

Alzheimer's Disease and Related Dementia in the Hispanic/Latino Community



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MHP Salud

MHP Salud is a national nonprofit organization that implements and runs Community Health Worker (CHW) programs. Our CHWs have been serving America's Latino community for 38 years. These programs provide peer health education, increase access to health resources and bring community members closer. MHP Salud also has extensive experience offering health organizations training and technical assistance on CHW programming tailored to their specific needs as well as key issues affecting older Hispanic adults.

The Alzheimer's Association®

The Alzheimer's Association® is the leading voluntary health organization in Alzheimer's care, support, and research.

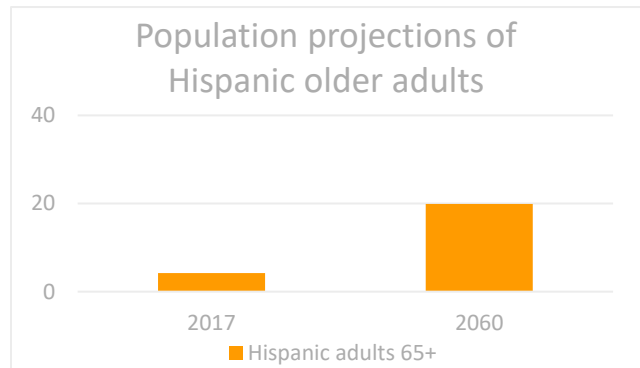
Our Vision: A world without Alzheimer's and all other dementia®

Our Mission: The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

This resource was developed by MHP Salud with essential guidance and understanding about ADRD provided by Alzheimer's Association – San Antonio and South Texas Chapter. This resource was created to bring information to service providers and caregivers about how dementia affects the Hispanic/Latino community. We will use the term "dementia" to refer to Alzheimer's disease or related dementia (ADRD) throughout this resource. We will also use the term "Hispanic" to refer to both the Hispanic and Latino community and individuals of all reported races.

How does Dementia Affect the Hispanic Population?

The older adult population is growing in the United States. In 2017, there were an estimated 80.9 million adults aged 65 and older, and that number is projected to increase to 94.7 million by the year 2060.ⁱ According to US Census Bureau population projections, Hispanic older adults are expected to increase from approximately 4.2 million in 2017 to 19.9 million in 2060. In other words, approximately 1 in 5 older adults is expected to be Hispanic by 2060.ⁱⁱ



The Alzheimer's Association indicates that dementia is a general term for loss of memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life. Alzheimer's disease is the most common form of dementia; however, Lewy Body Dementia, Vascular Dementia, Frontotemporal Dementia, Parkinson's, and Huntington's are other forms of dementia. Although the likelihood of an individual developing dementia is decreasing due to prevention efforts,ⁱⁱⁱ the growth of the older adult population means there will be more individuals that will develop dementia in the coming decades. The US Centers for Disease Control and Prevention (CDC) estimates that the US burden of Alzheimer's disease and related dementia (ADRD) will double by 2060.^{iv}

Hispanics are 1.5 times more likely than non-Hispanic whites to develop Alzheimer's Disease.^v It is estimated that 3.2 million Hispanics will have Alzheimer's disease or a related dementia by 2060, the highest prevalence among any racial or ethnic group.^{vi} Hispanic individuals develop Alzheimer's at a younger age than their white counterparts. One study found that Hispanics were an average of four years younger than whites at the time of diagnosis (72.1 vs 76.4 years old),^{vii} while another found that Hispanics had a mean age at symptom onset of 6.8 years younger than whites.^{viii}

Alzheimer's disease is one of the costliest conditions in society, and it is the 6th leading cause of death among Hispanics in the US^{ix}. According to the Alzheimer's Association 2021 report, Hispanics with Alzheimer's or other dementias are paying much more than non-Hispanic whites in hospital care (\$8,004 vs \$5,915) and significantly less for Hospice Care (\$1,964 vs \$3,563).^x Hispanic unpaid caregivers experience significant financial loss due to missed work for caretaking responsibilities.

As the population grows, more Hispanic older adults will develop dementia, as will the number of caregivers for these individuals. People living with dementia and their caregivers will increasingly need culturally and linguistically appropriate supports and services to reduce the burden of dementia, reduce costs, and promote a better quality of life. This document will discuss reasons behind this health disparity, examine cultural influences to understanding and coping with

dementia among Hispanics, provide strategies for talking with Hispanics about dementia, and finally, discuss how to diagnose dementia.

Risk Factors for Dementia in the Hispanic Community

There are some risk factors that make Hispanics more likely to develop dementia over their lifetime. Below you will find more information about each:

Medical Conditions		
	Risk	Health Disparity
High blood pressure	Having high blood pressure increases the risk of developing dementia.	Hispanic adults have high prevalence of poorly controlled blood pressure compared to other racial and ethnic groups. ^{xi}
Diabetes	The presence of diabetes increases the risk of developing Alzheimer’s by 54%. ^{xii}	Hispanic adults have the second highest rate of diabetes (12.5%) of any racial/ethnic group in the US, second only to American Indians/Alaskan Natives. ^{xiii} It is expected that diabetes prevalence will continue to grow in the Hispanic population.
Heart disease	Heart disease can damage the functioning of the brain and is linked to dementia.	Approximately 7.4% of Hispanic adults had heart disease in 2017. ^{xiv}
Stroke	Stroke can cause vascular dementia and is also associated with the development of other forms of dementia.	Incidence of stroke is significantly higher among Hispanic adults than non-Hispanic whites and other racial and ethnic groups. They are also more likely to have a recurrent stroke. ^{xv}
Obesity	Being overweight, especially obese, makes an individual more likely to develop dementia. ^{xvi}	In 2018 Hispanic Americans were 1.2 times more likely to be obese than whites. ^{xvii}
Health-Related Behaviors		
Smoking	Smoking increases the risk for heart disease and stroke and developing diabetes, all of which are linked to developing dementia.	Some Hispanic subgroups have high prevalence of smoking [for example, higher rates among Cubans (50% men and 35% women) and Mexican individuals]. ^{xviii}
Sedentary Lifestyle	Sedentary lifestyle, or physical inactivity is a risk factor for developing dementia and is associated with several chronic conditions that are also associated with dementia. ^{xix}	Hispanic individuals are more likely to live in areas that are not conducive to or safe for engagement in physical activity. The specific barriers may change depending on the community but may include rural environments, unsafe urban environments, among other factors. ^{xx}

There are additional factors that impact an individual's risk for developing dementia, regardless of race/ethnicity. These include:

- **Age.** The likelihood of developing dementia increases with age. The longer someone has diabetes, the greater the likelihood they will develop dementia, and Hispanic individuals are often diagnosed with diabetes at a younger age.^{xxi}
- **Social Isolation.** Having few or infrequent social contacts is associated with about a 50% increased risk of dementia and other serious medical conditions.^{xxii}
- **Alcohol Use.** Those who drink alcohol excessively over long periods of time increase their risk of developing dementia.
- **Down Syndrome and mild cognitive impairment.** People with cognitive impairment have a significantly increased risk of developing dementia as they age.^{xxiii}
- **Homelessness.** Research suggests that homelessness, especially among homeless veterans, may increase the risk for developing dementia at a younger age.^{xxiv}

Cultural Influences and Barriers to Understanding and Coping with Dementia within the Hispanic Community

It is important to consider cultural influences and barriers that affect how the Hispanic/Latino community understands and copes with dementia in older adults.

- **Stigma.** There is a stigma around the topic of Alzheimer's and dementia. Because of this, there is a fear associated with being diagnosed and sharing that diagnosis with loved ones and family members. This can lead to a delayed diagnosis of dementia for Hispanic individuals.
- **Familismo.** This term refers to the cultural value in the Hispanic community that places the family's needs above the needs of the self. Older Hispanic adults may not tell anyone about their diagnosis because they do not want to be a burden to their loved ones. This may also contribute to a delay in seeking care and getting a diagnosis. *Familismo* also can be seen in the preference for family caregiving, which can create high-intensity caregiving situations when the older adult has dementia. This can affect caregiver health and financial stability.
- **Language.** 73% of Hispanics in the US speak Spanish at home.^{xxv} Many older adults who do not speak English are not able to communicate effectively with their health providers. Similarly, written materials are often only available in English and those that are in Spanish may not be at an appropriate reading level for the older adult Hispanic community.
- **Mistrust in the Medical Community.** Many Hispanic older adults have mistrust in the medical community. This is due to a long history of unethical medical practices in communities of color including in research and forced sterilization.
- **Structural Racism.** Socioeconomic factors, discrimination, and structural racism all play a role in increasing the probability of having medical conditions that put Hispanics at risk of developing dementia.^{xxvi} For example, tobacco products are advertised and promoted disproportionately to racial/ethnic minority communities,^{xxvii} contributing to higher rates of smoking and the ill health effects associated with it. These factors also limit access to

preventive health care and potentially early diagnosis and intervention for older Hispanic adults with undiagnosed dementia.

Strategies for Talking about Dementia with Older Hispanic Adults, Their Families and Caregivers

- **Build Trust.** Having a trusting relationship with the Hispanic community is important for service providers because there is often distrust of medical professionals.
- **Speak the Language.** As mentioned above, many Hispanic older adults and their caregivers speak Spanish at home. Therefore, it is important for service providers to communicate in the preferred language of the Hispanic community to have effective communication about dementia.
- **Provide Support.** Offering support to the family and caregivers is important when talking about dementia with Hispanics. Many informal caregivers feel a heavy burden, and they do not know what resources are available. In-person and virtual support groups and counseling are available. *See below for more information on finding a support group near you.
- **Community Health Workers (CHWs).** CHWs are trusted members of the community who empower their peers through education and connections to health and social resources. CHWs can educate the community about dementia and can provide support to families and caregivers through informal counseling, case management and other strategies. **Contact MHP Salud for more information about how CHWs can help address dementia in your community by visiting mhpsalud.org or emailing info@mhpsalud.org.**
- **Outreach and Education.** Provide education explaining that dementia is not a “normal” part of aging. Explain the importance of seeking treatment. In fact, some cognitive impairments may be due to conditions that are reversible and treatable!^{xxviii}
- **Address Stigma.** Although dementia is not a normal part of aging, it is not an uncommon diagnosis and the stigma and fear in the Hispanic community surrounding a diagnosis of dementia can prevent seeking a diagnosis. If providers normalize having conversations about dementia with the community, perhaps people will be more likely to open up about their concerns.

How is Dementia Diagnosed?

Alzheimer's disease and dementia are often underdiagnosed among Hispanics.^{xxix} There is no single diagnostic test that can determine if a person has dementia. If someone suspects they or a loved one are experiencing symptoms of dementia, they should visit their Primary Care Physician. If that doctor suspects dementia, a referral is made to a specialist who can help make a diagnosis. This may include geriatricians, neurologists, neuropsychologists, and geriatric psychiatrists. Although physicians can almost always determine if a person has dementia, it may be difficult to identify the exact cause. A dementia diagnosis usually involves the following^{xxx}:

- Asking questions about a person's medical history.
- Completing physical health and mental status exams.
- Carrying out some tests.

There are many different tests that can be used to determine if someone is suffering from dementia or another health condition. Some standard tests include cognitive tests such as memory testing, problem solving, attention, counting, and language and communication; medical tests such as blood and urine tests; neurological exams; and brain imaging. Some of these tests are done to rule out other causes for the dementia symptoms.^{xxxi}

Research is limited on dementia among Hispanics, but there are some studies being conducted to better understand how it affects this diverse community.^{xxxii} One thing is certain: we must provide culturally appropriate information when addressing dementia in the Hispanic community.

“Early diagnosis is key to helping people and their families cope with loss of memory, navigate the healthcare system, and plan for their care in the future.” - CDC Director Robert R. Redfield, M.D.^{xxxiii}

10 Warning Signs and Symptoms of Alzheimer's:

If we pay attention to warning signs of dementia, it is possible to get an early diagnosis and potentially treat some of the symptoms. Below you can find the ten warning signs and symptoms of Alzheimer's disease. Providers are encouraged to refer patients they suspect of having dementia to one of the above-mentioned specialists.

1. Memory loss that disrupts daily life.
2. Challenges in planning or solving problems.
3. Difficulty completing familiar tasks.
4. Confusion with time or place.
5. Trouble understanding visual images and spatial relationships.
6. New problems with words in speaking or writing.
7. Misplacing things or losing the ability to retrace steps.
8. Decreased or poor judgement.
9. Withdrawal from work or social activities.
10. Changes in mood or personality.

Families and/or caregivers can access the **Community Resource Finder** at www.alz.org/crf, a search engine provided by the Alzheimer's Association in partnership with AARP. In the Medical Services section, an individual can enter their zip code and it will generate a list of Neurologists and Geriatricians in their area. This resource finder can also be used to find support groups, education classes, early-stage engagement programs and other helpful resources.

*Families can also contact the **Alzheimer's Association's helpline at 800.272.3900**. The helpline is available 24 hour a day, 7 days a week. Through this free service, specialists and master's-level clinicians offer confidential support and information to people living with dementia, caregivers, families, and the public. Receive help in your preferred language through their bilingual staff or translation service, which accommodates more than 200 languages.

Preventing Dementia among Hispanic Older Adults

Promoting and maintaining good brain health may help prevent developing dementia. Individuals should be encouraged to: ^{xxxiv}

- **Maintain a healthy weight**
- **Eat healthy options**
- **Manage health problems and chronic conditions like diabetes, high blood pressure, and cholesterol**
- **Practice mental agility exercises like doing puzzles, reading, and practicing hobbies**
- **Don't smoke or drink alcohol excessively**
- **Engage in physical activity**
- **Interact socially with others and stay connected**

Hispanic communities experience disproportionate rates of dementia in their community. It is important to have an understanding of the unique barriers that this population faces when providing education about dementia and dementia services. To eliminate this health disparity, we need to address structural racism in our society which prevents equitable access to healthy lifestyles, financial stability, and social support for all communities.^{xxxv} With prevention efforts and culturally appropriate interventions, we can help reduce the burden of dementia in the Hispanic community.

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- ⁱ 018 Profile of Hispanic Americans Age 65 and Over was developed by the Administration for Community Living, U.S. Department of Health and Human Services.
- ⁱⁱ 018 Profile of Hispanic Americans Age 65 and Over was developed by the Administration for Community Living, U.S. Department of Health and Human Services.
- ⁱⁱⁱ <https://www.who.int/news-room/fact-sheets/detail/dementia#:~:text=Rates%20of%20dementia&text=The%20total%20number%20of%20people,%2D%20and%20middle%2Dincome%20countries.>
- ^{iv} <https://www.cdc.gov/media/releases/2018/p0920-alzheimers-burden-double-2060.html>
- ^v <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
- ^{vi} <https://www.cdc.gov/media/releases/2018/p0920-alzheimers-burden-double-2060.html>
- ^{vii} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4013239/>
- ^{viii} <https://jamanetwork.com/journals/jamaneurology/fullarticle/788487>
- ^{ix} <https://www.cdc.gov/nchs/fastats/alzheimers.htm>
- ^x <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
- ^{xi} <https://pubmed.ncbi.nlm.nih.gov/31045586/>
- ^{xii} https://www.usagainstalzheimers.org/sites/default/files/Latinos-and-AD_USC_UsA2-Impact-Report.pdf
- ^{xiii} <https://www.diabetes.org/resources/statistics/statistics-about-diabetes>
- ^{xiv} https://www.cdc.gov/nchs/spotlight/HeartDiseaseSpotlight_2019_0404.pdf
- ^{xv} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2621018/>
- ^{xvi} <https://www.nia.nih.gov/news/obesity-associated-higher-risk-dementia-new-study-finds>
- ^{xvii} <https://minorityhealth.hhs.gov/omh/browse.aspx?vl=4&lvlid=70>
- ^{xviii} <https://www.cdc.gov/tobacco/disparities/hispanics-latinos/index.htm>
- ^{xix} <https://www.nature.com/articles/s41398-020-0799-5>
- ^{xx} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5020509/>
- ^{xxi} <https://www.cdc.gov/diabetes/library/features/hispanic>
- ^{xxii} <https://www.cdc.gov/aging/publications/features/lonely-older-adults.html>
- ^{xxiii} <https://stanfordhealthcare.org/medical-conditions/brain-and-nerve/dementia/risk-factors.html>
- ^{xxiv} <https://www.va.gov/HOMELESS/nchav/resources/docs/veteran-populations/aging/Schinka-Early-Cognitive-Division-Decline-And-Dementia-In-Homeless-Veterans-January-2019-508.pdf>
- ^{xxv} <https://www.pewresearch.org/hispanic/2015/05/12/english-proficiency-on-the-rise-among-latinos/#:~:text=than%2020%20years.-,Spanish%20Language%20Use%20Among%20U.S.%20Hispanics,Hispanic%20population%20continues%20to%20grow.>
- ^{xxvi} <https://www.usagainstalzheimers.org/networks/latinos#:~:text=Latinos%20are%201.5%20times%20more,for%20Alzheimer's%20and%20other%20dementias>
- ^{xxvii} <https://www.cdc.gov/tobacco/disparities/hispanics-latinos/index.htm>
- ^{xxviii} <https://www.usagainstalzheimers.org/learn/early-detection>
- ^{xxix} <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
- ^{xxx} <https://stanfordhealthcare.org/medical-conditions/brain-and-nerve/dementia/diagnosis.html>
- ^{xxxi} <https://www.nia.nih.gov/health/how-alzheimers-disease-diagnosed>
- ^{xxxii} <https://www.nia.nih.gov/news/studies-explore-alzheimers-risk-factors-biomarkers-latinos>
- ^{xxxiii} <https://www.cdc.gov/media/releases/2018/p0920-alzheimers-burden-double-2060.html>
- ^{xxxiv} <https://stanfordhealthcare.org/medical-conditions/brain-and-nerve/dementia/prevention.html>
- ^{xxxv} <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>



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