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## End-of-Life Transitions among Nursing Home Residents with Cognitive Issues

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### Abstract

**BACKGROUND**—Health care transitions in the last months of life can be burdensome and potentially of limited clinical benefit for patients with advanced cognitive and functional impairment.

**METHODS**—To examine health care transitions among Medicare decedents with advanced cognitive and functional impairment who were nursing home residents 120 days before death, we linked nationwide data from the Medicare Minimum Data Set and claims files from 2000 through 2007. We defined patterns of transition as burdensome if they occurred in the last 3 days of life, if there was a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or if there were multiple hospitalizations in the last 90 days of life. We also considered various factors explaining variation in these rates of burdensome transition. We examined whether there was an association between regional rates of burdensome transition and the likelihood of feeding-tube insertion, hospitalization in an intensive care unit (ICU) in the last month of life, the presence of a stage IV decubitus ulcer, and hospice enrollment in the last 3 days of life.

**RESULTS**—Among 474,829 nursing home decedents, 19.0% had at least one burdensome transition (range, 2.1% in Alaska to 37.5% in Louisiana). In adjusted analyses, blacks, Hispanics, and those without an advance directive were at increased risk. Nursing home residents in regions in the highest quintile of burdensome transitions (as compared with those in the lowest quintile) were significantly more likely to have a feeding tube (adjusted risk ratio, 3.38), have spent time in an ICU in the last month of life (adjusted risk ratio, 2.10), have a stage IV decubitus ulcer (adjusted risk ratio, 2.28), or have had a late enrollment in hospice (adjusted risk ratio, 1.17).

**CONCLUSIONS**—Burdensome transitions are common, vary according to state, and are associated with markers of poor quality in end-of-life care. (Funded by the National Institute on Aging.)

Health care transitions, such As the hospitalization of nursing home residents, have the potential for fragmentation of care, changes in the management of chronic diseases, duplication of diagnostic workups, and medical errors.<sup>1–7</sup> Few previous reports have described health care transitions among nursing home residents who had advanced cognitive impairment. These patients and their family members are especially vulnerable to the adverse consequences resulting from transitions, particularly during end-of-life care.

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Pertinent sources of distress include the trauma of the physical transfer, increased confusion because of unfamiliar settings and providers, inadequate ability to address the patient's special needs (e.g., assistance with feeding), and lack of communication regarding goals of care. Transitions among patients with advanced dementia are often avoidable<sup>8–13</sup> because common complications in such patients can be treated with equal efficacy in the nursing home. When comfort is the main goal of care,<sup>14</sup> health care transitions are seldom consistent with that goal.<sup>15–18</sup>

To examine health care transitions among nursing home residents with advanced cognitive impairment at the end of life, we linked nationwide data from the Medicare Minimum Data Set (MDS) and claims files from 2000 through 2007. The objectives of the study were to describe rates of burdensome transition in this population, identify factors that were associated with an increased rate of burdensome transition, and examine the association between regional rates of burdensome transition and outcomes that are markers of poor quality in end-of-life care.

#### **METHODS**

#### STUDY POPULATION

We identified the study population using MDS data on all nursing home residents in the United States, which are regularly updated, and Medicare claims data from January 1, 2000, through December 31, 2007. The MDS is a federally mandated, comprehensive assessment tool that contains detailed demographic and clinical information. The criteria for eligibility included enrollment in a Medicare fee-for-service plan, residence in a nursing home 120 days before death, an age of more than 66 years, a need for extensive assistance or total dependence with respect to all seven activities of daily living (ADLs) that are captured in the MDS ADL scale, and advanced cognitive impairment (as defined by a cognitive performance score of 5 or 6 on the MDS assessment completed closest to 120 days before death). The ADL scale is a validated measure of physical functioning that ranges from 0 (independent in all seven ADLs) to 28 (total dependence in all seven ADLs).<sup>19</sup> A cognitive performance score of 5 (on a scale ranging from 0 [intact] to 6 [very severe impairment, with eating problems]) corresponds to a mean ( $\pm$ SD) score of 5.1 $\pm$ 5.3 on the Mini–Mental State Examination<sup>20</sup> (on which a score below 24 indicates cognitive impairment).

#### **DEFINITION OF BURDENSOME TRANSITION**

Transitions were identified with the use of the residential-history file, an algorithm that uses Medicare claims files and MDS data to track the location of Medicare beneficiaries on a daily basis.<sup>21</sup> A burdensome transition was defined on the basis of a previously conducted narrative analysis with families of persons who had died in a nursing home<sup>22</sup> and the expert opinion of geriatricians and palliative medicine specialists.

Three types of transitions were classified as being potentially burdensome: any transfer in the last 3 days of life, a lack of continuity of nursing home facilities before and after a hospitalization in the last 90 days of life (i.e., going from nursing home A to the hospital and then to nursing home B), and multiple hospitalizations in the last 90 days of life. Multiple hospitalizations were defined as either more than two hospitalizations for any reason or more than one hospitalization for pneumonia, urinary tract infection, dehydration, or sepsis in the last 90 days of life, as ascertained from Medicare claims files. Fewer hospitalizations were required for these diagnoses because they are predictable end-of-life events in patients with advanced cognitive impairment and are potentially manageable with appropriate advance care planning, without the need for hospitalization. A burdensome-transition score

was created (range, 0 to 3) on the basis of the occurrence of any event in each category during the last 90 days of life.

#### OTHER VARIABLES

The age of patients was taken from the Medicare denominator record. Data on sociodemographic characteristics (sex, race or ethnic group, and education) and health status were derived from the MDS assessment. Measurements of health status included the number of coexisting medical conditions; functional status; the presence or absence of weight loss, swallowing problems, pneumonia in the previous 7 days, orders to forgo life-sustaining treatment, and written advance directives; and the stability of the patient's condition (as rated by nursing home staff). Coexisting medical conditions included diabetes mellitus, congestive heart failure, hip fracture in the previous 90 days, stroke, coronary artery disease, renal disease, type of dementia, and cancer. Advance directives and orders to forgo life-sustaining treatment included the presence of a durable power of attorney for health care, a living will, a do-not-resuscitate order, and a do-not-hospitalize order.

Variables that characterized the quality of end-of-life care in patients with advanced dementia were based on the literature<sup>23</sup> and obtained from Medicare claims and MDS data. Measures included insertion of a feeding tube in the last 90 days of life, admission to an intensive care unit (ICU) in the last 30 days of life, and enrollment in hospice in the last 3 days of life. Among the nursing home residents with an MDS that was completed in the last 30 days of life, the presence of stage IV pressure ulcers was examined.

#### STATISTICAL ANALYSIS

We evaluated the characteristics of patients in the entire cohort and stratified these characteristics according to the number of burdensome transitions, using means for continuous variables and frequencies for categorical variables. The proportion of patients in each state (categorized into quartiles) who had at least one burdensome transition during the study period was calculated.

Adjusted risk ratios were calculated with the use of modified Poisson multivariate regression to examine the associations between characteristics of the patients derived from the baseline MDS and the number of burdensome transitions.<sup>24–26</sup> The multivariate model was adjusted for sociodemographic characteristics, the presence or absence of advance directives, and the above-mentioned health measures, as well as the MDS–CHESS (Changes in Health, End-Stage Disease, and Symptoms and Signs) score<sup>27</sup> (a measure of the risk of death among nursing home residents) and the year of death to adjust for secular trends. Standard errors of multivariate models are based on the robust (sandwich) variance estimator.<sup>24</sup>

In a second analysis, we examined the association between residence in hospital referral regions with ascending rates of burdensome transition and the quality of end-of-life care among cohort members who died in the 2006–2007 period. In order to avoid the bias of using the same years of data for the exposure and outcome (i.e., simultaneity bias), the rates of burdensome transition in hospital referral regions were calculated for the period from 2003 to 2005 and were grouped into quintiles. We used chi-square tests and t-tests to evaluate unadjusted associations. Multivariate analyses were conducted with adjustment for the above-mentioned characteristics. Adjusted risk ratios with 95% confidence intervals were derived from modified Poisson multivariate regression analyses that accounted for the binomial outcomes. Sensitivity analyses with the use of a log-binomial regression model<sup>24–26</sup> showed almost identical results. Sensitivity analyses were repeated among patients with a diagnosis of dementia and those with total dependence in all seven ADLs.

#### RESULTS

#### **CHARACTERISTICS OF THE PATIENTS**

Between 2000 and 2007, we identified 474,829 nursing home residents with advanced cognitive impairment 120 days before death. The residents' mean age at the time of death was  $85.7\pm7.6$  years; 78.0% were women, 83.0% were white, and 37.9% had less than a high-school education (Table 1). A total of 54.0% of residents had swallowing problems, and 15.4% had recent weight loss. The majority of residents had a do-not-resuscitate order (73.0%), but do-not-hospitalize orders were rare (6.8%).

#### **BURDENSOME TRANSITIONS**

A total of 90,228 nursing home residents (19.0%) had at least one burdensome transition in the last 90 days of life (Table 1). On the basis of our definitions, the distribution of the type of burdensome transition was as follows: 55,039 subjects (11.6%) had a health care transition in the last 3 days of life, 12,827 (2.7%) had a lack of continuity in nursing home provider after a hospitalization in the last 90 days of life, and 38,573 (8.1%) had multiple hospitalizations in the last 90 of life. The proportion of nursing home residents who had at least one burdensome transition varied widely across states, ranging from 2.1% in Alaska to 37.5% in Louisiana (Fig. 1, and Table 1 in the Supplementary Appendix, available with the full text of this article at NEJM.org). Over time, the rate of one or more burdensome transitions increased from 17.4% (in 2000) to 19.6% (in 2007), with the majority of that increase occurring between 2000 and 2003.

Table 2 describes each type of burdensome transition, including the overall rates and variations according to state. The results of univariate and multivariate analyses of the association between patients' characteristics and the number of burdensome transitions are presented in Tables 1 and 3, respectively. As compared with whites, members of other racial and ethnic groups were more likely to have a burdensome transition, including blacks (adjusted risk ratio, 1.24; 95% confidence interval [CI], 1.22 to 1.26) and Hispanics (adjusted risk ratio, 1.24; 95% CI, 1.21 to 1.27). Other variables associated with a significantly increased risk of a burdensome transition were male sex (adjusted risk ratio, 1.15; 95% CI, 1.18 to 1.22), lack of a written advance directive (adjusted risk ratio, 1.63; 95% CI, 1.61 to 1.65), and lack of a do-not-resuscitate order (adjusted risk ratio, 2.14; 95% CI, 2.06 to 2.23). Finally, residents who died in 2007, as compared with those who died in 2000, were slightly more likely to have a burdensome transition (adjusted risk ratio, 1.16; 95% CI, 1.13 to 1.19).

#### QUALITY OF END-OF-LIFE CARE

Table 4 examines the association between rates of burdensome transition, according to hospital referral region, and the risk of other markers of a poor quality of end-of-life care. Hospital referral regions were ranked into quintiles on the basis of rates of burdensome transition of nursing home residents who died between 2003 and 2005. The distribution of markers of a poor quality of end-of-life care among 102,620 nursing home residents with advanced cognitive impairment in 2006–2007 was as follows: 9324 (9.1%) were hospitalized in an ICU in the last 30 days of life, and 6222 (6.1%) were referred to hospice care in the last 3 days of life. Among 38,092 persons with an MDS assessment in the last 30 days of life, 5176 (13.6%) had a stage IV decubitus ulcer. Among 20,573 persons for whom Medicare Part B data were available, 881 (4.3%) had a feeding tube inserted in the last 90 days of life.

Residence in a region with an increased rate of burdensome transition was generally associated with a poorer quality of care. This association remained significant even after multivariate adjustment. As compared with regions in the lowest quintile of burdensome transitions, nursing home residents in the regions with the highest quintile were more likely to have a feeding tube (adjusted risk ratio, 3.38; 95% CI, 2.48 to 4.60), spend time in an ICU in the last 30 days of life (adjusted risk ratio, 2.10; 95% CI, 1.93 to 2.29), have a stage IV decubitus ulcer (adjusted risk ratio, 2.28; 95% CI, 2.04 to 2.54), or be enrolled in hospice late (adjusted risk ratio, 1.17; 95% CI, 1.07 to 1.28). All sensitivity analyses that were conducted for the subgroup of patients with a diagnosis of dementia and those with an ADL score of 28 (total dependence) had results that were similar to those of the main analyses.

#### DISCUSSION

Previous research on health care transitions has focused on hospital transitions. In this study, we attempted to define patterns of transition among persons with advanced cognitive impairment who were in a nursing home 120 days before death. For patients with dementia, which is a progressive, fatal illness, health care providers and families are faced with making decisions about transitions that should reflect a weighing of the goals of care and the risks and benefits of a transition. A total of 96% of family members report that comfort is the primary goal of care for their relatives with advanced dementia.<sup>14</sup> Yet as we found, the pattern of transitions among nursing home residents with advanced cognitive impairment is often inconsistent with that goal. From a societal perspective, these transitions are costly, and many are potentially avoidable through advance care planning or treatment of infections in the nursing home. In our study, 81% of the nursing home residents with advanced cognitive impairment did not have a burdensome transition. Yet nearly one in five residents had one or more such transitions, with rates in some states as high as 37.5%. High rates of burdensome transition were also associated with several markers of a poor quality of care.

Jencks and colleagues<sup>28</sup> reported that one in five Medicare patients who were discharged from an acute care hospital in 2003–2004 were readmitted within 30 days. However, the investigators did not address the issue of whether the initial hospitalization was appropriate. We specifically focused on a cohort of functionally dependent persons with advanced cognitive impairment, representing a population of patients for whom hospitalization may be avoidable and, in the majority of instances, is inconsistent with a goal of comfort. Since pneumonia and other infections are expected in end-stage dementia, recurrent hospitalizations for these conditions are potentially avoidable. A randomized, controlled trial of pneumonia treatment among nursing home residents showed that the majority of residents with pneumonia can be treated in the nursing home without a significant effect on mortality, level of functioning, or health-related quality of life.<sup>9</sup> These results are supported by observational studies.<sup>8,11</sup> Treatment of dehydration with hypodermoclysis can be safely provided in the nursing home.<sup>29</sup> Hospitalizations for both pneumonia and urinary tract infections are considered avoidable in the nursing home setting.<sup>30</sup> The Evercare model of capitated payments and the assignment of a nurse practitioner to oversee the care of frail nursing home residents were shown to result in fewer hospitalizations and saved \$103,000 per nurse practitioner in hospital costs.<sup>12,13</sup> The savings with the Evercare model were achieved with survival and quality outcomes that were similar to those with conventional care.

It is reassuring that 81% of nursing home residents had no burdensome transitions, which suggests that generally appropriate decisions are being made to avoid such transitions. But there are opportunities for improvement. The rate of burdensome transition increased by 2 percentage points during the 8 years of observation (from 17.4% in 2000 to 19.6% in 2007), and there was striking variation among states in the rate of burdensome transition. A

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potential explanation is the current financial incentives under Medicare and Medicaid. Hospitalization generally qualifies a nursing home resident with Medicaid coverage to receive Medicare payments for skilled services, which reimburse the nursing home at a higher rate. In addition, states' Medicaid payment rates and bed-holding policies that pay nursing homes to keep a bed open for hospitalized residents are associated with increased rates of hospitalization of nursing home residents.<sup>31–33</sup> These financial incentives probably result in health care transitions that contribute not only to excessive costs but also to a poorer quality of end-of-life care, as reflected in increased rates of feeding-tube insertion, time in an ICU, late hospice referral, and a stage IV decubitus ulcer before death.

Our study has several limitations. With the exception of advance directives and orders to forgo life-sustaining treatment, as noted in the MDS, we have no information regarding patients' preferences. However, two studies, by Barnato et. al.<sup>34</sup> and Teno et. al.,<sup>35</sup> showed that patients' preferences explain little about the regional variation in health care utilization at the end of life. In addition, we can report the associations between nursing home residence in a region with an increased rate of burdensome transition and markers of a poor quality of care at the end of life, but we cannot make causal inferences. It is possible that attributes of these regions other than the rate of burdensome transition may explain the observed lower quality of end-of-life care received by nursing home residents with advanced cognitive impairment. Research is needed to understand the multiple factors that contribute to the observed regional variation in rates of burdensome transition. Finally, we relied on a retrospective design that identified a cohort of nursing home residents who had advanced cognitive impairment and substantial functional impairment before death. Important concerns about bias with the use of a retrospective study design have been noted.<sup>36</sup> We attempted to minimize the bias by limiting the cohort to nursing home residents with a uniform diagnosis of advanced cognitive impairment and substantial functional impairment and by observing them for a short period of time before death. Despite these limitations, the patterns of transitions that we observed in a national sample of Medicare beneficiaries with advanced cognitive impairment suggest an important target for improvement.

For persons with advanced cognitive impairment, nursing homes are the predominant locus of care. Despite evidence that many infections can be treated in nursing homes without a significant effect on patient outcomes, the current financial incentives are aligned toward hospitalization. Evidence from demonstration programs suggests that rates of hospitalization can be reduced with improved survival and no diminution in the quality of care. Bundling of payment and development of integrated systems, as proposed by accountable care organizations,<sup>37,38</sup> may improve the care of patients with advanced cognitive impairment by reducing avoidable hospitalizations and improving care planning. We suggest that the measurement of burdensome transitions can be used to monitor the quality of end-of-life care in health systems. However, it is unlikely that public reporting alone will solve the problem. Ultimately, a decline in burdensome transitions will come about through a combination of improved provider incentives and decision making that elicits and respects the choices of patients.

#### **Supplementary Material**

Refer to Web version on PubMed Central for supplementary material.

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#### Figure 1.

State Variations in the Proportion of Nursing Home Residents with Advanced Cognitive Impairment Who Had at Least One Burdensome Transition.

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Characteristics of the Patients, According to the Number of Burdensome Transitions.\*

Age $-$ yr 85.7±7.6   Age $-$ yr 85.7±7.6   Female sex $-$ no. (%) 370,202 (78.0)   Race or ethnic group $-$ no. (%) <sup>†</sup> 370,202 (78.0)   Race or ethnic group $-$ no. (%) 370,202 (78.0)   Black 394,304 (83.0)   Hispanic 15,726 (3.3)   Asian 5,899 (1.2)	$0$ (N = 384,601) $85.7\pm7.6$ $86.0\pm7.6$ $370,202$ (78.0) $305,286$ (79.4) $370,202$ (18.0) $305,286$ (79.4) $57,022$ (12.0) $329,071$ (85.6) $57,022$ (12.0) $38,739$ (10.1) $15.726$ (3.3) $10,877$ (2.8) $5,899$ (1.2) $4,428$ (1.2) $1,647$ (0.3) $1,299$ (0.3) $231$ (<0.1) $187$ (<0.1)		<b>1</b> (N = 75,368) 84.5±7.7 54.804 (72.7) 55,593 (73.8) 14,442 (19.2) 3,861 (5.1) 1,145 (1.5) 293 (0.4)	<b>2 (N = 13,509)</b> 83.7±7.7 9,239 (68.4) 8,774 (64.9) 3,498 (25.9) 884 (6.5) 295 (2.2) 51 (0.4)	<b>3</b> (N = 1351) 83.3±7.6 873 (64.6) 866 (64.1) 343 (25.4) 104 (7.7) 31 (2.3) 4 (0.3)
- yr lle sex no. (%) or ethnic group no. (%) <sup>†</sup> hite ack spanic ian			84.5±7.7 54.804 (72.7) 55.593 (73.8) 14,442 (19.2) 3,861 (5.1) 1,145 (1.5) 293 (0.4)	83.7±7.7 9,239 (68.4) 8,774 (64.9) 3,498 (25.9) 884 (6.5) 295 (2.2) 51 (0.4)	83.3±7.6 873 (64.6) 866 (64.1) 343 (25.4) 104 (7.7) 31 (2.3) 4 (0.3)
) — no. (%) <sup>†</sup>			54,804 (72.7) 55,593 (73.8) 14,442 (19.2) 3,861 (5.1) 1,145 (1.5) 293 (0.4)	9,239 (68.4) 8,774 (64.9) 3,498 (25.9) 884 (6.5) 295 (2.2) 51 (0.4)	873 (64.6) 866 (64.1) 343 (25.4) 104 (7.7) 31 (2.3) 4 (0.3)
— no. (%)†			55,593 (73.8) 14,442 (19.2) 3,861 (5.1) 1,145 (1.5) 293 (0.4)	8,774 (64.9) 3,498 (25.9) 884 (6.5) 295 (2.2) 51 (0.4)	866 (64.1) 343 (25.4) 104 (7.7) 31 (2.3) 4 (0.3)
lic			55,593 (73.8) 14,442 (19.2) 3,861 (5.1) 1,145 (1.5) 293 (0.4)	8,774 (64.9) 3,498 (25.9) 884 (6.5) 295 (2.2) 51 (0.4)	866 (64.1) 343 (25.4) 104 (7.7) 31 (2.3) 4 (0.3)
lic			14,442 (19.2) 3,861 (5.1) 1,145 (1.5) 293 (0.4)	3,498 (25.9) 884 (6.5) 295 (2.2) 51 (0.4)	343 (25.4) 104 (7.7) 31 (2.3) 4 (0.3)
		(2.8) (1.2) (0.3) <0.1)	3,861 (5.1) 1,145 (1.5) 293 (0.4) 34 (-01)	884 (6.5) 295 (2.2) 51 (0.4)	104 (7.7) 31 (2.3) 4 (0.3)
		(1.2) (0.3) <0.1)	1,145 (1.5) 293 (0.4) 34 (_01)	295 (2.2) 51 (0.4)	31 (2.3) 4 (0.3)
		(0.3) <0.1)	293 (0.4) 34 (~0 1)	51 (0.4)	4 (0.3) 3 (0.2)
American Indian 1,647 (0.3)		<0.1)	34 (~0 1)		3 (0.7)
Missing data 231 (<0.1)			(1.00) +0	7 (<0.1)	(7:0) 0
Education — no. (%)					
Less than high school 180,048 (37.9)	180,048 (37.9) 140,898 (36.6)		32,072 (42.6)	6,403 (47.4)	675 (50.0)
High-school graduate 148,148 (31.2)	148,148 (31.2) 120,762 (31.4)		23,031 (30.6)	3,972 (29.4)	383 (28.3)
Some college or technical school 49,103 (10.3)	49,103 (10.3) 40,792 (10.6)	(10.6)	7,103 (9.4)	1,094 (8.1)	114 (8.4)
College degree or higher 32,910 (6.9)	32,910 (6.9) 27,753 (7.2)	(7.2)	4,486 (6.0)	614 (4.5)	57 (4.2)
Missing data 64,620 (13.6)	64,620 (13.6) 54,396 (14.1)	(14.1)	8,676 (11.5)	1,426 (10.6)	122 (9.0)
Medical condition — no. (%)					
Unstable cognition or ADL status <sup><math>\ddagger</math></sup> (43.0)	204,247 (43.0) 164,699 (42.8)		32,742 (43.4)	6,161 (45.6)	645 (47.7)
Swallowing problem 256,392 (54.0)	256,392 (54.0) 202,990 (52.8)		44,048 (58.4)	8,489 (62.8)	865 (64.0)

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Characteristic	All Residents $(N = 474, 829)$	Residents Acco	Residents According to Number of Burdensome Transitions	of Burdensome	Transitions
		0 (N = 384,601)	1 (N = 75,368)	2 (N = 13,509)	<b>3</b> (N = 1351)
Recent weight loss	73,208 (15.4)	60,438 (15.7)	10,463 (13.9)	2,088 (15.5)	219 (16.2)
Presence of advance directive — no. (%)					
Durable power of attorney for health care	168,945 (35.6)	144,516 (37.6)	21,369 (28.4)	2,780 (20.6)	280 (20.7)
Living will	91,759 (19.3)	78,929 (20.5)	11,285 (15.0)	1,401 (10.4)	144 (10.7)
Do-not-resuscitate order	346,439 (73.0)	295,087 (76.7)	44,412 (58.9)	6,358 (47.1)	582 (43.1)
Do-not-hospitalize order	32,512 (6.8)	30,188 (7.8)	2,166 (2.9)	142 (1.1)	16 (1.2)
Missing data	1,803 (0.4)	1,522 (0.4)	242 (0.3)	36 (0.3)	3 (0.2)
Coexisting condition — no. (%)					
Diabetes mellitus	112,527 (23.7)	84,744 (22.0)	22,484 (29.8)	4,814 (35.6)	485 (35.9)
Congestive heart failure	68,584 (14.4)	53,158 (13.8)	12,253 (16.3)	2,601 (19.3)	302 (22.4)
Hip fracture	19,101 (4.0)	15,675 (4.1)	2,894 (3.8)	482 (3.6)	50 (3.7)
Stroke	138,989 (29.3)	107,449 (27.9)	25,703 (34.1)	5,290 (39.2)	547 (40.5)
Chronic obstructive pulmonary disease	40,209 (8.5)	30,512 (7.9)	7,781 (10.3)	1,728 (12.8)	188 (13.9)
Cancer	17,884 (3.8)	14,777 (3.8)	2,585 (3.4)	473 (3.5)	49 (3.6)
Pneumonia	22,075 (4.6)	15,072 (3.9)	5,360 (7.1)	1,476 (10.9)	167 (12.4)
Missing data	867 (0.2)	746 (0.2)	102 (0.1)	19 (0.1)	0
Dementia — no. (%)					
Alzheimer's disease	99,164 (20.9)	83,173 (21.6)	13,665 (18.1)	2,109 (15.6)	217 (16.1)
Other than Alzheimer's disease	144,984 (30.5)	118,561 (30.8)	22,108 (29.3)	3,960 (29.3)	355 (26.3)
Cognitive performance score of 6: very severe impairment — no. (%)	389,628 (82.1)	313,771 (81.6)	62,903 (83.5)	11,722 (86.8)	1,182 (87.5)

(9 E2) 900 CUE	vil Residents (N = 474,829)   Residents According to Number of Burdensome Transitions
307 006 (63 6)	$0 \ (N = 384, 601)  1 \ (N = 75, 368)  2 \ (N = 13, 509)  3 \ (N = 1351)$
	242,736 (63.1) 48,851 (64.8) 9,475 (70.1) 944 (69.9)

Pus-minus values are means ±SD. P<0.001 for the overall comparison among groups in each category, with the exception of unstable cognition or status with respect to activities of daily living (ADL) status (P = 0.07).

 $\stackrel{\scriptstyle +}{\tau} {\rm Race}$  or ethnic group was provided in the database records.

<sup>2</sup>Unstable cognition and unstable ADL status are indicators on Medicare's Minimum Data Set (MDS) suggesting that the condition of a nursing home resident is deteriorating.

 $\frac{8}{8}$  score of 28 indicates that the MDS assessment completed closest to 120 days before death documented that a nursing home resident was totally dependent in all seven items on the ADL scale.

#### Table 2

Variation in Rates of Burdensome Transitions among 474,829 Patients, According to State.

Criterion for a Burdensome Transition	Overall Rate for All Patients %	State with Lowest Rate*	State with Highest Rate <sup>*</sup>
Transition 72 hours before death			
To hospice	4.4	Alaska (0)	Nevada (8.0)
From nursing home to acute care hospital	5.8	Vermont (1.1)	Mississippi (12.7)
From hospital to nursing home	2.3	Alaska (0)	Mississippi (3.9)
Lack of continuity in hospitalization			
From nursing home A to hospital to nursing home B in last 90 days	2.7	Alaska (0)	Louisiana (10.9)
Multiple hospital admissions in the last 90 days of life			
≥2 Episodes of pneumonia	2.3	Alaska (0)	Louisiana (6.0)
≥2 Episodes of urinary tract infection	3.9	Vermont (0.1)	Louisiana (11.8)
≥2 Episodes of dehydration	2.7	Alaska (0)	Louisiana (7.6)
≥2 Episodes of septicemia	2.1	Alaska, Idaho, and Wyoming (0)	Louisiana (5.2)
≥3 Hospitalizations for any reason	4.2	Oregon (0.1)	Louisiana (12.2)

\*Values in parentheses are state rates.

#### Table 3

Adjusted Risk of a Burdensome Transition among 469,411 Patients, According to Subgroup.\*

Characteristic	Adjusted Risk Ratio	95% Confidence Interval
Age		
66–80 yr	Reference	
81–85 yr	0.96	0.95-0.98
86–90 yr	0.93	0.92-0.95
≥91 yr	0.84	0.82-0.85
Male sex	1.20	1.18-1.22
Race or ethnic group		
White	Reference	
Black	1.24	1.22–1.26
Hispanic	1.24	1.21–1.27
Native American	1.00	0.90-1.10
Asian	1.02	0.98-1.08
Advance directive		
No written advance directive	1.15	1.14–1.17
No do-not-resuscitate order	1.63	1.61–1.65
No do-not-hospitalize order	2.14	2.06-2.23
Year of death		
2000	Reference	
2001	1.09	1.06–1.12
2002	1.11	1.08–1.13
2003	1.11	1.09–1.14
2004	1.14	1.11–1.17
2005	1.16	1.13–1.19
2006	1.15	1.12–1.18
2007	1.16	1.13-1.19

\* The association between sociodemographic characteristics, the presence or absence of an advance directive or order not to use life-sustaining treatment, and year of death with the number of burdensome transitions was analyzed in a multivariate regression model with the use of a Poisson distribution. All data have been adjusted for the variables listed in Table 1, as well as scores on the Medicare Minimum Data Set–Changes in Health, End-Stage Disease, and Symptoms and Signs (MDS–CHESS) scale, a score that predicts the rate of death at 1 year. Data were missing for 5418 patients, predominantly with respect to the MDS–CHESS score, educational level, diagnosis, presence or absence of difficulty in swallowing or chewing, and weight loss.

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# Table 4

Association between Residence in a Region with an Increased Rate of Burdensome Transitions and Markers of Poor Quality in End-of-Life Care among 102,620 Patients in 2006–2007.\*

Marker of Poor Quality of Care		Π)	Culture of trospital releft at regions	Suc	
	First Quintile (N = 19,679)	Second Quintile (N = 21,141)	Third Quintile (N = 19,870)	Fourth Quintile (N = 21,374)	Fifth Quintile $(N = 20,556)$
In the last 90 days of life					
Feeding-tube insertion					
Percentage of patients $^{\dagger}$	1.4	1.8	3.9	4.9	9.4
Adjusted risk ratio (95% CI)	Reference	1.14(0.81 - 1.62)	1.97 (1.43–2.70)	2.06 (1.51–2.81)	3.38 (2.48-4.60)
In the last 30 days of life					
Stage IV decubitus ulcer					
Percentage of patients $\sharp$	5.7	9.5	12.6	17.2	21.9
Adjusted risk ratio (95% CI)	Reference	1.48 (1.31–1.66)	1.65 (1.48–1.85)	2.00 (1.79–2.23)	2.28 (2.04–2.54)
Stay in intensive care unit					
Percentage of patients	3.4	5.9	9.1	11.0	15.8
Adjusted risk ratio (95% CI)	Reference	1.47 (1.34–1.61)	1.85 (1.69–2.01)	1.86 (1.71–2.03)	2.10 (1.93–2.29)
In the last 3 days of life					
Referral to hospice					
Percentage of patients	5.3	6.8	6.9	5.9	5.3
Adjusted risk ratio (95% CI)	Reference	1.33 (1.23–1.44)	1.40 (1.29–1.51)	1.25 (1.15–1.36)	1.17 (1.07–1.28)

scale, a score that predicts the rate of death at 1 year. To avoid simultaneity bias, the rates of burdensome transitions in each hospital referral region were calculated for the period from 2003 to 2005 and grouped into quintiles.

 $^{\dagger}$ The percentage of patients who received a feeding tube was based on a random sample of 20% of patients for whom both Medicare Part A and B data were available, totaling 20,546 patients (first quintile, 3860; second quintile, 4301; third quintile, 379; fourth quintile, 4325; and fifth quintile, 4081).

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 $^{4}$ The percentage of patients with a stage IV decubitus ulcer is based on 38,092 nursing home residents with an MDS assessment that was completed in the last 30 days of life (first quintile, 7021; second quintile, 7715; third quintile, 7491; fourth quintile, 8018; and fifth quintile, 7847).