2013 WEBINAR SERIES
STATE OF THE SCIENCE:
DEMENTIA EVALUATION AND MANAGEMENT AMONG DIVERSE OLDER ADULTS AND THEIR FAMILIES

Sponsored by Stanford Geriatric Education Center in conjunction with American Geriatrics Society, California Area Health Education Centers, & Community Health Partnership

CULTURE AND HOME AND COMMUNITY BASED SERVICES FOR DEMENTIA
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Apr 3, 2013

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Q & A after the presentation

- We will reserve time at the end of the presentation for questions. If you have any questions, please use the “Chat” feature located on the right side of your screen. Please send your chat to everyone if possible.
- After the Q and A, We would like to ask each of the participants to answer the short evaluation questionnaire.

Please complete our short survey. We appreciate your feedback.

NOTE: Continuing Education Participants must complete a final survey in order to receive CEU/CME credit.

“Culture and Home and Community Based Services for Dementia”

About the Presenter

Rosaly Correa de Araujo, M.D., M.Sc., Ph.D.

Currently serves as the Senior Scientific Advisor to the Director of the Division of Geriatrics and Clinical Gerontology, National Institute on Aging, National Institutes of Health. Her work on older adults’ health started early in her career with the development of principles for medication use and inclusion of older adults in clinical studies. These principles were adopted by the International Pharmaceutical Federation. Her own multicultural background, work on global health issues, research on health care disparities and experience with the delivery of culturally competent care have contributed to the health and wellbeing of vulnerable populations. She is an active member of the American Geriatrics Society’s Ethnogeriatrics Committee.

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Prevalence of Dementia

- World: 30 million have dementia
  - Rates likely to double every 20 years
  - > 60% live in developing countries
- United States: 5.2 million older adults ≥ 65 years have Alzheimer’s disease
  - 3.4 million are women
  - 1.8 million are men


- Majority of people with dementia (70 to 81%) live in the community.
  - 75% cared by family and friends.
  - 10 million Americans cared for people with Alzheimer’s disease and other dementias in 2007
- Rates of institutionalization for minority older adults with dementia tend to be lower and reliance in family caregivers is greater.

Source: Brodaty & Donkin, 2009; Nápoles et al., 2010

Case Study

Juan Sanchez, an 88 years old Latino man, migrated to the U.S. in 1950. He married Leslie, an African-American teacher. Mr. Sanchez worked in the sales business until he retired (age 65). He and his wife (age 72) have 2 children and 5 grandchildren. Mr. & Mrs. Sanchez have become frail in the past few years, but continue to live independently in their home and caring for each other. Lately, Mr. Sanchez is having difficulties in managing his activities of daily living, is becoming quite forgetful and confused at times. Their children feel that their mother will not be able to continue to look after their father and proceed to contact the local Community Health Center to verify what can be done to help. Mr. and Mrs. Sanchez are reluctant to visit that center, but agree to do so. Upon arrival, the center’s manager says: “Come in Juan and Leslie, we have all you need here” and continued to describe the services available until interrupted by Mr. Sanchez who stated he had to leave. Mr. & Mrs Sanchez refused to return or use any help.
Case Study

- What went wrong?
- If you were to do Mr. Sanchez's assessment, what information on his cultural background do you already have from this story?
- What additional information on Mr. and Mrs. Sanchez' background would you need to do a good assessment of both Mr. and Mrs. Sanchez?

Perceptions of Dementia in Ethnic Communities

African-Americans

- Key Issues to Consider:
  - Population growth
  - Rates of high blood pressure, high cholesterol, diabetes
  - Barriers:
    - Lack of awareness
    - Cultural issues
    - Socioeconomic disadvantage
    - Limited access to care

Source: Krishnamoorthy et al, 2010; Doorway Thoughts, 2004; Yeo & Gallagher-Thompson, 1996

Perceptions of Dementia in Ethnic Communities

African-Americans

- Attitudes Toward Community Care
  - Less likely to ask for support, lack trust in service providers.
  - Multigenerational households & multiple decision makers.
  - Families: active in the community. Faith communities: ministers, church groups.

- Attitudes Toward Residential Care
  - Long-term care is last resource. Care by extended family & network of friends.
  - Families not aware of care options and resources.

- Attitudes Toward Counseling
  - Families refuse service, believe not needed.
  - Trust is extremely important in delivering services.
  - Less open to physical contact, personal space.
Perceptions of Dementia in Ethnic Communities
Hispanics/Latinos

Key Issues to Consider:
- Population growth.
- Dementia symptoms may come earlier. Diabetes, high blood pressure, vascular diseases.
- Considerable impact on caregivers.

Barriers:
- Cultural
- Language
- Limited access to services
- Lack of awareness

Source: Krishnamoorthy et al., 2010; Doorway Thoughts, 2004; Yeo & Gallagher-Thompson, 1996

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Perceptions of Dementia in Ethnic Communities
Hispanics/Latinos

Attitudes Toward Community Care
- Last resource, only if family unable to care.
- Well accepted if in own language, but generally unaware of services.
- Language barriers preclude services system navigation.
- Lack confidence.

Attitudes Toward Residential Care
- Not acceptable option, “end of the line”.
- Families not fulfilling role, ungrateful, failure, negative views toward daughters.
- Reluctant to residential care as a form of respite.

Attitudes Toward Counseling
- Not aware of, use as face-to-face interaction, prefer in own language.
- Time need to build trust and respect.
- Form of social/info support. Phone counseling seen as difficult/impersonal.

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Perceptions of Dementia in Ethnic Communities
Asian-Americans

Key Issues to Consider:
- Population growth.
- Limitations with health insurance.

Barriers:
- Cultural
- Language
- Limitations with services
- Lack of awareness

Source: Krishnamoorthy et al., 2010; Doorway Thoughts, 2004; Yeo & Gallagher-Thompson, 1996

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Perceptions of Dementia in Ethnic Communities
Asian-Americans

- **Attitudes Toward Community Care**
  - Senior citizens, support and planned activity groups highly valued.
  - Generally welcome available services particularly provided in own language.
  - Ethnic organizations sought for information.

- **Attitudes Toward Residential Care**
  - Still perceived negatively as last resource.
  - More acceptable if in Chinese-specific facility.
  - Respite care becoming more acceptable.

- **Attitudes Toward Counseling**
  - Not used widely, but preferable if in own language.
  - Perceived as not useful for mental illness.
  - Deal with these issues privately.

Ethnic Differences in Caregiving Compared to a Control Group
(Napoles et al., 2010; Finchart & Sorenson, 2006; Gallagher-Thompson et al., 2000)

<table>
<thead>
<tr>
<th></th>
<th>African-Americans</th>
<th>Latinas</th>
<th>Asian-Americans</th>
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<tbody>
<tr>
<td>Psychosocial Health</td>
<td>Better</td>
<td>Worse</td>
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<tr>
<td>Caregiving Appraisals</td>
<td>More positive</td>
<td>More</td>
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<tr>
<td>Coping Appraisals</td>
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<td>Spirituality</td>
<td>Greater</td>
<td>Greater</td>
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<td>Use of Prayers</td>
<td>Greater</td>
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<tr>
<td>Social Support</td>
<td>More</td>
<td></td>
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<tr>
<td>Beliefs about filial responsibility</td>
<td>Stronger</td>
<td>Stronger</td>
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<td>familism</td>
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<tr>
<td>Extended Family Network</td>
<td>Higher value</td>
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<tr>
<td>Institutionalization of relatives</td>
<td>Greater aversion</td>
<td>Greater aversion</td>
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<td>Misconceptions/Stigmatization</td>
<td>Stronger</td>
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Evidence-Based Non-Pharmacological Treatments for People with Dementia and Their Caregivers

- Education, support, case management, respite care, multicomponent interventions for caregivers. Exercise, cognitive training and combination of both are promising practices for people with dementia.
- Awareness and promotion of translation into practices still limited.
- Major gaps:
  - Lacking or limited inclusion of various racial/ethnic groups
  - Lacking sustainable research funding to develop, implement, evaluate
- A classification system is needed to categorize types of treatment/care practices

Sources:
- Rosalynn Carter Institute for Caregiving
  - http://www.rosalynncarter.org/caregiver_intervention_database/
- Maslow K, 2012
  - http://www.springshare.org/content/articles/271202

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Translation Studies of Evidence-based Non-Pharmacological Treatments and Care Practices

- 10 treatments and care practices
- People with Alzheimer’s disease or other dementia and family caregivers.
- Challenges with conducting these studies:
  - Recruiting people
  - Finding community-service providers
  - Funding

Sources: Rosalynn Carter Institute for Caregiving
http://www.caregiverresearch.org/caregiver_intervention_database
Maslow
http://www.agingresearch.org/content/article/detail/2173

BRI Care Counseling
Coping with Caregiving
New York University Caregiver Intervention
Partners in Dementia Care
Reducing Disability in Alzheimer’s Disease
REACH II
Savvy Caregiver
Skills/Care (Environmental Skill Building)
STAR Caregiver
Tailored Activities Program

Cultural Tailoring of Psychosocial Support Interventions

- Systematic Review of Literature
  - 18 of 47 psychosocial interventions
  - 11 considered cultural factors in the design
  - 8 addressed cultural tailoring (REACH)

Source: Nápoles et al., 2010

Psychosocial Support Interventions
African-American Family Caregivers

- Decreased burden and upset with memory problems of care recipient.
- Better affect, more positive ratings of caregiving.
- Greater happiness and self-efficacy for improving assistance with IADLs.

Source: Nápoles et al., 2010
Psychosocial Support Interventions
Latino Family Caregivers

- Decreased burden, depression, negative coping, stress, and behavioral bother.
- Better anger control and self-efficacy.

Source: Nápoles et al., 2010

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Psychosocial Support Interventions
Chinese-American Family Caregivers

- Decreased depression and behavioral bother.

In home behavioral management intervention.
Sensitive to several cultural factors among Chinese-Americans.
Services in the home and language differences.

Source: Gallagher-Thompson et al., 2003

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Key Messages on Culturally Tailored Interventions (1)

- Caregiving increases the risk of adverse mental and physical outcomes.
- Minority caregivers are at higher risk because their care recipients have higher prevalence of dementia-related behaviors, greater physical and functional impairment, and are less likely to use support services.

Source: Nápoles et al., 2010

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Key Messages on Culturally Tailored Interventions (2)

- Literature on minority caregivers is growing but randomized trials of interventions to promote the physical and mental health of these caregivers are limited.
- REACH: improvement of coping skills and quality of life of diverse caregivers.
- Future studies should address socioeconomic and language barriers, and integration of religious coping to some caregiver groups.

Source: Nápoles et al., 2010

Main Barriers to Culturally Competent HCBS for People with Dementia and their Caregivers

<table>
<thead>
<tr>
<th>African-American</th>
<th>Hispanic/Latino</th>
<th>Asian and Pacific Islander</th>
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<tbody>
<tr>
<td>• Lack of awareness</td>
<td>• Cultural issues</td>
<td>• Cultural issues</td>
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<tr>
<td>• Cultural issues</td>
<td>• Limited culturally competent services</td>
<td>• Language</td>
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<tr>
<td>• Limited culturally competent services</td>
<td>• Lack of awareness</td>
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<tr>
<td></td>
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HCBS for People with Dementia and their Caregivers

SPOEs - Single Point of Entry Systems

- One-stop access to information, support, and linkages to local care services.
- Aging and Disability Resource Centers (ADRCs).
- Area Agencies on Aging (AAA).


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Dementia Capable Services

- Skilled at identifying older adults with Alzheimer’s disease and other dementias.
- Knowledgeable of types of services for older adults with dementia and their caregivers.
- Capable of providing linkages to community agencies that can help.

Sources: Alzheimer’s Association & RTI International; Gould & Yuen, 2011.

HCBS for People with Dementia and Their Caregivers

- COMPONENTS OF BEST PRACTICES
  - Culturally appropriate assessment.
  - Culturally competent information for both patients and caregivers.
  - Family and community outreach, education, networking.
  - Link to local resources, services.
  - Support caregivers.

Sources: Alzheimer’s Association & RTI International; National Institute on Aging; Gould & Yuen, 2011; Schneider & Lafrenza, 2012.

HCBS for People with Dementia and Their Caregivers

- Culturally Appropriate Assessment Check List:
  - Appropriate form of address
  - Country of origin
  - Language:
    - Preferred language
    - English language proficiency
    - Whether interpreter is required
    - Other languages
  - Think about the effects of dementia on language!
  - Focus on what is relevant to your case!

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HCBS for People with Dementia and Their Caregivers (2)

**Culturally Appropriate Assessment Check List:**
- Religion
- Cultural/ethnic background
- Education
- Employment
- Migration
- Income source

Focus on what is relevant to your case!

HCBS for People with Dementia and Their Caregivers (3)

**Culturally Appropriate Assessment Check List:**
- Family value and customs
- Health literacy and practices
- Dietary preferences
- Death and dying

Focus on what is relevant to your case!

People with Alzheimer’s Disease and Other Dementia Who Live Alone in the United States

- Racial and Geographic Disparities
  - 800 people with Alzheimer’s disease live alone
  - Racial/ethnic minorities more likely to live alone
  - Older female with less cognitively impaired
  - More likely to live in poverty
  - Have had dementia for a shorter period
  - Fewer impairments in performing daily activities
  - No identifiable caregiver

Nevertheless, still have significant impairments in their ability to perform tasks (financial management, shopping, traveling in the community, housekeeping, preparing meals, taking medications safely).

Source: 2012 Alzheimer’s Disease Facts and Figures

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People with Alzheimer’s Disease and Other Dementia Who Live Alone in the United States

- Risks and Unmet Needs
  - Delayed or missed diagnosis
  - Nursing home placement
  - Self-neglect, help with household chores and self-care
  - Falls, wandering, emergencies, fatal injuries prevention
  - Psychiatric syndrome, recognition and help for psychological distress and other health issues
  - Social isolation and loneliness

Source: 2012 Alzheimer's Disease Facts and Figures

Programs Tested by Community Agencies

- Identification of People with Dementia
  - Gatekeeper Model
- Increasing Community Awareness, Planning, Implementing
- Providing specific services
  - Standing in the Gap
  - Senior Watch Program
- Developing Teams
  - The Vulnerable Isolated Persons Project

Source: 2012 Alzheimer’s Disease Facts and Figures; Gould et al., 2010

Services and Programs for People with Dementia Who Live Alone

- Diagnosing and planning for the future.
- Services use, assistive technology.

Culturally Competent Approach Needed

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Opportunities
National Plan to Address Alzheimer’s Disease

- Goal 1 - Prevent and effectively treat Alzheimer’s Disease by 2025.
- Goal 2 - Enhance care quality and efficiency.
- **Goal 3 - Expand support for people with Alzheimer’s disease and their families.**
- Goal 4 - Enhance public awareness and engagement
- Goal 5 - Improve data to track progress.

Source: National Plan to Address Alzheimer’s Disease, HHS, May 2012.

Opportunities
National Plan to Address Alzheimer’s Disease

- **Goal 3 - Expand supports for people with Alzheimer’s disease and their families**
  - Ensure receipt of culturally sensitive education, training, support materials
  - Enable family caregivers to continue to provide care while maintaining their own health and well-being
  - Assist families in planning for future needs
  - Maintain the dignity, safety and rights of people with Alzheimer’s disease
  - Assess and address the housing needs of people with Alzheimer’s disease

Source: National Plan to Address Alzheimer’s Disease, HHS, May 2012.

Opportunities
Programs Mandated by the 2010 Affordable Care Act

- Section 3021: Health Care Innovation Awards.
- Section 3022: Accountable Care Organizations.
- Section 3026: Medicare Community-Based Care Transitions Program.
- Section 2703: Medicaid Health Homes.
- Section 4302: Data Collection Standards, Disparities.

Source: 2010 Patient Protection Affordable Care Act
Conclusions

- Racial/Ethnic and linguistically challenged communities do not have a consistent understanding of dementia as a disease and the benefits from acknowledging it and seeking support services.
- Stigma or shame associated with dementia is one of the reasons for lack of acknowledgement.
- Social isolation may result when friends and families find it uncomfortable dealing with a person who has dementia.

Conclusions

- Dementia perceptions within a community, however, may change over time.
- How a community understands and approaches dementia affects its identification and delivery of health and support services.
- Numerous causes affect access to HCBS by racial/ethnic groups.
- Access barriers, challenges with cognitive assessment of people from different cultural backgrounds contribute to late diagnosis and receipt of health and support services.
- Culturally competent care is part of the patient/person-centered care approach to dementia.

Conclusions

- Dementia imposes a tremendous burden in those who have the disease and their caregivers.
- Culturally tailored non-pharmacological interventions targeting both people with dementia and their caregivers are limited, but evidence of benefit is mounting.
- Dementia capable organizations can make a difference in providing one single entry door to easy and successful access to information, health and support services for people with dementia and their caregivers.
- Partnerships among federal, state, local, private organizations and interested community groups is critical to make information and services available and deliver the best care possible.
Conclusions

- Opportunities to improve culturally competent care for minorities with dementia and their caregivers are a priority in the National Plan to Address Alzheimer’s Disease and in the 2010 Affordable Care Act.
- Culturally competent HCBS have the potential to facilitate independent living and improve quality of life for both people with dementia and their caregivers.

Q & A

- We now have some time to answer your questions. If you have any questions, please use the “Chat” feature located on the right side of your screen. Please send your chat to everyone if possible.
- After the Q and A, we would like to ask each of the participants to answer the short evaluation questionnaire.

Final Question
Thank You for Participating!