Mortality Due to SUDEP and Status Epilepticus

Abstract

Mortality in patients with epilepsy (PWE) is increased compared to the general population. For this reason the National Stroke and Stroke Prevention Programme of the Health Service Executive’s which was established under the Health Service Executive’s National Director for Clinical Strategy and Programmes, identified a reduction in mortality from epilepsy as a key quality metric to monitor the success of their Health Strategy. 

SUDEP is defined as the sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death of patients with epilepsy including frequent convulsive seizures and polytherapy with anti-epileptic drugs (AEDs). 

Introduction

Preliminary Irish data reported for an elderly cohort admitted with confusion, indicated a mortality rate of 50% in those with confirmed non-convulsive status suggesting that non-convulsive status in this age group, due to its under-recognised presentation, may be associated with a higher mortality than convulsive status. 

SUDEP is defined as the sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death of patients with epilepsy with or without evidence of seizure, excluding documented SE, and in whom post-mortem examination does not reveal a structural or toxicological cause for death. 

Status Epilepticus (SE)

SE can be categorised as either convulsive or non-convulsive. Non-convulsive status, where seizure activity primarily manifests as altered behaviour or depressed consciousness, is often under diagnosed especially if EEG facilities are unavailable. 

Case fatality rates (CFRs) for SE varied in European studies from 9.9/100,000 per year in Switzerland to 17.1/100,000 in Germany with similar figures in white populations in the United States, with incidence rates of 18.1/100,000 in Rochester and 20.0/100,000 in Richmond. This review found lower mortality rates from SE in Europe compared with the United States. 

While it is not possible under data protection rules to link the two datasets, looking at them separately indicates that deaths related to epilepsy occur more commonly outside of the hospital setting which would be consistent with the figures from the review by Tomson et al which showed greater number of deaths from SUDEP than SE. 

Mortality in patients with epilepsy due to SUDEP and SE account for between 48 and 162 deaths per year in Ireland and sources of mortality information currently available possibly underestimate the numbers involved especially if deaths due to non-convulsive status are included. 

Methods

A separate analysis of mortality related to epilepsy was carried out using Health Atlas Ireland to analyse epilepsy-related deaths from the CSO and HIPE prevalence figures for Ireland which had not previously been available. 

In estimating a mortality figure for cases of SUDEP and SE in Ireland, a range of incidence rates and CFRs (where available) was combined with the 2011 Census population estimate for Ireland. 

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Methods

A separate analysis of mortality related to epilepsy was carried out using Health Atlas Ireland to analyse epilepsy-related deaths from the CSO and HIPE datasets. This approach identified 65 deaths (eight occurring in hospital) where epilepsy was the cause of death in 2005, 53 (seven in hospital) in 2006, 64 (14 in hospital) in 2007 and 39 (five in hospital) in 2008. This gave an estimated incidence of SUDEP for the Irish population of 13-95. This range incorporates the estimated range of deaths due to SUDEP and SE in Ireland. These estimates indicate that mortality in patients with epilepsy due to SUDEP and SE account for between 48 and 162 deaths per year in Ireland and sources of mortality information currently available possibly underestimate the numbers involved especially if deaths due to non-convulsive status are included.
The Health Service Executive National Clinical Programme in Epilepsy Care uses international evidence to create a programme of improvement in quality, access and care for PWE and their families. There is evidence that seizure frequency and failure to achieve remission are associated with increased risk for both SE and SUDEP. Evidence and expert opinion would indicate the importance of access to a specialist multidisciplinary service for the assessment and treatment of patients with epilepsy, to improve the management of their epilepsy. It is expected that improved patient care will increase the number of PWE entering remission and decrease their risk of mortality. Central to improved patient care, is the requirement for robust information systems to accurately capture the mortality and morbidity associated with epilepsy. The proposed roll out of an electronic epilepsy patient record as part of the National Programme will allow the prospective collection of accurate data on SE, SUDEP and other epilepsy-associated conditions.

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References
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