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The direct medical costs of epilepsy in children and young people: A population-based study of health resource utilisation

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Summary We described the health resource utilisation (HRU) and associated direct medical costs of managing epilepsy in children and young people (CYP) using population-level data from the United Kingdom.

The study cohort were CYP born between 1988 and 2004 who were newly diagnosed with epilepsy and identified using a nationally representative primary care database from the United Kingdom. Reference unit costs were applied to each element of HRU to calculate annual direct medical costs per child. We assessed whether HRU and costs differed by time from diagnosis, age, sex and socioeconomic deprivation.

Of 798 CYP newly diagnosed with epilepsy, 56% were male and the mean age at diagnosis was 5.6 years. The highest burden of HRU was in the first year following diagnosis with a mean annual cost of £930 (95% confidence interval (CI) £839—1022) per child in this first year. This decreased to £461 (95%CI 368—551) in the second year which remained fairly constant each subsequent year (£413 (95% CI 282—540) in the 8th year). The highest contribution to the annual medical costs was from inpatient hospital admissions followed by the costs of AEDs. Mean annual medical costs were significantly higher in children under 6 years of age compared with older children ($p < 0.01$), but were similar across socioeconomic groups ($p = 0.62$).

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The direct medical costs of HRU in CYP with epilepsy are higher in the first year after diagnosis compared to subsequent years, reflecting HRU related to the diagnostic process in the first year. Medical costs did not vary substantially by sex or socioeconomic deprivation indicating a similar level of consultation and care across these groups.

Introduction

Epilepsy is a serious chronic neurological disorder that has a higher incidence (70—116 per 100,000 person-years) in children and young people (CYP), under 18 years, than in adults (30—55 per 100,000 person-years) (Forsgren et al., 2005; Kotsopoulos et al., 2002; Meeraus et al., 2013). As many clinical subtypes of childhood epilepsy persist into adulthood (Guerrini, 2006), epilepsy has long term clinical care requirements and a high economic burden at individual, family, health service and societal levels in the United Kingdom (UK) and in Europe (Pugliatti et al., 2007).

The total direct medical cost of epilepsy to the United Kingdom (UK) National Health Service (NHS) was estimated to be £170 million in 1994 when the population was 59.8 million people (Cockerell et al., 1994). This included antiepileptic drug (AED) treatment, outpatient attendances, inpatient hospital admissions, diagnostic imaging, blood chemistry tests, general practitioner and specialist consultations. This estimate was based on aggregated data of 1628 adults and children with epilepsy. In 2005, Beghi et al. reviewed published studies on the cost of childhood epilepsy and concluded that there was very limited knowledge of the economic impact of epilepsy in CYP due to the scarcity, inconsistency and poor comparability of published articles (Beghi et al., 2005) and no subsequent studies have estimated these costs at a population level in the UK.

Nevertheless, there are appear to be wide differences in incidence, prognosis and management between adults and CYP with epilepsy (Beghi et al., 2005). Studies of health resource utilisation (HRU) in regions of Canada and Wales have indicated that CYP under 18 years of age are more likely than adults to see neurologists, visit emergency departments, and have more inpatient and outpatient hospital admissions (Jette et al., 2008; Morgan et al., 2000). Studies in these populations, consisting mainly of adults, also showed HRU differences by sociodemographic factors, such as increased hospital care utilisation for epilepsy in those with higher socioeconomic deprivation in Wales (Jette et al., 2008; Morgan et al., 2000). These studies, however, did not assess relationships specifically in CYP nor did they estimate any associated costs, which are required to inform service configuration and evaluation for CYP. Updated HRU and cost data should help service planning and provision by understanding whether there are areas where cost budgets need to be rebalanced between epilepsy diagnosis, treatment and acute management and services. In addition, identifying whether and how epilepsy HRU and costs differ across sociodemographic groups is crucial for planning area-level population service provisions and modifications.

Epilepsy in the UK is managed principally via primary care in collaboration with secondary care settings (Stokes et al., 2004). The aim of our study was to use a large population-based general practice database to estimate patient-level direct medical costs of managing epilepsy in CYP. We also assessed whether HRU and direct medical costs varied by age, sex, socioeconomic status and the time from diagnosis of epilepsy.

Methods

Data source

Data were extracted from The Health Improvement Network (THIN), a computerised primary care database that contained longitudinal electronic medical records from 255 general practices across the UK at the time data were extracted. In 2004, THIN had approximately 3.2 million patients which, covered 5.3% of the UK population (THIN, 2012). Data in THIN include anonymised patient records with demographic information, medical diagnoses (including those resulting from referrals to specialists), prescriptions, laboratory results, records of hospital admissions and medical measurements. Diagnoses and investigations are recorded using Read codes which have a hierarchical structure and include comprehensive clinical terminology (Stuart-Buttle et al., 1996).

Study population

From an initial population of all CYP born between January 1st, 1988 and November 30th, 2004, we identified all CYP (up to age 16 years) with newly diagnosed epilepsy. We defined CYP as having epilepsy if they had at least one diagnostic Read code for epilepsy, selected according to consistency with the 1989 International League Against Epilepsy (ILAE, 1989) and section G40 of the International Statistical Classification of Diseases, 10th Revision, and at least one prescription for an AED shown in Table 1. To avoid misdiagnosis of epilepsy, we excluded codes of disorders that mimic epilepsy such as febrile convulsions and we also excluded antiepileptic drugs prescribed for diseases other than epilepsy (Ali, 2012). Our code lists were constructed with consultation from a Clinical Associate Professor of Paediatric Neurology in the Division of Child Health, the University of Nottingham's Queen Medical Centre. In addition, to be considered as incident cases their first epilepsy diagnosis and any related treatment had to occur at least 6 months after their date of registration with the general practice to be considered as newly diagnosed, unless they had been registered within the first 6 months of life (70% of the population were registered within 6 months of birth). We also included only CYP who had at least one year of registered follow-up data and CYP were followed up to 8 years after their initial diagnosis of epilepsy or, if earlier, to their date of death, the date when they transferred out of the general practice or the last date of data collection on