Twin Ports Conference
Session 202
Memory Loss and Dementia: An African American and Health Equity Lens

Alzheimer’s Association:
Robbin Frazier, Director of Diversity and Inclusion
E-mail: rfracier@alz.org
Work phone: 952.767.7566

Our mission
Is to eliminate Alzheimer’s disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.

Our vision
Is a world without Alzheimer’s.

Learning Objectives
- Prevalence of Dementia and Alzheimer’s
- Risk Factors Non-modifiable (no control) & Modifiable
- Health Disparities – populations impacted
- Impact of race, ethnicity and culture
- Unique Barriers and Challenges for African Americans
- Advancing Health Equity
Prevalence of Dementia and Alzheimer’s

Types of Dementia
- Dementia: loss of memory due to changes in the brain
- Alzheimer’s is the most common form
- Many mixed cases
- Many memory disorders are reversible and not truly dementia

Alzheimer’s disease...
- Is a brain disease functioning severe enough to interfere with everyday life
- Is the most common type of dementia (+60%)
- Has no proven, evidenced based prevention
- Has no treatment (other than symptomatic) to slow progression or delay onset
- Has no cure
- Is fatal
10 Warning Signs of Alzheimer’s disease

Alzheimer’s Risk Factors
- Non-modifiable (no control)
- Modifiable
Risk Factors Non-modifiable (no control) Modifyable (*we can control)

- Age Gender
- Family History (1st degree – parent’s & siblings)
- Genetics (less than 1%)
- Mild Cognitive Impairment (MCI)
- Down Syndrome
- Cardiovascular Disease*
- Diabetes (Type 1 and 2)*
- Head Trauma/Traumatic Brain Injury*

Age is the #1 Risk Factor for Alzheimer’s

- Base Rates
  - 1 in 9 people age 65 and older (11%) have AD
  - 1 in 3 people age 65 and older (32%) have AD
  - 81% of the people who have AD are age 75 or older

- Age Range Percent with Alzheimer’s
  - < 65 years 4%
  - 65–74 years 15%
  - 75–84 years 44%
  - 85 + years 38%

Gender is the #2 Risk Factor for Alzheimer’s

- Gender is a key risk factor
  - Almost two-thirds of Americans with Alzheimer’s are women
  - At age 71 and older, 16% of the women have Alzheimer’s/dementia compared with 11% for men

- Why are women at great risk
  - Women live longer than men on average
  - Men who survive beyond age 65 may have a healthier cardiovascular risk profile
  - Research needed on linkage to education, life experiences, and biological or genetic variations
Health Disparities

ALZHEIMER’S CAN AFFECT ANYONE

Women are nearly 2x as likely as men to develop Alzheimer’s disease.

African Americans are 2x more likely than whites to have Alzheimer’s or another dementia.

Hispanics/Latinos are 1.5x more likely than whites to have Alzheimer’s or another dementia.

What Accounts for Racial/Ethnic Differences

- Genetic factors do not appear to account for differences among racial and ethnic groups
- African Americans and Latino/Hispanics have a higher prevalence of cardiovascular and chronic conditions associated with an increased risk for ADAD
  - High blood pressure
  - High cholesterol
  - Heart disease
  - Diabetes
Alzheimer’s Modifiable Risk Factors

- Risk Factors that CAN BE changed or modified to reduce the risk of cognitive decline
- Management of Cardiovascular Risk Factors
  - Diabetes (including impaired glucose processing a precursor diabetes)
  - Midlife Obesity
  - Smoking
  - Midlife Hypertension
  - Midlife High Cholesterol

New Research on Race/Ethnic Dementia Risk

- Variations in health, lifestyle, and socioeconomics likely account for some of the differences
  - Lower levels of education
  - Higher rates of poverty
  - Occupation
- Greater exposure to discrimination
- Higher rates of stress due to traumatic events
- Geographical disparities – high infant mortality states

Stress & Racial Disparities Impact Cognitive Health

- Stress experiences that cluster and accumulate across a lifetime can contribute to cognitive health disparities.
- African Americans report significantly more stressful experiences
- Each reported experience equivalent correlates to four years of cognitive aging.
- Lifetime stress is associated with poorer cognition later in life and can contribute to racial disparities.

FINDINGS FROM THE WISCONSIN REGISTRY FOR ALZHEIMER’S PREVENTION (WRAP) STUDY
https://www.alzheimersanddementia.com/article/S1552-5260(17)33001-7/fulltext
**Dementia Link - Early Life Adverse Conditions**

- Being born in a state that has a high infant mortality rate (HIMS) has been linked to poorer long-term health outcomes.
- African Americans born in states with the highest levels of race specific infant mortality rates had a 40% increase in risk of dementia.
- Compared to Whites born outside HIMS, Blacks born inside HIMS had almost 80% elevated dementia risk after adjusting for education and vascular comorbidities.


**Impact of Race, Ethnicity and Culture**

**Racial/Ethnic Differences in Diagnosis**

- Evidence that missed diagnoses of Alzheimer’s and other dementias are common among older African-Americans and Latino/Hispánics.
- Diagnosis rates
  - 6.9% of white older adults
  - 9.4% of African-Americans
  - 11.5% of Latino/Hispánics
- The rates of diagnosis for African-Americans should be twice as high as those for whites (approximately 13.8 percent instead of 9.4 percent).
Personal Impact of Missed or Late Diagnosis

- Lack of disease knowledge can result in fear and burden
  - Missed opportunity to rule out other health problems
  - Misunderstanding = Stigma, Silence, and Shame
  - Negative outcomes due to inability to manage medications

- Late diagnosis/treatment = Crisis Decisions and Care
  - Missed opportunity to make their wishes known
  - Less time to get education, symptomatic treatments, trials
  - Fewer options and significant financial impact on assets
  - Loss of independence can sometimes be sudden and painful

Caregiver Impact of Missed or Late Diagnosis

- Late Diagnosis and Treatment = Crisis Management
  - Missed opportunity to know the wishes of loved ones and make proactive financial, legal, housing and care plans

- Negative Health and Wellness Impact
  - 59% of Caregivers rate emotional stress as high to very high
  - Caregiving over long durations and involves daily personal care

- Work Related Losses – wages, careers, and dreams
  - 57% Had to go in late/leave early/take time off
  - 18% Had to go from full-time to part-time work
  - 16% Had to take a leave of absence
  - 9% Quit work entirely
  - 8% Turned down a promotion

National Racial & Ethnic Disparities

- MN has some of the largest disparities by race and ethnicity in the U.S. comparing white, non Hispanic/Latino to all persons of color

- The Twin Cities Top U.S. metro’s ranks as:
  - Poverty rate (largest disparity among large metros)
  - Homeownership (largest)
  - Employment (2nd largest, tied with Philadelphia)
  - Educational attainment (4th largest, tied with San Diego)
  - Per capita income (8th largest)

Source: Metro Council Disparities Unmasked: Twin Cities Metro in 2014, Metro stats: research@metc.state.mn.us
State Racial & Ethnic Disparities

- State Level – Fewer healthy years for older black Minnesotans
  - On average white Minnesotans age 65 and older can expect 77.5% of their remaining years to be healthy, in contrast black Minnesotans can expect a little over half of their remaining years or 57% to be healthy
  - MN whites (over age 65) can expect about 15.6 years of healthy life, and blacks have a healthy life expectancy of about 11.5 years

Source: Metro Council Disparities Unmasked: Twin Cities Metro in 2014, Metro stats: research@metc.state.mn.us

Unique Barriers and Challenges for African Americans

- Population: 12.8%; the number of African-Americans over 65 will double in the next 40 years
- Alzheimer’s twice as high than for Caucasian individuals
- History of health disparities and dying younger
- 79% say religion is an important part of their life and practice in a faith community, offer health programming
- Give 25% more money to charity than Caucasians peers
African American Caregivers Greater Burden

- African American spouses as caregivers and female caregivers are at a higher risk for experiencing task difficulties, symptoms of depression, and negative life changes.
- 50% of caregivers reported working a full-time job while providing 10-40+ hours of care per week.
- Male caregivers reported needing more help with finances and finding care aides.
- Females caregivers reported needing resources on how to have a family discussions.

https://www.alzheimersanddementia.com/article/S1552-5260(16)32313-5/fulltext

Historical Trauma

- The Tuskegee Experiment
  - U.S. Public Health Service Study
  - Recruited 623 African American men to study “the effects of untreated syphilis in the negro male”
  - Denied care for 40 years, even after penicillin

- Mrs. Henrietta Lacks
  (wife, mother of five)
  - Diagnosed and suffered with cervical cancer
  - Her cancer cells, HeLa, were taken from her body without her permission for medical research
  - HeLa cells lead to a medical revolution
  - No recognition or family profit
Racial Discrimination

- Slavery followed by Jim Crow Laws
  - Separation of families
  - Loss of language, cultural, freedom
  - Medical experiments

- Growing up within a segregated environment
  - Education
  - Healthcare
  - Military
  - Social services system

Cultural Considerations

- Responsibility to care for one another
- Resistance to outside assistance
- Use of home remedies and herbs an important component of health care
- Faith community may inform health care beliefs and behaviors
- African Americans often describe their churches as church homes and church families

- Find solace in religion; families use faith/spirituality as a coping resource; church is an all-inclusive network
- Community may see the formal and white health care system as part of an overall oppressive system
- Many African Americans struggle to believe they can expect the same medications, treatments and quality of care as whites receive from doctors and institutions
- Elders and families may be “on alert” and on guard
Advancing Health Equity at the Alzheimer’s Association

Enhance Care and Support for ALL Affected

- Take into consideration health disparities and inequities
- Seek the attainment of the highest level of health for all people
- Practice cultural awareness and competence
- Provide culturally responsive resource

Advancing Health Equity at ALZ

- Accepted Health Equity Call to Action from ACT HELG
- Strategic hires - Director of Diversity, Program Manager Latino Outreach
- Senior Leadership Support and Board Engagement
- Launched the chapter’s first D & I Committee
- Ongoing recruitment of Board, Staff and Volunteers
- Conducted over 15 interviews with stakeholders from diverse communities, reviewed research, and conducted SWOT
Advancing Health Equity at ALZ Cont’d

- Stakeholder interviews identified key barriers regarding dementia care and use of association programs
- Explored health models and systems to frame community needs and identify potential ways to mitigate barriers
  - Maslow’s Hierarchy of Needs
  - Social Determinants of Health
  - Inclusive Model and Definition of Health System

Advancing Health Equity
Maslow’s Hierarchy of Needs

Determinants Influence: Health Equity, Dementia Care Planning and Services, and Interventions
Advancing Health Equity – Reinvisioning

What is a Health System?

- Direct services
  - Primary care
  - Specialty care
  - Hospital care
- Enabling services
  - Population-based services
  - Infrastructure services

---

ALZ Health Equity Advancement

- Ongoing
  - Community outreach, education, collaboration
  - Professional & family dementia conference scholarships
  - Culturally sensitive and responsive care and support
- Next steps
  - Recruitment and engagement of volunteers
  - Mitigation of clinic/provider barriers
  - Strategies to combat myths, stigma, shame and silence

---

Advancing Health Equity

- Understanding race and culture
  - Historical and current trauma
  - Disparities and inequities
  - Client’s belief, values, strengths
- Recognize cultural humility is a lifelong process
- Build relationships based on respect and trust
- Develop provider and community partnerships
- Use a strength-based approach focusing on the cultural values, beliefs, and assets
Cultural Resources

Alzheimer’s Association overview
www.alz.org/co/helping_you/diverse_communities

Cultural Competence and Awareness | ACT on Alzheimer’s Resources
Supporting health care providers, staff, and administrators in providing culturally competent care in Minnesota.
www.actionatz.org/cultural-competence-and-awareness

Cultural Care Connection (online learning and resources center)
Supporting healthcare providers, staff and administrators in providing culturally competent care in MN
www.culturecareconnection.org

Caregiver Services for African American Families | Volunteers of America
African American Caregivers Services
www.voamnwi.org/caregiver-services-afam

Think Cultural Health (web-based resources and tools for cultural and linguistic competency) Advancing health equity by developing and promoting culturally appropriate services across public health and health care systems
www.thinkculturalhealth.hhs.gov/resources

Presentation References and Sources

Alzheimer’s Association Facts and Figures for 2018
www.alz.org/facts

WRAP - STUDY LIFETIME STRESSFUL EXPERIENCES, RACIAL DISPARITIES, AND COGNITIVE PERFORMANCE: FINDINGS
https://www.alzheimersanddementia.com/article/S1552-5260(17)30001-7/fulltext

BIRTH IN A HIGH INFANT MORTALITY STATE: RACE AND RISK OF DEMENTIA
https://www.alzheimersanddementia.com/article/S1552-5260(16)32313-5/fulltext

Greater Burden on African American Caregivers
https://www.alzheimersanddementia.com/article/S1552-5260(16)32313-5/fulltext

Cultural Awareness in Dementia Care: Working with African American Elders
2018 Presented by Dorothea Harris - MSW LICSW, Program Manager of African American Caregiver Support, Volunteers of America MN/WI