2022 Alzheimer’s Disease Facts and Figures Report
More Than Normal Aging: Understanding Mild Cognitive Impairment

The prevalence of Alzheimer's disease and other types of dementia in the United States is increasing, and there is an evident growing burden of increased and specialized caregiving needs for people with Alzheimer’s. It is a type of brain disease caused by damage to nerve cells (neurons). Mild cognitive impairment (MCI) is a distinct condition from Alzheimer's disease and represents a critical turning point in the disease's progression. Individuals with mild symptoms of Alzheimer's disease may continue to work, drive and participate in their favorite activities, but will need increased help from family members, friends, and professional caregivers throughout the disease's progression in order to carry out activities of daily living and to keep the individual safe.

Alzheimer’s Disease or Dementia?

Dementia is an overall umbrella term used for a particular group of symptoms and has several root causes. Cognitive skills are progressively affected due to damage in specific brain regions. Common causes of dementia can include Alzheimer’s, Cerebrovascular disease, Lewy Body disease, Frontotemporal lobar degeneration, Parkinson's disease, Hippocampal Sclerosis, and other mixed pathologies. Alzheimer's disease is one type of dementia, entailing processes that include the accumulation of abnormal proteins called beta-amyloid and phosphorylated tau, as well as the degeneration of nerve cells.

Brain Changes of Alzheimer’s Disease

The brain contains over 100 billion neurons. These cells have cell bodies, axons, and long branching extensions called dendrites that allow them to form connections with other neurons. These connections create memories, thoughts, sensations, emotions, movements, and skills. The accumulation of beta-amyloid and abnormal tau proteins inside neurons are two of several brain changes associated with Alzheimer's disease. These changes prevent neural communication which leads to cell damage and eventual destruction of neurons, called neurodegeneration. Brain changes linked with Alzheimer's disease include inflammation and atrophy. Biomarkers can be used to help determine underlying brain changes that are causing presented symptoms, such as abnormal levels of beta-amyloid and tau in cerebrospinal fluid and a decreased ability to metabolize glucose. Some individuals have a rare genetic mutation that causes Alzheimer's disease. Biomarkers of neurodegeneration begin to appear about 22 years before symptoms are expected to develop, and levels of beta-amyloid and glucose metabolism begin to decrease 18 years before symptoms are expected to develop.

Mixed Dementia

Many people with dementia have brain changes correlated with more than one potential cause. This is called mixed dementia, and there are many distinct combinations of mixed dementia. This type is especially common at advanced ages and may account for the wide variety of memory and thinking problems experienced by people living with dementia. In the early stages of Alzheimer's disease, individuals may have measurable brain changes, but no symptoms. These changes include abnormal levels of beta-amyloid and tau protein and decreased metabolism of glucose. Although research settings can identify some early brain changes of Alzheimer's, additional research is needed to fine-tune current tools' accuracy before they become available for widespread use in hospitals, doctor's offices, and other clinical settings. People with MCI due to Alzheimer's disease have biological evidence of brain changes along with new but subtle symptoms such as problems with memory, language, and thinking.

Alzheimer’s Disease Continuum

- Preclinical Alzheimer’s Disease

Individuals may have measurable brain changes that indicate possible biomarkers of Alzheimer’s disease. Symptoms have not yet developed such as memory loss.

- Mild Alzheimer’s Dementia

In the mild stage of Alzheimer's dementia, people may need assistance with some activities, but they can still drive, work and participate in their favorite activities.

- Moderate Alzheimer’s Dementia

In the moderate stage of Alzheimer's dementia, individuals may experience more problems with memory and language, become confused, and have personality and behavioral changes.

- Severe Alzheimer’s Dementia

In the severe stage of Alzheimer's dementia, individuals are likely to require around-the-clock care and become bed-bound. This makes them vulnerable to physical complications including blood clots, skin infections, and sepsis, which triggers body-wide inflammation that can result in organ failure.

When Dementia-Like Symptoms Are Not Dementia

Some people experience dementia-like symptoms without the progressive brain changes of Alzheimer's or other degenerative brain diseases. These symptoms may be reversed with treatment, unlike Alzheimer's dementia and other types of dementia. Among those with MCI, 15% develop dementia after two years, and one-third develop dementia due to Alzheimer's within five years. However, some individuals with MCI revert to normal cognition. Dementia due to Alzheimer's disease, or Alzheimer's dementia, is characterized by noticeable memory, language, thinking, or behavioral symptoms that impair a person's ability to function in daily life.

Treatments

The U.S. Food and Drug Administration has approved six drugs to treat Alzheimer's disease. These drugs improve symptoms by increasing the number of chemicals called neurotransmitters in the brain. The sixth drug approved to treat Alzheimer's disease, aducanumab, reduces beta-amyloid plaques in the brain and may be appropriate for people with MCI or mild dementia due to Alzheimer's disease. It is not a cure for Alzheimer's disease and should be monitored closely for amyloid-related imaging abnormalities (ARIA). Aducanumab was approved through a process called the accelerated approval pathway, which requires the company that makes the drug to verify clinical benefit in a post-approval trial.

Non-drug treatments for Alzheimer's disease include cognitive stimulation, music-based therapies, and psychological treatment. These treatments may be used to reduce behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation, and aggression. When non-drug treatments are not successful and behavioral and psychiatric symptoms have the potential to cause harm, physicians may prescribe drugs approved for similar symptoms in people with other conditions. However, antipsychotics are associated with an increased risk of stroke and death in people with dementia.

Active Management of Dementia Due to Alzheimer’s Disease

Proactive management of Alzheimer's and other dementias includes appropriate use of available treatment options, effective management of coexisting conditions, providing family caregivers with effective training, and maintaining a sense of self-identity and relationships with others.

Risk Factors for Alzheimer’s

Most individuals who develop Alzheimer's disease are age 65 or older. It is believed to be caused by multiple factors.

- Age

The percentage of people with Alzheimer's dementia increases dramatically with age, but it is important to note that being a part of older adult populations alone is not sufficient to cause Alzheimer's dementia.

- Genetics

Researchers have found several genes that increase the risk of Alzheimer's. APOE-e4 has the strongest impact on the risk of late-onset Alzheimer's. The e4 form of APOE increases one's risk of developing Alzheimer's compared with the e3 form but does not guarantee that an individual will develop Alzheimer's. The e2 form may decrease one's risk compared with the e3 form. A meta-analysis of 20 published articles found that 56% of people with Alzheimer's had one copy of the APOE-e4 gene, and 11% had two copies. Most research to date has studied individuals of European ancestry, and results have been inconsistent. Some studies have found that having the e4 allele did not increase risk among Blacks, while others have found that it significantly increased risk. Researchers found that the effect of APOE-e4 on cognitive decline differed among individuals from six Latino backgrounds, suggesting that factors related to geographic background and genetic ancestry may alter the extent to which APOE-e4 contributes to cognitive decline.

>Trisomy in Down Syndrome

Down syndrome is a genetic disorder in which an individual is born with three copies of chromosome 21 instead of two. People with Down syndrome have an increased risk of developing Alzheimer's. Those with Down syndrome develop Alzheimer's disease at an earlier age than people without Down syndrome, and the brain changes of Alzheimer's disease are more common than these percentages indicate. As individuals with Down syndrome age, they are more likely to develop symptoms of Alzheimer's disease. Dementia is the leading cause of death for adults with Down syndrome.

>Genetic Mutations

A small percentage of 1% or less of Alzheimer's cases develop as a result of mutations to three specific genes. These involve the APP gene and presenilin 1 and 2. Those inheriting an Alzheimer's mutation are virtually guaranteed to develop the disease.

>Family History

A family history of Alzheimer's increases an individual's risk of developing the disease, but it is not necessarily a done deal. Non-genetic factors may also play a role. Although age, genetics, and family history cannot be changed, many other risk factors can be changed or modified to reduce the risk of cognitive decline and dementia.

>Modifiable Risk Factors

Modifiable risk factors have been the subject of much research, and addressing these risk factors may reduce the risk of dementia and cognitive decline. Taking steps to reduce the risk of cognitive decline and dementia does not mean that an individual will not develop dementia, and factors that increase or decrease risk may not necessarily affect the brain changes associated with Alzheimer's disease.

>Cardiovascular Disease Risk Factors, Physical Activity, and Diet

Brain health is affected by the health of the heart and blood vessels. Smoking, diabetes, high blood pressure, high cholesterol, and obesity are all associated with an increased risk of dementia, but late-life obesity and hypertension onset after age 80 are linked with a decreased risk of dementia. Researchers have found that factors that protect the heart may also protect the brain and reduce the risk of developing dementia. Physical activity and a heart-healthy diet may be effective in reducing dementia risk. Researchers have begun studying combinations of health factors and health behaviors to prevent cognitive decline, MCI, and Alzheimer's dementia. These studies have not found clear cognitive benefits, but the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) showed a slower cognitive decline.

>Education and Educational Opportunities

Those with more years of formal education are at lower risk for Alzheimer's and other dementias than those with fewer years of formal education. The underlying reasons for this presented relationship are unclear. Researchers emphasize the indirect effects of formal education on dementia, such as its effects on socioeconomic status and the likelihood of experiencing poor nutrition, being less physically active, having a higher risk of diabetes, and smoking.

>Social and Cognitive Engagement

Studies suggest that remaining socially and mentally active throughout life may help build cognitive reserve and reduce the risk of Alzheimer's and other dementias.

>Traumatic Brain Injury (TBI)

According to the Centers for Disease Control and Prevention (CDC), falls and motor vehicle crashes are the leading causes of traumatic brain injuries (TBI). There are two ways to classify the severity of TBI: by the duration of loss of consciousness or post-traumatic amnesia, and by the individual's initial score on the 15-point Glasgow Coma Scale. People with a history of TBI are at increased risk of dementia. The relationship between TBI and CTE is a growing area of research. Among former amateur and professional football players, the odds of developing CTE increased by 30% per year played, and there is no test to determine if someone has CTE-related brain changes during life.

>Other Risk Factors

The emergence of the coronavirus disease in 2019 (COVID-19) drastically increased the number of hospitalizations among older adults and the risk of cognitive impairment following critical illness. Exposure to air pollution may be related to dementia risk. Higher levels of long-term exposure to fine particulate matter air pollution are associated with worse cognitive decline.

Looking to the Future

The discovery that Alzheimer's disease symptoms begin 20 years or so before symptoms start helps explain why it has been difficult to prevent and treat Alzheimer's disease effectively. However, scientific procedures are always advancing and are likely to help identify effective methods to prevent and treat Alzheimer's disease. A fuller understanding of Alzheimer's depends on being able to include participants from diverse racial and ethnic groups in all realms of Alzheimer's research. The populations of older adults that pertain to these groups make up nearly a quarter of older adult populations in general, and that share is projected to grow. The inclusion of participants from underrepresented groups is important in order to expand the range of lived experiences among participants and to better understand how risk factors and interventions work in different populations. The incidence rate of Alzheimer's is declining, but the number of people with Alzheimer's is expected to continue growing due to an increase in the number of adults aged 65 and over, and the COVID-19 pandemic.

Prevalence of Alzheimer’s and Other Dementias in the United States

This section reports on the number and proportion of people with Alzheimer's disease so as to describe the magnitude of the effect Alzheimer's has on communities and healthcare systems. The percentage of people with Alzheimer's dementia increases with age, and about 110 of every 100,000 people have younger-onset dementia. About 11% of people age 65 and older in the United States have dementia. A systematic review of more than 30 studies of MCI found that 16.6% of people age 65 and older had MCI, and about half of the people with MCI had

Alzheimer's-related brain changes. Therefore, roughly 8% of people age 65 and older may have MCI due to Alzheimer's disease.

In the primary care setting, only about half of Medicare beneficiaries with a diagnosis of Alzheimer's or another dementia report being told of the diagnosis. Therefore, a substantial portion of Americans with Alzheimer's may not know they have it. Subjective cognitive decline refers to a self-perceived worsening of memory and other thinking abilities, separate from cognitive testing, a physician's diagnosis or anyone else noticing. It may be a way to identify people at high risk of developing Alzheimer's disease and other dementias.

Estimates of the Number of People with figure 4 Alzheimer's Dementia by State

Based on projections, every state will have experienced an increase in the number of people with Alzheimer's between 2020 and 2025, especially in the West and Southeast. This increase will have a marked impact on states' healthcare systems and the Medicaid program.

Incidence of Alzheimer's Dementia

According to estimates from the CHAP study and the U.S. Census Bureau, approximately 910,000 people age 65 or older developed Alzheimer's dementia in the United States in 2011. The number of new cases of Alzheimer's increases dramatically with age, and is projected to double by 2050 because of the increasing number of people aged 65 and older in the United States.

Lifetime Risk of Alzheimer's Dementia

Data from the Framingham Heart Study was used to estimate lifetime risks of Alzheimer's dementia by age and sex. The risks were slightly higher at age 65. Almost two-thirds of Americans with Alzheimer's are women. Although most studies have found no significant difference between men and women in the proportion who develop Alzheimer's or other dementias at any given age, some studies have reported higher incidence for men.

Differences Between Women and Men in the Prevalence and Risk of Alzheimer's and Other Dementias

Studies suggest that the observed difference in dementia risk between men and women may be an artifact of survival bias, in which men are more likely to die of other health factors before developing dementia. Although differences in the rates at which men and women develop Alzheimer's or other dementias do not appear to be large or consistent, there may be differences in how men and women experience certain social and cultural factors such as education, occupation, and health behaviors. The APOE-e4 genotype, the best-known common genetic risk factor for Alzheimer's dementia, may have a stronger association with Alzheimer's dementia and neurodegeneration in women than in men, although age played an interesting interactive role.

Racial and Ethnic Differences in the Prevalence of Alzheimer’s and Other Dementias

Older non-Hispanic Black and Hispanic Americans are disproportionately more likely than older White individuals to have Alzheimer's or other types of dementia. However, there is evidence that prevalence may differ from one specific Hispanic ethnic group to another. The higher chance of Alzheimer's disease in Black and Hispanic populations compared with White populations appears to be due to a higher risk of developing dementia. Research suggests that structural racism is to blame for the health and socioeconomic disparities between older Black and Hispanic populations and older White populations in the United States, which are rooted in the history of discrimination against Black individuals and other people of color in the United States.

Differences in the social and physical environment by race/ethnicity across one's course of life may increase the risk for chronic conditions that are associated with higher dementia risk, such as cardiovascular disease and diabetes. This may partially explain the elevated risk of dementia among Black and Hispanic populations. Alzheimer's and other dementias are more common among Black and Hispanic older adults than among White older adults, with its effects and symptoms being greater. A study of electronic medical records of members of a large health plan in California indicated that dementia incidence was highest for African American older adults, intermediate for Latino older adults, American Indian and Native Alaskan older adults, Pacific Islander older adults, and White older adults, and lowest for Asian American older adults.

Trends in the Prevalence and Incidence of Alzheimer’s Dementia Over Time

Although some studies indicate that the prevalence and incidence of Alzheimer's and other dementias may have declined in the past 25 years, the total number of people with dementia is expected to continue to increase dramatically. Recent findings are promising, but it is unclear whether these trends will continue, given worldwide increases in diabetes and obesity among persons under 65 years old, which may lead to a rebound in dementia risk in the coming years.

Looking to the Future

In 2011, the largest-ever generation of the American population started reaching age 65. By 2030, the segment of the U.S. population aged 65 and older will have grown substantially, and the number of people with Alzheimer's dementia will increase rapidly. The older adult population will continue to increase in the United States, primarily due to a decline in fertility and mortality improvements experienced in older age. As a result, a smaller share of the population will be of working age. The number of Americans surviving into their 80s, 90s, and beyond is expected to grow dramatically, and this will increase the number of people aged 85 and older, who are at the highest risk for developing Alzheimer's disease. The group of older adults at risk for Alzheimer's in the coming years will be socially, culturally, and economically different from previous groups, and their risk and resilience to Alzheimer's will become clearer in the decades ahead. Future older adult populations will have different life experiences, which will affect dementia incidence and insistence. A birth cohort perspective will be increasingly important for understanding risk and resilience.

Deaths from Alzheimer’s Disease

The data presented in this section are from 2019 and give an accurate representation of long-term trends in mortality and morbidity due to Alzheimer's and other dementias in the United States. According to the CDC, 121,499 people died from Alzheimer's disease in 2019. The term "Alzheimer's disease" is used on death certificates, but the determination is made based on clinical symptoms in almost every case. The number of deaths from dementia of any type is much higher than the number of reported Alzheimer's disease deaths. Severe dementia frequently causes complications such as immobility, swallowing disorders, and malnutrition, which increases the risk of serious acute conditions that can cause death. Pneumonia is the most commonly identified immediate cause of death among older adults with Alzheimer's or other dementias.

A study estimated that 500,000 deaths among people aged 75 and older could be attributed to Alzheimer's dementia in the United States in 2010, while only 5% of death certificates listed dementia as the underlying cause of death for this age group. According to 2014 Medicare claims data, one-third of all Medicare beneficiaries who die in a given year have been diagnosed with Alzheimer's or another dementia. A cause of death listed as Alzheimer's disease may not be accurate, as 15% to 30% of people diagnosed with Alzheimer's dementia during life do not have the brain changes of Alzheimer's disease.

Public Health Impact of Deaths from Alzheimer’s Disease

The number of deaths from Alzheimer's disease has increased significantly in the last two decades before the COVID-19 pandemic, probably due to increased reporting of Alzheimer's deaths over time by physicians, coroners, and others who assign causes of death.

State-by-State Deaths from Alzheimer’s

Table 5 provides information on the number of deaths due to Alzheimer's disease by the state in 2019, the most recent year for which state-by-state data are available.

Alzheimer’s Death Rates

Since 2000, the rate of deaths due to Alzheimer's has risen substantially in the United States, especially among people aged 65 and older. This increase has been disproportionately affected older adult populations. There is an increase in the death rate of people age 85 and older.

Duration of Illness from Diagnosis to Death

People age 65 and older with Alzheimer's disease live an average of four to eight years after a diagnosis, yet some live as long as 20 years with Alzheimer's.

The Burden of Alzheimer’s Disease

Scientists have developed methods to measure the burden of Alzheimer's disease on a population, which takes into account the number of years of illness before death and the number of healthy years lost. Alzheimer's disease is a very tiresome disease, not only for the individuals with the disease but also for their families and informal caregivers. It has increased more dramatically in the United States in recent years than the burden of other diseases. These estimates should be interpreted with consideration of challenges in the availability of data across time and place, and the incorporation of disability. They do not account for the context in which disability is experienced.

Looking to the Future

Alzheimer's disease is responsible for more and more deaths and poor health and disability in the United States. Future reports will assess the influence of the COVID-19 pandemic on trends in mortality and morbidity from Alzheimer's disease.

Unpaid Caregivers

Eighty-three percent of help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. In 2021, caregivers of people with Alzheimer's or other dementias provided 16 billion hours of informal assistance, valued at $271.6 billion. This is approximately 49% of Walmart's total revenue in the fiscal year 2020 and 14 times the revenue of McDonald's. Caregivers often indicate love and a sense of duty and obligation when describing what motivates them to assume care responsibilities for a relative or friend living with dementia. Individuals with dementia living in the community are more likely to rely on multiple unpaid caregivers than older adults without dementia. Nearly half of the individuals with dementia live alone, perhaps making it more difficult to ask for and receive informal care.

Who are Caregivers

Several sources have examined the demographic background of family caregivers of people with Alzheimer's or other dementias in the United States and have found that two-thirds are women, 30% are age 65 or older, over 60% are married, living with a partner or in a long-term relationship, and 40% have college degrees.

>Caregiving and Women

Two-thirds of dementia caregivers are women, and they spend more time providing services than male caregivers. Women experience higher levels of stress, impaired mood, depression, and impaired health than men typically. This is perhaps because women spend more in the assigned role of caregiving, assume more caregiving tasks, and care for someone with more cognitive, functional, and/or behavioral problems.

>Race/Ethnicity and Dementia Caregiving

In population-based studies, African-American caregivers are more likely to provide more than 40 hours of care per week and to care for someone with dementia but are less likely to use respite services. Hispanic, Black, and Asian American caregivers have indicated greater care demands. In a nationally representative study, African-American and Hispanic participants had poorer health before becoming caregivers, and Black caregivers reported higher psychological well-being than White identifying caregivers. Research has shown that Black dementia caregivers have better self-rated health than White or Hispanic caregiver. Positive perceived relationships with their care recipients are associated with better self-rated health.

>Caregiving Tasks

> Dementia caregiving is common, regardless of race or ethnicity, but studies of caregivers often lack sufficient numbers of diverse participants to confirm these findings or delve deeper into them for important insights. Family caregivers of people with dementia provide more extensive assistance with ADLs, monitoring the health of the care recipient, and providing health or medical care. They also need culturally responsive services and support. When a person with Alzheimer's or another dementia moves to an assisted living residence or a nursing home, the family caregiver provides emotional support.

In 2014, 86% of dementia caregivers assisted for at least the past year, and 57% of family caregivers provided care for four or more years. In 2021, 11.3 million families and other unpaid caregivers of people with dementia provided 16 billion hours of unpaid help. The value of unpaid care provided by family and other unpaid caregivers for people with Alzheimer's disease and other dementias increased by 18% with each additional year of providing care and further increased as the care recipient's cognitive abilities declined.

Caregiving for someone with dementia involves immediate demands that are also time-intensive. The amount of time required for caregiving increases as dementia progresses and caregivers report providing 27 hours more care per month on average than caregivers of people without dementia. Caring for a person with Alzheimer's poses special challenges, including helping them manage their judgment, orientation, and ability to understand and communicate effectively. Caregivers may also experience increased emotional stress and depression, new or exacerbated health problems, and depleted income and finances.

Caregiver Emotional and Social Well-Being

Intimacy, shared experiences, and memories that are often part of the relationship between a caregiver and a person living with dementia may be threatened due to memory loss, functional impairment, and psychiatric/behavioral disturbances.

>Burden and Stress

Caregivers of people with dementia report greater emotional, financial, and physical difficulties than caregivers of people without dementia. Spousal dementia caregivers experience increased burdens over time, and caregivers of people with dementia who have co-occurring chronic conditions report increased emotional difficulties with care. Dementia caregivers are more likely to experience depression and anxiety than non-caregivers and are more likely to indicate depressive symptoms than non-dementia caregivers. Dementia caregivers in the United States are more likely to have experienced depression or anxiety than dementia caregivers from Japan. Caregivers of individuals with Alzheimer's report more subjective cognitive problems and greater declines in cognition over time than non-caregivers matched on age and other characteristics.

>Strain

Caregivers of people with Alzheimer's or other dementias report greater strain than caregivers of individuals without dementia and indicate a greater decline in social network size. They also report greater difficulty completing medical/nursing-related tasks, and often believe they have no choice in taking on the role of caregiver.

>Stress of Care Transitions

Admitting a relative to a care residence may have mixed effects on the emotional and psychological well-being of family caregivers. Some studies suggest that stress caused by this change remains the same or even increases after a relative is admitted to a care residence, but other studies have found that stress declines overall for dementia caregivers. The demands of caregiving may cause declines in caregivers' health, and the stress of providing dementia care increases caregivers' susceptibility to disease and health complications. In addition, many caregivers contend with health challenges of their own.

Caregiver Physical Health and Conditions

Caregivers of people with Alzheimer's or other dementias are more likely to report poor health and lower health-related quality of life than non-caregivers, but some studies suggest that caregiving tasks keep older caregivers more physically active than non-caregivers.

>Physiological Changes

A meta-analysis of studies found that dementia caregivers had modestly elevated inflammation but slight reductions in immune function.

>Health Care

Persons with dementia who also have depression, behavioral disturbances, or low functional status have a higher risk of emergency department visits and hospitalization than people with dementia alone.

>Mortality

Studies have found mixed results regarding how the health of people with dementia affects their caregivers' risk of dying. However, the Health and Retirement Study found that dementia caregivers were less likely to die than non-caregivers of similar age over 12 years.

Caregiver Employment and Finances

Six in 10 caregivers of people with Alzheimer's or other types of dementia were employed or had been employed in the prior year while providing care. 18% of dementia caregivers reduced their work hours due to care responsibilities. Caregivers of a spouse with dementia indicate higher home health care expenditures but lower outpatient expenditures than those who do not have a spouse with dementia, 48% cut back on other spending, and 43% cut back on savings due to care-related costs.

Effects of Stress and Other Caregiving Factors on People with Dementia

Researchers have documented the effects of caregiver stress on people with dementia and their use of healthcare services. Stress is associated with increased odds of institutionalization, exacerbated behavioral and psychological challenges in the person with dementia, and increased likelihood of someone with dementia being abused. Interventions aimed at improving the health and well-being of dementia caregivers include providing education, helping caregivers manage dementia-related symptoms, improving social support, and providing caregivers with respite.

Interventions Designed to Assist Caregivers

According to a publication on dementia caregiver interventions, effective interventions involve family caregivers actively participating, and must be tailored to meet changing familial needs as well as meet the needs of people living with dementia. A prior report examined 44 caregiver interventions that benefited both individuals with dementia and caregivers. A meta-analysis of over 60 meta-analyses and systematic reviews of dementia caregiver interventions found that interventions that initially enhance caregiving competency, gradually address the care needs of the person with dementia, and offer emotional support appeared most effective. Interventions for dementia caregivers have been implemented in the community, but are still not widespread or available to all family caregivers. More studies are needed to define which interventions are most effective for specific situations and how these interventions are successful. In 2019, the National Institute on Aging awarded funding to create the NIA Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory, and in 2020, the Centers for Disease Control and Prevention established three Public Health Centers of Excellence.

Trends in Dementia Caregiving

Families are now better at managing care for relatives with dementia than in the past, with fewer caregivers reporting physical and financial difficulties, and more caregivers using respite care.

>COVID-19 and Dementia Caregiving

The COVID-19 pandemic has caused significant challenges to family members and friends who provide care for people with dementia, including fatigue and burnout, and a lack of access to services and supports for themselves and for the people for whom they provide care.

Family caregivers of relatives in nursing homes or similar residential settings report several challenges, including severely limited contact with relatives due to visitation restrictions, a lack of transparent information and communication from care residences, fears of relatives dying alone, and concerns about the overburdened staff at care residences. The COVID-19 pandemic has motivated some service providers to transition their support programs toward remote/virtual care delivery, although concerns remain about the "digital divide" facing caregivers who do not have reliable broadband access. The number of family members available to provide care to older relatives with health needs is likely to decrease due to a range of sociodemographic and health trends in the U.S. The Alzheimer's Association has undertaken several efforts to improve how dementia care is studied and delivered. These efforts focus on placing individuals with dementia and their caregivers at the center of how care should be delivered and emphasizes the importance of maintaining or improving skills and abilities when living with dementia.

Diagnosis

Studies show that PCPs frequently make the initial diagnosis of dementia, and that of those diagnosed by a specialist, 44% were diagnosed by a neurologist, 34% by a psychiatrist, and 22% by a geriatrician. In a survey conducted by the Alzheimer's Association in 2019, 589 nearly 40% of PCPs reported never or only sometimes being comfortable personally making a diagnosis of Alzheimer's or other dementias, and more than 25% reported being only sometimes or never comfortable answering patient questions about Alzheimer's or other dementias. In 2050, the United States will need nearly triple the number of geriatricians as there will be 10% of the population age 65 and older will need geriatrician care. States will have different needs for geriatricians. Hawaii and Washington, D.C. will have enough geriatricians to care for those projected to have Alzheimer's dementia, while 12 states will need to increase the number of geriatricians by at least 13 times.

These data were obtained from IQVIA in December 2021 and represent the number of practicing geriatricians at that time. The Alzheimer's Association will be working to standardize how the productivity of medical specialists is determined to better understand future needs. A shortage of specialists means people living with dementia are not getting timely and accurate diagnoses, which means they are missing out on potentially life-changing treatments, care delivery, and supportive services. PCPs in large cities and suburbs near large cities reported a shortage of dementia specialists, while PCPs in small cities and rural areas reported a lack of specialists.

Treatment

Professionals who provide care for older adults include nurse practitioners, registered nurses, social workers, pharmacists, physician assistants, and case workers. Only 4% of social workers have formal certification in geriatric social work. Licensed healthcare professionals provide skilled care, such as physical therapy, occupational therapy, wound care, intravenous injections, and catheter care. Involving skilled care workers in a primary care setting to boost dementia workforce numbers may provide quality care in cost-effective ways, such as by reducing emergency room visits, ambulance rides, and hospitalizations.

Care

Direct care workers help older adults live at home or in nursing homes by providing nutrition, exercise, and social engagement and helping with activities of daily living. They also play an important role in delaying nursing home placement and reducing repeated hospitalizations. As shown in Table 13, double-digit percentage increases in home health and personal care aides will be needed in all but two states between 2018 and 2028. Direct care workers have difficult jobs and may not receive the training necessary to provide dementia care. They have low wages and turnover rates are high, and recruitment and retention are persistent challenges. Low wages lead to turnover and understaffing, which can lead to direct care workers being mandated to work extra shifts, potentially compromising their health. A high number of on-the-job injuries is another potential reason for turnover among direct care workers, and the COVID-19 pandemic adds to the danger experienced by these essential workers. According to "Making Care Work Pay," shortages of direct care workers may leave care recipients and their families scrambling to fill the gaps and may result in worsening health outcomes.

Workforce Needs for New Therapies

As new therapies for Alzheimer's are developed, the demands on the dementia care workforce will change. For example, in 2021 the U.S. Food and Drug Administration approved aducanumab, which requires careful monitoring of patients for a serious potential side effect called amyloid-related imaging abnormalities (ARIA). The Rand Corporation projected that the shortage of dementia specialists would slow access to new disease-modifying therapies, and point to the need for additional dementia specialists.

Members of the Alzheimer’s and Dementia Care Workforce

PCPs often do not have the time, tools, or expertise to diagnose Alzheimer's disease or other dementias, and are uncertain how to go about providing cognitive assessments to Medicare patients. According to the American Public Health Association, bolstering the dementia care workforce has unique challenges, including recruitment, retention, career advancement, regulation, and training. Dementia and geriatric education are needed across myriad professions, but dementia-specific training requirements across the nation are sparse and inconsistent.

Looking to the Future

Physicians who specialize in the health of older individuals are needed to meet the healthcare needs of the rapidly increasing numbers of Americans age 65 and older who are at a highest risk of developing Alzheimer's. Healthcare systems could expand the roles of physician assistants, nurse practitioners, social workers, and other care providers to include coordinating services with families, caregivers, and community resources to enhance the patient experience both before and after the diagnosis of dementia. Collaborative care models can improve care coordination, thereby reducing healthcare costs. For example, an interprofessional memory care clinic can reduce health care costs by $3,474 over a year for individuals with memory problems. The National Academies notes that direct care workers are well-positioned to implement non-pharmacologic interventions for behavioral and psychological symptoms.The Gerontological Society of America KAER model suggests that non-clinical office staff participate in the primary care team's efforts to detect cognitive impairment and that health coaches can be used as liaisons between a dementia care partner team and people with dementia and their caregivers.The dementia care workforce's time may also be optimized by turning to technology, such as using computerized or digital screening tools for cognitive assessments before and between physician visits. Remote assessments through telephone or video could help reach those in rural areas and those with mobility challenges.Technologies such as wrist-worn devices and game-like assessments on mobile phones may produce digital biomarkers of MCI.

Total Cost of Health Care and Long-Term Care

Table 14A14 shows that Medicare beneficiaries with Alzheimer's or other dementias received over three times as much in health care and long-term care payments in 2021 as Medicare beneficiaries without dementia. Despite financial assistance, individuals with Alzheimer's or other dementias still incur high out-of-pocket costs for health care and long-term care services. Researchers have evaluated the additional costs of dementia, including health care, residential long-term care, and family caregiving. They found that the additional costs are higher for women than men and that the incremental Medicaid costs are 70% higher. A fourth group of researchers found that the lifetime cost of care for individuals with Alzheimer's dementia was $321,780 in 2015 dollars ($377,621 in 2021 dollars). Researchers have found that individuals with dementia spend more out-of-pocket on healthcare services than individuals without dementia, with the largest portion of the difference due to higher spending on home healthcare and prescription drugs. Researchers found that end-of-life costs were 57% higher for individuals with dementia than for people without dementia and that out-of-pocket costs represented a substantially larger proportion of total wealth for those with dementia.

Use and Costs of Health Care Services

People with Alzheimer's or other dementias have more hospital stays, skilled nursing facility stays, and home health care visits per year than other older people. There are a recorded 518 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer's or other dementias compared with 234 hospital stays per 1,000 Medicare beneficiaries age 65 and older without these conditions. The average length of stay is 5.1 days compared to 4.5 days for beneficiaries without these conditions. In 2018, there were 1,545 emergency department visits per 1,000 Medicare beneficiaries with Alzheimer's or other dementias, compared to 640 visits per 1,000 Medicare beneficiaries without Alzheimer's or other dementias. There were 188 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer's or other dementias per year. Twenty-six percent of Medicare beneficiaries age 65 and older with Alzheimer's or other dementias have at least one home health visit during the year. Medicare covers most home health services.

Medicare beneficiaries with Alzheimer's or other dementias receive higher per-person payments for health care services and prescription medications than other Medicare beneficiaries in the same age group. There is substantial geographic variation in health care utilization and Medicare payments by individuals with Alzheimer's or other dementias. Healthcare costs increase with the presence of dementia but are not significantly different from costs for individuals with mild cognitive impairment. Research has found that health care and prescription drug spending are higher in the year before diagnosis, two years before diagnosis, and one year after diagnosis for individuals with Alzheimer's or another dementia than for otherwise similar individuals without the disease. Researchers also found that healthcare costs increased in the year immediately before and the year immediately after a diagnosis of Alzheimer's or another dementia, but decreased over time. One possible explanation is that individuals with cognitive decline who sought care from a specialist had a shorter time to diagnosis.

In 2019, 46% of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 46% had chronic kidney disease, 37% had diabetes, 34% had congestive heart failure and 20% had chronic obstructive pulmonary disease. Medicare beneficiaries who have Alzheimer's or other dementias and a coexisting medical condition have higher average per-person payments for most healthcare services than Medicare beneficiaries who do not have Alzheimer's or other dementia.

Use and Costs of Long-Term Care Services

Individuals with Alzheimer's disease or other types of dementias live in the community, receive care from family members and other unpaid caregivers, and may also receive paid services at home, in adult day centers, assisted living residences, or nursing homes. Those who live at home receive unpaid help from family members and friends, as well as paid home- and community-based services. Thirty-two percent of individuals using home health services, 28% of individuals use adult day services, 34 percent of residents in residential care settings have Alzheimer's or other dementias, and sixty-one percent of residential care communities are small (four to 25 beds). There are 58% of residential care settings that offer programs for residents with Alzheimer's or other dementias, and 48% of nursing home residents have Alzheimer's or other dementias. In 2014, 61% of nursing home residents with Alzheimer's or other dementias had moderate or severe cognitive impairment. Alzheimer's special care units are dedicated units in nursing homes and other residential care settings that provide tailored services for individuals with Alzheimer's or other dementias.

Medicaid covers 43% of long-term services and supports, followed by Medicare (21%), and out-of-pocket payments (15%). State Medicaid programs are shifting long-term care services from institutional care to home- and community-based services to reduce unnecessary costs. Between 2008 and 2018, Medicaid spending on home and community-based services increased from 43% to 56% of total long-term services and support expenditures. Additionally, spending on home care for Medicare beneficiaries with Alzheimer's or other dementias increased dramatically between 2004 and 2018.

>Transitions Between Care Settings

Individuals with dementia often transition between a nursing facility, hospital, and home, creating challenges for caregivers and providers to ensure that care is coordinated across intersecting settings. In 2020, the median cost of home care was $24 per hour and $4,652 per month (in 2021 dollars), and adult day centers were $75 per day. The median cost of assisted living in 2020 was $4,429 per month or $53,148 per year. The cost of nursing home care increased by 3% annually on average between 2015 and 2020.

>Affordability of Long-Term Care Services

Medicare beneficiaries with a dementia diagnosis tend to have lower household incomes than beneficiaries without a dementia diagnosis and have fewer savings than beneficiaries without a dementia diagnosis.

>Long-Term Care Insurance

Private long-term care insurance covers care provided in nursing homes, assisted living residences, and Alzheimer's special care residences, as well as community-based services such as adult day care and services provided in the home, including nursing care and help with personal care. Washington passed a law that will create a public long-term care insurance program that will be funded by a payroll tax on employees and self-employed individuals.

>Medicaid Costs

Medicaid covers nursing home care and long-term care services in the community for individuals who meet program requirements. The program's coverage of long-term care and support services varies by state. 24% of Medicare beneficiaries with Alzheimer's or other dementias also have Medicaid coverage, and Medicaid pays for more nursing homes and other long-term care services for people with dementia. Although Medicare covers care in a long-term care hospital, skilled nursing care in a skilled nursing home, and hospice care, it does not cover long-term care in a nursing home. Medicare covers skilled nursing care for the first 20 days after a hospital stay, with $185.50 per day in coinsurance.

A long-term care hospital provides specialized care for people who stay more than 25 days. Medicare covers these services. Medicare Part A is free to individuals age 65 or older, who have a permanent disability or have end-stage renal disease, and Medicare Part B requires enrollees to pay a monthly premium. Medicare Advantage Plans are becoming more common. Medicare is a federal program, and Medicaid is a joint federal and state program. Dual eligibles are individuals who are enrolled in both Medicare and Medicaid. Medicaid spending for people with Alzheimer's or other dementias is projected to be $60 billion in 2022, 22 times as great as Medicaid spending for other Medicare beneficiaries.

Use and Costs of Care at the End of Life

Hospice care provides medical care, pain management, emotional and spiritual support, and bereavement services for people who are dying, including people with Alzheimer's or other dementias. Medicare pays for hospice care, but private insurance, Medicaid, and other sources also pay for hospice care. Medicare beneficiaries with Alzheimer's and other dementias are more likely to have hospice care than Medicare beneficiaries without Alzheimer's or other dementias. In 2017, 4,254 hospice care companies provided care in the home, assisted living communities, long-term care residences, inpatient hospitals, and inpatient hospice and other settings. Additionally, 18% of Medicare beneficiaries who received hospice care had a primary diagnosis of dementia, including Alzheimer's dementia. Medicare reimbursement for home hospice services changed in 2016 from a daily rate to a two-tiered approach that provides higher reimbursement for days 1 to 60 than for subsequent days and a service intensity add-on payment for home visits by a registered nurse or social worker. Medicare beneficiaries with advanced dementia who are enrolled in hospice care are less likely to die in the hospital and are more likely to receive regular pain treatment. Based on data from the National Hospice Survey for 2008 to 2011, nearly all hospices cared for individuals with dementia, and 67% of hospices had residents with a primary diagnosis of dementia. Researchers found that individuals receiving palliative care had fewer hospitalizations and emergency department visits in the last seven and 30 days of life compared to those who did not receive palliative care. Despite the introduction of advanced care planning as a billable service in 2016, its use remains low.

>Feeding Tube Use at the End of Life

Researchers found that people with frequent transitions between healthcare settings are more likely to have feeding tubes at the end of life. The use of feeding tubes has decreased with the expansion of Medicare-supported hospice care.

>Place of Death for Individuals with Alzheimer’s or Other Dementias

During the same period, the proportion of individuals with Alzheimer's who died at home increased from 15% to 32%.

Use and Costs of Health Care and Long-Term Care Services by Race/Ethnicity

Medicare beneficiaries with Alzheimer's or other dementias received higher Medicare payments than other beneficiaries, but after adjusting for socioeconomic characteristics and functional status, total healthcare spending did not significantly differ among groups. Researchers found significant differences in the costs of care by race/ethnicity among Medicare-Medicaid dually eligible beneficiaries diagnosed with Alzheimer's disease. Preventable hospitalizations are a common measure of healthcare quality. Unplanned hospital readmissions within 30 days are another type of hospitalization that potentially could have been avoided with appropriate post-discharge care. Based on data from the Health and Retirement Study and Medicare, individuals with dementia had a 30% greater risk of having a preventable hospitalization than those without a neuropsychiatric disorder.

The COVID-19 pandemic has disproportionately affected Americans living with Alzheimer's and other dementias, and individuals living in long-term care communities have been extremely vulnerable to COVID-19 due to the communal nature of these settings. One study found that individuals with Alzheimer's had twice the odds of being diagnosed with COVID-19 as individuals without Alzheimer's and that Black adults with dementia had nearly three times the odds compared with White adults. Evidence is still emerging on how healthcare utilization changed during the pandemic for individuals with Alzheimer's and other dementias, but they had the highest rates of hospitalization for COVID-19 among all 21 chronic conditions analyzed in 2020.

Medicare beneficiaries with Alzheimer's or other types of dementias and a serious coexisting medical condition are more likely to be hospitalized than people with the same coexisting medical condition but without dementia. For those residing in the community, individuals with dementia are more likely to have a potentially preventable hospitalization, emergency department visit, or emergency department visit that results in hospitalization. Changes in healthcare delivery and payment models may impact healthcare utilization for individuals with

Alzheimer's disease or other dementias. Skilled nursing facilities that share providers with at least one hospital have better outcomes.

Projections for the Future

The total annual payments for health care, long-term care, and hospice care for people with Alzheimer's or other dementias are projected to increase from $321 billion in 2022 to just under $1 trillion in 2050. While there are currently no FDA-approved treatments for Alzheimer's disease, a recently FDA-accelerated approved anti-amyloid therapy reduces amyloid plaques, which may result in clinical benefit. Researchers have estimated the health and long-term care costs of people with Alzheimer's if a treatment were introduced in 2025 that delayed the onset of dementia by five years. Studies have shown that treatments that delay the onset of Alzheimer's disease by one to five years can reduce healthcare spending. However, the additional healthcare costs may be offset by lower informal care costs. Early diagnosis of Alzheimer's disease may reduce health and long-term care costs, as a smaller spike in costs occurs immediately before and after diagnosis during the MCI phase compared with the higher-cost dementia phase. Potential savings from treatment or an earlier diagnosis may depend on structural changes to the healthcare system. For example, capacity constraints could severely restrict access to new treatments.

Confronting MCI and Why It Matters

Mild cognitive impairment (MCI) is a condition that causes cognitive changes that are serious enough to be noticed by family members and friends but may not affect the individual's ability to carry out everyday activities. MCI is characterized by subtle changes in memory and thinking and can be caused by a variety of factors. MCI due to Alzheimer's disease is a subtype of MCI. Individuals with MCI may have a higher risk of developing dementia, but some individuals revert to normal cognition or do not have additional cognitive decline. Identifying individuals with MCI who are more likely to develop dementia is important in preparing for future treatment.

>Strongest risk factors for MCI 740

A person with non-amnestic MCI could have difficulty keeping their train of thought during a conversation, finding their way around a once familiar place, or finishing everyday tasks, such as paying a bill.The number of people living with MCI increases with age. It can be caused by medication side effects, sleep deprivation or anxiety, or by stroke or other vascular diseases. To diagnose MCI, physicians review the patient's medical history, conduct patient questionnaires, clinical exams, and brief assessments, and evaluate thinking and memory function. There is no specific treatment for MCI, but physicians may be able to identify reversible causes of cognitive impairment, such as depression, medication side effects, or sleep apnea.When someone is diagnosed with MCI, the outcome can vary depending on the underlying cause and other factors. In some cases, MCI will revert to normal cognition or remain stable.

MCI Due to Alzheimer’s Disease: A Distinct Condition

MCI due to Alzheimer's disease has a specific underlying cause, which is caused by distinct biological changes that lead to the damage and death of nerve cells in the brain. Biomarkers of Alzheimer's disease can be used to diagnose MCI due to Alzheimer's disease. New blood tests are under development that can detect Alzheimer's disease biomarkers even before symptoms appear, which could help identify patients at risk of MCI due to Alzheimer's disease earlier in the disease process. Estimates suggest that 5 million Americans have MCI due to Alzheimer's disease, but the true number is likely far higher. Blood-based biomarkers may help identify individuals with MCI due to Alzheimer's disease.

Progression to Alzheimer’s Dementia Is Not Certain

Evidence suggests that 30% to 50% of people with MCI due to Alzheimer's disease progress to Alzheimer's dementia over a 5- to 10-year period. Accurate diagnosis of MCI due to Alzheimer's disease is crucial for determining when to intervene. Early treatment may be associated with lower overall healthcare costs and a higher quality of life. The development of new treatments for Alzheimer's disease has accelerated in the last 20 years, with 104 drugs being evaluated in clinical trials or at various stages of regulatory approval. The Alzheimer's Association commissioned Versta Research to conduct surveys of U.S. adults and primary care physicians to better understand real-world awareness, diagnosis, and treatment of MCI and MCI due to Alzheimer's disease in the United States.

Understanding MCI and MCI Due to Alzheimer’s Disease Today Key Findings

Americans' awareness of MCI is low, and more than half of all Americans say MCI sounds like "normal aging". They express concern, but also a reluctance to see their doctor. Nearly one-half of Americans worry about developing MCI in the future, and 85% say they would want to know if they had Alzheimer's disease early. However, only 40% say they would talk to their doctor right away when experiencing symptoms of MCI. PCPs are reluctant to diagnose MCI and MCI due to Alzheimer's disease, and many are unfamiliar with clinical trials and research advances that may help diagnose and manage MCI and MCI due to Alzheimer's disease now and in the future. PCPs recommend lifestyle changes, perform laboratory testing for reversible causes of MCI, and/or refer patients to a specialist when MCI is detected. Only 4 in 10 PCPs are familiar with current biomarker tests to aid in the diagnosis of Alzheimer's disease.

Survey Design and Research Methods

A survey of 2,434 U.S. adults was conducted online or via phone from November 5 to December 5, 2021. It included 662 people who were aged 60 or older and 1,772 people who were aged 18 to 59. A survey of 801 U.S. primary care physicians was conducted from November 1, 2021, to November 22, 2021. Physicians reported spending an average of 93% of their time in direct patient care, and 45% of their patients were age 60 or older. Consumers and PCPs express optimism for future Alzheimer's disease treatments. More than 7 in 10 Americans expect new treatments to delay the progression of Alzheimer's disease, and more than half expect new treatments to stop Alzheimer's disease progression. The Alzheimer's Association survey of U.S. adults found that fewer than 1 in 5 Americans are familiar with MCI, and more than 2 in 5 have never heard of MCI. Americans aged 60 and older indicated no greater awareness of MCI.

Patient Reticence in Addressing Concerns About MCI and MCI Due to Alzheimer's

Nearly one-half of Americans worry about developing MCI, and 13% worry "a lot". Asian and Hispanic Americans are more likely to worry than Native, White, and Black Americans. 42% of Americans worry about developing MCI due to Alzheimer's disease, with 14% of individuals indicating they worry "a lot". Despite these concerns, 85% of Americans say they would want to know if they had Alzheimer's disease early, including during the MCI stage. Hispanic and Black Americans are least likely to want to know if they had Alzheimer's disease during an earlier stage, especially when compared with White Americans. Asian and Native Americans are most likely to want to know. Most Americans say they would talk to someone about symptoms of MCI, but only 40% report that they would talk to their doctor right away. The Alzheimer's Association survey revealed that almost 8 in 10 Americans would have concerns about seeing a doctor when experiencing MCI symptoms. Hispanic, Black, Asian, and Native Americans were more likely to cite not having good access to health care as a concern for not seeing a doctor right away for MCI symptoms than White Americans. Despite concerns and some delay, most Americans see value in having MCI and MCI due to Alzheimer's disease diagnosed. However, 27% of Americans see little value in having these diagnoses.

Primary Care Physicians: On the Front Lines of Diagnosing and Caring for Individuals With MCI

PCPs play an integral role in providing dementia care, with 62% of PCPs reporting they receive questions about symptoms consistent with MCI at least weekly. Almost all PCPs are familiar with MCI, and most are comfortable answering patient questions about it. Many PCPs have sought information on MCI due to Alzheimer's disease, and most patients view their PCP as a trusted source for information on the disease. Challenges in making an MCI diagnosis due to Alzheimer's disease include a lack of specialists/facilities to perform diagnostic testing, patient reluctance to pursue follow-up testing, and PCP reluctance to diagnose. Fewer than 1 in 10 PCPs are familiar with biomarker testing for Alzheimer's disease, which could explain why so few patients are referred for testing when MCI is detected. The Alzheimer's Association survey found that nearly all PCPs believe it is important to assess patients for cognitive impairment, but only half of them conduct assessments. PCPs recommend lifestyle changes, laboratory testing for reversible causes of MCI, and/or referral to a specialist when MCI is detected in patients, but infrequently recommend testing for Alzheimer's disease biomarkers or referring patients to clinical trials. There are more than 100 disease-modifying treatments for Alzheimer's disease, yet fewer than 1 in 4 PCPs are familiar with them. More than 7 in 10 Americans expect new treatments to delay the progression of Alzheimer's disease to be available within the next decade, and more than half expect new treatments to stop Alzheimer's disease progression.

A Path Forward: Increasing Awareness and Diagnosis of MCI and MCI Due to Alzheimer's Disease

The Alzheimer's Association proposes four broad efforts to improve the current situation regarding MCI, including MCI due to Alzheimer's disease, among the American public and primary care physicians. Public awareness campaigns and community-based disease education programs can help improve cognitive assessments in the primary care setting and increase physician ability to diagnose cognitive impairment. These programs can help increase public awareness of memory concerns and Alzheimer's disease and encourage more Americans to be proactive in recognizing early symptoms of cognitive impairment and addressing concerns with their physician.

The Alzheimer's Association has partnered with the Ad Council on a campaign to encourage families to discuss cognitive concerns with each other and their doctor sooner to enable early diagnosis of Alzheimer's disease and related dementias. Community-based disease education programs can be tailored to reach diverse communities and raise awareness about MCI, including MCI due to Alzheimer's. Studies indicate that routine use of brief cognitive assessments can increase detection and diagnosis of cognitive impairment two- to threefold. CMS has tried to increase cognitive assessment utilization by making it a requirement of the Medicare Annual Wellness Visit, reimbursing it as a separate visit, and making telehealth evaluation permanent.

Rethinking Assessment Approaches

Currently, many physicians administer cognitive assessments themselves, but time is a barrier to uptake. Using computerized or digital screening assessments outside of exam room time is one approach to overcome time constraints.

Resources

Limited expertise is a barrier to performing cognitive assessments, and was raised by PCPs in the current Alzheimer's Association survey.

Culturally Appropriate Assessment

Clinicians need more cognitive assessment tools for diverse and underserved populations. Adapting existing cognitive assessments or developing new cognitive assessments that are designed specifically for historically underrepresented groups may improve early diagnosis rates among those that are disproportionately affected by Alzheimer's disease and related dementias. Primary care physicians and care teams must be equipped to diagnose and manage MCI and MCI due to Alzheimer's disease, especially in light of a worsening shortage of other specialists, such as geriatricians. The low diagnosis rates for MCI due to Alzheimer's disease can be partially explained by the challenges primary care physicians report in administering diagnostic tests. However, new diagnostic tools, such as blood-based biomarker tests, could simplify the adoption of future diagnostic tools.

As reported in the 2017 Special Report, "Alzheimer's Disease: The Next Frontier", researchers are working to discover new biomarkers and evaluate this approach. These advances will help primary care physicians rule out modifiable causes of symptoms and ascertain when it may be appropriate to refer patients to clinical trials. Although less frequently cited than other challenges, physicians acknowledge that they have difficulty diagnosing MCI due to Alzheimer's disease. The Alzheimer's Association is partnering with primary care clinicians to increase equitable access to timely detection, accurate diagnosis, and quality, person-centered care for people living with dementia. The UCLA Alzheimer's and Dementia Care Program uses nurse practitioners and dementia care specialists to manage the care of people living with dementia, reducing emergency department visits, days spent in the hospital, admissions to nursing homes for long-term care, and overall Medicare costs.

Recommendations outlined in the Alzheimer's Association 2021 Alzheimer's Disease Facts and Figures Special Report still hold true this year. A diverse, representative, culturally-competent primary care workforce would strengthen trust with underserved populations. Public awareness campaigns, community outreach efforts, and online patient communities can all be used to help recruit people for Alzheimer's disease clinical trials. Building relationships with community-based organizations and trusted leaders from underrepresented groups can also help facilitate education and the delivery of dementia-related information and resources. PCPs may not see the value in referring their patients to clinical trials due to potential risks, concerns from their patients, and logistical obstacles. The Alzheimer's Association survey of PCPs found that fewer than 4 in 10 believe participation in clinical trials is an important benefit of early detection of Alzheimer's disease. Education regarding the value and benefits of clinical trial participation is warranted, as well as a heightened need for PCP referral.

Conclusion

The Alzheimer's Association urges the public to be aware of MCI, including MCI due to Alzheimer's disease, and to help primary care physicians identify, diagnose and manage patients' cognitive impairment at its earliest stages.

Alzheimer's Association. (2020). *On the Front Lines: Primary Care Physicians and Alzheimer’s Care in America*. https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf