

Nursing Home Participation in End-of-Life Programs: United States, 2004

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The purpose of this report is to define the extent to which US nursing homes (NH) participate in end-of-life programs, using a nationally representative, cross-sectional sample of US NH. Data on EoL programs including Five Wishes, Last Acts, and Physician Orders for Life-Sustaining Treatment (POLST) were collected. In 2004, 17.2% of NH reported participating in 1 or more of these programs, with the largest proportion participating in POLST (13.3%) and smaller proportions in Five Wishes (5.6%) and Last Acts (4.2%). Nursing homes were more likely to participate in EoL programs if they also offered specialty programs and staff training

for hospice, end-of-life, pain management, and dementia services. In 2004, fewer than 1 in 5 US NH participated in an EoL program. However, facilities that had EoL programs were more likely to have programs and staff training for services related to EoL care, a finding that suggests a clustering of these programs, services, and training. Provision of appropriate staff training may be a key to expanding EoL program participation in skilled nursing.

Keywords: end-of-life care; nursing home; advance directive; survey; epidemiology

Introduction

Nursing homes (NH) are increasingly becoming the location of death for older adults. One quarter of all deaths in the United States occur in the NH setting¹ and this number will likely increase as the demand for long-term care grows.² Nursing home residents

are often chronically or seriously ill with life-limiting conditions and many have impaired decisional capacity.³ Advance care planning ensures that resident-centered care is provided to residents up to and including at the end of life.⁴

Advance directives are an essential component of advance care planning. These documents enable individuals to outline their preferences for treatment in the event of incapacitation, thus preserving decisional autonomy. The concept of advance directives arose out of concerns that newly developed medical technologies would be used to prolong life indiscriminately.⁵ Traditional advance directives allow control over treatment decisions through documentation of treatment preferences and values as well as the identification of someone to make decisions on one's behalf. There are 2 types of advance directives: surrogate appointment forms and living wills. Surrogate appointment forms allow an individual to identify a designated decision maker for health care decisions in the event that he or she becomes incapacitated. Alternate names for a surrogate include health care proxy, durable power of attorney over health care, or medical power of attorney. Living

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wills permit an individual to describe his or her treatment preferences in the event of incapacity and record those preferences in writing. Often, living wills focus on the use or withholding of life-sustaining treatments such as ventilator support or artificial nutrition in a narrow set of circumstances, such as when a person is “close to death” or in a “persistent vegetative state.”

Most traditional advance directive documents were developed by state legislative processes which specify the content and rules about use.⁶ Organizations such as the now defunct Last Acts and its successor, Caring Connections,⁷ provide easy access to these traditional advance directives in combination with educational outreach to consumers and health care providers. However, some believe that traditional advance directives are of limited use as they typically contain legalistic language that is confusing to both consumers and residents. The instructions may be too narrow in focus to be of practical use and it can be difficult to determine when an advance directive should be activated.⁸

Five Wishes is an advance directive program developed by the nonprofit organization Aging with Dignity in response to the limitations of statutory advance directives. Five Wishes addresses preferences in 5 areas: identifying a surrogate; preferences for wanted and unwanted medical treatments; wishes for comfort care interventions; how one wishes to be treated; and what one wishes to share with loved ones. The program was developed in 1998 and is now legal in 40 states and the District of Columbia.⁹ It is also possible for Five Wishes to be used as a supplemental advance directive even in states where it does not meet legal requirements for advance directives. However, a search of the literature yields no information regarding use of Five Wishes in the NH setting.

Traditional advance directives are not always effective at ensuring treatment wishes are honored due to a variety of factors, including a lack of availability in crisis and challenges in interpretation.¹⁰ The Physician Orders for Life-Sustaining Treatment (POLST) Program was developed in Oregon in the 1990s to overcome the challenges of traditional advance directives by documenting treatment preferences in the form of medical orders. Unlike traditional advance directives, POLST is immediately actionable and can be followed by emergency medical personnel and nursing staff. The POLST Program is effective at limiting unwanted

treatments in the nursing facility setting¹¹ and is viewed as useful to guide treatment decisions by emergency medical personnel.¹² A study in 2002 found it is used by 71% of Oregon NH¹³ but there are no published data regarding use of the POLST in NH nationally. Available information suggests programs based on the POLST paradigm are in use in California, Idaho, New York, North Carolina, Pennsylvania, Washington, West Virginia, and Wisconsin, with many more states developing programs.¹⁴ However, it is possible that POLST use is more widespread given variations in state laws and regulations that may permit use without legislative action.⁶

An analysis of the Minimum Data Set data showed that in 1993, 13.3% of residents had an advance directive and 52% were listed as do-not-resuscitate (DNR).¹⁵ An analysis of NH residents receiving hospice care suggests 27% had a living will and 81% were listed as DNR.¹⁶ The most recent national data on documentation of advance directives among US NH residents showed that in 2004, 70% of residents aged ≥ 65 years had an advance directive and 60.3% were listed as DNR.¹⁷ Despite improved understanding of the extent to which advance directives are documented among NH residents, there are virtually no data on NH participation in EoL programs. The 2004 National Nursing Home Survey assessed facility participation in 3 EoL programs—Last Acts, Fives Wishes, and POLST—and offers an opportunity to document the extent of participation in these programs as well as facility characteristics that are associated with participation.

We hypothesized that participation in EoL programs would be associated with facility characteristics related to advance care planning and life-sustaining treatments. For example, we hypothesized that NH with Alzheimer and hospice units would be more likely to participate in EoL programs than facilities that do not have these units. Similarly, we hypothesized that NH that have special programs and trained staff for hospice, pain management, and dementia would be more likely to participate in EoL programs than facilities that do not offer these programs and training. Accordingly, the purpose of this report is to document the extent to which US NH participate in selected EoL programs and to understand the association between participation in these programs and facility characteristics related to EoL services, programs, and training.

Methods

Study Design and Data Collection

In the 2004 National Nursing Home Survey (NNHS), 1500 facilities were selected from a sampling frame of US NH. The sampling frame was drawn from 2 sources: (1) the Centers for Medicare and Medicaid Services Provider of Services file of US NH and (2) State licensing lists. Of the 1500 sampled facilities, 283 refused to participate and 43 were considered out of scope for 1 or more of the following reasons: the NH had gone out of business, it failed to meet the definition used in the survey, or it was a duplicate of another facility in the sample. A total of 1174 NH participated, resulting in a response rate of 81%.¹⁸

End-of-Life Programs

The NNHS was administered using a computer-assisted personal interviewing (CAPI) system. The Facility Component of the survey contains data collected during an in-person interview with the NH administrator. During this part of the survey, the administrator was asked whether the facility participated in any of 3 end-of-life programs that were presented to him/her on a card. The question was worded as, "Does [FACILITY] participate in any of the following end-of-life programs on this card?" The choices were Five Wishes, POLST, Last Acts, and No end-of-life initiatives. Instructions were to select all programs that applied to the sampled facility. The CAPI system included help screens for respondents who had questions on these response options. The explanatory material found on the help screens is provided as an appendix to this report. All questionnaires and survey materials can be found online.¹⁹

Facility Characteristics

The 2004 NNHS contained information on ownership status (for-profit vs all others, including nonprofit, local and state government and Veterans Affairs). The terms for-profit (FP) and not-for-profit (NFP) are used to describe this variable. Variables describing whether the facility was a member of a chain (yes/no) and the number of beds (3-49, 50-99, and 100+) were also recorded.

Specialized Units, Contracts, Services, and Programs

Data were collected on whether facilities had units for residents with specific needs including Alzheimer's disease, behavioral issues (non-Alzheimer), hospice, and rehabilitation. Items describing whether facilities had outside contracts for provision of hospice, psychiatry/psychology, and behavioral management services were also collected as were variables describing whether the facility offered services that are often life-sustaining including hemodialysis, peritoneal dialysis, ventilator/pulmonary therapy, and parenteral nutrition. Finally, data were collected on whether facilities had specialty programs and trained staff for services including hospice, palliative care/end-of-life, pain management, and dementia including Alzheimer's disease. The latter variables were studied individually in relation to participation in EoL programs and a composite variable representing provision of any specialty program was also examined.

Statistical Analysis

Analyses were conducted with the PROC SURVEY procedures in SAS, which take into account the strata, cluster, and weight variables that define the complex sampling approach used in the NNHS. In addition, the finite population correction was used per NCHS recommendations. Weighted proportions and cross-sectional associations of interest were therefore generated in a manner that renders results generalizable to all US NH in 2004. Point estimates and their 95% confidence intervals (95% CI) are provided.

Reliability of estimates for the NNHS is based on the relative standard error (RSE) of the estimate and the number of observations on which the estimate is based. Estimates are not presented unless a reasonable assumption regarding the probability distribution of the sampling error is possible. The following guidelines, which are recommended by NCHS, are used in presenting estimates in this report: Estimates based on cell sizes less than 30 are not reported. If the cell size is 30 to 59 or if the cell is 60 or more and the RSE is >30%, the estimate is reported, but should not be assumed reliable. This is indicated by an asterisk (*). If the cell size is ≥ 60 and the RSE is $\leq 30\%$, the estimate is reported and is considered reliable.²⁰

Table 1. Selected Characteristics of Nursing Homes, United States, 2004

Characteristic	Estimate (%)	95% CI
Ownership		
For profit	61.5	58.8-64.2
Non profit	38.5	35.8-41.2
Bedsizes		
3-49	13.9	13.1-14.8
50-99	37.3	35.9-38.7
≥100	48.7	47.4-50.0
Member of a chain		
Yes	54.2	51.3-57.0
No	45.8	43.0-48.7
End-of-life programs		
Any program	17.2	15.1-19.4
POLST	13.3	11.3-15.2
Five Wishes	5.6	4.2-6.9
Last Acts	4.2 ^a	3.1-5.4
Specialty units		
Alzheimer's disease	26.9	24.6-29.3
Behavior (non-Alzheimer)	3.3 ^a	2.3-4.3
Hospice	5.6	4.3-6.9
Rehabilitation	9.6	7.9-11.3
Formal contract for outside services		
Hospice	78.1	75.8-80.3
Psychiatric facility/behavior management	26.9	24.3-29.5
Psychiatry/psychology	48.5	45.7-51.3
Provision of life-sustaining treatments		
Hemodialysis	3.6 ^a	2.5-4.7
Peritoneal dialysis	10.0	8.3-11.7
Ventilator/pulmonary therapy	9.3	7.7-11.0
Parenteral nutrition	46.6	43.7-49.5
Special program with specially trained staff		
Hospice	18.8	16.6-21.1
Palliative care/end-of-life	16.7	14.6-18.9
Pain management	25.6	23.1-28.1
Dementia, including Alzheimer's disease	31.5	29.0-34.1

Abbreviations: CI, confidence interval; POLST, Physician Orders for Life-Sustaining Treatment.

^a Estimate may not be reliable.

Results

In 2004, 17.2% (95%CI: 15.1%-19.4%) of US NH reported participating in 1 or more of the 3 EoL programs that were ascertained in the NNHS. This proportion was driven largely by participation in POLST, with 13.3% (95%CI: 11.3%-15.2%) of facilities reporting participation, and to a smaller extent by participation in Five Wishes (5.6%, 95% CI: 4.2%-6.9%) and in Last Acts (4.2%, 95% CI: 3.1%-5.4%).

About two thirds of US NH are for-profit, slightly less than half have ≥100 beds, and 54% were members of a chain (Table 1). Although more than one quarter had specialty units for Alzheimer's disease (26.9%), units for other resident groups such as those receiving hospice services (5.5%) were much less common. Engagement in formal contracts for outside services was common, particularly for hospice services (78.1%) and psychiatry and psychology services (48.5%). Provision of potentially life-sustaining services was infrequent, with only 3.6% of facilities providing hemodialysis, 9.3% providing ventilatory/pulmonary therapy. However, a much larger proportion of NH provided parenteral nutrition (46.6%).

Provision of specialty programs and special staff training for programs potentially associated with advance care planning varied. Nearly 17% of facilities had specialty programs and staff training for palliative care/end-of-life, while 18.8%, 25.6%, and 31.5% had specialty programs and training for hospice, pain management, and dementia, respectively. Facilities that were not part of a chain were more likely to have EoL programs than those that were part of a chain (19.5% vs 15.1%, $P = .05$) and facilities with <50 beds were more likely to have these programs than those with 50-99 and ≥100 beds (26.5%, 15.8%, and 15.7%, respectively, $P < .01$, data not shown). Facility ownership was not associated with participation in EoL programs.

Figure 1 shows participation in EoL programs according to provision of key services. Cell sizes in some analyses precluded reporting of estimates. Among comparisons for which reliable estimates could be obtained, the data showed consistent associations between participation in EoL programs and whether facilities also had special programs and staff training in a number of service areas including hospice ($P < .01$), palliative care/end-of-life ($P < .001$), pain management ($P < .001$), and dementia ($P < .001$). Among facilities that offered none of these specialty programs, 12.6% participated in an EoL program; among facilities that offered at least 1 of these programs, 22.2% participated in an EoL program.

Discussion

In 2004, 17.2% of US NH participated in at least 1 of several end-of-life programs. The POLST Program

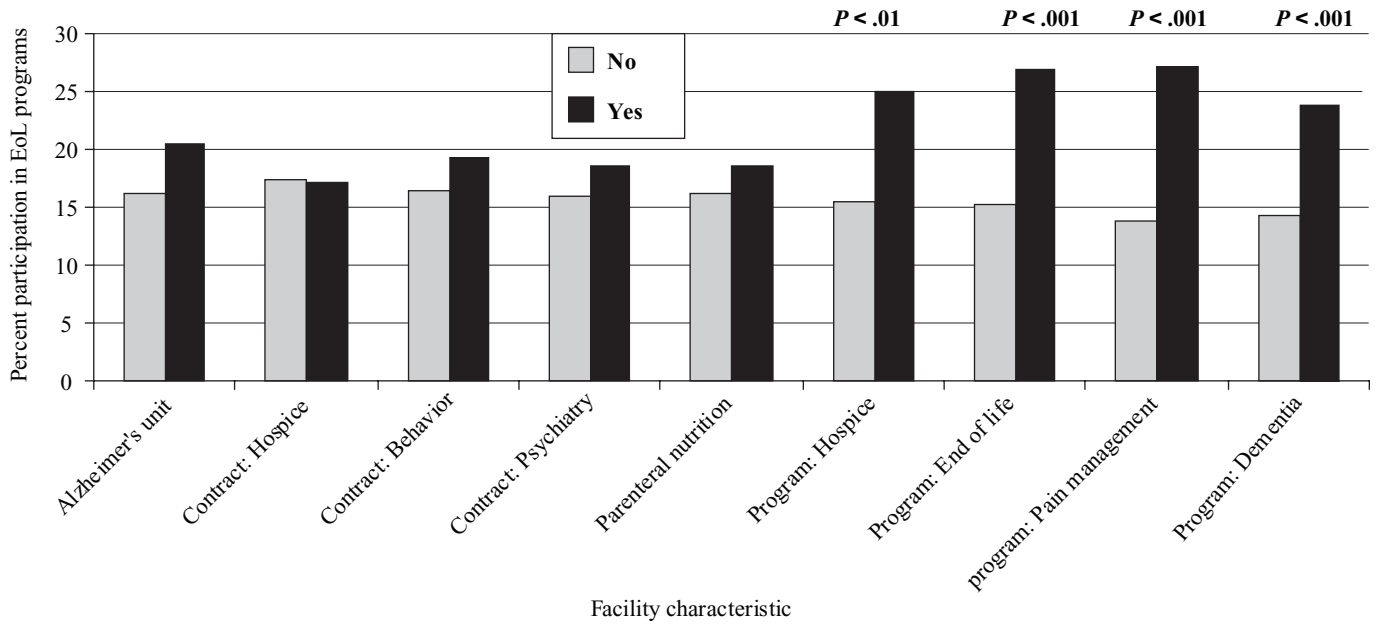


Figure 1. Participation in end-of-life programs by selected facility characteristics, United States, 2004.

was the most common EoL program in which US nursing facilities participated. Estimates of use of the POLST Program, Five Wishes, and Last Acts are the first reliable national data describing NH participation in EoL programs. These data represent a valuable benchmark for tracking changes in program participation over time. To the extent that increased participation in EoL programs in NH enhances resident-centered care, benchmarking of these programs is a useful first step in nationwide monitoring of a key aspect of nursing facilities' attention to defining and acting on EoL choices among their residents. However, it should be emphasized that the 3 EoL programs that were ascertained in the 2004 NNHS were heterogeneous in terms of their origin, use, and impact. Of the 3 EoL programs assessed in the NNHS, POLST is the only one that reflects a binding medical order. Five Wishes and Last Acts represent traditional advance directive programs and likely suffer from the same limitations identified elsewhere.¹⁰ A key limitation is that traditional advance directives do not carry the weight of a medical order. Nursing homes' participation in POLST may therefore represent the most accurate indicator of NH residents' access to actionable EoL planning.

Our data also showed that facilities offering special services and specialized staff training for hospice, end-of-life, pain management, and dementia

were more likely to participate in an EoL program, with facilities offering 1 or more of these specialty services being about twice as likely to participate in an EoL program. It is perhaps not surprising that facilities that offer these specialized services are also more likely to participate in EoL programs because these specialty services are utilized by residents who would also consider participation in an EoL program. A recent report for the NNHS showed a relationship between programs for pain management and behavioral problems and staff with special training in providing hospice or palliative/end-of-life care,²¹ suggesting a link between training and programming. Although the specialty services we examined were more common than EoL program participation, our findings nonetheless suggest that the combination of EoL programs and provision of these services may cluster in a subset of US NH. Consumer demand, community norms, and other factors may be associated with facilities' likelihood of adopting these services and programs and represent an important line of future investigation. Importantly, specialized training has been found to enhance staff's ability to recognize terminal decline and increase timely referrals to hospice.²² It is possible that access to and interest in specialized training in programs could be a means to increase facility level participation in EoL programs and thereby enhance resident-

centered care regarding end-of-life choices. However, the cross-sectional design of the NNHS precludes examination of the temporal association between provision of specialty services and adoption of EoL programs. Nonetheless, a valuable avenue for future research will involve studies designed to improve understanding of factors that increase facilities' adoption of EoL programs and services as these are critical to maximizing autonomy and quality of life at the end of life.

This report has several limitations that should be considered. As noted above, the NNHS is cross-sectional, a design feature that prevents examination of longitudinal associations between facility characteristics and participation in EoL programs or other cause-and-effect questions. However, the NNHS provides the first nationally representative data on participation in specific EoL programs in NH, making this data source extremely valuable for benchmarking future changes in EoL program participation in this care setting. This is particularly important given that NH are a common care setting for death and one in which residents often reside for long periods of time prior to death. These features render NH an appealing target for enhancing resident-centered care involving end-of-life choices for both the resident and his or her family. A recent study on end-of-life discussions among advanced cancer patients and their informal caregivers showed that persons who engaged in end-of-life discussions had lower rates of ventilation, ICU admission and resuscitation, and earlier hospice enrollment. These discussions also had positive effects on quality of life for both patients and their caregivers.²³ To the extent that these findings apply to NH residents and their families, it is likely that expansion of EoL programs in NH could have far-reaching impact on multiple aspects of the end-of-life experience for a growing number of older adults and their families.

Another limitation of this study involves the relatively small overall proportion of facilities participating in EoL programs. Only about 17% of all US NH reported participating in an EoL program, and only 13% participated in POLST. Thus, a number of associations of interest could not be examined due to sparse cell sizes that violated analytic guidelines.²⁰ Nonetheless, a number of the analyses (eg, the examination of EoL programs in relation to availability of hospice units) were highly suggestive but not statistically significant. Accordingly, it is important to differentiate between negative findings that were

based on valid comparisons that showed no association and those comparisons for which no findings were reported due to small sample sizes, with the latter analyses requiring further investigation.

A final limitation of this report is that there is no general question capturing use of EoL programs other than those listed in the survey. Additional options for EoL programs include facility-specific programs and state-specific programs. Although Last Acts may be used to represent a state form, the phrasing in the NNHS may not have been obvious to all respondents. The limited number of response options for EoL programs in the survey may therefore underestimate the true level of facility-level participation in EoL programs. In future cycles of the NNHS, it may therefore be prudent to expand the EoL items to include state-specific forms and facility-specific forms.

Despite these limitations, these data provide an important springboard for future work aimed at increasing participation in EoL programs nationally. Our data suggest that the latter goal might occur in part through mechanisms aimed at facilitating adoption of specialty programs and staff training that are related to advance care planning and end-of-life care.

Reader's Appendix

"Help Screen" used in the 2004 National Nursing Home Survey to provide clarification on response items related to participation in end-of-life programs.

Palliative care or End-of-life programs refer to nonhospice services that provide care for end-stage or terminal conditions.

Five Wishes is a document that helps one to express how they want to be treated (medically, emotionally, and spiritually) if they become seriously ill and cannot speak for themselves.

POLST (Physician Orders for Life-Sustaining Treatment)—orders signed by the patient's physician that have resulted from discussions at or near the time of admission to the facility to help patients near the end of their lives reflect on the goals of their treatment. These orders are brief, simple, portable, authoritative, and highly visible. The form is usually in hot pink.

Last Acts—a national coalition to improve care and caring near the end of life. Protocols operational in most states protected people from unwanted, aggressive, life-sustaining treatment by emergency medical service personnel.

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