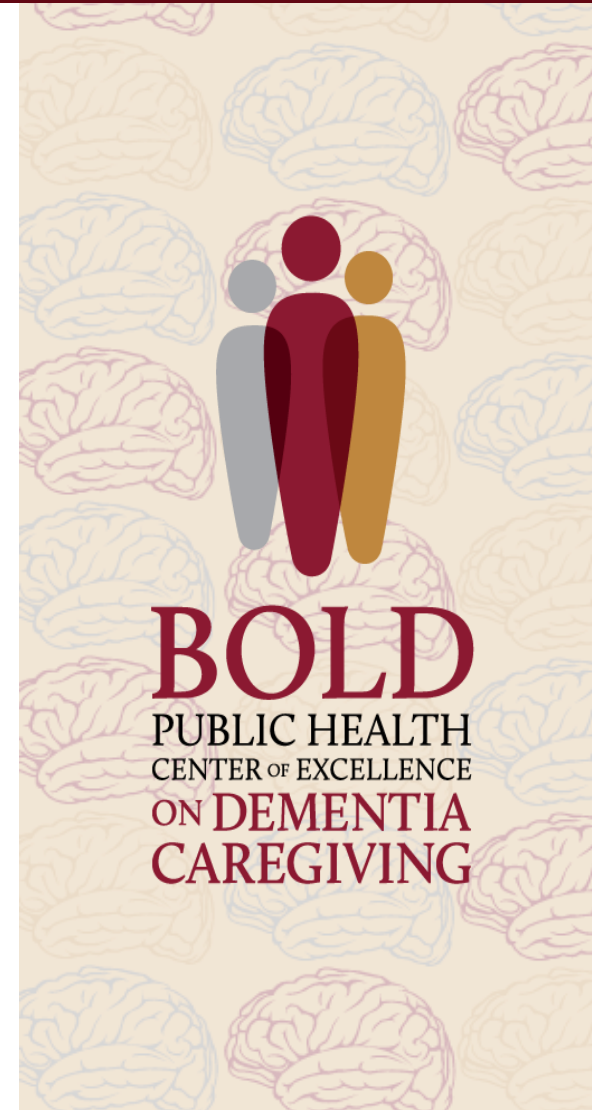


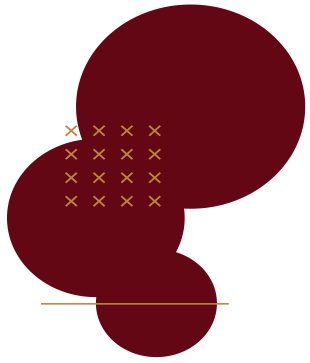
Equity and Cultural Adaptation in Dementia Caregiving II

(Native American/American Indian and Asian American Communities)

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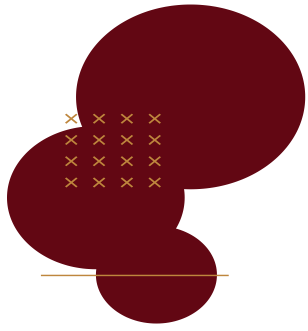
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Why are we still here (yet, again) chatting about inequities among American Indian and Alaska Native dementia caregiving?

- Hint #1: It's not THEM.
- Hint #2: It's more than one thing (many more).
- Hint #3: Ask what have our personal, professional, and political assumptions blinded us to?
- Main item in our answer cloud: The cultural demands and assumptions of our worksite systems (details to follow).



A real-life story of organizational impediments to non-majority caregiver outreach

1. Administration on Aging 2-year grant
2. Goal: develop ethnic-specific Alzheimer's support groups for caregivers
3. Year 1: I got a long, vicious tirade from the state unit on aging director that nothing has happened except that I took the money.
4. Year 2: 4 ethnic-specific ADRD support groups are operating in two different cities (African-American & Spanish-speaking communities).
5. Analysis: extreme conflict of bureaucratic outcome norms with community-based outcome norms: numbers AND relationships.

Seeking caregiver equity among AI/AN's: Musings

- If we just knew more about AI/AN's we could help them fix their problems.
 - This thought reflects an unstated assumption that the problem of persistent caregiver inequity is located with Natives.
- I'm not biased; I've read about Natives and their "plight."
 - This is the old **US—THEM** false dichotomy
- Others are not failed attempts at being us.
 - *Special note: WE are the "other" to THEM*



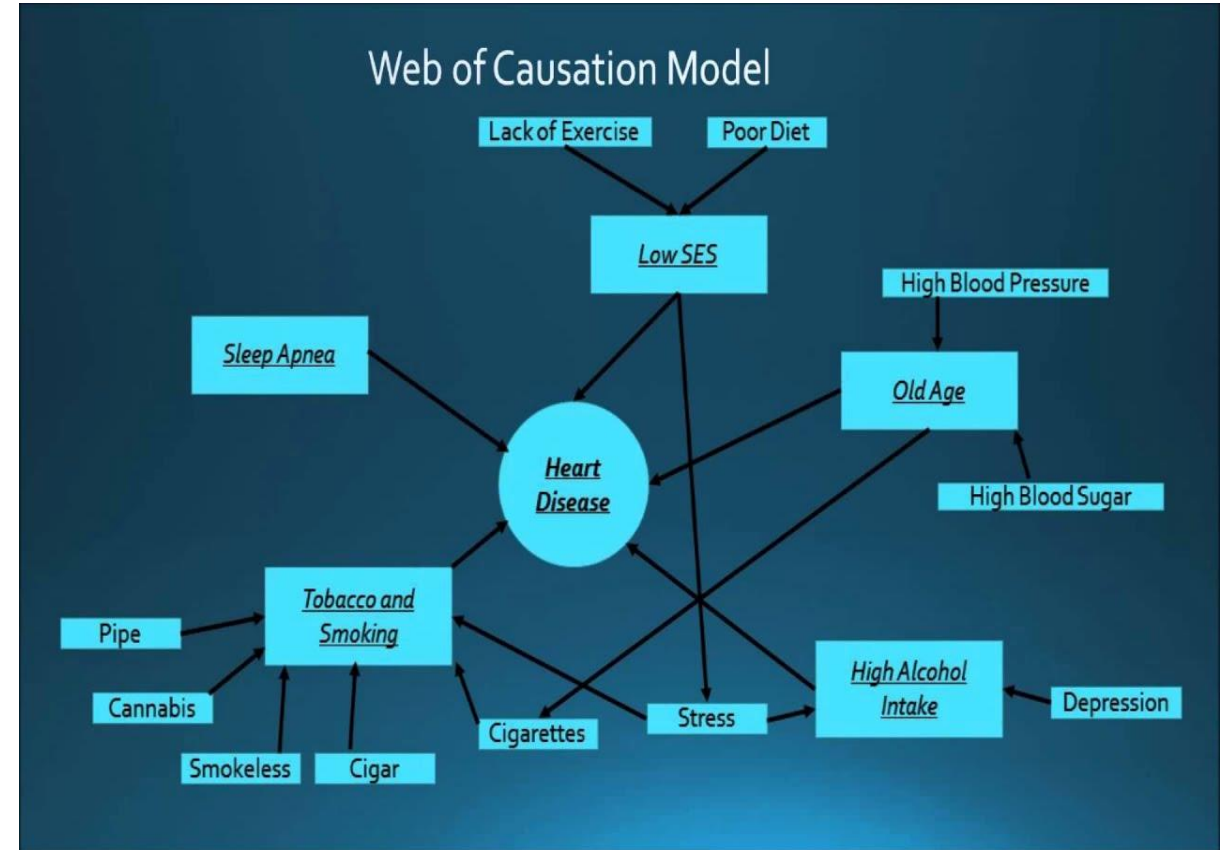


So, what could possibly be the problem with US?

1. Rigid bureaucratic systems
2. Bean-counting accountability: a proxy for real, difficult to measure outcomes
3. Desk-top derived productivity goals
4. Grant-time cycles: we work in a place called *Grant Land, USA*.
5. Intervention protocols and outcomes are imagined and written prior to collaboration: reality won't be what we imagined
6. Very quick results demanded
7. Huge results demanded
8. We are ensnared in an organizational *Cult of Numbers and Fast Results*

Seeking caregiver equity among AI/AN's

- There is NOT a check-box list of steps that will unlock Indian Country to all the “wonderous” PH/Aging Program interventions out there.
- There is a web of interacting paths of social interactions, value negotiations, belief system variances, political power levels, economic/financial variances, religious beliefs, health beliefs that collectively operate to promote or prevent the changes needed to induce caregiver equity.



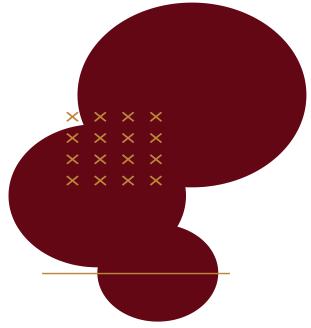


What to do?? We must...

1. Acknowledge that Native people HAVE and DESERVE dignity.
2. Check tribal web site for health program/elder services director.
3. Call on the phone: voice, not email/text only.
4. Strive for a high degree of personalism– the opposite of social distancing by remote communications.
5. ASK if there might be an interest in working on helping with elder health, caregiving, and CI.
6. Suggest that we'd be very happy and willing go to their location for a meeting.
7. Set aside our professional personas and pomposity. Have a friend-to-friend relationship.
8. Offer free help; don't just take; give something back: in-service training is often appreciated.
9. Build-in TIME. Time to develop relationships. Time for interactions to evolve. Time for inputs to become sustainable.

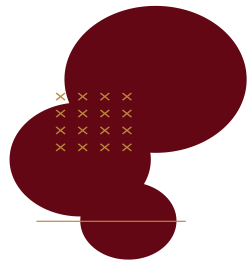


**I'M PERFECT
YOU ADJUST.**



Specific AI/AN caregiver factors

- Acknowledge the caregiver's unique life contexts: culture, location, resources, medical pluralism, kinship expectations, elder value, plus others.
- What might be beliefs about causation that influence the ways in which the CI is assigned value (e.g., stigma, positive due to new insights like the other side, interpretation of confusion may be partly having access to dimensions of reality that most people are oblivious to, etc.).
- Can caregiving be seen as a ceremony of care that honors the elder?
- What are culturally relevant pleasant activities that apply to that family in that place and that time? Ask caregivers. Examine the physical and cultural environment. That's where modifications can be made. Music, dances, ceremony, food, etc.



3 take-homes:

1. To connect with **THEM**, first look in the mirror.
2. Bend your organizational culture—it won't break.
3. Take action: no more hollow rituals at conferences masquerading as sufficient concern.





Working with Dementia Family Caregivers from Asian Background: Equity and Cultural Adaptions

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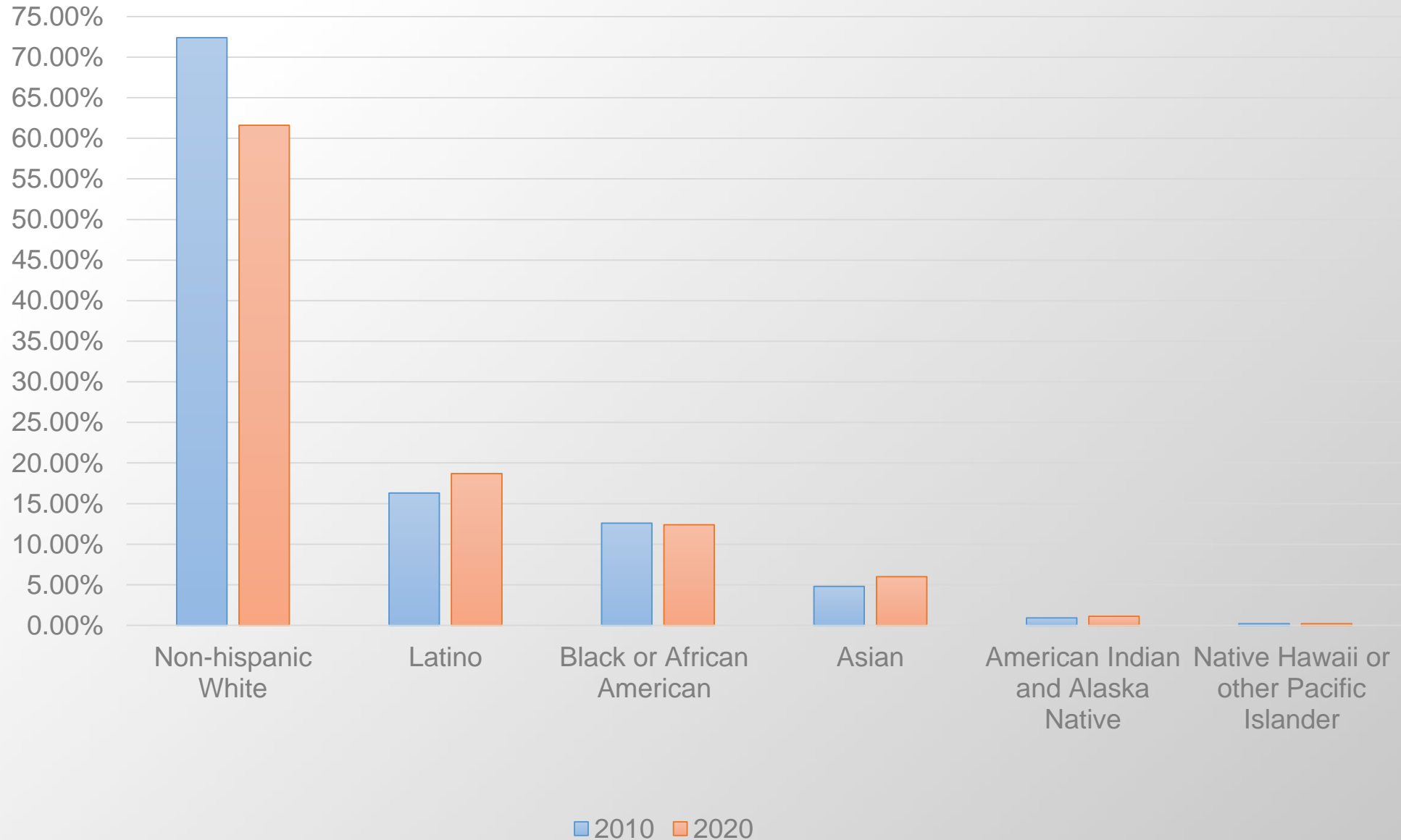
Outline

- Background and significance.
- Understanding dementia family caregiving among Asian Americans through a cultural lens.
- Common needs among Asian American family caregivers .
- Implications for culturally relevant public health policy and practice through health education, skills training, and provision of supportive services.



Background & Significance

- Over 20 million Asian Americans
- As the fastest growing population in this country (35.5% increase from 2010 to 2020)
- Coming from over 20 Asian countries
- Over 85% of the Asian Americans from six origin groups
- 13% of them aged 65 or older



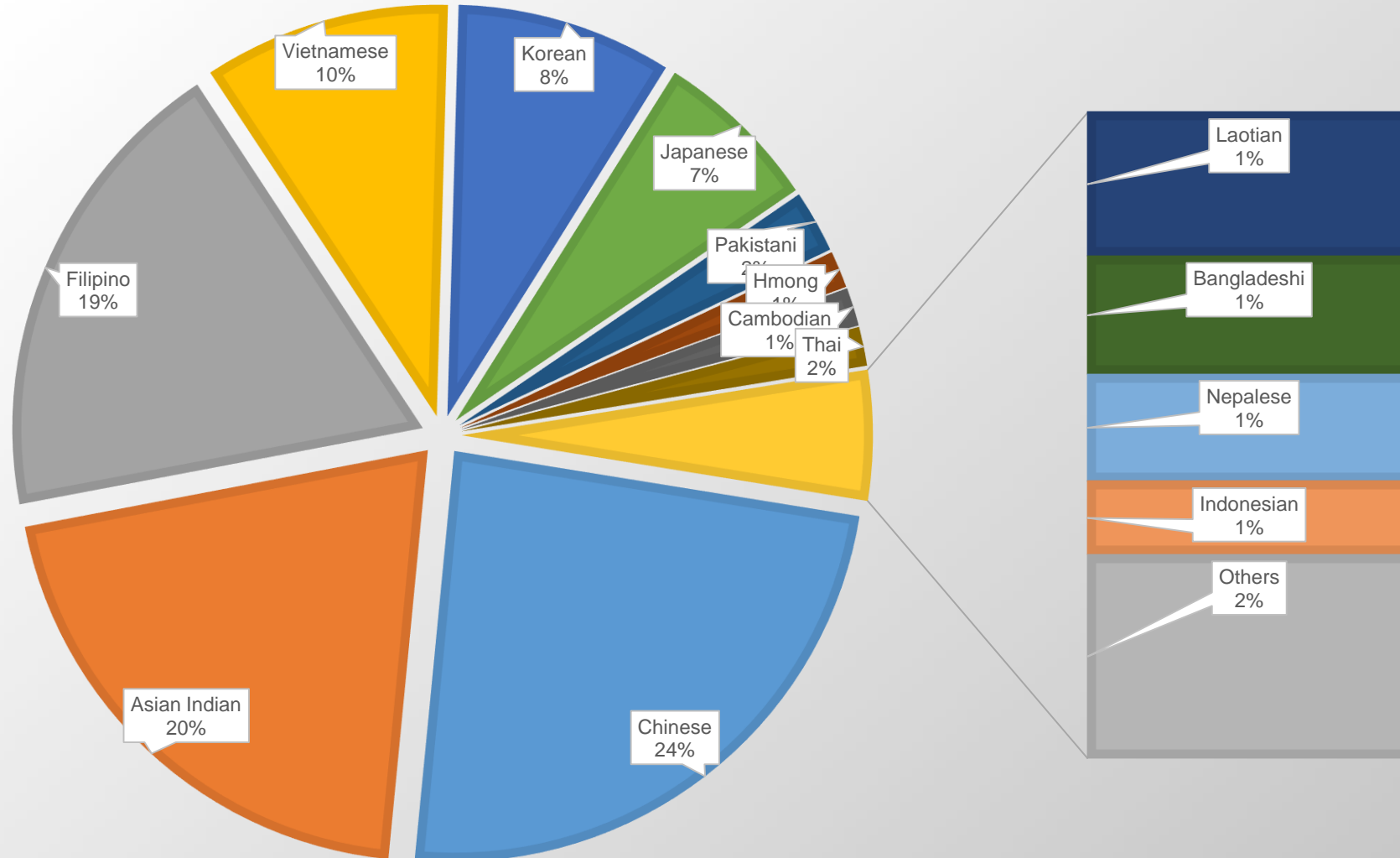


Asian Americans by population size in 2019

1. Chinese (5,398,763)
2. Asian Indian (4,605,550)
3. Filipino (4,211,440)
4. Vietnamese (2,182,735)
5. Korean (1,908,053)
6. Japanese (1,484,186)



- Chinese
- Japanese
- Laotian
- Asian Indian
- Pakistani
- Bangladeshi
- Filipino
- Hmong
- Nepalese
- Vietnamese
- Cambodian
- Indonesian
- Korean
- Thai
- Others

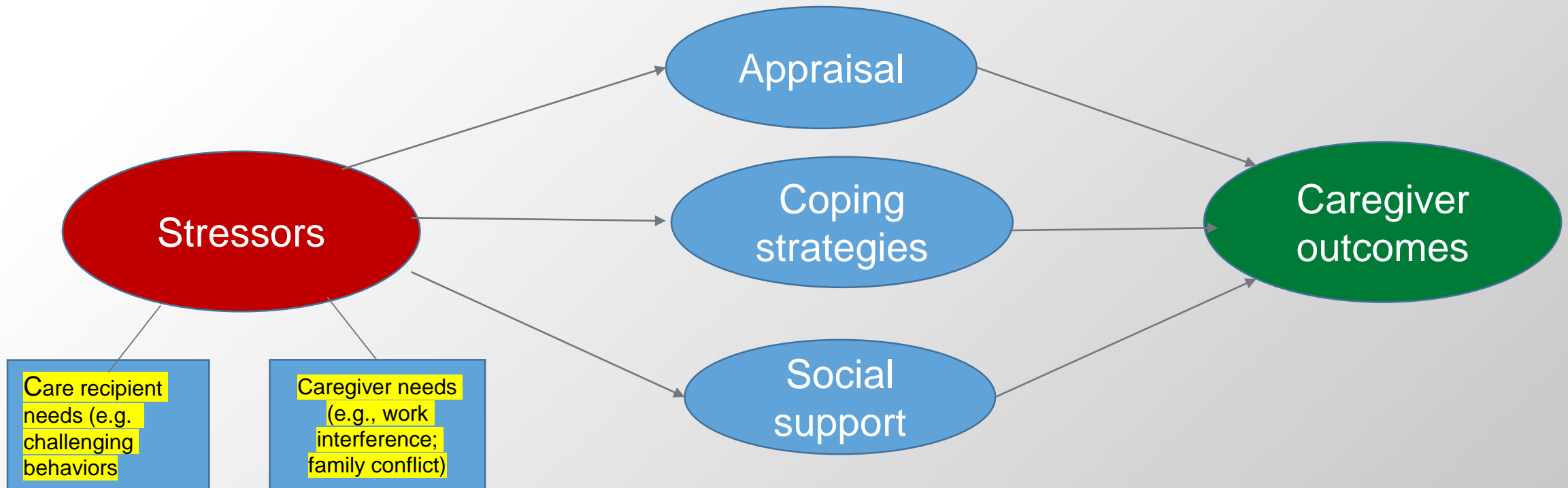


No data on the prevalence of dementia on Asian Americans;

Limited data on the annual incidence of dementia (Filipinos highest (1.7%), Asian Indians lowest (1.25%), Chinese (1.4%), and Japanese (1.5%), compared to 1.93% for non-Latino Whites (Mayeda, et al., 2017)



Understanding stress and burden of Asian American dementia caregivers



Contextual factors: demographics, socioeconomics

Values toward elder care; family; and seeking help from others



Concept of filial Piety

- 孝顺 in Chinese
- **Utang na loob** in Filipino
- *Oya-koko* in Japanese
- 효 in Korean
- **bakti** in **Bahasa Indonesia**
- lòng hiếu thảo in Vietnamese



Higher filial
piety

More caregiving tasks

X

Less perceived bother

Higher threshold for
positive appraisal of
caregiving

Caregiver
competency (coping
and support)





Lower filial
piety

Fewer caregiving tasks

X

Higher perceived bother

Lower threshold for
positive appraisal of
caregiving

Caregiver
competency (coping
and support)





Common unmet needs among Asian American Dementia Family Caregivers

1. Limited knowledge and biased beliefs toward dementia and its diagnosis and treatment.
2. Concrete needs (e.g., assistance with ADL tasks; transportation to doctor visits; care planning)
3. Access to culturally relevant and adapted services and support for care recipients and caregivers (e.g., services addressing family conflicts/disharmony culturally adapted respite care)
4. Financial needs



Implications for Culturally Relevant Policies and Practice



1) Provide outreach and education

- a) to isolated and underserved groups (e.g., living alone, married to other ethnic groups, poor SES status)
- b) improve literacy about dementia and dementia care----to reduced stigma, promote care planning and quality of care
- c) improve knowledge about brain health and promote healthy behaviors---reduced anxiety and risks for developing dementia

Physical health



Risk Factors

- Cardiovascular diseases
- Nutrition
- Pain
- Poor quality of sleep



Recommendations

- Exercise: Taiji
- Healthy eating



Psychological



Risk factors

- Depression and anxiety
- Trauma
- Lack of mental health (dementia) literacy

Recommendations

- Intergenerational/family support
- Peer support in the housing apartment
- Attending health workshops



Social Aspects



Risk factors

- Social isolation and loneliness
- Low familiarities with or lack of trust of formal services as 80% not born in the U.S.

Recommendations

- Social participation (volunteering in one's own community, joining community clubs)
- Social activities: board and card games(e.g., playing Mahjong, shared gardening)



Cognitive Aspect: Learning a new thing and making a new friend

- “I love xxx food”

For Chinese people, you can say “I love dumplings”

我爱饺子。
“Wo Ai Jiaozi”





2) Provide ongoing training and support to manage caregiver stress

- a) Coping skills training aligned with the person's personality, spirituality and cultural values (e.g., filial piety, and acculturation levels)

- b) Counseling and empowerment



3) Making culturally relevant community support and services available and accessible along the caregiving journey

- a) Facilitating access to culturally relevant ongoing support through integration of cultural elements in existing service models (e.g., Peer support groups, involving respectful elders/community leaders to mediate family conflicts; consultation by a trusted expert that speaks the language of the group).

- a) Developing or advocating for more culturally relevant services (e.g., in home services, day care centers, respite care) for Asian American groups



Conclusion

- As a fast-growing group, Asian American community is diverse and heterogonous.
- Cultural values can be both strengths and barriers to caregiver health and mental health outcomes.
- Provide culturally relevant and adapted services aligned to individual caregiver's needs through outreach and information assistance, assessment and care planning, counseling, support groups, education, respite care and other services and supports.



Thank you !
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