EPIDEMIOLOGY OF EPILEPSY IN TASMANIA

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Abstract

Background

Better understanding of the demographic distribution of epilepsy and the prevalence of 'more specific forms of epilepsy' in community-based settings would improve our understanding of this disorder at the population level. Although we now have good estimates of epilepsy prevalence for most countries, we still lack knowledge on its demographic distribution by age, ethnicity, region, and socioeconomic status. In addition, no studies to date have reported the prevalence of epilepsy syndromes using patient interview outside a hospital setting. This thesis provides the first community-based estimates of the prevalence of the most common clinical group of epilepsies presumed to have a genetic basis – The Idiopathic Generalised Epilepsies (IGE) - by patient and witness interview.

Methods

This thesis has involved conducting five pieces of new research: (i) a series of reviews and analyses of descriptive data on epilepsy prevalence, particularly focusing on the critical methodological issues of ascertainment, diagnosis and classification of epilepsy for epidemiological purposes; (ii) the validation of a modified diagnostic epilepsy questionnaire adapted for administration in population studies; (iii) recruitment of a community-based cohort – The Tasmanian Epilepsy Register (TER) - through the Australian national prescription database; (iv) estimation of the overall prevalence and distribution of self-reported treated epilepsy in Tasmania by imputation methods; (v)

estimation of the prevalence and distribution of IGE in Tasmania by telephone interviewing.

Results

My modified diagnostic questionnaire, administered by telephone interviewing and interpreted with standardized guidelines, demonstrated excellent agreement with an epilepsy specialist's clinical assessment in diagnosing the presence of epilepsy ($\kappa = 0.94$), seizure-onset types ($\kappa = 0.84$), simple or complex partial seizures ($\kappa=0.87$), any generalized non-convulsive seizure ($\kappa=0.82$), and IGE ($\kappa = 0.82$). Although still substantial, agreement was not as close for secondarily generalized seizures ($\kappa = 0.74$), and generalized tonic-clonic seizures ($\kappa = 0.79$).

7541 patients treated with antiepileptic drugs (AEDs) in the preceding year in Tasmania were eligible for recruitment through the Australian national prescription database. After three mail contacts, 54.0% responded, with 43.6% who indicated treatment for epilepsy representing 86.0% of total possible epilepsy cases by imputation (n=2063) in Tasmania. 1180 agreed to participate in the TER, 90.0% of participants received their AEDs either exclusively from their general practitioner (70.9%) or in combination with a medical specialist (19.1%) in the preceding twelve months. The adjusted treated epilepsy prevalence was 4.36 per 1000 (95% CI 4.34, 4.39); this was: lower in women (prevalence ratio 0.92 (95% CI 0.84, 1.00); greater with increasing age ($p< 0.001$); similar in the three main geographical regions; and similar by categories of socioeconomic status based on postcode of residence.

Following enrolment, 959/1083 (88.6%) eligible TER participants completed the diagnostic telephone interviewing, with partial epilepsy classified in two thirds, and generalised epilepsy in slightly more than one-fifth. IGE was observed in 20.3%, with tonic-clonic seizures (17.03%) and the absence epilepsies combined (11.01%) being the most common IGE seizure types and syndromes respectively. The estimated prevalence of IGE was 0.89 per 1000; is highest between the ages of 20-39 years and in females, but was similar between Tasmanian regions and socio-economic groups. IGE prevalence beyond childhood related to refractory childhood or adolescent disease rather than older-onset cases, and was characterised by the presence of myoclonic and tonic-clonic seizures. Generalised seizures, but not IGE, were less prevalent in southern Tasmania.

Conclusions

Utilising the design approach described in this thesis may provide an alternative to neurological assessment, and when coupled with case ascertainment through prescription data, can provide a valid estimate of the prevalence of 'more specific forms of epilepsy' in countries with high access to health services. The observed pattern of high elderly epilepsy prevalence, is similar to patterns in recent studies in other developed countries, and has important implications for future planning of health services in these countries. IGE represents a considerable proportion of community-treated disease with important aetiological and prognostic determinants occurring at the seizure rather than syndrome level of classification.

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Abbreviations

AED	Anti-epileptic drug
BMEI	Benign Myoclonic Epilepsy of Infancy
CAE	Childhood Absence Epilepsy
CATI	Computer-assisted-telephone-interviewing
CDC	Centers for Disease Control
CTB	Computed Tomography of the Brain
EEG	Electroencephalogram
EMA	Epilepsy with Myoclonic Absences
FDG-PET	Fluoro-deoxyderibose glucose positron emission testing
SPECT	Single photon emission computerized tomography
FRACP	Fellow of the Royal Australasian College of Physicians
GEFS+	Generalised Epilepsy with Febrile Seizures Plus
GPRD	The General Practice Research Database
GTCS	Generalised tonic clonic seizures
HIC	Health Insurance Commission
ICEBERG	The International Community-based Research Group
IGE	Idiopathic Generalised Epilepsy
IGEU	Idiopathic Generalised Epilepsy not otherwise specified
ILAE	International League Against Epilepsy
JAE	Juvenile Absence Epilepsy
JS	Jeavon's Syndrome
JME	Juvenile Myoclonic Epilepsy
MAE	Epilepsy with Myoclonic Astatic seizures
MRI	Magnetic resonance imaging
MRIB	Magnetic resonance imaging of the brain
NGPSE	National General Practice Study on Epilepsy
NHIS	National Health Interview Survey
NHMRC	National Health and Medical Research Council (Australia)
NHS	National Health Service
NHSCR	National Health Service Central Register
NHNN-GPLS	The National Hospital for Neurology and Neurosurgery General Practice Linkage Scheme
NPV	Negative Predictive Value
OREp	Osservatorio Regionale per l'Epilessia
PPV	Positive Predictive Value
SSCI	Semi-structured seizure classification interview
SEIFA	Socio-economic status index for postcode area
SENS	Sensitivity
SNES	The Sicilian Neuroepidemiology Study
SPEC	Specificity
TER	Tasmanian Epilepsy Register
UK	United Kingdom
WHO	World Health Organisation
YI	Youden's Index