The South Carolina Alzheimer's Disease Registry: A Unique Asset for Statewide Surveillance and Research
Presenters

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- Arnold School of Public Health at USC
Presentation Outline

• South Carolina Alzheimer’s Disease Registry
  • Background
  • History and goals
  • Data collection procedures
• Results from 2018 Annual Report
• Strengths of the Registry
• In 2017, the percentage of those 65 years and older in SC was estimated to be 17.2% of the total population

• By 2030, it is estimated that 1.1 million South Carolinians will be over 65 representing 1 in 5 residents.

• An estimated 5.4 million people in the U.S. are currently living with Alzheimer’s disease (AD)

• By 2050, the number of people age 65+ with AD may nearly triple to a projected 13.8 million

Sources: US Census Bureau and Alzheimer’s Association
Registry History

- The SC Alzheimer's Disease Registry was founded in 1988
- Includes data about individuals with Alzheimer's disease and related dementias (ADRD)
- One of only three population-based state AD registries in the nation
Registry Goals

• Maintain the most comprehensive state registry of ADRD in the nation
• Provide disease prevalence estimates to enable better planning for social and medical services
• Identify differences among groups
• Help caregivers for individuals with ADRD
• Foster ADRD research
*Duplicates* occur because individuals often use more than one name, social security number, or other identifying information when using health or social services.
Identifying Registry Cases

- Alzheimer’s disease (AD)
- Vascular dementia
- Mixed dementia (AD + Vascular dementia)
- Dementia in other medical conditions
  - e.g., alcohol/drug-induced dementia, Parkinson’s disease, dementia with Lewy bodies
  - conditions (e.g., HIV) + a dementia code
Information in the Registry

- Diagnosis (ADRD type)
- Sociodemographic Information
  - Age
  - Gender
  - Race
- Location
  - Facility
  - Community
  - Unknown
- Contact information for caregiver (if available)
Registry Legislation

➢ Authorized/established by state law in 1990

➢ Grants permission for Registry to contact cases and caregivers

➢ Establishes an advisory committee for the Registry
2018 Annual Report Summary

• 93,310 individuals were living with ADRD in 2014

• Based on the Registry and US Census estimates:
  • 11% of South Carolinians age 65+ have ADRD
  • 44% of South Carolinians age 85+ have ADRD

• 63% of South Carolinians with ADRD are women

• African Americans are at notably higher risk of an ADRD diagnosis than are non-Hispanic whites
  • 20% of South Carolinians age 65+ are African American
  • African Americans represent 28% of Registry cases
Age (in years, percent total)

- Under 65: 10%
- 65-74: 21%
- 75-84: 30%
- 85+: 39%
Type of ADRD

• 58% had a diagnosis of AD
• 12% had a diagnosis of Vascular dementia
• 4% had a diagnosis of Mixed dementia
• 26% had a dementia related to other medical conditions
## Type of ADRD

<table>
<thead>
<tr>
<th>Dementia in Other Medical Conditions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other cerebral degenerations</td>
<td>15,303</td>
</tr>
<tr>
<td>Dementia with other conditions</td>
<td>7,079</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies</td>
<td>2,343</td>
</tr>
<tr>
<td>Alcohol dementia</td>
<td>1,734</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>1,725</td>
</tr>
<tr>
<td>HIV/AIDS dementia</td>
<td>192</td>
</tr>
<tr>
<td>Frontotemporal</td>
<td>170</td>
</tr>
<tr>
<td>Drug-induced dementia</td>
<td>65</td>
</tr>
<tr>
<td>Pick’s disease</td>
<td>55</td>
</tr>
<tr>
<td>Chronic Traumatic Encephalopathy</td>
<td>25</td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td>24</td>
</tr>
<tr>
<td>Organic brain syndrome</td>
<td>14</td>
</tr>
<tr>
<td>Creutzfeldt-Jakob disease</td>
<td>8</td>
</tr>
<tr>
<td>Traumatic Brain Injury Dementia</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total (N)</strong></td>
<td><strong>22,951</strong></td>
</tr>
</tbody>
</table>
# Type of ADRD* by Age

<table>
<thead>
<tr>
<th>Age</th>
<th>AD N</th>
<th>AD %</th>
<th>Vascular N</th>
<th>Vascular %</th>
<th>Mixed N</th>
<th>Mixed %</th>
<th>Other N</th>
<th>Other %</th>
<th>Total N</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>3,446</td>
<td>7</td>
<td>1,481</td>
<td>14</td>
<td>166</td>
<td>5</td>
<td>4,255</td>
<td>19</td>
<td>9,348</td>
<td>10</td>
</tr>
<tr>
<td>65 - 74</td>
<td>9,730</td>
<td>18</td>
<td>2,500</td>
<td>23</td>
<td>665</td>
<td>20</td>
<td>5,692</td>
<td>25</td>
<td>18,587</td>
<td>21</td>
</tr>
<tr>
<td>75 - 84</td>
<td>16,298</td>
<td>31</td>
<td>3,325</td>
<td>30</td>
<td>1,147</td>
<td>34</td>
<td>6,512</td>
<td>28</td>
<td>27,282</td>
<td>30</td>
</tr>
<tr>
<td>85 +</td>
<td>23,513</td>
<td>44</td>
<td>3,547</td>
<td>33</td>
<td>1,405</td>
<td>41</td>
<td>6,517</td>
<td>28</td>
<td>34,982</td>
<td>39</td>
</tr>
<tr>
<td>Total</td>
<td>52,987</td>
<td>59</td>
<td>10,853</td>
<td>12</td>
<td>3,383</td>
<td>4</td>
<td>22,976</td>
<td>25</td>
<td>90,199</td>
<td>100</td>
</tr>
</tbody>
</table>

*Note. AD=Alzheimer’s disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer’s disease and Vascular dementia; Other=dementia in other medical conditions.*
Registry Cases by Gender and Type of ADRD*

*Note. AD=Alzheimer’s disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer’s disease and Vascular dementia; Other=dementia in other medical conditions.
ADRD Prevalence by County

ADRD Prevalence for Individuals 50+, 2014

Legend
Prevalence per 100
- 2.6%-3.4%
- 3.5%-4.4%
- 4.5%-5.4%
- 5.5%-6.4%
- 6.5%-7.3%

Data from SC Alzheimer’s Disease Registry (2014) and Census Annual County Population Estimates (2010-2016)
Registry Cases by Age Group and Place of Residence

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Community</th>
<th>Nursing Facility</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;65</td>
<td>79</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>65-74</td>
<td>74</td>
<td>19</td>
<td>7</td>
</tr>
<tr>
<td>75-84</td>
<td>70</td>
<td>24</td>
<td>6</td>
</tr>
<tr>
<td>85+</td>
<td>64</td>
<td>31</td>
<td>5</td>
</tr>
</tbody>
</table>

Place of Residence:
- Community
- Nursing Facility
- Unknown
Deaths among Registry Cases by Type of ADRD*

- Of those people identified with ADRD since 1988, a total of 168,885 have died.

<table>
<thead>
<tr>
<th>Years in Registry</th>
<th>AD N</th>
<th>AD %</th>
<th>Vascular N</th>
<th>Vascular %</th>
<th>Mixed N</th>
<th>Mixed %</th>
<th>Other N</th>
<th>Other %</th>
<th>Total N</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2 years</td>
<td>59,898</td>
<td>55</td>
<td>12,118</td>
<td>59</td>
<td>4,875</td>
<td>53</td>
<td>18,129</td>
<td>60</td>
<td>95,020</td>
<td>56</td>
</tr>
<tr>
<td>2-5 years</td>
<td>30,294</td>
<td>28</td>
<td>5,152</td>
<td>25</td>
<td>2,790</td>
<td>31</td>
<td>7,059</td>
<td>24</td>
<td>45,295</td>
<td>27</td>
</tr>
<tr>
<td>5+ years</td>
<td>18,951</td>
<td>17</td>
<td>3,354</td>
<td>16</td>
<td>1,473</td>
<td>16</td>
<td>4,792</td>
<td>16</td>
<td>28,570</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>109,143</td>
<td>65</td>
<td>20,624</td>
<td>12</td>
<td>9,138</td>
<td>5</td>
<td>29,980</td>
<td>18</td>
<td>168,885</td>
<td>100</td>
</tr>
</tbody>
</table>

*Note. AD=Alzheimer’s disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer’s disease and Vascular dementia; Other=dementia in other medical conditions.
Strengths of the Registry

• Statewide population-based registry
• Multiple data sources with a history of validity checks
• Diagnosis by physicians of all specialties
• Potential for expanded research
The South Carolina Alzheimer's Disease Registry is a unique resource for statewide ADRD surveillance and research, and it is an asset for community planning in both health and social services.
If you are interested in requesting data or would like to learn more about the Registry contact us at:

osainfo@mailbox.sc.edu