THE JOURNAL OF RURAL HEALTH

ORIGINAL ARTICLE

Associations Among Health Literacy, End-of-Life Care Expenditures, and Rurality

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Disclosures: Dr. Wang receives research support from Genentech. The source of support was not used for any portion of the current manuscript. None of the other coauthors have conflicts to report.

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doi: 10.1111/jrh.12513

Abstract

Purpose: To examine differential associations between health literacy (HL) and end-of-life (EOL) care expenditures by rurality.

Methods: This cross-sectional study included all urban and rural counties in the United States. County-level HL data were estimated using 2010 US Census and 2011 American Community Surveys data; EOL expenditures in 2010 were derived from the Dartmouth Atlas of Health Care database. Hierarchical generalized linear regressions were used to assess associations between HL and EOL care, controlling for county-level characteristics and focusing on rurality (with areas classified as urban, rural micropolitan, or rural noncore).

Findings: Of 3,137 US counties, 100 (3.2%) counties where 7.6 million Americans live had low HL (LHL). Counties with LHL had significantly higher average expenditures in the last 6 months of life and during terminal hospitalization than counties with high HL (HHL) (both $P < .001$). There was a statistically significant interaction between HL and rurality ($P < .001$). EOL expenditures were significantly higher in LHL counties than HHL counties in urban areas, while no such relationship appeared in rural areas. Average estimated EOL expenditures among LHL counties decreased by rurality ($16,953, $14,939, and $12,671 for urban, rural micropolitan, and rural noncore areas, respectively), while average estimated expenditures in HHL counties were around $14,000 in each of these areas.

Conclusions: HL and EOL expenditures were inversely associated with urban America but unrelated to rural areas. Counties with HHL had constant expenditures regardless of rurality. Interventions targeting HL may help reduce EOL expenditures and rural-urban disparities in EOL care.

Key words EOL care, expenditures, health literacy, rurality.

End-of-life (EOL) care in the United States is generally aggressive, accounting for a quarter of all Medicare expenditures.[1] In 2014, Medicare per capita spending for decedents, on average, was nearly 4 times higher ($34,529) than surviving beneficiaries ($9,121).[1] Intensive EOL care and life-sustaining medical care, such as repeated hospitalizations, multiple transitions,[2] high frequency of emergency department visits,[3] and intensive care unit admissions,[4,5] all contribute to high EOL care expenditures,[6,7] which pose an enormous financial burden on patients, their families, and society.[8]

According to the National Institutes of Health (NIH), health literacy (HL) is "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate

health decisions."[9] HL is generally related to education and socioeconomic status and is an important determinant of health outcomes and medication and health care service use.[10,11] Researchers found that inadequate HL was associated with delayed care or difficulties in locating a provider,[12] less participation in medical decision making,[13] and decreased patient adherence to treatment,[14] along with repeated hospitalizations,[15] worse health status, lower patient satisfaction,[16] higher health care utilization,[17] and increased mortality.[18,19]

Evidence on the role of HL in EOL care is emerging but still limited. Researchers found that HL was strongly associated with EOL planning and decision making,[20] where low health literacy (LHL) can hinder one's abilities to be involved in meaningful EOL discussions.[21,22] Patients with LHL had lower completion rates of advance directives[23,24] and preferred aggressive EOL treatments,[20] which might contribute to high EOL expenditures. Indeed, prior literature has demonstrated that inadequate HL was associated with several concerning patterns related to health care expenditure. For instance, LHL was associated with increased overall health care expenditures due to emergency department use and acute inpatient care.[25,26] In addition, a national study showed that LHL patients had higher costs from prescription medications compared to high health literacy (HHL) patients ($3,362 vs $910 per year per person).[27] Another study on veterans also found that annual costs for medical and pharmacy for veterans with LHL were more than 25% higher than their peers with HHL from 2007 to 2009.[28] To date, however, researchers have not explored the association between HL and health care expenditures in EOL care settings.

NIH has called for research to promote HL and improve quality of EOL care based on the premise that LHL is associated with high EOL care expenditures.[29] However, such an association is complex, as geographic accessibility to specialized treatments might compound this association in underserved areas, such as rural communities. In previous studies, HL was lower in rural residents than urban residents.[30,31] Likewise, EOL care expenditures in rural areas were also lower than those in urban areas.[32,33] Given these seemingly contradictory findings, we hypothesized that differential associations exist between HL and EOL care expenditures in rural versus urban areas. Specifically, we expected that LHL is associated with high EOL care expenditures in the urban areas but that the association may diminish or even disappear in the rural areas since access to care might play an essential role in EOL care.[34] An improved understanding of these relationships could provide critical insights relevant to planning HL interventions.

Methods

Study Population and Study Design

We conducted a county-level cross-sectional study using data from multiple datasets (Table 1). We derived HL scores from the Health Literacy Map produced by the University of North Carolina at Chapel Hill.[35] Specifically, the score was estimated through a predictive model that used data from the 2010 US Census and 2011 5-year American Community Surveys. The predictive model estimated the mean HL score at census block group level. Variables in the predictive model included gender, age, race/ethnicity, language spoken at home, income, education, marital status, time spent in the United States, and metropolitan statistical area.[35] We aggregated HL to the county level with population-weighted averages. We obtained EOL care expenditure data for 2010 from the Dartmouth Atlas of Health Care, which contains integrated databases from the Centers for Medicare & Medicaid Services.[36] We used measures of inpatient spending in the last 6 months of life and during the terminal hospitalization at the Hospital Service Area (HSA) level. These measures were adjusted for age, sex, and race.[36] Using HSA-level EOL care expenditures and the HSA-ZIP Code crosswalk in the 2010 Dartmouth Atlas Supplemental Research Data,[37] we first estimated ZIP Code-level EOL care expenditures by assigning HSA-level expenditure to all ZIP Codes within a certain HSA. We then converted expenditures to the county level by using the ZIP Code-county crosswalk from Office of Policy Development and Research.[38] This source provided ratios of ZIP Code to county by number of residential addresses within a county, which we used to deal with the overlapping ZIP Code and county borders.

We obtained rural-urban data from the United States Department of Agriculture, based on the 2013 urban influence codes, which distinguish metropolitan counties based on population size and nonmetropolitan counties based on the size of largest city or town in the area.[39] Using 2010 National Historical Geographic Information System, we also abstracted county-level population characteristics, including age, gender, race, ethnicity, education, household income, poverty level, marital status, and origin.[40]

Measurements

Based on the National Assessment of Adult Literacy definition, we categorized HL into below basic/basic HL (LHL; HL score $\leq$ 225) and above basic HL (HHL; HL score >225),[35] as our key independent variable. We classified counties into 3 rurality categories (urban, rural

Table 1 Description of Study Variables

Variable	Categories	Level of Measurement	Year	Source of Data
Population characteristics	Age, gender, race, ethnicity, education, income, poverty level, marital status, and nativity	County	2010	NHGIS https://data2.nhgis.org/main
Health literacy	Low (< = 225) and high (>225)	Census Block	US Census, 2010 and 5-year American Community Surveys, 2011	UNC health literacy http://healthliteracymap.unc.edu/
End of life medical expenditures	Inpatient spending and terminal hospitalization Inpatient spending, last 6 months	Health Service Areas	2010	Dartmouth Atlas https://atlasdata.dartmouth.edu/long_data/new
Rurality	Urban, rural micropolitan, and rural noncore	County	2013	Urban Influence Codes 2013 https://www.ers.usda.gov/data-products/urban-influence-codes.aspx

micropolitan, and rural noncore), following the categories used by the Office of Management and Budget.[39]

Statistical Analysis

We described the frequency distributions of demographic and socioeconomic characteristics by HL levels for the full sample. We compared LHL and HHL counties in terms of EOL expenditures. We assessed statistical significance with *t*-tests for continuous variables and chi-square tests for categorical variables.

To account for the right-skewed expenditures data and accommodate the clustering of counties within states, we used hierarchical generalized linear models with a log link function and gamma distribution.[41,42] We used the variance inflation factors of independent variables to assess multicollinearity across covariates. We further identified the interactions between HL and rurality, and calculated marginal effects at the mean of all other covariates. For these analyses, we did not control for age, gender, and race because the original expenditures had already been adjusted for these variables. We performed all analyses in SAS version 9.4 (SAS Institute Inc., Cary, NC) and Stata version 15.0 (StataCorp, College Station, TX). Significance tests were 2-sided with a threshold of $P < .05$.

Results

Demographic Distribution

Our sample consisted of 3,137 counties, representing 303,897,545 individuals nationally (Table 2). Of all counties, 100 counties (3.2%) were categorized as having LHL. There was no significant difference in the average number of residents in LHL and HHL counties. The distributions of almost all other county-level demographic characteristics were significantly different between counties with low and high HL levels. Compared to HHL counties, LHL counties had, on average, higher proportions of residents who were African American, had less than a high school education, had incomes below the poverty level, were never married, and came from foreign countries (all $P < .001$). Rural counties, including rural micropolitan and rural noncore areas, were more likely to be LHL than urban counties.

End-of-Life Expenditure and Health Literacy

In unadjusted analyses, average EOL expenditure in the last 6 months of life in LHL counties was $15,801, compared to $13,994 in the HHL counties ($P < .001$; eFigure 1A, available online only). Rurality was also significantly associated with EOL care expenditures. Specifically, counties in the urban areas had higher EOL expenditures than those in the rural areas. When separated by rurality, the mean spending in LHL counties was significantly higher than that in HHL counties in urban, micropolitan, and rural noncore areas ($P < .05$, $< .001$, and $< .05$, respectively). For instance, in urban areas, unadjusted average spending in LHL counties was approximately $6,000 more than that in HHL counties (eFigure 1A, available online only). We observed a similar pattern of results for inpatient expenditures during terminal hospitalization (eFigure 1B, available online only).

When we accounted for clustering of counties within states but without adjusting for county characteristics,

Table 2 County-Level Population Characteristics by Health Literacy Level

	Low Health Literacy (N = 100 Counties) Mean percentage (SD)[a]	High Health Literacy (N = 3,037 Counties) Mean percentage (SD)[a]	*P*[b]
Mean number of residents per county	76,074.7 (296,210)	97,560.1 (309,254)	.49
Age distribution (years)			
0-64	86.2 (3.0)	84.4 (4.3)	< .001
65-74	7.5 (1.7)	8.3 (2.2)	< .001
75+	6.3 (1.9)	7.3 (2.5)	< .001
Gender			.020
Male	51.0 (4.7)	49.9 (2.2)	
Female	49.0 (4.7)	50.1 (2.2)	
Race			
White	52.4 (26.2)	84.9 (15.3)	< .001
Black or African American	37.8 (32.6)	8.0 (12.6)	< .001
American Indian or Alaska Native	1.2 (4.6)	1.9 (7.6)	.16
Asian	0.9 (5.2)	1.2 (2.5)	.63
Two or more	1.1 (1.5)	1.9 (2.0)	< .001
Other[c]	6.6 (9.0)	2.2 (3.6)	< .001
Ethnicity			< .001
Hispanic	33.4 (37.3)	7.0 (10.2)	
Non-Hispanic	66.6 (37.3)	93.0 (10.2)	
Education			
Less than high school	31.8 (7.1)	16.4 (6.8)	< .001
High school degree	33.6 (7.0)	35.7 (6.9)	< .001
Some college or Associate degree	22.3 (4.5)	28.6 (5.3)	< .001
Bachelor's degree	8.0 (2.6)	12.7 (5.3)	< .001
Graduate or Doctoral degree	4.2 (2.0)	6.5 (3.9)	< .001
Household income ($ per year)[d]			
0-19,999 (below or near poverty)	26.6 (6.8)	15.4 (5.6)	< .001
20,000-45,000 (low)	39.5 (5.0)	36.1 (6.1)	< .001
45,000-150,000 (middle)	31.5 (7.7)	44.0 (7.8)	< .001
150,000+ (high)	2.5 (1.9)	4.5 (3.7)	< .001
Poverty level[e]			< .001
<1.00 (Below)	28.7 (7.7)	15.1 (5.9)	
> = 1.00 (Above)	71.4 (7.7)	84.9 (5.9)	
Marital status			
Never married	35.5 (7.4)	25.4 (6.6)	< .001
Now married	45.8 (8.3)	56.3 (6.4)	< .001
Widowed	8.7 (3.4)	7.3 (1.9)	< .001
Divorced	9.9 (2.2)	11.0 (2.3)	< .001
Origin			< .001
Native	90.6 (13.2)	95.8 (5.1)	
Foreign	9.5 (13.2)	4.2 (5.1)	
Rurality			
Urban	12.0	38.0	< .001
Rural micropolitan	28.0	20.2	< .001
Rural noncore	60.0	41.8	< .001

[a] Note: Percentages may not sum to 100% due to rounding.

[b] *P* value is for *t*-test test (continuous variables) or chi-square test (categorical variables).

[c] Other races include Native Hawaiian, other Pacific Islander, and some other races.

[d] Household income categories ("Table HINC-01, 2018 Household Income Survey," US Census, 2018).

[e] Ratios below 1.00 indicate that the income for a family or individual is under the official definition of poverty, while ratios of 1.00 or greater indicate that the income is above the poverty level. For instance, a ratio of 1.25 means that the income was 125% above the poverty threshold. (US Census Bureau, 2004).

Table 3 Multivariate Associations Between End-of-Life Expenditures, Health Literacy, and Rurality

		End-of-Life Inpatient Expenditures, Last 6 Months (N = 3,097)				End-of-Life Inpatient Expenditures, Terminal Hospitalization (N = 2,948)			
		Unadjusted		Adjusted[a]		Unadjusted		Adjusted[a]	
		β (SE)	*P* value	β (SE)	*P* value	β (SE)	*P* value	β (SE)	*P* value
Health literacy	Low	Reference	-	Reference	-	Reference	-	Reference	-
	High	–0.12 (0.06)	.030	–0.18 (0.06)	.005	–0.18 (0.03)	< .001	–0.30 (0.10)	.003
Rurality	Urban area	-	-	Reference	-	-	-	Reference	-
	Rural micropolitan	-	-	–0.13 (0.06)	.046	-	-	–0.16 (0.07)	.018
	Rural noncore	-	-	–0.29 (0.06)	< .001	-	-	–0.34 (0.07)	< .001
Interaction[b]	High∗rural micropolitan	-	-	0.11 (0.06)	.086	-	-	0.16 (0.07)	.027
	High∗rural noncore	-	-	0.27 (0.06)	< .001	-	-	0.32 (0.08)	< .001

[a] Notes: All models adjusted for ethnicity, education, income, nativity, marital status, and county clustering within states. Results of the full models are in Appendices eTable 1 (available online only).
[b] The joint interaction effects are significant at $P < .001$ for both outcomes.

LHL counties had higher expenditures ($1,241 more, on average) in the last 6 months of life than HHL counties (Table 3; $\beta = -.12$; $P = .030$). In the full model, we found a statistically significant interaction between HL and rurality ($P < .001$ in an *F*-test), indicating that the association between HL and EOL expenditure differs by rurality. Figure 1A shows the estimated EOL expenditures in LHL and HHL counties stratified by rurality after adjusting for county-level characteristics. In urban areas, EOL expenditures in LHL counties were significantly higher than in HHL counties ($16,953 vs $14,230, $P = .01$). In contrast, there was no statistically significant difference between LHL counties and HHL counties in rural micropolitan areas ($14,939 vs $14,006; $P = .183$). Furthermore, in rural noncore areas, EOL expenditures in LHL counties were significantly lower than those in HHL counties ($12,671 vs $13,912, $P = .012$). Interestingly, EOL expenditures in LHL counties were highest in urban areas, lowest in rural noncore areas, and in between in rural micropolitan areas. In contrast, in HHL counties, EOL expenditures were similar across urban, rural micropolitan, and rural noncore areas.

We found a similar pattern for the association between HL and EOL expenditures during terminal hospitalization ($P < .05$ for both unadjusted and adjusted models; Table 3). There was also a significant interaction between HL and rurality ($P < .001$ in an *F*-test). In urban areas, the estimated EOL expenditure during terminal hospitalization in LHL counties was $5,069, which was significantly higher than the $3,761 in HHL counties ($P = .010$; Figure 1B). We found no significant difference in EOL expenditures during terminal hospitalization between LHL and HHL counties in either rural micropolitan or noncore areas. The estimated expenditures in LHL and HHL counties were $4,304 and $3,471, respectively, in rural micropolitan areas, and $3,623 and $3,708, respectively, in rural noncore areas. The detailed results from the full model are given in eTable 1 (available online only).

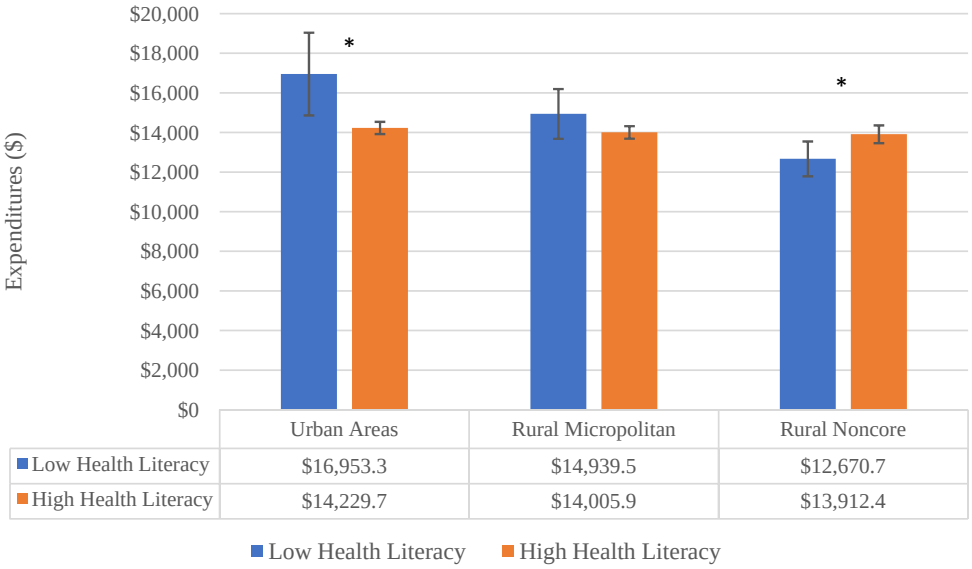
Discussion

To our knowledge, we provide the first national results regarding the association between HL and EOL expenditures. Our study demonstrated that LHL counties, on average, had significantly higher EOL care expenditures than HHL counties. The results are consonant with prior evidence on increased use of inpatient admissions, emergency room visits, physician visits, prescription medications, and health care expenditures in patients with LHL.[15,16,19,26–28]

We also uncovered geographic differences in the relationship between HL and EOL expenditures. Notably, rural noncore counties with HHL had higher EOL expenditures than those with LHL; the opposite was true for urban counties, in which HHL was associated with lower EOL expenditures. Interestingly, HHL counties across urban and rural areas had similar EOL expenditures. In contrast, among LHL counties, we observed increased EOL expenditures with urbanicity, even after adjusting for county-level sociodemographic and socioeconomic variations. The reasons for these different associations between rural and urban areas are likely multifactorial, including EOL care attitudes and access to care. Indeed, residents of rural and urban areas tend to have different preferences about EOL care.[43] Yet, our findings suggest that the urban-rural differences in EOL expenditures were only among LHL counties. Patients with LHL might not be actively engaged in care conversations with caregivers and thus

Figure 1 End-of-Life Expenditure, by Health Literacy Level and Rurality. (A) Last 6 Months Inpatient Expenditure. (B) Terminal Hospitalization Expenditure. Notes: Error bars indicate 95% confidence intervals; estimated values were calculated using hierarchical generalized linear models with a log link function and gamma distribution of each expenditure outcome, as shown in Table S1 (available online only). ∗ Significant at the .05 probability level.

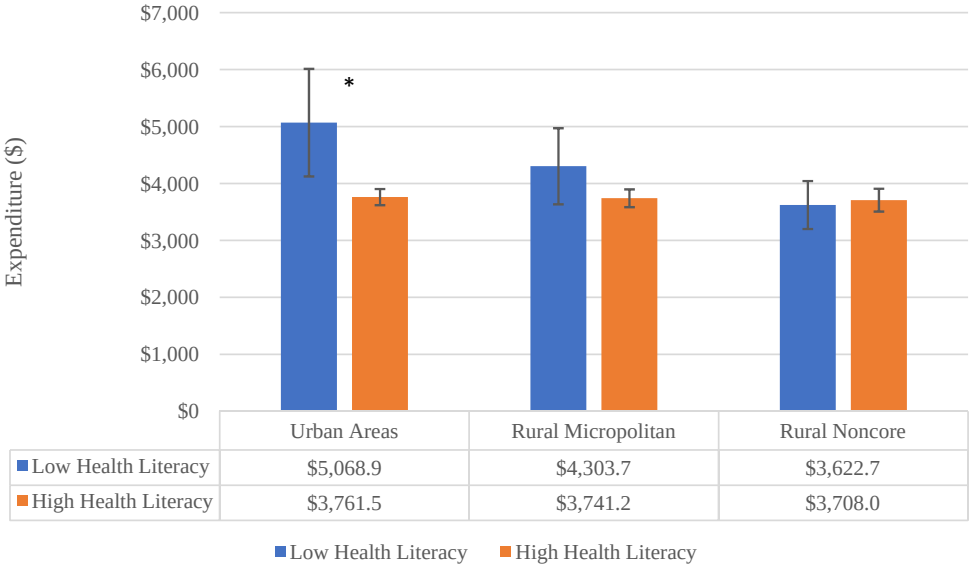
(A) Last 6 Months Inpatient Expenditure.



	Urban Areas	Rural Micropolitan	Rural Noncore
Low Health Literacy	$16,953.3	$14,939.5	$12,670.7
High Health Literacy	$14,229.7	$14,005.9	$13,912.4

Low Health Literacy High Health Literacy

(B) Terminal Hospitalization Expenditure.



	Urban Areas	Rural Micropolitan	Rural Noncore
Low Health Literacy	$5,068.9	$4,303.7	$3,622.7
High Health Literacy	$3,761.5	$3,741.2	$3,708.0

Low Health Literacy High Health Literacy

receive aggressive care.[21] However, individuals in HHL areas might work with providers or their families to lay out EOL transition plans to ensure the consistency of EOL care with their personal preferences without getting burdensome and expensive treatments near death.

The fact that EOL expenditures in urban LHL counties are significantly higher than those in urban HHL counties raises a concern regarding EOL care for vulnerable populations in urban communities. Although there were only 12 urban counties categorized as LHL in our analysis, they represented more than 6 million people (about 82% of the total LHL population). Research found that more than 20% of the patients in sampled urban clinics had limited HL, most of whom were older, lower income, and

less educated.[44] Furthermore, unmet health care needs associated with regional poverty were found to be equal in both rural and urban communities.[45] Prior study in urban settings showed that patients with LHL had worse disease understanding and poor treatment compliance, resulting in greater disease progression.[46] Such inequities in urban counties raise concerns over health care utilizations and existing financial burdens facing individuals and families with LHL. Since LHL was also demonstrated to have a great overall impact on EOL decision making, including less completion of advance care planning and less use of palliative and hospice care because of difficulties in oral and written communication and limited disease knowledge,[24,47] efforts targeting the elderly living in urban communities are needed.

Of course, access to health care resources might compound differences in EOL care between high and low HL areas.[32,48,49] For example, rural patients, compared to urban patients, used more skilled nursing facilities and outpatient services than inpatient, hospice, and home care.[32,50] The fact that rural areas had few and scattered EOL service providers, including palliative and hospice care,[51] limited access to specialists,[34] and increased hospital closures, might have contributed to the lower EOL expenditures among rural patients. These services, specialists, and assistive technologies may only be available to rural residents at great distances and expense of time, which may delay or prevent enrolling in hospice and promote the use of resource-intensive care.[52] On the other hand, access to resourceful life-sustaining interventions and specialists in urban communities might explain the great variations in EOL expenditures.

Compared to the dramatic gap in EOL expenditures between rural and urban areas in LHL counties, average EOL expenditures in HHL counties were similar across rural and urban areas. This suggests that enhancing overall HL levels may alleviate the disparities in EOL expenditures across urban and rural areas.

Our study has important policy implications. HL generally affects health outcomes through access and utilization of health care, the provider-patient relationship, and self-care.[53] Three ways to improve HL include providing information, effective communication, and structured education.[54] In one randomized trial, patients were more willing to choose comfort care (to maximize comfort and relieve pain) instead of life-prolonging care (to prolong life at any cost) after watching an educational video.[55] Health care providers could design more user-friendly media with easy illustrations, simple instructions, culturally sensitive examples, and in multiple languages to enhance patients' understanding of necessary health information for making reasonable decisions.[17] Although there is no etiological association between EOL conversations and health outcomes, patients in prior research who had EOL discussions about preferences and goals for treatment method had, on average, less aggressive medical care, earlier hospice referrals,[56] better quality of life, and lower health care costs in their final week of life than patients who did not have EOL discussions.[6] Since 2016, Medicare has reimbursed clinicians for EOL conversations with patients to discuss their preferences and goals for medical care in the last stage of life.[21] Efforts to improve patient-provider communications among patients with LHL could reduce EOL care expenditures substantially.[6] Moreover, patients in several studies with inadequate EOL care knowledge were less willing to consider advance care planning, such as advanced directives,[23,24] and were likely to pursue futile and aggressive EOL care prematurely.[21] Structured education, such as mobile-based health education messaging, is effective in improving HL.[57] Education on test results and the risks and benefits of preventive services, such as screening,[16,19] enables well informed and health decision making, which can help avoid the costs of aggressive care.

Our analyses have several limitations. First, although our sample is national, our analysis was at the level of counties, not individuals. Second, we analyzed HL data from 2010, the most recent year with available nationwide data on HL. We matched the demographic and EOL expenditure data from the closest year to maintain consistency with the HL data. Third, during the crosswalk between ZIP Code and county, several ZIP Codes' expenditure data were missing. For these ZIP Codes, we calculated weighted-average expenditures across other ZIP Code areas in the same county. The results with this approach and with the exclusion of counties that have missing expenditure values were similar (eTable 2, available online only).

Conclusion

Linking multiple nationwide datasets, we found that EOL expenditures in both the last 6 months of life and during terminal hospitalization were higher in counties with LHL than HHL. Furthermore, the association between HL and EOL expenditure differed between rural and urban areas. Counties with LHL had higher EOL expenditures than those with HHL in urban areas, but had lower EOL expenditures in rural areas. This indicates that interventions targeting HL should account for rurality. Public interventions encouraging communication and education to enhance HL may help improve appropriate care use, reduce unnecessary EOL care, and close the rural-urban gap in EOL costs.

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Supporting Information

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

Supporting Information