Addressing Alzheimer’s Disease in Asian American and Pacific Islander Older Adults
An Action Guide for Service Providers

Caring for a relative with Alzheimer’s disease or related dementia (ADRD) is challenging and can pose distinct challenges for some Asian American and Pacific Islander (AAPI) families. Stigma against individuals with ADRD and their families has been noted in several AAPI cultures (Gerdner & Yeo, 2013), which can lead to social isolation and caregiver burnout (Arnsberger, 2005). Strong values of filial piety contribute to AAPI being twice as likely to care for a grandparent or grandparent-in-law compared to the general population (18% vs. 8%) (National Alliance for Caregiving, 2009). Reluctance to use formal services for care may be due to a lack of culturally appropriate services. A study of California Alzheimer’s Disease Diagnostic and Treatment Centers found that only the center with bilingual staff and targeted outreach efforts was seeing the expected number of AAPI patients based on community demographics (Chow, Ross, Fox, Cummings, & Lin, 2000).

To explore ways to improve early detection of ADRD among this population, focus groups were conducted with Chinese and Japanese American individuals in King County, Washington, to test messages intended to encourage adult children to bring their parents to a provider for a cognitive evaluation. Participants identified a need for more information on how to identify warning signs of ADRD, what to expect from a physician’s visit, the value of diagnosis, and options and resources available in the event of a positive diagnosis. One of the most challenging barriers identified was how to start a conversation with older relatives about suspected memory loss. With strong cultural values placed on respect for elders and politeness, participants did not know how to broach what they considered to be a sensitive topic.

Based on the findings from the focus groups and other research, the current authors have assembled Connecting with AAPIs About Dementia: An Action Guide for Service Providers (access http://depts.washington.edu/hprc/resources/products-tools/aapi-dementia-action-guide) in partnership with the National Asian Pacific Center on Aging to help service providers connect with AAPI communities about dementia. There are three key recommendations:

- Advocate for adequate resources to end Alzheimer’s disease for all American individuals, including AAPI individuals. There is a need for more research dollars to improve treatment, respite care, and provider training for ADRD, which needs to be inclusive of the AAPI community. A companion Action Guide for policymakers is available to aid advocacy efforts.
To help overcome the barriers Asian American and Pacific Islander families face in accessing providers, it is important to use culturally and linguistically appropriate screening tools, educational resources, and messages....

- Collect disaggregated race data to tailor education and long-term services and supports. Covering more than 50 subpopulations and 100 different languages, the term “AAPI” is too broad to be useful when thinking about tailoring services or calculating risk. Disaggregating race data can help determine more about the population being served. The 2010 census offers 25 subcategories and identifies the largest ethnicities in cities around the country (Hoeffel, Rastogi, Kim, & Shahid, 2012).

- Facilitate access to culturally and linguistically appropriate education and services. To help overcome the barriers AAPI families face in accessing services, it is important to use culturally and linguistically appropriate screening tools, educational resources, and messages (see the Action Guide for resources and tips on designing effective messages).

Despite the challenges AAPI individuals face when coping with ADRD, evidence shows that tailored services and tools can help overcome these challenges. A group in San Francisco, California that increased outreach efforts in the Chinatown neighborhood was successfully able to recruit Chinese American individuals for ADRD research (Chao et al., 2011). In another instance, an informational program for caregivers that was adapted for South Asian families in the United Kingdom was well attended and resulted in improved knowledge and understanding of dementia and available services, and changes in care practice (Parveen, Blakey, & Oyebode, 2018).

When working with AAPI patients and caregivers, nurses need to remember that they may be reluctant to disclose psychological symptoms, and diseases such as depression may be expressed differently (Arnsberger, 2005). Nurses are in a strong position to use diagnostic and screening tools developed for the target population (Trockman et al., 1997). The Action Guide provides links to tools specific to ADRD and AAPI communities.

In sum, we hope nurses and other service providers will find the Action Guide useful in providing care for AAPI older adults.

REFERENCES


toolkit


Nikki Eller, MPH
Program Specialist & Community Liaison
Healthy Brain Research Network
University of Washington
Seattle, Washington

Basia Belza, PhD, RN, FAAN
Aljoya Endowed Professor of Aging
School of Nursing
Adjunct Professor
School of Public Health
University of Washington
Seattle, Washington

The authors have disclosed no potential conflicts of interest, financial or otherwise. Support was received from the City of Seattle Innovation Fund and University of Washington Healthy Brain Research Network, a Prevention Research Centers program funded by the Healthy Aging Program–Healthy Brain Initiative through a cooperative agreement (#U48 DP 005013) from the Centers for Disease Control and Prevention (CDC). The findings and conclusions in this editorial are those of the authors and do not necessarily represent the official position of the CDC or the city of Seattle.

The authors acknowledge Lesley Steinman as Principal Investigator of the focus group and thank Lynne Korte and Marci Getz for their review.

doi:10.3928/00999114-20180313-01