

# Hospice and Nonhospice Nursing Home Residents

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## ABSTRACT

**Objective:** To compare hospice residents in nursing homes with residents who are noted as end-stage, but not in hospice programs.

**Design:** Descriptive comparison of the outcomes reported on Minimum Data Set (MDS) for all residents admitted to Missouri nursing homes in 1999.

**Setting:** Nursing homes.

**Participants:** Residents of nursing homes designated as either hospice or end-stage on admission MDS.

**Measurements:** Percentage of hospice residents having various conditions as compared with other end-stage residents.

**Results/Conclusions:** Overall the clinical conditions of both hospice and nonhospice end-stage residents were similar. A greater percentage of hospice residents were found to have living wills, DNR orders, and cancer, and to be in moderate or severe pain. Hospice and nonhospice residents experienced similar time from admission to death or discharge (20 and 36 days, respectively). Based on the clinical condition of the two groups, it would appear that there are limited clinical reasons for the low utilization of the hospice benefit in nursing homes. The increased prevalence of advance care planning may lead toward use of hospice or may result from hospice enrollment. Hospice services seem to be thought of more frequently for residents with cancer and residents experiencing pain. Nursing homes must recognize their role as caregivers to the dying before palliative care is seen as a need for nursing home residents. Nursing homes need education in determining when a patient is appropriate for palliative care as only 4% are designated as end of life, and only 2% are shown to be receiving hospice care in hospice-contracted facilities.

## INTRODUCTION

A RICH BODY OF KNOWLEDGE exists about dying in nursing home settings. Studies have consistently found that pain is not well managed, that symptoms are not treated appropriately, and that emotional and spiritual problems are ignored.<sup>1,2</sup> Bereavement care is not part of standard nursing home care, and the needs of surviving

family members often go unaddressed.<sup>3</sup> Public policy creates a barrier to the provision of adequate palliative medicine because quality standards and reimbursement rules promote restorative care rather than labor-intensive palliative medicine.<sup>4</sup>

Hospice care improves end-of-life (EOL) care in the nursing home. Hospice residents have better pain management, more treatment for depression

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and anxiety, fewer hospitalizations, less dyspnea, and fewer invasive procedures.<sup>5</sup> In addition, nursing home residents' family members have reported believing that hospice improves the quality of symptom management, adds value and service for residents, and results in less hospitalization. They describe specific services hospice provides to their loved ones, including pain management, supportive visits, special attention through gifts, and the creation of a home-like environment.<sup>6</sup>

Variations in the use of hospice between communities are well documented.<sup>4</sup> Researchers have linked this variance to differences in resident demographic characteristics, local health care resources, community customs and culture, physician practices, and the geographic development of hospice.<sup>7</sup> Fewer researchers have explored differences in clinical conditions of residents known to be at the (EOL) as possible contributing factors. Among residents recognized as dying, are there clinical differences between hospice and nonhospice residents? The research question for the project asked, "How do residents of nursing facilities who are enrolled in hospice compare with those who are designated to have a limited life expectancy and not enrolled in hospice?" The study sought to compare residents with regard to the use of advance care directives, use of technological interventions, diagnoses, and clinical indicators, such as pain, incontinence, skin conditions, activities of daily living (ADLs), depression, and weight loss.

## METHODS

The study used Minimum Data Set (MDS) assessment data for nursing home residents in the state of Missouri. The population comprised all residents admitted to certified nursing facilities in Missouri in 1999 who had admission MDS assessments transmitted to the MDS database at the Missouri Division of Aging. MDS data were obtained from the Missouri Division of Aging under the terms of a data use agreement with the Division of Health Care Financing Administration. The study also used data from 1999 Medicaid cost reports for Missouri nursing facilities obtained from the Missouri Department of Social Services to identify those homes with hospice contracts. Approval for the study was obtained from the Institutional Review Board at the University of Missouri—Columbia.

The MDS is a comprehensive standardized assessment instrument of more than 400 items. A full assessment is required within 14 days of a patient's admission, annually, and after a significant change in status. The goals of the MDS are to standardize assessment, stimulate learning, improve care planning and care provision, and remain amendable to future updates.<sup>8</sup> There is growing evidence in the literature that supports the reliability and validity of the MDS instrument and data.<sup>8-12</sup>

The definition used to designate residents as at the EOL was based on two items in the MDS version 2.0. The first item, J.5.c., is under the section heading Health Conditions and the subcategory Stability of Conditions where "End-stage disease, 6 or fewer months to live" can be selected. The second item, P.1.a.o., is under the section heading Special Treatments and Procedures and the subcategory Programs where "Hospice Care" can be selected. A resident was defined as being at the EOL if either or both of these two items had been selected. Additionally, a resident was classified as a hospice resident if the MDS nurse responsible for the form had box P.1.a.o. checked, which indicated that he or she was a hospice resident. A resident was deemed "end-stage, non-hospice" if he or she had box checked J.5.c on the MDS, but not checked P.1.a.o.

Variables for analysis were selected from the MDS items that are clinically relevant for those residents at the EOL, for example, pain, incontinence, skin condition, ADLs, depression, and weight loss. Various treatment variables, such as oxygen therapy, intravenous therapy, chemotherapy, and radiation therapy, applicable to EOL were also compared. Finally, items regarding advance directives and diagnoses were selected.

As part of the statistical data collected in Medicaid cost reports, nursing facilities record the total number of patient days allocated to hospice care. For purposes of this study, facilities providing hospice care were defined as those reporting one or more patient days of hospice care on their 1999 cost reports.

The MDS data used for this study consisted of all 1999 admissions to non-hospital-based nursing facilities that could be matched to cost reports of those facilities reporting one or more days of hospice care (therefore including all facilities in which hospice was available). A total of 159 facilities were matched and, therefore, used in the analysis. When a resident had more than one 1999

admission assessment, only data from the first admission was used in the analysis. Summary statistics consisted of means and standard deviations for interval and ordinal level variables and the percentage of residents positive on conditions recorded as present/absent. To appreciate better the magnitude of the differences between hospice and nonhospice residents, we also present 95% confidence intervals for the differences of percentages (see Table 2). A cross-sectional comparison of hospice and non-hospice residents was also performed using the same set of variables.

Kaplan–Meier methods were used to explore differences in survivorship for hospice and nonhospice residents in hospice-accepting homes. The MDS discharge record includes the date of death for residents who die in the nursing home, but does not provide a date of death for residents who die during an acute-care hospitalization. Thus, survival times are censored for residents who were alive at the point of final discharge or for whom the MDS record terminates without a discharge. Because of the weakness of the MDS data for tracking mortality, the survival analysis presented here is properly regarded as a study of “in-facility” survival times.

Survival functions for the two groups’ residents (hospice and nonhospice) were plotted and compared using the Generalized Wilcoxon Test and the log-rank test. Two tests were used because each is sensitive to different characteristics of the survival curves. The Wilcoxon test gives more weight to early deaths, whereas the log-rank test gives equal weight to all cases.<sup>13</sup>

The ADL measure was formed by summing nine of the self-performance ADL items in G.1. of the MDS, thus giving an ADL scale with a total score range of between 0 and 36, with larger scores indicating greater impairment. Because it was analyzed separately, item G1 (eating) was excluded from this sum. Residents’ cognitive status was assessed using the Cognitive Performance

Scale (CPS) derived from the MDS by Morris et al.<sup>10</sup> The CPS is a seven-point ordinal scale with a range from 0 to 6 with a score of 0 indicating normal functioning and 6 severe cognitive impairment. The depression scale, also a scale derived from MDS items, is based on the 17-item Hamilton Depression Rating Scale and the Cornell Scale for Depression in Dementia, creating a screening tool for the condition.<sup>14</sup> Using this methodology, a score of 3 or more may be suggestive of depression. This MDS-based scale was found to compare favorably with the Geriatric Depression Scale when tested against actual psychiatric diagnoses.<sup>14</sup>

## RESULTS

We first analyzed the data for all residents in the 159 nursing facilities providing hospice care. Results were similar for the sample of newly admitted residents and the cross-sectional sample. Therefore, we reported on only admission MDS for residents in 1999 ( $n = 9,615$ ). The resulting sample included 171 residents designated as hospice residents on the admission MDS (2%). An additional 192 residents were designated as end-stage with 6 or fewer months left to live, but were not enrolled in hospice programs (2%).

Table 1 shows that hospice residents and those end-stage but not in hospice were similar in age, cognitive performance, ADL abilities, physician visits, and frequency of physician orders. The average age of hospice residents was 76 years. Hospice residents averaged 2.4 on the cognitive performance scale (6 as maximum), 25.8 on the ADL scale (0–36), and 1.5 on the depression scale. For both groups, physicians had visited residents an average of 0.8 times in the 14 days prior to admission and changed orders an average of 3.2 days prior to the assessment.

Figure 1 provides a plot of the survivorship

TABLE 1. SIMILARITIES BETWEEN HOSPICE AND NONHOSPICE END-STAGE RESIDENTS

Variable	Hospice (n = 171)	SD	Nonhospice (n = 192)	SD
Age (years)	76.2	12.5	76.0	11.1
Cognitive performance (score)	2.2	1.9	2.4	2.1
ADLs (score)	24.8	11.1	25.8	9.8
Depression (score)	1.9	1.5	1.5	2.4
Number of physician visits	0.8	1.0	0.8	0.7
Number of physician order changes	3.2	2.3	3.1	2.4

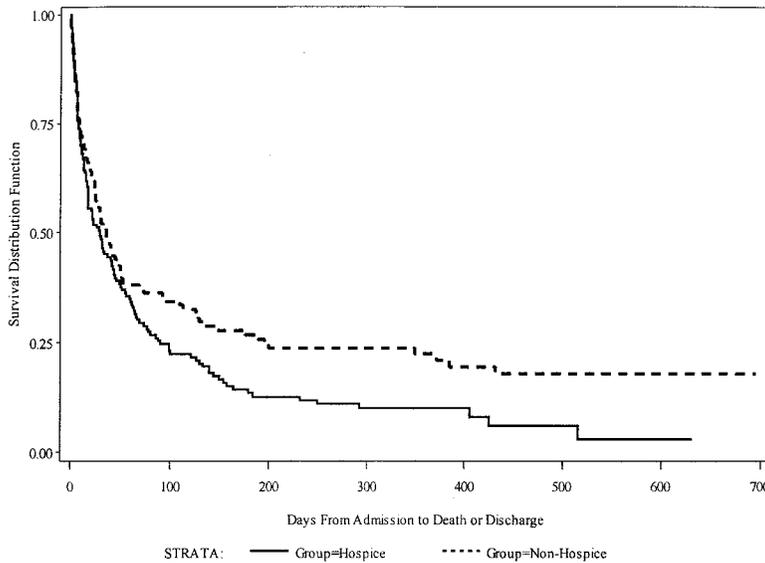


FIG. 1. Time to death or discharge for hospice and nonhospice residents.

functions for hospice and nonhospice residents. The median time to death or discharge for the hospice group is 30 days with a 95% confidence interval (CI) for the median extending from 17 to 43 days. For the nonhospice group, the median survival was 36 days (95% CI: 25,51). Using the conventional 0.05 criteria for statistical significance, the survivorship functions for the two groups are not statistically different by Generalized Wilcoxon test ( $p = 0.20$ ), but do differ ( $p = 0.03$ ) when compared using the log-rank test. This is because the Wilcoxon test gives greater weight than does the log-rank test to differences in survival functions at early time points. From Fig. 1, we see that for about the first 50 days after admission, the two groups have nearly identical survival probabilities, after which the nonhospice group has a slightly higher probability of survival. A small percentage of each group was living at the end of 1 year.

Table 2 shows differences were found between the groups with regard to several variables. There were no significant differences between hospice and nonhospice residents in prevalence of dehydration, weight loss, need for oxygen therapy, incontinence, or skin ulcers. Thirty percent of hospice residents in nursing facilities had living wills or advance directives compared with 19% of nonhospice residents. Hospice patients were more likely to have a do-not-resuscitate (DNR) order as demonstrated by a difference of 21% (95% CI: 12.4, 29.6). Cancer was by far the most prevalent

diagnosis in hospice residents; 67% of hospice residents had cancer. Hospice residents were less likely to be receiving such treatments as chemotherapy, dialysis, radiation, and IV therapy. Moderate pain within the past 7 days was reported in 70% of hospice residents, and severe pain within the same time frame was considered a problem for 25.5% of residents. In comparison with nonhospice residents, 11% more hospice patients reported moderate pain, and 4% more reported severe pain.

## DISCUSSION

Nursing homes are increasingly becoming places where people die. Thirty percent of nursing home residents will die within 1 year of their admission.<sup>15</sup> Twenty-eight percent of all deaths in Missouri occur in nursing homes.<sup>16</sup> Despite the regular occurrence of death in these facilities, this study found that only 4% of nursing home admissions, in homes providing hospice, are labeled "end-stage" with a life expectancy of less than 6 months. Only half of those admitted are enrolled in hospices. Hospice and nonhospice residents experienced similar time from death or discharge (30 and 36 days, respectively).

It is not surprising that hospice residents in nursing homes would be more likely to have cancer, as it is the predominant diagnosis in the hospice general population. The National Hospice

TABLE 2. SUMMARY OF PREVALENCE OF VARIABLES FOR HOSPICE AND NONHOSPICE RESIDENTS

<i>Variable</i>	<i>% of hospice residents reporting condition (n = 192)</i>	<i>% of nonhospice residents reporting condition (n = 171)</i>	<i>Differences of % (95% CI for difference)</i>
<b>Advance care planning</b>			
DNR	86.5	65.5	21.0 (12.4, 29.6)
Living will	29.7	19.3	10.4 (1.6, 19.2)
<b>Clinical conditions</b>			
Moderate pain	69.8	58.5	11.3 (1.5, 21.1)
Severe pain	25.5	19.3	6.2 (-2.3, 14.7)
Weight loss	20.8	26.9	-6.1 (-14.9, 2.7)
Incontinence	34.1	37.6	-3.5 (-13.4, 6.4)
Skin ulcers	25.0	26.9	-1.9 (-10.9, 7)
Dehydration	5.2	6.4	-1.2 (-6, 3.6)
<b>High-tech treatment</b>			
Dialysis	0.5	11.1	-10.6 (-15.4, -5.8)
Oxygen therapy	38.0	46.2	-8.2 (-18.3, 1.9)
IV therapy	1.6	8.8	-7.2 (-11.8, -2.6)
Feeding tube	4.2	11.1	-6.9 (-12.4, -1.4)
Chemotherapy	1.0	5.3	-4.3 (-7.9, -0.7)
Radiation	0.5	2.9	-2.4 (-5.1, 0.3)
<b>Diagnosis</b>			
Cancer	67.2	48.5	18.7 (8.7, 28.7)
CHF	13.5	27.5	-14.0 (-22.3, -5.7)
Alzheimer's	2.1	1.2	-0.9 (-15.2, -4.6)
Renal failure	6.8	16.4	-9.6 (-16.2, -3.0)
COPD	21.9	25.7	-3.8 (-12.6, 5)
Parkinson's	1.6	2.3	-0.7 (-3.6, 2.2)
CVA	13.0	12.9	0.1 (-6.8, 3.6)

and Palliative Care Organization reports that one half of Americans dying of cancer each year receive hospice services.<sup>17</sup> The hospice industry is struggling with educating physicians and other health care providers that cancer is not the only terminal diagnosis requiring palliative care. However, the Medicare hospice benefit lends itself to the slowly declining cancer resident rather than the resident with chronic heart failure or lung disease. It is also not surprising that hospice residents receive fewer high-tech interventions (such as chemotherapy or radiation therapy); the hospice philosophy advocates low-tech approaches to palliation.

The tendency of hospice residents to do advance care planning is not surprising. There are several possible explanations for this finding. Those with living wills and DNR orders may be more likely to use hospices, perhaps as a result of good advance care planning. It is also possible that the physicians who work with residents on advance care planning are the same ones who focus on palliative care and support hospice. An-

other possibility is that hospices may facilitate this planning as one of their services. It is not unusual for hospice programs to discuss resuscitation and hospitalization with residents and families upon admission. This finding raises the additional question of whether hospice is more easily accepted when there has been advance care planning. Regardless, admission to hospice, at least, represents an acknowledgment by the physician, family member, nursing home resident, and nursing home staff that the EOL is near.

The finding that pain was more prevalent in hospice residents generates similar questions. A recently published study found that hospice residents were more likely than other end-stage residents to experience moderate or severe pain. It also showed that hospice residents with daily pain were 93% more likely to receive pain management and were twice as likely to receive strong pain relievers compared with other residents.<sup>5</sup> The increased reports of pain among hospice residents may have several possible sources. First, there maybe increased assessment and doc-

umentation of pain due to an increased focus by either hospice or nursing home staff. Second, residents with advanced cancer, and therefore referred to hospice, may be more likely to have pain. Finally, as nursing home staff identify hospice staff as more knowledgeable in pain management,<sup>18</sup> they may be more likely to refer residents to hospice if they are experiencing pain. Further exploration of these possible explanations is needed.

This study is limited in its design and exploratory nature, and it is unable to infer causes for the findings. The reliability of the MDS as an assessment instrument for EOL is not yet known. Data are limited by the admission information reported on the MDS form. In our study, hospice residents were more likely to experience pain, but, unlike researchers in the Brown University study,<sup>5</sup> we could not analyze treatment. Additionally, the identification of hospice and end-stage residents is dependent on the MDS nurse in each facility labeling residents as such. The directions for completing the two fields delineating the sample on the MDS are not clear, as evidenced by some residents having been designated as hospice, but not as having a life expectancy of less than 6 months, when, by definition, a hospice resident has such an expectancy. It is also not known if residents identified as receiving hospice actually were enrolled in a licensed hospice program, nor were we able to identify the identity of the hospice provider. Our survival analysis indicates a high mortality rate following admission for both hospice and nonhospice residents, with nonhospice residents have slightly longer survival following admission. Future studies may link MDS and death certificate data to estimate better the survival time and to study further the place of death following admission to a nursing home. Finally, these two groups do not fully define the cohort of dying nursing home residents. The last point is less relevant if we believe that appropriate care for dying residents is only likely to occur if they are recognized as dying.

These findings confirm that end-stage disease in the nursing home is infrequently acknowledged, despite data that suggest that 30% of people entering nursing homes will die within the next year.<sup>15</sup> In spite of these mortality statistics, nursing homes do not view themselves as caring for the dying, and they do not readily label residents as such. Despite clinical evidence that end-stage residents differ from the overall resident

population, these findings confirm that all end-stage residents are clinically similar. Only a few receive palliative hospice care, and only a handful more are labeled as needing it. Unless residents are seen as dying, and given dying roles, their access to palliative care will be restricted.<sup>18</sup>

Attending physicians, nurses, and medical directors should strive to identify residents at high risk of dying on admission to nursing homes. This process could be the first step toward more meaningful advance care planning and ensuring that systems are in place to provide that care. As a part of developing a care plan, collaboration with hospice may be an appropriate component of the care of nursing home residents with shortened life expectancies. Such collaboration may also promote a continuing care plan consistent with the goals of nursing home residents and family members, one that focuses on symptom management, quality, not quantity, of life, comfort care, and bereavement. Because EOL care in nursing facilities has been found to be better for hospice patients,<sup>5</sup> an increase in collaboration and referral to hospice could improve the quality of life for those patients who are end-stage, but not in hospice.

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