

# Barriers to Excellent End-of-life Care for Patients with Dementia

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**While great strides have been made recently in improving end-of-life care in the United States, people with dementia often die with inadequate pain control, with feeding tubes in place, and without the benefits of hospice care. In this paper, we discuss the most important and persistent challenges to providing excellent end-of-life care for patients with dementia, including dementia not being viewed as a terminal illness; the nature of the course and treatment decisions in advanced dementia; assessment and management of symptoms; the caregiver experience and bereavement; and health systems issues. We suggest approaches for overcoming these barriers in the domains of education, clinical practice, and public policy. As the population ages, general internists increasingly will be called upon to provide primary care for a growing number of patients dying with dementia. There are great opportunities to improve end-of-life care for this vulnerable and underserved population.**

**KEY WORDS:** palliative care; end-of-life care; dementia; Alzheimer's disease; hospice.

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Great strides are being made in improving end-of-life care in the United States. Leading journals have published major series on end-of-life care.<sup>1,2</sup> Palliative care fellowships are increasing in number and major research and training initiatives in end-of-life care have been funded.<sup>3-5</sup> Despite this progress, people with dementia still receive suboptimal end-of-life care. Many patients with dementia die with feeding tubes in place, up to 44% of nursing home residents with dementia in some states,<sup>6-8</sup> despite research suggesting little to no benefit from this treatment.<sup>9,10</sup> Dementia increases the risk of inadequate pain treatment; even severe and persistent pain goes untreated in many patients with dementia.<sup>11</sup> Finally, while hospice use is increasing, only 7% of patients enrolled in hospice in 2001 had dementia.<sup>12</sup> Thus, about 50,000 patients with dementia were cared for in hospice in 2001—versus roughly 10 times that number dying with dementia.<sup>13</sup> All of this occurs at a time when the number of people with dementia is growing tremendously.<sup>14</sup> Why is it so difficult to provide excellent end-of-life care for people with dementia?

In this paper, we discuss the most important and persistent challenges to providing excellent end-of-life care for patients with dementia. These barriers to quality end-of-

life care include dementia not being viewed as a terminal illness; the nature of the course and treatment decisions in advanced dementia; assessment and management of symptoms; the caregiver experience and bereavement; and health systems issues. We suggest approaches for overcoming these barriers in the domains of education, clinical practice, and public policy. As general internists probably are the largest group of physicians providing primary care for patients with dementia, we believe they have the greatest opportunity to improve on the status quo for this vulnerable and underserved population.

## Is Dementia a Terminal Illness?

To enroll a patient in hospice in the United States under Medicare (and most insurance plans), a physician must certify that the patient has a 6-month life expectancy and the patient (or family if the patient lacks decisional capacity) must agree to forgo rehospitalization for conditions related to the primary diagnosis. Patients usually forgo CPR and many other life-sustaining treatments, too. While many in palliative medicine argue persuasively that one need not be dying to receive measures directed at comfort,<sup>15</sup> it is clear that identifying an individual as dying or terminally ill more readily allows clinicians, patients, and families to consider hospice and other palliative measures. Because identifying a patient as dying represents a critical first step toward hospice enrollment, this represents a major obstacle for people with dementia. Even though many experts in the field characterize Alzheimer disease (AD) and other progressive dementias as terminal illnesses, professionals and family members have difficulty viewing dementia as an illness from which one dies. The National Center for Health Statistics did not include AD as a rankable cause of death until 1994.<sup>16</sup> Studies of death certificates continue to document dementia being overlooked as a cause of or contributor to death.<sup>17-19</sup> In a recent model demonstration program aimed at integrating palliative care into the ongoing care of patients with dementia,<sup>20</sup> 70% of families interviewed after the death of the patient believed the patient was terminally ill and dying prior to the death. More than two thirds of those family members, however, believed that the patient was dying from something other than dementia (unpublished data).

Dementia differs considerably from diseases such as cancer that are viewed as death causing in two important ways. First, the time from diagnosis to death is usually much longer in dementia. The length of survival in AD, for example, is typically several years. While a recent study suggests the median survival may be as short as 4 years,<sup>21</sup> most other studies report a median survival around 9 years.<sup>22</sup> Given this protracted course and the gradual

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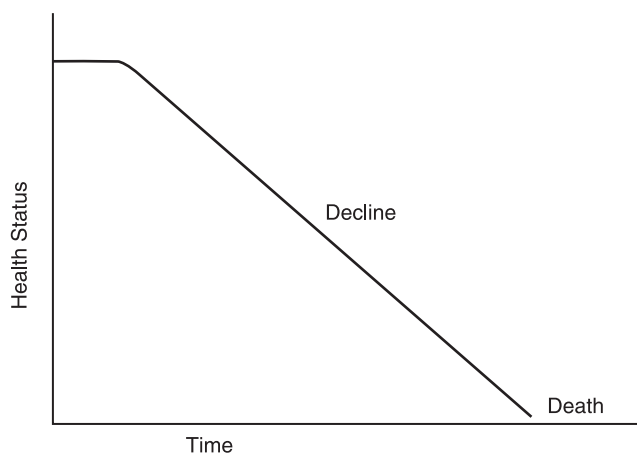
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loss of cognition and function, physicians and families understandably struggle to view someone with dementia as dying. Efforts to diagnose patients at earlier stages, even at a predementia or mild cognitive impairment state, as well as the development of new treatments that can be used in advanced dementia,<sup>23</sup> may make it even harder for many to view patients with dementia as dying.

Second, even if people can appreciate that dementias are progressive, incurable diseases, families and clinicians may continue to have difficulty viewing them as causing death. Patients' relatives and our medicine house staff in our geriatrics clinics routinely ask, "What do people with dementia actually die from?" Pneumonia, cardiac disease, and cerebrovascular disease tend to be the diagnoses listed as the cause of death on death certificates for demented and nondemented individuals alike.<sup>17,19</sup> Most families and clinicians probably view the terminal event, a pneumonia or urinary tract infection, as the proximate cause of death in someone with dementia.<sup>24</sup> People with dementia in its advanced stages, however, do develop apraxia, dysphagia, and decreased mobility that increase the risk of infection, malnutrition, and other adverse outcomes.<sup>25,26</sup> If considered at all, the dementia is probably seen as predisposing or contributing to the terminal pneumonia, rather than the cause of death.

### The Disease Course and Nature of Treatment Decisions

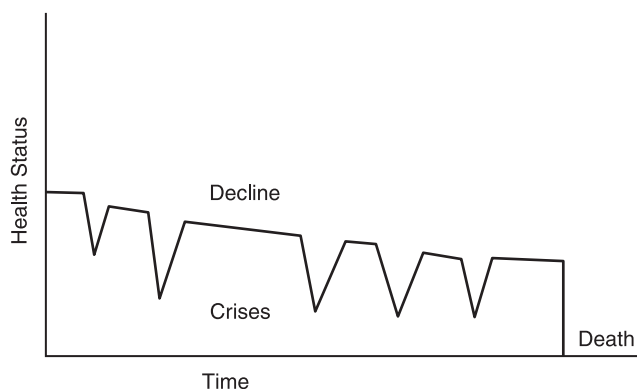
Many diseases that cause death, including many cancers, reach an advanced or metastatic stage and then follow a fairly predictable downhill course over weeks or months.<sup>27,28</sup> This makes it possible to recognize a terminal phase, predict a life expectancy of less than 6 months, and refer to hospice. Many had hoped that one could similarly identify prognostic markers in noncancer diagnoses, including dementia, which would reliably predict imminent death.<sup>29,30</sup> Unfortunately, potential prognostic markers for advanced dementia (functional dependency, recurrent hospitalizations, and weight loss of 10% or more in preceding 6 months) that were incorporated into guidelines published by the National Hospice Organization (now NHPHO) have not accurately predicted 6-month life expectancy in subsequent work.<sup>31,32</sup> In addition, Christakis and Escarce demonstrated that dementia is the hospice diagnosis with the greatest variability around the median length of survival.<sup>33</sup> Given the lack of reliable prognostic markers and variability in survival, physicians are understandably tentative in referring patients with dementia to hospice. The nature of the terminal events, primarily infections, and the treatment decisions that surround them make the trajectory in advanced dementia even more complicated. When a patient with cancer enters the final stages, a predictable trajectory occurs, making it easier to estimate a 6-month prognosis (see Fig. 1). In congestive heart failure (CHF) or chronic obstructive pulmonary disease, a sawtooth pattern with a slight downhill trajectory depicts the overall course



**FIGURE 1.** Death trajectory typical in cancer. Reprinted with permission from *Approaching Death* ©1997, by the Institute of Medicine, Courtesy of the National Academies Press, Washington, DC.

(Fig. 2). Potentially life-threatening, acute exacerbations mark the course of these diseases, but many of these crises are treatable. Difficulty arises because the acute exacerbation that becomes the terminal event looks so similar to all of the previous, reversible downturns. Identifying the terminal phase of these noncancer diagnoses remains a challenge.

Dementia is typically thought of as having a gradual downhill course. Our experience<sup>20</sup> suggests the true trajectory of the typical patient dying from dementia looks more like Figure 2, though with a steeper overall downward slope. The gradual downhill course is punctuated by declines caused by acute illness<sup>34</sup> that often are accompanied by delirium and decrements in mental and functional status. Unlike the patient with CHF who recovers from an acute illness near the prior baseline, the patient with dementia more commonly establishes a new, lower level of cognitive and physical functioning.<sup>35</sup>



**FIGURE 2.** Death trajectory typical in chronic diseases. Reprinted with permission from *Approaching Death* ©1997, by the Institute of Medicine, Courtesy of the National Academies Press, Washington, DC.

As in the case of a CHF exacerbation, any one of the downturns in dementia could become the terminal event, especially if life-sustaining treatment is withheld. In our experience, survival appears to be quite sensitive to the treatment provided. For example, two patients with advanced dementia at similar stages (nonverbal, functionally dependent in all activities of daily living) had radically different courses because of decisions made by the families. When one patient experienced a dramatic decline in oral intake and was found to have his first pneumonia, the patient's wife refused antibiotics and chose hospice care. That patient soon died peacefully at home with hospice care. At a similar juncture, the second patient's family chose hospitalization, intravenous antibiotics, and tube feeding. Over the next 18 months, this patient was hospitalized seven more times for infections and alterations in mental status before her family opted for home hospice care. The second patient also died peacefully at home.

Our experience with these two patients is consistent with Volicer and colleagues' seminal study of antibiotic use for fever in advanced dementia. They demonstrated that antibiotics in the end stage of dementia offered no improvement in either survival or comfort over comfort care measures alone.<sup>36</sup> Patients who were not end stage, however, did live considerably longer if they received antibiotics—like our second patient above. Thus, the primary care physician can play a pivotal role when decisions need to be made about interventions such as hospitalization, antibiotics, intravenous fluid, or enteral nutrition. Primary care physicians should guide discussions about care in light of a patient's prior wishes, the agreed upon goals of therapy, and the potential benefits and burdens of the treatment options.

Another key distinction for patients dying from dementia is the nature of the interventions typically required in these downturns. In patients with metastatic cancer, aggressive treatments such as cardiopulmonary resuscitation or mechanical ventilation are mostly ineffective. Therapies for a severe CHF exacerbation—admission to an intensive care unit, right heart catheterization, mechanical ventilation, and intravenous medications—may be effective but are invasive, burdensome, and expensive. In a person with dementia, the therapies for a typical downturn caused by an infection—intravenous antibiotics, fluids, and adjustment of electrolytes—are fairly routine, not burdensome, relatively inexpensive, and usually effective. Thus, if palliative care is chosen, both the treating physician and the family of the patient with dementia must consider forgoing treatments that seem in the short run ordinary, minimally invasive, relatively painless, and effective. This can be emotionally and psychologically challenging. By withholding treatment such as antibiotics, families may feel that they are directly responsible for the patient's dying. It takes skillful communication and support from the primary care physician to help families negotiate the emotional and psychological challenges, including guilt, which surround end-of-life decision making in dementia.<sup>37</sup>

## Assessment and Management of Symptoms

Whether or not patients with dementia receive hospice services, the cognitive, communication, functional, and behavioral problems that arise in dementia make it more difficult to provide palliative care to this population. As a patient's cognitive and communication abilities decline, it becomes harder to assess symptoms. For example, assessing pain in cancer patients is relatively straightforward—one asks the patient. Patients with dementia, however, have difficulties with recall, interpretation of sensations, and verbal expression. In the advanced stages of the disease, instead of relying on the patient's report of pain alone, experts recommend utilizing a combination of patient report, caregiver report, and direct observation of the patient.<sup>38</sup> Experts also suggest considering undiagnosed or undertreated pain if changes in behavior or mental status occur.<sup>39</sup> While dementia does not cause physical pain per se, patients with dementia are likely to be suffering from arthritis, osteoporosis, peripheral neuropathy, and many other pain-causing comorbid conditions that increase in prevalence with advanced age. Thus, the assessment and management of pain in dementia requires a broad and thoughtful approach by physicians involving histories from patient and caregiver; a careful physical exam including observation for nonverbal indicators of pain; and an openness to empirical trials of analgesics when pain is suspected, including when pain might be the underlying cause of nonspecific symptoms such as decreased oral intake or agitation or other challenging behaviors.<sup>38,40</sup>

Patients with dementia frequently suffer from behavioral problems and psychiatric symptoms that warrant treatment. Such challenging and difficult to manage symptoms may include anxiety, depression, paranoia, visual or auditory hallucinations, aggression, agitation, and shouting. While an extensive review is beyond the scope of this paper, there are many pharmacological and nonpharmacological approaches for managing these symptoms in dementia.<sup>41,42</sup> Treatment of these and other symptoms may require referral to a psychiatrist or other specialist.

## Caregiving and the Nature of Bereavement in Dementia

Primary care physicians appreciate that family caregivers play a pivotal role in the management of older patients with any chronic illness, often doing so over a period of many years at significant financial and personal cost. In fact, a recent study found caregivers who were categorized as "strained" to have a 63% increased mortality rate compared with family members who were not acting as caregivers for an ill relative.<sup>43</sup> Caregiving for someone with dementia appears to be especially burdensome. Ory et al.<sup>44</sup> found that compared to nondementia caregivers, dementia caregivers reported more hours spent on caregiving, more detrimental effects on employment, more emotional and physical strain, and a greater likelihood of

suffering mental or physical health problems due to caregiving. Families caring for someone with dementia face additional conflict-provoking decisions over the course of the disease including getting the patient to stop driving; taking over the management of finances and medications; and, in many cases, eventually relocating the patient to a relative's home or a nursing home.<sup>45,46</sup> Finally, as increasing numbers of patients with dementia die in nursing homes,<sup>47</sup> usually without the benefit of hospice, families rarely receive any kind of bereavement services.<sup>48,49</sup> Because the nature of bereavement may be different in dementia, grieving at the time of diagnosis or when the patient no longer recognizes family, for example, grief and bereavement services may need to be restructured.<sup>50,51</sup> Families can benefit greatly from physicians directing them to a social worker, local chapter of the Alzheimer's Association, and other resources in the community that can provide assistance and support.<sup>52</sup>

### Health System Challenges

As others have pointed out, Medicare was established for and remains oriented toward treatment of acute illnesses.<sup>53,54</sup> Medicare's policies create discontinuities in care for patients with dementia who experience repeated acute illnesses superimposed on a chronic decline. In our experience, the following pattern of care is typical: acute illness resulting in hospitalization; followed by relatively sharp decline in cognition and function; starting, re-starting, or increasing the intensity of home care services; plateau of function at new baseline below prehospital baseline<sup>55</sup>; discontinuation of Medicare-covered nursing, therapy, and other services; and continued, gradual decline in function due to underlying dementia until the next acute illness restarts the cycle.<sup>56</sup>

The financial incentives built into the existing health system often work directly against the provision of pallia-

tive care,<sup>57</sup> especially for people with dementia who are long-term residents of nursing homes. Continuity of care, both in terms of location and familiar staff, is important for these patients,<sup>58</sup> especially because they are at significant risk of delirium and distress on transfer to hospital.<sup>59</sup> Yet, the financial incentives for health care providers are aligned against providing end-of-life care in the nursing home.<sup>60</sup> As patients require more time from staff to manage symptoms and provide comfort near death, the facility ends up bearing this increased cost without receiving additional reimbursement. If the patient is transferred to the hospital for acute care, the nursing facility not only avoids the cost of the increased staff time, they may be paid a "bed hold" if the patient's stay is under Medicaid. Hospital transfer also decreases the facility's chance of both liability for "allowing a patient to die," as it can be perceived by misinformed family members, and for regulatory citations for weight loss or dehydration that occur as death approaches.<sup>61</sup> The treating physician has a financial incentive to transfer the patient because Medicare reimbursement for an admission visit for a hospitalized patient greatly exceeds that for a subsequent nursing home visit.<sup>62</sup> The hospital likely also makes money especially because fewer resources tend to be used for the oldest old.<sup>63</sup> All of the involved professionals and institutions have financial incentives to admit the dying dementia patient to the hospital. The only parties who may not be better off from that transfer are the patient and family.

### Overcoming the Barriers

We believe that important strides can be made in overcoming the barriers to excellent end-of-life care in dementia through action taken on the educational, clinical practice, and health system levels. General internists are positioned to play important roles on all of these levels (see Table 1).

**Table 1. Barriers to Excellent End-of-life Care for Patients with Dementia and Potential Remedies**

Barrier	Potential Remedy
Dementia not seen as a terminal illness appropriate for palliative care approach	Educate health professionals and the public; publicize innovative models integrating palliative and primary care
Nature of advanced dementia and treatment decisions	Educate health professionals
Psychological and emotional challenges of withholding treatments such as antibiotics and tube feeding	Have physicians shape patient care plans in more palliative fashion, sharing greater portion of decision-making burden
Assessment and management of pain in cognitively impaired individuals	More broadly disseminate expert guidance on this topic Routinely utilize assessments by patient and caregiver, as well as observe patient Consider behavior change as a trigger for investigation and possible treatment of pain
Management of behavioral problems and psychiatric symptoms	Educate health professionals Refer to psychiatrists, geriatric psychiatrists, and other specialists
Challenging caregiver stress and bereavement issues	Educate of health professionals Develop innovative bereavement programs
Economic and systemic disincentives for providing excellent end-of-life care to patients with dementia	Replicate and disseminate innovative programs Modify payment systems to align incentives Incorporate measures of end-of-life care for patients with dementia to quality improvement and quality measurement efforts

On the educational level, much more needs to be done to teach physicians and other health professionals about dementia and end-of-life care. The increasing prevalence of dementia warrants its being a featured topic as palliative care and end-of-life care gain stronger footholds in medical and nursing school curricula. As residency review bodies and specialty boards incorporate end-of-life care competencies into their requirements and exams, the special skills required for caring for people with dementia should be recognized. Continuing education is needed to reach professionals already in practice. The EPEC (Educating Physicians in End-of-Life Care) program has reached a large number of practicing physicians, but its modules contain little on dementia. The American Geriatrics Society is working on a revised version of EPEC that would address geriatric content areas, including dementia.

Public education is greatly needed. The Last Acts campaign has demonstrated the benefits of working with television writers and others in the media to educate the public and reshape our culture's attitudes toward death. Public education will be critical for addressing the appropriateness of a palliative care approach for persons with dementia, even though dementia may not be seen as a terminal illness or causing death, as families face difficult treatment decisions such as antibiotics and tube feeding. Physicians can help educate the general public and families caring for relatives with dementia about these issues.

Individual physicians can do much to improve end-of-life care for patients with dementia. Understanding at diagnosis that a patient with a progressive dementia will lose decision-making capacity puts a premium on physicians discussing advance care planning with patients and families. Over time, primary care physicians can counsel families of patients with dementia gradually toward more palliation and away from diagnostic procedures and treatments that may cause more burdens than benefits. While prognostic scales lack the desired precision for an individual patient, many of the items found in hospice referral guidelines for dementia are associated with about a 50% 6-month mortality in populations of patients with dementia.<sup>64-66</sup> We have found these markers adequate to at least begin discussing hospice with families: 1) FAST stage 7C (nonambulatory, loss of meaningful conversation, dependent in most or all activities of daily living) combined with developing complications such as weight loss of 10% or more, recurrent infections, and multiple pressure sores<sup>29,64</sup>; 2) hip fracture or pneumonia in advanced dementia<sup>65</sup>; and 3) need for insertion of a feeding tube.<sup>66</sup> Physicians can incorporate assessment of pain, behavioral problems, and caregiver stress into routine visits with patients and families affected by dementia. They can become familiar with national and local resources regarding palliative care for patients with dementia.<sup>67,68</sup>

On the organization level, clinical practices and health systems should look to end-of-life care for patients with dementia as an area ripe for quality improvement (QI) efforts. Tools for undertaking QI programs in end-of-life

care are available through the Institute for Healthcare Improvement, the medical literature, and web sites.<sup>69,70</sup> Organizations that monitor or evaluate quality of care, such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and National Committee for Quality Assurance (NCQA), need to add end-of-life care for people with dementia to the list of issues they examine. Quality indicators, in nursing homes, for example, need to acknowledge that many conditions including dehydration and weight loss will occur near the end-of-life even with the best care.<sup>61</sup> Efforts should be made to try and align the financial incentives in the system with the provision of palliative care. For example, nursing facilities might receive a slightly higher rate of reimbursement for patients who are identified as having primarily palliative care goals, perhaps countering the incentive to transfer dying patients to the hospital. The entry criteria for hospice might be relaxed to facilitate earlier referral of patients with dementia without waiting until death is clearly imminent, or perhaps hospices could be allowed to perform palliative care consultations for these patients.<sup>60</sup> We believe, however, that innovative models aiming to integrate palliative care into the ongoing primary care of patients over years rather than months need to be explored further.<sup>20,53,70</sup> These models are especially important because, as discussed above, dementia presents such challenges for prognostication, recognition of a terminal phase, and treatment decision making. It is the nature of the illness, not physician behavior or faulty prognostic scales, which is the root cause of the problem and that calls for creative solutions. Many of the demonstration programs funded under the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care initiative downplay the need for accurately estimating a 6-month prognosis and switching completely from a curative to a hospice approach. Instead, these programs target patients with life-altering, eventually fatal illnesses, such as cancer and dementia, and offer a gradually changing blend of curative, restorative, and palliative care services as patients decline in function and the goals of care shift. Some do this within a fee-for-service framework, while others take place under managed care, as Lynn et al. have proposed with the Medicaring model.<sup>71</sup>

## Conclusion

We are cautiously optimistic about the prospects for improving end-of-life care for people with dementia. Innovative programs demonstrate that excellent end-of-life care for patients with dementia is quite attainable.<sup>20,67</sup> We believe that there will need to be greater efforts that specifically target this growing portion of the population and that general internists should play a major role in this movement.

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