

# A Profile of Residents Admitted to Long-Term Care Facilities for End-of-Life Care

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**Introduction:** Permanent placement in a Long-Term-Care (LTC) facility following hospitalization or when staying at home is no longer a viable option is the reality for a growing number of Americans. When death is imminent, the specialized knowledge and skill of the hospice team is required and accepted as an important component of end-of-life (EOL) care. The provision of appropriate care at the EOL is contingent on accurate identification of those residents who are approaching the final stage of life. This study describes the prevalence, profile, and survivorship of residents admitted to LTC facilities, using the Minimum Data Set (MDS) designation of being at the EOL.

**Methods:** A descriptive, correlational, retrospective cohort design was used to analyze all residents admitted to certified LTC facilities with hospice contracts in Missouri in 1999. 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, activities of daily living (ADLs), depression, and weight loss. In addition, items regarding advance directives, use of special treatments, and

diagnoses were selected because they are important to the care of residents at the EOL.

**Results:** Of 492 eligible facilities, 159 were confirmed as providing hospice care. Of 9615 admissions to these facilities, 432 (4.5%) met the EOL care definition; half of these were receiving specialist hospice care. The EOL residents were distinguishable in terms of symptoms. Median survival time for EOL admissions was 33 days. At 6 months, only 17% of EOL admissions remained in the facility.

**Conclusions:** Residents designated as EOL who are admitted to LTC are a distinct group from other new residents, with identifiable needs requiring specialist attention. Accurate recognition that EOL is imminent is required for the development of appropriate strategies and resources for care. (*J Am Med Dir Assoc* 2003; 4: 16–22)

**Keywords:** Palliative care; hospice; nursing homes; symptoms; survivorship.

The need for a change in the goals of care required for nursing home residents approaching the end of their lives is being widely recognized. This is demonstrated by the growing interest in palliative care and hospice care in the nursing home.<sup>1–5</sup> Rehabilitative care is a prominent goal for most residents admitted to nursing homes and has been encouraged by the level of financial reimbursement for those services. In

fact, the presumed expectation for functional improvement denies the unavoidable decline that must ultimately occur for all long-term residents.<sup>6</sup> In order to provide high quality end-of-life (EOL) care, we must be able to identify accurately those residents approaching the final state of life. As Travis and colleagues noted, the ability to make a prognosis of 6 or fewer months is difficult.<sup>7</sup>

The current study seeks to determine if data from the Minimum Data Set (MDS) can be used to gain greater insight into the population of people near end-of-life who are admitted to long-term care (LTC) facilities. This retrospective cohort study was conducted using the MDS data for Missouri with the following research questions:

1. What is the prevalence in LTC facilities of new admissions designated as EOL?
2. Are there differences in the demographics, characteristics, and symptom occurrence in LTC residents at the EOL and those residents who are not so designated?
3. What is the length of stay at LTC facilities before death for EOL residents?

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## METHOD

The population comprised all residents admitted to certified LTC facilities in Missouri in 1999 who had MDS assessments transmitted to the MDS database at the Missouri Division of Aging (DA). Our research team has a cooperative agreement with the Missouri DA, and staff are committed to using MDS data to improve the quality of care of residents in nursing facilities. 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.

## Variables

The MDS is a comprehensive standardized assessment instrument of more than 400 items. A full assessment is required within 14 days of admission, annually, and after significant change in status. Furthermore, a shorter version of the MDS is used to collect data quarterly. The goals of the MDS are to standardize assessment, stimulate learning, improve care planning and provision, and be amenable to future updates.<sup>8</sup> There is growing evidence in the literature of the reliability and validity of many of the items of the MDS instrument and data.<sup>8–14</sup>

The definition used for this analysis to identify residents designated to be 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 Subcategory of 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 subcategory of “Programs” where “Hospice Care” can be selected. A resident was defined as being in the EOL if either or both of these two items had been selected. The reasoning behind accepting either/or for these categories was that some LTC facilities might admit EOL residents but are not covered by a Medicare hospice contract. Similarly, there may be cases in which a hospice care program has been initiated for a resident without the acknowledgment by the data collector that death may occur in less than 6 months.

An informal survey of MDS nurses was sent to determine the method by which the EOL designation was made. The responses showed that a written or verbal medical order was the main source of information. Alternatively, if a new resident was receiving hospice care, then it was assumed that the resident met the EOL criteria for the MDS.

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, activities of daily living (ADLs), depression, and weight loss. In addition, items regarding advance directives, use of special treatments, and diagnoses were selected because they are important to the care of residents at the EOL.

The ADL measure was determined by summary scores on nine items in G.1. (all items except h., which was analyzed separately), resulting in a total score between 0 and 36, with

higher scores indicating more impairment. Residents’ cognitive status was assessed using the Cognitive Performance Scale (CPS), which is a scale derived from the MDS by Morris and colleagues.<sup>11</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 indicating 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>15</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>15</sup>

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 LTC facilities that could be matched to the cost report reports, thus including in the subsequent analysis, all facilities in which hospice care was available. 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 proportions for binary variables, and means and standard deviations for the ordinal and interval level variables. Associations between nominal variables and admission status (EOL versus non-EOL) was further quantified by the use of odds ratios with 95% confidence intervals.

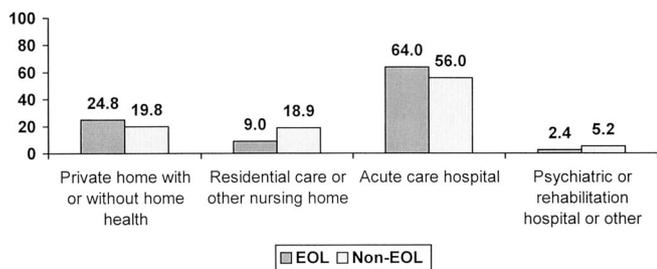
Kaplan-Meier curves were constructed to study the distribution of survival times for the EOL and non-EOL populations. The MDS discharge tracking forms record in-facility deaths but do not necessarily date of death information for residents who die outside the nursing facility, such as while being discharged to an acute care hospital. For this reason, survival times for residents discharged alive were censored at the discharge date.

## Findings

The MDS data was matched to 1999 Medicaid cost report data for 492 of Missouri’s 512 LTC facilities. Of these 492 facilities, 159 were identified as providing hospice care. There were a total of 9615 admissions to hospice-providing facilities with 432 (4.5%) of these admissions meeting the EOL care definition. Just over half of EOL residents (53%) were also reported to have specialist care provided by a hospice service, and 17% were reported as having specialist hospice services but admissions were not designated as EOL.

The majority of new residents to LTC facilities were admitted from acute hospital settings. Figure 1 illustrates the locations from which residents were admitted.

The profile of residents categorized as EOL were compared on a number of demographics and other relevant characteristics that would indicate that these residents were identifiably



**Fig. 1.** Percentage distribution of location before admission to long-term care facility for end-of-life and non-end-of-life residents.

different from a usual admission and that the end of their life was probably to be expected. Table 1 details the demographic and primary diagnosis of admissions. These specific diagnoses were targeted for comparison because palliative care is known to be helpful during the terminal phase of these illnesses.<sup>16</sup>

The documentation of advance directives for all residents of LTC facilities is encouraged; however, it would be expected that those being admitted for EOL care would have expressed their wishes with regard to resuscitation and hospitalization decisions. Preferences and prohibitions on treatments such as antibiotics or futile medical interventions would also be expected in this population. Indeed, all items pertaining to advanced directives are more prevalent in the EOL admissions; however, the percentages are still low given the knowledge that residents are facing EOL issues. Table 2 outlines the data available in the MDS on advance directives.

It was assumed that subjective physical or psychological symptoms would be more prevalent in EOL admissions. This assumption was upheld in the MDS data as presented in Table 3 with pain being very prevalent.

The length of stay at a LTC facility was difficult to determine for residents designated as EOL. The MDS has a dis-

charge tracking form, which reports on discharges from the LTC facility to various places including death. In some cases, EOL residents are discharged to an acute care facility. However, it was possible to estimate the median survival of residents known to have died in the LTC facility to which they were admitted. There were a total of 9124 residents in this analysis (379 EOL and 8745 non-EOL). In the EOL group there were 287 in-facility deaths (75.7%) and 1704 (19.5%) in the non-EOL group. Median survival times were 33 and 725 days for the EOL and non-EOL groups, respectively. The difference is statistically significant with  $P < 0.0001$ . At the 6-month marker, only 17% of EOL admissions were still living in the same LTC facility. These findings are illustrated in Figure 2.

## DISCUSSION

The profile of residents admitted for EOL care shows some distinct differences from non-EOL admissions. The odds ratio statistic confirms that the following disease-related and treatment-related characteristics were more likely to occur in residents designated as EOL care: diagnosis of cancer, emphysema, or renal failure; and having advance directives documented, in particular do not resuscitate and do not hospitalize orders. EOL residents were also more likely to be receiving medical treatment such as parenteral or IV therapy, tube feeding, chemotherapy, radiation therapy, dialysis, or oxygen therapy. The appropriateness of any of these interventions could be debated extensively, but without more specific information on individual cases the discussion could only be hypothetical and at great risk of hyperbole. Palliative chemotherapy and radiation therapy along with dialysis and oxygen therapy can be used successfully to promote comfort at the EOL. The issue of feeding through extraordinary means is more difficult to resolve, particularly as the data does not reveal how close to death the residents were when the MDS reports were filed.

**Table 1.** Percent Distribution of Non-end-of-life (EOL) (N = 8800) and EOL (N = 424) Admissions by Demographics and Disease Variables. Odds Ratio that the Resident has been Designated as EOL.

	EOL admissions %	Non-EOL admissions %	Odds Ratio EOL	95% CI
<b>Demographics</b>				
Male	40	35	1.21	0.99–1.49
Married	29	25	1.25	1.00–1.56
Medicare	22	41	0.42	0.33–0.53
<b>Primary Diagnosis</b>				
CHF	20	24	0.77	0.6–0.99
CVA	14	21	0.61	0.45–0.81
Parkinson's disease	2	6	0.37	0.17–0.72
Emphysema/COPD	24	18	1.42	1.12–1.80
Cancer	56	8	14.61	11.82–18.07
Renal failure	11	5	2.29	1.63–3.15
HIV	0	0	0	0
Alzheimer's/Dementia	2	7	0.23	0.09–0.49

CHF, congestive heart failure; CVA, cerebrovascular accident; COPD, chronic obstructive pulmonary disease; HIV, human immunodeficiency virus.

**Table 2.** Percent Distribution of Non-EOL (N = 8800) and EOL (N = 424) Admissions by Advance Directives. Odds Ratio that the Resident Has Been Designated as EOL.

	EOL admissions %	Non-EOL admissions %	Odds Ratio EOL	95% CI
Advance directives				
Living will	24	18	1.41	1.11–1.78
Do not resuscitate	77	37	5.52	4.37–7.01
Do not hospitalize	6	1	5.50	3.32–8.79
Feeding restrictions	13	9	1.49	1.09–1.99
Medication restrictions	10	6	1.96	1.39–2.72
Other treatment restrictions	17	10	1.87	1.42–2.43
Absence of advance directives	18	51	0.21	0.16–0.27

EOL residents were more likely to have the following conditions reported: incontinence, dehydration, insufficient fluid intake, weight loss, and skin ulceration. This would be consistent with the final weeks and days of life and to be expected. What is of concern is that in LTC facilities that provide EOL care these expected conditions would adversely affect the quality indicators routinely reported from MDS data. Our analysis on these data did not find any impact on quality indicators for these facilities because generally there was only one or two residents with EOL designation at a given time point. However, should the numbers of residents in the EOL group rise, or should a LTC facility specialize in EOL care, then the usual MDS quality indicators would need revision to prevent regulatory interpretation that could disadvantage the facility. This problem was identified and discussed by Zerzan and colleagues who noted that the focus of MDS items is on restorative care, and therefore the natural

and expected decline associated with dying was then a trigger for initiating treatment to restore and maintain function.<sup>17</sup> These goals are not appropriate for the dying patient.

Indeed, Medicare reimbursement incentives encourage nursing homes to focus on restorative care, with its highest reimbursement being for intensive rehabilitation nursing and therapy following hospitalization. Lower reimbursement is assigned to personal care and symptom management; thus, as Zerzan and colleagues illustrate the point, the reimbursement for rehabilitation of a fractured hip is twice that for the care of a resident with metastatic bone disease and a pathological hip fracture.<sup>17</sup>

Knowing the prevalence of new admissions to LTC facilities for EOL care raises the question of the preparedness of nursing staff and the supporting attending physicians in provision of quality palliative care. Some indication of adequate palliative care comes from the level of symptom distress re-

**Table 3.** Percent Distribution of Non-EOL (N = 8800) and EOL (N = 424) Admissions by Physical and Psychological Symptoms or Problems. Odds Ratio that the Resident Has Been Designated as EOL.

	EOL admissions %	Non-EOL admissions %	Odds Ratio EOL	95% CI
Physical symptoms/problems				
Pain - moderate to severe almost every day	66	31	4.37	3.54–5.40
Pain - severe to excruciating every day	21	4	6.98	5.32–9.10
Incontinent - bowels or bladder	37	31	1.30	1.01–1.67
Dehydrated	5	2	2.98	1.82–4.69
Insufficient fluid	12	4	3.15	2.25–4.35
Weight loss	23	10	2.77	2.16–3.52
Parenteral/IV	4	2	2.16	1.24–3.56
Feeding tube	8	6	1.20	0.80–1.74
Skin ulcer (including pressure ulcer)	25	13	2.24	1.76–2.82
Chemotherapy	3	<1	7.79	3.49–16.11
Dialysis	5	1	3.52	2.06–5.75
Oxygen therapy	4	2	3.71	3.01–4.56
Radiation	1	<1	3.49	1.20–8.43
Psychological symptoms/problems				
Depression	2	1	1.56	1.19–2.03
Openly expresses conflict	6	4	1.38	0.85–2.13
Absence of personal contact with family/friends	5	5	0.88	0.52–1.40
Recent loss of close family member/friend	3	2	1.60	0.77–2.97

EOL, end of life.

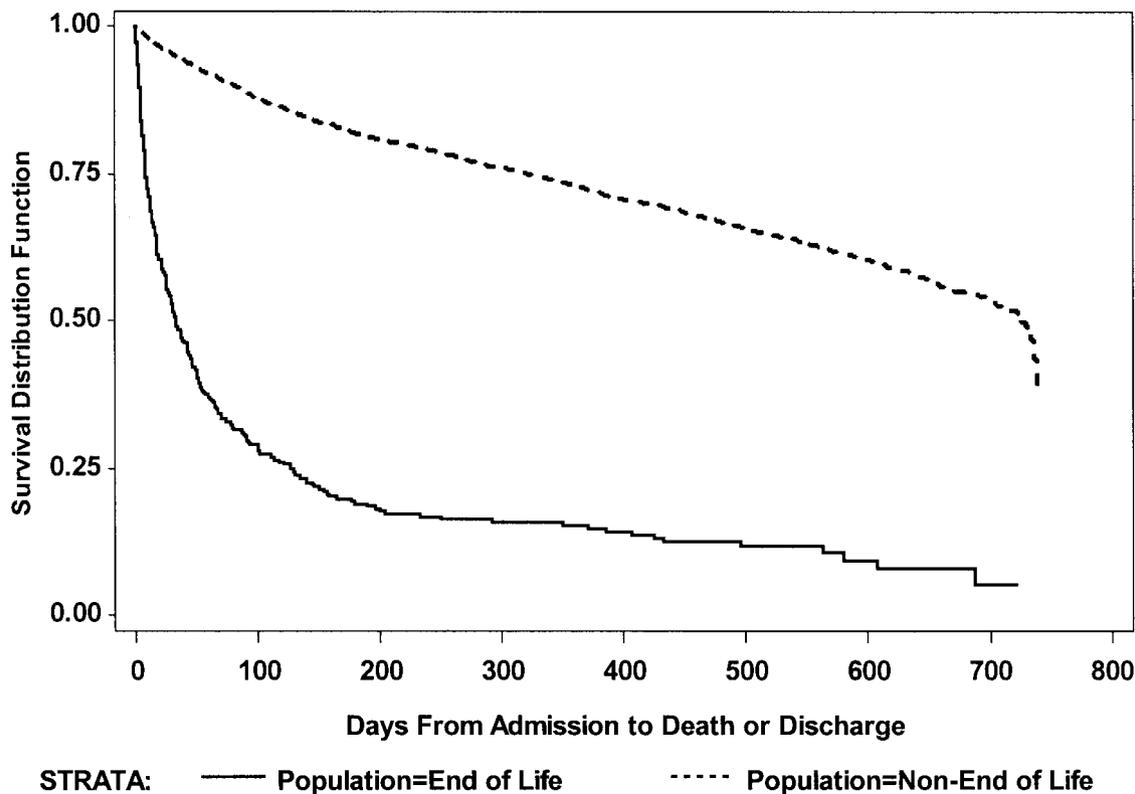


Fig. 2. Kaplan-Meier survival curves for EOL and non-EOL residents.

ported. Most remarkable in the data presented here is the finding that about two-thirds of EOL residents were reported as being in moderate to severe pain nearly every day, a proportion much greater than the non-EOL residents. Furthermore, we found that one in five EOL residents was reported as having excruciating pain every day, again much higher than the non-EOL residents (less than 1 in 20). There is some contention over what the MDS pain items mean, but recent research by Fries and colleagues suggests that the items are valid in detecting pain and compare favorably with a pain Visual Analogue Scale.<sup>18</sup> The reliability in rating the pain therefore becomes important to establish.

The data about depression were interesting. Although it was not surprising to find that more EOL residents were reported to have depression, the low level of depression generally at 1% of non-EOL residents and 2% for EOL residents is remarkable. Other studies specifically focusing on depression in LTC facilities have estimated prevalence of major depression at 15.7% and for minor depression 16.5%.<sup>19</sup> Furthermore, depression in the cancer population in general is estimated to be between 15–25%.<sup>20</sup> This probably indicates another example of underreporting of depression in nursing homes.

Given that 66% of EOL residents were relocated to the nursing home from an acute care hospital, it could be suggested that these people did not have sufficient family support to return home or were too frail to cope at home with the extra demands of terminal illness; an assumption supported by

previous research.<sup>21</sup> The finding that 50% of these new admissions had died within a month of transfer raises a question regarding the appropriateness of relocating residents so close to death. Moreover, the question of appropriate specialty care being available and staff being prepared to provide high quality EOL care must also be raised. Clearly, it is imperative that we become better at identifying not only those probably in the last 6 months of life but also those who are within the last month of life.

The EOL designation on admission indicates that a resident is expected to have fewer than 6 months to live. At 6 months after admission, only 17% of the EOL admissions remained in the same nursing home. This finding would suggest that the EOL designation made on admission had been fairly accurate.

One would expect a reasonable length of stay at the LTC facility to warrant the disruption and distress that relocation is known to cause. However, calculation of the median survival time for EOL admissions reveals that the median survival for EOL residents is just 4 weeks. This statistic is cause for some concern, particularly in relation to the appropriateness of placing people in the EOL in LTC and for the staff of those facilities to be able to recognize signs of dying in new residents. Furthermore, the need to educate LTC staff in the care of the dying patient and to call on the specialist skills and knowledge of hospice becomes obvious.

The differences shown in these data between EOL and non-EOL residents indicates that the focus of care is going to

be different and that suggests that specialist skills will be needed. Appropriate educational preparation for registered nurses and other staff in LTC facilities, along with the attending physicians and medical directors, is necessary to provide quality EOL care to residents and to promote the continuing mental and emotional health of caregivers.

The Brown University web site, in conjunction with the Robert Wood Johnson Foundation, reports that about 28% of all deaths occur in LTC facilities such as nursing homes (<http://www.chcr.brown.edu/dying/brownatlas.htm>) making nursing homes a common site for death to occur and suggesting that terminal care would be an integral part of the services provided. More recent (2000) statistics from the US Department of Health and Human Services (HHS) reveal that 30% of LTC residents will die within the first year following admission, whereas only 13% of those residents already located in the LTC facility will die by the end of that year. This statistic suggests that the first year following relocation to a LTC facility is the most vulnerable time for a resident.

The survival graph (Figure 2) illustrates the important fact that approximately 5% of non-EOL residents had died within one month of admission and almost 15% had died within 6 months of admission. These figures appear to support the HHS figures quoted above about death in the first year of admission. Furthermore, the high death rate (50%) in the first month of residency for the EOL admissions also indicates the greater acuity associated with admitting EOL residents.

From our data it can be concluded that many of these deaths occur in people who have been residents in nursing homes for some time and only a very small proportion of new admissions are specifically for EOL care. However, with the increasing pressure on acute care beds and the recognition by more acute specialties that palliation at the EOL is appropriate for their patients, it is likely that the number of people admitted to nursing homes for EOL care will rise. This will continue to be monitored in Missouri.

### Limitations and Future Directions

The analysis was limited to residents in LTC facilities that were known to have hospice contracts, and thus assumed to acknowledge the change in goals of care for residents at the end of their lives. The profile of residents in LTC facilities who do not have access to hospice services was not determined, and it would be interesting to profile these residents to determine any differences between LTC facilities.

Clearly, not all residents who were in the last 6 months of life were identified by the MDS. Research is planned to determine reliable indicators for residents who are transitioning to the end of life. The findings from such research would assist LTC facilities in providing the opportunity to review the goals of care and to provide appropriate care for residents at the end of life. Only by accurate recognition that residents are near the end of life will we develop appropriate strategies and resources for proper care. This will necessitate a multidisciplinary activity with leadership provided by medicine and nursing, including communication about advance care planning, skills, symptom assessment and management, and access

to other human resources such as pastoral care and social work.

Another important consideration in understanding the significance of accurate EOL prediction is in terms of quality management in nursing homes. Currently, nursing homes are monitored by the use of quality indicators, for example, weight loss, dehydration, and pressure ulcer development. The deterioration of a resident in certain quality indicators may also be indicative of the EOL, being a natural and inevitable part of the dying process. If these indicators indicate decreased quality, surveyors may take action against the nursing home because the care may be perceived as poor, or abusive, when in fact, the nursing home is dealing with a special population in need of palliative rather than curative or restorative care.

The findings from this study also point to the need for further education of LTC staff. Topics such as assessment of physical and emotional care of residents at the EOL, pain, and symptom management are strongly indicated.

Several important questions are not addressed by our findings. What percentage of nursing home residents in which the primary goal is comfort care at the end of life receive that care? Can the MDS become a tool helpful in identifying this population of people admitted to long-term care facilities? Will this information be used to guide prognosis and discussion about patient or proxy preference around EOL care? Do those facilities with hospice services available provide better EOL care?

### CONCLUSION

Examining the MDS data for Missouri LTC facilities shows that nearly 1 in 20 admissions is of a resident with a life expectancy of fewer than 6 months. As expected, EOL admissions also had the symptoms (pain, incontinence, and dehydration) and conditions (cancer, chronic obstructive pulmonary disease, and congestive heart disease) one would expect in persons near the EOL. Furthermore, although many more of the EOL admissions have advanced directives than non-EOL admission, still there remains approximately 20% of EOL residents without even a "do not resuscitate" order. Of the EOL residents, half will die within 30 days of admission, and less than 20% remain in the LTC facility at the 6-month marker.

Future research will attempt to answer these questions. At the same time, we must strive to ensure that all residents of long-term care facilities receive appropriate, planned, and high quality care during the final stage of life.

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