Implications of Diversity in Dementia Care, Services and Supports

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“Diversity is the realization that the person is much more than a disease, condition, or circumstance.”

Multisystemic Approach to Dementia Care Research
Older Hispanics who have faced cultural or language barriers say these difficulties have led to a variety of complications

Two-thirds who have experienced language or cultural barriers say they led to additional stress or delays in getting needed care.

- Additional stress: 67%
- Delays in getting care: 65%
- Additional effort to overcome barriers: 51%
- Not receiving the needed care: 48%
- Costs higher than expected: 43%
- Receiving low-quality care: 33%
- Needing to travel far for care: 30%
- Receiving the wrong type of care: 26%

AP-NORC; http://www.longtermcarepoll.org/Pages/Polls/Long-Term-Care-in-America-Hispanics-Cultural-Concerns-and-Difficulties-with-Care.aspx
Few think long-term care services in their area will be able to accommodate the cultural needs of older Hispanics

Less than a quarter think nursing homes, assisted living communities, and home health care aides in their area will be able to accommodate the cultural needs of older Hispanics. More have confidence in hospitals.

16% ARE CONFIDENT IN NURSING HOMES
18% ARE CONFIDENT IN ASSISTED LIVING COMMUNITIES
20% ARE CONFIDENT IN HOME HEALTH AIDES
34% ARE CONFIDENT IN HOSPITALS

AP-NORC; http://www.longtermcarepoll.org/Pages/Polls/Long-Term-Care-in-America-Hispanics-Cultural-Concerns-and-Difficulties-with-Care.aspx

Hispanics are less likely to be planning for long-term care needs.†

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>% HISPANICS</th>
<th>% NON-HISPANICS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussing funeral arrangement preferences*</td>
<td>47</td>
<td>68</td>
</tr>
<tr>
<td>Creating a living will or advance directive*</td>
<td>30</td>
<td>55</td>
</tr>
<tr>
<td>Discussing ongoing living assistance preferences*</td>
<td>26</td>
<td>43</td>
</tr>
<tr>
<td>Modifying their home</td>
<td>22</td>
<td>28</td>
</tr>
<tr>
<td>Setting aside money to pay for long-term care*</td>
<td>15</td>
<td>34</td>
</tr>
<tr>
<td>Looking for information about aging</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>Making plans to move into a community or facility designed for older adults</td>
<td>4</td>
<td>8</td>
</tr>
</tbody>
</table>

†Statistically significant difference from non-Hispanics (p<.05).

AP-NORC; http://www.longtermcarepoll.org/Pages/Polls/Long-Term-Care-in-America-Hispanics-Cultural-Concerns-and-Difficulties-with-Care.aspx
<table>
<thead>
<tr>
<th>Study: Jang et al., 2017</th>
<th>Total N=2,609</th>
<th>Chinese n=640 (ref.)</th>
<th>Asian Indian n=574</th>
<th>Korean n=471</th>
<th>Vietnamese n=513</th>
<th>Filipino n=265</th>
<th>Other Asian n=146</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AD LITERACY</strong></td>
<td></td>
<td></td>
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<tr>
<td>Perceived AD knowledge (somewhat/very much) (%)</td>
<td>55.5</td>
<td>38.1</td>
<td>48.8***</td>
<td>70.8***</td>
<td>62.2***</td>
<td>68.3***</td>
<td>61.4***</td>
</tr>
<tr>
<td>Awareness of local AD programs &amp; services (yes/no) (%)</td>
<td>7.8</td>
<td>6.9</td>
<td>4.5</td>
<td>7.1</td>
<td>7.3</td>
<td>16.2***</td>
<td>13.4*</td>
</tr>
<tr>
<td><strong>CULTURAL BELIEFS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AD is a normal process of aging</td>
<td>49.3</td>
<td>49.1</td>
<td>43.0*</td>
<td>48.6</td>
<td>63.2***</td>
<td>42.6*</td>
<td>40.6*</td>
</tr>
<tr>
<td>AD is a matter of fate</td>
<td>14.0</td>
<td>13.3</td>
<td>15.2</td>
<td>11.2</td>
<td>15.0</td>
<td>16.0</td>
<td>14.7</td>
</tr>
<tr>
<td>Not right to place family member with AD in nursing home</td>
<td>30.0</td>
<td>27.1</td>
<td>35.8**</td>
<td>15.8***</td>
<td>36.1**</td>
<td>38.0**</td>
<td>31.4</td>
</tr>
<tr>
<td><strong>OUTCOME</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Plans for possibility of AD</td>
<td>11.6</td>
<td>8.6</td>
<td>2.3***</td>
<td>12.2*</td>
<td>25.2***</td>
<td>14.0*</td>
<td>7.0</td>
</tr>
</tbody>
</table>

*The LGBT community has stepped up in the past to address coming out, AIDS, and civil rights. The next wave has to be aging.*

63-year-old gay man

- Discrimination in continuum of care & social services
- Low access to senior centers & meal programs
- Denial of healthcare or received inferior care
- Victimization and threats of disclosure of sexual and gender identity

Retooling the Provider & Scientific Workforce
African Americans

(Gaskin et al., 2013)

Values ➔ Rights ➔ Thrive

Transform provider and scientific workforce, education, & training programs

Increase number of providers and scientific workforce across systems

Integrate African-American centric beliefs and values, beliefs, preferences for care

Collaboration between key informants & programs with expertise with African Americans care AND dementia care training programs

Recommendations

- Increase **AD and dementia research funding** to further investments in diversity-focused research on care, services and supports.

- Coordinate public awareness & outreach efforts with **culturally tailored** brain health messaging and information on health, long-term care, and community-based services.

- Improve access to **quality care, services and supports in multiple languages**, for at-risk or underserved groups, geographical regions, etc.

- Grow the enrollment of underrepresented groups in clinical trials and services research through recruitment strategies and study designs that better reflect community and organizational realities.
Recommendations (cont.)

- Recruit and train a more diverse provider and scientific workforce to address delays in diagnosis, improve treatment, and quality care, supports, and services.

- Decrease the gap in translation of research to sustained practice based on latest findings in dissemination, implementation, and improvement sciences.

- Examine large-scale policies that promote person-, family-, and community-centered care across multiple systems: educational; employment/workplace; economic; health and long-term care; environmental; immigration; etc.