Alzheimer's Association Report

2019 Alzheimer's disease facts and figures

Alzheimer's Association*

Abstract

This article describes the public health impact of Alzheimer's disease (AD), including incidence and prevalence, mortality and morbidity, use and costs of care, and the overall impact on caregivers and society. The Special Report examines the use of brief cognitive assessments by primary care physicians as a tool for improving early detection of dementia. An estimated 5.8 million Americans have Alzheimer's dementia. By mid-century, the number of people living with Alzheimer's dementia in the United States may grow to 13.8 million, fueled in large part by the aging baby boom generation. In 2017, official death certificates recorded 121,404 deaths from AD, making AD the sixth leading cause of death in the United States and the fifth leading cause of death among Americans age ≥65 years. Between 2000 and 2017, deaths resulting from stroke, heart disease, and prostate cancer decreased, whereas reported deaths from AD increased 145%. In 2018, more than 16 million family members and other unpaid caregivers provided an estimated 18.5 billion hours of care to people with Alzheimer's or other dementias. This care is valued at nearly $234 billion, but its costs extend to family caregivers' increased risk for emotional distress and negative mental and physical health outcomes. Average per-person Medicare payments for services to beneficiaries age ≥65 years with Alzheimer's or other dementias are more than three times as great as payments for beneficiaries without these conditions. Total payments in 2019 for health care, long-term care and hospice services for people age ≥65 years with dementia are estimated to be $290 billion. Early detection of Alzheimer's offers numerous medical, emotional and financial benefits—benefits that accrue to affected individuals and their families as well as to society at large. Alzheimer's Association surveys regarding brief cognitive assessments for detection of dementia found that while a large majority of seniors and primary care physicians say the assessments are important, only half of seniors have received an assessment, and only 16 percent of seniors receive regular cognitive assessments. Many educational opportunities exist to facilitate increased use of brief cognitive assessments in the primary care setting.

1. About this report

2019 Alzheimer's Disease Facts and Figures is a statistical resource for U.S. data related to Alzheimer's disease, the most common cause of dementia. Background and context for interpretation of the data are contained in the overview. Additional sections address prevalence, mortality and morbidity, caregiving and use and costs of health care, long-term care and hospice. A Special Report discusses Alzheimer's detection in the primary care setting.

1.1. Specific information in this report

Specific information in this year's *Alzheimer's Disease Facts and Figures* includes:
- Brain changes that occur with Alzheimer's disease.
- Risk factors for Alzheimer's disease.
- Number of Americans with Alzheimer's dementia nationally and for each state.
- Lifetime risk for developing Alzheimer's dementia.
- Proportion of women and men with Alzheimer's and other dementias.

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- Number of deaths due to Alzheimer's disease nationally and for each state, and death rates by age.
- The impact of caregiving on caregivers.
- Number of family caregivers, hours of care provided, and economic value of unpaid care nationally and for each state.
- National cost of care for individuals with Alzheimer's or other dementias, including costs paid by Medicare and Medicaid and costs paid out of pocket.
- Medicare payments for people with dementia compared with people without dementia.
- Attitudes toward cognitive assessment among seniors and primary care physicians.
- Awareness and use of the Medicare Annual Wellness Visit among seniors and primary care physicians.

The Appendices detail sources and methods used to derive statistics in this report.

When possible, specific information about Alzheimer's is provided; in other cases, the reference may be a more general one of "Alzheimer's or other dementias."

2. Overview of Alzheimer's disease

Alzheimer's disease is a type of brain disease, just as coronary artery disease is a type of heart disease. It is also a degenerative disease, meaning that it becomes worse with time. Alzheimer's disease is thought to begin 20 years or more before symptoms arise [1–6], with small changes in the brain that are unnoticeable to the person affected. Only after years of brain changes do individuals experience noticeable symptoms, such as memory loss and language problems. Symptoms occur because nerve cells (neurons) in parts of the brain involved in thinking, learning and memory (cognitive function) have been damaged or destroyed. Individuals typically live with Alzheimer's symptoms for years. Over time, symptoms tend to increase and start interfering with individuals' ability to perform everyday activities. At this point, the individual is said to have dementia due to Alzheimer's disease, or Alzheimer's dementia.

As the disease progresses, neurons in other parts of the brain are damaged or destroyed. Activities that used to be core to the individual's identity, such as planning family events or participating in sports, may no longer be possible. Eventually, neurons in parts of the brain that enable a person to carry out basic bodily functions, such as walking and swallowing, are affected. People in the final stages of Alzheimer's disease are bed-bound and require around-the-clock care. Alzheimer's disease is ultimately fatal.

2.1. Brain changes associated with Alzheimer's disease

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 neuronal circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements and skills.

The accumulation of the protein fragment beta-amyloid (called beta-amyloid plaques) *outside* neurons and the accumulation of an abnormal form of the protein tau (called tau tangles) *inside* neurons are two of several brain changes associated with Alzheimer's. Beta-amyloid plaques may contribute to cell death by interfering with neuron-to-neuron communication at synapses, while tau tangles block the transport of nutrients and other essential molecules inside neurons. As the amount of beta-amyloid increases, a tipping point is reached at which abnormal tau spreads throughout the brain [7].

Other brain changes include inflammation and atrophy. The presence of toxic beta-amyloid and tau proteins activates immune system cells in the brain called microglia. Microglia try to clear the toxic proteins as well as widespread debris from dead and dying cells. Chronic inflammation is believed to set in when the microglia can't keep up with all that needs to be cleared. Atrophy, or shrinkage, of the brain occurs because of cell loss. Normal brain function is further compromised by the decreased ability of the brain to metabolize glucose, its main fuel.

A recent study [5] of people with rare genetic mutations that cause Alzheimer's found that levels of beta-amyloid in the brain were significantly increased starting 22 years before symptoms were expected to develop (individuals with these genetic mutations usually develop symptoms at the same, or nearly the same, age as their parent with Alzheimer's). Glucose metabolism began to decrease 18 years before expected symptom onset, and brain atrophy began 13 years before expected symptom onset.

When the early changes of Alzheimer's occur, the brain initially compensates for them, enabling individuals to continue to function normally. As the damage to nerve cells continues, the brain can no longer compensate for the changes, and individuals show subtle decline in cognitive function. As time passes, plaques and tangles appear not only in areas of the brain involved in cognitive function, but also in other areas of the brain [8]. Later, damage to nerve cells is so significant that individuals show obvious cognitive decline, including symptoms such as memory loss or confusion as to time or place, as well as behavioral symptoms such as depression, personality changes and loss of interest in activities they used to enjoy. Later still, basic bodily functions such as swallowing are impaired.

2.2. Stages of Alzheimer's disease

Current research identifies three stages of Alzheimer's disease: preclinical Alzheimer's disease, mild cognitive

impairment (MCI) due to Alzheimer's disease, and dementia due to Alzheimer's disease [9–12]. In the last two stages, symptoms are present, but to varying degrees.

2.2.1. Preclinical Alzheimer's disease

In this stage, which is still under investigation, individuals have measurable changes in the brain, cerebrospinal fluid and blood that indicate the earliest signs of Alzheimer's disease (biomarkers), but they have not yet developed symptoms such as memory loss. While research settings have the tools and expertise to identify some of the early brain changes of Alzheimer's, additional research is needed to fine-tune the tools' accuracy before they become available for widespread use in hospitals, doctor's offices and other clinical settings. It's important to note that not all individuals with an Alzheimer's biomarker go on to develop MCI or dementia [13,14], although many do.

2.2.2. MCI due to Alzheimer's disease

People with MCI due to Alzheimer's disease have biomarker evidence of an Alzheimer's-related brain change (for example, elevated levels of beta-amyloid) and show cognitive decline greater than expected for their age, but this decline does not significantly interfere with everyday activities [15]. In MCI, changes in thinking abilities may be noticeable to family members and friends, but may not be noticeable to others.

Approximately 15 percent to 20 percent of people age 65 or older have MCI [15] from any cause. People with MCI, especially MCI involving memory problems, are more likely to develop Alzheimer's or another dementia than people without MCI [16,17]. A recent analysis found that after 2 years' follow-up, 15 percent of individuals older than 65 with MCI had developed dementia [18]. A systematic review, in which data from multiple studies are pooled and summarized, found that 32 percent of individuals with MCI developed Alzheimer's dementia within 5 years' follow-up [19]. In addition, a meta-analysis, a method of analysis in which results of multiple studies are examined, found that among individuals with MCI who were tracked for 5 years or longer, 38 percent developed dementia [17]. Identifying which individuals with MCI are more likely to develop Alzheimer's or other dementias is a major goal of current research.

Not all cases of MCI are due to Alzheimer's. In some individuals, MCI reverts to normal cognition or remains stable. In other cases, such as when a medication inadvertently causes cognitive changes, MCI is mistakenly diagnosed. Individuals also can be mistakenly diagnosed with MCI or dementia due to Alzheimer's because the differences between typical age-related cognitive changes and the cognitive changes of Alzheimer's can be subtle (see Table 1). It is important that people experiencing cognitive changes seek medical help to determine if the changes are normal for one's age, reversible or a symptom of Alzheimer's or another dementia.

In recent years, researchers have begun to recognize the importance of older adults reporting their own experiences of memory and thinking problems, without (or before) a formal examination by a doctor. This personal experience of problems with cognitive function is called subjective cognitive decline. One reason researchers are interested in subjective cognitive decline is that in some instances it may indicate an early stage of Alzheimer's disease. Many (but not all) people with subjective cognitive decline go on to develop MCI and dementia (see Prevalence section).

2.2.3. Dementia due to Alzheimer's disease

Dementia due to Alzheimer's disease is characterized by noticeable memory, thinking and behavioral symptoms that impair a person's ability to function in daily life, along with evidence of an Alzheimer's-related brain change.

Individuals with Alzheimer's dementia experience multiple symptoms that change over a period of years. These symptoms reflect the degree of damage to nerve cells in different parts of the brain. The pace at which symptoms of dementia advance from mild to moderate to severe differs from person to person.

In the mild stage of Alzheimer's dementia, most people are able to function independently in many areas but are likely to require assistance with some activities to maximize independence and remain safe. They may still be able to drive, work and participate in favorite activities.

In the moderate stage of Alzheimer's dementia, which is often the longest stage, individuals may have difficulties communicating and performing routine tasks, including activities of daily living (such as bathing and dressing); become incontinent at times; and start having personality and behavioral changes, including suspiciousness and agitation. In the severe stage of Alzheimer's dementia, individuals need help with activities of daily living and are likely to require around-the-clock care.

The effects of Alzheimer's disease on an individual's physical health become especially apparent in the severe stage of Alzheimer's dementia. Because of damage to areas of the brain involved in movement, individuals become bed-bound. Being bed-bound makes them vulnerable to conditions including blood clots, skin infections and sepsis, which triggers body-wide inflammation that can result in organ failure. Damage to areas of the brain that control swallowing makes it difficult to eat and drink. This can result in individuals swallowing food into the trachea (windpipe) instead of the esophagus (food pipe). Food particles may be deposited in the lungs and cause lung infection. This type of infection is called aspiration pneumonia, and it is a contributing cause of death among many individuals with Alzheimer's (see Mortality and Morbidity section).

It's important to note that some individuals have dementia-like symptoms without the progressive brain changes of Alzheimer's or other degenerative brain diseases. Common causes of dementia-like symptoms are depression, untreated sleep apnea, delirium, side effects of medications,

Table 1
Signs of Alzheimer's or other dementias compared with typical age-related changes*

Signs of Alzheimer's or other dementias	Typical age-related changes
Memory loss that disrupts daily life: One of the most common signs of Alzheimer's is memory loss, especially forgetting recently learned information. Others include forgetting important dates or events, asking for the same information over and over, and increasingly needing to rely on memory aids (for example, reminder notes or electronic devices) or family members for things that used to be handled on one's own.	Sometimes forgetting names or appointments, but remembering them later.
Challenges in planning or solving problems: Some people experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe, keeping track of monthly bills or counting change. They may have difficulty concentrating and take much longer to do things than they did before.	Making occasional errors when balancing a checkbook.
Difficulty completing familiar tasks at home, at work or at leisure: People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.	Occasionally needing help to use the settings on a microwave or record a television show.
Confusion with time or place: People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they forget where they are or how they got there.	Getting confused about the day of the week but figuring it out later.
Trouble understanding visual images and spatial relationships: For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast, which may cause problems with driving.	Vision changes related to cataracts, glaucoma or age-related macular degeneration.
New problems with words in speaking or writing: People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a watch a "hand clock").	Sometimes having trouble finding the right word.
Misplacing things and losing the ability to retrace steps: People with Alzheimer's may put things in unusual places, and lose things and be unable to go back over their steps to find them again. Sometimes, they accuse others of stealing. This may occur more frequently over time.	Misplacing things from time to time and retracing steps to find them.
Decreased or poor judgment: People with Alzheimer's may experience changes in judgment or decisionmaking. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.	Making a bad decision once in a while.
Withdrawal from work or social activities: People with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.	Sometimes feeling weary of work, family and social obligations.
Changes in mood and personality: The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zones.	Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

*For more information about the symptoms of Alzheimer's, visit alz.org/10signs.

thyroid problems, certain vitamin deficiencies and excessive alcohol consumption. Unlike Alzheimer's and other dementias, these conditions often may be reversed with treatment.

2.3. Biomarkers: Tools for diagnosis and advancing research

A biomarker is a biological factor that can be measured to indicate the presence or absence of a disease, the risk of developing a disease or disease progression. For example, high blood glucose level is a biomarker of diabetes, and high blood pressure is a biomarker of heart disease risk. Among several factors being studied as biomarkers for Alzheimer's are the amounts of beta-amyloid and abnormal tau in the brain as shown on positron emission tomography (PET) imaging, levels of certain proteins in fluid (for example, levels of beta-amyloid and tau in cerebrospinal fluid and levels of particular groups of proteins in blood), and level of glucose metabolism in the brain as shown on PET imaging using the radiotracer fluorodeoxyglucose.

Finding a simple and inexpensive test, such as a blood test, to diagnose Alzheimer's would be ideal for patients, physicians and scientists. Research is underway to develop such a test.

2.4. Diagnosis of dementia due to Alzheimer's disease

There is no single test for dementia due to Alzheimer's disease. Instead, physicians (often with the help of specialists such as neurologists, geriatricians and geriatric psychiatrists) use a variety of approaches and tools to help make a diagnosis. They include the following:

- Obtaining a medical and family history from the individual, including psychiatric history and history of cognitive and behavioral changes.
- Asking a family member to provide input about changes in thinking skills and behavior.
- Conducting cognitive tests and physical and neurologic examinations.

Table 2
Common causes of dementia and associated characteristics

Cause	Characteristics
Alzheimer's disease	Alzheimer's disease is the most common cause of dementia, accounting for an estimated 60 to 80 percent of cases. Recent large autopsy studies show that about half of individuals with Alzheimer's dementia have Alzheimer's disease brain changes (pathology) as well as the brain changes of one or more other causes of dementia, such as cerebrovascular disease or Lewy body disease. This is called mixed pathology, and if recognized during life is called mixed dementia.
	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, behavioral changes and, ultimately, difficulty speaking, swallowing and walking.
	The hallmark pathologies of Alzheimer's disease are the accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are accompanied by the damage and death of neurons. Alzheimer's is a slowly progressive brain disease that begins many years before symptoms emerge.
Cerebrovascular disease	Cerebrovascular disease refers to the process by which blood vessels in the brain are damaged and brain tissue is injured. People with dementia whose brains show evidence of cerebrovascular disease are said to have vascular dementia. About 5 percent to 10 percent of individuals with dementia show evidence of vascular dementia alone [27,28]. However, it is more common as a mixed pathology, with most cases showing the brain changes of cerebrovascular disease and Alzheimer's disease.
	Impaired judgment or impaired 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 Alzheimer's. In addition to changes in cognitive function, people with vascular dementia can have difficulty with motor function, especially slow gait and poor balance.
	Vascular dementia occurs most commonly from blood vessel blockage or damage leading to areas of dead tissue 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.
Lewy body disease	Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia (called dementia with Lewy bodies or DLB) can result. People with DLB have some of the symptoms common in Alzheimer's, 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.
	About 5 to 10 percent of individuals with dementia show evidence of DLB alone, but most people with DLB also have Alzheimer's disease pathology.
Mixed pathologies	When an individual shows the brain changes of more than one cause of dementia, mixed pathologies are considered the cause. When these pathologies result in dementia symptoms during life, the person is said to have mixed dementia.
	Studies suggest that mixed dementia is more common than previously recognized, with about 50 percent of people with dementia who were studied at Alzheimer's Disease Centers having pathologic evidence of more than one cause of dementia [28]. In community-based studies, the percentage of mixed dementia cases is considerably higher [27]. The likelihood of having mixed dementia increases with age and is highest in the oldest-old (people age 85 or older) [29,30].
Frontotemporal lobar degeneration (FTLD)	FTLD includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy.
	Typical early symptoms include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of disease.
	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 abnormal protein inclusions (usually tau protein or the transactive response DNA-binding protein).
	The symptoms of FTLD may occur in those age 65 years and older, similar to Alzheimer's, but most people with FTLD develop symptoms at a younger age. About 60 percent of people with FTLD are ages 45 to 60. FTLD accounts for less than 10 percent of dementia cases [31].
Parkinson's disease (PD)	Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD.
	In PD, alpha-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 [32,33].
	As PD progresses, it often results in dementia secondary to the accumulation of alpha-synuclein in the cortex (similar to DLB) or the accumulation of beta-amyloid clumps and tau tangles (similar to Alzheimer's).

- Having the individual undergo blood tests and brain imaging to rule out other potential causes of dementia symptoms, such as a tumor or certain vitamin deficiencies.
- In some circumstances, using brain imaging tools to find out if the individual has high levels of beta-amyloid, a hallmark of Alzheimer's; normal levels would suggest Alzheimer's is not the cause of dementia.

Although physicians can almost always determine if a person has dementia, it may be difficult to identify the exact cause. Alzheimer's disease is the most common cause of dementia, but there are other causes as well [20,21]. As shown in Table 2, different causes of dementia are associated with distinct symptom patterns and brain abnormalities. Many people with dementia have brain changes associated with more

than one cause of dementia [22-27]. This is called mixed dementia. Some studies [27,28] report that the majority of people with the brain changes of Alzheimer's also had the brain changes of a second cause of dementia on autopsy. It is important that individuals receive an accurate diagnosis to ensure they receive treatment and follow-up care appropriate to their specific form of dementia.

2.5. Treatment of Alzheimer's dementia

2.5.1. Pharmacologic treatment

None of the pharmacologic treatments (medications) available today for Alzheimer's dementia slow or stop the damage and destruction of neurons that cause Alzheimer's symptoms and make the disease fatal. The U.S. Food and Drug Administration (FDA) has approved six drugs for the treatment of Alzheimer's—rivastigmine, galantamine, donepezil, memantine, memantine combined with donepezil, and tacrine (tacrine is now discontinued in the United States). With the exception of memantine, these drugs temporarily improve symptoms by increasing the amount of chemicals called neurotransmitters in the brain. Memantine blocks certain receptors in the brain from excess stimulation that can damage nerve cells. The effectiveness of these drugs varies from person to person and is limited in duration.

Many factors contribute to the difficulty of developing effective treatments for Alzheimer's. These factors include the slow pace of recruiting participants to clinical studies, gaps in knowledge about the precise molecular changes and biological processes in the brain that cause Alzheimer's disease, and the relatively long time needed to observe whether an investigational treatment affects disease progression.

Many researchers believe that future treatments to slow or stop the progression of Alzheimer's disease and preserve brain function will be most effective when administered early in the disease process, either at the MCI due to Alzheimer's or preclinical stage. Biomarker tests will be essential to identify which individuals are in these early stages and should receive treatments when they are available. Biomarkers also will be critical for monitoring the effects of treatment. Already, biomarker tests are playing an important role in drug development because they enable researchers to recruit into clinical trials only those individuals with the Alzheimer's brain changes that the drug has been designed to affect [34]. The most effective biomarker test or combination of tests may differ depending on the stage of the disease and other factors [35].

2.5.2. Non-pharmacologic therapy

Non-pharmacologic therapies are those that do not involve medication. They have been studied in people with Alzheimer's dementia and in cognitively normal individuals who would like to prevent dementia or slow cognitive decline.

2.5.2.1. People with Alzheimer's dementia

Non-pharmacologic therapies are often used in people with Alzheimer's dementia with the goal of maintaining or improving cognitive function, the ability to perform activities of daily living or overall quality of life. They also may be used with the goal of reducing behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression. Examples include computerized memory training, listening to favorite music as a way to stir recall, and incorporating special lighting to lessen sleep disorders. As with current pharmacologic therapies, non-pharmacologic therapies do not slow or stop the damage and destruction of neurons that cause Alzheimer's symptoms and make the disease fatal.

A meta-analysis [36] and systematic reviews [37,38] of non-pharmacologic therapies tested in randomized controlled trials (in which participants are randomly assigned to either receive or not receive a therapy, and the results for the two groups are compared) have found that some are beneficial to people with Alzheimer's dementia. Among these are exercise [36,37] and cognitive stimulation [38]. Specifically, the meta-analysis found that aerobic exercise and a combination of aerobic and non-aerobic exercise had positive effects on cognitive function, while a systematic review [37] found that exercise has a positive effect on overall cognitive function and may slow the rate of cognitive decline in people with Alzheimer's. However, researchers caution that additional randomized controlled trials involving larger numbers of participants are needed to understand to what extent exercise may slow cognitive decline.

A second systematic review [38] found that cognitive stimulation had beneficial effects on cognitive function and some aspects of well-being in people with Alzheimer's dementia. Cognitive stimulation ranged from object categorization activities to reality orientation exercises. No single type of cognitive stimulation was identified as being more effective than another. Benefits to cognitive function lasted up to 3 months after cognitive stimulation activities ended. Cognitive stimulation did not affect mood, challenging behaviors or ability to perform activities of daily living. A third systematic review [39] reported that cognitive stimulation was associated with improved scores on tests of depression in people with mild-to-moderate Alzheimer's dementia.

2.5.2.2. Cognitively normal individuals

Cognitively normal individuals may use nonpharmacologic therapies with the goal of slowing cognitive decline or preventing dementia. A systematic review [40] of the use of supplements, including (but not limited to) C, D and E vitamins, omega-3 fatty acids, and ginkgo biloba, found little to no benefit of over-the-counter supplements in preventing cognitive decline, MCI or Alzheimer's dementia. Evidence from a systematic review [41] of whether cognitive training prevents cognitive decline found that cognitive training improved performance in the specific domain tested (for example, processing speed, executive function, memory or reasoning), but the evidence was insufficient to show that cognitive training prevented or delayed cognitive decline or dementia. A third systematic review [42] examined whether physical activity prevented cognitive decline and Alzheimer's dementia. The review found that the evidence

was largely insufficient to show that short-term, single-component physical activity interventions promoted cognitive function or prevented cognitive decline or dementia in older adults.

2.6. Living with Alzheimer's dementia

Studies have consistently shown that active management of Alzheimer's and other dementias can improve quality of life for affected individuals and their caregivers [43–45]. Active management includes:

- Appropriate use of available treatment options.
- Effective management of coexisting conditions.
- Coordination of care among physicians, other health care professionals and lay caregivers.
- Participation in activities that are meaningful and bring purpose to one's life.
- Having opportunities to connect with others living with dementia; support groups and supportive services are examples of such opportunities.
- Becoming educated about the disease.
- Planning for the future.

To learn more about managing Alzheimer's dementia, as well as practical information for living with dementia and being a caregiver, visit alz.org.

2.7. Uncommon genetic factors associated with Alzheimer's disease

Certain genetic mutations and the extra copy of chromosome 21 that characterizes Down syndrome are uncommon genetic factors that strongly influence Alzheimer's risk. There are also common genetic factors, such as the e2, e3 and e4 forms of the gene apolipoprotein E, that influence Alzheimer's risk.

2.7.1. Genetic mutations

A small percentage of Alzheimer's cases (an estimated 1 percent or less) [46] develop as a result of mutations to any of three specific 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 (APP) and the genes for the presenilin 1 and presenilin 2 proteins. Those inheriting an Alzheimer's mutation to the APP or presenilin 1 genes are guaranteed to develop the disease. Those inheriting an Alzheimer's mutation to the presenilin 2 gene have a 95 percent chance of developing the disease [47]. Individuals with Alzheimer's mutations in any of these three genes tend to develop symptoms before age 65, sometimes as young as age 30, while the vast majority of individuals with Alzheimer's have late-onset disease, in which symptoms appear at age 65 or older.

2.7.2. Trisomy in Down syndrome

In Down syndrome, an individual is born with three copies of chromosome 21 (called trisomy 21) instead of two. People with Down syndrome have an increased risk of developing Alzheimer's, and this is believed to be related to trisomy 21. Chromosome 21 includes the gene that encodes for the production of APP, which in people with Alzheimer's is cut into beta-amyloid fragments that accumulate into plaques. Having an extra copy of chromosome 21 may increase the production of beta-amyloid fragments produced in the brain.

Overall, people with Down syndrome develop Alzheimer's at an earlier age than people without Down syndrome. By age 40, most people with Down syndrome have significant levels of beta-amyloid plaques and tau tangles in their brains [48]. As with all adults, advancing age increases the likelihood that a person with Down syndrome will exhibit symptoms of Alzheimer's. According to the National Down Syndrome Society, about 30 percent of people with Down syndrome who are in their 50s have Alzheimer's dementia [49]. About 50 percent of people with Down syndrome in their 60s have Alzheimer's dementia [49].

2.8. Risk factors for Alzheimer's dementia

With the exception of cases of Alzheimer's linked to genetic mutations and trisomy 21, experts believe that Alzheimer's, like other common chronic diseases, develops as a result of multiple factors rather than a single cause.

2.8.1. Age, APOE-e4 and family history

The greatest risk factors for late-onset Alzheimer's are older age [50,51], carrying the e4 form of the APOE gene [52,53] and having a family history of Alzheimer's [54–57].

2.8.1.1. Age

Age is the greatest of these three risk factors, with the vast majority of people with Alzheimer's dementia being age 65 or older. As noted in the Prevalence section, the percentage of people with Alzheimer's dementia increases dramatically with age: 3 percent of people age 65-74, 17 percent of people age 75-84 and 32 percent of people age 85 or older have Alzheimer's dementia [51]. It is important to note that Alzheimer's dementia is not a normal part of aging [58], and older age alone is not sufficient to cause Alzheimer's dementia.

2.8.1.2. APOE

The APOE gene provides the blueprint for a protein that transports cholesterol in the bloodstream. Everyone inherits one of three forms (alleles) of the APOE gene—e2, e3 or e4 — from each parent, resulting in six possible APOE pairs: e2/e2, e2/e3, e2/e4, e3/e3, e3/e4 and e4/e4. Researchers have found differences in the frequency of these pairs in different racial and ethnic groups. For example, recent data show that a higher percentage of black/African Americans than European Americans have at least one copy of the e4 allele (see Table 3) [59–61].

Table 3
Percentage of black/African Americans and European Americans with specified APOE pairs

APOE pair	Black/African Americans*	European Americans
e3/e3	45.2	63.4
e3/e4	28.6	21.4
e3/e2	15.1	10.2
e2/e4	5.7	2.4
e4/e4	4.5	2.4
e2/e2	0.7	0.2

*Percentages do not total 100 due to rounding. Created from data from Rajan and colleagues [59].

Having the e4 form of APOE increases one's risk of developing Alzheimer's compared with having the e3 form, but does not guarantee that an individual will develop Alzheimer's. Having the e2 form may decrease one's risk compared with having the e3 form. Those who inherit one copy of the e4 form have three times the risk of developing Alzheimer's compared with those with two copies of the e3 form, while those who inherit two copies of the e4 form have an eight- to 12-fold risk [62–64]. In addition, those with the e4 form are more likely to develop Alzheimer's at a younger age than those with the e2 or e3 forms of the APOE gene [65]. A meta-analysis including 20 published articles describing the frequency of the e4 form among people in the United States who had been diagnosed with Alzheimer's found that 56 percent had one copy of the APOE-e4 gene, and 11 percent had two copies of the APOE-e4 gene [66]. Another study found that among 1770 diagnosed individuals from 26 Alzheimer's Disease Centers across the United States, 65 percent had at least one copy of the APOE-e4 gene [67].

However, studies of Alzheimer's risk based on APOE status among black/African Americans have had inconsistent results. For example, some have found that having one or more copies of APOE-e4 did not increase risk among black/African Americans [60,61,68], while other studies have found that APOE-e4 significantly increased risk among black/African Americans [69,70]. More research is needed to better understand the genetic mechanisms involved in Alzheimer's risk among different racial and ethnic groups.

2.8.1.3. Family history

A family history of Alzheimer's is not necessary for an individual to develop the disease. However, individuals who have a parent, brother or sister with Alzheimer's dementia are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's [54,62]. Those who have more than one first-degree relative with Alzheimer's are at even higher risk [57]. When diseases run in families, heredity (genetics) and shared environmental and lifestyle factors (for example, access to healthy foods and habits related to physical activity) may play a role. A recent large, population-based study found that having a parent with dementia increases risk independent of known genetic risk factors such as APOE-e4 [71]. While some

studies have suggested that an individual whose mother had dementia is more likely to have the early brain changes of dementia than an individual whose father developed dementia [72,73], this study found that after adjusting for risk factors such as APOE status, dementia risk was similar regardless of whether one's mother or father had dementia.

2.8.2. Modifiable risk factors

Although risk factors such as age and family history cannot be changed, other risk factors can be changed, or modified, to reduce risk of cognitive decline and dementia. It's important to note that "reducing risk" of cognitive decline and dementia is not synonymous with preventing cognitive decline and dementia. Individuals who take measures to reduce risk may still develop dementia, but are less likely to develop it. A report [74] evaluating the state of the evidence on the effects of modifiable risk factors on cognitive decline and dementia concluded that there is sufficiently strong evidence, from a population-based perspective, that regular physical activity and management of cardiovascular risk factors (especially diabetes, obesity, smoking and hypertension) is associated with reduced risk of cognitive decline and may be associated with reduced risk of dementia. It also concluded that there is sufficiently strong evidence that a healthy diet, lifelong learning and cognitive training are associated with reduced risk of cognitive decline. A report from the National Academy of Medicine (formerly the Institute of Medicine) examined the evidence regarding modifiable risk factors for cognitive decline and reached similar conclusions [75]. More research is needed to understand the biological mechanisms by which these factors reduce risk.

2.8.2.1. Cardiovascular disease risk factors

Brain health is affected by the health of the heart and blood vessels. Although it makes up just 2 percent of body weight, the brain consumes 20 percent of the body's oxygen and energy supplies [76]. A healthy heart ensures that enough blood is pumped to the brain, while healthy blood vessels enable the oxygen- and nutrient-rich blood to reach the brain so it can function normally.

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of dementia [77]. These factors include smoking [78–82] and diabetes [83–86]. Some studies propose that impaired glucose processing (a precursor to diabetes) may also result in an increased risk for dementia [87–89]. The age at which some risk factors develop appears to affect dementia risk. For example, midlife obesity [87,90–93], hypertension [87,94–98], prehypertension (systolic blood pressure from 120 to 139 mm Hg or diastolic pressure from 80 to 89 mm Hg) [98] and high cholesterol [99,100] are associated with an increased risk of dementia. However, late-life obesity [101] and hypertension onset after age 80 [102] have been associated with decreased risk of dementia. More research

is needed to understand why the effects of some modifiable risk factors may change with age. Regarding blood pressure, there is now strong evidence from a large-scale clinical trial that intensive medical treatment to reduce blood pressure can safely and significantly reduce the occurrence of MCI and a combined outcome of MCI and dementia in older adults who have hypertension [103].

Building on the connection between heart health and brain health, researchers have found that factors that protect the heart may also protect the brain and reduce the risk of developing Alzheimer's or other dementias. Physical activity [104–111] appears to be one of these factors. Although researchers have studied a wide variety of exercises, they do not yet know which specific types of exercises, what frequency of exercise or what duration of activity may be most effective in reducing risk. In addition to physical activity, emerging evidence suggests that consuming a heart-healthy diet may be associated with reduced dementia risk [112–116]. A heart-healthy diet emphasizes fruits, vegetables, whole grains, fish, chicken, nuts and legumes while limiting saturated fats, red meat and sugar.

Researchers have begun studying combinations of health factors and lifestyle behaviors (for example, blood pressure and physical activity) to learn whether combinations of risk factors better identify Alzheimer's and dementia risk than individual risk factors. They are also studying whether intervening on multiple risk factors simultaneously has a greater chance of reducing risk than addressing a single risk factor. Indeed, one such study [117], the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER), found that a multidomain lifestyle intervention was associated with beneficial effects on cognitive function in elderly individuals at high risk for cognitive decline. The success of FINGER has led to the launch of multidomain lifestyle intervention studies in other countries, including the Alzheimer's Association U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER) [118].

2.8.2.2. Education

People with more years of formal education are at lower risk for Alzheimer's and other dementias than those with fewer years of formal education [60,119–123]. Some researchers believe that having more years of education builds "cognitive reserve." Cognitive reserve refers to the brain's ability to make flexible and efficient use of cognitive networks (networks of neuron-to-neuron connections) to enable a person to continue to carry out cognitive tasks despite brain changes [124,125] such as beta-amyloid and tau accumulation. The number of years of formal education is not the only determinant of cognitive reserve. Having a mentally stimulating job and engaging in other mentally stimulating activities may also help build cognitive reserve [126–129].

In addition, having fewer years of formal education is associated with lower socioeconomic status [130], which in turn may increase one's likelihood of experiencing poor nutrition and decrease one's ability to afford health care or medical treatments, such as treatments for cardiovascular risk factors. In addition, people with fewer years of education tend to have more cardiovascular risk factors for Alzheimer's, including being less physically active [131] and having a higher risk of diabetes [132–134] and cardiovascular disease [135].

2.8.2.3. Social and cognitive engagement

Additional studies suggest that remaining socially and mentally active throughout life may support brain health and possibly reduce the risk of Alzheimer's and other dementias [136–146]. Remaining socially and mentally active may help build cognitive reserve, 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.

2.8.2.4. Traumatic brain injury (TBI)

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. According to the Centers for Disease Control and Prevention (CDC), approximately 2.8 million TBI-related emergency department visits, hospitalizations, and deaths occurred in 2013, the latest year for which information is available [147]. The leading causes of TBI that resulted in emergency department visits were falls, being struck by an object and motor vehicle crashes [147].

Two ways to classify the severity of TBI are by the duration of loss of consciousness or post-traumatic amnesia [148] and by the individual's initial score on the 15-point Glasgow Coma Scale [149].

- *Mild TBI* (also known as a concussion) is characterized by loss of consciousness or post-traumatic amnesia lasting 30 minutes or less, or an initial Glasgow score of 13-15; about 75 percent of TBIs are mild [150].
- *Moderate TBI* is characterized by loss of consciousness or post-traumatic amnesia lasting more than 30 minutes but less than 24 hours, or an initial Glasgow score of 9-12.
- *Severe TBI* is characterized by loss of consciousness or post-traumatic amnesia lasting 24 hours or more, or an initial Glasgow score of 8 or less.

TBI increases the risk of dementia, including Alzheimer's dementia [151]. The risk of dementia increases with the number of TBIs sustained. Even those who experience mild TBI are at increased risk of dementia compared with those who have not had a TBI. A recent study found that mild TBI is associated with a two-fold increase in the risk of dementia diagnosis [152].

Chronic traumatic encephalopathy (CTE) is a neuropathologic diagnosis (meaning it is characterized by brain changes that can only be identified at autopsy) associated with repeated blows to the head, such as those that may occur while playing contact sports. It is also associated with the development of dementia. Currently, there is no test to determine if someone has CTE-related brain changes during life. A recent review of available literature indicates that the greatest risk factor for developing CTE-related brain changes is repetitive brain trauma—repeated, forceful blows to the head that do not, individually, result in symptoms [153]. Like Alzheimer's dementia, CTE is characterized by tangles of an abnormal form of the protein tau in the brain. Unlike Alzheimer's dementia, these tangles typically appear around small blood vessels, and beta-amyloid plaques are not commonly present [154,155]. How the brain changes associated with CTE are linked to cognitive or behavioral dysfunction is unclear.

2.9. Looking to the future

The identification of biomarkers for Alzheimer's enables early detection of the disease and will accelerate the development of new therapies by ensuring that appropriate people are enrolled in clinical trials. With the discovery that Alzheimer's may begin 20 years or more before the onset of symptoms, a substantial window of time has been opened to intervene in the progression of the disease. In the future, more will be understood about which therapies will be most effective at which points in the disease continuum.

3. Prevalence

Millions of Americans have Alzheimer's or other dementias. As the size and proportion of the U.S. population age 65 and older continue to increase, the number of Americans with Alzheimer's or other dementias will grow. This number will escalate rapidly in coming years, as the population of Americans age 65 and older is projected to grow from 55 million in 2019 to 88 million by 2050 [156,157]. The baby boom generation has already begun to reach age 65 and beyond [158], the age range of greatest risk of Alzheimer's dementia; in fact, the oldest members of the baby boom generation turn age 73 in 2019.

This section reports on the number and proportion of people with Alzheimer's dementia to describe the magnitude of the burden of Alzheimer's on the community and health care system. The prevalence of Alzheimer's dementia refers to the number and proportion of people in a population who have Alzheimer's dementia at a given point in time. Incidence refers to the number or rate of new cases per year. Estimates from selected studies on the number and proportion of people with Alzheimer's or other dementias
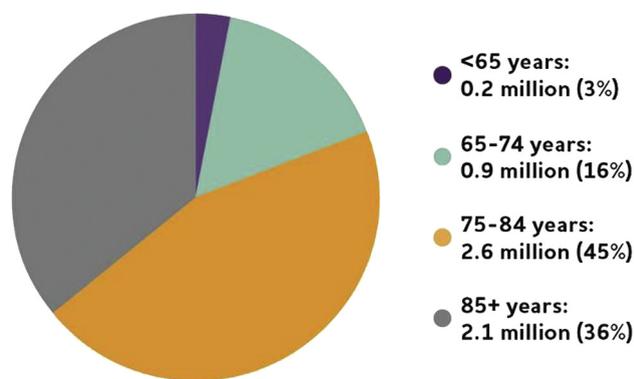

Fig. 1. Ages of people with Alzheimer's dementia, 2019. Created from data from Hebert and colleagues [51].[A2]

- <65 years: 0.2 million (3%)
- 65-74 years: 0.9 million (16%)
- 75-84 years: 2.6 million (45%)
- 85+ years: 2.1 million (36%)

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

3.1. Prevalence of Alzheimer's and other dementias in the United States

An estimated 5.8 million Americans of all ages are living with Alzheimer's dementia in 2019. This number includes an estimated 5.6 million people age 65 and older [51],[A1] and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's, though there is greater uncertainty about the younger-onset estimate [159]. Of the 5.8 million people who have Alzheimer's dementia, 81 percent are age 75 or older (Fig. 1) [51].[A2]

Out of the total U.S. population:

- One in 10 people (10 percent) age 65 and older has Alzheimer's dementia [51,157].[A3]
- The percentage of people with Alzheimer's dementia increases with age: 3 percent of people age 65-74, 17 percent of people age 75-84, and 32 percent of people age 85 and older have Alzheimer's dementia [51].

The estimated number of people age 65 and older with Alzheimer's dementia comes from a study using the latest data from the 2010 U.S. Census and the Chicago Health and Aging Project (CHAP), a population-based study of chronic health conditions of older people [51].

National estimates of the prevalence of all dementias are not available from CHAP, but they are available from other population-based studies including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults [160,161].[A4] Based on estimates from ADAMS, 14 percent of people age 71 and older in the United States have dementia [160].

Prevalence studies such as CHAP and ADAMS are designed so that everyone in the study is evaluated for dementia. But outside of research settings, a substantial portion of those who would meet the diagnostic criteria for Alzheimer's and other dementias are not diagnosed with dementia by a physician [162–165]. Furthermore, fewer

than half of Medicare beneficiaries who have a diagnosis of Alzheimer's or another dementia in their Medicare billing records (or their caregiver, if the beneficiary's cognitive impairment prevented him or her from responding) report being told of the diagnosis [166–170]. Because Alzheimer's dementia is often underdiagnosed—and if it is diagnosed, people are often unaware of their diagnosis—a large portion of Americans with Alzheimer's may not know they have it.

The estimates of the number and proportion of people who have Alzheimer's in this section refer to people who have Alzheimer's dementia based on clinical diagnostic criteria. However, as described in the Overview, current diagnostic guidelines [9–12] recognize that Alzheimer's disease begins many years before the onset of symptoms of dementia and that Alzheimer's disease is defined by pathological changes in the brain, not by symptoms. A biomarker-based diagnosis of Alzheimer's disease will eventually enable biomarker-based prevalence estimates.

Biomarker-based prevalence estimates could significantly affect the estimates of the number of people with the disease. Currently, individuals with Alzheimer's biomarkers but no dementia are not included in this section's prevalence estimates, which are limited to those in the dementia stage. However, autopsy studies in individuals who were cognitively normal for their age found that roughly 30 percent had Alzheimer's-related brain changes (plaques and/or tangles) at death [8,13,14]. A biomarker-based prevalence estimate—when we have biomarkers that can reliably detect the changes in the brain—could include the number of people throughout the continuum of Alzheimer's disease, including those who have mild cognitive impairment (MCI) due to Alzheimer's and, eventually, those in the preclinical stage of the disease, even though not all such individuals will go on to develop Alzheimer's dementia.

Additionally, it is worth noting that some individuals now counted as having Alzheimer's dementia may not have the biological brain changes associated with Alzheimer's disease because their diagnosis was made based on clinical symptoms rather than based on biomarkers. Both autopsy studies and clinical trials have found that up to 30 percent of individuals who met the clinical criteria for Alzheimer's dementia did not have the required Alzheimer's-related brain changes at death [58]. That is, they had dementia without Alzheimer's biomarkers, and thus did not have Alzheimer's dementia; rather, their dementia was caused by something other than Alzheimer's disease.

The ultimate result of a biomarker-based prevalence estimate could be a significantly larger total number of people living with Alzheimer's disease because of the inclusion of those with MCI due to Alzheimer's and, eventually, those in the preclinical stage, but a smaller number of individuals in the dementia stage of the disease.

A biomarker-based prevalence estimate is years away. One reason is that it requires epidemiologic and related studies to gather biomarker data from their participants so that we can ascertain which biomarkers to use to determine prevalence. The Mayo Clinic Study of Aging has long collected such data that could be helpful toward this end. The Healthy Cognitive Aging Project (HCAP)—a sub-study of the Health and Retirement Study (HRS)—is now testing the feasibility of including biomarker data in future. But these are the exceptions, not the rule. Furthermore, in developing well-grounded biomarker-based prevalence estimates, numerous questions remain unanswered, such as: Which biomarkers predict Alzheimer's dementia in the preclinical stage? What is the minimum biomarker data needed to diagnosis Alzheimer's disease? How much biomarker study data is sufficient to estimate national and state prevalence? Is amyloid-related biomarker data sufficient, or is biomarker data on the presence of abnormal tau also necessary? Answering these questions now will speed up the day when biomarker-based prevalence estimates can be made. In that light, the Alzheimer's Association is currently convening an expert think tank to identify a framework on biomarker-based prevalence estimates.

3.1.1. Prevalence of subjective cognitive decline

The experience of worsening or more frequent confusion or memory loss (often referred to as subjective cognitive decline) is one of the earliest warning signs of Alzheimer's disease and may be a way to identify people who are at high risk of developing Alzheimer's or other dementias as well as MCI [171–175]. Subjective cognitive decline refers to self-perceived worsening of memory and other thinking abilities by an individual, separate from cognitive testing, clinical diagnosis or anyone else noticing. Not all of those who experience subjective cognitive decline go on to develop MCI or dementia, but many do [176–178]. According to a recent study, those who over time consistently reported subjective cognitive decline that they found worrisome were at higher risk for developing Alzheimer's dementia [179]. The Behavioral Risk Factor Surveillance System (BRFSS) survey, which includes questions on self-perceived confusion and memory loss, found that in 2015-2016, 11 percent of Americans age 45 and older reported subjective cognitive decline, but 55 percent of those who reported it had not consulted a health care professional about it [180]. Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

3.2. Incidence of Alzheimer's dementia

While prevalence refers to *existing* cases of a disease in a population at a given time, incidence refers to *new* cases of a disease that develop in a given period of time in a defined population—in this case, the U.S. population age 65 or older. Incidence provides a measure of risk for developing a disease. According to one study using data from the Established Populations for Epidemiologic Study of the Elderly (EPESE), approximately 487,000 people age 65 or older will develop Alzheimer's dementia in the United States in 2019.[A5] Other studies have arrived at incidence estimates
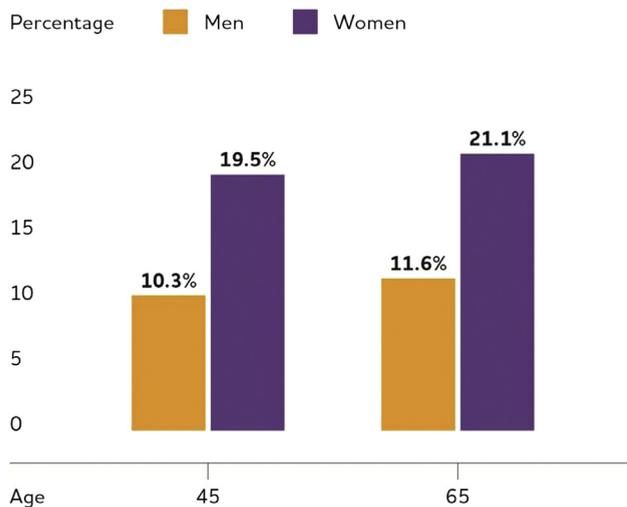
Fig. 2. Estimated lifetime risk for Alzheimer's dementia, by sex, at ages 45 and 65. Created from data from Chene and colleagues [184].

that are much higher. For example, according to CHAP estimates approximately 910,000 people age 65 or older developed Alzheimer's dementia in the United States in 2011 [181]. A study using data from the Adult Changes in Thought (ACT) study, a cohort of members of the Group Health health care delivery system in the Northwest United States, reported similar incidence rates [182]. The number of new cases of Alzheimer's increases dramatically with age: according to estimates from CHAP, in 2011 the average annual incidence in people ages 65-74 was 0.4 percent (meaning four of every 1,000 people will develop Alzheimer's dementia in a year); in people ages 75-84, the annual incidence was 3.2 percent (32 of every 1,000 people); and for ages 85 and older (the "oldest-old"), the incidence was 7.6 percent (76 of every 1,000 people) [181]. Because of the increasing number of people age 65 and older in the United States, particularly the oldest-old, the annual number of new cases of Alzheimer's and other dementias is projected to double by 2050 [183].

3.3. Lifetime risk of Alzheimer's dementia

Lifetime risk is the probability that someone of a given age who does not have a particular condition will develop the condition during his or her remaining life span. Data from the Framingham Heart Study were used to estimate lifetime risks of Alzheimer's dementia by age and sex [184].[A6] As shown in Fig. 2, the study found that the estimated lifetime risk for Alzheimer's dementia at age 45 was approximately one in five (20 percent) for women and one in 10 (10 percent) for men. The risks for both sexes were slightly higher at age 65 [184].

3.4. Estimates of the number of people with Alzheimer's dementia by state

Table 4 lists the estimated number of people age 65 and older with Alzheimer's dementia by state for 2019, the

projected number for 2025, and the projected percentage change in the number of people with Alzheimer's between 2019 and 2025 [185].[A7]

As shown in Fig. 3, between 2019 and 2025 every state across the country is expected to experience an increase of at least 12 percent in the number of people with Alzheimer's. These projected increases in the number of people with Alzheimer's are due to projected increases in the population age 65 and older in these states. The West and Southeast are expected to experience the largest percentage increases in people with Alzheimer's dementia between 2019 and 2025. These increases will have a marked impact on states' health care systems, as well as the Medicaid program, which covers the costs of long-term care and support for some older residents with dementia.

3.5. Differences between women and men in the prevalence and risk of Alzheimer's and other dementias

More women than men have Alzheimer's or other dementias. Almost two-thirds of Americans with Alzheimer's are women [51].[A8] Of the 5.6 million people age 65 and older with Alzheimer's in the United States, 3.5 million are women and 2.1 million are men [51].[A8] Based on estimates from ADAMS, among people age 71 and older, 16 percent of women have Alzheimer's or other dementias compared with 11 percent of men [160].

There are a number of potential biological and social reasons why more women than men have Alzheimer's or other dementias [186]. The prevailing view has been that this discrepancy is due to the fact that women live longer than men on average, and older age is the greatest risk factor for Alzheimer's [184,187,188]. But when it comes to difference in the actual risk of developing Alzheimer's or other dementias for men and women of the same age, many studies of incidence have found no significant difference between men and women in the proportion who develop Alzheimer's or other dementias at any given age [182,188,189].

Alternatively, some studies have found a difference between men and women in the risk of developing Alzheimer's or other dementias, but have attributed the difference to differences in other related health factors. A recent study using data from the Framingham Heart Study suggests that because men have a higher rate of death from cardiovascular disease in middle age, men who survive beyond age 65 may have a healthier cardiovascular risk profile and thus an apparent lower risk for dementia than women of the same age [184]. Epidemiologists call this "survival bias" because the men who survive to older ages and are included in studies tend to be the healthiest men; as a result, they may have a lower risk of developing Alzheimer's and other dementias than the men who died at an earlier age from cardiovascular disease. More research is needed to support this finding.

Other researchers are questioning whether the risk of Alzheimer's could actually be higher for women at any given

Table 4
Projections of total numbers of Americans age ≥65 years with Alzheimer's dementia by state

State	Projected number with Alzheimer's (in thousands)		Percentage increase
	2019	2025	2019-2025
Alabama	94	110	17.0
Alaska	8	11	37.5
Arizona	140	200	42.9
Arkansas	57	67	17.5
California	670	840	25.4
Colorado	73	92	26.0
Connecticut	78	91	16.7
Delaware	19	23	21.1
District of Columbia	8.9	9	1.1
Florida	560	720	28.6
Georgia	150	190	26.7
Hawaii	29	35	20.7
Idaho	26	33	26.9
Illinois	230	260	13.0
Indiana	110	130	18.2
Iowa	65	73	12.3
Kansas	54	62	14.8
Kentucky	73	86	17.8
Louisiana	89	110	23.6
Maine	28	35	25.0
Maryland	110	130	18.2
Massachusetts	130	150	15.4
Michigan	190	220	15.8
Minnesota	97	120	23.7
Mississippi	55	65	18.2
Missouri	110	130	18.2
Montana	21	27	28.6
Nebraska	34	40	17.6
Nevada	47	64	36.2
New Hampshire	25	32	28.0
New Jersey	180	210	16.7
New Mexico	41	53	29.3
New York	400	460	15.0
North Carolina	170	210	23.5
North Dakota	14	16	14.3
Ohio	220	250	13.6
Oklahoma	65	76	16.9
Oregon	67	84	25.4
Pennsylvania	280	320	14.3
Rhode Island	23	27	17.4
South Carolina	92	120	30.4
South Dakota	17	20	17.6
Tennessee	120	140	16.7
Texas	390	490	25.6
Utah	33	42	27.3
Vermont	13	17	30.8
Virginia	150	190	26.7
Washington	110	140	27.3
West Virginia	38	44	15.8
Wisconsin	110	130	18.2
Wyoming	10	13	30.0

Created from data provided to the Alzheimer's Association by Weuve and colleagues [185].[A7]

age due to biological or genetic variations or differences in life experiences [190]. A number of studies have shown that the APOE-e4 genotype, the best known genetic risk factor for Alzheimer's dementia, may have a stronger association with Alzheimer's dementia in women than in men [191,192] or a stronger relationship with Alzheimer's disease biomarkers in women [193]. However, a recent meta-analysis, which combined data from a number of independent studies, found no difference between men and women in the association between APOE genotype and Alzheimer's dementia except for a slightly elevated risk for women with the APOE-e3/e4 genotype compared with men with the same genotype between ages 65 and 75 [194]. It is unknown why the APOE gene could convey different risk for women, but some evidence suggests that it may be due to an interaction between the APOE-e4 genotype and the sex hormone estrogen [195,196]. Finally, because low education is a risk factor for dementia, it is possible that lower educational attainment in women than in men born in the first half of the 20th century could account for a higher risk of Alzheimer's and other dementias in women [197].

3.6. Racial and ethnic differences in the prevalence of Alzheimer's and other dementias

Although there are more non-Hispanic whites living with Alzheimer's and other dementias than any other racial or ethnic group in the United States, older black/African Americans and Hispanics are more likely, on a per-capita basis, than older whites to have Alzheimer's or other dementias [198–203]. Most studies indicate that older black/African Americans are about twice as likely to have Alzheimer's or other dementias as older whites [181,204,205]. Some studies indicate Hispanics are about one and one-half times as likely to have Alzheimer's or other dementias as older whites [205–207].[A9] Recent studies suggest the increased likelihood for Hispanics may be slightly lower than this, depending upon the specific Hispanic ethnic group observed (for example, Mexican Americans compared with Caribbean Americans) [208].

The higher prevalence of Alzheimer's dementia in minorities compared with whites appears to be due to a higher incidence of dementia in these groups [203,208]. Variations in health, lifestyle and socioeconomic risk factors across racial groups likely account for most of the differences in risk of Alzheimer's and other dementias [209]. Despite some evidence that the influence of genetic risk factors on Alzheimer's and other dementias may differ by race [68,70,210], genetic factors do not appear to account for the large differences in prevalence or incidence among racial groups [209,211]. Instead, health conditions such as cardiovascular disease and diabetes, which are associated with an increased risk for Alzheimer's and other dementias, are believed to account for these differences, as they are more prevalent in black/African-American and Hispanic people [212,213]. Socioeconomic characteristics, including lower levels of education, higher rates of poverty, and greater exposure to adversity and discrimination, may also increase risk in
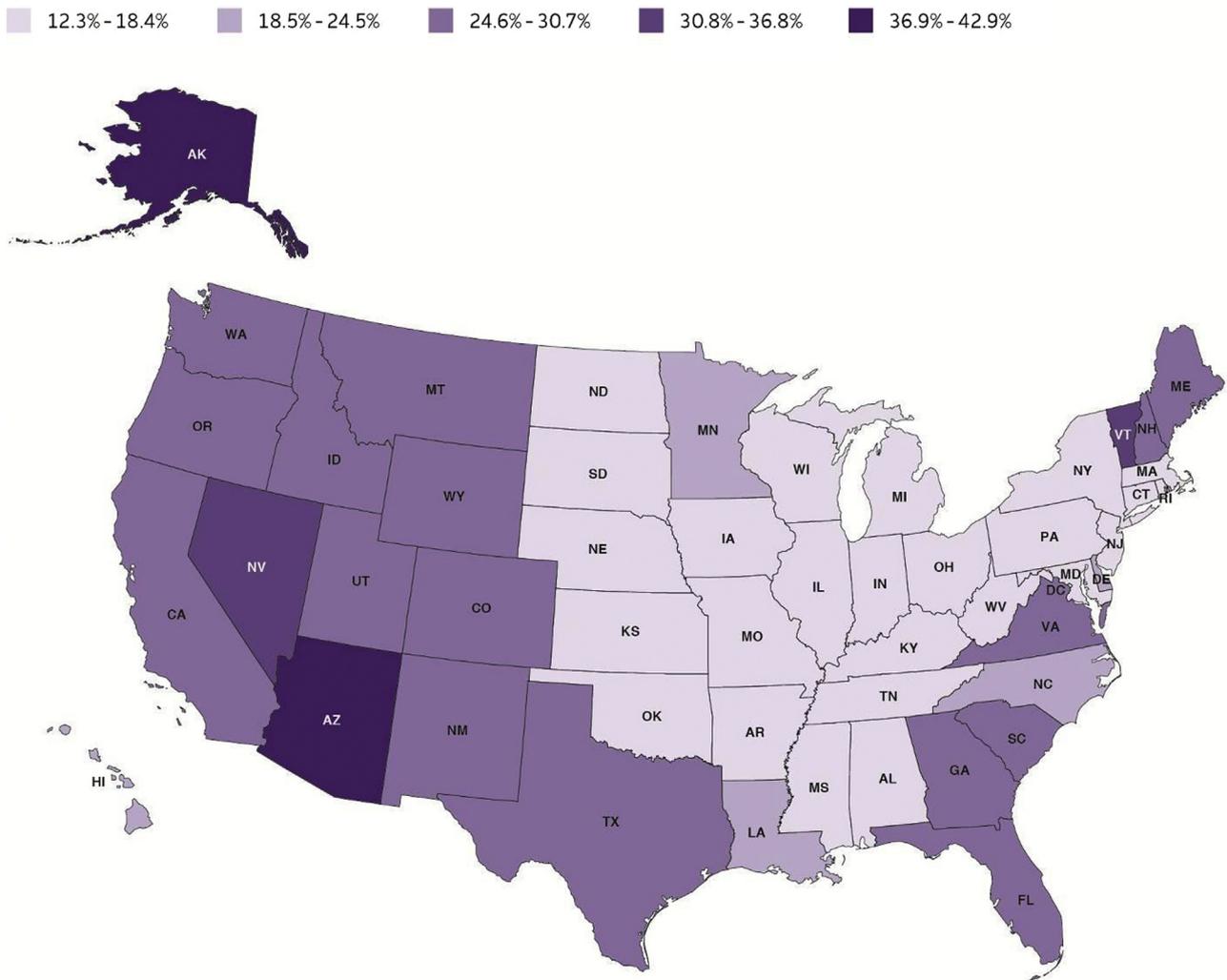
Fig. 3. Projected increases between 2019 and 2025 in Alzheimer's dementia prevalence by state. Change from 2019 to 2025 for Washington, D.C.: 1.1%. Created from data provided to the Alzheimer's Association by Weuve and colleagues [185].[A7]

black/African-American and Hispanic communities [68,212–214]. Some studies suggest that differences based on race and ethnicity do not persist in rigorous analyses that account for such factors [120,160,209].

There is evidence that missed diagnoses of Alzheimer's and other dementias are more common among older black/African Americans and Hispanics than among older whites [215,216]. Based on data for Medicare beneficiaries age 65 and older, Alzheimer's or another dementia had been diagnosed in 10.3 percent of whites, 12.2 percent of Hispanics, and 13.8 percent of black/African Americans [217]. Although rates of diagnosis were higher among black/African Americans than among whites, according to prevalence studies that detect all people who have dementia irrespective of their use of the health care system, the rates should be even higher for black/African Americans.

There are fewer data from population-based cohort studies regarding the national prevalence of Alzheimer's and other dementias in racial and ethnic groups other than whites, black/African Americans, and Hispanics. However, a study examining electronic medical records of members of a large health plan in California indicated that dementia incidence—determined by the presence of a dementia diagnosis in members' medical records—was highest in black/African Americans, intermediate for Latinos (the term used in the study for those who self-reported as Latino or Hispanic) and whites, and lowest for Asian Americans [218]. A follow-up study with the same cohort showed heterogeneity within Asian-American subgroups, but all subgroups studied had lower dementia incidence than whites [219]. A recent systematic review of the literature found that Japanese Americans were the only Asian-American subgroup with reliable prevalence data, and that they had the lowest prevalence of dementia compared with all other ethnic groups [208]. More studies, especially those involving population-based cohorts, are necessary to draw conclusions about the prevalence of Alzheimer's and other dementias in Asian Americans and how it may differ by subgroup.
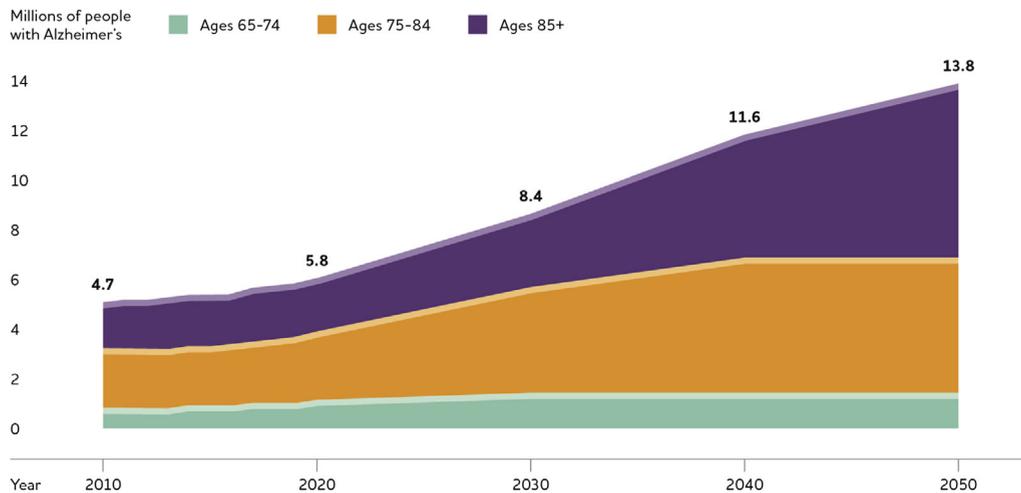
Fig. 4. Projected number of people age ≥65 years (total and by age) in the U.S. population with Alzheimer's dementia, 2010 to 2050. Created from data from Hebert and colleagues [51].[A10]

3.7. Trends in the prevalence and incidence of Alzheimer's dementia over time

A growing number of studies indicate that the prevalence [220–229] and incidence [224,229–237] of Alzheimer's and other dementias in the United States and other higher-income Western countries may have declined in the past 25 years [223–236], though results are mixed [50,181,238,239]. These declines have been attributed to increasing levels of education and improved control of cardiovascular risk factors [223,225,230,234,240,241]. Such findings are promising and suggest that identifying and reducing risk factors for Alzheimer's and other dementias may be effective. Although these findings indicate that a person's risk of dementia at any given age may be decreasing slightly, the total number of people with Alzheimer's or other dementias in the United States and other high-income Western countries is expected to continue to increase dramatically because of the increase in the number of people at the oldest ages.

It is unclear whether these positive trends will continue into the future given worldwide trends showing increases in diabetes and obesity—potential risk factors for Alzheimer's dementia—which may lead to a rebound in dementia risk in coming years [91,222,224,242,243], or if these positive trends pertain to all racial and ethnic groups [181,220,240,241,244]. Thus, while recent findings are promising, the social and economic burden of Alzheimer's and other dementias will continue to grow. Moreover, 68 percent of the projected increase in the global prevalence and burden of dementia by 2050 will take place in low and middle-income countries, where there is currently no evidence that the risk of Alzheimer's and other dementias has been declining [245].

3.7.1. Looking to the future: Aging of the baby boom generation

A large segment of the American population—the baby boom generation—has begun to reach age 65 and older, ages when the risk for Alzheimer's and other dementias is elevated. By 2030, the segment of the U.S. population age 65 and older will increase substantially, and the projected 74 million older Americans will make up over 20 percent of the total population (up from 16 percent in 2019) [157,246]. As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer's dementia, as shown in Fig. 4 [51].[A10]

- By 2025, the number of people age 65 and older with Alzheimer's dementia is projected to reach 7.1 million—almost a 27 percent increase from the 5.6 million age 65 and older affected in 2019 [51].[A11]
- By 2050, the number of people age 65 and older with Alzheimer's dementia may grow to a projected 13.8 million, barring the development of medical breakthroughs to prevent, slow or cure Alzheimer's disease [51].[A10]

3.7.2. Growth of the oldest-old population

The number of Americans surviving into their 80s, 90s and beyond is expected to grow dramatically due to medical advances, as well as social and environmental conditions [246]. Longer life expectancies and the aging of the large baby boom cohort will lead to an increase in the number and percentage of Americans who will be 85 and older, the oldest-old. Between 2012 and 2050, the oldest-old are

expected to comprise an increasing proportion of the U.S. population age 65 and older—from 14 percent in 2012 to 22 percent in 2050 [246]. This will result in an additional 12 million oldest-old people—individuals at the highest risk for developing Alzheimer's dementia [246].

- In 2019, about 2.1 million people who have Alzheimer's dementia are age 85 or older, accounting for 36 percent of all people with Alzheimer's dementia [51].
- When the first wave of baby boomers reaches age 85 (in 2031), it is projected that more than 3 million people age 85 and older will have Alzheimer's dementia [51].
- By 2050, 7 million people age 85 and older are projected to have Alzheimer's dementia, accounting for more than half (51 percent) of all people 65 and older with Alzheimer's dementia [51].

4. Mortality and morbidity

Alzheimer's disease is officially listed as the sixth-leading cause of death in the United States [247]. It is the fifth-leading cause of death for those age 65 and older [247]. However, it may cause even more deaths than official sources recognize. Alzheimer's is also a leading cause of disability and poor health (morbidity). Before a person with Alzheimer's dies, he or she lives through years of morbidity as the disease progresses.

4.1. Deaths from Alzheimer's disease

It is difficult to determine how many deaths are caused by Alzheimer's disease each year because of the way causes of death are recorded. According to data from the Centers for Disease Control and Prevention (CDC), 121,404 people died from Alzheimer's disease in 2017 [248]. The CDC considers a person to have died *from* Alzheimer's if the death certificate lists Alzheimer's as the underlying cause of death, defined as "the disease or injury which initiated the train of events leading directly to death [249]."

Severe dementia frequently causes complications such as immobility, swallowing disorders and malnutrition that significantly increase the risk of serious acute conditions that can cause death. One such condition is pneumonia (infection of the lungs), which is the most commonly identified cause of death among elderly people with Alzheimer's or other dementias [250,251]. One autopsy study found that respiratory system diseases were the immediate cause of death in more than half of people with Alzheimer's dementia, followed by circulatory system disease in about a quarter [251]. Death certificates for individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's [252–254]. As a result, people with Alzheimer's disease who die due to these acute conditions

may not be counted among the number of people who die from Alzheimer's disease, even though Alzheimer's disease may well have caused the acute condition listed on the death certificate. This difficulty in using death certificates to determine the number of deaths from Alzheimer's has been referred to as a "blurred distinction between death *with* dementia and death *from* dementia [255]."

Another way to determine the number of deaths from Alzheimer's disease is through calculations that compare the estimated risk of death in those who have Alzheimer's with the estimated risk of death in those who do not have Alzheimer's. A study using data from the Rush Memory and Aging Project and the Religious Orders Study estimated that 500,000 deaths among people age 75 and older in the United States in 2010 could be attributed to Alzheimer's (estimates for people age 65 to 74 were not available), meaning that those deaths would not be expected to occur in that year if those individuals did not have Alzheimer's [256].

The true number of deaths caused by Alzheimer's is somewhere between the number of deaths from Alzheimer's recorded on death certificates and the number of people who have Alzheimer's disease when they die. According to 2014 Medicare claims data, about one-third of all Medicare beneficiaries who die in a given year have been diagnosed with Alzheimer's or another dementia. Based on data from the Chicago Health and Aging Project (CHAP) study, in 2019 an estimated 700,000 people age 65 and older in the United States will have Alzheimer's when they die [257]. Although some seniors who have Alzheimer's disease at the time of death die from causes that are unrelated to Alzheimer's, many of them die from Alzheimer's disease itself or from conditions in which Alzheimer's was a contributing cause, such as pneumonia.

Irrespective of the cause of death, among people age 70, 61 percent of those with Alzheimer's dementia are expected to die before age 80 compared with 30 percent of people without Alzheimer's dementia [258].

4.2. Public health impact of deaths from Alzheimer's disease

As the population of the United States ages, Alzheimer's is becoming a more common cause of death. Although deaths from other major causes have *decreased* significantly or remained approximately the same, official records indicate that deaths from Alzheimer's disease have *increased* significantly. Between 2000 and 2017, the number of deaths from Alzheimer's disease as recorded on death certificates has more than doubled, increasing 145 percent, while the number of deaths from the number one cause of death (heart disease) decreased 9 percent (Fig. 5) [248,259]. The increase in the number of death certificates listing Alzheimer's as the underlying cause of death probably reflects both changes in patterns of reporting
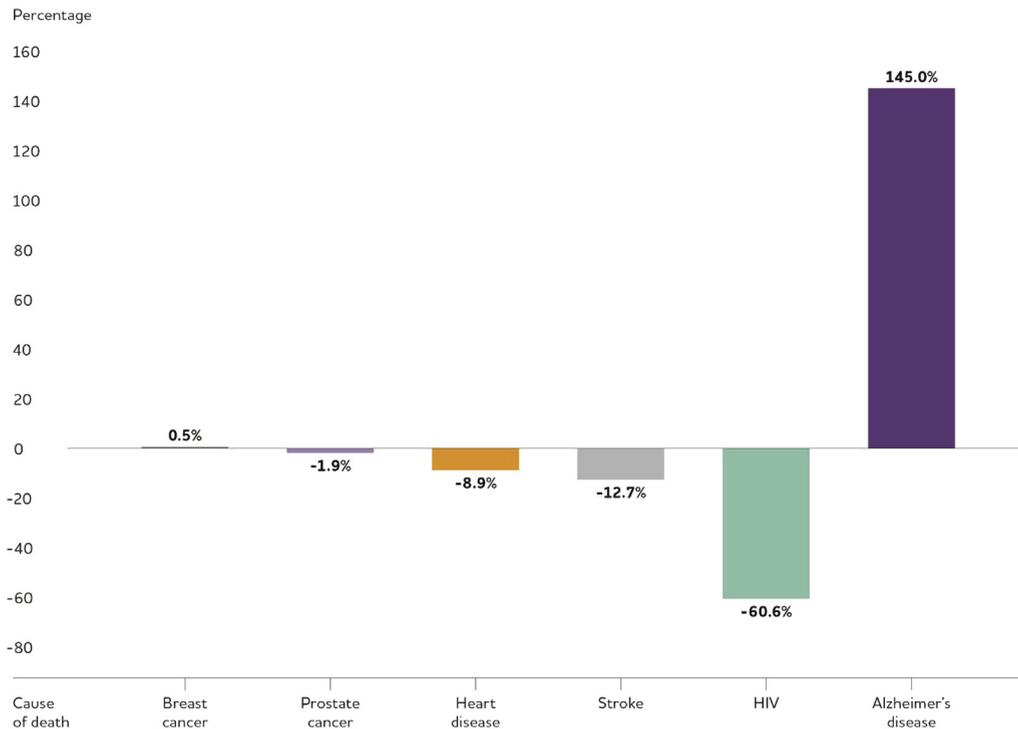
Fig. 5. Percentage changes in selected causes of death (all ages) between 2000 and 2017. Created from data from the National Center for Health Statistics [248,259].

deaths on death certificates over time as well as an increase in the actual number of deaths attributable to Alzheimer's.

4.3. State-by-state deaths from Alzheimer's disease

Table 5 provides information on the number of deaths due to Alzheimer's by state in 2017, 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 Alzheimer's disease across states with varying population sizes. For the United States as a whole, in 2017, the mortality rate for Alzheimer's disease was 37.3 deaths per 100,000 people [248].[A12]

4.4. Alzheimer's disease death rates

As shown in Fig. 6, the rate of deaths due to Alzheimer's has risen substantially since 2000 [248]. Table 6 shows that the rate of death from Alzheimer's increases dramatically with age, especially after age 65 [248].[A12] The increase in the Alzheimer's death rate over time has disproportionately affected the oldest-old [259]. Between 2000 and 2017, the death rate from Alzheimer's increased 31 percent for people age 65 to 74, but increased 57 percent for people age 75 to 84, and 86 percent for people age 85 and older [248]. A recent report by the CDC determined that even after adjusting for differences in age distributions over time, the

annual Alzheimer's death rate in the United States increased substantially between 1999 and 2014 [260]. Therefore, the growing proportion of older adults in the country is not the only explanation for the increase in Alzheimer's death rates. Other possible reasons include fewer deaths from other common causes of deaths in old age such as heart disease and stroke; increased diagnosis of Alzheimer's especially at earlier stages; and increased reporting of Alzheimer's as a cause of death by physicians and others who fill out death certificates [260].

4.5. Duration of illness from diagnosis to death

Studies indicate that people age 65 and older survive an average of 4 to 8 years after a diagnosis of Alzheimer's dementia, yet some live as long as 20 years with Alzheimer's dementia [182,261–268]. This reflects the slow, insidious and uncertain progression of Alzheimer's. Of the total number of years that they live with Alzheimer's dementia, individuals will spend an average of 40 percent of this time in dementia's most severe stage [258]. Much of this time will be spent in a nursing home. At age 80, approximately 75 percent of people living with Alzheimer's dementia are expected to live in a nursing home compared with only 4 percent of the general population at age 80 [258]. In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions [269].

Table 5
Number of deaths and annual mortality rate (per 100,000) due to
Alzheimer's disease by state, 2017

State	Number of deaths	Mortality rate
Alabama	2563	52.6
Alaska	98	13.2
Arizona	3058	43.6
Arkansas	1436	47.8
California	16,238	41.1
Colorado	1830	32.6
Connecticut	1077	30.0
Delaware	377	39.2
District of Columbia	125	18.0
Florida	6980	33.3
Georgia	4298	41.1
Hawaii	465	32.6
Idaho	672	39.1
Illinois	4021	31.4
Indiana	2771	41.6
Iowa	1597	50.8
Kansas	894	30.7
Kentucky	1765	39.6
Louisiana	2188	46.7
Maine	601	45.0
Maryland	1191	19.7
Massachusetts	1841	26.8
Michigan	4428	44.4
Minnesota	2474	44.4
Mississippi	1626	54.5
Missouri	2545	41.6
Montana	285	27.1
Nebraska	698	36.4
Nevada	779	26.0
New Hampshire	436	32.5
New Jersey	2829	31.4
New Mexico	572	27.4
New York	3521	17.7
North Carolina	4289	41.7
North Dakota	387	51.2
Ohio	5117	43.9
Oklahoma	1752	44.6
Oregon	1850	44.7
Pennsylvania	4213	32.9
Rhode Island	435	41.1
South Carolina	2549	50.7
South Dakota	444	51.1
Tennessee	3522	52.4
Texas	9545	33.7
Utah	991	31.9
Vermont	370	59.3
Virginia	2549	30.1
Washington	3710	50.1
West Virginia	770	42.4
Wisconsin	2428	41.9
Wyoming	212	36.6
U.S. Total	**121,404**	**37.3**

Created from data from the National Center for Health Statistics [248].[A12]

4.6. Burden of Alzheimer's disease

The long duration of illness before death contributes significantly to the public health impact of Alzheimer's disease 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 takes into account not only the number of people with the condition, but also the number of years of life lost due to that disease and the number of healthy years of life lost by virtue of being in a state of disability. The primary measure of disease burden is called disability-adjusted life years (DALYs), which is the sum of the number of years of life lost due to premature mortality (YLLs) and the number of years lived with disability (YLDs), totaled across all those with the disease or injury. These measures indicate that Alzheimer's is a very burdensome disease, not only to the individuals with the disease, but also to their families and informal caregivers, and that the burden of Alzheimer's has increased more dramatically in the United States than the burden of other diseases in recent years. According to the most recent Global Burden of Disease classification system, Alzheimer's disease rose from the 12th most burdensome disease or injury in the United States in 1990 to the 6th in 2016 in terms of DALYs. In 2016, Alzheimer's disease was the 4th highest disease or injury in terms of YLLs and the 19th in terms of YLDs [270].

Taken together, these statistics indicate that not only is Alzheimer's disease responsible for the deaths of more and more Americans, but also that the disease is contributing to more and more cases of poor health and disability in the United States.

5. Caregiving

Caregiving refers to attending to another person's health needs. Caregiving often includes assistance with one or more activities of daily living (ADLs), including bathing and dressing, as well as multiple instrumental activities of daily living (IADLs), such as paying bills, shopping and using transportation [271,272]. Caregivers also provide emotional support to people with Alzheimer's as well as many other forms of help (e.g., communicating and coordinating care with other family members and health care providers, ensuring safety at home and elsewhere, and managing health conditions; see Table 7). More than 16 million Americans provide unpaid care for people with Alzheimer's or other dementias.[A13] In addition to providing descriptive information, this section compares caregivers of people with dementia to either caregivers of people with other medical conditions, or if that comparison is not available, to non-caregivers.

5.1. Unpaid caregivers

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers [273]. Nearly half of all caregivers (48 percent) who provide help to older adults do so for someone with Alzheimer's or another dementia [274]. In 2018, caregivers of people with Alzheimer's or other
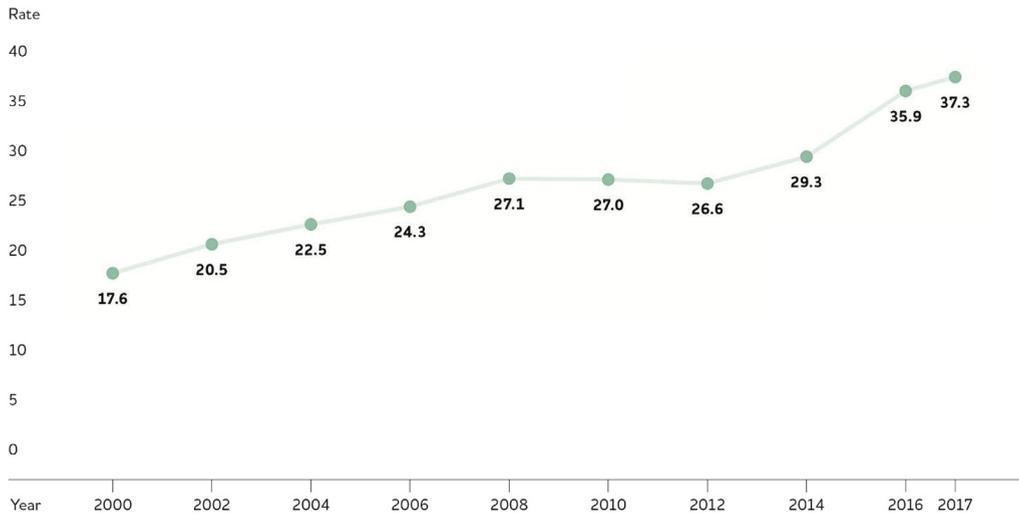
Fig. 6. U.S. annual Alzheimer's death rate (per 100,000 people) by year. Created from data from the National Center for Health Statistics [248].

dementias provided an estimated 18.5 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at $233.9 billion. This is approximately 46 percent of the net value of Walmart's total revenue in 2018 ($500.3 billion) [275] and 10 times the total revenue of McDonald's in 2017 ($22.8 billion) [276]. The total lifetime cost of care for someone with dementia was estimated at $350,174 in 2018 dollars. The costs associated with family care make up 70 percent of lifetime dementia care costs [277,278]. These estimates may underestimate the impact of a relative's dementia on family caregivers' health and workplace productivity [279].

The three primary reasons caregivers provide care and assistance to a person with Alzheimer's or another dementia are (1) the desire to keep a family member or friend at home (65 percent), (2) proximity to the person with dementia (48 percent) and (3) the caregiver's perceived obligation to the person with dementia (38 percent).[A14] Individuals with dementia living in the community are more likely than older adults without dementia to rely on multiple unpaid caregivers (often family members); 30 percent of older adults with dementia rely on three or more unpaid caregivers, whereas 23 percent of older adults without dementia rely on three or more unpaid caregivers [280]. Only a small percentage of older adults with dementia do not receive help from family

members or other informal care providers (8 percent). Of these individuals, nearly half live alone, perhaps making it more difficult to ask for and receive informal care [280]. Living alone with dementia may be a particular challenge for certain subgroups, such as lesbian, gay, bisexual and transgender (LGBT) individuals who may experience greater isolation for reasons ranging from social stigma to a diminished social network of available care providers [281].

5.1.1. Who are the caregivers?

Several sources have examined the demographic background of family caregivers of people with Alzheimer's or other dementias in the United States, and found the following [282–286]:[A14]

- Approximately two-thirds of dementia caregivers are women [282,283].[A14]
- About one in three caregivers (34 percent) is age 65 or older.[A14]
- Over 60 percent of caregivers are married, living with a partner or in a long-term relationship [283].[A14]
- Two-thirds of caregivers are non-Hispanic white [282,283,286],[A14] while 10 percent are black/African American, 8 percent are Hispanic, and 5 percent are Asian.[A14] These percentages may in part reflect the

Table 6
U.S. annual Alzheimer's death rates (per 100,000 people) by age and year

Age	2000	2002	2004	2006	2008	2010	2012	2014	2016	2017
45-54	0.2	0.1	0.2	0.2	0.2	0.3	0.2	0.2	0.2	0.2
55-64	2.0	1.9	1.8	2.1	2.2	2.1	2.2	2.1	2.7	2.8
65-74	18.7	19.6	19.5	19.9	21.1	19.8	17.9	19.6	23.6	24.5
75-84	139.6	157.7	168.5	175.0	192.5	184.5	175.4	185.6	214.1	219.7
85+	667.7	790.9	875.3	923.4	1002.2	987.1	936.1	1006.8	1216.9	1244.7

Created from data from the National Center for Health Statistics [248].[A12]

Table 7
Dementia caregiving tasks

Helping with instrumental activities of daily living (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 activities of daily living (ADLs), such as bathing, dressing, grooming and 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:
- 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.
- Managing other health conditions (i.e., "comorbidities"), such as arthritis, diabetes or cancer.
- Providing emotional support and a sense of security.

prevalence of Alzheimer's disease and related dementias among different racial/ethnic groups.
- Approximately 40 percent of dementia caregivers have a college degree or more education [283,286].[A14]
- Forty-one percent of caregivers have a household income of $50,000 or less.[A14]
- Among primary caregivers (individuals who indicate having the most responsibility for helping their relatives) of people with dementia, over half take care of their parents [285,287–289].
- Most caregivers (66 percent) live with the person with dementia in the community [280].
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers—meaning that they care not only for an aging parent, but also for children under age 18 [286,287].[A14]

5.1.2. Caregiving and women

The responsibilities of caring for someone with dementia often fall to women. As mentioned above, approximately two-thirds of dementia caregivers are women [282,283, 288,289],[A14] and over one-third of dementia caregivers are daughters [274,280]. It is more common for wives to provide informal care for a husband than vice versa [290]. On average, female caregivers spend more time caregiving than male caregivers [280]. According to the 2014 Alzheimer's Association Women and Alzheimer's Poll, which surveyed both men and women, of those providing care for 21 to more than 60 hours per week, 67 percent were women [291]. Similarly, the 2015-17 BRFSS surveys found that of all dementia caregivers who spend more than 40 hours per week providing care, 73 percent were women [287]. Two and a half times as many women reported living with the person with dementia full time [291]. Of those providing care to

someone with dementia for more than 5 years, 63 percent are women [287]. Similarly, caregivers who are women may experience slightly higher levels of burden, impaired mood, depression and impaired health than men, with evidence suggesting that these differences arise because female caregivers tend to spend more time caregiving, assume more caregiving tasks, and care for someone with more cognitive, functional and/or behavioral problems [292,293]. Of dementia caregivers who indicate a need for individual counseling, support groups or respite care, the large majority are women (individual counseling, 83 percent versus 17 percent; support groups, 73 percent versus 27 percent; and respite care, 71.5 percent versus 28.5 percent) [287].

5.1.3. Caregiving tasks

The care provided to people with Alzheimer's or other dementias is wide-ranging and in some instances all encompassing. Table 7 summarizes some of the most common types of dementia care provided.

Though the care provided by family members of people with Alzheimer's or 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 to monitor the health of people living with dementia than are caregivers of people without dementia (79 percent vs. 66 percent) [294]. Data from the 2011 National Health and Aging Trends Study [273,282] indicated that caregivers of people with dementia are more likely than caregivers of people without dementia to provide help with self care and mobility (85 percent vs. 71 percent) and health or medical care (63 percent vs. 52 percent). Seventy-seven percent of older adults with dementia receive informal assistance with at least one ADL or household
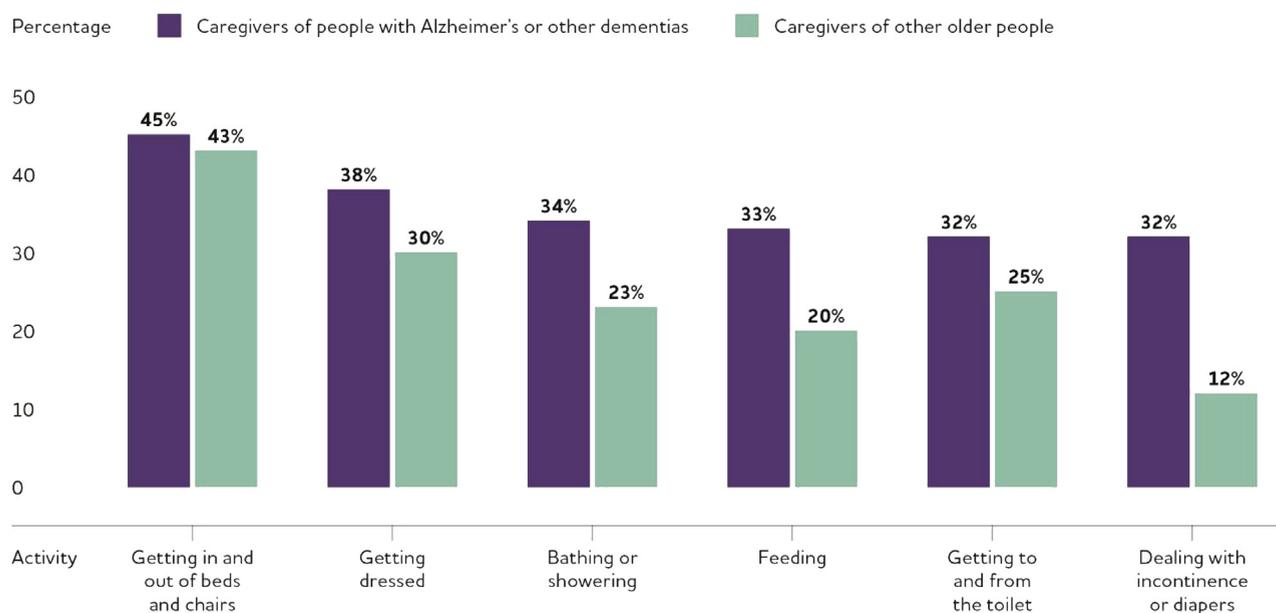
Fig. 7. Proportion of caregivers of people with Alzheimer's or other dementias versus caregivers of other older people who provide help with specific activities of daily living, United States, 2015. Created from data from the National Alliance for Caregiving and AARP [286].

activity in contrast to only 20 percent of older adults without dementia; nearly 40 percent of people with dementia receive informal help with three or more ADLs compared with 14 percent of people without dementia [280]. Fig. 7 illustrates how family caregivers of people with dementia are more likely than caregivers of other older people to assist with ADLs. Over half of individuals with dementia (53 percent) receive assistance from family members or other informal caregivers for ADLs compared with 11 percent of older adults without dementia [286].

In addition to assisting with ADLs, more caregivers of people with Alzheimer's or other dementias advocate for these individuals with community agencies and care providers (65 percent) and manage finances (68 percent) compared with caregivers of people without dementia (46 percent and 50 percent, respectively) [286]. More caregivers of people with Alzheimer's or other dementias arrange for outside services (46 percent) and communicate with health care professionals (80 percent) compared with caregivers of people without dementia (27 percent and 59 percent, respectively) [286]. Caregivers of people with dementia are more likely to coordinate health care for these individuals than caregivers of people without dementia (86 percent vs. 72 percent) [282]. One in five caregivers of people with Alzheimer's or other dementias (22 percent) report problems dealing with a bank or credit union when helping to manage the finances of people living with dementia, compared with 9 percent of caregivers of people without dementia [286]. Caring for a person with dementia also means managing symptoms that caregivers of people with other diseases may not face, such as neuropsychiatric symptoms (for example, anxiety, apathy and lack of

inhibition) and severe behavioral problems. Family caregivers of people with Alzheimer's or other dementias are more likely than family caregivers of people without dementia to help with emotional or mental health problems (41 percent vs. 16 percent) and behavioral issues (15 percent vs. 4 percent) [286].

When a person with Alzheimer's or another dementia moves to an assisted living residence or a nursing home, the help provided by his or her family caregiver usually changes from the comprehensive care summarized in Table 7 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 [295–297].

5.1.4. Duration of caregiving

Eighty-six percent of dementia caregivers have provided care and assistance for at least the past year, according to the national 2014 Alzheimer's Association Women and Alzheimer's Poll.[A14] According to another study, well over half (57 percent) of family caregivers of people with Alzheimer's or other dementias in the community had provided care for 4 or more years [280]. More than six in 10 (63 percent) Alzheimer's caregivers expect to continue having care responsibilities for the next 5 years compared with less than half of caregivers of people without dementia (49 percent) [286].

5.1.5. Hours of unpaid care and economic value of caregiving

In 2018, the 16.2 million family and other unpaid caregivers of people with Alzheimer's or other dementias

provided an estimated 18.5 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.[A15] With this care valued at $12.64 per hour,[A16] the estimated economic value of care provided by family and other unpaid caregivers of people with dementia across the United States was $233.9 billion in 2018. Table 8 shows the total hours of unpaid care as well as the value of care provided by family and other unpaid caregivers for the United States and each state. Unpaid caregivers of people with Alzheimer's or other dementias provided care valued at more than $4 billion in each of 21 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. A longitudinal study of the monetary value of family caregiving for people with dementia found that the overall value of daily family care increased 18 percent with each additional year of providing care, and that the value of this care increased as the people living with dementia's cognitive abilities declined [298,299]. Additional research is needed to estimate the future value of family care for people with Alzheimer's disease and other dementias as the U.S. population continues to age.

Apart from its long duration, the immediate demands of caregiving are also time-intensive. Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours vs. 65 hours) than caregivers of people without dementia, with over half providing more than 21 hours of care per week [282,294]. A 2017 national poll found that 42 percent of caregivers of people with dementia provided care for an average of 9 hours per day [289]. An analysis of national caregiving trends from 1999 to 2015 found that the average hours of care per week increased from 45 in 1999 to 48 in 2015 for dementia caregivers; over the same time period, weekly hours of care decreased for non-dementia caregivers from 34 to 24 [300].

5.1.6. Impact of Alzheimer's caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. For example, people in the middle to later stages of Alzheimer's experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people with Alzheimer's manage these issues. The personality and behavior of a person with Alzheimer's are affected as well, and these changes are often among the most challenging for family caregivers [301–303]. Individuals with Alzheimer's also require increasing levels of supervision and personal care as the disease progresses. As symptoms worsen, the care required of family members can result in increased emotional stress and depression; new or exacerbated health problems; and depleted income and finances due in part to disruptions in employment and paying for health care or other services for themselves and people living with dementia [304–312].

5.1.6.1. Caregiver emotional and social well-being

The intimacy, shared experiences and memories that are often part of the relationship between a caregiver and person living with dementia may also be threatened due to the memory loss, functional impairment and psychiatric/behavioral disturbances that can accompany the progression of Alzheimer's. However, in a national poll, 45 percent of respondents indicated that caring for someone with dementia was very rewarding [289]. Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others [313–318],[A14] they also frequently report higher levels of stress.

5.1.6.1.1. Stress

- More dementia caregivers were classified as having a high level of burden than caregivers of people without dementia (46 percent vs. 38 percent) based on the 2015 National Alliance for Caregiving/American Association of Retired Persons (NAC/AARP) survey's Burden of Care Index, which combined the number of hours of care and the number of ADL tasks performed by the caregiver into a single numerical score [286].
- Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties [282].
- Fifty-nine percent of family caregivers of people with Alzheimer's or other dementias rated the emotional stress of caregiving as high or very high (Fig. 8).[A14] Nearly half of dementia caregivers (49 percent) indicate that providing help is highly stressful compared with 35 percent of caregivers of people without dementia [286].

5.1.6.1.2. Depression and mental health

- Approximately 30 to 40 percent of family caregivers of people with dementia suffer from depression, compared with 5 to 17 percent of non-caregivers of similar ages [319–324]. A recent meta-analysis reported that caregivers of people with dementia were significantly more likely to experience depression and anxiety than non-caregivers [293].
- The prevalence of depression (see above) is higher among dementia caregivers than other caregivers, such as those who provide help to individuals with schizophrenia (20 percent) or stroke (19 percent) [323–325].
- Depression risk increases as cognitive impairment worsens in the person with dementia [326].
- In a meta-analysis, type of relationship was the strongest predictor of caregiver depression; caregivers of spouses had two and a half times higher odds of having depression than caregivers of people who were not spouses [323].

Table 8
Number of caregivers of people with Alzheimer's or other dementias, hours of unpaid care, economic value of unpaid care and higher health care costs of caregivers by state, 2018*

State	Number of caregivers (in thousands)	Hours of unpaid care (in millions)	Value of unpaid care (in millions of dollars)	Higher health care costs of caregivers (in millions of dollars)[†]
Alabama	305	347	$4392	$200
Alaska	33	38	479	33
Arizona	339	386	4883	198
Arkansas	178	203	2560	119
California	1621	1846	23,337	1109
Colorado	252	287	3631	155
Connecticut	178	202	2559	158
Delaware	55	62	786	50
District of Columbia	29	33	415	31
Florida	1141	1299	16,419	832
Georgia	533	607	7678	317
Hawaii	65	74	941	43
Idaho	85	97	1223	53
Illinois	588	670	8471	440
Indiana	340	387	4890	255
Iowa	136	155	1961	101
Kansas	151	172	2179	105
Kentucky	273	311	3936	197
Louisiana	232	264	3335	164
Maine	69	79	998	60
Maryland	293	334	4224	228
Massachusetts	340	387	4889	324
Michigan	517	589	7444	376
Minnesota	255	291	3677	205
Mississippi	207	236	2979	142
Missouri	317	361	4568	232
Montana	50	57	723	37
Nebraska	83	94	1190	63
Nevada	151	172	2168	91
New Hampshire	68	77	974	59
New Jersey	448	511	6455	359
New Mexico	108	123	1552	70
New York	1014	1155	14,594	895
North Carolina	473	538	6806	311
North Dakota	30	35	437	27
Ohio	603	687	8681	474
Oklahoma	224	256	3230	154
Oregon	186	212	2682	136
Pennsylvania	676	770	9732	565
Rhode Island	53	61	769	46
South Carolina	313	357	4511	206
South Dakota	38	44	552	31
Tennessee	439	500	6324	291
Texas	1429	1627	20,570	903
Utah	155	177	2235	84
Vermont	30	34	434	28
Virginia	465	529	6693	317
Washington	348	396	5011	249
West Virginia	106	121	1527	90
Wisconsin	195	222	2802	154
Wyoming	28	31	396	21
U.S. Total	**16,250**	**18,505**	**$233,903**	**$11,789**

*State totals may not add to the U.S. total due to rounding.
[†]Higher health care costs are the dollar amount difference between the weighted per capita personal health care spending of caregivers and non-caregivers in each state.[A17]
Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare & Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.[A13,A15–A17]
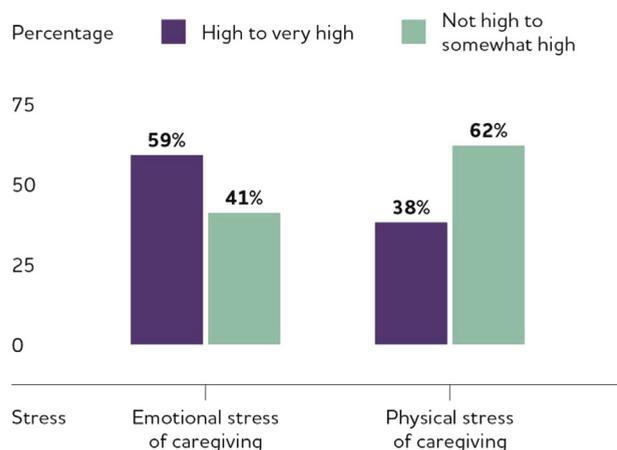
Fig. 8. Proportion of caregivers of people with Alzheimer's or other dementias who report high to very high emotional and physical stress due to caregiving. Created from data from the Alzheimer's Association.[A14]

- The prevalence of anxiety among dementia caregivers is 44 percent, which is higher than among caregivers of people with stroke (31 percent), for example [323,324].
- Caregivers of individuals with Alzheimer's report more subjective cognitive problems (for example, problems with memory) and experience greater declines in cognition over time than non-caregivers matched on age and other characteristics [327,328].
- Caring for people with dementia who have four or more behavioral and psychological symptoms (for example, aggression, self-harm and wandering) represents a "tipping point" for family caregivers, as they are more likely to report clinically meaningful depression and burden [329].

5.1.6.1.3. Strain

- Caregivers of people with Alzheimer's or other dementias were twice as likely as caregivers of individuals without dementia (22 percent compared with 11 percent) to report that completing medical/nursing-related tasks (for example, injections, tube feedings and catheter/colostomy care) was difficult [294].
- More than half of caregivers (51 percent) of people with Alzheimer's or another dementia indicate having no experience performing medical/nursing-related tasks [294], and they often lack the information or resources necessary to manage complex medication regimens [330–333].
- According to the 2014 Alzheimer's Association poll of caregivers, respondents often believed they had no choice in taking on the role of caregiver.[A14]
- The poll also found that more than half of women with children under age 18 felt that caregiving for someone with Alzheimer's was more challenging than caring for children (53 percent).[A14]

- Many caregivers of people with Alzheimer's or other dementias provide help alone. Forty-one percent of dementia caregivers in the 2014 Alzheimer's Association poll reported that no one else provided unpaid assistance.[A14]
- A population-based sample of caregivers found that although dementia caregivers indicated greater strain than non-dementia caregivers, no substantial differences in strain between white and black/African-American dementia caregivers were evident [334].

5.1.6.1.4. Stress of care transitions

- Admitting a relative to a residential care facility 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 following admission [297,335,336].
- The demands of caregiving may intensify as people with dementia approach the end of life [337]. In the year before the death of the person living with dementia, 59 percent of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful [338]. The same study found that 72 percent of family caregivers experienced relief when the person with Alzheimer's or another dementia died [338].

5.1.6.2. Caregiver physical health

For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of providing dementia care increases caregivers' susceptibility to disease and health complications [339]. As shown in Fig. 8, 38 percent of Alzheimer's and dementia caregivers indicate that the physical stress of caregiving is high to very high.[A14] Building on this, a recent analysis found that 29 percent of caregivers of people with Alzheimer's or other dementias report that providing care results in high physical strain compared with 17 percent of caregivers of people without dementia [286]. The distress associated with caring for a relative with Alzheimer's or another dementia has also been shown to negatively influence the quality of family caregivers' sleep [340,341].

5.1.6.2.1. General health

Seventy-four percent of caregivers of people with Alzheimer's or other dementias reported that they were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver.[A14] Forty-two percent of caregivers of people with Alzheimer's or another dementia report that their health is excellent or very good, which is lower than caregivers of people without dementia (50 percent) [286]. In addition, 35 percent of caregivers of people with Alzheimer's or another dementia report that their health has gotten worse due to care

responsibilities compared with 19 percent of caregivers of people without dementia [286]. A 2017 poll reported that 27 percent of dementia caregivers delayed or did not do things they should for their own health [289]. Dementia caregivers indicated lower health-related quality of life than non-caregivers and are more likely than non-caregivers or other caregivers to report that their health is fair or poor [306,310,342–344]. Data from the Health and Retirement Study showed that dementia caregivers who provided care to spouses were much more likely (41 percent increased odds) than other spousal caregivers of similar age to become increasingly frail during the time between becoming a caregiver and their spouse's death [345]. Other studies, however, suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers [346].

5.1.6.2.2. *Physiological changes*

The chronic stress of caregiving may be associated with physiological changes that could increase the risk of developing chronic conditions. For example, several studies found that under certain circumstances some Alzheimer's caregivers were more likely to have elevated biomarkers of cardiovascular disease risk and impaired kidney function risk than those who were not caregivers [347–352].

Caregivers of a spouse with Alzheimer's or another dementia are more likely than married non-caregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones [353], impaired immune function [304,354], slow wound healing [355], coronary heart disease [356], impaired function of the endothelium (the inner lining of blood vessels) and increased incidence of hypertension [304,353–360]. However, reviews of studies examining the association between caregiving and biomarkers of stress and inflammation (e.g., cortisol) found few consistent results, suggesting the need for greater work in this area.

5.1.6.2.3. *Health care*

The physical and emotional impact of dementia caregiving is estimated to have resulted in $11.8 billion in health care costs in the United States in 2018.[A17] Table 8 shows the estimated higher health care costs for caregivers of people with Alzheimer's or other dementias in each state. In separate studies, hospitalization and emergency department visits were more likely for dementia caregivers who helped care for people who were depressed, had low functional status or had behavioral disturbances [361,362]. Increased depressive symptoms among caregivers over time are also linked to more frequent doctor visits, a higher number of outpatient tests and procedures, and greater use of over-the-counter and prescription medications [362].

5.1.6.2.4. *Mortality*

The health of a person with dementia may also affect the caregiver's risk of dying, although studies have reported mixed findings [363]. 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 (after accounting for differences in caregiver age) [364]. Another study found that caregivers who perceive higher strain due to care responsibilities are at higher risk for death than caregivers who perceive little or no strain [365].

5.1.6.3. *Caregiver employment and finances*

Six in 10 caregivers of people with Alzheimer's or another dementia were employed in the past year while providing care [286]. These individuals worked an average of 35 hours per week while caregiving [286]. Among people who were employed in the past year while providing care to someone with Alzheimer's or another dementia, 57 percent reported sometimes needing to go in late or leave early compared with 47 percent of non-dementia caregivers. Eighteen percent of dementia caregivers reduced their work hours due to care responsibilities, compared with 13 percent of non-dementia caregivers. Other work-related changes among dementia and non-dementia caregivers who had been employed in the past year are summarized in Fig. 9 [286].

In 2018, dementia caregivers reported nearly twice the average out-of-pocket costs (e.g., medical, personal care and household expenses for the person with dementia; personal expenses and respite services for the caregiver) of non-dementia caregivers ($11,233 versus $6075) [278,366]. Data from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey reported in *2016 Alzheimer's Disease Facts and Figures* indicated that among care contributors (a friend or relative who paid for dementia expenses and/or provided care for someone with dementia at least once a month in the prior year), 48 percent cut back on spending and 43 percent cut back on saving due to the out-of pocket costs of providing help to someone with dementia [311]. Due to care responsibilities in the year prior to the survey, close to four in 10 care contributors indicated that the "food they bought just didn't last, and they didn't have money to get more," and three in 10 ate less because of care-related costs [311].

5.1.7. *Interventions designed to assist caregivers*

For more than 30 years, strategies to support family caregivers of people with Alzheimer's have been developed and evaluated. The types and focus of these strategies (often called "interventions") are summarized in Table 9 [308,367].

In general, the goal of interventions is to improve the health and well-being of dementia caregivers by relieving the negative aspects of caregiving. Some also aim to delay nursing home admission of the person with dementia by providing caregivers with skills and resources (emotional, social, psychological, and/or technological) to continue
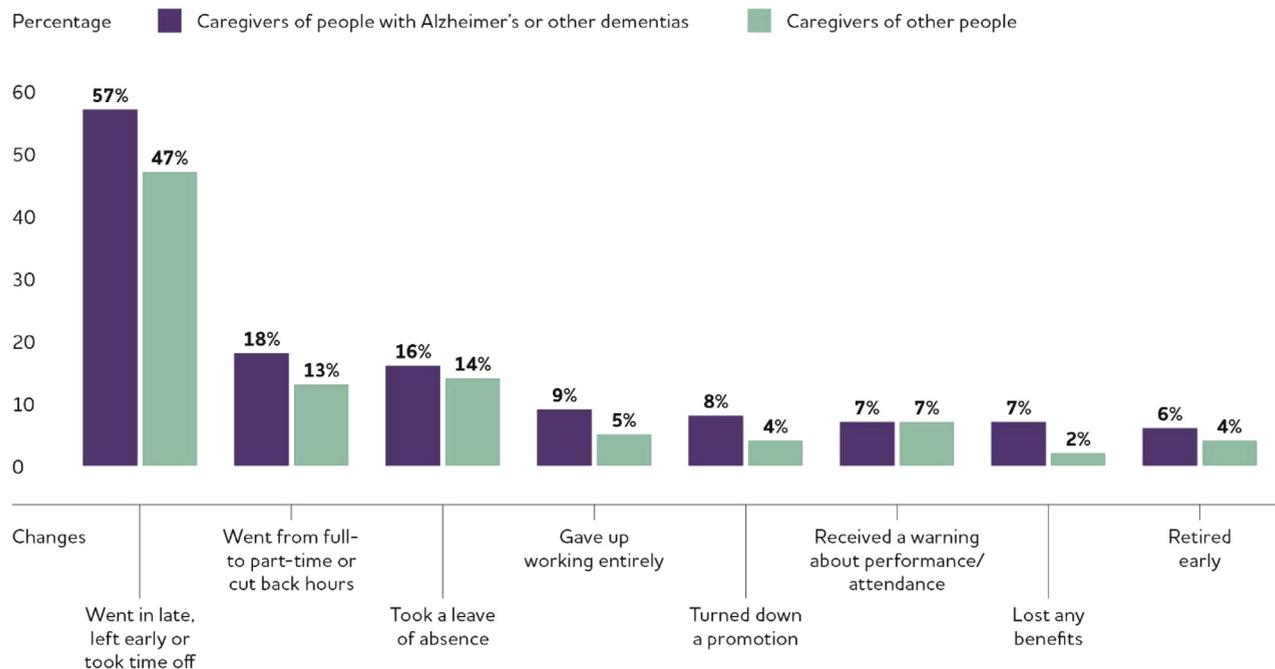
Fig. 9. Work-related changes among caregivers of people with Alzheimer's or other dementias who had been employed at any time since they began caregiving. Created from data from the National Alliance for Caregiving and AARP [286].

helping their relatives or friends at home. Specific approaches used in various interventions include providing education to caregivers, helping caregivers manage dementia-related symptoms, improving social support for caregivers and providing caregivers with respite from caregiving duties.

According to a publication on dementia caregiver interventions that reviewed seven meta-analyses and 17 systematic reviews of randomized controlled trials, the following characteristics distinguish interventions that are effective: family caregivers are actively involved in the intervention, in contrast to passively receiving infor-

mation; the intervention is tailored and flexible to meet the changing needs of family caregivers during the course of a relative's dementia; and the intervention meets the needs not only of caregivers, but of people living with dementia as well [368]. A 2012 report identified 44 interventions in the United States that have benefits for individuals with Alzheimer's or other dementias as well as their family caregivers, based on randomized, controlled studies, and more such evaluations are emerging each year [369,370]. A meta-analysis examined the components of dementia caregiver interventions that are most beneficial.

Table 9
Type and focus of caregiver interventions

Type	Focus
Case management	Provides assessment, information, planning, referral, care coordination and/or advocacy for family caregivers.
Psychoeducational approaches	Include 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 (that is, cognitive impairment, behavioral symptoms and care-related needs). Include lectures, discussions and written materials and are led by professionals with specialized training.
Counseling	Aims to resolve pre-existing personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Support groups	Are less structured than psychoeducational or psychotherapeutic interventions. Support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of social isolation.
Respite	Provides 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.
Psychotherapeutic approaches	Involve the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, 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	Are characterized by 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).

Created from data from Pinquart and colleagues and Gaugler and colleagues [308,367].

Interventions that address caregiving competency initially, gradually address the care needs of the person with dementia, and offer emotional support for loss and grief only when needed appeared most effective in reducing depression among dementia caregivers [371]. Interventions for dementia caregivers that have demonstrated efficacy in scientific evaluations have been gradually implemented in the community, but are still not widespread or available to all family caregivers [372–386]. When interventions are implemented, they are generally successful at improving how caregiver services are delivered, and have the potential to reach a large number of families while also helping caregivers cope with their responsibilities [387]. In one example, researchers utilized an "agile implementation" process to more rapidly select, localize, evaluate, and replicate a collaborative care model for dementia care. This care model has successfully operated for nearly a decade in an Indianapolis health care system [388]. Other efforts have attempted to broaden the reach and accessibility of interventions for dementia caregivers through the use of technologies (for instance, video-phone delivery and online training) and have shown some success [389–396]. The 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers convened many of the leading experts in research, practice, and policy in dementia care and identified similar research priorities in these areas [397].

Because caregivers and the settings in which they provide care are diverse, more studies are required to define which interventions are most effective for specific situations and how these interventions are successful [398–401]. Improved tools and measures to personalize services for caregivers to maximize their benefits represent an emerging area of research [402–407]. More studies are also needed to adapt proven interventions or develop new intervention approaches for families from different racial, ethnic and socioeconomic backgrounds and from different geographic settings. Additional research on interventions focused on disease stages is also needed, as well as research on specific intervention needs for LGBT caregivers [281,408–420].

5.2. Paid caregivers

5.2.1. Direct-care workers for people with Alzheimer's or other dementias

Direct-care workers, such as nurse aides, home health aides, and personal and home care aides, provide most of the paid long-term care to older adults living at home or in residential settings [421,422]. In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents [423–425]. Nursing assistants help with bathing, dressing, housekeeping, food preparation and other activities. Most nursing assistants are women, and they come from increasingly diverse ethnic, racial and geographic backgrounds.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care [424,426–428]. Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges [427,429]. Inadequate education and challenging work environments have also contributed to higher turnover rates among nursing staff across care environments [430]. Studies have shown that staff training programs to improve the quality of dementia care in nursing homes and hospitals have modest benefits [426,431–435]. The National Academies of Sciences, Engineering, and Medicine have recommended that federal requirements for general direct-care worker training be increased from 75 hours to 120 hours, and that instruction content focus more on knowledge and skills related to caring for individuals with Alzheimer's and other dementias [427,428].

5.2.2. Shortage of geriatric health care professionals

Professionals who may receive special training in caring for older adults include physicians, nurse practitioners, registered nurses, social workers, pharmacists, physician assistants and case workers [427]. It is estimated that the United States has approximately half the number of certified geriatricians that it currently needs [436]. As of 2016, there were 7293 certified geriatricians in the United States, or one geriatrician for every 1924 Americans age 65 or older in need of care [437]. The American Geriatrics Society estimates that, due to the increase in vulnerable older Americans who require geriatric care, an additional 23,750 geriatricians should be trained between now and 2030 to meet the needs of an aging U.S. population [438]. There were 234,000 nurse practitioners in the United States in 2016. Nine percent of nurse practitioners had special expertise in gerontological care, and 4 percent of nurse practitioners had expertise in gerontological care with a primary care focus [439]. Less than 1 percent of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics [427]. Although 73 percent of social workers serve clients age 55 and older, only 4 percent have formal certification in geriatric social work [427]. Furthermore, the overall aging of the long-term care workforce may affect the number of paid caregivers [430].

5.2.3. Enhancing health care for family caregivers

There is a growing consensus that professionals caring for people with Alzheimer's and other dementias should acknowledge the role family caregivers play in facilitating the treatment of dementia, and that professionals should assess the well-being of family caregivers to improve overall disease management of the person with dementia [440–444]. Recognizing that the complex care challenges of people with dementia also require interprofessional collaboration and education [445,446], ongoing efforts have attempted to integrate innovative care management practices with traditional primary care for people with dementia [447–450]. One example involves a skilled

professional who serves as the care manager of the person with dementia. The care manager collaborates with primary care physicians and nurse practitioners to develop personalized care plans. These plans can provide support to family caregivers, help people with dementia manage care transitions (for example, a change in care provider or site of care), and ensure the person with dementia has access to appropriate community-based services. Other models include addressing the needs of family caregivers simultaneously with comprehensive disease management of the people living with dementia to improve the quality of life of both family caregivers and people with dementia in the community [451]. Several evaluations have suggested that such approaches have considerable potential for improving outcomes for people with dementia and their family caregivers (for example, delayed nursing home admission and reduction in caregiver distress) [452–459]. Current research is attempting to determine the feasibility of these models beyond the specialty settings in which they currently operate [460,461].

In 2016, the National Academies of Sciences, Engineering, and Medicine released *Families Caring for an Aging America,* a seminal report that includes a number of recommendations to refocus national health care reform efforts from models of care that center on the patient (person-centered care) to models of care that also explicitly engage and support the patient's family (person- and family-centered care) [462]. These service models recognize the important role family members play in providing care and incorporate family caregivers during the delivery of health care to their relatives with dementia. Furthermore, these models encourage health care providers to deliver evidence-based services and support to both caregivers and people living with dementia [462,463].

In January 2017, Medicare began reimbursing physicians, physician assistants, nurse practitioners and clinical nurse specialists for health care visits that result in a comprehensive dementia care plan. Comprehensive care planning is a core element of effective dementia care management and can result in the delivery of services that potentially enhance quality of life for people with dementia and their caregivers. Effective care planning for people living with dementia should include family caregivers. The Alzheimer's Association has developed a care planning kit (alz.org/careplanning) to help guide providers to deliver effective care planning for people with dementia and their family caregivers.

5.3. Trends in dementia caregiving

There is some indication that families are better managing the care they provide to relatives with dementia than in the past. From 1999 to 2015, dementia caregivers were significantly less likely to report physical difficulties (from 30 percent in 1999 to 17 percent in 2015) and financial difficulties (from 22 percent in 1999 to 9 percent in 2015)
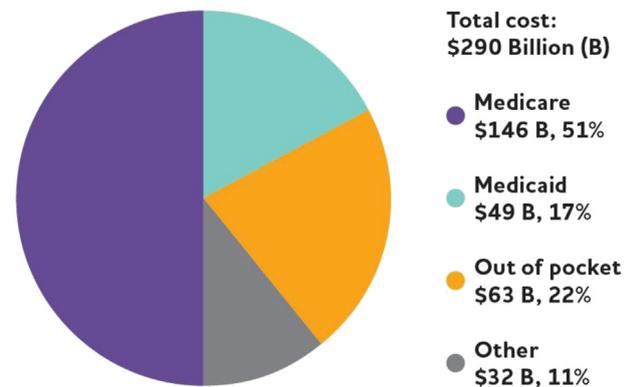

Fig. 10. Distribution of aggregate costs of care by payment source for Americans age ≥65 years with Alzheimer's or other dementias, 2019. Data are in 2019 dollars. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care. Created from data from the Lewin Model.[A18]

related to care provision. In addition, use of respite care by dementia caregivers increased substantially (from 13 percent in 1999 to 27 percent in 2015) [300]. However, as noted above, more work is needed to ensure that interventions for dementia caregivers are available and accessible to those who need them. A 2016 study of the Older Americans Act's National Family Caregiver Support Program found that over half (52 percent) of Area Agencies on Aging did not offer evidence-based family caregiver interventions [464].

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

The costs of health care and long-term care for individuals with Alzheimer's or other dementias are substantial, and dementia is one of the costliest conditions to society [465]. Total payments in 2019 (in 2019 dollars) for all individuals with Alzheimer's or other dementias are estimated at $290 billion (Fig. 10). Medicare and Medicaid are expected to cover $195 billion, or 67 percent, of the total health care and long-term care payments for people with Alzheimer's or other dementias. Out-of-pocket spending is expected to be $63 billion, or 22 percent, of total payments.[A18] Throughout the rest of this section, all costs are reported in 2018 dollars unless otherwise indicated.[A19]

6.1. Total cost of health care and long-term care

Table 10 reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias. Total per-person health care and long-term care payments in 2018 from all sources for Medicare beneficiaries with Alzheimer's or other dementias were over three times as great as payments for other Medicare beneficiaries in the same age group ($48,977 per person

Table 10
Average annual per-person payments by payment source for health care and long-term care services, Medicare beneficiaries age ≥65 years, with and without Alzheimer's or other dementias, in 2018 dollars

Payment source	Beneficiaries with Alzheimer's or other dementias	Beneficiaries without Alzheimer's or other dementias
Medicare	$24,598	$7561
Medicaid	8565	365
Uncompensated	381	382
Health maintenance organization	1261	1544
Private insurance	2253	1422
Other payer	937	242
Out of pocket	10,798	2336
Total*	**48,977**	**13,976**

*Payments from sources do not equal total payments exactly due to the effects of population weighting. Payments for all beneficiaries with Alzheimer's or other dementias include payments for community-dwelling and facility-dwelling beneficiaries.
Created from unpublished data from the Medicare Current Beneficiary Survey for 2011 [466].

for those with dementia compared with $13,976 per person for those without dementia) [466].[A20]

Twenty-seven percent of older individuals with Alzheimer's or other dementias who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without dementia [466]. 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 with dementia translates into high costs to Medicaid. Average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias ($8565) were 23 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias ($365) (Table 10) [466].

Despite these and other sources of financial assistance, individuals with Alzheimer's or 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. On average, Medicare beneficiaries age 65 and older with Alzheimer's or other dementias paid $10,798 out of pocket annually for health care and long-term care services not covered by other sources (Table 10) [466].

Researchers have evaluated the additional or "incremental" health care, residential long-term care and family caregiving costs of dementia (that is, the costs specifically attributed to dementia when comparing people with and without dementia who have the same coexisting medical conditions and demographic characteristics) [277,465,467,468]. One group of researchers found that the incremental health care and nursing home costs for those with dementia were $28,501 per person per year in 2010 dollars ($35,512 in 2018 dollars) [465].[A19,A21] Another group of researchers found that the incremental

lifetime cost of Alzheimer's dementia was substantially higher for women than men, due to a greater lifetime risk of developing Alzheimer's dementia (see Prevalence section) [469]. Additionally, because women are more likely to be widowed and living in poverty, the incremental Medicaid costs associated with Alzheimer's dementia were 70 percent higher for women than men. A third group of researchers found that the lifetime cost of care, including out-of-pocket, Medicare and Medicaid expenditures, and the value of informal caregiving, was $321,780 per person with Alzheimer's dementia in 2015 dollars ($350,174 in 2018 dollars) [277]. Compared with an individual without Alzheimer's dementia, the incremental lifetime cost of Alzheimer's dementia was $184,500 ($199,871 in 2018 dollars). Another group of researchers found that community-dwelling individuals age 65 and older with Alzheimer's dementia had $1101 (in 2012 dollars; $1284 in 2018 dollars) higher out-of-pocket health care spending than individuals without Alzheimer's dementia, after controlling for differences in patient characteristics [470]. The largest portion of this difference was due to higher spending on home health care and prescription drugs. Furthermore, individuals with Alzheimer's dementia spent 12 percent of their income on out-of-pocket health care services compared with 7 percent for individuals without Alzheimer's dementia.

Other researchers compared end-of-life costs for individuals with and without dementia and found that the total cost in the last 5 years of life was $287,038 per person for individuals with dementia in 2010 dollars and $183,001 per person for individuals without dementia ($357,650 and $228,020, respectively, in 2018 dollars), a difference of 57 percent [471]. Additionally, out-of-pocket costs represented a substantially larger proportion of total wealth for those with dementia than for people without dementia (32 percent vs. 11 percent).

6.2. Use and costs of health care services

6.2.1. Use of health care services

People with Alzheimer's or other dementias have twice as many hospital stays per year as other older people [472]. Moreover, the use of health care services by 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 Alzheimer's or other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

In addition to having more hospital stays, older people with Alzheimer's or other dementias have more skilled nursing facility stays and home health care visits per year than other older people.

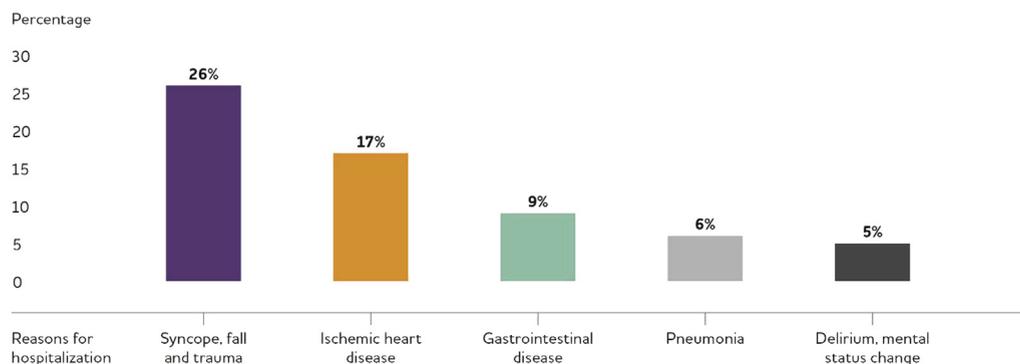- Hospital. There are 538 hospital stays per 1000 Medicare beneficiaries age 65 and older with Alzheimer's or

Fig. 11. Reasons for hospitalization of individuals with Alzheimer's dementia: Percentage of hospitalized individuals by admitting diagnosis. All hospitalizations for individuals with a clinical diagnosis of probable or possible Alzheimer's were used to calculate percentages. The remaining 37 percent of hospitalizations were due to other reasons. Created from data from Rudolph and colleagues [474].

other dementias compared with 266 hospital stays per 1000 Medicare beneficiaries age 65 and older without these conditions [472]. A person with dementia in 2012 had, on average, 23 inpatient days—defined as days in a hospital or skilled nursing facility—compared with 5 days for the Medicare population as a whole [473]. The most common reasons for hospitalization of people with Alzheimer's dementia are syncope (fainting), fall and trauma (26 percent); ischemic heart disease (17 percent); and gastrointestinal disease (9 percent) (Fig. 11) [474]. In a study of inpatient hospitalizations of adults age 60 and older, those with Alzheimer's were at 7 percent greater risk of dying during the hospital stay and stayed nearly a day longer than individuals without Alzheimer's dementia [475]. Among Medicare beneficiaries with Alzheimer's or other dementias, 21 percent of hospital stays are followed by a readmission within 30 days [466]. (While not directly comparable, one study of a portion of Medicare beneficiaries found an overall 30-day readmission rate of 18 percent [476].)

- Emergency department. There are 1471 emergency department visits per 1000 Medicare beneficiaries with Alzheimer's or other dementias per year [477]. (While not directly comparable, there were 640 emergency department visits per 1000 Medicare beneficiaries per year in a review of utilization patterns of a subset of Medicare beneficiaries [476].)
- 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 [478]. There are 283 skilled nursing facility stays per 1000 beneficiaries with Alzheimer's or other dementias per year compared with 73 stays per 1000 beneficiaries without these conditions—a rate nearly four times as great [472].
- Home health care. Twenty-five percent of Medicare beneficiaries age 65 and older with Alzheimer's or

other dementias have at least one home health care visit during the year, compared with 10 percent of Medicare beneficiaries age 65 and older without Alzheimer's or other dementias [472].

6.2.2. Costs of health care services

Average per-person payments for health care services (hospital, physician and other medical provider, nursing home, skilled nursing facility, hospice and home health care) and prescription medications were higher for Medicare beneficiaries with Alzheimer's or other dementias than for other Medicare beneficiaries in the same age group (Table 11) [466].

6.2.3. Use and costs of health care service by state

Substantial geographic variation exists in health care utilization and Medicare payments by individuals with Alzheimer's or other dementias (Table 12). Emergency

Table 11
Average annual per-person payments by type of service for health care and long-term care services, Medicare beneficiaries age ≥65 years, with and without Alzheimer's or other dementias, in 2018 dollars

Service	Beneficiaries with Alzheimer's or other dementias	Beneficiaries without Alzheimer's or other dementias
Inpatient hospital	$11,306	$3652
Medical provider*	5728	3568
Skilled nursing facility	6977	477
Nursing home	15,984	774
Hospice	2060	156
Home health care	2578	374
Prescription medications†	3503	3005

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

†Information on payments for prescription medications is only available for people who were living in the community, that is, not in a nursing home or an assisted living facility. Created from unpublished data from the Medicare Current Beneficiary Survey for 2011 [466].

Table 12
Emergency department (ED) visits, hospital readmissions and per capita
Medicare payments in 2018 dollars by Medicare beneficiaries with
Alzheimer's or other dementias by state, 2015

State	Number of ED visits per 1000 beneficiaries	Percentage of hospital stays followed by readmission within 30 days	Per capita Medicare payments
Alabama	1366	20.7	$22,075
Alaska	1398	18.2	22,062
Arizona	1441	19.1	24,356
Arkansas	1510	21.2	21,782
California	1428	21.7	30,665
Colorado	1383	16.9	21,840
Connecticut	1483	21.2	27,290
Delaware	1576	20.7	28,522
District of Columbia	1737	25.2	30,291
Florida	1482	23.1	28,636
Georgia	1528	21.1	23,698
Hawaii	1074	16.1	17,965
Idaho	1305	14.7	19,478
Illinois	1528	21.9	27,193
Indiana	1419	19.6	24,969
Iowa	1243	16.8	17,265
Kansas	1308	18.0	21,394
Kentucky	1635	22.2	23,703
Louisiana	1703	21.2	28,935
Maine	1574	17.9	19,827
Maryland	1509	22.1	29,011
Massachusetts	1504	22.5	28,996
Michigan	1598	23.4	27,244
Minnesota	1279	18.7	20,430
Mississippi	1685	22.2	26,758
Missouri	1458	21.7	22,425
Montana	1230	16.3	17,455
Nebraska	1092	16.8	20,251
Nevada	1592	23.0	32,006
New Hampshire	1366	19.2	22,623
New Jersey	1423	22.4	30,054
New Mexico	1421	18.9	21,920
New York	1384	23.2	29,385
North Carolina	1615	20.2	21,901
North Dakota	1059	16.1	15,405
Ohio	1519	21.5	25,101
Oklahoma	1625	20.7	25,175
Oregon	1482	18.0	19,521
Pennsylvania	1409	20.8	25,723
Rhode Island	1608	22.2	26,358
South Carolina	1506	20.5	23,674
South Dakota	1030	15.9	17,731
Tennessee	1565	21.2	23,695
Texas	1451	20.5	29,897
Utah	1129	14.7	21,051
Vermont	1455	18.8	21,071
Virginia	1567	21.7	22,592
Washington	1415	17.7	20,674
West Virginia	1758	22.4	23,669
Wisconsin	1382	18.5	20,083
Wyoming	1344	16.0	19,142
Average	**1471**	**21.3**	**25,937***

*The average per capita Medicare payments differ slightly from the figure
in Table 10 due to different underlying sources of data. Created from data
from the U.S. Centers for Medicare & Medicaid Services [477].

department visits range from 1030 per 1000 beneficiaries in South Dakota to 1758 per 1000 beneficiaries in West Virginia, and the percentage of hospital stays followed by hospital readmission within 30 days ranges from 14.7 percent in Utah and Idaho to 25.2 percent in the District of Columbia. Medicare spending per capita ranges from $15,405 in North Dakota to $32,006 in Nevada (in 2018 dollars) [477].

6.2.4. Use and costs of health care services across the spectrum of cognitive impairment

Health care costs increase with the presence of dementia. In a population-based study of adults ages 70 to 89, annual health care costs were significantly higher for individuals with dementia than for those with either mild cognitive impairment (MCI) or normal cognition [479]. Annual health care costs for individuals with MCI were not significantly different, however, from costs for individuals with normal cognition.

Several groups of researchers have found that both health care and prescription drug spending are significantly higher in the year prior to diagnosis [480–482], 2 years prior to diagnosis [483], and one year after diagnosis [480,481], compared with otherwise similar individuals not diagnosed with Alzheimer's or another dementia, although there are differences in the sources of increased spending. In one study, the largest differences were in inpatient and post-acute care [481], while in another study the differences in spending were primarily due to outpatient care, home care and medical day services [482]. In a third study, the differences were due to home health care, skilled nursing care and durable medical equipment [483]. Additionally, two groups of researchers have found that spending in the year after diagnosis continued to be higher than for individuals not diagnosed with the disease, by amounts ranging from $9333 in additional costs in 2011 dollars based on individuals enrolled in a Medicare Advantage Prescription Drug plan ($11,286 in 2018 dollars) [480] to $17,852 in additional costs in 2014 dollars based on individuals with Medicare fee-for-service coverage ($19,848 in 2018 dollars) [481]. One group of researchers, however, found no difference in health care spending in the 2 years after diagnosis [483]. One possible explanation for the spike in health care costs in the year immediately prior to and after diagnosis of Alzheimer's or another dementia relates to delays in timely diagnosis. One group of researchers has found that individuals with cognitive decline who sought care from a specialist (that is, a neurologist, psychiatrist or geriatrician) had a shorter time to diagnosis of Alzheimer's disease [484]. Additionally, individuals diagnosed with cognitive impairment by a specialist had lower Medicare costs in the year after receiving a diagnosis of Alzheimer's dementia than those diagnosed by a non-specialist.

Table 13
Percentage of Medicare beneficiaries age ≥65 years with Alzheimer's or other dementias who have specified coexisting conditions

Coexisting condition	Percentage
Coronary artery disease	38
Diabetes	37
Chronic kidney disease	29
Congestive heart failure	28
Chronic obstructive pulmonary disease	25
Stroke	22
Cancer	13

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014 [472].

6.2.5. Impact of Alzheimer's and other dementias on the use and costs of health care in people with coexisting medical conditions

Medicare beneficiaries with Alzheimer's or other dementias are more likely than those without dementia to have other chronic conditions [472]. While 26 percent of Medicare beneficiaries age 65 and older with Alzheimer's or other dementias have five or more chronic conditions (including Alzheimer's or other dementias), only 4 percent of Medicare beneficiaries without Alzheimer's or other dementias have five or more chronic conditions [472]. Table 13 reports the percentage of people with Alzheimer's or other dementias who had certain coexisting medical conditions. In 2013, the latest year for which information is available, 38 percent of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 37 percent had diabetes, 29 percent had chronic kidney disease, 28 percent had congestive heart failure and 25 percent had chronic obstructive pulmonary disease [472].

Medicare beneficiaries who have Alzheimer's or other dementias and a coexisting medical condition have higher average per-person payments for most health care services than Medicare beneficiaries with the same medical condition but without dementia. Table 14 shows the average per-person Medicare payments for seven specific medical conditions among beneficiaries who have Alzheimer's or other dementias and beneficiaries who do not have Alzheimer's or another dementia [472]. Medicare beneficiaries with Alzheimer's or other dementias had higher average per-person payments in all categories except hospital care payments for individuals with congestive heart failure.

6.3. Use and costs of long-term care services

An estimated 70 percent of older adults with Alzheimer's or other dementias live in the community, compared with 98 percent of older adults without Alzheimer's or other dementias [466]. Of those with dementia who live in the community, 74 percent live with someone and the remaining 26 percent live alone [466]. As their disease progresses, people with Alzheimer's or other

Table 14
Average annual per-person payments by type of service and coexisting medical condition for Medicare beneficiaries age ≥65 years, with and without Alzheimer's or other dementias, in 2018 dollars*

Medical condition by Alzheimer's/ dementia (A/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 A/D	**$27,450**	$8525	$2221	$4674	$2455	$3012
Without A/D	**17,132**	6140	1581	1502	1017	392
Diabetes						
With A/D	**26,573**	8111	2175	4520	2375	2713
Without A/D	**14,670**	5081	1393	1305	884	267
Congestive heart failure						
With A/D	**30,120**	9580	2333	5109	2571	3616
Without A/D	**25,554**	9726	2095	2766	1825	845
Chronic kidney disease						
With A/D	**29,313**	9180	2278	4973	2429	3221
Without A/D	**21,017**	7587	1796	2007	1258	496
Chronic obstructive pulmonary disease						
With A/D	**29,098**	9206	2306	4928	2513	3341
Without A/D	**19,850**	7373	1742	1864	1258	630
Stroke						
With A/D	**27,853**	8413	2199	4864	2361	3351
Without A/D	**20,066**	6844	1771	2445	1524	633
Cancer						
With A/D	**26,387**	7981	2129	4192	2172	2998
Without A/D	**16,736**	5246	1461	1119	725	507

*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 to the total per-person Medicare payments.
Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014 [472].

dementias generally receive more care from family members and other unpaid caregivers. 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 during the often long course of the disease. The average costs of these services increased moderately between 2017 and 2018 (assisted living: from $45,000 to $48,000 per year [485,486] and nursing home care: from $85,775 to $89,297 per year for a semi-private room and from $97,455 to $100,375 per year for a private room [485,486]), and 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 Alzheimer's or 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. People with Alzheimer's or other dementias make up a large proportion of all elderly people who receive adult day services and nursing home care.

- Adult day services. Thirty-one percent of individuals using adult day services have Alzheimer's or other dementias [487]. Overall, 69 percent of adult day service programs offer specific programs for individuals with Alzheimer's or other dementias, and 14 percent of adult day service centers primarily serve individuals with Alzheimer's or other dementias [488].
- Residential care facilities. Forty-two percent of residents in residential care facilities (that is, housing that includes services to assist with everyday activities, such as medication management and meals), including assisted living facilities, have Alzheimer's or other dementias [489]. Small residential care facilities (four to 25 beds) have a larger proportion of residents with Alzheimer's or other dementias than larger facilities (51 percent in facilities with four to 25 beds compared with 44 percent in facilities with 26 to 50 beds and 39 percent in facilities with more than 50 beds) [489]. Fifty-eight percent of residential care facilities offer programs for residents with Alzheimer's or other dementias [490].
- Nursing home care. Fifty percent of nursing home residents in 2014 had Alzheimer's or other dementias [491], and 61 percent had moderate or severe cognitive impairment [492]. Nursing home admission by age 80 is expected for 75 percent of people with Alzheimer's dementia compared with only 4 percent of the general population [258].
- Alzheimer's special care units. An Alzheimer's special care unit is a dedicated unit in a nursing home that has tailored services for individuals with Alzheimer's or other dementias. Nursing homes had a total of 73,742

beds in Alzheimer's special care units in 2014 [493]. These Alzheimer's special care unit beds accounted for just 4 percent of all nursing home beds, despite 50 percent of nursing home residents having Alzheimer's or other dementias [491] and 72 percent of Medicare beneficiaries with Alzheimer's disease having a nursing home stay in the last 90 days of life [494].

6.3.1.1. Long-term care services provided at home and in the community

Nationally, state Medicaid programs are shifting long-term care services from institutional care to home- and community-based services as a means to both reduce unnecessary costs and meet the growing demand for these services by older adults. The federal and state governments share the management and funding of the program, and states differ greatly in the services covered by their Medicaid programs. In 2016, home- and community-based services represented the majority (57 percent) of Medicaid spending on long-term services and supports, with institutional care representing the remaining 43 percent [495]. Between 2013 and 2016, Medicaid spending on home- and community-based services increased 26 percent overall, while spending on institutional care increased only 1.5 percent over the same period. Additionally, total spending on home care for Medicare beneficiaries with Alzheimer's or other dementias nearly doubled between 2004 and 2011, although increases in spending may be due to a variety of factors, including more people being diagnosed with Alzheimer's dementia, more people using home care, an increase in the number of coexisting medical conditions, more intensive use of home care services and an increase in Medicaid coverage by older adults [466,496]. In two recent systematic reviews of the cost-effectiveness of home support interventions for individuals with dementia, researchers found some evidence to support occupational therapy, home-based exercise and some psychological and behavioral treatments as potentially cost-effective approaches, although the research that has evaluated both the costs and benefits of home support interventions is scant [497,498].

6.3.1.2. Transitions between care settings

Individuals with dementia often move between a nursing facility, hospital and home, rather than remaining solely in a nursing facility. In a longitudinal study of primary care patients with dementia, researchers found that individuals discharged from a nursing facility were nearly equally as likely to be discharged home (39 percent) as discharged to a hospital (44 percent) [499]. 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 researchers have 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 and late enrollment in hospice

[500]. The number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States [501].

6.3.2. Costs of long-term care services

Long-term care services include home- and community-based services, assisted living and nursing home care. The following estimates are for all users of these services.

- Home care. The median cost for a paid non-medical home health aide is $22 per hour and $132 per day [486]. Home care costs have increased 2.5 percent annually over the past 5 years.
- Adult day centers. The median cost of adult day services is $72 per day [486]. The cost of adult day services has increased 2.1 percent annually over the past 5 years.
- Assisted living facilities. The median cost for care in an assisted living facility is $4000 per month, or $48,000 per year [486]. The cost of assisted living has increased 3.0 percent annually over the past 5 years.
- Nursing homes. The average cost for a private room in a nursing home is $275 per day, or $100,375 per year, and the average cost of a semi-private room is $245 per day, or $89,297 per year [486]. The cost of nursing home care has increased 3.6 percent and 3.4 percent annually over the past 5 years for a private and semi-private room, respectively.

6.3.2.1. Affordability of long-term care services

Few individuals with Alzheimer's or 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 Alzheimer's or other dementias specifically, but 50 percent of Medicare beneficiaries have incomes of $26,200 or less in 2016 dollars ($27,347 in 2018 dollars), and 25 percent have incomes of $15,250 or less in 2016 dollars ($15,917 in 2018 dollars) [502].
- Fifty percent of Medicare beneficiaries had total savings of $74,450 or less in 2016 dollars ($77,708 in 2018 dollars), 25 percent had savings of $14,550 or less in 2016 dollars ($15,187 in 2018 dollars), and 8 percent had no savings or were in debt. Median savings were substantially lower for black/African American and Hispanic beneficiaries than for white Medicare beneficiaries [502].

6.3.2.2. Long-term care insurance

Long-term care insurance typically covers the cost of care provided in a nursing home, assisted living facility and Alzheimer's special care facility, as well as community-based services such as adult day care and services provided in

the home, including nursing care and help with personal care [503]. Results from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey revealed that 28 percent of adults believed Medicare covered the cost of nursing home care for people with Alzheimer's, and 37 percent did not know whether it covered the cost of nursing home care [311]. While Medicare covers care in a long-term care hospital, skilled nursing care in a skilled nursing facility and hospice care, it does not cover long-term care in a nursing home [504].

Industry reports estimate that approximately 7.2 million Americans had long-term care insurance in 2014 [505]. The median income for individuals purchasing long-term care insurance was $87,500 in 2010, in 2010 dollars ($100,617 in 2018 dollars), with 77 percent having an annual income greater than $50,000 ($57,496 in 2018 dollars) and 82 percent having assets greater than $75,000 ($86,243 in 2018 dollars) [505]. Private health care and long-term care insurance policies funded only about 8 percent of total long-term care spending in 2013, representing $24.8 billion of the $310 billion total in 2013 dollars ($26.7 billion of the $334 billion in 2018 dollars) [506]. The private long-term care insurance market is highly concentrated and has consolidated since 2000. In 2000, 41 percent of individuals with a long-term care policy were insured by one of the five largest insurers; in 2014, 56 percent were insured by one of the five largest insurers [505].

6.3.2.3. 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 of 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. While Medicaid covers the cost of nursing home care, its coverage of many long-term care and support services, such as assisted living care, home-based skilled nursing care and help with personal care, varies by state.

Total Medicaid spending for people with Alzheimer's or other dementias is projected to be $49 billion in 2019 (in 2019 dollars).[A18] Estimated state-by-state Medicaid spending on people with Alzheimer's or other dementias in 2019 (in 2019 dollars) is included in Table 15. Total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's or other dementias were 23 times as great as Medicaid payments for other Medicare beneficiaries [466]. Much of the difference in payments for beneficiaries with Alzheimer's or other dementias and other beneficiaries is due to the costs associated with long-term care (nursing homes and other residential care facilities, such as assisted living facilities)

Table 15
Total Medicaid payments for Americans age ≥65 years living with Alzheimer's or other dementias by state*

State	2019 (in millions of dollars)	2025 (in millions of dollars)	Percentage increase
Alabama	$896	$1114	24.4
Alaska	71	109	52.9
Arizona	386	540	40.0
Arkansas	367	449	22.3
California	3925	5181	32.0
Colorado	596	780	30.9
Connecticut	962	1174	21.9
Delaware	238	309	29.7
District of Columbia	122	133	9.0
Florida	2601	3414	31.2
Georgia	1180	1575	33.5
Hawaii	232	281	21.2
Idaho	144	194	34.7
Illinois	1713	2176	27.0
Indiana	1020	1219	19.5
Iowa	654	783	19.7
Kansas	441	537	21.7
Kentucky	778	938	20.6
Louisiana	740	923	24.7
Maine	205	271	32.6
Maryland	1166	1518	30.2
Massachusetts	1696	2008	18.4
Michigan	1422	1718	20.9
Minnesota	876	1075	22.7
Mississippi	587	721	22.9
Missouri	923	1124	21.8
Montana	157	201	27.7
Nebraska	361	406	12.6
Nevada	185	274	48.5
New Hampshire	246	331	34.6
New Jersey	2090	2585	23.7
New Mexico	207	276	33.3
New York	5037	6243	23.9
North Carolina	1252	1610	28.6
North Dakota	184	213	15.6
Ohio	2452	2907	18.5
Oklahoma	499	604	20.9
Oregon	244	313	28.5
Pennsylvania	3543	3984	12.5
Rhode Island	455	559	22.6
South Carolina	613	809	31.8
South Dakota	174	209	20.4
Tennessee	1050	1361	29.6
Texas	2913	3907	34.1
Utah	180	233	29.6
Vermont	110	145	31.7
Virginia	952	1252	31.5
Washington	517	682	31.8
West Virginia	430	515	19.7
Wisconsin	752	914	21.6
Wyoming	81	110	34.7
Total	**$48,628**	**$60,907**	**25.3**

*All cost figures are reported in 2019 dollars. State totals may not add to the U.S. total due to rounding.

Created from data from the Lewin Model.[A18]

and the greater percentage of people with dementia who are eligible for Medicaid.

6.3.3. Use and costs of care at the end of life

Hospice care provides medical care, pain management, and emotional and spiritual support for people who are dying, including people with Alzheimer's or other dementias, either in a facility or at home. Hospice care also provides emotional and spiritual support and bereavement services for families of people who are dying. The main purpose of hospice is to allow individuals to die with dignity and without pain and other distressing symptoms that often accompany terminal illness. Medicare is the primary source of payment for hospice care, but private insurance, Medicaid and other sources also pay for hospice care. Based on data from the National Hospice Survey for 2008 to 2011, nearly all (99 percent) hospices cared for individuals with dementia, although only 67 percent of hospices cared for individuals with a primary diagnosis of dementia [507]. Fifty-two percent of individuals in for-profit hospices had either a primary or comorbid diagnosis of dementia, while 41 percent of individuals in nonprofit hospices had a diagnosis of dementia. More research is needed to understand the underlying reasons for the differences in the percentage of people with dementia in for-profit versus nonprofit hospices.

Nineteen percent of Medicare beneficiaries with Alzheimer's and other dementias have at least one hospice claim annually compared with 2 percent of Medicare beneficiaries without Alzheimer's or other dementias [472]. Expansion of hospice care is associated with fewer individuals with dementia having more than two hospitalizations for any reason or more than one hospitalization for pneumonia, urinary tract infection, dehydration or sepsis in the last 90 days of life [508]. In 2016, there were 4336 hospice companies in the United States that provided hospice care in the home, assisted living facilities, long-term care facilities, unskilled nursing facilities, skilled nursing facilities, inpatient hospitals, inpatient hospice facilities and other facilities. Additionally, 19 percent of Medicare beneficiaries who received hospice care had a primary diagnosis of dementia, including Alzheimer's dementia (Table 16) [509,510]. Dementia was the third most common primary diagnosis for Medicare beneficiaries admitted to hospice overall, with cancer being the most common primary diagnosis, followed by heart disease and other circulatory conditions. Forty-five percent of hospice users in 2014 had a primary or secondary diagnosis of Alzheimer's or other dementias, suggesting that a large proportion of hospice users have Alzheimer's as a comorbid condition [491]. The average length of hospice stay for individuals with a primary diagnosis of dementia was

Table 16
Number and percentage of Medicare beneficiaries admitted to hospice with a primary diagnosis of dementia by state, 2016

State	Number of beneficiaries	Percentage of beneficiaries
Alabama	5855	20
Alaska	103	14
Arizona	7078	19
Arkansas	2974	18
California	27,436	20
Colorado	3056	15
Connecticut	2356	16
Delaware	667	12
District of Columbia	226	17
Florida	19,547	16
Georgia	9873	22
Hawaii	961	18
Idaho	1465	18
Illinois	8854	17
Indiana	5593	17
Iowa	2991	16
Kansas	2588	18
Kentucky	2733	15
Louisiana	4717	20
Maine	1405	19
Maryland	3618	16
Massachusetts	6763	23
Michigan	8626	16
Minnesota	5096	21
Mississippi	3215	20
Missouri	5297	16
Montana	580	13
Nebraska	1544	18
Nevada	1969	18
New Hampshire	904	16
New Jersey	7459	23
New Mexico	1476	16
New York	7564	16
North Carolina	8416	18
North Dakota	448	19
Ohio	11,984	17
Oklahoma	3960	19
Oregon	3559	18
Pennsylvania	11,948	17
Rhode Island	1504	25
South Carolina	5813	21
South Dakota	418	13
Tennessee	5852	19
Texas	25,824	23
Utah	2275	19
Vermont	480	17
Virginia	5836	19
Washington	5305	21
West Virginia	1504	15
Wisconsin	4981	17
Wyoming	78	7
Total	**264,774**	**19**

Created from data from the U.S. Centers for Medicare & Medicaid Services [509].

more than 50 percent longer than for individuals with other primary diagnoses, based on data from the 2008 to 2011 National Hospice Survey [507]. Individuals with a primary diagnosis of dementia stayed an average of 112 days versus 74 days for individuals with other primary diagnoses.

Per-person hospice payments among all individuals with Alzheimer's dementia averaged $2060 compared with $156 for all other Medicare beneficiaries [466]. In 2016 Medicare reimbursement for home hospice services changed from a simple daily rate for each setting to a two-tiered approach that provides higher reimbursement for days 1-60 than for subsequent days and a service intensity add-on payment for home visits by a registered nurse or social worker in the last 7 days of life. In 2018, the rates were $192.78 per day for days 1-60 and $151.41 per day for days 61 and beyond [511]. In a simulation to evaluate whether the reimbursement change will reduce costs for Medicare, a group of researchers found that the new reimbursement approach is anticipated to reduce costs for Medicare, although individuals with dementia who receive hospice care will have higher Medicare spending than individuals with dementia who do not receive hospice care [512].

For Medicare beneficiaries with advanced dementia who receive skilled nursing facility care in the last 90 days of life, those who are enrolled in hospice are less likely to die in the hospital [513]. Additionally, those enrolled in hospice care are less likely to be hospitalized in the last 30 days of life [514] and more likely to receive regular treatment for pain [515,516]. Nearly half of individuals with dementia die while receiving hospice care [494]. Satisfaction with medical care is higher for families of individuals with dementia who are enrolled in hospice care than for families of individuals with dementia not enrolled in hospice care [517].

6.3.3.1. Feeding tube use at the end of life

Individuals with frequent transitions between health care settings are more likely to have feeding tubes at the end of life, even though feeding tube placement does not prolong life or improve outcomes [473]. The odds of having a feeding tube inserted at the end of life vary across the country and are not explained by severity of illness, restrictions on the use of artificial hydration and nutrition, ethnicity or gender. Researchers found that feeding tube use was highest for people with dementia whose care was managed by a subspecialist physician or both a subspecialist and a general practitioner. By contrast, feeding tube use was lower among people with dementia whose care was managed by a general practitioner [518,519]. With the expansion of Medicare-supported hospice care, the use of feeding tubes in the last 90 days of life has decreased for individuals with Alzheimer's or other dementias [508]. Finally, with the increased focus on the lack of evidence supporting feeding tube use for people with advanced dementia, the proportion of nursing home residents receiving a feeding tube in the 12 months prior to death decreased from nearly 12 percent in 2000 to less than 6 percent in 2014 [519].

6.3.3.2. Place of death for individuals with Alzheimer's or other dementias

Between 1999 and 2016, the proportion of individuals with Alzheimer's who died in a nursing home decreased from 68 percent to 51 percent, and the proportion who
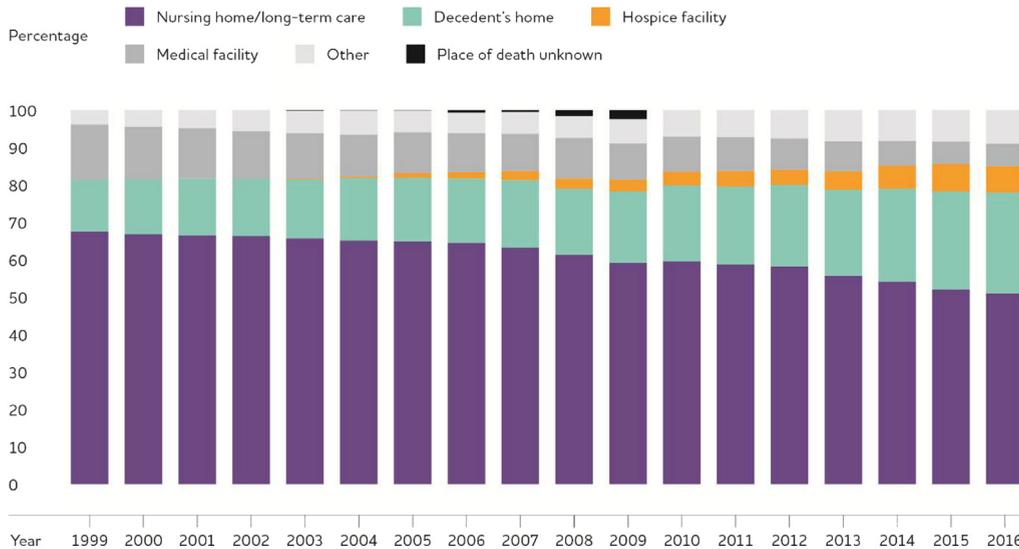
Fig. 12. Place of death due to Alzheimer's disease, 1999 to 2016. Created from data from the National Center for Health Statistics [248].

died in a medical facility decreased from 15 percent to 6 percent [248]. During the same period, the proportion of individuals who died at home increased from 14 percent to 27 percent (Fig. 12).

6.4. Use and costs of health care and long-term care services by race/ethnicity

Among Medicare beneficiaries with Alzheimer's or other dementias, black/African Americans had the highest Medicare payments per person per year, while whites had the lowest payments ($27,935 vs. $20,658, respectively) (Table 17). The largest difference in payments was for hospital care, with black/African Americans incurring 1.7 times as much in hospital care costs as whites ($9433 vs. $5604) [472].

In a study of Medicaid beneficiaries with a diagnosis of Alzheimer's dementia that included both Medicaid and Medicare claims data, researchers found significant differences in the costs of care by race/ethnicity [520]. These results demonstrated that black/African Americans had significantly higher costs of care than whites or Hispanics, primarily due to more inpatient care and more comorbidities. These differences may be attributable to later-stage diagnosis, which may lead to higher levels of disability while receiving care; delays in accessing timely primary care; lack of care coordination; duplication of services across providers; or inequities in the access to care. However, more research is needed to understand the reasons for this health care disparity.

6.5. Avoidable use of health care and long-term care services

6.5.1. Preventable hospitalizations

Preventable hospitalizations are one common measure of health care quality. Preventable hospitalizations are hospitalizations for conditions that could have been avoided with better access to, or quality of, preventive and primary care. Unplanned hospital readmissions within 30 days are another type of hospitalization that potentially could have been avoided with appropriate post-discharge care. In 2013, 21 percent of hospitalizations for fee-for-service Medicare enrollees with Alzheimer's or other dementias were either unplanned readmissions within 30 days or for an ambulatory care sensitive condition, that is, a condition that was potentially avoidable with timely and effective ambulatory care. The total cost to Medicare of these

Table 17
Average annual per-person payments by type of service and race/ethnicity for Medicare beneficiaries age ≥65 years, with Alzheimer's or other dementias, in 2018 dollars

Race/Ethnicity	Total Medicare payments per person	Hospital care	Physician care	Skilled nursing facility care	Home health care	Hospice care
White	$20,658	$5604	$1627	$3588	$1775	$3276
Black/African American	27,935	9433	2206	4448	2170	2425
Hispanic	22,141	7584	1919	3419	1872	1806
Other	26,877	8530	2158	3582	3845	2670

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014 [472].

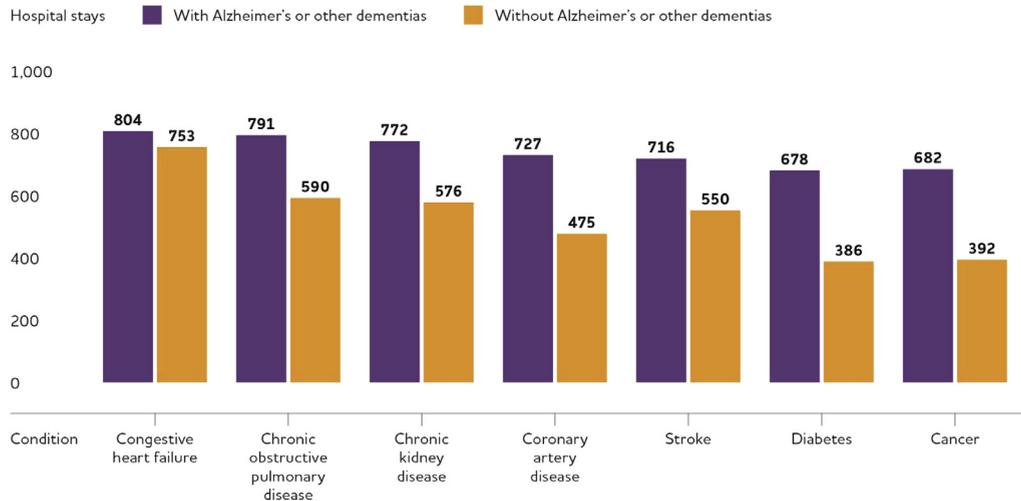Hospital stays ■ With Alzheimer's or other dementias   ■ Without Alzheimer's or other dementias

Fig. 13. Hospital stays per 1000 Medicare beneficiaries age ≥65 years with specified coexisting medical conditions, with and without Alzheimer's or other dementias, 2014. Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014 [472].

potentially preventable hospitalizations was $4.7 billion ($5.4 billion in 2018 dollars) [521]. Of people with dementia who had at least one hospitalization, 18 percent were readmitted within 30 days. Of those who were readmitted within 30 days, 27 percent were readmitted two or more times. Ten percent of Medicare enrollees had at least one hospitalization for an ambulatory care sensitive condition, and 14 percent of total hospitalizations for Medicare enrollees with Alzheimer's or other dementias were for ambulatory care sensitive conditions.

Based on data from the 2006 to 2008 Health and Retirement Study and from Medicare, preventable hospitalizations represented 25 percent of the total hospitalizations for individuals with Alzheimer's or other dementias [169]. The proportion was substantially higher, however, for black/African Americans, Hispanics and individuals with low incomes. Hispanic older adults had the highest proportion of preventable hospitalizations (34 percent).

Based on data from the 1998 to 2008 Health and Retirement Study and from Medicare, after controlling for demographic, clinical and health risk factors, individuals with dementia had a 30 percent greater risk of having a preventable hospitalization than those without a neuropsychiatric disorder (that is, dementia, depression or cognitive impairment without dementia). Moreover, individuals with both dementia and depression had a 70 percent greater risk of preventable hospitalization than those without a neuropsychiatric disorder [522].

Medicare beneficiaries who have Alzheimer's or other dementias and a serious coexisting medical condition (for example, congestive heart failure) are more likely to be hospitalized than people with the same coexisting medical condition but without dementia (Fig. 13) [472]. One research team found that individuals hospitalized with heart failure are more likely to be readmitted or die after hospital discharge if they also have cognitive impairment [523]. Another research team found that Medicare beneficiaries

with Alzheimer's or 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 [524].

Differences in health care use between individuals with and without dementia are most prominent for those residing in the community. Based on data from the Health and Retirement Study, community-residing individuals with dementia were more likely to have a potentially preventable hospitalization, an emergency department visit that was potentially avoidable, and/or an emergency department visit that resulted in a hospitalization [525]. For individuals residing in a nursing home, there were no differences in the likelihood of being hospitalized or having an emergency department visit.

6.5.2. Initiatives to reduce avoidable health care and nursing home use

Recent research has demonstrated that two types of programs have potential for reducing avoidable health care and nursing home use, with one type of program focusing on the caregiver and the other focusing on the care delivery team. The Caregiving section describes a number of caregiver support programs, and some of these also hold promise for reducing transitions to residential care for individuals with Alzheimer's or other dementias. Additionally, collaborative care models—models that include not only geriatricians, but also social workers, nurses and medical assistants, for example—can improve care coordination, thereby reducing health care costs associated with hospitalizations, emergency department visits and other outpatient visits [454]. For example, an interprofessional memory care clinic was shown to reduce per-person health care costs by $3474 in 2012 dollars ($4052 in 2018 dollars) over a year for individuals with memory problems compared with others with memory problems whose care was overseen by a primary care provider only [454]. More than half of the

cost savings was attributed to lower inpatient hospital costs. The program was relatively low cost per person, with an average annual cost of $618 ($721 in 2018 dollars) — a nearly 6-to-1 return on investment.

Another group of researchers found that individuals with dementia whose care was concentrated within a smaller number of clinicians had fewer hospitalizations and emergency department visits and lower health care spending overall compared with individuals whose care was dispersed across a larger number of clinicians [526]. More research is needed to understand whether continuity of care is a strategy for decreasing unnecessary health care use for people with Alzheimer's or other dementias.

6.6. Projections for the future

Total annual payments for health care, long-term care and hospice care for people with Alzheimer's or other dementias are projected to increase from $290 billion in 2019 to more than $1.1 trillion in 2050 (in 2019 dollars). This dramatic rise includes four-fold increases both in government spending under Medicare and Medicaid and in out-of-pocket spending.[A18]

6.6.1. Potential impact of changing the trajectory of Alzheimer's disease

While there are currently no treatments that prevent or cure Alzheimer's disease, several groups of researchers have estimated the cost savings of future interventions that either slow the onset of dementia or reduce the symptoms [277,527–529]. One group of researchers estimated that a treatment introduced in 2025 that delays the onset of Alzheimer's by 5 years would reduce total health care payments 33 percent and out-of-pocket payments 44 percent in 2050 [527]. A second group of researchers estimated the cost savings of delaying the onset of Alzheimer's disease by 1 to 5 years. For individuals age 70 andolder, they projected a 1-year delay would reduce total health care payments 14 percent in 2050, a 3-year delay would reduce total health care payments 27 percent, and a 5-year delay would reduce health care payments 39 percent [528]. They also projected that a delay in onset may increase per capita health care payments through the end of life due to longer life, although the additional health care costs may be offset by lower informal care costs. A third group of researchers estimated that a treatment that slows the rate of functional decline by 10 percent would reduce average per-person lifetime costs by $3880 in 2015 dollars ($4122 in 2018 dollars), while a treatment that reduces the number of behavioral and psychological symptoms by 10 percent would reduce average per-person lifetime costs by $680 ($722 in 2018 dollars) [277].

The Alzheimer's Association commissioned a study of the potential cost savings of early diagnosis in two scenarios [529]. The partial early diagnosis scenario assumed that 88 percent of individuals who will develop Alzheimer's disease are diagnosed in the MCI stage rather than the dementia stage or not at all, and the second scenario assumed that all individuals who will develop Alzheimer's disease receive the diagnosis in the MCI stage. In the partial early diagnosis scenario, approximately $7 trillion could be saved in medical and long-term care costs for individuals who were alive in 2018 and will develop Alzheimer's disease. If all individuals who were alive in 2018 and will develop Alzheimer's disease were diagnosed during the MCI stage, $7.9 trillion could be saved. Cost savings were due to a smaller spike in costs immediately before and after diagnosis, due to the diagnosis being made during the MCI stage rather than the dementia stage that has higher costs, and lower medical and long-term care costs for individuals who have diagnosed and managed MCI and dementia compared with individuals with unmanaged MCI and dementia.

These projections suggest that a treatment that prevents, cures or slows the progression of the disease could result in substantial savings to the U.S. health care system. Without changes to the structure of the U.S. health care system, however, access to new treatments for Alzheimer's may be severely restricted by capacity constraints. For example, one group of researchers developed a model of capacity constraints that estimated that individuals would wait an average of 19 months for treatment in 2020 if a new treatment is introduced by then [530]. Under this model, approximately 2.1 million individuals with MCI due to Alzheimer's disease would develop Alzheimer's dementia between 2020 and 2040 while on waiting lists for treatment. However, it is important to note that this model assumed both that the hypothetical treatment would require infusions at infusion centers and that it would depend on people being evaluated with amyloid PET scans; neither assumption is certain. It is also possible that future treatments will be in pill or other convenient forms and not require PET scans. For these reasons, it is difficult to know in advance what the true capacity constraints will be.

7. Special Report: Alzheimer's detection in the primary care setting—connecting patients with physicians

Early detection of Alzheimer's and other dementias provides a number of medical, social, emotional and planning benefits for affected individuals and their caregivers [529,531,532]. According to a recent Alzheimer's Association study, it also has financial benefits for both affected individuals and the country as a whole [529]. A cornerstone of early detection of impairment is the routine assessment of cognition. Primary care providers may be especially well-suited to perform this evaluation and ensure timely follow-up care. Through the use of physician and consumer surveys, this Special Report explores the state of cognitive assessment—termed "brief cognitive assessment" here—in the primary care setting and identifies potential solutions for existing barriers to widespread adoption of assessment in primary care settings.

7.1. Brief cognitive assessment in primary care

7.1.1. Overview of the primary care setting

The goals of primary care include providing the first point of contact for medical care, as well as care that is continuous over time, is comprehensive and coordinates with other parts of the health system [533]. Primary care providers who treat older adults include family physicians, general internists, geriatricians, nurse practitioners and physician assistants, and they practice in a variety of settings: private practices, hospital outpatient departments, community health centers and integrated care systems [534]. In 2017, primary care physicians (PCPs) comprised one-third of the total physician workforce, and family and general internal medicine physicians combined comprised 75 percent of office-based PCPs [535]. Estimates of non-physician primary care providers in 2016 indicate that 52 percent of nurse practitioners and 43 percent of physician assistants work in the primary care setting [535].

7.1.2. Primary care utilization

In 2017, there were 217 physicians per 100,000 people nationwide, 69 of whom were PCPs, which translates to one PCP for every 1450 Americans [535]. There is significant variation in the number of PCPs per 100,000 individuals across states, ranging from 48 in Mississippi to 102 in Maine. In general, the Northeast, Northwest and northern Midwest have the highest ratios of PCPs per 100,000 people [535]. Including nurse practitioners and physician assistants, there are 101 primary care providers per 100,000 people, or about 1 for every 1000 Americans [535].

According to the 2015 National Ambulatory Medical Care Survey, 51 percent of office visits were to primary care physicians [536]. In the 2017 National Health Interview Survey, 86 percent of respondents reported having a "usual place of health care [537]." In an analysis of 2015-2017 data from the U.S. Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System survey, 17 percent of women and 28 percent of men in the United States report not having a personal health care provider [538,539].

7.1.3. Benefits of primary care for first-line cognitive assessment

Compared with neurology, psychiatry or other specialist care settings, the primary care setting may be better suited for brief cognitive assessment of seniors for several reasons. As the health care professionals likely to have the longest relationship with patients, and the practitioners whom patients tend to see most frequently, primary care providers may be in the best position to spot the earliest signs of cognitive decline. Continuity of care in a primary care setting is associated with lower mortality in older adults [540,541], as well as fewer hospitalizations and emergency department visits and improved patient satisfaction in the general adult population [542].

> ### WHAT IS A "BRIEF COGNITIVE ASSESSMENT"?
>
> For the purposes of this report, a brief cognitive assessment is a short medical evaluation for cognitive impairment performed by a primary care practitioner that can take several forms. The practitioner may do one or more of the following:
> - ask the patient directly about cognitive concerns
> - observe patient interactions and cognitive function directly during the visit
> - may seek input about cognitive function from a patient's family or friends
> - take physical exams, medical history, and family history into account
> - use one or more brief structured assessment tools to obtain objective measures of cognitive function
>
> This Special Report uses the term "brief cognitive assessment" to avoid confusion with a longer, more comprehensive cognitive evaluation and to avoid confusion with an informal, nonmedical cognitive screening that might be performed online or at a health fair.

In addition, patients are more likely to discuss sensitive issues such as cognitive concerns with a provider they know and trust. Data from the 2016 Health Reform Monitoring Survey revealed that 74 percent of adults younger than 65 rated their trust in their usual provider as above a 7 on a scale from 0 to 10 [543], and 90 percent would be comfortable talking to their usual provider about a potentially sensitive issue [544]. In a 2006 telephone survey of 1000 adults, more than 74 percent would advise a close friend or family member to check with a health professional about cognitive concerns, and 69 percent think a general physician is the best place to start [545].

7.2. Medicare Annual Wellness Visit

7.2.1. Overview

One potential opportunity for early identification of cognitive decline in the primary care setting is the Medicare Annual Wellness Visit (AWV), a benefit that began in 2011 as part of the 2010 Patient Protection and Affordable Care Act. A required component of the AWV is an assessment of cognitive function.

Any Medicare beneficiary who has received Medicare Part B benefits for at least 12 months and has not had an Initial Preventive Physical Exam or AWV within the last 12 months is eligible for the AWV.

7.2.2. Utilization

Use of the AWV among eligible Medicare beneficiaries has grown over time but is still generally low. According to a 2012 private survey of 1028 adults age 65 and older, only one-third of respondents had heard of the AWV, and only 17 percent had had an AWV [546]. According to

the Centers for Medicare & Medicaid Services (CMS), in 2016, just 19 percent of the 55.3 million eligible Medicare Part B and Medicare Advantage beneficiaries utilized the AWV [547]. This was up from 17 percent in 2015 [548], 16 percent in 2014 [549] and 8 percent in 2011 [549].

7.2.3. AWV cognitive assessment

CMS provides limited guidelines concerning the exact nature of the brief cognitive assessment: "Assess the beneficiary's cognitive function by direct observation, while considering information from beneficiary reports and concerns raised by family members, friends, caregivers, and others. If appropriate, use a brief validated structured cognitive assessment tool. For more information, refer to the National Institute on Aging's Alzheimer's and Dementia Resources for Professionals website [550,551]."

A number of professional organizations provide additional information to help primary care providers perform brief cognitive assessments. The Alzheimer's Association *Cognitive Assessment Toolkit* includes the Medicare Annual Wellness Visit Algorithm for Assessment of Cognition as well as recommendations for operationalizing the detection of cognitive impairment during the AWV (alz.org/professionals/healthcare-professionals/cognitive-assessment) [552]. The Gerontological Society of America *Kickstart Assess Evaluate Refer (KAER) Toolkit*, the American Academy of Family Physicians *Cognitive Care Kit* and Minnesota's Act on Alzheimer's® Provider Practice Tools also provide recommendations for identifying cognitive impairment [553-555].

7.3. The state of brief cognitive assessment in primary care: PCP and consumer surveys

How many seniors are receiving brief cognitive assessments, how often, and what do they entail? How important do PCPs and seniors think these assessments are, and do PCPs feel adequately trained to perform them? Are seniors aware that an AWV should include a brief cognitive assessment? What barriers to brief cognitive assessments exist, and how might they be overcome?

Knowledge of the overall usage, procedures and outcomes of brief cognitive assessment in older adults is quite sparse, and most of the limited data that does exist is at least a decade old. Therefore, the Alzheimer's Association commissioned Versta Research to conduct surveys of PCPs and seniors to explore awareness and utilization of brief cognitive assessments in the primary care setting.[A22]

7.3.1. Alzheimer's Association surveys

Physicians included in the Alzheimer's Association Primary Care Physician Cognitive Assessment Survey[A22] were recruited through WebMD's Medscape Physician Panel, which includes 68 percent of all practicing PCPs in

the United States. To qualify for the survey, physicians were required to have practiced for at least 2 years, spend at least half of their time in direct patient care, and have a practice in which at least 10 percent of their patients are age 65 and older. A total of 1000 PCPs, balanced by region, practice type and years in practice, completed the survey by phone or online.

The Alzheimer's Association Consumer Cognitive Assessment Survey[A22] polled consumers aged 65 and older via the research organization NORC at the University of Chicago's AmeriSpeak panel, a probability sample of the full U.S. population. A total of 1954 individuals completed the survey by phone or online.

The Alzheimer's Association surveys revealed that, although nearly all PCPs and four of five seniors think brief cognitive assessments are beneficial, only half of seniors are being assessed and just one in seven is getting regular brief cognitive assessments. This number is in sharp contrast to the high percentages of seniors who receive routine assessments of other aspects of their health such as blood pressure and cholesterol levels. The surveys also found a disconnect between patient and PCP expectations: a large majority of seniors expect their physicians to recommend brief cognitive assessments, but physicians are waiting for patients or family members to report symptoms or request an assessment before doing so. In addition, most seniors are aware of the AWV provided by Medicare, but just one-third know that an AWV should include a brief cognitive assessment and only one-third are aware that Medicare will pay for testing and care planning for individuals with dementia. Nine of ten PCPs want more guidance on nearly all aspects of the brief cognitive assessment process, including which assessment tools to use and how to use them, which patients to assess, and what to do when an assessment indicates possible cognitive impairment.

Overall, the survey results highlight significant underusage of this important health assessment and identify several areas where both PCP and senior education could be improved.

7.3.2. Survey results

7.3.2.1. Usage of brief cognitive assessments in primary care

The results of the consumer survey show that nearly all seniors (94 percent) have seen a PCP for routine exams in the last year, but fewer than half (47 percent) have ever discussed their thinking or memory abilities with a health care provider. Less than a third (28 percent) have ever been assessed for cognitive problems.

In fact, just one in seven seniors (16 percent) receives regular cognitive assessments for problems with memory or thinking during routine health checkups, which stands in sharp contrast to their usage of regular screening or preventative services for other health factors: blood pressure
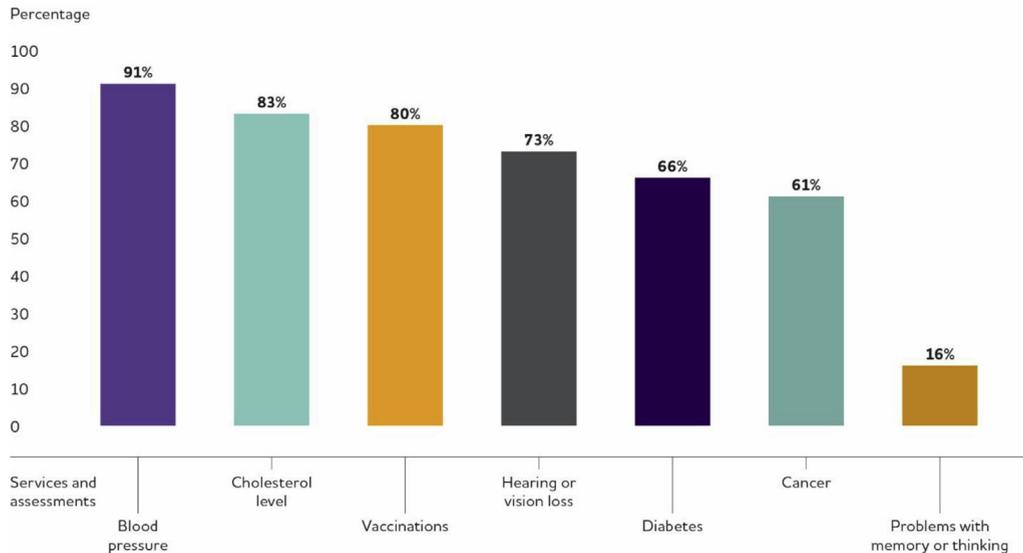
Fig. 14. Percentage of seniors receiving regular preventive health care services and assessments for specified health factors. Created from data based on the Alzheimer's Association Consumer Cognitive Assessment Survey[A22].

(91 percent); cholesterol (83 percent), vaccinations (80 percent), hearing or vision (73 percent), diabetes (66 percent) and cancer (61 percent) (Fig. 14).

The results of the PCP survey show that PCPs perform brief cognitive assessments for an average of 50 percent of their patients age 65 and older, and roughly half of PCPs (47 percent) report that performing brief cognitive assessments for all patients over age 65 is their standard protocol. Of those who reported performing brief cognitive assessments as part of their standard protocol, 72 percent do so annually, 22 percent do so at least every 2 years, and 6 percent do so less frequently.

There are limited older data on how often cognitive assessments were performed in primary care. An analysis of 2000-2002 data from the Aging, Demographics, and Memory Study (ADAMS) of 845 community-based seniors over age 70 found that only 8 percent had ever received a cognitive evaluation by a physician [164]. More generally, a 2008 survey of 1000 PCPs shows that 40 percent reported discussing cognitive impairment risk with adults who did not have a diagnosis of dementia "often" or "very often," in the last six months, and another 39 percent reported having this discussion "sometimes [556]."

7.3.2.2. Brief cognitive assessment procedures

Of the 28 percent of seniors who report ever having had a cognitive assessment, 89 percent say they were administered a test to measure their thinking and memory abilities; 59 percent were asked questions about cognitive symptoms; 28 percent were asked questions about symptoms that family, friends or caregivers had noticed; and 19 percent say their friends, family or caregivers were asked directly about the patient's symptoms.

More than 95 percent of PCPs report that they use their own observations during visits, ask the patient questions about his or her cognition, and ask caregivers, family and friends about the patient's cognition during a brief cognitive assessment. Nine of 10 also report using one or more structured assessments. The assessments PCPs most commonly report using the Mini-Mental State Examination (MMSE; 80 percent), Clock Drawing Test (CDT; 64 percent) and the Mini-Cog (52 percent).[A23] Among those PCPs who used structured assessments, a large majority (77 percent) consider their structured testing not definitive enough to make a diagnosis, instead favoring more testing. This view is consistent with recent data indicating that brief structured assessment instruments are imperfect tools and comprise just one aspect of the diagnostic process [557,558].

PCPs reported relying mostly on continuing medical education (CME) (92 percent), professional journals (85 percent), colleagues (77 percent) and scientific meetings (58 percent) for information about brief cognitive assessment best practices. However, their familiarity with resources designed to assist PCPs with brief cognitive assessments offered by specific professional groups is relatively low. Less than 40 percent of PCPs are familiar with, and less than one-third report using, the Alzheimer's Association Medicare AWV Algorithm, the Alzheimer's Association Cognitive Assessment Toolkit, or the American Academy of Family Physicians Cognitive Care Kit.

A 2008 PCP survey found that 42 percent obtain cognitive health information from professional journals, 17 percent from CME sources, and 17 percent from professional websites or listservs [556]. In a focus group of primary care providers collected in 2007-2008 as part of the Healthy Brain Study, online information and CME were the major sources of information about cognitive health [559].
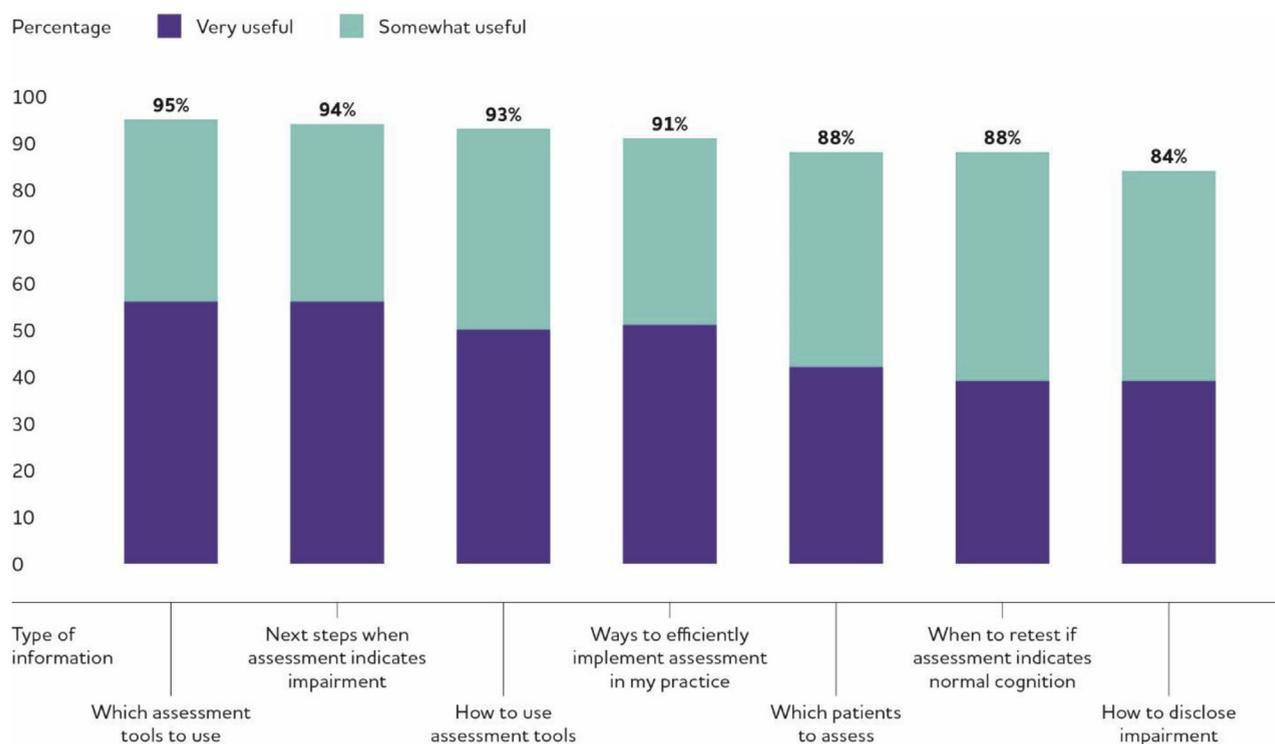
Fig. 15. Percentage of primary care physicians who say specific types of additional information would be helpful for brief cognitive assessments. Created from data based on the Alzheimer's Association Primary Care Physician Cognitive Assessment Survey[A22].

Nearly all respondents in the Alzheimer's Association Primary Care Physician Cognitive Assessment Survey say that more information about several aspects of the brief cognitive assessment and follow-up process would be useful to them (Fig. 15), consistent with earlier studies suggesting that PCPs could benefit from, and desire, more information about how to conduct brief cognitive assessments [560–563]. For example, structured cognitive assessment tools are incorrectly scored or reported in one-quarter to one-third of cases [561,562].

7.3.2.3. Decision whether or not to assess

Nearly all PCPs say the decision to assess patients for cognitive impairment is driven, in part, by reports of symptoms and/or requests. This includes reports of symptoms from family, caregivers or friends (98 percent) or patients themselves (97 percent), or requests for an assessment from family or caregivers (98 percent) or patients (94 percent). Ninety-six percent assess a patient for cognitive impairment if their own subjective assessment during an office visit indicates potential impairment. Three-quarters or more assess patients based upon age (74 percent) or if the patient's medical history indicates a higher risk of cognitive impairment (87 percent), but just 32 percent rely on other sociodemographic risk factors such as race or sex in deciding whether or not to assess a patient.

When PCPs choose *not* to assess a patient age 65 or older for cognitive impairment, most often it is because a patient presents with no symptoms or complaints (68 percent). Another reason for not assessing patients given by more than half of PCPs is a lack of time during patient visits (58 percent), a response that is consistent with data indicating that the U.S. primary care system is beyond capacity. For example, estimates from 2003 and 2009 suggest that a PCP with 2500 patients would need more than 7 hours per work day to complete all of the recommended preventive services [564] and nearly 22 hours per work day to provide preventive services and chronic disease management [565].

A majority also cite patient resistance as a reason for not always assessing, including resistance to initial assessment (57 percent) and high patient refusal rates for follow-up testing (34 percent). Several studies have also reported high refusal rates, ranging from 48 percent to 67 percent [163,566–568]. Nearly half of PCPs sometimes choose not to assess a patient because treatment options are limited. Additional concerns about the impact of a diagnosis on the patient, lack of confidence in assessing, business concerns, and difficulties with patients were also cited.[A24]

7.3.2.4. Next steps following a brief cognitive assessment

7.3.2.4.1. Medical follow-up

When PCPs detect cognitive impairment, 97 percent recommend laboratory testing for reversible causes of cognitive impairment, and 99 percent make referrals to specialists. However, only 56 percent of PCPs recommend

laboratory testing for all patients with a detected impairment, and only 17 percent make specialist referrals for all patients with a detected impairment.

7.3.2.4.2. Disclosure of diagnosis

When cognitive impairment is detected, PCPs say they inform their patients 92 percent of the time (on average), and 64 percent report that they always inform patients. Nearly all seniors (95 percent) would want their health care provider to tell them if they were showing signs of thinking and memory problems, and 99 percent believe they have a right to know this information. Nine of ten seniors would also want to undergo further testing to learn more about the problem and how it might be treated.

Among the 36 percent of surveyed PCPs who inform less than 100 percent of their patients, 73 percent say it's because early disclosure before a full diagnostic workup is premature, and 41 percent say that brief cognitive assessments have high rates of false positives or false negatives. Fifty-four percent also note that treatment options are limited. Additional reasons PCPs decide not to disclose are similar to reasons cited for not assessing all patients, and include concerns about the impact of a diagnosis on the patient, a lack of confidence or expertise, business concerns and difficulties with patients, including refusal of follow-up testing.[A25]

7.3.2.5. Seniors' concerns about cognition

Half of all seniors (51 percent) report sometimes or frequently noticing changes in their ability to think, understand or remember things, and nearly one-quarter (22 percent) worry about such changes. Furthermore, one in nine seniors (11 percent) say that these changes interfere with their ability to function in activities such as cooking, getting dressed, and grocery shopping. Forty-eight percent of seniors report doing activities or hobbies specifically because they hope it will help them with memory or thinking. This contrasts with the 84 percent who reported spending time doing activities that are beneficial for brain health in a 2006 telephone survey conducted by the American Society on Aging and the MetLife Foundation of attitudes and awareness of brain health involving 1000 adults aged 42 and older [545].

7.3.2.6. Discussion of cognitive concerns with health care providers

Of the 51 percent who sometimes or frequently notice changes in their cognition, most discuss these changes with family (67 percent) and friends (54 percent), but only 40 percent have talked to a health care provider about the changes. Among those who have, 37 percent talked to their primary health care provider and 12 percent talked to a specialist. Among the entire population of seniors surveyed, 47 percent have ever discussed their thinking and memory abilities with a health care provider, and 34 percent have done so in the last year.
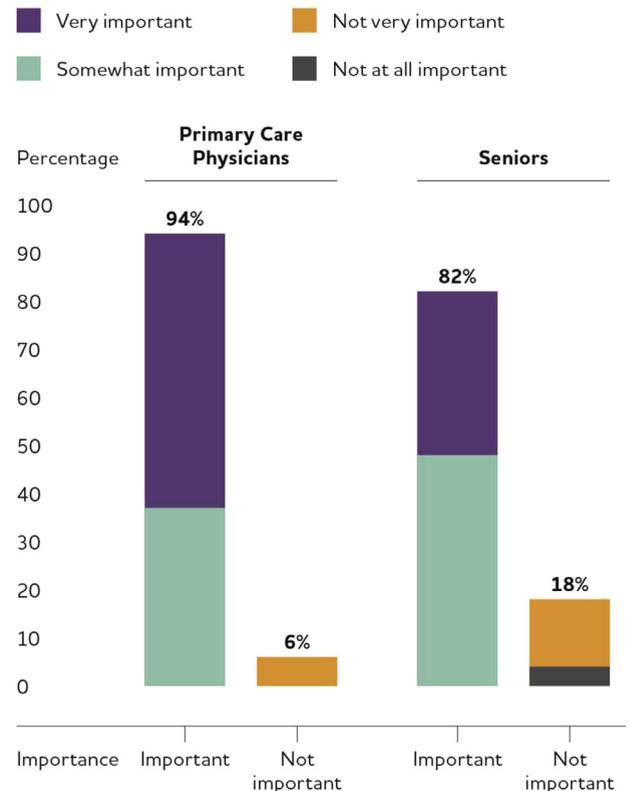

Fig. 16. Perceived importance of brief cognitive assessments. Created from data based on the Alzheimer's Association Consumer Cognitive Assessment and Primary Care Physician Cognitive Assessment Surveys.[A22]

Only one-quarter of seniors report that a health care provider has ever asked them if they have concerns about their thinking and memory without the seniors bringing it up first, and just 15 percent report having ever brought up concerns on their own, without a health care provider raising the topic first. Of those who haven't talked to a health care provider about their concerns, a large majority say it's because the changes seem like a normal part of aging (93 percent) and are not severe (80 percent). A number of other reasons were also provided.

When asked whether they agree or disagree with the statement "I trust that my doctor will recommend testing for thinking and memory problems if it is needed," 93 percent of seniors agreed (54 percent of all seniors strongly agreed and 39 percent somewhat agreed).

7.3.3. Attitudes toward cognitive assessment

7.3.3.1. Seniors' attitudes toward cognitive testing

Despite widespread lack of cognitive assessments, four of five seniors believe it is important to have their thinking and memory checked, similar to how they might have other routine physical check-ups and assessments, findings that are broadly consistent with earlier data (Fig. 16) [545,563].

Eighty-nine percent of participants in the consumer survey think every senior should ask his or her doctor to check for thinking or memory problems, and 94 percent believe that early detection of cognitive decline is mostly
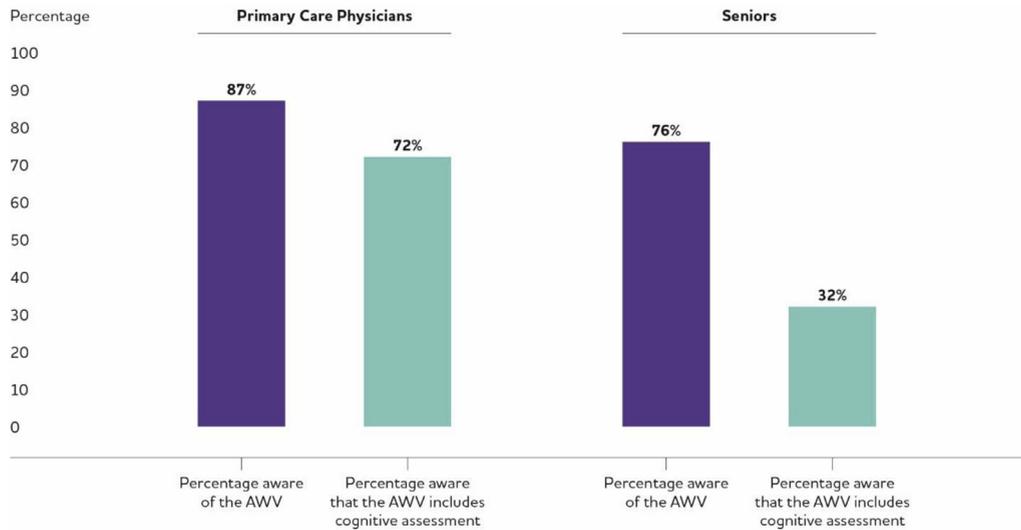
Fig. 17. Awareness of the Medicare Annual Wellness Visit (AWV) among primary care physicians and seniors. Created from data based on the Alzheimer's Association Consumer Cognitive Assessment and Primary Care Physician Cognitive Assessment Surveys[A22].

beneficial.[A26] Only 2 percent of seniors believe that early detection of cognitive impairment is mostly harmful, and the top reasons focus on the negative psychological impact it may have.

Although most seniors believe in the value of screening and early detection, a substantial minority (up to one-third) also express concerns about screening and testing: 29 percent believe that tests for thinking or memory problems are unreliable; 24 percent agree that the idea of all seniors being tested for thinking or memory problems is insulting; and 19 percent believe there is no cure or treatment for thinking or memory problems, so why bother testing for them.

7.3.3.2. PCP attitudes toward early detection of cognitive impairment

Nearly all PCPs (94 percent) say they consider it important to assess all patients age 65 and older for cognitive impairment, and 58 percent say it is very important (Figure 16). Ninety-nine percent of PCPs consider it important to assess high-risk patients for cognitive impairment, and 87 percent consider it very important. High-risk patients were defined as those with a family history of dementia, personality changes, depression, unexplained deterioration of a chronic disease, or falls and balance issues. Taken together, these statistics demonstrate to PCPs that their colleagues do indeed value brief cognitive assessments.

PCPs are generally well aware of the importance of early detection, and see value in the opportunities for planning, support and potential treatment that early detection affords [529,531,532]. Early detection of cognitive impairment is seen as beneficial for two-thirds of patients, as it allows for planning and potential intervention. In all, PCPs estimate that 64 percent of patients benefit from early detec-

tion of cognitive impairment, while 7 percent are harmed, and 29 percent are neither benefited nor harmed.

More than nine of 10 PCPs say the benefits of early detection include allowing the patient and family to plan for the future; allowing testing and treatment for reversible causes; encouraging patients and families to seek support and education; and addressing potential safety issues ahead of time. The majority of PCPs also identified potential benefits, including allowing patients to understand what is happening to them and beginning health measures to preserve existing cognitive function for as long as possible. The majority of PCPs also identify additional benefits, including early treatment, more time to assemble medical and caregiving teams, and relieving patient concerns about other things that might be wrong. Surprisingly, just 35 percent of PCPs cite participation in clinical trials or other research as an important benefit of early detection.

While most PCPs say potential treatment and prevention are important, fewer than half (45 percent) believe there is strong scientific evidence supporting strategies to slow the rate of cognitive decline, including strategies such as smoking cessation, regular exercise, and control of hypertension and other cardiovascular risk factors. The remaining PCPs believe there is moderate (39 percent) or weak (16 percent) evidence.

7.3.3.3. Awareness and utilization of Medicare benefits

7.3.3.3.1. Annual Wellness Visit

Seventy-eight percent of seniors say they think knowledgeable about what their Medicare benefits cover, and 63 percent say they pay close attention to changes in Medicare laws and the benefits that are covered. Most (54 percent) also say they try to make full use of their benefits, getting all the tests, assessments and doctor visits available to them.

Conversely, 46 percent say they use their Medicare benefits only when they are having a problem or need medical care.

Seventy-six percent of seniors are aware that Medicare specifically provides for a free AWV, and 64 percent report ever having seen a health care provider for an AWV (Fig. 17). However, only half as many (32 percent) are aware that an AWV includes a review of memory or thinking problems they might have, and only one-third (32 percent) recall a health care provider asking them about memory or thinking problems at an AWV (Fig. 17).

Eighty-seven percent of PCPs are aware that Medicare provides free AWVs, and 72 percent are aware that AWVs specifically provide services to help detect cognitive impairment (Fig. 17). On average, those who are aware that AWVs provide services to help detect cognitive impairment report performing an assessment at four of five AWVs. However, PCPs report, on average, that just four in 10 of their patients are coming in for AWVs.

7.3.3.3.2. Care planning benefits

Roughly one-third of seniors are aware that Medicare will pay for testing and care planning for people who have Alzheimer's disease, other dementia or cognitive impairment. Just under one-third of PCPs (30 percent) are aware that Medicare provides reimbursement for a clinical visit that results in a comprehensive care plan, including cognition-focused evaluation (CPT® code 99483) and fewer than one in four (22 percent) report having billed under CPT® code 99483.

7.3.3.4. Differences among PCPs based on years in practice

PCPs who have been in practice fewer than 25 years (n = 622) are more focused on assessing patients for cognitive impairment than those who have been in practice for 25 years or more (n = 378). For example, those with fewer years in practice assessed a greater percentage of their older patients for cognitive impairment (53 percent versus 46 percent), are more likely to assess all of their patients as part of their standard protocol (49 percent versus 43 percent) and think that early detection is beneficial for a higher percentage of their patients (66 percent versus 61 percent) than those with 25 or more years in practice. They are also more likely to use structured assessments during cognitive evaluations (91 percent versus 86 percent) and refer patients to a specialist when cognitive impairment is detected (61 percent versus 57 percent). All differences are statistically significant.

7.4. Toward better cognitive assessment: Challenges and steps forward

Taken together, the Alzheimer's Association surveys provide a detailed view of the current state of brief cognitive assessments in the primary care setting and shed light on several opportunities for better education of both seniors and PCPs that have the potential to improve the quality and quantity of cognitive assessments.

7.4.1. Educational opportunities for seniors

The Alzheimer's Association Primary Care Physician Cognitive Assessment Survey reveals that nine of 10 PCPs believe regular assessments are important for all adults age 65 or older. It also indicates that PCPs are responsive to seniors bringing up cognitive symptoms. Important messages for seniors are that their doctors think cognitive assessments are valuable, and that they should speak to their doctor if they have concerns about their thinking or memory.

Despite nearly 80 percent of seniors reporting that they are knowledgeable about what their Medicare benefits cover, only 32 percent are aware that AWVs include cognitive assessment. This represents an important opportunity to increase seniors' knowledge of the benefits available to them.

While the Alzheimer's Association senior survey showed that four of five older adults think brief cognitive assessments are beneficial and nine of 10 say they would want further testing if an impairment was detected, nearly 30 percent of seniors surveyed believe that tests for thinking or memory problems are unreliable. Furthermore, 57 percent of PCPs cite patient resistance to initial assessment, and 34 percent cite refusal of follow-up testing, as reasons they don't always provide brief cognitive assessments, consistent with earlier studies documenting these two phenomena [163]. Thus, seniors would benefit from increased awareness of the importance of brief cognitive assessments and of follow-up testing when cognitive impairment is detected.

7.4.2. Educational opportunities for PCPs

In addition to highlighting key messages for older Americans, the Alzheimer's Association surveys identified key trends for PCPs to understand. With four of five seniors indicating that brief cognitive assessments are beneficial and nine of 10 saying they trust their doctor to recommend cognitive testing, it is clear not only that seniors value cognitive assessments, but also that they are waiting for their doctor to ask about their thinking and memory symptoms.

Although PCPs are generally well aware of the many medical, financial and social/emotional benefits of early detection [529,531,532], fewer than four in 10 cite participation in clinical trials or other forms of research as an important benefit of early detection, suggesting an opportunity for increased education about the many ways that clinical trial participation can be helpful to their patients.

7.4.2.1. Resources on brief cognitive assessment best practices

The Alzheimer's Association PCP survey showed that nearly all PCPs desire more information about several aspects of brief cognitive assessments. In recognition of the lack of clear guidelines from CMS on how to perform cognitive assessment during an AWV, in 2017, the

Alzheimer's Association convened a Diagnostic Evaluation Clinical Practice Guideline Workgroup (the AADx-CPG Workgroup), composed of experts across disciplines in dementia care and research, that focuses on the evaluation, diagnosis and disclosure process in all care settings, particularly in primary care. When published, these clinical practice guidelines will be an important resource for PCPs.

Just four out of ten PCPs are aware of, and just three of 10 use, the existing resources for brief cognitive assessment best practices created by professional societies. The Alzheimer's Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition and the Cognitive Assessment Toolkit provide guidance on review of patient health risk assessment information, patient observation, informal questioning about cognition, as well as the use of specific structured patient and informant cognitive assessment tools [552,569]. The American Academy of Family Physicians Cognitive Care Kit contains resources on cognitive assessments, diagnosis and disclosure, and disease management, as well as prevention, long-term planning and caregiver resources [554]. Increasing PCP awareness and use of these tools is an important step to empowering physicians to increase the quantity and quality of brief cognitive assessments.

The Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map, published by the CDC and the Alzheimer's Association, outlines 25 action items to maximize cognitive health, including several strategies aimed at providing better education about brief cognitive assessments to PCPs [570]. In addition, in 2018, the Alzheimer's Association launched an innovative pilot program that is connecting dementia care experts with health care providers. The program includes information and resources relevant to clinical practice and is aimed at helping primary care providers not specialized in dementia care to better diagnose, care and support individuals with Alzheimer's and other dementias.

A handful of primary care provider training programs have been developed to aid cognitive assessment in the primary care setting. Studies of these programs, which involved small sample sizes, had mixed results. Positive outcomes reported by these studies include increased cognitive assessment rates, improved ability to detect dementia, increased clinician confidence in diagnosis and dementia care overall, and higher patient satisfaction [563,571–573]. More research is needed to further evaluate the utility of cognitive assessment training programs.

7.4.2.2. New diagnostic modalities

As research on additional ways to diagnose Alzheimer's disease and other dementias moves forward, new tools for diagnosis are becoming available to clinicians. Three positron emission tomography (PET) radiotracers are currently approved by the U.S. Food and Drug Administration to assist clinicians in the diagnosis of Alzheimer's disease, although they cannot yet be used to conclusively diagnose the disease in clinical practice. The Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) Study, led by the Alzheimer's Association, is currently assessing whether amyloid PET imaging can impact treatment decisions and medical outcomes in people with MCI or dementia of uncertain origin. Preliminary results indicate that amyloid PET imaging led to a change in patient management in more than 60 percent of participants [574].

Cerebrospinal fluid (CSF) biomarkers are another promising diagnostic tool for Alzheimer's disease currently under development [529]. In preparation for the inclusion of CSF biomarkers in the diagnostic process of Alzheimer's disease, the Alzheimer's Association convened a multidisciplinary workgroup that developed appropriate use criteria for lumbar puncture and CSF testing to guide clinicians [575].

It is important to note that these tools are likely to be utilized in tertiary care rather than primary care. They are not needed to diagnose the presence of cognitive decline or dementia, but rather may be used to determine the specific cause or causes of a person's cognitive symptoms. As new diagnostic tools become available for clinical practice, physician and consumer attitudes and practices with respect to brief cognitive assessments may also evolve.

7.4.3. Trends of hope

Despite significant challenges to improving brief cognitive assessments in the primary care setting, there are a number of encouraging signs that the United States is moving toward better and more numerous assessments, and better awareness of cognitive decline. Both seniors and PCPs think cognitive assessments are important, indicating that there is a strong foundation of knowledge on which to build going forward. PCPs are asking for information about how to better conduct assessments, demonstrating a desire for improvement. The fact that PCPs who have been in practice for fewer than 25 years are conducting more brief cognitive assessments and placing more importance on them than their older counterparts also suggests that the future will see improved early detection of cognitive decline. Finally, as awareness and usage of the Medicare AWV and the new care planning benefit grows, it will become progressively more common to regularly assess the cognition of older adults.

7.5. Conclusions

The Alzheimer's Association Primary Care Physician and Consumer Cognitive Assessment Surveys provide a clear picture of the state of cognitive assessment in the primary care setting. Despite seniors' and PCPs' widespread awareness of the benefits of early detection and widely held beliefs that regular cognitive assessments are important, just half of seniors are being assessed, and only one in seven is receiving regular assessments.

The surveys highlight a number of educational opportunities for seniors and PCPs alike that have the potential to lead to the better utilization of the brief cognitive

assessments and the greater detection and diagnosis of cognitive impairment and dementia that are so urgently needed.

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End notes

[A1]*Number of Americans age 65 and older with Alzheimer's dementia for 2019 (prevalence of Alzheimer's in 2019)*: The number 5.6 million is from published prevalence estimates based on incidence data from the Chicago Health and Aging Project (CHAP) and population estimates from the 2010 U.S. Census [51].

[A2]*Percentage of total Alzheimer's dementia cases by age groups*: Percentages for each age group are based on the estimated 200,000 people under 65 [51], plus the estimated numbers for people ages 65 to 74 (0.9 million), 75 to 84 (2.6 million), and 85+ (2.1 million) based on prevalence estimates for each age group and incidence data from the CHAP study.

[A3]*Proportion of Americans age 65 and older with Alzheimer's dementia*: The 10 percent for the age 65 and older population is calculated by dividing the estimated number of people age 65 and older with Alzheimer's dementia (5.6 million) by the U.S. population age 65 and older in 2019, as projected by the U.S. Census Bureau (54.6 million) = approximately 10 percent [157]. Please note that the proportion of Americans age 65 and older with Alzheimer's dementia has gone down slightly in recent years despite the number of Americans with Alzheimer's dementia in this age range going up; this is because of the large number of baby boomers who have started to enter this age range and increased the overall number of seniors, but at the early low risk years in this range [246].

[A4]*Differences between CHAP and ADAMS estimates for Alzheimer's dementia prevalence*: ADAMS estimated the prevalence of Alzheimer's dementia to be lower than CHAP, at 2.3 million Americans age 71 and older in 2002 [160], while the CHAP estimate for 2000 was 4.5 million [576]. At a 2009 conference convened by the National Institute on Aging 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 Alzheimer's, even if they exhibited clinical symptoms of Alzheimer's [161]. Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's dementia and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common [25], the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's dementia in the United States.

[A5]*Number of new cases of Alzheimer's dementia in 2019*: The East Boston Established Populations for Epidemiologic Study of the Elderly (EPESE) estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020 (see Hebert et al. [183]). The Alzheimer's Association calculated the incidence of new cases in 2019 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.9 (for the number of years from 2010 to 2019 divided by the number of years from 2010 to 2020), adding that result (33,300) to the Hebert et al. estimate for 2010 (454,000) = 487,300 [183]. Rounded to the nearest thousand, this is 487,000 new cases of Alzheimer's dementia in 2019.

[A6]*Criteria for identifying people with Alzheimer's or other dementias in the Framingham Study*: From 1975 to 2009, 7901 people from the Framingham Study who had survived free of dementia to at least age 45, and 5937 who had survived free of dementia until at least age 65 were followed for incidence of dementia [184]. Diagnosis of dementia was made according to *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)* criteria and required that the participant survive for at least 6 months after onset of symptoms. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose Alzheimer's dementia. The definition of Alzheimer's and other dementias used in the Framingham Study was very strict; if a definition that included milder disease and disease of less than 6 months' duration were used, lifetime risks of Alzheimer's and other dementias would be higher than those estimated by this study.

[A7]*State-by-state prevalence of Alzheimer's dementia*: These state-by-state prevalence numbers are based on an analysis of incidence data from CHAP, projected to each state's population, with adjustments for state-specific age, gender, years of education, race and mortality [185]. Specific prevalence numbers for 2019 were derived from this analysis and provided to the Alzheimer's Association by a team led by Liesi Hebert, Sc.D., from Rush University Institute on Healthy Aging.

[A8]*Number of women and men age 65 and older with Alzheimer's dementia in the United States*: The estimates for the number of U.S. women (3.5 million) and men (2.1 million) age 65 and older with Alzheimer's in 2019 is from unpublished data from CHAP. For analytic methods, see Hebert et al [51].

[A9]*Prevalence of Alzheimer's and other dementias in older whites, black/African Americans and Hispanics*: The statement that black/African Americans are twice as likely and Hispanics one and one-half times as likely as whites to have Alzheimer's or 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 the Alzheimer's Association's *2010 Alzheimer's Disease Facts and Figures*.

[A10]*Projected number of people with Alzheimer's dementia*: This figure comes from the CHAP study [51]. Other projections are somewhat lower (see, for example, Brookmeyer et al. [577]) because they relied on more conservative methods for counting people who currently have Alzheimer's dementia.[A4] Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with Alzheimer's dementia over the coming decades.

[A11]*Projected number of people age 65 and older with Alzheimer's dementia in 2025*: The number 7.1 million is

based on a linear extrapolation from the projections of prevalence of Alzheimer's for the years 2020 (5.8 million) and 2030 (8.4 million) from CHAP [51].

[A12]*Annual mortality rate due to Alzheimer's disease by state*: Unadjusted death rates are presented rather than age-adjusted death rates in order 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 Alzheimer's—a burden that appears smaller relative to other states when the rates are adjusted for age.

[A13]*Number of family and other unpaid caregivers of people with Alzheimer's or other dementias*: To calculate this number, the Alzheimer's Association started with data from the BRFSS survey. In 2009, the BRFSS survey asked respondents age 18 and over 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 age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2018. Available at: https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-detail.html. Accessed on January 3, 2019. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or another dementia, the Alzheimer's Association used data from the results of a national telephone survey also conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP [578]. The NAC/AARP survey asked respondents age 18 and over whether they were providing unpaid care for a relative or friend age 18 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 percent of caregivers said that: (1) Alzheimer's or another dementia was the main problem of the person for whom they provided care, or (2) the person had Alzheimer's or other mental confusion in addition to his or her main problem. The 26 percent figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 16.2495 million Alzheimer's and dementia caregivers.

[A14]*The 2014 Alzheimer's Association Women and Alzheimer's Poll*: This poll questioned a nationally-representative sample of 3102 American adults about their attitudes, knowledge and experiences related to Alzheimer's and dementia from Jan. 9, 2014, to Jan. 29, 2014. An additional 512 respondents who provided unpaid help to a relative or friend with Alzheimer's or a related dementia were asked questions about their care provision. Random selections of telephone numbers from landline and cell phone exchanges throughout the United States were conducted. One individual per household was selected from the landline sample, and cell phone respondents were

selected if they were 18 years old or older. Interviews were administered in English and Spanish. The poll "oversampled" Hispanics, selected from U.S. Census tracts with higher than an 8 percent concentration of this group. A list sample of Asian Americans was also utilized to oversample this group. A general population weight was used to adjust for number of adults in the household and telephone usage; the second stage of this weight balanced the sample to estimated U.S. population characteristics. A weight for the caregiver sample accounted for the increased likelihood of female and white respondents in the caregiver sample. Sampling weights were also created to account for the use of two supplemental list samples. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend age 50 or older with Alzheimer's or another dementia. Questionnaire design and interviewing were conducted by Abt SRBI of New York.

[A15]*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, Nov. 11, 2009). These data show that caregivers of people with Alzheimer's or other dementias provided an average of 21.9 hours a week of care, or 1139 hours per year. The number of family and other unpaid caregivers (16.2495 million)[A13] was multiplied by the average hours of care per year, which totals 18.505 billion hours of care. This is slightly lower than the total resulting from multiplying 1139 by 16.2495 million because of rounding.

[A16]*Value of unpaid caregiving*: To calculate this number, the Alzheimer's Association used the method of Amo and colleagues [579]. This method uses the average of the federal minimum hourly wage ($7.25 in 2018) and the mean hourly wage of home health aides ($18.02 in July 2018) [580]. The average is $12.64, which was multiplied by the number of hours of unpaid care (18.505 billion) to derive the total value of unpaid care ($233.903 billion; this is slightly higher than the total resulting from multiplying $12.64 by 18.505 billion because 18.505 is a rounded number for the hours of unpaid care).

[A17]*Higher health care costs of Alzheimer's 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 percent higher than non-caregivers' [581]. To determine the dollar amount represented by that 8 percent figure nationally and in each state, the 8 percent figure and the proportion of caregivers from the 2009 BRFSS[A13] were used to weight each state's caregiver and non-caregiver per capita personal health care spending in 2014 [582], inflated to 2017 dollars. The dollar amount difference between the weighted per capita personal health care spending of caregivers and non-caregivers in

each state (reflecting the 8 percent higher costs for caregivers) produced the average additional health care costs for caregivers in each state. Nationally, this translated into an average of $727. The amount of the additional cost in each state, which varied by state from a low of $540 in Utah to a high of $1084 in the District of Columbia, was multiplied by the total number of unpaid Alzheimer's and dementia caregivers in that state[A13] to arrive at that state's total additional health care costs of Alzheimer's and other dementia caregivers as a result of being a caregiver. The combined total for all states was $11.789 billion. 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 [583]."

[A18]*Lewin Model on Alzheimer's and dementia costs*: These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice—as well as state-by-state Medicaid spending—for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 2011 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the prevalence levels from Hebert and colleagues [51] and included in this report (5.8 million in 2019,[A2] rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (the Centers for Medicare and Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) the most recent (2014) state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data.

[A19]*All cost estimates were inflated to year 2018 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.

[A20]*Medicare Current Beneficiary Survey Report*: These data come from an analysis of findings from the 2011 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Avalere Health [466]. The MCBS, a continuous survey of a nationally representative sample of about 15,000 Medicare beneficiaries, is linked to Medicare claims. The survey is supported by the U.S. Centers for Medicare & Medicaid Services (CMS). 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, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a staff member designated by the facility administrator as the most appropriate to answer the questions. Data from the MCBS analysis that are included in *2019 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 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 Alzheimer's disease or dementia in their medical record.
- Survey participants who had at least one Medicare claim with a diagnostic code for Alzheimer's or 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 Alzheimer's or 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 2011 and reported in 2018 dollars.

[A21]*Differences in estimated costs reported by Hurd and colleagues*: Hurd and colleagues [465] estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2019 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 and colleagues 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 the Hurd et al.

estimated costs reflect an effort to isolate the incremental costs associated with Alzheimer's and other dementias (those costs attributed only to dementia), while the per-person costs in *2019 Alzheimer's Disease 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).

[A22]*Alzheimer's Association Consumer and Primary Care Physician Cognitive Assessment Surveys*: The consumer survey was conducted by Versta Research from December 13, 2018, through December 26, 2018. The survey was offered in English and Spanish and as either an online Web survey or a phone survey. The 1,954 respondents had the following demographics: 55 percent were female and 45 percent were male. Forty-one percent were age 75 and older, 33 percent were age 65-69, and 26 percent were age 70-74. Thirty-eight percent resided in the South, 22 percent in the West, 21 percent in the Midwest, and 19 percent in the Northeast. Forty-two percent had an annual household income below $40,000, 30 percent had an income between $40,000 and $74,999, and 28 percent had an income above $75,000. Seventy-seven percent of respondents identified as white and non-Hispanic, 9 percent as black and non-Hispanic and 8 percent as Hispanic. Seventy-six percent were retired, and 17 percent were working. The primary care physician survey was conducted by Versta Research from December 10, 2018, through January 8, 2019. Of the 1,000 respondents, 68 percent spent less than 90 percent of their professional time in direct patient care, while 32 percent spent between 90 and 100 percent of their time in direct patient care. On average, 49 percent of their patients were age 18-64 and 42 percent were age 65 and older. Thirty-two percent had been in practice for 15-24 years, 31 percent for fewer than 15 years, 24 percent for 25-34 years, and 14 percent for 35 years or more. Eighty-four percent had office-based practices, and 14 percent had hospital-based practices. Fifty-one percent had a primary medical specialty of family medicine, 46 percent specialized in internal medicine, and 3 percent were general practitioners. Thirty-six percent of respondents resided in the South, 23 percent in the West, 22 percent in the Midwest, and 19 percent in the Northeast.

[A23]*Additional structured assessments used by primary care physicians*: Additional responses, ranked by the percentage of participants who selected that choice, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100.

Montreal Cognitive Assessment (MoCA): 25 percent
Memory Impairment Screen (MIS): 22 percent
General Practitioner Assessment of Cognition (GPCog): 12 percent
Cambridge Cognitive Examination (CAMCOG): 7 percent

[A24]*Other reasons primary care physicians choose not to assess*: Additional responses, grouped by theme, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100. *Concerns about the patient:* Few services are available for diagnosed patients (32 percent); Diagnosis of cognitive impairment may be stigmatizing (25 percent); Early diagnosis does not provide benefits (19 percent). *Lack of confidence in assessing:* Specialists are better equipped to assess and diagnose (38 percent); Cognitive assessments have high rates of false positive or negatives (28 percent); Lack of training or confidence in performing such assessments (25 percent). *Business concerns:* Lack of financial reimbursement for time spent discussing results (22 percent); Lack of financial reimbursement for performing an assessment (21 percent); Follow-up care for diagnosed patients would strain primary care resources (17 percent). *Difficulties with patients:* Managing patients with cognitive impairment is difficult or time consuming (29 percent); Disclosing a diagnosis to patients is difficult or time consuming (24 percent).

[A25]*Other reasons primary care physicians choose not to disclose*: Additional responses, grouped by theme, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100. *Concerns about the patient:* Early disclosure of results may be stigmatizing (44 percent); Few services are available for diagnosed patients (40 percent); Early disclosure does not provide benefits to a patient (29 percent). *Lack of confidence or expertise:* Disclosing results is difficult (44 percent); Specialists are better equipped to discuss results (43 percent); Do not feel equipped to address potential implications, such as employment, driving, etc. (34 percent); Lack of training or confidence in disclosing results (30 percent). *Business Concerns:* Lack of time during visits (40 percent); Follow-up care for diagnosed patients would strain primary care resources (24 percent); Lack of financial reimbursement for time spent discussing results (23 percent). *Difficulties with Patients*: The patient refusal rate for follow up testing is high (44 percent); Managing patients with cognitive impairment is difficult or time consuming (36 percent).

[A26]*Additional reasons seniors believe early diagnosis is important*: Additional responses, ranked by the percentage of participants who selected that choice: It allows for earlier treatment of symptoms with medication or other interventions (93 percent); A person can begin health measures to preserve existing cognitive function for as long as possible (92 percent); It helps to understand what is happening (91 percent); It allows the person and their family to plan for the future (91 percent); It allows the person to be tested and treated for reversible causes of thinking or memory problems (91 percent); It helps a person address potential safety issues ahead of time (90 percent); It encourages the person and his or her family to seek support and education (89 percent); It allows for more time to assemble medical and caregiving teams (83 percent); It relieves concerns about other things that might be wrong (76 percent); It allows the person to participate in clinical trials and other research (71 percent). Participants were allowed to select more than one answer, so percentages do not add up to 100.