End-of-Life Care for Persons With Alzheimer's Disease

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Because of the rapidly increasing number of older adults with chronic disabling conditions and because of advancements in lifesaving technologies, end-of-life care has become a significant component of the health care system. Although end-of-life care is a relatively common option for patients with terminal cancer, it has become available only recently for patients with Alzheimer's disease.

In September 2001 Medicare issued a memorandum that stated that claims for hospice services should not be automatically denied just because a patient has a diagnosis of dementia (personal communication, Alzheimer's Association, 2004). The National Hospice and Palliative Care Organization reported that approximately 8 percent of patients in hospices in 2002 had Alzheimer's disease (1). Current federal Medicare regulations require that a patient have a prognosis of less than six months of life in order to be eligible for hospice benefits. This requirement is widely viewed as being inadequate, especially in regard to Alzheimer's disease. Although the guidelines for determining prognoses of selected noncancer diseases are based on severity-of-illness criteria, it can be challenging and controversial to apply these guidelines to the end stage of Alzheimer's disease (2). The practice guideline of the American Psychiatric Association briefly discusses hospice care in end-stage Alzheimer's disease, but it lacks practical information (3). This column explores end-of-life situations unique to patients with end-stage Alzheimer's disease and their caregivers that demonstrate why practice guidelines and Medicare criteria should be revised.

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Clinical issues

General features

Alzheimer's disease is the most common cause of dementia among persons older than 65 years. Current projections state that the number of individuals with Alzheimer's disease will increase to 13.2 million by 2050. Although the course of Alzheimer's disease is predictable, the rate of disease progression is not. In two prospective studies median survival time for outpatients with Alzheimer's disease was largely dependent on age of onset and ranged from 3.3 to 9.3 years (4,5). A prospective study demonstrated that comorbid conditions—such as diabetes, congestive heart failure, and ischemic heart disease—were associated with reduced survival of patients with Alzheimer's disease (6).

The end stage of Alzheimer's disease may last as long as two to three years (7). Patients in this stage have significantly reduced verbal output, have incontinence, have a decreased ability to ambulate, and require total assistance with activities of daily living (8). Their ability to recognize once familiar people is significantly diminished. These patients are mostly bedridden. Multiple and painful joint contractures often develop (9). Pneumonia, urinary tract infection, dehydration, malnutrition, and bedsores are commonly listed as causes of death.

Pain

As many as 45 to 80 percent of nursing home residents have pain that contributes materially to functional impairment and decreased quality of life (10). Pain becomes an especially challenging issue among patients with cognitive impairment (11). Pain is often not identified and tends to be undertreated in long-term-care facilities and is also common among patients who require end-of-life care (12).

One of the causes for inadequate pain control among patients with Alzheimer's disease is the difficulty in detecting and assessing intensity of pain. In one study of 158 nursing home residents, the 0-to-10 pain rating scale was grossly inadequate in measuring pain (13). Pain Assessment in Advanced Dementia and Pain Assessment for the Dementing Elderly are recently published tools that were developed specifically for patients with Alzheimer's disease, but further research is needed to test their reliability and validity (14,15).

Effective pain management may have important implications for improving quality of life among individuals with end-stage Alzheimer's disease. Acetaminophen can be safely used around the clock in this population, but there is a risk of hepatotoxicity with chronic use. Although nonsteroidal anti-inflammatory drugs often work well for these patients, clinicians should be aware that they have various side effects. Additionally, it is important for clinicians to know that

nonsteroidal anti-inflammatory drugs have a low ceiling effect.

Opiate drugs, such as morphine, have no ceiling effect and have been shown to relieve all types of pain (16). Also, opiate drugs are probably underused in the geriatric population and may be safer than other drug strategies that are used (17). However, clinicians should be aware that opiate drugs can increase confusion among patients with end-stage Alzheimer's disease.

The transdermal fentanyl patch may be helpful among patients who are unable to swallow pills. However, because of the drug's extreme potency and the potential for overdose, it should not be used among elderly patients who are opiate naive or among those who are unaccustomed to the respiratory depression caused by opiates (18).

Finally, a nonnarcotic agent, tramadol, may be useful. Tramadol has the same potency as codeine, but it rarely causes respiratory depression.

Neuropsychiatric symptoms

In the later stages of Alzheimer's disease more than 50 percent of patients exhibit behavioral symptoms, such as aggression, combativeness, shouting, and disinhibition (19,20). However, as patients approach the end stage of Alzheimer's disease, they typically become mute and apathetic. They may cry out for no clear reason, but agitation is generally no longer a challenge that the clinician has to deal with. If they become agitated, it is very important to rule out underlying physical disorders.

Antipsychotic drugs are the mainstay of treatment for psychotic symptoms and aggression in this population. High-potency agents, such as haloperidol, are effective in controlling behavioral symptoms. Second-generation antipsychotic agents can be used for the same purpose.

Although it can be difficult to diagnose depression among noncommunicative patients with end-stage Alzheimer's disease, the presence of mood swings with crying spells and irritability may be indicative of depression (21). Selective serotonin reuptake inhibitors are preferred agents to use when treating depression and have a favorable side-effect profile.

Delirium

Patients with end-stage Alzheimer's disease are susceptible to various medical conditions. Comorbid medical conditions and cognitive impairment are serious risk factors for the development of delirium (22). This problem may go unnoticed among patients in this population, especially when they have no appreciable behavioral manifestations of delirium. However, delirium is commonly accompanied by a wide array of behavioral changes, such as aggression, hallucinations, delusions, anxiety, and reversed sleep cycle. These behavioral disturbances can be overwhelming to patients and caregivers. It is important to provide these patients comfort and safety by using psychopharmacologic and environmental interventions while their underlying medical conditions are treated. Behavioral symptoms generally respond well to antipsychotic agents, regardless of the cause of delirium. Soft restraints may be necessary to keep these patients in beds or to keep them from pulling out intravenous lines.

Food refusal

Some patients with Alzheimer's disease resist or refuse to eat for many reasons. However, in end-stage Alzheimer's disease, dysphagia is common and can be a significant challenge to clinicians and caregivers (23). Individuals in this stage may simply forget how to eat, or a loss of brain cells may cause impairment of the swallowing mechanisms. Some patients with end-stage Alzheimer's disease are apathetic and have no interest in eating at all. Many patients in this stage may need assistance with much cueing or total feeding. Choking can be prevented by avoiding thin liquids, giving boluses of food with sufficient moisture, and keeping patients in a sitting position (24).

Enteral (tube) feeding is inevitably addressed when patients with end-stage Alzheimer's disease stop eating or experience significant difficulty swallowing. A review of existing literature by Finucane and associates (25) concluded that there was no evidence that tube feeding among these patients prevents aspiration pneumonia, prolongs life, reduces incidence of pressure sores or infections, improves function, or provides palliation.

Caregivers' perspectives on end-of-life care

Settings

For the past century, nursing homes and hospitals have increasingly become the site of death. Approximately half of all Americans who live to the age of 65 years will enter a nursing home before they die, and 20 percent will die there (26). However, because nursing home care is more focused on restorative services, the palliative needs of persons with end-stage Alzheimer's disease in nursing homes are not adequately managed (27). Additionally, a shortage of nursing staff and high rates of staff turnover are most likely to negatively affect the quality of end-of-life care in nursing homes (27).

In an extensive survey of family members of 1,578 decedents, Teno and colleagues (28) concluded that many people dying in nursing homes or hospitals have unmet needs for symptom amelioration, communication with a physician, emotional support, and respectful attention. Also, they found that family members of decedents who received care at home with hospice services had fewer concerns about the amount of emotional support that was provided to the patients.

End-stage decisions

Multiple issues can be addressed with the caregivers of persons with end-stage Alzheimer's disease. Ideally, patients have already prepared advance directives and a living will and appointed durable power of attorney before the onset of dementia. When these advance directives are unavailable, clinicians should help caregivers think through the relevant issues and come to their own decisions. These issues can be best addressed with caregivers in terms of the outcomes of various treatment options, goals of medical care, and risks. Clinicians need to be clear and direct, avoid medical jargon, and be empathic with caregivers' feelings. It is important to assure caregivers that their loved ones will receive supportive measures, even if caregivers decide not to opt for acute medical interventions.

Emotional support

Caregivers of persons with Alzheimer's disease experience stressful demands,

especially because of the length of time that care is required, the behavioral symptoms of patients, and the severity of decline of patients during the course of the illness (29). Insufficient attention has been given to how end-of-life care affects caregivers or to caregivers' responses to the death of the patient. A study conducted by Schulz and associates (30) indicated that caregivers needed intervention, and support services were needed most often immediately before the patient's death.

Caregivers may need help in resuming their own lives after the patient's death. Psychiatrists who are called in as consultants or who have a long-term relationship with the patient or caregiver are uniquely positioned to assist the caregiver with his or her emotional needs that are associated with end-of-life care or the patient's demise (31,32). Support can also be obtained from local chapters of the Alzheimer's Association (www.alz.org) and the National Hospice and Palliative Care Organization (www.nhpco. org). 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 and caregiver satisfaction in the psychological and psychiatric aspects of care (33).

Conclusions

End-of-life care for individuals with end-stage Alzheimer's disease is increasingly important because of the rising number of patients with this disease. However, there are barriers to providing high-quality end-of-life care. Revising Medicare regulations for hospice benefits and medical guidelines of the National Hospice and Palliative Care Organization may improve end-of-life care for this population. Additionally, clinical practice guidelines specific to end-of-life care of individuals with end-stage Alzheimer's disease and their caregivers would assist practitioners in further enhancing their care of individuals with this disease. Regardless of where persons with end-stage Alzheimer's disease receive care, health care systems and clinicians should make efforts to ameliorate the suffering of patients with this disease and their caregivers. ♦

References

1. Facts on Hospice and Palliative Care. National Hospice and Palliative Organization. Available at www.nhpco.org/i4a/pages/index.cfm?pageid=3362
2. Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases. Available at http://vaww.va.gov/oaa/flp/nho_med_guidelines.asp
3. Practice guidelines for the treatment of patients with Alzheimer's disease and other dementias of late life: American Psychiatric Association. American Journal of Psychiatry 154(suppl 5):S28–S32, 1997
4. Walsh B, Welch HG, Larson EB: Survival of outpatients with Alzheimer type dementia. Annals of Internal Medicine 113:429–434, 1990
5. Wolfson C, Wolfson DB, Asgharian M, et al: A reevaluation of the duration of survival after the onset of dementia. New England Journal of Medicine 344:1111–1116, 2001
6. Larson EB, Shadlen MF, Wang L, et al: Survival after initial diagnosis of Alzheimer's disease. Annals of Internal Medicine 140:501–509, 2004
7. Brookmeyer R, Corrada MM, Curriero FC, et al: Survival following a diagnosis of Alzheimer's disease. Archives of Neurology 59:1764–1767, 2002
8. Reisberg G, Ferris S, DeLeon M, et al: The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry 139:1136–1139, 1982
9. Souren LE, Franssen EH, Reisberg B: Contractures and loss of function in patients with Alzheimer's disease. Journal of the American Geriatrics Society 43:650–655, 1995
10. Ferrell BA: Pain evaluation and management in the nursing home. Annals of Internal Medicine 123:681–687, 1995
11. Ferrell BA, Ferrell BR, Rivera L: Pain in cognitively impaired nursing home patients. Journal of Pain and Symptom Management 10:591–598, 1995
12. Moss MS, Braunschweig H, Rubinstein RL: Terminal care for nursing home residents with dementia. Alzhemer's Care Quarterly 3:233–246, 2002
13. Weiner D, Peterson B, Ladd K, et al: Pain in nursing home residents: an exploration of prevalence, staff perspectives, and practical aspects of measurement. Clinical Journal of Pain 15:92–101, 1999
14. Warden V, Hurley AC, Volicer L: Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. Journal of the American Medical Directors Association 4:9–15, 2003
15. Vilaneuva MR, Smith TL, Erickson JS, et al: Pain assessment for the dementing elderly (PADE): reliability and validity of a new measure. Journal of the American Medical Directors Association 4:1–8, 2003
16. Portenoy RK: Opiate therapy for chronic noncancer pain: can we get past the bias? American Pain Society Bulletin 1:4–7, 1991
17. Ferrell BA: Managing pain and discomfort in older adults near the end of life. Annals of Long-Term Care 12:49–55, 2004
18. Ferrell BA: Pain evaluation and management, in Medical Care of the Nursing Home Resident. Edited by Besdine RW, Rubenstein LZ, Snyder L. Philadelphia, American College of Physicians, 1996
19. Eisdorfer C, Cohen D, Paveza GJ, et al: An empirical evaluation of the Global Deterioration Scale for staging Alzheimer's disease. American Journal of Psychiatry 149:190–194, 1992
20. Mega MS, Cummings JL, Fiorello T, et al: The spectrum of behavioral changes in Alzheimer's disease. Neurology 46:130–135, 1996
21. Volicer L: Care at the end of life. Alzheimer's Care Quarterly 2:59–66, 2001
22. Elie M, Cole M, Primeau F, et al: Delirium risk factors in elderly hospitalized patients. Journal of General Internal Medicine 13: 204–212, 1998
23. Volicer L, Seltzer B, Rheaume Y, et al: Progression of Alzheimer-type dementia in institutionalized patients: a cross-sectional study. Journal of Applied Gerontology 6: 83–94, 1987
24. Mahoney EK, Volicer L, Hurley AC: Food refusal, in Management of Challenging Behaviors in Dementia. Baltimore, Health Professions Press, 2000
25. Finucane TE, Christmas C, Travis K: Tube feeding in patients with advanced dementia: a review of the evidence. JAMA 282:1365–1370, 1999
26. Zerzan J, Stearns S, Hanson L: Access to palliative care and hospice in nursing homes. JAMA 284:2489–2494, 2000
27. Aupperle PM, MacPhee ER, Strozeski JE, et al: Hospice use for the patient with advanced Alzheimer's disease: the role of the geriatric psychiatrist. American Journal of Alzheimer's Disease and Other Dementias 19:94–104, 2004
28. Teno JM, Clarridge BR, Casey V, et al: Family perspectives on end-of-life care at the last place of care. JAMA 291:88–93, 2004
29. Hurly AC, Volicer L: Alzheimer's disease: "It's OK, Mama, if you want to go, it's OK." JAMA 288:2324–2331, 2002
30. Schulz R, Mendelsohn AB, Haley WE, et al: End-of-life care and the effects of bereavement on family caregivers of persons with dementia. New England Journal of Medicine 349:1936–1942, 2003
31. Spiess JL, Northcott CJ, Offsay JD, et al: Palliative care: something else we can do for our patients. Psychiatric Services. 53:1525–1529, 2002
32. Holt J: Psychiatry and spirituality at the end of life: a case report. Psychiatric Services 55:618–622, 2004
33. Clinical Practice Guidelines. The National Consensus Project for Quality Palliative Care. Available at www.nationalconsensusproject.org/guidelines.html