High Mortality Rates, Distressing Symptoms, and Burdensome Interventions for Nursing Home Residents with Advanced Dementia

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Study Overview

Objective. To describe the clinical course of nursing home residents with advanced dementia.

Design. Multicenter, prospective cohort study.

Setting and participants. Study subjects were recruited between 2003 and 2007 from 22 nursing homes in the Boston area. Inclusion criteria were age 60 years or older; length of stay more than 30 days; and score of 5 or 6 on the Cognitive Performance Scale. The Cognitive Performance Scale is a validated measure that uses 5 variables from the Minimum Data Set to categorize residents by cognition, ranging from intact (score of 0) to very severe impairment (score of 6). Residents meeting these inclusion criteria were evaluated for the following additional requirements: cognitive impairment due to dementia, as documented in the chart; stage 7 on the Global Deterioration Scale, as determined by the resident's nurse (range, 1 through 7; at stage 7, patients have profound cognitive deficits, minimal verbal communication, total functional dependence, incontinence of urine and stool, and inability to ambulate independently); and the availability of an appointed health care proxy who could communicate in English.

Main outcome measures. Data collected included functional status (quantified by nurses using the Bedford Alzheimer's Nursing Severity Subscale; range of scores 7–~~to~~28, with higher scores indicating greater functional disability), cognitive status (evaluated by the Test for Severe Impairment; range of scores 0–~~to~~24, with lower scores indicating greater impairment), clinical complications (including suspected pneumonia, febrile episodes, eating problems, and other sentinel events), interventions (including parenteral therapy, hospitalizations, emergency room visits, and tube feedings), and signs of pain and dyspnea (as observed and documented by the residents' care provider and dichotomized as "none" or "rarely" versus "sometimes," "often," or "almost daily"). Aspiration, agitated behavior, and pressure ulcers were ascertained through interviews with nurses. Data collected from health care proxies at baseline included whether the proxy understood the type of clinical complications expected in advanced dementia and whether a nursing home physician had informed the proxy of the prognosis or the clinical complications expected. At quarterly assessments, the health care proxy was asked whether he or she thought the resident had less than 6 months to live.

Main results. Of the 572 residents with advanced dementia who met all eligibility criteria, 323 residents and their health care proxies were enrolled (56.5%). The mean age of residents was 85.3 years; 85.4% were women; and 89.5% were white. The median length of nursing home stay was 3.0 years, and the median time since diagnosis of dementia was 6.0 years. Alzheimer's disease was the leading cause of dementia (72.4%). Residents had severe functional disability (mean score of the Bedford Alzheimer's Nursing Severity Subscale, 21.0) and cognitive disability (72.7% scored 0 on the Test for Severe Impairment). Over half (54.8%) died over the 18-month study period. The probability of death within 6 months was 24.7%. During the 18-month study period, the probability of at least 1 episode of pneumonia was 41.1%; a febrile episode, 52.6%; and an eating problem, 85.8%. Adjusted 6-month mortality rates after the development of pneumonia, a febrile episode, and eating problems were 46.7%, 44.5%, and 38.6%, respectively. A total of 42 sentinel events (including seizures, gastrointestinal bleeding, hip fractures, other fractures, stroke, pulmonary embolus, and myocardial infarction) occurred in 31 of 323 residents (9.6%). Sentinel events rarely precipitated death—only 7 events occurred during the last 3 months of life among residents who died. The proportion of residents who had distressing symptoms were as follows: dyspnea, 46%; pain, 39.1%; pressure ulcers, 38.7%; agitation, 53.6%; and aspiration, 40.6%. Among residents who died, the proportion who had dyspnea, pain, pressure ulcers, and aspiration increased as the end of life approached. In the last 3 months of life, 40.7% of residents underwent at least 1 burdensome intervention (hospitalization, emergency room visit, parenteral therapy, or tube feeding). Residents whose health care proxies believed that the

resident had less than 6 months to live and understood the clinical complications expected in advanced dementia were less likely to undergo a burdensome intervention during the final 3 months of life than were residents whose health care proxies did not have this understanding (adjusted odds ratio, 0.12 [95% confidence interval, 0.04–0.37]). Receipt of physician counseling was not associated with the likelihood of interventions.

Conclusion. Nursing home residents with advanced dementia have a high mortality rate. Infections and eating problems are likely to develop and are associated with decreased survival. Distressing symptoms are common and increase as death approaches. Many residents undergo burdensome interventions in the final months of life. Residents were less likely to undergo these interventions when health care proxies were aware of the poor prognosis and expected clinical complications.

Commentary

Dementia is a leading cause of death in the United States, and mortality rates are increasing [1]. However, the prognosis, clinical course, and symptom burden associated with advanced dementia remain less well understood than those for more commonly recognized end-of-life conditions such as metastatic cancer [2]. The high mortality rates among residents with advanced dementia in this study, and the fact that the majority of deaths were preceded by complications such as pneumonia, febrile episodes, and eating problems and not by other sentinel events, such as seizures, stroke, pulmonary embolus, and myocardial infarction, support the idea that advanced dementia is itself a terminal illness. The information provided by this study on the type and frequency of such complications, as well as the associated decreased probability of survival, can be used to inform families and caregivers about the expected clinical course of this disease.

This study extends prior work describing distressing symptoms in advanced dementia by demonstrating that these symptoms are increasingly common as death approaches. Furthermore, many participants in this study received aggressive interventions such as tube feedings in the final months of life that may have been of limited benefit. An increased focus on symptom management in advanced dementia and attention to the quality of palliative care in nursing homes (which may be provided concomitantly with more aggressive treatments) are needed.

In recent studies, simply having had a discussion about end-of-life care was associated with less aggressive medical care near death, better patient quality of life, improved caregiver bereavement adjustment, and lower health care costs [3,4]. In this study, receiving counseling was not associated with the likelihood of interventions; however, an awareness of the clinical complications and expected course of advanced dementia was associated with fewer potentially burdensome interventions in the final months of life. These finding supports continued efforts to improve the frequency and quality of end-of-life communication between providers, patients, and family members. In previous work, showing a brief video of a patient with advanced dementia significantly changed preferences for care and eliminated differences in preferences associated with race/ethnicity and educational level [5,6], suggesting that relatively simple interventions may increase understanding about the clinical course of this terminal disease.

The authors note several limitations that should be considered in the interpretation of their results. First, nursing homes included in this study were located in the Boston area and the majority of patients were white. Findings therefore may not generalize to other geographic areas or more diverse patient groups. Second, data were obtained primarily from chart review and nursing reports, which may not be accurate. In particular, distressing symptoms may have been underreported. Third, it is not possible to determine causality in the reported associations between health care proxies' perceptions of prognosis and expected clinical complications and the use or nonuse of burdensome interventions. Finally, it was not possible to determine the time when advanced dementia was first diagnosed. Therefore, survival times reported in this study do not represent survival from disease onset.

Applications for Clinical Practice

This study provides useful information for providers and caregivers about mortality rates and expected clinical complications among patients with advanced dementia. Improvements in the quality of palliative care in nursing homes are needed in order to reduce the number of residents who experience distressing symptoms. Ensuring that caregivers understand the clinical course of this disease may reduce the number of patients who undergo burdensome interventions of unclear benefit.

—Review by Yael Schenker, MD

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