Kronkosky Charitable Foundation

Research Brief

Alzheimer's Disease

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Alzheimer's disease is the most common form of dementia, constituting 60-80% of all dementia cases. The 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) by the American Psychiatric Association includes two dementia categories in the diagnostic classification of neurocognitive disorders:

- *Mild neurocognitive disorder* classification requires that "individual must have evidence of modest cognitive decline, but the decline does not interfere with everyday activities (individuals can still perform complex activities such as paying bills or managing medications, but the activities require greater mental effort)" (Simpson, 2014, p.160)
- *Major neurocognitive disorder* classification requires that an individual must have evidence of significant cognitive decline including "memory, attention, learning, language, perception, and social cognition" (Grohol, 2018) and the decline must interfere with independence in everyday activities

Alzheimer's disease is a degenerative brain disease where nerve cells in the brain are damaged and no longer function properly (Alzheimer's Association, 2018a). Plaques represent a type of physical abnormality seen in brains of people with Alzheimer's disease. Plaques occur when the protein amyloid-beta builds up between neurons, causing the neurons to clump and die. Another brain abnormality in Alzheimer's patients is the presence of tangles. Tangles occur when the protein tau causes neurons to twist, resulting in tremendous neuron damage (Mayo Clinic, 2018).

Criteria and Guidelines

"In 2011, the National Institute on Aging (NIA) and the Alzheimer's Association proposed revised criteria and guidelines for diagnosing Alzheimer's disease," and in 2012, "the NIA and the Alzheimer's Association also developed new guidelines to help pathologists describe and categorize the brain changes associated with Alzheimer's disease and other dementias on autopsy" (Alzheimer's Association, 2018a, p.15). Incorporating scientific advances since the original guidelines were published in 1984; the new guidelines identify three stages of Alzheimer's disease and include the use of biomarker tests. These recommended guidelines are not yet in use in clinical settings pending additional research on biomarker tests. Levels of certain proteins in blood and cerebrospinal fluid are being studied as potential biomarkers for Alzheimer's disease similar to the way that blood glucose levels are used to diagnose diabetes.

Three Stages of Alzheimer's

1. *Preclinical Alzheimer's disease*. "In this proposed stage, which must be validated with additional research, individuals have measureable changes in the brain, cerebrospinal fluid and/or blood (biomarkers) that indicate the earliest signs of disease, but they have not yet developed symptoms such as memory loss." (Alzheimer's Association, 2018a, p. 15). It is estimated that

brain changes occur as many as 20 years before symptoms are evident.
2. *Mild Cognitive Impairment (MCI) due to Alzheimer's disease.* Includes individuals who have mild but measureable changes in thinking abilities that do not affect the ability to carry out everyday activities. It is estimated that 15-20 percent of people age 65 and older have MCI.
3. *Dementia due to Alzheimer's disease.* Cognitive impairment interferes with an individual's ability to function in daily life and is caused by Alzheimer's disease-related processes.

(Alzheimer's Association, 2018a)

The Progression of Alzheimer's Disease

Alzheimer's disease progressively affects memory, thinking, and behavior. According to the Global Deterioration Scale (Alzheimer Society Canada, 2018), there are seven key stages of Alzheimer's development:

Stage One: *No cognitive impairment*
- No memory problems evident

Stage Two: *Very mild cognitive decline*
- Memory lapses for familiar words and names
- Lapses not evident to friends, family, co-workers, or doctors

Stage Three: *Mild cognitive decline*
- Friends, family, and co-workers begin to notice deficiencies in memory
- Problems with memory, retention, and concentration
- Difficulty naming objects or people
- Decreased performance of daily activities
- Decline in ability to plan or organize

Stage Four: *Moderate cognitive decline*
- Clear cut deficiencies in knowledge of recent events
- Decreased capacity to perform complex tasks such as planning Thanksgiving dinner or managing finances
- Demeanor may be subdued or withdrawn

Stage Five: *Moderately severe cognitive decline*
- Major gaps in memory and cognitive functioning
- Need for assistance with daily functions
- Confusion about location and date

Stage Six: *Severe cognitive decline*
- Increased memory deficits
- Significant personality changes
- Difficulty recalling personal history
- Tendency to wander and become lost
- Impaired ability to execute common actions such as dressing oneself

Stage Seven: *Very severe cognitive decline*
- Little to no ability to speak
- Failure to recognize objects and people
- Loss of voluntary muscle control
- Assistance required for all daily functions

Patients may not exhibit all signs and symptoms of each stage, nor does the disease progress at an equal rate in every patient. The Alzheimer's Association reports "studies indicate that people age 65 and older survive an average of 4 to 8 years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years with Alzheimer's" (Alzheimer's Association, 2018a, p.28).

Prevalence and Risk Factors

Currently, an estimated 5.7 million people in the United States are living with Alzheimer's disease. The majority, 5.5 million, are over age 65, while only 200,000 are younger than 65 (Alzheimer's Association, 2018a, p.17).

The single greatest known risk factor for Alzheimer's disease is age. Approximately 10% of Americans over the age of 65 have Alzheimer's disease with higher incidence as age increases. Approximately 32% of seniors 85 and older have Alzheimer's disease (Alzheimer's Association, 2018a).

It is estimated that Alzheimer's disease effects one in ten people aged 65 and older. As a result of a longer life expectancy, women are more likely to develop Alzheimer's disease than men and currently two-thirds of Alzheimer's patients are women. Alzheimer's disease and dementias account for approximately 16 percent of women as opposed to only 11 percent of men. While women represent 3.4 million of Americans with Alzheimer's, men represent 2.1 million but there is no indication that women were more likely than men to develop the

disease at any given age (Alzheimer's Association, 2018a).

The first baby boomers only recently (2011) reached the age of 65. "When the first wave of baby boomers reaches age 85 (in 2031), it is projected that more than 3 million people age 85 and older will have Alzheimer's dementia." (Alzheimer's Association, 2018a, p.23). As Americans live longer and the baby boomer generation ages, rates of Alzheimer's disease are also projected to grow exponentially:

Year	Estimated new U.S. cases
2010	454,000
2030	615,000
2050	959,000

(Alzheimer's Association, 2018a)

This growth in Alzheimer's cases is also expected to occur in Texas. While 380,000 Texans aged 65 and older were projected to have Alzheimer's in 2018, it is projected that the number of cases will increase to 490,000 by 2025 (Alzheimer's Association, 2018a, p.19).

Other risk factors for Alzheimer's disease include family history, genetics, environmental factors, and history of severe head injury. It is believed that certain genetic factors may increase the potential for developing Alzheimer's disease. "Most people with Down syndrome develop Alzheimer's. This may be because people with Down syndrome have an extra copy of chromosome 21, which contains the gene that generates harmful amyloid" (NIA, 2016).

The genetic presence of particular forms of the protein Apoliprotein-E (ApoE4) gene, which occurs in people with late-onset Alzheimer's disease, has been identified as a potential risk factor. Early- onset Alzheimer's disease has been linked to mutations in three genes. "A blood test can identify which APOE alleles a person has, but results cannot predict who will or will not develop Alzheimer's disease" (NIA, 2015). Except for research (clinical trials) and to help doctors diagnose early-onset Alzheimer's, genetic testing is not recommended. Other risk-factor genes are under investigation.

Researchers are also investigating the association between various lifestyle factors related to the cardiovascular system and their influence on Alzheimer's disease. Because the brain contains numerous blood vessels, conditions such as smoking, obesity (especially in midlife), diabetes, high cholesterol in midlife, and hypertension in midlife may be linked to the onset of Alzheimer's disease (Alzheimer's Association, 2018a).

Recent research suggests that the prevalence and risk of Alzheimer's disease is higher in both Hispanics and African Americans, as compared with other Americans, perhaps due to socioeconomic factors as well as higher rates of cardiovascular diseases. Specific prevalence rates among each racial and ethnic group remain unclear. This ambiguity is largely attributable to African Americans and Hispanic Americans avoiding or delaying treatment, causing the disease to go undiagnosed (Alzheimer's Association, 2018a).

Additionally, new research has linked fewer years of education to an increased risk of developing Alzheimer's disease. The exact cause of this association remains unclear. Some researchers theorize that additional years of education allow for the development of more brain synapses resulting in a greater reserve as individuals age while others believe that those with lower education also are subject to other risk factors common to lower socioeconomic groups including increased risk for disease in general and less access to medical care (Alzheimer's Association, 2018a).

TREATMENT

No known cure for Alzheimer's disease exists, but there are two types of FDA approved drugs which can delay its progression:

1. *Cholinesterase inhibitors*
    a. Prevent the breakdown of the chemical acetylcholine (which aids memory and thinking)
    b. Delay symptoms for 6-12 months in approximately half of patients.
    c. Used for those with mild to moderate Alzheimer's disease

2. N-methyl D-aspartate (NMDA) antagonists
    a. Help regulate the activity of glutamate (which aids information processing)
    b. Used for those with moderate to severe Alzheimer's disease

(NIA, 2018)

"These drugs work by regulating neurotransmitters, the brain chemicals that transmit messages between neurons…these drugs don't change the underlying disease process. They are effective for some, but not all people and may help only for a limited time" (NIA, 2016).

Several drugs targeting beta-amyloid, the chief component of plaques, are under investigation. "This includes blocking activity of beta-secretase enzyme; preventing the beta-amyloid fragments from clumping into plaques; and even using antibodies against beta-amyloid to clear it from the brain (Alzheimer's Association, 2017).

Other medical treatments seek to alleviate Alzheimer's symptoms beyond cognitive impairment such as sleeplessness, agitation, wandering, anxiety, aggression, and depression (NIA, 2016). Currently there are 44 supported Geriatrics Workforce Enhancement Program grantees that provide dementia education and training to healthcare providers as well as over 9,000 research projects from around the world to discover and develop new therapies (U.S. Department of Health and Human Services [HHS], 2018).

Respite Services

Proper care and support is essential to reduce the complications common to Alzheimer's, including pneumonia, infections, falls, fractures, and malnutrition (Mayo Clinic, 2018). Currently, over 16 million Americans, usually relatives or friends, provide unpaid care for individuals suffering from dementia or Alzheimer's disease. In 2017, 1.4 million Texas caregivers provided 1.6 billion hours of unpaid care to dementia and Alzheimer's patients. Because it is possible for a patient to live with the disease for many years, the emotional and financial burden on caregivers can be overwhelming. Consequently, it is common for the caregivers themselves to suffer from illnesses such as heart disease, high-blood pressure, and poor mental health (depression). These health issues are often directly related to the stress and anxiety that comes with caring for a loved one with Alzheimer's disease (Alzheimer's Association, 2018a). Fortunately, there are several types of services that exist to support caregivers.

One option available to caregivers is in-home care services, which involves a professional coming to the home to assist the caregiver and individual suffering from dementia with a variety of tasks. The following are common in-home care services:

- ***Companion services***: assist caregiver with supervision, recreational activities, and visiting
- ***Personal care services***: provide help with bathing, dressing, toileting, exercising, or other personal care needs
- ***Homemaker services***: provide assistance with housekeeping, shopping, and meal preparation
- ***Skilled care***: assists with wound care, injections, physical therapy and other medical needs, usually conducted by a licensed health professional

(Alzheimer's Association, 2019a)

Outside of the home, adult day services provide those suffering from dementia or Alzheimer's disease opportunities for social interaction and a safe environment to participate in activities. These adult day programs provide a variety of services, including meals, social and educational activities, exercise, and various types of therapy, counseling, and medical treatment. Typically, these services are available daily and most programs are flexible with attendance requirements. "Over 80% of participants attend full days and 46% attend five days per week, enabling family caregivers to remain in the workforce" (National Adult Day Services Association, n.d.). Most adult day centers also provide a variety of caregiver support programs including education, support groups, and counseling.

Locating respite services for adults can be challenging for caregivers. There are several

online locator services that can help. Network of Care (2019) lists 34 adult day care centers in Bexar County, eight in Comal County, and one in Kendall County while the National Respite Network and Resource Center (n.d.), lists 20 facilities that offer respite care for adults age 60 and over in Bexar County and three in Comal County. The Alzheimer's Association (2018b) has a Community Resource Finder that lists 35 adult day care programs in Bexar County and 4 in Comal County. Many, but not all, programs are listed on more than one site.

Long-term respite care facilities include assisted living facilities, residential care facilities, and nursing homes. These programs provide overnight, weekend, or long-term stays when a caregiver experiences illness or other emergency situations. Services include meals, daily living help, therapeutic activities, and a safe setting to reduce wandering (Alzheimer's Association, 2019b).

For those individuals who need specialty care, there are several different kinds of facilities which assist in care for different stages of Alzheimer's. These facilities include:

- ***Retirement housing*** for early stage Alzheimer's patients who are still able to care for themselves and require no more than limited supervision, social activities, and transportation
- ***Assisted living*** *(also called board and care, adult living or supported care)* offers moderately independent Alzheimer's patients housing, meals, supportive services, and health care (these facilities are not government regulated)
- ***Nursing homes*** *(also called skilled nursing facility, long-term care facility or custodial care)* offer around-the-clock care and long-term medical treatment for mid to late-stage Alzheimer's patients (these facilities are regulated by both state and federal governments)
- ***Alzheimer's special care units (SCUs)*** *(also called memory care units)* assist those with dementia or Alzheimer's disease and can be found in many types of care facilities
- ***Continuing care retirement communities (CCRC)*** give either independent, assisted living, or nursing home levels of care depending on individual need

(Alzheimer's Association, 2019b)

The High Cost of Alzheimer's Disease

Alzheimer's disease also creates an enormous economic responsibility for caregivers, the government, through Medicare and Medicaid, and independent businesses. The following statistics, provided by the Alzheimer's Association (2018a, p.50), represent typical costs associated with Alzheimer's care.

Average costs for Alzheimer's services:

- ***Adult day care service*** – $70 per day
- ***Assisted living*** – approximately $3,750 per month or $45,000 per year (dementia care often results in additional charges)
- ***Nursing Homes*** – about $267 per day or $97,455 per year (for a semi-private room the cost is around $235 per day or $85,775 per year)
- ***Home care*** – cost for a nonmedical home health aide was $22 per hour or $135 for an eight-hour day

The high costs incurred from Alzheimer's disease are also reflected on United States businesses due to caregiver absenteeism, loss of productivity, and employee turnover. Independent businesses accrue additional costs from health care, long-term care, and hospice for people with Alzheimer's disease and other dementias. The total estimated cost for health care and long-term care for people aged 65 and older with Alzheimer's disease and other types of dementia is expected to be $277 billion for the year 2018. By the year 2050, the cost is expected to rise to more than $1.1 trillion (Alzheimer's Association, 2018a).

Mortality

Although physicians have developed advanced ways of detecting dementia, Alzheimer's disease can only be definitively diagnosed through an autopsy (NIA, 2016). In any given year, one-third of all seniors who die are found to have Alzheimer's or some form of dementia. For people aged 65 and older, "recent

estimates indicate that the disorder may rank third, just behind heart disease and cancer, as a cause of death" (NIA, 2016). Alzheimer's disease is officially listed as the sixth-leading cause of death in the United States (Alzheimer's Association, 2018a, p.25).

For the year 2015, Alzheimer's disease was the underlying cause of death for 8,903 individuals in Texas. The U.S. annual Alzheimer's death rates show that deaths attributed to the disease increase drastically with age. The increase in deaths attributed to Alzheimer's disease over time has disproportionately affected the oldest-old: "Between 2000 and 2015, the death rate from Alzheimer's increased only 20 percent for people age 65 to 74, but increased 52 percent for people age 75 to 84, and older" (Alzheimer's Association, 2018a, p.29).

Researchers at the U.S. Department of Health and Human Services (HHS) hope to have preventative and treatment options by 2025. The HHS plans to accelerate any medication that may be able to prevent or treat the illness and hope to be able to expedite the clinical trials. Researchers are currently attempting to create new medications that will either slow the progression of the disease, or lessen the symptoms (HHS, 2018).

"Scientists have developed methods to measure and compare the burden of different diseases on a population in a way that takes into account not only the number of people with the condition, but also both the number of years of life lost due to that disease as well as the number of healthy years of life lost by virtue of being in a state of disability. These measures indicate that Alzheimer's is a very burdensome disease and that the burden of Alzheimer's has increased more dramatically in the United States than other diseases in recent years. The primary measure of disease burden is called disability-adjusted life years (DALYs), which is the sum of the number of years of life lost due to premature mortality and the number of years lived with disability, totaled across all those with the disease. Using this measure, Alzheimer's rose from the 25th most burdensome disease in the United States in 1990 to the 12th in 2015. No other disease or condition increased as much" (Alzheimer's Association, 2018a, pp.29-30).

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