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The costs of epilepsy misdiagnosis in England and Wales

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Summary

Background: The management of epilepsy incurs significant costs to the United Kingdom (UK) National Health Service (NHS). Making a diagnosis of epilepsy can, however, be difficult and misdiagnosis frequently occurs when patients are seen by non-specialists. This study estimates the financial costs of epilepsy misdiagnosis in the NHS in England and Wales.
Methods: Standard costing methods were applied to estimate the costs attributable to epilepsy misdiagnosis. The primary data were published in UK studies on the prevalence of epilepsy, epilepsy misdiagnosis and costs identified from Medline, Cinahl and Embase (1996—May 2006).
Results: An estimated total of 92,000 people were misdiagnosed with epilepsy in England and Wales in 2002. The average medical cost per patient per year of misdiagnosis was £316, with the chief economic burdens being inpatient admissions (45%), inappropriate prescribing of antiepileptic drugs (AEDs) (26%), outpatient attendances (16%) and general practitioner (GP) care (8%). The estimated annual medical costs in England and Wales were £29,000,000, while total costs could reach up to £138,000,000 a year.
Conclusions: Allowing for uncertainty, and considering the analysis exclusively from the NHS/CBS (community based services) perspective the opportunity costs of misdiagnosis are substantial. There is a need for health care commissioners to ensure that misdiagnosis is kept to a minimum by ensuring that individuals with a recent onset suspected seizure are seen as soon as possible by a specialist medical practitioner with training and expertise in epilepsy.

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Introduction

The management of epilepsy incurs significant costs to the United Kingdom (UK) National Health Service (NHS). The medical cost to the NHS in 1992/1993 of newly diagnosed epilepsy in the first year of diagnosis was calculated as £18 million and the total annual cost of established epilepsy estimated at £2 billion, over 69% of which was due to unemployment and excess mortality (indirect costs).[1] The costs of treating epilepsy are likely to significantly increase given the new trends in prescribing patterns towards newer and more expensive antiepileptic drugs (AEDs).[2–4]

A correct diagnosis of epilepsy requires that the clinician differentiate between seizures and other causes of transient neurological disturbance and collapse, such as syncope, and between acute symptomatic and unprovoked epileptic seizures. In an individual diagnosed with epilepsy, it is important that the correct classification of seizure type and epilepsy syndrome is made so that the individual with epilepsy can receive appropriate investigations, appropriate treatment, and information about the likely prognosis of the seizure type and/or syndrome.[5–7,29]

Making a diagnosis of epilepsy can be difficult. Misdiagnosis is a frequent occurrence, occurring in around 25% of cases.[8,9] The majority of these occur when the diagnosis is made by a non-specialist.[9] Individuals misdiagnosed with epilepsy may experience social and financial deprivation as a result of having the wrong diagnostic label and from side-effects of antiepileptic medication.[10,11] In addition, there may be a risk of unnecessary teratogenicity as a result of antiepileptic drug (AED) therapy in women incorrectly diagnosed as having epilepsy. In a small number of cases, individuals may die prematurely because the correct diagnosis was not made.[12] Individuals who have symptoms due to epileptic seizures but who are wrongly diagnosed as having psychiatric or associated disorders are disadvantaged by being labelled with an incorrect diagnosis and by the effects of continuing seizure activity because AEDs are not used.

In contrast to the documented physical and psychosocial effects of epilepsy misdiagnosis, little is known about the health economic costs of misdiagnosis in the United Kingdom (UK). The one published cost of illness study of epilepsy in the UK is now more than ten years old and focused on epilepsy in general, not the specific costs of misdiagnosis.[1] This study aimed to estimate the financial costs of epilepsy misdiagnosis in the NHS in England and Wales.

Methods

Standard costing methods[13] were applied to estimate the costs attributable to epilepsy misdiagnosis. The primary data were published UK studies on the prevalence of epilepsy, epilepsy misdiagnosis and costs identified from Medline, Cinahl and Embase (1966—May 2006). A systematic literature search was undertaken to identify these studies, the details of which are reported elsewhere.[7]

The total number of misdiagnosed cases in epilepsy includes the number of true epilepsy cases diagnosed as other non-epileptic conditions plus the number of non-epileptic conditions diagnosed as epilepsy. The analysis focused only on estimating the costs of other conditions wrongly diagnosed as epilepsy (''false positives'') because this is the most common form of misdiagnosis and the majority of the published evidence addresses this type of misdiagnosis.

The perspective of the reference case is that of the National Health System (NHS) and Community Based Services (CBS).[a] The complete financial burden of epilepsy misdiagnosis can, however, only be represented through a wider societal perspective, that includes, for example, the lost productivity due to morbidity or mortality for not treating the underlying condition and/or for being stigmatized as an individual with epilepsy (such as problems with employment or mobility problems due to driving restrictions).

The following steps were taken:

- To estimate the number of misdiagnosed patients in England and Wales assuming prevalence and misdiagnosis rates based on published UK literature and applying these to the 2002 population of England and Wales. Only UK prevalence and misdiagnosis studies were included as it is important that these estimates can be generalised to the England and Wales population. In particular, variations in health care systems mean that misdiagnosis rates from non-UK settings are unlikely to be generalisable.
- To estimate the annual average uses of resources and costs incurred by a misdiagnosed individual based on assumptions derived from published literature. All costs are estimated at 2003/4 prices adjusted for inflation by the hospital and community health and services (HCHS) pay and price index.[14]

[a] Includes medical costs and community-based social services costs. Medical resources include: hospital inpatient visits, antiepileptic medication, outpatient attendances, GP visits, A&E attendances. Community based social services resources include: health visitor, social worker, psychology/psychiatry, remedial school, residential care and day care.