**Our Mission:** Helping to prepare Iowa’s health practitioners to care for our growing population of elders. *E-NEWS* is one of our methods of teaching through technology.

Each month, *E-NEWS* delivers abstracts from current multidisciplinary healthcare journal articles related to a specific geriatric topic. This month’s *E-NEWS* focuses on **TRANSITIONS IN CARE AND HOSPICE CARE IN DEMENTIA**.

**TRANSITIONS IN CARE AND HOSPICE CARE IN DEMENTIA**

In this issue of the *E-NEWS*, you will find abstracts for:

- A study that analyzes the quality of hospice care for individuals with dementia.
- A study that describes transitions in care for older adults with and without dementia with attention to nursing facility transitions.
- A study that examines end-of-life health care transitions among nursing home residents with cognitive issues.
- A study that explores the influence of hospice on nursing home residents with advanced dementia who received skilled nursing facility care near the end of life.
- A study that evaluates the growth of access to hospice care for people with dementia in U.S. nursing homes.
- An article that discusses priorities for advanced dementia in the next decade, including treatment, access to services, and coordination of care.
- A study that compares the Advanced Dementia Prognostic Tool (ADEPT) with hospice eligibility guidelines to estimate 6-month survival of nursing home residents with advanced dementia.
- An article that addresses transitions in dementia care.
- A white paper that defines optimal palliative care in older adults with dementia.

BACKGROUND: Patients with dementia constitute an increasing proportion of hospice enrollees, yet little is known about the quality of hospice care for this population. The aim of this study was to quantify differences in quality of care measures between hospice patients with and without dementia. DESIGN: Cross-sectional analysis of data. SETTING: 2007 National Home and Hospice Care Survey. PARTICIPANTS: Four thousand seven hundred eleven discharges from hospice care. MEASUREMENTS: A primary diagnosis of dementia at discharge was defined according to International Classification of Diseases, Ninth Revision, codes (290.0-290.4x, 294.0, 294.1, 294.8, 331.0-331.2, 331.7, and 331.8). Quality-of-care measures included enrollment in hospice in the last 3 days of life, receiving tube feeding, depression, receiving antibiotics, lack of advanced directive or do not resuscitate order, Stage II or greater pressure ulcers, emergency care, lack of continuity of residence, and a report of pain at last assessment. RESULTS: Four hundred fifty (9.5%) individuals were discharged with a primary diagnosis of dementia. In multivariable analysis, individuals with dementia were more likely to receive tube feeding (odds ratio (OR) = 2.6, 95% confidence interval (CI) = 1.4-4.5) and to have greater continuity of residence (OR = 1.8, 95% CI = 1.1-3.0) than other individuals in hospice and less likely to have a report of pain at last assessment (OR = 0.6, 95% CI = 0.3-0.9). CONCLUSIONS: The majority of quality-of-care measures examined did not differ between individuals in hospice with and without dementia. Use of tube feeding in hospice care and methods of pain assessment and treatment in individuals with dementia should be considered as potential quality-of-care measures. © 2013, Copyright the Authors.


OBJECTIVES: To describe transitions in care of persons with dementia with attention to nursing facility transitions. DESIGN: Prospective cohort. SETTING: Public health system. PARTICIPANTS: Four thousand one hundred ninety-seven community-dwelling older adults. MEASUREMENTS: Participants' electronic medical records were merged with Medicare claims, Medicaid claims, the Minimum Data Set (MDS), and the Outcome and Assessment Information Set (OASIS) from 2001 to 2008 with a mean follow-up of 5.2 years from the time of enrollment. RESULTS: Older adults with prevalent (n = 524) or incident (n = 999) dementia had greater Medicare (44.7% vs 44.8% vs 11.4%, P < .001) and Medicaid (21.0% vs 16.8% vs 1.4%, P < .001) nursing facility use, greater hospital (76.2% vs 86.0% vs 51.2%, P < .001) and home health (55.7% vs 65.2% vs 27.3%, P < .001) use, more transitions in care per person-year of follow-up (2.6 vs 2.7 vs 1.4, P < .001), and more mean total transitions (11.2 vs 9.2 vs 3.8, P < .001) than those who were never diagnosed (n = 2,674). For the 1,523 participants with dementia, 74.5% of transitions to nursing facilities were transfers from hospitals. For transitions from nursing facilities, the conditional probability was 41.0% for a return home without home health care, 10.7% for home health care, and 39.8% for a hospital transfer. Of participants with dementia with a rehospitalization within 30 days, 45% had been discharged to nursing facilities from the index hospitalization. At time of death, 46% of participants with dementia were at home, 35% were in the hospital, and 19% were in a nursing facility. CONCLUSION: Individuals with dementia live and frequently die in community settings. Nursing facilities are part of a dynamic network of care characterized by frequent transitions. © 2012, Copyright the Authors.


BACKGROUND: Health care transitions in the last months of life can be burdensome and potentially of limited clinical benefit for patients with advanced cognitive and functional impairment. METHODS: To examine health care transitions among Medicare decedents with advanced cognitive and functional impairment who were nursing home residents 120 days before death, we linked nationwide data from the Medicare Minimum Data Set and claims files from 2000 through 2007. We defined patterns of transition as burdensome if they occurred in the last 3 days of life, if there was a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or if there were multiple hospitalizations in the last 90 days of life. We also considered various factors explaining variation in these rates of burdensome transition. We examined whether there was an association between regional rates of burdensome transitions and the likelihood of feeding-tube insertion, hospitalization in an intensive care unit (ICU) in the last month of life, the presence of a stage IV decubitus
ulcer, and hospice enrollment in the last 3 days of life. RESULTS: Among 474,829 nursing home decedents, 19.0% had at least one burdensome transition (range, 2.1% in Alaska to 37.5% in Louisiana). In adjusted analyses, blacks, Hispanics, and those without an advance directive were at increased risk. Nursing home residents in regions in the highest quintile of burdensome transitions (as compared with those in the lowest quintile) were significantly more likely to have a feeding tube (adjusted risk ratio, 3.38), have spent time in an ICU in the last month of life (adjusted risk ratio, 2.10), have a stage IV decubitus ulcer (adjusted risk ratio, 2.28), or have had a late enrollment in hospice (adjusted risk ratio, 1.17). CONCLUSIONS: Burdensome transitions are common, vary according to state, and are associated with markers of poor quality in end-of-life care.


OBJECTIVES: To examine differences in outcomes according to hospice status of skilled nursing facility (SNF) care recipients. DESIGN: Retrospective cohort. SETTING: Three thousand three hundred fifty-three U.S. nursing homes (NHs). PARTICIPANTS: Four thousand three hundred forty-four persons with advanced dementia who died in NHs in 2006 and received SNF care within 90 days of death were studied, 1,086 of these also received hospice before death: 705 after SNF care, and 381 concurrent with SNF care. MEASUREMENTS: Treatments, persistent pain and dyspnea, and hospital death. RESULTS: Decedents with any hospice received fewer medications, injections, feeding tubes, intravenous fluids, and therapy services and more hypnotics than those without hospice (all P < .001). Decedents with hospice after SNF care received fewer antipsychotics and those with hospice concurrent with SNF care received more antipsychotics than those without (all P < .001). Multivariate logistic regressions showed that decedents with hospice after SNF had lower likelihood of persistent dyspnea (adjusted odds ratio (AOR) = 0.63, 95% confidence interval (CI) = 0.45-0.87) and hospital death (AOR = 0.02, 95% CI = 0.01, 0.07) than those without hospice. Decedents with hospice concurrent with SNF care had a higher likelihood of persistent pain (AOR = 1.65, 95% CI = 1.23, 2.19) and a lower likelihood of hospital death (AOR = 0.13, 95% CI = 0.07, 0.26) than those without hospice. CONCLUSION: Residents dying with advanced dementia who received SNF care in the last 90 days of life had fewer aggressive treatments and lower odds of hospital death if they also received hospice care at any point during that time. Associations between hospice and persistent pain or dyspnea differed according to whether hospice care was received concurrent with or after SNF care. © 2012, Copyright the Authors.


BACKGROUND/RATIONALE: Persons with dementia often die in nursing homes (NHs); however, concerns exist about their low use of Medicare hospice. METHODS: For 1999 through 2006 in all US states and DC we merged NH resident assessment data with Medicare claims and enrollment data to identify NH decedents with dementia and hospice use. We studied two groups, those with advanced dementia and those with mild-to-moderately severe dementia. RESULTS: Across study years, 22.2% of all NH decedents had mild-to-moderately severe dementia and 19.6% had advanced dementia. In 1999, 14.5% of decedents with advanced and 13.2% with mild-to-moderately severe dementia accessed hospice, increasing to 42.5% and 37.9% respectively in 2006. Between 1999 and 2006, mean days of hospice stays increased from 46 to 118 for advanced dementia and from 39 to 79 for mild-to-moderately severe dementia. These mean length of stay differences resulted from a relatively lower proportion of short hospice stays (≤ 7 days) together with higher proportions of longer stays (≥ 181 days) among advanced versus mild-to-moderately severe dementia decedents. Hospice access and lengths of stay among US states varied widely. CONCLUSIONS: Over 40% of US NH decedents have mild-to-moderately severe or advanced dementia. For these NH decedents, access to and duration of Medicare hospice has increased. However, there is considerable variation in hospice use across US states.

Dementia is a leading cause of death in the United States. This article outlines the current understanding of advanced dementia and identifies research priorities for the next decade. Research over the past 25 years has largely focused on describing the experience of patients with advanced dementia. This work has delineated abundant opportunities for improvement, including greater recognition of advanced dementia as a terminal illness, better treatment of distressing symptoms, increased access to hospice and palliative care services, and less use of costly and aggressive treatments that may be of limited clinical benefit. Addressing those opportunities must be the overarching objective for the field in the coming decade. Priority areas include designing and testing interventions that promote high-quality, goal-directed care; health policy research to identify strategies that incentivize cost-effective and evidence-based care; implementation studies of promising interventions and policies; and further development of disease-specific outcome measures. There is great need and opportunity to improve outcomes, contain expenditures, reduce disparities, and better coordinate care for the millions of persons in the United States who have advanced dementia.

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CONTEXT: Estimating life expectancy is challenging in advanced dementia, potentially limiting the use of hospice care in these patients. OBJECTIVE: To prospectively validate and compare the performance of the Advanced Dementia Prognostic Tool (ADEPT) and hospice eligibility guidelines to estimate 6-month survival in nursing home residents with advanced dementia. DESIGN, SETTING, AND PARTICIPANTS: A prospective cohort study conducted in 21 nursing homes in Boston, Massachusetts, of 606 residents with advanced dementia who were recruited between November 1, 2007, and July 30, 2009. Data were ascertained at baseline to determine the residents’ ADEPT score (range, 1.0-32.5; higher scores indicate worse prognosis) and whether they met Medicare hospice eligibility guidelines. Survival was followed up to 6 months. MAIN OUTCOME MEASURES: Assessment and comparison of the performance of the ADEPT score and hospice guidelines to predict 6-month survival using sensitivity, specificity, and the area under the receiver operating characteristic (AUROC) curve. RESULTS: At baseline, the residents’ mean (SD) ADEPT score was 10.1 (3.1) points and 65 residents (10.7%) met hospice eligibility guidelines. Over 6 months, 111 residents (18.3%) died. The AUROC for the ADEPT score's prediction of 6-month mortality as a continuous variable was 0.67 (95% confidence interval [CI], 0.62-0.72). The AUROC for Medicare hospice eligibility guidelines was 0.55 (95% CI, 0.51-0.59), the specificity was 0.89 (95% CI, 0.86-0.92), and the sensitivity was 0.20 (95% CI, 0.13-0.28). Using a cutoff of 13.5 on the ADEPT score, which also had specificity of 0.89, the AUROC was 0.58 (95% CI, 0.54-0.63) and the sensitivity was 0.27 (95% CI, 0.19-0.36). CONCLUSIONS: When prospectively validated at the bedside and used as a continuous measure, the ability of the ADEPT score to identify nursing home residents with advanced dementia at high risk of death within 6 months was modest, albeit better than hospice eligibility guidelines. Care provided to these residents should be guided by their goals of care rather than estimated life expectancy.

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There are several predictable transitions in the course of dementia, and care is often provided by family members in the earlier stages. Later stages often include the move to one or more care settings. Important transitions for those with dementia and their families and/or caregivers include the initial diagnosis of dementia; advanced planning for financial concerns and healthcare considerations; driving cessation; managing behavioral symptoms; changes in settings; and preparing for end-of-life. Evidence has emerged to inform the important roles nurses may have in each of the transitions. In this article, we explore the concept of transitional care and how it relates to nursing care of older adults with Alzheimer's disease and other dementias. We begin by briefly describing a middle-range theory of transitions. Next, we describe the dementia trajectory and provide evidence for expanding nursing roles in transitions. Also included are recommendations for research in the area of roles and transitional care.

IMPORTANCE: A recent Centers for Disease Control and Prevention report found that more persons die at home. This has been cited as evidence that persons dying in the United States are using more supportive care. OBJECTIVE: To describe changes in site of death, place of care, and health care transitions between 2000, 2005, and 2009. DESIGN, SETTING, AND PATIENTS: Retrospective cohort study of a random 20% sample of fee-for-service Medicare beneficiaries, aged 66 years and older, who died in 2000 (n = 270,202), 2005 (n = 291,819), or 2009 (n = 286,282). A multivariable regression model examined outcomes in 2000 and 2009 after adjustment for sociodemographic characteristics. Based on billing data, patients were classified as having a medical diagnosis of cancer, chronic obstructive pulmonary disease, or dementia in the last 180 days of life. MAIN OUTCOME MEASURES: Site of death, place of care, rates of health care transitions, and potentially burdensome transitions (e.g., health care transitions in the last 3 days of life). RESULTS: Our random 20% sample included 848,303 fee-for-service Medicare decedents (mean age, 82.3 years; 57.9% female, 88.1% white). Comparing 2000, 2005, and 2009, the proportion of deaths in acute care hospitals decreased from 32.6% (95% CI, 32.4%-32.8%) to 26.9% (95% CI, 26.7%-27.1%) to 24.6% (95% CI, 24.5%-24.8%), respectively. However, intensive care unit (ICU) use in the last month of life increased from 24.3% (95% CI, 24.1%-24.5%) to 26.3% (95% CI, 26.1%-26.5%) to 29.2% (95% CI, 29.0%-29.3%). (Test of trend P value was <.001 for each variable.) Hospice use at the time of death increased from 21.6% (95% CI, 21.4%-21.7%) to 32.3% (95% CI, 32.1%-32.5%) to 42.2% (95% CI, 42.0%-42.4%), with 28.4% (95% CI, 27.9%-28.5%) using a hospice for 3 days or less in 2009. Of these late hospice referrals, 40.3% (95% CI, 39.7%-40.8%) were preceded by hospitalization with an ICU stay. The mean number of health care transitions in the last 90 days of life increased from 2.1 (interquartile range [IQR], 0.0-5.0) to 2.8 (IQR, 1.0-4.0) to 3.1 per decedent (IQR, 1.0-5.0). The percentage of patients experiencing transitions in the last 3 days of life increased from 10.3% (95% CI, 10.1%-10.4%) to 12.4% (95% CI, 12.3%-2.5%) to 14.2% (95% CI, 14.0%-14.3%). CONCLUSION AND RELEVANCE: Among Medicare beneficiaries who died in 2009 and 2005 compared with 2000, a lower proportion died in an acute care hospital, although both ICU use and the rate of health care transitions increased in the last month of life.


Background: Dementia is a life-limiting disease without curative treatments. Patients and families may need palliative care specific to dementia. Aim: To define optimal palliative care in dementia. Methods: Five-round Delphi study. Based on literature, a core group of 12 experts from 6 countries drafted a set of core domains with salient recommendations for each domain. We invited 89 experts from 27 countries to evaluate these in a two-round online survey with feedback. Consensus was determined according to predefined criteria. The fourth round involved decisions by the core team, and the fifth involved input from the European Association for Palliative Care. Results: A total of 64 (72%) experts from 23 countries evaluated a set of 11 domains and 57 recommendations. There was immediate and full consensus on the following eight domains, including the recommendations: person-centered care, communication and shared decision-making; optimal treatment of symptoms and providing comfort (these two identified as central to care and research); setting care goals and advance planning; continuity of care; psychosocial and spiritual support; family care and involvement; education of the health care team; and societal and ethical issues. After revision, full consensus was additionally reached for prognostication and timely recognition of dying. Recommendations on nutrition and dehydration (avoiding overly aggressive, burdensome or futile treatment) and on dementia stages in relation to care goals (applicability of palliative care) achieved moderate consensus. Conclusion: We have provided the first definition of palliative care in dementia based on evidence and consensus, a framework to provide guidance for clinical practice, policy and research.
Next Month’s Issue:

Mild Cognitive Impairment

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