

EDITORIALS



Dying from Dementia

Greg A. Sachs, M.D.

As a teenager, I had the unfortunate but ultimately career-shaping experience of watching my maternal grandmother decline from Alzheimer's disease. She resided in a nursing home, where her final months were marked by repeated courses of antibiotics for infections and the use of restraints or medications to control her agitation before she died from one last infection. Seeing my grandmother in that state was so distressing that my mother eventually stopped taking the grandchildren to visit. My grandmother had little in the way of either comfort or company toward the end. In my medical training, I learned how my grandmother's final months were typical for people dying from dementia. Now, some 30 years after my grandmother's death, end-of-life care for many patients with dementia doesn't look all that different from the treatment she received. Patients in nursing homes who have dementia are at risk for undertreatment of pain and for treatment with burdensome and possibly nonbeneficial interventions, including tube feeding. They are also referred to hospice care at rates far lower than those for patients dying from cancer.¹

Palliative and hospice care could greatly improve the care of patients with advanced dementia — and perhaps simultaneously reduce the cost of care. Hospice care in nursing homes during the last 30 days of life has been associated with a reduction in hospitalization of almost 50%² and with improvements in pain assessment and management.³ Studies have shown that patients with dementia who receive hospice care also have fewer hospitalizations⁴ and milder psychiatric symptoms⁵ as compared with those not receiving hospice care. In addition, the families of patients with dementia who receive hospice care report greater

satisfaction with care.⁴ In fact, families of hospice enrollees with dementia rate the care provided as excellent in about 75% of cases, a rating similar to that reported by families with a relative for whom cancer was the diagnosis for hospice referral.⁶ Barriers to greater use of hospice care for patients with dementia include difficulties estimating prognosis and failure to recognize dementia as a terminal illness that requires palliative care.⁷

Fortunately, the article by Mitchell and colleagues in this issue of the *Journal*⁸ moves the field forward in major ways with respect to both prognosis and the terminal nature of advanced dementia. These investigators conducted a prospective, observational study of 323 patients with advanced dementia in 22 nursing homes in the Boston area, following the patients for up to 18 months. The study subjects could not recognize family members and were capable of minimal verbal communication. They were incontinent, unable to walk independently, and completely dependent on others for all care. Although quite frail, these patients are a typical segment of the nursing home population. The study was designed to provide a better understanding of the clinical epidemiology and lifespan trajectory of this population.

The patients in this study died at a very high rate. The median survival was only 478 days, comparable with the rate for patients who have terminal cancer; nearly 25% died within 6 months of study enrollment. Very few patients had “sentinel events,” such as a stroke, myocardial infarction, or hip fracture; rather, most patients died from infections, eating problems, and other conditions related to their underlying dementia. Pneumonia, febrile episodes, and eating problems were very common, with more than half of the patients hav-

ing febrile episodes and eating problems. Patients who had one of these conditions also had higher rates of death than the overall cohort, with 40 to 50% dying within 6 months of onset. Given this prognosis, it would clearly be possible to anticipate the death of patients in similar circumstances and to discuss goals of care and the option of hospice referral with their proxies.

Palliative care would also be warranted, regardless of prognosis, on the basis of the frequent occurrence of distressing symptoms in the study population. Dyspnea, pain, and agitation — all treatable symptoms — occurred in 40 to 50% of the patients. These symptoms became more common as death neared. Many patients underwent burdensome interventions, such as parenteral therapy and hospitalization, even in the last 3 months of life. These medical treatments may have added to patients' suffering. Importantly, the perceptions of proxies were highly associated with the care patients received. If the proxy perceived that the patient had 6 months or less to live and understood the probable medical complications, the patient was far less likely to receive burdensome interventions in the last 3 months of life.

Clinicians, patients' families, and nursing home staff need to recognize and treat advanced dementia as a terminal illness requiring palliative care. The survival of these patients tends to be measured in months, especially after the occurrence of pneumonia, febrile episodes, or eating problems. Patients with advanced dementia do not need to have another serious illness to qualify for hospice care — dementia comes with a high burden of symptoms that warrant a palliative care approach. Nursing homes hold care planning meetings for patients on admission, quarterly, and after a significant change in clinical status. Thus, there is an existing venue in which providers and families can discuss the sorts of issues raised by Mitchell and colleagues and their implications for individual care. Such discussions could modify proxies' perceptions about prognosis and expected complications, alter decisions about the use of burdensome interventions, and increase referrals to palliative care programs and hospice.

The other audiences for this article should be the policymakers and funders of research, such as the National Institutes of Health, Congress, the

Centers for Medicare and Medicaid Services, and the Office of Inspector General are looking at revising hospice reimbursement,⁹ raising concerns about the provision of hospice care in nursing homes. Although no one can argue against the need to root out fraud and unseemly conflicts of interest, it would be a shame to take hospice away from patients with dementia, who could truly benefit from it. Much more research is needed on the use of palliative care for these patients, including studies on prognosis, patients in less advanced stages of dementia, alternative care settings, intervention trials, and, eventually, the effects of implementing programs designed to improve current systems of care. This research, as well as comparative effectiveness studies on the use of the usual approach to care as compared with a palliative care approach, could inform public policy.

Dr. Sachs reports receiving consulting fees from CVS Caremark and serving on the board of directors of the American Geriatrics Society and the Academic Task Force of the American Academy of Hospice and Palliative Medicine. No other potential conflict of interest relevant to this article was reported.

From the Division of General Internal Medicine and Geriatrics, Indiana University School of Medicine, the Indiana University Center for Aging Research, and the Regenstrief Institute — all in Indianapolis.

1. Volicer L. End-of-life care for people with dementia in residential care settings. Chicago: Alzheimer's Association, 2005. (Accessed September 24, 2009, at <http://www.alz.org/national/documents/endoflifelitreview.pdf>.)
2. Gozalo PL, Miller SC. Hospice enrollment and evaluation of its causal effect on hospitalization of dying nursing home residents. *Health Serv Res* 2007;42:587-610.
3. Miller SC, Mor V, Teno J. Hospice enrollment and pain assessment and management in nursing homes. *J Pain Symptom Manage* 2003;26:791-9.
4. Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Patients dying with dementia: experience at the end of life and impact of hospice care. *J Pain Symptom Manage* 2008;35:499-507.
5. Bekelman DB, Black BS, Shore AD, Kasper JD, Rabins PV. Hospice care in a cohort of elders with dementia and mild cognitive impairment. *J Pain Symptom Manage* 2005;30:208-14.
6. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med* 2004;19:1057-63.
7. Mitchell SL, Kiely DK, Miller SC, Connor SR, Spence C, Teno JM. Hospice care for patients with dementia. *J Pain Symptom Manage* 2007;34:7-16.
8. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009;361:1529-38.
9. Medicare Payment Advisory Commission (MedPac). Reforming Medicare's hospice benefit. In: Report to the Congress: Medicare payment policy. Washington, DC: MedPac, 2008:347-76. (Accessed September 24, 2009, at http://www.medpac.gov/chapters/Mar09_Ch06.pdf.)

Copyright © 2009 Massachusetts Medical Society.