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Objective

- Discuss the importance of culture
- Define adaptation
- Case study: Cultural Adaptation of ADS-Plus
Racial/Ethnic Aging in the U.S.

- It is expected that one in five Americans will be 65 and over by 2030, and by 2044 more than half of all Americans will belong to a racial/ethnic group other than non-Hispanic White alone.

- In addition to the aging of United States (US)-born minority adults, the growth and aging of immigrants will contribute to a further increase in racial/ethnic minority older adults.

- The implications of these demographic shifts are profound.
  - Needs of diverse older adults should be at forefront of research, practice, and policy agendas.
Racial/Ethnic Disparities in Health Outcomes

- Health disparities reflect and result from cumulative effects of socioeconomic conditions over the life course.
- Disparities in health outcomes translate to differences in how individuals access health services and resources for these conditions, including family care.
What is culture?

• Culture refers to an ever-changing set of shared symbols, beliefs, and customs that shapes individual and/or group behavior

• Culture and cultural frameworks are endorsed by those who identify with their beliefs, symbols and customs.

• Culture is learned through interaction with others, but it exerts its effects on beliefs and behavior internally
Importance of Culture

- Difference in culture is a major reason for observed disparities, as culture can impact both who provides care and how care is given and received within a given cultural context.

- For example, racial/ethnic minority caregivers in the US are more likely to receive support from friends and family compared to their White counterparts.

- Cultural norms and values influence who is responsible for providing care and how they interact with each other in society, while cultural meaning and perceptions inform the interpretation and behaviors related to these stated values.
What is an adaptation? Principles

• Adaptation of evidence is inevitable and necessary
• The science of adaptation is evolving
• A health equity lens can guide adaptation needs
• Adaptation involves an iterative and cyclic approach of adapting, evaluating, adapting again
What is an adaptation? Definition

• Judicious and deliberate changes
• Accidental/unintended changes to the original intervention or
• Adaptations occur prior to implementation, during implementation and thereafter to improve fit or effectiveness of the evidence
# Examples of Adaptations to Evidence-based Programs for Implementation in Healthcare Systems

<table>
<thead>
<tr>
<th>Prior to Implementation</th>
<th>During Implementation</th>
<th>Following Implementation</th>
<th>Prior to Scaling and Dissemination</th>
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<tr>
<td>Change in # of sessions</td>
<td>Change in dose/frequency of sessions</td>
<td>Modification to documentation</td>
<td>Enhance flexibility of all delivery characteristics</td>
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<tr>
<td>Change in who delivers the evidence-based program</td>
<td>Provision of additional materials</td>
<td>Modification to assessments to better fit workflow and context</td>
<td>Change mode of delivery (e.g., use of telehealth)</td>
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<tr>
<td>Change in language</td>
<td>Augmenting sessions based on need</td>
<td>Evaluation of impact of adaptations on outcomes</td>
<td>Shorten training of staff in evidence</td>
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Adaptations to Consider Specific to the Health Context

- Address caregiver and staff perceptions of therapeutic nihilism ("There is nothing we can do")
- Provide basic disease education to front line staff
- Streamline program materials and training to fit limited staff time
- Reduce or flex the number of sessions and/or their length to align with caregiver and/or staff schedules and workflows
- Identify costs, costs saving and payment approaches for delivery to address any perceived financial constraints
- Purposively link outcomes to existing quality assurance measures due to the heavily regulated nature of long-term care industry
Cultural Adaptation

• Cultural adaptation is the systematic modification of an evidence-based program to “consider language, culture, and context in such a way that it is compatible with the client’s cultural patterns, meanings, and values”

• Cultural adaptation explicitly addresses cultural patterns or values at the client, provider, or sociopolitical level.

• It also considers important socio-historical factors like medical mistrust or stigma.
Mindful of Terminology

• *Cultural adaptation* is “the systematic modification of an intervention protocol to consider language, culture, and context in such a way that it is compatible with the client's cultural patterns, meanings, and values”

  vs

• *Cultural attunement* describes additions to evidence-based intervention that are intended to boost engagement and retention of subcultural group members
  – Eg: providing services in clients’ native language, utilizing bicultural staff, and incorporating familiar cultural traditions.
  – *Attunement* involves changes to increase reach and engagement but does not modify core treatment components.
Case Study: Cultural Adaptation of the ADS-Plus Study
What is the ADS Plus Research Study?

Evaluate the extent that we can—

- Enhance wellbeing for persons with dementia and family caregivers
- Augment adult day services with systematic caregiver support
- Provide education and build skills for caregivers
- Improve strategies for better caregiving among adult day service clients
Eligibility Criteria

Eligible

• Family caregiver; providing care to someone with dementia who attends a participating ADS site
• Expect to use ADS for 1 week over 6 months
• Provide 8+ hours of care weekly
• 21 years or older
• Speak English*
• Able/willing to participate in 4 telephone interviews

Ineligible

• Plan to move in next 6 months
• Will not use ADS at least 1 week in next 6 months
• Hospitalized >3 times in past year
• Active treatment for terminal illness or in Hospice care
• Participating in another evidenced based program or study
ADS-Plus: Recruitment Challenges

- Language
  - Eligibility required one to speak English
  - Recruitment and other study-related material all in English
- Organizational challenges
  - Staff turnover
  - Staff burn-out = limited compliance with study protocol
  - First time participating in research study
ADS-Plus: Recruitment Solutions

- Targeted recruitment
  - Building relationship with research liaison, and training
  - Engagement with caregivers at ADS-site
- Administrative Supplement to translate ADS-Plus into Spanish
  - Recruitment material
  - Survey questions
  - Hired a Spanish speaking research team member to complete study-related activities in Spanish
- Growing waitlist for Spanish-speaking caregivers to participate
Cultural Adaptation of ADS Plus for Spanish Speaking Participants: Phases and Research Activities

Phase 1: Translation and adaptation of ADS Plus based on stakeholders’ needs
- Identified community needs, and adaptations to ADS Plus manual
- Translated all ADS Plus study-related material (recruitment materials, interview questionnaires, and intervention materials)

Phase 2: Preliminary adaptation test and refinement
- Conducted interviews/focus groups with ADS Plus interventionists to identify adaptations needed for study-related material
- Used feedback from interviews/focus groups to inform an adapted manual to pilot test

Phase 3: Adaptations are captured into tailored study-related material
- Conduct ongoing interviews with interventionists to inform possible further modifications

Key Points to Remember

• Important to understand how cultural norms and values, as well as structural barriers within a society, help shape the ties that exist within racial/ethnic population.

• Adaptation involves an ongoing iterative process that may occur before implementation, during, and thereafter
The Public Health Center of Excellence on Dementia Caregiving

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...

- Improving access to evidence-based programs and best practices
- Facilitating connections and collaboration among public health agencies and a wide range of service organizations
- Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies
QUESTIONS