

Conflicting Priorities in Alzheimer's Care, Primary Care, and Managed Care: Who Pays the Price?

David S. Geldmacher, MD

Beyond its devastating personal effects on individual patients and their families, Alzheimer's disease (AD) is a challenge to all who receive, provide, or pay for medical care. The Alzheimer's Association estimates that there are 4 million AD cases in the United States and that AD care costs approximately \$100 billion annually. This makes AD the third most expensive illness in the country, after cancer and cardiovascular disease. In addition, AD cases are expected to triple over the next several decades.

Despite these enormous figures, few major health insurers or managed care organizations (MCOs) have systematic approaches to managing the disease and its costs. A Medline search in September 2000 returned 8053 results for the subject "managed care" and 22,362 results for AD but only 14 results for the combination of the 2 subjects. One likely reason for the paucity of information about and services for AD in managed care settings is underrecognition and undercoding of the illness by physicians. In 1 study of hospitalized patients with dementia, for instance, only about 25% of the patients' primary care charts had any notation about their cognitive impairment.¹ Likewise, death certificates significantly underreport the presence of dementia, even when patients have been actively fol-

lowed for AD.² So far, dementia has not appeared in any of the guidelines issued by the Health Care Financing Administration, the National Commission on Quality Assurance (NCQA), or the Health Employer Data and Information Set (HEDIS), which drive the provision of services in this area. This commentary will address issues underlying conflicting demands in managed AD care and explore possibilities for reconciling them.

Alzheimer's Care

Ideal AD care is interdisciplinary. It focuses on the prevention of excess disability and requires a focus on the family (or the equivalent caregiving community) as the unit of care. This is a departure from medicine's traditional focus on the treatment of *disease* in an *individual*. A common theme among family caregivers is disappointment in the medical care system. They point to a lack of specific diagnosis, insufficient information about dementia, and inadequate support and referrals from their general practitioners.^{3,4} In addition, caregivers want tailored interventions, specially trained providers, and services in the home.⁴

Many essential functions in AD care do not require a physician. This means that they can be centralized, or at least concentrated, away from the medical office. This would seem to make AD an ideal model for managed

care. In addition, access to community resources is vital to the success of AD care. Most communities can provide some important elements of AD care and address many family concerns, but their facilities seem to be underused. Voluntary health organizations, led by the Alzheimer's Association, can provide clients with free services such as support groups and informational programs. Many chapters also coordinate respite services, provide financial advice or relief, and cooperate with MCOs to facilitate optimal AD care.⁵ Usually, however, neither government programs nor health insurers are willing to pay for this type of healthcare, which lies outside the bounds of traditional medical models. The cost efficacy of these programs and the possible restructuring of reimbursement for dementia-related services are both worthy of extensive study.

Primary Care

Primary care providers are an important link in the successful care of patients with AD, but conflicting demands often limit their effectiveness. Families affected by AD may expect their primary care providers to recognize and treat the problem the same way they expect them to identify an illness such as hypercholesterolemia or hypertension. Factors that limit the effectiveness of the primary care provider's role include the following: 1) the physician's poor understanding of the symptoms of mild dementia and appropriate responses, 2) a perceived lack of need to provide a specific diagnosis, 3) limited time, and 4) negative attitudes about the importance of dementia assessment and diagnosis.⁶

Each barrier must be overcome if the physician wants to keep up with the fast pace of AD research, which has led to a revolution in the understanding of dementia in the past several decades. Many practicing physicians were taught in medical school that AD is an unusual psychiatric disease of the

presenium, and that the dementia of late life is somehow distinct from it. More recently trained physicians were taught that AD is a default diagnosis, a diagnosis of exclusion. Today's physicians, bombarded with more information about healthcare than ever before, may have missed key literature about the changing state of dementia diagnosis and care. One such article reported a consensus statement that AD should now be considered a diagnosis of inclusion, because it can be recognized by a characteristic clinical pattern.⁷

Contrary to many physicians' views, the need for a specific diagnosis is clearly articulated by families³ and reflects an increasingly sophisticated public. AD-specific disease-modifying therapies, such as vitamin E and symptomatic therapies in the form of cholinesterase inhibitors, are becoming the standard of care. Primary care providers need to make an exact dementia diagnosis and devise a specific treatment plan to meet that standard. The potential for new, possibly more toxic AD drugs in the next decade makes this specificity important.

Time is in critically short supply in the medical office, and AD diagnosis is perceived as complex and time consuming. Although managed care is often blamed for the erosion of the time that a physician can spend with each patient, evidence suggests that more generalized financial and regulatory pressures may be at fault.⁶ Given the limited time available, and the typical inability of the patient with AD to report his or her own symptoms, most practitioners use passive diagnosis. They wait for the patient or someone else to complain about the patient's cognitive difficulties. Although the search for definitive and clinically useful biomarkers is under way, primary care providers need to become familiar with quick and easy clinical screening methods (eg, the 3-item recall, the clock drawing test). Furthermore, primary care providers need to overcome the protective and paternalistic atti-

tudes that keep them from sharing the diagnosis with the patient or trusted family members. The “war on cancer,” begun 3 decades ago, showed that destigmatization of a tragic disease is both desirable and possible.

In the end, the patients and their families pay the price of ineffective AD diagnosis and management. Function lost to disease progression is rarely restored. Caregiver stress and frustration accumulate along with the patient’s symptoms and disabilities when there is no official diagnosis. Without referrals to appropriate help, caregivers must find their own resources or founder. One outcome of dissatisfaction with the primary care provider is erosion of the doctor-patient relationship vital to good long-term dementia care.

Managed Care

As already noted, there is little published information on how MCOs structure AD care. In fact, informal surveys show that even Medicare-risk MCOs (capitated plans that contract with Medicare to provide service on Medicare’s behalf) generally have neither AD nor dementia care recommendations in place. The common argument is that AD is “below the radar” of the MCOs. In other words, they have not identified AD as a driver of overall cost. Underrecognition and undercoding of dementia are clear problems in this regard. One study of claims at a Medicare-risk HMO found dementia incidence to be only 0.83%.⁸ Epidemiologic estimates suggest that the incidence of dementia should be 8% to 10% in that population. It is possible that up to 90% of true dementia-related costs are being overlooked by this method of analysis. Mean costs of care for recognized patients with AD are 1.5 to 2 times as high as costs for control subjects.⁸⁻¹⁰

Despite underrecognition of dementia in their clients, many MCOs are concerned about pharmacy costs related to dementia care. There is

skepticism about whether the outcomes valued in antedementia drug trials (eg, cognitive test scores) are meaningful to MCOs. Nonetheless, evidence clearly suggests that a delay in AD’s progression can reduce overall

In the end, the patients and their families pay the price of ineffective AD diagnosis and management.

cost of care.¹¹ Despite their relatively high short-term costs, cholinesterase inhibitors can be an important contributor to overall savings.¹² Unfortunately, from a practical perspective, many of these savings are not immediately apparent on the MCO’s bottom line because they reflect diminished indirect (eg, caregiver) costs or deferred nursing home placement.

The conflict is obvious. Although there is clear value to the individual, the family, and the healthcare economy in alleviating AD progression, relieving the burdens of care, and maintaining the affected individual at home, this value does not translate to a financial benefit for the MCO and its members. Current payment structures assign the MCO only the direct costs of care and only over the short term. When the patient moves to long-term institutional care, where Medicaid or equivalent programs assume progressively larger portions of the cost, the MCO is relieved of much responsibility. Understandably, the managed care community has little incentive to revise its current diagnostic and pharmaceutical approaches to dementia. National accrediting initiatives (eg, NCQA, HEDIS) seem the most likely agents of change. Stronger consumer demand and aggressive AD

advocacy might result in new regulations, laws, or voluntary MCO changes. The drastic, but highly unlikely, alternative is a total realignment of fiscal responsibility across the continuum of AD care.

What Does the Future Hold?

AD will devour an ever-expanding portion of public health expenditures until better means of early diagnosis are found and more effective ways of preventing or slowing the disease are available. For the next decade or more, we will continue to try to solve sometimes conflicting problems: needs of the patient with AD, the pressures on primary care providers, and the financial realities of paying for direct medical care. Furthermore, these problems must be constantly reassessed in light of changing economic realities. As the number of older adults grows dramatically and AD cases proliferate, we face increasing conflicts between providing optimal affordable public healthcare and maintaining our traditional advocacy for the afflicted individual.

Acknowledgment

Supported in part by the National Institute on Aging (NIA) Alzheimer's Disease Research Center Grant #AG08012.

... REFERENCES ...

1. Callahan CM, Hendrie HC, Tierney WM. Documentation and evaluation of cognitive impairment in elderly primary care patients. *Ann Intern Med* 1995;122:422-429.
2. Raiford K, Anton-Johnson S, Haycox S, et al. CERAD part 7: Accuracy of reporting dementia on death certificates of patients with Alzheimer's disease. *Neurology* 1994;44:2208-2209.
3. Haley WE, Clair JM, Saulsberry K. Family caregiver satisfaction with medical care of their demented relatives. *Gerontologist* 1992;32:219-226.
4. Della Buono M, Busato R, Mazzetto M, et al. Community care for patients with Alzheimer's disease and nondemented elderly people: Use and satisfaction with services and unmet needs in family caregivers. *Int J Geriatr Psychiatry* 1999;14:915-924.
5. Newcomer R, Yordi C, DuNah R, et al. Effects of the Medicare Alzheimer's Disease Demonstration on caregiver burden and depression. *Health Serv Res* 1999;34:669-689.
6. Boice L, Camicioli R, Morgan DL, et al. Diagnosing dementia: Perspectives of primary care physicians. *Gerontologist* 1999;39:457-464.
7. Small GW, Rabins PV, Barry PP, et al. Diagnosis and treatment of Alzheimer disease and related disorders: Consensus statement of the American Association of Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society. *JAMA* 1997;278:1363-1371.
8. Gutterman EM, Markowitz JS, Lewis B, Fillit H. Cost of Alzheimer's disease and related dementia in managed-Medicare. *J Am Geriatr Soc* 1999;47:1065-1071.
9. Newcomer R, Clay T, Luxenberg JS, Miller RH. Misclassification and selection bias when identifying Alzheimer's disease solely from Medicare claims records. *J Am Geriatr Soc* 1999;47:215-219.
10. Weiner M, Powe NR, Weller WE, et al. Alzheimer's disease under managed care: Implications from Medicare utilization and expenditure patterns. *J Am Geriatr Soc* 1998;46:762-770.
11. Ernst RL, Hay JW, Fenn C, Tinklenberg J, Yesavage JA. Cognitive function and the costs of Alzheimer's disease. An exploratory study. *Arch Neurol* 1997;54:687-693.
12. Schumock GT. Economic considerations in the treatment and management of Alzheimer's disease. *Am J Health Syst Pharm* 1998;55(suppl 2):S17-21.