Rural–Urban Differences in Medical Care for Nursing Home Residents with Severe Dementia at the End of Life

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OBJECTIVES: To identify factors associated with the use of selected medical services near the end of life in cognitively impaired residents of rural and urban nursing homes.

DESIGN: Retrospective cohort study using Centers for Medicare and Medicaid Services administrative data for 1998 through 2002.

SETTING: Minnesota and Texas nursing homes.

PARTICIPANTS: Nursing home residents aged 65 and older with severe cognitive impairment who subsequently died during 2000/01.

MEASUREMENTS: Minimum Data Set and Medicare Provider Analysis and Review, Hospice, and Denominator files were used to identify subjects and to assess medical service use. U.S. Department of Agriculture metro–nonmetro continuum county codes defined rural (codes 6–9) and urban (codes 0–2) nursing homes. Nursing home residents with hospice or health maintenance organization benefits were excluded. Use of hospital services at the end of life was adjusted for use of corresponding services before the last year of life. Outcome variables were feeding tube use, any hospitalization, more than 10 days of hospitalization, and intensive care unit (ICU) admission.

RESULTS: The population included 3,710 subjects (1,886 rural, 1,824 urban). In multivariable logistic regression analyses (all $P < .05$), feeding tube use was more common in urban nursing home residents, whereas rural nursing home residents were at greater risk for hospitalization. Rural residence was also associated with lower risk of more than 10 days of hospitalization and ICU admission. Nonwhite race and stroke were associated with higher use of all services.

CONCLUSION: Rural nursing home residence is associated with lower likelihood of use of the most-intensive medical services at the end of life. **J Am Geriatr Soc 54:1199–1205, 2006.**

Key words: rural health; urban health; end-of-life care

For more than 20 years, the use of intensive and expensive medical care at the end of life has attracted the interest of ethicists, clinicians, and others concerned about health policy.[1–5] Approximately 27% to 30% of Medicare beneficiaries' lifetime payments are made for care in the last year of life.[1,2,6–8] The use of intensive care at the end of life has been found to be widespread; 22.4% of all deaths were associated with intensive care unit (ICU) admission in one study,[9] and another found that one in five Medicare beneficiaries who died in the hospital in 1999 had a ventilator.[1] The examination of intensive medical care at the end of life has been inspired both by concerns that such care may be burdensome to patients and families, and that the cost of such care may be burdensome to society.

Several factors are associated with the use of intensive medical care at the end of life. Nonwhite populations—especially African Americans—are more likely than whites to receive potentially life-extending medical interventions.[2,10–12] For Medicare beneficiaries aged 65 and older, younger age is associated with more-intensive and -expensive care,[4,9,12–14] and men tend to receive more-intensive care than women.[12,15] Conversely, the use of advance directives is associated with lower rates of feeding tube use in nursing home residents with advanced cognitive impairment[12] and with lower overall charges during terminal hospitalization.[16]

Regional variations in the use of Medicare services in the last 6 months of life have been documented extensively in the Dartmouth Atlas,[17] with higher use of intensive care in the south and along the east coast and lower use in the midwestern and mountain areas of the country. States that have more deaths in the hospital than in nursing homes[11] also use more feeding tubes,[18,19] although more-intensive use of Medicare resources is not associated with better outcomes or satisfaction with care.[20,21]

Regional differences in the use of intensive medical services at the end of life may reflect several factors, including

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DOI: 10.1111/j.1532-5415.2006.00824.x

0002-8614/06/$15.00

differences in medical practice, the makeup and expectations of patient populations, and the rural–urban distribution of the population. Rural–urban differences may be significant, because the few studies that include this variable suggest that residents of rural areas consistently use less-intensive care at the end of life. Residents of rural nursing homes were found to be less likely to die in hospitals than their urban counterparts.[11] Cognitively impaired residents of urban nursing homes have been found to be more likely to have a feeding tube at the end of life than similar rural residents.[12,15] In Kansas, rural–urban differences in feeding tube use were greater than the differences associated with race or type of cognitive impairment,[15] and the urban rate of feeding tube use was higher for most subpopulations, including men, women, whites, nonwhites, and those eligible and ineligible for Medicaid.[22] Recent findings from focus groups suggest that rural and urban families may regard death somewhat differently and that these differences may be reflected in the healthcare decisions that they make.[23]

The present study examined the use of medical services before death in older people with severe and persistent cognitive impairment. Advanced cognitive impairment is a defining feature of extreme frailty, which is the most common clinical pattern before death, occurring in 47% of Medicare decedents.[24] The slow, inexorable progression of cognitive impairment late in life provides family and professional caregivers with ample opportunity to make many medical decisions with the knowledge that death is approaching, albeit without a specific timetable. The use of medical services near the end of life has been found to be similar in patients with and without dementia.[8,25]

This study was undertaken to enhance understanding of rural–urban differences in end-of-life care, with a long-range goal of determining whether rural communities may serve as models for low-intensity care at the end of life.

METHODS

Study Population

The study population was defined on the basis of the Minimum Data Set (MDS) records of individuals who were residents of Minnesota and Texas nursing homes between January 1, 2000, and March 31, 2002. These two states were selected to assure adequate size and diversity in the population to be studied, and because their rural–urban differences in Medicare reimbursement are consistent with national patterns. Lastly, the large number of relatively small counties in Minnesota and Texas, and the relatively similar ratio of rural-to-urban counties, was consistent with the intention of using counties as the unit of analysis for rural–urban differences.

The population was restricted to individuals with severe and chronic cognitive impairment who died during 2000/01. Residents who were younger than 67 on their last available MDS report were excluded, because many such individuals would not have been eligible for Medicare coverage during the prior 2-year period. Individuals with health maintenance organization (HMO) enrollment or hospice option during the 2 years before death were also excluded, because limited Medicare data are available for HMO enrollees and hospice beneficiaries.

Cognitive Impairment

Residents with severe and chronic cognitive impairment were identified by applying the Cognitive Performance Scale (CPS) algorithm, which uses data from selected MDS items, such as memory, cognitive skills for daily decision-making, ability to express information, and ability to take nourishment independently. CPS values range from 0 (intact cognitive performance) to 6 (very severely impaired).[26] Severe impairment was defined as a CPS score of 6 on two or more consecutive MDS reports separated by at least 60 days at any time during 2000/01. Persistent cognitive impairment was defined as the absence of MDS reports with a CPS score of 4 (moderately severely impaired) or less after the presence of severe cognitive impairment, as defined above. Individuals who had coma reported in their MDS record were excluded.

Definition of Urban and Rural

Each nursing facility was characterized by location based on U.S. Department of Agriculture 1993 metro–nonmetro continuum county codes.[27] The matching was performed using facility postal ZIP codes and state and county Federal Information Processing Standards codes (ranging from 0 for core counties of Metropolitan Statistical Areas to 9 for frontier counties). Counties with codes 0 to 2 were defined as urban, with codes 3 to 5 as intermediate, and with codes 6 to 9 as rural. Because the purpose of this study was to compare residents of rural and urban counties, residents in nursing facilities in intermediate counties were excluded from analysis.

Data Sources

The MDS is a federally mandated national database of all residents in Medicare- and Medicaid-certified nursing facilities. Only admission, quarterly, and annual MDS reports were included in this analysis, because only these reports contain sufficient data to calculate the CPS. Individual linkage between Centers for Medicare and Medicaid Services (CMS) files was performed using Medicare Health Insurance Claim numbers. The eligibility file determined from the MDS records was linked to the 1998–2001 Medicare Denominator files; the Denominator files provided dates of death and enrollment characteristics. Medicare Hospice files (1998–2001), linked using Health Insurance Claim numbers, identified hospice beneficiaries. Facility characteristics such as facility size and profit status were extracted from the CMS 2001 Provider of Services file matched to the MDS facility file. Medical care utilization variables were extracted from the CMS Medicare Provider Analysis and Review files (1998–2001) for the 3,710 individuals who qualified for inclusion in the study.

Dependent Variables

Four medical services variables were selected to serve as measures of intensity of medical care near the end of life. End of life was defined as the last 90 days of life for hospital services use and as the time of the last MDS report for feeding tube use. Feeding tube use was determined according to a positive response to MDS item K5b "presence of a feeding tube." Hospitalization was defined as having at least one claim record for a hospital stay that was completely or partially within the last 90 days of life. Total

hospital days were calculated based on total length of hospital stay within the last 90 days of life. ICU days were determined on the basis of the total number of ICU days during the last 90 days of life. For hospitalizations that were partially within the 90-day period, these numbers were prorated.

For the purpose of analysis, all medical service variables were dichotomized, examining the presence or absence of tube feeding, hospitalization, total hospital use for more than 10 days, and use of the ICU during the last 90 days of life.

Explanatory Variables

The independent variables included subjects' age, sex, and race (white vs nonwhite). In addition, living will and resuscitation status, do-not-hospitalize orders, evidence of Medicaid payments, and clinical characteristics such as a history of stroke, Alzheimer's disease, and other dementia were extracted from available MDS records. The MDS includes data on the presence of a living will or a do-not-resuscitate order; for the purpose of the analysis, living will and resuscitation status were combined into an "advance directive" variable. Alzheimer's disease and other dementia were combined in an "any dementia" variable. Other medical conditions were evaluated but not included in the final analysis.

Characteristics of the facilities where study subjects received care included state (MN vs TX), location (rural vs urban county); facility size (<100 vs ≥ 100 total beds), and facility profit status (nonprofit or government vs for profit).

Statistical Analyses

Comparisons between rural and urban groups were made using chi-square tests for dichotomous variables and Student *t* tests for continuous variables. Bivariate analyses (chi-square tests) were used to assess factors potentially associated with the feeding tube use, hospitalization, more than 10 days of hospital use, or ICU use near the end of life.

The effect of urban or rural location on the selected outcomes was evaluated using multiple logistic regression; models were adjusted for demographic variables and state. In addition, the measures of hospital and ICU use were adjusted for corresponding baseline utilization. Baseline was defined as the 12-month period immediately before the last year of life (months 13–24 before death, inclusive). Hospitalization and hospital use for more than 10 days during the last 90 days of life were adjusted for any hospitalization during the baseline period. ICU use was adjusted for any ICU use during baseline period. Analyses for more than 10 days of hospital use or ICU use were performed on the subpopulation of subjects who were hospitalized during the last 90 days of life. Other covariates included presence of advance directives, evidence of Medicaid per diem, and history of stroke. Stroke was included as a covariate, because prior research has shown that feeding tube use is more strongly associated with stroke than with other causes of cognitive impairment.[15]

A separate analysis stratified by county type was conducted to assess factors that may be associated with the selected medical care services in rural and urban populations. These stratified models were adjusted similarly to full models for corresponding outcomes.

Potential confounding between facility characteristics (size and profit status) with parameters of location was investigated. Neither nursing facility profit status nor facility size was included in the multivariable models because of strong association between these variables and state and county type.

All data management and statistical analyses were performed using SAS version 8.2 (SAS Institute, Inc., Cary, NC). Statistical significance was defined at the 5% level.

RESULTS

Study Population

The derivation of the study population is summarized in Figure 1. Using MDS reports, 188,405 individuals were identified as residing in Minnesota and Texas nursing homes from January 1, 2002, through March 31, 2002. Of these, 23,162 had severe, chronic, and irreversible cognitive impairment. After exclusions, the study population consisted of 3,710 residents, with 1,886 from rural nursing homes and 1,824 from urban nursing homes.

The demographic and clinical characteristics of the rural and urban populations are summarized in Table 1. The rural nursing home residents were more likely to be older (median age 88 vs 87) and white, to have a do-not-resuscitate order, a living will, or both and to have been covered by Medicaid while in the nursing home than their urban counterparts. Urban residents were more likely to have had a stroke. More than half of Texas nursing home residents were in urban counties (1,558/2,808, 55.5%), compared with just over a quarter of Minnesota residents (266/902, 29.5%; $P<.001$ MN vs TX). Overall, 75.7% of the study population was from Texas, and 24.3% was from Minnesota.

Rural and Urban Nursing Homes

Individuals included in this analysis resided in 1,016 nursing homes: 747 (73.5%) in Texas and 269 (26.5%) in Minnesota. Not surprisingly, urban nursing homes tended to be

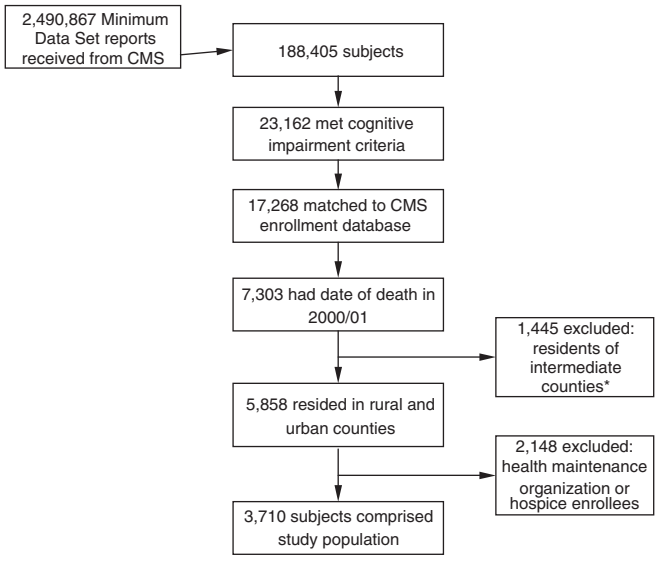

Figure 1. Study population selection. CMS = Centers for Medicare and Medicaid Services. *Residents of nursing homes in counties intermediate between rural and urban, as defined in the Methods section.

Table 1. Study Population: Demographic and Clinical Characteristics (N = 3,710)

Characteristic	NH County		*P*-value*
	Rural (n = 1,886; 50.8%)	Urban (n = 1,824; 49.2%)	
Age, mean ± standard deviation	87.8 ± 7.4	86.7 ± 7.7	<.001
White (n = 3,707), n (%)	1,744 (92.5)	1,441 (79.1)	<.001
Female, n (%)	1,433 (76.0)	1,400 (76.8)	.58
Stroke (n = 3,709), n (%)	553 (29.3)	597 (32.7)	.02
Alzheimer's disease, n (%)†	565 (32.5)	521 (31.3)	.47
Other dementia, n (%)†	887 (51.0)	839 (50.5)	.75
Any dementia, n (%)†	1,272 (73.2)	1,208 (72.7)	.74
Do not resuscitate, n (%)‡	1,356 (78.0)	1,101 (66.3)	<.001
Living will, n (%)‡	398 (22.9)	316 (19.0)	.006
Do not hospitalize, n (%)‡	89 (5.1)	108 (6.5)	.09
Medicaid per diem, n (%)‡	1,159 (66.7)	982 (59.1)	<.001
State, n (%)			<.001
Texas	1,250 (66.3)	1,558 (85.4)	
Minnesota	636 (33.7)	266 (14.6)	
NH size ≥100 beds, n (%)	868 (46.0)	1,440 (78.9)	<.001
For-profit NH, n (%)	1,179 (62.5)	1,364 (74.8)	<.001

* Comparison rural and urban groups, chi-square test.
† n = 3,400 due to missing values in Minimum Data Set (MDS) records.
‡ n = 3,399 due to missing values in MDS records.
NH = nursing home.

larger than rural nursing homes; 73.2% facilities in urban counties had 100 beds or more, compared with 35.9% in rural counties ($P<.001$). Urban nursing homes were also more likely to be for-profit facilities (81.6% vs 64.9%, $P<.001$). For-profit facilities were predominant in Texas (85.1% vs 24.9% in MN, $P<.001$).

Use of Medical Services in the Last 90 days of Life

Medical care use by subjects residing in rural and urban nursing homes is summarized in Table 2. Rural subjects were more likely to be hospitalized during the last 90 days of life than their urban counterparts, but urban subjects were more likely to have had more than 10 days of hospitalization, ICU admission, and feeding tube use. Tables 3 and 4 summarize the effect of four covariates—race, stroke, Medicaid, and advanced directives—on the use of medical services by rural and urban subjects. Nonwhite race was associated with greater use of all services by urban subjects and greater use of feeding tubes and hospitalization by rural subjects. Stroke was associated with greater likelihood of feeding tube use and hospitalization for more than 10 days for rural and urban subjects. Medicaid was associated with lower likelihood of any hospitalization and of hospitalization for more than 10 days but was not associated with feeding tube or ICU use by rural or urban subjects. Advance directives were associated with lower likelihood of admission to the hospital and the ICU for rural and urban subjects.

DISCUSSION

After adjusting for baseline levels of medical service use, it was found that rural nursing home residence was generally associated with lower intensity of medical care at the end of life. This was true for the three services that may arguably be considered the most intensive in the last 90 days of life: feeding tube use, more than 10 days of hospitalization, and ICU admission. Conversely, in multivariable analysis, higher risk of any hospitalization in the last 90 days of life was associated with rural nursing home residence. This finding

Table 2. Medical Care Utilization in the Last 90 Days of Life

Outcome	Rural n (%)	Urban n (%)	Odds Ratio (95% Confidence Interval)*	*P*-value
Tube feeding (n = 3,710)†	399 (21.2)	715 (39.2)	1.67 (1.41–1.98)	<.001
Hospitalization (n = 3,710)†	703 (37.3)	791 (43.4)	0.78 (0.67–0.91)	.002
Hospital days >10 (n = 1,494)‡	184 (26.2)	316 (40.0)	1.41 (1.11–1.80)	.006
Intensive care unit use (n = 1,494)‡	88 (12.5)	230 (29.1)	2.28 (1.70–3.07)	<.001

* For urban versus rural (reference) use from multivariable logistic regression models adjusted for age, sex, and other covariates (see text).
† n = 3,396; 314 observations deleted in multivariable analysis due to missing values.
‡ n = 1,392; 102 observations deleted in multivariable analysis due to missing values.

Table 3. Tube Feeding and Hospitalization in the Last 90 Days of Life (n = 3,710) by Nursing Home Location

	Tube Feeding				Hospitalization			
	Rural*		Urban†		Rural*		Urban†	
Characteristic	OR (95% CI)‡	*P*-value	OR (95% CI)‡	*P*-value	OR (95% CI)§	*P*-value	OR (95% CI)§	*P*-value
Race								
Nonwhite	2.75 (1.84–4.11)	<.001	3.63 (2.75–4.73)	<.001	1.54 (1.03–2.32)	.04	2.41 (1.83–3.18)	<.001
White	reference		reference		reference		reference	
Stroke								
Yes	2.94 (2.28–3.80)	<.001	2.60 (2.06–3.28)	<.001	1.37 (1.08–1.74)	.009	1.18 (0.94–1.49)	.16
No	reference		reference		reference		reference	
Medicaid per diem								
Present	1.25 (0.96–1.64)	.10	0.97 (0.77–1.21)	.77	0.63 (0.50–0.79)	<.001	0.76 (0.61–0.95)	.02
Absent	reference		reference		reference		reference	
Advance directive								
Present	0.86 (0.63–1.16)	.32	0.68 (0.53–0.87)	.002	0.52 (0.39–0.69)	<.001	0.49 (0.39–0.63)	<.001
Absent	reference		reference		reference		reference	

* n = 1,737; 149 rural observations deleted due to missing values.
† n = 1,659; 165 urban observations deleted due to missing values.
‡ From logistic regression model adjusted for age, sex, and state.
§ From logistic regression model adjusted for age, sex, state, and prior hospitalization.
OR = odds ratio; CI = confidence interval.

echoes previous findings, which showed that rural nursing home residence was associated with greater risk of hospitalization.[28] Several factors, including the limited staffing of rural nursing homes, which may decrease the capacity to provide care for failing residents, may affect the low threshold for the transfer of rural nursing home residents to the hospital. In addition, rural hospitals are more likely than urban hospitals to have administrative relationships with long-term care providers.[29]

Decisions to forgo hospitalization are made late in the course of dementia, with many occurring in the last 30 days.[14] The last 90 days of life was used as the end-of-life period for the purposes of analysis; this is somewhat broader than that used in many other studies. For example, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments found that nearly half of do-not-resuscitate) orders were written in the last 48 hours of life.[30] The findings of the current study pertain to the use of medical

Table 4. Hospitalization for More than 10 Days and Intensive Care Unit (ICU) Use of Nursing Home Residents Hospitalized in the Last 90 Days of Life (N = 1,494) by Nursing Home Location

	Hospitalization for More than 10 Days				ICU Use			
	Rural*		Urban†		Rural*		Urban†	
Characteristic	OR (95% CI)‡	*P*-value	OR (95% CI)‡	*P*-value	OR (95% CI)§	*P*-value	OR (95% CI)§	*P*-value
Race								
Nonwhite	1.27 (0.75–2.16)	.38	2.45 (1.74–3.45)	<.001	1.31 (0.68–2.53)	.41	1.59 (1.12–2.25)	.01
White	reference		reference		reference		reference	
Stroke								
Yes	1.66 (1.16–2.39)	.006	1.47 (1.06–2.03)	.02	0.66 (0.39–1.12)	.12	0.80 (0.57–1.14)	.22
No	reference		reference		reference		reference	
Medicaid per diem								
Present	0.64 (0.44–0.92)	.01	0.50 (0.36–0.70)	<.001	1.18 (0.71–1.97)	.51	0.92 (0.66–1.29)	.62
Absent	reference		reference		reference		reference	
Advance directive								
Present	0.77 (0.51–1.14)	.19	0.57 (0.41–0.79)	.001	0.29 (0.18–0.48)	<.001	0.52 (0.32–0.74)	<.001
Absent	reference		reference		reference		reference	

* n = 659; 44 rural observations deleted due to missing values.
† n = 733; 58 urban observations deleted due to missing values.
‡ From logistic regression model adjusted for age, sex, and prior hospitalization.
§ From logistic regression model adjusted for age, sex, and prior ICU utilization.
OR = odds ratio; CI = confidence interval.

services in the last months of life of nursing home residents with severe and persistent cognitive impairment. For insights into the use of medical services in residents who are actively dying, a shorter end-of-life period should be used.

The overall intensity of medical service use in this population of severely cognitively impaired residents is noteworthy. Residents with less functional independence and greater cognitive impairment—such as those that made up the population examined in this study—are less likely to be hospitalized at the end of life than other nursing home residents.[11] The findings that 40.3% of this population was hospitalized in the last 90 days of life and that 8.3% was admitted to an ICU are notable. These findings echo the findings of others regarding the intensity of medical service utilization at the end of life. Levy concluded that "patients transferred to the hospital include a large number of nursing home residents who are very impaired."[11] Other investigators have noted that advanced cognitive impairment is not uniformly recognized as a terminal condition.[14]

The fact that it is often difficult to know when the "end of life" has arrived complicates the examination of end-of-life decision-making. The population examined in this study consisted of elderly nursing home residents with severe and persistent cognitive impairment. Although the precise timing of death in dementia is often difficult to predict, the low likelihood of recovery and the inexorable progression of dementia assure that many families and providers of care come to recognize and anticipate the approach of death. Indeed, the slow progression of dementia ensures that many decisions can be made without the pressure of a medical emergency. In this light, it was felt that the examination of medical decisions made on behalf of subjects with advanced dementia would provide valuable insights into end-of-life decision-making.

This study was designed to assess the association between rural and urban location of nursing home and the use of medical services at the end of life, after adjusting for the intrinsic (baseline) rural–urban differences in use of medical services. Such an adjustment was necessary in view of known rural–urban differences in access to services, and other factors—known and unknown—that affect rural–urban differences in the patterns of medical service use at times remote from the end of life.

These findings contribute to understanding of the patients and circumstances in which intensive care is likely to be used at the end of life. The use of early identification of those at greatest risk for receiving aggressive care at the end of life may facilitate efforts to moderate such care. For example, nursing home residents at high risk for hospitalization and aggressive care at the end of life could be targeted for interventions designed to support their remaining in the nursing home at the end of life. These results, coupled with those from qualitative research directed at understanding rural and urban decision-making near the end of life, suggest that further study of rural practices may be important as we work to restrain the use of intensive care near the end of life.

MDS data were used to identify the study population, and for several of the variables used in the analysis, the findings should be interpreted in light of the limitations of such administrative data.

Nursing home residents who were covered by hospice or HMO at any time during the last 2 years of life were excluded from the study population. The exclusion of hospice beneficiaries affected a larger proportion of urban (38%) than rural (13%) nursing home residents and may have contributed to the finding that the remaining (non-hospice) urban nursing home residents tended to use more-intensive care at the end of life.[31] That is, more patients and families who elected to use lower-intensity services were excluded from the urban cohort than from the rural cohort, although the significance of this factor must be weighed in light of studies that have demonstrated the modest effect that hospice enrollment has on overall cost of healthcare services at the end of life.

This study was initially designed to incorporate facility-level factors in the analysis; it was not possible to pursue this line of analysis because of the low number of subjects per facility. Facility-level factors should be considered in future research, because the size, ownership and staffing of nursing homes may affect the use of medical services.[11,14,32–35]

Finally, although possible regional differences were adjusted for (MN vs TX), this study was not designed to examine regional differences per se, such as those documented in the Dartmouth Atlas[17] and in recent studies of feeding tube use.[18,19] Regional variation in end-of-life care should be borne in mind in future studies of rural–urban differences.

ACKNOWLEDGMENTS

Financial Disclosure: This research was supported by Grant 1R03HS013022–01A1 from the Agency for Healthcare Research and Quality. The authors have no financial or other conflict of interest to report. None of the authors has any financial or other relationships that might lead to a conflict of interest.

Author Contributions: Each author helped to draft the article and revised it critically for important intellectual content. Each author made a meaningful contribution to the conception and design of the work and the analysis and interpretation of data.

Sponsor's Role: None.

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