Those with advanced dementia require nursing home level care in NHs. For these patients, our results indicate that an increasing number of Americans with advanced dementia residing in NHs. This is paralleled by a growing body of research that advances dementia as a terminal illness.  

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### Invited Commentary

**Recognizing Dementia as a Terminal Illness in Nursing Home Residents**

The number of persons with dementia is expected to triple to 13.2 million over the next 40 years, and many will die in nursing homes. Up to 90% of those with advanced dementia require nursing home level care at some point in their lives, and 67% of dementia-related deaths in the United States occur in nursing homes. Yet, many nursing home residents with advanced dementia do not receive optimal end-of-life care. Advance care planning is underused; burdensome interventions such as tube feedings are overused; and distress-

### REFERENCES


ing symptoms such as dyspnea, pain, pressure ulcers, agitation, and aspiration are common and not adequately managed. A major barrier to improving end-of-life care is that very few nursing home residents with advanced dementia are recognized as being at high risk for death. For example, one study found that only 1% of nursing home residents with advanced dementia were perceived to have a life expectancy of less than 6 months, when, in fact, more than 70% died within that period. Therefore, while improving end-of-life care for nursing home residents with dementia will require a multifactorial approach, a critical first step is recognizing dementia as a terminal illness in nursing home residents.

Recognizing when patients with advanced dementia are likely to die involves prognostication, which can be difficult, but it is often important to patients and their families. Hospice criteria for advanced dementia include inability to ambulate independently, urinary and fecal incontinence, and dependence in activities of daily living, such as dressing. Also, the development of medical problems such as pneumonia is associated with approximately 50% 6-month mortality in nursing home residents with advanced dementia. However, despite the high mortality rates that are associated with advanced dementia, only 10% to 30% of nursing home residents who die of advanced dementia are enrolled in hospice, and more than half receive hospice services for much less than 90 days. To expand the number of nursing home residents who receive symptom-focused care at the end of life, we may need to expand the Medicare hospice criteria for advanced dementia to include admission to a nursing home for the primary reason of dementia care since this is an important factor that contributes to a poor prognosis.

Furthermore, we need to expand knowledge of geriatrics and palliative care principles among nursing home care providers. The 2008 Institute of Medicine report, “Re-tooling for an Aging America,” identified significant gaps in the training of our health care workforce to meet the demands of an aging population. Even in 2009, the Association of American Medical Colleges medical student graduate questionnaire found that one-fifth of graduating medical students consider their training in end-of-life care and pain management to be inadequate. Strides are being made to improve geriatrics and palliative care training for physicians. Leipzig et al recently defined 26 minimum geriatrics competencies for all graduating medical students, which include accurately identifying clinical situations in which life expectancy, functional status, patient preference, or goals of care should override standard treatment recommendations in older adults, as well as assessing and providing initial management of key symptoms based on a patient’s goals of care. Also, fewer than 1% of the nation’s practicing registered nurses and pharmacists are certified in geriatrics, and only one-third of baccalaureate nursing programs require exposure to geriatrics. Similarly, certified nursing assistants, who account for more than 40% of full-time-equivalent employees in nursing homes, provide the majority of hands-on direct care after just 75 to 150 hours of training. Ideally, supporting all members of the nursing home interdisciplinary team to obtain a set of core geriatrics competencies will improve recognition of the trajectory of dementia, allowing the care team to focus time and therapies toward those meaningful activities that can improve a resident’s quality of life.

In this issue of the Archives, Givens et al help us understand how antibiotic therapy for pneumonia affects the survival and quality of life for nursing home residents with advanced dementia based on data from 323 nursing home residents with advanced dementia from 22 Boston, Massachusetts, nursing homes. The authors elucidate some potential benefits and harms of using antibiotic therapy to treat pneumonia in this population, in which 41% of the residents experienced at least 1 episode of pneumonia during the 18-month follow-up period. On the one hand, they found that antibiotic therapy may extend the number of days lived. On the other hand, they found that antibiotic therapy did not improve comfort and that aggressive approaches (eg, intravenous antibiotics or hospitalization) might decrease comfort. These findings suggest that in addition to the antibiotic risks that are normally discussed (eg, allergic reactions, medication side effects), we need to expand discussions of potential harms to include the possibility that the use of antibiotics will decrease comfort at the end of life (ie, increase the frequency of pain, dyspnea, depression, fear, anxiety, agitation, skin breakdown, or resistance to care.) Patients and families need to know that when goals are to “treat the pneumonia,” more time is spent administering medications and less time is focused on therapeutic touch, listening, comforting, and interacting. We hope that more studies of therapeutic interventions in older adults, especially in those with advanced dementia, will include the impact of therapies on quality of life so that clinicians, patients, and families can make informed decisions.

Recognizing dementia as a terminal illness in nursing home residents and understanding which therapies improve quality of life provide the basis for initiating and guiding advance care discussions about prognosis, expected outcomes of therapy, and goals of care. Advance care discussions are critical for all nursing home residents with dementia and need to be revisited often, especially with each change in condition. They are not limited to code status discussions about whether cardiopulmonary resuscitation and intubation should be attempted. They are discussions that uncover a person’s core values. What is most important and meaningful? Is it enjoying a favorite meal, decreasing pain, or interacting with and lessening the burden on loved ones? Ninety-six percent of health care proxies of nursing home residents with advanced dementia believe comfort to be the primary goal of care. Therefore, when these patients develop pneumonia, discussions should address big picture questions: “Where are we now in his or her disease trajectory? What are the risks and benefits of the proposed therapies? What are his or her goals of care?”

All interventions, including antibiotic therapy, need to be individualized and considered thoughtfully in the context of a nursing home resident’s progressive dementia, effects on quality of life, and goals of care. Thoughtful individualization is needed because all interventions have potential downsides. More studies like that of Givens and colleagues, which determine the
impact of interventions on quality of life, will help clinicians guide patients and their families through the often complex decisions at the end of life. In envisioning the future of our health care system, policies and incentives must be developed to support a workforce with an adequate knowledge base in the principles of geriatrics and palliative care and to encourage individualized decision making based on prognosis and goals of care.

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