

SPECIAL REPORT

American Perspectives on Early Detection of Alzheimer's Disease in the Era of Treatment



In 2017, the *Alzheimer’s Disease Facts and Figures Special Report* highlighted the promise of biomarkers, stating, “... we envision a future in which Alzheimer’s disease is placed in the same category as other chronic diseases, such as cardiovascular disease or diabetes, which can be readily identified with biomarkers and treated before irrevocable disability occurs.”¹⁰⁶² Less than a decade later, we are close to realizing that promise. Highly accurate blood-based biomarker tests for detecting Alzheimer’s disease may soon be available in physicians’ offices.

There have also been great strides in treatment of Alzheimer’s disease. The U.S. Food and Drug Administration (FDA) has approved new treatment options that address the underlying biology and slow the decline of memory, thinking and function in a meaningful way for some people diagnosed with Alzheimer’s disease in the early stages. By slowing the progression of Alzheimer’s, individuals could have more time to participate in daily life and live independently — underscoring the importance of early detection and diagnosis.

Implications of Early Detection and Diagnosis for Treatment to Slow Alzheimer’s Progression

People diagnosed in the earlier stages — mild cognitive impairment (MCI) or mild dementia due to Alzheimer’s disease — are the only ones for whom the new anti-amyloid medications donanemab (Kisunla™) and lecanemab (Leqembi®) are approved.¹⁰⁶³ Both medications remove beta-amyloid to reduce cognitive and functional decline, thereby slowing the typical progression of the disease (see Treatments to Slow Alzheimer’s Disease section, page 14).

Throughout this Special Report, “anti-amyloid medication” is used interchangeably with “treatments to slow progression.” To be eligible for treatment to slow disease progression, an Alzheimer’s diagnosis must be confirmed with tests showing elevated levels of beta-amyloid in the brain. Establishing this with diagnostic testing can be a lengthy process, often involving multiple steps and various clinicians.

People considering anti-amyloid treatments should discuss the risks and benefits of all approved therapies and other health care considerations with their physicians to develop a tailored treatment plan.¹⁰⁶³

Considerations include:

- Current anti-amyloid medications are administered as infusions at specialty outpatient clinics.
- Possible side effects of anti-amyloid medications include amyloid-related imaging abnormalities (ARIA), infusion-related reactions, headaches or falls; some of these can be serious.
- Appropriate use recommendations that require magnetic resonance imaging (MRI) scans before select infusions to identify and manage ARIA.
- Incorporation of other approaches, such as medications that manage symptoms or non-drug treatments.
- Insurance coverage of the desired treatment.
- Personal preferences for interventions and care.

Early Detection and Diagnosis Could Ease Other Concerns

In addition to determining eligibility for and facilitating access to treatment, early detection and diagnosis of Alzheimer’s disease could have emotional and practical benefits, such as:^{526,1059,1064-1067}

- Reducing anxiety and promoting peace of mind associated with knowing one’s status, even in light of a diagnosis, and the improved clarity, education and understanding that follow.
- Empowering individuals through knowledge to promote a sense of self-control and agency over decisions.
- Improving personal and financial planning in conversation with family and caregivers to allow for informed decision-making.
- Promoting healthy behaviors, such as physical activity and a nutritious diet.
- Prompting proactive safety measures, such as managing driving ability, medication adherence and home modifications.
- Creating the potential for better outcomes as a result of earlier intervention and improved quality of life.

Current State of Early Detection and Diagnosis

While not everyone experiencing cognitive decline has or will develop Alzheimer’s disease, early detection and diagnosis can offer deeper insight to help navigate potential next steps, including treatment options. Today, early detection and diagnosis of Alzheimer’s are closely linked. Unlike screening tests for other diseases that may pick up biological signals before outward physical symptoms appear, detecting and diagnosing Alzheimer’s depends on physician assessment, often prompted by the individual’s or a family member’s observations of memory and thinking problems.

Clinically, early diagnosis is recognized as when an individual meets the requirements for cognitive impairment with early functional impact or mild dementia with functional impairment (Stages 3 and 4; see the Alzheimer's Disease Continuum, page 10, for more information).⁵³ "Functional impact" means self-reported or observed increases in the amount of time it takes to independently complete complex activities of daily living, whereas "functional impairment" describes more noticeable difficulties with everyday tasks.⁵³ Accurate diagnosis currently hinges on combining evidence from medical history, neurological exams, cognitive assessments and brain imaging. No one test can definitively establish that the cause of cognitive symptoms is Alzheimer's or another dementia. This diagnostic complexity currently limits early diagnosis.

Barriers to accessing health care — including logistical issues, e.g., work schedules and access to transportation, staff workforce shortages and financial constraints — present additional challenges to early detection and timely diagnosis. Although primary care physicians (PCPs) can perform standardized cognitive assessments, they may not feel equipped to administer the screening or interpret and discuss the results. Furthermore, PCPs often refer patients to specialists for additional confirmatory testing to evaluate the cause of memory issues before an official diagnosis. Patients may encounter long wait times for comprehensive testing, in part due to the scarcity of dementia specialists. Additionally, brain imaging equipment or specialized expertise to perform other diagnostic tests may not be locally available, further delaying confirmatory diagnosis.

Early Detection With Blood-Based Biomarker Tests Could Lead to More Timely Diagnosis

The limitations of current detection methods, including their complexity and accessibility challenges, highlight the need for more efficient and readily available tools. The latest promising advancement in Alzheimer's detection is blood-based biomarker tests (see the Looking to the Future: Importance of Biomarkers section, page 26). Blood tests are relatively simple to administer in a clinical setting and are commonly used to monitor health status, detect medical conditions and, in some cases, definitively diagnose a disease. Alzheimer's blood-based biomarker tests signal a shift to a more accessible method of early detection, potentially prevailing over currently expensive and/or invasive methods that are not always within reach for patients.

Blood tests for Alzheimer's disease offer potential advantages. Experts believe blood-based biomarker tests could improve the accuracy and speed of diagnosis when used as a complement to other testing, offering a viable path to earlier Alzheimer's detection and diagnosis. As of the writing of this Special Report, such tests are limited to use in

At a Glance: Alzheimer's Disease Biomarkers and Biomarker Testing

What are biomarkers?

Biomarkers are measurable biological changes that can:

- Indicate the presence or absence of disease.
- Assess the risk of developing symptoms of a disease.

What are biomarkers for Alzheimer's disease?

Biomarkers for Alzheimer's disease include the proteins beta-amyloid and phosphorylated tau (p-tau). Researchers are studying other possible biomarkers.

What biomarker tests are used to detect Alzheimer's disease?

When Alzheimer's disease is suspected, a physician can order medical tests to measure biomarkers, specifically brain imaging scans or samples of cerebrospinal fluid (CSF).

What do Alzheimer's biomarker tests look for?

Current biomarker tests primarily measure accumulation of beta-amyloid or p-tau as evidence of the hallmark brain changes of Alzheimer's disease.

What's the state of biomarker testing?

Current research is investigating novel, simple medical tests to detect biomarkers of Alzheimer's disease. Blood-based biomarker tests that detect p-tau or beta-amyloid are the furthest along and the closest to being widely available. A number of researchers are also exploring retinal biomarkers (e.g., proteins associated with retinal neurodegeneration and changes in the thickness and cell structure of the retina), cerebrovascular changes or even changes in sleep quality. Other emerging biomarker research includes examining components in saliva and the skin for signals that may indicate early biological changes in the brain.

Can biomarker tests diagnose Alzheimer's disease?

No, the presence of these biomarkers alone is not sufficient to determine an Alzheimer's diagnosis at this time.

specialty care clinics to aid in the diagnostic workup of symptomatic individuals and are still being validated in clinical trials. The Alzheimer's Association® does not recommend their use in asymptomatic individuals at this time.

Much remains to be learned about Americans' willingness to pursue testing, diagnosis and treatment to slow Alzheimer's disease progression, which was the impetus for the 2025 Alzheimer's Disease Facts and Figures Special Report survey.

Attitudes About Early Detection and Treatment of Alzheimer's Disease

This year's Special Report offers new insights into the public's knowledge, interest and views regarding detection and treatment of Alzheimer's disease.

To better understand these topics, the Alzheimer's Association commissioned Versta Research to survey U.S. adults age 45 and older. The survey aimed to identify key knowledge gaps, measure public awareness, and uncover attitudes and beliefs about Alzheimer's across different demographic groups.

Key Findings

Attitudes about early detection and diagnosis

The vast majority of Americans believe diagnosis at the early stages of Alzheimer's disease is important.

- Nearly all (99%) Americans said it is important to diagnose Alzheimer's in the early stages of the disease.
- Most (59%) also viewed cognitive screening for Alzheimer's or other dementia as a very important aspect of preventive health care.

Most Americans would want to know if they have Alzheimer's disease when they have no symptoms or minor symptoms of cognitive decline.

- Nearly 4 in 5 Americans (79%) would want to know if they had Alzheimer's disease before experiencing symptoms or before symptoms interfere with daily activities.

Consistent with interest in early diagnosis, nearly all Americans would want to undergo a simple test, e.g., a blood-based biomarker test, to detect Alzheimer's disease if it were available.

- More than 9 in 10 Americans would definitely or probably want a simple medical test if it were available.
 - 91% would want testing before symptoms appear (presymptomatic).
 - 95% would want testing when experiencing early symptoms (postsymptomatic).
- Four in 5 Americans (80%) said they would ask for a simple medical test rather than wait for their doctor to suggest it; this was consistent across all populations surveyed.

The top reason to seek a simple medical test is the potential for earlier health care intervention.

- More than 4 in 5 Americans (83%) would want to undergo simple medical testing for Alzheimer's because it would allow for earlier treatment and care.
- Other leading reasons included that detection allows time for planning (76%), encourages action to preserve existing cognitive function (68%) and helps with understanding what is happening (67%).

Implications for future insurance coverage are the major concern related to testing that detects Alzheimer's.

- More than 2 in 5 Americans (44%) had concerns about insurance companies not covering subsequent care after testing.
- Other leading concerns about being given a simple medical test included test accuracy (41%), losing confidence in one's ability to carry out daily activities (40%) and the cost of testing (39%).

Attitudes about anti-amyloid medications

The option for treatment to slow progression elevates the importance of an early Alzheimer's diagnosis.

- Nearly 3 in 4 survey respondents (73%) said being able to take medication to slow the progression of Alzheimer's during its early stages would influence their feelings about an early diagnosis.

If diagnosed with Alzheimer's, most Americans would want medication to slow the progression of the disease and highly value information about it.

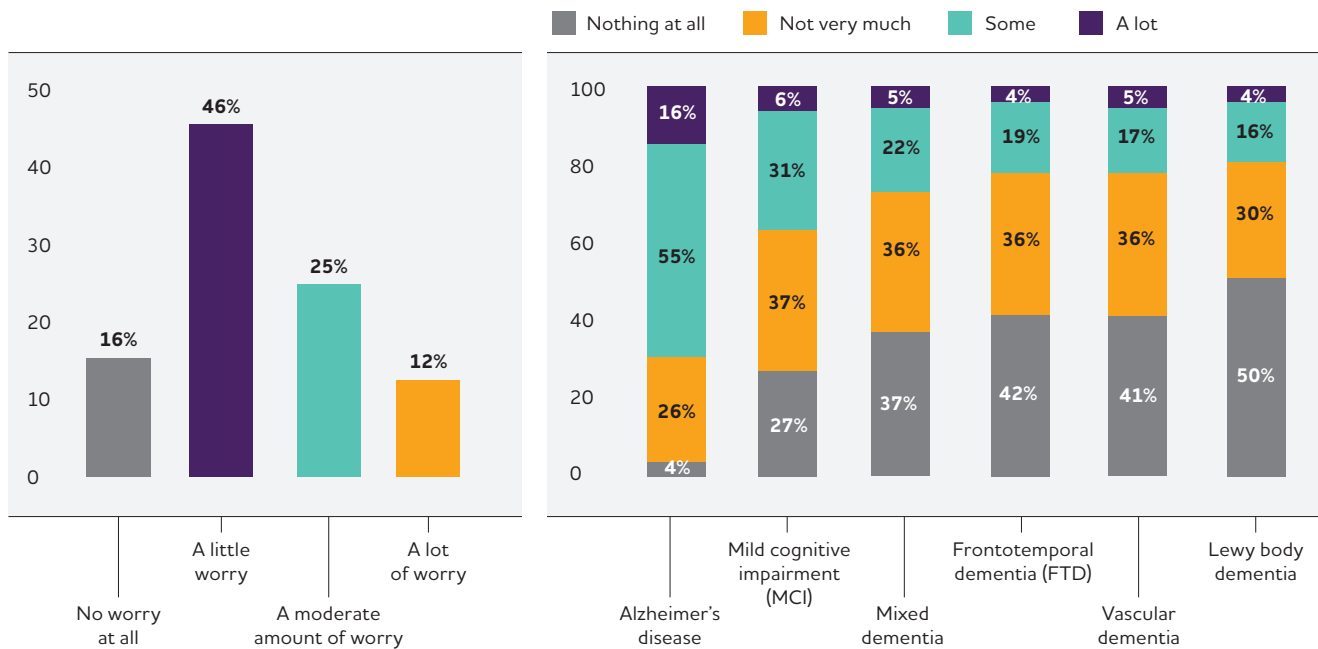
- More than 9 in 10 Americans (92%) would probably or definitely want a medication that could slow the progression of Alzheimer's disease following a diagnosis.
 - Nearly 2 in 3 Americans (64%) knew that anti-amyloid medications targeting underlying causes to slow disease progression exist.
- Information about treatments that slow the progression of the disease (72%) and information about Alzheimer's disease (69%) top the list of most valued information people want to receive following a diagnosis.
- Survey participants expressed equally strong interest in other options to manage and treat Alzheimer's disease — 94% would want medications that lessen symptoms, and 90% would want education and support for lifestyle changes.

Treatment risks and logistics do not diminish interest in anti-amyloid medication.

- Nearly 3 in 5 Americans (58%) would accept moderate or high levels of medication risk to slow the progression of Alzheimer's disease.
- Three in 4 Americans (74%) said visiting an outpatient clinic at least once a month for treatment would not affect their interest in an anti-amyloid medication.

FIGURE 19

Worry About Developing Alzheimer’s Disease Knowledge of Alzheimer’s Disease and Related Conditions



Attitudes about the future of Alzheimer’s treatment

Americans expressed high expectations and optimism for the next 10 years, as well as a desire to contribute to progress in Alzheimer’s disease treatment.

- Up to 4 in 5 Americans feel optimistic about new Alzheimer’s treatments in the next decade.
 - 81% expect new treatments to **stop** progression.
 - 66% expect new treatments to **prevent** Alzheimer’s disease.
 - 49% expect new treatments to **cure** Alzheimer’s disease.
- If diagnosed with Alzheimer’s disease, more than 4 in 5 Americans (83%) said they would be interested in participating in a clinical trial to evaluate a medication that would slow or cure Alzheimer’s.

Survey design and research methods

A survey of 1,702 U.S. adults age 45 and older was conducted from Nov. 7-18, 2024. The sample was sourced via NORC’s AmeriSpeak Panel at the University of Chicago. AmeriSpeak is a probability-based panel of all U.S. households. The full sample included oversampling of Hispanic (n=296), Black (n=309), Asian (n=282) and Native (n=166) Americans for robust analysis of subgroups. The final data was weighted by select criteria to match population totals from the U.S. Census Bureau. The survey was offered in both English and Spanish as an online or phone survey.

Survey results

Americans Are Worried About Alzheimer’s Disease Despite Knowing Little About It

Worry about developing Alzheimer’s disease is common. In the survey, more than 4 in 5 U.S. adults (83%) expressed some level of worry, with more than 1 in 10 (12%) expressing a lot of worry (Figure 19). Hispanic Americans and those with a family history worried most about Alzheimer’s disease (see box, Perspectives of Individuals with a Family History of Alzheimer’s, page 112). Hispanic Americans reported significantly higher levels of worry than all other groups surveyed, with nearly 1 in 3 (29%) saying they had a lot of worry compared with 14% of Native Americans, 12% of Asian Americans, 13% of Black Americans and 9% of White Americans.

Although worry is prevalent, understanding of both Alzheimer’s and other diseases that cause dementia remains considerably limited. Fewer than 1 in 5 Americans (16%) said they knew a lot about Alzheimer’s disease, and even fewer said they knew much about MCI or other diseases that cause dementia (Figure 19). MCI due to Alzheimer’s disease is the symptomatic precursor to Alzheimer’s dementia.

These findings echo those of the 2022 Alzheimer’s Disease Facts and Figures Special Report, *More Than Normal Aging: Understanding Mild Cognitive Impairment*, which surveyed American adults ages 18 and older about their awareness

of MCI.¹⁰⁶⁴ That survey found that 42% of Americans had some level of worry about developing MCI due to Alzheimer's disease, with 14% worrying "a lot."¹⁰⁶⁴ The 2022 Special Report also found that knowledge of MCI was limited.¹⁰⁶⁴

Most U.S. Adults Want to Know Early If They Have Alzheimer's Disease

Americans overwhelmingly viewed early diagnosis of Alzheimer's disease as important (99%), with 4 in 5 (79%) indicating that early diagnosis of Alzheimer's disease is very important (Figure 20).

White Americans were less likely to say early diagnosis was very important (76%) versus Black Americans (91%), Native Americans (87%), Hispanic Americans (86%) and Asian Americans (80%).

Strong Preference for Diagnosis Before Noticeable Symptoms or When Symptoms Are Minor

Americans indicated a strong preference for diagnosis as early as possible. Half of Americans (50%) would want to know if they had Alzheimer's disease even before experiencing symptoms, and 1 in 3 (29%) would want to know at the point where they are experiencing minor symptoms (Figure 21). Fewer survey participants said that they wanted to know their diagnosis as symptoms worsened — 11% when experiencing mild symptoms, 3% when experiencing moderate symptoms and 2% when symptoms were severe. Only 5% said they would never want to know if they had Alzheimer's disease (Figure 21).

This preference for the timing of diagnosis varied among different population groups. Black Americans most wanted to know about Alzheimer's disease at the earliest stage before symptoms arise, especially when compared with White Americans (58% versus 48%, respectively). Greater percentages of Native and Hispanic Americans said they would never want to know compared with other groups (11% and 13%, respectively, versus 1% of Asian Americans, 7% of Black Americans and 4% of White Americans).

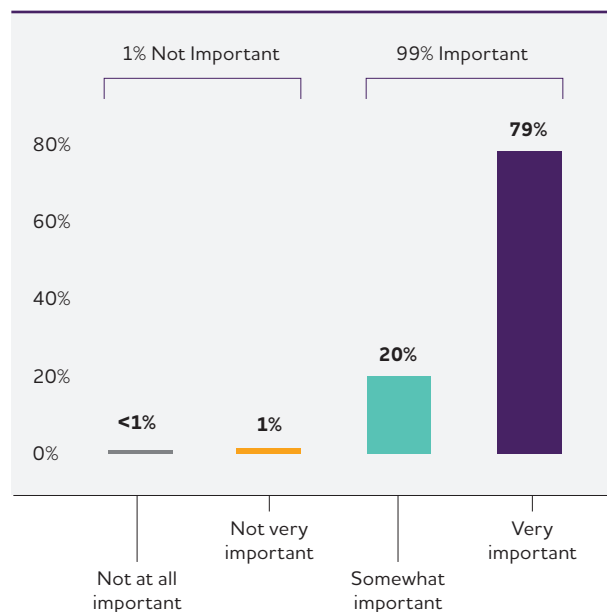
Again, these responses are consistent with the 2022 Special Report, which found that 54% of Americans ages 18 and older would want to know they had Alzheimer's disease at the MCI stage, and only 5% would never want to know their diagnosis.¹⁰⁶⁴ As with this year's findings, very few people were interested in waiting until the severe stages of the disease to be diagnosed.¹⁰⁶⁴ Taken together with current findings, the public sentiment appears to be "earlier is better" when it comes to an Alzheimer's diagnosis.

The Public Values Cognitive Assessments and Is Aware of Diagnostic Tests but Lacks Biomarker Test Knowledge

Preventive health care screenings and services — such as cholesterol or cancer screening — become a more frequent part of recommended care as one ages and are

FIGURE 20

Perceived Importance of Early Alzheimer's Disease Diagnosis



essential tools for risk assessment and identifying diseases in their early stages. Most Americans (59%) believed cognitive screening for Alzheimer's or other dementia is very important, albeit less so than other preventive services and screenings (Figure 22). (Note: While routine screening for Alzheimer's and other dementias is not recommended without recognizable cognitive signs and symptoms, assessment for any potential cognitive impairment is part of the Medicare Annual Wellness Visit.⁷⁹²)

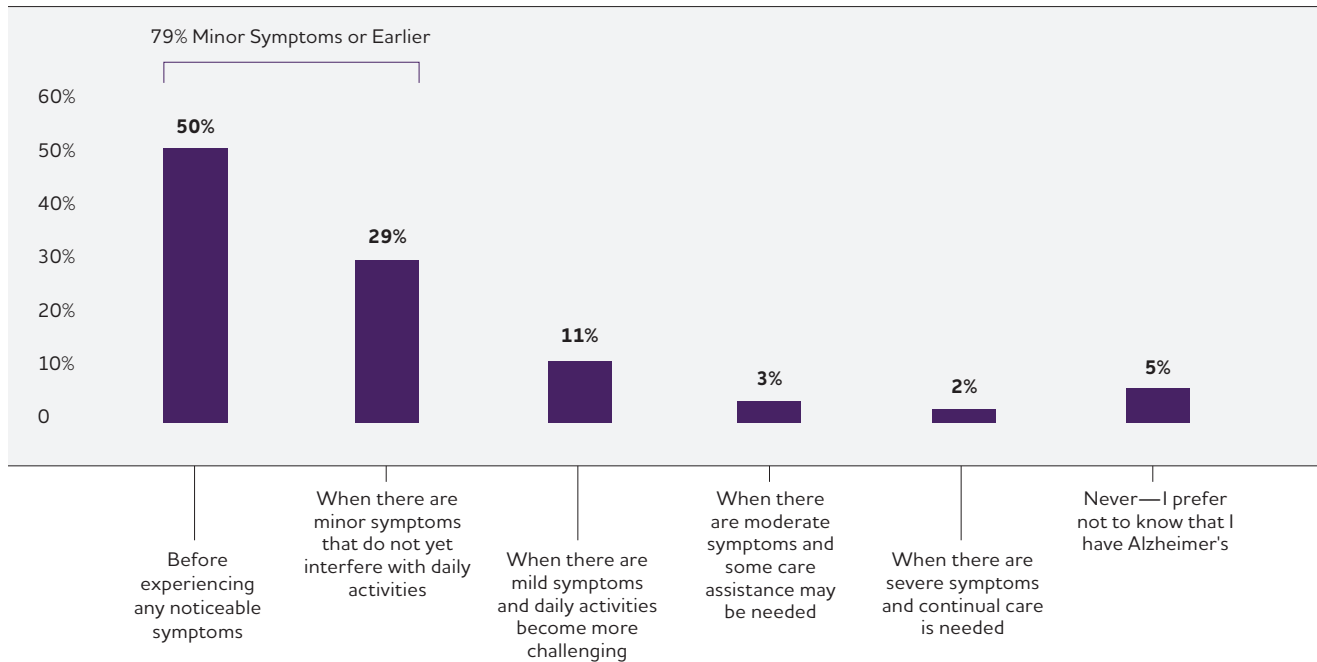
Americans reported high awareness of medical tests to aid in diagnosing Alzheimer's disease, including cognitive testing, brain imaging and neurological exams.

However, only 1 in 3 (31%) were aware of blood tests being evaluated in clinical trials and available primarily in specialty care settings to aid in the diagnostic workup of symptomatic individuals. The percentage aware of various testing methods is:

- Tests to measure memory, activities and emotional/psychological changes (70%).
- Brain imaging (67%).
- Neurological exams (65%).
- Medical history interviews (55%).
- Computerized cognitive tests (49%).
- Genetic testing (46%).
- Physical exams (43%).
- Blood tests (31%).
- Autopsy (29%).
- Cerebrospinal fluid (CSF) tests (14%).

FIGURE 21

Stage at Which U.S. Adults Age 45+ Would Want to Know If They Had Alzheimer’s Disease



Overall, survey participants reported very limited knowledge about biomarker tests to support Alzheimer’s disease diagnoses, with fewer than 1 in 10 Americans (9%) feeling they knew much about them.

Nearly All Americans Would Want a Simple Medical Test for Alzheimer’s if Available, and Many Would Proactively Request It

Although Americans reported little knowledge of biomarker tests, there was strong interest in them when framed as a hypothetical simple medical test. More than 9 in 10 Americans reported that they would want a simple medical test for Alzheimer’s (Figure 23, left and middle panels). Ninety-one percent expressed interest in being tested before experiencing symptoms (presymptomatic; Figure 23, left panel). The appearance of symptoms did not seem to influence interest level, with only slightly more (95%) wanting a test if they noticed problems with their ability to think, understand or remember things (postsymptomatic; Figure 23, middle panel). Four in 5 Americans (80%) indicated they would ask for a simple medical test to detect Alzheimer’s rather than waiting for a doctor to suggest it (Figure 23, right panel). Overall, interest in a simple medical test to detect Alzheimer’s disease remained strong across all populations surveyed.

Preparedness Tops Benefits, While Loss of Insurance Coverage Is Noted as a Risk of Testing

Americans cited feeling prepared as a reason to want a simple Alzheimer’s test. Preparedness encompasses allowing for earlier treatment and care, general planning for the future, encouraging action to preserve cognitive function for as long as possible, addressing safety issues in advance, and assembling medical and caregiving teams.

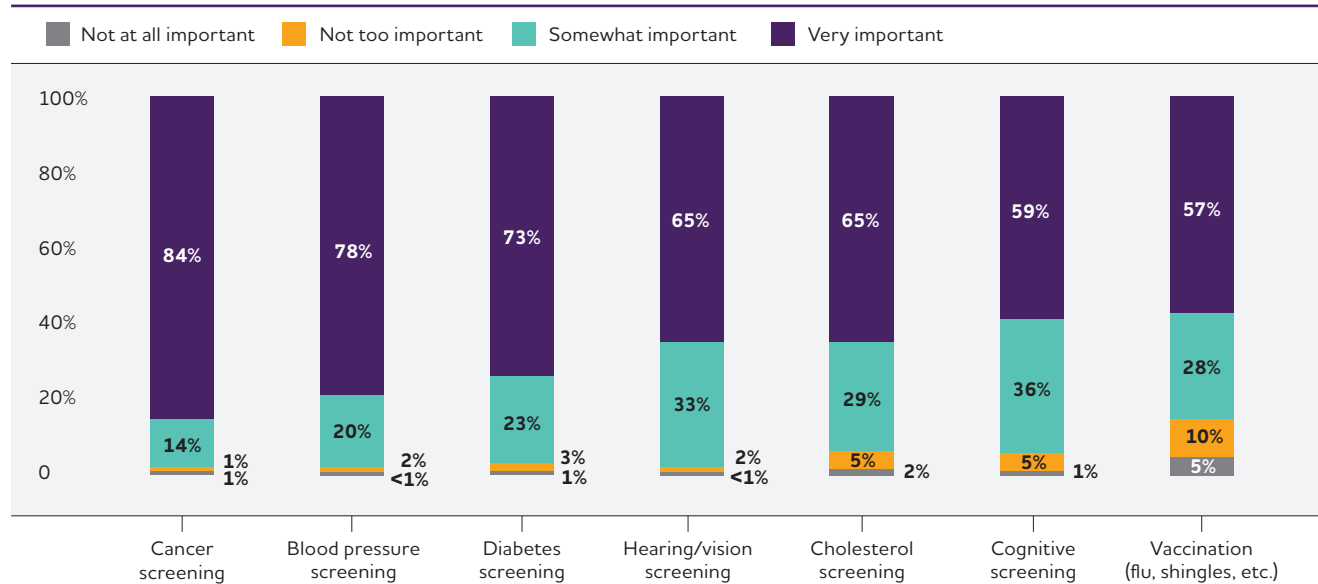
The top reason for wanting a test to detect Alzheimer’s disease was that it would allow for earlier treatment and care (4 in 5 respondents, 83%). Three in 4 (76%) respondents said another reason is it would allow them to better plan for the future with their family, and 2 in 3 (68%) said it would encourage them to take actions that could help preserve their cognitive function (Figure 24, top panel).

Wanting education is also a reason for seeking testing. Americans said they would want a test because it could help them understand what is happening (67%) and encourage them to seek support and education (58%; Figure 24, top panel).

Regarding the medical benefits of simple tests for Alzheimer’s disease, there was stronger than anticipated interest in testing to inform clinical trial participation, with nearly 1 in 2 respondents (48%) saying this would be a reason for them to undergo testing. More than half (55%) also indicated interest if the test could rule out other causes of memory problems (Figure 24, top panel).

FIGURE 22

Perceived Importance of Preventive Health Care Services or Screenings



Insurance was the most prominent concern about being tested. More than 2 in 5 Americans (44%) reported apprehension about how this would affect coverage of future care (Figure 24, bottom panel). Other common concerns included test accuracy (41%), losing confidence in abilities to carry out daily tasks (40%), cost of testing (39%) and being prohibited from activities such as driving (38%). Concerns related to worry, access and stigma were less common but still meaningful to some survey participants (Figure 24, bottom panel). Nearly 1 in 5 respondents (17%) had no concerns about testing. Only a few respondents believed that testing would not matter because treatment options are limited (14%) or there is no cure (13%).

In the 2022 Special Report survey, Americans age 18 and older indicated their top reasons for wanting to know early if they had Alzheimer’s disease were to plan for the future, allow for earlier treatment of symptoms, take steps to preserve cognitive function and understand what was happening.¹⁰⁶⁴ Participation in clinical trials was another, but less prominent, reason for wanting an early diagnosis of Alzheimer’s disease. Reasons for wanting early detection overlap with those for seeking early diagnosis. In this year’s Special Report, Americans 45 and older cited these same reasons for wanting a simple medical test to detect Alzheimer’s disease, supporting the trend toward early Alzheimer’s diagnosis first identified in the 2022 Special Report.¹⁰⁶⁴

Americans Are More Inclined to Want an Early Alzheimer’s Diagnosis When They Have the Option of Treatment to Slow Cognitive Decline

There was high awareness of current treatment options for Alzheimer’s disease. Many Americans (73%) were aware of medications to lessen symptoms. Nearly 2 in 3 Americans (64%) said they knew of medications that can now slow the progression of Alzheimer’s disease (anti-amyloid medications). However, aside from general awareness, familiarity with treatments that can slow the disease progression was low (15% familiar versus 85% not familiar).

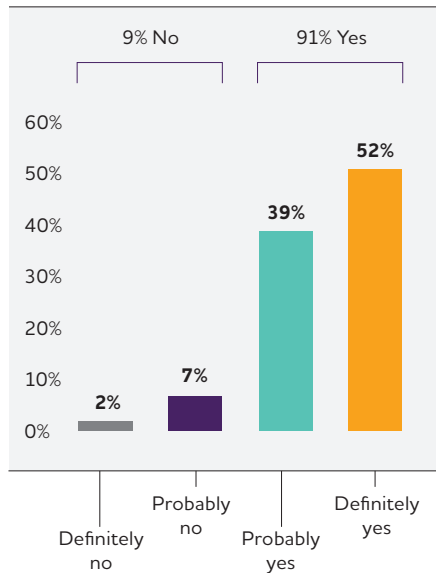
A higher percentage of Hispanic Americans were not sure of options for treatment and management of Alzheimer’s disease. They also reported lower awareness than other populations of all current options; for example, 1 in 2 (52%) indicated they had heard of medications that could slow Alzheimer’s disease progression, and 57% were aware of medications to lessen symptoms.

Many people were also aware of alternatives to medication that could help manage Alzheimer’s disease, such as community resources (56%), lifestyle changes (55%), and counseling and psychotherapy (43%).

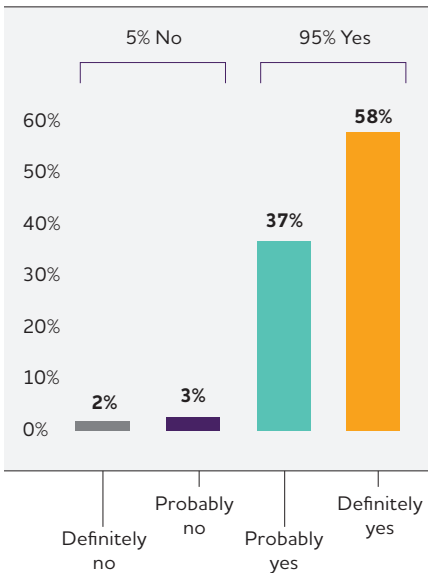
When asked, “If you could take a medication that would slow the progression of Alzheimer’s disease during the early stages of the disease, would that change your feelings about when you would want to know if you had Alzheimer’s?”, nearly 3 in 4 survey respondents (73%) said it would change their preference (Figure 25, left panel).

FIGURE 23

Interest in Presymptomatic Alzheimer's Disease Testing

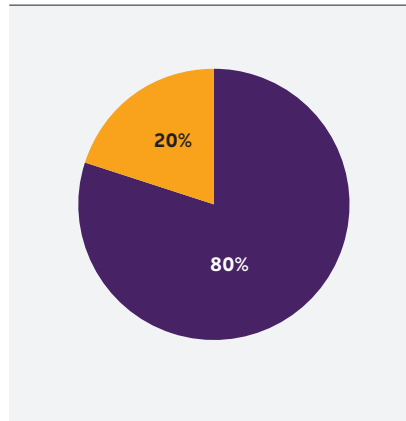


Interest in Postsymptomatic Alzheimer's Disease Testing



Who Would Initiate Alzheimer's Disease Testing

Would wait for doctor to suggest (orange) | Would ask for test (purple)



Americans Expressed Strong Interest in Anti-Amyloid Medications if Diagnosed with Alzheimer's Disease

Nine in 10 Americans (92%) surveyed said they would want to take medication to slow progression if they were diagnosed with Alzheimer's at a stage when experiencing only mild symptoms (Figure 25, right panel). Assuming they were diagnosed early, participants also expressed similarly strong interest in taking medications to lessen symptoms (94%), as well as receiving education and support for lifestyle changes (90%) (Figure 25, right panel).

Apart from expressing interest in being treated with anti-amyloid medication, Americans reported that if they were diagnosed with Alzheimer's disease, information about such treatments would be the most valuable. More broadly, they said they wanted education on the health impacts of the disease and health care planning. If diagnosed with Alzheimer's, survey respondents would most value:

- Information about treatments that slow progression (72%).
- Information about the disease (69%).
- Information about the treatments to address disease-related symptoms (62%).
- A point of contact on the care team to answer questions and connect to resources (otherwise known as a care navigator, 59%).
- Information about financial and legal resources and protections (59%).

- Information about non-medication management of symptoms (57%).
- Information about Alzheimer's clinical trials (50%).
- Information about caregiver support (49%).
- Information about local support resources (44%).

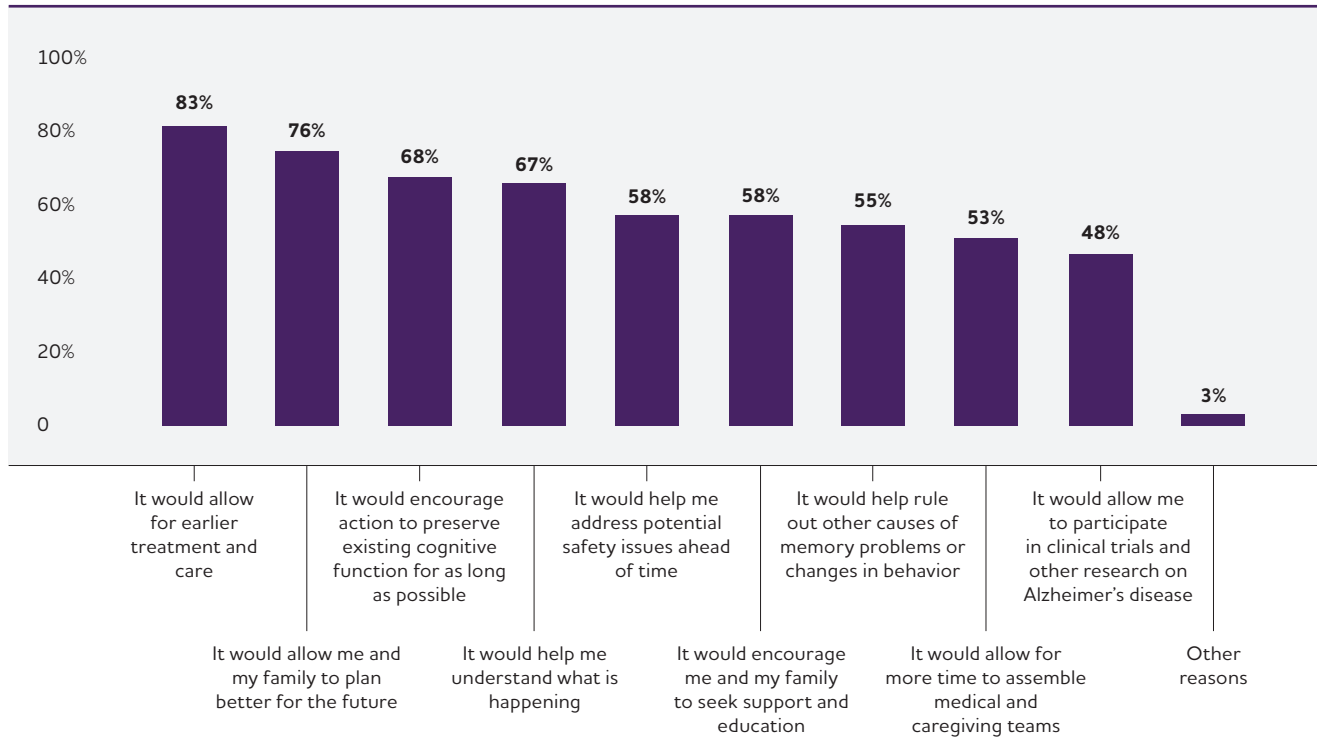
Interest in Treatment to Slow Alzheimer's Progression Is Not Diminished by Barriers to Access or Potential Risks Associated with Medication

Today's anti-amyloid treatments are administered as infusions at least once per month in a clinical setting, such as a hospital or specialty outpatient clinic. This schedule may create barriers to access for some individuals due to clinic location or distance, scheduling and transportation. These barriers had little impact on attitudes, with 3 in 4 Americans (74%) saying it would not change their interest in receiving treatment (Figure 26, top left panel). Of those who were less likely to want outpatient treatment, insurance coverage was their top concern (60%), followed by experiencing side effects at home (52%; Figure 26, top right panel).

Additionally, nearly 3 in 5 Americans (58%) would accept moderate to very high levels of medication risk to slow the progression of Alzheimer's disease in the early stages. More than 1 in 3 (36%) expressed willingness to accept moderate risk, 8% were willing to accept a high amount of risk, and 14% responded that they would be willing to do everything possible to slow progression (Figure 26, lower panel).

FIGURE 24

Reasons for Wanting a Simple Test for Alzheimer's

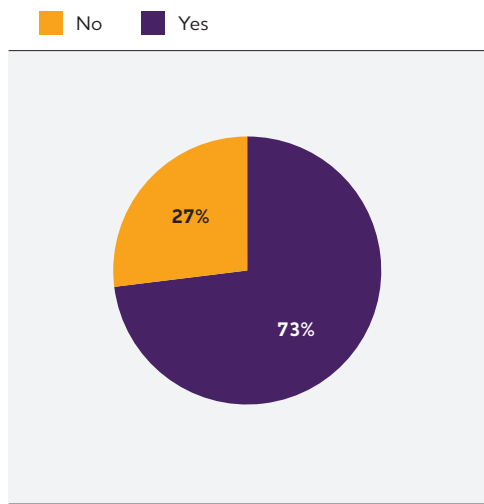


Concerns about Alzheimer's Testing

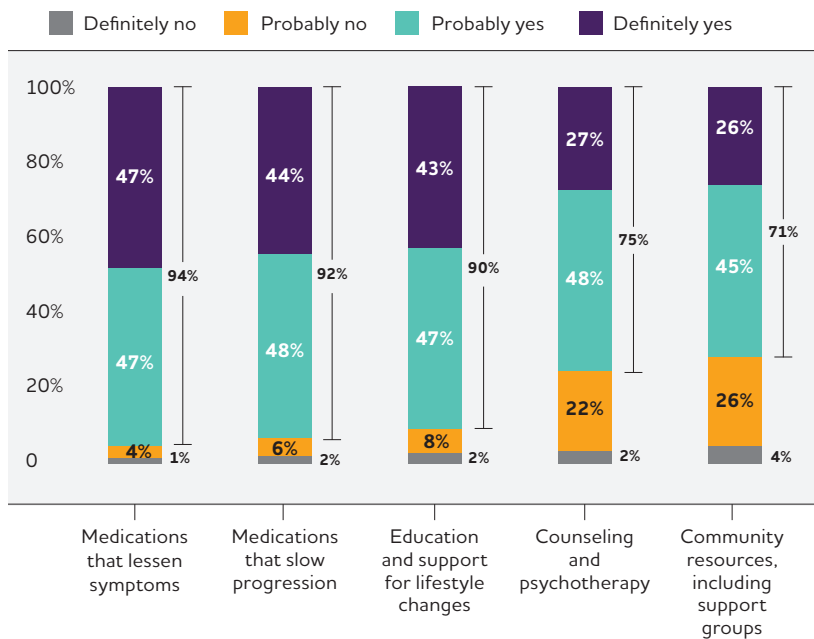
Insurance companies not covering future care	44%
Whether the test is truly accurate	41%
Losing confidence in my ability to do typical daily activities	40%
Cost of testing	39%
Being prohibited from certain activities, such as driving	38%
Starting to feel worried	33%
Others in my family feeling worried	33%
Lack of access to specialists who have appropriate expertise	23%
Lack of access to good health care following testing	20%
Having it on my medical record	17%
Treatment options for Alzheimer's disease are limited, so it doesn't matter	14%
There is no cure for Alzheimer's disease, so it doesn't matter	13%
Feeling stigmatized by family and friends	13%
Feeling stigmatized by others in my community	10%
I would have no concerns	17%

FIGURE 25

Whether Anti-Amyloid Treatment Potential Changes Preference for Earlier Diagnosis



Interest in Options for Managing and Treating Alzheimer's Disease



White Americans had somewhat higher risk tolerance, with 61% saying they would accept moderate to very high levels of risk with anti-amyloid treatment versus 48% of Asian Americans and 45% of Black Americans. Many Native and Hispanic Americans also said they would accept moderate to very high levels of risk (58% and 53%, respectively).

Americans Envision a Bright Future for Alzheimer's Treatment

Although Alzheimer's disease continues to affect the lives of many across the nation, Americans remain hopeful about the potential for new treatments and signaled strong support for research that aims to advance medical breakthroughs. More than 4 in 5 Americans (83%) expressed interest in participating in clinical trials that could help slow or cure Alzheimer's disease. Additionally, survey respondents were optimistic about treatment advances in the next 10 years:

- Four in 5 (81%) believe treatments to **stop** the progression of Alzheimer's disease are within reach.
- Two in 3 (66%) say treatments to **prevent** Alzheimer's disease are likely.
- Half (49%) think there might be a treatment to **cure** Alzheimer's disease.

These responses mostly align with public views on future Alzheimer's treatment reported in 2022, with a shift toward greater optimism about a future treatment to stop disease

progression (60% of Americans 18 and over in 2022 versus 81% of Americans 45 and older in 2025).¹⁰⁶⁴

White respondents were generally less optimistic about future progress in preventing and treating Alzheimer's disease. Among those surveyed, a majority of Hispanic (80%), Black (77%), Native (74%), and Asian Americans (73%) believed it likely that a treatment will be developed in the next decade to prevent Alzheimer's disease. A smaller majority of White Americans (62%) shared this belief. Many Black (65%), Asian (63%), Native (61%) and Hispanic Americans (60%) also thought that a cure was likely on the horizon. White Americans were the least hopeful, with 43% believing a cure for Alzheimer's disease was plausible in this timeframe.

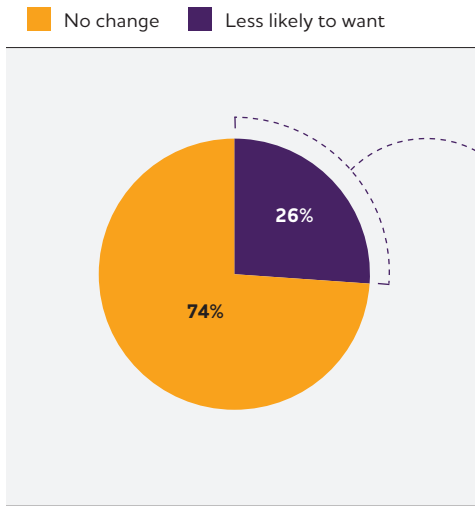
A Path Forward: Facilitating the Future of Alzheimer's Detection, Diagnosis and Treatment

The 2025 Alzheimer's Disease Facts and Figures Special Report underscores the need to strengthen early detection and diagnosis of Alzheimer's disease for more Americans. Possible steps include:

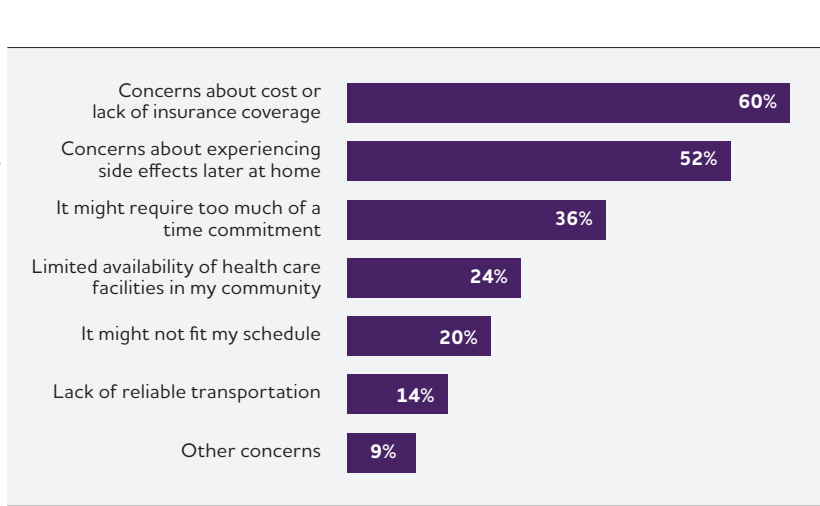
- Continuing research to discover, validate and advance biomarker testing modalities.
- Establishing clinical practice guidelines to assist with detection and diagnosis and to ensure that evaluation and treatment are grounded in actionable evidence.

FIGURE 26

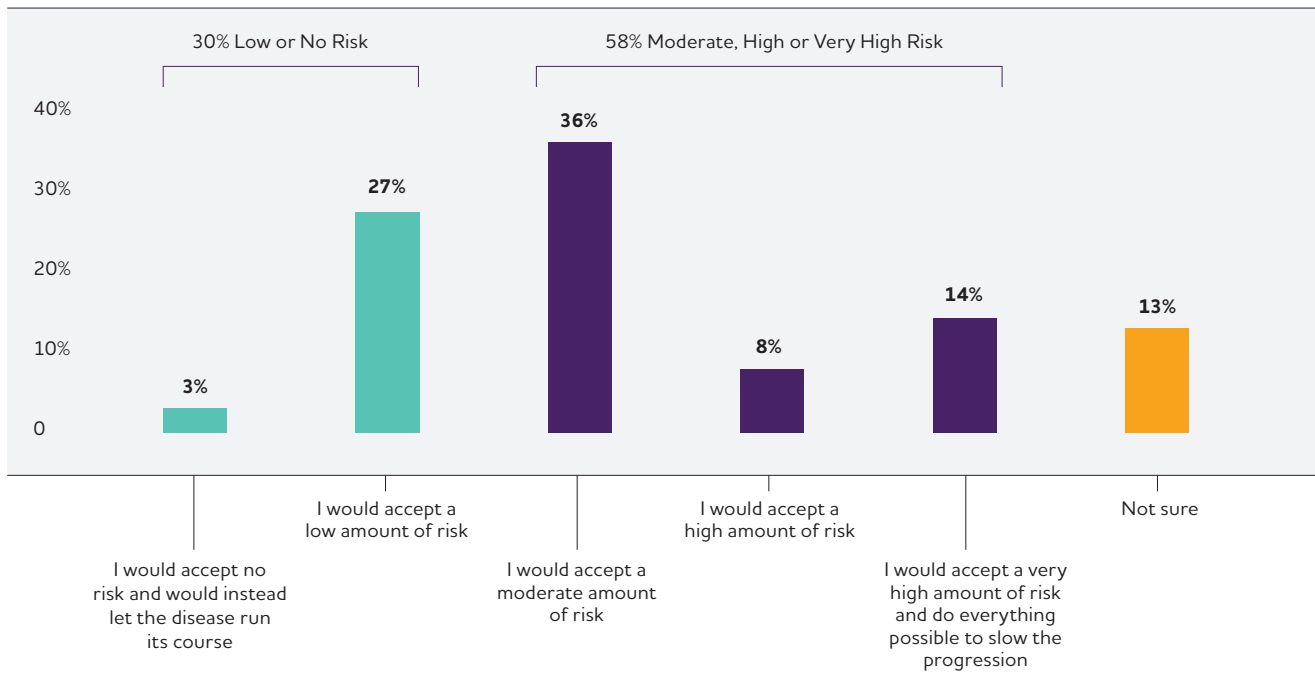
Impact of Monthly Outpatient Care on Interest in Anti-Amyloid Treatment



Reasons for Less Interest in Anti-Amyloid Treatment Requiring Monthly Outpatient Care



Acceptable Levels of Risk for Treatments that Slow the Progression of Alzheimer’s Disease



- Improving conversations among patients, caregivers and clinicians about testing, diagnosis and treatment.
- Recognizing potential ethical concerns with early detection.
- Securing future access to biomarker testing through legislation and policy initiatives that aim to guarantee insurance coverage.
- Leveraging public health efforts to promote the importance of early detection and diagnosis through awareness campaigns and provider education.

Ensuring Support for Research, Development and Validation of Novel Biomarker Tests

Research advancements on clinical assessments, psychometric testing, and emerging blood-based and established biomarker tests are increasing the likelihood of being able to detect hallmarks of neurodegenerative diseases at their earliest stages.¹⁰⁶⁸

The Alzheimer's Association has been at the forefront of these cutting-edge research efforts, investing millions annually to propel a variety of aspects of dementia research.¹⁰⁶⁹ In 2024, 15% of funded projects focused on developing tools and methods for earlier diagnosis, timelier interventions and more effective monitoring of disease progression.¹⁰⁶⁹ These efforts encompass studies that develop and expand the use of brain scans, fluid biomarkers such as blood tests, and clinical tools, as well as studies that

integrate these measures to further their development, standardization and validation.

In addition, more than 10 years ago, the Alzheimer's Association established the Global Biomarker Standardization Consortium (GBSC) to convene key researchers, clinicians, industry members and regulatory and government leaders.¹⁰⁶⁸ The GBSC's objective is to achieve consensus on the best ways to standardize and validate biomarker tests — a critical part of ensuring consistent test results — for Alzheimer's and other dementia for use in global clinical practices.

In 2018, the Alzheimer's Association launched a working group under the GBSC umbrella to focus on consensus procedures for standardizing collection and processing of blood samples. This working group, the Standardization of Alzheimer's Blood Biomarkers (SABB) Program, brings together those with expertise in fluid biomarkers from academia, government and industry. The SABB published standardized procedures for handling blood samples and continues to research new and emerging biomarkers to inform the scientific and clinical communities.¹⁰⁷⁰ Furthermore, in 2024, the GBSC launched a new workgroup, the Alzheimer's Association Certified Reference Material for Plasma p-tau217, to facilitate global standardization measurements and improve diagnostic accuracy of this key biomarker for Alzheimer's disease.

Perspectives of Individuals With a Family History of Alzheimer's

In this year's survey, 1 in 4 U.S. adults reported having a biological grandparent, parent or sibling with Alzheimer's disease. This personal experience was a significant differentiator of attitudes, awareness and interest in early detection, diagnosis and treatment.

Compared with survey participants who did not report having a relative with Alzheimer's disease, those with a family history:

- Worried more about developing Alzheimer's disease themselves (38% worried a moderate amount and 21% worried a lot versus 20% and 9% for those without a family history, respectively).
- Saw cognitive screening as being more important (66% perceived it as very important versus 56% of those without a family history).
- Expressed stronger interest in blood-based biomarker testing (62% were definitely interested in presymptomatic and 67% were definitely interested in postsymptomatic testing versus 48% and 54% without a family history, respectively).
- Were somewhat more familiar with anti-amyloid treatments (20% versus 13%) and expressed the strongest interest in this treatment option (50% would definitely want treatment versus 42%).
- Expressed somewhat greater interest in participating in future clinical trials studying treatments to slow or possibly cure Alzheimer's disease (46% were very interested in future clinical trials versus 37%).

Focus Groups Mirror Survey Findings

As part of its Healthy Brain Initiative Cooperative Agreement with the Centers for Disease Control and Prevention, the Alzheimer's Association initiated focus groups to gather perceptions and attitudes about the early detection and treatment of Alzheimer's disease beyond what could be gleaned from the survey. Focus groups reiterated several of the Special Report survey findings, and views overlapped in many areas.

Most participants understood early detection to be regular health screenings and preventive care, and personal experiences through family members significantly shaped views of early detection of Alzheimer's disease.

Thoughts on Early Detection

“When you have knowledge, you are that much more powerful.” — American Indian participant who indicated they would want to know if they had Alzheimer's disease before noticeable symptoms.

The preference for early-stage detection (before noticeable or with only minor symptoms) was clear in the focus groups. Attitudes and opinions on the advantages were consistent with the survey responses. However, the focus groups were able to probe deeper into the disadvantages of early detection, particularly the potential emotional drawbacks.

The focus groups also explored whether knowing about medication to treat the early stages of Alzheimer's influenced the timing of diagnosis. Knowledge about new medication to slow disease progression reinforced preferences to know their diagnosis in the early stages of the disease. However, this information raised questions for many participants about medication access and affordability, including access to insurance coverage, efficacy and side effects.

Advantages

“Even if it's not in your family, you should still be doing things to protect your brain or your health. I'm not going to do anything that's going to jeopardize my brain because I don't want to get Alzheimer's. I'm going to prevent it [in] any way possible.” — Asian American and Pacific Islander participant

Cross-cutting findings and themes:

Planning and preparation

- Ability to get affairs in order while cognitively capable.
- Ability to express care preferences.
- Time for family to prepare and plan for care.
- Opportunity to make financial and legal arrangements.

Medical benefits

- Potential access to treatment.
- Opportunity to participate in research or clinical trials.
- Better chance to participate in care decisions.

Safety and support

- Time to build a support network.
- Ability to make living arrangements.
- Prevention of crisis situations.

Disadvantages

“I would not want to know too early. I wouldn't want to deal with the anxiety.”
— White participant

Cross-cutting findings and themes:

Psychological impact

- Anxiety about the future.
- Stress of knowing that there is no cure.
- Potential depression or hopelessness.
- Fear about the loss of independence.

Emotional burden

- Living with diagnosis while still functioning well.
- Uncertainty about progression timeline and treatment options.
- Challenge of timing disclosure to others.

Practical challenges

- Insurance coverage.
- Limited treatment options or access to care.

Family and social concerns

- Family stress and worry.
- Changes in relationships.
- Stigma and social implications.
- Potential isolation.

Focus group methodology

L&M Policy Research was engaged to conduct 11 focus groups with 69 participants (14 White, 14 African American, 18 American Indian/Alaska Native [AI/AN], nine Asian American and Pacific Islander [AAPI], and 14 Hispanic, Spanish-speaking [HIS-SPA]).

In 2022, the Association published *Appropriate Use Recommendations for Blood Biomarkers in Alzheimer's Disease*, which provides guidance for clinicians and researchers using these tests in clinical trials, as well as priorities for future research in this area.²⁷⁷

Establishing Clinical Practice Guidelines to Bridge Scientific Advances and Clinical Care

The Alzheimer's Association is building an updated library of clinical guidance that distills the latest scientific evidence and translates it into clear and actionable recommendations for clinical practices. This process involves close collaboration with clinical and subject-matter experts, methodologists, peer organizations, early-career researchers and patient representatives. Expert panels will move from evidence to recommendations using a transparent methodology called the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach to vet the quality of evidence used to inform recommendations. Numerous reputable organizations, including the World Health Organization, the American College of Physicians and the Cochrane Collection follow the GRADE principles and format for systematic reviews and clinical guidelines.¹⁰⁷¹

Recognizing that specialists need more detailed and comprehensive recommendations to provide high-quality care and promote early detection and diagnosis, the Association is currently preparing guidelines on:

- Blood-based biomarker tests: Specialized health care settings (anticipated in 2025).
- Cognitive assessment tools: Primary health care settings (anticipated in 2025).
- Clinical implementation of Alzheimer's disease staging criteria and treatment (anticipated in 2026).

These guidelines are expected to be updated annually to reflect the rapidly evolving science, new evidence and practical experiences of health care professionals.

Fostering Better Conversations About Testing, Diagnosis and Treatment

Clinical practice guidelines provide the framework for high-quality dementia care, but the foundation of trust is built on communication among patients, caregivers and clinicians.

Effective communication is absolutely necessary for improving testing, diagnosis and treatment for Alzheimer's and other dementias. Primary Care Physicians (PCPs) are often on the frontlines of dementia diagnosis and care. However, the *2020 Alzheimer's Disease Facts and Figures Special Report* found that PCPs feel inadequately prepared to care for patients with Alzheimer's and other dementias, citing difficulty answering questions, making diagnoses and staying current with the latest developments in

management, treatment and screening/testing.¹⁰⁷² Beyond these challenges faced by PCPs, communication barriers exist between patients and clinicians. Both groups are often uncomfortable raising concerns or discussing cognitive symptoms, which can hinder crucial next steps for detection, diagnosis and treatment.

Enhancing patient-clinician dialogue is paramount not only for improving communication about next steps but for engaging patients and caregivers in the dementia care journey. To achieve this, it is essential to develop and invest in training that increases comfort with difficult conversations and prioritizes listening to patient concerns, responding with empathy and providing clear, jargon-free explanations of complex medical information.¹⁰⁷³ Furthermore, training should teach techniques for collaborative decision-making that integrate patient preferences and values into the discussion.⁹¹⁸

Future clinical guidelines will offer recommendations on how to broach the topic of blood-based biomarkers with patients. In the meantime, there is a growing body of language to help clinicians, including PCPs and dementia specialists, convey information about diagnosis and treatment in a balanced and realistic way. In 2024, The Alzheimer's Association Clinical Meaningfulness Workgroup presented recommendations and suggested language to help health care providers communicate clearly, accurately and empathetically about newly approved anti-amyloid medications to patients diagnosed with early Alzheimer's disease and their caregivers.⁵⁸

The workgroup's recommendations for discussing and personalizing care plans encapsulated the following core themes:

- Balanced, accurate communication.
- Eligibility and personalization.
- Informed consent and risks.
- APOE genetic testing.
- Ongoing monitoring and safety.
- Financial and logistical considerations.
- Support for caregivers.
- A holistic care approach.

Many of these themes are directly applicable to eventual discussions about early detection. For example, patients and caregivers will need accurate information about how tests work, the meaning of test results, and the risks and benefits associated with receiving positive test results, which may lead to early diagnosis.

The Alzheimer's Association provides a range of resources to support health systems and clinicians in these critical areas, including materials on early detection and diagnosis, management of Alzheimer's and other dementias, care planning and support services. Prioritizing communication

efforts and using available resources creates a dementia care environment where patients and caregivers feel heard, respected and empowered — ultimately resulting in higher quality of care and strengthening the patient-clinician relationship. For a complete listing of available Association resources to support health systems and clinicians, visit alz.org/professionals/health-systems-clinicians.

Examining Potential Ethical Considerations Associated with Advances in Biomarker Testing

The evolving ability to detect protein signals of Alzheimer's disease in presymptomatic individuals, particularly through blood-based biomarker tests, raises important ethical considerations.^{281,1066,1074} As stated earlier in the Special Report, no guidance today recommends biomarker testing for individuals who are not experiencing cognitive symptoms. Experts must establish a clear delineation between detection, which measures indicators of potential risk, and formal diagnosis of Alzheimer's disease, which is a multifaceted process involving cognitive screening, other assessments and, ultimately, clinical judgment.

Possible ethical considerations are heightened by the anticipated FDA approval of these tests for use in primary care settings, where health care professionals may not be as familiar with the critical distinction between detection and diagnosis as specialists are, nor as equipped to accurately convey this to patients as they weigh the benefits and risks of such tests. The health care community can learn from approaches used in clinical research settings, where presymptomatic biomarker information is carefully disclosed to study participants and care partners.^{281,1074} A pattern has been observed of participants in research studies sharing biomarker test results with their care partners, a practice that may well continue when test results are available in the clinic.^{1066,1074}

Pre-counseling patients is an additional proactive approach to respond to possible concerns related to biomarker test results. This approach can set realistic expectations about what these tests can and cannot do, explain the possible implications of results both now and in the future, and educate patients on the distinctions between detection and diagnosis of Alzheimer's disease. Laying this groundwork for patients is vital given the increasing availability of medical test results, including blood tests and imaging, through patient portals — often without sufficient context or clinical interpretation. Premature release of results to patients before physicians are able to provide context and interpretation can lead to misinterpretation and emotional distress.

Furthermore, the potential for discrimination based on the results of biomarker testing, whether in medical settings, the workplace or the community, must be carefully considered to determine how and with whom to share

results. In the clinical research setting, concerns about stigma and discrimination are cited as reasons not to share biomarker test results.^{1066,1074}

This year's Special Report found that individuals are pragmatic about the use of simple medical tests, such as blood-based biomarker tests, for Alzheimer's detection. They stated that they would use the results to plan ahead, be more aware of potential symptoms and seek treatment earlier if symptoms appear.

Advancing Legislative and Policy Initiatives to Secure Insurance Coverage for Current and Future Biomarker Tests

Currently, insurance coverage for biomarker testing, which includes imaging and blood tests, has not kept pace with scientific discoveries and progress in treatment. The majority of states do not require insurance carriers to cover biomarker testing, which gives private insurance plans significant latitude in what they cover. As a result, individuals in these states may not have access to necessary biomarker testing. State Medicaid programs may elect to not cover biomarker testing for a wide variety of reasons, further challenging access. Existing health care disparities and challenges to obtaining a dementia diagnosis may be exacerbated if new biomarker testing opportunities cannot be accessed.

“By ensuring access to necessary biomarker testing, states can reduce the time it takes to receive a diagnosis and enable access to new disease-modifying treatments and care planning.”

With new evidence in the field of biomarker testing and FDA consideration of blood-based amyloid biomarker testing tools expected in the near future, the Association is engaging state governments to ensure adequate coverage of biomarker tests and future access to diagnosis and treatment — reflecting the Association's commitment to these priorities.

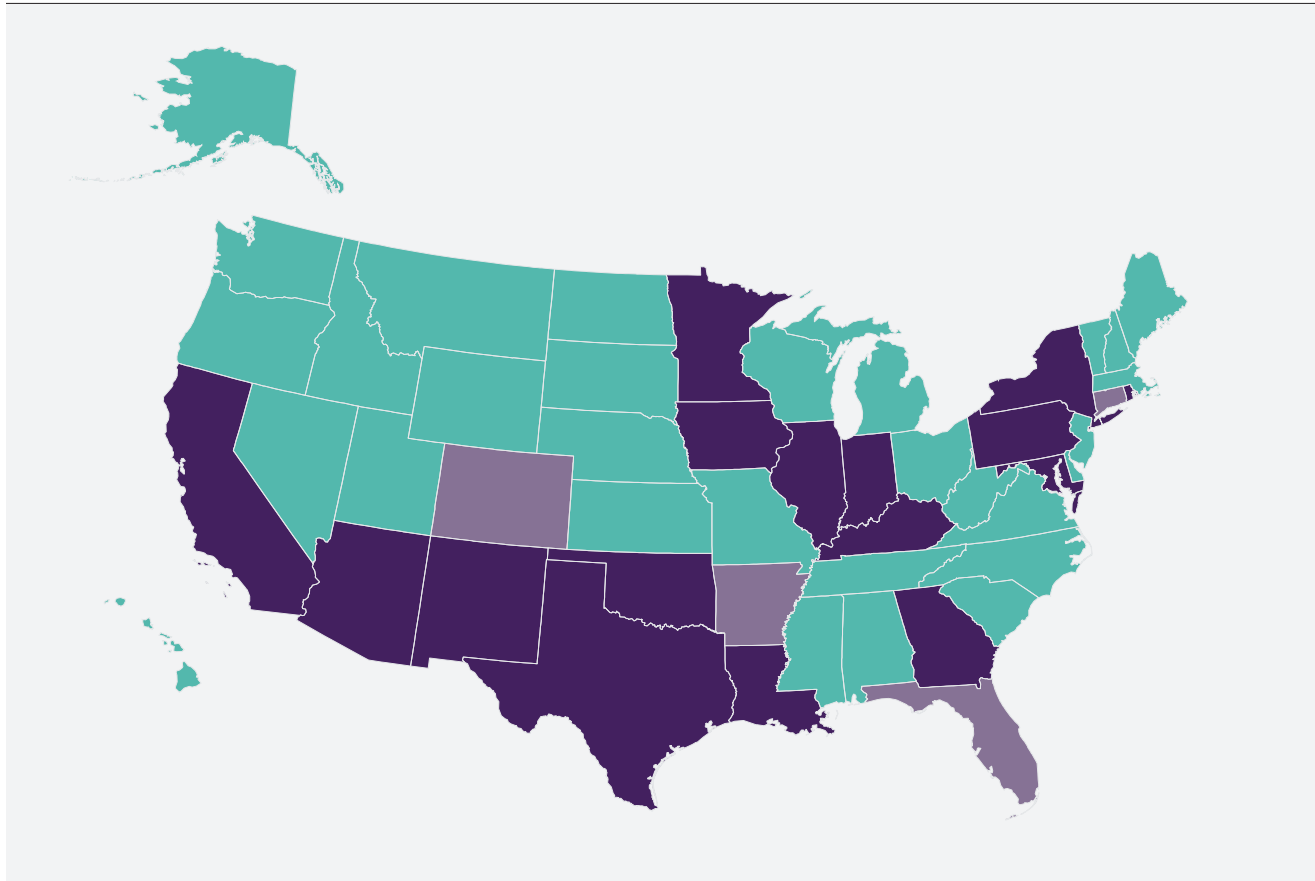
The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) are part of a national coalition of patient advocates committed to ensuring insurance coverage for comprehensive biomarker testing. National coalition members include the American Cancer Society Cancer Action Network (ACS CAN), the ALS Association and the Arthritis Foundation. AIM is working with policymakers to advance and pass state legislation requiring insurers to cover biomarker testing (Figure 27). As of January 2025:

- 16 states require coverage in both public and private insurance plans (AZ, CA, GA, IA, IL, IN, LA, KY, MD, MN, NM, NY, RI, OK, PA, TX).
- Two states require private pay only (AR, CO).
- Two states require public pay only (CT, FL).

FIGURE 27

Successful AIM Insurance Coverage Legislation Efforts (As of January 2025)*

■ Enacted legislation ■ Enacted with some coverage ■ States without coverage requirements



* AIM = Alzheimer's Impact Movement

Implementing Public Health Efforts to Promote Early Detection and Diagnosis

As more treatments become available, early detection and diagnosis of Alzheimer's disease become essential to improving the health of communities. Public health agencies play a critical role in educating the public and health care providers about the latest research, best practices and importance of early detection and diagnosis.

Alzheimer's Association initiatives with public health agencies to increase understanding emphasize education about warning signs of dementia and improve access to diagnostic services and supports. Efforts also include working to lessen stigma around discussing memory and thinking problems in communities and normalizing these conversations in health care settings to help make early detection and diagnosis more commonplace. The resulting materials and campaigns to promote early detection and diagnosis must be leveraged in every

community and developed in culturally sensitive and relevant ways. The survey and focus group results from this and previous Special Reports can provide valuable insights to guide these efforts.

Beyond education, the Alzheimer's Association also collaborates with state and local public health departments, tribal health organizations, health systems and other stakeholders to establish population-based strategies covering risk reduction, early detection and diagnosis, and quality of care. These collaborative efforts are vital for creating a comprehensive and coordinated approach to addressing Alzheimer's and dementia across the life course.

Through broad, ongoing initiatives and collaborations, public health has the power to significantly lessen the burden of Alzheimer's disease on individuals, families and the nation as a whole.

Appendices

End Notes

- A1. Racial and ethnic identifiers: Facts and Figures keeps the racial and ethnic terms used in source documents when describing study findings. When not referring to data from specific studies, adjectives such as “Black,” “Hispanic” and “White” may be used (for example, Black populations and Hispanic communities).
- A2. Estimated prevalence (number and proportion) of Americans age 65 and older with Alzheimer’s dementia for 2025: The estimated 7.2 million individuals ages 65 years and older with Alzheimer’s dementia and the estimated numbers of individuals with Alzheimer’s in each age group were reported from a study that used data from the Chicago Health and Aging Project (CHAP) in combination with population projections from the U.S. Census.²⁹³ The number, 7.2 million, is higher than estimated from previous study that also combined CHAP and U.S. Census data. This is because the more recent study used updated Census projections and incorporated information from Hispanic/Latino American individuals. The proportion of the population with Alzheimer’s dementia (among people age 65 and older and by age group) is calculated using as the numerators the numbers of people with Alzheimer’s dementia, as reported by the recent study in CHAP.²⁹³ The denominators were the U.S. Census population projections for the specific age groups of interest.
- A3. Differences between CHAP and HRS-HCAP estimates for Alzheimer’s dementia prevalence: The number of people estimated to have any form of dementia in the U.S. in 2016 from the Health and Retirement Study’s (HRS) Harmonized Cognitive Assessment Protocol (HCAP; 4.92 million) is lower than the CHAP estimate of how many people were living with Alzheimer’s dementia only (6.07 million).¹⁷³ This is because of differences in dementia ascertainment between the two studies: both studies used scores on batteries of cognitive tests, but the HRS-HCAP study additionally required an informant report of functional impairment (i.e. disability). Because the more stringent threshold for dementia in HRS-HCAP may miss people with mild Alzheimer’s dementia, 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.
- A4. Criteria for identifying people with Alzheimer’s or other dementias in the Framingham Heart Study: From 1975 to 2009, 7,901 people from the Framingham Study who had survived free of dementia to at least age 45, and 5,937 who had survived free of dementia until at least age 65 were followed for incidence of dementia.³⁴⁰ Diagnosis of dementia was made according to the 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 six months’ duration were used, lifetime risks of Alzheimer’s and other dementias would be higher than those estimated by this study.
- A5. Projected number of people with Alzheimer’s dementia, 2020-2060: This figure comes from the CHAP study.²⁹³ Other projections are somewhat lower (see, for example, Brookmeyer et al.¹⁰⁷⁹) because they relied on more conservative methods for counting people who currently have Alzheimer’s dementia.⁴³ 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.
- A6. 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 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.
- A7. 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 Behavioral Risk Factor Surveillance System (BRFSS) survey. Since 2016, all states and the District of Columbia utilized the BRFSS caregiver module. This module identified respondents age 18 and over who 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. The module asks a series of follow-up questions, including asking the caregiver to identify what the main health problem, long-term illness, or disability that the person they care for has. One of the reported condition categories is “Alzheimer’s disease, dementia, or other cognitive impairment.” In the BRFSS surveys conducted in 2019 and after, an additional follow-up question was included, asking if the caregiving recipient also had dementia in addition to their main condition. Prior to 2019, the survey did not include caregivers of recipients for whom dementia was not their main condition, so these numbers were imputed using data collected in 2019 by the National Alliance for Caregiving (NAC)/AARP survey. 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: 11% of respondents reported dementia as the main condition of their care recipient, while 26% of all respondents reported the presence of dementia. Using this ratio in combination with BRFSS data, the Alzheimer’s Association was able to determine the percentage of adults in all states and the District of Columbia who are caregivers for individuals living with Alzheimer’s or another dementia. These percentages were applied to the estimated number of people age 18 and older in each state in July 2024, using U.S. Census Bureau data available at: <https://www.census.gov/programs-surveys/popest/data/tables.html>. This resulted in a total of 11,926 million Alzheimer’s and dementia caregivers across all 50 states and the District of Columbia.
- A8. Number of hours of unpaid care: The BRFSS survey asks caregivers to identify, within five time frames, the number of hours they provide care in an average week. Using the method developed by Rabarison and colleagues,⁵¹⁷ the Alzheimer’s Association assumed the midpoint of each time frame was the average number of hours for each caregiver within that time frame and then calculated the overall average number of hours of weekly care provided by dementia caregivers in each state. This number was then converted to a yearly average and multiplied by the number of caregivers in each state⁴⁷ to determine the total number of hours of care provided. When added together, across all 50 states and the District of Columbia, the total number of hours provided by Alzheimer’s and dementia caregivers is 19.161 billion hours.
- A9. Value of unpaid caregiving: For each state, the hourly value of care was determined as the average of the state minimum hourly wage¹⁰⁷⁶ and the most recently available state median hourly cost of a home health aide. (For Nevada, the minimum wage used was the average of the minimum wage for those who are not provided health insurance and the minimum wage for those who are provided health insurance.)⁹⁹² The average for each state was then multiplied by the total number of hours of unpaid care in that state⁴⁸ to derive the total value of unpaid care. Adding the totals from all states and the District of Columbia resulted in an economic value of \$413.452 billion for dementia caregiving in the United States in 2024.

- A10. The 2014 Alzheimer's Association Women and Alzheimer's Poll: This poll questioned a nationally representative sample of 3,102 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/Latinos, selected from U.S. Census tracts with higher than an 8% 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.
- A11. 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). The Lewin Model's state-specific Medicaid costs for 2025 are based on an earlier estimate of state prevalence than reported here (Weuve J, Hebert LE, Scherr PA, Evans DA. Prevalence of Alzheimer disease in U.S. states. *Epidemiology* 2015;26(1):E4-6) and are inflated to 2024 dollars.
- A12. All cost estimates were inflated to year 2024 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.
- A13. 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: Payments are unadjusted, and therefore, do not account for differences in patient characteristics, such as age or sex. Additionally, payments are based on health care utilization and payments in 2018 for the Medicare Current Beneficiary Survey and 2019 for Medicare claims data, prior to the COVID-19 pandemic, and do not reflect any post-pandemic-related changes in utilization.
- A14. Enrollment in fee-for-service Medicare versus Medicare Part C: Individuals eligible for Medicare can enroll in traditional Medicare, also referred to as fee-for-service Medicare and original Medicare, or Medicare Advantage, also referred to as Medicare Part C.¹⁰⁷⁷ With traditional Medicare, beneficiaries can receive care from any doctor or hospital in the United States that accepts Medicare. Generally, beneficiaries can seek care from a specialist without a referral. Traditional Medicare has fixed cost sharing, which includes coinsurance of 20% of the Medicare-approved amount for services covered by Part B after the deductible is met. Individuals enrolled in traditional Medicare can also enroll in Medicare Supplemental Insurance (also referred to as Medigap) to help cover the out-of-pocket costs. Traditional Medicare does not have an annual limit on the amount beneficiaries pay out-of-pocket. Benefits are the same for all individuals enrolled in traditional Medicare. Individuals enrolled in traditional Medicare can also enroll in a Medicare Part D plan to cover some of the costs of prescription drugs. Medicare Part D enrollment has a separate premium. With Medicare Advantage, individuals must enroll in a specific private plan. Premiums, benefits and out-of-pocket costs may vary across plans. Medicare Advantage plans have an annual limit on the amount individuals pay out-of-pocket. Individuals enrolled in a Medicare Advantage plan are not allowed to enroll in Medigap. Medicare Advantage plans are also allowed to offer additional benefits not included in traditional Medicare, such as vision, hearing and dental services as well as some non-health care benefits, such as transportation costs and gym memberships. Many Medicare Advantage plans include prescription drug coverage (Medicare Part D). Individuals enrolled in a Medicare Advantage plan have a specific network of doctors and hospitals that enrollees need to use for services to be paid by the Medicare Advantage plan. Additionally, individuals enrolled in a Medicare Advantage plan may need a referral to see a specialist. Enrollment in Medicare Advantage has increased dramatically over the past decade, with 51% of all Medicare beneficiaries enrolled in a Medicare Advantage plan in 2023 compared with 29% in 2013.¹⁰⁰⁰
- A15. Medicare Current Beneficiary Survey Report: These data come from an analysis of findings from the 2018 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Health Care Cost Institute.⁹⁴¹ 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 setting, 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 *2025 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 setting 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 2018. 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 G30.0, G30.1, G30.8, G30.9, G31.01, G31.09, G31.83, F01.50, F01.51, F02.80, F02.81, F03.90, F03.91 and F10.27.

Costs from the MCBS analysis are based on responses from 2018 and reported in 2024 dollars.

A16. Differences in estimated costs reported by Hurd and colleagues:

Hurd and colleagues⁹⁴⁰ estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. 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 *2025 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).

Appendices

References

1. Villemagne VL, Burnham S, Bourgeat P, et al. Amyloid s deposition, neurodegeneration, and cognitive decline in sporadic Alzheimer's disease: A prospective cohort study. *Lancet Neurol* 2013;12(4):357-367.
2. Reiman EM, Quiroz YT, Fleisher AS, et al. Brain imaging and fluid biomarker analysis in young adults at genetic risk for autosomal dominant Alzheimer's disease in the presenilin 1 E280A kindred: A case-control study. *Lancet Neurol* 2012;11(2):1048-1056.
3. Jack CR, Lowe VJ, Weigand SD, et al. Serial PiB and MRI in normal, mild cognitive impairment and Alzheimer's disease: Implications for sequence of pathological events in Alzheimer's disease. *Brain* 2009;132:1355-1365.
4. Bateman RJ, Xiong C, Benzinger TL, et al. Clinical and biomarker changes in dominantly inherited Alzheimer's disease. *N Engl J Med* 2012;367(9):795-804.
5. Gordon BA, Blazey TM, Su Y, et al. Spatial patterns of neuroimaging biomarker change in individuals from families with autosomal dominant Alzheimer's disease: A longitudinal study. *Lancet Neurol* 2018;17(3):241-250.
6. Braak H, Thal DR, Ghebremedhin E, Del Tredici K. Stages of the pathologic process in Alzheimer disease: Age categories from 1 to 100 years. *J Neuropathol Exp Neurol* 2011;70(11):960-969.
7. Quiroz YT, Zetterberg H, Reiman EM, et al. Plasma neurofilament light chain in the presenilin 1 E280A autosomal dominant Alzheimer's disease kindred: A cross-sectional and longitudinal cohort study. *Lancet Neuro* 2020;19(6):513-521.
8. Barthelemy N, Joseph-Mathurin N, Gordon BA, et al. A soluble phosphorylated tau signature links tau, amyloid and the evolution of stages of dominantly inherited Alzheimer's disease. *Nat Med* 2020;26:398-407.
9. Karlawish J, Peterson A, Kleid M, et al. Caregiver accounts of lucid episodes in persons with advanced dementia. *Gerontologist* 2024;64(6):gnad170.
10. Gilmore-Bykovskiy A, Block L, Benson C, et al. "It's You": Caregiver and Clinician Perspectives on Lucidity in People Living With Dementia. *Gerontologist* 2023;63(1):13-27.
11. Batthyány A, Greyson B. Spontaneous remission of dementia before death: Results from a study on paradoxical lucidity. *Psychol Conscious: Theory, Research, and Practice* 2021;8(1):1-8.
12. Mashour GA, Frank L, Batthyany A, et al. Paradoxical lucidity: A potential paradigm shift for the neurobiology and treatment of severe dementias. *Alzheimers Dement* 2019;15(8):1107-1114.
13. Ramirez M, Teresi JA, Silver S, et al. The lucidity in dementia experience: perspectives from family and professional caregivers. *Age Ageing* 2024;53(8):afae174.
14. Griffin JM, Kim K, Finnie DM, et al. Developing and describing a typology of lucid episodes among people with Alzheimer's disease and related dementias. *Alzheimers Dement* 2024;20(4):2434-2443.
15. Tom SE, Hubbard RA, Crane PK, et al. Characterization of dementia and Alzheimer's disease in an older population: Updated incidence and life expectancy with and without dementia. *Am J Public Health* 2015;105(2):408-413.
16. Ganguli M, Dodge HH, Shen C, Pandav RS, DeKosky ST. Alzheimer disease and mortality: A 15-year epidemiological study. *Arch Neurol* 2005;62(5):779-784.
17. Waring SC, Doody RS, Pavlik VN, Massman PJ, Chan W. Survival among patients with dementia from a large multi-ethnic population. *Alzheimer Dis Assoc Disord* 2005;19(4):178-183.
18. Brookmeyer R, Corrada MM, Curriero FC, Kawas C. Survival following a diagnosis of Alzheimer disease. *Arch Neurol* 2002;59(11):1764-1767.
19. Larson EB, Shadlen MF, Wang L, et al. Survival after initial diagnosis of Alzheimer disease. *Ann Intern Med* 2004;140(7):501-509.
20. Helzner EP, Scarmeas N, Cosentino S, Tang MX, Schupf N, Stern Y. Survival in Alzheimer disease: A multiethnic, population-based study of incident cases. *Neurology* 2008;71(19):1489-1495.
21. Xie J, Brayne C, Matthews FE. Survival times in people with dementia: Analysis from a population based cohort study with 14-year follow-up. *BMJ* 2008;336(7638):258-262.
22. Brodaty H, Seeher K, Gibson L. Dementia time to death: A systematic literature review on survival time and years of life lost in people with dementia. *Int Psychogeriatr* 2012;24(7):1034-1045.
23. Todd S, Barr S, Roberts M, Passmore AP. Survival in dementia and predictors of mortality: A review. *Int J Geriatr Psychiatry* 2013;28(11):1109-1124.
24. Smith AD, Smith SM, de Jager CA, et al. Homocysteine-lowering by B vitamins slows the rate of accelerated brain atrophy in mild cognitive impairment: A randomized controlled trial. *Plos One* 2010;5(9):e12244.
25. Kapasi A, DeCarli C, Schneider JA. Impact of multiple pathologies on the threshold for clinically overt dementia. *Acta Neuropathol* 2017;134(2):171-186.
26. Brenowitz WD, Hubbard RA, Keene CD, et al. Mixed neuropathologies and estimated rates of clinical progression in a large autopsy sample. *Alzheimers Dement* 2017;13(6):654-662.
27. National Institute on Aging. What are frontotemporal disorders? Accessed December 16, 2024. Available at: <https://www.nia.nih.gov/health/what-are-frontotemporal-disorders>.
28. Hogan DB, Jette N, Fiest KM, et al. The prevalence and incidence of frontotemporal dementia: A systematic review. *Can J Neurol Sci* 2016;43(suppl):S96-109.
29. Amador-Ortiz C, Ahmed Z, Zehr C, Dickson DW. Hippocampal sclerosis dementia differs from hippocampal sclerosis in frontal lobe degeneration. *Acta Neuropathol* 2007;113(3):245-252.
30. Kane JPM, Surendranathan A, Bentley A, et al. Clinical prevalence of Lewy body dementia. *Alzheimers Res Ther* 2018;10(1):19.
31. National Institute on Aging. What Is Limbic-Predominant Age-Related TDP-43 Encephalopathy (LATE)? Accessed December 21, 2024. Available at: <https://www.nia.nih.gov/health/alzheimers-and-dementia/what-limbic-predominant-age-related-tdp-43-encephalopathy-late>.
32. De Reuck J, Maurage CA, Deramecourt V, et al. Aging and cerebrovascular lesions in pure and in mixed neurodegenerative and vascular dementia brains: A neuropathological study. *Folia Neuropathol* 2018;56(2):81-87.
33. James BD, Bennett DA, Boyle PA, Leurgans S, Schneider JA. Dementia from Alzheimer disease and mixed pathologies in the oldest old. *JAMA* 2012;307(17):1798-1800.
34. Stojkowska I, Krainc D, Mazzulli JR. Molecular mechanisms of α -synuclein and GBA1 in Parkinson's disease. *Cell Tissue Res* 2018;373(1):51-60.
35. Aarsland D, Zaccai J, Brayne C. A systematic review of prevalence studies of dementia in Parkinson's disease. *Mov Disord* 2005;20(10):1255.
36. Kawas CH, Kim RC, Sonnen JA, Bullain SS, Trieu T, Corrada MM. Multiple pathologies are common and related to dementia in the oldest-old: The 90+ Study. *Neurology* 2015;85(6):535-542.
37. Viswanathan A, Rocca WA, Tzourio C. Vascular risk factors and dementia: How to move forward? *Neurology* 2009;72:368-374.
38. Schneider JA, Arvanitakis Z, Bang W, Bennett DA. Mixed brain pathologies account for most dementia cases in community-dwelling older persons. *Neurology* 2007;69:2197-2204.
39. Schneider JA, Arvanitakis Z, Leurgans SE, Bennett DA. The neuropathology of probable Alzheimer disease and mild cognitive impairment. *Ann Neurol* 2009;66(2):200-208.
40. Jellinger KA, Attems J. Neuropathological evaluation of mixed dementia. *J Neurol Sci* 2007;257(1-2):80-87.

41. Jellinger KA. The enigma of mixed dementia. *Alzheimers Dement* 2007;3(1):40-53.
42. Boyle PA, Lei Y, Wilson RS, Leurgans SE, Schneider JA, Bennett DA. Person-specific contribution of neuropathologies to cognitive loss in old age. *Ann Neurol* 2018;83(1):74-83.
43. Boyle PA, Yu L, Leurgans SE, et al. Attributable risk of Alzheimer's dementia attributed to age-related neuropathologies. *Ann Neurol* 2019;85(1):114-124.
44. Jellinger KA, Attems J. Prevalence of dementia disorders in the oldest-old: an autopsy study. *Acta Neuropathol* 2010;119:421-433.
45. Social Security Administration. Minimizing the risk of scams for people living with dementia. Accessed December 22, 2024. Available at: <https://blog.ssa.gov/minimizing-the-risk-of-scams-for-people-living-with-dementia/>.
46. Memory and Aging Center, UCSF Weill Institute for Neurosciences. Executive functions. Accessed December 22, 2024. Available at: <https://memory.ucsf.edu/symptoms/executive-functions>.
47. Heerema E. How executive functioning is affected by dementia. Verywell Health. Accessed December 22, 2024. Available at: <https://www.verywellhealth.com/executive-functioningalzheimers-98596>.
48. Gresenz CR, Mitchell JM, Rodriguez B, et al. The Financial consequences of undiagnosed memory disorders. Federal Reserve Bank of New York Staff Reports, 2024, no. 1106. <https://doi.org/10.59576/sr.1106>.
49. National Council on Aging. Understanding Wandering Risks in Older Adults. Accessed December 22, 2024. Available at: <https://www.ncoa.org/adviser/medical-alert-systems/dementia-wandering/>.
50. Alzheimer's Association. Wandering. Accessed November 6, 2024. Available at <https://www.alz.org/help-support/caregiving/stages-behaviors/wandering>.
51. Byard RW, Langlois NEI. Wandering dementia: A syndrome with forensic implications. *J Forensic Sci* 2019;64(2):443-445.
52. Woolford MH, Weller C, Ibrahim JE. Unexplained absences and risk of death and injury among nursing home residents: A systematic review. *J Am Med Dir Assoc* 2017;18(4):366.e1-366.e15.
53. Jack CR, Andrews JS, Beach TG, et al. Revised criteria for diagnosis and staging of Alzheimer's disease: Alzheimer's Association Workgroup. *Alzheimer's Dement* 2024;20:5143-5169.
54. Vermunt L, Sikkes SAM, van den Hout A, et al. Duration of preclinical, prodromal, and dementia stages of Alzheimer's disease in relation to age, sex, and APOE genotype. *Alzheimers Dement* 2019;15:888-898.
55. van Dyck CH, Swanson CJ, Aisen P, et al. Lecanemab in early Alzheimer's disease. *NEngl J Med* 2023;388:9-21.
56. Sims JR, Zimmer JA, Evans CD, et al. Donanemab in early symptomatic Alzheimer disease: The TRAILBLAZER-ALZ 2 randomized clinical trial. *JAMA* 2023;330(6):512-527.
57. Cummings J, Apostolova L, Rabinovici GD, et al. Lecanemab: Appropriate use recommendations. *J Prev Alzheimers Dis* 2023;10(3):362-377.
58. Rentz DM, Aisen PS, Atri A, et al. Benefits and risks of FDA-approved amyloid-targeting antibodies for treatment of early Alzheimer's disease: Navigating clinician-patient engagement. *Alzheimer's Dement* 2024;20(11):8162-8171.
59. Athar T, Al Balushi K, Khan SA. Recent advances on drug development and emerging therapeutic agents for Alzheimer's disease. *Mol Biol Rep* 2021;48:5629-5645.
60. Lao K, Ji N, Zhang X, Qiao W, Tang Z, Gou X. Drug development for Alzheimer's disease: Review. *J Drug Target*. 2019;27:164-173.
61. Cummings J, Zhou Y, Lee G, et al. Alzheimer's disease drug development pipeline: 2024. *Alzheimers Dement (NY)* 2024;10(2):e12465.
62. Van der Mussele S, Le Bastard N, et al. Agitation-associated behavioral symptoms in mild cognitive impairment and Alzheimer's dementia. *Aging Ment Health* 2015;19(3):247-257.
63. Ralph SJ, Espinet AJ. Increased all-cause mortality by antipsychotic drugs: Updated review and meta-analysis in dementia and general mental health care. *J Alzheimers Dis Rep* 2018;2:1-26.
64. Maust DT, Kim HM, Seyfried LS, et al. Antipsychotics, other psychotropics, and the risk of death in patients with dementia: number needed to harm. *JAMA Psychiatry* 2015;72:438-445.
65. Rogowska M, Thornton M, Creese B, et al. Implications of adverse outcomes associated with antipsychotics in older patients with dementia: A 2011-2022 update. *Drugs Aging* 2023;40(1):21-32.
66. Lim MM, Gerstner JR, Holtzman DM. The sleep-wake cycle and Alzheimer's disease: What do we know? *Neurodegener Dis Manag* 2014;4(5):351-362.
67. Lloret M-A, Cervera-Ferri A, Nepomuceno M, Monllor P, Esteve D, Lloret A. Is sleep disruption a cause or consequence of Alzheimer's disease? Reviewing its possible role as a biomarker. *Int J Mol Sci* 2020;21:1168.
68. Rose KM, Fagin CM, Lorenz R. Sleep Disturbances in Dementia: What They Are and What To Do. *J Gerontol Nurs* 2010;36(5):9-14.
69. Watt JA, Goodarzi Z, Veroniki AA, et al. Comparative efficacy of interventions for aggressive and agitated behaviors in dementia. *Ann Internal Med* 2019;171(9):633-642.
70. Abbramo I, Rimland JM, Trotta FM, et al. Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series. *BMJ Open* 2017;7(3):e012759.
71. Koch J, Amos JG, Beattie E, et al. Non-pharmacological interventions for neuropsychiatric symptoms of dementia in residential aged care settings: An umbrella review. *Int J Nurs Stud* 2022;128:104187.
72. Meyer C, O'Keefe F. Non-pharmacological interventions for people with dementia: A review of reviews. *Dementia (London)* 2020;19(6):1927-1954.
73. Livingston G, Huntley J, Liu KY, et al. Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. *Lancet* 2024; 404(10452):P572-628.
74. Hebert LE, Bienias JL, Aggarwal NT, et al. Change in risk of Alzheimer disease over time. *Neurology* 2010;75:786-791.
75. National Institute on Aging. Accessed December 15, 2024. Available at: <https://www.nia.nih.gov/health/what-causes-alzheimersdisease>.
76. Saunders AM, Strittmatter WJ, Schmechel D, et al. Association of apolipoprotein E allele epsilon 4 with late-onset familial and sporadic Alzheimer's disease. *Neurology* 1993;43:1467-1472.
77. Farrer LA, Cupples LA, Haines JL, et al. Effects of age, sex, and ethnicity on the association between apolipoprotein E genotype and Alzheimer disease: A meta-analysis. *JAMA* 1997;278:1349-1356.
78. Green RC, Cupples LA, Go R, et al. Risk of dementia among white and African American relatives of patients with Alzheimer disease. *JAMA* 2002;287(3):329-336.
79. Fratiglioni L, Ahlbom A, Viitanen M, Winblad B. Risk factors for late-onset Alzheimer's disease: A population-based, case-control study. *Ann Neurol* 1993;33(3):258-266.
80. Mayeux R, Sano M, Chen J, Tatemichi T, Stern Y. Risk of dementia in first-degree relatives of patients with Alzheimer's disease and related disorders. *Arch Neurol* 1991;48(3):269-273.
81. Lautenschlager NT, Cupples LA, Rao VS, et al. Risk of dementia among relatives of Alzheimer's disease patients in the MIRAGE Study: What is in store for the oldest old? *Neurology* 1996;46(3):641-650.
82. Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology* 2013;80(19):1778-1783.
83. Nelson PT, Head E, Schmitt FA, et al. Alzheimer's disease is not "brain aging": Neuropathological, genetic, and epidemiological human studies. *Acta Neuropathol* 2011;121:571-587.

84. Bellenguez C, Kucukali F, Jansen IE, et al. New insights into the genetic etiology of Alzheimer's disease and related dementias. *Nat Genet* 2022;54:412-436.
85. Loy CT, Schofield PR, Turner AM, Kwok JBJ. Genetics of dementia. *Lancet* 2014;383:828-840.
86. Qian J, Wolters FJ, Beiser A, et al. APOE-related risk of mild cognitive impairment and dementia for prevention trials: An analysis of four cohorts. *PLoS Med* 2017;14(3):e1002254.
87. Spinney L. Alzheimer's disease: The forgetting gene. *Nature* 2014;510(7503):26-28.
88. Ward A, Crean S, Mercaldi CJ, et al. Prevalence of apolipoprotein e4 genotype and homozygotes (APOE e4/4) among patients diagnosed with Alzheimer's disease: A systematic review and meta-analysis. *Neuroepidemiology* 2012;38:1-17.
89. Mayeux R, Saunders AM, Shea S, et al. Utility of the apolipoprotein E genotype in the diagnosis of Alzheimer's disease. *N Engl J Med* 1998;338:506-511.
90. Evans DA, Bennett DA, Wilson RS, et al. Incidence of Alzheimer disease in a biracial urban community: Relation to apolipoprotein E allele status. *Arch Neurol* 2003;60(2):185-189.
91. Tang M, Stern Y, Marder K, et al. The APOE-e4 allele and the risk of Alzheimer disease among African Americans, whites, and Hispanics. *JAMA* 1998;279:751-755.
92. Weuve J, Barnes LL, Mendes de Leon CF, et al. Cognitive aging in black and white Americans: Cognition, cognitive decline, and incidence of Alzheimer disease dementia. *Epidemiology* 2018;29(1):151-159.
93. Hendrie HC, Murrell J, Baiyewu O, et al. APOE ε4 and the risk for Alzheimer disease and cognitive decline in African Americans and Yoruba. *Int Psychogeriatr* 2014;26(6):977-985.
94. Reitz C, Jun G, Naj A, et al. Variants in the ATP-binding cassette transporter (ABCA7), apolipoprotein E epsilon 4, and the risk of late-onset Alzheimer disease in African Americans. *JAMA* 2013;309(14):1483-1492.
95. Gottesman RF, Albert MS, Alonso A, et al. Associations between midlife vascular risk factors and 25-year incident dementia in the Atherosclerosis Risk in Communities (ARIC) cohort. *JAMA Neurol* 2017;74(10):1246-1254.
96. Bakulski KM, Vadari HS, Faul JD, et al. Cumulative genetic risk and APOE ε4 are independently associated with dementia status in a multiethnic, population-based cohort. *Neurol Genet* 2021;7:e576.
97. Rajan KB, Barnes LL, Wilson RS, et al. Racial differences in the association between apolipoprotein E risk alleles and overall and total cardiovascular mortality over 18 years. *JAGS* 2017;65:2425-2430.
98. Kataoka S, Robbins DC, Cowan LD, et al. Apolipoprotein E polymorphism in American Indians and its relation to plasma lipoproteins and diabetes. *The Strong Heart Study. Arterioscler Thromb Vasc Biol* 1996;16:918-925.
99. Xiao C, Pappas I, Aksman LM, et al. Comparison of genetic and health risk factors for mild cognitive impairment and Alzheimer's disease between Hispanic and non-Hispanic white participants. *Alzheimers Dement* 2023 Nov;19:5086-5094.
100. Belloy ME, Andrews SJ, Le Guen Y, et al. APOE Genotype and Alzheimer Disease Risk Across Age, Sex, and Population Ancestry. *JAMA Neurol* 2023;80(12):1284-1294.
101. Le Guen Y, Raulin AC, Logue MW, et al. Association of African ancestry-specific APOE missense variant R145C with risk of Alzheimer disease. *JAMA* 2023;329(7):551-560.
102. Granot-Hershkovitz E, Tarraf W, Kurniansyah N, et al. APOE alleles' association with cognitive function differs across Hispanic/Latino groups and genetic ancestry in the study of Latinos investigation of neurocognitive aging (HCHS/SOL). *Alzheimer's Dement* 2021;17:466-474.
103. Sirkis DW, Bonham LW, Johnson TP, et al. Dissecting the clinical heterogeneity of early-onset Alzheimer's disease. *Mol Psychiatry* 2022;27:2674-2688.
104. Bekris LM, Yu CE, Bird TD, Tsuang DW. Genetics of Alzheimer disease. *J Geriatr Psychiatry Neurol* 2010;23(4):213-227.
105. Goldman JS, Hahn SE, Bird T. Genetic counseling and testing for Alzheimer disease: Joint practice guidelines of the American College of Medical Genetics and the National Society of Genetic Counselors. *Genet Med* 2011;13:597-605.
106. Lopera F, Marino C, Chandrachud AS, et al. Resilience to autosomal dominant Alzheimer's disease in a Reelin-COLBOS heterozygous man. *Nat Med* 2023 May;29(5):1243-1252.
107. Arboleda-Velasquez JF, Lopera F, O'Hare M, et al. Resistance to autosomal dominant Alzheimer's disease in an APOE3 Christchurch homozygote: a case report. *Nat Med* 2019;25(11):1680-1683.
108. Lott IT, Dierssen M. Cognitive deficits and associated neurological complications in individuals with Down's syndrome. *Lancet Neurol* 2010;9(6):623-633.
109. Rubenstein E, Tewolde S, Michals A, et al. Alzheimer dementia among individuals with Down syndrome. *JAMA Netw Open* 2024 Sep 3;7(9):e2435018.
110. Hithersay R, Startin CM, Hamburg S, et al. Association of dementia with mortality among adults with Down syndrome older than 35 years. *JAMA Neurol* 2019;76(2):152-160.
111. Wolters FJ, van der Lee SJ, Koudstaal PJ, et al. Parental family history of dementia in relation to subclinical brain disease and dementia risk. *Neurology* 2017;88:1642-1649.
112. Ronnema E, Zethelius B, Lannfelt L, Kilander L. Vascular risk factors and dementia: 40-year follow-up of a population-based cohort. *Dement Geriatr Cogn Disord* 2011;31(6):460-466.
113. Kivimaki M, Luukkonen R, Batty GD, et al. Body mass index and risk of dementia: Analysis of individual-level data from 1.3 million individuals. *Alzheimers Dement* 2018;14:601-609.
114. Gottesman RF, Schneider AL, Zhou Y, et al. Association between midlife vascular risk factors and estimated brain amyloid deposition. *JAMA* 2017;17(14):1443-1450.
115. Abell JG, Kivimaki M, Dugravot A, et al. Association between systolic blood pressure and dementia in the Whitehall II cohort study: Role of age, duration, and threshold used to define hypertension. *Eur Heart J* 2018;39(33):3119-3125.
116. Debette S, Seshadri S, Beiser A, et al. Midlife vascular risk factor exposure accelerates structural brain aging and cognitive decline. *Neurology* 2011;77:461-468.
117. Anstey KJ, Ashby-Mitchell K, Peters R. Updating the evidence on the association between serum cholesterol and risk of late-life dementia: Review and meta-analysis. *J Alzheimers Dis* 2017;56(1):215-228.
118. Marden JR, Tchetgen EJ, Kawachi I, Glymour MM. Contribution of Socioeconomic Status at 3 Life-Course Periods to Late-Life Memory Function and Decline: Early and Late Predictors of Dementia Risk. *Am J Epidemiol* 2017;186(7):805-814.
119. Caunca MR, Odden MC, Glymour MM, et al. Association of Racial Residential Segregation Throughout Young Adulthood and Cognitive Performance in Middle-aged Participants in the CARDIA Study. *JAMA Neurol* 2020;77(8):1000-1007.
120. Chen R, Williams DR, Nishimi K, Slopen N, Kubzansky LD, Weuve J. A life course approach to understanding stress exposures and cognitive function among middle-aged and older adults. *Soc Sci Med* 2022;314:115448.
121. George KM, Lutsey PL, Kucharska-Newton A, Palta P, Heiss G, Osypuk T, Folsom AR. Life-Course Individual and Neighborhood Socioeconomic Status and Risk of Dementia in the Atherosclerosis Risk in Communities Neurocognitive Study. *Am J Epidemiol* 2020;189(10):1134-1142.
122. George KM, Gilsanz P, Peterson RL, et al. Impact of Cardiovascular Risk Factors in Adolescence, Young Adulthood, and Midlife on Late-Life Cognition: Study of Healthy Aging in African Americans. *J Gerontol A Biol SciMed Sci* 2021;76(9):1692-1698.
123. Huh J, Arpawong TE, Gruenewald TL, et al. General cognitive ability in high school, attained education, occupational complexity, and dementia risk. *Alzheimer's Dement* 2024(4):2662-2669.

124. James BD, Bennett DA. Causes and patterns of dementia: An update in the era of redefining Alzheimer's disease. *Ann Rev Public Health* 2019;40:65-84.
125. Nianogo RA, Rosenwohl-Mack A, Yaffe K, Carrasco A, Hoffmann CM, Barnes DE. Risk factors associated with Alzheimer disease and related dementias by sex and race and ethnicity in the US. *JAMA Neurol* 2022;79(6):584-591.
126. Park SY, Setiawan VW, Crimmins EM, et al. Racial and ethnic differences in the population-attributable fractions of Alzheimer disease and related dementias. *Neurology* 2024;102(3):e208116.
127. World Health Organization. Risk reduction of cognitive decline and dementia: WHO guidelines. <https://www.who.int/publications/i/item/risk-reduction-of-cognitive-decline-and-dementia>.
128. Institute of Medicine. *Cognitive Aging: Progress in Understanding and Opportunity for Action*. Washington, D.C.: The National Academies Press; 2015.
129. Mergenthaler P, Lindauer U, GA Dienel, Meisel A. Sugar for the brain: The role of glucose in physiological and pathological brain function. *Trends Neurosci* 2013;36(10):587-597.
130. Kuźma E, Lourida I, Moore SF, Levine DA, Ukoumunne OC, Llewellyn DJ. Stroke and dementia risk: A systematic review and meta-analysis. *Alzheimers Dement* 2018;14(11):1416-1426.
131. Samieri C, Perier MC, Gaye B, et al. Association of cardiovascular health level in older age with cognitive decline and incident dementia. *JAMA* 2018;320(7):657-664.
132. Matthew J, Lennon MJ, Lipnicki DM, et al. Blood pressure, antihypertensive use, and late-life Alzheimer and non-Alzheimer dementia risk. *Neurology*. 2024;103(5).
133. Rajan KB, Barnes LL, Wilson RS, et al. Blood pressure and risk of incident Alzheimer's disease dementia by antihypertensive medications and APOE ε4 allele. *Ann Neurol* 2018;83(5):935-944
134. Gudala K, Bansal D, Schifano F, Bhansali A. Diabetes mellitus and risk of dementia: A meta-analysis of prospective observational studies. *Diabetes Investig* 2013;4(6):640-650.
135. Vagelatos NT, Eslick GD. Type 2 diabetes as a risk factor for Alzheimer's disease: The confounders, interactions, and neuropathology associated with this relationship. *Epidemiol Rev* 2013;35(1):152-160.
136. Reitz C, Brayne C, Mayeux R. Epidemiology of Alzheimer disease. *Nat Rev Neurol* 2011;7(3):137-152.
137. Johnson AL, Nystrom NC, Piper ME, et al. Cigarette smoking status, cigarette exposure, and duration of abstinence predicting incident dementia and death: A multistate model approach. *J Alzheimers Dis* 2021;80(3):1013-1023.
138. Peters R, Poulter R, Warner J, Beckett N, Burch L, Bulpitt C. Smoking, dementia and cognitive decline in the elderly, a systematic review. *BMC Geriatr* 2008;8:36.
139. Clocchiatti-Tuozzo S, Rivier CA, Renedo D, et al. Life's essential 8 and poor brain health outcomes in middle-aged adults. *Neurology* 2024;103(10):e209990.
140. Ogino E, Manly JJ, Schupf N, Mayeux R, Gu Y. Current and past leisure time physical activity in relation to risk of Alzheimer's disease in older adults. *Alzheimers Dement* 2019;15(12):1603-1611.
141. Najjar J, Ostling S, Gudmundsson P, et al. Cognitive and physical activity and dementia: A 44-year longitudinal population study of women. *Neurology* 2019;92(12):e1322-e1330.
142. Buchman AS, Yu L, Wilson RS, et al. Physical activity, common brain pathologies, and cognition in community-dwelling older adults. *Neurology* 2019;92(8):e811-e822.
143. Ian ZS, Spartano NL, Beiser AS, et al. Physical activity, brain volume, and dementia risk: The Framingham Study. *J Gerontol A Biol Sci Med Sci* 2017;72:789-795.
144. Stephen R, Hongistro K, Solomon A, Lonroos E. Physical activity and Alzheimer's disease: A systematic review. *J Gerontol A Biol Sci Med Sci* 2017;72(6):733-739.
145. Blondell SJ, Hammersley-Mather R, Veerman JL. Does physical activity prevent cognitive decline and dementia? A systematic review and meta-analysis of longitudinal studies. *BMC Public Health* 2014;14:510.
146. Guure CB, Ibrahim NA, Adam MB, Said SM. Impact of physical activity on cognitive decline, dementia, and its subtypes: Meta-analysis of prospective studies. *Biomed Res Int* 2017;2017:9016924.
147. Jensen CS, Simonsen AH, Siersma V, et al. Patients with Alzheimer's disease who carry the APOE ε4 allele benefit more from physical exercise. *TRCI* 2019;5:99-106.
148. Felisatti F, Gonneaud J, Palix C, et al. Role of cardiovascular risk factors on the association between physical activity and brain integrity markers in older adults. *Neurology* 2022;98(20):e2023-e2035.
149. Casaletto K, Ramos-Miguel A, VandeBunte A, et al. Late-life physical activity relates to brain tissue synaptic integrity markers in older adults. *Alzheimers Dement* 2022;18(11):2023-2035.
150. Nguyen S, LaCroix AZ, Hayden KM, et al. Accelerometer-measured physical activity and sitting with incident mild cognitive impairment or probable dementia among older women. *Alzheimers Dement* 2023;19(7):3041-3054.
151. Wu W, Ding D, Zhao Q, et al. Dose-response relationship between late-life physical activity and incident dementia: A pooled analysis of 10 cohort studies of memory in an international consortium. *Alzheimers Dement* 2024;19(1):107-122.
152. Iso-Markku P, Aaltonen S, Kujala UM, et al. Physical activity and cognitive decline among older adults: A systematic review and meta-analysis. *JAMA Netw Open* 2024;7(2):e2354285.
153. Hardman RJ, Kennedy G, Macpherson H, Scholey AB, Pipingas A. Adherence to a Mediterranean-style diet and effects on cognition in adults: A qualitative evaluation and systematic review of longitudinal and prospective trials. *Front Nutr* 2016;3:22.
154. Lourida I, Soni M, Thompson-Coon J, et al. Mediterranean diet, cognitive function, and dementia: A systematic review. *Epidemiology* 2013;24:479-489.
155. Morris MC, Tangney CC, Wang Y, et al. MIND diet slows cognitive decline with aging. *Alzheimers Dement* 2015;11(9):1015-1022.
156. Morris MC, Tangney CC, Wang Y, Sacks FM, Bennett DA, Aggarwal NT. MIND diet associated with reduced incidence of Alzheimer's disease. *Alzheimers Dement* 2015;11:1007-1014.
157. Van den Brink AC, Brouwer-Broisma EM, Berendsen AAM van de Rest O. The Mediterranean, Dietary Approaches to Stop Hypertension (DASH), and Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) Diets are associated with less cognitive decline and a lower risk of Alzheimer's disease: A review. *Adv Nutr* 2019;10:1040-1065.
158. Ballarini T, Melo van Lent D, Brunner J, et al. Mediterranean diet, Alzheimer disease biomarkers and brain atrophy in old age. *Neurology* 2021;96(24):e2920-e2932.
159. Agarwal P, Leurgans SE, Agrawal S, et al. Association of Mediterranean-DASH Intervention for Neurodegenerative Delay and Mediterranean Diets With Alzheimer Disease Pathology. *Neurology* 2023;100(22):e2259-e2268.
160. Barnes LL, Dhana K, Liu X, et al. Trial of the MIND Diet for prevention of cognitive decline in older persons. *N Engl J Med* 2023;389(7):602-611.
161. Grant WB, Steven M. Diet's role in modifying risk of Alzheimer's disease: History and present understanding. *J Alzheimer's Dis* 2023;96(4):1353-1382.
162. Martinez-Gonzalez MA, Gea A, Ruiz-Canela M. The Mediterranean diet and cardiovascular health: A critical review. *Circulation Res* 2019;124:779-798.
163. Sanches Machado d'Almeida K, Spillere SR, Zuchinali P, Souza GC. Mediterranean diet and other dietary patterns in primary prevention of heart failure and changes in cardiac function markers: A systematic review. *Nutrients* 2018;10:58.

164. Walker ME, O'Donnell AA, Himali JJ, et al. Associations of the Mediterranean-Dietary Approaches to Stop Hypertension Intervention for Neurodegenerative Delay diet with cardiac remodelling in the community: The Framingham Heart Study. *Br J Nutr* 2021;126(12):1888-1896.
165. Vyas CM, Manson JE, Sesso HD, et al. Effect of multivitamin-mineral supplementation versus placebo on cognitive function: results from the clinic subcohort of the COcoa Supplement and Multivitamin Outcomes Study (COSMOS) randomized clinical trial and meta-analysis of 3 cognitive studies within COSMOS. *Am J Clin Nutr* 2024;119(3):692-701.
166. Baker LD, Manson JE, Rapp SR, et al. Effects of cocoa extract and a multivitamin on cognitive function: A randomized clinical trial. *Alzheimers Dement* 2022;18:1308-1319.
167. Butler M, Nelson VA, Davila H, et al. Over-the-counter supplement interventions to prevent cognitive decline, mild cognitive impairment, and clinical Alzheimer-type dementia. *Ann Intern Med* 2018;168:52-62.
168. Fitzpatrick AL, Kuller LH, Ives DG, et al. Incidence and prevalence of dementia in the Cardiovascular Health Study. *J Am Geriatr Soc* 2004;52(2):195-204.
169. Kukull WA, Higdon R, Bowen JD, et al. Dementia and Alzheimer disease incidence: A prospective cohort study. *Arch Neurol* 2002;59(11):1737-1746.
170. Stern Y. Cognitive reserve in ageing and Alzheimer's disease. *Lancet Neurol* 2012;11(11):1006-1012.
171. Sando SB, Melquist S, Cannon A, et al. Risk-reducing effect of education in Alzheimer's disease. *Int J Geriatr Psychiatry* 2008;23(11):1156-1162.
172. Hendrie HC, Smith-Gamble V, Lane KA, Purnell C, Clark DO, Gao S. The Association of early life factors and declining incidence rates of dementia in an elderly population of African Americans. *J Gerontol B Psychol Sci Soc Sci* 2018;16(73, suppl 1):S82-S89.
173. Manly JJ, Jones RN, Langa KM, et al. Estimating the Prevalence of Dementia and Mild Cognitive Impairment in the US: The 2016 Health and Retirement Study Harmonized Cognitive Assessment Protocol Project. *JAMA Neurol* 2022;79(12):1242-1249.
174. Rawlings AM, Sharrett AR, Mosley TH, Wong DF, Knopman DS, Gottesman RF. Cognitive reserve in midlife is not associated with amyloid- β deposition in late-life. *J Alzheimers Dis* 2019;517-521.
175. Wilson RS, Yu L, Lamar M, Schneider JA, Boyle PA, Bennett DA. Education and cognitive reserve in old age. *Neurology* 2019;92(10):e1041-e1050.
176. Stern Y. What is cognitive reserve? Theory and research application of the reserve concept. *J Int Neuropsychol Soc* 2002;8:448-460.
177. Stern Y, Arenaza-Urquijo EM, Bartres-Faz D, et al. Whitepaper: Defining and investigating cognitive reserve, brain reserve, and brain maintenance. *Alzheimers Dement* 2020;16(9):1305-1311.
178. Ngandu T, Lehtisalo J, Solomon A, et al. Occupational complexity and cognition in the FINGER multidomain intervention trial. *Alzheimers Dement* 2022;18:2438-47.
179. Pool LR, Weuve J, Wilson RS, Bultmann U, Evans DA, Mendes de Leon CF. Occupational cognitive requirements and late-life cognitive aging. *Neurology* 2016;86(15):1386-1392.
180. Coleman ME, Roessler MEH, Peng S, et al. Social enrichment on the job: Complex work with people improves episodic memory, promotes brain reserve, and reduces the risk of dementia. *Alzheimers Dement* 2023;19(6):2655-2665.
181. Soh Y, Eng CW, Mayeda ER, et al. Association of primary lifetime occupational cognitive complexity and cognitive decline in a diverse cohort: Results from the KHANDLE study. *Alzheimers Dement* 2023;19(9):3926-3935.
182. Soh Y, Whitmer RA, Mayeda ER, et al. State-level indicators of childhood educational quality and incident dementia in older Black and White adults. *JAMA Neurol* 2023;80(4):352-359.
183. Liu C, Murchland AR, VanderWeele TJ, Blacker D. Eliminating racial disparities in dementia risk by equalizing education quality: A sensitivity analysis. *Soc Sci Med* 2022;312:115347.
184. Sisco S, Gross AL, Shih RA, et al. The role of early-life educational quality and literacy in explaining racial disparities in cognition in late life. *J Gerontol B Psychol Sci Soc Sci* 2015;70(4):557-567.
185. Crowe M, Clay OJ, Martin RC, et al. Indicators of childhood quality of education in relation to cognitive function in older adulthood. *J Gerontol A Biol Sci Med Sci* 2013;68(2):198-204.
186. Staff RT, Hogan MJ, Williams DS, Whalley LJ. Intellectual engagement and cognitive ability in later life (the "use it or lose it" conjecture): Longitudinal, prospective study. *BMJ* 2018;363:k4925.
187. Karp A, Paillard-Borg S, Wang H-X, Silverstein M, Winblad B, Fratiglioni L. Mental, physical and social components in leisure activities equally contribute to decrease dementia risk. *Dement Geriatr Cogn Disord* 2005;21(2):65-73.
188. Di Marco LY, Marzo A, Munoz-Ruiz M, et al. Modifiable lifestyle factors in dementia: A systematic review of longitudinal observational cohort studies. *J Alzheimers Dis* 2014;42(1):119-135.
189. James BD, Wilson RS, Barnes LL, Bennett DA. Late-life social activity and cognitive decline in old age. *J Int Neuropsychol Soc* 2011;17(6):998-1005.
190. Yates LA, Ziser S, Spector A, Orrell M. Cognitive leisure activities and future risk of cognitive impairment and dementia: Systematic review and meta-analysis. *Int Psychogeriatr* 2016;9:1-16.
191. Hall CB, Lipton RB, Sliwinski M, Katz MJ, Derby CA, Verghese J. Cognitive activities delay onset of memory decline in persons who develop dementia. *Neurology* 2009;73:356-361.
192. Sanjeev G, Weuve J, Jackson JW, et al. Late-life cognitive activity and dementia. *Epidemiology* 2016;27(5):732-742.
193. Wang Z, Marseglia A, Shang Y, Dintica C, Patrone C, Xu W. Leisure activity and social integration mitigate the risk of dementia related to cardiometabolic diseases: A population-based longitudinal study. *Alzheimers Dement* 2020;16:316-335.
194. Sommerlad A, Sabia S, Singh-Manoux A, Lewis G, Livingston G. Association of social contact with dementia and cognition: 28-year follow-up of the Whitehall II cohort study. *PLoS Med* 2019;16(8):e1002862.
195. Mahalingam G, Samtani S, Lam BPC, et al. Social connections and risk of incident mild cognitive impairment, dementia, and mortality in 13 longitudinal cohort studies of ageing. *Alzheimer's Dement* 2023;19:5114-5128.
196. Chen Y, Grodstein F, Capuano AW, et al. Late-life social activity and subsequent risk of dementia and mild cognitive impairment. *Alzheimers Dement* 2024;1-9. Available at: <https://doi.org/10.1002/alz.14316>.
197. Grodstein F, Capuano AW, Wang T, Bennett DA, James BD. Late-life social activity and subsequent risk of dementia and mild cognitive impairment. *Alzheimers Dement* 2025; in press.
198. Edwin TH, Håberg AK, Zotcheva E, et al. Trajectories of occupational cognitive demands and risk of mild cognitive impairment and dementia in later life: The HUNT4 70+ Study. *Neurology* 2024;102(9):e209353.
199. Kivimaki M, Walker KA, Pentti J, et al. Cognitive stimulation in the workplace, plasma proteins, and risk of dementia: three analyses of population cohort studies. *BMJ* 2021;374:n1804.
200. Shi L, Chen S, Ma M, et al. Sleep disturbances increase the risk of dementia: A systematic review and meta-analysis. *Sleep Med Rev* 2018;40:4-16.
201. Sabia S, Fayosse A, Dumurgier J, van Hees VT, Paquet C, Sommerlad A. Association of sleep duration in middle and old age with incidence of dementia. *Nat Commun* 2021;12(1):2289.
202. Winer JR, Keters KD, Kennedy G, et al. Association of short and long sleep duration with amyloid- β burden and cognition in aging. *JAMA Neurol* 2021;78(10):1187-1196.
203. Makin S. Deep sleep gives your brain a deep clean: Slow-wave activity during dreamless slumber helps wash out neural detritus. *Scientific American* Nov 1, 2019. Accessed December 15, 2024. Available at: <https://www.scientificamerican.com/article/deep-sleep-gives-your-brain-a-deep-clean/>.

204. Insel PS, Mohlenhoff BS, Neylan TC, Krystal AD, Mackin RS. Association of sleep and β -amyloid pathology among older cognitively unimpaired adults. *JAMA Netw Open* 2021;4(7):e2117573.
205. Bubun OM, Andrade AG, Umasabor-Bubu OQ, et al. Obstructive sleep apnea, cognition and Alzheimer's disease: A systematic review integrating three decades of multidisciplinary research. *Sleep Med Rev* 2020 Apr;50:101250.
206. Andrade A, Bubun OM, Varga AW, Osorio RS. The relationship between obstructive sleep apnea and Alzheimer's disease. *J Alzheimers Dis* 2018; 64(Suppl 1):S255-S270.
207. Wang C, Holtzman DM. Bidirectional relationship between sleep and Alzheimer's disease: Role of amyloid, tau, and other factors. *Neuropsychopharmacol* 2020;45:104-120.
208. Ju YE, Lucey BP, Holtzman DM. Sleep and Alzheimer disease pathology—a bidirectional relationship. *Nat Rev Neurol* 2014;10(2):115-159.
209. Lucey BP. It's complicated: The relationship between sleep and Alzheimer's disease in humans. *Neurobiol Dis* 2020;144:105031.
210. Ju Y-ES, McLeland JS, Toedebusch CD, et al. Sleep quality and preclinical Alzheimer disease. *JAMA Neurol* 2013;70(5):587-593.
211. Lao XQ, Liu X, Deng HB, et al. Sleep quality, Sleep duration, and the risk of coronary heart disease: A prospective cohort study with 60,586 adults. *J Clin Sleep Med* 2018;14(1): 109-117.
212. Lad M, Sedley W, Griffiths TD. Sensory loss and risk of dementia. *Neuroscientist* 2024;30(2):247-259.
213. Reed NS, Oh ES. New insights into sensory impairment and dementia risk. *JAMA Netw Open* 2022;5(5):e2210740.
214. Kotecha AM, Corrêa ADC, Fisher KM, Rushworth JV. Olfactory dysfunction as a global biomarker for sniffing out Alzheimer's disease: A meta-analysis. *Biosensors (Basel)* 2018;8(2):41.
215. McLaren AMR, Kawaja MD. Olfactory dysfunction and Alzheimer's disease: A review. *J Alzheimers Dis* 2024;99: 811-827.
216. Silva MME, Mercer PBS, Witt MCZ, Pessoa RR. Olfactory dysfunction in Alzheimer's disease Systematic review and meta-analysis. *Dement Neuropsychol* 2018;12:123-32.
217. Son G, Jahanshahi A, Yoo SJ, Boonstra JT, Hopkins DA, Steinbusch HWM, Moon C. Olfactory neuropathology in Alzheimer's disease: a sign of ongoing neurodegeneration. *BMB Rep* 2021;54(6):295-304.
218. Bouhaben J, Delgado-Lima AH, Delgado-Losada ML. The role of olfactory dysfunction in mild cognitive impairment and Alzheimer's disease: A meta-analysis. *Arch Gerontol Geriatr* 2024;123:105425.
219. Fatuzzo I, Niccolini GF, Zoccali F, et al. Neurons, nose, and neurodegenerative diseases: Olfactory function and cognitive impairment. *Int J Mol Sci* 2023;24:2117.
220. Dintica CS, Marseglia A, Rizzuto D, et al. Impaired olfaction is associated with cognitive decline and neurodegeneration in the brain. *Neurology* 2019;92:e700-e709.
221. Ge S, McConnell ES, Wu B, Pan W, Dong X, Plassman BL. Longitudinal association between hearing loss, vision loss, dual sensory loss, and cognitive decline. *J Am Geriatr Soc* 2021;69:644-50.
222. Loughrey DG, Kelly ME, Kelley GA, Brennan S, Lawlor BA. Association of age-related hearing loss with cognitive function, cognitive impairment, and dementia: A systematic review and meta-analysis. *JAMA Otolaryngol Head Neck Surg* 2018;144(2):115-126.
223. Thomson RS, Auduong P, Miller AT, Gurgel RK. Hearing loss as a risk factor for dementia: A systematic review. *Laryngoscope Invest Otolaryngol* 2017;2:69-79.
224. Ford AH, Hankey GJ, Yeap BB, et al. Hearing loss and the risk of dementia in later life. *Maturitas* 2018;112:1-11.
225. Huang AR, Roth DL, Cidav T, et al. Social isolation and 9-year dementia risk in community-dwelling Medicare beneficiaries in the United States. *J Am Geriatr Soc* 2023;71:765-773.
226. Shen C, Rolls ET, Cheng W, et al. Associations of social isolation and loneliness with later dementia. *Neurology* 2022;99(2):e164-e175.
227. U.S. Environmental Protection Agency Integrated science assessment (ISA) for particulate matter (final report, 2019). EPA/600/R-19/188. Washington, DC.
228. Weuve J, Bennett EE, Ranker L, et al. Exposure to air pollution in relation to risk of dementia and related outcomes: An updated systematic review of the epidemiologic literature. *Environ Health Perspect* 2021;129(9):96001.
229. Peters R, Ee N, Peters J, Booth A, Mudway I, Anstey KJ. Air Pollution and Dementia: A Systematic Review. *J Alzheimers Dis* 2019;70(s1):S145-S163.
230. Zhang B, Weuve J, Langa KM, et al. Comparison of particulate air pollution from different emission sources and incident dementia in the U.S. *JAMA Intern Med* 2023;183(10): 1080-1089.
231. Abolhasani E, Hachinski V, Ghazaleh N, et al. Air pollution and Incidence of dementia: A systematic review and meta-analysis. *Neurology* 2023;100(2):e242-e254.
232. Elser H, Frankland TB, Chen C, et al. Wildfire smoke exposure and incident dementia. *JAMA Neurol* 2024:e244058.
233. Oudin A, Segerström D, Adolffsson R, Forsberg B. Association between air pollution from residential wood burning and dementia incidence in a longitudinal study in Northern Sweden. *PLoS One* 2018;13(6):e0198283.
234. Sprung J, Knopman DS, Petersen RC, et al. Association of hospitalization with long-term cognitive trajectories in older adults. *J Am Geriatr Soc* 2021;69(3):660-668.
235. James BD, Wilson RS, Capuano AW, et al. Cognitive decline after elective and nonelective hospitalizations in older adults. *Neurology* 2019;92(7):e690-e699.
236. Brown CH, Sharrett AR, Coresh J, et al. Association of hospitalization with long-term cognitive and brain MRI changes in the ARIC cohort. *Neurology* 2015;84:1443-1453.
237. Pandharipande PP, Girard TD, Jackson JC, et al. Long-term cognitive impairment after critical illness. *N Engl J Med* 2013;369(14):1306-1336.
238. Ehlenbach WJ, Hough CL, Crane PK, et al. Association between acute care and critical illness hospitalization and cognitive function in older adults. *JAMA* 2010;303(8): 763-770.
239. Mart MF, Pun BT, Pandharipande P, Jackson JC, Ely EW. ICU survivorship - The Relationship of delirium, sedation, dementia, and Acquired weakness. *Crit Care Med* 2021;49(8):1227-1240.
240. James BD, Wilson RS, Capuano AW, et al. Hospitalization, Alzheimer's Disease and Related Neuropathologies, and Cognitive Decline. *Ann Neurol* 2019;86(6):844-852.
241. Fong TG, Inouye SK. The inter-relationship between delirium and dementia: The importance of delirium prevention. *Nat Rev Neurol* 2022;18(10):579-596.
242. Centers for Disease Control and Prevention. Surveillance Report: Traumatic Brain Injury-Related Deaths by Age Group, Sex, and Mechanism of Injury. Accessed December 15, 2024. Available at: <https://www.cdc.gov/traumaticbraininjury/pdf/TBI-surveillance-report-2018-2019-508.pdf>.
243. Fann JR, Ribe AR, Pedersen HS, et al. Long-term risk of dementia among people with traumatic brain injury in Denmark: A population-based observational cohort study. *Lancet Psychiatry* 2018;5(5):424-431.
244. LoBue C, Munro C, Schaffert J, et al. Traumatic brain injury and risk of long-term brain changes, accumulation of pathological markers, and developing dementia: A review. *J Alzheimers Dis* 2019;70(3):629-654.
245. Schneider ALC, Selvin E, Latour L, et al. Head injury and 25-year risk of dementia. *Alzheimers Dement* 2021;17: 1432-1441.
246. Centers for Disease Control and Prevention. TBI Data. Accessed January 16, 2025. Available at: <https://www.cdc.gov/traumaticbraininjury/data/index.html>.
247. Plassman BL, Havlik RJ, Steffens DC, et al. Documented head injury in early adulthood and risk of Alzheimer's disease and other dementias. *Neurology* 2000;55(8):1158-1166.

248. Teasdale G, Jennett B. Assessment of coma and impaired consciousness: A practical scale. *Lancet* 1974;2(7872):81-84.
249. Centers for Disease Control and Prevention. Traumatic Brain Injury & Concussion. Potential Effects. Accessed December 15, 2024. Available at: <https://www.cdc.gov/traumaticbraininjury/outcomes.html>.
250. Shively S, Scher AI, Perl DP, Diaz-Arrastia R. Dementia resulting from traumatic brain injury: what is the pathology? *Arch Neurol* 2012;69(10):1245-1251.
251. LoBue C, Wadsworth H, Wilmoth K, Clem M, Hart J Jr, Womack KB. Traumatic brain injury history is associated with earlier age of onset of Alzheimer disease. *Clin Neuropsychol* 2017;31(1):85-98.
252. Schaffert J, LoBue C, White CL, et al. Traumatic brain injury history is associated with an earlier age of dementia onset in autopsy-confirmed Alzheimer's disease. *Neuropsychology* 2018;32(4):410-416.
253. Nowinski CJ, Bureau SC, Buckland ME, et al. Applying the Bradford Hill Criteria for Causation to Repetitive Head Impacts and Chronic Traumatic Encephalopathy. *Front Neurol* 2022;13:938163.
254. National Institutes of Health. Focus on Traumatic Brain Injury Research. Accessed October 27, 2024. Available at: <https://www.ninds.nih.gov/current-research/focus-disorders/focus-traumatic-brain-injury-research>.
255. Turk KW, Geada A, Alvarez VE, et al. A comparison between tau and amyloid- β cerebrospinal fluid biomarkers in chronic traumatic encephalopathy and Alzheimer disease. *Alz Res Therapy* 2022;14(1):28.
256. Stein TD, Montenegro PH, Alvarez VE, et al. Beta-amyloid deposition in chronic traumatic encephalopathy. *Acta Neuropathol* 2015;130(1):21-34.
257. Asken BM, Sullan MJ, DeKosky ST, Jaffee MS, Bauer RM. Research gaps and controversies in chronic traumatic encephalopathy: A review. *JAMA Neurol* 2017;74(10):1255-1262.
258. Mez J, Daneshvar DH, Abdolmohammadi B, et al. Duration of American football play and chronic traumatic encephalopathy. *Ann Neurol* 2020;87(1):116-131.
259. Harris CD, Watson KB, Carlson SA, Fulton JE, Dorn JM, Elam-Evans L. Adult participation in aerobic and muscle-strengthening physical activities — United States, 2011. *Morb Mortal Wkly Rep* 2013;62(17):326-330.
260. Menke A, Casagrande S, Geiss L, Cowie CC. Prevalence of and trends in diabetes among adults in the United States, 1988-2012. *JAMA* 2015;314(10):1021-1029.
261. Sims M, Diez Roux AV, Boykin S, et al. The socioeconomic gradient of diabetes prevalence, awareness, treatment, and control among African Americans in the Jackson Heart Study. *Ann Epidemiol* 2011;21(12):892-898.
262. Lee TC, Glynn RJ, Pena JM, et al. Socioeconomic status and incident type 2 diabetes mellitus: Data from the Women's Health Study. *PLoS One* 2011;6(12):E27670.
263. Gillespie CD, Hurvitz KA. Prevalence of hypertension and controlled hypertension — United States, 2007-2010. *MMWR* 2013;62(3):144-148.
264. Centers for Disease Control and Prevention. Current Cigarette Smoking Among Adults in the United States. Accessed December 15, 2024. Available at: https://www.cdc.gov/tobacco/data_statistics/fact_sheets/adult_data/cig_smoking/index.htm.
265. Kweon H, Aydogan G, Dagher A, et al. Human brain anatomy reflects separable genetic and environmental components of socioeconomic status. *Sci Adv* 2022;8(20):eabm2923.
266. World Health Organization. Social Determinants of Health. Accessed November 1, 2024. Available at: https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1.
267. Besser LM, Edwards K, Lobban NS, Tolea MI, Galvin JE. Social determinants of health, risk and resilience against Alzheimer's disease and related dementias: The Healthy Brain Initiative. *J Alzheimers Dis Rep* 2024;8(1):637-646.
268. Majoka MA, Schimming C. Effect of social determinants of health on cognition and risk of Alzheimer disease and related dementias. *Clin Ther* 2021;43(6):922-929.
269. Li JM, Boustani MA, French DD. Social determinants of health in community-dwelling dementia patients aged 65 and over: Analysis of the 2019 National Health Interview Survey. *Gerontol Geriatr Med* 2023;9:23337214231190244.
270. Bernard SM, McGeehin MA. Prevalence of blood lead levels \geq 5 micro g/dL among US children 1 to 5 years of age and socioeconomic and demographic factors associated with blood of lead levels 5 to 10 micro g/dL, Third National Health and Nutrition Examination Survey, 1988-1994. *Pediatrics* 2003;112(6 Pt 1):1308-1313.
271. Griffith M, Tajik M, Wing S. Patterns of agricultural pesticide use in relation to socioeconomic characteristics of the population in the rural U.S. South. *Int J Health Serv* 2007;37(2):259-277.
272. Alzheimers.gov. Can I Prevent Dementia? Accessed September 5, 2024. Available at <https://www.alzheimers.gov/life-with-dementia/can-i-prevent-dementia?>
273. Palmqvist S, Tideman P, Mattsson-Carlgren N, et al. Blood biomarkers to detect Alzheimer disease in primary care and secondary care. *JAMA* 2024;332(15):1245-1257.
274. O'Bryant SO, Petersen M, Hall J, et al. Medical comorbidities and ethnicity impact plasma Alzheimer's disease biomarkers: Important considerations for clinical trials and practice. *Alzheimers Dement* 2023;19(1):36-43.
275. Syrjanen JA, Campbell MR, Algeciras-Schimmich A, et al. Associations of amyloid and neurodegeneration plasma biomarkers with comorbidities. *Alzheimers Dement* 2022;18(6):1128-1140.
276. Ramanan VK, Graff-Radford J, Syrjanen J, et al. Association of plasma biomarkers of Alzheimer disease with cognition and medical comorbidities in a biracial cohort. *Neurology* 2023;101(14):e1402-11.
277. Hansson O, Edelmayer RM, Boxer AL, et al. The Alzheimer's Association Appropriate Use Recommendations for Blood Biomarkers in Alzheimer's Disease. *Alzheimers Dement* 2022;18(12):2669-2686.
278. Dickerson BC, Atri A, Clevenger C, Karlawish J, Knopman D, Lin P-J, et al. The Alzheimer's Association clinical practice guideline for the diagnostic evaluation, testing, counseling, and disclosure of suspected Alzheimer's disease and related disorders (DETeCD-ADRD): Executive summary of recommendations for specialty care. *Alzheimers Dement* 2024. doi: 10.1002/alz.14337. Published online ahead of print.
279. Atri A, Dickerson BC, Clevenger C, Karlawish J, Knopman D, Lin P-J, et al. The Alzheimer's Association clinical practice guideline for the diagnostic evaluation, testing, counseling, and disclosure of suspected Alzheimer's disease and related disorders (DETeCD-ADRD): Executive summary of recommendations for primary care. *Alzheimers Dement* 2024. doi: 10.1002/alz.14333. Published online ahead of print.
280. Atri A, Dickerson BC, Clevenger C, Karlawish J, Knopman D, Lin P-J, et al. The Alzheimer's Association clinical practice guideline for the diagnostic evaluation, testing, counseling, and disclosure of suspected Alzheimer's disease and related disorders (DETeCD-ADRD): Validated clinical assessment instruments. *Alzheimers Dement* 2024. doi: 10.1002/alz.14335. Published online ahead of print.
281. Erickson CM, Clark LR, Ketchum FB, et al. Implications of preclinical Alzheimer's disease biomarker disclosure for US policy and society. *Alzheimers Dement* 2022;14(1):e12339.
282. National Institutes of Health. Clearly Communicating Research Results Across the Clinical Trials Continuum. Accessed November 8, 2024. Available at: <https://www.nih.gov/health-information/nih-clinical-research-trials-you/clearly-communicating-research-results-across-clinical-trials-continuum#ref9>.
283. Long CR, Stewart MK, Cunningham TV, Warmack TS, McElfish PA. Health research participants' preferences for receiving research results. *Clin Trials* 2016;13:582-591.

284. Long CR, Purvis RS, Flood-Grady E, et al. Health researchers' experiences, perceptions and barriers related to sharing study results with participants. *Health Res Policy Syst* 2019;17(1):25.
285. Walter S, Taylor A, Tyrone J, et al. Disclosing Individual results in dementia research: A proposed study participant's bill of rights. *J Alzheimers Dis* 2022;90:945-952.
286. Barnes LL. Alzheimer disease in African American individuals: increased incidence or not enough data? *Nat Rev Neurol* 2022;18(1):56-62.
287. Administration for Community Living 2020 Profile of Older Americans: May 2021. Accessed December 15, 2024. Available at: https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2020ProfileOlderAmericans.Final_.pdf.
288. Gilmore-Bykovskiy A, Croff R, Glover CM, et al. Traversing the aging research and health equity divide: Toward intersectional frameworks of research justice and participation. *Gerontologist* 2022;62(5):711-720.
289. U.S. Census Bureau. National Population Projections: Downloadable Files. 2023. Accessed December 15, 2024. Available at: <https://www.census.gov/data/tables/2023/demo/popproj/2023-summary-tables.html>.
290. Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Services. A Profile of Older Americans: 2016. Accessed December 15, 2024. Available at: <https://www.acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2016-Profile.pdf>.
291. Guerreiro R, Bras J. The age factor in Alzheimer's disease. *Genome Med* 2015;7:106.
292. Hudomiet P, Hurd MD, Rohwedder S. Trends in inequalities in the prevalence of dementia in the United States. *Proc Natl Acad Sci USA* 2022;119(46):e2212205119.
293. Rajan KB, Weuve J, Barnes LL, McAninch EA, Wilson RS, Evans DA. Population estimate of people with clinical AD and mild cognitive impairment in the United States (2020-2060). *Alzheimers Dement* 2021;17(12):1966-1975.
294. Hendriks S, Peetoom K, Bakker C, et al. Global prevalence of young-onset dementia: A systematic review and meta-analysis. *JAMA Neurol* 2021;78(9):1080-1090.
295. James BD, Wilson RS, Boyle PA, Trojanowski JQ, Bennett DA, Schneider JA. TDP-43 stage, mixed pathologies, and clinical Alzheimer's-type dementia. *Brain* 2016;139(11):2983-2993.
296. Serrano-Pozo A, Qian J, Monsell SE, et al. Mild to moderate Alzheimer dementia with insufficient neuropathological changes. *Ann Neurol* 2014;75:597-601.
297. Barnes LL, Leurgans S, Aggarwal NT, et al. Mixed pathology is more likely in black than white decedents with Alzheimer dementia. *Neurology* 2015;85:528-534.
298. Petersen RC, Lopez O, Armstrong MJ, et al. Practice guideline update summary: Mild cognitive impairment: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology. *Neurology* 2018;90(3):126-135.
299. Petersen RC, Aisen P, Boeve BF, et al. Mild cognitive impairment due to Alzheimer disease in the community. *Ann Neurol* 2013;74(2):199-208.
300. Rabinovici GD, Gatsonis C, Apgar C, et al. Association of amyloid positron emission tomography with subsequent change in clinical management among Medicare beneficiaries with mild cognitive impairment or dementia. *JAMA* 2019;321(13):1286-1294.
301. U.S. Census Bureau. National Population Projections Tables: Main Series. 2023. Accessed December 15, 2024. Available at: <https://www.census.gov/data/tables/2023/demo/popproj/2023-summary-tables.html>.
302. Jack CR Jr, Thorneau TM, Weigand SD, et al. Prevalence of biologically vs clinically defined Alzheimer spectrum entities using the National Institute on Aging-Alzheimer's Association Research Framework. *JAMA Neurol* 2019;76(10):1174-1183.
303. Gustavsson A, Norton N, Fast T, et al. Global estimates on the number of persons across the Alzheimer's disease continuum. *Alzheimers Dement* 2023;19(2):658-670.
304. Brookmeyer R, Abdalla N, Kawas CH, Corrada MM. Forecasting the prevalence of preclinical and clinical Alzheimer's disease in the United States. *Alzheimers Dement* 2018;14(2):121-129.
305. Kotagal V, Langa KM, Plassman BL, et al. Factors associated with cognitive evaluations in the United States. *Neurology* 2015;84(1):64-71.
306. Taylor DH, Jr., Ostbye T, Langa KM, Weir D, Plassman BL. The accuracy of Medicare claims as an epidemiological tool: The case of dementia revisited. *J Alzheimers Dis* 2009;17(4):807-815.
307. Gianattasio KZ, Prather C, Glymour MM, Ciarleglio A, Power MC. Racial disparities and temporal trends in dementia misdiagnosis risk in the United States. *Alzheimer's & Dementia* 2019;5:891-898.
308. Lang L, Clifford A, Wei L, et al. Prevalence and determinants of undetected dementia in the community: A systematic literature review and a meta-analysis. *BMJ Open* 2017;7(2):e011146.
309. Lin PJ, Daly AT, Olchanski N, et al. Dementia diagnosis disparities by race and ethnicity. *Med Care* 2021;59(8):679-686.
310. Amjad H, Roth DL, Sheehan OC, Lyketsos CG, Wolff JL, Samus QM. Underdiagnosis of dementia: An observational study of patterns in diagnosis and awareness in US older adults. *J Gen Intern Med* 2018;33(7):1131-1138.
311. Nguyen HQ, Borson S, Khang P, et al. Dementia diagnosis and utilization patterns in a racially diverse population within an integrated health care delivery system. *Alzheimers Dement (N Y)* 2022;8(1):e12279.
312. Grodstein F, Chang C-H, Capuano AW, Power MC, Marquez DX, Barnes LL. Identification of Dementia in Recent Medicare Claims Data, Compared With Rigorous Clinical Assessments. *J Gerontol A Biol Sci Med Sci* 2022;77(6):1272-1278.
313. Grodstein F, James BD, Chen Y, et al. Identification of Dementia in Medicare Claims Compared to Rigorous Clinical Assessments in African Americans. *J Gerontol A Biol Sci Med Sci* 2024 Jan 1;79(1):glad235.
314. Chen Y, Tysinger B, Crimmins E, Zissimopoulos JM. Analysis of dementia in the US population using Medicare claims: Insights from linked survey and administrative claims data. *Alzheimers Dement (N Y)* 2019;5:197-207.
315. Healthy People 2030. Accessed December 15, 2024. Available at: <https://health.gov/healthypeople/objectives-and-data/browse/objectives/dementias/increase-proportion-older-adults-dementia-or-their-caregivers-who-know-they-have-it-dia-01>.
316. Barrett AM, Orange W, Keller M, Damgaard P, Swerdlow RH. Short-term effect of dementia disclosure: How patients and families describe the diagnosis. *J Am Geriatr Soc* 2006;54(12):1968-1970.
317. Zaleta AK, Carpenter BD, Porensky EK, Xiong C, Morris JC. Agreement on diagnosis among patients, companions, and professionals after a dementia evaluation. *Alzheimer Dis Assoc Disord* 2012;26(3):232-237.
318. Amjad H, Roth DL, Samus QM, Yasar S, Wolff JL. Potentially unsafe activities and living conditions of older adults with dementia. *J Am Geriatr Soc* 2016;64(6):1223-1232.
319. Alzheimer's Association. 2015 Alzheimer's Disease Facts and Figures. Special report: Disclosing a diagnosis of Alzheimer's disease. Accessed December 15, 2024. Available at: [https://www.alzheimersanddementia.com/article/S1552-5260\(15\)00058-8/fulltext](https://www.alzheimersanddementia.com/article/S1552-5260(15)00058-8/fulltext).
320. Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. Special report: Alzheimer's detection in the primary care setting — connecting patients with physicians. Accessed December 15, 2024. Available at: [https://www.alzheimersanddementia.com/article/S1552-5260\(19\)30031-7/fulltext](https://www.alzheimersanddementia.com/article/S1552-5260(19)30031-7/fulltext).
321. Qian Y, Chen X, Tang D, Kelley AS, Li J. Prevalence of memory-related diagnoses among U.S. older adults with early symptoms of cognitive impairment. *J Gerontol A* 2010;76(10):1846-1853.

322. Power MC, Willens V, Prather C, et al. Risks and benefits of clinical diagnosis around the time of dementia onset. *Gerontol Geriatr Med* 2023;9:23337214231213185.
323. Spargo D, Zur R, Lin PJ, Synnott P, Klein E, Hartry A. Estimating prevalence of early symptomatic Alzheimer's disease in the United States. *Alzheimers Dement (Amst)* 2023;15(4):e12497.
324. Liu Y, Jun H, Becker A, Wallick C, Mattke S. Detection rates of mild cognitive impairment in primary care for the United States Medicare population. *J Prev Alzheimers Dis* 2023. Accessed December 15, 2024. Available at: <https://link.springer.com/article/10.14283/jpad>.
325. Reisberg B, Gauthier S. Current evidence for subjective cognitive impairment (SCI) as the pre-mild cognitive impairment (MCI) stage of subsequently manifest Alzheimer's disease. *Int Psychogeriatr* 2008;20(1):1-16.
326. Jessen F, Wolfsgruber S, Wiese B, et al. AD dementia risk in late MCI, in early MCI, and in subjective memory impairment. *Alzheimers Dement* 2014;10(1):76-83.
327. Jessen F, Amariglio RE, van Boxtel M, et al. A conceptual framework for research on subjective cognitive decline in preclinical Alzheimer's disease. *Alzheimers Dement* 2014;10(6):844-852.
328. Buckley RF, Maruff P, Ames D, et al. Subjective memory decline predicts greater rates of clinical progression in preclinical Alzheimer's disease. *Alzheimers Dement* 2016;12(7):796-804.
329. Gifford KA, Liu D, Lu Z, et al. The source of cognitive complaints predicts diagnostic conversion differentially among nondemented older adults. *Alzheimers Dement* 2014;10(3):319-327.
330. Kaup AR, Nettiksimmons J, LeBlanc ES, Yaffe K. Memory complaints and risk of cognitive impairment after nearly 2 decades among older women. *Neurology* 2015;85(21):1852-1858.
331. Reisberg B, Shulman MB, Torossian C, Leng L, Zhu W. Outcome over seven years of healthy adults with and without subjective cognitive impairment. *Alzheimers Dement* 2010;6(1):11-24.
332. Fernandez-Blazquez MA, Avila-Villanueva M, Maestu F, Medina M. Specific features of subjective cognitive decline predict faster conversion to mild cognitive impairment. *J Alzheimers Dis* 2016;52(1):271-281.
333. Jessen F, Amariglio RE, Buckley RF, et al. The characterisation of subjective cognitive decline. *Lancet Neurol* 2020;19(3):271-278.
334. Wolfsgruber S, Kleineidam L, Wagner M, et al. Differential risk of incident Alzheimer's disease dementia in stable versus unstable patterns of subjective cognitive decline. *J Alzheimers Dis* 2016;54(3):1135-1146.
335. Unpublished data from the 2019-2020 Behavioral Risk Factor Surveillance System survey conducted in 46 states and the District of Columbia, analyzed and provided to the Alzheimer's Association by the Alzheimer's Disease Program, Centers for Disease Control and Prevention.
336. Dhana K, Beck T, Desai P, Wilson RS, Evans DA, Rajan KB. Prevalence of Alzheimer's disease dementia in the 50 US states and 3142 counties: A population estimate using the 2020 bridged-race postcensal from the National Center for Health Statistics. *Alz Dement* 2023;19(10):4388-4395.
337. Howard G, Howard VJ. Twenty Years of Progress Toward Understanding the Stroke Belt. *Stroke* 2020;51(3):742-750.
338. Rajan KB, Weuve J, Barnes LL, Wilson RS, Evans DA. Prevalence and incidence of clinically diagnosed Alzheimer's disease dementia from 1994 to 2012 in a population study. *Alzheimers Dement* 2019;15(1):1-7.
339. Hebert LE, Beckett LA, Scherr PA, Evans DA. Annual incidence of Alzheimer disease in the United States projected to the years 2000 through 2050. *Alzheimer Dis Assoc Disord* 2001;15(4):169-173.
340. Chene G, Beiser A, Au R, et al. Gender and incidence of dementia in the Framingham Heart Study from mid-adult life. *Alzheimers Dement* 2015;11(3):310-320.
341. U.S. Census Bureau. 2014 National Population Projections: Downloadable Files. Accessed December 15, 2024. Available at: <https://www.census.gov/data/datasets/2014/demo/popproj/2014-popproj.html>.
342. Seshadri S, Wolf PA, Beiser A, et al. Lifetime risk of dementia and Alzheimer's disease. The impact of mortality on risk estimates in the Framingham Study. *Neurology* 1997;49(6):1498-1504.
343. Hebert LE, Scherr PA, McCann JJ, Beckett LA, Evans DA. Is the risk of developing Alzheimer's disease greater for women than for men? *Am J Epidemiol* 2001;153(2):132-136.
344. Gong J, Harris K, Lipnicki DM, et al. Sex differences in dementia risk and risk factors: Individual-participant data analysis using 21 cohorts across six continents from the COSMIC consortium. *Alzheimers Dement* 2023;19(8):3365-3378.
345. Kawas C, Gray S, Brookmeyer R, Fozard J, Zonderman A. Age-specific incidence rates of Alzheimer's disease: The Baltimore Longitudinal Study of Aging. *Neurology* 2000;54(11):2072-2077.
346. Zahodne LB, Schofield PW, Farrell MT, Stern Y, Manly JJ. Bilingualism does not alter cognitive decline or dementia risk among Spanish-speaking immigrants. *Neuropsychology* 2014;28(2):238-246.
347. Fratiglioni L, Viitanen M, von Strauss E, Tontodonati V, Herlitz A, Winblad B. Very old women at highest risk of dementia and Alzheimer's disease: Incidence data from the Kungsholmen Project, Stockholm. *Neurology* 1997;48:132-138.
348. Letenneur L, Gilleron V, Commenges D, Helmer C, Orgogozo JM, Dartigues JF. Are sex and educational level independent predictors of dementia and Alzheimer's disease? Incidence data from the PAQUID project. *J Neurol Neurosurg Psychiatry* 1999;66:177-183.
349. Matthews FE, Stephan BC, Robinson L, et al. A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II. *Nat Commun* 2016;7:11398.
350. Mielke MM, Ferretti MT, Lulita MF, Hayden K, Khachaturian AS. Sex and gender in Alzheimer's disease — Does it matter? *Alzheimers Dement* 2018;14(9):1101-1103.
351. Rocca WA. Time, Sex, gender, history, and dementia. *Alzheimer Dis Assoc Disord* 2017;31(1):76-79.
352. GBD 2021 Demographics Collaborators. Global age-sex-specific mortality, life expectancy, and population estimates in 204 countries and territories and 811 subnational locations, 1950-2021, and the impact of the COVID-19 pandemic: a comprehensive demographic analysis for the Global Burden of Disease Study 2021. *Lancet* 2024;403(10440):1989-2056.
353. Shaw C, Hayes-Larson E, Glymour MM, Dufouil C, Hohman TJ, Whitmer RA. Evaluation of selective survival and sex/gender differences in dementia incidence using a simulation model. *JAMA Netw Open* 2021;4(3):e211001.
354. Beam CR, Kaneshiro C, Jang JY, et al. Differences between women and men in incidence rates of dementia and Alzheimer's disease. *J Alzheimers Dis* 2018; 64(4):1077-1083.
355. Gilsanz P, Lee C, Corrada MM, Kawas CH, Quesenberry CP, Jr., Whitmer RA. Reproductive period and risk of dementia in a diverse cohort of health care members. *Neurology* 2019;92(17):e2005-e2014.
356. Mielke MM, Vemuri P, Rocca WA. Clinical epidemiology of Alzheimer's disease: Assessing sex and gender differences. *Clin Epidemiol* 2014;6:37-48.
357. Mielke MM, Aggarwal NT, Vila-Castelar C, et al. Consideration of sex and gender in Alzheimer's disease and related disorders from a global perspective. *Alzheimers Dement* 2022;18(12):2707-2724.
358. Arenaza-Urquijo EM, Boyle R, Casaletto K, et al. Sex and gender differences in cognitive resilience to aging and Alzheimer's disease. *Alzheimers Dement* 2024 Aug; 20(8):5695-5719.
359. Rocca WA, Mielke MM, Vemuri P, Miller VM. Sex and gender differences in the causes of dementia: A narrative review. *Maturitas* 2014;79(2):196-201.

360. Langa KM, Larson EB, Crimmins EM, et al. A comparison of the prevalence of dementia in the United States in 2000 and 2012. *JAMA Intern Med* 2017;177(1):51-58.
361. Launer LJ, Andersen K, Dewey ME, et al. Rates and risk factors for dementia and Alzheimer's disease: Results from EURODEM pooled analyses. EURODEM Incidence Research Group and Work Groups. *European Studies of Dementia. Neurology* 1999;52(1):78-84.
362. Russ TC, Stamatakis E, Hamer M, Starr JM, Kivimaki M, Batty GD. Socioeconomic status as a risk factor for dementia death: individual participant meta-analysis of 86 508 men and women from the UK. *Br J Psychiatry* 2013;203(1):10-17.
363. Lam JO, Whitmer RA, Corrada MM, et al. Gender differences in the association between education and late-life cognitive function in the LifeAfter90 Study: A multiethnic cohort of the oldest-old. *Alzheimers Dement* 2024;20(11):7547-7555.
364. Mayeda RM, Mobley TM, Weiss RE, Murchland AR, Berkman LF, Sabbath EL. Association of work-family experience with mid-and late-life memory decline in US women. *Neurology* 2020; e3072-33080.
365. Mielke MM, James BD. Women who participated in the paid labor force have lower rates of memory decline: Working to remember. *Neurology* 2020;95(23):1027-1028.
366. Population Reference Bureau. Women, Work, and the COVID Pandemic: Myths and Realities. Accessed December 15, 2024. Available at: <https://www.prb.org/articles/blog-u-s-women-work-andthe-covid-pandemic-myths-and-realities>.
367. Zamarro G, Prados MJ. "Gender Differences in Couples' Division of Childcare, Work, and Mental Health During COVID-19." *Rev Econ Househ* 2021;19(1):11-40.
368. Center for American Progress. Calculating the Hidden Cost of Interrupting a Career for Child Care. Accessed December 15, 2024. Available at: <https://www.americanprogress.org/article/calculating-the-hidden-cost-of-interrupting-a-career-for-childcare/>
369. Carter CL, Resnick EM, Mallampalli M, Kalbarczyk A. Sex and gender differences in Alzheimer's disease: Recommendations for future research. *J Womens Health* 2012;21(10):1018-1023.
370. Altmann A, Tian L, Henderson VW, Greicius MD, Alzheimer's Disease Neuroimaging Initiative Investigators. Sex modifies the APOE-related risk of developing Alzheimer disease. *Ann Neurol* 2014;75(4):563-573.
371. Ungar L, Altmann A, Greicius MD. Apolipoprotein E, gender, and Alzheimer's disease: An overlooked, but potent and promising interaction. *Brain Imaging Behav* 2014;8(2):262-273.
372. Hohman TJ, Dumitrescu L, Barnes LL, et al. Sex-specific association of apolipoprotein E with cerebrospinal fluid levels of tau. *JAMA Neurol* 2018;75(8):989-998.
373. Neu SC, Pa J, Kukull W, et al. Apolipoprotein E genotype and sex risk factors for Alzheimer disease: A meta-analysis. *JAMA Neurol* 2017;74(10):1178-1189.
374. Yaffe K, Haan M, Byers A, Tangen C, Kuller L. Estrogen use, APOE, and cognitive decline: Evidence of gene-environment interaction. *Neurology* 2000;54(10):1949-1954.
375. Kang JH, Grodstein F. Postmenopausal hormone therapy, timing of initiation, APOE and cognitive decline. *Neurobiol Aging* 2012;33(7):1129-1137.
376. Dilworth-Anderson P, Hendrie HC, Manly JJ, Khachaturian AS, Fazio S. Diagnosis and assessment of Alzheimer's disease in diverse populations. *Alzheimers Dement* 2008;4(4):305-309.
377. Manly JJ, Mayeux R. Ethnic differences in dementia and Alzheimer's disease. In: Anderson N, Bulatao R, Cohen B, eds. *Critical perspectives on racial and ethnic differentials in health in late life*. Washington, D.C.: National Academies Press; 2004: p. 95-141.
378. Demirovic J, Prineas R, Loewenstein D, et al. Prevalence of dementia in three ethnic groups: The South Florida Program on Aging and Health. *Ann Epidemiol* 2003;13(6):472-478.
379. Harwood DG, Ownby RL. Ethnicity and dementia. *Curr Psychol Report* 2000;2(1):40-45.
380. Perkins P, Annegers JF, Doody RS, Cooke N, Aday L, Vernon SW. Incidence and prevalence of dementia in a multiethnic cohort of municipal retirees. *Neurology* 1997;49(1):44-50.
381. Steenland K, Goldstein FC, Levey A, Wharton W. A meta-analysis of Alzheimer's disease incidence and prevalence comparing African-Americans and Caucasians. *J Alzheimers Dis* 2015;50(1):71-76.
382. Power MC, Bennett EE, Turner RW, et al. Trends in relative incidence and prevalence of dementia across non-Hispanic black and white individuals in the United States, 2000-2016. *JAMA Neurology* 2021;78(3):275-284.
383. Potter GG, Plassman BL, Burke JR, et al. Cognitive performance and informant reports in the diagnosis of cognitive impairment and dementia in African Americans and whites. *Alzheimers Dement* 2009;5(6):445-453.
384. Gurland BJ, Wilder DE, Lantigua R, et al. Rates of dementia in three ethnorracial groups. *Int J Geriatr Psychiatry* 1999;14(6):481-493.
385. Haan MN, Mungas DM, Gonzalez HM, Ortiz TA, Acharya A, Jagust WJ. Prevalence of dementia in older Latinos: The influence of type 2 diabetes mellitus, stroke and genetic factors. *J Am Geriatr Soc* 2003;51:169-177.
386. Samper-Ternent R, KuoYF, Ray LA, Ottenbacher KJ, Markides KS, Al Snih S. Prevalence of health conditions and predictors of mortality in oldest old Mexican Americans and non-Hispanic whites. *J Am Med Dir Assn* 2012;13(3):254-259.
387. Mehta KM, Yeo GW. Systematic review of dementia prevalence and incidence in United States race/ethnic populations. *Alzheimers Dement* 2017;13(1):72-83.
388. Gonzalez HM, Tarraf W, Schneiderman N, et al. Prevalence and correlates of mild cognitive impairment among diverse Hispanics/Latinos: Study of Latinos-Investigation of Neurocognitive Aging results. *Alzheimers Dement* 2019;15(12):1507-1515.
389. Yaffe K, Falvey C, Harris TB, et al. Effect of socioeconomic disparities on incidence of dementia among biracial older adults: Prospective study. *BMJ* 2013;347:f7051.
390. Kornblith E, Bahorik A, Boscardin WJ; Xia F, Barnes DE, Yaffe K. Association of Race and Ethnicity With Incidence of Dementia Among Older Adults. *JAMA* 2022;327(15):1488-1495.
391. Chin AL, Negash S, Hamilton R. Diversity and disparity in dementia: The impact of ethnorracial differences in Alzheimer disease. *Alzheimer Dis Assoc Disord* 2011;25(3):187-195.
392. Froehlich TE, Bogardus Jr. ST, Inouye SK. Dementia and race: Are there differences between African Americans and Caucasians? *J Am Geriatr Soc* 2001;49(4):477-484.
393. Glymour MM, Manly JJ. Lifecourse social conditions and racial and ethnic patterns of cognitive aging. *Neuropsychol Rev* 2008;18(3):223-254.
394. Bailey ZD, Feldman JM, Bassett MT. How Structural Racism Works - Racist Policies as a Root Cause of U.S. Racial Health Inequities. *N Engl J Med* 2021;384(8):768-773.
395. Bailey ZD, Krieger N, Agenor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: Evidence and interventions. *Lancet* 2017;389(10077):1453-1463.
396. Lamar M, Lerner AJ, James BD, et al. Relationship of early-life residence and educational experience to level and change in cognitive functioning: Results of the Minority Aging Research Study. *J Gerontol B Psychol Sci Soc Sci* 2020;75(7):e81-e92.
397. Peterson RL, George KM, Barnes LL, et al. Timing of School Desegregation and Late-Life Cognition in the Study of Healthy Aging in African Americans (STAR). *JAMA Netw Open* 2021;4(10): e2129052.
398. Banks MP, Byrd GS, Caban-Holt A, et al. Self-reported experiences of discrimination and incident dementia. *Alzheimers Dement* 2023;19(7):3119-3128.
399. Lines LM, Sherif NA, Wiener JM. Racial and ethnic disparities among individuals with Alzheimer's disease in the United States: A literature review. Research Triangle Park, NC: RTI Press; 2014.

400. Zhang Z, Hayward MD, Yu YL. Life course pathways to racial disparities in cognitive impairment among older Americans. *J Health Soc Behav* 2016;57(2):184-199.
401. Reddy KP, Eberly LA, Julien HM, et al. Association between racial residential segregation and Black-White disparities in cardiovascular disease mortality. *Am Heart J* 2023;264:143-152.
402. Mentias A, Mujahid MS, Sumarsono A, et al. Historical Redlining, Socioeconomic Distress, and Risk of Heart Failure Among Medicare Beneficiaries. *Circulation* 2023;148(3):210-219.
403. Mujahid MS, Gao X, Tabb LP, et al. Historical redlining and cardiovascular health: The Multi-Ethnic Study of Atherosclerosis. *Proc Natl Acad Sci U S A* 2021 Dec 21; 118(51): e2110986118.
404. Reddy NM, Mayne SL, Pool LR, et al. Exposure to neighborhood-level racial residential segregation in young adulthood to midlife and incident subclinical atherosclerosis in Black adults: The Coronary Artery Risk Development in Young Adults Study. *Circ Cardiovasc Qual Outcomes* 2022;15(2):e007986.
405. Egede LE, Walker RJ, Campbell JA, et al. Historic Redlining and Impact of Structural Racism on Diabetes Prevalence in a Nationally Representative Sample of U.S. Adults. *Diabetes Care* 2024;47(6):964-969.
406. Linde S, Walker RJ, Campbell JA, et al. Historic Residential Redlining and Present-day Diabetes Mortality and Years of Life Lost: The Persistence of Structural Racism. *Diabetes Care* 2022;45(8):1772-1778.
407. Plassman BL, Langa KM, Fisher GG, et al. Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology* 2007;29(1-2):125-132.
408. Walsemann KM, Hair NL, Farina MP, et al. State-level desegregation in the U.S. South and mid-life cognitive function among Black and White adults. *Soc Sci Med* 2023;338:116319.
409. Gutierrez S, Whitmer RA, Soh Y, et al. School-based racial segregation, social support, and late-life cognitive function in the Study of Healthy Aging in African Americans (STAR). *Alzheimers Dement* 2024;20(9):6257-6267.
410. Pohl DJ, Seblova D, Avila JF, et al. Relationship between Residential Segregation, Later-Life Cognition, and Incident Dementia across Race/Ethnicity. *Int J Environ Res Public Health* 2021;18(21):11233.
411. Matthews KA, Xu W, Gaglioti AH, et al. Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥ 65 years. *Alzheimers Dement* 2019;15(1):17-24.
412. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers Dement* 2016;12(3):216-224.
413. Mayeda ER, Glymour MM, Quesenberry CP, Jr., Whitmer RA. Heterogeneity in 14-year dementia incidence between Asian American subgroups. *Alzheimer Dis Assoc Disord* 2017;31(3):181-186.
414. Ajrouch KJ, Zahodne LB, Antonucci TC. Arab American Cognitive Aging: Opportunities for Advancing Research on Alzheimer's Disease Disparities. *Innov Aging* 2017;1(3):ix034.
415. Suchy-Dacey AM, Domoto-Reilly K, Nelson L, et al. Epidemiology and prevalence of dementia and Alzheimer's disease in American Indians: Data from the Strong Heart Study. *Alzheimers Dement* 2024;20(6):4174-4184.
416. Zhu Y, Park S, Kolady R, et al. A systematic review/meta-analysis of prevalence and incidence rates illustrates systemic underrepresentation of individuals racialized as Asian and/or Asian-American in ADRD research. *Alzheimers Dement* 2024;20(6):4315-4330.
417. Hayes-Larson E, Zhou Y, Wu Y, et al. Estimating dementia incidence in insured older Asian Americans and Pacific Islanders in California: An application of inverse odds of selection weights. *Am J Epidemiol* 2024;kwae182.
418. Abner EL, Jicha GA, Christian WJ, Schreurs BG. Rural-urban differences in Alzheimer's disease and related disorders diagnostic prevalence in Kentucky and West Virginia. *J Rural Health*. 2016;32(3):314-320.
419. Wing JJ, Levine DA, Ramamurthy A, Reider C. Alzheimer's disease and related disorders prevalence differs by Appalachian residence in Ohio. *J Alzheimers Dis*. 2020;76(4):1309-1316.
420. Flatt JD, Cicero EC, Lambrou NH, Wharton W, Anderson JG, Bouldin ED, McGuire LC, Taylor CA. Subjective cognitive decline higher among sexual and gender minorities in the United States, 2015-2018. *Alzheimers Dement* 2021;7(1):e12197.
421. Liu H, Hsieh N, Zhang Z, Zhang Y, Langa KM. Same-sex couples and cognitive impairment: Evidence from the health and retirement study. *J Gerontol B* 2021;76(7):1388-1399.
422. Hsieh N, Liu H, Lai WH. Elevated risk of cognitive impairment among older sexual minorities: Do health conditions, health behaviors, and social connections matter? *Gerontologist* 2021;61(3):352-362.
423. Perales-Puchalt J, Gauthreaux K, Flatt J, Teylan MA, Resendez J, Kukull WA, Chan KCG, Burns J, Vidoni ED. Risk of dementia and mild cognitive impairment among older adults in same-sex relationships. *Int J Geriatr Psychiatry* 2019;34(6):828-835.
424. Dragon CN, Guerino P, Ewald E, Laffan AM. Transgender Medicare beneficiaries and chronic conditions: exploring fee-for-service claims data. *LGBT health* 2017;4(6):404-411.
425. Hughto JM, Varma H, Babbs G, et al. Disparities in health condition diagnoses among aging transgender and cisgender Medicare beneficiaries, 2008-2017. *Front Endocrinol (Lausanne)* 2023;14:1102348.
426. Guo Y, Li Q, Yang X, Jaffee MS, Wu Y, Wang F, Bian J. Prevalence of Alzheimer's and Related Dementia Diseases and Risk Factors Among Transgender Adults, Florida, 2012-2020. *Am J Public Health* 2022;112(5):754-757.
427. Romanelli RJ, Rosenblatt AS, Marcum ZA, Flatt JD. Cognitive Impairment in Sexual and Gender Minority Groups: A Scoping Review of the Literature. *LGBT Health* 2024;11(3):178-192.
428. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull* 2003;129(5):674-697.
429. Flatt JD, Johnson JK, Karpiak SE, Seidel L, Larson B, Brennan-Ing M. Correlates of Subjective Cognitive Decline in Lesbian, Gay, Bisexual, and Transgender Older Adults. *J Alzheimers Dis* 2018;64(1):91-102.
430. Brady B, Zheng L, Kootar S, Anstey KJ. Sex and gender differences in risk scores for dementia and Alzheimer's disease among cisgender, transgender, and non-binary adults. *Alzheimers Dement* 2024;20(1), 5-15.
431. Brennan-Ing M, Seidel L, Larson B, Karpiak SE. Social care networks and older LGBT adults: challenges for the future. *J Homosex* 2014;61(1):21-52.
432. Cohen RA, Seider TR, Navia B: HIV effects on age-associated neurocognitive dysfunction: premature cognitive aging or neurodegenerative disease? *Alzheimers Res Ther* 2015;7:37.
433. Lam JO, Hou CE, Hojilla JC, et al. Comparison of dementia risk after age 50 between individuals with and without HIV infection. *AIDS* 2021;35(5):821-828.
434. Cicero EC, Lett E, Flatt JD, Benson GP, Epps F. Transgender Adults From Minoritized Ethnoracial Groups in the U.S. Report Greater Subjective Cognitive Decline. *J Gerontol B Psychol Sci Soc Sci* 2023;78(6):1051-1059.
435. Hill Collins P. *Intersectionality as Critical Social Theory*. Duke University Press; 2019.
436. Correro AN, Nielson KA. A review of minority stress as a risk factor for cognitive decline in lesbian, gay, bisexual, and transgender (LGBT) elders. *J Gay Lesbian Ment Health* 2020;24(1):2-19.
437. Flatt JD, Cicero EC, Kittle KR, Brennan-Ing M. Recommendations for advancing research with sexual and gender minority older adults. *J Gerontol B* 2022;77(1):1-9.
438. Wolters FJ, Chibnik LB, Waziry R, et al. Twenty-seven-year time trends in dementia incidence in Europe and the United States. *The Alzheimer Cohorts Consortium*. *Neurology* 2020;95(5):e519-e531.

439. Rocca WA, Petersen RC, Knopman DS, et al. Trends in the incidence and prevalence of Alzheimer's disease, dementia, and cognitive impairment in the United States. *Alzheimers Dement* 2011;7(1):80-93.
440. Wu YT, Beiser AS, Breteler MMB, et al. The changing prevalence and incidence of dementia over time: Current evidence. *Nat Rev Neurol* 2017;13(6):327-339.
441. Schrijvers EM, Verhaaren BF, Koudstaal PJ, Hofman A, Ikram MA, Breteler MM. Is dementia incidence declining? Trends in dementia incidence since 1990 in the Rotterdam Study. *Neurology* 2012;78(19):1456-1463.
442. Qiu C, von Strauss E, Backman L, Winblad B, Fratiglioni L. Twenty-year changes in dementia occurrence suggest decreasing incidence in central Stockholm, Sweden. *Neurology* 2013;80(20):1888-1894.
443. Satizabal CL, Beiser AS, Chouraki V, Chene G, Dufouil C, Seshadri S. Incidence of dementia over three decades in the Framingham Heart Study. *N Engl J Med* 2016;374:523-532.
444. Cerasuolo JO, Cipriano LE, Sposito LA, et al. Population-based stroke and dementia incidence trends: Age and sex variations. *Alzheimers Dement* 2017;13(10):1081-1088.
445. Derby CA, Katz MJ, Lipton RB, Hall CB. Trends in dementia incidence in a birth cohort analysis of the Einstein Aging Study. *JAMA Neurol* 2017;74(11):1345-1351.
446. Ahmadi-Abhari S, Guzman-Castillo M, Bandosz P, et al. Temporal trend in dementia incidence since 2002 and projections for prevalence in England and Wales to 2040: Modelling study. *BMJ* 2017;358:j2856.
447. Sullivan KJ, Dodge HH, Hughes TF, et al. Declining incident dementia rates across four population-based birth cohorts. *J Gerontol A Biol Sci Med Sci* 2019;74(9):1439-1445.
448. Matthews FE, Arthur A, Barnes LE, et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the Cognitive Function and Ageing Study I and II. *Lancet* 2013;382(9902):1405-1412.
449. Wiberg P, Waern M, Billstedt E, Ostling S, Skoog I. Secular trends in the prevalence of dementia and depression in Swedish septuagenarians 1976-2006. *Psychol Med* 2013;43:2627-2634.
450. Wimo A, Sjolund BM, Skoldunger A, et al. Cohort effects in the prevalence and survival of people with dementia in a rural area in Northern Sweden. *J Alzheimers Dis* 2016;50:387-396.
451. Hall KS, Gao S, Baiyewu O, et al. Prevalence rates for dementia and Alzheimer's disease in African Americans: 1992 versus 2000. *Alzheimers Dement* 2009;5(3):227-233.
452. Farina MP, Zhang YS, Kim JK, Hayward MD, Crimmins EM. Trends in dementia prevalence, incidence, and mortality in the United States (2000-2016). *J Aging Health* 2022;34(1):100-108.
453. van den Kommer TN, Deeg DJH, van der Flier WM, Comijs HC. Time trend in persistent cognitive decline: Results from the longitudinal aging study Amsterdam. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S57-S64.
454. Sekita A, Ninomiya T, Tanizaki Y, et al. Trends in prevalence of Alzheimer's disease and vascular dementia in a Japanese community: The Hisayama Study. *Acta Psychiatr Scand* 2010;122(4):319-325.
455. Gao S, Burney HN, Callahan CM, Purnell CE, Hendrie HC. Incidence of Dementia and Alzheimer Disease Over Time: A Meta-Analysis. *J Am Geriatr Soc* 2019;67(7):1361-1369.
456. Crimmins EM, Saito Y, Kim JK, Zhang Y, Sasson I, Hayward MD. Educational differences in the prevalence of dementia and life expectancy with dementia in the United States: Changes from 2000 to 2010. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S20-S28.
457. Choi H, Schoeni RF, Martin LG, Langa K M. Trends in the prevalence and disparity in cognitive limitations of Americans 55-69 years old. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S29-S37.
458. Zheng H. A New Look at Cohort Trend and Underlying Mechanisms in Cognitive Functioning. *J Gerontol B Psychol Sci Soc Sci* 2021;76(8):1652-1663.
459. Freedman VA, Kasper JD, Spillman BC, Plassman BL. Short-term changes in the prevalence of probable dementia: An analysis of the 2011-2015 National Health and Aging Trends Study. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S48-S56.
460. Langa KM. Is the risk of Alzheimer's disease and dementia declining? *Alzheimers Res Ther* 2015;7(1):34.
461. Larson EB, Yaffe K, Langa KM. New insights into the dementia epidemic. *N Engl J Med* 2013;369(24):2275-2277.
462. Sheffield KM, Peek MK. Changes in the prevalence of cognitive impairment among older Americans, 1993-2004: Overall trends and differences by race/ethnicity. *Am J Epidemiol* 2011;174(3):274-283.
463. Weuve J, Rajan KB, Barnes LL, Wilson RS, Evans DA. Secular trends in cognitive performance in older black and white U.S. adults, 1993-2012: Findings from the Chicago Health and Aging Project. *J Gerontol B Psychol Sci Soc Sci* 2018;73(Suppl 1):S73-S81.
464. Prince MJ, Wimo A, Guerchet M, Ali G-C, Wu Y-T, Prina M. World Alzheimer Report 2015: The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends. Available at <https://www.alzint.org/u/WorldAlzheimerReport2015.pdf>. Accessed Feb 24, 2025.
465. de Erausquin GA, Snyder H, Carrillo M, Hosseini AA, Brugha TS, Seshadri S. The chronic neuropsychiatric sequelae of COVID-19: The need for a prospective study of viral impact on brain functioning. *Alzheimers Dement* 2021;17(6):1056-1065.
466. Arias E, Tejada-Vera B, Kochanek KD, Ahmad FB. Provisional Life Expectancy Estimates for 2021. National Vital Statistics System, Report No. 23, 2022. Accessed December 15, 2024. Available at: <https://www.cdc.gov/nchs/data/vsrr/vsrr023.pdf>.
467. The World Bank. Fertility, total (births per woman)—US. Accessed December 15, 2024. Available at: <https://data.worldbank.org/indicator/SP.DYN.TFRT.IN?locations=US>.
468. U.S. Census Bureau. 2017 National Population Projections Tables. Accessed December 15, 2024. Available at: <https://www.census.gov/data/tables/2017/demo/popproj/2017-summary-tables.html>.
469. Administration for Community Living. 2019 Profile of Older Americans. May 2020. Accessed January 17, 2025. Available at https://acl.gov/sites/default/files/Profile%20of%20AACL_ProfileOlderAmericans2023_508.pdf.
470. Bauman K. Shift Toward Greater Educational Attainment for Women Began 20 Years Ago. U.S. Census Bureau. Accessed December 15, 2024. Available at: <https://www.census.gov/newsroom/blogs/random-samplings/2016/03/shift-toward-greater-educational-attainment-for-women-began-20-years-ago.html>.
471. Population Reference Bureau. Why is the U.S. Birth Rate Declining? 2021. Accessed December 15, 2024. Available at: <https://www.prb.org/resources/why-is-the-u-s-birth-rate-declining/>.
472. Horowitz JM, Igielnik R, Kochhar R. Trends in income and wealth inequality. Pew Research Center. Accessed October 28, 2024. Available at: <https://www.pewresearch.org/social-trends/2020/01/09/trends-in-income-and-wealth-inequality/>.
473. Cottrill A, Cubanski J, Neuman T, Smith K. Income and Assets of Medicare Beneficiaries in 2023. KFF. 2024. Accessed October 27, 2024. Available at: <https://www.kff.org/medicare/issue-brief/income-and-assets-of-medicare-beneficiaries-in-2023/>.
474. Tom SE, Phadke M, Hubbard RA, Crane PK, Stern Y, Larson EB. Association of Demographic and Early-Life Socioeconomic Factors by Birth Cohort with Dementia Incidence Among US Adults Born Between 1893 and 1949. *JAMA Netw Open* 2020;3(7):e2011094.
475. Skoog I. Dementia incidence: The times, they are a-changing. *Nature Rev Neurol* 2016;12:316-368. Accessed December 15, 2024. Available at: <https://www.nature.com/articles/nrneuro.2016.55>.

476. Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 2018-2022 on CDC WONDER Online Database, released in 2024. Data are from the Multiple Cause of Death Files, 2018-2022, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed December 22, 2024. Available at: <http://wonder.cdc.gov/ucd-icd10-expanded.html>.
477. Mokdad AH, Ballestros K, Echko M, Glenn S, Olsen HE, Mullany E. The State of US Health, 1990-2016: Burden of Diseases, Injuries, and Risk Factors Among US States. *JAMA* 2018;319(14):1444-1472.
478. World Health Organization. International Statistical Classification of Diseases and Related Health Problems. 10th revision. 2nd edition. WHO Press: Geneva, Switzerland; 2004.
479. Burns A, Jacoby R, Luthert P, Levy R. Cause of death in Alzheimer's disease. *Age Ageing* 1990;19(5):341-344.
480. Brunnstrom HR, Englund EM. Cause of death in patients with dementia disorders. *Eur J Neurol* 2009;16(4):488-492.
481. Ives DG, Samuel P, Psaty BM, Kuller LH. Agreement between nosologist and Cardiovascular Health Study review of deaths: Implications of coding differences. *J Am Geriatr Soc* 2009;57(1):133-139.
482. Romero JP, Benito-Leon J, Louis ED, Bermejo-Pareja F. Under reporting of dementia deaths on death certificates: A systematic review of population-based cohort studies. *J Alzheimers Dis* 2014;41(1):213-221.
483. Ganguli M, Rodriguez EG. Reporting of dementia on death certificates: A community study. *J Am Geriatr Soc* 1999;47(7):842-849.
484. Stokes AC, Weiss J, Lundberg DJ, et al. Estimates of the association of dementia with US mortality levels using linked survey and mortality records. *JAMA Neurol* 2020;77(12):1543-1550.
485. Unpublished tabulations based on data from the 100% National Sample Medicare Fee-for-Service Beneficiaries for 2019. Prepared under contract by Health Care Cost Institute, November 2021.
486. Weuve J, Hebert LE, Scherr PA, Evans DA. Deaths in the United States among persons with Alzheimer's disease (2010-2050). *Alzheimers Dement* 2014;10(2):E40-E46.
487. Arrighi HM, Neumann PJ, Lieberburg IM, Townsend RJ. Lethality of Alzheimer disease and its impact on nursing home placement. *Alzheimer Dis Assoc Disord* 2010;24(1):90-95.
488. U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. National Center for Health Statistics. CDC WONDER online database: About Provisional Mortality Statistics, 2018 through Last Month. <https://wonder.cdc.gov/mcdicd10-provisional.html>.
489. Centers for Disease Control and Prevention. National Center for Health Statistics. Excess Deaths Associated with COVID-19. Accessed December 15, 2024. Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid19/excess_deaths.htm.
490. Gilstrap L, Zhou W, Alsan M, Nanda A, Skinner JS. Trends in Mortality Rates Among Medicare Enrollees With Alzheimer Disease and Related Dementias Before and During the Early Phase of the COVID-19 Pandemic. *JAMA Neurol* 2022;79(4):342-348.
491. Chen R, Charpignon M, Raquib RV, et al. Excess Mortality With Alzheimer Disease and Related Dementias as an Underlying or Contributing Cause During the COVID-19 Pandemic in the US. *JAMA Neurol* 2023;80(9):919-928.
492. Tejada-Vera B. Mortality from Alzheimer's disease in the United States: Data for 2000 and 2010. National Center for Health Statistics Data Brief, No. 116. National Center for Health Statistics, Hyattsville, MD; 2013.
493. Taylor C, Greenlund S, McGuire L, Lu H, Croft J. Deaths from Alzheimer's Disease — United States, 1999-2014. *MMWR Morb Mortal Wkly Rep* 2017;66:521-526.
494. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc* 2005;53(2):299-305.
495. U.S. Burden of Disease Collaborators, Mokdad AH, Ballestros K, et al. The state of U.S. health, 1990-2016: Burden of diseases, injuries, and risk factors among U.S. states. *JAMA* 2018;319(14):1444-1472.
496. Barker C, Green A. Opening the debate on DALYs (disability-adjusted life years). *Health Policy Plan* 1996;11(2):179-183.
497. Tough H, Siegrist J, Fekete C. Social relationships, mental health and wellbeing in physical disability: a systematic review. *BMC Public Health* 2017 May 8;17(1):414.
498. Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health* 2015 Apr;105 Suppl 2(Suppl 2):S198-206.
499. Gaugler JE, Kane RL, Kane RA. Family care for older adults with disabilities: Toward more targeted and interpretable research. *Int J Aging Hum Dev* 2002;54(3):205-231.
500. Schulz R, Quittner AL. Caregiving through the life-span: Overview and future directions. *Health Psychol* 1998;17:107-111.
501. Friedman EM, Shih RA, Langa KM, Hurd MD. U.S. prevalence and predictors of informal caregiving for dementia. *Health Aff* 2015;34(10):1637-1641.
502. Spillman B, Wolff J, Freedman VA, Kasper JD. Informal Caregiving for Older Americans: An Analysis of the 2011 National Health and Aging Trends Study. Accessed December 22, 2024. Available at: <https://aspe.hhs.gov/reports/informal-caregiving-older-americans-analysis-2011-national-study-caregiving>
503. Walmart: 2024 Annual Report. Accessed December 21, 2024. Available at: https://s201.q4cdn.com/262069030/files/doc_financials/2024/ar/2024-annual-report-pdf-final-final.pdf.
504. McDonald's Corporation Report 2023. Accessed December 21, 2024. Available at: https://corporate.mcdonalds.com/content/dam/sites/corp/nfl/pdf/2023%20Annual%20Report_vf.pdf.
505. Jutkowitz E, Kane RL, Gaugler JE, MacLehose RF, Dowd B, Kuntz KM. Societal and family lifetime cost of dementia: Implications for policy. *J Am Geriatr Soc* 2017;65(10):2169-2175.
506. Official Data Foundation. CPI inflation calculator. Accessed December 15, 2024. Available at: <http://www.in2013dollars.com/2017-dollars-in-2018?amount=139765>.
507. Deb A, Thornton JD, Sambamoorthi U, Innes K. Direct and indirect cost of managing Alzheimer's disease and related dementias in the United States. *Expert Rev Pharmacoecon Outcomes Res* 2017;17(2):189-202.
508. Greenwood N, Smith R. Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatr* 2019;19(1):169.
509. Ingraham BC, Barthold D, Fishman P, Coe NB. Caregiving for dementia: trends pre-post onset and predictive factors of family caregiving (2002-2018). *Health Aff Sch* 2024;2(3):qxae020.
510. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff* 2015;34(10):1642-1649.
511. Ornstein KA, Wolff JL, Bollens-Lund E, Rahman OK, Kelley AS. Spousal caregivers are caregiving alone in the last years of life. *Health Aff (Millwood)* 2019;38(6):964-972.
512. Alzheimer's Association. Issues Brief: LGBT and Dementia. Accessed December 15, 2024. Available at: <https://www.alz.org/media/Documents/lgbt-dementia-issues-brief.pdf>.
513. Fredriksen-Goldsen KI, Jen S, Bryan AEB, Goldsen J. Cognitive impairment, Alzheimer's disease, and other dementias in the lives of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers: Needs and competencies. *J Appl Gerontol* 2018;37(5):545-569.
514. Candrian C, Burke ES, Kline D, Torke AM. Experiences of caregiving with Alzheimer's disease in the LGBT community. *BMC Geriatr* 2023;23(1):293.
515. Anderson JG, Flatt JD, Jabson Tree JM, Gross AL, Rose KM. Characteristics of Sexual and Gender Minority Caregivers of People With Dementia. *J Aging Health* 2021;33(10):838-851.

516. Kasper JD, Freedman VA, Spillman BC. Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study. U.S. Department of Health and Human Services; 2014. Accessed December 15, 2024. Available at: <http://aspe.hhs.gov/report/disability-and-care-needsolder-americans-dementia-status-analysis-2011-national-healthand-aging-trends-study>.
517. Rabarison KM, Bouldin ED, Bish CL, McGuire LC, Taylor CA, Greenlund KJ. The economic value of informal caregiving for persons with dementia: Results from 38 states, the District of Columbia, and Puerto Rico, 2015 and 2016 BRFSS. *Am J Public Health* 2018;108(10):1370-1377.
518. National Alliance for Caregiving in Partnership with the Alzheimer's Association. Dementia Caregiving in the U.S. Bethesda, MD. Accessed December 15, 2024. Available at: https://www.caregiving.org/wp-content/uploads/2020/05/Dementia-Caregiving-in-the-US_February-2017.pdf.
519. Unpublished data from the 2015, 2016 and 2017 Behavioral Risk Factor Surveillance System survey, analyzed by and provided to the Alzheimer's Association by the Alzheimer's Disease and Healthy Aging Program (AD+HP), Centers for Disease Control and Prevention (CDC).
520. Fisher GG, Franks MM, Plassman BL, et al. Caring for individuals with dementia and cognitive impairment, not dementia: Findings from The Aging, Demographics, and Memory Study. *J Am Geriatr Soc* 2011;59(3):488-494.
521. Riffin C, Van Ness PH, Wolff JL, Fried T. Family and other unpaid caregivers and older adults with and without dementia and disability. *J Am Geriatr Soc* 2017;65(8):1821-1828.
522. National Poll on Healthy Aging. Dementia Caregivers: Juggling, Delaying and Looking Forward. Accessed December 15, 2024. Available at: http://www.healthyagingpoll.org/sites/default/files/2017-10/NPHA_Caregivers-Report-PROOF_101817_v2.pdf.
523. Caregiving in the U.S.: 2020 Report. Accessed December 15, 2024. Available at: <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>.
524. Ohno S, Chen Y, Sakamaki H, Matsumaru N, Yoshino M, Tsukamoto K. Burden of caring for Alzheimer's disease or dementia patients in Japan, the US, and EU: results from the National Health and Wellness Survey: a cross-sectional survey. *J Med Econ* 2021;24(1):266-278.
525. National Alliance for Caregiving and AARP. Caregiving in the U.S.: Unpublished data analyzed under contract for the Alzheimer's Association; 2009.
526. Alzheimer's Association. 2014 Alzheimer's Disease Facts and Figures. Special Report: Women and Alzheimer's Disease. *Alzheimers Dement* 2014;10:e75-e81.
527. Xiong C, Biscardi M, Astell A, et al. Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. *PLoS One* 2020;15(4):e0231848.
528. Pinquart M, Sorensen. Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2006;61(1):P33-P45.
529. Ma M, Dorstyn D, Ward L, Prentice S. Alzheimer's disease and caregiving: A meta-analytic review comparing the mental health of primary carers to controls. *Aging Ment Health* 2018;22(11):1395-1405.
530. Roberts HL, Bollens-Lund E, Ornstein KA, Kelley AS. Caring for aging parents in the last years of life. *J Am Geriatr Soc* 2023;71(9):2871-2877.
531. Feng K, Song X, Caswell H. Kinship And Care: Racial Disparities In Potential Dementia Caregiving In The U.S. From 2000 To 2060. *J Gerontol A Biol Sci Med Sci* 2024;79(Suppl. 1):S32-S41.
532. Fabius CD, Wolff JL, Kasper JD. Race differences in characteristics and experiences of black and white caregivers of older Americans. *Gerontologist* 2020;60(7):1244-1253.
533. Moon HE, Rote SM, Sears J, Schepens Niemiec SL. Racial Differences in the Dementia Caregiving Experience during the COVID-19 Pandemic: Findings from the National Health and Aging Trends Study (NHATS). *J Gerontol B Psychol Sci Soc Sci* 2022;77(12):e203-e215.
534. Yoshikawa A, Bouldin ED, López-Anuarbe M, et al. Use of Caregiving Support Services Among Diverse Dementia Caregivers by Geographic Context. *The Gerontologist* 2024;64(2):gnad067.
535. Liu R, Chi I, Wu S. Caregiving Burden Among Caregivers of People With Dementia Through the Lens of Intersectionality. *Gerontologist* 2022;62(5):650-661.
536. Wang D, Mangal RK, Daniel A, Gould M, Stead TS, Ganti L. Racial disparities in subjective cognitive decline and its implications among Alzheimer's caretakers. *J Natl Med Assoc* 2024;116(2 Pt 1):170-173.
537. Parker LJ, Fabius CD. Racial differences in respite use among black and white caregivers for people living with dementia. *J Aging Health* 2020;32(10):1667-1675.
538. Ejem D, Atkins GC, Perkins M, Morhardt DJ, Williams IC, Cothran FA. Stressors and Acceptability of Services Among Black Caregivers of Persons With Memory Problems. *J Gerontol Nurs* 2022;48(6):13-18.
539. Rote SM, Angel JL, Moon H, Markides K. Caregiving across diverse populations: New evidence from the National Study of Caregiving and Hispanic EPESE. *Innov Aging* 2019;3(2):ig033.
540. Pinquart M, Sorensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist* 2005;45(1):90-106.
541. Dilworth-Anderson P, Moon H, Aranda MP. Dementia caregiving research: Expanding and reframing the lens of diversity, inclusivity, and intersectionality. *Gerontologist* 2020;60(5):797-805.
542. Chen C, Thunell J, Zissimopoulos J. Changes in physical and mental health of Black, Hispanic, and White caregivers and non-caregivers associated with onset of spousal dementia. *Alzheimers Dement (N Y)* 2020;6(1):e12082.
543. Cothran FA, Chang E, Beckett L, Bidwell JT, Price CA, Gallagher-Thompson D. A Landscape of Subjective and Objective Stress in African-American Dementia Family Caregivers. *West J Nurs Res* 2022;44(3):239-249.
544. Liu C, Badana ANS, Burgdorf J, Fabius CD, Roth DL, Haley WE. Systematic review and meta-analysis of racial and ethnic differences in dementia caregivers' well-being. *Gerontologist* 2021;61(5):e228-e243.
545. Baik D, Centi S, McNair B. Assessing racial and ethnic differences in cardiovascular disease in U.S. family caregivers of persons with dementia: Analysis of data from the 2015-2020 Behavioral Risk Factor Surveillance System. *Res Gerontol Nurs* 2023;16(5):241-249.
546. Brewster GS, Bonds K, McLennon S, Moss KO, Epps F, Lopez RP. Missing the Mark: The Complexity of African American Dementia Family Caregiving. *J Fam Nurs* 2020;26(4):294-301.
547. Lewis JP, Manson SM, Jernigan VB, Noonan C. "Making Sense of a Disease That Makes No Sense": Understanding Alzheimer's Disease and Related Disorders Among Caregivers and Providers Within Alaska Native Communities. *Gerontologist* 2021;61(3):363-373.
548. Parker LJ, Fabius C. Who's Helping Whom? Examination of care arrangements for racially and ethnically diverse people living with dementia in the community. *J Appl Gerontol* 2022;41(12):2589-2593.
549. Idorenyin Imoh U, Charity T. Cultural and Social Factors in Care Delivery Among African American Caregivers of Persons With Dementia: A Scoping Review. *Gerontol Geriatr Med* 2023;9:23337214231152002.
550. Ta Park VM, Ly Q, von Oppenfeld J, et al. A scoping review of dementia caregiving for Korean Americans and recommendations for future research. *Clin Gerontol* 2023;46(2):223-239.
551. Moraes Balbim G, Magallanes M, Marques IG, et al. Sources of caregiving burden in middle-aged and older Latino caregivers. *J Geriatr Psychiatry Neurol* 2020;33(4):185-194.

552. Jaldin MA, Balbim GM, Colin SJ, et al. The influence of Latino cultural values on the perceived caregiver role of family members with Alzheimer's disease and related dementias. *Ethn Health* 2023;28(4):619-633.
553. Martinez IL, Gonzalez EA, Quintero C, Vania MJ. The Experience of Alzheimer's Disease Family Caregivers in a Latino Community: Expectations and incongruences in support services. *J Gerontol B Psychol Sci Soc Sci* 2022;77(6):1083-1893.
554. Sloan DH, Johnston D, Fabius C, Pyatt T, Antonsdottir I, Reuland M. Transcending inequities in dementia care in Black communities: Lessons from the maximizing independence at home care coordination program. *Dementia (London)* 2022;21(5):1653-1668.
555. Rote SM, Moon HE, Kacmar AM, Moore S. Exploring Coping Strategies and Barriers in Dementia Care: A Mixed-Methods Study of African American Family Caregivers in Kentucky. *J Appl Gerontol* 2022;41(8):1851-1859.
556. Alexander K, Oliver S, Bennett SG, Henry J, Hepburn K, Clevenger C. "Falling between the cracks": Experiences of Black dementia caregivers navigating U.S. health systems. *J Am Geriatr Soc* 2022;70(2):592-600.
557. Golden BP, Block L, Benson C, et al. Experiences of in-hospital care among dementia caregivers in the context of high neighborhood-level disadvantage. *J Am Geriatr Soc* 2023;71(11):3435-3444.
558. Leggins B, Hart DM, Jackson AJ, et al. Perceptions about dementia clinical trials among underrepresented populations: A nationally representative survey of U.S. dementia caregivers. *Alzheimers Res Ther* 2024;16(1):224.
559. Bonner GJ, Freels S, Ferrans C, et al. Advance Care Planning for African American Caregivers of Relatives With Dementias: Cluster Randomized Controlled Trial. *Am J Hosp Palliat Care* 2021;38(6):547-556.
560. Meyer OL, Sun M, Do T, et al. Community-Engaged Research with Vietnamese Americans to Pilot-Test a Dementia Caregiver Intervention. *J Cross Cult Gerontol* 2020;35(4):479-492.
561. Fields NL, Xu L, Richardson VE, Parekh R, Ivey D, Calhoun M. Utilizing the Senior Companion Program as a platform for a culturally informed caregiver intervention: Results from a mixed methods pilot study. *Dementia (London)* 2021;20(1):161-187.
562. Guest MA, Smith MP. In Our Community, Dementia Speaks: Pilot of a person-centered training targeting African-American caregivers of persons-living with dementia (innovative practice). *Dementia (London)* 2021;20(1):391-397.
563. Withers M, Cortez-Sanchez K, Herrera J, Ringman JM, Segal-Gidan F. "My backpack is so heavy": Experiences of Latino caregivers of family with early-onset Alzheimer's. *J Am Geriatr Soc* 2021;69(6):1539-1547.
564. Epps F, Heidbreder V, Alexander K, Tomlinson A, Freeman V, Williams N. A dementia-friendly church: How can the African American church support families affected by dementia? *Dementia (London)* 2021;20(2):556-569.
565. Park VT, Grill JD, Zhu J, et al. Asian Americans and Pacific Islanders' perspectives on participating in the CARE recruitment research registry for Alzheimer's disease and related dementias, aging, and caregiving research. *Alzheimers Dement (N Y)* 2021;7(1):e12195.
566. Portacolone E, Palmer NR, Lichtenberg P, et al. Earning the Trust of African American Communities to Increase Representation in Dementia Research. *Ethn Dis* 2020;30(Suppl 2):719-734.
567. Liu J, Lou Y, Wu B, Mui A. "I've been always strong to conquer any suffering:" challenges and resilience of Chinese American dementia caregivers in a life course perspective. *Aging Ment Health* 2021;25(9):1716-1724.
568. Bonds K, Song MK, Whitlatch CJ, Lyons KS, Kaye JA, Lee CS. Patterns of Dyadic Appraisal of Decision-Making Involvement of African American Persons Living With Dementia. *Gerontologist* 2021;61(3):383-391.
569. Epps F, Alexander K, Brewster GS, et al. Promoting dementia awareness in African-American faith communities. *Public Health Nurs* 2020;37(5):715-721.
570. Racine L, Ford H, Johnson L, Fowler-Kerry S. An integrative review of Indigenous informal caregiving in the context of dementia care. *J Adv Nurs* 2022;78(4):895-917.
571. Epps F, Moore M, Chester M, et al. The Alter Program: A nurse-led, dementia-friendly program for African American faith communities and families living with dementia. *Nurs Adm Q* 2021;46(1):72-80.
572. Pruitt A, Croff R, Boise L, Kaye J. Are We Talking About the Same Thing? Black/African Americans' Response to the BRFSS Cognitive Decline and Caregiver Modules. *J Cross-Cult Gerontol* 2024;39(4):435-456.
573. Ch'en P, Patel PB, Ramirez M. Caregivers' and Health Care Providers' Cultural Perceptions of and Experiences With Latino Patients With Dementia. *Neurol Clin Pract* 2024;14(4):e200307.
574. Freedman VA, Patterson SE, Cornman JC, Wolff JL. A day in the life of caregivers to older adults with and without dementia: Comparisons of care time and emotional health. *Alzheimers Dement* 2022;18(9):1650-1661.
575. National Alliance for Caregiving and AARP. Caregiving in the U.S. (2015 Report). Accessed December 15, 2024. Available at: <https://www.aarp.org/content/dam/aarp/ppi/2015/caregivingin-the-united-states-2015-report-revised.pdf>.
576. Spillman BC, Freedman VA, Kasper JD, Wolff JL. Change over time in caregiving networks for older adults with and without dementia. *J Gerontol B Psychol Sci Soc Sci* 2020;75(7):1563-1572.
577. Port CL, Zimmerman S, Williams CS, Dobbs D, Preisser JS, Williams SW. Families filling the gap: Comparing family involvement for assisted living and nursing home residents with dementia. *Gerontologist* 2005;45(Special Issue 1):87-95.
578. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA* 2004;292(8):961-967.
579. Rattinger GB, Schwartz S, Mullins CD, et al. Dementia severity and the longitudinal costs of informal care in the Cache County population. *Alzheimers Dement* 2015;11(8):946-954.
580. Song M-K, Paul S, Happ MB, Lea J, Pirkle JL, Jr., Turberville-Trujillo L. Informal Caregiving Networks of Older Adults With Dementia Superimposed on Multimorbidity: A Social Network Analysis Study. *Innov Aging* 2023;7(4):igad033.
581. Wolff JL, Mulcahy J, Huang J, Roth DL, Covinsky K, Kasper JD. Family Caregivers of Older Adults, 1999-2015: Trends in characteristics, circumstances, and role-related appraisal. *Gerontologist* 2018;58(6):1021-1032.
582. Jutkowitz E, Gaugler JE, Trivedi AN, Mitchell LL, Gozalo P. Family caregiving in the community up to 8-years after onset of dementia. *BMC Geriatr* 2020;20(1):216.
583. Gaugler JE, Zarit SH, Pearlin LI. The onset of dementia caregiving and its longitudinal implications. *Psychol Aging* 2003;18(2):171-180.
584. Jutkowitz E, Gozalo P, Trivedi A, Mitchell L, Gaugler JE. The effect of physical and cognitive impairments on caregiving. *Med Care* 2020;58(7):601-609.
585. Lei L, Maust DT, Leggett AN. Functional decline over time and change in family and other unpaid care provided to community-dwelling older adults living with and without dementia. *J Gerontol B Psychol Sci Soc Sci* 2023;78(10):1727-1734.
586. Galske J, Chera T, Hwang U, et al. Daily care hours among caregivers of older emergency department patients with dementia and undiagnosed cognitive impairment. *J Am Geriatr Soc* 2024;72(10):3261-3264.
587. Ornstein K, Gaugler JE. The problem with "problem behaviors": A systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. *Int Psychogeriatr* 2012;24(10):1536-1552.

588. Vaingankar JA, Chong SA, Abdin E, et al. Psychiatric morbidity and its correlates among informal caregivers of older adults. *Compr Psychiatry* 2016;68:178-185.
589. Feast A, Moniz-Cook E, Stoner C, Charlesworth G, Orrell M. A systematic review of the relationship between behavioral and psychological symptoms (BPSD) and caregiver well-being. *Int Psychogeriatr* 2016;28(11):1761-1774.
590. Lin X, Moxley JH, Czaja SJ. Caring for Dementia Caregivers: Psychosocial Factors Related to Engagement in Self-Care Activities. *Behav Sci (Basel)* 2023 Oct 18;13(10):851.
591. Waligora KJ, Bahouth MN, Han HR. The Self-Care Needs and Behaviors of Dementia Informal Caregivers: A Systematic Review. *Gerontologist* 2019;59(5):e565-e583.
592. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA* 1999;282:2215-2260.
593. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003;129(6):946-972.
594. Liu W, Gallagher-Thompson D. Impact of dementia caregiving: Risks, strains, and growth. In: Qualls SH, Zarit SH, eds. *Aging families and caregiving*. Hoboken, NJ: John Wiley & Sons, Inc.; 2009: p. 85-112.
595. Pinquart M, Sorensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2003;58(2):112-128.
596. Sorensen S, Duberstein P, Gill D, Pinquart M. Dementia care: Mental health effects, intervention strategies, and clinical implications. *Lancet Neurol* 2006;5(11):961-973.
597. Goren A, Montgomery W, Kahle-Wroblewski K, Nakamura T, Ueda K. Impact of caring for persons with Alzheimer's disease or dementia on caregivers' health outcomes: Findings from a community based survey in Japan. *BMC Geriatr* 2016;16:122.
598. Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures. *Alzheimer Dement* 2016;12(4):459-509.
599. Jones RW, Lebec J, Kahle-Wroblewski K, et al. Disease progression in mild dementia due to Alzheimer disease in an 18-month observational study (GERAS): The impact on costs and caregiver outcomes. *Dement Geriatr Cogn Dis Extra* 2017;20(7(1)):87-100.
600. Leggett AN, Meyer OL, Bugajsky BC, Polenick CA. Accentuate the Positive: The association between informal and formal supports and caregiving gains. *J Appl Gerontol* 2021;40(7):763-771.
601. Quinn C, Toms G. Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *Gerontologist* 2019;59(5):e584-e596.
602. Zarit SH. Positive aspects of caregiving: More than looking on the bright side. *Aging Ment Health* 2012;16(6):673-674.
603. Cheng ST, Mak EP, Lau RW, Ng NS, Lam LC. Voices of Alzheimer caregivers on positive aspects of caregiving. *Gerontologist* 2016;56(3):451-460.
604. Monin JK, Schulz R, Feeney BC. Compassionate love in individuals with Alzheimer's disease and their spousal caregivers: Associations with caregivers' psychological health. *Gerontologist* 2015;55(6):981-989.
605. Roth DL, Dilworth-Anderson P, Huang J, Gross AL, Gitlin LN. Positive aspects of family caregiving for dementia: Differential item functioning by race. *J Gerontol B Psychol Sci Soc Sci* 2015;70(6):813-819.
606. Lloyd J, Patterson T, Muers J. The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London)* 2016;15(6):1534-1561.
607. Yu DSF, Cheng S-T, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *Int J Nurs Stud* 2018;79:1-26.
608. Cheng ST. Positive aspects of caregiving attenuate the relationship between behavioral bother and anxiety and depressive symptoms in dementia family caregivers. *Geriatr Gerontol Int* 2023;23(5):366-370.
609. Wennberg AM, Anderson LR, Cagnin A, Chen-Edinboro LP, Pini L. Howboth positive and burdensome caregiver experiences are associated with care recipient cognitive performance: Evidence from the National Health and Aging Trends Study and National Study of Caregiving. *Front Public Health* 2023;11:1130099.
610. van den Kieboom R, Snaphaan L, Mark R, Bongers I. The trajectory of caregiver burden and risk factors in dementia progression: A systematic review. *J Alzheimers Dis* 2020;77(3):1107-1115.
611. Polenick CA, Min L, Kales HC. Medical Comorbidities of dementia: Links to caregivers' emotional difficulties and gains. *J Am Geriatr Soc* 2020;68(3):609-613.
612. Sheehan OC, Haley WE, Howard VJ, Huang J, Rhodes JD, Roth DL. Stress, Burden, and Well-Being in Dementia and Nondementia Caregivers: Insights From the Caregiving Transitions Study. *Gerontologist* 2021;61(5):670-679.
613. Sallim AB, Sayampanathan AA, Cuttitan A, Chun-Man Ho R. Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. *J Am Med Dir Assoc* 2015;16(12):1034-1041.
614. Thunyadee C, Sitthimongkol Y, Sangon S, Chai-Aroon T, Hegadoren KM. Predictors of depressive symptoms and physical health in caregivers of individuals with schizophrenia. *J Nurs Health Sci* 2015;17:412-429.
615. Harris ML, Titler MG, Hoffman GJ. Associations between Alzheimer's disease and related dementias and depressive symptoms of partner caregivers. *J Appl Gerontol* 2021;40(7):772-780.
616. Vitaliano PP, Ustundag O, Borson S. Objective and subjective cognitive problems among caregivers and matched non-caregivers. *Gerontologist* 2017;57(4):637-647.
617. Dassel KB, Carr DC, Vitaliano P. Does caring for a spouse with dementia accelerate cognitive decline? Findings from the Health and Retirement Study. *Gerontologist* 2017;57(2):319-328.
618. Arthur PB, Gitlin LN, Kairalla JA, Mann WC. Relationship between the number of behavioral symptoms in dementia and caregiver distress: What is the tipping point? *Int Psychogeriatr* 2018;30(8):1099-1107.
619. Solimando L, Fasulo M, Cavallero S, Veronese N, Smith L, Vernuccio L. Suicide risk in caregivers of people with dementia: a systematic review and meta-analysis. *Aging Clin Exp Res* 2022;34(10):2255-2260.
620. Ivey-Stephenson AZ, Crosby AE, Hoening JM, Gyawali S, Park-Lee E, Hedden SL. Suicidal Thoughts and Behaviors Among Adults Aged ≥18 Years — United States, 2015–2019. *MMWR Surveill Summ* 2022;71(No. SS-1):1-19.
621. Gillespie R, Mullan J, Harrison L. Managing medications: The role of informal caregivers of older adults and people living with dementia: A review of the literature. *J Clin Nurs* 2014;23(23-24):3296-3308.
622. Alsaeed D, Jamieson E, Gul MO, Smith FJ. Challenges to optimal medicines use in people living with dementia and their caregivers: A literature review. *Int J Pharm* 2016;512(2):396-404.
623. Polenick CA, Stanz SD, Leggett AN, Maust DT, Hodgson NA, Kales HC. Stressors and resources related to medication management: Associations with spousal caregivers' role overload. *Gerontologist* 2020;60(1):165-173.
624. Aston L, Hilton A, Moutela T, Shaw R, Maidment I. Exploring the evidence base for how people with dementia and their informal carers manage their medication in the community: A mixed studies review. *BMC Geriatr* 2017;17(1):242.
625. Liu C, Fabius CD, Howard VJ, Haley WE, Roth DL. Change in Social Engagement among Incident Caregivers and Controls: Findings from the Caregiving Transitions Study. *J Aging Health* 2021;33(1-2):114-124.
626. Anderson JG, Jabson Tree JM, Flatt JD, Gross AL, Williams IC, Rose KM. A comparative analysis of family quality of life between heterosexual and sexual minority caregivers of people with dementia. *J Appl Gerontol* 2022;41(6):1576-1584.

627. Lee J, Baik S, Becker TD, Cheon JH. Themes describing social isolation in family caregivers of people living with dementia: A scoping review. *Dementia (London)* 2022;21(2):701-721.
628. Alhasan DM, Hirsch JA, Jackson CL, Miller MC, Cai B, Lohman MC. Neighborhood Characteristics and the Mental Health of Caregivers Cohabiting with Care Recipients Diagnosed with Alzheimer's Disease. *Int J Environ Res Public Health* 2021;18(3):913.
629. Vetter M, Donelan K, Guzikowski S, et al. The needs of family caregivers of persons living with dementia cared for in primary care practices. *J Eval Clin Pract* 2023;29(8):1243-1246.
630. Kramer BJ. Gain in the caregiving experience: Where are we? What next? *Gerontologist* 1997;37(2):218-232.
631. Burgdorf JG, Amjad H. Impact of diagnosed (vs undiagnosed) dementia on family caregiving experiences. *J Am Geriatr Soc* 2023;71(4):1236-1242.
632. Couch E, Belanger E, Gadbois EA, et al. "I know that my role is going to change": a mixed-methods study of the relationship between amyloid- β PET scan results and caregiver burden. *Aging Clin Exp Res* 2023;35(2):387-397.
633. Gaugler JE, Mittelman MS, Hepburn K, Newcomer R. Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. *BMC Medicine* 2010;8:85.
634. Mausbach BT, Chattillion EA, Ho J, et al. Why does placement of persons with Alzheimer's disease into long-term care improve caregivers' well-being? Examination of psychological mediators. *Psychol Aging* 2014;29(4):776-786.
635. Lee K, Chung J, Meyer KN, Dionne-Odom JN. Unmet needs and health-related quality of life of dementia family caregivers transitioning from home to long-term care: A scoping review. *Geriatr Nurs* 2022;43:254-264.
636. Peacock SC. The experience of providing end-of-life care to a relative with advanced dementia: An integrative literature review. *Palliat Support Care* 2013;11(2):155-168.
637. Schulz R, Mendelsohn AB, Haley WE, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med* 2003;349(20):1936-1942.
638. Kumar V, Ankuda CK, Aldridge MD, Husain M, Ornstein KA. Family Caregiving at the End of Life and Hospice Use: A national study of Medicare beneficiaries. *J Am Geriatr Soc* 2020;68(10):2288-2296.
639. Fonareva I, Oken BS. Physiological and functional consequences of caregiving for relatives with dementia. *Int Psychogeriatr* 2014;26(5):725-747.
640. Parker LJ, Fabius C, Rivers E, Taylor JL. Is Dementia-Specific Caregiving Compared With Non-Dementia Caregiving Associated With Physical Difficulty Among Caregivers for Community-Dwelling Adults? *J Appl Gerontol* 2022;41(4):1074-1080.
641. Peng H-L, Chang Y-P. Sleep disturbance in family caregivers of individuals with dementia: A review of the literature. *Perspect Psychiatr C* 2012;49(2):135-146.
642. Gao C, Chapagain NY, Scullin MK. Sleep Duration and Sleep Quality in caregivers of patients with dementia: A systematic review and meta-analysis. *JAMA Netw Open* 2019;2(8):e199891.
643. Liu Y, Song Y, Johnson FU, et al. Characteristics and predictors of sleep among spousal care dyads living with chronic conditions. *J Gerontol B Psychol Sci Soc Sci* 2023;78(Suppl 1):S38-S47.
644. Brewster GS, Wang D, McPhillips MV, Epps F, Yang I. Correlates of Sleep Disturbance Experienced by Informal Caregivers of Persons Living with Dementia: A Systematic Review. *Clin Gerontol* 2022;47(3):380-407.
645. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci* 2009;11(2):217-228.
646. von Kanel R, Mausbach BT, Dimsdale JE, et al. Refining caregiver vulnerability for clinical practice: Determinants of self-rated health in spousal dementia caregivers. *BMC Geriatr* 2019;19(1):18.
647. Dassel KB, Carr DC. Does dementia caregiving accelerate frailty? Findings from the Health and Retirement Study. *Gerontologist* 2016;56(3):444-450.
648. Fredman L, Bertrand RM, Martire LM, Hochberg M, Harris EL. Leisure-time exercise and overall physical activity in older women caregivers and non-caregivers from the Caregiver-SOF Study. *Prev Med* 2006;43:226-269.
649. Secinti E, Wu W, Kent EE, Demark-Wahnefried W, Lewson AB, Mosher CE. Examining Health Behaviors of Chronic Disease Caregivers in the U.S. *Am J PrevMed* 2022;62(3):e145-e158.
650. Beach SR, Schulz R, Yee JL, Jackson S. Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychol Aging* 2000;15(2):259-271.
651. von Kanel R, Mausbach BT, Dimsdale JE, et al. Effect of chronic dementia caregiving and major transitions in the caregiving situation on kidney function: A longitudinal study. *Psychosom Med* 2012;74(2):214-220.
652. Kiecolt-Glaser JK, Dura JR, Speicher CE, Trask OJ, Glaser R. Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosom Med* 1991;53:345-362.
653. Kiecolt-Glaser JK, Marucha PT, Mercado AM, Malarkey WB, Glaser R. Slowing of wound healing by psychological stress. *Lancet* 1995;346(8984):1194-1196.
654. Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, Siegler I. A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosom Med* 2002;64:418-435.
655. Mausbach BT, Romero-Moreno R, Bos T, et al. Engagement in pleasant leisure activities and blood pressure: A 5-year longitudinal study in Alzheimer caregivers. *Psychosom Med* 2017;79(7):735-741.
656. Shaw WS, Patterson TL, Ziegler MG, Dimsdale JE, Semple SJ, Grant I. Accelerated risk of hypertensive blood pressure recordings among Alzheimer caregivers. *J Psychosom Res* 1999;46(3):215-227.
657. Mausbach BT, Roepke SK, Ziegler MG, et al. Association between chronic caregiving stress and impaired endothelial function in the elderly. *J Am Coll Cardiol* 2010;55(23):2599-2606.
658. Allen AP, Curran EA, Duggan A, et al. A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neurosci Biobehav Rev* 2017;73:123-164.
659. Roth DL, Sheehan OC, Haley WE, Jenny NS, Cushman M, Walston JD. Is family caregiving associated with inflammation or compromised immunity? A meta-analysis. *Gerontologist* 2019;59(5):e521-e534.
660. Roth DL, Haley WE, Sheehan OC, et al. The transition to family caregiving and its effect on biomarkers of inflammation. *Proc Natl Acad Sci USA* 2020;117(28):16258-16263.
661. Meyer K, Gassoumis Z, Wilber K. The Differential Effects of Caregiving Intensity on Overnight Hospitalization. *West J Nurs Res* 2022;44(6):528-539.
662. Daddato AE, Gleason KS, Dollar BA, et al. Understanding Experiences of Caregivers of Spouses With Dementia During Caregiver Health Care Emergencies. *The Gerontologist*;64(7):gnad165.
663. Schubert CC, Boustani M, Callahan CM, Perkins AJ, Hui S, Hendrie HC. Acute care utilization by dementia caregivers within urban primary care practices. *J Gen Intern Med* 2008;23(11):1736-1740.
664. Zhu CW, Scarmeas N, Ornstein K, et al. Health-care use and cost in dementia caregivers: Longitudinal results from the Predictors Caregiver Study. *Alzheimers Dement* 2015;11(4):444-454.
665. Leggett AN, Sonnega AJ, Lohman MC. Till death do us part: Intersecting health and spousal dementia caregiving on caregiver mortality. *J Aging Health* 2020;32(7-8):871-879.

666. Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: A reappraisal from population-based studies. *Gerontologist* 2015;55(2):309-319.
667. Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. *N Engl J Med* 2006;354:719-730.
668. Perkins M, Howard VJ, Wadley VG, et al. Caregiving strain and all-cause mortality: Evidence from the REGARDS Study. *J Gerontol B Psychol Sci Soc Sci* 2013;68(4):504-512.
669. Gaugler JE, Jutkowitz E, Peterson CM, Zmora R. Caregivers dying before care recipients with dementia. *Alzheimers Dement (NY)* 2018;4:688-693.
670. Kelley AS, McGarry K, Bollens-Lund E, et al. Residential setting and the cumulative financial burden of dementia in the 7 years before death. *J Am Geriatr Soc* 2020;68(6):1319-1324.
671. AARP. Family Caregiving and Out-of-Pocket Costs: 2016 Report. Accessed December 15, 2024. Available at: https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/familycaregiving-costs-fact-sheet.doi.10.26419%252Fres.00138.002.pdf.
672. Albert SM. Are Medical Care Expenses Higher for Spouses Who Provide Dementia Care? *Am J Geriatr Psychiatry* 2021;29(5):476-477.
673. Chu J, Benjenk I, Chen J. Incremental Health Care Expenditures of the Spouses of Older Adults With Alzheimer's Diseases and Related Dementias (ADRD). *Am J Geriatr Psychiatry* 2021;29(5):462-472.
674. Stall NM, Kim SJ, Hardacre KA, et al. Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. *J Am Geriatr Soc* 2019;67(3):609-617.
675. Leggett AN, Koo HJ, Strominger J, Maust DT. Gatekeepers: The Association of Caregiving Network Characteristics With Emergency Department Use by Persons Living With Dementia. *J Gerontol B Psychol Sci Soc Sci* 2023;78(6):1073-1084.
676. Amjad H, Mulcahy J, Kasper JD, et al. Do caregiving factors affect hospitalization risk among disabled older adults? *J Am Geriatr Soc* 2021;69(1):129-139.
677. Sullivan SS, de Rosa C, Li CS, Chang YP. Dementia caregiver burdens predict overnight hospitalization and hospice utilization. *Palliat Support Care* 2022;1-15.
678. Liu R, Wyk BV, Quiñones AR, Allore HG. Longitudinal Care Network Changes and Associated Healthcare Utilization Among Care Recipients. *Res Aging* 2024 May-Jun;46(5-6):327-338.
679. Cheng S-K, Li K-K, Or PPL, Losada A. Do caregiver interventions improve outcomes in relatives with dementia and mild cognitive impairment? A comprehensive systematic review and meta-analysis. *Psychol Aging* 2022;37(8):929-953.
680. Gaugler JE, Jutkowitz E, Shippee TP, Brasure M. Consistency of dementia caregiver intervention classification: An evidence-based synthesis. *Int Psychogeriatr* 2017;29(1):19-30.
681. Gitlin LN, Hodgson N. Caregivers as therapeutic agents in dementia care: The evidence-base for interventions supporting their role. In: Gaugler JE, Kane RL, eds. *Family caregiving in the new normal*. Philadelphia, Pa.: Elsevier, Inc.; 2015: p. 305-356.
682. Liew TM, Lee CS. Reappraising the efficacy and acceptability of multicomponent interventions for caregiver depression in dementia: The utility of network meta-analysis. *Gerontologist* 2019;16;59(4):e380-e392.
683. Williams F, Moghaddam N, Ramsden S, De Boos D. Interventions for reducing levels of burden amongst informal carers of persons with dementia in the community. A systematic review and meta-analysis of randomised controlled trials. *Aging Ment Health* 2019;23(12):1629-1642.
684. Kaddour L, Kishita N, Schaller A. A meta-analysis of low-intensity cognitive behavioral therapy-based interventions for dementia caregivers. *Int Psychogeriatr* 2019;31(7):961-976.
685. Nguyen H, Terry D, Phan H, Vickers J, McInerney F. Communication training and its effects on carer and care-receiver outcomes in dementia settings: A systematic review. *J Clin Nurs* 2019;28(7-8):1050-1069.
686. Jutten LH, Mark RE, Wicherts JM, Sitskoorn MM. The effectiveness of psychosocial and behavioral interventions for informal dementia caregivers: Meta-analyses and meta-regressions. *J Alzheimers Dis* 2018;66(1):149-172.
687. Maslow K. Translating Innovation to Impact: Evidence-Based Interventions to Support People with Alzheimer's Disease and their Caregiver at Home and in the Community. Washington, D.C.: Administration on Aging; 2012. Accessed December 15, 2024 Available at: <https://www.agingresearch.org/app/uploads/2017/12/50820Compliant20AoA-White-Paper20for20Release.pdf>
688. Rosalynn Carter Institute for Caregiving. Accessed December 15, 2024. Available at: <https://www.rosalynncarter.org/>.
689. Larson EB, Stroud C. Meeting the Challenge of Caring for Persons Living With Dementia and Their Care Partners and Caregivers: A Report From the National Academies of Sciences, Engineering, and Medicine. *JAMA* 2021;325(18):1831-1832.
690. Cheng ST, Li KK, Or PPL, Losada A. Do caregiver interventions improve outcomes in relatives with dementia and mild cognitive impairment? A comprehensive systematic review and meta-analysis. *Psychol Aging* 2022;37(8):929-953.
691. Cheng S-T, Li K-K, Losada A, et al. The effectiveness of nonpharmacological interventions for informal dementia caregivers: An updated systematic review and meta-analysis. *Psychol Aging* 2020;35(1):55-77.
692. Walter E, Pinquart M. How Effective Are Dementia Caregiver Interventions? An Updated Comprehensive Meta-Analysis. *Gerontologist* 2020;60(8):609-619.
693. Gitlin LN, Jutkowitz E, Gaugler JE. Dementia caregiver intervention research now and into the future: Review and recommendations. Washington, D.C.: Commissioned paper for the National Academies of Science, Engineering and Medicine NIA Decadal Study. Accessed December 15, 2024. Available at: https://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_198208.pdf.
694. Lee M, Ryoo JH, Chung M, Anderson JG, Rose K, Williams IC. Effective interventions for depressive symptoms among caregivers of people with dementia: A systematic review and meta-analysis. *Dementia (London)* 2020;19(7):2368-2398.
695. Cheng S-T, Zhang F. A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers. *BMC Geriatr* 2020;20(1):137.
696. Perales-Puchalt J, Barton K, Ptomey L, et al. Effectiveness of "Reducing Disability in Alzheimer's Disease" Among Dyads With Moderate Dementia. *J Appl Gerontol* 2021;40(10):1163-1171.
697. Bass DM, Hornick T, Kunik M, et al. Findings from a real-world translation study of the evidence-based "Partners in Dementia Care". *Innov Aging* 2019;3(3):igz031.
698. Hodgson N, Gitlin LN (in press). Implementing and sustaining family care programs in real world settings: Barriers and facilitators. In J. E. Gaugler (Ed.), *Bridging the Family Care Gap*. Academic Press: San Diego, CA.
699. Fauth EB, Jackson MA, Walberg DK, et al. External validity of the New York University Caregiver Intervention: Key caregiver outcomes across multiple demonstration projects. *J Appl Gerontol* 2019;38(9):1253-1281.
700. Hodgson NA, Petrovsky DV, Finegan K, Kallmyer BA, Pike J, Fazio S. One call makes a difference: An evaluation of the Alzheimer's Association National Helpline on dementia caregiver outcomes. *Patient Educ Couns* 2021;104(4):896-902.
701. Reuben DB, Evertson LC, Jackson-Stoeckle R, Epstein-Lubow G, Spragens LH, Haggerty KL. Dissemination of a successful dementia care program: Lessons to facilitate spread of innovations. *J Am Geriatr Soc* 2022;70(9):2686-2694.
702. Gitlin LN, Roth DL, Marx K, et al. Embedding caregiver support within adult day services: Outcomes of a multi-site trial. *Gerontologist* 2024;64(4):gnad107.

703. Boustani M, Alder CA, Solid CA. Agile implementation: A blueprint for implementing evidence-based healthcare solutions. *J Am Geriatr Soc* 2018;66(7):1372-1376.
704. Boots LM, de Vugt ME, van Knippenberg RJ, Kempen GI, Verhey FR. A systematic review of internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psych* 2015;29(4):331-344.
705. Griffiths PC, Whitney MK, Kovaleva M, Hepburn K. Development and implementation of tele-savvy for dementia caregivers: A Department of Veterans Affairs Clinical Demonstration Project. *Gerontologist* 2016;56(1):145-154.
706. Gaugler JE, Zmora R, Mitchell LL, et al. Six-month effectiveness of remote activity monitoring for persons living with dementia and their family caregivers: An experimental mixed methods study. *Gerontologist* 2019;59(1):78-89.
707. Waller A, Dilworth S, Mansfield E, Sanson-Fisher R. Computer and telephone delivered interventions to support caregivers of people with dementia: A systematic review of research output and quality. *BMC Geriatr* 2017;17(1):265.
708. Hopwood J, Walker N, McDonagh L, et al. Internet-based interventions aimed at supporting family caregivers of people with dementia: Systematic review. *J Med Internet Res* 2018;20(6): e216.
709. Leng M, Zhao Y, Xiao H, Li C, Wang Z. Internet-based supportive interventions for family caregivers of people with dementia: Systematic review and meta-analysis. *J Med Internet Res* 2020;22(9):e19468.
710. Pleasant M, Molinari V, Dobbs C, Meng H, Hyer K. Effectiveness of online dementia caregivers training programs: A systematic review. *Geriatr Nurs* 2020;50197-4572(20):30209-30213.
711. Etxeberria I, Salaberria K, Gorostiaga A. Online support for family caregivers of people with dementia: a systematic review and meta-analysis of RCTs and quasi-experimental studies. *Aging Ment Health* 2021;25(7):1165-1180.
712. Saragih ID, Tonapa SI, Porta CM, Lee BO. Effects of telehealth intervention for people with dementia and their carers: A systematic review and meta-analysis of randomized controlled studies. *J Nurs Schol* 2022;54(6):704-719.
713. Fortinsky RH, Gitlin LN, Pizzi LT, et al. Effectiveness of the care of persons with dementia in their environments intervention when embedded in a publicly funded home-and community-based service program. *Innov Aging* 2020;4(6):igaa053.
714. Haggerty KL, Campetti R, Stoeckle RJ, Epstein-Lubow G, Evertson LC, Spragens L. Dissemination of a successful dementia care program: Lessons from early adopters. *J Am Geriatr Soc* 2022;70(9):2677-2685.
715. Maslow K, Bass DM, Rentsch JH. Update on the status of effective programs to help dementia family caregivers in the United States: Observations from the search for programs to include in Best Practice Caregiving. In Gaugler JE, ed. *Bridging the Family Care Gap*. Academic Press; 2021:247-302.
716. Gaugler JE, Potter T, Pruinelli L. Partnering with caregivers. *Clin Geriatr Med* 2014;30(3):493-515.
717. Gitlin LN, Marx K, Stanley IH, Hodgson N. Translating evidence-based dementia caregiving interventions into practice: State-of-the-science and next steps. *Gerontologist* 2015;55(2):210-226.
718. Wethington E, Burgio LD. Translational research on caregiving: Missing links in the translation process. In: Gaugler JE, Kane RL, eds. *Family caregiving in the new normal*. Philadelphia, Pa.: Elsevier, Inc; 2015: p. 193-210.
719. Zarit SH. Past is prologue: How to advance caregiver interventions. *Aging Ment Health* 2017;16:1-6.
720. Gonella S, Mitchell G, Bavelaar L, Conti A, Vanalli M, Basso I. Interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes: A mixed-methods systematic review. *Palliat Med* 2022;36(2):268-291.
721. Kishita N, Hammond L, Dietrich CM, Mioshi E. Which interventions work for dementia family carers?: an updated systematic review of randomized controlled trials of carer interventions. *Int Psychogeriatr* 2018;30(11):1679-1696.
722. Zarit SH, Lee JE, Barrineau MJ, Whitlatch CJ, Femia EE. Fidelity and acceptability of an adaptive intervention for caregivers: An exploratory study. *Aging Ment Health* 2013;17(2):197-206.
723. Van Mierlo LD, Meiland FJ, Van Hout HP, Drees RM. Toward an evidence-based implementation model and checklist for personalized dementia care in the community. *Int Psychogeriatr* 2016;28(5):801-813.
724. Gaugler JE, Reese M, Tanler R. Care to Plan: An online tool that offers tailored support to dementia caregivers. *Gerontologist* 2016;56(6):1161-1174.
725. Jennings LA, Ramirez KD, Hays RD, Wenger NS, Reuben DB. Personalized goal attainment in dementia care: Measuring what persons with dementia and their caregivers want. *J Am Geriatr Soc* 2018;66(11):2120-2127.
726. Whitlatch CJ, Orsulic-Jeras S. Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. *Gerontologist* 2018;58(suppl_1):S58-S73.
727. Akarsu NE, Prince MJ, Lawrence VC, Das-Munshi J. Depression in carers of people with dementia from a minority ethnic background: Systematic review and meta-analysis of randomised controlled trials of psychosocial interventions. *Int J Geriatr Psychiatry* 2019;34(6):790-806.
728. Llanque SM, Enriquez M. Interventions for Hispanic caregivers of patients with dementia: A review of the literature. *Am J Alzheimers Dis Other Demen* 2012;27(1):23-32.
729. Napoles AM, Chadiha L, Eversley R, Moreno-John G. Reviews: Developing culturally sensitive dementia caregiver interventions: Are we there yet? *Am J Alzheimers Dis Other Demen* 2010;25:389-406.
730. Luchsinger JA, Burgio L, Mittelman M, et al. Comparative effectiveness of 2 interventions for Hispanic caregivers of persons with dementia. *J Am Geriatr Soc* 2018;66(9): 1708-1715.
731. U.S. Department of Health and Human Services. National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers. Accessed December 15, 2024. Available at: <https://aspe.hhs.gov/national-research-summit-care-servicesand-supports-persons-dementia-and-their-caregivers>.
732. Young HM, Bell JF, Whitney RL, Ridberg RA, Reed SC, Vitaliano PP. Social determinants of health: Underreported heterogeneity in systematic reviews of caregiver interventions. *Gerontologist* 2020;60(Suppl 1):S14-S28.
733. Brewster GS, Epps F, Dye CE, Hepburn K, Higgins MK, Parker ML. The effect of the "Great Village" on psychological outcomes, burden, and mastery in African American caregivers of persons living with dementia. *J Appl Gerontol* 2020;39(10):1059-1068.
734. Demanes A, Ward KT, Wang AT, Hess M. Systematic Review of Dementia Support Programs with Multicultural and Multilingual Populations. *Geriatrics (Basel)* 2021;7(1):8.
735. Di Lorito C, Bosco A, Peel E, Hinchliff S, Dening T, Calasanti T. Are dementia services and support organisations meeting the needs of Lesbian, Gay, Bisexual and Transgender (LGBT) caregivers of LGBT people living with dementia? A scoping review of the literature. *Aging Ment Health* 2022;26(10): 1912-1921.
736. Kittle KR, Lee R, Pollock K, et al. Feasibility of the Savvy Caregiver Program for LGBTQ+ Caregivers of people living with Alzheimer's disease and related dementias. *Int J Environ Res Pub Health* 2022;19(22):15102.
737. Gaugler JE, Borson S, Epps F, Shih RA, Parker LJ, McGuire LC. The intersection of social determinants of health and family care of people living with Alzheimer's disease and related dementias: A public health opportunity. *Alzheimers Dement* 2023;19(12):5837-5846.
738. Gaugler JE. Unpaid dementia caregiving: a policy and public health imperative. *Public Policy Aging Rep* 2022;32(2): 51-57.
739. Alzheimer's Association. Alzheimer's Association Dementia Care Practice Recommendations. Accessed December 15, 2024. Available at: <https://www.alz.org/media/Documents/alzheimersdementia-care-practice-recommendations.pdf>.

740. Hennelly N, Cooney A, Houghton C, O'Shea E. Personhood and Dementia Care: A Qualitative Evidence Synthesis of the Perspectives of People With Dementia. *Gerontologist* 2021;61(3):e85-e100.
741. Camp CJ. Denial of human rights: We must change the paradigm of dementia care. *Clin Gerontol* 2019;42(3): 221-223.
742. Gaugler JE, Bain LJ, Mitchell L, et al. Reconsidering frameworks of Alzheimer's dementia when assessing psychosocial outcomes. *Alzheimers Dement (NY)* 2019;5: 388-397.
743. Burton A, Ogden M, Cooper C. Planning and enabling meaningful patient and public involvement in dementia research. *Curr Opin Psychiatry* 2019;32(6):557-562.
744. The Lewin Group. Process Evaluation of the Older Americans Act Title III-E-National Family Caregiver Support Program: Final Report, 2016. Accessed December 15, 2024. Available at: https://acl.gov/sites/default/files/programs/2017-02/NFCSP_Final_Report-update.pdf.
745. Stone RI. Factors affecting the future of family caregiving in the United States. In: JE Gaugler, RL Kane, eds. *Family Caregiving in the New Normal*. San Diego, CA: Elsevier, Inc; 2015: p. 57-77.
746. Gaugler JE. Supporting family care for older adults: Building a better bridge. In J. E. Gaugler (Ed.), *Bridging the Family Care Gap*. Academic Press; 2021: p. 427-452.
747. Greenberg NE, Wallick A, Brown LM. Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. *Psychol Trauma* 2020;12(S1):S220-S221.
748. Carbone EA, de Filippis R, Roberti R, Rania M, Destefano L, Russo E. The Mental Health of Caregivers and Their Patients With Dementia During the COVID-19 Pandemic: A Systematic Review. *Front Psychol* 2021;12:782833.
749. Gaigher JM, Lacerda IB, Dourado MCN. Dementia and Mental Health During the COVID-19 Pandemic: A Systematic Review. *Front Psychiatry* 2022;13:879598.
750. Oliver S, Alexander K, Bennett SG, Hepburn K, Henry J, Clevenger CK. Experiences of Black American Dementia Caregivers During the COVID-19 Pandemic. *J Fam Nurs* 2022;28(3):195-204.
751. Perales-Puchalt J, Peltzer J, Fracachan-Cabrera M, Perez A, Ramirez-Mantilla M, Greiner KA. Impact of the COVID-19 pandemic on Latino families with Alzheimer's disease and related dementias: Perceptions of family caregivers and primary care providers. *medRxiv* 2022;2022.05.25.22275517.
752. Masoud S, Glassner AA, Mendoza M, Rhodes S, White CL. "A Different Way to Survive": The Experiences of Family Caregivers of Persons Living With Dementia During the COVID-19 Pandemic. *J Fam Nurs* 2022;28(3):243-257.
753. Turner RL, Reese-Melancon C, Harrington EE, Andreo M. Caregiving during the COVID-19 pandemic: Factors associated with feelings of caregiver preparedness. *J Appl Gerontol* 2023;42(10):2089-2099.
754. Humber MB, Yefimova M, Lessios AS, Trivedi RB, Sheffrin M, Martin M. "It isn't the same": Experiences of informal caregivers of older adults enrolled in a home-based senior care program during COVID-19. *J Gerontol Nurs* 2023;49(3):19-26.
755. Shrestha P, Fick DM, Boltz M, Loeb SJ, High AC. Caregiving for persons living with dementia during the COVID-19 pandemic: Perspectives of family care partners. *J Gerontol Nurs* 2023;49(3):27-33.
756. Arthur P, Li CY, Southern Indiana Dementia Workgroup. Living with dementia during the COVID-19 pandemic: A nationwide survey informing the American experience. *J Alzheimers Dis Rep* 2022;6(1):733-737.
757. Chyu J, Cantu P, Mehta N, Markides K. Caregiving for people with dementia or cognitive impairment during the COVID-19 pandemic: A review. *Gerontol Geriatr Med* 2022;8:23337214221132369.
758. Friedman EM, Kirkegaard A, Kennedy DP, Edgington S, Shih RA. Change in Caregiving to Older Adults During the COVID-19 Pandemic: Differences by Dementia Status. *J Appl Gerontol* 2023;42(12):2277-2282.
759. Macchi ZA, Ayele R, Dini M, et al. Lessons from the COVID-19 pandemic for improving outpatient neuro-palliative care: A qualitative study of patient and caregiver perspectives. *Palliat Med* 2021;35(7):1258-1266.
760. Hwang Y, Connell LM, Rajpara AR, Hodgson NA. Impact of COVID-19 on Dementia Caregivers and Factors Associated With their Anxiety Symptoms. *Am J Alzheimers Dis Other Demen* 2021;36:15333175211008768.
761. Savla J, Roberto KA, Bliesner R, McCann BR, Hoyt E, Knight AL. Dementia caregiving during the "stay-at-home" phase of COVID-19 pandemic. *J Gerontol B Psychol Sci Soc Sci* 2021;76(4):e241-e245.
762. Kusmaul N, Miller VJ, Cheon JH. "They Just Took Him Out of My Life": Nursing Home Care Partner Experiences During the COVID-19 Pandemic. *J Gerontol Nurs* 2022;48(2):7-11.
763. Mitchell LL, Albers EA, Birkeland RW, et al. Caring for a relative with dementia in long-term care during COVID-19. *J Am Med Dir Assoc* 2022;23(3):428-433.e1.
764. Yan K, Sadler T, Brauner D, Pollack HA, Konetzka RT. Caregiving for older adults with dementia during the time of COVID-19: A multi-state exploratory qualitative study. *J Appl Gerontol* 2023;42(10):2078-2088.
765. Brungardt A, Cassidy J, LaRoche A, et al. End-of-Life Experiences Within a Dementia Support Program During COVID-19: Context and Circumstances Surrounding Death During the Pandemic. *Am J Hosp Palliat Care* 2023;40(7): 778-783.
766. Hunt JFV, Le Caire TJ, Schroeder M, O'Toole Smith K, Marschall K, Walaszek A. The use of health care and community-based services by people living with dementia and their caregivers during the COVID-19 pandemic. *WMJ* 2022;121(3):226-230.
767. Gaugler JE. Our vast family care system for the elderly is at risk of collapse. Accessed December 15, 2024. Available at: <https://www.startribune.com/our-vast-family-care-system-forthe-elderly-is-about-to-collapse/572221182/>.
768. Lloyd SL, Caban-Holt A, Starks TD, Clark JC, Byrd GS. Assessing gender differences on the impact of COVID-19 on the medical and social needs of dementia caregivers. *J Gerontol Soc Work* 2024;67(2):207-222.
769. Sadarangani T, Zhong J, Vora P, Missaïlides L. "Advocating Every Single Day" so as Not to be Forgotten: Factors Supporting Resiliency in Adult Day Service Centers Amidst COVID-19-Related Closures. *J Gerontol Soc Work* 2021;64(3):291-302.
770. Gaugler JE, Marx K, Dabelko-Schoeny H, et al. COVID-19 and the Need for Adult Day Services. *J Am Med Dir Assoc* 2021;22(7):1333-1337.
771. Monin JK, Ali T, Syed S, et al. Family communication in long-term care during a pandemic: Lessons for enhancing emotional experiences. *Am J Geriatr Psychiatry* 2020;S1064-7481(20):30478-30484.
772. Pickering CEZ, Maxwell CD, Yefimova M, Wang D, Puga F, Sullivan T. Early Stages of COVID-19 Pandemic Had No Discernable Impact on Risk of Elder Abuse and Neglect Among Dementia Family Caregivers: A Daily Diary Study. *J Fam Violence* 2022;5:1-11.
773. Albers EA, Mikal J, Millenbah A, Finlay J, Jutkowitz E, Mitchell L. The Use of Technology Among Persons With Memory Concerns and Their Caregivers in the United States During the COVID-19 Pandemic: Qualitative Study. *JMIR Aging* 2022;5(1):e31552.
774. Yoon SO, Paek EJ. Video call usage in older adults with or without dementia impacted by the COVID-19 pandemic. *Am J Alzheimers Dis Other Demen* 2023;38:15333175231160679.
775. O'Connor MK, Nicholson R, Epstein C, et al. Telehealth support for dementia caregivers during the COVID-19 pandemic: Lessons learned from the NYU family support program. *Am J Geriatr Psychiatry* 2023;31(1):14-21.

776. Nkodo J-A, Gana W, Debaq C, et al. The Role of Telemedicine in the Management of the Behavioral and Psychological Symptoms of Dementia: A Systematic Review. *Am J Geriatr Psychiatry* 2022;30(10):1135-1150.
777. Liang J, Aranda MP. The use of telehealth among people living with dementia-caregiver dyads during the COVID-19 pandemic: Scoping review. *J Med Internet Res* 2023;25:e45045.
778. Perales-Puchalt J, Peltzer J, Fracachan-Cabrera M, et al. Impact of the COVID-19 Pandemic on Latino Families With Alzheimer Disease and Related Dementias: Qualitative Interviews With Family Caregivers and Primary Care Providers. *JMIRx Med* 2024;5:e42211.
779. National Institute on Aging. NIA COVID-19 Response. Accessed December 4, 2024. Available at: <https://www.nia.nih.gov/research/grants-funding/nia-covid-19-response>.
780. Weems JA, Rhodes S, Powers JS. Dementia Caregiver Virtual Support-An Implementation Evaluation of Two Pragmatic Models during COVID-19. *Geriatrics (Basel)* 2021;6(3):80.
781. Masoud SS, Meyer KN, Sweet LM, Prado PJ, White CL. "We Don't Feel so Alone": A Qualitative Study of Virtual Memory Cafes to Support Social Connectedness Among Individuals Living With Dementia and Care Partners During COVID-19. *Front Public Health* 2021;9:660144.
782. Administration for Community Living. 2022 National Strategy to Support Family Caregivers. Accessed December 15, 2024. Available at: https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf.
783. Administration for Community Living. Progress Report: Federal Implementation of the 2022 National Strategy to Support Family Caregivers. Accessed November 10, 2024. Available at: https://acl.gov/sites/default/files/2024ProgressReport_StrategyToSupportCaregivers.pdf.
784. U.S. Centers for Medicare & Medicaid Services. Guiding an Improved Dementia Experience (GUIDE) Model. Accessed December 4, 2024. Available at: <https://www.cms.gov/priorities/innovation/innovation-models/guide>.
785. American Public Health Association. Strengthening the dementia care workforce: A public health priority 2020. Accessed December 22, 2024. Available at: <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2021/01/13/strengthening-the-dementia-care-workforce>.
786. Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative. State and Local Public Health Partnerships to Address Dementia: The 2018–2023 Road Map. Chicago, IL: Alzheimer's Association; 2018.
787. Sideman AB, Ma M, Hernandez de Jesus A, et al. Primary Care Practitioner Perspectives on the Role of Primary Care in Dementia Diagnosis and Care. *JAMA Netw Open* 2023;6(9):e2336030.
788. de Levante Raphael D. The Knowledge and Attitudes of Primary Care and the Barriers to Early Detection and Diagnosis of Alzheimer's Disease. *Medicina (Kaunas)* 2022;58(7):906.
789. HealthCare.gov. Primary Care Provider. Accessed November 10, 2024. Available at: <https://www.healthcare.gov/glossary/primary-care-provider/>.
790. Bernstein A, Rogers KM, Possin KL, et al. Dementia assessment and management in primary care settings: A survey of current provider practices in the United States. *BMC Health Serv Res* 2019;19: 919.
791. Liss JL, Seleri Assuncao S, Cummings J, et al. Practical recommendations for timely, accurate diagnosis of symptomatic Alzheimer's disease (MCI and dementia) in primary care: a review and synthesis. *J Intern Med* 2021;290(2):310-334.
792. Owens DK, Davidson KW, Krist AH, et al. Screening for cognitive impairment in older adults: US Preventive Services Task Force Recommendation Statement. *JAMA* 2020;323: 757-763.
793. Cordell CB, Borson S, Boustani M, et al. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimers Dement* 2013;9:141-150.
794. Galvin JE, Sadowsky CH. Practical guidelines for the recognition and diagnosis of dementia. *J Am Board Fam Med* 2012;25:367-382.
795. Centers for Medicare & Medicaid Services. Cognitive Assessment & Care Plan Services. Accessed December 18, 2024. Available at: <https://www.cms.gov/medicare/payment/fee-schedules/physician/cognitive-assessment>.
796. Medicare.gov. Cognitive Assessment & Care Plan Services. Accessed December 15, 2024. Available at: <https://www.medicare.gov/coverage/cognitive-assessment-care-plan-services>
797. U.S. Government Accountability Office. Medicare Cognitive Assessments: Utilization Tripled between 2018 and 2022, but Challenges Remain. December 11, 2023. Accessed December 17, 2024. Available at: <https://www.gao.gov/products/gao-24-106328>.
798. Hinton L, Franz CE, Reddy G, Flores Y, Kravitz RL, Barker JC. Practice constraints, behavioral problems, and dementia care: Primary care physicians' perspectives. *J Gen Intern Med* 2007;22:1487-1492.
799. Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and delayed diagnosis of dementia in primary care. *Alzheimer Dis Assoc Disord* 2009;23:306-314.
800. Tsoy E, Kiekhof RE, Guterma EL, et al. Assessment of racial/ethnic disparities in timeliness and comprehensiveness of dementia diagnosis in California. *JAMA Neurol* 2021;6: 657-665.
801. Lee SA, Kim D, Lee H. Examine Race/Ethnicity Disparities in Perception, Intention, and Screening of Dementia in a Community Setting: Scoping Review. *Int J Environ Res Pub Health* 2022;19(14): 8865.
802. Davis MA, Lee KA, Harris M, et al. Time to dementia diagnosis by race: A retrospective cohort study. *JAGS* 2022;70(11):3250-3259.
803. Bernstein A, Rogers KM, Possin KL, et al. Primary care provider attitudes and practices evaluating and managing patients with neurocognitive disorders. *J Gen Intern Med* 2019;34:1691-1692.
804. 2020 Alzheimer's disease facts and figures. *Alzheimers Dement* 2020;doi:10.1002/alz.12068.
805. Sideman AB, Harrison KL, Garrett SB, Paladino J, Naasan G, Ritchie CS. Dementia specialty care clinicians' perspectives on their role in the dementia diagnostic process and diagnostic disclosure. *J Geriatr Psychiatry Neurol* 2025;38(1):3-12.
806. Drabo EF, Barthold D, Joyce G, Ferido P, Chui HC, Zissimopoulos J. Longitudinal analysis of dementia diagnosis and specialty care among racially diverse Medicare beneficiaries. *Alzheimers Dement* 2019;15:1402-1411.
807. American Geriatrics Society. (n.d.) State of the geriatric workforce. Geriatrics workforce by the numbers. Accessed December 20, 2024. Available at: <https://www.americangeriatrics.org/geriatrics-profession/about-geriatrics/geriatrics-workforce-numbers>.
808. Foley KT, Luz CC. Retooling the Health Care Workforce for an Aging America: A Current Perspective. *Gerontologist* 2021;61(4):487-496.
809. Fried LP, Hall WJ. Editorial: Leading on behalf of an aging society. *J Am Geriatr Soc* 2008;56(10):1791-1795.
810. Callahan CM, Weiner M, Counsell SR. Defining the domain of geriatric medicine in an urban public health system affiliated with an academic medical center. *J Am Geriatr Soc* 2008;56(10):1802-1806.
811. Warshaw GA, Bragg EJ, Fried LP, Hall WJ. Which patients benefit the most from a geriatrician's care? Consensus among directors of geriatrics academic programs. *J Am Geriatr Soc* 2008;56(10):1796-1801.

812. U.S. Census Bureau. Older Americans Month: May 2023 [Press release]. May 2023. Accessed December 16, 2024. Available at: <https://www.census.gov/newsroom/stories/older-americans-month.html>.
813. American Geriatrics Society. Current number of board certified geriatricians by state 2022. Accessed December 20, 2024. Available at: <https://www.americangeriatrics.org/sites/default/files/inline-files/Current%20Number%20of%20Board%20Certified%20Geriatricians%20by%20State%20%28July%202022%29.pdf>.
814. Farrell TW, Korniyenko A, Hu G, Fulmer T. Geriatric medicine is advancing, not declining: A proposal for new metrics to assess the health of the profession. *J Am Geriatr Soc* 2025;73(1):323-328.
815. U.S. Department of Health and Human Services, Health Resources and Services Administration, National Center for Health Workforce Analysis. Workforce Projections Dashboard. Accessed December 18, 2024. Available at: <https://data.hrsa.gov/topics/health-workforce/workforce-projections>
816. University of Virginia, Weldon Cooper Center for Public Service. National 50+ state population projections: 2030, 2040, 2050. Accessed December 17, 2024. Available at: <https://coopercenter.org/national-population-projections>.
817. Andrilla CHA, Patterson DG, Garberson LA, Coulthard C, Larson EH. Geographic variation in the supply of selected behavioral health providers. *Am J PrevMed* 2018;54(6, Suppl 3):S199-S207.
818. Douthit N, Kiv S, Dwolatzky T, Biswas S. Exposing some important barriers to health care access in the rural USA. *Pub health* 2015;129(6):611-620.
819. Xue Y, Poghosyan L, Lin Q. Supply and Geographic Distribution of Geriatric Physicians and Geriatric Nurse Practitioners. *JAMA Netw Open* 2024;7(11):e2444659.
820. Neprash HT, Everhart A, McAlpine D, Smith LB, Sheridan B, Cross DA. Measuring primary care exam length using electronic health record data. *Med care* 2021;59(1):62-66.
821. National Resident Matching Program. Results and Data: Specialties Matching Service. Washington, DC. 2023. Accessed December 17, 2024. Available at: <https://www.nrmp.org/wp-content/uploads/2023/04/2023-SMS-Results-and-Data-Book.pdf>.
822. U.S. Department of Health and Human Services, Health Resources and Services Administration, National Center for Health Workforce Analysis. Physician Workforce Projections: 2022-2037. Accessed December 18, 2024. Available at: <https://bhw.hrsa.gov/sites/default/files/bureau-health-workforce/data-research/physicians-projections-factsheet.pdf>.
823. American Board of Psychiatry and Neurology. Certifications by Year - Subspecialties. Accessed December 15, 2024. Available at: <https://www.abpn.org/wp-content/uploads/2023/03/Certifications-by-Year-Subspecialties-2022.pdf>.
824. Juul D, Colenda CC, Lyness JM, Dunn LB, Hargrave R, Faulkner LR. Subspecialty training and certification in geriatric psychiatry: a 25-year overview. *Am Journal Geriatr Psych* 2017;25(5):445-453.
825. Liu JL, Baker L, Chen A, Wang J. Geographic variation in shortfalls of dementia specialists in the United States. *Health Aff Scholar*;2(7):qxae088.
826. Majersik JJ, Ahmed A, Chen IH, et al. A Shortage of Neurologists— We Must Act Now: A Report From the AAN 2019 Transforming Leaders Program. *Neurology* 2021;96(24):1122-1134.
827. Warsaw GA, Bragg EJ. Preparing the health care workforce to care for adults with Alzheimer's disease and related dementias. *Health Aff* 2014;33(4):633-641.
828. Kozikowski A, Honda T, Segal-Gidan F, Hooker RS. Physician assistants in geriatric medical care. *BMC Geriatr* 2020;20(1):1-8.
829. Poghosyan L, Brooks JM, Hovsepian V, Pollifrone M, Schlak AE, Sadak T. The growing primary care nurse practitioner workforce: A solution for the aging population living with dementia. *Am J Geriatr Psychiatry* 2021;29(6):517-526.
830. Auerbach DI, Buerhaus PI, Staiger DO. Implications of the rapid growth of the nurse practitioner workforce in the US: An examination of recent changes in demographic, employment, and earnings characteristics of nurse practitioners and the implications of those changes. *Health Aff* 2020;39(2):273-279.
831. American Association of Nurse Practitioners. Nurse Practitioners are the Providers of Choice for Millions of Americans. Accessed December 17, 2024. Available at: https://storage.aanp.org/www/documents/NP_Infographic_111122.pdf
832. The Social Work Profession: Findings from Three Years of Surveys of New Social Workers. Accessed December 15, 2024. Available at: <https://www.cswe.org/CSWE/media/Workforce-Study/The-Social-Work-Profession-Findings-from-Three-Years-of-Surveys-of-New-Social-Workers-Dec-2020.pdf>.
833. Cummings S, Galambos C. Predictors of graduate social work students' interest in aging-related work. *Journal of Gerontol Soc Work* 2002;39(3):77-94.
834. Cummings S, Adler G, DeCoster V. Factors influencing graduate social-work students' interest in working with elders. *Educational Gerontology* 2005;31(8):643-655.
835. Curl A, Simons K, Larkin H. Factors affecting willingness of social work students to accept jobs in aging. *J Soc Work Education* 2005;41(3):393-406.
836. Kolb P. Interest of racially and ethnically diverse social work students in gerontological social work. *Educational Gerontol* 2008;34(10):907-922.
837. Ferguson A. Wanted: Gerontological social workers — Factors related to interest in the field. *Educational Gerontology* 2012;38(10):713-728.
838. Ferguson A. The future of gerontological social work: what we know and what we don't know about student interest in the field. *J Evid Inf Soc Work* 2015;12(2):184-197.
839. Scales K, Wagner LM. Direct care workers are the foundation of a dementia-capable workforce. *Generations* 2023;47(1):1-9.
840. PHI. Direct Care Workers in the United States: Key Facts. New York, NY: PHI 2024. Accessed January 16, 2025. Available at: <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2024/>.
841. Campbell S, Drake ADR, Espinoza R, Scales K. Caring for the Future: The Power and Potential of America's Direct Care Workforce. Bronx, NY: PHI; 2021. <https://www.phinational.org/resource/caring-for-the-future-the-power-and-potential-of-americas-direct-care-workforce/>.
842. Reckrey JM, Tsui EK, Morrison RS, et al. Beyond functional support: the range of health-related tasks performed in the home by paid caregivers in New York. *Health Aff (Project Hope)* 2019;38(6):927-933.
843. Lyons TL, Champion JD. Nonpharmacological interventions for management of behavioral and psychological symptoms of dementia in long-term care facilities by direct caregivers: A systematic review. *J Gerontol Nurs* 2022;48(7):18-23.
844. Eaton J, Cloyes KG, Paulsen B, Madden C, Ellington L. The development of knowledgeable nursing assistants as creative caregivers (KNACC). *Geriatr Nurs* 2023;51:95-101.
845. Kemp CL, Bender AA, Morgan JC, Burgess EO, Epps FR, Hill AM, Perkins MM. Understanding capacity and optimizing meaningful engagement among persons living with dementia. *Dementia* 2023;22(4):854-874.
846. Dokos M, Schultz R, Gossner JD, Fauth EB. Supporting persons with dementia: perspectives from certified nurse's assistants. *Innov Aging* 2023;7(5):igad049.
847. Toot S, Swinson T, Devine M, Challis D, Orrell M. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *Int Psychogeriatr* 2017;29(2):195-208.

848. Carnahan JL, Slaven JE, Callahan CM, Tu W, Torke AM. Transitions From Skilled Nursing Facility to Home: The Relationship of Early Outpatient Care to Hospital Readmission. *J Am Med Dir Assoc* 2017;18(10):853-859.
849. Feltner C, Jones CD, Cene CW, et al. Transitional care interventions to prevent readmissions for persons with heart failure: a systematic review and meta-analysis. *Ann Intern Med* 2014;160(11):774-784.
850. Murtaugh CM, Deb P, Zhu C, et al. Reducing Readmissions among Heart Failure Patients Discharged to Home Health Care: Effectiveness of Early and Intensive Nursing Services and Early Physician Follow-Up. *Health Serv Res* 2017;52(4):1445-1472.
851. Guo W, Cai S, Caprio T, Schwartz L, Temkin-Greener H. End-of-Life Care transitions in assisted living: associations with state staffing and training regulations. *J Am Med Dir Assoc* 2023;24(6):827-832.
852. Shepherd H, Livingston G, Chan J, Sommerlad A. Hospitalisation rates and predictors in people with dementia: a systematic review and meta-analysis. *BMC Med* 2019;17(1):1-13.
853. LaMantia MA, Stump TE, Messina FC, Miller DK, Callahan CM. Emergency department use among older adults with dementia. *Alzheimer Dis Assoc* 2016;30(1):35-40.
854. National Institute on Aging. Gaps in the Dementia Care Workforce: Research Update and Data Needs. Committee on Population (CPOP) Semi-Annual Meeting, May 23, 2019. Accessed December 15, 2024. Available at: <https://www.nia.nih.gov/sites/default/files/2019-11/Seminar-Gaps-Dementia-Workforce-Final-508.pdf>.
855. Yoon JM, Trinkoff AM, Kim M, Kim E. State-level nursing home in-service dementia training requirements and inappropriate psychotropic medication use. *Geriatr Nursing* 2023;51:209-214.
856. Centers for Medicare & Medicaid Services (CMS). Long-term services and supports rebalancing toolkit. Accessed December 15, 2024. Available at: <https://www.medicare.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-toolkit.pdf>.
857. Shih RA, Friedman EM, Chen EK, Whiting GC. Prevalence and correlates of gray market use for aging and dementia long-term care in the US. *J Appl Gerontol* 2022; 41(4):1030-1034.
858. Donlan A. After 3-Year Dip, Home Care Turnover Soars to 77%. *Home Health Care News*, May 24, 2023. Accessed September 18, 2024. Available at: <https://homehealthcarenews.com/2023/05/after-dipping-for-three-years-home-care-turnover-rate-soared-to-77-in-2022/>.
859. Gandhi A, Yu H, Grabowski DC. High nursing staff turnover in nursing homes offers important quality information. *Health Aff* 2021;40(3):384-391.
860. Institute of Medicine. Committee on the Future Health Care Workforce for Older Americans. Retooling for an Aging America: Building the Health Care Workforce. Washington (DC): National Academies Press (US); 2008.
861. Trinkoff AM, Han K, Storr CL, Lerner N, Johantgen M, Gartrell K. Turnover, staffing, skill mix, and resident outcomes in a national sample of US nursing homes. *J Nurs Adm* 2013;43(12):630-636.
862. Scales K. Transforming direct care jobs, reimagining long-term services and supports. *J Am Med Dir Assoc* 2022;23(2): 207-213.
863. Weller C, Almeida B, Cohen M, Stone R. Making Care Work Pay. Accessed December 15, 2024. Available at: <https://www.ltsscenter.org/wp-content/uploads/2020/09/Making-Care-Work-Pay-Report-FINAL.pdf>.
864. Reckrey JM, Perez S, Watman D, Ornstein KA, Russell D, Franzosa E. The need for stability in paid dementia care: family caregiver perspectives. *J Appl Gerontol* 2023;42(4):607-616.
865. Manchha AV, Walker N, Way KA, Dawson D, Tann K, Thai M. Deeply discrediting: A systematic review examining the conceptualizations and consequences of the stigma of working in aged care. *Gerontologist* 2021;61(4):e129-e146.
866. Khavjou O, Suarez G, Tyler D, Squillace M, Dey J, Oliveira I. Wages of direct care workers lower than other entry-level jobs in most states (Issue brief). Washington, DC: Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services. Accessed September 18, 2024. Available at: <https://aspe.hhs.gov/sites/default/files/documents/7a611d901c615e5611ea095b1dcf8d08/wages-dcw-lower-ib.pdf>.
867. Burke G, Orlowski G. Training to serve people with dementia: is our health care system ready? Accessed December 15, 2024. Available at: https://www.justiceinaging.org/wp-content/uploads/2015/08/Training-to-serve-people-with-dementia-Alz1_Final.pdf.
868. U.S. Bureau of Labor Statistics (BLS). Occupational injuries and illnesses and fatal injuries profiles. Accessed December 15, 2024. Available at: <https://www.bls.gov/iif/>.
869. Paraprofessional Healthcare Institute (PHI). Workplace Injuries and the Direct Care Workforce. Accessed December 15, 2024. Available at: <https://phinational.org/resource/workplace-injuriesdirect-care-workforce>.
870. Quinn MM, Markkanen PK, Galligan CJ, Sama SR, Lindberg JE, Edwards MF. Healthy aging requires a healthy home care workforce: the occupational safety and health of home care aides. *Curr Environ Health Rep* 2021;8(3):235-244.
871. Bonner A, Walsh A, Shue J, Morton G, Fulmer T. (2023). Generations: Dementia-Friendly Initiatives for Individuals Living with Dementia, Care Partners, and Communities. Accessed October 28, 2024. Available at: <https://generations.asaging.org/dementiafriendly-initiatives>.
872. Hebert CA, Scales K. Dementia friendly initiatives: A state of the science review. *Dementia* 2019;18(5):1858-1895.
873. Alzheimer's Disease International. Dementia Friendly Communities: Global Developments. 2016. Accessed December 15, 2024. Available at: <https://www.alzint.org/u/dfc-developments.pdf>.
874. The White House. Fact sheet: The White House Conference on Aging. Accessed December 17, 2024. Available at: <https://obamawhitehouse.archives.gov/the-press-office/2015/07/13/fact-sheet-white-house-conference-aging>.
875. ACT on Alzheimer's. About ACT on Alzheimer's. Accessed December 17, 2024. Available at: <https://actonalz.org/about>
876. Cherry DL. HCBS can keep people with dementia at home. *Generations* 2012;36(1) 83-90.
877. Dickey TJ. "Public Libraries' Contribution to Sustainable Dementia-Friendly Communities". Williams-Cockfield, KC. and Mehra, B. (Ed.) *How Public Libraries Build Sustainable Communities in the 21st Century (Advances in Librarianship, Vol. 53)*, Emerald Publishing Limited, Bingley, 2023. pp. 283-292.
878. van Buuren LPG, Mohammadi M. Dementia-friendly design: A Set of design criteria and design typologies supporting wayfinding. *HERD* 2022;15(1):150-172.
879. Devos P, Aletta F, Thomas P, et al. Designing supportive soundscapes for nursing home residents with dementia. *Int J Environ Res Public Health* 2019;16(24):4904.
880. Anetzberger GJ, Palmisano BR, Sanders M, Bass D, Dayton C, Eckert S, Schimer MR. A model intervention for elder abuse and dementia. *Gerontologist* 2000;40(4):492-497.
881. Dong XQ, Chen R, Simon MA. Elder abuse and dementia: A review of the research and health policy. *Health Aff (Millwood)* 2014;33(4):642-649.
882. Sun F, Gao X, Brown H, Winfree LT. Police officer competence in handling Alzheimer's cases: The roles of AD knowledge, beliefs, and exposure. *Dementia* 2019;18(2):674-684.
883. Brown RT, Ahalt C, Rivera J, Stijacic C, Zenger I, Wilhelm A, Williams BA. Good cop, bad cop: Evaluation of a geriatrics training program for police. *J Am Geriatr Soc* 2017;65(8):1842-1847.
884. Anderson KA, Cimbali AM, Maile JJ. Hairstylists' relationships and helping behaviors with older adult clients. *J Appl Gerontol* 2010;29(3):371-380.

885. Che SL, Wu J, Chuang Y-C, Van IK, Leong SM. The willingness to help people with dementia symptoms among four occupation practitioners in Macao. *Am J Alzheimers Dis Other Demen* 2022;37:15333175221139172.
886. Alam RB, Ashrafi SA, Pionke JJ, Schwingel A. Role of Community Health Workers in Addressing Dementia: A Scoping Review and Global Perspective. *J Appl Gerontol* 2021;40(12):1881-1892.
887. Sawyer RJ. The growing challenge of dementia care. *NEJM Catal Innov Care Deliv* 2021;2(9):doi: 10.1056/CAT.21.0285.
888. Kern LM, Bynum JPW, Pincus HA. Care fragmentation, care continuity, and care coordination: how they differ and why it matters. *JAMA Intern Med* 2024; 184(3): 236-237.
889. Amjad H, Carmichael D, Austin AM, Chang CH, Bynum JP. Continuity of care and health care utilization in older adults with dementia in fee-for-service Medicare. *JAMA Intern Med* 2016; 176(9): 1371-1378.
890. Timmins L, Kern LM, O'Malley AS, Urato C, Ghosh A, Rich E. Communication gaps persist between primary care and specialist physicians. *Ann Fam Med* 2022; 20(4): 343-347.
891. Institute for Healthcare Improvement. Americans' experiences with medical errors and views on patient safety. https://www.ihl.org/sites/default/files/2023-09/IHI_NPSF_Patient_Safety_Survey_Fact_Sheets_2017.pdf.
892. Sundwall DN, Munger MA, Tak CR, Walsh M, Feehan M. Lifetime prevalence and correlates of patient-perceived medical errors experienced in the U.S. ambulatory setting: a population-based study. *Health Equity* 2020; 4(1): 430-437.
893. Kern LM, Riffin C, Phongtankuel V, Aucapina JE, Banerjee S, Ringel JB, Tobin JN, Fisseha S, Meiri H, Bell SK, Casale PN. Gaps in the coordination of care for people living with dementia. *J Am Geriatr Soc* 2024;72(10):3119-3128.
894. Heintz H, Monette P, Epstein-Lubow G, Smith L, Rowlett S, Forester BP. Emerging collaborative care models for dementia care in the primary care setting: a narrative review. *Am J Geriatr Psychiatry* 2020;28(3):320-330.
895. Frost R, Rait G, Aw S, et al. Implementing post diagnostic dementia care in primary care: a mixed-methods systematic review. *Aging Ment Health* 2021;25(8):1381-1394.
896. French DD, LaMantia MA, Livin LR, Herceg D, Alder CA, Boustani MA. Healthy Aging Brain Center improved care coordination and produced net savings. *Health Aff* 2014;33(4):613-618.
897. Haggerty KL, Epstein-Lubow G, Spragens LH, et al. Recommendations to improve payment policies for comprehensive dementia care. *J Am Geriatr Soc* 2020;68(11):2478-2485.
898. Jennings LA, Laffan AM, Schlissel AC, et al. Health care utilization and cost outcomes of a comprehensive dementia care program for Medicare beneficiaries. *JAMA Int Med* 2019;179:161-166.
899. Gerontological Society of America. KAER Toolkit for Brain Health. Accessed December 17, 2024. Available at: <https://gsaenrich.geron.org/kaer-toolkit-for-brain-health>
900. Possin KL, Merrilees JJ, Dulaney S, et al. Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use: The Care Ecosystem Randomized Clinical Trial. *JAMA Intern Med* 2019;179(12):1658-1667.
901. Guterma EL, Kiekhof RE, Wood AJ, Allen IE, Kahn JG, Dulaney S. Care ecosystem collaborative model and health care costs in Medicare beneficiaries with dementia: A secondary analysis of a randomized clinical trial. *JAMA Intern Med* 2023;183(11):1222-1228.
902. Rosenbloom MH, Kashyap B, Diaz-Ochoa A, et al. Implementation and review of the care ecosystem in an integrated healthcare system. *BMC Geriatr* 2023;23(1):515.
903. Care Ecosystem. Care Ecosystem Toolkit. Accessed January 29, 2025. Available at: <https://memory.ucsf.edu/sites/memory.ucsf.edu/files/wysiwyg/CareEcosystemToolkit.pdf>.
904. Alzheimer's Association. 2024 Alzheimer's Disease Facts and Figures. Special report: Mapping a Better Future for Dementia Care Navigation.
905. Ty D, McDermott M. Building Workforce Capacity to Improve Detection and Diagnosis of Dementia. Milken Institute; 2021. Accessed October 28, 2024. Available at: <https://milkeninstitute.org/sites/default/files/2021-05/Building%20Dementia%20Workforce.pdf>
906. Office of the Governor of California. On World Alzheimer's Day, Governor Newsom signs legislation to take on dementia and help Californians thrive as they age. Accessed December 19, 2024. Available at: <https://www.gov.ca.gov/2024/09/21/on-world-alzheimers-day-governor-newsom-signs-legislation-to-take-on-dementia-and-help-californians-thrive-as-they-age/>.
907. Parke B, Boltz M, Hunter KF, et al. A scoping literature review of dementia-friendly hospital design. *Gerontologist* 2017;57(4):e62-e74.
908. Kirch J, Marquardt G. Towards human-centred general hospitals: the potential of dementia-friendly design. *Arch Sci Rev* 2023;66(5):382-390.
909. Riquelme-Galindo J, Lillo-Crespo M. Designing dementia care pathways to transform non dementia-friendly hospitals: Scoping review. *Int J Environ Res Public Health* 2021;18(17):9296.
910. Shiells K, Pivodic L, Holmerova I, Van den Block L. Self-reported needs and experiences of people with dementia living in nursing homes: a scoping review. *Aging Ment Health* 2020;24(10):1553-1568.
911. Scher CJ, Somerville C, Greenfield EA, Coyle C. Organizational characteristics of senior centers and engagement in dementia-friendly communities. *Innov Aging* 2023;7(5):igad050.
912. Gan D, Chaudhury H, Mann J, Wister AV. Dementia-friendly neighborhood and the built environment: A scoping review. *Gerontologist* 2022;62(6):e340-e356.
913. Hung L, Hudson A, Gregorio M, Jackson L, Mann J, Horneet N. Creating dementia-friendly communities for social inclusion: A scoping review. *Gerontol Geriatr Med* 2021;7:23337214211013596.
914. Warshaw GA, Bragg EJ. The essential components of quality geriatric care. *Generations* 2016;40(1):28-37.
915. Mate K, Fulmer T, Pelton L, Berman A, Bonner A, Huang W, Zhang J. Evidence for the 4Ms: Interactions and Outcomes across the Care Continuum. *J Aging Health* 2021;33(7-8):469-481.
916. Goldberg GR, Solis G, John JT, Olvet DM, Kranz KA. 4Ms for Early Learners: A Skills-Based Geriatrics Curriculum for Second-Year Medical Students. *MedEdPORTAL* 2022;18:11264.
917. Avallone M, Perweiler E, Pacetti S. Using the 4Ms framework to teach geriatric competencies in a community clinical experience. *Nurs Forum* 2021;56(1):83-88.
918. Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Special Report: Race, Ethnicity and Alzheimer's in America. *Alzheimers Dement* 2021;17:377-385.
919. Diaz-Santos M, Yanez J, Suarez PA. Alzheimer's disease in bilingual Latinos: clinical decisions for diagnosis and treatment planning. *J Health Service Psychol* 2021;47(4):171-179.
920. Chejor P, Laging B, Whitehead L, Porock D. Experiences of older immigrants living with dementia and their carers: a systematic review and meta-synthesis. *BMJ open* 2022;12(5):e059783.
921. Nowaskie DZ, Sewell, DD. Assessing the LGBT cultural competency of dementia care providers. *Alzheimers Dement* 2021;7(1): e12137.
922. Eller N, Belza B. Addressing Alzheimer's disease in Asian American and Pacific Islander older adults: An action guide for service providers. *J Gerontol Nurs* 2019;44(4):3-4.
923. Abramsohn EM, Paradise KM, Glover CM, et al. Community Rx: Optimizing a community resource referral intervention for minority dementia caregivers. *J Appl Gerontol* 2022;41(1):113-123.
924. American Geriatrics Society. GWEP coordinating center. Accessed December 15, 2024. Available at: <https://www.americangeriatrics.org/programs/gwep-coordinating-center>

925. Alzheimer's Association. The Alzheimer's and Dementia Care ECHO® Program for clinicians. Accessed December 18, 2024. Available at: <https://www.alz.org/professionals/health-systems-medical-professionals/echo-alzheimers-dementia-care-program>
926. National Institutes of Health. NIH RePorter: The National Dementia Workforce Study. Accessed December 15, 2024. Available at: <https://reporter.nih.gov/search/tmkzdvxu9Uaz2nxxwrypybw/project-details/10774551>.
927. Boustani M, Alder CA, Solid CA, Reuben D. An alternative payment model to support widespread use of collaborative dementia care models. *Health Aff (Millwood)* 2019;38(1):54-59.
928. Pizzi LT, Jutkowitz E, Prioli KM, Lu E, Babcock Z, McAbee-Sevick H, Wakefield DB, Robison J, Molony S, Piersol CV, Gitlin LN. Cost-benefit analysis of the COPE program for persons living with dementia: Toward a payment model. *Innov Aging* 2022;6(1):igab042.
929. Alzheimer's Association. Cognitive Assessment and Care Planning Services: Alzheimer's Association Expert Task Force Recommendations and Tools for Implementation. Accessed December 15, 2024. Available at: <https://www.alz.org/careplanning/downloads/cms-consensus.pdf>.
930. Alzheimer's Association Fact Sheet: CPT Code 99483, Explanatory Guide for Clinicians. Accessed December 15, 2024. Available at: <https://portal.alzimpact.org/media/serve/id/5ab10bc1a3f3c>.
931. Li J, Andy C, Mitchell S. Use of Medicare's new reimbursement codes for cognitive assessment and care planning, 2017-2018. *JAMA Netw Open* 2021;4(9):e2125725.
932. Dementia Care Aware. Early Detection. Better Care. Accessed December 18, 2024. Available at: <https://www.dementiacareaware.org/>.
933. California Department of Health Care Services. Medi-Cal Rates. Accessed December 18, 2024. Available at: <https://mcweb.apps.prd.cammi.medi-cal.ca.gov/rates?tab=rates>
934. Winters A, Block L, Maxey H, Medlock C, Ruane K, Hockenberry S. State Strategies for Sector Growth and Retention for the Direct Care Health Workforce. 2021. Washington, DC: National Governors Association Center for Best Practices. Accessed December 15, 2024. Available at: https://www.nga.org/wp-content/uploads/2021/10/NGA_SectorGrowth-DirectCare_report.pdf.
935. Scales K. State policy strategies for strengthening the direct care workforce. Accessed December 15, 2024. Available at: <https://www.phinational.org/resource/state-policy-strategiesfor-strengthening-the-direct-care-workforce/>.
936. Muirhead K, Macaden L, Smyth K, Chandler C, Clarke C, Polson R, O'Malley C. Establishing the effectiveness of technology-enabled dementia education for health and social care practitioners: a systematic review. *Syst Rev* 2021;10(1):1-26.
937. Geddes MR, O'Connell ME, Fisk JD, Gauthier S, Camicioli R, Ismail Z. Remote cognitive and behavioral assessment: Report of the Alzheimer Society of Canada Task Force on Dementia Care Best Practices for COVID-19. *Alzheimers Dement* 2020;12(1):e12111.
938. Yi JS, Pittman CA, Price CL, Nieman CL, Oh ES. Telemedicine and dementia care: a systematic review of barriers and facilitators. *J Am Med Dir Assoc* 2021;22(7):1396-1402.
939. Pappada A, Chattat R, Chirico I, Valente M, Ottoboni G. Assistive technologies in dementia care: an updated analysis of the literature. *Front Psych* 2021;12:644587.
940. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med* 2013;368:1326-1334.
941. Unpublished tabulations based on data from the Medicare Current Beneficiary Survey for 2018. Prepared under contract by Health Care Cost Institute, December 2021.
942. Yang Z, Zhang K, Lin PJ, Clevenger C, Atherly A. A longitudinal analysis of the lifetime cost of dementia. *Health Serv Res* 2012;47(4):1660-1678.
943. Murman DL, Chen Q, Powell MC, Kuo SB, Bradley CJ, Colenda CC. The incremental direct costs associated with behavioral symptoms in AD. *Neurology* 2022;59:1721-1729.
944. Yang Z, Levey A. Gender differences: A lifetime analysis of the economic burden of Alzheimer's disease. *Women Health Iss* 2015;25(5):436-440.
945. White L, Fishman P, Basu A, Crane PK, Larson EB, Coe NB. Medicare expenditures attributable to dementia. *Health Services Res* 2019;54(4):773-781.
946. Coe NB, White L, Oney M, Basu A, Larson EB. Public spending on acute and long-term care for Alzheimer's disease and related dementias. *Alzheimers Dement* 2023;19(1):150-157.
947. Oney M, White L, Coe NB. Out-of-pocket costs attributable to dementia: A longitudinal analysis. *J Am Geriatr Soc* 2022;70(5):1538-1545.
948. Hudomiet P, Hurd MD, Rohwedder S. The relationship between lifetime out-of-pocket medical expenditures, dementia and socioeconomic status in the U.S. *J Econ Ageing* 2019;14:100181.
949. Dwivedi N, Findley AP, Wiener C, Shen C, Sambamoorthi U. Alzheimer disease and related disorders and out-of-pocket health care spending and burden among elderly Medicare beneficiaries. *Medical Care* 2018;56:240-246.
950. Leniz J, Yi D, Yorganci E, et al. Exploring costs, cost components, and associated factors among people with dementia approaching the end of life: A systematic review. *Alzheimers Dement (NY)* 2021;7(1):e12198.
951. Kelley AS, McGarry K, Gorges R, Skinner JS. The burden of health care costs for patients with dementia in the last 5 years of life. *Ann Intern Med* 2015;163:729-736.
952. Unpublished data tabulations from the Healthcare Cost and Utilization Project (HCUP) National (Nationwide) Inpatient Sample (NIS) for 2021 from the Agency for Healthcare Research and Quality. Prepared by the Alzheimer's Association, January 2025.
953. U.S. Centers for Medicare & Medicaid Services. State Level Chronic Conditions Table: Prevalence, Medicare Utilization and Spending, 2007-2018.
954. Kamdar N, Syrjamaki J, Aikens JE, Mahmoudi E. Readmission Rates and Episode Costs for Alzheimer Disease and Related Dementias Across Hospitals in a Statewide Collaborative. *JAMA Netw Open* 2023;6(3):e232109.
955. Cairns C, Kang K. National Hospital Ambulatory Medical Care Survey: 2022 emergency department summary tables. Accessed December 8, 2024. Available at: https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHAMCS/doc22-ed-508.pdf.
956. Hill JD, Schmucker AM, Siman N, et al. Emergency and post-emergency care of older adults with Alzheimer's disease/Alzheimer's disease related dementias. *J Am Geriatr Soc* 2022;70(9):2582-2591.
957. Cairns C, Kang K, Santo L. National Hospital Ambulatory Medical Care Survey: 2018 emergency department summary tables. Accessed December 8, 2024. Available at: https://www.cdc.gov/nchs/data/nhamcs/web_tables/2018_ed_web_tables-508.pdf.
958. Cairns C, Kang K. National Hospital Ambulatory Medical Care Survey: 2019 emergency department summary tables. Accessed December 8, 2024. Available at: <https://dx.doi.org/10.15620/cdc.115748>.
959. Cairns C, Kang K. National Hospital Ambulatory Medical Care Survey: 2020 emergency department summary tables. Accessed December 8, 2024. Available at: <https://dx.doi.org/10.15620/cdc.121911>.
960. Cairns C, Kang K. National Hospital Ambulatory Medical Care Survey: 2021 emergency department summary tables. Accessed December 8, 2024. Available at: https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHAMCS/doc21-ed-508.pdf.
961. Medicare. Skilled Nursing Facility Care. Accessed December 20, 2024. Available at: <https://www.medicare.gov/coverage/skilled-nursing-facility-care>.
962. U.S. Centers for Medicare and Medicaid Services. Medical Monthly Enrollment. Accessed December 20, 2024. Available at: <https://data.cms.gov/summary-statistics-on-beneficiary-enrollment/medicare-and-medicare-reports/medicare-monthly-enrollment>.

963. U.S. Centers for Medicare & Medicaid Services. Mapping Medicare disparities by population. Accessed November 30, 2024. Available at: <https://data.cms.gov/tools/mapping-medicare-disparities-by-population>.
964. Leibson CL, Hall Lon K, Ransom JE, et al. Direct medical costs and source of cost differences across the spectrum of cognitive decline: A population-based study. *Alzheimers Dement* 2015;11(8):917-932.
965. Suehs BT, Davis CD, Alvir J, et al. The clinical and economic burden of newly diagnosed Alzheimer's disease in a Medicare Advantage population. *Am J Alzheimers Dis Other Dement* 2013;28(4):384-392.
966. Lin P-J, Zhong Y, Fillit HM, Chen E, Neumann PJ. Medicare expenditures of individuals with Alzheimer's disease and related dementias or mild cognitive impairment before and after diagnosis. *J Am Geriatr Soc* 2016;64:1549-1557.
967. Geldmacher DS, Kirson NY, Birnbaum HG, et al. Pre-diagnosis excess acute care costs in Alzheimer's patients among a U.S. Medicaid population. *Appl Health Econ Health Policy* 2013;11(4):407-413.
968. Zhu CW, Cosentino S, Ornstein K, et al. Medicare utilization and expenditures around incident dementia in a multiethnic cohort. *J Gerontol A Biol Sci Med Sci* 2015;70(11):1448-1453.
969. Kirson NY, Desai U, Ristovska L, et al. Assessing the economic burden of Alzheimer's disease patients first diagnosed by specialists. *BMC Geriatrics* 2016;16:138.
970. Aigbogun MS, Stellhorn R, Hartry A, Baker RA, Fillit H. Treatment patterns and burden of behavioral disturbances in patients with dementia in the United States: A claims database analysis. *BMC Neurology* 2019;19:33.
971. Sengupta M, Lendon JP, Caffrey C, Melekin A, Singh P. Post-acute and long-term care providers and services users in the United States, 2017–2018. *National Center for Health Statistics. Vital Health Stat* 3(47). 2022.
972. Centers for Medicare & Medicaid Services. Home health services. Accessed November 8, 2024. Available at: <https://www.medicare.gov/coverage/home-health-services>.
973. Davis-Ajami ML, Lu ZK, Wu J. Exploring the home healthcare workforce in Alzheimer's disease and related dementias: Utilization and cost outcomes in US community dwelling older adults. *Arch Gerontol Geriatr* 2022;98:104536.
974. Freed M, Fuglesten Biniek J, Damico A, Neuman T. Medicare Advantage in 2024: Premiums, out-of-pocket limits, supplemental benefits, and prior authorization. Kaiser Family Foundation. Accessed November 8, 2024. Available at: <https://www.kff.org/medicare/issue-brief/medicare-advantage-in-2024-premiums-out-of-pocket-limits-supplemental-benefits-and-prior-authorization/>.
975. Centers for Medicare & Medicaid Data. Special Needs Plan (SNP) Data. SNP Comprehensive Report 2024-10. Accessed November 8, 2024. Available at: <https://www.cms.gov/data-research/statistics-trends-and-reports/medicare-advantagepart-d-contract-and-enrollment-data/special-needs-plan-snp-data>.
976. U.S. Centers for Medicare & Medicaid Services. National Health Expenditures Tables: Table 21. Expenditures, Enrollment and Per Enrollee Estimates of Health Insurance, Calendar Years 1987-2023. Accessed December 20, 2024. Available at: <https://www.cms.gov/data-research/statistics-trends-and-reports/national-health-expenditure-data/nhe-fact-sheet>.
977. National Center for Health Statistics. Biennial Overview of Postacute and Long-term Care in the United States. Accessed November 25, 2024. Available at: <https://data.cdc.gov/d/wibz-pb5q>.
978. Knox S, Downer B, Haas A, Ottenbacher KJ. Home health utilization association with discharge to community for people with dementia. *Alzheimers Dement* 2022;8(1):e12341.
979. Rome V, Penn Lendon J, Harris-Kojetin L. Differences in characteristics of adult day services centers by level of medical service provision. *National Center for Health Statistics* 2020;3(45):1-28.
980. Sengupta M, Caffrey C. Characteristics of residential care communities by percentage of resident population diagnosed with dementia: United States, 2016. *National Health Statistics Reports* 2020;148:1-7.
981. Caffrey C, Melekin A, Lu Z, Sengupta M. Variation in residential care community resident characteristics, by size of community: United States, 2020. NCHS Data Brief, no 454. Hyattsville, MD: National Center for Health Statistics; 2022.
982. Caffrey C, Harris-Kojetin L, Rome V, Sengupta M. Variation in operating characteristics of residential care communities by size of community: United States, 2014. NCHS Data Brief, No. 222. November 2015.
983. Colelo KJ., Sorenson I. Who pays for long-term services and supports? Congressional Research Service, In Focus, IF10343. September 19, 2023. Accessed October 24, 2024. Available at: <https://crsreports.congress.gov/product/pdf/IF/IF10343>.
984. McGarry BE, Grabowski DC. Medicaid home and community-based services spending for older adults: Is there a "woodwork" effect? *J Am Geriatr Soc* 2023;71(10):3143-3151.
985. Murray C, Eckstein M, Lipson D, Wysocki A. Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2020. Chicago, IL: Mathematica, June 9, 2023.
986. Bynum J. Characteristics, Costs, and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey. Unpublished; provided under contract with the Alzheimer's Association. Lebanon, N.H.: Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research, January 2009.
987. Clarkson P, Davies L, Jasper R, Loynes N, Challis D. Home Support in Dementia (HoSt-D) Programme Management Group. A systematic review of the economic evidence for home support interventions in dementia. *Value in Health* 2017;20:1198-1209.
988. Nickel F, Barth J, Kolominsky-Rabas PL. Health economic evaluations of non-pharmacological interventions for persons with dementia and their informal caregivers: A systematic review. *BMC Geriatrics* 2018;18:69.
989. Callahan CM, Arling G, Tu W, et al. Transitions in care among older adults with and without dementia. *J Am Geriatr Soc* 2012;60(5):813-820.
990. Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011;365(13):1212-1221.
991. Teno JM, Mitchell SL, Skinner J, et al. Churning: The association between health care transitions and feeding tube insertion for nursing home residents with advanced cognitive impairment. *J Palliat Med* 2009;12(4):359-362.
992. Genworth. Cost of Care Trends & Insights. Accessed October 11, 2024. Available at: <https://www.genworth.com/aging-and-you/finances/cost-of-care/cost-of-care-trends-and-insights>.
993. Unpublished data from the 2018 Medicare Current Beneficiary Survey (MCBS), analyzed by the Alzheimer's Association. October 2020.
994. Koma W, Neuman T, Jacobson G, Smith K. Medicare beneficiaries' financial security before the coronavirus pandemic. Issue Brief. Kaiser Family Foundation. April 2020. <https://www.kff.org/medicare/issue-brief/medicare-beneficiaries-financial-security-before-the-coronavirus-pandemic/#:~:text=Half%20of%20all%20Medicare%20beneficiaries%20had%20savings%20below%20%2473%2C800%20per,no%20home%20equity%20at%20all>.
995. Hamel L, Montero A. The affordability of long-term care and support services: Findings from a KFF survey. Kaiser Family Foundation. November 14, 2023. Accessed December 20, 2024. Available at: <https://www.kff.org/health-costs/poll-finding/the-affordability-of-long-term-care-and-support-services/>.
996. U.S. Centers for Medicare & Medicaid Services. What Are Medicare and Medicaid? CMS Product No. 11306. May 2023. Accessed December 20, 2024. Available at: <https://www.medicare.gov/publications/11306-Medicare-Medicaid.pdf>.

997. U.S. Centers for Medicare & Medicaid Services. Your Medicare Coverage. Long-Term Care. Accessed December 15, 2024. Available at: <https://www.medicare.gov/coverage/long-term-care>.
998. U.S. Centers for Medicare & Medicaid Services. Original Medicare (Part A and B) Eligibility and Enrollment. Accessed December 21, 2024. Available at: <https://www.cms.gov/Medicare/Eligibility-and-Enrollment/OrigMedicarePartABEligEnrol>.
999. U.S. Centers for Medicare & Medicaid Services. Understanding Medicare Advantage Plans. CMS Product No. 12026. November 2024. Accessed December 20, 2024. Available at: <https://www.medicare.gov/publications/12026-understanding-medicare-advantage-plans.pdf>.
1000. Freed M, Fuglesten Biniak J, Damico A, Neuman T. Medicare Advantage in 2024: Enrollment update and key trends. Kaiser Family Foundation. August 9, 2023. Accessed December 6, 2024. Available at: <https://www.kff.org/medicare/issue-brief/medicare-advantage-in-2024-enrollment-update-and-key-trends/>.
1001. U.S. Centers for Medicare & Medicaid Services. What Are Long-Term Care Hospitals? CMS Product No. 11347. Revised July 2022. CMS Product No. 11347. Accessed December 21, 2024. Available at: <https://www.medicare.gov/publications/11347-What-are-long-term-care-hospitals.pdf>.
1002. National Association of Insurance Commissioners and the Center for Insurance Policy and Research. The State of Long-Term Care Insurance: The Market, Challenges and Future Innovations. CIPR Study Series 2016-1. May 2016.
1003. U.S. Centers for Medicare & Medicaid Services. Skilled nursing facility care. Accessed December 20, 2024. Available at: <https://www.medicare.gov/coverage/skilled-nursing-facility-care>.
1004. U.S. Centers for Medicare & Medicaid Services. 2025 Medicare Parts A & B Premiums and Deductibles. November 8, 2024. Accessed December 7, 2024. Available at: <https://www.cms.gov/newsroom/fact-sheets/2025-medicare-parts-b-premiums-and-deductibles>.
1005. U.S. Department of Health and Human Services. What is Long-Term Care Insurance? Accessed December 15, 2024. Available at: <https://acl.gov/ltc/costs-and-who-pays/what-is-long-term-care-insurance>.
1006. American Association for Long-Term Care Insurance. Long-term care insurance facts - data - statistics - 2022 reports. Accessed November 15, 2024. Available at: <https://www.aaltci.org/longterm-care-insurance/learning-center/lcfacts-2022.php>.
1007. AHIP. Long-term care insurance coverage: State-to-state 2023. Accessed November 15, 2024. Available at: https://ahiporg-production.s3.amazonaws.com/documents/AHIP_LTC_State_Data_Report.pdf.
1008. U.S. Department of the Treasury. Long-Term Care Insurance: Recommendations for Improvement of Regulation. Report of the Federal Interagency Task Force on Long-Term Care Insurance. August 2020. Accessed December 16, 2024. Available at: <https://home.treasury.gov/system/files/136/Report-Federal-Interagency-Task-Force-Long-Term-Care-Insurance.pdf>.
1009. Washington State Legislature. Chapter 50B.04 RCW. Long-Term Services and Supports Program. Accessed December 21, 2024. Available at: <https://app.leg.wa.gov/RCW/default.aspx?cite=50B.04>.
1010. Washington State Department of Social and Health Services. About the WA Cares Fund. Accessed December 20, 2024. Available at: <https://wacaresfund.wa.gov/about>.
1011. LTC News. Multiple states considering implementing long-term care tax. Updated April 25, 2024. Accessed December 21, 2024. Available at: <https://www.ltcnews.com/articles/multiple-states-considering-implementing-long-term-care-tax>.
1012. U.S. Centers for Medicare & Medicaid Services. Seniors & Medicare and Medicaid enrollees. Accessed December 15, 2024. Available at: <https://www.medicare.gov/medicaid/eligibility/seniors-medicare-and-medicare-enrollees/index.html>.
1013. U.S. Centers for Medicare & Medicaid Services. Medicare and hospice benefits: Getting Started. Care and support for people who are terminally ill. CMS Product No. 11361. May 2023. Accessed December 15, 2024. Available at <https://www.medicare.gov/publications/11361-medicare-hospice-getting-started.pdf>.
1014. Centers for Medicare & Medicaid Services. Medicare Hospice Benefits. March 2023. CMS Product 02154. Accessed December 19, 2024. Available at: <https://www.medicare.gov/publications/02154-medicare-hospice-benefits.pdf>.
1015. Davis MA, Chang C-H, Simonton, S, Bynum J. Trends in US Medicare decedents' diagnosis of dementia from 2004 to 2017. *JAMA Health Forum* 2022;3(4):e220346.
1016. U.S. Centers for Medicare & Medicaid Services. Post-Acute Care and Hospice Provider Data 2017. Accessed December 15, 2024. Available at: <https://www.hhs.gov/guidance/document/post-acute-care-and-hospice-provider-data-0>.
1017. De Vleminck A, Morrison RS, Meier DE, Aldridge MD. Hospice care for patients with dementia in the United States: A longitudinal cohort study. *J Am Med Dir Assoc* 2018;19:633-638.
1018. Aldridge MD, Hunt L, Husain M, Li L, Kelley A. Impact of Comorbid Dementia on Patterns of Hospice Use. *J Palliat Med* 2022;25(3):396-404.
1019. Russell D, Diamond EL, Lauder B, et al. Frequency and risk factors for live discharge from hospice. *J Am Geriatr Soc* 2017;65:1726-1732.
1020. U.S. Department of Health and Human Services. Centers for Medicare & Medicaid Services. 42 CFR Part 418. Medicare Program; FY 2025 Hospice Wage Index and Payment Rate Update, Hospice Conditions of Participation Updates, and Hospice Quality Reporting Program Requirements. Accessed December 20, 2024. Available at: <https://www.federalregister.gov/documents/2024/04/04/2024-06921/medicare-program-fy-2025-hospice-wage-index-and-payment-rate-update-hospice-conditions-of>.
1021. National Archives. Code of Federal Regulations (eCFR). Certification of terminal illness. Accessed December 15, 2024. Available at: <https://www.ecfr.gov/current/title-42/chapter-IV/subchapter-B/part-418/subpart-B/section-418.22>.
1022. Gozalo P, Plotzke M, Mor V, Miller SC, Teno JM. Changes in Medicare costs with the growth of hospice care in nursing homes. *N Engl J Med* 2015;372:1823-1831.
1023. Miller SC, Lima JC, Looze J, Mitchell SL. Dying in U.S. nursing homes with advanced dementia: How does health care use differ for residents with, versus without, end-of-life Medicare skilled nursing facility care? *J Palliat Med* 2012;15:43-50.
1024. Miller SC, Gozalo P, Mor V. Hospice enrollment and hospitalization of dying nursing home patients. *Am J Med* 2001;11(1):38-44.
1025. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc* 2010;58(12):2284-2291.
1026. Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Patients dying with dementia: Experience at the end of life and impact of hospice care. *J Pain Symptom Manage* 2008;35(5):499-507.
1027. Lin PJ, Zhu Y, Olchanski N, et al. Racial and ethnic differences in hospice use and hospitalizations at end-of-life among Medicare beneficiaries with dementia. *JAMA Netw Open* 2022;5(6):e2216260.
1028. Miller SC, Lima JC, Orna I, Martin E, Bull J, Hanson LC. Specialty palliative care consultations for nursing home residents with dementia. *J Pain Symptom Manage* 2017;54:9-16.
1029. Palmer MK, Jacobson M, Enguidanos S. Advance care planning for Medicare beneficiaries increased substantially, but prevalence remained low. *Health Aff* 2021;40:613-621.
1030. Zhu Y, Olchanski N, Cohen JT, Freund KM, Faul JD, Fillit HM, Neumann PJ, Lin PJ. Life-sustaining treatments among Medicare beneficiaries with and without dementia at the end of life. *J Alzheimers Dis* 2023;96(3):1183-1193.

1031. Bynum JPW, Meara E, Chang C-H, Rhoads JM. Our Parents, Ourselves: Health Care for an Aging Population. A Report of the Dartmouth Atlas Project. The Dartmouth Institute for Health Policy & Clinical Practice; 2016.
1032. Mitchell SL, Mor V, Gozalo PL, Servadio JL, Teno JM. Tube feeding in U.S. nursing home residents with advanced dementia, 2000–2014. *JAMA* 2016;316(7):769–770.
1033. Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 1999–2020 on CDC WONDER Online Database, released in 2021. Data are from the Multiple Cause of Death Files, 1999–2020, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed December 12, 2024. Available at: <http://wonder.cdc.gov/ucd-icd10.html>.
1034. Park S, Chen J. Racial and ethnic patterns and differences in health care expenditures among Medicare beneficiaries with and without cognitive deficits or Alzheimer's disease and related dementias. *BMC Geriatrics* 2020;20:482.
1035. Gilligan AM, Malone DC, Warholak TL, Armstrong EP. Health disparities in cost of care in patients with Alzheimer's disease: An analysis across 4 state Medicaid populations. *Am J Alzheimers Dis Other Dement* 2013;28(1):84–92.
1036. Lin P-J, Zhong Y, Fillit HM, Cohen JT, Neumann PJ. Hospitalizations for ambulatory care sensitive conditions and unplanned readmissions among Medicare beneficiaries with Alzheimer's disease. *Alzheimers Dement* 2017;13(10):1174–1178.
1037. U.S. Department of Health and Human Services. Reduce the proportion of preventable hospitalizations in older adults with dementia — DIA-02. *Healthy People 2030*. Accessed December 6, 2024. Available at: <https://odphp.health.gov/healthypeople/objectives-and-data/browse-objectives/dementias/reduce-proportion-preventable-hospitalizations-older-adults-dementia-dia-02>.
1038. Davydow DS, Zibin K, Katon WJ, et al. Neuropsychiatric disorders and potentially preventable hospitalizations in a prospective cohort study of older Americans. *J Gen Intern Med* 2014;29(10):1362–1371.
1039. Guterman EL, Allen IE, Josephson SA, et al. Association between caregiver depression and emergency department use among patients with dementia. *JAMA Neurol* 2019;76:1166–1173.
1040. Patel A, Parikh R, Howell EH, Hsieh E, Landers SH, Gorodeski EZ. Mini-Cog performance: Novel marker of post discharge risk among patients hospitalized for heart failure. *Circ Heart Fail* 2015;8(1):8–16.
1041. Lin PJ, Fillit HM, Cohen JT, Neumann PJ. Potentially avoidable hospitalizations among Medicare beneficiaries with Alzheimer's disease and related disorders. *Alzheimers Dement* 2013;9(1):30–38.
1042. MacNeil-Vroomen JL, Nagurney JM, Allore HG. Comorbid conditions and emergency department treat and release utilization in multimorbid persons with cognitive impairment. *Am J Emerg Med* 2020;38(1):127–131.
1043. Feng Z, Coots LA, Kaganova Y, Wiener JM. Hospital and ED use among Medicare beneficiaries with dementia varies by setting and proximity to death. *Health Aff* 2014;33(4):683–690.
1044. White EM, Kosar CM, Rahman M, Mor V. Trends in hospitals and skilled nursing facilities sharing medical providers. *Health Affairs* 2020;39(8):1312–1320.
1045. Chidambaram P, Burns A. Ten things about long-term services and supports (LTSS). Kaiser Family Foundation. July 2024. Accessed November 16, 2024. Available at: <https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/>.
1046. U.S. Centers for Medicare & Medicaid Services. Medicare COVID-19 cases & hospitalizations. January 2022. Accessed December 15, 2024. Available at: <https://data.cms.gov/covid-19/medicare-covid-19-cases-hospitalizations/data>.
1047. Lamont H, Samson LW, Zuckerman R, Dey J, Oliveira I, Tarazi W. The Impact of COVID-19 on Medicare Beneficiaries with Dementia (Issue Brief). Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. April 6, 2021.
1048. Wang Q, Davis PB, Gurney ME, Xu R. COVID-19 and dementia: Analyses of risk, disparity, and outcomes from electronic health records in the US. *Alzheimers Dement* 2021;17(8):1297–1306.
1049. Centers for Medicare & Medicaid Services. The Impact of COVID-19 on Medicare Beneficiaries in Nursing Homes. Accessed December 15, 2024. Available at: <https://www.cms.gov/files/document/medicare-covid-19-nursing-home-analysis.pdf>.
1050. Cubanski J, Neuman T. FAQs on Medicare Financing and Trust Fund Solvency. Kaiser Family Foundation, May 29, 2024. Accessed December 15, 2024. Available at: <https://www.kff.org/medicare/issue-brief/faqs-on-medicare-financing-and-trust-fund-solvency/>.
1051. Burke JF, Kerber KA, Langa KM, Albin RL, Kotagal V. Lecanemab: Looking before we leap. *Neurology* 2023;101(15):661–665.
1052. Rosenthal MB. Novel Alzheimer Disease Treatments and Reconsideration of US Pharmaceutical Reimbursement Policy. *JAMA* 2023;330(6):505–506.
1053. Global Eisai. Eisai's Approach to U.S. Pricing for Leqembi (Lecanemab), a Treatment for Early Alzheimer's Disease, Sets Forth Our Concept of "Societal Value of Medicine" in Relation to "Price of Medicine." Published January 7, 2023. Accessed December 21, 2024. Available at: www.eisai.com/news/2023/news202302.html.
1054. Biogen. Biogen Announces Reduced Price for ADUHELM(R) to Improve Access for Patients with Early Alzheimer's Disease. Published December 20, 2021. Accessed December 21, 2024. Available at: <https://investors.biogen.com/news-releases/news-release-details/biogen-announces-reduced-price-aduhelmr-improve-access-patients#:~:text=CAMBRIDGE%2C%20Mass.%2C%20Dec.,United%20States%20by%20approximately%2050%25>.
1055. U.S. Centers for Medicare & Medicaid Services. CMS announces new details of plan to cover new Alzheimer's drugs. Published June 22, 2023. Accessed December 10, 2024. Available at: <https://www.cms.gov/newsroom/fact-sheets/cms-announces-new-details-plan-cover-new-alzheimers-drugs>.
1056. Pittock RR, Aakre J, Castillo AM, et al. Eligibility for Anti-Amyloid Treatment in a Population-Based Study of Cognitive Aging. *Neurology* 2023;101(19):e1837–e1849.
1057. Alzheimer's Association. Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars. Accessed December 15, 2024. Available at: <https://www.alz.org/media/documents/changing-the-trajectory-r.pdf>.
1058. Zissimopoulos J, Crimmins E, St Clair P. The value of delaying Alzheimer's disease onset. *Forum Health Econ Policy* 2014;18(1):25–39.
1059. Alzheimer's Association. 2018 Alzheimer's Disease Facts and Figures. Special Report: Financial and Personal Benefits of Early Diagnosis. *Alzheimers Dement* 2018;14(3):404–411.
1060. Liu JL, Hlavka JP, Hillestad R, Mattke S. Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment. Santa Monica, CA: RAND Corporation; 2017. Accessed December 15, 2024. Available at: https://www.rand.org/pubs/research_reports/RR2272.html.
1061. Mattke S, Hanson M. Expected wait times for access to a disease-modifying Alzheimer's treatment in the United States. *Alzheimers Dement* 2022 May;18:1071–1074.
1062. Alzheimer's Association. 2017 Alzheimer's Disease Facts and Figures. *Alzheimer's Dement* 2017;13:325–373.
1063. Alzheimer's Association. Navigating treatment options. Accessed February 17, 2025. Available at: <https://www.alz.org/alzheimers-dementia/treatments/navigating-treatment-options>.

1064. Alzheimer's Association. 2022 Alzheimer's Disease Facts and Figures, Special Report: More Than Normal Aging: Understanding Mild Cognitive Impairment. *Alzheimer's Dement* 2022;18:754-767.
1065. Ostergren JE, Heeringa SG, Leon CFM, Connell CM, Roberts JS. The influence of psychosocial and cognitive factors on perceived threat of Alzheimer's disease. *Am J Alzheimers Dis Other Dement*. 2017;32(5):289-299.
1066. Largent EA, Stites SD, Harkins K, Karlawish J. 'That would be dreadful': The ethical, legal, and social challenges of sharing your Alzheimer's disease biomarker and genetic testing results with others. *J Law Biosci*. 2021;8(1):lsab004. doi:10.1093/jlb/lsab004.
1067. Alzheimer's Association. Why get checked. Accessed February 20, 2025. Available at: <https://www.alz.org/alzheimers-dementia/diagnosis/why-get-checked>.
1068. Alzheimer's Association. Global Biomarker Standardization Consortium (GBSC). Accessed February 17, 2025. Available at: https://www.alz.org/research/for_researchers/partnerships/gbsc.
1069. Alzheimer's Association. Portfolio summaries. Accessed February 17, 2025. Available at: https://www.alz.org/research/for_researchers/grants/portfolio_summaries.
1070. Verberk IMW, Misdorp EO, Koelewijn J, et al. Characterization of pre-analytical sample handling effects on a panel of Alzheimer's disease-related blood-based biomarkers: Results from the Standardization of Alzheimer's Blood Biomarkers (SABB) working group. *Alzheimer's Dement*. 2022;18:1484-1497.
1071. Schünemann HJ, Higgins JPT, Vist GE, Glasziou P, Akl EA, Skoetz N, Guyatt GH. Chapter 14: Completing 'Summary of findings' tables and grading the certainty of the evidence [last updated August 2023]. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). *Cochrane Handbook for Systematic Reviews of Interventions* version 6.5. Cochrane, 2024. Available at: www.training.cochrane.org/handbook.
1072. Alzheimer's Association. 2020 Alzheimer's Disease Facts and Figures. Special Report: On the Front Lines: Primary Care Physicians and Alzheimer's Care in America. *Alzheimer's Dement*. 2020;16:433-440.
1073. Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Special Report: The Patient Journey In an Era of New Treatments. *Alzheimer's Dement*. 2023;19:1656-1669.
1074. Ketchum FB, Chin NA, Erickson C, et al. The importance of the dyad: Participant perspectives on sharing biomarker results in Alzheimer's disease research. *Alzheimer's Dement: TRCI* 2023;9. DOI: 10.1002/trc2.12416.
1075. Brookmeyer R, Gray S, Kawas C. Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *Am J Public Health*. 1998;88:1337-1342.
1076. U.S. Department of Labor. Changes in Basic Minimum Wages in Non-Farm Employment Under State Law: Selected Years 1968 to 2020. Accessed December 15, 2024. Available at: <https://www.dol.gov/agencies/whd/state/minimum-wage/history>.
1077. U.S. Centers for Medicare & Medicaid Services. Your coverage options. Accessed December 11, 2024. Available at: <https://www.medicare.gov/basics/get-started-with-medicare/getmore-coverage/your-coverage-options>.

The Alzheimer's Association acknowledges the contributions of Joseph Gaugler, Ph.D., Bryan James, Ph.D., Tricia Johnson, Ph.D., Jessica Reimer, Ph.D., Kezia Scales, Ph.D., Sarah Tom, Ph.D., M.P.H., Jennifer Weuve, M.P.H., Sc.D., and Jarmin Yeh, Ph.D., M.P.H., M.S.S.W., in the preparation of *2025 Alzheimer's Disease Facts and Figures*.

Special thanks to reviewers Jose Abisambra, Ph.D., Erin Emery-Tiburcio, Ph.D., Fayron Epps, Ph.D., R.N., Andrea Gilmore-Bykovskyi, Ph.D., R.N., Paola Gilsanz, Sc.D., Pei Jung Lin, Ph.D., and Melinda Power, Sc.D.

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