Mortality Due to SUDEP and Status Epilepticus

Abstract

Morbidity in patients with epilepsy (PWE) is increased compared to the general population. For this reason the National Programme of Epilepsy Care, 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 the programme in the first year of its launch. Progress in the field of epilepsy care has been predominantly related to the underlying cause but there remains a persistent elevation in mortality rates especially amongst newly diagnosed patients. This group of patients includes those who present with status epilepticus (SE) or sudden unexpected death in epilepsy (SUDEP) or status epilepticus (SE). This paper identifies a number of studies on mortality in epilepsy from SE and SUDEP and uses this data to generate an estimate for annual mortality from SUDEP and SE in Ireland. There were 10 deaths in 2005, 12 in 2006, 11 in 2007, 4 in 2008, 11 in 2009, and seven in 2010 in Ireland. The corresponding figure for all deaths in Ireland from the CSO figures showed greater number of deaths from SUDEP than SE. Our predication of mean number of deaths in SE 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.

Introduction

Patients with epilepsy have higher mortality rates than the general population. The greatest excess in mortality is found in cohorts of hospital patients with longstanding severe epilepsy. A large general hospital based population of patients with epilepsy had a Standardized Mortality Ratio (SMR) of 3 and a cohort of epilepsy surgery patients was found to have an SMR of 6.3. Population based studies have shown SMRs between 1.6 and 2.5. Deaths in patients with epilepsy may be unrelated to epilepsy, related to the underlying cause or directly related to seizures. Mortality in newly diagnosed patients is higher and more likely to be related to the underlying cause. The longer a patient is diagnosed the greater the chance of a death being directly related to epileptic seizures. A death where epilepsy was the cause of death in the CSO figures from 2006 showed six deaths where the patient’s principal diagnosis was epilepsy and seven where the principal diagnosis was SE. The corresponding figures for 2007 were epilepsy, 11 and SE 11, 2008, epilepsy 11 and SE 4, 2009, epilepsy 13 and SE 9, and 2010, the number of deaths recorded in HPE where the patient’s principal diagnosis was either epilepsy or SE ranged from 13 to 32 with a mean of 21.

Sudden Unexpected Death in Epilepsy (SUDEP)

SUDEP occurs, witnessed or unobserved, 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. While SUDEP may occur infrequently in community based populations, within hospital based populations it is considered to occur in 0.3% to 2% of hospital admissions (rates between 1.1 and 5.37). Case control studies identified risk factors for SUDEP linked to poorly controlled epilepsy including medication and co-morbidities, convulsive seizures and polytherapy with anti-epileptic drugs (AEDs).

Data from Irish Studies

Using 2011 census population, the incidence rates were 1.0 between 1992-1995 in South Dublin and Wicklow found an overall rate of SUDEP of 1/680 per year for the first three years of the study. Using an estimated epilepsy prevalence of 0.5% and extrapolating this data to the national population provided an estimated number of cases of SUDEP in Ireland of 25 per year. A study using secondary data source identified an estimated annual incidence rate for severe and protracted convulsive epilepsy for Ireland which had not previously been available. This estimated the prevalence of epilepsy at between 8.3 and 9.0 /1000 persons 5 years and older.

Estimates of mortality from SUDEP and SE in Ireland

In estimating a mortality figure for cases of SUDEP and SE in Ireland, a range of incidence rates and CFRs (where relevant) from the studies described above, 8-15 were combined with the 2011 census population for Ireland and the Irish epilepsy prevalence figure. The results are presented in table 1. In estimating mortality due to SUDEP a range of incidence rates [0.33-2.3] [7,8] was combined with the Irish prevalence figure for epilepsy and the 2011 census population. This gave an estimated incidence of SUDEP for the Irish population of 13.95. This range incorporates the figure from the Irish work by Langan et al. To estimate the mortality due to SE, a range of incidence rates for SE [5.9 to 15.8], for European studies from the review by Logroscino et al was combined with the 2011 census population from the CSO to provide an estimated annual range of 454 to 724 cases of SE Ireland. Using the CFRs in the review paper for the European studies (Logroscino et al) but excluding the outlier figure from Bologna, gives an estimated CFR range of 7.6 to 9.3. This lies in the lower range of CFRs for SE (7.6-22%) given in the review on mortality in epilepsy by Hilirio et al which included a number of American studies which contained cases due to anoxic encephalopathy. This range of CFRs (7.6-9.3%) provides an estimated range of deaths due to SE of between 35 and 67 deaths per year based on the 2011 Irish population (Table 1). Combining these mortality estimates provides an estimate of deaths due to SUDEP and SE in Ireland to be between 48 and 162 deaths per year in Ireland (Table 1).

A separate analysis of mortality related to epilepsy was carried out using Health Atlas Ireland15 to analyse epilepsy-related deaths from the CSO and HPE 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 52 in 2008 using the death occurrence data from the CSO. This provides a range of 53 to 77 with a mean value of 65 for deaths where epilepsy was the underlying cause. An examination of the HPE dataset found only one death due to epilepsy related deaths in 2004 and 2005. While the mean number of deaths in the CSO dataset is higher, our estimate of the number of deaths in 2005 in the CSO dataset is 53, which is within the range of 48-162 deaths due to SUDEP and SE. However, the mean number of deaths available from the death occurrence data for the years 2005-2008 15 can be interpreted with caution. The CSO figures for epilepsy related deaths fall just within the lower limit of our estimates with a range of 48-72. 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 findings of the studies described above. However, a number of studies found a higher mortality than convulsive status seizures. Mortality in SE studies is not well documented and not available.

The Health Service Executive National Clinical Programme in Epilepsy Care uses international evidence to develop 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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