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End-of-Life Care in Nursing Homes: 2004 National Nursing Home Survey

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Abstract

Objectives—This report presents information on nursing home residents receiving end-of-life (EOL) care in nursing homes. Residents receiving EOL care are compared with those not receiving EOL care on demographics, functional and cognitive status, reported pain, medications, and diagnoses. Residents receiving EOL care are further categorized by whether they started EOL care on or prior to admission to the nursing home or after admission to the nursing home. These two groups receiving EOL care are compared with each other on demographics, functional and cognitive status, medications, diagnoses, length of time receiving EOL care, and treatments received.

Methods—Data are from the resident component of the 2004 National Nursing Home Survey (NNHS). The 2004 NNHS is a nationally representative, cross-sectional probability sample survey of all current residents in nursing homes in the United States with three or more beds and either certified by Medicare or Medicaid or licensed by the state. All information is derived from interviews with nursing home staff.

Results—Nursing home residents receiving EOL care were older, more functionally and cognitively impaired, and more likely to have reported pain in the previous 7 days compared with nursing home residents not receiving EOL care. They were also more likely to have at least one advance directive. Three-fourths of residents who received EOL care in the nursing home started EOL care after admission to the nursing home. Differences in age, functional impairment, and cognitive impairment were observed among residents receiving EOL care depending on when they started EOL care. However, no differences in services and treatments received were observed depending on whether EOL care started on or prior to admission or after admission to the nursing home. The mean length of time on EOL care was approximately 5 months and did not differ by whether the care started on or prior to admission or after admission to the nursing home.

Keywords: nursing home • hospice • end-of-life care • palliative care • pain • National Nursing Home Survey

Introduction

Approximately one in five of all deaths in the United States occurs in a nursing home (1). At the same time, studies of quality of life and family satisfaction with EOL care of nursing home residents reveal a need for improvement in the EOL care provided to dying nursing home residents (2,3). EOL care encompasses both hospice and palliative services. Although the purpose of hospice and palliative care is to alleviate symptoms and provide support, hospice care is for a person with a life expectancy of months, whereas palliative care can be provided at any point in the course of the person's illness. Although the benefits of hospice and palliative care are clear (4–10), estimates of the proportion of nursing home decedents who had received such care range from less than 10% to 30% (2,9,11,12). This proportion may reflect the barriers and challenges of providing such care in a nursing home. Differences among hospice and nursing home philosophies of care, nursing homes' reimbursement mechanisms and regulation, and resident characteristics can create challenges to providing EOL care in the nursing home (6,13–20).

Although options for long-term care have expanded, nursing homes will

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likely retain a major role in caring for the most severely impaired and vulnerable population. Their role will be especially important in rural areas, where distance makes provision of care difficult. In order to provide optimal EOL care, residents receiving EOL care must be characterized. The purpose of this report is to characterize and compare nursing home residents receiving EOL care with nursing home residents not receiving EOL care. EOL care recipients are further compared based on whether they started EOL care on or prior to admission to the nursing home or after admission to the nursing home. These comparisons will provide an information base to assist in targeting EOL services. This report presents the first nationally representative estimates of the characteristics of nursing home residents receiving EOL care. Estimates are based on data from the 2004 National Nursing Home Survey (NNHS).

Methods

The data source is the resident component of the 2004 NNHS, a nationally representative, cross-sectional, two-stage probability sample survey. Nursing homes were sampled first and then current residents were sampled within each participating facility. The final sample had 13,507 current residents, each with a weight signifying the case's representation of the total number of current residents in nursing homes. Results described in this report are population estimates based on this sample. Data on facility services and residents were obtained through personal interviews with facility administrators and designated staff. Respondents used administrative records to answer questions about the facilities, staff, services, and programs and used medical records to answer questions about the residents. Further details on the 2004 NNHS methods are in the "Technical Notes" and on the National Center for Health Statistics website at http://www.cdc.gov/nchs/nnhs.htm.

Nursing home residents were defined as receiving EOL care if agency respondents said the residents either 1) were assigned a bed on a specialty unit for hospice care or 2) received services from a special program for any of the following: hospice, palliative, or EOL care (end stage or terminal condition).

Residents identified as receiving EOL care were further categorized by whether EOL care started 1) on or prior to admission to the nursing home or 2) after admission to the nursing home. Six hundred residents (1.5%) receiving EOL care were missing information on the onset of EOL care. These residents were excluded from analyses that compared residents receiving EOL care based on the onset of EOL care. See the "Technical Notes" for further explanation of the categorization of residents receiving EOL care and for a discussion of the effects of misclassification.

See the "Technical Notes" for definitions of terms used in the report.

Statistical analysis

All estimates and associated standard errors were generated using SUDAAN (21), a software package designed to handle the complex sample design.

Residents receiving EOL care were compared with the residents not receiving EOL care. In addition, the two groups of residents receiving EOL care (those who started EOL care on or prior to admission or after admission) were compared. *T*-tests were used to assess differences between groups with a p value of 0.05 to indicate statistical significance. Terms relating to differences such as "greater than" or "less than" indicate that the difference is statistically significant.

Results

Of the current residents residing in the nursing home on the day of NNHS, 2.5% were receiving hospice, palliative, or EOL care (37,800 of a total weighted sample of 1,492,200 residents sampled). Given this small sample size, results are suggestive and should be interpreted with caution. (Note that prevalence estimates based on current residents will differ from estimates based on a sample of discharges. See the "Discussion" section.)

Length of time in nursing home and on EOL care

The mean length of time in the nursing home from admission to the date that NNHS was administered was more than 2 years, both for residents who started EOL care after their nursing home admission and residents who did not receive EOL care. Nursing home residents who did not receive EOL care had a mean length of time from admission of 837 days (median of 462 days). Nursing home residents who received EOL care had a mean length of time from admission of 761 days (median of 479 days). The mean length of time in the nursing home from admission, excluding the time on EOL care, for residents who received EOL care after admission was 777 days (median of 508 days). (These numbers exclude residents who were only in the nursing home for EOL care.) Nursing home residents who received EOL care, regardless of when the EOL care started, had a mean length of time on EOL care of 147 days (median of 104 days).

Comparison of residents receiving and not receiving EOL care

Among residents receiving EOL care and those not receiving EOL care, the majority were female, white, non-Hispanic, widowed, and admitted to the nursing home from a location other than their residences. Most were severely functionally impaired, with over one-half requiring assistance in all five of the activities of daily living (ADL). Less than one-half were either independent or modified independent in their decision-making abilities. (See "Technical Notes" for definitions of terms.)

Compared with residents who did not receive EOL care, a greater proportion of residents who received EOL care were widowed and older, both on the interview date and on admission to the nursing home. They were more likely to be incontinent of bladder or

bowel and to be moderately or severely impaired in their decision-making ability (Table 1).

More than 90% of residents who received EOL care had at least one advance directive, which is greater than those who did not receive EOL care (65%). Of those residents who did not receive EOL care, 55% had a do-not-resuscitate (DNR) order, lower than the 87% of those receiving EOL care.

Almost 40% of residents who received EOL care reported pain in the previous 7 days, which is higher than the 22% of residents who did not receive EOL care (Table 1). All residents who reported pain had at least one type of order for pain management. More than 70% of all residents had a PRN (as needed) order for pain medication. About three-fourths of residents who received EOL care had a standing order for pain management, a greater proportion than the 46% of residents who did not receive EOL care.

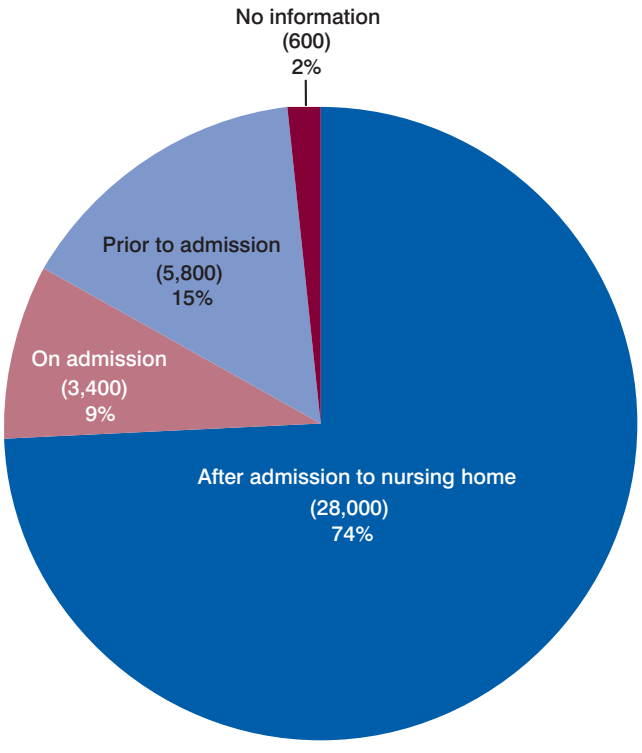
Overall, residents had an average of 10 medications (median of 8) listed on their medication administration records. Although the overall number of medications did not vary by receipt of EOL care, the types of medications did vary (Table 2). A smaller proportion of residents who received EOL care were prescribed hematologic agents, cardiovascular or renal drugs, metabolic nutrients, vitamins or minerals, and hormones and were more likely to receive medications for the skin or mucous membranes and pain medications. Almost two-thirds of all residents received at least one medication for relief of pain. The type of pain medication, however, varied by receipt of EOL care. Although residents receiving EOL care were more likely to receive medications for pain, this was mostly a result of the greater proportion of residents receiving EOL care who received narcotic analgesics. Residents receiving EOL care were less likely to receive nonnarcotic analgesics, antiarthritics, and antipyretics than residents not receiving EOL care.

The most common admission diagnoses for nursing home residents, regardless of whether they received EOL care, were diseases of the circulatory system, mental disorders, cerebrovascular disease, heart disease, diseases of the nervous system and sense organs, and diseases of the respiratory system (Table 3). Nursing home residents receiving EOL care were more likely to have an admission diagnosis of malignant neoplasms than residents not receiving EOL care.

Residents receiving EOL care had a mean of 6.3 (median of 5.5) current diagnoses, similar to residents not receiving EOL care (mean of 6.2 current diagnoses and median of 5.4) (up to 16 current diagnoses were collected). Almost two-thirds of all residents had a current diagnosis of mental disorders, and more than one-half had a current diagnosis of essential hypertension or heart disease. Nursing home residents who received EOL care were more likely to have at least one current diagnosis of malignant neoplasms, congestive heart failure, heart disease, or diseases of the genitourinary system (Table 3).

Comparison of residents receiving EOL care by timing of onset of EOL care

Almost three-quarters of nursing home residents receiving EOL care started the care after their admission to the nursing home (Figure 1). Nursing home residents who started EOL care after admission to the nursing home had a total mean length of time in the nursing home since admission (including EOL care) of 956 days (median of 657 days), with a mean length of stay prior to start of EOL care of 777 days (median of 508 days). The mean length of time residents received EOL care was almost 5 months, regardless of whether EOL care started before or after admission. The mean length of time residents received EOL care was similar,



NOTES: The proportion admitted to the nursing home on the same day that end–of–life (EOL) care started is an under–estimate. Residents who did not have the exact start date of EOL care were classified based on the nursing home's statement of whether care started before or after admission. Nursing homes did not consistently classify residents who started nursing home care on the same day they were admitted to the nursing home.

SOURCE: CDC/NCHS, 2004 National Nursing Home Survey.

Figure 1. Start of end-of-life care for residents in relation to admission to nursing home: National Nursing Home Survey, 2004

whether or not EOL services were covered under the Medicare hospice benefit (Table 4).

Among residents receiving EOL care, residents who started EOL care after admission had a higher mean age at interview (85 years compared with 80 years). Almost 75% required assistance in five ADL, compared with 58% of residents who started EOL care at or prior to admission. Of the residents who started EOL care after admission, 77% were moderately or severely impaired in their decision-making ability, compared with 52% of residents who started EOL care on or prior to admission (Table 5).

Almost 96% of residents who started EOL care after admission to the nursing home had at least one advance directive, compared with 83% of residents who started EOL care on or prior to admission. The most common type of advance directive was a DNR order.

Almost one-half of residents who started EOL care on or prior to admission reported pain in the previous 7 days, a greater proportion than the 37% of those who started EOL care after admission. Of the residents who started EOL care on or prior to admission to the nursing home, 87% had a PRN order for pain management, which was greater than the 69% of residents who started EOL care after admission.

Nursing home residents who started EOL care on or prior to admission had a mean of 8.2 medications (median of 7.4), which is not significantly different from residents who started EOL care after admission (mean of 9.2 and median of 7.7). Residents who started EOL care on or prior to admission were more likely to receive medications for the respiratory tract (36% compared with 19%) and less likely to receive medications for the central nervous system (57% compared with 71%) (Table 6).

The most common admission diagnoses for residents who started EOL care after admission to the nursing home were diseases of the circulatory system (23%), diseases of the nervous system and sense organs (21%), and mental disorders (16%). Because of small sample sizes, the reporting of admission diagnosis is not possible for residents who started EOL care on or prior to admission.

Residents who started EOL care after admission were more likely to have a current diagnosis of mental disorders than residents who started EOL care on or prior to admission (73% compared with 49%). In addition, they were less likely to have a diagnosis of diseases of the respiratory system (17% compared with 35%) or malignant neoplasms (13% compared with 37%) than residents who started EOL care on or prior to admission to the nursing home. Residents who started EOL care after admission had a mean of 6.6 current diagnoses (median of 5.9), a greater number than residents who started EOL care on or prior to admission (mean of 5.4 and median of 4.0) (Table 7).

EOL care treatments and services

The most common types of specialized services received by residents on EOL care were pain and symptom management and emotional support for the family. These services were received by more than one-half of the residents who received EOL care. Residents who started EOL care after admission were less likely than residents who started EOL care on or prior to admission to receive pain management (54% compared with 72%). Other services included pastoral or spiritual care (received by approximately 40% of residents on EOL care), counseling or assistance with ethical or legal issues and grief (27%), and loss and bereavement counseling (27%). Death preparation was received by 17% of residents receiving EOL care. The most common formal care treatments were aggressive pain management, oxygen and respiratory therapy, and bowel training regimen. Oxygen-respiratory therapy was more likely to be received by nursing home residents who started EOL care on or prior to admission than by residents who started care after admission to the nursing home (Table 8).

Discussion

Residents receiving EOL care were more likely to be older and more physically and cognitively impaired than residents not receiving EOL care. Among nursing home residents who received EOL care, almost three-fourths started EOL care after admission to the nursing home. Thus, the differences between residents who received EOL care and those who did not reflect the characteristics of the residents who started EOL care after admission to the nursing home. The nursing home residents who started EOL care after admission to the nursing home were similar in sex, race, marital status, and living situation, but they were older and more functionally and cognitively impaired than residents who started EOL care on or prior to admission. However, both groups received similar EOL treatments and services.

The average duration of EOL care was approximately 5 months, with no differences by whether care started before or after admission to the nursing home. This is longer than indicated in several other studies of both nursing home residents and recipients of hospice care (11,22–24) and similar to results in the Department of Health and Human Services Office of the Inspector General's 1997 report on hospice recipients in nursing homes (25). Some of the discrepancy may result from the fact that results reported here from the 2004 NNHS include palliative, EOL, and hospice care independent of whether Medicare hospice coverage had started, whereas other studies (11,25) focused on Medicare-financed hospice care. However, results reported here from the 2004 NNHS found no differences in duration of EOL care by whether Medicare coverage had started, suggesting that Medicare coverage and therefore formal hospice care may not differentiate the duration of EOL care.

Another possible explanation is differences in populations and study design. The NNHS used a cross-sectional design and a current resident

sample. A cross-sectional study does not include the entire episode of care, and it is more likely to sample long-stay residents, resulting in an overestimate of actual length of time of EOL care in the nursing home. Studies based on discharge samples, which collect information on an entire episode of care, are more likely to capture short episodes of care, and thus the length of time on EOL care will be shorter than a study based on current residents. Han et al. (22) demonstrated how length of stay can be overestimated if only information from current patients is used, with a converse underestimation by using discharged patients. In addition, use of a current resident sample is also likely to underestimate the short-stay population, which would disproportionately include residents receiving EOL care. Therefore, estimates of the number and proportion of nursing home residents receiving EOL care reported here should be interpreted with caution and considered an underestimate. In addition, because the estimates of residents receiving EOL care are small, results based on these populations should be interpreted with caution.

The proportion of one-fifth of nursing home residents reporting pain (in this study, it is in the previous 7 days) is within the broad range reported in the literature for all nursing home residents and those receiving EOL care (26–33). From the data, one cannot determine whether the reported pain was while on pain medication (in which case further work on pain management is needed) or whether reported pain led to prescription of pain medication (in which case pain management is adequate).

In spite of alternative modes of long-term care, the number of hospice patients receiving care in nursing homes has greatly increased. Using data from the National Home and Hospice Care Surveys, Han et al. found that the number of adult hospice patients who received hospice care in inpatient facilities (mainly nursing homes) increased more than ninefold between 1991–1992 and 1999–2000 (34). A comparison of estimates from the 2004 and 1999 NNHS of current residents receiving hospice care also shows an increase, from 1.8% of current residents in 1999 to 2.5% of current residents in 2004.

Nursing homes will likely continue to play a major role as a last home for the aging population. Results of this study suggest that residents receiving EOL care in the nursing home consisted of a broad range of residents who differed in function, cognition, reported pain, and diagnoses, yet they appeared to have received similar EOL care. Other studies have found differences in admitting diagnoses, reported pain, and treatment among nursing home hospice beneficiaries, depending on when they started hospice care (11,35). Han et al. found differences in characteristics of hospice beneficiaries by whether they received care at home or in a nursing home (36). In this study, nursing home residents who started EOL care on or prior to admission to the nursing home seemed similar to the group in Han's study who received hospice care at home, perhaps representing EOL care recipients who went to a nursing home when they could no longer be cared for at home. Although these findings comparing the characteristics and length of service among nursing home residents by when they started receiving EOL care differ from some studies in the literature, some differences are most likely due to study design and population definition. The essential point is that providers of EOL care in the nursing home serve multiple subgroups of EOL care recipients with different needs and different levels of cognitive impairment.

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Table 1. Number and percent distribution of nursing home residents by receipt of end-of-life care: National Nursing Home Survey, 2004

Resident characteristic	Nursing home residents not receiving EOL care		Nursing home residents receiving EOL care	
	Number	Percent distribution	Number	Percent distribution
All nursing home residents	1,454,400	100.0	37,800	100.0
Sex				
Male	420,100	28.9	10,300	27.4
Female	1,034,300	71.1	27,400	72.6
Race[1]				
White	1,241,900	85.4	34,100	90.2
Black	183,300	12.6	*	*
All other	29,200	2.0	*	*
Hispanic or Latino origin				
Yes	56,300	3.9	*	*
No	1,390,500	95.6	36,900	97.7
Marital status[1]				
Married or living with partner	292,500	20.1	8,900	23.5
Widowed	773,100	53.2	22,700	60.1
Divorced, separated, never married or single	367,800	25.3	*5,800	*15.2
Living arrangements prior to admission to nursing home				
Admitted from home	422,900	30.0	11,700	32.5
Admitted from place other than home	985,800	70.0	24,200	67.5
Living situation for those admitted from home				
Lived alone	175,300	41.1	*3,600	*31.0
Lived with others	218,300	51.2	7,400	63.3
Mean age at interview[1]	80.3	. . .	84.0	. . .
Mean age at admission[1]	78.0	. . .	81.9	. . .
Functional status[1]				
Required assistance on up to four ADL[2]	701,300	48.8	11,300	29.9
Required assistance in all five ADL[2]	736,700	51.2	26,500	70.1
Continence				
Bowel continence[1]				
Used appliance	21,200	1.5	*	*
Fully continent	634,900	43.7	8,700	22.9
Usually continent to incontinent	782,700	53.8	28,800	76.1
Bladder continence[1]				
Used appliance	100,400	6.9	*3,800	*10.2
Fully continent	414,700	28.5	*3,800	*10.1
Usually continent to incontinent	923,600	63.5	30,100	79.8
Decision-making ability[1]				
Independent or modified independent	615,300	42.3	10,700	28.2
Moderately or severely impaired	817,600	56.2	26,600	70.4
Advance directives				
Had at least one advance directive[1]	939,400	64.6	35,000	92.5
Had a do-not-resuscitate order[1]	801,800	55.1	32,700	86.6
Had a living will[1]	261,700	18.0	10,100	26.8
Reported pain and pain management strategies				
Reported pain in the previous 7 days[1]	323,000	22.2	15,000	39.8
Had a PRN (as needed) order for pain management	254,700	75.0	11,200	74.2
Had standing order for pain management[1]	157,300	46.3	11,200	74.3

* Figure does not meet standards of reliability or precision because the sample size is less than 30. Estimates accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the sample size is greater than 59 but has a relative standard error of 30 percent or more.

. . . Category not applicable.

[1]Significant differences between residents receiving EOL care and residents not receiving EOL care at $p < 0.05$.

[2]ADL is activities of daily living. See "Technical Notes" for further definition of ADL.

NOTES: EOL is end-of-life. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table 2. Number and percent distribution of nursing home residents' medication use by receipt of end-of-life care: National Nursing Home Survey, 2004

Medication class according to the 1995 *National Drug Code Directory*[1]	Nursing home residents not receiving EOL care		Nursing home residents receiving EOL care	
	Number	Percent distribution	Number	Percent distribution
Total	1,454,400	100.0	37,800	100.0
Anesthetic drugs (0100)	25,800	1.8	*	*
Antidotes (0200)	*5,700	*0.4	*	*
Antimicrobial agents (0300)	193,000	13.3	*4,900	*12.9
Hematologic agents (0400)[2]	526,500	36.2	8,900	23.7
Cardiovascular-renal drugs (0500)[2]	1,071,700	73.7	22,600	59.7
Central nervous system (0600)	994,900	68.4	25,800	68.2
Antidepressants (0630)	674,000	46.3	15,900	42.1
Gastrointestinal agents (0800)	1,024,700	70.5	27,300	72.4
Metabolic/nutrients (0900)[2]	1,094,900	75.3	21,500	57.0
Vitamins/minerals (0913)[2]	837,800	57.6	15,400	40.8
Hormones/hormonal mechanisms (1000)[2]	600,800	41.3	13,300	35.2
Immunologics (1100)	*4,000	*0.3	*	*
Skin/mucous membrane (1200)[2]	76,400	5.3	*3,400	*8.9
Neurologic drugs (1300)	430,400	29.6	11,300	29.8
Oncolytics (1400)	69,800	4.8	*	*
Opthalmics (1500)	256,900	17.7	6,100	16.2
Otologics (1600)	45,500	3.1	*	*
Relief of pain (1700)[2]	923,800	63.5	28,000	74.1
Analgesics/general (1720)	95,100	6.5	*	*
Analgesics, narcotic (1721)[2]	240,900	16.6	16,200	42.9
Analgesics, non-narcotic (1722)[2]	643,000	44.2	13,900	36.9
Antiarthritics (1724)[2]	456,000	31.3	8,800	23.2
Nonsteroidal anti-inflammatory (NSAID) (1727)	184,400	12.7	*5,100	*13.6
Antipyretics (1728)[2]	609,100	41.9	13,100	34.8
Antiparasitics (1800)	21,700	1.5	*	*
Respiratory tract (1900)	313,300	21.5	8,900	23.5
Unclassified/miscellaneous (2000)	49,000	3.4	*	*
Homeopathic products (2100)	37,100	2.5	*	*

* Figure does not meet standards of reliability or precision because the sample size is less than 30. Estimates accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the sample size is greater than 59 but has a relative standard error of 30 percent or more.

[1]See "Technical Notes" for further information on the National Nursing Home Survey data collection and classification of prescribed medications.

[2]Residents not receiving EOL care significantly different than residents receiving EOL care at $p < 0.05$.

NOTES: EOL is end-of-life. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table 3. Number and percent distribution of nursing home residents by admission and any-listed current diagnoses by receipt of end-of-life care: National Nursing Home Survey, 2004

ICD–9 code	Admission diagnosis				Current diagnoses[1]			
	Nursing home residents not receiving EOL care		Nursing home residents receiving EOL care		Nursing home residents not receiving EOL care		Nursing home residents receiving EOL care	
	Number	Percent distribution	Number	Percent distribution	Number	Percent distribution	Number	Percent distribution
Total	1,454,400	100.0	37,800	100.0	1,454,400	100.0	37,800	100.0
Infectious and parasitic diseases (001–139)	15,200	1.0	*	*	35,900	2.5	*	*
Malignant neoplams (140–208, 230–234)[2,3]	23,400	1.6	*3,300	*8.8	99,600	6.8	7,400	19.5
Benign neoplasms and of uncertain behavior (210–229, 235–239)	*3,400	*0.2	*	*	13,900	1.0	*	*
Endocrine, nutritional, and metabolic diseases and immunity disorders (240–279)	79,500	5.5	*	*	680,700	46.8	16,000	42.3
Diabetes (250)	56,200	3.9	*	*	351,200	24.1	7,600	20.2
Diseases of the blood and blood forming organs (280–289)	8,300	0.6	*	*	270,400	18.6	7,800	20.5
Mental disorders (290–319)	239,000	16.4	*5,000	*13.3	965,400	66.4	25,200	66.6
Senile dementia or organic brain syndrome (290,310)	20,300	1.4	*	*	88,800	6.1	*	*
Diseases of the nervous system and sense organs (320–389)	202,100	13.9	*6,600	*17.4	606,600	41.7	14,300	37.8
Alzheimer's disease (331.0)	122,400	8.4	*	*	235,200	16.2	*5,900	*15.6
Parkinson's (332)	27,000	1.9	*	*	89,900	6.2	*	*
Diseases of the circulatory system (390–459)	344,700	23.7	8,300	22.1	1,128,300	77.6	28,100	74.3
Essential hypertension (401)	54,400	3.7	*	*	766,400	52.7	19,100	50.4
Heart disease (391–392.0, 393–398, 402,404,410–416, 420–429)[3]	119,100	8.2	*4,700	*12.4	822,200	56.5	23,800	63.1
Congestive heart failure (428.0)[3]	60,800	4.2	*	*	268,500	18.5	8,900	23.5
Cerebrovascular disease (430–438)	150,300	10.3	*3,200	*8.6	289,700	19.9	7,200	19.0
Diseases of the respiratory system (460–519)	96,400	6.6	*3,600	*9.6	287,200	19.7	8,200	21.6
Pneumonia (480–486)	36,700	2.5	*	*	32,000	2.2	*	*
Chronic obstructive pulmonary disease and allied conditions (490–496)	40,500	2.8	*	*	219,900	15.1	*6,600	*17.4
Diseases of the digestive system (520–579)	45,400	3.1	*	*	508,900	35.0	13,000	34.4
Diseases of the genitourinary system (580–629)[3]	50,200	3.5	*	*	259,900	17.9	9,000	23.8
Diseases of the skin and subcutaneous tissue (680–709)	20,500	1.4	*	*	81,700	5.6	*	*
Diseases of the musculoskeletal system and connective tissue (710–739)	66,000	4.5	*	*	639,100	43.9	15,800	41.8
Rheumatoid and osteoarthritis and allied disorders (714, 715)	23,900	1.6	*	*	299,600	20.6	7,700	20.5
Congenital anomalies (740–759)	*3,900	*0.3	*	*	21,700	1.5	*	*
Symptoms, signs and ill-defined conditions (780–799)	80,900	5.6	*	*	477,600	32.8	13,500	35.8
Injuries and poisoning (800–999)	19,700	1.4	*	*	153,700	10.6	*	*
Post hospital aftercare (V42–V46, V52, V53.3–V53.7, V54–V58)	130,100	8.9	*	*	45,300	3.1	*	*
No diagnosis or unknown	13,400	0.9	*	*	43,400	3.0	*	*

* Figure does not meet standards of reliability or precision because the sample size is less than 30. Estimates accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the sample size is greater than 59 but has a relative standard error of 30 percent or more.

[1]Any of 16 listed current diagnoses. There is only one admission diagnosis.

[2]Significant differences in admission diagnosis between nursing home residents receiving EOL care and not receiving EOL care at $p < 0.05$.

[3]Significant differences in current diagnoses between nursing home residents receiving EOL care and not receiving EOL care at $p < 0.05$.

NOTES: EOL is end-of-life. ICD–9 is the *International Classification of Diseases, Ninth Revision*. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table 4. Length of time on end-of-life care by timing of onset of end-of-life care and Medicare coverage: National Nursing Home Survey, 2004

Length of time on EOL care (in days) by timing of onset of EOL care[1]			
	Number	Mean	Median
Total length of time on EOL care[2]	31,100	147	104
Started EOL care after admission to nursing home	24,700	145	104
Started EOL care on same day as admission to nursing home	*3,400	*144	*81
Started EOL care prior to admission to nursing home	*2,900	*175	*112
Days of EOL care prior to admission to nursing home	*2,900	*77	*23
Days of EOL care in nursing home	*2,900	*97	*26
Length of time on EOL care (in days) by Medicare coverage for hospice care[1]			
	Number	Mean	Median
Medicare coverage started	18,700	142	104
Medicare coverage not started	8,300	149	89
Not eligible for Medicare or unknown	*4,100	*169	*138

* Figure does not meet standards of reliability or precision because the sample size is less than 30. Estimates accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the sample size is greater than 59 but has a relative standard error of 30 percent or more.

[1]No significant differences between groups at $p < 0.05$.

[2]The length of time on EOL care could not be calculated for 6,700 residents who received EOL care because they did not have the date when they started the care. These residents are not included in calculation of length of time on EOL care.

NOTE: EOL is end-of-life.

Table 5. Number and percent distribution of nursing home residents by timing of onset of end-of-life care: National Nursing Home Survey, 2004

Resident characteristic	Nursing home residents who started EOL care on or prior to admission		Nursing home residents who started EOL care after admission	
	Number	Percent distribution	Number	Percent distribution
Nursing home residents receiving EOL care[1]	9,200	100.0	28,000	100.0
Sex				
Male	*3,400	*36.5	6,700	24.0
Female	*5,900	*63.5	21,300	76.0
Race				
White	8,100	87.8	25,800	92.2
Hispanic or Latino origin				
No	8,900	96.9	27,400	97.9
Marital status				
Married or living with partner	*	*	6,800	24.5
Widowed	*5,400	*58.2	16,900	60.3
Divorced, separated, never married, or single	*	*	*4,000	*14.1
Living arrangements prior to admission to nursing home				
Admitted from home	*3,200	*35.9	8,300	31.6
Admitted from place other than home	*5,800	*64.1	18,000	68.4
Living situation for those admitted from home				
Lived alone	*	*	*	*
Lived with others	*	*	*5,200	*63.2
Mean age at interview[2]	80.1	. . .	85.4	. . .
Mean age at admission	79.6	. . .	82.7	. . .
Functional status[2]				
Required assistance on up to four ADL	*3,900	*42.4	7,100	25.2
Required assistance in all five ADL	*5,300	*57.6	20,900	74.8
Continence				
Bowel continence[2]				
Used appliance	*	*	*	*
Fully continent	*3,400	*36.8	*5,100	*18.1
Usually continent to incontinent	*5,800	*62.5	22,600	80.8
Bladder continence[2]				
Used appliance	*	*	*	*
Fully continent	*	*	*	*
Usually continent to incontinent	*6,200	*67.3	23,500	83.9
Decision-making ability[2]				
Independent or modified independent	*4,000	*43.1	*6,400	*22.7
Moderately or severely impaired	*4,800	*51.9	21,600	77.0
Advance directives				
Had at least one advance directive[2]	7,700	83.1	26,900	95.9
Had a do-not-resuscitate order	7,600	81.9	24,900	88.8
Had a living will	*	*	7,900	28.1
Reported pain and pain management strategies				
Reported pain in the previous 7 days[2]	*4,500	*48.7	10,400	37.0
Had a PRN (as needed) order for pain management[2]	*3,900	*87.0	7,200	69.4
Had standing order for pain management	*3,200	*70.4	7,800	75.5

* Figure does not meet standards of reliability or precision because the sample size is less than 30. Estimates accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the sample size is greater than 59 but has a relative standard error of 30 percent or more.

. . . Category not applicable.

[1]Excludes 600 residents who received EOL care but were missing information when the care started.

[2]Residents who started EOL care on or prior to admission were significantly different from residents who started EOL care after admission at $p < 0.05$.

NOTES: EOL is end-of-life care. ADL is activities of daily living. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table 6. Number and percentage of nursing home residents receiving end-of-life care by timing of onset of end-of-life care and selected medication use: National Nursing Home Survey, 2004

Medication class according to 1995 *National Drug Code Directory*[1]	Nursing home residents who started EOL care on or prior to admission to nursing home		Nursing home residents who started EOL care after admission to nursing home	
	Number	Percent	Number	Percent
Cardiovascular-renal drugs (0500)	*5,400	*59.0	16,700	59.6
Central nervous system (0600)[2]	5,300	57.1	19,900	71.2
Antidepressants (0630)	*3,300	*35.3	12,100	43.2
Gastrointestinal agents (0800)	6,400	69.8	20,500	73.1
Metabolic/nutrients (0900)	*4,000	*43.9	16,900	60.4
Vitamins/minerals (0913)	*3,100	*34.0	11,700	41.9
Hormones/hormonal mechanisms (1000)	*3,700	*39.6	9,500	33.8
Relief of pain (1700)	6,500	70.9	21,000	75.1
Analgesics, narcotic (1721)	*4,400	*47.4	11,600	41.4
Respiratory tract (1900)[2]	*3,400	*36.3	*5,400	*19.1

* Figure does not meet standars of reliability or precision. Estimates accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the sample size is greater than 59 but has a relative standard error of 30 percent or more.

[1]See "Technical Notes" for further information on the National Nursing Home Survey data collection and classification of prescribed medications.

[2]Residents who started EOL care on or prior to admission were significantly different from residents who started EOL care after admission at $p < 0.05$.

NOTES: EOL is end-of-life. Table excludes 600 residents who received EOL care but were missing information when the care started. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table 7. Number and percent distribution of nursing home residents by any-listed current diagnoses and timing of onset of end-of-life care: National Nursing Home Survey, 2004

ICD–9 code	Current diagnoses[1]					
	All residents receiving EOL care[2]		Nursing home residents who started EOL care on or prior to admission to nursing home		Nursing home residents who started EOL care after admission to nursing home	
	Number	Percent distribution	Number	Percent distribution	Number	Percent distribution
Total	37,800	100.0	9,200	100.0	28,000	100.0
Malignant neoplams (140–208, 230–234)[3]	7,400	19.5	*3,400	*36.9	*3,600	*13.0
Endocrine, nutritional, and metabolic diseases and immunity disorders (240–279)	16,000	42.3	*4,000	*43.5	11,800	42.0
Diseases of the blood and blood forming organs (280–289)	7,800	20.5	*	*	*6,100	*21.9
Mental disorders (290–319)[3]	25,200	66.6	*4,500	*48.6	20,400	72.8
Diseases of the nervous system and sense organs (390–459)	14,300	37.8	*	*	11,800	42.3
Diseases of the circulatory system (320–389)	28,100	74.3	*5,900	*64.3	21,600	77.1
Essential hypertension (401)	19,100	50.4	*	*	15,300	54.8
Heart disease (391–392.0, 393–398, 402, 404, 410–416, 420–429)	23,800	63.1	*5,600	*60.2	18,000	64.2
Cerebrovascular disease (430–438)	7,200	19.0	*	*	*6,100	*21.9
Diseases of the respiratory system (460–519)[3]	8,200	21.6	*3,200	*34.5	*4,800	*17.1
Diseases of the digestive system (520–579)	13,000	34.4	*	*	10,900	38.9
Diseases of the genitourinary system (580–629)	9,000	23.8	*	*	*7,500	*26.7
Diseases of the musculoskeletal system and connective tissue (710–739)	15,800	41.8	*	*	13,400	47.9
Symptoms, signs and ill-defined conditions (780–799)	13,500	35.8	*	*	10,300	36.7

* Figure does not meet standards of reliability or precision because the sample size is less than 30. Estimates accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the sample size is greater than 59 but has a relative standard error of 30 percent or more.

[1]Any of 16 listed current diagnoses.

[2]Includes 600 residents who received EOL care but were missing information when the care started.

[3]Significant differences at $p < 0.05$ in current diagnoses between nursing home residents who stated EOL care on or prior to admission and who started EOL care after admission to the nursing home.

NOTES: EOL is end-of-life. ICD–9 is the *International Classification of Diseases, Ninth Revision.* Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table 8. Number and percent distribution of nursing home residents receiving end-of-life formal services or treatments in the 7 days prior to interview: National Nursing Home Survey, 2004

Formal service or treatment	Nursing home residents receiving EOL care[1]		Nursing home residents who started EOL care on or prior to admission to nursing home		Nursing home residents who started EOL care after admission to nursing home	
	Number	Percent distribution	Number	Percent distribution	Number	Percent distribution
Nursing home residents receiving EOL care	37,800	100.00	9,200	100.0	28,000	100.0
Services received in the 7 days prior to interview						
Pain management[2]	22,000	58.3	*6,600	*72.1	15,100	53.8
Symptom management	20,800	55.1	5,400	58.9	15,400	55.1
Emotional support for family	19,600	52.0	*4,000	*43.5	15,600	55.8
Pastoral or spiritual care	15,100	39.9	*3,400	*37.0	11,400	40.8
Grief, loss, and bereavement counseling	10,500	27.7	*	*	8,500	30.3
Counseling or assistance with ethical or legal issues	10,300	27.2	*	*	*7,100	*25.2
Other services	7,800	20.6	*	*	*5,000	*17.9
Death preparation	*6,500	*17.3	*	*	*5,100	*18.1
Types of formal care or treatments received in 7 days prior to interview						
Aggressive pain management including radiation for pain relief	13,800	36.5	*4,100	*44.1	9,400	33.6
Oxygen-respiratory therapy[2]	11,800	31.3	*4,000	*43.9	7,800	27.8
Bowel training regimen	10,000	26.5	*	*	7,400	26.4
Subcutaneous therapy, IV therapy, parenteral hydration, and artificial nutrition[3]	*3,600	*9.7	*	*	*3,200	*11.6
Durable medical equipment	*3,600	*9.5	*	*	*	*

* Figure does not meet standards of reliability or precision because the sample size is less than 30. Estimates accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the sample size is greater than 59 but has a relative standard error of 30 percent or more.

[1]Includes 600 residents who received EOL care but were missing information on when the care started.

[2]Residents who started EOL care on or prior to admission were significantly different from residents who started EOL care after admission at $p < 0.05$.

[3]IV and subcutaneous therapies may also be used for pain relief. From the data, it is not possible to determine for what the therapies were used.

NOTES: EOL is end-of-life. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Technical Notes

2004 National Nursing Home Survey

The 2004 National Nursing Home Survey (NNHS) is one in a continuing series of nationally representative sample surveys of U.S. nursing homes. NNHS was first conducted in 1973–1974 and repeated in 1977, 1985, 1995, 1997, 1999, and (most recently) 2004. The 2004 NNHS utilized a two-stage probability sample design, with the first stage being the selection of facilities and the second stage being the selection of residents.

Data for the survey were obtained through personal interviews with facility administrators and designated staff. Respondents used administrative records to answer questions about the facilities, staff, services, and programs, and they used medical records to answer questions about the residents. No residents were interviewed directly.

Facility sample selection

From a sampling frame of approximately 16,600 U.S. nursing homes, 1,500 nursing home facilities were selected. The sampling frame was drawn from two sources: 1) the Centers for Medicare and Medicaid Services' Provider of Services file of U.S. nursing homes and 2) state licensing lists compiled by Verispan (the vendor for SMG). Nursing homes were considered eligible to participate in the survey if they 1) had at least three beds and 2) were either certified by Medicare or Medicaid or had a state license to operate as a nursing home. Of the 1,500 nursing homes selected, 283 refused to participate and 43 were considered out of scope. Thus, a total of 1,174 nursing homes participated in the first stage by providing facility information, resulting in a first-stage response rate of 81%.

Resident sample selection

Among participating facilities, current residents were selected as the second stage of sampling. In the 2004 NNHS, only current residents were sampled. The sample frame for current residents was the total number of residents on the rolls of the facility as of midnight of the day prior to the day of the survey. Residents who were physically absent from the facility because of overnight leave or a hospital visit but had a bed maintained for them at the facility were included in the sample frame. Sampling of residents was conducted by the interviewers at the time of their visits to the facilities. A list of eligible residents was obtained from the nursing facility, and 12 current residents were randomly selected. If the facility had fewer than 12 residents, then all residents were selected. Information was collected for 96% of those sampled, with 13,507 resident questionnaires completed. Thus, the overall response rate for the resident component of NNHS was 78% (81% multiplied by 96%).

Cases selected for analysis

Identification of nursing home residents receiving end-of-life (EOL) care

In this study, EOL care includes hospice and palliative care and is not predicated on Medicare payment. (Although the purpose of hospice and palliative care is to alleviate symptoms and provide support, hospice care is for persons with a life expectancy of months, whereas palliative care can be provided at any point in the course of the person's illness.)

Nursing home residents were defined as receiving EOL care if agency respondents said the residents either 1) were assigned a bed on a specialty unit for hospice care or 2) received services from a special program for any of the following: hospice, palliative, or EOL care (end stage or terminal condition). (See http://www.cdc.gov/nchs/data/nnhsd/2004NNHS_Resident_Questionnaire_072506tags.pdf, questions HN2b and HN3.)

Residents missing information on whether they received EOL care were classified as not receiving EOL care. Thus, because some of these residents with missing information may actually have been receiving EOL care, the estimate of nursing home residents receiving EOL care may be an underestimate.

In addition, estimates based on a sample of current residents will differ from a sample based on discharges, also resulting in an underestimate of the number of nursing home residents receiving EOL care. See the section titled "Analytic considerations due to study design and sample size."

Initiation of EOL care

Residents identified as receiving EOL care were categorized based upon onset of receipt of EOL care: a) whether care started on or prior to admission to the nursing home or b) whether care started after admission to the nursing home. The following algorithm was used:

- If the date the resident started EOL care was available, then this date and the date of admission were compared.
- If the date the resident started EOL care was not available, the response to the question, "Did the resident start receiving palliative or hospice care before or after admission to the facility?" was used.
- To determine the accuracy of the response to this question, the calculated initiation of EOL care for residents who had both the start date of EOL care recorded and an answer to the above question were compared. Among these residents, those who started EOL care either before or after admission, but not the same day as admission to the nursing home, were consistently classified appropriately, based on comparison of the classification with the dates for starting EOL care and for admission to the nursing home. However, residents who started EOL care on the same day they were admitted (according to the recorded start date of EOL care) were not consistently classified as starting EOL care before admission compared with after admission by responses to the above question. Some nursing homes classified residents starting EOL care on the same day as admission as

starting EOL care before admission, and some nursing homes classified the residents as starting care after admission. Thus, the estimate of residents who started EOL care on or prior to admission to the nursing home is likely an underestimate. Conversely, residents who actually started EOL care on admission may be included as residents who started EOL care after admission to the nursing home. This potential misclassification would result in attenuating differences among residents receiving EOL care. Thus, reported differences between these groups may actually be larger than described.

Definitions of terms

Activities of daily living (ADL)—ADL include transferring, dressing, eating, toileting, and bathing. NNHS questions about ADL were identical to the Minimum Data Set items that nursing homes that participate in Medicare are required to report to the Centers for Medicare & Medicaid Services. Transferring is defined as how a resident moves between surfaces, such as to or from the bed, chair, or wheelchair, and it excludes movement to or from the bathroom or toilet. Dressing refers to how a resident puts on, fastens, and takes off all items of street clothing, including donning or removing prostheses. Eating refers to how a resident eats and drinks (regardless of skill) and includes intake of nourishment by other means, such as tube feeding. Toileting refers to how a resident uses the toilet room, commode, bedpan, or urinal, including transferring on and off, cleaning, changing pad, management of ostomy or catheter, and adjustment of clothes. Bathing refers to how a resident takes a full-body bath, shower, or sponge bath and transfers in and out of the tub or shower. Bathing excludes washing of the back and hair. To be coded as independent for transferring, dressing, eating, or toileting, the resident needed to have either received no help or oversight or help or oversight only once or twice during the last 7 days. To be coded as independent for bathing, a resident needed to have received no help or oversight.

Decision-making ability—Assessment of decision-making ability is based on the question, ''Please describe how the respondent makes decisions regarding tasks of daily life. Is he/she independent, does he/she exhibit modified independence, is he/she moderately impaired, or is he/she severely impaired?'' ''Independent'' is defined as a resident who makes decisions that are consistent or reasonable; ''modified independent'' is defined as a resident who has some difficulty in new situations only; ''moderately impaired'' is defined as poor decisions, with cues or supervision required; and ''severely impaired'' is defined as never or rarely made decisions.

Continence—Residents' continence was divided into three categories: used appliance, fully continent, or usually continent to incontinent. Residents who used either an external (condom) catheter or an indwelling catheter to manage bladder incontinence were categorized as ''used appliance'' when determining bladder continence. Of residents who did not receive EOL care, 7% (n = 100,400) used an appliance to manage bladder incontinence, and 10% (n = 3,700) of residents who received EOL care had either an internal or external catheter. Residents who had an ostomy were categorized as ''used appliance'' when determining bowel continence. Of residents who did not receive EOL care, 1.5% (n = 21,200) had an ostomy. The number of residents receiving EOL care who had an ostomy was too small to report.

Reported pain and pain management strategies—To assess prevalence of reported pain, respondents were asked, ''In the past 7 days, that is, since [date 7 days prior to interview], has [subject] reported or shown evidence of pain? Please include grimacing or other nonverbal signs that suggest pain.''

Questions on pain management were asked only of residents who reported pain. The question text was, ''What strategies are used to manage [subject]'s pain, according to the medical record?'' Respondents were shown a card with the following options and asked to select all that applied:

- Standing order for pain medication.
- PRN (as needed) order for pain medication.
- Nonpharmacological methods (e.g., distraction, heat or cold massage, positioning, and music therapy).
- Other.

Advance directives—For this study, advance directives were defined to include living wills, do-not-resuscitate orders, do-not-hospitalize orders, feeding restrictions, medication restrictions, or other treatment restriction orders. Although NNHS included questions about organ donation and autopsy, these were not included as advance directives for this study.

Length of time in nursing home and on EOL care since admission—Because of the cross-sectional design, lengths of time in the nursing home and on EOL care since admission do not represent a complete episode of care. Length of time in the nursing home is calculated as the number of days between nursing home admission date and survey date. For residents who started EOL care after admission to the nursing home, length of time in the nursing home prior to EOL care is calculated as the number of days between admission to the nursing home and the start of EOL care. Two measures for length of time on EOL care are calculated. The overall length of time on EOL care is calculated as the number of days from the start of EOL care to the survey date. For residents who started EOL care prior to admission to the nursing home, the length of EOL care prior to admission is the number of days between the start of EOL care and admission to the nursing home.

Medications—Data on medications were collected for all sampled residents using the nursing homes' medication administration records. The generic or brand name was collected for all medications in the resident's medical record (including those available as over-the-counter drugs, such as some pain relievers and dietary supplements). Respondents were asked about the following:

1. Medications taken by the resident during the 24 hours before the facility interview, including standing or routine medications or PRN medications.
2. Medications taken regularly by the resident but not during the 24 hours before the facility interview, including standing but not PRN medications.

For each question, 25 medicines could be entered for each resident, for a total of up to 50 medicines per resident.

Medications were classified using the 1995 *National Drug Code Directory* into 21 major therapeutic classes and 139 therapeutic subclasses. For further information on the Prescribed Medications Files, coding, and availability of data, see http://www.cdc.gov/nchs/about/major/nnhsd/drugdatabase.htm.

Diagnoses—The primary diagnosis at time of admission and up to 16 current diagnoses at the time of survey were collected using the *International Classification of Diseases, Ninth Revision, Clinical Modification* codes (37). These diagnoses were sorted into the categories as listed in the tables.

Analytic considerations due to study design and sample size—The 2004 NNHS collected data only on current residents. Thus, information on completed episodes of care is not available, and length of stay in the nursing home and receipt of EOL care do not represent a completed episode of care. In addition, a current resident sample is more likely to contain long-term nursing home residents and, conversely, to undersample short-stay nursing home residents. This situation results from the fact that short-stay residents are less likely to be on the nursing home rolls on a given night and be available to be sampled. Thus, short-stay nursing home residents, whether or not they received EOL care, are less likely to be represented in the survey.

Nursing home residents were sampled without consideration of whether they received EOL care. Because of small sample sizes, results are suggestive, and should be interpreted with caution.

Standard errors—See Tables I through VIII for standard errors.

Table I. Standard errors of number and percentage of nursing home residents by receipt of end-of-life care: National Nursing Home Survey, 2004

Resident characteristic	Nursing home residents not receiving EOL care		Nursing home residents receiving EOL care	
	Number	Percent	Number	Percent
All nursing home residents	11,308	. . .	2,774	. . .
Sex				
Male	9,094	0.6	1,309	2.8
Female	11,962	0.6	2,269	2.8
Race[1]				
White	15,139	0.8	2,640	2.1
Black	10,901	0.7	*	*
All other	3,875	0.3	*	*
Hispanic or Latino origin				
Yes	5,443	0.4	*	*
No	12,415	0.4	2,738	0.9
Marital status[1]				
Married or living with partner	7,035	0.5	1,205	2.7
Widowed	11,394	0.6	2,081	3.1
Divorced, separated, never married, or single	9,330	0.6	*931	*2.3
Living arrangements prior to admission to nursing home				
Admitted from home	11,742	0.8	1,434	3.1
Admitted from place other than home	14,576	0.8	2,116	3.1
Living situation for those admitted from home				
Lived alone	7,237	1.1	*853	*5.9
Lived with others	7,396	1.1	1,087	5.9
Standard error of mean age at interview[1]	0.2	. . .	0.7	. . .
Standard error of mean age at admission[1]	0.3	. . .	0.7	. . .
Functional status[1]				
Required assistance on up to 4 ADL[2]	11,656	0.8	1,367	3.0
Required assistance in all 5 ADL[2]	13,256	0.8	2,278	3.0
Continence				
Bowel continence[1]				
Used appliance	2,017	0.1	*	*
Fully continent	10,080	0.6	1,124	2.5
Usually continent to incontinent	11,623	0.6	2,369	2.6
Bladder continence[1]				
Used appliance	4,278	0.3	*790	*2.0
Fully continent	8,575	0.6	*707	*1.7
Usually continent to incontinent	11,625	0.6	2,422	2.5
Decision-making ability[1]				
Independent or modified independent	10,406	0.7	1,269	2.8
Moderately or severely impaired	11,875	0.7	2,271	2.8
Advance directives				
Had at least one advance directive[1]	14,461	0.8	2,625	1.6
Had a do-not-resuscitate order[1]	14,328	0.9	2,512	2.3
Had a living will[1]	10,749	0.7	1,327	2.9
Reported pain and pain management strategies				
Reported pain in the previous 7 days[1]	8,363	0.6	1,645	3.2
Had a PRN (as needed) order for pain management	7,535	1.5	1,403	4.4
Had standing order for pain management[1]	6,009	1.4	1,424	5.0

. . . Category not applicable.

* Figure does not meet standards of reliability or precision. When the standard error is not reported, it is because the sample size for the estimate is less than 30, which does not meet the standards of reliability or precision. Standard errors accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the ratio of the standard error to the reported estimate is 30 percent or more.

[1]Significant differences between residents receiving EOL care and residents not receiving EOL care at $p < 0.05$.

[2]ADL is activities of daily living. See "Technical Notes" for further definition of ADL.

NOTES: EOL is end-of-life. SE is standard error. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table II. Standard errors of number and percentage of nursing home residents' medication use by receipt of end-of-life care: National Nursing Home Survey, 2004

Medication class according to 1995 *National Drug Code Directory*[1]	Nursing home residents not receiving EOL care		Nursing home residents receiving EOL care	
	Number	Percent	Number	Percent
Total	11,308	. . .	2,774	. . .
Anesthetic drugs (0100)	2,061	0.1	*	*
Antidotes (0200)	*1,024	*0.1	*	*
Antimicrobial agents (0300)	5,354	0.4	*899	*2.1
Hematologic agents (0400)[2]	8,926	0.5	1,126	2.6
Cardiovascular-renal drugs (0500)[2]	10,987	0.5	2,008	3.2
Central nervous system (0600)	11,275	0.6	2,152	3.1
Antidepressants (0630)	10,177	0.6	1,554	3.0
Gastrointestinal agents (0800)	11,654	0.6	2,291	2.9
Metabolic/nutrients (0900)[2]	11,540	0.6	1,874	3.1
Vitamins/minerals (0913)[2]	11,456	0.7	1,567	3.2
Hormones/hormonal mechanisms (1000)[2]	9,281	0.6	1,442	2.9
Immunologics (1100)	*849	*0.1	*	*
Skin/mucous membrane (1200)[2]	3,921	0.3	*730	*1.9
Neurologic drugs (1300)	8,151	0.5	1,353	3.0
Oncolytics (1400)	3,297	0.2	*	*
Opthalmics (1500)	7,457	0.5	974	2.3
Otologics (1600)	2,826	0.2	*	*
Relief of pain (1700)[2]	11,455	0.6	2,328	3.0
Analgesics/general (1720)	5,381	0.4	*	*
Analgesics, narcotic (1721)[2]	6,524	0.4	1,694	3.2
Analgesics, non-narcotic (1722)[2]	10,796	0.6	1,628	3.3
Antiarthritics (1724)[2]	8,656	0.5	1,200	2.7
Nonsteroidal anti-inflammatory (NSAID) (1727)	5,461	0.4	*960	*2.3
Antipyretics (1728)[2]	10,553	0.6	1,585	3.3
Antiparasitics (1800)	1,801	0.1	*	*
Respiratory tract (1900)	6,720	0.4	1,143	2.5
Unclassified/miscellaneous (2000)	3,625	0.2	*	*
Homeopathic products (2100)	2,918	0.2	*	*

. . . Category not applicable.

* Figure does not meet standards of reliability or precision. When the standard error is not reported, it is because the sample size for the estimate is less than 30, which does not meet the standards of reliability or precision. Standard errors accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the ratio of the standard error to the reported estimate is 30 percent or more.

[1]See "Technical Notes" for further information on the National Nursing Home Survey data collection and classification of prescribed medications.

[2]Residents not receiving EOL care significantly different than residents receiving EOL care at $p < 0.05$.

NOTES: EOL is end-of-life. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table III. Standard errors of number and percentage of nursing home residents by admission and any listed current diagnosis, by receipt of end-of-life care: National Nursing Home Survey, 2004

ICD–9 code	Admission diagnosis				Current diagnoses[1]			
	Nursing home residents not receiving EOL care		Nursing home residents receiving EOL care		Nursing home residents not receiving EOL care		Nursing home residents receiving EOL care	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total	11,308	. . .	2,774	. . .	11,308	. . .	2,774	. . .
Infectious and parasitic diseases (001–139)	1,872	0.1	*	*	2,695	0.2	*	*
Malignant neoplams (140–208, 230–234)[2,3]	1,915	0.1	*684	*1.7	4,230	0.3	1,004	2.4
Benign neoplasms and of uncertain behavior (210–229, 235–239)	*702	*0.0	*	*	1,413	0.1	*	*
Endocrine, nutritional, and metabolic diseases and immunity disorders (240–279)	3,721	0.3	*	*	10,510	0.6	1,769	3.3
Diabetes (250)	3,214	0.2	*	*	7,807	0.5	1,057	2.4
Diseases of the blood and blood forming organs (280–289)	1,073	0.1	*	*	7,228	0.5	1,084	2.5
Mental disorders (290–319)	7,867	0.5	*881	*2.1	12,233	0.7	2,114	3.0
Senile dementia or organic brain syndrome (290,310)	2,055	0.1	*	*	4,617	0.3	*	*
Diseases of the nervous system and sense organs (320–389)	6,585	0.4	*1,197	*2.8	11,217	0.7	1,483	2.9
Alzheimers disease (331.0)	5,542	0.4	*	*	7,291	0.5	*922	*2.1
Parkinson's (332)	2,045	0.1	*	*	3,773	0.3	*	*
Diseases of the circulatory system (390–459)	7,608	0.5	1,139	2.7	12,076	0.6	2,331	2.7
Essential hypertension (401)	3,681	0.3	*	*	10,880	0.6	1,915	3.2
Heart disease (391–392.0, 393–398, 402,404,410–416, 420–429)[3]	4,213	0.3	*900	*2.2	11,141	0.6	2,123	3.1
Congestive heart failure (428.0)[3]	3,053	0.2	*	*	6,740	0.4	1,116	2.5
Cerebrovascular disease (430–438)	4,991	0.3	*643	*1.6	7,138	0.5	1,013	2.3
Diseases of the respiratory system (460–519)	4,235	0.3	*722	*1.8	6,737	0.4	1,127	2.5
Pneumonia (480–486)	2,560	0.2	*	*	2,605	0.2	*	*
Chronic obstructive pulmonary disease and allied conditions (490–496)	2,604	0.2	*	*	6,070	0.4	*966	*2.3
Diseases of the digestive system (520–579)	2,926	0.2	*	*	10,735	0.7	1,445	3.1
Diseases of the genitourinary system (580–629)[3]	2,995	0.2	*	*	6,893	0.5	1,320	2.9
Diseases of the skin and subcutaneous tissue (680–709)	1,838	0.1	*	*	3,760	0.3	*	*
Diseases of the musculoskeletal system and connective tissue (710–739)	3,281	0.2	*	*	11,684	0.7	1,630	3.2
Rheumatoid and osteoarthritis and allied disorders (714,715)	2,008	0.1	*	*	8,464	0.5	1,114	2.6
Congenital anomalies (740–759)	*833	*0.1	*	*	1,811	0.1	*	*
Symptoms, signs and ill-defined conditions (780–799)	4,102	0.3	*	*	10,150	0.7	1,488	3.0
Injuries and poisoning (800–999)	1,991	0.1	*	*	6,459	0.4	*	*
Post hospital aftercare (V42-V46, V52, V53.3-V53.7, V54-V58)	4,966	0.3	*	*	3,446	0.2	*	*
No diagnosis or unknown	3,898	0.3	*	*	5,005	0.3	*	*

. . . Category not applicable.

* Figure does not meet standards of reliability or precision. When the standard error is not reported, it is because the sample size for the estimate is less than 30, which does not meet the standards of reliability or precision. Standard errors accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the ratio of the standard error to the reported estimate is 30 percent or more.

0.0 Quantity more than zero but less than 0.05.

[1]Any of 16 listed current diagnoses. There is only one admission diagnosis.

[2]Significant differences in admission diagnosis between nursing home residents receiving EOL care and not receiving EOL care at $p < 0.05$.

[3]Significant differences in current diagnoses between nursing home residents receiving EOL care and not receiving EOL care at $p < 0.05$.

NOTES: EOL is end-of-life. ICD–9 is *International Classification of Diseases, Ninth Revision.* Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table IV. Standard errors of number and mean and median of length of time on end-of-life care, by timing of onset of end-of-life care and Medicare coverage: National Nursing Home Survey, 2004

Length of time on EOL care (in days) by timing of onset of EOL care[1]	Number	Standard error of mean	Standard error of median
Total length of time on EOL care[2]	31,100	10.1	12.3
Started EOL care after admission to nursing home	24,700	10.7	13.4
Started EOL care on same day as admission to nursing home	*3,400	*30.0	*39.8
Started EOL care prior to admission to nursing home	*2,900	*40.0	*80.1
Days of EOL care prior to admission to nursing home	*2,900	*27.2	*16.3
Days of EOL care in nursing home	*2,900	*35.9	*21.4
Length of time on EOL care (in days) by Medicare coverage for hospice care[1]	**Number**	**Standard error of mean**	**Standard error of median**
Medicare coverage started	18,700	12.3	13.5
Medicare coverage not started	8,300	21.5	25.5
Not eligible for Medicare or unknown	*4,100	*27.2	*39.2

* Figure does not meet standards of reliability or precision. Standard errors accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the ratio of the standard error to the reported estimate is 30 percent or more.

[1]No significant differences between groups at $p < 0.05$.

[2]The length of time on EOL care could not be calculated for 6,700 residents who received EOL care because they did not have the date when they started the care. These residents are not included in calculation of length of time on EOL care.

NOTE: EOL is end-of-life.

Table V. Standard errors of number and percentage of nursing home residents by timing of onset of end-of-life care: National Nursing Home Survey, 2004

	Nursing home residents who started EOL care on or prior to admission		Nursing home residents who started EOL care after admission	
	Number	Percent	Number	Percent
Nursing home residents receiving EOL care[1]	1,216	. . .	2,369	. . .
Sex				
Male	*700	*6.0	1,063	3.2
Female	*959	*6.0	2,001	3.2
Race				
White	1,157	3.7	2,279	2.0
Hispanic or Latino origin				
No	1,192	2.0	2,346	1.1
Marital status				
Married or living with partner	*	*	1,086	3.1
Widowed	*945	*5.9	1,761	3.7
Divorced, separated, never married, or single	*	*	*786	*2.6
Living arrangements prior to admission to nursing home				
Admitted from home	*672	*6.0	1,152	3.4
Admitted from place other than home	*953	*6.0	1,827	3.4
Living situation for those admitted from home				
Lived alone	*	*	*	*
Lived with others	*	*	*945	*6.5
Standard error of mean age at interview[2]	1.9	. . .	0.7	. . .
Standard error of mean age at admission	1.9	. . .	0.7	. . .
Functional status[2]				
Required assistance on up to 4 ADL	*777	*6.4	1,048	3.2
Required assistance in all 5 ADL	*917	*6.4	2,030	3.2
Continence				
Bowel continence[2]				
Used appliance	*	*	*	*
Fully continent	*693	*5.9	*869	*2.7
Usually continent to incontinent	*949	*5.9	2,092	2.8
Bladder continence[2]				
Used appliance	*	*	*	*
Fully continent	*	*	*	*
Usually continent to incontinent	*952	*6.0	2,150	2.7
Decision making ability[2]				
Independent or modified independent	*782	*6.3	*978	*2.9
Moderately or severely impaired	*867	*6.4	2,012	2.9
Advance directives				
Had at least one advance directive[2]	1,108	4.6	2,309	1.4
Had a do-not-resuscitate order	1,104	4.7	2,189	2.5
Had a living will	*	*	1,203	3.5
Reported pain and pain management strategies				
Reported pain in the previous 7 days[2]	*844.1	*6.2	1,391	3.8
Had a PRN (as needed) order for pain management[2]	*812.6	*5.2	1,127	5.5
Had standing order for pain management	*721.5	*8.3	1,185	6.2

. . . Category not applicable.

* Figure does not meet standards of reliability or precision. When the standard error is not reported, it is because the sample size for the estimate is less than 30, which does not meet the standards of reliability or precision. Standard errors accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the ratio of the standard error to the reported estimate is 30 percent or more.

[1]Excludes 600 residents who received EOL care but were missing information when the care started.

[2]Residents who started EOL care on or prior to admission were significantly different from residents who started EOL care after admission at $p < 0.05$.

NOTES: EOL is end-of-life. ADL is activities of daily living. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table VI. Standard errors of number and percentage of nursing home residents receiving end-of-life care by timing of onset of end-of-life care, by selected medication use: National Nursing Home Survey, 2004

Medication class according to 1995 *National Drug Code Directory*[2]	Nursing home residents who started EOL care on or prior to admission to nursing home		Nursing home residents who started EOL care after admission to nursing home	
	Number	Percent	Number	Percent
Cardiovascular-renal drugs (0500)	*909	*5.9	1,680	3.8
Central nervous system (0600)[3]	833	6.4	1,944	3.5
Antidepressants (0630)	*631	*5.7	1,407	3.7
Gastrointestinal agents (0800)	1,037	6.0	1,914	3.3
Metabolic/nutrients (0900)	*773	*6.4	1,673	3.7
Vitamins/minerals (0913)	*692	*6.3	1,362	3.7
Hormones/hormonal mechanisms (1000)	*697	*5.8	1,220	3.3
Relief of pain (1700)	1,024	5.5	2,005	3.4
Analgesics, narcotic (1721)	*824	*6.1	1,448	3.8
Respiratory tract (1900)[3]	*683	*6.1	*913	*2.7

* Figure does not meet standards of reliability or precision. Standard errors accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the ratio of the standard error to the reported estimate is 30 percent or more.

[1]Excludes 600 residents who received EOL care but were missing information when the care started.

[2]See "Technical Notes" for further information on the National Nursing Home Survey data collection and classification of prescribed medications.

[3]Residents who started EOL care on or prior to admission were significantly different from residents who started EOL care after admission at $p < 0.05$.

NOTES: EOL is end-of-life. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table VII. Standard errors of number and percentage of nursing home residents by any-listed current diagnoses and timing of onset of end-of-life care: 2004 National Nursing Home Survey, 2004

ICD–9 code	Current diagnoses[1]					
	All residents receiving EOL care[2]		Nursing home residents who started EOL care on or prior to admission to nursing home		Nursing home residents who started EOL care after admission to nursing home	
	Number	Percent	Number	Percent	Number	Percent
Total	2,774	. .	1,216	. .	2,369	. . .
Malignant neoplams (140–208, 230–234)[3]	1,004	2.4	*752	*6.4	*655	*2.3
Endocrine, nutritional, and metabolic diseases and immunity disorders (240–279)	1,769	3.3	*757	*6.1	1,505	3.9
Diseases of the blood and blood forming organs (280–289)	1,084	2.5	*	*	*967	*3.0
Mental disorders (290–319)[3]	2,114	3.0	*786	*6.5	1,960	3.3
Diseases of the nervous system and sense organs (320–389)	1,483	2.9	*	*	1,343	3.6
Diseases of the circulatory system (390–459)	2,331	2.7	*954	*6.0	2,097	3.1
Essential hypertension (401)	1,915	3.2	*	*	1,740	3.7
Heart disease (391–392.0, 393–398, 402,404,410–416, 420–429)	2,123	3.1	*927	*6.1	1,873	3.7
Cerebrovascular disease (430–438)	1,013	2.3	*	*	*946	*2.9
Diseases of the respiratory system (460–519)[3]	1,127	2.5	*693	*6.0	*865	*2.7
Diseases of the digestive system (520–579)	1,445	3.1	*	*	1,303	3.7
Diseases of the genitourinary system (580–629)	1,320	2.9	*	*	*1,248	*3.7
Diseases of the musculoskeletal system and connective tissue (710–739)	1,630	3.2	*	*	1,553	3.7
Symptoms, signs and ill-defined conditions (780–799)	1,488	3.0	*	*	1,336	3.6

. . . Category not applicable.

* Figure does not meet standards of reliability or precision. When the standard error is not reported, it is because the sample size for the estimate is less than 30, which does not meet the standards of reliability or precision. Standard errors accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the ratio of the standard error to the reported estimate is 30 percent or more.

[1]Any of 16 listed current diagnoses.

[2]Includes 600 residents who received EOL care but were missing information when the care started.

[3]Significant differences at $p < 0.05$ in current diagnoses between nursing home residents who stated EOL care on or prior to admission and who started EOL care after admission to the nursing home.

NOTES: EOL is end-of-life. ICD–9 is the *International Classification of Diseases, Ninth Revision*. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Table VIII. Standard errors of number and percentage of nursing home residents receiving end-of-life formal services or treatments in the 7 days prior to interview: National Nursing Home Survey, 2004

Formal service or treatment	Nursing home residents receiving EOL care[1]		Nursing home residents who started EOL care on or prior to admission to nursing home		Nursing home residents who started EOL care after admission to nursing home	
	Number	Percent	Number	Percent	Number	Percent
Nursing home residents receiving EOL care	1,573	. . .	1,117	. . .	1,650	. . .
Services received in the 7 days prior to interview						
Pain management[2]	1,680	3.6	*995	*5.5	1,460	4.2
Symptom management	1,642	3.7	919	6.8	1,382	4.1
Emotional support for family	1,653	3.6	*768	*6.6	1,525	4.0
Pastoral or spiritual care	1,651	3.8	*777	*6.5	1,437	4.3
Grief, loss, and bereavement counseling	1,466	3.6	*	*	1,323	4.2
Counseling or assistance with ethical or legal issues	1,496	3.6	*	*	*1,303	*4.1
Other services	1,052	2.7	*	*	*867	*3.0
Death preparation	*1,317	*3.2	*	*	*1,130	*3.7
Types of formal care or treatments received in 7 days prior to interview						
Aggressive pain management including radiation for pain relief	1,459	3.4	*810	*6.6	1,230	3.9
Oxygen-respiratory therapy[2]	1,295	3.1	*821	*6.7	1,049	3.4
Bowel training regimen	1,208	3.2	*	*	969	3.4
Subcutaneous therapy, IV therapy, parenteral hydration, and artificial nutrition[3]	*768	*2.0	*	*	*746	*2.6
Durable medical equipment	*660	*1.7	*	*	*	*

. . . Category not applicable.

* Figure does not meet standards of reliability or precision. When the standard error is not reported, it is because the sample size for the estimate is less than 30, which does not meet the standards of reliability or precision. Standard errors accompanied by an asterisk (*) indicate that the sample size is between 30 and 59, or the ratio of the standard error to the reported estimate is 30 percent or more.

[1]Includes 600 residents who received EOL care but were missing information on when the care started.

[2]Residents who started EOL care on or prior to admission were significantly different from residents who started EOL care after admission at $p < 0.05$.

[3]IV and subcutaneous therapies may also be used for pain relief. From the data, it is not possible to determine for what the therapies were used.

NOTES: EOL is end-of-life. Numbers may not add to totals because of rounding. Percentages are based on the unrounded numbers.

Suggested citation

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