

2010

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~ ANNUAL REPORT ~

South Carolina ALZHEIMER'S DISEASE REGISTRY

2010*

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

*Unless otherwise noted, data included in this report cover the period
January 1, 2008 through December 31, 2008,
the most current period with available and comprehensive data.

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~ Executive Summary ~

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

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

**Since January 1, 1988, the Registry has identified 165,597 cases of ADRD.
During calendar year 2008, the Registry maintained information on
69,404 individuals alive on January 1, 2008.**

Registry Goals:

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

Registry Overview:

Of South Carolinians with diagnosed ADRD:

- 63% have Alzheimer's disease
- 15% have a dementia due to stroke
- 22% have a dementia related to other chronic conditions
- 33% live in an institution
- 65% are women
- 31% are African American
- 41% of those with AD are 85 years or older

Population Prevalence of ADRD, South Carolina, 2008:

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

- 9.8% of South Carolinians age 65 or over have ADRD
- 32.7% 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 1.81 times more likely to have ADRD as are non-Hispanic whites.

Trends of new registry cases:

The number of new cases added to the registry has increased from 2004-2008 at an average of 2.9% per year. The greatest average yearly increase of 10.5% occurred in the age group of 50-64. These results suggest that, over the 5 year time period, the number of individuals diagnosed with ADRD has been the highest in what is considered a "younger" age group in the ADRD spectrum. This has important implications since the Baby Boomers will not have arrived at the age of 65 until 2011 and this report is based on data through 2008. For more details on these trends and others, see the report featured on page 7.

Other Activities of the OSA:

In addition to maintaining the Registry and conducting research using this valuable state resource, the OSA works to provide South Carolina's older persons and their families with access to quality, reliable health and long term care service delivery systems. Specifically, OSA's focus includes the following:

- **Provide education** on ADRD management
- **Develop training** on long term care issues
- **Contribute technical assistance** for programs for older South Carolinians
- **Develop programs** including the SC Vulnerable Adult Guardian ad litem
- **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**, for access to data;
- The **SC Department of Health and Human Services**, for core support and access to data;
- The **SC Employee Insurance Program**, for 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* ~

Someone in America develops Alzheimer's every 72 seconds; by mid-century someone will develop Alzheimer's every 33 seconds.¹

In 2008, the U.S. Census Bureau estimated that there were 597,091 people 65 years of age and over living in the State of South Carolina, and the state was ranked 26th among other states for the highest percentage of persons aged 65 years and older. Since that time, the elderly population in South Carolina has grown at a rapid rate. In fact, by 2030, the U.S. Census Bureau projects that South Carolina will be home to 1.1 million people ages 65 years and older, potentially propelling South Carolina to a ranking of 15th in the nation for the highest percentage of residents over 65 years of age.¹

Alzheimer's disease and related disorders (ADRD) represent an ever-increasing area of concern for the healthcare community and families. Nationwide, an estimated 5.4 million people in the United States are currently living with Alzheimer's disease. By 2030, this estimate is expected to reach 7.7 million; by 2050, the number of persons affected with Alzheimer's disease could be between 11 and 16 million.²

With increasing age as a leading risk factor for Alzheimer's disease, South Carolina's rapidly growing population of persons aged 65 years and older presents a challenge to families, communities and those who plan and deliver services for the state.

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

This report covers calendar year 2008 (those alive on Jan 1, 2008), 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 (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.

¹ US Census Bureau, Population Division, September, 2011

² Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures.

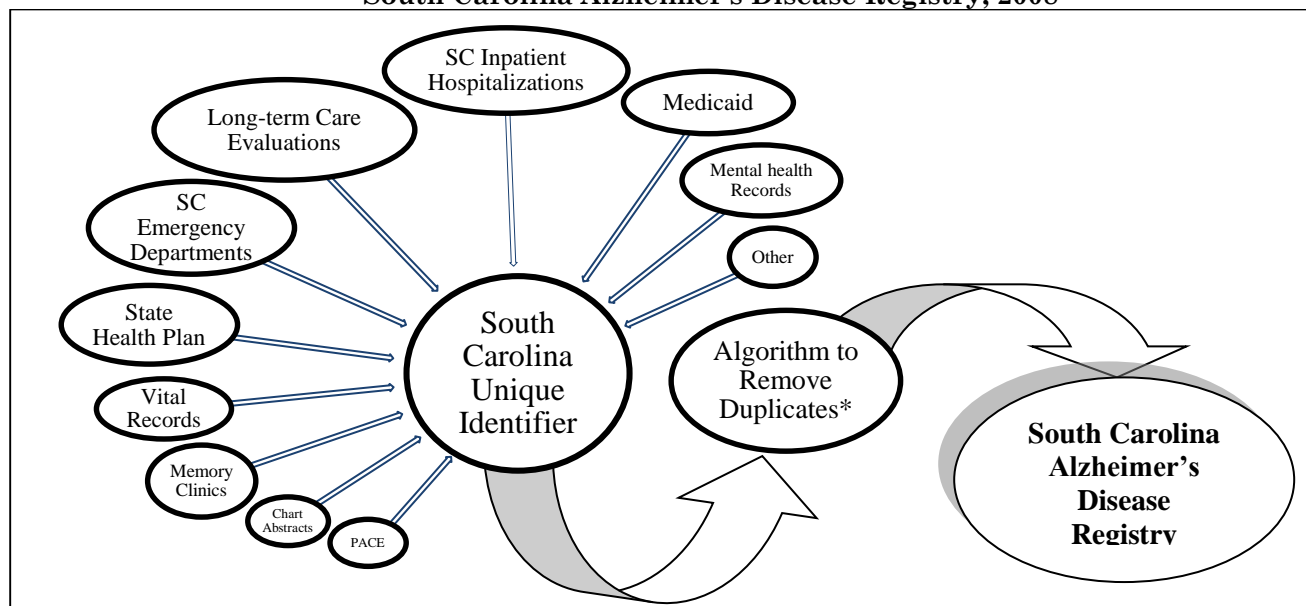
~ *Alzheimer's Disease and Related Disorders in South Carolina* ~

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.¹

In 2000, South Carolina residents 75 years and older were 5.4% of the total population; their numbers totaled 215,285. By 2030, it is projected that South Carolina residents 75 years and older will represent 10% of the total population.²

We do not 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, but lack a diagnosis, 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.³ What we do know is that the South Carolina Alzheimer's Disease Registry is the best population-based Registry of ADRD in the country. There are only two other such registries in existence. One, in New York, is in practice limited to records from in-patient hospital stays.⁴ The second is located in West Virginia and began collecting data in May 2008. Our South Carolina Registry uses data from a wide variety of sources to capture as many diagnoses as possible.

Figure 1
Registry Data Sources
South Carolina Alzheimer's Disease Registry, 2008



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

¹DA Evans, et al. Prevalence of Alzheimer's disease in a community population of older persons. Higher than previously reported. JAMA 1989;262:2551-6.

² US Census Bureau, Population Division, Interim State Population Projections, 2005.

³ LE Hebert et al. Alzheimer disease in the US population: Prevalence estimates using the 2000 Census. Archives of Neurology, 2003; Vol 60, 1119-1122.

⁴ 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

~ History of the Registry ~

1988

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 (ADRD).

1990

On May 31, 1990, Governor Carroll A. Campbell, Jr., signed a state law authorizing the Registry. This law (R653, H4924) amended Title 44, Code of Laws of South Carolina 1976, relating to health, by adding Chapter 36 establishing a voluntary Statewide Alzheimer's Disease and Related Disorders Registry in the Arnold School of Public Health, University of South Carolina. 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.

1993

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.

1997

The registry was moved back to the School of Public Health. The registry is currently maintained by the Office for the Study of Aging, Arnold School of Public Health, USC.

2008

In 2008 the Alzheimer's Disease Registry celebrated its 20th anniversary. It is one of only three statewide registries for Alzheimer's disease and Related Disorders in the United States. It continues to collect and provide prevalence data to public and private entities for planning, advocate for caregivers, and foster research in risk factors for ADRD and the risk of institutionalization.

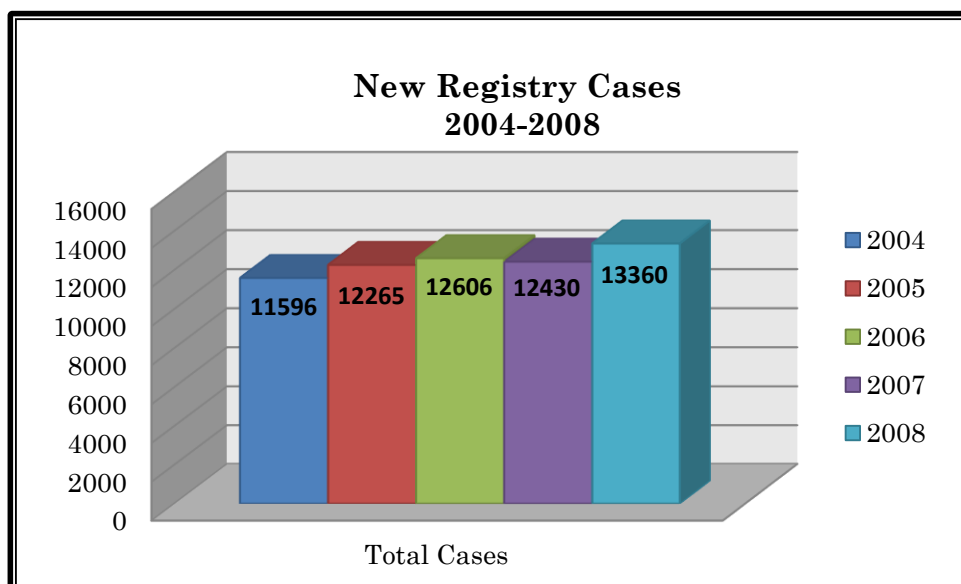
This project has received widespread support and interest from the academic community, lay support groups, state agencies, and other public and private organizations as part of a statewide effort to study the growing impact of Alzheimer's disease on the health and welfare of older South Carolinians.

~ Trends in New Cases of the Alzheimer's Disease Registry in South Carolina from 2004-2008~

There is considerable interest in the possible increase in the number of individuals with ADRD. The SC Alzheimer's Disease Registry is in a unique position to respond to this question with population-based data. This is a report of new cases added to the South Carolina Alzheimer's Disease Registry over the 5 year period from 2004 to 2008. The following are some findings from the data:

- In 2008, a total of 13,360 new cases of ADRD were added to the registry. This total is a 7.5% increase from the previous year and the largest percent change over the 5 year period.*
- The number of new cases added to the registry has increased from 2004-2008 at an average of 2.9% per year. Over the 5 year time period there was one instance where there was a decrease in the number of new cases, this occurred from 2006 to 2007 when the number declined by 1.4%.

Figure 2



* A new data source was added to the registry in 2008 but, in order for equivalent comparison to previous years, those cases were not included in the totals for this report on trends in new cases.

Age

From 2004-2008, there has been a steady increase in new cases aged 50 to 84 with the greatest average yearly increase of 10.5% occurring in the 50-64 age group. Upward trends were also seen in the 65-74 and 75-84 age groups. The average yearly increase was 6.8% for the 65-74 age group and 4.0% for the 75-84 age group. The number of new cases in our two extreme age groups, under the age of 50 and 85 and older, has fluctuated over the 5 year time period.

Figure 3
New Registry Cases by Age Group

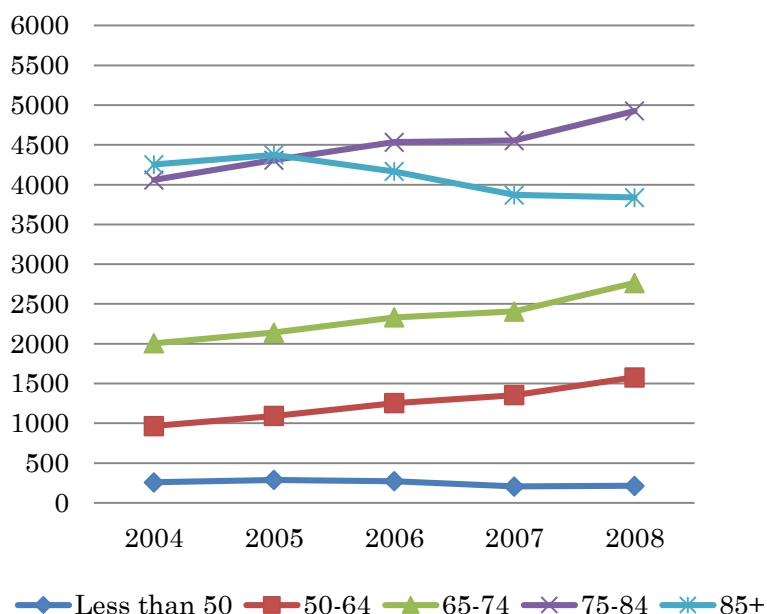
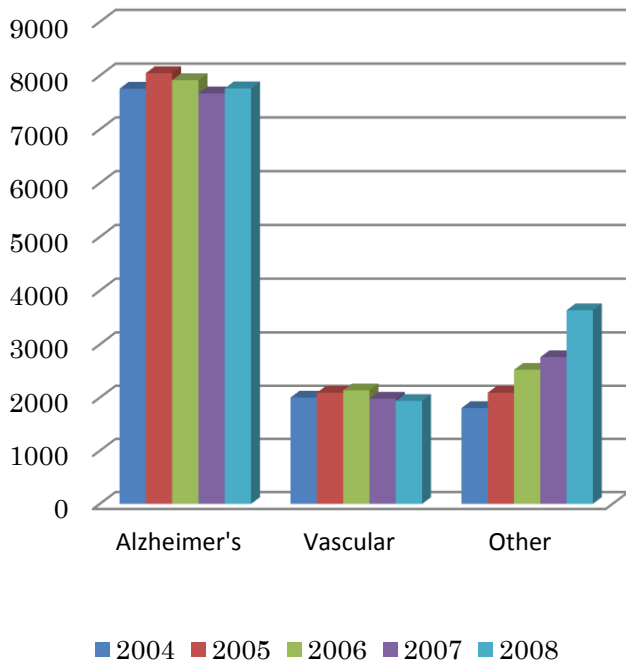


Figure 4
New Registry Cases by Dementia Type



Dementia type

Over the 5 year time period, the number of new registry cases diagnosed with Alzheimer's Disease and Vascular Dementia remained consistent. There was a marked increase in registry cases diagnosed with "Other types" of dementia over the 5 year period with an average increase of 15.6% per year. The "Other types" category includes the following diagnoses: Dementia with other conditions, Other cerebral degenerations, Alcohol dementia, Parkinson's disease, Dementia with Lewy bodies, HIV/AIDS dementia, Drug-induced dementia, Huntington's disease, and Organic brain syndrome.

Gender

From 2004-2008, the number of male new cases has increased an average of 3.5% per year while the number of female new cases increased an average of 2.7% per year. As expected, the total number of new cases has been higher among females than males over the 5 year time period, although the average yearly percent increase for males has been greater than the average yearly percent increase for females.

Race

The total number of new cases has been higher among Whites than African Americans from 2004-2008. The number of whites has increased an average of 3.1% per year. The number of African American new cases fluctuated from year to year and did not have the clear upward trend as seen in the White new cases. The number of Hispanics stayed consistent over the 5 year time period.

Conclusion

The Alzheimer's Disease Registry is capturing more and more new cases of ADRD in South Carolina every year. Some noteworthy findings from this trend analysis are:

- The greatest average yearly increase of 10.5% occurred in the age group of 50-64. These results suggest that, over the 5 year time period, the number of individuals diagnosed with ADRD has been the highest in what is considered a “younger” age group in the ADRD spectrum. This has important implications since the Baby Boomers will not have arrived at the age of 65 until 2011 and this report is based on data through 2008.
- The average yearly increase of 15.6% in new registry cases diagnosed with “Other types” of dementia. These findings suggest that, over this 5 year time period, there may have been improvements in ADRD diagnosis allowing for more specific conclusions related to disease type.

~CHARACTERISTICS OF ADRD IN SOUTH CAROLINA~

BASED ON 2008 ALZHEIMER'S DISEASE REGISTRY DATA

Since January 1, 1988, 165,597 cases of Alzheimer's disease and related disorders (ADRD) have been identified in South Carolina. This report describes demographic characteristics and medical information for the 69,404 cases alive on January 1, 2008, displayed by type of ADRD.

Type of ADRD

Among the 69,404 current Registry cases, 63 percent had a diagnosis of Alzheimer's disease and 10 percent had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both Alzheimer's disease and vascular dementia the case was reported in a Mixed dementia category. Five percent of all Registry cases are in the Mixed category. The additional 22%, for the total number of "Other Conditions," had a dementia related to other medical conditions, such as Parkinson's disease (see Table 2 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

More registry cases resided in the community (62%) than in a nursing facility (33%) or unknown locations (5%) (Figure 5). As shown in Figure 6, the distribution of the types of ADRD was similar in the community and in nursing facilities.

Table 1
Registry Cases by Dementia Type
and Community, Nursing Facility or Unknown Location
 South Carolina Alzheimer's Disease Registry, 2008

Dementia Type	Community		Nursing Facility		Unknown		Total	
	N	%	N	%	N	%	N	%
Alzheimer's Disease	26,610	62	15,457	67	1,792	58	43,859	63
Vascular dementia	4,555	11	2,510	11	239	8	7,304	10
Mixed dementia	1,620	4	1,579	7	90	3	3,289	5
Other conditions	10,350	24	3,643	16	959	31	14,952	22
Total	43,135	62	23,189	33	3,080	5	69,404	100

~ *Location and ADRD in South Carolina* ~
(continued)

Figure 5
Registry Cases by Community,
Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2008

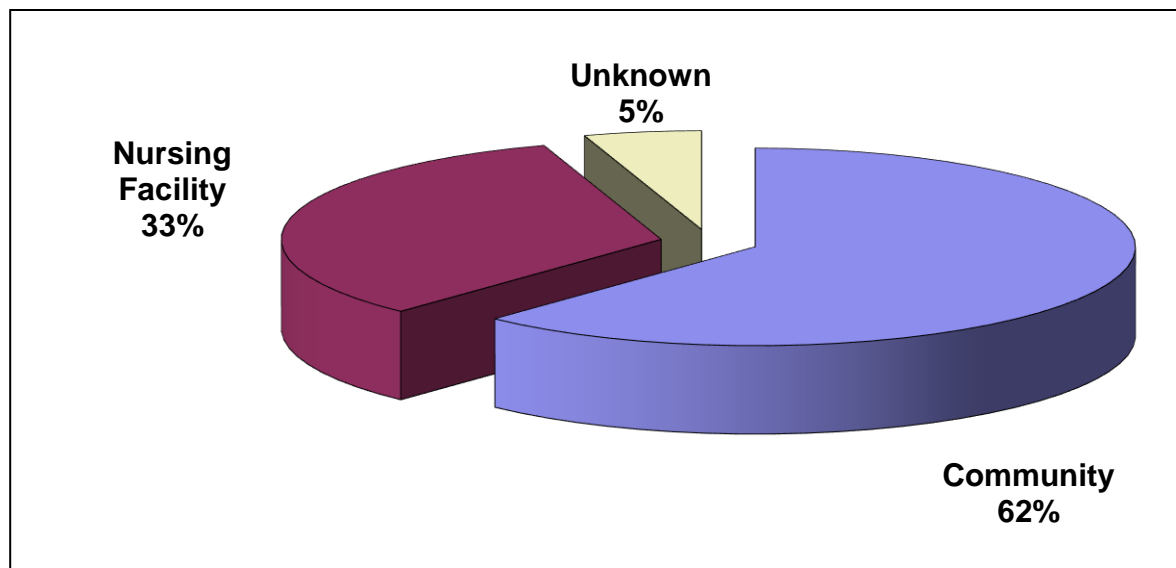
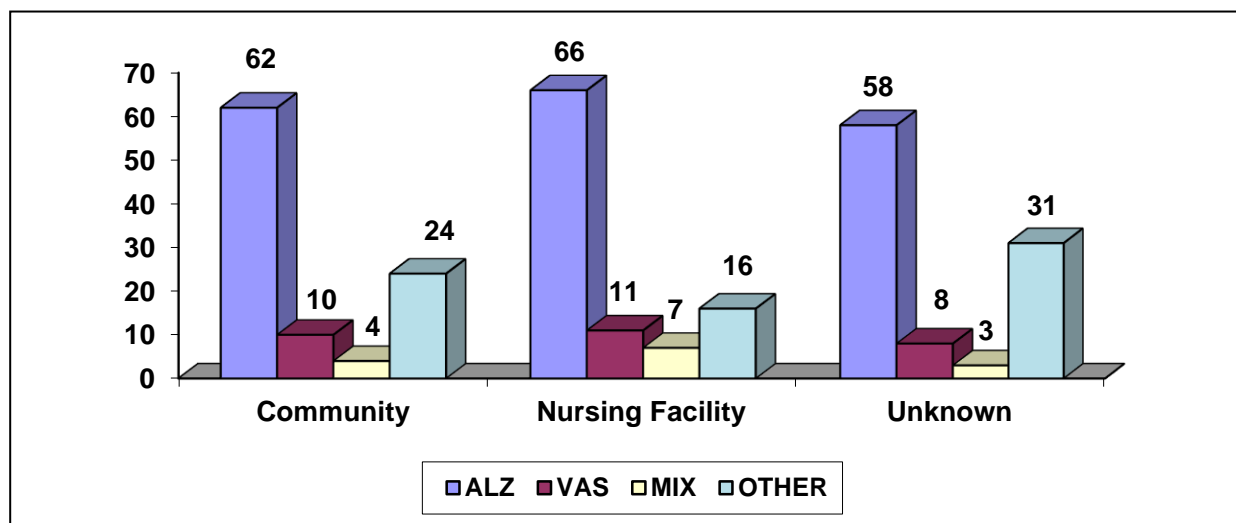


Figure 6
Registry Cases in Community,
Nursing Facility or Unknown Location,
by Dementia Type
South Carolina Alzheimer's Disease Registry, 2008



~ *Dementia in Other Medical Conditions* ~

In addition to Alzheimer's disease, the Registry tracks dementias that are associated with other medical conditions, such as Parkinson's disease, alcohol and drug abuse, and HIV/AIDS. In the 2008 Registry, there are 14,937 persons with a dementia associated with one of these conditions, who do not also have a diagnosis of Alzheimer's disease or vascular dementia. Eight percent of them have dementia associated with Parkinson's disease, and 54% have an indication of dementia associated with some other medical condition (please see Table 2 footnote). The percentages in the table are not mutually exclusive due to the fact that some persons' records indicate that they have more than one medical condition. A few individuals have as many as three such conditions.

Dementia with Lewy Bodies

Dementia with Lewy Bodies (DLB) is a progressive brain disease characterized by abnormal round structures in the areas of the brain that control thinking and movement. Hence, DLB causes symptoms similar to those commonly associated with both Alzheimer's disease and Parkinson's disease. Like Alzheimer's disease, it can cause confusion, memory loss, and depression, while other possible symptoms are slowed movement, rigid muscles, and tremors, symptoms normally found in those with Parkinson's disease. Persons with DLB may also have hallucinations and experience day-to-day changes in their symptoms. Currently, there is no cure for Dementia with Lewy Bodies. Medications used to treat Alzheimer's disease, Parkinson's disease, and depression are typically used to manage DLB symptoms. Dementia with Lewy Bodies (DLB) is the second most common cause of dementia, after Alzheimer's disease. Estimates suggest that DLB accounts for approximately 20% of all dementia cases.¹

Table 2
Dementia in Other Medical Conditions by Age Group
South Carolina Alzheimer's Disease Registry, 2008*

	Under 65	65–74	75–84	85+	Total	
	%	%	%	%	N	%
Alcohol dementia	21	10	3	2	1154	10
Drug-induced dementia	1	1	0	0	69	1
Organic brain syndrome	0	0	0	0	14	0
Other cerebral degenerations	48	86	69	58	8244	69
Parkinson's disease	2	7	10	9	899	8
Huntington's disease	0	0	0	0	14	0
HIV/AIDS dementia	5	0	0	0	174	1
Dementia with Lewy bodies	2	8	13	9	1067	9
Frontotemporal dementia	0	0	0	0	24	0
Pick's disease	0	0	0	0	26	0
Dementia with other conditions*	44	46	44	70	6391	54
Total (N)	4,026	4,174	5,595	4,281	18,076	

*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.

¹ Lewy Body Dementia Association. www.lewybodydementia.org. Accessed March 7, 2008

Pick's disease: A frontotemporal dementia ~

Frequently misdiagnosed as Alzheimer's disease or as a psychiatric disorder, Pick's disease is a form of dementia affecting the frontal and temporal lobes of the brain¹. These areas of the brain are associated with personality, behavior, and language. Because of the affected brain areas, Pick's disease is classified as a frontotemporal dementia (FTD). Onset of Pick's disease and other FTDs are characterized by changes in personality, behavior, and/or impaired speech or writing.

Five characteristics are used in the early stages of Pick's disease to distinguish it from Alzheimer's disease. If three or more are present, then an individual is more likely to have Pick's disease rather than Alzheimer's disease. They are:

1. Onset before age 65
2. Initial personality changes
3. Loss of normal controls, e.g., gluttony, hypersexuality
4. Lack of inhibition
5. Roaming behavior.²

The onset of Pick's disease is usually more rapid than that of Alzheimer's disease. Onset may begin as early as age 40.

Frontotemporal dementia ... The second most common cause of early onset dementia after Alzheimer's disease

Primary progressive aphasia (PPA) and semantic dementia (SD) are also classified as FTDs. Unlike Alzheimer's disease, the memory of an individual with PPA remains largely intact for the initial years of the condition. Instead, the initial years of PPA typically involve increasing dysfunction in the areas of word choice, object naming, syntax, and/or word

comprehension. Semantic dementia also causes deficits in the areas of word comprehension, as well as in the recognition of faces and objects.^{3,4}

While the exact cause is unknown, FTDs exhibit a strong genetic component, and they often run in families.^{2,5} The standard prognosis for individuals with FTDs is poor. The dementias often progress rapidly, and individuals may succumb to the disease within 2 – 10 years of diagnosis.⁵ Median survival time is 7 years.⁶

At this time, the FDA has not approved any medications for the treatment of Pick's disease or any of the other frontotemporal dementias. Medications may be used to manage behavioral problems, but currently no developed drugs are effective at treating the disease.

1 Frontotemporal dementia. Retrieved June 24, 2010, from <http://www.mayoclinic.com/health/frontotemporal-dementia/ds00874>.

2 Rose, A, Russell D. Pick's disease: signs, symptoms, treatment, and support. Retrieved June 24, 2010, from http://helpguide.org/elder/picks_disease.htm.

3 Mesulam, M-3 Lewy Body Dementia Association. www.lewybodydementia.org. Accessed March 7, 2008M. Primary progressive aphasia – a language-based dementia. N Engl J Med 2003; 349: 1535-42.

4 Hodges, JR, Patterson K. Semantic dementia: a unique clinicopathological syndrome. Lancet Neurol 2007; 6: 1004-14.

5 NINDS frontotemporal dementia information page. Retrieved June 24, 2010, from <http://www.ninds.nih.gov/disorders/picks/picks.htm>.

6 Haberland, C. Frontotemporal dementia or frontotemporal lobar degeneration – overview of a group of proteinopathies. *Ideggyogy Sz.* 2010 Mar 30;63(3-4):87-93.

~ Age and ADRD in South Carolina ~

Table 3 shows that 41% of persons with Alzheimer's disease are 85 years of age or older. Figure 7 shows this information graphically for all dementias included in ADRD, with 37% of persons over 85 years of age. Figure 8 indicates that for people with ADRD, over 60% of those 75 to 84 years of age are being cared for in the community. Living in the community is most often the location of choice for the individual and family. However, as Figure 8 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, 2008*

	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
AGE										
Under 65	2,743	6	1,019	15	171	5	2,850	20	6,783	10
65 – 74	7,392	17	1,584	22	595	18	3,302	23	12,873	19
75 – 84	15,212	36	2,319	33	1,211	37	4,250	30	22,992	34
85 +	17,321	41	2,149	30	1,279	40	3,739	27	24,488	37
Total	42,668	64	7,071	10	3,256	5	14,141	21	67,136	100

*2,268 records for individuals have missing values for the variables required for inclusion in this table or have ages either less than 50 or greater than 110.

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

Figure 7
Registry Cases by Age Group
South Carolina Alzheimer's Disease Registry, 2008

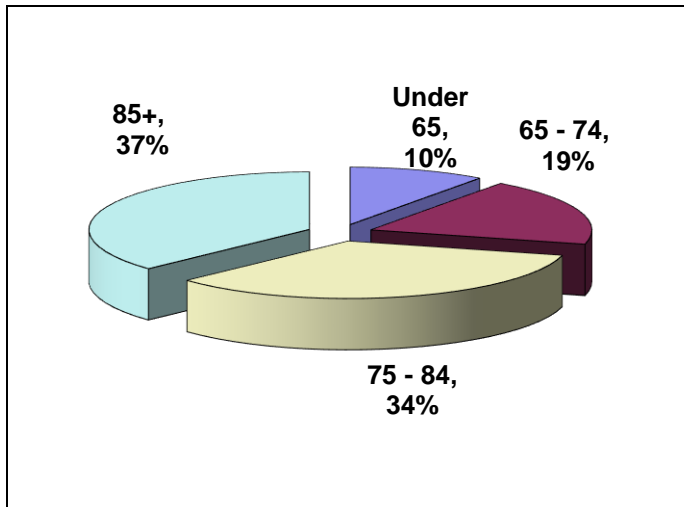
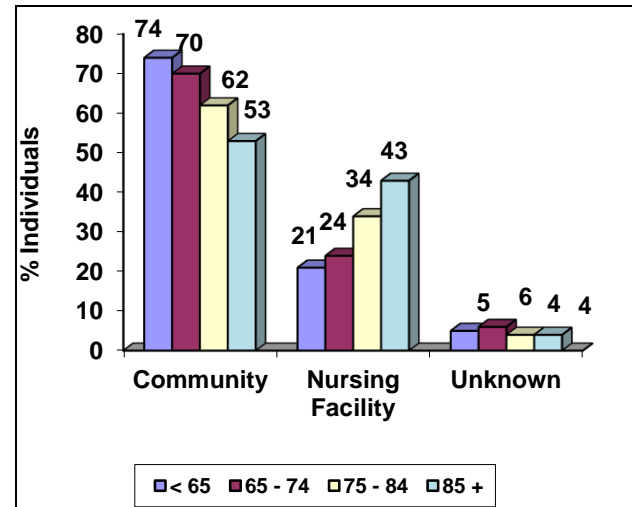


Figure 8
Registry Cases by Age Group in Community, Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2008



~ Gender and ADRD in South Carolina ~

Table 4 shows Registry cases by gender, dementia type, and age group. For each dementia type, the number of women is notably larger than the number of men in all but the youngest age category. In particular, among those age 85 or over, the number of women with ADRD is 3.25 times the number of men with ADRD. More women than men in this population were diagnosed with ADRD (Fig.9). 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 10.

Table 4
Registry Cases by Gender, Age Group and ADRD Type
South Carolina Alzheimer's Disease Registry, 2008*

	<i>AD</i>		<i>VASCULAR</i>		<i>MIXED</i>		<i>OTHER</i>		TOTAL	
	N	%	N	%	N	%	N	%	N	%
MEN										
Under 65	1,248	10	560	20	79	7	1,678	27	3,565	15
65 – 74	2,994	23	749	27	289	27	1,686	28	5,727	25
75 – 84	4,849	37	915	32	414	38	1,688	28	7,866	34
85 +	3,947	30	589	21	301	28	1,046	17	5,883	64
WOMEN										
Under 65	1,490	5	457	11	92	4	1,171	15	3,210	7
65 – 74	4,389	15	828	19	297	14	1,614	20	7,128	16
75 – 84	10,337	35	1,402	33	795	37	2,554	32	15,088	35
85 +	13,312	45	1,552	37	971	45	2,678	33	18,513	42

*Records for 2,268 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 9
Registry Cases by Gender

South Carolina Alzheimer's Disease Registry, 2008

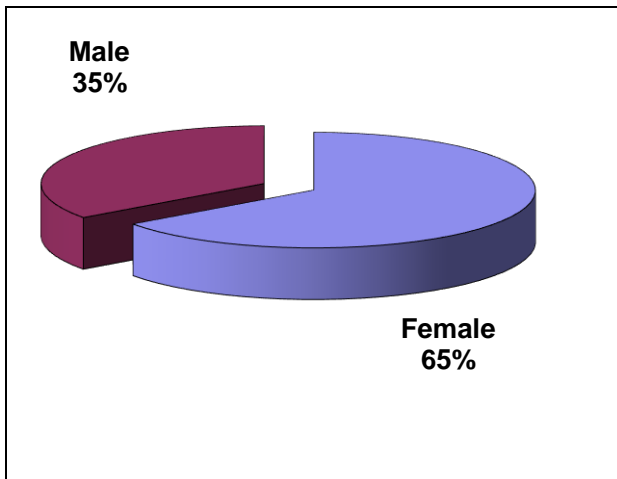
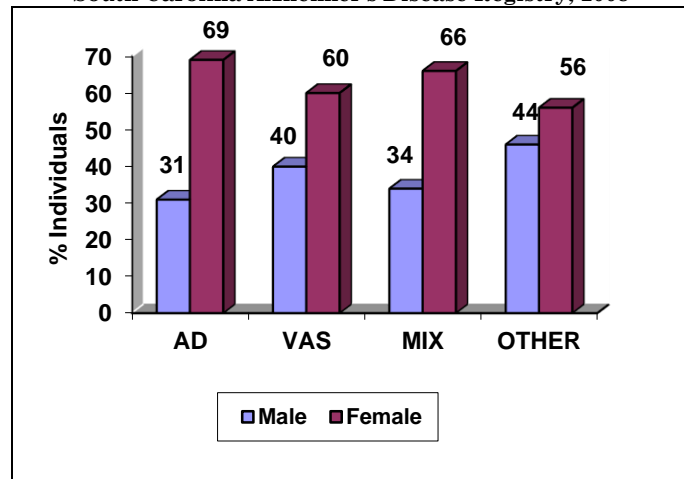


Figure 10
Registry Cases by Gender and ADRD Type

South Carolina Alzheimer's Disease Registry, 2008



~ Race and ADRD in South Carolina ~

Compared with whites, African Americans, who comprise nearly 21% of the adult South Carolina population 65 years and older, were over-represented in Vascular dementia (41%) and in the overall Alzheimer's Disease Registry with 31% (Table 5). Sixty-seven percent of African Americans with ADRD reside in the community, compared to 60% of whites living in the community (Figure 12).

Table 5
Registry Cases by Race and ADRD Type
South Carolina Alzheimer's Disease Registry, 2008*

	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
RACE										
White	29,218	67	4,059	56	2,040	62	8,741	58	44,058	64
African-American	12,373	28	2,979	41	1,156	35	4,860	33	21,368	31
Hispanic	173	<1	29	<1	8	<1	76	1	286	<1
All Others	2,095	5	237	3	85	3	1,275	8	3,692	5
Total	43,859	63	7,304	10	3,289	5	14,952	22	69,404	

*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 11
Registry Cases by Race

South Carolina Alzheimer's Disease Registry, 2008

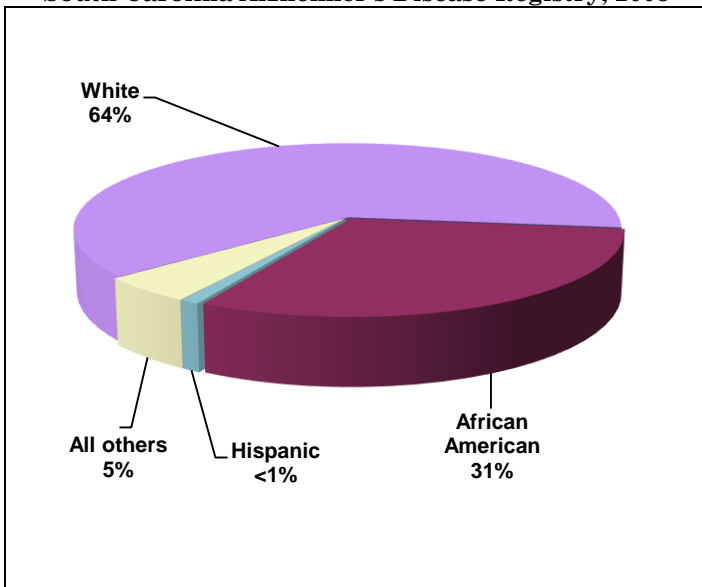
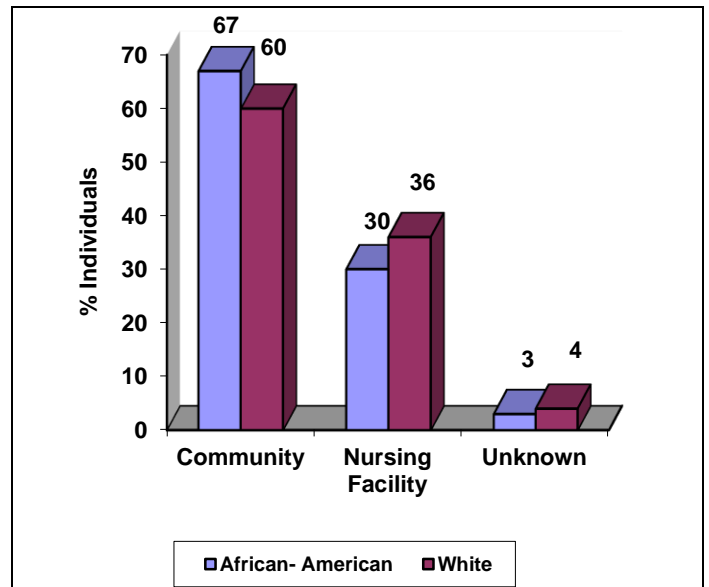


Figure 12
Registry Cases by Race in Community, Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2008



~ 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, 96,193 have died. The individual's first date of diagnosis may not be known to the Registry in every instance. For example, if an individual is first diagnosed during a physician office visit, then that diagnosis is not available to the Registry. We use the first date that a person entered one of the systems reporting to us as their entry date (Table 6).

Table 6
Length of Time from Entry to Death by ADRD Type
South Carolina Alzheimer's Disease Registry, 2008*

	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
ENTRY to DEATH										
< 2 years	39,251	62	8,224	66	3,479	59	10,335	70	61,289	64
2-5 years	16,315	26	2,835	23	1,729	30	2,866	20	23,745	25
5 + years	7,678	12	1,361	11	641	11	1,479	10	11,159	11
Total	63,244	66	12,420	13	5,849	6	14,680	15	96,193	100

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

Table 7 lists the top 10 underlying causes of death for persons 65 years of age or older in the South Carolina Alzheimer's Disease Registry who died during 2008. The #1 underlying cause of death for these persons was attributed to senility and organic mental disorders. This category includes Alzheimer's Disease and many other dementing illnesses. Nationally, the leading causes of death for persons ages 65 years and older were: heart disease, cancer, stroke, chronic lower respiratory diseases, Alzheimer's disease, diabetes, influenza and pneumonia.¹ As can be seen in the table below, the underlying causes of death for those with ADRD in the Registry nearly mirror the national trend.

Table 7
Top 10 Underlying Causes of Death Among Those 65 Years or Older
South Carolina Alzheimer's Disease Registry, 2008*

Rank	
1	Senility and Organic Mental Disorders
2	Acute Cerebrovascular Disease
3	Coronary Atherosclerosis and Other Heart Disease
4	Acute Myocardial Infarction
5	Chronic Obstructive Pulmonary Disease
6	Pneumonia**
7	Congestive Heart Failure; Non-hypertensive
8	Diabetes Mellitus without Complication
9	Cancer of Bronchus; Lung
10	Hypertension with Complications and Secondary Hypertension

*Only includes persons who died during the 2008 calendar year.

**Except pneumonia caused by tuberculosis or sexually transmitted disease.

1 CDC/NCHS, National Vital Statistics System. Xu JQ, Kochanek KD, Murphy SL, Tejada-Vera B. Deaths: Final data for 2007. National vital statistics reports; vol 58 no 19. Hyattsville, MD: NCHS; 2010.

~ *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 8.

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, SC Employee Insurance Program, and the SC Budget and Control Board.

Table 8
Classification of ADRD by ICD-9-CM Codes
South Carolina Alzheimer's Disease Registry, 2008

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
435 - 438	Cerebrovascular disease (with a dementia code*)
MIXED DEMENTIA	
Both Alzheimer's disease and Vascular dementia	
DEMENTIA IN OTHER MEDICAL CONDITIONS (see note below)	
291.2	Alcohol dementia
292.82	Drug-induced dementia
294.1	Dementia with other conditions
331.82	Dementia with Lewy bodies
(the same code is used for dementia with Parkinsonism)	
The following conditions are included with a dementia code*:	
310.1	Organic brain syndrome
331.1 - 331.9	Other cerebral degeneration
332.0 - 332.1	Parkinson's disease
333.4	Huntington's disease
042	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.

~ *Registry Core Data Items* ~

The registry core data set (Table 9) consists of case-identifying data and diagnostic data (ICD-9-CM codes), and the place from which the records were obtained. Other information collected, *if available*, includes other medical diagnoses, educational status, caregiver contact data for follow-up and marital status.

Table 9
Registry Core Data Items
South Carolina Alzheimer's Disease Registry, 2008

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

~Research Projects & Other Activities~

In addition to registering and tracking individuals with ADRD, the staff of the Alzheimer's Disease Registry and Office for the Study of Aging (OSA) also conduct other activities focused on aging issues of older individuals.

Research

Association between Behavioral Disturbances and Nursing Home Admission in Patients with Alzheimer's disease

Caregivers of individuals with Alzheimer's disease were interviewed to identify specific behavioral disturbances of the individual with Alzheimer's disease that are associated with nursing home admission. See page 23 for the complete report.

Faith and Health

The USC Faith and Health Project explores the complex patterns related to social capital, aspects of faith, and health through in-depth interviews and brief survey instruments. Study groups included United Methodist members who had participated in a holistic health program, regular attendees of United Methodist churches (not part of the holistic health program) and infrequent /non-attendees of religious services, with each category stratified by race (AA and Caucasian). Based on findings and existing literature, a survey instrument has been developed to assess social capital, health outcomes, and multiple dimensions of faith and practice.

Exercise

Move for Life

OSA in collaboration with a Duke Endowment Grant and other Arnold School of Public Health Departments has developed an exercise DVD designed to increase physical activity. These exercises are for adults who are 50 years and older and younger people who haven't been exercising regularly or who have limitations. The DVD contains exercise instructions, deep breathing and stretching, strength and balance exercises and a cardio routine in 10 minute segments or a full routine of 28 minutes. Further information can be found at www.sph.sc.edu/osa.

Placemat Strength Training Program

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

~Research Projects & Other Activities (continued)~ Training

Dementia Dialogues

“Dementia Dialogues” consists of 5 parts, each approximately 1.5 hours in length, which allows participants to integrate new ideas with information they already possess. Part 1 consists of **“The Basic Facts”**, an overview of ADRD, Part 2 **“Keeping the Dialogue Going”**, strategies for effective communication, Part 3 **“It’s a Different World”**, understanding the impact of the environment and ways to promote independence in activities of daily living, Part 4 **“It’s Nothing Personal”**, addressing challenging behaviors and Part 5 **“Now What Do I Do”**, creative problem solving.

Each participant receives a certificate of participation for each unit and a Dementia Specialist Certificate upon completing all five Units. This program is offered at no cost to participants and is held regionally. ***Over 16,000 professional, non- professional and family caregivers in South Carolina have received this training.*** For further information please contact: Jan Merling, MA, Office for the Study of Aging, Arnold School of Public Health, University of South Carolina, 803-318-1601, jmerling@sc.edu or www.sph.sc.edu/OSA/programs_dementia.html

Dementia Dialogues Train-The-Trainer

A “Train-The-Trainer” curriculum for “Dementia Dialogues” has been developed and implemented for those who have completed Dementia Dialogues and wish to conduct these trainings in their facilities and agencies. In addition there is an annual one-day update to provide continuing education on dementia topics. 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.

Elder Mistreatment Prevention Training

The OSA, in collaboration with the Center for Child and Family Studies in the College of Social Work and with the support of the SC Department of Health and Human Services has developed an Elder Mistreatment Prevention Training ***We Each Have a Story*** for nursing home management and direct care staff. 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.

Recruitment and Retention Training

Partnerships around CNA Training and Mentoring (PACT) Program

OSA staff in collaboration with Goodwill Industries of Upstate/Midlands South Carolina, Inc. is piloting a program that trains and supports nurse aides to become certified, employed and retained. This project is in response to:

- the increased need for trained direct care workers in long term care facilities
- employers' desire for experienced workers
- the need for new CNAs to acquire enhanced training beyond the basic CNA training
- the turnover of direct care workers

OSA is involved in training mentors in the placement facilities as well as providing enhanced monthly training to the newly placed CNAs and facility mentors by providing monthly "Lunch & Learn" sessions for one year at participating facilities.

Outcome evaluation is being conducted to measure the CNA's acquisition of new knowledge at the Lunch & Learn Sessions and the impact of training and mentorship on retention of newly hired CNAs.

Recruitment and Retention Training and Technical Assistance

Practical solutions and tools are included in a series of courses on issues surrounding recruitment and retention of direct care staff in long term care. This training and technical assistance is available to assist administrators and managers to maintain a quality staff to provide services to the aging and disabled population. For course descriptions:

http://www.sph.sc.edu/osa/programs_recruitment.html.

Technical Assistance & Evaluation

Person-Centered Hospital Discharge Planning Model

Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. The person-centered Approach allows consumer-direction to take place. In collaboration with the South Carolina Lt. Governor's Office on Aging, staff is involved in a Center for Medicare and Medicaid grant to identify and evaluate a person-centered hospital discharge planning model. Activities include being members of the core planning team, providing training and technical assistance in person-centered planning, and outcome evaluation.

Caregiver Coaching Service

The Office for the Study of Aging staff is working in collaboration with the South Carolina Department of Health and Human Service Community Long Term Care (CLTC) staff to pilot a Caregiver Coaching Service to provide training to family caregivers of CLTC participants in order to improve the caregivers' competence in specific areas. Topics include Dementia care, Incontinence care, and a Wellness module to promote resilience and empowerment of the caregivers.

Research

~Association between Behavior Disturbances and Nursing Home Placement in Patients with Alzheimer's Disease~

The Office for the Study of Aging was provided funding in September 2009 to conduct phone interviews with caregivers of individuals with Alzheimer's disease to determine risk factors for the decision to place the individuals in institutions (Cases) rather than keeping them at home (Controls). The drug company was particularly interested in validating a particular tool called the Neuropsychiatric Inventory (NPI). It asked questions about 12 different sets of problem behaviors and the frequency, severity and bothersomeness of the behavior to the caregiver. Those behaviors were delusions, hallucinations, agitation/aggression, depression, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability, aberrant motor behavior, sleep and nighttime behavior disorders, and appetite and eating changes. We also asked questions from the Zarit Burden Interview and the CES-D depression scale and captured information on the caregivers' feelings of role captivity, competency, and demographics.

We completed 705 interviews, 363 cases (individuals with Alzheimer's disease in nursing homes), and 342 controls (individuals with Alzheimer's disease cared for at home). These individuals were identified with Alzheimer's disease by self report and confirmed by ICD-9 code found on a hospital discharge or emergency room visit files. The interviews were completed between February 2010 and September 2010.

The analysis for the contract with the drug company was completed by March 2011. By using a propensity score matching system to match on race, gender, age within 5 years and assessment for nursing home placement eligibility within 120 days of study initiation, 354 cases matched with 289 controls. The race of the caregivers and the clients were almost the same with 163 controls and caregivers of the controls being African American and 156 cases and 157 caregivers of cases being African American. 126 controls and caregivers of controls were Caucasian and 196 cases and caregivers of cases (195) were Caucasian. More than 75% of the caregivers were females (253 cases; 211 controls) and 80% of the caregivers for cases reported being a high school graduate or higher education while 72% of the control caregivers reported being a high school graduate.

The analysis showed that the NPI Total Score was found to be a statistically significant predictor of Nursing Home Admission (NHA), where each 10% increase in score (i.e., more impairment) resulted in 30% greater odds of NHA; the NPI-4 Score (consisting of the combined scores from the following behaviors: agitation/aggression, irritability, disinhibition, and aberrant motor behavior) resulted in a 21% greater odds of NHA.

Nursing home admissions occurred more likely if the caregivers were males or married. NHA was also more likely if the person with AD had more psychiatric conditions or had an increased risk for morbidity based on the Charleson Comorbidity Index (a widely used index of comorbid conditions derived from the assessment for nursing home placement).

We also asked the open-ended question “What was the main reason for placing your ____ (relationship) in the nursing home? (Cases) or What is the main reason for keeping your ____ (relationship) at home? (Controls).

The qualitative analysis of the open ended questions showed that overall, in our control group, the most frequently reported theme was *issues with caregivers* which contained themes involving a sense of obligation (n=161), emotions (n=20), help (n=25), and opportunity (n=27). The results of our qualitative analysis suggest that caregiver issues play a major role in the decision to keep their loved one at home rather than placing them in a nursing home.

Among the cases, the most frequently reported theme was *issues with the patient* which contained themes involving physical health problems (n=219), behavior problems (n=121), hospice (n=7), loss of ability to self care (n=56), medication problems (n=12). The results of our qualitative analysis suggest that patient issues play a major role in the decision to place a loved one in a nursing home rather than at home.

Although our work with the drug company is complete, we plan to do further analysis of the role of the caregiver burden, caregiver depression and caregiver work status on the decision for nursing home placement as well as further analysis of the open ended questions.

~Research Projects & Other Activities(continued)~ **Program Development**

South Carolina Vulnerable Adult Volunteer Guardians ad Litem Program (SCVAGAL)

In 2010 in South Carolina, there were over 3,000 reports received of vulnerable adults being abused, neglected or exploited. Over 500 of these reports resulted in court proceedings. The Office for the Study of Aging, in collaboration with the Department of Health and Human Services, Department of Social Service, Adult Protective Service, Adult Protective Coordinating Council, the South Carolina Bar, South Carolina Legal Services and Court Administration, has developed and is conducting a two year pilot program that will recruit, train and support volunteer Guardians ad Litem to act as an unbiased representative for vulnerable adults under Adult Protective Services custody in cases of abuse, neglect and exploitation.

SCVAGAL has targeted licensed social work as volunteers. They will receive training developed by the Office for the Study of Aging. After completing the training, the volunteers will be responsible for gathering information, interviewing the vulnerable adult and other involved parties and making recommendations to the court as to what is in the best interest of the vulnerable adult. The volunteers will be court appointed and will appear in court on behalf of the vulnerable adult.

This pilot program is being evaluated to identify the volume of cases, the number of volunteers needed, the time commitment involved and the associated costs.

The statewide program became operational August 1, 2011. Persons interested in additional information or in becoming a volunteer Guardian ad Litem can contact SCVAGAL at (803) 629-0277 or by email at SCVAGAL@mailbox.sc.edu

Community Outreach

The staff of the Office for the Study of Aging provides expertise and technical assistance to the community through its involvement on committees that include: Alzheimer's Resource Coordination Center, Caregiver Coalition of the Midlands, Advisory Committee for Nurse Aide Training, Nurse Aide Training Coordinator's & Instructors Annual Workshop, and the South Carolina Respite Coalition.

The Purple Ribbon Task Force was created by a concurrent resolution adopted by the General Assembly to study the current and future impact of Alzheimer's disease in South Carolina and assess the resources for the needs of persons with Alzheimer's disease and related disorders so as to develop a state strategy to address this health issue. An OSA staff member was appointed to this task force and participated in the development of recommendations. A final report entitled "Conquering the Specter of Alzheimer's Disease in South Carolina" was submitted to the General Assembly. The report can be found at <http://aging.sc.gov>

~ *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, consumer directed care and elder mistreatment prevention.

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

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.

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

Candace N. Porter, M.S., PhD(c), **Statistical Research Associate** for the Alzheimer's Disease Registry and related projects. Her research interests include AIDS dementia, Alzheimer's disease and related disorders as causes of death, survival analysis, and count data models. She is a Ph.D. candidate in Epidemiology and Biostatistics.

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

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

Maria Patton, MSW, **Director**, South Carolina Vulnerable Adults Guardian ad litem, Pilot Project (SCVAGAL). Her interests include geriatrics, promoting community based services for the elderly and working with the vulnerable population. She is also a certified Geriatric Care Manager.

Maggi Miller, M.P.H., PhD(c), **Graduate Research Assistant**, is a Ph.D. candidate in Epidemiology and Biostatistics. Her research interests are in aging, exercise and holistic health.

Angela Johnson, B.A., **Graduate Research Assistant**, is a MPH candidate in Health Promotion, Education and Behavior. Her interests include aging, health education for older adults, and health policy. She is assisting with the SCVAGAL program.

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

~ Office Publications ~

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

- Schulz, RM, Porter, CN, Lane, MJ, Cornman, CB, Brannon, L. Impact of a Medication Management System on Nursing Home Admission Rate in a Community-Dwelling Nursing Home Eligible Medicaid Population. *American Journal of Geriatric Pharmacotherapy*, 9:1, 69-79, 2010.
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- Anderson LS, Bailey F, Benson WF, Cherry D, Case G, Hendrie HC, Laditka JN, Lappin D, McConnell S, Morrison-Bogorad, Rabins P, Rusinack RL (Author list in Alphabetical Order). *The Health Brain Initiative: A National Public Health Roadmap to Maintaining Cognitive Health*. Centers for Disease Control and Prevention and the Alzheimer's Association. Chicago, IL: Alzheimer's Association, 2007.
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~ *Further Information* ~

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