

2004

2004 Annual Report

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▪ **ANNUAL REPORT** ▪

SOUTH CAROLINA
Alzheimer's Disease Registry

▪ **A N D** ▪

OFFICE FOR THE STUDY OF AGING

2004

ARNOLD SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF SOUTH CAROLINA
COLUMBIA, SC 29208
August 2004

Unless otherwise noted, data included in this report cover the period
January 1, 2002 through December 31, 2002,
the most current period with available and comprehensive data.

▪ TABLE OF CONTENTS ▪

EXECUTIVE SUMMARY	1
ACKNOWLEDGMENTS	3
INTRODUCTION.....	4
Scope of the Alzheimer’s Disease Problem.....	5
History of the Registry.....	6
CHARACTERISTICS OF ADRD IN SOUTH CAROLINA, 2002	
Type of ADRD.....	7
Location	8
Age.....	9
Gender.....	10
Race.....	11
Deaths	12
Population-based ADRD Rates.....	13
RESEARCH PROJECTS AND TRAINING ACTIVITIES.....	15
REGISTRY PROCEDURES	18
CORE DATA ITEMS.....	19
STAFF	20
AFFILIATED PROFESSIONALS	21
REGISTRY PUBLICATIONS	23
REGISTRY PRESENTATIONS.....	25
AWARDS.....	25
FURTHER INFORMATION	25

▪ LIST OF TABLES ▪

Table 1	Registry Cases by Dementia Type and Community, Nursing Facility, or Unknown Location.....	7
Table 2	Registry Cases by Age Group and Dementia Type	9
Table 3	Registry Cases by ADRD Type, Gender, and Age Group.....	10
Table 4	Registry Cases by Race and ADRD Type	11
Table 5	Length of Time from Entry to Death, by ADRD Type.....	12
Table 6	Classification of ADRD by ICD-9-CM Codes	18
Table 7	Core data items	19

▪ LIST OF FIGURES ▪

Figure 1	Registry Data Sources.....	6
Figure 2	Registry Cases by Community, Nursing Facility or Unknown Location	8
Figure 3	Registry Cases in Community, Nursing Facility or Unknown Location by Dementia Type.....	8
Figure 4	Registry Cases by Age Group.....	9
Figure 5	Registry Cases by Age Group in Community, Nursing Facility or Unknown Location	9
Figure 6	Registry Cases by Gender.....	10
Figure 7	Registry Cases by Gender and ADRD Type.....	10
Figure 8	Registry Cases by Race.....	11
Figure 9	Registry Cases by Race in Community, Nursing Facility or Unknown Location	11
Figure 10	ADRD Prevalence by Age	13
Figure 11	Percentage of Living Persons Age 85 or Over with ADRD, by County (MAP)	14

▪ EXECUTIVE SUMMARY ▪

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

This report uses the abbreviation **ADRD** to indicate “Alzheimer's disease or related disorder.” The “related disorders” refer to dementias associated with vascular disease, and with chronic conditions such as Parkinson’s disease. Where we refer specifically to “Alzheimer’s disease” (**AD**), we limit the analysis to individuals with AD only.

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.

Since January 1, 1988, the Registry has identified 91,099 cases of ADRD. During calendar year 2002, the Registry maintained information on 42,758 individuals alive on January 1, 2002.

Population Prevalence of ADRD, South Carolina, 2002:

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

- 7.8% of South Carolinians age 65 or over have ADRD.
- 31% 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 through 84, for example, African American South Carolinians are about twice as likely to have ADRD as are non-Hispanic whites.

▪ EXECUTIVE SUMMARY ▪

(Continued)

Registry Contents:

Of South Carolinians with diagnosed ADRD:

- 61% have Alzheimer's disease.
- 17% have a dementia due to stroke.
- 22% have a dementia related to other chronic conditions.
- 40% live in an institution.
- 67% are women.
- 38% are African American.
- 43% 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 double in the next fifteen years.***

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.

▪ **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 and the Budget and Control Board**, for access to data;
- The **SC Department of Health and Human Services**, for core support and access to data;
- The **SC Department of Health and Environmental Control, Vital Records and Public Health Statistics**; and
- The **Lieutenant Governor's Office, Office on Aging**, for their continued support.

■ INTRODUCTION ■

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

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

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

ADRD is an umbrella term that encompasses many types of cognitive impairment. The Diagnostic and Statistical Manual of Mental Disorder (Third Edition) (DSM-III-R) defines Alzheimer’s disease as an impairment of intellectual abilities such as memory, abstract thinking, judgment, other disturbances of higher cortical functions and behavior and personality change severe enough to interfere significantly with everyday activities. Alzheimer’s disease (AD) is a type of ADRD with an insidious onset and a generally progressive deteriorating course for which all other specific causes have been excluded. Other types of ADRD include vascular ADRDs (such as those related to stroke) 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 2002 (those alive on Jan 1, 2002) 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, 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 acute care hospital. 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 2002.

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.⁶ What we do know is that the South Carolina Alzheimer's Disease Registry is the best population-based Registry of ADRD in the county. The only other such registry, in New York, is in practice limited to records from in-patient hospital stays.⁷ 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, 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, Vol. 1, No. 1, 1-9

▪ 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.

Registry goals are:

- 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.

The Registry uses data from a variety of data sources, as shown in Figure 1.

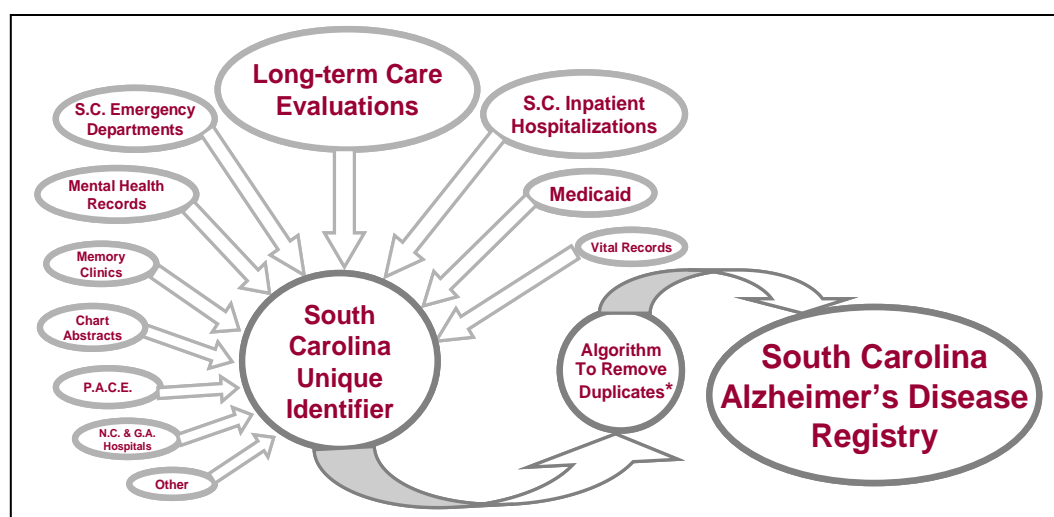


FIGURE 1. Registry Data Sources.

**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 2002 ALZHEIMER'S DISEASE REGISTRY DATA

Since January 1, 1988, 91,099 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 42,758 cases alive on January 1, 2002 displayed by type of ADRD.

Type of ADRD

Among the 42,758 current Registry cases, 61 percent had a diagnosis of Alzheimer's disease and 17 percent had a diagnosis of vascular (or stroke) dementia. In the event of a multiple diagnosis (e.g., records showing both Alzheimer's disease and vascular dementia) the case was reported in vascular disease category. The additional 22% for the Total Number of "Other Conditions" had a dementia related to other chronic conditions, such as Parkinson's disease (see Table 6 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

More registry cases resided in the community (54%) than in a nursing facility (40%) or unknown locations (6%) Figure 2. As shown in Figure 3, 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, 2002					
Dementia Type	Community Number (%)	Nursing Facility Number (%)	Unknown Number (%)	Total Number (%)	
Alzheimer's disease	13,803 (60)	10,643 (62)	1,686 (66)	26,132 (61)	
Vascular dementia	3,684 (16)	3,306 (19)	185 (7)	7,175 (17)	
Other conditions	5,486 (24)	3,292 (19)	673 (27)	9,451 (22)	
Total	22,973 (100)	17,241 (100)	2,544 (100)	42,758 (100)	

Location and ADRD in South Carolina (Continued)

FIGURE 2
Registry Cases by Community, Nursing Facility or Unknown Location
 South Carolina Alzheimer's Disease Registry, 2002

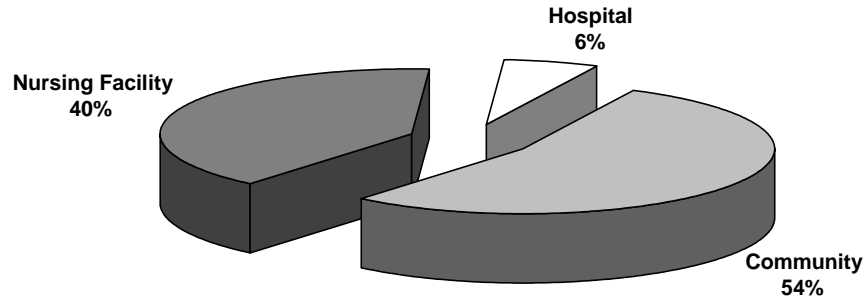
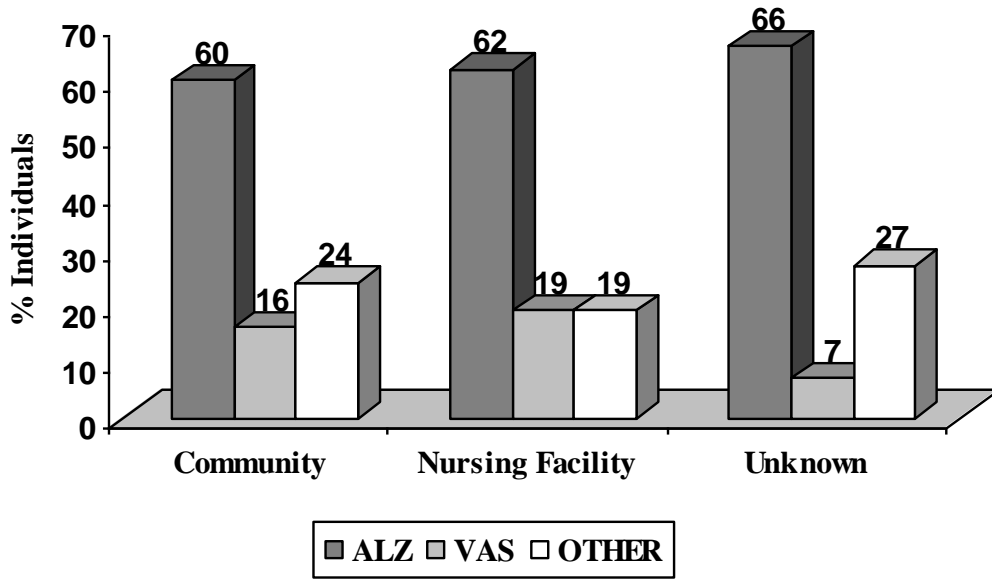


FIGURE 3
Registry Cases in Community, Nursing Facility or Unknown Location, by Dementia Type
 South Carolina Alzheimer's Disease Registry, 2002

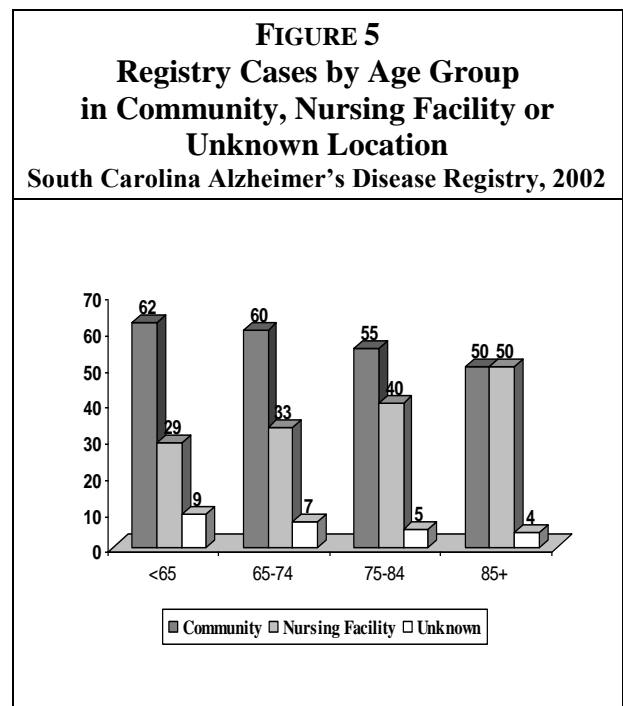
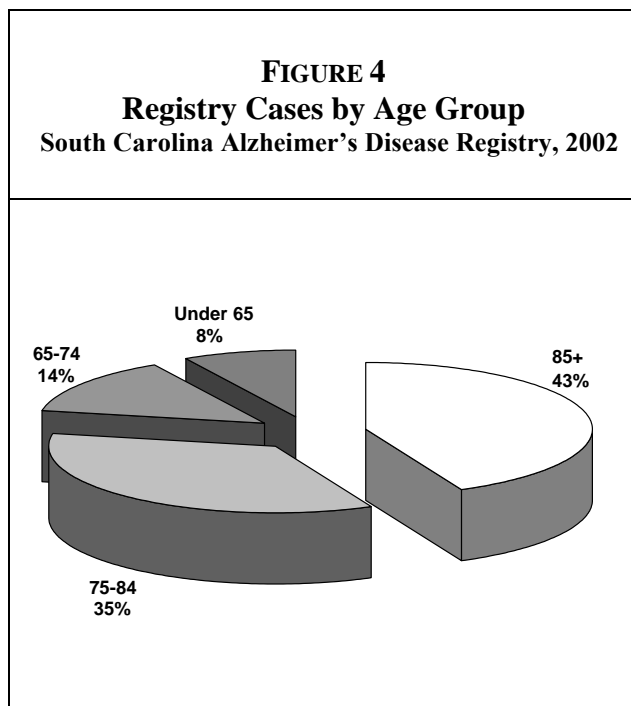


Age and ADRD in South Carolina

Table 2 shows that forty-five percent of persons with Alzheimer’s disease are 85 years of age or older; Figure 4 shows this information graphically for all dementias included in ADRD, with 43% of persons over 85 years of age. Figure 5 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 5 indicates with age comes an increase in movement to nursing facilities.

TABLE 2 Registry Cases by Age Group and Dementia Type South Carolina Alzheimer’s Disease Registry, 2002*				
AGE	AD n=25,289 (%)	VASCULAR n=7,102 (%)	OTHER n=9,261 (%)	TOTAL n=41,652 (%)
Under 65	1,679 (7)	607 (9)	963 (10)	3,249 (8)
65-74	3,402 (13)	1,042 (15)	1,193 (13)	5,637 (14)
75-84	8,876 (35)	2,387 (34)	3,425 (37)	14,688 (35)
85+	11,332 (45)	3,066 (43)	3,680 (40)	18,078 (43)

* 1,106 records for individuals have missing values for the variables required for inclusion in this table, or have ages either less than 50 or greater than 110. AD =Alzheimer’s disease or senile dementia; VASCULAR=Vascular dementia; OTHER =dementia in other chronic conditions



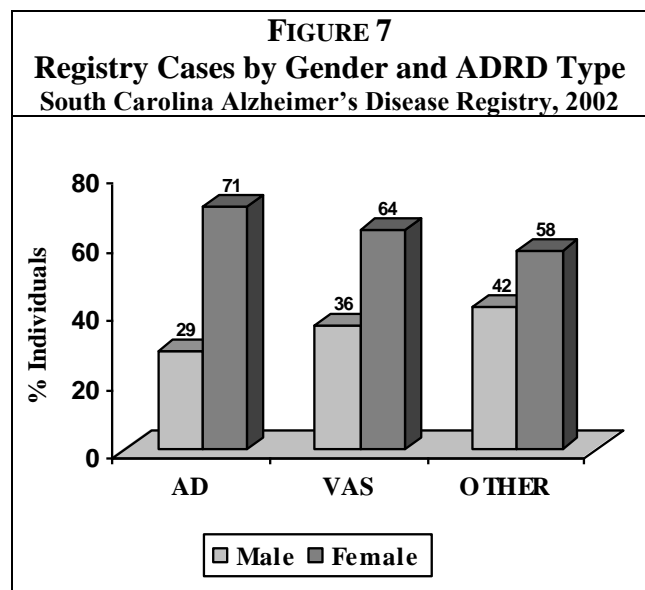
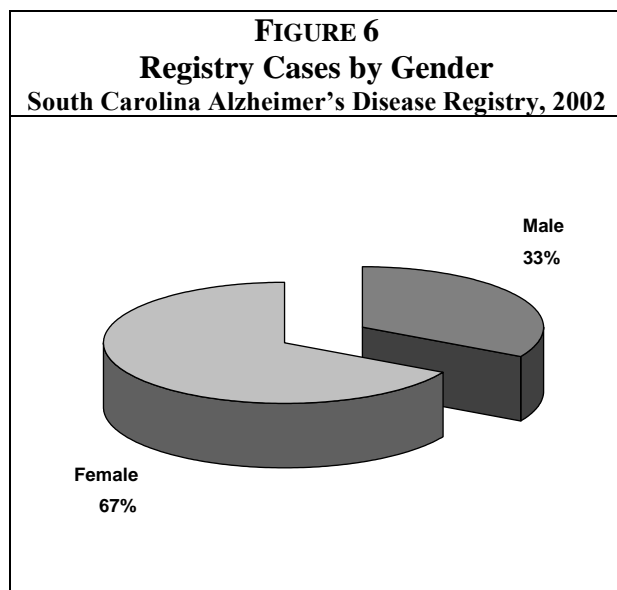
Gender and ADRD in South Carolina

Table 3 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 2.5 times the number of men with ADRD.

More women than men in this population were diagnosed with ADRD (Fig. 6). This is likely due to the larger number of women alive after age 75. The differences in the ADRD diagnosis by gender are shown graphically in Figure 7.

	AD N (%)	VASCULAR N (%)	OTHER N (%)	TOTAL N (%)
MEN	n = 7,158	n = 2,572	n = 3,809	n = 13,539
<65	631 (9)	275 (11)	598 (16)	1,504 (11)
65-74	1,204 (17)	441 (17)	544 (14)	2,189 (16)
75-84	2,581 (36)	845 (33)	1,357 (36)	4,783 (35)
85+	2,742 (38)	1,011 (39)	1,310 (34)	5,063 (27)
WOMEN	n = 18,088	n = 4,523	n = 5,446	n = 28,057
<65	1,048 (6)	330 (7)	365 (7)	1,743 (6)
65-74	2,196 (12)	601 (13)	649 (12)	3,446 (12)
75-84	6,280 (35)	1,539 (34)	2,064 (38)	9,883 (35)
85+	8,564 (47)	2,053 (45)	2,368 (43)	12,985 (46)

* Records for 1,162 individuals have missing values for gender or age.



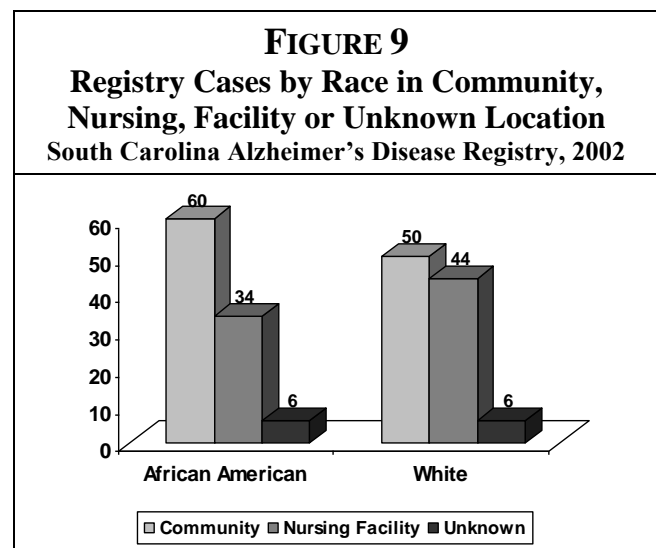
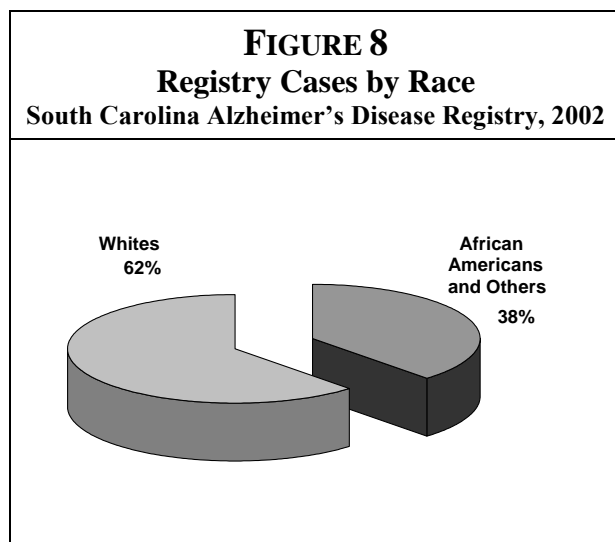
Race and ADRD in South Carolina

Compared with whites, African Americans, who comprise nearly 22% of the adult South Carolina population 65 years and older, were over-represented in AD and VASCULAR types of dementia and in the overall Alzheimer’s Disease Registry with 38% (Table 4 and Figure 8). Sixty percent of African Americans with ADRD reside in the community compared to 50% of whites living in the community (Figure 9).

TABLE 4
Registry Cases by Race and ADRD Type
South Carolina Alzheimer’s Disease Registry, 2002*

RACE	AD N (%)	VASCULAR N (%)	OTHER N (%)	TOTAL N (%)
White	15,896 (62)	3,713 (52)	6,451 (69)	26,060 (62)
African-American	9,598 (37)	3,350 (47)	2,874 (30)	15,822 (38)
Hispanic	69 (<1)	11 (<1)	37 (<1)	117 (<1)
All others	75 (<1)	21 (<1)	31 (<1)	127 (<1)

*632 records for individuals have missing values for the variables required for inclusion in this table.
AD=Alzheimer’s disease or senile dementia; VASCULAR=Vascular dementia; OTHER=dementia in other chronic conditions.



Deaths among Individuals in the Registry

The Alzheimer's Disease Registry data are linked with death certificates to summarize the deaths occurring among persons entering the Registry. Of those people identified with ADRD since 1988, 48,341 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 5).

TABLE 5 Length of Time from Entry to Death, by ADRD Type South Carolina Alzheimer's Disease Registry, 2002				
ENTRY TO DEATH	AD n = 31,338	VASCULAR n = 9,455	OTHER n = 7,548	TOTAL n = 48,341
< 2	21,585 (69)	6,567 (69)	5,505 (73)	33,579 (70)
2 - 5	6,917 (22)	2,132 (23)	1,277 (17)	10,326 (21)
> 5	2,836 (9)	756 (8)	766 (10)	4,358 (9)

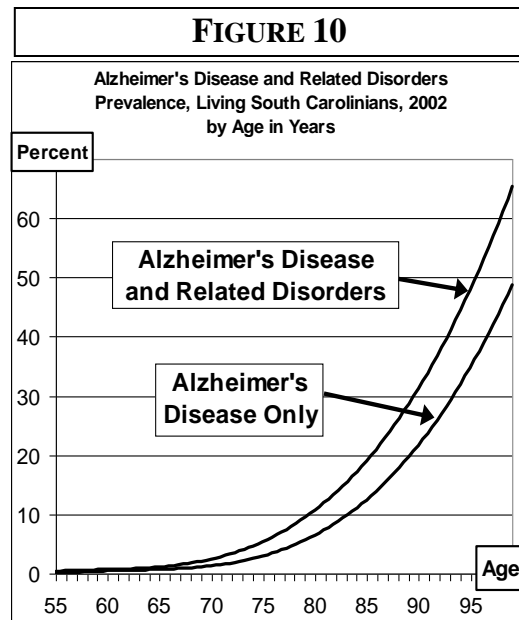
*AD =Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia;
OTHER=dementia in other chronic conditions*

Population-based ADRD Rates in South Carolina

New to our analyses in this Annual Report are estimates of population disease rates for South Carolina. These rates are calculated using the latest Registry information linked with the United States Census. Among our findings from these data:

- **7.8% 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.
- **21.5% of South Carolina residents age 85 or older have Alzheimer’s disease.**
- Figure 10 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.**

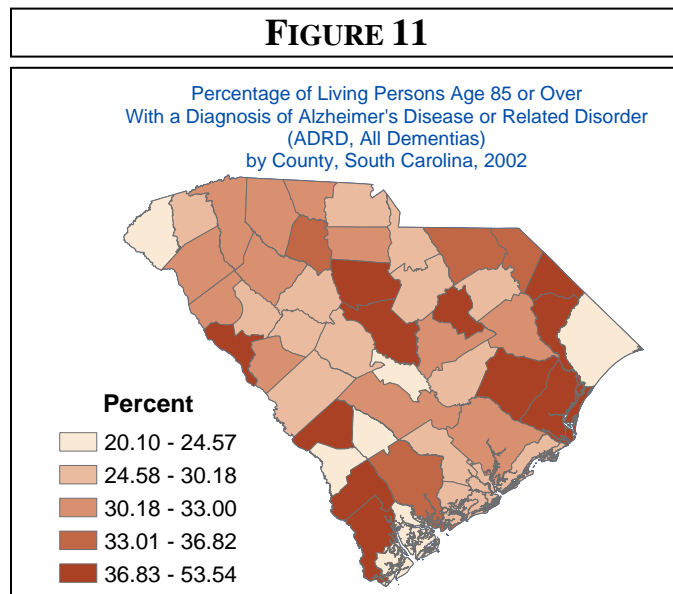


- The figure also shows the prevalence of ADRD. Related disorders include vascular dementia and dementias associated with chronic diseases such as Parkinson’s disease. **The prevalence of these related disorders also rises with age. About 67% of those who reach age 100 have at least one type of dementia.**
- **The figure provides the nation’s first look at an age distribution of Alzheimer’s disease and related disorders** that is not based merely on projections from small samples. **No other data source in the United States enables researchers to accurately calculate the age distribution of Alzheimer’s disease.**
- **African Americans are at notably higher risk of an Alzheimer’s disease diagnosis than are non-Hispanic whites.** At ages 55 through 64, African Americans are about 3 times as likely to have Alzheimer’s disease, and 3.8 times as likely to have ADRD. The risk is particularly great for African American men at these ages, who are 4.9 times as likely to have ADRD as are white men. At ages 65 through 84, African Americans are about 2.1 times as likely to have Alzheimer’s disease or ADRD. At ages 85 and over, African Americans are about 1.8 times as likely to have Alzheimer’s disease or ADRD. The declining difference with age may be due to earlier onset or diagnosis of

Population-based ADRD Rates in South Carolina (Continued)

Alzheimer's disease for African Americans, combined with earlier death for African Americans with the disease. **No previous research has had access to a sufficiently large sample to reveal this phenomenon. These findings illustrate the rich research capabilities of the South Carolina Alzheimer's Disease Registry.**

- According to the U.S. Census, there were only 2,727 Hispanics/Latinos age 65 or over in South Carolina in 2,000. This group is of interest because of the state's growing Hispanic population. The 2002 Registry indicates ADRD prevalence for these Hispanics was 3.8%, compared with 7.8% for the total population at those ages. The average age of Hispanics in the Registry did not differ notably from the average age for others; however, among those without ADRD, the age profile of older Hispanics and others may differ. This could account for the prevalence difference. Also, if many older Hispanic South Carolinians are immigrants, they may represent a relatively healthy population, as immigrants generally come to this country in good health.
- **The prevalence of Alzheimer's disease and related disorders (ADRD, all dementias) may vary notably among SC counties.** For example, the Figure 11 shows the percentage of individuals age 85 or over with ADRD. 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.**

▪ 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 life of individuals with Alzheimer's disease and related disorders, their caregivers and families through coordination, service development, communication and caregiver support. A member of the staff has 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 and evaluation services to the South Carolina Department of Health and Human Services as CLTC 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 & TRAINING ACTIVITIES ▪

(Continued)

Functional Status Measurement

A study 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:

- Incorporating hospital discharge data from Georgia and North Carolina, to capture ADRD diagnoses for South Carolinians who use hospitals in those states.
- 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.

▪ 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 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 medical records through codes using the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM, 1980) and are classified into three general categories for reporting purposes as shown in Table 6.

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.

<p>TABLE 6 Classification of ADRD by ICD-9-CM Codes South Carolina Alzheimer's Disease Registry, 2001</p>
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ALZHEIMER'S DISEASE

290.0 - 290.3	Senile or presenile dementia
290.8 - 290.9	
331.0	Alzheimer's disease

VASCULAR DEMENTIA

290.4 - 290.43	Arteriosclerotic dementia
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DEMENTIA IN OTHER CHRONIC CONDITIONS

291.2	Alcohol dementia
292.82	Drug-induced dementia
294.1	Dementia with other conditions
310.10	Organic brain syndrome
331.1 - 331.9	Other cerebral degeneration
332.0 - 332.1	Parkinson's disease (with a dementia code)
333.4	Huntington's disease
042	HIV
331.82	Dementia with Lewy bodies (the same code is used for dementia with Parkinsonism)

Where an individual is diagnosed with both Alzheimer's disease and another dementia, the Registry records the other dementia for that individual.

▪ CORE DATA ITEMS ▪

The registry core data set (Table 7) 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.

<p style="text-align: center;">TABLE 7 Registry Core Data Items South Carolina Alzheimer's Disease Registry, 2002</p>
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- 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)

▪ 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.

Bettina Fisher Drake, M.P.H., **Graduate Research Assistant**, is a doctoral student in Epidemiology. Her research interests focus on the epidemiology of aging, Alzheimer's disease, and health disparities.

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 for activities related to the Placemat Strength Training Program and other program activities. 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.

■ AFFILIATED PROFESSIONALS ■

Cheryl Addy, Ph.D., is an Associate Dean for Academic Affairs, Arnold School of Public Health.

Geri Adler, is an Associate Professor, College of Social Work.

Sam Baker, Ph.D., is an Associate Professor, Department of Health Services Policy and Management, Arnold School of Public Health

Shawn Chillag, M.D., is Chairman and Professor, USC School of Medicine, Department of Internal Medicine, Division of Geriatrics.

Sara Corwin, Ph.D., is an Assistant Professor and Interim Director, Office of Public Health Practice, Arnold School of Public Health

Ramie Cox, M.D., is an Assistant Professor, USC School of Medicine, Department of Internal Medicine

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

Paul G. Eleazer, M.D., F.A.C.P., is Director, Division of Geriatrics, Department of Internal Medicine, USC School of Medicine.

Elaine Frank, Ph.D., is Chair and Associate Professor, Department of Communication Sciences and Disorders, Arnold School of Public Health

David Greenhouse, M.D., is Assistant Professor, USC School of Medicine, Department of Internal Medicine

Joyce Gossard, M.S., is an Instructor, Department of Exercise Science, Arnold School of Public Health

Greg Hand, Ph.D., is an Associate Professor, Department of Exercise Science, Arnold School of Public Health

James Hebert, Sc.D., is a Professor of Epidemiology in the Department of Epidemiology and Biostatistics, Arnold School of Public Health.

Victor A. Hirth, M.D., is an Assistant Professor of Medicine in the Division of Geriatrics, Department of Internal Medicine, USC School of Medicine

▪ **AFFILIATED PROFESSIONALS** ▪

(Continued)

Vijaya Korrapati, M.D., is an Assistant Professor, USC School of Medicine, Department of Internal Medicine

Sarah Laditka, Ph.D., is an Associate Professor, Department of Health Services and Policy Management, Arnold School of Public Health

Bruce McClenaghan, PED, MPT, is Professor, Department of Exercise Science, Arnold School of Public Health

Robert McKeown, Ph.D., is an Associate Professor, Department of Epidemiology and Biostatistics, Arnold School of Public Health

Jamal Moloo, M.D., is an Associate Professor, USC School of Medicine, Department of Internal Medicine

Dave Murday, Ph.D., is Assistant Director, Center for Public Health Services and Policy Research, Arnold School of Public Health

Nancy Richeson, M.D., is Professor, USC School of Medicine, Department of Internal Medicine

Richard M. Schultz, Ph.D., is Professor in the USC College of Pharmacy.

M. Shawn Stinson, M.D., is Associate Professor, USC School of Medicine, Department of Internal Medicine

John Vena, Ph.D., is Chair, Department of Epidemiology and Biostatistics, Arnold School of Public Health

Kenneth Watkins, Ph.D., is an Associate Professor in Health Promotion, Education and Behavior, Arnold School of Public Health

Darryl Weiland, Ph.D., M.P.H., is Professor, Division of Geriatrics, Department of Medicine, USC School of Medicine.

Sarah Wilcox, Ph.D., is an Associate Professor in Exercise Science. Arnold School of Public Health

Harriet G. Williams, Ph.D., is a Professor, Department of Exercise Science, Arnold School of Public Health.

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

▪ REGISTRY 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.

- Lin HC, Xirasagar S, Laditka JN (2004). Patient Perceptions of Service Quality in Group versus Solo Practice Clinics. *International Journal for Quality in Health Care* (In Press).
- Laditka JN, Laditka SB. (2004). Insurance Status and Primary Care Access: Disparate Outcomes for Preventable Hospitalization. *Journal of Health and Social Policy*. (In Press).
- Laditka JN (2004). Physician Supply, Physician Diversity, and Outcomes of Primary Health Care for Older Persons in the United States. *Health and Place*, 10, 231-244.
- Laditka SB, Fischer M, Laditka JN, Segal DR. (2004). Attitudes about Aging and Gender among Young, Middle Age, and Older College-Based Students. *Educational Gerontology*, 30, 403-421.
- Laditka SB, Trevisani, G. D'Accurzio A, Laditka JN, Scherzer GD, Kane L. (2003). 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.
- Laditka JN (2003). Hazards of Hospitalization for Ambulatory Care Sensitive Conditions among Older Women: Evidence of Greater Risks for African Americans and Hispanics. *Medical Care Research and Review*, 60(4), 468-495.
- Laditka JN, Laditka SB, Mastanduno MP (2003). Hospital Utilization for Ambulatory Care Sensitive Conditions: Health Outcome Disparities Associated with Race and Ethnicity. *Social Science and Medicine*, 57/8, 1429-1441.
- Laditka JN, Laditka SB. (2003). Increased Hospitalization Risk for Recently Widowed Older Women and the Protective Effects of Social Contacts. *Journal of Women and Aging*, 15(2/3), 7-28. Also published as a chapter in *On Their Own Again: Widows and Divorcees in Later Life*, CL Jenkins (Ed.) New York: Haworth Press.
- Sanderson M, Benjamin J, Lane M, Cornman C, Davis D, Application of Capture-Recapture Methodology to Determine the Prevalence of Dementia in South Carolina, *Annals of Epidemiology*, Vol. 13, No7, 2003
- Sanderson M, Wang J, Davis D, Lane M, Cornman C, Fadden M, Co-morbidity Associated with Dementia, *American Journal of Alzheimer's Disease and Other Dementias* 17(2):73-78, 2002.
- Cornman CB, Lane, MJ, Davis DR, Sanderson M, Alzheimer's Disease in South Carolina, 1998. *Journal of the South Carolina Medical Association* 96:18-21, 2000.
- Brill PA, Cornman CB, Davis DR, Lane MJ, Mustafa T, Sanderson M, Macera CA. The Value of Strength Training for Older Adults. *Home Care Provider* 4(2):62-66, 1999.
- Lane MJ, Davis DR, Cornman CB, Macera CA, Sanderson M. Location of Death as an Indicator of End-of-life Costs for the Person with Dementia. *American Journal of Alzheimer's Disease* 13(4):208-210, 1998.
- Scott WK, Macera CA, Cornman CB, Sharpe PA. Functional health status as a Predictor of Mortality in Men and Women Over 65. *Journal of Clinical Epidemiology* 50(3):291-296, 1997.
- Scott WK, Edwards KB, Davis DR, Cornman CB, Macera CA. Risk of Institutionalization Among Community Long-Term Care Clients With Dementia. *The Gerontologist* 37(1):46-51, 1997.

▪ REGISTRY PUBLICATIONS ▪

(Continued)

- Zheng D, Macera CA, Croft JB, Giles WH, Davis DR, Scott WK. Major depression and All-Cause Mortality among White Adults in the United States. *Annals of Epidemiology* 3:213-218, 1997.
- Anderson G., Functional Fitness Workshop. *Creative Forecasting* 8(7):38, 1996.
- Scott WK, Huang Y, Cornman CB, Neff LJ, Torres ME, Otterness C, Eleazer P, Macera CA. Alzheimer's Disease in South Carolina, 1994. *Journal of the South Carolina Medical Association* 91:257-259, 1995.
- Huang Y, Macera CA, Cornman CB, Davis DR, Scott WK, Neff L. Survival of Alzheimer's disease patients with regard to pattern of care in South Carolina, 1988-1993. *Journal of the South Carolina Medical Association* 90:51-55, 1994.
- Macera CA, Huang Y, Eleazer GP, Scott WK, Cornman CB. Epidemiology of Alzheimer's disease. *Journal of the South Carolina Medical Association* 90:404-406, 1994.
- Macera CA, Eaker ED, Jannarone RJ, Davis DR, Stoskopf CH. A measure of perceived burden among caregivers. *Evaluation and the Health Professions* 16:204-211, 1993.
- Macera CA, Eaker ED, Jannarone RJ, Davis DR, Stoskopf CH. The association of positive and negative events with depressive symptomatology among caregivers. *International Journal of Aging and Human Development* 36:75-80, 1993.
- Macera CA, Eaker ED, Goslar PW, DeAndrade SJ, Cornman C, Jannarone RJ. Ethnic differences in the burden of caregiving. *American Journal of Alzheimer's Care and Related Disorders and Research* 7:4-7, 1992.
- Macera CA, Sun RKP, Yeager KK, Brandes DA. Sensitivity and specificity of death certificate diagnoses for dementing illnesses, 1988-1990. *Journal of American Geriatrics Society* 40:479-481, 1992.
- Mintzer JE, Macera CA. Prevalence of depressive symptoms among white and African-American caregivers of demented patients (letter). *American Journal of Psychiatry* 149:575-576, 1992.
- Brandes DA, Macera CA, Still CN, Abramson R. Problems in establishing case definitions for Alzheimer's disease registries. *American Journal of Alzheimer's Care and Related Disorders and Research* 6(6):29-31,42, 1991.
- Macera CA, Davis DR, Brandes DA, Still CN. A report on dementia in South Carolina, 1988-1990. *Journal of the South Carolina Medical Association* 87(11):531-535, 1991.
- Macera CA, Still CN, Brandes DA, Abramson RK, Davis DR. The South Carolina Alzheimer's disease patient registry: a progress report. *American Journal of Alzheimer's Care and Related Disorders and Research* 6(1):35-38, 1991.
- Macera CA, Still CN, Thompson SJ, Brandes DA. The need for an Alzheimer's disease patient registry in South Carolina. *Journal of the South Carolina Medical Association* 86(8):457-460, 1990.
- Still CN, Jackson KL, Brandes DA, Abramson RK, Macera CA. Distribution of major dementias by race and sex in South Carolina. *Journal of the South Carolina Medical Association* 86(8):453-456, 1990.

▪ RECENT REGISTRY PRESENTATIONS ▪

(2003 - 2004)

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

Cornman CB, Lane, ML, Davis DR, Laditka JN, Porter CN, *Alzheimer's Disease and Related Disorders in South Carolina*. 1st Annual Research Day, Charleston, SC, March, 2004

Cornman CB, Lane ML, Davis CB, *Consumer-Direction in 1915 (c) Waiver for E/D, From Principle to Person-Centered Practice*, Centers for Medicare and Medicaid Services Conference, Baltimore, MD, March 2004

Laditka JN, Laditka SB, Cornman CB. *Evaluating Care for Hospitalized Individuals with Alzheimer's Disease or Other Dementias Using Quality Indicators*. 56th Annual Scientific Meetings of the Gerontological Society of America, San Diego, CA, November 21-25, 2003.

Laditka SB, Laditka JN. *Racial and Ethnic Disparities Associated with Potentially Preventable Hospitalization for Six Chronic Conditions*. 56th Annual Scientific Meetings of the Gerontological Society of America, San Diego, CA, November 21-25, 2003.

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 Cruces, NM, June 2003

▪ AWARDS ▪

At the South Carolina Conference on Aging in Columbia, SC, the Placemat Strength Training Program was awarded the 1997 Governor's Health Promotion for Older South Carolinians Research Award.

▪ FURTHER INFORMATION ▪

This Annual Report is available on line at www.sph.sc.edu/osa/osamain.asp. 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.