

ONEIDA

Equity in Alzheimer's and Dementia Care


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Introduction

- People of all color need to feel seen and heard in the navigation of Alzheimer's Disease and related dementias. Understanding the need for health equity and the impact of health disparities for those affected and their care providers is crucial to improving the trust and relationships we have with the members of our community.
- In this session:
 - we will discuss how Dementia caregiving should be common, regardless of race or ethnicity.
 - We will understand the impact of Health Equity from the patient and caregiver perspective.
 - We will discuss how a tribal organization has made strides to grow and understand dementia.



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Statistics

In a 2024 Special Report on "Mapping a Better Future for Dementia Care Navigation," the Alzheimer's Association reported higher rates of discrimination among people of color when seeking health care:

- 50% of Black Americans.
- 42% of Native Americans.
- 34% of Asian Americans.
- 33% of Hispanic Americans.

Non-Hispanic White Americans reported discrimination at a much lower rate of 9%.
(Barriers to equity in Alzheimer's and dementia care 2021)




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Statistics

According to the March 2004 Alzheimer's Association Facts and figures report:

- There are 205,000 Alzheimer's and Dementia Family Caregivers across Wisconsin providing an estimated 297 million hours of unpaid care valued at \$5.5 Billion dollars
- Dementia caregivers report higher rates of chronic conditions like stroke, heart disease, diabetes and cancer.
- The prevalence of depression is higher among dementia caregivers, in Wisconsin, 27.8% of caregivers report depression.
- 74% of dementia caregivers report they are somewhat to very concerned about their ability to maintain their own health.
- 59% of dementia caregivers across the country report high to very high emotional stress due to caregiving
- 38% of dementia caregivers report high to very high physical stress due to caregiving

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Why does culture matter?

- Culture refers to integrated patterns of human behavior that include language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious or social groups.



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Culture Shapes

- How health care information is received
- How patient rights are exercised
- What a person considers to be a health problem
- How symptoms and concerns are shared with family and others
- Who should treat the problem

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Common Cultural Beliefs About Alzheimer's and Dementia

Cultural beliefs about Alzheimer's and dementia vary between different races and ethnicities. There are many possible reasons:

- Tendency to view Alzheimer's as a normal part of aging or "old timer's disease"
- Lack of awareness and education about Alzheimer's and other mental health conditions
- Shame and guilt about mental health conditions
- Distrust in Western medicine, doctors, or clinical trials
- Respect for elders and their wishes for their health care
- Not sharing "private family matters" with strangers
- Choosing to look to religious leaders for support and guidance
- Using religion or prayer to cope with caregiver stress and burnout




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What is the Impact on Dementia Care?

Dementia healthcare trajectory

- Initial assessment, diagnosis, and referral:** Delayed diagnosis, Misdiagnosis, Fewer specialist referrals.
- Ongoing treatment and support:** Less likely to receive & more likely to discontinue anti-dementia meds.
- Later stages, end-of-life care:** Increased antipsychotic use, Increased hospitalization and emergency room utilization.
- Reside in long-term care facilities with lower quality of care:** Less advanced care planning, More aggressive and costly care, Lower utilization of hospice care.

Equity in Alzheimer's and Dementia Care (Hinton et al., 2024)




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Caregivers Also Face Discrimination

The 2004 report released by the Alzheimer's Association found that "Among non-white caregivers, half or more say they have also faced discrimination when navigating the health care system for their care recipient"

(2024 Alzheimer's Facts and Figures)




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How can that be?

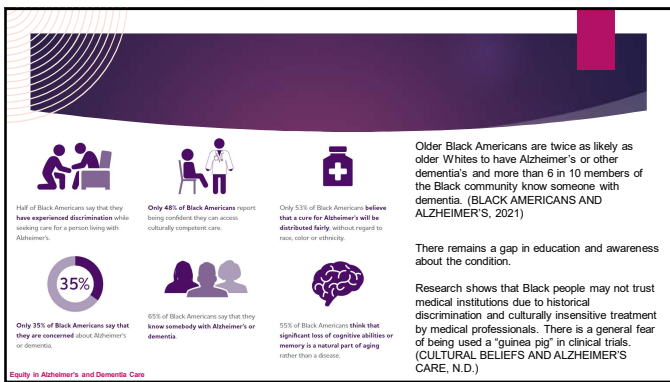
Caregivers report that they have felt that the providers or staff do not listen to them because of their race or ethnicity.

- Black caregivers (42%)
- Native American (31%)
- Asian American (30%)
- Hispanic (28%)
- Fewer than 1 in 5 White caregivers (17%) expressed this view.



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Half of Black Americans say that they have experienced discrimination while seeking care for a person living with Alzheimer's.

Only 48% of Black Americans report being confident they can access culturally competent care.

Only 53% of Black Americans believe that a cure for Alzheimer's will be distributed fairly, without regard to race, color or ethnicity.

Older Black Americans are twice as likely as older Whites to have Alzheimer's or other dementia's and more than 6 in 10 members of the Black community know someone with dementia. (BLACK AMERICANS AND ALZHEIMER'S, 2021)

There remains a gap in education and awareness about the condition.

Research shows that Black people may not trust medical institutions due to historical discrimination and culturally insensitive treatment by medical professionals. There is a general fear of being used a "guinea pig" in clinical trials. (CULTURAL BELIEFS AND ALZHEIMER'S CARE, N.D.)

35%
Only 35% of Black Americans say that they are concerned about Alzheimer's or dementia.

65%
65% of Black Americans say that they know somebody with Alzheimer's or dementia.

55%
55% of Black Americans think that significant loss of cognitive abilities or memory is a natural part of aging rather than a disease.

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Asian Americans are less likely to have Alzheimer's which makes it more difficult for families to recognize symptoms and seek professional care.

Most Asian languages do not have a word to describe Alzheimer's. Most of their descriptions translate to some form of "crazy" or a "state of confusion."

More than 4 in 10 Asian Americans believe medical research is biased against people of color so they do not get professional help until they absolutely have to which likely worsens the outcome.

(Asian Americans and Pacific Islanders and Alzheimer's, 2021)

Quick facts

- One in four (25%) of Asian Americans report a lack of family support as a barrier.
- Almost half (45%) of Asian Americans believe that medical research is biased against people of color.
- Only 22% of Asian Americans report that they face no barriers to accessing Alzheimer's and dementia care.

56%
More than half (56%) of Asian Americans believe the significant loss of memory or cognitive skills (such as thinking or learning) ability is a normal part of aging.

Almost half (46%) of Asian Americans say that they are concerned about developing Alzheimer's or dementia.



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Approximately 13% of Hispanics who are 65 or older have Alzheimer's or another dementia.

Hispanic Americans are more likely to develop Alzheimer's than any other racial or ethnic group.

Family ties are strong in the Hispanic culture and when elders in the community start to show signs of dementia, it is mostly thought to be aging. Generally, a female relative will take over the caregiving at home which might delay diagnosis and proper care. (Cultural beliefs and Alzheimer's care)

(Hispanic Americans and Alzheimer's 2021)

Quick facts


Like any other demographic group, Hispanic Americans have a variety of backgrounds, roles, attitudes and experiences. If you are a health care or service provider, advocate or otherwise serve people living with Alzheimer's or their families, there is no substitute for engaging local voices to learn about your community needs and how to meet those needs.

White Hispanics are 1.5 times more likely than Whites to have dementia. More research is needed to understand why.

One-third of Hispanic Americans (33%) report that they have experienced discrimination when seeking health care.

Almost 9 out of 10 Hispanics (85%) say it is important for Alzheimer's and dementia care providers to understand their ethnic or race background and experiences.

Almost 6 in 10 (57%) believe that a significant loss of memory or cognitive abilities is a normal part of aging.



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1 in 5 Native American adults aged 45 and older report memory or thinking problems. 1 in 3 Native Americans will develop Alzheimer's or some form of dementia.

Native Americans are more likely to develop Alzheimer's or other forms of dementia than White or Asian Americans.


Older people within the Native American Community are called "Elders" out of respect for their age and wisdom. They are more likely to be cared for at home which increases the likelihood of caregiver stress and a delay in detection. (Cultural beliefs and Alzheimer's care)

(Native Americans and Alzheimer's 2021)

Quick facts

Native Americans are [more likely to develop Alzheimer's](#) or other forms of dementia than White or Asian Americans. At the same time, American Indians report having less access to healthcare and health services and are less likely to be diagnosed once they show symptoms, making [caring for Native Americans, Alzheimer's](#) and other dementias. In addition, Native American cultures hold great respect for Elders and are more likely to take care of their Elders at home. This may mean [less for caregivers](#).

- As many as [1 in 3 Native American Elders](#) will develop Alzheimer's or some other form of dementia.
- Between 2020 and 2050, the number of American Indian/Alaska Native individuals aged 65 and older living with dementia is projected to increase four-fold.
- The vast majority (92%) of Native Americans say that it is important for Alzheimer's and dementia care providers to understand their ethnic or racial background and experiences. However, only 49% of Native Americans say that they have access to culturally competent providers.
- 63% of Native Americans say that affordability of care is a barrier.
- More than one-fourth (27%) of Native American caregivers report being treated with less respect than others.
- Four in 10 (40%) of Native Americans believe that medical research is biased against people of color and only 60% believe that an Alzheimer's care will be shared fairly regardless of race, color or ethnicity.




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Lesbian, gay, bisexual, transgender, and queer (LGBTQ) community

- LGBTQ folks are more likely to face unique, additional challenges with Alzheimer's compared to others. Even though over 2.7 million LGBTQ people have the condition, they often find it difficult to find culturally sensitive care, reliable support networks, and other resources to help them through it.
- Issues may include:
 - Lack of family support
 - Stigma
 - Poverty
 - Loneliness
- Such things may delay care or diagnosis, and symptoms might worsen in the long run.

(Cultural beliefs and Alzheimer's care)



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Cultural Competence

- The Centers for Disease Control and Prevention define cultural competence as "The integration of knowledge about people into specific policies, practices and attitudes used in appropriate cultural settings to increase the quality of services, thereby producing better outcomes" (Cultural competence in health and human services 2024).
- Cultural competence emphasizes the idea of effectively operating in different cultural contexts and altering practices to reach different cultural groups. A culturally competent health care system can help improve health outcomes and quality of care and can contribute to the elimination of racial and ethnic health disparities (Cultural competence in health care: Is it important for people with chronic conditions? 2019).

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What Does Culturally Competent Care Look Like?

To better serve different racial and ethnic communities affected by Alzheimer's and improve access and quality of care, health care providers should plan for culturally competent person-centered planning.

What does this mean? As people of color tend to have unique needs and deeper involvement as caregivers to those with Alzheimer's, doctors should plan to include several family members or loved ones throughout the treatment plan.

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What Does Culturally Competent Care Look Like?

Professionals Should:

- Spend time getting to know the family and caregivers of those with Alzheimer's. This might include extended family and neighbors if they're involved in caregiving.
- Spend time explaining complex medical terms and treatment steps to family.
- Provide examples or stories to explain difficult medical concepts.
- Not push American values during care. For example, doctors must understand the importance of customs like filial piety, especially if they need to discuss long-term nursing care as an option.
- Understand that dinner invitations or refreshments are offered as a sign of gratitude.

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What Does Culturally Competent Care Look Like? (cont.)

Professionals Should:

- Avoid ethnic stereotypes. This worsens the distrust in medical care.
- Avoid rushing through meetings and appointments.
- Use plain language to explain issues. Use a translator, if necessary, to make sure there's no miscommunication.
- Work with a community member as a liaison to help fill any gaps in communication and increase referrals.
- Educate the family about the condition. They might pass on the information to others within the community and lower barriers to care.
- Hire medical staff to reflect the ethnic community they serve.


(Cultural beliefs and Alzheimer's care)



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Health Disparities



Health disparities are preventable differences in the burden of disease, injury, violence or in opportunities to achieve optimal health experienced by socially disadvantaged racial, ethnic and other population groups and communities. (What is public health? n.d.)


"When the term 'health disparity' was coined in the United States around 1990, it was not meant to refer to all possible health differences among all possible groups of people. Rather, it was intended to denote a specific kind of difference, namely, worse health among socially disadvantaged people and, in particular, members of disadvantaged racial/ethnic groups and economically disadvantaged people within any racial/ethnic group" (Braveman, 2014).




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Health Equity



- "To CMS, health equity means the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes." (Barriers to equity in Alzheimer's and dementia care 2021)



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Is Lack of Diversity to Blame?

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Access to Health Care Providers Who Understand Racial and Ethnic Backgrounds Among U.S. Adults

Disparities in Alzheimer's disease health care providers by race/ethnicity and dementia and Alzheimer's disease care by race/ethnicity

Race/Ethnicity	Understand racial and ethnic backgrounds (%)	Do not understand racial and ethnic backgrounds (%)
Hispanic Americans	85%	58%
Black Americans	85%	48%
Asian Americans	85%	65%
Native Americans	85%	45%

Medical providers need to understand how different racial and ethnic groups view, access, and experience health care.

It is projected that by 2030, people of color will account for over half of the population (Barriers to equity in Alzheimer's and dementia care 2021).

There is a strong need for dementia health care providers who understand different racial and ethnic backgrounds. Unfortunately, this is greatly lacking in Wisconsin and across the country.

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How do we Bridge the Gap?

- We need to prepare the healthcare workforce on how to care for a racially and ethnically diverse aging population
- We need to increase diversity among providers for dementia care
- We need to engage, recruit and retain diverse populations in Alzheimer's research and clinical trials
- We need to increase community capacity to address Alzheimer's and dementia and promote brain health equity by providing culturally tailored education, programming and literacy resources

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The Oneida Nation

<https://oneida.nsn.gov/resources/health/about/>

- VISION:** A progressive sustainable health system that promotes ts'niyukwalhot* (Our Ways).
- MISSION:** We provide the highest quality, holistic health care to ensure the wellness for OUR Oneida Community.
- VALUES:**
 - Responsive Leadership
 - Safety
 - Communication
 - Culturally Sensitive
 - Respect
 - Trust is the foundation

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Oneida Nation Community Profile

The Oneida Nation Reservation is located within the boundaries of Brown and Outagamie Counties in Northeast Wisconsin. It covers 65,400 acres, with approximately 27,569 being tribally owned. The Nation has approximately 17,272 citizens, with about 7,881 enrolled members living within Brown & Outagamie Counties.

Oneida Enrolled Members by Location

Location	Percentage
Living in Oneida	25%
Living in the Oneida Nation Reservation	27%
Living off the reservation in Brown & Outagamie Counties	19%
Living in other Wisconsin counties	14%

Oneida Enrolled Members by Age

Age Group	Percentage
Age 0-14	14%
Age 15-24	14%
Age 25-34	14%
Age 35-44	14%
Age 45-54	14%
Age 55-64	14%
Age 65+	14%

Source: Oneida Enrollments (2022)




The Oneida Nation

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Oneida Comprehensive Health Division and Public Health

- Oneida Comprehensive Health is a AAAHC Accredited Health Care Facility!
- In addition, we have a PHAB Accredited Public Health Department
- Under our Public Health Department, we have 5 departments that oversee varying pieces of public health, to include:
 - Chronic Disease Case Management
 - Long Term Care Case Management
 - Health Promotion Disease Prevention
 - WIC/Nutrition Services
 - Population-Based Programming

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How is the Oneida Nation Addressing Alzheimer's and Dementia?

COMMUNITY HEALTH ASSESSMENT

- We have focused questions on our Community Health Assessment related to Alzheimer's and Dementia
- We use this data to determine the next 5 years of services

DEDICATED DEMENTIA CARE SPECIALIST

- The Oneida Nation was one of the original 2 tribes in Wisconsin to hire a Dementia Care Specialist through funding from the Department of Health Services.
- We have the position in our Comprehensive Health Division at the Oneida Health Center which has increased referrals for patients and families facing a memory care diagnosis.

CLINICAL TRIALS

- The Oneida Nation partners with UW Madison to have community members participate in clinical trials related to Alzheimer's and dementia.

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2022 Oneida Community Health Assessment Data

Dementia & Caregiving

38% of Oneida population aged 65+ have cognitive impairment, including Alzheimer's disease.

15% have a health problem that requires the use of long-term care services, such as a care, residential, special care or respite.

Alzheimer's disease is the most common type of dementia. Between 2010 and 2020, the number of American Indian and Alaska Natives aged 65 and older living with memory loss is projected to grow over five times.

16% of American adults aged 65+ are caregivers, providing care to someone with a health condition.

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Alzheimer's and Dementia in Oneida

We have taken things farther to address Alzheimer's and Dementia on the Reservation:

- We have a permanent, dedicated position in our Health Division for a Dementia Care Specialist
- Provide Purple Angel Training to all staff
- We are working to conduct Purple Angel Training to the entire community and all business entities on the Oneida Reservation and at our Southeastern Oneida Tribal Services Office (SEOTS)
- Bringing the Virtual Dementia Tour to Comprehensive Health Division Medical Providers and staff
- We host a monthly Memory Café for those with dementia and their caregiver
- We partner with other Wisconsin Tribes to hold virtual caregiver support group meetings and book clubs

WE ARE DEMENTIA FRIENDLY

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Questions?

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THANK YOU!

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