

Alzheimer's Association Report

2014 Alzheimer's disease facts and figures

Alzheimer's Association*

Abstract

This report discusses the public health impact of Alzheimer's disease (AD), including incidence and prevalence, mortality rates, costs of care, and overall effect on caregivers and society. It also examines the impact of AD on women compared with men. An estimated 5.2 million Americans have AD. Approximately 200,000 people younger than 65 years with AD comprise the younger onset AD population; 5 million are age 65 years or older. By mid-century, fueled in large part by the baby boom generation, the number of people living with AD in the United States is projected to grow by about 9 million. Today, someone in the country develops AD every 67 seconds. By 2050, one new case of AD is expected to develop every 33 seconds, or nearly a million new cases per year, and the total estimated prevalence is expected to be 13.8 million. In 2010, official death certificates recorded 83,494 deaths from AD, making AD the sixth leading cause of death in the United States and the fifth leading cause of death in Americans aged 65 years or older. Between 2000 and 2010, the proportion of deaths resulting from heart disease, stroke, and prostate cancer decreased 16%, 23%, and 8%, respectively, whereas the proportion resulting from AD increased 68%. The actual number of deaths to which AD contributes (or deaths *with* AD) is likely much larger than the number of deaths *from* AD recorded on death certificates. In 2014, an estimated 700,000 older Americans will die with AD, and many of them will die from complications caused by AD. In 2013, more than 15 million family members and other unpaid caregivers provided an estimated 17.7 billion hours of care to people with AD and other dementias, a contribution valued at more than \$220 billion. Average per-person Medicare payments for services to beneficiaries aged 65 years and older with AD and other dementias are more than two and a half times as great as payments for all beneficiaries without these conditions, and Medicaid payments are 19 times as great. Total payments in 2014 for health care, long-term care, and hospice services for people aged 65 years and older with dementia are expected to be \$214 billion. AD takes a stronger toll on women than men. More women than men develop the disease, and women are more likely than men to be informal caregivers for someone with AD or another dementia. As caregiving responsibilities become more time consuming and burdensome or extend for prolonged durations, women assume an even greater share of the caregiving burden. For every man who spends 21 to more than 60 hours per week as a caregiver, there are 2.1 women. For every man who lives with the care recipient and provides around-the-clock care, there are 2.5 women. In addition, for every man who has provided caregiving assistance for more than 5 years, there are 2.3 women.

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Keywords:

Alzheimer's disease; Dementia; Diagnostic criteria; Prevalence; Incidence; Mortality; Morbidity; Caregivers; Family caregiver; Spouse caregiver; Health-care costs; Health-care expenditures; Long-term care costs; Medicare spending; Medicaid spending; Caregiving burden; Women caregivers

1. About this report

2014 Alzheimer's Disease Facts and Figures is a statistical resource for US data related to Alzheimer's disease

(AD), the most common type of dementia, as well as other dementias. Background and context for interpretation of the data are contained in the Overview. This information includes definitions of the various types of dementia and a summary of current knowledge about AD. Additional sections address prevalence, mortality and morbidity, caregiving, and use and costs of care and services. The Special Report discusses women and Alzheimer's disease.

*Corresponding authors: Keith Fargo, Ph.D., and Laura Bleiler. Tel.: 312-335-5893; Fax: 866-521-8007.
E-mail address: lbleiler@alz.org

Specific information in this year's *Alzheimer's Disease Facts and Figures* includes:

- Proposed criteria and guidelines for diagnosing AD from the National Institute on Aging (NIA) and the Alzheimer's Association.
- Overall number of Americans with AD nationally and for each state.
- Proportion of women and men with AD and other dementias.
- Estimates of lifetime risk for developing AD.
- Number of deaths due to AD nationally and for each state, and death rates by age.
- Number of family caregivers, hours of care provided, economic value of unpaid care nationally and for each state, and the impact of caregiving on caregivers.
- Use and costs of health care, long-term care, and hospice care for people with AD and other dementias.
- The burden of Alzheimer's disease on women compared with men.

The [Appendices](#) detail sources and methods used to derive data in this report.

This report frequently cites statistics that apply to individuals with all types of dementia. When possible, specific information about AD is provided; in other cases, the reference may be a more general one of "AD and other dementias."

2. Overview of AD

AD is the most common type of dementia. Dementia is an overall term for diseases and conditions characterized by a decline in memory or other thinking skills that affects a person's ability to perform everyday activities. Dementia is caused by damage to nerve cells in the brain, which are called neurons. As a result of the damage, neurons can no longer function normally and may die. This, in turn, can lead to changes in one's memory, behavior, and ability to think clearly. In AD, the damage to and death of neurons eventually impair one's ability to carry out basic bodily functions such as walking and swallowing. People in the final stages of the disease are bedbound and require around-the-clock care. AD is ultimately fatal.

2.1. Dementia

2.1.1. Definition and diagnosis

Physicians often define dementia based on the criteria given in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. In 2013, the American Psychiatric Association released the fifth edition of the *DSM (DSM-5)*, which incorporates dementia into the diagnostic categories of major and mild neurocognitive disorders [1].

To meet *DSM-5* criteria for *major neurocognitive disorder*, an individual must have evidence of significant cognitive decline (e.g., decline in memory, language, or

learning), and the cognitive decline must interfere with independence in everyday activities (e.g., assistance may be needed with complex activities such as paying bills or managing medications).

To meet *DSM-5* criteria for *mild neurocognitive disorder*, an individual must have evidence of modest cognitive decline, but the decline does not interfere with everyday activities. (Individuals can still perform complex activities such as paying bills or managing medications, but the activities require greater effort.)

For both major and mild neurocognitive disorders, *DSM-5* instructs physicians to specify whether the condition is due to AD, frontotemporal lobar degeneration, Lewy body disease, or a variety of other conditions.

2.1.2. Types of dementia

When an individual has symptoms of dementia, a physician must conduct tests to identify the underlying brain disease or other condition that is causing symptoms. Different types of dementia are associated with distinct symptom patterns and brain abnormalities, as described in [Table 1](#). Increasing evidence from long-term observational and autopsy studies indicates that many people with dementia, especially those in the older age groups, have brain abnormalities associated with more than one type of dementia [2–6]. This is called mixed dementia.

Some conditions result in symptoms that mimic dementia but that, unlike dementia, may be reversed with treatment. An analysis of 39 articles describing 5620 people with dementia-like symptoms reported that 9% had symptoms that were mimicking dementia and potentially reversible [7]. Common causes of these symptoms are depression, delirium, side effects from medications, thyroid problems, certain vitamin deficiencies, and excessive use of alcohol. In contrast, AD and other dementias cannot be reversed with current treatments.

2.2. Alzheimer's disease

AD was first identified more than 100 years ago, but research into its symptoms, causes, risk factors, and treatment has gained momentum only in the last 30 years. Although research has revealed a great deal about AD, much is yet to be discovered about the precise biologic changes that cause AD, why it progresses at different rates among affected individuals, and how the disease can be prevented, slowed, or stopped.

2.2.1. Symptoms

AD affects people in different ways. The most common initial symptom is a gradually worsening ability to remember new information. This occurs because the first neurons to malfunction and die are usually neurons in brain regions involved in forming new memories. As neurons in other parts of the brain malfunction and die, individuals

Table 1
Types of dementia and their typical characteristics*

Type of dementia	Characteristics
AD	<p>Most common type of dementia; accounts for an estimated 60% to 80% of cases. About half of these cases involve solely Alzheimer's pathology; many have evidence of pathologic changes related to other dementias. This is called mixed dementia (see mixed dementia in this table).</p> <p>Difficulty remembering recent conversations, names, or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavior changes and, ultimately, difficulty speaking, swallowing, and walking.</p> <p>Revised criteria and guidelines for diagnosing AD were proposed and published in 2011. They recommend that AD be considered a slowly progressive brain disease that begins well before clinical symptoms emerge.</p> <p>The hallmark pathologies of AD are the progressive accumulation of the protein fragment β-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are eventually accompanied by the damage and death of neurons.</p>
Vascular dementia	<p>Previously known as multi-infarct or poststroke dementia, vascular dementia is less common as a sole cause of dementia than AD, accounting for about 10% of dementia cases. However, it is very common in older individuals with dementia, with about 50% having pathologic evidence of vascular dementia (infarcts). In most cases, the infarcts coexist with AD pathology [8].</p> <p>Impaired judgment or the ability to make decisions, plan, or organize is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of AD.</p> <p>Vascular dementia occurs most commonly from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain. The location, number, and size of the brain injuries determine whether dementia will result and how the individual's thinking and physical functioning will be affected.</p> <p>In the past, evidence of vascular dementia was used to exclude a diagnosis of AD (and vice versa). That practice is no longer considered consistent with the pathologic evidence, which shows that the brain changes of both types of dementia commonly coexist. When two or more types of dementia are present at the same time, the individual is considered to have mixed dementia (see mixed dementia in this table).</p>
DLB	<p>People with DLB have some of the symptoms common in AD but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations and slowness, gait imbalance, or other parkinsonian movement features. These features, as well as early visuospatial impairment, may occur in the absence of significant memory impairment.</p> <p>Lewy bodies are abnormal aggregations (or clumps) of the protein α-synuclein that accumulates in neurons. When they develop in a part of the brain called the cortex, dementia can result. α-Synuclein also aggregates in the brains of people with PD, in which it is accompanied by severe neuronal loss in a part of the brain called the substantia nigra. Although people with DLB and PD both have Lewy bodies, the onset of the disease is marked by motor impairment in PD and cognitive impairment in DLB.</p> <p>The brain changes of DLB alone can cause dementia. But very commonly, brains with DLB have coexisting AD pathology. In people with both DLB and AD pathology, symptoms of both diseases may emerge and lead to some confusion in diagnosis. Vascular dementia can also coexist and contribute to the dementia. When evidence of more than one dementia is present, the individual is said to have mixed dementia (see mixed dementia in this table).</p>
FTLD	<p>Includes dementias such as behavioral-variant FTLT, primary progressive aphasia, Pick's disease, corticobasal degeneration, and progressive supranuclear palsy.</p> <p>Typical early symptoms include marked changes in personality and behavior and difficulty with producing or comprehending language. Unlike AD, memory is typically spared in the early stages of disease.</p> <p>Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly atrophied (shrunken). In addition, the upper layers of the cortex typically become soft and spongy and have protein inclusions (usually tau protein or the transactive response DNA-binding protein).</p> <p>The brain changes of behavioral-variant FTLT may occur in those aged 65 years and older, similar to AD, but most people with this form of dementia develop symptoms at a younger age (at about age 60 years). In this younger age group, FTLT is the second most common degenerative dementia.</p>
Mixed dementia	<p>Characterized by the hallmark abnormalities of more than one type of dementia—most commonly AD combined with vascular dementia, followed by AD with DLB, and AD with vascular dementia and DLB. Vascular dementia with DLB is much less common [3,4].</p> <p>Recent studies suggest that mixed dementia is more common than previously recognized, with about half of those with dementia having mixed pathologies [3,4].</p>
PD dementia	<p>Problems with movement (slowness, rigidity, tremor, and changes in gait) are common symptoms of PD.</p> <p>In PD, α-synuclein aggregates appear in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine.</p> <p>The incidence of PD is about one-tenth that of AD. As PD progresses, it often results in dementia secondary to the accumulation of Lewy bodies in the cortex (similar to DLB) or the accumulation of β-amyloid clumps and tau tangles (similar to AD).</p>
Creutzfeldt-Jakob disease	<p>This very rare and rapidly fatal disorder impairs memory and coordination and causes behavior changes.</p> <p>Results from a misfolded protein (prion) that causes other proteins throughout the brain to misfold and malfunction.</p> <p>May be hereditary (caused by a gene that runs in one's family), sporadic (unknown cause) or caused by a known prion infection.</p> <p>A specific form called variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.</p>

(Continued)

Table 1
Types of dementia and their typical characteristics* (Continued)

Type of dementia	Characteristics
Normal pressure hydrocephalus	Symptoms include difficulty walking, memory loss, and inability to control urination. Caused by impaired reabsorption of cerebrospinal fluid and the consequent buildup of fluid in the brain, increasing pressure in the brain. People with a history of brain hemorrhage (particularly subarachnoid hemorrhage) and meningitis are at increased risk. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

Abbreviations: AD, Alzheimer's disease; DLB, dementia with Lewy bodies; PD, Parkinson's disease; FTLN, frontotemporal lobar degeneration.

*For more information on these and other types of dementia, visit www.alz.org.

experience other difficulties. The following are common symptoms of AD:

- Memory loss that disrupts daily life.
- Challenges in planning or solving problems.
- Difficulty completing familiar tasks at home, at work, or at leisure.
- Confusion with time or place.
- Trouble understanding visual images and spatial relationships.
- New problems with words in speaking or writing.
- Misplacing things and losing the ability to retrace steps.
- Decreased or poor judgment.
- Withdrawal from work or social activities.
- Changes in mood and personality, including apathy and depression.

For more information about symptoms of AD, visit www.alz.org/10signs.

Individuals progress through AD at different rates. As they pass through different stages of the disease, individuals' cognitive and functional abilities decline. In the final, advanced stage of the disease, people need help with basic activities of daily living (ADLs) such as bathing, dressing, eating, and using the bathroom; lose their ability to communicate; fail to recognize loved ones; and become bedbound and reliant on around-the-clock care. When individuals have difficulty moving, they are more vulnerable to infections, including pneumonia (infection of the lungs). AD-related pneumonia is often a contributing factor to the death of people with AD.

2.2.2. Changes in the brain that are associated with AD

A healthy adult brain has about 100 billion neurons, each with long, branching extensions. These extensions enable individual neurons to form connections with other neurons. At such connections, called synapses, information flows in tiny bursts of chemicals that are released by one neuron and detected by a receiving neuron. The brain contains about 100 trillion synapses. They allow signals to travel rapidly through the brain's circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements, and skills. AD interferes with the proper functioning of neurons and synapses.

Among the brain changes believed to contribute to the development of AD are the accumulation of the protein β -amy-

loid *outside* neurons (called β -amyloid plaques) and the accumulation of an abnormal form of the protein tau *inside* neurons (called tau tangles). In AD, information transfer at synapses begins to fail, the number of synapses declines, and neurons eventually die. The accumulation of β -amyloid is believed to interfere with the neuron-to-neuron communication at synapses and to contribute to cell death. Tau tangles block the transport of nutrients and other essential molecules in the neuron and are also believed to contribute to cell death. The brains of people with advanced AD show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

The brain changes of AD may begin 20 or more years [9–11] before symptoms appear. The time between the initial brain changes of AD and the symptoms of advanced AD is considered by scientists to represent the "continuum" of AD. At the start of the continuum, the individual is able to function normally despite these brain changes. Further along the continuum, the brain can no longer compensate for the neuronal damage that has occurred, and the individual shows subtle decline in cognitive function. Later, the damage to and death of neurons is so significant that the individual shows obvious cognitive decline, including symptoms such as memory loss or confusion as to time or place. Later still, basic bodily functions such as swallowing are impaired.

2.2.3. Genetic mutations that cause AD

A small percentage of AD cases, an estimated 1% or less [12], develop as a result of mutations in any of three genes. A genetic mutation is an abnormal change in the sequence of chemical pairs that make up genes. These mutations involve the gene for the amyloid precursor protein and the genes for the presenilin 1 and 2 proteins. Inheriting any of these genetic mutations guarantees that an individual will develop AD. In such individuals, disease symptoms tend to develop before the age of 65 years, sometimes as early as age 30 years, whereas the vast majority of individuals with AD have late-onset disease, occurring at age 65 years or later.

2.2.4. Risk factors for AD

With the exception of the rare cases of AD caused by known genetic mutations, experts believe that AD, like other common chronic diseases, develops as a result of multiple factors rather than a single cause. Following are known risk factors for AD.

2.2.4.1. Age

The greatest risk factor for AD is advanced age. Most people with AD are diagnosed at age 65 years or older. People younger than 65 years can also develop the disease, although this is much rarer. (See the Prevalence section.) While age is the greatest risk factor, AD is not a normal part of aging, and advanced age alone is not sufficient to cause the disease.

2.2.4.2. Family history

Individuals who have a parent, brother, or sister with AD are more likely to develop the disease than those who do not have a first-degree relative with AD [13–15]. Those who have more than one first-degree relative with AD are at even higher risk [16]. When diseases run in families, heredity (genetics), shared environmental and lifestyle factors, or both may play a role. The increased risk associated with having a family history of AD is not entirely explained by whether the individual has inherited the apolipoprotein E (*APOE*) ϵ 4 risk gene.

2.2.4.3. *APOE* ϵ 4 gene

The *APOE* gene provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the *APOE* gene— ϵ 2, ϵ 3, or ϵ 4—from each parent. The ϵ 3 form is the most common [17], with about 60% of the US population inheriting ϵ 3 from both parents [18]. The ϵ 2 and ϵ 4 forms are much less common. An estimated 20% to 30% of individuals in the United States have one or two copies of the ϵ 4 form [17,18]; approximately 2% of the US population has two copies of ϵ 4 [18]. The remaining 10% to 20% have one or two copies of ϵ 2.

Having the ϵ 3 form is believed to neither increase nor decrease one's risk of AD, whereas having the ϵ 2 form may decrease one's risk. The ϵ 4 form, however, increases the risk of developing AD and of developing it at a younger age. Those who inherit two ϵ 4 genes have an even higher risk. Researchers estimate that between 40% and 65% of people diagnosed with AD have one or two copies of the *APOE* ϵ 4 gene [17,19,20].

Unlike inheriting a known genetic mutation that causes AD, inheriting the ϵ 4 form of the *APOE* gene does not guarantee that an individual will develop AD. This is also true for several genes that appear to increase the risk of AD but that have a limited overall effect in the population because they are rare or only slightly increase risk.

2.2.4.4. Mild cognitive impairment

Mild cognitive impairment (MCI) is a condition in which an individual has mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends but that do not affect the individual's ability to carry out everyday activities. People with MCI, especially MCI involving memory problems, are more likely to develop AD and other dementias than people without MCI. However, MCI does not always lead to dementia. For some individuals, MCI reverts to normal cognition on

its own or remains stable. In other cases, such as when a medication causes cognitive impairment, MCI is mistakenly diagnosed. Therefore, it is important that people experiencing cognitive impairment seek help as soon as possible for diagnosis and possible treatment.

The proposed criteria and guidelines for diagnosis of AD published in 2011 [21–24] suggest that in some cases, MCI is actually an early stage of AD or another dementia.

2.2.4.5. Cardiovascular disease risk factors

Growing evidence suggests that the health of the brain is closely linked to the overall health of the heart and blood vessels. The brain is nourished by one of the body's richest networks of blood vessels. A healthy heart helps ensure that enough blood is pumped through these blood vessels, and healthy blood vessels help ensure that the brain is supplied with the oxygen- and nutrient-rich blood it needs to function normally.

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of developing AD and other dementias. These factors include smoking [25–27], obesity (especially in midlife) [28–34], diabetes [27,35–39], high cholesterol in midlife [30,40], and hypertension in midlife [30,33,41–43].

Conversely, factors that protect the heart may also protect the brain and reduce the risk of developing AD and other dementias. Physical activity [37,44–46] appears to be one of these factors. In addition, emerging evidence suggests that consuming a diet that benefits the heart, such as one that is low in saturated fats and rich in vegetables and vegetable-based oils, may be associated with reduced AD and dementia risk [37].

Unlike genetic risk factors, many of these cardiovascular disease risk factors are *modifiable*—that is, they can be changed to decrease the likelihood of developing cardiovascular disease and, possibly, AD and other forms of dementia.

2.2.4.6. Social and cognitive engagement

Additional studies suggest that other modifiable risk factors such as remaining mentally and socially active may support brain health and possibly reduce the risk of AD and other dementias [47–59]. Remaining socially and cognitively active may help build cognitive reserve (see *Education*), but the exact mechanism by which this may occur is unknown. More research is needed to better understand how social and cognitive engagement may affect biological processes to reduce risk.

2.2.4.7. Education

People with fewer years of formal education are at higher risk for AD and other dementias than those with more years of formal education [60–64]. Some researchers believe that having more years of education builds a “cognitive reserve” that enables individuals to better compensate for changes in the brain that could result in symptoms of AD or another dementia [63,65–67]. According to the cognitive reserve hypothesis, having more years of

education increases the connections between neurons in the brain and enables the brain to compensate for the early brain changes of AD by using alternate routes of neuron-to-neuron communication to complete a cognitive task. However, some scientists believe that the increased risk of dementia among those with lower educational attainment may be explained by other factors common to people in lower socioeconomic groups such as increased risk for disease in general and less access to medical care [68].

2.2.4.8. Traumatic brain injury

Moderate and severe traumatic brain injuries (TBIs) increase the risk of developing AD and other dementias [69]. TBI is the disruption of normal brain function caused by a blow or jolt to the head or penetration of the skull by a foreign object. Not all blows or jolts to the head disrupt brain function. Moderate TBI is defined as a head injury resulting in loss of consciousness or posttraumatic amnesia that lasts more than 30 minutes. If loss of consciousness or posttraumatic amnesia lasts more than 24 hours, the injury is considered severe. Half of all moderate and severe TBIs are caused by motor vehicle accidents [70]. Moderate TBI is associated with twice the risk of developing AD and other dementias compared with no head injuries, and severe TBI is associated with 4.5 times the risk [71].

Groups that experience repeated head injuries such as boxers, football players, and combat veterans are at higher risk of dementia, cognitive impairment, and neurodegenerative disease than individuals who experience no head injury [72–78]. Evidence suggests that even repeated mild TBI might promote neurodegenerative disease [79–81]. Some of these neurodegenerative diseases, such as chronic traumatic encephalopathy, can only be distinguished from AD on autopsy.

2.2.5. Diagnosis

A diagnosis of AD is most commonly made by an individual's primary care physician. The physician obtains a medical and family history, including psychiatric history and history of cognitive and behavioral changes. The physician also asks a family member or other person close to the individual to provide input. In addition, the physician conducts cognitive tests and physical and neurologic examinations and may request that the individual undergo magnetic resonance imaging scans. Magnetic resonance imaging scans can help identify brain changes such as the presence of a tumor or evidence of a stroke that could explain the individual's symptoms.

2.2.6. A modern diagnosis of AD: Proposed criteria and guidelines

In 2011, the NIA and the Alzheimer's Association proposed revised criteria and guidelines for diagnosing AD [21–24]. These criteria and guidelines updated diagnostic criteria and guidelines published in 1984 by the Alzheimer's Association and the National Institute of

Neurological Disorders and Stroke [82]. In 2012, the NIA and the Alzheimer's Association also proposed new guidelines to help pathologists describe and categorize the brain changes associated with AD and other dementias [83].

It is important to note that more research is needed before the proposed diagnostic criteria and guidelines can be used in clinical settings such as in a doctor's office.

2.2.6.1. Differences between the original and proposed criteria

The 1984 diagnostic criteria and guidelines were based chiefly on a doctor's clinical judgment about the cause of an individual's symptoms, taking into account reports from the individual, family members, and friends; results of cognitive tests; and general neurologic assessment. The new criteria and guidelines incorporate two notable changes:

- (1) They identify three stages of AD, with the first occurring before symptoms such as memory loss develop. In contrast, for AD to be diagnosed using the 1984 criteria, memory loss and a decline in thinking abilities must have already occurred.
- (2) They incorporate biomarker tests. A biomarker is a biological factor that can be measured to indicate the presence or absence of disease or the risk of developing a disease. For example, blood glucose level is a biomarker of diabetes and cholesterol level is a biomarker of heart disease risk. Levels of certain proteins in fluid (e.g., levels of β -amyloid and tau in the cerebrospinal fluid and blood) are among several factors being studied as possible biomarkers for AD.

2.2.6.2. The three stages of AD proposed by the 2011 criteria and guidelines

The three stages of AD proposed by the 2011 criteria and guidelines are preclinical AD, MCI due to AD, and dementia due to AD. An individual who does not yet have outward symptoms of AD but does have some of the early brain changes of AD (as detected by brain imaging and other biomarker tests) would be said to have preclinical AD. Those who have very mild symptoms but can still perform everyday tasks would be described as having MCI due to AD. Individuals whose symptoms are more pronounced and interfere with carrying out everyday tasks would be said to have dementia due to AD.

2.2.6.2.1. Preclinical AD

In this stage, individuals have measurable changes in the brain, cerebrospinal fluid, and/or blood (biomarkers) that indicate the earliest signs of disease, but they have not yet developed noticeable symptoms such as memory loss. This preclinical or presymptomatic stage reflects current thinking that AD-related brain changes may begin 20 years or more before symptoms occur [9–11]. Although the 2011 criteria and guidelines identify preclinical disease as a stage of AD, they do not establish diagnostic criteria that doctors can use now.

Rather, they state that additional research is needed before this stage of AD can be identified.

2.2.6.2.2. MCI due to AD

Individuals with MCI have mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends but that do not affect the individual's ability to carry out everyday activities. Studies indicate that as many as 10% to 20% of people aged 65 years or older have MCI [84–86]. Among people whose MCI symptoms cause them enough concern to contact their physicians for an examination, as many as 15% progress from MCI to dementia each year. Nearly half of all people who have visited a doctor about MCI symptoms will develop dementia in 3 or 4 years [87].

When MCI is identified through community sampling, in which individuals in a community who meet certain criteria are assessed regardless of whether they have memory or cognitive complaints, the estimated percentage of people who will progress to AD is slightly lower—up to 10% per year [88]. Further cognitive decline is more likely among individuals whose MCI involves memory problems than among those whose MCI does not involve memory problems. Over 1 year, most individuals with MCI who are identified through community sampling remain cognitively stable. Some, primarily those without memory problems, experience an improvement in cognition or revert to normal cognitive status [89]. It is unclear why some people with MCI develop dementia and others do not. When an individual with MCI goes on to develop dementia, many scientists believe the MCI is actually an early stage of the particular form of dementia, rather than a separate condition.

After accurate and reliable biomarker tests for AD have been identified, the 2011 criteria and guidelines recommend biomarker testing for people with MCI to learn whether they have biological changes that put them at high risk of developing AD and other dementias. If testing shows that changes in the brain, cerebrospinal fluid, and/or blood are similar to the changes of AD, the proposed criteria and guidelines recommend a diagnosis of MCI due to AD. However, this diagnosis cannot currently be made, as additional research is needed to validate the 2011 criteria before they can be used in clinical settings.

2.2.6.2.3. Dementia due to AD

This stage, as described by the 2011 diagnostic criteria and guidelines, is characterized by quite noticeable memory, thinking, and behavioral symptoms that, unlike MCI, impair a person's ability to function in daily life.

2.2.6.3. Biomarker tests

The 2011 criteria and guidelines identify two biomarker categories: (1) biomarkers showing the level of β -amyloid accumulation in the brain and (2) biomarkers showing that neurons in the brain are injured or actually degenerating.

Many researchers believe that future treatments to slow or stop the progression of AD and preserve brain function

(called “disease-modifying” treatments) will be most effective when administered during the preclinical and MCI stages of the disease. Biomarker tests will be essential to identify which individuals are in these early stages and should receive disease-modifying treatment. They also will be critical for monitoring the effects of treatment. At this time, however, more research is needed to validate the accuracy of biomarkers and better understand which biomarker test or combination of tests is most effective in diagnosing AD. The most effective test or combination of tests may differ depending on the stage of the disease and the type of dementia [90].

2.2.6.4. Progress toward implementing criteria and validating biomarkers

Since the revised criteria were published in 2011, dozens of scientists have published results of studies implementing the revised criteria in research settings, examining the accuracy of biomarker tests in detecting and predicting AD, and using biomarker tests to distinguish AD from other forms of dementia. Although additional studies are needed before the revised criteria and guidelines are ready for use in physicians' offices, preliminary evidence supporting the revised criteria and biomarker tests is growing [91–107].

2.2.7. Treatment of AD

2.2.7.1. Pharmacologic treatment

Pharmacologic treatments are treatments in which medication is administered to slow or stop an illness or treat its symptoms. None of the treatments available today for AD slows or stops the malfunction and death of neurons in the brain that cause AD symptoms and eventually make the disease fatal. However, dozens of drugs and therapies aimed at slowing or stopping neuronal malfunction and death are being studied by scientists around the world. Five drugs have been approved by the US Food and Drug Administration that temporarily improve symptoms of AD by increasing the amount of chemicals called neurotransmitters in the brain. The effectiveness of these drugs varies from person to person.

Despite the lack of disease-modifying therapies, studies have consistently shown that active management of AD and other dementias can improve quality of life through all stages of the disease for individuals with dementia and their caregivers [108–110]. Active management includes (1) appropriate use of available treatment options, (2) effective management of coexisting conditions, (3) coordination of care among physicians, other health-care professionals, and lay caregivers, (4) participation in activities and/or adult day care programs, and (5) taking part in support groups and supportive services.

2.2.7.2. Nonpharmacologic therapy

Nonpharmacologic therapies are those that use approaches other than medication such as physical therapy and reminiscence therapy (therapy in which photos and other familiar items may be used to elicit recall). As with

pharmacologic therapies, nonpharmacologic therapies have not been shown to alter the course of AD. Rather than altering the disease course, nonpharmacologic therapies are often used with the goal of maintaining cognitive function or helping the brain compensate for impairments. Nonpharmacologic therapies are also used with the goals of improving quality of life or reducing behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation, and aggression.

A wide range of nonpharmacologic interventions have been proposed or studied. The Cochrane Database of Systematic Reviews of published articles on nonpharmacologic therapies found that few have sufficient evidence supporting their effectiveness [111]. Of the 25 categories of nonpharmacologic therapies reviewed in the Cochrane Database, only cognitive stimulation had findings that suggested a beneficial effect. A different systematic review found that there were too few high-quality studies to show that nonpharmacologic therapy for dementia was effective. However, of the high-quality studies reviewed, cognitive training, cognitive stimulation, and training in ADLs appeared most successful in reaching the aims of the interventions [112]. A meta-analysis, which combines results from many studies, found the most successful nonpharmacologic interventions for neuropsychiatric symptoms of dementia were multicomponent, tailored to the needs of the caregiver and person with dementia, and delivered at home with periodic follow-up [113].

3. Prevalence

Millions of Americans have AD and other dementias. The number of Americans with AD and other dementias will grow each year as the size and proportion of the US population aged 65 years and older continue to increase. The number will escalate rapidly in coming years as the baby boom generation ages.

Estimates from selected studies on the prevalence and characteristics of people with AD and other dementias

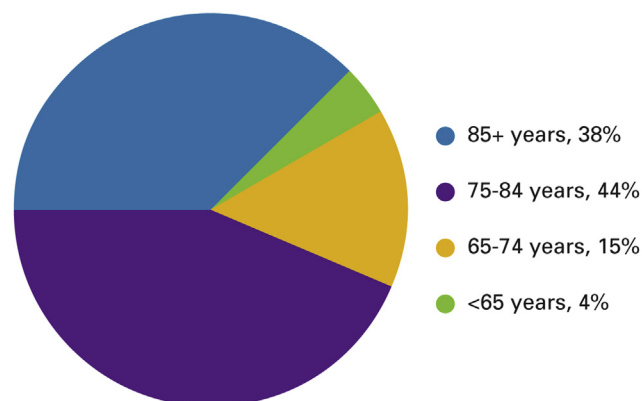


Fig. 1. Proportion of people with AD in the United States by age. Percentages may not total 100 because of rounding. Created from data from Hebert et al. [114].^{A3}

vary depending on how each study was conducted. Data from several studies are used in this section.

3.1. Prevalence of AD and other dementias

The prevalence of AD refers to the proportion of people in a population who have AD at a given point in time. People who have AD at a given time are said to have prevalent disease. Prevalence and the number of prevalent cases describe the magnitude of the burden of AD on the community and the health-care system, but it does not provide an estimate of the risk of developing the disease. An estimated 5.2 million Americans of all ages have AD in 2014. This includes an estimated 5 million people aged 65 years and older [114]^{A1} and approximately 200,000 individuals younger than 65 years who have younger onset AD [115].

- One in nine people aged 65 years and older (11%) has AD.^{A2}
- About one-third of people aged 85 years and older (32%) have AD [114].
- Of those with AD, the vast majority (82%) are age 75 years or older (Fig. 1) [114].^{A3}

The estimated prevalence of AD for people aged 65 years and older comes from a recent study using the latest data from the 2010 US Census and the Chicago Health and Aging Project (CHAP), a population-based study of chronic health diseases of older people [114].

National estimates of the prevalence of all forms of dementia are not available from CHAP but are available from other population-based studies, including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults [116,117].^{A4} Based on estimates from ADAMS, 13.9% of people aged 71 years and older in the United States have dementia [116].

Prevalence studies such as CHAP and ADAMS are designed so that all individuals with dementia are detected. But in the community, only about half of those who would meet the diagnostic criteria for AD and other dementias have received a diagnosis of dementia from a physician [118]. Because AD is underdiagnosed, half of the estimated 5.2 million Americans with AD may not know they have it.

3.1.1. Preclinical AD

The estimates from CHAP and ADAMS are based on commonly accepted criteria for diagnosing AD that have been used since 1984. These criteria are applicable only after the onset of symptoms. But as described in the Overview, revised criteria and guidelines by the Alzheimer's Association and NIA were published in 2011 [21–24] proposing that AD begins before the onset of symptoms. The 2011 criteria identify three stages of AD: preclinical AD, MCI due to AD, and dementia due to AD. Because more research is needed to validate the accuracy of biomarker tests in detecting preclinical AD and MCI due to AD, the number of people in these stages is difficult to estimate. However, if AD could be detected before symptoms developed, the

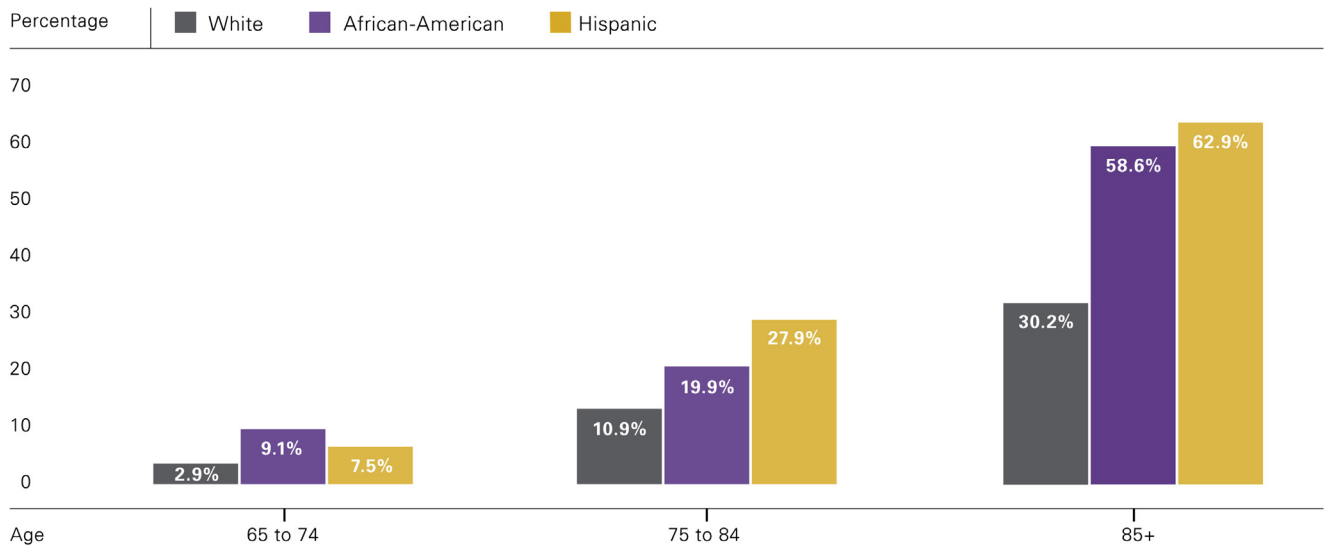


Fig. 2. Proportion of people aged 65 years or older with AD and other dementias. The Hispanic group for this study was primarily Caribbean-American. Created from unpublished data from Gurland et al. [133].

number of people reported to have AD (both preclinical and clinical) would be much larger than what is presented in this report.

3.1.2. Subjective cognitive decline

The experience of worsening or more frequent confusion or memory loss (often referred to as subjective cognitive decline) can be one of the earliest warning signs of AD. Because of this, researchers have recently begun to study subjective cognitive decline as a way to identify people who are at high risk of developing AD and other dementias [119,120], as well as MCI. Subjective cognitive decline does not refer to occasionally forgetting your keys or the name of someone you recently met; it refers to more serious issues such as having trouble remembering how to do things you have always done or forgetting things that you would normally know. Not all those who experience subjective cognitive decline go on to develop MCI or AD and other dementias, but many do [121]. In 2011, 22 states added questions on self-perceived confusion and memory loss to their Behavioral Risk Factor Surveillance System (BRFSS) surveys, which are developed in coordination with the Centers for Disease Control and Prevention (CDC). Data from 21 of the states showed that 12.7% of Americans aged 60 years and older reported experiencing worsening confusion or memory loss, but 81% of them had not consulted a health-care professional [122]. Individuals experiencing serious declines in memory and other cognitive abilities should consult a health-care professional about these issues.

3.1.3. Prevalence of AD and other dementias in women and men

More women than men have AD and other dementias. Almost two-thirds of Americans with AD are women [114].^{A5} Of the 5 million people aged 65 years and older

with AD in the United States, 3.2 million are women and 1.8 million are men [114].^{A5} Based on estimates from ADAMS, among people aged 71 years and older, 16% of women have AD and other dementias compared with 11% of men [116,123].

The observation that more women than men have AD and other dementias is primarily explained by the fact that women live longer, on average, than men, and older age is the greatest risk factor for AD [123,124]. Many studies of the age-specific incidence (development of new cases) of AD [61,62,124–128] or any dementia [60,61,125,126,129] have found no significant difference between the percentages of men and women who develop AD or other dementias. Thus, there is no evidence that women are more likely than men to develop dementia at any given age.

3.1.4. Prevalence of AD and other dementias by years of education

People with fewer years of education appear to be at higher risk for AD and other dementias than those with more years of education [60–64]. Some of the possible reasons are explained in the Risk Factors for AD section of the Overview.

3.1.5. Prevalence of AD and other dementias in older whites, African-Americans, and Hispanics

Although there are more non-Hispanic whites living with AD and other dementias than any other racial or ethnic group in the United States, older African-Americans and Hispanics are more likely than older whites to have AD and other dementias [130,131]. A review of many studies by an expert panel concluded that older African-Americans are about twice as likely to have AD and other dementias as older whites [132], and Hispanics are about 1.5 times as likely

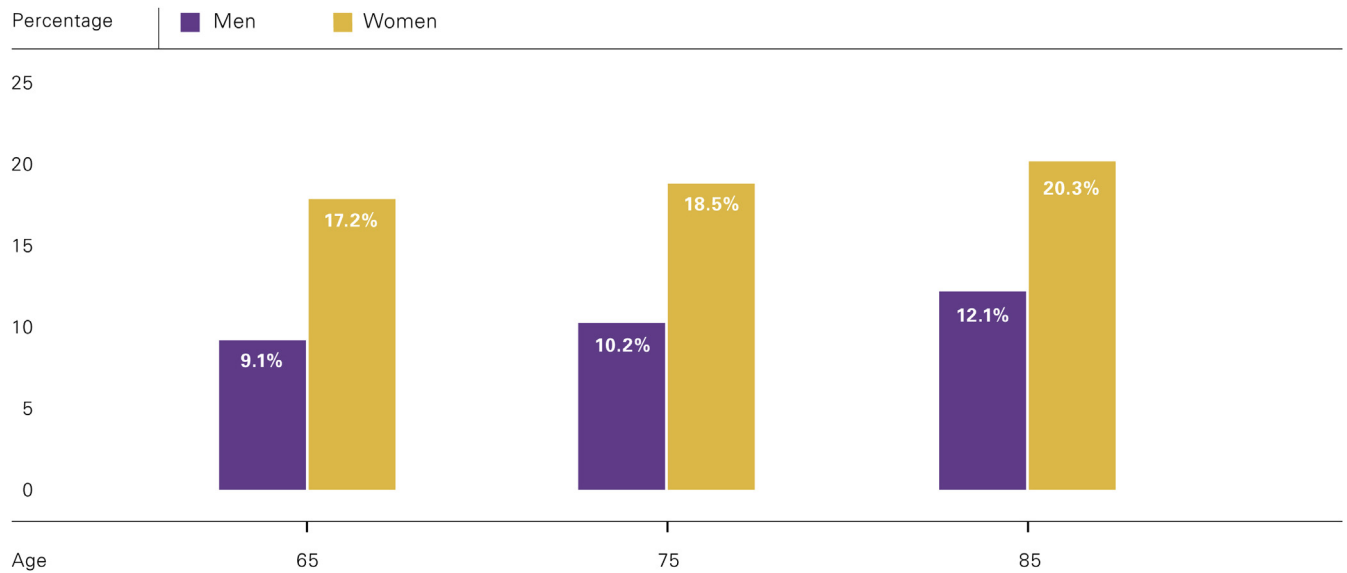


Fig. 3. Estimated lifetime risks for AD, by age and sex, from the Framingham Study. Created from data from Seshadri et al. [142].

to have AD and other dementias as older whites [133].^{A6} Fig. 2 shows the estimated prevalence for each group, by age, according to one large study. (Note: the Hispanic group for this study was primarily Caribbean-American, whereas most Hispanics in the United States are Mexican-American. The prevalence in Caribbean-Americans may be more similar to that in African-Americans, contributing to the higher observed prevalence for Hispanics in this study than estimated by the expert panel.)

Despite some evidence of racial differences in the influence of genetic risk factors on AD and other dementias [134], genetic factors do not appear to account for the large prevalence differences among racial groups [135,136]. Instead, health conditions such as high blood pressure and diabetes that may increase one's risk for AD or another dementia are believed to account for these differences because they are more prevalent in African-American and Hispanic people. Lower levels of education and other socioeconomic characteristics in these communities may also increase risk. Some studies suggest that differences based on race and ethnicity do not persist in detailed analyses that account for these factors [61,116].

There is evidence that missed diagnoses are more common among older African-Americans and Hispanics than among older whites [137,138], but it is unclear whether disparities in missed diagnoses have lessened in recent years. Recent data for Medicare beneficiaries found that AD or another dementia had been diagnosed in 8.2% of white beneficiaries, 11.3% of African-American beneficiaries, and 12.3% of Hispanic beneficiaries [139]. Although rates of diagnosis were higher among African-Americans than among whites, this difference was not as great as would be expected (twice the percentage of whites) based on the estimated differences found in prevalence studies (Fig. 2), which are designed to detect all people who have dementia.

3.2. Incidence of AD

While prevalence is the number of *existing* cases of a disease in a population at a given time, incidence is the number of *new* cases of a disease that develop in a given period of time in a defined population—in this case, the United States population aged 65 years or older. Approximately 469,000 people aged 65 years or older will develop AD in the United States in 2014.^{A7} The number of new cases of AD increases dramatically with age: in 2014, there will be approximately 59,000 new cases among people aged 65 to 74 years, 172,000 new cases among people aged 75 to 84 years, and 238,000 new cases among people aged 85 years and older (the “oldest old”) [140].^{A7} Although some studies have reported that incidence rates do not continue to rise after age 90 years, at least one large study indicates that previous observations of a leveling off of incidence among the oldest old may be due to sparse data for this group [141]. Because of the increasing number of people aged 65 years and older in the United States, particularly the oldest old, the annual number of new cases of AD and other dementias is projected to double by 2050 [140].

- Every 67 seconds, someone in the United States develops AD.^{A8}
- By mid-century, someone in the United States will develop the disease every 33 seconds.^{A8}

3.3. Lifetime risk of AD

Lifetime risk is the probability that someone of a given age will develop a condition during their remaining life span. Data from the Framingham Study were used to estimate lifetime risks of AD and any dementia [142].^{A9} The study found that 65-year-old women without dementia had a 20% chance of developing dementia during the

Table 2
Projections of total numbers of Americans aged 65 years and older with Alzheimer's disease by state

State	Projected Number w/ Alzheimer's (in thousands) 2014	Projected Number w/Alzheimer's (in thousands) 2025	Percentage Change 2014-2025
Alabama	86.0	110.0	27.9
Alaska	6.1	11.0	80.3
Arizona	120.0	200.0	66.7
Arkansas	52.0	67.0	28.8
California	580.0	840.0	44.8
Colorado	63.0	92.0	46.0
Connecticut	72.0	91.0	26.4
Delaware	16.0	23.0	43.8
District of Columbia	9.2	9.0	-2.2
Florida	480.0	720.0	50.0
Georgia	130.0	190.0	46.2
Hawaii	25.0	35.0	40.0
Idaho	22.0	33.0	50.0
Illinois	210.0	260.0	23.8
Indiana	100.0	130.0	30.0
Iowa	62.0	73.0	17.7
Kansas	50.0	62.0	24.0
Kentucky	67.0	86.0	28.4
Louisiana	81.0	110.0	35.8
Maine	25.0	35.0	40.0
Maryland	97.0	130.0	34.0
Massachusetts	120.0	150.0	25.0
Michigan	170.0	220.0	29.4
Minnesota	88.0	120.0	36.4
Mississippi	51.0	65.0	27.5
Missouri	110.0	130.0	18.2
Montana	18.0	27.0	50.0
Nebraska	33.0	40.0	21.2
Nevada	37.0	64.0	73.0
New Hampshire	22.0	32.0	45.5
New Jersey	170.0	210.0	23.5
New Mexico	34.0	53.0	55.9
New York	380.0	460.0	21.1
North Carolina	150.0	210.0	40.0
North Dakota	14.0	16.0	14.3
Ohio	210.0	250.0	19.0
Oklahoma	60.0	76.0	26.7
Oregon	59.0	84.0	42.4
Pennsylvania	270.0	320.0	18.5
Rhode Island	22.0	27.0	22.7
South Carolina	79.0	120.0	51.9
South Dakota	16.0	20.0	25.0
Tennessee	110.0	140.0	27.3
Texas	330.0	490.0	48.5
Utah	28.0	42.0	50.0
Vermont	11.0	17.0	54.5
Virginia	130.0	190.0	46.2
Washington	97.0	140.0	44.3
West Virginia	36.0	44.0	22.2
Wisconsin	100.0	130.0	30.0
Wyoming	8.5	13.0	52.9

remainder of their lives (estimated lifetime risk), compared with a 17% chance for men. As shown in Fig. 3, for AD specifically, the estimated lifetime risk at the age of 65 years was nearly one in six (17.2%) for women compared with nearly 1 in 11 (9.1%) for men

[142]. As previously noted, these differences in lifetime risks between women and men are largely due to women's longer life expectancy.

The definition of AD and other dementias used in the Framingham Study required documentation of moderate-to-severe disease and symptoms lasting a minimum of 6 months. Using a definition that also includes milder disease and disease of less than 6 months' duration, lifetime risks of AD and other dementias would be much higher than those estimated by this study.

3.4. Estimates of the number of people with AD by state

Table 2 summarizes the projected number of people aged 65 years and older with AD (prevalent cases of AD) by state for 2014 and the projected percentage change in the number of people with AD between 2014 and 2025.^{A10} (Note: the total number of people with AD is larger for states with larger populations such as California and New York.) Comparable estimates and projections for other types of dementia are not available.

As shown in Fig. 4, between 2014 and 2025, every state and region across the country is expected to experience double-digit percentage increases in the numbers of people with AD because of increases in the population aged 65 years and older. The West and Southeast are expected to experience the largest increases in numbers of people with AD between 2014 and 2025. The increasing number of individuals with AD will have a marked impact on states' health-care systems, as well as on families and caregivers.

3.5. Looking to the future

The number of Americans surviving into their 80s, 90s, and beyond is expected to grow dramatically because of advances in medicine and medical technology, as well as social and environmental conditions [143]. Additionally, a large segment of the American population—the baby boom generation—has begun to reach the age range of elevated risk for AD and other dementias, with the first baby boomers having reached the age of 65 years in 2011. By 2030, the segment of the US population aged 65 years and older is expected to grow dramatically, and the estimated 72 million older Americans will make up approximately 20% of the total population (up from 13% in 2010) [143].

As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of AD, as shown in Fig. 5 [114].^{A11}

- In 2000, there were an estimated 411,000 new cases of AD. For 2010, that number was estimated to be 454,000 (a 10% increase); by 2030, it is projected to be 615,000 (a 50% increase from 2000); and by 2050, 959,000 (a 130% increase from 2000) [140].

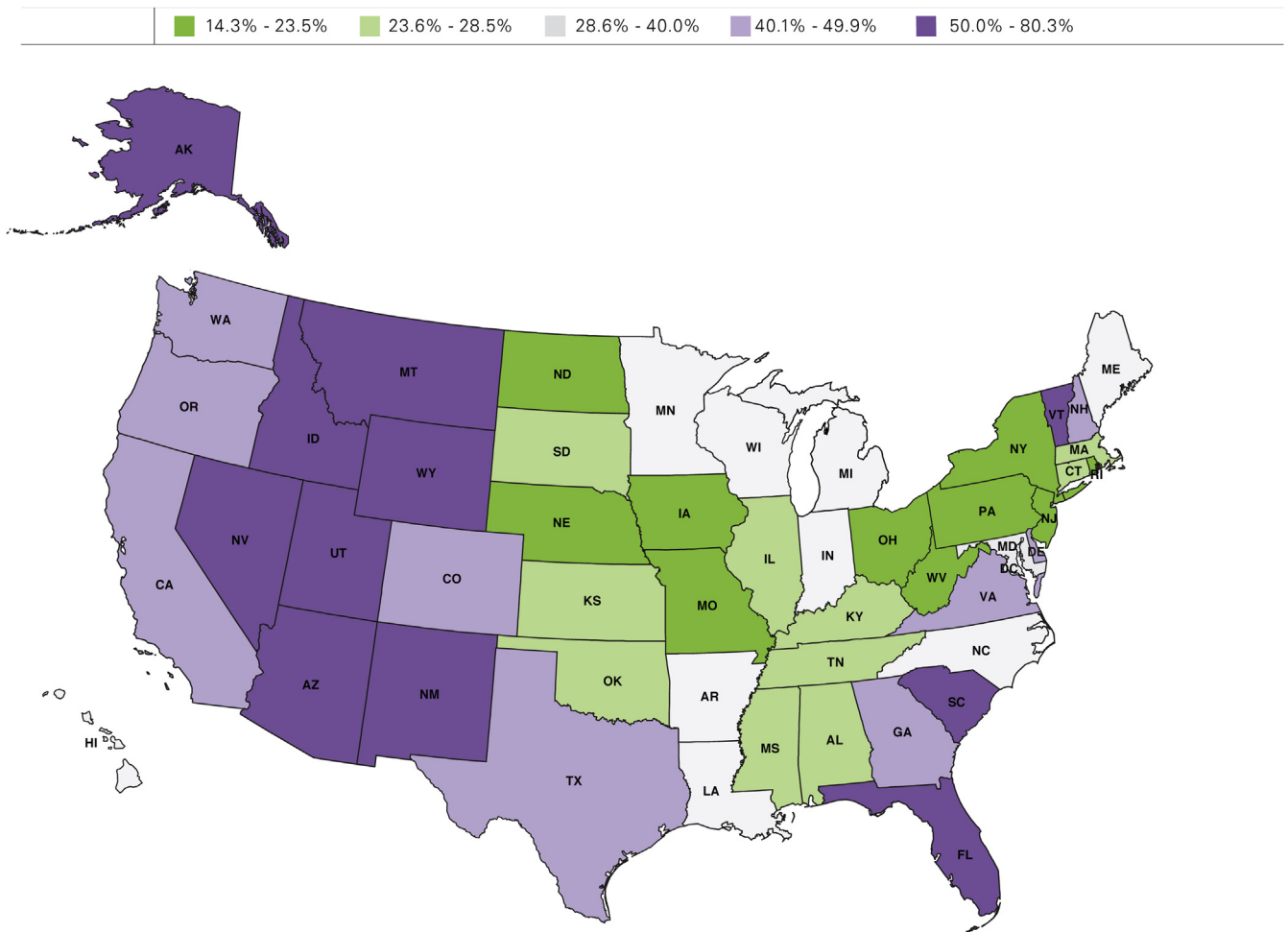


Fig. 4. Projected changes between 2014 and 2025 in AD prevalence by state. Change from 2014 to 2025 for Washington, D.C.: -2.2%. Created from unpublished data provided to the Alzheimer's Association by Hebert et al.^{A10}

- By 2025, the number of people aged 65 years and older with AD is estimated to reach 7.1 million—a 40% increase from the 5 million aged 65 years and older currently affected [114].^{A12}
- By 2050, the number of people aged 65 years and older with AD may nearly triple, from 5 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent, slow, or stop the disease [114].^{A11} Previous estimates based on high-range projections of population growth provided by the US Census suggest that this number may be as high as 16 million [144].^{A13}
- In 2014, the population aged 85 years and older includes about 2 million people with AD or 40% of all people with AD aged 65 years and older [114].
- When the first wave of baby boomers reaches the age of 85 years (in 2031), it is projected that more than 3 million people aged 85 years and older will have AD [114].
- By 2050, there could be as many as 7 million people aged 85 years and older with AD, accounting for half (51%) of all people aged 65 years and older with AD [114].

4. Mortality and morbidity

Longer life expectancies and aging baby boomers will also increase the number and percentage of Americans who will be among the oldest old. Between 2010 and 2050, the oldest old are expected to increase from 14% of all people aged 65 years and older in the United States to 20% of all people aged 65 years and older [143]. This will result in an additional 13 million oldest old people—individuals at the highest risk for developing AD [143].

AD is officially listed as the sixth leading cause of death in the United States [145]. It is the fifth leading cause of death for those aged 65 years and older [145]. However, it may cause even more deaths than official sources recognize. In addition to being a leading cause of death, AD is a leading cause of disability and poor health (morbidity). Before a person with AD dies, he or she lives through years of morbidity as the disease progresses.

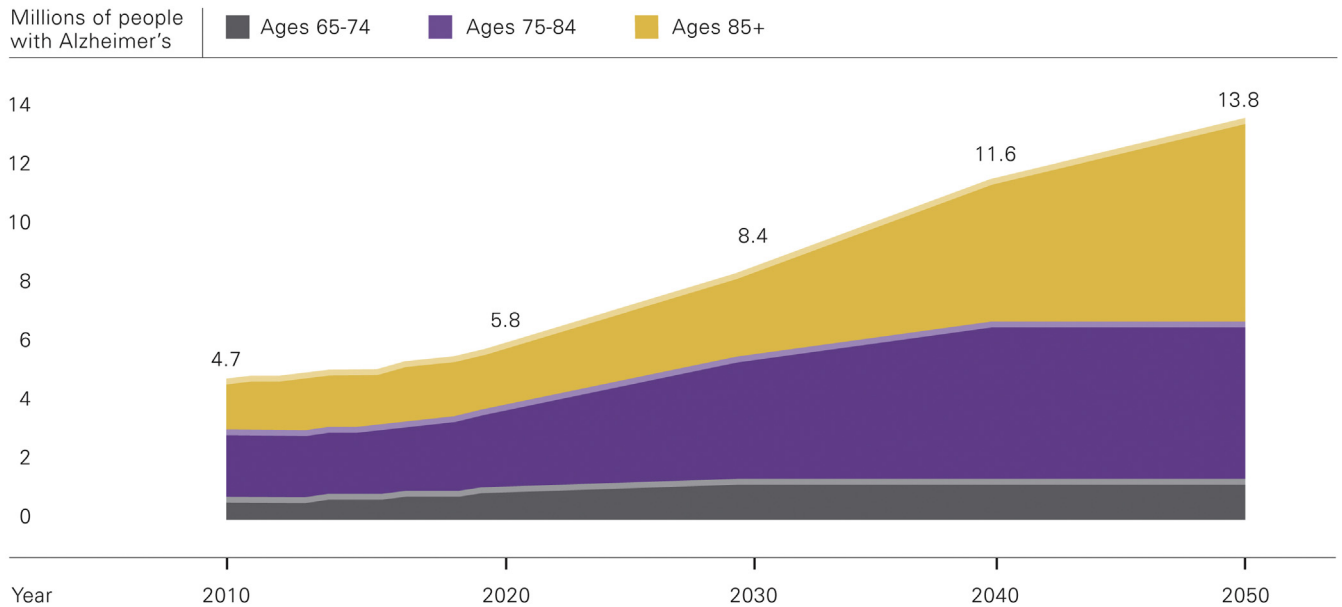


Fig. 5. The projected number of people aged 65 years or older (total and by age group) in the United States population with AD, 2010 to 2050. Created from data from Hebert et al. [114].^{A11}

4.1. Deaths from AD

It is difficult to determine how many deaths are caused by AD each year because of the way causes of death are recorded. According to final data from the National Center for Health Statistics of the CDC, 83,494 people died from AD in 2010 (the most recent year for which final data are available) [145]. The CDC considers a person to have died *from* AD if the death certificate lists AD as the underlying cause of death, defined by the World Health Organization as “the disease or injury which initiated the train of events leading directly to death” [146]. However, death certificates for individuals with AD often list acute conditions such as pneumonia as the primary cause of death rather than AD [147–149]. Severe dementia frequently causes complications such as immobility, swallowing disorders, and malnutrition that can significantly increase the risk of other serious conditions that can cause death. One such condition is pneumonia, which has been found in several studies to be the most commonly identified cause of death among elderly people with AD and other dementias [150,151]. The number of people with AD who die while experiencing these other conditions may not be counted among the number of people who died *from* AD according to the CDC definition, although AD is likely a contributing cause of death. Thus, it is likely that AD is a contributing cause of death for more Americans than is indicated by CDC data.

The situation has been described as a “blurred distinction between death *with* dementia and death *from* dementia” [152]. According to data from the CHAP, an estimated 600,000 people aged 65 years and older died *with* AD in the United States in 2010, meaning they died after developing AD [153].^{A14} Of these, an estimated 400,000 were aged 85 years and older and an estimated 200,000 were aged 65 to

84 years. Other investigators, using data from the Rush Memory and Aging Project and the Religious Orders Study, estimated that 500,000 deaths among people aged 75 years and older were attributed to AD in the United States in 2010 (estimates for people aged 65 to 74 years were not available) [154]. Furthermore, according to Medicare data, one-third of all seniors who die in a given year have been diagnosed with AD or another dementia [139,155]. Although some seniors who die with AD die from causes that are unrelated to AD, many of them die from AD itself or from conditions in which AD was a contributing cause such as pneumonia. A recent study evaluating the contribution of individual common diseases to death using a nationally representative sample of older adults found that dementia was the second largest contributor to death behind heart failure [156]. Thus, for people who die with AD, the disease is expected to be a significant direct contributor to their deaths.

Based on CHAP data, an estimated 700,000 people in the United States aged 65 years or older will die *with* AD in 2014 [153].^{A14} The true number of deaths caused by AD is likely to be somewhere between the official estimated numbers of those dying from AD (as indicated by death certificates) and those dying with AD. Regardless of the cause of death, among people aged 70 years, 61% of those with AD are expected to die before the age of 80 years compared with 30% of people without AD [157].

4.2. Public health impact of deaths from AD

As the population of the United States ages, AD is becoming a more common cause of death. Although deaths from other major causes have decreased significantly, deaths from AD have increased significantly. Between 2000 and 2010, deaths attributed to AD increased 68%, whereas those

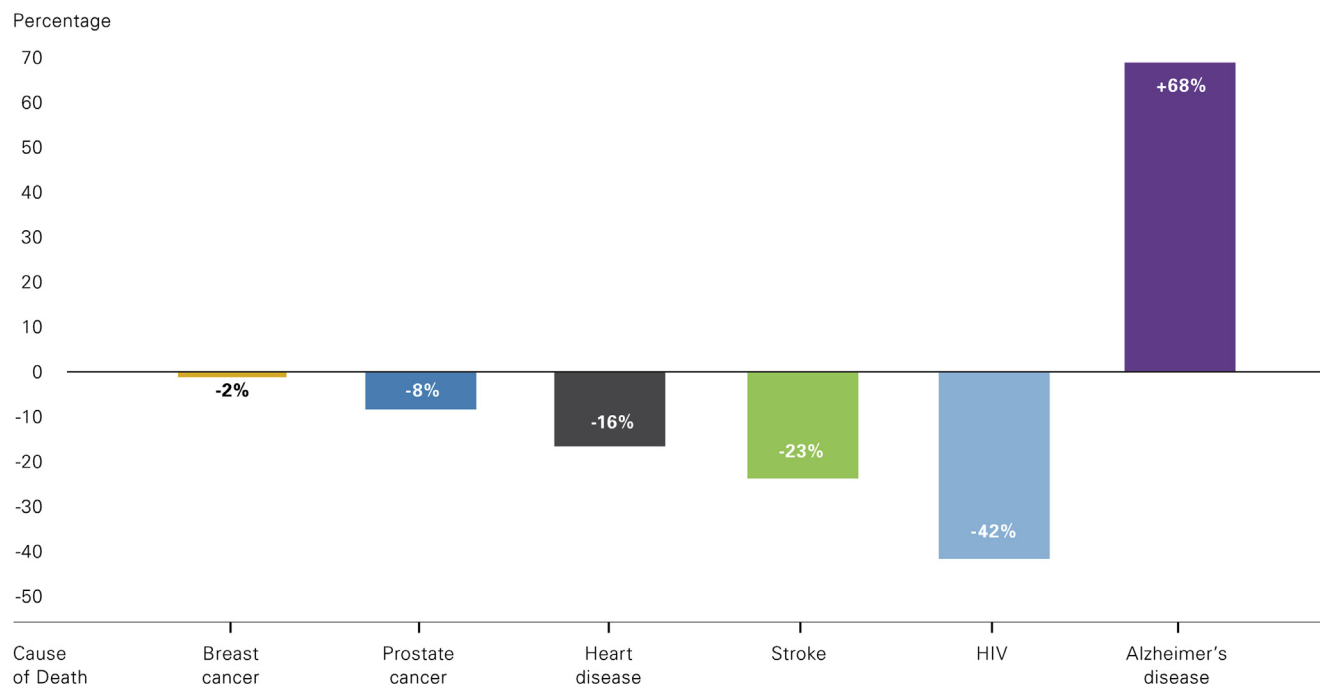


Fig. 6. Percentage changes in selected causes of death (all ages) between 2000 and 2010. Created from data from the National Center for Health Statistics [145, 158].

attributed to the number one cause of death, heart disease, decreased 16% (Fig. 6) [145,158]. The increase in the number and proportion of death certificates listing AD as the underlying cause of death reflects both changes in patterns of reporting deaths on death certificates over time and an increase in the actual number of deaths attributable to AD.

Another way to describe the impact of AD on mortality is through a statistic known as population-attributable risk. It represents the proportion of deaths (in a specified amount of time) in a population that may be preventable if a disease were eliminated. The population-attributable risk of AD on mortality over 5 years in people aged 65 years and older is estimated to be between 5% and 15% [159,160]. This means that over the next 5 years, 5% to 15% of all deaths in older people can be attributed to AD.

4.3. State-by-state deaths from AD

Table 3 provides information on the number of deaths due to AD by state in 2010, the most recent year for which state-by-state data are available. This information was obtained from death certificates and reflects the condition identified by the physician as the underlying cause of death. The table also provides annual mortality rates by state to compare the risk of death due to AD across states with varying population sizes and attributes. For the United States as a whole, in 2010, the mortality rate for AD was 27 deaths per 100,000 people [145].

4.4. Death rates by age

Although people younger than 65 years can develop and die from AD, the highest risk of death from AD is in people

aged 65 years or older. As listed in Table 4, death rates for AD increase dramatically with age. The increase in deaths attributed to AD over time has disproportionately affected the oldest old. Between 2000 and 2010, death rates from AD increased 6% for people aged 65 to 74 years, 32% for people aged 75 to 84 years, and 48% for people aged 85 years and older [161].

4.5. Duration of illness from diagnosis to death

Studies indicate that people aged 65 years and older survive an average of 4 to 8 years after a diagnosis of AD, yet some live as long as 20 years with AD [160,162–166]. This indicates the slow, insidious nature of the progression of AD. On average, a person with AD will spend more years (40% of the total number of years with AD) in the most severe stage of the disease than in any other stage [157]. Much of this time will be spent in a nursing home, as nursing home admission by age 80 years is expected for 75% of people with AD compared with only 4% of the general population [157]. In all, an estimated two-thirds of those dying of dementia do so in nursing homes compared with 20% of people with cancer and 28% of people dying from all other conditions [167].

4.6. Burden of AD

The long duration of illness before death contributes significantly to the public health impact of AD because much of that time is spent in a state of disability and dependence. Scientists have developed methods to measure and compare the burden of different diseases on a population in a way that

Table 3
Number of deaths and annual mortality rate (per 100,000) due to Alzheimer's disease by state, 2010

State	Number of deaths	Mortality rate
Alabama	1523	31.9
Alaska	85	12.0
Arizona	2327	36.4
Arkansas	955	32.8
California	10,856	29.1
Colorado	1334	26.5
Connecticut	820	22.9
Delaware	215	23.9
District of Columbia	114	18.9
Florida	4831	25.7
Georgia	2080	21.5
Hawaii	189	13.9
Idaho	410	26.2
Illinois	2927	22.8
Indiana	1940	29.9
Iowa	1411	46.3
Kansas	825	28.9
Kentucky	1464	33.7
Louisiana	1295	28.6
Maine	502	37.8
Maryland	986	17.1
Massachusetts	1773	27.1
Michigan	2736	27.7
Minnesota	1451	27.4
Mississippi	927	31.2
Missouri	1986	33.2
Montana	302	30.5
Nebraska	565	30.9
Nevada	296	11.0
New Hampshire	396	30.1
New Jersey	1878	21.4
New Mexico	343	16.7
New York	2616	13.5
North Carolina	2817	29.5
North Dakota	361	53.7
Ohio	4109	35.6
Oklahoma	1015	27.1
Oregon	1300	33.9
Pennsylvania	3591	28.3
Rhode Island	338	32.1
South Carolina	1570	33.9
South Dakota	398	48.9
Tennessee	2440	38.4
Texas	5209	20.7
Utah	375	13.6
Vermont	238	38.0
Virginia	1848	23.1
Washington	3025	45.0
West Virginia	594	32.1
Wisconsin	1762	31.0
Wyoming	146	25.9
US total	83,494	27.0

NOTE. Created from data from the National Center for Health Statistics [145].^{A15}

takes into account both the number of years of life lost because of that disease and the number of healthy years of life lost by virtue of being in a state of disability. These measures indicate that AD is a very burdensome disease

Table 4
US annual Alzheimer's disease death rates (per 100,000) by age

Age (y)	2000	2002	2004	2006	2008	2010
45–54	0.2	0.1	0.2	0.2	0.2	0.3
55–64	2.0	1.9	1.8	2.1	2.2	2.1
65–74	18.7	19.6	19.5	19.9	21.1	19.8
75–84	139.6	157.7	168.5	175.0	192.5	184.5
85+	667.7	790.9	875.3	923.4	1002.2	987.1
Total death rate*	18.1	20.8	22.6	23.7	25.8	25.1

*Reflects the overall death rate for ages 45 years and older.

NOTE. Created from data from the National Center for Health Statistics [161].

and that the burden of AD has increased more dramatically in the United States in recent years than other diseases. The primary measure of disease burden is called disability-adjusted life-years, which is the sum of the number of years of life lost because of premature mortality and the number of years lived with disability. Based on disability-adjusted life-years, between 1990 and 2010, AD rose from the 25th most burdensome disease in the United States to the 12th; no other disease or condition increased that much [168]. Looking at years of life lost, AD rose from 32nd to 9th, the largest increase for any disease. Looking at years lived with disability, AD went from ranking 17th to 12th; only kidney disease equaled AD in as high a jump in rank.

Taken together, the numbers in this section indicate that AD is not only responsible for the deaths of more and more Americans, but also contributes to more and more cases of poor health and disability in the United States.

5. Caregiving

Caregiving refers to attending to another individual's health needs. Caregiving often includes assistance with one or more ADLs (such as bathing and dressing) [169,170]. More than 15 million Americans provide unpaid care for people with AD and other dementias.^{A16}

5.1. Unpaid caregivers

Unpaid caregivers are usually immediate family members, but they also may be other relatives and friends. In 2013, these individuals provided an estimated 17.7 billion hours of informal (i.e., unpaid) care, a contribution to the nation valued at over \$220.2 billion. This is approximately half of the net value of Walmart sales in 2012 (\$443.9 billion) [171] and nearly eight times the total revenue of McDonald's in 2012 (\$27.6 billion) [172]. According to a recent report [173], the value of informal care was nearly equal to the direct medical and long-term care costs of dementia. Eighty-five percent of help provided to all older adults in the United States is from family members [174].

5.1.1. Who are the caregivers?

Several sources have examined the demographic background of family caregivers of people with AD and other

dementias [175].^{A17} Data from the 2009 and 2010 BRFSS surveys conducted in eight states and the District of Columbia [175] found that 65% of caregivers of people with AD and other dementias were women; 21% were aged 65 years and older; 44% had some college education or had received a degree; 64% were currently employed, a student, or a homemaker; and 71% were married or in a long-term relationship [175].

ADAMS, based on a nationally representative subsample of older adults from the Health and Retirement Survey [176], compared two types of "primary" caregivers (individuals who indicate having the most responsibility for helping their relatives): those caring for people with dementia and those caring for people with cognitive problems who did not reach the threshold of dementia. The primary caregiver groups did not differ significantly by age (60 vs. 61 years, respectively), gender (71% vs. 81% female), race (66% vs. 71% non-Hispanic white), or marital status (70% vs. 71% married). Over half of primary caregivers (55%) of people with dementia took care of parents [177].

5.1.2. Ethnic and racial diversity in caregiving

Among caregivers of people with AD and other dementias, the National Alliance for Caregiving (NAC) and AARP found the following [178]:

- Fifty-four percent of white caregivers assist a parent compared with 38% of individuals from other racial/ethnic groups.
- On average, Hispanic and African-American caregivers spend more time caregiving (approximately 30 h/wk) than non-Hispanic white caregivers (20 h/wk) and Asian-American caregivers (16 h/wk).
- Hispanic (45%) and African-American (57%) caregivers are more likely to experience high burden from caregiving than whites (33%) and Asian-Americans (30%).

5.1.3. Sandwich generation caregivers

Traditionally, the term "sandwich generation caregiver" has referred to a middle-aged person who simultaneously cares for dependent minor children and aging parents. This phenomenon has received a good deal of attention in recent years, as it has been argued that demographic changes (such as parents of dependent minors being older than in the past and the aging of the US population) have led to increases in the number of sandwich generation caregivers [179–181]. NAC/AARP found that 30% of AD and dementia caregivers had children under the age of 18 years living with them [178]. Other studies have found that sandwich generation caregivers are present in 8% to 13% of households in the United States [182,183]. It is not clear what proportion of care recipients in these studies had AD or another dementia, but in other studies, about one-third of elderly care recipients have AD or another dementia [184]. Various studies have concluded that sandwich generation caregivers experience unique challenges related to the demands of providing care for both aging parents and dependent children. Such challenges include limited time, energy, and financial resources [180,185,186]. Some authors have therefore concluded that sandwich generation caregivers can experience anxiety and depression as well as lower quality of life due to the unique challenges these individuals experience [186,187].

5.1.4. Caregiving tasks

The care provided to people with AD and other dementias is wide ranging and in some instances all-encompassing. Table 5 summarizes some of the most common types of dementia care provided.

Although the care provided by family members of people with AD and other dementias is somewhat similar to the help provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance. Family caregivers of people with dementia are more likely than caregivers of other older people to assist with any

Table 5
Dementia caregiving tasks

Help with IADLs such as household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances and legal affairs, and answering the telephone.
Helping the person take medications correctly, either via reminders or direct administration of medications.
Helping the person adhere to treatment recommendations for dementia or other medical conditions.
Assisting with personal ADLs such as bathing, dressing, grooming, feeding, and helping the person walk, transfer from bed to chair, use the toilet, and manage incontinence.
Managing behavioral symptoms of the disease such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity, and nighttime disturbances.
Finding and using support services such as support groups and adult day service programs.
Making arrangements for paid in-home, nursing home, or assisted living care.
Hiring and supervising others who provide care.
Assuming additional responsibilities that are not necessarily specific tasks such as
<ul style="list-style-type: none"> • Providing overall management of getting through the day. • Addressing family issues related to caring for a relative with Alzheimer's disease, including communication with other family members about care plans, decision making, and arrangements for respite for the main caregiver.

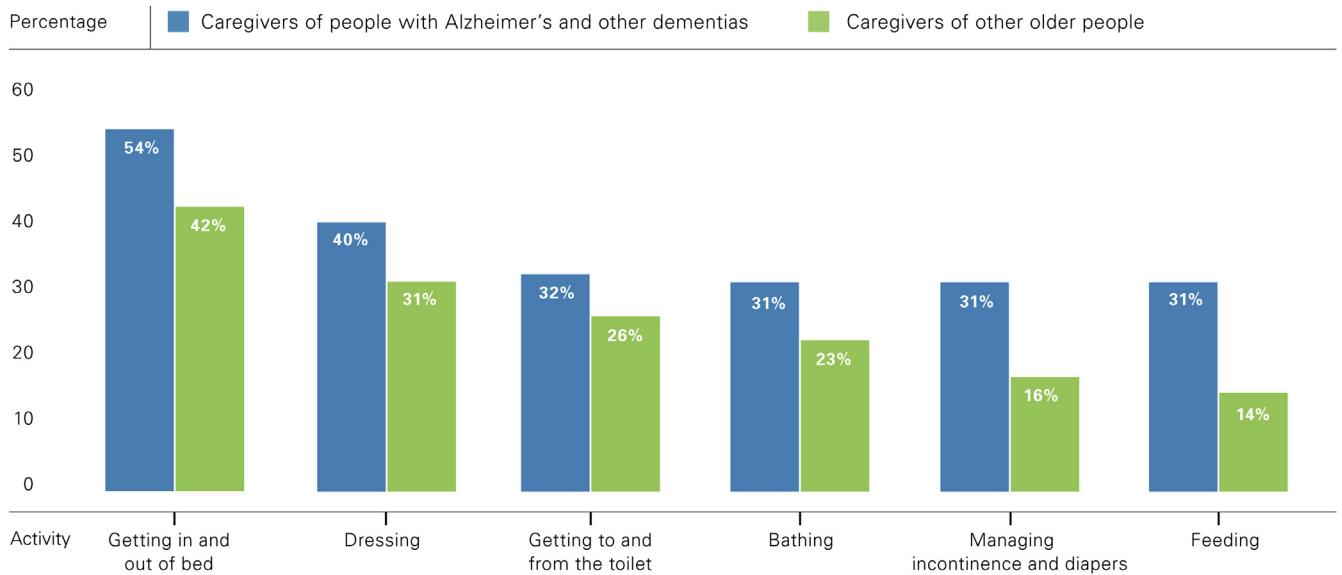


Fig. 7. Proportion of caregivers of people with AD and other dementias versus caregivers of other older people who provide help with specific activities of daily living, United States, 2009. Created from data from the National Alliance for Caregiving and AARP [178].

ADL (Fig. 7). More than half of dementia caregivers report providing help with getting in and out of bed, and about one-third provide help to their care recipients with getting to and from the toilet, bathing, managing incontinence, and feeding. These findings are consistent with the heightened degree of dependency experienced by some people with AD and other dementias. Fewer caregivers of other older people report providing help with each of these types of care [178].

In addition to assisting with ADLs, almost two-thirds of caregivers of people with AD and other dementias advocate for their care recipient with government agencies and service providers (64%), and nearly half arrange and supervise paid caregivers from community agencies (46%). By contrast, caregivers of other older adults are less likely to advocate for their family member (50%) and supervise community-based care (33%) [178]. Caring for a person with dementia also means managing symptoms that family caregivers of people with other diseases may not face such as neuropsychiatric symptoms and severe behavioral problems.

When persons with AD or another dementia move to an assisted living residence or a nursing home, the help provided by their family caregiver usually changes from the comprehensive care summarized in Table 5 to providing emotional support, interacting with facility staff, and advocating for appropriate care. However, some family caregivers continue to help with bathing, dressing, and other ADLs [188–190]. Admitting a relative to a residential care setting has mixed effects on the emotional and psychological well-being of family caregivers. Some studies suggest that distress remains unchanged or even increases after a relative is admitted to a residential care facility, but other studies have found that distress declines significantly after admission [190,191]. The relationship between the caregiver and the person with dementia may explain these

discrepancies. For example, husbands, wives, and daughters are significantly more likely than other family caregivers to indicate persistent burden up to 12 months after placement, and husbands are more likely than other family caregivers to indicate persistent depression up to a year after a relative's admission to a residential care facility [191].

5.1.5. Duration of caregiving

Caregivers of people with AD and other dementias provide care for a longer time, on average, than do caregivers of older adults with other conditions. As shown in Fig. 8, 43% of caregivers of people with AD and other dementias provide care for 1 to 4 years compared with 33% of caregivers of people without dementia. Similarly, 32% of dementia caregivers provide care for over 5 years compared with 28% of caregivers of people without dementia [178].

5.1.6. Hours of unpaid care and economic value of caregiving

In 2013, 15.5 million family and other unpaid caregivers of people with AD and other dementias provided an estimated 17.7 billion hours of unpaid care. This number represents an average of 21.9 hours of care per caregiver per week or 1139 hours of care per caregiver per year.^{A18} With this care valued at \$12.45 per hour,^{A19} the estimated economic value of care provided by family and other unpaid caregivers of people with dementia was \$220.2 billion in 2013. Table 6 lists the total hours of unpaid care and the value of care provided by family and other unpaid caregivers for the United States and each state. Unpaid caregivers of people with AD and other dementias provide care valued at more than \$1 billion in each of 39 states. Unpaid caregivers in each of the four most populous states—California, Florida, New York, and Texas—provided care valued at more than \$14 billion.

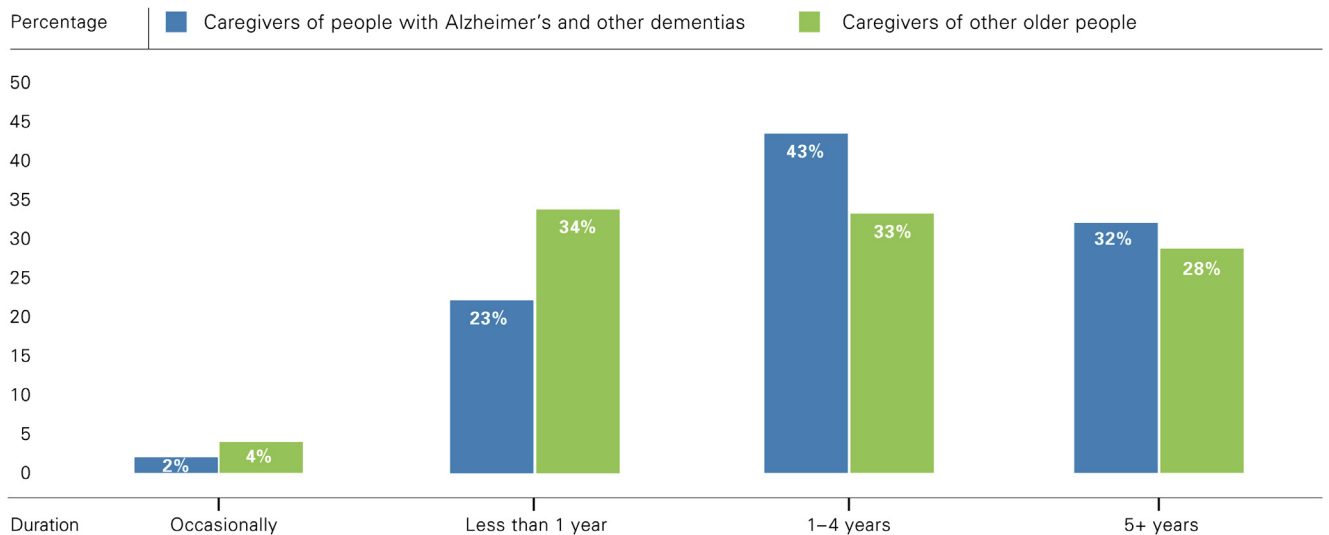


Fig. 8. Proportion of AD and dementia caregivers versus caregivers of other older people by duration of caregiving, United States, 2009. Created from data from the National Alliance for Caregiving and AARP [178].

Other studies suggest that primary family caregivers (or those who indicate the most responsibility in caring for their relatives) provide particularly extensive amounts of care. For example, a 2011 report from ADAMS found that primary family caregivers of people with dementia reported spending an average of 9 h/d providing help to their relatives [177].

5.1.7. Impact of AD caregiving

Caring for a person with AD or another dementia poses special challenges. For example, people with AD experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people with AD manage these issues. The personality and behavior of a person with AD are affected as well, and these changes are often among the most challenging for family caregivers [192]. Individuals with dementia may also require increasing levels of supervision and personal care as the disease progresses. As symptoms worsen with the progression of a relative's dementia, the care required of family members can result in increased emotional stress, depression, impaired immune system response, health impairments, lost wages due to disruptions in employment, and depleted income and finances [193–198].^{A17} The intimacy and history of experiences and memories that are often part of the relationship between a caregiver and care recipient may also be threatened because of the memory loss, functional impairment, and psychiatric/behavioral disturbances that can accompany the progression of AD.

5.1.7.1. Caregiver emotional well-being

Although caregivers report some positive feelings about caregiving, including family togetherness and the satisfaction of helping others [199],^{A17} they also report high levels of stress over the course of providing care:

- Based on a Level of Care Index that combined the number of hours of care and the number of ADL tasks performed by the caregiver, fewer dementia caregivers in the 2009 NAC/AARP survey were classified in the lowest level of burden than caregivers of people without dementia (16% vs. 31%, respectively) [178].
- Fifty-nine percent of family caregivers of people with AD and other dementias rated the emotional stress of caregiving as high or very high (Fig. 9).^{A17}
- Many family caregivers report “a good amount” to “a great deal” of caregiving strain concerning financial issues (47%) and family relationships (52%).^{A17}
- Earlier research in smaller samples found that over one-third (39%) of caregivers of people with dementia suffered from depression compared with 17% of non-caregivers [200,201]. A meta-analysis of research comparing caregivers affirmed this disparity in the prevalence of depression between caregivers of people with dementia and noncaregivers [197]. In the ADAMS sample, 44% of primary caregivers of people with dementia indicated depressive symptoms compared with 27% of primary caregivers of people who had cognitive impairment but no dementia [177]. Among family members supporting an older person who has MCI, 23% were found to have depression [202], a much higher percentage than found in the general population (7%) [203]. In a small, recent study of dementia family caregiving and hospitalization [204], clinical depression rates of 63% and 43% were found among family caregivers of people with dementia who were or were not hospitalized, respectively.
- In the 2009 NAC/AARP survey, caregivers most likely to indicate stress were women, older, residing with the care recipient, and white or Hispanic. In addition, these

Table 6
Number of Alzheimer's disease and dementia (AD/D) caregivers, hours of unpaid care, economic value of the care, and higher health-care costs of caregivers by state, 2013

State	AD/D caregivers (in thousands)	Hours of care per year (in millions)	Value of unpaid care (in millions of dollars)	Higher caregiver health-care costs (in millions of dollars)
Alabama	299	341	\$4240	\$164
Alaska	33	37	\$466	\$26
Arizona	307	350	\$4358	\$147
Arkansas	173	197	\$2455	\$94
California	1547	1761	\$21,927	\$853
Colorado	229	261	\$3254	\$121
Connecticut	176	201	\$2497	\$134
Delaware	52	59	\$732	\$39
District of Columbia	27	31	\$381	\$25
Florida	1037	1181	\$14,709	\$654
Georgia	499	569	\$7080	\$240
Hawaii	64	73	\$910	\$39
Idaho	77	88	\$1091	\$38
Illinois	587	668	\$8322	\$350
Indiana	330	376	\$4686	\$194
Iowa	133	151	\$1884	\$81
Kansas	149	170	\$2112	\$89
Kentucky	267	304	\$3789	\$155
Louisiana	228	260	\$3237	\$137
Maine	68	77	\$964	\$51
Maryland	286	326	\$4056	\$189
Massachusetts	325	370	\$4610	\$266
Michigan	505	575	\$7163	\$294
Minnesota	245	280	\$3481	\$161
Mississippi	205	233	\$2900	\$117
Missouri	310	354	\$4402	\$190
Montana	48	54	\$677	\$28
Nebraska	80	91	\$1134	\$50
Nevada	137	156	\$1938	\$69
New Hampshire	65	74	\$919	\$45
New Jersey	443	505	\$6287	\$296
New Mexico	105	120	\$1495	\$62
New York	1010	1150	\$14,316	\$742
North Carolina	442	504	\$6272	\$252
North Dakota	29	33	\$415	\$20
Ohio	591	674	\$8386	\$369
Oklahoma	218	248	\$3093	\$125
Oregon	173	196	\$2446	\$100
Pennsylvania	669	762	\$9492	\$456
Rhode Island	52	60	\$744	\$38
South Carolina	291	331	\$4127	\$161
South Dakota	37	42	\$521	\$23
Tennessee	418	476	\$5922	\$235
Texas	1302	1482	\$18,457	\$679
Utah	140	159	\$1980	\$62
Vermont	30	34	\$422	\$20
Virginia	447	509	\$6342	\$247
Washington	319	363	\$4518	\$191
West Virginia	108	123	\$1536	\$73
Wisconsin	190	217	\$2698	\$122
Wyoming	28	31	\$392	\$17
US total	15,533	17,689	\$220,233	\$9332

Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare and Medicaid Services, National Alliance for Caregiving, AARP, and U.S. Department of Labor. ^{A13, A16, A17, A18}

NOTE. State totals may not add up to US total due to rounding.

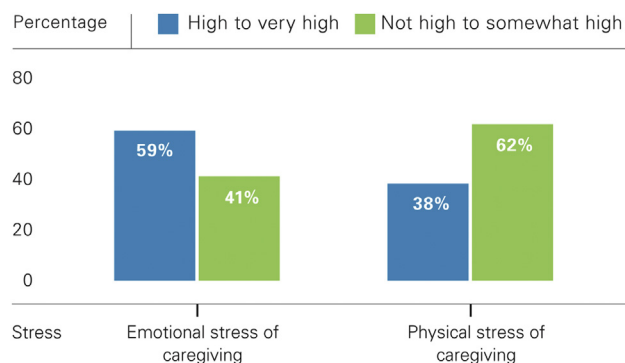


Fig. 9. Proportion of AD and dementia caregivers who report high or very high emotional and physical stress due to caregiving. Created from data from the Alzheimer's Association.^{A17}

caregivers often believed there was no choice in taking on the role of caregiver [178].

- When caregivers report being stressed because of the impaired person's behavioral symptoms, it increases the chance that they will place the care recipient in a nursing home [178,205].
- Seventy-six percent of family caregivers of people with AD and other dementias said that they somewhat agree or strongly agree that it is "neither right nor wrong" when families decide to place their family member in a nursing home. Yet many such caregivers experience feelings of guilt, emotional upheaval, and difficulties in adapting to admission (e.g., interacting with care staff to determine an appropriate care role for the family member) [188,190,206,207].^{A17}
- The demands of caregiving may intensify as people with dementia approach the end of life [208]. In the year before the person's death, 59% of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful [209]. One study of end-of-life care found that 72% of family caregivers said they experienced relief when the person with AD or another dementia died [209].

5.1.7.2. Caregiver physical health

For some caregivers, the demands of caregiving may cause declines in their own health. Thirty-eight percent of caregivers of people with AD and other dementias reported that the physical impact of caregiving was high to very high (Fig. 9).^{A17} Sleep disturbances, which can occur frequently when caring for a relative with AD or dementia, have also been shown to negatively influence family caregivers' health [210].

5.1.7.2.1. General health

Seventy-four percent of caregivers of people with AD and other dementias reported that they were "somewhat concerned" to "very concerned" about maintaining their own

health since becoming a caregiver.^{A17} Dementia caregivers were more likely than noncaregivers to report that their health was fair or poor [195]. Dementia caregivers were also more likely than caregivers of other older people to say that caregiving made their health worse [178,211]. Data from the 2009 and 2010 BRFSS caregiver surveys found that 7% of dementia caregivers say the greatest difficulty of caregiving is that it creates or aggravates their own health problems compared with 2% of other caregivers [175]. Other studies suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than noncaregivers [212].

5.1.7.2.2. *Physiological changes*

The chronic stress of caregiving is associated with physiological changes that could increase the risk of developing chronic conditions. For example, a series of recent studies found that under certain conditions, some AD caregivers were more likely to have elevated biomarkers of cardiovascular disease risk and impaired kidney function risk than those who were not caregivers [213–218].

Caregivers of a spouse with AD or another dementia are more likely than married noncaregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones [219], reduced immune function [193,220], slow wound healing [221], and increased incidence of hypertension [222], coronary heart disease [223], and impaired endothelial function (the endothelium is the inner lining of the blood vessels). Some of these changes may be associated with an increased risk of cardiovascular disease [224]. Overall, the literature is fairly consistent in suggesting that the chronic stress of dementia care can have potentially negative influences on caregiver health.

5.1.7.2.3. *Health-care utilization*

The physical and emotional impact of dementia caregiving is estimated to have resulted in \$9.3 billion in health-care costs in the United States in 2013.^{A20} Table 6 lists the estimated higher health-care costs for AD and dementia caregivers in each state.

Dementia caregivers were more likely to visit the emergency department or be hospitalized in the preceding 6 months if the care recipient was depressed, had low functional status, or had behavioral disturbances than if the care recipient did not exhibit these symptoms [225].

5.1.7.2.4. *Mortality*

The health of a person with dementia may also affect the caregiver's risk of dying, although studies have reported mixed findings on this issue. In one study, caregivers of spouses who were hospitalized and had dementia in their medical records were more likely to die in the following year than caregivers whose spouses were hospitalized but did not have dementia, even after accounting for the age of caregivers [226]. However, other studies have found that caregivers have lower mortality rates than noncaregivers [227,228]. One study reported that higher levels of stress

were associated with higher rates of mortality in both caregivers and noncaregivers [228]. These findings suggest that it is high stress, not caregiving per se, that increases the risk of mortality. Such results emphasize that dementia caregiving is a complex undertaking; simply providing care to someone with AD or another dementia may not consistently result in stress or health problems for caregivers. Instead, the stress of dementia caregiving is influenced by a number of other factors such as dementia severity, how challenging caregivers perceive certain aspects of care to be, available social support, and caregiver personality. All these factors are important to consider when understanding the health impact of caring for a person with dementia [229].

5.1.7.3. *Caregiver employment*

Among caregivers of people with AD and other dementias, 75% reported being employed at any time since assuming care responsibilities. Eighty-one percent of AD caregivers younger than 65 years were employed, and 35% aged 65 years and older were employed [178]. Employed dementia caregivers indicate having to make major changes to their work schedules because of their caregiving responsibilities. Fifty-four percent said they had to go in late, leave early, or take time off, and 15% had to take a leave of absence while caregiving.^{A17} Other work-related changes pertaining to caregiving are summarized in Fig. 10.

5.1.8. *Caregiver interventions that may improve caregiver outcomes*

Intervention strategies to support family caregivers of people with AD have been developed and evaluated. The types and focus of these interventions are summarized in Table 7 [230].

In general, these interventions aim to ameliorate negative aspects of caregiving with the goal of improving the health and well-being of dementia caregivers. Methods used to accomplish this objective include enhancing caregiver strategies to manage dementia-related symptoms, bolstering resources through enhanced social support, and providing relief/respite from daily care demands. Desired outcomes of these interventions include decreased caregiver stress and depression and delayed nursing home admission of the person with dementia.

Characteristics of effective caregiver interventions include programs that are administered over long periods, interventions that approach dementia care as an issue for the entire family, and interventions that train dementia caregivers in the management of behavioral problems [231–234]. Multidimensional interventions appear particularly effective. These approaches combine individual consultation, family sessions and support, and ongoing assistance to help caregivers manage changes that occur as dementia progresses. Examples of successful multidimensional interventions are the New York University Caregiver Intervention [235,236], the Resources for

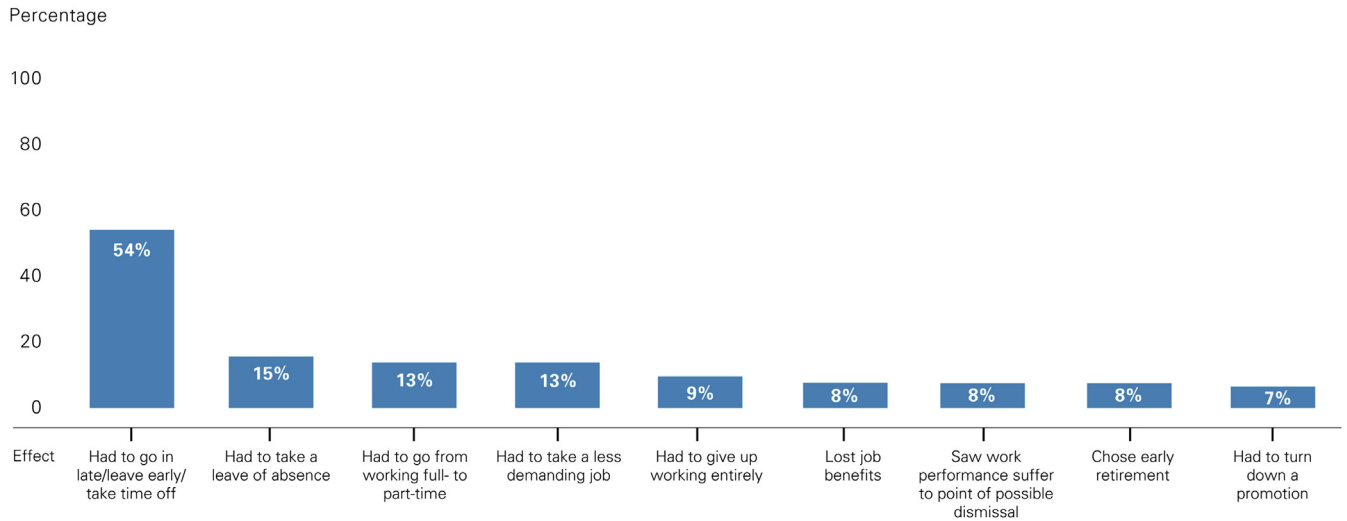


Fig. 10. Effect of caregiving on work: work-related changes among caregivers of people with AD and other dementias. Created from data from the Alzheimer's Association.^{A17}

Enhancing Alzheimer's Caregiver Health II protocol [198,230,237–239], and the Savvy Caregiver program [240–242]. Other multidimensional approaches that recently have demonstrated promising results include Partners in Dementia Care, a care coordination program that enhances access to needed services and strengthens the family care support network [243], and Acquiring New Skills While Enhancing Remaining Strengths, a program that incorporates caregiver skills training with cognitive rehabilitation for the person with dementia [244].

Although less consistent in their demonstrated benefits, support group strategies and respite services such as adult day programs have the potential to offer encouragement or relief to enhance caregiver outcomes. The effects of pharmacologic therapies for treating symptoms of dementia (e.g.,

acetylcholinesterase inhibitors, memantine, antipsychotics, and antidepressants) also appear to modestly reduce caregiver stress [245]. Mindfulness-based stress reduction (a strategy to reduce stress through meditation techniques that create attention focused on the moment and nonjudgmental awareness) has shown recent promise as an effective approach to reduce dementia caregiver distress [246]. Structured, group-based, psychoeducational programs that include both family care providers and care recipients with early-stage AD have helped to improve feelings of preparation and confidence among family members and emotional well-being among people with early-stage AD [247–249].

Several sources [230,234,235,250–255] recommend that clinicians identify the risk factors and outcomes perceived as important to each caregiver and select interventions

Table 7
Type and focus of caregiver interventions

Type of intervention	Focus
Case management	Provides assessment, information, planning, referral, care coordination, and/or advocacy for family caregivers.
Psychoeducational	Includes a structured program that provides information about the disease, resources, and services and about how to expand skills to effectively respond to symptoms of the disease (i.e., cognitive impairment, behavioral symptoms, and care-related needs). Includes lectures, discussions, and written materials and is led by professionals with specialized training.
Counseling	Aims to resolve preexisting personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Support groups	Less structured than psychoeducational or therapeutic interventions, support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of social isolation.
Respite	Planned temporary relief for the caregiver through the provision of substitute care; examples include adult day services and in-home or institutional respite for a certain number of weekly hours.
Training of the person with dementia	Memory clinic or similar programs aimed at improving the competence of the care recipient, which may also have a positive effect on caregiver outcomes.
Psychotherapeutic approaches	Involves the establishment of a therapeutic relationship between the caregiver and a professional therapist (e.g., cognitive-behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
Multicomponent approaches	Intensive support strategies that combine multiple forms of interventions such as education, support, and respite into a single, long-term service (often provided for 12 months or more).

NOTE. Created from data from Sørensen et al. [230] and Pinquart et al. [260].

appropriate for them [234]. More work is needed, however, to test the efficacy of intervention programs among different caregiver groups to ensure their benefits for caregivers across diverse clinical, racial, ethnic, socioeconomic, and geographic contexts [256].

5.1.9. Caregiver interventions and their effects on people with AD

Several reviews have sought to determine whether caregiver interventions improve outcomes for people with AD or other dementias. One recent review found that caregiver-focused interventions are effective in reducing behavioral or psychiatric problems in people with dementia [113]. Multidimensional interventions for dementia caregivers have also been shown to prevent or delay nursing home admission [112,257,258]. However, it is important to note that these conclusions are not uniform; a recent review that restricted its scope to high-quality evaluations (i.e., randomized, controlled trials) indicated a lack of consistent effects of caregiver interventions on people with AD and other dementias [259].

5.2. Paid caregivers

5.2.1. Direct-care workers for people with AD and other dementias

Direct-care workers such as nurse aides, home health aides, and personal and home care aides comprise most of the formal long-term care delivery system for older adults (including those with AD and other dementias). In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents [261–263]. Most nursing assistants are women, and they come from increasingly diverse ethnic, racial, and international backgrounds. Nursing assistants help with bathing, dressing, housekeeping, food preparation, and other activities.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care [262,264]. One review found that direct-care workers received, on average, 75 hours of training that included little focus on issues specific or pertinent to dementia care [262]. Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges [265]. Reviews have shown that staff training programs to improve the quality of dementia care in nursing homes have modest positive benefits [266,267].

5.2.2. Shortage of geriatric health-care professionals in the United States

Professionals who may receive special training in caring for older adults include physicians, physician assistants, nurses, social workers, pharmacists, case workers, and others [265]. It is projected that the United States will need an additional 3.5 million health-care professionals by 2030 just to maintain the current ratio of health-care profes-

sionals to the older population [265]. The need for health-care professionals trained in geriatrics is escalating, but few providers choose this career path. It is estimated that the United States has approximately half the number of certified geriatricians that it currently needs [268]. In 2010, there were 4278 physicians practicing geriatric medicine in the United States [269]. An estimated 36,000 geriatricians will be required to adequately meet the needs of older adults in the United States by 2030 [265]. Other health-related professions also have low numbers of geriatric specialists relative to the population's needs. According to the Institute of Medicine, less than 1% of registered nurses, physician assistants, and pharmacists identify themselves as specializing in geriatrics [265]. Similarly, although 73% of social workers serve clients aged 55 years and older and about 8% of social workers are employed in long-term care settings, only 4% have formal certification in geriatric social work [265]. The complex care challenges of many people with dementia often require the simultaneous expertise of professionals trained in multiple care disciplines. There is a continuing need for interprofessional collaboration and education to enhance the overall care of people with dementia [270].

6. Use and costs of health care, long-term care, and hospice

The costs of health care, long-term care, and hospice for individuals with AD and other dementias are substantial, and AD is one of the costliest chronic diseases to society [173]. Total payments in 2014 (in 2014 dollars) for all individuals with AD and other dementias are estimated at \$214 billion (Fig. 11). Medicare and Medicaid are expected to cover \$150 billion, or 70%, of the total health-care and long-term care payments for people with AD and other dementias. Out-of-pocket spending is expected to be \$36 billion, or 17% of total payments.^{A21} Unless otherwise indicated, all costs in this section are reported in 2013 dollars.^{A22}

6.1. Payments for health care, long-term care, and hospice

Table 8 reports the average annual per-person payments for health-care and long-term care services for Medicare beneficiaries with and without AD and other dementias. Total per-person payments from all sources for health care and long-term care for Medicare beneficiaries with AD and other dementias were three times as great as payments for other Medicare beneficiaries in the same age group (\$46,669 per person for those with dementia compared with \$14,772 per person for those without dementia) [155].^{A23}

Twenty-nine percent of older individuals with AD and other dementias who have Medicare also have Medicaid coverage compared with 11% of individuals without dementia [155]. Medicaid pays for nursing home and other long-term care services for some people with very low income and low assets, and the high use of these services by people

Total cost: \$214 Billion (B)

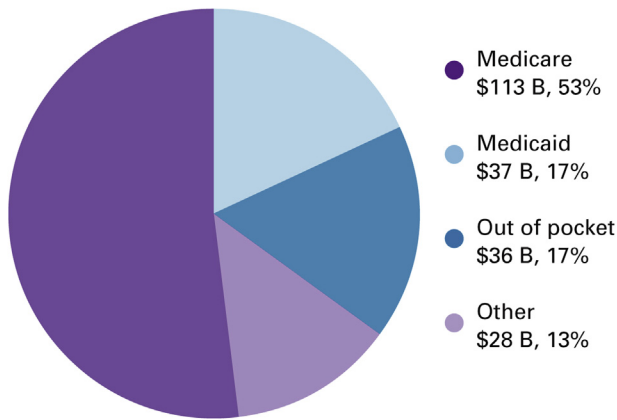


Fig. 11. Aggregate costs of care by payer for Americans aged 65 years or older with AD and other dementias, 2014. Data are in 2014 dollars. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations, and uncompensated care. Created from data from the application of the Lewin model^{A21} to data from the Medicare Current Beneficiary Survey for 2008 [155].

with dementia translates into high costs for the Medicaid program. Average Medicaid payments per person for Medicare beneficiaries with AD and other dementias (\$10,771) were 19 times as great as average Medicaid payments for Medicare beneficiaries without AD and other dementias (\$561; Table 8) [155].

Despite these and other sources of financial assistance, individuals with AD and other dementias still incur high out-of-pocket costs. These costs are for Medicare and other health insurance premiums and for deductibles, copayments, and services not covered by Medicare, Medicaid, or additional sources of support. Medicare beneficiaries aged 65 years and older with AD and other dementias paid \$9970 out of pocket on average for health-care and long-term care services not covered by other sources (Table 8) [155]. Average per-person out-of-pocket payments were highest

(\$19,196 per person) for individuals living in nursing homes and assisted living facilities and were almost six times as great as the average per-person payments for individuals with AD and other dementias living in the community [155].

Recently, researchers evaluated the *incremental* health-care and caregiving costs of dementia (i.e., the costs specifically attributed to dementia for people with the same coexisting medical conditions and demographic characteristics) [173,271]. One group of researchers found that the incremental health-care and nursing home costs for those with dementia was \$31,141 [173].^{A24}

6.2. Use and costs of health-care services

People with AD and other dementias have more than three times as many hospital stays per year as other older people [155]. Moreover, the use of health-care services for people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke, or cancer who *also* have AD and other dementias have higher use and costs of health-care services than people with these medical conditions but no coexisting dementia.

6.2.1. Use of health-care services

Older people with AD and other dementias have more hospital stays, skilled nursing facility stays, and home health-care visits than other older people.

- **Hospital:** There are 780 hospital stays per 1000 Medicare beneficiaries aged 65 years and older with AD and other dementias compared with 234 hospital stays per 1000 Medicare beneficiaries aged 65 years and older without these conditions [155]. The most common reasons for hospitalization of people with AD include syncope (fainting), fall, and trauma (26%); ischemic heart disease (17%); and gastrointestinal disease (9%; Fig. 12) [272].

Table 8

Average annual per-person payments for health care and long-term care services, Medicare beneficiaries aged 65 years and older, with and without Alzheimer's disease and other dementias and by the place of residence, in 2013 dollars

Payment source	Beneficiaries with Alzheimer's disease and other dementias by place of residence			Beneficiaries without Alzheimer's disease and other dementias
	Overall	Community dwelling	Residential facility	
Medicare	\$21,095	\$18,787	\$24,319	\$8005
Medicaid	10,771	237	25,494	561
Uncompensated	290	417	114	328
HMO	1058	1642	241	1543
Private insurance	2407	2645	2074	1619
Other payer	964	174	2067	153
Out of pocket	9970	3370	19,196	2431
Total*	46,669	27,465	73,511	14,772

Abbreviation: HMO, health maintenance organization.

*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer's disease and other dementias include payments for community-dwelling and facility-dwelling beneficiaries.

NOTE. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008 [155].

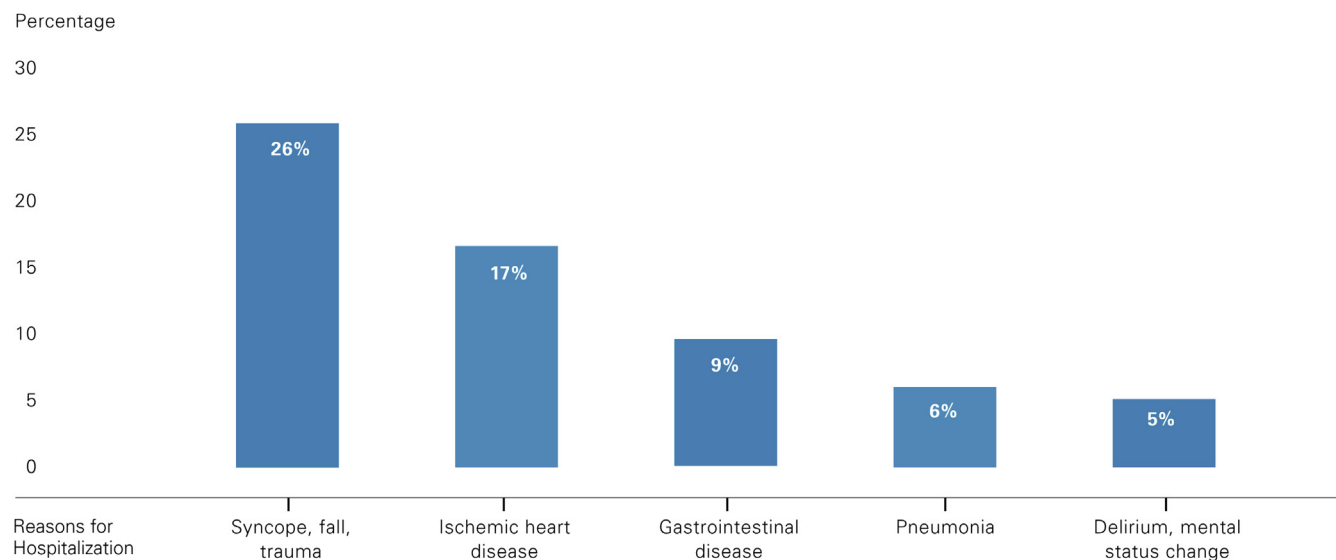


Fig. 12. Reasons for hospitalization of individuals with AD: percentage of hospitalized individuals by admitting diagnosis. All hospitalizations for individuals with a clinical diagnosis of probable or possible AD were used to calculate percentages. The remaining 37% of hospitalizations were due to other reasons. Created from data from Rudolph et al. [272].

- **Skilled nursing facility:** Skilled nursing facilities provide direct medical care that is performed or supervised by registered nurses such as giving intravenous fluids, changing dressings, and administering tube feedings [273]. There are 349 skilled nursing facility stays per 1000 beneficiaries with AD and other dementias compared with 39 stays per 1000 beneficiaries for people without these conditions [155].
- **Home health care:** A total of 23% of Medicare beneficiaries aged 65 years and older with AD and other dementias have at least one home health visit during the year compared with 10% of Medicare beneficiaries aged 65 years and older without AD and other dementias [139].

Table 9

Average annual per-person payments for health-care services provided to Medicare beneficiaries aged 65 years and older with and without Alzheimer's disease and other dementias, in 2013 dollars

Health-care service	Beneficiaries with Alzheimer's disease and other dementias	Beneficiaries without Alzheimer's disease and other dementias
Inpatient hospital	\$10,748	\$4321
Medical provider*	6220	4124
Skilled nursing facility	4072	474
Nursing home	18,898	840
Hospice	1880	184
Home health	1507	486
Prescription medications†	2799	2853

*"Medical provider" includes physician, other medical provider and laboratory services, and medical equipment and supplies.

†Information on payments for prescription drugs is available only for people who were living in the community; that is, not in a nursing home or assisted living facility.

NOTE. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008 [155].

6.2.2. Costs of health-care services

With the exception of prescription medications, average per-person payments for health-care services (hospital, physician and other medical provider, nursing home, skilled nursing facility, hospice, and home health care) were higher for Medicare beneficiaries with AD and other dementias than for other Medicare beneficiaries in the same age group (Table 9) [155]. The fact that only payments for prescription drugs are lower for those with AD and other dementias underscores the lack of effective treatments available to those with dementia.

6.2.3. Use and costs of health-care services for individuals newly diagnosed with AD

Those newly diagnosed with AD have higher health-care use and costs in the year before diagnosis and in the 2 subsequent years than those who do not receive this diagnosis, according to a study of Medicare Advantage enrollees (i.e., Medicare beneficiaries enrolled in a private Medicare health insurance plan) [274]. Enrollees with a new diagnosis of AD had \$2472 more in health-care costs (medical and pharmacy) in the year before diagnosis, \$9896 more in costs in the year after diagnosis, and \$6109 more in costs in the second year after diagnosis. Although more work is needed to understand the underlying drivers of increased utilization immediately before and after receiving a diagnosis of AD, the additional health-care use may be attributed to treatments related to the cognitive impairment or coexisting medical conditions and care related to diagnosing the disease.

6.2.4. Impact of coexisting medical conditions on use and costs of health-care services

Medicare beneficiaries with AD and other dementias are more likely than those without dementia to have other

Table 10
Specific coexisting medical conditions among Medicare beneficiaries aged 65 years and older with Alzheimer's disease and other dementias, 2009

Coexisting condition	Percentage of beneficiaries with Alzheimer's disease and other dementias who also had coexisting medical condition
Coronary artery disease	30
Diabetes	29
Congestive heart failure	22
Chronic kidney disease	17
Chronic obstructive pulmonary disease	17
Stroke	14
Cancer	9

NOTE. Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009 [139].

chronic conditions [139]. Table 10 reports the proportion of people with AD and other dementias who have certain coexisting medical conditions. In 2009, 30% of Medicare beneficiaries aged 65 years and older with dementia also had coronary artery disease, 29% also had diabetes, 22% also had congestive heart failure, 17% also had chronic kidney disease, and 17% also had COPD [139].

People with AD and other dementias and a serious coexisting medical condition (e.g., congestive heart failure) are more likely to be hospitalized than people with the same coexisting medical condition but without dementia (Fig. 13) [139]. Research has demonstrated that Medicare beneficiaries with AD and other dementias have more potentially avoidable hospitalizations for diabetes complications and hypertension, meaning that the hospitalizations could possibly be prevented through proactive care management in the outpatient setting [275].

Similarly, Medicare beneficiaries who have AD and other dementias and a serious coexisting medical condition have higher average per-person payments for most health-care services than Medicare beneficiaries who have the same medical condition without dementia. Table 11 lists the average per-person Medicare payments for seven specific medical conditions among beneficiaries who have AD and other dementias and beneficiaries who do not have dementia [139]. Medicare beneficiaries with dementia had higher average per-person payments in all categories except total Medicare and hospital care payments for individuals with congestive heart failure.

6.3. Use and costs of long-term care services

An estimated 60% to 70% of older adults with AD and other dementias live in the community compared with 98% of older adults without AD and other dementias [155,276]. Of those with dementia who live in the community, 75% live with someone and the remaining 25% live alone [155]. People with AD and other dementias generally receive more care from family members and other unpaid caregivers as their disease progresses. Many

people with dementia also receive paid services at home; in adult day centers, assisted living facilities, or nursing homes; or in more than one of these settings at different times in the often long course of the disease. Given the high average costs of these services (adult day services, \$72 per day [276]; assisted living, \$43,756 per year [276]; and nursing home care, \$83,230–\$92,977 per year [276]), individuals often deplete their income and assets and eventually qualify for Medicaid. Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the late stages of their illnesses.

6.3.1. Use of long-term care services by setting

Most people with AD and other dementias who live at home receive unpaid help from family members and friends, but some also receive paid home- and community-based services such as personal care and adult day care. A study of older people who needed help to perform daily activities—such as dressing, bathing, shopping, and managing money—found that those who also had cognitive impairment were more than twice as likely as those who did not have cognitive impairment to receive paid home care [277]. In addition, those who had cognitive impairment and received paid services used almost twice as many hours of care monthly as those who did not have cognitive impairment [277].

People with AD and other dementias make up a large proportion of all elderly people who receive nonmedical home care, adult day services, and nursing home care.

- *Home care:* According to state home care programs in Connecticut, Florida, and Michigan, more than one-third (about 37%) of older people who receive primarily nonmedical home care services such as personal care and homemaker services have cognitive impairment consistent with dementia [278–280].
- *Adult day services:* At least half of elderly attendees at adult day centers have dementia [281,282].
- *Assisted living:* 42% of residents in assisted living facilities (i.e., housing that includes services to assist with everyday activities such as medication management and meals) had AD and other dementias in 2010 [283].
- *Nursing home care:* Of all Medicare beneficiaries aged 65 years and older with AD and other dementias, 31% live in a nursing home [155]. Of all Medicare beneficiaries residing in a nursing home, 64% have AD and other dementias [155].
- *AD special care units:* An AD special care unit is a dedicated unit in a nursing home that has tailored services for individuals with AD and other dementias. Nursing homes had a total of 75,876 beds in AD special care units in 2013, a decrease of 4% compared with the previous year [284]. These AD special care unit beds accounted for 72% of all special care unit beds and

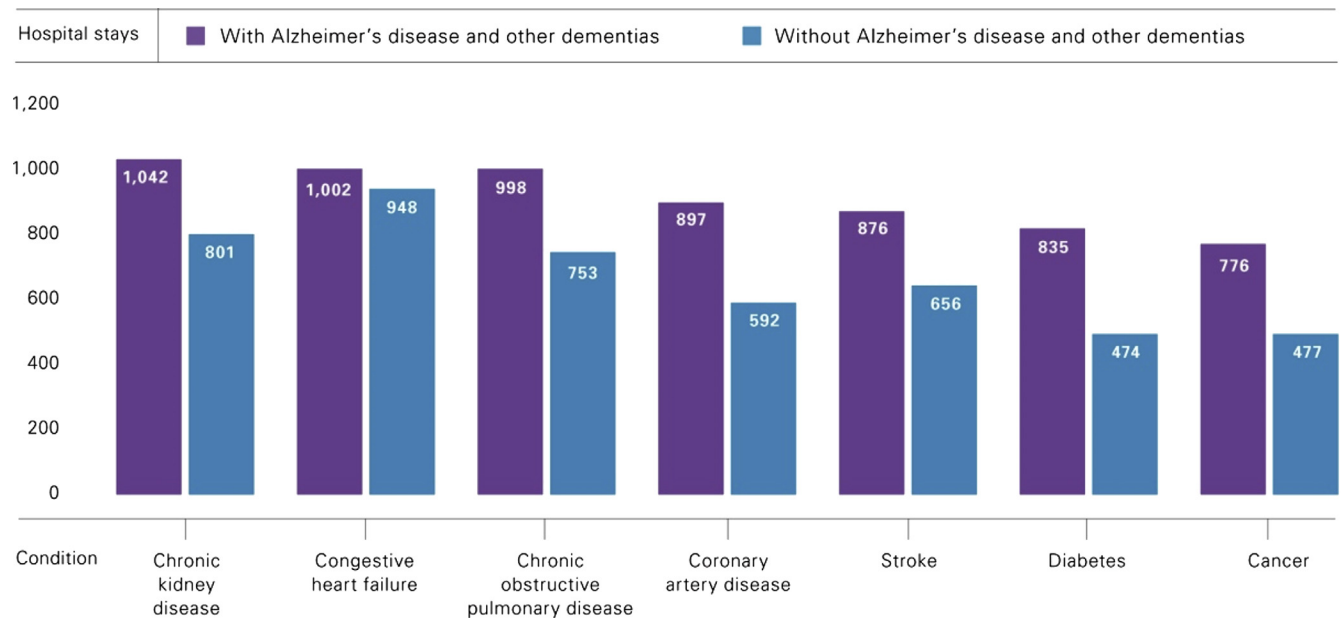


Fig. 13. Hospital stays per 1000 beneficiaries aged 65 years or older with specified coexisting medical conditions, with and without AD and other dementias, 2009. Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009 [139].

4.5% of all nursing home beds. Rhode Island has the largest percentage of AD special care unit beds as a proportion of total beds (13.3%), whereas Tennessee has the smallest percentage of AD special care unit beds (0.3%; Table 12).

Recent research demonstrates that individuals with dementia often move between a nursing facility, hospital, and home rather than remaining in a nursing facility [285]. In a longitudinal study of primary care patients with dementia, researchers found that those discharged from a nursing facility were nearly equally as likely to be discharged home (39%) as discharged to a hospital (44%). Additionally, 74% of individuals admitted to a nursing facility came directly from a hospital. Individuals with dementia may also transition between a nursing facility and hospital or between a nursing facility, home, and hospital, creating challenges for caregivers and providers to ensure that care is coordinated across settings. Other research has shown that nursing home residents frequently have burdensome transitions at the end of life, including admission to an intensive care unit in the last month of life, late enrollment in hospice, and receipt of a feeding tube [286]. Care coordination for nursing home residents with advanced cognitive impairment, as measured by the number of care transitions, varies substantially across geographic regions of the United States [287]. Researchers also found that both the number of transitions between health-care settings and the odds of having a feeding tube inserted at the end of life varied across the country. Furthermore, individuals with frequent transitions between health-care settings were more likely to have feeding tubes at the

end of life, although feeding tube placement has little or no benefit.

Research has also demonstrated a decrease in the proportion of individuals with AD who die in an acute care hospital, with end-of-life care shifting to home and nursing homes [288]. Additionally, more than twice as many individuals with the disease were receiving hospice care at the time of death in 2009 compared with 2000 (19.5% in 2000 vs. 48.3% in 2009).

Demand for nursing home services and services from long-term care hospitals is increasing. Long-term care hospitals serve individuals whose acute medical conditions require long-term care. Individuals are often transferred from the intensive care units of acute care hospitals to long-term care hospitals for medical care related to rehabilitation services, respiratory therapy, and pain management. Despite this increasing demand, there have been a number of restrictions on adding facilities and increasing the number of beds in existing facilities. In addition, the Medicare, Medicaid, and State Children's Health Insurance Program Extension Act of 2007 issued a 3-year moratorium on both the designation of new long-term care hospitals and increases in Medicare-certified beds for existing long-term care hospitals [289]. This moratorium was in response to the need for Medicare to develop criteria for admitting beneficiaries to long-term care hospitals, where stays average more than 25 days [290]. The moratorium expired in late 2012 [289,291]. In 2011, certificate-of-need programs were in place in 37 states to regulate the number of nursing home beds, and a number of these states had implemented a certificate-of-need moratorium to prevent growth in the number of beds and/or facilities [292].

Table 11

Average annual per-person payments by the type of service and coexisting medical condition for Medicare beneficiaries aged 65 years and older, with and without Alzheimer's disease and other dementias, 2009, in 2013 dollars*

Medical condition by Alzheimer's disease/dementia (AD/D) status	Average per-person Medicare payment					
	Total Medicare payments	Hospital care	Physician care	Skilled nursing facility care	Home health care	Hospice care
Coronary artery disease						
With AD/D	\$27,033	\$9769	\$1701	\$4309	\$2721	\$2348
Without AD/D	16,768	7020	1301	1160	1171	342
Diabetes						
With AD/D	26,381	9296	1593	4177	2803	2121
Without AD/D	14,581	5730	1121	1193	1111	240
Congestive heart failure						
With AD/D	25,907	11,095	1756	4777	2848	2944
Without AD/D	29,756	11,359	1755	2589	2244	833
Chronic kidney disease						
With AD/D	31,892	12,246	1884	4807	2659	2560
Without AD/D	24,538	10,264	1649	1983	1646	530
Chronic obstructive pulmonary disease						
With AD/D	29,326	10,914	1793	4709	2821	2651
Without AD/D	20,072	8554	1474	1716	1516	665
Stroke						
With AD/D	27,517	9625	1653	4521	2578	2759
Without AD/D	19,755	7461	1405	2317	1891	652
Cancer						
With AD/D	25,322	8653	1552	3624	2221	2890
Without AD/D	16,572	5871	1190	981	788	593

*This table does not include payments for all kinds of Medicare services, and as a result, the average per-person payments for specific Medicare services do not sum up to the total per-person Medicare payments.

NOTE. Created from unpublished data from the National 20% Sample Medicare Fee for Service Beneficiaries for 2009 [139].

6.3.2. Costs of long-term care services

Costs are high for care provided at home or in an adult day center, assisted living facility, or nursing home. The following estimates are for all users of these services. The only exception is the cost of AD special care units in nursing homes, which only applies to people with AD and other dementias.

- **Home care:** In 2012, the average cost for a paid non-medical home health aide was \$21/h or \$168 for an 8-hour day [276].
- **Adult day centers:** In 2012, the average cost of adult day services was \$72/d. Ninety-five percent of adult day centers provided care for people with AD and other dementias, and 2% of these centers charged an additional fee for these clients [276].
- **Assisted living facilities:** In 2012, the average cost for basic services in an assisted living facility was \$3646/mo, or \$43,756/y. Seventy-two percent of assisted living facilities provided care to people with AD and other dementias, and 52% had a specific unit for people with AD and other dementias. In facilities that charged a different rate for individuals with dementia, the average rate was \$4937/mo, or \$59,250/y, for this care [276].
- **Nursing homes:** In 2012, the average cost for a private room in a nursing home was \$255/d or \$92,977/y. The average cost of a semiprivate room in a nursing home was \$228/d or \$83,230/y. Approximately 80% of nursing homes that provide care for people with AD charge

the same rate for those with AD as they do for those without the disease. In the few nursing homes that charged a different rate, the average cost for a private room for an individual with AD was \$13 higher (\$268/d or \$97,820/y), and the average cost for a semi-private room was \$8 higher (\$236/d or \$86,140/y) [276]. Fifty-five percent of nursing homes that provide care for people with AD and other dementias had separate AD special care units [276].

6.3.3. Affordability of long-term care services

Few individuals with AD and other dementias have sufficient long-term care insurance or can afford to pay out of pocket for long-term care services for as long as the services are needed.

- Income and asset data are not available for people with AD and other dementias specifically, but 50% of Medicare beneficiaries had incomes of \$22,604 or less, and 25% had incomes of \$13,616 or less in 2010 [293,294].
- Fifty percent of Medicare beneficiaries had retirement accounts of \$2236 or less, 50% had financial assets of \$32,319 or less, and 50% had total savings of \$56,224 or less, equivalent to less than 1 year of nursing home care in 2010 [294].

6.3.4. Long-term care insurance

In 2010, about 7.3 million people had long-term care insurance policies [295]. Private health and long-term care

Table 12
Total nursing home beds and Alzheimer's disease special care unit beds by state, 2013

State	Total beds	Alzheimer's disease special care unit beds	Alzheimer's disease beds as a percentage of total beds
Alabama	26,685	1245	4.7
Alaska	778	37	4.8
Arizona	16,668	887	5.3
Arkansas	24,527	321	1.3
California	121,356	2984	2.5
Colorado	20,462	2078	10.2
Connecticut	27,837	1691	6.1
Delaware	4986	375	7.5
District of Columbia	2766	70	2.5
Florida	83,145	3880	4.7
Georgia	39,817	1455	3.7
Hawaii	4260	106	2.5
Idaho	5842	226	3.9
Illinois	99,196	4835	4.9
Indiana	59,480	6166	10.4
Iowa	34,831	1672	4.8
Kansas	25,643	422	1.6
Kentucky	26,161	541	2.1
Louisiana	35,592	1652	4.6
Maine	7020	640	9.1
Maryland	28,536	884	3.1
Massachusetts	48,640	3874	8.0
Michigan	47,007	1039	2.2
Minnesota	30,526	2512	8.2
Mississippi	18,576	229	1.2
Missouri	55,138	4487	8.1
Montana	6713	542	8.1
Nebraska	15,936	1278	8.0
Nevada	5979	278	4.6
New Hampshire	7513	592	7.9
New Jersey	52,281	1008	1.9
New Mexico	6716	510	7.6
New York	116,849	3903	3.3
North Carolina	44,549	1608	3.6
North Dakota	6151	454	7.4
Ohio	91,785	3630	4.0
Oklahoma	29,296	758	2.6
Oregon	12,267	259	2.1
Pennsylvania	88,200	6351	7.2
Rhode Island	8715	1162	13.3
South Carolina	19,721	89	0.5
South Dakota	6903	552	8.0
Tennessee	37,234	124	0.3
Texas	135,066	2462	1.8
Utah	8464	590	7.0
Vermont	3199	195	6.1
Virginia	32,667	1254	3.8
Washington	21,654	864	4.0
West Virginia	10,888	137	1.3
Wisconsin	34,960	2663	7.6
Wyoming	2984	305	10.2
United States	1,702,165	75,876	4.4

NOTE. Created from data from the American Health Care Association [284].

insurance policies funded only about 7% of total long-term care spending in 2009, representing \$19 billion of the \$271 billion in long-term care spending [296]. The private

long-term care insurance market has decreased substantially since 2010, however, with five major insurance carriers either exiting the market or substantially increasing premiums, making policies unaffordable for many individuals [297].

6.3.5. Medicaid costs

Medicaid covers nursing home care and long-term care services in the community for individuals who meet program requirements for level of care, income, and assets. To receive coverage, beneficiaries must have low incomes. Most nursing home residents who qualify for Medicaid must spend all their Social Security income and any other monthly income, except for a very small personal needs allowance, to pay for nursing home care. Medicaid only makes up the difference if the nursing home resident cannot pay the full cost of care or has a financially dependent spouse.

The federal and state governments share in managing and funding the program, and states differ greatly in the services covered by their Medicaid programs. Medicaid plays a critical role for people with dementia who can no longer afford to pay for long-term care expenses on their own. In 2008, 58% of Medicaid spending on long-term care was allocated to institutional care, and the remaining 42% was allocated to home- and community-based services [296].

Total Medicaid spending for people with AD and other dementias is projected to be \$37 billion in 2014 (in 2014 dollars).^{A21} Total per-person Medicaid payments for Medicare beneficiaries aged 65 years and older with AD and other dementias were 19 times as great as Medicaid payments for other Medicare beneficiaries. Much of the difference in payments for beneficiaries with AD and other dementias is due to the costs associated with long-term care (nursing homes and other residential care facilities such as assisted living facilities) and the greater percentage of people with dementia who are eligible for Medicaid. Medicaid paid an average of \$25,494 per person for Medicare beneficiaries with AD and other dementias living in a long-term care facility compared with \$237 for those with the diagnosis living in the community and an average of \$561 for older adults without the diagnosis living in the community and long-term care facilities (Table 8) [155].

In a study of Medicaid beneficiaries with a diagnosis of AD, researchers found significant differences in the cost of care by race/ethnicity. These results demonstrated that non-Hispanic blacks had significantly higher cost of care than whites or Hispanics, primarily due to more inpatient care and greater severity of illness. These differences may be attributable to delays in accessing timely primary care, lack of care coordination, and duplication of services across providers. However, more research is needed to understand the reasons for this health-care disparity [298].

6.4. Use and costs of hospice care

Hospices provide medical care, pain management, and emotional and spiritual support for people who are dying,

including people with AD and other dementias. Hospices also provide emotional and spiritual support and bereavement services for families of people who are dying. The main purpose of hospice care is to allow individuals to die with dignity and without pain and other distressing symptoms that often accompany terminal illness. Individuals can receive hospice care in their homes, assisted living residences, or nursing homes. Medicare is the primary source of payment for hospice care, but private insurance, Medicaid, and other sources also pay for hospice care.

In 2009, 6% of people admitted to hospices in the United States had a primary hospice diagnosis of AD (61,146 people) [299]. An additional 11% of those admitted to hospices in the United States had a primary hospice diagnosis of non-AD dementia (119,872 people) [299]. Hospice length of stay has increased over the past decade. The average length of stay for hospice beneficiaries with a primary hospice diagnosis of AD increased from 67 days in 1998 to 106 days in 2009 [299]. The average length of stay for hospice beneficiaries with a primary diagnosis of non-AD dementia increased from 57 days in 1998 to 92 days in 2009 [299]. Average per-person hospice care payments for beneficiaries with AD and other dementias were 10 times as great as for all other Medicare beneficiaries (\$1880 per person compared with \$184 per person) [155].

6.5. Projections for the future

Total annual payments for health care, long-term care, and hospice care for people with AD and other dementias are projected to increase from \$214 billion in 2014 to \$1.2 trillion in 2050 (in 2014 dollars). This dramatic rise includes a sixfold increase in government spending under Medicare and Medicaid and a fivefold increase in out-of-pocket spending.^{A21}

7. Special report: Women and AD

In 2010, the Alzheimer's Association conducted a groundbreaking poll with the goal of exploring the compelling connection between AD and women. Data from that poll were published in *The Shriver Report: A Woman's Nation Takes on Alzheimer's* [300], which also included essays and reflections that gave personal perspectives to the poll's numbers. That report revealed not only the striking impact of the disease on individual lives, but also its especially strong effects on women—women living with the disease, as well as women who are caregivers, relatives, friends, and loved ones of those directly affected.

Inspired by compelling findings published in *The Shriver Report*, the Alzheimer's Association conducted a follow-up poll in 2014^{A17} to continue exploring how AD affects the lives of Americans. This special report reveals results of this new poll with a focus on women, and it discusses recent research discoveries on AD and gender.

7.1. Incidence and prevalence

As discussed in the Prevalence section, almost two-thirds of Americans with AD are women. The prevailing view as to why women account for such a high percentage of existing cases is that, on average, women have longer life spans than men and are thereby more likely to reach an age of high risk for AD. As noted in the Prevalence section, there is no evidence that women are more likely than men to develop dementia at any given age. Nevertheless, various explanations have been proposed to explain the differing prevalence of AD between women and men.

Earlier in the report, incidence data from the Framingham Study are presented showing that, at the age of 65 years, women have a higher lifetime risk of AD than men. Another type of analysis from the Framingham Study was published very recently; the goal of that analysis was to explore how the incidence of AD or dementia was affected by other causes of death in people between ages of 45 and 65 years [301]. The study confirmed that men have a higher rate of death from cardiovascular disease than women in that age range. Furthermore, because a high risk of cardiovascular disease is also associated with a high risk of AD, the researchers concluded that the death of men from cardiovascular disease between ages 45 and 65 was reducing the pool of men at high risk for AD at later ages. They estimated that this effect explained 20% to 50% of the difference in incidence of AD among men and women older than 65 years.

Other possible explanations for the higher incidence and prevalence of AD among women have been proposed [301,302], but definitive scientific evidence is sparse. There are well-established differences in brain structure between men and women, some of which may be associated with an increased risk of cognitive decline or dementia. Furthermore, women and men exhibit different forms of behavioral changes associated with the disease [303], possibly suggesting that the disease affects male and female brains in different ways. This concept is supported by recent evidence from imaging studies suggesting that the disease causes structural changes in the brain that differ between men and women [304].

Women and men also have different hormonal physiology, and sex-specific hormones are known to have effects on the brain. There are also differences in the molecular characteristics of cells in women and men, including genetic differences. Several genetic variants have been shown to be associated with an increased risk of AD, including the $\epsilon 4$ variant of the *APOE* gene. This gene variant is the strongest genetic risk factor yet identified for late-onset AD. Increasing evidence suggests that the higher risk for AD associated with *APOE* $\epsilon 4$ is more pronounced in women than men [305].

Several studies have found brain changes associated with AD or MCI that differ between men and women, including a recent study using brain imaging in which specific brain

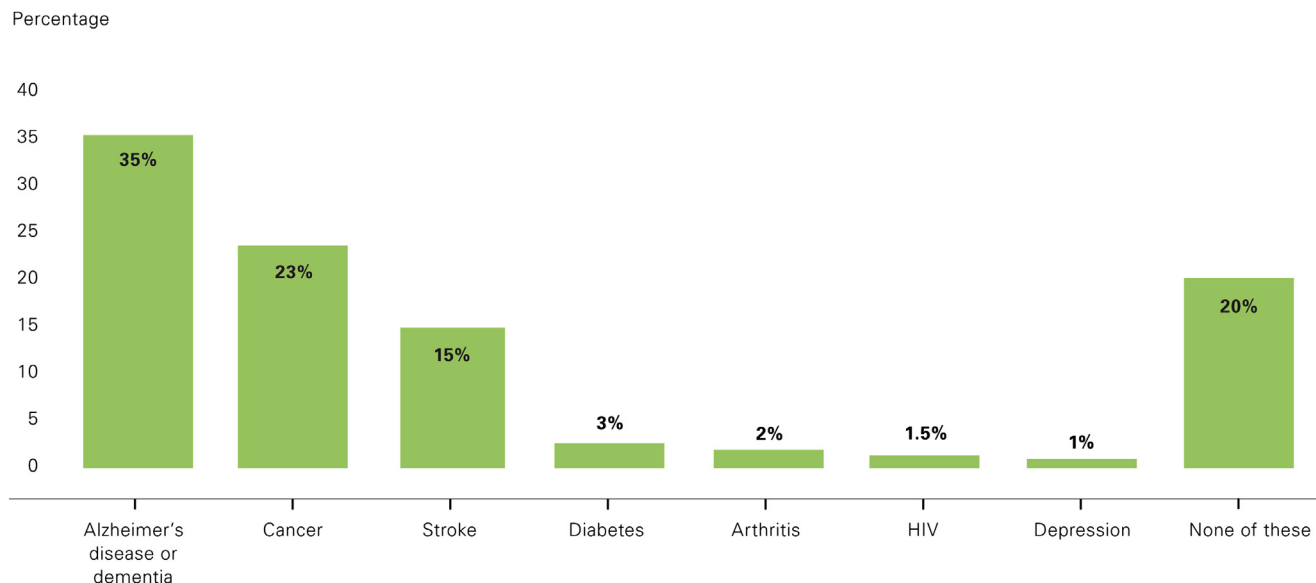


Fig. 14. Responses of Americans aged 60 years or older when asked which condition they were most afraid of getting. Created from data from the YouGov survey.^{A25}

regions changed at different rates in women versus men [306]. At this time, however, much more research is needed to define biological differences in the disease process between women and men.

7.2. Knowledge and attitudes about AD and dementia

The 2014 Alzheimer's Association Women and Alzheimer's Poll^{A17} questioned 3102 American adults about their attitudes, knowledge, and experiences related to AD and dementia. Adults identified as informal caregivers were asked additional questions about their caregiving experiences (see section 7.3 on Caregiving).

Fifty-six percent of all respondents reported knowing someone with the disease. Those who knew someone with the disease were also more likely to have heard or read about the disease than those who did not know someone with the disease.

As discussed in the Overview, heredity (family history) is only one of many risk factors for AD, and many cases occur in people with little or no family history. However, 24% of poll respondents agreed with the erroneous statement that AD must run in their family for them to be at risk. The rates of agreement were similar among women and men, but there were large differences across ethnic groups. Among people who self-identified as Latino or Asian, 33% and 45%, respectively, agreed with this statement. These findings reveal a need for additional education about risk factors for AD across all sectors of the population and an even greater need in certain ethnic groups.

Women showed higher levels of concern than men that they or someone in their immediate family would get AD or dementia, with 56% of women and 44% of men saying they were "very concerned" about that possibility. When

asked if the idea of getting AD "frightened" them, 58% of women said yes compared with 43% of men. These findings are consistent with a recent survey^{A25} of people aged 60 years and older conducted by YouGov, which found that AD or dementia was more feared than other chronic conditions, including cancer, heart disease, and stroke (Fig. 14).

The 2014 Alzheimer's Association poll also asked respondents about the aspects of AD that frightened them most. The five most common answers are shown in Fig. 15 (multiple responses were allowed). Overall, women and men gave similar responses to this question.

Concern or fear about the possibility of getting AD may have psychological or behavioral consequences, but those consequences are not well understood, and more research into this issue has been recommended [302]. Excessive fear or concern about developing a chronic condition can be associated with unproductive anxiety, chronic stress, and ill-advised behaviors, such as seeking unnecessary testing or treatment or attempting to ward off the disease by using unproven and potentially dangerous "remedies." On the other hand, some degree of concern may be beneficial as it may promote better education, appropriate screening, and healthful behaviors such as physical activity and a healthy diet.

In the 2014 Alzheimer's Association poll, 26% of women had thought about what care options might be available to them if they were to get AD or dementia. Only 19% of men had thought about potential care options. Caregivers of someone with AD or dementia, and especially women caregivers, were much more likely to have thought about potential care options (women, 48%, and men, 25%).

When asked about the care options they would prefer if they were to get AD or dementia, women and men gave similar responses. About 36% would prefer to be taken care of at home by a spouse or children, and nearly the same

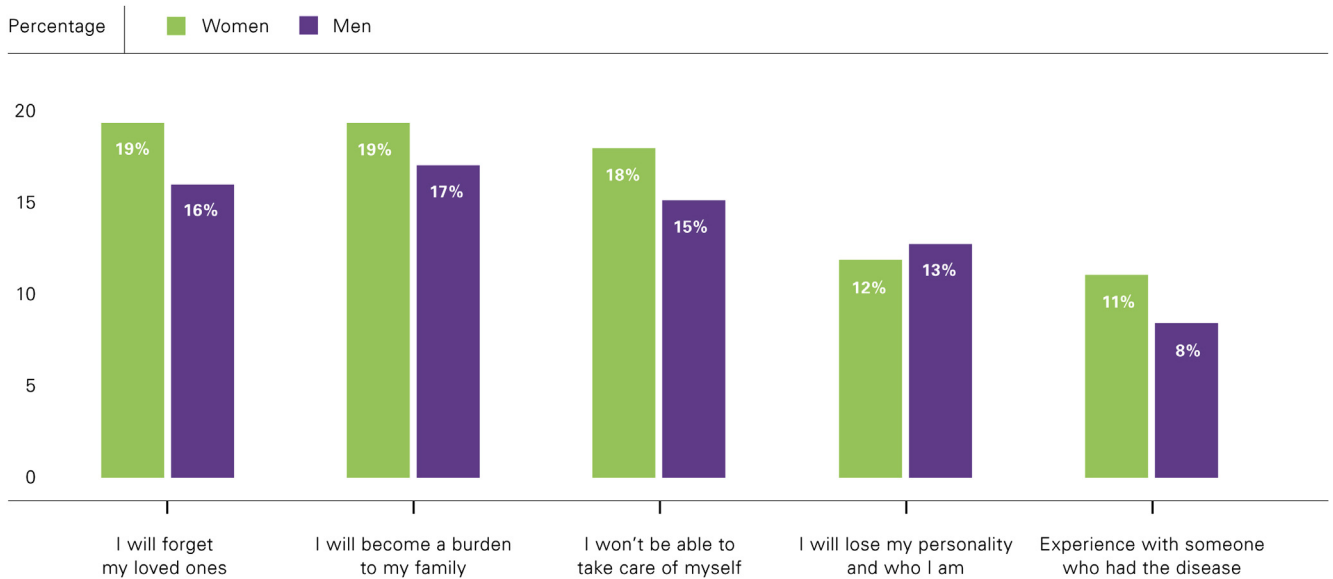


Fig. 15. Why does the possibility of getting AD frighten you? Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.^{A17}

percentage (38%) would want to be placed in an assisted living home that specializes in AD care. Fewer (20%) stated that they would want to receive care in their own home from a paid caregiver.

7.3. Caregiving

In the 2014 Alzheimer's Association poll, 512 people^{A26} identified themselves as providing the majority of care for someone (not living in a residential care facility) with AD or dementia or equally sharing those responsibilities with another person. Of these informal caregivers, 63% were women, consistent with *The Shriver Report* and other studies that have found that women constitute about 60% to 70% of all informal caregivers for seniors [177,178,184,300,307,308]. Because many people do not report the care of an ailing spouse as caregiving and because it is more common for a wife to be caring for an ailing husband than the converse, women may account for even more informal caregiving than these studies suggest [307].

Many factors influence how, why, and when a person becomes a caregiver for someone with AD or dementia. In the 2014 Alzheimer's Association poll, 37% of caregivers agreed with the statement, "I had no choice in becoming a caregiver." A higher percentage of female caregivers agreed with that statement (39%) than male caregivers (33%), consistent with previous studies [184,300]. These findings have important implications for the caregiver's experience and the perceived burden of caregiving. For example, caregivers who believed they had no choice in accepting the caregiving role, or who felt captured by that role, perceived the emotional stress and burden of caregiving to be significantly higher than caregivers who felt they had a choice [309,310]. Research indicates that women who anticipated becoming caregivers for their aging parents

were better able to adapt to their caregiving role than those who become caregivers unexpectedly [311].

Like the 2010 poll, the 2014 Alzheimer's Association poll explored other factors that influenced why respondents became caregivers for someone with AD or dementia. The results of the 2014 poll are shown in Fig. 16 and are similar to the results from the 2010 poll. In both polls, the factors most frequently cited has having "a lot" of importance were the desire to keep the care recipient in their home and the proximity of the caregiver to the care recipient. Women and men shared many values regarding the factors affecting their decisions to become caregivers. The factors with the largest differences were desire to keep the care recipient in their home, cost of in-home help, insurance coverage, and guilt.

In the 2014 Alzheimer's Association poll, informal caregivers were asked about the number of hours they spent each week performing caregiving duties. About half of all caregivers spent 20 hours or less each week performing those duties. However, there is a distinct group of caregivers who live with the care recipient and are "on duty" as caregivers 24 hours a day, 7 days a week. They account for about 23% of all caregivers. These full-time caregivers are much more likely to be women than men. Fig. 17 shows ratios of female to male caregivers in different categories according to the amount of time spent in caregiving activities each week. Among caregivers reporting less than 10 h/wk of caregiving activity, the ratio of women to men was 1.1:1, indicating that there were 1.1 female caregivers for every male caregiver in that category. As the amount of time dedicated to caregiving activity increased, the ratio of female to male caregivers increased in a marked and stepwise manner. Among caregivers spending 21 to more than 60 h/wk, there were more than 2 women for every man. Among caregivers who live with the care recipient and are on duty 24 hours a day, there were 2.5 women for every man.

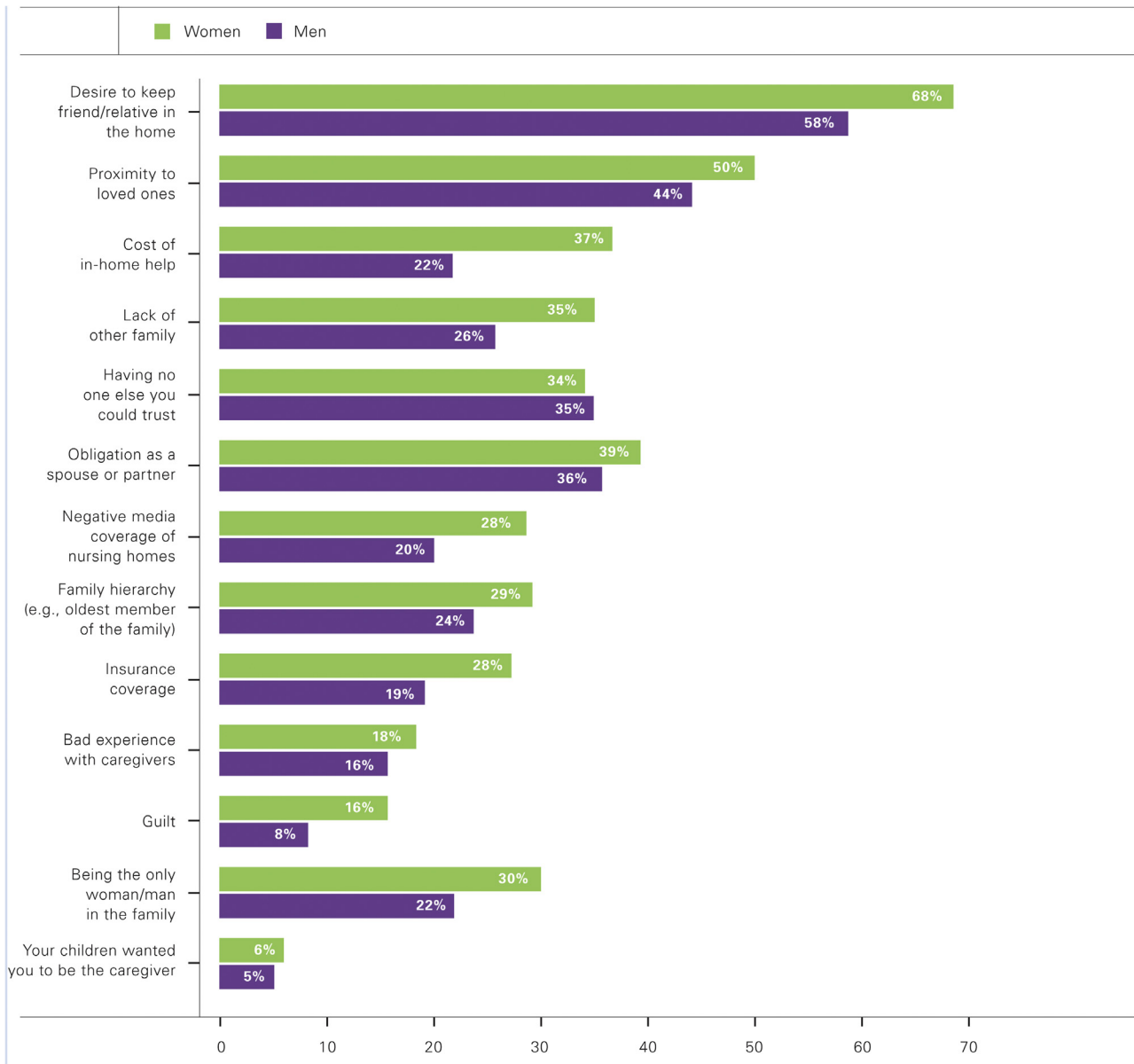


Fig. 16. Factors cited by caregivers as having “a lot” of influence on their decision to assume caregiving responsibilities. Created from data from the 2014 Alzheimer’s Association Women and Alzheimer’s Poll.^{A17}

These results of the 2014 poll are similar to results of a 2008 Canadian poll, a 2009 NAC/AARP poll, and the 2010 Alzheimer’s Association poll [178,300,307]. Considered together, these studies support the conclusion that women are substantially more likely than men to assume intensive time-consuming caregiving roles such as those in which the care recipient lives in the caregiver’s household and requires around-the-clock care.

7.3.1. Caregiver burden

As discussed in the Caregiving section (5.1.7.), providing informal care for someone with AD or dementia can be a

heavy burden, straining finances, employment, family relationships, and the caregiver’s own health and well-being. Some older studies have found that those strains are even more severe when the caregiver lives with the care recipient and is on duty 24 hours a day [312]. As shown in Fig. 18, the percentage of female caregivers reporting stresses and strains associated with caregiving are substantially higher among full-time caregivers than among those providing care for 20 h/wk or less.

Although full-time caregivers carried a much heavier burden than those providing care for less than 20 h/wk, the burden carried by the latter group was still quite heavy, with the potential to cause significant disruption in life. For example,

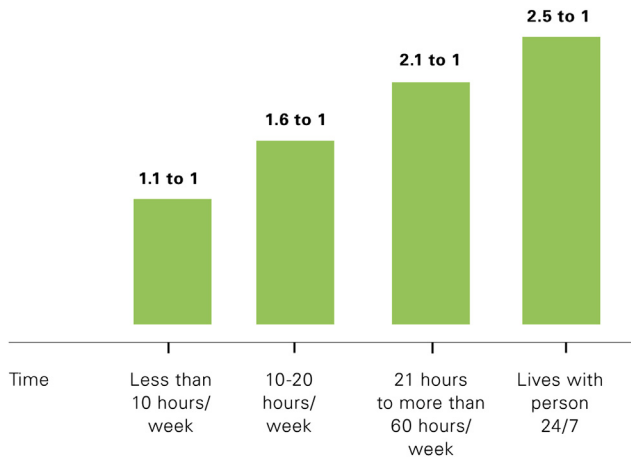


Fig. 17. Ratios of the number of female to male caregivers according to the amount of time spent caregiving each week. Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.^{A17}

among those providing care for less than 20 hours each week, 24% reported that it led to marital strain or was emotionally stressful. Nearly as many reported strains on finances and family relationships.

Studies have consistently found that the burden of caregiving is felt more strongly by women than men, and the 2014 poll reaffirms those findings.

- Forty-seven percent of women and 24% of men considered their caregiving role to be physically stressful (defined as 4 or 5 on a scale of 1–5, with 5 being “very stressful”).
- Sixty-two percent of women and 52% of men considered their caregiving role to be emotionally stressful.
- About 30% of caregivers reported feeling isolated in their caregiving roles, and this rate was similar among men and women. But among those who reported feeling isolated, women were much more likely than men to link isolation with feeling depressed (17% compared with 2%).
- Women were also more likely than men to report marital strain and spending less time with their spouse as consequences of caregiving.
- Among those caregivers who were employed when they started caregiving, women were more likely than men to experience several adverse consequences related to employment. The consequences showing the greatest difference between men and women are shown in Fig. 19. Nearly seven times as many women as men went from working full-time to working part-time while being a caregiver, and more than twice as many women as men reported having to give up work entirely or to have lost job benefits.

7.3.2. Sources of caregiving burden

Several explanations have been offered as to why the burden of caregiving is heavier on women than men, and it is likely that several factors contribute. One factor has already

been discussed: women are more likely than men to be caring for a loved one who lives in their household and to be on duty 24 hours a day.

Another contributing factor may be differences in caregiving duties assumed by women and men. In at least two previous polls of caregivers, female caregivers were substantially more likely than male caregivers to help the care recipient with personal aspects of care such as bathing, dressing, toileting, and managing incontinence [300,307]. At least one other study reached similar conclusions [313].

Another study of caregivers for elderly people found that women were more likely than men to perform caregiving tasks requiring a regular schedule, possibly adding to the burden of caregiving and competing with other responsibilities such as employment [307]. This aspect of caregiving may be related to responses to a question in the 2014 Alzheimer's Association poll asking caregivers assisting someone outside of their household how often they visited that person. Thirty-seven percent of female caregivers answered that they visited every day, whereas only 25% of male caregivers visited every day.

Another factor contributing to the burden of caregiving is the availability of other caregivers and sources of support. In the 2014 Alzheimer's Association poll, slightly fewer female caregivers (56%) than male caregivers (60%) reported that another person provided caregiving help to the care recipient. Conversely, 56% of female caregivers and 47% of male caregivers reported seeking additional caregiving resources. Other studies have also found that female caregivers received less caregiving support than male caregivers [307,314,315]. Even women caring for husbands with advanced AD or near the end of life received less support from family and friends than men caring for wives in similar situations [313,316].

Another difference between female and male caregivers found in the 2014 Alzheimer's Association poll, as well as the 2009 NAC/AARP poll, was that women, on average, had been providing informal caregiving for longer than men. In the 2014 poll, 35% of female caregivers and 26% of male caregivers had been providing care for more than 5 years. Among caregivers reporting that they had been providing care for less than a year (Fig. 20), the ratio of female to male caregivers was 1.2:1 (for every male caregiver, there were 1.2 female caregivers). As the duration of caregiving increased, the ratio of female to male caregivers also increased, to 1.5 (1–3 years), 1.7 (4–5 years), and 2.3 (more than 5 years). These results suggest that women are more likely than men to continue caregiving for prolonged durations.

Several studies have found that the burden of caregiving is dependent not only on the gender of the caregiver [310] but also on the gender of the care recipient [317]. Furthermore, caregiver burden is substantially higher when the care recipient exhibits behavioral problems [177,310,318]. A recent study comparing the experiences of men and women caring for spouses with dementia confirmed earlier studies

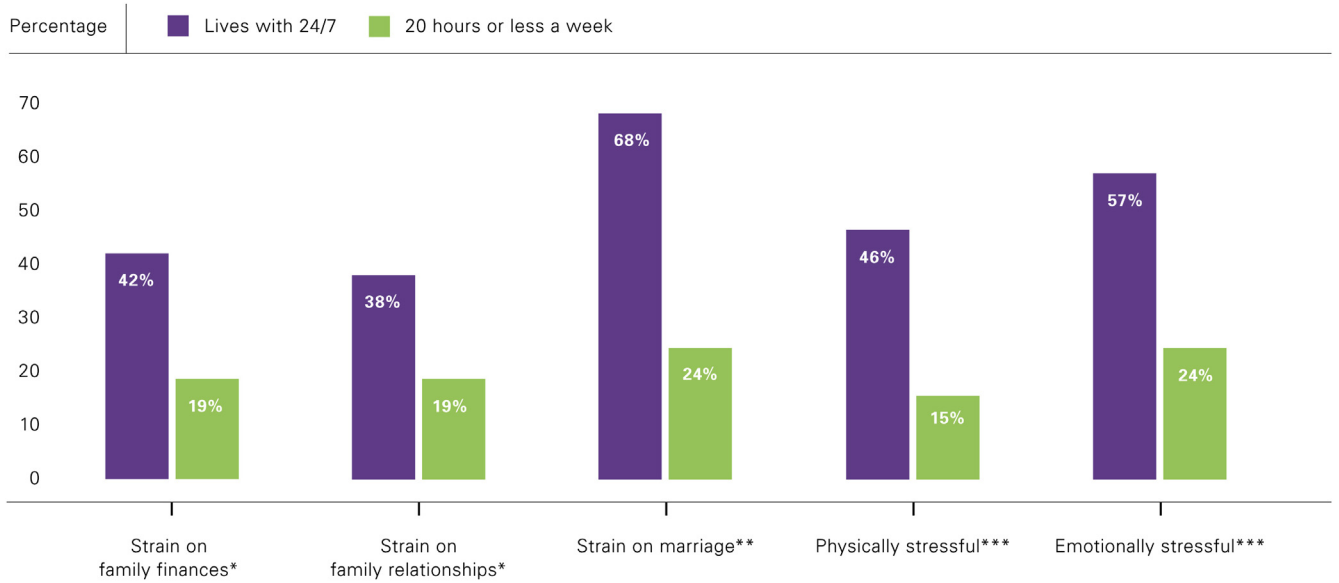


Fig. 18. Burdens of caregiving among women providing around-the-clock informal care or 20 hours or less of informal care for someone with AD or dementia. *A “great deal” or “good amount” of strain reported. **Responded “yes” when questioned whether caregiving was causing marital strain. ***Responded 5 (very stressful) when asked to rate stress on a scale of 1 to 5. Created from data from the 2014 Alzheimer’s Association Women and Alzheimer’s Poll.^{A17}

showing that men with dementia exhibited more severe behavioral problems than women with dementia [315]. As a consequence, women caring for a husband with dementia were more likely to experience a high burden because of behavioral problems than men caring for a wife. In the 2014 Alzheimer’s Association poll, 16% of caregivers were caring for a spouse, and the situation in which a wife was caring for a husband with dementia was about twice as common as a husband caring for a wife with dementia.

7.4. Paid personal care and home health aides

Personal care aides assist older people or others with ADLs, either in the care recipient’s home or in a care fa-

cility. Home health aides work in the care recipient’s home and may assist with health care and personal care such as bathing, dressing, and grooming. Personal care and home health aides provide valuable services for people with AD or dementia, allowing many to stay in their own homes. They also provide support and respite to family, friends, and other informal caregivers and perform services that some informal caregivers are unable to perform. For many people with AD or dementia, a personal care aide or home health aide is the only personal contact they experience on a daily basis.

According to the US Department of Labor, women account for about 85% of all personal care aides and home health aides [319]. Despite the fact that these occupations

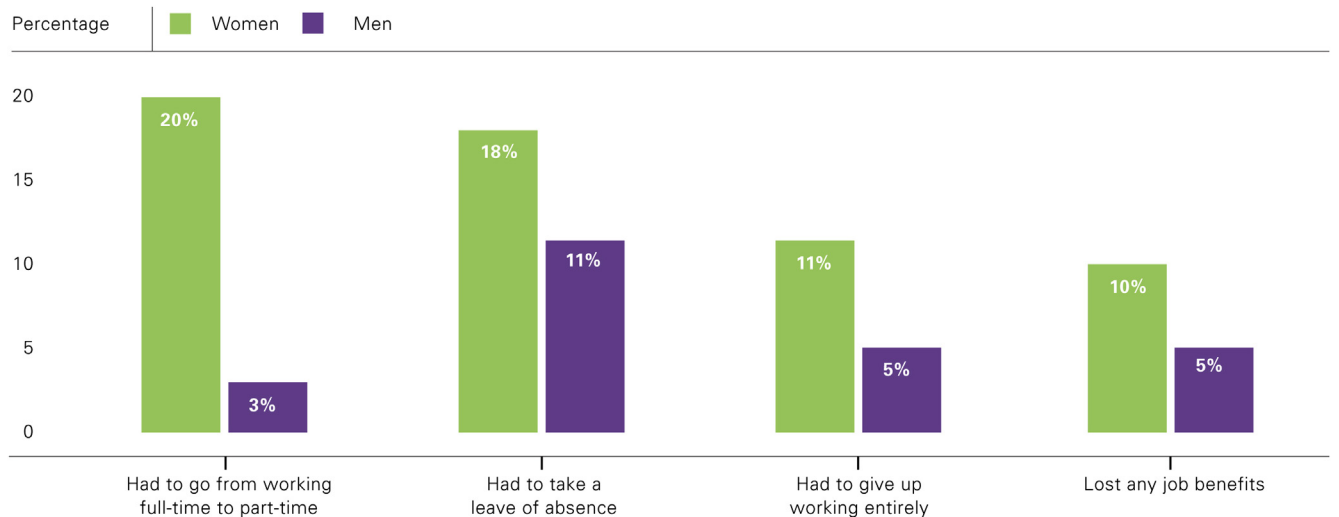


Fig. 19. Consequences of caregiving on aspects of employment among female and male caregivers. Created from data from the 2014 Alzheimer’s Association Women and Alzheimer’s Poll.^{A17}

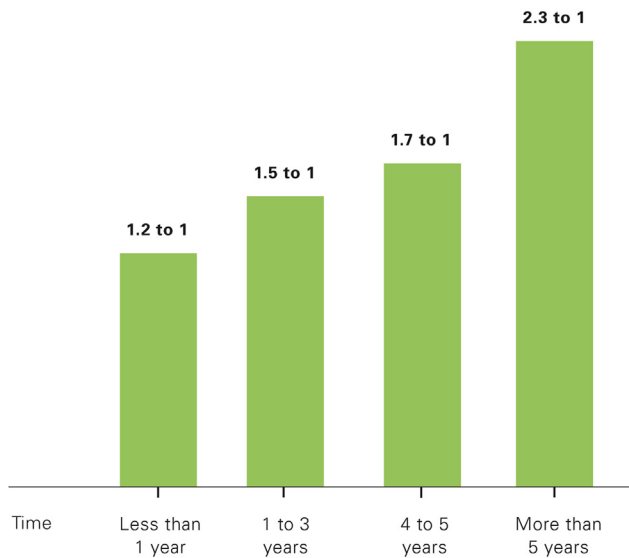


Fig. 20. Ratio of female to male caregivers according to duration of caregiving. Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.^{A17}

are among the fastest growing occupations with the highest demand for workers in the United States, the average wage for such workers was only slightly above \$10/h in 2012 [320,321]. Average annual wages for personal care aides and home health aides were below \$22,000 in 2012, only 51% of the national average of \$42,700 for all workers. Surprisingly, even these professions exhibit a gender pay gap; in 2012, the median weekly earnings of male personal care aides were about 13% higher than earnings of female personal care aides [319].

7.5. Conclusions

Results of the 2014 Alzheimer's Association Women and Alzheimer's Poll provide yet more evidence that AD takes a stronger toll on women than men. More women than men develop the disease, and women are more likely than men to be informal caregivers for someone with AD or dementia. Results from the 2014 poll also reveal that as caregiving responsibilities become more time-consuming and burdensome or extend for prolonged durations, women assume an even greater share of the caregiving burden. In addition, women are less likely than men to receive outside help for caregiving. The higher caregiving burden placed on women has many consequences, including higher emotional and physical stress, strained family relationships, and lost employment opportunities.

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End Notes

^{A1}*Number of Americans aged 65 years and older with AD for 2014 (prevalence of AD in 2014):* The number 5 million is from published prevalence estimates based on incidence data from the CHAP and population estimates from the 2010 US Census [114].

^{A2}*Proportion of Americans aged 65 years and older with AD:* The 11% is calculated by dividing the estimated number of people aged 65 years and older with AD (5 million) by the US population aged 65 years and older in 2014, as projected by the US Census Bureau (44.7 million) = 11%. Eleven percent is the same as one in nine.

^{A3}*Percentage of total AD cases by age groups:* Percentages for each age group are based on the estimated 200,000 under 65 years, plus the estimated numbers (in millions) for people aged 65 to 74 (0.8), 75 to 84 (2.3), and 85+ years (2.0) based on prevalence estimates for each age group and incidence data from the CHAP [114].

^{A4}*Differences between CHAP and ADAMS estimates for AD prevalence:* ADAMS estimates the prevalence of AD to be lower than does the CHAP, at 2.3 million Americans aged 71 years and older in 2002 [116]. (Note that CHAP estimates referred to in this end note are from an earlier study using 2000 US Census data [144]) At a 2009 conference convened by the NIA and the Alzheimer's Association, researchers determined that this discrepancy was mainly due to two differences in diagnostic criteria: (1) a diagnosis of dementia in ADAMS required impairments in daily functioning and (2) people determined to have vascular dementia in ADAMS were not also counted as having AD, even if they exhibited clinical symptoms of AD [117]. Because the more stringent threshold for dementia in ADAMS may miss people with mild AD and because clinicopathologic studies have shown that mixed dementia

due to both AD and vascular pathology in the brain is very common [4], the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of AD in the United States.

^{A5}*Number of women and men aged 65 years and older with AD in the United States:* The estimates for the number of US women (3.2 million) and men (1.8 million) aged 65 years and older with AD in 2013 is from unpublished data from the CHAP. For analytical methods, see Hebert et al. [114].

^{A6}*Prevalence of AD and other dementias in older whites, African-Americans, and Hispanics:* The statement that African-Americans are twice as likely and Hispanics 1.5 times as likely as whites to have Alzheimer's disease and other dementias is the conclusion of an expert review of a number of multiracial and multiethnic data sources, as reported in detail in the Special Report of *2010 Alzheimer's Disease Facts and Figures*.

^{A7}*Number of new cases of AD this year (incidence of AD in 2014):* The CHAP study estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020 [140]. The Alzheimer's Association calculated that the incidence of new cases in 2014 would be 461,400 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.4 (for the number of years from 2010 to 2014 divided by the number of years from 2010 to 2020), adding that result (14,800) to the Hebert et al. [140] estimate for 2010 (454,000) = 468,800. Rounded to the nearest thousand, this is 469,000 new cases of AD in 2014. The same technique for linear extrapolation from 2000 to 2010 projections was used to calculate the number of new cases in 2014 for ages 65 to 74, 75 to 84, and 85 years and older. The increases in number of new cases of AD from year to year appears to be mostly due to changes in demographics rather than changes in the underlying incidence rate for AD, which in a recent analysis was shown to remain stable over a decade [322]. The age group-specific AD incident rate is the number of new people with AD per population at risk (the total number of people in the age group in question). These incidence rates are expressed as number of new cases per 1000 people. The total number of people per age group for 2014 was obtained from population projections from the 2000 US Census (see 2000 National Population Projections: Summary Tables located at <http://www.census.gov/population/projections/files/natproj/summary/np-t3-d.pdf>).

^{A8}*Number of seconds for the development of a new case of AD:* Although AD does not present suddenly like stroke or heart attack, the rate at which new cases occur can be computed in a similar way. The 67 seconds number is calculated by dividing the number of seconds in a year (31,536,000) by the number of new cases in a year.^{A7} The number of seconds in a year (31,536,000) divided by 468,800 = 67.3 seconds, rounded to 67 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 (from Hebert et al [140]) = 32.8 seconds, rounded to 33 seconds.

^{A9}*Criteria for identifying subjects with AD and other dementias in the Framingham Study:* Starting in 1975, nearly 2800 people from the Framingham Study who were aged 65 years and free of dementia were followed for up to 29 years. Standard diagnostic criteria (DSM-IV criteria) were used to diagnose dementia in the Framingham Study, but, in addition, the subjects had to have at least "moderate" dementia according to the Framingham Study criteria, which is equivalent to a score of 1 or more on the Clinical Dementia Rating scale, and they had to have symptoms for 6 months or more. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose AD. The examination for dementia and AD is described in detail in Seshadri et al. [123].

^{A10}*State-by-state prevalence of AD:* These state-by-state prevalence numbers are based on an unpublished analysis of incidence data from the CHAP, projected to each state's population, with adjustments for state-specific age, gender, years of education, race, and mortality provided to the Alzheimer's Association in 2013 by a team led by Liesi Hebert, Sc.D., from Rush University Institute on Healthy Aging.

^{A11}*Projected number of people with AD:* This comes from the CHAP study [114]. Other projections are somewhat lower (e.g., Brookmeyer et al [323]) because they relied on more conservative methods for counting people who currently have AD.^{A4} Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with AD over the coming decades.

^{A12}*Projected number of people aged 65 years and older with AD in 2025:* The number 7.1 million is based on a linear extrapolation from the projections of prevalence of AD for the years 2020 (5.8 million) and 2030 (8.4 million) from CHAP [114].

^{A13}*Previous high and low projections of AD prevalence in 2050:* High and low prevalence projections for 2050 from the U.S. Census were not available for the most recent analysis of CHAP data. The previous high and low projections indicate that the projected number of Americans with AD in 2050 aged 65 years and older will range from 11 to 16 million [144].

^{A14}*Deaths with AD:* The estimates for the number of Americans dying with AD, 600,000 in 2010 and 700,000 in 2014, come from Weuve et al [153]. Please note that the figures reported in *2013 Alzheimer's Disease Facts and Figures* were erroneously too low due to a summing error.

^{A15}*Annual mortality rate due to AD by state:* Unadjusted death rates are presented rather than age-adjusted death rates to provide a clearer depiction of the true burden of mortality for each state. States such as Florida with larger populations of older people will have a larger burden of mortality due to AD.

^{A16}*Number of family and other unpaid caregivers of people with AD and other dementias:* To calculate this number, the Alzheimer's Association started with data from the BRFSS. In 2009, the BRFSS survey asked respondents

aged 18 years and older whether they had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness, or disability. To determine the number of family and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the CDC, Healthy Aging Program, unpublished data) to the number of people aged 18 years and older nationally and in each state from the US Census Bureau report for July 2013. Available at www.census.gov/popest/data/datasets.html. Accessed on January 6, 2014. To calculate the proportion of family and other unpaid caregivers who provide care for a person with AD or another dementia, the Alzheimer's Association used data from the results of a national telephone survey conducted in 2009 for the NAC/AARP [184]. The NAC/AARP survey asked respondents aged 18 years and older whether they were providing unpaid care for a relative or friend aged 18 years or older or had provided such care during the past 12 months. Respondents who answered affirmatively were then asked about the health problems of the person for whom they provided care. In response, 26% of caregivers said that (1) AD or another dementia was the main problem of the person for whom they provided care or (2) the person had AD or other mental confusion in addition to their main problem. The 26% figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 15,553,389 AD and dementia caregivers.

^{A17}*The 2014 Alzheimer's Association Women and Alzheimer's Poll*: This poll was conducted by telephone between January 9 and 29, 2014. Target respondents were community-dwelling adults aged 18 years and older living in the United States. Telephone numbers were chosen randomly in separate samples of landline and cell phone exchanges from across the nation. Respondents were contacted by either landline or cell phone. When a household was contacted by landline, one adult from the household was chosen at random to respond to survey questions. The survey was designed to contain "oversamples" of Hispanics, Asian-Americans, and households known to have an adult with AD. Respondents included 1746 women and 1356 men (total of 3102 respondents); 2278 respondents identified themselves as white non-Hispanic; 469 as of Hispanic Latino or Spanish origin; 413 as black or African-American; 131 as Asian or Asian-American; and 293 as another racial or ethnic group. These cases were weighted to account for differential probabilities of selection and overlap in the landline and cell phone sampling frames. The sample was adjusted to match census demographic benchmarks for gender, age, education, race/ethnicity, region, and telephone service. The resulting interviews (including the oversamples) comprise a probability-based, nationally representative sample of US adults. The margin of sampling error is approximately ± 2 percentage points at the 95% confidence interval. For sub-groups, the margin of error will be higher.

^{A18}*Number of hours of unpaid care*: To calculate this number, the Alzheimer's Association used data from a follow-up analysis of results from the 2009 NAC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, November 11, 2009). These data show that caregivers of people with AD and other dementias provided an average of 21.9 hours a week of care, or 1139 h/yr. The number of family and other unpaid caregivers (15,553,389)^{A16} was multiplied by the average hours of care per year, which total 17,689,423,440 hours of care.

^{A19}*Value of unpaid caregiving*: To calculate this number, the Alzheimer's Association used the method of Amo et al. [324]. This method uses the average of the federal minimum hourly wage (\$7.25 in 2013) and the mean hourly wage of home health aides (\$17.65 in July 2013) [325]. The average is \$12.45, which was multiplied by the number of hours of unpaid care (17,689,423,440)^{A18} to derive the total value of unpaid care (\$220,233,321,824).

^{A20}*Higher health care costs of AD caregivers*: This figure is based on a methodology originally developed by Brent Fulton, Ph.D., for *The Shriver Report: A Woman's Nation Takes on Alzheimer's*. A survey of 17,000 employees of a multinational firm based in the United States estimated that caregivers' health-care costs were 8% higher than noncaregivers' [326]. To determine the dollar amount represented by that 8% figure nationally and in each state, the 8% figure and the proportion of caregivers from the 2009 BRFSS^{A16} were used to weight each state's caregiver and noncaregiver per capita personal health care spending in 2009, inflated to 2013 dollars [327]. The dollar amount difference between the weighted per capita personal health care spending of caregivers and noncaregivers in each state (reflecting the 8% higher costs for caregivers) produced the average additional health-care costs for caregivers in each state. Nationally, this translated into an average of \$601. The amount of the additional cost in each state, which varied by state from a low of \$443 in Utah to a high of \$916 in the District of Columbia, was multiplied by the total number of unpaid AD and dementia caregivers in that state^{A16} to arrive at that state's total additional health-care costs of AD and other dementia caregivers as a result of being a caregiver. The combined total for all states was \$9,331,554,412. Fulton concluded that this is "likely to be a conservative estimate because caregiving for people with Alzheimer's is more stressful than caregiving for most people who don't have the disease" [300].

^{A21}*Lewin model on AD and dementia and costs*: These numbers come from a model created for the Alzheimer's Association by The Lewin Group, modified to reflect the more recent estimates and projections of the prevalence of AD [114]. The model estimates total payments for community-based health-care services using data from the Medicare Current Beneficiary Survey (MCBS). The model was constructed based on 2004 MCBS data; those data have been replaced with the more recent 2008 MCBS data.^{A23} Nursing

facility care costs in the model are based on The Lewin Group's Long-Term Care Financing Model. More information on the model, its long-term projections, and its methodology is available at www.alz.org/trajjectory.

^{A22}All cost estimates were inflated to year 2013 dollars using the Consumer Price Index (CPI): All cost estimates were inflated using the seasonally adjusted average prices for medical care services from all urban consumers. The relevant item within medical care services was used for each cost element. For example, the medical care item within the CPI was used to inflate total health-care payments; the hospital services item within the CPI was used to inflate hospital payments; and the nursing home and adult day services item within the CPI was used to inflate nursing home payments.

^{A23}MCBS report: These data come from an analysis of findings from the 2008 MCBS. The analysis was conducted for the Alzheimer's Association by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research (155). The MCBS, a continuous survey of a nationally representative sample of about 16,000 Medicare beneficiaries, is linked to Medicare part B claims. The survey is supported by the US Centers for Medicare and Medicaid Services. For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility such as an assisted living residence, a retirement home, or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a nurse who is familiar with survey participants and their medical record. Data from the MCBS analysis that are included in *2013 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries aged 65 years and older. For this MCBS analysis, people with dementia are defined as:

- Community-dwelling survey participants who answered yes to the MCBS question, "Has a doctor ever told you that you had Alzheimer's disease or dementia?" Proxy responses to this question were accepted.
- Survey participants who were living in a nursing home or other residential care facility and had a diagnosis of AD or dementia in their medical record.
- Survey participants who had at least one Medicare claim with a diagnostic code for AD and other dementias in 2008: The claim could be for any Medicare service, including hospital, skilled nursing facility, outpatient medical care, home health care, hospice or physician, or other health-care provider visit. The diagnostic codes used to identify survey participants with AD and other dementias are 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 331.82, 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 291.2, 294.0, 294.1, 294.10, and 294.11.

Costs from the MCBS analysis are based on responses from 2008 and reported in 2013 dollars.

^{A24}*Differences in estimated costs reported by Hurd et al.:* Hurd et al. [173] estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. 2014 Alzheimer's Disease Facts and Figures estimated per-person costs using data from the Medicare Current Beneficiary Survey (MCBS). One reason that the per-person costs estimated by Hurd et al. are lower than those reported in Facts and Figures is that ADAMS, with its diagnostic evaluations of everyone in the study, is more likely than MCBS to have identified individuals with less severe or undiagnosed Alzheimer's. By contrast, the individuals with Alzheimer's registered by MCBS are likely to be those with more severe, and therefore more costly, illness. A second reason is that Hurd et al.'s estimated costs reflect an effort to isolate the incremental costs associated with Alzheimer's disease and other dementias (those costs attributed only to dementia), while the per-person costs in Facts and Figures incorporate all costs of caring for people with the disease (regardless of whether the expenditure was related to dementia or a coexisting condition).

^{A25}*YouGov survey:* Sample targets for this August 2013 survey by YouGov were set based on demographic characteristics of adults aged 60 years or older from the 2010 American Community Survey. After proximity matching, the matched set of survey respondents were then weighted to known characteristics in the United States using propensity score weighting. The final weights were then poststratified by demographic characteristics to be representative of the general population aged 60 years or older. The YouGov survey was conducted with financial support from the Alzheimer's Association; data analysis was supported by the CDC.

^{A26}*Number of respondents who identified themselves as caregivers for someone with AD or dementia:* The 2014 Alzheimer's Association Women and Alzheimer's Poll^{A17} included 205 caregivers of people with AD or dementia. This was supplemented with 310 interviews from a listed sample of caregivers to people with AD. For this survey, a caregiver was defined as an adult older than age 18 years who, in the past 12 months, has provided unpaid care to a relative or friend aged 50 years or older with AD or dementia. Furthermore, caregivers had to report that they provided the majority of care or equally shared caregiving responsibilities with another person. Unfortunately, there are no official demographic benchmarks for the AD caregiver population. As a substitute, benchmark estimates for this population were derived from the characteristics of the caregivers reached in the landline and cell phone samples, which are probability based and nationally representative. The weight for the caregiver sample balances all caregiver cases to the weighted estimates for gender and race/ethnicity derived from the landline and cell phone caregivers. This weighting adjusted for the fact that the caregivers reached through the list sample were somewhat more likely to be female and white than those reached in the probability-based component of the study.