2007

2007 Annual Report

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~ ANNUAL REPORT ~

South Carolina
ALZHEIMER'S DISEASE REGISTRY

2007

*Unless otherwise noted, data included in this report cover the period January 1, 2005 through December 31, 2005, the most current period with available and comprehensive data.
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~ Executive Summary ~

The Arnold School of Public Health of the University of South Carolina (USC), in cooperation with the South Carolina (SC) Department of Health and Human Services, the SC Department of Mental Health, the USC School of Medicine, and the SC Office of Budget and Control, maintains a statewide Registry of SC residents diagnosed with Alzheimer's disease or related disorders.

This report uses the abbreviation ADRD to indicate "Alzheimer's disease or related disorder." The "related disorders" refer to dementias associated with vascular disease, mixed dementia and with other medical conditions such as Parkinson's disease. Where we refer specifically to "Alzheimer's disease" (AD), we limit the analysis to individuals with AD only.

Since January 1, 1988, the Registry has identified 125,772 cases of ADRD. During calendar year 2005, the Registry maintained information on 56,754 individuals alive on January 1, 2005.

Registry Goals:

- Maintain the most comprehensive and accurate state registry of ADRD in the nation.
- Provide disease prevalence estimates to enable better planning for social and medical services.
- Identify differences in disease prevalence among demographic groups.
- Help those who care for individuals with ADRD.
- Foster research into risk factors for ADRD.

Registry Overview:

Of South Carolinians with diagnosed ADRD:

- 65% have Alzheimer's disease.
- 16% have a dementia due to stroke.
- 19% have a dementia related to other chronic conditions.
- 36% live in an institution.
- 66% are women.
- 33% are African American.
- 39% of those with AD are 85 years or older.
Executive Summary

Population Prevalence of ADRD, South Carolina, 2005:

Based on the Registry and population estimates from the United States Census,

- 9% of South Carolinians age 65 or over have ADRD.
- 30% of South Carolinians age 85 or over have ADRD, an increase of 3% over last year.
- Alzheimer’s disease prevalence rates vary notably among SC counties.
- African Americans are at notably higher risk of an Alzheimer’s disease diagnosis than are non-Hispanic whites. At ages 65 and older, for example, African American South Carolinians are about twice as likely to have ADRD as are non-Hispanic whites.

South Carolina ADRD Projection:

Based on methods commonly used to estimate prevalence, the number of South Carolinians with Alzheimer’s disease and related disorders will increase by 150% in the next fifteen years. (see Figure 2)

Office for the Study of Aging Promotes Brain Health:

In partnership with the Centers for Disease Control and Prevention, the Alzheimer’s Association, the National Institutes of Health, the AARP, and other brain health partners, OSA is helping to lead efforts to reduce the future prevalence of Alzheimer’s Disease and Related Disorders in South Carolina and the nation.

Other Activities of the Office for the Study of Aging:

In addition to maintaining the Registry and conducting research using this valuable state resource, the Office for the Study of Aging works to provide South Carolina’s older persons and their families with access to quality, reliable health and long term care service delivery systems. We:

- Provide education on ADRD management.
- Develop training on long term care issues.
- Contribute technical assistance for programs for older South Carolinians.
- Help to evaluate programs for older South Carolinians.
- Conduct research on aging issues.
- Promote brain health.
~ Acknowledgments ~

The South Carolina Alzheimer's Disease Registry has developed into one of the nation's most important resources for understanding ADRD. The growth and development of the Registry and the related research program in aging at the Office for the Study of Aging has been due to the support of many individuals and organizations. We particularly want to acknowledge the contribution of:

- The Arnold School of Public Health at USC, for core support;
- The Office of Research and Statistics of the State Budget and Control Board, for its extensive cooperation in maintaining the Registry;
- The USC School of Medicine (Department of Medicine, Division of Geriatrics), for providing collaboration;
- The SC Department of Mental Health, for access to data;
- The SC Department of Health and Human Services, for core support and access to data;
- The SC Department of Health and Environmental Control, Vital Records and Public Health Statistics; and
- The Lieutenant Governor's Office, Office on Aging, for their continued support.
Introduction

Alzheimer’s Disease: The Insidious and Progressive Disease with Great Costs to South Carolina

“The U.S. Census Bureau predicts the 65 and older population will grow from one in eight Americans today to one in six by 2020. The mature adult population will total 53.7 million, representing a 53.8 percent increase over today’s 34.9 million mature adult population.”1 South Carolina’s older residents show the same trends. Adults 65 and older in South Carolina showed a 22.3% growth rate between 1990 and 2000. In 2000, South Carolina boasted 485,333 residents 65 and older, a number that has increased by approximately 100,000 each decade from 1970-2000.2

With this increase in the aging population comes an increase in age related diseases. Alzheimer’s Disease and Related Disorders (ADRD) are a major robber of quality of life among this older population as the prevalence of Alzheimer’s Disease (AD) doubles every five years beyond age 65.”3

ADRD is an umbrella term that encompasses many types of cognitive impairment. The Diagnostic and Statistical Manual of Mental Disorder (Third Edition) (DSM-III-R) defines Alzheimer’s disease as an impairment of intellectual abilities such as memory, abstract thinking, judgment, other disturbances of higher cortical functions and behavior and personality change severe enough to interfere significantly with everyday activities. Alzheimer’s disease (AD) is a type of ADRD with an insidious onset and a generally progressive deteriorating course for which all other specific causes have been excluded. Other types of ADRD include those related to stroke, mixed dementia (with both Alzheimer’s and Vascular dementia) and dementias associated with medical conditions such as Parkinson’s Disease, Huntington’s Disease, Dementia with Lewy Bodies (DLB), AIDS, and alcohol or drug abuse.

This report covers calendar year 2005 (those alive on Jan 1, 2005), the most recent full year of data available from all reporting sources. Registry cases in this report are defined as Alzheimer’s Disease (AD), vascular ADRDs (Vascular), mixed dementias (Mixed) and ADRDs in medical conditions (Other). Registry cases are identified by location of residence, either in a facility (nursing facilities, residential care facilities), in the community (home or adult day care) or in an unknown location. Exclusions of some demographic information are due to the voluntary method of data collection. It should be noted that many cases may be identified at a late stage of the disease rather than at onset. This affects the time from entry into the Registry until death.

This Alzheimer’s Disease Registry Annual Report provides information about persons with ADRD in South Carolina for the calendar year 2005.

1 The South Carolina Mature Adults Count Report.
2 US Bureau of the Census
Scope of the Problem

The prevalence of ADRD in the United States in 1989, was estimated to be over 10 percent among persons aged 65 and older, and about 47 percent among those aged 85 and older.\(^4\)

In 1990, South Carolina residents 75 years and older were 4.3% of the total population; their numbers totaled 151,000. By 2000, there were 215,000 South Carolina residents 75 years and older, representing 5.4% of the total population or a 42% increase.\(^5\)

We cannot know the total number of persons with ADRD in South Carolina with certainty. National estimates of ADRD prevalence vary widely from one study to another. Individuals who have mild forms of the disease that are not yet diagnosed do not appear in our Registry data. Previous studies suggest that the number of individuals with ADRD may be nearly 50% greater than the number with diagnosed ADRD.\(^6\) What we do know is that the South Carolina Alzheimer's Disease Registry is the best population-based Registry of ADRD in the country. There are only two other such registries in existence. One, in New York, is in practice limited to records from in-patient hospital stays.\(^7\) A second, in West Virginia, is just now under development. Our South Carolina Registry uses data from a wide variety of sources to capture as many diagnoses as possible. These sources are shown in Figure 1.

Figure 1
Registry Data Sources
South Carolina Alzheimer's Disease Registry, 2005

*Duplicates occur because individuals often use more than one name, social security number, or other identifying information when using health or social services.

---


\(^5\) South Carolina Matured Adults Count Report.


~Projections of Alzheimer’s Disease in South Carolina~

Figure 2
Prevalence Projections through 2030
Alzheimer’s Disease and Related Disorders in South Carolina, 2004


The projections are based on age- and gender-specific prevalence rate estimates from the Registry. The projections assume a constant ADRD rate over time. This approach is consistent with generally accepted national ADRD projections. However, this approach may over- or under-estimate the actual growth of ADRD in South Carolina. As obesity, hypertension, and diabetes are known risk factors for ADRD, notably increasing rates of these conditions in our population may raise actual rates considerably above those suggested by the projections. Similarly, minorities have higher rates of ADRD; if the proportion of South Carolina seniors who are minorities grows notably, this would also be likely to raise the rates above the projections shown in the figure. On the other hand, our state may be enjoying immigration of relatively highly educated seniors, with relatively high incomes. These individuals would be likely to have lower ADRD risks than the general U.S. population, and considerably lower risks than the SC population. A larger proportion of these individuals with lower ADRD risks in our senior population would tend to moderate the rise in ADRD prevalence.

It should be noted that the prevalence projections are for the Registry. The population prevalence of ADRD will be higher than the projection shown in the figure in any given year, because the Registry includes records only for individuals diagnosed by Registry data sources. The Registry includes records for individuals using health care and social services. Individuals who do not use such services, primarily those with early stages of cognitive impairment, are not represented in the Registry or in the projections.
History of the Registry

The Alzheimer's Disease Registry, previously the Statewide Alzheimer's Disease and Related Disorders Registry, was established in 1988 to record specific information about South Carolinians who develop Alzheimer's disease and related disorders. The registry is currently located in The Arnold School of Public Health, USC. From July 1993 to May 1996, the Registry was located at the James F. Byrnes Center for Geriatric Medicine, Education, and Research, a geriatric research hospital jointly sponsored by the USC School of Medicine and the SC Department of Mental Health. This project has received widespread support and interest from the academic community, lay support groups, state agencies, and other public and private organizations as part of a statewide effort to study the growing impact of Alzheimer's disease on the health and welfare of older South Carolinians. On May 31, 1990, Governor Carroll A. Campbell, Jr., signed a state law authorizing the Registry. This law (R653, H4924) amended Title 44, Code of Laws of South Carolina 1976, relating to health, by adding Chapter 36 establishing a voluntary Statewide Alzheimer's Disease and Related Disorders Registry in the Arnold School of Public Health. The law has strict confidentiality requirements but does allow registry staff to contact the families and physicians of persons diagnosed as having Alzheimer's disease or a related disorder to collect relevant data and to provide information about public and private health care resources available to them.
CHARACTERISTICS OF ADRD IN SOUTH CAROLINA BASED ON 2005 ALZHEIMER’S DISEASE REGISTRY DATA

Since January 1, 1988, 125,772 cases of Alzheimer’s disease and related disorders (ADRD) have been identified in South Carolina. This report describes demographic characteristics and medical information for the 56,754 cases alive on January 1, 2005 displayed by type of ADRD.

Type of ADRD

Among the 56,754 current Registry cases, 65 percent had a diagnosis of Alzheimer’s disease, and 12 percent had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both Alzheimer’s disease and vascular dementia the case was reported in a Mixed dementia category. Four percent of all Registry cases are in the Mixed category. The additional 19%, for the total number of “Other Conditions,” had a dementia related to other medical conditions, such as Parkinson’s disease (see Table 2 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

More registry cases resided in the community (57%) than in a nursing facility (35%) or unknown locations (8%) (Figure 3). As shown in Figure 4, the distribution of the types of ADRD was similar in the community and in nursing facilities.

Table 1
Registry Cases by Dementia Type and Community, Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2005

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Community</th>
<th>Nursing Facility</th>
<th>Unknown</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>20,899</td>
<td>65</td>
<td>13,706</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2,469</td>
<td>58</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>3,633</td>
<td>11</td>
<td>2,812</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>359</td>
<td>8</td>
</tr>
<tr>
<td>Mixed dementia</td>
<td>1,116</td>
<td>3</td>
<td>1,008</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>76</td>
<td>2</td>
</tr>
<tr>
<td>Other conditions</td>
<td>6,670</td>
<td>21</td>
<td>2,629</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1,377</td>
<td>32</td>
</tr>
<tr>
<td>Total</td>
<td>32,318</td>
<td>57</td>
<td>20,155</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4,281</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>56,754</td>
</tr>
</tbody>
</table>
~ Location and ADRD in South Carolina (continued) ~

Figure 3
Registry Cases by Community, Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2005

![Pie chart showing distribution of cases by location: Community 57%, Nursing Facility 35%, Unknown 8%]

Figure 4
Registry Cases in Community, Nursing Facility or Unknown Location, by Dementia Type
South Carolina Alzheimer's Disease Registry, 2005

![Bar chart showing distribution of cases by dementia type and location:
- Community:
  - ALZ: 65
  - VAS: 11
  - MIX: 3
  - OTHER: 21
- Nursing Facility:
  - ALZ: 68
  - VAS: 14
  - MIX: 5
  - OTHER: 13
- Unknown:
  - ALZ: 58
  - VAS: 8
  - MIX: 2
  - OTHER: 32]
In addition to Alzheimer’s disease, the Registry tracks dementias that are associated with other medical conditions, such as Parkinson’s disease, alcohol and drug abuse, dementia with Lewy Bodies and HIV/AIDS. In the 2005 Registry, there are 10,676 persons with a dementia associated with one of these conditions, who do not also have a diagnosis of Alzheimer’s disease or vascular dementia. Nine percent of them have dementia associated with Parkinson’s disease, and 57% have an indication of dementia associated with some other medical condition (please see Table 2 footnote). The cell counts in the table are not mutually exclusive, due to the fact that some persons’ records indicate that they have more than one medical condition. A few individuals have as many as three such conditions.

Dementia with Lewy Bodies (DLB) is the second most common cause of dementia, after Alzheimer’s disease. Estimates suggest that DLB accounts for approximately 20% of all dementia cases. The public’s lack of familiarity with the disease and its low frequency in the SC Alzheimer’s Disease Registry can partially be attributed to the fact that an ICD-9-CM code for DLB has only been available since 2003.

Dementia with Lewy Bodies is a progressive brain disease characterized by abnormal round structures in the areas of the brain that control thinking and movement. Hence, DLB causes symptoms similar to those commonly associated with both Alzheimer’s disease and Parkinson’s disease. Like Alzheimer’s disease, it can cause confusion, memory loss, and depression, while other possible symptoms are slowed movement, rigid muscles, and tremors, symptoms normally found in those with Parkinson’s disease. However, unlike persons affected by Alzheimer’s or Parkinson’s disease, those with DLB may have hallucinations and experience day-to-day changes in their symptoms.

Currently, there is no cure for Dementia with Lewy Bodies. Medications used to treat Alzheimer’s disease, Parkinson’s disease, and depression are typically used to manage DLB symptoms.

### Table 2

<table>
<thead>
<tr>
<th></th>
<th>Under 65</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol dementia</td>
<td>17%</td>
<td>7%</td>
<td>2%</td>
<td>1%</td>
<td>904</td>
</tr>
<tr>
<td>Drug-induced dementia</td>
<td>1%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>53</td>
</tr>
<tr>
<td>Organic brain syndrome</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>6</td>
</tr>
<tr>
<td>Other cerebral degenerations</td>
<td>30%</td>
<td>41%</td>
<td>34%</td>
<td>22%</td>
<td>4,020</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>2%</td>
<td>7%</td>
<td>10%</td>
<td>10%</td>
<td>898</td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>13</td>
</tr>
<tr>
<td>HIV/AIDS dementia</td>
<td>5%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>175</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>1%</td>
<td>5%</td>
<td>6%</td>
<td>4%</td>
<td>509</td>
</tr>
<tr>
<td>Dementia with other conditions</td>
<td>45%</td>
<td>38%</td>
<td>48%</td>
<td>63%</td>
<td>6,163</td>
</tr>
</tbody>
</table>

* Dementia with other conditions includes those with an ICD-9-CM code in 294.1(dementia in conditions classified elsewhere) on their medical record. This code is listed along with the ICD-9-CM code of the dementia-causing condition. However, the dementia-causing condition may not be identifiable from the record, and therefore, may not be in the above table.

Age and ADRD in South Carolina

Table 3 shows that 39% of persons with Alzheimer’s disease are 85 years of age or older. Figure 5 shows this information graphically for all dementias included in ADRD, with 35% of persons over 85 years of age. Figure 6 indicates that for people with ADRD, over half of those 75 years of age or older are being cared for in the community. Living in the community is the location of choice for the individual and family. However, as Figure 6 indicates, with age comes an increase in movement to nursing facilities.

Table 3
Registry Cases by Age Group and Dementia Type
South Carolina Alzheimer’s Disease Registry, 2005*

<table>
<thead>
<tr>
<th>AGE</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>2,251</td>
<td>6</td>
<td>896</td>
<td>14</td>
<td>128</td>
<td>6</td>
<td>2,208</td>
<td>22</td>
<td>5,483</td>
<td>10</td>
</tr>
<tr>
<td>65 – 74</td>
<td>6,070</td>
<td>17</td>
<td>1,353</td>
<td>21</td>
<td>410</td>
<td>19</td>
<td>2,154</td>
<td>22</td>
<td>9,987</td>
<td>18</td>
</tr>
<tr>
<td>75 – 84</td>
<td>13,849</td>
<td>38</td>
<td>2,326</td>
<td>35</td>
<td>904</td>
<td>41</td>
<td>3,123</td>
<td>32</td>
<td>20,202</td>
<td>37</td>
</tr>
<tr>
<td>85 +</td>
<td>14,020</td>
<td>39</td>
<td>2,020</td>
<td>31</td>
<td>744</td>
<td>34</td>
<td>2,428</td>
<td>24</td>
<td>19,212</td>
<td>35</td>
</tr>
<tr>
<td>Total</td>
<td>36,190</td>
<td>66</td>
<td>6,595</td>
<td>12</td>
<td>2,186</td>
<td>4</td>
<td>9,913</td>
<td>18</td>
<td>54,884</td>
<td>100</td>
</tr>
</tbody>
</table>

*1,870 records for individuals have missing values for the variables required for inclusion in this table or have ages either less than 50 or greater than 110.
AD=Alzheimer’s disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer’s disease and Vascular dementia; OTHER=dementia in other medical conditions.

Figure 5
Registry Cases by Age Group
South Carolina Alzheimer’s Disease Registry, 2005

Figure 6
Registry Cases by Age Group
in Community, Nursing Facility or Unknown Location
South Carolina Alzheimer’s Disease Registry, 2005
Gender and ADRD in South Carolina

Table 4 shows Registry cases by gender, dementia type, and age group. For each dementia type, the number of women is notably larger than the number of men in all but the youngest age category. In particular, among those age 85 or over, the number of women with ADRD is almost 3.5 times the number of men with ADRD.

More women than men in this population were diagnosed with ADRD (Fig. 7). This is likely due to the larger number of women alive after age 75. The differences in the ADRD diagnoses by gender are shown graphically in Figure 8.

### Table 4

<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>VASCULAR</th>
<th>MIXED</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>MEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>1,015</td>
<td>491</td>
<td>65</td>
<td>1,372</td>
<td>2,943</td>
</tr>
<tr>
<td>65 - 74</td>
<td>2,374</td>
<td>645</td>
<td>172</td>
<td>1,092</td>
<td>4,383</td>
</tr>
<tr>
<td>75 - 84</td>
<td>4,160</td>
<td>888</td>
<td>298</td>
<td>1,196</td>
<td>6,542</td>
</tr>
<tr>
<td>85 +</td>
<td>2,993</td>
<td>477</td>
<td>166</td>
<td>673</td>
<td>4,309</td>
</tr>
<tr>
<td>WOMEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>1,232</td>
<td>399</td>
<td>63</td>
<td>835</td>
<td>2,529</td>
</tr>
<tr>
<td>65 - 74</td>
<td>3,674</td>
<td>706</td>
<td>234</td>
<td>961</td>
<td>5,577</td>
</tr>
<tr>
<td>75 - 84</td>
<td>9,421</td>
<td>1,428</td>
<td>601</td>
<td>1,920</td>
<td>13,609</td>
</tr>
<tr>
<td>85 +</td>
<td>10,953</td>
<td>1,534</td>
<td>577</td>
<td>1,746</td>
<td>14,810</td>
</tr>
</tbody>
</table>

*Records for 2,057 individuals have missing values for gender or age.

AD=Alzheimer’s disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer’s disease and Vascular dementia; OTHER=dementia in other medical conditions.
~High Rates of Vascular Risk Factors and Dementia among African American Women in South Carolina: A Public Health Intervention Opportunity~

Alzheimer's disease and vascular dementia are major contributors to cognitive impairment. These two conditions constitute a large proportion of dementing illnesses. There is increasing evidence that a majority of cases of Alzheimer's disease are complicated by vascular damage. Diabetes, hypertension, obesity, and physical inactivity are known risk factors for vascular damage and vascular dementia, and have been increasingly linked with the risk of developing Alzheimer's disease. Notably, these risk factors all have behavioral components. The South Carolina Alzheimer's Disease Registry examined the prevalence of health behavior risk factors for vascular disease, and the prevalence of physician-diagnosed Alzheimer's disease (AD) and vascular dementia among older African American and non-Hispanic white (hereafter white) women.

To examine risk factors for AD and vascular dementia, we used the 2003 South Carolina Behavioral Risk Factor Surveillance System. We also estimated AD and vascular dementia prevalence using the 2003 South Carolina Alzheimer's Disease Registry. Data for 2003 for women with AD and vascular dementia (n ~ 20,450) were combined with US Census 2003 population estimates to calculate prevalence. The Chi-square statistic tested comparisons; all reported comparisons were significant at p<.05.

Our results showed that, compared with white women, African American women had notably higher rates of diabetes (15.5% compared to 7.3%), hypertension (35.8%, 27.0%), obesity (37.8%, 20.4%), and physical inactivity (22.5%, 11.8%). African American women were less likely to have cholesterol checked or to eat fruits and vegetables, less likely to have Hemoglobin A1c testing for diabetes control, and had diabetes, stroke or myocardial infarction at younger ages. At all ages, African American women had a higher prevalence of AD than whites: at ages 65-74, the prevalence among African American women was 2.2 times as great as that among white women. This was also true for vascular dementia: at ages 65-74, African American women were 2.9 times as likely to have a diagnosis of vascular dementia than were white women.

From these results, we concluded that lifestyle may contribute to higher risks for AD and vascular dementia among African American women in South Carolina. In the U.S., rates of poor nutrition, inactivity, diabetes, hypertension, and obesity are increasing, suggesting that national rates of AD and vascular dementia may rise notably above current projections, which do not consider the impact of these higher risk factor rates on the development of future disease. On the other hand, it is possible that more effective medical treatment for these diseases may counteract the increasing prevalence of disease risk factors. The results of our study highlight the usefulness of public health interventions to reduce behavioral risks for dementia.

Details of the study can be found in:
Race and ADRD in South Carolina

Compared with whites, African Americans, who comprise nearly 21% of the adult South Carolina population 65 years and older, were over-represented in Vascular dementia (43%) and in the overall Alzheimer’s Disease Registry with 33% (Table 5). Sixty-one percent of African Americans with ADRD reside in the community, compared to 56% of whites living in the community (Figure 10).

Table 5
Registry Cases by ADRD Type, Gender and Age Group
South Carolina Alzheimer's Disease Registry, 2005*

<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>VASCULAR</th>
<th>MIXED</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>RACE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>24,661</td>
<td>67</td>
<td>3,717</td>
<td>55</td>
<td>1,414</td>
</tr>
<tr>
<td>African-American</td>
<td>11,427</td>
<td>31</td>
<td>2,925</td>
<td>43</td>
<td>731</td>
</tr>
<tr>
<td>Hispanic</td>
<td>180</td>
<td>&lt;1</td>
<td>38</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>All Others</td>
<td>806</td>
<td>2</td>
<td>124</td>
<td>2</td>
<td>44</td>
</tr>
<tr>
<td>Total</td>
<td>37,074</td>
<td></td>
<td>6,804</td>
<td></td>
<td>2,200</td>
</tr>
</tbody>
</table>

AD=Alzheimer’s disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer’s disease and Vascular dementia; OTHER=dementia in other medical conditions.

Figure 9
Registry Cases by Race
South Carolina Alzheimer’s Disease Registry, 2005

Figure 10
Registry Cases by Race in Community, Nursing Facility or Unknown Location
South Carolina Alzheimer’s Disease Registry, 2005
~Alzheimer’s Disease among Hispanics: Prevalence Estimates from the South Carolina Alzheimer’s Disease Registry~

The prevalence of Alzheimer’s disease and related disorders (ADRD) among Hispanics in the United States is highly relevant to public health and social services, because this population is growing rapidly. ADRD presents a notable prevention opportunity, because physical inactivity and other behavioral risk factors have been identified. Some studies suggest ADRD prevalence among Hispanics may be twice that of non-Hispanic whites; others find no difference. Most studies focus on small populations. South Carolina (SC) has 1.1 million residents age 65+. The number of SC Hispanics age 65+, about 3,000, far exceeds the number of Hispanics in previous ADRD studies. We examined ADRD prevalence among Hispanics and non-Hispanic whites. We used the SC Alzheimer’s Disease Registry, with diagnosis data from medical encounters, Medicaid, the mental health system, adjacent states, vital records, and other sources, with one record per case. Registry data for 2004 were combined with US Census 2004 estimates. We calculated prevalence separately for women and men, and for ages 65-74, 75-84, and 85+. Chi-square tested comparisons. At ages 65-74, 2.26% of Hispanic women had ADRD; at ages 75-84, 12.29%; at 85+, 26.01%. Comparable rates for non-Hispanic women were: 2.85, 10.23, and 23.49. For Hispanic men at these ages, rates were 3.34, 8.36, and 18.68; comparable rates for non-Hispanic white men were 2.40, 7.52, and 20.10. None of the age-group comparisons between Hispanics and non-Hispanic whites were statistically significant. Thus, our large, population-based study found little evidence that Hispanics are notably more likely to be diagnosed with ADRD than non-Hispanic whites.
~ Deaths among Individuals in the Registry ~

The Alzheimer’s Disease Registry data are linked with death certificates to summarize the deaths occurring among persons in the Registry. Of those people identified with ADRD since 1988, 69,018 have died. The individual’s first date of diagnosis may not be known to the Registry in every instance. For example, if an individual is first diagnosed during a physician office visit, then that diagnosis is not available to the Registry. We use the first date that a person entered one of the systems reporting to us as their entry date (Table 6).

**Table 6**
Length of Time from Entry to Death, by ADRD Type
South Carolina Alzheimer's Disease Registry, 2005*

<table>
<thead>
<tr>
<th>ENTRY to DEATH</th>
<th>AD</th>
<th>%</th>
<th>VASCULAR</th>
<th>%</th>
<th>MIXED</th>
<th>%</th>
<th>OTHER</th>
<th>%</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2 years</td>
<td>28,957</td>
<td>67</td>
<td>8,382</td>
<td>68</td>
<td>495</td>
<td>74</td>
<td>9,313</td>
<td>73</td>
<td>47,147</td>
</tr>
<tr>
<td>2-5 years</td>
<td>10,044</td>
<td>23</td>
<td>2,783</td>
<td>23</td>
<td>131</td>
<td>20</td>
<td>2,457</td>
<td>19</td>
<td>15,415</td>
</tr>
<tr>
<td>5+ years</td>
<td>4,275</td>
<td>10</td>
<td>1,069</td>
<td>9</td>
<td>42</td>
<td>6</td>
<td>1,070</td>
<td>8</td>
<td>6,456</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>43,276</td>
<td>63</td>
<td>12,234</td>
<td>18</td>
<td>668</td>
<td>18</td>
<td>12,840</td>
<td>19</td>
<td>69,018</td>
</tr>
</tbody>
</table>

AD=Alzheimer’s disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer’s disease and Vascular dementia; OTHER=dementia in other medical conditions.
Population-based ADRD Rates in South Carolina

These estimates are of population disease rates for South Carolina. These rates are calculated using the 2003 Registry information linked with the 2003 United States Census. Among our findings from these data:

- **8.1% of South Carolinians over the age of 65 have ADRD.** 4.9% of South Carolina residents have a diagnosis of Alzheimer’s disease. Previous research suggests that the number of individuals with some cognitive impairment may be nearly 50% greater than this estimate, because diagnosed cases do not include individuals with Mild Cognitive Impairment, a condition that can develop into Alzheimer’s disease.

- **27.3% of South Carolina residents age 85 or older have ADRD.**

Figure 11 shows how the prevalence of Alzheimer’s disease increases with age. Although about 21.5% of those at ages 85 or older have Alzheimer’s disease (not including related memory disorders), the risk for individuals in their 80s is considerably smaller than this summary number suggests. At age 85, the prevalence is about 12.5%. By age 90, it is about 21%. As the figure illustrates, the greatest risk comes at much older ages.

- The figure also shows the prevalence of ADRD. Related disorders include vascular dementia and dementias associated with medical diseases such as Parkinson's disease. The prevalence of these related disorders also rises with age. About 67% of those who reach age 100 have at least one type of dementia.

- The figure provides the nation’s first look at an age distribution of Alzheimer’s disease and related disorders that is not based merely on projections from small samples. No other data source in the United States enables researchers to accurately calculate the age distribution of Alzheimer’s disease.

- **African Americans are at notably higher risk of an Alzheimer’s disease diagnosis than are non-Hispanic whites.** At ages 55 through 64, African Americans are about 3 times as likely to have Alzheimer’s disease, and 3.8 times as likely to have ADRD. The risk is particularly great for African American men at these ages, who are 4.9 times as likely to have ADRD as are white men. At ages 65 through 84, African Americans are about 2.1 times as likely to have Alzheimer’s disease or ADRD. At ages 85 and over, African Americans are about 1.8 times as likely to have Alzheimer’s disease or ADRD. The declining difference with age may be due to earlier onset or diagnosis of Alzheimer’s disease for African Americans, combined
with earlier death for African Americans with the disease. **No previous research has had access to a sufficiently large sample to reveal this phenomenon.** These findings illustrate the rich research capabilities of the South Carolina Alzheimer’s Disease Registry.

- According to the U.S. Census, there were only 2,727 Hispanics/Latinos age 65 or over in South Carolina in 2,000. This group is of interest because of the state’s growing Hispanic population. The 2002 Registry indicates ADRD prevalence for these Hispanics was 3.8%, compared with 7.8% for the total population at those ages. The average age of Hispanics in the Registry did not differ notably from the average age for others; however, among those without ADRD, the age profile of older Hispanics and others may differ. This could account for the prevalence difference. Also, if many older Hispanic South Carolinians are immigrants, they may represent a relatively healthy population, as immigrants generally come to this country in good health.

- **The prevalence of Alzheimer’s disease and related disorders (ADRD, all dementias) may vary notably among SC counties.** For example, Figure 12 shows the percentage of individuals age 85 or over with ADRD in 2002. The county prevalence rates vary from a low of about 20.10%, to a high of about 53.5%. We examined the possibility that some of these rates for border counties might be affected by South Carolina residents obtaining hospital care in North Carolina or Georgia; few older South Carolinians with an ADRD diagnosis use hospital services in bordering states. **This county variation provides an important starting point for epidemiological studies of Alzheimer’s disease and related memory disorders.**

It should be noted that counties where residents enjoy particularly long lives are likely to have greater percentages of individuals with ADRD. This is so because the risks of ADRD rise dramatically at older ages. Thus, the map should not be interpreted to suggest that the incidence of ADRD is higher in counties with higher prevalence. However, the map is useful because it illustrates where the greatest service needs are for the oldest old, who are more likely than others to require institutional care.
A definitive diagnosis of ADRD is difficult, especially in the early stages. The registry staff is not directly involved in diagnosis; the physician's diagnosis is collected from the individual's medical records through codes using the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM, 1980). An individual is then classified into four general categories for reporting purposes as shown in Table 7.

Table 7
Classification of ADRD by ICD-9-CM Codes
South Carolina Alzheimer's Disease Registry, 2005

<table>
<thead>
<tr>
<th>ALZHEIMER'S DISEASE</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>290.0 - 290.3</td>
<td>Senile or presenile dementia</td>
</tr>
<tr>
<td>290.8 - 290.9</td>
<td></td>
</tr>
<tr>
<td>331.0</td>
<td>Alzheimer's disease</td>
</tr>
<tr>
<td>VASCULAR DEMENTIA</td>
<td></td>
</tr>
<tr>
<td>290.4 - 290.43</td>
<td>Arteriosclerotic dementia</td>
</tr>
<tr>
<td>435 - 438</td>
<td>Cerebrovascular disease (with a dementia code*)</td>
</tr>
<tr>
<td>MIXED DEMENTIA</td>
<td></td>
</tr>
<tr>
<td>Both Alzheimer's disease and Vascular dementia</td>
<td></td>
</tr>
<tr>
<td>DEMENTIA IN OTHER MEDICAL CONDITIONS (see note below)</td>
<td></td>
</tr>
<tr>
<td>291.2</td>
<td>Alcohol dementia</td>
</tr>
<tr>
<td>292.82</td>
<td>Drug-induced dementia</td>
</tr>
<tr>
<td>294.1</td>
<td>Dementia with other conditions</td>
</tr>
<tr>
<td>331.82</td>
<td>Dementia with Lewy bodies</td>
</tr>
<tr>
<td>(the same code is used for dementia with Parkinsonism)</td>
<td></td>
</tr>
<tr>
<td>The following conditions are included with a dementia code*:</td>
<td></td>
</tr>
<tr>
<td>310.1</td>
<td>Organic brain syndrome</td>
</tr>
<tr>
<td>331.1 - 331.9</td>
<td>Other cerebral degeneration</td>
</tr>
<tr>
<td>332.0 - 332.1</td>
<td>Parkinson's disease</td>
</tr>
<tr>
<td>333.4</td>
<td>Huntington's disease</td>
</tr>
<tr>
<td>042</td>
<td>HIV</td>
</tr>
</tbody>
</table>

NOTE: In the case where a person's record contains multiple indicators of the above categories, Alzheimer's disease and vascular dementia take precedence, except in the case where there are indications of both Alzheimer's disease and vascular dementia. In this case, the person is classified as having mixed dementia. Those classified with dementia in other medical conditions have no indications of Alzheimer's disease or vascular dementia.

*One of the following dementia codes must also be present: 290.0-290.3, 290.8-290.9, 331.0, 290.4-290.43, 291.2, 292.82, 294.1, 331.82.
The registry core data set (Table 8) consists of case-identifying data and diagnostic data (ICD-9-CM codes), caregiver contact data for follow-up, and the place from which the records were obtained. Other information collected, if available, includes other medical diagnoses, educational status, and marital status.

Table 8
Registry Core Data Items
South Carolina Alzheimer’s Disease Registry, 2005

Identification of case (for matching purposes only)
Location of case (for follow-up)
Name and location of caregiver/contact person (if available)
Sociodemographic data (education, marital status, gender, race, age)
Diagnosis (current dementia diagnosis and other medical diagnoses)
~ Research Projects & Other Activities ~

In addition to registering and tracking individuals with ADRD, the staff of the Alzheimer’s Disease Registry and Office for the Study of Aging (OSA) also conduct other activities focused on aging issues of older individuals, training of direct care staff and professionals in topics on ADRD, and exercise.

Community Outreach

The staff of the Office for the Study of Aging provides expertise and technical assistance to the community through the involvement on committees that include: Alzheimer’s Resource Coordination Center, Caregiver Coalition of the Midlands, Family Caregiver Coalition of South Carolina, New Advisory Committee for Nurse Aide Training, Nurse Aide Training Coordinator’s & Instructors Annual Workshop, South Carolina Emergency Preparedness Committee on Special Populations and the Carolina Center for Medical Excellence Nursing Home Quality Initiative Quality Committee and Home Health Stakeholders Committee.

Person Centered Planning

Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. The Office for the Study of Aging has provides technical assistance and training on person centered planning. See OSA website www.sph.sc.edu/OSA/programs_consumer.html.

Dementia Dialogues

“Dementia Dialogues” consists of 5 parts, each approximately 1.5 hours in length, which allows participants to integrate new ideas with information they already possess. Part 1 consists of “The Basic Facts”, an overview of ADRD, Part 2 “Keeping the Dialogue Going”, strategies for effective communication, Part 3 “It’s a Different World”, understanding the impact of the environment and ways to promote independence in activities of daily living, Part 4 “It’s Nothing Personal”, addressing challenging behaviors and Part 5 “Now What Do I Do”, creative problem solving. Each participant receives a certificate of participation for each unit and a Dementia Specialist Certificate upon completing all five Units. This program is offered at no cost to participants and is held regionally. Over 10,000 professional, non-professional and family caregivers in South Carolina have received this training. For further information please contact: Jan Merling, MA, Office for the Study of Aging, Arnold School of Public Health, University of South Carolina, 803-318-1601, jmerling@sc.edu, or www.sph.sc.edu/OSA/programs_dementia.html

Dementia Dialogues Train-The-Trainer

A “Train-The-Trainer” curriculum for “Dementia Dialogues” has been developed and implemented for those who have completed Dementia Dialogues and wish to conduct these trainings in their facilities and agencies.
Disaster Preparedness in Long Term Care

In collaboration with the Department of Health Services Policy and Management in the Arnold School of Public Health, the OSA staff has collected information regarding readiness for disasters from nursing homes, homes health agencies and home care agencies in South Carolina and also sheltering nursing homes in Mississippi after Hurricane Katrina. The information has been utilized to develop educational modules for master's and doctoral level students.

Elder Mistreatment Prevention Training

The OSA, in collaboration with the Center for Child and Family Studies in the College of Social Work and with the support of the SC Department of Health and Human Services is developing Elder Mistreatment Prevention Training for nursing homes. This training will be offered to nursing homes statewide upon completion of the development and piloting.

Functional Status Measurement

A study in cooperation with the Department of Exercise Science has resulted in a simple, reliable, objective assessment tool for evaluating and monitoring functional status that would complement and expand the current assessment of activities of daily living in community dwelling frail elderly.

Medication Adherence Management Service Evaluation

In collaboration with the College of Pharmacy, a study has been conducted to assess the effectiveness of a service to improve medication adherence and potentially reduce health care utilization and cost. A prospective cohort design with 300 cases and a comparison group of matched controls will be utilized to evaluate the effectiveness of this service. Analysis is underway.

Placemat Strength Training Program

Training home care workers to assist clients in maintaining independence by improving physical functioning through strength training has resulted in the Placemat Strength Training Program (PSTP). This exercise program has been specifically designed for the person who has met nursing home level of care and has chosen to remain at home. This program is being implemented through Community Long-Term Care and is available to anyone. See www.sph.sc.edu/OSA/programs_placemat.html
Promoting Brain Health

Recent scientific advances strongly suggest that lifestyle measures aimed at improving brain health may notably reduce the risk of Alzheimer's disease, vascular dementia, and cognitive decline. Obesity, diabetes, hypertension, and being physically inactive are all known risk factors for brain diseases and cognitive decline. Our research at the Registry suggests that learning about the connection between lifestyles and the risks of brain problems may motivate many South Carolinians to improve their lifestyles. The OSA is helping to lead efforts to reduce the future prevalence of Alzheimer's disease and related disorders in South Carolina and the nation. We are working with the Centers for Disease Control and Prevention (CDC), the Alzheimer's Association, the National Institutes of Health (NIH), the AARP, and other brain health partners, to change knowledge, attitudes, and behavioral intentions about brain health, and to promote brain-healthy lifestyle choices.

As part of this work, the OSA is helping to develop a national public health "Roadmap" for brain health. The Roadmap will include agendas for policy, surveillance, communications, and research, all designed to mobilize the public health community into action.

The OSA is also assisting the Alzheimer's Association in the development of a program specifically designed to promote brain health among African American baby boomers. We know from our work with the Registry that African Americans are at high risk of developing Alzheimer's disease and related disorders. One of our goals is to eliminate this brain health disparity.

Nine research universities in the Healthy Aging Research Network are involved in a four-year project to better understand how people in various demographic groups think about brain health issues, and to design and implement a national public health intervention to promote behaviors that will protect brain health.

Recruitment and Retention

OSA staff is providing training and technical assistance on issues surrounding the recruitment and retention of direct care staff in community residential care facilities. These activities serve as a pilot to develop a training package to assist administrators and managers to recruit and retain direct care staff.
Maggi Chandlee, M.P.H., Graduate Research Assistant, is a Ph.D. candidate in Epidemiology and Biostatistics. Her research interests are in aging and exercise.

Carol B. Cornman, B.S., R.N., P.A., Director of the Alzheimer’s Disease Registry and related projects. She handles all requests for information from the registry. Her research interests include ethnic differences in ADRD, incorporating wellness activities that maintain independence in the elderly, and consumer directed care.

Courtney Davis, M.H.A., Research Associate, provides technical assistance and program evaluation for activities related to the office for the Study of Aging and conducts research and training in the area of long term care. Her interests include consumer-directed care, disaster preparedness for vulnerable adults, elder mistreatment, and quality improvement in facility and community-based health services.

Dorothy Davis, B.A., serves as Data Manager for the Alzheimer’s Disease Registry, including Community Long Term Care (CLTC), vital records, Department of Mental Health, and other registry databases.


Marcia J. Lane, M.P.H., Associate Director of the Alzheimer’s Disease Registry, provides program coordination and evaluation. Her research interests include older women’s health issues, physical activity, ADRD, medication adherence, elder mistreatment, quality of life in long-term care, and consumer directed care.

Rui Liu, M.P.H., Graduate Research Assistant, is a Ph.D. candidate in Epidemiology and Biostatistics. Her research interests are in brain health and qualitative analysis.

Jan Merling, M.A., CTRS, Education Coordinator, is the trainer for “Dementia Dialogues” and the Placemat Strength Training Program. Her interests include adult learning and quality of life for older persons.

Dale Morris, A.S., Administrative Assistant, coordinates administrative activity and data entry for all projects.

Holly Pope, MSPH, Research Associate, is the project manager for “Understanding Social & Personal Aspects of Faith and Practice Related to Health.” She is a Ph.D. candidate in the Department of Health Promotion, Education, and Behavior. Her research interests include holistic health, quality of life and long term care among the older adult population.

Candace N. Porter, M.S., Statistical Research Associate for the Alzheimer’s Disease Registry and related projects. Her research interests include AIDS dementia, Alzheimer's disease and related disorders as causes of death, survival analysis, and count data models. She is a Ph.D. candidate in Epidemiology and Biostatistics.
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Sudha Xirasagar, Ph.D., is Research Assistant Professor, Department of Health Services and Policy Management, Arnold School of Public Health.
The following is a list of the manuscripts and reports generated by the Registry staff. Reprints of these articles can be obtained from the registry office.


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~ Office Publications (continued) ~


Further Information

This Annual Report is available online at http://osa.sph.sc.edu/alzheimers_registry.html. Any state or local agency may request the registry staff to provide specific data summaries (without identifiers). These requests are handled on an individual basis and will be provided free of charge, as time allows. Contact the registry staff at (803) 777-5337 for further information, or e-mail Carol Cornman at: ccornman@sc.edu.