



Welfare cost of childhood- and adolescent-onset epilepsy: A controlled national study



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ABSTRACT

Objectives: Epilepsy is associated with a significant burden to patients and society. We calculated the factual excess in direct and indirect costs associated with childhood- and adolescent-onset epilepsy.

Methods: Using records from the Danish National Patient Registry (1998–2002), we identified 3123 and 5018 patients with epilepsy aged 0–5 years and 6–20 years at the time of diagnosis, respectively. The two age groups of patients with epilepsy were matched to 6246 and 10,036 control persons without epilepsy, respectively, by gender, age, and geography. The controls were randomly chosen from the Danish Civil Registration System. Welfare costs included outpatient services, inpatient admissions, and emergency room visits based on the Danish National Patient Registry and information from the primary health-care sector based on data from the Danish Ministry of Health. This allowed the total health-care cost of epilepsy to be estimated. The use and costs of drugs were based on data from the Danish Medicines Agency. The frequencies of visits to outpatient clinics and hospitalizations and costs from primary sectors were based on data obtained from the National Patient Registry.

Results: Children with epilepsy had higher welfare costs than controls. The highest cost was found one year after diagnosis, with higher costs up to 10 years after diagnosis compared with controls. Children aged 0–5 years incurred greater health-care costs than those aged 6–20 years.

Conclusion: Epilepsy has major socioeconomic consequences for the individual person with epilepsy and for society.

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1. Introduction

Epilepsy is one of the most important and common chronic neurological disorders and affects persons of all ages. It is strongly associated with significant comorbidities, mortality, stigma, reduced quality of life, and educational and professional problems and, consequently, has a substantial socioeconomic impact [1–4]. Estimation of the total societal burden of epilepsy is necessary to provide information for health planning. Studies on the economic impact of epilepsy have mainly focused on model information, questionnaires, and other direct or indirect information in selected groups of patients, and estimates of the economic burden extracted from this information have been primarily reported for adults [5–21].

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However, the association between epilepsy in children and direct and indirect costs has not often been described [2,22–26]. There are limited data about long-term costs in children with epilepsy based on prospective studies. Recently, we described factual direct and indirect costs in children and adults diagnosed with epilepsy in Denmark [27]. These data suggested that epilepsy causes a substantial burden, not only at the time of diagnosis and after but also before diagnosis. However, this study assessed the total costs from the whole national population; there has been little focus on the welfare cost in children.

For the Danish population, using a unique identification number, it is possible to identify persons with and without epilepsy and to link this status to health and socioeconomic information. We aimed to evaluate the long-term welfare consequences of early onset epilepsy.

2. Methods

2.1. The cohort of persons with epilepsy and control subjects

Patients hospitalized with epilepsy in Denmark between 1998 and 2002 were identified from historical medical archives and matched by

age, gender, and geographic region to a randomly chosen control group from the background population. Detailed information about education, employment, welfare benefits, family relations, hospital contacts, visits to general practitioners, and use of medication for the total Danish population was drawn from several nationwide registers. These data enabled us to identify the long-term social effect of epilepsy with a follow-up time of 10 years after diagnosis. Since April 1968, all Danish citizens have been assigned a unique identification number (Central Personal Registration number), which is recorded in the Danish Civil Registration System along with information about place of birth, place of residence, vital status, and marital status. In Denmark, all patient contacts are recorded in the Danish National Patient Registry (NPR) by time of contact and primary diagnosis. The NPR also includes administrative information and diagnostic and treatment procedures using several international classification systems including the International Classification of Disorders (ICD-10). The NPR is a time-based national database with details of all patient contacts, so the data may be considered representative of all patients in Denmark who have received a diagnosis of epilepsy in public and private hospitals.

To analyze the health consequences (costs and comorbidity) in the first 10 years after a diagnosis of epilepsy (index date), a cohort of patients with epilepsy alive 10 years after the index date was identified. The patients in the cohort were diagnosed with epilepsy for the first time between years 1998 and 2002 and followed up to the end of 2012.

All patients were individually matched to two control persons by age, gender, and living location. The use and costs of drugs were based on data from the National Danish Medicine Agency, including the retail price of the drug (with dispensing costs) multiplied by the number of transactions.

The control group was not matched to patients' education, because it is not possible to obtain a perfect match for the entire population based on child age. Instead, we controlled systematically for parental education i.e., skilled or college (short, medium, and long-term education) by including a dichotomous explanatory variable distinguishing trained and not trained in the statistical analysis.

The analysis was based on a prediction of annual health-care costs for patients with epilepsy and their controls over a 10-year period after diagnosis (postindex period).

Postindex health expenses were divided into those for outpatient services, hospital admissions, accident and emergency, primary health sector, and medication prescriptions redeemed.

Redemption of prescriptions, hospitalizations, outpatient visits, and accident and emergency visits were included after the index date.

Index diagnosis costs of hospitalization, ambulatory visits, and accident and emergency visits were therefore not included.

Annual health-care costs were predicted from a generalized estimating equation (GEE) model in which parents' education (skilled and college) was also included as an explanatory variable (0 = neither parent trained, 1 = least one parent trained).

3. Results

Three thousand one hundred twenty-three patients aged 0–5 years and 5018 patients age 6–20 years at the time of diagnosis of epilepsy were identified and compared with 6246 and 10,036 controls, respectively. Patient characteristics are shown in Table 1. More boys than girls had epilepsy, although the distribution between the sexes was approximately equal for older children and adolescents. The parental educational level was lower among parents of children with epilepsy.

3.1. Health-care cost estimation for the 10-year postindex period

Outpatient services, inpatient admissions, accident and emergency, primary health-care sector, uses of medication, and consequently, total health-care costs were all significantly higher in 0- to 5- and 6- to 20-year-old patients (Tables 2A and 2B and Fig. 1 and 2). The costs in children with epilepsy diagnosed at age 0–5 years were higher than in patients aged 6–20 years at diagnosis (Fig. 2). The welfare costs were highest during the first year after diagnosis. For patients aged 0–5 years at the time of diagnosis, the cost of inpatient admissions constitutes the major part of the costs associated with epilepsy (Table 2A). The costs were lower for children diagnosed at 6–20 years of age, especially those of hospital admissions (Table 2B).

4. Discussion

This is one of the largest studies evaluating the welfare cost of childhood- and adolescent-onset epilepsy in a national cohort with gender-, age-, and geographically-matched controls. Compared with those in controls, the welfare costs were higher in both age groups of patients for all domains including general practice, hospital visits, emergency room visits, and medication use. The costs were highest during the first year after diagnosis and were higher for up to 10 years after the index date. Welfare costs were highest with early-onset epilepsy.

Onset of epilepsy in childhood, adolescence, and younger adulthood had a significant welfare impact. Total health costs were more than four

Table 1
Basic characteristics of persons with epilepsy aged 0–5 and 6–20 years at time of epilepsy diagnosis compared with controls.

	Diagnosis of epilepsy at age 0–5 years					Diagnosis of epilepsy at age 6–20 years				
	Persons with epilepsy		Controls		P	Persons with epilepsy		Control		P
	N = 3123		N = 6246			N = 5018		N = 10,036		
	Mean	SD	Mean	SD		Mean	SD	Mean	SD	
Age at diagnosis of epilepsy (index date)	2.2	1.7				12.1	4.2			
	N	%	N	%	P	N	%	N	%	P
Gender										
Male	1693	54.2				2603	51.9			
Female	1430	45.8				2415	48.1			
Education										
Parents' highest level of education at index date										
Primary	507	16.2	688	11.0	<0.001	908	18.1	1,466	14.6	<0.001
Secondary	136	4.4	281	4.5	<0.001	149	3.0	273	2.7	<0.001
Vocational	1366	43.7	2670	42.7	<0.001	2268	45.2	4343	43.3	<0.001
College	1099	35.2	2578	41.3	<0.001	1648	32.8	3820	38.1	<0.001
Unknown	15	0.5	29	0.5	<0.001	45	0.9	134	1.3	<0.001

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