

CLINICAL INVESTIGATION

Associations between dementia diagnosis and end-of-life care utilization

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Abstract

Background: Dementia is a leading cause of death for older adults and is more common among persons from racial/ethnic minoritized groups, who also tend to experience more intensive end-of-life care. This retrospective cohort study compared end-of-life care in persons with and without dementia and identified dementia's moderating effects on the relationship between race/ethnicity and end-of-life care.

Methods: Administrative claims data for 463,590 Medicare fee-for-service decedents from 2016 to 2018 were analyzed. Multivariable logistic and linear regression analyses examined the association of dementia with 5 intensive and 2 quality of life-focused measures. Intensity measures included hospital admission, ICU admission, receipt of any of 5 intensive procedures (CPR, mechanical ventilation, intubation, dialysis initiation, and feeding tube insertion), hospital death, and Medicare expenditures (last 30 days of life). Quality of life measures included timely hospice care (>3 days before death) and days at home (last 6 months of life). Models were adjusted for demographic and clinical factors.

Results: 54% of Medicare decedents were female, 85% non-Hispanic White, 8% non-Hispanic Black, and 4% Hispanic. Overall, 51% had a dementia diagnosis claim. In adjusted models, decedents with dementia had 16%–29% lower odds of receiving intensive services (AOR hospital death: 0.71, 95% CI: 0.70–0.72; AOR hospital admission: 0.84, 95% CI: 0.83–0.86). Patients with dementia had 45% higher odds of receiving timely hospice (AOR: 1.45, 95% CI: 1.42–1.47), but spent 0.74 fewer days at home (adjusted mean: –0.74, 95% CI: (–0.98)–(–0.49)). Compared to non-Hispanic White individuals, persons from racial/ethnic minoritized groups were more likely to receive intensive services. This effect was more pronounced among persons with dementia.

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Conclusions: Although overall dementia was associated with fewer intensive services near death, beneficiaries from racial/ethnic groups minoritized with dementia experienced more intensive service use. Particular attention is needed to ensure care aligns with the needs and preferences of persons with dementia and from racial/ethnic minoritized groups.

KEYWORDS

care intensity, dementia, end-of-life care, health disparities, race/ethnicity

INTRODUCTION

Dementia is a leading and growing cause of death for individuals over age 65.¹ However, the relationship between dementia and end-of-life (EOL) care intensity is not well-established, varying by the EOL care measure studied.²⁻⁹ Care “intensity” can be measured in several ways including the principal domains of greater intensity represented by measures of medical care utilization intended to prolong life.^{2,3,10} However, uncertainty in the relationship between dementia and EOL care intensity is evident in studies dating to the 2000’s. For example, 40% of primarily non-Hispanic White persons living with dementia (PLWD) in a sample of Massachusetts nursing homes received intensive EOL services including hospitalization and artificial nutrition.⁴ In a national sample of nursing home data, in-hospital deaths remained lower among PLWD than residents without dementia.¹¹ An analysis of pre-2008 Health and Retirement Study data indicated PLWDs were less likely to undergo intensive procedures including mechanical ventilation, intubation, hemodialysis, and CPR at the EOL.³ Moreover, previous studies are limited in that they only examined selected measures of EOL care intensity,^{3,10,12,13} focused on specialized patient populations (e.g., individuals with cancer),¹³ or used small samples from limited geographic areas or particular care settings (e.g., nursing homes).^{2,4,10} Finally, dying PLWD also increasingly experience care that promotes their quality of life, including hospice care and home death.¹ These shifts underscore the need to better understand both intensive and comfort-focused EOL care in this population. Patients often experience both intensive and quality of life-promoting care near the EOL, as evidenced by trends in increased care intensity, hospice use, and days at home.¹⁴ However, studies tend to focus on selected measures of care intensity without addressing quality of life-focused care. In this study, we address these gaps by analyzing multiple dimensions of both intensive and quality-of-life promoting EOL care in a recent, large, national sample of Medicare decedents in all care settings.

Key points

- Fifty-one percent (51%) of Medicare decedents had a claim with a dementia diagnosis and received less intensive care at the end of life
- Persons from racial and ethnic minoritized groups received more intensive services, an effect that was more pronounced among persons with dementia.

Why does this paper matter?

Improved understanding of end-of-life care preferences of persons with dementia and from racial and ethnic minoritized groups is needed to ensure differences in care intensity are consistent with preferences.

Furthermore, differences in dementia prevalence and EOL care intensity by racial and ethnic groups raise questions regarding how dementia and race/ethnicity interact with EOL experiences. Dementia is more prevalent among Black and Hispanic persons, who are also diagnosed at later stages of the disease, are less likely to participate in clinical trials, and are less often prescribed dementia medication.¹ Black and Hispanic individuals receive more intensive EOL care¹⁵ and enroll in hospice at lower rates than non-Hispanic Whites.¹⁶ These differences underscore the importance of understanding the role of dementia with respect to racial/ethnic differences in EOL care, specifically whether disparities in dementia diagnosis and care extend to and exacerbate differences in EOL care. To our knowledge, this is the first study to analyze differential experiences of dementia burden by racial/ethnic groups, exploring the potentially moderating effects of dementia on the relationship between race/ethnicity and EOL care.

METHODS

Data

This retrospective cohort study used 2016–2018 administrative claims data from a 20% random sample of Medicare beneficiaries ($n = 13,583,622$) with continuous fee-for-service coverage during the study period ($n = 6,173,615$); who died in 2017–2018 ($n = 530,945$); and did not have a first dementia diagnosis claim in the last month of life, were under age 65, or missing information on hospital referral region ($n = 463,590$) (Figure S1). Information was used from the outpatient, carrier, and Medicare Data on Provider Practice and Specialty (MD-PPAS) files. In sensitivity analyses, we conducted the analyses described below including beneficiaries with a first dementia diagnosis in the last month of life; the results did not substantively differ (Tables S1 and S2).

End-of-life care outcomes

We analyzed seven measures of EOL care: five related to care intensity and two to quality of life-focused outcomes. We used binary (yes = 1) measures for four intensive services: hospital admission, ICU admission, or receipt of one or more of five inpatient intensive procedures (CPR, mechanical ventilation, intubation, feeding tube initiation, and new dialysis) in the last 30 days of life; and hospital death. Based on prior literature and in consultation with two hospitalists, a geriatrician/palliative care physician, and one nephrologist/palliative care physician, we selected the five hospital-based intensive procedures using ICD-9 and ICD-10 procedure codes,^{10,17–21} and CPT billing codes (Table S3). We measured Medicare expenditures in the last 30 days of life continuously, with higher costs indicating greater care intensity.²² We calculated expenses by aggregating costs from inpatient, outpatient, carrier, skilled nursing facility (SNF), and hospice claims during the last 30 days of life.

Quality of life-focused measures included timely hospice use (>3 days of hospice care = 1; 0–3 days = 0²³) and number of days at home in the last 6 months of life (measured continuously). Hospice is associated with better quality of life at the EOL. However, patients must receive a timely referral (at least 72 h before death²³) for the benefits of hospice care to take effect. Additionally, most adults (86%) express a desire to spend their final days at home,²⁴ and home time is considered a quality-of-life measure for dying individuals.²⁵ We defined “days at home” as those not spent in an acute care facility, inpatient rehabilitation facility, SNF, or inpatient hospice

unit,²⁵ with more days at home indicating more quality of life-focused care. Our “days at home” calculation includes assisted living and other non-SNF, long-term care facilities where many PLWD reside during their final years. For these beneficiaries, the facility is their baseline, and therefore considered their “home.” The 6-month lookback period for this measure is consistent with others’ approaches^{25,26} and provides more stability to the measure in the event an individual was hospitalized during the look-back period.

Key predictors

We identified persons with a dementia diagnosis using the Chronic Condition Warehouse algorithm, which flags patients based on the presence of at least one inpatient, SNF, home health, outpatient, or carrier claim with an Alzheimer’s disease or related dementia ICD-10 diagnosis code during the enrollment year or up to two years preceding the enrollment year (Table S4),²⁷ excluding individuals whose first dementia diagnosis claim occurred in the last 30 days of life. Dementia diagnosis codes are known to be highly specific, although the literature on their sensitivity is mixed.²⁸ However, there are no validation studies focusing on PLWD near the end of life. This method yields similar dementia prevalence estimates to nationally representative survey data,²⁹ although it likely provides a conservative estimate of dementia diagnoses, as it potentially under-identifies dementia, particularly among racial/ethnic minoritized groups.³⁰ Race/Ethnicity included non-Hispanic White, non-Hispanic Black, Hispanic, Asian/Pacific Islander, and other race/ethnicity (includes unknown) based on the Research Triangle Institute algorithm in the Master Beneficiary Summary File.

Covariates

We controlled for patient demographic and health characteristics that may be confounded with EOL care intensity and dementia. Being male, younger, Medicare-Medicaid dual-enrolled, and advance care planning (ACP) completion are associated with intensive EOL care.^{3,22,31,32} We identified ACP services using CPT codes 99,497 and 99,498. Being female, older, and having less education are associated with an increased risk of dementia.¹ We adjusted models for patient health factors that might affect EOL care complexity. We controlled for multiple morbidities, which may necessitate complex EOL care, using the Elixhauser comorbidity score in the 6 months before death.³³ We controlled for frailty in the

year before death using the claims-based frailty index (CFI): non frail (CFI <0.10), prefrail (CFI = 0.10–0.19), mildly frail (CFI = 0.20–0.29), moderately frail (CFI = 0.30–0.39), and severely frail (CFI ≥0.40).³⁴ The CFI captures multiple factors in addition to comorbidity and is recommended for inclusion alongside age, sex, and comorbidity measures in multivariable analyses.³⁵ We excluded claims from the last 30 days of life for comorbidity and frailty measures to remove overlap with the timing of outcomes measurement. To account for potential differences in resources and practice over time and variations in patients' exposure to a potential dementia diagnosis we controlled for year of death. Additionally, to account for geographic variation in health services, we grouped patients into hospital referral region (HRR) spending categories, assigning each patient to an HRR based on zip codes.³⁶ We calculated the average Medicare expenditure for each HRR using the age-, sex-, and race-adjusted expenses for all beneficiaries in that HRR over a 5-year period from 2012 to 2016.³⁶ Based on the distribution and to aid interpretation, we then categorized each HRR into one of three spending levels: high (>75th percentile), medium (25th–75th percentile), or low (<25th percentile).

Analysis

For each outcome and covariate, we calculated descriptive statistics for the cohorts with and without a dementia diagnosis at death. We used chi-square tests and t-tests to identify significant differences in EOL care outcomes between persons with and without a dementia diagnosis for binary and continuous variables, respectively. To model the association between dementia and each of the EOL care outcomes, we used multivariable logistic and linear regression models for binary and continuous outcome measures, respectively, for decedents with no missing information on any covariates, adjusting for demographic and clinical factors. In our primary analysis, we reported adjusted odds ratios and mean adjusted differences for dementia only. In the secondary analysis, we included interaction terms to determine whether more intensive EOL care among persons from racial/ethnic minoritized groups persists among PLWD. For multivariable analyses, we applied a Bonferroni correction to account for multiple comparisons, considering p values <0.007 significant. To account for the potential effect of receipt of hospice care on intensive end-of-life care, we conducted sensitivity analyses controlling for hospice admission between 30 and 180 days prior to death in care intensity models. All analyses were conducted using SAS 9.4.

RESULTS

There were 463,590 Medicare beneficiaries who died in 2017–2018, of whom 234,737 (51%) had a dementia diagnosis claim (Table 1). The sample was predominantly non-Hispanic White (85%), followed by non-Hispanic Black (8%) and Hispanic (4%). Over a quarter (28%) were Medicaid-Medicare dual eligible, 88% did not have a claim for physician-led ACP more than 30 days before death, and 42% were classified as moderately or severely frail. Compared to persons without dementia, a higher percentage of PLWD were female (47% versus 61%), Medicaid-Medicare dual eligible (18% versus 37%), moderately or severely frail (22% versus 61%), and had completed ACP more than a month before death (7% versus 10%) ($p < 0.0001$ for all comparisons).

PLWD received intensive services less often than persons without dementia (Table 2). Compared to persons without dementia, PLWD were admitted to the ICU in the last month of life (23% vs. 14%) and received intensive procedures (18% vs. 10%) less often. Results for quality of life-focused care measures were mixed. PLWD received more hospice care than those without dementia (52% vs. 34% spent >3 days in hospice). Surprisingly, despite fewer hospital admissions and more hospice days, PLWD spent fewer days at home in the last 6 months of life (155 vs. 165) ($p < 0.0001$ for all comparisons).

The relationship between dementia and less intensive EOL care persisted in models adjusting for demographic and clinical factors (Table 3). Compared to persons without dementia, PLWD had 16%–29% lower odds of dying in the hospital (AOR: 0.71; 95% CI: 0.70–0.72; $p < 0.0001$), being admitted to the hospital (AOR: 0.84; 95% CI: 0.83–0.86; $p < 0.0001$) or ICU (AOR: 0.75; 95% CI: 0.74–0.77; $p < 0.0001$), or receiving intensive procedures in the last 30 days of life (AOR: 0.73; 95% CI: 0.71–0.748; $p < 0.0001$). PLWD had on average \$2154–\$2648 lower total Medicare expenditures in the last 30 days of life ($p < 0.0001$). PLWD had 45% higher odds of receiving a timely hospice referral (AOR: 1.45; 95% CI: 1.42–1.47; $p < 0.0001$). PLWD spent 0.74 fewer days at home, including long-term residence in non-SNF nursing homes, in the last 6 months of life (mean difference: –0.74, 95% CI: (–0.98)–(–0.49), $p < 0.0001$).

In our secondary analysis, several of the interactions between dementia status and race/ethnicity were significant (Table S4). Generally, across all racial/ethnic groups persons with a dementia diagnosis received less intensive EOL care for all measures compared to persons without dementia. As with prior studies, persons from racial/ethnic minoritized groups (non-Hispanic Black, Hispanic, Asian/Pacific Islander persons, and those of other race/ethnicity) had higher odds of receiving intensive EOL

TABLE 1 Characteristics of 463,590 fee-for-service medicare patients, 65+ years in 20% sample who died in 2017 or 2018, and end-of-life service use, by dementia status

	Total sample		No dementia diagnosis		Dementia diagnosis	
	n/mean	%/sd	n/mean	%/sd	n/mean	%/sd
All patients	463,590	100.0%	228,853	49.4%	234,737	50.6%
Key predictors						
<i>Race</i>						
Non-Hispanic White	392,081	84.6%	194,542	85.0%	197,539	84.2%
Non-Hispanic Black	36,336	7.8%	16,462	7.2%	19,874	8.5%
Hispanic	19,621	4.2%	9363	4.1%	10,258	4.4%
Asian/Pacific Islander	8526	1.8%	4165	1.8%	4361	1.9%
Other	7026	1.5%	4321	1.9%	2705	1.2%
Covariates						
<i>Sex</i>						
Male	212,123	45.8%	120,213	52.5%	91,910	39.2%
Female	251,467	54.2%	108,640	47.5%	142,827	60.8%
<i>Age</i>	83	9.1	79.5	8.8	85.8	8.2
<i>Dual medicaid-medicare eligibility</i>						
	128,224	27.7%	41,623	18.2%	86,601	36.9%
<i>ACP</i>						
No	407,672	87.9%	204,907	89.5%	202,765	86.4%
First ACP in last 30d	16,604	3.6%	8364	3.7%	8240	3.5%
First ACP before last 30d	39,314	8.5%	15,582	6.8%	23,732	10.1%
<i>HRR medicare spending level</i>						
Low	82,545	17.8%	44,278	19.3%	38,267	16.3%
Medium	256,258	55.3%	127,252	55.6%	129,006	55.0%
High	124,787	26.9%	57,323	25.0%	67,464	28.7%
<i>Elixhauser comorbidity score in the last 1–6mos of life</i>						
0	7088	1.5%	4298	1.9%	2790	1.2%
1	12,432	2.7%	5931	2.6%	6501	2.8%
2	20,057	4.3%	8968	3.9%	11,089	4.7%
3	26,993	5.8%	11,535	5.0%	15,458	6.6%
4	31,972	6.9%	13,648	6.0%	18,324	7.8%
5+	356,868	77.0%	177,245	77.4%	179,623	76.5%
<i>Frailty in the last 1–12mos of life</i>						
Non-frail	11,914	2.6%	11,040	4.8%	874	0.4%
Pre-frail	91,522	19.7%	75,007	32.8%	16,515	7.0%
Mildly frail	167,638	36.2%	92,519	40.4%	75,119	32.0%
Moderately frail	141,174	30.5%	40,295	17.6%	100,879	43.0%
Severely frail	51,342	11.1%	9992	4.4%	41,350	17.6%
<i>Year of death</i>						
2017	238,180	51.4%	119,196	52.1%	118,984	50.7%
2018	225,410	48.6%	109,657	47.9%	115,753	49.3%

Note: All *p* values are <0.0001 when comparing no and yes dementia samples using chi-square (for categorical variables) and t-test (for continuous variables) tests. Comorbidities missing for 8180 individuals. Percentages calculated based on 448,322 persons for which there was comorbidity data. Comorbidity score and frailty scores exclude data from last 30 days of life to avoid overlap with outcome measures. Medicare expenditures are drawn from the outpatient, carrier, and MD-PPAS files.

Abbreviations: 12mo, 12 months; 30d, 30 days; 6mo, 6 months; ACP, advance care planning; *n*, number; SD, standard deviation.

TABLE 2 Characteristics of 463,590 fee-for-service Medicare patients, 65+ years in 20% sample who died in 2017 or 2018, and end-of-life service use, by dementia status

	Total sample		No dementia diagnosis		Dementia diagnosis	
	n/mean	%/sd	n/mean	%/sd	n/mean	%/sd
All patients	463,590	100.0%	228,853	49.4%	234,737	50.6%
Intensive care						
<i>Hospital admission in the last 30d</i>						
	220,550	47.6%	120,716	52.7%	99,834	42.5%
<i>ICU visit in the last 30d</i>						
	85,402	18.4%	53,071	23.2%	32,331	13.8%
<i>Any life-sustaining treatment in last 30d</i>						
	63,921	13.8%	41,636	18.2%	22,285	9.5%
Dialysis initiated	7868	1.7%	5365	2.3%	2503	1.1%
Feeding tube inserted	12,106	2.6%	6773	3.0%	5333	2.3%
Mechanical ventilation	48,650	10.5%	32,435	14.2%	16,215	6.9%
Intubation	40,696	8.8%	27,299	11.9%	13,397	5.7%
Resuscitation	13,478	2.9%	9577	4.2%	3901	1.7%
<i>In Hospital Death</i>	92,726	20.0%	57,905	25.3%	34,821	14.8%
<i>Medicare expenditure in the last 30d</i>						
	\$16,479	\$23,711	\$19,008	\$25,696	\$14,129	\$21,439
<i>Medicare expenditure in the last 30d stratified by HRR</i>						
Low	\$15,289	\$22,235	\$18,200	\$26,414	\$12,088	\$15,854
Medium	\$15,845	\$24,124	\$18,470	\$24,762	\$13,368	\$23,235
High	\$18,555	\$23,653	\$20,830	\$27,070	\$16,722	\$20,306
Quality of life-focused care						
<i>Timing of hospice referral</i>						
No or late hospice [≤3d before death]	264,552	57.1%	151,063	66.0%	113,489	48.3%
Timely hospice [>3d before death]	199,038	42.9%	77,790	34.0%	121,248	51.7%
<i>Days at home in 6mos of life</i>						
	160.30	37.10	165.40	29.30	155.30	42.90

Note: All *p* values are <0.0001 when comparing no and yes dementia samples using chi-square (for categorical variables) and t-test (for continuous variables) tests. Medicare expenditures are drawn from the outpatient, carrier, and MD-PPAS files.

Abbreviations: 3d, 3 days; 30d, 30 days; 6mo, 6 months; HRR, hospital referral region; ICU, intensive care unit; *n*, number; SD, standard deviation.

care compared to non-Hispanic Whites. However, the magnitude of this effect differed by dementia status (Table 4). For example, among persons without dementia, Asian/Pacific Islander persons had 73% higher odds of receiving intensive procedures. However, among persons with a dementia diagnosis, Asian/Pacific Islander persons had 175% higher odds of receiving intensive procedures. Similar patterns were observed for all intensive care measures. Figure 1 depicts adjusted odds ratios of four intensive EOL care measures by race/ethnicity and dementia status.

DISCUSSION

Main findings

This paper examines differences in intensity and quality of life-focused EOL measures based on dementia status for Medicare decedents. We captured multiple aspects of care in our analysis, including procedures, location, and financial expenditure. We found that over half of Medicare decedents had a dementia diagnosis claim in the three years before death, and that, adjusting for

TABLE 3 Adjusted odds ratios and mean adjusted differences of effect of dementia diagnosis on intensive and comfort care measures at the end of life for fee-for-service Medicare patients, 65+ years in 20% sample who died in 2017 or 2018

Outcome	AOR/MD	95% CI
Intensive care		
<i>Hospital admission in last 30d</i>	0.84	0.83–0.86
<i>ICU stay in last 30d</i>	0.75	0.74–0.77
<i>Any intensive treatment in last 30d</i>	0.73	0.71–0.7
<i>Hospital death</i>	0.71	0.70–0.72
Medicare expenditures in last 30d by HHR spending class		
Low	\$ –2648	(–\$3003) – (–\$2292)
Medium	\$ –2328	(–\$,2551) – (–\$2106)
High	\$ –2154	(–\$2468) – (–\$1840)
Quality of life-focused care		
<i>Timely hospice referral (>3d before death)</i>	1.45	1.42–1.47
<i>Days at home in last 6mo</i>	–0.74	(–0.98) – (–0.50)

Note: All models adjusted for race, sex, age, dual eligibility, frailty, ACP, Elixhauser comorbidity score, and year of death. All models were corrected for multiple comparisons where the Bonferroni-corrected threshold for significance was $p = 0.007$. p value <0.0001 for all models. Medicare expenditures are drawn from the outpatient, carrier, and MD-PPAS files. Adjusted odds ratios and mean differences reported for effect of dementia (reference = no dementia). Abbreviations: 3d, 3 days; 30d, 30 days; 6mo, 6 months; AOR, adjusted odds ratios; CI, confidence interval; HRR, hospital referral region; ICU, intensive care unit; MD, mean difference.

demographic and clinical characteristics, having dementia was associated with receiving lower intensity services and lower total Medicare expenditures at the end of life. The relationship between dementia and lower intensity services persisted in sensitivity analyses that controlled for hospice admission between 30 and 180 days prior to death. A mixed picture emerged with respect to quality of life-focused measures. Having dementia was associated with timely hospice use, but with fewer at-home days in the last 6 months of life. However, these findings are consistent with studies showing PLWDs are at increased risk of extended hospice stays (>6 months)³⁷ and more likely to die in a nursing facility.³⁸

We also found the odds of receiving intensive or quality of life-focused EOL services based on dementia status are not evenly distributed across racial/ethnic groups. Compared to non-Hispanic Whites, persons from racial/ethnic minoritized groups were more likely to be hospitalized, admitted to the ICU, receive intensive services, or die in a hospital. Among PLWD, associations between race/ethnicity and EOL care were more pronounced. Sensitivity analyses controlling for hospice admission between 30 and 180 days prior to death yielded similar results. Our finding that persons from marginalized racial/ethnic minoritized groups receive more intensive EOL care is consistent with prior research on Black and Hispanic samples,^{15,39,40} which has been attributed to preferences for more aggressive care³⁹ and poorer physician communication with patients from these groups.⁴⁰

Moreover, disparities in dementia diagnosis and differences in EOL care among racial/ethnic minoritized groups underscore the importance of understanding EOL care for PLWD from these groups. There is a higher prevalence of dementia among Black and Hispanic persons,¹ partially due to greater health and socioeconomic risk factors and exposure to discrimination and structural racism.^{1,41} Studies with large samples of Asian/Pacific Islander persons are less common, making ours a new contribution to the field (see Jia, et al 2021⁷ and Bell, et al 2009⁶ for exceptions). This difference is not problematic if it reflects patient preferences for intensive services.³⁹ However, additional research is needed to understand whether these differences may be attributable to other factors including systemic racism, discrimination, poor physician communication, and other barriers to accessing healthcare.^{1,41} Moreover, particular attention should be given to identifying and respecting care preferences of persons from marginalized racial/ethnic minoritized groups with dementia as ACP is less common among these populations,⁴² has been shown to not result in goal-concordant care,⁴³ and may result in increased psychological harm⁴⁴ among Black persons.

Limitations

This study has limitations. First, we are unable to ascertain whether EOL care received was consistent with the

TABLE 4 Adjusted odds ratios and mean adjusted differences in intensive and comfort care measures at the end of life comparing racial/ethnic groups to non-Hispanic White for dementia and no dementia groups for fee-for-service medicare patients, 65+ years in 20% sample who died in 2017 or 2018

	Among persons with dementia diagnosis			Among persons without dementia diagnosis		
	AOR/MD	95% CI	p value	AOR/MD	95% CI	p value
INTENSIVE CARE						
<i>Hospitalization in last 30d</i>						
<i>NHB</i>	1.52	1.47–1.57	<0.0001	1.15	1.11–1.20	<0.0001
<i>Asian/PI</i>	1.75	1.64–1.88	<0.0001	1.24	1.15–1.33	<0.0001
<i>Hispanic</i>	1.63	1.56–1.71	<0.0001	1.25	1.19–1.31	<0.0001
<i>Other</i>	1.36	1.25–1.48	<0.0001	1.05	0.98–1.13	0.16
<i>ICU admission in last 30d</i>						
<i>NHB</i>	1.64	1.58–1.7	<0.0001	1.15	1.10–1.19	<0.0001
<i>Asian/PI</i>	1.97	1.82–2.13	<0.0001	1.47	1.36–1.58	<0.0001
<i>Hispanic</i>	1.85	1.76–1.95	<0.0001	1.30	1.23–1.37	<0.0001
<i>Other</i>	1.30	1.17–1.44	<0.0001	1.08	1.00–1.16	0.039
<i>Any intensive treatment in last 30d</i>						
<i>NHB</i>	2.45	2.35–2.55	<0.0001	1.52	1.46–1.58	<0.0001
<i>Asian/PI</i>	2.75	2.53–2.99	<0.0001	1.73	1.60–1.87	<0.0001
<i>Hispanic</i>	2.37	2.24–2.51	<0.0001	1.48	1.40–1.56	<0.0001
<i>Other</i>	1.56	1.39–1.74	<0.0001	1.14	1.06–1.23	0.0006
<i>Hospital death</i>						
<i>NHB</i>	1.54	1.48–1.60	<0.0001	1.25	1.20–1.29	<0.0001
<i>Asian/PI</i>	2.30	2.14–2.48	<0.0001	1.45	1.35–1.55	<0.0001
<i>Hispanic</i>	1.71	1.62–1.79	<0.0001	1.29	1.23–1.36	<0.0001
<i>Other</i>	1.61	1.47–1.77	<0.0001	1.19	1.11–1.27	<0.0001
<i>Medicare expenditures by HRR spending level</i>						
Low						
<i>NHB</i>	\$4169	\$2709–\$5628	<0.0001	\$4606	\$3095–\$6116	<0.0001
<i>Asian/PI</i>	\$4574	\$3393–\$5755	<0.0001	\$2074	\$879–\$3270	<0.0001
<i>Hispanic</i>	\$4445	\$3289–\$5602	<0.0001	\$5566	\$4514–\$6618	<0.0001
<i>Other</i>	\$3528	\$2052–\$5003	<0.0001	\$4321	\$3141–\$5501	<0.0001
Medium						
<i>NHB</i>	\$3679	\$32,230–\$4128	<0.0001	\$2422	\$1931–\$2912	<0.0001
<i>Asian/PI</i>	\$7246	\$5997–\$8495	<0.0001	\$8588	\$7329–\$9846	<0.0001
<i>Hispanic</i>	\$4541	\$3792–\$5290	<0.0001	\$4780	\$3968–\$5591	<0.0001
<i>Other</i>	\$1669	\$311–\$3028	0.016	\$3455	\$2361–\$4549	<0.0001
High						
<i>NHB</i>	\$4811	\$4239–\$5383	<0.0001	\$2975	\$2295–\$3655	<0.0001
<i>Asian/PI</i>	\$8948	\$7805–\$10,091	<0.0001	\$9257	\$7885–\$10,629	<0.0001
<i>Hispanic</i>	\$5568	\$4890–\$6245	<0.0001	\$5633	\$4772–\$6493	<0.0001
<i>Other</i>	\$4116	\$2402–\$5830	<0.0001	\$2036	\$4,99–\$3574	0.009
QUALITY OF LIFE-FOCUSED CARE						
<i>Timely Hospice referral (>3d before death)</i>						
<i>NHB</i>	0.82	0.80–0.85	<0.0001	0.74	0.71–0.77	<0.0001

TABLE 4 (Continued)

	Among persons with dementia diagnosis			Among persons without dementia diagnosis		
	AOR/MD	95% CI	p value	AOR/MD	95% CI	p value
<i>Asian/PI</i>	0.69	0.65–0.73	<0.0001	0.88	0.82–0.94	0.0004
<i>Hispanic</i>	0.93	0.89–0.97	0.0004	0.89	0.85–0.94	<0.0001
<i>Other</i>	0.79	0.73–0.85	<0.0001	0.83	0.76–0.89	<0.0001
<i>Days at home in last 6mos</i>						
<i>NHB</i>	–2.73	(–3.25)–(–2.22)	<0.0001	0.31	(–0.25)–0.88	0.28
<i>Asian/PI</i>	0.73	(–0.32)–1.78	0.17	1.37	0.26–2.48	0.016
<i>Hispanic</i>	3.39	2.67–4.09	<0.0001	3.2	2.43–3.97	<0.0001
<i>Other</i>	0.42	(–0.90)–1.74	0.91	1.01	(–0.06)–(2.08)	0.063

Note: Reference category = non-Hispanic White. Adjusted odds ratios and mean differences between racial/ethnic group listed compared to non-Hispanic White. All models adjusted for sex, age, dual eligibility, frailty, ACP, Elixhauser comorbidity score, and year of death. All models were corrected for multiple comparisons where the Bonferroni-corrected threshold for significance was $p = 0.007$. Medicare expenditures are drawn from the outpatient, carrier, and MD-PPAS files.

Abbreviations: 3d, 3 days; 30d, 30 days; 6mo, 6 months; AOR, adjusted odds ratios; CI, confidence interval; HRR, hospital referral region; ICU, intensive care unit; MD, mean difference; NHB, non-Hispanic Black; NHW, non-Hispanic White; PI, Pacific Islander; Ref, reference category.



FIGURE 1 Adjusted odds ratios of four measures of intensive end-of-life care by race/ethnicity and dementia. Reference category = non-Hispanic White. For example, among persons without dementia, non-Hispanic Black persons had 15% higher odds of hospitalization in the last 30 days of life compared to non-Hispanic White persons. Among persons with a dementia diagnosis, non-Hispanic Black persons had 52% higher odds of hospitalization in the last 30 days of life compared to non-Hispanic Whites. Hospitalization, ICU stay, and intensive treatment measured within the last 30 days of life. “Any intensive treatment” refers to resuscitation, mechanical ventilation, intubation, feeding tube insertion, or new dialysis. Models adjusted for demographic and health characteristics, advance care planning, hospital referral region spending, and year of death. All categories are significantly greater than non-Hispanic Whites except, among persons without dementia, “Other/Unknown race/ethnicity” for hospitalizations ($p = 0.16$) and ICU admission ($p = 0.04$). p value for all significant categories <0.0001 except for among persons without dementia, “Other/Unknown race/ethnicity” intensive procedures ($p = 0.0006$)

values and preferences of decedents and families. Additional research is needed in this area, particularly for persons from racial/ethnic minoritized groups. Second, the dementia diagnosis flag in claims data does not provide information about the cause of death or severity or type of dementia, which may affect the care required at the end of life. Dementia severity should not explain racial/ethnic differences in care. However, persons living with advanced dementia are often admitted to the hospital for infections, falls, and behavioral disturbances, possibly requiring fewer intensive services.⁴⁵ The dementia flag we used may result in misclassification of individuals (i.e., diagnosing individuals with mild or no cognitive impairment with dementia, missed dementia diagnosis of cognitively impaired persons),^{28,46,47} particularly among racial/ethnic minoritized groups.²⁹ However, recently proposed alternative methods of identifying dementia in claims data require additional cognitive tests²⁸ or years of data⁴⁶ unavailable to us. Moreover, these methods do not examine data specifically for patients near the end of life. Third, although we include physician ACP billing in adjusted analyses, we cannot assess the content or quality of ACP conversations or account for unbilled ACP. Fourth, we were unable to capture the experiences of persons with Medicare Advantage, who may utilize EOL care differently. Fifth, these data cannot be analyzed by decedent place of residence. As such, we cannot account for differences in care utilization (e.g., hospice use, hospitalization) or costs between nursing home residents and community-dwellers. The Minimum Data Set captures whether an individual was in a nursing home at the time the survey was administered but does not indicate the length of stay. Nor does the measure used to calculate days at home distinguish between community-dwelling individuals and those whose primary residence is a non-SNF nursing home, where PLWD are disproportionately represented. However, our days-at-home measure is consistent with other EOL studies.^{25,26} Finally, we did not incorporate Medicaid costs into our analysis. However, since a large majority of EOL costs are due to inpatient and SNF care, which is covered mostly by Medicare, Medicaid expenditures should not be as relevant in this analysis.

Conclusion and Implications for research, policy, and practice

Calls for changes to care systems, legislation, and policy to support PLWD have focused on improved diagnosis, long-term care, and care partner supports as dementia progresses.⁴⁸ However, efforts to understand and improve EOL care and outcomes for PLWD, who

comprise over half of Medicare decedents, are needed. Our findings indicate persons with dementia receive less intensive EOL care. However, care is more intensive for persons from racial/ethnic minoritized groups. What must be clarified is whether care received reflects patient and family member preferences and promotes the high quality of life, or whether the observed differences are the results of biases—implicit or otherwise—in healthcare encounters and delivery systems. Our results underscore a need for EOL care models that carefully elicit and support the preferences of PLWD, particularly those from racial/ethnic minoritized groups. Policies including Medicare reimbursement for physician-led ACP conversations could represent a step in this direction, but their uptake is low, especially among persons from racial/ethnic minoritized groups,⁴⁹ and their effectiveness with PLWD is unknown. Therefore, alternative means of support and communication that are responsive to the needs and preferences of persons from racial/ethnic minoritized groups are needed.

AUTHOR CONTRIBUTIONS

Elizabeth Luth is responsible for study concept and design, data interpretation, and manuscript preparation. Adoma Manful is responsible for study design, data analysis and interpretation, and manuscript preparation. Holly Prigerson is responsible for study concepts and manuscript preparation. Lingwei Xiang is responsible for data analysis and interpretation and manuscript preparation. Amanda Reich is responsible for study design and manuscript preparation. Robert Semco is responsible for manuscript preparation. Joel Weissman is responsible for study concept and design, data acquisition and interpretation, and manuscript preparation.

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CONFLICT OF INTEREST

The authors have no financial, personal, or other conflicts of interest to disclose. The Sponsor had no role in the design, methods, analysis, or preparation of the paper.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

Figure S1. Flow diagram of the decedent study population.

Table S1. Sensitivity analysis including individuals with first dementia diagnosis in the last 30 days of life. Adjusted odds ratios and mean adjusted differences of the effect of dementia diagnosis on intensive and comfort care measures at the end of life for fee-for-service Medicare patients, 65+ years in 20% sample who died in 2017 or 2018.

Table S2. Sensitivity analysis including individuals with first dementia diagnosis in the last 30 days of life. Adjusted odds of intensive and comfort care measures by dementia status, race/ethnicity, and dementia*race/

ethnicity interaction at the end of life for fee-for-service Medicare patients, 65+ years in 20% sample who died in 2017 or 2018.

Table S3. ICD/ CPT codes used to identify dementia diagnosis and intensive procedures in Medicare claims data.

Table S4. Adjusted odds of intensive and comfort care measures by dementia status, race/ethnicity, and dementia*race/ethnicity interaction at the end of life for fee-for-

service Medicare patients, 65+ years in 20% sample who died in 2017 or 2018.

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