Addressing health disparities in people living with and at risk for dementia

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Part of the National Alzheimer’s and Dementia Resource Center webinar series sponsored by the Administration for Community Living.
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www.radc.rush.edu
Outline of Presentation

• Brief description of racial disparities in Alzheimer’s Disease (AD)
• Minority Aging Research Study (MARS)
• Selected findings on risk factors in African Americans
U.S. is becoming increasingly diverse
Alzheimer’s Association estimates that African Americans are about 2 times more likely than Whites to have Alzheimer’s disease.

40% less likely to receive anti-dementia medications.

Alzheimer’s disease facts and figures. Alzheimer’s Association; Alzheimer’s & Dementia, 6 (2015); Hernandez et al., 2010
African Americans are about twice as likely to have AD.
Dementia incidence rates by age and ethnicity 2003-2013

Mayeda et al., 2015, Alz & Dementia
Minorities tend to score lower on cognitive function tests

- Tests used in diagnosis
- Performance influenced by many factors
- These factors vary by race
- Presents challenges in interpretation
Longitudinal design is a strong approach for examining disparities in AD

- Reliable estimate of change in cognitive function over time
- Control for baseline level of function
- Each person serves as own control
- Can examine how risk factors influence change over time
Rationale for longitudinal cohort design in AD research

- Identify risk factors
- Determine biologic pathways linking risk factors to disease
- Develop strategies to prevent AD
  - Alter life behaviors
  - Identify drugable targets and develop effective therapeutics

Risk Factors
Genetic
Lifestyle

Alzheimer’s Disease
Minority Aging Research Study (MARS)

- Began recruitment in August 2004
- >750 African Americans (~70% women), >65 years
- Recruited from churches, senior buildings & organizations in the metropolitan Chicago area (city/suburbs)
- Invited to join if no “known” dementia
- Annual in-home evaluations consisting of cognitive testing, risk factor assessment, and blood draw
- Follow-up rate > 92% among survivors (up to 14 years follow-up)
- ~ 5% developed Alzheimer’s dementia; 18% MCI
- Began recruitment for autopsy in 2011
  - 345 have agreed to donate brain
  - 79 brains from African Americans across studies to date
The Memory and Aging Project
... because memories should last a lifetime

- Began in 1997
- >2,100 older persons without dementia from across northeastern Illinois
- All agreed to annual clinical evaluation and annual blood donation
- All agreed to donate brain, spinal cord, muscle, nerve
- >300 have developed dementia
- ~800 autopsies

PI: Bennett, R01AG17917
Although there are level differences by race, little difference in rates of decline across race.

Wilson, et al. 2015
No race differences in rates of cognitive decline in older African Americans and Whites

Weuve et al., 2018

Figure 1. Expected trajectory in global cognitive score, by age and race, as predicted from a model with terms for race, age, sex, time, (race) x (age), (race) x (time), (age) x (time), and (sex) x (time).
Some risk factors appear to operate the same across race

<table>
<thead>
<tr>
<th>*Decrease Risk of decline</th>
<th>*Increase Risk of decline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive activity</td>
<td>Smoking</td>
</tr>
<tr>
<td>Social networks</td>
<td>Depressive symptoms</td>
</tr>
<tr>
<td>Vitamin E</td>
<td>Cytomegalovirus</td>
</tr>
<tr>
<td>Fish consumption</td>
<td>Low Body Mass Index (BMI)</td>
</tr>
<tr>
<td>Life space</td>
<td></td>
</tr>
<tr>
<td>Purpose in life</td>
<td></td>
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</tbody>
</table>

*Data come from published studies from CHAP, MAP, and MARS cohorts*
Other risk factors appear to show race differences

*Decrease Risk of decline*
- Social Engagement (W)
- Early life adversity (B)
- Physical activity (W)

*Increase Risk of decline*
- Distress Proneness (W)
- Neighborhood social disorder (W)
- $APOE-\varepsilon4$

Data come from published studies from CHAP, MAP, and MARS cohorts.
Lower BMI is related to faster decline

Arvanitakis et. al, *JGMS*, 2018
African Americans have higher BMI, but effect on decline does not vary by race

Arvanitakis et al., JGMS, 2018
Self-reported Experiences of Discrimination

• Discrimination is an important psychosocial stressor with links to adverse health outcomes

• Some, but not all studies have found it partially explains disparities in health
Those with higher perceived discrimination scores performed worse on cognitive tests.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Global cognition</th>
<th>Episodic memory</th>
<th>Perceptual speed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.02 (.004)**</td>
<td>-0.03 (.004)**</td>
<td>-0.04 (.005)**</td>
</tr>
<tr>
<td>Sex</td>
<td>-0.08 (.052)</td>
<td>-0.17 (.064)*</td>
<td>-0.17 (.076)*</td>
</tr>
<tr>
<td>Education</td>
<td>0.07 (.007)**</td>
<td>0.04 (.008)**</td>
<td>0.09 (.010)**</td>
</tr>
<tr>
<td>Discrimination</td>
<td><strong>-0.02 (.010)</strong></td>
<td><strong>-0.03 (.013)</strong></td>
<td><strong>-0.04 (.015)</strong></td>
</tr>
</tbody>
</table>
Discrimination and C-Reactive Protein

Those with higher perceived discrimination scores had more abnormal protein in their blood.

Self-reported experiences of everyday discrimination are associated with elevated C-reactive protein levels in older African-American adults

Tené T. Lewis\textsuperscript{a,*}, Allison E. Aiello\textsuperscript{b}, Sue Leurgans\textsuperscript{c,d,e}, Jeremiah Kelly\textsuperscript{c,d}, Lisa L. Barnes\textsuperscript{c,d,f}

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Lewis et al., 2010
Preliminary Data: Resting State fMRI and Race

- Compared to Whites, African Americans with higher perceived discrimination showed greater connectivity between insula and left caudate.
- Prior work suggests that this network is important for emotional-cognitive processing.

Adjusted for age, sex, education, and cognitive function.
Perceived stress is related to faster decline in cognition. The degree to which a person finds their lives unpredictable, uncontrollable, and overloading is negatively correlated with global cognition over the study years.
Early life residence and cognition

African Americans born in the South perform worse on cognitive function tests than those born in the North.

Lamar et al., in progress
Summary and opportunities to improve our understanding of risk of AD in African Americans

• Longitudinal designs are important in disparities research
• Need to understand which risk factors are important for risk of disease
  – Some conditions more prevalent (e.g., vascular conditions)
  – Social context of a person’s life is important to understand
  – Integrated approach that takes into account interaction of risk and resilience factors, across the entire life course
• Need to increase minority populations in clinical research in general
  – African Americans need to be educated about why research is needed
  – Drivers of disease may be different
• Need studies with biologic outcomes
  – Most studies only describe the differences
  – Limited understanding of biologic mechanisms underlying disparities
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Participants of Rush cohorts and RADC staff
Addressing Health Disparities in People Living with, and at Risk for, Dementia

United Family Caregivers

Supporting African American Caregivers in Milwaukee County

Andrea Garr Dementia Care Specialist
Milwaukee County Department on Aging
United Family Caregivers (UFC)

- Funded by Administration for Community Living (ACL)
- Alzheimer’s Disease Supportive Services Program Grant (ADSSP)
- Emphasis on conducting outreach and providing services to African American caregivers as an underserved population
- An initiative that supports the Wisconsin Dementia Care Redesign
- Two proposed project sites: Milwaukee and Dane counties
- Culturally-competent intervention
- Data collection to gain understanding about why African Americans do not reach out for help at the same rate as whites and when they do, which intervention is more effective
Main Goals

• Increase awareness about dementia and the resources available to help

• Reduce the stigma associated with dementia in the African American community

• Improve access among African-American caregivers to dementia interventions and other dementia-related supportive services

• Reduce burden and improve caregiver well-being, while supporting caregivers’ goal to continue to provide care at home for as long as possible
African Americans in Wisconsin

• Per U.S. Census Bureau state and county QuickFacts, the 2014 estimated African American population for Milwaukee County was 27.2%.

• The African American population increased 9.7 percent since the 2000 Census. Milwaukee County is home to 240,203 African Americans, comprising 69.4 percent of Wisconsin's African American population. This group is the largest racial minority group in Wisconsin.

(Feb 24, 2016 Wisconsin Dept. Health Services)
Prevalence of Cognitive Impairment in Communities of Color

- African-Americans are 2 times (and Hispanics 1.5x) more likely to have dementia than are white Americans
- Onset is often at a younger age than whites

African-Americans and Dementia

• Less likely to have a formal diagnosis

• Higher level of stigma attached to dementia

• Less informed about dementia, the risk factors and the community resources available to help

• Less likely to access resources, services and supports to reduce caregiver stress and improve well-being
African-Americans and Modern Health Care Systems

- Inequities and health disparities across the lifespan for African Americans
- Fear and distrust of modern healthcare systems & interventions due to history of abusive practices
- Lack of awareness and greater stigma around dementia “in my right mind” “I’m not crazy”
- Cultural differences in beliefs, values and expectations around caregiving (for example, honoring elders, making sacrifices and “giving back,” respect, privacy, pride and self-sufficiency)
United Family Caregivers (UFC)

• Intervention (optional)
  • Two different intervention models were used
    • MCC model (Memory Care Connections)
    • UCC model (United Community Center)

• Caregiver Support & Services: All caregivers were provided education, resource referral, assistance with short- and long-term care planning and ongoing support

• Friendly Visitor

• Music and Memory

• Respite
United Family Caregivers

• Data Collection
  • To enable a comparison of the efficacy of two evidence-based interventions (MCC & UCC models)
  • To document what cultural adaptations were necessary within each of the models
  • To document the factors that might facilitate or inhibit African American caregivers access to community supports and services
  • To measure the impact of the provision of respite/companionship care on quality of life and caregiver stress
Outcomes to Date

• Approximately 45 participants enrolled in an intervention
• Usual length of participation was approximately 6 months
• More than 350 families/caregivers served by the program with information, resources, and support
• Outreach activities have touched approximately 1500 people with the primary goal of increasing awareness around dementia and/or dementia-related resources available in the community
UFC Baseline / Follow-up Comparison

Improvement in caregiver well-being:

- Zarit Caregiver Burden – Emotional: Baseline mean 26.75, Follow-up mean 22.91
- Zarit Total Sum: Baseline mean 37.58, Follow-up mean 33.91
- PHQ-9 (a depression scale): Baseline mean 18.33, Follow-up mean 12.56
- Quality of Life measure (source: NYUCI model): Baseline mean 52.5, Follow-up mean 62.33
Caregivers’ Experience

Reasons for not reaching out for help (sooner):

• Lack of awareness about what community supports and services are out there and how it access them

• Lack of awareness about dementia as a neurological disorder and not a part of “normal aging”

• Privacy – don’t want anyone else to know (don’t put business in the street)

• Wanting to honor our elders. Providing care is a way of expressing gratitude for the sacrifices they made on our behalf

• Respect – a desire to have the “permission” or “consent” of the care recipient before the caregiver accesses a community resource

• A belief that the care demands can be handled on their own

• A belief that the resources are “not for us”
The Importance of Establishing Relationship & Building Trust

• Be authentic!
• People are often influenced and/or motivated based upon “relationship”.
• Don’t assume that you know better than your client does about what is needed. When it comes to their situation, they are the expert!
• Ask what services/supports would be most meaningful to the caregiver/family. Help make the connection between the intervention and the caregiver’s stated needs, goals and preferences.
The Importance of Establishing Relationship & Building Trust

• Don’t just “tell” someone (what they need to do). If possible, journey “with” them.

• Don’t make assumptions about financial resources or priorities.

• Don’t make ANY assumptions! Ask! Then, listen!

• Be humble, open and prepared to learn from those you serve. Serving others is often a reciprocal relationship.
A Few Cultural Tendencies as it Pertains to Caregiving:

• Sometimes, it can be a “family affair.” There can often be two or more “primary caregivers” sharing the burden of care.

• It is not uncommon to include several family members, including the person with dementia, in the decision-making process.

• Avoid using terminology such as “respite,” “caregiver burden” and “placement.” Instead, discuss these concepts using terms such as “help” or “break,” “stress” and “planning for when your loved one’s care demands exceed what you can safely provide at home.”
Cultural Values and Long Term Care

• Placement is not for everyone nor every family. Help families to explore all of the possible care options, including 24/7 care at home. Help caregivers create care plans, and contingency plans, that honor their choices, preferences and values and meet their loved one’s increasing care requirements within available resources.
Contact information

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Visit our website at
https://county.milwaukee.gov/EN/Department-on-Aging