

DEATHS IN CHILDREN WITH EPILEPSY (EXCL. SCOTLAND)

Abstract

Epilepsy is the most common long-term disabling condition of the nervous system affecting around 600,000 people in the UK.¹ People with epilepsy are 2 to 3 times more likely to die early than the general population.² Children with epilepsy may die from a number of causes including sudden unexplained death in epilepsy (SUDEP). Different studies with different cohorts show that SUDEP is responsible for anything between 2%-18% of all deaths in patients with epilepsy.³ The risk in children remains uncertain but is thought to be considerably less. Although the causes of SUDEP are undetermined, the most important risk factor in adults seems to be frequency of seizures. Young people with severe epilepsy and learning disability may be at even higher risk of SUDEP, with one previous study showing a death rate almost 16 times greater than expected.⁴

A prospective pilot study is much needed, to determine the size of the problem of death in children affected by epilepsy, to compare the differences between SUDEP and other causes of epilepsy deaths, and to allow future studies in this field. Using the BPSU national surveillance system we aim to investigate the incidence of deaths in children with epilepsy in the UK and Ireland, and describe the demographic characteristics of affected children. The study will contribute to our understanding of the epidemiology of mortality in epilepsy in children in the UK and Ireland, and help us to evaluate the effectiveness of current public health measures.

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Website

www.rcpch.ac.uk/bpsu/epilepsy

Coverage

United Kingdom (Excluding Scotland) and the Republic of Ireland

Duration

October 2016 to October 2017 (13 months of surveillance)

Research Questions	<ul style="list-style-type: none"> ▪ To estimate the current incidence of death in children under 16 years of age with epilepsy in the UK. ▪ To undertake a comprehensive descriptive study of deaths in epilepsy in UK children over a 13 months surveillance period. ▪ To compare characteristics of deaths from SUDEP to deaths in children with epilepsy from other causes. ▪ To develop appropriate information for young people with epilepsy and their families about incidence of SUDEP and characteristics of epilepsy deaths.
Case definition	Any child who dies aged between 1 month and 16 years of age who also has the simultaneous diagnosis of epilepsy. The child must have had seizures or been treated with antiepileptic medication within the last 5 years.
Reporting instructions	Please report any new cases you have seen in the last month which meet the surveillance definition. Please report all suspected cases, even if the results of investigations are pending. Please report to the BPSU even if you believe the case may have been reported from elsewhere.
Methods	<p>Each paediatrician reporting a child who meets the above case definition of deaths in children with epilepsy will be sent a clinical questionnaire by the study team, which explores demographic and clinical information about the affected child.</p> <p>Throughout the study, all patient data will be dealt with in strict confidence, and families will not be contacted directly by the deaths in children with epilepsy study team at any stage.</p>
Funding	This study is being funded through SUDEP Action (www.sudep.org).
Ethics approval	This study has been approved by the London Central REC (Ref: 16/LO/1265) and has been granted Section 251 CAG permission (Ref: 16/CAG/0093).
Support group	Epilepsy Action , Epilepsy Research UK and SUDEP Action .
References	<ol style="list-style-type: none"> 1. Hanna N, Black M, Sander J et al. (2002). National Sentinel clinical audit of epilepsy-related death: report 2002. <i>Epilepsy-death in the shadows</i> 2. Appleton R (2003). Mortality in paediatric epilepsy. <i>Archives of disease in childhood</i>; 88(12): 1091-1094 3. Ficker DM (2000). Sudden unexplained death and injury in epilepsy. <i>Epilepsia</i> 41 (supl 2): S7–12. 4. Nashef L, Fish DR, Garner S et al (1995) Sudden death in epilepsy: A study of incidence in a young cohort with epilepsy and learning disability. <i>Epilepsia</i>; 36(12): 1187–1194.

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