



Validity of health insurance data to identify people with epilepsy

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ABSTRACT

Background: Large administrative databases may prove useful to assess epilepsy-related comorbidity and mortality. Despite their increased use, their validity as data source in epilepsy is yet under-ascertained.

Methods: Achmea is a large Dutch health insurance company covering about 25% of the population. We performed a retrospective cohort study using data from the Achmea Health Insurance Database (AHID) over the period 2006–2009. To assess the validity of epilepsy codes in the AHID, we randomly invited 1000 individuals (age 18–75 years insured by Achmea), attending an epilepsy centre or a district hospital during 2006–2009, to participate. Informed consent was provided and 293 were eligible for inclusion. We compared the diagnostic codes for epilepsy in AHID with the diagnosis in their case-notes (reference standard). As additional measure of validity, we compared prevalence of epilepsy codes in AHID (based on anonymized data of all 26.297 subjects with this code in AHID) with epilepsy prevalence rates in the general Dutch population to estimate an age-specific standardized prevalence ratio.

Results: We identified 293 participants with an epilepsy code in AHID. The majority (278) of them had a definite or possible diagnosis of epilepsy in the case-notes; i.e. a positive predictive value of 0.95 (95% CI 0.92–0.97). The overall prevalence of epilepsy codes in the AHID was slightly higher than the putative prevalence in the general Dutch population (7.4/1.000 vs. 6.8/1.000) with a Standardized Prevalence Ratio of 1.08 (95% CI: 1.08–1.09).

Conclusions: Our findings demonstrate the validity of AHID data for a diagnosis of epilepsy and confirm previous work on using administrative data for epilepsy research.

1. Introduction

Epilepsy is a neurological condition characterized by recurring seizures usually requiring antiepileptic drugs (AED). (Loscher and Schmidt, 2011; Sander, 2003) People with epilepsy often have comorbid conditions. (Gaitatzis et al., 2012; Hermann et al., 2008; Keezer et al., 2016) The risk of premature mortality is 2–3 times higher than in the general population. (Neligan et al., 2011) Premature mortality may be explained by several factors such as epilepsy-related causes including accidents, Sudden Unexpected Death in Epilepsy (SUDEP), or may be related to comorbid conditions such as a cerebrovascular disease. (Novy et al., 2013; Surges et al., 2009) Precise figures on epilepsy mortality and comorbidity are, however, still needed. Case-control studies in high risk populations (from specialized epilepsy centres) may suffer from selection bias, small sample sizes and a disregard of comorbid conditions. Population-based cohorts are also often limited by

relative small samples of the epilepsy population and have a too long study run time for surveillance of the actual burden and risk profiles of epilepsy-related comorbidities and mortality.

Large population based studies using administrative health insurance data provide opportunities to increase power of data and obtain comprehensive surveillance data. (England et al., 2012; Hesdorffer et al., 2013; Smeets et al., 2011) This “big data” approach has been successfully used to address epilepsy-related questions, e.g. concerning psychiatric comorbidity in premature mortality (Fazel et al., 2013) or epilepsy-related psychiatric and somatic comorbidities e.g. migraine, autism, stroke, diabetes. (Chen et al., 2011; Chou et al., 2016; Oh et al., 2017; Selassie et al., 2014; Sundelin et al., 2016; Wannamaker et al., 2015) Previous work validated the diagnostic codes for epilepsy from administrative databases. (Christensen et al., 2007; Ertl et al., 2016; Jette et al., 2010; Parko and Thurman, 2009; Reid et al., 2012) Yet the validity of epilepsy diagnostic codes using health insurance databases is

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still under-ascertained and needs confirmation in every database given the variety in health care and coding systems. (Thurman et al., 2011)

Dutch health insurance databases are a potentially useful source for epilepsy research. The Netherlands has a health care system with a mandatory and ubiquitous health insurance coverage. Insurers register all reimbursed health care visits based on diagnostic codes provided by the treating physician. (Braithwaite et al., 2017; Schoen et al., 2007) We assessed the validity of diagnostic codes for epilepsy derived from Achmea, one of the major health insurance companies in the Netherlands. The Achmea Health Insurance Database (AHID) was previously found representative of the health care utilization of the total Dutch population with respect to age, gender and socioeconomic status. (Smeets et al., 2011) We assessed accuracy by comparing diagnostic codes for epilepsy in AHID with the diagnosis in case-notes (reference standard). As additional measure of validity, we compared the prevalence of epilepsy codes in AHID with epilepsy prevalence rates in the general Dutch population.

2. Methods

2.1. Population and setting

Retrospective cohort data, with respect to demographics and health care utilization over the period 2006–2009, was retrieved from AHID, which covers around 4.1 million policyholders (25% of the total Dutch population). All health care reimbursement claims are collected and continuously monitored to ensure an accurate and valid database. (Smeets et al., 2011) During the period 2006–2009 the yearly average number of people ≥ 18 years in AHID was 3.247.887.

To assess the validity of the diagnostic epilepsy codes, we set to enrol around 1% of epilepsy cases in AHID based on an estimated prevalence of 0.7% (Gommer et al., 2010). From two hospital registries: 1) a tertiary epilepsy referral centre and 2) a district hospital, we selected all individuals with at least one epilepsy-related visit to a neurologist between 2006 and 2009. This selection was made using the hospital based claims database. All subjects aged 18–75 years, insured by Achmea for at least one year during the study period, were eligible. Those with incomplete contact details and those in residential care were excluded. Of 2916 potentially eligible subjects, we randomly invited, by post, 1000 (70% from tertiary care and remaining from the district hospital) to participate. This included an information letter and a request to provide informed consent to access their case-notes and AHID data for comparison. A total of 293 respondents were eligible for inclusion.

We also had access to anonymized AHID data of all 26.297 adults with an epilepsy diagnostic code in the same period. This allowed the delineation of the AHID epilepsy-cohort and to estimate epilepsy prevalence amongst them. The study was fully compliant with Dutch regulations and approved by the Medical Ethics Committee of Leiden University Medical Center and by Achmea's Scientific and Privacy Committee.

2.2. Data collection

AHID data included demographics (sex, year of birth and death (if applicable) and duration of insurance by Achmea) and health care utilization over the period of interest. This included information on all primary, secondary and tertiary care visits and drug prescriptions (ATC codes and number of daily defined dose (DDD)), with corresponding dates. Hospital visits are coded by a Diagnostic Treatment Protocol (DTP, in Dutch: 'Diagnose Behandel Combinatie'): an administrative code combining hospital registration of diagnoses (International Classification of Disease 9th revision (ICD-9) with therapeutic interventions i.e. classification in generalized and focal epilepsy based on the ICD 345.xx coding for epilepsy. For all participants in the validation subset, we requested a personal identifiable code to link the AHID data

to information retrieved from the case-notes.

Clinical data for the period participants were insured by Achmea were extracted from the hospital case-notes. This included information on epilepsy diagnosis (history, seizure description, MRI, EEG etc.), antiepileptic drug (AED) use, comorbid conditions and co-medication. Neurological diagnosis were classified into three categories: (1) *definite or probable epilepsy* in case diagnostic work-up of the treating neurologist supported a diagnosis and no alternative diagnosis suggested (Thurman et al., 2011); (2) *suspect epilepsy* in case epilepsy was thought most likely but other alternatives were considered (Thurman et al., 2011) (3) *no epilepsy* in case other conditions like syncope or psychogenic non-epileptic seizures were considered to most likely. For each category, we recorded whether AED were prescribed (i.e. all drugs within the AED subgroup of the ATC classification system except for benzodiazepines), thus resulting in a total of six categories expressing the likelihood of the epilepsy diagnosis including its treatment status. From the AHID we included all those with a DTP for (generalized and focal) epilepsy, corresponding to the ICD 345.xx codes for epilepsy and treatment status. Data extraction and classification was performed by one author (MW). An audit was performed on a subset by RT and JC to minimize potential misclassification. In case of uncertainty RT & JC reviewed and discussed to reach consensus.

2.3. Statistical analysis

We assessed baseline demographics, epilepsy and AED prescription data. The validation subset was compared to the total number of epilepsy cases, aged 18–75 years, in AHID to assess the representativeness of our sample. The prevalence of epilepsy in AHID was compared to epilepsy prevalence data of Statistics Netherlands based on DTP codes for epilepsy in the general population. (CBS Statline, 2016) An age-specific standardized prevalence ratio and 95% CI was calculated.

We assessed the percentage of correct DTPs for epilepsy in AHID validation subset by comparing them to the reference standard (case-notes). Its positive predictive value (PPV and 95% CI) is presented as measure of diagnostic accuracy (number of correctly classified cases). The PPV refers to the proportion of epilepsy cases (category 1–3 from the case-notes) from all those identified with a DTP for epilepsy in the AHID. As a sensitivity analysis we assessed the effect of reclassifying suspect cases (category 3 or 4) as epilepsy or as non-epilepsy cases. All statistical analyses were performed with IBM SPSS Statistics for Windows, version 22.0 (Armonk, NY: IBM Corp).

3. Results

A total of 293 respondents had a diagnostic code for epilepsy in AHID and were eligible for inclusion i.e. for review of their case-notes over 2006–2009 (Fig. 1). Baseline characteristics of 293 participants are listed in Table 1. These were compared to 23.493 individuals, aged 18–75 years, with an epilepsy code in AHID. Participants in the validation study were slightly younger than the total cohort of people with an epilepsy code (median age 46 vs. 47 years, p -value 0.003 and more likely to have an AED prescription (92% vs. 76%, p -value < 0.001).

Of the average 3.247.887 people of 18 years and older in AHID during 2006–2009, 24.188 persons per year had at least one DTP for epilepsy. These numbers were used to estimate prevalence. This does not equal the total number of people (26.297, of whom 23.493 between 18 and 75 years) found with an epilepsy code due to variation in the duration of the insurance policy. During the four year period 19% of all insured switched to an alternative insurance provider, emigrated or died. The overall epilepsy prevalence using DTP codes in AHID was slightly higher than the prevalence rate for the same codes in the general population (CBS Statline, 2016): 7.4/1.000 vs. 6.8/1.00 with a Standardized Prevalence Ratio of 1.08 (95% CI: 1.08–1.09). The prevalence increased with advancing age in both groups (Table 2).

Of the total 293 cases with an epilepsy code in AHID, 278 were

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