



**CARE**  
COLLABORATIVE APPROACH FOR  
ASIAN AMERICANS & PACIFIC ISLANDERS  
RESEARCH & EDUCATION


HEALTH ACROSS THE LIFESPAN

**First Annual Brain Trust Meeting**  
January 22, 2021

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## Agenda

1:00 – 1:30pm	<b>Overview of CARE Registry &amp; Recruitment Protocol</b> <i>Van Ta Park, PhD, MPH (UCSF)</i>
1:30 – 1:45pm	<b>First Q&amp;A and Raffles</b>
1:45 – 1:55pm	<b>How to use CARE</b> <i>Joshua Grill, PhD (UCI)</i>
1:55 – 2:25pm	<b>Panel Discussion with CARE Research &amp; Community Partners</b> <i>Joon Bang, President and CEO, National Asian Pacific Center on Aging</i> <i>Quyen Vuong, Executive Director, International Children’s Assistance Network</i> <i>Dolores Gallagher-Thompson, PhD, Professor Emerita, Stanford University School of Medicine</i>
2:25 – 2:30pm	<b>Second Raffle</b>
2:30 – 2:55pm	<b>Final Q&amp;A + Third Raffle</b>
2:55 – 3:00pm	<b>Evaluation and Adjourn</b>



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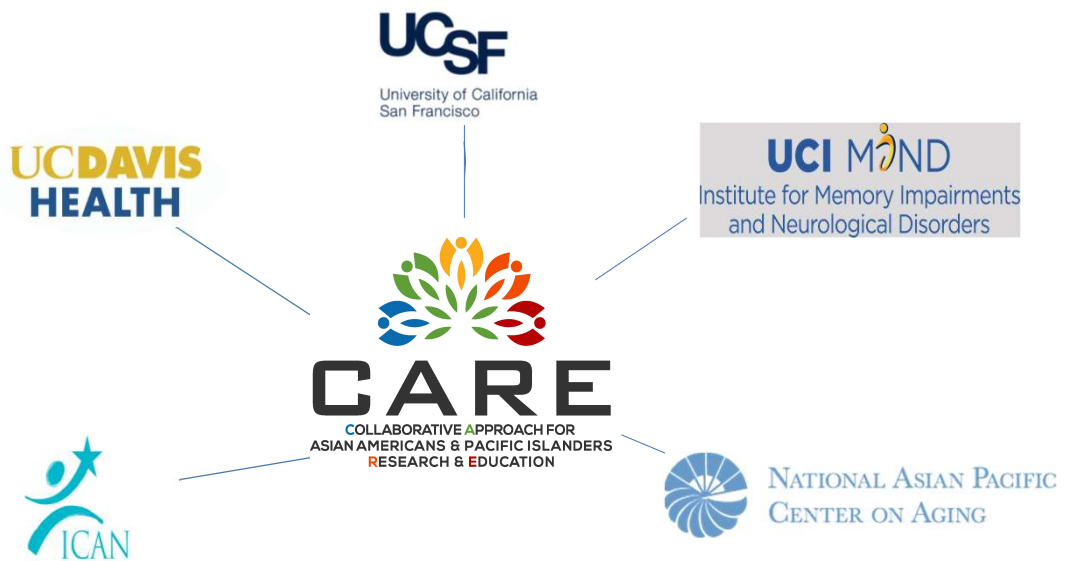
# Overview of CARE Registry & Recruitment Protocol

Van Ta Park, PhD, MPH

CARE Principal Investigator

UCSF School of Nursing, Department of Community Health Sciences

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<https://careregistry.ucsf.edu/>



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## CARE Partners & Community Advisory Board

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## Asian Americans and Pacific Islanders (AAPI)

Asian Americans are the fastest growing racial group in the U.S.:

- 7% of the population
- 30 AA & 21 PI groups
- 20 million AA & 1.6 million PI

- Heterogeneous group
- Languages & Dialects (>100)
- Cultural groups (>50)
- Immigration patterns
- Religions
- Diet
- SES

Source: [https://www.census.gov/newsroom/releases/archives/facts\\_for\\_features\\_special\\_editions/cb11-f06.html](https://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb11-f06.html)

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## Disparities in Research Participation for AAPI



- Clinical research projects focusing on AAPI participants funded by the National Institute of Health (NIH) was less than 1% of its total budget between 1992 and 2018.<sup>1</sup>
- 96.8% of participants in industry sponsored Alzheimer's Disease clinical trials were Caucasian, only 0.9% were Asian.<sup>2</sup>
- Barriers to AAPI participation in research:
  - Cultural differences
  - Linguistic limitations
  - Lack of education in research practices

<sup>1</sup>Doan, Takata, Sakuma, & Irvin (2019). *JAMA Network Open*.  
<sup>2</sup>Faison et al. (2007). *International Psychogeriatrics*.



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## Family Caregiving in AAPI Populations

- AAPIs more than any other group, believed that caring for parents was expected of them (73% vs. 49%).
- AAPI families are less likely to put their older family members into a facility.
- 42% of AAPIs were caring for an older adult, versus just 22% of the general population.<sup>3</sup>



<sup>3</sup>AARP. (2014). Caregiving among Asian Americans and Pacific Islanders age 50+. [https://www.aarp.org/content/dam/aarp/home-and-family/caregiving/2014-11/caregiving\\_aapis\\_english.pdf](https://www.aarp.org/content/dam/aarp/home-and-family/caregiving/2014-11/caregiving_aapis_english.pdf)



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## Paving the Way for Meaningful Inclusion of AAPI in Research

- To address the gap and reduce disparities in research participation in AD/DR, aging, caregiving, and other health issues across the lifespan among AAPI.
- CARE will implement culturally appropriate and innovative recruitment strategies with our community partners across California to enroll 10,000 AAPI.
- We aim to give AAPI a voice and the opportunity to participate in such future research through enrollment in the CARE registry!



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## CARE Enrollment Process

- Who can enroll?
  - ✓ AAPI
  - ✓ 18+ years old
  - ✓ Speak and read English, Chinese Korean, or Vietnamese
  - ✓ Interested in participating in potential research
- Participants complete an online survey (10-15 min) or by phone (NAPCA toll-free lines)
- CARE Enrollment Survey available in 5 languages
- Participants have the option to receive a \$10 gift card after completing the enrollment survey



CARE has officially launched in English, Chinese, Korean, and Vietnamese!

[CLICK HERE TO SEE OUR FULL PRESS RELEASE.](#)



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## CARE Enrollment Survey Questions

Socio-demographic information

Health conditions (e.g., neurological disease and related symptoms such as Alzheimer's disease; heart disease; cancer; mood-related issues)

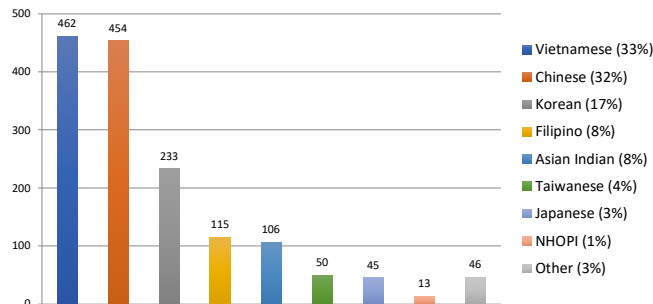
Health behaviors (e.g., smoking; physical activity; diet)

Caregiving experiences (if applicable)



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## CARE Snapshot (N=1,400 as of Jan 9, 2021)



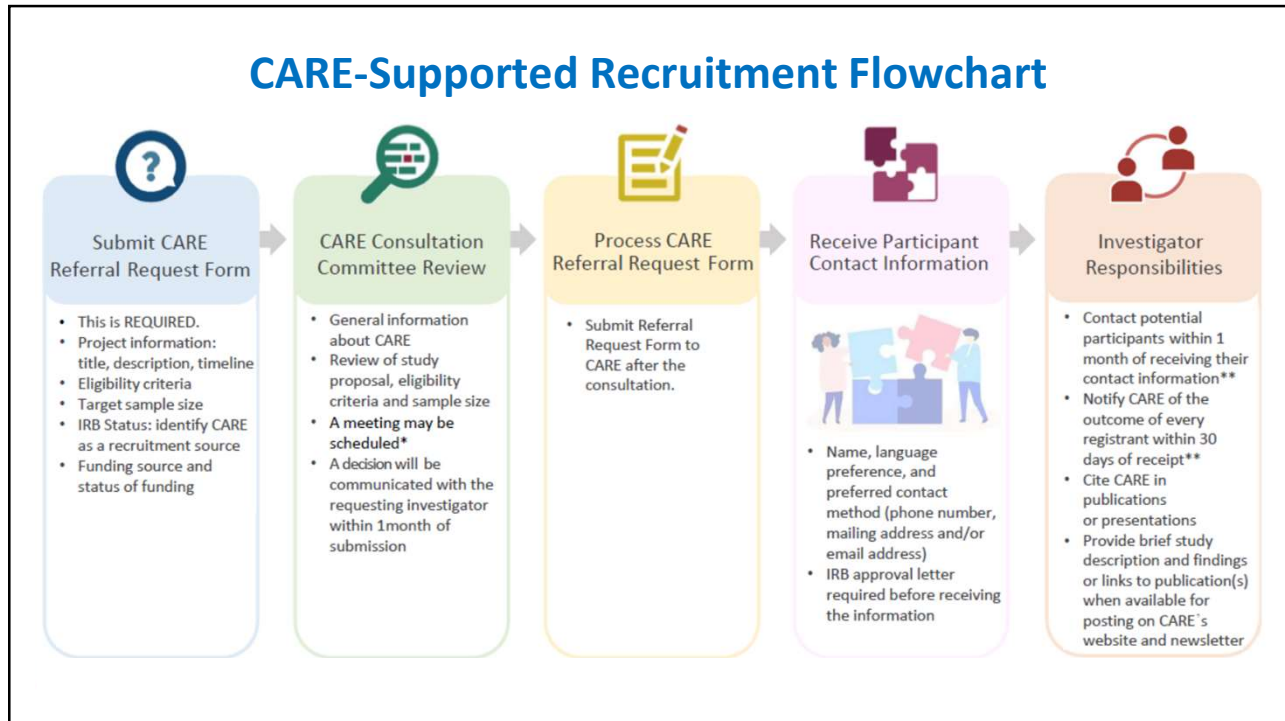
- Mean age = 46.2 (range 18-92)
- 63.6% Female, 35.2% Male
- 29.8% Limited English proficiency
- Language used to complete the survey:
  - English (72%)
  - Vietnamese (16%)
  - Korean (9%)
  - T. Chinese (2%)
  - S. Chinese (1%)

- 71.8% Born outside of U.S.
- 87% Californian
- 11% Caregivers of older adults

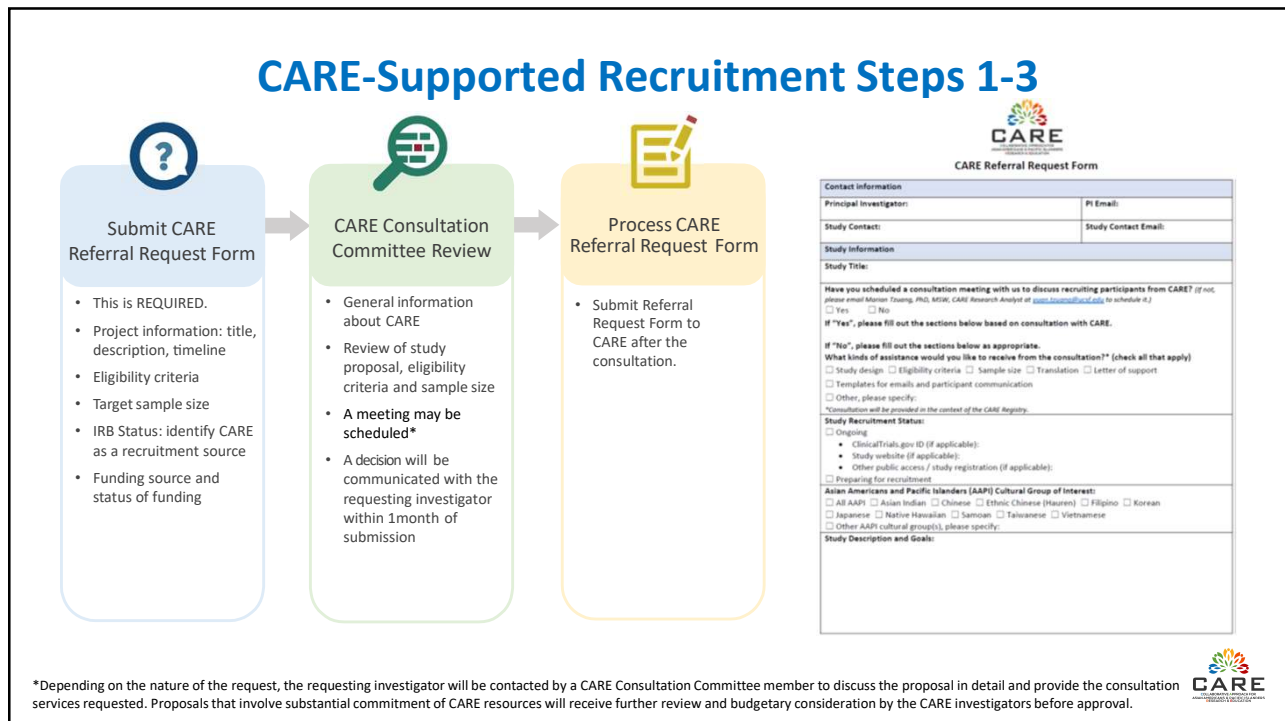
Official launch date: October 15, 2020



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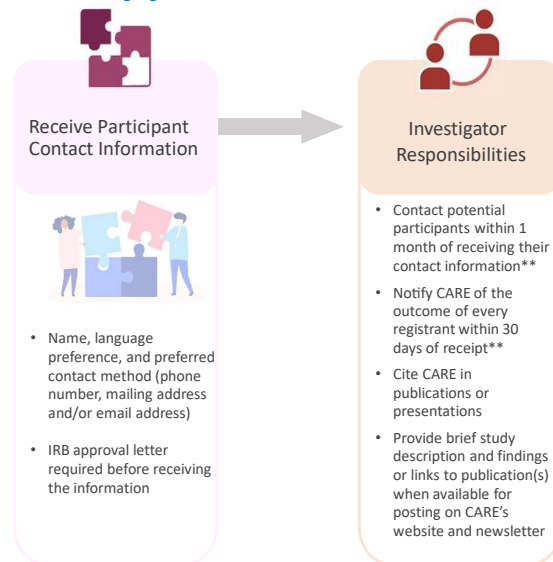


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## CARE-Supported Recruitment Steps 4-5



\*\*This is a general guideline primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs (e.g., surveys). 

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## CARE-Supported Recruitment

- CARE team may request a consultation meeting to discuss the proposed recruitment referral in detail.
- Proposals that involve substantial commitment of CARE resources will receive further review and budgetary consideration by the CARE investigators before approval.
- The guidelines presented is primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs such as survey.



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Q&A



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## How to use CARE

Joshua Grill, PhD

CARE Co-Investigator

UC Irvine Institute for Memory Impairments and Neurological Disorders

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## Main Ways to Use CARE

- Ask novel research questions about AAPI
  - Surveys of CARE participants
  - Recruitment of whole samples from CARE
- Recruit participants to increase diversity of a study population
- Recruit participants as a novel comparison group

## Answer Novel Research Questions About AAPI

- Disseminate a survey to the CARE registrants
  - All CARE registrants
  - Specific CARE registrants (e.g., Chinese immigrants >65 years)
  - Compare within or across AAPI groups
- Utility:
  - Needs assessments
  - Preliminary data
  - Complete studies



## Example Survey Study Design

- Hypothesis: Immigrants differ from second generation AAPI in their attitudes toward Alzheimer's disease prevention research
- Participants: Older (age 55 and up) CARE participants
- Methods: Send an electronic (REDCap) survey to all eligible CARE registrants
- Primary Analysis: Compare AAPI born in this country to those born in another country for differences in willingness to participate in AD prevention research

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## Recruit AAPI to Your Study

- Recruit CARE registrants to your prospective study\*
  - Answer specific questions about AAPI
  - Recruit AAPI CARE registrants to improve diversity in your sample
  - Recruit specific CARE registrants of interest to compare to other groups (e.g., non-Hispanic Whites)
  - Compare different AAPI groups



Investigator

\* Recruiting from CARE may produce important sample bias that is best addressed in study designs (post-recruitment)

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## Example Study Recruitment

- Study design: Randomized interview study assessing the impact of biomarker testing and disclosure on AD prevention trial recruitment
- Use of CARE: Recruit participants meeting inclusion criteria (age, English-speaking, no major neurological or psychiatric disorders/diagnoses)
  - Participants recruited from CARE included in study that also includes participants from other sources. Randomization overcomes issues around sample bias
  - Goal is to study more inclusive, representative sample
  - Secondary analyses might compare effect modification by race

## Caveats and Conclusions

- CARE is not a community based epidemiologic cohort
- It cannot provide information (or opportunities to study) on disease prevalence or population characteristics
- It can assist in examining potential cultural and racial associations, hypothesis generation, and comparison studies
- It can improve recruitment of AAPI and assist in diversifying research

## Panel Discussion

**Joon Bang**, National Asian Pacific Center on Aging  
**Quyên Vuong**, International Children's Assistance Network  
**Dolores Gallagher-Thompson**, Stanford University School of Medicine

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### Partnership with Communities Lead to Meaningful Solutions

 Northwest Asian Weekly

Old people at home will get vaccinated, but maybe not their ...

In her letter, Tu cited the National Asian Pacific Center on Aging, which found that 42% of Asian American and Pacific Islanders (AAPIs) are ...  
6 days ago



Source: Northwest Asian Weekly (January 14, 2021).  
<https://nwasianweekly.com/2021/01/old-people-at-home-will-get-vaccinated-but-maybe-not-their-caregivers-state-announces/>



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# International Children Assistance Network (ICAN)



Quyen Vuong – Executive Director



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## ICAN's Mission

To **ENGAGE**, **INFORM**, and **INSPIRE** Vietnamese-Americans to raise the next generation of Caring leaders through **Humanitarian Programs**, **Culturally Responsive Social Programs**, and **Community Based Research**

We strive to help children and youth realize their potential by building strong families and community support networks to provide them with the skills, confidence, and opportunities to succeed in life.

Through our programs, we empower children and youth to become caring, responsible, and productive members of their families and communities. By spreading the spirit of "youth empowering youth," they will pioneer the way to a brighter future.



[www.ican2.org](http://www.ican2.org)



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## Engaged, Informed, Inspired –

### *To Raise the Next Generation of Caring Leaders*



[www.ican2.org](http://www.ican2.org)



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## Quyen Vuong – Executive Director

*“What inspires ICAN to partner with the CARE team is the opportunity to give Vietnamese Americans a voice in research.*





*We believe that if we can help produce relevant information about Vietnamese Americans in research, then the Vietnamese American community can get relevant research about ourselves that would benefit our community as well as the broader AAPI community.*

*The key to CARE is the important relationship between the academic partners (UCSF, UCD, UCI) and the community engagement partners like ICAN.”*



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<b>Community-based Research</b>	<b>Ongoing studies</b>
Outreach through different angles and address different needs	• <b>CARE</b> ( <a href="http://careregistry.ucsf.edu/">careregistry.ucsf.edu/</a> )
↓	
Engage and educate community on variety of issues	• <b>COMPASS</b> ( <a href="http://compass.ucsf.edu/">compass.ucsf.edu/</a> )
↓	
Increase representation of Vietnamese Americans in research	• <b>Dementia &amp; caregiving related studies</b>
↓	
Build lasting impact and trust with the community	
<a href="http://www.ican2.org">www.ican2.org</a>	 

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**Community Academic Partnerships:**  
Working Together to Study  
Family Members Who Care for a  
Loved One with Memory Loss

*Dolores Gallagher-Thompson, PhD, ABPP*

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## Family Caregiving

**Definition:** Individuals who provide unpaid care to a relative or friend 18 years or older to help them take care of themselves. The care-recipient often has one or more chronic medical conditions that make it difficult for them to do their own self-care. Some have cognitive impairments due to stroke, Alzheimer's disease, or other illnesses that affect the brain. These individuals usually need the most assistance from family members.



Source: The National Alliance for Caregiving, (2020). Caregiving in the U.S.  
<https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>



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## Caregiving Among AAPIs

- Most caregivers help with personal needs, household chores, managing finances, arranging for outside services, or visiting regularly to see how the person is doing.
- Compared to non-Hispanic whites, more Asian caregivers are\*:
  - living with their care recipient
  - more often report having to take a leave of absence from work
  - find their role highly emotionally stressful
  - more likely to want caregiving help or information about managing stress and finding non-English language materials
- However, due to limited AAPI caregiver data, there are many questions yet to be answered – some key ones are:
  - Do AAPI caregivers provide similar caregiving tasks?
  - Are they providing more care? Does this differ by caregiver-care recipient relationship?

Source: National Alliance for Caregiving and AARP. (2020). Caregiving in the U.S. 2020 Report. The "Typical" Asian Caregiver Fact Sheet.  
[https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_CGProfile\\_Asian\\_508.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_CGProfile_Asian_508.pdf)



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## Common Negative Impacts on Caregivers' Physical and Mental Health

- ❖ Less energy to do things
- ❖ Fatigue- feeling tired, often
- ❖ Problem sleeping through the night
- ❖ Putting off doctor's appointments and tests related to one's own health
- ❖ Impaired immune responses – infections take longer to heal
- ❖ More stress-related health problems such as high blood pressure
- ❖ Increased use of medications or alcohol to help deal with stress
- ❖ Frequent reports of stress
- ❖ Increased loneliness and social isolation
- ❖ Increased conflict among family members
- ❖ Behaviorally: doing less of what you enjoy
- ❖ Increased signs of depression
- ❖ Increased anxiety, worry, & frustration
- ❖ Decreased feelings of well-being



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## Resilience: One Reason Why Caregivers Report both Positive and Negative Effects

- Resilience is being able to deal effectively and flexibly with stressful situations. It's not a trait but a skill set that can be learned.
- Resilience is associated with being able to see the positive aspects of a situation while also appreciating and responding to the negatives.
- Some cultural values may foster resiliency – such as filial piety, which is a strongly held value among many AAPI. One of the few studies done with Chinese American caregivers found that those who strongly adhered to this value were more likely to focus on positive aspects of caregiving and achieve a balance between what was rewarding about caregiving and its stressful components.



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## Fostering Family Caregiver Research with the CARE Registry

- Background: Existing research findings on caregiving stress and ways of coping may not apply to AAPIs. Why? Because AAPIs have not been well-represented in caregiving studies.
- Rationale: They may not be a focus of caregiving research because of challenges such as cultural and linguistic diversity and historical differences among sub-groups. Often there are practical issues too, such as lack of bilingual/bicultural research faculty and staff.
- This highlights the need to bring together researchers and community-based organizations who may represent specific sub-groups and who actually serve family caregivers.



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## Example #1: Surveys or interviews with caregivers about stressors and coping strategies

- Potential research questions to ask each of several identified groups:
  - What stressors are most common? What coping strategies are often used?
  - Do these strategies vary by caregiver relationship to the care recipient – e.g., husband/wife; mother/ daughter; son/ father, etc.
  - What are some unique characteristics of AAPIs caring for a relative with memory loss? e.g., living in multigenerational households may encourage caregiving to be shared among several family members vs. a “primary” CG
- Thoughts on “asking the right questions” as a non-AAPI researcher?
- Academic and community partners should all be “at the table” to both design and implement the project. This often means hiring interviewers and other research staff from the community-based agency in a cost-sharing arrangement, and “giving back” to the community by disseminating results and lessons learned when the project is completed.



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## Example #2: What kinds of interventions are most helpful to AAPI family caregivers?

- Potential research questions:
  - Would it be most effective to design **novel programs** and interventions that are unique for each ethnic/cultural sub-group?
  - Or: it is equally effective to “culturally tailor” existing evidence-based interventions?
  - If we do that: How can we improve them for AAPI caregivers? What to add? Subtract?
  - Which program/service/intervention for **which** caregivers? Do adult daughters, for example, benefit from the same kind of programs as spouse caregivers? Likely not, since the issues are not the same.
  - **When** should we provide these programs/services/interventions?
- Limited representation of AAPIs in evidence-based or evidence-informed interventions for family caregivers of older persons with significant memory loss or dementia. So, in this field, a great deal of work remains to be done!
- Developing community and academic partnerships will allow us to be in a better position to design, and test, appropriate programs and services that will truly benefit distressed family caregivers.



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## Example of a CARE-Supported Collaborative Study



Develop online or phone surveys for caregivers of several AAPI subgroups



Contact and send survey to interested caregivers in CARE



Conduct follow-up semi-structured interview with subset of caregivers



Share results with the communities involved and jointly plan next phase of research



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# Questions?

Contact  
Dr. Dolores Gallagher-Thompson  
[dolorest@stanford.edu](mailto:dolorest@stanford.edu)

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# Final Q&A + Raffles

Please complete our evaluation survey:

[https://ucsf.co1.qualtrics.com/jfe/form/SV\\_5cnJg65jzX5kBN4](https://ucsf.co1.qualtrics.com/jfe/form/SV_5cnJg65jzX5kBN4)

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