. To assure continuity, the same staff member made all the phone calls to patient, family member, or caregiver 4 to 10 days after admission to hospice. When the staff member called the home, she would first ask to speak with the patient, and if the patient was unavailable, then the caller would ask to speak to an adult in the home who could provide information about the services received from admission to the date of the call. Participants were asked to assess the quality of the hospice services provided from admission to present. The data were used by the hospice organization immediately to make changes in the plan of care if needed. The same procedure was used for all patients whether they were admitted to hospice at their place of residence in the community or to one of the inpatient facilities.

Demographic variables included in the study were race/ethnicity (white, African American, or other), primary diagnosis (cancer vs noncancer), care location (home or inpatient), and relationship to the patient (self, spouse, adult child, or other). The questionnaire included questions that asked the respondent whether they were satisfied with specific hospice interventions and outcomes. The hospice interventions were explanation of plan of care, information about patient's condition, and emotional support. The hospice outcomes were satisfaction with pain management, satisfaction with other symptom management, and overall satisfaction with hospice care.

The survey items for overall satisfaction were measured using a 5-point Likert-type response ranging from *very dissatisfied* to *very satisfied*. Since we had few answering in each category, we collapsed the satisfaction variable into a dichotomous variable of satisfied versus not satisfied. The answers to the survey were entered into a de-identified database which was used for this study. We analyzed only the de-identified data.

Data Presentation and Statistical Analyses

Descriptive statistics and logistic regression were used to address the research questions. Because of the small number of participants in the race/ethnicity category "other," we collapsed white and other in the regression analyses. We first examined the univariate associations between race/ethnicity and the hospice interventions and hospice outcomes using a logistic regression model that linked race-ethnicity (black vs other race) to each hospice intervention and outcome. Next we assessed whether hospice outcomes were associated with the demographic variables and hospice interventions. In order to minimize potential collinearity between the 3 hospice intervention variables, we fitted 3 separate logistic regression models that included 1 hospice intervention variable at a time with all demographic variables.²⁸ Because primary diagnosis and patient location were not significantly associated with any of the hospice outcomes in these models, our final multivariate models did not include these 2 variables. Results are presented as odds ratios (OR) and 95% confidence intervals (CI). International Business Machines (IBM) SPSS version 18.0 was used to compute results (version 18.0, SPSS, Chicago, Illinois).²⁹

Results

During the 8-month study period, 2073 patients were admitted to hospice; 621 (30%) died within 7 days of admission before they could be surveyed. Of the 1452 people who were alive at the time of the survey, 617 (42%) either declined participation or could not be reached. Thus, 835 (58%) patients or family members participated in the telephone survey. Ninety-two surveys were excluded from data analysis: 24 were duplicate data entry mistakes. Patient and/or family members were not contacted twice. In all 68 were removed because of missing data for at least one of the variables. Thus, a total of 743 surveys were included in this study.

In Table 1 personal characteristics of the sample are presented. Of the 743 respondents, 633 (85.2%) were white, 86 (11.6%) were African American, and 24 (3.2%) were of another race (Table 1). The majority of patients had a noncancer diagnosis (400 or 53.8%) and were cared for at home (501 or 67.4%). Only 121 (16.3%) patients were respondents. The most common respondents were adult children (289, 38.9%) and spouses (188 25.3%).

Satisfaction with each of the hospice interventions was very high: 698 (93.9%) respondents were satisfied with the explanation of the plan of care, 679 (91.4%) were satisfied with information provided about the patient's condition, and 696 (93.7%) were satisfied with emotional support. (Table 1 describes satisfaction with the hospice interventions and outcomes.) Satisfaction with hospice outcomes was also high. Of the total sample, 700

(94.2%) respondents were satisfied with pain management, 703 (94.6%) were satisfied with other symptom management, and 716 (96.4%) were satisfied with overall hospice care.

Table 2 presents univariate associations between race/ethnicity and satisfaction with the 3 hospice interventions (explanation of plan of care, information about the patient condition, and emotional support) and the 3 hospice outcomes (satisfaction with pain management, satisfaction other symptom management, and overall satisfaction with hospice care). Race/ethnicity was not significantly associated with explanation of the plan of care (OR = 1.90, 95% CI = 0.57-6.23), information about the patient's condition (OR = 1.07, 95% CI = 0.47-2.43), emotional support (OR = 1.11, 95% CI = 0.43-2.88) or satisfaction with pain management (OR = 1.18, 95% CI = 0.54-5.93), other symptom management (OR = 1.11, 95% CI = 0.41-3.43), and hospice care (OR = 0.56, 95% CI 0.21-1.52).

Table 3 presents the results of multivariate logistic regression linking each of the hospice outcomes (satisfaction with pain management, other symptoms, and overall satisfaction) to the covariates considered. The results revealed that patients were less likely to be satisfied with overall hospice care (OR = 0.23, 95% CI = 0.065-0.80, $P = .021$) compared to other type of respondents. No differences were found for the 3 hospice interventions or the other 2 hospice outcomes. Examining the association between the 3 hospice interventions and 3 hospice outcomes revealed that the hospice intervention, explanation of plan of care, was associated with the 2 outcomes: satisfaction with other symptom management (OR = 3.00, 95% CI = 1.19-7.59, $P = .020$) and overall satisfaction with hospice care (OR = 18.24, 95% CI = 7.73-43.07, $P = .000$; Table 3).

The other 2 hospice interventions, information about the patient's condition and providing emotional support, were associated with all 3 outcomes (Table 3). For example, satisfaction with emotional support was associated with the increased likelihood of satisfaction with pain management (OR = 3.82, 95% CI = 1.66-8.83, $P = .002$), the increased likelihood of satisfaction with other symptom management (OR = 6.17, 95% CI = 2.80-13.64, $P < .001$), and the increased likelihood of overall satisfaction with hospice care (OR = 20.22, 95% CI = 8.64-7.35, $P < .001$).

Discussion

Our study had 4 key findings: (1) there was no difference in satisfaction with hospice interventions and hospice outcomes between African Americans and other race/ethnic groups, (2) type of respondent influenced overall satisfaction with hospice care, (3) the hospice intervention, explanation of plan of care, was associated with overall satisfaction, and (4) the hospice interventions, providing information about patient's condition and emotional support, were associated with all 3 hospice outcomes. Each of the findings will be discussed below.

In regard to our first finding of no difference in satisfaction with hospice interventions and hospice outcomes between the racial/ethnic groups, overall satisfaction with the hospice interventions and outcomes were high for all respondents. In the literature, when perceptions of satisfaction with hospice interventions and outcomes between racial/ethnic groups are explored a different picture is revealed. While the overall satisfaction ratings of hospice care are high regardless of the race/ethnicity of the respondent,^{5,22} perceptions of the quality of hospice interventions and hospice outcomes differ.^{22,30} When hospice interventions are evaluated, African American families are more likely to report that their family member had unmet needs for symptom management (pain and dyspnea) and emotional support^{23,30} than white families. When hospice outcomes are evaluated, African Americans are less likely than whites to rate the overall quality of hospice services high.^{23,30} Disparities in symptom

management outcomes for African Americans, especially pain, are well documented,^{31–33} and further work is needed to compare and contrast perceptions of quality between racial/ethnic groups related to symptom management and emotional support. Our contrasting results may reflect several issues.

Our sample had a higher proportion of African Americans compared to the national average (11.6% vs 8.7%). When the demographic characteristics of our sample were compared to the admission statistics for the hospice program where the study was conducted, however, no difference was found. Of the total number of patients admitted in 2010, 11.6% were African American (Haven Hospice, 2010 unpublished data).³⁴ Perhaps this specific hospice organization was better at serving African American's hospice needs than other hospice providers. Also the hospice organization had experience in providing a full range of services including staffing for continuous care at home during an acute medical crisis. They also provided care in freestanding hospice units across a service area of more than 13 000 square miles.³⁴ Finally, the hospice organization had an average daily census of 630 patients, placing it among the 1.2% of hospices nationally, which have an average daily census of 500 patients or more. In contrast, 40% of the 4700 hospice programs in the United States have an average daily census of less than 25 patients.³⁵

Our second finding that patients are less likely to be satisfied with overall hospice care compared to other type of respondents is noteworthy. While adult children and spouses were the most common respondents, we did have a large proportion of patients answering the survey. In contrast, the majority of studies on hospice outcomes use data collected from family members after the death of the patient. Family members provide valuable information about the quality of the services provided, but they may not be the best source of information on subjective outcomes such as satisfaction with hospice services.^{36,37,21} In hospice and palliative care the unit of care is recognized as the patient/family¹ and therefore we need information from both patients and families to tailor interventions that support both during their hospice care.

Relating to our third finding, explanation of the plan of care is associated with higher overall satisfaction with hospice care. When hospice care is being initiated, the patient/family outcomes are not always easily quantified or understood by patients and their families.³⁸ Explaining the plan of care at admission and how the care is modified as the patient's status changes is therefore important for patients and families who express higher satisfaction ratings. Explaining the plan of care at admission and how the care is modified as the patient's status changes is therefore important for patients and families who express higher satisfaction ratings. Given that more caregivers work outside of the home or are long-distance caregivers³⁹, timely communication helps them plan when to be at the patient's side. Our fourth finding that the 2 hospice interventions, providing information about patient's condition and emotional support, are associated with higher satisfaction in all 3 hospice outcomes is encouraging. These findings suggest that communicating with families on all hospice interventions is important to achieve high satisfaction. In other studies communication with patients/families is considered an important quality indicator for hospice organizations.^{3,4,16,22,27,40} Families rely on information from the hospice team about the patient's condition and evaluation of symptom management, not only for updates on the patient status but also for affirmation of the care they are providing. Communication with patient/families and providing support are very powerful interventions. More work is needed to identify effective strategies to communicate about the patient's condition, to explain the plan of care, and to provide emotional support to patient/families using hospice service.

Limitations

Our study had several limitations including insufficient racial–ethnic diversity of the sample to make more in-depth comparisons according to race. We did compare African Americans and other racial/ethnic groups, but given the small numbers of respondents from other racial/ethnic groups, such as Hispanics, Asians, Pacific-Islanders, or Native Americans we can draw no conclusions about their satisfaction with hospice interventions and outcomes. Additionally, we were limited to what demographic variables we could include. Perhaps the variables that we chose did not fully capture factors that influence patient, family member, or caregiver satisfaction with hospice interventions or services. Other personal characteristics that have been identified as factors that influence satisfaction with hospice care include, patient's specific diagnosis as opposed to the binary variable (cancer/noncancer) we used,^{5,26} gender of patient and caregiver,⁴¹ patient's socioeconomic status,⁵ and geographic location.^{42–44} Nevertheless, our study is one of the few studies on the quality of hospice care to use prospective data that include the perceptions of patients and families. Most studies using quantitative data are from family members after the patients have died.^{22–23} Since the data were already being collected by the hospice organization, we were able to take advantage of this unique opportunity without causing undue burdens to patients and families. The hospice organization was willing to expand their use of the data for quality improvement to a full-fledged research study. Future research should consider similar approaches where academic and community organizations partner to develop new knowledge using existing resources. Future research studies should include (1) increasing the number of participants who represent African American and other minority groups, (2) exploring the association between other characteristics such as patient's specific diagnosis, gender of patient and caregiver, geographic location (rural vs urban), average daily census of the hospice program, and satisfaction with hospice interventions and outcomes, and (3) identifying effective strategies for communication with patients and families using hospice services about the patient's condition, the plan of care, and provide emotional support.

Conclusion

Our findings affirm the importance of symptom management, communication, and emotional support to patients, family members, and caregivers who are using hospice services. Satisfaction ratings were high for patients and families enrolled in this large community-based hospice program regardless of race/ethnicity of the respondent, suggesting they may serve as a model for other smaller hospice organizations who want to improve their satisfaction scores. Collecting data prospectively about quality of care allow hospice providers the opportunity to improve care when the patient and family can still benefit, during the often physically and emotionally challenging period of hospice care. Since patient and family satisfaction with hospice care differed, we need to continue to develop strategies to capture data from both the patient and family/caregiver. Only then can we provide high-quality hospice care and a dignified peaceful death.

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Table 1

Personal characteristics and overall satisfaction with hospice intervention and outcomes N = 743

Personal characteristics	
Race	
Caucasian, n (%)	633 (85.2)
African American, n (%)	86 (11.6)
Other, n (%)	24 (3.2)
Primary diagnosis	
Cancer, n (%)	343 (46.2)
Noncancer, n (%)	400 (53.8)
Care location (patient location)	
Home, n (%)	501 (67.4)
Inpatient, n (%)	242 (32.6)
Relationship to patient	
Adult child, n (%)	289 (38.9)
Spouse, n (%)	188 (25.3)
Self, n (%)	121 (16.3)
Other, n (%)	145 (19.5)
Hospice intervention	
Explanation of plan of care (%) ^a	698 (93.9)
Information about patient's condition (%) ^a	679 (91.4)
Emotional support (%) ^a	696 (93.7)
Hospice satisfaction	
Satisfaction with pain management (%) ^a	700 (94.2)
Satisfaction with symptom management other than pain (%) ^a	703 (94.6)
Overall satisfaction with hospice care (%) ^a	716 (96.4)

^aPercentage satisfied.

Table 2

Univariate Analyses by Racial/Ethnic Group for Satisfaction With Hospice Interventions and Outcomes(N = 743)

	African American n = 86, n (%)	Other ^a n = 657, n (%)	OR (95% CI)	P
Hospice interventions				
Explanation of Care	83 (96.5)	615 (93.6)	1.90 (0.57-6.23)	.288
Information about patient's condition	79 (91.9)	600 (91.3)	1.07 (0.47-2.43)	.868
Emotional support	81 (94.2)	615 (93.6)	1.11 (0.43-2.88)	.836
Outcomes				
Pain management	83 (96.5)	617 (93.9)	1.179 (0.54-5.93)	.332
Other symptoms	82 (95.3)	621 (94.5)	1.11 (0.41-3.43)	.749
Overall satisfaction	81 (94.2)	635 (96.7)	0.561 (0.21-1.52)	.251

Abbreviations: OR, odds ratio; CI, confidence interval.

^a Caucasian and other race/ethnicities in sample.

Table 3

Multivariate Logistic Regression for Satisfaction With Pain Management, Other Symptoms, and Overall Satisfaction

	Hospice outcomes		
	Satisfaction with pain management OR (95% CI), <i>P</i>	Satisfaction with other symptoms OR (95% CI), <i>P</i>	Overall satisfaction with hospice care OR (95% CI), <i>P</i>
Race			
African American (vs other)	1.81 (.54-6.08), .341	1.14 (0.38-3.39), .814	0.39 (0.11-1.4), .150
Respondent			
Patient (vs other)	1.03 (0.42-2.56), .944	0.61 (0.27-1.41), .247	0.23 (0.065-0.80), .021
Hospice intervention ^a			
Explanation of plan of care(Q5)	1.60 (.55-.47), .391	3.00 (1.19-7.59), .020	18.24 (7.73-43.07), .000
Information about patient condition (Q6)	6.26 (3.09 -12.69), .000	7.46 (3.62-15.35), .000	77.44, (26.36 -227.46), .000
Emotional support (Q7)	3.82 (1.66-8.83), .002	6.17 (2.80-13.64), .000	20.22 (8.64-47.35), .000

^aHospice intervention variables were entered one at a time into the logistic model that included race and respondent for each of the hospice outcomes.