

End-stage care of persons with alzheimer's disease

Abstract

Alzheimer's disease is a devastating neurodegenerative disorder that irreversibly affects our cognitive functions, especially memory. This review will give an overview of clinical issues associated with the end-of-life care of AD. By the time end-stage AD is present, the ability to communicate their pain and discomfort with caregivers as well as having significant ability to perform ADL have significantly decreased. These changes are frequently accompanied by neuropsychiatric symptoms that further complicate the patient's EOL care. Delirium is additionally a common clinical challenge among the patients in this stage. When the patients start becoming indifferent towards eating, refusing food or experiencing impaired swallowing, their caregiver involvement plays a substantial role in decision-making. In the process of all these changes, caregivers often experience the burden of emotional, physical, and financial stressors. The authors address the importance of healthcare systems and clinicians making efforts to ameliorate the sufferings of the patients with end-stage AD and their caregivers.

Keywords: alzheimer's disease, end-of-life care, pain, neuropsychiatric symptoms, delirium, food refusal, end-stage decisions, emotional support

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Abbreviations: AD, alzheimer's disease; EOL, end-of-life;
ADL, activities of daily living; NH, nursing homes

Introduction

With the impending influx of the baby boomers into the existing geriatric cohort with chronic disabling conditions, end-of-life (EOL) care has increasingly become a significant component of the health care system. Additionally, the expected rise in survival among Americans is secondary to environmental and social factors, as well as improvements in life saving technologies.¹ While EOL care has been a relatively common option for terminal cancer patients, the utilization of EOL care in Alzheimer's disease (AD) and other dementias has only become available more recently. The National Hospice and Palliative Care Organization (NHPCO) reports that approximately 9.8 percent of the nation's hospice census of 2005 was comprised of patients with dementia.² Although current Medicare regulations require that patients have a prognosis of less than six months of life in order to be eligible for hospice benefits, they can still get hospice care if their physician recertifies that the patient is terminally ill. In this article, the author will explore situations unique to patients with end-stage AD and their caregivers that can contribute to improved care strategies.

General features

Alzheimer's disease (AD) is the most common cause of dementing disorders among persons over age 65, with expectations of individuals diagnosed with AD impacting an estimated 13.8 million by 2050.³ In fact, new diagnosis of AD will be made every 33 seconds by 2050. Initially presenting with difficulty in solidifying new memories,⁴ AD is "officially listed as the sixth-leading cause of death in the United States".⁵ Whereas the course of AD is predictable, the rate of disease progression is not. Marked by gradual decline, with significant morbidity during end stage,⁶ survival time, on average, following diagnosis of AD is between 4-8 years.⁷ A prospective study demonstrated that comorbid conditions, such as diabetes, congestive heart failure, and ischemic heart disease were associated with reduced survival of these patients.⁸ The end stage of AD is marked by loss of independent functioning.⁹ In addition, the patient often is unable

to communicate with loved ones, as well as having significant impairment in ability to perform activities of daily life (ADL).¹⁰ Importantly, difficulties in swallowing, immobility, and malnutrition are particular challenges to the population, which advances risk for life ending conditions, most notably, pneumonia.¹¹

Pain

An estimated 50-93% of patients with AD experience pain,¹² with resulting associated emotional distress impacting quality of life.¹³ In fact, contributions from associated comorbidities, including pressure ulcers, falls, osteoarthritis, and neuropathy often impact the AD population.¹⁴ Complicated by impaired communication, patients with severe AD have difficulty with self-reporting pain, leading to reduced detection and delayed management.¹⁵ Interestingly, observational pain assessments utilize six domains of behavioral interpretation of pain, highlighted by American Geriatric Society, specifically body language, alterations in mental status, activity variation, facial expression, interactions with others, and negative vocalization.¹⁶ Similarly, painful indicators can include grimacing, moaning, wandering, agitation, inappropriate speech, aggression, restlessness are often useful.¹⁷ Lastly, the Pain Assessment in Advanced Dementia (PAINAD) and Pain Assessment for the Dementing Elder (PADE) are tools developed specifically for patients with AD, but they need further research for reliability and validity.^{18,19} The most common intervention in pain management is to use a variety of analgesic agents.²⁰ The transdermal fentanyl patch may be helpful to patients who are unable to swallow pills. But because of the drug's extreme potency and the potential for over dosage, this patch should not be used in "opiate-naïve" elderly patients or in those unaccustomed to the respiratory depression caused by opiates.²¹ A non-narcotic agent, tramadol, may be useful to patients with end-stage AD, which has potency similar to that of codeine but rarely causes respiratory depression.²²

Neuropsychiatric symptoms

An estimated 80-90% of patients with AD experience neuropsychiatric symptoms during illness course.²³ Behavioral manifestations of end stage AD are characterized by verbal and physical agitation, perceptual disturbances, and dis-inhibition.²³ Such

manifestations are associated with institutionalization, emotional distress, and mortality.²⁴ In presence of agitation, it is critical to investigate additional potential causes of agitation, including underlying medical disorders, side effects of medications, hunger, fecal impaction or pain and searching for bedsores.²⁵ Providers should continue with current psychotropic agents until patients are unable to swallow the pills.²⁵ Antipsychotic drugs are the mainstay of treatment for psychotic symptoms and aggression and high-potency agents such as haloperidol are effective in controlling these behavioral symptoms. Second-generation antipsychotic agents such as risperidone, quetiapine, olanzapine and ziprasidone have an improved side-effect profile compared to its predecessors.²⁶ Selective serotonin reuptake inhibitors are preferred agents with a favorable side-effect profile.²⁷ Further attention should be given on expanding role of non-pharmacologic interventions of neuropsychiatric symptoms, specifically limiting environmental stimuli, behavioral strategies, and providing caregiver education.²⁸

Delirium

The presence of cognitive impairment in end stage AD is a serious risk factor for the development of delirium.²⁹ Importantly, delirium can feature behavioral manifestations, such as aggression, hallucinations, delusions, anxiety, and reversed sleep cycle.²⁹ These behavioral disturbances can be overwhelming to the patient themselves and caregivers.²⁹ However, lack of these manifestations can aid to mask presence of delirium.³⁰ Critical to approach of delirious patients is to provide comfort and ensure safety through use of various non-pharmacologic and pharmacologic interventions.³¹ Behavioral symptoms of delirious patients with end-stage AD generally respond well to antipsychotic agents regardless of causes of delirium.³¹

Food refusal

Maintaining adequate nutritional status in patients with end stage AD represents a significant challenge, with dysphagia contributions from presence of apraxia and cognitive decline.³² Patients will often be indifferent towards eating, refuse food, and may have impaired swallowing.³³ As a result, caregiver involvement plays a substantial role in supporting feeding habits.³⁴ Furthermore, choking may be prevented by avoidance of thin liquids, providing boluses of food with sufficient moisture, and keeping patients in a seated position.³⁵ Enteral tube feeding is inevitable when patients with end-stage AD stop eating or experience significant difficulty in swallowing.³⁶

Settings of EOL care

Over the past century, the site of death for AD patients has shifted to nursing homes (NH) and homes.³⁷ In fact, “nearly 70% of persons with advanced dementia die” under NH care.³⁸ Unfortunately, nursing homes have difficulty managing palliative care needs of end stage AD. Notably, assessment and management of pain are frequent concerns.³⁹ Furthermore, in an extensive survey of family members of 1578 decedents,⁴⁰ Teno and her colleagues concluded that many people dying in NH or hospitals have unmet needs for symptom amelioration, physician communication, emotional support, and respectful attention. Also, family members of decedents who received care at home with hospice services had fewer concerns with the amount of emotional support provided to the patients.⁴⁰

Caregiver end-stage decisions

Prior to onset of dementia, patient would ideally have prepared an advance directive, living will and appointed Durable Power of Attorney.⁴¹ When unavailable, providers should discuss relevant EOL

issues with caregivers, including cardio-pulmonary resuscitation (CPR), hospitalization, artificial feeding and use of antibiotics for recurrent infections.⁴² It is often useful to address treatment concerns in terms of the potential outcomes of various options, goals of medical care, and associated risks. Providers need to ensure clear and direct guidance to caregivers, while assuring consideration and respect for treatment values.⁴³ Lastly, it is important to assure caregivers that their loved ones will receive supportive measures, even if they decide not to opt for acute medical interventions.⁴³

Emotional support

Caregivers often experience the burden of emotional, physical, and financial stressors associated with end stage AD.⁴⁴ Likely secondary to duration of care, associated behavioral symptoms, and decline during illness course,⁴⁴ caregivers frequently experience depressive symptoms.⁴⁵ Insufficient attention has been given to the impact of EOL care on caregivers or to their responses to the death of the patient. For instance, care strain is a significant factor in advancing mortality risk of associated caregiver.⁴⁶ Psychiatrists are uniquely positioned to assist caregivers with their emotional needs associated with EOL care of AD patients.⁴⁷ The local Alzheimer's Association and the National Hospice and Palliative Care Organization also provide such support. The guidelines recently developed by the National Consensus Project for Quality Palliative Care offer a comprehensive format to improve the quality of care, efficiency of care delivery, and patient/caregiver satisfaction in psychological and psychiatric aspects of care.⁴⁸

Conclusion

EOL care for individuals with end-stage AD is increasingly important because of the rising number of AD patients. However, barriers exist to the provision of high-quality EOL care for these patients. Future consideration of developing clinical practice guidelines specific to the EOL care of such individuals and their caregivers would assist practitioners in further enhancing their care of individuals with end-stage AD. Regardless of the last place of their care, healthcare systems and clinicians should make efforts to ameliorate the sufferings of the patients with end-stage of AD and their caregivers.

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Conflict of interest

The author declares no conflict of interest.

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