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STATEWIDE ALZHEIMER'S DISEASE AND RELATED DISORDERS REGISTRY
SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF SOUTH CAROLINA

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Unless otherwise noted, data included in this report cover the period
January 1, 1993 through December 31, 1993
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EXECUTIVE SUMMARY

The University of South Carolina, in cooperation with the SC Health and Human Services Finance Commission and the SC Department of Mental Health, maintains a statewide registry of SC residents diagnosed with Alzheimer's disease or a related disorder. The registry is located in the James F. Byrnes Medical Center. All cases are identified by a medical records search; inclusion in the registry is voluntary. The goals of the registry include:

- reporting annual prevalence of Alzheimer's disease and related disorders by demographic characteristics;
- providing data to public agencies for planning purposes; and
- fostering research into the risk factors for Alzheimer's disease and caregiver distress.

In 1993, the registry maintained information on 5,772 individuals in South Carolina with a diagnosis of Alzheimer's disease or a related dementia. Almost 60% had a diagnosis of Alzheimer's disease and an additional 15% had a diagnosis of dementia due to stroke. The rest were due to alcohol or drug-induced dementia (12%), and dementia secondary to other medical conditions (14%). Highlights of the 1993 data include:

- Over half of the registry cases living in the community have a diagnosis of Alzheimer's disease.
- Those with Alzheimer's disease are most often diagnosed between the ages of 65 and 84.
- Over 40% of registry cases with Alzheimer's disease are currently over 84 years of age.
- 77% of the community cases with Alzheimer's disease are currently over 74 years of age.
- 87% of the institutionalized cases with Alzheimer's disease are currently over 74 years of age.
- More women than men are affected with Alzheimer's disease and multi-infarct dementia, most likely due to the larger proportion of women alive after age 65.
- African Americans, who comprise nearly 30% of the adult South Carolina population, are over-represented in all dementia categories (over 40%).
- Over 50% of Alzheimer's disease cases in the community are African American.
• Approximately half the dementia cases have less than a high school education.

• For Alzheimer's disease cases there is no difference in educational status between those in institutions and those in the community.

• 70% of Alzheimer's disease cases are single, widowed, divorced, or separated (77% of those in institutions and 62% of those in the community).

• About half the Alzheimer's disease and multi-infarct cases have a record of a mini-mental status examination and about 25% of all the dementia cases have had a CAT (computed axial tomography) scan.

• Summary information on the number of deaths between 1988 and 1993 indicates that 41% to 46% of the dementia diagnoses are made within two years of death and about 20% of the dementia diagnoses, not due to medical causes, are diagnosed more than 5 years before death.

• The onset of symptoms occurs more than 5 years before death for almost half the dementia cases.

The growth and development of the registry and the related research program in aging has been due to the support of many individuals and organizations. We particularly want to acknowledge the contribution of the School of Public Health for core support, the School of Medicine (Department of Medicine, Division of Geriatrics) for providing space and collaboration, the Department of Mental Health for continued support, access to data, and for providing space in the Byrnes Medical Center, the SC Health and Human Services Finance Commission for core support and access to data, and the Office of the Governor, Division on Aging for their continued support.

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) 734-4098 for further information.
OVERVIEW

Scope of the Problem

The prevalence of dementia is estimated to be about 5% among persons aged 65 or older, and about 20% in those aged 80 or older. While the proportion of persons over age 65 increased nationally by 19% between 1980 and 1988, the percentage increase in South Carolina was 32%. By the year 2000 the population over age 65 in South Carolina is expected to increase by 76% over the 1980 population. However, the largest increase (247%) is expected in the over 85 age group (Source: SC State Budget & Control Board, 1984).

Although we have no information on the total number of persons with dementia in South Carolina, we can estimate the number of people in the community with severe cognitive impairment by applying estimates obtained from studies conducted in other parts of the country. To determine the expected number of severely cognitively impaired persons in South Carolina, and to make projections for the years 1995 and 2000, we used estimates developed from the Epidemiologic Catchment Area Program and weighted these estimates by the age, race, sex, marital status, and educational level of the South Carolina population, county by county. These statewide results, for adults age 18 or over, are shown below.

Table 1

<table>
<thead>
<tr>
<th>Year</th>
<th>Population Estimate</th>
<th>Case Estimate</th>
<th>Rate per/100</th>
<th>AD Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>2,872,273</td>
<td>51,365</td>
<td>1.79</td>
<td>33,387</td>
</tr>
<tr>
<td>2000</td>
<td>3,100,398</td>
<td>57,299</td>
<td>1.85</td>
<td>37,244</td>
</tr>
</tbody>
</table>

1Rate is adjusted for age, race, sex, marital status, and education
2Estimated to be 65% of those with severe cognitive impairment

Considering the increasing numbers of affected persons, the lack of effective treatment, and the length of time that persons with dementia and their families require resources, this disease is likely to influence health care financing on a national level. A statewide registry such as ours can help South Carolina effectively plan for this emerging health problem.
History of the Registry

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. Since July, 1993, the registry has been housed in the James F. Byrnes Medical Center, a geriatric research hospital jointly sponsored by the University of South Carolina and the South Carolina 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 this emerging major public health problem. On May 31, 1990, a state law authorizing the registry was signed by Governor Carroll A. Campbell, Jr. This law (R653, H4924) amends Title 44, Code of Laws of South Carolina 1976, relating to health, by adding Chapter 36 so as to establish a voluntary Statewide Alzheimer's Disease and Related Disorders Registry in the School of Public Health. The law has strict confidentiality requirements, but does allow registry staff to contact the families and physicians of patients diagnosed as having Alzheimer's disease or a related disorder to collect relevant data and to provide them with information about available public and private health care resources.

The goals of the registry are to collect information on all persons in South Carolina with a diagnosis of Alzheimer's disease or a related dementia as of January 1, 1988; to report annual incidence and prevalence of Alzheimer's disease and related disorders in South Carolina by demographic characteristics; to provide data to public agencies for planning purposes; to study the familial transmission of Alzheimer's disease; and to foster research into the risk factors for Alzheimer's disease.

In 1993, the Aging Research Group was established and located adjacent to the registry offices at the James F. Byrnes Medical Center. The purpose of this group is to plan, develop, and implement research projects focused on issues related to aging.

Registry Procedures

Dementia can be defined as the global impairment of intellectual and cognitive functions such as memory, abstract thinking, or judgement. Dementia seriously interferes with normal social and occupational activities. The diagnosis of dementia includes Alzheimer's disease, multi-infarct (vascular) dementia, alcoholic dementia, Parkinson's disease with dementia, Huntington's disease, and other dementing illnesses. However, the definitive diagnosis of dementia is difficult, especially in the early stages. The registry staff are not directly involved in diagnosis; they record verbatim the physician's diagnosis from the patient's medical record. These diagnoses are coded using the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM, 1980). These diagnoses are classified into four general categories for reporting purposes. These categories are shown in Table 2.
### Table 2

Classification of Dementias by ICD-9-CM Codes  
Statewide Alzheimer's Disease and Related Disorders Registry, 1993

<table>
<thead>
<tr>
<th>Code</th>
<th>Diagnosis</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>Alzheimer's disease</td>
</tr>
<tr>
<td>331.0</td>
<td></td>
</tr>
<tr>
<td>290.4 - 290.43</td>
<td>Arteriosclerotic dementia</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>310.10</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 chorea</td>
</tr>
<tr>
<td>334.2 - 334.29</td>
<td>Primary cerebellar degeneration</td>
</tr>
<tr>
<td>334.9 - 334.99</td>
<td>Spinocerebellar disease</td>
</tr>
</tbody>
</table>

The medical record is abstracted from hospitals, clinics, or private physicians' offices. The cases of dementia are usually identified as they (or their family members) require public provider services. Since no single system identifies all newly diagnosed patients with dementia, new cases are collected from several sources: monthly reports from the Department of Mental Health (including the Community Mental Health Services); University-affiliated clinics (Medical University of South Carolina, University of South Carolina Department of Neuropsychiatry and Behavioral Science at William S. Hall Psychiatric Institute); Community Long-Term Care; Nursing Homes and Residential Care Facilities; and persons who attend Alzheimer's disease support groups.
After proper permissions are obtained, the research nurse abstracts registry core data from the patient's medical record (see Table 3). Core data consists of patient identifying data and diagnostic data (using ICD-9-CM codes), caregiver contact data for follow-up, and the place where the records were abstracted. The abstracting form also includes medical diagnoses, tests performed, scores on mini-mental state exams, and educational status. Illiteracy and mental retardation are noted if present. If there is a family history of dementia, it is also recorded. This abstract form contains all items recommended for a national core data set on dementia.

Table 3

Registry Core Data Items
Statewide Alzheimer's Disease and Related Disorders Registry, 1993

| Identification of patient (for matching purposes) |
| Location of patient (for follow-up) |
| Name and location of caregiver/contact person |
| Sociodemographic data (education, marital status, etc.) |
| Diagnosis (current dementia diagnosis and other medical diagnoses) |
| Diagnostic tests |
| Death/autopsy data |

CHARACTERISTICS OF DEMENTIA IN SOUTH CAROLINA, 1993

Type of Dementia

Among 1993 prevalent dementia cases, 59% have a diagnosis of Alzheimer's disease (AD) and 15% have a diagnosis of multi-infarct (or stroke) dementia (MID). In the case of multiple diagnoses (e.g., those showing both AD and MID) the patient is reported in the AD category. Therefore, as shown in Table 4, the 852 cases who have a diagnosis of MID dementia do not have an additional AD diagnosis in their record. The diagnosis shown represents the most current diagnosis in the medical record.

Over half of the registry cases live in the community. Because of the difference in needs between those in institutions and those in the community, the following Figures (1-4) separate the cases by location. The distribution of dementia types, shown in Figure 1, is similar for institution and community. While Alzheimer's disease is by far the most prevalent of the dementia types, a higher proportion of the institutionalized cases have Alzheimer's disease or senile dementia (68%) when compared to the proportion of the community cases with Alzheimer's disease (53%).
Table 4
Percentage of Registry Cases by Dementia Type
Statewide Alzheimer’s Disease and Related Disorders Registry, 1993

<table>
<thead>
<tr>
<th>Dementia type</th>
<th>Institution Number (%)</th>
<th>Community Number (%)</th>
<th>Total Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's disease</td>
<td>1,866 (66)</td>
<td>1,542 (53)</td>
<td>3,430 (59)</td>
</tr>
<tr>
<td>Multi-infarct</td>
<td>390 (14)</td>
<td>462 (16)</td>
<td>852 (15)</td>
</tr>
<tr>
<td>Alcoholic/drug-induced</td>
<td>246 (9)</td>
<td>416 (14)</td>
<td>662 (12)</td>
</tr>
<tr>
<td>Medical conditions</td>
<td>312 (11)</td>
<td>516 (17)</td>
<td>828 (14)</td>
</tr>
<tr>
<td>Total</td>
<td>2,814 (100)</td>
<td>2,958 (100)</td>
<td>5,772 (100)</td>
</tr>
</tbody>
</table>

Figure 1. Percentage of Registry Cases by Dementia Type and Community or Institution Location.
Age

The tables in this section (Tables 5 to 9) describe demographic characteristics and medical information of all 1993 prevalent cases, displayed by type of dementia. Figures 2 to 4 show only Alzheimer's disease cases. As shown in Table 5, those with Alzheimer's disease were most often diagnosed between the ages of 65 and 84, while over 40% are currently over 84 years of age. Focusing on those with Alzheimer's disease, Figure 2 indicates that over 87% of the institutionalized cases are currently over 74 years of age. It is notable that among community cases, only 77% are currently over 74 years of age.

Table 5

Percentage of Registry Cases by Diagnosis Age, Current Age, and Dementia Type
Statewide Alzheimer's Disease and Related Disorders Registry, 1993

<table>
<thead>
<tr>
<th>DIAGNOSIS AGE</th>
<th>AD n=3,430</th>
<th>MID n=852</th>
<th>ALC/DRUG n=662</th>
<th>MEDICAL n=828</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>10</td>
<td>23</td>
<td>69</td>
<td>60</td>
</tr>
<tr>
<td>65-74</td>
<td>25</td>
<td>30</td>
<td>22</td>
<td>20</td>
</tr>
<tr>
<td>75-84</td>
<td>45</td>
<td>33</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>85 +</td>
<td>20</td>
<td>14</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CURRENT AGE</th>
<th>AD n=3,430</th>
<th>MID n=852</th>
<th>ALC/DRUG n=662</th>
<th>MEDICAL n=828</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>4</td>
<td>15</td>
<td>50</td>
<td>51</td>
</tr>
<tr>
<td>65-74</td>
<td>14</td>
<td>22</td>
<td>30</td>
<td>17</td>
</tr>
<tr>
<td>75-84</td>
<td>41</td>
<td>37</td>
<td>16</td>
<td>22</td>
</tr>
<tr>
<td>85 +</td>
<td>41</td>
<td>26</td>
<td>4</td>
<td>10</td>
</tr>
</tbody>
</table>

AD = Alzheimer's disease
MID = multi-infarct dementia
ALC/DRUG = alcohol or drug-induced dementia
MEDICAL = dementia secondary to a medical condition
Figure 2. Percentage of Alzheimer's Disease Cases by Current Age and Community or Institution Location.
Sex and Ethnicity

Table 6 indicates that there are more women than men affected with Alzheimer's disease and multi-infarct dementia, most likely due to the larger proportion of women alive after age 65. As for ethnicity, African Americans, who comprise nearly 30% of the adult South Carolina population, are overrepresented in all dementia categories. Furthermore, over 50% of Alzheimer's disease cases in the community are African American (Figure 3).

Table 6
Percentage of Registry Cases by Sex, Ethnicity and Dementia Type
Statewide Alzheimer’s Disease and Related Disorders Registry, 1993

<table>
<thead>
<tr>
<th></th>
<th>AD n=3,430</th>
<th>MID n=852</th>
<th>ALC/DRUG n=662</th>
<th>MEDICAL n=828</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SEX</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>33</td>
<td>48</td>
<td>79</td>
<td>58</td>
</tr>
<tr>
<td>Women</td>
<td>67</td>
<td>52</td>
<td>21</td>
<td>42</td>
</tr>
<tr>
<td><strong>ETHNICITY</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>58</td>
<td>51</td>
<td>41</td>
<td>55</td>
</tr>
<tr>
<td>African American</td>
<td>41</td>
<td>48</td>
<td>59</td>
<td>45</td>
</tr>
</tbody>
</table>

AD = Alzheimer's disease  
MID = multi-infarct dementia  
ALC/DRUG = alcohol or drug-induced dementia  
MEDICAL = dementia secondary to a medical condition
Figure 3. Percentage of Alzheimer’s Disease Cases by Ethnicity and Community or Institution Location

- White
- African-American

- 59%
- 41%

Percentage of Subjects

Location

Institution

Community

68
32

48
52

White
African-American
Education and Marital Status

While we do not have complete information on educational status (around 20% of the records do not include information on education), it appears as if at least half the dementia cases in our registry have less than a high school education. This is similar to the state statistics for older South Carolinians. For those with Alzheimer's disease, we found no differences between those in institutions and in the community by educational status.

Because of the older age of diagnosis of Alzheimer's disease and the length of life after diagnosis, it is not surprising that many are individuals are widowed, divorced or separated (Table 7). Furthermore, it is not surprising that a higher proportion of those in institutions are unmarried, either widowed, divorced, separated, or single (Figure 4). The large proportion of unmarried individuals with Alzheimer's disease living in the community suggests that family support systems and social services to assist families are particularly important.

Table 7

Percentage of Registry Cases by Education, Marital Status and Dementia Type
Statewide Alzheimer's Disease and Related Disorders Registry, 1993

<table>
<thead>
<tr>
<th></th>
<th>AD n=3,430</th>
<th>MID n=852</th>
<th>ALC/DRUG n=662</th>
<th>MEDICAL n=828</th>
</tr>
</thead>
<tbody>
<tr>
<td>EDUCATION</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>57</td>
<td>56</td>
<td>58</td>
<td>40</td>
</tr>
<tr>
<td>High school or more</td>
<td>43</td>
<td>44</td>
<td>42</td>
<td>60</td>
</tr>
<tr>
<td>MARITAL STATUS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>30</td>
<td>36</td>
<td>20</td>
<td>30</td>
</tr>
<tr>
<td>Widow/Divorced/Sep</td>
<td>61</td>
<td>56</td>
<td>53</td>
<td>41</td>
</tr>
<tr>
<td>Single</td>
<td>9</td>
<td>8</td>
<td>27</td>
<td>29</td>
</tr>
</tbody>
</table>

AD = Alzheimer's disease
MID = multi-infarct dementia
ALC/DRUG = alcohol or drug-induced dementia
MEDICAL = dementia secondary to a medical condition
Figure 4. Percentage of Alzheimer's Disease Cases by Marital Status and Community or Institution Location

- Married: 30%
- Wid/Div/Sep: 9%
- Single: 61%

Bar chart showing:
- Institution: Married = 23, Wid/Div/Sep = 12, Single = 6
- Community: Married = 65, Wid/Div/Sep = 38, Single = 56
Medical History

Other diagnoses present on the medical record are shown on Table 8. Because of the strong relationship of age with the other diagnoses, these percentages were adjusted for age. About 30% of those with a dementia diagnosis (AD, ALC/DRUG, MEDICAL) also have a diagnosis of cardiovascular disease, while 70% of those with a dementia diagnosis of MID have such a diagnosis.

About half the Alzheimer's disease and multi-infarct cases have a record of a mini-mental status examination and about 25% of all the dementia cases have had a CAT (computed axial tomography) scan. Differential diagnosis typically involves a combination of medical and symptom onset history, and specific tests to rule out medical causes. Those that follow a course suggesting Alzheimer's disease with no other identified cause are classified as Alzheimer's disease or senile dementia.

Table 8
Percentage* of Registry Cases by Medical History and Dementia Type
Statewide Alzheimer's Disease and Related Disorders Registry, 1993

<table>
<thead>
<tr>
<th></th>
<th>AD n=3,430</th>
<th>MID n=852</th>
<th>ALC/DRUG n=662</th>
<th>MEDICAL n=828</th>
</tr>
</thead>
<tbody>
<tr>
<td>HISTORY OF</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>16</td>
<td>24</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>4</td>
<td>3</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Depression</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Head injury</td>
<td>8</td>
<td>6</td>
<td>5</td>
<td>26</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>37</td>
<td>70</td>
<td>30</td>
<td>32</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>14</td>
<td>16</td>
<td>15</td>
<td>14</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>19</td>
<td>22</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>Syphilis</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

* These percentages are adjusted for age

AD = Alzheimer's disease
MID = multi-infarct dementia
ALC/DRUG = alcohol or drug-induced dementia
MEDICAL = dementia secondary to a medical condition
Length of Illness

The number of deaths that have occurred between 1988 and 1993 are summarized in Table 9. These statistics indicate that 41% to 46% of the dementia diagnoses were made within two years of death. However, about 20% of the dementia diagnoses that were not due to medical causes were diagnosed more than 5 years before death. Considering that the diagnosis date may not be an accurate indication of the length of the illness, we categorized the cases from date of onset to date of death. In this situation, the onset of symptoms occurred more than 5 years before death for almost half the dementia cases. The length of illness and the relatively older age at onset for those with Alzheimer's disease suggests the magnitude of the problem, especially at the community level.

Table 9

Percentage of Registry Deaths by Length of Illness and Dementia Type
Statewide Alzheimer's Disease and Related Disorders Registry, 1988-1993

<table>
<thead>
<tr>
<th></th>
<th>AD n=823</th>
<th>MID n=220</th>
<th>ALC/DRUG n=68</th>
<th>MEDICAL n=116</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DIAGNOSIS TO DEATH</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;2 years</td>
<td>42</td>
<td>43</td>
<td>41</td>
<td>46</td>
</tr>
<tr>
<td>2-5 years</td>
<td>34</td>
<td>34</td>
<td>38</td>
<td>21</td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>24</td>
<td>23</td>
<td>21</td>
<td>33</td>
</tr>
<tr>
<td><strong>ONSET TO DEATH</strong>§</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;2 years</td>
<td>20</td>
<td>19</td>
<td>22</td>
<td>33</td>
</tr>
<tr>
<td>2-5 years</td>
<td>34</td>
<td>35</td>
<td>36</td>
<td>20</td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>46</td>
<td>46</td>
<td>46</td>
<td>47</td>
</tr>
</tbody>
</table>

§If date of onset was not available, date of diagnosis was substituted

AD = Alzheimer's disease
MID = multi-infarct dementia
ALC/DRUG = alcohol or drug-induced dementia
MEDICAL = dementia secondary to a medical condition
County of Residence

The reference map (Figure 5) displays the counties within the state. The maps shown in Figures 6 and 7 depict the number of persons with a diagnosis of Alzheimer's disease by county of residence for those who still live in the community and by county of previous residence for those who are now in institutions.

Figure 5. Reference Map of South Carolina

In Figure 6, the distribution of community cases is shown by county of residence. Most of the cases live in the three main population centers of the state (Greenville county, Richland county, and Charleston county). The distribution for those currently in institutions by county of previous residence (Figure 7), shows the same pattern.
Figure 6. Number of Persons with Alzheimer's Disease Living in the Community by County of Residence

Figure 7. Number of Persons with Alzheimer's Disease Living in Institutions by County of Previous Residence
RESEARCH ACTIVITIES

Research Staff

The following staff form the Aging Research Group (ARG). The major focus of the ARG is to maintain the Alzheimer's Disease and Related Disorders Registry and to support research activities focused on health problems of older individuals.

Director

Caroline A. Macera, Ph.D., Professor of epidemiology. Her research interests are chronic disease epidemiology, including health aspects of physical activity, aging related issues, and caregiver burden.

Support Staff

Carol B. Cornman, B.S., R.N., P.A., serves as the clinical and field coordinator for ARG projects.

Dorothy Davis, B.A., serves as data manager for ARG projects.

Graduate Research Assistants

William K. Scott, M.S.P.H., doctoral student in epidemiology. His research interests include neuroepidemiology, gerontological health, and the epidemiology of sexually transmitted diseases.

Linda J. Neff, B.S., Master's student in epidemiology. Her research interests include women's health issues (including violence against women), nutritional epidemiology, and cardiovascular epidemiology.

Youjie Huang, M.D., M.P.H., doctoral student in epidemiology. His research interests include the epidemiology of chronic diseases.

Conrad Ottermess, B.A., Master's student in epidemiology. His research interests include infectious disease epidemiology, control and treatment.


Affiliated Research Staff

Patricia A. Sharpe, Ph.D., M.P.H., behavioral scientist and Assistant Professor in the Department of Health Promotion and Education, School of Public Health.
Elaine Frank, Ph.D., Assistant Professor in the Department of Speech, Language, Audiology and Pathology, School of Public Health.

Pamela W. Goslar, Ph.D., epidemiologist, Arizona State Health Department.

Research in Progress

In addition to maintaining the registry, the staff are involved in several research projects. Some of the projects currently underway include:

Blue Ribbon Task Force on Alzheimer's Disease

The registry staff provided data and participated in the development of a statewide report to plan, coordinate and deliver services to individuals with Alzheimer's disease and their families. This Task Force was created by Act 195 of the General Assembly and signed by the Governor. Along with the report, there was a request for funding an Alzheimer's Caregiver Resource Coordination Center under the Governor's Office, Division on Aging, and expansion of respite programs for families of individuals with Alzheimer's disease.

Evaluation of Caregiver Service Project

The ARG is working with the Division on Aging to evaluate a demonstration project (Project COPE) designed to increase service availability and coordination for underserved populations of South Carolina. Project COPE, funded by HRSA, is operating in two sites and has several components including service utilization, outreach, and training especially designed to increase the use of services to minority and rural individuals with Alzheimer's disease, and their families.

Functional Limitations Study

This project uses data from a preventive medicine clinic and prospectively assesses functional limitations among physically fit and unfit individuals to determine the possible role of physical activity in preventing functional limitations.

Service Utilization of Alzheimer's Disease Patients and Caregivers

A proposal has been submitted to the Helen Bader Foundation to study service utilization and needs of families with Alzheimer's disease in a rural, predominately African-American area of the state. The results will be useful to the statewide organization coordinating services for Alzheimer's patients and caregivers.
The Caregiver Study

A proposal has been submitted to the National Institute of Aging (NIA) for a study assessing the correlates of burden associated with caregiving for a demented relative. The proposal uses data from a 3-year pilot study completed by registry staff in 1993.

Naming in Dementia

Registry staff provided statistical analysis support for a project studying differences in naming impairments among subjects with Alzheimer's disease, Parkinson's disease, and Huntington's disease.

Survival of Alzheimer's Disease Patients with Regard to Pattern of Care

This study determined if the variation in a patient's longevity is related to the care offered to that patient.

Oral Health of Mexican-Americans

The Hispanic HANES (HHANES) dataset was analyzed to identify male/female differences in tooth loss and nutrition among elderly Mexican-Americans.
Publications and Presentations

The following is a list of the manuscripts and reports published by the ARG. Reprints of these articles can be obtained from the registry office.


Registry staff have made presentations around the state, at local and national meetings, and to various agencies. The presentations listed here are a sampling of those made during 1993.

1. "The Statewide Alzheimer's Disease and Related Disorders Registry -- An Overview of Research Activities" Presented at the South Carolina Public Health Association Annual Meeting, Myrtle Beach, SC.


SUMMARY

Acknowledgements

The growth and development of the registry and related research program in aging has been due to the support of many individuals and organizations. We particularly want to acknowledge the contribution of the School of Public Health for core support, the Department of Mental Health for continued support, access to data, and for providing space in the Byrnes Medical Center, the SC Health and Human Services Finance Commission for core support and access to data, the School of Medicine (Department of Medicine, Division of Geriatrics) for providing opportunities for collaboration, and the Office of the Governor, Division of Aging for their continued support.

Further Information

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) 734-4098 for further information.

There are several opportunities for participation in research projects open to students interested in the health of older adults. For further information please contact the registry office at (803) 734-4098.