“Old person dull disease”
Cultural Issues in Dementia
Craig Hou, MD
Common Chinese term for “dementia” or “Alzheimer’s”

老人 痴呆症

lǎo rén chī dāi zhèng

“old person” “dull disease”
What is dementia?

- Impairment in memory
- Associated with
  - Impairment in abstract thinking
  - Impaired judgment
  - Other disturbances of higher cortical function
  - Personality change
- *Interfere with work or usual activities*

DSM-IV, 1994
Behavioral symptoms in Alzheimer’s disease

- Depression
- Irritability, agitation
- Paranoia, delusions, hallucinations
- Insomnia
- Restlessness, wandering
Dementia is a major health issue

- 4 million in U.S. with Alzheimer’s disease
- # of affected people doubles in every 5 year group after age 65
- 360,000 new cases each year
- Estimated 13 million affected by 2050

Hebert, Arch Neurol 2003
Early diagnosis and treatment is important

Early evaluation leads to:

- Better diagnostic accuracy
- Longer stability of cognition and function
- Earlier use of resources
- Less caregiving and family stress
Growing diversity of the elderly

Age > 65 years

2000

2025

2050

U.S. Census Bureau, 2000

White
African-American
Latino
Asian
General issues: Influences of culture on dementia

• Variable pre-morbid level of activity & education
• Symptoms not recognized
  – Belief that dementia is normal aging
• Non-disclosure of symptoms
  – Reluctance to seek assistance
• Traditional approach to caregiving
Under-recognition of memory loss

• Older Japanese-American men in Hawaii
• 21% of family members failed to recognize memory problems in people with dementia
• Of the remaining 79% who recognized memory problems, only half (53%) sought medical attention

Ross, JAMA 1997
Less perceived threat of dementia among non-Whites

<table>
<thead>
<tr>
<th>Scale items</th>
<th>% agreeing (median response)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>African American</td>
</tr>
<tr>
<td>The thought of developing AD scares me.</td>
<td>45 (undecided)</td>
</tr>
<tr>
<td>AD is one of the worst diseases I can think of.</td>
<td>39 (undecided)</td>
</tr>
<tr>
<td>I would like to know if I am going to develop AD.</td>
<td>43 (undecided)</td>
</tr>
<tr>
<td>I am worried I will develop AD.</td>
<td>26 (disagree)</td>
</tr>
<tr>
<td>I occasionally think I will develop AD.</td>
<td>26 (disagree)</td>
</tr>
<tr>
<td>I believe that I will someday develop AD.</td>
<td>15 (disagree)</td>
</tr>
<tr>
<td>I think about developing AD at least once a week.</td>
<td>6 (disagree)</td>
</tr>
</tbody>
</table>

Roberts, Alzheimer Dis Assoc Disord 2003
Reasons for different perception

• Belief that dementia is normal aging
• Less awareness of facts

<table>
<thead>
<tr>
<th>Knowledge of AD/Ethnicity</th>
<th>Percentage of people who responded correctly</th>
<th>Significant difference&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>African American (&lt;i&gt;n = 30&lt;/i&gt;)</td>
<td>Asian (&lt;i&gt;n = 30&lt;/i&gt;)</td>
</tr>
<tr>
<td>1. AD could be contagious (&lt;i&gt;False&lt;/i&gt;)</td>
<td>73.3</td>
<td>46.7&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>2. All humans if they live long enough, will probably develop AD (&lt;i&gt;False&lt;/i&gt;)</td>
<td>66.7</td>
<td>36.7</td>
</tr>
<tr>
<td>3. AD is a form of insanity (&lt;i&gt;False&lt;/i&gt;)</td>
<td>60.0</td>
<td>36.7</td>
</tr>
<tr>
<td>4. AD is a normal process of aging, like graying of hair or wrinkles (&lt;i&gt;False&lt;/i&gt;)</td>
<td>50.0</td>
<td>16.7</td>
</tr>
</tbody>
</table>

Ayalon, Int J Geriatr Psychiatry 2004
<table>
<thead>
<tr>
<th>Cultural Tradition &amp; Symptom Perception</th>
<th>Dementia Caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Filial piety</td>
<td>Resistance to outside help</td>
</tr>
<tr>
<td>Mental illness</td>
<td>Symptoms denied</td>
</tr>
<tr>
<td>Normal aging</td>
<td>Expected role reversal</td>
</tr>
<tr>
<td>Non-biological or psychic process</td>
<td>Proper diet, meditation, etc</td>
</tr>
<tr>
<td>Hopeless situation</td>
<td>Delay in seeking help</td>
</tr>
</tbody>
</table>

Adapted evaluation of dementia in Chinese

• Discussion of problems
  – Memory loss discussed openly
  – Behavioral symptoms brought up indirectly

• Different questions and topics
  – Emphasis on food & meals
  – Navigation around neighborhood

• Avoidance of potentially negative terms
  – “Lao ren chi dai zheng”
Differences between academic & community clinics

<table>
<thead>
<tr>
<th>UCSF</th>
<th>Chinatown Public Health Center</th>
</tr>
</thead>
<tbody>
<tr>
<td>75</td>
<td>67</td>
</tr>
<tr>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>60.2</td>
<td>68.5</td>
</tr>
<tr>
<td>60%</td>
<td>14%</td>
</tr>
<tr>
<td>2%</td>
<td>42%</td>
</tr>
</tbody>
</table>

- Younger
- Less education
- Better test scores
- Less Alzheimer’s
- More non-dementia diagnoses
Summary

• Growing diversity of older age groups make cultural issues in dementia important.
• Cultural beliefs and traditions delay diagnosis and help-seeking in dementia.
• Community-based outreach clinics are improve service and access, despite patient differences.