


# Hospice Care for Persons With Dementia: The Growth of Access in US Nursing Homes

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Susan C. Miller, PhD<sup>1,2</sup>, Julie C. Lima, PhD<sup>2</sup>, and Susan L. Mitchell, MD, MPH<sup>3,4</sup>

## Abstract

**Background/Rationale:** Persons with dementia often die in nursing homes (NHs); however, concerns exist about their low use of Medicare hospice. **Methods:** For 1999 through 2006 in all US states and DC we merged NH resident assessment data with Medicare claims and enrollment data to identify NH decedents with dementia and hospice use. We studied two groups, those with advanced dementia and those with mild-to-moderately severe dementia. **Results:** Across study years, 22.2% of all NH decedents had mild-to-moderately severe dementia and 19.6% had advanced dementia. In 1999, 14.5% of decedents with advanced and 13.2% with mild-to-moderately severe dementia accessed hospice, increasing to 42.5% and 37.9% respectively in 2006. Between 1999 and 2006, mean days of hospice stays increased from 46 to 118 for advanced dementia and from 39 to 79 for mild-to-moderately severe dementia. These mean length of stay differences resulted from a relatively lower proportion of short hospice stays ( $\leq 7$  days) together with higher proportions of longer stays ( $\geq 181$  days) among advanced versus mild-to-moderately severe dementia decedents. Hospice access and lengths of stay among US states varied widely. **Conclusions:** Over 40% of US NH decedents have mild-to-moderately severe or advanced dementia. For these NH decedents, access to and duration of Medicare hospice has increased. However, there is considerable variation in hospice use across US states.

## Keywords

dementia, nursing home, hospice, length of stay, death

## Introduction

In 2001, 67% of US older adults with dementia who died did so in nursing homes (NHs), ranging from 40% in Texas to 89% in Rhode Island. Studies have shown high proportions of persons with dementia dying in NHs have distressing symptoms and burdensome interventions.<sup>1-6</sup> However, research shows NH decedents who receive hospice care have fewer hospitalizations<sup>7,8</sup> and better pain management,<sup>9,10</sup> compared to nonhospice NH decedents, and these benefits extend to hospice NH residents with dementia. Even so, NH residents with dementia have enrolled in hospice less frequently than residents without dementia.<sup>11</sup>

Recent Medicare claims analyses have documented growth in the use of Medicare hospice, and this growth extends to persons with noncancer diagnoses.<sup>12</sup> However, these analyses have not examined whether or how hospice growth extends to persons dying in NHs. Therefore, despite the fact that the majority of persons with dementia receive their terminal care in NHs, recent data on their hospice use are sparse.<sup>5,13,14</sup> Still, across NH and non-NH settings and for all hospice claims diagnoses there has been a 10% average annual growth in Medicare hospice beneficiaries between 2000 and 2007. There have also been large increases in mean hospice lengths of stay and in

stays greater than 180 days, and these increases have been greatest for persons with diagnoses of Alzheimer's and other cerebrodegenerative diseases.<sup>14</sup>

Medicare hospice eligibility is tied to a physician's certified terminal prognosis of 6 months or less (if the disease runs its normal course), but this prediction for persons with advanced dementia is difficult at best. In fact, the determination of a 6-month prognosis for persons with advanced dementia is viewed by physicians to be the greatest barrier to hospice referral.<sup>15</sup> In addition, although hospice eligibility guidelines exist, they do not accurately predict 6-month survival.<sup>16,17</sup> Efforts to develop and validate models to predict this survival have been

<sup>1</sup> Department of Community Health, Brown University, Providence, RI, USA

<sup>2</sup> Center for Gerontology and Health Care Research, Brown University, Providence, RI, USA

<sup>3</sup> Institute for Aging Research, Hebrew SeniorLife, Deaconess Medical Center, Boston, MA, USA

<sup>4</sup> Department of Medicine, Beth Israel, Deaconess Medical Center, Boston, MA, USA

## Corresponding Author:

Susan C. Miller, 121 South Main Street, Room 618, Providence, RI 02912, USA  
Email: Susan\_Miller@brown.edu

limited<sup>16-23</sup> or moderately successful.<sup>24</sup> Nevertheless, NH residents with advanced dementia have a 6-month mortality rate of 25% and a median survival of 1.3 years.<sup>5</sup> This life expectancy is similar to other terminal conditions such as metastatic breast cancer<sup>25</sup> and stage IV congestive heart failure (CHF).<sup>26</sup>

Prognosis inaccuracy can result in both short and long hospice stays, but given that very long stays increase overall Medicare costs,<sup>14,27</sup> policy makers have raised concerns about the growth of extended hospice stays.<sup>14,28</sup> Although hospice patients who live beyond their initial 6-month prognosis can be physician certified at 60-day intervals for continued hospice stay, initiatives focusing on reducing long hospice stays could disproportionately and adversely affect the timing of hospice referral for persons with dementia. In light of previously articulated concerns regarding hospice access for NH residents with dementia<sup>11,29</sup> as well as recent policy concerns,<sup>14,28</sup> a better understanding of hospice use for NH decedents with dementia is needed.

Two recent studies have shown an increase in NH hospice use by persons dying with dementia in NHs.<sup>5,13</sup> One prospective study (2002-2005) conducted in 31 NHs in 5 states found 55% of dementia decedents used hospice.<sup>13</sup> Another study (2003-2007) in the Boston area found 30% of decedents with advanced dementia were referred to hospice, and of these, equal proportions (26%) had either short ( $\leq 7$  days) or long ( $>181$  days) hospice stays.<sup>5</sup> Further understanding is needed as to whether these findings are generalizable to the US NH population as well as whether and how hospice lengths of stays have changed for NH decedents with dementia diagnoses.

This study aimed to document how the use of hospice (ie, enrollment and length of stay) for US NH residents dying with advanced and mild-to-moderately severe dementia has changed over time. It is the first study to present these population data and to estimate the proportion of US NH decedents who die with dementia. Additionally, it is the first study to present data on how hospice use varies across the 50 US states (and District of Columbia [DC]) for NH decedents with dementia. As such, this study provides important information to inform policy and practice.

## Methods

### Data and Study Population

A signed data use agreement from the Center for Medicare and Medicaid Services (CMS) was secured to use 1999-2006 NH resident assessment data (minimum data set [MDS]) for the 50 US states and the DC, matched to Medicare Part A claims data (ie, for hospice, hospital, home health, outpatient, and skilled nursing facility [SNF] care) and to Medicare enrollment data (which includes vital statistics data). Because this study's focus was on decedents, it was exempt from institutional review board review.

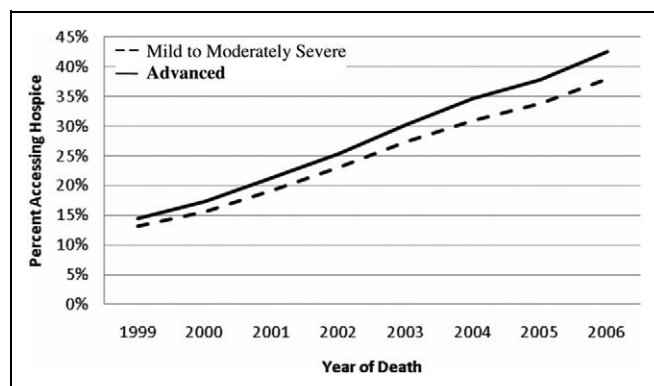
The above data were concatenated to create a residential history file<sup>30</sup> that was used to determine where NH residents died and the care they received in the days and weeks prior to death.

The population of NH residents was first identified using 1999-2006 MDS data from Medicare-/Medicaid-certified NHs (97% of US NHs). Then, to determine Medicare eligibility and whether, when and where death occurred, these data were matched to Medicare enrollment data and Medicare claims. Nursing home decedents were defined as Medicare beneficiaries if their deaths occurred within 1 day of an identified NH stay or within 7 days of hospital transfer from an NH (as done in previous research).<sup>7,31</sup> In study year 1999, to enable capture of at least 180 days of a hospice stay, we only included NH residents who died in July through December. The total number of confirmed NH decedents in the latter half of 1999 through 2006 in the 50 states and DC was 4,029,584. From this population, we removed those with the missing MDS data items needed to derive the cognitive performance scale ([CPS]; 181,470; 4.5%),<sup>22,32</sup> since the CPS was needed to categorize the severity of the resident's dementia. A total of 3,848,114 decedents were included in the final cohort.

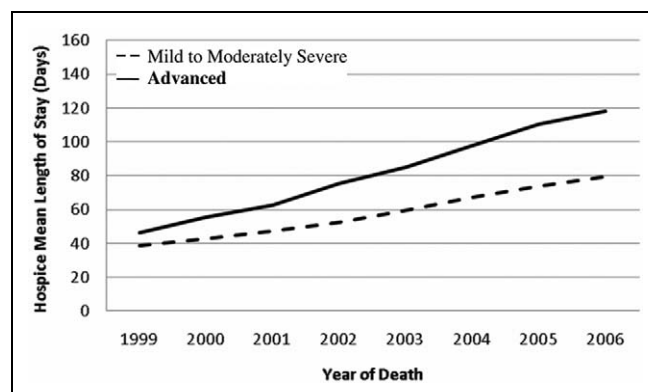
The cohort was categorized into 2 groups for analyses; decedents with advanced and those with mild-to-moderately severe dementia. Decedents in both groups required a diagnosis of dementia on the MDS closest to death ("Alzheimer's" or "Dementia other than Alzheimer's" documented as present) or an *International Classification of Diseases, Ninth revision, Clinical Modification (ICD-9-CM)* coded dementia diagnosis on any Medicare Part A claims in the last 12 months of life. The severity of dementia was determined using the CPS derived from the MDS closest to death.<sup>22,32</sup> The CPS groups residents into 7 cognitive performance categories based on 5 MDS items: 0 = *intact*, 1 = *borderline intact*, 2 = *mild impairment*, 3 = *moderate impairment*, 4 = *moderately severe impairment*, 5 = *severe impairment*, and 6 = *very severe impairment with eating problems*. A CPS score of 5 corresponds to a mean Mini Mental State Examination score of  $5.1 \pm$  (standard deviation [SD]) 5.3.<sup>22,32</sup> Decedents were defined as having advanced dementia if their CPS scores equaled 5 or 6<sup>22,32</sup> (N = 754,532; 19.6% of all decedents with nonmissing MDS data) and as having mild-to-moderately severe dementia when their scores equaled 2, 3, or 4 (N = 854,709; 22.2% of all decedents with nonmissing MDS data). In total, 41.8% of NH decedents in the study years had dementia; this proportion was 40.6% in 2006.

### Nursing Home Hospice Use

Nursing home hospice use was identified when dates on hospice claims overlapped with dates of NH stays. Dates on hospice claims were used to identify the hospice length of stay (ie, total number of days on the Medicare hospice benefit). When more than 1 hospice episode occurred (ie, individual was discharged and readmitted to hospice), the days from each episode were totaled. Hospice days prior to NH admission were included in totals when these days were part of a continuous hospice episode (ie, resident admitted on hospice) or when the community episode/episodes occurred within 6 months of the NH hospice episode.



**Figure 1.** Growth in use of hospice by dementia diagnosis, 1999-2006.



**Figure 2.** Mean hospice lengths of stay by dementia status: 1999-2006.

### Resident Characteristics

To describe decedents, we obtained demographic and social variables from the MDS closest to death, including age, gender, marital status, and education. Age was a continuous variable. Race/ethnicity was categorized as non-Hispanic white, non-Hispanic black, Hispanic, and other; marital status as married, widowed/divorced, separated, and never married; and level of education as less than high school, high school, and some college, and included a category for “missing” since approximately 4% of the decedents’ MDSs did not document the level of their education. From the MDS we also captured the presence of selected comorbid conditions that are prevalent among NH residents—arteriosclerotic heart disease (ASHD), cancer, chronic obstructive pulmonary disease (COPD), CHF, cerebrovascular accident (stroke), other cardiovascular disease, and renal failure. To describe functional impairment, an activities of daily living (ADLs) scale derived from the MDS and ranging from the 0 to 28 (indicating lesser to greater impairment) was used, and ADL impairment was described using mean scores (with SD).<sup>33</sup> In addition, we determined (using the MDS) whether decedents had a do not resuscitate (DNR) or do not hospitalize (DNH) order in place. Finally, we identified decedents as having either short ( $\leq 90$  days) or long ( $>90$  days) NH lengths of stay and as having any or no health maintenance organization (HMO) enrollment at the time of death (as documented in the Medicare enrollment file).

### Analyses

The longitudinal analyses used proportions and means to portray hospice enrollment and lengths of stay over time for the populations studied. In addition, for 2006 cross-sectional analyses, proportions and means were used to compare the characteristics of decedents with advanced versus mild-to-moderate dementia, and within each group those who did and did not access hospice in the NH. The 2006 cross-sectional analyses also compared the rates of hospice enrollment and lengths of hospice stay across the 50 US states and DC.

## Results

### Longitudinal Findings

As shown in Figure 1, hospice access for NH decedents with advanced dementia tripled between 1999 and 2006; the rate of use was 14.5% in 1999 and 42.5% in 2006. Rates also nearly tripled for decedents with mild-to-moderate dementia, rising from 13.2% in 1999 to 37.9% in 2006. Greater access was accompanied by increases in mean lengths of hospice stay, which were more pronounced among decedents with advanced compared to those with mild-to-moderate dementia (see Figure 2). Mean stays rose from 46.1 days in 1999 to 118.2 days in 2006 for advanced dementia decedents whereas they increased from 38.7 to 79.5 days (respectively) for decedents with mild-to-moderately severe dementia.

### 2006 Cross-Sectional Findings

Table 1 shows 2006 decedent characteristics by the 2 dementia groups and by hospice enrollment. Compared to decedents with mild-to-moderate dementia, advanced dementia decedents were younger and higher proportions were female. In addition, higher proportions of advanced versus other had at least high school educations, stroke diagnoses, DNR or DNH orders, and long NH stays. Lower proportions of the advanced dementia group were non-Hispanic white and had diagnoses of ASHD, cancer, COPD, CHF, other cardiovascular disease, and renal failure. Advanced dementia decedents were more functionally and cognitively impaired than decedents with mild-to-moderate dementia.

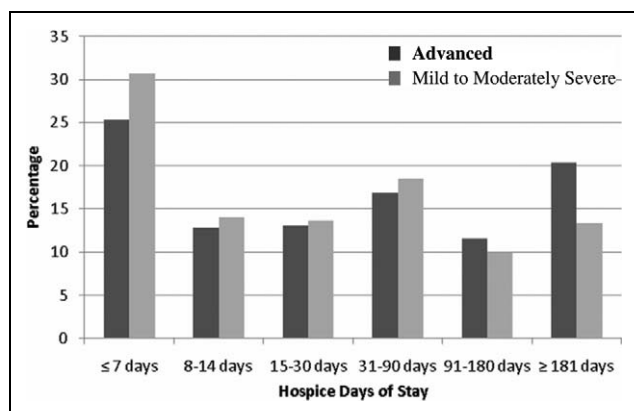
In both dementia groups, residents who had NH hospice (vs no hospice) were more frequently female, non-Hispanic white, and higher proportions had higher levels of education, cancer diagnoses, other cardiovascular disease, renal failure, DNR or DNH orders, and long NH stays ( $\geq 90$  days; Figure 1). Lower proportions of residents in both groups with NH hospice had ASHD, COPD, CHF, or were enrolled in HMOs. Residents in both groups who had the additional diagnoses of cancer or other cardiovascular disease were more likely to access hospice compared to those without these diseases. Those with advanced

**Table 1.** Characteristics of US Nursing Home Decedents With Dementia in 2006, By End-of-Life Dementia Status and Hospice Use

	Advanced (n = 85,942)		Mild-to-Moderately Severe (n = 117,531)	
	No Hospice (n = 49,408)	Hospice (n = 36,534)	No Hospice (n = 72,950)	Hospice (n = 44,581)
Female	68.2%	73.4%	63.0%	68.7%
Age at death	85.7 (8.1)	85.4 (8.2)	86.1 (7.8)	86.3 (7.7)
Race				
Non-Hispanic white	85.4%	87.0%	88.8%	90.5%
Non-Hispanic black	10.0%	9.1%	7.3%	6.4%
Hispanic	2.9%	2.9%	2.3%	2.3%
Other	1.6%	1.0%	1.5%	0.8%
Marital status				
Married	27.9%	26.2%	25.1%	23.7%
Widowed	58.3%	60.6%	59.9%	62.6%
Single	13.9%	13.2%	15.0%	13.7%
Education				
<High school	37.0%	33.8%	36.1%	33.0%
High school	37.8%	41.1%	39.0%	42.0%
Some college	20.4%	22.3%	21.5%	23.0%
Education missing	4.9%	2.8%	3.4%	2.0%
Diagnoses (other) <sup>a</sup>				
Arteriosclerotic heart disease	12.9%	11.3%	14.5%	13.0%
Cancer	4.6%	6.6%	6.1%	10.2%
Chronic obstructive pulmonary disease	14.4%	12.0%	20.3%	18.4%
Congestive heart failure	22.6%	18.9%	30.1%	27.8%
Other cardiovascular disease	12.6%	13.9%	15.3%	16.7%
Renal failure	5.0%	5.3%	6.0%	6.9%
Stroke	23.8%	22.7%	20.0%	20.4%
Advance directives				
Do not resuscitate order	77.5%	82.8%	69.7%	77.5%
Do not hospitalize order	11.2%	12.3%	7.5%	9.9%
Length of NH stay				
Long stay (>90 days)	79.2%	89.4%	75.1%	85.9%
ADL scale (0-28)	25.4 (3.8)	25.6 (3.6)	20.4 (6.1)	21.1 (5.8)
CPS score	5.7 (0.5)	5.7 (0.5)	3.2 (0.6)	3.2 (0.6)
Enrolled in HMO at time of death	10.0%	8.6%	11.1%	9.7%

Abbreviations: ADL, activities of daily living; CPS, cognitive performance scale; HMO, health maintenance organization; MDS, minimum data set; NH, nursing home.

<sup>a</sup> Selected nondementia diagnoses on the resident assessment instrument (MDS) closest to death. Decedents may have had more than one of the diagnoses listed.



**Figure 3.** Hospice length of stay distributions for US nursing home (NH) decedents with dementia in 2006, by end-of-life dementia status.

dementia and stroke diagnoses were less likely to access hospice whereas those with mild-to-moderate dementia and stroke diagnoses were slightly more likely.

Decedents with advanced versus mild-to-moderate dementia had longer mean hospice stays in 2006. Figure 3 shows 2006 mean length of stay differences result from a relatively lower proportion of short hospice stays together with higher proportions of longer stays among advanced versus mild-to-moderate dementia decedents.

Table 2 displays the state variation in hospice use for decedents with advanced dementia. States with the lowest rates of hospice use include the more rural states of Alaska, Wyoming, Hawaii, and Vermont (at 2.7%, 5.4%, 9.9%, and 10.9%, respectively) and states with the highest use included Texas, Kansas, Iowa, and Oklahoma (at 59.2%, 60.6%, 62.2%, and 71.7%, respectively). Of note, among decedents with mild-to-

**Table 2.** Nursing Home Hospice Use Across US States: 2006 Nursing Home Decedents With Advanced Dementia

State	Confirmed NH Deaths (N)	Hospice Use		Hospice Length of Stay, 2006					
		%	n	Mean	SD	Median	90th Percentile	% ≤7 Days	% >180 Days
Total	85942	42.5	36534	118.2	205.3	28	344	25.3	20.4
AK	37	2.7	1	67.0	.	67	67	0.0	0.0
AL	2006	43.3	869	188.0	256.5	71	504	16.3	34.3
AR	985	37.0	364	132.4	230.9	30	420	26.6	21.4
AZ	633	56.6	358	146.4	225.2	41	444	24.0	27.9
CA	6839	34.0	2325	119.1	222.8	22	364	27.4	19.3
CO	772	55.4	428	117.9	210.4	27	341	28.7	22.0
CT	1637	35.2	576	59.5	104.5	14	181	33.7	10.2
DC	83	28.9	24	17.3	20.7	11.5	37	33.3	0.0
DE	269	49.4	133	126.3	195.8	29	399	22.6	21.1
FL	4750	56.0	2661	139.8	231.8	35	414	23.4	23.9
GA	2378	46.5	1105	121.6	213.3	32	348	23.3	19.3
HI	141	9.9	14	68.7	78.0	17.5	191	28.6	14.3
IA	1098	62.8	690	80.8	127.2	20	245.5	32.0	15.7
ID	250	20.4	51	102.2	183.1	24	239	23.5	17.6
IL	3543	47.0	1664	122.0	208.4	27	360	25.1	21.6
IN	1742	46.9	817	126.4	218.7	33	364	24.7	22.5
KS	1154	62.2	718	88.2	158.6	22	257	25.9	15.5
KY	1485	26.9	399	82.6	143.1	20	243	29.8	14.8
LA	1474	56.6	834	104.6	185.0	30	291	20.6	17.6
MA	3490	38.9	1357	101.4	163.8	27	290	25.9	19.0
MD	2043	30.0	612	78.8	139.9	18	255	30.1	12.9
ME	791	29.2	231	118.6	165.2	39	324	22.9	23.4
MI	3083	44.9	1385	139.1	230.4	38	432	22.5	22.7
MN	1485	37.6	558	73.6	114.3	20	219	31.0	13.8
MO	2005	54.7	1096	109.9	181.2	29.5	321	22.4	20.1
MS	768	35.2	270	170.8	265.7	59.5	496	19.3	28.9
MT	215	23.7	51	52.6	81.9	13	179	39.2	9.8
NC	2439	36.6	893	104.9	155.6	31	300	23.7	19.4
ND	435	25.7	112	154.3	222.1	62	421	22.3	26.8
NE	621	47.0	292	88.4	135.1	24	244	27.7	16.8
NH	415	46.5	193	72.9	120.7	23	217	29.5	12.4
NJ	2495	46.7	1164	84.1	157.3	18	250	30.9	14.3
NM	325	44.9	146	217.8	312.8	60.5	740	24.7	34.2
NV	243	44.9	109	98.9	192.8	15	338	26.6	17.4
NY	4796	24.0	1149	90.1	150.5	26	265	26.6	16.7
OH	4257	53.7	2285	101.3	182.7	24	298	28.2	17.5
OK	1246	71.7	893	294.7	362.0	155	802	12.7	46.6
OR	565	33.6	190	88.1	116.7	28	253.5	25.3	17.9
PA	5383	46.8	2520	94.5	162.0	22	277.5	28.2	17.3
RI	593	51.6	306	97.5	153.1	29.5	298	22.9	19.0
SC	1504	38.2	575	176.5	239.7	73	504	19.3	33.2
SD	519	24.3	126	61.6	92.3	16	173	34.9	8.7
TN	2917	34.9	1018	128.7	212.5	34	390	21.5	21.5
TX	4947	60.6	3000	123.8	228.4	29	356	23.6	20.0
UT	289	59.2	171	139.5	241.3	37	339	22.8	21.6
VA	1810	28.7	519	96.0	168.3	21	288	29.5	16.4
VT	175	10.9	19	55.1	98.1	21	299	36.8	10.5
WA	1610	28.2	454	88.2	134.9	21	295	31.9	17.0
WI	2506	28.8	721	125.4	217.3	31	360	24.1	21.5
WV	530	14.9	79	117.4	194.2	29	433	21.5	19.0
WY	166	5.4	9	140.7	212.2	29	612	33.3	33.3

Abbreviations: AK, Alaska; AL, Alabama; AR, Arkansas; AZ, Arizona; CA, California; CO, Colorado; CT, Connecticut; DC, District of Columbia; DE, Delaware; FL, Florida; GA, Georgia; HI, Hawaii; IA, Iowa; ID, Idaho; IL, Illinois; IN, Indiana; KS, Kansas; KY, Kentucky; LA, Louisiana; MA, Massachusetts; MD, Maryland; ME, Maine; MI, Michigan; MN, Minnesota; MO, Missouri; MS, Mississippi; MT, Montana; NC, North Carolina; ND, North Dakota; NE, Nebraska; NH, New Hampshire; NJ, New Jersey; NM, New Mexico; NV, Nevada; NY, New York; OH, Ohio; OK, Oklahoma; OR, Oregon; PA, Pennsylvania; RI, Rhode Island; SC, South Carolina; SD, South Dakota; TN, Tennessee; TX, Texas; UT, Utah; VA, Virginia; VT, Vermont; WA, Washington; WI, Wisconsin; WV, West Virginia; WY, Wyoming.

moderate dementia, rates of hospice use were lower compared to those with advanced dementia in 46 of 50 US states and in DC (data not shown).

Hospice lengths of stay varied dramatically, with 3 states having substantially higher median lengths of stay (Table 2). At 155 days, Oklahoma has the longest median stay, with the next highest medians being 73 days in South Carolina and 71 days in Alabama. In Oklahoma, 46.6% of NH hospice decedents had stays greater than 180 days, whereas this proportion was 33.2% in South Carolina and 34.3% in Alabama. In almost all states, median hospice stays for decedents with mild-to-moderate dementia were much lower than observed for advanced dementia decedents; for example, in Oklahoma the median hospice stay of 72.5 days for decedents with mild-to-moderate dementia was less than half the 155-day median for advanced dementia decedents (data not shown).

## Discussion

In 2006, 40.6% of persons dying in US NHs had dementia and 40.1% of these decedents accessed Medicare hospice. There has been a 3-fold increase in access between 1999 and 2006, and this increase was similar for NH residents dying with advanced and with mild-to-moderate dementia. In addition, mean lengths of hospice stays increased between 1999 and 2006 among US NH residents with dementia; however, this increase was most pronounced among more severely impaired residents. In 2006, rates of hospice access and lengths of stay varied substantially across US states.

The growth in hospice use by NH residents with dementia is greater than that observed for US NH decedents generally. Overall, the rates of NH hospice use doubled between 1999 and 2006 (from 14% to 33.1%, respectively),<sup>12</sup> but for advanced dementia decedents the rates tripled to 42.5%, and to 37.9% for those with earlier stage dementia. In addition, in 2006, the mean hospice stay of 118 days for NH advanced dementia decedents was longer than the 93-day mean stay for US NH decedents generally.<sup>12</sup> However, NH decedents with mild-to-moderate dementia had an 80-day mean hospice length of stay.

In examining 2006 data, we found NH decedents with advanced versus mild-to-moderate dementia differed in many respects. As expected, those with advanced dementia had greater functional and cognitive impairment, and higher proportions had DNR and DNH orders in place. Importantly and also expected, those with less severe dementia compared to those with advanced dementia had a greater prevalence of all the selected comorbid diagnoses except stroke.

Differences in hospice enrollment by decedent characteristics were essentially similar to previous NH research (Table 1),<sup>31</sup> and there were few differences in hospice access across dementia groups. However, 1 comorbid condition stands out as being differentially related to hospice use across dementia groups. Decedents with cancer diagnoses more frequently accessed hospice when they had mild-to-moderate dementia versus advanced dementia. Since cancer decedents are more likely to access hospice,<sup>31</sup> it is plausible that cancer diagnoses

drive hospice admissions more frequently for residents with mild-to-moderate dementia versus advanced dementia. In addition, decedents with CHF were slightly more likely to access hospice when they had advanced versus less severe dementia. Since NH decedents with CHF less frequently enroll in hospice,<sup>31</sup> it may be that the presence of advanced dementia was associated with this greater use.

Hospice length of stay distributions for 2006 NH decedents reveal differences in hospice referral/election patterns between the 2 dementia groups. For those with advanced dementia, the 2006 hospice length of stay distribution was bimodal, with 25% of decedents having stays of 1 week or less and 20% having stays of over 6 months. This bimodal distribution, similar to that observed in the Boston-area study of NH decedents with advanced dementia,<sup>5</sup> reflects the challenges of predicting 6-month survival for persons with end-stage dementia as well as the poor discrimination of hospice referral guidelines.<sup>34</sup> In addition, however, longer hospice stays are believed to be driven in part by financially motivated provider behavior since, regardless of length of stay, hospices are paid the same daily rates for routine hospice home care (95% of all hospice care days) and a hospice's profit margin is greater when its stays are longer.<sup>14</sup> This belief is supported in part by previous NH research, showing hospice users generally had greater increases in the lengths of long hospice stays (stays at the 90th percentile) when they resided in states with the most versus least (for-profit) hospice provider growth.<sup>12</sup>

For 2006 NH decedents with mild-to-moderately severe dementia, short hospice stays were prevalent (at 31%), whereas long stays were less so (at 13%). Nonetheless, like advanced dementia decedents, poor prediction of 6-month survival probably adversely influenced the timing of referral. Another explanation may relate to the fact that to enroll in Medicare hospice, beneficiaries must forgo other Medicare-Part A care (when such care is related to the terminal illness) and this includes hospital and skilled NH care. Additionally, beneficiaries must abandon expensive treatments such as blood transfusions or palliative radiation (when hospices lack financial resources to support such care).<sup>35-37</sup> Therefore, given the greater presence of noncancer diagnoses for decedents with less severe dementia, it is likely that the high prevalence of short hospice stays for this group of decedents may in part result from the desire of residents and/or their families to continue life-sustaining and/or expensive treatments to manage their illnesses.

The 2006 data show rates of hospice use and lengths of stay varied widely among states. Therefore, while access to NH hospice for dementia decedents has increased, there are still states where low NH hospice use remains an issue. States with lower hospice use tended to be more rural states and this observation is in agreement with previous research showing rates of hospice use decrease as rurality of geographic areas increase.<sup>38</sup> The large state variation in hospice length of stay distributions supports the notion that differential referral practices exist. As shown in related research,<sup>39</sup> differing Medicare fiscal intermediary oversight may have contributed in part to these differences as may have provider and/or health care market factors.

Further analytic study is needed to understand how these factors may be associated with the observed state differences.

The MedPAC has recommended changing the Medicare payment system so the per diem rate for hospice routine home care (provided in NHs and homes in the community) better reflects the intensity of hospice service provision,<sup>14</sup> since research has shown hospice visits to be more frequent at time periods closer to the beginning and end of hospice episodes.<sup>28,40,41</sup> The MedPAC has also recommended closer scrutiny of recertification of hospice patients after the 180th day of stay; specifically, they propose requiring patient visits by physicians or advanced practice nurses to evaluate their continued eligibility and need for care.<sup>14</sup> Although these recommended approaches to curbing Medicare costs appear to be a viable option for both retaining hospice access while reducing the number of long (costly) hospice stays (some of which may result from perverse financial incentives), the potential implications of such changes are of concern. In particular, given the long stays of persons with advanced dementia, the fear is that the payment and policy changes may result in higher prevalence of short stays and/or in lower hospice use generally. Therefore, it is critical that the creation of any new policy explicitly consider the challenges inherent in the timing of hospice referral for NH residents dying with dementia. For NH and physician providers, it is important that scrutiny of long hospice stays does not prompt later hospice referrals but rather continued documentation of the rationale for a 6-month terminal prognosis (if the disease runs its normal course).

This study has limitations that deserve comment. First, the diagnosis of dementia and its grouping into advanced and mild-to-moderately severe were determined indirectly using secondary data contained in the MDS and Medicare claims. However, in a Maryland study focusing on newly admitted NH residents, prevalence estimates of dementia were similar when using an expert panel and *Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R)* criteria (48.0%) versus using the residents' charts (shown to agree substantially with the MDS) and Medicare claims (48.6%).<sup>42</sup> In addition, our finding that 41.8% of US NH decedents had dementia is similar to the Maryland estimates. Second, other resident-level demographic and clinical data were obtained from the MDS, and the possibility of inaccuracies must be considered. Additionally, this research describes hospice use by NH decedents with dementia. We are unable to comment on the decision making around hospice referral and on factors associated with referral other than those represented in our secondary data sources.

In conclusion, persons dying in NHs with advanced or mild-to-moderately severe dementia have considerably increased access to Medicare hospice care, but access varies substantially across US states. In addition, although mean lengths of hospice stay have increased substantially, high proportions of decedents with advanced dementia had very long stays and high proportions with mild-to-moderate dementia having very short hospice stays. Anticipated policy changes as advocated by MedPAC must be carefully crafted to address current perverse

financial incentives while not jeopardizing access to and duration of Medicare hospice for dementia decedents. Providers are advised to respond to policy changes and oversight by continuing to document their "good faith" justifications for a predicted 6-month survival, not by increasing their hesitancy to refer.

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