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# Using Pilot Studies to Inform ePCTs in Hispanic/Latino People Living with Dementia and their Care Partners



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# Housekeeping

- All participants will be muted
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions from chat box and ask them at the end
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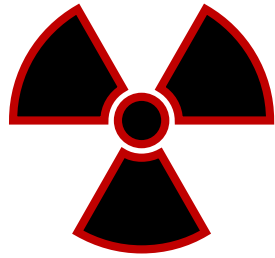
# Patient Priorities Care for Hispanics with Dementia (PPC-HD)

Rafael Samper-Ternent MD, PhD

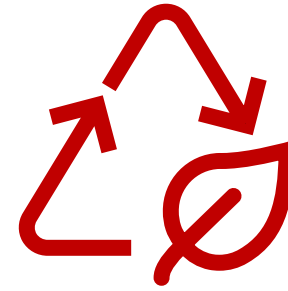
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# Hispanics\Latinos with Dementia



**Incidence  
risk**



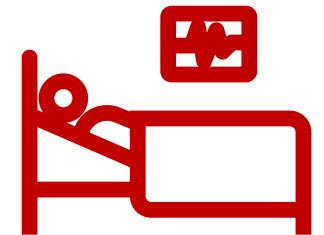
**Socioeconomic  
Factors**



**Diagnosis**



**Cultural  
Barriers**



**Healthcare  
Access**



Hispanic Culture

Life-course characteristics

Health disparities

Hispanic Values, Goals and Preferences

### IDENTIFY HEALTH PRIORITIES

- Values (What Matters most to the patient)
- Actionable, specific, realistic health outcome goals
- Health care preferences (which care the patient finds helpful and which burdensome) and any tradeoffs
- "One Thing" - the health goal the patient most wants to address to help achieve what Matters most

### ALIGN CARE WITH HEALTH PRIORITIES

#### Consider if current and potential care is:

- Consistent with health outcome goals including patient's "One Thing"?
- Consistent with care preferences?

#### Use the patient's priorities:

- As the focus for communication with the patient
- As the goal for serial trials to start, stop or continue interventions
- To prioritize care decisions, especially where differing perspectives exist

Update components as needed

Better Patient-centered health outcomes

Samper-Ternent et al.  
JAGS. 2022  
Jun;70(6):1889-1894

# Cultural Adaptation of PPC

- Ecological Validity Model (EVM) has 8 dimensions to guide cultural adaptation of EBI.
- The Heuristic Framework facilitates adaptation based on the EVM in 4 steps.
- We used these steps for our pilot.

## Patient Priorities Care for Hispanics with Dementia (PPC-HD)

Aanand Naik, MD & Rafael Samper-Ternent, MD, PhD | University of Texas School of Public Health

ClinicalTrials.gov Identifier: NCT05303194

**Objective:** To adapt the Patient Priorities Care (PPC) approach for older Hispanics with multiple chronic conditions (MCC) and dementia and pilot test its implementation in an outpatient clinic setting in preparation for an ePCT to evaluate the effectiveness.

### Design, Setting, and Participants

- Single-armed exploratory pilot study
- Community-based, geriatric outpatient clinic serving older adults in Galveston, Texas
- Community-dwelling Hispanic adults living with MCC and dementia and their family care partners

### Intervention and Implementation

- The PPC approach helps older adults with MCC identify their health priorities and work with their primary care providers (PCP) to align the care they received with what matters most to them.
- PPC has been culturally tailored for Hispanics and consists of two steps: 1) A health priorities identification step, conducted by anyone trained in PPC; and 2) A care alignment step, conducted by a PCP.

### Measures

Implementation evaluation endpoints:

- Completion of both steps of the PPC approach in > 80% of study participants.
- Documentation of patients' health priorities in the electronic health record (EHR) of 100% of participants.
- Documentation of care alignment attempts in the EHR by PCPs in > 80% of EHR

Primary clinical outcome:

- Good acceptability and ease of use of the PPC approach reported by Hispanic patients and their care partners and PCP

**Relevance:** This pilot study will set the foundation for a full-scale ePCT evaluating the impact of PPC in reducing treatment burden and improving communication between Hispanic patients and their PCP. This work has the potential to reduce the care burden and improve satisfaction with care received by Hispanics with MCC and their care partners.

# Pilot Results

**Table 1. Characteristics of study participants and their care partners**

<b>Characteristic</b>	<b>Study Participant (n=21)</b>	<b>Care partner (n=16)</b>
<b>Mean Age (SD) in years</b>	84.5 (+/- 6.2)	56.2 (+/- 14.2)
<b>Sex, n female (%)</b>	14 (67.7)	13 (81.3)
<b>Education Level</b>		
None + primary, n(%)	14 (66.7)	1 (6.3)
Secondary +, n(%)	7 (33.3)	15 (93.8)
<b>Cognitive Status*, n(%)</b>		
AD/ADRD	15 (71.4)	
MCI	1 (4.8)	
Normal	5 (23.8)	16 (100%)
<b>Preferred Language Spanish, n(%)</b>	10 (47.6)	6 (37.5)
<b>Main Language Spoken Spanish, n (%)</b>	16 (76.2)	7(43.8)

\*MCI: Mild cognitive impairment; AD/ADRD: Alzheimer's disease and related dementias



## Implementation Outcomes

- Both PPC steps completed in 95% participants
- Health priorities documented in EHR for all participants
- Care alignment attempts documented in 95% participants

## Acceptability

- Mean score in satisfaction with PPC > 4.4;  
\*\*Men more satisfied than women
- PCP reported health priorities eased clinical decisions and helped to learn what matters most to patients
- One PCP struggled to use information and incorporate it into the visit, which made visit longer

## Ease of use

- Coordination of steps was challenging
- Time to discuss values, goals, and preferences deemed important
- Individual, healthcare system, research, and community factors impact pragmatic interventions

# Pilot Results

- Previous studies show the PPC approach reduces treatment burden using the Treatment Burden Questionnaire (TBQ)
- TBQ scores range between 0-150, with higher scores indicating a higher treatment burden

Connecticut Study	Cleveland Clinic Study	Our Study
Mean TBQ = 24.7	Mean TBQ = 11.9	Mean TBQ = 31.4

# Exploratory Result

We explored using Goal Attainment Scaling as a pragmatic outcome in four participants.

<b>Worse than now (-2)</b>	<b>Current State (-1)</b>	<b>Goal (0)</b>	<b>Somewhat better (+1)</b>	<b>Much better (+2)</b>

Did not achieve goal

Achieved goal

# Sample Goals

**PPC021:** “I would like to improve the strength of my legs so I can go to the grocery store with my family once a month” Attained goal (Score +1)

**PPC020:** “I want to feel less worried, anxious and nervous so I can go to church once a week.” Attained goal (Score 0)

**PPC018:** “I want better control of my leg pain so I can go outside and take care of my garden 1-2 times per week” Didn’t attain goal (Score -1)

**PPC017:** “Water the flower plants in the house twice a week” Didn’t attain goal (Score -2)



- Communication
- Priorities
- Psychosocial Factors



- HEALTHCARE SYSTEMS**
- Identify priorities and capabilities
  - Innovative Approaches to leverage resources
  - Don't add burden



- RESEARCH TEAM**
- Diverse team
  - Include community leaders
  - Prioritize Interests
  - Communication



- COMMUNITY**
- Prioritize community interests
  - Community engaged research framework
  - CAB or LPSC

# Acknowledgments

- Aanand D. Naik, MD
- Alejandra Mera, MSc
- Brylee Lavoie, MD/MPH  
Student
- UTMB Patients
- UTMB Colleagues
- IMPACT HET
- IMPACT Colleagues

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# IMPACT Pilot Study: Virtual Training for Latino Caregivers to Manage Symptoms of Dementia



**Maggie Ramirez, PhD, MS, MS**

Assistant Professor, University of Washington School of Public Health

# Learning Objectives

Upon completion of this presentation, you should be able to:

- Describe the key stages in culturally adapting an evidence-based intervention
- Provide specific adaptations made to STAR-C for Latino caregivers
- Apply these insights to enhance your own work with family caregivers



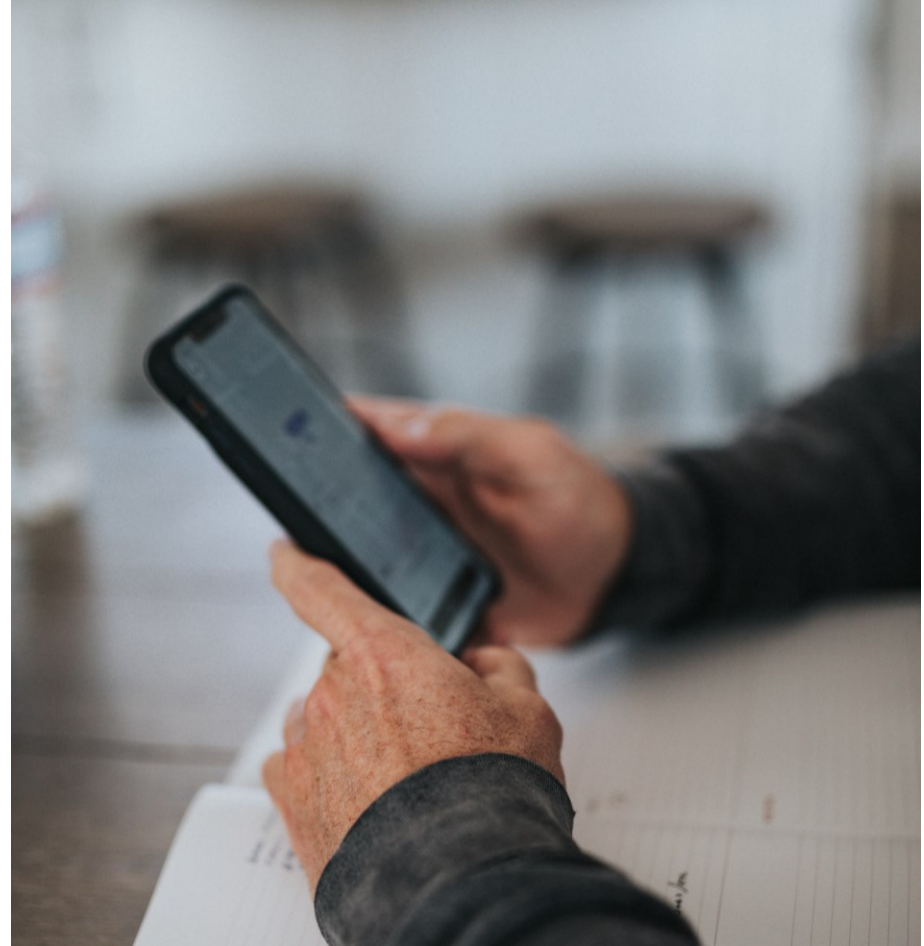
# STAR-Caregivers (STAR-C)

- STAR-C coach (e.g., social worker)
- Home visits and phone calls
- Core training topics
  - Dementia education
  - Effective communication
  - ABC problem-solving
  - Pleasant events
  - Caregiver support strategies



# STAR-C Virtual Training & Follow-up

- Same training topics
- Different modality
  - e-learning modules
  - Phone check-ins
  - Asynchronous support via email



# Latino Family Caregivers



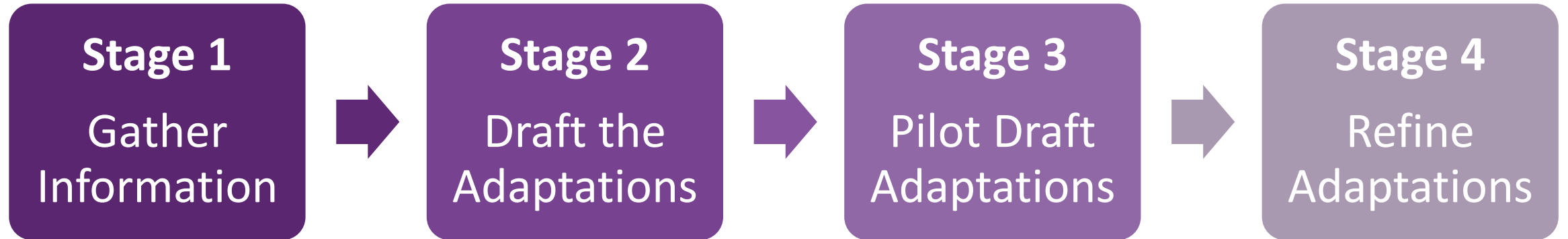
Most are women in their 40s providing unpaid care

Provide intensive informal care (200+ hours/month)

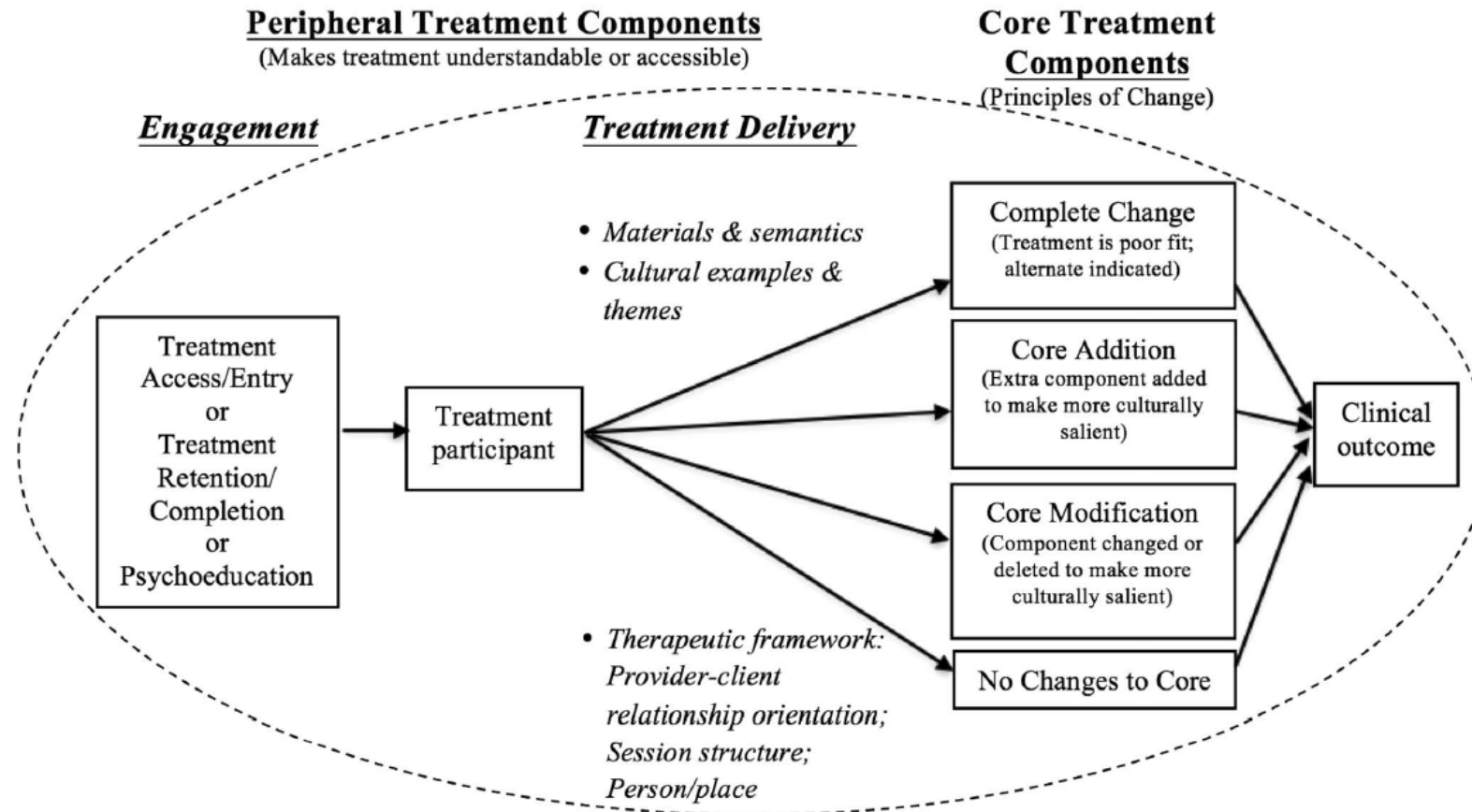
Help with more ADLs: 2.6 vs. 1.9

High stress, depression, unmet support

# Cultural Adaptation Process



# Cultural Treatment Adaptation Framework (CTAF)



# Findings from qualitative interviews

Latino caregivers (n=45) and providers (N=14) in Washington State

## *CTAF 'Core Treatment Components'*

- More support in understanding ADRD and its causes.
- Not receiving adequate guidance from healthcare providers about the links between ADRD and behavioral and psychological symptoms.
- May feel hesitant to discuss symptoms with healthcare providers.

Ramirez, M., Duran, M. C., Penfold, R. B., Pabiniak, C. J., Hansen, K. E., & Ornelas, I. J. (2023). STAR-Caregivers Virtual Training and Follow-up: a cultural adaptation for Latino caregivers of people with dementia. *Translational Behavioral Medicine*, 13(9), 625-634.

Garcia, C. N., Duran, M. C., & Ramirez, M. (2024). Refining Cultural Adaptations of a Behavioral Intervention for Latino Caregivers of People Living With Dementia: Qualitative Interview Study in Washington State. *JMIR aging*, 7, e53671.

# Findings from qualitative interviews (N=59)

## Latino caregivers (n=45) and providers (N=14) in Washington State

### *CTAF 'Materials & Semantics'*

- Certain words or phrases are stigmatizing, offensive, culturally irrelevant, or not commonly used.
  - “Alzheimer’s disease” and “dementia”
  - “Caregiver burden”
  - “Challenging,” “problematic,” or “bothersome”
  - “Care partner” or “caregiver”

Ramirez, M., Duran, M. C., Penfold, R. B., Pabiniak, C. J., Hansen, K. E., & Ornelas, I. J. (2023). STAR-Caregivers Virtual Training and Follow-up: a cultural adaptation for Latino caregivers of people with dementia. *Translational Behavioral Medicine*, 13(9), 625-634.

Garcia, C. N., Duran, M. C., & Ramirez, M. (2024). Refining Cultural Adaptations of a Behavioral Intervention for Latino Caregivers of People Living With Dementia: Qualitative Interview Study in Washington State. *JMIR aging*, 7, e53671.

# Findings from qualitative interviews (N=59)

## Latino caregivers (n=45) and providers (N=14) in Washington State

### *CTAF 'Cultural Examples & Themes'*

- Limited formal services use due to structural barriers and cultural factors.
- Many families are living in multigenerational homes.
- Multiple family members involved in caring for person with dementia.
- Strong family bonds and respect for older family members.

Ramirez, M., Duran, M. C., Penfold, R. B., Pabiniak, C. J., Hansen, K. E., & Ornelas, I. J. (2023). STAR-Caregivers Virtual Training and Follow-up: a cultural adaptation for Latino caregivers of people with dementia. *Translational Behavioral Medicine*, 13(9), 625-634.

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# IMPACT Pre-Pilot Study Objectives

**1**

To culturally adapt the content of the STAR-C e-learning modules.

**2**

To pilot test the culturally adapted content.





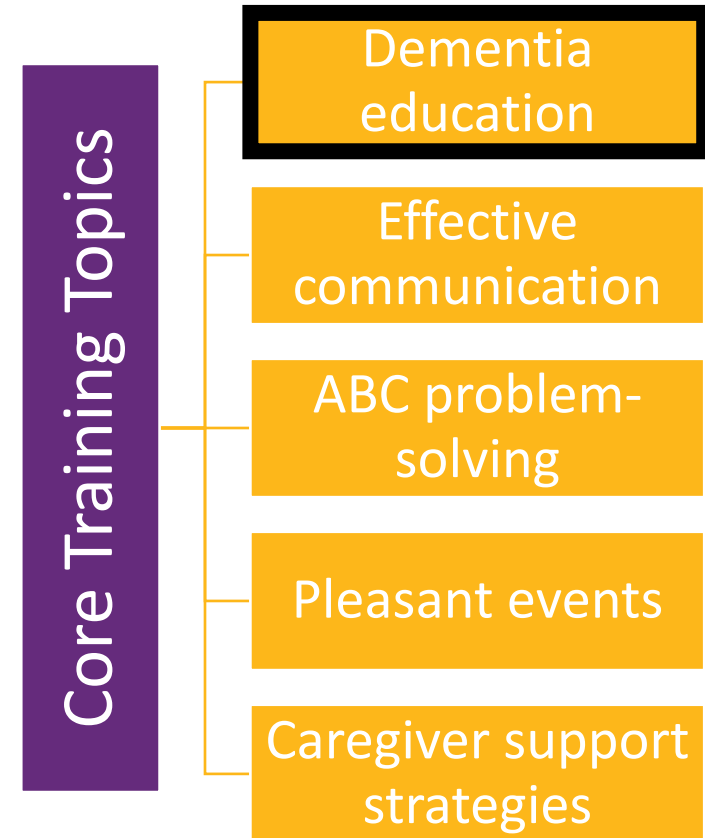
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Aim 1:  
Cultural  
Adaptations

# Adaptations to Core Training Topics

- Clarified that dementia is not normal aging, with examples of typical vs. dementia-related changes.
- Explained dementia's impact on behavior, highlighting that changes are progressive and unintentional.
- Acknowledged reluctance to seek help from healthcare providers.



# Adaptations to Materials & Semantics

- Revised all module language to remove stigmatizing, offensive, culturally irrelevant, or uncommon terms.
  - Stopped using “burden” to describe caregiving.
  - Stopped describing symptoms as “challenging,” “problematic,” or “bothersome.”
  - Replaced “caregiver” with descriptive phrases: “*Persona que cuida a alguien con demencia*” (person who cares for someone with dementia)
- Added more empathy-centered messaging to reinforce a compassionate approach to caregiving.

# Included Cultural Examples & Themes

- Deemphasized reliance on formal services (e.g., hiring a professional for respite care).
- Modified content to reflect varying levels of family involvement in dementia care.
- Added examples of multigenerational family settings.





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**Aim 2:**  
**Pilot Testing**

# Methods

## Study Design

- Pre-post study
- Qualitative exit interviews

## Intervention

- All participants received seven weekly e-learning modules

## Eligibility Criteria

- Caregiver identifies as Hispanic/Latino/a/e/x
- Care recipient is experiencing behavioral & psychological symptoms

## Recruitment

- University of Washington Alzheimer's Disease Research Center
- Alzheimer's Prevention Registry

## Clinical Outcomes

- Revised Memory and Behavior Problem Checklist
- Preparedness for Caregiving Scale

## Implementation Outcomes

- System Usability Scale
- Caregiver satisfaction with culturally adapted modules

# Characteristics of Study Participants (N=16)

Characteristic	Study Participants
Age, mean (SD)	51 (13)
Women, n (%)	12 (75%)
Mexican, Mexican American, Chicana/o, n (%)	10 (63%)
Spanish as primary language spoken at home, n (%)	8 (50%)
Caregiver's relationship to person with dementia, n (%)	
Adult child	9 (56%)
Spouse or partner	3 (19%)
Other relative or friend	4 (25%)

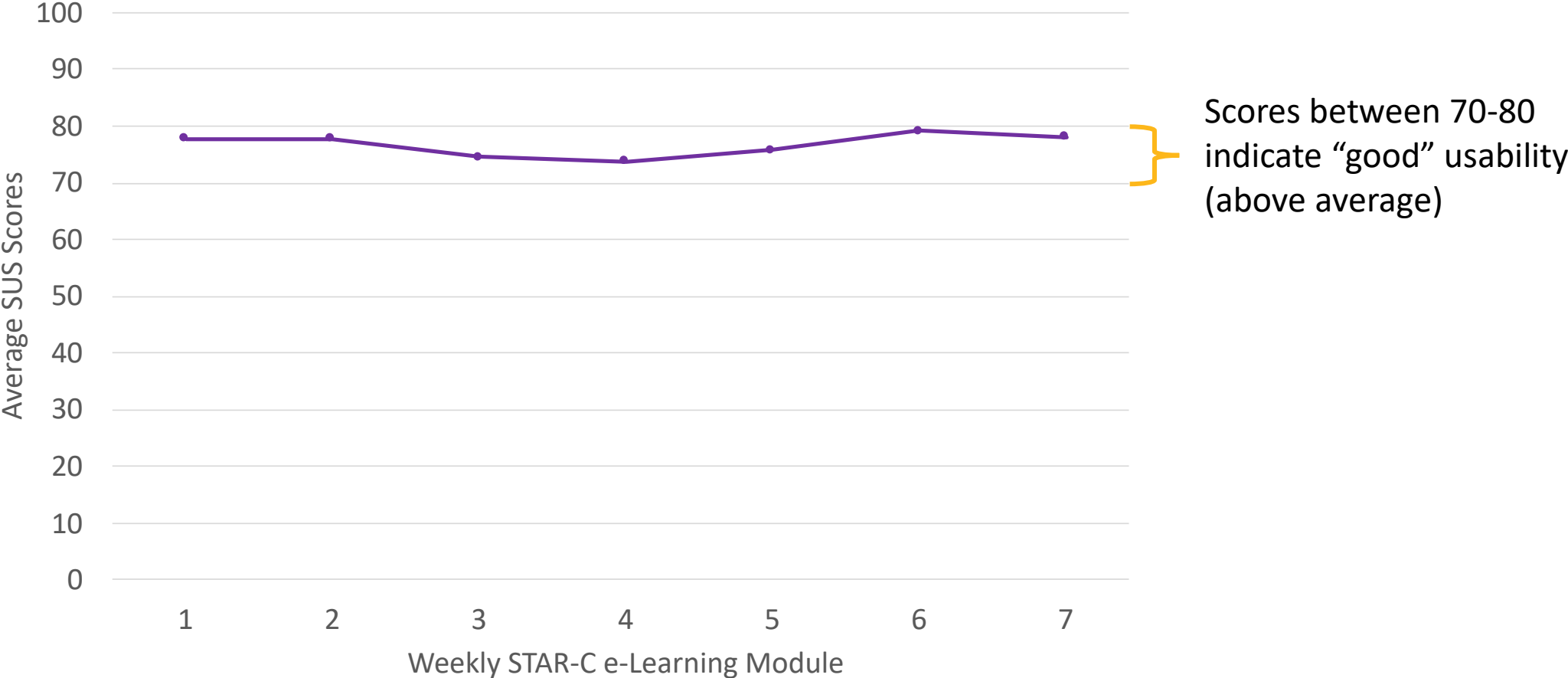




# Clinical Outcomes

Outcome Measure, mean (SD)	Baseline	Post-Intervention
<b>Revised Memory &amp; Behavior Problem Checklist</b>		
Frequency of problems score	28.2 (18.3)	21.3 (16.8)
Caregivers' reaction score	40.4 (16.7)	37.2 (14.6)
<b>Preparedness for Caregiving score</b>	2.0 (0.3)	2.4 (0.3)

# System Usability Scale (SUS)



# Qualitative Feedback



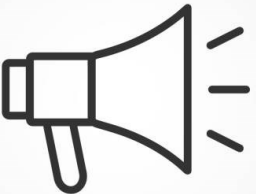
## Satisfaction with STAR-C content & design

- Caregivers valued dementia education and ABC problem-solving strategy
- Empathetic messaging helped promoted patience and understanding



## Suggestions for improvement

- Desired more resources and interactive content (e.g., quizzes)
- Suggested caregiver testimonials and video reenactments



## Sharing STAR-C with other caregivers

- Caregivers shared STAR-C info with family members
- Recommend outreach via community groups and social media

# Acknowledgements

## Mentors

- Rob Penfold, PhD, Kaiser Permanente Washington Health Research Institute
- James Ralston, MD, MPH, Kaiser Permanente Washington Health Research Institute
- India Ornelas, PhD, MPH, UW School of Public Health
- Sue McCurry, PhD, UW School of Nursing

## Research Assistants & Staff

- Miriana Duran, MPH
- Celeste Garcia, MPH
- Miguel Mariscal, MPH
- Lily Zavala, BA
- JP Lopez Garcia, BA

## Funding Sources

CATALyST K12 Program, AHRQ & PCORI  
Research Grant, Alzheimer's Association  
Pilot Grant, NIA IMPACT Collaboratory



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**Questions?**

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