Introduction

Effects of early life conditions on Alzheimer's disease (AD) and related dementia (RD) risk have been hypothesized. However, prospective studies are potentially cost prohibitive. Retrospective studies using routinely collected health records in large cohorts may be a feasible way to carry out such research, but diagnostic accuracy should be determined.

Objectives and Approach

We aim to determine accuracy of AD/RD diagnoses in electronic health records (EHR) (inpatient, ambulatory surgery, and Medicare) and death certificates (DC) compared to gold standard. The Cache County Study on Memory in Aging (CACHE, 1995–2008) enrolled 90% of the county's residents age ≥ 65 years (N=5092). Over the course of 12 years/4 triennial waves of thorough dementia ascertainment, 942 persons (18.5%) were identified with dementia. Prevalence of AD or AD comorbid with other dementia (AD mixed) was 12.8% and for RD alone, 5.7%. We used the Utah Population Database, linking EMR/DCs (1995–2008) to CACHE participants (98% linkage).

Results

The prevalence of AD/AD mixed and RD in EHR/DCs was 12.2% and 35.8%. Among linked CACHE participants diagnosed with AD or AD mixed (n=628), 505 (80%) were captured by EHR/DCs as having some form of dementia (AD, AD mixed, or RD) with 301 (60%) correctly classified as having AD or AD mixed. Among those with RD (n=399), 275 (69%) were captured by EHR/DCs as having some form of dementia, with 163 (60%) correctly classified as having RD. Sensitivity, specificity, positive and negative predictive values, and area under the curve (AUC) were 48%, 93%, 49%, 93%, and 0.70 for AD or AD mixed; and 67%, 67%, 15%, 96%, and 0.67 for RD. Overall dementia agreement between CACHE diagnoses and EHR/DCs was fair (Cohen's $\kappa = 0.34$).

Conclusion/Implications

In this well-characterized cohort, routinely collected health record diagnoses of AD/AD mixed and RD have only fair correlation with carefully phenotyped diagnoses. Determining additional features of a person’s medical record that may be predictive of AD/RD via formal classification modeling is warranted.