

ASSESSMENT OF DEMENTIA AND CAREGIVING FOR AFRICAN AMERICAN ELDERS

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OUTLINE: Dementia Assessment

- BACKGROUND
- ISSUES IN ASSESSMENT OF DEMENTIA
 - Perceptions of Dementia
 - Language Issues
 - Factors Affecting Cognitive Testing
 - Specific Measures and their Efficacy

OUTLINE: Working with African American Caregivers

- Case Example
- African American Caregiver Characteristics
- Perceptions/Attitudes toward Care giving
- Case Example Recommendations

BACKGROUND

- Census projects that by 2033 there will be 77% increase in Caucasian elders and 164% increase in African Americans
- Prevalence of dementia in African Americans is 14-100% higher than in Caucasians
- African Americans elders compared to Caucasian elders with dementia at the time of diagnosis are more likely to have poorer overall health, greater cognitive impairment, greater functional impairment and fewer financial resources (e.g. pensions, health insurance, savings)

ISSUES IN ASSESSMENT OF DEMENTIA



- Perceptions of Dementia
- Language Issues
- Specific Measures and their Effectiveness

PERCEPTIONS OF DEMENTIA

- A recent study found that African Americans compared to Whites were more likely to believe that Alzheimer's was caused by
 - Stress
 - Mental illness
 - God's will
 - Normal aging
 - Alcohol
 - Exposure to toxins

All of the above contribute to delays in seeking assessment or treatment of dementia

Roberts, Akinleye, Hipps et al. Beliefs about prevention and treatment of Alzheimer's disease among African Americans
www.alz.org/preventionconference/pc2005/061905newresearch.asp

LANGUAGE ISSUES



Landrie 1995, African American Acculturation Scale

- Literacy levels and language skills of African American elders vary widely, depending on the individual's educational background.
- Lower levels of acculturation among African American elders are associated with lower scores on tests of verbal and non-verbal abilities (Manly et al. 1998)*
- Levels of educational attainment are not the same as literacy levels.

FACTORS AFFECTING COGNITIVE TESTING



- Stereotype Threat
 - The fear that one's behavior will confirm an existing stereotype of one's own group, leading to impaired performance
- Family's Beliefs About Cognitive Testing
 - Importance
 - Relevance to function
 - Practical advice

SPECIFIC MEASURES AND THEIR EFFECTIVENESS

- Sources of measurement bias for African Americans
 - Limited normative data for minority patients
 - No consistent controls for literacy
 - Culture specific factors related to individual test items
 - Limited use of comprehensive test batteries
 - Most studies have small sample size
 - Absence of randomized selection process

SPECIFIC MEASURES AND THEIR EFFECTIVENESS

- Mattis Dementia Rating Scale
 - 36 item test used to screen for and track cognitive impairment
 - Effect of culture/ethnicity inconclusive
- Mini-Mental State Exam
 - 11 item screening test
 - Results are affected by ethnicity, education and socioeconomic status
 - Sensitivity and specificity is lower in African American elders (Mast 2001)

SPECIFIC MEASURES AND THEIR EFFECTIVENESS

- Blessed Orientation Memory-Concentration Test
 - 6 item test derived from BIMC and highly correlated with MMSE
 - Reduced sensitivity & specificity in African Americans (Fillenbaum 1989)

SPECIFIC MEASURES AND THEIR EFFECTIVENESS

- Short Portable Mental Status Examination
 - 10-item instrument which focuses on orientation but includes items on memory and concentration
 - Normed on community sample of African Americans and non-Hispanic whites
- Boston Naming Test
 - 60 item instrument that tests naming abilities
 - Has been standardized for all ages
 - Lichtenberg et al. 1994 reported ethnic differences in performance but small sample population

ISSUES IN ASSESSMENT OF DEMENTIA

Conclusions



- **Perceptions of Dementia**
 - May lead to delays in assessment and treatment
- **Language Issues**
 - Educational levels and literacy need to be considered
- **Specific Measures and their Effectiveness**
 - Short Portable Mental Status examination is the only measure that that has been normed on community sample of African Americans

WORKING WITH AFRICAN AMERICAN FAMILY CAREGIVERS



CASE EXAMPLE

- Mr. Jones an 83 y/o African American widowed man is brought to a primary care clinic by his daughter and son. The daughter who lives in a neighboring town is concerned that her father has lost 40 lbs in 6 months, sleeps only 2-3 hours per night, and is increasingly confused and disoriented. In the past month he has been in 2 car accidents and has gotten lost going to the grocery store.
- For the past year the daughter had taken over his grocery shopping and his next door neighbor cooks dinner for him twice a week.
- The patient's son who lived in another state isn't convinced that the patient is ill and feels that all he needs is vitamins to give him a little more pep.

AFRICAN AMERICAN CAREGIVERS Characteristics



- Women 40-60 years old with adult children
- Caring for minor children
- Have limited assistance from family and social network
- Unmarried, with limited formal education and fewer financial resources.
- Caring for one or more severely impaired elders

AFRICAN AMERICAN CAREGIVER American Caregivers Characteristics



- Caregivers include family members, friends and neighbors
- Care provided in a collectivist manner
- Large family networks may not be present for practical support
- In the future African Americans maybe accessing formal services more often

AFRICAN AMERICAN CAREGIVERS Reported unmet needs



- Greater financial stress
- More out of pocket costs
- Provide more hours of high intensity care
- Minimal respite available
- Greater barriers to geriatric medical/mental health services

PERCEPTIONS AND ATTITUDES TOWARD CAREGIVING



- Repaying the debt to parents
- Continuing a family tradition of mutual concern
- Setting an example for one's children
- Cultural and community expectations favoring home care may delay entry into formal care

PERCEPTIONS AND ATTITUDES TOWARD CAREGIVING

- AA caregivers report
 - Greater satisfaction and mastery
 - Less subjective burden
 - Less intrusion in their lives
- Greater religiosity
- Lower prevalence of anxiety

PERCEPTIONS AND ATTITUDES TOWARD CAREGIVING



- Caregivers may be reluctant to report caregiver burden
- AA caregivers do suffer negative psychological, economic and physical effects of caring for a person who is impaired
- Burden is a predictor of admission to a long-term care facility

PERCEPTIONS AND ATTITUDES ABOUT CAREGIVING

Hidden signs of Burden

- **Greater prevalence of self reported symptoms and poorer physical health**
- **Engagement in unhealthy behaviors (substance abuse, overeating, lack of exercise)**
- **Some qualitative interviews report recurrent themes of burnout, loss and alienation**

RECOMMENDATIONS



CASE EXAMPLE

RECOMMENDATIONS

- **Respect Family Values**
 - Support home based care as long as possible
 - Educate about dementia symptoms and course of illness
- **Trust building**
 - Self disclosure, active listening, TIME
- **Mobilize the support network**
 - Engage family members, friends, community, church
- **Offer practical information/ resources**
 - SAFE return program, The Complete Bedside Companion, AARP, Family Caregiver Alliance, Alzheimer's Association website, psychoeducation for behavioral management
- **Aggressive case management**
 - Stress the importance of comprehensive medical/mental health assessment and follow up
 - Stress health maintenance for caregivers

RECOMMENDATIONS

- Promote increased minority research in medical, psychological and social aspects of dementia
- Participate in public education and community outreach

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Topics Include:

Part I: Risk of Dementia

Part II: Assessment of Dementia in Diverse Populations

Part III: Treatment and Management of Dementia

Part IV: Working With Families
(14 chapters featuring diverse populations)

Part V: Community Partnerships for Support of Ethnic Elders and Families

Preview Available at: 

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