Racial Differences in Processes of Care at End of Life in VA Medical Centers: Planned Secondary Analysis of Data from the BEACON Trial

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Abstract

Background: Racial differences exist for a number of health conditions, services, and outcomes, including end-of-life (EOL) care.

Objective: The aim of the study was to examine differences in processes of care in the last 7 days of life between African American and white inpatients.

Methods: Secondary analysis was conducted of data collected in the Best Practices for End-of-Life Care for Our Nation's Veterans (BEACON) trial (conducted 2005–2011). Subjects were 4891 inpatient decedents in six Veterans Administration Medical Centers. Data were abstracted from decedents' medical records. Multi-variable analyses were conducted to examine the relationship between race and each of 18 EOL processes of care controlling for patient characteristics, study site, year of death, and whether the observation was pre- or post-intervention.

Results: The sample consisted of 1690 African American patients (34.6%) and 3201 white patients (65.4%). African Americans were less likely to have: do not resuscitate (DNR) orders (odds ratio [OR]: 0.67; $p=0.004$), advance directives (OR: 0.71; $p=0.023$), active opioid orders (OR: 0.64, $p=0.0008$), opioid medications administered (OR: 0.61, $p=0.004$), benzodiazepine orders (OR: 0.68, $p<0.0001$), benzodiazepines administered (OR: 0.61, $p<0.0001$), antipsychotics administered (OR: 0.73, $p=0.004$), and steroids administered (OR: 0.76, $p=0.020$). Racial differences were not found for other processes of care, including palliative care consultation, pastoral care, antipsychotic and steroid orders, and location of death.

Conclusions: Racial differences exist in some but not all aspects of EOL care. Further study is needed to understand the extent to which racial differences reflect different patient needs and preferences and whether interventions are needed to reduce disparities in patient/family education or access to quality EOL care.

Introduction

ABUNDANT LITERATURE DOCUMENTS racial differences in health care. For example, the Institute of Medicine (IOM),¹⁻⁴ the Dartmouth Atlas,⁵ and others^{6,7} have documented racial and ethnic variation in access to and use of health care services in the United States. The IOM's 2012

report, "How Far Have We Come in Reducing Health Disparities,"¹ concluded that health disparities persist for a number of health conditions, services, and outcomes including end-of-life (EOL) care. The IOM's 2014 report, "Dying in America,"⁸ suggested that geography⁹ and system-level factors, such as quality and number of hospital providers play a critical role in explaining racial differences in EOL care.

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The literature also describes a paradoxical trend in health care, such that non-whites, particularly African Americans, typically receive less care than whites over the majority of the lifespan, but proportionally more intense care than whites at EOL. For example, compared with whites, non-whites have lower rates of cardiac revascularization procedures,^{10,11} surgical oncology procedures,^{12,13} and rehabilitation services.^{14,15} Yet at the EOL, non-whites are more likely than whites to be hospitalized¹⁶⁻¹⁹ and receive aggressive acute care.¹⁹⁻²² In addition, in the Veterans Administration (VA) health care system, emergency room utilization during the last month of life has been reported to be higher for African American cancer patients compared with white cancer patients.²³ African Americans are less likely to have advance directives,^{22,24,25} have their preferences honored,²⁶ and enroll in hospice care.^{16,18,19,27} A systematic review of EOL care for cancer patients found that African Americans were more likely to recognize a need for hospice services, but less likely to have information regarding EOL care options.²⁸

In the past two decades a number of national policy initiatives instituted by both private (e.g., Robert Wood Johnson Foundation) and governmental entities, including the VA health care system,²⁹ have aimed to reduce or eliminate health disparities on a systems level. The VA health care system underwent major organizational changes in the 1990s to reduce variations in care, including the development of an electronic medical record and the introduction of standardized performance metrics for managers and health care staff.³⁰ Despite such notable efforts, some studies have noted persistent racial differences in care.^{31,32} For example, an analysis of VA quality of care data between 2000 and 2009 identified significant racial disparities in blood pressure, glucose, and cholesterol assessments.³¹

Nonetheless, promising outcomes of such efforts to reduce disparities were reported in some studies. A review of VA processes of cancer care by Zullig and colleagues found a small, but clinically insignificant, difference in survival time between African American and white patients.³³ In a single-site study of VA processes of EOL care, Fischer and colleagues reported that African Americans and other racial/ethnic minorities were as likely or more likely than whites to have a do not resuscitate (DNR) order and a documented advance directive discussion.³⁴

The first step in addressing racial variations in the processes of EOL care is to describe specific areas where such variations exist to guide future intervention development and system improvements. A recent systematic review concluded that this is especially imperative in a VA system where few interventions have been developed and tested specifically to improve racial and ethnic disparities.³⁵ Thus, the purpose of this study was to examine differences between African American and white patients in processes of care in the last 7 days of life in six VA medical centers (VAMCs).

Methods

This was a secondary analysis of data from the Best Practices for End-of-Life Care for Our Nation's Veterans (BEACON) trial, described in detail elsewhere.³⁶ Briefly, BEACON was a multi-center implementation trial to evaluate an education-based intervention strategy to improve EOL care processes in six VAMCs. The multi-component inter-

vention included training inpatient staff to identify actively dying patients, communicate prognosis to patients/families, and implement home hospice best practices in the inpatient setting. Educational and technical resources included pocket card decision support tools and an electronic order set. The intervention also facilitated policy changes to ensure availability of palliative care clinical interventions. The study was approved by the Institutional Review Boards of the coordinating site and all participating clinical sites.

Sample and data collection

Data for this study were abstracted from the medical records of 6066 veterans who died pre- and post-intervention in the six participating VAMCs during a 6-year period (January 2005–February 2011). A chart abstraction tool designed for the study was used to derive data on processes of care in the last 7 days of life. Demographic data, including race, were obtained from VA national datasets and from medical records as needed.

A priori, 18 processes of care were identified to indicate quality of EOL care (Table 1). The processes of care included both the ordering and administering of medications for managing symptoms at EOL. Although not every patient will need every medication, the process of making it available by maintaining an active order is a quality indicator, because it enables prompt relief of emerging symptoms. The 18 processes of care were based on clinical experience and were consistent with the Clinical Guidelines from The National Consensus Project for Quality Palliative Care.³⁷ For the purpose of this analysis, we excluded the records of 590 veterans who died within a nursing home unit. We also excluded 585 whose race was neither white nor African American, leaving a sample of 4891 decedent records.

Analysis

Outcomes were modeled using generalized estimating equations (GEE) to account for the clustering of patients within sites.³⁸ Due to this clustering, outcomes for patients within a site correlate among the patients, and the estimation of this correlation must be included in the model for accurate *p* values to be estimated. Analyses were first conducted to

TABLE 1. PROCESS OF CARE END POINTS
IN THE LAST 7 DAYS OF LIFE

-
- Palliative Care Consultation
 - Do Not Resuscitate Order
 - Advance Directive
 - Pastoral Care
 - Opioid Ordered (active order at time of death)
 - Opioid Administered
 - Benzodiazepine Ordered
 - Benzodiazepine Administered
 - Antipsychotic Ordered
 - Antipsychotic Administered
 - Steroid Ordered
 - Steroid Administered
 - Medication Administered for Death Rattle
 - Sublingual Medication Administration
 - Death in an Intensive Care Unit
 - Nasogastric Tube
 - Intravenous Line (infusing at time of death)
 - Physical Restraints
-

examine the relationship between race (African American, white) and each of the processes of care, with year of death and whether the observation was pre- or post-intervention included in the model. Then GEE modeling was conducted for each end point, expanding the covariates to include site, patient age, gender, income level, terminal condition (cancer versus other), and length of stay. Adjustment of the degrees of freedom was conducted to account for the known issues of using GEE with small numbers of sites.³⁹⁻⁴² Data were analyzed using SAS software version 9.4 (SAS Institute Inc., Cary, NC).

Results

Characteristics of the sample

The characteristics of the sample are presented in Table 2. The sample was predominantly male (98%) with a mean age

of 70.4 years. The majority were white (65.4%) and 34.6% were African American. The most common terminal conditions were cancer (29.3%) and heart disease (20.7%).

Racial differences in processes of care

In the initial analyses, controlling only for year of death and pre- versus post-intervention, racial differences were significant for several processes of care. African Americans were less likely to have a: DNR order, advance directive, active opioid order, opioid medication administered, benzodiazepine order, benzodiazepine administered, and antipsychotic administered.

In the multi-variable analyses controlling for other variables thought to be potentially related to the end points, racial differences remained significant for all variables (Table 3). In addition, steroid administered also emerged as statistically significant (Fig. 1). Racial differences were not found for other processes of care, including palliative care consultation, pastoral care, antipsychotic and steroid orders, medication for death rattle, location of death, and presence of nasogastric tube, intravenous fluids, and physical restraints.

Discussion

This study examined racial differences in EOL processes of care in the VA inpatient setting to document the prevalence of such differences and to identify targets for potential health care system interventions and improvements. Racial differences were found in some, but not all aspects of care at EOL. African Americans were less likely than whites to receive medications for pain and agitation, to have a DNR order, and to have an advance directive. However, African Americans had similar rates of dying in the intensive care unit (ICU), of being restrained, and of having a palliative care consultation. This is consistent with previous research with ethnically and racially diverse hospitalized Veterans that has also reported both differences and commonalities in EOL care.⁴³

Consistent with previous studies,⁴⁴ African Americans were less likely than whites to have opioids, benzodiazepines, and antipsychotic medications ordered and administered for pain, anxiety, and agitation. Such differences can be attributed to multiple factors. First, clinicians may under-assess pain and distress in African American patients. In a national study of pain screening rates in the VA health care system, Burgess and colleagues found that African American patients were significantly less likely than whites to be screened for pain.⁴⁵ However, the disparity was small (odds ratio [OR]: 0.79) and explained, in part, by racial variation in prior health care utilization. Although it is not within the scope of this analysis to examine conscious or unconscious provider bias in screening for pain or the administering of pain medication, research on racial concordance between provider and patient reported evidence of a decreased neurological empathic response to others' pain when dealing with persons of a different race.⁴⁶

Second, cultural variations in patients' beliefs about medication may play a role in observed differences.⁴⁷ Research has documented African American patients' preference for using spiritual and religious approaches for dealing with pain.⁴⁸ When suffering is considered by many African Americans as God's test of one's religious convictions, reliance on comfort measures can be viewed as avoiding this test, and therefore, being incompatible with their beliefs.⁴⁹

TABLE 2. CHARACTERISTICS OF THE SAMPLE

Variable	African American (n = 1690)	White (n = 3201)
Age, years, mean $\pm$ SD	67.7 $\pm$ 12.6	71.5 $\pm$ 10.6
Gender, n (%)		
Female	34 (2.0)	57 (1.8)
Male	1656 (98.0)	3144 (98.2)
Terminal condition, n (%)		
Cancer	559 (33.1)	873 (27.3)
Dementia	120 (7.1)	286 (8.9)
Lung disease	88 (5.2)	319 (10.0)
Heart disease	239 (14.1)	774 (24.2)
Kidney disease	131 (7.8)	133 (4.2)
Liver disease	94 (5.6)	191 (6.0)
Stroke	115 (6.8)	225 (7.0)
HIV	64 (3.8)	13 (0.4)
Site, n (%)		
1	412 (24.4)	593 (18.5)
2	97 (5.7)	635 (19.8)
3	339 (20.1)	487 (15.2)
4	201 (11.9)	370 (11.6)
5	333 (19.7)	717 (22.4)
6	308 (18.3)	399 (12.5)
Year of Death, n (%)		
2005	287 (17.0)	607 (19.0)
2006	280 (16.6)	571 (17.8)
2007	278 (16.5)	496 (15.5)
2008	274 (16.2)	573 (17.9)
2009	236 (14.0)	389 (12.2)
2010	283 (16.8)	467 (14.6)
2011	52 (3.1)	98 (3.1)
Intervention, n (%)		
Pre	947 (56.0)	1775 (55.5)
Post	743 (44.0)	1426 (45.5)
Income category, n (%)		
Below \$10,000	702 (42.2)	1001 (31.7)
\$10,000-\$19,999	477 (28.7)	977 (30.9)
\$20,000-\$29,999	169 (10.2)	464 (14.7)
\$30,000 or more	315 (18.9)	718 (22.7)
Length of Stay, n (%)		
$\leq$ 24 hours	99 (5.9)	230 (7.2)
>24 hours, but <7 days	695 (41.1)	1354 (42.3)
$\geq$ 7 days	896 (53.0)	1617 (50.5)

HIV, human immunodeficiency virus; SD, standard deviation.

TABLE 3. MULTIVARIABLE ANALYSES^a

Variable	Odds ratio	Confidence interval	P value
Palliative care consultation	0.97	(0.73,1.30)	0.811
Do not resuscitate order	0.67	(0.55,0.84)	0.004
Advance directive	0.71	(0.54,0.93)	0.023
Pastoral care	0.81	(0.65,1.01)	0.058
Opioid ordered	0.64	(0.54,0.75)	0.0008
Opioid administered	0.61	(0.47,0.79)	0.004
Benzodiazepine ordered	0.68	(0.63,0.72)	<0.0001
Benzodiazepine administered	0.61	(0.54,0.68)	<0.0001
Antipsychotic ordered	0.87	(0.73,1.04)	0.138
Antipsychotic administered	0.73	(0.62,0.86)	0.004
Steroid ordered	0.80	(0.63,1.00)	0.057
Steroid administered	0.76	(0.62,0.94)	0.020
Medication administered for death rattle	0.84	(0.63,1.11)	0.171
Subcutaneous medication administration	0.67	(0.32,1.43)	0.235
Death in intensive care unit	0.86	(0.66,1.12)	0.206
Nasogastric tube	1.25	(0.95,1.65)	0.093
Intravenous line	1.01	(0.80,1.27)	0.908
Physical restraints	0.92	(0.73,1.16)	0.386

^aAnalyses adjusted for study site, patient age, gender, income, terminal condition (cancer versus other), length of stay, year of death, and whether the observation was pre- versus post-intervention.

Fears of addiction, undesirable side effects, and being labeled a complainer may also play a role in African American patients' under-utilization of opioid medications.⁵⁰

An alternative explanation is that differences in care may not be explained sufficiently by differences in patients' choice due to religious or other health care beliefs. A robust literature has demonstrated repeatedly that the actual care one

receives while dying can contrast sharply with the care one previously expressed desiring, particularly among African Americans (e.g., in an advance directive).⁵¹ Hence, it is imperative to explore factors other than patient preferences for care that may impact EOL medication administration (e.g., patient-provider communication or lack thereof), particularly given that these medications are being used to specifically

FIG. 1. Odds ratios and 95% confidence intervals for racial differences in EOL processes of care controlling for study site, patient age, gender, income, terminal condition (cancer versus other), length of stay, year of death, and whether the observation was before versus after intervention. EOL, end of life; ICU, intensive care unit.

treat causes of a patient's suffering, including pain, anxiety, and agitation. Racial differences in EOL care may vary by physician specialty, as well as physician psychosocial-spiritual attributes. The interface of physician characteristics with patient and family preferences should be explored.

Research is needed to articulate the full extent of the problem of under-diagnosis and under-treatment of pain across the health care spectrum. In their 2011 report, "Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research," the IOM identified serious gaps in the literature and concluded additional evidence is needed, particularly as it pertains to racial and ethnic minorities, military veterans, and people at EOL, among others.⁵²

In our study, African Americans and whites had similar chances of dying in the ICU. This is contrary to evidence reported elsewhere. For example, Barnato and colleagues⁵³ examined the terminal admissions of 192,705 adults in 1999 hospital discharge data and found higher odds for non-whites of dying in the ICU; however, the authors also found that non-white patients tended to die in hospitals with greater overall use of ICU care at EOL. They concluded that racial differences in ICU admissions at death were due primarily to differences in hospital practice patterns rather than differences in practices by individual practitioners. We recommend that efforts to reduce unwanted ICU care at EOL be targeted to hospital policies and practice patterns and not confined to individual practitioners.

Finally, although it is important to identify and address differences in EOL care between African Americans and whites, future research is needed to examine variations within racial groups and identify factors associated with those differences. In an examination of cultural beliefs shaping EOL preferences among African Americans and whites, Johnson and colleagues found that differences in socioeconomic and sociodemographic characteristics contributed to significant within-group variation in preferred modalities of EOL care.²⁶ Such within-group diversity often is overlooked, limiting our understanding of how race interacts with other factors to impact health care processes.

Within the VA health care system, in particular, such research can lead to the identification of crosscutting mechanisms that contribute to differences in key areas of EOL care, equally affecting Veterans without regard to race or ethnicity. Recent research on EOL care within a large safety net hospital found that racial differences were not associated with hospice utilization, suggesting that factors other than race influence EOL care preferences in underserved populations.⁵⁴ Factors could include the availability of economic and social resources that enable informal caregivers to provide hospice care at home. Ultimately, differences in care at EOL should not be driven by a patient's socioeconomic circumstances or race, but rather by the optimal combination of an individual patient's values and preferences, and evidenced-based health care.⁷

Exploring patient preferences throughout the course of life-limiting illness can facilitate a smoother transition to EOL care. A care alignment tool exploring the patient's understanding of illness and prognosis, eliciting goals of care, and identifying concerns and fears may increase the utilization of comfort-directed goals. Recent efforts by the Centers for Medicare and Medicaid Services to reimburse practi-

tioners for advance care planning consultations could help to improve patients' knowledge about EOL care options, as well as practitioners' understanding of the values and preferences that patients hold. A number of investigators are making progress in this area by using novel web-based⁵⁵ and video²⁴ decision support approaches to advance care planning to address the important area of health literacy. In particular, culturally tailored methods and materials for families that specifically address the concerns of African Americans as a group may be helpful. Further research should seek opportunities to ensure patients, regardless of race, are receiving evidence-based and preference-driven sensitive care.

There were several limitations to our analysis. First, the sample consisted of six VAMCs located in the Southeast, limiting generalizability to other regions of the United States. However, it is notable that the Southeast states have the highest proportion of non-white populations. Second, all hospitals included in this analysis were VAMCs. This may limit generalizability to non-VA medical centers and health systems where there may be distinct EOL institutional policies, culture, and practice patterns. Third, we do not have information on patients' specific preferences for EOL care. As discussed above, it is possible that variation in preferences for EOL care may differ by race to the extent that race, in itself, represents a distinct set of shared cultural values. Because this is unknown, we are unable to comment on the degree of appropriateness or inappropriateness our findings have in regard to expected or reasonable benchmarks for processes of care at EOL.

The IOM defines "disparities" as "racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention" (pp. 3–4).³ Inherent in this definition is the notion that, to be deemed a disparity, differences between groups should not merely represent an inequality, but an unjust inequity. Further, debate continues in the literature about how to best judge when differences in health outcomes are sufficiently large enough to be called disparities.^{56,57} Thus, the purpose of this study was not to identify a true racial disparity but rather to ascertain what differences in EOL care exist (as opposed to why these differences exist). Further study is needed to understand the extent to which racial differences reflect different patient needs and preferences and whether interventions are needed to reduce disparities in patient education and access to quality care at EOL.

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Author Disclosure Statement

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