



USC Edward R. Roybal Institute on Aging

Alzheimer's Disease and Related Dementias (ADRD) in Asian American Communities

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Facts and Figures



- Currently, 5.8 million Americans are living with AD, and this number is projected to be double by 2050.
- The total cost of caring for those with AD in 2016 was \$236 billion, about 68% of which being covered by Medicare and Medicaid.

Alzheimer's Association. (2020). 2020 Alzheimer's disease facts and figures. Retrieved from <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>



Family members and friends provided nearly **\$244 billion** in unpaid care to people with Alzheimer's and other dementias in 2019.

SOURCE: <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

MetLife Foundation Alzheimer's Survey: What America Thinks



- Alzheimer's disease is the second most feared disease among American adults, behind cancer.
- More than 62% of survey participants report that they know little or nothing about Alzheimer's disease.

SOURCE: <https://www.21co.com/wp-content/uploads/2019/07/alzheimers-2011.pdf>

ADRD in Racial/Ethnic Minorities



- Racial and ethnic minorities have limited knowledge of AD, delayed AD diagnosis, and underutilization of AD-related services.

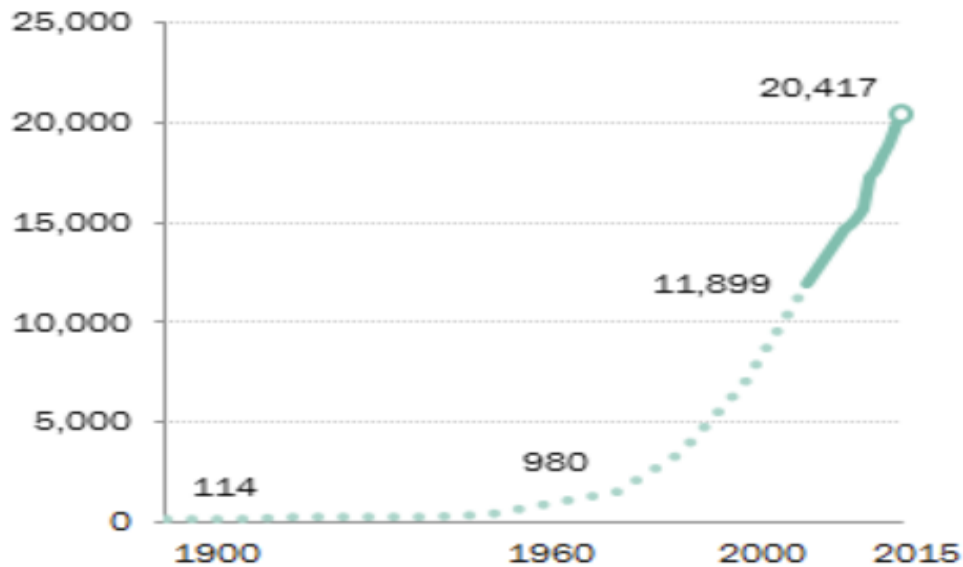
Kenning, C., Daker-White, G., Blakemore, A., Panagioti, M., & Waheed, W. (2017). Barriers and facilitators in accessing dementia care by ethnic minority groups. *BMC Psychiatry*, 17(1), 316.

- Not much is known about the Asian American population.



The Asian population in the U.S. has grown 72% since 2000

In thousands



Note: In 2000 and later, Asians include the mixed-race and mixed-group populations, regardless of Hispanic origin. Prior to 2000, the census only allowed one race category to be selected. Asians include Pacific Islanders in 1980 and earlier years.

Source: 2000 and 2010 population estimates from U.S. Census Bureau, "The Asian Population: 2010" Census Brief, Table 6. For 2006-2009 and 2011-2015, American Community Survey 1-year estimates (American Fact Finder). For 1990, U.S. Census Bureau, "Asian Population: 2000" Census Brief, Table 2. For 1980 and earlier years, Campbell Gibson and Kay Jung, "Historical Census

<https://pewrsr.ch/2lheXin>



Study 1

Community Readiness for ADRD: Findings from the AAQoL Survey

- Target population: Asian American residents in Austin (aged 18+)



<https://austintexas.gov/departments/about-asian-american-quality-life>



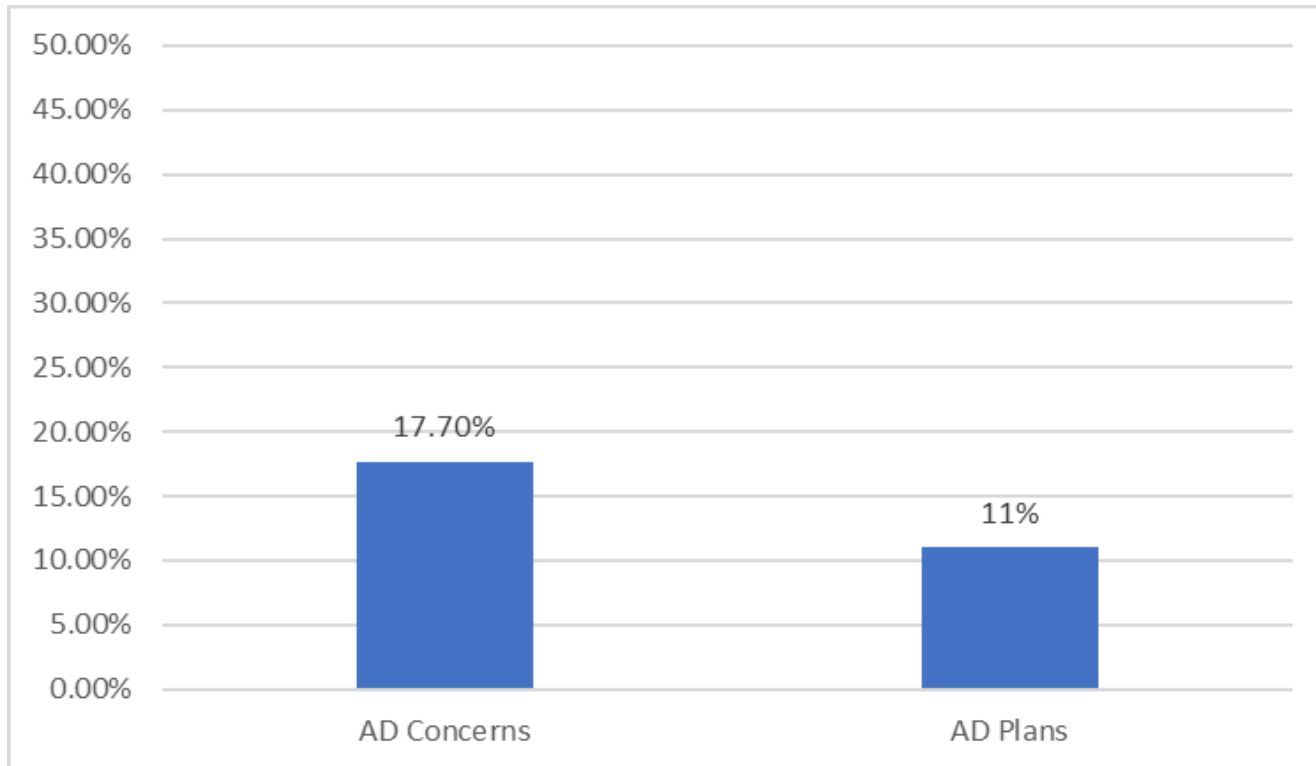
Culturally and Linguistically Sensitive Approach

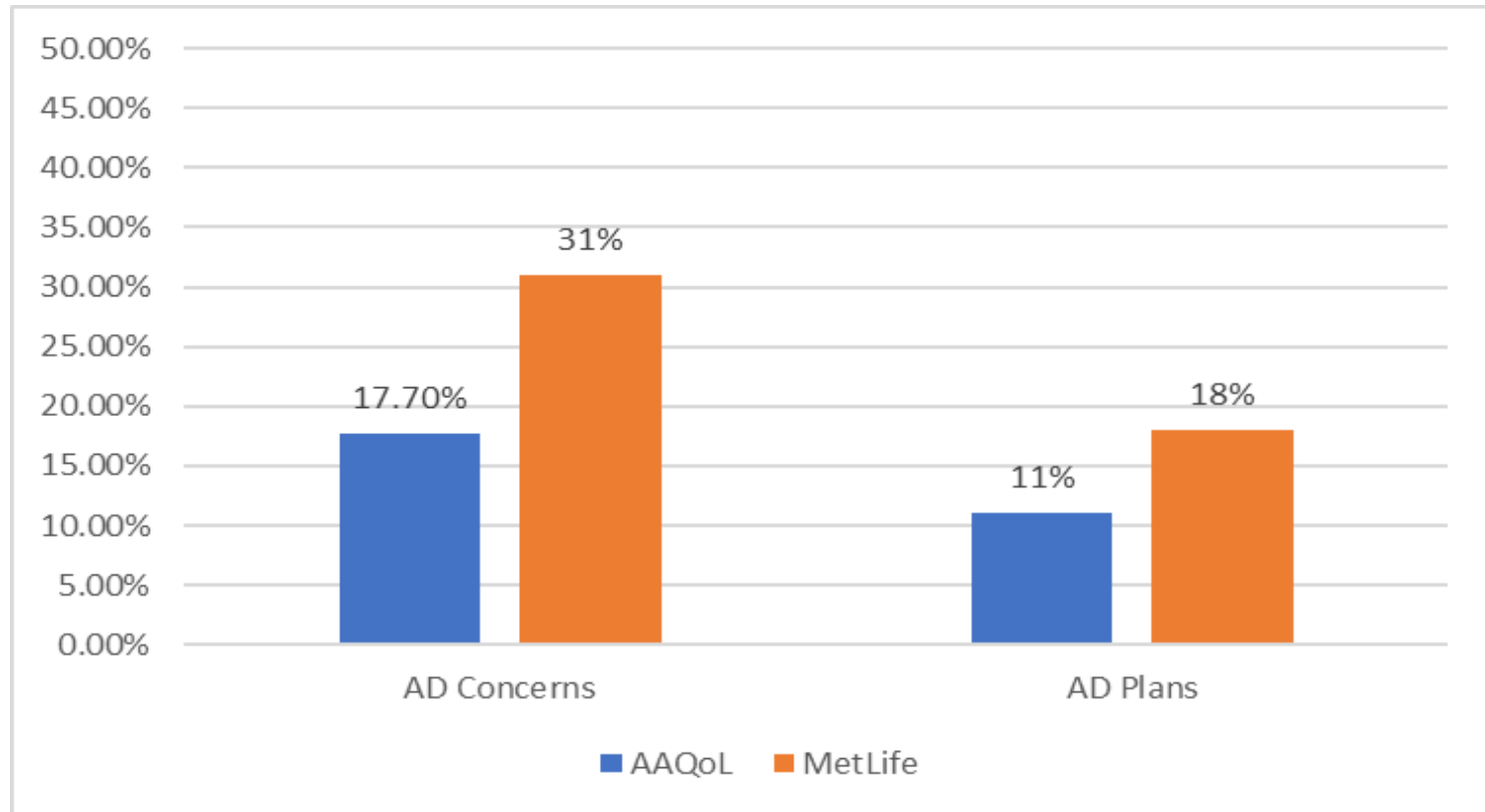
- Asian language versions of the survey
- Survey assistants who share the same culture and language of the target population
- Community partnerships





- Final Sample Size = 2,609
 - 640 Chinese
 - 574 Asian Indians
 - 471 Koreans
 - 513 Vietnamese
 - 265 Filipinos
 - 146 Asians of other ethnic backgrounds








Stigmatizing Beliefs about ADRD in Asian American Communities

- AD is a normal process of aging. 49.3%
- Developing AD is a matter of fate. 14.0%
- Social interaction with people with AD should be avoided. 5.6%
- It is embarrassing to have a family member with AD. 5.9%



Asian Americans' concerns and plans about Alzheimer's disease: The role of exposure, literacy and cultural beliefs

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Abstract

Responding to the increase of the Asian American population and the growing imperative to address issues on Alzheimer's disease (AD) in diverse populations, this study examined Asian Americans' concerns about AD (both concerns about one's own de-

Jang, Y., Yoon, H., Park, N. S., Rhee, M. K., & Chiriboga, D. A. (2018). Asian Americans' concerns and plans about Alzheimer's disease: The role of exposure, literacy, and cultural beliefs. *Health and Social Care in the Community*, 26(2), 199-206.



Stigmatising beliefs about Alzheimer's disease: Findings from the Asian American Quality of Life Survey

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Abstract

Responding to the public health significance of Alzheimer's Disease (AD) and lack of information on AD-related issues in Asian Americans, the present study examined the

Liang, J., Jang, Y., & Aranda, M. P. (2020, online first). Stigmatizing beliefs about Alzheimer's disease in diverse ethnic groups of Asian Americans. *Health and Social Care in the Community*. doi.org/10.1111/hsc.13208

Major Findings



- People with low education and acculturation were subject to stigmatizing beliefs.
- Stigmatizing beliefs were associated with higher levels of AD concerns.
- However, the link between AD concerns and plans was weak.



Implications

- Educational programs for ADRD awareness and stigma reduction
- Special attention to those with low education and acculturation
- Efforts to leverage AD concerns to AD plans



Study 2

AD Knowledge and Service Awareness in Older Korean Americans: The Role of Social Capital

- Social capital as promoting factors
 - Prior exposure to AD
 - Social network
 - Social activity participation
 - Community social cohesion

Study of Older Korean Americans (SOKA)



- 2,150 participants in multi-states surveys conducted in 2017-2018
 - California (Los Angeles), $n = 650$
 - New York (New York City), $n = 548$
 - Texas (Austin), $n = 322$
 - Hawaii (Honolulu), $n = 322$
 - Florida (Tampa), $n = 308$

Knowledge About Alzheimer's Disease and Awareness of Alzheimer's Disease-Related Services in Older Korean Americans: The Role of Social Capital

Journal of Applied Gerontology
1-8

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DOI: 10.1177/0733464820911533

journals.sagepub.com/home/jag



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Hyunwoo Yoon³ , and David A. Chiriboga¹

Abstract

The purpose of the study was to investigate factors associated with Alzheimer's Disease (AD)-related knowledge and service awareness in older Korean Americans. Considering the importance of social resources in the lives of older immigrants, the focus was on exploring the role of social capital-related factors (e.g., prior exposure to AD, social network, activity

Park, N. S., Jang, Y., Rhee, M. K., Yoon, H., & Chiriboga, D. A. (2021). Knowledge about Alzheimer's disease and awareness of Alzheimer's disease-related services in older Korean Americans: The role of social capital. *Journal of Applied Gerontology*, 40(2), 220-227.

Regression Models of AD Knowledge and Service Awareness



	Perceived Knowledge about AD β	Awareness of AD-related Services Odds Ratio (95% Confidence Interval)
Demographic variable		
Age	-.11***	1.02* (1.01, 1.05)
Female	.07**	1.34 (.97, 1.86)
Married	.05*	.86 (.63, 1.17)
Education	.25***	1.14 (.97, 1.35)
Region (ref = California)		
New York	-.06*	1.05 (.73, 1.51)
Texas	-.04	1.03 (.66, 1.62)
Hawaii	-.07**	1.09 (.71, 1.67)
Florida	.02	.44 (.48, 1.16)
Immigration-related variable		
Length of stay in the U.S.	.02	.99 (.98, 1.01)
Acculturation	.17***	1.03* (1.01, 1.06)
Social capital-related variable		
Prior AD exposure	.06**	1.72** (1.26, 2.34)
Social network	.07**	1.03* (1.01, 1.06)
Activity participation	.03	1.09** (1.04, 1.14)
Community social cohesion	-.01	1.02 (.98, 1.06)
Summary statistics	$R^2 = .20***$	-2 Log likelihood = 1446.5 $\chi^2/df = 73.0***/14$



Study 3

ADRD Caregiving in Linguistic and Social Isolation: A Qualitative Study

- In-depth interviews with multiple stakeholders
 - 3 service providers in ADRD service agencies
 - 5 service providers in Korean-specific social service agencies
 - 5 Korean American caregivers of a family member with ADRD

From the Perspective of ADRD Service Agencies



- **Challenges in reaching out to ethnic minority communities**

“We haven’t successfully reached out to Korean American caregivers. It is primarily because we don’t have staff representing Korean communities. We only have a few volunteers who speak Korean. Without bilingual and bicultural staff, it is hard to build connections.”

From the Perspective of Korean-specific Social Service Agencies



- **Discomfort w/ lack of specialty training**

“Our program is pretty much geared toward healthy older adults, keeping them and active and happy. Providing service to those with dementia is beyond the capacity of our Center.”

From the Perspective of Korean American Caregivers



- *“I feel extremely **isolated**. My social life has been totally cut off since I started taking care of my mom.”*
- *“I had to figure out everything on my own. Now I think I know a bit about the disease and how to handle my mom, but I had to **learn the hard way**. I wish someone had told me.... I had to spend so much of my time and emotion in figuring things out.”*



- “I wish there is something like a *small group meeting* where people like me *share information* and know-hows. I often wonder how other people do their caregiving, but I haven’t met anyone yet.”
- “It will be great to get to know other caregivers in Korean communities. Sometimes I just want *to talk with somebody who understands what I am going through.*”
- “Having this interview is actually a treat for me. This is a wonderful *get-away* from my everyday caregiving routine.”



Implications

- Needs for inter-agency partnerships
 - Referrals for specialty services
 - Cultural and linguistic support
- Caregiver support programs
 - Caregiver education and counseling
 - Respite service
 - Peer support group
 - Cultural and linguistic accommodations



Study 4

Adapting an Evidence-Based Intervention for ADRD Caregivers with Limited English Proficiency: A Study with the Savvy Caregiver Program (SCP)

PI: Yuri Jang

Co-I: Kenneth Hepburn (Emory University)

Community Partners: Angela Yeh (Alzheimer's Los Angeles)

Kwan Park (Koreatown Senior and Community Center)

National Institute on Aging R21



Funding Acknowledgement

- The City of Austin's Asian American Quality of Life initiative (#26-8275-39)
- National Institute on Aging (R01 AG 047106)
- NIA Administrative Supplement on ADRD



**Thank
You!!!**

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