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Issue Brief

Alzheimer's Disease: Research Advances and Medical Reality

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ABSTRACT: Alzheimer's disease was the eighth-leading cause of death in 2001. There is no cure and no effective treatment. Alzheimer's disease presents policy-makers with several challenges, including the level of funding and direction of federally funded research, as well as the cost pressures on Medicare and Medicaid of long-term care. These challenges will increase in intensity as demographic changes, particularly the aging of baby boomers, take hold. Better prevention of Alzheimer's, advances in therapy, and appropriate care modalities will likely require significant investment.

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Introduction

Some 4.5 million Americans have Alzheimer's disease (AD), the eighth-leading cause of death in 2001.¹ Primarily a disease of the elderly, about 12.8 percent of those over 65 years and perhaps as many as 35 to 40 percent of those over 80 years are affected.² AD is a progressive neurodegenerative disease resulting in the gradual decline of a person's memory and ability to learn, reason, make judgments, communicate, and carry out daily activities.³ By 2050, with the combination of an aging population and increases in longevity, an estimated 11.3 to 16 million Americans will suffer from Alzheimer's,⁴ whose course can run from two to over 20 years. The illness and recent death of former President Reagan brought wider attention to the disease and its impact on patients and their families. This brief addresses what is known about the disease, its human and financial costs, promising areas of research, and policy challenges and considerations.

Background: Alzheimer's Disease

The exact causes of AD are not understood and there is no known cure. While several treatments are available, they have had limited success in slowing

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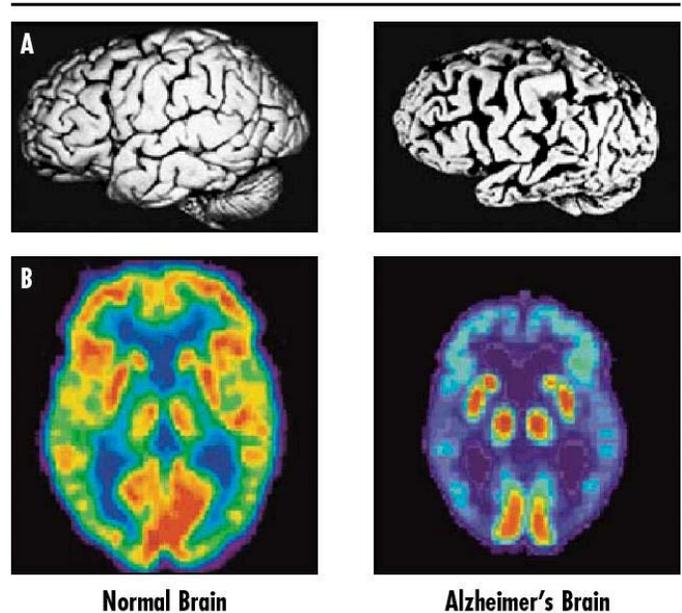
the progression of the disease and generally have been a disappointment to patients and their physicians.⁵ As the number of AD patients climbs, families increasingly bear the burden of caring for loved ones, and in the process suffer adverse health outcomes themselves. Recent studies show higher rates of depression and depressive symptoms among AD caregivers.^{6,7}

Alzheimer's is the leading cause of dementia. Other leading types of dementia include vascular dementia which results from reduced blood flow to the brain, and Parkinson's disease.⁸ The early-onset form of AD, before age 60, may be related to inherited genetic mutations. The greatest risk factor for AD, however, is age. Late-onset Alzheimer's occurs after age 60 and accounts for between 90 to 95 percent of all AD.

Several tests—including brain scans and neuropsychological tests—are used to diagnose a patient with AD. Genetic tests can predict fewer than 5 percent of cases of AD. Researchers hope that the use of PET* scans may enable the diagnosis of AD at an earlier stage, though this test is not currently the standard of care. Recently, Medicare approved coverage for the scans in cases in which an AD diagnosis was in doubt after standard examinations.⁹ Testing cerebrospinal fluid, taken by spinal tap (lumbar puncture), is also under investigation as a possible early predictor.

* PET, positron emission tomography, is used to provide images of the brain and brain function and can be used to detect changes in brain metabolism that occur in AD.

Figure 1. PET Scans (Glucose Utilization) of Normal and Alzheimer's Diseased Brain¹⁰



Alzheimer's disease results in shrinkage of brain regions involved in learning and memory which is correlated with major reductions in cellular energy metabolism in living patients. **A)** Compared with the brain of a healthy person, the brain of an Alzheimer's disease patient exhibits marked shrinkage of gyri in the temporal lobe (lower part of the brain) and frontal lobes (left part of the brain). **B)** Positron emission tomography (Pet) images showing glucose uptake (red and yellow indicate high levels of glucose uptake) in a living healthy person and a normal control subject. The Alzheimer's patient exhibits large decreases in energy metabolism in the frontal cortex (top of brain) and temporal lobes (sides of the brain).

Health professionals and caregivers track the progression of disease using a variety of standardized tests, including the Functional Assessment Staging (FAST) scale, a tool developed by Alzheimer's researchers. Diagnosis at early stages of the disease is critical for several reasons: existing treatments may be more effective at earlier stages of disease, and early diagnosis allows patients and

Table 1. The Functional Assessment Staging (FAST) Scale¹¹

FAST Scale Stage	Characteristics
1. Normal adult	No functional decline.
2. Normal older adult	Personal awareness of some functional decline.
3. Early Alzheimer's disease	Noticeable deficits in demanding job situations.
4. Mild Alzheimer's	Requires assistance in complicated tasks such as handling finances and planning parties.
5. Moderate Alzheimer's	Requires assistance in choosing proper attire.
6. Moderately severe Alzheimer's	Requires assistance in dressing, bathing, and toileting. Has urinary and fecal incontinence.
7. Severe Alzheimer's	Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up.

their families to address many of the legal and financial issues that will likely arise, including the development of advanced directions and decisions about the use of palliative care.

There are five FDA-approved drugs for treatment of AD symptoms. These drugs can treat symptoms of mild-to-moderate cases but do not slow down the progression of the disease. The drugs work to either increase levels of acetylcholine, a protein important for memory and thinking, by inhibiting an enzyme responsible for its breakdown or by regulating levels of the brain protein glutamate, which is thought to accumulate in people with AD and kills brain cells. In a recent study, researchers found that one of these, Aricept, led to a 6-month delay in further symptoms.¹²

Although patients with AD have inflammation in the brain, the use of nonsteroidal anti-inflammatory drugs, such as ibuprofen, as well as steroids such as Prednisone, have not slowed the course of the disease. The use of statins is being investigated, though it is not approved for use in AD. Protease inhibitors, which may reduce levels of beta-amyloid, are being prepared for clinical trials. Infusion of antibodies to beta-amyloid are now in testing.

Alternative and complementary therapies, gene therapy, and vaccine approaches are being studied. Scientific evidence supporting the use of particular vitamins and other substances is not substantial, but some new studies seek to bring scientific rigor to the debate. The role of mental and physical activities in warding off dementia and improving the symptoms of AD has been of interest to researchers and several studies have investigated this connection.^{13,14} Two recent studies have found a reduced risk of dementia and improved cognitive function in individuals who lead active lifestyles.^{15,16}

Research on the use of gene therapy to treat AD is in its infancy, with the first early clinical trials just completed, and Phase II efficacy trials were tentatively scheduled for late 2004. Phase I trials

have shown the therapy to be reasonably safe and, while researchers noted that there was no placebo group in the small Phase I study, they saw a 50 percent reduction in the rate of intellectual decline.¹⁷ Animal studies in which a vaccine was directed to help the immune system inhibit beta-amyloid have shown promise, although side effects halted the first vaccine trial in humans.¹⁸ More recent studies of this approach have lent credence to the immune system stimulation theory.¹⁹

Role of the Government: Research and Development, and Financing Care

Research and Development

Research and development is centered on: understanding the mechanism of disease, developing targeted treatments to reduce symptoms and slow or stall the progression of disease, and developing better models of care. Public funding, mainly through the Department of Health and Human Services (HHS) and the National Institutes of Health (NIH), has focused on studies of models of care, understanding the pathophysiology of disease, developing treatments, and possible prevention strategies.

At the NIH, the National Institute on Aging (NIA), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Mental Health (NIMH), and the National Center for Research Resources (NCRR) support the lion's share of research on AD.

NIA, for example, launched a Genetics Initiative in 2003, aimed at spurring research on the genetic basis of AD by creating a databank of DNA and cell lines from families afflicted by AD. The Initiative, which has enlisted about 500 families thus far²⁰, seeks to develop strategies for identifying genes involved in late-onset AD and environmental factors that may trigger development of AD, and to understand better the interaction of genes and the environment in the development of AD. NIMH has funded several clinical trials related to Alzheimer's therapy, depression in AD, as well as

brain imaging. NCCR recently funded research on the role of estrogen and vitamin E in the progression of AD. NCCAM and NIA are collaborating on a large prevention trial studying the effects of ginkgo biloba.

HHS funds the Alzheimer's disease Demonstration Grants to States (ADDGS) Program through the Administration on Aging. This initiative, funded at \$6.78 million in July 2004 and taking place in 38 states, is aimed at improving home and community-based services to those with dementia as well as their caregivers, and developing innovative models of care.²¹

The private sector also invests in AD research, and has over two dozen medicines in development.²³ The current market for Alzheimer's

drugs has been valued at over a billion dollars.²⁴ Nongovernmental organizations such as foundations, philanthropic organizations, and advocacy groups contribute to AD research as well.

Financing Care

The annual health care costs for Alzheimer's patients are estimated at \$100 billion per year.²⁵ In 2002, AD cost businesses \$61 billion in absenteeism, productivity losses, worker replacement costs, continuing insurance for workers on leave and temporary worker replacement fees, and employee assistance programs.²⁶ Of this total, \$36.5 billion was attributed to the costs of family caregiving and \$24.6 billion to the business share of health and long-term care expenditures. Excluded

Table 2. Spending on Alzheimer's Disease Across NIH, FY 2003–2005²²

Participating Institutes and Centers*	FY2003 Actual (\$ millions)	FY2004 Estimated (\$ millions)	FY2005 Estimated (\$ millions)
NCI	\$ 1.6	\$ 1.8	\$ 1.9
NHLBI	2.4	2.5	2.6
NIDCR	0.4	0.4	0.4
NIDDK	2.3	2.4	2.4
NINDS	47.3	48.9	49.6
NICHHD	2.9	3.0	3.1
NEI	0.0	0.0	0.0
NIEHS	6.2	6.4	6.6
NIA	501.8	517.9	533.5
NIAMS	0.5	0.5	0.5
NIDCD	2.9	2.9	3.0
NIMH	62.0	63.9	65.7
NIAAA	0.4	0.5	0.5
NINR	3.7	3.7	3.8
NHGRI	3.3	3.4	3.5
NIBIB	1.1	1.1	1.1
NCCR	15.9	16.5	17.0
NCCAM	3.0	3.1	3.2
FIC	0.4	0.4	0.4
NCMHD	0.1	0.1	0.1
OD	0.3	0.5	0.2
NIH (Total)	\$658.5	\$679.9	\$699.0

* NCI (National Cancer Institute), NHLBI (National Heart, Lung, and Blood Institute), NIDCR (National Institute of Dental and Craniofacial Research), NIDDK (National Institute of Diabetes and Digestive and Kidney Diseases), NICHHD (National Institute of Child Health and Human Development), NEI (National Eye Institute), NIEHS (National Institute of Environmental Health Services), NIAMS (National Institute on Arthritis and Musculoskeletal and Skin Diseases), NIDCD (National Institute on Deafness and Other Communication Disorders), NIAAA (National Institute on Alcohol Abuse and Alcoholism), NINR (National Institute of Nursing Research), NHGRI (National Human Genome Research Institute), NIBIB (National Institute on Biomedical Imaging and Bioengineering), NCCAM (National Center for Complementary and Alternative Medicine), FIC (Fogarty International Center), NCMHD (National Center on Minority Health and Health Disparities), OD (Office of the Director).

from the analysis were the costs associated with the estimated 250,000 workers in the labor force with AD.²⁷

There are three major models of care for AD patients: nursing home care, home-based care, and community-based care. Medicare covers limited nursing home care, but it is the Medicaid program that funds most nursing home care for the poor elderly. In recent years, there has been a shift from nursing home care to home care.²⁸

The government spends a considerable amount on the diagnosis, treatment, and care of AD patients through the Medicare and Medicaid programs, as well as the Veterans Health Administration. Most of those with AD are over age 65, and thus receive health insurance coverage under the Medicare program. Medicare covers inpatient hospital fees, a portion of doctors' fees, limited skilled nursing facility services post-hospitalization, and limited home health services. Medicare does not cover over-the-counter nutritional supplements, adult day care, respite care (except as under the program's hospice benefit), personal aid assistance (except as under the home health benefit), custodial care in a nursing home, incontinence supplies, or experimental treatments.²⁹ Beginning in 2006, a voluntary prescription drug benefit will be offered.

AD also impacts the Medicare program through its effect on other health conditions. Patients with dementia who become hospitalized incur \$4,000 more in costs than other patients and remain hospitalized, on average, four days longer.³⁰ Patients suffering from AD are more likely to have preventable medical crises. People with dementia have twice as many hip fractures as their peers.³¹ Medicare is also affected through spending on caregivers of AD patients. About a third of these are Medicare beneficiaries themselves. They visit physicians 46 percent more often and use 70 percent more prescription drugs than their contemporaries and are more likely to experience health complications directly related to their caregiving

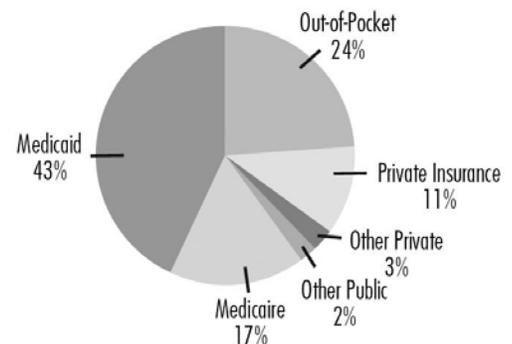
roles.³² More recent estimates put the cost of caring for AD patients to Medicare in 2000 at \$62 billion, projected to increase to \$189 billion by 2015.^{33,34}

Medicare will cover up to 100 days in a skilled nursing facility if the beneficiary was admitted after at least three days in a hospital and within 30 days of hospital discharge, and if the beneficiary requires and receives care for the condition for which he or she was hospitalized. For 2005, there is no deductible and the coinsurance for days 21–100 is \$114/day.³⁵ In 1999, the number of nursing home residents diagnosed with AD was 231,900, or 14 percent of the total nursing home population, and over 50 percent of nursing home residents were cognitively impaired or demented. The average length of stay for discharges with Alzheimer's as a primary diagnosis was 620 days.³⁶ Finally, despite the availability of a Medicare Hospice benefit, less than 3 percent of patients in hospice care have AD.³⁷

For individuals under 65 who qualify for Medicaid, and those over-65 Medicare beneficiaries who also qualify for Medicaid (so-called "dual-eligibles"), the federal-state health insurance program covers nursing home care and some home-based care. About half of all nursing home residents³⁸ and about a fifth of all dual-eligibles

Figure 2
National Spending on Long-Term Care, 2002⁴²

Total = \$139.3 Billion



Source: Ellen O'Brien and Risa Elias; Medicaid and Long-Term Care; Kaiser Family Foundation, May, 2004.

have Alzheimer's. Long-term care services account for a third of all Medicaid spending. Medicaid was responsible for 43 percent of the total spending on long-term care in 2002.³⁹ Medicaid is expected to spend \$33 billion on nursing home care for AD beneficiaries by 2010.⁴⁰

Some individuals spend down or shift assets in an effort to qualify for Medicaid, a practice discouraged by federal law.* Often a patient will enter a nursing home with private insurance, will pay out of pocket, and eventually deplete his or her assets to the point where the individual qualifies for Medicaid. In 2000, 40 percent of patients entering nursing homes were covered by Medicaid, while 60 percent of current nursing home residents had Medicaid as their primary insurer.⁴¹ Under federal law, Medicaid programs must cover nursing facility services as well as home health care services. Some states provide optional services such as case management services, prescription drugs, personal care services, and home and community-based services.

The cost of long-term care is of concern, especially to state governments addressing the costs of their Medicaid programs.⁴³ Long-term care (LTC), critical to Alzheimer's patients, is not covered by Medicare and insurance and services must be purchased on the private market.

While not widely purchased, LTC insurance (LTCI) can cover home health care, nursing home care, and assisted living and adult day care. In 2000, about \$4.8 billion was spent on premiums for LTCI, most of which (80 percent) were individual policies. Individual premiums accounted for over 90 percent of the total premiums.⁴⁴ Approximately 60 percent of individuals over the age of 65 can expect to require the kind of assistance covered by LTCI.⁴⁵ Like most insurance, LTCI plans differ in their generosity of benefits. Today, about 9 million Americans have purchased LTCI.⁴⁶

Over 70 percent of patients with AD receive care at home and 75 percent of that care is delivered by family members rather than nurses or other health professionals. Medicare has limited home health benefits: to qualify, beneficiaries must be "homebound," meaning that leaving the home must require a "considerable and taxing effort." Although Medicaid's home health benefit is mandatory, state programs differ in which populations are covered, copayments, prior approval requirements, coverage limitations, and reimbursement methodologies.

Specialized community-based care and assisted living environments exist for patients. Community care services, such as adult day care, exist to give home caregivers a "break" from care, and allow them to keep their jobs while still caring for relatives at home. Assisted living facilities provide comprehensive assistance with activities of daily living, such as dressing and personal care.

In addition to insurance premiums, deductibles, co-pays, and lost wages, most patients and their families will incur significant expenses. About a third of the costs for long-term care are paid out-of-pocket by patients and families.

Policy Challenges and Considerations

Policy considerations are twofold: the future direction and funding of R&D and the costs associated with diagnosis and delivery of care. Publicly funded research is focused on understanding the mechanism of disease, developing targeted therapies, and better managing the course of illness through appropriate care models. (Some experts in the field believe that AD may be one of the diseases least likely to be addressed through the use of embryonic stem cells.⁴⁷ This is due to the nature of the disease, which affects the whole brain instead of particular cells, in contrast to type-1 diabetes.)

As new therapies develop, patients will live longer and perhaps with less disability. Both Medicare and Medicaid will likely have to adjust to these changes and modify the kinds of services covered, as well as cope with the costs of care over

* The Department of Health and Human Services (HHS) performs audits for three years prior to an individual's application for Medicaid benefits, to ensure that the individual has not purposely shed assets in an effort to qualify for benefits. The law is complicated and there are exceptions.

a longer period of time. In addition, the retirement of the baby boomers (and thus more individuals with AD) is likely to strain federal and state budgets, as well as individual and household budgets.

Legislation in the 108th Congress

A number of bills were introduced in the 108th Congress that specifically address Alzheimer's disease. None received action. These bills sought to increase funding and strengthen programs for AD research, prevention, and treatment, authorize tax credits for AD caregivers, or improve Medicare benefits for AD patients. They included:

Funding for AD Research, Prevention and Treatment

- The Alzheimer's Disease Research, Prevention, and Care Act of 2003 (H.R.1138/S.566) aimed at increasing NIH funding for AD research, prevention, and treatment programs. The bill called for funding in excess of \$1 billion to the NIH through 2008.
- The Alzheimer's Treatment and Caregiver Support Act (H.R.3451) would amend the Public Health Service Act to provide grants to public and nonprofit health care providers to expand services for AD patients and their families and caregivers.
- The Ronald Reagan Alzheimer's Breakthrough Act of 2004 (H.R.4595/S.2533) would double the NIH budget for AD and fund a public education campaign intended to inform the public about early detection and prevention of AD through lifestyle changes.

Tax Code Reforms

- S.2029 would amend the tax code to allow individuals with dependents affected by AD to deduct related expenses from their income taxes.
- The Ronald Reagan Alzheimer's Breakthrough Act of 2004 (H.R.4595/S.2533) would allow individuals to deduct premiums paid for long-term care insurance. In addition, the bill provides a tax credit for those who care for individuals

who require long-term care. In 2005, this credit would be \$1,500 for each dependent.

Improving Medicare

- The Geriatric and Chronic Care Management Act of 2004 (S.2593/H.R.4689) would facilitate the delivery of care for chronic illnesses through changes in Medicare. The bill would permit reimbursement to caregivers known as "chronic care managers," for such services as monitoring medications and coordinating care across different specialists.

Conclusion

Alzheimer's disease presents policymakers with several challenges, including the level of funding and direction of federally funded research, and the cost pressures on Medicare and Medicaid of long-term care. These challenges will increase in intensity as demographic changes, particularly the aging of baby boomers, take hold. Better prevention of Alzheimer's, advances in therapy, and appropriate care modalities will likely require significant investment.

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