Health Care Issues of Older Asian Americans



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Learning objectives:

- Describe the changing demographics of older Asian Americans
- Identify some health disparities in older Asian Americans
- List some cultural practices affecting care of Asian Americans
- Identify cultural issues affecting endof-life care

Changing demographics

- Asian American's grew 72% from 2000 to 2015, the fastest growth rate of any major ethnic group.
- Elderly Asian Americans grew faster than total of Asian Americans and all Americans 65 and older

See "Asians in America: A Demographic Overview",

https://www.americanimmigrationcouncil.org/research/asians-america-demographic-overview

Older Asian American Diversity

- Chinese, Filipinos, Japanese, Korean, South Asians, and Vietnamese comprise over 90 % of the Asian elderly population,
- More than 66% of older Asian Americans are foreign born
- Besides Hawaii, 24% of Asian Americans live in California and Washington.

US Census Bureau, 2010.

US Census 2000 identified at least 24 Asian American groups

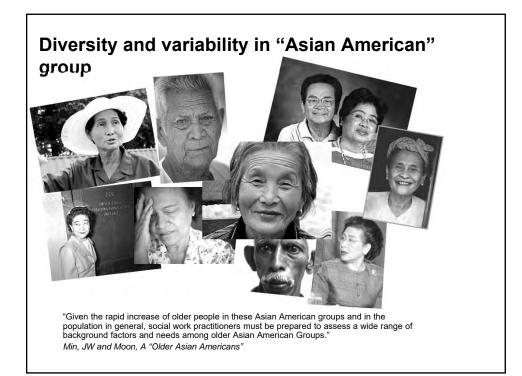


Asian Indian, Bangladeshi, Bhutanese, Burmese, Cambodian, Chinese, Filipino, Hmong, Indo-Chinese, Indonesian, Iwo Jiman, Japanese, Korean, Laotian, Malaysian, Maldivian, Nepalese, Okinawan, Pakistani, Singaporean, Sri Lankan, Taiwanese, Thai, and Vietnamese

Diversity within diversity

- Differences not only in ethnicity and language
- English proficiency
- Refugees vs. immigrant
- Age at immigration
- Length of residence
- Acculturation and Assimilation
- Religion
- Socioeconomic status

Spector, R. 2004. Cultural Diversity in Health and Illness. Pearson Prentice Hall



Take away on Diversity

- Caution with how you view aggregated data about AAPI
- Caution how you approach a person who you identify as Asian American
- Remember, even within same race and ethnicity, there is diversity

Health Disparities

- "A disproportionate burden of preventable disease, disability and death, among specific racial and ethnic populations."
 - Disproportionate compared with reference 'white' U.S. population:
 - Implies a measurable disparity
 - Implies an avoidable and inequitable difference

Definition from Washington State Board of Health See Carter-Pokras, O and Baquet, C. "What is a 'Health Disparity'?", Public Health Reports, 2002;117:426-434.

Health Disparities

- Infectious Diseases
 - Hepatitis B related diseases:
 - Cirrhosis of liver
 - Hepatocellular cancer
 - H. pylori infection:
 - Peptic ulcer disease
 - Stomach Cancer
 - Tuberculosis
 - Latent TB infection
 - Active TB

Health Disparities

Cancer

- Cervical Cancer in Vietnamese and Korean women (low rates of screening)
- Liver cancer in hepatitis B and C carriers
- Nasopharyngeal cancer in Chinese from southern China
- Stomach cancer in Korean, Chinese, and Japanese

See also Asian Pacific Islander American Health Forum http://www.apiahf.org/programs/cdp/index.htm

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Health Disparities

Chronic Illnesses

- Diabetes in ethnic Japanese, Filipinos, South Asian Americans
- Heart disease in South Asians, Filipinos
- Osteoporosis in older Asian women
- Stroke in Chinese, Vietnamese
- Anemia and hemoglobinopathies (thalassemia, G6PD deficiency, hemoglobin E)

Health Disparities

■ Social/Mental Health Issues

- Family Violence
- Smoking in Asian men
- Post traumatic stress disorder and depressive disorders in refugees
- Somatization disorders
- Cultural stigma for mental illnesses

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Health Disparities

Oral Health

- Lack of Preventive Dental Care
- Periodontal Disease
- Caries and Missing Teeth

Take away on Health Disparities

- Make sure that immigrants and refugees have been tested for hepatitis B (and C)
- Consider testing and treating for latent TB infection
- Social/mental health issues are often prevalent but hidden

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Traditional Health Beliefs

- Chinese medicine teaches that health is a state of physical and energy harmony with nature.
- Preventing and treating disease in traditional Chinese medicine consists of balancing energies in different meridians of the body (Yin/Yang), and Qi (chi) or vital energy, as well as paying special attention to five elements (metal, wood, water, fire, and earth)

Spector, R. Cultural Diversity in Health and Illness, 2004.

Traditional Health Beliefs

- Traditional Hmong and Mien health beliefs characterized by:
 - Interventions of a wide variety of spirits that promote health or cause illness; and
 - Risk of loss of soul that brings illness
 - Use of shamans to perform rituals to address appease or dispel spirits

Curriculum in Ethnogeriatrics, 2nd edition. Stanford University

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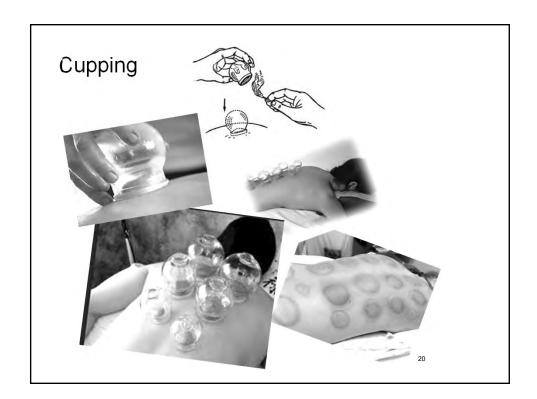
Traditional Health Beliefs

- Older Asian immigrants may view Western medicine, with its reliance on pills and surgery, as external assaults on the body
- Eastern medicine, in contrast, may be seen as an attempt to correct internal body imbalances
- Western medicine is often viewed as more powerful for acute conditions of illness, whereas Eastern medicine is viewed as essential to regulating daily health functioning

Chin, JL and Bigby, J. "Care of Asian Americans". In Bigby, J, ed., Cross-Cultural Medicine 2003 .

Traditional Healing Practice

- Acupuncture: needles inserted at specific points of along a meridian, a network of points that connect to internal organs. Treatment goal is to restore balance of yin and yang. Also moxibustion, acupressure
- Herbal teas: combination of dried herbs and other natural products, slow simmered to a thick broth
- Cupping and Coining: Methods used to remove 'bad wind' from the body
- Tui Na: treatment for musculoskeletal problems, including broken bones, involving use of massage, manipulation, medicinal poultices and ointments





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Traditional Health Beliefs

- Reluctance to have blood drawn. Blood is seen as the source of life and is not easily regenerated
- Reluctance to take Western medicine. Western medications are often seen as causing too much 'internal heat', so contributing to imbalance of the bodies energies
- Reluctance to have surgery. Traditional Chinese medicine believes in the integrity of the body

Spector, R. Cultural Diversity in Health and Illness, 2004.

Traditional Healing Practice

- Several studies have found that between 40% and 80% of patients do not report complementary or alternative medicine (CAM) use.
- Nondisclosure of CAM use may increase the likelihood of an adverse interaction with conventional treatment and obscures the diagnosis and treatment of adverse interactions.
- Provider cultural competence may increase reporting of CAM use and reduce the prevalence and impact of this public health problem.

Reducing Health Disparities in AAPI Populations: AAPI Medical Traditions

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Adulteration of Traditional Chinese Medicine (TCM)

Though there is perception that herbs and proprietary herbal compounds are generally safe, DNA sequencing tools showed in one recent study that 92% of TCM herbal products had at least one type of contaminant (with undeclared natural or pharmaceutical products).

Scientific Reports volume 5, Article number: 17475 (2015) https://www.nature.com/articles/srep17475

Adulteration of Traditional Chinese Medicine (TCM)

A study from Hong Kong in 2017 showed that The six most common categories of adulterants detected were nonsteroidal anti-inflammatory drugs (17.7%), anorectics (15.3%), corticosteroids (13.8%), diuretics and laxatives (11.4%), oral antidiabetic agents (10.0%) and erectile dysfunction drugs (6.0%).

Br J Clin Pharmacol, 84: 172–178. doi: <u>10.1111/bcp.13420</u>. http://onlinelibrary.wiley.com/doi/10.1111/bcp.13420/full

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Take away on Adulteration

- · Ask about use of TCM products
- Don't rely on labels or internet information as to the exact ingredients
- Keep in mind possibility of pharmaceutical or heavy metal contaminants in unexplained illnesses in those using TCM products

Br J Clin Pharmacol, 84: 172–178. doi: <u>10.1111/bcp.13420.</u> http://onlinelibrary.wiley.com/doi/10.1111/bcp.13420/full

Case study

TP is a 60 y.o. Khmer (Cambodian) woman refugee woman who lost 2 children and her parents during the Khmer Rouge era. Fleeing with her husband and remaining daughter, she resettled in Seattle. She was treated for many years for depression and schizophrenia, including hospitalization for a month in 2008.

- In Sept. 2010, without prior warning she shot and killed her son-in-law, 2 granddaughters, and herself, while injuring her daughter.
- In the previous weeks, she told family members she could not tolerate colors, that she only wanted to see white. She began wearing all white, a color of purity.
- Her daughter later said "her mother rarely spoke of her experiences in her native Cambodia..."

 $\underline{\text{http://seattletimes.nwsource.com/html/localnews/2013031989_luellen30m.htm}}$

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Mental Illness

- 82% of Cambodian elders have poor English skills. About 29% live below federal poverty level.
- "Mental illness traditionally hidden from public view, . . . they bring shame to the family."
- "Survivors of the genocide are at higher risk for depression, PTSD, and occult brain insults. Rates of alcohol and drug abuse, homicide, and assault also higher in Cambodian American communities."

Doorway Thoughts: Cross-cultural Health Care for Older Americans. American Geriatrics Society, 2006.

- Many Asian immigrants come from cultures that may stigmatize mental illness even more than American culture does. Mental illness is often thought of as incurable, and counseling is considered only for those with severe impairments to functioning.
- Being labeled as mentally ill brings shame on the person and his or her family. This can explain the reluctance of some patients to keep counseling appointments, although many patients may be too polite to decline outright.

Recognizing Mental Illness in Culture-bound Syndromes. *Am Fam Physician*. 2010 Jan 15;81(2):206-210

Case Study

- KW, 74 y.o. Chinese woman living in an ALF for the past year, transferring care from another PCP in the community.
- PMH significant for osteoporosis w/ compression fracture in past year, depression, and HTN
- No family listed on her information

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- 6/08 c/o weakness in legs and whole body, w/ trouble sleeping on trazodone. She did not appear depressed to me.
- 7/08 c/o poor appetite. Stated that there was some problem affecting her appetite, but adamant about not talking about what that was. Can't sleep, not happy. Mood subdued, no agitation. Given mirtazapine (Remeron) for depression and sleep.
- 8/08 Still having insomnia, wants to see sleep specialist. Can't sleep at all past few days due to family affair, but doesn't want to talk about it, even with a counselor.

- 3 days later, she was found dead in her room by hanging.
- A few days after, the ALF found out that indeed she did have family in the area. One of her daughters, with whom she apparently had lived with, had committed suicide about 1 year ago. There were 2 remaining children, but no further information available on their status.

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Suicide in Asian Americans

Although suicide rates for Whites and Native Americans were higher than those of Chinese, Japanese and Filipino Americans overall, Chinese and Japanese Americans (mostly women) over age 65 had overall the highest rates of any age/ethnic cohort. Hanging was the major method.

(Lester, D. 1994 in Omega 29(2))

- Traditional Chinese culture may play a role, for women especially are not encouraged to disclose their feelings to friends or family members, certainly not to members outside the family. Mental problems also may be viewed as social disgrace and shame. "Regular depression screening for older Chinese women is recommended so that timely interventions can be received."
- Besides cultural barriers to disclosing mental problems, language difficulties with mainstream providers also adds to difficulty with expressing feelings.

(Zhan, L. 1999 Health Practice in Chinese Older Women in Asian Voices)

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Case Study

MN is a 68 y.o. Vietnamese woman, who is transferring care from another PCP. Before I see her, her daughter-in-law, who is also a coworker, approaches me saying that they just found out she has lung cancer and will need treatment for it. The family doesn't want her to know about the cancer. As provider, the challenge is how to prepare for the my first visit with her.

End of Life Care

- 3 dimensions in end-of-life treatment that may differ culturally:
 - Communication of 'bad news'
 - Locus of decision making
 - Attitudes toward advance directives and end-of-life care.

Searight, HR and Gafford, J. Cultural Diversity at the End of Life. *Am Fam Physician 2005; 71: 515-522.*

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Communication of 'Bad News'

- Emphasis in US on informed consent and avoiding physician 'paternalism,' is based on value of individual autonomy
- Although many in the US value autonomy, other cultures emphasize beneficence more, thus protecting patients from the emotional and mental harm of hearing 'bad news'

Communication of 'Bad News'

- "Assuming a Chinese woman would not want to be told her diagnosis because she is Chinese is stereotyping.
- Insisting that she *must* be told, even at the risk of violating her rights, is a form of cultural imperialism.
- The challenge is to navigate between these poles."

Kagawa-Singer, M and Blackhall, L. Negotiating Cross-Cultural Issues at the End of Life. *JAMA* 2001; 285: 2993-3001

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Communication of 'Bad News'

- Have trained interpreters available, don't use family members
- Check for understanding: "Please share with me what your understanding of your condition is and the treatment we're considering?"
- Informed refusal: "Some patients want to know everything about their condition, and others would prefer the doctors to mainly talk to their families. How you like to be told?"

Kagawa-Singer, M and Blackhall, L. Negotiating Cross-Cultural Issues at the End of Life. *JAMA* 2001; 285: 2993-3001

Locus of Decision making

- Cultures that place a higher value on beneficence and avoiding harm relative to autonomy have a long tradition of familycentered health care decisions.
- Among Asian cultures, family based medical decisions are a function of filial piety. Illness is considered a family event rather than an individual occurrence.
- Family centered decision making may be seen as "protecting the dying patient from the burden of making difficult choices..."

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Locus of Decision making

- Determine key family members and ensure they are included in discussions as desired by patient.
- "Is there anyone else that I should talk to about your condition?"

Advanced Directives and End of Life Care

- Significantly lower rates of advance directive completion among Asians, Hispanics, and African Americans.
- In every subgroup, Asian Americans much less likely to accept hospice services than whites

Kwak J, Haley WE. *Gerontologist*, 2005 Oct; 45(5):634-41. Kagawa-Singer and Blackhall.

Advanced Directives and End of Life Care

- Filial piety leads to the expectation that children will care for their elders
- But it also creates a sense of obligation that makes it difficult for family to request other than aggressive care.
- With hospice, issue of 'face' may play a role in showing how adequately the family is providing care in the home

Kagawa-Singer, M and Blackhall, L. Negotiating Cross-Cultural Issues at the End of Life. *JAMA* 2001; 285: 2993-3001

Cross-Cultural Interview Questions for End-of-Life Care

- Some people want to know everything about their medical condition, and others do not. What is your preference?"
- "Do you prefer to make medical decisions about future tests or treatments for yourself, or do you prefer that other people make them for you?"

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Cross-Cultural Interview Questions for End-of-Life Care

- If indicated family members, "Would you prefer that I speak to _____ alone, or would you like to be present?"
- "If you change your mind at any point and want more information, please let me know. I will always answer any questions you may have."
- Document in chart

Cross-Cultural Interview Questions for End-of-Life Care

- Confirm understanding (especially using an interpreter): "I want to be sure that I am explaining things accurately. Can you tell me what you understand about your _____'s condition and the treatment we are recommending?"
- "Is there anything else that would be helpful for me to know about how your family/community/religion views serious illnesses and treatments like this?"

Searight, HR and Gafford, J. Cultural Diversity at the End of Life. Am Fam Physician 2005; 71: 515-522

Arthur Kleinman's eight questions

- What do you call the problem?
- What do you think has caused the problem?
- Why do you think it started when it did?
- What do you think the sickness does? How does it work?
- How severe is the sickness? Will it have a short or long course?

Fadiman, A. The Spirit Catches You and You Fall Down

Arthur Kleinman's eight questions

- What kind of treatment do you think the patient should receive? What are the most important results you hope he/she receives from this treatment?
- What are the chief problems the sickness has caused?
- What do you fear most about the sickness?"

Fadiman, A. The Spirit Catches You and You Fall Down

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Case Study

- MN chose a middle ground, she wanted her family to make most of the decisions, but did want to know about her test results.
- She received chemotherapy for her lung cancer, and now knows she has cancer. Unfortunately her cancer has not responded to treatment.
- Though she transferred her care to another institution, I planted the seeds for hospice with my co-worker and was told that they were involved in her care.

Case Study

- GC is a 78 y.o. Chinese man living in low income senior housing with no family. He has been diagnosed 4 months ago with what appears to be metastatic lung cancer.
- He is slowly declining in health, yet continues to live alone, refusing offers to move to a nursing home or accept hospice care. His main support is a young case manager from a housing alliance organization.

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- At his last visit with me, he expressed gratitude for my care and stated that he had plans to return to Taiwan to die. He said he had been in contact with friends there who would assist him, though he had not seen them for several decades.
- 2 days later he was found dead from his disease, alone in his apartment in Seattle.

Hospice services

Non-white racial or ethnic groups generally lacked knowledge of advance directives and were less likely than Whites to support advance directives. Asians and Hispanics were more likely to prefer family-centered decision making than other racial or ethnic groups.

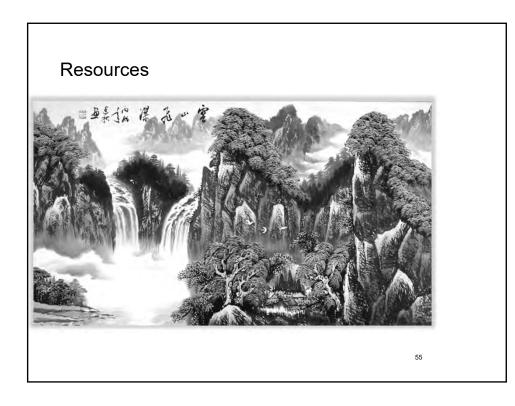
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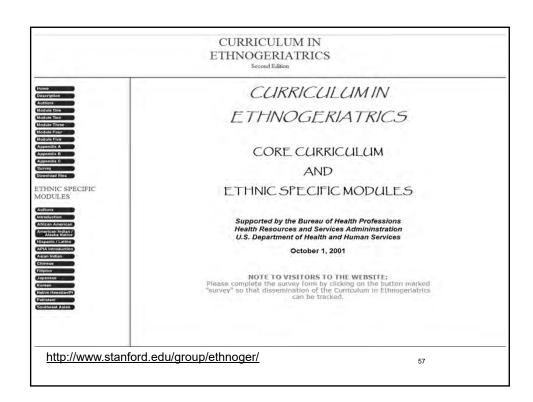
Hospice services

- For minority populations, lack of information about hospice, lack of ethnic and cultural practitioners, lack of appropriate cultural models for end-of-life leads to lower acceptance
- In 2004, of those who died while receiving hospice services, only 4% were Asian American, 6% were African American, and 15% were Latino, contrasted with 74% who were white

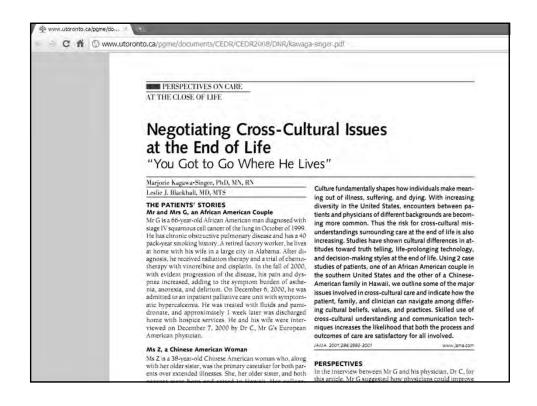
Crawley, L and Kagawa-Singer. Racial, Cultural, and Ethnic Factors Affecting the Quality of End-of-Life Care in California

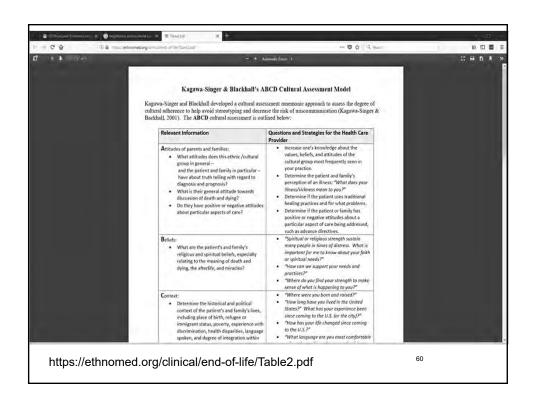


















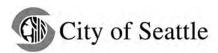


Connecting with AAPI About Dementia

Nikki Eller, MPH Healthy Brain Research Network University of Washington





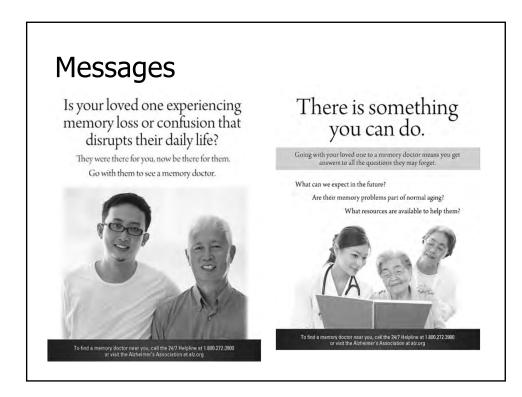




Memory Messaging - Background

Messages aimed to increase earlier dementia identification by encouraging adult children to accompany older parent(s) to a visit with a memory specialist if they have concerns about their cognition.

Focus groups conducted to test the messages with Chinese and Japanese Americans



Local Memory Messaging



- Asian Americans and Pacific Islanders (AAPI) are the fastest growing population in WA state – and the fastest growing minority group in America.
- A higher proportion of AAPI are providing care or support for older relatives than other racial/ethnic groups.



Social Stigma

From literature review, clear that stigma against persons with Alzheimer's Disease and related dementias and their families exists in multiple AAPI cultures.

Chinese word for dementia: "Catatonic and crazy"

"[1]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

What are you most concerned about?

- Health care and long-term care cost, availability, cultural appropriateness
- What resources are available to support us?
- Maintaining independence and quality of life
- How to talk about these issues with parent

Action Item 1:

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

More research is needed to improve treatment, respite care, and provider training, and it needs to include AAPI.



Action Item 2:

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

The term "AAPI" encompasses over 50 sub-populations and 100+ languages. Too broad for tailoring services or calculating risk.

Action Item 3:

Facilitate access to culturally and linguistically appropriate education and services.

To overcome barriers to getting to a provider and getting a diagnosis, important to use appropriate screening tools, educational resources, and messages.

Resources

Links to AAPI-specific resources to address gaps identified by focus group participants:

- Why go to a memory doctor (or primary care doctor).
- How to find a memory doctor.
- How to start a conversation with family members about cognitive decline.
- Support for caregivers translated legal documents and stress release.
- Resources for providers cultural competency training, screening tools, and organizational tools.

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 Utdu. 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 Assocation 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%20 dealing%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 a handout on advance directives in Chinese:

https://www.healthinfotranslations.org/pdfDocs/AdvanceDirectives_TCH.pdf and more information for caregivers available in English: https://medlineplus.gov/alzheimerscaregivers.html

Kokua 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_order_resources.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.org

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. https://sites.duke.edu/centerforaging/cerad/

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

Community Partnerships Local, State, and National













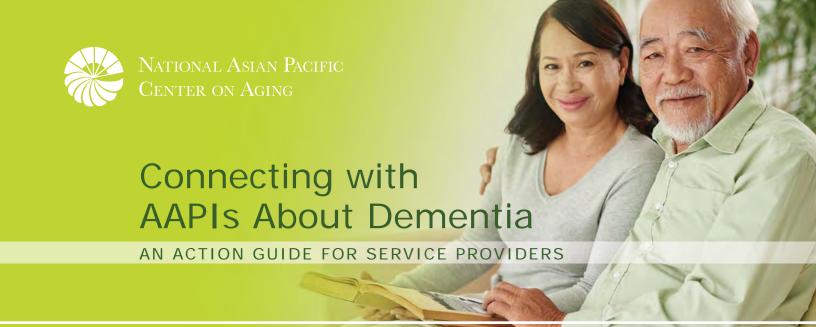


Contact Us

- Nikki Eller ellern@uw.edu
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- Link to Action Guide: <u>http://depts.washington.edu/hprc/resource</u> <u>s/products-tools/aapi-dementia-action-guide/</u>

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The findings of this research are those of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the City of Seattle.



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 and Prevention, 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 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 "Be there now, like they were there for you."
- Not all adult children have strong or positive relationships (currently and/or in the 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,
 showing authentic relationships between parents and children.
- Make the call to action clear. For example, 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 Assocation 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 Assocation 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 a handout on advance directives in Chinese:

https://www.healthinfotranslations.org/pdfDocs/AdvanceDirectives_TCH.pdf and more information for caregivers available in English: https://medlineplus.gov/alzheimerscaregivers.html

Kokua 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_order_resources.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.org

The Alzheimer's Assocation 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.

https://sites.duke.edu/centerforaging/cerad/

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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