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Hospice Utilization and Outcomes Among Nursing Home Residents with Advanced Dementia

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Abstract

Objectives—To identify characteristics of nursing home (NH) residents with advanced dementia and their health care proxies (HCPs) associated with hospice referral; and examine the association between hospice use and 1) the treatment of pain and dyspnea, and 2) unmet needs during the last 7 days of life.

Design—Prospective cohort study.

Setting—Twenty-two Boston-area NHs.

Participants—323 NH residents with advanced dementia and their HCPs.

Measurements—Data were collected at baseline and quarterly up to 18 months. Hospice referral, the frequency pain and dyspnea were experienced, and treatment of these symptoms was ascertained. HCPs reported unmet needs during the last 7 days of the residents' lives for the following domains: communication, information, emotional support, and help with personal care.

Results—Twenty-two percent of residents were referred to hospice. After multivariable adjustment, factors associated with hospice referral included: non-White race, eating problems, HCP's perception the resident's prognosis was < 6 months, and better HCP mental health. Residents on hospice were more likely to receive scheduled opioids for pain (adjusted odds ratio (AOR), 3.16; 95% confidence interval (CI_{95%}), 1.57–6.36), and oxygen, morphine, scopolamine or hyoscyamine for dyspnea (AOR, 3.28; CI_{95%}, 1.37–7.86). HCPs of residents on hospice reported fewer unmet needs in all domains during the last 7 days of the residents' life.

Conclusion—A minority of NH residents with advanced dementia received hospice care. Hospice recipients were more likely to received scheduled opioids for pain and symptomatic treatment for dyspnea, and had fewer unmet needs at the end of life.

Keywords

Hospice; palliative care; Alzheimer's disease; dementia; nursing homes

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Introduction

Dementia is a leading cause of death in the US and mortality due to this disease is increasing faster than any other leading fatal condition.¹ Prior work has highlighted the need to improve the palliative care provided to the growing number of Americans dying with advanced dementia.²⁻⁶

The United States Medicare hospice benefit provides end-of-life care to terminally ill patients and their families. In 1996, hospice eligibility guidelines were extended to serve dying patients with non-cancer diagnoses, including dementia.⁷ Historically, patients with dementia have been relatively under-served by hospice.⁴ Barriers to providing hospice services to these patients include the under-recognition of dementia as a terminal disease,^{2, 4, 8-9} challenges of prognostication,¹⁰ and accessing hospice services in nursing homes (NHs) where approximately 70% of dementia patients die.^{4, 11} However, recent trends suggest that hospice referrals among dementia patients are gradually increasing.¹²⁻¹³ The National Hospice and Palliative Care Organization reported that 11% of hospice recipients had a primary diagnosis of dementia in 2008 (versus. 38% with cancer); an increase from 10% in the prior year.¹² Thus, as the number of patients with dementia continues to grow, so will the absolute number of hospice recipients with dementia.

Research suggests that hospice care is beneficial for dementia patients.¹⁴ Miller et al. reported that NH residents dying with dementia who received hospice services had better pain management and fewer terminal hospitalizations compared to those not receiving hospice services.¹⁵ In a small community-based study, families of dementia patients referred to hospice reported greater satisfaction with end-of-life care and hospice recipients were more likely to die at home and in their location of choice.¹⁶ In a post-death survey, 73% of families whose loved ones died with dementia evaluated hospice services as excellent, similar to that reported for other terminal conditions.¹⁴ This modest amount of early work, while encouraging, is limited due to retrospective study designs,¹⁴⁻¹⁵ exclusive focus on a community-based sample,¹⁶ and small sample sizes.¹⁶

To further our knowledge of hospice services for dementia patients, this report analyzed data from a prospective study of 323 NHs residents with advanced dementia and their health care proxies (HCPs) (94% were family members) living in 22 Boston-area facilities. The three objectives of this report were: 1) to identify resident and HCP factors associated with hospice referral; 2) to examine the association between the receipt of hospice services and the treatment of pain and dyspnea; and 3) to examine the association between the receipt of hospice services and the HCPs' evaluation of unmet care needs during the residents' last 7 days of life.

Methods

Data Source

Data were obtained from the CASCADE (Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life) study; a prospective cohort study of NH residents with advanced dementia and their HCPs. A detailed description of its methodology is provided elsewhere.¹⁷ The Institutional Review Board at Hebrew SeniorLife approved the conduct of this study.

Study sample

Residents were recruited from 22 Boston-area facilities between February 2003 and August 2007. Participating facilities included NHs with greater than 60 beds located within a 60-

mile radius of Boston. At baseline, and quarterly thereafter, residents residing in these NHs were screened to identify who met the following eligibility criteria: 1) ≥ 60 years, 2) a diagnosis of dementia as documented in the medical record, 3) Global Deterioration Scale (GDS) score of 7 as determined from the resident's primary care nurse (range 1-7, higher scores indicate worse dementia),¹⁸ and 4) a designated HCP who could communicate in English. At GDS stage 7, patients have very severe cognitive deficits, minimal verbal communication, total functional dependence, incontinence of urine and stool, and inability to ambulate independently. The HCPs of eligible residents provided consent for the residents' and their own participation.

Data Collection Protocol

Trained research assistants conducted resident assessments and HCP telephone interviews at baseline and quarterly intervals thereafter for up to 18 months. Resident assessments included a chart review, nursing interview and brief clinical examination. If the resident died, a chart review and nursing interview were completed within 14 days of death and HCP interviews were conducted 2 months post-death.

Resident Variables

At each assessment, it was determined whether the resident was referred to hospice and if so, the date of referral. At baseline, the following data were obtained from the chart: age, gender, race, education (high school graduate or greater), marital status, whether the resident lived in a special care dementia unit, length of stay in the NH (defined as the number of days between the assessment date and the NH admission date), and underlying cause of dementia (Alzheimer's disease, vascular, or other). For these analyses, length of stay was dichotomized at the median (1114 days).

Additional information was collected at both baseline and quarterly assessments. The presence of a "do not hospitalize" directive was determined. The Test for Severe Impairment (TSI) (range 0-24, lower scores indicate greater impairment) was administered to the residents to assess their cognition.¹⁹ Since the majority of residents scored zero on the TSI, this variable was dichotomized as equal to or greater than 0. The Bedford Alzheimer's Nursing Severity-Subscale (BANS-S) (range 7-28; higher scores indicate greater functional disability) was assessed by nurses to measure functional disability,²⁰ and was dichotomized at the median (22).

Clinical complications occurring since the prior assessment were determined from chart review at each follow-up assessment, including: infectious episodes (suspected pneumonia and febrile episodes), eating problems, and other sentinel events. A febrile episode was defined as an oral ($\geq 100^{\circ}\text{F}$), rectal ($\geq 101^{\circ}\text{F}$), or axillary ($\geq 99^{\circ}\text{F}$) temperature at least once within a 7-day period (> 1 recorded fever during a 7-day period was considered a single episode). Eating problems were characterized by documentation of any of the following: weight loss, swallowing problems (e.g., aspiration), chewing problems (e.g., spitting food) and refusal to eat. Sentinel events were defined as acute medical illnesses that had the potential to lead to a significant change in health status (e.g., hip fracture). Finally, the dates of all hospitalizations and emergency room visits were obtained. For purposes of the analyses, a variable denoting "acute event in past 90 days" was created and defined as the occurrence of any of the following: suspected pneumonia, febrile episode, eating problem, hospitalization, emergency room visit, or other sentinel event.

At each assessment, the frequency of pain and dyspnea that occurred since the prior assessment was ascertained. Pain and dyspnea were quantified based on documentation in the chart as follows: 0) never, 1) rarely (< 5 days/month), 2) sometimes (5-10 days/month),

3) often (11-20 days/month) and 4) almost daily (>20 days/month). For residents who experienced any pain (e.g., > never), it was determined whether they received oral or parenteral opioids on a regularly scheduled basis. For residents who experienced any dyspnea (e.g., > never), it was determined if they were treated with any of the following: oxygen, morphine, scopolamine or hyoscyamine

Health Care Proxy (HCP) Variables

HCP information collected at the baseline assessment included age, gender, education, religion, relationship to the resident, and whether the HCP lived with the resident prior to NH admission.

At each assessment, the number of hours per week the HCP spent visiting the resident was determined and dichotomized as > 7 hours versus ≤ 7 hours. At the baseline interview, HCPs were asked whether a NH facility health care provider spent at least 15 minutes discussing the resident's advance directives with them at the time of NH home admission. To understand HCP preparation for the advanced stages of dementia, HCPs were asked whether they understood the type of clinical complications expected in advanced dementia (baseline only), and whether they felt the resident had fewer than 6 months to live (all follow-up interviews).

The SF-12 mental health subscale, a measure of HCP mental health was collected at each quarterly and the 2-month post-death interview. This subscale of the SF-12 has a U.S. population normative mean of 50 with a standard deviation of 10 points, with higher scores indicating greater mental health.²¹

The Satisfaction with Care at the End-of-Life in Dementia Scale (SWC-EOLD) was used to assess the HCP's satisfaction with overall end-of-life care provided to the resident.^{22,23} This scale, assessed quarterly, ranges from 10-40 with higher scores indicating greater satisfaction.

Unmet Needs in the Last 7 Days of Life

A modified version of the “Toolkit After-Death Bereaved Family Member Interview” was administered to HCPs at the 2-month post death interview. This validated instrument measures key palliative care outcomes based on a conceptual model of patient-focused and family-centered medical care.²⁴⁻²⁶ The following problem domains representing potential “unmet needs” were studied in relation to the residents' care during the last 7 days of life: 1) communication and shared decision making, 2) information received from providers, 3) emotional support provided to the family, and 4) the amount of help the resident received with personal care needs (e.g., bathing, dressing, feeding, toileting), taking medications or getting dressings change. Appendix I provides the detailed questions that comprised each domain. HCPs were considered to have an “unmet need” in a specific domain if they answered “yes” to at least one question within each domain. Responses to these questions were either yes or no.

Analyses

Descriptive information, including means and standard deviations for continuous variables, and counts and percentages for categorical variables, was used to characterize the study cohort. SAS Version 9.2 for Windows (SAS Institute, Inc., Cary, NC) was used for all analyses.

Analyses were conducted to identify resident and HCP factors associated with hospice referral during the follow-up period. Residents living in one facility that did not contract

with a hospice provider were excluded from this analysis (N=46). Residents who were on hospice at baseline were also excluded (N=18).

Based on clinical experience and the literature,²⁷⁻²⁸ factors believed to be potentially associated with hospice referral were selected. Stable independent variables (e.g., gender) were ascertained from the baseline assessment. For residents referred to hospice, static independent variables were taken from the baseline assessment. Dynamic independent variables were ascertained from the same assessment at which the hospice referral was first documented, with the exception of TSI, pain, dyspnea, SF 12 mental health, whether they felt the resident had fewer than 6 months to live, and SWC EOLD which were taken from the prior assessment.

For residents not referred to hospice, a sampling strategy was used to identify a follow-up assessment from which to draw dynamic independent variables. This was achieved by randomly selecting follow-up assessments for non-hospice residents that matched the distribution of the dates of hospice referrals among residents who had them. An extension of logistic regression was used to examine the association between resident and HCP factors (independent variables) and whether or not the resident was referred to hospice at any point of during the follow-up period (outcome). This analysis was conducted at the resident level and generalized estimating equations (GEE) were used to account for clustering at the facility level. Bivariable analyses were conducted to determine the association between each independent variable and hospice referral. Independent variables associated with hospice referral in the bivariable analyses at $\alpha=0.15$ were included in the initial multivariable inferential model from which odds ratios (ORs) and 95% confidence intervals (CIs_{95%}) were generated.

Additional analyses were conducted to compare the treatment of pain and dyspnea (dichotomous outcomes) between residents who did and did not receive hospice services (main independent variable). The regular use of opioids was the outcome when examining the treatment of pain (e.g., versus no opioids or given on 'as needed' basis), and the use of either oxygen, morphine, scopolamine, or hyoscyamine (versus none of these treatments) was the outcome when examining the treatment of dyspnea. These analyses were conducted at the assessment level and included only those assessments at which the resident experienced the symptom of interest (e.g., more than never). Repeated assessments per resident were accounted for by using an extension of logistic regression based on GEE to generate ORs and CIs_{95%}. These analyses were adjusted for: resident age and gender, whether or not the resident lived in special care dementia unit, the occurrence of an acute illness in the prior 90 days, and the frequency of the symptom (e.g., rarely, sometimes, often and almost daily).

Finally, among residents who died, analyses were conducted to compare the proportion of HCPs' reporting unmet needs during the last 7 days of life among residents who were and were not on hospice care when they died. Only residents whose HCPs who could be reached at the 2-month post-death interview were included in these analyses. The association between hospice use (main independent variable) and the presence of an unmet need (outcome) was examined separately for each of the four domains using unadjusted logistic regression, generating ORs and CIs_{95%}. In addition, whether or not the resident had an unmet need in at least one of these four domains was examined as an outcome. For the analysis examining the domain of help with personal care, no residents in the non-hospice group had an unmet need. In this instance, logistic regression using exact methods was used to generate an OR and CI_{95%}.²⁹

Results

A total of 323 residents were enrolled in the CASCADE study and 22.3% (N=72) of residents received hospice services. Table 1 provides basic descriptive characteristics of these 323 residents and their HCPs at baseline. The mean age of residents was 85.3 years, most were female (85.4%), White (89.5%) and had at least a high school education (77.4%). The average age (years) of the HCPs was 60.0, and the majority were female (63.8%), Christian (Catholic or Protestant) (77.4%), and had at least a high school education (95.7%). A total of 67.5% of HCPs were the residents' children.

Referral to Hospice

The analysis examining factors associated with hospice referral excluded residents who lived in the one participating facility that did not contract with a hospice provider (N=46), as well as those who were on hospice at baseline (N=18). Among the remaining 259 residents, 53 (20.5%) were referred to hospice at some point over the 18-month follow-up period. Table 2 presents the associations between resident and HCPs' characteristic, and hospice referral. In bivariable analyses, resident characteristics associated with hospice referral at a p-value < 0.15 included: non-White race, shorter NH stay, and presence of an eating problem, HCP characteristics associated with hospice referral included: female, belief that the resident < 6 months to live, and higher SF-12 scores (e.g., better mental health). Factors independently associated with hospice referral in the multivariable model included: non-White race of residents (adjusted odds ratio (AOR) = 2.55, CI_{95%} = 1.36-4.76), presence of an eating problem (AOR = 4.21, CI_{95%} = 1.99-8.90), HCP perception that resident had < 6 months to live (AOR = 3.83, CI_{95%} = 1.29-11.37), and better HCP mental health on the SF-12 (AOR = 1.04, CI_{95%} = 1.01-1.06).

Impact of Hospice Referral on Treatment of Pain and dyspnea

Table 3 presents the associations between the receipt of hospice and the treatment of pain and dyspnea. At total of 323 residents contributed 1394 follow-up assessments to these analyses. On 432 (31.0%) of these assessments, residents were recorded as having pain (e.g., greater than never). Residents received scheduled opioids to treat their pain on only 23.4% (N=101/432) of these assessments. After multivariate adjustment, treatment of pain with scheduled opioids was significantly more likely when residents were on hospice compared to when they were not on hospice (48.3% versus 19.4%)(AOR = 3.16, CI_{95%} = 1.57-6.36).

On 381 of the 1394 (27.3%) follow-up assessments, residents were recorded as having dyspnea (e.g., greater than never). Residents received either oxygen, morphine, scopolamine or hyoscyamine to treat their dyspnea on 67.5% (N=257/381) of these assessments. In the adjusted analysis, treatment of dyspnea with one of these modalities was significantly more common among residents on hospice compared to residents not on hospice (83.1% versus 65.5%) (AOR = 3.28, CI_{95%} = 1.37-7.86).

Unmet Needs in the Last 7 Days of Life

A total of 177 residents died during the study. The HCPs of 137 (77.4%) of these decedents completed the 2-month post-death follow-up interview and provided information regarding the care their loved ones during the last week of life. Among these 137 residents, 41 (29.9%) received hospice care. The median time between the initial hospice referral and death was 58 days. As shown in Figure 1, the proportion of HCPs who felt there were unmet needs was lower for all problem domains among residents on hospice. (No residents who received hospice care had an unmet need with help for their personal care.) A total of 68.3% of residents with hospice care had an unmet need in at least one domain compared to 81.3% who did not receive hospice services. Odds ratios and CI_{95%} were calculated comparing the

effect of hospice on each of the unmet need. However, despite the moderately strong protective effects, the relatively small sample size produced wide CIs_{95%} such that statistical significance was not achieved at an alpha level of .05, with the exception for the “unmet help needs” domain ($p=.04$).

Discussion

This study reports the factors and outcomes associated with hospice in a rigorously defined, prospectively followed, cohort of NH residents with advanced dementia. Hospice care was provided to 22.3% of all residents over 18 months and to 29.9% of those who died. Several factors were associated with a greater likelihood of hospice referral including non-White race, the presence of an eating problem, the perception by family members that the resident had less than six months to live, and better mental health among family members. Residents who received hospice services were more likely to receive scheduled opioids for pain and symptomatic treatment for dyspnea, and had fewer unmet needs during the last 7 days of life. Nonetheless, even among hospice recipients, our findings demonstrate opportunities to improve the end-of-life care provided to NH residents with advanced dementia.

Previously studies reported that rates of hospice utilization among Americans with dementia vary widely (6%-43%).^{8, 16, 27, 30} This variation is likely attributable to differing study designs, settings, and years of publication. Nonetheless, the rate of hospice utilization observed in this NH population (22.3%), supports the widely held view that dementia patients are largely under-served by hospice services.^{2, 4, 8-11}

To our knowledge, this is the first study to examine factors associated with hospice use in NH residents with advanced dementia. Two small community-based studies failed to identify any factors predicting hospice utilization in dementia patients other than whether or not the patient lived alone.^{16, 27} Non-White race is one of the most consistent factors associated with lower hospice utilization rates.³⁰⁻³⁸ Thus, it is striking that we found non-White residents (97% African Americans) were more likely to receive hospice services compared to White residents. However, a national study from 2002 that used Medicare claims and death certificate data to examine racial disparities in hospice utilization in the US,³⁰ found that Alzheimer's disease was the only specific cause of death among eleven reported for which hospice utilization rates were higher among African-Americans compared to Whites (45% versus 40%). This difference was most marked among females and older age groups. The reason why non-White patients with dementia, in contrast to other conditions, would be more likely to receive hospice care is unclear.

The onset of eating problems in advanced dementia often heralds that the patient is nearing the end-of-life. Thus, it is not surprising that residents with eating problems were more likely to be referred to hospice compared to those without this problem. Similarly, residents whose family members perceived that they had less than 6 months to live were more likely to receive hospice care compared to those whose families do not recognize that the resident was in the terminal stage of the disease. This finding supports the notion that the challenge of prognostication in advanced dementia may a key barrier to delivering hospice services to these patients.^{4, 10} Better prognostic awareness among family members is also associated with less use of burdensome intervention in the last 90 days of life among NH residents with advanced dementia.⁹

Our study confirms prior research by Miller et al. which found an association between hospice enrollment and greater use of opioids to treat pain among NH residents with dementia.³⁹ Our study extends this observation specifically to residents specifically with end-stage dementia and to the treatment of dyspnea among those receiving hospice. In a

mortality follow-back survey, Teno et al. reported that bereaved family members perceived fewer unmet needs among a diverse group of terminally ill patients who received hospice care compared to those who were not recipients of hospice.²⁶ This study extends this finding to NH residents with advanced dementia. Consistent with other reports,^{14, 26} lack of emotional support and inadequate information from providers, were the most common unmet needs reported by bereaved family members.

This study has several noteworthy limitations. First, the study's generalizability is limited by the fact that it was conducted in the Boston-area, examined a predominately White, educated cohort, and did not include community-dwelling patients with advanced dementia. Second, this was an observational study, not a randomized trial of hospice care. Thus, while we adjusted for several important variables (e.g., special care dementia units, frequency of pain and dyspnea, occurrence of acute illness, dementia severity), and to the extent possible, took advantage of the study's prospective design, it is conceivable that unmeasured confounders influenced the analyses examining the outcomes of hospice care. In addition, confounding by indication precluded a valid analysis examining whether or not hospice recipients had better symptomatic control (e.g., reduced pain levels) compared to residents who were not on hospice. Third, despite consistent trends demonstrating fewer unmet needs among hospice recipients during the last 7 days of life, with one exception, we lacked adequate power to detect significant differences. Fourth, data obtained from chart reviews, nurse reports, and HCP interviews are subject to information and recall bias, although any misclassification is likely non-differential between residents who did and did not receive hospice care. Finally, we considered using propensity scores in the analyses but chose not to use them because only 4 variables differed significantly between hospice and non-hospice groups in our multivariate model, propensity scores do not address unobserved covariates any differently than multivariate analyses, and nearly always exclude participants because matches cannot be made.

It is important for health care providers, family members, and policy-makers to have a better understanding of the role of hospice services for dementia patients given the numbers of Americans dying with this condition. Our study suggests that promoting greater prognostic awareness among family members is a modifiable factor that may increase the use of hospice services. Moreover, our results strongly support the notion that hospice is a beneficial, although under-utilized, service for NH residents with advanced dementia and their families. Finally, our findings clearly demonstrate that opportunities exist to improve the end-of-life care for NH residents, not only through greater use of hospice, but also by providing better treatment of pain and dyspnea and addressing unmet needs during the dying process.

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Appendix I: Questions included in each problem of “unmet needs” domain

If any of these needs were not met, then the problem with “unmet needs” was considered present.

“Communication and Shared Decision Making” problem domain

1. HCP did not understand what any doctor said about what to expect from the resident's treatment.
2. HCP did not feel that the doctors listened to concerns about the resident's medical treatment.
3. HCP did not received the right amount (e.g., too much or too little) of information from a doctor concerning the resident's medical condition.

“Information Received” problem domain

1. HCP or family wanted more information about what to expect while the resident was dying.
2. HCP or family wanted more information about what to do at the time of the resident's death.
3. HCP or family wanted more information about the medicines that would be used to manage the resident's pain, shortness of breath or other symptoms.
4. HCP was not always informed about the resident's condition.

“Emotional Support” problem domain

1. No one talked with the HCP about his/her religious or spiritual beliefs.
2. If it was done, this was not done in a sensitive manner.
3. If it was done, there was not enough talking done.
4. There was not enough support in dealing with the HCP's feelings about the resident's death.
5. None of the professional staff taking care of the resident talked in a sensitive manner about how the HCP might feel after the resident's death.
6. Though the HCP did not receive it, the HCP wanted the professional staff taking care of the resident to talk about how the HCP might feel after the resident's death.

“Help” problem domain

1. There was not enough help available to meet the resident's personal care needs, like bathing, dressing, feeding, and going to the bathroom.
2. There was not enough help with medications and getting dressings changed. If any of these needs were not met, then the “help” problem with “unmet needs” was considered present.

References

1. Hebert LE, Scherr PA, Bienias JL, et al. Alzheimer disease in the US population: prevalence estimates using the 2000 census. *Arch Neurol* 2003;60:1119–1122. [PubMed: 12925369]
2. Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med* 2004;164:321–326. [PubMed: 14769629]
3. NIH. National Institutes of Health. State-of-Science Conference Statement: Improving End-of-Life Care. 2005

4. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med* 2004;19:1057–1063. [PubMed: 15482560]
5. Sloane PD, Zimmerman S, Hanson L, et al. End-of-life care in assisted living and related residential care settings: Comparison with nursing homes. *J Am Geriatr Soc* 2003;51:1587–1594. [PubMed: 14687388]
6. Volicer L, Hurley AC, Blasi ZV. Characteristics of dementia end-of-life care across care settings. *Am J Hosp Palliat Care* 2003;20:191–200. [PubMed: 12785040]
7. Medical guidelines for determining prognosis in selected non-cancer diseases. The National Hospice Organization. *Hosp J* 1996;11:47–63. [PubMed: 8949013]
8. Mitchell SL, Morris JN, Park PS, et al. Terminal care for persons with advanced dementia in the nursing home and home care settings. *J Palliat Med* 2004;7:808–816. [PubMed: 15684848]
9. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009;361:1529–1538. [PubMed: 19828530]
10. Mitchell SL, Kiely DK, Hamel MB, et al. Estimating prognosis for nursing home residents with advanced dementia. *JAMA* 2004;291:2734–2740. [PubMed: 15187055]
11. Mitchell SL, Teno JM, Miller SC, et al. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc* 2005;53:299–305. [PubMed: 15673356]
12. NHPCO Facts and Figures: Hospice Care in American. 2009 [January 15, 2010]. Edition: <http://www.nhpc.org/i4a/pages/index.cfm?pageid=5994>
13. Miller SC, Kiely DK, Teno JM, et al. Hospice care for patients with dementia: Does volume make a difference? *J Pain Symptom Manage* Mar.2008 35:283–291. [PubMed: 18215499]
14. Mitchell SL, Kiely DK, Miller SC, et al. Hospice care for patients with dementia. *J Pain Symptom Manage* 2007;34:7–16. [PubMed: 17509813]
15. Miller SC, Gozalo P, Mor V. Hospice enrollment and hospitalization of dying nursing home patients. *Am J Med* 2001;111:38–44.
16. Shega JW, Hougham GW, Stocking CB, et al. Patients dying with dementia: Experience at the end of life and impact of hospice care. *J Pain Symptom Manage* 2008;35:499–507. [PubMed: 18261878]
17. Mitchell SL, Kiely DK, Jones RN, et al. Advanced dementia research in the nursing home: the CASCADE study. *Alzheimer Dis Assoc Disord* Jul-Sep;2006 20(3):166–175. [PubMed: 16917187]
18. Reisberg B, Ferris SH, de Leon MJ, et al. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry* 1982;139:1136–1139. [PubMed: 7114305]
19. Albert M, Cohen C. The Test for Severe Impairment: An instrument for the assessment of patients with severe cognitive dysfunction. *J Am Geriatr Soc* 1992;40:449–453. [PubMed: 1634695]
20. Volicer L, Hurley AC, Lathi DC, et al. Measurement of severity in advanced Alzheimer's disease. *J Gerontol* 1994;49:M223–226. [PubMed: 8056941]
21. Ware J Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Med Care* 1996;34:220–233. [PubMed: 8628042]
22. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of End-of-life care in dementia. *Alzheimer Dis Assoc Disord* 2001;15:194–200. [PubMed: 11723370]
23. Kiely DK, Volicer L, Teno J, et al. The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis Assoc Disord* 2006;20:176–181. [PubMed: 16917188]
24. Teno JM, Casey VA, Welch LC, et al. Patient-focused, family-centered end-of-life medical care: Views of the guidelines and bereaved family members. *J Pain Symptom Manage* 2001;22:738–751. [PubMed: 11532587]
25. Teno JM, Clarridge B, Casey V, et al. Validation of toolkit after-death bereaved family member interview. *J Pain Symptom Manage* 2001;22:752–758. [PubMed: 11532588]
26. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291:88–93. [PubMed: 14709580]
27. Bekelman DB, Black BS, Shore AD, et al. Hospice care in a cohort of elders with dementia and mild cognitive impairment. *J Pain Symptom Manage* 2005;30:208–214. [PubMed: 16183004]

28. duPreez AE, Smith MA, Liou JI, et al. Predictors of hospice utilization among acute stroke patients who died within thirty days. *J Palliat Med* 2008;11:1249–1257. [PubMed: 19021489]
29. Hirji KF, Mehta CR, Patel NR. Computing distributions for exact logistic regression. *JASA* 1987;82:1110–1117.
30. Connor SR, Elwert F, Spence C, et al. Racial disparity in hospice use in the United States in 2002. *J Palliat Med* 2008;22:205–213.
31. Colon M, Lyke J. Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *Am J Hosp Palliat Care* 2003;20:182–190. [PubMed: 12785039]
32. Enguidanos S, Yip J, Wilber K. Ethnic variation in site of death of older adults dually eligible for Medicaid and Medicare. *J Am Geriatr Soc* 2005;53:1411–1416. [PubMed: 16078971]
33. Givens J, Tjia J, Zhou C, et al. Racial differences in hospice utilization for heart failure. *Arch Intern Med* 2010;170:427–432. [PubMed: 20212178]
34. Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. *J Am Geriatr Soc* 2003;51:970–978. [PubMed: 12834517]
35. Han B, Remsburg RE, Iwashyna TJ. Differences in hospice use between black and white patients during the period 1992 through 2000. *Med Care* 2006;44:731–737. [PubMed: 16862034]
36. Johnson KS, Kuchibhatla M, Tanis D, et al. Racial differences in the growth of noncancer diagnoses among hospice enrollees. *J Pain Symptom Manage* 2007;34:286–293. [PubMed: 17555922]
37. Smith AK, Earle CC, McCarthy EP. Racial and ethnic differences in end-of-life care in fee-for-service Medicare beneficiaries with advanced cancer. *J Am Geriatr Soc* 2009;57:153–158. [PubMed: 19054185]
38. Virnig BA, Marshall McBean A, Kind S, et al. Hospice use before death: Variability across cancer diagnoses. *Med Care* 2002;40:73–78. [PubMed: 11748429]
39. Miller SC, Mor V, Teno J. Hospice enrollment and pain assessment and management in nursing homes. *J Pain Symptom Manage* 2003;26:791–799. [PubMed: 12967728]

Figure 1.

Percent of health care proxies perceiving unmet needs in four domains of care for nursing home (NH) residents (N=137) with advanced dementia during the last 7 days of life including: 1) communication with NH providers, 2) information received by NH providers, 3) emotional support provided to the HCPs, and 4) help with basic care provided to the resident. Blue columns represent residents who received hospice care while dying (N=41) and the red columns represent residents who did not receive hospice care while dying (N=96). (No residents who received hospice care had an unmet need with help for their basic care.) The last set of columns presents the proportion of residents who experienced an unmet need in at least one of the four domains. Odds ratios (95% confidence intervals) are presented to estimate the relative protective effect of hospice services on unmet needs.

Table 1
Baseline characteristics of nursing home residents with advanced dementia and their health care proxies (N=323)

Characteristic	No. (%) or Mean $\pm$ SD
Resident	
Hospice utilization	72 (22.3)
Age (years)	85.3 $\pm$ 7.5
Female	276 (85.4)
Race	
White	289 (89.5)
African-American	33 (10.2)
Asian	1 (0.3)
Education $\geq$ high school graduate	236 (77.4)
Marital status	
Widowed	197 (61.0)
Married	64 (19.8)
Divorced or never married	62 (19.2)
Health Care Proxy	
Age (years)	60.0 $\pm$ 11.6
Female	206 (63.8)
Education $\geq$ high school graduate	309 (95.7)
Religion	
Catholic	178 (55.1)
Protestant	72 (22.3)
Jewish	48 (14.9)
Other	25 (7.7)
Relationship to resident	
Son or daughter (child)	218 (67.5)
Spouse	33 (10.2)
Niece or nephew	28 (8.7)
Sibling	16 (5.0)
Grandchild	1 (1.2)
Legal guardian	10 (3.1)
Other	14 (4.3)

Table 2
Factors associated with hospice referral in nursing home residents with advanced dementia (N=259).*

Characteristic	Residents not Referred to Hospice Mean (SD) or No. (%) N=206	Residents Referred to Hospice Mean (SD) or No. (%) N=53	Unadjusted Odds Ratio [†] (95% CI)	Adjusted Odds Ratio [†] (95% CI)
Resident				
Age (years)	85.0 (7.2)	86.0 (7.9)	1.00 (0.97-1.04)	-
Female	175 (84.9)	44 (83.0)	0.85 (0.43-1.70)	-
Non-White race	19 (9.2)	12 (22.6)	2.14 (1.08-4.25)	2.55 (1.36-4.76)
Lived in Special-Care Dementia Unit	83 (40.3)	21 (39.6)	0.81 (0.35-1.87)	-
Length of Stay > 1114 days (median)	109 (52.9)	21 (39.6)	0.59 (0.37-0.92)	-
Alzheimer's Disease (vs. other dementia)	153 (74.3)	44 (83.0)	1.44 (0.76-2.72)	-
Do Not Hospitalize	127 (63.5)	36 (67.9)	1.60 (0.74-3.48)	-
Resident				
TSI > 0 [‡]	33 (16.0)	8 (15.1)	1.11 (0.53-2.44)	-
BANS-S score > 6 status [§]	65 (31.5)	20 (37.7)	1.23 (0.77-1.96)	-
Eating Problem	30 (14.6)	28 (52.8)	4.10 (1.99-8.45)	4.21 (1.99-8.90)
Acute Event (prior 90 days) [¶]	44 (21.4)	16 (30.2)	1.29 (0.80-2.10)	-
Pain [#]	14 (9.0)	4 (10.8)	1.16 (0.50-2.66)	-
Dyspnea ^{**}	19 (12.2)	5 (13.5)	1.07 (0.60-1.90)	-
Heath Care Proxy				
Age	60.6 (11.7)	58.2 (10.6)	0.99 (0.96-1.01)	-
Female	132 (64.1)	36 (67.9)	1.47 (0.92-2.37)	-
Education > high school graduate	196 (95.1)	51 (96.2)	1.01 (0.31-3.28)	-
Christian (vs. other religion)	181 (90.5)	45 (86.5)	0.61 (0.28-1.36)	-
Child of the resident	137 (66.5)	34 (64.1)	0.86 (0.52-1.43)	-
Previously lived with resident	82 (39.8)	19 (35.8)	0.81 (0.58-1.18)	-
Visits resident > 7 hours per week	32 (15.5)	9 (17.3)	1.07 (0.67-1.70)	-
> 15 minutes spent discussing advance directives	98 (49.7)	31 (58.5)	1.13 (0.59-2.15)	-
Heath Care Proxy				
Understood expected clinical complications	66 (32.0)	16 (30.2)	0.74 (0.49-1.14)	-
Believes resident has < 6 months to live	6 (2.3)	8 (15.1)	3.54 (1.53-8.21)	3.83 (1.29-11.37)
SF 12 mental subscale ^{††}	51.0 (10.0)	53.4 (7.5)	1.03 (1.00-1.05)	1.04 (1.01-1.06)
SWC-EOLD scale ^{‡‡}	32.3 (4.6)	31.5 (5.1)	0.97 (0.92-1.02)	-

SD = standard deviation

CI = Confidence Interval

* Among the 323 residents in the cohort, this analysis excluded residents who lived in a facility that did not contract with a hospice provider (N=46), as well as those who were on hospice at baseline (N=18), for a sample size of N=259.

[†] General estimated equations accounted for clustering at the facility level in both the unadjusted and adjusted analyses.

[‡] TSI – Test for Severe Impairment (possible scores 0-24; lower scores indicate greater impairment).

[§] BANS-S – Bedford Alzheimer Nursing Scale – Severity Subscale (possible scores 7-28; higher scores indicate greater functional disability; median = 6).

^{||} Eating problem - documentation of any of the following: weight loss, swallowing problems (e.g., aspiration), chewing problems (e.g., spitting food) and refusal to eat.

[¶] Acute event - the occurrence of any of the following: suspected pneumonia, febrile episode, new eating problem, other sentinel event, hospitalization, or emergency room visit.

[#] Pain - binary: none or rarely (< 5 days /month) code as 0; sometimes (5-10 days/month) or often (11-20 days/month) or almost daily (>20 days/month) coded as 1.

^{**} Dyspnea - binary: none or rarely (< 5 days /month) coded as 0; sometimes (5-10 days/month) or often (11-20 days/month) or almost daily (>20 days/month) coded as 1.

^{††} SF-12 mental – Medical Outcomes Survey 12-item Short Form (higher scores indicating greater mental health).

^{‡‡} SWC-EOLD – Satisfaction with Care at End-of-Life in Dementia Scale (possible scores 10-40; higher scores indicate more satisfaction)

Table 3

Association between hospice utilization and treatment for distressing symptoms (pain and dyspnea) among nursing home residents with advanced dementia.*

Hospice status at time of assessment	Treatment provided for pain ^f 101/432 (23.4%)	Unadjusted Odds Ratio (Confidence Interval _{95%})	Adjusted ^g Odds Ratio (Confidence Interval _{95%})	Treatment provided for dyspnea ^h 257/381 (67.5%)	Unadjusted Odds Ratio (Confidence Interval _{95%})	Adjusted ^g Odds Ratio (Confidence Interval _{95%})
On Hospice	29/60 (48.3%)	3.90 (2.11 – 7.21)	3.16 (1.57 – 6.36)	64/77 (83.1%)	2.83 (1.34 – 6.00)	3.28 (1.37 – 7.86)
Not on Hospice	72/372 (19.4%)	Referent	Referent	193/304 (63.5%)	Referent	Referent

* Analyses were conducted at the level of the assessment. Assessments were obtained on a quarterly basis over 18 months from 323 residents with advanced dementia. At each assessment, the frequency with which resident experience distressing symptoms were recorded (never, rarely (< 5 days /month), sometimes (5-10 days/month), often (11-20 days/month), or almost daily (>20 days/month). Only assessments where the residents experienced symptoms (i.e., > never) were analyzed. There were 432 assessments on which residents had pain and 381 assessments on which residents had dyspnea.

^f Treatment for any pain: scheduled oral or parenteral (intravenous, subcutaneous, transdermal, or sublingual) opioid (as needed or prn dosing not included).

^g Treatment for any shortness of breath included any of the following modalities: oxygen, morphine, scopolamine, or hyoscyamine.

^h Adjusted for the age, gender, special care unit, occurrence of an acute illness over the prior 90 days (the occurrence of any of the following: suspected pneumonia, febrile episode, new eating problem, other sentinel event, hospitalization, or emergency room visit.), and frequency of the distressing symptom. Clustering at the resident level was accounted for using general estimated equations.