

NHPCO Original Article

Geographic Variation in Hospice Use in the United States in 2002

Stephen R. Connor, PhD, Felix Elwert, PhD, Carol Spence, RN, MSN,
and Nicholas A. Christakis, MD, PhD

National Hospice and Palliative Care Organization (S.R.C., C.S.), Alexandria, Virginia;
and Department of Health Care Policy (F.E., N.A.C.), Harvard Medical School, Boston,
Massachusetts, USA

Abstract

Complete Center for Disease Control death certificate records and Centers for Medicare and Medicaid Services 100% Standard Analytic File for hospice claims for 2002 were used to describe the whole population of hospice users and nonusers in the United States. The overall hospice utilization rate for persons 65 years and older was 28.6%. Hospice utilization varied by cause of death, and was highest for individuals with malignancies (65%), kidney disease and nephritis (55%), and Alzheimer's disease (41%). Hospice utilization was lowest for conditions leading to rapid or unexpected death, such as accidents and suicide (0%), influenza and pneumonia (3%), and sepsis (6%). Considerable geographic differences in hospice utilization existed, with hospice use higher in the South and the Southwest and lower in the Midwest and the Northeast. State-specific usage rates ranged from 8% in Alaska to 49% in Arizona. Our findings highlight opportunities for the hospice industry to provide more care, opportunities defined by diagnostic and geographic axes. *J Pain Symptom Manage* 2007;34:277–285. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Hospice, database, palliative, mortality

Introduction

Hospice services are increasingly becoming standard in end-of-life care in the United States. Since the enactment of the Medicare

hospice benefit, which for the first time offered to pay for hospice services for all older Americans, hospice utilization has grown rapidly. Little is known, however, about differences in access to, and utilization of, hospice care among subgroups of the population defined by age, sex, and geography. Han et al. found that the total number of hospice patients tripled between 1991–1992 and 1999–2000.¹ The number of patients aged 85 years and older increased more than fivefold. The percentage of noncancer hospice patients doubled during this period, and the percentage with Alzheimer's disease or dementia increased significantly.

This study was sponsored by the National Hospice and Palliative Care Organization.

Address reprint requests to: Stephen R. Connor, PhD, National Hospice and Palliative Care Organization, Research and International Development, 1700 Diagonal Road, Suite 625, Alexandria, VA 22314, USA. E-mail: sconnor@nhpco.org

Accepted for publication: March 8, 2007.

Literature on hospice use is increasing in relation to the growth of the field. Greiner et al. analyzed hospice use by minorities in the National Mortality Followback Survey for 1993 and found that hospice use was negatively associated with African-American race.² Virnig et al. found, using the 100% hospice claims file for 1999, that rates of hospice care were negatively associated with rurality.³ Keating et al. and Locher et al. both looked at hospice use among cancer patients using limited data sets and found considerable variation in hospice usage.^{4,5} None of these studies compared national data from both the complete mortality and hospice use data sets.

We used complete Center for Disease Control (CDC) death certificate records and Centers for Medicare and Medicaid Services (CMS) 100% Standard Analytic File for hospice claims for 2002 (the most recent year for which comprehensive data are currently available) to describe the whole population of hospice users, and nonusers, in the United States. This report provides detailed estimates of differences in hospice utilization along potential demographic and geographic axes. The analysis focuses on deaths at ages 65 years and older (representing 74% of annual deaths⁶ in 2002).

Methods

Hospice Utilization Ratio

The hospice utilization ratio (HUR) was used in this study. We defined the HUR_i of a specific group of decedents, i , as the fraction of decedents in that group who used Medicare-reimbursed hospice care at some point during the year before their death.

$$HUR_i = \frac{\text{no. of hospice users in group } i}{\text{no. of decedents in group } i}$$

Data Sources

We focused on Medicare-based hospice utilization in the 12 months prior to death among older Americans who died in 2002. Data are from the Standard Analytic File Hospice (SAF-H) maintained by the CMS and from the Compressed Mortality File (CMF) maintained by the National Center for Health Statistics.

Numerators with the number of decedents who used hospice care in a given group come from the 2002 SAF-H, a complete record of reimbursement claims for the Medicare hospice benefit in 2002. The SAF-H contains individual-level demographic information for each beneficiary, such as age, race, and sex, state and county of residence, as well as detailed diagnostic information. The vast majority of beneficiaries enter the SAF-H through a single hospice stay ending at death. For individuals who had multiple records in the SAF-H, only the most recent hospice stay and most recent claim were included.

Denominators with the total number of decedents in a given group come from the 2002 CMF, a complete record of deaths among U.S. residents in 2002. This file contains a single record for each individual decedent, noting state and county of residence, age at death, race, sex, and underlying cause of death from individual death certificates.

Because the numerator and denominator come from different sources, and because both data sources are beneficiary-encrypted public-use databases, certain statistical assumptions were made to address unavoidable compatibility issues. First, the SAF-H only covers Americans who were enrolled in the Medicare program. Because almost all Americans are eligible for Medicare at age 65 years, we restricted the analysis to deaths at age 65 years and above. Despite this restriction, however, not all hospice deaths are included in the SAF-H. Approximately 4% of eligible Americans are not enrolled in Medicare,⁷ and some patients use hospice services not covered by Medicare (though this is known to be very uncommon). Therefore, the HURs computed in this study slightly understate the extent of overall hospice utilization among older Americans. However, Medicare-based hospice utilization among older Americans is fully captured.

Second, not all individuals who receive hospice care die within the 12 months following first hospice use (up to 8%).⁸ Likewise, not all individuals enroll in hospice and die during the same calendar year. Moreover, some individuals who receive hospice services in the 12 months prior to death terminate hospice prior to their death. We included all individuals who died while receiving hospice care in 2002 and excluded all individuals who received hospice

services but were known to have remained hospice patients beyond their last claim in the 2002 SAF-H. We included all other individuals who received hospice services in 2002 and were discharged to home or hospital according to their last hospice claim on record in 2002 on the assumption that most likely died shortly after terminating hospice. These procedures—in essence, steady-state assumptions—were judged to accurately capture the intended population of individuals who died during the calendar year of 2002 and used hospice services in the 12 months prior to their deaths.

Because the SAF-H provides a complete picture of hospice services provided under the Medicare program, and because the CMF is a complete census of deaths, we suggest interpreting the HUR as the *ratio of Medicare-based hospice utilization* among older Americans in 2002. That is, this is a measure of the “market penetration” of hospice, or the fraction of decedents of various types who use hospice care.

Cause of Death

The CMF contains decedents’ primary cause of death from individual death certificates, but the SAF-H does not. Therefore, the principal diagnosis associated with individuals’ last hospice claim was used as a proxy for cause of death. The CMF codes causes of death in ICD-10 format, whereas the SAF-H gives principal diagnosis codes in the older ICD-9 format. Therefore, ICD-9 codes were converted into ICD-10 codes using the method described by Anderson et al.⁹ This conversion is considered unproblematic for most causes of death, particularly at our level of aggregation. One exception, however, is for Alzheimer’s disease for which the conversion from ICD-9 to ICD-10 created a clear discontinuity in trend, in that a significant number of deaths that had been categorized as senile or presenile organic psychotic conditions and pneumonias under ICD-9 are now categorized as Alzheimer’s disease.⁹

To achieve sufficiently large cell sizes and to guard against issues associated with converting from ICD-9 to ICD-10, we collapsed data into 11 broad cause-of-death categories: heart disease, cancer, cerebral vascular accident/stroke, chronic obstructive pulmonary disease, accident/suicide, diabetes, influenza/pneumonia, Alzheimer’s disease, nephritis/kidney

disease, sepsis, and “all other.” These categories represent a collapsed version of the 113-category classification used by the CDC. In collapsing data into these cause-of-death categories, we noted that a greater proportion of decedents in the SAF-H than in the CMF fell into the “all other causes” category (25% vs. 15%). Close inspection of the primary claim diagnosis codes in the SAF-H revealed that a nontrivial proportion of SAF-H diagnosis codes gave symptoms (e.g., “psychosis”) rather than underlying diseases, which artificially inflated the “all other causes” category in the numerator of the HUR. To adjust for this inflation of the “all other causes” category, we redistributed excess observations from the “all other causes” category across the 10 specific cause-of-death categories in the SAF-H numerator on a pro rata basis. Specifically, we assumed that the proportion of individuals dying of “all other causes” should be the same in numerator and denominator, and that all diseases were equally likely to be miscoded as “all other” in the SAF-H. Based on these assumptions, we redistributed the excess of cases in the “all other” category across the 10 specific causes of death proportional to their representation in the SAF-H. This adjustment, which was only applied in tables where cause of death was a grouping variable, preserved the relative ranking of HURs across causes of death. Because the adjustment affects the percentage-point difference between race-specific HURs for specific causes of death, we present only adjusted HURs.

Region-Specific HURs

Both CMF and SAF-H contain information on place of residence (state and county), but do not record place of death. Therefore, region-specific HURs are presented by place of residence. Geographic coverage was restricted to decedents residing in the 50 states and the District of Columbia. Due to a small amount of mismatch in the county codes in the SAF-H and the CMF, a negligible number of observations for the county-level analysis were lost (but not for other analyses). Specifically, this mismatch led to the omission of 60 hospice users across three counties from the SAF-H and 1,261 decedents across 58 counties from the CMF nationwide. Another 362 hospice users were omitted due to missing county codes in the SAF-H record.

Small Cells

When classifying a population of decedents along multiple dimensions, data size limitations are encountered, even in a study such as this, which uses an almost complete census of the relevant population. For example, a complete cross-classification of the decedent population in the United States along all dimensions considered in this report would generate close to 400,000 categories ($2 \text{ race} \times 2 \text{ sex} \times 3 \text{ age} \times 3,000 \text{ counties} \times 11 \text{ causes of death} = 396,000$) for only 624,946 hospice users in 2002. Therefore, we limited the number of dimensions considered simultaneously and flagged HURs computed from sparsely populated cells. Group-specific HURs with numerators containing less than 20 hospice users and/or denominators containing less than 100 decedents were flagged and subsequently disregarded.

Statistical Analysis

This study used data that completely enumerate the population of interest (deaths and Medicare hospice users aged 65+ years in the United States in 2002). Therefore, the HURs computed in this report are descriptive population level quantities rather than sample-based estimates. Because no sampling was involved in data collection or analysis, sampling theory-derived statistical tests are not computed. The analysis was executed using the Stata software package, version 9.2.¹⁰

Table 1
Hospice Utilization Rate
by Demographic Variables

Variable	Rate of Hospice Use
Sex	
Male	0.27
Female	0.30
Race	
White	0.29
Black	0.22
Other	Unknown ^a
Age (years)	
65–74	0.27
75–84	0.29
85+	0.29

^aCMF data are unreliable for race information other than black/white differences.

Results

Hospice Utilization Overall

There were 1,811,720 persons aged 65 years and older who died in the United States in 2002. In the same year, 518,078 unique individuals used hospice services under the Medicare program and likely died. Therefore, the overall hospice utilization rate among older Americans in 2002 is estimated as 28.6%.

Hospice Utilization by Demographic Variables and Cause of Death

Hospice utilization rates by demographic variables are presented in Table 1. Female decedents were more likely to use hospice than were male decedents (30% vs. 27%), and white

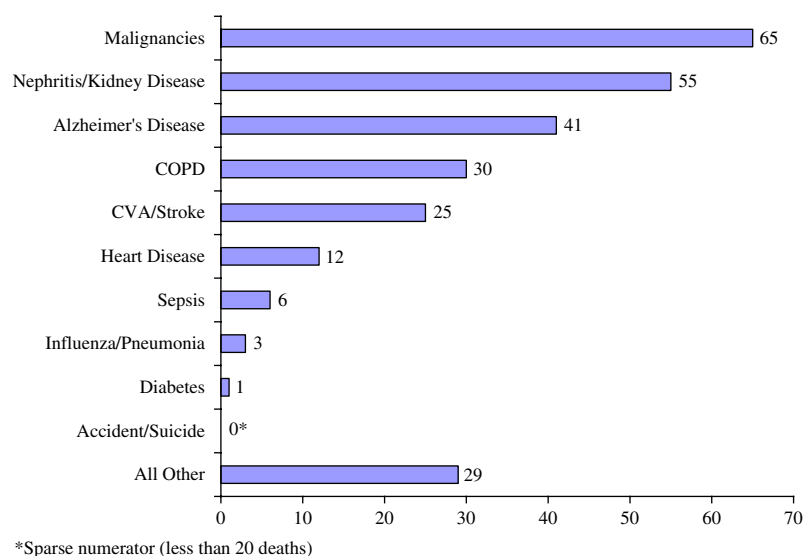


Fig. 1. Hospice utilization rate by cause of death.

decedents were more likely to use hospice than black decedents (29% vs. 22%). Overall, older decedents were slightly more likely to use hospice in the year of their death.

Hospice utilization varied considerably by cause of death (Fig. 1), and was highest for individuals dying from malignancies (65%), kidney disease and nephritis (55%), and Alzheimer's disease (41%). Hospice utilization was lowest for individuals with conditions leading to a rapid or unexpected death, such as accidents and suicide (0%), influenza and pneumonia (3%), and sepsis (6%). Hospice use was also uncommon for deaths due to diabetes (1%), most likely because many of the individuals dying of diabetes are treated as deaths due to kidney disease. Table 2 shows

Table 2
Hospice Utilization Rate by Age
and Cause of Death

Cause of Death	Age (years)	Total
Heart disease	65–74	0.07
	75–84	0.11
	85+	0.15
Malignancy	65–74	0.61
	75–84	0.66
	85+	0.68
CVA/stroke	65–74	0.19
	75–84	0.25
	85+	0.27
COPD	65–74	0.29
	75–84	0.31
	85+	0.30
Accident/fracture/suicide	65–74	0.00 ^a
	75–84	0.00 ^a
	85+	0.00 ^a
Diabetes	65–74	0.01
	75–84	0.01
	85+	0.01
Influenza/pneumonia	65–74	0.02
	75–84	0.03
	85+	0.03
Alzheimer's disease	65–74	0.55
	75–84	0.48
	85+	0.36
Nephritis/kidney disease	65–74	0.55
	75–84	0.58
	85+	0.53
Sepsis	65–74	0.04
	75–84	0.06
	85+	0.08
All other	65–74	0.17
	75–84	0.26
	85+	0.37

CVA = cerebral vascular accident; COPD = chronic obstructive pulmonary disease.

^aLess than 20 hospice users in numerator.

hospice utilization rates by age at death and cause of death. For seven of the 11 cause-of-death categories, the hospice utilization rate was notably lower for the youngest age category (65–74 years) than for the oldest age categories. For Alzheimer's disease, however, hospice utilization decreased considerably with age (55% for 65–74-year olds, 48% for 75–84-year olds, and 36% for ≥85 years).

Hospice Utilization by Geographic Location

There were considerable geographic differences in hospice utilization among older decedents in the United States by state of residence (Table 3, Fig. 2). States with the highest hospice utilization rates included Arizona (49%), Colorado (45%), and Florida (42%). States with the lowest hospice utilization rates included Alaska (8%), Maine (14%), South Dakota (16%), and Wyoming (16%). In general, hospice utilization was higher in the South

Table 3
Hospice Utilization Rate by State

State	Overall		State	Overall	
	Rate	Rank		Rate	Rank
Alabama	0.32	39	Missouri	0.29	33
Alaska	0.08	1	Montana	0.22	12
Arizona	0.49	51	Nebraska	0.26	28
Arkansas	0.24	18	Nevada	0.37	48
California	0.29	32	New Hampshire	0.24	16
Colorado	0.45	50	New Jersey	0.25	20
Connecticut	0.24	19	New Mexico	0.35	45
D.C.	0.18	6	New York	0.19	7
Delaware	0.30	34	North Carolina	0.25	22
Florida	0.42	49	North Dakota	0.18	5
Georgia	0.32	40	Ohio	0.34	41
Hawaii	0.20	9	Oklahoma	0.34	44
Idaho	0.23	15	Oregon	0.37	47
Illinois	0.30	35	Pennsylvania	0.27	31
Indiana	0.25	26	Rhode Island	0.24	17
Iowa	0.31	38	South Carolina	0.25	21
Kansas	0.30	36	South Dakota	0.16	3
Kentucky	0.25	24	Tennessee	0.20	10
Louisiana	0.25	23	Texas	0.36	46
Maine	0.14	2	Utah	0.34	42
Maryland	0.26	27	Vermont	0.19	8
Massachusetts	0.23	13	Virginia	0.23	14
Michigan	0.34	43	Washington	0.31	37
Minnesota	0.26	29	West Virginia	0.22	11
Mississippi	0.26	30	Wisconsin	0.25	25
			Wyoming	0.16	4

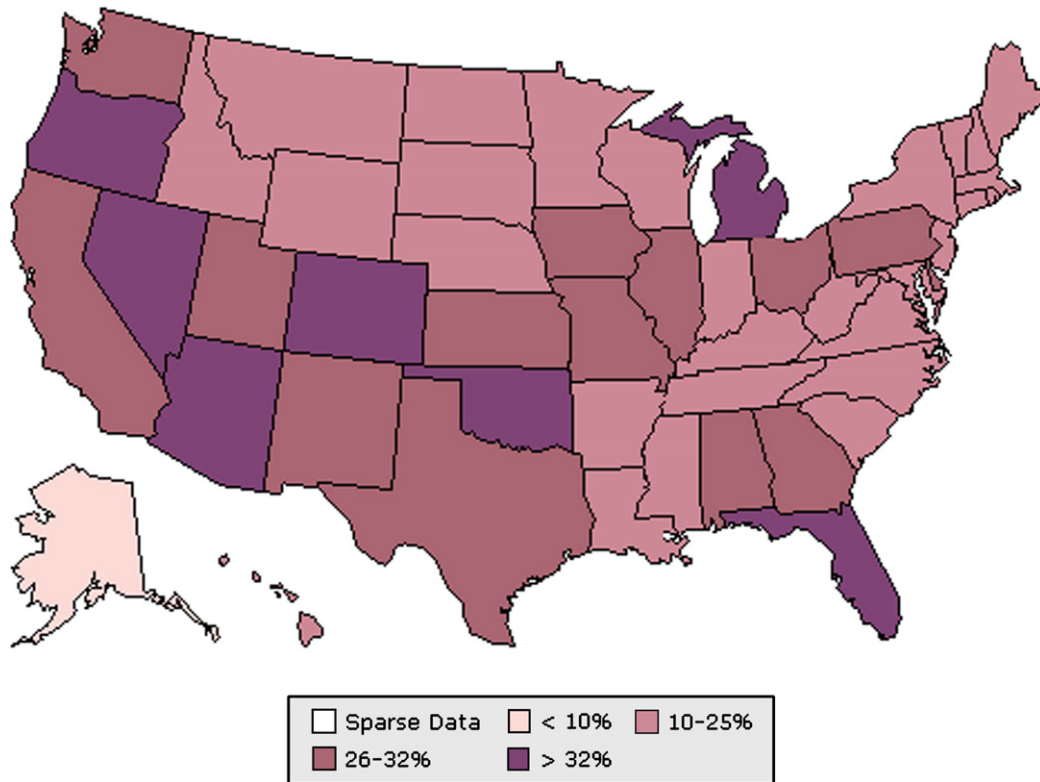


Fig. 2. Overall hospice utilization by state.

and the Southwest and lower in the Midwest and the Northeast.

Fig. 3 presents HURs by county of residence for the entire decedent population in 2,101 of 3,068 counties with valid and sufficiently populated observations. Due to the large number of counties in the United States, a considerable number of counties contained too few observations to meet the standards of inclusion described above. Due to data size limitations, it was not possible to disaggregate county-specific HURs along any additional dimensions.

Discussion

Our study provides detailed estimates of Medicare-based hospice utilization by older Americans in 2002 using comprehensive national level data. We found important differences in hospice use by cause of death, sex, age, and place of residence. We found that women were more likely than men to use hospice care toward the end of life (30% vs. 27%), which is consistent with prior work based on

data from the early 1990s.¹¹ Older decedents, overall, were slightly more likely to use hospice in the year of their death.

Hospice use is higher in the South and the Southwest, and lower in the Northeast and Midwest. Our findings are similar to findings of other researchers. For example, Virnig et al.¹² reported that rates of hospice use in Ft. Lauderdale, Florida were 11-fold higher than in Portland, Maine. Arizona and Florida have very high use, probably in large part due to the specific age distribution of their populations. There are likely other features that are relevant—a kind of “local culture” in each state regarding the acceptability and desirability of hospice care, or factors related to hospice availability.¹³

While not a variable in this study, it is widely acknowledged that hospices themselves are a source of considerable variation in access. Provider policies that limit admission to patients with certain diagnoses, and limit admission of patients who are receiving disease-modifying therapies, contribute considerably to region-by-region variation. The Medicare hospice

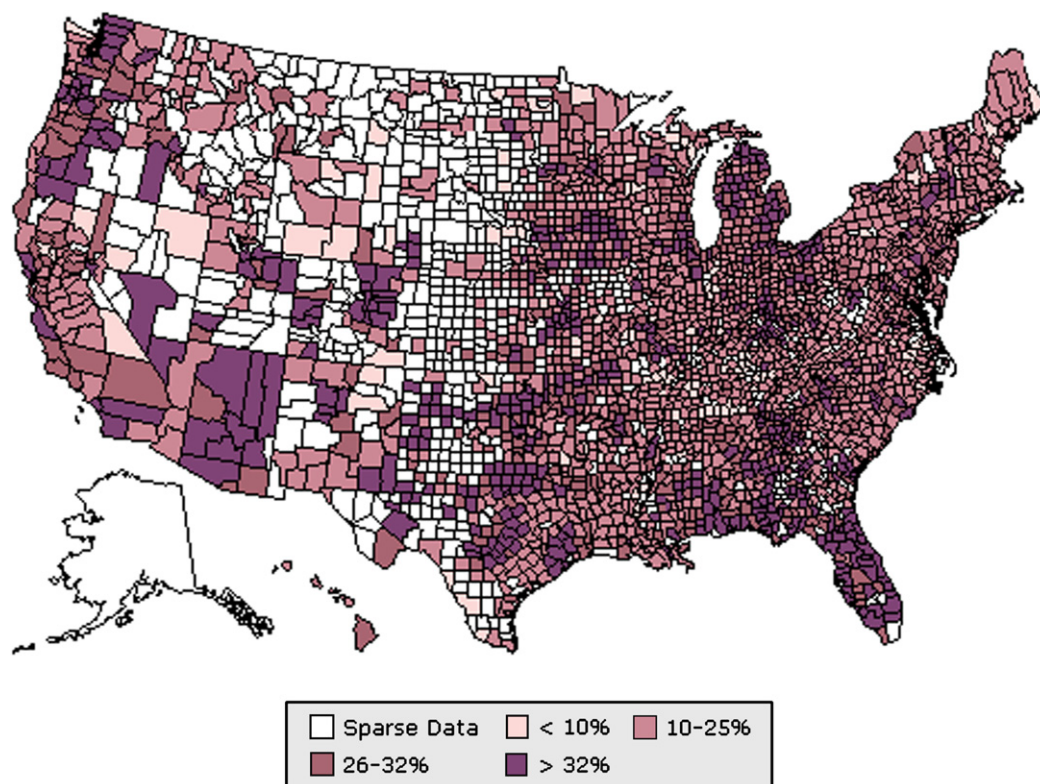


Fig. 3. Overall hospice utilization by county.

benefit allows each hospice to set policies on which therapies are curative (not allowed) and which are palliative (allowed). Most current therapies are not curative per se but may be directed at disease modification or remission. These therapies can be viewed as palliative and are often expensive.

Hospice use was higher for diseases that impose a high burden on caregivers or diseases that predictably lead to death.^{14,15} The three causes of death with the highest HURs (i.e., malignancies, nephritis/kidney disease, and Alzheimer's disease) correspond to diseases that commonly impose high burdens of caregiving on family caregivers and/or that make it easier for decision makers to predict the time frame of death. While usage is high in patients with malignancies, however, we did not evaluate the timing of enrollment in hospice. Several studies have documented the fact that the timing of referral is very late, and that over 30% of patients die within a week of referral to hospice.¹⁶ Hospice use in patients with renal disease is high relative to total deaths from this disease; however,

a recent report highlights continuing problems with access to hospice for patients on the end-stage renal dialysis program.¹⁷ Still there has been a major shift toward serving patients with nonmalignant primary diagnoses. In the early days of hospice care, the population was predominantly cancer patients while now the hospice population is becoming more consistent with the major causes of death from chronic illness diagnoses.

We found that hospice use tends to increase with age for most causes of death with the exception of Alzheimer's disease. As noted previously, however, Alzheimer's disease is the one cause of death among aggregated causes considered in this report most affected by the switch from ICD-9 to ICD-10.⁹ Moreover, there are other vagaries in the ascertainment of dementia that are difficult to resolve with data such as these. For example, in the present analysis, only ICD-9 code 331 (i.e., its relevant subcategories) was treated as "Alzheimer's dementia," even though many individuals with dementia are given ICD-9 codes 290, 294, 298, and 797 by hospice programs. And,

many patients with dementia who die of cancer or heart disease are treated as having died of the latter rather than of dementia in the denominator data at our disposal.

The results of our study were similar to results regarding hospice use that appeared in the Dartmouth Atlas of Health Care released in March of 2006.¹⁸ Overall, our findings and the Dartmouth Atlas are in close agreement with respect to the rank order of hospice utilization across states.

While this is the first time that comprehensive national mortality data and hospice utilization data have been used together to fully enumerate hospice use in the United States for a given year, we have acknowledged a number of limitations primarily related to differences in these two data sets. Data on race are unreliable except for Black/White differences, we do not have reliable data on site of death, diagnostic data are quite variable and we were unable to exactly match hospice users in both data sets.

Hospice use is growing at a very rapid rate. The National Hospice and Palliative Care Organization estimates that for 2005 close to one-third of all decedents of all ages and causes of death were under the care of a hospice provider.¹⁶ This is very consistent with the findings in this research (28.6% in 2003 and 33% in 2005). It is anticipated that the rate of hospice usage will eventually decrease as a steady-state is achieved and all those are served who can reasonably receive palliative care prior to death. It is unclear what the percentage of decedents receiving hospice care will be at the steady-state, or what the optimal percentage is, though some have suggested a percentage as high as 67%.¹⁹ However, our results, which document substantial variation by diagnosis and place of residence, suggest that the United States is still not at the steady-state with respect to hospice care “market penetration” and that there is valuable room for increased, and, we believe, beneficial, use of hospice care at the end of life.

Acknowledgments

The authors gratefully acknowledge the support of the National Hospice and Palliative Care Organization in funding this project.

References

1. Han R, Remsburg RE, McAuley WJ, Keay TJ, Travis SS. National trends in adult hospice use: 1991–1992 to 1999–2000. *Health Aff* 2006;25:792–799.
2. Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. *J Am Geriatr Soc* 2003;51(7):970–978.
3. Virnig BA, Moscovice IS, Durham SB, Casey MM. Do rural elders have limited access to Medicare hospice services? *J Am Geriatr Soc* 2004;52(5):731–735.
4. Keating NL, Herrinton LJ, Zaslavsky AM, Liu L, Ayanian JZ. Variations in hospice use among cancer patients. *J Natl Cancer Inst* 2006;98(15):1053–1059.
5. Locher JL, Kilgore ML, Morrissey MA, Ritchie CS. Patterns and predictors of home health and hospice use by older adults with cancer. *J Am Geriatr Soc* 2006;54(8):1206–1211.
6. Hoyert DL, Kung HC, Smith BL. Deaths: preliminary data for 2003. *Natl Vital Stat Rep* 2005;53:1–48.
7. Hatten J. Medicare’s common denominator: the covered population. *Health Care Financ Rev* 1980;2:53–64.
8. Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med* 1996;335:172–178.
9. Anderson RN, Miniño AM, Hoyert DL, Rosenberg HM. Comparability of cause of death between ICD-9 and ICD-10: preliminary estimates. *Natl Vital Stat Rep* 2001;49:1–32.
10. StataCorp. Stata Statistical Software: Release 9.2. College Station, TX: StataCorp LP, 2006.
11. Iwashyna TJ, Zhang JX, Christakis NA. Disease-specific patterns of hospice and related healthcare use in an incidence cohort of seriously ill elderly patients. *J Palliat Med* 2002;5:531–538.
12. Virnig BA, Kind S, McBean M, Fisher E. Geographic variation in hospice use prior to death. *J Am Geriatr Soc* 2000;48:1117–1125.
13. Iwashyna TJ, Chang VW, Zhang JX, Christakis NA. The lack of effect of market structure on hospice use. *Health Serv Res* 2002;37:1531–1551.
14. Christakis NA, Iwashyna TJ. The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Soc Sci Med* 2003;57:465–475.
15. Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. *N Engl J Med* 2006;354:719–730.

16. National Hospice and Palliative Care Organization. NHPCO's facts and figures—2005 findings. Available from <http://www.nhpco.org/files/public/2005-facts-and-figures.pdf>. Accessed November 26, 2006.
17. Murray AM, Arko C, Chen S, Gilbertson DT, Moss A. Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol* 2006;1: 1248–1255.
18. Dartmouth Atlas of Health Care. The care of patients with severe chronic illness: A report on the Medicare program by the Dartmouth Atlas Project. Lebanon, NH: Center for the Evaluative Clinical Sciences at Dartmouth, 2006. Available from http://www.dartmouthatlas.org/atlas/2006_Chronic_Care_Atlas.pdf. Accessed November 26, 2006.
19. Connor S. New initiatives transforming hospice care. *Hosp J* 1999;14:193–203.