Associations between Race and Dementia Status and the Quality of End-of-Life Care

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Abstract

Background: Non-Hispanic black and dementia patients receive more invasive and futile treatment at end of life (EOL) relative to others. Little is known about the relationship between race/ethnicity, dementia, and EOL care quality.

Objective: Identify the relationship between race/ethnicity, dementia, and proxy reporters' evaluation of EOL care quality in older adults.

Design: Latent class analysis (LCA) of national survey data.

Setting: 1588 deceased Medicare beneficiaries age 65 and older from the National Health and Aging Trends Study (2011–2016).

Measurements: LCA identified three types of quality EOL care using nine measures of symptom management, quality of healthcare encounters, and dignified treatment. Race and dementia were primary predictors of EOL care quality type. Adjusted models controlled for decedent education, sex, marital status, age, number of illnesses, number of hospitalizations, self-rated health, place of death, hospice involvement, and proxy relationship to decedent and familiarity with care.

Results: Over 20% of proxies report that dying individuals experienced suboptimal EOL care quality, characterized by pain, sadness, poor communication, and inattention to personal care needs. In adjusted analyses, proxies for non-Hispanic black decedents were less likely to provide negative care assessments than proxies for non-Hispanic white decedents (adjusted odds ratio [AOR]: 0.58; 95% confidence interval [CI]: 0.40–0.86). Proxies for decedents with dementia were less likely to provide negative assessments than proxies for decedents without dementia (AOR: 0.70; 95% CI: 0.51–0.97).

Implications: Efforts to improve EOL care quality are needed. More positive EOL care quality assessments for non-Hispanic Black and dementia decedents appear counterintuitive given research demonstrating that these groups of individuals are likely to have received suboptimal EOL care. Because caregiver expectations for care may differ by decedent race and dementia status, research is needed to explore the role of caregiver expectations for EOL care to explain these paradoxical findings.

Keywords: care quality; dementia; proxy report; race/ethnicity

Introduction

RESEARCH SHOWS END-OF-LIFE (EOL) care varies by decedent race and dementia status. Non-Hispanic black (hereafter, “black”) individuals and those with dementia receive more invasive, aggressive, expensive, and futile care at EOL than their non-Hispanic white (hereafter, “white”) and cognitively intact counterparts. Black individuals are more likely than white individuals to be hospitalized in the last six months of life and to receive aggressive and expensive life-sustaining interventions at EOL, including ICU ad-

mission, mechanical ventilation, and tube feeding.^{1–3} Similarly, dying individuals with advanced dementia experience more frequent hospitalizations, undergo more difficult transitions between care settings, use more feeding tubes, and have lower rates of hospice enrollment than individuals with mild or no cognitive impairment.^{4–7}

Furthermore, racial and ethnic disparities in care are documented among individuals with advanced dementia. Attitudes toward EOL care for dementia patients are similar regardless of race/ethnicity, with most family members desiring comfort as the primary goal of care.^{7,8} However, black

individuals with dementia are at increased risk at EOL of burdensome transitions and invasive care such as feeding tubes than white or Hispanic patients.^{7,8}

By contrast, studies of race/ethnic differences in EOL care quality assessments present mixed assessments. In a large retrospective study, family members of black decedents indicate less overall satisfaction with care, poorer communication with physicians, and being less informed about the decedent's condition at EOL than white decedents.⁹ A more recent study of family caregivers for deceased older adults found no racial differences for several measures of EOL care quality, and that caregivers for white decedents reported respectful care less often.¹⁰ While research focuses on factors related to caregiver satisfaction with EOL care among dementia patients,^{11,12} fewer studies explore differences in EOL care quality assessments based on dementia versus nondementia status (exception: Mitchell et al.¹³). In this study, we analyze the effect of deceased older adults' race/ethnicity and dementia status on a multidimensional measure of EOL care quality assessments.

Methods

Design

The National Health and Aging Trends Study (NHATS)¹⁴ is a prospective study of a nationally representative sample of adults age 65 and older, enrolled in Medicare, and living in the contiguous United States. Starting in 2011, respondents answer surveys annually. A replacement sample was added to NHATS in 2015. After a respondent dies, a proxy reporter provides feedback about the decedent's care in their last month of life.¹⁵ This study pools data from six rounds of publicly available NHATS survey data (2011–2016), and uses a combination of predeath respondent- or proxy-reported sociodemographic and health characteristics and post-death, proxy-reported information about EOL care quality, place of death, and hospice involvement. Weill Cornell Medicine's IRB determined this study did not constitute human subjects research and so did not require IRB approval or a notice of exemption.

Setting and participants

We analyzed 1588 deceased NHATS respondents ("decedents") who completed at least one wave of the NHATS survey, for whom a proxy reporter provided information for at least one of the nine measures of EOL care quality, who self-identified as non-Hispanic white, non-Hispanic black, or Hispanic, and who had no missing values on dementia status or any of the other covariates listed in Table 1.

Measures

To assess quality of death, we use nine measures of proxies' perceptions of EOL care quality in the last month of life with respect to symptoms, quality of healthcare encounters (HE), and dignified care (DC). The measures have been validated elsewhere.¹⁶ Table 1 provides a summary of the original survey questions and final measures used in the latent class analysis (LCA). For all responses, indicators of higher quality care are coded with higher values to facilitate interpretation of results.

Three items assess symptoms commonly reported at EOL: pain, dyspnea, and sadness or anxiety. We combined three

questions about whether the decedent experienced a symptom, whether they received help for the symptom, and whether it was the right amount if help into a three-category variable for each symptom: "None" (no reported symptom), "Managed" (experienced symptom and received "about the right amount of help"), and "Unmanaged" (experienced symptom and received no, less, or more help than needed).

Four questions address quality of HE and two address DC. Two HE variables use Yes/No responses to measure whether (1) treatment decisions were made without the decedent's or family members' input, and (2) the decedent received unwanted care. We dichotomize whether the decedent was treated with respect (DC), their personal care needs were met (DC), and they or their family were informed about her health condition (HE), as "Always" and "Usually/Sometimes/Never." We measure coordination of care (HE) by combining two questions: whether there was more than one doctor involved in care and, if yes, whether it was clear which doctor oversaw care. We divide individuals into two groups: "One doctor/Clear doctor in charge if care" and "Unclear who was in charge of care."

We measure decedent race/ethnicity with dummy variables for self-reported black and Hispanic (reference category = white). Decedents with probable or possible dementia are grouped together (coded 1) and compared with those with no dementia (coded 0) based on self- or proxy-report of dementia diagnosis, AD8 Dementia Screening Interview score, and cognitive tests evaluating memory, orientation, and executive function.^{17,18}

The analysis also controls for factors that may affect EOL care quality.^{19–27} Decedent sociodemographic characteristics include: more than high school education, male, marital status, and five-year intervals of age at interview before death (top-coded at age 90). As reported in the survey before death, self-rated health (excellent/very good = 1), frequent hospitalization (2 or more), and number of diagnoses (0–5) with five chronic conditions that commonly cause death in older adults (cancer, diabetes, heart disease, lung problems, stroke) are controlled. Retrospective proxy reports of place of death, hospice involvement in the last month of life (2013–2016), familiarity with EOL care (very familiar = 1), and close relationship to the decedent (spouse or child = 1) are controlled. The analysis controls for survey round of last month of life interview (2012–2016) and if the decedent was added to NHATS in 2015.

Statistical analyses

LCA was used to identify statistically and conceptually distinct categories of EOL care quality based on responses to the nine measures outlined above (Table 2). LCA identifies unobserved (latent) subgroups based on response patterns to multiple categorical variables measured in the data. The resulting subgroups, or latent classes, represent discrete categories of EOL care quality. The LCA software we use accounts for missing data using a full information maximum likelihood technique, allowing for inclusion of decedents in the analysis, provided the proxy reporter answered at least one item used to determine the latent classes.^{28,29} As a result, the number of responses to each of the nine items about EOL care varies from 1433 to 1521 (out of 1588). Exploratory LCA indicates three classes best fit the data in this analysis. Next, we performed LCA with covariates, which uses logistic

TABLE 1. SUMMARY OF NINE MEASURES OF QUALITY OF END-OF-LIFE CARE USED IN LATENT CLASS ANALYSIS

<i>Variable</i>	<i>Measurement categories</i>	<i>Survey questions</i>
Pain	1. Unmanaged (yes to Q1, no to Q2; yes to Q1 & Q2, less or more help than needed to Q3)	1. During the last month of life, were there times when [deceased] experienced [pain, trouble breathing, feelings of anxiety or sadness]? (yes/no)
Breathlessness	2. Managed (yes to Q1 & Q2, about right amount of help to Q3)	2. If “yes” to question 1, Did [deceased] get any help in dealing with [symptom]? (yes/no).
Sadness/anxiety	3. None (no to Q1)	3. If “yes” to question 2, How much help in dealing with pain did [deceased] receive? (less than needed, more than needed, about right amount).
Involved in healthcare decisions	1. No	During the last month of [deceased]’s life, was there ever a decision made about {his/her} care or treatment without enough input from [deceased] or {his/her} family?
No unwanted care	2. Yes	During the last month of [deceased]’s life, was there any decision made about care or treatment that [deceased] would not have wanted? (yes=0, no=1)
Care coordination	1. Unclear who was in charge of care (yes to Q1, no to Q2)	1. During the last month of [deceased]’s life, was there more than one doctor involved in {his/her} care? (yes/no);
	2. One doctor/Clear doctor in charge of care (no to Q1; yes to Q1 & Q2)	2. If “yes,” During the last month of [deceased]’s life, was it always clear to you which doctor was in charge of {his/her} care? (yes/no).
Informed about condition	1. Usually, sometimes, never	During the last month of [deceased]’s life, how often were you or other family members kept informed about [deceased] condition?
Personal Care Needs Met	2. Always	During the last month of [deceased]’s life, how often were {his/her} personal care needs, such as bathing, dressing, and changing bedding, taken care of as well as they should have been?
Treated with respect		During the last month of [deceased]’s life, how often were [deceased] treated with respect by those who were taking care of [deceased]?

Measures taken from 2011 to 2016 NHATS. All responses provided by a proxy respondent familiar with decedent’s last month of life.

regression to determine the extent to which a single variable predicts membership in the previously identified latent classes. To focus on how race/ethnicity and dementia operate with respect to positive versus negative assessments of EOL care quality, we combined two latent classes representing positive assessments and use binomial logistic regression to compare the combined group to the latent class representing negative assessments.²⁸ We conducted latent class analyses with Stata 14/MP, using the doLCA command.³⁰

Results

Table 2 shows descriptive statistics for 1588 NHATS decedents. Proxies most often reported pain (72%) and 56% reported dyspnea or sadness/anxiety at EOL. Proxies positively rated other aspects of EOL care: 82–92% positively endorsed four measures of HEs and two measures of DC. White decedents comprised 72% of the sample; 23% were identified as black and 5% as Hispanic. Nearly 60% of decedents reported or exhibited cognitive impairment.

LCA (Table 3) indicates proxies report three types of EOL care quality. The two largest classes reflect positive assess-

ments of EOL care quality, with 88–95% probability proxies positively rate HEs and DC. Two-fifths (41%) of proxies are likely to also report that the decedent experienced no EOL symptoms (53–72% probability no pain, dyspnea, or sadness/anxiety). Thirty-seven percent report managed symptoms (56–82% probability managed pain, dyspnea, or sadness/anxiety), which may be unavoidable in some EOL contexts. The third class reflects negative assessments of EOL care quality. In this class, 22% of proxies are likely to report unmanaged or managed pain (39% and 50%, respectively) and sadness/anxiety (56% and 24%, respectively), and are less likely to report positive HEs and DC (40–78% probability across six measures), specifically always being informed about the decedent’s condition (40% probability) and decedent’s personal care needs always being met (44% probability).

Table 4 shows results for LCA with covariate models comparing odds of negative assessments of EOL care (unmanaged or managed pain and sadness/anxiety, more negative HEs and DC) to positive assessments (no or managed symptoms, positive HEs, and DC combined into a single reference category). The model adjusts for key predictors (race/ethnicity, dementia status) and additional factors that

TABLE 2. DESCRIPTIVE STATISTICS FOR 1588 NHATS DECEDENTS

	<i>Proportion/mean (SD)</i>	<i>n</i>
Quality (last month of life) ^a		
Pain		1489
Unmanaged	0.16	
Managed	0.56	
None	0.28	
Dyspnea		1489
Unmanaged	0.11	
Managed	0.45	
None	0.44	
Sadness or anxiety		1433
Unmanaged	0.26	
Managed	0.31	
None	0.44	
Involved in decisions	0.92	1482
Always informed about condition	0.82	1516
No unwanted treatment	0.89	1491
Clear care coordination	0.87	1472
Personal care needs always met	0.83	1521
Always treated with respect	0.89	1518
Key predictors		
Decedent race/ethnicity		1588
Non-Hispanic white (ref cat)	0.72	
Non-Hispanic black	0.23	
Hispanic	0.05	
Decedent dementia	0.59	1588
Decedent sociodemographic characteristics		
More than high school education	0.37	1588
Male	0.44	1588
Age at interview before death		1588
65–69	0.03	
70–74	0.09	
75–79	0.12	
80–84	0.21	
85–89	0.24	
90+	0.30	
Marital status		1588
Married (ref cat)	0.34	
Divorced/separated	0.10	
Widowed	0.52	
Never married	0.04	
Decedent health characteristics (interview before death)		
Number chronic conditions ^b	1.53 (1.14)	1588
2+ recent hospitalizations	0.22	1588
Excellent/very good self-rated health	0.19	1588
EOL care		
Place of death		1588
Home (ref cat)	0.38	
Hospital	0.35	
Nursing home	0.19	
Other	0.09	
Hospice involvement	0.45	1588
Proxy reporter characteristics		
Very familiar with EOL care	0.79	1588
Spouse or child	0.70	1588
Survey controls		
Round of last month of life interview		1588
R2 (2012)	0.21	
R3 (2013)	0.24	
R4 (2014)	0.18	
R5 (2015)	0.14	
R6 (2016)	0.22	
Respondent added to sample in R5	0.09	1588

National Health and Aging Trends Study. Analysis pools data from 2011 to 2016 annual surveys.

^aLCA model employs full information maximum likelihood, allowing for inclusion of decedents for whom proxy respondents answer at least one end-of-life care measure.

^bChronic conditions are cancer, diabetes, heart disease, lung problems, stroke.

EOL, end-of-life; LCA, latent class analysis; SD, standard deviation.

TABLE 3. ITEM RESPONSE PROBABILITIES FOR 3 CLASSES OF PERCEIVED END-OF-LIFE CARE QUALITY

	Negative assessment	Positive assessment	
	Unwanted pain and sadness/anxiety, poor-quality care	No symptoms, high-quality care	Managed symptoms, high-quality care
Predicted latent class size	22%	41%	37%
Pain			
Unmanaged	0.39	0.12	0.06
Managed	0.50	0.35	0.82
None	0.11	0.53	0.12
Dyspnea			
Unmanaged	0.23	0.09	0.06
Managed	0.43	0.30	0.63
None	0.34	0.62	0.31
Sadness or anxiety			
Unmanaged	0.56	0.17	0.18
Managed	0.24	0.12	0.56
None	0.21	0.72	0.26
Involved in decisions	0.78	0.96	0.95
Always informed about condition	0.40	0.92	0.95
No unwanted treatment	0.76	0.96	0.88
Clear care coordination	0.62	0.94	0.94
Personal care needs always met	0.44	0.93	0.94
Always treated with respect	0.58	0.97	0.97

LCA of proxy reports for 1588 decedents from the 2011 to 2016 NHATS.

TABLE 4. ADJUSTED ODDS RATIOS AND 95% CONFIDENCE INTERVALS PREDICTING NEGATIVE END-OF-LIFE CARE QUALITY ASSESSMENTS

	AOR	(95% CI) ^a
Key predictors		
Race/ethnicity (ref=non-Hispanic white)		
Non-Hispanic black	0.58	(0.40–0.86)
Hispanic	0.79	(0.37–1.69)
Decedent dementia	0.70	(0.51–0.97)
Decedent sociodemographic characteristics		
More than high school education	0.96	(0.71–1.29)
Male	0.97	(0.72–1.32)
Marital status (ref=married)		
Divorced/separated	1.90	(1.08–3.34)
Widowed	1.78	(1.21–2.64)
Never married	1.13	(0.46–2.76)
Age at interview before death ^b	0.86	(0.76–0.98)
Number of chronic conditions ^c (0–5) ^d	1.07	(0.93–1.22)
2 or more hospitalizations ^d	1.03	(0.73–1.46)
Self-rated health ^d	1.01	(0.71–1.45)
EOL characteristics		
Place of death (ref=home)		
Hospital	2.69	(1.85–3.90)
Nursing home	1.84	(1.17–2.90)
Other	3.01	(1.76–5.12)
Hospice involvement	1.02	(0.76–1.38)
Proxy characteristics		
Very familiar with EOL care	0.43	(0.30–0.62)
Spouse or child	1.66	(1.15–2.38)
Survey controls		
Round of last month of life interview (R2–R6)	1.04	(0.93–1.17)
Added to sample in R5	0.85	(0.48–1.50)

LCA with covariates of nine proxy-reported measures of end-of-life care quality for 1588 decedents from the 2011 to 2016 NHATS.

^aBolded AOR and 95% confidence intervals are significant at $p < 0.05$.

^bAge is recorded in five-year intervals, starting with 65–69 and top-coded at 90+.

^cChronic conditions are cancer, diabetes, heart disease, lung problems, stroke.

^dAs reported in interview before death.

AOR, adjusted odds ratio; CI, confidence interval.

research suggests are related to EOL care outcomes (decedent sociodemographic and health characteristics, place of death, hospice involvement, and proxy characteristics). Decedent race and dementia status independently predict assessments of EOL care quality. Proxies for black decedents and for decedents with dementia are less likely to report poor-quality EOL care than proxies for white decedents and decedents with no dementia (black adjusted odds ratio [AOR]: 0.58, 95% confidence interval [CI]=0.40–0.86; dementia AOR: 0.70, 95% CI=0.51–0.97). There were no differences in reports by proxies for Hispanic and white decedents.

Discussion

Our analyses reveal three distinct types of proxy-reported EOL care quality. The largest two classes—a combined 78% of the sample—represent positive assessments of HEs and DC, and are distinguished from one another by no or managed pain, dyspnea, and sadness/anxiety. A sizeable proportion (37%) of proxies positively assesses HEs and DC, even in the context of managed symptoms. Symptom abatement is associated with increased satisfaction with medical encounters.³¹ As such, these proxies may be acknowledging high-quality care in cases where unavoidable symptoms at EOL are effectively addressed.

In contrast, over one-fifth of proxies negatively assess EOL care quality, suggesting ample room for improvement. Our results suggest certain combinations of EOL care lend themselves to negative perceptions. For some proxies, the presence of pain and sadness/anxiety—even when adequately managed—was associated with reporting not always being informed about the dying individual's condition and that personal care needs (e.g., bathing, dressing) were not always addressed. Seriously ill individuals and their family members report it is very important that they know what to expect at EOL and that dying individuals be kept clean.³² In cases where these two needs are not addressed and symptoms are present, proxies may negatively assess EOL care quality. Curative treatment and chronic condition management may focus on specific symptoms earlier in disease trajectories. However, high-quality EOL care requires an approach that concurrently addresses multiple dimensions of patient needs. Results suggest symptom management, communication about condition, and personal care needs are particularly important elements to address together.

Decedent race and dementia status independently predict proxy EOL care quality assessments in models adjusting for additional factors. Proxies for black decedents are more likely to positively assess EOL care quality compared with proxies for white decedents. NHATS data do not allow us to assess actual EOL treatment. However, prior research indicates that black individuals receive more expensive^{33,34} and intensive care at EOL.^{1–3} Moreover, hospital deaths are associated with more aggressive EOL care,³⁵ and black decedents generally,³⁶ and in this sample, are more likely to die in hospital than white decedents (bivariate correlation not shown). Overall, hospital death (compared with home death) is associated with negative assessments of EOL care quality (Table 4). So, it is surprising that proxies for black decedents provide more positive assessments of EOL care than proxies for white decedents, given black decedents are more likely to have died in hospital and received aggressive EOL care.

Observed racial differences in perceived EOL care quality may reflect the relationship between expectations for care and perceptions of care quality. Expectations for medical care are linked to perceptions of and satisfaction with care: unmet expectations are associated with decreased satisfaction.^{31,37,38} Although cancer patients express similar desires to control their medical treatment regardless of race/ethnicity,³⁹ black and white patients report different expectations for medical care.³⁸ Prior research indicates black patients expect more referrals, tests, and physical exams than white patients in primary care,^{40,41} and older and seriously ill black adults prefer more treatments at EOL.^{42–44} Recent work suggests black–white differences in perceptions of EOL care are due to differences in relationships with providers, communication, illness understanding, and patient preferences, rather than religious and cultural values.⁴⁵ However, the reasons for racial differences in expectations for medical care are not well understood and require additional research.⁴⁰ Our findings suggest the importance of assessing caregiver expectations to provide value-consistent EOL care and understand differences in perceived care quality.

Similar to proxies for black decedents, proxies for decedents with dementia are more likely to positively assess EOL care quality than proxies for cognitively intact decedents. This finding is also puzzling, as persons with dementia are more likely to receive aggressive and futile care at EOL.^{4–7} Differences in caregiver expectations for EOL care may influence their perceptions of EOL care. Caregivers report less satisfaction with EOL care when it is more intense than expected.⁴⁶ Caregiving for dementia patients can be particularly burdensome; caregivers for dementia patients report high levels of physical and psychological burden associated with caregiving.^{47–49} However, because dementia patients often experience a prolonged and gradual decline, caregiving for dementia patients at EOL may not differ from caregiving at other points.⁵⁰ Moreover, caregivers for dementia may be more prepared for the care recipient's death. A majority of caregivers report they were prepared for the dementia patient's death⁵¹ and reported the death was a relief to them and the patient.^{48,52,53} Preparedness for the death of a loved one is associated with less severe levels of prolonged grief after the loss, particularly in caregivers of dementia patients.^{51,54} Caregivers of decedents with dementia in this analysis may be better prepared for their loved ones' deaths and so positively assess care quality.

This study has four limitations. Study data do not account for actual EOL treatments, and so a direct comparison between EOL treatment and perceptions of care quality is not possible. Second, NHATS does not capture cause of death or information about the dying trajectory. Sudden versus prolonged death may affect the types of interventions an individual receives, the ability to put effective comfort care measures in place, and perceptions of the dying individual's degree of suffering. We control for chronic conditions and frequent hospitalization in the year before death as markers of chronic and acute care needs close to EOL. Third, we use dementia status as a marker of progressive cognitive decline that impacts EOL care needs and quality. However, the NHATS dementia variable construction allows for variability, including improvement, in cognitive functioning over time. In our analysis we limit dementia status to the interview before death to approximate cognitive status as close to EOL as possible. Future research should examine the relationship

between variable dementia trajectories and EOL care quality. Finally, we cannot account for how variation in hospice care setting (e.g., home, nursing home) may affect perceptions of EOL care quality for dementia patients. However, dementia patients are likely to undergo multiple burdensome transitions between care settings at EOL.^{6,7} The dementia decedents in NHATS may have received hospice in multiple settings, including being discharged from hospice at the time of death (as suggested in bivariate correlation not shown), which we cannot accurately assess with NHATS.

Conclusion

Additional efforts are needed to improve perceptions of care for the one-in-five proxies who negatively assess EOL care quality. Targeting emotional and physical pain, improving communication, and addressing personal care needs simultaneously could improve perceptions of EOL care quality. Additional research is needed to understand the mechanisms linking decedent race and dementia status to proxy EOL care assessments. Identifying how differing expectations for EOL care shape perceptions of care quality is a potentially promising area for future research. Expectations can potentially be modified to align more closely with a dying individual's likely clinical course. Moreover, identifying expectations provides an opportunity to deliver value-centered care concordant with those expectations.

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