Cultural Competency and Dementia Care

August 16, 2012

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U.S. Population Aged 65 and Older

- **White**:
  - 2010: 80%
  - 2050: 59%

- **African American**:
  - 9% (2010)
  - 12% (2050)

- **Hispanics**:
  - 7% (2010)
  - 20% (2050)

- **Asian**:
  - 4% (2010)
  - 9% (2050)
What We Know

• Over 5 million Americans with Alzheimer’s disease
• African-Americans are almost two times more likely Alzheimer’s and other dementias
• Older Hispanics are at least one and one-half times more likely to have Alzheimer’s and other dementias
Risk Factors

• High blood pressure, diabetes, heart disease and stroke

• Socioeconomic Factors
  – low level of education
  – low income
  – resided in a rural area as a child,

• No known genetic factors can account for the differences in the prevalence
Table 11: Percentage of Americans Aged 55 and Older with Selected Diseases by Race/Ethnicity and Cognitive Status, Health and Retirement Study, 2006

<table>
<thead>
<tr>
<th>Race/Ethnicity and Cognitive Status</th>
<th>High Blood Pressure</th>
<th>Heart Disease</th>
<th>Diabetes</th>
<th>Stroke</th>
<th>Cancer</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>N=9,744</td>
<td>N=4,468</td>
<td>N=3,463</td>
<td>N=1,381</td>
<td>N=2,519</td>
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<tr>
<td><strong>White</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>54</td>
<td>26</td>
<td>17</td>
<td>7</td>
<td>16</td>
</tr>
<tr>
<td>With normal cognition</td>
<td>52</td>
<td>13</td>
<td>16</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>With cognitive impairment</td>
<td>61</td>
<td>41</td>
<td>20</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td><strong>African-American</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>72</td>
<td>24</td>
<td>31</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>With normal cognition</td>
<td>69</td>
<td>19</td>
<td>30</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>With cognitive impairment</td>
<td>80</td>
<td>36</td>
<td>33</td>
<td>25</td>
<td>13</td>
</tr>
<tr>
<td><strong>Hispanic</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>55</td>
<td>17</td>
<td>29</td>
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<td>14</td>
</tr>
</tbody>
</table>

Created from data from the Health and Retirement Study, 2006.™
Diagnosis

- African-Americans and Hispanics are less likely than whites to have been diagnosed with Alzheimer’s or other dementia.
- Long delays between first recognition of symptoms and scheduling of a medical evaluation.
Diagnostic Barriers

• Cost for evaluation
• General distrust of doctors and medical clinics
• Fear the person will lose insurance coverage
• Fear of losing his/her driver’s license
• Perception that Alzheimer’s is a normal part of aging
Use and Cost of Medical Care

• Medicare-funded medical services are substantially higher for African-American and Hispanic beneficiaries aged 65 and older

• Medicare Payments (hospital, physician and home health services)
  – 45% higher for African-Americans
  – 37% higher for Hispanics
Use and Cost of Medical Care

• Hospice Care
  – White Medicare beneficiaries are more likely to use hospice care than African-Americans and Hispanic beneficiaries

• Medications
  – Whites are more likely to use Alzheimer’s medications than African-American and Hispanic people
Five Elements of Becoming Culturally Competent

- Value Diversity/Awareness and Acceptance of Differences
- Self – Awareness
- Dynamics of Differences
- Knowledge of Client’s Culture
- Adaptation of Skills
Ten Steps to Providing Culturally Sensitive Dementia Care

1. Consider each person as an individual
2. Understand the linguistic, economic and social barriers
3. Understand that families are from different cultures
4. Do not place everyone in a particular ethnic group into the same category
5. Respect cultural differences regarding physical distance and contact
Ten Steps to Providing Culturally Sensitive Dementia Care

6. Cultivate relationships with families over time
7. Consider the family’s background and experience
8. Consider the culture’s typical perceptions
9. Understand the impact of a family’s culture
10. Regard the faith community for various cultures as a critical support system
Culturally Sensitive Dementia Care

Black/African-American Culture

• Largest minority group in the U.S.
• Represent 12% of the U.S. population
• 2.7 million African-Americans age 65 and over.
• Projected to be 8.6 million by 2050
Cultural Perspectives of Alzheimer’s Disease

- “Just getting old”
- “Old-timer’s disease”
- “Normal part of aging”
- Tend to downplay significance of cognitive and behavioral changes
- Did not view the changes as the result of illness
Family and Home

• Caregivers hold strong values of responsibility toward the family and the extended family network
• Care is usually provided by extended family, including a network of friends who are considered family
• Elders are respected, obeyed and considered a source of wisdom
• Generations often live in the same home, with care provided to children and elders at the same time
• Likely to keep relative at home longer, prior to placement in nursing home- last resort
• Families may refuse services because they do not believe they need it, in spite of high levels of stress
Barriers to Obtaining a Diagnosis

• Respect for the individual’s independence, dignity and wishes for as long as possible

• Negative perception of health care provider attitudes and behavior
  – Denigrated
  – Devalued
  – Disrespected observations and concerns
  – Dismissed

• Crisis triggers need of being evaluated
Facilitators to Obtaining a Diagnosis

- Informal networking
  - Most influential facilitator
- Clear, unambiguous communication
- Referral to/coordination of support services
- Self education
Getting a Diagnosis

• Less likely to take relative to specialty clinic
• More likely to use neighborhood health clinics, hospital out-patient departments, emergency rooms and public clinics
• May result in fewer opportunities for referral and follow-up
Help Seeking Methods

• Frequently seek support from their faith community, including ministers and church groups
  – Most frequently used coping strategy is prayer
• Caregivers often find solace in their religion, and use it as a means of coping with their feelings about their loved one’s illness.
• Families are typically very private, not sharing concerns with strangers.
<table>
<thead>
<tr>
<th></th>
<th>Hispanics</th>
<th>Vietnamese</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family and Home</strong></td>
<td>- Family is center of most activity and support</td>
<td>- Family is foundation of daily living</td>
</tr>
<tr>
<td></td>
<td>- Care provided by extended family</td>
<td>- Elders are highly respected and obeyed</td>
</tr>
<tr>
<td></td>
<td>- Unlikely to seek out long term care options</td>
<td>- Oppose long-term care – shameful to place in residential care</td>
</tr>
<tr>
<td><strong>Cultural Perspectives</strong></td>
<td>- Normal part of aging</td>
<td>- Mental illness with shame attached</td>
</tr>
<tr>
<td></td>
<td>- Punishment for past sins, bad blood or mental illness</td>
<td>- Shame extends to entire family</td>
</tr>
<tr>
<td></td>
<td>- Don’t seek out services – brings shame to family</td>
<td>- Seen as natural consequence of aging</td>
</tr>
<tr>
<td></td>
<td>- “el mal de ojo”</td>
<td></td>
</tr>
<tr>
<td><strong>Religion and Spirituality</strong></td>
<td>- Most practice Catholicism, some are members of Protestant denominations</td>
<td>- 2/3 practice Buddhism</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Substantial influence on beliefs and lifestyle</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Confucianism and Taoism</td>
</tr>
<tr>
<td><strong>Help Seeking Methods</strong></td>
<td>- Doctors viewed as authority figures</td>
<td>- Language barriers prevent access</td>
</tr>
<tr>
<td></td>
<td>- May receive health care information from Spanish language media</td>
<td>health care information and other services</td>
</tr>
<tr>
<td></td>
<td>- Typically desire personal relationship with service providers</td>
<td>- Family provides most of care – disregard long-term care</td>
</tr>
<tr>
<td></td>
<td>- Older Hispanics often do not drive, transportation issues</td>
<td>- the important virtue and primary duty of respect, obedience, and care for one’s parents and elderly family members.</td>
</tr>
</tbody>
</table>
Challenges in Outreach to People from Diverse Cultures

- Lack of culturally appropriate outreach
- Limited funding
- Failure to engage local leaders
- Failure to use peers
- Language and communication barriers
- Attitudinal barriers
- Shortage of individuals from diverse cultures in disability services professions
- Lack of information about resources
- Lack of coordinated services
Outreach Recommendations

Person-Centered Planning
1. Increase marketing efforts in ethnic communities
2. Use non-traditional outreach methods
3. Conduct focus groups

Hasnain, Sotnik and Ghiloni (2003)
Person-Centered Planning

Marketing Strategies

• Provide examples/stories to explain abstract concepts
• Work with community-based organizations and identify a contact person as a collaborator
• Identify a gatekeeper
• Avoid pushing American values on individualism into practice
• Encourage community ownership
Person-Centered Planning

Family and Cultural Influences

• Spend extra time getting to know the family
• Include extended family members and kin relationships
• Be prepared to spend time with family after the meeting
• Accept refreshments or insistent dinner invitations
Person-Centered Planning

Communication Strategies

• Avoid ethnic stereotyping
• Avoid rushing or giving that impression as it can lead to distancing
• Provide language and other related accommodations
• Avoid the use of jargon and service delivery terminology
Person-Centered Planning

Building Capacity

• Use cultural informants to assist in working with their communities
• Use the media to inform the community
• Use a community liaison to gather information and to generate possible referrals
• Use network of consumers/parents to educate and inform other families
Characteristics of Programs with Culturally Competent Principles/Values

- Clearly defined philosophy and policies
- Staffing patterns that reflect the ethnic makeup of the population served
- Emphasis on training, education and curriculum development to address cultural issues
- Empowerment – most critical element of cultural competence
Hispanic Outreach

Latinos y Alzheimer

Y se estima que el número de Latinos que sufren de la enfermedad de Alzheimer aumentará un 600 por ciento en el año 2050. Aprender sobre la enfermedad para poder mejor cuidar no solamente de su ser querido pero también de usted mismo.

EMPÍEZA AHÍ

10 señales de advertencia de la enfermedad de Alzheimer

Colocar cosas fuera de lugar es una de las 10 señales de advertencia de la enfermedad de Alzheimer. Reconocer los síntomas es el primer paso en hacer algo acerca de ello. Aprenda acerca de 10 señales.

Encuentre su oficina local

24/7 de ayuda 1-800-272-3900 info@alz.org

Latinos y el Alzheimer

Mientras que la ciencia apenas está descubriendo el impacto que la enfermedad tiene en los Latinos, lo que

alzheimer's association
African-American Outreach

Is it Alzheimer’s or just signs of aging?
10 signs every African-American should know

Staying strong
Stress relief for the African-American caregiver

CDC
Centers for Disease Control and Prevention

strong heart and sharp mind
A guide to heart and brain health for African-Americans

What’s good for your heart is good for your brain
A public awareness program of the American Heart Association and Alzheimer’s Association

Larry Nance
Alzheimer’s Champion
# International Diversity

## Inside the Brain: An Interactive Tour

The Brain Tour explains how the brain works and how Alzheimer’s affects it.

**START TOUR ➔**

**Taking the tour:** There are 16 interactive slides. As you view each slide, **roll your mouse over any colored text** to highlight special features of each image. Then, click on the arrow to move to the next slide.

### Take the Brain Tour in...

<table>
<thead>
<tr>
<th>Language</th>
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<th>Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>العربية</td>
<td>Vodić kroz Mozak</td>
<td>中文</td>
</tr>
<tr>
<td>(Arabic)</td>
<td>(Bosnian)</td>
<td>(Chinese)</td>
</tr>
<tr>
<td>Exploration du cerveau</td>
<td>Gehirn-Tour</td>
<td>Il viaggio interattivo nel cervello</td>
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<tr>
<td>(French)</td>
<td>(German)</td>
<td>(Italian)</td>
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<tr>
<td>ブレインツアーは</td>
<td>네 투어</td>
<td>Podróž wyczep mózgu</td>
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<tr>
<td>(Japanese)</td>
<td>(Korean)</td>
<td>(Polish)</td>
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<tr>
<td>A viagem ao cérebro</td>
<td>Посещение головного мозга</td>
<td>Cerebro gira</td>
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<tr>
<td>(Portuguese)</td>
<td>(Russian)</td>
<td>(Spanish)</td>
</tr>
<tr>
<td>Tham quan Nào</td>
<td>(Vietnamese)</td>
<td></td>
</tr>
</tbody>
</table>
International Diversity

alz.org

- Chinese
- Japanese
- Korean
- Vietnamese
- Spanish

24/7 Helpline
1.800.272.3900

Translation Line for Over 140 Languages
Questions?