



2022 Annual Report South Carolina Alzheimer's Disease Registry



Office for the Study of Aging
Arnold School of Public Health
UNIVERSITY OF SOUTH CAROLINA

2022 Annual Report South Carolina Alzheimer's Disease Registry

**ARNOLD SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF SOUTH CAROLINA**

As noted within, data included in this report covers two periods

1) January 1, 2018 through December 31, 2018,

1) January 1, 2019 through December 31, 2019,

the most current years with available and comprehensive data.



Office for the Study of Aging

Arnold School of Public Health

UNIVERSITY OF SOUTH CAROLINA

Table Of Contents

| | |
|---|----|
| Cover Letter | 1 |
| Executive Summary | 2 |
| Registry Goals | 2 |
| Other Activities of OSA..... | 2 |
| Acknowledgments | 3 |
| Introduction..... | 4 |
| Alzheimer's Disease and Related Dementias (ADRD) in South Carolina..... | 5 |
| History of the Registry..... | 6 |
| Registry Procedures | 7 |
| Registry Core Data Items | 8 |
| South Carolina Alzheimer's Disease Registry Report | 9 |
| Characteristics of ADRD in South Carolina | 10 |
| Additional Programs and Trainings at the OSA..... | 28 |
| Office for the Study of Aging Directory..... | 34 |
| Core Team | 34 |
| Affiliate Faculty | 37 |
| Advisors | 38 |
| Collaborators/Partners | 39 |

List Of Tables

| | |
|--|----|
| Table 1. Classification of ADRD by ICD-10-CM Codes, 2018-2019..... | 7 |
| Table 2. Registry Cases by Dementia Type and Place of Residence, 2018..... | 11 |
| Table 3. Dementia with Other Medical Conditions by Age Group, 2018..... | 13 |
| Table 4. Registry Cases by Age Group and Dementia Type, 2018..... | 14 |
| Table 5. Registry Cases by Gender, Age Group and ADRD Type, 2018..... | 15 |
| Table 6. Registry Cases by Race and ADRD Type, 2018..... | 16 |
| Table 7. Length of Time in Registry by ADRD Type, 2018..... | 17 |
| Table 8. Top 10 Underlying Causes of Death Among Those 65 Years or Older, 2018..... | 17 |
| Table 9. Registry Cases by Dementia Type and Place of Residence, 2019..... | 21 |
| Table 10. Dementia with Other Medical Conditions by Age Group, 2019..... | 23 |
| Table 11. Registry Cases by Age Group and Dementia Type, 2019..... | 24 |
| Table 12. Registry Cases by Gender, Age Group and ADRD Type, 2019..... | 25 |
| Table 13. Registry Cases by Race and ADRD Type, 2019..... | 26 |
| Table 14. Length of Time in Registry by ADRD Type, 2019..... | 27 |
| Table 15. Top 10 Underlying Causes of Death Among Those 65 Years or Older, 2019..... | 27 |

List Of Figures

| | |
|--|----|
| Figure 1. Registry Data Sources, 2018-2019..... | 5 |
| Figure 2. ADRD Prevalence in South Carolina, 2018..... | 10 |
| Figure 3. Registry Cases by Place of Residence at Time of Diagnosis, 2018..... | 12 |
| Figure 4. Registry Cases by Place of Residence and Dementia Type, 2018..... | 12 |
| Figure 5. Registry Cases by Age Group, 2018..... | 14 |
| Figure 6. Registry Cases by Age Group and Place of Residence at Time of Diagnosis, 2018..... | 14 |
| Figure 7. Registry Cases by Gender, 2018..... | 15 |
| Figure 8. Registry Cases by Gender and ADRD Type, 2018..... | 15 |
| Figure 9. Registry Cases by Race, 2018..... | 16 |
| Figure 10. Registry Cases by Race in Community, Nursing Facility or Unknown Location,2018..... | 16 |
| Figure 11. ADRD Prevalence in South Carolina, 2019..... | 20 |
| Figure 12. Registry Cases by Place of Residence at Time of Diagnosis, 2019..... | 22 |
| Figure 13. Registry Cases by Place of Residence and Dementia Type, 2019..... | 22 |
| Figure 14. Registry Cases by Age Group, 2019..... | 24 |
| Figure 15. Registry Cases by Age Group and Place of Residence at Time of Diagnosis, 2019..... | 24 |
| Figure 16. Registry Cases by Gender, 2019..... | 25 |
| Figure 17. Registry Cases by Gender and ADRD Type, 2019..... | 25 |
| Figure 18. Registry Cases by Race, 2019..... | 26 |
| Figure 19. Registry Cases by Race in Community, Nursing Facility or Unknown Location,2019..... | 26 |



Office for the Study of Aging

Arnold School of Public Health

UNIVERSITY OF SOUTH CAROLINA

ALZHEIMER'S DISEASE REGISTRY ANNUAL REPORT

We are pleased to present the 2022 Annual Report on the South Carolina Alzheimer's Disease Registry. This report is issued by the Office for the Study of Aging at the University of South Carolina's Arnold School of Public Health.

The following pages describe the significant and multifaceted impact of Alzheimer's disease and related dementias (ADRD) on our state. ADRD affect 11% of the population of South Carolina aged 65 years and older and 52% of those over age 85. Caring for someone with ADRD can cause a major burden for caregivers and other family members.

The South Carolina Alzheimer's Disease Registry is one of only three statewide population-based registries of ADRD in the United States and is the oldest and most comprehensive. Data have been collected on South Carolinians with ADRD since 1988. The Registry was established and is maintained by the Office for the Study of Aging with the invaluable support of the South Carolina Department of Health and Human Services and the Revenue and Fiscal Affairs Office. In this Annual Report you will also find a wide range of research, evaluations, programs, and trainings that address the needs of older South Carolinians and their families.

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. We hope you will visit our website at <https://osa-sc.org/>.

Thank you for your continued support!

If you have any questions about the Alzheimer's Registry or our Office's activities, please contact Dr. Maggi Miller, Registry Manager (803-777-0214 or chandlmj@mailbox.sc.edu).

Best Regards,

Daniela B. Friedman, MSc, PhD
Joseph Lee Pearson, MS, DrPH
Co-Directors

Mindi Spencer, MA, PhD
Associate Director of Research

Maggi C. Miller, MS, PhD
Registry Manager

915 Greene Street • Columbia, South Carolina 29208

An Equal Opportunity Institution

Executive Summary

The Office for the Study of Aging (OSA) at the University of South Carolina (USC) Arnold School of Public Health, in cooperation with the South Carolina Department of Health and Human Services (SCDHHS), the South Carolina Department of Mental Health, the USC School of Medicine, and the South Carolina Revenue and Fiscal Affairs Office, maintains a statewide Registry of South Carolina residents diagnosed with Alzheimer's disease and related dementias (ADRD).

This report is published in fulfillment of the requirement of South Carolina Code of Law Section 44 36 10 and Section 44 36 50 which established the registry for the people of South Carolina and tasked the Arnold School of Public Health and OSA with its upkeep, management, and the dissemination of an annual report.

This report uses the abbreviation ADRD 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.

Since January 1, 1988, the Registry has identified 340,921 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 South Carolinians
- **Develop programs** including **Dementia Dialogues®**
- **Evaluate programs** for South Carolina's aging population
- **Conduct research** on aging and public health issues

Acknowledgments

The South Carolina Alzheimer's Disease Registry has developed into one of the nation's most important and premier resources for understanding ADRD. 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 and staff of 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 mid-century 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 2018, and 2019. 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, 2022 Alzheimer's Disease Facts and Figures.

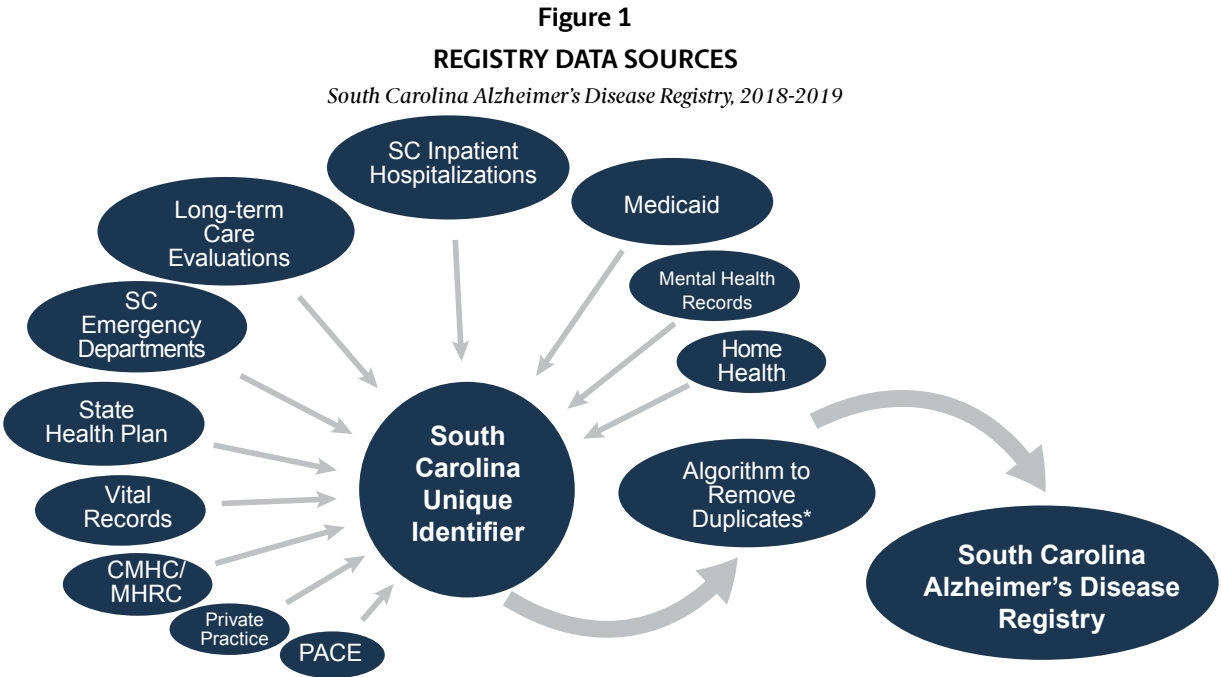
³ American Psychiatric Association, 2021, Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC.

ADRD in South Carolina

The prevalence of AD in the United States is currently estimated to be 11% among persons aged 65 and older.¹ In 2019, there were 938,374 South Carolina residents 65 years and older, representing 17.7% of the total population, an almost 78% increase since the Registry began in 1988.²

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 two 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.^{4,5}

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.



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... 2022
⁵ Georgia Alzheimer's Disease and Related Dementia Registry. <https://dph.georgia.gov/AlzheimersDisease>. Accessed September 2022

History of the Registry

1988 The Alzheimer's Disease Registry was established in 1988 to record specific information about South Carolinians who develop 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 Dementias Registry located within the School of Public Health at USC. The law has strict 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.

1993 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.

1997 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.

2015  The 25th Registry report was published, with a celebration of the 25th anniversary of the legislation authorizing the Registry being signed into law.

2018 The 30th 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, 2018 - 2019

| 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*) |
| I67.0-I67.9 | |
| I69.00-I69.998 | |
| MIXED DEMENTIA (see note below) | |
| Both Alzheimer's disease and Vascular dementia | |
| DEMENTIA IN OTHER MEDICAL 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 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 |
| G91.0-G91.9 | |
| G93.7-G94 | |
| G20 | Parkinson's disease |
| G21.11-G21.8 | |
| G10 | Huntington's disease |
| B20 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: 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.

2018 South Carolina Alzheimer's Disease Registry Report

**ARNOLD SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF SOUTH CAROLINA**

Data included in this report covers
January 1, 2018 through December 31, 2018,
the most current years with available and comprehensive data.



Office for the Study of Aging
Arnold School of Public Health
UNIVERSITY OF SOUTH CAROLINA

2018 South Carolina Alzheimer's Disease Registry Report

South Carolina Population Prevalence of ADRD

- In 2018 the Registry maintained information on 115,563 individuals living with ADRD.
- Based on the Registry and 2018 population estimates from the United States Census:
 - 11% of South Carolinians age 65 or over have ADRD;
 - 52% 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 2018:

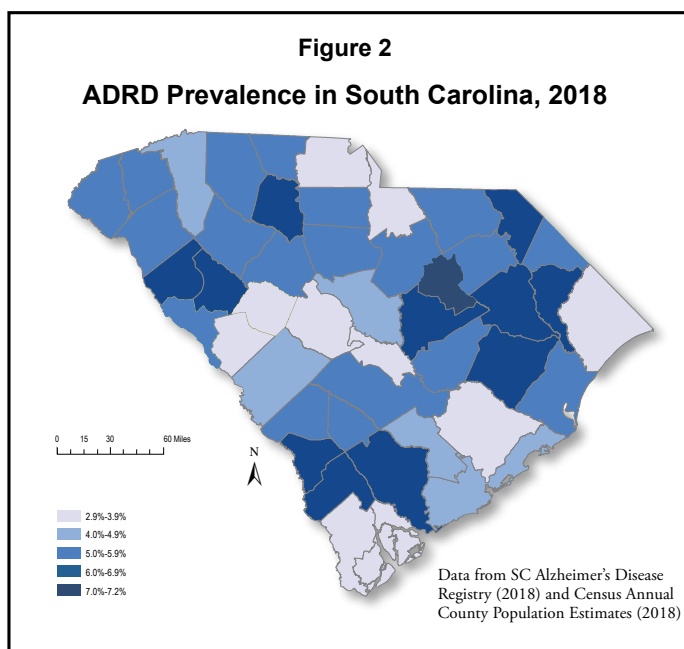
- 73% have AD;
- 8% have a dementia due to stroke;
- 16% have a dementia related to other chronic conditions;
- 24% live in an institution at the time of diagnosis;
- 57% are women;

ADRD Prevalence across South Carolina Counties

Figure 2 shows the percentage of individuals age 50 or over with ADRD in 2018. The county prevalence rates vary from a low of about 3.0% 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, 323,227 cases of ADRD have been identified in South Carolina.



This report describes demographic characteristics and medical information for the 115,563 cases who were alive on January 1, 2018 displayed by type of ADRD.

Type of ADRD

Among the 115,563 Registry cases in 2018, 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 3 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

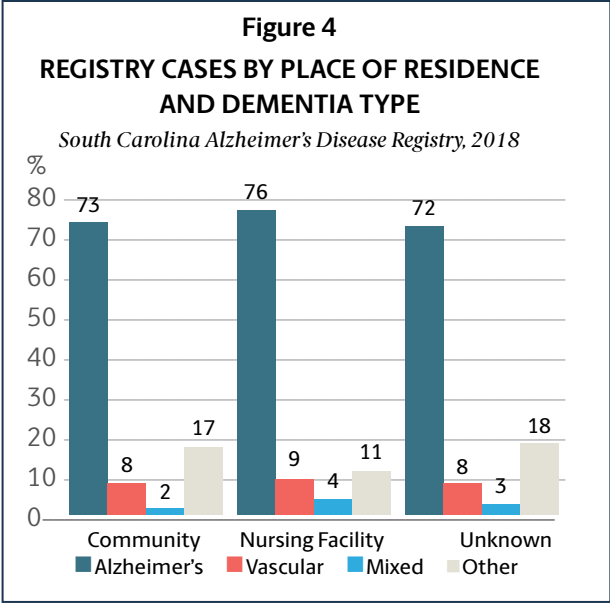
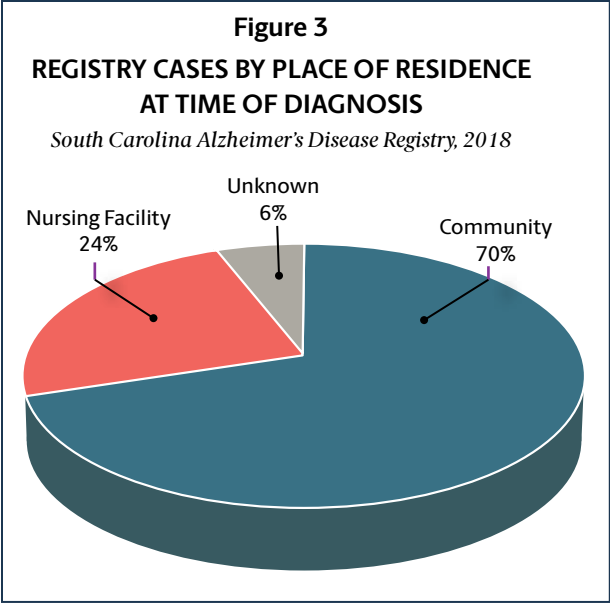
As shown in Figure 3, more Registry cases resided in the community (69%) than in a nursing facility (24%) or unknown locations (6%). The distribution of the types of ADRD was similar in the community and in nursing facilities (Table 2, Figure 4).

Table 2
REGISTRY CASES BY DEMENTIA TYPE AND PLACE OF RESIDENCE

South Carolina Alzheimer’s Disease Registry, 2018

| Dementia Type | Community | | Nursing Facility | | Unknown | | Total | |
|---------------------|--------------|-----------|------------------|-----------|-------------|----------|----------------|------------|
| | N | % | N | % | N | % | N | % |
| Alzheimer’s disease | 58,321 | 73 | 21,292 | 76 | 5,176 | 72 | 84,789 | 73 |
| Vascular dementia | 6,592 | 8 | 2,530 | 9 | 546 | 8 | 9,668 | 8 |
| Mixed dementia | 1,887 | 2 | 1,074 | 4 | 195 | 3 | 3,156 | 3 |
| Other conditions | 13,413 | 17 | 3,227 | 11 | 1,310 | 18 | 18,144 | 16 |
| Total | 80213 | 69 | 28,123 | 24 | 7227 | 6 | 115,563 | 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 2018 Registry, there were 16,725 persons with a dementia associated with one of these conditions who did not also have a diagnosis of AD or vascular dementia. Thirteen percent had dementia associated with Parkinson’s disease and 39% 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 7, 2022.

Table 3
DEMENTIA WITH OTHER MEDICAL CONDITIONS BY AGE GROUP

South Carolina Alzheimer's Disease Registry, 2018

| | Under 65 | 65–74 | 75–84 | 85+ | Total | |
|----------------------------------|-----------------|--------------|--------------|--------------|---------------|----|
| | % | % | % | % | N | % |
| Alcohol dementia | 26 | 12 | 5 | 2 | 1,525 | 9 |
| Drug-induced dementia | 1 | 0 | 0 | 0 | 55 | 0 |
| Organic brain syndrome | 1 | 1 | 1 | 1 | 122 | 1 |
| Other cerebral degenerations | 33 | 59 | 59 | 44 | 8,372 | 50 |
| Parkinson's disease | 5 | 12 | 20 | 12 | 2,170 | 13 |
| Huntington's disease | 0 | 0 | 0 | 0 | 24 | 0 |
| HIV/AIDS dementia | 7 | 1 | 0 | 0 | 242 | 1 |
| Dementia with Lewy Bodies | 3 | 9 | 15 | 10 | 1,674 | 10 |
| Frontotemporal dementia | 3 | 2 | 2 | 1 | 302 | 2 |
| Pick's disease | 1 | 0 | 0 | 0 | 55 | 0 |
| Creutzfeldt-Jakob disease | 0 | 0 | 0 | 0 | 6 | 0 |
| Traumatic Brain Injury Dementia | 1 | 1 | 1 | 0 | 87 | 1 |
| Chronic Traumatic Encephalopathy | 0 | 0 | 0 | 0 | 24 | 0 |
| Dementia with other conditions* | 41 | 33 | 44 | 40 | 6,601 | 39 |
| Total (N) | 2,604 | 4,267 | 4,457 | 5,397 | 16,725 | |

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 4 shows that in 2018, 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 42% of persons over 85 years of age.

Figure 6 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 6 indicates, with age comes an increase in the numbers of those who reside in nursing facilities.

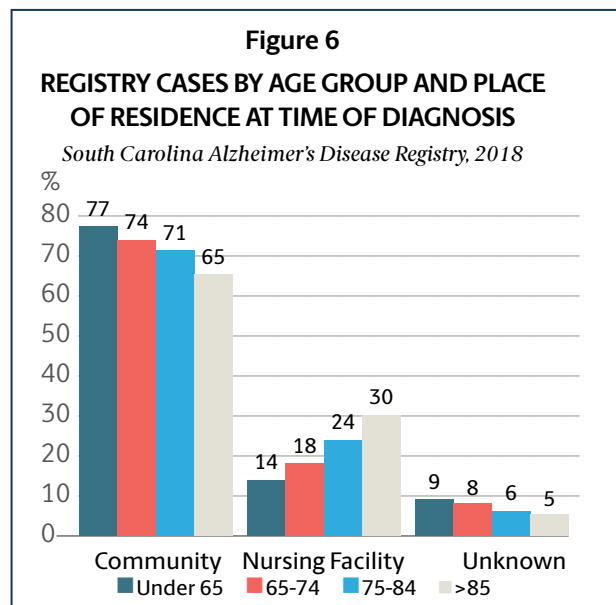
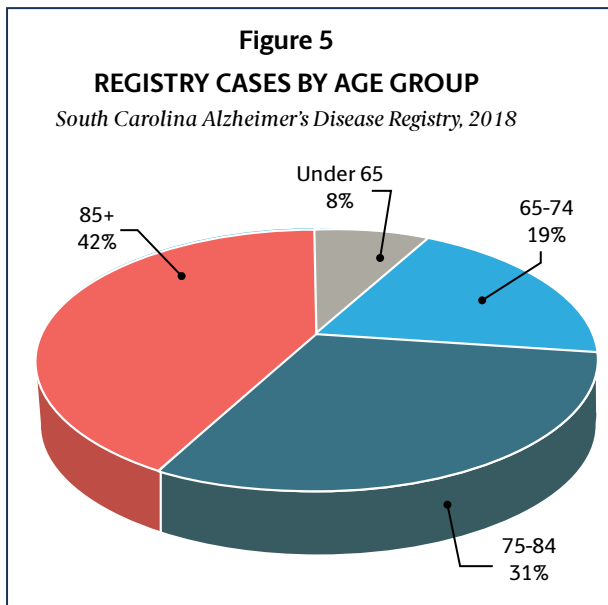
Table 4
REGISTRY CASES BY AGE GROUP AND DEMENTIA TYPE

South Carolina Alzheimer's Disease Registry, 2018

| | AD | | Vascular | | Mixed | | Other | | Total | |
|--------------|---------------|-----------|--------------|----------|--------------|----------|---------------|-----------|----------------|------------|
| | N | % | N | % | N | % | N | % | N | % |
| Under 65 | 4,438 | 5 | 1,202 | 13 | 131 | 4 | 2,617 | 16 | 8,388 | 8 |
| 65 – 74 | 14,346 | 18 | 2,143 | 23 | 569 | 18 | 4,272 | 26 | 21,330 | 19 |
| 75 – 84 | 26,632 | 33 | 2,665 | 29 | 1,004 | 32 | 4,458 | 27 | 34,759 | 31 |
| 85 + | 36,486 | 45 | 3,252 | 35 | 1,391 | 45 | 5,400 | 32 | 46,529 | 42 |
| Total | 81,902 | 74 | 9,262 | 8 | 3,095 | 3 | 16,747 | 15 | 111,006 | 100 |

*4557 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 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 7). This is likely due to the larger number of women alive after age 75. The differences in the ADRD diagnoses by gender are shown graphically in Figure 8.

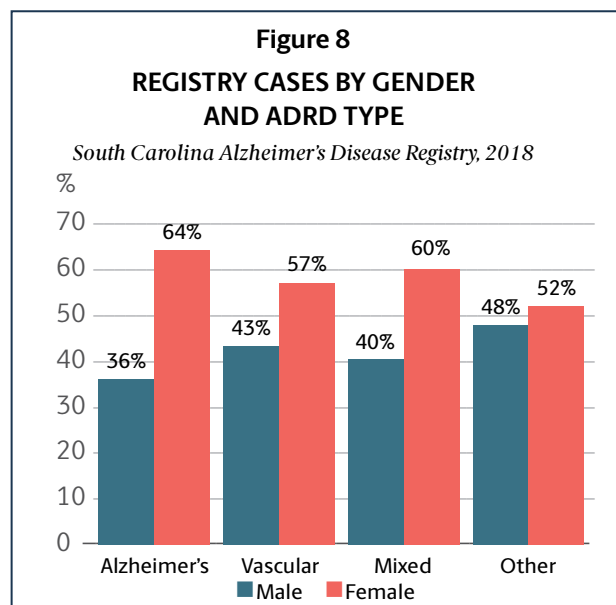
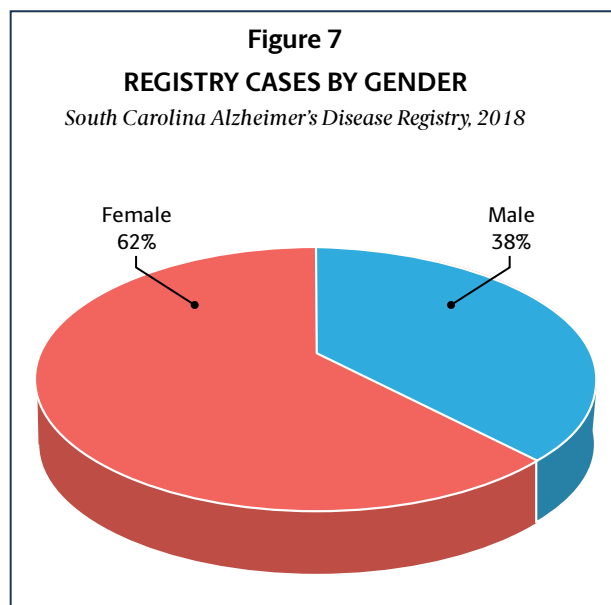
Table 5
REGISTRY CASES BY GENDER, AGE GROUP AND ADRD TYPE

South Carolina Alzheimer's Disease Registry, 2018

| | AD | | Vascular | | Mixed | | Other | | Total | |
|---------------|--------|----|----------|----|-------|----|-------|----|--------|----|
| | N | % | N | % | N | % | N | % | N | % |
| Male | | | | | | | | | | |
| Under 65 | 1,612 | 6 | 532 | 15 | 62 | 5 | 1,446 | 19 | 3,652 | 9 |
| 65 – 74 | 5,693 | 21 | 958 | 26 | 270 | 22 | 2,205 | 29 | 9,126 | 23 |
| 75 – 84 | 9,466 | 35 | 1,090 | 30 | 414 | 34 | 2,058 | 27 | 13,028 | 33 |
| 85 + | 10,056 | 37 | 1,047 | 29 | 483 | 39 | 1,912 | 25 | 13,498 | 34 |
| Female | | | | | | | | | | |
| Under 65 | 1,872 | 4 | 450 | 9 | 63 | 3 | 956 | 12 | 3,341 | 5 |
| 65 – 74 | 7,366 | 15 | 951 | 20 | 288 | 16 | 1,893 | 23 | 10,498 | 17 |
| 75 – 84 | 15,108 | 31 | 1,354 | 28 | 573 | 32 | 2,199 | 27 | 19,234 | 30 |
| 85 + | 24,273 | 50 | 2,023 | 42 | 889 | 49 | 3,252 | 39 | 30,437 | 48 |

*12,749 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.



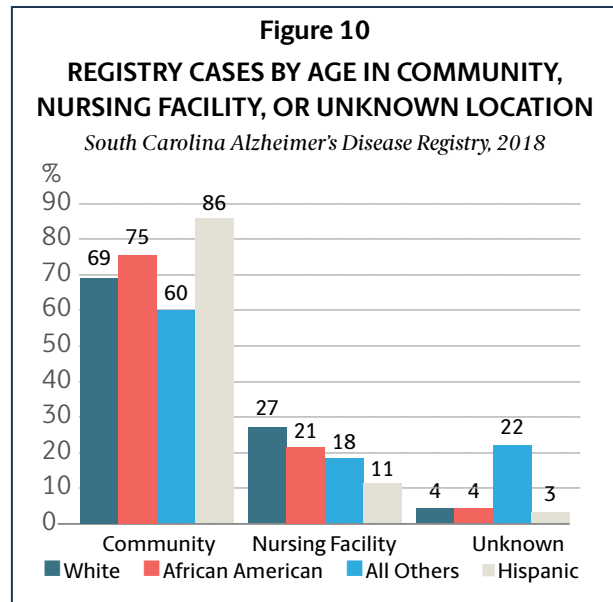
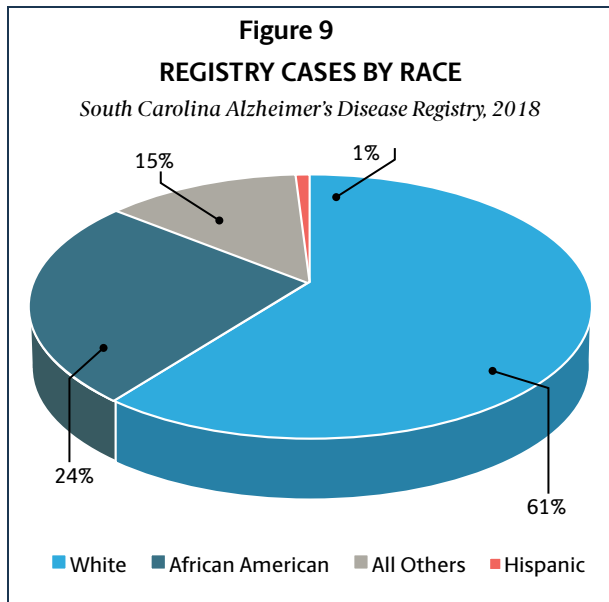
Race and ADRD in South Carolina

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 (32%; Table 6). At ages 65 and older, for example, African American South Carolinians were 35% more likely to have ADRD than non-Hispanic whites*. Seventy five percent of African Americans with ADRD resided in the community compared to 69% of whites (Figure 10).

Table 6
REGISTRY CASES BY RACE AND ADRD TYPE
*South Carolina Alzheimer's Disease Registry, 2018**

| Race | AD | | Vascular | | Mixed | | Other | | Total | |
|------------------|---------------|-----------|--------------|----------|--------------|----------|---------------|-----------|----------------|------------|
| | N | % | N | % | N | % | N | % | N | % |
| White | 53,225 | 63 | 4,864 | 50 | 1,882 | 60 | 10,806 | 60 | 70,777 | 61 |
| African-American | 18,491 | 22 | 3,102 | 32 | 922 | 29 | 4,756 | 27 | 27,271 | 24 |
| Hispanic | 416 | <1 | 58 | 1 | 15 | <1 | 125 | 1 | 614 | 1 |
| All Others | 12,657 | 15 | 1,644 | 17 | 337 | 11 | 2,263 | 13 | 16,901 | 15 |
| Total | 84,789 | 73 | 9,668 | 8 | 3,156 | 3 | 17,950 | 16 | 115,563 | 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, 207,663 have died. Table 7 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 7
LENGTH OF TIME IN REGISTRY BY ADRD TYPE

*South Carolina Alzheimer's Disease Registry, 2018**

| | AD | | Vascular | | Mixed | | Other | | Total | |
|-------------------|----------------|-----------|-----------------|-----------|---------------|----------|---------------|-----------|----------------|------------|
| | N | % | N | % | N | % | N | % | N | % |
| Years in Registry | | | | | | | | | | |
| < 2 years | 82,515 | 55 | 13,896 | 56 | 5,659 | 52 | 20,232 | 56 | 122,302 | 55 |
| 2–5 years | 39,507 | 26 | 6,159 | 25 | 3,216 | 30 | 8,804 | 24 | 57,686 | 26 |
| 5 + years | 28,753 | 19 | 4,567 | 19 | 1,900 | 18 | 6,860 | 19 | 42,080 | 19 |
| Total | 150,775 | 68 | 24,622 | 11 | 10,775 | 5 | 35,896 | 16 | 222,068 | 100 |

*38006 records for individuals have missing values

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 were heart disease, malignant neoplasms, chronic lower respiratory diseases, cerebrovascular diseases, AD, diabetes, accidents, influenza and pneumonia, nephritis, and Parkinson's Disease.¹ 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, 2018

| Rank |
|---|
| 1 Alzheimer's Disease |
| 2 Senility and organic mental disorders |
| 3 Atherosclerotic heart disease of native coronary artery |
| 4 Chronic obstructive pulmonary disease |
| 5 Stroke, not specified as hemorrhage or infarction |
| 6 Parkinson's Disease |
| 7 Heart failure |
| 8 Acute myocardial infarction |
| 9 Malignant neoplasms of unspecified part of bronchus or lung |
| 10 Pneumonia |

*Only includes persons who died during the 2018 calendar year.

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

¹ CDC NCHS https://www.cdc.gov/nchs/nvss/mortality_tables.htm Accessed September 14, 2022

2019 South Carolina Alzheimer's Disease Registry Report

**ARNOLD SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF SOUTH CAROLINA**

Data included in this report covers
January 1, 2019 through December 31, 2019,
the most current years with available and comprehensive data.



Office for the Study of Aging

Arnold School of Public Health

UNIVERSITY OF SOUTH CAROLINA

2019 South Carolina Alzheimer's Disease Registry Report

- In 2019 the Registry maintained information on 118,807 individuals living with ADRD.
- Based on the Registry and 2019 population estimates from the United States Census:
 - 11% of South Carolinians age 65 or over have ADRD;
 - 53% 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 2019:

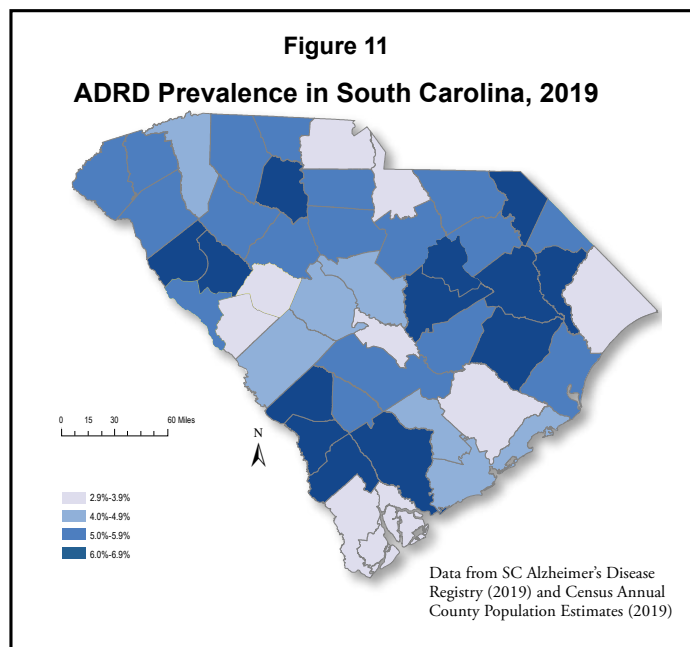
- 74% have AD;
- 8% have a dementia due to stroke;
- 15% have a dementia related to other chronic conditions;
- 24% live in an institution at the time of diagnosis;
- 61% are women;
- 23% are African American; and
- 45% of those with AD are 85 years or older.

ADRD Prevalence across South Carolina Counties

Figure 11 shows the percentage of individuals age 50 or over with ADRD in 2019. The county prevalence rates vary from a low of about 3.0% to a high of 6.9%. 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, 340,921 cases of ADRD have been identified in South



Carolina. This report describes demographic characteristics and medical information for the 118,807 cases who were alive on January 1, 2019 displayed by type of ADRD.

Type of ADRD

Among the 118,807 Registry cases in 2019, 74% 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 10 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

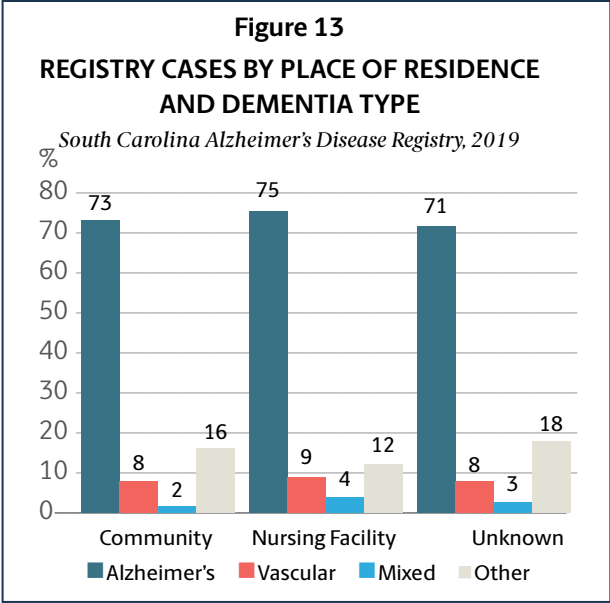
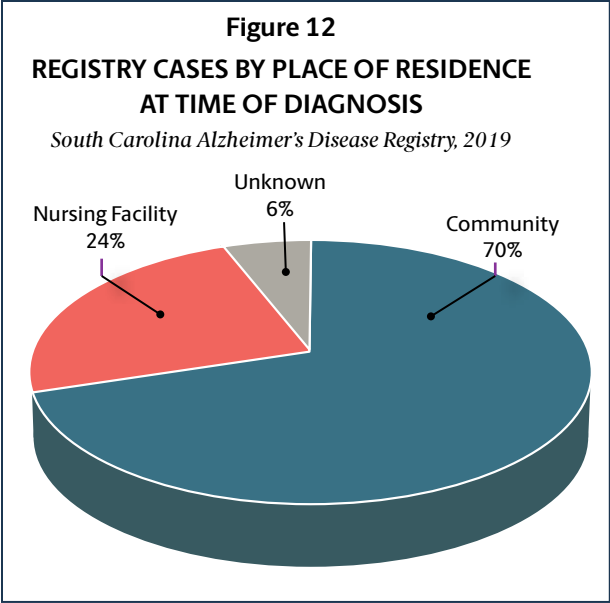
As shown in Figure 12, more Registry cases resided in the community (70%) than in a nursing facility (24%) or unknown locations (6%). The distribution of the types of ADRD was similar in the community and in nursing facilities (Table 9, Figure 13).

Table 9
REGISTRY CASES BY DEMENTIA TYPE AND PLACE OF RESIDENCE

South Carolina Alzheimer’s Disease Registry, 2019

| Dementia Type | Community | | Nursing Facility | | Unknown | | Total | |
|---------------------|---------------|-----------|------------------|-----------|--------------|----------|----------------|------------|
| | N | % | N | % | N | % | N | % |
| Alzheimer’s disease | 60,633 | 73 | 21,543 | 75 | 5,269 | 71 | 87,445 | 74 |
| Vascular dementia | 6,719 | 8 | 2,644 | 9 | 575 | 8 | 9,938 | 8 |
| Mixed dementia | 1,936 | 2 | 2,224 | 4 | 244 | 3 | 3,294 | 3 |
| Other conditions | 13,431 | 16 | 3,342 | 13 | 1,357 | 18 | 18,130 | 15 |
| Total | 82,719 | 70 | 28,643 | 24 | 7,445 | 6 | 118,807 | 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 2019 Registry, there were 16,837 persons with a dementia associated with one of these conditions who did not also have a diagnosis of AD or vascular dementia. Fifteen 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 7, 2021.

Table 10
DEMENTIA WITH OTHER MEDICAL CONDITIONS BY AGE GROUP

South Carolina Alzheimer's Disease Registry, 2019

| | Under 65 | 65–74 | 75–84 | 85+ | Total | |
|----------------------------------|-----------------|--------------|--------------|--------------|---------------|----|
| | % | % | % | % | N | % |
| Alcohol dementia | 26 | 12 | 5 | 2 | 1,470 | 9 |
| Drug-induced dementia | 1 | 0 | 0 | 0 | 58 | 0 |
| Organic brain syndrome | 1 | 1 | 1 | 0 | 117 | 1 |
| Other cerebral degenerations | 29 | 55 | 54 | 42 | 7,847 | 48 |
| Parkinson's disease | 5 | 14 | 23 | 13 | 2,553 | 15 |
| Huntington's disease | 1 | 0 | 0 | 0 | 29 | 0 |
| HIV/AIDS dementia | 7 | 1 | 0 | 0 | 252 | 1 |
| Dementia with Lewy Bodies | 4 | 9 | 15 | 10 | 1,748 | 10 |
| Frontotemporal dementia | 3 | 2 | 2 | 1 | 325 | 2 |
| Pick's disease | 1 | 0 | 0 | 0 | 52 | 0 |
| Creutzfeldt-Jakob disease | 0 | 0 | 0 | 0 | 9 | 0 |
| Traumatic Brain Injury Dementia | 1 | 1 | 1 | 0 | 97 | 1 |
| Chronic Traumatic Encephalopathy | 0 | 0 | 0 | 0 | 25 | 0 |
| Dementia with other conditions* | 46 | 38 | 50 | 44 | 7,473 | 46 |
| Total (N) | 2,370 | 4,212 | 4,618 | 5,637 | 16,837 | |

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 2019, 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 42% of persons over 85 years of age.

Figure 15 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 15 indicates, with age comes an increase in the numbers of those who reside in nursing facilities.

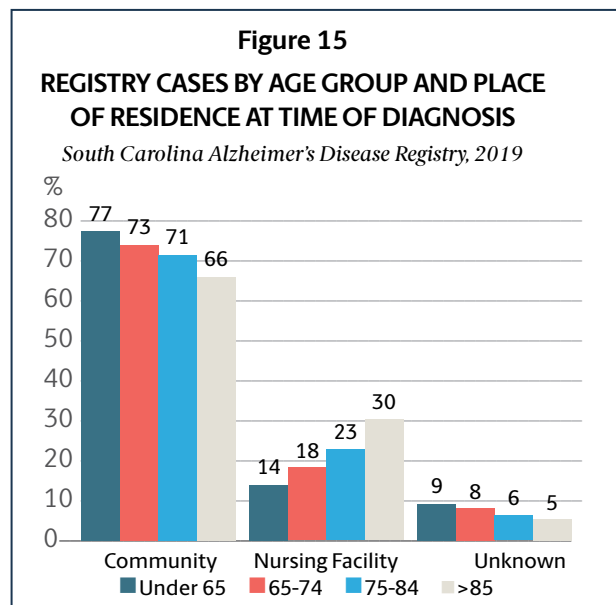
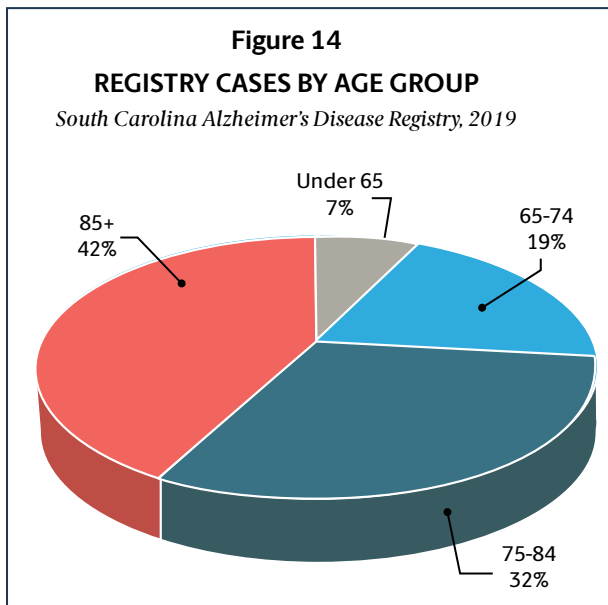
Table 11
REGISTRY CASES BY AGE GROUP AND DEMENTIA TYPE

South Carolina Alzheimer's Disease Registry, 2019

| Age | AD | | Vascular | | Mixed | | Other | | Total | |
|--------------|---------------|-----------|--------------|----------|--------------|----------|---------------|-----------|----------------|------------|
| | N | % | N | % | N | % | N | % | N | % |
| Under 65 | 4,569 | 5 | 1,202 | 13 | 149 | 5 | 2,383 | 14 | 8,303 | 7 |
| 65 – 74 | 14,355 | 17 | 2,157 | 23 | 73 | 18 | 4,216 | 25 | 21,301 | 19 |
| 75 – 84 | 27,721 | 33 | 2,782 | 29 | 1,0524 | 33 | 4,620 | 27 | 6,175 | 32 |
| 85 + | 37,719 | 45 | 3,340 | 35 | 1,454 | 45 | 5,640 | 33 | 48,153 | 42 |
| Total | 84,364 | 74 | 9,481 | 8 | 3,228 | 3 | 16,859 | 15 | 113,932 | 100 |

*4875 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.

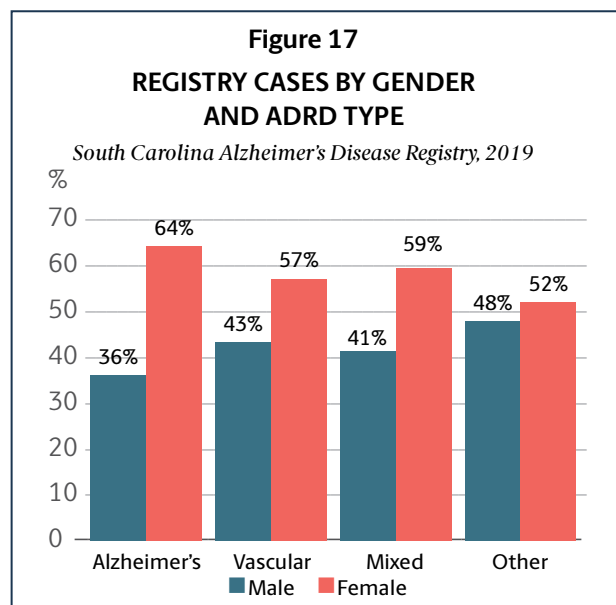
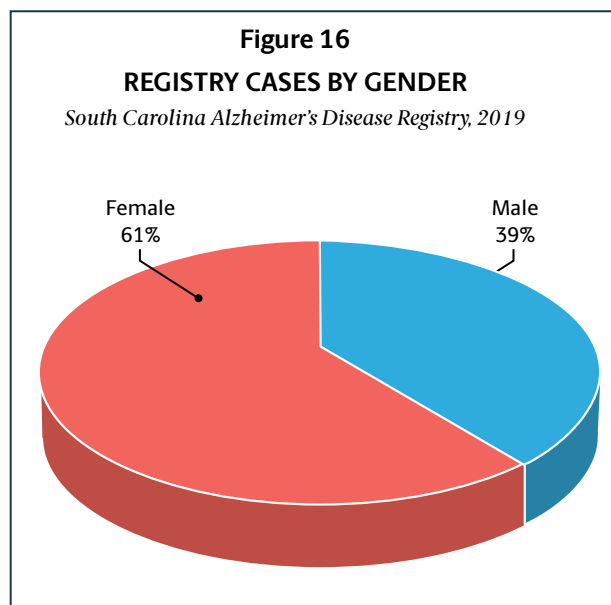
Table 12
REGISTRY CASES BY GENDER, AGE GROUP AND ADRD TYPE

South Carolina Alzheimer's Disease Registry, 2019

| | AD | | Vascular | | Mixed | | Other | | Total | |
|---------------|--------|----|----------|----|-------|----|-------|----|--------|----|
| | N | % | N | % | N | % | N | % | N | % |
| Male | | | | | | | | | | |
| Under 65 | 1,612 | 6 | 532 | 15 | 62 | 5 | 1,446 | 19 | 3,652 | 9 |
| 65 – 74 | 5,693 | 21 | 958 | 26 | 270 | 22 | 2,205 | 29 | 9,126 | 23 |
| 75 – 84 | 9,466 | 35 | 1,090 | 30 | 414 | 34 | 2,058 | 27 | 13,028 | 33 |
| 85 + | 10,056 | 37 | 1,047 | 29 | 483 | 39 | 1,912 | 25 | 13,498 | 34 |
| Female | | | | | | | | | | |
| Under 65 | 1,872 | 4 | 450 | 9 | 63 | 3 | 956 | 12 | 3,341 | 5 |
| 65 – 74 | 7,366 | 15 | 951 | 20 | 288 | 16 | 1,893 | 23 | 10,498 | 17 |
| 75 – 84 | 15,108 | 31 | 1,354 | 28 | 573 | 32 | 2,199 | 27 | 19,234 | 30 |
| 85 + | 24,273 | 50 | 2,023 | 42 | 889 | 49 | 3,252 | 39 | 30,437 | 48 |

*4207 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.



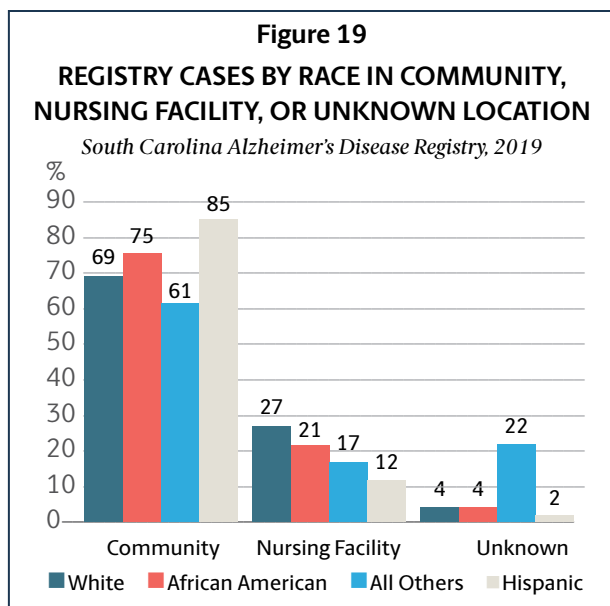
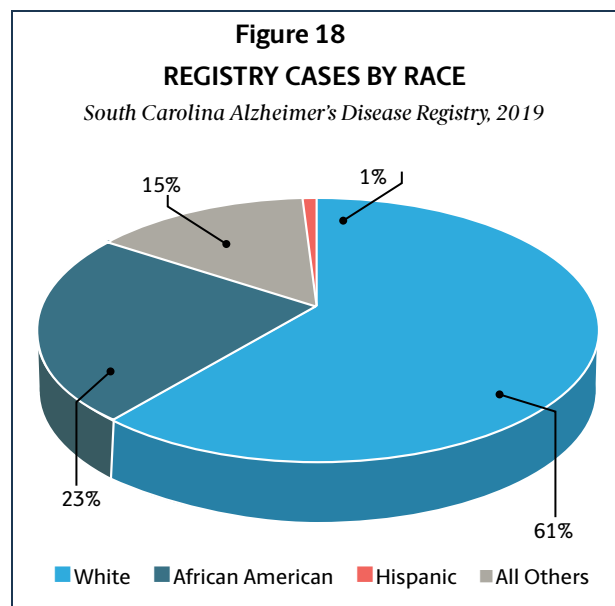
Race and ADRD in South Carolina

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 (31%; 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 69% of whites (Figure 19).

Table 13
REGISTRY CASES BY RACE AND ADRD TYPE
*South Carolina Alzheimer's Disease Registry, 2019**

| Race | AD | | Vascular | | Mixed | | Other | | Total | |
|-------------------|---------------|-----------|--------------|----------|--------------|----------|---------------|-----------|----------------|------------|
| | N | % | N | % | N | % | N | % | N | % |
| White | 54,779 | 63 | 5,008 | 50 | 1,945 | 59 | 10,974 | 61 | 72,706 | 61 |
| African-American. | 19,175 | 22 | 3,070 | 31 | 961 | 29 | 4,624 | 26 | 27,830 | 23 |
| Hispanic. | 453 | 1 | 59 | 1 | 15 | <1 | 126 | 1 | 653 | 1 |
| All Others | 13,038 | 15 | 1,801 | 18 | 373 | 11 | 2,406 | 13 | 17,618 | 15 |
| Total | 87,445 | 74 | 9,938 | 8 | 3,294 | 3 | 18,130 | 15 | 118,807 | 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, 222,113 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, 2019**

| | AD | | Vascular | | Mixed | | Other | | Total | |
|-------------------|----------------|-----------|-----------------|-----------|---------------|----------|---------------|-----------|----------------|------------|
| | N | % | N | % | N | % | N | % | N | % |
| Years in Registry | | | | | | | | | | |
| < 2 years | 88,308 | 54 | 14,328 | 56 | 5,872 | 52 | 20,760 | 60 | 29,268 | 55 |
| 2–5 years | 43,061 | 26 | 6,399 | 25 | 3,344 | 30 | 9,1232 | 4 | 561,927 | 26 |
| 5 + years | 31,238 | 19 | 4,869 | 19 | 2,012 | 18 | 7,343 | 20 | 45,462 | 19 |
| Total | 162,207 | 69 | 25,596 | 11 | 11,228 | 5 | 37,226 | 16 | 236,657 | 100 |

*38006 records for individuals have missing values

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 15 lists the top 10 underlying causes of death for persons 65 years of age or older in the Registry who died during 2019. 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 were heart disease, malignant neoplasms, chronic lower respiratory diseases, cerebrovascular diseases, AD, diabetes, accidents, nephritis, influenza and pneumonia, and Parkinson's Disease.¹ 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, 2019

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

*Only includes persons who died during the 2019 calendar year.

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

¹ CDC NCHS https://www.cdc.gov/nchs/nvss/mortality_tables.htm Accessed October 18, 2022

Additional Programs and Trainings 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 COORDINATOR:** Megan Byers, MSW, LMSW

Dementia Dialogues® is a 5-module, evidence-informed, nationally registered training course designed to educate community members and caregivers for persons who exhibit signs and symptoms of Alzheimer's disease and related dementias (ADRD).

Individuals who attend and complete all five modules of the training course will be awarded a **Dementia Dialogues®** Specialist Certificate. The five modules include the following:

1. **The Basic Facts:** An Overview of Alzheimer's Disease and related Dementias
2. **Keep the Dialogue Going:** Strategies for Effective Communication
3. **It's a Different World:** Understanding the Impact of the Environment & Ways to Promote Independence
4. **It's Nothing Personal:** Addressing Challenging Behaviors
5. **Now What Do We Do?** Creative Problem Solving

Since 2001, over 21,000 individuals have been trained in at least one module and over 10,000 individuals have completed the entire course. **Dementia Dialogues®** is provided at no cost to participants through the Office for the Study of Aging at the Arnold School of Public Health, University of South Carolina. For further information including training materials and contact information for trainers please visit: https://sph.sc.edu/dementia_dialogues

B. Carolina Center on Alzheimer’s Disease and Minority Research (CCADMR)

- **FUNDING SOURCE:** National Institute on Aging, P30 Alzheimer’s disease-related Resource Center on Minority Aging Research, 2018-2023
- **PRINCIPAL INVESTIGATORS:** Sue E. Levkoff, ScD and Daniela B. Friedman, MSc PhD

The overall goal of the Carolina Center on Alzheimer’s Disease and Minority Research (CCADMR) is to increase the diversity of the research workforce focused on population health and determinants of ADRD disparities through sustained infrastructure that will support underrepresented, and minority (URM) faculty focused on the health and well-being of minority elders. The Specific Aims are to:

1. increase the capacity of URM scholars to advance the science on the sociocultural, behavioral, and environmental factors that influence ADRD outcomes in order to reduce ADRD-related disparities, with a focus on African Americans, and
2. advance the science of ADRD research focused on population health and determinants of ADRD disparities through research education in population-based, secondary data analysis, interdisciplinary co-mentoring teams, well-established strategies for recruitment of AD-RCMAR Scientists, and education on Health Disparities and Minority Aging Research.

The CCADMR is a state-wide collaboration, providing mentorship and education on determinants of ADRD disparities using population-based datasets for URM faculty throughout South Carolina, at the three major research institutions, including University of South Carolina (USC), Medical University of South Carolina (MUSC), and Clemson University (CU), and three Historically Black Colleges and Universities (HBCUs), including Allen University, Claflin University, and South Carolina State University.

C. Promoting High-Impact Alzheimer’s Disease Research through the Use of Statewide Registries: Expanding Diversity in Aging Research

- **FUNDING SOURCE:** National Institutes of Health: National Institute on Aging
- **PRINCIPAL INVESTIGATORS:** Lucy A. Ingram (Contact PI), Daniela B. Friedman, Sue E. Levkoff
- **PROGRAM COORDINATOR:** Quentin McCollum, MPH
- **PROJECT TITLE:** Promoting High-Impact Alzheimer’s Disease Research through the Use of Statewide Registries: Expanding Diversity in Aging Research

Establishing mechanisms for increasing the pipeline of scientists who conduct research in aging and Alzheimer’s disease and related dementias (ADRD), and mentoring these scientists, are national public health priorities. The NIA-funded, annual conference series entitled, “Promoting High-Impact Alzheimer’s Disease Research through the Use of Statewide Registries: Expanding Diversity in Aging Research” seeks to increase the number of underrepresented minority and minoritized (URM) scientists who conduct research in aging and ADRD, thus ultimately contributing to the long-term goal of creating a community of scientists that is representative of the entire US population. In particular, the conference series is an opportunity to highlight the regional impact of ADRD and establish a pipeline for URM researchers to address the growing disparities in this area.

The specific aims of the conference series are to: 1: Provide a forum for underrepresented minority (URM) and non-URM researchers to learn how to conduct high-impact ADRD research using statewide registries; 2: Provide a mechanism for senior faculty/experts to mentor junior URM researchers in AD registry research through the submission of a) an abstract for presentation at the following year’s R13 conference, and b) a manuscript to a peer-reviewed journal; 3: Provide a mechanism to support ongoing networking among URM and non-URM researchers; and 4: Conduct process and outcome evaluations of the program, making modifications as needed.

D. Monitoring Activities of Daily Living (ADLs) in Individuals with Alzheimer's Disease (AD) using Floor Vibrations

- **FUNDING SOURCE:** University of South Carolina, Office of the Vice President for Research- Advanced Support for Innovative Research Excellence (ASPIRE) II Integration Program (2022-2023)
- **PRINCIPAL INVESTIGATOR:** Juan Caicedo, PhD
- **CO-PRINCIPAL INVESTIGATOR:** Yohanna Mejia Cruz, PhD
- **CO-INVESTIGATOR:** Maggi Miller, PhD

This research aims at understanding if floor vibrations can be used to evaluate the need for intervention of individuals with Alzheimer's disease who live alone. The proposed work will produce preliminary data to prepare an extramural proposal that allows finding meaningful patterns in the information collected and its relationship with activities of daily living (ADLs). The objectives of this study are:

- i) to evaluate if changes in ADLs are concise with changes in floor vibrations,
- ii) to conform a multidisciplinary team of health scientists and engineers to secure external funding, and
- iii) to submit a research proposal to an NSF-NIH solicitation.

To accomplish these objectives, the team will recruit three participants with AD in the mild stage, collect floor vibrations data and surveys on ADLs, and analyze the data for changes or anomaly levels of activity. The execution of this proposal will result in a dataset of continuous activity for a timeframe of 12 months that will be made publicly available in Open Science Framework and the submission of an external proposal to an NSF/NIH solicitation to secure external funding.

E. Graduate Student Scholarship in Aging Research Awards Program

- **SPONSOR:** Gerry Sue and Norman J. Arnold Institute on Aging

Through the generous support of Norman and Gerry Sue Arnold, 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. The Graduate Scholar in Aging (GSA) was inaugurated in 2017 and continues to support graduate students.

F. Arnold Aging Lecture

- **SPONSOR:** Gerry Sue and Norman J. Arnold Institute on Aging

The Annual Arnold Aging Lecture is sponsored by the Office for the Study of Aging and the Gerry Sue and Norman J. Arnold Institute on Aging. The Arnold Aging Lecture's goal is to promote healthy aging across the lifespan through current research by topic experts. The Lecture is offered to the public and UofSC students, faculty, and staff without charge.

OSA Directory

Core Team

Daniela B. Friedman, *Co-Director (up to June 2022)*

Daniela Friedman, Professor and Chair of the Department of Health Promotion, Education, and Behavior, is the Co-Director of the Arnold School of Public Health's OSA. She is a leader in gerontology and community- engaged health promotion in South Carolina, dedicated to improving health literacy and reducing health disparities among older adults across the state. Dr. Friedman's federally funded research network, includes the Centers for Disease Control and Prevention-funded South Carolina Cancer Prevention and Control Research Network, focusing on the communication and dissemination of evidence-based health messages and programs. Dr. Friedman also directs the university-wide Certificate of Graduate Study in Health Communication.

Lee Pearson, *Co-Director (up to June 2022)*

Lee Pearson has more than 20 years of experience in addressing public health priorities in South Carolina, including a specific focus on the unique needs of the state's aging population. In 2014, he helped to lead a statewide taskforce on long-term care. Dr. Pearson holds a Doctor of Public Health degree in health promotion, education and behavior, as well as a graduate certificate in gerontology. He served as the co-director of OSA through June of 2022. In that role, he worked with the entire OSA team to advance the core mission and promote expanded opportunities with collaborative partners. In addition to his former role with OSA, Dr. Pearson is the associate dean for operations and accreditation in the Arnold School of Public Health and serves on the board of the SC chapter of the Alzheimer's Association. He has previously served on the Joint Legislative Committee to Study Services, Programs and Facilities for the Aging.

Mindi Spencer, *Associate Director of Research*

Mindi Spencer is an Associate Professor in the Department of Health Promotion, Education, and Behavior, with a joint appointment in the Institute for Southern Studies. Broadly, her research focuses on how cultural and psychosocial factors influence health in older adulthood. She also conducts research on caregiving and mental health among American Indian and African American elders. Dr. Spencer is the Principal Investigator of the "Youth Empowered Against HIV!" Project and a partner in the "Equalize Health" LGBT cultural competence training program for health care providers. Dr. Spencer serves on the Lt. Governor's Alzheimer's Resource Coordination Center and on the Minority Task Force of the Gerontological Society of America.

Maggi Miller, *Co-Director (July 2022 to current) 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 (July 2022 to current) and Dementia Dialogues® Program Manager*

Megan Byers (she/her) has worked in the field of aging for nearly 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, *Assistant Professor*

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.

Katherine Leith, *Research Associate*

Dr. Leith has been working and teaching in the fields of social work, aging, and public health for more than 20 years. She has extensive experience in both academia and community practice. Initially, Dr. Leith worked as social work case manager for the NC Department of Mental Health, as coordinator of an adult day program for persons with mental illness and intellectual disabilities. Later she served as medical social worker at a SC dialysis clinic. Her most recent clinical practice was with the SC Department of Mental Health, as social work supervisor at Bryan Psychiatric Hospital, Forensics. After joining the University of South Carolina, Dr. Leith collaborated with several SC State Agencies, such as the State Department of Aging, SC DHEC and SCDMH, where she served as evaluator on a number of evidence-based community prevention programs, primarily in the areas of mental health, chronic disease self-management education, and falls prevention. She also taught, and continues to teach, Social Welfare and Policy, Human Behavior in the Social Environment, Social Work Research, Aging, and Advanced Practice courses in the College of Social Work and in the Department of Health Promotion, Education and Behavior at the Arnold School of Public Health, as well as for Simmons College and for Walden University. Dr. Leith also serves as course lead and tutor for Apollon University in Bremen, Germany and as grant reviewer/panel chair for ACL, ACF, and CMS. She is an associate editor for *Frontiers in Public Health*. As a member of the Office for the Study of Aging in the Arnold School of Public Health, she is the Coordinator of the Certificate for Graduate Study in Aging and contributes to the research endeavors of the office's team on projects related to Alzheimer's, caregiving and other aging-related issues.

Fanli Yi, PhD Student

Fanli Yi is a third year Ph.D. Candidate of Epidemiology. Her research interests are on evaluating the impacts of cardiovascular procedures on the trend of coronary heart disease in Western Australia; the Affordable care act and Medicare on the incidence and mortality rates of colorectal cancer in South Carolina; and the periodontal antibodies on the cognitive function. Fanli has expertise in unique data linkages, administrative data claims analysis, data management of complex data systems, creation of complex data coding algorithms for clinical procedures, and analysis and interpretation of scientific findings.

Mansi Verma, PhD Student

Mansi Verma is a PhD student in Epidemiology in the Arnold School of Public Health. She holds both a Bachelor of Science in Neuroscience and a Bachelor of Science in Psychology at Michigan State University, and a Master of Public Health in Epidemiology at the University of Michigan. Her research interests include dementia, mental health conditions such as depression and anxiety and social determinants of health

Eric Misio Bawa, PhD Student

Eric Mishio Bawa is first year Ph.D. student in Epidemiology at the Arnold School of Public Health. He is a Field Epidemiologist, with training from the Ghana Field Epidemiology and Laboratory Training Program (GFELTP). He is also an AHPC licensed Medical Laboratory Scientist. His core competencies as a field epidemiologist are surveillance system design and evaluation, surveillance data analysis, outbreak investigations, and manuscript writing. As a laboratory scientist, he has competencies in testing, quality control, and laboratory management. He has expertise in all aspects of the research process (e.g -literature review, data linkage, data analysis, manuscript writing, the use of data capture tools such as RedCap, etc.). Eric is currently interested in aging, non-communicable diseases, artificial intelligence, and maternal-child health research

Affiliate Faculty

OSA is proud of its strong partnerships with faculty who represent multiple disciplines from across the UofSC campus.

ARNOLD SCHOOL OF PUBLIC HEALTH

OFFICE OF THE DEAN

Sara Corwin

EPIDEMIOLOGY & BIostatISTICS

Monique Brown

Angela Liese

Myriam Torres

Jingkai Wei

Anwar Merchant

HEALTH PROMOTION, EDUCATION, AND BEHAVIOR

Ken Watkins

Lucy Ingram

EXERCISE SCIENCE

Mei Sui

Delia West

Sara Wilcox

Chih-Hsiang “Jason” Yang

COLLEGE OF SOCIAL WORK

Sue Levkoff

Otis Owens

SCHOOL OF MEDICINE

Donna Ray

SCHOOL OF NURSING

Lorie Donelle

Advisors

The OSA benefits from numerous partnerships and the active input of stakeholders from across South Carolina. The key advisors listed below provide strategic guidance on the mission and overall direction of OSA.

Community

Darryl Broome, *Advisor on Aging Services and State Policy*

Marti Colluci, *Leeza's Care Connection*

Brenda Hyleman, *Aging Life Care Professional*

Beth Sulkowski, *Alzheimer's Association South Carolina*

Sam Waldrep, *Advisor on Aging Services and State Policy*

Jennifer Brewton, *SC Department on Aging*

Nicholas Rescinti, *UofSC Leonard Davis School of Gerontology*

Nikki Hutchinson, *AARP*

Research and Clinical

James W. Davis, *MD, Memory Health Program, PRISMA Health Upstate Network*

Julius Fridriksson, *PhD, Arnold School of Public Health, Department of Communication Sciences and Disorders*

Jacobo Mintzer, *MD, MBA, Roper St. Francis*

Collaborators/Partners

The OSA collaborates with many organizations and agencies to improve the lives of older adults in South Carolina. These partnerships strengthen the OSA's ability to fulfill its mission through the sharing of resources and expertise.

AARP – South Carolina: <http://states.aarp.org/region/south-carolina/>

Alzheimer's Association – South Carolina Chapter: <http://www.alz.org/sc/>

Alzheimer's Resource Coordination Center: <https://aging.sc.gov/programs-initiatives/alzheimers-resource-coordination-center-arcc>

Centers for Medicare and Medicaid Services: <https://www.cms.gov/>

Clemson University Institute for Engaged Aging: <https://www.clemson.edu/cbshs/centers-institutes/aging/>

Healthy Brain Research Network: <http://prevention.sph.sc.edu/projects/braincenter.html>

Leeza's Care Connection: <https://leezascareconnection.org/>

Medical University of South Carolina: <https://medicine.musc.edu/departments/centers/aging>

South Carolina Area Health Education Consortium: <http://www.scahec.net/>

South Carolina Center on Aging: <http://academicdepartments.musc.edu/neuro-research/research/centers/aging/>

South Carolina Department on Aging: <https://aging.sc.gov/>

South Carolina Department of Health and Environmental Control: <https://scdhec.gov/>

South Carolina Department of Health and Human Services: <https://www.scdhhs.gov/>

South Carolina Department of Mental Health: <https://scdmh.net/>

South Carolina Health Care Association: <https://www.schca.org/>

South Carolina Institute of Medicine and Public Health: <http://www.imph.org>

South Carolina Respite Coalition: <http://www.screstitecoalition.org/>

The Carolinas Center for Medical Excellence: <http://www.thecarolinascenter.org/>

The FriendShip Village: <http://www.thefriendship.org/>

University of South Carolina College of Social Work: <http://www.cosw.sc.edu/>

University of South Carolina School of Medicine Columbia: https://sc.edu/study/colleges_schools/medicine/education/clinical_departments/internal_medicine/index.php

Utah Department of Health and Human Services: <https://dhhs.utah.gov/>

This Annual Report is available online at osa-sc.org

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.

Contact Dr. Maggi Miller, Office for the Study of Aging Co-director and Registry Manager, at chandlmj@mailbox.sc.edu for further information.



Office for the Study of Aging

Arnold School of Public Health

UNIVERSITY OF SOUTH CAROLINA