



Connecting with AAPIs About Dementia

AN ACTION GUIDE FOR SERVICE PROVIDERS

This action brief is for community-based organizations working to educate and empower Asian-American and Pacific Islander (AAPI) communities about dementia. The purpose of the brief is to share information on:

- Why dementia is such an important issue for the AAPI community,
- Barriers to dementia detection, treatment, and support for the AAPI community,
- Recent findings from a research study to test culturally appropriate messages to improve early identification of dementia by engaging adult children and their families,
- Recommendations and resources for better reaching the AAPI community.

Background

Asian Americans and Pacific Islanders (AAPI) are the fastest growing minority group in America.¹ Between 2010 and 2030, the AAPI older adult population is projected to increase by 145%.¹ As this aging population rapidly increases, AAPI older adults face a public health crisis similar to older adults from other ethnic backgrounds, as age is the largest risk factor for Alzheimer's disease.²

The prevalence and incidence of Alzheimer's disease and related dementias within AAPI communities is not well understood. Researchers acknowledge that data on AAPI subpopulations is lacking.³ Limited disaggregated research unveils that rates may vary by subpopulation, as Vietnamese older adults have a disproportionately high prevalence of cognitive problems (16.6%), more than double the rate for Koreans at 7.6%.⁴ Native Hawaiians and Pacific Islanders have a higher risk of cognitive issues and activities of daily living impairments, which is two times the risk as compared to Chinese older adults.⁴

In 2011, 13.8% of older AAPIs reported an increase in confusion or memory loss, which was the second highest of all ethnic groups.⁵ This finding is based on Behavioral Risk Factor Surveillance System (BRFSS) self-reports, and so whereas this data is limited by the lack of clinical measurement, it highlights the need to facilitate linkages to health care providers to ensure timely and accurate diagnosis of Alzheimer's disease and related dementias. Despite high rates of self-disclosure through BRFSS interviews, many AAPIs do not report symptoms of dementia to a medical professional, and consequently, AAPIs are unlikely to receive a diagnosis of Alzheimer's disease until the disease has progressed to the later stages.²

Barriers

[I]n my family or maybe my culture we don't like to visit doctor or tell anyone they are sick (especially aging parents). They are afraid give us extra burden if they tell they are sick. - 39 year old Chinese woman.

Cultural barriers and stigma prevent many AAPIs from talking with a medical professional about cognitive concerns. In Chinese, for example, dementia translates as “crazy catatonic,” and the signs and symptoms of dementia are interpreted as a mental illness.⁶ Consequently, stigma permeates Chinese communities, with dementia triggering an intense negative response that impedes their seeking diagnosis, information, and assistance. However, research has shown that brief exposure to information about the symptoms of dementia led to a reduction in stigma among Chinese, suggesting that community education may play a critical role in reducing this barrier to early detection.⁷

The Japanese also have very stigmatized labels that are applied to people with dementia, and similarly see dementia as a mental illness that shames the whole family. Across many AAPI ethnicities, dementia is interpreted as a normal part of aging, and is thought to be caused by too much worrying, bad karma, suppressed emotions, or other causes that reflect badly on the patient and their family.⁸

Research Study to Evaluate Public Health Messages for the AAPI Community

In 2016, the University of Washington (UW) Healthy Brain Research Network (HBRN), funded by the Centers for Disease Control, collaborated with the Washington State Department of Health and National Asian Pacific Center for Aging (NAPCA) to assess whether public health messages are acceptable to the AAPI community. These messages, or ads, were developed and assessed by the University of Pennsylvania to encourage White and Black adult children to take their older loved one in for a cognitive evaluation with a **trained healthcare provider who can evaluate memory and thinking issues and diagnose dementia**. Our study tested how these eight messages were received by AAPI adults, modifying the messages with AAPI photos and encouragement to contact the Alzheimer's Association to get connected with a trained healthcare provider.

UW HBRN and NAPCA conducted 6 focus groups with Chinese and Japanese adults in King County, Washington with at least one living older parent age 65+. Chinese participants were primarily foreign-born, immigrated to the U.S. in the last 3 decades, and more than half spoke Chinese as their first language. Japanese participants mainly spoke English as their first language and were U.S. born, representing primarily nisei and sansei generations of Japanese immigrants. Findings from this study informed three recommendations for service providers to educate and empower the AAPI community. Specific study results are provided in recommendation #3. Specific study results are provided in the next section.

Based on findings from this study, three recommendations are presented for Public Health and Aging Service Networks:

1. Advocate for adequate resources to end Alzheimer's Disease for all Americans, including AAPIs.

Consider advocating for the following:

- Federal and state funding for Alzheimer's disease and related dementias research, particularly, research that prioritizes vast inclusion of diverse AAPI communities.
- State and national Alzheimer's disease and related dementias plans.
- An increase in respite care funding, also ensuring that caregivers are eligible for such respite services regardless of the age and financial status of the individual with Alzheimer's disease. AAPIs are significantly more likely to assume caregiving roles, with 42% of AAPIs providing care to an older adult, compared to 22% of the general population.⁹
- Reimbursement for primary care provider cognitive assessment.
- Training for new (e.g. higher education, certification) and existing providers (e.g. CEU) to do cognitive evaluations.

"One thing that it makes me think with these messages, like the other one says to go with your person to the doctor... I feel like well, what do you want me to do? How am I going to get there? How am I going to take off all of this time from work? Not that I'm complaining to take them, but how am I supposed to do that?"
- 28 year old Chinese woman

2. Collect disaggregated race data to tailor education and long-term services and supports.

AAPIs represent more than 50 subpopulations and over 100 different languages. Aggregating AAPIs into a homogenous population masks unique subpopulation variations that are vital to better understand and more effectively serve this diverse and growing population. When AAPIs are viewed as a homogenous population, it leads to sweeping generalizations that AAPIs are the highest-income, best-educated, and healthiest racial group in the country, with few, if any, needs.

Public health and aging service professionals have an instrumental role in understanding the variations of Alzheimer's disease and related dementias among AAPI subpopulations by documenting disaggregated race data. This data can be used to tailor education and long-term services and supports and more effectively serve AAPI subpopulations.



3. Facilitate access to culturally and linguistically appropriate education and services.

To reduce stigma and cultural barriers, AAPIs need resources before they'll go and get an evaluation. [UW HBRN and NAPCA's study](#) found that, before bringing their older loved one for a cognitive evaluation, Chinese and Japanese adult children desire more information about:

- What a “memory doctor” is? Not knowing this, they preferred a primary care doctor because of trust, rapport and access.
- Why they should get a cognitive evaluation?
- What will happen at the visit?
- When they should get a cognitive evaluation?
- How to have the difficult conversation with their older loved one to encourage them to make that visit together?

AAPIs also need culturally and linguistically appropriate public health messages throughout this education. In general, the [UW HBRN and NAPCA's study](#) found that many memory messaging taglines were well-received and aligned with cultural values:

- Hopefulness and concreteness in there being something one can do about dementia
- An adult child and older loved one doing something together
- Framing adult children helping their older loved one in the context of their older loved one having helped them (be there now like they were there for you)
- Being explicit about memory loss, and calling out specific questions that you can get answered during a visit with a health care provider

When designing educational materials, [UW HBRN and NAPCA's study](#) found:

- Be direct and to the point. Participants preferred the tagline “Is your loved one experiencing memory loss or confusion that disrupts their daily life because it was explicit”.
- Likewise, messages with photos of doctors in them clearly showed the action to be taken.
- Use clear, concrete messages such as example questions that might get answered when they take their older loved one in for a cognitive evaluation. For example:
 - What can we expect in the future?
 - Are their memory problems part of normal aging?
 - What resources are available to help them?
- Participants did not like feeling guilty or being told what to do – some participants felt this way when seeing the tagline about being there now, like they were there for you.
- Not all adult children have strong or positive relationships (currently and/or in past) with their older loved ones so be sensitive to this in your practice.
- Photos should: get adult children's attention; display subjects with the appropriate age for adult children and older loved ones; show cognitive impairment (in expressions and actions), and, use natural poses that do not look too happy or sad and show authentic relationships between parents and children.
- Make the call to action clear – it did not stand out and was not clear how contacting the Alzheimer's Association would connect to an evaluation.

“...after thinking about this, I'm starting to feel a little guilty. In my immediate family we always rely on the sisters to handle things like this, and this is something that I've kind of tried to ignore maybe over the years. This might be a good wakeup call.” - 58 year old Japanese man

Resources

Public health and aging service professionals play a crucial role in facilitating access to culturally and linguistically appropriate long-term services and support for AAPIs who have been diagnosed with Alzheimer's disease or related dementias.

UW HBRN and NAPCA's Memory Messaging Project illuminated the need for information to increase awareness of Alzheimer's disease and related dementias among AAPIs, as well as resources for motivation, support, skill-building, and action.

I do believe that this message is very empowering. For someone who is just starting to notice cognitive changes in my parents, those are questions that may come across everyone's mind. So then when you know that there are specialists that could lead you to resources and prepare you for the future, that to me as a planner would be something that I would like. - 57 year old Japanese woman

Based on this finding, the following resources are presented to aid public health and aging service professionals in their work with AAPI families.

KNOWING WHEN TO GET A COGNITIVE EVALUATION

The Alzheimer's Association offers their website in Chinese, Japanese, Korean, and Vietnamese. Includes warning signs, basic information, and an interactive brain tour, also message boards, and support for caregivers. Local chapters may have additional resources available in specific languages. <http://www.alz.org/diversity/overview.asp>

Alzheimer's Australia offers fact sheets available in Cantonese, Hindi, Indonesian, Japanese, Korean, Mandarin, Tagalog, Thai, Vietnamese, Bengali, Khmer, Lao, Punjabi, and Urdu. <https://www.fightdementia.org.au/languages>

Dementia Today offers resources in Chinese, Japanese, Korean, and Vietnamese. <http://dementiatoday.com/alzheimers-disease-multiple-languages/>

HOW TO GET A COGNITIVE EVALUATION

The Alzheimer's Association offers Alzheimer's Navigator, which helps connect families to resources they need for everything from recognizing symptoms, to financial planning, and connecting with services. Only available in English. <https://www.alzheimersnavigator.org/>

The Alzheimer's Association also offers a great overview of what kind of providers are able to provide a diagnosis, how to connect with them, and what to expect. Only available in English. http://www.alz.org/alzheimers_disease_diagnosis.asp

The Family Caregiver Alliance has resources on recognizing symptoms of dementia, different types of dementia and how they're diagnosed, and the value of diagnosis. Available in Chinese, Vietnamese, and Korean by navigating to "Fact Sheets" and scrolling down to bottom. <https://www.caregiver.org/is-this-dementia-what-does-it-mean>

STARTING A CONVERSATION WITH FAMILY MEMBERS

The Baby Boomer's Handbook on Helping Parents Receive Care For Memory Problems is not AAPI specific, but has a good list of FAQ and a little bit of humor. <http://www.alzbrain.org/pdf/handouts/a%20bABY%20BOOMER%27s%20guide%20to%20dealing%20with%20memory%20problems%20in%20their%20parents.pdf>

The Hartford Financial Group has a guide to help families assess when it's time for a person with dementia to stop driving, and how to have that conversation. Includes worksheets at the back. <http://www.hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf>

SUPPORT FOR CAREGIVERS

Translated legal documents

Medline Plus has resources in Chinese on how to hire in-home help, do legal planning, and get support as a caregiver. <https://medlineplus.gov/languages/alzheimerscaregivers.html>

Kokuau Mau offers bilingual Advance Health Care Directive and POLST in Chinese (simplified and traditional), Japanese, Ilocano, Korean, Marshallese, Tagalog, Tongan, and Vietnamese. <http://kokuamau.org/languages>

Stress Release

Through **Stanford University**, you can order the evidence-based DVD and workbook for Chinese/Chinese American Caregivers of Older Adults with Dementia from the Stanford Geriatric Education Center for \$10. Shown to improve stress management in Chinese American caregivers in a controlled trial. http://sgec.stanford.edu/resources/sgec_publications.html

The Family Caregiver Alliance offers resources for coping with behavioral issues caused by dementia. Only available in English.

<https://www.caregiver.org/special-issues/behavior-management-strategies>

RESOURCES FOR PROVIDERS

Cultural Competency Training

National Resource Center on AAPI Aging. www.napca.com

The Alzheimer's Association offers some quick tips on cultural competence, and how to interact specifically with Korean, Vietnamese, Chinese, and Japanese families.

http://www.alz.org/Resources/Diversity/downloads/GEN_EDU-10steps.pdf

Stanford University offers hour long self-paced ethnogeriatric cultural competence training for care of Asian Indian, Chinese, Filipino, Hawai'ian and Pacific Islander, Hmong, Japanese, Korean, Vietnamese, and Pakistani. Not specific to dementia.

<http://geriatrics.stanford.edu/ethnomed.html>

Act on Alzheimer's website includes links to additional resources for providers on cultural competency training, as well as dementia screening and diagnostic tools for diverse populations.

<http://www.actonalz.org/cultural-competence-and-awareness>

The American Psychological Association has Guidelines on Multicultural Education, Training, Research, Practice and Organizational Change for Psychologists. Relevant to psychologists working with minority groups.

<http://www.apa.org/pi/oema/resources/policy/multicultural-guidelines.aspx>

The Asian American Mental Health YouTube channel offers lectures on mental health among AAPI. Not specific to dementia. <https://www.youtube.com/user/AsianAmericanMH>

Screening Tools for AAPI Populations

Stanford University offers webinars and handouts on assessment of dementia and caregiving among Chinese, Japanese, Korean, Hmong, and Filipino.

http://sgec.stanford.edu/video/2009-2010_Webinars.html

The Consortium to Establish a Registry for Alzheimer's disease (CERAD) offers materials for evaluating and diagnosing dementia in various languages, for use in both clinical practice and research. Includes translations into Chinese, Japanese, and Korean.

<http://cerad.mc.duke.edu/Default.htm>

Organizational Tools

The Alzheimer's Association offers a section on outreach that includes manuals and tools for assessing cultural competency and improving multicultural outreach at the institutional level.

http://www.alz.org/professionals_and_researchers_general_resources.asp

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