

Creating a culturally responsive dementia caregiving program for Asian American caregivers of persons with dementia

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Acknowledgements

Development of this presentation and all accompanying materials was funded by a grant from the Illinois Department of Public Health - Dementia Caregiver Program for Underserved Populations –2025.

The Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) also supported this work as part of a financial assistance award totaling \$620,918 with 67% percentage funded by ACL/HHS (Grant number # 90HDRC0011-02-00, PI: Mirza) and \$207,960 or 33% percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

Introduction

- At 8.5%, prevalence of ADRD is lowest among Asian American older adults of all racial/ethnic groups (Alzheimer's Association, 2023; CDC, 2018).
- Asian American and Pacific Islanders (AAPIs) are at higher risk for under-detection of cognitive impairment in addition to delayed diagnosis and suboptimal management of ADRD (Lee et al., 2014; Lim et al., 2020).
- AAPIs are twice as likely to assume caregiving roles for an older adult family member compared with the general population (AARP, 2020).
- AAPI caregivers of persons with ADRD face multiple barriers in accessing ADRD care such as lack of tailored cognitive assessments and support interventions.



Planning Early for Aging and Caregiving with Ease: Meeting the Information Needs of Dementia caregivers' (PEACE of MIND)



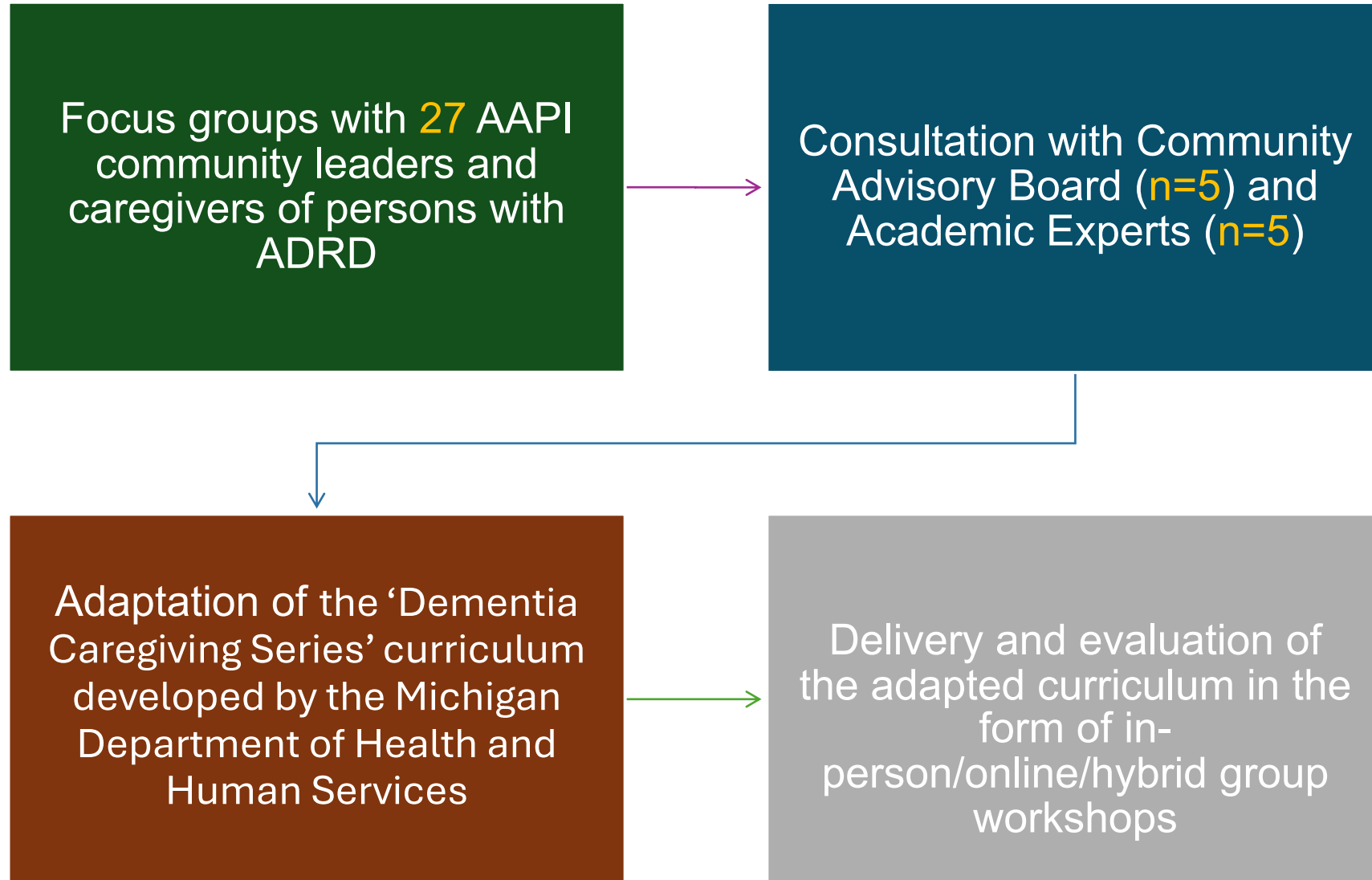
Goal: To develop and disseminate informational materials on dementia care for AAPI caregivers

Focus groups with 27 AAPI community leaders and caregivers of persons with ADRD

Consultation with Community Advisory Board (n=5) and Academic Experts (n=5)

Adaptation of the 'Dementia Caregiving Series' curriculum developed by the Michigan Department of Health and Human Services

Delivery and evaluation of the adapted curriculum in the form of in-person/online/hybrid group workshops



FOCUS GROUP THEMES

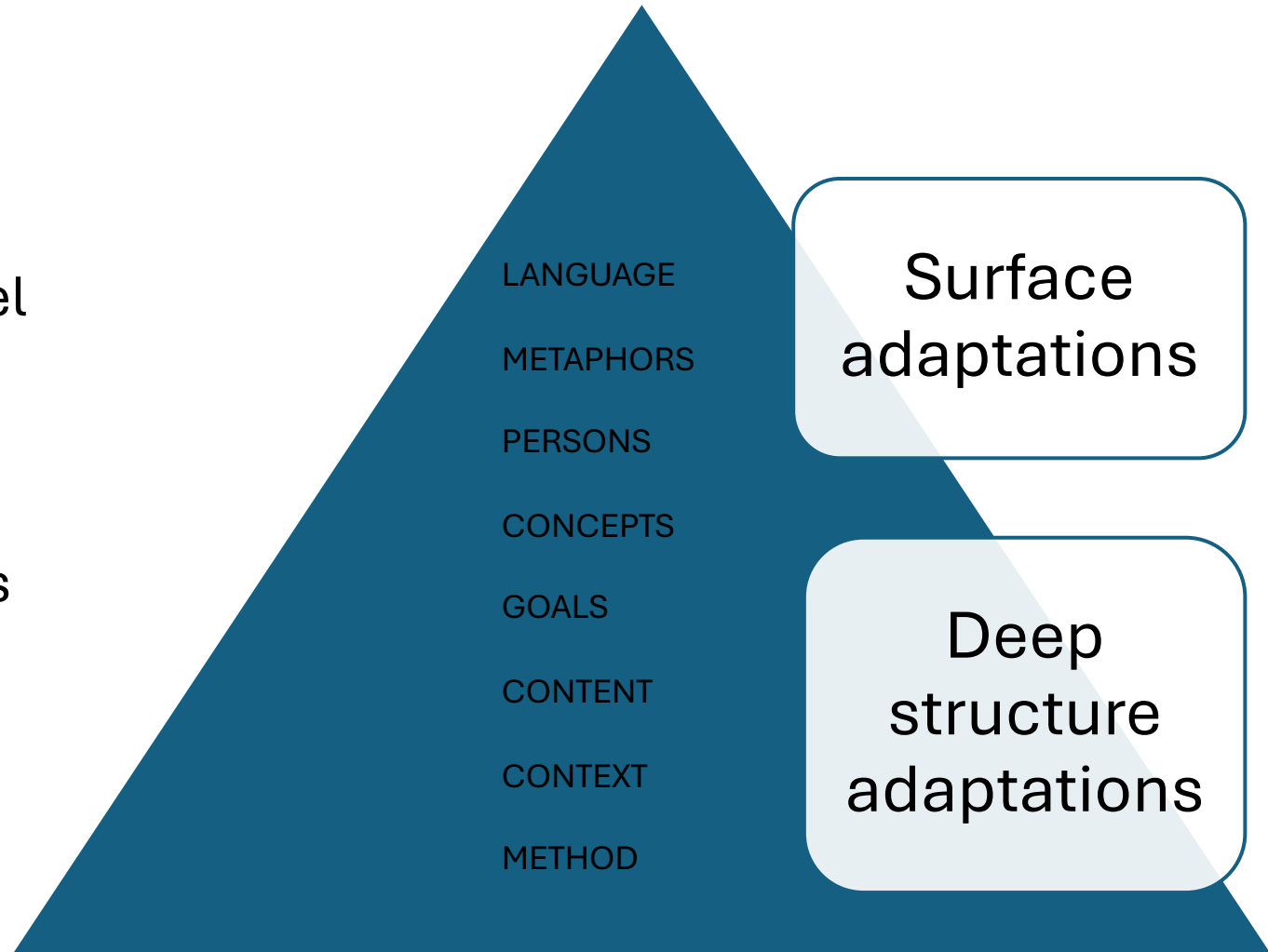
- Caregiver Concerns:
 - Unsafe Behaviors
 - Managing Dementia Behaviors
- Caregiver Impact:
 - Mental & Emotional Stress
 - Lack of Personal Time
- Caregiver Needs (Cutrona & Suhr, 1992):
 - Informational Support
 - Tangible/Logistical Support
 - Esteem Support
- Future Planning
 - Caring for the person at home
 - Communicating with healthcare providers



CURRICULUM ADAPTATION FRAMEWORKS

Ecological Validity Model
(Bernal et al., 1995)

Surface and deep
structure adaptations
(Resnicow et al.,
1999)



CURRICULUM ADAPTATIONS

SURFACE ADAPTATIONS

Categories	Asian American
Language	Translation to preferred language by a bilingual translator with native level proficiency and cultural knowledge
Metaphors	“Stress” as a broad metaphor for mental health impact of caregiving
Persons	Presence of a cultural insider in the team, preferred Difficult with some AAPI communities

SURFACE ADAPTATIONS

Research Study Title: “Planning Early for Aging and Caregiving with Ease: Meeting the Information Needs of Dementia caregivers’ (PEACE of MIND)

रसिर्च स्टडी का शीर्षक: " बढ़ती उम्र और आसानी से देखभाल करने के लिए पहले से योजना बनाना: डमिंशिया के देखभालकर्ताओं (केयरगविरस) की जानकारी संबंधी जरूरतों को पूरा करना" (पीस ऑफ माइंड)

Principal Investigator Name and Title: Mansha Mirza, Professor

मुख्य जांचकर्ता का नाम और पद: डॉ. माँशा मरिज़ा, प्रोफेसर

DEEP STRUCTURE ADAPTATIONS

Categories	Adaptations
Concepts and Goals	Retained from the original curriculum: <ul style="list-style-type: none">• Increase dementia knowledge• Increase caregiver efficacy• Decrease caregiver perceived stress, burden, and isolation
Methods	<ul style="list-style-type: none">• Minimize lectures; maximize multimedia content• Incorporate hands-on activities, make learning fun• Keep the messaging positive
Content	Customization in response to focus group themes

گھر پر صحت کی دیکھ بھال کرنے والا معاون عملہ

ابتدائی یا درمیانے مرحلے کے ڈیمینشیا میں مبتلا
افراد کے لیے۔

ان افراد کے لیے جنہیں گھریلو امور، روزمرہ کے
کاموں، اور ساتھ دینے میں مدد کی ضرورت ہو۔



Caregiver Needs

Focus Group Theme	Curricular Content
Emotional Support (listening support, comfort, knowing you're not alone)	Session 1 of curriculum (building a support network) Opportunity for sharing and mutual support throughout all sessions
Tangible Support (respite care, financial assistance, adaptive aids)	Resource Guide
Informational Support (what is dementia? Dementia versus normal aging)	Session 2 of curriculum Short educational video about dementia and 10 signs of dementia
Esteem Support (caregiving competence and efficacy)	Session 3 of curriculum (managing dementia behaviors) Short educational videos on Dos and Don'ts Four Rs of dementia care (Fridge Magnet based on Budson & O'Connor, 2021)

Caregiver Needs

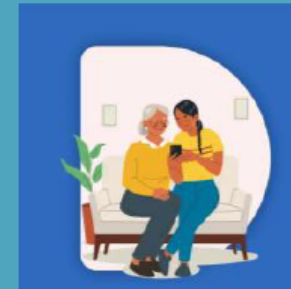
The 4 R's of Dementia Care

1. **Reassure** your loved one that everything is okay when they feel overwhelmed or agitated.
2. **Reconsider** your loved one's perspective.
3. **Redirect** your loved one to an activity they enjoy or an environment that calms them.
4. **Relax** and remain calm when faced with problem behavior. Practice good self-care.



डिमेंशिया देखभाल के लिए चार बदलाव

1. **सोच बदलें:** डिमेंशिया से पीड़ित व्यक्ति के दृष्टिकोण से स्थिति पर दोबारा सोचें
2. **प्रतिक्रिया बदलें:** शांत और स्थिर रहें, मद्धम स्वर में बोलें
3. **शब्द बदलें:** आश्वासन देनेवाले शब्दों का प्रयोग करें
4. **गतिविधि बदलें:** अपने प्रियजन को किसी शांत जगह और ऐसी गतिविधि की ओर ले जाएँ जो आनंददायक हो



Caregiver Concerns (Current)

Focus Group Theme	Curricular Content
Caregiving Concerns (managing dementia behaviors)	Session 3 of curriculum (managing dementia behaviors) Short educational videos on Dos and Don'ts <ul style="list-style-type: none">- Resistance to Hygiene Habits- Repetitive Questions and Stories
Caregiving Concerns (unsafe behaviors)	Session 3 of curriculum (managing dementia behaviors) Short educational videos on Dos and Don's <ul style="list-style-type: none">- Wandering and Elopement- Financial Scams

Caregiver Concerns (Current)

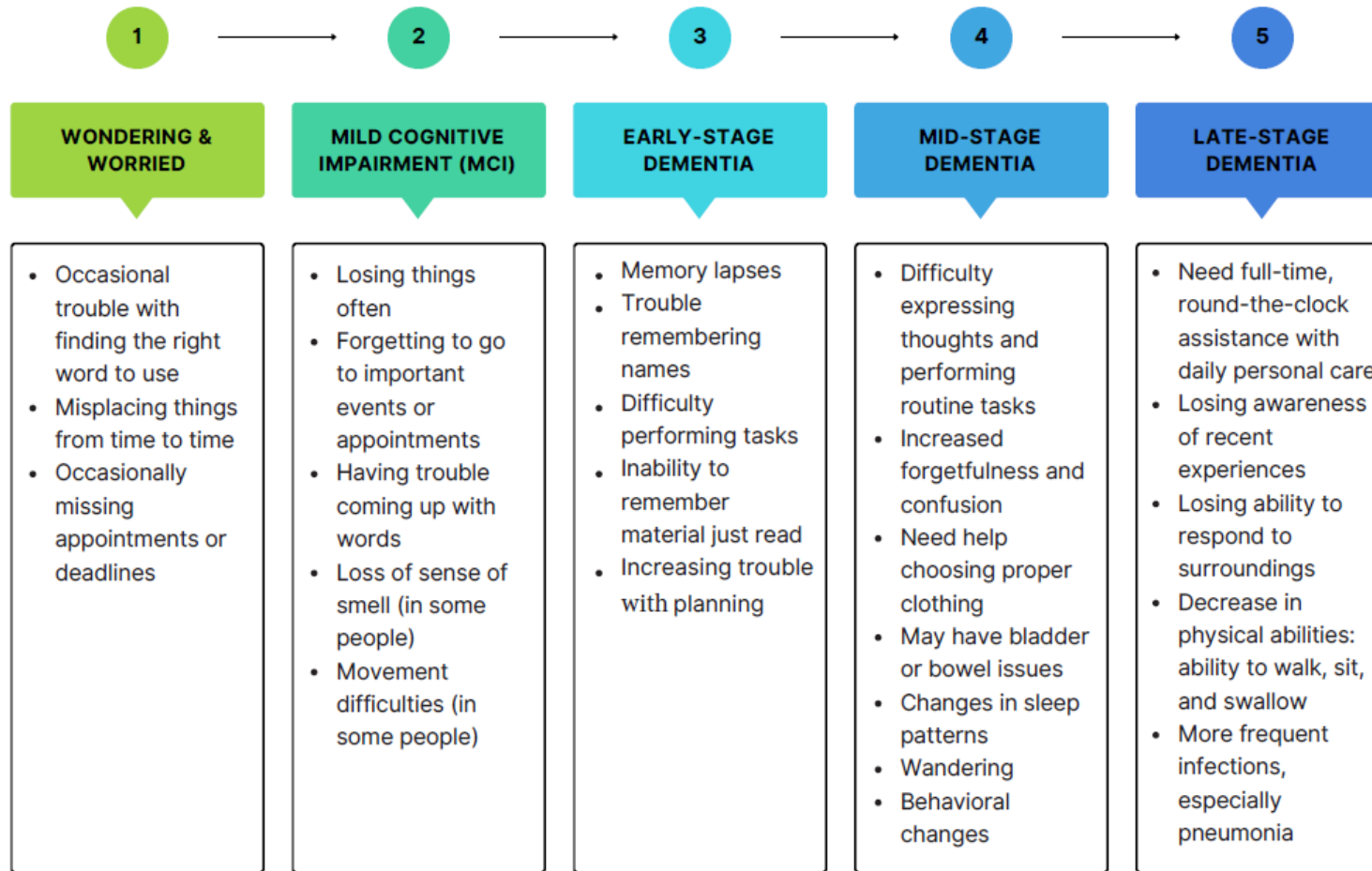


Caregiver Concerns (Future)

Focus Group Theme	Curricular Content
Planning for advancing needs (Don't know what to expect. Need a roadmap)	Session 2 of curriculum - Dementia Roadmap Activity
Impact on Caregiver Mental Health Impact – stress, guilt, depression, loss of networks	Session 1 of curriculum - Identifying signs of stress - Managing stress in the moment and long-term - Practicing self-care – goal planning worksheet
Alternatives to nursing home placement	Session of curriculum - Planning for ongoing care, animated video

Dementia Roadmap:

A Guide for Family and Care Partners



ADAPTIED FROM THE FOLLOWING SOURCES: Dementia Action Collaborative, Washington State Dementia Roadmap For aregivers, 2023.

<https://www.alz.org/alzheimers-dementia/treatments/questions-for-your-doctor>

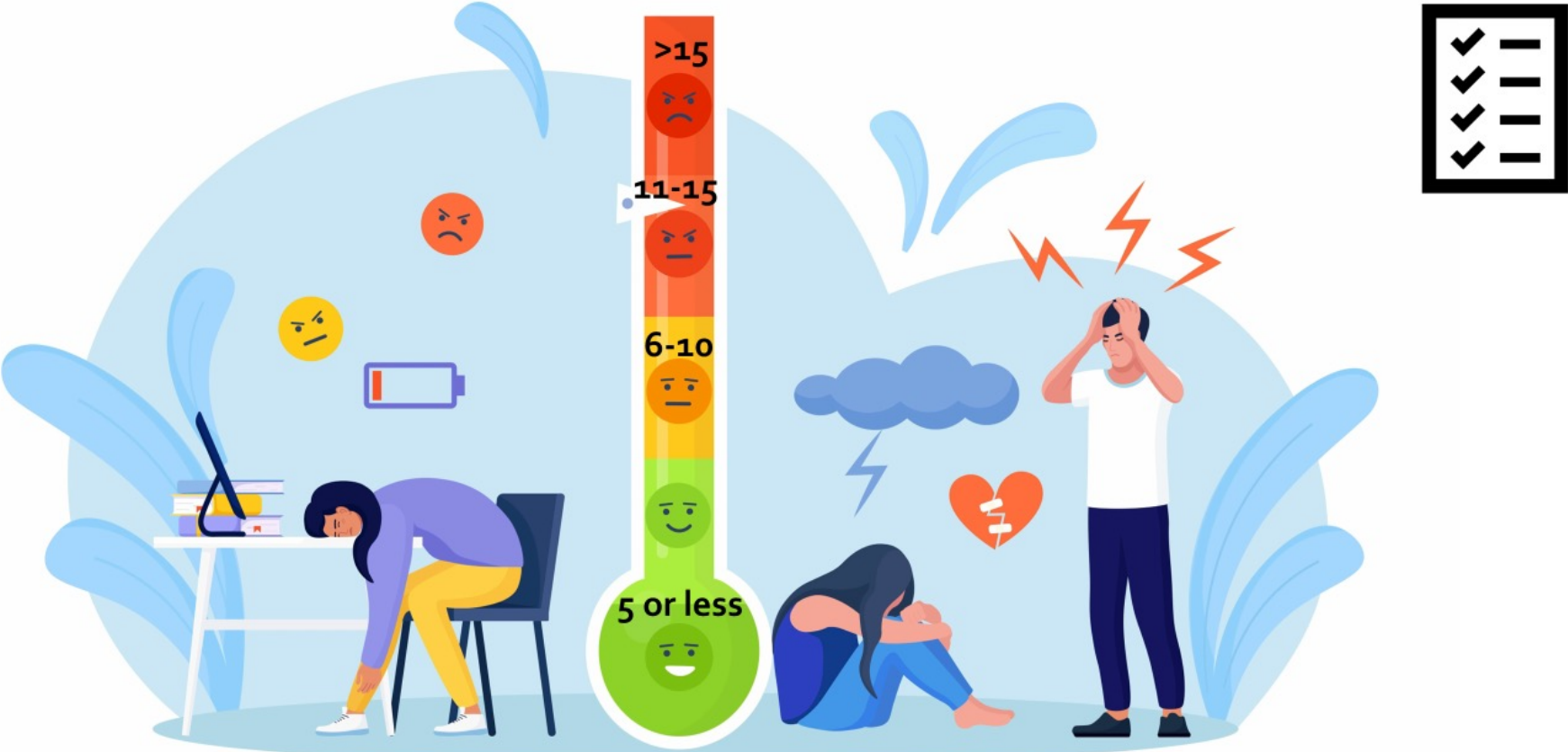
<https://www.aarp.org/health/brain-health/info-2021/dementia-diagnosis-questions.html#:~:text=What%20is%20the%20likely%20course,can%20I%20expect%20from%20them%3F>

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Caregiver Concerns (Future)

Measuring Your 'Stress Temperature'



Outcomes

- Number of community sites: 5
- Number of participants to date: 136
 - 20% formal caregivers; wide ranging relationships for formal caregivers
 - 74% female
 - 68% employed full or part time
 - 37% providing 1-4 hours of daily care; 24% providing 5 or more hours of daily care
 - Avg caregiver age: 49.8 years (SD 16.8)
 - Avg care recipient age: 78.2 years (SD 13.0)

Outcomes

Outcome	Assessment	
Perceived Caregiver Stress	Perceived Stress Scale (10-items)	0.4 ↓
Perceived Caregiving Burden	Zarit Burden Interview (12-items)	1.02 ↓
Perceived Isolation	UCLA Loneliness Scale (3 items)	0.07↑
Dementia Knowledge	Custom-generated (16 items)	0.32 ↓

Outcomes

The most helpful was the video where it was shown how the person with dementia kept repeating that they wanted to go home and how the caregiver diverted her attention by saying that let me eat first and then I will take you home. Now I am using those strategies with my clients.

When we were in the car going home, we reviewed two videos, and it helped [son] tremendously. The one video that stood out was how to affirm the clients understanding and not dismiss their perspective. My son has been practicing this with my wife when he comes to visit us.

The stress management scale has helped me to manage daily life. It has helped my family to manage stress in the moment. The thermometer allowed us to notice the distinctions between us as individuals and to see that different people would be at different levels of stress in the moment about the same situation.

References

- AARP, National Alliance for Caregiving. (2020). Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 50+. Retrieved from https://www.caregiving.org/wpcontent/uploads/2021/05/AARP1340_RR_Caregiving50Plus_508.pdf
- Alzheimer's Association (2023). Asian Americans and Pacific Islanders and Alzheimer's. Retrieved from <https://www.alz.org/help-support/resources/asian-americans-and-alzheimers#:~:text=Understand%20the%20Signs-,Asian%20Americans%20at%20risk,times%20higher%20in%20Pacific%20Islanders.>
- Budson, A., & O'Connor, M. (2021). Six Steps to Managing Alzheimer's Disease and Dementia: A Guide for Families. Oxford University Press.
- Centers for Disease Control and Prevention (2018). U.S. Burden of Alzheimer's disease, related dementias to double by 2060. Retrieved from <https://www.cdc.gov/media/releases/2018/p0920-alzheimers-burden-double-2060.html>
- Cutrona CE, Suhr JA. Controllability of stressful events and satisfaction with spouse support behaviors. *Communication Research*. 1992;19:154–174.
- Lee, H. B., Han, H. R., Huh, B. Y., Kim, K. B., & Kim, M. T. (2014). Mental health service utilization among Korean elders in Korean churches: preliminary findings from the Memory and Aging Study of Koreans in Maryland (MASK-MD). *Aging & mental health*, 18(1), 102-109.
- Lim, S., Mohaimin, S., Min, D., Roberts, T., Sohn, Y. J., Wong, J., ... & Trinh-Shevrin, C. (2020). Alzheimer's disease and its related dementias among Asian Americans, Native Hawaiians, and Pacific Islanders: A scoping review. *Journal of Alzheimer's Disease*, 77(2), 523-537.

Questions