



Welfare consequences for people with epilepsy and their partners: A matched nationwide study in Denmark



Poul Jennum^{a,*}, Anne Sabers^b, Jakob Christensen^c, Rikke Ibsen^d, Jakob Kjellberg^e

^a Danish Center for Sleep Medicine, Department of Clinical Neurophysiology, Faculty of Health Sciences, University of Copenhagen, Rigshospitalet, DK 2600, Glostrup, Copenhagen, Denmark

^b Department of Neurology, Faculty of Health Sciences, University of Copenhagen, Rigshospitalet, Copenhagen, Denmark

^c Department of Neurology, Aarhus University Hospital, Aarhus, Denmark

^d itracks, Klosterport 4E, 4, Aarhus, Denmark

^e Danish National Institute for Local and Regional Government Research, Copenhagen, Denmark

ARTICLE INFO

Article history:

Received 17 November 2016
Received in revised form 8 May 2017
Accepted 12 May 2017
Available online xxx

Keywords:

Epilepsy
Direct and indirect costs
Home care
Partner

ABSTRACT

Purpose: We aimed to evaluate the excess direct and indirect costs associated with epilepsy.

Methods: From the Danish National Patient Registry (1998–2013), we identified people within all ages with an epilepsy diagnosis and matched them to control individuals. Additionally, partners of people with epilepsy were identified, who were compared with control partners. Direct costs included frequencies and costs of hospitalizations and weighted outpatient use according to diagnosis-related group, and specific outpatient costs based on data from the Danish Ministry of Health. The use and costs of drugs were based on data from the Danish Medicines Agency. The frequencies of visits and hospitalizations, and costs from general practice were derived from data from the National Health Security. Indirect costs included labor supply-based income data, and all social transfer payments obtained from Coherent Social Statistics.

Results: A greater percentage of people with epilepsy and their partners compared with respective control subjects received social services (sick pay or disability pension). Those with epilepsy had a lower employment rate than did controls for equivalent periods up to eight years before the diagnosis was made. Mortality was significantly higher in people with epilepsy than in control individuals (hazard ratio 2.38 (95% CI: 2.34, 2.41)).

The additional direct and indirect annual costs of epilepsy compared with controls were € for persons with epilepsy and €2494 for their partners.

Conclusion: Epilepsy has major socioeconomic consequences for individual patients, their partners and society.

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1. Introduction

Epilepsy is a common and chronic neurological disorder affecting approximately 1% of people of all ages [1,2]. Despite diagnostic and therapeutic improvements, refractory epilepsy is relatively frequent and, due to significant comorbidity, is still one of the most common serious brain disorders worldwide. Epilepsy is associated with social stigma, psychosocial adversities, and reduced quality of life for patients and their caregivers and, thus, has a substantial socioeconomic impact [3–6].

Studies of the economic impact of epilepsy have mainly focused on questionnaires and other direct or indirect information obtained from selected groups of people with epilepsy, and have documented the combined socioeconomic consequences [7,8]. Furthermore, those with epilepsy may also find that the disorder has adverse consequences for their partner [3,6,9]. We have previously evaluated these combined costs in people with epilepsy by comparing a national sample of persons with epilepsy with controls, documenting significant health and social consequences for adults [2] and long-term consequences for children and their parents [10–12] compared to controls without epilepsy. However, these estimates only considered the consequences for the individual with epilepsy. A national factual economic estimate of the total disease cost for people with epilepsy and their partners compared with a control group has not previously been attempted.

* Corresponding author.

E-mail addresses: poul.joergen.jennum@regionh.dk (P. Jennum), anne.sabers@regionh.dk (A. Sabers), jakob@clin.au.dk (J. Christensen), rikke@itracks.dk (R. Ibsen), jakj@kora.dk (J. Kjellberg).

We therefore aimed to evaluate the total factual costs associated with epilepsy before and after its diagnosis, including health (direct) and social (indirect) costs of the disease, as determined in a national population-based study.

2. Materials and Methods

In Denmark, it is possible to calculate health sector costs and productivity losses related to diseases because information from public and private hospitals, general practice, privately practicing specialists, medication, social transfers, labor market income and employment for all Danes is registered in central databases. All patient contacts with the hospital system are recorded in the Danish National Patient Registry (NPR) at the time of contact and include the primary diagnosis [13]. The NPR is a time-based national database that includes data from all inpatient and outpatient contacts, meaning that the data that we can extract are representative of everyone in Denmark who has received a diagnosis of epilepsy in public and private hospitals. Since data are available for the entire observation period, we can trace patients retrospectively and prospectively, relative to the time of the epilepsy diagnosis. Furthermore, all contacts in the primary sector (general and specialist practices) and medication use are recorded in the databases of the National Health Security and the Danish Medicine Agency, respectively. There is some underestimation of the number of people with epilepsy, because those with a contact in the general practice sector only, in contrast to the in- and outpatients contacts in hospitals, are not recorded with an epilepsy diagnosis in the NPR.

The economic consequences of epilepsy for patients and their partners were estimated by determining the yearly cost of illness per patient diagnosed with the ICD-10 code for epilepsy (G40.0-9); these codes are given after patient evaluation in each hospital (based on a standardized evaluation of epilepsy). These figures are compared for patients and their spouses with those of an individual matched control group based on gender, age and municipality. The number of cases per control was 1:4. Matches was obtained in >99.9%. The estimated health cost was then divided into annual direct and indirect healthcare costs.

Direct costs, including hospitalization, costs of outpatient visits and uses of medication, were calculated using Diagnosis-Related Group (DRG) weights, and specific outpatient tariffs. These cost estimates were all based on data from the Danish Ministry of Health [2]. The use and costs of drugs were calculated from data from the National Danish Medicine Agency, consisting of the retail price of each drug (including dispensing costs) multiplied by the number of transactions. The frequencies and costs of consultations with general practitioners and other specialists were based on data from National Health Security.

The indirect costs (foregone earnings), which are those related to reduced labor supply, are based on figures from Danish Income Statistics [2]. Social-transfer payments, which are primarily publicly funded in Denmark, were also included. This includes subsistence allowances, pensions, social security, social assistance, publicly funded personal support for education, and others.

Cost-of-illness studies measure the economic burden resulting from disease and illness across a defined population and include direct and indirect costs. As patients leave the national data registers at the time of death, disappearance and emigration, the indirect cost estimate comprises only the production loss related to disease-related work disability. It is important to distinguish health-related costs from monetary transfer payments such as disability and welfare payments. These payments transfer purchasing power to the recipients from general taxpayers, but do not represent net increases in the use of resources, for which reason they are not included in the total cost estimate.

From the NPR, we identified all people who received a first diagnosis of epilepsy between 1997 and 2014. Then, using data from the Civil Registration System and the Statistics Denmark database (which includes information about social factors, marital and cohabiting status, incomes, pensions, etc.) [14], we randomly selected citizens who had the same age and sex as those with epilepsy. Social compensation was taken into account by selecting control subjects who resided in the same area of the country in which the patients lived, and who had the same civil status. The ratio of control subjects to those with epilepsy was 4:1. Data from people with epilepsy and matched control subjects who could not be identified in the Coherent Social Statistics database (<1%) were excluded from the sample, but more than 99% of the observations in the two groups were successfully matched. Patients and matched control subjects were followed from the year of diagnosis until 2013. Thus, people with an epilepsy diagnosis at the beginning of the period contributed follow-up data over 16 years; those experiencing an epilepsy diagnosis at the end of the period provided pre-diagnosis data, and all those in between provided varying amounts of pre- and post-diagnosis data. If a patient or control was not present in the CPR register on January 1st each year, then the corresponding control or person with epilepsy control was not included in the dataset for that year. People with epilepsy who are absent from the CPR register are typically deceased, in prison, or have emigrated to another country. All partners of people with epilepsy were also identified. A partner is defined as another adult sharing a home (i.e., not a parent-child household) with the subject, irrespective of gender, sexual, familiar, marital or civil status. A similar group of partners for control subjects was identified on the basis of age, gender and sociodemographic status.

Costs were measured on a yearly basis and adjusted to 2009 prices using the general price index. All costs were measured in DKK and converted to Euros using the exchange rate on June 30th 2011 (€1 = 7.45DKK).

The study was approved by the Danish Data Protection Agency. Data were handled in a manner that did not reveal the identity of anyone with epilepsy or of any control subjects, so neither individual nor ethical approval was required. Statistical analysis was done with SAS 9.1.3 (SAS, Inc., Cary, NC). Statistical significance of the cost estimates was assessed by nonparametric bootstrap analyses [15].

3. Results

In total, persons aged between 0 and >80 years of age with an epilepsy diagnosis were included and were matched with control subjects. Age distribution is shown in Table 1. Of these, 52.2% were males. 37.1% were married or co-living – partners of people with epilepsy and controls. Mortality was significantly higher in people

Table 1
Distribution of epilepsy by age group.

Age	Epilepsy	
	N	%
<20		26.1
20–29	9491	10.1
30–39		10.6
40–49		11.6
50–59		12.7
60–69		11.9
70–79	9731	10.3
≥80	6303	6.7
All	94.357	100

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