

# **End-of-Life Care in U.S. Nursing Homes: Resident and Facility Factors that Predict Presence and Use of Services**

Kimberly S. van Vulpen  
University of Maryland  
Baltimore, MD

## **Statement of the Research Problem**

Over 1.7 million older adults currently reside in U.S. nursing homes (Dobbs, Hanson, Zimmerman, Williams, & Munn, 2006; Hanson, Reynolds, Henderson, & Pickard, 2005). For those individuals, over half will die in those facilities (Bern-Klug, 2009). For the overall deaths in the United States, 20% of those are occurring in nursing home facilities (Rice, Coleman, Fish, Levy, & Kutner, 2004; Zerzan, Stearns, & Hanson, 2000). By 2040 this statistic is predicted to double with over 40% of U.S. deaths occurring in nursing homes (Ersek, Grant, & Kraybill, 2005).

Prior research on end-of-life care (EOL) has identified that the needs of individuals dying in nursing homes are not being met (Temkin-Greener, Zheng, Norton, Quill, Ladwig, & Veazie, 2009). These unmet needs often lead to physical (e.g., pain and dyspnea) and emotional (e.g., depression, anxiety, and loneliness) discomfort in the last days of life (Reynolds, Henderson, Schulman, & Hanson, 2002).

The benefits of offering specialized end-of-life services in these facilities have been supported in prior research and literature. One specialized service, hospice care, was found to have significant benefits to the dying residents including improved pain assessment and management (Baer & Hansen, 2000; Miller, Mor, Wu, Gozalo, & Lapane, 2002). In addition, hospice service was found to have extended benefits in addressing the emotional and spiritual needs of the residents (Baer & Hansen, 2000). Hospice utilization also reduced the need for acute care admissions allowing for management of symptoms to be offered in the facilities (Casarett et al., 2005; Gozalo & Miller, 2007). The specialized end-of-life approach to care in hospice was also found to be a benefit to the family members of the residents. In a study conducted by Casarett et al. (2005), family members of individuals receiving hospice care in the facility reported an increased satisfaction with the care of their loved-one during the last week of life.

Studies on providing care in nursing homes have identified barriers at both the resident and facility levels that impact quality EOL care access and service. At the facility level, barriers such as the need for adequate staffing, educational limitations in EOL practices, inadequate fee structures, and lack of practice policies or guidelines were all identified as factors impacting utilization (Brazil et al., 2006). Additional studies have

focused on characteristics specific to the nursing home resident. These characteristics included age, sex, marital status, race, and payment source. Buchanan, Choi, Wang, and Ju (2004) found that residents were more likely to utilize services if they were older, female, and widowed. Buchanan et al.'s (2004) study also identified racial disparities with White nursing home residents being more likely to access hospice compared to Black, Hispanic, Asian, and American Indian residents. Having an Advanced Directive (Living Will or Durable Power of Attorney) was also a predictor of utilization of services.

Specific diagnosis and physical needs were also identified as common predictors for use of services. Buchanan et al. (2004) reported that hospice nursing home residents were more likely to have cancer, report more significant pain, and exhibit more cognitive impairments than other residents diagnosed with end-stage diseases. Parker-Oliver, Porock, Zweig, Ranitz, and Petroski (2003) identified similar characteristics related to cancer diagnosis and presence of pain for those residents accessing hospice care in the facilities. In addition to cancer diagnosis and pain, Lu and Johantgen (2010) found that additional health needs including shortness of breath, functional dependence, and cognitive limitations increased the likelihood of accessing hospice care in nursing homes.

Although prior research has supported the benefits of providing specialized services to nursing home residents at the end-of-life, these studies identify that there is still a significant group of dying residents who are not receiving care. In addition, many of the studies only focus on hospice care and not other specialized end-of-life services. This current study aims to better understand what factors may serve as catalysts and barriers to not only nursing homes implementing specialized end-of-life services in their facilities, but also residents access and utilization of those services. Understanding these barriers may help in developing strategies for policies and procedures for providing quality end-of-life care.

In exploring EOL care in nursing homes, the terms palliative care and hospice care are often used interchangeably in the literature. There are, however, distinct differences in the two terms that may impact the approach to care. The Center to Advance Palliative Care (2011) defines palliation as the practice of reducing suffering in individuals with progressed illness, often in the later stages of their life. This form of practice takes an interdisciplinary team approach that focuses on the physical, emotional, and mental aspects of illness for individuals and their families (Bern-Klug, 2010; Phillips, Davidson, Jackson, Krisjanson, Daly, & Curran, 2006). Although hospice is a form of palliative care, the difference exists in the stage of disease progression. Hospice services are generally offered to individuals with a terminal diagnosis of six months or less (National Hospice and Palliative Care Organization [NHPCO], 2010a). As in palliative care, hospice is provided by an interdisciplinary team focusing on comfort care, not cure. For the purpose of this study, end-of-life care in nursing homes was explored based on the definition of palliative care. This study's end-of-life care focus was not limited to only hospice services, but also included the facility palliative care practices.

## Research Questions

This study explored the following two questions:

**Research Question 1:** What facility and administrative factors predict the presence of EOL services in nursing homes in the U.S.?

**Research Question 2:** What factors related to the nursing home organization and resident characteristics predict the utilization of EOL care services in nursing homes in the United States?

## Methodology

This study is a cross-sectional design utilizing secondary data from the 2004 National Nursing Home Survey. A sample of 1174 facilities and 13,419 residents was drawn from the 2004 National Nursing Home Survey (NNHS). The NNHS is a complex survey sample and required that each of the analyses accommodate for the weighted variables. The stratification, weighting, and cluster variables of the data set were utilized in the complex survey component of IBM Statistics 19 and Mplus Version 6.11.

Facility and resident variables in the secondary data set were selected using Andersen and Newman's (1973) behavioral model for health service utilization as a guide. The goal of Andersen and Newman's initial model was to provide a framework of understanding the individual and society determinants for utilization of health services. The variables in the study were categorized into domains: predisposing (age, gender, marital status, and race of resident), enabling (advanced directives, source of nursing home payment), and need (primary diagnosis, pain, distressed mood, and level of mobility). The health care system was the final factor of the model, identifying those organizational resources (payment sources, participation in EOL initiatives, and presence of EOL services) and structure (ownership, size, geographic location, medical director characteristics, and administrator characteristics) could also impact the provision of services. Figure 1 presents the conceptual framework for this study.

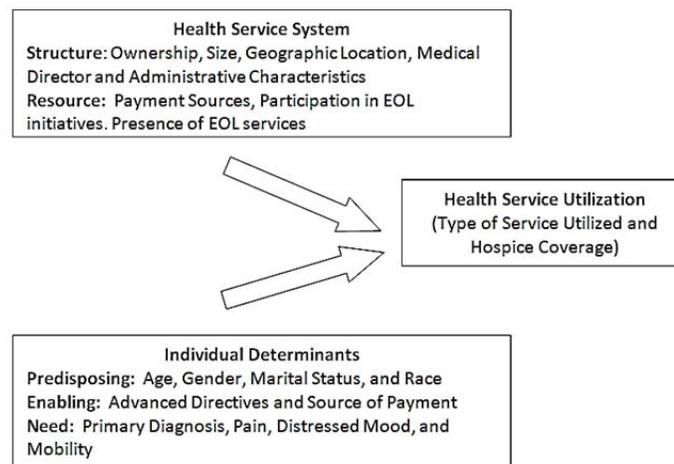


Figure 1: Conceptual Framework

## Facility Characteristics

Table 1 presents the basic demographic information for the estimated 16,100 nursing homes in the United States. Almost two-thirds (61%) were identified as for-profit facilities, and over half (54%) were part of a nursing home chain. The largest percentage of facilities (42%) had 100 to 199 resident beds. Two-fifths (41%) of the facilities had 60% to 79% of its residents with Medicaid as their primary payment source, and one-fifth (21%) of the facilities had over 80% of residents with Medicaid as primary insurance. One in six (17%) of the facilities reported participation in EOL planning programs that included directives such as Physicians' Orders for Life Sustaining Treatment (POLST), Five Wishes, or Last Acts. Over three-fourths (78%) of the facilities had formal contracts with outside hospice providers, and less than one-fourth of the facilities had special programs and trained staff (SPTS) for hospice care (19%) and palliative services (17%). More than four out of five (83%) facilities reported the presence of EOL services which combined the variables including those facilities that held contracts with outside hospice providers, and/or SPTS for hospice or palliative services.

**Table 1: Facility Characteristics (N=1174)**

	Weighted estimate	%	Unweighted count
<b>Nursing Home Ownership</b>			
For Profit	9,889	61.5	707
All others (private and government not-for-profit)	6,192	38.5	467
<b>Chain Affiliation</b>			
Yes	8,709	54.2	616
No	7,372	45.8	558
<b>Bed size of Facility</b>			
30-49 beds	2,242	13.9	174
50-99 beds	6,005	37.3	441
100-199 beds	6,840	42.5	485
200 or more	994	6.2	74
<b>Geographic Region</b>			
Northeast	2,805	17.4	171
Midwest	5,300	33.0	414
South	5,410	33.6	413
West	2,566	16	176
<b>Metropolitan Status</b>			
Metropolitan	10,893	67.7	663
Micro-polititan	2,607	16.2	260
Neither	2,581	16.0	251
<b>Percent of Residents with Medicare as Primary *</b>			
0-9%	8,418	52.6	636
10-19%	5,198	32.5	373
20% or more	2,383	14.9	157
<b>Percent of Residents with Medicaid as Primary*</b>			
0-19%	1,491	9.3	99
20-39%	1,215	7.6	81
40-59%	3,330	20.8	242
60-79%	6,531	40.8	484
80% or more	3,432	21.5	260
<b>Percent of Residents with Other Sources of Payment as Primary*</b>			
0-19%	7,996	50.1	590
20-39%	4,882	30.6	359
40% or more	3,084	19.3	214
<b>Any Facility Accreditation *</b>			
Yes	2,435	15.2	164
No	13,552	84.8	1004
<b>Participation in End of Life Initiatives*(yes)</b>	2,762	17.2	200
Five Wishes*(yes)	895	5.6	60
POLST*(yes)	2,130	13.3	155
Last Acts* (yes)	680	4.2	49
<b>Formal Hospice Contract with Outside Provider*(yes)</b>	12,553	78.1	900
<b>SPTS for Hospice*(yes)</b>	3,027	18.8	222
<b>SPTS for Palliative/EOL*(yes)</b>	2,687	16.7	196
<b>Physically Distinct Clusters of Beds for Hospice (yes)</b>	897	5.6	70
<b>Presence of EOL services*(yes) (DV)</b>	13,308	82.8	957

\*n is smaller than the unweighted sample of 1174 due to missing data

\*\* percentages are valid percents based on excluding missing data

## **Resident Characteristics**

Table 2 presents the sample characteristics of the residents in the study. A majority of the residents were unmarried white females of non-Hispanic descent. The average age of the resident was 81 years old (SE = 0.200). Circulatory Diseases (25%) and Mental Disorders (21 %) were listed as the most frequently charted primary diagnoses of the residents at the time of interview. Sixty-six percent of the residents had an advanced directive on file. Only 2.5% of the residents in the sample were identified as receiving services from hospice/palliative care or end-of-life programs in the facilities.

**Table 2: Resident Demographics (N = 13,419)**

	Weighted estimates	%	Unweighted Sample count
<b>Resident Gender</b>			
Male	424,421	28.6	3815
Female	1,057,543	71.4	9604
<b>Resident's Race<sup>1</sup></b>			
American Indian or Alaska Native	7,864.00	0.5	101
Asian	14,442	1.0	100
Black or African American	183,356	12.4	1385
Native Hawaiian or Pacific Islander	5,991	0.4	44
White	1,271,728	85.8	11799
<b>Hispanic or Latino Origin*</b>	54,643	3.7	428
<b>Resident's Primary Diagnosis*</b>			
Ncoplasms	33,701	2.3	298
Mental Disorders	325,529	22.2	2,886
Circulatory Diseases	372,675	25.4	3,393
Respiratory Diseases	73,770	5.0	677
Nervous System Diseases	238,810	16.3	2195
Endocrine System Diseases	109,595	7.5	1000
Musculoskeletal	77,390	5.3	725
Other diseases	236,625	16.1	2154
<b>Advanced Directives</b>			
Any Advanced Directives <sup>1*</sup>	970,635	66.2	9020
Living Will	271,197	18.5	2,544
Do not Resuscitate	832,615	56.8	7,877
Do not Hospitalize	51,810	3.5	406
Medication Restrictions	44,972	3.1	425
Feeding Instructions	154,936	10.6	1,381
<b>Resident Source of Payment<sup>1*</sup></b>			
Medicare	189,182	13.3	1,680
Medicaid	882,561	62.0	7,811
Self/Out of Pocket	947,231	66.6	8,769
Other Source	31,853	2.2	266
<b>Pain in past 7 days *</b>			
Yes	336,069	23.4	3,402
No	1,100,576	76.6	9,658
<b>Indicators of Distressed Mood (Depression, Sadness, or Anxiety)*</b>			
No Mood Indicators	828,537	56.8	7453
Indicators Present but Easily Altered	375,134	25.7	3403
Indicators Present not Easily Altered	255,536	17.5	2403
<b>Resident Level of Bed Mobility*</b>			
Independent	458,734	31.3	4,354
Supervision	85,341	5.8	753
Limited Assistance	264,708	18.0	2,448
Extensive Assistance	414,918	28.3	3,610
Total Dependence	241,073	16.4	2,147
No activity reported in last 7 days	1,923	0.1	17
<b>Receiving Services from Hospice/Palliative care/EOL Programs</b>			
Yes	36,429	2.5	331
No	1,431,384	97.5	12,998

Percentage totals more than 100% because respondents could mark more than one category.

\*N is smaller than the unweighted sample of 13,419 due to missing data.

A logistic regression analysis was conducted to answer Research Question 1 exploring what facility and administrative factors predict the presence of EOL services in nursing homes in the U.S.? Multi-level regression analyses were conducted to answer Research Question 2 exploring what factors related to the nursing home organization and resident characteristics predict the utilization of EOL care services in nursing homes in the United States?

## Results

In answering research question one, a three step logistic regression was conducted. At level one, the facility demographic characteristics were entered and revealed a significant model at  $p < .001$  with an overall model classification of 84 %. The second step of the hierarchical model introduced variables specific to the medical director at the facility. The second model remained significant at  $p < .001$  with the overall model classification improving to almost 86%. The final model was also significant at  $p < .001$  and revealed an improvement of model fit at 86.8%. Table 3 presents the final logistic regression model identifying the facility and administrative factors predicting the presence of EOL services.

**Table 3: Final Logistic Regression Model (N = 1174)**

	df	Model 3 Wald F	B	Exp(B)	C.I.	
<b>Facility Characteristics</b>						
Ownership (For-profit) Not-for-profit (gov't and private)	1	5.090	.000* -0.517	1 0.596*	0.380	0.935
Chain affiliation (Yes) No	1	0.215	.000* 0.107	1 1.112	0.708	1.747
Bedsize (3-49 beds) 50-99 beds 100-199 beds 200 or more beds	3	5.424	.000* 0.969 1.04 0.649	1** 2.636** 2.830** 1.915	1.536 1.618 0.745	4.524 4.948 4.923
Region (West) Northeast Midwest South	3	4.431	.000* 1.019 0.866 0.939	1** 2.770** 2.377** 2.557**	1.353 1.340 1.466	5.671 4.217 4.460
Medicare Percent (20% +) 0-9% 10-19%	2	0.575	.000* 0.377 0.413	1 1.458 1.511	0.662 0.699	3.215 3.268
Medicaid Percent (0-19%) 20-39% 40-59% 60-79% 80% or more	4	3.300	.000* 1.524 1.023 1.107 0.547	1* 4.589** 2.780* 3.025* 1.728	1.557 1.221 1.180 0.571	13.524 6.333 7.756 5.228
Other Insurance Percent (40% +) 0-19% 20%-39%	2	0.122	.000* -0.063 -0.158	1 0.939 0.854	0.387 0.402	2.280 1.815
Participation in EOL initiatives (Yes) No	1	6.040	.000* -.709	1 0.492*	0.279	0.867
<b>Medical Director Characteristics</b>						
Certified in Geriatrics (No) Yes	1	0.062	.000* 0.058	1 1.059	0.672	1.669
Certified in Palliative Care (No) Yes	1	0.079	.000* 0.096	1 1.100	0.564	2.147
Days working at facility/month	1	2.373	-0.027	0.974	0.941	1.007
Months at current facility	1	0.962	-0.003	0.997	0.992	1.003
Months at any facility	1	0.183	0.001	1.001	0.997	1.005
<b>Administrator Characteristics</b>						
Months at current facility	1	3.175	-0.003	0.997	0.993	1.000
Months at any facility	1	4.050	0.003	1.003*	1.000	1.006
Degree (other) High School Associates Degree Bachelor's Degree Master's Degree or Higher	4	0.626	.000* 0.227 0.248 0.350 0.620	1 1.255 1.281 1.419 1.859	0.372 3.590 0.568 0.717	4.234 3.590 3.546 4.819
Degree in Health Care Admin.(yes) No	1	0.340	.000* -0.141	1 0.869	0.541	1.394
Overall Model Significance		$p < .005$				
Wald F		2.949				
DF		29				
Pseudo R Square						
Cox and Snell		0.111				
Nagelkerke		0.191				
Classification Percent		86.2				

\*  $p < .05$ , \*\*  $p < .01$   
\* reference category

There were several facility variables that predicted the presence of end-of-life services in the facilities. Facilities that were for-profit, larger in size, and participated in end-of-life planning initiatives were more likely to offer end-of-life services. Facility geographic location was also a predictor with those nursing homes located in the West being less likely to offer end-of-life services.

In answering Research Question 2, two multilevel analyses were conducted utilizing the resident public data set. The dependent variable measured residents who were identified as receiving hospice, palliative, or EOL care in the facilities. Model 1 included resident variables at level one. Model 2 included the same resident variables at level one, but also added a facility variable (ownership) at level 2. The clustering variable in both models was the 1151 individual nursing homes in the study. Table 4 presents the variables explored nursing home and resident characteristics predicting EOL care utilization in the facilities.

**Table 4: Summary of Multilevel Regression Analysis on Public Data Set (N = 13,419)**

	Model 1		Model 2			
<u>Level 1 Fixed Variables</u>						
Age	0.024	3.186**	1.024	0.024	3.224**	1.025
Gender (female)	-0.226	-1.491	0.798	-0.224	-1.477	0.800
Race (white)	-0.157	-0.600	0.855	-0.151	-0.581	0.860
Hispanic (yes)	-0.205	-0.580	0.814	-0.209	-0.590	0.811
Marital Status (yes)	0.157	1.003	1.170	0.155	0.988	1.167
Private Insurance	-0.303	-1.185	0.739	-0.302	-1.194	0.739
Out of Pocket Payment	-0.249	-1.532	0.780	-0.250	-1.529	0.779
Medicare Insurance	-0.821	-3.298**	0.440	-0.823	-3.314**	0.439
Medicaid	-0.701	-4.227**	0.496	-0.715	-4.391**	0.489
Advanced Directives (yes)	1.807	7.578**	6.094	1.817	7.645**	6.152
Pain (yes)	0.816	5.692**	2.262	0.819	5.718**	2.268
Distressed Mood (ordinal)	0.212	2.534*	1.237	0.219	2.623**	1.244
Bed Mobility (ordinal)	0.425	8.062**	1.529	0.424	8.055**	1.528
Neoplasms	2.768	9.092**	15.932	2.776	9.073**	16.048
Mental Disorders	0.039	0.150	1.039	0.044	0.172	1.045
Cardiac	0.126	0.558	1.135	0.126	0.559	1.135
Respiratory	1.005	3.200**	2.732	1.010	3.212**	2.745
Nervous System	-0.173	-0.669	0.841	-0.161	-0.620	0.852
Endocrine	-1.519	-2.797**	0.219	-1.513	-2.787**	0.220
Musculoskeletal	-0.567	-1.426	0.567	-0.559	-1.407	0.572
<u>Level Two Variables</u>						
Ownership				-0.188	-0.968	
<u>Information Criteria</u>						
AIC	256,661.279		477,809.620			
BIC	257,006.474		478,169.832			
N = 13,419, p < .05*, p < .01**						

Only 2.5% of the residents in the sample were identified as receiving services from hospice/palliative care or end-of-life programs in the facilities. Factors specific to the nursing home resident that predicted utilization of end-of-life services included older age, decreased bed mobility, reports of pain, indicators of emotional distress (depression, sadness, or anxiety), and specific diagnoses (neoplasms and respiratory diseases). Having an advanced directive in place also increased the resident's odds of utilizing EOL services. Residents with primary payment sources of Medicare and Medicaid were found to be less likely to utilize services.

### **Utility for Social Work Practice**

Understanding the potential catalysts and barriers for both the nursing home in implementing programs and the resident in accessing the services is essential in developing strategies for policies and procedures for quality end-of-life care. By the nature of their training and education, social workers can be a valuable resource in addressing the gap in access to EOL care for individuals residing in the nursing home. Based on their skills and training, social workers can fill many roles (Bern-Klug, 2010). Social workers have the skills to assess not only the physical needs, but also the psychosocial needs of the residents for the purpose of more timely referrals to EOL services in the facility. This assessment also acknowledges the environmental factors that may help or hinder comfort care. Social workers can be an active part of a care team to help anticipate problems, and develop effective interventions in alleviating barriers to service. They have the training to educate staff and family members on the emotional, spiritual, and social needs of the individual and family; acknowledging that EOL care is a holistic approach that addresses all these factors. Understanding the importance of advanced care planning, social workers can actively work with residents ensuring that their EOL wishes are expressed and documented through Living Wills or Medical Power of Attorneys. Finally, social workers can also play a major role in advocacy at both the facility and policy levels.

### **Data Acknowledgement**

This project required the use of both the public and restricted data from the National Nursing Home Survey. The findings and conclusions in this paper are those of the author and do not necessarily represent the views of the Research Data Center, the National Center for Health Statistics, or the Centers for Disease Control and Prevention

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