



Two-year outcome audit in an adult learning disability population with refractory epilepsy

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Summary Current evidence suggests that epilepsy outcome for people with a learning disability is poor, with the majority remaining refractory to treatment. There is very little evidence from randomised controlled trials in this population and despite the many uncontrolled variables it is suggested that an outcome audit may be one method of adding to the evidence base.

This audit reports on the outcome for 37 patients with learning disability and refractory epilepsy. All patients were seen for the first time before March 2001 and the mean number of seizures for the sample was 10.4 per month. The exit audit included all patients at a date 2 years after their initial visit following a programme of medication changes. The mean seizure frequency had reduced to 5.9 per month. Ten patients had become seizure-free and 76% had experienced an improvement in seizure frequency overall.

A simple questionnaire was administered to carers and relatives at the exit audit in an attempt to establish an impression of global changes in alertness, assertiveness and challenging behaviour following interventions. Sixty-five percent of patients were regarded as being more aware and interactive with their surroundings following medication changes and 49% were reported to be more assertive. Thirty percent presented with an increase in behaviours regarded as challenging and 22% were reported to present with less challenging behaviour.

The results of this audit suggest that the outcome for the majority of patients with learning disability and refractory epilepsy may be better than that has been previously reported.

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Introduction

It is recognised that 14–24% of people with a learning disability are affected by epilepsy.¹ Multiple seizure types are common and it is suggested that up to three-quarters of patients remain refractory to treatment.²

There is little clinical trial data available on people with learning disability because of perceived ethical problems surrounding capacity to consent, diagnostic difficulties, investigative problems and issues regarding compliance with drug treatment. Where research evidence is lacking, the audit of clinical outcomes over a prolonged period remains one of the few ways of informing clinicians and providing an evidence base.

Many learning disabled patients remain on old fashioned treatment regimes and the hypothesis

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was that it was possible to withdraw older anti-epileptic drugs (AEDs), replacing them with more modern treatment and that this would lead to improvements in both epilepsy and quality of life.

This paper reports on the outcome for patients with learning disability and refractory epilepsy following 2 years of clinical intervention by a community learning disability service. The only changes in the service were the appointment of a consultant neuropsychiatrist with a special interest in epilepsy and specialist epilepsy training for two community learning disability nurses.

Methodology

As most clinicians aim to attain seizure freedom on one AED, this was considered to be the outcome standard, accepting that in most clinical trials, a 50% seizure reduction is considered to be a good outcome. The audit included all adults over the age of 19 within an established community learning disability service presenting for first consultation at the outpatient clinic before 1 March 2001.

The following parameters were measured: average number of seizures per month (over a 3-month period), type of seizures, number of AEDs and side-effects of medication.

The changes to AEDs reflected normal clinical practice with no formal protocols followed, but with the aim to withdraw older preparations replacing them with more modern treatment. Changes to AEDs were made on an individual basis with consideration of refractoriness of seizures, seizure type, the presence of potential adverse drug effects and the ability of the patient to tolerate different drug formulations or preparations. It is acknowledged that the AED changes implemented reflect the clinical preferences and clinical experience of a single consultant.

Community learning disability nurses negotiated detailed care plans for making the recommended AED changes with care staff and other support agencies such as day care providers. They also provided close monitoring of effectiveness and tol-

erability providing education and training for care staff where necessary.

Despite inconclusive evidence to support the view that behavioural problems are more frequently found in those people with a learning disability who also have epilepsy,³ the clinical impression frequently exists that people with a learning disability who also have epilepsy are more likely to have behaviour problems fuelled by the belief that both epilepsy and AEDs may affect behaviour.

As part of the exit audit, a questionnaire was administered to carers and relatives after completion of the 2-year cycle to determine any changes in levels of alertness, assertiveness and challenging behaviour (Fig. 1).

The outcome audit reviewed the parameters of seizure frequency, severity and type and potential adverse effects of medication at a date 2 years after the first consultation. A global average over the previous 3 months was used.

Results

Thirty-seven patients were included in the outcome audit. Details of current seizure frequency and seizure type had been recorded on a monthly basis since the first visit. Monthly seizure frequency ranged from 0.5 to 60 with a mean of 10.4 seizures for the group at the time of the first consultation (Table 1).

After 2 years, the mean monthly seizure frequency had reduced to 5.9. Twenty-eight patients had experienced a decrease in the frequency of their seizures (76%). Twenty-one patients (57%) had a greater than 50% reduction in seizure frequency and of these patients, 10 (27%) had been seizure-free for at least 6 months. Seven patients (19%) had an increase in seizure frequency and in two patients there was no reported change (Table 1).

Recognised side-effects were reported in 19 patients (51%) at the first consultation with excessive sedation (nine patients, 24%) the most commonly reported (Table 2). Side-effects were reported in

Statement	strongly agree	agree	no change	disagree	strongly disagree
The patient is more aware and interactive with their surroundings following drug changes	5	4	3	2	1
The patient is more assertive following drug changes	5	4	3	2	1
The patient presents with more challenging behaviour following drug changes	5	4	3	2	1

Figure 1 Questionnaire.

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