**ABSTRACT**

**International case control study of Sudden Unexpected Death in Epilepsy**

**(SUDEP)**

**Purpose:**

To identify factors associated with an increased or decreased risk of SUDEP.

**Method:**

The EpiNet study group is undertaking a prospective case-control study, aiming to recruit 200 participants from approximately 40 international centres over four years. Patients with epilepsy from a pre-defined cohort who die of definite or probable SUDEP will be included. Cases must be alive when the cohort is defined. For each case, three true controls and one proxy control will be recruited from the same cohort.

A structured telephone interview with the next-of-kin of SUDEP cases will be conducted. Controls will be asked about their epilepsy and lifestyle. Proxy controls will be asked about the control patient they know. Information regarding seizure type and medication, sleeping arrangements, nocturnal supervision, use of seizure-detection devices, socio-economic factors and other health issues will be entered into the EpiNet database. Pathologists' and coroners' data regarding circumstances and cause of death will also be recorded if available.

The data will be analysed to identify risk factors for SUDEP. Odds ratios will be calculated using the Mantel-Haenszel method and logistic regression to control for covariates. 200 cases and 800 controls will detect an odds ratio of 1.7 over a control exposure range of 22-65%, with 80% power and 95% confidence level (2-sided).

**Results:**

The study is now underway in 8 countries through Asia-Oceania, Europe and North America, COVID-19 has adversely affected case enrolment, and new centres are being sought.

**Conclusion:**

SUDEP is second only to stroke as the leading neurological cause of years of potential life lost. The causes remain uncertain. A large prospective case-control study is the best way to determine the extent of the association between specific variables and SUDEP, in particular, those that could be modified to prevent this tragedy. Anyone interested in participating is welcome to contact: epinetadmin@adhb.govt.nz.

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