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The Clinical and Cultural Challenges of Dementia in African American and Hispanic/Latino Communities

November 17, 2016

Featured Speakers

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Columbia University
- **Teresa Santos, LCSW**
Care Coordinator, Center for the Aging Brain and the
Memory Disorder Clinic, Montefiore Medical Center

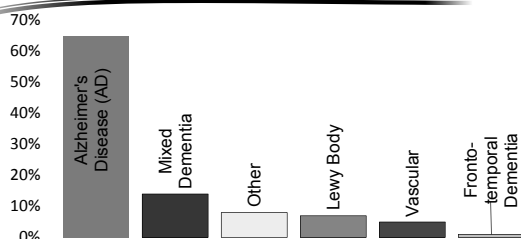
Objectives

- List at least three barriers in the diagnosis of Alzheimer's disease in Hispanics/Latinos and African Americans;
- Explain the principles of a dignified Alzheimer's disease diagnosis relative to Hispanic/Latino and African American communities; and
- Identify the educational resources available to caregivers/families for understanding Alzheimer's disease in African American and Hispanic/Latino patients.

What is Dementia?

- Dementia is a general term for a decline in memory or other thinking skills severe enough to interfere with daily life or social interactions
- Dementia is not one specific disease; it is an overall umbrella term

What is Dementia?



Dementia Symptoms

- Memory loss that disrupts daily function
- Decline in planning or problem solving
- Problems with completing familiar tasks at home, work, or hobbies
- Confusion with time and place
- Visual problems, like difficulty reading, judging distance, and problems with driving

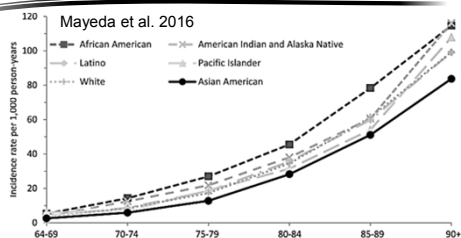
Dementia Symptoms

- New problems with speaking or writing
- Misplacing things
- Decreased judgment and decision-making
- Withdrawal from work or social activities
- Changes in mood and personality

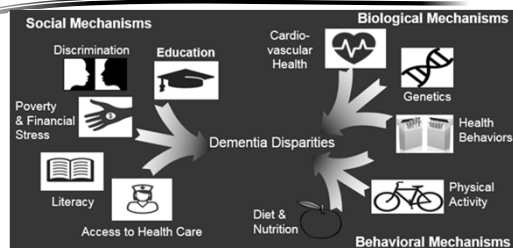
Alzheimer's Disease Impact

- Approx. 390,000 NYS residents have Alzheimer's disease
- Majority of Americans with Alz disease women, as are caregivers
- Older African Americans about 2x as likely, and Hispanics/Latinos about 1½ times as likely, as older whites to have AD/other dementias
- Expected increase in New York State's elderly population will lead to dramatic increases in Alz disease, to 460,000 people by 2025

Evidence of Disparities



Mechanisms of Disparities in Dementia



Stigma, Fear & Shame

- Stigma - "attribute that is deeply discrediting" and causes us to change our view of the person from "a whole and usual person to a tainted and discounted one" (Goffman, 1963)
- Stigma associated with dementia causes discomfort and embarrassment, which can lead to:
 - Delay in diagnosis and care
 - Poor interactions with medical care providers
 - Increased burden on caregivers
 - Social isolation
 - Lack of participation in clinical research

Awareness Among Medical Providers

- Limited knowledge of culture contributes to missed opportunities for medical providers (i.e. PCP's) to make an early diagnosis
 - Education needs to be disseminated amongst all medical providers, not only in larger institutions but also in private practices
- "Cognitive testing in minority ethnic groups can be complicated by demographic factors, including cultural background, language differences and lower educational levels" - www.NIH.gov

Mistrust & Research/Testing

Causes of mistrust of research:

- Lack of cultural and linguistic competency by scheduling, practitioners and billing
- Impact of Tuskegee and other medical abuses
- Legacy of IQ testing among minorities
- Little evidence of benefits of medical research for minorities
 - Intractable disparities
- Recent experiences of discrimination in the medical setting
- Lack of access to information

Under-diagnosis of Alzheimer's Disease

- Only about 50% of those who meet the diagnostic criteria for Alzheimer's disease are diagnosed with dementia by a physician (2015 Alzheimer's Disease Facts and Figures)
- Proportion may be much higher among African Americans and Hispanics/Latinos for a variety of reasons, including
 - stigma, fear and shame
 - recognition of the symptoms
 - degree of contact with the medical community

Cultural & Linguistic Appropriateness

Culturally and linguistically appropriate healthcare providers:

- Use translator services at healthcare facilities
- Provide documents in client's language
- Know how to identify literacy problems when they exist

Benefits of Early Diagnosis

- Some symptoms may be reversible
- Diagnosis is more accurate earlier in the process
- Allows people to make more of their own choices
- Helps families learn about dementia and plan for the future
- Allows for making better use of available resources

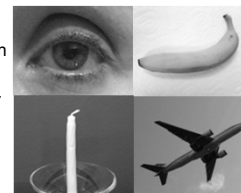
Steps to a Diagnosis

- Thorough medical history
- Testing of memory, thinking, and problem solving
- Physical and neurological exam
- Blood tests and brain imaging to rule out other causes of cognitive decline

Picture-Based Memory Impairment Screen for Dementia (pMIS)

Picture-based Memory Impairment Screen for Dementia (pMIS)

- Validated for use in low education population
- pMIS Score = (2 x Free Recall) + (1 x Cued Recall)
 - Total score= 8
 - Score ≤ 5 is impaired
 - Sensitivity 95%
 - Specificity 99%



Managing Chronic Conditions

- Chronic conditions are difficult and costly to manage
- Because of impairment in memory and other cognitive domains, people with dementia can't manage their own care for other chronic conditions
- People with dementia have more acute health episodes

National & NYS Strategy

- Working together to improve the health and quality of life for individuals, families, and communities by moving the nation from a focus on sickness and disease to one based on prevention and wellness
- Provide comprehensive assessment and created a "language" amongst providers to quickly assess and stratify patients/ caregivers
- Focused on the patient/caregiver as a DYAD

Caregivers

- African American and Hispanic/Latino families commonly distribute caregiving responsibilities among family members
- According to the U.S. Department of Health & Human Services : "There are more than 44 million Americans who provide unpaid care to an elderly or disabled person."
- New York State has the 4th highest number of unpaid caregivers for people living with Alzheimer's disease (1 million) in the country

Caregivers

- Encourage caregivers of impacted individuals to:
- Learn about caregiver support groups
 - Seek help from professional caregiver services: transportation, meal delivery, home health care services
 - Ask for help: family, friends, community/church
 - Make time for fun: see a movie, call friends
 - Take care of themselves: eat right, exercise, meditate
 - If needed, get professional help, including respite services

Principles for a Dignified Diagnosis

- First ever statement written by *people with dementia* on their Alzheimer's diagnosis experience

alzheimer's association
principles for a dignified diagnosis

Principles for a Dignified Diagnosis is the first statement of its kind written by people with dementia on the subject of the Alzheimer diagnosis experience.

- 1. **Talk to me directly, the person with dementia.**
I am the person with the disease, and though my loved ones will be affected, I am the person who needs to know first.
- 2. **Just the truth.**
Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.
- 3. **Just early.**
Helping me get an accurate diagnosis as soon as possible gives me more time to cope and time to help myself and to get information about appropriate clinical trials.
- 4. **Take my concerns seriously, regardless of my age.**
Age does not determine how the Alzheimer's Association should respond to my concerns.

Resources

alz.org | alzheimer's association

Diverse Communities and Alzheimer's

Diversity and Inclusive Statement

At the Alzheimer's Association, diversity is integral and vital to our mission. It is vital to what we do and in a promise we make to those we serve: a team of dedicated professionals understands that valuing diversity and inclusiveness is critical to the success of our mission.

We seek to be inclusive of the millions of people currently affected by Alzheimer's disease, the caregivers and the communities in which they live.



African-American Website

African-Americans are more likely to develop Alzheimer's disease than other populations. Get resources and special reports for this population.

- ▶ African-American Website
- ▶ Find a Clinical Trial

Hispanic Website

Research is beginning to uncover the impact of Alzheimer's among Hispanics. Find resources in Spanish including risk factors, stages and caregiver tips.

- ▶ Hispanic Website
- ▶ Know the 10 Signs Course
- ▶ Find a Clinical Trial

Asian Website

Our Asian resources include dementia-related topics in several languages, including warning signs, Alzheimer's basics and an interactive brain tour.

- ▶ Chinese Website
- ▶ Japanese Website
- ▶ Korean Website
- ▶ Vietnamese Website
- ▶ Find a Clinical Trial

Resources

- Alzheimer's Association, includes local chapters: www.alz.org
- Latinos y el Alzheimer: <http://www.alz.org/espanol/overview-espanol.asp>
- New York State Department of Health:
 - <http://www.health.ny.gov/diseases/conditions/dementia/>
- NIH Natl Inst of Neurological Disorders & Stroke Info Incluye publicaciones en Español: www.ninds.nih.gov/disorders/alzheimersdisease/alzheimersdisease.htm
- NIH Natl Inst on Aging - National Alzheimer's Project Act (NAPA)



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