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# **EXECUTIVE SUMMARY**



### **Background**

DURING THE 2013 GEORGIA LEGISLATIVE SESSION, the Georgia General Assembly created the Georgia Alzheimer's and Related Dementias State Plan Task Force (GARD) to meet during the following summer. The Task Force was charged with creating a State Alzheimer's Disease Plan, including recommendations to collect statewide data to inform the evaluation and care infrastructure. All four legislative healthcare committee chairs and state health agency commissioners served on the Task Force and chaired issue-specific subcommittees. The Department of Public Health Commissioner, Brenda Fitzgerald, MD., chaired the Healthcare Research and Data Collection Subcommittee which included clinical and state agency stakeholders. One goal for the Subcommittee was to identify and make recommendations about using surveillance data to enhance Alzheimer's awareness and inform action in public health programs and state planning.1 The Subcommittee found that there was a paucity of data about Alzheimer's disease and related Dementias in Georgia and that no central repository for these data exists. Furthermore, this has created a barrier to estimating accurate Alzheimer's disease and related dementias prevalence rates in Georgia to inform planning, research, and reporting efforts. One key recommendation was to establish a statewide Alzheimer's Disease and Related Dementias (ADRD) Registry that will provide accurate current data to address these urgent needs.

During the 2014 Georgia Legislative Session, legislation to establish an ADRD Registry within the Georgia Department of Public Health (DPH) (HB 966) was introduced and subsequently passed (O.C.G.A 31-2a-17).<sup>2</sup> As a major proprietor of health data in Georgia, DPH is uniquely situated to house such a registry. Given its existing footprint in the areas of health policy and promotion, DPH was identified as a prime coordinator of stakeholders and partners in the registry planning and development effort.

DPH has partnered with the Division of Aging Services within the Georgia Department of Human Services and the Association of State and Territorial Health Officials (ASTHO) to convene stakeholder meetings including more than 40 internal and external partners:

- Georgia Department of Human Services, Division of Aging
  - Georgia Alzheimer's Association
  - Georgia Hospital Association
  - Medical Association of Georgia
  - State Legislators
  - Georgia Department of Community Health (Medicaid, State Health Benefit Plan)
  - West Virginia and South Carolina Alzheimer's and Related Dementias Registry Staff
  - Carl Vinson Institute, University of Georgia
  - University of Georgia, College of Public Health
  - Emory University, Rollins School of Public Health
  - Members of the healthcare provider community

- GARD-PLAN pdf
- 2OCGA 31-2a-17, 2014, LexisNexis. http://web.lexisnexis.com/ research/xlink?app=00075&view= full&interface=1&docinfo= off&searchtype=get&search= 0.C.G.A.+%A7+31-2A-17SEARCH=

### Benefits of a State Alzheimer's and Related Dementias Registry

- Provide legislators, State planners and administrators, and members of the private sector with accurate data that will enable informed planning for current and future healthcare and social service needs (e.g. nursing home beds, adult day care, etc.).
- Provide a resource for Georgia researchers to secure National Institute for Health (NIH) funding and establish an environment that will attract clinical trial and biotechnology investments, and create new jobs.
- Serve the people of the State of Georgia by guiding efforts to educate the public on ADRD and serve as an information clearing house on ADRD for patients and caregivers.
- To further serve Georgians by supporting cutting edge clinical research into more effective treatments for dementing diseases.

#### **Goals for the ADRD Registry in Georgia**

- Collect and disseminate usable data to inform programs and services for the aging population.
- Determine the burden of ADRD among Georgians.
- Identify epidemiologic trends.
- Bring awareness at the state level to issues of ADRD and increase the potential for positive statewide health outcomes and influence the management of associated healthcare costs.
- Inform stakeholders for planning and for future registry needs.

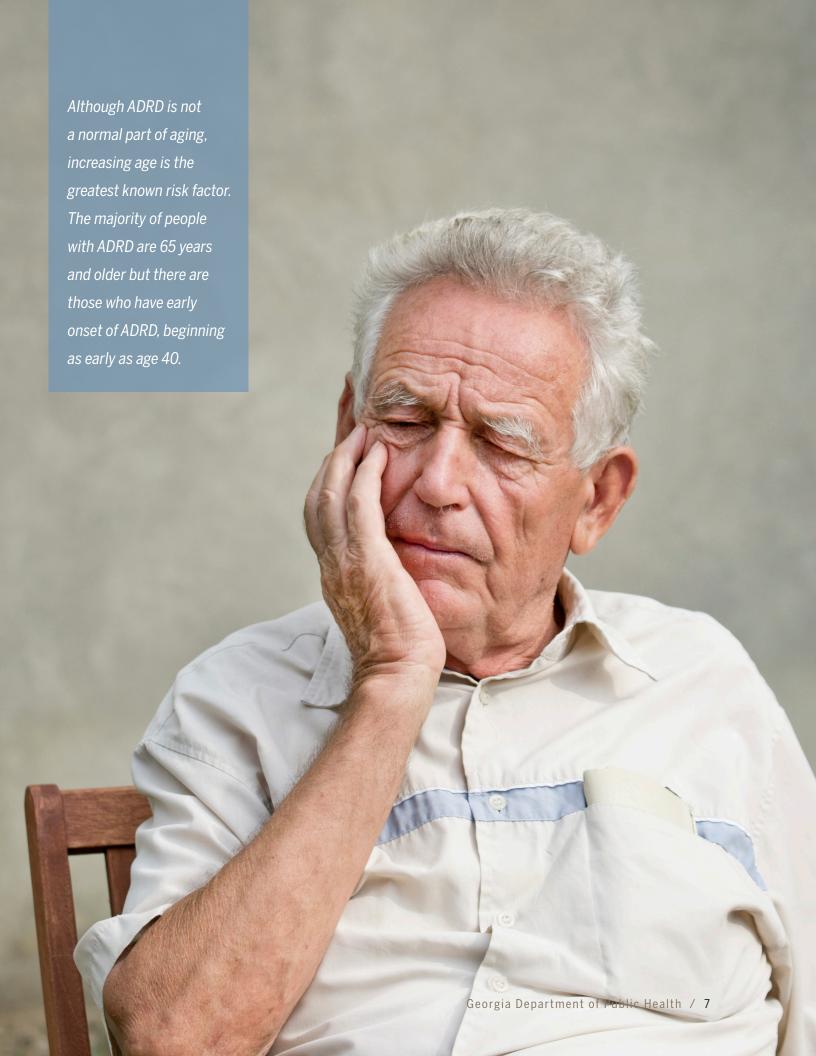
### Sources of Data for the Registry

Medicare
State Health Benefit Plan
Nursing Home Data
Emergency Room Visits data
Physicians reporting Portal
Medicaid
Georgia Regents Health Plan
Hospitalizations Data
Vital Records data

<sup>\*</sup>The current report is based on Medicare data only.

#### **2013 Medicare Data Overview**

- Approximately 112,430 Medicare beneficiaries in Georgia had ADRD diagnoses as of 2013. - Of those diagnosed with ADRD, about 20,700 (representing 18.4 percent) died during 2013. - Among beneficiaries with ADRD who died during 2013, the median number of months from diagnosis of ADRD to death was about 33 months. - There were 91,772 Medicare beneficiaries with ADRD diagnosis who were alive in Georgia at the end of 2013. This represented ADRD prevalence of 6.4 percent among the Medicare beneficiaries at the end of 2013. - Approximately 1 in 3 Medicare beneficiaries 85 years and older in Georgia had ADRD diagnoses. - Medicare beneficiaries with ADRD diagnoses had more chronic conditions than the general Medicare population in Georgia.



# PREVALENCE



Although ADRD is not
a normal part of aging,
increasing age is the
greatest known risk factor.
The majority of people
with ADRD are 65 years
and older but there are
those who have early

onset of ADRD, beginning

as early as age 40.

### Prevalence of ADRD among Medicare Population, Georgia, 2013

**IN GEORGIA,** as of 2013, there were approximately 112,430 Medicare beneficiaries with diagnosed ADRD. Approximately 20,700 (representing 18.4 percent) of Georgia Medicare beneficiaries with ADRD died during 2013.

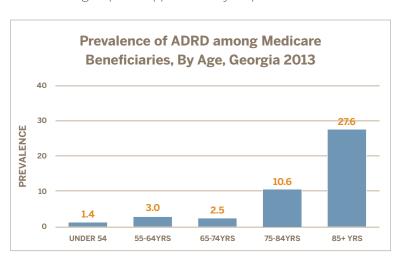
There were approximately 91,772 beneficiaries with ADRD diagnosis in Georgia who were alive as of December 31, 2013. This represented ADRD prevalence of 6.4 percent among the Medicare beneficiaries in Georgia.

As of December 31, 2013, of those with diagnosed ADRD, approximately 45 percent had Alzheimer's disease. The prevalence of ADRD among the Medicare population in Georgia differed by age, sex, race and geographic locations.

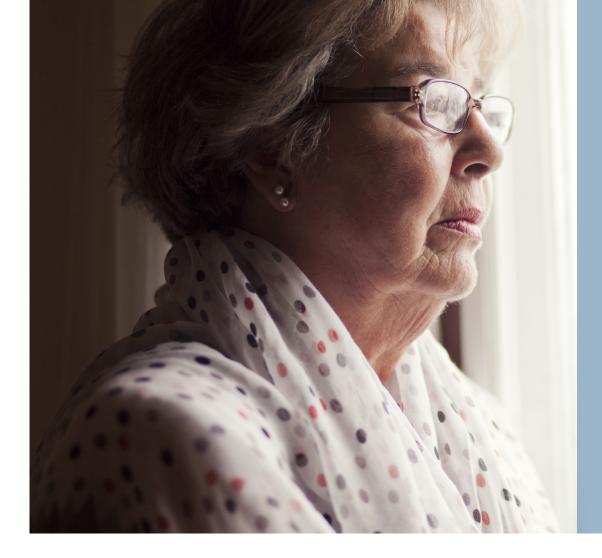
#### **Prevalence by Age**

In Georgia, at the end of 2013, the median age at ADRD diagnosis among the Medicare beneficiaries was 78 years. The prevalence of ADRD among this population increased with increasing age, with the highest prevalence being among seniors 85 years and older. The ADRD prevalence in this group was approximately 28 percent.

Overall, Medicare beneficiaries with ADRD were older than those without ADRD. While the mean age of beneficiaries with ADRD was 80 years, the mean age of the beneficiaries without ADRD was 69 years as of December 31, 2013.



Among the beneficiaries with ADRD, the mean age at ADRD diagnosis was different by sex and race; it was lower for males (73 years) than for females (76 years), and lower for blacks (73 years) than for whites (76 years), Asians (76 years) or Hispanics (75 years).



Like other chronic diseases. ADRD is not randomly distributed in the population. It is more common in certain demographics than others, such as older adults and women.

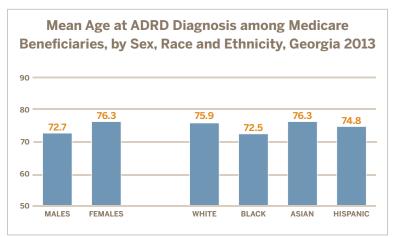
ADRD disproportionately affects women in both prevalence and severity. underlying these sex differences, is however, not fully understood.3

#### **Prevalence by Sex**

In Georgia, at the end of 2013, ADRD was more common among female Medicare beneficiaries (7.7 percent) than their male counterparts (4.8 percent). However, the mean age at diagnosis was lower for males (73 years) than for females (76 vears).



The prevalence of ADRD among the Georgia Medicare population during 2013 was



higher among whites than blacks, Asians or Hispanics. This is in contrast to the high prevalence of ADRD reported among blacks in other studies4. In addition, the mean age at ADRD diagnosis among blacks (73 years) was lower than those observed in the other racial groups (76 years for whites, 76 years for Asians and 75 years for Hispanics). This is in contrast to the high prevalence of ADRD reported among blacks in other studies. 4

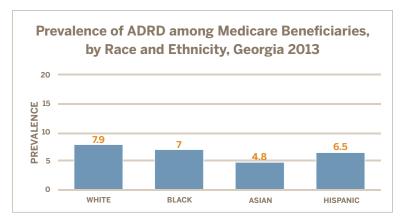
<sup>&</sup>lt;sup>3</sup>Carter, C.L., et al., Sex and gender differences in Alzheimer's disease: recommendations for future research. J Womens Health (Larchmt), 2012. **21**(10): p. 1018-23.

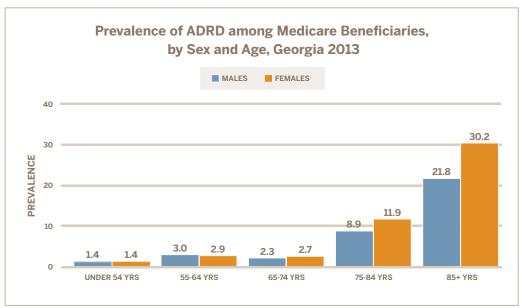
## **PREVALENCE**

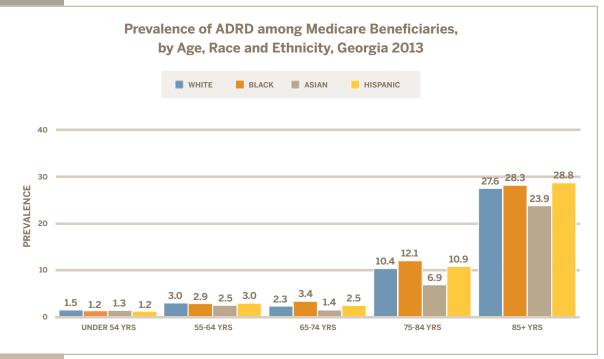


The prevalence of ADRD is higher among blacks than in whites. Some that older blacks are about two times more likely than older whites to

have Alzheimer's disease and other

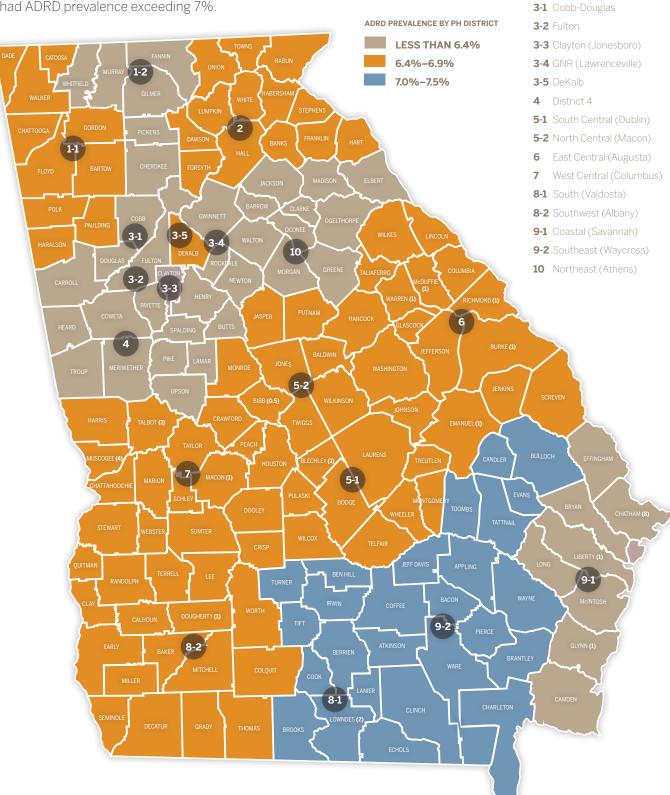






#### **Prevalence by Geographic Location**

In Georgia, at the end of 2013, the prevalence of ADRD among Medicare beneficiaries was lower among residents of the metro Atlanta areas except for the DeKalb Public Health District. The South (Valdosta) and Southeast (Waycross) Public Health Districts had ADRD prevalence exceeding 7%.



1-1 Northwest (Rome)

2 North (Gainesville)

1-2 North Georgia (Dalton)

# DEATH



1 in 3 seniors dies with ADRD. ADRD is the 6th leading cause of death in the U.S. It is also the only cause of death in the top 10 in the U.S. that cannot be prevented, slowed down or cured.<sup>5</sup>

Alzheimer's Association. 2015
Alzheimer's Disease Facts and
Figures. 2015 [cited 2015
11/5/2015]; Available from:
https://www.alz.org/facts/

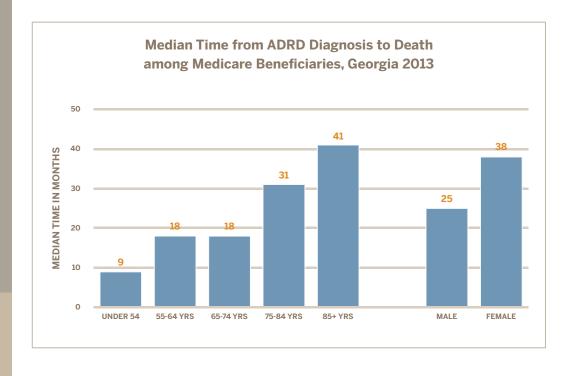
### **Death among ADRD Patients**

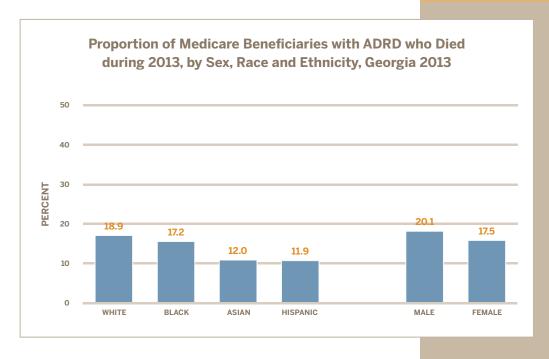
WHEREAS 3.9 PERCENT of the overall Georgia Medicare beneficiaries died during 2013, 18.4 percent of those with ADRD died during the year.

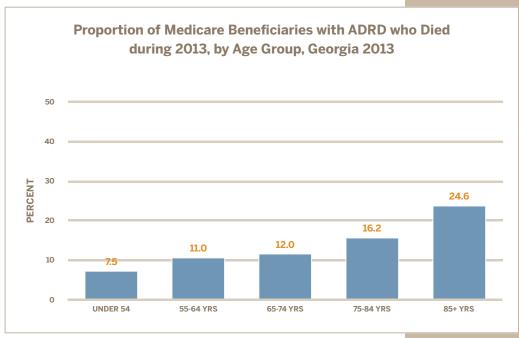
On average, at death, Georgia Medicare beneficiaries with ADRD were older than the general Medicare population. Whereas the mean age at death was 84 years for beneficiaries with ADRD, the mean age at death for the overall Medicare beneficiaries was 77 years.

The median time from ADRD diagnosis to death was approximately **33 months** (or 2 years and 9 months).

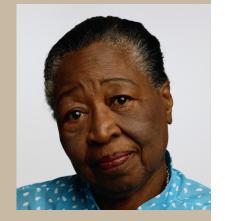
This median time was different for the different age groups. Among beneficiaries with ADRD that died during 2013, the time from diagnosis to death was shorter for younger adults than older adults. Similarly, the time was shorter for males than was for females as indicated by the figure below. There was less variability in the median time between ADRD diagnosis and death by race.





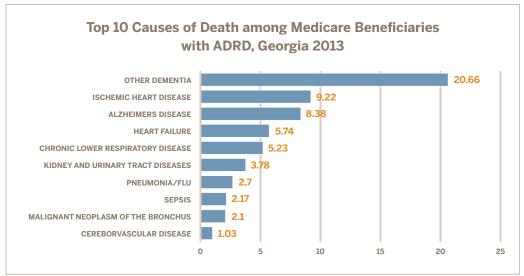


## **DEATH**



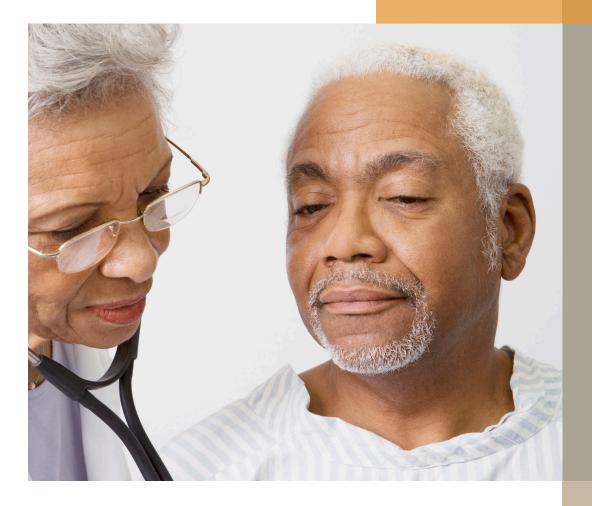
#### **Underlying and Contributing Causes of death among beneficiaries with ADRD**

Among Georgia Medicare beneficiaries with ADRD who died during 2013, **30 percent** had ADRD listed as the primary cause of death. The remaining **70 percent** died from other conditions such as ischemic heart attack, heart failure, pneumonia/flu, and sepsis as the primary cause of death. Of the 70 percent who died from causes other than ADRD, about 13 percent had ADRD listed as a contributing cause of death on their death certificates.





## **CHRONIC DISEASES**



Individuals with ADRD also tend to have other coexisting chronic conditions such as hypertension, coronary heart diseases and congestive heart failure. These coexisting conditions may exacerbate cognitive symptoms and may also make them more difficult to treat effectively.6

#### **Chronic Diseases among ADRD Patients**

WE ESTIMATED the proportion of Georgia Medicare beneficiaries with ADRD and those without ADRD that had at least **one** of the **ten** common chronic conditions. These ten conditions were: hypertension, hyperlipidemia, rheumatoid arthritis, diabetes, ischemic heart disease, anemia, chronic kidney disease, depression, congestive heart failure and chronic obstructive pulmonary disease (COPD).

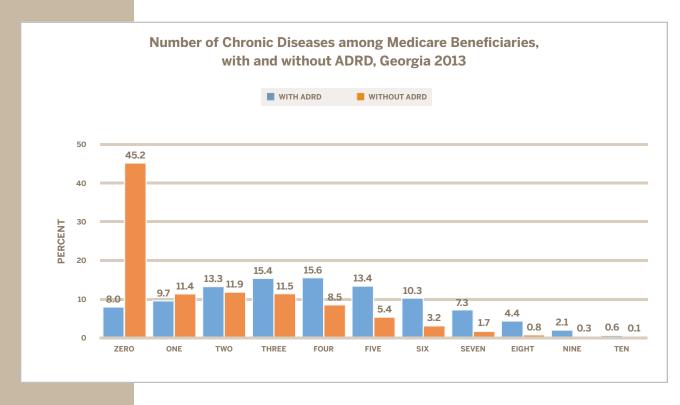
Higher prevalence of these comorbidities was observed among Georgia beneficiaries with ADRD compared to those without ADRD.

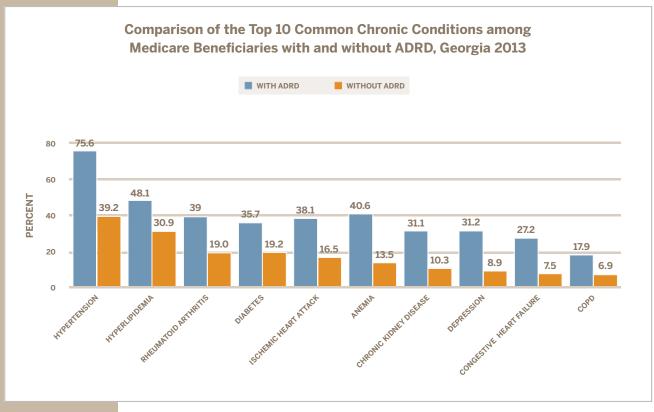
In Georgia, at the end of 2013, among Medicare beneficiaries with ADRD, only 8 percent did not have any of chronic diseases listed above whereas among beneficiaries without ADRD, **45 percent** did not have any of the chronic diseases listed above.

Three out of four (3/4) and almost one out of two (1/2) beneficiaries with ADRD had hypertension and dyslipidemia, respectively.

Over **50 percent** of the beneficiaries with ADRD had four or more of the ten chronic diseases listed whereas only 20 percent of beneficiaries without ADRD had four or more of the ten chronic diseases listed on previous page (page 14).

# CHRONIC DISEASES







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## SERVICE UTILIZATION



The total cost of hospice care among Medicare beneficiaries with ADRD during 2013 was over \$312 million.

The total cost of home health agency services among Medicare beneficiaries with ADRD in Georgia during 2013 was over \$157 million.

# Service Utilization among Medicare Beneficiaries with ADRD, Georgia, 2013

**ADRD IS ONE OF THE COSTLIEST** chronic diseases to society. Individuals with ADRD are high users of health care, hospice and long term care. The spending on ADRD patients is also higher compared to those without it. It is estimated that the average per person Medicare spending for individuals with ADRD is almost three times higher compared to the spending for those without ADRD.

### **Hospice Care Utilization**

Approximately **20,000** Georgia Medicare beneficiaries with ADRD used hospice care during 2013.

Hospice care was utilized **85,791** times by the beneficiaries with ADRD. This represented **54 percent** of all the hospice care services utilized by the Medicare beneficiaries in Georgia during 2013.

Of the beneficiaries with ADRD who died during 2013, about 62 percent utilized hospice care.

The total cost of hospice care among beneficiaries with ADRD during 2013 was **\$312,469,867**. This amount represented about **56 percent** of all Hospice care spending among Georgia Medicare beneficiaries during 2013.

Considering that less than 8 percent of the Medicare beneficiaries in Georgia had ADRD during 2013, the utilization of 56 percent of all hospice expenditure on this population was remarkable.

#### **Home Health Agency Utilization**

In Georgia during 2013, **29,040** Medicare beneficiaries with ADRD utilized home health agency services.

The median number of times beneficiaries received home health service was **14** times during the calendar year.

The total count of home health visits that Georgia Medicare beneficiaries with ADRD received during 2013 was **57,597** costing an estimated **\$157,360,000**.

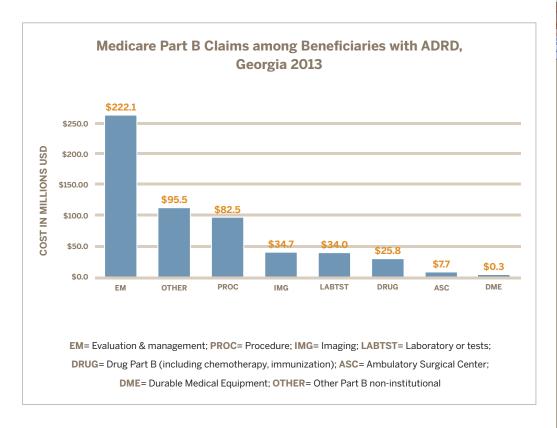
<sup>&</sup>lt;sup>7</sup> Alzheimer's Association. Cost of Alzheimer's to Medicare. 2015; Available from: http://act.alz.org/site/DocServer/2012\_Costs\_Fact\_Sheet\_version\_2.pdf?docID=7161.

#### **Carrier services (Part B Non-Institutional Claims)**

In Georgia during 2013, among the Medicare beneficiaries with ADRD, over 95 percent utilized Medicare non-institutional services. (See box at right for explanation of services).

The overall cost associated with non-institutional services for beneficiaries with ADRD in Georgia during 2013 was \$502,540,063.

The category of services with the largest cost was called "evaluation and management (EM)", which included cost from services such as anesthesia, dialysis services, oncology procedures, eye procedures, and major cardiac procedures.



DATA SOURCE: This report is based on the 2013 Medicare data for Georgia. The dataset was received from the Centers for Medicare and Medicaid Services (CMS). The report is based on the analysis of data for fee-for-service institutional and non-institutional Medicare claims data. Those who had no claims during the year 2013 were included. The report does not include claims for services provided to Medicare beneficiaries with managed care plans.



The carrier claims include data for Non-Institutional physicians, physician assistants, clinical social workers, nurse practitioners, independent clinical laboratories, ambulance providers, and freestanding ambulatory

The total cost of part B non-institutional claims 'carrier' services among Medicare beneficiaries with ADRD diagnosis during 2013 was over \$502 million.



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