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 ADVANCE CARE PLANNING AND FAMILY ISSUES IN DEMENTIA.

ADVANCE CARE PLANNING AND FAMILY ISSUES IN DEMENTIA

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

- A study that seeks to determine whether advance care planning influences the quality of end-of-life care for older adults.
- An article that discusses the Physician Orders for Life-Sustaining Treatment (POLST) program.
- A study that analyzes the incidence and predictors of advance care planning among persons with cognitive impairment.
- A study that examines sources of stress for family members of nursing home residents with advanced dementia.
- A study that addresses surrogate decision makers' beliefs and values regarding dementia, goals of care, and personhood.
- A study that evaluates advance care planning in early dementia.
- A study that explores how caregivers' understanding of dementia predicts patients' comfort at death.
- A study that assesses advance directives and physicians' orders in nursing home residents with dementia.

OBJECTIVES: To determine whether advance care planning influences quality of end-of-life care. DESIGN: In this observational cohort study, Medicare data and survey data from the Health and Retirement Study (HRS) were combined to determine whether advance care planning was associated with quality metrics. SETTING: The nationally representative HRS. PARTICIPANTS: Four thousand three hundred ninety-nine decedent subjects (mean age 82.6 at death, 55% women). MEASUREMENTS: Advance care planning (ACP) was defined as having an advance directive (AD), durable power of attorney (DPOA) or having discussed preferences for end-of-life care with a next of kin. Outcomes included previously reported quality metrics observed during the last month of life (rates of hospital admission, in-hospital death, >14 days in the hospital, intensive care unit admission, >1 emergency department visit, hospice admission, and length of hospice ≤3 days). RESULTS: Seventy-six percent of subjects engaged in ACP. Ninety-two percent of ADs stated a preference to prioritize comfort. After adjustment, subjects who engaged in ACP were less likely to die in a hospital (adjusted relative risk (aRR) = 0.87, 95% confidence interval (CI) = 0.80-0.94), more likely to be enrolled in hospice (aRR = 1.68, 95% CI = 1.43-1.97), and less likely to receive hospice for 3 days or less before death (aRR = 0.88, 95% CI = 0.85-0.91). Having an AD, a DPOA or an ACP discussion were each independently associated with a significant increase in hospice use (P < .01 for all). CONCLUSION: ACP was associated with improved quality of care at the end of life, including less in-hospital death and increased use of hospice. Having an AD, assigning a DPOA and conducting ACP discussions are all important elements of ACP. © 2013, Copyright the Authors.


Physician Orders for Life-Sustaining Treatment (POLST) is a process that translates a patient's goals for care at the end of life into medical orders that follow the patient across care settings. POLST overcomes the limitations of traditional advance directives. It enables physicians and other health care professionals, through a conversation with a patient or surrogate, to assess and convey the wishes of patients with serious life-limiting illness who may have a life expectancy of less than 1 year, or of anyone of advanced age interested in defining his or her wishes for end-of-life care.


OBJECTIVE: Persons with mild cognitive impairment (MCI) and Alzheimer disease (AD) are at heightened risk for future decisional incapacity. We sought to characterize advance care planning (ACP) rates over time in individuals who had no advance directives (living will or durable power of attorney) in place when they initially presented for a cognitive evaluation. DESIGN: Retrospective analysis of data that had been prospectively collected. SETTING: Alzheimer's Disease Research Center memory disorders clinic. PARTICIPANTS: Persons (N = 127) with a diagnosis of MCI or early AD (n = 72) or moderate to severe AD (n = 55) and no advance directives upon initial presentation for a cognitive evaluation. MEASUREMENTS: Extraction of responses to items pertaining to ACP assessed during annual semistructured interviews. RESULTS: By 5 years of follow-up, 39% of the sample had initiated ACP, with little difference by baseline diagnosis. Younger subjects (younger than 65 years) were significantly more likely to initiate advance directives (43%) than older subjects (37%). This age effect was more pronounced in men than in women as well as in married subjects, those with a family history of dementia, those with no depressive disorder, and subjects with moderate to severe AD (versus those with MCI or early AD) at baseline. CONCLUSION: Only a minority of subjects initiated ACP. The findings suggest the need for interventions aimed at enhancing ACP completion rates, particularly among older adults with cognitive impairment, since these individuals may have a time-limited opportunity to plan for future medical, financial, and other major life decisions.
The sources of stress for families of nursing home (NH) residents with advanced dementia have not been well described. Semistructured interviews were conducted with 16 family members previously enrolled in the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life study, a prospective cohort of 323 NH residents with advanced dementia and their family members. Questions were asked pertaining to the experience of having a family member in the NH, communication with health-care professionals, surrogate decision making, emotional distress, and recommendations for improvement in care. Transcripts were analyzed using the constant comparative method. The majority of the participants were women (63%), children of the resident (94%), and white (94%). The average age was 62 years. Four themes emerged: (1) inadequate resident personal care, resulting in family member vigilance and participation in care; (2) stress at the time of NH admission; (3) lack of communication with NH physicians; and (4) challenges of surrogate decision making, including the need for education to support advance care planning and end-of-life decisions. Our results support the provision of emotional support to families upon resident admission, education regarding prognosis to guide decision making, improved resident care, and greater communication with health care professionals.

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Surrogate decision makers for persons with advanced dementia play a key role in making decisions about medical treatments for their loved ones. We conducted in-depth interviews of 20 surrogates to examine their goals of care preferences and beliefs about personhood. All surrogates believed the goal of comfort was important, and 30.0% believed that curing physical problems was important. Significant proportions of surrogates acknowledged dementia-related changes in patients' ability to reason, communicate, and relate to others. Qualitative findings demonstrated diverse beliefs regarding the impact of dementia on factors related to personhood, for example, dignity, respect from others, and having a life worth living. In conclusion, the surrogates we interviewed expressed diverse preferences regarding goals of care and diverse assessments about the impact of dementia on personhood.

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Patients and carers found ACP a positive intervention that helped them think about the future, enabled people with dementia to make their wishes known, and resulted in their feeling relieved and less worried about the future. The importance of sharing the ACP documentation between health service providers was highlighted. CONCLUSIONS: This qualitative evaluation of ACP in early dementia has encouragingly positive results which support the wider application of the intervention in memory services and community mental health teams. Strategies are suggested to support the implementation of ACP further in clinical practice.
van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, Ribbe MW, Deliens L. Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study. 

BACKGROUND: Patients with dementia frequently do not receive adequate palliative care which may relate to poor understanding of the natural course of dementia. We hypothesized that understanding that dementia is a progressive and terminal disease is fundamental to a focus on comfort in dementia, and examined how family and professional caregivers' understanding of the nature of the disease was associated with patients' comfort during the dying process. METHODS: We enrolled 372 nursing home patients from 28 facilities in The Netherlands in a prospective observational study (2007 to 2010). We studied both the families and the physicians (73) of 161 patients. Understanding referred to families' comprehension of complications, prognosis, having been counseled on these, and perception of dementia as "a disease you can die from" (5-point agreement scale) at baseline. Physicians reported on this perception, prognosis and having counseled on this. Staff-assessed comfort with the End-of-Life in Dementia - Comfort Assessment in Dying (EOLD-CAD) scale. Associations between understanding and comfort were assessed with generalized estimating equations, structural equation modeling, and mediator analyses. RESULTS: A family's perception of dementia as "a disease you can die from" predicted higher patient comfort during the dying process (adjusted coefficient -0.8, 95% confidence interval (CI): -1.5; -0.06 point increment disagreement). Family and physician combined perceptions (-0.9, CI: -1.5; -0.2; 9-point scale) were also predictive, including in less advanced dementia. Forty-three percent of the families perceived dementia as a disease you can die from (agreed completely, partly); 94% of physicians did. The association between combined perception and higher comfort was mediated by the families' reporting of a good relationship with the patient and physicians' perception that good care was provided in the last week. CONCLUSIONS: Awareness of the terminal nature of dementia may improve patient comfort at the end of life. Educating families on the nature of dementia may be an important part of advance care planning.


BACKGROUND: Advance care planning (ACP) is an important element of high-quality care in nursing homes, especially for residents having dementia who are often incompetent in decision-making toward the end of life. The aim of this study was describe the prevalence of documented ACP among nursing home residents with dementia in Flanders, Belgium, and associated clinical characteristics and outcomes. METHODS: All 594 nursing homes in Flanders were asked to participate in a retrospective cross-sectional postmortem survey in 2006. Participating homes identified all residents who had died over the last two months. A structured questionnaire was mailed to the nurses closely involved in the deceased resident's care regarding the diagnosis of dementia and documented care planning, i.e. advance patient directives, authorization of a legal representative, and general practitioners' treatment orders (GP orders). RESULTS: In 345 nursing homes (58% response rate), nurses identified 764 deceased residents with dementia of whom 62% had some type of documented care plan, i.e. advance patient directives in 3%, a legal representative in 8%, and GP orders in 59%. Multivariate logistic regression showed that the presence of GP orders was positively associated with receiving specialist palliative care in the nursing home (OR 3.10; CI, 2.07-4.65). Chances of dying in a hospital were lower if there was a GP order (OR 0.38; CI, 0.21-0.70). CONCLUSIONS: Whereas GP orders are relatively common among residents with dementia, advance patient directives and a legal representative are relatively uncommon. Nursing home residents receiving palliative care are more likely to have a GP order. GP orders may affect place of death.

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Next Month’s Issue:

Transitions in Care and Hospice Care in Dementia

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