



## How is epilepsy treated in people with a learning disability? A retrospective observational study of 183 individuals

H. Ring<sup>a,\*</sup>, A. Zia<sup>b</sup>, N. Bateman<sup>a</sup>, E. Williams<sup>a</sup>, S. Lindeman<sup>b</sup>, K. Himlok<sup>a</sup>

<sup>a</sup> Developmental Psychiatry Section, University of Cambridge, Douglas House, 18b Trumpington Road, Cambridge CB2 8AH, UK

<sup>b</sup> Cambridgeshire and Peterborough Mental Health Partnership NHS Trust, The Learning Disability Service, The Gloucester Centre, Peterborough, Cambs PE2 0JU, UK

### ARTICLE INFO

#### Article history:

Received 13 June 2008

Received in revised form 27 August 2008

Accepted 23 October 2008

#### Keywords:

Epilepsy  
Learning disability  
Treatment  
Care pathways

### ABSTRACT

Epilepsy in those with learning disability (LD) is currently managed by various health agencies with no obvious criteria for selecting particular care pathways and limited evidence-based descriptions of optimal treatment. The aim of this study was to examine relationships between management strategies and clinical outcomes in a community-based cohort of individuals with epilepsy and LD. The results may inform epilepsy management directly and contribute to an evidence base to support development of formal clinical trials.

An attempt was made to recruit all individuals with epilepsy and LD known to community LD health services in one geographic area. However, those with profound LD were under-represented in the final sample. Information relating to the epilepsy, the severity of the LD, comorbidities and epilepsy management were obtained retrospectively both from the clinical notes and from interviews with carers and clinicians.

We recruited 183 individuals of whom 33% had no reported seizures in the previous three months whilst 12% recorded more than 20 seizures per month. 73 individuals were receiving monotherapy, 66 were treated with two AEDs and 42 were prescribed three or more AEDs at the time of the study. In those taking monotherapy, there was no difference in the mean monthly seizure frequency between groups taking different AEDs. Similarly, for those prescribed two AEDs, no particular combination was associated with significantly lower seizure frequency. One third of the sample was receiving epilepsy management from hospital neurology services but no criteria determining choice of treatment pathway were identified. The findings suggest that more research needs to be carried out to identify both optimal care pathways and AED strategies.

© 2008 British Epilepsy Association. Published by Elsevier Ltd. All rights reserved.

### 1. Introduction

The prevalence of learning disability in the general population is reported as 3.7 per 1000 of the population.<sup>1</sup> Epilepsy is common in those with a learning disability (LD) and its frequency increases progressively with more severe intellectual impairment. Overall lifetime prevalence of epilepsy in those with mild to moderate learning disability (IQ 35–70) has been estimated at 15% whilst in those with severe to profound learning disability (IQ less than 50) a prevalence of 30% has been reported.<sup>2</sup> Prognosis for seizure control

in people with learning disability and epilepsy has been poorer than for those with epilepsy without learning disability.<sup>3</sup> These higher rates of inadequately controlled epilepsy bring increased rates of morbidity and also mortality.<sup>4</sup> In a Swedish study of over 1400 patients with learning disability, followed up for seven years, the standardised mortality ratio (SMR) for those with learning disability without epilepsy was 1.6 but the SMR increased to 5.0 in those with concomitant epilepsy.<sup>5</sup> Despite the fact that epilepsy is a serious problem in those who have a learning disability, there is a lack of randomised control trial evidence-based descriptions of optimal treatment approaches in this clinical group.<sup>6,13</sup> Within the UK, epilepsy management in those with LD has been provided by various combinations of primary care, specialist epilepsy and neurology services as well as learning disability mental health services and social care agencies, with no clear indications as to which service provides what treatment to any particular individual or why a particular care pathway was followed. The recent

\* Corresponding author. Tel.: +44 1223 746100 fax: +44 1223 746122.

E-mail addresses: [har28@cam.ac.uk](mailto:har28@cam.ac.uk) (H. Ring), [asif.zia@cambsmh.nhs.uk](mailto:asif.zia@cambsmh.nhs.uk) (A. Zia), [nb362@medschl.cam.ac.uk](mailto:nb362@medschl.cam.ac.uk) (N. Bateman), [eiw20@medschl.cam.ac.uk](mailto:eiw20@medschl.cam.ac.uk) (E. Williams), [steve.lindeman@cambsmh.nhs.uk](mailto:steve.lindeman@cambsmh.nhs.uk) (S. Lindeman), [karenhimlok@gmail.com](mailto:karenhimlok@gmail.com) (K. Himlok).

National Institute for Clinical Excellence clinical guidelines on the diagnosis and management of epilepsy (2004)<sup>6</sup> stated that “qualitative and quantitative studies are needed to determine the experience of individuals with learning disabilities and, in particular, to compare outcomes for people with epilepsy and learning disabilities managed by different groups of clinicians”. In the light of such a limited evidence base from which to establish best practice for the management of epilepsy in those with a learning disability there is a need to describe current treatment practices and to consider the efficacy of these. The aim of this study was to collect this information from a community-based cohort of individuals with epilepsy and LD and to examine the relationships between management strategies and clinical outcomes. Such data may contribute to the optimisation of epilepsy management in this historically neglected clinical group with complex needs, both directly and by providing an evidence base to inform the development of formal clinical trials.

## 2. Method

With the support of the five Community LD Services covering one county of England we attempted to recruit all patients with epilepsy known to these services whether or not the epilepsy was itself a focus of management by the learning disability teams. The clinical teams, having identified all those with LD and epilepsy known to the teams, then approached them and their carers, asking if they would consider participating in this study. Capacity to consent was supported by participants' carers and use of visual aids and sign language and those considered to lack capacity, even with this support, were excluded from the study. The study was approved by the local NHS Research Ethics Committee. Participants were only included when there was consensus amongst the teams caring for them, based on clinical and sometimes EEG evidence that they had a diagnosis of epilepsy. The participants recruited do not represent an epidemiological sample but are rather a selected majority within each of the involved clinical services of individuals known to have LD and epilepsy.

Data were obtained retrospectively from participants' clinical notes. Data were also collected from interviews with carers, LD team members, any neurology-based clinicians involved in their management and General Practitioners. We collected data describing each patient's state over the preceding three months, including current seizure types and frequency, the nature of the clinical support and management received for the epilepsy, including current antiepileptic drugs (AEDs), current or recent co-morbid neurological and psychiatric pathologies and the nature and severity of the LD.

## 3. Results

### 3.1. Population ascertained

Participants were recruited from the five locality-based community adult LD services that covered one county of England with a total population of 737,900 (Office for National Statistics [www.statistics.gov.uk](http://www.statistics.gov.uk): Mid 2004 population estimates based on the 2001 Census population). Out of 1487 individuals under the care of these teams at the time of the study a total of 183 individuals provided data for this survey, representing 12% of all the individuals with LD under the care of these teams and 71% of the total number of individuals with epilepsy and LD identified by the participating community LD teams as being under their care. The mean age of the participants was 40 years with a range of 16–72 years and 55% were male. The measure of the severity of the LD of the participants was obtained from the community teams and

was based on their historical, functional and psychological assessments. Of the study population, 20% had a mild LD (IQ 70–50), 16% a moderate (IQ 50–35), 57% a severe (IQ 35–20) and 7% a profound (IQ < 20) LD. Considering the likely cause of the LD, this was unclear in 61%. The most commonly ascribed specific causes were cerebral palsy in 19% and a chromosomal disorder in 12%, most commonly Down syndrome.

### 3.2. Description of epilepsy within the study population

The duration of diagnosed epilepsy extended from 1 to 71 years with a mean of 26 years. Within the study population 75 individuals (41%) had epilepsy for at least 30 years. As expected, a wide range of epilepsy syndromes were manifest by the participants, with 39% described as having an idiopathic generalised epilepsy syndrome and 14% described as having symptomatic or probably symptomatic focal epilepsy. However, in 47% of the sample it was not possible to classify the nature of the epilepsy syndrome. 46% of the study population had just one type of seizure with the remainder being reported as having multiple seizure types. Considering the frequency of epileptic seizures in the study population, the mean number of seizures per month was 15, with a range of 0–559. Overall, 33% of individuals had no seizures in the three months preceding data acquisition whilst 22 (12%) had recorded an average of more than 20 seizures per month. Chi-squared testing demonstrated that those with severe or profound LD were more likely to have had at least 1 seizure in the three months preceding the survey than those with less severe LD (Chi-squared 12.2,  $df=4$ ,  $P=0.016$ ). There were no significant differences between the mean numbers of seizures per month reported for those with idiopathic, focal or unclassified epilepsy. Four participants were recorded as having more than 100 seizures per month of whom two had myoclonic seizures, one had myoclonic and absence seizures and one had absence seizures. After excluding these four patients, the mean number of seizures per month over the three months preceding the study was 7.2 (sd 14.1). Over the year preceding the study 85% of patients had no recorded episodes of status epilepticus whilst 8% had one episode, 3% had two episodes and 4% had three or more episodes of status.

### 3.3. Relationships between seizure frequencies and different antiepileptic drug regimens

The mean monthly seizure frequencies associated with different antiepileptic drug (AED) regimens are listed in [Table 1](#) for all those regimens prescribed to at least two participants. This describes the findings from 137 individuals and excludes the data from the four individuals who had more than 100 seizures per month. Considering the study sample overall, two patients were not taking any AEDs, 73 were receiving monotherapy, 66 were being treated with two AEDs and 42 were prescribed three or more AEDs at the time of the study.

- i. There was no significant difference between the numbers of AEDs prescribed to those with idiopathic, focal or unclassified epilepsy.
- ii. As noted above, 33% of the study population had no seizures in the three month period considered in the study. It can be seen from [Table 2](#) that each of the three most commonly prescribed monotherapy regimens (carbamazepine, lamotrigine or sodium valproate) was given in approximately equal proportions to those with and without ongoing seizures.
- iii. Considering the monotherapy regimens ([Table 1](#)), there was no difference in mean monthly seizure frequency with respect to which AED was prescribed (carbamazepine, lamotrigine,

متن کامل مقاله

دریافت فوری ←

**ISI**Articles

مرجع مقالات تخصصی ایران

- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان دانلود رایگان ۲ صفحه اول هر مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات