ARNOLD SCHOOL OF PUBLIC HEALTH
OFFICE FOR THE STUDY OF AGING
UNIVERSITY OF SOUTH CAROLINA



2023 Annual Report South Carolina Alzheimer's Disease Registry

Celebrating 35 years of promoting broader research, training, and other collaborative activities that enhance quality of life for our state's older adult population, their families, and their caregivers.



2023 Annual Report South Carolina Alzheimer's Disease Registry

ARNOLD SCHOOL OF PUBLIC HEALTH UNIVERSITY OF SOUTH CAROLINA

The 2023 report includes the most current, available, and comprehensive data from two calendar years: January 1 through December 31 of 2020 and 2021.



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Executive Summary

The South Carolina Alzheimer's Disease Registry ("Registry") is the nation's first and most comprehensive registry of its kind. It is one of only four statewide population-based registries of Alzheimer's disease and related dementias (ADRD) in the United States. The Registry was established, and has been maintained, by the Office for the Study of Aging (OSA) since 1988 in cooperation with the South Carolina Department of Health and Human Services, South Carolina Department of Mental Health, USC School of Medicine, and the South Carolina Revenue and Fiscal Affairs Office.

The annual Registry report is published in fulfillment of the requirement of South Carolina Code of Law \$44-36-10 and \$44-36-50 which established the Registry for the people of South Carolina and tasked the Arnold School of Public Health and Office for the Study of Aging with its upkeep, management, and the dissemination of an annual report.

Throughout this report, there are continuous abbreviations including ADRD and AD. The abbreviation ADRD is to indicate "Alzheimer's disease and related dementias." The term "related dementias" refers to dementias associated with vascular disease, mixed dementia and with other medical conditions such as Parkinson's disease. Where the report refers specifically to "Alzheimer's disease" (AD), analysis is limited to individuals with AD only.

The Office for the Study of Aging is proud to provide services that strive to improve the quality of life of our older adult population, their families and their caregivers. If you have questions about the Registry or Office's activities, visit our website at osa-sc.org.

Thank you for your continued support.

Sincerely,

Maggi C. Miller, MS, PhD

Co-Director & Registry Manager

Megan Byers, LMSW

Co-Director & Dementia Dialogues® Manager

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Since January 1, 1988, the Registry has identified 377,143 cases of ADRD in South Carolina.

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

Other Activities of OSA:

In addition to maintaining the Registry and conducting research using this valuable state resource, OSA works to promote broader research, training and other collaborative activities that enhance quality of life for our state's older adult population. Specifically, OSA's activities include the following:

- Provide education on ADRD management
- **Develop training** on long-term care issues
- Contribute technical assistance for programs for older adults
- **Develop programs** including Dementia Dialogues®
- Evaluate programs for the aging population
- Conduct research on aging and public health issues

Acknowledgments

The growth and development of the Registry and the related research and training programs at OSA have been due to the support of many organizations and agencies. The leadership OSA want to acknowledge the particular contributions of:

- The **Arnold School of Public Health** at USC, for core support;
- The **SC** Revenue and Fiscal Affairs Office Health and Demographics Section, 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 Public Employee Benefit Authority, for access to data;
- The SC Department of Health and Environmental Control, Vital Records and Public Health Statistics; for access to data; and
- The **SC Department on Aging,** for its continued collaboration.

Introduction

Someone in America develops Alzheimer's every 65 seconds; by midcentury someone will develop Alzheimer's every 33 seconds.¹

In 1988, the U.S. Census Bureau estimated that there were 474,073 people 65 years of age and older living in South Carolina, and the state was ranked 25th among other states with regard to the percentage of persons aged 65 years and older. In 2010, there were 631,784 people 65 years of age and older living in South Carolina, and the state was ranked 23rd. Since that time, the older adult 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 1.4 million people ages 65 years and older, potentially propelling South Carolina to a ranking of 15th in the nation for the percentage of residents over 65 years of age.¹

ADRD represent an ever-increasing area of concern for families and the healthcare community. An estimated 6.5 million people in the United States are currently living with AD. By 2050, the number of people age 65 and older with AD may grow to a projected 12.7 million.² With increasing age as a leading risk factor for AD, 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.

This report covers data from calendar year 2020 and 2021. Registry cases in this report are defined as AD, vascular dementia, mixed dementias (mixed) and ADRD in other medical conditions (other). Registry cases are also identified by location of residence; either in a facility (nursing facilities or 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.

In this report, ADRD is an umbrella term that encompasses many types of neurocognitive disorders. The Diagnostic and Statistical Manual of Mental Disorders - 5th Edition (DSM-5) states that AD can be diagnosed with a level of certainty if there is 1) clear evidence of decline in memory and learning and at least one other cognitive domain (based on detailed history or serial neuropsychological testing), 2) steadily progressive, gradual decline in cognition, without extended plateaus, and 3) no evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological, mental, or systemic disease or condition likely contributing to cognitive decline). AD is a type of ADRD with an insidious onset and gradual progression of cognitive and behavioral symptoms.³ 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), frontotemporal, AIDS, and alcohol or drug abuse.

¹ US Census Bureau, Population Division, January 2022..

² Alzheimer's Association, 2023 Alzheimer's Disease Facts and Figures.

³ American Psychiatric Association, 2021, Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC.

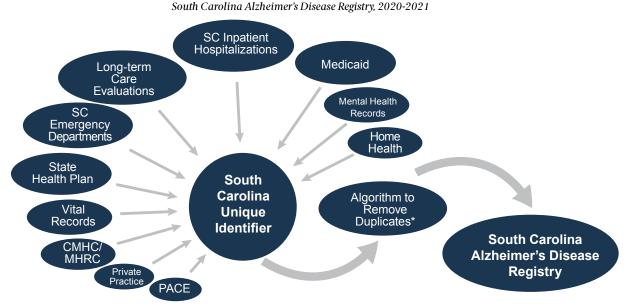
ADRD in South Carolina

The prevalence of AD in the United States is currently estimated to be 11% among persons aged 65 and older. In 2019, there were 970,183 South Carolina residents 65 years and older, representing 18.7% of the total population, an almost 78% increase since the Registry began in 1988.

The total number of persons with ADRD in South Carolina is not known 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 the Registry data. Previous research suggests that the number of individuals with ADRD may be nearly 50% greater than the number with diagnosed ADRD.³ *With that being said, the South Carolina Alzheimer's Disease Registry is the oldest and most comprehensive population-based Registry of ADRD in the country.* There are only three other such registries in existence. One, is located in West Virginia and began collecting data in 2008 and the second is in Georgia and began collecting data in 2014, and the third was recently established in Virginia.^{4,5,6}

Individuals with ADRD are usually identified when they or their family members seek provider services. Since no single system identifies all newly diagnosed patients with ADRD, cases in the Registry are collected from several sources (see Figure 1). This ensures that the Registry captures as many diagnoses as possible.

Figure 1
REGISTRY DATA SOURCES



NOTE: CMHC = Community Mental Health Center; MHRC = Mental Health and Rehabilitation Clinics; PACE = Program of All-inclusive Care for the Elderly

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

¹ Alzheimer's Association, 2022 Alzheimer's Disease Facts and Figures.

² US Census Bureau, Population Division, Interim State Population Projections, 2018-2019.

³ Hebert et al. Alzheimer's Disease in the US Population: Prevalence estimates using the 2000 Census. Archives of Neurology, 2003; Vol. 60, 119-1122.

⁴ West Virginia Alzheimer's Disease Registry. https://wvadr.hsc.wvu.edu/. Accessed September 2023

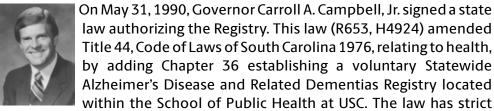
⁵ Georgia Alzheimer's Disease and Related Dementia Registry. https://dph.georgia.gov/AlzheimersDisease. Accessed September 2023

⁶ Virginia Memory Project. https://vcoa.chp.vcu.edu/initiatives/va-memory-project/. Accessed December 2023

History of the Registry

The Alzheimer's Disease Registry was established in 1988 to record specific information about South Carolinians who develop ADRD.

1990



confidentiality requirements but does allow Registry staff to contact the families and physicians of persons diagnosed as having ADRD to collect relevant data and provide information about public and private health care resources available to them.

- From July 1993 to May 1996, the Registry was moved to 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 South Carolina Department of Mental Health.
- The Registry was moved back to the Arnold School of Public Health at USC, where it continues to be maintained by the Office for the Study of Aging. It provides prevalence data to public and private entities for planning and fosters research on risk factors for ADRD, including the risk of institutionalization.



- **2008** The Registry celebrated its 20th anniversary in 2008.
- The 25th Registry report was published, with a celebration of the 25th anniversary of the legislation authorizing the Registry being signed into law.
- The 30th Anniversary celebrating thirty years of collecting data since the establishment of the Registry in 1988.
- The 35th Anniversary celebrating the establishment of the Registry, which continues to receive widespread support and interest from the academic community, support groups, state agencies, and other public and private organizations as part of a statewide effort to study the growing impact of ADRD on the health and welfare of South Carolinians.

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, 10th revision, Clinical Modification (ICD-10-CM, 2010). An individual is then classified into four general categories for reporting purposes as shown in Table 1.

Individuals with ADRD are usually identified when they or their family members seek provider services. Since no single system identifies all newly diagnosed patients with ADRD, cases are collected from several sources (see Figure 1, page 6).

Table 1
CLASSIFICATION OF ADRD BY ICD-10-CM CODES
South Carolina Alzheimer's Disease Registry, - 2020 - 2021

ALZHEIMER'S DISEASE	
F03.90 – F03.91	Senile or presenile dementia
G30.0 – G30.9	Alzheimer's Disease
VASCULAR DEMENTIA	
FO1.50 – F01.51	Arteriosclerotic dementia
G45.0 – G45.9	Cerebrovascular disease (with a dementia code*)
167.0-167.9	
169.00-169.998	
MIXED DEMENTIA (see n	ote below)
Both Alzheimer's d	isease and Vascular dementia
DEMENTIA IN OTHER M	EDICAL CONDITIONS
F10.27 – F10.97	Alcohol dementia
F19.97	Drug-induced dementia
F02.80-F02.81	Dementia with other conditions
G31.83	Dementia with Lewy bodies
G31.01	Pick's Disease
G31.09	Frontotemporal dementia
The following conditions are	e included with a dementia code*:
A81.00-A81.09	Creutzfeldt-Jakob disease
F04-F09	Organic brain syndrome
F48.2	
F07.81	Chronic traumatic encephalopathy
G31.1 – G31.9	Other cerebral degeneration
	-

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.

Parkinson's disease

Huntington's disease

G91.0-G91.9 G93.7-G94 G20

G21.11-G21.8

G10

B20 HIV

^{*}One of the following dementia codes must also be present: F03.90 – F03.91, G30.0 – G30.9, FO1.50 – F01.51, F10.27 – F10.97, F19.97, F02.80-F02.81, G31.83

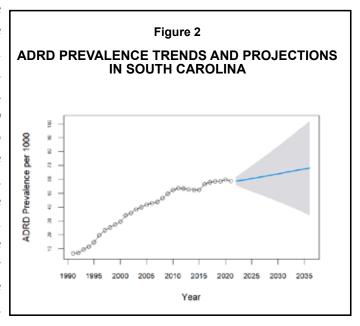
Registry Core Data Items

The registry core data set consists of case-identifying data (for matching purposes, to remove duplicate records, and for linking to other data sources), diagnostic data (ICD 9 + 10 CM codes), the place from which the records were obtained, location of case (facility or community), gender, race, and age. Other information collected, if available, includes other medical diagnoses, educational status, marital status, and name and location of caregiver/contact person for follow up.

Prevalence of ADRD in South Carolina: A Longitudinal Perspective

The longevity of the Registry provides a unique opportunity to gain a longitudinal perspective about ADRD prevalence in South Carolina. For this report, Registry data and interim state population projections from the Census Bureau were combined to calculate a 30-year prevalence

for ADRD in South Carolina. A time series analysis and 15-year prevalence projection were performed using an **ARIMA** (autoregressive integrated moving average) model in R software. For individuals 50 and over, ADRD prevalence was estimated from 1991 to 2021 and projected through 2036. The dots in Figure 2 illustrate the observed ADRD prevalence and the solid line represents the projected prevalence with the shaded parts representing the range that the expected values could possibly fall. While there are fluctuations in the observed prevalence, the overall trend is steadily increasing. ADRD prevalence



increased at an average rate of 8.1% annually from 1991 to 2021, with the prevalence increasing over 8 fold during the past 30 years. From 1991 to 2011, the average prevelance rate increased by 11.7%, then from 2012 to 2017 the rate decreased to an average of 1.4% annualy. Between 2018 and 2021 the annual rate decreased to 0.36%, suggesting a plateauu. This finding has been mirrored in other research that suggests more education, better prevention, and treatment of hypertension have reduced the incidence of ADRD in the United States over the 20th century, ^{1,2}. Although these findings may indicate ADRD prevalence is remaining steady, it should be noted that annual percent change of ADRD prevalence is expected to continue to increase due to the population's shift to older ages, especially given that the baby-boom generation (people born between 1946-1964) are reaching the age range of greatest risk of ADRD, with the oldest members of the generation turning 77 in 2023¹. This is highlighted in the projections through 2036, where the projected average ADRD prevalence rate between 2021 and 2036 would be a 16% increase annually, with a potential range of -26% to 74%. This estimation could be impacted by an increase in older adults migrating to South Carolina during the past decade, for example

Census data shows that 5,846 people migrated to South Carolina in 2010 and increased to a notable 59,694 individuals in 2020³. Such influxes can also cause the prevalence of ADRD to increase further than is currently projected. It is also unknown how the COVID-19 pandemic will potentially influence the prevalence of ADRDs both nationally and worldwide in the years to come.

It should be noted that the prevalence projections are for the Registry. The population prevalence of ADRD will be higher than the projections shown in the figure in any given year because the Registry includes records only for individuals diagnosed through Registry data sources (i.e, individuals who use health care and social services). Individuals who do not use such services, primarily those with early stages of cognitive impairment, are not represented in the Registry or in the projections.

2020 Registry Data Report

ARNOLD SCHOOL OF PUBLIC HEALTH UNIVERSITY OF SOUTH CAROLINA

The 2023 report includes the most current, available, and comprehensive data from two calendar years: January 1 through December 31 of 2020 and 2021.

The following section contains data from 2020, herein referred to as the 2020 Registry Data Report.



2020 Registry Data Report

South Carolina Population Prevalence of ADRD

- In 2020 the Registry maintained information on 120,375 individuals living with ADRD.
- Based on the Registry and 2020 population estimates from the United States Census:
 - 11% of South Carolinians age 65 or over have ADRD;
 - 54% of South Carolinians age 85 or over have ADRD;
 - ADRD prevalence rates vary notably among SC counties; and
 - African Americans are at notably higher risk of an ADRD diagnosis than are non-Hispanic whites. At ages 65 and older, for example, African American South Carolinians are 45% more likely to have ADRD as are non-Hispanic whites.

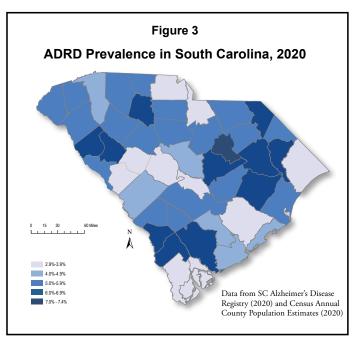
Registry Overview:

Of South Carolinians with diagnosed ADRD in 2018:

- 74% have AD:
- 8% have a dementia due to stroke:
- 15% have a dementia related to other chronic conditions;
- 24% live in an institution at the time of diagnosis;
- 56% are women:
- 23% are African American; and
- 45% of those with AD are 85 years or older.

ADRD Prevalence across South Carolina Counties

Figure 2 shows the percentage of individuals age 50 or over with ADRD in 2020. The county prevalence rates vary from a low of about 3.0% to a high of 7.4%. This county variation provides an important starting point for epidemiological studies of ADRD. It should be noted that counties with a larger older adult population are likely to have greater percentages of individuals with ADRD. This is because the risks of ADRD rise dramatically at older ages. 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.



Characteristics of ADRD in South Carolina

Since 1988, 357,045 cases of ADRD have been identified in South Carolina. This report describes demographic characteristics and medical information for the 120,375 cases who were alive on January 1, 2020 displayed by type of ADRD.

Type of ADRD

Among the 120,375 Registry cases in 2020, 73% had a diagnosis of AD and 8% had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both AD and vascular dementia, the case was reported in a mixed dementia category (3% of all Registry cases). The additional 15% for the total number of "Other Conditions" had a dementia related to other medical conditions, such as Parkinson's disease (see Table 3 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

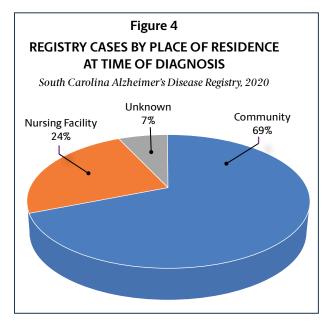
As shown in Figure 4, more Registry cases resided in the community (69%) than in a nursing facility (24%) or unknown locations (7%). The distribution of the types of ADRD was similar in the community and in nursing facilities (Table 2, Figure 5).

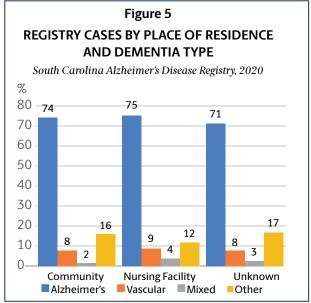
Table 2
REGISTRY CASES BY DEMENTIA TYPE AND PLACE OF RESIDENCE

South Carolina Alzheimer's Disease Registry, 2020

Dementia Type	Community		Nursing	Nursing Facility		own	Total	
	N	%	Ν	%	N	%	N	%
Alzheimer's disease	61,142	73	22,005	75	5,709	71	88,856	74
Vascular dementia	6,910	8	2,653	9	633	8	10,196	8
Mixed dementia	2,039	2	1,160	4	271	3	3,470	3
Other conditions	13,020	16	3,460	12	1,373	17	17,854	15
Total	83,111	69	29,278	24	7,986	7	120,375	100

NOTE: Mixed dementia = both Alzheimer's and Vascular dementia; Other conditions = dementia in other medical conditions.





Dementia in Other Medical Conditions

In addition to AD, 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 2020 Registry, there were 16,515 persons with a dementia associated with one of these conditions who did not also have a diagnosis of AD or vascular dementia. Seventeen percent had dementia associated with Parkinson's disease and 46% had an indication of dementia associated with some other medical condition (Table 3 footnote). The percentages in the table are not mutually exclusive due to the fact that some records indicate more than one medical condition.

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 AD and Parkinson's disease. Like AD, 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 DLB. Medications used to treat AD, Parkinson's disease, and depression are typically used to manage DLB symptoms. National estimates suggest that DLB accounts for approximately 10-25% of all dementia cases.¹ In the South Carolina Registry, DLB accounted for 10% of the dementia in other medical conditions category and only 2% of all dementia cases.

 $^{^1\,}Alzheimer's\,Association.\,http://www.alz.org/dementia/dementia-with-lewy-bodies-symptoms.asp\,Accessed\,October\,30,\,2023.$

Table 3
DEMENTIA WITH OTHER MEDICAL CONDITIONS BY AGE GROUP

South Carolina Alzheimer's Disease Registry, 2020

	Under 65	65-74	75–84	85+	Total	
	%	%	%	%	N	%
Alcohol dementia	27	13	5	2	1,452	9
Drug-induced dementia	1	0	0	0	60	0
Organic brain syndrome	1	1	1	0	112	1
Other cerebral degenerations	24	53	51	42	7,368	45
Parkinson's disease	7	15	26	14	2,784	17
Huntington's disease	1	0	0	0	30	0
HIV/AIDS dementia	7	2	0	0	250	2
Dementia with Lewy Bodies	4	9	14	11	1,725	10
Frontotemporal dementia	4	3	2	1	341	2
Pick's disease	0	0	0	0	51	0
Creutzfeldt-Jakob disease	0	0	0	0	8	0
Traumatic Brain Injury Dementia	1	1	1	0	93	1
Chronic Traumatic Encephalopathy	1	0	0	0	32	0
Dementia with other conditions*	51	41	52	44	7,663	47
Total (N)	2,184	3,993	4,629	5,709	16,515	

NOTE: The percentages in the table are not mutually exclusive due to the fact that some records indicate more than one medical condition.

Age and ADRD in South Carolina

Table 4 shows that in 2020, 45% of persons with AD were 85 years of age or older. Figure 5 shows this information graphically for all dementias included in ADRD, with 43% of persons over 85 years of age. Figure 7 indicates that for people with ADRD, 70% of those 75 - 84 years of age were being cared for in the community at the time of diagnosis. Living in the community is most often the location of choice for the individual with ADRD and the family. However, as Figure 7 indicates, with age comes an increase in the numbers of those who reside in nursing facilities.

Table 4
REGISTRY CASES BY AGE GROUP AND DEMENTIA TYPE

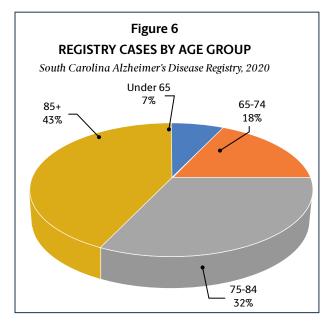
South Carolina Alzheimer's Disease Registry, 2020

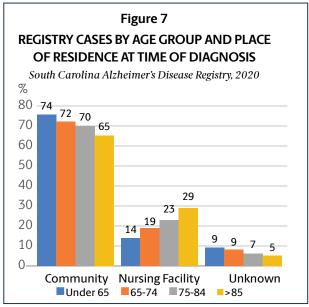
	ΑC)	Vascular		Mix	Лixed		ner	Tot	Total	
	N	%	Ν	%	N	%	N	%	N	%	
Under 65	4,622	5	1,240	13	152	4	2,198	13	8,212	7	
65 - 74	14,432	18	2,177	22	588	17	3,996	24	21,193	18	
75 – 84	27,761	33	2,812	29	1,127	33	4,631	28	36,331	32	
85 +	38,706	45	3,457	36	1,526	45	5,712	35	49,401	43	
Total	85,521	74	9,686	8	3,393	3	16,537	14	115,137	100	

^{*5,238} 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.

NOTE: AD=Alzheimer's disease; Vascular=vascular dementia; Mixed=both Alzheimer's disease and vascular dementia; Other=dementia with other medical conditions.

^{*}Dementia with other conditions includes those with an ICD-10-CM code F02.80 - F02.81 (dementia in conditions classified elsewhere) on their medical record. This code is listed along with the ICD-10-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.





Gender and ADRD in South Carolina

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Table 5 shows Registry cases by gender, ADRD type, and age group. For each dementia type, the number of women was 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 was more than two times the number of men with ADRD. More women than men in this population were diagnosed with ADRD (Figure 8). 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 9.

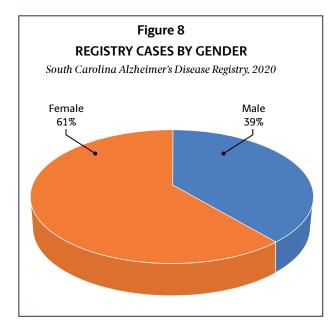
Table 5
REGISTRY CASES BY GENDER, AGE GROUP AND ADRD TYPE

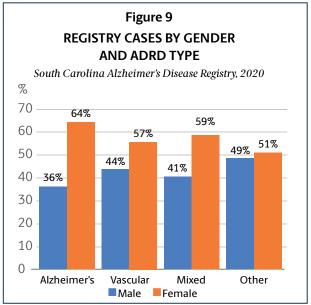
South Carolina Alzheimer's Disease Registry, 2020

	ΑĽ	AD		ular	Mixed		Other		Total	
	N	%	N	%	N	%	N	%	N	%
Male										
Under 65	1,657	6	489	13	77	6	1,165	15	3,388	8
65 – 74	5,663	20	998	26	285	21	2,087	28	9,033	22
75 – 84	10,038	35	1,115	30	498	36	2,189	29	13,840	33
85 +	11,272	39	1,175	31	526	38	2,087	28	15,060	36
Female										
Under 65	1,796	4	433	9	71	4	753	9	3,053	5
65 – 74	7,313	15	904	19	288	15	1,695	21	10,200	16
75 – 84	15,753	31	1,377	29	615	32	2,235	28	19,980	31
85 +	25,329	50	2,082	43	975	50	3,382	42	31,768	49

^{*8,561} records for individuals have missing values for gender or have ages either less than 50 or greater than 110.

NOTE: AD=Alzheimer's disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer's disease and Vascular dementia; Other=dementia in other medical conditions.





Race and ADRD in South Carolina

Total

Compared with whites, African Americans, who comprise approximately 23% of the population 65 years and older, were over-represented in vascular dementia of the South Carolina and in the overall Registry (30%; Table 6). At ages 65 and older, for example, African American South Carolinians were 45% more likely to have ADRD than non-Hispanic whites*. Seventy four percent of African Americans with ADRD resided in the community compared to 69% of whites (Figure 11).

Table 6
REGISTRY CASES BY RACE AND ADRD TYPE

South Carolina Alzheimer's Disease Registry, 2020* AD Vascular Mixed Other **Total** Ν % Ν Ν Ν Ν % Race White 55,473 62 5.017 49 2,042 59 10.810 61 73,342 61 African-American. 19.567 22 3.103 30 1.005 29 4.464 25 28.139 23 Hispanic. 471 1 63 1 16 144 1 694 1 <1 All Others 13,345 15 2,013 20 407 12 2,435 14 18,200 15

3.470

*AD=Alzheimer's disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer's disease and Vascular dementia; Other=dementia in other medical conditions.

10.196

88.856

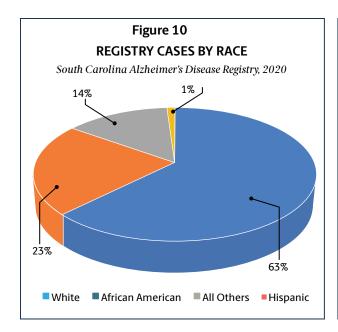
74

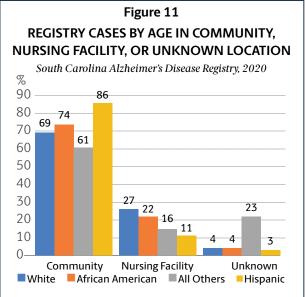
20.375

100

151

17,853





Deaths Among Individuals in the Registry

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. The Registry uses the first date that a person entered one of the systems reporting to us as their entry date. 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, 254,268 have died. Table 7 illustrates the number of years from date of diagnosis to death.

Table 7
LENGTH OF TIME IN REGISTRY BY ADRD TYPE

South Carolina Alzheimer's Disease Registry, 2020*

	ΑC)	Vascı	ılar	Mix	ed	Oth	ner	Tot	al
Years in Registry	N	%	N	%	N	%	N	%	N	%
< 2 years	94,893	54	14,884	56	6,169	52	21,380	55	137,326	54
2–5 years	47,573	27	6,699	25	3,524	30	9,500	24	67,296	26
5 + years	34,364	19	5,218	19	2,141	18	7,923	20	49,646	20
Total	176,830	70	26,801	11	11,834	5	38,803	16	254,268	100

^{*38006} records for individuals have missing values

18 Office for the Study of Aging

^{*} Odds ratio was calculated comparing prevalence of ADRD in 65+ African Americans and Whites.

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 8 lists the top 10 underlying causes of death for persons 65 years of age or older in the Registry who died during 2018. The #1 underlying cause of death for these persons was attributed to Alzheimer's Disease. The leading causes of death for persons ages 65 years and older nationally were heart disease, malignant neoplasms, COVID-19, cerebrovascular diseases, Alzheimer's Disease, chronic lower respiratory diseases, diabetes, accidents, nephritis, and influenza and pneumonia. As can be seen in Table 8, the underlying causes of death for those with ADRD in the Registry closely mirror the national trend.

Table 8
TOP 10 UNDERLYING CAUSES OF DEATH AMONG REGISTRY CASES 65 YEARS OR OLDER

South Carolina Alzheimer's Disease Registry, 2020

Rank

- 1 Alzheimer's Disease
- 2 COVID-19
- 3 Unspecified dementia
- 4 Atherosclerotic heart disease of native coronary artery without angina pectoris
- 5 Senile degeneration of brain, not elsewhere classified
- 6 Chronic obstructive pulmonary disease
- 7 Stroke, not specified as hemorrhage or infarction
- 8 Parkinson's Disease
- 9 Heart failure
- 10 Vascular dementia

^{*}Only includes persons who died during the 2020 calendar year.

^{**}Excludes pneumonia caused by tuberculosis or sexually transmitted disease.

 $^{^1\ \}mathsf{CDC}\ \mathsf{NCHS}\ \mathsf{https://www.cdc.gov/nchs/nvss/mortality_tables.htm}\ \mathsf{Accessed}\ \mathsf{October}\ \mathsf{18,2023}$

2021 Registry Data Report

ARNOLD SCHOOL OF PUBLIC HEALTH UNIVERSITY OF SOUTH CAROLINA

The 2023 report includes the most current, available, and comprehensive data from two calendar years: January 1 through December 31 of 2020 and 2021.

The following section contains data from 2021, herein referred to as the 2021 Data Report.



2021 Registry Data Report

- In 2021 the Registry maintained information on 122,699 individuals living with ADRD.
- Based on the Registry and 2021 population estimates from the United States Census:
 - 11% of South Carolinians age 65 or over have ADRD;
 - 55% of South Carolinians age 85 or over have ADRD;
 - ADRD prevalence rates vary notably among SC counties; and
 - African Americans are at notably higher risk of an ADRD diagnosis than are
 - non-Hispanic whites. At ages 65 and older, for example, **African American South** Carolinians are 34% more likely to have ADRD as are non-Hispanic whites.

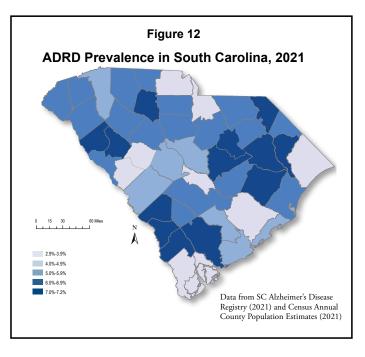
Registry Overview:

Of South Carolinians with diagnosed ADRD in 2021:

- 73% have AD:
- 9% have a dementia due to stroke:
- 16% have a dementia related to other chronic conditions;
- 23% live in an institution at the time of diagnosis;
- 56% are women;
- 22% are African American; and
- 45% of those with AD are 85 years or older.

ADRD Prevalence across South Carolina Counties

Figure 12 shows the percentage of individuals age 50 or over with ADRD in 2019. The county prevalence rates vary from a low of about 2.9% to a high of 7.2%. This county variation provides an important starting point for epidemiological studies of ADRD. It should be noted that counties with a larger older adult population are likely to have greater percentages of individuals with ADRD. This is because the risks of ADRD rise dramatically at older ages. 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.



Characteristics of ADRD in South Carolina

Since 1988, 377,143 cases of ADRD have been identified in South Carolina. This report describes demographic characteristics and medical information for the 122,699 cases who were alive on January 1, 2021 displayed by type of ADRD.

Type of ADRD

Among the 122,699 Registry cases in 2021,73% had a diagnosis of AD and 8% had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both AD and vascular dementia, the case was reported in a mixed dementia category (3% of all Registry cases). The additional 16% for the total number of "Other Conditions" had a dementia related to other medical conditions, such as Parkinson's disease (see Table 10 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

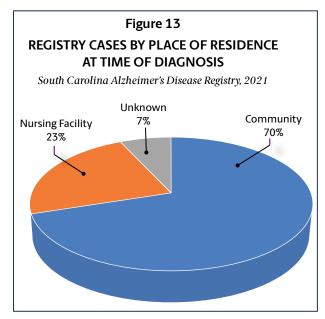
As shown in Figure 13, more Registry cases resided in the community (70%) than in a nursing facility (24%) or unknown locations (7%). The distribution of the types of ADRD was similar in the community and in nursing facilities (Table 9, Figure 14).

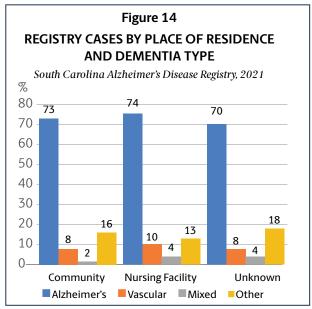
Table 9
REGISTRY CASES BY DEMENTIA TYPE AND PLACE OF RESIDENCE

South Carolina Alzheimer's Disease Registry, 2021

Dementia Type	Comm	unity	Nursing	Nursing Facility		own	Total	
	N	%	N	%	N	%	N	%
Alzheimer's disease	62,453	73	21,074	74	5,269	70	89,236	73
Vascular dementia	7,228	8	2,778	10	659	8	10,665	8
Mixed dementia	2,019	2	1,113	4	315	4	3,447	3
Other conditions	14,223	17	3,686	13	1,442	18	19,351	16
Total	85,923	70	28,651	24	8,125	7	122,699	100

NOTE: Mixed dementia = both Alzheimer's and Vascular dementia; Other conditions = dementia in other medical conditions.





Dementia in Other Medical Conditions

In addition to AD, 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 2021 Registry, there were 19,351 persons with a dementia associated with one of these conditions who did not also have a diagnosis of AD or vascular dementia. Eighteen percent had dementia associated with Parkinson's disease and 41% had an indication of dementia associated with some other medical condition (Table 3 footnote). The percentages in the table are not mutually exclusive due to the fact that some records indicate more than one medical condition.

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 AD and Parkinson's disease. Like AD, 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 DLB. Medications used to treat AD, Parkinson's disease, and depression are typically used to manage DLB symptoms. National estimates suggest that DLB accounts for approximately 10-25% of all dementia cases.¹ In the South Carolina Registry, DLB accounted for 10% of the dementia in other medical conditions category and only 2% of all dementia cases.

 $^{^1\,}Alzheimer's\,Association.\,http://www.alz.org/dementia/dementia-with-lewy-bodies-symptoms.asp\,Accessed\,October\,30,\,2023.$

Table 10
DEMENTIA WITH OTHER MEDICAL CONDITIONS BY AGE GROUP

South Carolina Alzheimer's Disease Registry, 2021

	Under 65	65-74	75–84	85+	Total	
	%	%	%	%	N	%
Alcohol dementia	26	12	5	2	1,448	9
Drug-induced dementia	2	0	0	0	71	0
Organic brain syndrome	1	1	1	0	109	1
Other cerebral degenerations	19	48	45	39	7,284	41
Parkinson's disease	8	18	26	15	3,275	18
Huntington's disease	1	0	0	0	39	0
HIV/AIDS dementia	8	2	1	0	261	1
Dementia with Lewy Bodies	4	10	13	10	1,827	10
Frontotemporal dementia	4	3	2	1	386	2
Pick's disease	1	0	0	0	49	0
Creutzfeldt-Jakob disease	0	0	0	0	10	0
Traumatic Brain Injury Dementia	1	1	1	0	113	1
Chronic Traumatic Encephalopathy	1	0	0	0	49	0
Dementia with other conditions*	56	47	59	50	9,492	53
Total (N)	2,082	4,236	5,279	6,341	17,938	

NOTE: The percentages in the table are not mutually exclusive due to the fact that some records indicate more than one medical condition.

*Dementia with other conditions includes those with an ICD-10-CM code F02.80 - F02.81 (dementia in conditions classified elsewhere) on their medical record. This code is listed along with the ICD-10-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.

Age and ADRD in South Carolina

Table 11 shows that in 2021, 45% of persons with AD were 85 years of age or older. Figure 15 shows this information graphically for all dementias included in ADRD, with 43% of persons over 85 years of age.

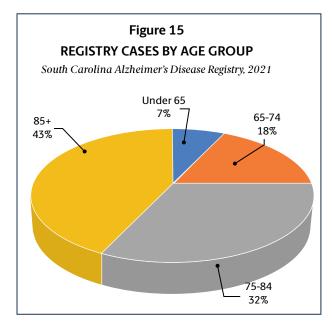
Figure 16 indicates that for people with ADRD, 71% of those 75 - 84 years of age were being cared for in the community at the time of diagnosis. Living in the community is most often the location of choice for the individual with ADRD and the family. However, as Figure 16 indicates, with age comes an increase in the numbers of those who reside in nursing facilities.

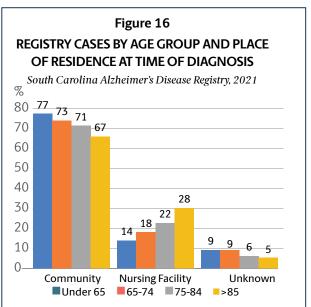
Table 11
REGISTRY CASES BY AGE GROUP AND DEMENTIA TYPE

	AD		Vascular		Mixed		Other		Total	
Age	N	%	N	%	N	%	N	%	N	%
Under 65	4,063	5	1,265	13	128	4	2,094	12	8,150	7
65 – 74	14,435	17	2,334	23	585	17	4,240	24	21,594	18
75 – 84	27,961	33	2,957	29	1,086	32	5,281	27	37,285	32
85 +	38,534	45	3,532	35	1,549	46	6,344	35	49,959	43
Total	85,593	73	10,088	9	3,348	3	17,959	15	116,988	100

^{*5,711} 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.

NOTE: AD=Alzheimer's disease; Vascular=vascular dementia; Mixed=both Alzheimer's disease and vascular dementia; Other=dementia with other medical conditions.





Gender and ADRD in South Carolina

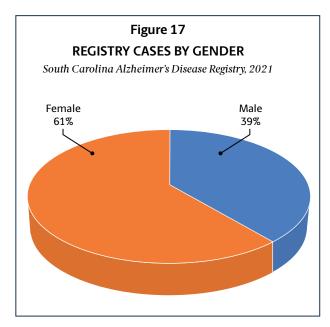
Table 12 shows Registry cases by gender, ADRD type, and age group. For each dementia type, the number of women was notably larger than the number of men in all but the youngest age category. In particular, among those age 85 or over, the number of women with ADRD was more than two times the number of men with ADRD. More women than men in this population were diagnosed with ADRD (Figure 16). 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 17.

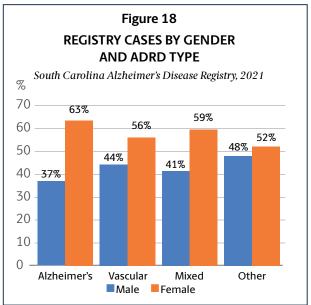
Table 12
REGISTRY CASES BY GENDER, AGE GROUP AND ADRD TYPE

	AD		Vascular		Mixed		Other		Total	
	N	%	N	%	N	%	N	%	N	%
Male										
Under 65	1,647	6	477	13	70	5	1,118	14	3,312	8
65 – 74	5,646	19	984	26	266	20	2,191	27	9,087	22
75 – 84	10,217	35	1,165	30	476	35	2,415	30	14,273	34
85 +	11,515	40	1,210	32	544	40	2,327	29	15,596	37
Female										
Under 65	1,794	4	417	9	55	3	718	8	2,984	5
65 – 74	7,278	14	957	20	307	16	1,833	20	10,375	16
75 – 84	15,863	32	1,420	29	598	31	2,682	30	20,563	31
85 +	25,323	50	2,103	43	987	51	3,824	34	32,237	49

^{*8,561} records for individuals have missing values for gender or have ages either less than 50 or greater than 110.

NOTE: AD=Alzheimer's disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer's disease and Vascular dementia; Other=dementia in other medical conditions.





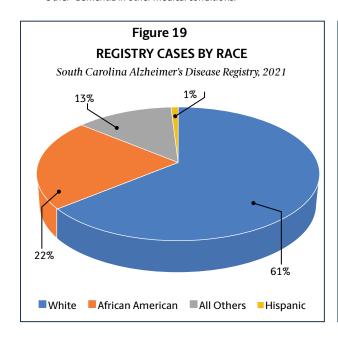
Race and ADRD in South Carolina

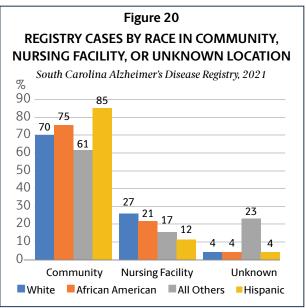
Compared with whites, African Americans, who comprise approximately 22% of the population 65 years and older, were over-represented in vascular dementia of the South Carolina and in the overall Registry (29%; Table 13). At ages 65 and older, for example, African American South Carolinians were 34% more likely to have ADRD than non-Hispanic whites*. Seventy five percent of African Americans with ADRD resided in the community compared to 70% of whites (Figure 20).

Table 13
REGISTRY CASES BY RACE AND ADRD TYPE

		South (Carolina Alzh	eimer's D	isease Registr	y, 2021*				
	AD		Vascular		Mixed		Other		Total	
	N	%	N	%	N	%	N	%	N	%
Race										
White	55,220	62	5,087	48	1,904	55	11,929	62	74,140	60
African-American.	19,267	22	3,134	29	913	27	4,687	24	28,001	23
Hispanic.	525	1	70	1	18	1	169	1	782	1
All Others	14,224	16	2,374	22	612	18	2,566	13	19,776	16
Total	89 236	73	10 665	9	3 447	3	19 351	16	122 699	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.





Deaths Among Individuals in the Registry

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. The Registry uses the first date that a person entered one of the systems reporting to us as their entry date. 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, 270,752 have died. Table 14 illustrates the number of years from date of diagnosis to death.

^{*} Odds ratio was calculated comparing prevalence of ADRD in 65+ African Americans and Whites.

Table 14
LENGTH OF TIME IN REGISTRY BY ADRD TYPE

South Carolina Alzheimer's Disease Registry, 2021*

50 and 5 an other 1 2 to the 1 to 5 to										
	AD		Vascular		Mixed		Other		Total	
Years in Registry	N	%	N	%	N	%	N	%	N	%
< 2 years	101,178	53	15,399	55	6,428	52	22,138	55	145,143	54
2–5 years	51,347	27	7,017	25	3,674	30	9,927	24	71,965	27
5 + years	31,238	20	5,561	20	2,278	18	8,4863	21	53,644	20
Total	189,844	70	27,977	10	12,380	5	40,551	15	270,752	100

^{*38006} records for individuals have missing values

Table 15 lists the top 10 underlying causes of death for persons 65 years of age or older in the Registry who died during 2021. The #1 underlying cause of death for these persons was attributed to Alzheimer's Disease. The leading causes of death for persons ages 65 years and older nationally were heart disease, malignant neoplasms, COVID-19, cerebrovascular diseases, Alzheimer's Disease, chronic lower respiratory diseases, accidents, diabetes, nephritis, and Parkinson's Diseasewere heart disease, malignant neoplasms, chronic lower respiratory diseases, cerebrovascular diseases, AD, diabetes, accidents, nephritis, influenza and pneumonia, and Parkinson's Disease. AS can be seen in Table 15, the underlying causes of death for those with ADRD in the Registry closely mirror the national trend..

Table 15
TOP 10 UNDERLYING CAUSES OF DEATH AMONG REGISTRY CASES 65 YEARS OR OLDER

South Carolina Alzheimer's Disease Registry, 2021

Rank

- 1 Alzheimer's Disease, unspecified
- 2 COVID-19
- 3 Unspecified dementia
- 4 Senile degeneration of brain, not elsewhere classified
- 5 Atherosclerotic heart disease of native coronary artery without angina pectoris
- 6 Parkinson's Disease
- 7 Chronic obstructive pulmonary disease
- 8 Stroke, not specified as hemorrhage or infarction
- 9 Heart failure
- 10 Acute myocardial infarction, unspecified.

AD=Alzheimer's disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer's disease and Vascular dementia; Other=dementia in other medical conditions.

^{*}Only includes persons who died during the 2021 calendar year.

^{**}Excludes pneumonia caused by tuberculosis or sexually transmitted disease.

 $^{^1\ \}mathsf{CDC}\ \mathsf{NCHS}\ \mathsf{https://www.cdc.gov/nchs/nvss/mortality_tables.htm}\ \mathsf{Accessed}\ \mathsf{October}\ \mathsf{18}, \mathsf{2023}$

Additional Programs at the OSA

A. Dementia Dialogues®

- FUNDING SOURCE: South Carolina Department of Health and Human Services,
- PRINCIPAL INVESTIGATOR: Daniela B. Friedman, MSc, PhD
- CO-PRINCIPAL INVESTIGATOR: Lee Pearson, MS, DrPH
- PROGRAM MANAGER: Megan Byers, MSW, LMSW

Dementia Dialogues® provides the most current and practical information about how to care for people with dementia. This program is a nationally registered and evidence-informed, intervention program. Dementia Dialogues® is a 5-module training course designed to educate community members and caregivers (formal or informal) for persons who exhibit signs and symptoms of Alzheimer's disease and related dementias (ADRD). The modules cover valuable information and recommendations including an overview of dementia, strategies for effective communication, understanding the environment and ways to promote independence, addressing challenging behaviors, and creative problem solving. Dementia Dialogues® is offered nationwide by Certified Instructors in-person and virtually, and as a virtual self-guided training at no cost to participants.

B. Graduate Student Scholarship in Aging

The Arnold School of Public Health is committed to developing future leaders in aging research. Therefore, it has established the Graduate Student Scholarship in Aging to recognize up to two outstanding graduate students who exemplify the highest standards of scholarship focused on aging.

C. Research Fellowship in Aging

The Arnold School of Public Health (ASPH) is committed to advancing research and education on aging related issues. The Research Fellowship is designed to support faculty and professional staff in the ASPH to conduct research in the multidisciplinary field of aging.

D. Arnold Aging Lecture

The Arnold Aging Lecture is sponsored by the OSA and the Gerry Sue and Norman J. Arnold Institute on Aging. The lecture's goal is to promote healthy aging across the lifespan through sharing of current research by experts in the field. The lecture is offered to the public and USC students, faculty, and staff without charge.

E: Certificate of Graduate Study in Aging

The Certificate of Graduate Study in Aging is designed to address the educational needs of graduate students and professionals who are or plan to be, engaged in work with older adults. The overarching goal of the CGA is to prepare students and professionals for competent and compassionate practice to be better able to promote the health and well-being of, and improve the quality of life for, older adults. Students learn to assess a variety of domains (e.g., functional and cognitive status, health literacy), apply relevant theories in a health promotion and social and environmental context, and choose and implement effective interventions specifically for older adults.

F. South Carolina's Operation to Confront Isolation and Loneliness

South Carolina's Operation to Confront Social Isolation and Loneliness (SOCIAL Aging), is a state-wide coalition dedicated to reducing social isolation in older adults. Members are comprised of state-level and community experts and those with lived expertise. The OSA serves as the coalition's backbone infrastructure.

OSA Leadership

The OSA is comprised of a core team dedicated to achieving its missions of education, research, and service to the aging community. The team supports and facilitates collaborations with affiliated members from within and outside the University. For a comprehensive list of advisors, partners and collaborators, and affiliates, visit our website at osa-sc.org.

Maggi Miller, Co-Director) and Alzheimer's Disease Registry Manager

Maggi Miller has 15 years of experience in aging-related public health research and practice. She received her MS in health promotion from the University of Delaware and a PhD in epidemiology from the University of South Carolina Arnold School of Public Health. She is a research assistant professor in the Department of Epidemiology and Biostatistics. At the OSA, Dr. Miller manages the SC Alzheimer's Disease Registry and focuses on dementia and aging research, in addition to, program evaluation. Her research interests include Alzheimer's disease and related dementias and caregivers of individuals with dementia.

Megan Byers, Co-Director and Dementia Dialogues® Manager

Megan Byers (she/her) has worked in the field of aging for over a decade. She has developed policies and training curricula, monitored legislative sessions to determine their impact on vulnerable adults, educated stakeholders on issues of adult maltreatment and dementia, taught at universities as an adjunct instructor, presented at state and national conferences, and is a published author. She holds a Master of Social Work, a Graduate Certificate in Gerontology, and Certificates in Research Administration, and in Innovative and Experimental Learning. Ms. Byers is a Licensed Master Social Worker in South Carolina.

Matthew Lohman, Research Faculty

Dr. Lohman is an Assistant Professor of Epidemiology in the Department of Epidemiology and Biostatistics and is a core faculty member of the OSA. His primary research areas are in psychiatric epidemiology, gerontology, geriatric mental health services, and the epidemiology of adverse health outcomes such as falls, hospitalizations, and acquired disabilities among older adults. Dr. Lohman is particularly interested in the role of long-term care services and settings, such as nursing homes and home health care nursing, in the prevention of age-related cognitive and physical decline. He is the current recipient of a grant from the National Institute on Aging to study mechanisms increasing fall risk among older adults with depression. He currently teaches epidemiological methods and psychiatric epidemiology for masters and doctoral students.



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