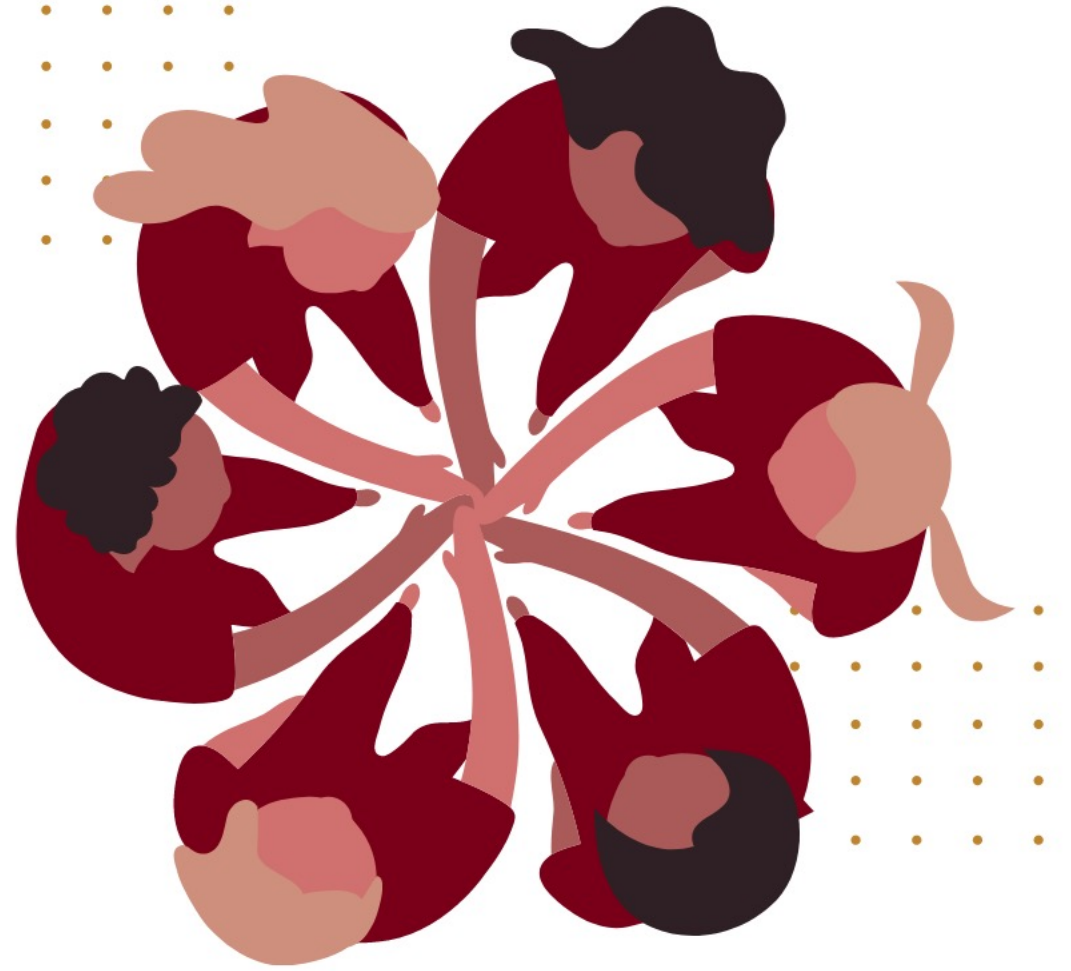


Public Health Considerations and Models for Cultural Adaptation in Dementia Caregiving



Presented by:



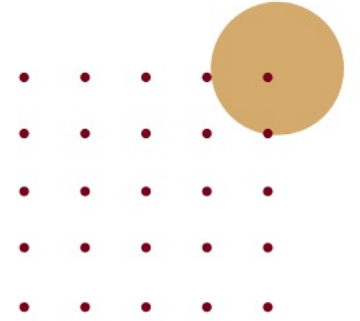
BOLD
PUBLIC HEALTH
CENTER OF EXCELLENCE
ON DEMENTIA
CAREGIVING

In collaboration with:



USAGAINSTALZHEIMER'S CENTER *for*
BRAIN HEALTH EQUITY

Land acknowledgement



The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. We acknowledge with gratitude the Land itself and the People. We take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.



Follow the Conversation on Twitter!

Use **#CultureMattersinDementia**
to follow and keep the conversation
going!

 @PHCOE_DC



Welcoming our presenters...



Nina Darby, MA

Trainer, Diverse Elders Coalition



Lauren J. Parker, PhD, MPH

Assistant Scientist, Johns Hopkins
School of Public Health



Ishan Williams, PhD, FGSA

Associate Professor of Nursing,
Assistant Dean of Diversity and
Inclusion



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...



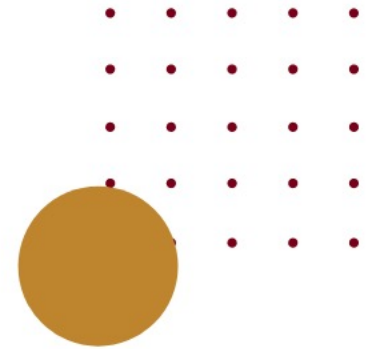
Improving access to evidence-based programs and best practices



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



Coming Soon!

- Join us for Part 2 of our Cultural Adaptation Series, details coming soon!
- Website Launch July 1st, 2021

Visit us online at <https://bolddementiacaregiving.org> to....

- ✓ Find today's slides and recording
- ✓ Request Technical Assistance to support your public health work in dementia caregiving
- ✓ Access resources and materials
- ✓ Stay up to date with PHCOE-DC activities!

Follow us on Twitter to learn more!  @PHCOE_DC





DIVERSE
ELDERS
COALITION

Caring for Those Who Care

Resources for Providers: Meeting the Needs of Diverse Family Caregivers

Toolkit accessible at:

<https://www.diverseelders.org/wp-content/uploads/2021/03/DEC-Toolkit-Final-R2.pdf>

Presented by Nina Darby, MA

Cultural Adaptations of Dementia Supports and Services for Racial and Ethnic Communities

Ishan C. Williams, PhD, FGSA

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and Inclusion



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Objectives

- Discuss the ***importance of cultural sensitivity and relevance to developing dementia supports and services for diverse populations*** around dementia and related disorders.
- Learn about ***health disparities research in dementia*** and the role of culture in understanding the need for early diagnosis and treatment among at risk groups.
- Learn about the ***process of adapting supports and services*** based on culture, race, and other identity characteristics among diverse populations.

Importance of Cultural Sensitivity and Relevance to Conducting Research

- We must address health equity and health disparities across the health care continuum.
- Diverse older adults and their families, should have access to culturally relevant and meaningful transitional care models/ services.
- Multilevel strategies and recommendations for research, practice, and policy should consider strength-based, mixed methods.
 - *Including the voice of both patient and family/caregiver*
- Researchers & clinicians have an important leadership role to engage, locally, nationally and globally to advocate for the ethical and health needs of the most vulnerable populations.

MINORITY AGING IN THE U. S.

- The fastest growing population
 - Individuals over the age of 85 (19% of elderly population)
- By 2050, there will be a decline in the proportion of non-Hispanic Whites, but an increase in the proportion of Blacks, Asians, and Hispanics (Federal Interagency Forum on Aging Related Statistics, 2010)
- The implications of these demographic shifts are profound
 - Needs of diverse older adults should be at forefront of research, practice, and policy agendas

Health Disparities

- Disparities related to dementia among African American adults
 - At a **greater risk** for developing dementia
 - **Wide range of services** necessary for care of those suffering from dementia who have ethno racial differences compared with majority groups
 - The higher rates of dementia found in Latino and African American groups, relative to non-Latino Whites, are associated with clear and **substantial functional dependencies**

1 in 3

seniors
dies with
Alzheimer's
or another
dementia

It kills more
than breast
cancer and
prostate
cancer
combined

Who is at risk?

- Age
- Family history
- Heredity
- Head injury
- Lifestyle



Risk factors for Cognitive Loss

- Tobacco Use
- Excess Alcohol
- Toxins
- Environmental Exposures
- Polypharmacy (>4-6 medications)
- High Risk Medications
- Poor Nutrition
- Vascular Risk Factors
- Chronic Medical Conditions
- Depression and Anxiety

All adversely affect brain health

Many risk factors have higher prevalence in underserved populations causing disproportionate ↑ risk

**BLACK / AFRICAN
AMERICANS** are about

2x

and **HISPANIC / LATINOS**
are about

1.5x

more like than **WHITES** to
have Alzheimer's or other
dementias...



- ...YET they are less likely to receive a diagnosis

LGBTQ Older Adults



The estimated 2.7 million U.S. older adults who self-identify as LGBTQ will increase exponentially to more than 4 million by 2030.

LGBTQ older adults age 50 and over experience a higher prevalence of chronic disease and disability, as well as a poorer physical and mental health status.

...and experience major health disparities.

Among LGBT elders, aged 50+



39% have seriously thought of suicide, and 31% report depression.



47% have a disability.



38% of lesbians do not report receiving regular cervical cancer screenings, leading to a much higher risk of cervical cancer.



12% have reported drug use



One quarter of transgender elders age 50+ are in poor health, and 22% could not afford to see a doctor.



Among elders of color

Black people are 2X, and Latino people are about 1.5X more likely, than their White counterparts to have Alzheimer's and other dementias.



It is estimated that as many as 1 in 10 Asian and Pacific Islander people are living with the hepatitis B virus.



American Indian/Alaska Native people have higher rates of heart disease and diabetes than other racial/ethnic groups.



Approximately 30% of all Latinos lack health insurance and a regular source of health care.



MORE THAN ONE IN TEN LGBT PEOPLE AGE 50+ have been denied healthcare or provided inferior care.



Source: Services and Advocacy for Gay, Lesbian, Bisexual, & Transgender Elders

Rural-Dwelling Adults

- Account for 20% of the US population
- Suffer worse health outcomes compared with the rest of the nation
- Are particularly vulnerable to cognitive impairment



Rural-Dwelling Adults

- Under-utilize medical and social services
- Face difficulties to undergoing cognitive evaluations and accessing care delivery
- Experience lost opportunities to treat modifiable risk factors or treatable conditions



Non-English Native Language Speakers

- Language noncongruence creates an artificial barrier and set up for care inequity
- Insufficient and underutilized translator services
- Time constraints on health care providers may limit translation use
- Individuals may not feel empowered or comfortable to self-advocate
- “Lost in translation” details can delay diagnosis in early disease
- Overlook early language changes

Objectives



Use a strengths- based approach when working with older adults representing diverse cultures



Understand power differentials and cultural norms for individualized care plans



Delineate the importance of culture in shaping preferences regarding care



Examine culture as a factor in effective communication with families

Conducting research with older adults

- Vulnerable versus Under-resourced
 - Hard to reach
- Social Networks
 - Provide greatest amount of care and support
- Culture
 - Collectivist-centered
 - Often seek and receive help from friends and fictive kin who are often considered “family”
 - Sense of duty, respect, and obligation



Family Dynamics

Family dynamics are the patterns and interactions we have with different members of our family.

- Influences behavior, ideas, and how people interact.
- Resilient families → maintains hope to look beyond condition

Family Belief Systems



Shared beliefs that shape how they adapt to stress and change.



Families must make meaning out of the challenges they face. What seems overwhelming and difficult for one family may be embraced as a valuable difference in another.



Health professionals should attend to the meaning and value families assign to any difference or disability.

Family Belief Systems



Resilient families can increase agency by gaining a sense of coherence, maintaining hope, focusing on growth, and forging a group identity that includes but goes beyond the disability.



For some families, spiritual beliefs and practices unite family or can break them apart.

Key Issues 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 this population.
- People want to be **valued**
 - No matter what race/ethnicity
- People want to be **respected**
 - No matter what gender/social identity
- People want **honest communication**
 - Health literacy is important



Understanding through Strengths Approach

Client's perspective of their problems, strengths, and goals should inform their needs.

Role of provider is of collaborator and resource and not expert

Goals and design should focus on:

Access

Choice

Opportunities

Culturally-Tailored Interventions

Taking Care of Sugar

Utz, S.W., Williams, I.C., Jones, R., Hinton, I., Alexander, G., Yan, G., Moore, C., Blankenship, J., Steeves, R. & Oliver, N. (2008). Culturally-tailored Intervention for Rural African Americans with Type 2 Diabetes. *The Diabetes Educator*, 34(5), 854-865.

Family Quality of Life

Rose, K. M., Williams, I. C., Anderson, J. G., & Geldmacher, D. S. (2020). Development and Validation of the Family Quality of Life in Dementia Scale. *The Gerontologist*.

Community Advisory Boards

Culture

- Models of Explaining Cultural Differences (Cauce, Coronado & Watson, 1998)
 - Cultural Deviance Model
 - Differences or deviations between groups are seen as deviant and inferior.
 - Cultural Equivalence Model
 - Superior socioeconomic status has provided advantages
 - Cultural Variant Model
 - Resilience in the face of oppression
 - Culturally rooted, internal explanations for differences

Cauce, A. M., Coronado, N., & Watson, J. (1998). Conceptual and methodological issues in conducting culturally competent research. *M., Hernandez, R. Isaacs, (Ed.), Promoting cultural competence in children's mental health services. N. J: Brookes.*

Why Significant?



Historically, being stigmatized results in poorly managed care and transitions, poorer health outcomes, and increased health care costs



Trust and communication between team members and families, empowerment of patients and families, and culturally tailored coaching will make care and transitions smoother

Culturally Sensitive Approach

- Diagnosis can be overwhelming and may present challenges for aging families (i.e., limited resources, multiple health issues)
- Provide culturally sensitive approaches on how to assist in maintaining their health and well-being
 - Understand individual/patient's background, ethnicity, belief system
 - Use of patient's language/interpreters when appropriate
 - Emphasis on improving care and health outcomes
 - Build trust and a shared understanding
 - Appropriately inquiring about and being supportive of a patient's sexual orientation and/or gender identity to enhance the patient-provider interaction and regular use of care.

Health Disparities and Culture



- Cultural factors influence AD screening, diagnosis, and access to care
- Some disparity caused by economic and structural barriers to access, treatment, and diagnosis
- Disparity influenced by the cultural interpretation of disease

Strategies for Mitigation: Health Disparities

- Educate and Empower
 - Share best practices on cognitive aging and brain health
 - Raise awareness of disparities in care (i.e., race/ethnicity; geographic region, gender identity)
- Increase messages that emphasizes the role of the Care Partner/Caregiver
- Improve access to services and supports to enhance health, well-being, and independence
- Engage in partnerships that support inclusive communities for people with dementia and their families

In Summary: Cultural Adaptation



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Information gathering

Preliminary design

Preliminary adaptation tests

Adaptation refinement



Thank You!

Thank you for joining us today!

Please take a moment to complete our evaluation form
at the end of this presentation.

