



Featured Article

Dementia prevalence and incidence in a federation of European Electronic Health Record databases—The European Medical Informatics Framework resource

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Abstract

Introduction: The European Medical Information Framework consortium has assembled electronic health record (EHR) databases for dementia research. We calculated dementia prevalence and incidence in 25 million persons from 2004 to 2012.

Methods: Six EHR databases (three primary care and three secondary care) from five countries were interrogated. Dementia was ascertained by consensus harmonization of clinical/diagnostic codes. Annual period prevalences and incidences by age and gender were calculated and meta-analyzed.

Results: The six databases contained 138,625 dementia cases. Age-specific prevalences were around 30% of published estimates from community samples and incidences were around 50%. Pooled prevalences had increased from 2004 to 2012 in all age groups but pooled incidences only after age 75 years. Associations with age and gender were stable over time.

Discussion: The European Medical Information Framework initiative supports EHR data on unprecedented number of people with dementia. Age-specific prevalences and incidences mirror estimates from community samples in pattern at levels that are lower but increasing over time.

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Keywords: Dementia; Incidence; Prevalence; Electronic Health Records; European Medical Informatics Framework

1. Introduction

Electronic health records (EHRs) are increasingly replacing paper records across health care sectors, creating large volumes of digitized data on real-world clinical interventions and outcomes. Applications of such data extend beyond clinical care to planning and costing health services, and health surveillance. For research, EHR-derived databases offer large sample sizes and are particularly suited to investigations of intervention outcomes in routine care, such as predictors of response, safety, comparative effectiveness, and health economic evaluations, as well as etiologic investigations of rare exposures/outcomes.

EHRs have been underused in dementia research, although examples include identification in primary care [1], resource use in Alzheimer's disease [2], comorbidities [3], case capture efficiency [4], dementia incidence [5], dementia-free life expectancy [6], risks associated with medication exposures [7] and other disorders [8], atypical antipsychotics and mortality in vascular dementia [9], and cognitive trajectories before and after acetylcholinesterase inhibitor initiation [10].

EHR data on dementia, as with most clinical research data, are limited to people who have received a diagnosis. These are a subset of people living with dementia in the community, many of whom will not receive a diagnosis and can only be ascertained in surveys applying case-ascertainments. However, epidemiologic studies of dementia tend to focus on incidence and risk factors (i.e., investigating up to the point of onset), and most research on dementia outcome, including service costs, involves cohorts who have received a clinical diagnosis rather than screened community samples. The relationships between community incidence/prevalence and incidence/prevalence of diagnosed dementia are therefore important to understand because of these different samples. Such relationships may vary both geographically and temporally: settings with active dementia diagnosis centers are likely to see a higher proportion of community cases appear on health care databases, and these are likely to increase over time with greater public awareness and a higher salience in primary care.

Advances in medical research require an increasing quantity and detail of health data to answer today's complex questions. At the same time, huge volumes of health data are being collected and electronically stored, either in routine EHR databases or through research-driven cohort studies associated with biobanks and other efforts. To help improve access to patient-level data, the European Medical Information Framework (EMIF) was launched in 2013. As part of the broader European Innovative Medicines Initiative, EMIF

aims to create an environment that allows efficient reuse of health data in two therapeutic areas: Alzheimer's disease and metabolic disorders. In the first year of operation, EMIF explored several EHR resources to render data available for analysis with robust data security and governance. In this study, we provide initial data on number of cases of dementia detected on six EHR sources—three primary care and three secondary care. Our objective was partly to describe this data resource and partly to provide prevalence and incidence estimates for diagnosed dementia in European populations, comparing these across the different databases and years of data collection.

2. Methods

2.1. Databases

Using the collaborations and platform for analysis set up by EMIF, the following six EHR databases were interrogated: (1) Agenzia regionale di sanità della Toscana (ARS), (2) Aarhus University Hospital (AUH), (3) the Health Search Database (GENOMEDICS), (4) the Information System of Parc de Salut Mar (IMIM-UPF), (5) Integrated Primary Care Information (IPCI), and (6) The Health Improvement Network (THIN). Characteristics of databases are summarized in Table 1. Number of active patients on each database on January 1, 2013 varied from around 900,000 in GENOMEDICS to around 3.8 million in THIN.

2.1.1. Catchment databases

The ARS database contains secondary health care data from the Tuscany region of Italy, including pharmacy, outpatient and hospital data along with linked data on death, and birth and malformation registries. The AUH database contains data from secondary health care registries covering the northern and central region of Jutland, Denmark, including information on all inpatient, emergency room, and outpatient visits, inpatient treatments, laboratory data, and prescriptions. The IMIM-UPF database contains secondary health care data from the Barcelona area, including acute, long term, and mental health services with information on inpatient, emergency room, and outpatient visits.

2.1.2. Primary care databases

IPCI, GENOMEDICS, and THIN contain primary care data from selected general practices in the Netherlands, Italy, and United Kingdom, respectively.

Considering broader health care settings, Italy has a government-funded universal health care system in which free health care is provided to all citizens, all persons in Italy

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