

Dying With Advanced Dementia in the Nursing Home

Susan L. Mitchell, MD, MPH, FRCPC; Dan K. Kiely, MPH, MA; Mary Beth Hamel, MD, MPH

Background: Nursing homes are important providers of end-of-life care to persons with advanced dementia.

Methods: We used data from the Minimum Data Set (June 1, 1994, to December 31, 1997) to identify persons 65 years and older who died with advanced dementia (n=1609) and terminal cancer (n=883) within 1 year of admission to any New York State nursing home. Variables from the Minimum Data Set assessment completed within 120 days of death were used to describe and compare the end-of-life experiences of these 2 groups.

Results: At nursing home admission, only 1.1% of residents with advanced dementia were perceived to have a life expectancy of less than 6 months; however, 71.0% died within that period. Before death, 55.1% of demented residents had a do-not-resuscitate order, and 1.4% had a do-not-hospitalize order. Nonpalliative interventions were common among residents dying with advanced dementia: tube feeding, 25.0%; laboratory tests, 49.2%; restraints, 11.2%; and intravenous therapy, 10.1%.

Residents with dementia were less likely than those with cancer to have directives limiting care but were more likely to experience burdensome interventions: do-not-resuscitate order (adjusted odds ratio [OR], 0.12; 95% confidence interval [CI], 0.09-0.16), do-not-hospitalize order (adjusted OR, 0.33; 95% CI, 0.16-0.66), tube feeding (adjusted OR, 2.21; 95% CI, 1.51-3.23), laboratory tests (adjusted OR, 2.53; 95% CI, 2.01-3.18), and restraints (adjusted OR, 1.79; 95% CI, 1.23-2.61). Distressing conditions common in advanced dementia included pressure ulcers (14.7%), constipation (13.7%), pain (11.5%), and shortness of breath (8.2%).

Conclusions: Nursing home residents dying with advanced dementia are not perceived as having a terminal condition, and most do not receive optimal palliative care. Management and educational strategies are needed to improve end-of-life care in advanced dementia.

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AS MUCH AS 90% OF THE 4 million Americans with dementia will be institutionalized before death.¹ Therefore, nursing homes are important providers of end-of-life care for demented older persons. Recent research²⁻⁷ has highlighted the need to improve the quality of palliative care in the nursing home setting.

Most health care providers and families believe that palliation is appropriate for advanced dementia.⁸ Nonetheless, earlier studies^{9,10} on acute care settings have shown that hospitalized older patients with advanced cognitive impairment often undergo inappropriate burdensome and nonpalliative interventions despite having a limited life expectancy. Unlike metastatic cancer, advanced dementia is not generally regarded as a terminal condition. As such, care may not be directed toward comfort until death is perceived as

imminent despite the need for palliation throughout the final phase of this illness.

Conceivably, the nursing home, with its focused geriatric expertise, would be better suited to provide end-of-life care for older persons with advanced dementia than the acute care hospital, where decision making is rushed, care is fragmented, and technology is readily available. However, the dying experience of this population in the nursing home has not been well examined. Therefore, to better describe the end-of-life care of nursing home residents with advanced dementia, we conducted a retrospective study using data from the Minimum Data Set (MDS).^{11,12} To contrast their experience to the standard of palliative care currently provided in the nursing home setting, we defined a comparative cohort of residents with cancer who were explicitly perceived as dying. We hypothesized that despite the theoretical advantages of the

From the Research and Training Institute, Hebrew Rehabilitation Center for Aged (Dr Mitchell and Mr Kiely), the Department of Medicine (Dr Mitchell and Mr Kiely), and the Division of General Medicine and Primary Care (Dr Hamel), Beth Israel Deaconess Medical Center, and the Division on Aging, Harvard Medical School (Dr Mitchell), Boston, Mass. The authors have no relevant financial interest in this article.

nursing home as a site of terminal care for residents with advanced dementia, less emphasis would be placed on palliation before death compared with another group of incurably ill older persons who were clearly recognized as dying.

METHODS

POPULATION

We used MDS data from June 1, 1994, to December 31, 1997, to identify persons 65 years and older who died within 1 year of admission to any of the 643 New York State nursing homes. Data were obtained from the MDS (version 1+), a federally mandated, validated instrument that assesses the health conditions, disease diagnoses, treatments, and functional and cognitive status of residents living in all licensed US nursing homes.^{11,12} Data were collected by trained staff at each facility and were submitted to a central state agency for computerization, where they were reviewed for completeness. An MDS assessment is completed within 2 weeks of nursing home admission and quarterly thereafter. Individuals whose primary payer was Medicare were excluded because we did not want to study patients admitted exclusively for rehabilitative or subacute care.

Death within 1 year of admission was assessed in several ways. Residents were excluded if they were present in the MDS database 1 year beyond their admission date. A search of the National Death Index was performed for all other residents.¹³ Matches were attempted on 18 variables, including each digit of the Social Security number, date of birth, first and last name, race, and last known state of residence. A complete match was defined as an exact match on all 18 variables or a match on 17 variables and an error in a single digit of the Social Security number. Individuals were included if a complete match was found and the date of death was within 1 year of admission to the nursing home. Residents who died after December 31, 1997, were not included in the sample because MDS data were not available after that date.

Participants were identified based on data from their admission MDS assessment. Advanced dementia was defined as having a diagnosis of dementia (Alzheimer disease or other causes) and a Cognitive Performance Scale score of 5 or 6.^{14,15} The Alzheimer disease and dementia diagnoses have been used for epidemiologic research¹⁶ and have intraclass correlation coefficients of 0.89 and 0.79, respectively.¹² The Cognitive Performance Scale is a validated measure of cognitive impairment in nursing home residents that uses 5 MDS variables to group residents into 7 hierarchical cognitive performance categories: 0 indicates intact; 1, borderline intact; 2, mild impairment; 3, moderate impairment; 4, moderately severe impairment; 5, severe impairment; and 6, very severe impairment with eating problems. Thus, a Cognitive Performance Scale score of 5 or 6 clearly distinguishes residents with dementia who are in the advanced stages of the disease.

We wanted to contrast the dying experience of residents with advanced dementia to a benchmark of palliative care provided in the nursing homes. Therefore, we identified a comparative group of residents with terminal cancer defined as having a diagnosis of cancer and a perceived life expectancy of less than 6 months (specific MDS variable). The diagnosis of cancer from the MDS has an intraclass correlation coefficient of 0.81¹² and has been used previously in other epidemiologic investigations.^{5,6}

Residents who met the criteria for both terminal cancer and advanced dementia were excluded ($n=54$). We only included residents who had an MDS assessment completed within 120 days of death. This time frame was chosen because we be-

lieved it was a reasonable interval to reflect end-of-life care and because it captured more than 90% of the final assessments for both cohorts.

DEFINITION OF VARIABLES

Variables were selected from the data set that were thought to represent important features of end-of-life care based a priori on our knowledge of the literature and clinical experience.^{3-7,9,10} Variables were categorized as follows: advance care planning, non-palliative interventions, signs and symptoms, and psychiatric conditions and treatments. Data describing these variables were derived from the MDS assessment completed closest to death within a 120-day window. The MDS items analyzed in this study have met a high standard of reliability (intraclass correlation coefficient ≥ 0.60).¹²

In the category of advance care planning, we examined whether there was a do-not-resuscitate (DNR) order, a do-not-hospitalize (DNH) order, and a directive to withhold tube feeding (excluding residents with feeding tubes). We also determined whether residents had a living will and whether a substitute decision maker was appointed.

Nonpalliative interventions included feeding tubes, any laboratory tests (blood tests or urinalysis) performed in the previous 30 days, trunk or limb restraints used in the 7 days before the assessment, and intravenous fluids or medications administered. Signs and symptoms included pain (daily or almost daily complaints), shortness of breath, constipation, pressure ulcers (with at least some loss of skin integrity), pneumonia, fever, recurrent lung aspirations, swallowing or chewing problems, and weight loss ($>5\%$ in 30 days or $>10\%$ in 180 days).

We examined the presence of the following psychiatric conditions: hallucinations, a diagnosis of depression, and symptoms of anxiety. We also determined whether anxiolytic, antipsychotic, or antidepressant agents were administered in the week before the assessment. Finally, we examined the presence of behavior problems (wandering or physical agitation).

We also assessed the following variables: age at death (years), length of stay (days from nursing home admission until death), functional status on admission, body mass index (BMI) (calculated as weight in kilograms divided by the square of height in meters) on admission, race or ethnicity (white vs other), and sex. Functional status was quantified using the MDS Activity of Daily Living Long Form Scale.¹⁷ The scale measures functional ability in 7 domains: dressing, personal hygiene, toilet use, locomotion, transferring, bed mobility, and eating. Each domain is scored as follows: 0 indicates independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence. A score of 28 represents complete dependence in all 7 domains.

STATISTICAL ANALYSIS

All analyses were performed using statistical software (SAS version 8.1; SAS Institute Inc, Cary, NC).¹⁸ Disease status (advanced dementia vs terminal cancer) was the main independent variable in all analyses. Descriptive statistics were used to report resident characteristics.

Bivariate analyses were conducted to compare the characteristics of residents with advanced dementia with those of residents with terminal cancer. χ^2 Tests and 2-sample t tests were used to analyze dichotomous and continuous variables, respectively.

Based on the bivariate analyses, end-of-life variables that differed significantly ($P<.05$) between residents with cancer and residents with dementia were selected for examination using multivariate techniques. Logistic regression was used to adjust for variables that could potentially confound the associa-

Table 1. Characteristics of the Study Participants

Characteristic	Dementia Group (n = 1609)	Cancer Group (n = 883)	P Value
Age at death, mean ± SD, y	83.5 ± 7.1	79.1 ± 7.2	<.001
Time from admission until death, mean ± SD, d	121.6 ± 104.7	62.4 ± 73.9	<.001
Activity of Daily Living Long Form Scale score at admission, mean ± SD	23.3 ± 5.8	18.3 ± 7.6	<.001
Body mass index <23 kg/m ² , %	29.1	32.6	.06
Nonwhite, %	20.5	11.0	<.001
Women, %	57.1	52.1	.03

tion between the outcome variable (eg, DNR status) and the disease status. Age at death, sex, functional status, ethnicity, length of stay, and number of days between the last assessment and death were included as covariates in all multivariate models. Additional potential confounders were selected based on the individual analyses. The appointment of a substitute decision maker and the presence of a living will were included as covariates in the models for DNR, DNH, and requests for feeding tube restrictions. The following variables were included as covariates when tube feeding was the outcome: chewing or swallowing problems, BMI, weight loss, and recurrent lung aspirations. The presence of pneumonia, chronic obstructive pulmonary disease, and congestive heart failure were included in the model in which shortness of breath was the dependent variable. Body mass index and weight loss were included as additional covariates when the presence of pressure ulcers was the dependent variable. Finally, hallucinations and behavior problems (wandering and agitation) were included as covariates when antipsychotic medication therapy was the outcome.

RESULTS

PARTICIPANT CHARACTERISTICS

There were 1784 residents with advanced dementia and 918 residents with terminal cancer who died within 1 year of nursing home admission in New York State between June 1, 1994, and December 31, 1997. Among these residents, 1609 (90%) with advanced dementia and 883 (96%) with terminal cancer had an MDS assessment completed within 120 days of death and were included in the analysis. Age, sex, race, and functional status on admission did not differ according to whether the resident's death assessment was missing.

Residents with advanced dementia were older, lived longer from admission until death, and had higher Activity of Daily Living Long Form Scale scores (indicating greater functional impairment) than the terminal cancer group. Demented residents were more likely to be female and nonwhite. The proportion of residents with a BMI less than 23 on admission did not significantly differ between the 2 groups (**Table 1**).

Six months after nursing home admission, 92% of the cancer cohort and 71% of the residents with advanced dementia had died. Only 20 (1.1%) of the 1784 residents with advanced dementia were perceived as having a life expectancy of less than 6 months at the time of admission. At the last assessment before death, 66 (4.1%)

Table 2. Bivariate Analyses of Characteristics Within 120 Days of Death: Nursing Home Residents Dying With Advanced Dementia vs Terminal Cancer

Characteristic	Advanced Dementia Group, % (n = 1609)	Terminal Cancer Group, % (n = 883)	P Value
Advance care planning			
Do not resuscitate	55.1	86.1	<.001
Do not hospitalize	1.4	4.2	<.001
No tube feeding*	7.6	12.9	<.001
Living will	11.3	11.8	.71
Substitute decision maker	94.7	92.1	.02
Nonpalliative treatments			
Feeding tube	25.0	5.2	<.001
Laboratory tests performed in the previous 30 d	49.2	32.3	<.001
Trunk or limb restraints	11.2	6.3	<.001
Intravenous fluids or medications	10.1	7.1	.01
Signs and symptoms			
Daily or almost daily pain	11.5	56.6	<.001
Shortness of breath	8.2	27.6	<.001
Constipation	13.7	32.7	<.001
Pressure ulcers	14.7	6.0	<.001
Pneumonia	10.8	3.6	<.001
Fever	13.4	6.8	<.001
Recurrent lung aspirations	3.0	1.8	.06
Chewing or swallowing problems	45.9	33.6	<.001
Weight loss†	26.1	41.7	<.001
Psychiatric conditions and treatments			
Diagnosis of depression	9.1	12.7	.01
Anxiety	2.8	5.0	.01
Hallucinations	2.0	5.1	<.001
Antidepressant drug therapy	11.9	18.7	<.001
Anxiolytic drug therapy	11.4	30.7	<.001
Antipsychotic drug therapy	24.9	14.4	<.001

*Residents with feeding tubes were excluded.

†Weight loss of greater than 5% in 30 days or 10% in the past 180 days.

of the 1609 demented residents included in the study were recognized as having a prognosis of less than 6 months to live.

For all residents, the mean ± SD time between the final MDS assessment and death was 31.9 ± 9.9 days (median, 23 days), and 95% of residents had their last assessment completed within 92 days of death. The mean ± SD time between the last assessment and death was, on average, 5.5 days longer for the residents with advanced dementia than for those with cancer (33.8 ± 31.7 vs 28.3 ± 25.9 days; $P < .001$).

ADVANCE CARE PLANNING

The frequencies and bivariate comparisons of the end-of-life characteristics among residents with advanced dementia and those with terminal cancer are presented in **Table 2**. **Table 3** gives the results of the multivariate analyses.

At the last assessment before death, residents with advanced dementia were significantly less likely than those with terminal cancer to have advance directives limiting

Table 3. Multivariate Analyses of Characteristics Within 120 Days of Death: 1609 Nursing Home Residents Dying With Advanced Dementia vs 883 With Terminal Cancer

Characteristic	Adjusted Odds Ratio* (95% Confidence Interval)
Advance directives†	
Do not resuscitate	0.12 (0.09-0.16)
Do not hospitalize	0.33 (0.16-0.66)
No tube feeding‡	0.56 (0.38-0.83)
Nonpalliative treatments	
Feeding tube§	2.21 (1.51-3.23)
Laboratory tests performed in the previous 30 d	2.53 (2.01-3.18)
Trunk or limb restraints	1.79 (1.23-2.61)
Signs and symptoms	
Daily or almost daily pain	0.10 (0.08-0.14)
Shortness of breath	0.14 (0.10-0.20)
Constipation	0.29 (0.22-0.38)
Pressure ulcers¶	1.69 (1.16-2.45)
Pneumonia	2.28 (1.46-3.54)
Fever	1.52 (1.07-2.18)
Psychiatric conditions and treatments	
Hallucinations	0.27 (0.15-0.50)
Anxiolytics drug therapy	0.32 (0.25-0.42)
Antipsychotic drug therapy#	2.71 (1.62-4.58)

*All models are adjusted for age at death, sex, race (white vs nonwhite), days from nursing home admission until death, days between the date of final assessment and death, and ability to perform activities of daily living.

†All advance directive models are also adjusted for the presence of a substitute decision maker and living will.

‡Excludes residents with feeding tubes.

§The tube feeding model is also adjusted for the presence of chewing or swallowing problems, recurrent lung aspirations, recent weight loss, and body mass index.

||The shortness of breath model is also adjusted for the presence of pneumonia, congestive heart failure, and chronic obstructive pulmonary disease.

¶The pressure ulcer model is also adjusted for body mass index and recent weight loss.

#The antipsychotic drug therapy model is also adjusted for the presence of hallucinations and behavior problems.

aggressive care. Only 55.1% of demented residents had a DNR order just before death compared with 86.1% of residents with terminal cancer ($P < .001$). A few residents in either group had DNH orders, but this proportion was significantly lower among residents with advanced dementia (1.4% vs 4.2%; $P < .001$). Residents dying with dementia were also less likely than those with cancer to have an advance directive to withhold tube feeding (among residents without feeding tubes) (7.6% vs 12.9%; $P < .001$). These associations remained statistically significant after multivariate adjustment (DNR: odds ratio [OR], 0.12; 95% confidence interval [CI], 0.09-0.16; DNH: OR, 0.33; 95% CI, 0.16-0.66; and a directive to withhold tube feeding [among those without feeding tubes]: OR, 0.56; 95% CI, 0.38-0.83).

The percentage of residents with a living will did not differ between the 2 groups (11.3% vs 11.8%; $P = .71$). Most residents in both groups had a designated substitute decision maker (94.7% vs 92.1%; $P = .02$); this was not associated with disease status after multivariate adjustment.

Residents dying with advanced dementia experienced uncomfortable or aggressive interventions at the end of life. Twenty-five percent of demented residents died with a feeding tube compared with 5.2% of residents with terminal cancer ($P < .001$). Laboratory tests (49.2% vs 32.3%; $P < .001$), restraints (11.2% vs 6.3%; $P < .001$), and intravenous therapy (10.1% vs 7.1%; $P = .01$) were also more prevalent among residents dying with advanced dementia. After multivariate adjustment, the likelihood of tube feeding (OR, 2.21; 95% CI, 1.51-3.23), laboratory tests (OR, 2.53; 95% CI, 2.01-3.18), and restraint use (OR, 1.79; 95% CI, 1.23-2.61) just before death remained significantly associated with advanced dementia. Intravenous therapy was not associated with disease status in the multivariate analysis.

SIGNS AND SYMPTOMS

It was not unusual for residents with advanced dementia to experience distressing signs and symptoms at the end of life that were potentially amenable to palliative treatment. Certain uncomfortable symptoms, although not uncommon among residents dying with advanced dementia, were reported more frequently among those with terminal cancer, including pain (11.5% vs 56.6%), shortness of breath (8.2% vs 27.6%), and constipation (13.7% vs 32.7%) ($P < .001$ for all). These associations remained significant after multivariate adjustment.

Nearly 14.7% of residents with dementia died with pressure ulcers compared with 6.0% of terminal cancer residents ($P < .001$). Pneumonia (10.8% vs 3.6%) and fever (13.4% vs 6.8%) ($P < .001$ for both) were also more common among residents dying with advanced dementia. These associations remained significant after adjusting for potential confounders. Recurrent lung aspiration was infrequently reported in either group and was not associated with disease status.

The 2 most prevalent conditions reported in the demented and the terminal cancer cohorts were chewing or swallowing problems and recent weight loss. Approximately half (45.9%) of all residents with advanced dementia and one third (33.6%) of those with cancer experienced chewing or swallowing problems near the end of life ($P < .001$). As such, weight loss was common among both groups of residents as they approached death, affecting 26.1% of demented residents and 41.7% of those with terminal cancer ($P < .001$). These characteristics did not differ significantly between groups after multivariate adjustment.

PSYCHIATRIC CONDITIONS AND TREATMENTS

Depression was the most prevalent psychiatric condition reported among nursing home residents dying with advanced dementia (9.1%). After multivariate adjustment, the prevalence of depression and anxiety did not differ between the 2 groups. Hallucinations were uncommon and significantly less likely among residents with advanced dementia (OR, 0.27; 95% CI, 0.15-0.50).

Approximately one quarter (24.9%) of residents with advanced dementia received antipsychotic medications at the end of life. Moreover, even after adjusting for the presence of behavior problems (physical agitation and wandering) and hallucinations, the likelihood of being prescribed antipsychotic medications was significantly greater among residents dying with advanced dementia than among those with terminal cancer (OR, 2.71; 95% CI, 1.62-4.58).

COMMENT

This study demonstrates that older persons with advanced dementia who die in nursing homes are not recognized as having a terminal condition and do not receive care that promotes palliation and comfort at the end of life. In contrast to residents dying of terminal cancer, many severely demented residents did not have advance directives limiting aggressive care and received uncomfortable interventions just before death. In addition, potentially manageable distressing symptoms (pain, shortness of breath, fever, and constipation) were not uncommon among residents dying with advanced dementia. Finally, markers that are generally associated with poor quality of nursing home care, such as pressure ulcers, the use of restraints, and treatment with antipsychotic medications, were more prevalent among residents with advanced dementia than among those with terminal cancer. These findings may help focus future interventions to improve the end-of-life care of nursing home residents with advanced dementia.

Older persons dying with advanced dementia in the nursing home were 8 times less likely to have a DNR order than were residents with terminal cancer. This finding supports earlier work from the acute care setting⁹ and extends this observation to the nursing home population. Only 55.1% of nursing home residents with advanced dementia in this study had a DNR order at the last assessment before they died. This proportion is similar to that reported among severely demented nursing home residents in general, regardless of the timing relative to death.^{19,20} In contrast, 86.1% of residents with terminal cancer had a DNR order, which is comparable to the proportion reported among nursing home residents enrolled in hospice programs.²¹ This observation suggests that DNR orders are more likely to be instituted when death is perceived as imminent.

Only a few residents in this study had advance directives to avoid hospitalization. This number was especially small among the group with advanced dementia (1.4%). Do-not-hospitalize orders reflect a broad acceptance of comfort as the goal of care. Earlier work²² has shown that nursing home residents with pneumonia who have DNH orders do not get hospitalized and are effectively managed in the long-term care setting with conservative treatment. Therefore, to promote the comfort of nursing home residents with advanced dementia at the end of life, it may be worthwhile to encourage advance care planning that limits transfer to acute care hospitals.

More than 92% of residents dying of cancer and dementia had a substitute decision maker. This overall high percentage may be attributable to the 1991 Patient Self-Determination Act,²³ which mandates the discussion of

advance directives with all nursing home residents. Residents with advanced dementia are more likely to rely on surrogate decision making compared with intact residents with terminal cancer. Therefore, the more aggressive approach to end-of-life care observed in the severely demented group may reflect, in part, the reluctance of substitute decision makers to forego life-sustaining treatments in this population.²⁴

Nursing home residents with advanced dementia frequently experienced nonpalliative interventions at the end of life. These treatments included laboratory tests involving phlebotomy, mechanical restraints, and placement of intravenous catheters, all of which are known to be associated with significant pain or discomfort.²⁵ Twenty-five percent of demented residents died with a feeding tube compared with 5% of cancer residents. Similarly, a study⁹ in New York found that 51% of patients with advanced dementia received a new feeding tube during a terminal hospitalization compared with 11% of patients with metastatic cancer. This widespread practice of tube feeding in end-stage dementia is concerning amid growing empirical data and expert opinion that the intervention has no demonstrable health benefits in this population and may be associated with undesirable outcomes, such as the use of restraints.²⁶⁻²⁸

Pain was not uncommon among residents with advanced dementia but was more prevalent among those with terminal cancer. It is possible that pain was undetected in the severely demented group.²⁹ Previous research³⁻⁵ has demonstrated that residents with dementia are less likely to receive pain management than are residents with intact cognition. It has also been shown that pain is inadequately treated in the nursing home even when recognized.³⁻⁶

Advanced dementia was independently associated with greater use of antipsychotic medications and restraints at the end of life. Approximately 1 in 4 residents with advanced dementia were receiving antipsychotic medications just before death, and 1 in 10 were restrained. It is conceivable that these interventions were being used to inappropriately manage untreated pain that may manifest as agitation in demented patients. Mechanical and chemical restraints are associated with considerable morbidity in older persons with severe dementia and are generally regarded as markers of poor quality of nursing home care. Moreover, patients describe mechanical restraints as among the most uncomfortable medical interventions, and they clearly do not promote palliation at the end of life.²⁵

There are several limitations of this study that deserve comment. First, we could not determine which residents were enrolled in a hospice program from the version of the MDS used in this study. Hospice services in nursing homes can improve pain management, promote advance care planning, and reduce the use of invasive treatments.²¹ Nursing home residents with dementia are less likely to receive hospice care than are residents with cancer.³⁰ Therefore, a difference in exposure to hospice services between the 2 cohorts may explain some of the results. If this is true, it only further emphasizes the underrecognition of advanced dementia as a terminal condition for which hospice services would be appropriate. Sec-

ond, this study is limited to nursing homes in New York, where state legislation mandates a very high standard of evidence clearly indicating a patient's previously expressed wish to withhold or withdrawal artificial nutrition. As such, the proportion of nursing home residents with advanced dementia who are tube fed in New York is among the highest in the country.²⁰ Such legislation may affect the generalizability of the overall prevalence of tube feeding but not necessarily the comparison between residents with dementia vs cancer. Third, we did not have information regarding advance care planning discussions and the process of shared decision making between health care providers and family members. It is possible that the quality of counseling differed in the setting of end-stage cancer vs advanced dementia. A recent ethnographic study³¹ in Dutch nursing homes highlighted the importance of discussing the terminal nature of advanced dementia with families in the context of decisions relating to the administration of artificial hydration and nutrition. Finally, there may be some inaccuracies in the resident assessments. However, the data are collected uniformly, the variables are explicitly defined in a coding manual, and nurses are specifically trained in its use. Moreover, any misclassification is likely to be nondifferential between residents with cancer and residents with dementia.

We believe that palliation is a primary goal of care for most older persons dying with advanced dementia. The results of this study suggest that the end-of-life care provided to these residents in the nursing home setting is suboptimal; advance care planning is not adequately addressed, uncomfortable interventions are common, and distressing symptoms may not be adequately recognized or managed. Thus, future research should focus on educational strategies designed to promote the adoption of a palliative approach in advanced dementia and to improve end-of-life care in the nursing home.

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Corresponding author and reprints: Susan L. Mitchell, MD, MPH, FRCPC, Research and Training Institute, Hebrew Rehabilitation Center for Aged, 1200 Centre St, Boston, MA 02131 (e-mail: smitchell@mail.hrca.harvard.edu).

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