

Dementia and the Asian American and Pacific Islander Population

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Introduction



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Housekeeping



We will leave 10-15 minutes at the end of this session for Q&A. Throughout the webinar, you can put your questions into the Q&A/chat functions, and some may be answered in real time.



We will share instructions for claiming Continuing Education (CE) credit at the end of this webinar and via email within 48 hours.



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You can also access the webinar slides and recording from the Dementia Care Aware website and YouTube channel.



Dementia Care Aware Program Offerings









Warmline: 1-800-933-1789

A provider support and consultation service that connects primary care teams with Dementia Care Aware experts

Trainings:

- Online Trainings e.g., Cognitive Health Assessment training
- Monthly Webinars
- Podcasts

•

Interactive Case Conferences:

 UCLA and UCI ECHO (Extension for Community Healthcare Outcome) conferences

DementiaCareAware.org

Practice change support:

- UCLA Alzheimer's and Dementia Care Program
- Alzheimer's Association Health Systems

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Our Training

Welcome!

Welcome to the Dementia Care Aware (DCA) learning management system. This site provides access to the training modules for the DCA program. When you registered, you were automatically enrolled in the "*The Cognitive Health Assessment: The Basics*" course. Select Start in the "The Cognitive Health Assessment: The Basics" block below to begin.





Screening for Dementia: The Cognitive Health Assessment (CHA)

Goal: Screen patients older than age 65 annually (who don't have a pre-existing diagnosis of dementia)





Sign Up for Upcoming Live CHA Trainings

- Dementia Care Aware offers the CHA training as **a free 1-hour live session** multiple times each month.
- Led by Dementia Care Aware partners at the Alzheimer's Association and UC, Irvine.
- Open for anyone who is interested.
- Eligible participants can claim **1 free** CE/CME/MOC credit.





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Learning Objectives

- 1. Understand the cultural, linguistic, and socioeconomic diversity of Asian American and Pacific Islander (AAPI) populations in the United States.
- 2. Recognize factors associated with cognitive impairment and dementia risks among AA and PI older adults.
- 3. Discuss considerations for conducting dementia assessments with AA and PI older adults.
- 4. Identify gaps and future directions for advancing dementia research and care in AA and PI populations.



Background and Terminology

Most standards for reporting race and ethnicity are modeled after or consistent with the categories established by the U.S. Office of Management and Budget (OMB).

There is no consensus regarding the appropriateness of any aggregate classification or reference, and different categories have been proposed: "Asian Pacific American" (API), "Asian American and Pacific Islander" (AAPI), "Asian American and Native Hawaiian and Other Pacific Islander" (AANHOPI), etc.

The most recent update to the Race and Ethnicity Standards was published in March 2024¹.

Asian	Individuals with origins in any of the original peoples of Central or East Asia, Southeast Asia, or South Asia, including, for example, Chinese, Asian Indian, Filipino, Vietnamese, Korean, and Japanese.	
Native Hawaiian or Pacific Islander	Individuals with origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands, including, for example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, and Marshallese.	



Asian American and Pacific Islanders in the U.S.

2020 U.S. Census Bureau estimates

• 24 million Asian residents²

Five Largest Detailed Asian Alone and Alone or In Any Combination Groups: 2020

Rank	Asian alone detailed group	Number	Rank	Asian alone or in any combination detailed group	Number
1	Asian Indian	4,397,737	1	Chinese, except Taiwanese	5,205,461
2	Chinese, except Taiwanese	4,128,718	2	Asian Indian	4,768,846
3	Filipino	3,076,108	3	Filipino	4,436,992
4	Vietnamese	1,951,746	4	Vietnamese	2,293,392
5	Korean	1,508,575	5	Korean	1,989,519

• 1.7 million Pacific Islander residents²

Five Largest Detailed Native Hawaiian and Other Pacific Islander (NHPI) Alone and Alone or In Any Combination Groups: 2020

Rank	NHPI alone detailed group	Number	Rank	NHPI alone or in any combination detailed group	Number
1	Native Hawaiian	199,880	1	Native Hawaiian	680,442
2	Samoan	133,148	2	Samoan	256,997
3	Chamorro	70,704	3	Chamorro	143,947
4	Tongan	48,536	4	Tongan	78,871
5	Marshallese	47,300	5	Fijian	54,006



Data Aggregation and Overgeneralization

Recent studies highlight the limitations and potential dangers of generalizing research findings generated from historically collected public health data in the U.S. using an aggregate "API" reporting standard.



GBD US Health Disparities Collaborators, 2022 Lancet³



"The authors' systematic erasure of known NHPI disparities, through use of the aggregated API population category, obscures the truth and reinforces the marginalisation of these Indigenous people."

Taparra & Pellegrin, 2022 Lancet4

- Native Hawaiians and Samoans have the shortest life expectancies of HI's seven major ethnic groups: 9–13 years shorter than Chinese, Japanese, and Korean residents and 5– 8 years shorter than NH Whites and Filipinos.⁵
- The median age of NHOPI in the U.S. is 10 years younger than for the U.S. population as a whole (27.1 years vs. 37.6 years).⁵

Asian Americans: Population Overview

Asian Americans are the fastest-growing major racial and ethnic group in the United States, especially among older adult (65+) populations.⁶

Asian population in U.S. nearly doubled between 2000 and 2019 and is projected to surpass 46 million by 2060



Asians projected to become the largest immigrant group in the U.S., surpassing Hispanics

% of immigrant population





Asian Americans: Population Overview

- Asian Americans are extremely diverse in their nations of origins and languages representing over 50 ethnicities and 100 different languages and dialects.^{6,7}
- The majority of the U.S. Asian population (85%) is represented by the following ethnic groups: Chinese, Filipino, Indian, Vietnamese, Korean, and Japanese.⁶
- U.S.-born Asian Americans are more likely to be younger than foreign-born Asian Americans.⁶
- Self-reported English proficiency varies widely across ethnic groups and by nativity status.⁶
 - Japanese (85%)
 - Filipinos (84%)
 - Indians (82%)
 - Bhutanese (36%)
 - Burmese (38%)

In 2019, nearly three-quarters of the U.S. Asian population speaks English proficiently; among the U.S. born, nearly two-thirds speak only English at home





Asian Americans: Important Considerations

Model Minority Stereotype (MMS)⁸

- 1966New York Times Magazine's "Success Story, Japanese-American Style"
- 1966 U.S. News and World Report's *"Success Story of One Minority in U.S."* about Chinese Americans
- The MMS, when extended to health, perpetuates the idea that Asian Americans are well-positioned with regard to their health status and, therefore, are not disadvantaged or underrepresented in health studies.

Model Minority Myth^{7,8}

- Asian Americans have the largest within-race income divide and poverty rates vary widely across ethnic origins.⁶⁻⁸
- Educational attainment rates also vary widely: e.g., 75% of Indian adults have a BA compared to 15% of Bhutanese.⁶
- Health implications:
 - Despite having the lowest rates of hypertension and heart disease mortality as an aggregated group, many Asians have greater proportionate mortality from hypertension compared to non-Hispanic Whites
 - Chinese women=1.69, Filipino women=1.50, Asian Indian women=1.46, Korean women=1.30, Japanese women=1.23, Chinese men=1.27, Filipino men=1.38, Asian Indian men=1.18⁸



Asian Americans: Important Considerations

National Health and Nutrition Examination Survey 2011–2018: 2,869 adults aged 60 and older (421 Asians, 768 non-Hispanic Blacks, 651 Hispanics, and 1,029 non-Hispanic Whites)⁷







Asian Americans: Dementia Epidemiology

There are significant gaps in research on dementia epidemiology and risk factors in Asian American populations.

• Underrepresentation of AANHOPI populations has persisted for more than 25 years, with an average of 0.17% of NIH expenditures involving, but not necessarily focusing on these populations.⁸

Extrapolation of findings from ethnic groups residing in Asia are inappropriate given substantial societal, economic, and cultural differences between populations.⁹

Prevalence

• A systematic review of 45 studies reported an average prevalence of 10.9%, ranging from 0.4% to 46%.¹⁰

Incidence

- A systematic review reported an average incidence of 20.03 (12.01-33.8) per 1000 person-years, ranging from 75.19 to 13.59.¹⁰
- A study of 23,032 Asian Americans (Chinese=8384; Japanese=4478; Filipino=6210; South Asian=197; Other Asian=3763) and Whites (n=206,490) who were Kaiser Permanente Northern California members aged 64+ and followed over 14 years.¹¹



FIGURE 1. Age-standardized dementia incidence rates per 1000 person-years estimated from 14 years of follow-up (Kaiser Permanente Northern California members, 2000 to 2013).



Asian Americans: Risk Factors

While genetic and ancestral studies remain largely limited in both Asian and Asian American older adults, social determinants of health and lifestyle factors exert well-known effects on cognitive health and dementia risk:¹²

- Demographic and social:
 - older age, low education and income, and occupational factors (e.g., workplace safety/conditions, physical labor)
- Midlife vascular health:
 - higher BMI, hypertension, sleep apnea symptoms, impaired glucose tolerance
- Late-life comorbid conditions:
 - cancer, type 2 diabetes, cardiovascular diseases, and depression

Furthermore, current research focusing on the role of immigration history, early life adversity, acculturation stress, and language proficiency may identify these as unique factors that confer ADRD risk in Asian Americans.



Native Hawaiians & Other Pacific Islanders: Population Overview

- Native Hawaiians and Pacific Islanders (NHOPI) are individuals from nearly 30 island nations across three geographical regions of Oceania (Melanesia, Micronesia, and Polynesia) with cultures, languages, histories, and voyaging heritage that are distinct from those of the peoples of Asia.⁴
- Largest subgroups include Native Hawaiians, Samoans, Chamorros, and Micronesians.¹³
- Older adults comprise 5% of Guam's population, <4% of American Samoa's population, and about 13% of Native Hawaiian population.¹³
- NHOPI older adults have among the lowest per capita incomes and highest poverty rates of all American ethnic groups.¹³
- English is not the first language of 45.9% of NHOPI elders and 13.8% of NHOPI older adults report that they do not speak English well or at all.¹³



Native Hawaiians & Other Pacific Islanders: Important Considerations

- NHOPI are among the most underrepresented ethnic and cultural groups in ADRD research.
- By contrast to the immigration histories of Asian populations, NHOPI have a shared history of trauma and oppression through colonization.⁴
 - The first contact with European people in Hawai'i precipitated the near complete erasure of Native Hawaiians, with more than 95% of the population killed by foreign diseases.
- NHOPI adults have higher rates of chronic diseases, including obesity, diabetes, kidney disease, substance use disorders, asthma, cancer, and cardiovascular diseases compared with Asians.^{4,13}
- These disparities are compounded by social determinants of health.
 - For example, Native Hawaiians in Hawai'i have the highest rates of high school dropout, ecigarette use, adolescent suicidal ideation, uninsured rates, poverty, homelessness, and incarceration.⁴
- Across Oceania, Indigenous Pacific Islander populations are consistently reported to experience worse health disparities, including lower life expectancies, than non-Indigenous populations.⁴



Native Hawaiians & Other Pacific Islanders: Dementia Epidemiology

Prevalence

• A population-based survey of Chamorros aged 65+ on Guam suggested a point prevalence of all-cause dementia in 2004 of 12.2%, including 8.8% Guam dementia (clinically equivalent to AD), 1.5% Parkinson's dementia, 1.3% pure vascular dementia, and 0.6% other.¹⁴

Incidence

- No studies on incidence of ADRD or cognitive disorders in NHOPI.
- Two reports on dementia incidence in Aboriginal and Torres Strait Islander peoples suggested an incidence rate of 21.0 to 35.9 per 1000 person-years for those aged 60+.¹⁵



Native Hawaiians & Other Pacific Islanders: Risk Factors

- Most review studies suggest that risk and protective factors associated with dementia for NHOPI peoples are congruent with the evidence available for non-Indigenous populations.^{12,13,15}
- However, given known health and healthcare disparities within this community, the significance of social determinants of health across the life course may be more pronounced.
- For example, male sex was associated with a greater risk of dementia in certain Indigenous cohorts in contrast to most non-Indigenous populations where dementia is more common in women.¹⁵
 - These differences may be related to survival bias or greater exposure to other lifestyle and social risk factors such as heavy alcohol use, history of police custody and incarceration, and low education.
- Experiences of trauma, discrimination, and greater prevalence of mental health conditions can confer additional risk for ADRD in certain communities.¹³
 - Prevalence of severe or moderately severe depression was 4.8% among NHOPI in Hawai'i, almost twice as high as the state prevalence (2.7%) and 3 times higher than the prevalence for Asians (1.5%).



Clinical Considerations for Dementia Assessment

Language barriers / Acculturation¹⁶

- It is important to collect detailed linguistic and social history, including history of immigration (if relevant) and acculturation experiences
- Interpreter services are essential but healthcare providers should educate themselves about cultural and social norms and patient and family preferences
- Develop and maintain a professional network of resources and referral services

If you are not comfortable with your physician, who doesn't speak your language, they don't know, don't understand your everyday diet and they don't quite connect with your lifestyle, you know, as a patient you're not going to share much of the very intimate details with your healthcare provider

> (Asian American, Native Hawaiian, and Pacific Islander-serving social service organizational leader, formerly with an Alzheimer's research institute).



Clinical Considerations for Dementia Assessment

Health and healthcare literacy / Attitudes and perceptions of dementia^{16,17}



More than half (56%) of Asian Americans believe that **significant loss of memory** or cognitive (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.

It's the confusion with the signs of aging versus the clinical symptoms of Alzheimer's [disease]. There is still a need to raise that awareness in the community and expand their knowledge base so they can differentiate [the two] and do the... assessment and prompt them to seek medical advice as needed.

(Filipino social service care provider)



Clinical Considerations for Dementia Assessment

Discrimination / Structural barriers^{16,17}





Almost half (45%) of Asian Americans **believe that medical research is biased** against people of color. Only 12% of Asian Americans report that they have **no barriers to excellent Alzheimer's and dementia care**. What I've heard from families is: you know it's great that there is an office on aging, but you still have to call, you still have to be your own advocate for a lot of these pieces. And that's hard when you're working full time and the stacks of forms are pretty significant and if you yourself are not familiar with filling out those forms. [It means that] the likelihood of you following through for your parent or grandparent is reduced.

(Native Hawaiian health service provider)



Cognitive Assessment Considerations

While a number of brief screening tools have been translated into several languages spoken by AANHOPI older adults, only a few have been culturally adapted and validated to assess ADRD in the United States.¹⁸

Among the most commonly used tools are:

- The Mini Mental State Examination (MMSE)
- The Montreal Cognitive Assessment (MoCA)
- The Cognitive Abilities Screening Instrument (CASI)



Available Tools

	Description	Languages
MMSE ^{18,19}	30-item scale Known educational effects Published cutoffs vary widely Copyrighted	French, German, Dutch, Spanish for the US, Spanish for Latin America, European Spanish, Hindi, Russian, Italian, and Simplified Chinese
MoCA ^{18,19}	30-item scale More pronounced educational effects Racial and cultural bias Published cutoffs vary widely Requires training & certification for certain settings	Over 100 per publisher, including many languages spoken in Asia
CASI ¹⁸⁻²⁰	25-item scale Cutoffs based on educational attainment	Japanese, English, Chinese dialects



Important Considerations for Interpretation

MMSE18,19

- Asian Americans in Hawai'i: over 60% were unable to repeat "No ifs, ands, or buts"
- Highly variable cut-offs were reported, ranging from 17 to 29
- Limited normative data and validation studies of Asian Americans (most data are reported in Asians residing in Asia)

MoCA18,19

- Many forms with linguistic modifications are available for different populations (12 forms for Chinese speakers)
- Alterations to letter fluency some languages spoken in Asia are not alphabetic
- Highly variable cut-offs were reported, ranging from 21 to 26
- Limited normative data and validation studies of Asian Americans (most data are reported in Asians residing in Asia)



Important Considerations for Interpretation

CASI18-20

- MMSE, the Modified Mini-Mental State Test, and the Hasegawa Dementia Screening Scale scores can be estimated from subsets of the CASI items.
- The cutoff scores are based on educational groups in a Taiwanese sample:
 - Edu = 0:49/50
 - Edu = 1-5: 67/68
 - Edu >/=6: 79/80
- Culturally tailored to certain groups: for example, both solar and lunar year dates are accepted

	Written	Spoken
China, Singapore, Malaysia	Simplified	Mandarin
Hong Kong	Traditional	Cantonese
Taiwan	Traditional	Mandarin
USA	Simplified & Traditional	Cantonese & Mandarin





AANHOPI in California²¹

HCS

CALIFORNIA DEPARTMENT OF HEALTH CARE SERVICES

DEMENTIA Care Aware

Early detection. Better care.

Table 1. Sample Characteristics of Older Asian Americans in California							
Characteristic	Total Asian	Chinese	Japanese	Korean	Filipino	Vietnamese	<i>P</i> -Value*
Age, mean (SE) (range 60–96)	70.7 (0.35)	71.6 (0.69)	74.4 (0.65)	68.7 (0.72)	69.6 (0.74)	67.6 (0.72)	<.001*
Female, %	54.2	55. 1	68.2	57.4	58.7	38.3	<.001
Married, %	72.1	74.6	64.4	71.7	69.1	80.9	.25
Educational attainment, %							<.001
<high school<="" td=""><td>19.1</td><td>26.9</td><td>10.7</td><td>19.5</td><td>5.7</td><td>44.5</td><td></td></high>	19.1	26.9	10.7	19.5	5.7	44.5	
High school graduate	25.5	20.5	31.6	29.8	25.4	30.9	
\geq Some college	55.4	52.6	57.7	50.7	68.9	24.6	
Annual household income, \$, mean (SE)	48,854 (2,023.6)	50,463 (4,107.4)	61,630 (4,871.2)	36,326 (3,530.4)	49,141 (4,171.6)	23,743 (2,820.7)	<.001*
Uninsured, %	5.8	4.5	1.3	20.7	3.0	10.2	<.001
Foreign born, %	83.3	89.0	31.5	99.1	93.5	100.0	<.001
Limited English proficiency, %	37.8	56.2	6.6	74.2	7.8	83.4	<.001

AANHOPI in California²²

Asian Medicare beneficiaries in California are significantly less likely to receive

• a timely diagnosis of ADRD and



• a comprehensive dementia diagnostic assessment.



Resources and Research Opportunities

Alzheimer's Association: https://www.alz.org/help-support/resources/asian-americans-and-alzheimers

Asian Americans and Pacific Islanders and Alzheimer's

Resources	Asian Americans are the fastest grow	ing major racial group in the U.S., but they are in scientific research. This can make it harder fo
ALZ Talks Virtual Events	individuals or families to recognize the what the Alzheimer's Association is do	e symptoms and seek professional care. Learn
ALZNavigator	support for Asian Americans and Paci	ific Islanders living with Alzheimer's or other
Veterans and Dementia	Gementia.	
What Causes Memory Loss?	Quick facts	Volunteer in your community
Assessing Symptoms and Seeking	Asian Americans at risk	Association partnerships
Help	Participate in a clinical trial	Find help, support and local resources
The Knight Family Dementia Care		<u> </u>





Research Opportunities

Asian Cohort for Alzheimer's Disease (ACAD): <u>https://acadstudy.org/</u>







Research Opportunities

The Vietnamese Insights into Aging Program (VIP): https://health.ucdavis.edu/neurology/vip/index.html



The Vietnamese Insights into Aging Program (VIP) aims to understand factors that impact thinking and memory in the Vietnamese American community.

Study Goals:

 To enroll 285 people at UC Davis and 285 people at UC San Francisco with a total of about 570 people in Northern California





Research Opportunities: UCSF (memory.ucsf.edu)





Boon Lead Tee, MD



Serggio Lanata, MD

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Gil Rabinovici, MD



Bruce Miller, MD



Kate Possin, PhD

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Take-Home Points

- Asian American and Native Hawaiian and Other Pacific Islander populations represent an incredibly diverse group of individuals across ethnic, linguistic, cultural, and sociodemographic backgrounds.
- These populations remain severely underrepresented in clinical research and experience health and healthcare disparities often masked by historical aggregation of data.
- Research on risk and protective factors for dementia is emerging, but known risk factors are more prevalent in certain cultural and ethnic groups within AANHOPI community.
- Patient-centered and culturally-informed approaches are critical for diagnosis and care for AANHOPI older adults with cognitive impairment.



Thank You! Questions?



Have more questions? Get answers through our Warmline (a) **1-800-933-1789** or our <u>support page</u>!

What cognitive assessment should I

use for a Spanish

speaking patient

experiencing

homelessness?

Here are some examples!

What do I prioritize if my patient tests positive for cognitive impairment?

> What medications should I avoid if my patient has cognitive complaints?

Open your phone camera and scan the QR code to submit questions:



Or visit: www.dementiacareaware.org





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