Palliative Care in Advanced Dementia

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KEYWORDS

• Dementia • Palliative care • End-of-life care • Cognitive impairment
• Skilled nursing facilities • Advance directives

KEY POINTS

- Neurodegenerative dementias are progressive and ultimately fatal diseases for which currently there is no cure. A palliative approach focusing on comfort, quality of life, and support of family and caregivers is appropriate.
- Primary care providers for patients with dementia should become proficient in the following: basic discussions of prognosis and goals of care, advance care planning, avoidance of polypharmacy when possible, pain management, and initial management of behavior and mood issues.
- There is no evidence that enteral feeding improves survival or comfort in patients with advanced dementia, and it may increase the risk of pressure ulcers and aspiration pneumonia. Careful hand-feeding is the recommended alternative.
- Infections are common in advanced dementia; antibiotics may very modestly prolong life, but may decrease comfort and contribute to antibiotic resistance and burdensome care transitions at the end of life.
- Patients with advanced dementia and behavioral disturbance should be assessed for delirium and pain, and empiric treatment of pain is often warranted.

Cure sometimes, treat often, comfort always.
—Hippocrates

THE EPIDEMIOLOGY OF ADVANCED DEMENTIA

Approximately 35.6 million people worldwide are thought to be currently living with dementia, approximately 0.5% of the population, and numbers will increase as more

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individuals live into advanced age. In the United States, the number of people with dementia is estimated to increase from 4.4 million in 2010 to 11 million in 2050.[1] Alzheimer disease (AD) is the most common type of dementia, representing 50% to 80% of cases (depending on whether "pure" or "mixed" cases are included), followed by vascular dementia (20%–30%), frontotemporal dementia (5%–10%), and dementia with Lewy bodies (<4–7.5%).[2,3] These types of dementia have different neuropathologies and variable symptoms, but all are progressive and incurable. This article focuses on common issues in advanced dementia in elderly patients with AD or vascular or mixed dementia; similar principles apply to younger patients in the final stages of these and other dementing diseases.

THE RATIONALE BEHIND A PALLIATIVE APPROACH IN DEMENTIA

Many clinicians and family members of people with dementia do not consider dementia to be a progressive and ultimately fatal illness.[4] In 2010, however, AD was noted as the sixth leading cause of death in the United States, and the fifth leading cause of death in those 65 years or older.[5] Understanding the trajectory and prognosis of dementia are essential to people with dementia and their family members as they plan for the future. Recent research has attempted to understand the trajectory of dementia, and to identify risk factors for poorer prognosis. In a recent review, Todd and colleagues noted the median survival from dementia to range from approximately 3 to 12 years after onset and approximately 3 to 7 years after diagnosis.[6] Increased age at diagnosis and impaired functional status are associated with greater mortality.

Unfortunately, 2 recent reviews noted that previous studies have not found consistent factors that increase the risk of death in people with dementia.[6,7] Although tools to help estimate prognosis in dementia exist, this lack of clarity on which factors increase the risk of death has prevented these tools from being widely adopted.[7] Without good tools to estimate prognosis in dementia and with dementia progressing at different rates in different individuals, it can be difficult for clinicians to correctly estimate prognosis, and to recognize when a patient may be eligible for hospice. The occurrence of an acute illness in a patient with advanced dementia does suggest a poor prognosis, however, and can be an opportunity to readdress prognosis and goals of care. One study of nursing home residents with dementia found a 6-month mortality rate for residents with pneumonia of 47%, a febrile episode of 45%, and "an eating problem" of 38.6%.[8]

In addition to difficulty estimating prognosis, clinicians face numerous other challenges in providing the best possible care to those living with dementia. First, there are not enough physicians trained in geriatric medicine and geriatric psychiatry to care for every patient with dementia. Palliative medicine faces similar workforce issues, and generalists will need to provide primary care, including palliative care for patients with life-limiting illnesses including dementia.[9] Second, caring for someone with dementia can be economically and psychologically costly to families.[10] Thus, caring for an individual with dementia should involve sensitivity to the needs of that individual's significant others. Third, there is no cure for dementia, and available medications have modest effects at slowing dementia progression. For these reasons, a palliative approach, including identifying the patient's goals, maximizing quality of life, aggressively managing bothersome symptoms, and focusing not only on the needs of the patient, but also the patient's family is an optimal way to care for this population.

The National Consensus Project for Quality Palliative Care's Clinical Practice Guidelines identify that palliative care is appropriate for "patients at all ages living with a persistent or recurring medical condition that adversely affects their daily functioning or will predictably reduce life expectancy," including "people living with progressive