Virtual Training for Managing Symptoms of Dementia: A Cultural Adaptation for Latino Caregivers

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Background

- Older Latino adults are 1.5 times more likely to develop dementia compared to older White adults
- Family members are the largest source of care
- Caregiving is complicated by symptoms of dementia
- Latino caregivers at higher risk for adverse health outcomes
STAR-C Teaches Caregivers to Manage Symptoms of Dementia

About Dementia | Effective Communication | ABC Problem-Solving | Pleasant Events | Coping with Caregiving

Teri et al. (2005)  
*The Gerontologist*

McCurry et al. (2017)  
*Journal of Applied Gerontology*
STAR-C Virtual

Caregivers:

> Complete six weekly STAR-C training modules online
> Have six 30-min weekly phone calls with consultant
> Receive ongoing support via secure email messages

PI: Robert Penfold, PhD
ClinicalTrials.gov, NCT04271046
To make STAR-C accessible to Latino families:

What adaptations are needed to improve the cultural and linguistic appropriateness of STAR-C?
Cultural Treatment Adaptation Framework

Methods

> Participant selection (N=44)
  > Recruited 30 Latino caregivers from Kaiser Permanente Washington, UW Medicine, and the community
    > Hispanic/Latino/a/x
    > Age 21 years or older
    > Adult child, spouse/partner, or close friend of person living with dementia
    > Provides at least 8 hours of care per week
  > Recruited 14 healthcare and social service providers with expertise working with Latino clients
> Conducted interviews in-person, phone call, or Zoom
> Used thematic analysis methods to code and analyze data
Caregivers

- Mexican, Mexican American, or Chicano/a (67%)
- Women (67%)
- Preferred to speak Spanish (60%)
- Adult child of person living with dementia (63%)
- Provided ≥35 hours of care per week (70%)

Providers

- Health educators or case managers (64%)
- Spanish-English bilingual and bicultural (71%)
Believe dementia is a normal part of aging process

Were not expecting changes in mood and behavior

Reluctant to speak to providers about changes in mood and behavior

Unaware providers could help with symptom management
Overview of Dementia

Diseases cause brain changes, leading to behavior changes.

Common causes of dementia:
- Alzheimer’s disease
- Microvascular diseases
Example: Expanded Content in “Overview of Dementia”

Adapted

Dementia is *not* normal aging.

Dementia makes it hard for a person to do everyday tasks, like driving, using a phone, or finding their way home.

Normal memory loss does not disrupt a person’s daily life in a big way.
Eliminate Stigmatizing, Offensive, & Culturally Inappropriate Language

- Stigma associated with words “Alzheimer’s” and “dementia”
- Dislike negative adjectives to describe symptoms
- Dislike using “burden” to describe caregiving
- Most do not label themselves as a “caregiver”
Example: Eliminated Use of “Burden” to Describe Caregiving

Original

**Asking for Help**

Who in your life could help? What could they do to give you a hand?

Sharing the burden can boost your health and make it easier to problem-solve.
Example: Eliminated Use of “Burden” to Describe Caregiving

Ask for Help

Who in your life can help? What can they do to give you a hand?

Having another person help with your family member is good for your own health.
Formal respite services were prohibitively expensive

Most received extensive support from family & friends

Many lived in multi-generational homes

Caregiver programs do not consider the family unit

Incorporate Family Structure & Caregiving in Latino Families
Example: Added Examples of Multigenerational Living

“Just the two of us. There’s nobody helping me to care for her.”

“Hiring somebody to keep an eye on her.”
Example: Added Examples of Multigenerational Living

“Just the two of us. My daughter was at work and the kids at school.”

“Doing the laundry when my daughter or grandchildren can keep an eye on her.”
Reworded Content to Reduce Reading Levels & Translated to Spanish

- Original STAR-C virtual content written at 8th grade level – adaptations written 4th grade

- STAR-C virtual content available only in English – now also available in Spanish
Key Takeaways

1. Provide more education about dementia (not normal aging), causes, and what to expect as the disease progresses

2. Probe about behavioral & psychological symptoms and let families know help is available

3. Avoid describing impact of caregiving as a “burden” or symptoms as “problematic,” “challenging,” and “bothersome”

4. Consider family unit, not just the primary person providing care
Acknowledgements

> Collaborators
- Miriana Duran, MPH, UW School of Public Health
- Rob Penfold, PhD, KPWA Health Research Institute
- India Ornelas, PhD, MPH, UW School of Public Health
- James Ralston, MD, MPH, KPWA Health Research Institute
- Sue McCurry, PhD, UW School of Nursing
- Linda Teri, PhD, UW School of Nursing

> Sponsors
- CATALyST K12 Program, AHRQ/PCORI
- Research Grant, Alzheimer’s Association
- Pilot Grant, NIA IMPACT Collaboratory
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