



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.

Table 1 Seizure outcome after 2 years.

Outcome parameter (<i>n</i> = 37)	Patient numbers
Reduced seizure frequency	28 (76%)
>50% reduction in seizure frequency	21 (57%)
Seizure-free for at least 6 months	10 (27%)
Seizures unchanged	2 (5%)
Increased seizure frequency	7 (19%)
Mean average seizure frequency at first consultation	10.4 (0.5–60)
Mean average seizure frequency at end of 2 years	5.9 (0–44)

nine patients (24%) at the exit audit with tremor being the most commonly reported (six patients, 16%) (Table 2). Twenty-one patients (57%) in the sample continued to have generalised tonic-clonic seizures (primary or secondary) as their main seizure type compared to 30 (81%) at the first consultation.

The results of the questionnaire showed that following changes to AEDs, 24 patients (65%) were regarded as being more aware and interactive with their surroundings. Two patients (5%) were reported to be less aware and 11 patients (30%) remained unchanged (Table 3).

Eighteen patients (49%) were regarded as more assertive following drug changes with 16 (43%)

Table 2 Side-effects of medication (some patients reported more than one side-effect).

Side-effect	First consultation (19 patients)	Two-year outcome (9 patients)
Sedation/drowsiness	9	2
Ataxia/unsteadiness	6	1
Weight gain	2	2
Weight loss	1	2
Tremor	3	6
Behaviour problems	6	4

unchanged and 3 (8%) showing less assertiveness. Eleven patients (30%) presented with an increase in behaviours regarded as challenging, 8 patients (22%) had less challenging behaviour and 18 (49%) were unchanged (Table 3). The only apparent differences between the group who became seizure-free and the group who experienced a worsening of seizures was that the worsening of seizures appeared to be associated with less awareness and interaction with surroundings for some patients (Table 4).

Table 5 shows the AEDs taken at the first consultation compared with the AEDs following medication changes at the end of the 2 years. Of the eight patients who withdrew phenytoin, two (25%) became seizure-free, four (50%) experienced a greater than 50% reduction in seizure frequency and two (25%)

Table 3 Results of questionnaire.

Statement (<i>n</i> = 37)	Increased (4 or 5)	Unchanged (3)	Decreased (1 or 2)
Awareness and interaction with surroundings following drug changes	24 (65%)	11 (30%)	2 (5%)
Assertiveness following drug changes	18 (49%)	16 (43%)	3 (8%)
Challenging behaviour following drug changes	11 (30%)	18 (49%)	8 (22%)

Table 4 Outcome of questionnaire in seizure-free patients and those who experienced worsening of seizures.

Outcome parameter	Increased (4 or 5)	Unchanged (3)	Decreased (1 or 2)
Awareness/interaction with surroundings in seizure-free patients (<i>n</i> = 10)	5 (50%)	5 (50%)	0 (0%)
Awareness/interaction with surroundings and worse seizure frequency (<i>n</i> = 7)	4 (57%)	1 (14%)	2 (29%)
Assertiveness in seizure-free patients (<i>n</i> = 10)	4 (40%)	5 (50%)	1 (10%)
Assertiveness and worse seizure frequency (<i>n</i> = 7)	2 (29%)	4 (57%)	1 (14%)
Challenging behaviour in seizure-free patients (<i>n</i> = 10)	3 (30%)	5 (50%)	2 (20%)
Challenging behaviour and worse seizure frequency (<i>n</i> = 7)	2 (29%)	5 (71%)	0 (0%)

Table 5 AED changes over audit cycle.

AED	Number of patients at first consultation	Number of patients after 2 years
Phenytoin	8	0
Primidone	3	0
Carbamazepine	20	2
Sodium valproate	24	28
Topiramate	1	2
Lamotrigine	14	28
Vigabatrin	1	0
Levetiracetam	0	20
Diazepam	2	1
Clobazam	3	0

experienced a worsening of seizures. Almost 90% showed increased awareness and interaction with their surroundings following drug withdrawal and there was no significant impact on the levels of challenging behaviour.

In the group of 20 patients who withdrew carbamazepine, 5 (25%) became seizure-free, 9 (45%) experienced reduced seizure frequency and of these 7 patients (35%) had a greater than 50% reduction in frequency. In total 70% showed an improvement following carbamazepine withdrawal (Table 6). In 13 (65%) there was a reported increased awareness and interaction with surroundings (Table 7).

In the group of 28 patients who were taking Lamotrigine at the exit audit, 20 (71%) had an improvement in seizure frequency, including 6 (21%) who became seizure-free, and 10 (36%) who had a greater than 50% seizure reduction (Table 6). Of the 14 patients started on Lamotrigine, 9 (64%) were reported to be more aware and interactive with surroundings (Table 7).

Twenty patients started on the new AED Levetiracetam were still taking this medication at the 2-year exit audit. In this sample, 14 (70%) reported reduced seizure frequency with 3 patients (15%) becoming seizure-free and 7 (45%) reporting a greater than 50% reduction. Six patients reported a

Table 6 Outcome following specific AED changes.

Outcome parameter	Seizure-free	>50% seizure reduction	Increase in seizures
Following phenytoin withdrawal (<i>n</i> = 8)	2 (25%)	4 (50%)	2 (25%)
Following carbamazepine withdrawal (<i>n</i> = 20)	5 (25%)	7 (35%)	6 (30%)
Patients taking Lamotrigine (<i>n</i> = 28)	6 (21%)	10 (36%)	8 (29%)
Patients taking Levetiracetam (<i>n</i> = 20)	3 (15%)	7 (45%)	6 (30%)

Table 7 Outcome for patients following specific drug changes.

Outcome parameter	Increased (4 or 5)	Unchanged (3)	Decreased (1 or 2)
Awareness and interaction with surroundings following phenytoin withdrawal (<i>n</i> = 8)	7 (87.5%)	1 (12.5%)	0 (0%)
Assertiveness following phenytoin withdrawal (<i>n</i> = 8)	5 (62.5%)	3 (37.5%)	0 (0%)
Challenging behaviour following phenytoin withdrawal (<i>n</i> = 8)	1 (12.5%)	6 (75%)	1 (12.5%)
Awareness and interaction with surroundings following carbamazepine withdrawal (<i>n</i> = 20)	13 (65%)	7 (35%)	0 (0%)
Assertiveness following carbamazepine withdrawal (<i>n</i> = 20)	10 (50%)	9 (45%)	1 (5%)
Challenging behaviour following carbamazepine withdrawal (<i>n</i> = 20)	5 (25%)	9 (45%)	6 (30%)
Awareness and interaction with surroundings following Lamotrigine initiation (<i>n</i> = 14)	9 (64%)	5 (36%)	0 (0%)
Assertiveness following Lamotrigine initiation (<i>n</i> = 14)	7 (50%)	6 (43%)	1 (7%)
Challenging behaviour following Lamotrigine initiation (<i>n</i> = 14)	4 (29%)	6 (43%)	4 (29%)
Awareness and interaction with surroundings following Levetiracetam initiation (<i>n</i> = 20)	14 (70%)	4 (20%)	2 (10%)
Assertiveness following Levetiracetam initiation (<i>n</i> = 20)	11 (55%)	7 (35%)	2 (10%)
Challenging behaviour following Levetiracetam initiation (<i>n</i> = 20)	7 (35%)	8 (40%)	5 (25%)

worsening of seizures (30%) (Table 6). Fourteen (70%) showed an increase in awareness and interaction with their surroundings and 7 (35%) patients were considered to be more challenging (Table 7).

Discussion

The result of this audit suggests that there is scope to improve the outcome for those people with a learning disability who are considered to have refractory epilepsy.

Whilst the numbers are small and there is no randomisation or comparator group, it is difficult to ignore the fact that there was globally an almost 50% reduction in seizures for the group as a whole (average reduction in seizures from 10.4 to 5.9 per month) and a substantial number of individuals had become seizure-free over the 2-year period.

There could be an assumption that, at the initial assessment, side-effects of medication were under-diagnosed because a number of individuals had little or no verbal communication. It is therefore heartening to have observed a 47% reduction in side-effects over the 2-year period (19 patients at the outset and 9 after 2 years).

Previously reported poor outcomes for patients with learning disability compared to the rest of the epilepsy population,⁴ may not necessarily be correct. Guidelines for managing epilepsy in people with learning disability have recently been published⁵ with a significant emphasis on the importance of many factors other than medication changes. Nonetheless this audit suggests that withdrawing older AEDs with more significant side-effects and replacing them with newer AEDs can result in an improvement in epilepsy (with a reduction in seizure frequency) and an improvement in awareness and assertiveness (with a presumptive improvement in quality of life).

It is difficult to attribute the improvements seen in this audit population to AED changes alone or in-

deed to any single factor. There was an assumption at the outset that the service could not run without significant input from the community learning disability nurses.

It is suggested that improvement was achieved through a combination of factors including multidisciplinary team working, the appointment of a specialist with experience in managing epilepsy, the community-based nature of the service and switching to more modern AEDs. It is also suggested that improved outcomes for this population do not necessarily require substantial additional funding since this service was provided within the existing resources of an established community learning disability service.

Further research needs to examine the relationship between epilepsy, AEDs, challenging behaviour and quality of life in people with a learning disability. The challenge will be to do this as a prospective study with an attempt to control as many of the variables as possible.

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