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Association of Racial Differences With End-of-Life Care Quality in the United States

Rashmi K. Sharma, MD, MHS,

Division of General Internal Medicine, University of Washington, Seattle

Vicki A. Freedman, PhD,

Institute for Social Research, University of Michigan, Ann Arbor

Vincent Mor, PhD,

Department of Health Services, Policy, and Practice, Brown University School of Public Health, Providence, Rhode Island

Judith D. Kasper, MD,

Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland

Pedro Gozalo, MD, and

Department of Health Services, Policy, and Practice, Brown University School of Public Health, Providence, Rhode Island

Joan M. Teno, MD, MS

Division of Gerontology and Geriatric Medicine, University of Washington, Seattle

Prior studies have identified racial disparities in multiple areas of end-of-life care, including symptom management, communication, and clinical outcome.¹ Recent efforts to improve palliative care and hospice services may help reduce these disparities.^{2,3} We investigated whether racial differences in the quality of end-of-life care persist in the United States.

Methods

We analyzed survey data collected from 2011 to 2015 for the National Health and Aging Trends Study (NHATS). That study provides longitudinal data on functioning in late life using a prospective national cohort of Medicare enrollees 65 years or older, with

Corresponding Author: Rashmi K. Sharma, MD, Division of General Internal Medicine, University of Washington, 1959 NE Pacific St, Campus Box 356526, Seattle, WA 98195 (rasharma@uw.edu).

Author Contributions: Drs Sharma and Kasper had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Kasper, Teno.

Acquisition, analysis, or interpretation of data: All authors.

Drafting of the manuscript: Sharma.

Critical revision of the manuscript for important intellectual content: Freedman, Mor, Kasper, Gozalo, Teno.

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oversampling of age and black race.⁴ Participants self-reported their race in a baseline survey by answering the question “What race do you consider yourself to be: white, black or African American, American Indian, Alaska native, Asian, native Hawaiian, Pacific islander, or something else?” A proxy respondent, usually a family member, completed an interview regarding the decedent’s last month of life, responding to questions describing the participant’s end-of-life experience. Respondent perceptions of the quality of the end-of-life care were assessed using validated items from a National Quality Forum quality measure that incorporated the following domains: pain and symptom management, decision making, emotional support, and an overall quality rating.⁵ The protocol for collecting data from NHATS was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board. This study was deemed exempt from needing approval and informed patient consent by the Brown University Institutional Review Board.

We used proportions to examine racial differences in respondent perceptions of each quality measure followed by multivariate logistic regression analyses using survey sampling weights with StataCorp 2015 software (Stata Statistical Software Release 14; StataCorp LP). Analyses were limited to surveys completed by bereaved family members or close friends. A 2-sided α level less than .05 was considered statistically significant.

Results

Of 1726 interviews, 1106 were completed by a family member or close friend of a white (825) or black (281) decedent. Sample characteristics are provided in Table 1. Whereas home was the modal site of death for black and white individuals, black patients were more likely than white patients to die in the hospital and specifically in the intensive care unit. Fewer black than white decedents used hospice services in the last month of life. Respondents for white decedents were more likely than those for black decedents to report that the person was not always treated with respect (16.8% vs 11.3%, $P = .02$) (Table 2). There were no significant differences between black and white decedents for the other quality measures nor were there differences by round of data collection. Approximately 1 of 5 respondents for both black and white decedents reported that family members were not always kept informed. Fewer respondents for black than white decedents reported that care decisions were either inconsistent with the patient’s preferences (10.4% vs 13.7%) or with insufficient input from the decedent or family (8.2% vs 10.1%). Despite overall ratings of quality of care not differing significantly between black and white individuals, fewer than half of respondents for both black and white decedents (47.7% and 49.4%, respectively) reported that the decedent had received excellent end-of-life care. Although subgroup analyses are not shown in Table 2, our findings for patients who died in the hospital were similar. In addition, among patients who used hospice in the last month of life, there were no significant racial differences in care quality.

Discussion

Using 2011–2015 NHATS data, we found no significant racial differences in various aspects of the quality of end-of-life care in the United States. We also found, however, that respondents reported many deficiencies in the quality of end-of-life care for both black and

white decedents, including unmet symptom needs, problems with communication, and suboptimal decision making. By excluding people living in residential care settings who had surveys completed by staff members or nonfamilial guardians, our results may have failed to capture racial differences in the quality of end-of-life care for those individuals. Nevertheless, that overall care quality was rated good, fair, or poor (rather than very good or excellent) for approximately 1 of 5 included decedents adds to previously reported concerns that the quality of end-of-life care may be worsening for older people in general⁶ and suggests that improvements are needed for all patients in the United States.

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Table 1

Characteristics of Decedents and Respondents by Racial Group

Variable	Decedents, % ^a		P Value
	Black (n = 281)	White (n = 825)	
Decedent characteristics			
Aged >85 y	32.6	42.0	.002
Female	55.8	56.7	.83
Married	34.7	47.7	.001
High school degree or above	44.8	74.3	<.001
Cancer diagnosis	10.5	13.8	.22
Functional decline	48.8	39.2	.05
Geographic location			
New England	0.3	5.1	
Mid-Atlantic	9.3	14.2	
Midwest (east)	14.2	16.1	
Midwest (west)	2.7	10.7	
South Atlantic	29.2	17.4	.002
Southeast	18.1	6.6	
Southwest	16.4	9.7	
Mountain	0.6	2.5	
Pacific	9.3	17.5	
Place of death			
Home	31.5	40.0	
Hospital (general medical care)	14.6	12.4	
Intensive care unit	20.0	8.6	<.001
Nursing home	16.8	16.9	
Hospice/palliative care unit	14.5	19.3	
Other	2.6	2.9	
Hospice in last month of life	31.0	42.3	.05
Respondent relationship			
Spouse	20.1	30.3	.009
Child	52.0	53.5	.18
Other family	23.4	8.1	<.001
Other friend	13.2	10.3	.18

^aData are presented as survey-weight adjusted percentages.

Table 2

Racial Differences in Quality of End-of-Life Care

Bereaved Family Member Report	Decedents, % ^a		Adjusted Odds Ratio (95% CI) ^b
	Black (n = 281)	White (n = 825)	
Unmet need for pain management	17.8	22.8	0.77 (0.46-1.29)
Unmet need for anxiety/depression	51.9	48.0	1.15 (0.66-1.97)
Unmet need for dyspnea	15.5	21.4	0.63 (0.32-1.24)
Not always treated with respect	11.3	16.8	0.53 (0.30-0.91)
Religious/spiritual concerns	56.1	56.8	1.05 (0.69-1.61)
Decision made without enough input from the decedent or family	8.2	10.1	0.71 (0.40-1.28)
Decision made that the decedent would not have wanted	10.4	13.7	0.78 (0.49-1.24)
Family not always kept informed	20.4	22.9	0.80 (0.52-1.22)
Overall care ^c			
Excellent	47.7	49.4	1.07 (0.76-1.52)
Very good	29.9	31.6	
Good	12.0	12.0	
Fair/poor	10.4	7.0	

^aData are presented as survey-weight adjusted percentages.

^bAdjusted for decedent age, respondent relationship to decedent, round of NHATS, pattern of functional decline as indicated by not getting out of bed, and presence of a cancer diagnosis.

^cUsing ordinal logistic regression analysis.