1995

1995 Annual Report

Office for the Study of Aging

Follow this and additional works at: https://scholarcommons.sc.edu/osa_alzheimers_registry

Publication Info
1995.

This Article is brought to you by the Office for the Study of Aging at Scholar Commons. It has been accepted for inclusion in Office for the Study of Aging: Alzheimer’s Registry by an authorized administrator of Scholar Commons. For more information, please contact dillarda@mailbox.sc.edu.
ANNUAL REPORT

DECEMBER 31, 1995

ALZHEIMER'S DISEASE REGISTRY
PREVENTION CENTER
SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF SOUTH CAROLINA

Caroline A. Macera, Ph.D., Director
Carol B. Cornman, B.S., R.N., P.A., Associate Director
(803) 777-4253
FAX (803) 777-5042

James F. Byrnes Center for Geriatric Medicine, Education, and Research
P.O. Box 119
Columbia, SC 29202

Unless otherwise noted, data included in this report cover the period
January 1, 1995 through December 31, 1995
# TABLE OF CONTENTS

EXECUTIVE SUMMARY ................................................................. 1

OVERVIEW

Scope of the Problem ............................................................... 3
History of the Registry .............................................................. 5
Registry Procedures ................................................................. 5

CHARACTERISTICS OF DEMENTIA IN SOUTH CAROLINA, 1995

Type of Dementia ................................................................. 7
Age ......................................................................................... 9
Gender and Ethnicity ............................................................ 11
Education and Marital Status ................................................... 13
Medical History ..................................................................... 15
Length of Illness ..................................................................... 16

RESEARCH ACTIVITIES

Research Staff ......................................................................... 17
Research in Progress ............................................................. 19
Publications and Presentations ............................................... 21

ACKNOWLEDGMENTS ............................................................. 23

FURTHER INFORMATION and ORDER FORM ............................. 23
LIST OF TABLES

Table 1  Projected Prevalence of Dementia Among South Carolina Adults Aged 65 and Older, from 1995 to 2020 ........................................ 3
Table 2  Classification of Dementias by ICD-9-CM Codes ........................................ 6
Table 3  Registry Core Data Items ................................................................. 7
Table 4  Percentage of Registry Cases by Dementia Type .................................... 8
Table 5  Percentage of Registry Cases by Diagnosis Age, Current Age and Dementia Type ............................................................... 9
Table 6  Percentage of Registry Cases by Gender, Ethnicity and Dementia Type ............ 11
Table 7  Percentage of Registry Cases by Education, Marital Status and Dementia Type .............................................................. 13
Table 8  Percentage of Registry Cases by Medical History and Dementia Type ............. 15
Table 9  Percentage of Registry Deaths by Length of Illness and Dementia Type ............ 16
LIST OF FIGURES

Figure 1  Projected Prevalence of Dementia in South Carolina for Age 65+, 75+ or 85+, from Year 1995 to 2020  ........................................ 4

Figure 2  Percentage of Registry Cases by Type of Dementia and by Community or Institution Location ......................................... 8

Figure 3  Percentage of Alzheimer's Disease Cases by Current Age and Community or Institution Location .................................. 10

Figure 4  Percentage of Alzheimer's Disease Cases by Ethnicity and Community or Institution Location ................................. 12

Figure 5  Percentage of Alzheimer's Disease Cases by Marital Status and Community or Institution Location ........................... 14
EXECUTIVE SUMMARY

The Prevention Center, University of South Carolina (USC) School of Public Health, in cooperation with the South Carolina (SC) Department of Health and Human Services, the SC Department of Mental Health, and the USC School of Medicine, 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 Center for Geriatric Medicine, Education and Research. All cases are identified from a computerized 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.

Current estimates for 1995 suggest that over 30,000 individuals among those aged 65 and older in South Carolina have some form of dementia. Approximately 65 percent have Alzheimer’s disease (about 20,000 individuals). These numbers will almost double in ten years and more than triple in 25 years with about 102,440 individuals aged 65 and over with dementia and about 66,586 with Alzheimer’s disease.

During the calendar year 1995, the registry maintained information on 6,045 individuals with a diagnosis of Alzheimer’s disease or a related dementia. Sixty-two percent had a diagnosis of Alzheimer’s disease and an additional 14 percent had a diagnosis of dementia due to stroke. Others were diagnosed with alcohol or drug-induced dementia (nine percent), and dementia secondary to other medical conditions (15 percent). Highlights of the 1995 prevalence data include:

- 43% of those with Alzheimer's disease were first diagnosed between the ages of 75 and 84
- 22% of those with Alzheimer's disease were first diagnosed at age 85 years or older.
- 37% of those with Alzheimer's disease are currently over 84 years of age.
- Almost 60% of those with Alzheimer's disease reside in the community.
- 75% of those with Alzheimer's disease who reside in the community are currently over 74 years of age.
82% of those with Alzheimer's disease living in institutions are currently over 74 years of age.

More women than men are affected with Alzheimer's disease and multi-infarct dementia, possibly 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 45 percent in each category).

53% of those with Alzheimer's disease who reside in the community are African American.

36% of those with Alzheimer's disease who reside in institutions are African American.

At least half of those with Alzheimer's disease have less than a high school education.

64% of those with Alzheimer's disease are widowed, divorced, or separated (66% of those residing in institutions and 63% of those residing in the community).

For 46% of those with Alzheimer's disease, death occurred within 2 years of diagnosis.

For 37% of those with Alzheimer's disease, death occurred more than 5 years after the onset of symptoms.

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 Prevention Center, USC School of Public Health for core support; the USC School of Medicine (Department of Medicine, Division of Geriatrics) for providing space and collaboration; the SC Department of Mental Health for continued support, access to data, and for providing space in the James F. Byrnes Center for Geriatric Medicine, Education, and Research; 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 for 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) 777-4253 for further information.
OVERVIEW

Scope of the Problem

The prevalence of dementia is estimated to be over 10 percent among persons aged 65 and older, and about 47 percent among those aged 85 and older. While the proportion of persons over age 65 increased nationally by 16 percent from 1980 to 1995, the percentage increase in South Carolina was 54 percent. By the year 2020, the population over age 65 in South Carolina is expected to increase by 174 percent over the 1980 population, with the largest increase (380 percent) expected in the over 85 age group.

Although we have no information on the total number of persons with dementia in South Carolina, we can estimate this number by applying data obtained from studies conducted in other parts of the country. To determine the expected number of dementia and Alzheimer's disease cases in South Carolina, and to make projections for the years 1995 and 2020, we used prevalence estimates from a 1980 Minnesota study and weighted these estimates by the age distribution of the South Carolina population. These statewide results, for adults age 65 and over, are shown in Table 1.

Table 1

Projected Prevalence of Dementia Among South Carolina Adults Aged 65 and Older, from 1995 to 2020

<table>
<thead>
<tr>
<th>Year</th>
<th>Population Aged 65+</th>
<th>Rate per 100*</th>
<th>Projected Dementia</th>
<th>Alzheimer's Disease**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>443,000</td>
<td>7</td>
<td>31,010</td>
<td>20,157</td>
</tr>
<tr>
<td>2000</td>
<td>481,000</td>
<td>9</td>
<td>43,290</td>
<td>28,139</td>
</tr>
<tr>
<td>2005</td>
<td>518,000</td>
<td>11</td>
<td>56,980</td>
<td>37,037</td>
</tr>
<tr>
<td>2010</td>
<td>575,000</td>
<td>12</td>
<td>69,000</td>
<td>44,850</td>
</tr>
<tr>
<td>2015</td>
<td>670,000</td>
<td>13</td>
<td>87,100</td>
<td>56,615</td>
</tr>
<tr>
<td>2020</td>
<td>788,000</td>
<td>13</td>
<td>102,440</td>
<td>66,586</td>
</tr>
</tbody>
</table>

*Rate is adjusted for age
**65% of dementia is estimated to be Alzheimer's disease

The predicted prevalence of dementia for those aged 65 and older, 75 and older, or 85 and older will increase considerably in the next few decades. By the year of 2020, the prevalence will increase by 86 percent for the 65+ age group, 93 percent for the 75+ age group, and 97 percent for the 85+ age group compared to 1995. Dementia prevalence appears to increase faster in the 85+ age group than in the 65+ or 75+ age groups due to the projected increase in the number and proportion of those in the older age groups. Also, over time, more patients diagnosed at ages 65+ and 75+ will survive into the 85+ age group (Figure 1).

**Figure 1. Projected Prevalence of Dementia in South Carolina for Age 65+, 75+ or 85+ from Year 1995 to 2020**

![Graph showing projected prevalence of dementia in South Carolina for Age 65+, 75+ or 85+ from Year 1995 to 2020.](image-url)
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. Since July 1993, the registry has been 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, 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 establishing 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 at the James F. Byrnes Center for Geriatric Medicine, Education, and Research. 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, that 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; the physician's diagnosis is collected from the patient's medical record. These diagnoses are coded using the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM, 1980) and are classified into four general categories for reporting purposes as shown in Table 2.
Table 2

Classification of Dementias by ICD-9-CM Codes
Alzheimer’s Disease Registry, 1995

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>ICD-9-CM Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALZHEIMER’S DISEASE</td>
<td></td>
</tr>
<tr>
<td>Senile or presenile dementia</td>
<td>290.0 - 290.3</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>290.8 - 290.9</td>
</tr>
<tr>
<td></td>
<td>331.0</td>
</tr>
<tr>
<td>MULTI-INFARCT DEMENTIA</td>
<td></td>
</tr>
<tr>
<td>Arteriosclerotic dementia</td>
<td>290.4 - 290.43</td>
</tr>
<tr>
<td>ALCOHOL or DRUG-INDUCED DEMENTIA</td>
<td></td>
</tr>
<tr>
<td>Alcohol dementia</td>
<td>291.2</td>
</tr>
<tr>
<td>Drug-induced dementia</td>
<td>292.82</td>
</tr>
<tr>
<td>MEDICAL DIAGNOSES WITH DEMENTIA</td>
<td></td>
</tr>
<tr>
<td>Dementia with other conditions</td>
<td>294.1</td>
</tr>
<tr>
<td>Organic brain syndrome</td>
<td>310.10</td>
</tr>
<tr>
<td>Other cerebral degeneration</td>
<td>331.1 - 331.9</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>332.0 - 332.1</td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td>333.4</td>
</tr>
<tr>
<td>Primary cerebellar degeneration</td>
<td>334.2 - 334.29</td>
</tr>
<tr>
<td>Spinocerebellar disease</td>
<td>334.9 - 334.99</td>
</tr>
</tbody>
</table>

Those with 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, cases are collected from several sources: the SC Department of Mental Health, the Community Mental Health Centers, the Medical University of South Carolina, Community Long-Term Care, Nursing Homes and Residential Care Facilities, and the SC Department of Health and Environmental Control, Vital Records and Public Health Statistics.

The registry core data set (Table 3) consists of patient 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: medical diagnoses, scores on mental status examinations, educational status, literacy, mental retardation, family history of dementia, and other items recommended for a national core data set on dementia.

Table 3

Registry Core Data Items
Alzheimer's Disease Registry, 1995

| Identification of patient (for matching purposes only) |
| 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) |

CHARACTERISTICS OF DEMENTIA IN SOUTH CAROLINA, 1995

Tables 4-9 and Figure 2 describe demographic characteristics and medical information of all 6,045 current cases, displayed by type of dementia. Because of the difference in needs between those in institutions and those in the community, Figures 3-5 separate the cases by location and show only Alzheimer's disease cases.

Type of Dementia

Among the 6,045 current cases, 62 percent have a diagnosis of Alzheimer's disease and 14 percent have a diagnosis of multi-infarct (or stroke) dementia. In the event of a multiple diagnosis (e.g., records showing both Alzheimer's disease and multi-infarct dementia) the patient is reported in the Alzheimer's disease category. Therefore, as shown in Table 4, the 874 cases who have a diagnosis of multi-infarct dementia do not have an additional Alzheimer's disease diagnosis in their record. The diagnosis shown represents the most current diagnosis in the medical record.

Over 60 percent of all registry cases live in the community. The distribution of dementia types, shown in Figure 2, is similar between the institution and the community cases. 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 (69 percent) when compared to the proportion of the community cases with Alzheimer's disease or senile dementia (58 percent).
Table 4
Percentage of Registry Cases by Dementia Type
Alzheimer's Disease Registry, 1995

<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>1511 (69)</td>
<td>2211 (58)</td>
<td>3722 (62)</td>
</tr>
<tr>
<td>Multi-infarct</td>
<td>240 (11)</td>
<td>634 (16)</td>
<td>874 (14)</td>
</tr>
<tr>
<td>Alcohol/drug-induced</td>
<td>183 (8)</td>
<td>348 (9)</td>
<td>531 (9)</td>
</tr>
<tr>
<td>Medical conditions</td>
<td>271 (12)</td>
<td>647 (17)</td>
<td>918 (15)</td>
</tr>
<tr>
<td>Total</td>
<td>2205 (100)</td>
<td>3840 (100)</td>
<td>6045 (100)</td>
</tr>
</tbody>
</table>

Figure 2. Percentage of Registry Cases by Dementia Type and Community or Institution Location
Age

As shown in Table 5, those with Alzheimer's disease were most often diagnosed between the ages of 75 and 84, with 37 percent currently over 84 years of age. Focusing on those with Alzheimer's disease, Figure 3 indicates that 82 percent of the institutionalized cases are currently over 74 years of age and 75 percent of community cases are over 74 years of age.

Table 5

Percentage of Registry Cases by Diagnosis Age, Current Age, and Dementia Type
Alzheimer's Disease Registry, 1995

<table>
<thead>
<tr>
<th>DIAGNOSIS AGE</th>
<th>AD n=3722</th>
<th>MID n=874</th>
<th>ALC/DRUG n=531</th>
<th>MEDICAL n=918</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>10</td>
<td>22</td>
<td>74</td>
<td>60</td>
</tr>
<tr>
<td>65-74</td>
<td>25</td>
<td>27</td>
<td>20</td>
<td>19</td>
</tr>
<tr>
<td>75-84</td>
<td>43</td>
<td>34</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>85+</td>
<td>22</td>
<td>17</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CURRENT AGE</th>
<th>AD n=3722</th>
<th>MID n=874</th>
<th>ALC/DRUG n=531</th>
<th>MEDICAL n=918</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>6</td>
<td>18</td>
<td>53</td>
<td>54</td>
</tr>
<tr>
<td>65-74</td>
<td>16</td>
<td>23</td>
<td>32</td>
<td>17</td>
</tr>
<tr>
<td>75-84</td>
<td>41</td>
<td>34</td>
<td>13</td>
<td>20</td>
</tr>
<tr>
<td>85+</td>
<td>37</td>
<td>26</td>
<td>2</td>
<td>10</td>
</tr>
</tbody>
</table>

AD = Alzheimer's disease or senile dementia
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 Current Age and Community or Institution Location

- Under 65
- 65-74
- 75-84
- 85+

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Institutions</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>65-74</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>75-84</td>
<td>43</td>
<td>40</td>
</tr>
<tr>
<td>85+</td>
<td>39</td>
<td>35</td>
</tr>
</tbody>
</table>

37%  
41%  
6%  
16%
Gender and Ethnicity

Table 6 indicates that more women than men are affected with Alzheimer's disease and multi-infarct dementia, possibly due to the larger proportion of women alive after age 65. As for ethnicity, African Americans, who comprise nearly 30 percent of the adult South Carolina population, are over represented in all dementia categories compared to whites. Furthermore, 53 percent of Alzheimer's disease cases in the community are African American (Figure 4).

Table 6

Percentage of Registry Cases by Gender, Ethnicity and Dementia Type
Alzheimer's Disease Registry, 1995

<table>
<thead>
<tr>
<th></th>
<th>AD n=3722</th>
<th>MID n=874</th>
<th>ALC/DRUG n=531</th>
<th>MEDICAL n=918</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GENDER</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>30</td>
<td>40</td>
<td>78</td>
<td>58</td>
</tr>
<tr>
<td>Women</td>
<td>70</td>
<td>60</td>
<td>22</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>54</td>
<td>44</td>
<td>38</td>
<td>54</td>
</tr>
<tr>
<td>African-American</td>
<td>46</td>
<td>56</td>
<td>62</td>
<td>46</td>
</tr>
</tbody>
</table>

AD = Alzheimer's disease or senile dementia
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 Ethnicity and Community or Institution Location

![Pie Chart: 46% White, 54% African-American]

![Bar Chart: 64 Institution White, 36 Institution African-American, 47 Community White, 53 Community African-American]
Education and Marital Status

While we do not have complete information on educational status (around 20 percent of the records do not include information on education), it appears as if about half the dementia cases in our registry have less than a high school education. This information is similar to the state statistics for older South Carolinians.

Regardless of dementia diagnosis, the majority of the registry population is divorced, widowed or separated (Table 7). There appears to be little difference in marital status and location of residence (Figure 5).

Table 7

Percentage of Registry Cases by Education, Marital Status and Dementia Type
Alzheimer’s Disease Registry, 1995

<table>
<thead>
<tr>
<th></th>
<th>AD n=3722</th>
<th>MID n=874</th>
<th>ALC/DRUG n=531</th>
<th>MEDICAL n=918</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>65</td>
<td>66</td>
<td>58</td>
<td>45</td>
</tr>
<tr>
<td>High school or more</td>
<td>35</td>
<td>34</td>
<td>42</td>
<td>56</td>
</tr>
<tr>
<td>MARITAL STATUS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>27</td>
<td>32</td>
<td>21</td>
<td>28</td>
</tr>
<tr>
<td>Divorced/Widowed/Separated</td>
<td>64</td>
<td>58</td>
<td>52</td>
<td>40</td>
</tr>
<tr>
<td>Single</td>
<td>9</td>
<td>10</td>
<td>27</td>
<td>32</td>
</tr>
</tbody>
</table>

AD = Alzheimer’s disease or senile dementia
MID = multi-infarct dementia
ALC/DRUG = alcohol or drug-induced dementia
MEDICAL = dementia secondary to a medical condition
Figure 5: Percentage of Alzheimer's Disease Cases by Marital Status and Community or Institution Location

- Married
- Div/Wid/Sep
- Single

Pie chart and bar graph showing the distribution of Alzheimer's disease cases by marital status and location (institution vs. community). The percentages are as follows:

- Married: 64%
- Div/Wid/Sep: 9%
- Single: 27%

Number of subjects in each category:

- Institution:
  - Married: 21
  - Div/Wid/Sep: 13
  - Single: 31

- Community:
  - Married: 66
  - Div/Wid/Sep: 63
  - Single: 6
Medical History

Other diagnoses present on medical records are shown on Table 8. Because of the strong relationship of age with the other diagnoses, these percentages were adjusted for age. About 24 percent of those with a dementia diagnosis of Alzheimer’s disease, alcohol or drug-induced dementia, or dementia secondary to a medical condition, also have a diagnosis of cardiovascular disease. On their medical record only 51 percent of those with a diagnosis of multi-infarct dementia also have a diagnosis of cardiovascular disease.

Table 8

Percentage* of Registry Cases by Medical History and Dementia Type
Alzheimer's Disease Registry, 1995

<table>
<thead>
<tr>
<th></th>
<th>AD n=3722</th>
<th>MID n=874</th>
<th>ALC/DRUG n=531</th>
<th>MEDICAL n=918</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HISTORY OF</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>10</td>
<td>13</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>4</td>
<td>4</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Depression*</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Head injury</td>
<td>6</td>
<td>3</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>26</td>
<td>51</td>
<td>25</td>
<td>22</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>12</td>
<td>14</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>23</td>
<td>38</td>
<td>15</td>
<td>23</td>
</tr>
<tr>
<td>Syphilis</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

* These percentages are adjusted for age
* includes major depression and bipolar affective disorder

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

Table 9 summarizes deaths that occurred between 1988-1995, through the merging of death certificate and registry data. Other than among those with a diagnosis of dementia due to alcohol or drug abuse, the majority of deaths occurred within two years of the diagnosis. 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 of symptoms to date of death. In this situation, the onset of symptoms occurred more than 5 years before death for more than a third of 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.

Table 9

Percentage of Registry Deaths by Length of Illness and Dementia Type
Alzheimer's Disease Registry, 1988-1995

<table>
<thead>
<tr>
<th></th>
<th>AD (n=2364)</th>
<th>MID (n=540)</th>
<th>ALC/DRUG (n=184)</th>
<th>MEDICAL (n=294)</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>46</td>
<td>52</td>
<td>35</td>
<td>48</td>
</tr>
<tr>
<td>2-5 years</td>
<td>34</td>
<td>32</td>
<td>39</td>
<td>31</td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>20</td>
<td>17</td>
<td>26</td>
<td>21</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>31</td>
<td>32</td>
<td>19</td>
<td>37</td>
</tr>
<tr>
<td>2-5 years</td>
<td>32</td>
<td>31</td>
<td>31</td>
<td>24</td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>37</td>
<td>37</td>
<td>50</td>
<td>39</td>
</tr>
</tbody>
</table>

\*If date of onset was not available, date of diagnosis was substituted

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

Research Staff

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

Caroline A. Macera, Ph.D., Director, is a professor of epidemiology at the School of Public Health, USC. Her research interests are chronic disease epidemiology, including health aspects of physical activity, aging related issues, and caregiver burden.

Carol B. Cornman, B.S., R.N., P.A., Associate Director, serves as the clinical and field coordinator for the Alzheimer's Disease Registry and ARG projects. She handles all requests for information from the registry. Her research interests include ethnic differences in dementia and incorporating wellness activities into the lives of the elderly.

Dorothy Davis, B.A., serves as data manager for ARG and Community Long Term Care (CLTC) projects. She also provides access to national data sets.

Bonita D. Clemons, M.P.H., research associate at the Alzheimer's Disease Registry. Her research interests include African-American women's health issues and nutrition in the elderly.

Graduate Research Assistants

William K. Scott, M.S.P.H., Ph.D. in epidemiology. His research interests include neuroepidemiology (specifically Alzheimer's disease and Huntington's disease), gerontological health, and the epidemiology of sexually transmitted diseases.

Conrad M. Otterness, B.A., M.P.H. in epidemiology. His research interests include infectious disease epidemiology, control and treatment, program evaluations, and the study of environmental risk issues.

Myriam E. Torres, R.N., M.S.P.H., Ph.D. candidate in epidemiology. Her research interests include Hispanic health issues, cardiovascular disease risk factors, the epidemiology of Alzheimer's disease and related disorders, and caregiver issues.
Deyi Zheng, M.B., M.S., Ph.D. candidate in epidemiology. His research interests include neuroepidemiology and gerontology, in particular, Alzheimer's disease and related disorders.

Kristin B. Edwards, B.S., M.S.P.H. in biostatistics. Her research interests include power analysis and sample size determination for categorical data.

Tami S. Ashford-Carroll, M.P.H., M.S.W., B.A., Ph.D. candidate in epidemiology. Her research interests include African-American health issues, gerontological health, and chronic disease epidemiology.

Martin W. Durkin, M.D., M.P.H. candidate in epidemiology. His research interest is the application of artificial neural networks in epidemiology.

Paul E. Szwejbka, B.S., M.P.H. candidate in epidemiology. His research interests include cognitive degeneration, neuro protection, and the epidemiology of aging.

**Affiliated Research Staff**

Patricia A. Brill, Ph.D., Research Assistant Professor at the USC Prevention Center, School of Public Health. Her research interests include strength training in the elderly, functional limitations, and activities of daily living associated with physical inactivity.

Elaine M. Frank, Ph.D., Assistant Professor in the Department of Speech-Language Pathology and Audiology, School of Public Health. Lexical and semantic associations in dementia patients, and the investigation of language and speech with the neurogenic disease population are her research interests.

Youjie Huang, M.D., Dr. P.H., M.P.H, research associate at the USC Prevention Center, School of Public Health. His research interests include cardiovascular disease, functional health, and environmental exposures.

Marcia J. Lane, M.P.H., research associate at the USC Prevention Center, School of Public Health. Her research interests are older women's health issues, physical activity, and cardiovascular disease.

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. Her research interests are caregiving issues and health promotion interventions with the older adult.
Research in Progress

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

**Polypharmacy and Cognitive Impairment**

Polypharmacy is a term widely used with definitions that vary from the number of drugs being taken, the classes of drugs being taken and/or the appropriateness of a particular drug, with no consensus of the definition found in the literature. The registry staff is involved in the analysis of these issues as they relate to cognitive impairment in the older adult.

**The Comparison of Different Methods of Projecting the Prevalence of Dementia**

Due to the increasing proportion of and absolute number of aging individuals in recent years, the projecting of the prevalence of dementia has become important. The registry staff is comparing several methods of projected prevalence and applying them to the population of South Carolina to be used to develop effective strategies for health care education, planning and service delivery.

**Location of Death as an Indicator of End Of Life Cost for the Person with Dementia**

Costs of health services during the last four weeks of life differ dramatically according to the location of the person receiving those services. With the increasing numbers of individuals over the age of 65 and the increasing incidence of dementia with age, the location of the individual with dementia becomes increasingly important. The registry staff is analyzing the location of death of persons with dementia using death certificates to evaluate the impact of cost and quality of life on those with a dementia diagnosis.

**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. Along with the report, funding was obtained for an Alzheimer's Resource Coordination Center administered by the Governor's Office Division on Aging. Two members of the staff have been appointed by the Governor to the Advisory Council of the Center and continue to be actively involved in providing support of Alzheimer's disease issues, especially the expansion of respite programs for families of individuals with Alzheimer's disease through small grants to community organizations.
Nutrition Interventions at Congregate Meal Sites

Data and analytical support were supplied by the registry staff for this project that involves nutritional interventions conducted at congregate meal sites by the Department of Health Promotion and Education, School of Public Health, USC.

Dementia Caregiver Support Intervention

The Department of Health Promotion and Education, School of Public Health, USC, is training family caregivers of persons with dementia to act as peer counselors for new caregivers. The registry staff has provided support in subject recruitment.

Evaluation of Caregiver Service Project

The registry staff work 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 Health Resources and Services Administration (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 Studies

These projects use data from a preventive medicine clinic to prospectively assess functional limitations among physically fit and unfit individuals to determine the possible role of strength, physical fitness, and physical activity in preventing functional limitations.

Naming Impairments 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.

Effect of Huntington's Disease on Speech and Language

Registry staff assisted in the data collection and analysis for a project assessing the language effects of Huntington's disease. The project is the result of collaboration between the Huntington's Disease Test Center, William S. Hall Psychiatric Institute, and the USC Department of Speech-Language Pathology and Audiology.
Effects of Exercise on Functional Mobility in the Elderly

Registry staff provided analytical support for a study evaluating the efficacy of an exercise intervention on functional mobility. This study is being conducted in the Prevention Center, USC School of Public Health.

Publications and Presentations
The following is a list of the manuscripts and reports. 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 1995:

Gerontology Society of America Annual Meeting, Los Angeles, California
“Dementia: A Diagnostic and Educational Challenge”.
“Functional Health Status as a Predictor of Mortality in the Community-Dwelling Elderly”.

South Carolina Public Health Association Meeting, Myrtle Beach, SC
“Prevalence of Alzheimer's Disease in South Carolina, 1994”.

Society for Epidemiologic Research Annual Meeting, Snowbird, Utah
“Mental Status Questionnaire Scores Among Patients with Alzheimer's Disease in Community Long Term Care: Does Ethnicity Make a Difference?”.

American Public Health Association Annual Meeting, San Diego, California
“Acculturation and Nutritional Status Among Mexican-Americans, Cuban-Americans, and Puerto Ricans”.
“Depression and Death of Cardiovascular Disease Among U.S. Adults Aged 18 and Older”.
“Decline in Functional Health and Institutionalization Among Community Long Term Care Clients with Dementia”.

22
ACKNOWLEDGMENTS

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 USC School of Public Health for core support; the SC Department of Mental Health for continued support, access to data, and for providing space in the James F. Byrnes Center for Geriatric Medicine, Education, and Research; the SC Department of Health and Human Services for core support and access to data; the USC School of Medicine (Department of Medicine, Division of Geriatrics) for providing opportunities for collaboration; the SC Department of Health and Environmental Control, Vital Records and Public Health Statistics for access to data; 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. For further information, contact the registry staff at (803) 777-4253 or e-mail ccornman@sph.sc.edu.

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) 777-4253.
Alzheimer’s Disease Registry Order Form

1995 TRANSPARENCIES AND SLIDES

Alzheimer’s Disease Registry Prevention Center
School of Public Health
University of South Carolina
Columbia, SC 29208

Fax Number: (803) 777-9007
Phone Number: (803) 777-4253

Customer Information

INDIVIDUAL/COMPANY NAME: ____________________________ TITLE: ____________________________
ADDRESS: ____________________________ SUITE: ____________________________
CITY: ____________________________ STATE: ____________________________ ZIP: ____________________________
ATTN: ____________________________ WORK PHONE: ____________________________

SPECIAL INSTRUCTIONS: _______________________________________________________________

ORDER LIST:

<table>
<thead>
<tr>
<th>ORDER</th>
<th># OF SETS</th>
<th>UNIT PRICE</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black and White Overhead Transparencies</td>
<td>—</td>
<td>$10.00</td>
<td>—</td>
</tr>
<tr>
<td>(12 transparencies per set)</td>
<td>—</td>
<td>$10.00</td>
<td>—</td>
</tr>
<tr>
<td>Color Slides (12 color slides per set)</td>
<td>—</td>
<td>$10.00</td>
<td>—</td>
</tr>
<tr>
<td>Overhead Transparencies and Color Slides</td>
<td>—</td>
<td>$15.00</td>
<td>—</td>
</tr>
<tr>
<td>$15.00 for both</td>
<td>—</td>
<td>$15.00</td>
<td>—</td>
</tr>
<tr>
<td>$15.00 for both</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Allow 2 weeks for delivery. Please make additional copies of this order form for future use.

Make check payable to USC Prevention Center and mail to:
Doris Page
Prevention Center
School of Public Health
University of South Carolina
Columbia, SC 29208

BILLING INFORMATION

FORM OF PAYMENT - (CHECK ONE)

____ CHECK  ____ PURCHASE ORDER  ____ IIT  ____ IDT