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~ ANNUAL REPORT ~

South Carolina ALZHEIMER'S DISEASE REGISTRY and OFFICE FOR THE STUDY OF AGING

2005 *

ARNOLD SCHOOL OF PUBLIC HEALTH UNIVERSITY OF SOUTH CAROLINA COLUMBIA, SC 29208 November 2005

* Unless otherwise noted, data included in this report cover the period January 1, 2003 through December 31, 2003, the most current period with available and comprehensive data.

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~ Executive Summary ~

The Office for the Study of Aging in 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 Research and Statistics of the Budget and Control Board, 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 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 101,813 cases of ADRD. During calendar year 2003, the Registry maintained information on 48,640 individuals alive on January 1, 2003.

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.

Population Prevalence of ADRD, South Carolina, 2003:

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

- 8% of South Carolinians age 65 or over have ADRD.
- 27% of South Carolinians age 85 or over have ADRD.
- 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.

Registry Overview:

Of South Carolinians with diagnosed ADRD:

- 64% have Alzheimer's disease.
- 16% have a dementia due to stroke.
- 20% have a dementia related to other chronic conditions.
- 38% live in a nursing facility.
- 66% are women.
- 33% are African American.
- 38% of those with AD are 85 years or older.

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 1).

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.
- 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." 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 ADRDs associated with medical conditions such as Parkinson's Disease, Huntington's Disease, AIDS, and alcohol or drug abuse.

This report covers calendar year 2003 (those alive on Jan 1, 2003), 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 2003.

¹ The South Carolina Mature Adults Count Report.

² US Bureau of the Census

³ Progress Report on Alzheimer's Disease 1998. NIH Pub. No.99-3616. Alzheimer's Disease Education and Referral (ADEAR) Center, PO Box 8250, Silver Spring, MD 20907-8250.

~ 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. What we do know is that the South Carolina Alzheimer's Disease Registry is the best population-based Registry of ADRD in the country. The only other such registry, in New York, is in practice limited to records from in-patient hospital stays. Our South Carolina Registry uses data from a wide variety of sources to capture as many diagnoses as possible.

⁴ DA Evans, et al. Prevalence of Alzheimer's disease in a community population of older persons. Higher than previously reported. JAMA 1989;262:2551-6.

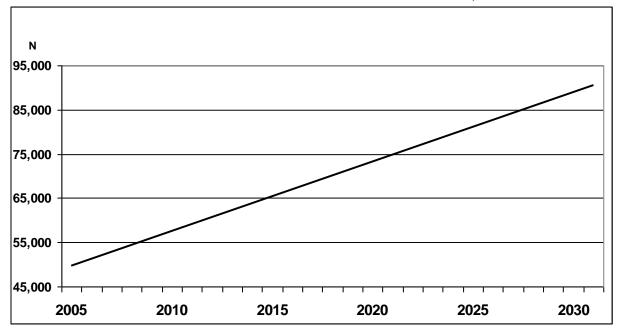
⁵ South Carolina Mature Adults Count Report.

⁶ LE Hebert et al. Alzheimer disease in the US population: Prevalence estimates using the 2000 Census. Archives of Neurology, 2003; Vol 60, 1119-1122

⁷ PP Lillquist. Challenges in Surveillance of Dementias in New York State. Preventing Chronic Disease: Public Health Research, Practice, and Policy, 2004; Vol. 1, No. 1, 1-9

~Projections of Alzheimer's Disease in South Carolina~

Figure 1
Prevalence Projections through 2030
Alzheimer's Disease and Related Disorders in South Carolina,2003



South Carolina ADRD projections, based on the South Carolina Alzheimer's Disease Registry and Interim State Projections of Population by Single Year of Age and Sex, July 1, 2004 to 2030. Source: U.S. Census Bureau, Population Division, Interim State Population Projections, 2005. Release Date, April 21, 2005.

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 inmigration 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.

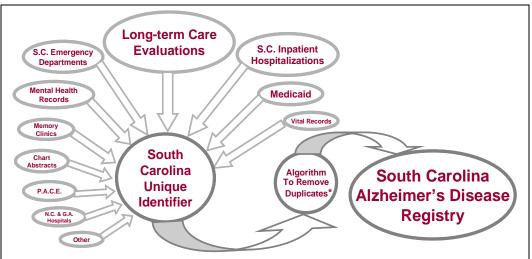
It should be noted that the prevalence projections are for the Registry. The population prevalence of ADRD will be higher than the projection shown in the figure in any given year, because the Registry includes records only for individuals diagnosed by Registry data sources. The Registry includes records 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) 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 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.

The Registry uses data from a variety of data sources, as shown in Figure 2.

Figure 2
Registry Data Sources
South Carolina Alzheimer's Disease Registry, 2003



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

CHARACTERISTICS OF ADRD IN SOUTH CAROLINA~

BASED ON 2003 ALZHEIMER'S DISEASE REGISTRY DATA

Since January 1, 1988, 101,813 cases of Alzheimer's disease and related disorders (ADRD) have been identified in South Carolina. This report describes demographic characteristics and medical information on the 48,640 cases alive on January 1, 2003 displayed by type of ADRD.

Type of ADRD

Among the 48,640 current Registry cases, 64 percent had a diagnosis of Alzheimer's disease, and 14 percent had a diagnosis of vascular (or stroke) dementia. In the event of a multiple diagnosis (records showing both Alzheimer's disease and vascular dementia) the case was reported in a Mixed disease category with 2.5%. The additional 20% for the total number of "Other Conditions" had a dementia related to other medical conditions, such as Parkinson's disease (see Table 2 for compete 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 (38%) or unknown locations (5%) Figure 3. As shown in Figure 4, the distribution of the types of ADRD was similar among community and nursing facilities.

Table 1
Registry Cases by Dementia Type
and Community, Nursing Facility or Unknown Location

South Carolina Alzheimer's Disease Registry, 2003

Dementia Type	Commur	nity	Nursing	Unk	nown	Total		
	N	%	N	%	N	%	N	%
Alzheimer's disease	17,405	63%	12,045	65%	1,519	63%	30,969	64%
Vascular dementia	3,279	12%	3,068	17%	226	9%	6,573	14%
Mixed dementia	586	2%	552	3%	59	2%	1,197	2%
Other conditions	6,515	23%	2,770	15%	616	26%	9,901	20%
Total	27,785		18,435		2,420		48,640	100%

~ Location and ADRD in South Carolina (continued) ~

Figure 3
Registry Cases by Community,
Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2003

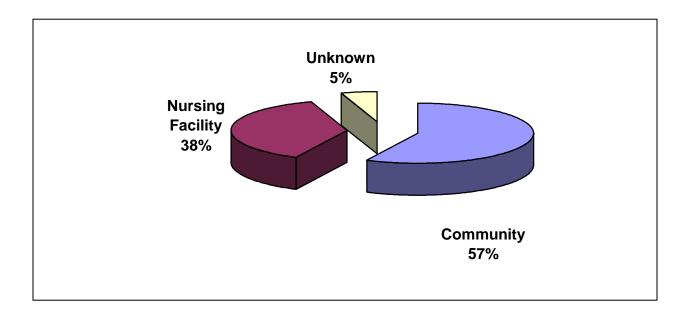
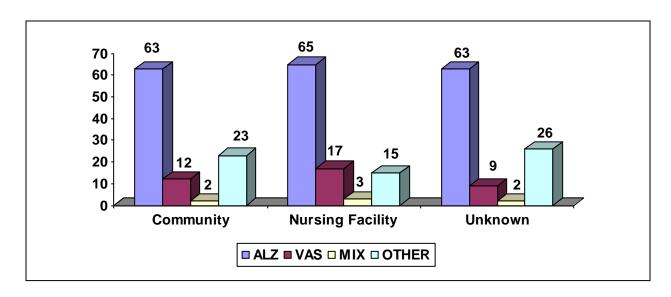


Figure 4
Registry Cases in Community,
Nursing Facility or Unknown Location,
by Dementia Type
South Carolina Alzheimer's Disease Registry, 2003



~ Dementia in Other Medical Conditions ~

In addition to Alzheimer's disease, the Registry tracks other medical conditions, such as Parkinson's disease, alcohol and drug abuse, and HIV/AIDS, that contribute to or cause dementia. In the 2003 Registry, there are 9,901 persons with a medical condition other than Alzheimer's disease or vascular disease contributing to their dementia. Eleven percent of them have dementia associated with Parkinson's disease, and 63% 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 with a few having as many as three.

Table 2

Dementia in Other Medical Conditions
South Carolina Alzheimer's Disease Registry, 2003

	Under 65	65 - 74	75 - 84	85 +	Total	
	%	%	%	%	N	%
Alcohol dementia	15%	7%	1%	1%	644	6%
Drug-induced dementia	<1%	<1%	<1%	<1%	39	<1%
Organic brain syndrome	<1%	0%	0%	<1%	4	<1%
Other cerebral degenerations	18%	26%	17%	13%	1,994	18%
Parkinson's disease	2%	10%	16%	13%	1,227	11%
Huntington's disease	<1%	<1%	<1%	0%	13	<1%
HIV/AIDS	5%	<1%	<1%	<1%	145	1%
Dementia with Lewy bodies	<1%	1%	1%	1%	76	1%
Dementia with other conditions*	58%	56%	64%	72%	7,121	63%
Total	2,472	2,106	3,962	2,723	11,263	100.00

^{*}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.

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~ Age and ADRD in South Carolina ~

Table 3 shows that 38% 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 34% 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.

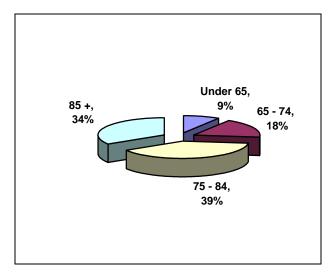
Table 3
Registry Cases by Age Group and Dementia Type
South Carolina Alzheimer's Disease Registry 2003*

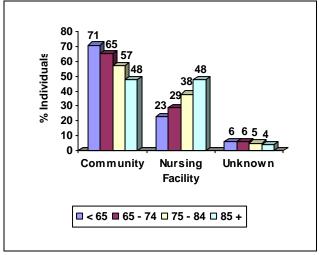
	AD	VASCULAR MIXE			MIXED	OTHER			TOTAL	
	N	%	N	%	N	%	N	%	N	%
Age										
Under 65	1,831	6%	782	12%	68	6%	1,678	18%	4,359	9%
65 - 74	4,966	16%	1,328	21%	211	18%	1,852	20%	8,357	18%
75 - 84	11,944	40%	2,380	37%	538	45%	3,330	36%	18,192	39%
85 +	11,600	38%	1,922	30%	376	31%	2,370	26%	16,268	34%
Total	30,341		6,412		1,193		9,230		47,176	

^{*1,464} 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.

Figure 5
Registry Cases by Age Group
South Carolina Alzheimer's Disease Registry,
2003

Figure 6
Registry Cases by Age Group
in Community, Nursing Facility or
Unknown Location
South Carolina Alzheimer's Disease Registry, 2003





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

~ 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. Among those age 85 or over, in particular, the number of women with ADRD is more than 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
Registry Cases by ADRD Type, Gender, and Age Group
South Carolina Alzheimer's Disease Registry, 2003*

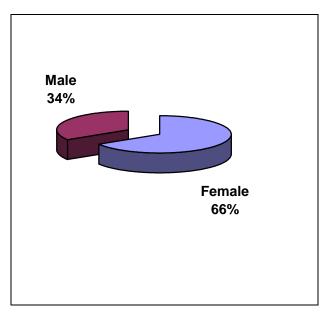
	AD	VA	SCULAF	₹	MIXED	(OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
MEN	8,826		2,395		404		3,823		15,448	
< 65	832	9%	433	18%	41	10%	1,083	28%	2,389	15%
65 - 74	1,976	22%	626	26%	96	24%	935	24%	3,633	24%
75 - 84	3,589	41%	876	37%	188	46%	1,214	32%	5,867	38%
85 +	2,429	28%	460	19%	79	20%	591	16%	3,559	23%
WOMEN	21,422		3,993		784		5,400		31,599	
< 65	995	5%	343	9%	27	3%	595	11%	1,960	6%
65 - 74	2,981	14%	698	17%	114	15%	917	17%	4,710	15%
75 - 84	8,334	39%	1,497	38%	347	44%	2,114	39%	12,292	39%
85 +	9,112	42%	1,455	36%	296	38%	1,774	33%	12,637	40%

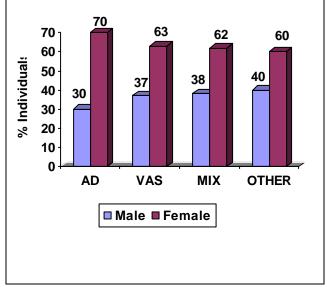
^{*}Records for 1,593 individuals have missing values for gender or age.

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

Figure 7
Registry Cases by Gender
South Carolina Alzheimer's Disease Registry, 2003

Figure 8
Registry Cases by Gender and ADRD Type
South Carolina Alzheimer's Disease Registry, 2003





~ Race and ADRD in South Carolina ~

Compared with whites, African Americans, who comprise nearly 22% of the adult South Carolina population 65 years and older, were over-represented in Vascular dementia (44%) and in the overall Alzheimer's Disease Registry with 33% (Table 5 and Figure 9). Sixty-three percent of African Americans with ADRD reside in the community compared to 54% of whites living in the community (Figure 10).

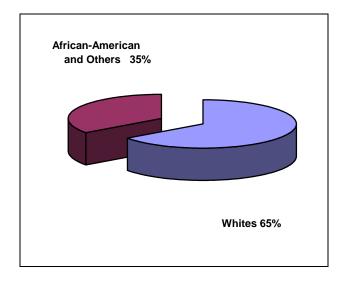
Table 5
Registry Cases by Race and ADRD Type
South Carolina Alzheimer's Disease Registry, 2003*

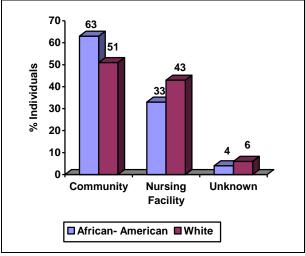
	AD		VASCULAR		MIXE)	OTHE	R	TOTAL	
	N	%	N	%	N	%	N	%	N	%
RACE										
White	20,795	67%	3,631	55%	787	66%	6,543	66%	31,756	65%
Aftican-American	9,578	31%	2,859	43%	385	32%	3,130	32%	15,952	33%
Hispanic	144	<1%	20	<1%	7	<1%	35	0%	206	<1%
All Others	453	1%	63	1%	18	2%	193	2%	726	1%
Total	30,969		6,573		1197		9,901		48640	

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, 2003

Figure 10
Registry Cases by Race in Community,
Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry,2003





~ 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, 53,173 have died. Because actual diagnosis dates are not included in the data available to us, 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, 2003

	AD		VASCULAR MIXED			D	OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
ENTRY to										
DEATH										
< 2	22,830	69%	7,025	71%	59	68%	7,741	76%	37,655	71%
2 - 5	7,102	21%	2,077	21%	23	26%	1,632	16%	10,834	20%
5 +	3,143	10%	781	8%	5	6%	755	7%	4,684	9%
Total	33,075		9,883		87		10,128		53,173	

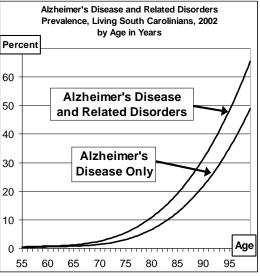
AD =Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer's disease and Vascular dementia; OTHER =dementia in other medical conditions.

~ 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 often develops 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.

Figure 11



- 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

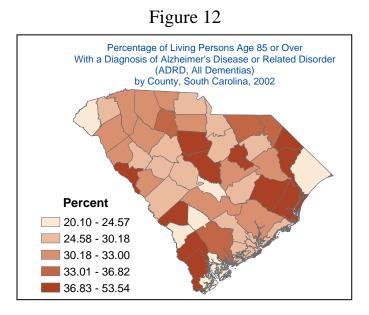
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findings illustrate the rich research capabilities of the South Carolina Alzheimer's Disease Registry.

- 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, the 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

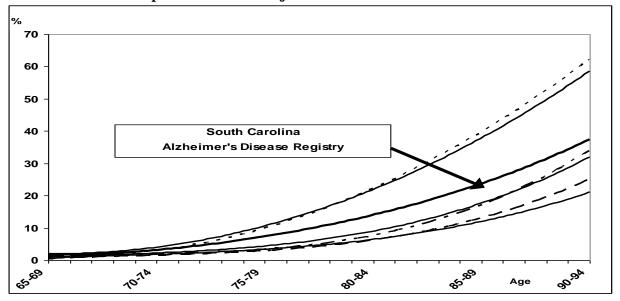


counties where residents enjoy particularly long lives are likely to have greater percentages of individuals with ADRD. This is so because the risks of ADRD rise dramatically at older ages. Thus, the map should not be interpreted to suggest that the incidence of ADRD is higher in counties with higher 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.

~ Comparison to Other Studies ~

Figure 13
Prevalence of Diagnosed ADRD in the South Carolina Alzheimer's Disease Registry
Compared to Other Major Studies of ADRD Prevalence



The Figure shows the age-specific prevalence of diagnosed ADRD in the South Carolina Alzheimer's Disease Registry, compared to corresponding prevalence estimates from other major national studies of ADRD. (Estimates in the figure from: Hy & Keller, Prevalence of AD among whites: a summary by levels of severity. Neurology, 2000;55(2):198-204.). Several observations can be made about this figure:

- It should be noted that other major national studies focus primarily on whites. The Registry has revealed that African Americans have much higher ADRD rates than whites in South Carolina. Thus, because we have a notable African American population in South Carolina, we would expect the SC estimates to be higher than those of other studies. This is what the figure shows, with the exception of two other studies.
- In the two studies with higher prevalence estimates, the prevalence estimates included very mild forms of cognitive impairment, representing individuals who would be unlikely to require medical or social services for ADRD. The Registry does not include such cases.
- It is now widely accepted that obesity, hypertension, and diabetes are major risk factors for dementia. South Carolina has higher rates of these conditions than much of the rest of the country. Thus, we would expect the SC rates to be higher than those from other studies. This is what the figure shows, again excepting the two studies that included very mild forms of cognitive impairment.

In summary, the figure suggests that our estimates of diagnosed ADRD from the Registry are reasonable. The figure also suggests that our higher rates of risk factors for ADRD in South Carolina have produced higher rates of ADRD than those found in many other parts of the country. Recent emerging knowledge about the importance of hypertension, diabetes, and obesity as risk factors for dementia suggest that we may have an opportunity to reduce the future growth of ADRD in our state, by encouraging healthy lifestyles.

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~ Registry Procedures ~

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.

Individuals with ADRD are usually identified, as they (or their family members) require provider services. Since no single system identifies all newly diagnosed patients with ADRD, 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, the SC Department of Health and Environmental Control, Vital Records and Public Health Statistics and the South Carolina Budget and Control Board.

Table 7
Classification of ADRD by ICD-9-CM Codes
South Carolina Alzheimer's Disease Registry, 2003

ALZHEIN	MER'S DISEAS	E					
2	90.0 - 290.3	Senile or presenile dementia					
2	90.8 - 290.9						
3	31.0	Alzheimer's disease					
VASCUL	AR DEMENTI	A					
2	90.4 - 290.43	Arteriosclerotic dementia					
4	35 - 438	Cerebrovascular disease (with a dementia code*)					
MIXED I	DEMENTIA						
В	Both Alzheimer's disease and Vascular dementia						
DEMENT	TIA IN OTHER	MEDICAL CONDITIONS (see note below)					
		Alcohol dementia					
$\frac{1}{2}$	92.82	Drug-induced dementia					
2		Dementia with other conditions					
3		Dementia with Lewy bodies					
_		(the same code is used for dementia with Parkinsonism)					
Т	The following co	onditions are included with a dementia code*:					
	_	Organic brain syndrome					
3		· ·					
		Parkinson's disease					
3	33.4	Huntington's disease					
0		HIV					

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.

~ Core Data Items ~

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, 2003

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 & Training 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 also conduct other activities focused on health problems of older individuals, training of direct care staff and professionals in topics on ADRD, and exercise.

Alzheimer's Resource Coordination Center

The Alzheimer's Resource Coordination Center (ARCC) was established to improve the lives of individuals with Alzheimer's disease and related disorders, their caregivers and families through coordination, service development, communication and caregiver support. Two members of the staff have been appointed by the Governor to serve on the 23 member Advisory Council to the ARCC. They are actively involved in providing support for Alzheimer's disease issues, especially the expansion of respite programs for families of individuals with Alzheimer's disease through providing small grants to community organizations.

Consumer Directed Care

Consumer directed care 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 is providing technical assistance, training and evaluation services to the South Carolina Department of Health and Human Services as Community Long Term Care pilots consumer directed care.

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. 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.

~ Research Projects and Training Activities ~ (continued)

Functional Status Measurement

A study in cooperation with the Department of Exercise Science is in progress to develop 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.

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.

Current Research Using the Registry

Several projects are underway to further develop and use the Registry:

- Developing computerized decision-rules to remove duplicate observations from the Registry. (For example, an individual may be hospitalized using two or more different names on separate occasions, creating multiple records that should be captured as only a single case in the Registry.)
- Mapping disease prevalence for demographic groups defined by sex, age, and race/ethnicity.
- Identifying the impact on the Registry of including ADRD diagnoses from physician office visits using the State Health Plan, an approximately 10% sample of South Carolinians.
- Estimating the hospital costs of ADRD.
- Providing estimates of the overall success of the primary health care system for individuals with Alzheimer's disease.
- Conducting research on access to health care and social services for individuals with Alzheimer's disease and their families.
- Examining the epidemiology of AIDS Dementia.
- Examining the epidemiology of dementia related to Parkinson's disease.

~ Other Research at the Office for the Study of Aging ~

Researchers of the Office for the Study of Aging have conducted numerous research projects, using the Registry and other data sources to study aging processes. In addition to several studies of Alzheimer's Disease in South Carolina, these have included research published in American Journal of Alzheimer's Care and Related Disorders and Research, American Journal of Alzheimer's Disease and Other Dementias, American Journal of Psychiatry, Annals of Epidemiology, Creative Forecasting, Evaluation and the Health Professions, The Gerontologist, Home Care Provider, International Journal of Aging and Human Development, Journal of American Geriatrics Society, Journal of Clinical Epidemiology, and The Journal of the South Carolina Medical Association. Complete citations appear later in this report. The subjects of these research articles have included:

- Use of capture-recapture methodology to determine the prevalence of ADRD in South Carolina.
- Comorbidity associated with ADRD.
- The value of strength training for older adults.
- Location of death as an indicator of end-of-life costs for the person with ADRD.
- Functional health status as a predictor of mortality in men and women over 65.
- Risk of institutionalization among community long-term care clients with ADRD.
- Major depression and all-cause mortality among white adults in the United States.
- A functional fitness workshop.
- Survival of Alzheimer's disease patients with regard to pattern of care in South Carolina.
- Epidemiology of Alzheimer's disease.
- Perceived burden among caregivers.
- The association of positive and negative events with depressive symptomatology among caregivers.
- Ethnic differences in the burden of caregiving.
- Sensitivity and specificity of death certificate diagnoses for dementing illnesses.
- Problems in establishing case definitions for Alzheimer's disease registries.

In addition, our current researchers have published aging-related studies of caregiving, health services supply, active life expectancy, hospitalization risks, effects of recent widowhood on health, protective effects of social contacts on health, health care use by individuals with diabetes, home and community-based services, eligibility for long-term care services, managed care, medical savings accounts, preventable hospitalization, and the compression of morbidity. These studies have appeared in *Archives of Internal Medicine, Home Health Care Services Quarterly, Health and Place, The Journal of Applied Gerontology, The Journal of Health and Social Policy, The Journal of Women and Aging, Medical Care Research and Review, Research on Aging, and Social Science and Medicine.*

~ Registry Staff ~

- **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 program evaluation for activities related to the office for the Study of Aging. Her research interests include consumer directed care.
- **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.
- **Sara Lauren Fehling,** B.A., **Graduate Research Assistant**, is a masters student in Health Services, Policy and Management. Her research interests focus on disaster preparedness in nursing homes.
- **James N. Laditka**, D.A., Ph.D., M.P.A., M.A.T., **Research Director** of the Office for the Study of Aging, provides direction of the Office's research. His research focuses on the epidemiology of Alzheimer's disease and related disorders, health and health care disparities among older populations, active life expectancy, and quality of life in long-term care.
- **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, and consumer directed care.
- **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.
- **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 longitudinal data analysis.
- Whitney Wall, B.S., Graduate Research Assistant, is a master's student in Health Promotion, Education and Behavior. Her research interests focus on educating health workers.

~ Affiliated Professionals ~

Cheryl Addy, Ph.D., is Executive Associate Dean, Arnold School of Public Health.

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Keith Davis, Ph.D., is Professor, Department of Psychology.

Keith Elder, Ph. D., is an Assistant Professor, Health Services and Policy Management, Arnold School of Public Health.

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~ Affiliated Professionals ~

(Continued)

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John Woods, Ph.D., Director, Center for Public Health Services and Policy Research, Arnold School of Public Health.

~ Office Publications ~

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.

- Laditka JN, Laditka SB, Probst J, More May be Better: Evidence that a Greater Supply of Primary Care Physicians Reduces Hospitalization for Ambulatory Care Sensitive Conditions. *Health Services Research*. (In Press)
- Laditka JN, Laditka SB, Cornman CB, Evaluating hospital care for individuals with Alzheimer's disease using impatient quality indicators. *American Journal of Alzheimer's Disease and Other Dementias*, Vol 20 No1, 2005.
- Lin HC, Xirasagar S, Laditka JN, Patient Perceptions of Service Quality in Group versus Solo Practice Clinics. *International Journal for Quality in Health Care* (In Press).
- Laditka JN, Laditka SB, Insurance Status and Primary Care Access: Disparate Outcomes for Preventable Hospitalization. *Journal of Health and Social Policy*. (In Press).
- Laditka JN, Physician Supply, Physician Diversity, and Outcomes of Primary Health Care for Older Persons in the United States. *Health and Place*, *10*, 231-244, 2004.
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- Laditka SB, Trevisani, G. D'Accurzio A, Laditka JN, Scherzer GD, Kane L, Early Readmission of Patients with Congestive Heart Failure in a Community Hospital: Identifying Risk and Potentially Remediable Factors. *Journal of Management Research*, SUNY Institute of Technology, *4*, 15-23, 2003.
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~ Recent Office Presentations ~

(2003 - 2005)

- Laditka JN, Laditka SB, Cornman CB, Porter CN, Davis DR. Life Expectancy for Individuals with Alzheimer's Disease or Related Disorders: Evidence of Black/White Mortality Crossover. Réseau Espérance de Vie en Santé (International Network on Health Expectancy and Disability Process). Population Health and Health Expectancy—Policy Implications. Beijing, China, May 18-20, 2005.
- Conrman CB, Lane MJ, Patton M. The Self-Directed Service Delivery Model in the Palmetto State. 21st National Home and Community Based Services Waiver Conference, Orlando, FL, May 17, 2005.
- Davis CB, Cornman CB, Lane MJ. The Philosophical Shift...From Manager to Facilitator, SC's Care Advisor Training Model. National Home and Community Based Services Waiver Conference, Orlando FL, May 17, 2005.
- Laditka JN, Corman CB, Porter CN, Davis DR. Impact of Alzheimer's Disease on Families, Business, and Government. White House Conference on Aging—South Carolina. Myrtle Beach, SC, April 26, 2005.
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- Lane MJ, Davis CB. Preliminary Report of the Evaluation of SC Choice South Carolina's Real Choice. Statewide Advisory Committee, Columbia, SC. January 24, 2005.
- Cornman CB, Davis CB, Lane MJ. Transformation in Long Term Care, A Sneak Preview. National Social Work Annual Conference, Springmaid, SC. March 3, 2005.
- Laditka JN, Cornman CB, Lane MJ, Porter, CN, Davis, DR. *Epidemiology of Alzheimer's Disease:* Race Effects, Area Variation, and Clustering. 9th International Conference on Alzheimer's Disease and Related Disorders. July 17-22, 2004. Philadelphia, PA.
- Laditka JN, *Epidemiology of Alzheimer's Disease and Related Disorder in South Carolina*, 1st Annual Research Day, Charleston, SC, March, 2004
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- Tolma E, Lane M, Cornman C, Uddin A, Horne K, *The Evaluation of an Exercising Program at an Assisted Living Facility*, American Public Health Association 131st Annual Meeting and Exposition, San Francisco, CA, November 2003.
- Tolma E, Lane M, Cornman C, Uddin A, Horne K, *What Motivates Frail Elderly to Continue to Exercise? A case study at an Assisted Living Facility*, American Public Health Association 131st Annual Meeting and Exposition, San Francisco, CA, November 2003
- Tolma E, Lane M, Cornman C, Uddin A, Horne K, *The Evaluation of an Exercising Program at an Assisted Living Facility*, Society for Public Health Education, Las Cruses, NM, June 2003

~ Further Information ~

This Annual Report is available on line 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) 734-9137 for further information, or e-mail Carol Cornman at: ccornman@sc.edu.