The prevalence of Alzheimer’s disease (AD) continues to increase as the general population ages. The number of persons with AD is predicted to reach 13.2 million by 2050. With the baby boom generation entering the age of increasing risk, even more families will find themselves caring for a loved one with AD over the next decade. Family members or friends typically become caregivers while the affected person is living in the community. Because patients with AD may live for 8 to 10 years following symptom onset, caregivers typically find themselves providing care over the long term. In this role, the majority of caregivers will make the decisions about medical care for their loved ones who have advanced beyond mild AD.

Although AD is characterized by cognitive decline, it is the deterioration in the patient’s functional abilities and the emergence of behavioral disturbances that prove most challenging for caregivers. In the early stages of AD, the patient may have difficulty with calculations, problem solving, and recall. Daily function suffers, leading to difficulty with managing finances, shopping, and performing work-related tasks. As cognitive abilities decline, patients progressively lose the ability to perform instrumental (eg, managing finances, preparing food) and basic (eg, dressing, eating) activities of daily living (ADLs) (Figure 1). In the middle stages of AD, behaviors such as wandering and agitation may become problematic. In late-stage AD, the loss of basic ADLs and the presence of behavioral disturbances (eg, agitation, insomnia, delusions) eventually lead to total dependence on others for care.

**Caregiver Issues**

Family caregivers are often elderly spouses or grown children who may themselves suffer from compromised health and functioning.

**Abstract**

The prevalence of the most common form of dementia, Alzheimer’s disease (AD), is expected to triple by 2050 as a result of the aging of the general population. To meet the challenge of managing increased numbers of patients with AD, it is crucial to understand the impact of AD on patients and families as well as their goals for disease management. Despite the emotional, physical, and financial hardships that families face when they care for patients with AD, they regard delaying nursing home placement as an important part of preserving their loved ones’ quality of life. An integrated approach to long-term AD management, which includes psychosocial interventions and pharmacologic treatments, may help alleviate symptoms of AD, reduce caregiver burden, and delay nursing home placement, providing meaningful benefit to patients, caregivers, and society. (Adv Stud Med. 2004;4(6):308-313)
giver often experiences significant physical, emotional, and financial strain as the patient's condition worsens and as increasing levels of assistance are required. The patient's need for constant supervision and physical support places significant demands on caregivers. Although caregivers may receive support from other family members or home health aides while assisting their loved ones with ADLs, they are challenged by the patient's highly distressing neuropsychiatric symptoms and the disruptive behaviors that represent important risk factors for institutionalization.

Patients with AD are typically admitted to long-term care facilities due to worsening symptoms or caregivers becoming overwhelmed. However, transferring a patient with AD to a nursing home (NH) facility can be disorienting for the patient and may lead to increased neuropsychiatric disturbances such as agitation. In an interview-based study of caregivers, 77.5% rated delaying NH placement as "very" or "extremely" important and regarded such a delay as preserving the patient's quality of life. Thus, despite the burdens endured by caregivers—emotional, psychologic, and financial—a primary goal for many families is to maintain their loved ones in the home environment for as long as possible.

Caring for patients with AD also imposes considerable financial burdens on both the patient and the caregivers. Some home healthcare costs are at least partly covered by Medicare (Table), though the nature and extent of the support services available are largely specific to the geographic area where the patient resides.

**ECONOMIC IMPACT OF AD**

The costs of AD include both formal care (supplied by paid professionals) and informal care (supplied by family and friends), with the bulk of the costs typically borne by family members. For example, caregivers frequently pay out-of-pocket expenses for formal services that provide assistance with ADLs. Family caregivers often reduce their work hours to accommodate the increasing demand of providing assistance to their loved ones. An analysis of the 1998 National Longitudinal Caregiver Study reported total annual costs of informal care of $18,385 per patient. Caregiving time (34%) and lost earnings (58%) accounted for the majority of these costs. The investigators excluded the caregivers' excess health costs (ie, costs they would not have sustained if they not been caregivers), and documented the amount of money spent out-of-pocket on formal caregiving services. When combined with lost productivity, indirect caregiving costs are often higher than direct medical costs.

Formal care costs escalate when patients enter NHs. In 1998, monthly formal costs of care for a patient with AD residing in alternative residential settings or NHs were estimated at $3,073 compared with $683 for those residing in the community. At earlier stages of the disease, therapies that slow the cognitive and functional decline over the long term may help patients remain in the community and delay the costs associated with NH placement.

The financial burden increases with disease progression—doubling when the patient moves from the mild to severe stages—and with the number of comorbidities (Figure 2). Total annual per patient costs have been estimated at $19,008 for patients with AD and no comorbid conditions, $22,572 with 1 or 2 comorbid conditions, and $31,296 with 3 or more comorbid conditions (in 1996 dollars). These increased costs may be partially associated with the late detection of comorbid illness, as patients with AD frequently

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**Precipitators of Nursing Home Placement**

- Patient-related
  - Cognitive and functional impairment
  - Problematic or disruptive behaviors
- Caregiver-related
  - Lack of support network (friends, family, agencies)
  - Feelings of captivity
  - Poor caregiver health
  - Demands on caregiver time
underreport symptoms. Treatments that ameliorate the symptoms of AD may be expected to delay the costs associated with more advanced stages of the disease. In addition, because caregiver burden increases with disease severity, therapies that reduce symptoms across disease stages may reduce caregiver burden and, ultimately, healthcare costs. If these treatments provide functional or behavioral benefits without prolonged survival, then a decrease in overall dementia-related costs would still be predicted.

**Strategies for Managing Patients With AD**

An integrated approach is an essential part of a long-term AD management program. The key to long-term management of the patient with AD is recognizing that the patient loses the ability to adapt to situations and that the home environment must be modified to suit the patient’s needs.10 Psychosocial interventions, including caregiver training and support programs, may help enable patients to remain in the community.11,12 In one study, spouse-caregivers who obtained family and individual counseling and joined support groups were better able to care for a loved one at home than those who did not. The risk of NH admission was reduced 2.5- to 5-fold, thus substantially increasing the time that patients were able to remain at home from a median of about 2.4 years to about 3.3 years.11 Social services, home health aides, adult daycare, or respite programs can also provide relief for the caregiver. Nevertheless, the extent to which availability and use of home healthcare services might affect the timing of institutionalization remains to be firmly established.

In addition, interventions that alleviate patient symptoms and address the challenges those symptoms present can contribute to a caregiver’s ability to tend to the loved one at home. Effective management reduces the number or severity of disturbances and problem behaviors, eases caregiver burden, and facilitates patient care. Potentially valuable interventions include reassuring and distracting the patient, maintaining a daily routine, and providing a structured environment. Simple interventions such as ensuring that hearing aids and spectacles are appropriate to the patient’s needs may also help. Teaching caregivers behavior modification techniques to use with the patient with AD can reduce psychologic stress. In a recent study, family caregivers were trained in strategies for caregiving, relieving burden, preventing depression, and reacting to patient behaviors.12 Trained caregivers reported improvement in their reactions to behaviors, as well as less stress, depression, and burden than untrained caregivers. These results indicate that training caregivers to care appropriately for patients with AD can substantially impact their ability to manage their loved ones at home.

Exercise also may have a role in delaying institutionalization of patients with AD. A recent study showed that a regular program of physical activity for the patient, combined with caregiver training in behavioral interventions, reduced institutionalization of patients with problem behaviors.13 However, it is unclear to what extent caregiver training alone con-

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*The terms of Medicare coverage are due to change in 2006. Adapted from Department of Health and Human Services.
tributed to those results. Further studies will be required to determine whether exercise alone delays institutionalization of patients with AD.

**ROLE OF SOCIAL SUPPORT NETWORKS**

Attending to caregiver issues such as burden and physical health, providing emotional support, and encouraging caregivers to join a support group or other community-based programs can help maintain patients with AD in the community. The demands of a busy primary care practice often make it impossible for the physician to meet all of the caregiver’s expectations for psychosocial support; therefore, it is important to shift the psychosocial support role to organizations, like the Alzheimer’s Association, that provide community-based advocacy, education, and support. Other family members, clergy, and community mental health workers also may be valuable sources of support. In the absence of a social support network for families, hospital social work departments and mental health visiting nurse agencies can be useful resources. Using community resources effectively creates more satisfied families and reduces the burden on the physician.

The importance of support networks was demonstrated in a study showing that the patient’s problematic behaviors and the caregiver’s feelings of captivity contributed to the decision to institutionalize. In this study, caregivers who reported good health and received family support with ADLs and overnight respite were able to tend to their loved one at home for longer periods than caregivers not receiving the same help. Support groups and counseling can also ameliorate the depression that is often associated with long-term caregiving.

**ROLE OF DRUG THERAPY**

Pharmacologic treatments that improve patient functioning and behavioral symptoms may offer another means of maintaining patients in their homes. Clinical trials have repeatedly demonstrated the beneficial effects of cholinesterase inhibitor (ChEI) treatment on cognition, global function, and ADLs. Recent studies have also suggested that these agents effectively relieve the psychiatric and behavioral symptoms of AD. As a result, ChEIs are increasingly being considered for managing abnormal behaviors in patients with mild to moderate AD, as well as what have been traditionally classified as psychiatric symptoms (eg, depression, anxiety).

**COST BENEFIT AND COST EFFECTIVENESS**

Although multiple modeling studies predict that ChEI treatment decreases overall costs by delaying symptom progression, few controlled studies have been performed. In a retrospective analysis of administrative claims for patients with AD and related dementias, ChEI treatment with donepezil was associated with reduced total costs for medical services and prescription drugs. In a prospective, randomized, double-blind, placebo-controlled trial that determined the pharmacoeconomic impact of ChEI treatment, donepezil was shown to be cost effective after 1 year of treatment.

**PATIENT FUNCTIONING AND CAREGIVER TIME**

The patient’s loss of function is associated with significant caregiver burden and the decision to institutionalize patients. The demand on caregiver time may be reduced when patients with AD are able to maintain their ability to perform ADLs. In a 1-year, double-blind, placebo-controlled study, patients in the donepezil group maintained functional abilities longer than patients treated with placebo. The benefit was evident as early as 12 weeks and maintained at all subsequent visits during the year. In an open-label extension study, patients treated with galantamine 24 mg daily for 12 months maintained functional abilities near baseline.

The benefits of ChEI therapy include reducing the time spent providing care to patients with AD. The prospective, randomized, double-blind study by Wimo et al demonstrated that caregivers spent one third fewer hours caring for patients with AD in the donepezil group than did the caregivers of the patients in the placebo group. In a study of patients with moderate to severe AD, caregivers of patients in the
donepezil group reported spending nearly 1 hour less per day helping patients with ADLs than did caregivers of patients in the placebo group.24 Similarly, caregivers of galantamine-treated patients reported spending less time providing assistance to patients with moderate AD than caregivers of placebo-treated patients.25

Treatment regimens that combine ChEIs with other drugs are beginning to be explored. For example, a retrospective chart review suggested that a combination of donepezil and vitamin E slowed cognitive decline while no treatment did not slow the decline.26 A more recent study has shown that a combination of a ChEI with memantine, a drug approved for treatment in more severe stages of AD,27 is well tolerated by patients with AD.28 However, studies comparing the efficacy of combination therapies with that of ChEI monotherapy have not been reported.

**ChEI Therapy and NH Placement**

When NH placement is included as an outcome measure in studies of ChEI treatment in patients with mild to moderate AD, the required observation period is long; therefore, few studies have been conducted with this endpoint.29-31 However, in a follow-up study of a 30-week randomized, double-blind, placebo-controlled trial evaluating tacrine treatment, patients with AD whose doses were titrated to >80 mg daily and who remained on the medication for 2 years experienced a lower risk of NH placement than did patients who discontinued treatment or took lower doses of tacrine.29 Tacrine treatment was also associated with decreased mortality in a study of NH patients with dementia.30

In a 1-year study to assess the clinically relevant milestone of NH placement, ChEI treatment (99% of patients received donepezil, 1% received rivastigmine) was associated with a reduced risk for NH admission.30 In this study, ChEI-treated patients performed better cognitively and functionally after 1 year of treatment than did untreated patients. After 3 years of follow-up, only 6% of treated patients were institutionalized, compared with 40% of untreated patients.

In the largest trial to date of the effect of ChEI treatment on the time to NH admission (n = 671), the status of patients previously enrolled in 1 of 3 randomized, double-blind, placebo-controlled clinical trials of donepezil was assessed. To address variability between studies and establish a gradient of donepezil utilization, categories of donepezil exposure were defined according to whether patients were able to complete specified periods of time on the drug and whether patients took at least the minimum therapeutic dose of 5 mg daily.31 A strong association was reported between donepezil treatment and significant delays in NH placement of patients with AD, with the risk of NH placement declining with longer continuous utilization of donepezil.31 The median time to NH admission was 44.7 months for the group who received donepezil for <6 months and 66.1 months for those who received donepezil for 9 to 12 months.

**Conclusion**

Caring for loved ones with AD in the home environment for as long as possible is an important goal of family caregivers. Clearly, nonpharmacologic treatments have an important role to play in maintaining patients at home, but the optimal implementation and cost effectiveness of these strategies have not yet been determined. Pharmacologic treatment with ChEI therapy has been shown to have beneficial effects on patient symptoms and may delay institutionalization. Both tacrine and donepezil therapy have been strongly associated with significant delays in NH placement in patients with AD. Although it is tempting to extrapolate these results to the entire class of ChEIs, clinical trials with other agents using delayed NH placement as an outcome will be needed to ascertain the possible effects of other ChEIs on NH placement.

The primary care physician can help families maintain their loved ones at home by educating caregivers on principles of AD treatment, management, and outcomes, perhaps most effectively by directing families to community resources such as the Alzheimer’s Association. Both families and society stand to benefit from ChEI treatment, as patients may be able to stay at home longer, thus postponing the costs of NH care. In addition, ChEI therapy may reduce caregiver stress and healthcare costs, facilitating caregivers’ ability to care for their loved ones. Therapies such as donepezil, which have been associated with positive outcomes—treating AD symptoms, reducing caregiver burden, and postponing NH placement—may significantly contribute to reducing the family burden of AD.

**REFERENCES**