

Alzheimer's Disease Electronic Registry: Providing Data to Describe the Epidemiological Profile of People Living with Alzheimer's Disease in Puerto Rico

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Background

Alzheimer's disease (AD) is a neurodegenerative disease, best known for its negative effects in mental processes such as memory loss, learning and attention capacities, linguistic and motor functions, among others. It is the fourth leading cause of death in Puerto Rico (PR) and the sixth in the United States of America. Morbidity data is scarce; therefore, there is not a clear overview of the epidemiological profile of people living with AD in PR. On May 2014, the Puerto Rico Department of Health (PRDOH) established an electronic registry to report cases as required by Law 237-1999. The PRDOH have been working to educate and empower physicians and hospitals in the use of the registry to improve the timeliness of the registry data.

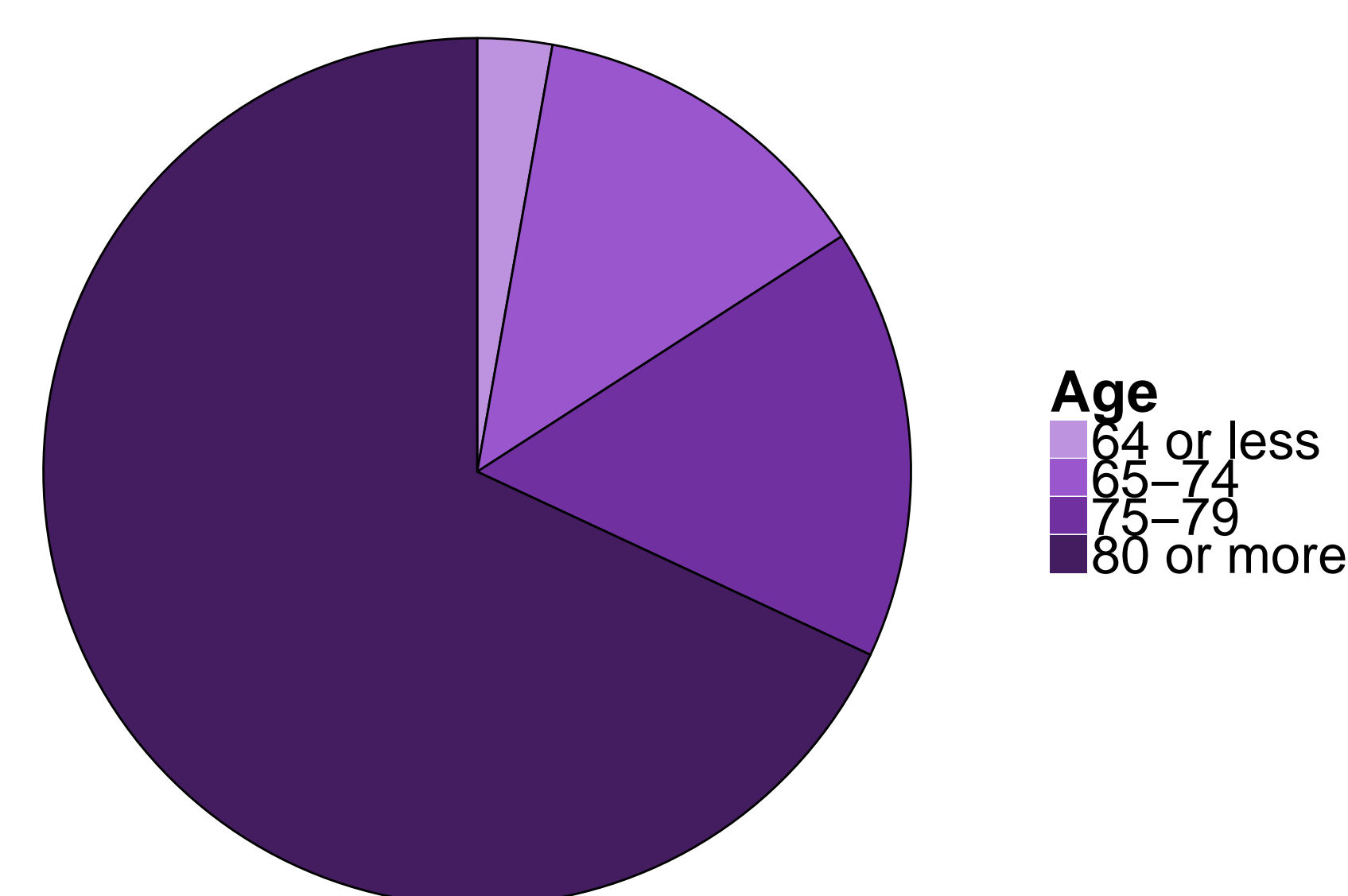
Methodology

The Alzheimer's electronic registry captures data from 49 of the 63 hospitals in PR. The collected data include sociodemographics, medical and family histories, pharmacological treatment, among other variables. The registry provided the mechanisms to minimize duplicated cases by creating a unique identification number using 3 variables. It also generates a database in a format that can be easily exported to various statistical analysis packages. The registry publishes quarterly reports with statistics to describe the reported cases. Statistics are calculated using R version 3.2.0. Health measures in this report have been taken and validated from the electronic report of the Alzheimer's Disease Electronic Registry. Socio-demographic variables, as age and gender, were evaluated to calculate distribution percentages. Comorbidities for the population were also obtained and analyzed in this survey. The total of persons with Alzheimer's in the registry by municipality was established by the variable of town of residency. Other variables were not analyzed because there was a high proportion of missing values.

Results

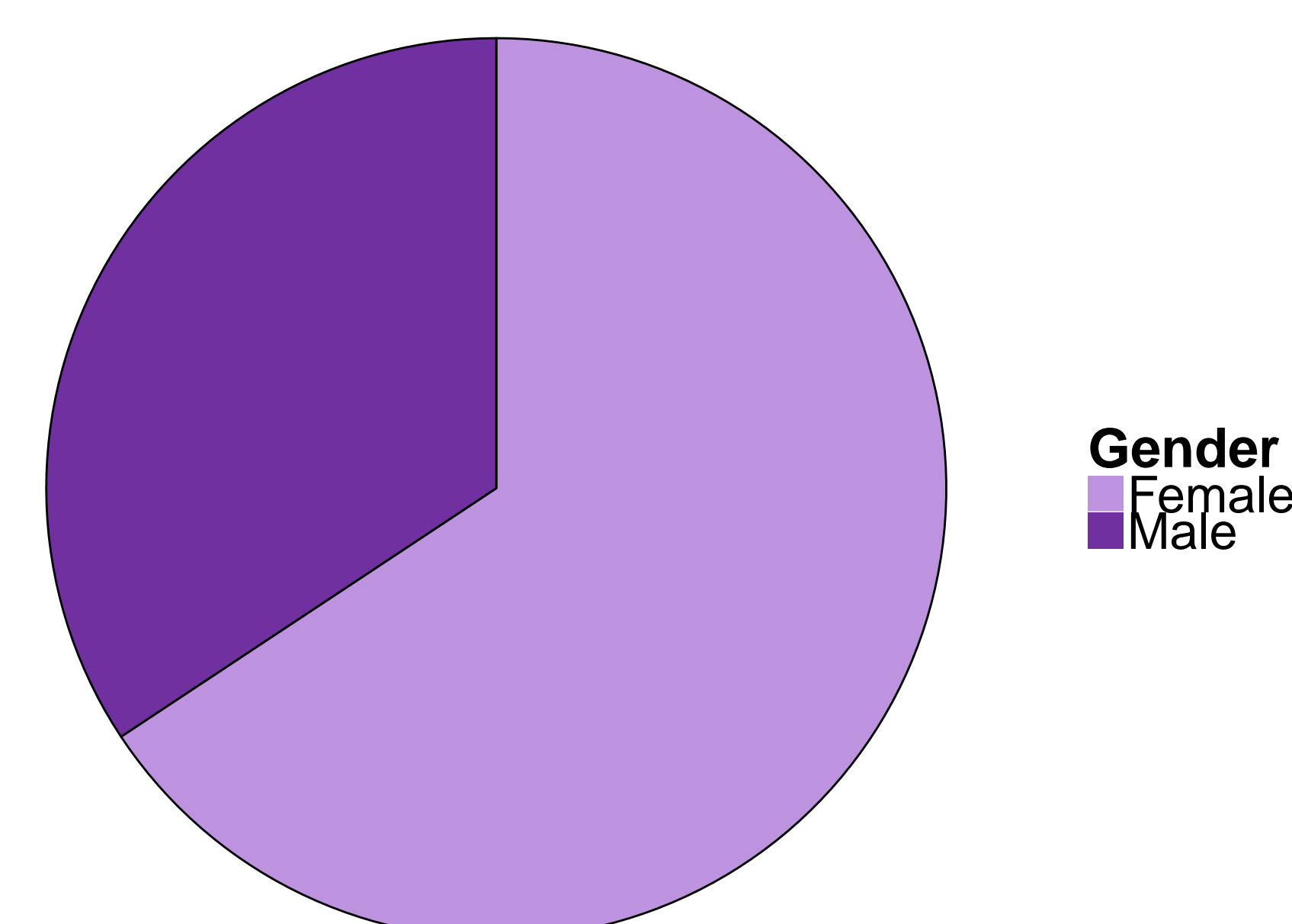
Up to June 1, 2015 there were a total of 7,690 cases reported to the registry. The cases registered among people ≥ 80 years old represented 68% of all cases. There is a decrease in the percentage of persons reported to the registry in other age groups from 16% among people with 75-79 years old to 13% of cases in people from 65-75 years old. Only 2.8% were reported cases had less than 65 years of age.

Percentual Age Distribution



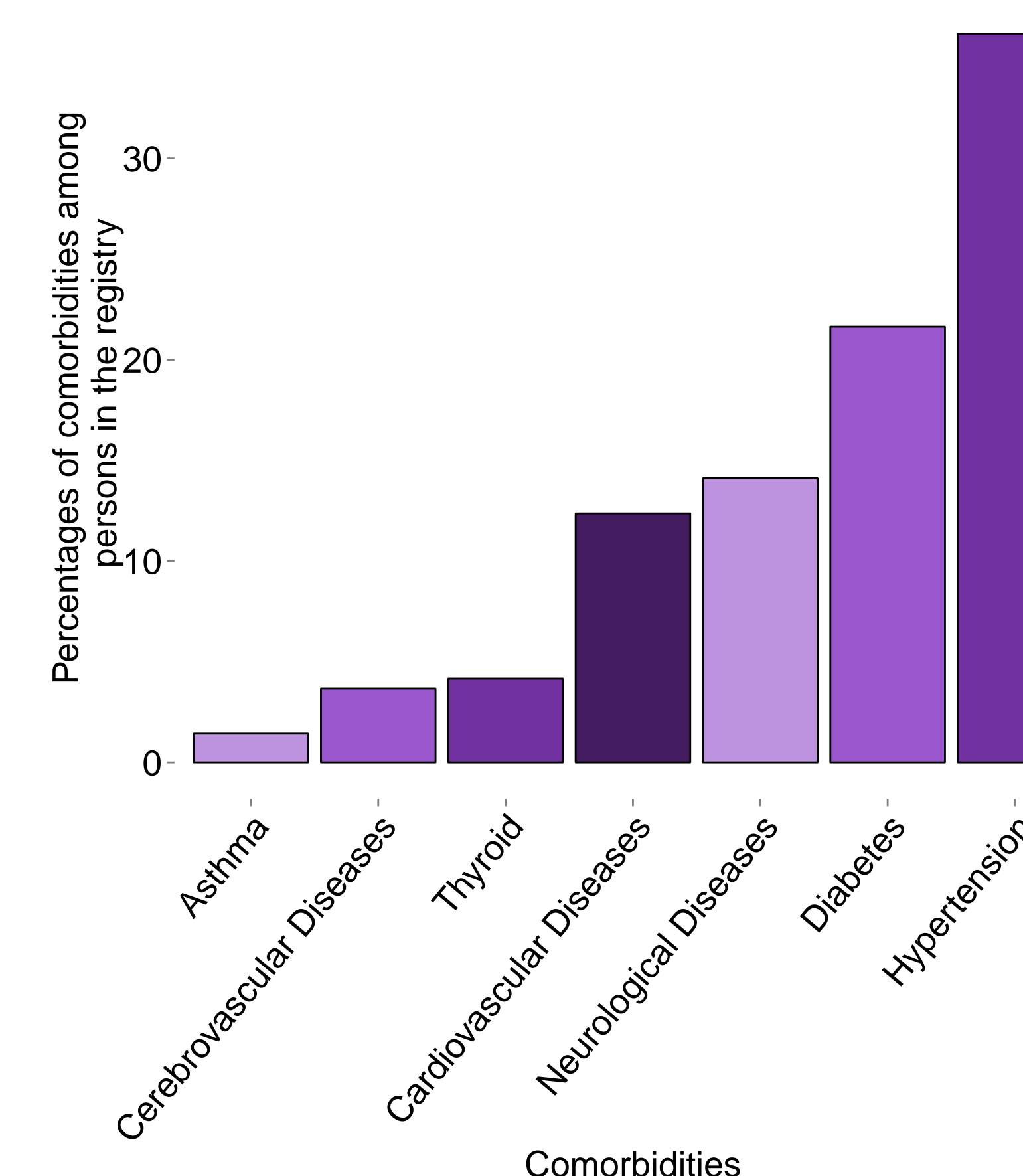
The majority of the reported cases in the Alzheimer's registry were women. Meanwhile, men represented 33.9% of the adults with the condition. There are approximately 2 women per each man with the condition.

Percentual Gender Distribution



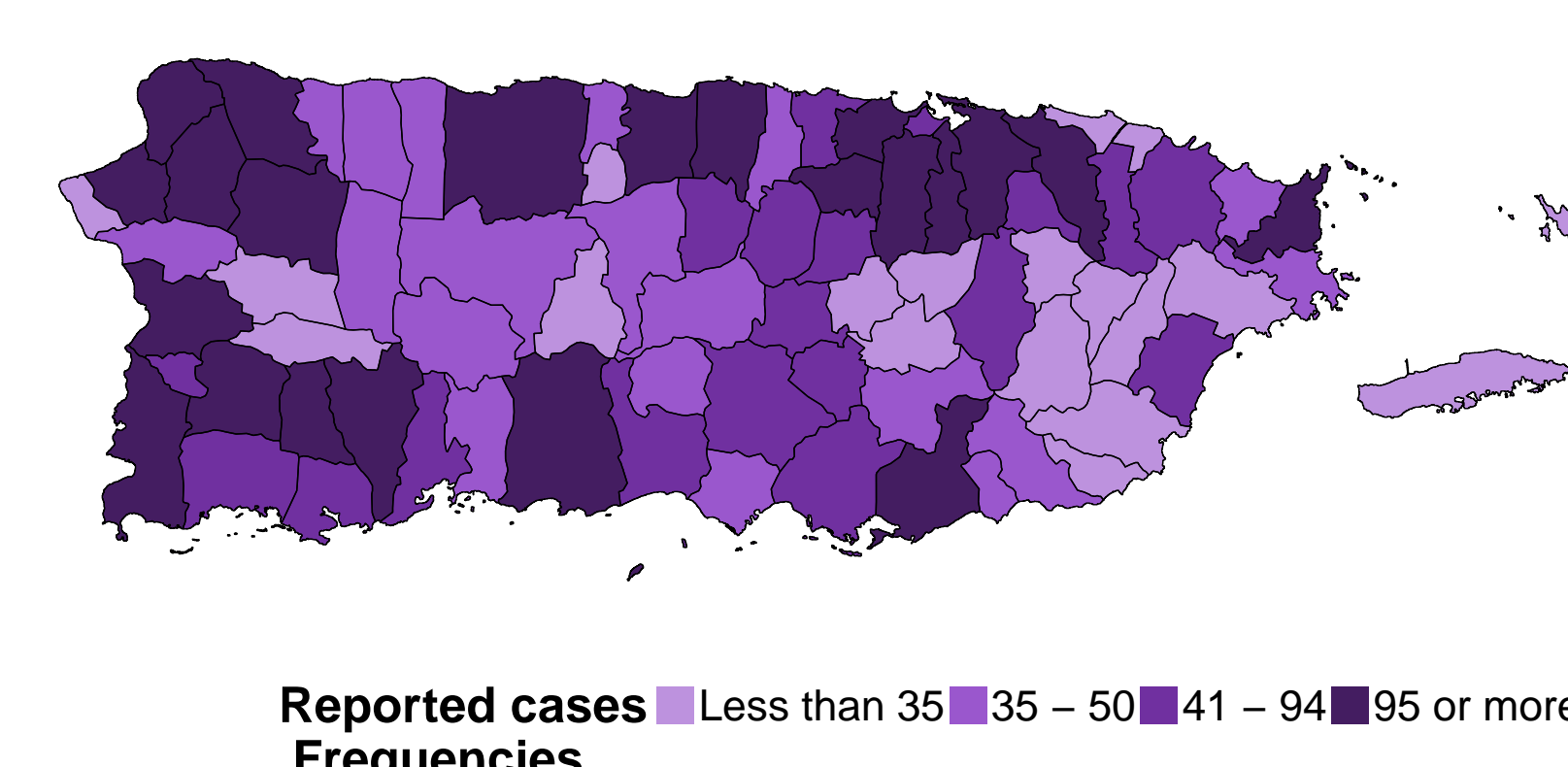
Older adults have a higher risk of having multiple chronic conditions. In this registry, on average, cases had at least three comorbidities. The most frequent comorbidities were hypertension (36.2%), diabetes (21.6%), and other neurological disorders (14.1%). The majority of the reported cases had health insurance coverage (73.6%).

Comorbidities



The following thermal map presents the Alzheimer's prevalence in reported cases in each of the municipalities of the island.

Frequencies of reported cases by municipality



Conclusion

This is the analysis of the first cases reported to the PR Alzheimer's Electronic Registry. From data collected and aggregated by health insured companies, an estimated of 34,000 adults in Puerto Rico had an AD diagnosis in their claims in 2013. We estimate that the registry has captured about 22.6% of diagnosed AD cases in PR. Despite of this, the sociodemographic distributions of reported cases are similar to what has been reported in other population-based studies. The majority of cases reported to the registry were among those ≥ 65 years old. This corresponds to the USA literature, that more than 90% of cases are ≥ 65 years old (late onset AD)[1]. This also match the data collected from the health insurance companies in PR, where 91% of the cases were 65 years old and older, acknowledging that age is the greatest risk factor for AD. The PR 2010 Census revealed that people ≥ 65 years old represented 14.7% of the population of PR [2]. It is expected that the proportion of older people will rise to 20% in 2020 [2], increasing also the prevalence of Alzheimer's in PR. PR needs to direct resources to early detection of the disease to help slow the progression of symptoms and improve the quality of life of people living with AD, their caregivers and families. Our main limitation is the amount of missing information in other variables that do not permit us to better describe the cases in terms of medical and family histories. In the future, our efforts must focus on increasing the number of providers reporting cases and encouraging them to complete the questionnaire to reduce missing data. This will enable us to better understand the epidemiological profile of AD in PR, plan services, and adequately allocate resources for this population, their family, and caregivers.

References

- [1] 2015 Alzheimer's Disease Facts and Figures, Alzheimer's Association.
- [2] Puerto Rico: 2010, *Population and Housing Unit Counts* United States Census 2010