BRAIN HEALTH MATTERS

Understanding the Role of Culture in African Americans to Address Alzheimer’s

The National Brain Health Center for African-Americans is a program of The Balm In Gilead
Supported by: The Centers for Disease Control and Prevention’s Healthy Brain Initiative
The mission of The Balm In Gilead is to prevent diseases and to improve the health status of people of the African Diaspora by providing support to faith and other institutions in areas of program design, implementation and evaluation which strengthens their capacity to deliver programs and services that contribute to the elimination of health disparities.
MEMORY SUNDAY

WHAT IS MEMORY SUNDAY?
MEMORY SUNDAY, the SECOND SUNDAY IN JUNE, is a designated Sunday, within congregations serving African Americans, that provides education on Alzheimer’s: prevention, treatment, research studies and caregiving.

PURPOSE
The purpose of MEMORY SUNDAY is to bring national and local attention to the tremendous burden that Alzheimer’s and other Dementias are having on the African American community; to utilize the power and influence of the African American pulpit to bring awareness; to distribute the facts about Alzheimer’s; to encourage participation in research studies and to support persons living with Alzheimer’s and their caregivers.
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OBJECTIVE 1

Raise awareness of the issues affecting cognitive health among African Americans via the capacity development of African Americans congregations to become an integral partner in prevention, disease management, caregiving and engagement in clinical studies.
OBJECTIVE 2

Train health professionals regarding issues affecting cognitive health among African Americans via a partnership with the National Black Nurses Association and National Medical Association.
BRAIN HEALTH FOR AFRICAN AMERICANS

Alzheimer’s Disease in the US
1 in 3 seniors die from Alzheimer’s or dementia; since 2000, deaths related to Alzheimer’s increased by 123%

In 2018, there are 5.7 Americans living with Alzheimer’s Disease

5.5 million of those with Alzheimer’s disease are 65 years and older

200,000 of those with Alzheimer’s disease are younger than 65 years of age and have younger-onset Alzheimer’s

1 in 3 seniors die from Alzheimer’s or dementia; since 2000, deaths related to Alzheimer’s increased by 123%
Alzheimer’s Disease in the US

• Every 65 seconds, someone in America develops Alzheimer’s – resulting in nearly half a million new cases each year.

• Almost two-thirds of Americans with Alzheimer's are women.

• Causes more deaths than breast cancer and prostate cancer combined

Data from Alzheimer’s Association 2018 Facts and Figures
Impact on Caregivers

• In 2017, 16 million family members and friends provided 18.4 billion hours of unpaid care to people with Alzheimer’s and other dementias.

• The physical and emotional impact of caregiving on Alzheimer’s and other dementia caregivers resulted in an estimated $11.4 billion in increased caregiver healthcare costs.

• 35% of caregivers of loved ones with Alzheimer’s report poor health due to responsibilities as a caregiver compared, almost double the percentage of those not caring for someone with Alzheimer’s (19%)
Financial Impacts

- In 2018, the direct costs to American society of caring for those with Alzheimer’s will total $277 billion.

- Among all Americans alive today, if those who will get Alzheimer’s disease were diagnosed when they had mild cognitive impairment, it would collectively save $7 trillion in health and long term care costs.

- Undiagnosed dementia or dementia diagnosed in later stages of the disease drive up cost.

Data from Alzheimer’s Association 2018 Facts and Figures
Alzheimer’s Disease in the US

Risk Factors

• Greatest risk factors are age, family history and having the APOE e-4 gene.

• Multiple modifiable risks – physical inactivity, hypertension

• Education and social/cognitive engagement
Alzheimer’s Disease & African Americans

• Alzheimer’s disease is the sixth leading cause of death in the United States and the 5th leading cause of death for older African Americans.

• African Americans are twice as likely to develop dementia than Caucasians.

• African Americans are generally diagnosed at later stages of Alzheimer’s disease limiting the effectiveness of treatments.

• Vascular dementia accounts for a larger proportion of dementia in African-Americans than in whites.
Alzheimer’s Disease & African Americans

• Research is beginning to show evidence for various risk factors for developing Alzheimer’s and other dementias

• More research is needed to fully understand the linkage between risk factors and the development of dementia

• In the next slides, we will highlight emerging evidence around potential risk factors
Alzheimer’s Disease & African Americans

Impact of Co-morbid Conditions

• African Americans have higher rates of chronic disease like diabetes and heart disease that significantly increases risk of developing Alzheimer’s

• Persons with a history of either high blood pressure or high cholesterol are *twice as likely* to get Alzheimer’s

• Those with both risk factors are *4 times as likely* to develop dementia
What we are learning about Alzheimer’s Disease & African Americans

**Impact of Co-morbid Conditions – High Cholesterol**

- Excess serum cholesterol triggers beta-amyloid plaque formation
- Those who had total cholesterol levels over 224 mg/dL in mid- to late life were at least **seven times** more likely to have beta-amyloid plaques in their brains by the time they died
- People with high LDL levels were at least **eight times** more likely to display pathologic features of Alzheimer’s disease
What we are learning about Alzheimer’s Disease & African Americans

*Impact of Co-morbid Conditions – Hypertension*

- Nearly 60% of African Americans over the age of 20 have uncontrolled high blood pressure
- Risk of dementia mortality 29% higher among African Americans born in the stroke belt states (Alabama, Arkansas, Georgia, Mississippi, North Carolina, South Carolina and Tennessee)
- Different and/or poor therapeutic response to anti-hypertensive medications
What we are learning about Alzheimer’s Disease & African Americans

*Impact of Co-morbid Conditions – Stroke*

- Dementia in people with a history of stroke is approximately 3.4 to 5.8 times higher than in those without stroke history
- Incidence of dementia over 10 to 25 years in those with a history of stroke is doubled that observed in those free of stroke
- CVA or Stroke, Ischemic white matter lesions, Silent infarcts and atherosclerosis – all related to Alzheimer’s disease pathology
BRAIN HEALTH
FOR AFRICAN AMERICANS

Health Impacts of Alzheimer’s on Caregivers
Challenges for Caregivers

Utilization of Available Resources –

• Most African American caregivers who provide care informally are well positioned to profit from the services and resources that Medicaid Assistance Programs provide:
  • Home and Community Based Services (HCBS)
  • Waiver programs, such as:
    • Adult day care
    • In-home care
    • Respite care

• Caregivers receiving Medicaid identified respite care, adult day care, and financial assistance as their most important need

• African American caregivers choose to rely upon the resources within their family structure, creating a trend toward underutilization of available services and resources

• African American caregivers have lower participation rates in support groups than their white counterparts
Physical and Health Related Challenges for Caregivers

• **Concerns About Own Health** - studies indicate caregivers report being “somewhat concerned or very concerned” about maintaining their own health.

  - Caregivers are more likely than non-caregivers to report their health as “fair” or “poor”.
  - Caregivers believe that the greatest difficulty of caregiving is that it creates or aggravates their own health problems.
  - Hospital and emergency room visits tend to be frequent among caregivers.
  - Several studies have found that under certain circumstances, Alzheimer’s caregivers were more likely to have elevated biomarkers of cardiovascular disease risk and impaired kidney function risk than non-caregivers.

• **Fatigue and Exhaustion**

• **Sleep Deprivation**
Emotional, Mental, & Social Impact on Caregivers

- Depression and Isolation

- Isolation and Withdrawal

- Chronic stress
  - Caregivers of spouse are more likely than non-caregivers to have high levels of stress hormones, reduced immune function, slow wound healing, increased incidence of hypertension, coronary heart disease and impaired function of endothelium (inner lining of blood vessels)
Ways for Providers to Support Caregivers

• **Staffing and Utilization of Community-based programs**
  • Peer-to-Peer programs, Patient Navigation Services, and Service Coordination programs

• **Streamline and improve referral processes to increase access and utilization of available resources**
  • Dramatic increase in Medicaid enrollment occurs when social workers assisted elderly African American recipients and their families with the application process

• **Provide support to caregivers through:**
  • Engagement into healthcare system as a patient
  • Assess barriers and limitations of caregivers to identify gaps, needs, and resources
  • Provide and/or encourage caregivers to participate in support groups and other psychosocial programs to help combat stress and fatigue
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Barriers to Diagnosis, Treatment, and Improved Health Outcome
Barriers, Barriers, Barriers

**Socioeconomic**
- Income
- Education
- Lack of Awareness

**Cultural**
- Unconscious Bias/Discrimination
- Mistrust
- Lack of Cultural Competency

**Environmental**
- Limited/Poor Access to Healthcare
- Lack of Supportive Services
- Poor quality of care
Challenges to Barriers

• Co-morbid conditions, underlying psychiatric conditions, under utilization or ineffective use of screening tools
• Changing family dynamics
• Limited resources for patients once a diagnosis is made
• Poor health literacy and understanding
• Lack of consistent and routine training related to cognitive health and diagnosis for providers
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Role of Faith and Culture on Diagnosis, Treatment, and Clinical Research Outcomes for African Americans
Cultural Competency = Cultural Respect
Why is Cultural Competency Important in Healthcare

• Cultural competence is defined as the ability of providers and organizations to effectively deliver health care services that meet the social, cultural, and linguistic needs of patients

• Necessary to improve health outcomes and overall quality of care

• Helps to reduce racial and ethnic health disparities

• Certain aspects of culture has direct relationship to health behaviors thus impacts health statuses and risk factors associated with several chronic health conditions
Impact of Culturally Incompetent Care

- Poor communication between provider and clients
- Reduced utilization of healthcare services
- Ineffective health literacy and education
- Poor treatment and medication adherence
- Increased dissatisfaction and mistrust of healthcare system
Impact of Culturally Incompetent Care

• Based on national quality measures 42% of African Americans receive worse care than their white counterparts

• Approximately 56% of African Americans that are poor to low-income receive worse care than higher income whites

• In 2016, there was little to no change in the access and utilization of healthcare services for minorities

https://www.ahrq.gov/research/findings/nhqrdr/nhqdr16/index.html
African Americans, Faith & Health

African Americans and Religion

• 75% say religion is very important in their lives, compared to 56% among the general US population.

• More than half of African-Americans (53%) report attending religious services at least once a week, compared to 39% of the general population.

• More than three quarters (76%) say they pray on at least a daily basis, compared to 58% of the general population.
Tools and Strategies to Address Culture and Health Disparities

• Using community-participatory based approach in healthcare planning and delivery

• Utilizing Community Healthcare Worker Model – this includes training and usage of faith-based healthcare coordinator and health ministry workers

• Expand access to healthcare through partnerships with faith and community-based partners to increase health promotion and utilization

• Intentional and meaningful diversity and inclusion of healthcare staff
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http://brainhealthcenterforafricanamericans.org