Thank You to our Sponsors:
- University at Albany School of Public Health
- NYS Department of Health

Conflict of Interest & Disclosure Statements
The planners and presenters do not have any financial arrangements or affiliations with any commercial entities whose products, research or services may be discussed in this activity.

No commercial funding has been accepted for this activity.

Evaluations & CE Credits
Nursing Contact Hours, CME CHES and Social Work credits are available.

Please visit www.phlive.org to fill out your evaluation and complete the post-test.

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

November 17, 2016

Featured Speakers
- Jennifer J. Manly, PhD
  Associate Professor, Department of Neurology, 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?

- 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

Dementia Symptoms

- 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

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
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)
- 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

Resources

- Alzheimer’s Association, includes local chapters: www.ALZ.org
- New York State Department of Health: https://www.health.ny.gov/diseases/conditions/dementia/
- NIH Nall Inst on Aging - National Alzheimer’s Project Act (NAPA)

Resources

- Evaluations & Continuing Education: Nursing Contact Hours, CME and CHES and Social Work credits are available. Please visit www.phlive.org to fill out your evaluation and complete the post-test.
- Conflict of Interest Disclosure Statement: The planners and presenters do not have any financial arrangements or affiliations with any commercial entities whose products, research or services may be discussed in this activity. No commercial funding has been accepted for this activity.

Thank you!
Let us know how you use Public Health Live!

We invite you to take a brief survey on our main program webpage to tell us how you use PHL in your workplace.

Thank you!